The Finnish Register of Visual Impairment

Annual Statistics 2023

Finnish Federation of the Visually Impaired

Finnish Institute for Health and Welfare

Sisällysluettelo

What is the Finnish Register of Visual Impairment?

The purpose of the Finnish Register of Visual Impairment is to study the incidence of visual impairment in Finland. The Register serves as a basis for preventive measures and treatment of visual impairment, as well as for the planning of rehabilitation and other special services for persons with visual impairment. In addition, the Register provides research material on ophthalmological diseases and visual impairment, and aims to promote and support research in the field.

The Register is maintained by the Finnish Federation of the Visually Impaired and operates under the auspices of the National Institute for Health and Welfare (THL). The Register was established by the National Board of Health in 1983. Its operation is regulated by the Act (552/2019) on the Secondary Use of Social and Health Data. Health care authorities, institutions, and personnel are required, under the above-mentioned Act, to forward to the Register information on persons with visual impairment as specified in the related Decree.

Notification of Visual Impairment

Notification must be made by a specialist in ophthalmology or by a hospital's ophthalmological unit. A notification must be submitted if the patient's corrected visual acuity is permanently less than 0.3 in the better eye, or if the person must, for some other reason, be considered comparable to a person with a permanent visual impairment as described above.

Data in the Register

A notification form is used to collect the personal data of persons with visual impairment and to record information on the nature (diagnoses), severity (visual acuity and visual field), and etiology of the impairment, as well as on multiple impairments and the patient's visual abilities in relation to reading and mobility. When records are updated, the Central Population Register provides information on the individual's mother tongue, marital status, and, where applicable, date of death. The cause of death is reported by the Central Statistical Office.

All information compiled in the Finnish Register of Visual Impairment is confidential. Information concerning an individual with a visual impairment is not released to any third party without the approval of the National Institute for Health and Welfare.

Maintenance of the Register

A central goal of the Register is to compile as comprehensive a database as possible on visual impairment to serve the needs of researchers and other interested parties. Special statistics are drawn up based on the records in the Register. Key statistics illustrating the

profile of visual impairment are published in the statistical section of the Register's annual report.

Promotion of Research on Visual Impairment

The Register promotes research on visual impairment by providing special statistics based on its records and by offering bibliographical references to researchers and students. In addition, the Register surveys study topics related to visual impairment, maintains contacts with researchers in the field, participates in joint research projects and international activities, and organizes research seminars.

Administration and Contact Information

The Register operates on the premises of the Finnish Federation of the Visually Impaired in Helsinki.

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Annual Statistics 2023

The Register has been collecting information about visually impaired individuals for 40 years (since January 1, 1983). It is estimated that there are approximately 55,000 visually impaired people in Finland (population 5.5 million). The Register contains data on 64,884 visually impaired persons, of whom 16,965 were alive as of December 31, 2023. Each year, 1,800–2,000 new registrations are recorded. New entries in recent years have not significantly altered the overall profile of visual impairment established through the Register. It can be assumed that the Register contains a representative sample of individuals who have accessed ophthalmological health care services in Finland since 1983.

The Register is not exhaustive; it is based on a sample. Therefore, the main distributions describing the registered individuals are presented in the following tables as relative frequencies (percentage distributions).

Table 1. Gender

Registered visual impairment in Finland
in 2023 (total and new registerations)

	Total %	New 2023 %
Female	60,0	62,0
Male	40,0	38,0
Total	100,0	100.0
N	**16 965**	**1175**

Table 2. Age groups

Registered visual impairment in Finland
in 2023 (total and new registerations)

Age	**Total %**	**New 2023 %**
0–14	2,2	1,6
15–24	3,7	0,7
25–34	5,	0,9
35–44	5,2	1,1
45–54	5,9	1,4
55–64	8,4	3,4
65–74	11,8	10,6
75–84	20,5	32,2
85 +	37,1	48,1
Total	**100.0**	**100.0**

Age	Total %	New 2023 %
N	**16 965**	**1 175**
0–17	3,1	1,9
18–39	10,5	1,7
40–64	16,9	5,5
65–84	32,4	42,8
85 +	37,1	48,1
Mean age	**79**	**84**

Figure 1. Age groups

New registrants in Finland in 2023 (N = 1 175)

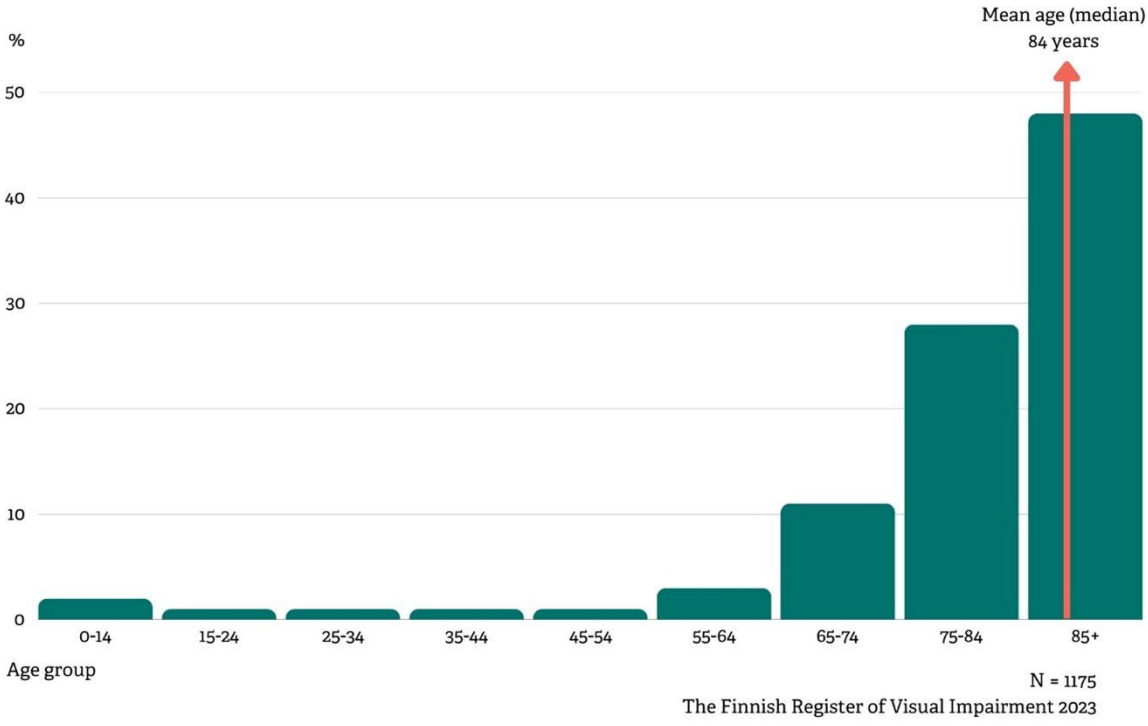


Figure 2. Age and gender

All registrants in Finland in 2023 (N=16 695)

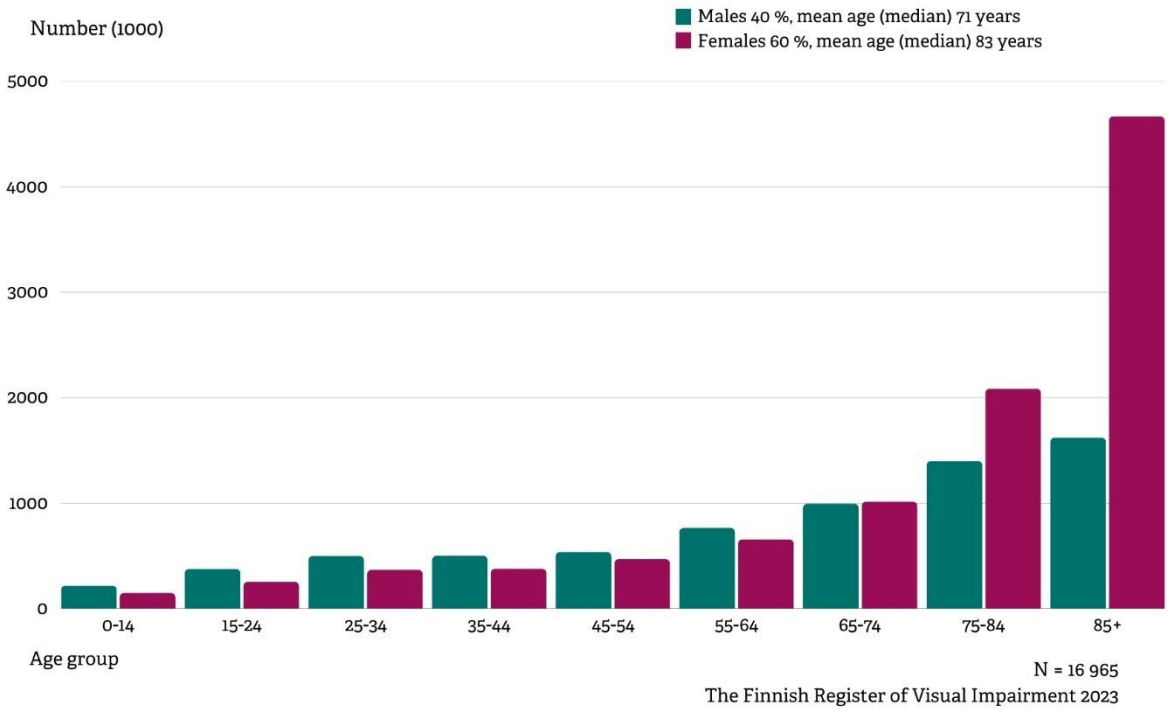


Figure 3. New registerations by age group, 1983–2023, %

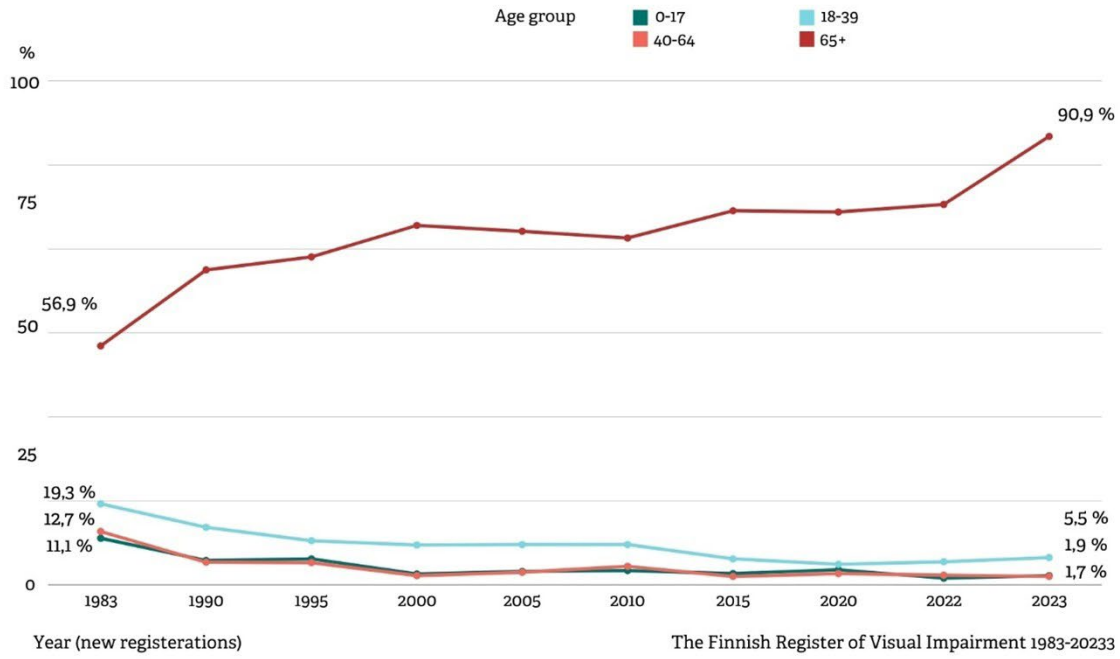


Figure 3 shows the percentage distribution of newly registered individuals with visual impairments by age group from 1983 to 2023. In the early years of the register's operation, a large number of children, young people, and working-age adults were registered. Since then, the proportions of these groups have steadily decreased, while the proportion of elderly individuals has increased. The proportion of individuals aged 65 and older has continuously grown.

The proportion of 0–17-year-olds among new registrations has decreased from 11,1 % in 1983 to less than two percent. The proportion of 18–39-year-olds among new registrations has steadily declined throughout the observation period. In 1983, the age group accounted for 12,7 %. It reached its lowest point (1,4 %) in 2018 and has remained between two and three percent since then. The proportion of 40–64-year-olds among new registrations has decreased steadily from 19,3 % in 1983. In 2000, the proportion first dropped below 10 %. Since then, it has fluctuated between 5 % and 13 %. The proportion of individuals aged 65 and older has increased significantly from 56,9 % in 1983. In the 2000 s, this proportion has remained around 80 %, and in the last five years, it has surpassed 90 %.

Diagnosis of Visual Impairment

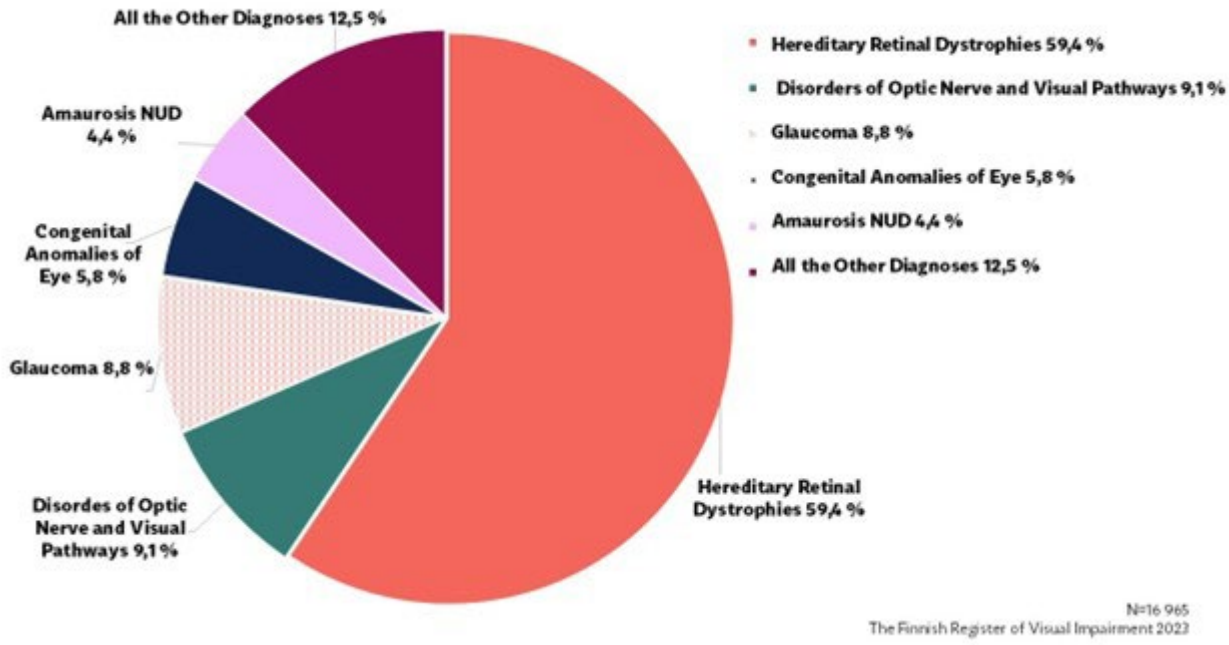
The primary diagnosis recorded is the one most recently impairing the vision of the better eye. Up to three additional diagnoses can also be reported. Diagnosis distributions are based on primary diagnoses, of which there are 357 in the Register. Diagnoses are classified according to a Finnish adaptation of the ICD-9 classification for ophthalmological diseases, which is more detailed than ICD-10 for eye diseases.

If a hereditary disease underlying the visual impairment is reported or can be inferred, it is also recorded. A total of 85 different hereditary diseases are registered, and hereditary etiology is noted for 2,873 individuals (17 % of registrants), although for many the specific disease remains unspecified.

The most common hereditary conditions include Retinitis Pigmentosa, Retinoschisis, Usher Syndrome, Stargardt Disease, Leber’s diseases, Gyrate Atrophy, Aniridia, Choroideremia, Achromatopsia, Cone-Rod Dystrophy, and Spielmeyer Syndrome.
Distribution of Diagnoses

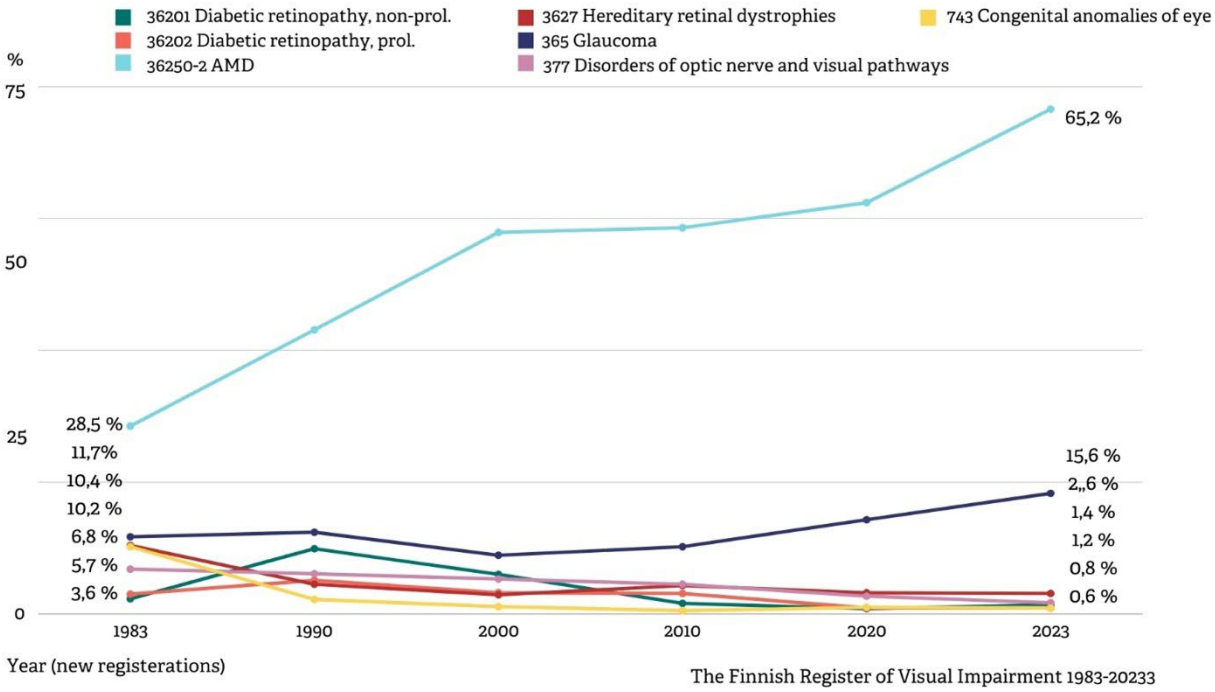
The etiology of visual impairment is strongly age-related. Table 5 and Figure 7 show all registered individuals by primary diagnosis. In unclear cases, codes for unspecified visual loss or blindness are used.

Figure 4A. All registerations by primary diagnoses, 2023



The leading cause of visual impairment in Finland is age-related macular degeneration (AMD), accounting for 35,9 % of all diagnoses, followed by hereditary retinal dystrophies (10,6 %), and diseases of the visual pathways (9,1 %). Other notable causes include glaucoma (8,8 %), congenital developmental disorders (5,8 %), unspecified visual loss (4,4 %), and diabetic retinopathy (3,1 %). These six categories represent 75 % of all diagnoses. Among new registrations in 2023, AMD was dominant (65,2 %), with glaucoma (15,6 %) and diseases of the visual pathways (1,4 %) following. There has been a declining trend in hereditary retinal dystrophies, diabetic retinopathy, diseases of the visual pathways, and congenital developmental disorders.

Figure 4B. New registerations by primary diagnoses, 1983–2023, %



Trends from 1983–2023 show:

- A continuous rise in AMD cases from 28, 5 % to 65 %.
- Fluctuations in glaucoma, with shares above 10 % in recent years.
- A decline in diseases of the visual pathways, non-proliferative diabetic retinopathy, and hereditary retinal dystrophies.
- A sharp decline in congenital developmental disorders among new cases.

Diagnoses by Age Group

Among children and adolescents (0–17 years), the most common causes are diseases of the visual pathways (27,5 %) and congenital developmental disorders (24,8 %), followed by unspecified visual loss and hereditary retinal dystrophies.

Among working-age adults (18–64 years), hereditary retinal dystrophies (20,9 %) and diseases of the visual pathways (20,3 %) are most common, with congenital disorders and diabetic retinopathy also significant. Among new cases, pathological myopia and unspecified visual loss are increasing.

Among the elderly (65+ years), AMD is overwhelmingly the leading cause (51,4 %), followed by glaucoma (11,3 %) and diseases of the visual pathways (6,6 %). In 2023, AMD accounted for 71,3 % of new elderly registrations.

Table 3. Principal diagnoses of Visual Impairment by age groups

Registered visual impairment in Finland in 2023, total distribution and new registerations

A. AGE GROUP 0–17 YEARS

	Total %	New 2023 %
Disorders of optic nerve and visual pathways	27,5	13,6
- cortical blindness	13,3	0
Congenital anomalies of eye	24,8	27,3
Hereditary retinal dystrophies	7,2	18,2
Amblyopia NUD	10,8	18,2
Albinism	5,7	4,5
Nystagmus	0,2	0,0
ROP, retinopathy of prematurity	1,7	0
Disorders of refraction and accomodation	3,0	0
Strabismus otc.	3,0	0
Other diagnoses	5,5	4,5
0 - 17 years total (total N = 528, new cases N = 22)	**100.0**	**100.0**

B. AGE GROUP 18–64 YEARS

	Total %	New 2023 %
Hereditary retinal dystrophies	20,9	23,5
Disorders of optic nerve and visual pathways	20,3	7,1
- optic atrophy	10,8	7,1
Congenital anomalies of eye	14,7	2,4
Amblyopia NUD	5,5	10,6
Diabetic retinopathy	2,3	4,7
Visual field defectes, other vis. disturbances	3,5	0
ROP, retinopathy of prematurity	11,8	0,0
Glaucoma	2,6	5,9
High myopia (myopia maligna)	3,4	20,0
Disorders of choroid	2,7	0
Nystagmus (Irregular eye movement)	1,9	1,2
Amaurosis NUD	2,3	1,2
Disorders of cornea	0,8	4,7
Other diagnoses	7,3	18,7
18–64 years total (total N = 4 650, new cases N = 85)	**100.0**	**100.0**

C. AGE GROUP 65+ YEARS

	Total %	New 2023 %
AMD, Age-related macular degeneration	51,4	71,3
Glaucoma	11,3	15,5
Hereditary retinal dystrophies	2,4	1,6
Disorders of optic nerve and visual pathways	6,6	0,7
Diabetic retinopathy	1,7	0,4
Amblyopia NUD	2,4	1,3
Disorders of cornea	1,5	0,3
Retinal hole	4,4	0,8
High myopia (myopia maligna)	0,5	0
Retinal vascular occlusion	1,6	0,6
Other diagnoses	16,2	7,5
65+ years total (total N = 11 787, new cases N = 1 068)	**100.0**	**100.0**

Table 4. Age at the onset of Visual Impairment

Registered visual impairment in Finland in 2023
(total and new registerations)

	Total %	New 2023 %
0	10,2	0,6
1 – 17	5,1	0,2
18 – 39	7,0	0,9
40 – 64	10,3	15,1
65+	28,8	27,9
Unknown/not reported	38,5	55,2
Total	**100.0**	**100.0**
N	**16 965**	**1 175**

Table 5. Categories of Visual Impairment by WHO´s definition

Registered visual impairment in Finland in 2023 (N = 16 965)

	Visual acuity	Visual field (Ø)	Total %	New 2023 %
1 Moderate low vision	less than 0.3 → ≥ 0.1, near vision <0.3		60,7	79,9
2 Severe low vision	less than 0.1 → ≥ 0.05		10,3	8,9
low vision, not specif			0,3	0,3
Low vision total	less than 0.3 → ≥ 0.05		**74,1**	**89,0**
3 Profound low vision	less than 0.05 → ≥ 0.02	less than 20°	9,8	5,4
4 Near-total blindness	less than 0.02 → 1/∞	less than 10°	8,4	3,4
5 Total blindness	0		2,2	0,5

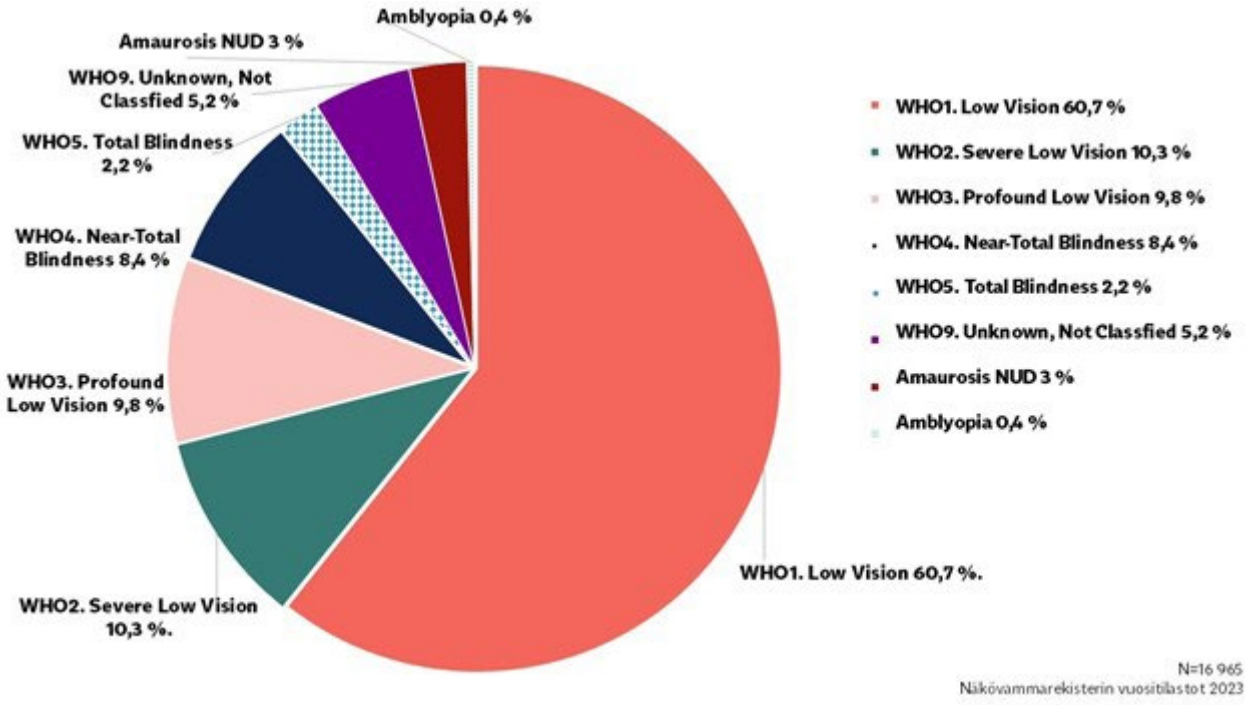
	Visual acuity	Visual field (Ø)	Total %	New 2023 %
blindness not specified			0,4	0,0
Blindness total	less than 0.05	less than 20°	**20,7**	**9,4**
9 Unknown (Other)			5,3	5,2
Total			**100.0**	**100.0**
N			**16 965**	**1 175**

WHO's Classification of Visual Impairment Severity

The register follows the WHO's recommended classification for the severity of visual impairment, which is supplemented by categories for "Unspecified Visual Impairment" (amblyopia) for the visually impaired and "Unspecified Blindness" (amaurosis) for the blind.

Among registrants, 74 % are visually impaired, 21 % are blind, and around 5 % fall under the "severity not specified" category.

Figure 5. Categories of Visual Impairment by WHO´s Definition with Finnish Modification 2023, %



For the visually impaired, 60,7 % are categorized as WHO category 1 (mild visual impairment), and 10,3 % are in category 2 (moderate visual impairment). The unspecified impairment category (amblyopia) accounts for 3 %. Among those classified as blind, 9,8 % fall under WHO category 3 (severely visually impaired), and 8,4 % under category 4 (nearly blind). Only 2,2 % are totally blind (WHO category 5), and less than half a percent are categorized as "unspecified blindness."

Figure 6. Categories of Visual Impairment by WHO´s Definition with Finnish Modification, 1983–2023, %

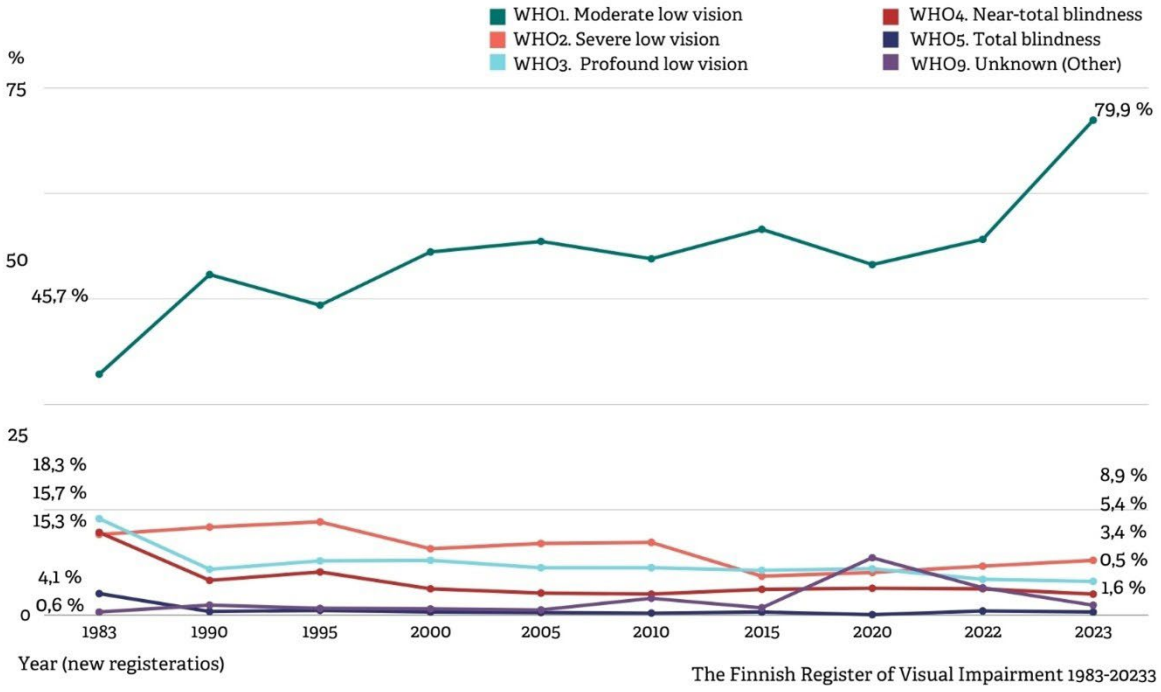


Figure 6 shows that the percentage of visually impaired individuals (WHO categories 1 and 2) has significantly increased. In 1983, only 61 % were visually impaired, but by the late 1990 s, this figure rose to 80 %. The percentage in WHO category 1 has steadily increased from 45,7 % in 1983 to over 70 % in 2005. The percentage in category 2 has fluctuated between 6,0 % and 15,5 %, showing a declining trend.

Conversely, the percentage of blind individuals (WHO categories 3, 4, 5) has decreased. In 1983, 38 % of new registrants were blind, but this fell to 20 % in the 1990 s and below 15 % in the early 2000 s. Recently, this percentage has hovered around 14 %.

The percentage of individuals in WHO category 3 (severely visually impaired) has sharply decreased, from 18,3 % in 1983 to 8,7 % in 1990. It has since fluctuated between 5,4 % and 12,3 %. The trend for nearly blind individuals (WHO category 4) follows a similar pattern to category 3, decreasing from 15,7 % in 1983 to around 5 % in the 2020 s. The percentage

of totally blind individuals (WHO category 5) has steadily decreased, from 4,1 % in 1983 to between 0,1 % and 1,3 % over the past 20 years.

The "other" or "severity not specified" categories have remained relatively small until a significant increase in 2015. In 2023, this group made up 1,6 % of new registrations.

Table 6. Native Language

Registered visual impairment in Finland in 2023
(total and new registerations)

	Total %	New 2023 %
Finnish	90,0	88,3
Swedish	5,8	7,9
Russian	0,7	0,9
Arabic	0,1	0,1
German	0,1	0,3
Other, unknown/not reported	2,6	2,5
Total	**100.0**	**100.0**
N	**16 965**	**1 175**

The distribution of native languages among the registered individuals is shown in Table 7. 90 % of the registered individuals speak Finnish, and 5,8 % speak Swedish. After these two dominant language groups, the largest group is Russian speakers, who make up 0,7 % of the registered individuals. There are 5 individuals who speak Sami (Northern Sami), which is one of the domestic languages.

There are 64 languages spoken by registered visually impaired individuals in Finland. Following the aforementioned three domestic languages and Russian, the next most spoken languages are Arabic (93), Estonian (57), Somali (51), English (37), Kurdish (35), Albanian (18), Farsi (18), Turkish (18), Vietnamese (12), Ukrainian (12), German (11), Spanish (10), Bosnian (9), Bulgarian (9), Chinese (9), Romanian (7), French (7), Urdu (6), Swahili (6), Hungarian (5), Northern Sami (5), Thai (5), and Italian (5). Additionally, there are 38 other languages spoken by 1–4 registered individuals. The "Other/Unknown" category includes 91 individuals.

The native language distribution of newly registered individuals in 2023 follows the same pattern as that of all registered individuals. The proportion of Swedish speakers (7,4 %) is slightly higher than their share in the overall register. The proportion of individuals who speak languages other than Finnish, Swedish, Sami, or Russian remains the same. New languages added to the list in the table include Norwegian, Nepali, Azeri, Wolof, Turkmen, Tigrinya, Serbian, Kongo, and Armenian.

Statistics on Social Status 2018–2020

Table 7. Family Status in Age Groups

Registered visually impaired 15–64 years old persons % in Finland according to National Cencus in 2018%

Age group	0–14 y	15–24 y	25–44 y	45–64 y	65 y+	Total
A	95.8	59.2	15.5	3.6	0.0	7.0
B	-	7.9	33.5	47.8	34.2	34.0
C	-	27.8	43.1	44.2	61.2	54.1
D	4.2	5.0	7.9	4.5	4.5	4.8
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

A Child in a family
B Spouse, partner, mother/father
C Not belonging to families
D Unknown, institutionalised population

Table 8. Main Type on Activity

Registered visually impaired 15–64-year-old persons in Finland according to National Cencus in 2018 compaired with the whole population

	Registered vis.impaired persons %	Whole population %
Fully employed	24.8	72 (employed, all)
Partially employed	15.6	
Unemployed	3.2	7
Students	3.3	21 (pensioners, students, other)
Pensioners	50.0	
Other or unknown	1.9	
Total	**100.0**	**100.0**
N (the registered visually impaired persons in this study)	**4 747**	

Figure 7. Level on Education

Registered visually impaired 15–64-year-old persons in Finland according to National Cencus in 2018 compaired with the whole population

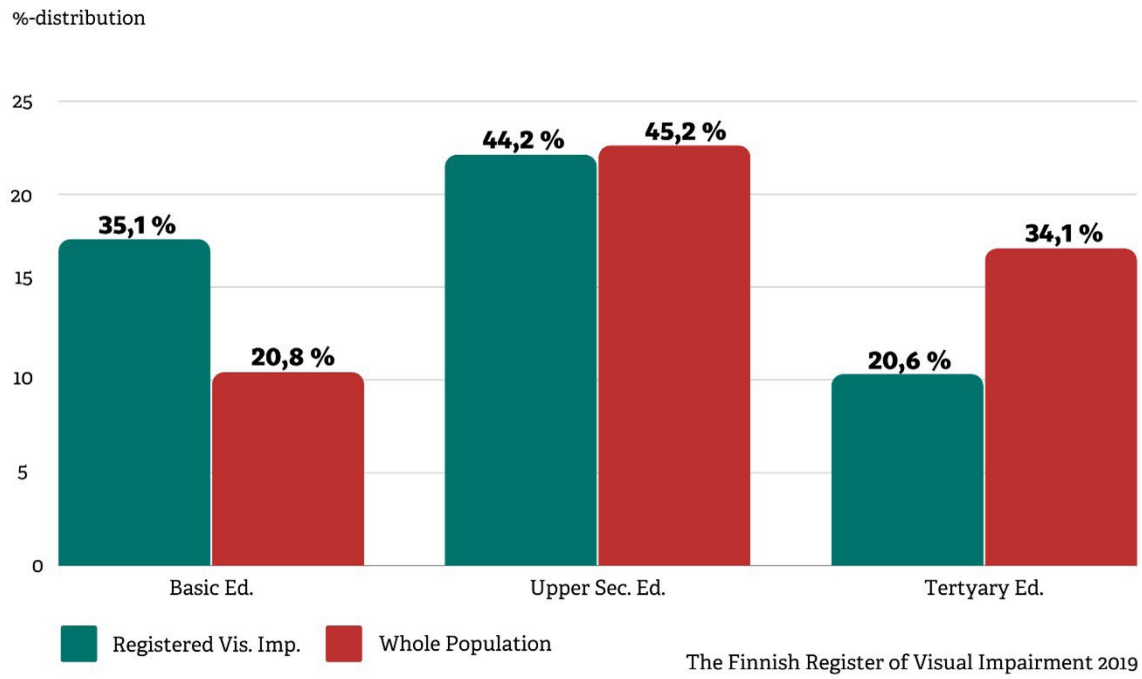


Table 9. Level of Education

Registered visually impaired 15–64 years old persons in Finland according to National Census data from 2018 compared to the whole population

Level of education (1)	**The duration of education**	**Regist.vis.imp. % 2018**	**Whole population % 2018**
Basic education	up to 9 years	35.1	20.8
Upper secondary educ.	10–12 years	44.2	45.2
Tertyary education	13 years +	20.6	34.1
Total		**100.0**	100.0
N (the registered visually impaired persons in this study)		**4 747**	

(1) The Finnish Standard Classification of Education

Household Size

Household size refers to the number of people living permanently in the household on December 31st, 2020 (N=15,677). Among visually impaired individuals, 50 % live alone, 35 % live in two-person households, 7% in three-person households, 4 % in four-person households, and 4 % in households with five or more residents. Notably, hundreds of visually impaired individuals live in households with 5–9 people. In Finland, 78 % of all households are small, consisting of one or two people (2022), a trend that is also observed among the visually impaired.

Number of Children Under 25

As of December 31st, 2020, the number of children under 25 in households with visually impaired individuals (N=10,649) is as follows:

- No children under 25: 5,589 individuals (52 %)
- One child: 6 %
- Two children: 6 %
- Three children: 3 %
- 4–11 children: 2 %

Type of Housing

As of December 31st, 2020, the housing types of visually impaired individuals (N=17,910) are as follows:

- Apartment buildings: 42 % (7,538 individuals)
- Detached houses, semi-detached houses, and residential buildings similar to small houses (e.g., permanently inhabited holiday homes): 31 % (5,517 individuals)
- Row houses and terraced houses: 13 % (2,296 individuals)
- Other buildings or unknown housing type: 14 % (2,450 individuals)

Housing Tenure

The housing tenure of visually impaired individuals (N=15,677) as of December 31, 2020 is as follows:

- Owns the house: 32 % (4,997 individuals)
- Owns apartment shares: 36 % (5,513 individuals)
- ARA rental housing: 11 % (1,733 individuals)
- Interest-subsidized rental housing: 3 % (439 individuals)
- Other rental housing: 16 % (2,552 individuals)
- Right of occupancy housing: 1 % (227 individuals)
- Other/unknown: 1 % (216 individuals)

Income of Visually Impaired Individuals

The median income of visually impaired individuals (N=17,910) as of December 31, 2020 was €16,796 annually, approximately €1,400 per month. This includes taxable income, such as wages, business income, and other taxable state income (e.g., pension, social security benefits). According to Statistics Finland, the median income of a Finnish wage earner was €3,314 per month, or €39,768 annually (2021). Visually impaired individuals earn significantly less than the average.

Family Status of Visually Impaired Individuals

The family status classification for visually impaired individuals (N=17,831) as of December 31, 2020 shows the following:

- Not belonging to a family: 54 %
- Head of the household: 17 %
- Spouse: 7 %
- Child: 7 %
- Head of household or spouse in a cohabiting family: 4 %
- Unknown: 5 %

Of the total Finnish population, 27 % do not belong to a family, and visually impaired individuals are more often outside family structures compared to the general population.