

Participation and Health of Persons with Multiple Disabilities and Visual Impairment

Chair: Aly Waninge, PhD

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In 1986, Aly Waninge graduated as a physical therapist and she started working at the Royal Dutch Visio in the Netherlands. Her PhD project 'Measuring physical fitness in persons with severe/profound intellectual and multiple disabilities' began in 2007 and was finished in 2011. From 2011, Aly is professor within a professorship at the Hanze University, Research Group Healthy Ageing, Allied Health Care and Nursing. This professorship was established by Royal Dutch Visio. Her research themes are: Participation and health in persons with intellectual and visual disabilities. She currently supervises 6, and from January 2017, 7 PhD projects. Royal Dutch Visio and the Hanze University closely collaborate with the Research Centre on Profound Intellectual and Multiple Disability of Rijksuniversiteit of Groningen to perform research in persons with MDVI.

Symposium abstract

It is estimated that visual and severe or profound intellectual disabilities affect 10,000 to 15,000 adults in the Netherlands, 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. Comorbidity is very common in these adults, i.e., they often experience other physical impairments, sensory impairments, or medical problems. People with severe or profound intellectual disabilities and visual impairment (MDVI) encounter numerous physical health problems simultaneously. In addition, they have lower physical activity and physical fitness levels compared to the general population. As a consequence, their ability to perform activities of daily living is decreased. Last but not least, persons with MDVI appear to be at risk of decreased participation. In this symposium, research by Royal Dutch Visio, the Hanze University and the Research Centre on Profound Intellectual and Multiple Disability of the Rijksuniversiteit Groningen and that of international research groups will be presented concerning the following topics: participation, physical health problems, optometric issues, motor activation, and measuring muscle strength of persons with MDVI.

1. Participation for adults with profound intellectual disabilities: Staff and managers' conceptions

L. Talman, Msc

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Background A goal of disability policies in Sweden and elsewhere is to ensure people with disabilities an equal level of participation as other citizens. Yet, what everyday life participation is for adults with profound intellectual disabilities (PID) is relatively unexplored. For adults with PID, participation is mainly achieved through the assistance of others, mostly from group home staff or by personal assistants. Therefore, it is important to explore staff and managers' conceptions of what participation is and how support for participation can be undertaken for adults with PID.

Aim To elucidate and describe conceptions of participation among staff and managers' that provide support and services to adults with PID in order to highlight variations of conceptions on the organisational and operational levels.

Method A phenomenographic methodology was used to identify the multiple conceptions, or meanings, that staff and managers' had of the phenomenon. Data were collected by interviewing social care managers and staff (n = 27) in in a medium-sized Swedish municipality.

Result The phenomenon participation is abstract and hard to operationalise for both staff and managers' and the municipal social care organisation lack a definition of participation. There are different conceptions of participation, including "To do things" (e.g. eat by yourself), to "To decide" (e.g. decide over one owns life). The result also shows that interlinked individual and organisational conditions are needed for facilitating participation.

Conclusion Divergent conceptions of participation was found in the studied organisation, this being understood as a lack of consensus of the meaning of the phenomenon of participation. The lack of consensus can make it difficult to work towards common goals in supporting adults with PID. To reach the goals for people with PID, it is therefore important that organisations share a definition of participation and that this is known in the whole organisation.

2. Operationalization of concept of Participation of adults with visual and severe or profound intellectual disabilities: perspectives of parents, professionals, and experts.

G. Hanzen, Bsc

Royal Dutch Visio - de Brink, Vries, the Netherlands

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 these adults with VSPID.

Aim The objective of our study was to define and operationalize the concept Participation of adults with visual and severe or profound intellectual disabilities.

Method With an online concept mapping procedure, parents or family members, professionals, and experts of adults with VSPID offered their opinions regarding the participation of these adults and the meaning of this concept. The data were analyzed quantitatively using multidimensional scaling and qualitatively with triangulation.

Results The definition and operationalization, based on these three perspectives, offer an improved understanding of the content of participation in this population.

Conclusion The results of this study and preliminary results of the analyses of care plans of adults with VSPID will be presented at the Congress. In addition, upcoming plans for further research based on these results, and new interventions to improve participation of these adults will be illustrated.

3. Physical health issues in persons with severe or profound intellectual and motor disabilities (SPIMD)

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Background: People with severe or profound intellectual and motor disabilities (SPIMD) have complex health needs due to the severe or profound cognitive and motor disabilities, minimal communication skills and concurrent numerous serious physical health problems. There is a great risk for physical health problems to go unrecognized in people with SPIMD, which can lead to aggravation of these health problems, discomfort, pain and decreased

physical function. There are hardly any measurement instruments to identify physical health problems that have been standardized exclusively for people with SPIMD.

Aim: The aim of the PhD-project is to determine the prevalence of physical health problems in people with SPIMD and to determine which tools and measures are being used to detect and monitor them.

Method: A systematic review and a cross-sectional study were performed in order to determine the prevalence of physical health problems in people with SPIMD. Furthermore, patterns in multimorbidity were explored. In addition, an inventory study was performed in order to determine which tools are being used for the detection and monitoring of physical health problems.

Results People with SPIMD encounter a wide range of physical health problems, with a mean of 12 problems per person. Frequently reported physical health problems are for example: constipation, visual impairment, epilepsy, spasticity, scoliosis, incontinence and gastroesophageal reflux disease. The patterns in multimorbidity and the tools and measures used to recognize and monitor physical health problems will be presented at the Congress.

Conclusion: The severity and combination of the intellectual and motor disability and the cumulative effect of concurrent physical health problems in people with SPIMD presents a major challenge for healthcare providers and direct support workers. There is a need for comprehensive research regarding tools and measures of physical health problems. We will discuss the implications for practice and research with the audience.

4. Overview of the Icelandic MDVI population from birth to 67 years of age: medical condition, vision Impairment and functional vision, additional disabilities, activity and participation.

E.D. Björnsson Msc, & Roxana E. Cziker PhD

National Institute for the blind, visually impaired, and deafblind, Reykjavík, Iceland

Background The National Institute for the Blind, Visually Impaired, and Deafblind was founded in 2009 and provides services mainly in the rehabilitation and education area and does not provide initial medical diagnosis or medical treatment. The Center is responsible for a national database regarding visually impaired, blind, and deafblind individuals.

Aim The objective of the study is to provide a qualitative statistic related to detection, following up and supporting in daily life activities, people with visual impairment and multiple disabilities in Iceland from birth to 67 years of age, following the principle of International Classification of Functioning, Disability and Health approach.

Method Data collected from the national database was analysed using qualitative statistics.

Results The estimated population with vision impairment and multiple disabilities between birth up to 67 years of age in Iceland is around 166 individuals, which represents 0.06% reported to the total number of population within the age group. The medical conditions which lead to additional disabilities are mainly neurological disorders like cerebral palsy, genetic disorders, and acquired brain damages. Part of this population encounters different levels of physical disorders / difficulties. According to the level of integration in activity and participation in educational and social life, the group is heterogeneous. More details about support and inclusion will be presented during the congress.

Conclusion Along the 8 years of experience with people with vision impairment, the institute developed interdisciplinary approach through both national and international cooperation and exchanges of experiences.

5. Development of a program to promote physical activity among people with visual impairment and multiple disabilities

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Groningen, the Netherlands*

Background People with visual impairment and multiple disabilities (MDVI) obviously benefit from being physically active. However, they hardly participate in physical activities. This may be caused by a lack of evidence-based physical activity interventions specifically designed for people with MDVI. Happily, recently support professionals developed all kinds of initiatives to promote physical activity among people with MDVI. This study investigated and evaluated the use of these initiatives and aimed to develop an evidence-based program to promote structural and specific physical activity in the support of people with MDVI.

Method A convenience sample of support professionals (n = 42) completed a questionnaire about the physical activities offered in their organization. By means of multiple sources (documents, personal interviews, and observations) this study investigated the quality and potential of these practical initiatives by the use of on an existing format. Subsequently, based on the practical initiatives this study developed an individualized physical activity program to structurally integrate individually selected physical activities in the support of people with MDVI.

Results During the congress, first an overview of provided physical activities and their potential effectiveness will be presented. Second, the development process of the individualized physical activity program will be presented.

Conclusions This study will increase the knowledge on the quality and potential of different practical initiatives aimed at physical activity participation among people with MDVI. This knowledge is important to select physical activities based on the individual needs, preferences, and possibilities of people with MDIV in order to optimize their life situation and support on physical activity.

6. Measuring strength and strength endurance measurements in adults with severe intellectual and visual disabilities.

A. Dijkhuizen, Bsc

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Background Sufficient physical fitness is important for good health, well-being, participation and quality of life. By the use of valid instruments, strength as an important component of physical fitness can be measured, for identifying high-risk groups at an early stage. However, until now, feasible and reliable instruments to measure strength for persons with severe intellectual and visual disability (SIVD) are not available.

Aim The aim of our study was to determine the feasibility, learning period and reliability of the Minimum Sit-to-Stand Height test (MSST), the Leg Extension test (LE) and the 30 seconds Chair-Stand test (CS) for persons with severe intellectual and visual disabilities.

Method 29 Participants performed the MSST, LE and CS within one session, once a week for a period of seven to ten weeks. To determine the feasibility the percentage of succeeded assessments was registered. Paired t-test was used to investigate whether there was a difference in mean between two consecutive measurements. A non-significant difference indicated the end of the learning period for these methods. At the end of the learning period test-retest reliability was analyzed by an intra-class correlation coefficient (ICC, one way random). Pearson correlation (two-tailed) were calculated to investigate whether the MSST, LE and CS correlate with each other.

Results The results show a sufficient feasibility for the MSST, LE and the CS in persons with severe intellectual and visual disabilities (SIVD) and learning periods of up to five repeats. All three methods had a sufficient test re-test reliability for persons experiencing SIVD. Low to moderate correlations were found between the MSST, the CS, and the LE.

Conclusion The MSST, the LE and the CS are feasible methods for persons with SIVD with a sufficient test re-test reliability and a reasonable learning period. The low to moderate association between the tests may indicate that these measurements measure different aspects of muscle strength.