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## Participation of adults with visual and severe or profound intellectual disabilities

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# **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***

CFP+ 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

Direct Support Professionals	Group			
	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
<b>Gender</b>				
Female	42 (97.7)	16 (100)	14 (100)	12 (92.3)
Male	1 (2.3)			1 (7.7)
<b>Support type</b>				
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)
<b>Work experience (in years)</b>				
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)
<b>Age-range clients</b>				
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)
<b>Wheelchair use clients</b>				
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)
<b>Hearing impaired clients</b>				
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)
<b>Adults with VSPID</b>	<b>Total</b>	<b>CFP+</b>	<b>PMM</b>	<b>Usual care</b>
	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
<b>Gender</b>				
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)
<b>Level of intellectual disability</b>				
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)
<b>Visual limitations</b>				
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.*

<b>Adults with VSPID</b>	<b>Group</b>			
	<b>Total</b> n=43 (%)	<b>CFP+</b> n=16 (%)	<b>PMM</b> n=14 (%)	<b>Usual care</b> n=13 (%)
<b>Use of wheelchair</b>				
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)
<b>Auditory impairment</b>				
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)
<b>Physical health problems</b>				
Yes (%)	43 (100)	16 (100)	14 (100)	13 (100)
No (%)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
<b>Mental health problems</b>				
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.

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*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 temporarily 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.

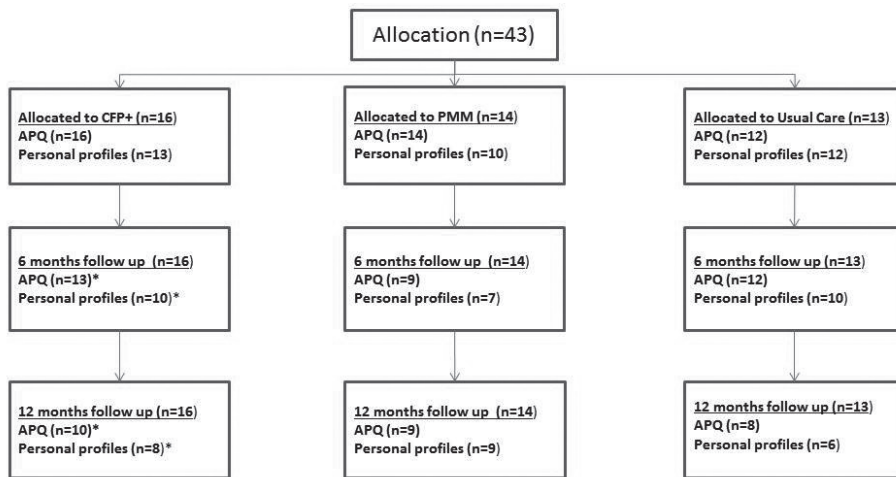
The overall longitudinal effects on the APQ were analyzed with linear mixed models (maximum likelihood estimations) for the nine APQ scales separately. As an important assumption for using linear mixed models, it was assumed that data were missing at random; reasons mentioned were, for example, maternity 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

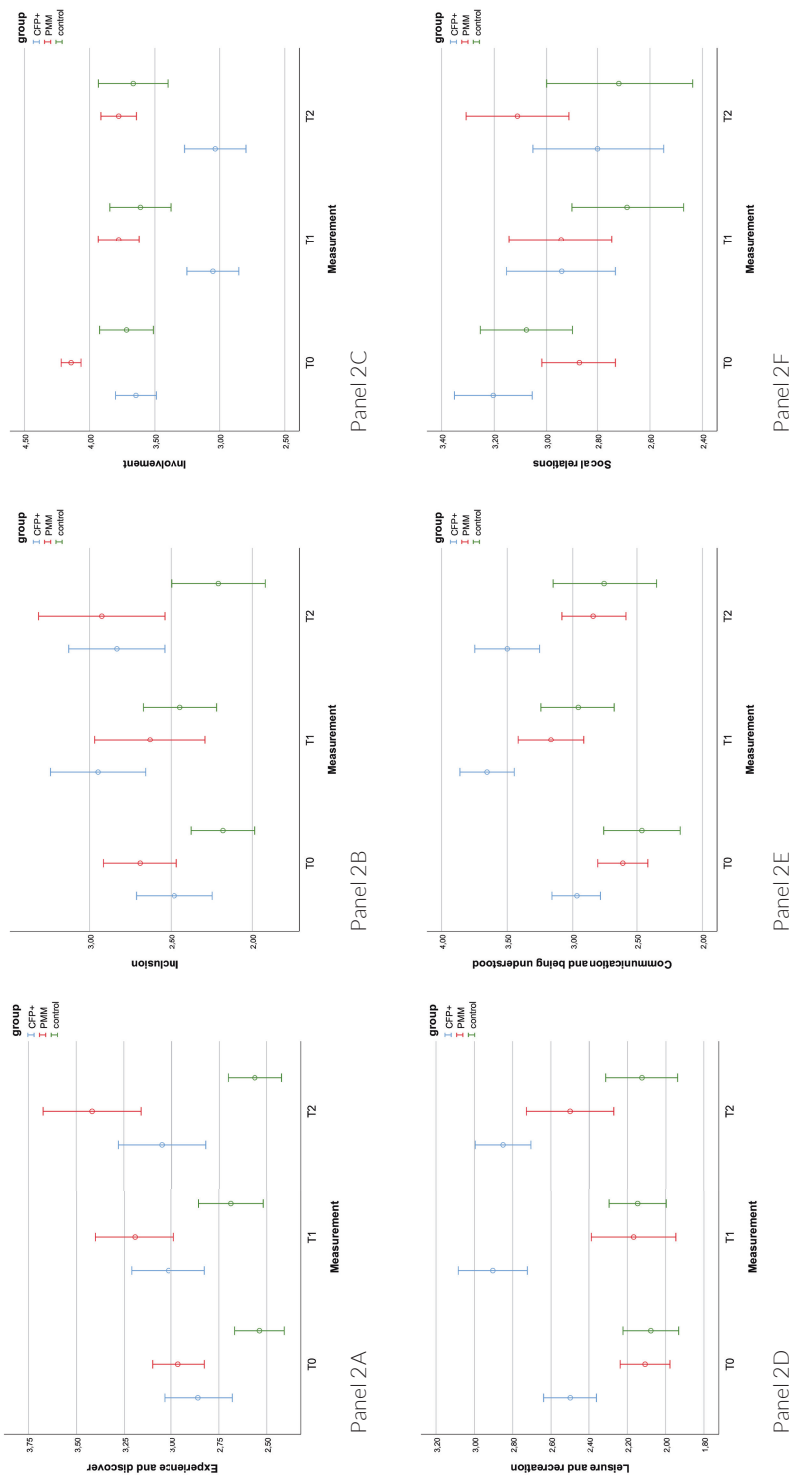
**Table 2** | *Continued.*

	Communication & being understood		Social Relations		Self-management & autonomy		Knowledge of participation		Ability to act on participation	
	B (SE) M1	B (SE) M2	B (SE) M1	B (SE) M2	B (SE) M1	B (SE) M2	B (SE) M1	B (SE) M2	B (SE) M1	B (SE) 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)*		.19(.24)		.12(.17)		.19(.15)		.22(.28)
		(CI 0.15-1.19)		(CI -0.29-0.67)		(CI -0.22-0.46)		(CI -0.11-0.49)		(CI -0.06-0.50)
Group PMM		.11(.27)		.14(.25)		-.15(.16)		.09(.16)		.39(.26)
		(CI -0.43-0.65)		(CI -0.36-0.64)		(CI -0.17-0.47)		(CI -0.23-0.41)		(CI -0.13-0.91)
Time x group CFP+				.05(.15)						.26(.14)#
				(-0.25-0.35)						(CI -0.02-0.54)
Time x group PMM				.35(.15)*						.31(.15)*
				(CI 0.05-0.65)						(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

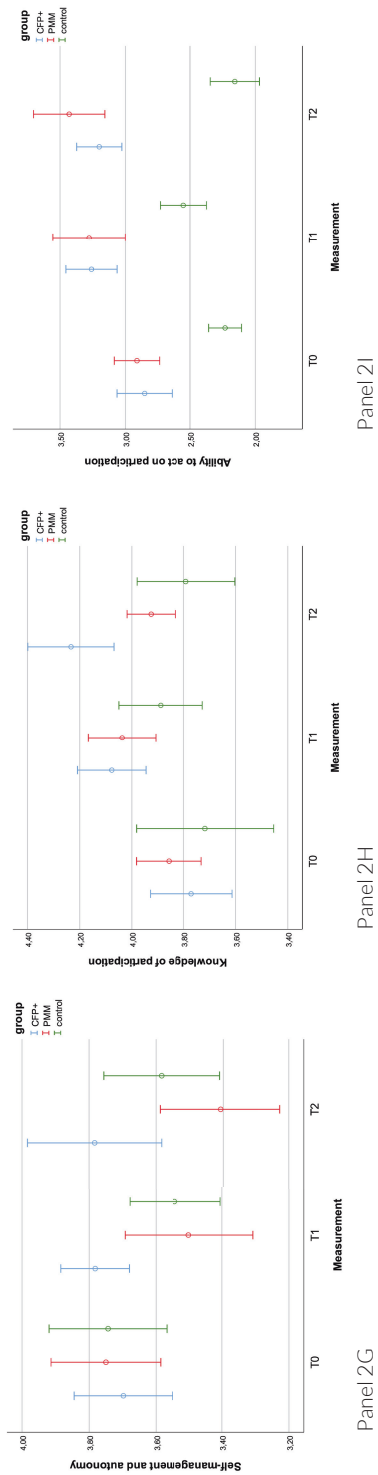
Notes: B = regression coefficient; SE = Standard error; CI = Confidence interval; coefficient +/- 2 x SE  
M1: empty model; M2: final model; \*significance at alpha .05 (i.e., the coefficient is larger than two times the standard error) #; significance at an alpha between 0.05 and 0.1.

CFP+ = Care for Participation+, PMM = Participation Mind Map





**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



**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

Variable	Group			p-value
	CFP+ median	PMM median	Usual care median	
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	
<b>personal preferences</b>				
baseline	2	2	1.5	0.37
after 6 months	1	1	0.5	0.42
after 12 months	1	0	0	0.64
<b>personal possibilities</b>				
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
<b>disabilities and limitations</b>				
baseline	4	4	4	0.82
after 6 months	2	6	4.5	0.005
after 12 months	3.5	5	5	0.41
<b>actions related to preferences</b>				
baseline	1	0	0	0.49
after 6 months	0	1	0	0.12
after 12 months	0	0	0	0.81
<b>actions related to disabilities and limitations</b>				
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

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*

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### **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.*

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**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.