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The population features of visually impaired children aged between 0 and 14 in Hungary

Kiss, Erika – Pajor, Emese

This paper focuses on the crucial features of the healthcare and pedagogical services provided for 1,432 visually impaired (VI) children aged 0–14 who participated in an exploratory research project conducted between 2014 and 2019. In order to explore the population characteristics of visually impaired children in Hungary, the paper relies on two major data sources: the census data of the Hungarian Central Statistical Office between 1990-2016, and the examination documents of the Corps of Pedagogical Services of Visually Impaired Children from 2009 to 2013. The following data were analysed: the ratio of blind and low vision children in the various phases of special and majority educational institutions; the frequency of premature birth among blind and low vision children in relation to gestational weeks; the frequency of ophthalmologist diagnoses among groups of VI children; the frequency of ophthalmologist diagnoses among groups of VI children; associated disabilities of VI children. The results suggest that the population of visually impaired children is under transformation: visually impaired groups based on the classical interpretation of visual performance are being replaced by new groups governed by needs.

Keywords: visual impaired children, age-related prevalence of VI children in Hungary, ophthalmologist diagnoses, chronic diseases among blind and low vision children, associated disabilities of VI children

Introduction

In 2018, vision impairment (VI) was classified by the International Classification of Diseases 11 (WHO, 2020) into two groups: distance and near presenting vision impairment. Distance vision impairment comprises four sub-groups, such as (1) Mild – presenting visual acuity worse than 6/12; (2) Moderate – presenting visual acuity worse than 6/18; (3) Severe – presenting visual acuity worse than 6/60; (4) Blindness – presenting visual acuity worse than 3/60. Presenting near visual acuity worse than N6 or M.08 with existing correction. Near vision impairment: Near visual acuity worse than N6 or M.08 at 40cm. (WHO, 2021) "A person's experience of vision impairment varies depending upon many different factors. This includes for example, the availability of prevention and treatment interventions, access to vision rehabilitation (including assistive products such as glasses or white canes), and whether the person experiences problems with inaccessible buildings,

transport and information." (WHO, 2020). At present at least 2.2 billion people around the world have vision impairment, out of whom at least one billion have a vision impairment that could have been prevented or is yet to be addressed (WHO, 2020). Globally, among adults the leading causes of vision impairment are uncorrected refractive errors, cataracts, age-related macular degeneration, glaucoma, diabetic retinopathy, corneal opacity, and trachoma. Little information exists about childhood vision impairment. According to the statistics of WHO, among children the causes of vision impairment vary considerably across countries. For example, in low-income countries congenital cataracts is a leading cause, whereas in middle-income countries retinopathy of prematurity is more prevalent (WHO, 2020). Globally, ninety million children under the age of fifteen years are visually impaired. Among them, two million children are blind, thirty million children experience moderate to severe vision loss. Fifty-eight million children have mild vision impairment (IAPB, 2021).

Objective

In Hungary, surveys about the visually impaired children's population have been conducted based upon medical (Németh et al., 2005; Nagy et al., 2017), *pedagogical-psychological* (Prónay, 2004; Paraszkay, 2007), and *sociological* (KSH, 2014, 2018) approaches. While medical and pedagogical-psychological studies mostly aim to describe the quality features of the population (age, type of illness, the severity of the visual impairment, type of pedagogical and medical care, educational, pedagogical, examining and developing methods specific of the visual impairment specific), sociological studies focus on the number of cases or the frequency of occurrence. Certain aspects of the population features appear as fragmented or incomplete: the qualitative features of visually impaired children are very often linked to an educational institute, a group of visually impaired children, or illnesses (Paraszkay, 2007; Krähling, 2017).

The age group prevalence of visually impaired children has not been identified in Hungary, which hinders comparison with international data. As the authors of this study are practising special education teachers while one is a former employee of the national special pedagogical diagnostical centre (the Centre of Pedagogical Services – Board for Special Education, Early Intervention of Visually Impaired Children, in short: the Centre of Pedagogical Services), we learned that the Centre has a documentary collection regarding the qualitative and quantitative features of the tested visually impaired children and their parents. The documents in question have been collected for several decades and contain otherwise incompletely accessible, but — from the pedagogical, medical, and social care perspective — relevant and very sensitive data for a very high number of children. Processing the data for the more than a thousand cases contained in this collection has not been carried out before this study.

Theme

The focus of the examination are the visually impaired children, who from the pedagogical perspective qualify as children with *sensory special educational needs* or visually impaired if they have an impairment of visual functioning even after treatment and/or standard refractive correction, and have a visual acuity of 0–0.33 (0–33%), or a visual field of less than ten degrees from the point of fixation in either direction, that is twenty degrees altogether [OH, 2020]. Whether or not a child has visual impairment in the pedagogical sense *(Sensory Special Educational Needs)* is determined by the Centre of Pedagogical Services that provides pedagogical diagnosis and rehabilitation services for children.

From a (special) pedagogical perspective, not all children with an ophthalmologic diagnosis are visually impaired, but all children who are categorized as visually impaired from a pedagogical perspective have an ophthalmologic or neurological diagnosis stating that their visuality is modified to the extent that an optical aid may not prevent them from experiencing a considerable limitation in gaining knowledge and having proper orientation (Kiss & Pajor, 2020, p. 296). From a pedagogical-educational perspective, visually impaired children may be categorized as blind children, children with *severe visual impairment*, and *children with moderate visual impairment* (OH, 2020). The category of *severe visual impairment* has become less frequently used in the pedagogical praxis (Kiss & Pajor, 2020, p. 295). Gilbert and Ellwein (2008) suggest that the occurrence of childhood visual impairment may be estimated based on the level of social and economic development and the mortality below the age of 5 (Gilbert & Ellwein, 2008). Accordingly, in countries with low income and a high mortality rate below the age of 5, the average blindness rate for 1000 children is 1.5. This rate *in developed countries is only 0.3.* Research by Philip and Dutton (2014) points out that in developing countries the rate of visually impaired children below the age of 16 is 40 children/10000 live-births, whereas *in developed countries this rate is only 10-22 children/10000 live-births* (Philip & Dutton, 2014). Based on the above, WHO estimates that all around the world there are about 1.4 million blind children, the two-third of whom live in the poorest regions of Africa and Asia. The number of children with moderate or severe visual impairment is estimated to be 18 million (Philip & Dutton, 2014). In Hungary the *2011* census (carried out by KSH) registers *all together 2591 persons as visually impaired children aged between 0 and 14,* from whom 247 children were categorized as blind and 2344 children were categorized as children with moderate visual impairment (KSH, 2001). *This is the 0.026% of the total population, and 0.18% of the population within the same age group*.

The goals of this fact-finding research are:

– Determining the quantitative features *(sample size, rate, prevalence)* of visually impaired children aged between 0 and 14 in an organizing manner on a representative sample.
– Fact-finding data-collecting and data processing of the qualitative features *(pedagogical, psychological, medical and demographic classification)* of

visually impaired children aged between 0 and 14 based on the diagnostical data of the Corps VI.

During the research we aim at answering research questions that are of exploratory nature. During this process we do not apply an examination suitable for testing a hypothesis; therefore, we pose the following research questions, which relate to the exploratory examination of the population features of visually impaired children and their parents:

1. What is the age-related prevalence of visual impairment in Hungary like compared to the international data?
2. What features may be revealed from the data of the Corps VI?

Method

The methodology of the research relies on two comprehensive quantitative analytical methods:

Method I.: filtering and analysing the data from The Hungarian Central Statistical Office [KSH 2001, 2011, 2016] referring to the visually impaired children aged between 0 and 14.

Method II.: Large sample, complex data collecting with document analysis about the demographic, medical, and pedagogical features of children with sensory special educational needs (and their parents) based on the examination documents from 2009-2013 of the Corps VI archives. The *analytical sample* contains only data of children aged between 0 and 14 in the cases of whom the medical and pedagogical diagnostic process unambiguously confirmed the fact of vision impairment (sensory SEN). The sample size of the analytical sample is 1432 persons, which means that the so called 'examination file' (on paper) of 1432 visually impaired children aged between 0 and 14 were analysed. During collecting data, we managed to collect categorical data from the anamnesis reports, medical reports, birth discharge summaries and the recapitulatory pedagogical-psychological discharge summaries; then by further analysing these data we determined the occurrence frequencies. Due to limited access to the data, only handwritten notes not including personal data that could have made identification possible were allowed to be prepared based on the paper documents. At the moment there is no clear principle or administrative/public educational protocol regulating the research on the continuously growing number of documents, stored in the various institutes dealing with the pedagogical diagnostics of the national or county pedagogical special services. Giving out and sharing these very sensitive data fall under the full responsibility of the head of the institute or the head of the educational district. Despite its large sample size, the analytical sample may not be considered representative of the whole population, because not all children who may be suspected to have visual impairment get in touch with the Corps VI. However, there is no other institute or data base that would have reliable data concerning children with *sensory special educational needs* with such a large sample size. The study discusses in detail the background of the visually impaired children who stay outside the pedagogical diagnostic system.

Results

Results I.

Based on the data tables of The Hungarian Central Statistical Office (KSH 1990, 2001) the occurrence rates of visually impaired children aged 0 and 14 were determined and summarized in table format *(Table 1)* within the whole population and in their age-group.

More accurate methodological and conceptual establishment of principles (KSH 2014, 2018) are connected to the samples of the *2011 Census and the 2016 Microcensus* (KSH 2011, 2016), therefore prevalence values were determined more emphatically in these two samples. Based on the aggregated data, the prevalence of childhood visual impairment is 0.26‰ in 2011 and 0.22‰ in 2016 in the entire population. *This means that in every ten thousand people 2.6 adult and 2.1 children are visually impaired.* The age group prevalence is 1.8‰ in 2011 and 1.5‰ in 2016, that is, *from ten thousand children of the same age group (aged between 0 and 14) 18 are visually impaired in 2011 and 15 are visually impaired in 2016.*

Table 1.
The number of disabled people, visually impaired people, and visually impaired people below the age of 14, and their rate within the entire population and within the population aged between 0 and 14. (Census data)

	Population	entire population		in the population aged bw. 0 and 14		
		disabled	VI	number	disabled	VI
Census 1990	10 374 823	368 270 *3.55%**	51 400 *0.50%**	2 130 549 *20.5%**	33 485 *1.57%*** *0.32%**	4135 *0.19%***, *0.040%**
Census 2001	10 198 315	577 006 *5.66%**	64 558 *0.63%**	1 694 936 *16.6%**	28 803 *1.70%***, *0.28%**	3065 *0.18%***, *0.030%**
Census 2011	9 937 628	490 578 *4.94%**	82 484 *0.83%**	1 447 659 *14.6%**	23 190 *1.60%***, *0.23%**	2591 *0.18%***, *0.026%**
Microcensus 2016	9 803 837	408 021 *4.16%**	69 747 *0.71%**	1 421 937 *14.5%**	22 857 *1.61%***, *0.23%**	2137 *0.15%***, *0.022%**

* rate in the entire population, ** rate in the population aged between 0 and 14

The collected data of the visually impaired population aged between 0 and 14 recorded in all four surveyed periods were further categorized into *low vision* and *blind categories (Table 2),* and we completed these categories with individual visual impairment categories that vary according to the surveys (*blind in one eye*, *deafblind).*

Table 2
Categories of visually impaired children aged between 0 and 14 based on Census data

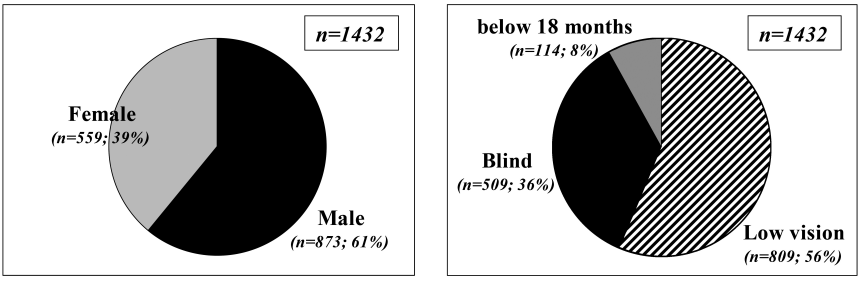
	Blind	Low vision	All VI	Blind in one eye	Deafblind
Census 1990	1020	3115	4135	635	no data
Census 2001	334	2731	3065	438	no data
Census 2011	247	2344	2591	no data	124
Microcensus 2016	335	1802	2137	no data	75

Due to the evident signs of condition for blindness, international literature (Gilbert & Ellwein, 2008) determines prevalence value only for the blind population, so using the 2011 age-group population number (1 447 659), *the age-group prevalence value for blindness is 0.17‰.* Using the 2016 data, *the age-group prevalence value for blindness is 0.23 ‰.* Thus in 2011 from 10 000 children below the age of 14 1.7 persons were found blind; in 2016 this value is 2.3 persons.

Results II.

Figures 1 and 2 show the gender ratio and the visual impairment ratio of the analytical sample of the Corps VI.

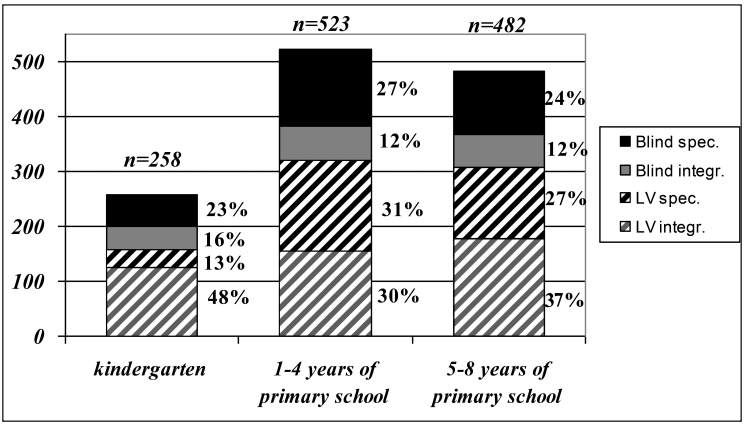
Figures 1 and 2
The composition of the analytical sample based on the gender ratio and the visual impairment categories



8 percent (114 persons) of the sample is made up of babies and toddlers below the age of 18 months who may not be categorized with certainty as blind or low vision but need early intervention due to their condition signs and/or their ophthalmologic or neurologic diagnosis.

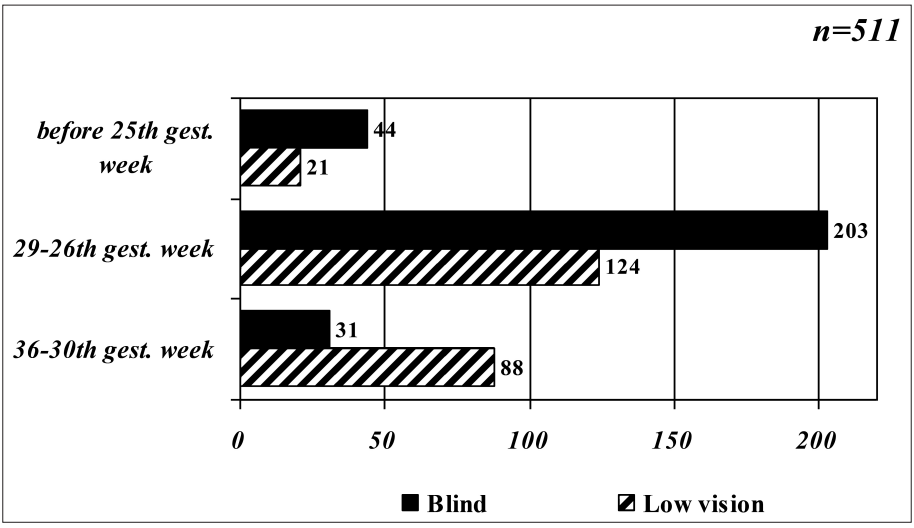
Features of institutional care: *11.8% (169 persons)* of the analytical sample *received early intervention, 18% attended kindergarten, 36.5 % attended one of the 1-4 years of primary school and 33.7% attended one of the 5-8 years of primary school* as of their last examination report. The ratio of blind and low vision children attending kindergarten and primary school is demonstrated in Figure 3, indicating within that the ratio of majority institutional care and the special pedagogical care.

Figure 3
The ratio of blind and low vision children in the various phases of special and majority educational institutions



Features of preterm birth: 35.6% of the sample (511 children) were prematurely born. This ratio is 54.6% among blind children and 28.8% among children with low vision. Figure 4 shows that pre-term babies who become visually impaired are born on the 26-29 gestational week.

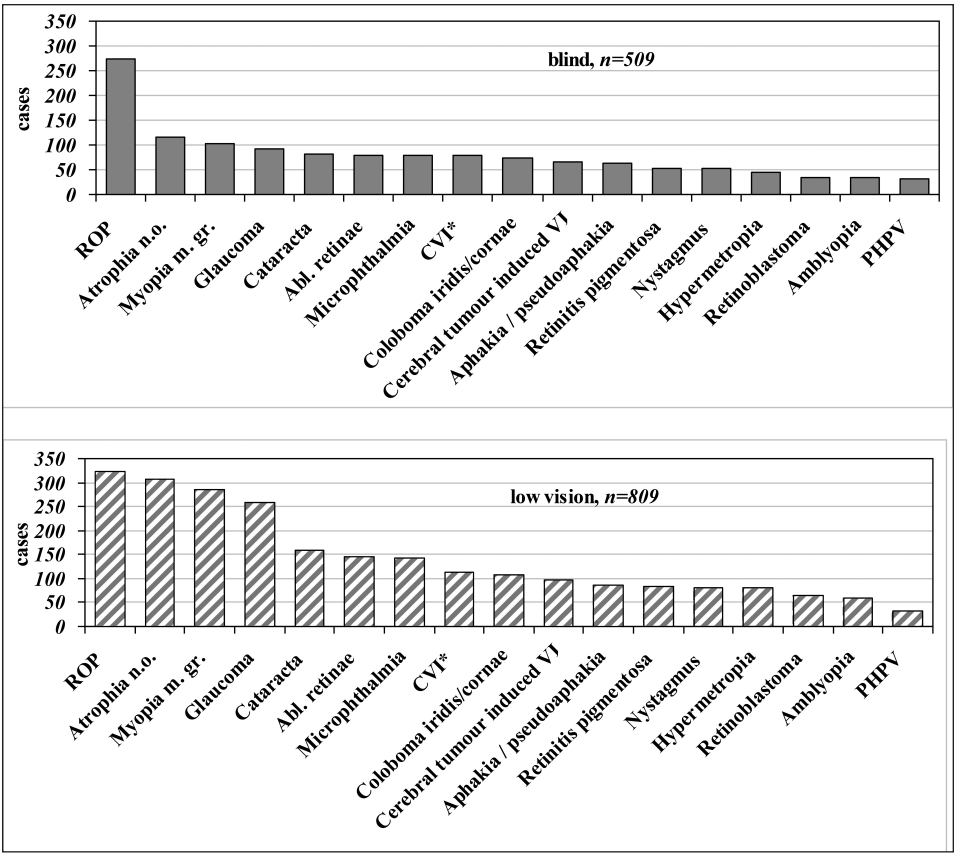
Figure 4
The frequency of premature birth among blind and low vision children in relation to gestational weeks



Features of ophthalmologist diagnoses: 932 of the 1432 children (65%) received their diagnosis before the age of 6, while 500 (35%) after the age of 6. After detailed analysis it is to be highlighted that from the perspective of the correctability and early rehabilitation it is a positive result that half of the children (50.9 % – 467 children) were properly diagnosed before the age of 1 and 18% of the children (262 children) were already diagnosed at birth. The frequency of ophthalmologist diagnoses among the groups of blind and low vision children is shown in *Figure 5*:

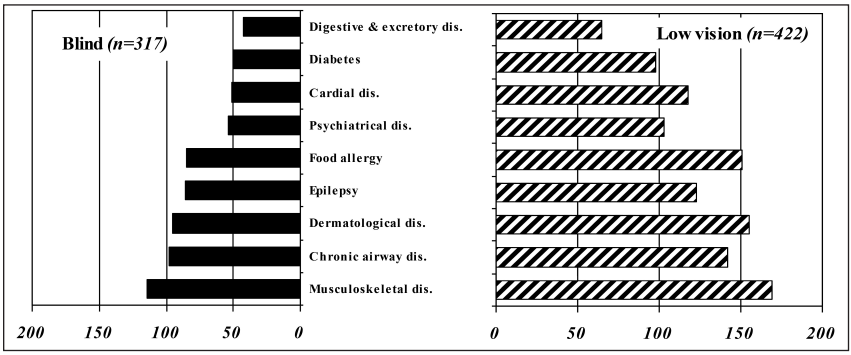
Figure 5

The frequency of ophthalmologist diagnoses in the groups of blind and low vision children (ROP, Atrophia nervi optici, Myopia majus gradis, Glaucoma, Cataracta, Ablatio retinae, Microphthalmia, CVI, Coloboma iridis/cornae, Cerebral tumour induced VI, Aphakia/pseudoaphakia, Retinitis pigmentosa, Nystagmus, Hypermetrophia, Retinoblastoma, Amblyopia, PHPV



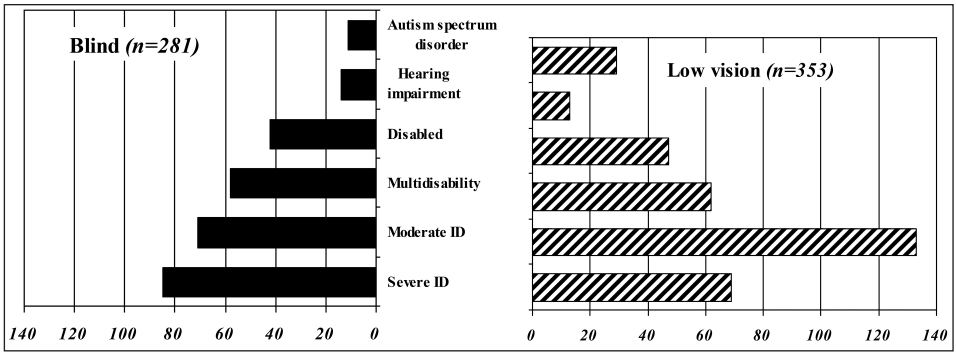
Features of chronic diseases *(Figure 6):* 62.2% of blind children and 52.2% of low vision children have chronic diseases, many of them have 2-3 diseases.

Figure 6
Frequently occurring chronic diseases among blind and low vision children (Digestive & excretory system diseases, Diabetes, Cardial diseases, Psychiatrical diseases, Food allergy, Epilepsy, Dermatological diseases, Chronic airway diseases, Musculoskeletal diseases)



Disabilities which can be revealed by special pedagogical and psychological tools and are associated with impaired vision *(Figure 7)* (autism spectrum disorder, hearing impairment, disability, multiple disabilities, moderate intellectual disability, severe intellectual disability) were identified in 634 cases, that is, 44.2% of the sample.

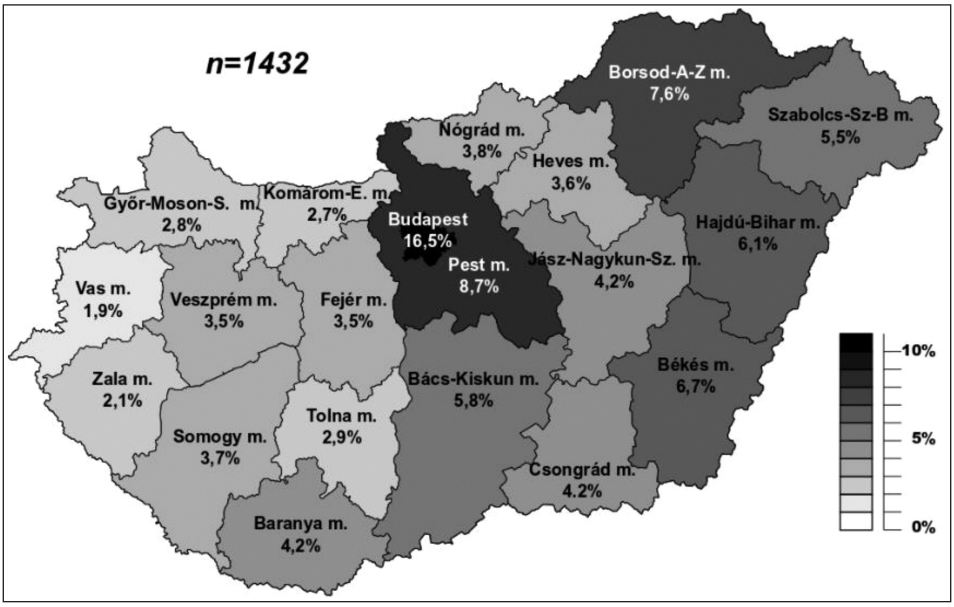
Figure 7
Associated disabilities of blind and low vision children



In both groups a separate category was created for those with *multiple disabilities*. There are 58 (20.6%) such children in the *blind group* and 62 (17.6%) in the low vision group. This category shows the ratio of children who have *severe and multiple disabilities* and receive medical and pedagogical care within the framework of special needs education, often in social and healthcare institutions.

The *demographic features* of the sample showed that the most children with visual impairment come to the pedagogical diagnostic examination from Budapest, Pest county and Borsod-Abaúj-Zemplén county. *Figure 8* shows the county distribution of the children who attended the examination according to their and their primary caregivers' registered address.

Figure 8
County distribution according to registered address



Fewer children arrived from the Transdanubian counties than from the Danube-Tisza Interfluve and Eastern Hungary. The exceptions are Baranya, Nógrád and Heves counties. Most children arrived from cities with county rights (33%), fewer came from small towns and large villages (29.6%). The ratio of those living in smaller villages was 20.9% and Budapest residents made up 16.5% of the sample.

Conclusions and implications

The following conclusions in connection with the results were received during the exploratory analyses. Based on the data of the 2011 census (considered representative) and the 2016 microcensus (both conducted by KSH) (KSH 2011, 2016) the age group prevalence of the Hungarian visually impaired children aged between 0 and 14 years does not exceed the values estimated for developed countries (Table 3). When using the data of the 2016 microcensus, we must take it into consideration that it was conducted with a sampling fraction of 10% of the population. Therefore, the data are to be regarded as highly reliable estimates, but in the case of smaller populations, such as the group of visually impaired children, the reliability may somewhat decrease. When using these data, it is important to emphasize that they are based on estimation and accordingly, the statistical power of the possible conclusion is limited.

Table 3
Age group prevalence of visually impaired children

	Philip and Dutton (2014)	**Gilbert and Ellwein (2008)**
out of 10 000 0-16 year old children	10-22 visually impaired	3 blind
	Kiss and Pajor (2020) based on 2011 census (KSH)	
out of 10 000 0-14 year old children	18 visually impaired	1.7 blind
	Kiss and Pajor (2020) based on 2016 microcensus (KSH)	
out of 10 000 0-14 year old children	15 visually impaired	2.3 blind

In the analytical sample, among both *blind and low vision* children there is a high rate of associated disabilities and chronic diseases. It can be established that the more severe the visual impairment is, the more disabilities and chronic diseases are associated with it. The rate of preterm birth among blind children is 54.6% (among low vision children this rate is only 28.8%). These results are in accord with those in neonatology, according to which *retinopathia prematurorum, bronchopulmonary dysplasia, intraventricular haemorrhage and periventricular leukomalatia* are the most frequent chronic neonatal morbidities which have a fundamental impact on the children's quality of life (Balla & Szabó, 2013, p. 1499–1503). Visually impaired children with complex handicaps or multiple disabilities need differential medical and pedagogical diagnosis, aftercare and therapeutic attitude. The actors of the medical and pedagogical care system must differentiate between the services they offer and the methodologies they apply: they must change the methods of examination and treatment, and they must apply therapies tailored to the needs of the individuals, they must incorporate alternative communications, strategies in the care system and they must ensure accessibility to the environment of the care system's facilities.

It is a priority to provide visual impairment specific training and continued professional support for the experts working in early intervention and inclusive education**.**

Steps must be taken in order to **e**nsure the broader knowledge of the characteristics of low vision especially in state administration. Awareness-raising and publicity campaigns and programmes are recommended.

It would be beneficial to work out a directive that regulates the researchability of the sensitive and crucial data of the pedagogical assistance services.

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