The World in the Mind and Sculpture of Deafblind People

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Plein-air sculptural workshops in Orońsko for deafblind people are a truly unique initiative. The present author has failed to find information about any other initiative of such a kind either in Europe or in Poland. Due to the immeasurable effort of the sculptor Ryszard Stryjecki, the founder of the workshops, deafblind people transform themselves into artists. They cease to be people closed behind a wall of silence and darkness and trespass the boundaries set by their disability. They become cheerful and find the energy and passion to create. Sculpture brings them back the joy of life, self-respect and self-trust and it builds a positive attitude towards reality.

During numerous visits to Orońsko conducted first as a caregiver, then as a sculpture instructor, the present author experienced creative fascination together with the deafblind artists. The following book is an attempt to define the phenomena commonly referred to as an act of creation and what, taking into consideration the artists' capabilities, was achieved through a specific approach. It will describe both the act of creation itself, the creative process and its conditions determined by the participants' condition and, finally, the effects – the sculptures by the deafblind artists.

Bearing in mind the risk that the interpretations conducted with the use of research tools may fail to capture the subtle element of the act of creation i.e. the illumination which releases imagination and imposes the execution, the present author spent long hours observing the moments of emotional tension of the sculptors in order to describe the process with even more insight.

The present book discusses the creative capabilities of a deafblind person enclosed in a sculpture. The participants are people with severe disability, deprived of the two most important senses that are extremely important in orientating oneself in reality – the sense of sight and the sense of hearing. People with sight loss do not experience space, do not perceive colours, are not able to notice the shape of the objects that remain out the reach of their hands. People with hearing loss remain isolated in the world of silence and, what is more important, are unable to communicate in their ethnic language. Even if the ethnic language is shaped in the first years of one's life, the deafness that develops later leads to a gradual disappearance of the language from one's mind.

I adopt one of the long-existing theories of cognition and linguistics that it is the ethnic language, naturally acquired and easily accessible by a hearing person, that constructs the image of reality in the human mind and makes it possible to convey knowledge about oneself and the world to other participants in social life.¹ People deprived of their ethnic language remain in their own world that is inaccessible to others. It is constructed according to one's emotional capabilities (for deafblind people, in extreme cases, they may be limited to the sense of touch, taste and smell) and is a particularly individualised socialisation process. Thanks to socialisation, the deafblind have access to scant cultural knowledge acquired through a variety of codes only with immense effort - through their knowledge of sign language, fingerspelling or the spontaneous use of mimicry or gestures.

It is also assumed that a sculpture is always a projection of knowledge about reality and its phenomena conveyed through a form selected by the artist, a form in which the artist's experiences and emotions are inscribed. It seems that hearing and sight impaired people, who remain in their subjective world of experiences, acquire their own way to project the phenomena of reality, giving them certain forms and enriching them with experiences and emotions that they recognise.

The responsibility of the person studying the sculpture by the deafblind is firstly to learn what the sculptor's knowledge about the phenomena of reality is, and then to discover the way this knowledge is formed into a sculpture as well as to explore and describe the experiences and emotional states of the artists. That is the course of action followed while executing the methods of this study, which will result in the present dissertation.

The study material is comprised of sculptures created at five plein-air workshops for the deafblind artists in Orońsko. The subject of the author's observation were the sculptors, the effects of a creative process as well as the creative process itself. Participating in all five workshops, in the role of a sculpture instructor, the author had a chance to observe the creative process starting from an intuitive idea all the way to the final statement of its creator. The entire process was observed and its consecutive stages were documented in recorded conversations and photographs or on film.

Great inspiration in this field was provided by the research of S. Grabias: Język w zachowaniach społecznych (UMCS, Lublin 2003), K. Krakowiak: Fonogesty jako narzędzie formowania języka dzieci z uszkodzonym słuchem (UMCS, Lublin 1995), and J. Cieszyńska: Od słowa przeczytanego do wypowiedzianego. Droga nabywania systemu językowego przez dzieci niesłyszące w wieku poniemowlęcym i przedszkolnym, Wydawnictwo Naukowe (AP, Kraków 2000).

The basic method of studying the creative process was discussions with the deafblind artists about the world and individual phenomena of reality, about the act of creating a sculpture, as well as their experiences accompanying the act of creation and its finalisation, when it was time to assess their piece of art.

In the following research the interviewer adjusted to the abilities of the interviewees communicating their messages either with sign language, fingerspelling or gestures (in the case of artists with complete sight loss, the message was signed into their hands or their hands were used to sign), occasionally the Braille alphabet as well as ethnic language (in the case of people with slight hearing impairment).

The proposed methods fall into the category of cognitive research tools. They are used to enter the minds of deafblind artists in order to describe the rules for conceptualising a piece of art, discover the motives behind its creation and reveal the artist's assessment of their work.

It should be noted that the key to the proposed model of the creative act analysis is the concept of a sign developed by semiotics (Ch. Morris and E. Peirce). For, if we assume that a sculpture is a 'sign', then we should, as in the case of every semiotic sign, notice its semantics (which results from the relationship established between the sculpture and the phenomena it refers to), its syntactics (established between a sculpture and other sculptures; in the case of deafblind sculptors the field of comparison should be the socalled 'naïve' sculpture) and pragmatics (which results from the relationship between the sculpture and its creator, as well as the sculpture and its audience).

The entire proposed research process is to be completed by an objective assessment of the sculptures conducted by competent critics educated in the field of art interpretation, selected from among the students of the Faculty of Arts of the Maria Curie Skłodowska University (MCSU) in Lublin. The tool used here was a questionnaire organising opinions about the features of a piece of art, assigned to it by the theory of art. The students assessed the artistic competence of the sculptors. What is more, the questionnaire attempted to answer the question: to what extent is the assessment of the sculpture affected by the disability of its creator.

The study was conducted on twelve people and sixteen of their sculptures. The above-mentioned blind artists had limited ability to communicate with the use of their ethnic language. The first group, extremely important for the purpose of this research, comprised people with inborn hearing loss. As their hearing organ was damaged before they managed to learn the language

(before they were two years old), they are included in the group with pre-lingual deafness. The only possibility to establish contact with this group was by means of non-verbal communication, namely sign language (signed into the hands or with the use of the hands of a deafblind person). The contact was with the people who did not have any skills of socialised communication and were able to communicate only through spontaneous gestures.

The second group were the people who had lost their hearing between the age of two and six. The means of communication with this group was sign language (signed into the hand or with the use of the deafblind person's hands), fingerspelling, the Braille alphabet as well as some elements of the ethnic language. The last group comprised of people who had lost their hearing at or after the age of six, when they had already learned the language (post-lingual deafness). In this group the language played a valid role in the cognition and creation of their reality. Communication with the use of ethnic language was possible with the participants from this group.

This primary division resulting from the level of linguistic abilities was also affected by the level of sight and hearing loss. Therefore, the classification was as follows: deaf and blind people, blind and with hearing loss, deaf and with sight loss and people with hearing and sight loss.

In this way, six groups of participants were established, taking into account both perspectives simultaneously: the level of linguistic competency and the level of hearing and sight loss. The group of people with complete pre-lingual deafblindness (the research was conducted on six people with such dysfunction), people with complete peri-lingual deafblindness (only one person took part in the research as there was only one participant in the workshops from this group), people with complete post-lingual deafblindness (here also only one person), blind people with post-lingual hearing loss (two persons), people with sight loss and pre-lingual deafness (only one person) and people with post-lingual sight and hearing loss (also only one person).

The present publication is an abridged version of a PhD thesis that opens with a theoretical chapter entitled 'Physical and mental abilities of people with simultaneous sight and hearing loss', familiarising the reader with the situation in which the deafblind people perceive the world and presenting the conditions for their functioning in a social group. The second chapter 'Sculpture as the result of creative activity' discusses the complicated problem of the relation between the piece of art and reality. It reflects on the way the emotions of the artist are expressed in his/her work as well as on the mere form of a sculpture. Special attention is devoted to the creative acts of those sculptors

who represent the so-called 'naïve' art. What is more, it describes the creative atmosphere created at the plein-air sculptural workshops in Orońsko. In Chapter III, 'Research methodology', the subject of the research is carefully posed with the correct characterisation of the deafblind sculptors and description of the procedures and methods used in the research. Chapter IV, 'Creation of reality in sculptures by the deafblind – sculpture by the deafblind as a sign. Semiotic analysis' is a description and interpretation of the sculptures from the perspective of semiotics. It focuses on the semantic relationship, the syntactic relationship marked with the scope and the means, which considers the studied sculptures in relation to other sculptures by the deafblind and sculptures classified as 'naïve', as well as the pragmatic relation directing the attention of the researcher to the image of emotions and other motives, i.e. the value system constituting the artist's inner life expressed in their art. Chapter V, 'Sculptures by the deafblind assessed by the audience (students of the Faculty of Arts)', summarises the results of an experiment. Sixty students of the Faculty of Arts of MCSU in Lublin, an audience with shaped aesthetic sensitivity, assessed both the form and the content of the presented sculptures.

The final part of the dissertation presents the conclusions concerning the problems in question as well as the bibliography of the external sources used, including a list of photographs of the analysed sculptures, tables, and photographs of twelve sculptures subjected to the students' assessment.

The Physical and Mental Abilities of People with Simultaneous Sight and Hearing Loss

1. Definitions of deafblindness

Deafblindness is an exceedingly complex disability. It is classified as one of the 'multirange' impairments of the organism and is referred to as a 'multiple disability'.² The high level of impairment of sight and hearing results in the inability to benefit from social achievements which are available to persons with non-multiple impairments, such as sight impairment or hearing impairment. For this reason, according to the Polish expert T. Majewski, deafblindness must be considered as a separate disability that requires from the afflicted persons special methods of communication and peculiar means of overcoming difficulties in performing everyday tasks.³

The definition of deafblindness which functions in the official and medical procedures was established by the Polish Association of the Blind. It asserts that a deafblind person is someone who, because of simultaneous sight and hearing impairment, encounters difficulties that are different from impediments caused by deafness or blindness alone, especially in terms of movement and communication.⁴

The American Federal definition of deafblind children also applies the options between multiple impairment and single impairment of a sense and points to the effects of these impairments in the didactic process. According to this definition, deafblind children, because of 'simultaneous sight and hearing impairment, have special needs in terms of communication, development and education, and these needs cannot be fulfilled properly by

² A. Twardowski, Pedagogika osób ze sprzężonymi upośledzeniami, in: Pedagogika specjalna, ed. W. Dycik, (Poznań: UAM, 1998), 258.

³ T. Majewski, Edukacja i rehabilitacja osób głuchoniewidomych (Warszawa: TPG/ PZN, 1995), 88.

⁴ Ibid, 25.

special educational programmes for children and youths with either sight or hearing impairment.²⁵

The Polish Association for the Welfare of the Deafblind offers a similar definition. It considers a child as deafblind when 'he/she has difficulties in understanding spoken language without a hearing aid, and the sight impairment is big enough to obstruct or largely impede the use of common print. These limitations minimise a child's capabilities to learn, do everyday activities, move independently and communicate with the environment.'6

All the definitions of deafblindness, as well as the above-mentioned definitions, assume a twofold criteria for its occurrence:

- biological, measured by medical tools, which point to simultaneous serious impairment of sight and hearing apparatus;
- social and functional, which point to the effects of this impairment on various spheres of human activity – personal, professional and social life.⁷

2. Biological criteria of classifying deafblind people

The main criterion for distinguishing deafblindness is simultaneous serious impairment of sight and hearing apparatus.

Impairment of sight apparatus

The two most important sight function impairments influencing the social functioning of a person are the impairment of central vision and the impairment of peripheral vision, which are overlapped by such features as the acuity of vision, visual field and colour sensations.

The impairment of central vision is interlinked with lowering the acuity of vision. A person with such an impairment cannot see the proper size of objects from a distance, unlike a person with normal visual acuity. The degree of sight impairment is determined by the so-called Sneller charts or, more frequently, by means of a new generation of computers used for sight examination. Sneller

⁵ Serving children and youth who are deafblind, Technical Assistance Project, New York, 1994.

⁶ M. Zaorska, *Głuchoniewidomi w Polsce. Specjalna pomoc, edukacja i rehabilitacja* (Olsztyn: UWM, 2002), 18.

⁷ Ibid.

charts contain proper graphic signs (letters, digits, pictures) of different size and line thickness which have such proportions that an eye of normal visual acuity differentiates them from a specific distance. The sight acuity of an examined person is described as the ratio between the distance from which a person sees a given sign and the distance from which he/she should see it. According to T. Majewski, this ratio is expressed as a fraction or a decimal. For example, if an examined person reads a sign on the chart from the distance of 5 m and the sign is designated for this distance, then this person's visual acuity (V) equals V = 5/5 = 1.0, thus it is normal. If the person sees from this distance merely a sign corresponding to the distance of 50 m (tenfold bigger), then his/her visual acuity (V) equals 5/50 = 0.1, thus it is decreased tenfold in relation to the norm.⁸

The International Classification of Impairments Disabilities and Handicaps adopts the following classification and degrees of visual impairment:⁹

Category	Degree of visual impairment	Visual acuity after correction	Terminology (name)
Vision within the normal range	-	from 0.8 to 1.0	normal vision
	mild	< 0.8	near-normal vision
Low vision	moderate	< 0.3	moderate low vision
	severe	< 0.1	severe low vision
	profound	< 0.05	profound low vision or moderate blindness
Blindness	near-total	< 0.02	near-total blindness– light perception
	total	0	total blindness

Source: Given in the form suggested by T. Majewski: *Edukacja i rehabilitacja osób głuchoniewidomych*, Warszawa, 1995, 29.

⁸ T. Majewski, op. cit., 26-28.

⁹ T. Majewski, op. cit., 29, International Classification of Impairments, Disabilities and Handicaps. World Health Organization, Geneva, 1980.

According to T. Majewski's interpretation, normal vision is above acuity of 0.3 and is divided into normal and near-normal. Low vision ranges from 0.3 to 0.05 acuity and is divided into moderate and profound low vision. Blindness involves not only total cessation of visual functions but also light perception and visual acuity within the range of 0.05 to 0.02. In relation to the last category, two nomenclatures have been adopted: moderate blindness and profound low vision.¹⁰

Peripheral vision impairment manifests itself as limitations and defects of the visual field. The normal visual field of every eye in the horizontal plane equals around 150°, and around 130° in the vertical plane. When the visual fields of both eyes partially superimpose, the full visual field equals 200°. The World Health Organization assumes the following classification of visual field impairment:

- 1. Concentric (even) defects of visual field can be:
- small diameter of field from 60° to 120°,
- moderate diameter of field from 20° to 60°,
- profound diameter of field from 5° to 20°,
- severe diameter of field below 5°,
- tunnel vision seeing with only a small part of the retina, as if through a keyhole;
- 2. Hemianopia (hemianopic blindness) loss of a half of the visual field, either of the left or right side;
- 3. Other defects of the visual field which include diffuse defects in the form of scotomata, for example central scotoma in the area of macula, wedge-shaped defect of visual field etc.¹¹

Alongside these two main vision functions, colour vision can also be impaired. T. Majewski distinguishes between the following defects of colour vision:

- 1. Monochromacy seeing black, white and grey colours;
- 2. Dichromacy, that is blindness or defect in part of the spectrum it can pertain to seeing red, green or blue colour.

Among other vision defects, the binocular (stereoscopic) vision defect often manifests itself, for example in the case of strabismus. Night vision,

¹⁰ T. Majewski, op. cit., 29-30.

¹¹ T. Majewski, op. cit., 30.

that is the process of adaptation to seeing in poor light conditions, is also often impaired. In this case, the afflicted person cannot see either at twilight or by poor light.¹²

All of the above-mentioned functions are impaired in a totally blind person. A person with low vision does not only experience defects in the main vision function, for example a decrease in vision acuity. He/she can also experience a different range and degree of defects in other vision functions, for example narrowing of the visual field, colour vision deficiency, disorders of binocular vision or mesopic vision defects. Low vision can thus have various degrees of decrease in vision acuity.

A decrease in vision acuity results in an imprecise visual perception of things and shapes. Narrowing of the visual field is the reason for deterioration in the sense of direction and independent movement. Other, different defects of vision function cause further problems in the everyday lives of blind people.¹³

Impairment of hearing apparatus

There are four main criteria used in audiology¹⁴ and clinical practice and pedagogy¹⁵ to classify hearing impairment:

- the place of impairment of the auditory analyser,
- the degree of its impairment,
- the moment of its impairment in relation to the stage of speech development,
- the causes of impairment.¹⁶

Considering the place¹⁷ of impairment of the auditory analyser, one can distinguish between conductive hearing loss, sensorineural hearing loss

¹² Ibid, 30-31.

¹³ T. Majewski, op. cit., 30-31.

¹⁴ T. Bystrzanowska, Audiologia kliniczna (Warszawa: PZWL, 1978); H. Skarżyński, M. Mueller-Malesińska, W. Wojnarowska, 'Klasyfikacja zaburzeń słuchu,' Logopedia vol. 28 (2000), 49-60.

¹⁵ B. Szczepankowski, Pomoce techniczne dla osób niepełnosprawnych (Warszawa: CNBSI, 1994), 122; K. Krakowiak, Fonogesty, op. cit., 17; Z. M. Kurkowski, Mowa dzieci sześcioletnich z uszkodzonym narządem słuchu (Lublin: UMCS, 1996), 53-58.

¹⁶ In this order K. Krakowiak poses and formulates problems: op. cit., 17.

¹⁷ H. Skarżyński, M. Mueller-Malesińska, W. Wojnarowska, op. cit., 51-52.

Chapter I

(sensorineural deafness), central hearing loss (central deafness) and mixed hearing loss or mixed deafness (conductive-sensorineural).

Conductive hearing loss involves impairment of the inner or middle ear and disrupts the reception of sound waves through the air. This hinders the reception of sounds from the environment but does not preclude the hearing of one's own voice. These are usually small defects, the reason being that the bone conduction works properly. The results may include delayed speech development, alterations in the strength and tone of the voice and defective pronunciation of low sound formants, since this type of impairment limits the ability to hear low tones.

Sensorineural and mixed impairments are related to the damage of the organ of the Corti or acoustic nerve. Depending on the degree of damage to the hearing apparatus, these hearing impairments can involve various speech and language development dysfunctions. In such a case, the ability to intercept one's own speech and utterances from the environment is limited. Impairment largely pertains to perception of high-pitched sounds. In the worst case scenario, this may lead to total inability to learn language and communicate with the environment. The impairment of auditory canals and auditory centres in the brain is called central hearing loss or central deafness.

The degree of hearing loss, or its depth, is measured on the basis of audiometric analysis of auditory sensitivity to pure tones. The degree is measured in decibels compared with the auditory field of a person with normal hearing. The following frequencies in Hertz (Hz) for speech hearing have been measured (500, 1000, 2000 and 4000 Hz if, at a given frequency, the sensitivity threshold is lower than at 2000 Hz).

When analysing hearing loss, the better hearing ear is taken into account. The result of 20 dB is considered the norm, while other results are evaluated according to the table prepared by the International Office for Audiophonology:¹⁸

Table 2. Hearing lo	oss classification
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Hearing loss range (dB)	Degree of hearing loss
above 20 to 40	mild
above 40 to 70	moderate

¹⁸ B. Szczepankowski, *Pomoce*, op. cit., 122, Z. M. Kurkowski, 'Kształtowanie się zdolności słuchowych a rozwój mowy', in: *Zaburzenia mowy*, ed. S. Grabias (Lublin: UMCS, 2001), 267-272.

above 70 to 90	severe
above 90	mild

With the first and the second degree of impairment – mild and moderate – it is possible to hear and understand speech under favourable acoustic conditions. The severe degree of hearing loss prevents the hearing and understanding of speech without the use of a hearing aid (although it is not always possible to differentiate between all sounds). Profound hearing loss makes it impossible to understand speech; even with a hearing aid one can only partially hear sounds.

Depending on the degree of hearing impairment, one can differentiate between deafness and hearing loss. Deafness is defined as a total cessation of the functions of hearing apparatus or their deep impairment. Despite the use of hearing aids, the defect prevents or limits auditory orientation in the environment and communication. Hearing loss is defined as hearing impairment which can be corrected with the help of a hearing aid. This type of impairment does not cause more serious difficulties and limitations to auditory orientation in the environment and communication.¹⁹

The division into deafness and hearing loss, although precise, is insufficient in terms of social practice. As J. Sowa observed, the precise consideration of the degree of hearing loss²⁰ has a great importance for the organisation of the learning process and methods of all therapies, also the methods of teaching language and speech. Fowler has prepared a classification of degrees of hearing loss which is widely used nowadays.²¹

Degree of auditory perception impairment	Designation of hearing loss	Reaction to speech from 1.5 m	Qualifies to school
0-20 dB	mild	at about 20 dB a whisper cannot be heard	normal
20-40 dB	moderate	weak articulation of speech is not heard	normal

Table 3. Degrees of hearing	g loss according to Fowler

¹⁹ T. Majewski, op. cit., 33.

²⁰ J. Sowa, *Pedagogika specjalna w zarysie* (Rzeszów: Wydawnictwo Oświatowe FOSZE, 1998), 178.

²¹ O. Lipkowski, Pedagogika specjalna (Warszawa: PWN, 1981), 122.

40-60 dB	moderately severe	moderately loud speech is not heard	for the hard of hearing
60-80 dB	severe	loud speech is not heard	for the hard of hearing
above 80 dB	profound	a scream is not heard	for the deaf
lack of auditory perception	total deafness	a loud scream is not heard	for the deaf

Source: O. Lipkowski, Pedagogika specjalna, (Warszawa: PWN, 1981), 122.

Depending on the influence of deafness on the development of speech, one can distinguish between the following categories of children with hearing impairment:

- 1. hard of hearing children audiometric analyses show a decrease in hearing ability up to 20 dB (the children's speech essentially develops as normal);
- 2. audibly impaired children hearing loss is about 40 dB (the children cannot hear speech from a far distance, their speech is not normal, some sounds are pronounced incorrectly);
- 3. children with average hearing loss of 60 dB (they can hear loud speech from a close distance, their speech is severely underdeveloped and pronunciation is distorted);
- 4. children with large hearing loss within 70-90 dB (despite the help of hearing aids, verbal contact with these children is impossible);
- children with total deafness hearing loss amounts to 90 dB (children cannot hear words, the only means of communication is reading speech from lips).²²

Teachers of the deaf and speech therapists (K. Krakowiak, M. Kurkowski), who take into account the possibilities of using language, point to the time of hearing damage in relation to the stages of human life. They distinguish between:

- pre-lingual deafness which appears before a person learns to talk, that is usually until 2-3 years of age,
- peri-lingual deafness which appears during the time when a person learns to talk, that is at 3-6 years of age,

²² Z. Sękowska, *Tyflopedagogika* (Warszawa: PWN, 1981), 167-168, K. Krakowiak, op. cit., 14-24.

post-lingual deafness which appears after 6 years of age.²³

In the case of pre-lingual and peri-lingual deafness, speech does not develop independently and the child requires organised, complex medical, psychological and pedagogical care. In the case of post-lingual deafness, there is a possibility of starting or continuing education in integrating conditions, however under specialist care.²⁴

3. Social and functional criteria of classifying deafblind people

Apart from medical criteria, there are also functional ones which define deafblindness. They determine those spheres of life which are specifically influenced by dysfunctions of sight and hearing. T. Majewski distinguishes between the following fields of human activity:

- 1) access to information and knowledge,
- 2) communication with the environment,
- 3) everyday activities,
- 4) orientation and movement in space,
- 5) professional career,
- 6) participation in cultural and social life.²⁵

The results of deafblindness are visible in all of these spheres of life. The dysfunction of sight and hearing causes difficulties and limitations in personal and social life, often to the extent that the afflicted person is not able to function independently. In such cases the assistance of another person is necessary.

²³ Ibid, 18-24, Z. M. Kurkowski, Mowa, op. cit., 18-45.

²⁴ B. Szczepankowski, op. cit., 127.

²⁵ T. Majewski, op. cit., 34, M. Zaorska, 'Wczesna rewalidacja dziecka ze złożonymi zaburzeniami słuchu i wzroku szansą na integrację', in: *Dylematy pedagogiki specjalnej*, eds. A. Rakowska, J. Baran (Kraków: Wydawnictwo Naukowe Akademii Pedagogicznej, 2000), 201.

Chapter I

4. Causes of sight and hearing loss

From an etiological perspective there is a distinction between deafblind people with congenital deafblindness and acquired deafblindness.

Congenital deafblindness is preconditioned by genetic and innate factors. In the first case, deafblindness is of a hereditary nature; in the second case, it appears during the foetal stage. The impairment of the sight and hearing senses can also cause perinatal injury and a history of illnesses in the first months of life (e.g. meningitis, scarlet fever).

The most common factors which cause impairment of sight and hearing are those which cause congenital deafblindness:

1. Congenital rubella syndrome

Rubella which occurs in pregnant women is very dangerous in the first four months of pregnancy. The sight and hearing organs of the foetus are at this time especially under a threat of injury. It is estimated that 15% of deafblind people were afflicted by their mothers' rubella during pregnancy.²⁶

2. Usher syndrome

Vision problems of afflicted persons start with night vision impairment, and then central vision impairment. The disorder is of a progressive nature and often ends with total blindness. As estimated by T. Majewski, around 90% of cases involve profound congenital hearing impairment accompanied by balance disorder. Degenerative changes in the retina start to occur before the age of maturity. In many cases the progressing degenerative process ends with total blindness. Another type of Usher syndrome occurs in about 10% of cases and the process is milder. Usher syndrome is a congenital disease which appears only in children whose both parents carry the disease. It is estimated that 5 in 100,000 persons suffer from this syndrome.²⁷

Apart from the above-mentioned diseases, there are many other syndromes which involve simultaneous impairment of sight and hearing. However, they occur rarely. The most commonly listed syndromes are:

²⁶ T. Majewski, op. cit., 34.

²⁷ Ibidem; Zespół Ushera (Warszawa: TPG, 1993).

CHARGE, Hallagren, Alström, Cockayn, Keans-Sayre,²⁸ Bardet-Biedl, Refsum, Wolfrem, Norrie, Woardenburg and Gorlin-Cohen.²⁹

3. Prematurity

There is a certain percentage of children with simultaneous sight and hearing impairment among premature babies. In the various statistical surveys which are carried out in order to diagnose the deafblind community, prematurity as the cause of sight and hearing disorders is ranked very high, usually just after rubella.

Studies conducted by the Perkins School for the Blind in Watertown (USA) on a group of 6,400 children diagnosed as deafblind have shown that deafblindness was caused by the mother's rubella during pregnancy (15%), prematurity (4%), Usher's syndrome (4%), encephalitis or meningitis (4%) and CHARGE syndrome (3%). Furthermore, 40% of the children were diagnosed with various aetologies, none of which occurred in more than 2% of cases.³⁰

5. Typology of the deafblind according to the level of coexistence of the sight and hearing loss

Deafblind people comprise an exceedingly diverse group which can be divided according to the following criteria:

- 1. Degree of hearing and sight impairment;
- 2. Period of life in which deafblindness occurred.

Considering the degree of sight and hearing impairment, the following groups are identified:

- totally deafblind,
- · totally deaf and visually impaired,
- · hearing impaired and totally blind,
- hearing impaired and visually impaired.³¹

²⁸ B. Jacórzyński, M. Książek, 'Dziedziczne zespoły słuchowo-wzrokowe', Świat Ciszy no. 6 (1994), 12.

²⁹ M. Zaorska, Głuchoniewidomi, op. cit., 43-48.

³⁰ T. Majewski, op. cit., 42-43.

³¹ Ibidem, 46.

Considering the second criterion - the time of occurrence of impairment among the deafblind - one can distinguish between the following persons:

- · congenitally deafblind,
- · people with congenital hearing impairment and acquired sight impairment,
- · people with congenital sight impairment and acquired hearing impairment,
- people with acquired sight and hearing impairment.³²

Combining these two categories results in the following representation of the deafblind persons' population:

- I. Among persons with congenital deafblindness there are:
- 1. people with total congenital deafblindness,
- 2. people with total deafness and congenital visual impairment,
- 3. people with total blindness and congenital hypoacusis,
- 4. people with hypoacusis and congenital visual impairment;
- II. Among deafblind persons with congenital hearing impairment and visual impairment acquired later in life there are:
- 1. people with congenital total deafness and acquired total blindness,
- 2. people with congenital total deafness and acquired visual impairment,
- 3. people with congenital hypoacusis and acquired total blindness,
- 4. people with congenital hypoacusis and acquired visual impairment;

III. Among persons with congenital visual impairment and acquired hearing impairment there are:

- 1. people with congenital total blindness and acquired total deafness,
- 2. people with congenital total blindness and acquired hypoacusis,
- 3. people with congenital low vision and acquired total deafness,
- 4. people with congenital low vision and acquired hypoacusis;

IV. Among persons who acquired sight and hearing impairment later in life there are:

- 1. people with acquired total deafness and acquired total blindness,
- 2. people with acquired total deafness and acquired low vision,
- 3. people with acquired total blindness and acquired hypoacusis,

³² M. Zaorska, op. cit., 24, L. Ludikova, *Vzdělávání hluchoslepých I* (Praha: Scientia, 2000).