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Measuring participation in children and young adults with visual impairment: the development of instruments

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Chapter 1

General introduction

Increased participation is often one of the most important outcomes of rehabilitation in persons with a disability. Successful participation is related to increased physical, social and emotional wellbeing, which are the most important determinants of quality of life.¹⁻³ In turn, limited participation might have a negative impact on wellbeing, health and quality of life.^{4,5}

Having an irreversible visual impairment has a major impact on a person's life. In case of children, adolescents and young adults it means they have many years ahead in which they live with their visual impairment. To ensure the wellbeing of these children, adolescents and young adults, it is important to aim for the highest levels of participation and quality of life. This is also stressed by the UN Convention on the Rights of Persons with Disabilities. This convention was ratified in the Netherlands in 2016, reaffirming that persons with all types of disabilities have the right to enjoy all human rights and fundamental freedoms. Furthermore, the convention states that research on services, facilities, and new technologies for persons with disabilities should be promoted and that (relevant information on) interventions should be available for intervention users.⁶

In the Netherlands, expertise centres for the blind and visually impaired assist persons with visual impairment, including children, adolescents and young adults, to maintain or improve their quality of life and participation in society by offering assistive devices, intervention programmes, training and guidance. For the best results, care should be patient-centred and meet the needs of the child, adolescent and young adult.

The first part of this thesis focuses on defining the concept of participation for children, adolescents and young adults with visual impairment and on gaining insight in interventions to increase participation. The second part focuses on the psychometric properties of questionnaires to assess and monitor participation needs of these children, adolescents and young adults. This introductory chapter provides a background overview of the healthcare problem, and theoretical concepts that motivated the aims and design of this thesis.

Visual impairment in children, adolescents and young adults

The definition for low vision and blindness of the World Health Organisation (WHO) is often used to classify visual impairment in categories. Low vision is defined as the best corrected visual acuity of <0.3 but ≥ 0.05 (Snellen notation) and/or visual field of $<20^\circ$ around the central point of fixation in the better eye. Blindness is defined as the best corrected visual acuity <0.05 and/or visual field of $<10^\circ$ around the central point of fixation.⁷ Worldwide, various definitions of visual impairment are used. In this thesis, the definition of the Dutch guideline on visual impairments, rehabilitation and referral is used, stating that someone has a visual acuity ≤ 0.3 and/or visual field of $\leq 30^\circ$ around the central point of fixation (or other severe visual field defects, such as hemianopia) and/or experiences limitations in daily living due to visual impairment that cannot be solved by regular healthcare services.⁸

It is estimated that 252.6 million people worldwide are visually impaired, of whom 36 million people are classified as blind.⁹ The burden of visual impairment is not equally distributed: the

majority of the burden is carried by south, east and southeast Asia (61.9%), and prevalence is highest in those aged 50 years and older (80.5%).⁹ Worldwide, the number of children below the age of 15 years who have visual impairment is estimated to be 19 million, of whom 1.4 million are blind.¹⁰ No accurate prevalence data are available in the Netherlands.¹¹ It is estimated that approximately 2600 children aged 0-14 years have visual impairment.¹² Visual impairment among Western children are predominantly caused by developmental disorders and genetic modifications. The most common diagnosis in Dutch children are cerebral visual impairment, albinism, nystagmus, congenital cataract and secondary optic atrophy.¹¹

Impact of visual impairment

Having visual impairment has a major impact on functioning and participation in daily life, along with psychosocial consequences. Developmental delays are a significant problem in children with visual impairment; greater severity of visual impairment is associated with increased risk of poor developmental outcomes.^{13,14} Furthermore, these children experience delays in motor skills compared to their sighted counterparts.¹⁵⁻¹⁸ Moreover, children with visual impairment are less physically active, have more sedentary lifestyles and poorer physical fitness than children without visual impairment.¹⁹⁻²² Children and young people with visual impairment spend more time indoors or on individual activities than their sighted counterparts. They also perform fewer activities.^{23,24} Although several studies show that youth with visual impairment have similar levels of education as the general population, the employment rate is low.²⁵⁻²⁷

Research has shown that in Dutch rehabilitation plans of children, goals related to the domains learning and applying knowledge, mobility, and major life areas (i.e. goals regarding education) were well represented.²⁸ For young adults, the domain major life areas prevailed in the content of rehabilitation goals.²⁹ These findings are partly in line with the study of Salminen & Karhula, in which challenges regarding mobility and major life areas were also often reported.³⁰ However, participants in their study also reported challenges regarding domestic life, interpersonal interaction and relationships, and leisure activities, which were topics that were overshadowed in the former studies.²⁸⁻³⁰

In few studies, quality of life in children, adolescents and young adults with visual impairment has been investigated. Children with visual impairment have significantly lower quality of life scores than sighted age-matched comparison groups,³¹ and quality of life of children with congenital cataract is comparable to quality of life of children with severe systemic chronic diseases, including rheumatologic diseases and several cancers.³² Boulton et al. examined health-related quality of life in children with various visual conditions. They concluded that health-related quality of life was least compromised in children with nystagmus, whereas it was most compromised in children with visual pathway conditions, who often have additional impairments and disorders.³³ Adolescents with visual impairment also had significantly lower health-related quality of life than the comparison group,³⁴ and similar results were found for a relatively young group of adults.³⁵

Research has mainly focused on the consequences of visual impairment for social participation and social skills in adolescents and young adults, sometimes with competing results. A study of Gold and colleagues showed that youth with visual impairment are at risk for social isolation. A low percentage of the participants had been married, and there was a general pattern of preference for passive or moderately interactive social activities compared to highly interactive social activities. Youth with low vision experienced more social challenges than their peers who were blind.³⁶ This is in contrast to a study of Huurre & Aro, in which adolescents who were blind had more difficulties with respect to social relationships than those with low vision.³⁷ In general, studies found that adolescents and young adults with low vision had fewer friends, perceived the quality of their friendship to be lower, participated less often as a member of a subgroup, had smaller networks and reported more often feelings of loneliness compared to their sighted peers.^{30,38-41} They also dated less, were less successful in forming romantic relationships, had less sexual experiences and were older when having sexual experiences compared to youth without disabilities.⁴²⁻⁴⁴ Studies focusing on social support, self-perception and psychological wellbeing have shown mixed results as well. A study of Kef et al. showed that adolescents with visual impairment experienced less social support, specifically from peers compared to adolescents without impairments, while peer support affected their wellbeing stronger than the wellbeing of sighted adolescents.⁴⁵ Beatty found that adolescents with visual impairment demonstrated lower self-perception than their sighted peers.⁴⁶ However, Lifshitz et al. found that sighted and visually impaired adolescents had a similar self-concept profile; adolescents with visual impairment scored even better than their sighted counterparts on most domains.⁴¹ Huurre & Aro mostly found problems with psychological wellbeing specifically in female adolescents, but not in males.^{37,42}

Multidisciplinary low vision care for children and young adults

Having visual impairment has major consequences on the lives of children, adolescents and young adults, and there are several options available to decrease the impact, for instance by providing practical, pedagogical and psychological support. In the Netherlands, children, adolescents and young adults with visual impairment can be referred to an expertise centre for the blind and visually impaired by general practitioners, ophthalmologists or other physicians. It is also possible for patients to contact a centre themselves. In the Netherlands, two large expertise centres for the blind and visually impaired, who offer services to children, exist: 'Royal Dutch Visio' and 'Bartiméus'. Both organisations offer equal services and have regional centres throughout the Netherlands. Referral to either organisation is mostly based on location: Royal Dutch Visio has centres in the north and south of the Netherlands and is the largest organisation, whereas Bartiméus is located in the centre. The expertise centres offer a wide variety of services. Ophthalmologists, clinical physicists and optometrists examine visual functioning. Support, training in activities of daily living (e.g. mobility training, self-care training or computer training), individual and group counselling, and environmental support at school, work and home (e.g. advice on light and optimal floor plans) is offered by (educational and developmental) psychologists, social workers and occupational therapists. In addition, low vision aids are provided and training in their use is offered. Both organisations also provide special education for visually

impaired children, adolescents and young adults and offer ambulatory support at regular schools for example by orthopedagogues (general remedial educationalist).⁸

International Classification of Functioning, Disability and Health

The WHO offers a framework, the International Classification of Functioning, Disability and Health (ICF), and its related Child-Youth version (ICF-CY), to conceptualise functioning of children, adolescents and adults with disabilities.^{47,48} Figure 1 presents the ICF framework. Within this framework, disability is defined as a broad term for activity limitations, impairments and participation restrictions. The ICF and ICF-CY consist of two parts, which both consist of two components:

- Functioning and disability
 - **Body Functions:** the physiological functions of body systems (including psychological functions); and **Body Structures:** anatomical parts of the body such as organs, limbs and their components
 - **Activities:** the execution of a task or action by an individual; and **Participation:** involvement in a life situation
- Contextual factors
 - **Environmental factors:** the physical, social and attitudinal environment in which people live and conduct their lives (either serve as barriers or facilitators of the person's functioning)
 - **Personal factors:** a person's individual background

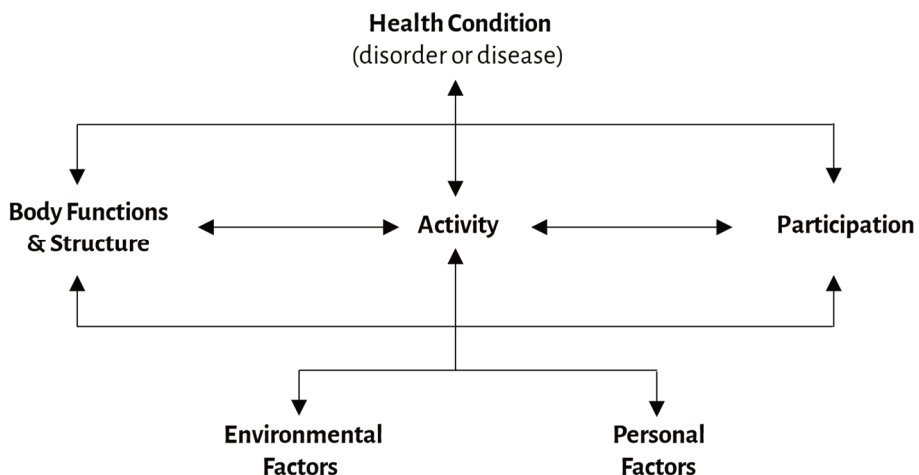


Figure 1. International Classification of Functioning, Disability and Health (ICF) framework^{47,48}

Participation is often regarded as the most important outcome of rehabilitation care for children, adolescents and young adults with visual impairment. Successful participation has positive influence on emotional and psychological well-being and thereby ultimately improves quality of life.¹⁻³ Participation is part of the 'Activities and Participation' component of the ICF and ICF-CY, and consists of nine domains: 1) learning and applying knowledge; 2) general tasks and demands; 3) communication; 4) mobility; 5) self-care; 6) domestic life; 7) interpersonal interactions and relationships; 8) major life areas; and 9) community, social and civic life.^{47,48} Although 'activity' and 'participation' are individually defined,^{47,48} by combining both terms in one ICF component it is often unclear what constitutes an 'activity' and what 'participation'. Some researchers argue that activities are often straightforward and unambiguous, while participation is more complex and abstract, generally involving the performance of several activities and requiring a social context, including environmental factors and other people.^{49,50} Others note that this distinction might not apply for children or those with disability, as they tend to be in interaction with or supported by others or use environmental modifications when performing an activity.^{51,52} For children and those with a disability, it might not be practical to place a clear boundary between these concepts.

Patient-centred care and patient reported outcomes

In recent years, more emphasis is being placed on patient-centred care,^{53,54} in which the individual needs of the patient and the patient perspective have a prominent place.⁵⁵ Investigating these needs is essential for shared decision-making, which is suggested to be particularly useful for long-term decisions, specifically in patients with irreversible impairments and interventions with durations exceeding one session.⁵⁶ The insights resulting from research related to patient-centred care and shared decision-making are incorporated in the Dutch guideline on visual impairments, rehabilitation and referral, stating that decisions on future treatment should be based on a shared decision-making process.⁸ To aid patient-centred care and shared decision-making, generic and disease-specific patient reported outcome measures (PROMs) have been developed. Using PROMs, health outcomes such as quality of life, functional status and disease severity, which are preferably reported by patients themselves, can be assessed and monitored.⁵⁷⁻⁵⁹ Research has been conducted on the methodologic quality of studies evaluating the measurement properties of questionnaires for children with disabilities in general, and visual impairment in particular.⁶⁰⁻⁶² The researchers conclude that the investigated instruments could benefit from further psychometric improvements.^{60,61} In addition, there seems to be a need for vision-specific age-appropriate PROMs for use in paediatric ophthalmology.⁶²

The Participation and Activity Inventory

Although many vision-specific questionnaires for adult populations exist (e.g. ⁶³⁻⁶⁹), these instruments have often been used as a global outcome of rehabilitation, or to measure specific domains, such as mobility or reading. However, they are not suitable to investigate the full range of individual rehabilitation needs and as such to evaluate the effectiveness of rehabilitation for individuals. To overcome this, Dutch expertise centres for the blind and visually impaired use the Participation and Activity Inventory (PAI, formerly known as the D-AI) to identify personal goals of

adult clients.⁷⁰ This questionnaire was developed and implemented in the Netherlands and originates from the Activity Inventory created by Massof et al.⁷¹ The PAI consists of the nine domains of the Activity and Participation component of the ICF,^{48,72} and was found to be feasible and to have sound psychometric properties.^{73,74} The PAI can be used to identify needs, set goals and create an individualised rehabilitation plan. Moreover, the PAI provides insight into the effectiveness of rehabilitation and can be considered a PROM.^{75,76}

The content of the PAI focuses on the needs of adults and is not applicable to identify the needs of children aged 0-17 years, since needs develop with increasing age.²⁸ Moreover, the life stage of young adults aged 18-25 years is characterised by the transition to becoming an adult, with a growing need for independence and autonomy,⁷⁷ making the extensive content of the PAI less applicable. Because expertise centres currently lack an instrument to identify the needs of children and young adults, they are dependent on their own knowledge and expertise when creating an inventory of needs. Relying solely on the personal expertise of low vision professionals (e.g. social workers, occupational therapists, educational and developmental psychologists) carries a risk of bias and an underrepresentation of needs.^{29,78} Furthermore, incorrect identification of rehabilitation needs might influence referral to specific interventions within centres and the quality of care provided.⁷⁹ This is the reason why Royal Dutch Visio wanted to investigate the concept of participation in children and adolescents and to develop a PROM comparable to the PAI. Moreover, both Royal Dutch Visio and Bartiméus asked to do a similar study in young adults. To aid interpretation of the PROM, which is called the PAI for Children and Youth (PAI-CY), four different age categories are formed based on WHO criteria: 0-2 years (infants and toddlers), 3-6 years (preschool children), 7-12 years (school-aged children), and 13-17 years (adolescents). For each age category, a different PAI-CY is developed. Simultaneously, a PAI for Young Adults (PAI-YA) is developed for the age category 18-25 years.

Aim and outline of the thesis

The first section is aimed at defining the concept of participation for children and young adults with visual impairment and at gaining insight in interventions to increase participation. In **Chapter 2** a conceptual model detailing the aspects of a child's life that are affected by low vision was developed by means of a combination of qualitative methods involving children, parents and professionals working at expertise centres and schools for the blind and visually impaired. Similar work is presented in **Chapter 3**, in which the impact of visual impairment on the lives of young adults is investigated by means of concept-mapping workshops with young adults and professionals. In **Chapter 4** the quality of life and participation of young adults with visual impairment is compared to population norms. Furthermore, this chapter explores the severity of vision loss and its association with participation and quality of life. In **Chapter 5** a systematic review on the effectiveness of interventions to improve functioning, participation and quality of life in children with visual impairment is presented. Literature is systematically searched and selected, and outcomes are presented according to thematic content.

The conceptual models presented in chapter 2 and 3 were used to operationalise participation by developing several PROMs based on the above-mentioned age-bands. The methods used to develop the conceptual models also ensured face and content validity of these PROMs.

The second section is aimed at investigating psychometric properties of the PROMs developed or used in this thesis. In **Chapter 6** a pilot study to assess the feasibility and acceptability of the PAI-CY and PAI-YA is presented. Moreover, content relevance for the questionnaires was investigated. Young adults, children and their parents, and professionals who were involved in the admission procedure were asked about their perceptions and experiences with the completion of the questionnaires. Based on these results, improvements were incorporated. An international comparison is made in **Chapter 7**, in which a cross-cultural validation study of the Functional Vision Questionnaire for Children and Young People (FVQ-CYP) was presented. This questionnaire originates in the UK, and was translated and culturally adapted for the Dutch population. It was used as a comparison instrument in the psychometric studies of the PAI-CY 7-12 years and 13-17 years, and as such had to have sound properties for the Dutch population as well. The remaining chapters each assess the psychometric properties of the PAI-CY and the PAI-YA. For this purpose, usually a combination of item response theory and classical test theory was applied, complemented with feedback from end-users. **Chapter 8** and **Chapter 9** focus on the PAI-CY questionnaires which are only completed by parents/caretakers of children, the PAI-CY 0-2 years and the PAI-CY 3-6 years respectively. **Chapter 10** and **Chapter 11** focus on the questionnaires which are completed by children/adolescents themselves and the parents/caretakers, the PAI-CY 7-12 years and the PAI-CY 13-17 years. Finally, **Chapter 12** focusses on the PAI-YA, which is only completed by young adults.

The final part of this thesis consists of a summary and discussion of the outcomes of these chapters and the recommendations and implications for daily practice and research. The thesis is concluded with a summary in the Dutch language.

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