



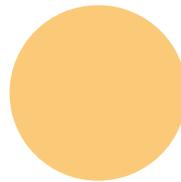
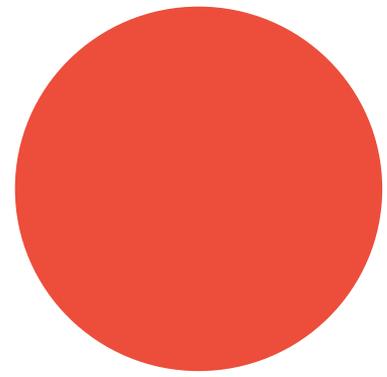
GENERAL GUIDELINES

for inclusive education and multidisciplinary care
of learners with spina bifida and hydrocephalus



Developed in partnership between:
Spina Bifida and Hydrocephalus-Bulgaria Association
Center for Early Intervention Trnava, Slovakia
and Slovak Association for Spina Bifida and/or Hydrocephalus
as associated partner

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ISBN 978-80-974287-2-3 [brochure]

ISBN 978-80-974287-3-0 [pdf]

Erasmus+ Project No. 2021-1-BG01-KA210-SCH-000031249

This document is part of a set of educational materials to support inclusion of children with spina bifida and hydrocephalus in schools and kindergartens, developed under the Multi-IN project. The Guidelines, together with the complementary Manuals and Educational video courses, aim to support the multidisciplinary efforts of professionals and family towards inclusive education of children with spina bifida and hydrocephalus.

All Multi-IN resources are open access articles, which permits unrestricted use, distribution, translation and reproduction in any medium, provided the original authors and source are credited. The full set is available on

www.multi-in.eu

The authors would like to thank all parents and children from Bulgaria and Slovakia who shared their personal stories and contributed with their experience in education to our research and development of Multi-IN outputs.

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AN AUTHORS' NOTE



Terézia Drdulová

The purpose of the guidelines is to introduce the life of children with diagnosis spina bifida and hydrocephalus and to help important people around them understand the condition - so they can make informed decisions and to provide effective support for the group of children and young people. Spina bifida is a complex of varieties. **Many professionals around the world working with the group refer spina bifida to “snowflake condition” - the situation of each of them is so different. No two people are affected by this diagnosis in the same way. There are also many consequences. It is similar to the diagnosis of hydrocephalus - it affects people in different ways.**

The guidelines aspire to introduce important points and to highlight prevention of the known ones.

Current knowledge makes it possible to prevent many serious and in the past common consequences in the development of children with spina bifida and hydrocephalus.

Many people living with the diagnosis are changing the picture of their life with the diagnoses. The focus of the Guidelines is to underline the rights based multidisciplinary, holistic, family - centered approach.

We are convinced that current knowledge from various fields, awareness of the rights of people with disabilities and opportunities for self-realization of these people are good basis for their fulfilled life.

School is one of the most important institutions that every child goes through, it is a key intervention environment with many opportunities for multidisciplinary cooperation. Its uniqueness allows you to capture and support the child and his family from an early age, regardless of whether his or her primary environment perceives this need. Throughout the school we support children and families.

In the document we present a proposal for multidisciplinary work in the school, thanks to which not only students and their families, but also teachers and the school management can feel the support.

All of us are so important to be supportive to develop functional abilities, independence, and self-esteem of children with spina bifida and hydrocephalus. It is possible if we believe in them, we know how to support them, we respect their rights, we fulfill their needs and cooperate. Let's do it together!



INTRODUCTION



Slaveya Kostadinova

The General Guidelines are the basic paper of the Multi-IN resource kit. This is the foundation from which all other Multi-IN resources are developed.

The paper unites previous international experience, research and good practices in the field of education and care of children with spina bifida and hydrocephalus and case studies from Bulgaria and Slovakia.

Focusing on the human rights approach, the General Guidelines present the main barriers to inclusion of students with spina bifida and hydrocephalus and examine their learning needs applying Maslow's hierarchy framework. The paper also includes specific tips for overcoming the barriers and meeting the needs, targeting the key stakeholders in the educational process.

Particular sections of the case studies are inserted in the text of the Guidelines, in order to illustrate the topics in a common language and to express their human appearance and fullness.

The authors recommend starting with a review of the General Guideline before moving forward to the specific Manuals and Educational video courses.



THE MULTI-IN PROJECT AND PARTNERS

Slaveya Kostadinova



„Multidisciplinary care for inclusive education of learners with spina bifida and hydrocephalus“, also called Multi-IN, is an Erasmus Plus project co-financed by the European Commission. Multi-IN unites the efforts of two organizations from Bulgaria and Slovakia, aimed at improving access to school and early childhood education, for students with spina bifida and hydrocephalus – a group with specific and complex educational needs.

These complex needs require a multidisciplinary approach in order to achieve effective inclusion at schools and kindergartens. Cooperation and in-depth knowledge of the specific needs of children with spina bifida and hydrocephalus by all stakeholders involved in the educational process are essential

Multi-IN encourages the main stakeholders to apply a multidisciplinary approach in the education of children with spina bifida and hydrocephalus and support them to develop specific skills and knowledge. Among the main stakeholders in the educational process, Multi-IN identifies the target groups of:

- Teachers, incl. class teachers, physical education teachers
- School leaders/School administration
- Special teachers
- School psychologists
- Nurses and and healthcare professionals in kindergartens and schools
- Assistants
- Parents and family members
- Learns with with spina bifida and hydrocephalus

The Multi-IN resource kit includes General Guidelines, a set of Manuals and a set of Educational Video Courses for each of the eight target groups identified.

All resources are available on our website: www.multi-in.eu





MULTI-IN PARTNERS

Multi-IN is a partnership project between Spina Bifida and Hydrocephalus-Bulgaria Association and Center for Early Intervention Trnava, Slovakia. Both partners contribute to the Multi-IN outputs development, including the General Guidelines, with their specific experience, expertise and knowledge.

SPINA BIFIDA AND HYDROCEPHALUS-BULGARIA (SBHB)

Spina Bifida and Hydrocephalus-Bulgaria (SBHB) is a parent association established in 2011, with the mission to improve quality of life for people with spina bifida and/or hydrocephalus in Bulgaria.

SBHB main activities are maintaining informational website for spina bifida and hydrocephalus issues; organizing local and national meetings, annual camps; organizing training for children and parents, in order to improve their awareness and quality of life; supporting new families; and advocacy. Spina Bifida and Hydrocephalus-Bulgaria supports more than 300 families from all over Bulgaria.

SBHB is a member of the International Federation for Spina Bifida and Hydrocephalus and the National Network for Children in Bulgaria.

SBHB is a leading partner. They guarantee that the needs of children are the basis of all resources created by the Multi-IN project. SBHB contributes with expertise and knowledge about the learners with spina bifida and hydrocephalus needs and the barriers in their education.

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CENTER FOR EARLY INTERVENTION TRNAVA (CVI TRNAVA)

Center for Early Intervention Trnava (CVI Trnava) is a non-profit organization, a licensed provider of social

services of early intervention in the Trnava region of Slovakia. The center has been operating since 2018. CVI Trnava supports more than 130 families of children with disabilities and children at risk from over 30 settlements in the Trnava region.

The services are provided in a building donated by the Municipality of Trnava or through mobile teams. They are in a wide range: psychological support, resource support, physiotherapy, social counseling and support for administrative actions. During the summer months, Center for Early Intervention Trnava organizes day camps to help children in building skills for independent living and encourage their contacts with peers. At the initiative of CVI Trnava, informal groups of parents have been formed to support and exchange experiences.

In the Multi-IN project, CVI Trnava provides expertise in inclusive education and early intervention. The experience they have in daily work with the main target groups in the Multi-IN project is truly valuable.

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Slovak Association for Spina Bifida and/or Hydrocephalus is an associated partner for developing Multi-IN outputs. They are one of the founders of the Center for Early Intervention Trnava. Both organizations work closely together to support children with spina bifida and hydrocephalus in Slovakia. Slovak Association adds the perspective of Slovakian children and the personal experience of the members in inclusion, described in the case studies.

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RIGHTS OF THE CHILDREN WITH DISABILITIES

Terézia Drdulová

There are two basic international legal documents which create the skeleton of the frameworks that define the status of children with disabilities and their rights. They were created by mutual agreement of most countries of the world and became The United Nations documents: UN Convention on the Rights of the Child and UN Convention on the Rights of Persons with Disabilities (CRPD). Both highlight that the importance of the best interests of the child shall be a primary and a default criteria taken into consideration in all actions concerning children with disabilities.

UN CONVENTION ON THE RIGHTS OF THE CHILD

One of the instruments to secure a certain level of enjoyment of human rights for a specific group of subjects - children - is with no doubt the UN Convention on the Rights of the Child, which specifically aims, at one of its articles, on children with disabilities. Article 23 of this convention is focused specifically on this most vulnerable group of children. This article consists of four paragraphs. Every one of these paragraphs covers different areas of life. The first paragraph includes general recognition of the same rights which are given to everyone for the children with disabilities, specifically mentioning decent life, in conditions **which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.**

The second paragraph recognizes the right **of every child with disability for specific care** which is appropriate to the condition and needs of the child and those who take care of the child.

The third paragraph highlights effectiveness, affordability, and accessibility of these above-mentioned

services, which should be provided for free or for proportional costs to the economic situation of the child and those responsible for him or her. This paragraph is aimed for eligibility and material enforceability of these rights and services with focus on the child 's needs in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and



spiritual development.

The last paragraph includes positive legal duties such as a duty to promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of children with disability, including dissemination of information and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas with a special focus on developing countries.

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

Children with disabilities are a vulnerable group of children and a specific group of persons with disabilities.

The United Nations presented the Convention on the Rights of Persons with Disabilities with the aim of reinforcing their full and effective participation in society. Because children are dependent on decisions of adults around them, it is crucial, which type of information and approach have these important adults on life of children with disability. The Convention says that respect for children's dignity is necessary and notifies that girls and women with disabilities are at greater risk of being abused or neglected, having their rights violated.

(r) Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child. (Preamble of CRPD - paragraph r)

CRPD (Convention) brings a new definition of disability. It highlights interaction between the person and barriers in society.

„Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. “

(Preamble of CRPD - paragraph e)

Adults around children with disabilities play a big role in identification of different barriers which can hinder his/her participation in different types of school, free time activities, sport, culture, and the other aspects of life.

„The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. “

[CRPD, Article 1]

People living with spina bifida around the world are still struggling for their dignity these days, even though many of them live independent lives and successfully represent states in sport, the arts, politics, science, and many other jobs.

The Convention contains 50 articles, of which we list 30 areas dealing with the most important areas of life for people with disabilities.

1. Purpose.
2. Definitions.
3. General principles.
4. General obligations.
5. Equality and non-discrimination.
6. Women with disabilities.
7. Children with disabilities.
8. Awareness-raising.
9. Accessibility.
10. Right to life.
11. Situations of risk.
12. Equality recognition before law.
13. Access to justice.
14. Liberty and security of person.
15. Freedom from torture or cruel, in human or degrading treatment or punishment.
16. Freedom from exploitation, violence, and abuse.
17. Protecting the integrity of the person.
18. Liberty of movement and nationality.

19. Living independently and being included in the community.
20. Personal mobility.
21. Freedom of expression and opinion, and Access to information.
22. Respect for privacy.
23. Respect for home and the family.
24. Education.
25. Health.
26. Habilitation and rehabilitation.
27. Work and employment.
28. Adequate standard of living and social protection.
29. Participation in political and public life.
30. Participation in cultural life, recreation, leisure, and sport.

The Convention repeatedly emphasizes the positive contribution of people with disabilities to society. Article 8 of the Convention emphasizes the importance of raising awareness about the rights of persons with disabilities and their positive perception. It encourages all means of mass communication to portray people with a disability in a manner consistent with the objective of this Convention.

Every child with disability has not only specific needs but also has her/his rights. He or she not only needs special support, but he/she has the right to be supported on the way of identifying existing barriers in the society and promoting reasonable accommodation.

We would like to introduce children with spina bifida and hydrocephalus, focusing on their positive image, strengths and present to professionals how they can increase them. There is no other way than to start by presenting people with spina bifida and hydrocephalus in a positive light.

Young man with spina bifida - Dominik Drdul from Slovakia - asked the audience before him in his speech:

”

**Can you see my strength?
My weaknesses are visible.**

“



When we think and speak about the rights of people with spina bifida and hydrocephalus, we consider it as important to apply it into everyday life of these children. **What we want to see is the integration of a holistic set of provisions for people with these disabilities, integrated into mainstream systems that are adequately resourced.**

The Convention therefore considers importance of the trainings for professionals and staff working with persons with disabilities as the rights recognized by the Convention and as a mean of improving the support and services guaranteed by the rights.

You can find **beliefs about people with spina bifida and hydrocephalus** in the next part of this Guidelines.

The Convention also recognizes the importance of persons with disabilities and **their individual autonomy and independence, including the freedom to make their own choices.**

It makes a difference when adults understand and strengthen the autonomy and independence of a child with disability and treat him/her with respect from his/her early years.

The Convention pays particular attention to the need to promote respect for the rights of people with disabilities at all levels of the education system and for all children from an early age. There is a very close link between education and human rights. We will write more about it in the chapter about inclusive education.



INCLUSIVE EDUCATION

Terézia Drdulová



"One of the main tasks of the education system is to know about and respond to diversity."

(European agency for special needs and inclusive education, 2016)

The UN Committee on the Rights of the Child **defines inclusive education as: "a set of values, principles and practices, which means meaningful, effective and quality education for all pupils.** At the same time, it justifies the diversity of educational conditions and requirements for all children, not just those with disabilities. Inclusive education is the very goal of education." (Matiaško, 2013).

The concept of inclusive education presupposes that mainstream schools should have all children, regardless of their physical, intellectual, emotional, social, linguistic or other conditions. Inclusive mainstream schools are considered to be the most effective means of combating discriminatory attitudes, creating welcoming communities and creating a healthy society. (The Salamanca Statement, 1994, Article 2)

Thomas and O'Hanlon (2007, In Kudláčová, 2011) named the inclusive approach as general ideal in education. Inclusive education is seen as part of a much broader process and the inclusion approach, which is defined as a never-ending process. There are two levels of perspective for inclusive education - pedagogical and legal. From a pedagogical point of view, this is a definition approach, characterization of the main features and definition of similar approaches. Legal The view looks at inclusive education for people with disabilities from the point of view of Article 24 UN Convention on the Rights of Persons with Disabilities, which deals with education.

UNESCO and UNICEF (2007) state that "The right to education requires a commitment from countries to ensure universal access to education, including the adoption of all necessary measures for the inclusion of even the most marginalized children. However, they warn that getting children to school is not enough. It is not a guarantee that they will receive an education that will enable them to achieve their economic and social goals and to acquire skills, knowledge, values and attitudes that lead to responsible and active citizenship."

Rights-based inclusive education for all requires a holistic approach while changing the view of teachers who are more than just content providers. According to UNESCO (2007), "Implementing a rights-based approach to education, with a view to moving towards greater inclusion, will require a comprehensive reform of education, including adjuhe education of persons, and in particular children, who are blind, deaf or

training systems, materials, learning environment, methodology, resource allocation, etc. Above all, however, it will require a change in the attitude of all people in the system so that they enjoy diversity and difference and perceive them as an opportunity rather than a problem"(p. 29).

Inclusive education is an overarching concept that has an impact on policies and approaches to its implementation during compulsory schooling, higher education, and teacher education. The goals of inclusive education are achieved only in an environment and system that values everyone equally and perceives the school as a community resource. **Inclusive education affects all students and aims to increase the meaningful participation of the individual in educational opportunities and reduce his or her exclusion from education and society at large.** In short, inclusive education is a principles-based and rights-based approach based on core values: equality, participation, community development and support, and respect for cultural diversity. The values that a teacher professes inevitably determine his behavior and actions. According to the World Report on Disability (*World Disability Report, 2011*), *"appropriate training for mainstream teachers is a prerequisite for them to be able to confidently teach children with different needs"* (p. 222). **The report emphasizes that teacher training should also focus on attitudes and values, not just knowledge and skills.**

Many countries signed an international document - the Convention on the Rights of Persons with Disabilities (hereinafter referred to as the Convention).

The Convention is the unique and most influential document of international disability law, which aims to promote, protect, and ensure the equality and completeness of the enjoyment of all human rights and fundamental freedoms by persons and children with disabilities and to promote respect for their inherent dignity. By signing it, the State has committed itself to adopting measures and implementing the provisions of the Convention. The Convention is largely a set of tools to improve the quality of life of people with disabilities and is also legally enforceable.

Article 24 - Education - in point one it reads:

„States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

- a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
- b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
- c) Enabling persons with disabilities to participate effectively in a free society

2. In realizing this right, States Parties shall ensure that:
- a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
 - b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
 - c) Reasonable accommodation of the individual's requirements is provided;
 - d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
 - e) **Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.**
3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
- a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
 - b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
 - c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.



4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.”

There are a number of views and definitions, the authors of which define inclusive education differently. Many clarify inclusive education by pointing out what inclusive education is not, to clearly define what cannot be considered inclusive education. The most common authors clarify the fundamental difference between the process of inclusion and integration, which often persists and is mistaken as being synonymous with inclusive education.

In this context, *Villa and Thousand (2016)* explain why integration is not the same as inclusive education. They point out that the integration determined which students should or could not education in mainstream schools and also that integration focused mainly on security physical and social accessibility with limited or no academic expectations from pupils with moderate and severe disabilities.

The same authors emphasize that Inclusive education is both a vision and an approach that welcomes, values, strengthens and supports diversity academic, social, emotional, language and communication learning of all students in shared environments and experiences - in order to achieve the desired goals of education.

Another problem in defining inclusive education is that it cannot be defined in one sentence, because as *Booth and Ainscow (2016)* state, inclusion is a complex concept.

Similarly, *Tannenberger (2016)* emphasizes that inclusive education is a system or process, not a one-off measure. It leads to a school for all, where heterogeneity is seen as an enrichment of the educational process. **Inclusion allows all children to attend regular primary schools in their area of residence.** Teachers at such a school must approach each student individually as an extraordinary personality. The whole education and philosophy of the school are based on an individualized approach. The educational strategy adapts to the pupil's abilities, talents or handicaps and focuses on ensuring that each pupil uses his / her full potential and at the same time learns to communicate and cooperate with others.

Tannenberger (ibid.) Emphasizes that inclusive education also views the failure of the person - the child. In integration, a person's failure is explained with respect to the person's assumptions and abilities. Inclusive education seeks redress in the system (in support measures) and not reconstitution or stigmatization of this failing child.

One of the main goals of inclusive education is to prepare students for a quality and successful life in today's modern society, which presupposes functioning in an inclusive environment with its natural pro-inclusiveness - atmosphere, form of education and environment.

Pedagogical concepts of inclusive education are currently considered to be the characteristics of a well-oriented "school of the future". Among the basic principles of inclusive education, which can be found not only in the professional literature but also in transnational legal documents, *Tannenberger (ibid.)* considers:

- 1. The principle of humanism and democracy** - inclusion in various spheres of life should be a natural consequence of the application of human rights and the values of a free and democratic society
- 2. The principle of heterogeneity** - diversity becomes a natural part of society and is considered a contribution and impulse to development.
- 3. The principle of cooperation** - the development of natural coexistence of people in society who have different talents and shortcomings.
- 4. The principle of regionalization** - all children from its surroundings have the right to attend a local school
- 5. The principle of openness and efficiency** - thoughtful and efficiently implemented education in a safe school environment.
- 6. The principle of individualization** - accepting the needs of each person in the educational environment and setting up the process so that it can fully develop.
- 7. The principle of wholeness** - the development of the student concerns the intellectual, social, ethical, physical, and other components of his personality.

Another comprehensive and specific concept of inclusive education can be found in the Handbook Index for Inclusion, the fourth edition of which was published in 2016 with the subtitle Handbook for School Development with an emphasis on inclusive values. It is used in more than 50 countries around the world. It offers a set of inclusive pedagogical principles and a curriculum outline for the 21st century, in which the authors answer the question:

"What should we know in order for us to live well here?"

Its authors *Booth and Ainscow (2016)* understand inclusive education as a never-ending process that deals with the involvement of individuals, the creation of participatory systems and environments, and the promotion of inclusive values. It is about increasing everyone's participation and reducing all forms of exclusion and discrimination. It is also about trying to listen to children's voices and act on their views. He thinks not only of children, but also of the families of children and school staff.

The handbook offers opportunities for school development in three interconnected dimensions:

1. Creating an inclusive culture - building a community, establishing inclusive values.

2. Implementation of inclusive measures - development of a school for all, support of diversity.

3. Development of inclusive practice - curriculum development for all, organization of teaching.

The European Agency for the Development of Inclusive and Special Education, based in Brussels, (www.european-agency.org) offers another specific tool for the development of inclusive education in the form of the Inclusive Teacher Profile. The Agency answers the following questions:

1. What kind of teachers does an inclusive society need in 21st century school?
2. What are the basic competencies of a teacher for inclusive education?

As a basis for the work of all teachers in inclusive education, there are four core values related to teaching and learning. They belong here:

1. Respecting the value of student diversity - differences are understood as a resource and a contribution to education.
2. Support for all students - teachers set high goals for each student.
3. Collaboration - Collaboration and teamwork are essential parts of every teacher's approach.
4. Personal professional development - teaching is a learning-related activity and therefore teachers also have a responsibility for their lifelong learning.

More details can be found here:

https://www.european-agency.org/sites/default/files/profile_of_inclusive_teachers_en.pdf

The same agency has developed a concept of quality inclusive early childhood education for all children. She divided the findings into three areas:

1. To enable all children to belong, engage and learn somewhere

Every child is unique in terms of inclusion. Instead of being limited to meeting national standards of competence, it is more necessary to monitor the progress of each child. This makes it possible to value all children in the same way - regardless of their degree of success - as active participants and pupils in a team of peers and to provide them with the support they need to make progress. Exemplary early childhood inclusive education facilities have sought to do so by first welcoming and appreciating each child in a creative, supportive learning community to which everyone belongs and where everyone enjoys good relationships with both employees and peers. In such a friendly atmosphere, children are then encouraged and allowed to:

- use their strengths,
- make decisions, especially in the game,
- practice their curiosity and independence,

- expressed their interest and goals and used them to get involved in solving problems,
- showed motivation and participated in the evaluated activities together and in interaction with a group of peers.

2. Development of self-reflection tool

The self-reflection tool is a set of specific questions. It focuses on preschool facilities as places of participation and education. It emphasizes the process and structural factors within the facility that affect children's experiences. The tool addresses eight aspects:

1. The overall welcoming atmosphere
2. Inclusive social environment
3. Child-centered approach
4. Child-friendly physical environment
5. Materials for all children
6. Opportunities for communication for all
7. Inclusive teaching and learning environment
8. Family friendly environment.



3. Adaptation of the ecosystem model of inclusive education in early childhood. This model covers all the main aspects of inclusive early childhood education that emerged from data obtained from various exemplary early childhood inclusive education facilities. It can serve as a framework for planning, improving, monitoring, and evaluating the quality of inclusive early childhood education at local, regional and national levels (see figure below).

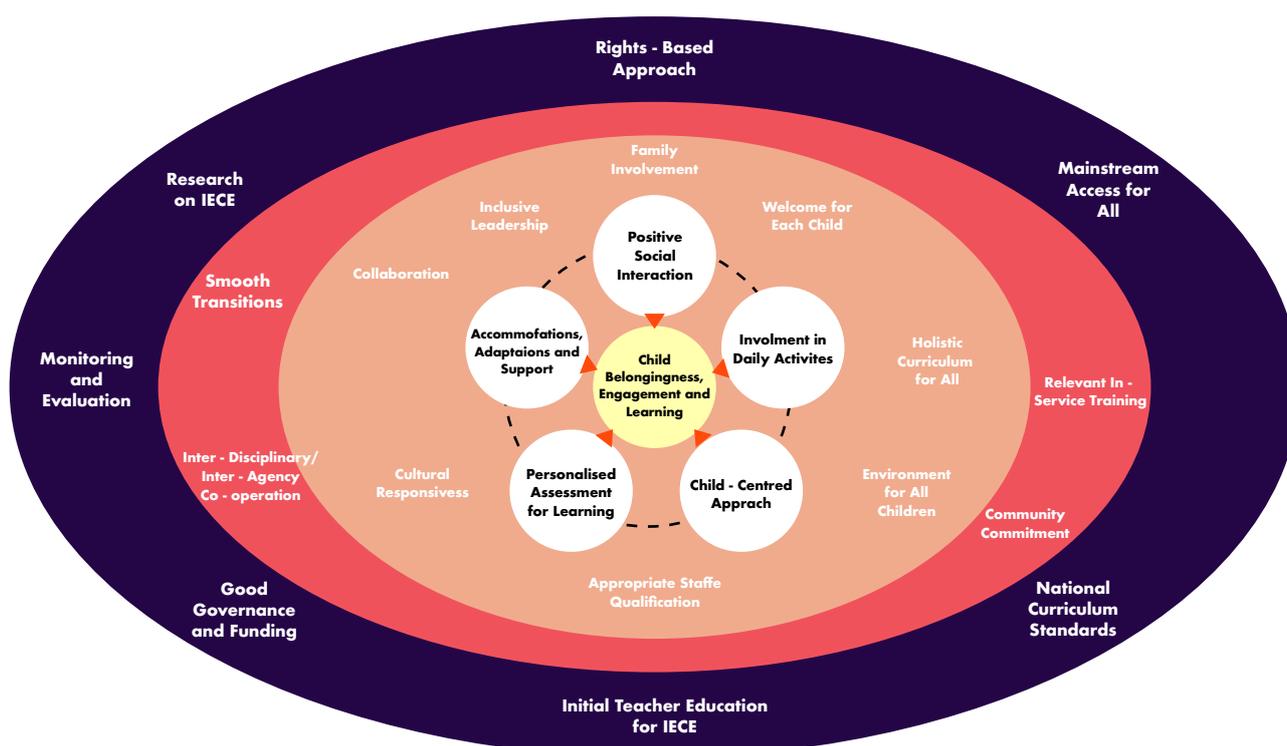


Figure 1. The Ecosystem Model of Inclusive Early Childhood Education

Emphasizes what we mentioned above: A rights-based approach, with good funding and governance, creating an environment for all children, working with different actors, ensuring smooth transitions, connecting with communities, involving qualified staff - all of which creates the necessary basis on which it is possible with a child-oriented approach, positive social interaction and adaptation - to involve each child in activities, with the aim of his participation, education and building his affiliation with the peer community. The methodology is available here:

<https://www.european-agency.org/sites/default/files/IECE-Summary-ENelectronic.pdf>

When educating children and students with spina bifida and hydrocephalus, it is essential to keep in mind that:

"The primary goal of the school for children with spina bifida and hydrocephalus is, in cooperation with parents, doctors and social workers, to help prepare children with SB, H for a full and independent life in the adult community - if their disability allows. It's not an easy task for anyone involved, but the role of teachers is key."

Children with spina bifida and/or hydrocephalus at school, page 38

It is obvious that every child with spina bifida is unique. Thousands of people with spina bifida are born each year. Most of them live to adulthood despite the difficult situation. The space and time between the birth and adulthood of these people is full of risks. They need a lot of support for a parent of a child with spina bifida and hydrocephalus to be well informed and to make his decisions with an impact on the child's future.

The teacher can be one of those pillars that will fundamentally affect the child's development. In doing so, they should have a common goal agreed with the parent, for example in the following form:

Characteristics of a well-adapted adult:

- Acquired social skills - the ability to interact with other people
- Respect for authorities
- Self-confidence as self-respect
- Ability to address challenges
- Ability to accept or request assistance

Further specific information on how to do this can be found in the manuals for the specific target groups of the Multi-IN project.

MULTIDISCIPLINARY APPROACH

Slaveya Kostadinova



The multidisciplinary team allows each discipline to independently contribute its particular expertise to the student's needs. Team members work in parallel to each other and direct interdisciplinary communication is a minimal exception through the team leader (Hall, 2001).

In respect of inclusive education, the multidisciplinary teams in school/kindergarten consist of several members from different fields, each of whom plays a role in addressing children's specific needs. The team may include varied professionals such as special education teachers, general education teachers, school administrators, school nurses, social workers and primary care providers. The team members depend on the specific needs of the student's and educational model. Often, they are funded in different ways, have different priorities and motivation. On one hand, this makes the team more difficult to manage and hinder communication between the individual members. **On the other hand, the multidisciplinary team approach is effective and flexible enough to be applied even if the educational system does not formally provide it or the school/kindergarten has no previous experience.**

The multidisciplinary team offers students a chance to collaborate with each team member in setting specific personal and educational goals for themselves. This allows the team to engage with the goals, holding themselves and the student accountable to the outcome. This approach also encourages family participation, which can improve care coordination, education and inclusion.



Even though the team members may work in parallel, they should follow a shared purpose and goals and contribute to positive outcomes for students with spina bifida and hydrocephalus.

One of the members is usually the team coordinator/leader. Over time, different members can take this role.

ROLES AND FUNCTIONS OF MULTIDISCIPLINARY TEAM MEMBERS

Teachers, inclusive class teachers, physical education teachers

The teacher has a main role in meeting the educational needs of children with spina bifida and hydrocephalus and supports the child at almost every level of the pyramid. The teacher is one of the most important members of the multidisciplinary team. Often, they act as coordinator or a team leader, as due to the nature of his duties the teacher most often interacts with other members.

The class teacher is the person who knows best the student's learning characteristics and difficulties, performance levels, and individualized learning outcomes. The teacher is engaged in planning, adaptation and modification of curriculum in ways that facilitate participation of students with spina bifida and hydrocephalus in typical class activities. Such decisions are usually made together with the special educator. **The teacher applies different teaching strategies such as differentiation, universal design, multilevel instruction, and curriculum overlapping, so that students can achieve their personal learning outcomes within shared class activities.**



The teacher is also the primary adult role model for the class to demonstrate acceptance and inclusion. The teacher facilitates interactions between peers by applying positive behavior supports and engaging students in all classroom activities, including sport.

School leaders

School leaders are principals, headmasters, and others who are responsible for the overall operation of a school. This definition also refers to other school administrators and leaders within the school such as assistant principals, lead teachers, and others who participate in school leadership activities.

The main role of the school leader in the multidisciplinary team is to provide a safe, positive and accessible school environment and to encourage inclusive attitudes among all team members. The school leader also facilitates opportunities for collaboration among teachers, special educators and other multidisciplinary team members.

Special teachers

The multidisciplinary team may include a special teacher whose role is to support the general education teacher in case of learning difficulties. As not every child with spina bifida and hydrocephalus has learning

difficulties, not every team includes such a specialist. Depending on students' current educational needs, the special teacher may join or leave the team over time.

The role of the special teacher is to provide specially designed instruction in a variety of formats, such as co teaching with the classroom teacher or individual tutoring, in accordance with the current curriculum and program of the class. The special teacher often applies various teaching strategies such as differentiation, universal design, multilevel instruction, and curriculum overlapping so that students with learning difficulties can pursue individually determined learning outcomes within shared class activities.

When the multidisciplinary team includes a special teacher, they have a role in curricular and instructional planning, adaptation, and decision making together with classroom teachers and related services personnel to adapt and modify curriculum.

Often the special teachers facilitate interactions between peers by teaching students with disabilities prosocial behaviors and applying positive behavior supports.

School psychologists

Just like the special teacher, the school psychologist is an optional member of the multidisciplinary team. The school psychologist supports students with spina bifida and hydrocephalus to fully access and participate in typical school and class activities. By providing counseling, the school psychologist helps students to develop and apply skills that address their educational or support needs. **The school psychologists are often involved in prevention and addressing the underlying causes of bullying.**

They usually coordinate their work with the other team members like teachers, special teachers, nurses, and family.

School nurses

The school nurse has a very important role in ensuring that the physiological and medical needs of the student with spina bifida and hydrocephalus are being met.

The school nurse is the health expert in the educational setting and from this position supports the work of teachers, special educators and psychologists in understanding how students' health conditions and needs may reflect on their performance and behavior in schools/



kindergarten. The nurse can support school administrators' decisions in regards to student's safety needs and accessible environment. The nurse can also promote developing self-care and advocacy skills related to a student's medical condition.

Our studies show that the role of the school nurse carries great potential, which is very often underestimated and underexplored. **Timely and high-quality medical care at school can be a decisive factor in improving the health and independence of students. A good regulatory framework where these obligations are clearly defined is needed. Supporting materials and training are also important.**

Assistants

The assistants provide support to students with spina bifida and hydrocephalus, as needed, to maintain appropriate and equitable participation in the school setting. There are pedagogical assistants in some countries or personal assistants in others. They have different competencies. The assistant supports students in accomplishing activities of daily living, including, but not limited to eating, toileting, dressing, transferring, mobility and positioning, as well as in traveling from one location to another within the school and community. The assistant operates and assists in the use of student mobility devices such as, walker, wheelchair, braces, canes, etc.

In case of learning difficulties, the assistants may directly support the student at the direction of the teacher and special education.

The role of the assistant in the multidisciplinary team is flexible and not clearly defined. In some cases, the assistant is an external person, appointed as a part of a community program or directly from the school or the family. A family member may also enter this role, often informally, just for specific activities such as heavy bag assistance or catheterization.

Parents and family members

Parents, although not professionals, are a very valuable and key member of the multidisciplinary team. The parents provide information to all other members about a student's needs, strengths, and interests, including information about their health conditions, motivations, interests, learning styles, talents, and history. They often help the team members to identify supports necessary for student success.

Together with their child, the parents are actively involved in identifying and setting learning priorities and educational goals. They make informed decisions and are responsible for the choices within the general education program and curriculum.

Students with spina bifida and hydrocephalus

Students with spina bifida and hydrocephalus also participate in the team that supports their own inclusive education. Commonly, the role of the students and their parents overlap, and students become more active over time, as growing older.

All members must provide their support in a way that encourages child's awareness and involvement in education, including in goal setting and decision-making.

The Multi-IN resources are targeted at the described eight groups, which could potentially form such a multidisciplinary team to support children with spina bifida and hydrocephalus at school and kindergarten. Since the Multi-IN resources aim to support the multidisciplinary team, the members are considered as Multi-IN target groups.

While the General Guidelines provide a holistic view of the inclusion, the Multi-IN Manuals and Educational video courses are aimed at specific target groups and include specific recommendations and practical tips, depending on their role in the team.



BELIEVES OF PROFESSIONALS ABOUT PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

Andrej Drdul and Terézia Drdulová

”

„ Knowledge is power, community is strength and positive attitude is everything. “

Lance Armstrong

“

1. Spina bifida or hydrocephalus does not define the child. **Their personality is made up of a unique set of characteristics, of which only one part is disability.** How his disability affects his development and future is decided at an early age and based on the right information and support which his family receives at that time.
2. Many children and young people with spina bifida and hydrocephalus are redefining the picture of these disabilities today. Developments in medicine, complex stimulation and aids enable these children to develop fundamentally differently and acquire skills than they have in the recent time.
3. **Parental counseling should be provided by experienced professionals.** Counseling should provide access to the full range of topics and issues related to life with spina bifida and hydrocephalus based on assessment.
4. Parents after the birth of a child with spina bifida and hydrocephalus deserve the time needed to adapt to a new situation.
5. Parents are the ones who make the decisions. **Professionals should treat parents with respect. At any time, parents should feel they have a choice.**
6. The quality of life of people with spina bifida and hydrocephalus depends on many factors. **Most adults with spina bifida emphasize that it is up to them to judge their quality of life.**
7. An association of people with the same diagnoses is a rich source of information, experience, contacts and can provide support.
8. Multidisciplinary cooperation is more effective, economically advantageous and preventive.
9. Experts from various fields offer their expertise, opinions, and opportunities. **At every stage of development, it is important to support and develop the functional abilities, independence, and high self-esteem of the child with spina bifida and hydrocephalus.**

SPINA BIFIDA AND HYDROCEPHALUS

Andrej Drdul and Terézia Drdulová



POSSIBILITIES OF MEDICINE AND SPINABIFIDODOLOGY

"I consider every child with a spina bifida or hydrocephalus to be a unique work of art that combines the wonderful beauty of a child with a unique taste of a disease that most people are unfamiliar with. It is not the flavor that is crucial for the child, but the artists who shape and complete the work of art."

T. Drdulová

Spina bifida is one of the rare diseases. It is also one of the most common birth defects. It belongs to the group of congenital neural tube defects. It is the most common congenital defect after congenital heart defects. It occurs in the first three weeks of pregnancy - by the 25th day after conception, when the neural tube forms as the basis for the brain and spinal cord. Incomplete closure of the neural tube - mostly in its caudal part - causes spina bifida - cleft spine. As a result, the spinal cord is not protected at the junction. Spina bifida cannot be cured, it is a lifelong condition. People living with spina bifida need the care of various professionals, not just doctors, throughout their lives.

SPINA BIFIDA IN NUMBERS

- Almost 300,000 babies with congenital neural tube defects are born each year worldwide.
- Spina bifida can occur in any pregnancy. On average, they are born 2.6 children with spina bifida out of 10,000 live births.
- In Slovakia, less than 5 out of 10,000 children with spina bifida are born each year.
- In the Czech Republic, 1.5 out of 10,000 children with spina bifida are born every year.
- In the United States, one child is born with spina bifida out of 1,250 children, which is approximately 3,000 children a year with congenital neural tube defects. Of these children, about half have the most severe form of spina bifida - meningomyelocele.
- More than 80% of people with spina bifida live to adulthood in the United States.
- More than 80% of people with spina bifida have average or above average intellect.
- People with spina bifida are living to an old age and have a good chance of having a good quality of life.
- Adults with spina bifida - even its most severe form - can have healthy children

DIAGNOSIS AND TREATMENT OF SPINA BIFIDA

It is possible to diagnose spina bifida before birth - especially by blood triple test, amniotic fluid collection and ultrasonographic examination. Once the diagnosis is made, it is not possible to unambiguously predict the child's prognosis, because spina bifida has a huge variability in manifestations. Spina bifida treatment is possible before or after the birth of a child. Most children undergo surgery after birth, but in many countries, it is possible to operate on the baby during pregnancy. It is important that parents who are expecting a child with spina bifida be informed, as this has a major impact on their important decisions and what type of surgery they choose.

Prenatal treatment of baby with spina bifida - before birth



Fetal surgery during pregnancy must be performed by the 26th week of pregnancy. Dráb cites the MOMS - Trial (Management Of Myelomeningocele Study) clinical study from 2010, thanks to which the care of patients with spina bifida has fundamentally changed. If spina bifida found during an ultrasound examination of the fetus, it is possible to perform surgery on the fetus between the 19th and 26th week of pregnancy, with sufficient qualifications. During the procedure, the open defect in the spine is anatomically closed so that no further neurological damage occurs in the spinal cord during the ongoing intrauterine development. **In this way, the effects of spina bifida can be significantly mitigated.**

One of the pioneers of fetal surgery - Professor Mueli from Switzerland - notes that the scope of possible research on children with spina bifida operated prenatally would be able to employ one generation of scientists in a unique masterpiece in modern spinabifidology.

Developments in prenatal defect closure techniques and reports of better uterine occlusion outcomes have revolutionized the neurosurgical approach to myelomeningocele. **There are also known risks, the most common of which is the subsequent premature birth of a baby, but research confirms that the benefits of prenatal surgery outweigh the complications of premature babies.** Most babies are born in the 37th week of pregnancy. The real benefits of fetal surgery include a reduction in the incidence of hydrocephalus, Arnold Chiari malformation II, a slight improvement in motor skills and a reduction in mortality. Demonstration video about fetal surgery: <https://www.youtube.com/watch?v=bLnYzCcTEEA>

Prenatal surgeries of spina bifida is no longer an experimental treatment. It is available in many countries as Belgium, Germany, Italy, Poland, Switzerland and other European countries. The costs are covered in accordance with the EU Cross Border Directive (CBD). One of the famous centers are in Zurich in Switzerland.

Treatment of a baby with spina bifida after birth

The pathological and anatomical characteristics of the spina bifida are diverse. One of the tasks of the vertebrae is to form a solid spinal cord cover. It is formed by the body of the vertebrae at the front and back of the arch, which is normally closed.

Neurosurgical intervention in children born with spina bifida tries to close open defects as soon as possible after the birth of the baby and to prevent **secondary complications**. These include open meningomyelocele and treatment of hydrocephalus, Arnold Chiari malformation II and possible spinal cord syndrome. Some countries provide better care for patients with spina bifida than others, but today's knowledge, not only in the field of medicine, makes it possible to provide quality and effective treatment as soon as possible after the birth of a child, which is an essential basis for overall child development. With appropriate postpartum health care, most patients with varying degrees of difficulty will survive, directly depending on the level of disability.

Meningomyelocele, as the most common form of spina bifida, arises as a result of an early developmental anomaly of the nervous system and leads to various structural abnormalities and associated functional neurological deficits. Neurological problems are therefore at the heart of all clinical problems. The operation does not return a neurological deficit. The patient has neurological damage.

Horn presents two basic divisions of neural tube defects according to McComb:

1. **caudal and cranial** - according to the place of occurrence. 96% of them are at the caudal (back) end, 3% at the cranial end (skull) and 1% are combined.
2. **open and closed**
 - Closed: Spina bifida occulta** as an asymptomatic spina bifida. It occurs in 25% of the population. It does not cause any difficulties.
 - Open: Meningocele** - there is a sac protruding from the spinal column. The sac includes spinal fluid but does not contain neural tissue.
 - Meningomyelocele** - an improperly developed spinal cord protrudes out through the unconnected arches of several vertebrae. It is the most common form of spina bifida, arises as a result of an early developmental anomaly of the nervous system and leads to various structural abnormalities and associated functional neurological deficits. Neurological problems are at the heart of all clinical problems.

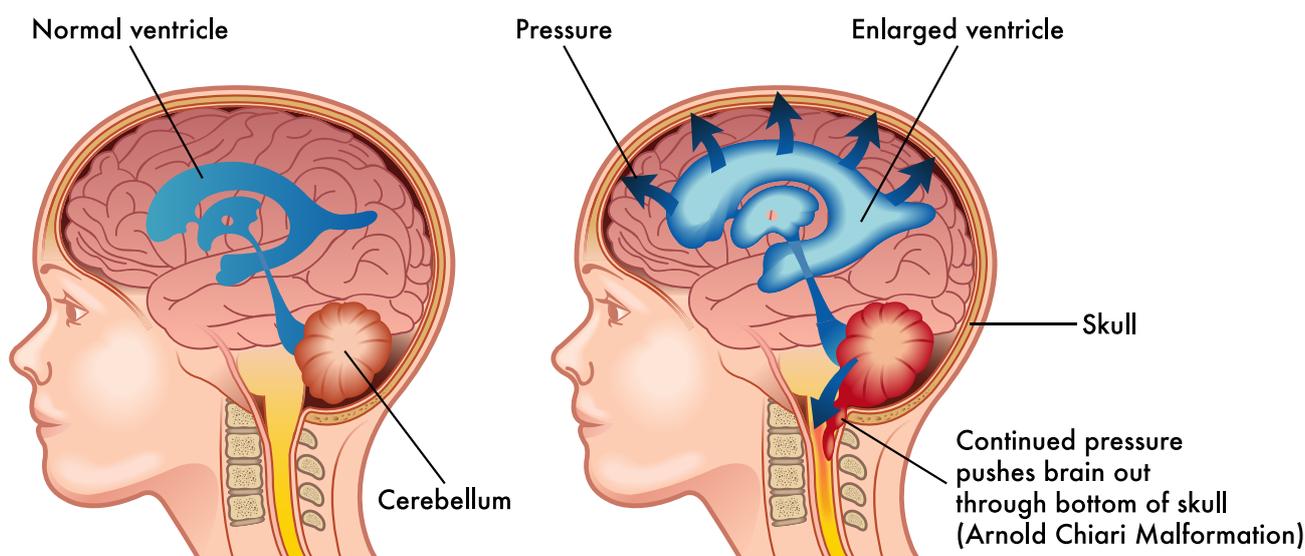
Constrained spinal cord management includes the diagnosis and surgical management of adhesions formed at the site of the original occlusion, the subsequent longitudinal traction stress associated with the spinal cord, and the resulting neurological signs and symptoms.

In terms of walking functionality, children with spina bifida are divided into three groups.

1. **Children are walking**
2. **Children are walking with aids** - with bars, using a walker. Walking is usually only functional for short distances.
3. **Children are mobile in wheelchairs** - some individually, others with the help of another person.

Treatment of a child with hydrocephalus

According to Smrek, hydrocephalus is a condition characterized by the multiplication of cerebrospinal fluid in the cerebral ventricles caused by a disorder of its formation, flow or absorption.



It can be congenital or acquired. It can occur at any age. The cause is another disease - such as meningomyelocele, Dandy - Walker syndrome, Arnold Chiari II malformations or a condition after infection or cerebral hemorrhage - for example in premature babies, injuries or brain tumors.

The basic treatment for hydrocephalus has been the operation of a device - a valve - into the ventricles of the brain for many decades. From there, it is most often discharged into the abdominal cavity by a valve - a system of pumps and hoses. It is a ventriculoperitoneal drainage - VP valve.

The second alternative is the operation of VA valve-ventriculoatrial drainage. The end of the catheter is inserted into the right atrium. This type of drainage is not used often.

Hydrocephalus can have several complications, such as infection or hyperdrainage, such as high valve permeability. Currently, programmable valves are implanted in which it is possible to regulate the amount of effluent by adjusting the permeability of the valve by another device from the outside. An alternative is also the operation of an antisiphon device during hyper drainage in front of the valve. On average, there are two valve revisions per drainage caused by a child's complications or growth.

Demonstration video about hydrocephalus made by the prominent American neurosurgery B. Warf: <https://www.youtube.com/watch?v=bHD8zYImKqA>

Today, it is possible to treat hydrocephalus without valve surgery by means of endoscopic ventriculostomy, when the base of the third cerebral ventricle is drilled with the help of a neuroendoscope so that the cerebrospinal fluid can drain.

Endoscopic third ventriculostomy (ETV) is administered with or without coagulation of the choroidal plexus. It is an attractive alternative strategy that avoids the morbidity and complications associated with valves. The choroid plexus produces cerebrospinal fluid. Removing part of its tissue reduces cerebrospinal fluid production.

Illustrative video about the ETV method: <https://www.youtube.com/watch?v=g3sVRWjHA98>



SYMPTOMS OF MALFUNCTION VALVE

Understanding Spina Bifida reports the following symptoms of valve failure, depending on the person's age:

- Toddler:**
- Fever
 - Vomiting (current)
 - Fatigue, hypersensitivity
 - Swelling, unnatural discoloration, redness along the valve and tubing
 - Loss or impairment of already acquired cognitive and motor functions (walking, speech, coordination and balance)
 - Seizures accompanied by twitching
 - Headache
 - Enlargement of the head caused by enlargement of the ventricles
 - Visual disturbances: blurring, double vision, excessive blinking or squinting
 - The edges of the eyes stretched downwards
 - Concentration and behavioral disorders
 - Illness, sedatio

- Child/adult:**
- Headache
 - Nausea, vomiting (current)
 - Fatigue, hypersensitivity
 - Illness, sedation
 - Hypersensitivity,
 - Back pain
 - Fever
 - Visual disturbances: blurring, double vision
 - Personality changes
 - Coordination disorders, clumsiness,
 - Disorders of mental abilities
 - Swelling, unnatural discoloration, redness along the valve and tubing
 - Walking disorders
 - Seizures accompanied by twitching
 - Reduced performance in or out of school
 - Illness, drowsiness
 - Waking up problems
 - Fainting
 - Decreased cognitive and motor skills
 - Headaches despite medication

What should be done if symptoms of valve malfunction appear?

1. If symptoms are sudden and persistent, seek medical attention.
2. Go to the nearest emergency room.
3. If the symptoms are less severe, see your neurosurgeon and discuss further treatment and treatment options.

PARADOXES OF SPINA BIFIDA

- Spina bifida is often characterized as the most complex congenital error compatible with survival.
- No two people with the same level of spina bifida are the same, do not have the same symptoms, consequences and their development is not the same.
- It is one of the few congenital malformations for which prevention is known.
- It is a scientifically proven possibility to effectively prevent the occurrence of this congenital defect by using folic acid (one of the group of B vitamins - B9).
- The use of folic acid in women of childbearing age one month before pregnancy and during the first four weeks of pregnancy in sufficient amounts reduces the risk of spina bifida by up to 75 percent.
- Enrichment of staple foods with folic acid (most often flour) has reduced the incidence of spina bifida by up to 30 percent in some countries.
- Although various causes are known to contribute to spina bifida, the cause is never a single factor, but the action of several factors at once.
- Although people with spina bifida are successful and well known in society in various fields, most people with this diagnosis are not born.
- The literature in many countries offers outdated and irrelevant information about the lives of people with spina bifida or hydrocephalus - despite the wealth of scientific knowledge and research-based data available and the many people with spina bifida visible in society.
- The quality of life of many adults with spina bifida - such as Paralympic athletes, doctors and others - is obvious, but before or after the birth of a child with this diagnosis they express mostly negative information and prognoses about the child.
- Due to the fact that most professionals do not meet people with spina bifida during their practice, they have a more negative view of these people and the principals and teachers of schools or other institutions have a similar setting. If they do not succumb to prejudice about people with spina bifida or hydrocephalus, they can have a fundamentally positive effect on the direction of their lives and be a source of opportunity for the child.

- We believe that these educational materials of the MULTI-IN project will also contribute to a more objective view of these people and, through informed experts, will open up new possibilities for children and young people with spina bifida and hydrocephalus.

Thanks to the spina bifida, a new direction has developed in medicine - prenatal fetal surgery. The baby is operated on until the 26th week of pregnancy - still in the mother's body. At present, prenatal surgery is also widespread for other diagnoses, not only for spina bifida.

CONSEQUENCES OF SPINA BIFIDA

The lightest form of spina bifida is the unconnected arch of one vertebra of the spine. Every fourth person has such an anatomical variant and does not mean any disease or consequences.

Approximately every one in thousand people have a serious type of defect. It can lead to varying degrees of paralysis and impaired lower limb mobility, as well as affect bowel function, bladder, obesity, impaired hand skills, vision, hearing and learning.

Timely and correct treatment is the prevention of many possible complications. People with spina bifida need the lifelong help of several specialists - doctors, therapists. The complexity of the consequences of the diagnosis requires coordinated care through the cooperation of experts. In a minimal form, it requires the exchange of information between different professions. In addition to specialist doctors - neurosurgeon, neurologist, urologist, orthopedist, rehabilitation doctor, there is useful also a physiotherapist, nutritionist, psychologist, social worker and others.

It is considered essential in the diagnosis of spina bifida that many secondary consequences and complications in any area of health can occur in a person during their lifetime. It is worth keeping in mind that the issue of spina bifida is very complex and requires a comprehensive view of several experts. Thanks to their mutual cooperation, it is possible to detect the solution more efficiently and easily.

Most children with the disease attend regular schools, more than 80% live to adulthood, and you can meet them anywhere in society: People with spina bifida have already sat in a ministerial chair, working and working in a variety of jobs, on a sports ground, in a white coat or for school department.

The prognosis differs for many people - also depending on whether the person developed hydrocephalus, whether he underwent surgery, what form the operation took, what the child's urological problems, deformities on the legs, knees, spine, but also whether one of the experts coordinates care of various

specialists, or even systematically manages them. It can be proven that coordinated and timely care significantly reduces the incidence of secondary complications and significantly saves financial costs. The absence of mutual communication between professionals increases the risk of ignoring potential complications of health. Globally, such coordinated care for adults with diagnoses of spina bifida and hydrocephalus is most absent, which significantly affects the quality of life of these people.

The goal of care should be to improve functionality, mobility (not the same as walking) and minimize the risk of possible complications. Spinal cord injury experts recommend that the International Standards for Neurological and Functional Classification of Spinal Cord Injuries, issued by the American Association for Spinal Cord Injuries, be used. They strongly recommend that parents be informed that there is no causal link between the possibility of active participation in society and whether it is possible for a person to walk. This presupposes knowledge of the risks that are common in people with spina bifida or hydrocephalus - such as the risk of obesity. At the same time, care for these people should be aimed at facilitating the transition to adulthood. The most effective is to connect specialists to community support services provided as close as possible to the person's place of residence, in order to make more use of routine and preventive care with a link to participation in the local community from an early age. **Health promotion also includes support of mental and long-term health, well-being not only for people with spina bifida or hydrocephalus, but also for their family members - parents, siblings. This leads to an improvement in their quality of life and, consequently, to the exercise of their rights.** One of them is the right to education, which should also take place in the local locality where the child lives and is likely to live in adulthood. **The right to education and the possibility of fulfilling it is considered a necessary basis for the exercise of other rights.** Focusing on the active participation of a child with a disability through early intervention programs and later social and psychosocial support with practical elements - given the other significant risks. Research confirms that children and adolescents with spina bifida have lower self-esteem and self-perception than their peers. Children with spina bifida achieve lower scores than their peers in the following areas:

1. physical appearance
2. social acceptance
3. school skills
4. personal satisfaction

Bladder and colon incontinence also have a significant effect, bringing social stigma and reduced self-esteem to young people. This limits their participation in activities and leads to social isolation. **Having control over defecation is a strong supportive measure in reducing feelings of fear, shame and anxiety.**

It is important to emphasize that although most children with spina bifida achieve average and above-average cognitive abilities, their performance at school is affected by a fundamentally different

brain development due to the diagnosis of hydrocephalus and Arnold Chiari malformation II. and related learning difficulties. This is manifested primarily by the child's impaired executive abilities, attention deficits, language and speech deficits, difficulties with self-regulation and organization, behavior, spatial orientation, perception, counting and others. At the same time, the symptoms are different in individual children with spina bifida or hydrocephalus and one profile does not apply to them.

In addition, according to research from the USA, most children with spina bifida experience a two - to five-year delay in the development of independence. These include skills such as dressing up, planning activities with peers, preparing pre-planned meals and more. **All these limitations should be known before the child is trained and the school should incorporate them into an individual education program while providing support measures for the child. The positive news is that targeted cognitive training can increase their functional independence and achieve better self-control.** [Stubberud and Riemer, 2012]

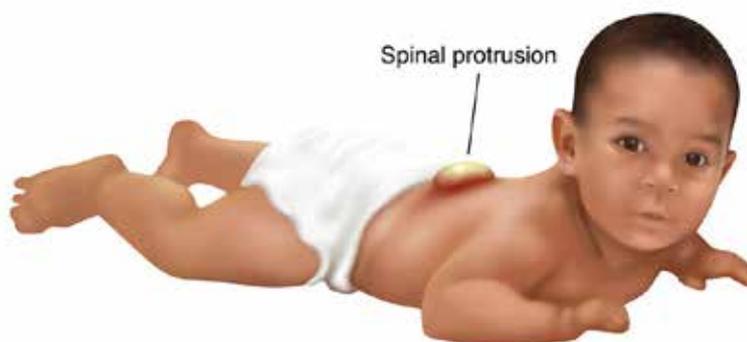
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"The primary task of us, who belong to the uniform majority, is to accept the fact that people who are different from us as a result of their birth defect or illness are not disabled or handicapped. They do not need regret or isolation. They are different from us; they are here to live. They are otherwise gifted. "

František Horn, pediatric surgeon

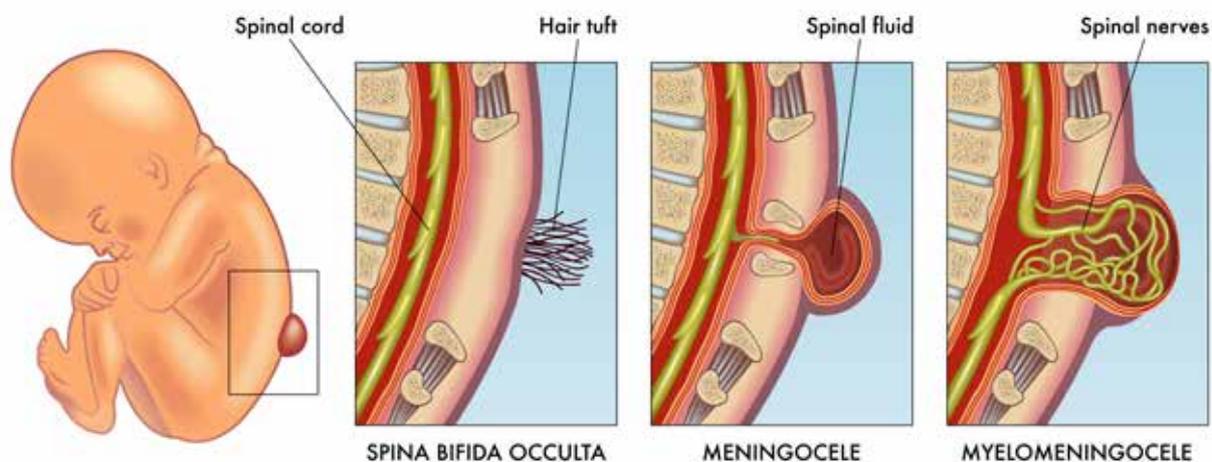
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SPINA BIFIDA BY PICTURES



1. Spina bifida occulta 2. Spina bifida with meningocele 3. Spina bifida with myelomeningocele

TYPES OF SPINA BIFIDA

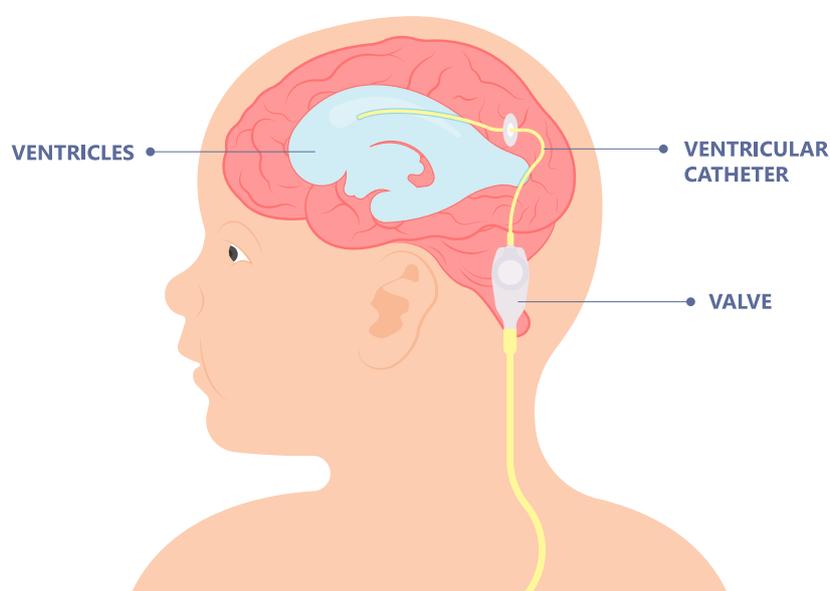


Hydrocephalus in numbers

- Valve - a system of pumps and hoses (catheters) has been used in various fields of medicine for more than 100 years.
- The first pump and hose system was created in 1960.
- The inventor of the revolutionary feasible valve is John Holter, an engineer and father of his son Casey with spina bifida and hydrocephalus.
There are currently more than 127 different valve designs.

Treatment of Hydrocephalus by VP Shunt

VENTRICULOPERITONEAL (VP) SHUNT



EDUCATIONAL NEEDS OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS

Slaveya Kostadinova



SPECIAL EDUCATIONAL NEEDS

In June 1994 representatives of 92 governments and 25 international organizations formed the World Conference on Special Needs Education, held in Salamanca, Spain.

The conference resulted in the Salamanca Statement, which reaffirms the need to provide equal education to all people with special educational needs throughout the world.

When referring to children with special education needs, The Salamanca Statement refers to all children who experience barriers in equal access and participation in education and declares their right to be educated together with all other children. The Statement lays stress on diversity and requires schools to include all children regardless of their individual differences or difficulties.



In this perspective, children with spina bifida and hydrocephalus, together with their unique characteristics, interests, abilities, have a complex range of special educational needs to be met in order to achieve successful inclusion at school and kindergarten. The full specter of these needs may vary depending on various factors and their combinations such as child's health conditions, degree of disability, family background, and socioeconomic status. **It is essential for the main stakeholders involved in the educational process to be able to identify and meet these needs. Due to the complex nature of the needs, this proves to be a difficult task even for professionals with extensive experience or family members who have spent years caring for their children.** The General Guidelines provide an overview of the specific needs that children with spina bifida and hydrocephalus may have at school, in order to support the stakeholders to identify them.

When talking about special needs, we would like to encourage readers to consider these needs not as a result of factors inside the child, but rather as a discrepancy between the resources ordinary provided by the educational system and the support child needs in their learning. Some other clarifications should also be made as follows:

- In this section we apply parts of case studies. The case studies are created within the Multi-IN project, based on a series of in-depth, semi-structured personal interviews conducted with parents

and children with spina bifida and hydrocephalus from Bulgaria and Slovakia.

- Even if described as special or specific, these needs do not impose or suggest the existence of a special education system such as special schools, special classes and other similarly segregated settings. **The place of the children with spina bifida and hydrocephalus is in an inclusive education system, where all learners with and without disabilities learn together.**
- The inclusion requirements of children with spina bifida and hydrocephalus must be met in the mainstream educational system, in schools and kindergartens, through special services designed and provided according to their needs.
- Following the philosophy for equal access and full participation, the described herein needs go beyond the social side of education.

APPLICATION OF MASLOW'S HIERARCHY MODEL IN ANALYSIS OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS EDUCATION NEEDS

This paper considers Maslow's model (Maslow, 1943) as a conceptual framework for systematization and analysis of the needs of the children with spina bifida and hydrocephalus at school. Maslow's hierarchy of needs is a motivational theory in psychology comprising a model of human needs, depicted in a form of pyramid with five hierarchical levels. From the bottom of the hierarchy upwards, the needs are:

- Physiological needs, such as food, water, clothing;
- Safety needs, such as protection from harm and non-threatening and comfortable environment;
- Belonging, including relationships with a partner, family and friends;
- Esteem, comprising achievement, recognition and prestige;
- Self-actualization, referring to the ultimate self-fulfillment, personal and creative self-growth.
- As people got closer to satisfaction of any given need, they would experience the next higher need on the hierarchy.

Maslow's Hierarchy of needs is a valuable assessment tool that is utilized in many different areas, which involve working and taking care of people. As other researchers have discovered, the model helps to examine and explore various educational contexts (Milheim, 2012), (Caraccio, 2017), (Fisher, 2020). It applies successfully especially to students with exceptionalities, because many times their needs are more difficult to identify and meet (Lutz, 2016). In our case, these are the needs of the children with spina bifida and hydrocephalus at school and kindergarten.

Multi-IN pyramid consists of seven levels. In this section, we examine each of them showing in detail certain needs within it and how they can be met, adding real-life examples.



The Multi-IN Pyramid of Inclusion adaptation of Maslow’s framework for students with spina bifida and hydrocephalus

FIRST LEVEL: PHYSIOLOGICAL NEEDS

The first level of Maslow’s model is physiological needs, which include the basic necessities of life, such as food, drinking water, sufficient rest, clothing, bathroom, shelter and overall health.

Here, we want to pay special attention to the general perception of the overall health of children with spina bifida and hydrocephalus. According to popular belief, all people with disabilities have a health condition.

However, **having an impairment does not mean being unhealthy**. Regardless of impairment or illness, people can be in good health, because they eat a good diet, take exercise, get enough sleep, are in a good emotional state, and pursue other healthy behaviors.

(Krahn. G.L., 2021)

With reasonable care and management of associated secondary conditions, children with spina bifida and hydrocephalus can enjoy good health and well-being. Well-being relates to the subjective sense of being healthy. Many people have static impairments, but report feeling healthy and are healthy. **The fact that a child moves and speaks differently does not make him or her sick.** Some of their functions might be affected, such as the ability to walk, but that does not mean that they are ill. Do not expect them to heal or recover. Do not treat them as sick, but help them stay healthy.



For 7 years Viktor's parents couldn't find a common language with the school management. The principle was well-intentioned and tried to help, according to her own understanding. She refused to leave the class on the first floor and to support his mother's advocacy efforts for providing a wheelchair lift at school, while at the same time organized fund-raising bazars "so Viktor could walk" without seeking the consent or notifying the parents in advance. This led to a number of awkward situations with neighbors who commented on the family's income and purchases in the local grocery store. Another whim of the director was for the boy to wear a white national costume in order to walk.

It is reasonable to expect the health worker at school to address the basic health care needs of learners, including children with spina bifida and hydrocephalus. Most often it is the school nurse who does it. However, health care, promotion and provision of healthy lifestyles are not the sole responsibility of the nurse. It is essential for all stakeholders in education to understand and accept the child's condition and to provide them with good care and service so that they can enjoy the best possible health.

The scope of the health care services for children with spina bifida and hydrocephalus at school and kindergartens may include:

Shunt problem monitoring

Approximately 85-90 percent of individuals with spina bifida also have hydrocephalus. It is usually surgically managed with a shunt placed to help drain excess fluid from the brain. In many children, shunts must be revised periodically due to blockages or malfunctions. It is important for school staff to know the signs of shunt failure. Children experiencing shunt malfunctions can present in many different ways, but some of the more common symptoms shown during shunt malfunction include: headache, fever, seizures (abnormal twitching), nausea or vomiting (especially projectile), unusual tiredness or difficulty staying awake or waking up, unusual irritability, arching of head backwards, dizziness or fainting, swelling along shunt tract.

Skin care management and monitoring

Spina bifida may cause little or no feeling in some areas of the skin, usually below the level of the lesion.

Some children are not able to feel pain, heat, cold, sharp objects, pressure or excessive moisture. A sore may develop quickly and can worsen rapidly.

The most common recommendations for skin care management of children with spina bifida include:

- Children should be allowed to wear wide and soft clothes made of natural fabrics like cotton; They may differ from the school uniform;
- Their seating place must be away from heat sources such as radiators, stoves or fireplaces, as well as hot metal surfaces in the summer or prolonged exposure to cold in the winter;
- Children will need assistance when carrying hot drinks;
- Teachers must pay attention when working with laptops, because children may receive burns from sitting hot laptops on their laps;
- Children should be encouraged to shift their weight or change their position frequently (about every 20-30 minutes);
- Special cushions to prevent pressure sores should be available;
- Scheduling frequent diapers changes is also very important to prevent irritations and rashes.

Latex allergy management

Children with spina bifida have an increased risk of developing a latex allergy. Latex is a form of natural rubber and is used in many items found in school environments such as erasers, gloves, balloons, rubber mats, flooring, balls, and racquet handles. The risk of allergy development increases with repeated exposure to latex. Therefore, latex products must be avoided and substituted with those made of vinyl or silicone whenever possible. Symptoms can include redness where contact was made, watery and itchy eyes, runny nose, hives, skin rash, even respiratory distress or anaphylaxis in extreme cases.

Students who are allergic or sensitive to latex may also be allergic to foods such as bananas, kiwi, papaya, avocados and chestnuts.

Prevention of urinary tract infections and urinary and bowel continence management

Urological disorders, including urinary infections, incontinence, and renal failure, represent a significant source of morbidity and mortality in patients with spina bifida. Long-term mortality is associated with urological causes in approximately 33% *[Gutiérrez-González A., 2020]*.

“Clean intermittent catheterization (CIC) remains the gold standard for bladder management in patients with spina bifida” (Lapides J, 1972).

The purpose of this information is to emphasize the importance of maintaining good urological health. It is

crucial that the school/kindergarten, where children spend most of their time, to provide appropriate conditions for this, such as:

- An accessible room (toilet, nurse's office, restroom), clean and wide enough to provide extra space for a caregiver if necessary. It should be equipped with a locker to ensure safety and privacy;
- A caregiver (assistant or nurse) to perform or supervise clean intermittent catheterization (in young children);
- Frequent bathroom breaks and extra time for the toilet including during lessons;
- Discreet and immediate support in case of problems with leakage or accidents.

When Boris was 3 years old, his mother decided to return to work. She started looking for a suitable kindergarten. The family's worries were related to the need for Boris to be catheterized 2-3 times during the working hours. His mother believed that she could seek help from the nurses that all kindergartens have. Although the regulations imposed this obligation on nurses in kindergartens and schools, his mother had heard of cases when they refused.



At the first meeting with the nurse, his mother carried with her all medical items and made a visual demonstration. The nurse agreed and started doing CIC in the doctor's office two or three times a day. She also changed the boy's diapers. Everything was going smoothly. His mother returned to work and the child feels well in the kindergarten. He has friends and goes there with desire.

More information on CIC procedure is available in the Manuals for school nurses and assistants.

Healthy lifestyle

Children with spina bifida and hydrocephalus are at high risk of becoming obese. After age six, at least 50% of children with spina bifida are overweight; and in adolescence and adulthood, over 50% are obese. A heavy body further limits mobility, independence and ability to manage activities of daily living. For that reason, promoting healthful eating habits is so important for this group of children. Moreover, a diet high in fiber and lots of water intake helps to regulate bowel movements. Although it is the family, who have a greater impact on eating habits, the school can also help in promoting a healthy lifestyle, especially in the field of sports and physical activities.

Our study showed that **applying adapted physical education programs for children with spina bifida and hydrocephalus is possible and can be successful**. Most of the children do not participate in physical education classes indeed. The arguments may be different, but behind them can easily be seen ignorance and misunderstanding. There are different ways to include a child with spina bifida in physical education classes.

In primary school, Victor's favourite subject was physical education. The sports hall was on the third floor, but his mother took him up whenever necessary. The teacher included him in the activities by inventing games with the children or assigning him individual tasks like boxing.

Mental health

Self-concept is a fundamental component of a child's psychological health and development. It comprises the child's perceived identity and their awareness of their own personal characteristics and attributes related to others. Children with spina bifida show scores significantly lower on the domains of physical appearance, athletic competence, social acceptance and school performance (Shields, 2008). They are also at-risk for depressive symptoms and anxiety (Padua, 2002).

This requires cooperation and involvement of all stakeholders, especially during puberty, when some children with spina bifida and hydrocephalus can experience serious difficulties.



Roza is sensitive to loud noises, changes her mood often, and sometimes has nervous crises. This has intensified after she entered puberty. When she was in the first grade, learning difficulties were identified after some examinations. A special pedagogue and a psychologist started working with her. Her mother is happy with the resource support, because it takes place in a quiet and peaceful environment and Roza is able to learn her lessons better. The school psychologist is very supportive during some of her pubertal crises.

...

While summarizing physiological needs of children with spina bifida and hydrocephalus at school and kindergarten, the main emphasis is put on overall health and health care. Attention should also be paid to the access to food and water, which can be difficult due to the inaccessibility of the environment, especially for children in wheelchairs.

Often canteens and cafeterias are located in the basement, on a high floor or outside the building; Sometimes water fountains cannot be reached by a person in a wheelchair. These specific cases must be taken into account and every child's access to food and water must be ensured. This may be a responsibility of the teacher on duty, assistant, or peers.

Further information on the physiological needs of children with spina bifida and hydrocephalus is available in the Manuals for each target group. Health care is described in detail in the Manual for Nurses.

SECOND LEVEL: SAFETY AND SECURITY

The second level of Maslow's classic hierarchy is safety needs and it should be a major concern in all schools and kindergartens. As any other students, children with spina bifida and hydrocephalus need to feel safe in the environment in which they are learning.

Emergency first aid

Every school or kindergarten should have at least one qualified first aider. The person who is responsible for this depends on the local health and safety legislation. It could be the school nurse, teachers or other non-teaching staff. If the school has medical staff, usually they take on this responsibility, because of their educational background and knowledge.

Symptoms of shunt malfunction, seizures, burns, breaking bones may require first aid and emergency treatment.

The school personnel who interact with the child should be trained when to notify the emergency contacts, first aider or 112 in case of emergency.

Evacuation in case of emergency

Natural disasters and other emergencies can happen at any time and schools and kindergartens should be prepared to handle them safely and effectively. They can improve student and staff safety by developing emergency evacuation plans and providing regular practice and training. **The emergency evacuation plan needs to contain clear procedures and responsibilities in regards to the persons who will require special assistance in the event of an emergency**, including students with spina bifida and hydrocephalus.

Emergency chairs or transfer slings could facilitate the escape of a mobility-impaired person as part of the organization's evacuation plans. If such are not available, moving the location of a class on the first floor could be an accessible and safe option.

Providing regular training is essential for staff and students in order to avoid community panic. They are also an indicator for what could happen in case of emergency.

A few months later, a fire drill was carried out at the school. During the last class for the day, a staff member entered the rooms and warned of a fire. The children rushed up the stairs, and 11-year-old Viktor entered the elevator and pressed the button. As he went down, the electricity was turned off and the child remained in complete darkness, closed between the floors. He could only hear the excited cries of "Fire!" He managed to

recover from the fear and called his father, who called the school administration. Until his father's call, no one had established Viktor's absence.

It was difficult for the boy to recover psychologically. Long after the accident, he could not stay inside closed premises and his grandmother had to accompany him to school for several months.

His mother filed complaints with various institutions, but never got to know who was responsible for the case.

Protection from bullying

According to UNESCO, learners with disabilities are disproportionately affected by bullying at all ages and in all learning settings, with serious negative impacts on their education, health and well-being.

Many studies have suggested that teachers commonly underestimate the prevalence of bullying in schools. Parents are much more likely than teachers to know whether their own child is being bullied at school (Demaray, 2013). **School authorities should maintain good and trustful communication with students and their parents and should observe carefully for warning signs of bullying, because some indirect forms of aggression are extremely hard to detect.** All stakeholders should act together calmly, respectfully, and firmly to ensure a supportive, caring and safe environment. **If a child with spina bifida and hydrocephalus is having trouble at school because of bullying, a school psychologist can also help the child develop resilience and confidence.**



Stela has no close friends at school. She communicates with one or two children. She was sometimes the object of insults and verbal abuse by a group of children in the class. One of the boys even kicked and hit her. The class teacher failed to deal with the problem. She did not take sides because these were "children's problems". Several times, her mother alarmed the principal, the Regional Department of Education, the Ministry of Education. She contacted a lawyer and was considering filing a lawsuit. Eventually, the boy was moved to another school and the situation calmed down.

It is difficult for Stela to accept insults from her classmates. There are times when she becomes very emotional and cries. Then, her mother stops her from school for a week or two until she calms down.

Safe and disabled friendly infrastructure in the school building, schoolyard and sidewalks

There is a degree of partial overlap with the upper Level 3: Accessibility. While "accessibility" is seen in the

context of an opportunity which provides access to rights and services, “safe infrastructure” is an existential minimum that schools and kindergartens must ensure.

Here are some examples in regards to the safe infrastructure at schools and kindergartens:

- Low or lack of sensation in the lower body could put at risk children with spina bifida and hydrocephalus. They sometimes find it difficult to feel when something in their body is not as it should be and could get burned or break a leg without feeling it. As it was already mentioned, it is important to reduce the risk factors by seating children next to heat sources;
- Classrooms should be arranged in a way that enables children with assistive devices to move around safely and freely so that they can participate in all workstation and group-work activities. All pathways should be accessible, wide enough and clean from bags, pencil cases and other scattered on the floor belongings;
- Ramps are one of the most affordable and used facilities that schools and kindergartens use to improve their architectural accessibility. Our study confirms that standards are rarely followed in renovations and improvements, including when installing ramps. Very often ramps are too steep, narrow and slipping. This makes most of the ramps unsafe and unusable.

The school had stairs to the first floor and the corridors are at levels. Her mother or grandmother took her in their arms to get her to the classroom on the first floor. Making use of an election campaign, her mother managed to obtain municipal funding for improving school accessibility. Ramps were installed at the back entrance and in the corridors, which, however, were of no help because of their steep slope. Later, at the initiative of the mother, the principal applied under a national program and received funding for an elevator to the first floor;

- Handrails on the exterior stairs and continuous handrails on both sides of the indoor stairs could improve children’s independence, mobility and feeling safe. This will have the most positive effect on students with mild motor deficits who do not use assistive devices. Our study shows that their safety needs remain often not identified and not met because of the presumption that they can walk and are independent. Important details are not taken into account: activities such as climbing stairs or walking to school are risky, take time and often not possible for a child with a heavy bag. They require assistance or take too much time.

The school has specialized rooms in physics, biology, geography, computer training, etc., which are located on different floors in the building. Going up and down the stairs is a challenge for her and takes all her time during breaks. As she can manage it, the school management does not consider it necessary to take measures and move the location of the class to one floor. The whole family is involved in Aleksandra’s education. Her father drives her in the morning, goes inside with her and carries her bag to the room on the second floor...;

- Schoolyard and sidewalks are also part of the school infrastructure and they have to be safe, supportive and disabled friendly. This may include regular cleaning of the schoolyard from leaves and snow, low curbs and safe sidewalks around the school without broken tiles.

Martin used to live 200 meters from primary school, but his father drives him every day. The sidewalk tiles were so broken that his wheelchair couldn't hardly move on. After several expensive repairs of the wheelchair, his father had taken the decision to use the car.

Katka is 17 years old and lives in a mountain town. Going to school during the winter months is a real challenge for her. The schoolyard is not cleared of snow, and children and teachers reach the building through a small icy path. Katka can't walk on it with crutches and her mother has to lead and pick her up every day;

Further information on the safety needs of children with spina bifida and hydrocephalus is available in the Manuals for each target group.

THIRD LEVEL: ACCESSIBILITY

According to the UN's definition, accessibility is about giving equal access to everyone. **Without being able to access the facilities and services found in the community, persons with disabilities will never be fully included.** (UN, n.d.) This statement is valid for inclusive education, along with every area of life. As accessibility is crucial for inclusion, it is part of the basic levels of the pyramid, along with physiological and safety needs.

The need for accessibility is so basic for children with spina bifida and hydrocephalus that in most cases not the school profile or the child's interests defines the school a child will attend, but the accessible environment.

Aleksandra did well with the study material. She made an impression of a diligent and curious student. She was often praised. At the matriculation exams, she received very good grades, which allowed her to choose among the best high schools in the city. After much deliberation, the family decided not to take this opportunity. Aleks continued in her current school. It was close to home, good relations were established with the team, as well as a CIC routine. These things prevailed over the interests and capabilities of the child.



Viktor's family chose his high school only because of the accessible architectural environment. The boy's interests and the profile of the school were not a factor. The building is equipped with a ramp to the first floor, an elevator and a toilet for people with disabilities. Viktor can go to all rooms on his own. He does not use any adult assistance at school.

Accessibility is not just about physical access, but also access to information, services and facilities.

Schools can take diverse measures to improve access to children with spina bifida and hydrocephalus to education. Some education-related accessibility measures can include, for example, building school facilities without mobility barriers, and availability of information, communication and teaching materials in formats other than print-only, all following the principles of Universal Design.

Accessible school infrastructure

Inaccessible transportation to school, as well as inaccessible entrances and inaccessible facilities in schools such as canteen, chemistry lab and computer lab, library and toilet, inappropriate classroom furniture, slippery flooring, can pose barriers to education of children with disabilities and children with spina bifida and hydrocephalus in particular. These infrastructural barriers need to be addressed and removed to ensure an inclusive school environment (*Making School Accessible, 2016*).

Accessible school infrastructure may require:

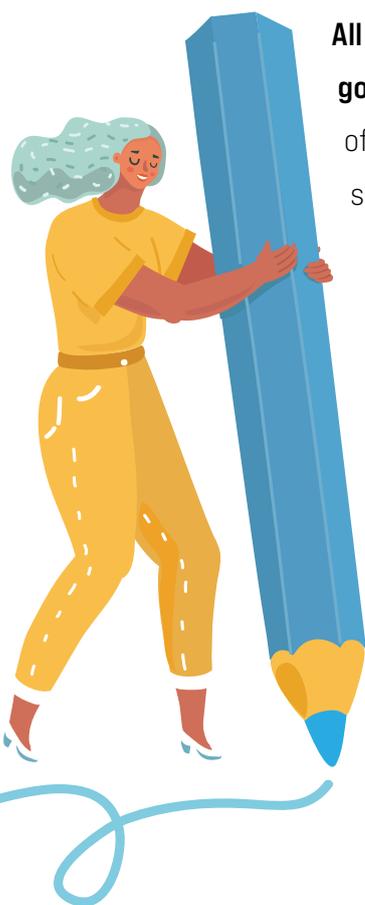
- Ramps inside and outside of the school;
- Handrails on the exterior stairs and continuous handrails, on both sides of the indoor stairs;
- A lift in a multi level building;
- Doorways wide enough to accommodate a student's wheelchair;
- Classrooms with enough wheelchair maneuvering space;
- Accessible toilet cubicle with sufficient wheelchair maneuvering space around the toilet and washbasins, grab bars and locker;
- Special need classroom furniture such as desks high enough to accommodate a wheelchair;
- Wheelchair accessible schoolyard, playgrounds and sidewalks;
- Green/black/white boards low enough so that children using wheelchairs can access them;
- Free access to the green/black/white boards without steps in front of;
- Disabled parking places.

In most cases, additional financial resources may be needed, although there are also practical and cost-effective solutions for making the physical environment of a kindergarten/school more accessible. The most common and affordable solution is to make the first floor fully accessible. In this case, a ramp is usually installed if external stairs exist; at least one toilet is adapted for the needs of persons with

disabilities; the location of the class is moved to the first floor and the classroom is rearranged in order to provide enough space. If a toilet cannot be adapted, an option is to provide access to another suitable room for catheterization, such as the nurse office.

This is not inclusive solution, as some of the facilities located on the upper floors such as library, labs, canteen, may remain inaccessible. In such cases, the school must provide alternative access to these services, for example a caregiver who will bring snacks, water or books from the library. This person can be a teacher, assistant or classmate.

Donka was referred to a nearby neighbourhood high school. They admitted Donka in a regular class. The principal found a room for the class on the first floor, which is at ground level. The building has a toilet for people with disabilities. The child can move independently in the classroom and in the corridors, go in and out of the building, and use the toilet.



All measures to improve accessibility must follow the relevant standards and / or good practices. Our study has found that due to lack of expertise and understanding of accessible standards among construction personnel and school administration, school infrastructure is often barrier-filled and unsafe for students with disabilities. In order to support the efforts of the school administration, the Multi-IN Manual for school leaders provides some design options, technical measures and useful tips for making the physical environment safe, accessible and friendly for children with disabilities.

Accessible information and educational materials

All materials and information provided in class should be accessible and usable by all children. Students with spina bifida and hydrocephalus may need some special materials to be provided such as:

- Extra set of books to keep at home;
- Copies of teachers' notes;
- Audio class notes;
- Assistive technology equipment;
- Speech-to-text and text-to-speech software/devices;

FORTH LEVEL: BELONGINGNESS AND SOCIAL INCLUSION

Advancing up the hierarchy pyramid, the fourth stage represents the need to belong on a social level. According to the original Maslow's theory, the social level generally becomes a priority only after basic levels have been sufficiently met and maintained. At this level, students want to feel a sense of belonging with other people in their environment; they need to identify with a group or groups of peers and need to feel that they do fit in. The lack of a sense of community among students often has a negative effect, leaving some feeling isolated or even excluded from the learning process. The biggest hindrance of students with exceptionalities is the lack of sense of belonging.

[Lutz, 2016]

Our study confirms these findings and also shows that peer contact is the most motivating factor among students with spina bifida and hydrocephalus and their parents in the learning process.

Her first four school years were in a regular class at a public school. Her parents enrolled her because they wanted her to have contact with other children. The girl couldn't learn any of the lessons because she couldn't hear. She couldn't learn how to read. She liked to draw and copied texts as pictures without knowing their meaning. Both a special pedagogue and a psychologist worked with Elif.

Building positive peer relationships in school and kindergarten may be difficult for the children with spina bifida and hydrocephalus as they often experience difficulties with personal and social issues. From an early age, they can encounter challenges with isolation, exclusion, and poor social skills. As a child with spina bifida progresses from early childhood through adolescence, increasing difficulties with self-esteem, confidence, body image, and depression are not uncommon. These issues are typical challenges of growing up for all youth and are most evident during the adolescent years; however, youth with spina bifida reported increased difficulties with these issues, possibly related to the additional challenges of having a disability.

Some of these challenges significantly hinder opportunities for informal peer interaction and making friends in school:

- Children with spina bifida and hydrocephalus usually spend longer time in the toilet for catheterization, which reduces the time for interaction with other students during breaks;
- Some children do not attend kindergarten and thus miss many opportunities for contacts with peers and gaining positive social experience;

- Most of them do not attend physical education classes, which are a great way to develop positive social and problem-solving skills and to cooperate with others;
- Regarding the transport to and from school, most of the children are dependent on their parents and caregiver. The reasons are different, from poor infrastructure to heavy bags. Time before and after school could be spent with friends;
- Continuous assistance and supervision by an adult caregiver creates barriers in peer communication;
- Most of the children with spina bifida and hydrocephalus do not participate in extracurricular activities, which are great opportunities to meet people with similar interests and make new friends.

Frequent hospitalizations and long school-leave periods for different health reasons such as repeating urinary tract infections, wound healing, etc., can make social inclusion even more difficult. They may need further support from their teachers and the other stakeholders in this direction.

FIFTH LEVEL: SELF-ESTEEM AND INDEPENDENCE

Self-esteem, like all the prior needs, must also be maintained in order full inclusion to be achieved. As mentioned earlier in regards to mental health, children with spina bifida often have lower self-concept and self-esteem. **Improving autonomy, functional life skills and competencies is crucial for building independence and self-esteem.**

In children with spina bifida, good muscle strength, mental ability and being independent in mobility appeared to be much more important for daily life function and quality of life than other medical indicators of the disorder [*Schoenmakers Uiterwaal, 2005*]. In practice, this means that schools and kindergartens must provide an accessible architectural environment, opportunities for optimal mental development and appropriate conditions for sports and physical activities, in order to promote independence and functional performance of their students with spina bifida and hydrocephalus.

This is a long process that requires effort from all stakeholders in education. Positive changes cannot happen immediately, especially in children who have been dependent on adult care their whole life and who have achieved basic independence behaviors 2 to 5 years after their typically developing peers (Beth Ellen Davis, 2006). All stakeholders must purposefully promote independence and self-management at every opportunity:

- Accessible environment is a defining factor for achieving independence in mobility in school for

children with mobility impairment. This is an essential precondition for children with spina bifida and hydrocephalus to exercise their rights freely, to participate in school life on equal basis with their peers, to improve their quality of life, independence and self-esteem.

All toilets in the school had squatting pans. The stalls were too narrow to be used with an assistant. The assistant often had to change Moni's diapers in the hallways while the other children were in class.;

- Some children with spina bifida are able to ambulate without the need of any kind of assistance while others may require orthoses or other assistive devices. Children should be taught how to use adaptive equipment as early as possible as mobility will have positive impacts on their cognitive, physical, and social development and independence. Because of the same reasons, older children should be familiar with the accessible transport services to school;
- The ages at self-CIC transition vary, but most children transition by age 10. Higher spinal lesions are associated with lower odds of self-CIC [Atchley TJ, 2020]. However, for some children aged 15-16, self-catheterization is still a challenge and they need parent involvement, without medical reason for this. The parents and other caregiver who perform CIC should encourage and prepare the child for self-catheterization from early age by involving her/him in the procedure;
- Some children with spina bifida and hydrocephalus can become too dependent on their parents or other caregivers, even for things they can do by themselves. Parents should be able to acknowledge this so they can help their children achieve emotional independence. Introducing an assistant who is not part of the family would be a good option in case of such emotional dependence;
- There are various options to minimize the weight of a student's school bag, such as providing a school student cupboard for personal belongings and a second set of textbooks; using sheets instead of notebooks for class work and emails for completed assignments and homework. This will reduce the need for adult assistance and will significantly improve their autonomy.

When Eva learned to do CIC her own, the assistant's help was limited to carrying the heavy bag to and from school. Eva expressed her desire to be alone at school. Her parents talked to the school management and the class teacher and with slight reorganizations they succeeded: the principal offered a second set of textbooks to be used only in school; Eva got a key to one of the toilets, where they installed a small first aid kit for her items; the child used single sheets instead of notebooks. Her bag was significantly lighter and she continued in 6th grade without her assistant. The children in the class help her when climbing stairs and carrying purchases;

- Special apps for smartphones and smartwatches can be very helpful in reminding students of routine care, such as healthy diet, pressure relief, catheterization, water intake and medications. They allow children to be more independent in their self-care skills, instead of relying upon an adult to prompt them;
- Although many students and school staff may want to help the children with disabilities as much as

possible, it is important to promote their independence as much as possible. It is better to allow them to do what they can without immediately jumping in to help and encourage the other students to ask permission before providing assistance. It is important to ask if and how they want help; Increasing physical activity for people with spina bifida may be critical since a loss of strength or fitness may lead to less independence and function in carrying out activities of daily living (Rimmer, 2005). Most of the children with spina bifida and hydrocephalus can participate in sports activities in school. They should be involved in physical exercises and adaptive physical education activities through awareness, thoughtful planning and some creative modifications.

A study in 2005 shows that there are no significant differences in the perceived competence between patients with MMC and the ones with milder forms of spina bifida, although patients with MMC were more disabled. (Schoenmakers Uiterwaal, 2005). Therefore, **all children with spina bifida and hydrocephalus need care and support to improve their abilities, performance and functionalities even those who can walk without assistive devices or are not identified as students with special educational needs.**

Monika could walk without any aids, but was unstable. Her mother was worried that the child could fall down the stairs or be injured by running children during breaks. The principal refused to provide additional railings on the stairs at the entrance or to move the class to the first floor because the child could walk and "there was no need".

SIXTH LEVEL: COGNITIVE NEEDS

Cognitive needs is the expression of the natural human need to learn, explore, understand and create. At this level, the student looks for ways to fulfill their personal potential for learning, and seek fulfillment in their learning. They strive for certain learning goals and seek to achieve them.

As every child is different, there can be a broad range of scores on IQ tests and academic performance among children with spina bifida and hydrocephalus, from exceptional performers to those with learning difficulties. However, most of the students with spina bifida and hydrocephalus have a common learning profile as follows (Porter, 2009):

- Most students have an IQ in the average range;
- The level of cognitive functioning is affected mainly by the illness parameters related to hydrocephalus such as the necessity of shunting, number of shunt revisions, encephalitis, epileptic seizures, and additional structural abnormalities of the central nervous system. (Wills, 1993), (Fletcher JM, 1996);

- Verbal skills and verbal IQs are usually stronger than nonverbal skills, particularly if the nonverbal tasks have a speed or motor requirement;
- A Verbal IQ score is a better predictor of a student's educational achievement scores than the Performance or Full Scale IQ score;
- Word reading and spelling skills are usually better, while reading comprehension and math skills are usually weaker;
- The higher the level at which the spinal cord is affected, the greater the possibility that intelligence and academic skills may be negatively affected;
- Students with spina bifida often demonstrate perceptual-motor problems;
- Health problems may negatively impact performance.

Generally, students with spina bifida and hydrocephalus have often unfairly been viewed as “lazy” or “unmotivated,” when they are actually having learning problems. They might have difficulty paying attention or work slowly, be restless, or lose things. They also might have trouble making decisions. For this reason, it is critical that school professionals are educated about their potential learning problems and strategies for addressing them. Often, a single teacher cannot cope successfully with the learning difficulties. This requires the applying multidisciplinary approach and simultaneous support from all possible parties.

The Manuals for each target group provide useful tips on how to address the cognitive needs of children with spina bifida and hydrocephalus. The most common learning difficulties, specific teaching strategies and good practices are described in detail in the Manuals for teachers and special teachers.

SEVENTH LEVEL: SELF-ADVOCACY AND ADVOCACY

In the final level of the hierarchy, the children with spina bifida and hydrocephalus are motivated through self-transcendence. They are driven to improve the school environment, their own life and the life of students around them. They do not identify themselves as vulnerable ones and feel ready to stand up for their own rights and for the rights of others.

Families are often their child's best advocate and the best role models for teaching these skills. However, teachers and the other stakeholders in education can also encourage the students in this direction and provide opportunities to learn about their rights and to practice advocating and self-advocacy.

Students with spina bifida and hydrocephalus themselves must understand their own rights as children and as persons with disabilities. They must be able to identify discrimination and to know techniques and

strategies to address it. They need proper knowledge and skills to take action. All this can be achieved through positive role models, good examples, mentoring support and child rights education in school.

More information on how each target group can support the children to improve their advocacy and self-advocacy skills is provided in each Manual.



CONCLUSION



Terézia Drdulová

"Information is the key to a better life for people with spina bifida and hydrocephalus."

International federation for spina bifida and hydrocephalus - IF SBH

The General Guidelines aims to guide professionals and family members on their journey to effective and meaningful education of children and young people with spina bifida and hydrocephalus, which has a positive impact on their entire lives.

Before starting any activity, the expert's beliefs are crucial. Many stereotypes, science - and technology-obsessed views of people with spina bifida and hydrocephalus justify requiring professionals to take a holistic approach, working together multidisciplinary to achieve a quality education. Learners with spina bifida and hydrocephalus cannot be viewed through the expertise of one professional.

The Internet, social networks, and the media portray people with spina bifida and hydrocephalus worldwide as those who are involved in society and are often very active in a field, such as sport, culture, or civil society.

Without education, the path to participation is much more difficult, even impossible. The right to education is compared to an elevator, thanks to which it is possible to fulfill other human rights. Comprehensive early care has an irreplaceable place in it. A child or young person with spina bifida is not a patient in the first place, even though he or she needs the care of several doctors throughout his or her life. A comprehensive view of the child through his needs - largely the same as that of ordinary children and through his rights - necessarily pushes professionals into mutual cooperation. The World Health Organization emphasizes not only the health and functional perspective but also the dimension of their participation in people with disabilities. Whether or not they can take an active part in any area of social life is primarily determined by the many barriers that are still present in society. It is the model of inclusive education that is the tool that opens new perspectives for people with disabilities - also by naming the barriers present and, if possible, removing them or looking for other ways to involve them.

Cooperation, active invocation, and family involvement in finding ways and making decisions are one of the strong pillars of inclusive education.

The process of building inclusive education requires constant self-reflection - how and why we act, what purpose our procedures serve, and established ways.

It is a proven experience that where professionals have been open to the inclusion and active participation of children and young people with spina bifida or hydrocephalus, this has brought enrichment and long-term positive consequences for most of those involved. **We believe that the presence of children with spina bifida and hydrocephalus in educational institutions can be the bridge of social inclusion for the learners with spina bifida and hydrocephalus and an effective tool for building such a necessary resilience of ordinary children in schools.**

None of us can save the whole world, but with the effective support of one child or a young person with spina bifida or hydrocephalus, anyone can change this child's world, and his future and open up further possibilities for him.

Thanks to everyone who decides to do this and invites others to cooperate! We are thus building a joint success. People with spina bifida and hydrocephalus are amazing, they have their rights, and they can enjoy an active life.



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GENERAL GUIDELINES

**for inclusive education and multidisciplinary care
of learners with spina bifida and hydrocephalus**

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ISBN 978-80-974287-2-3 [brochure]

ISBN 978-80-974287-3-0 [pdf]

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Co-funded by
the European Union

ISBN 978-80-974287-2-3 [brochure]

ISBN 978-80-974287-3-0 [pdf]

This project “Multidisciplinary care for inclusive education of learners with spina bifida and hydrocephalus” (Multi-IN) has been funded with support from the European Commission. This document reflects the views only of the Multi-IN partnership, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Erasmus+ Project No. 2021-1-BG01-KA210-SCH-000031249

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