Participation of adults with visual and severe or profound intellectual disabilities

Gineke Hanzen

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General introduction

Introduction

Over the last decade, the participation of people, including adults with visual and severe or profound intellectual disabilities (VSPID) has been increasingly emphasized. According to the definition formulated by Schalock et al. (2010), individuals with VSPID, whose intelligence quotients (IQs) fall within a range of 20–34, are considered to have severe intellectual disabilities (IDs) while those with IQs of below 20 are deemed to have profound IDs. These limitations in intellectual function further constrain these individuals' adaptive behaviours that relate to their social, conceptual, decision-making, and practical skills (Schalock et al., 2010). Individuals with severe or profound IDs often have motor and/or sensory impairments along with various medical problems, such as obstipation, epilepsy, and challenging behaviours (Nakken & Vlaskamp, 2007; Poppes, Van der Putten, & Vlaskamp, 2010; Van Timmeren, Van der Putten, Van Schrojenstein Lantman-de Valk, Van der Schans, & Waninge, 2016). The prevalence of blindness or visual impairments in individuals with severe or profound IDs is as high as 92% (Van Splunder, Stilma, Bernsen, & Evenhuis, 2006). A visual impairment is defined by the World Health Organization (WHO) as visual acuity < 6/18, while blindness is defined as a visual acuity < 3/60 and/or a visual field < 10 degrees around the point of fixation (ICD-10, 2016). Compensation mechanisms do not function in the case of adults with VSPID; they can neither compensate for their ID using their eyesight, nor can they compensate for vision loss through the employment of their cognitive capabilities. Consequently, visual and intellectual disabilities are mutually reinforcing (Kiestra, 2005), thereby compounding the limitations experienced by these individuals in their daily activities, for example, in communication, initiatives, and living skills (Evenhuis, Sjoukes, Koot, & Kooijman, 2009). Because of their limitations, adults with VSPID are dependent on others in almost all areas of their lives (Nakken & Vlaskamp, 2007).

In the Netherlands, the number of adults with VSPID ranges between 10,000 and 15,000, accounting for approximately 0.05–0.08% of the Dutch population (Limburg, 2007). Despite a general trend of deinstitutionalization that has been evident over the past 40 years in various Western countries (Chowdhury & Benson, 2011; Mansell & Beadle-Brown, 2010; Tøssebro et al., 2012), in the Netherlands, not all adults with VSPID currently live outside the institutions; they live in both residential facilities and in group homes within the society (Woittiez, Putman, Eggink, & Ras, 2014). The introduction of the citizenship paradigm (Van Gennep, 1997) in the 1990s prompted a process of deinstitutionalization in the Netherlands. Consequently, in the past 25 years, individuals with IDs have moved to ordinary neighbourhoods (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014). In addition, some residential facilities have changed into neighbourhoods in which people with and without IDs live side by side, called "reversed integration" (Venema, Otten, & Vlaskamp, 2016).

In recent years, perceptions of society relating to the participation of citizens have evidently shifted. The emphasis now is on promoting citizens' participation within society to the greatest extent possible. According to the United Nations Convention on the Rights of People with Disabilities, which has been effective in the Netherlands since July 14, 2016 (Nederlandse overheid, n.d.), disabled individuals, irrespective of the extent of their disabilities, have the right to participate fully within society and in community life (United Nations, 2006). This changed perception and the associated policy relating to participation and inclusion, which also extends to adults with VSPID, has far-reaching consequences for persons involved with individuals with VSPID, and at all levels in society. At the societal level, new demands are being made, because they have to open up to people with disabilities (Scior et al., 2020).

To achieve this vision of the participation and inclusion of adults with VSPID, policy-makers should propagate inclusiveness and provide necessary resources. Simultaneously, local communities, including these adults' neighbours, also have an important role to play in the realization of this goal (Overmars-Marx, Pepping, & Thomése, 2018; Van Alphen, Dijker, Bos, Van den Borne, & Curfs, 2011). Moreover, this changed policy has consequences for the individuals with VSPID themselves, their family members, and others involved in supporting them (Shelley et al., 2018). Influenced by the aforementioned citizenship paradigm, the role of the families of individuals living in residential care facilities and their involvement in the lives of these individuals have been strengthened in recent decades (Schuurman, 2014). For example, they may visit their family members, represent their interests, or attend events with these individuals outside of the residential facility (Axelsson & Wilder, 2014).

Within the residential facilities, adults with VSPID are facilitated by direct support professionals and by other healthcare professionals, such as healthcare psychologists, physiotherapists, speech therapists, and those with expertise in the field of blindness and visual impairments. The families, along with the support professionals in residential facilities, have to work together to support the individuals living in these facilities (Bigby & Fyffe, 2012; Grey, Griffith, Totsika, & Hastings, 2015; Jansen, Van der Putten, & Vlaskamp, 2017). As a result of the paradigm shift towards participation, residential facilities and their healthcare professionals are now faced with new requirements. Accordingly, they must reorient the methods and approaches they use to support persons with disabilities towards increasing their participation (in society), even if these individuals have severe or profound IDs (Bigby & Wiesel, 2015; Schippers, Bakker, & Peters, 2018; Venema, Otten, & Vlaskamp, 2016).

In general, participation is considered to be important for all people (United Nations, 2006). Additionally, the findings of studies conducted on individuals with IDs indicate that participation contributes to improved life quality (Cobigo et al., 2016; Schalock et al., 2010; Schippers et al., 2018). The reported positive effects of the participation of individuals with IDs cover different areas that include, for example, more choice-making opportunities, more independence, more friends, more meaningful activities, and more participation within community life (Mansell & Beadle-Brown, 2010; Taylor-Roberts, Strohmaier, Jones, & Baker, 2019). However, in research only partially revealed the assumed effects of participation, reported above, with regard to individuals with more severe IDs because these effects are associated with better adaptive skills (Kozma, Mansell, & Beadle-Brown, 2009). Studies have shown that compared with individuals who do not have these disabilities, those with severe or profound IDs are much less likely to engage in participation (Axelsson & Wilder, 2014; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Kamstra, Van der Putten, & Vlaskamp, 2015; Nijs, Penne, Vlaskamp, & Maes, 2016). The likelihood of participation is also low for individuals with visual impairments (Alma et al., 2011; Elsman, Van Rens, & Van Nispen, 2016; Salminen & Karhula, 2014). In addition, to achieve participation, adults with severe or profound IDs are highly dependent on persons in their environment because of the severity of their disabilities (Nakken & Vlaskamp, 2007). They are also affected by other environmental factors, such as the attitudes of staff members (Bigby et al., 2009; McConkey, & Collins, 2010; Talman, Gustafsson, Stier, & Wilder, 2017), family support (Axelsson & Wilder, 2014; Kamstra et al., 2015), and the availability of necessary facilities or resources (Maxwell, Alves, & Granlund, 2012). For adults with VSPID, we assume that participation may contribute to their lives in various areas. Nonetheless because of the significant risk of low participation of individuals with visual disabilities or severe/profound IDs, and the uncertainty associated with their dependence on their environments, the participation of adults with VSPID is expected to be suboptimal. However, data on the current participation levels of this group are lacking.

Although participation is assumed to be important for adults with VSPID, an additional problem is that the exact meaning of the concept of participation in relation to adults with VSPID remains unclear. Various authors have noted that there is still no scientific consensus on the concept of participation in general (e.g., Bigby, Anderson, & Cameron, 2018). Consequently, the definition and operationalization of the concept of participation varies within different models, such as the theoretical model of ID developed by the American Association on Intellectual and Developmental Disabilities (Luckasson et al., 2002) and the International Classification of Functioning, Disability and Health (ICF;WHO, 2001) as well as within various studies (Chang, Coster, & Helfrich, 2013; Coster & Khetani, 2008; Maxwell et al., 2012). Furthermore, it appears that different definitions of the concept of participation are used for different target groups. For example, definitions and modes of operationalizing the term for children and adults differ (Chien & Rodger, 2011; Rainey, Van Nispen, Van der Zee, & Van Rens, 2014). In sum, the concept appears to be multidimensional and requires further clarification (Adair, Ullenhag, Keen, Granlund, & Imms, 2015; Bigby et al., 2018). Because of the lack of definitional clarity and of a consensus regarding the mode of operationalization of participation for adults with VSPID, it is difficult for persons who support these adults to enhance the participation of this target group in practice. Therefore, research that yields a clear definition and concrete operationalization of the concept of participation is important for fostering clarity, thereby increasing the likelihood of improving the participation of this target group, which could, in turn, contribute to their quality of life.

It is not known precisely how the participation of adults with VSPID should be defined and operationalized. Consequently, their current participation levels are not known. While the participation of adults with VSPID is expected to be suboptimal, the precise extent and the specific areas of this suboptimal participation have not yet been ascertained. Additionally, it is not known how the expected suboptimal participation of adults with VSPID could be improved. Although possible factors that could influence participation, such as the attitudes of direct support professionals and other environmental factors, are known (Bigby et al, 2009; Maxwell et al., 2012), a number of questions arise. Notably, how could the participation of adults with VSPID be improved or increased? Further, what types of interventions would be effective for improving participation?

In sum, participation is considered important for people with IDs in general as well as specifically for adults with VSPID. However, many aspects of the participation of adults with VSPID remain unclear. The aim of this study was to gain insights into the participation of adults with VSPID and to explore ways of improving their participation through the development and testing of a new intervention. This thesis addresses the following research questions:

1. How should participation for adults with VSPID be defined and operationalized by concerned stakeholders?
2. To what extent do adults with VSPID participate, according to the, by concerned stakeholders, operationalized concept of participation for adults with VSPID?
3. What are the effects of a newly developed intervention on the participation of adults with VSIPD?

Outline of the thesis

In light of the general objectives of this thesis, the following chapters provide insights into the participation of adults with VSPID and explore ways of improving their participation. Chapter 2 presents a definition of the participation of adults with VSPID and clarifies the operationalization of participation of these individuals based on the findings of a study conducted to elicit the opinions of family members, professionals, and others with expertise relating to this target group. Chapter 3 subsequently presents the findings of research, premised on the above definition and operationalization of the target group's participation, on the current participation of adults with VSPID. This study was based on an assessment of individual support plans of adults with VSPID.

In light of the above findings, Chapter 4 describes the development of a new intervention, 'Care for Participation+' (CFP+), aimed at improving the participation of adults with VSPID, as operationalized by the concerned stakeholders. The chapter also presents the results of a process evaluation of this new intervention within a residential care facility for persons with VSPID in the Netherlands.

Chapter 5 presents the effects of the new CFP+ intervention on direct support professionals' attitudes towards the participation of adults with VSPID. The CFP+ intervention was tested in a pilot non-randomized controlled trial with three parallel intervention arms at two residential care facilities for persons with VSPID in the Netherlands.

Chapter 6 discusses the effects of CFP+ on the participation of adults with VSPID in terms of life quality, and active involvement in daily life activities. This discussion is based on the findings of the same above-mentioned pilot non-randomized controlled trial conducted at the two residential care facilities for persons with VSPID. Given the small sizes of the groups of research participants, qualitative methods were applied in addition to quantitative methods to gain deeper insights into the results.

Lastly, Chapter 7 presents a general discussion on the outcomes of the previous chapters in relation to the general aims of this thesis. Theoretical as well as methodological reflections are offered in this chapter, which concludes with some thoughts on future research and policy directions relating to the subject of this thesis.

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Participation of adults with visual and severe or profound intellectual disabilities: Definition and operationalization

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Abstract

Background

The available opinions regarding participation do not appear to be applicable to adults with visual and severe or profound intellectual disabilities (VSPID). Because a clear definition and operationalization are lacking, it is difficult for support professionals to give meaning to participation for adults with VSPID.

Aims

The purpose of the present study was to develop a definition and operationalization of the concept of participation of adults with VSPID.

Methods

Parents or family members, professionals, and experts participated in an online concept mapping procedure. This procedure includes generating statements, clustering them, and rating their importance. The data were analyzed quantitatively using multidimensional scaling and qualitatively with triangulation.

Results

A total of 53 participants generated 319 statements of which 125 were clustered and rated. The final cluster map of the statements contained seven clusters: 1) Experience and discover; 2) Inclusion; 3) Involvement; 4) Leisure and recreation; 5) Communication and being understood; 6) Social relations; and 7) Self-management and autonomy. The average importance rating of the statements varied from 6.49 to 8.95. A definition of participation of this population was developed which included these seven clusters.

Conclusions

The combination of the developed definition, the clusters, and the statements in these clusters, derived from the perceptions of parents or family members, professionals, and experts, can be employed to operationalize the construct of participation of adults with VSPID. This operationalization supports professionals in their ability to give meaning to participation in these adults. Future research will focus on using the operationalization as a checklist of participation for adults with VSPID.

Introduction

It is estimated that visual and severe or profound intellectual disabilities (VSPID) affect 10,000 to 15,000 adults in the Netherlands (Limburg, 2007), which is approximately 0.05-0.08% of the Dutch population. These adults have an intelligence quotient of less than 35 points, and their visual acuity is less than 6/18 (Batshaw, Pellegrino & Roizen, 2013). Comorbidity is very common in these adults, i.e. they often experience other physical impairments, sensory impairments, or medical problems (Nakken & Vlaskamp, 2007; Poppes, van der Putten & Vlaskamp, 2010). Since adults with VSPID cannot compensate their intellectual disability by using vision or compensate vision loss by employing their cognitive capabilities, these compensation mechanisms collapse and, as a result, the visual and intellectual disabilities reinforce each other (Kiestra, 2005), which causes additional limitations in daily activities, e.g. living skills, communication, initiative, and social skills (Evenhuis, Sjoukes, Koot & Kooijman, 2009).

In residential facilities for adults with VSPID, an important goal of support professionals is to improve quality of life of adults with VSPID. Participation in society is considered to be an important aspect of quality of life (Schalock et al., 2002). People with severe or profound intellectual disabilities appear to be at risk of decreased participation (Axelsson & Wilder, 2014; Dusseljee, Rijken, Cardol, Curfs & Groenewegen, 2011). A higher degree of participation is associated with a favorable attitude of the social environment (Colver et al., 2012). Support professionals working with adults with intellectual disabilities generally agree with the principles of choice, inclusion, and participation of their clients, but they find it difficult to apply these principles to people with more severe intellectual disabilities (Bigby, Clement, Mansell & Beadle-Brown, 2009). In practise, support professionals often choose activities that are available in the client's environment and give less consideration to expanding the client's participation by developing motor, communicative and social skills. (Jansma, 2013). Reasons why support professionals could find it difficult improving participation of their clients may be the work load, a lack of creativity, or a lack of knowledge about possibilities for development. However, another reason could be the diversity of definitions of participation without a clear operationalization for adults with VSPID, which hampers the ability of support professionals to give meaning to participation in this particular population. Firstly, existing instruments of measuring participation, as an operationalization of participation, are not applicable for adults with VSPID (Jansma 2013). These instruments contain components that are not applicable for adults with VSPID because of their limitations, e.g. manage their own money, shop independently, participate in a local sport club, or independently maintain friendships. Secondly, most instruments are not suitable for the VSPID population since the instruments had to be completed by the adults themselves and this is not possible because of the multiple impairments of the population. Furthermore, an adapted version of the Visual Activity and Participation (VAP) scales (Looijestijn, 2007) was also not applicable for adults with VSPID, particularly not for persons with motor problems, which are common in these adults (Jansma, 2013).

General opinions about participation do not seem to be applicable to adults with VSPID. In recent years, most researchers have utilized the International Classification of Functioning, Disability and Health (ICF) where participation is defined as 'involvement in a life situation' (Perenboom & Chorus, 2003; World Health Organization, 2001). Since the exact meaning of 'involvement in a life situation' is not described in the ICF, the use of this definition has resulted in significant debate (Coster & Khetani, 2008; Dijkers, 2010; Maxwell, Alves & Granlund, 2012). For obscure reasons, the ICF combines activities with participation in its classification, which further complicates the definition of participation (Granlund et al., 2012). Eyssen, Steultjens, Dekker and Terwee (2011) define participation as 'performing roles in the domains of social functioning, family, home, financial, work/education, or in a general domain'. In this definition, for example, self-care activities belong to activities and not to participation because there is no social context. Therefore, this definition is not always applicable to young children or people with intellectual disabilities (Chien & Roger, 2011; Rainey, van Nispen, van der Zee & van Rens, 2014) because these groups depend on others in almost all activities and life situations. In addition, participation without a social element is described as participating actively in solo activities (Imms, Adair, Keen, Ullenhag, Rosenbaum & Granlund, 2015). In contrast to the ICF definition, Kiestra (2005) describes participation of people with VSPID as having control over their lives and joining in important situations. Several authors describe two elements in their definition of participation of children with disabilities: attendance, i.e., the child's presence in the activity and the child's involvement in the activity while attending it (Axelsson & Wilder, 2014; Coster, Law, Bedell, Khetani, Cousins & Teplicky, 2012; Maxwell, Alves & Granlund, 2012). In similar contexts and populations, autonomy is another term often associated with the concept of participation (Cardol, De Jong & Ward, 2002).

Recent systematic reviews in the field of children with disabilities indicate that the concept of participation is multidimensional, but requires further clarification (Adair, Ullenhag, Keen, Granlund & Imms, 2015; Imms et al., 2015). A feasible definition of participation which applies to adults with VSPID does not yet exist, and available definitions do not offer a concrete operationalization of participation for use in clinical practice for adults with VSPID. Therefore, the aim of the current study was to investigate the concept of participation and to develop a definition and an operationalization that are applicable to adults with VSPID.

Methods

Study design

The study design was mainly based on qualitative procedures which also included quantitative data collection and analysis. Participants performed online concept mapping.

Participants

Thirty parents or family members of adults with VSPID and 30 professionals working with this population were invited to participate in the study in cooperation with three residential facilities for adults with VSPID throughout the Netherlands. The professionals had at least two years' experience in working with the population on a daily basis, as direct support professional, or as indirect support professional such as physiotherapists, behavioral scientists, or physicians, and all were interested in the subject.

Seventeen Dutch experts with at least three years' experience with adults with VSPID were also invited to participate in the study. The selection of experts was based on their (research) projects; accordingly, the experts were expected to have a more general perspective on the subject.

Data collection

Concept mapping is a method used to explore the content of complex concepts and to develop questionnaires (Buchbinder et al., 2011; Trochim, 1989). The experience of all of the stakeholders was verbalized in a structured process which included seven steps (Trochim, 1989): 1) Defining participants; 2) Formulating the focus prompt; 3) Brainstorming: generating statements; 4) Sorting of statements; 5) Rating of statements by importance; 6) Analyzing: representing statements using concept maps; and 7) Interpreting concept maps. Steps 3, 4, 5, and 6 were performed digitally using concept mapping software (Concept Systems Incorporated). Concept mapping online minimized the time investment for participants, which facilitated their recruitment.

The participants answered questions about their own role (being a parent, family member, professional or expert) and a number of questions about their child or family member or clients with VSPID (age, wheelchair use, and hearing impairment).

To collect a wide spectrum of the ideas of the stakeholders about participation of the population, participants generated statements in response to a focus prompt (the seeding statement): 'Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?' After three weeks, the number of participants who participated in the brainstorming and the number of statements were considered to be sufficient.

After the brainstorming phase, two researchers refined the statement set by removing duplicate statements and statements regarding personal or environmental factors that were not related to the research question. The statements that were excluded were retained for later reference. If necessary, the selected statements were divided so that only one distinct idea was expressed by a statement; if possible, the participants' responses were transcribed verbatim to the original meaning of a statement. The number of statements to be sorted and rated was limited to 125, since this is considered to be the maximum number of manageable statements according to concept mapping.

The participants sorted each of the structured statements into a category that was logical to them according to their view of the meaning or theme of the statements. They created as many categories as they believed useful and named each category according to its theme or contents. The participants rated the importance of the structured statements on a scale from 1 as being 'not important' to 10 being 'very important' regarding the participation of the adult with VSPID.

The sorting data of a participant were included if a minimum of 105 statements were sorted. Sorting data were excluded if the categories were defined in terms of degree of importance of the statements instead of in terms of theme or content. The rating data of a participant were included if a minimum of one statement was rated and if there was no pattern in the rates assigned to the statements which indicated disinterest.

Procedure

At the start of the online concept mapping, the participants gave informed consent and received instructions via an email containing personal log-in information. The instructions explained the purpose of the study and the online system. Participants were allowed three weeks to complete the brainstorming phase.

At the beginning of the sorting and rating phase, the participants received an additional email with a link to the concept mapping software program and instructions on how to perform the sorting and rating tasks. Participants were given two months to finish the phase of sorting and rating.

Data analysis

The data were analyzed using two multivariate statistical methods provided in the concept mapping software: multidimensional scaling and cluster analysis (Kane & Trochim, 2007). The sorting and rating of the statements of each stakeholder group were represented two-dimensionally by concept maps, and the final stress value of each concept map was subsequently calculated. In concept mapping projects, stress values ranging between 0.21 and 0.37 are considered sufficient; a lower stress value suggests a better overall fit (Kane & Trochim, 2007). Point maps were made of five groups: 1) Parents or family; 2) Professionals; 3) Experts; 4) Professionals and experts together; and 5) All participants. Pattern match and Pearson correlation coefficients were determined to compare the ratings of parents or family members with professionals and experts.

The software analyzed patterns among the generated statements resulting in cluster maps of item clusters representing content similarities and item priority. Based on the names assigned to the categories by the participants, the software named the clusters in each map. Cluster maps were created for each stakeholder group. The maximum number of clusters in a cluster map (i.e., most specific content analysis) and the minimum number of clusters (i.e., most general content analysis) that provided a sensible and relevant representation of the results were assessed by two researchers (GH-RN, GH-AW). Starting with 20 clusters, each step from 20 clusters to five clusters was analyzed by evaluating if each statement in a cluster matched the cluster name, i.e., the name that was provided by the software based on the participants' suggestions. In each step, the number of clusters was reduced by one cluster by combining two clusters into one. First, the percentage of statements that matched the cluster name in these two clusters was defined. Second, the percentage of statements that matched the cluster name of the combined cluster was defined. The procedure of reducing the number of clusters was continued if the percentage of the combined cluster was greater than the percentage of the separate clusters. If the statements in a cluster were consistent but the cluster name did not match with the statements in that cluster, an alternative name was selected from the category labels provided by the system. The procedure of reducing the number of clusters was concluded if the percentage of the combined cluster decreased.

The mean rating of all of the statements and the rating of the clusters of the resulting cluster maps were calculated.

Interpretation of cluster maps

The resulting cluster maps and the mean rating of the statements of the five groups were compared. Based on these results, the resulting cluster map of all of the participants was interpreted independently by four researchers. The researchers (GH, RN, AP, AW) discussed the outcome of the independent interpretation and achieved consensus on the number of clusters, the names of the clusters, and the statements in the clusters. The final cluster map was interpreted independently again by the same researchers to increase the reliability of the results. In a following consultation, they discussed until consensus was reached on the statements in the clusters.

Based on the clusters and statements in the final cluster map, the four researchers independently developed a definition of participation of adults with VSPID. In a consultation, the researchers discussed the definition until consensus was reached.

Results

Response and characteristics of adults with VSPID

The total number of 61 participants were assigned in the brainstorming phase, but eight ultimately did not participate (13%). Consequently, 53 participants generated statements in response to the focus prompt of which 34% were parents or family, 45% were professionals, and 21% were experts. Of the participants, 47% lived in the north, 26% in the middle, and 23% in the south of the Netherlands while 4% lived abroad. The participants answered questions about their child (or family member) or clients with VSPID. Of the 53 participants, 26% had a child (or family member) or worked with clients aged between 20-40 years, 28% above 40 years old, and 45% worked with clients in both age categories. Of all of the participants, 26% had a child (or family member) or worked with clients who had a wheelchair for daily use, 11% worked with clients who did not use a wheelchair, and 62% worked with clients in both categories. Of the participants, 20% had a child (or family member) or worked with clients with a hearing impairment, and 80% worked with clients without a hearing impairment.

New participants were included in order to obtain a sufficient number of participants to finish the sorting and rating tasks. The total number of participants assigned to the sorting phase was 76; of these, 56 participants began the sorting and 40 participants completed this phase. Nine participants indicated that they believed that the sorting phase was too difficult and time consuming. The number of participants with approved sorting data was 39 of which 28% were parents or family, 49% were professionals, and 23% were experts. In total, 48 participants started the rating and 38 finished this phase; 44 rating data were approved: 27% parents or family, 50% professionals, and 23% experts.

Brainstorming: generation of statements

In total, participants generated 319 statements based on the focus prompt. After the deduplication of the statements, the list of statements consisted of three different categories: 1) statements related to the research question (N=125); 2) statements related to conditions required for participation (N=49), and 3) statements related to special opinions or advice on participation (N=9). Statements in categories 2 and 3 were not employed in the further concept mapping procedures (see examples in Table 1). The statements (N=125) that were related to the research question were used in the sorting and rating phases.

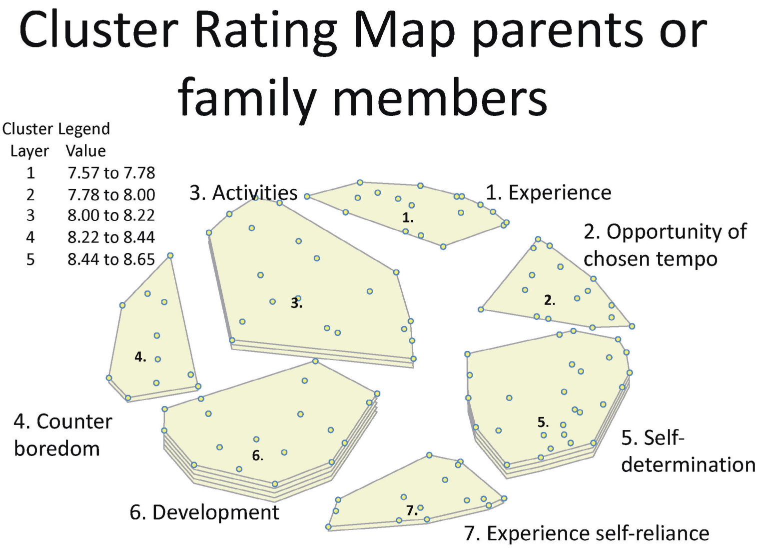
Table 1 | *Categories of excluded statements with examples*

	Category of statements	**Examples of statements**
2	Related to the conditions for participation	"there should be enough space in public buildings and shops" "a safe and clean environment with not too many sensory stimuli" "sufficient and well trained staff" "respect for the autonomy of the adult with VSPID" "a good analysis of the sensory impairments"
3	Related to the special opinion or advice on participation	"try to see possibilities, not only impossibilities" "it's difficult for adults with VSPID to express their wishes" "parents and professionals can disagree on the wishes of the adults with VSPID" "be aware of your influence on 'self-made choices' of the adults with VSPID"

Sorting and rating

The participants created a minimum of four to a maximum of 28 categories during the sorting phase (median 8). Participants rated the statements from 1 to 10. The lowest average rating of a statement by all participants was 6.49 (the statement: '(partly) takes care of own livelihood'), and the highest average rating was 8.95 ('have a right to the same medical care as people without disabilities').

The stress value of the concept map was 0.37 of parents or family members, 0.31 of professionals, and 0.33 of experts. Of all participants combined, the stress value was 0.29. In concept mapping projects, stress values ranging between 0.21 and 0.37 are considered sufficient; a lower stress value suggests a better overall fit. Figure 1 depicts the cluster rating maps of these groups.



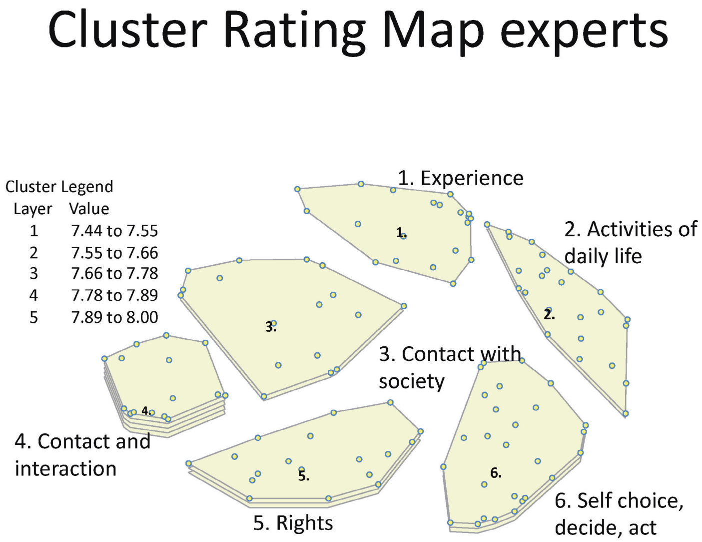
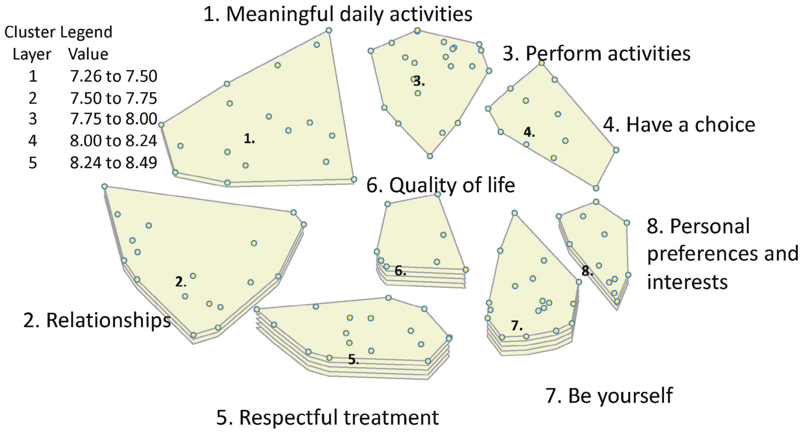


Figure 1 | *Cluster rating maps of parents/family members, professionals, experts, and all participants. The maps show clusters of items (the dots) that were considered similar in thematic content. More layers indicates greater importance. The value is the range between the minimum and the maximum rating of the statements in a cluster.*

Cluster Rating Map professionals



Cluster Rating Map all participants

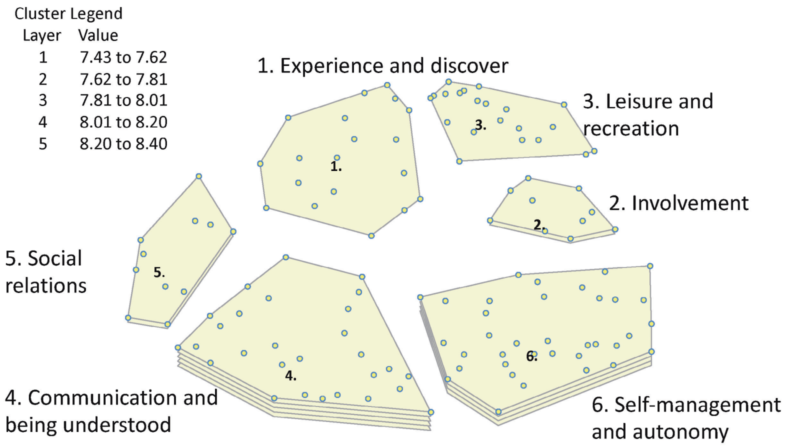


Figure 1 | *Continued.*

Based on the names of the clusters and the type of statements clustered in a specific category, there were a number of similarities in the cluster rating maps: 'experience and discover' (all participants) and 'experience' (parents/family members and experts); 'leisure and recreation' (all participants), 'activities' (parents/family member), 'meaningful daily activities and perform activities' (professionals) and 'activities of daily life' (experts); 'social relations' (all participants), 'relationships' (professionals), and 'contact and interaction' and 'contact with society' (experts). In addition, the names of a number of clusters were similar in meaning: 'self-management and autonomy' (all participants), 'self-determination' and 'experience self-reliance' (parents/family member), 'personal preferences and interest' and 'be yourself' (professional), and 'self choice, decide, act' (experts). The stress value of the cluster map of all of the participants (0.288) was the lowest of the four cluster maps which suggested a better overall fit. Therefore, the cluster map of all participants combined could be utilized as the cluster map that represented the ideas of the three stakeholder groups. This cluster map contained six clusters: 1) Experience and discover; 2) Involvement; 3) Leisure and recreation; 4) Communication and being understood; 5) Social relations; and 6) Self-management and autonomy. The cluster with the highest average rating was 'Communication and being understood' (8.40), and the clusters with the lowest average rating were 'Experience and discover' and 'Leisure and recreation' (7.43).

The average rating of the parents/family members was 7.95, and the average rating of professionals and experts together was 7.73. Figure 2 illustrates the pattern match between parents/family members versus professionals and experts together. Although parents/family members rated the clusters higher than professionals and experts together, the order of the importance of the clusters was comparable.

Table 2 demonstrates the Pearson correlation coefficients of the ratings between parents/family versus professionals and experts together. Pearson correlation coefficients range from 0.58 to 0.95, indicating moderate to strong correlation according to Feinstein (1987).

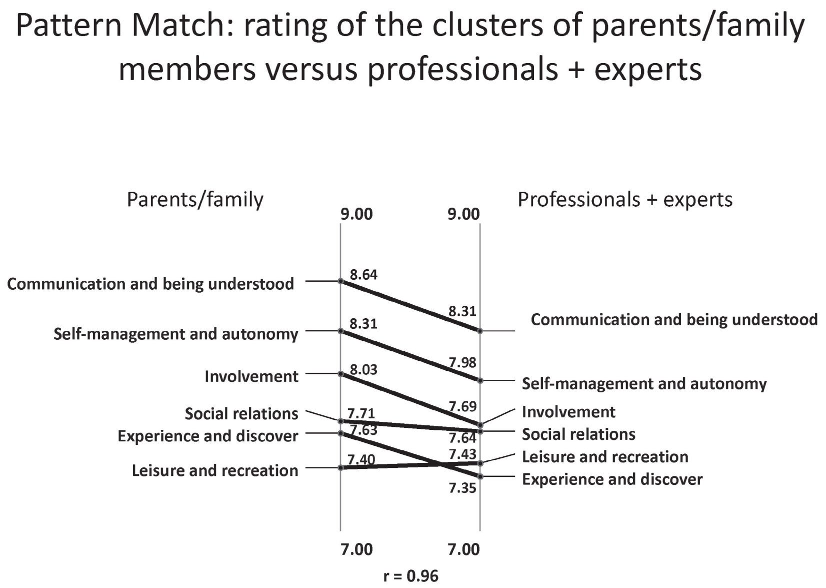


Figure 2 | *Pattern match between parents/family versus professionals and experts together*

Table 2 | *Pearson correlation coefficients of the ratings of the clusters between parents/family versus professionals and experts together*

Clusters	Pearson's r
Communication and being understood	0.58
Self-management and autonomy	0.70
Involvement	0.95
Social relations	0.77
Experience and discover	0.81
Leisure and recreation	0.77

Interpretation of cluster maps

The independent and common interpretation by the researchers of the final cluster map led to additional criteria for four clusters; these criteria advanced the clarity of the location of the statements in these clusters. Because of the content of the statements, the cluster 'Experience and discover' was separated into two clusters: 'Experience and discover' and 'Inclusion'. The extra criteria of the clusters were: 1)'Experience and discover': experiences with the senses; 2) 'Inclusion': do or have the same as other people and be part of society; 3) 'Involvement': active participation, and 4) 'Leisure and recreation': in spare time and, if possible, outside the residential care facility. Table 3 shows the final cluster names, the statements in the clusters, and the ratings of the statements of the three stakeholders.

Table 3 | *Cluster names, statements and their importance ratings by the three stakeholder groups*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Experience and discover	'within the possibilities, would like to experience much with their senses, with all their senses'	8.92	8.09	8.20
	'want to enjoy life, want to have a nice life'	9.42	8.95	8.20
	'experiencing rain and wind'	7.33	6.86	6.44
	'lying on the couch surrounded by a pleasant scent'	7.00	6.68	5.33
	'If the staff explains and guides it well, even as a blind person you can touch almost anything in stores.'	6.67	6.48	7.44
	'want to look for challenges more consciously'	7.08	7.05	7.22
	'should have the opportunity to discover for themselves'	8.58	8.32	8.11
	'want to go to the playground where they can experience motion'	7.42	7.14	7.11
	'want to get the opportunity to experience movements and/or to move, optionally with others'	8.17	7.77	7.00
	'can also learn new activities'	8.75	8.14	8.00
	'would like to be surprised, occasionally escape the daily routine and/or build new routines'	8.17	7.45	7.33
	'get the opportunity to always keep learning; want to learn'	8.58	8.36	7.89

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Inclusion	'at least once a month, with a trusted supervisor, leave the residential care facility'	7.67	7.09	7.78
	'a care farm provides opportunity for work-related activities'	7.17	6.76	7.11
	'participation can also be realized outside protected workplaces as we look at the possibilities of the individual and the workplace; individual consultation and guidance will be provided'	7.58	6.95	8.00
	'participation in meaningful work or work-related activities'	7.67	7.45	8.00
	'want their life and thoughts to be enhanced and interaction with the outside world to be promoted; for example: to the pool, festivals, shopping, holiday, music, concerts, cinema, and participating in bike tours'	8.33	7.68	8.00
	'entitled to the same good medical care as people without disabilities'	9.50	9.14	7.78
	'must benefit from good and independent representation of interests'	9.08	8.14	8.22
	'wish they could go on a holiday with their family'	7.17	7.00	7.00
	'wish there is enough space and adaptations in public buildings, shops, and public transport so they can go wherever they want to go'	7.83	7.55	8.33
	'wish to really be part of the neighborhood in which they live'	7.58	7.32	7.67
	'want to take part in a church service'	6.25	7.05	7.44
	'has a healthy lifestyle'	8.17	8.18	6.78

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Inclusion	'have the right to have a family life and/or a (surrogate) father or mother'	8.08	7.91	7.67
	'varied meals'	9.00	8.05	6.11
	'sometimes wish that life outside the door is brought to the person (for example through social internships)'	7.25	7.05	7.78
	'can make optimal use of resources'	8.75	8.36	8.11
	'want to discover what the world has to offer'	7.42	7.50	8.56
	'offer the opportunity besides "what we always do here" to look beyond the residential care facility; do not bring everything inside but provide the opportunity to go out of the facility'	8.83	7.95	8.22
	'make the familiar environment as broad as possible'	8.67	8.50	8.22
	'are also entitled to celebrate their birthday in a convivial way with visitors, gifts and cake'	8.75	8.09	7.56
	'look at the opportunities in the neighborhood in which they live, such as care by family and neighbors'	6.83	7.10	7.67
	'participating in activities in the street/neighborhood where they live'	7.00	7.18	8.22
	'live among other people in an ordinary neighborhood, not in the residential care facility'	7.17	6.19	6.78
	'can use facilities outside the residential care facility'	7.25	7.36	7.67
	'have a nice and good quality of life'	8.92	8.95	8.33
	'can participate in traffic as freely as possible'	6.17	6.68	7.78
	'would like the same as everyone else: nice atmosphere, happiness and structure'	9.00	8.55	8.11
	'The group in which the clients live is also part of society.'	8.17	7.82	6.67

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Involvement	'Involvement in general daily activities is very important: this happens in your life very often.'	8.75	8.19	7.44
	'small events also count; for example, picking a few flowers is also fine'	7.33	7.48	6.67
	'wish to be involved in and, if possible, to actively participate in daily chores; for example, taking a bib into the laundry basket or doing the dishes'	8.92	8.00	8.44
	'wish to undertake activities that suit interests and preferences'	9.08	8.41	8.78
	'wish people would think more in opportunities rather than limitations'	8.58	8.95	8.56
	'active participation or a producing role in cultural activities such as theatre, painting and making a movie, if possible'	6.58	6.09	7.56
	'have the right to explore, to choose, to obtain, and to maintain in the field of computers; want to use a simple computer program and/or Ipad'	7.33	7.18	7.22
	'meaningful daily schedule, which you can talk about in the evening, during dinner'	7.92	8.41	7.44
	'want to be involved in cooking'	7.83	7.32	7.33
	'listen to the news bulletins and the weather forecast on television in a quiet environment'	6.58	6.64	6.22

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Leisure and recreation	'would like someone to try something with them that (s)he is not sure whether they will like it: for example, ice skating, rapids in the pool, try perfume in the drugstore, and eat a herring'	7.92	7.73	7.70
	'wish to visit a garden center because it is fantastic: smelling the flowers and the sand, feeling the plants, the animals, the rough/ smooth stones and the water from a fountain, seeing the lights (of the Christmas show)'	7.33	7.09	6.70
	'want to visit a fun fair: there is always something to feel, smell or experience'	6.42	6.86	6.89
	'Doing grocery shopping in the village has added value above having everything delivered at home. In the supermarket, it smells of bread and apple pie; at the drugstore, it smells of deodorant and perfume.'	8.00	7.38	7.89
	'want to undertake more activities outside the residential care facility; for example, go to the market, the hairdresser, or a restaurant'	8.67	7.76	8.22
	'to the beach, possibly with wheelchairs that are easy to use in the soft sand'	6.58	6.82	7.11
	'offer something unexpected; for example, whitewater canoeing, camping in a tent, or visiting an island festival'	6.17	7.05	8.00
	'want to do something in their free time, not just sit and wait'	8.83	8.68	8.00
	'like to ride horses at a riding club'	6.83	7.18	6.22
	'want to enjoy nature'	8.42	7.50	7.44

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Leisure and recreation	'want to play (adapted) sports'	7.25	7.64	8.11
	'want to practice (adapted) hobbies'	7.25	7.73	8.22
	'want to visit a pub or restaurant and, if possible, sit outside with a drink and something to eat'	7.25	7.27	7.89
	'can go on a holiday and choose from multiple holiday possibilities and accommodations'	6.58	6.82	7.44
Communication and being understood	'do not want to suffer from pain or sounds'	8.67	8.73	7.30
	'want someone who stands up for them if they can't do it themselves'	9.50	8.91	8.30
	'would like to be guided by trusted staff who endeavor to (get to) know them well'	8.92	8.77	8.20
	'would like personal, honest attention, just like everyone else'	9.33	8.36	8.10
	'If there is pleasant contact during daily activities, continue it. For example, do not start to clear the table; you can do that at a later time'	8.50	8.33	7.44
	'want to be able to share positive and negative experiences with others'	7.00	7.82	8.00
	'want to know that they are seen, heard, and understood even if they are deaf and blind'	9.00	8.55	8.67
	'want attention for dealing with loss'	7.75	8.32	6.67

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Communication and being understood	'People with VSPID have something to contribute to other people: a smile, kind words, sounds, jokes, songs, a touch, and deeply human contact.'	7.75	7.73	7.89
	'have optimal communication tools'	8.17	9.09	8.78
	'wants the other to make an effort to know them well'	9.17	8.40	8.44
	'wants the other to regard him as a unique individual'	8.58	8.77	7.89
	'want to be understood and respected in the hospital'	9.08	8.36	7.67
	'should be able to anticipate their care or support'	8.08	8.23	7.89
	'want to be involved in a conversation'	7.67	8.09	8.22
	'get the opportunity to learn to express themselves or to communicate through gestures or icons'	8.92	8.91	8.33
	'want the group dynamics to suit their needs and to give sufficient rest'	9.17	8.27	7.11
	'want to be seen and treated as a person who is worth as much as anyone else'	9.50	8.68	8.33
	'have the opportunity to develop themselves by expressing feelings and thoughts'	8.08	8.41	8.22
	'want to experience that they matter; this makes them feel proud or appreciated'	9.08	8.50	7.67
	'wish that we look closely at their non-verbal behavior and say what we see'	9.00	8.77	8.11

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Social relations	'wish to have people around who undertake activities with them because they like to, for instance, because of a common interest and not because they are paid'	7.83	7.32	7.50
	'interaction with other individuals with VSPID'	7.92	7.45	7.56
	'want to be able to cooperate with other individuals with VSPID on work-related activities'	6.92	6.86	7.56
	'has a need for intimacy, love, warmth, patience, physical contact, and someone who helps them through hard times'	9.50	8.86	7.89
	'have contacts within their own living environment and outside their living environment: family, friends, neighbors, acquaintances, coworkers etc.'	8.50	8.36	8.78
	'can start a friendly or sexual relationship'	6.75	7.36	8.56
	'are able to perform several social roles'	7.08	7.52	7.78
	'there are some trusted counselors available'	8.08	8.05	7.56
Self-management and autonomy	'would like everything to go at their own pace and would like to be able to take their time for everything'	8.83	8.73	8.40
	'would like to be entitled to mistakes, wrong choices, and grumpy days'	8.00	8.23	7.10
	'would like to be enabled to influence whatever they can, even very small things'	8.25	8.41	8.30
	'want their bodily experience and their need for sexuality to be acknowledged and to be discussed, described and shaped honestly, seriously and respectfully'	8.25	8.05	7.40

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Rating Parents/ family	Rating Professionals	Rating Experts
Self-management and autonomy	'It doesn't always matter if someone doesn't seem to be enjoying something: maybe he will at another time.'	7.58	7.82	6.60
	'does not want the things they can do, would like to do, or could do with a little help to be taken away from them; stimulate self-management as much as possible'	8.50	8.18	8.50
	'wish that someone would find out what their preferences are, for instance, in music'	8.50	8.23	8.00
	'want to be able to make their own choices'	8.83	8.36	8.67
	'have autonomy and a feeling of autonomy in order to maintain dignity and self-respect'	8.75	8.41	8.78
	'would like conversation and decision-making to be with them, not about them'	7.42	8.23	8.67
	'want to get involved in which clothes they wear'	7.50	7.27	7.33
	'want to be able to be proud of what they do'	8.50	8.41	7.56
	'want to able to indicate their own will, even in tough situations'	8.50	8.14	7.78
	'want to decide what they eat or drink'	8.58	8.05	7.67
	'eat independently, if possible'	8.42	7.95	7.56
	'want to be able to decide what time they go to bed'	7.17	7.45	7.44
	'want variety in their lives, tailored to their needs'	8.75	8.27	8.33
	'want to look good and neat'	8.50	8.05	6.44
	'would like a balance between a clear day/week structure and challenges'	8.58	8.36	7.67

Table 3 | *Continued.*

Cluster name	Statement (In response to the focus prompt, “Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?”)	Rating Parents/ family	Rating Professionals	Rating Experts
Self-management and autonomy	‘have wishes like everyone else’	8.67	8.36	7.56
	‘let the elderly enjoy their life in peace; they don’t have to do everything themselves anymore’	8.33	8.38	6.56
	‘When you are at work, you have to do what is expected from you; when you are at home you can decide for yourself.’	8.08	7.64	6.78
	‘participation is being enabled to be who you are: lazy, active, social, helpful’	8.17	8.09	7.00
	‘The need of the patient is the base, not the social conventions; the participation in (daily) life is different for everyone.’	8.58	8.55	8.11
	‘are entitled to care based on their needs’	9.33	8.77	7.78
	‘receive education based on their needs’	7.25	6.91	7.67
	‘When they are ill, they can stay at home.’	9.00	8.91	7.56
	‘can be themselves in the house they live in’	9.50	8.77	7.67
	‘can have a day off without a reason’	8.58	7.86	6.22
	‘(partly) decides about their own possessions’	6.92	7.27	7.56
	‘functions autonomously whenever possible; helpful skills will be taught’	7.58	7.68	8.56
	‘(partly) takes care of own living’	5.83	6.59	7.11

Definition

Based on the clusters and the statements in the final cluster map, the authors developed the following definition: 'Participation of adults with VSPID means active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experiences and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ('being understood') wherein the adult with VSPID has an active and steering role ('self-management and autonomy').'

Discussion

The purpose of this study was to develop a definition and operationalization of participation of adults with VSPID based on the perceptions of parents or family members, professionals, and experts. The study has resulted in a definition of participation for this population based on a final cluster map containing seven clusters. These clusters and the statements in these clusters operationalize the concept of participation of adults with VSPID.

Our definition of participation reflects the hierarchal and multidimensional structure of the construct of participation in adults with VSPID. 'Active engagement and involvement' is an important part of the definition and indicates an active and engaged experience in a situation. This is in accordance with the studies of Coster et al. (2012), Hoogsteen and Woodgate (2010), and Maxwell, Augustine and Granlund (2012). In the current study, participation of adults with VSPID encompasses a broad range of dimensions: 'daily activities, social contact, and societal and leisure activities'. In the literature regarding participation of adults, 'daily activities' as in self-care activities are not always considered to be a component of participation (Eyssen et al., 2011). However, in the literature about childrens' participation, it is more common to include these activities into the concept of participation because small children are primarily performing daily activities together with others (Chien et al., 2011; Rainey et al., 2014). We suggest that the same applies for adults with VSPID. 'Societal and leisure activities', 'Inclusion' and 'Experiences and discovery' are three of our clusters, which indicate that the adult with VSPID should be offered the opportunity to attend these activities and situations. This theme, 'attendance' or 'be present', can be found in most of the literature concerning participation (Imms et al., 2015). Another aspect of participation of adults with VSPID is that not all activities require social interaction. Several statements indicate solo activities, for example, 'experience rain and wind', 'eat independently, if possible' and 'want to practice (adapted) hobbies'. These results are also in line with the findings of the study of Imms et al. (2015). The statements of the cluster 'Inclusion' refer to doing or having the same as other people and being part of society. It is apparent that these issues cannot be taken for granted for adults with VSPID who live in residential care facilities.

The participants mentioned the aspect of 'communication and being understood' very often (21 statements) and assigned this cluster the highest rating of all clusters (8.40 points), which is an obvious sign of the significant importance of this aspect to the participation of the adults with VSPID. As described in the definition, the aspect of communication appears to be a precondition for participation of adults with VSPID. In addition, by rating this aspect high, the participants could be indicating that communication with adults with VSPID is not without difficulties and, therefore, extra effort must be made. Also, for these adults, 'self-management and autonomy' are only possible if they are 'being understood'. 'Self-management and autonomy' could be perceived as results of 'being understood'. It seems that the participants emphasized both the importance and the difficulty of 'self-management and autonomy' for the participation of adults with VSPID. Furthermore, the results show that in the new definition the concepts of activities and participation are connected just like they are in the ICF model.

Although the participants in this study were all Dutch, it is likely that the concepts mentioned in the clusters apply to other socio-cultural contexts, although the exact statements and the rating of the statements could be different. This relies on the values, the habits and the possibilities in other socio-cultural contexts. For instance, a statement like 'would like someone to try something with them that (s)he is not sure whether they would like it: for example, ice skating, rapids in the pool, try perfume in the drugstore, and eat a herring' seems especially applicable for the Netherlands.

The excluded statements (statements related to the conditions required for participation (N=49) and statements related to special opinions or advice about participation (N=9)) were not related to the research question, however, the participants still mentioned these statements which could indicate an awareness of the difficulties of participation of adults with VSPID; participation of this population is challenging and requires extensive support from the environment. These statements could be mostly classified into the environmental factors of the ICF. For the participants, these statements appear to be important for the participation of adults with VSPID. The importance of environmental dimensions for the construct of participation is also described by Imms et al. (2015) and Maxwell et al. (2012).

Neither in the definition nor in the names of the clusters is the visual aspect of participation explicitly described. Nevertheless, a number of statements explicitly mentioned the visual aspect (‘if the staff explains and guides it well, even as a blind person, you can touch almost anything in stores’, ‘want to know that they are seen, heard, and understood, even if they are deafblind’), and other statements indicate the visual aspect more implicitly (‘within the possibilities, would like to experience much with their senses, with all their senses’, ‘experiencing rain and wind’, ‘wish to visit a garden center because it is fantastic: smelling the flowers and the sand, feeling the plants, the animals, the rough/smooth stones and the water from a fountain, seeing the lights (of the Christmas show)’, and ‘do not want to suffer from pain or sounds’). As a result, the visual aspect of participation will be included in the future operationalization of participation of adults with VSPID.

Strengths and limitations

A strength of this study is the combination of concepts and opinions of people who are very familiar with the population of adults with VSPID from different perspectives including parents or family members, professionals, and experts spread out across the Netherlands. They reacted on a focus prompt and offered a broad range of ideas about participation. Based on the statements put forward from these different perspectives, as well as their clustering and rating, the researchers, who also represent different backgrounds, developed the definition of participation in a clear process.

A limitation of the study could be the use of the online concept mapping procedure. Unlike face-to-face concept mapping that is more focused on consensus, the online procedure does not offer participants the possibility to react to each other. However, the online procedure did provide the participants with the possibility to freely express their opinions. In addition, because of the relatively minimal time investment, more participants were probably willing to participate.

Another limitation of this study is the use of the views of parents or family members, professionals and experts and not the views of the individual adults with VSPID. Interviewing adults with VSPID was not possible because they do not have the verbal and intellectual skills to give their opinion on the subject of participation. Therefore, we decided that the opinion of the proxies provides the best possible opportunity to obtain information about the meaning of participation of the adults with VSPID (Petry, Maes & Vlaskamp, 2007). By asking as many proxies as we did, we consider our definition representative and valid at this stage. In future studies, the use of direct observation of the active and engaged experience of adults with VSPID will provide additional information about the impact of the results of this study with proxies.

Recommendations for further research and practical implications

The developed definition, in combination with the clusters and the statements in these clusters, operationalize the concept of participation of adults with VSPID. For use in practice, a checklist based on the clusters and statements could be developed and evaluated in future research. This checklist could offer the possibility to gain insight into the actual participation of adults with VSPID. Additionally, this checklist could offer support professionals the ability to improve participation of the adults with VSPID.

Conclusion

In this study, for the first time, parents (or family members), professionals and experts offered their opinions about the participation of adults with VSPID through an online concept mapping procedure. Their input was used to establish a definition of the concept of participation of adults with VSPID. The combination of the developed definition, the clusters, and the statements in these clusters can be utilized to operationalize the construct of participation of adults with VSPID. This operationalization offers support professionals the ability to give meaning to participation of these adults. Future research will focus on the development of a checklist that is based on the clusters and statements ascertained in this study. Using this checklist, we could gain insight into the actual participation of adults with VSPID.

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Participation of adults with visual and severe or profound intellectual disabilities: Analysis of individual support plans

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Abstract

Background

The extent of participation of adults with visual and severe or profound intellectual disabilities (VSPID) is unclear.

Aims

To explore participation of adults with VSPID and the association between occurrence and importance of aspects of participation.

Methods

Individual support plans (ISPs) of 40 adults with VSPID were analyzed: selected text fragments were categorized according to 125 previously operationalized statements that had different levels of importance and were divided into seven participation clusters.

Results

The ISPs contained 2,791 text fragments that related to a statement. All clusters were covered: the clusters 'Experience and discover' (91.7%), 'Involvement' (90%), and 'Social relations' (87.5%) were well covered. 'Inclusion' (53.6%) and 'Leisure and recreation' (57.1%) were mentioned less often. Among the 36 high-importance statements, two related to 'Inclusion', 'Involvement' and 'Social Relations' each, three to 'Communication and being understood', and five to 'Self-management and autonomy' had at least 30 text fragments.

Conclusions

The participation domains 'Experience and discover', 'Involvement', and 'Social relations' are well-documented, suggesting that adults with VSPID participate in those areas. However, domains such as 'inclusion in society' and 'leisure in society' were not documented. This overview of participation offers residential facilities the opportunity to determine in which areas participation can be improved.

Introduction

The number of adults with visual and severe or profound intellectual disabilities (VSPID) is substantial, and it has been observed that these adults may experience problems in participation because of their limitations (Evenhuis, Sjoukes, Koot & Kooijman, 2009). In the Netherlands, there are 10,000 to 15,000 adults with VSPID which is approximately 0.05 to 0.08% of the Dutch population (Limburg, 2007). People with an intellectual disability combined with a visual disability may experience additional limitations in daily activities because the intellectual and the visual disabilities reinforce each other (Evenhuis et al., 2009; Kiestra, 2005).

According to the United Nations Convention on the Rights of People with Disabilities, people with disabilities have the right to participate fully in society and community life (United Nations, 2006). This UN convention has been effective in the Netherlands since July 14, 2016 (Nederlandse overheid, n.d.). Also, several studies have stressed the importance of participation (Bigby, Anderson & Cameron, 2017; Whiteneck & Dijkers, 2009). Research regarding persons with intellectual disabilities has indicated that participation in society contributes to better quality of life (Schalock et al., 2002). Furthermore, for persons with profound intellectual and multiple disabilities, participation is important for their individual development and emotional well-being (Axelsson, Imms & Wilder, 2014; Boren, Granlund, Wilder & Axelsson, 2016). As a consequence of the right of people with disabilities to participate fully in society and community life, society is asked to make an effort for inclusion of people with disabilities. This requires a new perception on usual care by society, including residential facilities who might need to reconsider their current support structure of people with intellectual disabilities. This means they might need to improve awareness and skills of their professionals. In order to establish innovative practice, it is important to consider what participation means for this population. When employees provide support and stimulate participation, the vulnerability of the population must be taken into account, i.e.: their visual and intellectual limitations affect their ability to participate. For example, participation of some adults with VSPID could be influenced by their dependence on auditory information in order to experience safety (van den Bosch, Andringa, Baskent & Vlaskamp, 2016).

The most frequently employed definition of participation is described by the International Classification of Functioning, Disability and Health (ICF): ‘involvement in a life situation’ (World Health Organization, 2001). However, this definition proved to be unclear in practice and, therefore, has prompted discussion (Coster & Khetani, 2008; Dijkers, 2010; Maxwell, Alves & Granlund, 2012). Recent reviews indicate that the concept of participation is a multidimensional and also ambiguous concept and requires further clarification related to the characteristics of people (Adair, Ullenhag, Keen, Granlund & Imms, 2015; Imms, Adair, Keen, Ullenhag, Rosenbaum & Granlund, 2015). Therefore, in our previous study (Hanzen, van Nispen, van der Putten & Waninge, 2017), we developed a definition and operationalization of participation for adults with VSPID that was derived from the perceptions of the individuals who are the most familiar with this population, i.e., parents or family members, professionals, and experts in the field of research. Based on the operationalization of participation, we developed the following definition: *'Participation of adults with VSPID means active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experiences and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ('being understood') wherein the adult with VSPID has an active and steering role ('self-management and autonomy')'.*

Until recently, data concerning the degree to which adults with VSPID participate were virtually unknown. Few studies have now shown that both people with visual impairments (Alma, van der Mei, Melis-Dankers, van Tilburg, Groothoff & Suurmeijer, 2011) as well as people with moderate, severe, or profound intellectual disabilities (Axelsson & Wilder, 2014; Bigby, Clement, Mansell & Beadle-Brown, 2009; Dusseljee, Rijken, Cardol, Curfs & Groenewegen, 2011) are at risk for decreased participation. In view of the severity of their disabilities, participation does not appear to be self-evident for people with severe or profound intellectual disabilities as they are highly dependent on persons in their environment and on other environmental factors. Examples of these environmental factors are the attitude of staff (Bigby et al., 2009; Egli, Feuer, Roper & Thompsom, 2002; Perry & Felce, 2005), family support (Heller, Miller & Hiesh, 2002), and the distance to community facilities (Buttimer & Tierney, 2005).

It can be contended whether the manner in which participation is examined in the studies mentioned above is also appropriate for adults with VSPID. Most studies investigated a particular component of participation or concentrated on only a small number of aspects of participation. In the study of Alma et al. (2011), participation was reflected in four of the nine chapters of the 'Activities and Participation' domain of the ICF, specifically, 'domestic life', 'interpersonal interactions and relationships', 'major life areas', and 'community, social, and civic life'. Axelsson and Wilder (2014) concentrated on participation in family activities, while Bigby et al. (2009) emphasized life in community, and Dusseljee et al. (2011) investigated community participation in the domains work, social contacts, and leisure activities. Unlike others, Talman, Gustafsson, Stier and Wilder (2017) did examine all areas of ICF in implementation plans; however, they emphasized the importance of further research into the opinions of staff about the concept of participation for individuals with a profound intellectual disability.

Currently, information about daily life activities and participation of adults with VSPID can be found in their individual support plans (ISPs) that residential care facilities in the Netherlands are required by law to use. ISPs are written documents that allow the support to be person-centered by describing what the possibilities, wishes, and needs are of a person. Subsequently, specific personal goals are established, and the services should make arrangements to achieve these goals (Herps, Buntinx, Schalock, van Breukelen, & Curfs, 2016; Mantousova-Done & Gates, 2006). Although ISPs differ in length and content, they provide multiple benefits (Clark & Gates, 2006; Herps et al., 2016; Poppes, Van der Putten & Vlaskamp, 2011). One of these benefits is that ISPs document and plan interventions in all aspects of the lives of persons with intellectual disabilities (Kamstra, Van der Putten & Vlaskamp, 2016) and should facilitate an assessment of the level of participation of adults with VSPID.

To determine the actual participation of adults with VSPID, the goal of this study was to explore their levels of participation by utilizing the ISPs. The research questions of this study were: 1) What is the extent to which adults with VSPID participate?; and 2) What is the relationship between the occurrence and importance of aspects of participation? This exploration may direct interventions to increase the participation of this population.

Methods

Participants and settings

In this study, ISPs of the participants were analyzed. The participants were adults with VSPID; all had a visual impairment (visual acuity < 6/18) or blindness (visual acuity < 3/60 and/or visual field < 10 degrees around the point of fixation, ICD-10, 2016) and an intelligence quotient of less than 35 points (Batshaw, Pellegrino & Roizen, 2013). The presence of auditory impairment and epilepsy were registered as well as level of mobility.

The participants were residing in three residential facilities for persons with visual and intellectual disabilities that were dispersed throughout the Netherlands. A random sample of 120 adults with VSPID were recruited: 60 in facility A (in the north of the Netherlands); 30 in B (in the south of the Netherlands); and 30 in C (in the center of the Netherlands).

The total number of participants for which written informed consent was provided by the legal representatives was 81: 50 (of 60: 83%) from facility A; 21 (of 30: 70%) from facility B; and ten (of 30: 33%) from facility C. Three participants passed away before the data collection began, therefore, they were excluded. From residential facility C, only ten legal representatives gave informed consent. To achieve a representative sample by taking into account the total number of adults with VSPID within the different residential facilities, 40 ISPs were analyzed: in addition to the ten ISPs from C, 20 were randomly chosen from A, and ten were randomly selected from B.

Characteristics of the participants are depicted in Table 1. Information regarding the characteristics was collected as documented in the ISPs. Because the used terminology of motor possibilities was inconsistent, we applied the term mobility. The mean age of the participants was 40.7 (range: 22-69, SD 13.8).

Data collection

In order to explore the extent to which adults with VSPID participate, data from the latest version of the ISPs of the participants were collected retrospectively. The digital ISPs from residential facilities A and B were collected by the first author and a master student of the Faculty of Behavioural and Social Sciences, Department of Pedagogy and Educational Sciences, unit of special needs education and youth care, University of Groningen. These data were accessible from a secure working environment using a personal username and password. Residential facility C anonymized the ISPs prior to sending them by mail to the researcher.

Table 1 | *Participant characteristics*

(n=40)	N (%)
Gender	
Male	25 (62.5)
Female	15 (37.5)
Intellectual disability	
Severe	20 (50.0)
Profound	20 (50.0)
Visual impairments	
Partially	18 (45.0)
Blind	22 (55.0)
Auditory problems	
None	31 (77.5)
Severe	7 (17.5)
Deaf	2 (5.0)
Mobility	
No	19 (47.5)
Partially	3 (7.5)
Yes	18 (45.0)
Epilepsy	
No	14 (35.0)
Yes	26 (65.0)

The information included parts of ISPs that described the long-term and short-term goals, personal descriptions, needed support and tools, and activity plans. Sections regarding history and evaluation were excluded because this information did not describe the current goals and plans.

ISPs were analyzed by collecting and studying text fragments related to participation that were according to the definition and operationalization of participation (Hanzen et al., 2017). The selected text fragments were categorized deductively according to the 125 statements and divided into the following clusters: 1) Experience and discover; 2) Inclusion; 3) Involvement; 4) Leisure and recreation; 5) Communication and being understood; 6) Social relations; and 7) Self-management and autonomy (Hanzen et al., 2017). Furthermore, the information on characteristics of the adults with VSPID was collected.

The consensus between the two researchers on the categorization of the text fragments in the statements was 83% (range: 76% - 88%). To increase validity and inter-rater reliability of the text selection, the researchers developed guidelines to categorize the text concerning participation into the statements and clusters. The statements consisted of complete sentences, and these sentences were rarely reflected literally in the ISPs, therefore, the researchers needed to interpret the text fragments. For example, a text fragment such as *'enjoy the visit of brothers and sisters'* was categorized into the statement 'have contacts within their own living environment and outside their living environment: family, friends, neighbors, acquaintances, coworkers etc.', and this statement is part of the cluster 'Social relations'. After independently categorizing one ISP of each residential facility, the researchers discussed the outcomes and supplemented the linking rules in the guidelines. With these adapted guidelines, both researchers independently selected and categorized text fragments from another six ISPs that were equally divided over the three facilities.

To calculate the intra-rater reliability, one researcher categorized the nine ISPs for the second time after two weeks; reliability ranged between 89% and 96%. After the reliability was considered to be sufficient, the researchers collected the characteristics of the participants and categorized the text fragments from the other 31 ISPs.

Data analysis

Descriptive statistics (frequencies, means, range, and standard deviation) were used for the analysis of the participants' characteristics and the categorization of the text fragments. It was analyzed how often text fragments that were related to the statements were documented in the ISPs as a sum and per person. Statements without text fragments could indicate that no attention was paid to these aspects of participation in the support of the adults with VSPID. As a mutual agreement, taken into account the total number of analyzed ISPs and the fact that we did not expect every statement in each ISP because not every statement is suitable for each person with VSPID we regarded 30 or more text fragments in a statement as sufficient attention for this particular aspect of participation within the ISPs and, therefore, also in the support of the population.

To examine the relationship between the occurrence and the importance of the statements, we first calculated the quartile of the statements with the highest ratings; ratings above 8.3 on a scale from 1 ('not important') to 10 ('very important') that were found in the previous study (Hanzen et al., 2017). We compared these statements with the statements having ≥ 30 text fragments in the current study and analyzed the amount of agreement. All of the statistical analyses were performed using the Statistical Package for the Social Sciences (IBM SPSS version 24) and Excel 2010.

Results

Clusters and statements: number of text fragments and number of persons with text fragments

Supplemental table provides an overview of the text fragments that were found divided by statements and clusters. It shows in which statements and clusters text fragments were determined that belonged to that statement and for how many participants these text fragments were found. The 40 ISPs contained a total of 2,791 text fragments. Text fragments were found for each of the seven clusters but not for every statement. In total, 26 statements had ≥ 30 text fragments. Additionally, 34 statements had no text fragments.

'Experience and discover'

In the cluster 'Experience and discover' (original number of 12 statements), one statement (8.3%) without text fragments was found ('want to go to the playground where they can experience motion') and three statements (25.0%) with ≥ 30 text fragments. For example, the statement 'within the possibilities, would like to experience much with their senses, with all their senses' had 151 text fragments in 36 ISPs. Examples of these text fragments were: *'she experiences the world based on what she sees, hears, tastes, feels and smells'* and *'she can enjoy her music box and listen to music'*.

'Inclusion'

The cluster 'Inclusion' (original number of 28 statements) had 13 statements (46.4%) without text fragments and three statements (10.7%) with 30 or more. Examples of statements without text fragments were 'wish to really be part of the neighborhood in which they live' and 'can use facilities outside the residential care facility'. Two statements had more than 100 text fragments. One of these statements was 'entitled to the same good medical care as people without disabilities' (171 text fragments in 39 ISPs) with text fragments such as *'he receives vaccination against flu every year'* or *'is being treated by the physiotherapist'*. The other statement with more than 100 text fragments was 'can make optimal use of resources' (162 text fragments in 34 ISPs) with text fragments such as *'he uses a wheelchair'* and *'he has a custom spoon'*.

'Involvement'

In the cluster 'Involvement' (original number of ten statements), there was one statement (10%) without text fragments ('listen to the news bulletins and the weather forecast on television in a quiet environment') and three statements (30%) with ≥ 30 text fragments. One of these statements was 'wish to undertake activities that suit interests and preferences' (101 text fragments in 37 ISPs) with text fragments such as *'she is interested in music and toys with special sounds'* or *'he is very focused on sports, especially football'*.

'Leisure and recreation'

The cluster 'Leisure and recreation' (original number of 14 statements) had six statements (42.9%) without text fragments and two statements (14.3%) with ≥ 30 text fragments. These statements were 'want to play (adapted) sports' (31 text fragments in 22 ISPs) and 'want to practice (adapted) hobbies' (33 text fragments in 20 ISPs). Examples of statements without text fragments were 'want to visit a fun fair: there is always something to feel, smell, or experience' and 'offer something unexpected; for example, whitewater canoeing, camping in a tent, or visiting an island festival'.

'Communication and being understood'

The cluster 'Communication and being understood' (original number of 21 statements) had six statements without text fragments (28.6%) and five statements (23.8%) with ≥ 30 text fragments. The statement with the most text fragments in this cluster was 'wish that we look closely at their non-verbal behavior and say what we see' (156 text fragments in 36 ISPs). Examples of text fragments in these statements were *'she cannot communicate verbally and screams when she has fun'* and *'he shows with body language and facial expressions whether he is tense'*. Examples of statements without text fragments were 'wants the other to regard him as a unique individual' and 'want to be understood and respected in the hospital'.

‘Social relations’

In the cluster ‘Social relations’ (original number of eight statements) was one statement (12.5%) without text fragments (‘there are some trusted counselors available’) and three statements (37.5%) with ≥ 30 text fragments. The statement with the most text fragments in this cluster was ‘have contacts within their own living environment and outside their living environment: family, friends, neighbors, acquaintances, coworkers etc.’ with 127 text fragments in 35 ISPs.

‘Self-management and autonomy’

The last cluster, ‘Self-management and autonomy’ (original number of 32 statements) had six statements (18.8%) without text fragments and seven statements (21.9%) with ≥ 30 text fragments. Two of these statements had more than 200 text fragments. One of these statements was ‘does not want the things they can do, would like to do, or could do with a little help to be taken away from them; stimulate self-management as much as possible’ (211 text fragments in 35 ISPs) with text fragments such as *‘he dresses himself’* and *‘she can turn herself on her side’*. The other statement with more than 200 text fragments was ‘are entitled to care based on their needs’ (256 text fragments in 40 ISPs). Examples of statements without text fragments in this cluster were ‘have wishes like everyone else’, ‘(partly) takes care of own living’, and ‘functions autonomously whenever possible; helpful skills will be taught’.

Figure 1 shows the differences in the clusters with regard to the number of statements with ≥ 30 text fragments and the number of statements without text fragments. In two clusters, more than 40.0% of the statements had no text fragments, specifically, the cluster ‘Inclusion’ (46.4%) and the cluster ‘Leisure and recreation’ (42.9%). In contrast with these clusters, three clusters had one statement without text fragments, namely, ‘Experience and discover’ and ‘Involvement’ and ‘Social relations’.

The number of statements with ≥ 30 text fragments within a cluster varied between two statements (in the cluster ‘Leisure and recreation’) and seven statements (in the cluster ‘Self-management and autonomy’). However, when examining the percentages of these statements within the cluster, we see that, in the cluster ‘Social relations’, 37.5% of the statements had ≥ 30 text fragments and, in the cluster ‘Inclusion’, 10.7% of the statements had ≥ 30 text fragments.

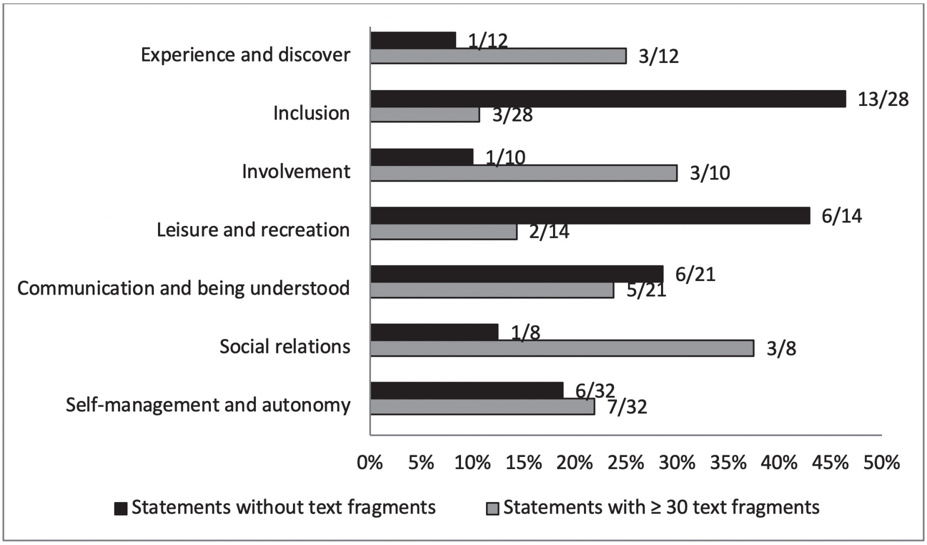

Figure 1 | *For each cluster: number of statements without text fragments/the total number of statements in the cluster (black bars) and number of statements with ≥ 30 text fragments/the total number of statements in the cluster (grey bars)*

Relationship between the occurrence and importance of statements

Table 2 shows the results of the relationship between statements that are documented with ≥ 30 text fragments in the ISPs and the statements with a high importance rating. The list of statements with ≥ 30 text fragments consisted of 26 out of 125 statements. The list of the quartile of statements with the highest importance ratings of the previous study consisted of 36 statements (with ratings above 8.3).

The list of statements with high ratings and the list of statements with ≥ 30 text fragments did not correspond. In total, 14 statements appeared in both lists: two statements in the clusters ‘Inclusion’, ‘Involvement’, and ‘Social Relations’; three statements in the cluster ‘Communication and being understood’; and five statements in the cluster ‘Self-management and autonomy’. This means that 34 statements appeared in just one list, 12 statements in the list of statements with ≥ 30 text fragments, and 22 statements in the list of highest ratings. In the clusters ‘Experience and discover’ and ‘Leisure and recreation’, none of the statements appeared in both lists. From the eight statements with more than 100 text fragments, seven appeared in the list with the highest ratings; only the statement ‘within the possibilities, would like to experience much with their senses, with all their senses’ (151 text fragments) did not appear in this list.

Table 2 | *Relationship between statements with ≥ 30 text fragments and statements with a high importance rating**

Statement **(In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")**	**Sum of text fragments**	**Rating (above 8.34)**
Cluster Experience and discover		
'within the possibilities, would like to experience much with their senses, with all their senses'	151	--
'want to enjoy life, want to have a nice life'	*1*	*8.80*
'should have the opportunity to discover for themselves'	*17*	*8.35*
'want to get the opportunity to experience movements and/or to move, optionally with others'	95	--
'get the opportunity to always keep learning; want to learn'	60	--
Cluster Inclusion		
'entitled to the same good medical care as people without disabilities'	**171**	**8.95**
'must benefit from good and independent representation of interests'	*0*	*8.42*
'want to take part in a church service'	32	--
'can make optimal use of resources'	**162**	**8.42**
'make the familiar environment as broad as possible'	*2*	*8.49*
'have a nice and good quality of life'	*1*	*8.81*
'would like the same as everyone else: nice atmosphere, happiness and structure'	*1*	*8.58*
Cluster Involvement		
'wish to be involved in and, if possible, to actively participate in daily chores; for example, taking a bib into the laundry basket or doing the dishes'	**78**	**8.39**
'wish to undertake activities that suit interests and preferences'	**101**	**8.70**
'wish people would think more in opportunities rather than limitations'	*1*	*8.80*
'want to be involved in cooking'	30	--

Table 2 | *Continued.*

Statement **(In response to the focus prompt, “Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?”)**	**Sum of text fragments**	**Rating (above 8.34)**
Cluster Leisure and recreation		
‘want to do something in their free time, not just sit and wait’	*29*	*8.58*
‘want to play (adapted) sports’	31	--
‘want to practice (adapted) hobbies’	33	--
Cluster Communication and being understood		
‘do not want to suffer from pain or sounds’	45	--
‘want someone who stands up for them if they can’t do it themselves’	*2*	*8.76*
‘would like to be guided by trusted staff who endeavor to (get to) know them well’	**34**	**8.51**
‘would like personal, honest attention, just like everyone else’	*28*	*8.60*
‘want to know that they are seen, heard, and understood even if they are deaf and blind’	*11*	*8.73*
‘have optimal communication tools’	**47**	**8.77**
‘wants the other to make an effort to know them well’	*0*	*8.63*
‘wants the other to regard him as a unique individual’	*0*	*8.53*
‘want to be understood and respected in the hospital’	*0*	*8.42*
‘should be able to anticipate their care or support’	73	--
‘get the opportunity to learn to express themselves or to communicate through gestures or icons’	*11*	*8.79*
‘want to be seen and treated as a person who is worth as much as anyone else’	*0*	*8.84*
‘want to experience that they matter; this makes them feel proud or appreciated’	*3*	*8.49*
‘wish that we look closely at their non-verbal behavior and say what we see’	**156**	**8.70**

Table 2 | *Continued.*

Statement **(In response to the focus prompt, “Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?”)**	**Sum of text fragments**	**Rating (above 8.34)**
Cluster Social relations		
‘interaction with other individuals with VSPID’	55	--
‘has a need for intimacy, love, warmth, patience, physical contact, and someone who helps them through hard times’	**65**	**8.84**
‘have contacts within their own living environment and outside their living environment: family, friends, neighbors, acquaintances, coworkers etc.’	**127**	**8.49**
Cluster Self-management and autonomy		
‘would like everything to go at their own pace and would like to be able to take their time for everything’	**70**	**8.60**
‘would like to be enabled to influence whatever they can, even very small things’	*8*	*8.38*
‘does not want the things they can do, would like to do, or could do with a little help to be taken away from them; stimulate self-management as much as possible’	**211**	**8.38**
‘want to be able to make their own choices’	**55**	**8.59**
‘have autonomy and a feeling of autonomy in order to maintain dignity and self-respect’	*9*	*8.61*
‘want to decide what they eat or drink’	50	--
‘eat independently, if possible’	58	--
‘want variety in their lives, tailored to their needs’	*19*	*8.42*
‘the need of the patient is the base, not the social conventions; the participation in (daily) life is different for everyone.’	**48**	**8.47**
‘are entitled to care based on their needs’	**256**	**8.72**
‘when they are ill, they can stay at home.’	*0*	*8.65*
‘can be themselves in the house they live in’	*7*	*8.74*

*: Statements in a list of statements with ≥ 30 or more text fragments are in normal print; *statements in the list with quartile of the highest rated statements are printed in italic;* **statements in both lists are printed in bold**

Discussion

This study aimed at exploring the degree of participation of adults with VSPID and has resulted in an overview of the extent to which participation was represented in ISPs of the population. It turned out that all of the general clusters of participation of adults with VSPID are described in the ISPs. However, they did not contain all of the statements operationalizing participation. Topics such as 'Experience and discover', 'Involvement', and 'Social relations' were seen the most. 'Communication and being understood' and 'Self-management and autonomy' occurred less often. More than 40% of the statements in the clusters 'Inclusion' and 'Leisure and recreation', were not described in the ISPs. Additionally, only 10.7% of the statements in the cluster 'Inclusion', had ≥ 30 text fragments.

Not all of the components of participation that family, professionals, and experts (as proxies) indicated as important in our previous study (Hanzen et al., 2017) were frequently described in the ISPs. This was particularly the case for the clusters 'Inclusion', 'Communication and being understood', and 'Self-management and autonomy'. Additionally, ISPs paid significant attention to topics that were considered less important by the proxies, particularly topics in the cluster 'Experience and discover'. On the other hand, the statements that were mostly described were also considered to be important by proxies, with the exception of one. These statements concerned (medical) care, use of resources, activities that suits interests and preferences, looking at non-verbal behavior, contacts within and outside their living environment, and 'do not want others to take over things they can do themselves'.

As documented in the ISPs, the attention within the clusters 'Experience and discover', 'Involvement', and 'Social relations' indicates that these aspects of participation are well implemented in the lives of persons with VSPID (Herps et al, 2016). For these clusters, the wishes and abilities of the population are well taken care of by the residential facilities. However, even within these clusters, several aspects are described in less than 25% of the ISPs, indicating that these aspects could contain opportunities to improve participation for this population.

In the cluster 'Inclusion', more than 40% of the statements were not described in the ISPs, and only 10.7% of the statements had ≥30 text fragments, reflecting that inclusion is only moderately implemented in the lives of these adults. Also, in the cluster 'Leisure and recreation', more than 40% of the statements was not described which indicates that not all possibilities for leisure and recreation are used in practice. A substantial number of statements with few text fragments in the clusters 'Inclusion' and 'Leisure and recreation' concerned participation outside the residential facility. In the cluster 'Inclusion', this concerned for example, *'can use facilities outside the residential care facility'* or *'participating in activities in the street/neighborhood where they live'*. In the cluster 'Leisure and recreation', *'offer something unexpected; for example, whitewater canoeing, camping in a tent, or visiting an island festival'* was another example. This indicates that support professionals in a residential facility are not focused on inclusion in society outside the facility. This result is in accordance with the conclusion of Bigby et al. (2009) that some staff in facilities finds it difficult to apply inclusion to persons with intellectual disabilities that are more severe. Besides the relationship with the attitude of staff, these statements are also related to external factors such as availability, accessibility, and affordability that are described by Maxwell et al. (2012). These factors could negatively influence participation. Finally, the question arises whether or not a residential facility considers participation outside of the facility as part of their responsibility or care.

Moreover, a number of statements that were hardly described concerned new or changing roles for adults with VSPID. This indicates that support professionals in residential facilities are not aware of the possibilities of these roles for these adults, which is in line with previous studies (Chenoweth & Clements, 2011; Talman et al., 2017) reporting that residential facilities find it difficult to explore new social roles. Examples of these statements are *'participation can also be realized outside protected workplaces as we look at the possibilities of the individual and the workplace; individual consultation and guidance will be provided'*, *'are able to perform several social roles'* or *'functions autonomously whenever possible; helpful skills will be taught'*.

The only statement with more than 100 text fragments that was not represented in the list of the highest importance rating was *'within the possibilities, would like to experience much with their senses, with all their senses'*. This statement appears to have a strong relationship with the visual disability of the VSPID population and seems to be well implemented in the support for these adults.

A substantial number of statements sometimes were described in the ISPs only once or not at all, even though they were rated as highly important. There could be different possible explanations of the low number of text fragments in a statement. Some statements may be too vague or too general to be described in an ISP, for example, *'want to enjoy life, want to have a nice life'* and *'have a nice and good quality of life'*. These statements are rarely described in an ISP, although it could be expected that these statements would be described in the general goals for a person with VSPID (Herps et al., 2016). On the other hand, some statements may be too specific, for example, *'want to visit a fun fair: there is always something to feel, smell or experience'*. However, if such a statement is not described in an ISP as a possibility, it will probably not be implemented in practice. Some statements might not have been described because it is part of the regular policy in the residential facility, such as the statement *'varied meals'*. Besides, some statements may not be appropriate for adults, for example *'want to go to the playground where they can experience motion'*. Finally, the definition of participation we developed applies for the entire population of adults with VSPID, but the individual characteristics of these adults and their individual wishes, needs, and (dis)abilities must of course be taken into account. As a consequence, some statements will not be suitable for all persons of the population, for example "participation in meaningful work or work-related activities".

Although the concepts of the clusters most likely also apply to other socio-cultural contexts, the exact degree of participation of adults with VSPID may differ because participation is influenced by external factors such as values, habits, and opportunities. The participants in this study all resided in residential facilities for persons with VSPID, and this situation could have influenced the description of participation in their ISPs. In other circumstances with other external factors, participation of these same adults could have been described differently.

Strengths and limitations

A strength of this study is that, for the first time, the degree of participation of adults with VSPID has been explored. This exploration is based on a broad concept of participation supported by family, professionals, and experts (Hanzen et al., 2017).

A limitation of this study turned out to be that the ISPs of the residential facilities differed in structure, length, and terminology and that these differences slightly complicated the comparison of the ISPs. The differences in structure may have influenced the choices made with regard to the parts of the ISPs that have been included. The length of an ISP may have determined the number of text fragments, however, it was realized that text fragments were often duplicated in the longer ISPs. Additionally, the different terminology used in the three settings required an ongoing interpretation of the text fragments; however, this was part of the method for all of the ISPs. Also, all of the ISPs in the study contained similar information about the possibilities, wishes, needs, and specific goals for the persons with VSPID. Because of this, it seemed possible to compare the ISPs of the residential facilities. In addition, we are uncertain if the ISPs from residential facility C, for which only ten legal representatives provided informed consent, were representative. However, these ISPs were largely comparable with the ISPs of the other residential facilities and since the populations of the three residential facilities are comparable as well, we have no reason to assume that they are not representative. Therefore, we decided to include these ISPs in the study.

A limitation of this study could be that we have not analyzed more than 40 ISPs; if we had analyzed more ISPs, we may possibly have determined text fragments that could be categorized into statements that had no text fragments at all. However, while analyzing 40 ISPs, we did not find new patterns in categorizing the text fragments. Because of this result, we decided to limit the analyses to 40 ISPs. In addition, taking into account the total number of adults with VSPID within the different residential facilities, we presumed that we had reached a representative sample with 40 ISPs.

The goal of this study was to investigate the actual participation levels of adults with VSPID. Information about participation is described in ISPs; however, an ISP is not necessarily an accurate reflection of the actual life of an adult with VSPID (Mansell & Beadle-Brown, 2004; Talman et al., 2017). Sometimes ISPs contain goals that are not worked on in practice and, on the other hand, not all participation activities of the person with VSPID may be described. Possibly, the latter applies in particular to activities that are done together with persons other than the support professionals of the residential facility such as family. In contrast, we have to consider that persons with profound intellectual disabilities usually have limited social contacts (Kamstra et al., 2015), therefore, the lack of activities with individuals other than support professionals is most likely a true description of the real life of adults with VSPID.

Recommendations for further research and practical implications

The exploration in this study provides insight into the extent of participation of adults with VSPID. Improving participation is an important goal of support professionals in residential facilities. The results of this study could offer residential facilities the opportunity to see in which areas participation may be improved for adults with VSPID. Additionally, the results can be utilized to develop interventions to increase the participation of this population. Future research will focus on the development and the effects of these interventions.

Conclusion

In this study, the extent of participation of adults with VSPID is investigated with an analysis of the ISPs using a previously developed operationalization of participation for this population. The results showed that some areas of participation are well described; however, other areas are not documented at all in ISPs. The latter mainly concerned 'inclusion' and 'leisure' in society outside the residential facility. 'Changing of' or 'accepting new roles' was also an aspect that was not described: an indication that support professionals in residential facilities find it difficult to explore new social roles of adults with VSPID.

In the ISPs, not all of the components that family, professionals, and experts in our previous study (Hanzen et al., 2017) considered to be important were documented, reflecting limited participation in these domains. In addition, significant attention is paid in ISPs to topics that were less important to proxies such as 'take part in a church service' or 'to get the opportunity to experience movements'. However, the topics that were most often documented such as (medical) care, utilization of resources, activities that suits interests and preferences, observing non-verbal behavior, contacts within and outside their living environment, and 'do not want others to take over things they can do themselves' were also considered important by proxies.

The overview of participation could provide instructions and the development of interventions for improving the participation of adults with VSPID. The development and evaluation of these interventions are the subjects of further research.

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Supplemental table | *Cluster names, statements, number of persons with a text fragment in this statement, and number of text fragments of 40 ISPs*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
	Experience and discover		
1	'within the possibilities, would like to experience much with their senses, with all their senses'	36	151
2	'want to enjoy life, want to have a nice life'	1	1
3	'experiencing rain and wind'	2	3
4	'lying on the couch surrounded by a pleasant scent'	3	4
5	'If the staff explains and guides it well, even as a blind person you can touch almost anything in stores.'	1	1
6	'want to look for challenges more consciously'	5	6
7	'should have the opportunity to discover for themselves'	9	17
8	'want to go to the playground where they can experience motion'	0	0
9	'want to get the opportunity to experience movements and/or to move, optionally with others'	39	95
10	'can also learn new activities'	7	9
11	'would like to be surprised, occasionally escape the daily routine and/or build new routines'	1	1
12	'get the opportunity to always keep learning; want to learn'	27	60
	Inclusion		
13	'at least once a month, with a trusted supervisor, leave the residential care facility'	1	1
14	'a care farm provides opportunity for work-related activities'	1	2
15	'participation can also be realized outside protected workplaces as we look at the possibilities of the individual and the workplace; individual consultation and guidance will be provided'	0	0
16	'participation in meaningful work or work-related activities'	9	16
17	'want their life and thoughts to be enhanced and interaction with the outside world to be promoted; for example: to the pool, festivals, shopping, holiday, music, concerts, cinema, and participating in bike tours'	17	29
18	'entitled to the same good medical care as people without disabilities'	39	171
19	'must benefit from good and independent representation of interests'	0	0

Supplemental table | *Continued.*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
20	'wish they could go on a holiday with their family'	4	4
21	'wish there is enough space and adaptations in public buildings, shops, and public transport so they can go wherever they want to go'	2	2
22	'wish to really be part of the neighborhood in which they live'	0	0
23	'want to take part in a church service'	21	32
24	'has a healthy lifestyle'	1	1
25	'have the right to have a family life and/or a (surrogate) father or mother'	0	0
26	'varied meals'	0	0
27	'sometimes wish that life outside the door is brought to the person (for example through social internships)'	0	0
28	'can make optimal use of resources'	34	162
29	'want to discover what the world has to offer'	0	0
30	'offer the opportunity besides "what we always do here" to look beyond the residential care facility; do not bring everything inside but provide the opportunity to go out of the facility'	0	0
31	'make the familiar environment as broad as possible'	2	2
32	'are also entitled to celebrate their birthday in a convivial way with visitors, gifts and cake'	7	8
33	'look at the opportunities in the neighborhood in which they live, such as care by family and neighbors'	0	0
34	'participating in activities in the street/neighborhood where they live'	0	0
35	'live among other people in an ordinary neighborhood, not in the residential care facility'	0	0
36	'can use facilities outside the residential care facility'	0	0
37	'have a nice and good quality of life'	1	1
38	'can participate in traffic as freely as possible'	4	4
39	'would like the same as everyone else: nice atmosphere, happiness and structure'	1	1
40	'The group in which the clients live is also part of society.'	0	0

Supplemental table | *Continued.*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
	Involvement		
41	'Involvement in general daily activities is very important: this happens in your life very often.'	14	16
42	'small events also count; for example, picking a few flowers is also fine'	2	2
43	'wish to be involved in and, if possible, to actively participate in daily chores; for example, taking a bib into the laundry basket or doing the dishes'	28	78
44	'wish to undertake activities that suit interests and preferences'	37	101
45	'wish people would think more in opportunities rather than limitations'	1	1
46	'active participation or a producing role in cultural activities such as theatre, painting and making a movie, if possible'	2	2
47	'have the right to explore, to choose, to obtain, and to maintain in the field of computers; want to use a simple computer program and/or Ipad'	10	13
48	'meaningful daily schedule, which you can talk about in the evening, during dinner'	5	5
49	'want to be involved in cooking'	23	30
50	'listen to the news bulletins and the weather forecast on television in a quiet environment'	0	0

Supplemental table | *Continued.*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
	Leisure and recreation		
51	'would like someone to try something with them that (s)he is not sure whether they will like it: for example, ice skating, rapids in the pool, try perfume in the drugstore, and eat a herring'	0	0
52	'wish to visit a garden center because it is fantastic: smelling the flowers and the sand, feeling the plants, the animals, the rough/smooth stones and the water from a fountain, seeing the lights (of the Christmas show)'	0	0
53	'want to visit a fun fair: there is always something to feel, smell or experience'	0	0
54	'Doing grocery shopping in the village has added value above having everything delivered at home. In the supermarket, it smells of bread and apple pie; at the drugstore, it smells of deodorant and perfume.'	11	14
55	'want to undertake more activities outside the residential care facility; for example, go to the market, the hairdresser, or a restaurant'	13	16
56	'to the beach, possibly with wheelchairs that are easy to use in the soft sand'	0	0
57	'offer something unexpected; for example, whitewater canoeing, camping in a tent, or visiting an island festival'	0	0
58	'want to do something in their free time, not just sit and wait'	17	29
59	'like to ride horses at a riding club'	0	0
60	'want to enjoy nature'	1	1
61	'want to play (adapted) sports'	22	31
62	'want to practice (adapted) hobbies'	20	33
63	'want to visit a pub or restaurant and, if possible, sit outside with a drink and something to eat'	4	5
64	'can go on a holiday and choose from multiple holiday possibilities and accommodations'	1	1

Supplemental table | *Continued.*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
	Communication and being understood		
65	'do not want to suffer from pain or sounds'	24	45
66	'want someone who stands up for them if they can't do it themselves'	2	2
67	'would like to be guided by trusted staff who endeavor to (get to) know them well'	24	34
68	'would like personal, honest attention, just like everyone else'	17	28
69	'If there is pleasant contact during daily activities, continue it. For example, do not start to clear the table; you can do that at a later time'	0	0
70	'want to be able to share positive and negative experiences with others'	2	4
71	'want to know that they are seen, heard, and understood even if they are deaf and blind'	9	11
72	'want attention for dealing with loss'	2	2
73	'People with VSPID have something to contribute to other people: a smile, kind words, sounds, jokes, songs, a touch, and deeply human contact.'	0	0
74	'have optimal communication tools'	23	47
75	'wants the other to make an effort to know them well'	0	0
76	'wants the other to regard him as a unique individual'	0	0
77	'want to be understood and respected in the hospital'	0	0
78	'should be able to anticipate their care or support'	30	73
79	'want to be involved in a conversation'	7	14
80	'get the opportunity to learn to express themselves or to communicate through gestures or icons'	6	11

Supplemental table | *Continued.*

Nr.	Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")	Number of persons with a text fragment in this statement (n=40)	Number of text fragments
81	'want the group dynamics to suit their needs and to give sufficient rest'	16	23
82	'want to be seen and treated as a person who is worth as much as anyone else'	0	0
83	'have the opportunity to develop themselves by expressing feelings and thoughts'	4	4
84	'want to experience that they matter; this makes them feel proud or appreciated'	3	3
85	'wish that we look closely at their non-verbal behavior and say what we see'	36	156
	Social relations		
86	'wish to have people around who undertake activities with them because they like to, for instance, because of a common interest and not because they are paid'	7	9
87	'interaction with other individuals with VSPID'	27	55
88	'want to be able to cooperate with other individuals with VSPID on work-related activities'	1	1
89	'has a need for intimacy, love, warmth, patience, physical contact, and someone who helps them through hard times'	32	65
90	'have contacts within their own living environment and outside their living environment: family, friends, neighbors, acquaintances, coworkers etc.'	35	127
91	'can start a friendly or sexual relationship'	2	2
92	'are able to perform several social roles'	1	2
93	'there are some trusted counselors available'	0	0

Supplemental table | *Continued.*

Nr.	**Statement (In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")**	**Number of persons with a text fragment in this statement (n=40)**	**Number of text fragments**
	Self-management and autonomy		
94	'would like everything to go at their own pace and would like to be able to take their time for everything'	30	70
95	'would like to be entitled to mistakes, wrong choices, and grumpy days'	0	0
96	'would like to be enabled to influence whatever they can, even very small things'	3	8
97	'want their bodily experience and their need for sexuality to be acknowledged and to be discussed, described and shaped honestly, seriously and respectfully'	16	23
98	'It doesn't always matter if someone doesn't seem to be enjoying something: maybe he will at another time.'	1	1
99	'does not want the things they can do, would like to do, or could do with a little help to be taken away from them; stimulate self-management as much as possible'	35	211
100	'wish that someone would find out what their preferences are, for instance, in music'	9	19
101	'want to be able to make their own choices'	24	55
102	'have autonomy and a feeling of autonomy in order to maintain dignity and self-respect'	7	9
103	'would like conversation and decision-making to be with them, not about them'	3	5
104	'want to get involved in which clothes they wear'	5	7
105	'want to be able to be proud of what they do'	3	3
106	'want to able to indicate their own will, even in tough situations'	16	24
107	'want to decide what they eat or drink'	25	50
108	'eat independently, if possible'	32	58

Supplemental table | *Continued.*

Nr.	**Statement** **(In response to the focus prompt, "Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of adults with visual and severe or profound intellectual disabilities?")**	**Number of persons with a text fragment in this statement (n=40)**	**Number of text fragments**
109	'want to be able to decide what time they go to bed'	6	8
110	'want variety in their lives, tailored to their needs'	14	19
111	'want to look good and neat'	5	6
112	'would like a balance between a clear day/week structure and challenges'	2	2
113	'have wishes like everyone else'	0	0
114	'let the elderly enjoy their life in peace; they don't have to do everything themselves anymore'	4	7
115	'then you are at work, you have to do what is expected from you; when you are at home you can decide for yourself.'	2	2
116	'participation is being enabled to be who you are: lazy, active, social, helpful'	3	3
117	'the need of the patient is the base, not the social conventions; the participation in (daily) life is different for everyone.'	26	48
118	'are entitled to care based on their needs'	40	256
119	'receive education based on their needs'	1	1
120	'When they are ill, they can stay at home.'	0	0
121	'can be themselves in the house they live in'	7	7
122	'can have a day off without a reason'	0	0
123	'(partly) decides about their own possessions'	7	9
124	'functions autonomously whenever possible; helpful skills will be taught'	0	0
125	'(partly) takes care of own living'	0	0
	Sum		**2791**

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Improving the participation of adults with visual and severe or profound intellectual disabilities: A process evaluation of a new intervention

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Abstract

Background

While the participation of adults with visual and severe or profound intellectual disabilities (VSPID) in society and community life is important, evidence-based interventions to improve their participation are lacking. We conducted a process evaluation of the implementation of 'Care for Participation+' (CFP+), a new intervention targeting the attitudes of direct support professionals (DSPs) toward the participation of adults with VSPID, within a residential facility in the Netherlands.

Methods

CFP+ was inspired by the Boston Psychiatric Rehabilitation Approach and adapted by adopting a new definition and operationalization of the concept of participation for adults with VSPID. Following systematic training, 16 DSPs of adults with VSPID were able to apply key elements of CFP+ to explore diverse roles and activities for this population, facilitating their self-management, teaching them necessary skills for participation, and organizing support. Our process evaluation entailed an investigation of the delivered dose, reach, fidelity, and adaptation of CFP+ during and after the CFP+ intervention. We also evaluated the mechanisms of impact and context using questionnaires, assignments, documentation, interviews, and a logbook.

Results

The intended dose, reach, and fidelity relating to the implementation of CFP+ were not achieved. Despite this fact, an assessment of the mechanisms of impact indicated that assignments of CFP+ were well (75%) or reasonably well (17%) understood by DSPs. CFP+ was applied by DSPs to stimulate self-management (83% of DSPs), new activities (100%), enhanced involvement in existing activities (67%) and to explore new roles (50%) for adults with VSPID. A negative contextual factor mentioned by the trainer and manager was the DSPs' lack of commitment to the training program. Another negative contextual factor mentioned by DSPs was the lack of time for implementing CFP+.

Conclusions

CFP+ provides new opportunities to improve the participation of adults with VSPID. Despite the non-optimal conditions for implementing CFP+ and the DSPs' general reluctance to apply the new intervention, some have actively used CFP+ within the residential facility. Future studies should focus on the outcomes of CFP+ regarding attitudinal changes among DSPs relating to the participation of adults with VSPID and their quality of life.

Background

Individuals with severe or profound intellectual disabilities frequently also experience visual limitations as well [1]. In the Netherlands, adults with visual and severe or profound intellectual disabilities (VSPID) comprise approximately 0.05 to 0.08% of the Dutch population [2]. These adults have a visual impairment (visual acuity < 6/18) or blindness (visual acuity < 3/60 and/or visual field < 10 degrees around the point of fixation), as defined by World Health Organization criteria, and an intelligence quotient of less than 35 points [3]. In addition, they often experience other sensory impairments (e.g. hearing loss), behavior problems (e.g. challenging behavior), and health problems [4–6]. Research by Van Timmeren, Van der Putten, Van Schrojenstein Lantman-de Valk, Van der Schans, and Waninge [6] has shown that an individual with VSPID has on average 12 health problems; in more than 50% epilepsy, spasticity, constipation, incontinence, deformations, and reflux has been reported. These problems of adults with VSPID are interrelated. For example, adults with VSPID cannot compensate their intellectual disability by using vision or compensate vision loss by employing their cognitive skills. Since these compensation mechanisms are not in place, the visual and intellectual disabilities seem to reinforce each other [7], which causes additional limitations in daily activities, e.g. living skills, communication, initiative, and social skills [8, 9]. Because of all these limitations, persons with VSPID are fully dependent on others and often live in residential care facilities [4]. Their dependence on others is complicated by the fact that they often communicate non-verbally, through facial expressions, vocalization and body language [10], and therefore, it is often not clear what their needs and preferences are to direct support professionals (DSPs) and family members. Considerable knowledge is required from DSPs and family members to explain the meaning of the behavior of individuals with VSPID. The accumulation of impairments, combined with the difficulties in explaining their behavior, makes people with VSPID a vulnerable group experiencing limitations and depending on others in all aspects of their lives. As a result, interventions that have been developed for people with intellectual disabilities are generally not suitable for individuals with VSPID because these interventions do not take sufficient account of the many and complex problems of the target group.

The United Nations Convention on the Rights of People with Disabilities [11] provides adults with VSPID with the right to participate fully in society and in community life. This Convention has been in effect in the Netherlands since July 14, 2016 [12]. Several studies have highlighted the importance of participation for individuals with severe intellectual disabilities [e.g., 13, 14]. Participation may contribute to an individual's development and emotional well-being [15, 16], as well as to better quality of life [17]. Due to the complex and interrelated limitations of adults with VSPID, it is a major challenge for DSPs to operationalize a broad concept such as participation. Consequently, a specific definition and operationalization of the concept of participation in relation to these individuals was necessary and, formulated in former research as follows:

Active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experiences, and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ('being understood') wherein the adult with VSPID has an active and steering role ('self-management and autonomy') [18].

The concept and operationalization of participation for adults with VSPID is relatively new and has not yet become established within society. A recent study of Hanzen, Waninge, Vlaskamp, Van Nispen, and Van der Putten [19] within residential facilities revealed that the support offered by DSPs in terms of participation appeared to focus mainly on having or maintaining social relations, gaining sensory experiences, and engaging in (daily) activities that matched their interests . Their participation was found to be much less focused on finding new leisure activities and seeking inclusion within society, especially outside of the residential facility. In addition, no efforts were made to change or introduce new social roles for adults with VSPID that could enhance their participation. These findings are in line with the results of a study of Talman, Gustafsson, Stier, and Wilder [20], which also showed that support professionals find it difficult to define potential roles for adults with profound intellectual (and multiple) disabilities.The importance of social roles have previously been described by Wolfensberger [21]. Related to the limitations of individuals with VSPID, frequently described examples of roles of people with VSPID are: 'client', 'patient' or 'participant of daycare activities'. Becoming aware of other (active) roles individuals with VSPID already have, such as 'a son' or 'a neighbor', or new roles they could have, such as e.g. 'an animal caretaker' (filled with activities such as stroking and helping to feed a rabbit), 'an assistant cook' (with an activity such as pressing a button to operate the mixer) instead of 'client', could encourage residential care facilities to develop more active and more suitable activities for the individual with VSPID. Because adults with VSPID are highly dependent on their environment and the support they receive from others [4], a possible explanation for their limited participation could lie in the attitudes and resources of DSPs. Research has shown that DSPs find it difficult to apply inclusive principles, which are key components of participation, in relation to individuals with severe or profound intellectual disabilities [22, 23]. Maxell and colleagues [24] concluded that other environmental factors, such as the availability of facilities or resources, accessibility to a specific situation, and affordability (financial constraints) may also result in limited participation.

In order to achieve a satisfactory level of participation of adults with VSPID within society and community life, new requirements have been imposed on society, including its residential facilities. As this is a relatively new development in the Netherlands, residential facilities have been actively seeking appropriate interventions for enhancing the participation of adults with VSPID [19]. Despite the implementation of initiatives to increase the participation of individuals with intellectual disabilities [25], until now, training for DSPs in residential facilities has mainly focused narrowly on their role as caretakers. Consequently, and especially in residential facilities, DSPs prioritize support relating to the provision of care and devote less attention to the issue of societal inclusion [26].

A number of interventions have been developed that appear to address only specific components of participation for adults with VSPID, as operationalized by Hanzen et al. [18]. For example, an intervention to improve community inclusion, described by Bolsenbroek [27], aims for an inclusive society for people with disabilities and uses insights from social role valorization. Interventions to increase engagement in social networks are described by Kruijswijk and colleagues [28]; these interventions are primarily aimed at people with mild or moderate intellectual disabilities. Another component of participation, self-management, is the aim of an intervention called 'On Your Own Two Feet' [29]. This intervention teaches support staff to encourage persons with intellectual disabilities to think about and solve problems by themselves, which could improve their self-management: due to the limitations in intellectual capacity, this intervention is not applicable for individuals with VSPID. In addition, an intervention termed "active support" has been developed for adults with intellectual disabilities aimed at strengthening their engagement in daily activities with appropriate staff support [30, 31]. The Boston Psychiatric Rehabilitation Approach (BPRA), entailing a broad approach to participation, was introduced in the Netherlands in 1992 [32]. This intervention, which was developed by the Center for Psychiatric Rehabilitation in Boston, supports individuals with psychiatric disabilities in achieving their participation needs [33]. However, the BPRA is less suitable for individuals with VSPID because it requires conversational skills that such individuals do not possess.

In sum, appropriate interventions for adults with VSPID as well as broader ones encompassing the participation areas 'to experience and discover', 'inclusion', 'involvement', 'leisure and recreation', 'communication and being understood', 'social relations', and 'self-management and autonomy', as described by Hanzen et al. [18], are lacking.Therefore, we developed an intervention, called 'Care for Participation+' (CFP+), designed to increase the participation of adults with VSPID. Since any implementation process affects the potential effects of an intervention, it is important to evaluate the implementation by a process evaluation [34-36]. Thus, the aim of this study was to conduct a process evaluation to observe the implementation phase of CFP+ within a residential facility.

Methods

Design

We conducted a process evaluation of the CFP+ intervention using measurements during the implementation phase. The intervention targeted one group of DSPs and adults with VSPID within a residential facility for people with VSPID in the Netherlands. Data were collected prior to implementation of the CFP+ intervention. In addition, measurements as described in Table 1 were taken during the training sessions, immediately after the conclusion of the training sessions, and four and six months after the intervention's implementation (see Table 1).

Development of the CFP+ intervention

1. Preliminary version of the CFP+ intervention

During an earlier phase of our work, the management and DSPs of a residential facility for people with VSPID indicated that they would like to promote the participation of their target group; the family of the people with VSPID also supported this goal. Since no suitable intervention was available for the target group, we developed Care for Participation (CFP) as a preliminary intervention for increasing the participation of adults with VSPID [37] (see 'Content of CFP+'). CFP was initially implemented through the delivery of a training program for DSPs who worked with adults with VSPID. CFP was inspired by the BPRA intervention that is designed to enhance the participation of individuals with psychiatric disabilities [33]. There are several reasons why the BPRA was chosen as the basis for CFP. The first relates to the BPRA's core underlying assumption that individuals have wishes, needs, and strengths rather than problems and limitations. Because adults with VSPID have many disabilities, their limitations rather than their strengths are often the focus of attention. This is in line with research conducted by Bigby et. al. [22] which indicated that the behavior of most support professionals towards inclusion is based on the attitude that the principles of inclusion and participation were not applicable for individuals with severe or profound intellectual disabilities. In addition, Talman et. al. [23] showed that participation of individuals with profound and multiple disabilities was often reduced because support professionals believed these people were not capable of participation. Therefore, a new intervention should also focus on improving the attitudes of DSPs regarding the participation of adults with VSPID. According to Pickens [38], changing an individual's attitude requires a focus on its three components: an affect (feeling), cognition (a belief or thought), and behavior (an action).

A second reason why we based our intervention on the BPRA relates to its aim of improving the various life roles of an individual, such as those of a son, an employee, or a friend. Adults with VSPID often have fewer roles than other individuals and those that they have mostly entail just a few activities [19].

A final set of reasons for the choice of the BPRA relates to the fact that it has a systematic structure, is easily transferable, and has proven to be effective when applied to the target group for which it was designed [39, 40]. The BPRA is a tailor-made, and context-free approach and can therefore be applied to multiple target groups. However, because the BPRA is framed as a conversational model, it needed to be adjusted for the population of adults with VSPID who have limited or no possibilities of language-based speech [37].

The BPRA was therefore modified and applied in a residential facility for individuals with VSPID. In this facility, the topic of participation and the possibilities offered by the BPRA approach were introduced to the managers, families, and DSPs of individuals with VSPID. The positive reactions to the BPRA's vision and systematic method led to the adjustment of the BPRA to make it appropriate for adults with VSPID. A BPRA specialist and an expert on adults with VSPID (the first author) jointly developed the CFP intervention, which included a four-day training program for DSPs working with adults with VSPID. The BPRA principles such as emphasis on wishes, needs, and strengths and on role functioning were retained in this modified intervention, but the method was changed from a conversation-oriented method to one that could be used in daily practice relating to the target population. The involvement of colleagues and the families of adults with VSPID enabled the DSPs to deploy their newly acquired skills to develop the roles and activities of adults with VSPID.

The CFP intervention was tested in a pilot study conducted at the same residential facility for individuals with VSPID [37]. The selection of DSPs was a convenience sample. The selected DSPs were asked if they were interested in the subject and if they liked to participate. During and after the training CFP, the 12 selected DSPs contributed to the further development of CFP by assessing which aspects of the CFP approach could be practically applied and which aspects required adaptation.

The results of the pilot study, obtained by analysis of questionnaires, files, and a logbook, indicated that the CFP approach could be applied for adults with VSPID. As a result of their use of the approach, DSPs were more focused on the strengths of adults with VSPID than on their disabilities. Moreover, the range of activities in which adults with VSPID engaged in daily practice had increased. DSPs noted the importance of integrating the CFP approach within the workflow and in case deliberations to strengthen its applicability. In addition, time was allocated for conducting evaluations of the CFP components. Because these evaluations were not required for the follow-up training, the duration of this training program was reduced from four to three days. Furthermore, the recommendations made during the pilot study were to focus on the concept of participation of adults with VSPID and on the applicability and long-term effects of CFP within larger groups of DSPs and adults with VSPID.

2. Adaptation of CFP and the development of CFP+

After consulting experts on BPRA and VSPID, the second stage of developing the CFP approach was initiated that retained the essential aspects of the CFP approach while integrating the definition and operationalization of the concept of participation within the intervention [18]. The definition and operationalization of participation were developed from the perspectives of proxies of the adults with VSPID using an online concept mapping procedure. This process led to the creation of a Participation Mind Map (PMM) that explains the definition and provides practical examples covering the seven areas described by Hanzen et al. [18]: experience and discover, inclusion, involvement, leisure and recreation, communication and being understood, social relations, and self-management and autonomy.

The PMM was integrated into the CFP+ approach in multiple ways. First, the PMM was included in the training material to enable its use during the initial steps of the CFP+ implementation process, entailing an exploration of the wishes and strengths of adults with VSPID. Second, elements of the PMM were added to the mission statement as well as to the initial and concluding (evaluation) sections of the CFP+ manual. Third, specific exercises for the DSPs, and goals associated with the achievement of more autonomy and more active involvement of adults with VSPID, were added to CFP+ to be incorporated into daily practice.

Content of CFP+

CFP+ is taught systematically with the aid of a manual including a training overview, the PMM, and worksheets with exercises covering each step of the CFP+ process. CFP+ comprises the following seven steps:

1. Exploring opportunities for increasing the self-management and autonomy of an adult with VSPID

The roles of an adult with VSPID and the activities through which those roles can be fulfilled are entered into a pre-established scheme. This scheme is then compared with the concerned person's personal profile that has been recorded by the DSP and by other significant individuals, providing details on the person's character, preferences, and strengths. The scheme should match the above-described personal profile. Possible outcomes entail a complete or partial fit of the activities with the profile or no fit at all.

2. Exploring possible areas of dissatisfaction and hidden needs/wishes

The DSP observes any dissatisfaction displayed by the adult with VSPID which could signify the need for a change and for the exploration of new activities or the elimination of obstacles to restore the individual's satisfaction with existing activities.

3. Choosing and formulating a goal: Developing a new activity and/or strengthening involvement in an existing activity

Possible wishes of the adult with VSPID are translated into a goal that is discussed by the DSP with the family and with colleagues. In a process that is as creative as possible, the DSP then comes up with new eligible activities, striving to be fully open and discounting any limitations, circumstances, or conditions relating to the concerned individual. Considering the individual's preferences, the DSP sets a goal that precisely describes the role, activity, and preferred environment of the adult with VSPID.

4. Achieving the goal

In consultation with colleagues and with the individual's family, the DSP determines what needs to be done to achieve the goal. During a brainstorming session, the DSPs are asked to think about factors that could contribute to making the goal attainable. Following this session, the various factors are listed under the heading of skills recorded for the adult with VSPID and under the heading of required support that can be obtained within the environment of the intervention. DSPs are taught to assess whether the goal enhances the satisfaction of the adult with VSPID as well as the satisfaction of those within the person's environment.

5. Teaching necessary skills to an adult with VSPID

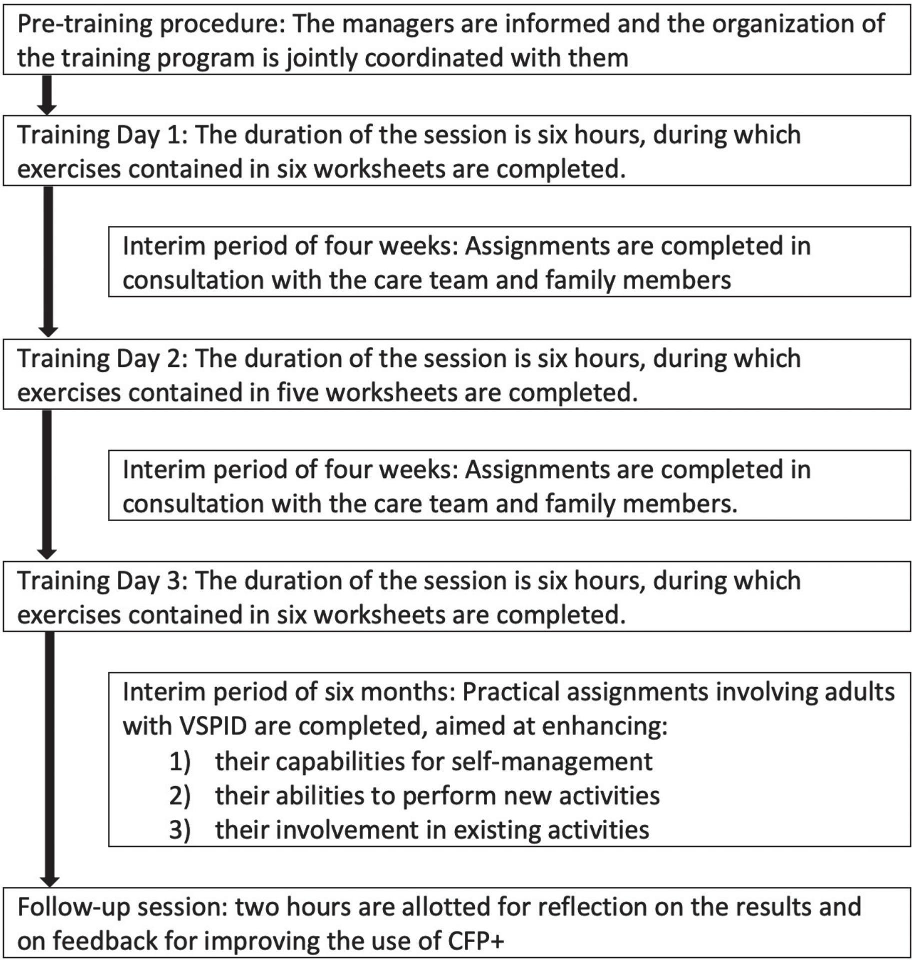
If an adult with VSPID needs to learn new skills to achieve a goal, the DSP considers whether or not the partial imparting of these skills to the individual is feasible. Through skills development, the individual's autonomy and self-management can be increased. If it is not possible to impart the required skills, the DSP will determine whether the goal can be achieved with support available within the environment.

6. Organizing support

The DSP will assess the type of support required to enable the adult with VSPID to carry out certain activities. This support may comprise resources and appointments with colleagues, volunteers, or family members who want to help the concerned individual to perform the desired activities. The DSP is trained to present the strengths and positive aspects of an adult with VSPID to the network of individuals who can offer support, considering their motivations and expectations.

7. Problem solving

The DSP is trained to evaluate new activities by describing the signs and gestures of an adult with VSPID that indicate involvement in and pleasure derived from an activity. Furthermore, the DSPs are trained to investigate factors that hinder the performance of activities and to design and implement an appropriate solution in a systematic manner.



Pre-training procedure: The managers are informed and the organization of the training program is jointly coordinated with them

Training Day 1: The duration of the session is six hours, during which exercises contained in six worksheets are completed.

Interim period of four weeks: Assignments are completed in consultation with the care team and family members

Training Day 2: The duration of the session is six hours, during which exercises contained in five worksheets are completed.

Interim period of four weeks: Assignments are completed in consultation with the care team and family members.

Training Day 3: The duration of the session is six hours, during which exercises contained in six worksheets are completed.

Interim period of six months: Practical assignments involving adults with VSPID are completed, aimed at enhancing:

1) their capabilities for self-management
2) their abilities to perform new activities
3) their involvement in existing activities

Follow-up session: two hours are allotted for reflection on the results and on feedback for improving the use of CFP+

Figure 1: *Planned schedule for the implementation of the CFP+ intervention*
Notes: VSPID = visual and severe or profound intellectual disabilities; CFP+ = Care for Participation+

Figure 1 depicts the schedule for the implementation of the final version of the CFP+ intervention. The time lapse between consecutive days of training organized for the DSPs of adults with VSPID (three in total) was about four weeks. During the training program, the DSPs conducted exercises that could feasibly be performed as part of their daily practice. During the interim periods, the DSPs completed assignments involving their colleagues and the family members of the adults with VSPID. This involvement was deemed necessary for acquiring a better understanding of adults with VSPID and were considered prerequisites for improving participation. Six months after the training program concluded, a two-hour session was held during which the DSPs reflected on the results of CFP+ and the problems they had encountered when attempting to execute the goals they had formulated. In consultation with the trainer, the DSPs searched for "anchors" within the CFP+ intervention that they could use to solve specific problems. To ensure that DSPs continue to use the CFP+ approach in future, this two-hour session program should be held on an annual basis.

Participants

A total of 16 DSPs participated in the process evaluation conducted during and after the delivery of the CFP+. Regarding selection of participants for CFP+, management decided within which homes of the residential facility DSPs were asked to participate in the study. The CFP+ trainer had set the maximum number of participants at 16: this way there was enough time to give every DSP sufficient attention and guidance during training.

In addition to providing the usual support for the individuals they worked with, DSPs received training and implemented the CFP+ intervention. The inclusion criteria of the DSPs were that they had at least six months of experience in supervising adults with VSPID in their homes at the residential facility or during daytime activities at the residential facility, and had expressed their intentions of continuing to support the adults with VSPID assigned to them throughout the study period. Each DSP was linked with an adult with VSPID with whom the DSP usually worked. Inclusion criteria for adults with VSPID were that they were at least 21 years old, had a visual impairment (visual acuity < 6/18 and/or visual field < 20 degrees around the point of fixation) or blindness (visual acuity < 3/60 and/or visual field < 10 degrees around the point of fixation) [43], and an intelligence quotient of less than 35 points. Additional chronic (health) problems that were considered stable were not included among the exclusion criteria. These criteria included diseases with an expected prognosis of a strong decline within one year and expected organizational disturbance within the group the adult with VSPID is living.

The DSPs and family members of adults with VSPID were informed about the study and provided their informed consent in writing. The study protocol for pilot testing CFP+ was approved by the Ethical Committee of the Department of Special Needs Education and Youth Care at the University of Groningen in the Netherlands.

Table 1 | *Operationalization of variables and data collection*

Variable	Data source	Time of data collection*
Implementation process, dose, adaptation, fidelity, and reach		
Implementation process: -Information sent in advance to the management of the residential facility -Information sent in advance to DSPs -Arrangements made within the residential facility	Logbook of researcher (GH)	T0
Characteristics of the DSPs	Online questionnaire completed by DSPs	T0
Adaptation of CFP+ during training	Logbook of researcher (GH)	T1
Dose: DSPs who received CFP+ training	Logbook of researcher (GH)	T1, T2
Dose of CFP+ training	Logbook of researcher (GH)	T1, T2
Dose: Time spent by DSPs practicing CFP+ after the training	Online questionnaire completed by DSPs	T3
Fidelity: conducting assignments	Evaluation forms completed by DSPs	T2
Fidelity: Use of worksheets by the DSPs as part of the intervention	Worksheets completed by DSPs Online questionnaire completed by DSPs	T1 T3
Fidelity: Extension of CFP+ to self-management, new activities, and greater involvement in existing activities of adults with VSPID	Telephone interviews conducted with DSPs	T4
Reach: dissemination of CFP+ by DSPs among team members	Telephone interviews conducted with DSPs	T4
Mechanism operating during the intervention that could have influenced the outcomes		
Quality of the teaching imparted by the trainer, as perceived by DSPs	Evaluation forms completed by DSPs	T2
Applicability of the teaching material as perceived by DSPs	Evaluation forms completed by DSPs	T2
Relevance for the work of DSPs	Evaluation forms completed by DSPs	T2
DSPs' understanding of the assignments in the worksheets	Worksheets completed by DSPs	T1
DSPs' logical choices reflected in successive worksheets	Worksheets completed by DSPs	T1
Trainer's feedback on the training of DSPs and their use of CFP+ tools	Evaluations of the trainer and one of the CFP+ developers	T2
Trainer's feedback on the behavior of the group during the training period	Evaluations of the trainer and one of the CFP+ developers	T2
Manager's feedback on the behavior of the group during the training period	Evaluation interview conducted with the manager of the residential facility	T2

Table 1 *Continued.*

Variable	Data source	Time of data collection*
Contextual factors that could have affected CFP+ outcomes		
DSPs' feedback on positive and negative conditions relating to the implementation of the CFP+ intervention	Evaluation forms completed by DSPs	T2
Trainer's feedback on the positive and negative conditions relating to the implementation of the CFP+ intervention	Evaluations of the trainer and one of the CFP+ developers	T2
Manager's feedback on positive and negative conditions relating to the implementation of the CFP+ intervention	Evaluation interview conducted with the manager of the residential facility	T2

Notes: DSP=direct support professional; CFP+=Care for Participation+;*T0 = before training; T1 = during training; T2 = after training; T3 = 4 months after training; T4 = 6 months after training

Data collection

Table 1 shows the operationalization of the variables, the data sources, and the timing of data collection. We followed the guidelines of the UK Medical Research Council when conducting the process evaluation [44]. As confirmed by Moore et al. [36], this guideline is relevant for conducting process evaluations of public health interventions as well as for complex intervention research in other areas of healthcare or in education. While variations in process evaluations are acknowledged within these guidelines, they specify three key aspects that researchers should prioritize in their investigations: implementation, mechanisms of impact, and context [36]. We operationalized and studied these aspects according to the following definitions: 1) The implementation process was experienced or defined in terms of the dose, adaptation, fidelity, and reach of CFP+ in practice; 2) Mechanisms of impact referred to those mechanisms generated by the CFP+ intervention that could have triggered changes in outcomes in terms of the DSPs' responses and potential mediators; and 3) Context referred to positive as well as negative contextual factors that affected the CFP+ intervention, as experienced by DSPs.

Data were gathered from DSPs who had received CFP+ training for the process evaluation. Additional observations were obtained from the trainer and the manager who supervised the study within the residential facility. Data were gathered before, during, and at the conclusion of the training program. Additional data were gathered four and six months after the conclusion of the training program (see supplementary file).

Data analyses

Documentary and content analyses were performed on qualitative data (see Table 1) while descriptive statistics were applied in the analysis of quantitative data (see Table 1) extracted from the evaluation forms. Included in the documentary and content analyses were (1) the notes in the logbook with regard to the information provided to management and DSPs in advance, the dosage, and adaptation of CFP+ were included in the analysis; (2) the worksheets of the DSPs, completed during the training, have been analyzed to evaluate whether the DSPs had properly understood the assignments and CFP+ in general. Using a four point Likert scale, it was assessed whether or not the DSPs understood the worksheets.(3) the structured interviews, they have been audio-recorded, and the answers to the predetermined questions about the implementation of CFP+ have been included in the analysis.

Results

Following the guidelines of the UK Medical Research Council, the results of the process evaluation of the implementation of CFP+ are organized in three chapters: (1) the implementation of CFP+ in practice which describes the implementation process, the dose, adaptation, fidelity, and reach; (2) Mechanism during the implementation period of CFP+ that could have influenced the outcomes; and (3) Contextual factors, either positive or negative, that may have affected the implementation of the intervention. Table 2 presents a summary of the findings of the process evaluation of the CFP+ intervention.

Table 2 | *Findings of the process evaluation*

Implementation process, adaptation, dose, fidelity, reach	
Implementation:	
-Information conveyed to management	May 2017
-Information conveyed to the DSPs	June 2017
-Arrangements made within the residential facility	September–November 2017
Adaptation of the CFP+ during training	Two components were added during the training: Explanations provided by the coordinator of the volunteers Demonstration of new activities developed for adults with VSPID
Dose: Number of DSPs who received CFP+ training	14/16 present on the first day of training 13/16 present on second day of training 14/16 present on the third day of training
Dose: Intended training time	N = 12 hours: 66.7% of intended training time Feedback session replaced by telephone contact
Dose: Time spent practicing CFP+ during the interval between the completion of training and T2**	N = 8*: 1 DSP spent 40 minutes, 1 DSP spent 30 minutes, 6 DSPs spent 0 minutes; Eight missing values
Fidelity: carrying out assignments during the training program, as reported by DSPs	N = 1: 7.1%: good N = 6: 42.9%: neutral N = 5: 35.7%: moderate N = 2: 14.3%: insufficient Two missing values
Fidelity: Use of the worksheets during and after the training	During the training: n = 169: 88% completed T2**: 0% completed (not used)
Fidelity: Concrete application of CFP+ up to T2, as reported by DSPs in the areas of:	12/16 reported
-self-management for adults with VSPID	N = 10: 83.3%
-new activities for adults with VSPID	N = 12: 100%
-involvement of adults with VSPID in existing activities	N = 8: 66.7%
-new roles for adults with VSPID	N = 6: 50%
Reach: dissemination of the CFP+ by DSPs within the team up to T2	N = 3: 25%: no dissemination N = 9: 75%: partial dissemination Four missing values

Table 2 *Continued.*

Mechanisms generated by CFP+ itself that could have influenced the outcomes: DSPs responses and mediators	
Quality of trainer's teaching, as reported by DSPs just after the training program	N = 7: 43.8%: good N = 8: 50%: neutral N = 1: 3.1%: moderate One missing value
Practical applicability of teaching material, as reported by DSPs just after the training program	N = 4: 26.7%: good N = 2: 13.3%: neutral N = 8: 53.3%: moderate N = 1: 6.7%: insufficient One missing value
Appropriateness in relation to DSPs' work, as reported by DSPs just after the training program	N = 1: 6.3%: good N = 2: 12.5%: neutral N = 6: 37.5%: moderate N = 7: 43.8%: insufficient
Understanding of the assignments provided in the worksheets during the training sessions, as assessed by the researcher (GH)	N = 129: 74.6%: well understood N = 29: 17.2%: reasonably understood N = 10: 5.9%: moderately understood N = 4: 2.4%: insufficiently understood
Responses in successive worksheets completed during the training sessions reflect logical choices, as assessed by the researcher (GH)	N = 29: 45.3%: satisfactory logical sequence N = 7: 10.9%: reasonably logical sequence N = 6: 9.3%: moderate logical sequence N = 5: 7.8%: absence of a logical sequence 17 missing values
Trainer's feedback about the training group and the DSPs' use of the CFP+ during the training program	Difficult to foster self-reflection Not aware of the added value of CFP+
Trainer's feedback regarding the behavior of the group during the training program	Not focused and poor concentration Dominance of some of the DSPs

Contextual factors that affected the implementation of CFP+	
DSPs' feedback on positive and negative conditions for implementing the CFP+ intervention	Not consulted by the manager or trainer to provide inputs prior to the training Lack of time to implement CFP+ up to T2 Non-availability of volunteers for implementing new activities up to T2
Trainer's feedback on positive and negative conditions for implementing the CFP+ intervention	Lack of commitment to the training demonstrated by DSPs
Manager's feedback on positive and negative conditions for implementing the CFP+ intervention	Convinced of CFP+'s added value both before and after the training program Convinced of the existence of opportunities for implementing CFP+ before and after the training program DSPs' lack of commitment to the training program

Notes: DSP = direct support professional; CFP+ = Care for participation+;
*Three DSPs could not be interviewed because they had changed jobs and were no longer employed by the residential facility; one DSP was absent; **T2 = 6 months after the training

Implementation in practice

Prior to implementing the intervention, the manager of the residential facility was informed about the purpose and content of the training program, and she subsequently informed the DSPs. The training program was scheduled to be held in a classroom within the residential facility over three days.

A total of 16 DSPs from the residential facility signed up for the CFP+ training program. Reasons for absences during the training were related to familial or work circumstances. Six months after the first training session was held, three of the DSPs in the original group had changed jobs and were no longer employed at the residential facility.

All of the DSPs were women, and their mean age was 35.6 years (ranging between 20 and 55 years). All of them belonged to the intended target group of DSPs working with adults with VSPID: nine worked as DSPs supporting in a home group at the residential facility, two worked as DSPs supporting in a daytime activity group at the residential facility, and five had a coordinating role, in addition to their supervisory roles.

The CFP+ training sessions were not carried out as scheduled; the training time had to be reduced from the planned six hours to four hours on each of the days of training because noise from the adjacent room affected the concentration spans of the trainees. In light of feasibility issues, and at the DSPs' request, the two-hour follow-up session that was scheduled to be held six months after the last day of training was replaced by a telephone conversation with each DSP. During this session, the DSP was reminded of the utilization and possibilities of CFP+ and of the possibility of requesting assistance to advance their use of CFP+.

As shown in Table 2, DSPs indicated in their evaluation forms that they were not always able to complete the assignments that were set for the periods between the training days for several reasons. These included "too little time," "it was not possible because the family lives far away," or "I had already filled it in during the training session."

During the training program, two additional components were added to the CFP+ that fitted within this specific residential facility and had a direct bearing on the possibilities for enhancing participation of the adults with VSPID. First, the individual who coordinated the volunteers at the residential facility explained the opportunities of the volunteers to the trainees (fits well in step six 'organizing support' of CFP+) and second, one of the DSPs introduced a number of new activities for adults with VSPID (fits well in step three 'choosing and formulating goals' of CFP+).

During the training program, 12 worksheets with exercises, spread over the three days training, were discussed by the DSPs with the trainer. Of the 192 worksheets (12 worksheets x 16 DSPs) , a total of 169 (88%) were completed by the DSPs.

Six months after the conclusion of the training program, the DSPs reported that they had not applied the exercises in the worksheets during the post-training period as instructed in relation to the adults with VSPID with whom they were associated during the study; nor had they applied these exercises in relation to any other adult with VSPID with whom they had worked. The most frequently mentioned reason provided by the DSPs for not implementing the worksheet exercises was the overlap with two other tools that are used within the residential facility: a diagnostic questionnaire and a management tool. Out of the 16 DSPs who received training, eight mentioned that they had spent between 0 and 40 minutes using the CFP+ methodology during the six-month period that followed the training.

After the training program, the DSPs applied the goals of the worksheets they had completed during the training in their daily practice: they reported working in the following areas: developing new activities, self-management and autonomy, active involvement in existing activities, and new roles.

Six months after the conclusion of the training, DSPs reported that while they had not implemented the CFP+ methodology in their daily practice, they had informed their colleagues about CFP+, indicating the achievement of reach. However, some DSPs reported that they had not disseminated the intervention practices within their teams.

Mechanisms generated by CFP+ that could have influenced the outcomes

The second aspect highlighted by the UK Medical Research Council and included in the process evaluation was mechanisms of impact, operationalized as mechanisms generated by the CFP+ intervention that could have triggered changes in outcomes in terms of DSPs' responses and potential mediators.

The DSPs' experiences of the CFP+ intervention and associated training program ranged from evaluations that it was "clear" to a view that it provided "good training but nothing new for us." Other relevant comments were that "The training would be very suitable for new employees because you learn to focus on the possibilities of the population in a different way" and "cooperation with other disciplines where work has been done with adults with VSPID has added value." In addition, there were comments about the overlap with other interventions already used within the residential facility, such as "[there is] a lot of repetition; we already do many [of these] things."

The analysis of the worksheets revealed whether the DSPs had properly understood the assignments. For example, the DSPs had to write about the different roles of the adults with VSPID with whom they worked in one of the worksheet assignments. If they listed roles such as "brother" or "roommate," these answers demonstrated a correspondence with the assignment, revealing that the DSP had understood its purpose. However, responses such as "he is very kind" or "he likes to swim," revealed a lack of correspondence with the purpose of the assignment, indicating that the DSP did not understand the assignment provided in the worksheet. Of the 169 completed worksheets, 126 worksheets indicated that the assignments were well understood (almost everything that was entered on the worksheet met the requirements of the assignment), 29 indicated that the assignments were reasonably well understood (the number of statements that matched the assignment exceeded those that were not correct), 10 were moderately well understood (the number of statements that matched the assignment was less than the number of statements that were correct), and four were insufficiently understood (almost all of the contents entered on the worksheet did not tally with the requirements of the assignment).

During the training period, we also assessed the extent of the DSPs' understanding of the cohesive nature of the CFP+ intervention. There were four occasions during the CFP+ training program when it was possible to determine whether the answers provided by the DSPs on successive worksheets matched and whether they had made logical choices. For example, in one of the worksheets, the DSPs had to formulate a goal for a new activity. In a subsequent worksheet, the DSP identified the skills that an adult with VSPID would have to acquire for conducting this new activity. An example of a goal was "be involved in cooking at home". If the DSP noted that the adult with VSPID "has to learn to stir the contents of the pan" in the following worksheet, this was considered to be a logical choice that was appropriate for the goal described in the previous worksheet. For the 16 DSPs, there were 64 (four occasions for 16 DSPs) possible sequence results. Of these results, 17 were missing (incomplete worksheets). From the remaining results, 29 results indicated a satisfactory logical sequence (almost everything on the worksheet followed logically from the previous worksheet). There were seven reasonable logical sequences (several statements followed logically), six moderate logical sequences (some statements followed logically), and five insufficient logical sequences (almost no logical connection existed with the previous worksheet).

The trainer further indicated that it was "difficult to provoke [DSPs'] self-reflection" and that "an in-depth understanding of the curriculum was not achieved." Moreover, she made the following observation: "From the submitted worksheets it appeared that parts were well used and could be used. However, from what the trained DSPs reported, it did not appear that they were aware of this. It is therefore to be expected that they will not include these worksheets in their repertoire of actions."

A number of the DSPs indicated that the training group was not focused. They reported "no enthusiasm and little attention," "too much distraction and limited concentration," and "too much distraction because the information is not new." The trainer also confirmed that the DSPs' concentration during the training was poor and that the opinions of some DSPs were decisive for the others: "A block was created, with a number of prominent DSPs having a decisive influence. It took a lot of effort to get others to speak. They sometimes had different ideas about the opportunities of CFP+, but did not get these across, or did not put much effort into it. The opinion that prevailed was, 'we already do what is expected for CFP+ and this adds nothing new.' Consequently, it was not possible to provoke a curious or inquiring attitude among the DSPs."

During the evaluation, the manager indicated that the DSPs did not find that the training program added much value to their work. However, according to the manager, the DSPs could hardly envisage how CFP+ was related to other approaches applied within the residential facility. She stated that a diagnostic questionnaire was in fact used, but unlike CFP+, this questionnaire did not constitute a systematic method with associated practical tools for achieving goals. In addition, the manager acknowledged the poor concentration of the DSPs during the training, revealing that this also applied to other training sessions that had been held within the residential facility. A possible explanation that she offered was that the DSPs exchanged work experiences during the training sessions because they do not have time to do so during regular working hours.

Contextual factors that affected the implementation of CFP+ intervention

The third aspect highlighted by the UK Medical Research Council and included in the process evaluation was context, operationalized as positive and negative contextual factors that affected CFP+, as experienced by DSPs.

Positive conditions mentioned by the manager were that the management was convinced, before as well as after the training program, of the added value that CFP+ provided. Moreover, the manager felt that there were opportunities for implementing at least some components of CFP+ within the residential facility.

Negative factors mentioned by the DSPs related to the lack of time for practicing CFP+ and of available volunteers for implementing new activities for adults with VSPID. Furthermore, the DSPs indicated that, unlike the management, they were not sufficiently informed and consulted before the commencement of the training program. Both the manager and the trainer pointed to a lack of commitment to the training among the DSPs because they felt that their participation was based on a top-down decision that was "forced" on them and because they found that it overlapped with other approaches used within the residential facility.

Discussion

The purpose of this study was to examine the implementation process of a new intervention for enhancing the participation of adults with VSPID within the daily practices at a residential facility in the Netherlands. The study described the development of the CFP+ intervention which included a training for DSPs aimed at improving the participation of adults with VSPID according to the broad perspective of participation as described by Hanzen et al. [18]. CFP+ entails a systematic method designed to change DSPs' attitudes toward the participation of adults with VSPID. Moreover, it is aimed at helping DSPs to improve these individuals' self-management and autonomy as well as to organize new activities for them or to increase their involvement in existing activities.

An important element of CFP+ entails its emphasis on the diverse roles that individuals with VSPID can have in different areas of life, such as social relations or leisure and recreation. This emphasis on varying roles that such individuals can assume within and outside the residential facility may induce changes in the attitudes of DSPs regarding the possibilities, opportunities, and activities that apply to the adults with VSPID with whom they work. The importance of attitudinal changes has been demonstrated in a study conducted by Talman et al. [20], who found that DSPs experience difficulty in developing new roles for individuals with profound intellectual disabilities. Experiences of implementing the preliminary version of the CFP+ intervention revealed that as a result of the intervention, DSPs focused more on possibilities and less on the disabilities of adults with VSPID. Consequently, they increased the range of activities for adults with VSPID within daily practices [37].

The findings of this process evaluation show that operationalization of the concept of participation in the context of adults with VSPID [18] closely matched that of the preliminary version of the intervention, with the inclusion of additional elements. The CFP+ intervention enabled DSPs to expand their focus to other areas of participation. Thus, in addition to developing new activities for adults with VSPID, they also considered self-management and a greater involvement of individuals with VSPID in existing activities. The finding that DSPs can contribute to improving the self-management and autonomy of adults with VSPID accords with the research of Hauwert, Meininger, and Kwekkeboom [45], who pointed to the important role of DSPs in adding meaning to different expressions of the self-management of individuals with profound intellectual disabilities.

Another important element of CFP+ is the involvement of family members in the intervention. This involvement is necessary to develop sufficient understanding relating to an individual with VSPID and is a prerequisite for enhancing the individual's participation, as noted by Axelsson et al. [15]. Moreover, the involvement of the family members of individuals with VSPID enables an exploration of their preferred activities while still living at home. Accordingly, new possibilities may arise. For example, a family member, after remembering that his brother used to enjoy swimming when he lived at home, could try to go swimming with his brother when he visits him at the residential facility.

Because CFP+ is grounded in the definition and operationalization of the concept of participation relating to adults with VSPID, it is tailor-made for this target group. The dimension of visual disabilities was addressed in the DSPs' worksheets, for example, in the context of searching for new activities that focus on listening to music or experiencing movements. Given that the BPRA is an individually oriented approach and is therefore applicable within multiple contexts, CFP+, which is derived from this approach, could also be suitable for other vulnerable adults who depend on others to express their wishes. However, before attempting to apply CFP+ more broadly, the definition and operationalization of the concept of participation in relation to the target groups must first be established.

Facilitators and barriers relating to the implementation process

The process evaluation revealed that the implementation of CFP+ was not executed as planned and that the intended dose, reach, and fidelity were not achieved. Nevertheless, DSPs did introduce new activities for adults with VSPID that could be implemented in daily practice, which can be considered a satisfactory outcome of the CFP+ intervention.

Facilitators were evident prior to commencing the CFP+ training program and included, for example, explaining the content of CFP+ to managing staff and convincing them of its added value, establishing arrangements, notably the dates and duration of the training program and the allocation of a classroom within the residential facility to avoid spending extra time and resources on DSPs. An additional facilitator was the association of all of the DSPs with the intended target group. During the training sessions, CFP+ could be adapted to specific opportunities that arose within the residential facility. For example, a number of new activities were developed for adults with VSPID. In general, such facilitators are expected to increase the implementation of an intervention [34, 46].

Although sufficient positive facilitators seemed to exist in advance of the CFP+ implementation, several barriers were also encountered during the process. First, the DSPs perceived their participation to be obligatory; they felt that a top-down decision on the training was being imposed on them. As confirmed by the findings of a study conducted by Knoster, Villa, and Thousand [47], this perception may have negatively influenced their motivation. The trainer, who was used to encountering an open, inquisitive attitude when teaching, experienced a considerable degree of resistance from the DSPs. Second, the training program could not be conducted as planned, which may have resulted in a suboptimal dose.

Nevertheless, CFP+ seemed to have been well understood, and the DSPs worked effectively on goals for the improvement of the participation of adults with VSPID, such as enhancing self-management, developing new roles and activities, and fostering active involvement of these adults in existing activities. However, a surprising finding was that the DSPs did not seem to consider their work on these goals to be an outcome of their engagement with a new intervention; rather, they viewed these efforts as an outcome of other seemingly similar interventions that had been previously introduced and for which they had received training. This may explain why so few DSPs reported using or disseminating CFP+ during the follow-up, and indicated low levels of fidelity and reach that in general may have a negative influence on the implementation of any intervention [34]. Poor concentration during the training sessions, possibly caused by the DSPs' resistance, was another barrier in the implementation of the CFP+ intervention. However, it is unclear whether the finding that DSPs have not changed their behaviors and attitudes toward participation is only based on their opinion; this can be verified after the effects of the CFP+ intervention have been analyzed.

Another barrier faced in the implementation of the CFP+ intervention, which is supported by Fleuren et al. [35], relates to the DSPs' perception that they did not have enough time to engage in new activities with the adults with VSPID. In addition, follow-up evaluations could not be conducted with three of the 16 DSPs who received training because they had changed jobs within six months of being trained. A high staff turnover hampers the continuation of an intervention [46] and requires efforts by managers to establish the adoption of interventions such as CFP+ within their facilities.

Strengths and limitations of the current study

The main strength of this study is that an innovative intervention designed to improve the participation of adults with VSPID, developed by experts in the field of adults with VSPID, was implemented into practice. In addition, the process evaluation enabled the identification and assessment of important barriers and facilitators that can be considered in future implementation exercises once the effectiveness of CFP+ has been validated.

A limitation of this study was that the intervention was only examined in the context of one residential facility, so the results were strongly influenced by the group dynamics of the concerned trainees. It is not clear whether implementation of the intervention in another environment, such as a small-scale facility, would lead to the same results. Consequently, these results cannot be generalized. In addition, CFP+ was tested in a residential facility that differed from the one where the earlier version, CFP, had been tested. Therefore the circumstances under which the intervention was implemented also differed. The results of our previous study [37] showed that the implementation of CFP proceeded smoothly in contrast to the implementation of CFP+. However, the findings of the process evaluation conducted for this study clearly indicated the importance of considering the above-mentioned barriers and facilitators when implementing CFP+ in residential facilities.

Recommendations for future research and practical implications

The United Nations Convention on the Rights of People with Disabilities obliges governments to invest more in the participation of individuals with disabilities, and this also applies to adults with VSPID. Optimal support for this target group should encompass activities in practice and in policy for advancing optimal participation. As a result, new interventions to improve participation for this target group should be developed and implemented. The level of participation of individuals with VSPID may depend not only on the effectiveness of the intervention itself, but also on whether the implementation has succeeded. In addition, an important facilitator is a government's willingness to stimulate new policies.

The description of CFP+ presented in this paper opens up opportunities to improve the participation of adults with VSPID. Residential facilities could include CFP+ in their arsenal of methodologies for supporting target populations. When applying CFP+, such facilities should consider the implementation conditions, as indicated by the findings of this study. For example, the manner of recruiting DSPs for the training appeared to prompt their resistance and hampered the intervention's implementation [34, 47]. Implementation could be encouraged by recruiting early adopters [48], that is, DSPs who recognize and endorse the importance of a new intervention. These early adopters could be identified by the managers of a residential facility prior to implementing CFP+.

Durlak et al. [34] found that the outcomes of an intervention are influenced by its implementation process. Therefore, it is plausible that both facilitators and barriers will influence the effects of CFP+. It is important to determine these effects because despite the suboptimal implementation process observed in this study, the DSPs seemed to have understood and applied some of the tools of the intervention. The findings of an analysis of these effects will be described in subsequent reports.

The conduct of a larger-scale study that includes more residential facilities, DSPs, and adults with VSPID is recommended in order to obtain generalizable findings on the implementation of CFP+. Future studies should also take into account the implementation barriers and facilitators identified in this study and adjust the implementation process in light of the precise contextual factors that contribute to effective implementation [34].

Conclusion

CFP+, which entails a broad definition and operationalization of the concept of participation that is tailored to adults with VSPID, is aimed at improving the participation of this population [18]. It is an intervention that includes the provision of training for DSPs who work directly with adults with VSPID that is intended to change DSPs' attitudes toward the participation of such individuals. It also supports them in enhancing the self-management of adults with VSPID and their involvement in existing activities and in developing new daily activities for them.

We have presented the findings of a process evaluation of CFP+ conducted in a residential facility for adults with VSPID. Although some facilitators were present during the CFP+ intervention, the barriers seem to have dominated the implementation process. The most important barrier is likely to have been the DSPs' experience of overlap with other interventions that they were applying. The fact that they reportedly did not use CFP+ after the training program means that they only applied it during the training period. Nevertheless, the introduction of new activities for adults with VSPID by DSPs, or their enhanced abilities to stimulate greater involvement of these adults in existing activities, may be attributed to the implementation of CFP+.

Future research will focus on examining the effects of CFP+ on the attitudes of DSPs regarding the participation of adults with VSPID and on the actual participation of the target group.

Acknowledgements

A preliminary version of the intervention, which is briefly discussed in the methods section, has previously been published by Hanzen, Korevaar, Van der Putten, Zijlstra, and Waninge (2016) in a Dutch journal titled *Nederlands tijdschrift voor de zorg aan mensen met verstandelijke beperkingen*. Permission was obtained to publish the version presented in this paper in an international journal. We gratefully acknowledge the assistance provided by Marjolein Hommels in the recruitment of adults with VSPID for the study and in the organization of the intervention within the residential facility.

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Supplementary file: questions from the online questionnaire, the evaluation forms, and the telephone interview.

Online questionnaire completed by direct support professionals (DSPs)

What is your age?
What is your gender?
What is your position? (support professional in a home group, support professional in a day-time activity group, or support professional with an additional coordinating role)
How much time did you spend using the CFP+ methodology during the six-month period that followed the training?
Have you applied the exercises in the worksheets of the CFP+ during the post-training period in relation to the adult with VSPID with whom you were associated during the study?

Evaluation forms completed by DSPs after the training CFP+

The questions were answered on a five-point Likert scale (from very good to very bad) with room for explanation
What is your opinion about the didactic qualities of the trainer?
What is your opinion about the applicability of the teaching material?
What is your opinion about the relevance of the training for your work situation?
What is your opinion about the making of the homework assignments between the different meetings of the training?
What is your opinion about the other participants in the training?
The following questions were not scored on a Likert scale:
What is your overall impression of the training?
Do you have any other comments on the training?

Telephone interview conducted with DSPs, 6 months after the training

Have you applied CFP+ to enhance the self-management of adults with VSPID?
Have you applied CFP+ to explore new roles for adults with VSPID?
Have you applied CFP+ to develop new activities for adults with VSPID?
Have you applied CFP+ to increase the active involvement in existing activities of adults with VSPID?
Did you inform your team members about CFP+ after the training?

preference

abilities

autonomy

tablet

work

hobby

nature

sport

job

social

participate

roles

involve

5

support

vacation

friends

wis

self-management

activ

attent

communication

movements

interaction

interest

vicinity

suprises

belong

possibilities

experience

inclusion

Intervention effects on professionals' attitudes towards the participation of adults with visual and severe or profound intellectual disabilities

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Abstract

Background

We investigated the effects of the "Care for Participation+" (CFP+) intervention on direct support professionals' (DSPs') attitudes regarding the participation of adults with visual and severe or profound intellectual disabilities (VSPID).

Methods

We implemented a pilot non-randomized controlled trial with two control groups to compare DSPs' attitudes toward CFP+ using the Attitudes toward Participation Questionnaire (APQ) and DSPs' written profiles of adults with VSPID.

Results

CPP+ and the Participation Mind Map control group showed a positive trend for the "leisure/recreation", "social relations", and "ability to act" APQ domains compared to the usual care control group. The CFP+ group described significantly fewer disabilities at six months, reflecting a more positive attitude than controls.

Conclusion

CFP+ had positive effects on DSPs' attitudes toward the participation of adults with VSPID. The small sample size, ceiling effects, measurement instruments used, and implementation difficulties may have hampered understanding the full potential of CFP+.

Background

Participation is a human right for people with disabilities (United Nations, 2006), including adults with visual and severe or profound intellectual disabilities (VSPID). Participation enhances the quality of life (Bigby, Anderson & Cameron, 2017; Schalock et al., 2002) and contributes to individuals' well-being and development (Axelsson, Imms, & Wilder, 2014; Boren, Granlund, Wilder, & Axelsson, 2016). The combination of disabilities of adults with VSPID exacerbates the limitations in daily activities and participation (Dijkhuizen, Hilgenkamp, Krijnen, Van der Schans, & Waninge, 2016; Hanzen, Waninge, Vlaskamp, Van Nispen, & Van der Putten, 2018). Recently, the concept of participation has been operationalized for persons with VSPID as follows:

Active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experiences and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ('being understood') wherein the adult with VSPID has an active and steering role ('self-management and autonomy'). (Hanzen, van Nispen, Van der Putten, & Waninge, 2017, p101)

Previous research has shown that support for adults with VSPID in residential facilities entails a limited focus on certain areas of participation, such as societal inclusion, new leisure activities, and new social roles (Hanzen et al., 2018). This limited focus may be related to environmental factors, such as availability, affordability, and accessibility (Maxell, Alves, & Granlund, 2012) as well as the components of the support provided by direct support professionals (DSPs).

Because of the dependency of adults with VSPID on others (Nakken & Vlaskamp, 2007), their opportunities to participate may be contingent on the DSPs' attitudes toward participation. For example, DSPs' views on the inclusion of individuals with intellectual disabilities, considered as a component of participation according to the aforementioned definition reportedly influence their associated efforts (Venema, Otten, & Vlaskamp, 2015). Other studies have shown that the DSPs of individuals with severe or profound intellectual disabilities find it difficult to apply inclusive principles (Bigby, Clement, Mansell, & Beadle-Brown, 2009) or to identify activities that match the roles of this target group (Talman, Gustafsson, Stier, & Wilder, 2017). Because of the limitations of adults with VSPID, DSPs may be inclined to focus on these limitations and care tasks and less on the capabilities, wishes, and participation of such individuals (McConkey & Collins, 2010).

Pickens (2005) defined an attitude as "a mindset or a tendency to act in a particular way due to both an individual's experience and temperament." It comprises elements that influence decisions: an affect (a feeling), cognition (belief or thought), and behavior (action). According to Rosenberg and Hovland (1960), if thoughts, feelings, and behaviors are congruent, then behavior changes are not required. This means that if DSPs' thoughts, feelings, and behaviors are aligned with the participation of the target population, they will not alter their behavior. Different strategies, such as consciousness raising and reappraisal, can be deployed to change behavior (Prochaska & Velicer, 1997).

An awareness of the lack of consideration of some participation components and of the possible influence of DSPs' attitudes on the participation of adults with VSPID led to the development of the "Care for Participation+" (CFP+) initiative (Hanzen, Van Nispen, Vlaskamp, Korevaar, Waninge, & Van der Putten, 2020) to address these issues. CFP+ includes a training for DSPs that focuses on their knowledge, consciousness, attitudes, and skills relating to the participation of adults with VSPID. The aim of this study was to examine the effects of CFP+ on DSPs' attitudes toward improving the participation of adults with VSPID.

Methods

Design

From September 2017 to May 2018, we implemented a three-armed pilot, non-randomized controlled trial (NRCT), entailing a parallel group design at two Dutch residential facilities for people with VSPID. Data were collected at the start of the intervention and 6 and 12 months after its implementation, and the effects on the attitudes of DSPs were evaluated.

The three trial intervention arms were: (1) the intervention group: DSPs who received training and delivered CFP+ on top of usual care and who had access to the Participation Mind Map (PMM); (2) a PMM control group: DSPs who received a brochure with information on the definition and meaning of participation of adults with VSPID that could be optionally integrated within their daily practice; and (3) a control group: DSPs providing usual care. We expected to observe the largest effects in the CFP+ group, fewer effects in the PMM group (considered as a "low dose" or specific element of CFP+), and no effects in the usual care group.

The ethical committee of the Department of Pedagogy and Educational Sciences at the University of Groningen in the Netherlands approved the study protocol. Legal representatives and DSPs gave written informed consent after they had been given information about the study.

Participants

The participants were 43 DSPs working at two residential facilities for people with VSPID. Inclusion criteria were: (1) a minimum of six months' work experience with the target group; (2) DSPs working in facilities during the day time with adults with VSPID or in their homes, and (3) DSPs intending to continue working in the same group during the study period. An exclusion criterion: the individual was working in a group with expected changes in the group's organization during the study period.

Each DSP was linked to one person with VSPID whom they regularly supported. Inclusion criteria for persons with VSPID were: (1) aged 21 years or above; (2) the presence of a visual impairment with a visual acuity < 6/18 and/or visual field < 20 degrees around the point of fixation or blindness with a visual acuity < 3/60, and/or a visual field < 10 degrees around the point of fixation (ICD-10, 2016); and (3) an intelligence quotient below 35 points. The exclusion criterion for adults with VSPID was having a disease with a significant expected decline within a 1-year period.

Table 1 shows the participants' characteristics. We performed chi-squared tests and one-way analyses of variance to assess differences among group characteristics. There were statistically significant differences between the groups of DSPs in the age-range of clients and the numbers of clients using wheelchairs: the DSPs in the usual care control group supported relatively older persons with VSPID, and the DSPs in the PMM group supported a relatively larger number of wheelchair users. In addition, significant differences among the three groups related to the mean age and the sexes of adults with VSPID: the mean age of adults with VSPID in the usual care control group was the highest, whereas the PMM control group had significantly more male adults with VSPID.

Table 1 | *Characteristics of DSPs and adults with visual and severe or profound intellectual disabilities in the three groups*

		Group		
Direct Support Professionals	**Total**	**CFP+**	**PMM**	**Usual care**
	n=43 (%)	n=16 (%)	n=14 (%)	n=13 (%)
Age, mean (in years)	37.5	36.8	37.4	38.5
(SD)	SD 10.4	SD 11.3	SD 9.3	SD 11.2
Range	20-56	20-55	23-55	23-56
Gender				
Female	42 (97.7)	16 (100)	14 (100)	12 (92.3)
Male	1 (2.3)			1 (7.7)
Support type				
DSP home	23 (53.5)	9 (56.3)	7 (50.0)	7 (53.9)
DSP day-activities	6 (14.0)	2 (12.5)	2 (14.3)	2 (15.4)
DSP home+day-activities	2 (4.7)	0 (0.0)	0 (0.0)	2 (15.4)
DSP coordinating	12 (27.9)	5 (31.3)	5 (35.7)	2 (15.4)
Work experience (in years)				
0-5	11 (25.6)	5 (31.3)	4 (28.6)	2 (15.4)
5-10	14 (32.6)	3 (18.8)	4 (28.6)	7 (53.9)
10-15	7 (16.3)	5 (31.3)	2 (14.3)	0 (0.0)
>15	11 (25.6)	3 (18.8)	4 (28.6)	4 (30.8)
Age-range clients				
20-40 years	6 (14.0)	3 (18.8)	3 (21.4)	0 (0.0)
>40 years	20 (46.5)	4 (25.0)	5 (35.7)	11 (84.6)
20-40 and >40 years	17 (39.5)	9 (56.3)	6 (42.9)	2 (15.4)
Wheelchair use clients				
Yes	10 (23.3)	1 (6.3)	6 (42.9)	3 (23.1)
No	2 (4.7)	1 (6.3)	0 (0.0)	1 (6.7)
Both: clients with and without wheelchair	31 (72.1)	14 (87.5)	8 (57.1)	9 (69.2)
Hearing impaired clients				
Yes	11 (25.6)	5 (31.3)	5 (35.7)	1 (6.7)
No	31 (72.1)	11 (68.8)	8 (57.1)	12 (92.3)
Unknown	1 (2.3)	0 (0.0)	1 (7.1)	0 (0.0)

Adults with VSPID	**Total**	**CFP+**	**PMM**	**Usual care**
	n=43 (%)	n=16 (%)	n=14 (%)	n=13 (%)
Age, mean (in years)	45.7	38.9	45.6	54.3
(SD)	SD 11.9	SD 12.4	SD 10.8	SD 5.9
Range	20-63	20-58	31-63	41-61
Gender				
Female (%)	25 (58.1)	10 (62.5)	4 (28.6)	11 (84.6)
Male (%)	18 (41.9)	6 (37.5)	10 (74.4)	2 (15.4)
Level of intellectual disability				
Severe (%)	15 (34.9)	6 (37.5)	6 (42.9)	3 (23.1)
Profound (%)	28 (65.1)	10 (62.5)	8 (57.1)	10 (76.9)
Visual limitations				
Visual impairment (%)	16 (37.2)	9 (56.3)	3 (21.4)	4 (30.8)
Blind (%)	27 (62.8)	7 (43.8)	11 (78.6)	9 (69.2)

Table 1 *Continued.*

		Group		
Adults with VSPID	**Total** n=43 (%)	**CFP+** n=16 (%)	**PMM** n=14 (%)	**Usual care** n=13 (%)
Use of wheelchair				
Yes (%)	9 (20.9)	1 (6.3)	4 (28.6)	4 (30.8)
Partial (%)	18 (41.9)	9 (56.3)	3 (21.4)	6 (46.2)
No (%)	16 (37.2))	6 (37.5)	7 (50.0)	3 (23.1)
Auditory impairment				
No (%)	31 (72.1)	10 (62.5)	9 (64.3)	12 (92.3)
Hard of hearing (%)	9 (20.9)	6 (37.5)	3 (21.4)	0 (0.0)
Deaf (%)	3 (7.0)	0 (0.0)	2 (14.3)	1 (7.7)
Physical health problems				
Yes (%)	43 (100)	16 (100)	14 (100)	13 (100)
No (%)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Mental health problems				
Yes (%)	34 (79.1)	11 (68.8)	12 (85.7)	11 (84.6)
No (%)	9 (20.9)	5 (31.3)	2 (14.3)	2 (15.4)

Notes: DSP = direct support professional; CFP+ = Care for participation+; PMM = Participation Mind Map

Intervention

CFP+ Intervention

CFP+, which is aimed at improving the participation of adults with VSPID, is based on the demonstrably effective Boston Psychiatric Rehabilitation Approach (Anthony, Cohen, Farkas, & Gagne, 2002), and adjusted for adults with VSPID (Hanzen, Korevaar, Van der Putten, Zijlstra, & Waninge, 2016; Hanzen et al., 2020). Additionally, CFP+ includes the previously established definition and operationalization of the concept of participation for this target group (Hanzen et al., 2017) that has been included in the PMM brochure.

The content of CFP+ has been described elsewhere (Hanzen et al., 2020). Briefly, CFP+ includes a training for DSPs with exercises directed at enhancing the participation of individuals with VSPID whom the trainees routinely support. The DSPs also involve other team members and family members to increase the participation of these individuals. DSPs are encouraged to focus less on the limitations of adults with VSPID and more on their wishes and possibilities. They are taught to develop new activities and to increase the target group's active involvement in existing activities. Within CFP+, special attention is paid to exploring (new) roles for adults with VSPID and broadening activities for their accomplishment. The duration of the training program is three days with an interval of four weeks between each training day and a follow-up session after six months. The DSPs receive a manual containing information on CFP+, the PMM, worksheets with exercises, home-based assignments, and tools for applying CFP+ in daily practice. After the training, DSPs are expected to carry out practical assignments and to introduce new activities as well as to improve the self-management and involvement of individuals with VSPID in existing activities.

DSPs follow a seven-step process during their CFP+ training. First, they describe the personal characteristics and capabilities of the concerned individuals with VSPID and compare with existing roles and activities within these roles. Second, they look for signs of dissatisfaction. Third, they define a goal for a new activity or more active involvement in consultation with their colleagues and the individual's family. Fourth, they identify what is needed to achieve this goal. Fifth, they teach skills to the individual with VSPID that make the goal more attainable. Sixth, they identify areas of support that are required to achieve the goal, such as resources, arrangements, or agreements. Last, they begin a process of evaluating goals, identifying barriers and teaching problem-solving skills.

Example of 7 steps of CFP+:
1. Role and person description: male, 45 years, fan of the local drum band.
2. Sign of dissatisfaction: he only visits the drum band once a year when they perform.
3. Goal definition: he should regularly attend the rehearsals of the drum band.
4. Needs to achieve the goal: travel arrangements to the rehearsals should be made.
5. Skills needed: he should be taught not to disturb the rehearsals.
6. Areas of support needed: a volunteer should accompany him to the rehearsals.
7. Evaluation: he appreciates the rehearsal of the trumpets more than the rehearsal of the drums. Therefore, only the rehearsals of the trumpets should be attended in future visits.

Participation Mind Map (PMM) control group

The PMM brochure includes the definition of the concept of participation for adults with VSPID (Hanzen et al., 2017). This definition is supplemented with examples of operationalization of this definition organized according to the following seven areas of participation for the target group: ”experience and discover,” ”inclusion,” “involvement,” “leisure and recreation,” “communication and being understood,” “social relations,” and “self-management and autonomy” (Hanzen et al., 2017). These examples could inspire the DSPs to enhance the participation of the target group.

In this study, after the behavioral experts within the residential facility gained familiarity with the PMM, they disseminated it to the participating DSPs. These DSPs then decided whether and how they would use the PMM to support the target population.

Usual care control group

DSPs provided usual care and had no access to CFP+ or to PMM. This control group was chosen because the residents of this group lived temporally outside one of the facilities. Therefore, DSPs with access to relevant interventional information did not influence them.

Allocation procedure

Two residential care facilities were involved in the NCRT. One accommodated the PMM group and the other accommodated the CFP+ and the usual care groups.

In the first residential care facility, approximately 140 individuals with visual and intellectual disabilities live together, divided over 20 group homes. The facility managers decided within which homes of the residential facility, family, and for these study associated DSPs, were asked for either the CFP+ group (out of four group homes) or the control group (out of two group homes).

In the second residential care facility, approximately 300 individuals with visual and intellectual disabilities live together in 54 homes (from 1 to 7 persons). The managers selected participants for the PMM group out of eight homes based on the recommendations, *e.g. about the severity of the disability*, of behavioral experts on which adults with VSPID and which DSPs to include.

Measures and data collection

DSPs were invited via email to complete an online questionnaire. If necessary, they were sent a reminder after three weeks.

Attitude toward Participation Questionnaire (APQ)

We developed a self-reporting questionnaire to measure DSPs' attitudes toward the participation of adults with VSPID. Drawing on Pickens' (2005) definition of attitude, the questionnaire comprised 39 items on DSPs' feelings, thoughts, and beliefs regarding the participation of adults with VSPID. The questionnaire was based on the seven operational domains of participation for adults with VSPID (Hanzen et al., 2017). Two additional domains, "knowledge" and "ability to act" that were expected to improve in the target group because of the intervention were included.

Each of the following two items were associated with and included in two domains. "I am seeking opportunities for the person with VSPID to exercise/move, or be moved" was categorized within both the "experience and discover" and the "leisure and recreation" domains. Similarly, "I teach the person with VSPID new skills that he or she needs to improve his/her participation" was categorized in the "experience and discover" and "ability" domains.

A five-point Likert scale with "totally disagree," "partially disagree," "neutral," "partially agree," and "totally agree" ratings was used to score 22 items. The response options for the remaining 17 questions were "never," "sometimes," "regularly," "often," and "always."

A preliminary version of the APQ was tested with 23 DSPs who did not participate in the main study. Descriptives were checked and test-retest reliability was evaluated (Kappa between 0.40 and 0.92, and intraclass correlation coefficients between 0.24 and 0.87). Some items were deleted to the questionnaire. More psychometric properties were investigated by combining the same testdata (n = 23) with baseline data from the DSPs involved in the NRCT (n = 43). If possible (the number of observations were low), investigations were performed with item response theory models, that is, graded response models, for every pre-defined scale in R. We examined the following assumptions: unidimensionality, monotonicity, and local dependence (outcomes available upon request). Some items were removed to improve internal consistency reliability or other properties of the scales. The final APQ questionnaire contained 37 items distributed over nine domains (see Table S1). Mean summary scores for attitudes toward the participation of adults with VSPID, ranging from 1 (negative) to 5 (positive), were calculated for each domain.

Profiles of adults with VSPID

To measure changes in the DSPs' attitudes regarding the possibilities and preferences of persons with VSPID, we analyzed the profiles they wrote for these individuals. DSPs were asked to "describe the individual with VSPID you are linked to during the study. Describe everything that you think is important to mention." There were no restrictions regarding the content and length of the text. We examined the following variables:

1. Personal preferences (e.g., "she likes to walk outside").
2. Personal abilities (e.g., "he walks a short distance independently").
3. Disabilities and limitations (e.g., "he is unable to take others into account").
4. Actions relating to preferences (e.g., "every week, his family picks him up so he can go to church").
5. Actions relating to disabilities and limitations (e.g., "he needs intensive support to prevent physical injury").

The agreement rate of the two researchers (GH and AW) who categorized the textual content of the individual profiles was 66%. After discussing the outcomes and linking rules, the researchers independently re-examined the individual profiles. Consequently, the agreement rate rose to 74%. The intra-rater reliability was 91%.

Analyses

Descriptives and test-retest reliability of the APQ were checked with the Statistical Package for the Social Sciences (IBM SPSS version 24), psychometric properties of the APQ were analyzed with R-Studio (version 3.5.3), and the effects of the APQ were analyzed with Mlwin.

The overall longitudinal effects on the APQ were analyzed with linear mixed models (maximum likelihood estimations) for the nine APQ scales separately. As an important assumption for using linear mixed models, it was assumed that data were missing at random; reasons mentioned were, for example, maternity leave and working in another group within the residential care facility. Models were analyzed stepwise by adding (1) the main effect on time; (2) main effect on intervention group; and (3) main effect on the time-intervention interaction term, using the usual care group as a reference. Then, due to imbalance between the groups, potential confounders, the ages and sexes of the adults with VSPID, were added in a stepwise procedure and kept in the models if they were relevant. Significance testing of model parameters was executed as described in Snijders and Bosker (2012), with a significance level set at 0.05 (two-sided). Deviance tests were applied for model comparison (Snijders & Bosker, 2012). Because of the small sample size, we decided to see if we could observe trends over time, arbitrarily defined as $p<0.1$. Additionally, we have taken into account practical relevance by checking the confidence intervals. As the scales have a range of 1 to 5, we regard confidence intervals including a more than 0.5 (10%) as practical relevant. For interaction models, the slopes were practical relevant at more than 0.25.

Descriptive statistics (frequencies, median) were used for the analysis of the categorization of the individual profiles. It was analyzed how often text fragments that were related to the five variables were documented in the written individual profiles by DSPs at baseline, after 6 and 12 months. An increase in words of the three variables 'Personal preferences', 'Personal abilities', and 'Actions related to preferences', and a decrease in words of the variables 'Disabilities and limitations' and 'Actions related to disabilities and limitations', were considered to indicate an improvement of attitudes of DSPs. Because the data were not normally distributed, the effects were analyzed using the Kruskal-Wallis test.

Results

Participants

Figure 1 presents the number of completed APQs and individual profiles written by DSPs in the three groups and for three time points. Job changes, illnesses, and holidays accounted for reduced numbers of follow-up APQs.

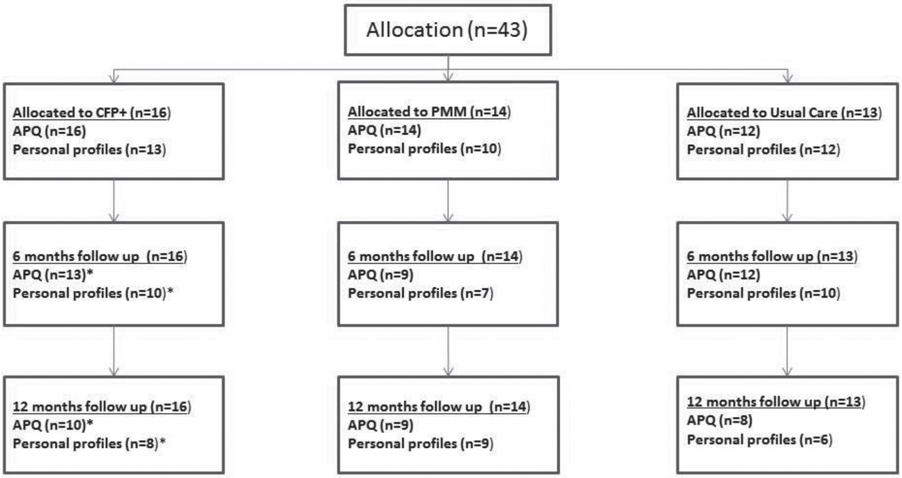


Figure 1 | *Flow chart response per arm, measurement, and time points*
Notes: CFP+ = Care for Participation+, PMM = Participation Mind Map, APQ = Attitudes towards Participation Questionnaire; *Two questionnaires/individual profiles were completed by substitute DSPs.

Attitudes of DSPs

Table 2 and Figure 2A-I show the results of the analysis of the nine APQ domains for the three groups. The CFP+ group evidenced a positive trend for the "leisure and recreation" and "ability to act on participation" domains in relation to the usual care group. The latter domain was adjusted for the ages of the adults with VSPID. No CFP+ effects were found for the domains "experience and discover," "inclusion," "involvement," "communication and being understood," "self-management and autonomy," and "knowledge of participation." Although not significantly different, confidence intervals show a practical relevant effect in the domain "social relations.". A comparison of the CFP+ group with the PMM control group over time revealed no significant trends. Comparing the PMM group to the usual care group revealed a significant and relevant improvement on attitudes in the domains "leisure and recreation," "social relations," and "ability to act on participation."

In the interaction models, in the domain "leisure and recreation," the slope of the CFP+ group was 0.2, of the PMM control group 0.25, and of the usual care control group 0.03. In the domain "social relations," the slope of the CFP+ group was -0.17, of the PMM control group 0.13, and of the usual care group -0.22. The domain "ability to act on participation" showed a slope of 0.22 in the CFP+ group, 0.27 in the PMM control group, and -0.04 in the usual care control group.

The CFP+ group's score was significantly lower at the baseline for "involvement" compared with the usual care group, but higher for "leisure and recreation" and "communication and being understood." Although not significant higher, the confidence intervals show a practical relevant higher baseline for "inclusion," "social relations," and "ability to act on participation." The PMM control group's mean score at the baseline was significantly higher for "experience and discover" compared with the usual care group. According to the confidence intervals, practical relevant higher baseline were noted for "leisure and recreation," "social relations," and "ability to act on participation."

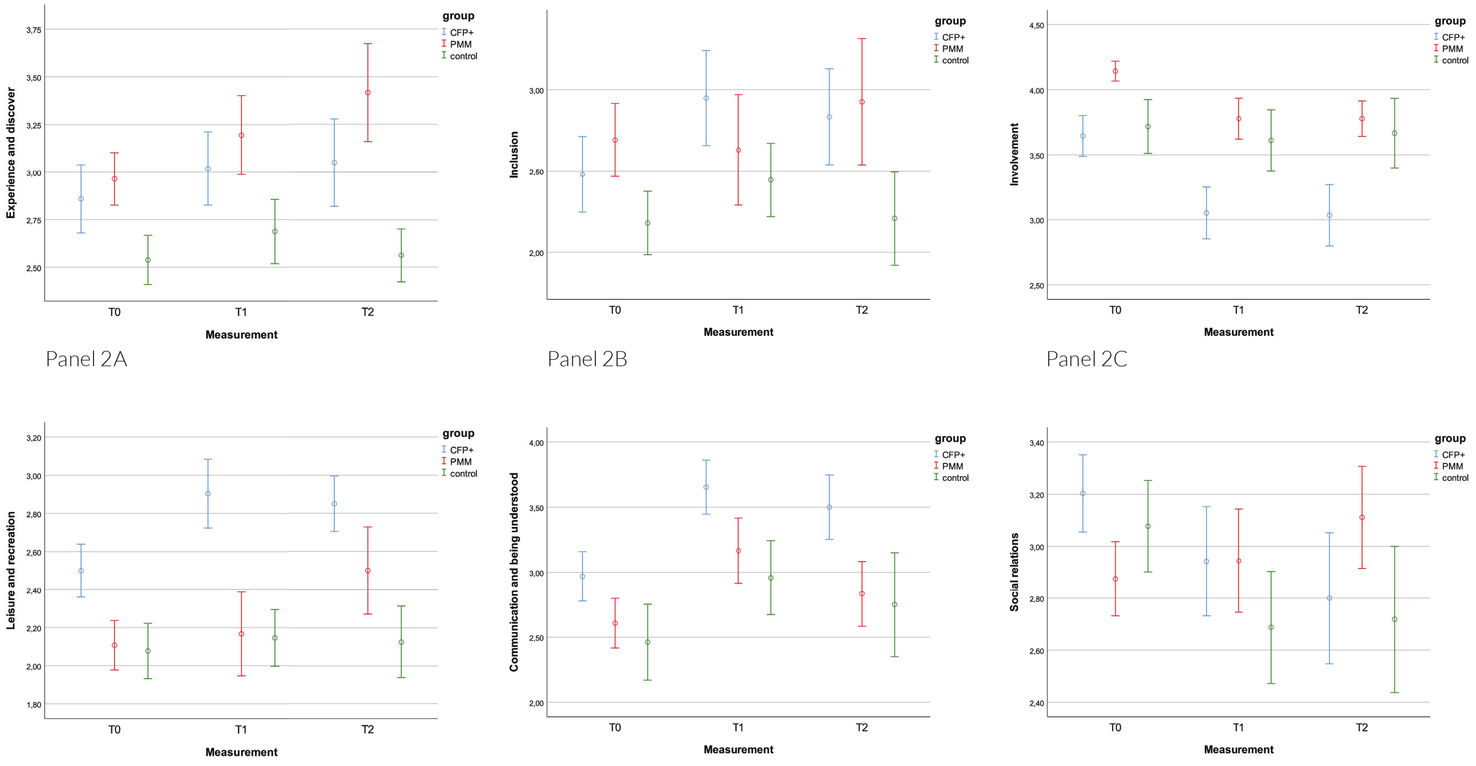
Table 2 | *Multilevel model results of the Attitudes Participation Questionnaire per arm and domain*

	Experience & discover		**Inclusion**		**Involvement**		**Leisure & Recreation**	
	B (SE)	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*
	M1	M2	M1	M2	M1	M2	M1	M2
Intercept	2.89(.09)	2.53(.15)	2.59(.13)	2.21(.24)	3.63(.09)	3.84(.14)	2.38(.09)	2.08(.15)
Time		.10(.05)*		.13(.06)*		-.20(.07)*		.03(.07)
Group CFP+		.33(.19)# (CI -0.05-0.61)		.36(.31) (CI -0.26-0.98)		-.37(.18)* (CI -0.73- -0.01)		.48(.20)* (CI 0.08-0.98)
Group PMM		.50(.20)* (CI.0.10-0.90)		.42(.32) (CI -0.22-1.06)		.27(.19) (CI -0.11-0.65)		.01(.21) (CI -0.41-0.43)
Time x group CFP+								.17(.10)# (CI -0.03-0.37)
Time x group PMM								.22(.10)* (CI 0.02-0.42)
Age adult VSPID								
Variance level 2	.24(.07)	.20(.06)	.60(.16)	.57(.15)	.15(.07)	.09(.05)	.25(.07)	.20(.05)
Variance level 1	.15(.03)	.15(.03)	.24(.04)	.22(.04)	.34(.06)	.30(.05)	.14(.02)	.10(.02)
-2 Log likelihood	166.6	157.4	226.9	220.4	213.8	193.74	157.2	129.9

Table 2 | *Continued.*

	Communication & being understood		**Social Relations**		**Self-management & autonomy**		**Knowledge of participation**		**Ability to act on participation**	
	B (SE)	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B(SE)*	*B (SE)*
	M1	M2	M1	M2	M1	M2	M1	M2	M1	M2
Intercept	2.94(.12)	2.52(.20)	2.96(.09)	3.01(.18)	3.67(.07)	4.47(.35)	3.90(.07)	3.72(.13)	2.87(.11)	3.49(.51)
Time		.18(.08)*		-.22(.11)*		-.06(.06)		.10(.06)#		-.04(.10)
Group CFP+		.67(.26)* (CI 0.15-1.19)		.19(.24) (CI -0.29-0.67)		.12(.17) (CI -0.22-0.46)		.19(.15) (CI -0.11-0.49)		.22(.28) (CI -0.06-0.50)
Group PMM		.11(.27) (CI -0.43-0.65)		.14(.25) (CI -0.36-0.64)		-.15(.16) (CI -0.17-0.47)		.09(.16) (CI -0.23-0.41)		.39(.26) (CI -0.13-0.91)
Time x group CFP+				.05(.15) (-0.25-0.35)						.26(.14)# (CI -0.02-0.54)
Time x group PMM				.35(.15)* (CI 0.05-0.65)						.31(.15)* (CI 0.01-0.61)
Age adult VSPID						-.02(.01)*				-.02(.01)*
Variance level 2	.36(.13)	.27(.10)	.20(.07)	.20(.07)	.09(.04)	.06(.04)	.07(.04)	.06(.04)	.37(.11)	.22(.07)
Variance level 1	.46(.08)	.43(.08)	.25(.05)	.22(.04)	.21(.04)	.21(.04)	.26(.05)	.26(.05)	.25(.04)	.21(.04)
-2 Log likelihood	257.3	245.4	195.6	186.2	162.3	154.8	176.3	172.3	212.3	183.3

Notes: *B* = regression coefficient; *SE* = Standard error; *CI* = Confidence interval: coefficient +/- 2 x SE
M1: empty model; M2: final model; *significance at alpha .05 (i.e., the coefficient is larger than two times the standard error) #: significance at an alpha between 0.05 and 0.1.
CFP+ = Care for Participation+, PMM = Participation Mind Map



Panel 2A

Panel 2B

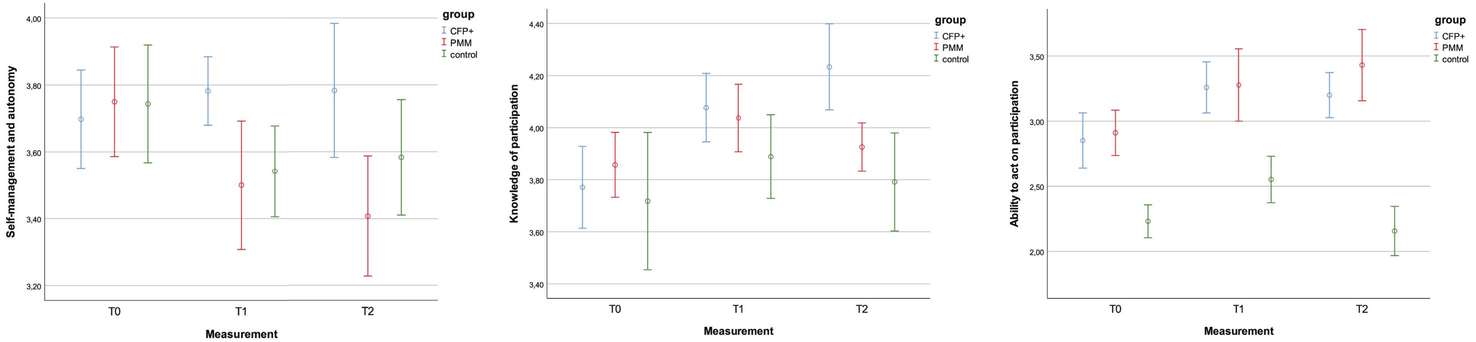
Panel 2C

Panel 2D

Panel 2E

Panel 2F

Figure 2: *Measurements of DSPs’ attitudes over time by domain for the three groups*
Panel A: experience and discover; Panel B: inclusion; Panel C: involvement; Panel D: leisure and recreation; Panel E: communication and being understood; Panel F: social relations



Panel 2G

Panel 2H

Panel 2I

Figure 2: *Continued.*
Panel G: self-management and autonomy; Panel H: knowledge of participation; Panel I; ability to act on participation

Individual profiles

Table 3 shows the median number of statements in the individual profiles of adults with VSPID written by DSPs in the three groups over time. For the "disabilities and limitations" variable, the DSPs of the CFP+ group described significantly fewer disabilities and limitations than in both control groups after six months. The results for the remaining four variables, showed no differences.

Table 3 | *Statements in the individual profiles per arm, measurement, and time point*

	Group			
Variable	**CFP+ median**	**PMM median**	**Usual care median**	**p-value**
baseline	n=13	n=10	n=12	
after 6 months	n=10	n=7	n=10	
after 12 months	n=8	n=9	n=6	
personal preferences				
baseline	2	2	1.5	0.37
after 6 months	1	1	0.5	0.42
after 12 months	1	0	0	0.64
personal possibilities				
baseline	3	2	2	0.13
after 6 months	1.5	2	0.5	0.71
after 12 months	2.5	1	1.5	0.53
disabilities and limitations				
baseline	4	4	4	0.82
after 6 months	2	6	4.5	0.005
after 12 months	3.5	5	5	0.41
actions related to preferences				
baseline	1	0	0	0.49
after 6 months	0	1	0	0.12
after 12 months	0	0	0	0.81
actions related to disabilities and limitations				
baseline	1	2	2	0.32
after 6 months	0	1	3	0.82
after 12 months	1	1	1.5	0.84

Discussion

We examined the effects of CFP+ on DSPs' attitudes regarding the participation of adults with VSPID. We hypothesized that the CFP+ intervention would result in improved attitudes of DSPs regarding the participation of the target group. Results showed that the attitudes of DSPs of the CFP+ group improved over time for a number of domains compared with the usual care group. Although these changes were not statistically significant, positive trends over time of CFP+ compared with usual care were found for the domains “leisure and recreation” and “ability to act on participation.” Additionally, confidence intervals indicated a relevant effect for the domain “social relations.” Results also showed that the attitudes of the PMM group improved compared with usual care for the domains “leisure and recreation,” “social relations,” and “ability to act on participation.” We also evaluated the effect sizes; they were small to moderate.

Additionally, our analysis of the individual profiles revealed that DSPs of the CFP+ group described significantly fewer disabilities and limitations of adults with VSPID after six months, which seems to indicate changed perceptions regarding participation (Hanzen et al., 2016). There were no significant differences for the other four variables relating to the profiles across trial arms.

A strength of this study is that it is the first evaluation of a new intervention to improve the attitudes of DSPs toward the participation of adults with VSPID. The demonstrably effective BPRA approach (Korevaar & Dröes, 2016; Swildens et al., 2011), adjusted for adults with VSPID (Hanzen et al., 2016) prompted the development of CFP+. Moreover, drawing on recent work on the definition and operationalization of the concept of participation of adults with VSPID (Hanzen et al., 2017; Hanzen et al., 2020), we tested CFP+ in a three-arm trial in which the PMM control group was considered a “low-dose” CFP+ intervention and the usual care control group served as a reference.

We developed the APQ in the absence of an instrument for measuring DSPs’ attitudes regarding the participation of the target group. Our evaluation of this new instrument revealed that the psychometric properties were not robust for all of the domains. The responsiveness of the APQ and the reliability and validity of APQ as an instrument for measuring DSPs’ attitudes regarding participation remain to be ascertained. This could have biased the (lack) of effect of CFP+.

A further point to note is that we considered the individual profiles to be indicators of the DSPs’ opinions regarding the preferences, abilities, and limitations of adults with VSPID. Because DSPs’ descriptions of the individuals with VSPID with whom they worked were elicited in response to an open question, they reflected their own thoughts and were not guided by structured questions. Therefore, we anticipated that the profiles would reveal whatever the DSPs considered to be important in relation to adults with VSPID. As noted by other researchers (Van der Putten, Vlaskamp, & Poppes, 2009), the compilation of specific knowledge regarding an individual with multiple disabilities facilitates more effective support of this individual. Thus, improved knowledge and, consequently, a positive attitude toward the preferences and abilities of adults with VSPID could strengthen DSPs' efforts to enhance the participation of individuals within the target group. Although, the inter-rater and intra-rater reliability of the individual profiles were sufficient, the responsiveness of the profiles was not examined.

While this study revealed some effects of the CFP+ intervention on DSPs' attitudes, they were fewer than expected. There are several possible reasons for this outcome. First, it is possible that CFP+ simply does not induce changes in DSPs' attitudes toward the participation of adults with VSPID. However, this finding would contradict the results of a previous study, which showed that after training, DSPs worked toward goals of improving self-management, involvement in existing activities, and developing new roles and activities for the target group (Hanzen et al., 2020). Nevertheless, our finding that DSPs were less focused on the disabilities of adults with VSPID could be understood as the first indication of a changing attitude, which is in line with a previous study (Hanzen et al., 2016).

A second possible reason for the lack of effects may be that the CFP+ training prompted increased awareness of the discrepancy between the DSPs' attitudes toward participation and the actual participation of the target group. In hindsight, this discrepancy may have been greater before the intervention was implemented and may have caused a "response shift." This tentative conclusion accords with the principle of becoming aware of shortcomings through education (Poppes et al., 2016).

Third, a lack of power resulting from the small sample size and its further reduction at follow-up impeded the demonstration of significant differences (Cohen, 1992). Limited resources and a relatively rare target group were key factors influencing what could be achieved in our study conducted with the participating residential care facilities.

Fourth, the implementation of CFP+ and PMM proved to be challenging. A process evaluation revealed a number of barriers, such as the DSPs' perception that their participation in the training program was obligatory and their belief that CFP+ overlapped with other approaches that they had already applied. These perceptions could have hampered the implementation of CFP+, thus accounting for limited positive changes in the attitudes of the participating DSPs (Knoster, Villa, & Thousand, 2000). Another barrier in the implementation of CFP+ reported by the DSPs was the lack of available time for practicing CFP+ and of available volunteers for performing new activities with the target group (Hanzen et al., 2020). According to Maxwell et al. (2012), affordability and availability of resources are important environmental factors influencing participation. The lack of time of DSPs could be indicative of a lack of resources. In addition, three DSPs in the CFP+ group changed jobs. This high turnover rate could also have influenced the intervention effects, as confirmed by Elinder, Sundblom, Zeebari, and Bergström (2018). Moreover, the PMM brochure was not fully implemented in the PMM group: about half of the DSPs were familiar with the brochure and fewer DSPs practically applied the PMM. The challenges entailed in implementing CFP+ and the PMM could have adversely influenced the results.

Fifth, the baseline scores for the CFP+ and PMM groups were significantly higher for several APQ domains compared with the usual care group. The high baseline scores on some subscales indicated a high level of support within the residential facilities in these areas . These facilities focus specifically on the care and participation of adults with VSPID and their DSPs are aware of the need to facilitate the participation of this vulnerable target group. These high baseline scores may have had a ceiling effect.

Unexpectedly, six of the 13 adults in the routine care group moved back to the residential facility shortly after the study commenced. Consequently, they were confronted with a different group composition while having to deal with a different environment. For these participating adults with VSPID, activities organized at the facility were both available and more accessible than they were outside the facility. These improved environmental factors could have positively influenced the DSPs' attitudes toward participation, resulting in smaller effects of CFP+ relative to usual care.

Recommendations for future research and practical implications

New, appropriate interventions such as CFP+ are needed to achieve optimal participation of the target group. Improving DSPs' attitudes regarding the participation of adults with VSPID may depend not only on the effectiveness of CFP+ itself, but also on its successful implementation. Factors contributing to successful implementation include particular environmental conditions, such as sufficient time and resources (Durlak, & DuPre, 2008; Maxwell et al., 2012). Although the impacts of the CFP+ intervention on DSPs' attitudes were weaker than expected, it is nevertheless important for residential care facilities to continue to focus on enhancing the participation of adults with VSPID. To improve participation, a modified version of CFP+ that includes the most effective elements combined with an improved implementation strategy and sufficient environmental factors could be applied and tested at an individual level.

Future studies could entail the implementation of CFP+ on a larger scale with more residential facilities, adults with VSPID, and DSPs to obtain generalizable results on the effects of CFP+ on DSPs' attitudes regarding the participation of the target group. In addition, an examination of the effectiveness of CFP+ elements should be conducted. In future studies, we also recommend investigations of the psychometric properties of the APQ applied within larger groups. In addition, because of expected cultural differences in attitudes towards participation of adults with VSPID between DSPs of different countries, cross-cultural validation of the APQ is recommended before it can be used for evaluations in other countries.

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Supplementary Material

Table S1 | _Attitude towards the Participation Questionnaire with items grouped into domains_

Experience and discover

-I am looking for opportunities for the person with VSPID to exercise/move or be moved.
-I go outside with the person with VSPID so that he or she can experience the weather conditions.
-I think the person with VSPID would like to be challenged to learn something new.
-I teach the person with VSPID new skills that he or she needs to improve participation.

Inclusion

-I make sure that the person with VSPID celebrates his or her birthday with visitors, presents and some treats.
-I am going to do something with the person with VSPID outside the residential facility that exactly suits him or her, such as visiting a concert, the cinema or the church.
-I regularly use the opportunities within the city where the person with VSPID lives to improve his or her participation.
- I think that society, outside the residential facility, has few opportunities for participation of a person with VSPID.*

Involvement

-I think that the (visual, intellectual, physical) limitations of the person with VSPID limit his or her participation.
-I think I should focus more at the possibilities of the person with VSPID to participate.
-I think I could look for more activities that are better suited to the person with VSPID.
-I involve the person with VSPID in daily chores.*

Leisure and recreation

-I visit with the person with VSPID, outside the residential facility, a cafe or restaurant.
-I am looking for opportunities for the person with VSPID to exercise/move or be moved.
-The person with VSPID uses a computer or tablet for relaxing activities.
-I think the person with VSPID has enough fun activities in his or her leisure time.

Communication and being understood

-I have sufficient time to give specific attention to the person with VSPID.
-I think the person with VSPID can express his or her thoughts and feelings well.

Social relations

-I think the person with VSPID can have friends.
-I encourage contact between the person with VSPID and others, such as family, friends, neighbors and acquaintances.
-I think I could involve the family of the person with VSPID even more in the participation of the person with VSPID.
-I think I could involve volunteers even more in the participation of the person with VSPID.

Self-management and autonomy

-I think the person with VSPID has too many (visual, intellectual, physical) limitations to be able to influence decisions.
-I think that as a DSP, I have to make most decisions for the person with VSPID because he or she cannot do that himself
-I let the person with VSPID decide what he or she wants to drink.
-I think it is important that the person with VSPID can do independently as much as possible.
-I think I have to take more account of the wishes and preferences of the person with VSPID to participate.
-I give the person with VSPID influence on the choice of music that can be heard.

Table S1 | *Continued.*

Knowledge of DSPs with regard to participation of the target group
-I know in which area improvement of participation is possible for the person with VSPID.
-I know how to evaluate new activities for the person with VSPID.
-I know how to approach and solve problems with new activities for the person with VSPID.
*-I can accurately assess whether the person with VSPID is satisfied in terms of participation.**
Ability of DSPs with regard to participation of the target group
-I use a systematic way to evaluate whether the person with VSPID is satisfied with regard to participation.
-I use a systematic way to determine if and in which area participation of the person with VSPID can be improved.
-I ensure that plans to improve the participation of the person with VSPID are included in the individual support plans (or reports) or I ask my colleague to do so.
-I make an overview of what is needed to start a new activity for the person with VSPID, such as involving the environment, teaching the person with VSPID skills and arranging support
-I use a systematic way to detect and resolve problems in performing activities.
-I teach the person with VSPID new skills that he or she needs to improve participation.
-I think improving the participation of the person with VSPID is an important part of my work.
-I feel supported by my supervisor in improving the participation of the person with VSPID.
*-I think that not all opportunities for participation of the person with VSPID have been tried.**

Note: * item removed to improve internal consistency reliability or other properties of the scales.

6

preference

abilities

autonomy

tablet

work

sport

hobby

nature

job

social

participate

roles

involve

support

vacation

wis

friends

self-management

activ

communication

attent

interest

vicinity

movements

interaction

suprises

belong

possibilities

experience

inclusion

The effects of the ‘Care for Participation+’ intervention on the participation of adults with visual and severe or profound intellectual disabilities: a non-randomized controlled trial

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Submitted

Abstract

Background

The “Care for Participation+” (CFP+) intervention was developed in order to change the attitudes of direct support professionals (DSPs) regarding the participation of adults with visual and severe or profound intellectual disabilities (VSPID).

Specific aims

The aim of this study was to evaluate the effects of CFP+ on the participation of the target group.

Methods

We performed a pilot non-randomized controlled trial with three arms. The effect of CFP+ on participation was compared with two control groups: a usual care control group (n = 13), and a control group in which one element of CFP+ was implemented (n = 14). Participation was measured using specific domains of the Quality Of Life of People with profound Multiple Disabilities that was completed by the legal representatives and DSPs of adults with VSPID, and video-recorded observations of (initiatives for prompting) active involvement within ten dyads comprising adults with VSPID and DSPs.

Findings

The results showed that the quality of life did not significantly change in the CFP+ group compared with the control groups. In the CFP+ group, these adults’ active involvement in activities and the number of DSPs’ initiatives to stimulate their active involvement exceeded those within the two control groups.

Discussion

CFP+ has positive effects on the active involvement of individuals with VSPID and on DSPs’ initiatives to enhance this involvement. The lower-than-expected effects of CFP+ on the participation of these adults could be explained by the previously found small effects of CFP+ on the attitudes of the DSPs regarding the participation of the target group which were probably related to implementation issues of CFP+. Accordingly, the most effective elements of CFP+ could be further developed and investigated in combination with an improved implementation strategy that incorporates sufficient positive environmental factors, such as resources and time, for practicing these elements.

Introduction

Participation is a human right that encompasses people with disabilities (United Nations, 2006) and contributes to the quality of life (Bigby, Anderson, & Cameron, 2018; Schalock et al., 2010). This right also extends to adults with visual and severe or profound intellectual disabilities (VSPID), whose participation is more likely to be limited because they suffer from a combination of visual and intellectual disabilities (Dijkhuizen, Hilgenkamp, Krijnen, Van der Schans, & Waninge, 2016; Evenhuis, Sjoukes, Koot, & Kooijman, 2009; Hanzen, Waninge, Vlaskamp, Van Nispen, & Van der Putten, 2018). The concept of participation of adults with VSPID has been defined as follows: "active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experiences, and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ("being understood") wherein the adult with VSPID has an active and steering role ("self-management and autonomy"). " (Hanzen, van Nispen, Van der Putten, & Waninge, 2017, p. 101)

Applying this definition, a previous study showed that the participation of this target group is reduced in areas such as recreation and societal inclusion (Hanzen et al., 2018). In addition, associated direct support professionals (DSPs) evidently experience difficulty identifying new social roles for this target group. Other studies have shown that individuals with severe intellectual disabilities are generally not actively involved in daily activities and that the activities available to them, such as watching television, are often passive (e.g., Beadle-Brown et al., 2016).

Adults with VSPID depend on the support of others in many areas of their lives (Nakken & Vlaskamp, 2007). Previous studies conducted on adults with profound intellectual and multiple disabilities have shown that their participation is dependent on the willingness and abilities of others in their environment (Granlund, Wilder, & Almqvist, 2013; Johnson, Douglas, Bigby, & Iacono, 2012; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). Therefore, the participation of adults with VSPID within residential care facilities is likely to depend largely on DSPs. However, DSPs appear to find participation difficult to operationalize. For example, research has shown that DSPs' attitudes influence their efforts to enhance inclusion (Venema, Otten, & Vlaskamp, 2015). If DSPs deem that inclusive principles do not apply to individuals with severe or profound intellectual disabilities, then inclusion of this group will be difficult to achieve (Bigby, Clement, Mansell, & Beadle-Brown, 2009). Other researchers have reported that discovering and developing new social roles for this target group is challenging for DSPs (Hanzen et al., 2018; Talman, Gustafsson, Stier, & Wilder, 2017). Moreover, they appear to be more focused on caring tasks (McConkey & Collins, 2010) and on protecting the physical safety of these individuals (Overmars-Marx, 2018) than on exploring and developing social contacts with neighbours or others.

In light of these issues, the 'Care for Participation+' (CFP+) intervention was developed with the aim of transforming the attitudes, knowledge, and skills of DSP, thereby enabling them to provide support that improves the participation of adults with VSPID (Hanzen, van Nispen, Vlaskamp, Korevaar, Waninge, & van der Putten, 2020). The results of a pilot study that examined a preliminary version of the CFP+ intervention was found to have positive effects on DSPs' attitudes, leading to a greater focus on the strengths rather than the disabilities of adults with VSPID. They also implemented more activities that involved adults with VSPID (Hanzen, Korevaar, van der Putten, Zijlstra, & Waninge, 2016). In a subsequent non-randomized controlled trial (NRCT) that included the delivery of an intensive training programme to DSPs, CFP+ recipients were compared with two control groups. The first group only received a participation mind map (PMM) comprising a brochure with information on the definition of participation. DSPs in the second control group provided care as usual. A process evaluation conducted for the above study revealed that DSPs applied CFP+ when attempting to develop new roles and activities for the targeted individuals and to promote their self-management, autonomy and active involvement in existing activities (Hanzen et al., 2020). The evaluation further revealed that the DSPs' attitudes towards participation improved after they had received CFP+ training. Although the outcomes were less convincing than expected, a positive trend was evident in terms of DSPs' changed attitudes regarding leisure and recreation and their ability to act to address the participation needs of the targeted group. Moreover, DSPs were less focused on the disabilities and limitations of the adults with VSPID (Hanzen, Waninge, van Nispen, Vlaskamp, Post, & van der Putten, 2020). In light of the above studies in which the impacts of CFP+ on DSPs' attitudes were assessed, our aim in the current study was to focus on adults with VSPID, evaluating the effects of CFP+ on their participation.

Methods

Study design

To evaluate the effects of the CFP+ intervention on the participation of adults with VSPID, we performed a pilot, non-randomized controlled trial with three arms entailing a parallel group design. The three arms were: (1) a CFP+ intervention group comprising DSPs who received CFP+ training, (2) a PMM control group comprising DSPs who only had access to the PMM brochure, and (3) a ‘usual care’ control group comprising DSPs with no access to CFP+ or PMM. The study was conducted in two residential care facilities for individuals with visual and intellectual disabilities in the Netherlands. We chose an NRCT design because randomization per dyad was not possible due to the high risk of inter-dyad contamination within locations and randomization per cluster was not possible because of the limited number of available clusters (two participating facilities). For reporting, we used the parts of the CONSORT checklist that were applicable for this study. The protocol for this study was approved by the ethical committee of the Department of Pedagogy and Educational Sciences of the University of Groningen on 22 March 2017.

Participants

Adults with VSPID in two residential care facilities in the Netherlands and their legal representatives, who in most of the cases were family members, were invited to participate in the study. A total of 43 teams of the adults with VSPID and their legal representatives with the DSP who usually took care of them took part in the study. The managerial staff within one of the residential facilities selected the residential groups of the facility within which the participants for the study were asked to participate in the CFP+ group (out of four group homes) or in the usual care control group (out of two group homes). The maximum number of participants in the CFP+ training group was set at 16: this way every DSP could receive sufficient guidance during the training. The participants in the usual care control group were selected from among individuals who were temporarily living outside of the facility. Therefore, the likelihood that the participants in the usual care control group would be exposed to those in the CFP+ intervention group was very small. In the second residential care facility, participants of the PMM control group were selected out of eight homes based on the advice of the healthcare psychologists.

The inclusion criteria for the participants with VSPID were as follows: (1) an intelligence quotient of below 35 points, (2) blindness, defined as a visual acuity < 3/60 and/or a visual field < 10 degrees around the point of fixation or a visual impairment, defined as a visual acuity < 6/18 and/or a visual field < 20 degrees around the point of fixation; and (3) a minimum age of 21 years. The exclusion criterion was a disease diagnosis with an expected prognosis of significant decline within a year.

Table 1 | *Characteristics of the participants of the three groups*

	Group			
Adults with VSPID	**Total**	**CFP+**	**PMM**	**Usual care**
	n=43 (%)	n=16 (%)	n=14 (%)	n=13 (%)
Age, mean (in years)	45.7	38.9	45.6	54.3
SD	11.9	12.4	10.8	5.9
Range	20-63	20-58	31-63	41-61
Gender (%)				
Female	25 (58.1)	10 (62.5)	4 (28.6)	11 (84.6)
Male	18 (41.9)	6 (37.5)	10 (74.4)	2 (15.4)
Level of intellectual disability (%)				
Severe	15 (34.9)	6 (37.5)	6 (42.9)	3 (23.1)
Profound	28 (65.1)	10 (62.5)	8 (57.1)	10 (76.9)
Visual limitations (%)				
Visual impairment	16 (37.2)	9 (56.3)	3 (21.4)	4 (30.8)
Blindness	27 (62.8)	7 (43.8)	11 (78.6)	9 (69.2)
Auditory impairment (%)				
None	31 (72.1)	10 (62.5)	9 (64.3)	12 (92.3)
Hardness of hearing	9 (20.9)	6 (37.5)	3 (21.4)	0 (0.0)
Deafness	3 (7.0)	0 (0.0)	2 (14.3)	1 (7.7)
Use of wheelchair (%)				
Yes	9 (20.9)	1 (6.3)	4 (28.6)	4 (30.8)
Partial	18 (41.9)	9 (56.3)	3 (21.4)	6 (46.2)
No	16 (37.2)	6 (37.5)	7 (50.0)	3 (23.1)
Physical health problems (%)				
Yes	43 (100)	16 (100)	14 (100)	13 (100)
No	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Mental health problems (%)				
Yes	34 (79.1)	11 (68.8)	12 (85.7)	11 (84.6)
No	9 (20.9)	5 (31.3)	2 (14.3)	2 (15.4)

Notes: VSPID = visual and severe or profound intellectual disabilities; CFP+ = Care for participation+; PMM = Participation Mind Map

Table 1 shows the participants' characteristics as documented in their individual support plans. Reported health problems included epilepsy, spasticity, constipation, and diabetes. We analysed differences in the characteristics of the participants across the three groups using chi-square tests and a one-way analysis of variance. The results revealed significant inter-group differences in the mean ages and sexes of the participants. The highest mean age was recorded for participants in the usual care group, while male participants were predominant in the PMM group.

The inclusion criteria applied to the DSPs were as follows: (1) employment as a DSP at a residential facility or taking care of daytime activities for the target group; (2) a minimum of six months experience as a DSP, and (3) an affirmed intention to continue to take care of the associated adult with VSPID during the study period. DSPs working in a group with anticipated changes in the organizational structure during the study period were excluded. Team members in all three groups were informed about the study and those who agreed to participate provided their written informed consent, including consent to be observed via video recordings.

CFP+

CFP+ is an intervention aimed at improving the participation of adults with VSPID. It is based on the 'Boston Psychiatric Rehabilitation Approach' that was developed to identify and aid efforts to meet the participation needs of individuals with psychiatric disorders (Anthony, Cohen, Farkas, & Gagne, 2002). This method was subsequently adjusted for adults with VSPID in the CFP+ intervention (Hanzen et al., 2016; Hanzen et al., 2020). CFP+ also includes the definition and operationalization of the concept of participation for the target group provided in the PMM (Hanzen et al., 2017).

CFP+ includes a training programme for DSPs, with exercises directly aimed at enhancing the participation of the persons with VSPID (Hanzen et al., 2020). To improve these individuals' participation, DSPs also include their legal representatives (LRs) or family and other team members. DSPs are encouraged to focus more on the capacities and wishes of the targeted individuals and less on their limitations. Special attention is paid to exploring (new) roles and to broadening the number of activities that can contribute to the fulfilment of these roles. The training takes place over three days with an interval of four weeks and a follow-up session is held after six months. The DSPs consult a manual with information on CFP+, the PMM, home assignments, and tools to apply CFP+ in their daily practice. After the three-day training course, DSPs are expected to carry out practical assignments aimed at improving the participation of the target group to enable them to fulfil their social roles. These assignments focus on improving their self-management, introducing new activities, and increasing their involvement in existing activities.

DSPs follow seven steps during the CFP+ training process. First, they describe the personal characteristics and capabilities of the adults with VSPID with whom they work. They then compare these descriptions with an inventory of their existing roles and associated activities. In the second step, DSPs examine whether the individual with VSPID shows signs of dissatisfaction in existing situations. Third, they select goals for a new activity or for enhanced involvement in an existing activity in consultation with their colleagues and the individuals' family members. Fourth, identify what is needed to achieve the goal. Fifth, they determine whether it is necessary and possible to teach adults with VSPID skills that would make the goal attainable. Sixth, they identify the kinds of support within the existing environment required to achieve the goal and how this support can be organized. Lastly, they learn how to evaluate goals and identify barriers if the activity does not proceed as planned. They also learn to solve problems that hamper the achievement of the goal.

Control groups

Participation Mind Map (PMM) control group

The PMM is a brochure that includes a definition of the concept of participation for adults with VSPID, as proposed by Hanzen et al. (2017), along with examples of its operationalization. These examples draw on previously established areas of participation of the target group: 'experience and discover', 'inclusion', 'involvement', 'leisure and recreation', 'communication and being understood', 'social relations', and 'self-management and autonomy' (Hanzen et al., 2017). The purpose of the PMM is to provide DSPs with examples to enable them to improve the participation of the target population. In this study, the healthcare psychologists at the residential facility were first familiarized with the PMM, which they subsequently distributed to the participating DSPs. In turn, the DSPs decided whether and how they would apply the PMM to support the individuals with VSPID.

Usual care control group

The DSPs in the usual care control group provided support as usual without receiving CFP+ training or the PMM brochure.

Outcome measures and data collection

Data were collected at the baseline before the start of the intervention (T0), and at six months (T1) and 12 months (T2) after the baseline measurement. Participation was operationalized as (1) specific quality of life domains for the target group, and (2) active involvement of adults with VSPID and the DSPs' initiatives to increase this involvement.

Participation

Participation was measured using several domains which are close to the target group-specific definition of participation of the Quality Of Life of People with Profound Multiple Disabilities (QOL-PMD) instrument (Petry, Maes, & Vlaskamp, 2009). This instrument is a validated, reliable, and feasible questionnaire developed in the Dutch language that can be administered by proxy. It comprises 55 questions covering six domains. With reference to the elements of the operationalization of participation of adults with VSPID, as identified by Hanzen et al. (2017), and as a result of CFP+ intervention, we expected changes in the following four domains of the QOL-PMD: 'communication and influence' (10 items), 'social well-being' (9 items), 'development' (9 items), and 'activities' (10 items). We expected smaller changes in the following two domains: ‘physical well-being’ (8 items) and ‘material well-being’ (9 items) because CFP+ is less focused on these dimensions. Nevertheless, these domains were also measured. For each item, formulated as a statement, the informant could choose from the following five response categories: ‘agree’, ‘partially agree’, ‘disagree’, ‘do not know’, or ‘not applicable’.

Originally, the QOL-PMD questionnaire was developed for use with individuals with profound multiple disabilities and demonstrated sound psychometric properties (Petry et al., 2009). Because our target group differed slightly from the original target group, we analysed the internal consistency reliability for both proxies. Our results showed that for the overall questionnaire, the Cronbach’s alpha values for DSPs and LRs were 0.88 and 0.91, respectively. For DSPs, the value of Cronbach’s alpha varied between 0.43 for the ‘social well-being’ domain and 0.79 for the ‘development’ domain. For LRs, this value varied between 0.40 for the ‘social well-being’ domain and 0.73 for the ‘material well-being’ domain.

The limits of agreement (LOA) between the scores of the LRs and DSPs were calculated using the procedure described by Bland and Altman (1986) for T0, T1, and T2. The mean differences between scores at T0, T1, and T2 were -2.57 ± 37.1 (LOA) (-39.67; 34.53); 3.78 ± 31.66 (LOA) (-27.88; 35.44); and 5.14 ± 35.72 (LOA) (-30.58; 40.86), respectively. Given these LOA values, we decided to analyse the data for these two groups of participants separately. The DSPs’ scores were lower than those of the LRs at T0 but were higher at T1 and T2; the scores of the LRs remained stable over time.

Active involvement

Following the study conducted by Granlund et al. (2012) on persons with multiple disabilities, we defined active involvement as the ‘active contribution or attention to the activity, reflected in behaviours such as approach, manipulation of objects, vocalization’. Given the emphasis on active involvement within CFP+, we expected it to improve as a result of the intervention.

To measure the active involvement of adults with VSPID in activities, and to observe the DSPs’ initiatives to stimulate active involvement, we observed dyads comprising an adult with VSPID and a linked DSP through video recordings. Because of the investments of time and resources incurred in video-recordings and their analysis, we opted for random selection of about a quarter of the dyads within each arm for this procedure. Thus, we selected five dyads from the CFP+ group, four from the PMM control group, and another four from the usual care control group for video recordings.

The video camera was placed in such a position that dyads could be recorded together. DSPs were asked to select two activities in advance, each lasting a minimum of 10 minutes, that they regularly performed with the linked individual with VSPID. Ideally, the same activities were recorded at the three time points.

Because active involvement can be expressed through various behaviours, and because it also depends on the functioning levels of adults with VSPID, we created individual scoring lists for each participant and for each type of behaviour. In addition, specific behaviours (initiatives) of DSPs that would be appropriate for stimulating the active involvement of these individuals were specified. Two kinds of scoring lists were used, as described below.

First, the individual scoring lists were used to measure the duration, in seconds, of the active involvement of adults with VSPID during an activity. These scoring lists were based on the possible behaviours of persons with visual, severe, or profound intellectual disabilities that could indicate positive or negative active involvement, as described in the literature (Brady & Bashinski, 2008; Hosteyn & Maes, 2009; Nijs, Penne, Vlaskamp, & Maes, 2016). Interviews were also held with the DSPs to make these behaviours explicit for the linked individual with VSPID. Finally, the scoring lists were supplemented with behaviours entailing the active involvement of the individuals with VSPID, as described in the individual support plans. The final lists of expressed behaviours based on these three sources of information included behaviours indicating active involvement and those that indicated a lack of active involvement. Examples of behaviours that could be included in the scoring list of an individual with VSPID were laughter, reaching towards materials, turning of the head towards the sound of music, and a verbal response to questions. Two researchers independently assigned scores to five (11.2%) video recordings of activities. One researcher scored nine (20.5%) of the video recordings for the second time after two weeks. The video recordings that were used to assess reliability were randomly chosen. The analysis of the reliability of the scoring list, which was conducted using a method that was analogous to that used in the study of Nijs et al. (2016), showed sufficient reliability: the Cohen's Kappa values for intra-rater and inter-rater reliability were 0.76 and 0.72, respectively.

Second, individual scoring lists were used to measure the number of initiatives of DSPs to stimulate the active involvement of the individuals with VSPID during an activity. These lists were based on possible behaviours of DSPs that could be indicative of initiatives for increasing individuals' active involvement, as described in the literature (Nijs, Vlaskamp, & Maes, 2018). Because not all individuals with VSPID have the same abilities, the lists were adapted to the (dis)abilities and preferences of the individuals with whom the DSPs were linked. For example, the active engagement of a person who is deaf cannot be increased through verbal stimulation provided by a DSP. Examples of DSPs' behaviours in these lists included giving an individual time to react to a question, using specific materials to introduce an activity, and responding to the expressions of the individual with VSPID. The reliability of the scoring lists relating to the number of DSPs' initiatives was sufficient: the Pearson's r values for intra-rater reliability agreement and inter-rater reliability were 0.99 and 0.85, respectively.

Data analysis

We used IBM's SPSS statistical software package (version 24) to analyse descriptive data, the consistency of the QOL-PMD domains and the reliability of the scoring lists for assessing active involvement and the DSPs' initiatives. The effects noted in the QOL-PMD questionnaire were analysed using the Mlwin software, while Microsoft Excel 2010 was used to analyse the effects of active involvement of adults with VSPID and DSPs' initiatives.

Participation

Subscale scores for the six domains were computed for the LRs and the DSPs. To assess the overall longitudinal effects of CFP+ on the QOL-PMD domains for the three measurements, we applied linear mixed models (maximum likelihood) to analyse data for each of the six subscales. The models were analysed through stepwise additions of (1) the main effect on time, (2) the main effect on the intervention group, and (3) the main effect on the time-intervention interaction term with reference to the usual care group. Because of existing imbalances among the groups, potential confounders, the mean ages, and the sexes of the individuals with VSPID were cumulatively added and retained in the model if they were significant ($p < 0.05$). Following Snijders and Bosker (2012), we performed significance testing of model parameters at a significance level of 0.05. Because of the small sample size, we arbitrarily defined trends over time as $p < 0.1$. By checking confidence levels, we ensured the practical relevance of the analysis. Confidence intervals, including 10 (10%), were regarded as clinically relevant because the scale ranged between 0 and 100.

Active involvement

First, we selected usable video fragments in which the dyads were clearly visible as they performed an activity. Four minutes of content were randomly selected from these fragments. For those fragments that did not contain four minutes of useful content, a time correction was applied. The video fragments were analysed twice. First, scores for active or non-active involvement of the person with VSPID were assigned at 5-second intervals. If a person was assigned scores for both active and non-active involvement within a 5-second interval, we halved this interval to 2.5 seconds. Within the 4-minute period, the total time of active involvement (in seconds) was calculated as follows: (the number of 5 second x 5 second occurrences) + (the number of 2.5 second x 2.5 second occurrences). For each dyad, the total time of active involvement of the person with VSPID was computed for every 4-minute activity fragment at the 3 time points. In addition, differences in active involvement between T0 and T1, and between T0 and T2, were computed. Because of the small sample size, we decided to combine the two control groups. To compare T0–T1 and T0–T2, we calculated the number of activities in which active involvement increased or decreased in the CFP+ group and in the controls. In addition, we calculated the mean difference in active involvement between time points (T0–T1 and T0–T2) in seconds both in the CFP+ intervention and in the controls.

Second, within the 4-minute fragments, the number of DSPs' initiatives for stimulating active involvement were assigned scores and computed for the three time points. Differences in the absolute numbers of initiatives between T0 and T1 and between T0 and T2 were calculated for each activity. To compare T0–T1 and T0–T2, it was calculated in how many activities in the CFP+ group and in the two combined control groups, the number of initiatives of DSPs increased or decreased. Additionally, we calculated the mean difference between the time points (T0–T1 and T0–T2) to ascertain the increase or decrease in the number of initiatives per activity performed in the CFP+ group and in the combined control groups. No significance testing was performed because of the small sample size and the qualitative nature of the data.

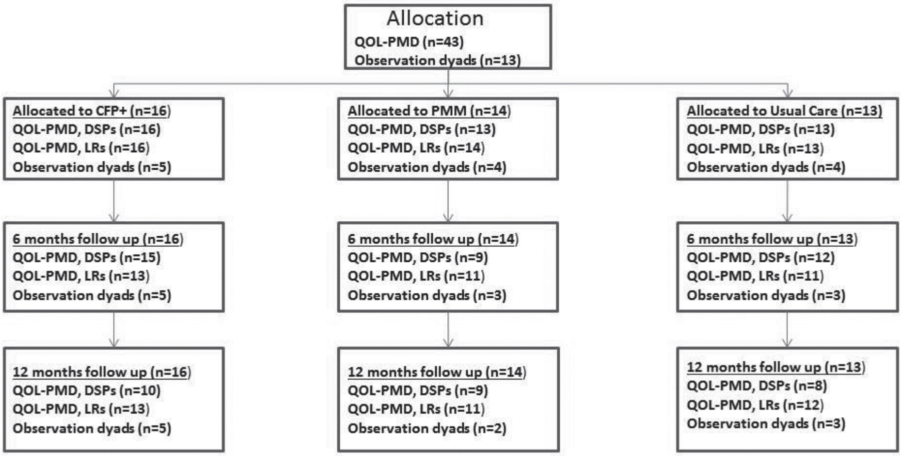


Figure 1 | *Flow chart response of QOL-PMD and observations of dyads per arm, measurement and time point*
Notes: QOL-PMD = quality of life of people with profound multiple disabilities; DSPs = direct support professionals, LRs = legal representatives, CFP+ = Care for Participation+, PMM = Participation Mind Map

Results

Participants

Figure 1 shows the number of completed QOL-PMD questionnaires submitted by DSPs and LRs and the observations of the dyads at the three time points. Job changes, vacations, and illness were the primary reasons for the loss to follow up in the group of DSPs.

Results of the QOL-PMD analysis

Table 2 presents the results of the multi-level analysis of the QOL-PMD data for the DSPs and the LRs. In addition, Figure 2 (panels A–L) shows the results obtained for the six QOL-PMD domains.

DSPs

No significant effects or trends were observed for the QOL-PMD participation domains for the CFP+ group compared with the usual care control group. Moreover, for the ‘communication and influence’ domain, the effects were significantly positive and practically relevant for the usual care control group but not for the CFP+ group. While we did not expect the ‘material well-being’ domain to be associated with the effects of CFP+, we found a significant positive and practically relevant effect for this domain relating to the usual care group but not to the CFP+ group.

Compared with the usual care control group, the PMM control group did not evidence any effects associated with the QOL-PMD domains. Similar to CFP+, for the ‘communication and influence’ domain, the effects were significant and relevant, and in the ‘material well-being’ domain, the effects were not significant but relevant in favour of the usual care instead of the PMM control group.

Compared with the scores obtained for the usual care group, the baseline scores for the CFP+ group were significant and relevant higher for the following domains: ‘communication and influence’, ‘activities’, ‘physical well-being’, and ‘material well-being’. They were also higher in relevance for the ‘social well-being’ and ‘development’ domains. Compared with the scores for the usual care group, the baseline scores for the PMM group were significantly higher for the ‘material well-being’ domain, while they were significant and relevant higher for the ‘communication and influence’, ‘social well-being’, ‘development’, and ‘physical well-being’ domains.

Table 2 | *Multilevel model of QOL-PMD of direct support professionals and legal representatives per arm and domain*

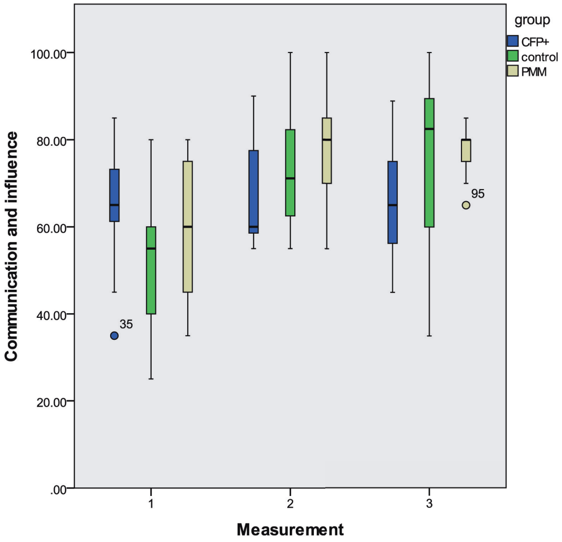
	Communication & influence				**Social well-being**			
	DSPs		LRs		DSPs		LRs	
	B (SE)	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*
	M1	M2	M1	M2	M1	M2	M1	M2
Intercept	66.87(1.58)	54.47(3.72)	67.13(1.89)	59.94(3.64)	45.72(2.18)	36.65(4.06)	46.88(2.29)	39.97(4.23)
Time		12.31(3.10)*		2.55(1.62)		4.54(1.62)*		1.03(1.45)
Group CFP+		12.85(5.05)*		6.73(4.51)		8.71(5.10)#		9.96(5.42)#
		(CI 2.75-22.95)		(CI -2.29-16.18)		(CI -1.49-18.91)		(CI -0.88-20.80)
Group PMM		6.10(5.28)		7.16(4.58)		6.21(5.43)		6.98(5.56)
		(CI -4.46-16.66)		(CI 2.00-16.32)		(CI -4.65-17.07)		(CI -4.14-18.10)
Time x group CFP+		-13.03(4.16)*		--		--		--
		(CI -21.35- -4.71)						
Time x group PMM		-2.61(4.32)		--		--		--
		(CI -11.25-6.03)						
Variance level 2	2.87(27.00)	13.24(22.67)	68.28(34.98)	63.25(33.09)	117.55(44.30)	114.31(41.48)	158.33(49.32)	145.07(46.26)
Variance level 1	254.69(44.00)	192.24(33.32)	216.93(35.92)	208.15(34.46)	184.74(32.48)	163.76(28.81)	167.09(27.77)	164.68(27.36)
-2 Log likelihood	880.85	856.77	962.48	957.11	884.84	874.52	968.46	964.60

	Development				**Activities**			
	DSPs		LRs		DSPs		LRs	
	B (SE)	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*
	M1	M2	M1	M2	M1	M2	M1	M2
Intercept	64.39(1.93)	54.64(3.76)	62.54(2.93)	57.45(5.35)	61.81(1.39)	56.51(2.80)	60.73(2.68)	56.67(4.81)
Time		5.70(2.04)*		1.26(1.80)		2.09(1.68)		.41(1.46)
Group CFP+		3.49(4.48)		11.63(6.90)#		6.55(3.23)*		10.16(6.31)
		(CI -5.47-12.45)		(CI -2.70-25.43)		(CI 0.09-13.01)		(CI -2.46-22.78)
Group PMM		4.91(4.79)		6.39(7.00)		3.08(3.46)		.15(6.42)
		(CI -4.67-14.49)		(CI -7.61-20.39)		(CI -3.89-10.00)		(CI -12.69-12.99)
Time x group CFP+								
Time x group PMM								
Variance level 2	32.36(37.83)	33.88(35.36)	262.0(79.69)	233.13(73.50)	0.00(0.00)	0.00(0.00)	237.01(66.27)	213.86(61.42)
Variance level 1	300.3(52.17)	273.28(47.51)	248.61(41.64)	249.46(41.78)	201.53(27.81)	190.94(26.35)	163.37(27.43)	163.19(27.34)
-2 Log likelihood	906.89	898.28	999.70	996.47	855.10	849.43	962.43	958.98

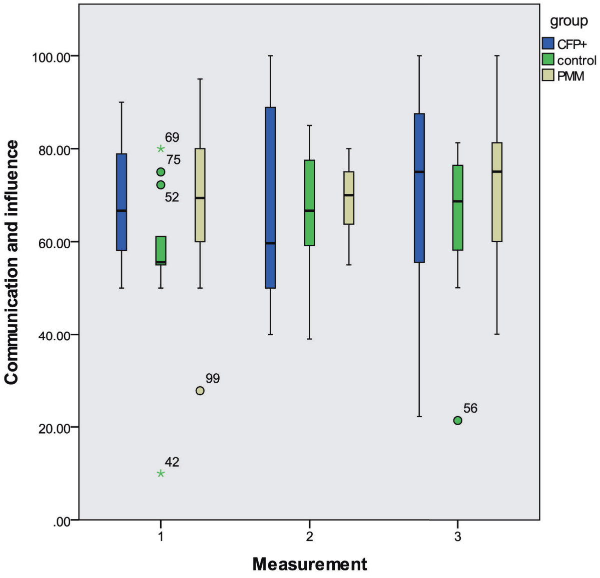
Table 2 (continued) | *Multilevel model of QOL-PMD of direct support professionals and legal representatives per arm and domain*

	Physical well-being				**Material well-being**			
	DSPs		LRs		DSPs		LRs	
	B (SE)	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*	*B (SE)*
	M1	M2	M1	M2	M1	M2	M1	M2
Intercept	54.95(2.94)	41.72(5.35)	57.25(2.74)	51.79(4.99)	63.04(1.46)	51.32(3.39)	56.74(1.78)	54.84(3.30)
Time		6.92(2.07)*		-0.28(1.65)		8.82(2.94)*		0.13(1.19)
Group CFP+		14.06(6.75)* (CI 0.56-27.56)		11.73(6.49)# (CI -1.25-24.71)		21.19(4.61)* (CI 11.97-30.41)		4.93(4.25) (CI -3.57-13.43)
Group PMM		6.51(7.18) (CI -7.85-20.87)		4.72(6.59) (CI -8.45-17.90)		18.72(4.82)* (CI 9.08-28.36)		0.02(4.31) (CI -8.60-8.64)
Time x group CFP+						-18.30(3.93)* (CI -25.89- -10.44)		
Time x group PMM						-13.09(4.09)* (CI -21.27- -4.91)		
Variance level 2	223.35(80.19)	209.31(72.37)	231.39(69.38)	211.04(64.96)	0.00(0.00)	0.00(0.00)	91.00(29.65)	83.16(28.08)
Variance level 1	312.32(54.96)	265.10(46.70)	212.99(35.49)	211.80(35.25)	224.16(30.94)	174.37(24.07)	108.96(18.12)	109.91(18.26)
-2 Log likelihood	942.94	928.33	991.65	988.37	866.28	839.90	907.39	905.60

Notes: B = regression coefficient; *SE* = Standard error; *CI* = Confidence intervals: coefficient =/- 2 x SE; QOL-PMD = quality of life of people with profound multiple disabilities ; CFP+ = Care for Participation+; PMM = Participation Mind Map; DSP= direct support professional; LR= legal representative; M1 = Empty model; M2 = Final model. * significance at alpha .05 (i.e., coefficient is larger than two times the standard error) # significance at alpha between 0.05 and 0.1.

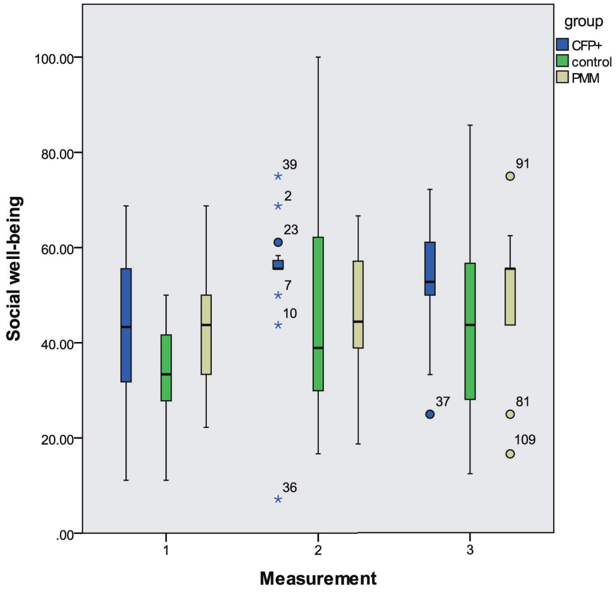


Panel 2A (DSPs)

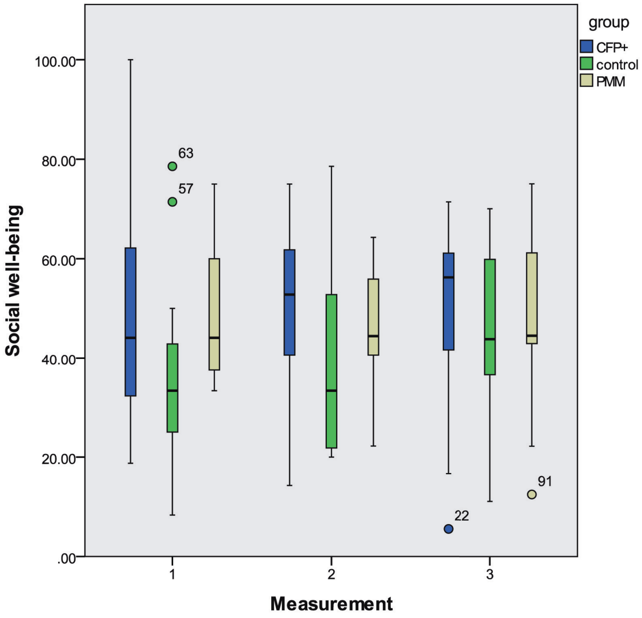


Panel 2B (LRs)

Figure 2 | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups Notes: CFP+ = Care for Participation+; PMM = Participation Mind Map; control = usual care; Panel A: communication and influence (DSPs); Panel B: communication and influence (LRs); Panel C: social well-being (DSPs); Panel D: social well-being (LRs); Panel E: development (DSPs); Panel F: development (LRs); Panel G: activities (DSPs); Panel H: activities (LRs); Panel I: physical well-being (DSPs); Panel J: physical well-being (LRs); Panel K: material well-being (DSPs); Panel L: material well-being (LRs)*

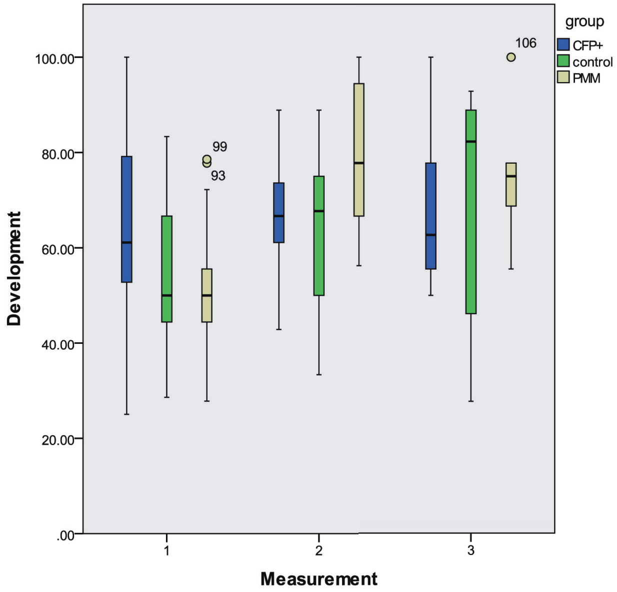


Panel 2C (DSPs)

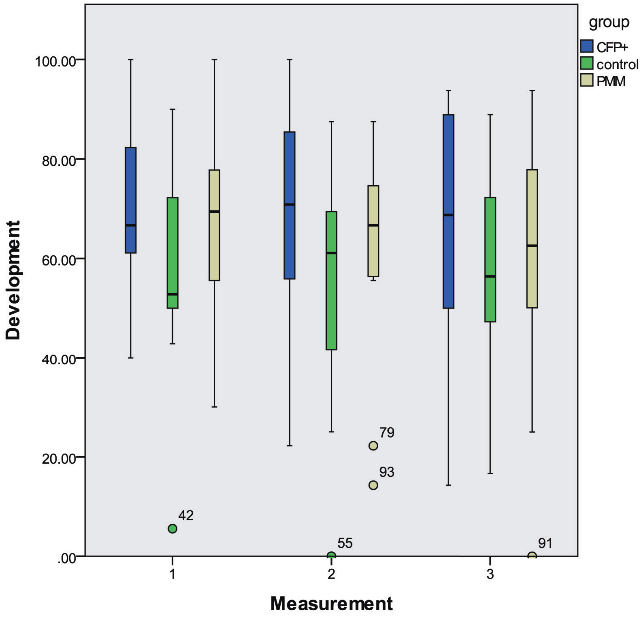


Panel 2D (LRs)

Figure 2 (continued) | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups*

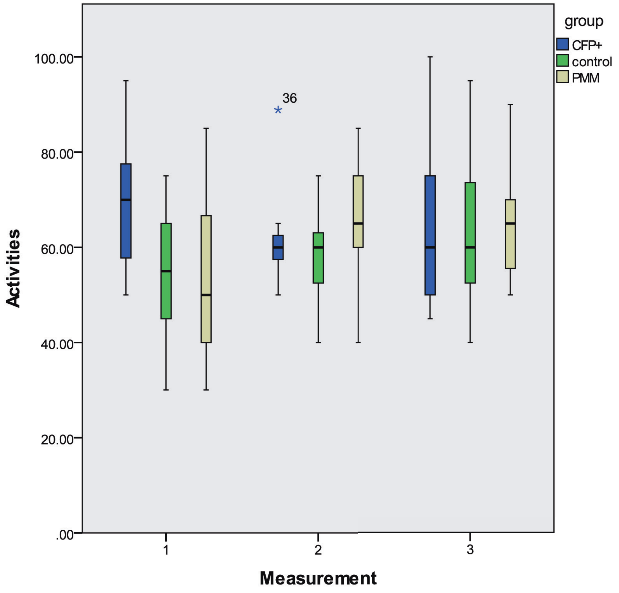


Panel 2E (DSPs)

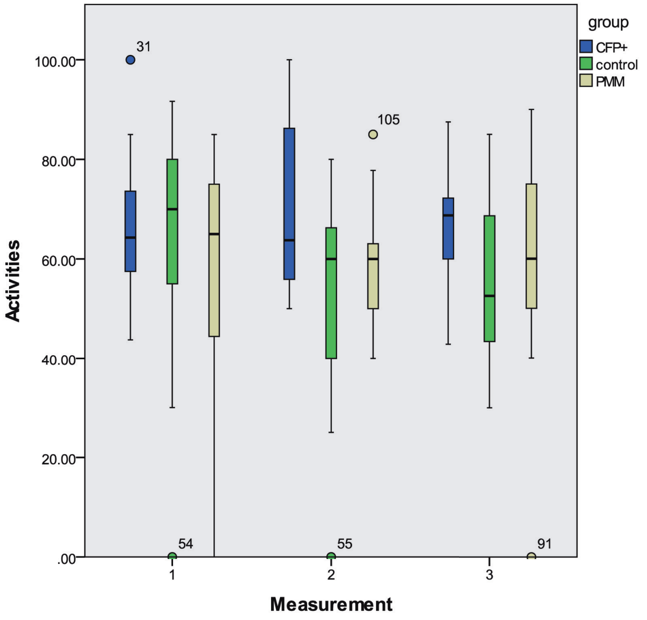


Panel 2F (LRs)

Figure 2 (continued) | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups*

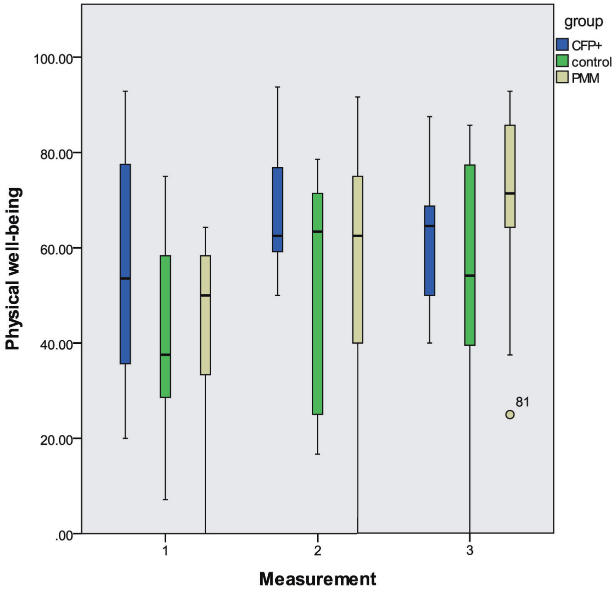


Panel 2G (DSPs)

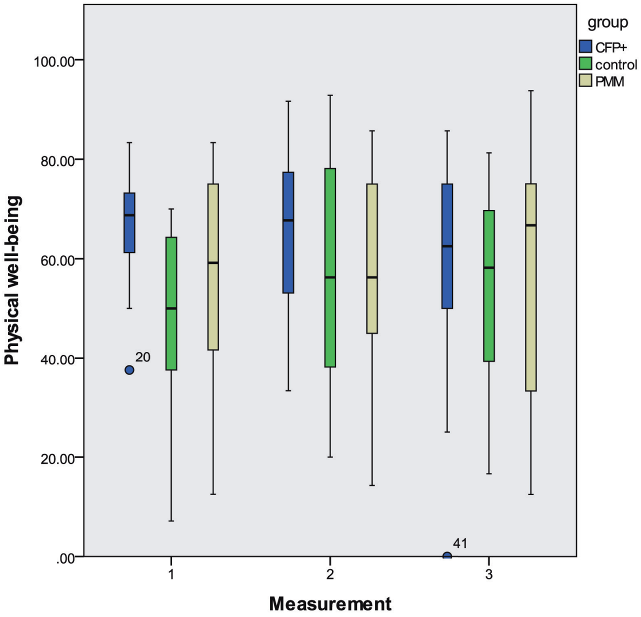


Panel 2H (LRs)

Figure 2 (continued) | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups*

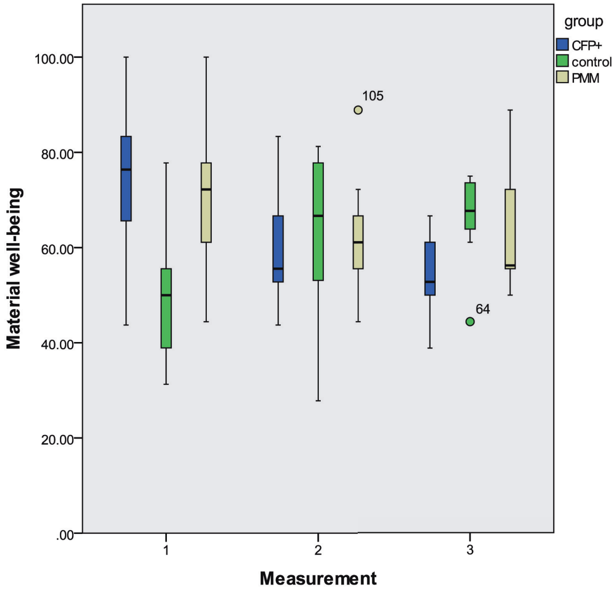


Panel 2I (DSPs)

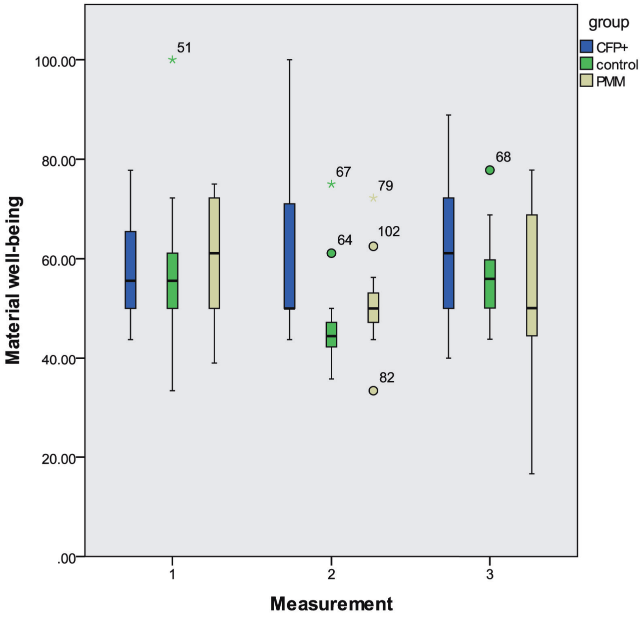


Panel 2J (LRs)

Figure 2 (continued) | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups*



Panel 2K (DSPs)



Panel 2L (LRs)

Figure 2 (continued) | *Scores of DSPs and legal representatives over time by domain of the QOL-PMD for the three groups*

Legal representatives

The results obtained for the QOL-PMD domains administered by the LRs revealed no significant effects or trends for either the CFP+ or the PMM groups compared with the usual care group. The baseline scores appeared to have a higher trend, which was also relevant, for CFP+ for the 'social well-being', 'development', and 'physical well-being' domains and, additionally, relevant higher scores for the domains 'communication and influence', 'activities', and 'material well-being' domains compared with either of the control groups. The baseline scores of the PMM group were higher in relevance for all of the domains except for the 'material well-being' domain compared with the score obtained for the usual care group.

Active involvement of adults with VSPID and DSPs' initiatives

Table 3 depicts the active involvement and initiatives of the dyads within the three groups at the three time points. At T1, the active involvement of most of the adults with VSPID in activities decreased in all three groups compared with their involvement in these activities at T0. The mean decreases per activity for the CFP+ group and for the combined control groups were 6.6 seconds and 10.5 seconds, respectively. At T2, the mean increase in active involvement for the CFP+ group (36 seconds) was higher than that for the control groups (20.3 seconds) compared with these values at T0. In addition, within the CFP+ group, the involvement of individuals with VSPID increased in three (33.3%) activities and decreased in five (55.6%) activities at T1, whereas involvement remained the same in one (11.1%) activity. Relative to T0, at T2, these individuals' involvement increased in seven (77.8%) activities and decreased in two (22.2%) activities. In the control groups, their involvement at T1 increased in four (40%) activities and decreased in five (50%) activities, with no change in involvement observed in one (10%) activity. At T2, increased involvement was observed in seven (70%) activities, whereas there was decreased involvement in one (10%) activity, and no change in two (20%) activities.

The increase over time in the number of DSPs' initiatives that were intended to stimulate the involvement of individuals with VSPID was higher in the CFP+ group than in the combined control groups. Relative to T0, at T1, the mean increase in the number of initiatives within the CFP+ group was 4.3, whereas the mean increase in these initiatives was 0.3 in the combined control groups. Relative to T0, at T2, the mean increase in the number of initiatives within the CFP+ group was 8.4, whereas it was 2.8 in the combined control groups. Further, the increase trends in the numbers of DSPs' initiatives within the CFP+ group at T1 and at T2 were the same: there were more initiatives for six (66.7%) activities and fewer initiatives for three (33.3%) activities. Within the control groups, at T1, the number of initiatives increased for four (40%) activities and decreased for six (60%) activities. At T2, the number of initiatives increased for six (60%) activities and decreased for four (40%) activities.

Table 3 | *Active involvement of adults with VSPID and initiatives of DSPs at the three measurements*

Dyads	**Activity**	**Active involvement**			**Initiatives**		
		Duration T0 (seconds*)	Difference T0–T1 (*seconds**)	T0– T2 (*seconds**)	Number at T0**	Difference T0– T1**	T0– T2**
CFP+							
1	Drinking coffee	70.0	**+50.0**	**+155.0**	25.0	**+4.7**	**+38.0**
	Walking outside	155.0	**+72.5**	**+85.0**	29.0	-3.0	**+6.0**
2	Walking outside	230.0	0.0	**+7.5**	26.0	-11.0	-13.0
3	Eating dinner	225.0	-55.0	-10,5	10.0	**+26.0**	**+13.5**
	Drinking tea	210.0	**+21.0**	**+30.0**	20.0	**+6.7**	**+1.8**
4	Eating dinner	230.0	-75.0	-5.0	12.0	**+27.0**	**+17.0**
	Walking outside	235.0	-10.0	**+5.0**	17.0	**+5.0**	-4.0
5	Movement games	160.0	-25.0	**+40.0**	59.0	**+1.0**	**+29.0**
	Drinking tea	210.0	-35.0	**+17.1**	35.0	-18.0	-12.7
Means of CFP+ group		191.7	-6.6	**+36.0**	25.9	**+4.3**	**+8.4**
PMM							
1	Eating dinner	240.0	-45.0	-5.0	32.0	-11.0	**+3.0**
	Playing with toys	210.0	-20.0	**+15.0**	25.0	**+10.0**	**+18.0**
2	Eating breakfast	195.0	**+15.0**	**+35.0**	38.0	-1.0	-10.0
	Washing and getting dressed	175.0	-37.5	**+30.0**	29.0	**+15.0**	**+5.0**
Usual care							
1	Moving passively	175.0	**+22.5**	**+25.0**	39.0	-5.0	**+20.0**
	Listening to music	240.0	-2.5	0.0	10.0	-4.0	-1.0
2	Showering and dressing	105.0	-65.0	**+40.0**	31.0	-16.0	**+1.0**
	Eating breakfast	167.5	**+7.5**	**+32.5**	15.0	**+3.0**	**+1.0**
3	Religious activity	220.0	**+20.0**	0.0	35.0	**+13.0**	-1.0
	Eating lunch	210.0	0.0	**+30.0**	41.0	-1.0	-8.0
Means of both control groups		193.8	-10.5	**+20.3**	29.5	**+0.3**	**+2.8**

Notes: VSPID = visual and severe or profound intellectual disabilities; DSP = direct support professional; CFP+ = Care for Participation+, PMM = Participation Mind Map;
* seconds of active involvement within the 4-minute observation period; ** number of DSP’ initiatives to stimulate active involvement within the observation period of 4 minutes

Figures 3 and 4 depict the active involvement of adults with VSPID and the number of DSPs' initiatives intended to stimulate the active involvement in two activities at the three time points for each dyad. Figure 3 (panels A-E) depicts the results for the CFP+ group.

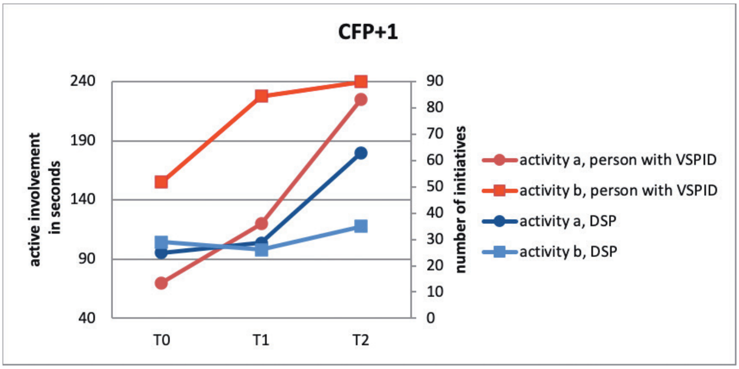
CFP+ Dyad 1: The two measured activities, namely drinking coffee and walking outside, were carried out effectively at the three time points. At T1 and T2, the number of initiatives introduced by the DSP and the active involvement of the targeted individual increased.

CFP+ Dyad 2: Only one of the chosen activities, namely walking outside, was performed at the three time points because of the decline in the physical health of the concerned individual with VSPID. In this activity, whereas this individual's active involvement increased slightly, the DSP's initiatives decreased slightly.

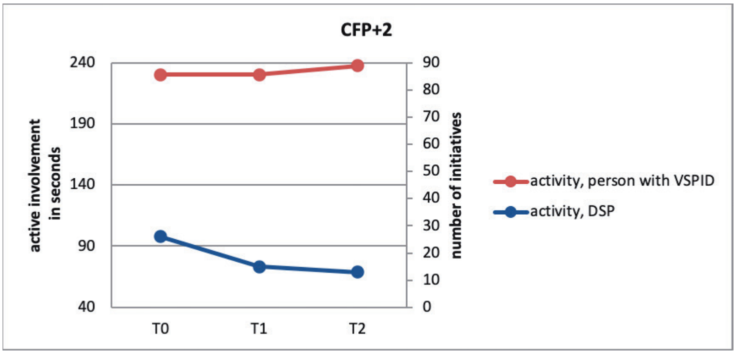
CFP+ Dyad 3: The concerned individual with VSPID was able to perform the activities of eating dinner and drinking tea independently; she only needed occasional encouragement. At T0 and T2, she ate dinner alone; at T1, she ate at a table with her peers, who distracted her. At that time, the DSP stimulated her more to become actively involved. During the tea-drinking activity, the DSP introduced more initiatives at T1 than at T0, and the active involvement of this individual increased.

CFP+ Dyad 4: This individual was able to perform the activity of eating dinner almost independently and only needed occasional encouragement. At T1, the DSP was not sitting next to her and was instead walking back and forth between clients. Nevertheless, she perceived that this individual was less actively involved and consequently introduced more initiatives to stimulate her involvement.

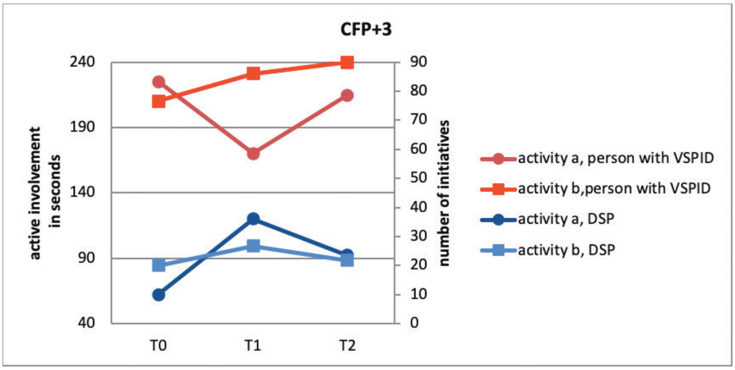
CFP+ Dyad 5: During the study period, this adult with VSPID developed dementia. At T2, the DSP introduced many initiatives to increase active involvement in two activities, namely games entailing movement and drinking tea, resulting in an increase in her active involvement.



Panel 3A: CFP+1; activity a = drinking coffee; activity b = walking outside

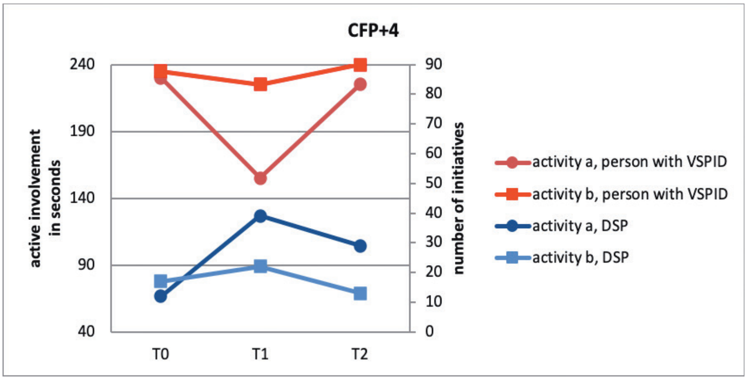


Panel 3B, CFP+2; activity = walking outside

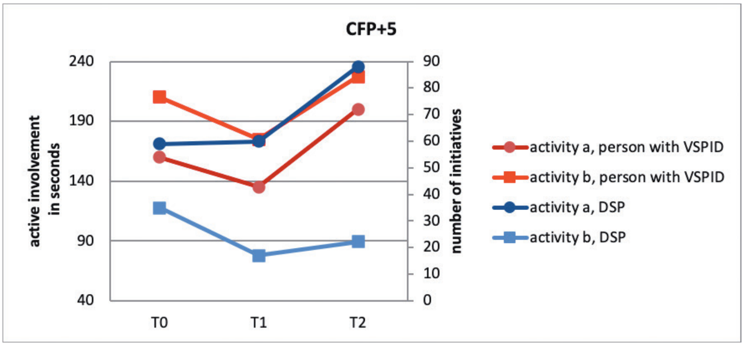


Panel 3C: CFP+3; activity a = eating dinner; activity b = drinking tea

Figure 3: *Measurements from the CFP+ group of active involvement of the persons with VSPID and initiatives of DSPs on the three measurements*
Notes: CFP+ = Care for participation+; DSP = direct support professional; Panel A: dyad CFP+1; Panel B: dyad CFP+2; Panel C: dyad CFP+3; Panel D: CFP+4; Panel E: CFP+5



Panel 3D: CFP+4; activity a = eating dinner; activity b = walking outside

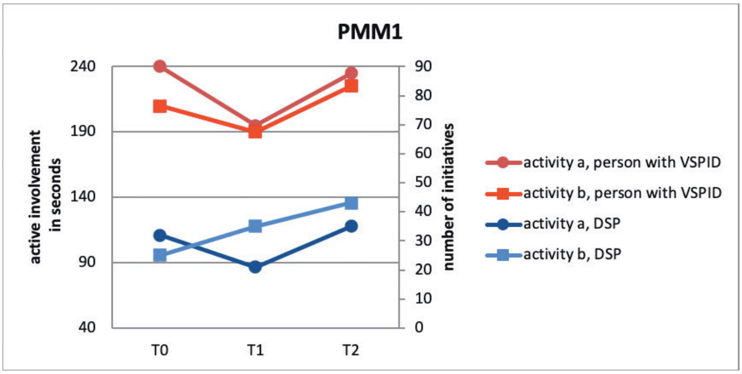


Panel 3E: CFP+5; activity a = movement games; activity b = drinking tea

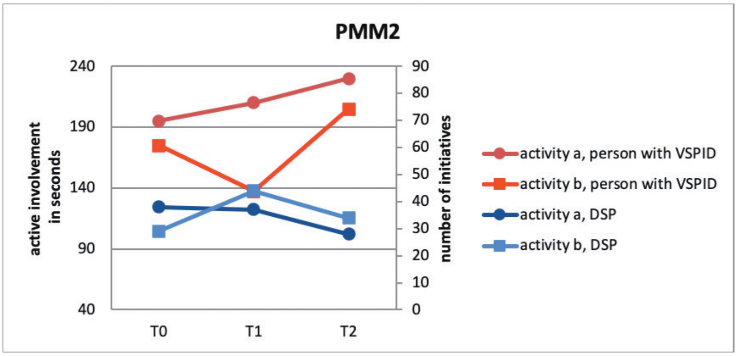
Figure 3 (continued) | *Measurements from the CFP+ group of active involvement of the persons with VSPID and initiatives of DSPs on the three measurements*
Notes: CFP+ = Care for participation+; DSP = direct support professional; Panel A: dyad CFP+1; Panel B: dyad CFP+2; Panel C: dyad CFP+3; Panel D: CFP+4; Panel E: CFP+5

The results obtained for the two control groups are shown in Figure 4 (panels A–E).

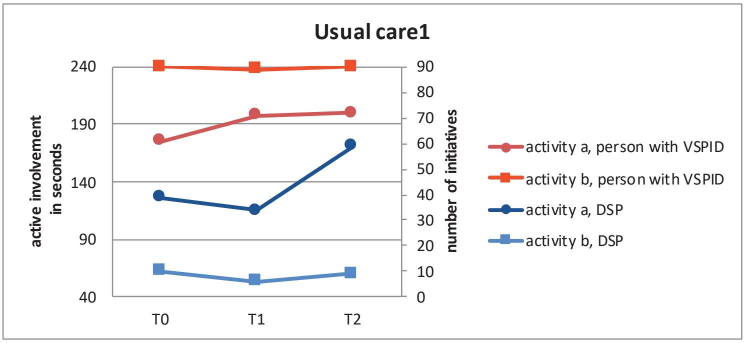
PMM Dyad 1: Because this individual with VSPID was deafblind as well as autistic, the DSP maintained constant contact during activities centring on eating dinner and playing with toys. At T1 and T2, the DSP was not yet familiar with the PMM. At T1, the DSP introduced few initiatives during the activity of eating dinner. Consequently, the active involvement of this individual decreased.



Panel 4A, PMM1; activity a = eating dinner; activity b = playing with toys

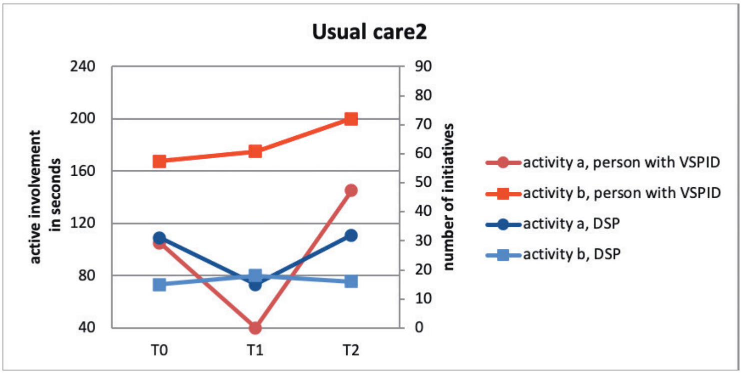


Panel 4B: PMM2; activity a = eating breakfast; activity b = washing and getting dressed

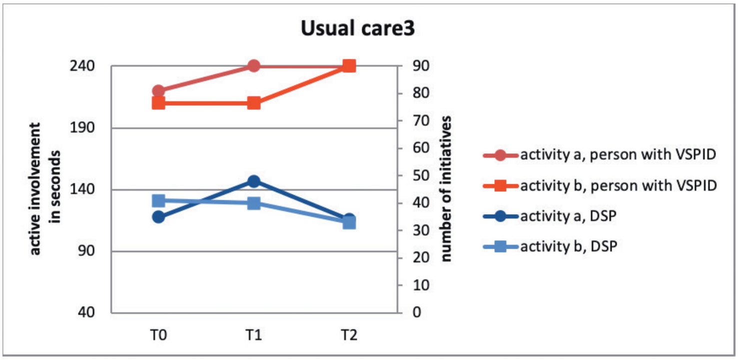


Panel 4C: Usual care1; activity a = moving passively; activity b = listening to music

Figure 4 | *Measurements from both control groups of active involvement of the persons with VSPID and initiatives of DSPs at the three time points*
Notes: PMM = Participation Mind Map; DSP = direct support professional; Panel A: PMM1; Panel B: PMM2; Panel C: Usual care1; Panel D: Usual care2; Panel E: Usual care3



Panel 4D: Usual care2; activity a = showering and dressing; activity b = eating breakfast



Panel 4E: Usual care3; activity a = religious activity; activity b = eating lunch

Figure 4 (continued) | *Measurements from both control groups of active involvement of the persons with VSPID and initiatives of DSPs at the three time points*
Notes: PMM = Participation Mind Map; DSP = direct support professional; Panel A: PMM1; Panel B: PMM2; Panel C: Usual care1; Panel D: Usual care2; Panel E: Usual care3

PMM Dyad 2: At T1, the active involvement of the participant with VSPID decreased during the activity of washing and getting dressed. Consequently, the DSP introduced many initiatives to increase her involvement. While the DSP was not familiar with the PMM at T1, she had gained familiarity with it at T2.

Usual care Dyad 1: Following the move of the adults with whom she lived just after T0, this individual with VSPID seemed to be more alert at T1 and T2. At T2, during the activity of moving passively, the DSP introduced more initiatives to enhance her active involvement, which was almost maximal at all three measured time points.

Usual care Dyad 2: At T1, the DSP decreased the number of initiatives to enhance the active involvement of the individual with VSPID during the activity of showering and dressing, leading to a decrease in active involvement.

Usual care Dyad 3: The active involvement of this individual with VSPID was practically maximal during religious activity and eating lunch at the three measured time points.

Discussion

In this study, we investigated the effects of CFP+ on the participation of adults with VSPID. We hypothesized that CFP+ would increase both the participation of adults with VSPID in specific QOL domains and their active involvement in daily activities. The results relating to changes in the participation of individuals in the intervention group over time showed no discernible effects when compared with the participation of the usual care group. The results of our qualitative study on the active involvement of individuals with VSPID appear to indicate a positive effect of CFP+ relative to the control groups. The active involvement of individuals in the CFP+ group in daily activities evidenced a greater increase compared with the involvement of individuals in the control groups. In addition, the increase in the number of DSPs’ initiatives to enhance active involvement both at T1 and T2 was higher in the CFP+ group than in the combined control groups.

Overall, the effects of CFP+ on the participation of adults with VSPID were less favourable than expected for various reasons. First, the baseline scores of the CFP+ group were significantly higher than those of the usual care group across several domains, and they were relevantly higher for all of the QOL-PMD domains. There was less room for improvement of the QOL-PMD domains in the CFP+ group. Consequently, the effects of CFP+ may have been difficult to measure.

Second, CFP+ may simply not lead to an improvement in the participation of adults with VSPID. However, this finding is not supported by those of another study, which revealed that the range of activities that encouraged the social relations, inclusion and autonomy of participating adults with VSPID had increased (Hanzen et al., 2016). In addition, the increases in the active involvement of the individuals with VSPID and in the DSPs’ initiatives in the CFP+ group, relative to the control groups, as shown in the current study, were indicative of the positive effects of CFP+ on the participation of the target group. This discrepancy in effects of CFP+ merits further investigation.

Third, the limited effect of CFP+ on participation in this study could be attributed to the post-training perceptions of the DSPs in the CFP+ group, who adopted a more critical view of the participation of their target group. Consequently, in the QOL-PMD questionnaire, they may have estimated the participation levels of individuals with VSPID to be lower at T1 and T2 than at T0. For example, one of the QOL-PMD items in the 'activities' domains was: 'The individual with VSPID regularly demonstrates active involvement in activities'. After receiving the CFP+ training, the DSPs could consider this aspect less high than it was before the training programme. Other researchers, notably Poppes et al., (2016) also attributed a lack of effects to shifts in responses.

Fourth, the CFP+ implementation process proved more difficult than expected (Hanzen et al., 2020). One of the implementation barriers faced was the DSPs' perception that the CFP+ training was compulsory and overlapped with other interventions already in use. As the above study showed, because of this perception, the DSPs' attitudes towards the participation of the target group did not improve as much as expected (Hanzen et al., 2020). As a result of this moderate improvement, and considering the fact that adults with VSPID are highly dependent on other people, including DSPs, we expected a moderate improvement in the participation of adults with VSPID. In addition, environmental factors, such as the lack of available volunteers for new activities and time for practicing CFP+, could have constrained the effectiveness of CFP+ in enhancing the participation of the target group. The choices of observed activities of DSPs working in the homes, namely eating, drinking, showering, dressing, and walking back after completing activities at the end of the day, could signal DSPs' time constraints. Evidently, they did not feel that they had sufficient time to engage in activities other than their usual activities with the individuals with VSPID. The availability of time for implementing an intervention is an environmental factor that enhances participation (Maxwell, Alves, & Granlund, 2012). Additionally, a high staff turnover within the CFP+ group could have undermined the effectiveness of CFP+ (Elinder, Sundblom, Zeebari, & Bergström, 2018) and, consequently, the participation of the target group. In addition, the implementation of the PMM was less effective than we expected; about half of the DSPs in this group actually received the PMM. In sum, the challenge entailed in implementing both the CFP+ and PMM could have affected the participation of the target group.

Fifth, the usual care control group changed considerably during the study. Unexpectedly, between the T0 and T1 time points, six of the 13 participants moved to the newly constructed houses of the residential care facility. This change in their living situation affected their circumstances as well as those of their associated DSPs. Specifically, activities within the residential facility became more easily accessible. It is likely that these changed circumstances accounted for the results obtained for the usual care group that had significantly higher scores for the 'material well-being' domain over time compared with the CFP+ and PMM groups. Although we did not equate this domain with the participation of adults with VSPID, as an environmental factor, improved 'material well-being' could have positively influenced their participation (Maxwell et al., 2012).

Although the scores for the active involvement of adults with VSPID and the DSPs' initiatives to stimulate this involvement were higher for the CFP+ group than for the control groups, in reality, these differences could have been even greater. To compare the observed activities, we focused on the same activities at the three time points. Accordingly, the DSPs selected these activities at T0 prior to the intervention. The main activities that were selected were daily activities, such as dressing and eating. It is likely that the new activities selected by the DSPs for individuals with VSPID after the CFP+ training programme were not the same as the observed activities: the new activities may have entailed more active involvement.

Methodological reflections

This was the first study to examine the effects of the new CFP+ intervention on the participation of adults with VSPID. CFP+ is based on the established and effective Boston Psychiatric Rehabilitation Approach used for individuals with psychiatric problems (Anthony et al., 2002; Korevaar & Dröes, 2016), which was adjusted for the target group (Hanzen et al., 2016). It includes the operationalization of the concept of participation for the target group (Hanzen et al., 2017; Hanzen et al., 2020). One of the strengths of this study was the three-arm design in which the CFP+ group was compared with the PMM group and a usual care control group. However, the groups were small, and loss to follow-up was observed in the QOL-PMD domains as well as the observations.

A second strength of this study was its reliability, which was sufficient for all of the QOL-PMD domains for the target group apart from 'social well-being'. Following the original use of the QOL-PMD instrument, we conducted separate analyses for the DSPs and the LRs (Petry et al., 2009). However, an associated limitation relating to the emphasis on the four QOL-PMD domains could have been that these domains were not entirely comparable with the operationalization of participation of adults with VSPID of Hanzen et al. (2017).

A third strength of the study was that the video observations provided an opportunity for individuals with VSPID to express their own 'opinions' regarding the activities and support offered. Because it was not possible to interview these individuals or to have them complete a questionnaire, observation that took the meaning of an individual's behaviour into account was considered an appropriate method for assessing their opinions (Munde, Vlaskamp, Ruijssenaars & Nakken, 2011; Vlaskamp, 2005).

The active involvement of this target group was operationalized through specific actions that contributed to the activity and through non-verbal behaviours that indicated that attention was being given to the activity. This operationalization of active involvement is in line with the approach used in other studies (Bedell, Khetani, Cousins, Coster, & Law, 2011; Mahler-Ridley, McWilliam, & Oates, 2000; Maxwell, Eriksson-Augustine, & Granlund, 2012). Another strength of this study was that triangulation, based on three sources, was conducted to assess the behaviours relating to the active involvement of the individuals with VSPID: literature (De Bal, 2011; Brady & Bashinski, 2008; Hostyn & Maes, 2009; Nijs et al., 2016), interviews conducted with the associated DSPs, and the support plans developed for the individuals with VSPID. A general problem encountered in observations of persons with profound intellectual disabilities relates to DSPs' interpretations of the visible behaviours of individuals with VSPID. By using three different sources as the basis for interpretation, we minimized the impact of this problem. However, it is possible that we missed some non-verbal behaviours that were not described in one of these sources. Further, it is possible that as a result of the CFP+ training programme, DSPs within the CFP+ group may have had more knowledge on behavioural responses during the video recordings, which could have led to biased results. In addition, although the inter-rater and intra-rater reliabilities of the video observations were sufficient, the responsiveness of the video observation was not examined.

It was necessary for DSPs to select activities before the training session was held to enable a comparison of the observations over time. New or existing activities with increased active involvement, which were selected by the DSPs in the CFP+ group after the training session, were probably not the same as the activities observed. Although this method was the only one that would enable a comparison of the same activities of the dyads at the three time points, it could be considered a limitation of the study.

Another possible limitation of the video observations was related to our expectation that more DSPs' initiatives would result in more active involvement of the individuals with VSPID. In practice, we also observed other links between the DSPs' initiatives and the active involvement of the target group. For example, if the individual with VSPID was already optimally involved in an activity (e.g. because he or she really liked the activity), then the number of DSPs' initiatives decreased without an associated reduction in the active involvement of the individual with VSPID. In other cases, after DSPs noticed that the active involvement of these individuals was low, they increased their initiatives to enhance the participants' involvement.

Practical implications of the study and recommendations for future research

Adhering to the United Nations Convention on the Rights of People with Disabilities, new interventions, such as CFP+, provide DSPs in residential care facilities with opportunities to improve the participation of adults with VSPID. Although the effects of CFP+ were less convincing than expected, previous research conducted on this intervention has shown that despite the challenges entailed in the process of implementing CFP+, small effects entailing the improvement of the DSPs’ attitudes were apparent. These improvements probably led to the positive effects observed in the current study relating to both the active involvement of adults with VSPID and the DSPs’ initiatives to enhance their involvement. In light of these results, the most effective CFP+ elements could be further developed and investigated. Moreover, larger-scale studies are required to obtain generalizable outcomes regarding the effects of CFP+ on the participation of adults with VSPID.

We found that improvements in the participation of this target group not only depended on the effectiveness of the CFP+ intervention itself but also on the implementation process and its influence on the DSPs’ attitudes towards the participation of the target group. In future studies, the implementation process could be improved in conjunction with the provision of sufficient positive environmental factors, such as resources and time for practicing elements of the CFP+ intervention (Durlak, & DuPre, 2008; Maxwell et al., 2012).

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General discussion

General discussion

The aim of this thesis was to gain insights into the definition, operationalization and, subsequently, the actual levels of participation of adults with visual and severe or profound intellectual disabilities (VSPID). In addition, we designed, implemented, and evaluated an intervention to explore ways of improving the participation of this target group.

Societal developments during the last decade appear to have prompted a fundamental change in public opinion regarding the participation of individuals with disabilities. This paradigm shift is reflected in the statement issued by the United Nations Convention on the Rights of People with Disabilities in 2006, affirming that participation is important for everyone, including people with intellectual disabilities (Mansell & Beadle-Brown, 2010; Schalock et al., 2010). However, the positive effects of participation appear to be related to the severity of associated limitations, as the level of participation of individuals with more severe disabilities is lower compared with that of individuals with less severe disabilities (Axelsson & Wilder, 2014; Kamstra, Van der Putten, & Vlaskamp, 2015; Kozma, Mansell, & Beadle Brown, 2009). Evidently, participation is also important for enhancing the quality of life of adults with VSPID. However, the likelihood of the participation of this group being suboptimal is also high because of their severe disabilities. A further problem relates to ambiguity around the concept of participation, leading to varying definitions and models used for different groups (Bigby, Anderson, & Cameron, 2018; Chien & Rodger, 2011; Imms et al., 2015). This lack of definitional consensus also implies a lack of clarity on what precisely participation entails for adults with VSPID and how it could be operationalized. In practice, the absence of a clear definition and of concrete operationalization of the concept of participation for adults with VSPID makes it more difficult for direct support professionals (DSPs) or these individuals' family members to facilitate improvements in their participation.

Main Findings

In the first study (**Chapter 2**), we applied a concept mapping approach to investigate how the concept of participation could be operationalized for adults with VSPID. The results of this investigation led us to define the concept of participation for adults with VSPID based on the perspectives of parents or other family members, DSPs, and scientists. The operationalization of the concept was found to cover a wide range of topics contained in 125 statements divided into the following seven clusters: (1) experience and discover, (2) inclusion, (3) involvement, (4) leisure and recreation, (5) communication and being understood, (6) social relations, and (7) self-management and autonomy. We subsequently developed a broad definition of participation as follows:

Participation of adults with VSPID means active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experience, and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment (‘being understood’) wherein the adult with VSPID has an active and steering role (‘self-management and autonomy’).

This definition and operationalization allows support professionals to increase their ability to give meaning to the participation of adults with VSPID.

Applying this operationalization, we retrospectively investigated the level of participation of adults with VSPID using data from individual support plans (**Chapter 3**). The results of this investigation revealed that support for adults with VSPID was mainly focused on their acquisition of experiences, their involvement, and their social relations, and less on their communication and self-management. Moreover, there was much less emphasis on inclusion, leisure, and recreation in the support that they received; this was especially true for inclusion and leisure activities conducted outside of the residential facilities. In addition, new or changing roles for adults with VSPID, considered an important aspect of participation, received no attention. Given the limited or even entirely absent opportunities for adults with VSPID to participate in certain areas, we concluded that adults with VSPID do not participate to the fullest extent. These findings point to opportunities to support adults with VSPID based on a better understanding of areas where full participation has not been achieved. Although strategies have not yet been deployed to enhance the actual participation of individuals within residential facilities, these findings signal an important step forward in the development of an intervention to improve the participation of the target group.

A new intervention was developed, given the absence of an appropriate existing intervention to improve the participation of adults with VSPID that is based on the above broad-based definition of participation (**Chapter 4**). In light of their physical, intellectual, and sensory limitations, adults with VSPID are highly dependent on others within their environment, such as DSPs (Nakken & Vlaskamp, 2007), and as a result their participation is influenced by these DSPs. However, previous research has shown that the attitudes of DSPs towards participation could hinder the target group’s optimal participation. The DSPs in these previous studies were found to be more focused on care and protective tasks and less on exploring roles and promoting social contacts for the target group (McConkey & Collins, 2010; Talman, Gustafsson, Stier, & Wilder, 2017; Venema, 2016). Therefore, a new intervention, “Care for Participation+” (CFP+), was developed that included a systematic training for DSPs, aimed at changing their attitudes towards the participation of the target group. The key elements of the CFP+ intervention are as follows: focusing on the self-management of adults with VSPID, exploring new and diverse roles for them, choosing and organizing new activities or increasing their involvement in existing activities, teaching adults with VSPID necessary skills for participation, and organizing support. Another important element in CFP+ entails the involvement of family members to develop a better understanding of the individuals with VSPID, which could give rise to ideas about new activities that would match their interests.

The results of the process evaluation of CFP+ (**Chapter 4**) showed that although the conditions for implementing this intervention were not optimal, most of the DSPs had a good understanding of the CFP+ assignments, and they also practically applied CFP+. Their efforts to introduce new activities and explore new roles for adults with VSPID, stimulate their involvement in existing activities, and enhance their self-management demonstrated their application of CFP+. These activities were derived from the previously established broad definition of participation. During the implementation phase, the intended dose, reach, and fidelity anticipated in the intervention design were not achieved as planned. Two factors that were negatively related to the implementation were the DSPs' perception of overlap with other interventions that they were already applying and insufficient time to implement CFP+.

In addition to the process evaluation of CFP+, we investigated the effects of CFP+ on the attitudes of DSPs towards the participation of adults with VSPID. Our hypothesis was that CFP+ would improve DSPs' attitudes towards the participation of adults with VSPID. To investigate this hypothesis, CFP+ was tested in a pilot three-armed non-randomized controlled trial (NRCT) at two large residential care facilities for persons with VSPID (**Chapter 5**). The results showed that there was a change in DSPs' attitudes towards participation in the CFP+ intervention group, as indicated by their reduced focus on the disabilities and limitations of the adults with VSPID compared with the DSPs in the two control groups. In addition, the DSPs' attitudes towards several domains of participation of the CFP+ group improved over time compared with the attitudes of DSPs in the care-as-usual control group. Positive and relevant improvement trends were found for domains such as "leisure and recreation," "ability to act on participation," and, "social relations" in the CFP+ group. However, these trends were not statistically significant. The attitudes of DSPs regarding the participation domains of "leisure and recreation," "social relations," and "ability to act on participation" also improved in the control group with only one element of the intervention; the Participation Mind Map (PMM). This element provided the new definition of participation for the target group along with a few illustrative examples of the operationalization of this concept.

In addition to evaluating the impact of the CFP+ intervention on DSPs' attitudes, we also investigated its effect on the actual participation of the adults with VSPID in the pilot NRCT (**Chapter 6**). The results of the qualitative study component in which data from video observations were used showed that DSPs' initiatives to enhance the active involvement of adults with VSPID evidenced an increase in the CFP+ group relative to both control groups. In addition, the active involvement of adults with VSPID in the CFP+ group increased compared with that of individuals in the control groups. Finally, our findings, derived from an analysis of questionnaires aimed at eliciting the perspectives of DSPs and legal representatives, indicated that CFP+ did not significantly contribute to improving aspects of participation.

Theoretical reflections

The theoretical contributions of the above studies are reflected in the diverse strategies that they deployed, all of which shed light on the participation of adults with VSPID but in different ways. The first theoretical contribution relates to the concept, definition, and operationalization of participation for this specific target group. Second, the research yielded insights into the levels of participation of the target group. Third, it revealed that participation of the target group in practice can improve if we recognize the important role of DSPs and focus on changing their attitudes by means of an intervention.

In this study, we operationalized and defined participation for adults with VSPID. There is a lack of consensus among researchers on the definition of the concept of participation (Bigby et al., 2018; Brown, Cobigo, & Taylor, 2015; Chang, Coster, & Helfrich, 2013), which requires further clarification (Adair, Ullenhag, Keen, Granlund, & Imms, 2015). Consequently, there is an evident need to evolve a definition of participation that specifically applies to adults with VSPID. According to the stakeholders associated with this target group, participation must be conceptualized beyond inclusion within society outside of the residential care facility. Participation could also be interpreted as acquiring experiences, social contacts, recreation, self-management, and involvement within the residential facility. The concepts of inclusion and participation are often used interchangeably, even though precise definitions of these concepts are lacking (Amado, Stancliffe, McCarron, & McCallion, 2013; Bigby et al., 2018; Schippers, Bakkers, & Peters, 2018; Taylor-Roberts, Strohmaier, Jones, & Baker, 2019). In our definition of participation relating to adults with VSPID, inclusion is one of the dimensions of participation, whereas Chang et al. (2013) differentiated between participation within the household and participation outside the household (community participation). However, our definition of participation for adults with VSPID includes both, within and outside the household. In addition, our definition foregrounds “active engagement and involvement” in line with the findings of other studies in the field of intellectual disabilities (Coster et al., 2012; Maxwell, Augustine, & Granlund, 2012). Moreover, our operationalization of involvement and self-management/autonomy includes aspects of self-care activities that are absent in existing definitions of adults’ participation (Eyssen et al., 2011) but are included in definitions of children’s participation (Chien, & Roger, 2011; Rainey et al., 2014). Adults with VSPID often cannot perform these activities independently; they require the support of others, such as DSPs, to carry them out. Additionally, some aspects of our operationalization refer to activities that are performed alone (e.g. experiencing rain and wind). Inclusion of such activities accords with the finding of Imms et al. (2015) that preferences, attendance, and involvement are elements of participation that do not require social interaction. It should also be noted that communication and being understood appear to be prerequisites for self-management and autonomy (Hauwert, 2018) and, by extension, for the participation of adults with VSPID. In sum, the definition and operationalization of participation of adults with VSPID, which is based on feedback obtained from the individuals who are most familiar with these adults (family members, professionals, and scientists), encompass a wide range of dimensions. There was a high level of agreement among the three stakeholder groups, resulting in one, joint, operationalization of the concept of participation. This definition and its operationalization could provide DSPs with input on how to improve the participation of the target group in their daily practice and spark new ideas.

Theoretically, CFP+ incorporates the PMM, which includes our definition of participation and examples of its operationalization that can be used to identify the wishes and strengths of individuals with VSPID. In addition, CFP+ includes exercises that are aimed at developing new activities in all areas covered under the definition of participation for the target group, and exercises focus especially on two areas of participation: more active involvement and more autonomy. This study demonstrated that in practice activities that are tailored to individual needs can be found in many different areas of the operationalization of participation. First, the DSPs made an inventory of the various roles of the individuals with VSPID. Subsequently, they chose activities that matched and strengthened these roles. One example included strengthening the role of “being a brother” by arranging to go swimming with his brother, which was associated with the domains of social relations, experience, and leisure and recreation. Another example was strengthening the role of “being a daughter of Indian parents” by cooking Indian food and doing the grocery shopping together with the DSPs (domains: inclusion, involvement, and experience). A third example was enhancing the role of “being an animal caretaker” by visiting the petting zoo and letting the person with VSPID take care of a rabbit (domains:

inclusion, involvement, and social relations). In addition, DSPs took more initiatives to stimulate the active involvement of individuals with VSPID, which increased in practice. The domains that are included in CFP+ accord with elements suggested in earlier studies for persons with profound intellectual disabilities, such as self-management and autonomy (Hauwert, 2018), social relations (Kamstra et al., 2015), inclusion (Mansell & Beadle-Brown, 2012), and involvement (Axelsson, Imms, & Wilder, 2014).

The suboptimal participation of adults with VSPID in areas such as inclusion, recreation, and the development of new roles, as found in our studies, accords with the findings of other studies conducted on people with severe or profound intellectual disabilities (Axelsson & Wilder, 2014; Bigby et al., 2009; Talman, Gustafson, Stier, & Wilder, 2017). Confirmation of the lack of sufficient participation in these areas prompted us to explore ways of improving this. In addition, the implementation of activities in support of areas such as communication and self-management of adults with VSPID was found to be moderate. Meanwhile, participation that relates to the acquisition of experiences, being involved, and having social relations was well implemented by DSPs. The finding that activities to strengthen the social relationships in the lives of people with VSPID were widely implemented was unexpected because other studies have shown that these relationships are often limited in number and intensity for individuals with profound intellectual and multiple disabilities (Kamstra, Van der Putten, & Vlaskamp, 2015; Nijs, Penne, Vlaskamp, & Maes, 2016). However, we found that there were gaps in the areas of social relations, experience and discovery, and involvement, indicating opportunities to enhance the participation of the target group in these areas. For example, involvement is an important part of participation because experiencing an event is determined more by active involvement in a situation than by physical presence (Coster et al., 2012; Maxwell, Augustine, & Granlund, 2012). In line with a study of Axelsson, Granlund, and Wilder (2013), active involvement in a situation is not self-evident for adults with VSPID. Consequently, its improvement requires further efforts. In sum, this overview of the participation of adults with VSPID not only indicates that their full participation has not yet been achieved but it also points to aspects that require further improvement, as revealed by the comprehensive operationalization of domains of participation of the target group in this research.

Because adults with VSPID are dependent on the support provided by their DSPs, the latter have a crucial role in promoting the participation of the target group. The CFP+ intervention has been specially developed to enhance the participation of adults with VSPID by improving DSPs' attitudes towards their participation. Our findings revealed that DSPs' attitudes towards participation could be positively influenced by CFP+.

However, previous studies have shown that the attitudes of DSPs towards certain areas of participation do often not stimulate them to engage in efforts to improve the actual participation of the target group. The application of inclusive principles has been found to be difficult for DSPs working with individuals who have severe or profound intellectual disabilities and multiple disabilities (Bigby, Clement, Mansell, & Beadle-Brown, 2009). Similarly, developing new roles for these individuals and formulating activities that match these roles is challenging (Talman et al., 2017). Our findings indicated that the CFP+ intervention positively influenced the abilities of DSPs to explore new roles and activities for adults with VSPID. In other studies, DSPs working with individuals with intellectual disabilities were often found to be much more focused on protective and caring support than on promoting social relationships within society for these individuals (Bos, 2016; McConkey & Collins, 2010; Overmars-Marx, Pepping, & Thomése, 2018; Venema, Otten, & Vlaskamp, 2015). By contrast, the DSPs in our study placed less emphasis on the disabilities and limitations of the target group after the CFP+ training, which can be interpreted as indicating the beginning of an attitudinal change among DSPs, who appear to be becoming more focused on the wishes and strengths of adults with VSPID. Consequently, we would expect them to be more open to new activities rather than focusing primarily on protection and caring tasks relating to the limitations of individuals within the target group.

Methodological reflections

Our research has several methodological strengths that include the use of mixed methods and the grounding of every study reported on in this thesis in knowledge that was derived from the previous studies accommodating the varying perspectives of relevant stakeholders. Although adults with VSPID were the target group in our studies, we were limited to obtain patient-reported data from their own perspectives because of the severity of their disabilities. Therefore, we included proxies, namely DSPs, research experts in this field, and legal representatives such as parents or other family members in the studies. We assumed that inclusion of the perspectives of these three proxy groups would yield the most comprehensive information about adults with VSPID (Petry, Maes, & Vlaskamp, 2007). However, proxy information always leads to certain levels of reporting bias because there is no guarantee that the opinions of the proxies match the opinions of the adults with VSPID (Claes et al., 2012; Koch et al., 2015). In addition, the observations of the responses of adults with VSPID to the activities offered to them, described in Chapter 6, represent a progressive step towards gaining knowledge of their opinions. However, in general, interpreting these observations is problematic because observations are subjective; they depend on the observer's knowledge of and previous experiences with the person with VSPID. Each individual's observations may vary, leading to differences in observation scores (Hogg, Reeves, Roberts, & Mudford, 2001; Munde, Vlaskamp, Vos, Maes, & Ruijssenaars, 2012; Vlaskamp, 2005). We attempted to alleviate this problem by applying three different sources as the basis of our interpretation: possible behaviours discussed in the literature (Hostyn & Maes, 2009; Nijs, Penne, Vlaskamp, & Maes, 2016); interviews conducted with the DSPs, focusing on the behaviours of individuals with VSPID who were known to them; and the behaviours of individuals with VSPID, as described in the individual support plans. The inter-rater reliability of the video-observations was found to be sufficient.

We used mixed methods to collect data for these studies. These complementary methods used for assessing the results (Heyvaert, Maes, & Onghena, 2013) were concept mapping, analyses of support plans, questionnaires, interviews, and observations. Notably, the findings of the qualitative studies relating to the effects of the intervention were more positive than those obtained using quantitative methods. This difference could be attributed to the larger number of options available using the qualitative methods for including individual differences between adults with VSPID as opposed to group differences that can mask improvements or deteriorations relating to particular individuals. While the small sample size in this study hindered the quantitative demonstration of significant effects, some trends were observable.

From a methodological perspective, a randomized controlled trial (RCT) design is the highest-rated method for investigating the effects of an intervention (Grossman & Mackenzie, 2005). In our study, randomization per dyad was not possible because of the high risk of inter-dyad contamination within locations. Cluster randomization was also not feasible because of the limited number of available clusters (two participating facilities). Consequently, we had to rely on what was methodologically feasible within these two facilities, namely an NRCT in which it was determined, beforehand, who would perform the intervention and where the two control conditions would be carried out.

Theoretically, an NRCT design enables the discovery of trends relating to the effectiveness of the intervention. However, in practice, problems arose that could have biased our interpretation of the intervention effects. The lack of effects of CFP+ could be explained by the unexpected environmental changes in the "usual care" control group. This control group had temporarily moved outside of the residential facility. However, half of this group unexpectedly moved back to the residential facility immediately after the first measurements had been taken, leading to a radical alteration in their circumstances. Other explanations for the lack of effects were problems encountered in the implementation of CFP+ and the loss to follow up because of high staff turnover (Chapter 4). Another problem was the heterogeneity of the target group, combined with a small sample size, which made it difficult to draw conclusions for the entire group, especially with regard to a topic such as participation, as optimal participation was expected to be tailored to individual needs. Despite these problems, it proved to be quite unique that we were able to perform a three-armed NRCT. Because of the heterogeneity and vulnerability of the target group, RCTs or NRCTs have rarely been performed within this complex field of study. The three-armed design enabled the inclusion of a distinct component of the intervention within a control group. Our findings indicated that within this control group, DSPs' attitudes towards several aspects improved, but there were no improvements in the participation of the adults with VSPID. This finding may indicate that while this part of the intervention did initiate a change in DSPs' attitudes, the associated change was still insufficient to promote the participation of the target group in practice. In future studies that are based on the NRCT design, we recommend increasing the sample size if possible. In addition, staff members at the residential facilities who are responsible for the inclusion of participants should be fully briefed on the research and on the criteria for including and excluding participants. These individuals usually have little research experience and can therefore unintentionally make mistakes when including participants. If the sample size is too small, a multi-case study instead of an NRCT may also be feasible. Although it is more difficult to generalize the results of these case studies, the analyses of these cases can provide in-depth insights into how CFP+ can be best applied and for whom.

Our research was conducted in residential facilities for adults with VSPID in the Netherlands. It is not clear whether the results of these studies can be generalized to other target groups, such as individuals with VSPID who live in community homes as opposed to residential facilities, children with VSPID, or persons with profound intellectual and multiple disabilities (PIMD). Research into the effects of living in the community has yielded positive results for a number of aspects relating to our broad operationalization of the participation for adults with VSPID, for example social relations, family contact, and self-determination (Mansell et al., 2010). On the one hand, we can expect that some of the results of our studies, such as the current participation of adults with VSPID, may not apply to individuals in the target group who live in communities. On the other hand, we must also realize that having a physical presence in society is no guarantee of the development of more social relationships (Chowdhury & Benson, 2011). This is because, first of all, familiarity with people with severe or profound intellectual disabilities is lacking within society (Bredewold, Tonkes, & Trappenberg, 2016; Schuurman, 2014; Van Alphen, Dijker, Van den Borne, & Curfs, 2010). Second, DSPs seem to be more focused on the safety of individuals with these limitations than on promoting their contacts within their neighbourhoods (Venema, 2016). The above explanations suggest that to a certain extent, the results of our study could extend to adults with VSPID living in the community. In addition, a question arises as to whether they could be extended to children with VSPID and persons with PIMD whose disabilities are similar to those of adults with VSPID. There is also an overlap between the groups of adults with VSPID and those with PIMD. Therefore, the broad definition of participation used in this study could be applicable to individuals within these target groups. In addition, as for adults with VSPID, the participation of children with VSPID and individuals with PIMD is dependent on the support provided by their family members and DSPs. Thus, the CFP+ intervention could also be introduced within these target groups, as changes in the attitudes of DSPs are also expected to be crucial for optimizing the participation of individuals within them. Further studies could investigate whether the outcomes of our research also apply to adults with VSPID living in the community, children with VSPID, and persons with PMID and the effects of CFP+ on their participation.

Another methodological issue concerns the CFP+ implementation process. The effects of an intervention not only depend on its content but also on its implementation process (Fleuren, Paulussen, Van Dommelen, & Van Buuren, 2014; Moore et al., 2015). The CFP+ implementation process was challenging, and negative processual factors may have influenced its effects. Consequently, we found fewer effects of the intervention than we had expected. It is not clear whether this disappointing finding could be attributed to the CFP+ intervention itself or to the barriers encountered in its implementation. Notable barriers were a suboptimal dose, insufficient time to apply CFP+ in practice, and DSPs' perceptions that their participation in the training was obligatory and that CFP+ overlapped with other interventions within the residential facility. These factors are mainly related to circumstances within the residential facility where the intervention took place and appear to be independent of the structure and content of the CFP+ intervention. Various elements within CFP+ are conducive to its implementation, such as the involvement of team members and family members of adults with VSPID, assignments that can be immediately put into practice, and the recording of goals in the worksheets. In addition, several CFP+ exercises are aimed at changing DSPs' attitudes, such as developing an inventory on the roles of the adults with VSPID combined with activities that are associated with these roles. Moreover, during the CFP+ training, the exercises follow a logical sequence that reinforces the changed attitudes of DSPs. These factors should all stimulate implementation. However, there are still several implementation factors that determine the effects of CFP+. Therefore, before deciding to implement CFP+, the managers of a residential facility should identify and assess these factors.

Apart from the issue of the unsatisfactory implementation of CFP+, a second constraint related to the implementation of the PMM, which was also not carried out as planned. The health-care psychologists at the residential facility chose to introduce the PMM during the annual consultations on the individuals with VSPID. However, this decision entailed a disadvantage, given that the PMM was implemented at different times during the year, making it more difficult to take measurements. This lack of adherence to the intervention design reveals that the design of a study is not always in alignment with the available time and resources for performing an appropriate implementation in practice. Nevertheless, it is important to recognize that this constraint is inherent to a pragmatic trial: in applied research practice, full control is likely to be unattainable.

One last methodological issue that should be noted is that we used new measurement instruments. Because it was not possible to measure DSPs' attitudes regarding the participation of the adults with VSPID, we developed two new instruments to resolve this issue: the Attitudes towards Participation Questionnaire (APQ) and individual profiles of adults with VSPID written by DSPs. The inter-rater and intra-rater reliability of the profiles were sufficient. However, the reliability and validity of the APQ have not yet been sufficiently investigated; this could have biased our interpretation of the effects of CFP+ on the attitudes of DSPs. Another possible reason for the lack of effects measured with the APQ may be the "response shift" phenomenon. During the course of the CFP+ training, DSPs may have become aware of the suboptimal participation of the target population and their own shortcomings regarding their attitudes towards participation.

Practical implications and recommendations for future research

Although we found positive trends relating to the DSPs' attitudes and the participation of adults with VSPID after the CFP+ intervention, we were unable to conclusively establish the effects of the CFP+ intervention in our study. However, it is important that support for this specific target group continues to focus on optimizing their participation in line with principles of the UN Convention on the Rights of Persons with Disabilities. In the future, we recommend focusing on the question of how the CFP+ intervention, which was designed specifically for the target group to increase their participation, can be applied in practice.

The findings of the current study show that participation in the context of adults with VSPID requires a much broader interpretation that differs from previous interpretations. Participation has been operationalized in various domains, both within and outside of residential facilities. Applying this operationalization, residential facilities and their employees can begin by systematically identifying the nature and level of the participation of their target group. Next, residential facilities can implement the CFP+ intervention, thereby initiating a process of enhancing the participation of adults with VSPID. To elaborate the broad operationalization of participation, the focus on roles and activities in all these domains, as taught in CFP+, can help to improve the participation of the target group in practice.

DSPs have a key role to play in the health care, the support, and the participation of adults with VSPID. Therefore, changing DSPs' attitudes towards the participation of the target group is a crucial prerequisite for improving the participation of this group. The first step in this process requires a shift in DSPs' focus from the limitations of adults with VSPID to their wishes, needs, and abilities. Moreover, their focus should be extended from options that fit within their daily routine at the residential facility to encompass options that do not yet fit within their facility and require creative solutions for their implementation. However, the process of changing DSPs' attitudes within a residential facility does not happen automatically. Therefore, much more emphasis needs to be placed on these aspects within DSP education and training programmes, which have largely been oriented to dealing with the limitations of the target group. The question that arises is whether residential facilities themselves can contribute to changing the attitudes of DSPs. As this study has shown, ideas and interventions originating from outside of the facility, such as CFP+, are likely to contribute to attitudinal changes.

Although changes in DSPs' attitudes are important, they are often not sufficient on their own to improve the participation of adults with VSPID, particularly when it comes to participation outside of the residential facility. As stated in the UN Convention on the Rights of People with Disabilities, participation of these adults is a collective responsibility: it is the responsibility not only of the residential facilities and their employees but also of all of the individuals who are involved with these adults within and outside of the residential facility. It could even be considered a responsibility for people who may not yet have much involvement with this target group. This shared responsibility requires more openness and inclusion of people with VSPID within society. Accordingly, while policy makers are responsible for providing sufficient resources to enable the participation and inclusion of the target group, community members also have the responsibility of being more open to initiating contact with individuals with VSPID. In recent years, various strategies aimed at promoting contact between individuals with disabilities and people within the community have been explored (Bigby & Wiesel, 2015; Kamstra, 2017; Overmars et al., 2018; Van Alphen et al, 2010; Venema, 2016). In addition, further efforts are needed to strengthen the role of the families of adults with VSPID, who provide knowledge about these individuals and are more tangibly involved in their participation. DSPs and families should work together to improve the participation of the target group. CFP+ can facilitate this process because family members are asked for their opinions about the present abilities and preferences of individuals with VSPID as well as those experienced when these individuals were still living at home. Residential facilities and their DSPs must also be prepared for changing roles within families because as the parents of individuals with VSPID age, other family members may be involved in the participation of individuals with VSPID.

Even though we have not been able to convincingly demonstrate the effectiveness of CFP+, the managers of residential facilities could still decide to implement CFP+ to improve the participation of adults with VSPID. Accordingly, conditions for the successful implementation of CFP+ should be optimized. Prior to its implementation, managers at the residential facility should check whether appropriate conditions for its introduction are present. First, in line with the UN convention, a broad perspective towards participation, as established in this study, should be adopted within the residential facility. This requires a systematic focus on changing DSPs' attitudes so that their support is more focused on improving participation. Our findings indicate that coordinated efforts to change DSPs' attitudes within the CFP+ intervention can be effective. Second, the residential facility should ensure that environmental conditions, such as adequate time for DSPs to apply CFP+ and available volunteers, will support the intervention. Third, all stakeholders should support the implementation of CFP+. Therefore, information sharing and consultations are required to brief them. Fourth, to ensure continuity, the goals and activities of CFP+ should be included in the individual support plans of adults with VSPID. In addition, the managers of the facility should encourage the participation of the most motivated DSPs as likely early adopters in the CFP+ training. This can strengthen the leadership skills of these DSPs, which could in turn improve the implementation of an intervention (Bigby & Beadle-Brown, 2018). Lastly, the residential facilities must attempt to guarantee staff continuity because a high staff turnover hinders the implementation of an intervention (Elinder, Sundblom, Zeebari, & Bergström, 2018).

There is a need to improve not only the implementation strategy of the residential facility, but also that of the CFP+ intervention itself. For example, the question of how DSPs' leadership roles could be improved during the CFP+ training requires further exploration. Additionally, the CFP+ worksheets should match the individual support plans within this facility based on previous consultations with the staff of the residential facility that is planning to implement CFP+. Consequently, the CFP+ goals and activities will remain up to date and will be available to new staff if the DSPs who received the CFP+ training switch jobs. In addition, the lack of sufficient time for the practical application of CFP+ can be partly prevented not only by developing new activities during the CFP+ training but also by identifying roles and associated activities that are not discernibly appreciated by the individual with VSPID. Omitting these activities can free up time for new activities without requiring the allocation of extra time by DSPs.

Although our findings on CFP+ were less favourable than expected, they did show that CFP+ has positive effects on both the attitudes of DSPs regarding the participation of the target group and the participation of the target group itself. Therefore, further in-depth research on the effects of CFP+ is required. Improving the above discussed implementation conditions may require a modification in the study design to ensure the allocation of sufficient time. The measurement methods used in the intervention, such as the APQ and the written profiles, should be further developed and investigated to evaluate the effects of CFP+. In addition, other measurement methods, such as goal attainment scaling, could be incorporated into future research designs to evaluate changes in individual adults with VSPID.

In sum, although professionals at residential facilities are increasingly focusing on the participation of adults with VSPID, more research and effort are required on the part of all concerned persons to achieve optimal participation of the target group. However, it is important to bear in mind that optimal participation means different things to different people, and this is certainly the case for individuals with VSPID whose abilities and interests vary. Additionally, the organization of more participation-related activities does not automatically lead to better participation. Because adults with VSPID often cannot speak for themselves what optimal participation entails in a way that people around them can easily understand, it is up to family members and DSPs to clarify what this means for them. The newly developed CFP+ intervention could guide and inform this process by creating more awareness and positive attitudes, ultimately resulting in tailored activities and optimal participation for adults with VSPID.

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Appendices

Summary

Samenvatting (summary in Dutch)

Dankwoord

Curriculum Vitae

Summary

In recent years, perceptions of people with disabilities have changed, leading to an increased focus on their participation. This changed perception has also been formative of policies, notably the United Nations Convention on the Rights of Persons with Disabilities, which was ratified by the Netherlands in 2016. This legislation provides persons with disabilities with the right to participate fully in society. The right to full participation also applies to adults with visual and severe or profound intellectual disabilities (VSPID). Such individuals are visually impaired or blind and have a severe or profound intellectual disability, with an intelligence quotient below 35 points. In addition, they often experience motor impairments and health problems, such as epilepsy and constipation. These limitations are interrelated and mutually reinforcing, constraining their independence and their abilities to develop social relationships and practical skills. Consequently, adults with VSPID are highly dependent on those around them, such as family members and healthcare professionals, who determine how they participate and to what extent. In addition, because adults with VSPID express their needs or preferences in individualized ways, they are not easily understood by those around them.

Participation is important for everyone, including adults with VSPID. Optimal participation appears to increase an individual's quality of life and leads, among other things, to more friends, more independence, more meaningful activities, and more participation within community life. However, research has shown that the positive effects of participation depend on the individual's limitations: those who have more limitations participate less. Thus, although participation is important for adults with VSPID, it is likely that their participation levels are not optimal because of their limitations. Moreover, there is limited existing knowledge about their participation.

Another problem concerns a lack of clarify regarding the concept of 'participation', which is defined and operationalized, both theoretically and in practice, in different ways. Partly because of this issue, it is also difficult for individuals who support adults with VSPID to find ways to enhance their participation.

The component studies of this research project were aimed at acquiring insights into the definition, operationalization, and current levels of participation of adults with VSPID. In addition, an intervention to improve the participation of the target group was developed. The effects of this intervention on the attitudes of direct support professionals (DSPs) towards the participation of the adults with VSPID whom they supported and on the participation of the adults with VSPID themselves were investigated.

Chapter 2 describes how the concept of participation was defined and operationalized for adults with VSPID. A concept mapping procedure was performed with 53 participants subdivided into family members of adults with VSPID, professionals working with the target group, and scientists. A total of 125 statements remained after the process of selection and removal of duplicate statements had been completed. Examples of the selected statements included: 'They want to experience as much as possible with all of their senses', 'they want to fulfil different social roles', and 'they want to choose the music themselves'. These statements were presented to the three groups of participants, who were requested to sort the statements into different categories that they then named. In addition, they were asked to assess the importance of the statements for the participation of the target group: the average ranking of statements across all of the participants varied between 6.5 and 9.0 on a scale from 1 to 10. Because of the high level of agreement among the different groups of participants, a single and broadly applicable formulation of the operationalization of the concept of participation for adults with VSPID was developed. This operationalization covered many areas under the following seven domains: 1) experience and discovery; 2) inclusion; 3) involvement; 4) leisure and recreation; 5) communication and being understood; 6) social relations; and 7) self-management and autonomy. Accordingly, participation for this target group was defined as follows: "Participation of adults with VSPID means active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experience, and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ("being understood"), wherein the adult with VSPID has an active and steering role ("self-management and autonomy")". A brochure titled the 'Participation Mindmap' (PMM), in which this definition is presented with examples of the operationalization of participation, was developed to facilitate the practical application of the concept of participation.

Chapter 3 provides an overview of the areas of participation of adults with VSPID in light of the newly formulated definition. These areas were identified through an analysis of the individual support plans of 40 adults with VSPID from three residential facilities across the Netherlands. In this study, text fragments were extracted from these plans using the domains described in chapter two. A total of 2,791 text fragments relating to the identified statements were extracted from the individual support plans. The best represented domains in relation to the statements were 'experience and discovery', 'involvement', and 'social contacts'. By contrast, statements from the domains of 'inclusion' and 'leisure and recreation' were used much less frequently; over 40% of the statements from these two domains were not described in any of the support plans. A further analysis of the statements that were not included in these two domains showed that they mainly referred to participation outside of the residential facility. Notably, statements that were not described often were those concerning new or changing roles of adults with VSPID in their daily lives. In light of these results, we concluded that the support provided to adults with VSPID within residential facilities covers a number of domains of participation. However, in some domains, particularly inclusion and leisure, participation remains limited and could be improved.

Chapter 4 describes the methodology applied to develop an intervention, 'Care for Participation+' (CFP+) and the findings of a process evaluation conducted to assess its implementation. This intervention aims to improve the participation of adults with VSPID and is based on an existing intervention, namely the Boston Psychiatric Rehabilitation Approach. CFP+ integrates the broad definition and operationalization of the concept of participation for the target group. Because adults with VSPID depend on the support of others in almost all areas of their daily lives, CFP+ includes a training programme for DSPs who support these individuals on a daily basis, with the aim of changing their attitudes towards the participation of the target group. DSPs are encouraged to focus more on the wishes and strengths of adults with VSPID and less on their problems and limitations. During the CFP+ training programme, DSPs involve their colleagues and the family members of the individuals with VSPID in efforts to increase the participation of these individuals. A particular focus of CFP+ is on developing (new) roles that individuals with VSPID can assume in their lives, such as 'friend', 'son', 'neighbour', or 'employee' and broadening the number of meaningful activities associated with these roles. After undergoing the training programme, DSPs are expected to introduce appropriate new activities or to increase the active involvement of individuals with VSPID within existing activities. In addition, they are expected to have learnt how to increase the self-management abilities of individuals with VSPID.

Care for Participation+: Content and steps for its implementation

The training programme takes place over three days, with a gap of four weeks between each training session and a follow-up meeting held after six months. The direct support professionals (DSPs) are provided with a manual containing information about CFP+ along with exercises and tools for applying CFP+ in their daily practice. The CFP+ training programme comprises seven steps that are taught in a systematic manner. First, the DSPs describe the personal characteristics and abilities of the individuals with VSPID whom they are supporting and compare them with these individuals' existing roles and the activities implemented to fulfil these roles. Second, they look for possible signs of dissatisfaction conveyed by the individuals with VSPID. Third, they set goals for new activities or more active involvement of the individuals with VSPID in existing activities in consultation with their colleagues and the individuals' family members. Fourth, they make inventories of what they consider necessary to achieve the goal. Fifth, they try to teach the persons with VSPID the skills required to achieve the target goals. Sixth, they identify areas of necessary support for achieving the goals, such as required materials or agreements with others. Finally, they evaluate the goals, identify obstacles in achieving the goals, and come up with appropriate solutions.

A total of 16 DSPs underwent the CFP+ training programme within a residential facility for people with VSPID. The findings of the process evaluation showed that the training programme did not proceed completely according to plan. The time slot assigned for each training day had to be reduced from the scheduled 6 hours to 4 hours, and the planned follow-up meeting was replaced by individual telephone consultations with each of the DSPs. Barriers identified during the implementation process were the DSPs' conviction that the CFP+ intervention partly overlapped with other methods that they had applied as well as insufficient time for implementing the new activities. Moreover, the evaluation results indicated that the DSPs had not applied parts of the intervention after the training. Considering the amount of time that had been planned for, the expected reach, and extent to which the DSPs adhered to the intervention's instructions, we concluded that the CFP+ intervention was not fully implemented. Nevertheless, a number of aspects of the implementation did proceed as expected. Most of the DSPs appeared to have a good or reasonably good understanding of the assignments associated with the intervention. It was also apparent that the DSPs applied CFP+ to increase the self-management of individuals with VSPID, develop new activities, increase their active involvement in existing activities, and develop new roles for them. In light of these results, we concluded that despite the sub-optimal conditions relating to the implementation of the CFP+ intervention, the DSPs applied CFP+ with the adults with VSPID whom they supported to some extent within different domains.

Chapters 5 and 6 describe the effects of CFP+ on the attitudes of the DSPs towards the participation of adults with VSPID and on the actual participation of the target group. The study was conducted within two residential facilities. The effects observed in the CFP+ group (n = 16) were compared with those observed in two control groups: in one group (n = 14), the DSPs only received the PMM brochure and in the other group (n = 13), the DSPs simply provided care as usual and did not have any exposure to either CFP+ or

PMM. Measurements were taken before the start of the intervention, after six months, and again after 12 months.

Chapter 5 describes the effects of the CFP+ intervention on the attitudes of DSPs towards the participation of adults with VSPID. Attitude was defined as 'a way of thinking to act in a certain way based on both the experience and personality of an individual'. During the study, each DSP was linked to one adult with VSPID, whose daily practice he or she supported. The DSPs wrote personal profiles about these adults, including their personal preferences, abilities, and limitations. The results of the analyses of these personal profiles showed that the DSPs in the CFP+ group described significantly fewer limitations of adults with VSPID six months after participating in the training programme compared with those in the control groups. This finding indicates a more positive attitude among DSPs in the CFP+ group towards the participation of the target group.

The DSPs also completed a questionnaire about their attitudes. Because the measurements of the DSPs were considered to be interdependent, regression models were used to analyse the data in the questionnaires. We found a positive trend for changes in the attitudes of DSPs in the CFP+ group in the following domains: 'leisure and recreation', 'social relations', and 'the ability to act on participation'. Despite this positive trend, these changes were, statistically, not significantly different from those obtained for the care-as-usual control group. In addition, the attitudes of DSPs in the PMM control group also showed improvements for these three domains. We concluded that CFP+ prompts small positive changes in DSPs' attitudes.

Chapter 6 reports on the effects of the CFP+ intervention on the participation of adults with VSPID. These effects were assessed using two measures. The first was an existing questionnaire on the quality of life of people with multiple disabilities corresponding to the domains of participation. The second measure comprised observations of the target individuals' active involvement during activities and the number of initiatives that the DSPs took to stimulate this active involvement. The results of the analysis of data derived from the questionnaires, which were completed by the DSPs and the legal representatives of the adults with VSPID, showed that neither the CFP+ group nor the PMM group scored higher compared to the care-as-usual group in the various domains of participation. Moreover, in the 'communication and influence' and 'material well-being' domains, the control group that received care as usual scored higher. Perhaps this finding can be explained by the relocation of half of this control group, resulting in changed circumstances for this group during the study.

By contrast, the observations of activities of adults with VSPID along with their DSPs indicated that compared with the methods applied in both of the control groups, the CFP+ intervention had a positive effect on the active involvement of the adults with VSPID as well as on the number of initiatives that DSPs took to increase their active involvement during these activities.

Although the implementation of the CFP+ intervention was sub-optimal, and its effects were less convincing than expected, the DSPs' attitudes evidenced a slight positive trend. The positive results relating to both the active involvement of adults with VSPID and the number of initiatives introduced by the DSPs to stimulate this involvement are probably attributable to these attitudinal shifts.

Chapter 7, which is the concluding chapter, presents a summary and discussion of the results of the research along with recommendations for practice and future research. An important outcome of this research was the operationalization and definition of the concept of participation for adults with VSPID. This definition and concrete operationalization will serve as guiding inputs for family members and DSPs for improving the participation of the target group. The participation of this target group is currently insufficient and this requires an intervention to improve their participation.

This thesis has described a research study focusing on the development and implementation of the CFP+ intervention to improve the participation of the target group. Because of the crucial role of DSPs, the focus of this intervention was on changing their attitudes towards the participation of the target group. After undergoing the training programme, DSPs appear to be less focused on the limitations of the target group and more focused on developing activities to strengthen the roles and associated activities of adults with VSPID. Consequently, the active involvement of these adults increased during the activities. DSPs' attitudes do not change automatically within a residential facility; extra attention to their education and training is thus required to achieve these changes.

Nevertheless, the effects of the CFP+ intervention were less convincing than expected. The sub-optimal implementation of CFP+, the unexpected changes in the control group that was not exposed to any interventions, the small sample size, and the new measuring instruments used in the study may have served to constrain the effects of CFP+. A non-randomized, controlled study design is rarely used for this target group, and despite its limitations, this design enabled us to compare the effects of CFP+ to the control groups. In follow-up studies based on this research design, the sample size should be increased if possible. To gain a deeper understanding of who should use CFP+ and how best to apply it, a multiple-case design should be considered if the sample is small.

The studies described above focused on adults with VSPID within residential facilities, but the findings of these studies may be equally relevant for related groups such as adults with VSPID living in community homes, children with VSPID, and persons with profound intellectual and multiple disabilities (PIMD). These groups often have similar limitations, and the DSPs who support them generally face the same constraints when trying to increase their participation.

Improving DSPs' attitudes is not the only factor affecting the participation of adults with VSPID; the task of encouraging their participation is shared by all of the individuals who are involved with them both within and outside residential facilities. In addition, it is important to optimize the implementation of CFP+ both with regard to conditions within the residential facilities as well as improving the CFP+ intervention itself to enhance its effects. Although the effects of CFP+ have not been conclusively established in this thesis, the target goal continues to be to ensure that support for adults with VSPID is aimed at improving their participation. In the future, research should be conducted into the best way of using CFP+ that is specially developed to improve the participation of the target group. CFP+ potentially increases the awareness of DSPs about the possibilities of strengthening the participation of the target group and offers them concrete tools to improve their participation. Ultimately, CFP+ can contribute to the optimal participation of the target group.

Samenvatting (Summary in Dutch)

De afgelopen jaren is de visie op mensen met beperkingen veranderd en is er meer aandacht gekomen voor hun participatie. Deze veranderde kijk heeft ook geleid tot ander beleid, zoals beschreven in de Conventie van de Verenigde Naties en ondertekend door Nederland in 2016, waarbij personen met beperkingen recht hebben op volledige participatie in de maatschappij. Dit geldt ook voor volwassenen met visuele en ernstige of zeer ernstige verstandelijke beperkingen ([Z]EVVB). Volwassenen met (Z)EVVB zijn slechtziend of blind en ze hebben een (zeer) ernstige verstandelijke beperking: hun intelligentiequotiënt (IQ) ligt beneden 35 punten. Verder hebben ze vaak motorische beperkingen en veelal gezondheidsproblemen zoals epilepsie en obstipatie. Deze beperkingen staan met elkaar in verband, versterken elkaar en bemoeilijken o.a. het aangaan van sociale relaties, ontwikkeling van praktische vaardigheden en hun zelfstandigheid. Deze beperkingen maken volwassenen met (Z)EVVB bijzonder afhankelijk van de mensen in hun omgeving zoals familie en zorgprofessionals. Deze afhankelijkheid maakt ook dat hun participatie sterk wordt bepaald door de mensen om hen heen. Daar komt bij dat volwassenen met (Z)EVVB op een individuele wijze aangeven wat ze nodig hebben of wat hun voorkeuren zijn en het voor de mensen om hen heen moeilijk is om dit te achterhalen.

Participatie is belangrijk voor iedereen en daarom ook voor volwassenen met (Z)EVVB. Een optimale participatie blijkt de kwaliteit van het bestaan te vergroten en onder andere te leiden tot meer vrienden, meer onafhankelijkheid, meer betekenisvolle activiteiten en een grotere deelname aan het gemeenschapsleven. Uit onderzoek blijkt echter dat de positieve effecten van participatie afhangen van de aanwezige beperkingen: mensen met meer beperkingen participeren minder. Dat betekent aan de ene kant dat participatie belangrijk is voor volwassenen met (Z)EVVB, maar aan de andere kant dat de kans groot is dat hun participatie niet optimaal is door de aanwezige beperkingen. Kennis over hun participatie is echter schaars.

Een ander probleem is dat het begrip ‘participatie’ onduidelijk is en op verschillende manieren gedefinieerd en geoperationaliseerd wordt binnen zowel de wetenschap als de praktijk. Mede hierdoor is het voor de mensen die volwassenen met (Z)EVVB begeleiden ook moeilijk om hun participatie te verbeteren.

De studies binnen dit onderzoek richten zich op het verkrijgen van inzicht in de definitie, de operationalisering en de huidige mate van participatie van volwassenen met (Z)EVVB. Daarnaast is een interventie ontwikkeld waarmee de participatie van de doelgroep kan worden verbeterd. Onderzocht is wat de effecten van deze interventie zijn op de attitudes van begeleiders ten aanzien van de participatie van de volwassenen met (Z)EVVB die ze begeleiden én op de participatie van volwassenen met (Z)EVVB.

In **hoofdstuk 2** wordt het onderzoek beschreven naar de operationalisering en definitie van het concept participatie voor volwassenen met (Z)EVVB. Voor dit onderzoek is gebruik gemaakt van een concept mapping procedure met 53 participanten, onderverdeeld in familie van volwassenen met (Z)EVVB, professionals die met de doelgroep werken en wetenschappers. Na het ontdubbelen en selecteren van de stellingen die gerelateerd waren aan de onderzoeksvraag bleven 125 stellingen over zoals “ze willen zo veel mogelijk ervaren met al hun zintuigen”, “ze willen verschillende sociale rollen vervullen” en “ze willen beslissen over de muziekkeuze”. Deze stellingen werden opnieuw voorgelegd aan de drie groepen participanten met de vraag om de stellingen te sorteren in categorieën en deze categorieën een naam te geven. Daarnaast werd gevraagd hoe belangrijk zij de stellingen vonden voor de participatie van de doelgroep: het gemiddelde belang van een stelling over alle participanten varieerde van 6.5 tot 9.0 op een schaal van 1 tot 10. De overeenkomst tussen de meningen van de verschillende groepen deelnemers was zodanig dat er een gezamenlijke operationalisering van het begrip participatie voor mensen met (Z)EVVB gemaakt kon worden. Deze operationalisering bleek veel gebieden te bestrijken en bevatte zeven domeinen: 1) ervaren en ontdekken; 2) inclusie; 3) deelname en betrokkenheid; 4) vrije tijd, ontspanning en recreatie; 5) communicatie en begrepen worden; 6) sociale contacten; en 7) eigen regie. Op basis van deze resultaten is participatie voor de doelgroep gedefinieerd als: “Actieve deelname en betrokkenheid binnen dagelijkse bezigheden, sociale, maatschappelijke en vrije tijd activiteiten, met mogelijkheden voor inclusie, ervaren en ontdekken. Dit is alleen mogelijk vanuit een relatie met de omgeving waarin de persoon met een visuele en (zeer) ernstige verstandelijke beperking een actieve en sturende rol heeft”. Voor de praktijk werden de definitie en voorbeelden van de operationalisering van participatie samengebracht in een brochure, de “Participatie Mindmap” (PMM).

Hoofdstuk 3 geeft een overzicht van de gebieden waarin volwassenen met (Z)EVVB volgens de nieuwe definitie participeren. Daartoe werden individuele ondersteuningsplannen geanalyseerd van 40 volwassenen met (Z)EVVB van drie residentiële voorzieningen, verspreid over Nederland. In dit onderzoek werden uit deze plannen tekstfragmenten geselecteerd aan de hand van binnen hoofdstuk twee beschreven domeinen. In totaal bevatten de 40 individuele ondersteuningsplannen 2791 tekstfragmenten die gerelateerd waren aan een stelling. De onderdelen “ervaren en ontdekken”, “deelname en betrokkenheid” en “sociale contacten” waren het meest vertegenwoordigd in de plannen. Daarentegen bleken de stellingen uit de onderdelen “inclusie” en “vrije tijd, ontspanning en recreatie” veel minder vaak te worden beschreven:

meer dan 40% van de stellingen uit deze twee domeinen werd in geen van de ondersteuningsplannen beschreven. Bij nadere analyse van de stellingen die niet werden beschreven binnen deze twee domeinen bleek dat het met name stellingen betrof van participatie buiten de residentiële voorziening. Verder viel op dat stellingen die niet werden beschreven vaak te maken hadden met nieuwe of veranderende rollen die volwassenen met (Z)EVVB kunnen hebben in hun leven. Op basis van deze resultaten wordt geconcludeerd dat de ondersteuning aan volwassenen met (Z)EVVB in residentiële voorzieningen gericht is op een aantal domeinen van participatie, maar dat op andere domeinen, zoals met name inclusie en vrije tijd, de participatie nog beperkt is en verbeterd zou kunnen worden.

Hoofdstuk 4 beschrijft de ontwikkeling en de proces evaluatie van de implementatie van een interventie, “Zorg voor Participatie+” (ZVP+). Deze interventie heeft als doel de participatie van volwassenen met (Z)EVVB te verbeteren en is gebaseerd op een bestaande interventie, de Boston Psychiatric Rehabilitation Approach. In ZVP+ zijn de brede definitie en operationalisering van het begrip participatie voor de doelgroep geïntegreerd. Omdat volwassenen met (Z)EVVB in vrijwel alle aspecten van hun leven afhankelijk zijn van anderen, bevat ZVP+ een training voor de begeleiders die deze personen dagelijks ondersteunen; ZVP+ is gericht op het veranderen van hun attitudes ten aanzien van de participatie van de doelgroep. Begeleiders worden aangemoedigd zich meer te focussen op de wensen en sterke kanten van volwassenen met (Z)EVVB en minder op hun problemen en beperkingen. Tijdens de training ZVP+ betrekken de begeleiders hun collega’s en familie van de personen met (Z)EVVB om de participatie van deze personen te vergroten. ZVP+ besteedt speciale aandacht aan het ontwikkelen van (nieuwe) rollen die mensen met (Z)EVVB in hun leven kunnen hebben, zoals bijvoorbeeld “vriend”, “zoon”, “buurman” of “medewerker” en het verbreden van het aantal betekenisvolle activiteiten binnen deze rollen. Na afloop van de training wordt verwacht dat de begeleiders voor de personen met (Z)EVVB nieuwe passende activiteiten introduceren of de actieve betrokkenheid tijdens bestaande activiteiten vergroten. Daarnaast hebben ze geleerd op welke manier ze de eigen regie van de persoon met (Z)EVVB kunnen vergroten.

Binnen een residentiële voorziening voor mensen met (Z)EVVB hebben 16 begeleiders de ZVP+ training gevolgd. Uit de procesevaluatie bleek dat de training niet geheel was uitgevoerd zoals bedoeld. De tijd per training dag moest noodgedwongen terug worden gebracht van de geplande 6 tot 4 uren en de geplande follow-up bijeenkomst werd vervangen door een telefonisch overleg met iedere begeleider apart. Belemmerende factoren tijdens de implementatie bleken de overtuiging van de begeleiders dat ZVP+ deels overlap vertoonde met andere methodes die ze toepasten en het gebrek aan tijd om de nieuwe activiteiten daadwerkelijk uit te voeren. Ook bleek na afloop van de training dat de begeleiders delen van de interventie niet hadden gebruikt. Als gevolg hiervan werd geconcludeerd, gezien de geplande tijd, het verwachte bereik en de mate waarin begeleiders zich hielden aan de instructies van de interventie, dat implementatie van ZVP+ niet volledig heeft plaatsgevonden. Desalniettemin gingen er ook een aantal aspecten van de implementatie wel volgens verwachting. Het bleek dat de meeste begeleiders de opdrachten binnen de interventie goed of redelijk goed begrepen. Ook bleek dat de begeleiders ZVP+ toepasten voor de personen met (Z)EVVB om de eigen regie te vergroten, nieuwe activiteiten te ontwikkelen, de actieve betrokkenheid in bestaande activiteiten te vergroten en nieuwe rollen te ontwikkelen. Op basis van deze resultaten wordt geconcludeerd dat, ondanks de suboptimale omstandigheden bij de implementatie van ZVP+, de begeleiders ZVP+ in meer of mindere mate toepasten op verschillende gebieden voor de volwassenen met (Z)EVVB die ze ondersteunden.

Zorg voor Participatie+: inhoud en stappen van de methode

De training bestaat uit drie dagen met een tussenruimte van 4 weken tussen iedere training en een follow-up bijeenkomst na 6 maanden. De begeleiders maken gebruik van een cursus map met informatie over ZVP+, oefeningen, en handvatten om ZVP+ te kunnen gebruiken in de dagelijkse praktijk. De training ZVP+ volgt zeven stappen die heel systematisch worden aangeleerd. Ten eerste beschrijven de begeleiders de persoonlijke kenmerken en mogelijkheden van de persoon met VSPID en vergelijken deze met de bestaande rollen en activiteiten waarmee deze rollen zijn vervuld. Ten tweede kijken ze naar mogelijke signalen van ontevredenheid van de persoon met VSPID. Als derde bepalen ze een doel voor een nieuwe activiteit of meer actieve betrokkenheid tijdens een bestaande activiteit in overleg met hun collega's en de familie van de persoon met VSPID. Als vierde inventariseren ze wat nodig is om het doel te bereiken. Als vijfde proberen ze de persoon met VSPID de vaardigheden aan te leren die nodig zijn om het doel te bereiken. Als zesde inventariseren ze wat nodig is aan ondersteuning om het doel te bereiken, zoals bijvoorbeeld materialen of afspraken met anderen. Als laatste evalueren ze de doelen, sporen hindernissen op in het bereiken van de doelen en bedenken passende oplossingen.

In de hoofdstukken 5 en 6 worden de effecten van ZVP+ beschreven op zowel de attitudes van begeleiders ten aanzien van participatie van volwassenen met (Z)EVVB als op de daadwerkelijke participatie van de doelgroep. Het onderzoek vond plaats binnen twee residentiële voorzieningen. De effecten in de ZVP+ groep (n=16) werden vergeleken met twee controle groepen: één groep (n=14) waarvan de begeleiders enkel de brochure PMM ontvingen en één groep (n=13) waarvan begeleiders niet beschikten over ZVP+ of PMM. Zij ontvingen gebruikelijke zorg. De metingen vonden plaats vóór de invoering van de interventie, na 6 en na 12 maanden.

In **hoofdstuk 5** wordt beschreven welke effecten ZVP+ had op de attitudes van begeleiders ten aanzien van de participatie van volwassenen met (Z)EVVB. Attitude wordt omschreven als ‘‘een wijze van denken om op een bepaalde manier te handelen op basis van zowel de ervaring als de persoonlijkheid van een individu’’. De begeleiders waren in het onderzoek gekoppeld aan één volwassene met (Z)EVVB die ze in de dagelijkse praktijk ondersteunden. Over deze volwassenen schreven de begeleiders persoonlijke profielen met onder andere de persoonlijke voorkeuren, mogelijkheden en beperkingen van deze mensen. De resultaten van de analyses van deze persoonlijke profielen lieten zien dat de begeleiders van de ZVP+ groep, vergeleken met de controlegroepen, zes maanden na de training significant minder beperkingen beschreven van de volwassenen met (Z)EVVB. Dit kan beschouwd worden als een positievere attitude ten aanzien van de participatie van de doelgroep.

De begeleiders hebben daarnaast een vragenlijst ingevuld over hun attitude. Doordat de metingen van de begeleiders als onderling afhankelijk werden beschouwd, zijn voor de analyse van de vragenlijsten regressiemodellen gebruikt. We vonden een positieve trend van ZVP+ op de domeinen “vrije tijd en recreatie”, “sociale contacten” en “de deskundigheid om te handelen op het gebied van participatie”. Ondanks deze positieve trend, waren deze veranderingen niet statistisch significant verschillend ten opzichte van de controlegroep die gebruikelijke zorg ontving. Daarnaast bleek ook in de PMM controlegroep op deze drie domeinen een verbetering in de attitude. Geconcludeerd wordt dat ZVP+ kleine positieve veranderingen teweeg brengt in de attitudes van begeleiders.

Hoofdstuk 6 doet verslag van de effecten van ZVP+ op de participatie van volwassenen met (Z)EVVB. Dit is gemeten met: 1) een bestaande vragenlijst op het gebied van kwaliteit van bestaan van mensen met meervoudige beperkingen die overeenkwam met de domeinen van participatie, en 2) observaties tijdens activiteiten waarbij gekeken is naar de mate van actieve betrokkenheid van de volwassenen met (Z)EVVB én het aantal initiatieven dat de begeleiders namen om deze actieve betrokkenheid te stimuleren. Uit de resultaten van de vragenlijst, ingevuld door de begeleiders en door de wettelijk vertegenwoordigers van de volwassenen met (Z)EVVB, bleek dat zowel ZVP+ als PMM geen hogere scores lieten zien op de domeinen van participatie. Het bleek zelfs dat op de domeinen “communicatie en invloed” en “materieel welbevinden” de controlegroep die gebruikelijke zorg ontving hoger scoorde. Wellicht kan dit worden verklaard door de verhuizing van de helft van deze controle groep, waardoor de omstandigheden van deze groep ingrijpend veranderden tijdens het onderzoek.

Echter, uit de resultaten van de observaties van activiteiten van volwassenen met (Z)EVVB samen met hun begeleiders bleek dat ZVP+, vergeleken met beide controlegroepen, een positief effect had op zowel de actieve betrokkenheid van de personen met (Z)EVVB als op het aantal initiatieven die begeleiders namen om de actieve betrokkenheid te vergroten tijdens deze activiteiten.

Hoewel de effecten van ZVP+ minder groot waren dan verwacht, bleken er, ondanks de suboptimale implementatie, kleine positieve trends op de attitudes van de begeleiders; en dit heeft waarschijnlijk geleid tot de positieve effecten op zowel de actieve betrokkenheid van de volwassenen met (Z)EVVB als op het aantal initiatieven van begeleiders om deze betrokkenheid te stimuleren.

Dit proefschrift sluit af met **hoofdstuk 7** waarin de resultaten van het onderzoek worden samengevat en bediscussieerd én er aanbevelingen worden gedaan voor de praktijk en toekomstig onderzoek. Een belangrijk resultaat van de uitgevoerde studies zijn een operationalisering en definitie van het begrip participatie voor volwassenen met (Z)EVVB. Deze definitie en concrete invulling bieden begeleiders en familie aanknopingspunten bij het verbeteren van de participatie van de doelgroep. Deze participatie van de doelgroep laat te wensen over en dit vraagt om een interventie om de participatie te verbeteren.

Dit proefschrift beschrijft de ontwikkeling en het onderzoek van de interventie ZVP+ om de participatie van de doelgroep te verbeteren. In verband met de cruciale rol van begeleiders wordt in ZVP+ ingezet op het veranderen van de attitudes van begeleiders ten aanzien van de participatie van de doelgroep. Begeleiders blijken na afloop van de training minder gericht op de beperkingen van de doelgroep en ontwikkelen activiteiten om de rollen van volwassenen met (Z)EVVB en de activiteiten die daar bij horen te versterken. Hierdoor neemt de actieve betrokkenheid van deze volwassenen tijdens activiteiten toe. Het veranderen van attitudes van begeleiders gaat niet vanzelf binnen een residentiële voorziening: dit vraagt extra aandacht in opleiding en training van begeleiders.

De effecten van ZVP+ waren echter minder overtuigend dan verwacht. De suboptimale implementatie van ZVP+, de onverwachte veranderingen in de controlegroep zonder interventies, de kleine onderzoeksgroep en de gebruikte nieuwe meetinstrumenten kunnen de effecten van ZVP+ hebben beperkt. Een niet-gerandomiseerd, gecontroleerd onderzoeksdesign wordt zelden gebruikt bij deze doelgroep en heeft, ondanks z'n beperkingen, de mogelijkheid gegeven de effecten van ZVP+ in drie groepen te vergelijken. Bij het gebruik van dit onderzoeksdesign in vervolgstudies is het raadzaam om de onderzoeksgroep, indien mogelijk, te vergroten. Om een dieper inzicht te krijgen voor wie en hoe ZVP+ het beste kan worden gebruikt, kan, bij een kleine onderzoeksgroep, ook overwogen worden om een multiple-case design te gebruiken.

De beschreven studies hebben zich gericht op volwassenen met (Z)EVVB binnen residentiële voorzieningen, maar de resultaten kunnen evenzeer van belang zijn voor aanverwante groepen zoals volwassenen met (Z)EVVB wonend binnen kleinschalige woonvormen, kinderen met (Z)EVVB en personen met zeer ernstige verstandelijke en motorische beperkingen. Deze groepen hebben veelal vergelijkbare beperkingen en begeleiders ervaren meestal ook vergelijkbare problemen bij hun participatie.

De verbetering van de attitudes van begeleiders is niet de enige factor die de participatie van volwassenen met (Z)EVVB beïnvloedt; het is een verantwoordelijkheid voor alle mensen die bij hen betrokken zijn, zowel binnen als buiten de residentiële voorziening. Daarnaast is het belangrijk om de implementatie van ZVP+ te optimaliseren om de effecten van deze interventie te vergroten: het gaat hierbij zowel om voorwaarden binnen de residentiële voorzieningen als om verbeteringen binnen ZVP+ zelf. Hoewel de effecten van ZVP+ in dit proefschrift niet onomstotelijk zijn vastgesteld, blijft het belangrijk dat de ondersteuning van volwassenen met (Z)EVVB gericht is op het verbeteren van hun participatie. In de toekomst zou onderzocht moeten worden op welke manier ZVP+, speciaal ontwikkeld om de participatie van de doelgroep te verbeteren, het beste kan worden gebruikt. ZVP+ vergroot in potentie de bewustwording van begeleiders ten aanzien van de mogelijkheden van participatie van de doelgroep en biedt hen concrete handvatten om de participatie daadwerkelijk te verbeteren. Uiteindelijk kan ZVP+ bijdragen aan een optimale participatie van de doelgroep.

Dankwoord

Promoveren kun je zien als een lang en intensief traject waarbij je vele hindernissen moet overwinnen. Dat klopt natuurlijk, maar daarnaast heb ik het traject ervaren als een heel inspirerend avontuur en dat kwam vooral door de mensen met wie ik heb samengewerkt en waarvan ik steun heb ontvangen in de afgelopen jaren. Deze mensen wil ik graag bedanken.

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Beste Aly, jij bent niet alleen copromotor bij mijn promotie maar ook al meer dan 30 jaar lang mijn directe collega fysiotherapeut bij de Brink. Dat schept een hele bijzondere band. Ik vond het al een hele eer dat ik paranimf mocht zijn bij jouw eigen promotie, maar ik vind het een nog grotere eer dat je copromotor bent bij mijn promotie. Dit proefschrift is begonnen met onze vraag wat een verbeterde conditie van onze cliënten bijdraagt aan hun participatie. Vanuit deze vraag zijn we, met behulp van vele anderen, langzaam het pad op gegaan van het onderzoek dat beschreven is in dit proefschrift. Ik heb tijdens het schrijven van het proefschrift van veel mensen hulp gehad; van jou heb ik echter niet alleen alle hulp gekregen maar mede door al ons ‘gefilosofeer’ voelt dit proefschrift als ons gezamenlijk product. Ik heb van jou veel geleerd over wetenschappelijk onderzoek, maar nog meer over samenwerken met anderen. Je bent altijd belangstellend en enthousiast, geeft positieve en razendsnelle feedback, en misschien wel het belangrijkste: je hebt mij altijd het vertrouwen gegeven dat ik dit proefschrift zou kunnen schrijven. Zelfs tijdens de aller moeilijkste periode in je eigen leven stond je altijd open voor overleg over deze onderzoeken. Aly, ik kan je daar niet genoeg voor bedanken. Ik verheug me er op om samen met jou verder te werken aan wetenschappelijk onderzoek binnen de Academische Werkplaats EMB.

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Beste Carla, als tweede promotor had je misschien iets meer afstand van de ‘dagelijkse’ begeleiding, maar ondanks deze afstand heb je enorm veel invloed gehad op mijn promotieproces. Jouw ervaring en kennis van het onderzoeksveld is ongeëvenaard: daar heb ik enorm veel van geleerd. Bij ieder contact met jou deed ik nieuwe inzichten op, niet alleen qua onderzoeksmethodes maar ook in het promotieproces. Jij hebt mij regelmatig de grote lijn in dit proces laten zien en dit vond ik zeer waardevol. Hierdoor kon ik bewuster keuzes maken en dit proefschrift voltooien. Carla, je was al met emeritaat als professor, maar ondanks dat heb je altijd de nodige tijd en aandacht besteed aan dit proefschrift: ik wil je daar heel hartelijk voor bedanken.

Beste Ruth, als copromotor uit een wat ander onderzoeksveld, onderzoek voor mensen met visuele beperkingen, heb ik zo veel van jou geleerd. Sterker nog: ik denk dat jouw ervaring, visie en kennis wezenlijk invloed hebben gehad op de opzet van de onderzoeken van dit proefschrift. Ik noem bijvoorbeeld het gebruik van concept mapping en de opzet van de NRCT studie. Daarnaast is het heel fijn om met je samen te werken omdat je altijd betrokken bent, qua onderzoek maar ook persoonlijk. Ik waardeer het bijzonder dat je verschillende keren van Amsterdam naar Vries bent gereisd om samen aan het onderzoek te werken. Je reageert snel op vragen en je geeft praktische hulp bij problemen. Je oogt rustig, maar bedenkt ondertussen vaak heel vlot ingenieuze en soms avontuurlijke oplossingen waar ik nog niet aan had gedacht. En bij je feedback geef je vaak niet alleen aan wat anders zou moeten, maar je doet meteen een voorstel voor een alternatief: dat heeft mij erg geholpen. Daarbij moet ik je natuurlijk ook bedanken voor alle verbeteringen van mijn Engels. Ruth, bedankt voor de geweldige samenwerking en ik denk ik dat we vast nog wel een project vinden waarin we opnieuw samen optrekken.

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Dit onderzoek was onmogelijk geweest zonder de steun van Koninklijke Visio en Bartiméus: de studies zijn uitgevoerd binnen deze twee organisaties voor mensen met visuele beperkingen. Ik dank in het bijzonder Marjolein Hommel en Angela Hese van Koninklijke Visio, de Blauwe Kamer en Arjan Maasland van Bartiméus: ik heb vaak een beroep op jullie moeten doen om onder andere deelnemers te includeren en jullie hebben mij iedere keer opnieuw geholpen. Ook wil ik de gedragsdeskundigen van Bartiméus bedanken voor het meedenken over het includeren van deelnemers en het verspreiden van de Participatie Mindmap binnen Bartiméus.

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Koninklijke Visio heeft mij op vele manier gesteund bij dit proefschrift. Ik ben trots dat ik bij Koninklijke Visio werk en dat de organisatie op allerlei manieren probeert het leven van mensen met visuele (en verstandelijke) beperkingen te verbeteren. Sanny van der Steen wil ik bedanken voor haar bijdrage aan het begeleiden van mijn promotie binnen Visio: jouw bijdrage getuigt van een grote betrokkenheid bij de doelgroep en bij mij persoonlijk. De directie en het management van de Brink heeft altijd achter mijn onderzoek gestaan en was altijd geïnteresseerd. Marie-José van den Driessche, Lex van Hemert, Ine Berkelmans en Gerard Kolstein: heel hartelijk dank voor jullie steun en vertrouwen. Ook wil ik Joost Heutink, Ellen Koudijs en Jolien Makkinga van de afdeling Kennis, Expertise en Innovatie (KEI) danken voor hun hulp en aanmoedigingen.

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Curriculum vitae

Gineke Hanzen werd geboren op 4 december 1961 in Veendam. Na het afronden van het VWO op de Winkler Prins Scholengemeenschap te Veendam, begon zij in 1980 met de opleiding tot fysiotherapeut aan de Academie voor Fysiotherapie in Groningen. Na het behalen van haar diploma heeft zij zowel in een verpleeghuis als in verschillende fysiotherapiepraktijken gewerkt. In 1987 startte zij parttime als fysiotherapeut bij de Brink in Vries (tegenwoordig Koninklijke Visio, locatie de Brink). Tot 1992 combineerde zij dit met het werken in een particuliere praktijk in Scheemda. In 1989 heeft ze de cursus Sensorische Informatieverwerking (voor Paramedici werkzaam met mensen met verstandelijke beperkingen) gevolgd en in 1990 heeft ze de opleiding Neuro Developmental Treatment afgerond. Daarnaast heeft ze verschillende verdiepende cursussen gevolgd op het gebied van o.a. sensorische informatieverwerking en haptonomie. Naast haar werk als fysiotherapeut is zij binnen Koninklijke Visio als ontwikkelaar en docent actief betrokken bij de verdiepende opleidingen voor begeleiders op het gebied van mensen met visuele en (zeer) ernstige verstandelijke beperkingen. Daarnaast is zij opgeleid tot trainer in het classificatiesysteem ICF en heeft ze jarenlang deel uitgemaakt van het ICF platform van Koninklijke Visio.

Na het afronden van de Masterclass Wetenschappelijk onderzoek van de VGN in 2014, startte zij in 2015 met haar promotieonderzoek. Het promotieonderzoek werd mogelijk gemaakt door subsidies van de Programmaraad Visuele Sector en de Academische Werkplaats EMB. Het promotieonderzoek heeft zij gecombineerd met haar werk als fysiotherapeut op de Brink. Na haar promotie zal Gineke actief blijven in het wetenschappelijk onderzoek door als postdoc onderzoeker aan te sluiten bij de Academische Werkplaats EMB.