Przegląd Badań Edukacyjnych
ISSN 1895-4308
nr 18 (1/2014), s. 23–36

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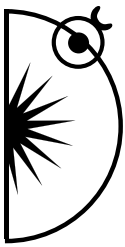

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Changes of the Population of Deafblindness in Russia

DOI: http://dx.doi.org/10.12775/PBE.2014.003

Introduction

In conferences and other professional gatherings it is expressed that the population has changed radically over the past 20 years, and that the group of persons with Deafblindness has become increasingly heterogeneous. From the beginning of 80-s' years after C.Best it became almost conventional to divide among experts deafblind people on «classical deafblind» E.Keller's type and «new deafblind» (C.Best, 1983). D.Brown's works and others' have shown that modern success of the medicine, rescuing prematurely born children who could not survive independently, the access to education and the development of social assistance to children with disabilities made it more possible to include children with more complex and severe difficulties in the places where they can get assistance of the specialists (D. Brown, 2000; M. Collins and others,1991; M. Riggio, 1992).

First Investigation

1990 in Russia we have also undertaken attempts to study structure changes of the deafblind in educational institutions since 1990. We also undertook attempts to study structure change of the deafblind population in educational institutions

since 1990. First we tried to compare the contingent of Children's home for Deafblind in Sergiev-Posad in 1970 and 1987. Comparative research of two groups of 50 deafblind children educated there in those that in 17 years of observation the age and etiology of deafblindness in children entering this institution changed considerably.

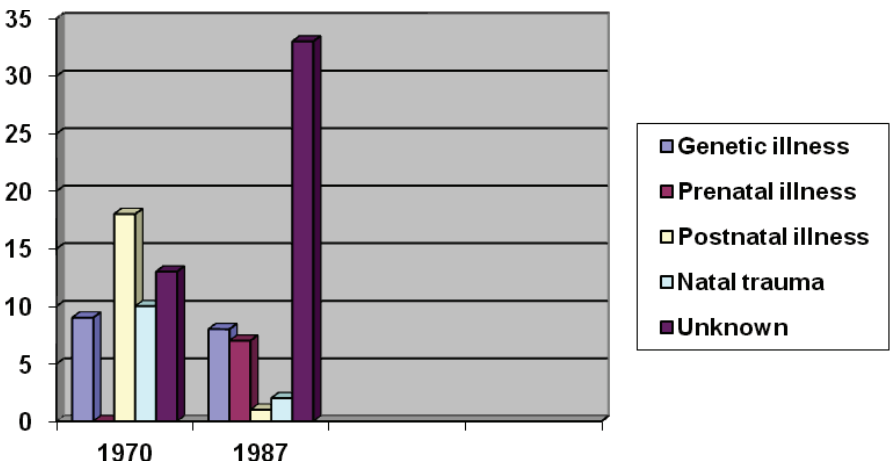

Fig. 1. Changes in the etiology of deafblindness in the pupils of Children's home for the Deafblind in Sergiev-Posad in 1970 and 1987

In this time the number of postnatal diseases (such as meningitis and meningoencephalitis) caused deafblindness considerably decreased (from 36 % to 2 %) and the number of pre-natal diseases (Rubella, flu, http://www.multitran.ru/c/m.exe?a=110&t=3662612_2_1&sc=3toxoplasmosis and syphilis) as a reason of deep impairments in sight and hearing increased a little (from 0 to 14 %) . The number of cases with the unstated reasons of deafblindness (from 26 % to 66 %) grew notably.

Table 1. Changes diagnoses of visual impairments in children in Children's home for Deafblind in Sergiev-Posad in 1970 and 1987

Diagnoses of visual impairments	Years of observations	
	1970	1987
Cataract	13(26%)	38(76%)
Optic nerve atrophy	21(42%)	4 (8%)

Table 1. Cd.

Severe myopia	7	3
Microphtalmus	2	0
Retinal Pigmentose	2	0
Others	5	5
In total	50 (100%)	50 (100%)

With changes in the etiology of deafblindness, diagnosis of visual impairments had also changed. In these 17 years the number of cases of atrophy of visual nerve (from 42% to 8%) as the reasons of deep visual impairments had considerably decreased and the number of congenital cataract (from 26% to 76%) has almost three times increased. In 1987 the majority of deafblind students of the background then educational institution for the deafblind were children with congenital impairments of sight and hearing because of a congenital cataract and a congenital severe hearing disorder. The majority of them (78%) were visually impaired deaf children (T. Basilova, 1990).

Second Investigation

The second attempt of a comparative study of children with complex sensory disorders was made in 2006. We analyzed data of a clinic-psychological research of 22 blind children with additional impairments (13 boys and 9 girls) of early and preschool age that had passed advisory inspection in 1973–93 and compared them to the data of the inspection of 36 blind peers (17 boys and 19 girls) at the age from 8 months till 7 years old in 1994–2004.

Table 2. Change the age of blind in other period of observation (1973–1993 and 1994–2004)

Period of observation	Age of blind children with additional impairments							In total
	0–1	1–2	2–3	3–4	4–5	5–6	6–7 .	
1973–1993	0	2 (9%)	2 (9%)	5 (23%)	3 (14%)	3 (14%)	7 (32%)	22(100%)
1994–2004	1 (3%)	10(28%)	8 (22%)	8 (22%)	1 (3%)	4 (11%)	4 (11%)	36(100%)
In total	1 (2%)	12(21%)	10(17%)	13(22%)	4 (7%)	7 (12%)	11(19%)	58(100%)

The condition of sight in the majority of all these children was estimated as blindness. But the causes and status of blindness was different.

Table 3. Change causes and status of blindness in different years of observations (1973–1993 and 1994–2004)

Causes of visual impairment/ Status of vision	Total blindness	Blind with light perception	Severely visually impaired	In total
1974–1994				
Retinopathy of Prematurity	1	1	0	2(9%)
Optic Nerve Atrophy	3	2	3	8(36%)
Cataracts	0	0	3	3(14%)
Uveitus	3	0	0	3(14%)
Retinoblastoma	2	0	0	2(9%)
Glaucoma	0	0	1	1(4%)
Others	1	0	2	3(14%)
In total	10 (45%)	3 (14%)	9(41%)	22(100%)
1994–2004				
Retinopathy of Prematurity	8	14	0	22 (61%)
Optic Nerve Atrophy	3	3	0	6 (17%)
Cataracts	0	0	2	2 (5, 5%)
Cortical visual impairment	3	0	1	4(11%)
Others	2	0	0	2(5, 5%)
In total	16(44%)	17(47%)	3 (9%)	36 (100%)

Table 4. Causes of illness which led to blindness with combined disorders at preschool age in different years of observations

Etiology of the complex disorder	1974–1994	1994–2004	In total
Genetic syndromes	4 (18%)	1 (3%)	5 (9%)
Prematurity	2 (9%)	22 (61%)	24 (41%)
Prenatal infections	5 (23%)	1 (3%)	6 (10%)
Brain tumor	1 (4%)	0	1 (2%)
Postnatal illness	4 (18%)	4 (11%)	8 (14%)
Crania-cerebral injury	2 (9%)	0	2 (3%)
Unknown	4 (18%)	8 (22%)	12 (21%)

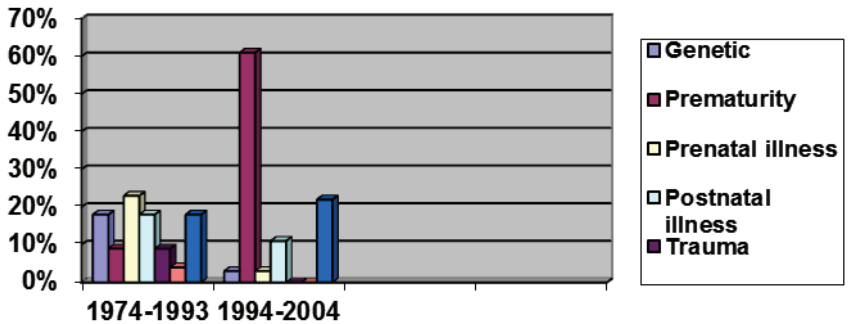

Fig. 2. Change in etiology of blind children with additional disabilities in different years of observations

This research demonstrated an evident increase in number of blind children with additional impairments received severe defect as a result of deep prematurity in the last decade. It is possible to tell that deep prematurity which consequence was retinopathy of prematurity (ROP) became the most widespread reason of blindness with additional disabilities (61% of observed cases). In 20 years of the first period of observation the number of children with ROP was only 9%. It is necessary to mention that in all years of studying of preschool children with severe impairments there is a high percent of cases having unknown etiology (18 and 20%). The most common diagnosis of blindness in 1974–1994 was optic nerve atrophy – 36% (8), in the next 10 years of observation the number of children with these diagnoses was only 17% (8).

Table 5. Structure of impairments in blindness with additional disorders in different years of observations. B-blind, D-deaf, M-motor, E-'emotion, Ep- epilepsy, Mr-mental retard

Number of groups	Structure of impairments	1973–1993	1994–2004	In total
1.	Functioning on average level (without mental retardation)	5 (18,2%)	8 (22,2%)	13(22,4%)
	MB	0	1	1
	EB	0	1	1
	DB	5	5	10
	DBM	0	1	1

Table 5. Cd.

2.	Functioning on low level (mental retardation with sensory disorders)	17 (77,3%)	28 (77,8%)	45(77,6%)
	MrB	2	4	6
	MrBM	2	6	8
	MrBMEp	0	3	3
	MrBE	3	6	9
	MrBEp	1	0	1
	MrDB	5	2	7
	MrDBM	0	5	5
	MrDBME	1	0	1
	MrDBMEp	0	1	1
	MrDBEp	1	1	2
	MrDBE	2	0	2
In total		22 (100%)	36 (100%)	58(100%)

Trying to describe structure of impairments in blind children with additional disorders observed by us, we faced great difficulties in ordering of these impairments. We divided all children into two big groups: children having complex disabilities with expressed delay in mental development and without such delay (functioning on average and low level). It appeared that in different years of observations the number of blind children with additional impairments, with rather safe mental development made about identical number (18–20%). Among these children we could allocate three cases of double impairments: Deafblindness (DB), blindness with ccerebral palsy (MB), blindness with emotional instability (autistic spectrum disorder – EB) and one case of threefold defect – deafblindness with additional movement disorder. Long observations showed that the condition of one part of children that seemed safe enough for the possibilities of mental development, became sharply worse as they came into puberty and in more senior age.

Deep backlog in mental development was characteristic for the major part of children with the complicated blindness surveyed in different years and has made more than 77% from all cases. For all blind children with the expressed backlog in mental development was characteristic to have also plurality of neurologic and mental impairments... We found 12 variants of combination of sensory, neurologic and mental impairments for this group of children. Actually,

only blindness with intellectual delay is possible to call double defect, while the others look more like a combination of three and more impairment in one child. For this group of children is very characteristic to have epileptic disorders. All these facts showed the high risk of deep retardations in mental development in children with severe visual impairments and the additional disabilities caused by congenital or early acquired disorders of CNS. (T. Basilova, N. Aleksandrova, 2006).

Third investigation

The third comparative research was done by us in 2009. We tried to analyze the data collected by us about all persons with bisensory impairment in 35 years of supervision. There is a particular characteristic of our sample: all these people were surveyed or observed by us personally. Their families addressed for consultation, came for diagnostical evaluation in the Lab of Deafblind Education in Institute of Defectology or they were observed by us in Children's Home for the Deafblind or special schools and centers.

43 % (196) of persons observed by us were educated in Children's home for the Deafblind for at least 1 year or more. 22% (103) studied at school for the deaf, 2% (11) of them – at school for the blind. 10% were brought up in social protection establishments. The others were not receiving any kind of education.

The total number of observations was 457 cases. All persons surveyed by us had the significant visual and hearing loss. 249 (52%) were male and 208 (47%) were female. They lived in different parts of the former USSR and modern Russia. Only 22% (100) lived in Moscow and Moscow Region.

The age of these deafblind children and adults varied from 8 months to 54 years. So, those were people of the most different years of birth. There was a man born in 1924, the others were born between 1942 and 2005.

The condition of sight in the majority of these people was estimated as low vision – 79% (330 cases) while 21% (127cases) had blindness. The most common diagnosis of visual impairment in these cases was cataract – 52% (238); refraction disorders (mop, farsightedness, astigmatism) were at the second place of occurrence – 12% (53); at the third place there was atrophy of optic nerves–11% (52) and pigmented retinitis (Retinitis Pigmentose) – 7% (31).

The most part of persons in our sample were deaf – 61% (278 cases), the others were hard of hearing – 39% (179).

The mental condition in the majority of them was estimated at the moment of inspection as normal for a person having bisensory disorder and had no

expressed additional impairments – 54% (248). 12% (53) of people had such additional impairments of moving system or somatic disorders. 12% of 34% (156) had significant mental delay, as well as additional disabilities such as CP, seizures, behavior challenges, somatic issues etc.

The etiology of 25% (116) cases was unknown. 25% (117) were born prematurely. In 33% of cases these persons had got different diseases or accidents before birth or right after birth. The genetic pathology was established in 17% of cases.

We broke the sample into groups in order to analyze the changes in population of deafblind adults and children observed by us. So, we received 13 groups based on the years of birth. So, it appeared that the greatest number of deafblind people which we observed was born between 1965 and 1984.

Table 6. Number of deafblind persons which born in different years

Number of groups	Year of Birth	Number of Cases
1.	Born before 1944 .	6
2.	1945–1949	7
3.	1950–1954	8
4.	1955–1959	10
5.	1960–1964	11
6.	1965–1969	91
7.	1970–1974	86
8.	1975–1979	81
9.	1980–1984	63
10.	1985–1989	40
11.	1990–1994	17
12.	1995–1999	26
13.	2000–2005	11
14.	In total	457

First of all we were interested in changes in an etiology of Deafblindness. It seemed to us that the number of deafblind people born deeply prematurely should be considerably increased in last decades, as our previous research showed.

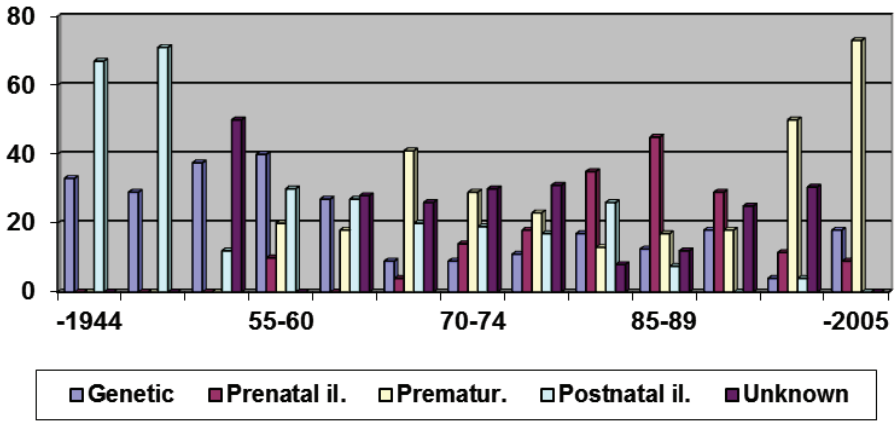

Fig. 3. Change in etiology of deafblindness within 35 years of observations

We tried to consider more attentively cases of pre-natal diseases, first of all Rubella basing on this kind of data received on a sample that is not very representative. It is clearly visible that the occurrence of this etiology had been growing since the middle of 70-s' and decreased by the end of 90-s'. We can see decrease numbers of cases of Deafblindness in last decades caused by such postnatal diseases as meningitis or meningoencephalitis. The growth of deep prematurity as a reason of double sensory loss since 40-s' years and especially in last 20 years is also evident.

There are fewer cases of early acquired deafblindness where only peripheral impairments of visual and hearing analyzer systems take place. We can witness more often the cases of the malformation of brain structure or early impairment of the central nervous system on the cortical level which brings to system disorders impacting the future development not only in the sensory but also in the emotional and intellectual fields of the child's development. A special analysis of all developmental case-histories of children having innate and early acquired blindness complicated by additional disorders shows that among this population in different years of observations there is a rather stable number of children who can have a rather good perspective of their psychological development (around 20% of cases). Long-time observations though showed that a part of these children who seemed to be in a good state from the point of view of their safe abilities got worse while entering into the adolescent and elder age; so at the end they became part of a group of the low functioning blind children with additional disabilities.

The above listed diseases the children had in different time and leading to blindness differently affected eye. The following diagrams show the prevalence of the most severe diagnoses of diseases of the eye (cataracts, atrophy of the optic nerves, retinopathy of prematurity and pigmentary retinal dystrophy) of deafblind who were born in different years.

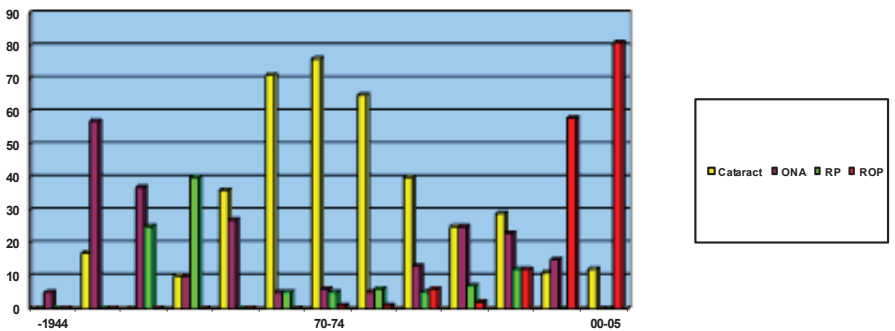

Fig. 4. Causes of visual impairments in deafblind persons born in different years

We can mention the growth of the representation of congenital cataract as a cause of severe vision in persons born in the period from about 1960–90-ies. Among other medical diagnoses of visual impairments representation of optic nerve atrophy (ONA), pigment retinitis (PR) is slightly reduced and it showed a remarkable increase in the number of retinopathy of prematurity (ROP) in people who were born in the period from early 90-es and up to the first decade of the 00-es.

It was also interesting for us to compare representation of congenital and acquired causes of dual sensory impairment in deafblind of different years of birth.

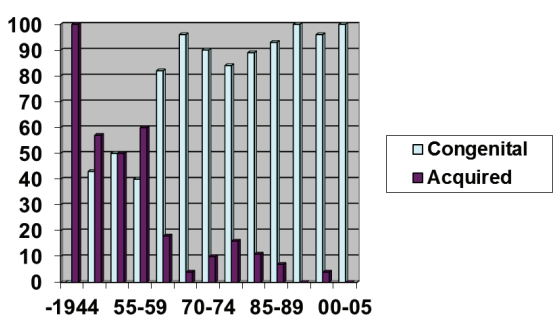

Fig. 5. Congenital and acquired causes in Deafblindness in person different years of birth

As seen in the chart data, we can observe a marked decrease in cases of acquired deafblindness (as a result of postnatal diseases and injuries) among the persons with dual sensory impairment born in the late 50es and later. And the overwhelming number of cases of congenital causes deafblindness among children and adults born in these years. As a consequence mainly of congenital causes severe visual and hearing impairment, we observe growth of deafblind persons functioning on low level (mental retardation with sensory disorders) born in the last 20–25 years (T. Basilova, A. Paikova, 2009; T. Basilova, 2011).

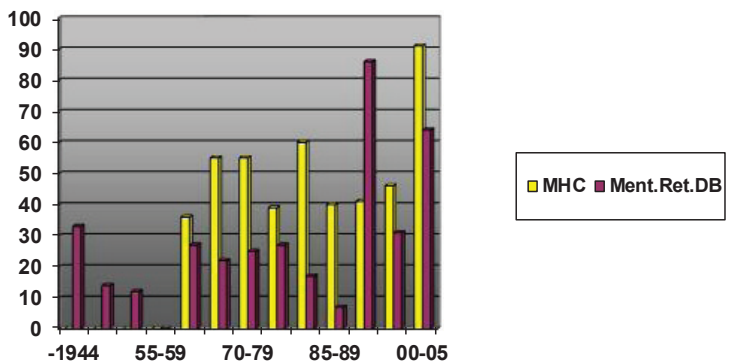

Fig. 6. Deafblindness with Mental Problems and with Other Additional Disabilities

Conclusion

1. Analysis of data confirmed our professional intuition that the population of deafblind people has significantly changed.
2. Changes in deafblind population in Russia have common tendencies with other countries:
   – The obtained data show significant decrease of acquired deafblindness and increase the number of persons with congenital visual and hearing impairments.
   – We start meeting children of more and more early age and help their families
   – DB people lately have got more and more additional disabilities
   – They have more challenges with acquiring of speech and having academic achievements
   – There are more cases with cortical damage and less cases with peripheral damage of distant senses

Between deafblind persons with mainly congenital causes of dual sensor слепоглухоты (не очень ясно) born in different years of observation is a big difference. In children and adults born between 1950 and 1980 years, we saw low number of multiple handicapped children with serious mental problems. The most common cause of hearing and visual impairment in these individuals was congenital cataract and deafness, the reasons of which are still not sufficiently clear. These children are quite successful in education suggesting that they have most peripheral level of the defect of the sensory systems as a result of early postnatal diseases in the first month of life (pneumonia, sepsis and other) and the nature of medical treatment in these years.

Collect and collate data about deafblind population in other countries in different years can not only identify the changes and plan to change the content of their training but also shed light on the possible reasons for the future severe disability in the world.

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Summary

Analysis of the data gathered during the last 35 years of observations as well as diagnostic studies and studies of catamnesis of deafblind, blind children with additional impairments and adults in Russia confirms the fact of significant changes in this population which is getting more severely impaired in the recent years. There are fewer cases of early acquired Deafblindness where only periphery impairments of visual and hearing analyser systems take place. We can witness more often the cases of the malformation of brain structure or early impairment of the central nervous system on the cortical level which bring to system disorders impacting the future development not only in the sensory but also in the emotional and intellectual fields of child's development. A special analysis of all developmental case-histories of children having innate and early acquired blindness complicated by additional disorders shows that among this population in different years of observations there is a rather stable number of children who can have a rather good prognosis of their psychological development (around 20% of cases). Long-time observations though showed that a part of these children who were seeming to be in a good state from the point of view of their safe abilities got worse while entering into the adolescent and elder age; so at the end they became part of a group of the low functioning or mental retarded children with additional sensory disabilities.

Keywords: blindness, deafblindness, etiology, population, prematurity, cataract.