Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study

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Abstract

Purpose To obtain the first representative and valid population-based prevalence figures on visual impairment and blindness in adults with intellectual disabilities (ID) and to identify risk groups.

Methods Study design: Cross-sectional survey. An age-Down's syndrome-stratified random sample of 1598 persons from a base population of 9012 adult users of ID services with mild to profound intellectual disabilities was screened. Participants underwent protocolled on-site screening of visual functions. Results were related to degree of ID, occurrence of Down's syndrome (DS) and age. Main outcome measure: Prevalences of visual impairment and blindness in the study population and in subgroups and weighted prevalences in the total Dutch population using ID services.

Results Prevalences of visual impairment ranged from 2.2% (95% confidence interval (CI), 0.5–6.4) in young adults with mild ID and no Down's syndrome to 66.7% (95% CI, 41.0–86.7) in older adults with profound ID and Down's syndrome; prevalences of blindness ranged from 0.7% (95% CI, 0.1–4.1) to 38.9% (95% CI, 28.1–50.3). Weighted prevalences of visual impairment and blindness in the total Dutch population of adult users of intellectual disability services are 13.8% (95% CI, 9.3–18.4) and 5.0% (95% CI, 3.8–6.2), respectively. Prior to this study, visual impairment or blindness had remained undiagnosed in 106/261 (40.6%) persons.

Conclusions As compared to published figures for the general Dutch population aged 55 years and over (visual impairment 1.4%, blindness 0.5%), prevalences of visual impairment and blindness are higher in all

subgroups with intellectual disabilities, including the young and mildly handicapped group. The diagnosis is too often missed. All persons with severe or profound intellectual disabilities, and all older adults with Down's syndrome, should be considered visually impaired until proved otherwise.

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Introduction

In the last decades, the awareness has grown that people with intellectual disabilities (ID) may have a higher risk of visual impairment.¹ However, it is still not known whether the whole ID-population, including young people with mild ID, by far the largest subgroup, has a higher risk of visual impairment, or whether this risk is limited to specific subgroups. Early investigations either covered small or selected adult groups or were collected from (incomplete) registrations.^{2–4} In more recent studies, assessing larger adult populations,^{5–10} samples were still selected and never large enough for statistical evaluation of subgroups. Epidemiological research of visual impairment in children with ID is scarce.¹¹ As a result, until now, no valid figures are available to serve as a basis for national health policies and the provision of specific low-vision services. This first population-based large-scale epidemiological study of visual and hearing impairment, covering 1598 adult users of intellectual disability services, both residential

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and daycare, was recently completed. The results of our investigation of ocular pathology in the study population have recently been published.¹²

The purpose of this article is to report the results of the screening of visual function, in order to answer the following questions:

- i What are the prevalences of visual impairment and blindness in adults with ID?
- ii How are these prevalences related to age, the presence of Down's syndrome and severity of ID?
- iii What is the result of generalisation of the study results to the total adult population with ID in the Netherlands?

Patients and methods

Population

The sampling and inclusion procedures have previously been described in detail.^{12,13} A random sample of 2100 clients was drawn from a representative base population of 9012 clients of Dutch intellectual disability services, both residential and day care. The small subgroup with Down's syndrome aged 50 years and over was oversampled in order to get valid results, whereas for logistical reasons the very large subgroup of persons younger than 50 years with ID due to other causes than Down's syndrome was undersampled. Institutional review board approval and informed consent were obtained for every participant. As a result of privacy considerations, the informed consent procedure was locally organised by the ID services in all cases, and supported by the research team. Through contact persons, the legal representatives were approached for written informed consent. Consent could be given for both file assessment and screening, or for file assessment alone. Clients who were able to communicate verbally, were informed by staff or family members according to their comprehensive capabilities and asked for their written or spoken consent.

Methods

After checking the medical records for cause and severity of ID (criteria of the American Association on Mental Retardation¹⁴) and ophthalmological history, protocolised assessment of visual functioning was performed on-site in one session. In all, 45 min were available for each complete screening.¹⁵ Sampling and assessment were performed between September 1998 and January 2002. Visual impairment and blindness were diagnosed according to WHO-criteria (visual impairment: visual acuity <0.30 , but not <0.05 and/or visual fields $<30^\circ$ around central fixation point;

blindness: visual acuity <0.05 and/or visual fields $<10^\circ$). Both presenting and best-corrected visual acuity were assessed; best-corrected visual acuity was used in the analyses. In practice, in this population, best-corrected visual acuity implied with new correction, if necessary and accepted by the patient, and otherwise presenting visual acuity. Reliability of visual acuity measurement was increased by the use of more than one assessment method, specially trained investigators and measurement of the inter-rater reliability. With every participant, preferably two of the following visual acuity tests were used: tests based on recognition (Snellen's chart,¹⁶ Burghardt's children's chart, Stycar single characters and matching¹⁷) and tests based on pattern resolution (Cardiff Acuity Cards¹⁸ and Teller Acuity Cards¹⁹). Acuity measurements based on recognition and pattern resolution are not exactly comparable.²⁰ However, as it turned out, the number of participants requiring pattern resolution tests was very small in the group with mild and moderate ID, whereas the number that could be assessed with recognition acuity tests was very small in the group with severe and profound ID. Therefore all outcomes were expressed in Snellen equivalents.²¹

Inter-rater reliability: the inter-rater reliability of the three examiners was tested with 30 participants each. No deviations were found to indicate that the classification of visual impairment should be adjusted.

Refraction was determined with the Nikon Retinomax K-plus Autorefractometer (Nikon Instruments Inc., Melville, New York, USA), or by retinoscopy. Since cycloplegic eyedrops had a strong adverse effect on the cooperation in a pilot group of 20 participants, these were removed from the protocol. To compensate for this, the testing rooms were made as dark as possible, in order to relax accommodation. Assessment of the visual fields was performed with the Stycar graded balls confrontational method.²²

Analyses

All data were stored in Access 97 (Microsoft Corporation, Redmond, USA) and analysed with SPSS version 10.0 (SPSS Inc., Chicago, IL, USA). The independent relationships between visual impairment or blindness, on the one hand, and Down's syndrome, degree of ID and age 50+ years, on the other hand, were evaluated by means of multiple logistic regression analysis. A multiple imputation technique,²³ using all relevant information, was applied to compensate for participants not included in the analysis.

The prevalence of visual impairment and blindness found could not be directly extrapolated to the whole adult population with ID in the Netherlands, because the

sample we assessed was stratified. It could, however, be assumed that the composition of the base population of 9012 adults was a reliable reflection of the total population of Dutch service users.^{24,25} Therefore a weighted prevalence was computed from the figures found in the $2 \times 2 \times 2$ cells: age 50–/50+, Down's syndrome –/+ , institutionalised/community care (direct standardisation).

Results

Population

Details on consent and participation have been published elsewhere.¹³ No consent was obtained for 634 clients and the consent procedure was stopped because of unacceptable delays in a very large community-based organisation: this accounted for 362 lost cases. Consent was obtained from 1598 clients, of whom 1539 actually took part in the visual screening. The composition of this population is shown in Table 1. There were 862 males (56.0%); age range was 20.2–88.7 years (mean age 45.7 years). As a result of the final under-representation of clients from community-based services, a majority of participants ($1133/1598 = 70.9\%$) were institutionalised, leading to an overrepresentation of more severe degrees of ID (Table 1).

Prevalence and severity of visual impairment and blindness

Reproducible and complete determination of visual function (visual acuity and visual field testing) was possible in 1358/1539 cases (88.2%). Among the 181 'dropouts' no over- or under-representation of the risk factors (age 50+, Down's syndrome, severe ID) was found. Visual impairment was diagnosed found in

183/1358 (13.5%; 95% confidence interval (CI), 11.7–15.4), blindness in 78/1358 (5.7%; 95% CI, 4.6–7.1). Multiple imputation²³ yielded higher prevalences for the total study population of 1598 participants for both visual impairment (16.8%; 95% CI, 8.4–25.2) and blindness (5.8%; 95% CI, 4.2–7.4). Visual problems had not been recognised prior to the present study in 106/261 (40.6%) persons: visual impairment not in 78/183 (42.6%) and blindness not in 28/78 persons (35.9%).

Relationship of visual impairment to age above 50 years, Down's syndrome and degree of ID

Tables 2 and 3 present the prevalences of visual impairment and blindness in the different subgroups. Prevalences of visual impairment increased from 2.2% in young persons with mild ID due to other causes than Down's syndrome to 66.7% in people aged 50 years and older, with Down's syndrome and profound intellectual disabilities. Blindness was most prevalent in people under 50 years with profound ID due to other causes than Down's syndrome. Table 4 presents the outcome of multiple logistic regression with visual impairment, including blindness, as dependent variable. A significant interaction was shown between Down's syndrome and age ($P < 0.0005$), which is also obvious in Table 2. Therefore stratified analysis was applied to the group with and the group without Down's syndrome (Table 4). Prevalence of visual impairment had a strong linear relationship with degree of intellectual disability in the group without Down's syndrome, whereas the association with advancing age was less obvious. In contrast, in the group with Down's syndrome, visual impairment had a stronger relationship with advancing age and a less obvious relationship with the degree of intellectual disability.

Table 1 Composition of the studied population ($N = 1539$)

Age	Down's syndrome absent	%	Down's syndrome present	%	Total	%
<i>Subjects <50</i>						
Mild ID (IQ 55–70)	146	9.4	23	1.5	169	11.0
Moderate ID (IQ 35–55)	258	16.8	141	9.2	399	25.9
Severe ID (IQ 25–35)	145	9.4	55	3.6	200	13.0
Profound ID (IQ <25)	106	6.9	18	1.2	124	8.1
Unknown	55	3.6	14	0.9	69	1.5
Total	710	46.1	251	16.3	961	62.4
<i>Subjects ≥50</i>						
Mild ID (IQ 55–70)	79	5.1	7	0.5	86	5.6
Moderate ID (IQ 35–55)	172	11.2	70	4.5	242	15.7
Severe ID (IQ 25–35)	82	5.3	44	2.9	126	8.2
Profound ID (IQ <25)	43	2.8	25	1.6	68	4.4
Unknown	44	2.8	12	0.8	56	3.6
Total	420	27.3	158	10.3	578	37.6

ID: intellectual disability; IQ: intelligence quotient.

Table 2 Prevalence (%) of visual impairment (WHO) by age, level of ID and Down's syndrome $\pm$ (N = 1358)

Age	Down's syndrome absent (N = 623)	95% CI	Down's syndrome present (N = 227)	95% CI
<i>Subjects <50</i>				
Mild ID	2.2	0.5–6.4	4.8	0.1–23.8
Moderate ID	3.9	1.8–7.3	6.2	2.7–11.8
Severe ID	19.4	12.8–27.4	22.9	12.0–37.3
Profound ID	28.8	19.2–40.0	28.6	8.4–58.1
Unknown	1.9	0.1–10.1	14.3	1.8–42.8
Total	9.6	7.4–12.2	11.5	7.6–16.3
	(N = 373)		(N = 135)	
<i>Subjects $\geq$50</i>				
Mild ID	8.3	3.1–17.3	20.0	0.5–74.6
Moderate ID	10.8	6.4–16.8	25.0	15.0–37.4
Severe ID	22.7	13.8–33.8	36.1	20.8–53.8
Profound ID	39.3	21.5–59.4	66.7	41.0–86.7
Unknown ID	2.4	0.1–12.9	25.0	5.5–57.2
Total	14.2	10.6–17.9	33.3	25.5–42.0

ID: intellectual disability; 95% CI: 95% confidence interval.

Table 3 Prevalence (%) of blindness (WHO) by age, level of ID and Down's Syndrome $\pm$ (N = 1358)

Age	Down's syndrome absent (N = 623)	95% CI	Down's syndrome present (N = 227)	95% CI
<i>Subjects <50</i>				
Mild ID	0.7	0.1–4.1	0.0	0.0–16.0
Moderate ID	2.2	0.7–5.0	0.0	0.0–2.8
Severe ID	4.0	1.3–9.2	4.2	0.5–14.3
Profound ID	38.9	28.1–50.3	28.6	8.4–58.1
Unknown	5.7	11.8–15.7	0.0	0–23.1
Total	7.2	5.3–9.5	2.6	0.9–5.7
	(N = 373)		(N = 135)	
<i>Subjects $\geq$50</i>				
Mild ID	2.8	3.4–9.7	0.0	0.0–52.2
Moderate ID	2.5	0.7–6.4	3.1	0.3–10.8
Severe ID	6.7	2.2–14.9	13.9	4.7–29.5
Profound ID	17.9	6.1–36.9	16.7	3.6–41.4
Unknown	2.4	0.1–12.9	0.0	0.0–26.4
Total	4.6	0.3–7.2	7.4	3.6–13.2

ID: intellectual disability; 95% CI: 95% confidence interval.

Generalisation of the results to the total Dutch population with ID

Computation of the weighted prevalences resulted in population prevalences of 13.8%. (95% CI, 9.3–18.4) for visual impairment and 5.0% (95% CI, 3.8–6.2) for blindness (Table 5). For the total population of around 75 000–87 000 adult ID service users in the

Table 4 Summary of multiple logistic regression model with visual impairment, including blindness (WHO), as the dependent variable

Parameter	Odds ratio	95% confidence interval	P-value
<i>Down's syndrome absent</i>			
Degree of ID: mild	—	—	—
Degree of ID: moderate	1.57	0.80–3.10	0.227
Degree of ID: severe	5.58	2.87–10.85	<0.0005
Degree of ID: profound	32.10	15.77–65.36	<0.0005
Age 50 + (years)	1.60	1.07–2.38	0.010
<i>Down's syndrome present</i>			
Degree of ID: mild	—	—	—
Degree of ID: moderate	1.51	0.33–6.98	0.600
Degree of ID: severe	5.52	1.18–25.86	0.030
Degree of ID: profound	23.55	4.40–126.10	<0.0005
Age 50 + (years)	4.08	2.28–7.29	<0.0005

ID: Intellectual disability.

Netherlands,^{24,25} this would signify that between 14 000 and 16 000 adults with ID are visually impaired or blind.

Discussion

This is the first population-based epidemiological study of visual impairment and blindness in a population with the full spectrum of ID. It covered a random sample of adult users of Dutch intellectual disability services, large enough to obtain valid population prevalences and allow valid identification of specific risk groups. The prevalence of visual impairment, diagnosed according to WHO-criteria, varied from 2.2% in the least affected subgroup (young adults with mild ID through other causes than Down's syndrome) up to 66.7% in the most affected subgroup (participants aged 50 years or older, with Down's syndrome and profound ID). The prevalence of blindness varied between 0.7% (young adults with mild ID through other causes than Down's syndrome) and 38.9% (young adults with profound ID through other causes than Down's syndrome). In 40.6% of the cases with visual impairment or blindness, the diagnosis had not been made prior to this study.

Severe or profound ID considerably increased the risk of visual impairment and blindness. In fact, adults with severe or profound ID may be considered visually impaired until proved otherwise. The same pertains to older adults with Down's syndrome. In people aged 50 years and older, Down's syndrome was the strongest risk factor. As a result of over- and under-sampling, incomplete inclusion and loss to participation, prevalences found in the total study population (16.8% for visual impairment and 5.8% for blindness) our study

Table 5 Extrapolation of current results to base population (N=9012)

Base population	9012	N/9012 (%)	Visual impairment per group ^a	Extrapolation to base population	Total prevalence (%)	Blindness per group ^a (%)	Extrapolation to base population	Total prevalence (%)
<i>Down's syndrome—</i>	7399	82.1						
Institutionalized	4074	45.2						
Age < 50	3042	33.8	15.3%	0.338 × 15.3	5.17	8.8	0.338 × 8.8	2.97
Age ≥ 50	1032	11.5	20.0%	0.115 × 20.0	2.30	6.0	0.115 × 6.0	0.69
Community care	3325	36.9						
Age < 50 (years)	2364	26.2	7.4%	0.262 × 7.4	1.94	2.1	0.262 × 2.1	0.55
Age ≥ 50 (years)	961	10.7	10.0%	0.107 × 10.0	1.07	2.2	0.107 × 2.2	0.24
<i>Down's syndrome +</i>	1613	17.9						
Institutionalized	772	8.6						
Age < 50 (years)	594	6.6	18.1%	0.066 × 18.1	1.19	4.4	0.066 × 4.4	0.29
Age ≥ 50 (years)	178	2.0	36.0%	0.020 × 36.0	0.72	9.4	0.020 × 9.4	0.19
Community care	841	9.3						
Age < 50 (years)	643	7.1	9.5%	0.071 × 9.5	0.67	0.0	0.071 × 0.0	0.00
Age ≥ 50 (years)	198	2.2	34.7%	0.022 × 34.7	0.76	3.7	0.022 × 3.7	0.08
					13.82			5.01
					<9.3–18.4> ^b			<3.8–6.2> ^b

^aPrevalence calculated after imputation.

^b95% confidence interval.

population was skewed towards older age and Down's syndrome. Therefore the found prevalences are not directly representative for the total population with ID. Nevertheless, the study population and its subgroups were large enough to apply computation of weighted prevalences, compensating for any bias in the prevalence estimate due to sampling, nonparticipation or noncooperation. Weighting our subgroup figures with the relative frequencies in the whole population of adult ID service users, resulted in population prevalences of 13.8% for visual impairment and 5.0% for blindness, with satisfyingly narrow intervals.

Another point is, that the studied population consisted of users of ID services and did not include unregistered people with ID. A possible bias might have been the fact that our study population is selected from service users. We think the bias due to this lack of nonservice users is of limited effect. In the Netherlands, almost every person registered as intellectually disabled is a user of some kind of intellectual disability service. Only a small minority is living at home, not using any service. These are primarily persons with mild or borderline ID, in which we might expect that prevalences of visual impairment are much lower.

Although we did not find any significant over-representation of any of the investigated risk factors among those who did not cooperate sufficiently with the tests, any over-representation might have lead to an underestimation of the prevelances.

In order to reliably test as many participants as possible, we used methods based on both recognition and pattern resolution. Kushner *et al*²⁶ concluded that

pattern resolution tests might underestimate a specified level of visual impairment. This could mean that in the group tested this way, there were more participants with visual impairment than we found, which would make figures even more impressive.

Other authors studying visual impairment in the United Kingdom and the Netherlands, have also looked at differences between subgroups. Published studies are based on selected and smaller samples, hampering the application of good statistical evaluation and comparison with the general population. McCulloch *et al*²⁷ assessed 63 institutionalised adults with ID. Their findings ranged from no visual impairment in people with mild ID up to almost 45% in the group with profound ID. Woodhouse *et al*⁹ assessed 154 adults with ID living in the community. They used a different classification for degree of ID and found significant differences in the prevalence of visual impairment between mild and more severe ID. Evenhuis *et al*¹⁰ assessed 672 institutionalised adults, using the same definitions as the present study, and found prevalence rates for visual impairment, including blindness, ranging from 4% (mild to moderate ID through other causes than Down's syndrome, age under 50 years) up to 78% (severe to profound ID, Down's syndrome, age over 50 years). Although an increased risk of visual impairment, at least for subgroups with more severe ID and Down's syndrome, was already suggested by these pioneering studies, their outcomes could not be generalised to the population with ID.

The most recent data on visual impairment and blindness according to WHO criteria in the general

population in the Netherlands, were obtained from the ongoing Rotterdam Study. This population-based epidemiological study focusses on age-related conditions in adults aged 55 years and older.²⁸ Visual impairment was found in 96/6775 participants (1.4%), blindness in 32/6775 (0.5%). These figures are comparable with studies in the United States and Australia, although slightly different criteria were used.^{29,30} The present study results show that for young adults with mild ID and no Down's syndrome, the least affected subgroup, the risk of visual impairment is already higher than that in the general Dutch population above the age of 55 years, whereas the risk of blindness in this younger group is comparable to the risk in the general ageing population.

Because the risk of visual impairment is increased in all adult subgroups with ID, including those younger than 50 years, one may assume that part of the diagnosed visual impairment and blindness was congenital or acquired in early childhood. Prevalence of visual impairment in children in the general American population was recently published by Mervis *et al.*¹¹ They used data from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) and found an overall prevalence of 10.7 (95% CI, 9.9–11.5) per 10 000 children. Intellectual disability was found to be the most common coexisting disability (58%), with a considerably higher risk in more severe ID. Age-related visual loss may be superimposed upon such congenital and earlier acquired impairments. Therefore, specific epidemiological research on visual impairment in children with ID, also evaluating implementation of routine early identification programmes in this group, is urgently needed. The International Association on the Scientific Studies in Intellectual Disabilities (IASSID) has stressed this point in an international consensus statement.²¹

The high prevalence of unidentified visual impairment and blindness in Dutch adults with ID, however, notwithstanding the Dutch consensus on active detection of visual impairment in persons with ID,²¹ subsequent skills courses in specific diagnostic methods and large-scale screening programmes by district visual advisory centres, underscores the need of active screening in the adult group also.

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