

From Deafblindness to Multiple Sensory Impairment: a few explanatory notes on definition, terminology, and historical context

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Abstract

In deafblindness (DB), the consequences of visual and hearing impairments are not additive, but multiplicative creating unique problems in information, communication and mobility, hence the need to recognize it as a distinct disability. There are three types of approaches that depend on several factors, taking into account the structure of educational and support services for people with DB/MSI and the nature of human, technological and financial resources. In our country, according to the law, the broadest approach is promoted, meaning the inclusion of other disabilities in addition to sight and/or hearing. In other countries there are other names that, depending on the context or user, are synonymous with DB. The huge variability of DB/MSI cases causes some specialists to refer to a spectrum disability in which there are different weights and different degrees of sensory loss, cognitive deficit, language impairments and/or somatic pathologies. All this individual “puzzle” generates a state of multi-handicap, which is reflected both in a specific pattern of learning and communication difficulties, and in the emergence of derived disabilities that hinder or obstruct the overall somatic and psychological development through restrictions on using the remaining hearing and sight.

Keywords: disability, deafblindness, sensory deficits, multiple sensory impairment, accessibility, inclusiveness, special education

Apparently, deafblindness (DB) can be defined as the cumulation of total sensory deficits of the distance senses (hearing and sight), with consequences upon psycho-individual and psycho-social development. The term has the quality of being expeditious and easy to remember and convey in the everyday communication. It imprints in the minds of the uninformed public the stereotypical representation of a dual sensory disability at the maximum level of hearing and vision loss, which, on the one hand, makes it easily diagnosed from a medical point of view and, on the other hand, relatively simple to be approached from an educational, social and legal point of view, by simply summing up the pedagogical methods and procedures used in educating deaf and blind children, the already existing organizational strategies and structures for the two categories of disability for school, social and professional integration and, finally, the relevant current legal provisions.

A rare syntagm used in common conversations is multiple sensory impairment/disability (MSI). Unlike DB, MSI does not refer exclusively to distance senses and does not impose a limit on the senses affected, neither in number, nor in level, nor in relative weight. Thus, a person with MSI may have congenital (innate) hearing loss associated with acquired (adventitious) blindness, amid an alteration of tactile sensitivity or vestibular disorders. Or other combinations, including olfactory and/or gustatory deficits. Although this phrase seems qualitatively superior to the term DB, in practice it is little used outside the field of special education (special psychopedagogy) due to the lack of a simple and clear definition of its content. One must not ignore the fact that individuals situated at decision-making tiers in the administrative, educational, economic, etc. areas seek benchmarks as little as possible subject to particular interpretations and amendments (individual in nature or belonging to small groups).

In the USA and the United Kingdom circulate competing terms (*combined sight and hearing loss*, *dual sensory impairment*) for various reasons related to either the specifics of that institution (for example, a school for the blind students organizing a class for deafblind children) or the relationship with the sponsors and organizations of the deaf and blind, or simply a local tradition. In this paper we will use the “deafblindness/multiple sensory impairment” (DB/MSI) syntagm or parts of it, “deafblindness” (DB), respectively “multiple sensory impairment” (MSI). As a referential we will use the definition in the annex approved by Order no. 3,071 of January 18, 2013², which, in the introduction, states that “deafblindness is a severe, multisensory impairment (combination of visual and hearing impairments), most often associated with other types of impairments.” In the annex on the educational content for early preschool intervention for children with multiple sensory impairments/deafblindness, the applicable terminology is explained, being included in the “deafblindness” term hearing and vision impairments (congenital or acquired in early childhood), congenital hearing impairment combined with acquired vision impairment, congenital visual impairment combined with acquired hearing impairment, respectively acquired hearing impairment and visual impairment, while the syntagm “multiple sensory impairments” refers to hearing and/or visual impairments (congenital or acquired), to difficulties in processing visual and auditory information at the central level (i.e. blindness, respectively cortical deafness), as well as to difficulties in processing visual and/or auditory information in the context of the existence of other disabilities (see “Introduction”). It should be mentioned that the cited document uses the “multiple sensory deficiencies” syntagm.

Our preference in this paper is for the singular formulation, because we wish to highlight the fact that deafblindness designates a unique disability (especially because of the consequences it has on the person in question), but also that it is, at the same time, a compound word which refers to a multitude of individual variations, difficult to group together otherwise.

The wording used in the legal definition above can be better understood if we refer to the reasons why the definition of DB/MSI is not by any means simple:

- a. The impairments leading to disability have a different weight for each affected individual, making up their own symptomatic profile; the interference created by them with the life environment of the said individual leads to difficulties in exploration and interaction with the environment, mobility and communication much greater than a simple addition of visual and hearing impairments;
- b. The negative effect on psycho-individual development is particularly marked in severe cases of DB/MSI, inactivating the benefits of natural compensation present in other disabilities;
- c. The very high variability of DB/MSI cases is combined with their extremely low frequency not only in the general population, but even in that of people with disabilities, leading to the most diverse difficulties, starting with the standardization of investigation and assessment tests of children with DB/MSI or with the validation through empirical evidence of certain therapies and educational-rehabilitation intervention strategies and ending with pinpointing of precise criteria for granting certain rights and facilities of socio-economic nature;
- d. Beyond the fact that DB/MSI is not a monolithic disability, convenient to be inserted in a text of law or in a set of criteria used for classification in a category of disability, DB/MSI has been continuously evolving, requiring periodic reassessments and taxonomic reclassifications;

² Published in the *Official Gazette of Romania*, Part I, no. 146 of March 19, 2013.

e. Independent developments in various scientific domains and applied areas of work influence over time both the usual diagnostic and rehabilitation models and the current life prospects of people with DB/MSI.

These competitive points of view create major differences in setting conceptual benchmarks at the institutional and specialist level, with a direct effect on case reporting and percentage allocations in various contexts (medical, educational, social, etc.), as well as on therapeutic, educational, socio-economic and legal decisions that are required. Therefore, comparing a prevalence³ of DB/MSI of 0.2% recorded in one country with that of 2% reported by another is not feasible without specifying the conceptual benchmarks⁴. Some national studies prefer to indicate the exact number of people identified as having DB/MSI⁵, leaving the reader to find out for her- or himself about the criteria used.

There are many varieties of DB/MSI, all depending on the various combinations of impairments involved and their evolution over time. In general, we distinguish between:

- a) congenital DB/MSI, when impairments are present from birth, and
- b) acquired DB/MSI, when impairments occur later.

Although it seems a simple dichotomous distinction, in reality it is not applicable, because there are situations in which the cause is genetic in nature, but the sensory disabilities manifest later (in adolescence, for example), or when the impairments are caused by accidents during the perinatal period (such as, for example, craniocerebral traumas caused by improper obstetric maneuvers). Perhaps such a distinction is useful in systematizing theoretical knowledge, but in practice it has too little relevance. The profound negative effects of the onset of DB/MSI on language and communication, as a result of contracting an infectious disease (e.g., meningitis, scarlet fever) at an early age, are not essentially different from those manifested in children born with multiple sensory impairments. On the other hand, the significant deterioration of visual and auditory performance in old age makes older people who have not needed specialized care services all their lives to become eligible for them.

³ *Prevalence* means the percentage of individuals in a population who manifest a particular disease at a given time or in a specified period of time. Prevalence differs from *incidence* in that it includes all cases (pre-existing and newly occurring) in a population at a given time, while incidence refers only to cases that have occurred in the time interval considered.

⁴ In Australia, for example, the prevalence of DB/MSI varies between 0.2 and 3.3% of the general population, with two-thirds of cases over the age of 65 (apud Fatah, 2015). An international study undertaken under the auspices of WFDB and published in 2018 indicates a range between 0.2 and 2% of the general population (value limits indicating people with severe DB and those with mild DB, respectively). In the European Union there would be between 150,000 and 3,000,000 people with DB (see below).

⁵ As of December 1, 2018, 647 young children (under the age of two) and 9,904 children and young people (aged 3 to 21) were officially registered as deafblind in the United States, representing less than 1% of the general population (apud NCDB, 2019). According to Sense (2019), last year there were approximately 390,000 deafblind people in the United Kingdom, which, with an estimated population of 66.8 million (apud ONS, 2020), means a share of 0.58%. Most European Union countries do not have an exact record of people with DB/MSI, but it is estimated that there would be about two million, with an incidence of 40 cases per 100,000 people (apud EDBN, 2012), or about three million (Jarrold, 2014). In our country, according to ANDPDCA (2020), 6 children and 72 adults with DB/MSI are officially registered, given that SIR reported in 2016 that over 500 children with SC in Romania were educated in classes established in 15 special schools (apud <http://www.sensabilitate.ro/despre/sense-international-romania/servicii-educationale-pentru-copii-cu-surdocecitate/>), and over 240 children and young people with DB/MSI have learned and have been learning in 8 vocational centers in the country trades such as digital printing, marzipan modeling and horticulture (SIR, 2019, p. 8).

What we are trying to say is that a textbook classification of DB/MSI is inoperative in everyday life situations or in concrete educational-rehabilitation contexts. These classifications are necessary from a diagnostic and administrative point of view (as is the case with assessment committees), but too little useful in the functional evaluation and design of the individualized intervention program. DB/MSI, in this context, poses a continuous challenge to the interveners both in the design and provision of optimal educational-rehabilitation activities, as well as in the most precise addressing to criteria and conditions imposed by various public institutions and legal documents.

Taking into account these clarifications, there are several possible situations in practice:

1. Child with congenital DB, of a genetic nature, the manifestations of which become evident later (e.g., Usher syndrome);
2. A child with normal sensory development, but who loses his hearing and sight before the age of two;
3. Child with good hearing and visual impairment, but insufficiently exploited by hearing aids and visual correction (with glasses);
4. A child with congenital deafness, but with a remaining sight good enough to allow the acquisition of language and communication through lip-reading and mimic-gestural in a natural way;
5. Child with deep DB and tactile hyperesthesia, refractory to touch;
6. Child with mild dual sensory impairment, but with associated cognitive impairments which severely impair sensory learning and the acquisition of oral verbal language;
7. Young person with multiple sensory impairment due to violent trauma (e.g., explosion, car accident) or acute medical condition;
8. Elderly with presbyopia and presbycusis, suffering from a neurodegenerative disease, etc.

In a seminal work, translated into Romanian, Stuart Aitken (2000)⁶ analyzed three types of conceptual approaches of DB/MSI, depending on the emphasis on the specialized nature of the instructional-educational methods required and the range of needs exhibited by the deafblind individuals:

- a restrictive approach, according to which the term “deafblindness” should be reserved only for children with pure congenital visual and hearing impairment.
- a permissive approach, including children who have impairments added to the primary disability (dual sensory disability).
- an extensive approach, according to which children with a single “distance sense” (hearing or sight) impaired and additional multiple associated disabilities can be considered as part of the DB-specific multi-handicap condition.

The restrictive approach is justified by the existence of specific educational-rehabilitation methods and strategies that, although inspired by the usual special education interventions employed with children with visual or hearing disabilities, have evolved independently over time

⁶ Cf. Stuart Aitken (2007). Surdocecitatea. O abordare conceptuală. In S. Aitken et al., *Procesul de predare-învățare la copiii cu surdocecitate. Contact – comunicare – învățare* (Romanian trans.) (pp. 1-34). Bucharest: Semne.

as a result of studies and observations conducted by researchers and practitioners in the field. Increasing the number of beneficiaries would decrease the availability of (human, technological, financial, etc.) resources for children with pure DB. In addition, any disability added to auditory and visual ones would complicate the state of multi-handicap, amplifying the requirements of individualized approach and, therefore, would further fragment this taxonomic category. This type of approach is tributary to the pioneering era, in which exceptional cases such as those of Laura Bridgman, Helen Keller, Olga Skorohodova or Vasile Adamescu required innovative techniques and methods.

In the second case, the main argument is that the state of multi-handicap exists *de facto*, because the negative effects of dual sensory impairment on communication, learning, personal and social autonomy, and personality development as a whole are as pernicious as the presence of supplementary impairments. The necessary interventions must respect the same principle of individualization, so that no real saving of resources is achieved. In addition, those persons who, for one reason or another, have not been able to qualify for interventions in the field of hearing or visual disability services may also have access to them.

Regarding the comprehensive approach to DB/MSI, Aitken (2000) argued that “techniques and methods used with children and young people who are deafblind often can be of benefit to others” (p. 10), advocating for a practical approach based on three empirical findings:

- a) especially in very young children, it is very difficult to account for learning difficulties, as well as everyday ones, generated strictly by dual sensory impairment;
- b) the effective DB therapeutic approaches proved to be useful also in the case of those individuals with a single sensory (auditory or visual) impairment but having associated disabilities;
- c) educational, medical or support services may be requested not only by the families of children with pure DB, but also by the families of those with visual or hearing impairments who have multiple disabilities.

Thus, instructional-rehabilitation intervention approaches and strategies designed for children with congenital (or early-onset) DB may also be effective in children and young people with congenital (or early onset) visual or hearing impairment who have associated disabilities (e.g., communication difficulties, learning disabilities or motor disabilities) (Aitken, 2000).

The Romanian definition of DB/MSI, stated above, takes into account all these insights in order to offer as many children with visual and/or auditory sensory deficits and other impairments as possible the possibility to be admitted in intervention programs according to their needs. There are many genetic causes of DB/MSI that impede the optimal psychological and somatic development. Therefore, it might be more appropriate to refer to a continuum of special needs in DB, starting with mild cases of hearing loss and amblyopia and reaching those in which profound and multiple learning difficulties are massively amplified by the visual-auditory deficit (DES, 1989).

For comparison, the federal definition of DB in the USA⁷ states that “deafblindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with

⁷ Included in PL 101-476 (known under the acronym IDEA), part B, law amended in 2015 by PL 114-95 (ESSA).

blindness” 34 CFR §300.8 (c) (2) (2006)⁸. The United States Code⁹ uses a much broader definition¹⁰ for people over the age of 18:

The term “deaf-blind individual” means any individual:

- a) (i) who has a central visual acuity of 20/200 or less in the better eye with corrective lenses, or a field defect such that the peripheral diameter of visual field subtends an angular distance no greater than 20 degrees, or a progressive visual loss having a prognosis leading to one or both these conditions; (ii) who has a chronic hearing impairment so severe that most speech cannot be understood with optimum amplification, or a progressive hearing loss having a prognosis leading to this condition; and (iii) for whom the combination of impairments described in clauses (i) and (ii) cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation;
- b) who despite the inability to be measured accurately for hearing and vision loss due to cognitive or behavioral constraints, or both, can be determined through functional and performance assessment to have severe hearing and visual disabilities that cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining vocational objectives; or
- c) meets such other requirements as the Secretary [of Education] may prescribe by regulation.

We note that this definition specifies very clearly the legal criteria for recognizing the status of adult “individual who is deaf-blind.”¹¹

In Europe, as in other countries of the world, each country that recognizes the existence of DB has its own definition, more or less similar to the American federal definition, which, on the one hand, takes into account the arguments of specialists in the field, and, on the other hand, it takes into account the resources that can be allocated for its implementation. Particular well known is the “northern” definition of DB, according to which “deafblindness is a combined visual and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other”, which is why DB is a “distinct disability”¹² The definition (updated in this form in 2016) is in use in Denmark, Finland, Iceland, Norway and Sweden¹³. Its initial form formed the basis for the inception of the Declaration on the Rights of Persons with Deafblindness—P5_TA (2004) 0277—adopted by the European Parliament on April 1, 2004, at the initiative of EDBN (Jarrold, 2014). Point A of this Declaration states that “deafblindness is a distinct disability that is a combination of both sight *and* hearing impairments, which results in difficulties having access to information, communication and mobility” (EP, 2004).¹⁴

⁸ See <https://sites.ed.gov/idea/regs/b/a/300.8/c/2>

⁹ The US Code is “a consolidation and codification by subject matter of the general and permanent laws of the United States” (<https://uscode.house.gov/>).

¹⁰ Helen Keller Act, U.S. Code, 29, chap. 21, §1905. Retrieved on August, 30, 2020 from: <https://www.law.cornell.edu/uscode/text/29/1905>.

¹¹ Details at: <https://www.helenkeller.org/hknc/lesson/introduction-deaf-blindness>

¹² Apud <https://nordicwelfare.org/wp-content/uploads/2018/03/nordic-definition-of-deafblindness.pdf>

¹³ The first meeting of people with DB took place at the 1974 conference of organizations for the blind in Sweden, Norway and Denmark. Apud <http://www.fldb.org/Filer/DBNSK%20English.pdf>

¹⁴ And at point B it was stated, without indicating the source of the information, that in the European Union there were about 150,000 people with DB (EP, 2004), while a report published ten years later advanced a number 20 times higher (cf Jarrold, 2014). The very large margin of estimates is probably the result of differences in approach (restrictive vs. extensive).

The declaration is all the more important as it affirms the equal rights of persons with DB with all other EU citizens, including the “right to participate in the democratic life of the European Union”, “to work and access training, with appropriate lighting, contrast and adaptations”, to enjoy individualized medical and social assistance, to benefit from access to lifelong learning, “to receive one-on-one support where appropriate from communicator-guides, deafblind interpreters and/or intervenors” (EP, 2004, D2).

The call for Member States to recognize by law the full civil rights of persons with DB in the Union automatically implies the invalidation of any forms of institutional discrimination or segregation, but also the need for more subtle, psycho-social changes that obviously cannot be legislated, but only promoted and argued through educational actions. However, there are a few comments to make.

The first observation concerns the term itself: “deafblindness.” The Romanian language does not register a derivative of it, as happens with “blindness” or “deafness”, unlike French (*sourdaveugle*) or English (*deafblind*), because this disability does not appear in everyday talk. In the Anglo-Saxon scientific community, for example, the terms “deafblind” and “deafblindness” have undergone transformations by losing the hyphen between the two component words to indicate the unitary, distinct character of disability (Lagati, 1995). More recently, following the model agreed upon by the deaf community, the lower-case word “deafblindness” refers to disability and the medical conditions that entail it, while the upper-case letter indicates the community of people with DB (Hofmann, 2006). Finally, as we have seen, the use of the syntagm “multisensory impairment” or “dual sensory impairment” does not distinguish the senses that are affected, leaving room for broader meanings. The shift from the focus on disability to the person does not seem, for the time being, to have been generalized in the official text wording, as happened, for example, with the transition from “handicapped” to “individual with disability”. Several explanations can be advanced, including the reduction of social stigma (real or perceived) by capitalizing the words “Deaf” and “Blind” as markers of cultural belonging to those communities. As many people with vision or hearing loss prefer disability-first language wording instead of person-first language as an identity marker, it is only natural that *deaf-blind individuals* (or *people*) to follow suit.

The second observation concerns the relationship with deafblind persons. The formal recognition of their civil rights and the facilitation of access to care, education, work and leisure through legal provisions does not in any way guarantee their effective exercise. The language itself contains expressions such as “see you”, “look up”, “unheard of” or “court hearing”. In an attempt to avoid embarrassing expressions, many speakers resort to useless language artifices, making the act of communication even more difficult. Whether done orally, in writing, or by touch, communication is often mediated by either technology or the interpreter, which increases participants' psychological discomfort. The procedures of most institutions and companies, when they exist, do not offer communication alternatives for people with DB or if they are, they are complicated and time and energy consuming. The proliferation of telephone communication in commercial and service activities has become counterproductive for people with DB, especially when it comes to voice caller identification. The phenomenon is endemic, at least in our country, in the case of courier companies, banks or mobile phone carriers. The impossibility of using a voice recognition program raises a technological barrier to interaction precisely in a society that should promote inclusion through technology. The very low incidence of DB makes it unlikely to change the communication policy at the level of institutions and companies at least in the near future, because offering viable alternatives is not profitable in a competitive economic context.

The third observation also refers to the relationship with people with DB, but in the context of the pandemic, given that it is necessary (and often mandatory) to wear a facial mask and maintain social distancing. The rules are based on the premise that the entire population has no communication problems or support needs, without suggesting alternatives for those with sensory impairments or other disabilities that massively limit personal autonomy. The presence of the sign language interpreter (in LSR) at the public announcement of military ordinances, for example, did not provide communication assistance to those with major hearing impairments in their daily activities or to those who interacted with them. In addition to the fact that many people with hearing impairments do not use or are not fluent in LSR, those with DB require the presence of an interpreter or a companion. Increased anxiety and stress in social relationships is increasingly present in people with hearing impairments, along with increasing the feeling of abandonment by state institutions (see Taylor, 2020). Organizations such as HKNC point out that, as far as the community of people with SC is concerned, there are no “one size fits all” options in communication¹⁵.

The fourth observation refers to the media coverage of issues related to the community of people with DB. In our opinion, the correct approach is the situational one. That is, when addressing a person or audience who has no basic knowledge of this disability and for whom the “label” is the one that sets the representation of a content (as happens, for example, in commercial marketing), it is sufficient to use the term “deafblindness” accompanied by minimal explanations. Whether it’s an advertising clip (part of an awareness or fundraising campaign) or a response to a thirty-second question from a reporter or someone with a passing interest in DB/MSI, the short but evocative reference can have the best impact. Often, especially in popularization stunts, attracting attention through some well-constructed media formulas in terms of verbal and imagistic “packaging” can generate and maintain motivations for information and involvement. Starting from a word with a certain phonetic resonance—deafblindness—a person (be it a student, parent, social activist, decision maker or just a citizen interested in a new field) might want to know more. We believe that one of the mistakes of communication is to make a scholarly presentation on a particular topic in front of an audience of circumstance, vaguely interested in the subject, in the context of a constant media “jamming.” Obviously, when it is the case of an in-depth study or the need to make decisions with considerable impact on the individual, their family or community, the precise delimitation of meanings and nuance of complex cases becomes mandatory.

Summarizing, in DB, the consequences of visual and hearing impairments are not additive, but multiplicative (Warren, 1984), creating unique problems in information, communication and mobility, hence the need to recognize it as a distinct disability (EP, 2004). There are three types of approaches that depend on several factors, taking into account the structure of educational and support services for people with DB/MSI and the nature of human, technological and financial resources. In our country, according to the law, the broadest approach is promoted, meaning the inclusion of other disabilities in addition to sight and/or hearing. In other countries there are other names that, depending on the context or user, are synonymous with DB. However, this practice can be confusing and does not serve the “scientific necessity for accurate communication” (Wittich et al., 2013, p. 199). The huge variability of DB/MSI cases causes some specialists to refer to a spectrum disability (Brown & Bates, 2005), in which there are different weights and different degrees of sensory loss, cognitive deficit, language impairments

¹⁵ Cf. <https://www.helenkeller.org/hknc/covid-19-communication-guidelines>

and/or somatic pathologies. All this individual “puzzle” generates a state of multi-handicap, which “is reflected both in a specific pattern of learning and communication difficulties, and in the emergence of derived disabilities that hinder or obstruct the overall somatic and psychological development through restrictions on using the remaining hearing and sight” (Buică, 2004, p. 256). Consequently, it is found:

1. lack of ability to have meaningful communication with others;
2. the appearance of a distorted perception of the world around;
3. lack of ability to anticipate events or consequences of one's actions;
4. extreme difficulties in establishing and maintaining interpersonal relationships;
5. the need to develop particular learning modalities, with a compensatory role of the effects of the multi-handicap state;
6. major shortcomings regarding the basic intrinsic motivations;
7. growth and development retardation, against the background of an added somatic pathology;
8. labeling such as “delayed” or “emotionally disturbed” (McInnes & Treffry¹⁶, 1982, p. 2).

Although DB/MSI has a very low prevalence (between 0.2% and 2% in the general population, depending on the restrictive or permissive criteria used in reporting data), even in the field of disabilities, and a high degree of heterogeneity, the European Parliament recognized the equal rights of persons with DB/MSI with those of citizens of the Union, instructing Member States to develop appropriate legislation in this regard. This means, first of all, highlighting the cultural perspective both by educating the citizens and reforming the institutions, as well as by facilitating the ways of information, communication and travel. Unfortunately, the medical, social and economic crisis generated by the Covid-19 pandemic has had a profound negative impact on people with DB/MSI and those close to them (family or professional), raising challenges (e.g., the obligation to wear a mask and respect for social distancing) which, so far, have not received the right answer.

Before concluding the paper, it is necessary to complete the context by mentioning some historical landmarks essential in understanding of DB in its evolution from a medical, educational and cultural perspective.

Enerstvedt (1996), in a highly documented synthesis of the beginnings of education of people with DB¹⁷, notes both the impact of exceptional cases (e.g., Helen Keller, Olga Skorohodova) on the collective mind, but also the trap of educational optimism derived from this media exposure. The performances achieved in recent years by Haben Girma or, in the case of our country, by Vasile Adamescu confirm the possibility of reaching a high level of cognitive development and the establishment of a complete and mature personality, but do not offer any guarantee in this regard to children with DB/MSI which follows a systematic, scientifically structured instructive-educational process. Disproportionate expectations in relation to reality, generated by the media coverage of these exemplary cases, condemn to failure any myth-based education and also do

¹⁶ J. M. McInnes & J. A. Treffry [2002]. *Copilul cu surdocecitate. Ghid de dezvoltare* (Romanian transl.). [Bucharest]: Semne '94

¹⁷ V. http://www.duxburysystems.org/downloads/library/history/Deafblind_ed.pdf

much harm to the development of people with DB (Enerstvedt, 1996). Separating the facts from the waste of sensationalism is the first condition in understanding the particularities of each person with DB/MSI, in the correct assessment of their development potential and in the elaboration of an educational program based on realistic and tangible objectives.

The first mention of people with hearing and vision impairments appears in 1637 in the diary of Governor John Winthrop, the founder of the Massachusetts Bay colony, who noted:

There was an old woman in Ipswich who came out of England, blind, and deaf, yet her son could make her understand anything, and know any man's name by her sense of feeling. He would write upon her hands some letters of the name, and by other such means would inform her.

(Quoted in Hosmer, 1908, p. 229).

Another, from 1648, belongs to the physician and philosopher John B. Bulwer, interested in gestural communication and the education of the deaf (Dekesel, 1992), who referred to a certain Anagildus who was cured of lack of sight, hearing and speech. after praying to St. Julian (Farrell, 1956). Furthermore, the author stated that: a man borne Blinde, Deafe and Dumbe, may be taught to heare the sound of words with his eies and thence to learne to speake with his tongue ... For the truth is, they speak not, because they cannot hear.

(Quoted in Farrell, 1956, p. 78)¹⁸.

Later in France, Abbot Deschamps (1779) published a paper describing a method of learning speech by children with DB by correctly positioning their tongue and lips, as a first step in their instruction, while in Madrid, in 1795, Lorenzo Hervás y Panduro's book on a method of instructing deafblind people through tact, smell, and taste has been published (Farrell, 1956)¹⁹.

I would compose a spelling book of letters in high relief; I should have the blind-deaf mute touch them with his fingers. Then I would present to him the word "bread" in raised letters; I would have him take a piece of bread and taste it and in this way I would make him understand what the word "bread" meant ... And so, the mind of the deaf-blind would acquire knowledge ... for experience shows that the knowledge of the deaf-blind is as if dammed up. It is manifested at first very slowly, but as soon as it is aroused, it runs rapidly like a torrent which has been held in restraint.

(Quoted in Farrell, 1956, p. 79).

Although the abbot De L'Épée showed a passing interest in the education of children with DB, perhaps also due to the famous *Lettre sur les aveugles à l'usage de ceux qui voient* by Denis Diderot (1749)²⁰, his successor, the abbot Roch-Ambroise Sicard, did not implement his ideas, merely indicating in 1803 that De L'Épée

¹⁸ More details in chap. 7, "Children of the silent night" (pp. 77-92).

¹⁹ Arriving in Rome, he visited the "dei sordomuti" school of Tommaso Silvestri, where he became acquainted with the gestural method of the abbot Charles Michel de L'Épée and which he later popularized in Spain.

²⁰ "If ever a philosopher, blind and deaf from his birth, were to construct a man after the fashion of Descartes, I can assure you, madam, that he would put the seat of the soul at the fingers' ends, for thence the greater part of the sensations and all his knowledge are derived. Who is to inform him that his head is the seat of his thoughts? If the labors of the imagination tire our brain, this is because the effort we make to imagine is somewhat similar to that to perceive very near or very small objects ... and I should not be surprised if, after a profound meditation, his fingers were as wearied as our heads." (Diderot, 1749/1916, p. 87, transl. by M. Jourdain)

planned to use an alphabet of polished iron letters to form the vocabulary for physical objects and actions identifiable by touch. He hoped to familiarize his pupil's hands with these letters, getting the hands to do the work of the eyes. The pupil was to touch the object with one hand and to spell its name with the other.

(Quoted in Lane, 2006, p. 100)

Sicard's comments were rather motivated by the fear that some of his deaf students might lose their sight, indispensable for lip-reading (apud Farrell, 1956).

An interesting case is that of James Mitchell, born in 1795 in Inverness, Scotland. He had congenital DB and reportedly used his remaining senses to explore and interact with others. For example, he could distinguish strangers by smell and, in the same way, identify their own clothing. Moreover, he had developed a system of signs by which he made it known to his mother and sisters that he was hungry and where the food was kept. He was able to move alone and even ride. However, two leading figures of the time, the philosopher Dugald Stewart and the surgeon and anatomist Astley Cooper, declared him uneducable in a report to the Royal Society of Edinburgh in 1812 (Farrell, 1956)²¹.

Although there have been other children with DB who have benefited from various forms of education²², the one who is considered to be the “father” of education for the deafblind people is Samuel Gridley Howe (1801-1876). Informed both of the ideas and methods circulating in Europe and of cases such as that of James Mitchell, Howe learned of the situation of Julia Brace, who was hospitalized at a institution for the deaf in Hartford, Connecticut. Julia Brace (1807-1884) suffered from typhus at the age of four and a half, as a result of which she lost both her hearing and her sight. At the age of 17 she was enrolled in a school for the deaf where, after a period of refusal, she became fluent in the use of tactile signs in communication. He learned to associate objects with their names by manipulating letters made of wood (but not embossed letters or the braille alphabet), but did not receive formal training. She was taught a number of household activities such as washing dishes or making beds, and in her free time she was knitting and sewing²³. In 1834, Samuel Howe visited Julia and devised a plan for her education, but which was unsuccessful (Farrell, 1956). He revisited it in 1841, accompanied by Laura Bridgman (who was only 12 years old), but Julia (then 34 years old) quickly lost interest in communicating with her because she did not know sign language. The following year, Julia enrolled in the *Perkins School for the Blind*²⁴ and made some progress in mastering the manual alphabet and digital naming of objects, but she always returned to familiar signs. For this reason, the following year she returned to her former school (now the *American School for the Deaf*)²⁵. Howe felt that her education failed because her instructors allowed her to use the so-called “natural language” of simple gestures, instead of forcing the use of the alphabet and words built on it (Freeberg, 2001).

²¹ Towards the end of the 19th century, the first statistics on the number of people with deafblindness appeared. For example, *The Census of 1871* listed 111 people with deafblindness in Britain, and *The Tenth Census of the United States* in 1880 featured 503 people, of whom 256 had dual sensory impairment, 217 had profound mental retardation, and 30 they also had severe mental illness (Enerstvedt, 1996).

²² E.g., Victorine Morriseau (1789-1832), in France; Anna Temmerman (1818-1859), Belgium; Sanzan Tani (1802-1867) in Japan.

²³ Apt <https://www.msa.state.mn.us/Content2/deafblind-history>

²⁴ Ibid.

²⁵ V. <https://archive.org/stream/annualreportoftr110perk#page/n155/mode/2up/search/bridgman>

However, Samuel Howe registered a considerable success in his work with Laura Bridgman (1829-1889). Laura had a normal development until the age of two, when she suffered from scarlet fever, a disease in which her brother and two older sisters died. Hardly surviving, Laura lost not only her hearing (completely) and sight (almost completely), but also her smell and taste; he relearned to walk a year later; and four years later he lost the ability to detect blurred images with his right eye. In October 1837 she was admitted to the *Perkins School for the Blind*, where she began by learning embossed words, then the manual alphabet (letters written in the palm of her hand), so that in 1839 she was able to write her own name in italics in an intelligible manner²⁶.

She uses the manual alphabet of the deaf mutes, with great facility and great rapidity; she has increased her vocabulary so as to comprehend the names of all common objects; she uses adjectives expressive of positive qualities, such as hard, soft, sweet, sour etc.; verbs expressive of action, as give, take, ride, run, etc., in the present, past, and future tense; she connects adjectives with nouns to express their qualities; she introduces verbs into sentences and connects them by conjunctions; for instance, a gentleman having given her an apple, *she said man give Laura sweet apple*.

(“Annual report”, 1840, p. 6).

More complex activities followed, developing language and reading and writing skills, as well as mathematical ones, followed by lessons in geography, literary composition, astronomy and history. Howe’s strategy to popularize the progress of Laura Bridgman in the press brought not only funds for the school, but also attracted the attention of some personalities of the time, including Charles Dickens. He visited the school in 1842, during his American tour, and dedicated 14 of the 30 pages of the chapter on Boston to Laura (Farrell, 1956).

It is strange to watch the faces of the blind, and see how free they are from all concealment of what is passing in their thoughts ... The thought occurred to me as I sat down in another room, before a girl, blind, deaf, and dumb; destitute of smell; and nearly so, of taste: before a fair young creature with every human faculty, and hope, and power of goodness and affection, enclosed within her delicate frame, and but one outward sense—the sense of touch. There she was, before me; built up, as it were, in a marble cell, impervious to any ray of light, or particle of sound; with her poor white hand peeping through a chink in the wall, beckoning to some good man for help, that an Immortal soul might be awakened.

(Dickens, 1969, pp. 35-36).

It happened that forty years later, Helen Keller’s mother read Dickens’ *American Notes* and learned of Laura Bridgman’s progress. The behavior of the six-year-old Helen was already less and less tolerated by her family, largely due to her difficulties in communication and interaction. Through Alexander Graham Bell²⁷ (whose wife, Mabel, had been a student at the school for the deaf where he had been teaching²⁸), the Keller family was put in touch with Michael Anagnos,

²⁶ The original name was *Perkins Institution and Massachusetts Asylum for the Blind*.

²⁷ Recommended by Dr. Chisholm, a famous Baltimore ophthalmologist (Enerstvedt, 1996).

²⁸ Bell’s mother had suffered from profound deafness, and both his grandfather and father had studied the voice in detail. Alexander Graham Bell was instructed by his father, the British linguist Alexander Melville Bell, in visible speech, a method of “de-muting” he invented, which he later, in 1871, began to practice at a school for the deaf in Boston (Winzer, 1993). As a tribute and friendship, Helen Keller dedicated her autobiography to him: “He who taught the deaf to speak and made the listening ear hear the speech, from the Atlantic to the Rocky [Mountains]” (Keller, 1902/1969).

Perkins' deputy school principal. On March 3, 1887, a former graduate of the school, Anne Sullivan (1866-1936), met Helen at her home in Tuscumbia, Alabama, as part of the education plan agreed upon with the Perkins teachers, bringing her a gift, a doll, dressed by Laura Bridgman (who still lived at school). The doll was used by Anne Sullivan as a means of teaching her name through the manual alphabet. After several attempts, the mental trigger occurred when Ann Sullivan held her hand under the water flowing at the pump, while she wrote the word “water” on her palm.

We walked down the path to the well-house, attracted by the fragrance of the honeysuckle with which it was covered. Someone was drawing water and my teacher placed my hand under the spout. As the cool stream gushed over one hand, she spelled into the other the word water, first slowly, then rapidly. I stood still, my whole attention fixed upon the motions of her fingers. Suddenly I felt a misty consciousness as of something forgotten—a thrill of returning thought; and somehow the mystery of language was revealed to me. I knew then that “w-a-t-e-r” meant the wonderful cool something that was flowing over my hand. That living word awakened my soul, gave it light, hope, joy, set it free! There were barriers still, it is true, but barriers that could in time be swept away.

(Keller, 1902/1968, p. 34)

In a letter dated April 5, 1887 (and added to the text of the book), Ann Sullivan noted: “She has learned that everything has a name, and that the manual alphabet is key to everything she wants to know” (Keller, 1902/1969, p. 273)²⁹.

Following the procedures already designed for Laura Bridgman, Helena Keller’s education reached its formal level, at which point she was enrolled at *Perkins*. Between 1889 and 1893, Helen attended school at her own pace, in an individualized and flexible manner, guided by interests and curiosity, under the careful guidance of her teacher. In 1898 she studied at the *Cambridge School for Young Ladies*, and in 1900 she was admitted to *Radcliffe College*, which she graduated with honors in 1904. Throughout her years of study, Ann Sullivan was with her, assisting her with the tactile interpretation of lectures and textbooks (apud Sardegna & Paul, 1991, quoted in Enerstvedt, 1996).

The media and political context of the times turned Helen Keller into an international celebrity. In the company of Anna Sullivan, she traveled to several countries around the world (in Australia, for example, she met Alice Betteridge, a deafblind person educated according to the principles of the *Perkins* school). Under the influence of the readings recommended by John Macy (socialist critic and reformer), Anne Sullivan’s future husband and the one who helped Helen write her autobiography, Helen Keller began to publish a series of essays, the best-known being “Optimism” (1903) and “The World I Live In” (1908), in which she expressed her views on society, generating a series of controversies due to her Christian and socialist options (Enerstvedt, 1996).

²⁹ Ann Sullivan, herself visually impaired, became, over time, the personification of the Teacher. The history of Helen Keller’s insight has been “played” many times on stage, in small shows held by the two during the country tours. Later, the story of the meeting between Helen and Ann Sullivan was made into a film at least three times, the 1962 version of *Miracle Worker* earning each of the two main protagonists an Oscar for their theatrical performance. Details at: <https://www.imdb.com/title/tt0056241/>

It is curious to observe what different ideals of happiness people cherish, and in what singular places they look for this well-spring of their life. Many look for it in the hoarding of riches, some in the pride of power, and others in the achievements of art and literature; a few seek it in the exploration of their own minds, or in the search for knowledge.

(Keller, 1903/2009, p. 87).

Helen Keller (1880-1968) has been a celebrity throughout her life, meeting personalities of the time (e.g., Charlie Chaplin, Albert Einstein), touring 35 countries and getting socially and politically involved in the day's affairs. In 1961 he suffered a series of strokes, as a result of which he retired from public life, until his death in 1968³⁰.

Helen Keller's popularity has given rise to a number of controversies, especially over the influence exercised upon her by those from her entourage and the effects of filtering communication through the role of interpreter assumed by Anne Sullivan (Enerstvedt, 1996). Beyond these discussions, the public's attention to the needs of people with disabilities has increased considerably, especially with regard to education and social integration, which, over time, has allowed the evolution of the medical paradigm (focused on disease and lack of rehabilitation), to the socio-cultural one (of inclusion and normalcy within the human diversity). On the other hand, maintaining the public's taste for sensationalism and relying on the emotional effect, the promoting campaign carried out on behalf of Helena Keller overshadowed other interesting cases from other countries and neglected the situation of children with dual sensory deficits who had other disabilities.

For example, Ragnhild Tollefsdatter Kaata (1873-1947), from Norway, became the first deafblind person to learn to speak. At the age of three and a half, she lost her sight, hearing and smell after falling ill with scarlet fever. The only words she uttered were "D'æ fæt" ("Det er fælt" meaning "It's awful" in Norwegian, the last words she said after recovering from her illness). Elias Hansen Hofgaard (1856-1906), the director of the school for the deaf in Hamar, Norway, took care of her education and adapted the oral methods used in the education of the deaf. She could write in capital letters (the Braille alphabet had not yet replaced the Latin alphabet in schools for the blind in Norway) and could read what was being said by touching the lips of the speakers (Enerstvedt, 1996).

In Australia, Thomas Pattison, a deaf emigrant from Scotland, founded the *Royal Institute for Deaf and Blind Children* (RIDBC) in 1860. While the first deaf children were enrolled in 1860 and the first visually impaired children in 1869, since 1908, those with DB have also been admitted. Alice Betteridge thus became the first DB person to be educated in Australia (RIDBC, 2012b). In 1948 she met Helen Keller, who was in Australia to raise funds at a school for the blind in Sydney. Like Helen Keller, Alice Betteridge suffered from meningitis, losing her hearing and sight at the age of two. In 1905, for three months, RIDBC Superintendent Samuel Watson, informed of Helen Keller's progress a few years earlier, made his first (unsuccessful) attempts at education. At the age of seven (in 1908), Alice Betteridge returned to the institute. Just as Helen Keller benefited from Anna Sullivan's human and professional devotion, Alice Betteridge had a dedicated mentor in Roberta Reid. Like Helena Keller, Alice experienced a moment of catharsis when she discovered the relationship between objects and their names. Roberta Reid used to put various things in her hand, typing their names into her palm, to no avail. As a country child, Alice used to run barefoot; however, to her bewilderment, unseen

³⁰ Details at: <https://www.hki.org/helen-kellers-life-and-legacy/>

hands insisted on putting on her shoes. One day, after Reid put a shoe in her hand and typed the word “shoe” at the same time, Alice answered with the same word before touching the shoe. Once the “object-word” connection was made, Alice became extremely interested in learning new words and learning as much as possible. She soon became able to learn to read and write in Braille, and by 1920 she had become the brightest student in the school. She was married for nine years to a blind man in Melbourne, who died in 1966 at the age of 65 (RIDBC, 2012a). Alice Betteridge School is today an internationally recognized educational institution for children with sensory and intellectual disabilities (Thompson, 1990).

In February 1895, in Saint-Gédéon, a small village on the Canadian-American border, Ludivine Lachance was born. Following a meningitis contracted at the age of two and a half, she lost both her sight and hearing. It was not until 1910 that abbot Deschamps, director of the *Montreal Institute for the Deaf and Dumb*, learned of the situation following a campaign in rural Quebec to identify hearing-impaired children. Ludivine’s sisters were taken care of by the *Sisters of Providence* (especially by Sister Angélique-Marie), but the long period of inactivity (15 years), as well as the probability of an intellectual disability, made Ludivine’s progress modest in language, but more significant in the area of manual skills (e.g., basket weaving). Religious education predominated in Ludivine’s life, until her death in 1918.

By the end, Ludivine is aware of the miracle of the hands, too: the chaplain's paternal hands, the hands of strength and firmness that knew how to break her off from her first inarticulate existence; the maternal hands of Sister Angélique-Marie, the sweet hands of light and understanding that opened all the closed doors for her.

(Rocheleau, 1927, pp. 232-233)

In the former Soviet Union, Ivan Afanasievich Sokoliansky³¹ (1889-1960) founded the first school for deafblind children in Kharkov, inspired by Samuel Howe and the techniques used at *Perkins*. In his introduction to Olga Skorohodova’s autobiographical book (1947/1950), Sokoliansky outlined the five stages of his strategy, which focused on:

1. *direct exploring of the objects and phenomena of the objective world* by accustoming the child to the environment and the patterns of interpersonal relationships. It involves voluntary observation and palpation, having a stimulating effect at the cognitive level by educating and training analysis, differentiation, identification and recognition. Imitation of human behaviors must be followed by initiative in social interactions;

2. *learning sign language*, as an intermediate means of communication, because the gesture leads to the activation and exercise of the symbolic function at the cognitive level; therefore, it has an evocative function, determining the updating of the mental cognitions and the reproduction of the designated actions;

3. *the acquisition of fingerspelling and the braille alphabet*, as forms of verbal language;

4. *learning to read and write in braille* (“de-muting” of cognition and formation of inner language);

5. *speech acquisition* (through speech therapy activities) (cf. Buică, 2004).

³¹ It should be mentioned that there are notable differences in the romanization of Russian and Ukrainian names in Romanian, English, French, etc.

Aleksandr Meshcheryakov (1923-1974) studied under Sokoliansky in 1955, and after his death in 1960 he succeeded him as head of the research laboratory in DB. Meshcheryakov recounted an episode in which the children he worked with had to relearn his facial expressions after shaving in order to restore “lost language” to his chin (Levitin, 1982, p. 147). Sokoliansky demanded that masks be made to reflect the most diverse facial expressions that children could tactilely explore, being aware of their extraordinary limitations in their relationships with other people. He found that it was much easier to work with children who had lost their hearing and sight at a very young age compared to those who had acquired these impairments later, without providing a rigorous scientific explanation for this phenomenon. The cause would probably consist in the interference and resistance generated by the already existing visual and auditory-verbal psychomotor schemata and patterns, but also by the training methods and familiar daily routines (Levitin, 1982).

Olga Skorohodova (1911-1982) was born into a poor family in southeastern Ukraine. Around the age of five, she contracted meningitis, losing her sight and hearing. After her mother’s death³² in 1922, she was sent to the school for the blind in Odessa, from where, in 1925, she was transferred to Professor Sokoliansky’s school. During the fighting between German and Soviet troops, the school was destroyed, with only two of the six deafblind children surviving³³. After the war, Sokoliansky resumed his work at the *Moscow Institute of Defectology* and, at his urging, Olga published her diary in the form of a book in which she recounted her experiences in various environmental and social contexts.

I don’t feel the light with my eyes at all, but if I go through a space that is not occupied by any objects placed above my head (or enter the open door), I have the feeling as if I were under the action of light. Interestingly, this sensation is not always the same: during a headache or poor general condition or fatigue, it is so weak that I do not always feel empty space. During a good somatic and mental state, the sensation of the surrounding temperature, of the movement of the air and of the empty space intensifies and it seems to me again that I feel little light, but not with the eyes, but with the whole face.

(Scorohodova, 1947/1950, pp. 25).

We perceive the world around us, the houses, the streets, the city, according to their position in space. We feel the symmetry, the perspective, we feel the space itself, in relation to the position of things ... It seems that especially the sound reflection—the echo of the halls, of the squares, of the streets, of the sidewalks—gives the blind the feeling of space. But what if not one is missing, but two of the five senses are missing at once: sight and hearing? And then there remains a way of perceiving the “big world”. The air remains, always accessible to perception, its movement and the direction of this movement, temperature, the presence of smells, etc. In addition to the sound echo, there is also an “aerial echo”. It can also be a wave of air aroused by a tram, by a car that has passed at speed. A gust of wind reflected by the high walls of a house, or barely perceptible drafts, which are “reflected” by houses, flowing through open windows, openings, etc. ... From these sensations that seem small, insignificant, a definitive, complete representation of the surrounding world is gradually formed.

(Scorohodova, 1947/1950, p. 185).

³² Her father had been enlisted in 1914 to fight in the Great War, from which he never returned (Meshcheryakov, 1974).

³³ A more extensive account of her survival during the German occupation (1941-1943), in Levitin (1982).

Olga Skorohodova's book was completed with two other volumes (published in 1954 and 1972). In 1961 she became a doctor of psychology and pedagogical sciences, then worked as a scientific researcher until the end of her life at the same institute where she had been educated. UNESCO dedicated two articles to her in her journal, containing excerpts from her main book (see Skorokhodova, 1974, 1981)³⁴, which made her name better known in the West.

Robert J. Smithdas (1925-2014) also lost his sight and hearing at the age of five from meningitis. After graduating from *Perkins School*, he attended *St. Paul's University*. John and received his master's degree from *New York University*. He later distinguished himself as a specialist in vocational counseling and rehabilitation for people with disabilities, defender of the rights of people with DB to education and work employment, poet. In his autobiography he recounts in detail events from his childhood and his school and social formation, in a colloquial style not without humor:

He handed me several cards on which were printed instructions.

"Wait on the platform until someone comes to you and offers help. Show him your first card, the one that says, 'Please help me onto the train to Queens Plaza.' When you're on the train show your second card to a passenger; it tells him to help you off at the Queens Plaza station. Then stay on the platform and tap your cane until you receive assistance. Your third card will get you on the Brooklyn train back to Nostrand; and while you're on it, show some passenger your fourth card, and he'll help you to get off at the right station."

I memorized the route thoroughly. In the afternoon we started out. I found the Nostrand Avenue station and went down to the turnstile. Everything seemed to go smoothly; a passer-by put me on the Plaza train, and another helped me off at my destination. Then the trouble began. As I stood on the platform at the Plaza, waiting for the return train to Brooklyn, I held out the third card and tapped my cane. A man grabbed my arm. I was aware of the vibrating roar of an approaching train. The stranger pressed my sleeve and I followed him meekly into the subway car. Someone stood up and offered me a seat; I sat down beside the individual who had helped me aboard and reached into my pocket for my fourth and final card. I held it up for him to read. He made no response. I pointed to the card. Still

no reply. The minutes passed. I became increasingly irritated. Suddenly the instructor who had been trailing me came rushing up.

"Bob, this is horrible! The man who helped you on the train is blind! He has a Seeing Eye dog with him."

I was aghast. "You mean he can't read my card?"

"No, and he's been talking to you and you couldn't hear him! He's getting angrier by the minute because you seemed so unfriendly after the help he had given you. Just let me explain it to him."

(Smithdas, 1958, pp. 118-119).

³⁴ Retrieved from <https://unesdoc.unesco.org/ark:/48223/pf0000108360>

Since the 1950s, concerns about people with DB have been exceeded the pioneering era, and with the identification of other categories of children with multiple sensory impairments, the first attempts to define and study this disability appeared. The rubella pandemic of the 1960s had a strong effect both on in-depth research into the infectious causes of DB/MSI and on solutions for prevention (e.g., through vaccination) and treatment. Also, with the advent of genetics as a science and the identification of several syndromes that, among others, lead to DB/MSI, the mechanisms of impairments have been better understood, how they evolve or not over time, the pervasive effects on mental processes and activities and, last but not least, the impact on social relations and the collective cognitions in general. The romantic era of Howe, Sullivan and Sokoliansky was coming to an end clearing the space for standardized instructional strategies, methods and techniques. Individual enterprises, based largely on systematized observation, reflection and syllogism, continuously adjusted by “trial and error”, were gradually replaced by long-term, systemic approaches, founded on curriculum. Although spectacular examples were beginning to be lacking, children with DB/MSI having various degrees of impairment, with pure dual sensory deficit or combined with other disabilities received more attention, especially those with congenital DB (cf. Miles & Riggio, 2009).

The new educational approach was spearheaded by the *Perkins school*, represented by Nan Robbins and Carol Crook. While Robbins excelled in systematizing and theoretically developing findings from school experience, Crook had the talent to put theoretical ideas and principles into practice and to interact subtly with her students (Enerstvedt, 1996). In the United Kingdom, Peggy Freeman (1975), herself the mother of a girl with DB (a consequence of contracting rubella during early pregnancy), promoted an educational program focused on communication, mobility, social interaction and emotional development to be applied with success in the first weeks of life, throughout schooling and beyond. In the Netherlands, and later in the United States at the *Perkins School for the Blind*, Jan van Dijk developed “child-guided” assessment strategies to highlight how children with DB/MSI react, communicate, socially relate, learn, memorize, solve problem situations (Van Dijk & Nelson, 1997; Nelson et al., 2002). In Canada, John McInnes and Jacquelyn Treffry asserted themselves as internationally renowned specialists, the development guide they published in 1982 still being part of the basic bibliography of vocational training in the field of DB. Robert Stillman, along with other specialists, has been developing the Callier-Azusa scales, originally published in 1974 and revised in 1978 by the Center for Communication Disorders in Dallas. In 1984, the H version appeared, co-authored by Christy Battle³⁵. Finally, the number of articles and books on DB/MSI has been gradually increasing, with the recognition of DB/MSI as a distinct disability first in academia, then in the legislation of different countries, with medical, educational, vocational and social caveats. Today, in the context of the transition to an inclusive society, based on the recognition of equal opportunities and the value of diversity, the cause of people with DB/MSI is no longer promoted just by their parents and relatives, specialists and social activists, but also by community members, Haben Girma being the best example in this regard.

Haben Girma was born in 1988 in Oakland, California, to parents from East Africa (Eritrea and Ethiopia). Her dual sensory impairment is probably of genetic origin (her brother also has

³⁵ Both scales (G and H) were translated into Romanian and appeared in 2010, under the auspices of Sense International Romania.

DB), with progressive evolution during early childhood³⁶. Benefiting from the curricular and technological advantages of the American education system, Haben successfully went through all the cycles of education, graduating from *Harvard Law School* in 2013. She has since established herself as an advocate for the rights of people with disabilities and as an influencer in the press and at conferences. On the occasion of a quarter of a century since the entry into force of the law on people with disabilities in the United States (known by the acronym IDEA), Haben was invited to the White House by President Barack Obama³⁷. In her autobiography, published in 2019, Haben recounted the events that impressed her, in a colloquial memorialist style.

Communities designed with just one kind of person in mind isolate those of us defying their narrow definition of personhood. This book takes readers on a quest for connection across the world, including building a school under the scorching Malian sun, climbing icebergs in Alaska, training with a guide dog in New Jersey, studying law at Harvard, and sharing a magical moment with President Obama at the White House. Unlike most memoirs, the stories here unfold in present tense. Hindsight may be 20/20, but 20/20 is not how I experience this ever-surprising world.

(Girma, 2019, p. 1).

Before concluding, we would like to give a special space to teacher Vasile Adamescu (1944-2018). Like other people with pure DB, Vasile Adamescu lost his hearing and sight at the age of two and a half, due to meningitis and lack of adequate treatment. At the age of 11, his father took him to the *School for the Blind* in Cluj, where he was accepted as a student, despite the reluctance of some teachers who thought that his place would have been more suitable for the school for the deaf. With the help of Valer Mare from *Babeş-Bolyai University*, the “psycho-pedagogical rehabilitation experiment” was started (Adamescu, 2012, p. 218), first with the support of Andalusia Leahu, at the kindergarten, then under the guidance of Florica Sandu, at the elementary school, until 1962.

One day, while I was studying in the school museum, it occurred to my teacher to teach me the letter *f*. Every time I tried to associate a word with the letter I was learning. Initially she showed me the position of the teeth and tongue, necessary for the pronunciation of this letter, after which she lit a match and handed it to me to make me understand that *f* is the first letter of the word *fire*. I got scared and dropped the match over the old carpets in the museum. I then bent down, trying to find it. I knew the idea of fire, but I didn’t know what word it was associated with. A story came to my mind from Borcea, my native village, when, by mistake, without knowing what I was doing, I set fire to the stable. This was when I began to understand that every object has a name. From now on I was curious to know the name of each object around me.

(Adamescu, 2012, p. 36).

In 1967, Vasile Adamescu graduated middle school, being admitted to the *Special High School for the Blind* in Cluj, which he graduated in 1973. In the summer session of the same year, he managed to enter the Department of Defectology (that is, Special Education) at the Faculty of History-Philosophy, from the Babeş-Bolyai University. Four years later, he graduated from university, becoming a defectology (special education) teacher at the same high school

³⁶ In her autobiography, Haben Girma noted that at the age of 12 she was still able to distinguish her outlines and hear her parents talking nearby, perceiving high-frequency sounds quite well (which allowed her to develop good phono-articulatory skills).

³⁷ V. <https://www.bbc.com/news/av/world-africa-34813162>

where he had studied and where he remained on tenure until retirement in 2004³⁸. In recent years he has continued to lead an active life, participating, along with Sense International Romania, in events organized in various cities (e.g., “The Sensability Caravan”³⁹), international conferences⁴⁰ and meetings with professors and students at psychology and education sciences colleges from university centers. He starred in television shows and documentaries and gave a series of interviews. In his free time, he was preoccupied with modeling in clay⁴¹ (between 1983 and 1986 he attended the courses of the folk school of fine arts in Cluj, sculpture section). Also, in the last years of his life he worked intensively on the autobiographical book *Facing Life*, of which three volumes appeared (the last in 2020).

At the end of this study there remains a question: is there a community of people with DB/MSI? A clear answer is impossible to give, although parallels can be drawn with the deaf and blind communities, respectively. In both cases we notice that these are communities of people who have severe or profound sensory deficits, thus excluding the hearing impaired and amblyopic. The reasons for exclusion are related to several causes, more or less historically and culturally generated, but with a strong linguistic foundation: the mimic-gestural (sign) language, in the case of the deaf, respectively the braille alphabet, in the case of the blind. Assuming a special cultural identity is much more important in the case of deaf people, who claim a culture per se and impose in several countries, including Romania⁴², the recognition of sign language as an independent language. In the case of the blind, the term “culture” is understood much more loosely compared to the deaf, which is limited to a specific life experiences common to those born with total or near-total visual impairment. Although there are communities of the blind, driven by common interests and needs, one cannot speak of a “culture of the blind” (Weisleder, 2012).

Based on this analysis, any description of a culture of people with DB should ultimately be based on:

- a common set of habits, values and beliefs;
- the feeling of belonging to a specific group;
- an identity crystallized as a DB person;
- a preferred language system;
- a common corpus of creations and artistic products specific to people with DB (Buică, 2015).

³⁸ It should be noted that, at the time of graduation, the department of defectology of the faculty, led then by Professor Ioan Radu, made a memorandum to the Ministry of Education asking that “V. Adamescu to be employed as a defectologist at the department of psychology at Babeş-Bolyai University in Cluj-Napoca, because nowhere else will he have the same favorable conditions to carry out his activity in such a way as to serve the interests of science to the maximum and, implicitly, of society” (Adamescu, 2018, pp. 131-132). Unfortunately, in the same year, the department of defectology was disbanded.

³⁹ Cf. <https://surdocecitate.ro/noutati/caravana-sensabilitate/>

⁴⁰ E.g., keynote speaker on the first day of the works of the sixteenth world conference of Deafblind International, held between May 25-30, 2015 in Bucharest.

⁴¹ E.g., opening of the exhibition “A Life”, Sibiu, 2014. Details at: <http://www.muzeulastra.com/2014/08/vernisajul-expozitiei-vasile-adamescu-o.html>

⁴² Cf. Law no. 27/2020 on the language of Romanian signs, published in the *Official Gazette*, Part I, no. 258 of 30.03.2020, entered into force on 02.04.2020. Art. 1 states that “this law recognizes the language of Romanian signs, hereinafter referred to as LSR, the mother tongue specific to deaf and/or deaf people.”

At present, the very small number of people with DB/MSI, combined with the great diversity of means of communication and personal life experiences, makes the real existence of an assumed culture of DB unlikely. Probably, however, in the near future, a community mediated by technology in the three essential components—information, mobility and communication—will emerge.

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Acronyms

ANDPDCA	Autoritatea Națională pentru Drepturile Persoanelor cu Dizabilități, Copii și Adopții
DES	Department of Education and Science
EDBN	European Deafblind Network
EP	European Parliament
ESSA	Every Student Succeeds Act
HKNC	The Helen Keller National Center
IDEA	Individuals with Disabilities Education Act
LSR	Limba Semnelor Române [Romanian Sign Language]
ONS	Office for National Statistics
NCDB	National Center on Deaf-Blindness
RIDBC	Royal Institute for Deaf and Blind Children
SIR	Sense Internațional România
WFDB	World Federation of the Deafblind

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