The Comprehensive Study of the Population Features of Visually Impaired Children Aged Between 0 and 14 and their Parents Living in Hungary

PhD thesis

Erika Kiss

Semmelweis University
Doctoral School of Mental Health Sciences

Supervisor: Tóth Pál Péter Ph.D., DSc.

Zászkaliczky Péter Ph.D.

Head of the Final Examination Committee: Túry Ferenc M.D., D.Sc.

Members of the Final Examination Committee: Feith Helga Ph.D.
Hidas Zoltán Ph.D., DSc.

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INTRODUCTION

Within the research focusing on the situation of families raising impaired children (Kálmán 1994; Bánfalvy 1996; Borbély, Jászberényi és Kedl 1998; Bass 2004, 2008; Radványi 2012; Borbély 2012; Garai és Kovács 2014; Berszán 2007, 2015; Mándoki 2018), no study about the situation and life quality of families raising visually impaired children has been published in the past few decades. Written for visually impaired children's parents, the work of outstanding importance in the field is Útmutató,¹ published in 1988 by Ferenc Pálhegyi and his colleagues, which primarily focuses on the development characteristics of blind children, and the pedagogical, developing parental tasks related to that. However, no study would inform us about the life circumstances and population features of the affected parents, and how they adapt to their children’s visual impairment. Our information about the visually impaired children’s parents mostly come from practising experts’ experience and assumptions, and in most cases the information is limited to describing a phenomenon or providing experience.

In Hungary, surveys about the visually impaired children’s population have had medical (Méhes 1962, 1982; Németh 2005; Nagy 2017), pedagogical-psychological (Valentin 2001, Prónay 2004; Paraszky 2007; Perlusz 2008; Vargáné 2011) and sociological (Bass 2008; Lakatos és Tausz 2009; KSH 2016, 2018) approaches. While the medical and pedagogical-psychological studies mostly aim at describing 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), the sociological studies focus on the number of cases, the frequency of occurrence. These data are not adequately organised: it does survey the pedagogical and developing needs of blind children as well as children with severe visual impairment and with moderate visual impairment / low vision (Paraszky 1998; Somorjai 2008; Somogyi 2008), their assessment specifics (Földiné, Gadó és Prónay 2012), and the specific features of their pedagogical and medical care ellátási rendszerük sajátosságait (Kovács 2000, Pajor 2017, Mándi és Somorjai 2017), but they exclude the study the relationship between the family system and the pedagogical, medical care system. Certain aspects of the population features appear as fragmented or incomplete: the qualitative features of visually impaired children are very often linked with an educational institute, a group of visually impaired children, or

illnesses (Jankó-Brezovay és Vargáné 2001, Paraszkay 2007, Mikola 2008, Csáktornyai 2017, Krähling 2017). The life quality features applicable in the context of visually impaired children and their parents (demographic, family structure data, household features) appear only for institutes of smaller number of children or in groups linked only to one county (Szirányi 2016, Kotroczó 2018). Furthermore, the age group prevalence of visually impaired children is not identified in Hungary, which hinders comparison with international data.

As a practising special education teacher and as a former employee of the national special pedagogical diagnostical center (the Center of Pedagogical Services – Board for Special Education, Early Intervention of Visually Impaired Children, in short: the Center of Pedagogical Services) I learned that the Center has a documentary collection about the qualitative and quantitive features of the visually impaired children and their parents, which have been collected for several decades, and it contains these otherwise incompletely accessible, but—from the pedagogical, medical and social care perspective—relevant and very sensitive data for a very high number of children. The processing of these data referring to more than a thousand cases was not carried out before this study.

**In one of the foci 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 10 degrees from the point of fixation in either direction, that is 20 degrees altogether (The Educational Authority, 2020). Whether or not a child has visual impairment in the pedagogical sense (Sensory special educational needs) is determined by the Center 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 a considerable limitation in gaining knowledge and having proper orientation (Kiss és Pajor 2020). 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 (The Educational Authority, 2020). The category of severe visual impairment has become functionally less frequently used in the pedagogical praxis (Kiss és Pajor 2020).
Gilbert és 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. 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 és Dutton (2014) point 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. 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 (Gilbert és Ellwein 2008). According to the latest data (Steinmetz et al. 2021) the situation is worse: the number of blind children under the age of 15 is estimated at 2 million and the number of children with moderate and severe visual impairment worldwide at 30 million. 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. This is the 0.026% of the total population, and 0.18% of the population within the same age group.

In the second focus of my research stands the features of parents raising impaired and visually impaired children. In the life of families, family members, thinking about and taking care of impaired children posits a permanent stress (Hornby 1992), which throws the family off balance for a longer or shorter period of time (Selignam és Darling 2007). As Mária Kopp (2001) states, the most important factors assuring the balance between person and environment and lessening the probability for the loss of control are: (1) adaptive coping strategy, conflict managing strategies (Folkman – Lazarus 1980); (2) adaptive attitudes; (3) social support, social net. The coping strategies may be categorized on the axis of adaptive – non-adaptive (Kopp és Prékopa 2011). Danis és Kalmár (2011) lists three main forms of coping abilities: forms aiming at problem-solving, emotional coping, and seeking supportive people. Coping with the fact of disability and the birth and the existence of a disabled child is not a universal phenomenon (Seligman és Darling 2007). Certain authors (Kübler-Ross 1988, Kálmán 1994) describe this coping process as one corresponding to the stages of grief processing, while others (Livneh és Antonak 1997, Livneh 2001) define it as a recurring, cyclically repetitive, spiral form. The latter theory also divides coping with difficulties into various stages, but they regularly return into one’s life. During the process characteristics of
the adaptive and non-adaptive approaches appear in a mixed form in the life of a family or a parent, and during the process a high number of moderating factors, that is, protective and risk factors (Danis és Kalmár 2011) are identifiable. In my dissertation I examine the coping factors of parents raising visually impaired children in this interpretative framework.

Several authors have pointed out that the quantitative and qualitative analyses examining the family or individual functioning of the parents raising children with disabilities mostly refer to white parents living in partnership and belonging to the middle class (Tunali és Power 2002, Davis 1993, O’Connor és Rutter 1996, Gray 2006), therefore the conclusions of these studies cannot be used for the whole of the affected parental population without limitations. Therefore, the cited research reports emphasize the importance of including parents with low soci-economic status reachable with qualitative methods and the examination of individual walks of life and parental narratives (Garai 2005, Bognár 2012).

OBJECTIVES

Based on the surveyed publications and my experience as a practicing expert, I defined the objectives of my fact-finding research as follows:

1) 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.

2) 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.

3) The exploratory examination of the coping factors applied by parents raising visually impaired children in representative parental sample (including low SES, single parents).

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

1. What data allow us to determine in a representative manner the composition and the group specifics of visually impaired children in Hungary?
2. What is the age-related prevalence of visual impairment in Hungary like compared to the international data?

3. What features may be revealed from the data of the Corps VI?

4. To what extent does the analytical sample based on the data of the Corps VI represent the group of visually impaired children and their parents?

5. What do mothers and fathers raising visually impaired children say about their own life situations?

METHODS

The methodology of the dissertation relies on three pillars, as I applied two comprehensive quantitative and a qualitative analytical method:

1. **Quantitative analytical method I.**: filtering and analyzing the data from The Hungarian Central Statistical Office (Census 1990; 2001; 2011; and Microcensus 2016) referring to the visually impaired children aged between 0 and 14.

2. **Quantitative analytical 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 analyzed. During collecting data I 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 I determined the the occurrence frequencies. Due to my limited access to the data, I could prepare handwritten notes based on the paper documents, which could not include personal data that could have made identification possible. Despite its large sample size, the analytical sample may not be considered representative of the whole population, because not all children who may be

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2 At the moment there is no clear principle or administrative/public educational protocol regulating the research on the continuously growing amount 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 head of the institute or the head of the educational district.
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; therefore, I consider the data coming from this sample as indicative from the perspective of special pedagogical and medical care system. The study discusses in detail the background of the visually impaired children who stay outside the pedagogical diagnostic system.

3. Qualitative analytical method: I made half-structured interviews with mothers (39 persons) and fathers (29 persons) raising visually impaired children. The demographic and family structure features correspond to the rates in the large sample of the Corps VI. Beside the socio-demographic data, I ask about the status of partnership, the duration of partnership, the number of children, the degree of their subjective feeling of satisfaction with their financial situation, the data concerning medical, pedagogical and institutional care, and the specifics of keeping contact with people in similar situation. I applied narrative categorical content analysis method (László és mtsai 2013) to analyze the texts of the individual interviews with the use of Webnarrcat text analytical softwer (Ehmann és mtsai 2014). When one uses analysis with NarrCat, there is a data reduction of a specific thematics: the softwer transforms determined units (sentences/parts of sentences) of the individual and group narratives into categories that later may serve as the basis for narrative psychological analysis (Ehmann és mtsai 2014). The core of the system is the narrative categorical, that is, psychothemetic modules. The four most robust of these are emotion, evaluation, agency and cognition (Ehmann és mtsai 2014: 139).

RESULTS

Results 1.: Based on the data tables of The Hungarian Central Statistical Office (Census 1990; 2001; 2011; and Microcensus 2016) I determined and summarized in table format (Table 1) the occurrence rates of visually impaired children aged 0 and 14 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-os Microcensus, 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)

<table>
<thead>
<tr>
<th>Population</th>
<th>entire population</th>
<th>in the population aged bw 0 and 14</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>disabled VI</td>
<td>number disabled VI</td>
</tr>
<tr>
<td>Census 1990</td>
<td>368 270</td>
<td>2 130 549</td>
</tr>
<tr>
<td></td>
<td>3.55%</td>
<td>20.5%</td>
</tr>
<tr>
<td></td>
<td>51 400</td>
<td>33 485</td>
</tr>
<tr>
<td></td>
<td>0.50%</td>
<td>1.57%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.32%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.19%</td>
</tr>
<tr>
<td>Census 2001</td>
<td>577 006</td>
<td>1 694 936</td>
</tr>
<tr>
<td></td>
<td>5.66%</td>
<td>16.6%</td>
</tr>
<tr>
<td></td>
<td>64 558</td>
<td>28 803</td>
</tr>
<tr>
<td></td>
<td>0.63%</td>
<td>1.70%</td>
</tr>
<tr>
<td></td>
<td>2 135 265</td>
<td>0.28%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.18%</td>
</tr>
<tr>
<td>Census 2011</td>
<td>490 578</td>
<td>1 447 659</td>
</tr>
<tr>
<td></td>
<td>4.94%</td>
<td>14.6%</td>
</tr>
<tr>
<td></td>
<td>82 484</td>
<td>23 190</td>
</tr>
<tr>
<td></td>
<td>0.83%</td>
<td>1.60%</td>
</tr>
<tr>
<td></td>
<td>1 424 144</td>
<td>0.23%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.18%</td>
</tr>
<tr>
<td>Microcensus 2016</td>
<td>408 021</td>
<td>1 421 937</td>
</tr>
<tr>
<td></td>
<td>4.16%</td>
<td>14.5%</td>
</tr>
<tr>
<td></td>
<td>69 747</td>
<td>22 857</td>
</tr>
<tr>
<td></td>
<td>0.71%</td>
<td>1.61%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.23%</td>
</tr>
</tbody>
</table>

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

I further categorized the collected data of the visually impaired population aged between 0 and 14 recorded in all four surveyed periods into low vision and blind categories (Table 2), and completed them 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

<table>
<thead>
<tr>
<th></th>
<th>Blind</th>
<th>Low vision</th>
<th>All VI</th>
<th>Blind in one eye</th>
<th>Deafblind</th>
</tr>
</thead>
<tbody>
<tr>
<td>Census 1990</td>
<td>1020</td>
<td>3115</td>
<td>4135</td>
<td>635</td>
<td>n.a.</td>
</tr>
<tr>
<td>Census 2001</td>
<td>334</td>
<td>2731</td>
<td>3065</td>
<td>438</td>
<td>n.a.</td>
</tr>
<tr>
<td>Census 2011</td>
<td>247</td>
<td>2344</td>
<td>2591</td>
<td>n.a.</td>
<td>124</td>
</tr>
<tr>
<td>Microcensus 2016</td>
<td>335</td>
<td>1802</td>
<td>2137</td>
<td>n.a.</td>
<td>75</td>
</tr>
</tbody>
</table>

Due to the evident signs of condition for blindness, international literature (Gilbert és 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 sex 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 sex 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.** Frequency of ophthalmologist diagnoses among the groups of blind and low vision children
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 various 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, or 44.2% of the sample.

In both groups I created a separate category 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 who 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.

The family features of the visually impaired children are summarized in Table 3. In most cases, the children have two parents or caregivers. Most children live with their biological parents (48.5%), but a significant number live in families where one of the parents is not the biological parent (26.5%). The rate of adopted children with impaired vision is 3.9% in the sample.

Table 3. Family structure of children with impaired vision

<table>
<thead>
<tr>
<th>FAMILY STRUCTURE</th>
<th>Blind</th>
<th>Low vision</th>
<th>Below 18 mo.</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two parents (biological)</td>
<td>206</td>
<td>292</td>
<td>63</td>
<td>561   (48.5%)</td>
</tr>
<tr>
<td>Two parents (biological + foster)</td>
<td>131</td>
<td>161</td>
<td>14</td>
<td>306   (26.5%)</td>
</tr>
<tr>
<td>Two parents (foster)</td>
<td>14</td>
<td>29</td>
<td>5</td>
<td>48    (4.2%)</td>
</tr>
<tr>
<td>Two adoptive parents</td>
<td>9</td>
<td>23</td>
<td>7</td>
<td>39    (3.4%)</td>
</tr>
<tr>
<td>One parent (biological)</td>
<td>29</td>
<td>61</td>
<td>22</td>
<td>112   (9.7%)</td>
</tr>
<tr>
<td>One parent (foster)</td>
<td>14</td>
<td>9</td>
<td>0</td>
<td>23    (1.9%)</td>
</tr>
<tr>
<td>One adoptive parent</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>6     (0.5%)</td>
</tr>
<tr>
<td>Orphanage</td>
<td>31</td>
<td>27</td>
<td>3</td>
<td>61    (5.3%)</td>
</tr>
</tbody>
</table>
58% of the parents living in relationships were married and 29% lived in cohabitation when they first registered at Corps VI. There were 141 parents (13%), who either claimed to raise their children alone as a single caregiver (some of these parents had divorced or their partner had died. Most visually impaired children had one sibling (49.75%), 17.9% of them had no siblings.

**Results III.:** in the parents’ sample I analyzed the interviews and narratives of 39 mothers (age range: 26-47; deviation: 6.57) and 29 fathers (age range: 26-49 év; deviation: 6.35). In order to encode and thematize the texts I used Webnarrcat text analysing software with the help of two independent encoding specialists. Based on the Webnarrcat score, I could separate the text parts with the highest score which contained the most frequent parental responses, *emotional and cognitive relations and factors for seeking social support*. Out of methodological considerations I listed these factors as *adaptive and non-adaptive features*. It is important to note that parents featured coping strategies, responses and relations from both categories, often at the same time. Within the adaptive and non-adaptive categories the motifs are listed in order of frequency. *Figure 9.* shows the summary of the explored coping factors of the parents.

**FATHERS’ adaptive char.:**
- reinforced support
- flexibility
- financial security
- participation in household chores
- relaxation sport
- play, humour
- staying in the present
- unique life history

**FATHERS’ non-adapt. char.:**
- exclusion
- chaos
- futurelessness
- failure
- overexertion
- lack of money
- too much responsibility

**MOTHERS’ adaptive char.:**
- family’s and friends’ support
- thinking in small steps
- communication, trust in the care system
- urban habitat
- belief in solution
- healthy sibling
- special parenthood

**MOTHERS’ non-adapt. char.:**
- fear of the future
- unrealistic expectations
- communication block
- sinfulness
- isolation
- small village
- lack of routine

*Figure 9.* Frequency of Characteristics of the Adaptive and Non-Adaptive Approaches via narrative category analysis

The narratives of the parents reveal a number of protective and risk factors: (1) it appears that social support is an important protective factor from the aspect of life quality: parents who live together and the presence of siblings, grandparents supportive friends and neighbours all
have a positive impact on the quality of life. (2) If the parents have more professional support and more information and they have more trust in experts and institutions, they can assess their situation significantly better. (3) If the child has moderate visual impairment, the parents are more often confronted with dilemmas: diagnoses show a progression of the condition, it takes longer for the children to be registered in the care system and the actors in majority education, basic children healthcare and state administration have deficient knowledge about the criteria of low vision, or none at all. (4) It considerably restricts access to the care system if the adequate institutions or services are located far from the families’ place of residence. (5) Most of the parents claimed that sooner or later they could acquire the basic information necessary to develop and take care of their children; however, they found no possibilities for receiving relief, either physical or mental, in the state-supported care system.

CONCLUSIONS

I have arrived at the following conclusions in connection with the results I received during the three exploratory analyses while I sought to find answers to my research questions:

1.) Based on the data of the 2011 census (considered representative) and the 2016 microcensus\(^3\) (both conducted by KSH) 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>
<thead>
<tr>
<th>Table 4: Age group prevalence of visually impaired children</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Philip and Dutton (2014)</strong></td>
</tr>
<tr>
<td>out of 10 000 0-16 year old children</td>
</tr>
<tr>
<td><strong>Kiss and Pajor (2020) based on 2011 census (KSH)</strong></td>
</tr>
<tr>
<td>out of 10 000 0-14 year old children</td>
</tr>
<tr>
<td><strong>Kiss and Pajor (2020) based on 2016 microcensus (KSH)(^3)</strong></td>
</tr>
<tr>
<td>out of 10 000 0-14 year old children</td>
</tr>
</tbody>
</table>

2.) 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 is the visual impairment, 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

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\(^3\) 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.
28.8%). These results are in accord with those in neonatology, according to which retinopathy 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 és Szabó 2013: 1498). 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 the accessibility of the environment of the care system’s facilities.

3.) It is of utmost importance to create for the parents concerned such mental hygiene and support services and information systems that take into account individual differences.

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

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

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

In summary, it can be established that in accord with the objectives of my exploratory research, I have succeeded in providing such current and professionally relevant information about the life situation of visually impaired children aged between 0 and 14 and their parents that may efficiently support the work of decision-makers, institutions, experts and national and local advocates, and may contribute to the development of quality services.
LIST OF OWN PUBLICATIONS

Publications related to the thesis


Other publications
