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

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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*

<b>(n=40)</b>	<b>N (%)</b>
<b>Gender</b>	
Male	25 (62.5)
Female	15 (37.5)
<b>Intellectual disability</b>	
Severe	20 (50.0)
Profound	20 (50.0)
<b>Visual impairments</b>	
Partially	18 (45.0)
Blind	22 (55.0)
<b>Auditory problems</b>	
None	31 (77.5)
Severe	7 (17.5)
Deaf	2 (5.0)
<b>Mobility</b>	
No	19 (47.5)
Partially	3 (7.5)
Yes	18 (45.0)
<b>Epilepsy</b>	
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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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'**

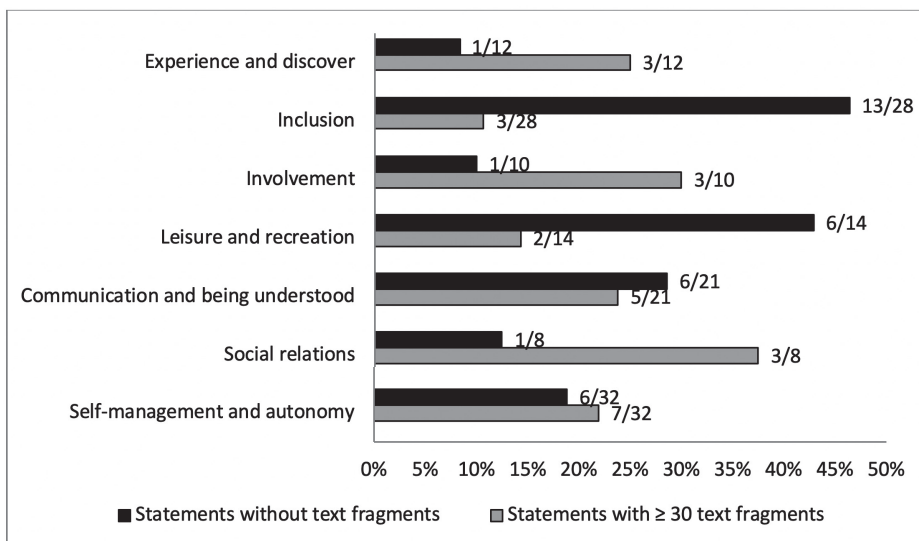
In the cluster 'Social relations' (original number of eight statements) was one statement (12.5%) without text fragments ('there are some trusted counselors available') and three statements (37.5%) with  $\geq 30$  text fragments. The statement with the most text fragments in this cluster was 'have contacts 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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  text fragments and, in the cluster 'Inclusion', 10.7% of the statements had  $\geq 30$  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  $\geq 30$  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)
<b>Cluster Experience and discover</b>		
'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	--
<b>Cluster Inclusion</b>		
'entitled to the same good medical care as people without disabilities'	<b>171</b>	<b>8.95</b>
'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'	<b>162</b>	<b>8.42</b>
'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
<b>Cluster Involvement</b>		
'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'	<b>78</b>	<b>8.39</b>
'wish to undertake activities that suit interests and preferences'	<b>101</b>	<b>8.70</b>
'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)
<b>Cluster Leisure and recreation</b>		
'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	--
<b>Cluster Communication and being understood</b>		
'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
<b>'would like to be guided by trusted staff who endeavor to (get to) know them well'</b>	<b>34</b>	<b>8.51</b>
'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
<b>'have optimal communication tools'</b>	<b>47</b>	<b>8.77</b>
'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
<b>'wish that we look closely at their non-verbal behavior and say what we see'</b>	<b>156</b>	<b>8.70</b>

Table 2 | *Continued.*

Statement	Sum of text fragments	Rating (above 8.34)
<b>Cluster Social relations</b>		
'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
<b>Cluster Self-management and autonomy</b>		
'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  $\geq 30$  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  $\geq 30$  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  $\geq 30$  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
<b>Experience and discover</b>			
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
<b>Inclusion</b>			
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
<b>Involvement</b>			
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
<b>Leisure and recreation</b>			
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
<b>Communication and being understood</b>			
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
<b>Social relations</b>			
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
<b>Self-management and autonomy</b>			
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 be 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 ever yone 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
	<b>Sum</b>		<b>2791</b>