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## POPULATION FEATURES OF VISUALLY IMPAIRED CHILDREN AND THEIR PARENTS LIVING IN HUNGARY\*\*

(Received: 4 March 2021; accepted: 13 May 2021)

This exploratory research (2014–2019) was conducted among visually impaired children aged 0–14 years and their parents. The paper focuses on the crucial features of the healthcare and pedagogical services provided for visually impaired children and analyses the situation of parents raising them. In order to explore the population characteristics of visually impaired children in Hungary, we relied 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 between 2009–2013. The research included data of 1,432 visually impaired children. In order to survey the situation of these children’s parents, we conducted semi-structured, individual interviews. We investigated the retrospective narratives of 39 mothers and 29 fathers through narrative categorical content analysis and performed the situation analysis of the parents, using the model of game theory between humans and environment, whilst we also took into consideration the Hungarian and international methodological context for researching parents raising visually impaired children. 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. What the parents of such children seem to lack the most in the Hungarian care system are the opportunities for physical and mental relief. It would be vital to improve the situation of the parents concerned by more flexible special education and social services that could support both single parents and couples to overcome their difficulties.

**Keywords:** visually impaired children; age-related prevalence of VI children in Hungary; parents raising VI children; protective and risk factors; narrative categorical content analysis

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\*\* Ethical approval: Permit was obtained separately from each interviewee.

Disclosure statement: The authors have stated explicitly that there are no conflicts of interest in connection with this article.

## 1. Introduction

Within the research focusing on the situation of families raising visually impaired children (GARAI & KOVÁCS 2014; MÁNDOKI 2018), no study about the situation and the quality of life of families raising visually impaired children has been published in the past few decades in Hungary. Also, we could not find any Hungarian researches which would inform us about the life circumstances and population features of the parents raising visually impaired children, and how they adapt to their children's visual impairment. Our information about the visually impaired children's parents mostly comes from practising experts' experience and assumptions, and in most cases the information is limited to describing a phenomenon or providing experience.

Studies exclude 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 (PARASZKAY 2007). The quality of life features applicable in the context of visually impaired children and their parents (demographic, family structure data, household features) appear only for institutes with smaller numbers of children or in groups linked only to one county (KOTROCZÓ 2018). Furthermore, the age group prevalence of visually impaired children is not identified in Hungary, which hinders comparison with international data.

As practising special education teachers 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 VI), we learned that the Center has been collecting the *qualitative and quantitative features of the visually impaired children and their parents* for several decades, and this documentary collection contains these otherwise incompletely accessible, but – from a pedagogical, medical and social care perspective – relevant and very sensitive data for a very high number of children. These data that refers to more than a thousand cases was not processed before our study.

## 2. Aim

In one of the foci of the examination are the visually impaired children, who from a pedagogical perspective qualify as children with *sensory special educational needs* (*sensory SEN*) 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 a 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 vision 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 & PAJOR 2020).

In the second focus of the research stand the features of parents raising impaired and visually impaired children. In the life of families, thinking about and taking care of impaired children posits a permanent stress to family members (ROBERTSON & BROWN 1992), which throws the family off balance for a longer or shorter period of time (SELIGMAN & DARLING 2007). As 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 & PRÉKOPA 2011). DANIS and KALMÁR (2011) list three main forms of coping abilities: forms aiming at *problem-solving, emotional coping, and seeking supportive people*. Coping with the fact of disability, the birth, and the existence of a disabled child has been described variously (SELIGMAN & DARLING 2007). Certain authors (KÜBLER-ROSS 1969; KÁLMÁN 1994) describe this coping process as one corresponding to the stages of grief processing, while others (LIVNEH & 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 this process, a high number of moderating factors, that is, protective and risk factors (DANIS & KALMÁR 2011) are identifiable. This research examines 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 a partnership and belonging to the middle class (DAVIS 1993; O'CONNOR & RUTTER 1996; TUNALI & POWER 2002; GRAY 2006); therefore, the conclusions of these studies cannot be applied to the whole population of parents raising children with a visual impairment without limitations. Thus, the cited research reports emphasize the importance of including parents with low socio-economic status. Such an objective is reachable with qualitative methods and the examination of individual walks of life and parental narratives (GARAI 2005; BOGNÁR 2012).

MAYO and colleagues (2018) have found that a significant relationship exists between the family environment in which children with visual impairment are managed and disability coping. It has important implications for the intervention, as it was found that a family environment with cohesion, organization, an intellectual-cultural, active-recreational and moral-religious family attitude is positively related to the use of adaptive coping strategies. As LUPÓN and colleagues (2018) claim, some

parents express feelings of helplessness, frustration, lack of attachment or guilt for not understanding their children's behavior. Parents raising children with a visual impairment are mainly worried about their children's future and their school performance; they also express concern about psychosocial issues and family organization aspects. Some examples of the coping strategies parents commonly use and define as empowering are as follows: a conscious attitude of acceptance, an active search for help, a feeling of responsibility towards the child, gaining knowledge about the VI, mutual respect and support within the family, talking about the situation, gaining a positive perspective of the situation, finding time for leisure or respite, helping children develop their skills and encourage the child's independence, amongst others. In addition, within the family context, better results and better adjustment of all family members (including the person with VI) are possible if the family is flexible, adaptable, cohesive, supportive, and well-functioning (BAMBARA et al. 2009).

### 3. Objectives

Based on the surveyed publications and our experience as practicing experts, we defined the objectives of our 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. (2) The exploratory examination of the coping factors applied by parents raising visually impaired children in a representative parental sample (*including low SES, single parents*).

The research aims at answering research questions that are of an 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:

What is the age-related prevalence of visual impairment in Hungary like compared to the international data?

What repetitive characteristics do mothers and fathers raising visually impaired children articulate in their retrospective narratives?

### 4. Methods

The methodology of the research relies on three pillars, as it applies two comprehensive quantitative methods and a qualitative analytical method.

#### 4.1. Quantitative analytical method I.

This quantitative analytical method involves filtering and analysing the data from The Hungarian Central Statistical Office: Census 1990; 2001; 2011; Microcensus 2016 (KSH [HCSO] 1993; 2018; CSORDÁS 2014) that refers to visually impaired children aged between 0 and 14.

## 4.2. Quantitative analytical method II.

This quantitative analytical method involves 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 Center 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 1,432 persons, which means that the so-called examination files (on paper) of 1,432 visually impaired children aged between 0 and 14 were analysed. During data collection, we managed to gather 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 a limited access to these data, researchers could only prepare handwritten notes based on the paper documents, which could not include personal data that could have made identification possible. (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 falls 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 Center VI. However, no other institute or database exists that would possess reliable data concerning children with *sensory special educational needs* that has such a large sample size. The study discusses in detail the background of the visually impaired children who stay outside the pedagogical diagnostic system.

## 4.3. Qualitative analytical method

In the course of our research, we contacted parents raising a visually impaired child who was at least 5 years old but not older than 16. The interviewees came from the past clientele of *the Center VI* and the *Early Intervention Centre Budapest*, who have used the special pedagogical services of these institutes between 2000 and 2014. Basing our research completely on voluntary participation and assuring complete anonymity, we contacted the parents via email or telephone. We could contact 136 possible interviewees, and with 68 of these parents we could do interviews resulting in processable narratives. Half-structured interviews were made 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 Corps VI. Beside the socio-demographic data, we asked 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. A narrative categorical content analysis method was applied (LÁSZLÓ et al. 2013) to analyse the texts of the individual interviews with the use of Webnarrcat text analytical software (EHMANN et al. 2014). When one analyses with NarrCat, there is a data reduction of a specific thematic: the software transforms determined units (sentences/parts of sentences) of the individual and group narratives into categories that later may serve as the basis for a narrative psychological analysis (EHMANN et al. 2014). The core of the system is the narrative categorical, that is, psycho-thematic modules. The four most robust of these are emotion, evaluation, agency and cognition (EHMANN et al. 2014, 139).

## 5. Results

### 5.1. Results I.

Based on the data tables of The Hungarian Central Statistical Office (HCSO) (Census 1990; 2001; 2011; Microcensus 2016) we determined and summarized in table format (*Table 1*) the occurrence rates of visually impaired children aged 0 to 14 within the whole population and in their age group. In the entire population, the prevalence of the VI group increases in every ten years. The prevalence of the VI group was 0.050% in 1990, but 0.063% in 2001 and 0.083% in 2011. Interestingly within the population aged between 0 and 14, the prevalence of the VI group decreases in every ten years. The prevalence of the ‘youth’ VI group was 0.04% in 1990, but 0.03% in 2001 and 0.026% in 2011.

A more accurate methodological and conceptual establishment of principles (KSH [HCSO] 2018) is connected to the samples of the *2011 Census and the 2016 Microcensus*; therefore, the prevalence values were determined more emphatically in these two samples. Based on the aggregated data, the prevalence of childhood visual impairment was 0.026% in 2011 and 0.022% in 2016 in the entire population. *This means that in every ten thousand people 2.6 adults and 2.1 children were visually impaired.* The age group prevalence is 0.18% in 2011 and 0.15% in 2016; that is, *out of ten thousand children of the same age group (aged between 0 and 14), 18 were visually impaired in 2011 and 15 were 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 0 to 14		
		Disabled	VI	Number	Disabled	VI
<i>Census 1990</i>	10,374,823	368,270 3.55%*	51,400 0.50%*	2,130,549 20.5%*	33,485 1.57%***, 0.32%*	4,135 0.19%***, 0.040%*
<i>Census 2001</i>	10,198,315	577,006 5.66%*	64,558 0.63%*	1,694,936 16.6%*	28,803 1.70%***, 0.28%*	3,065 0.18%***, 0.030%*
<i>Census 2011</i>	9,937,628	490,578 4.94%*	82,484 0.83%*	1,447,659 14.6%*	23,190 1.60%***, 0.23%*	2,591 0.18%***, 0.026%*
<i>Microcensus 2016</i>	9,803,837	408,021 4.16%*	69,747 0.71%*	1,421,937 14.5%*	22,857 1.61%***, 0.23%*	2,137 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 were further categorized and recorded in all four surveyed periods into *low vision* and *blind categories* (Table 2), and we completed them with individual visual impairment categories that vary according to the surveys (*blind in one eye, deafblind*). According to the Census 1,990, in the visually impaired population aged between 0 and 14, there were 4,135 children. The number of children with a visual impairment has declined over the next two decades. In 2001, there were 3,065 children with VI and in 2011, there were 2,591 children with VI.

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

	<i>Blind</i>	<i>Low vision</i>	<i>All VI</i>	<i>Blind in one eye</i>	<i>Deafblind</i>
<i>Census 1990</i>	1,020	3,115	4,135	635	no data
<i>Census 2001</i>	334	2,731	3,065	438	no data
<i>Census 2011</i>	247	2,344	2,591	no data	124
<i>Microcensus 2016</i>	335	1,802	2,137	no data	75

Due to the evident signs of condition for blindness, international literature (GILBERT & ELLWEIN 2008) determines a prevalence value only for the blind population,

so using the 2011 Hungarian age-group population number (1,447,659), the age-group prevalence value for blindness was 0.17‰. Using the 2016 data, the age-group prevalence value for blindness was 0.23 ‰. Thus in 2011, out of 10,000 children below the age of 14, 1.7 persons were found blind; in 2016, this value is 2.3 persons.

**5.2. Results II.**

In the group of children with visual impairment (n = 1,432) there are 559 girls (39%) and 873 boys (61%). 56 percent (n = 809) of the sample were children with low vision and 36 percent (n = 509) were children with blindness. According to the statistical analysis, 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 neurological diagnosis. The data about family features of the visually impaired children are summarized in Table 3. In most cases (82.6%), 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

FAMILY STRUCTURE n = 1,156 (no data = 276)	Blind	Low vision	Below 18 mo.	Total
Two parents (biological)	206	292	63	561 (48.5%)
Two parents (biological + foster)	131	161	14	306 (26.5%)
Two parents (foster)	14	29	5	48 (4.2%)
Two adoptive parents	9	23	7	39 (3.4%)
One parent (biological)	29	61	22	112 (9.7%)
One parent (foster)	14	9	0	23 (1.9%)
One adoptive parent	4	2	0	6 (0.5%)
Orphanage	31	27	3	61 (5.3%)

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 claimed to raise their children alone as single caregivers (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. 5.3% of the children with visual impairment live in orphanages.



**5.3. Results III.**

In the parents' sample, the interviews and narratives of 39 mothers (age range: 26–47; deviation: 6.57) and 29 fathers (age range: 26–49 years; deviation: 6.35) were analysed. In order to encode and thematize the texts, the *Webnarrcat* text-analysing software was used with the help of two independent encoding specialists. Based on the *Webnarrcat* scores, we could separate the highest scoring text parts which contained the most frequent parental responses, *emotional and cognitive relations* and *factors for seeking social support*. For methodological considerations, these factors were listed 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 1* shows the summary of the explored coping factors of the parents.

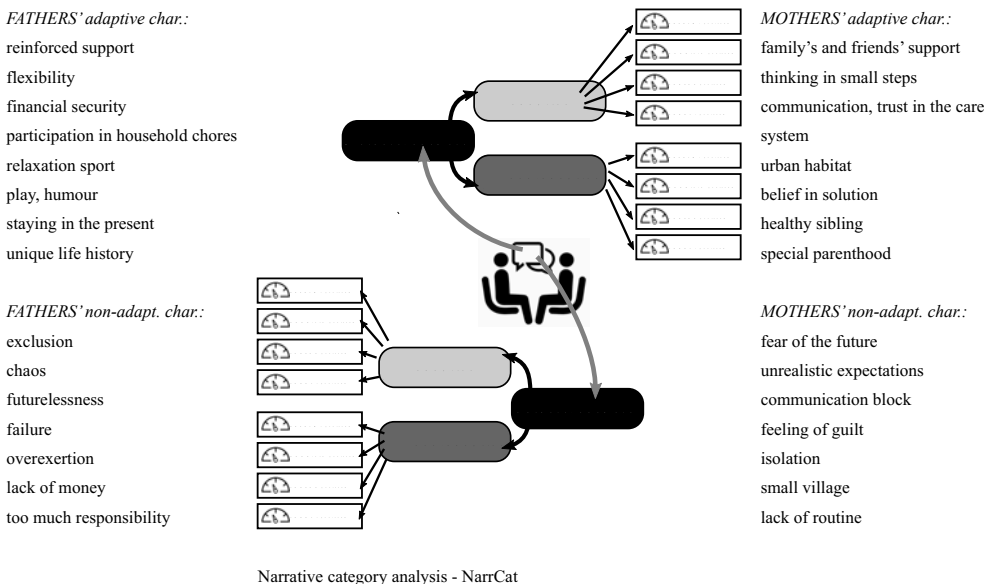


Figure 1.  
 Frequency of Characteristics of the Adaptive and Non-Adaptive Approaches via the narrative category analysis

The parents' narratives reveal a number of protective and risk factors: (1) it appears that social support is an important protective factor regarding quality of life: 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, 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 little if any knowledge about the criteria of low vision. (4) It considerably restricts access to the care system should the adequate institutions or services be 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.

## 6. Discussion

The age-related prevalence of visual impairment in Hungary, compared to the international data GILBERT and ELLWEIN (2008), suggests 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 1,000 children is 1.5. This rate *in developed countries is only 0.3*. The 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/10,000 live-births, whereas *in developed countries, this rate is only 10–22 children/10,000 live-births*. Based on the above, WHO estimates that all around the world there are about 1.4 million blind children, two-thirds 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 & ELLWEIN 2008). In Hungary, the 2011 census (carried out by HCSO) registers *altogether 2,591 persons as visually impaired children aged between 0 and 14*, out of whom 247 children were categorized as blind and 2,344 children were categorized as children with moderate visual impairment. *This is 0.026% of the total population, and 0.18% of the population within the same age group.*

Based on the 2011 census' data (considered representative) and the 2016 micro-census (both conducted by HCSO), 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.

We interviewed mothers and fathers raising visually impaired children to ask their opinions about their own life situations. By using a narrative content analysis of the parents' answers to our questions in the interview, we managed to identify the most frequently occurring adaptive and non-adaptive coping mechanisms in the groups of mothers and fathers. We aimed at using an examination sample of the parents that is representative of the whole population, but due to the actual number we could work with, the relations and the results may not be generally applied to the

whole population of parents raising visually impaired children. Instead, we emphasize the possible extension and the applicability of the research results to groups of parents raising children with other disabilities. In their adaptive mechanisms, fathers most frequently apply a problem-focused and social support strategy, and they mobilize their psychic immune systems so that they may be able to act in a strengthened social support role and to react to the various challenges in an effective manner. In the dimension of adaptive coping mechanisms, mothers tend to apply an emotion-focused coping mechanism, but a visible growth of cognitive and social factors is detectable. In the course of adaptive coping, we identified a new strategy: that of organising effectively the scope of the duties around the child, which is one of the keys to long-term adapting. Furthermore, in the cases of adaptive coping, we could detect a growing frequency of reinterpreting parenting roles ('special parenthood', 'unique walk of life', 'less is often more') (BOGNÁR 2012; GARAI & KOVÁCS 2014; BERSZÁN 2015; KISS 2020).

The parental mechanisms may not be divided into clear adaptive and non-adaptive groups. *Considering the narrative tones of the parental self-confessions and their temporal spheres, we may differentiate between periods during which the parents behave according to one of the dimensions alternately.* The events that may trigger a change in the parent's attitude from a generally stable position to a more positive or more negative tone are critical situations, such as the cyclically repeated birthday of the child, or changes of institutes, medical or pedagogical check-up examinations or bigger social events. This observation stands in harmony with the theory (LIVNEH 2001; DAVIS 1993; LIVNEH & ANTONAK 1997) stating that coping with the difficulties of having a child with disability is a recurring, cyclically repeated process. In the adaptive dimension of the parents' narratives, social support features (*personal and professional support, family resources*) frequently emerge. Especially, mothers gave a high proportion (81–100%) of answers with a social support thematic, but the answers provided by fathers also had a 61–70% frequency category for *family and professional support*. For parents, professional support means the activity and the communication by people who got into contact with their children and belong to the medical, pedagogical, or social care branches.

## 7. Limitations

This study has some limitations. The biggest problem is that in Hungary, no official protocol and/or directive for the methodology of investigating the documents and data of SEN children exists. The Principal or the Director of the Institute is in charge of these sensitive and important data. The documents are forbidden to be copied, so researchers must take notes by hand. That is the reason that this research, in which we processed 1,432 documents, took two years. The second limitation comes from the fact that the 2016 microcensus was conducted with a sampling fraction of 10% of the population, so we must take this into consideration when using its data. 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. The third limitation of the study, as was mentioned previously, is that despite the 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, the research could use only one institute because there are no more institutes or databases that would have reliable data concerning children with *sensory special educational needs* with such a large sample size.

## 8. Conclusion

It is of utmost importance to create for the parents concerned mental hygienic and support services, as well as information systems that take into account individual differences. It is also a priority to provide visual impairment specific training and continued professional support for the experts working in early intervention and inclusive education. All fields – social, medical and pedagogic – that are in connection with visually impaired children and their families, need more publications, brochures, or webpages about client pathways or VI children pathways.

What parents raising children with visual impairment seek most but do not find in the care system is support for their physical and mental relief. It would be important to improve the situation of parents raising a child with visual impairment with more flexible special education and social services in which both single and cohabiting parents receive support to solve their life situation difficulties. There would be a particular need to set up a system of mental health support and home help services that are available to the parents concerned, taking into account differences in individual family structures.

Families need more projects, workshops, and lectures for parents of VI children under and in school age to learn more about childhood development and parenting visually impaired children, to broaden their knowledge of the care system, and develop appropriate parental competences. A project or a brochure is better if it is made by not only professionals but parents having practical, everyday knowledge as experts by experience. An interactive website would help parents, families, and professionals find guidance on care paths, and would help families contact, as soon as possible, with the right care provider corresponding to their needs.

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