

Stakeholders' perspectives on how to improve the support for persons with an intellectual disability and challenging behaviors: a concept mapping study

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Introduction: People with an intellectual disability (ID) are at risk of developing challenging behavior. Although previous research provided important insights into how to support people with an ID and challenging behavior, it remains unclear what various stakeholders consider to be the most essential aspects to further improve their support.

Method: Statements regarding aspects perceived necessary to improve the support to people with an ID and challenging behavior were collected in focus groups. Afterwards participants individually prioritized and clustered these statements, resulting in concept maps for people with an ID, direct support workers, and psychologists. Since only three relatives participated in the entire concept mapping procedure, no concept map could be composed based on their input.

Results: Participants generated 200 statements. In the concept map of clients, statements were mentioned regarding relational aspects, providing clarity and structure, characteristics of support staff, and professional attitude of direct support workers. Direct support workers provided statements related to their own personal competencies, the necessity of feeling supported and appreciated, and a physical safe environment. Psychologists provided statements regarding their support for direct support workers, the support for the clients, the perspective on the client, and their role as psychologists.

Conclusion: The results of this study may be a starting point to foster increased evidence based practice for the support for persons with an ID and challenging behavior. Moreover, it provides opportunities to create care founded on mutual attunement, based on listening to each other's ideas and insight into perspectives and needs of various stakeholders.

Keywords: intellectual disability, challenging behaviors, support, concept mapping

Introduction

People with an intellectual disability are at risk of developing challenging behaviors (Emerson *et al.* 2001, Jones and Stenfert Kroese 2007, Sheehan *et al.* 2015), which may be expressed as externalizing behavior (e.g. aggression towards oneself or others), and as internalizing behavior (e.g. anxiety and depression). Prevalence rates range between 10 to 25% in people with an

intellectual disability (ID) (e.g. Bowring *et al.* 2017, Emerson *et al.* 2001, Jones and Stenfert Kroese 2007, Sheehan *et al.* 2015). These behaviors may be disturbing and harmful for the person displaying the behavior, but also for their social network, such as their relatives and direct support staff (Emerson *et al.* 2001, Jones and Stenfert Kroese 2008, Sheehan *et al.* 2015).

Challenging behaviors may arise when people with an ID experience a mismatch between their personal capacities and disabilities on the one hand, and the demands and possibilities in their environment on the other hand (Bell and Espie 2002, Delespaul *et al.* 2016, Wehmeyer 2013). Because of the interplay between the person and its environment, challenging behaviors are seen as a socially constructed phenomenon (Stevens 2006). As a result, challenging behaviors can be perceived as a means of communication to control the

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Table 1 Characteristics participants

	Clients	Relatives	Direct support workers	Psychologists
Gender				
Male	4	2	3	4
Female	5	3	4	5
Age	28.3 years (Range: 22–46)	63.8 years (Range: 43–74) (1 missing)	36.8 years (Range: 28–57)	43.6 years (Range: 28–65)
Years of experience	–	–	11.5 years (Range: 3.5–32)	20.1 years (Range: 5–45)
Years of experience in current job	–	–	6.4 years (Range: 2–20)	13.3 years (Range: 2.5–35)

environment and to show that the environment does not match one's capacities (Emerson and Bromley 1995, Ager and O'May 2001, Kevan 2003). Intensive professional support to people with an ID displaying challenging behaviors is needed to prevent escalation and unsafe situations (Emerson *et al.* 2001). Restraints might be applied in reducing their challenging behaviors (Heyvaert *et al.* 2014). Although, restraints may cause negative emotions in both the person with an ID and the person who applies the restraint such as feelings of physical exhaustion, anxiety, and insecurity. Because of these negative emotions, various interventions for reducing these restraints have been developed (e.g. Emerson 2001, Feldman *et al.* 2004, Heyvaert *et al.* 2010). These interventions may focus directly on the person with an ID displaying challenging behaviors, such as applied behavior analysis, psychotherapy, cognitive behavior therapy, pharmaceutical treatment, or positive behavior support (e.g. Ager and O'May 2001, LaVigna and Willis 2012, McClean *et al.* 2005). Interventions may also focus on the environment of the person with an ID. For example on the skills of direct support workers in trying to reduce, manage, or cope with the challenging behaviors (Cox *et al.* 2015, Embregts *et al.* 2019, van Oorsouw *et al.* 2013, Stoesz *et al.* 2016, Zijlmans *et al.* 2015) or focus on the team climate (Knotter *et al.* 2016, Willems *et al.* 2016).

Recent research also identified various factors considered important in the support for people with an ID displaying challenging behaviors. Griffith *et al.* (2013) concluded, based on a meta-synthesis of qualitative studies focusing broad on experiences in their care, that people with an ID and challenging behaviors themselves expect from direct support workers to have good interpersonal skills. In addition, based on a meta-analysis of scientific literature focusing on restrictive measures (Heyvaert *et al.* 2014), it is concluded that people with an ID express the wish to learn techniques to cope with aggressive or self-harm behaviors, and indicate the need for quiet time in their rooms and being distracted from the challenging behavior. Moreover, people with an ID and challenging behaviors indicate that proactive or protective interventions are more helpful than reactive or restrictive interventions (Griffith *et al.* 2013). Based on another meta-study

of Griffith and Hastings (2013) relatives of people with an ID and challenging behaviors reported to expect highly trained direct support workers to take care of their family member. In an explorative interview study, direct support workers themselves indicate that building a meaningful relationship with a client based on trust is fundamental to a good relationship and for maintaining the quality of the provided support (Hermsen *et al.* 2014).

Although previous research provided some important insights on how to support people with an ID and challenging behaviors in general, they mainly focus broadly on experiences in the care for persons with an ID and challenging behavior, but have no explicit focus on what each stakeholder group think could be relevant in improving the quality of care. It remains unclear what people with an ID themselves, their relatives, and professionals consider to be the most essential aspects to improve the support for people with an ID and challenging behaviors. Therefore, the aim of the current study is to explore the perspectives of various relevant stakeholders (i.e. people with an ID themselves, their relatives, and professionals) on how to improve the quality of care offered to this client group by applying a concept mapping method.

Materials and methods

Participants

In total, 30 participants took part in this study. They are all related to three care organizations providing support to people with an ID in the Netherlands (two organizations provided nine participants, the other provided 12 participants). Managers in the participating care organizations recruited participants via convenience sampling. The participants can be distinguished into four groups: (1) people with a mild ID or borderline intellectual functioning (IQ-score between 50 and 85) employed as experts-by-experience within their care organization ($n = 9$); (2) relatives of people with an ID and challenging behaviors ($n = 5$); (3) direct support workers ($n = 7$); and (4) psychologists ($n = 9$). All participants were aged 18 years or older and had the ability to verbally express themselves. The participating people with an ID were supported by their care organization for 9.3 years on average (range 3–16 years), with an IQ score on file ranging from 57 to 80 as provided by their

organization ($n = 2$ missing; If information on the level of intellectual functioning of the persons with an intellectual disability was lacking, the health psychologists confirmed the intellectual disability based on their clinical judgement.). Three relatives indicated having a child with an ID and challenging behaviors, and one relative was a sibling of a person with an ID and challenging behaviors ($n = 1$ missing). The direct support workers and the psychologists had a working experience in the field of ID of 11.5 years and 20.1 years respectively. Additional characteristics regarding the participants are provided in Table 1.

Procedure

After the Ethics Review Board of Tilburg University provided ethical approval (EC-2018.50), the study was conducted in cooperation with three care organizations in the Netherlands. These three organizations are part of a partnership of care organizations in long term care and share the ambition to increase the quality of care for persons with an ID and challenging behavior. Additionally, these three care organizations are members of the Academic Collaborative Center Living with an intellectual Disability (Tilburg, The Netherlands) in which science and practice collaborate closely in improving the care for persons with an ID. The authors contacted the managers responsible for knowledge development and research in these organizations to recruit people with an ID, relatives, direct support workers, and psychologists in their organization. After the managers were informed about the study, they selected potential participants who thereupon received an information letter from the researchers, explaining the aim and background of the study and informing the participants. The participants were free to stop their participation at any time, without providing a reason and without negative consequences. All participants provided written informed consent. After the concept mapping procedure (see next paragraph), all participants were invited for a joint, concluding session in which the results of the study were presented.

Concept mapping

The statements reflecting the perspective of the various stakeholders on how to improve the support of persons with an ID displaying challenging behaviors were collected, integrated, and conceptualized using the method of concept mapping. This method has been successfully applied in health care research (e.g. de Boer *et al.* 2019, van Bon-Martens *et al.* 2017), including research focusing on the care for persons with a disability (e.g. Niemeijer *et al.* 2013, Ruud *et al.* 2016). It is considered a useful method to help build evidence-based health care. Concept mapping is a computer-assisted mixed methods research design in which the integration of group processes and multivariate statistical analyses

is central (Trochim and Kane 2005). It is a participatory approach, which consists of four consecutive stages: (1) brainstorming to gather statements; (2) prioritizing and clustering of these statements; (3) statistical analysis; and (4) interpreting the resulting concept maps.

Step 1. Brainstorming to gather statements

The aim of this first step was to gather the perspectives of the four participant groups (i.e. people with an ID, relatives, direct support workers, and psychologists) on the subject of improving the support for persons with an ID and challenging behaviors. All participants gathered at the same location. A researcher explained them the concept mapping procedure. Next, each participant group took part in a separate focus group. In these groups they provided their perspectives with regard to the following predefined focus sentence: 'To provide better support for people with an ID and challenging behaviors, it is necessary to ...' Every focus group was supervised by two experienced ID researchers who avoided engagement in the discussion. In order to provide a psychologically safe environment, people with an ID were asked whether they preferred their direct support worker to attend their focus group for mental support. In case a direct support worker attended, they were requested not to engage in the discussion. To avoid potential biases, the focus group with direct support worker took place prior to the focus group with the people with an ID. All focus groups lasted one hour.

The focus groups were audio-recorded and transcribed verbatim afterwards. Assisted by the qualitative software package Atlas.ti (Muhir 2005), all statements with regard to the focus sentence were coded. Duplicate statements were only coded once.

Step 2. Prioritizing and clustering statements

In the second step, the participants were individually asked to prioritize and cluster all statements derived from the focus group they attended. To complete this task, all statements of each focus group were imported into the software program Ariadne 3.0 (Severens 1995), resulting in four sets of statements (i.e. one set per participant group). A few days after the focus groups, the relatives, direct support workers, and psychologists received an email explaining the prioritizing and clustering task together with a personal link to perform these tasks individually on the computer. They were asked to complete these tasks within two weeks, and were invited to pose questions if needed via email or telephone. The participating people with an ID were visited by the researchers at their care organization to support them in conducting the tasks. The provided support consisted of explaining the tasks, reading the statements aloud, and providing support in working on the computer. The participating relatives and professionals were also invited at these occasions for support in

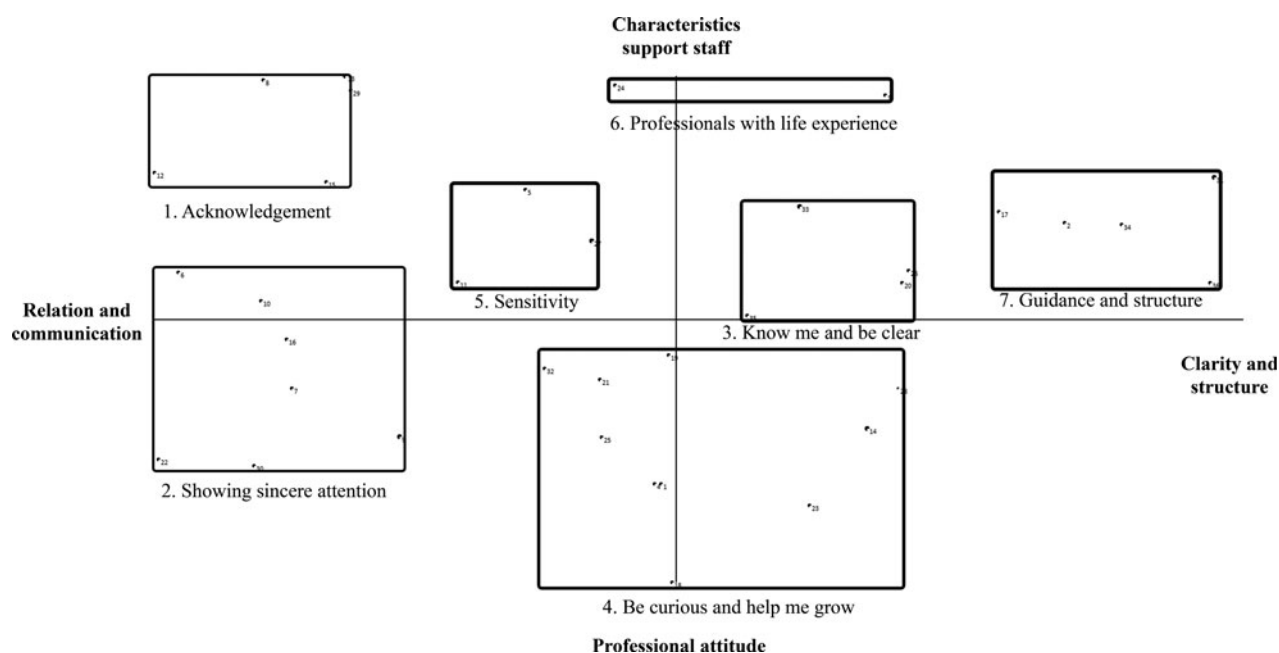


Figure 1. Concept map clients.

conducting the tasks if needed. None of them made use of this invitation.

In conducting the tasks, participants were first asked to rate the various statements named in their focus group on a five point Likert-scale (ranging from 1 = most important to 5 = least important) in relation to the predefined focus sentence (i.e. prioritizing task). For the clients, a more convenient three point Likert-scale was chosen (ranging from 1 = most important to 3 = least important). Second, in the clustering task, the participants were asked to group all statements based on the content of each statement, that is, which they felt belong to the same topic. The Ariadne software allows for a maximum of 10 clusters to be made.

Step 3. Statistical analysis

By use of Ariadne 3.0, all individually prioritized and clustered statements were combined into a group product per participant group. Statistical analysis consisted of quantitative techniques of multidimensional scaling and hierarchical cluster analysis which led to the production of visual concept maps (see Figures 1–3). These concept maps provide a visualization of the relatedness of the various statements and their relative importance. Based on the prioritization task, the average rating for each statement and cluster was calculated. The relative importance attached to each cluster is represented by the width of the line, which defines the cluster box. The thicker the line, the less important it was rated by the participants. Statements that are often placed in the same group during the clustering task are placed close to each other in the concept maps. In the concept map the clusters are divided over an x- and y-

axis, with both ends of the axis representing a different content of clusters.

Step 4. Interpreting the concept maps

A group of five experts interpreted the four concept maps during a face-to-face group discussion based on the focus sentence: what is needed to provide better support for people with an ID and challenging behaviors? The expert group consisted of three managers responsible for knowledge development and research in their care organization (each manager was related to one of the three participating care organizations in this study), an experienced ID health-psychologist (who also participated in step 1 and step 2), and the last author (PE). During this group discussion, which was moderated by two of the researchers (SN and ET), the experts discussed the content of each cluster and entitled them. Consensus was reached for every cluster.

Results

In total, 200 statements were gathered over the four focus groups. An overview of the statements is provided in Supplementary data. The amount of statements varied from 36 to 56 for each group (clients: $n = 36$; relatives: $n = 56$; direct support workers: $n = 55$; psychologists: $n = 53$). Since five relatives participated in the focus group and only three of them completed the prioritizing and clustering tasks, no concept map could be composed based on the input of the relatives. The statements provided by relatives could therefore not be analyzed and will not be presented. Table 2 provides an overview of the clusters generated by the three participant groups, together with the mean relative importance of each cluster. These clusters are based on

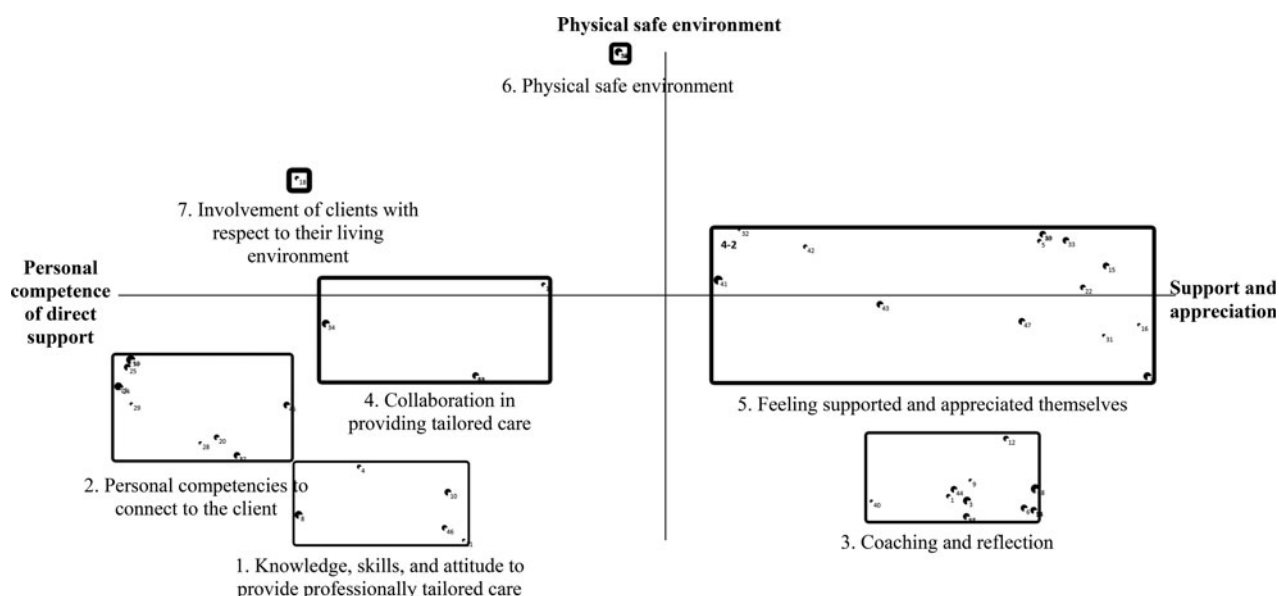


Figure 2. Concept map direct support workers.

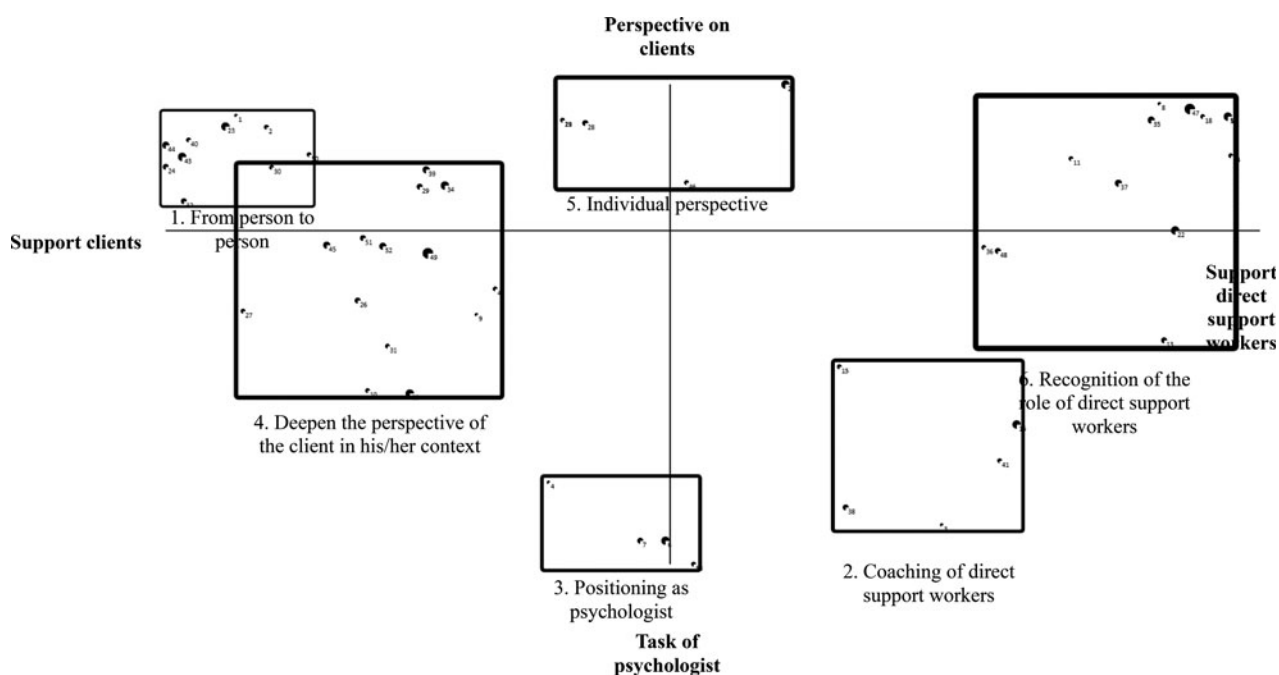


Figure 3. Concept map psychologists.

the individual prioritization and clustering of the statements by the participants, and consequently named by the expert group.

Concept map clients

The 36 statements provided by clients are grouped into seven clusters. These clusters are ranked in Table 2 and visualized in a concept map in Figure 1, with the clusters in ranked order of perceived importance (cluster 1 is perceived most important; cluster 7 received the lowest score in improving the quality of support to people with an ID and challenging behaviors). The cluster entitled ‘acknowledgment’ (cluster 1; n = 5 statements) is considered most important in improving the quality of

support offered and consists of statements related to being treated equally, and direct support workers showing sincere, personal interest in getting to know the person with an ID and challenging behaviors. The second cluster ‘showing sincere attention’ (n = 7 statements) is a further operationalization of the first cluster in entailing more concrete statements such as the importance of direct support workers listening to the client instead of only reading his/her file and active listening skills. Next, the cluster ‘know me and be clear’ (cluster 3; n = 4 statements) includes statements related to the need of direct support workers being clear in indicating when they do have time available for a client when it’s not convenient at a given time and the importance of

Table 2 Clusters and their average rating for each respondent group

Cluster number	Clients	Direct support workers	Psychologists
1	Acknowledgement (1.62)	Knowledge, skills, and attitude to provide professionally tailored care (2.00)	From person to person (2.06)
2	Showing sincere attention (1.67)	Personal competencies to connect to the client (2.34)	Coaching of direct support workers (2.58)
3	Know me and be clear (1.78)	Coaching and reflection (2.37)	Positioning as psychologist (2.71)
4	Be curious and help me grow (1.83)	Collaboration in providing tailored care (2.86)	Deepen the perspective of the client in his/her context (2.80)
5	Sensitivity (1.93)	Feeling supported and appreciated themselves (2.99)	Individual perspective (2.93)
6	Professionals with life experience (2.00)	Physical safe environment (3.17)	Recognition of the role of direct support workers (3.37)
7	Guidance and structure (2.04)	Involvement of clients with respect to their living environment (3.29)	

Note. Rating on a five point Likert-scale (ranging from 1 = most important to 5 = least important); for the clients three point Likert-scale was used (ranging from 1 = most important to 3 = least important).

being supported by a set group of direct support workers. In addition, it is considered important for direct support workers to be ‘curious and to help their clients grow’ (cluster 4; $n = 10$ statements). This cluster includes statements related to the ability of support staff to focus on the possibilities of the individual client and the provision of support to help the client further develop what he/she is capable of doing. Next, according to the clients, direct support workers should have a ‘sensitive’ attitude towards clients (cluster 5; $N = 3$ statements) and be ‘professionals with life experience’ (cluster 6; $n = 2$ statements). ‘Guidance and structure’ (cluster 7; $n = 5$ statements) received the lowest importance score. The clusters consists of statements related to direct support staff workers’ keeping to agreements, providing structure, and setting boundaries. As illustrated in the concept map, all clusters are grouped around an x- and y-axis (see Figure 1), with the x-axis ranging from a focus on relational aspects and communication towards the client to providing the clients with guidance and structure. The y-axis ranges from objective characteristics of direct support workers to their professional attitude.

Concept map direct support workers

Direct support workers provided 55 statements in response to the central question. These 55 statements are grouped into seven clusters (see Table 2, and Figure 2). Following the prioritization and clustering task, the cluster considered most important by direct support workers in improving the support for people with an ID and challenging behaviors is entitled ‘knowledge, skills, and attitude to provide professionally tailored care’. This cluster entails five statements related to having a basic knowledge of people with intellectual disabilities and having the ability to translate this general knowledge to the individual client. The cluster ‘personal

competencies to connect to the client’ (cluster 2; $n = 11$ statements) describes personal competencies such as being aware of your attitude towards a client, being patient and disposing of listening skills. The cluster ‘coaching and reflection’ ($n = 13$ statements) is ranked 3th in order of importance and entails statements referring to the need for professional supervision, making someone responsible to motivate and coach direct support workers and the need to better prepare direct support workers to working with this particular client group. The fourth cluster ‘collaboration in providing tailored care’ consists of statements ($n = 4$) related to proactively collaborating with relatives of the client and allowing direct support staff to attune the support provided to create a psychologically safe environment for each individual client. Next, direct support staff consider statements related to ‘feeling supported and appreciated themselves’ as important in improving the support provided (cluster 5; $n = 15$ statements). Statements related to reducing their workload, being provided with the opportunity to call in additional expertise in case of incidents and feeling appreciated for their commitment and knowledge constitute this cluster. The sixth cluster (‘physical safe environment’; $n = 6$ statements) consists of statements concerning the physical safety in this living environment of both the clients and the direct support staff themselves, such as having housing which allows support workers to move easily in case of incidents and housing consisting of construction material suitable for people with challenging (aggressive) behaviors. The cluster ‘involvement of clients with respect to their living environment’ received the lowest score and consists of one single statement, i.e. giving people with challenging behaviors a say in the decoration of their house/room. Visualized in the concept map (Figure 2), the clusters generated by the direct support workers range from their own

personal competencies to the necessity of feeling supported and appreciated (x-axis). The cluster related to a physical safe environment is placed on top of the y-axis, with no direct opposite at the bottom of the y-axis.

Concept map psychologists

Six clusters were formed based on the 53 statements provided by the psychologists. According to the psychologists, the most important factor in providing better support to clients with an ID and challenging behaviors is named 'from person to person' and gathers statements ($n=10$) focusing on the human interaction between the person with an ID and challenging behaviors and the psychologist him-/herself, such as 'getting to know the person instead of understanding his behavior' and 'seeing clients as individual human beings instead of a target group'. Cluster two consists of statements ($n=5$) pertaining to the 'coaching of direct support workers', with statements such as 'teaching direct support workers how to empathize with the client' and 'simplify methodologies and make them more suitable for daily practice'. In cluster three ($n=5$ statements) the 'positioning as psychologist' is central with example statements such as: 'using your expertise proactively instead of reactively' and 'daring to take the lead in a team of professionals'. Cluster four focuses on a 'deepen the perspective of the client in his/her context', with statements ($n=14$) such as 'engaging more often in contact with the client's relatives' and combining different perspectives of what is the 'truth' grouped in this cluster. The following cluster is entitled 'individual perspective' and consists of statements ($n=5$) focusing on the individual client, examples are the statements 'offering day center activities that correspond to individual client preferences' and 'having an individualized and differentiated housing offer'. The cluster 'recognition of the role of direct support workers' (cluster 6; $n=14$ statements) includes statements related to preconditions for direct support workers to provide support to people with an ID and challenging behaviors, such as providing direct support workers with sufficient time to focus on the client and having sufficient personnel. On the concept map, the x-axis ranges from how people with an ID and challenging behaviors should be supported to recognizing and supporting direct support workers in the support they provide to these clients. In addition, on the y-axis, a distinction can be made between the perspective of the clients and the perspective on their own professional role as psychologists.

Discussion

Using the concept mapping method, this study explored what people with an ID, direct support workers, and psychologists consider being the most important aspects to improve the support of people with an ID and

challenging behaviors. For each participant group a concept map was composed based on their jointly generated statements, which they subsequently prioritized and clustered individually. Although the clusters are ranked from most to least important it is important to note that the clusters ranked lowest in order of importance are still considered important to the participants giving the focus sentence they reacted to during the brainstorm session (i.e. 'To provide better support for people with an ID and challenging behaviors, it is necessary to ...'). Overall, the central position of direct care workers in supporting people with an ID and challenging behaviors became apparent in all three concept maps. People with an ID themselves assigned the highest priority to clusters reflecting a high quality relationship between the client and direct support staff, i.e. clusters including feelings of acknowledgement, being treated with sincere attention and a focus on a client's possibilities. This is in line with previous research amongst people with an ID, in which they indicate the wish to build good relationships and communicate with their direct support workers about their problems and feelings (Giesbers *et al.* 2019, Heyvaert *et al.* 2014). In addition, people with an ID highly value direct support workers' qualities such as respect, honesty, trust, and a caring, nurturing manner (Clarkson *et al.* 2009, Griffith *et al.* 2013, Roeleveld *et al.* 2011). People with an ID also indicate that negative interactions with support staff or feeling rejected by support staff may cause challenging behaviors (van den Bogaard *et al.* 2019). This also asks for high quality interactions between client and direct support staff. Direct support also considered the relationship with the person with an ID as important, given the high prioritization they assign to the cluster entitled 'personal competencies to connect to the client' (cluster 2; direct support workers). Hastings (2010) stressed the importance of good relationships between direct support workers and clients with an ID. Moreover, the importance of developing an interpersonal attitude towards the client with an ID and challenging behavior (Willems *et al.* 2014, Zijlmans *et al.* 2012) and focus on relational aspects of care practice (Jackson 2011) was underlined in previous research. However, direct support workers only mentioned one cluster pertaining to this relationship, with the other clusters consisting of statements related to conditions needed to facilitate such a high quality relationship. That is, direct support workers mention statements referring to their need for coaching and reflection (cluster 3), to feeling supported and appreciated by means of reduced workload and availability of additional expertise (cluster 5) and a physical safe working environment (cluster 6). Hastings *et al.* (2013) described a conceptual framework to identify why challenging behaviors occur in persons with developmental disabilities. They indicated that challenging behaviors are strongly related

to the context and that the behaviors of support staff are often more likely to maintain the challenging behavior instead of reducing this behavior. These behaviors of support staff are determined by their emotions, beliefs, and attitudes, which may be strongly impacted by the challenging behavior of the client. For example, in the framework is stated that support staff experience the challenging behavior as aversive and report increased levels of stress. In light of this conceptual framework, the needs regarding coaching, reflection, support and appreciation stated by the support workers can be understood. The psychologists in turn also stress the important role of direct support workers in mentioning ‘coaching of direct support workers’ (cluster 2) as essential aspects to provide high quality support of persons with an ID and challenging behaviors. Moreover, they explicitly described their own professional task in the need to position themselves as psychologist and to take the lead in a team of direct support workers (cluster 3).

The focus in the three concept maps on the relationship between the person with an ID presenting challenging behavior and support staff is in line with the concept of challenging behavior as a social construct, in which the interplay between the person and its environment is underlined (Stevens 2006). The concept maps of both the direct support workers and the psychologists show that they are aware of the importance of professional attitude, in addition to knowledge and skills. A professional attitude, consisting of the characteristics respect, expertise, attention, involvement, understanding, support, authenticity, empathy and warmth, is perceived fundamental for a high quality relationship (Kuis *et al.* 2010). An encouraging and facilitating learning environment is considered paramount in developing a reflective, professional attitude (Armson *et al.* 2015).

The current study identifies essential aspects to further improve the support for people with an ID and challenging behaviors, according to people with an ID themselves, direct support workers and psychologists. This is an important strength of our study, as it can be a starting point to foster increased evidence based practice for the support for persons with an ID and challenging behaviors. Moreover, it provides opportunities to create care which is based on mutual attunement, based on listening to each other ideas and insight in the various perspectives and needs. Future research should focus on how these concepts may be operationalized in practice, for example by additional in depth interviews and observations. The results of this study may also form the starting point for developing an intervention program in which the specific needs of all actors involved are taken into account.

Some limitations with regard to this study can be formulated. As the number of participating relatives was too low for the clustering and prioritizing task, a

concept map could not be composed for this group. Given their important role in the lives of people with an ID and challenging behaviors, it would be recommendable for future research to include a larger group of relatives so a concept map specifically based on their perspective could be composed. Information on comorbid diagnosis or information on the adaptive functioning of the participants with an ID was lacking which hinders a comprehensive overview of the study sample. Given the small sample sizes, it was not possible to compare and contrast participants based on for example gender, age, and work experience. Although this was not the focus in our research, it could be interesting to investigate the differences in perspectives between groups in future research. Further, some participants in the group of persons with an ID needed help during the prioritizing and clustering task. Although this help should only be limited to reading out loud statements or help with the computer, some participants asked for clarification of statements or asked for approval during the tasks. In order to reduce a possible bias, no approval was provided and only clarification of words or sentences they did not understand was provided. Finally, because managers employed by the care organization selected participants, we cannot exclude the possibility this has resulted in a sample with particular characteristics. A purposeful, non-random selection of participants would contribute to the scientific rigour of future research.

In sum, based on the results of this study organizations may further improve their care for persons with an ID and challenging behaviors. Since participants provided statements in reaction to the focus sentence as to what they perceived can be improved in the support for people with an ID and challenging behaviors, one can assume that (part of) these statements are already included in the support provided by the care organizations. The outcomes of this study thus provide valuable knowledge about different perspectives on which aspects can be improved in the care for persons with an ID and challenging behaviors, which may form the basis for improvements in quality of care based on an equal dialogue and in co-creation with the various actors.

Disclosure statement

The authors do not have any conflict of interest in publishing the results of this study.

Author contributions

This study has not been published before and is not being considered for publication elsewhere. All authors contributed to the manuscript agree to the order of authors as listed on the title page. S. Nijs, E. F. Taminiu, N. Frielink and P. J. C. M. Embregts conceived and designed the study, obtained ethics

approval, analyzed the data, and wrote the article in communality. S. Nijs, E. F. Taminau and N. Frielink collected the data.

Supplemental Data

Supplemental data for this article can be accessed [here](#).

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