



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 2791 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.

What this paper adds

For adults with visual and severe or profound intellectual disabilities (VSPID), it was unclear to what extent they participate. Additionally, it was unknown if the way they participate corresponded with the participation domains that family, professionals, and experts considered as being important. This study contributes to the knowledge of the participation of this population by providing an overview of areas in which they participate. Results indicate that participation domains such as ‘Experience and discover’, ‘Involvement’ and ‘Social relations’ are well represented, however, but other domains such as ‘Inclusion’ and ‘Leisure and recreation’

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showed many aspects that were not. Within the latter two clusters, this was especially observed for activities related to inclusion and recreation outside the residential facility and changing or new roles. This indicates that participation in residential facilities can be improved by paying extra attention to these aspects.

The topics that were most often described such as (medical) care, utilization of resources, activities that suit interests and preferences, observing non-verbal behavior, and contacts within and outside the living environment were also considered to be important by the proxies. However, not all aspects that were important to the proxies were documented, indicating directions for improvement of participation of adults with VSPID.

This overview of participation of adults with VSPID offers residential facilities the opportunity to determine in which areas participation can be increased and improved. In addition, it could provide guidelines for the development and evaluation of new interventions to improve participation of adults with VSPID.

1. 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 10,000–15,000 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 et al., 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 et al., 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, & Thompson, 2002; Perry & Felce, 2005), family support (Heller, Miller, & Hsieh, 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, Kamstra, van der Putten, and Vlaskamp, (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.

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