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Does visual impairment lead to additional disability in adults with intellectual disabilities?

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Abstract

Background This study addresses the question to what extent visual impairment leads to additional disability in adults with intellectual disabilities (ID).
Method In a multi-centre cross-sectional study of 269 adults with mild to profound ID, social and behavioural functioning was assessed with observant-based questionnaires, prior to expert assessment of visual function. With linear regression analysis the percentage of variance, explained by levels of visual function, was calculated for the total population and per ID level.
Results A total of 107/269 participants were visually impaired or blind (WHO criteria). On top of the decrease by ID visual impairment significantly decreased daily living skills, communication & language, recognition/communication. Visual impairment did not cause more self-absorbed and withdrawn behaviour or anxiety. Peculiar looking habits correlated with visual impairment and not with ID. In the groups with moderate and severe ID this effect seems stronger than in the group with profound ID.
Conclusion Although ID alone impairs daily functioning, visual impairment diminishes the daily functioning even more. Timely detection and treatment or rehabilitation of visual impairment may positively influence daily functioning, language development, initiative and persistence, social skills, communication skills and insecure movement.

Keywords intellectual disability, visual impairment

Introduction

When intellectual disability (ID), which in itself seriously afflicts psychosocial development and daily functioning, co-occurs with a visual impairment, it may be expected that overall disability will be more severe. Co-occurrence of intellectual and visual impairment is not uncommon: Splunder *et al.* (2006) have shown that 14% of the adult population with ID has a visual impairment and 5% is (socially) blind.

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The general effects of ID and visual impairment are well documented. ID impairs activities of daily life (ADL), linguistic skills, social skills and independent living skills (Kottorp *et al.* 2003). Such impairments remain relatively stable over time (Beadle-Brown *et al.* 2002), as does stereotyped behaviour (Thompson & Reid 2002). Childhood visual impairment delays motor development (Prechtl *et al.* 2001) and complicates and delays attachment, language, motor and learning skills (Levtzion-Korach *et al.* 2000; Atkinson *et al.* 2002; Dale & Sonksen 2002). Stereotyped behaviour like body-rocking, repetitive handling of objects, and eye-pressing or eye-poking is common (Dijk 1983; Jan *et al.* 1983; Fazzi *et al.* 1999).

Visual impairment in the general adult population interferes negatively with the ability to perform ADL (Haymes *et al.* 2002). At all ages, sleep problems have been reported for people with (profound) low vision or blindness (Brylewski & Wiggs 1999; Dale & Sonksen 2002; Didden *et al.* 2002; Zizi *et al.* 2002). Studies in groups aged 65 years and over have shown that the third most common condition causing a need for ADL assistance is age-related vision loss after arthritis and heart disease and this may lead to depression, anxiety, lethargy and social dissatisfaction (Shmuely-Dulitzki & Rovner 1997; Keller *et al.* 1999; Heine & Browning 2002; Warnecke 2003). However, as far as we know, no research has been published on the extra disability because of visual impairment in the population with ID. On the contrary, visual impairment and even blindness tend to remain 'invisible' in this population: in 40% of Dutch adults with ID the visual impairment (or blindness) had not been identified (Splunder *et al.* 2006). Possible explanations might be that persons with ID do not complain of visual loss or that symptoms of visual impairment are labelled as originating from the ID or autism. Another possibility is that those with low vision show less acting-out behaviour or ask less attention than people with ID and normal vision, thus suggesting that everything is going well.

The study addresses the question to what extent visual impairment leads to additional disability in adults with ID. We hypothesised that independent of the severity of ID, lower vision is associated with: (1) decreased independent living skills; (2) increased difficulties in communication; (3) more insecure movement; (4) more self-absorbed and withdrawn behaviour; and (5) less antisocial and disruptive behaviour.

Methods

Study design and procedure

A multi-centre cross-sectional study design was used to assess the relationship between the participants' levels of ID and visual functioning on the one hand, and behaviour and social functioning on the other hand.

The procedure is generally outlined here; details are given below. Both ID and visual function were categorised into four classes (Table 1). Behaviour and social functioning were assessed with observational questionnaires that addressed the following five areas: independent living skills, communication, insecure movement, peculiar looking habits, self-absorbed behaviour and antisocial/disruptive behaviour. Caregivers who knew the participants well completed these questionnaires. This was done prior to the screening of visual function, so caregivers were blind to the actual visual function of the participants. The study was approved by the Medical Ethics Committee of the Erasmus University Medical Center (MEC 197.075/2000/239).

Study population

Three Dutch ID service providers offering sheltered workshops, residential and day care, where a routine vision screening by a district low vision centre had been scheduled for 2002–2004, consented to participate in the study. The three involved low vision teams screened according to consensus guidelines of the International Association on the Scientific Studies of Intellectual Disability (IASSID) (Evenhuis & Nagtzaam 1997/1998). Because it was important to include enough participants in the different ID and visual function categories, we aimed to include both homes for clients needing care and homes for more independent clients in the screening. Because of the limited capacity of the low vision teams with their highly specialised staff, caregivers were asked to complete a short, non-validated observation-based questionnaire to estimate the possibility of visual problems.

Only clients with a possibly elevated risk of visual problems were invited for the screening. Criteria for inclusion in the study were age 18 years and over, no previous diagnosis of visual impairment, and no severe motor impairment or progressive disease (e.g. dementia or cancer). Written informed consent for participation was asked from the legal representatives and from clients who were able to understand the aims of the study.

General data

Information on the severity of ID, based on prior IQ testing, was obtained from the patient files, just as information on relevant co-morbidity (disruptive behaviour, hearing impairment, aetiology of ID, motor impairment and wheelchair use).

Visual function assessment

Visual functioning was assessed on-site in the homes or day activity centres, according to IASSID consensus guidelines (Evenhuis & Nagtzaam 1997/1998), by professionals of the regional low vision teams with a specific expertise on people with ID. Assessment included visual acuity with at least two tests (Snellen's chart, Burghardt's children's chart, Stycar single characters and matching, Cardiff Acuity Cards, Teller Acuity Cards), visual fields (confrontation), contrast sensitivity (Hiding Heidi), auto refraction or skiascopy, and assessment of strabismus. Referral for ophthalmologic diagnosis and treatment was advised if necessary.

Definitions and classifications

All participants were assigned to one of the ID and vision categories, as presented in Table 1.

For this study, visual function was defined as the visual acuity in the best eye (with optimal correction, if glasses were used). 'Visual impairment' and '(social) blindness' were classified according to criteria of the World Health Organisation (WHO 1980).

Behavioural questionnaires

Adaptive behaviour scale (SRZ)

Adaptive behaviour was measured with the Dutch Sociale Redzaamheidschaal voor Zwakzinnigen (SRZ) (Social Functioning Scale for people with ID) (Kraijer & Kema 1994). The questionnaire consists of 31 items, each with four descriptions of possible behaviour, from inapt to adequate, with corresponding rating values from 1 to 4. The item score is the rating value of the description that fits a participant's behaviour best. The SRZ total score is the sum of all ratings and ranges from 31 to 124. Adaptive behaviour is further specified with four sub-scales in which items are grouped: daily living skills (12 items), initiative & persistence (five items), social skills (five items) and communication & language development (nine items). The SRZ is found to be reliable and well validated (Kraijer & Kema 1994). The correlation with the Vineland Social Maturity Scale is 0.82 (Kraijer 2000). The instrument is widely used in the Netherlands for persons with moderate and severe ID aged 4 years and over.

Vision Related Behaviour Questionnaire (VRBQ)

The VRBQ is a new questionnaire for the assessment of specific vision-related behaviour in people with ID that we developed because there was no suitable instrument available for the population of this study. An expert group consisting of behavioural scientists from the three participating low vision expertise centres was formed to define examples of vision-related behaviour. The question-

Table 1 Classification of intellectual disability (ID) and visual function

ID level	IQ	Developmental age (years)	Visual function level	Visual acuity ($arcmin^{-1}$)
Mild	50–70	6–11	Normal vision	≥0.5
Moderate	35–50	3.5–6	Mild impairment	0.3–0.5
Severe	20–35	1.5–3.5	Visual impairment	0.05–0.3
Profound	<20	<1.5	(Social) blindness	<0.05

naire consists of 45 behavioural items pertaining to problems with eye–hand coordination, eye–foot coordination, recognition of persons and objects, spatial orientation, insecure movement, anxiety, peculiar looking habits and communication. The items are scored in terms of occurrence: always, often, sometimes or never present, with corresponding rating values 1–4. A higher rating corresponds to more normal behaviour.

Five clusters of vision-related behaviour were identified using principal component analysis (based on 41/45 items with a factor loading ≥ 0.4): eye–hand coordination & insecure movement (nine items), recognition & communicative skills (nine items), eye–foot coordination (eight items), anxiety/fear (six items) and peculiar looking habits (nine items). The maximum score for each sub-scale is the number of constituent items multiplied by 4. The VRBQ total score is the sum of all individual rating values and ranges from 45 to 180. The VRBQ has been shown to be reliable: Crohnbach α is 0.6383 (a scale is reliable when Crohnbach's $\alpha > 0.6$ (Malhotra 1993).

Development Behaviour Checklist (DBC)

The DBC was developed to identify emotional and behavioural problems in children with ID (Einfeld & Tonge 1995). It has been translated and validated for Dutch children, but it proved to be applicable to adults as well (Dekker *et al.* 2002; Ruiter *et al.* 2008). The DBC includes 95 descriptions of problem behaviour that are scored as either not true, partly true or true, with the rating values 0, 1 and 2. Higher scores indicate more emotional and behavioural problems. The DBC has the following five, partly overlapping sub-scales: disruptive & anti-social behaviour (27 items), self-absorbed behaviour (31 items), communication disturbance (13 items), anxiety (nine items) and social relating (10 items).

Analysis

The relation between visual function and ID levels was analysed with Spearman's correlation to determine to what extent ID is a predictor of visual impairment. Means and standard deviations of the questionnaire scores were computed for the ID and for the visual function levels separately. Spearman's ρ was calculated for the questionnaire total and sub-scale scores with levels of visual function and ID.

We investigated the effect of vision problems with linear regression adjusting for ID level, disruptive behaviour, Down syndrome, hearing impairment, wheelchair dependency and age. We computed the unstandardised B to determine the direction of the effects. To refine these results we repeated the linear regression analysis per ID level. The relevance is described using Cohen's criteria: effect sizes are considered small if the percentage of explained variance (PEV) is <5.9%, medium if PEV is between 5.9% and 13.0% and large if PEV exceeds 13.0% (Cohen 1988).

Results

Study population

Informed consent for participation was obtained of 277 clients, 63% female, median age 46 years, range 17–79 years. In eight cases, no visual function test was performed because of organisational problems. This left a study population of 269 persons. Aetiology of ID was Down syndrome in 45 cases (16.2%), autism spectrum disorders 24 (9.0%) (as mentioned by the psychologist), 25 other diagnoses in 49 cases (18.4%), and unknown in 156 cases (58.0%). The following co-morbidities were diagnosed: hearing impairment 49 (of whom 14 had hearing aids), no hearing impairment 124, hearing function unknown 96; disruptive behaviour 77, no disruptive behaviour 154, no data on behaviour 38, 14 cases were wheelchair dependant (11 in the group with profound ID and one in each of the other ID groups).

Levels of ID and visual function are presented in Table 2. Of the 269 participants, 107 were visually impaired or blind according to WHO criteria. There were only 11 participants with a mild ID, because most clients of the participating homes had a moderate or severe ID.

Outcomes

Response rates for the SRZ, VRBQ and DBC questionnaires were 86%, 89% and 89% respectively, but not all questionnaires were filled out com-

Table 2 Distribution of visual function levels over intellectual disability (ID) levels ($n = 269$)

	Mild ID	Moderate ID	Severe ID	Profound ID	Total
Normal vision	9 (82%)	46 (49%)	39 (32%)	6 (14%)	100
Mild impairment	2 (18%)	25 (26%)	23 (19%)	12 (29%)	62
Visual impairment	0 (0%)	21 (22%)	55 (45%)	18 (43%)	94
(Social) blindness	0 (0%)	2 (2%)	5 (4%)	6 (14%)	13
Total	11	94	122	42	269

Table 3 Linear regression analysis of total study population with Percentage of Explained Variance of vision level, with ID level, disruptive behaviour, Down syndrome, mobility†, hearing impairment and age as covariates

Percentage of explained variance by	Vision level	ID level	Disruptive behaviour	Down Syndrome	Wheelchair dependant	Hearing impairment	Age
SRZ total	5.9**	52.1**	1.4*				
Daily living skills	6.7**	44.6**					
Communication & language	3.9**	47.3**					
Initiative & persistence	3.9**	31.8**					
Social skills	4.1**	37.7**	3.6**				
VRBQ total	14.9**	29.5**					
Eye–hand coordination/mobility	9.5**	5.6**			28.7**	2.7**	2.7**
Recognition/communicative skills	8.9**	47.5**	2.0**				
Insecure movement	6.8**				5.0**		
Anxiety & fear							
Peculiar looking habits	7.6**	3.0*					
DBC total			29.6**				
Disruptive & antisocial			19.5**	2.4*			
Self-absorbed behaviour			28.2**				
Communication disturbances	7.4**		4.7**				3.7**
Anxiety							
Social relating			15.1**	4.5**			

† Mobility as the presence or absence of wheelchair dependency.

* Significance $P < 0.05$, ** Significance $P < 0.01$.

DBC, Development Behaviour Checklist; SRZ, Social Functioning Scale; VRBQ, Vision Related Behaviour Questionnaire.

pletely. There were no significant differences in age or sex between responders and non-responders.

Gender had no significant effect on any outcome and was not taken into account in the further analysis.

The interdependence of ID levels and visual impairment is illustrated in Table 2. Regression analysis yielded a Spearman's correlation $r_s = 0.3435$, meaning that visual impairment is predicted to an average degree by the level of ID.

Mean scores and standard deviations of all total and sub-scales of the SRZ, VRBQ and DBC were calculated (data not shown). The differences in mean scores between those with normal vision and those who were (socially) blind were 1.6 standard deviation (SD) for SRZ total scores, and 1.8 SD for VRBQ total scores, both significant at $P = 0.000$, showing that visual impairment lowers the SRZ and VRBQ total scores.

The results of the regression analysis of the total study population are presented in Table 3 and shown graphically in Fig. 1.

Intellectual disability decreases strongly the adaptive behaviour as measured with the SRZ. A large effect was found on the VRBQ total and recognition/communicative scales and a moderate effect on eye–hand coordination/insecure movement.

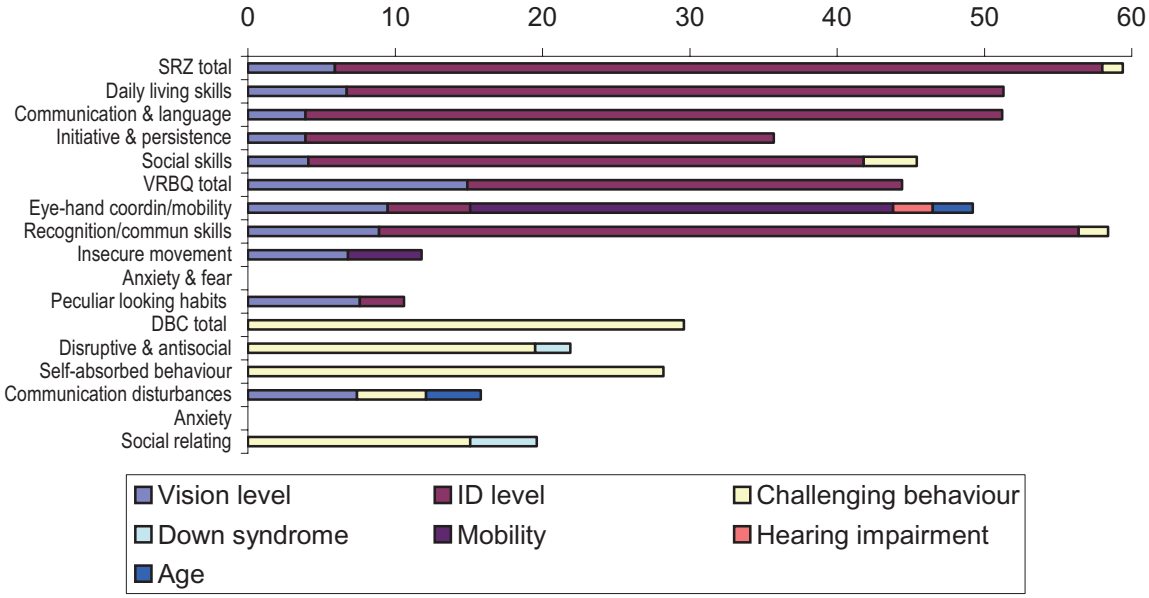

Figure 1 Graphical representation of linear regression analysis indicating the relative contribution of covariates. DBC, Development Behaviour Checklist; ID, intellectual disability; SRZ, Social Functioning Scale; VRBQ, Vision Related Behaviour Questionnaire.

The SRZ total scores show moderate and significant negative correlations with visual function as well as strong correlations with severity of ID, indicating that adaptive behaviour decreases with increasing intellectual and visual impairment. Similar correlations were found for all SRZ sub-scale scores. The VRBQ sub-scale scores show smaller, but significant correlations with both visual function and severity of ID. This means that vision-related behaviour, like eye–hand coordination/ mobility, and recognition/ communicative skills and secure movement become more difficult, whereas peculiar looking habits increase with increasing visual impairment and more severe ID.

The diagnosis of disruptive behaviour shows strong effects on DBC scores as could be expected, and is related to a small decrease of social skills on the SRZ. Visual impairment does not have relevant effects on the behavioural pathology as measured with the DBC.

People with Down syndrome scored lower on disruptive/antisocial behaviour and better on social relating scales of the DBC.

Hearing impairment and age only had small effects.

It appears that generally, ID has larger behavioural effects than visual impairment. However, there are distinct effects of visual impairment, whereas some sub-scales are influenced by visual impairment only.

The interdependence of ID level and visual impairment made it necessary to determine the behavioural effects of visual impairment for each ID level separately. Results of the regression analysis per ID group with both vision level and the diagnosis of disruptive behaviour as variables are shown in Table 4.

The group with mild ID was excluded because of its small size ($n = 11$), resulting in non-significant effects. Significant effects of visual impairment were found in all other ID level groups, with the largest number of effects in the largest groups (moderate and severe ID) and only on one item in the group with profound ID.

In the group with moderate ID ($n = 92$) all SRZ scores show large PEV, indicating less adaptive behaviour with lower vision. The VRBQ total score and the sub-scale score of recognition/ communicative skills were influenced negatively by lower vision whereas peculiar looking habits

Table 4 Regression analysis per ID group with Percentage of Explained Variance and the unstanderdised B of vision level with disruptive behaviour as covariate

	Moderate *n* = 94				**Severe *n* = 122**				**Profound *n* = 42**			
Covariate, unstandardised B	Vision level		Disruptive behaviour		Vision level		Disruptive behaviour		Vision level		Disruptive behaviour	
SRZ total	22.3**	−12.253			13.3**	−5.252					23.3**	+2.702
Daily living skills	12.3**	−4.737			14.4**	−2.820					16.6*	+1.411
Communication & language	12.2**	−3.193			8.5**	−1.593					12.3*	+1.048
Initiative & persistence	12.2**	−2.055										
Social skills	17.0**	−1.735										
VRBQ total	23.8**	−7.967			12.2**	−4.622						
Eye–hand coordination/mobility	7.5**	−1.362			15.2**	−2.081						
Recognition/communicative skills	16.1**	−2.479			20.4**	−2.112						
Insecure movement												
Anxiety & fear							5.6*	−1.580				
Peculiar looking habits	7.0*	−1.016			6.3*	−0.817						
DBC total			16.8**	+24.400	10.5*	−7.560	27.4**	+22.439				
Disruptive & antisocial			23.6**	+9.881	3.4*	−1.493	24.2**	+6.535			14.2*	+4.886
Self-absorbed behaviour			11.2**	+7.375			22.6**	+9.087				
Communication disturbances					19.3**	−1.542					18.3*	+2.786
Anxiety					5.1*	−0.636						
Social relating			17.1**	+3.354	8.1**	−0.987						

* Significance $P < 0.05$, ** Significance $P < 0.01$.

DBC, Development Behaviour Checklist; SRZ, Social Functioning Scale; VRBQ, Vision Related Behaviour Questionnaire.

increased. Lower visual acuity does not show relevant effects on DBC total and sub scores as opposed to a diagnosis of disruptive behaviour.

In the group with severe ID ($n = 122$) a similar overall pattern is visible for SRZ and VRBQ scores as in the group with moderate ID; however, the effects of the visual function are smaller. Again the DBC scores are influenced by a diagnosis of disruptive behaviour, but not by low vision.

In the group with profound ID ($n = 42$) no effect of vision level could be shown on any scale. The diagnosis of disruptive behaviour increased the SRZ total score and sub-scale scores daily living skills and communication and language and the DBC scale scores for disruptive behaviour (not surprising) and communication disturbances.

Discussion

This first cross-sectional study, investigating whether visual impairment leads to extra disability for adults with ID, shows that indeed this is the case. It is true that independent living skills, communication and social skills are primarily determined by the severity of ID. However, visual impairment has an additional influence (Fig. 1). The presence of disruptive behaviour increased the DBC scores strongly, as could be expected. In subgroups with moderate ID in accordance with our first hypothesis visual impairment leads to a large decrease of independent living skills (daily living skills, communication and language, initiative and persistence, social skills). Our second and third hypothesis that communication would become more difficult and that insecure movement would increase with lower vision could also be confirmed. Contrary to our fourth hypothesis, visual impairment is not related to more self-absorbed behaviour and in the subgroup with severe ID lower vision is even associated with less anxiety. Our fifth hypothesis that disruptive and antisocial behaviour would decrease with lower vision was not confirmed. The presence of disruptive behaviour was the most important factor for all DBC outcomes.

In the group with profound ID the above effects were not shown. The group size ($n = 42$) played a role, but another explanation can be that this is the group of people with the most limited daily living skills, therefore the need help with almost everything in daily life. As the burden of visual impairment is dependent of the requirements of the environment it may be that for people with profound ID low vision is not perceived as a problem, because always carers offer help.

We only included people who had not previously been diagnosed with low vision. This may have influenced our outcomes negatively, because maybe there are differences in behaviour between the group with early-diagnosed visual impairment and our research population that led to early diagnosis of visual impairment.

Most findings are basically in concordance with published effects of visual impairment and blindness in the general population, both in children and in ageing people, as has been elucidated in the Introduction. Only the findings of more depression, lethargy and anxiety, observed in persons with age-related visual impairment in the general population (Keller *et al.* 1999; Heine & Browning 2002; Warnecke 2003) could not be confirmed for the adult population with ID. This might be partially explained by the fact, that in the studied population, the newly diagnosed visual impairments may have existed since childhood.

A factor that may have influenced our outcomes was our selection of participants with a possibly increased risk of visual impairment, with a questionnaire for caregivers on observable behaviour that supposedly indicates low vision. In fact, to increase effectiveness of large-scale screening of clients with ID, all Dutch low vision centres use such questionnaires. None of these questionnaires has been validated, and indeed, 60% of the participants (162/269) had no visual impairment. Nevertheless, in spite of a selection of the study group towards behaviour suspect for low vision, significant differences between groups with and without visual impairment have been demonstrated. We conclude that assessment of a completely unselected population might have resulted in even more significant outcomes.

The present study was a cross-sectional investigation of an adult group with a mix of ages, of severities of ID, and of congenital, childhood and age-related visual impairments, giving first ideas on extra disability as a result of visual impairment. We could not pass a judgement on people with a mild

ID. Diagnosed and undiagnosed co-morbidities may have influenced the outcomes: the presence or absence of disruptive behaviour appeared influence the outcomes of the DBC much more than low vision does. Down syndrome, hearing impairment and age did not make much difference.

As long as 10 years ago, the special interest group 'Health Issues' of the IASSID has developed consensus guidelines for the active detection and diagnosis of visual and hearing impairment (Evenhuis & Nagtzaam 1997/1998). As far as the size of the risk is concerned, this guideline is now sufficiently evidence-based (Splunder *et al.* 2006). It has led to the organisation of large-scale screening in the Netherlands, but nevertheless, around 40% of both visual impairment and blindness remain unidentified (Splunder *et al.* 2006). The findings of this study explain to some extent why this is the case. People with visual impairment do not show more acting out behaviour and are not more anxious than others, so in the perspective of caregivers, they do not cause problems and appear at ease, whereas the fact that they need more help in ADL may not be a problem to professional caregivers. This explains why for the management of service providers, active detection and rehabilitation of visual impairment have a lower priority than the management of motor impairment, epilepsy, autism or disruptive behaviour.

Controlled prospective studies in children and in older people would produce more valid insight into the effects of visual impairment. Nevertheless, this study has provided a first scientific basis for the expectation that in groups especially with mild and moderate ID timely detection and treatment or rehabilitation of visual impairment and blindness may have a positive influence on daily living skills, language development, communication skills, initiative and persistence, social skills and insecure movement. In this way, it supports evidence for the existing IASSID consensus guideline, stressing the importance of the implementation of its recommendations.

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