

University of Groningen

Participation of adults with visual and severe or profound intellectual disabilities

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DOI:
[10.33612/diss.134517652](https://doi.org/10.33612/diss.134517652)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2020

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Hanzen, G. (2020). *Participation of adults with visual and severe or profound intellectual disabilities*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen.
<https://doi.org/10.33612/diss.134517652>

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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, Standliffe, 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, & Ruijsenaars, 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 PIMD 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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