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: Definition and operationalization

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Abstract

Background

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

Aims

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

Methods

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

Results

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

Conclusions

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

Introduction

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

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

be completed by the adults themselves and this is not possible because of the multiple impairments of the population. Furthermore, an adapted version of the Visual Activity and Participation (VAP) scales (Looijestijn, 2007) was also not applicable for adults with VSPID, particularly not for persons with motor problems, which are common in these adults (Jansma, 2013).

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

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

Methods

Study design

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

Participants

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

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

Data collection

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

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

To collect a wide spectrum of the ideas of the stakeholders about participation of the population, participants generated statements in response to a focus prompt (the seeding statement): 'Thinking as broadly as you can, generate statements as an answer to this question: what comes to your mind when you think of participation in the (daily) life of

adults with visual and severe or profound intellectual disabilities?' After three weeks, the number of participants who participated in the brainstorming and the number of statements were considered to be sufficient.

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

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

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

Procedure

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

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

Data analysis

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

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

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

Interpretation of cluster maps

The resulting cluster maps and the mean rating of the statements of the five groups were compared. Based on these results, the resulting cluster map of all of the participants

was interpreted independently by four researchers. The researchers (GH, RN, AP, AW) discussed the outcome of the independent interpretation and achieved consensus on the number of clusters, the names of the clusters, and the statements in the clusters. The final cluster map was interpreted independently again by the same researchers to increase the reliability of the results. In a following consultation, they discussed until consensus was reached on the statements in the clusters.

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

Results

Response and characteristics of adults with VSPID

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

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

Brainstorming: generation of statements

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

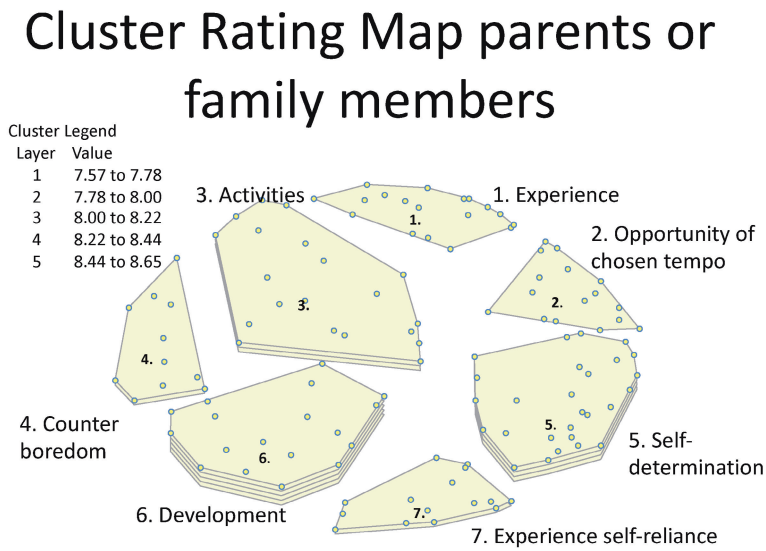
Table 1 | *Categories of excluded statements with examples*

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

Sorting and rating

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

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



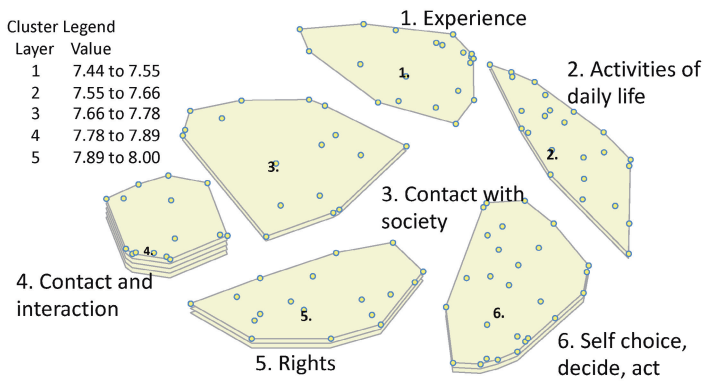
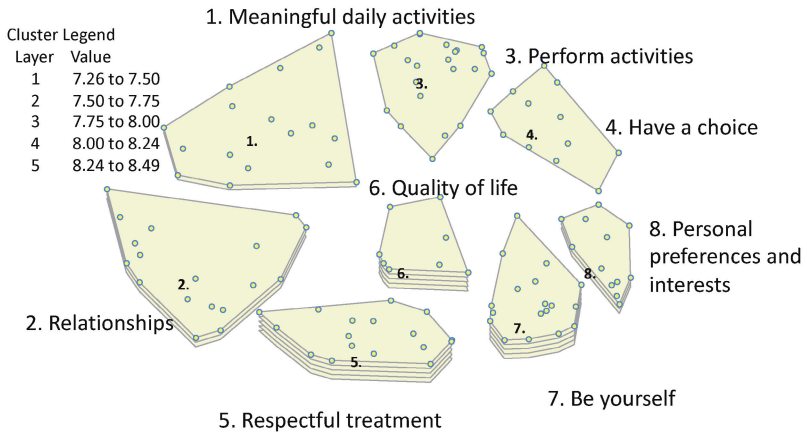


Figure 1 | *Cluster rating maps of parents/family members, professionals, experts, and all participants. The maps show clusters of items (the dots) that were considered similar in thematic content. More layers indicates greater importance. The value is the range between the minimum and the maximum rating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

Cluster Rating Map professionals



Cluster Rating Map all participants

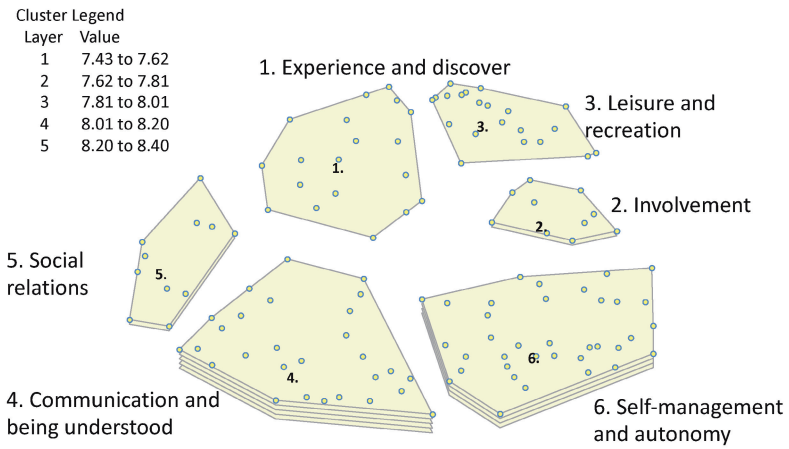


Figure 1 | *Continued.*

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

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

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

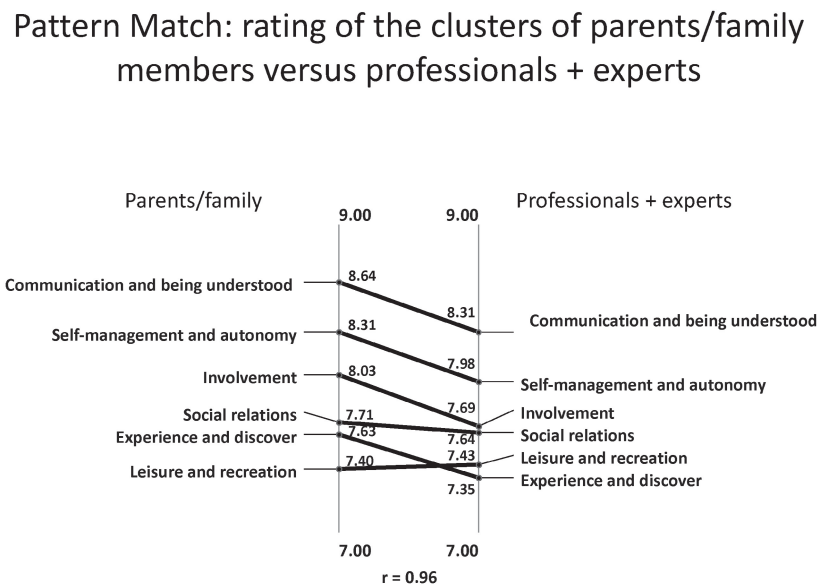


Figure 2 | *Pattern match between parents/family versus professionals and experts together*

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

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

Interpretation of cluster maps

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

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

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Table 3 | *Continued.*

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

Definition

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

Discussion

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

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

of the cluster 'Inclusion' refer to doing or having the same as other people and being part of society. It is apparent that these issues cannot be taken for granted for adults with VSPID who live in residential care facilities.

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

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

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

Neither in the definition nor in the names of the clusters is the visual aspect of participation explicitly described. Nevertheless, a number of statements explicitly mentioned the visual

aspect ('if the staff explains and guides it well, even as a blind person, you can touch almost anything in stores', 'want to know that they are seen, heard, and understood, even if they are deafblind'), and other statements indicate the visual aspect more implicitly ('within the possibilities, would like to experience much with their senses, with all their senses', 'experiencing rain and wind', 'wish to visit a garden center because it is fantastic: smelling the flowers and the sand, feeling the plants, the animals, the rough/smooth stones and the water from a fountain, seeing the lights (of the Christmas show)', and 'do not want to suffer from pain or sounds'). As a result, the visual aspect of participation will be included in the future operationalization of participation of adults with VSPID.

Strengths and limitations

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

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

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

Recommendations for further research and practical implications

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

Conclusion

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

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