



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.

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What this paper adds

For adults experiencing visual and severe or profound intellectual disabilities (VSPID), a definition and operationalization of participation that could be used in practice were not available. The current study is the first to ask parents or family

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members, professionals, and experts to offer their opinions regarding the participation of adults with VSPID and the meaning of this concept through an online concept mapping procedure. The definition based on these three perspectives offers an improved understanding of the content of participation in this population, specifically: 'Participation of adults with VSPID means active engagement and involvement in daily activities, social contacts, and societal and leisure activities, including opportunities for inclusion, experience and discovery. Active engagement and involvement of this population can only occur in the context of a relationship with the environment ('being understood') wherein the adult with VSPID has an active and steering role ('self-management and autonomy').'

The definition established in this study operationalizes the construct of participation and affords support professionals the ability to actually improve the participation of this population.

1. 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 (Schallock 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 practice, 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). Eysen, 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 & Rodger, 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 et al., 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

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