Visual functioning of persons with severe and profound intellectual disabilities: observations by direct support workers and staff members and information available in personal files

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Abstract

Background: Despite the high prevalence of visual impairments in persons with severe or profound intellectual disability (ID), often a formal diagnosis is unavailable. Direct support workers and staff members have access to the information of the visual functioning through the personal files and build knowledge based on their own experiences. In order to provide individualized and high quality support in daily life the accuracy and availability of this information of the visual functioning is essential.

Specific aims: This study investigates the knowledge of direct support workers and staff members on the visual functioning of their clients and the written information available in the personal files. It is investigated to what extent they do agree on their knowledge and how certain direct support workers and staff members are about their knowledge on the visual functioning. Additionally is investigated to what extent the information available in support files is based on formal assessment.

Method: For 104 clients with severe or profound ID a direct support worker and a staff member filled in a questionnaire about their visual functioning. Next, the personal files were analyzed.

Findings: Direct support workers and staff members respond significantly different on the questions on the impaired visual functions. Direct support workers rate the certainty level of their knowledge on their clients' visual functions higher than staff members. The personal files lack information on the visual functioning. If information is available it is mostly based on subjective impressions.

Discussion: The knowledge of direct support workers and staff members and the information available in the personal files provide no comprehensive picture of the visual functioning of the persons with severe or profound ID.

Introduction

Compared to the general population, persons with an intellectual disability (ID) have an increased chance on visual impairments (Boot, Pel, Vermaak, van der Steen, & Evenhuis, 2013, Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001; Evenhuis et al., 2004; Warburg, 2001a). A literature review of Owens et al. (2006) indicates that the exact prevalence of visual impairments in persons with ID varies depending on the etiology of the ID. In general it can be stated that the prevalence of visual impairments is related to the severity of the ID (Evenhuis et al., 2001; van Splunder, 2003; Warburg, 2001a). Persons with severe or profound ID face a higher risk of visual impairments than persons with ID in general (Evenhuis et al., 2001; Warburg, 2001a). van Timmeren, van der Putten, van Schrojenstein Lantman-de Valk, van der Schans and Waninge (2016) reported a prevalence of 87% of visual impairments in a sample of persons with severe and profound intellectual and multiple disabilities. van den Broek, van Romshorst and Deen (2006) investigated several visual functions in people with severe and profound ID and a visual impairment of any kind was diagnosed for 92%. For only 30% of the persons the particular visual impairment was already known before the study. Some authors state that persons with severe or profound ID should be considered as having a visual impairment until proven otherwise (van den Broek et al., 2006; van Splunder, 2003).

Visual impairments may negatively impact various developmental, learning, communication, and quality of life outcomes (Owens, Kerker, Zigler, & Horwitz, 2006). The high prevalence of visual impairments in persons with severe and profound ID and the potentially large impact of these impairments on their daily life make assessment of visual functioning in this group indispensable (Dijkhuizen, Hilgenkamp, Krijnen, van der Schans, & Waninge, 2016; Evenhuis, Sjoukes, Koot, & Kooijman, 2009). Sight problems limit experiences and make access to available information more difficult which impacts the person's physical, neurological, and emotional

development. Consequently, timely identified vision problems may prevent further impairments over time. A (Mervis, Yeargin-Allshopp, Winter, & Boyle, 2000; Owens et al., 2006). The underrecognition of visual impairments may lead to increased dependency and decreased quality of life (Das, Spowart, Crossley, & Dutton, 2010; Newsam, Walley, & McKie, 2010).

Often a distinction is made between lower and higher order visual functions. Lower order visual functions impact the quality of the image which is seen. These are the primary visual functions such as visual acuity, visual field, and light adaptation (Lennie & Van Hemel, 2002) and the oculomotor functions such as eye positioning (Akinci et al., 2008), eye movements (Wolters & Groenewegen, 2004), and the ability to fixate (Van den Broeck et al., 2006). Higher order visual functions refer to visual information processing in the brain, which consists of the visual-perceptional cognitive functions such as visual interest (Van den Broeck et al., 2006), and the visuo-motor functions for example the eye-hand coordination (Lennie & Van Hemel, 2002). Despite the high prevalence of visual impairments and the importance of timely diagnosis in the group of persons with severe and profound ID, only for a minority a clear diagnosis is available (e.g. Evenhuis et al., 2001; Warburg, 2001a). Three explanations can be given for this underdiagnoses.

First, due to diagnostic overshadowing, family and direct support workers attribute the atypical behaviors which may be linked to a visual impairment to other disabilities and not to a vision problem (Carvill, 2001; Evenhuis et al., 2009; van den Broek et al., 2006; Warburg, 2001b).

Second, underdiagnosis can be explained by the difficulty to assess the visual functioning of persons with ID (Evenhuis et al., 2001; Newsam et al., 2010; van den Broek et al., 2006). Traditional assessment procedures, which are often based on verbal responses and active participation of the person, are difficult to apply in the group of persons with severe or profound ID (Boot, Pel, Vermaak, van der Steen, & Evenhuis, 2013; Das et al., 2010, Kooiker, Pel, & van der Steen, 2015; Li et al., 2015).

Third, due to diffusion of responsibility visual impairments in persons with severe or profound ID may be underdiagnosed. This sociopsychological phenomenon whereby a person is less likely to take responsibility when others are involved in the same situation may lead to denial of their own responsibility (Latané & Darley, 1970). Often many caretakers (e.g. direct support workers, family, therapists, doctors) are involved in the care for a person with severe or profound ID. This may lead to the diffusion of responsibility where each caretaker assumes another caretaker to be responsible for the assessment and follow up of the visual impairments.

Due to the underdiagnoses of visual impairments in the group of persons with severe or profound ID, it may be assumed that the knowledge of daily caretakers on the visual functioning of these persons is limited. Direct support workers and staff members have access to the information of the visual functioning through the personal files and build knowledge based on their own experiences. In the present study the information available in the personal files and the direct support workers' and staff members' knowledge on the visual functioning of persons with severe or profound ID is investigated. In Belgium direct support workers provide daily support and care for persons with disabilities. Staff members are mostly psychologists or educational scientists who are responsible for the personal development plan and support the direct support workers. The accuracy and availability of this information and knowledge is of high relevance in order to provide individualized and high quality support in daily life (van den Broek et al., 2006).

The concrete research questions are:

- To what extent do direct support workers and staff members agree on their knowledge of the visual functioning and does this agree with the information available in the personal files?

- How certain are direct support workers and staff members about their knowledge on the visual functioning of their clients with severe and profound ID?
- To what extent is the information available in the support files based on formal assessment of visual functioning and what is the opinion of direct support workers and staff members on formal assessment of visual functions?

Method

Participants

Three large Belgian facilities for persons with ID were asked for their participation. Based on assessment data in the personal files staff members (psychologists or educational scientists) classified every client in groups of persons with a severe (IQ between 20 and 40 or developmental level between 2 and 5 years) or profound (IQ below 20 or developmental level below 24 months) ID. In the next step, in every group home of the three facilities two persons of the potential groups were selected randomly. In total 104 clients were selected of which 16 in facility A, 52 in facility B, and 36 in facility C. In total 46 clients with severe ID and 58 with profound ID were selected. The mean age of the persons with severe or profound ID was 42 (min. = 5; max. = 82), 49% were male (n = 51) and 51% were female (n = 53).

For every client a direct support worker and a staff member were asked to participate in this study. They were asked to anonymously fill in an online questionnaire about the visual functioning of the client. A single direct support worker could fill in a questionnaire for one or two clients. Consequently, we do not have information on the exact number of participating direct support workers. In total 13 staff members participated in this study, they filled in the questionnaire for multiple clients.

Procedure and questionnaire

In the first phase, a direct support worker and a staff member filled in an online questionnaire for every selected client. Table 1 provides an overview of the questions asked in the questionnaire. The questionnaire comprises 17 questions with predetermined answers. Questions 1-13 were based on a selection of visual functions which are relevant in persons with severe or profound ID (Thiry, 1992). Additionally to these questions the respondents had to address their level of certainty about their answer on a four level scale: (1) not sure, (2) presumption but not sure, (3) fairly sure, (4) absolutely sure. Four additional questions (questions 14a-17a) ask about the respondents' opinion on the added information a test of the visual functioning would deliver, who is responsible for the follow up of the visual functioning, and how they would judge their own knowledge about the visual functioning of the person.

In the second phase, the researchers analyzed the personal files of every selected client. To make comparison with the knowledge of the direct support workers and staff members possible, a format to collect the information on the same visual functions as in the questionnaire was developed. The first 13 items of the format correspond with the first 13 questions in the questionnaire. In the format for analyzing the files the response alternative: 'no information or not clearly mentioned' was added. Questions 14b and 15b specifically probed the visual functions of depth perception and eye-hand coordination. Questions 16b, 17b, and 18b asked for additional information on the nature of the information in the personal file and if the person has a brain injury which may cause visual problems. Two researchers filled in the format for every personal file independently. The percentage exact agreements between the two researchers for questions 1-15 was 91.5% and for the questions 16-18, 93.0%. Questions on which both researchers initially did not agree were discussed until a consensus was found.

[insert table 1 about here]

Analyses

Percentages were calculated of the number of persons with severe and profound ID having or not having a problem on a particular aspect of their visual functioning according to their direct support workers, the staff members and personal files. Based on the McNemar test significance levels for the differences between direct support workers and staff members were calculated.

A direct comparison of the answers on the questions of the visual functioning by direct support workers and staff members was made. Exact agreements deliver an indication of the proportion of direct support workers and staff members that agree on a certain aspect. Besides, the Cohen's kappa coefficient was calculated since κ takes into account the possibility of the agreement occurring by chance.

Direct support workers and staff members were asked to indicate their level of certainty about their answer on several questions. The average scores and standard deviations on the various questions were calculated. The scores given by direct support workers and staff members were compared using a Wilcoxon signed rank test.

Results

To what extent do direct support workers and staff members agree on their knowledge of the visual functioning and does this agree with the information available in the personal files?

Before being able to answer this question an important remark needs to be made. Only few personal files contained reliable information on the visual functioning of the client. In 63.5% of the personal files some sort of information on the visual functioning is available. Detailed information on the various aspects of the visual functioning is generally lacking (table 2). In 4.8% of the personal files, it is stated that the person has a visual impairment. Direct support workers and staff

members both indicate that 49.0% of the persons with a severe or profound ID have a visual impairment.

[insert table 2 about here]

Table 3 contains the percentages of clients having a specific visual limitation indicated by the direct support workers and staff members and according to the information in the personal files. For two aspects of the visual functioning the answers of the staff members and direct support workers show significant discrepancies. According to the direct support workers 15.4% of the clients have strabismus, staff members indicate twice as many (30.8%) clients having strabismus (McNemar test, p = .009, 2-sided). Also the percentage of direct support workers (10.6%) and staff members (18.3%) indicating difficulties in making eye-contact is significantly different (McNemar test, p = .039, 2-sided). Except for blindness, the percentages of persons with a severe or profound ID indicated with a specific visual limitation are lower in the personal files compared to what is indicated by the direct support workers and staff members. This confirms the limited information available in the personal files. A more detailed comparison between the estimates of the direct support workers and staff members with the information in the personal files turned out to be difficult.

[insert table 3 about here]

Looking in more detail to the answers provided by direct support workers and staff members, their answers on the questions about the various visual functions show no perfect agreements. Table 4 provides information on the agreements between direct support workers' and staff members' knowledge of the visual functions of their clients. The exact agreements range from 53.9% for 'visual acuity' to 95.2% for the 'ability to follow moving objects'. The Cohen's Kappa ranges from -.04 for the 'reaction to light', to .74 for the 'ability to follow moving objects'. For the answers on three questions, the Cohen's Kappa values indicate a poor agreement (eye position,

reaction to light, visual interest), for four a fair agreement (visual acuity, sight differences between both eyes, eye movements, severity of visual impairment), for four a moderate agreement (wearing glasses, ability to fixate on an object, making eye contact, visual field loss) and for one question a substantial agreement (ability to follow moving objects) (Landis & Koch, 1977).

[insert table 4 about here]

How certain are direct support workers and staff members about their knowledge on the visual functioning of their clients with severe and profound ID?

Most direct support workers described their knowledge on the visual functioning of their clients as average (34.6%) or good (51.0%). The majority of staff members described their knowledge as limited (33.7%) or average (47.1%). None of the staff members described their knowledge as very good whereas 8.7% of the direct support workers described their knowledge as very good (question 17a).

For questions one till 13, direct support workers and staff members indicated their level of certainty about their answer on a four level scale ranging from not sure, over presumption but not sure and fairly sure, to absolutely sure (table 5). Based on the Wilcoxon signed rank test, it can be concluded that direct support workers were significantly more certain about their answers compared to staff members.

[insert table 5 about here]

To what extent is the information, available in the support files, based on formal assessment of visual functioning and what is the opinion of direct support workers and staff members on formal assessment of visual functions?

For this question, only the personal files which contain information on the visual functioning, have been used (63.5%, 66 files). In 42.3% of these personal files the information on the visual functioning is based on impressions, in 12.5% it is based on a combination of impressions and objective tests, and in 8.7% all information is based on tests (questions 17b). 9.6% of the personal support files explicitly mention points of concern with regard to the visual functioning of the client (question 18b). In only two personal files a brain injury which may cause a limited visual functioning was mentioned (question 16b).

According to the direct support workers the visual functioning of 64.4% of the clients had been tested, the staff members indicated that this was done for 75.0% of the clients (question 13). In the personal files, only for 21.2% of the persons information on any test of the visual functioning was available (questions 17b). For almost half of the persons for whom the visual functioning has been tested, this was done more than two years ago, according to the direct support workers (42.3%) and the staff members (51.0%). Based on the personal files the visual functioning was tested more than two years ago in 11.5% of the persons.

According to the direct support workers a test for the visual functioning is necessary for 6.7% of the clients, staff members think this is necessary for 3.8%. For 51.0% (direct support workers) and 47.1% (staff members) of the clients a test could deliver useful information. For all others a test would not deliver additional useful information according to the direct support workers and staff members (question 14a).

Direct support workers and staff members do not agree upon who is responsible for the follow up of the client's visual functioning (see table 6). Direct support workers indicate for most clients the doctor (29.8%) as being responsible. Staff members indicate for most clients the direct support workers (31.7%) as being responsible while only 17.3% of the direct support workers indicate direct support workers (themselves) as being responsible (McNemar test, p = .015,

asymptotic). Also for the answer 'nobody is responsible' a significant difference between staff members and direct support workers was found (McNemar test, p = .039, 2-sided).

When asked who should be responsible for the follow up of the client's visual functioning both direct support workers and staff members indicated for most clients the doctor (28.8% - 36.5%) and the ophthalmologist (30.8% - 32.7%). The difference in opinion between direct support workers (17.3) and staff members (31.7%) about the extent in which direct support workers are responsible disappears when the question changes from 'who *is* responsible' to 'who *should be* responsible' (11.5% for direct support workers and 10.6% for staff members). The difference in the amount of staff members and direct support workers who think the family should be responsible is significant (McNemar test, p = .035, 2-sided).

[insert table 6 about here]

Discussion

In order to provide individualized and high quality support to persons with severe and profound ID, accurate information on their visual functioning is needed (van den Broek et al., 2006). Due to the underdiagnoses of visual impairments in this group it may be assumed that the available knowledge is not accurate, correct, or complete. This study focused on the direct support workers' and staff members' knowledge on the visual functioning of persons with severe or profound ID and the information available in their personal files.

First, it was investigated to what extent direct support workers and staff members agree on their knowledge of the visual functioning of the client and if this knowledge agrees with the information available in the personal files. While direct support workers and staff members indicate that 49.0% of their clients have a visual impairment, this is only formally stated in 4.8% of the personal files. Direct support workers and staff members agree upon the amount of clients who have a visual

impairment, but disagree on the specific impaired visual functions. Comparing this information with the personal files turned out to be difficult, because of the lack of information available in the files. This discrepancy and the lack of information in the files clearly illustrates the problem of underdiagnoses of visual impairments in the group of persons with severe and profound ID in the three facilities that participated in the present study (e.g. Evenhuis et al., 2001; Warburg, 2001a). Only limited formal information on the visual functioning is available in the personal files which may lead to poor knowledge of the visual functioning among caregivers.

Second, due to this underdiagnoses and lack of objective information in the personal files it may be assumed that caregivers are not certain about their knowledge on the visual functioning. In general, direct support workers rate the certainty level of their knowledge on their clients' visual functions higher than staff members. Also on the various visual functions direct support workers present significantly higher certainty scores compared to staff members. Due to the lack of objective information in the personal files, it is impossible to reliably verify the knowledge of the professionals. However, comparison with estimations on the prevalence of particular visual problems in people with severe and profound ID that are available from previous studies can be informative. For example, van den Broek et al. (2006) diagnosed visual field loss in 51% of the group. Comparison of this prevalence with the professionals' estimations of visual field loss in our study (14.4% according to direct support workers; 21.2% according to staff members) suggests a manifest underestimation of the prevalence of impairment in the visual field by caregivers. In the study of van den Broek et al. (2006) a prevalence of 92% of the group having a visual impairment was reported. Van Timmeren et al. (2016) reported a prevalence of 87% of visual impairments in a sample of persons with severe and profound intellectual and multiple disabilities. In our study, 49.0% of the persons with a severe or profound ID have a visual impairment according to the direct support workers and staff members. Concluding, knowledge of caregivers on the visual functioning of their clients with severe and profound ID in the three facilities that participated in the present study appears to be poor and cannot be taken as a reliable estimate of the prevalence of a visual impairment.

The third research question focused on the available information in the support files and it was investigated if this information was based on formal assessment of the visual functioning and what the opinion of caregivers is on formal assessment. The information available in the personal files is often based only on subjective impressions. A small fraction of the available information in the files is based on formal assessments of the person's visual functioning. Again, these results show the limited formal attention paid to the visual functioning (e.g. Evenhuis et al., 2001; Warburg, 2001a). For a minority of the clients the caregivers indicate that assessment of the visual functioning is necessary. For about half of the group they assume it would deliver additional information. Staff members and direct support workers do not agree upon who is responsible for the follow up of the visual functioning. Remarkably, the percentage of staff members indicating direct support workers as responsible (31.7%) is almost double of the percentage of direct support workers indicating themselves as responsible (17.3%). This observation clearly illustrates the mechanism of diffusion of responsibility (Latané & Darley, 1970). Interestingly, this difference between staff members and direct support workers disappears when the question changes from who is responsible to who should be responsible. Staff members and direct support workers agree that the doctors and ophthalmologists should be responsible.

Some limitations could be formulated with regard to this study. First, due to the lack of information in the personal files, it was only possible to give a partly answer to our first research question. The knowledge of the direct support workers and staff members could not be compared with the available information in the personal files. This limitation in itself is an important observation. The knowledge available on the visual functioning of persons with severe and

profound intellectual disabilities is mostly based on clinical experiences and not on objective information in the personal files. Second, staff members were asked to fill in the questionnaire for multiple clients where direct support workers filled in the questionnaire for one or two clients. Although, this asymmetry reflects the reality in practice where a staff member is responsible for a larger number of clients, different individual opinions may have had a relatively stronger impact in the smaller staff members group than in the direct support workers group. Third, there is a paucity of recent literature on this topic. Ironically, this supports the main messages of the present article. There is too little attention for the visual functioning in people with severe and profound intellectual disabilities, in daily practice but also in scientific literature.

Future research should focus on possibilities to gain better insight in the visual functioning of persons with severe and profound ID. There is a need for assessment procedures and experience exchange between direct support workers and staff members to get a good insight in the visual functioning of a client. Potentially, eye tracking technology may deliver new possibilities in objectively assessing the visual functioning of persons with severe and profound ID (Hathibelagal, Leat, Irving, Nandakumar, & Eizenman, 2015; Kooiker et al., 2016; Pel, Manders, & van der Steen, 2010). Based on these formal assessment procedures more in depth research on the visual functioning of persons with severe and profound ID and their impact on the persons' daily life can be done.

It is known that persons with severe and profound ID have an increased chance on having a visual impairment (Evenhuis et al., 2001; Evenhuis, van Splunder, Vink, Weerdenburg, van Zanten, & Stilma, 2004; Warburg, 2001a) and that knowledge on the visual functioning is needed to provide individualized and high quality support in daily life (van den Broek et al., 2006). Based on this study it can be concluded that the knowledge of direct support workers and staff members and the information available in the personal files in the three participating facilities provide no clear and comprehensive picture of the visual functioning of the persons with severe or profound ID in these facilities. Objective information is lacking in the personal files and the knowledge based on impressions is not agreed upon between direct support workers and staff members. Comparison with estimations in the scientific literature suggests that direct support workers and staff members considerably underestimate the prevalence of visual impairments in the group of people with severe and profound ID. The lack of knowledge and objective information on the visual functioning of these clients impede high quality support in daily life. It may be assumed that more information is provided in the medical files of the persons, however, this information is usually not accessible by those who support the person on a day to day basis.

This study provides important implications for policy and practice, for the results highlight the need for increased cooperation between the medical doctor, ophthalmologist and the daily caretakers. Their cooperation must lead to the increased availability of objective, correct and up to date information on the visual functioning of the persons with disabilities, which must be formalized in the personal files. Staff members and direct support workers need to know this information. Additionally, as diagnosis is difficult, direct support workers and staff members must have the chance to exchange their experiential expertise, their thoughts and experiences on the visual functioning of the client on a regular basis. This information needs to be formalized in the personal files which will help to provide constant and long term high quality support.

References

Akinci, A., Oner, O., Bozkurt, O., Guyen, A., Degerliyurt, A., & Munir, K. (2008).

Refractive errors and ocular findings in children with intellectual disability: A controlled study. *Journal of AAPOS, 12*, 477-481.

Boot, F., Pel, J., Vermaak, M., van der Steen, J., & Evenhuis, H. (2013). Delayed visual orienting responses in children with developmental and/or intellectual disabilities. *Journal of Intellectual Disability Research*, *57*(12), 1039-1103.

Das, M., Spowart, K., Crossley, S., & Dutton, G. (2010). Evidence that children with special needs all require visual assessment. *Archives of Disease in Childhood, 95*, 888-892.

Dijkhuizen, A., Hilgenkamp, T.I.M., Krijnen, W., van der Schans, C., & Waninge, A. (2016). The impact of visual impairment on the ability to perform activities of daily living for persons with severe/profound intellectual disability. *Research in Developmental Disabilities, 48*, 35-42.

Carvill, S. (2001). Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research*, *3*, 77-101.

Evenhuis, H.M., Sjoukers, L., Koot, H.M., & Kooijman, A.C. (2009). Does visual impairment lead to additional disability in adults with intellectual disabilities? *Journal of Intellectual Disability Research*, 53(1), 19-28.

Evenhuis, H.M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in Dutch institutionalised population with intellectual disability. *Journal of Intellectual Disability Research*, *45*, 457-464.

Evenhuis, H., van Splunder, J., Vinke, M., Weerdenburg, C., van Zanten, B., & Stilma, J. (2004). Obstacles in large-scale epidemiological assessment of sensory impairments in a Dutch population with intellectual disabilities. *Journal of Intellectual Disability Research, 48*(8), 708-718.

Hathibelagal, A. R., Leat, S. J., Irving, E. L., Nandakumar, K., & Eizenman, M. (2015). Measuring Infant Visual Acuity with Gaze Tracker Monitored Visual Fixation. Optometry and Vision Science, 92(7), 823-833.

Mervis, C.A., Yeargin-Allshopp, M., Winter, S., & Boyle, C. (2000). Aetiology of childhood vision impairment, metropolitan Atlanta, 1991-93. *Paediatric and Perinatal Epidemiology*, 14, 70-77.

Newsam, H., Walley, R.M., & McKie, K. (2010). Sensory Impairment in Adults With Intellectual Disabilities - An Exploration of the Awareness and Practices of Social Care Providers. *Journal of Policy and Practice in Intellectual Disabilities*, 7(3), 211-220.

Kooiker, M., Pel, J., & van der Steen, J. (2015). The Relationship Between Visual Orienting Responses and Clinical Characteristics in Children Attending Special Education for the Visually Impaired. *Journal of Child Neurology*, *30(6)*, 690-697.

Kooiker, M. J. G., Pel, J. J. M., Verbunt, H. J. M., de Wit, G. C., van Genderen, M. M., & van der Steen, J. (2016). Quantification of visual function assessment using remote eye tracking in children: validity and applicability. Acta Ophthalmologica, 94(6), 599-608.

Latané, B., & Darley, J.M. (1970). *The unresponsive bystander: Why doesn't he help?* New York, NY: Appleton-Century-Croft.

Landis, J.R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, *33*(1), 159–174.

Lennie, P., & Van Hemel, S.B. (2002). Visual impairments: Determining eligibility for social security benefits. Washington, DC: National Academy Press.

Li, J.C., Wong, K., Park, A.S.Y., Fricke, T.R., & Jackson, A.J. (2015). The challenges of providing eye care for adults with intellectual disabilities. *Clinical and Experimental Optometry*, *98*, 420-429.

Owens, P.L., Kerker, B.D., Zigler, E., & Horwitz, S.M. (2006). Vision and oral health needs of individuals with intellectual disabilities. *Mental Retardation and Developmental Disabilities*, *12*, 28-40.

Pel, J.J., Manders, J.C., & van der Steen, J. (2010). Assessment of visual orienting behaviour in young children using remote eye tracking: Methodology and reliability. *Journal of Neuroscience Methods*, 189, 252–256.

Thiry, P. (1992). Gezichtsstoornissen bij diep mentaal gehandikapten [Masterproef]. Leuven: KULeuven Bijzondere licentie gehandikaptenzorg.

van den Broek, E. J., van Ramshorst, T., & Deen, L. (2006). Visual impairments in people with severe and profound multiple disabilities: an inventory of visual functioning. *Journal of Intellectual Disability Research*, *50*(6), 470-475.

van Splunder, J. (2003). Visual impairment, Prevalence and Causes of Visual Impairment in Adults with Intellectual Disabilities. Utrecht: Universiteit Utrecht.

van Timmeren, E.A., van der Putten A.A.J., van Schrojenstein Lantman-de Valk, H.M.J.,

van der Schans, C.P., & Waninge, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: a cross-sectional study of medical records and care plans. *Journal of Intellectual Disability Research, 60*(11), 1109–1118.

Warburg, M. (2001a). Visual impairment in adult people with intellectual disability: literature review. *Acta Ophtamologica Scandinavica*, *45*, 429-438.

Warburg, M. (2001b). Visual impairment in adult people with moderate, severe and profound intellectual disability. *Acta Opthamologica Scandinavica*, 79, 450-454.

Wolters, E.C., & Groenewegen, H.J. (2004). Deel 3: Motoriek en bewegingen. In E.C. Wolters & H.J. Groenewegen (Eds.), Neurologie: structuur, functie en dysfunctie van het zenuwstelsel (pp. 20-287). Houten: Bohn Stafleu van Loghum.

	Aspect	Question	Answer options
1	Glasses	Does the person wear glasses	(1) never, (2) sometimes, (3) most of
		during the daytime?	the time, (4) always
2	Eye position	What is the eye position like?	(1) symmetric sight, (2) convergent strabismus, (3) divergent strabismus
3	Light	Does the size of the pupils vary depending on the light intensity?	(1) left and right, (2) only left pupilvaries, (3) only right pupil varies, (4)pupil sizes remain constant
4	Fixation	Is the person able to fixate on a fixed object for several seconds?	(1) yes, (2) no
5	Follow	Is the person able to follow a moving object?	(1) yes, (2) no
6	Visual acuity	What is the person's visual acuity like?	(1) the person cannot see the difference between dark and light, (2) the person can see the difference between dark and light, (3) the person's sight is not sharp, (4) the person's sight is moderately sharp, (5) the person's sight is very sharp
7	Sight differences between both eyes	Does the quality of the person's sight differ between both eyes?	(1) no difference, (2) left eye sight is worse compared to right eye sight, (3) right eye sight is worse compared to left eye sight
8	Visual field	Does the person have visual field loss?	(1) no visual field loss, (2) left visual field loss, (3) right visual field loss, (4 loss in both visual fields, (5) tunnel vision
9	Eye movements	Does the person present abnormal eye movements (nystagmus)?	(1) never, (2) sometimes, (3) always
10	Eye contact	Does the person make eye contact?	(1) yes, (2) no
11	Visual interest	Does the person show visual interest in his/her environment?	(1) not at all, (2) yes a little, (3) yes a lot
12	Visual impairment	What is the most applicable description of the visual impairment?	(1) no visual impairment, (2) mildvisual impairment, (3) moderate visualimpairment, (4) severe visualimpairment, (5) blind
13	Tested	Has the visual functioning of the person ever been tested systematically?	(1) never, (2) yes but longer than two years ago, (3) yes the person's visual functioning has not worsened since then

Table 1Overview of the content of the questionnaire

1.4		uestions for direct support worke	
14a	Test	A test of the visual functioning	(1) would deliver no additional valuable information, (2) would deliver valuable information, (3) is really
			necessary
15a	Currently Responsible	Who is currently responsible for the follow up of the person's visual functioning?	(1) nobody, (2) medical doctor, (3) ophthalmologist, (4) psychologist or educational scientist; (5) direct support staff, (6) family, (7) other
16a	Preferably responsible	Who should be responsible for the follow up of the person's visual functioning?	 (1) nobody, (2) medical doctor, (3) ophthalmologist, (4) psychologist or educational scientist; (5) direct support staff, (6) family, (7) other
17a	Knowledge	How would you judge your knowledge about the person's visual functioning?	(1) limited, (2) moderate, (3) good, (4) very good
	Qu	estions answered based on inform	nation in personal files
14b	Depth vision	Is there any problem with the person's depth vision?	(1) the depth vision is normal, (2) the depth vision is limited
15b	Eye-hand coordination	Is there any problem with the person's eye-hand coordination?	(1) the eye-hand coordination is normal, (2) the eye-hand coordination is limited
16b	Brain injury	Does the person suffer a brain injury which possibly causes limited visual functioning?	(1) yes, (2) no
17b	Objectivity	Is the available information in the personal file objective?	(1) data are based on subjective impressions, (2) data are partly objectified and partly based on impressions, (3) all data are objectified
18b	Points of concern	Are there points of attention with regard to the visual functioning formulated in the personal file?	(1) yes, (2) no

Questions for direct support workers and staff members

junci	ioning	
1	Glasses	94.2 %
2	Eye position	84.6 %
3	Light	93.3 %
4	Fixation	79.8 %
5	Follow	78.8 %
6	Visual acuity	84.6 %
7	Variations in both eyes	93.3 %
8	Visual field	88.5 %
9	Eye movements	92.3 %
10	Eye contact	92.3 %
11	Visual interest	78.8 %
12	Visual impairment	80.8 %
13	Tested	78.8 %
14b	Depth sight	94.2 %
15b	Eye-hand coordination	92.3 %

Percentage of personal files which contain no information on specific aspects of visual functioning

Table 3

		Direct	Staff	Personal
		support	members (%)	files (%)
		workers (%)		
1	The person wears glasses	8.7	7.7	2.9
2	The person has strabismus	15.4	30.8	2.9
3	No or no equal response of the pupils to	17.3	16.3	1.0
	light			
4	The person is not able to fixate	9.6	15.4	1.9
5	The person is not able to follow a moving	10.6	9.6	0
	object			
6	The person sees no difference between light	1.9	1.9	1.9
	and dark (blind)			
7	The person's sight differs in both eyes	10.6	7.7	5.8
8	The person has visual field loss	14.4	21.2	7.7
9	The person presents abnormal eye	32.7	42.3	4.8
	movements			
10	The person makes no eye contact	10.6	18.3	1.0
11	The person presents no visual interest	4.8	4.8	0.0
14b	The person's depth sight is limited	-	-	4.8
15b	The person's eye-hand coordination is	-	-	1.9
	limited			

Percentages of clients with a specific visual limitation, according to direct support workers, staff members, and their personal files

Table 4

		Exact agreement	Cohen's Kappa
1	Glasses	93.3%	.56
2	Eye position	64.4%	.08
3	Light	70.2%	04
4	Fixation	88.4%	.48
5	Follow	95.2%	.74
6	Visual acuity	53.9%	.27
7	Sight differences between both eyes	87.5%	.27
8	Visual field	81.7%	.41
9	Eye movements	62.3%	.24
10	Eye contact	88.5%	.54
11	Visual interest	66.3%	.09
12	Visual impairment	54.7%	.36

Agreement between the knowledge of the visual functioning by direct support workers and staff members

Table 5

Level of certainty addressed by direct support workers (SW) and staff members (SM) about their knowledge on the visual functioning of their clients

		not	sure	presur	nption	fairly	sure	absolute	ly sure	Mean	(SD)	Wilcoxon signed
		(%)		not sure	e (%)	(%)		(%)	-			rank test
		SW*	SM**	SW	SM	SW	SM	SW	SM	SW	SM	-
1	Glasses	0.0	4.8	0.0	4.8	0.0	9.6	100.0	80.8	4.00 (.000)	3.66 (.783)	-3.992 (p = .00)
2	Eye position	1.0	8.7	8.7	48.1	45.2	36.5	45.2	6.7	3.35 (.679)	2.41 (.745)	-6.876 (p = .00)
	Light	10.6	45.2	30.8	40.4	48.1	13.5	10.6	1.0	2.59 (.820)	1.70 (.736)	-6.752 (p = .00)
4	Fixation	1.9	7.7	6.7	21.2	45.2	41.3	46.2	29.8	3.36 (.696)	2.93 (.906)	-3.732 (p = .00)
5	Follow	0.0	8.7	5.8	11.5	33.7	46.2	60.6	33.7	3.55 (.605)	3.05 (.896)	-4.507 (p = .00)
6	Visual acuity	1.0	13.5	32.7	63.5	55.8	23.1	10.6	0.0	2.76 (.646)	2.10 (.600)	-6.358 (p = .00)
7	Variations in	12.5	37.5	51.9	47.1	28.8	14.4	6.7	1.0	2.30 (.774)	1.79 (.720)	-4.562 (p = .00)
	yes											
8	Visual field	16.3	26.0	32.7	53.8	42.3	19.2	8.7	1.0	2.43 (.868)	1.95 (.702)	-4.351 (p = .00)
9	Eye movements	8.7	17.3	26.0	44.2	47.1	35.6	18.3	2.9	2.75 (.856)	2.24 (.770)	-4.169 (p = .00)
10	Eye contact	0.0	3.8	3.8	17.3	23.1	36.5	73.1	42.3	3.69 (.541)	3.17 (.853)	-5.139 (p = .00)
11	Visual interest	0.0	0.0	3.8	14.4	26.0	47.1	70.2	38.5	3.66 (.551)	3.24 (.690)	-4.968 (p = .00)
12	Visual	18.3	22.1	48.1	32.7	32.7	33.7	1.0	11.5	2.92 (.772)	2.16 (.726)	-6.615 (p = .00)
	ment											
13	Test	22.1	29.8	32.7	53.8	33.7	14.4	11.5	1.9	2.35 (.951)	1.88 (.715)	-4.054 (p = .00)

* direct support workers

** staff members

Table 6

	Who is response	sible for the	Who should be responsible for		
	follow up of the	client's visual	the follow up of the client's		
	functionin	ng (%)	visual functioning (%)		
	Direct support	Staff	Direct support	Staff	
	workers	members	workers	members	
Nobody	7.7	1.0	0.0	0.0	
Doctor	29.8	26.9	28.8	36.5	
Ophthalmologist	14.4	7.7	30.8	32.7	
Direct support workers	17.3	31.7	11.5	10.6	
Family	22.1	21.2	17.3	8.7	
Other	8.7	11.5	11.5	11.5	

Who is and who should be responsible for the follow up of the client's visual functioning.