



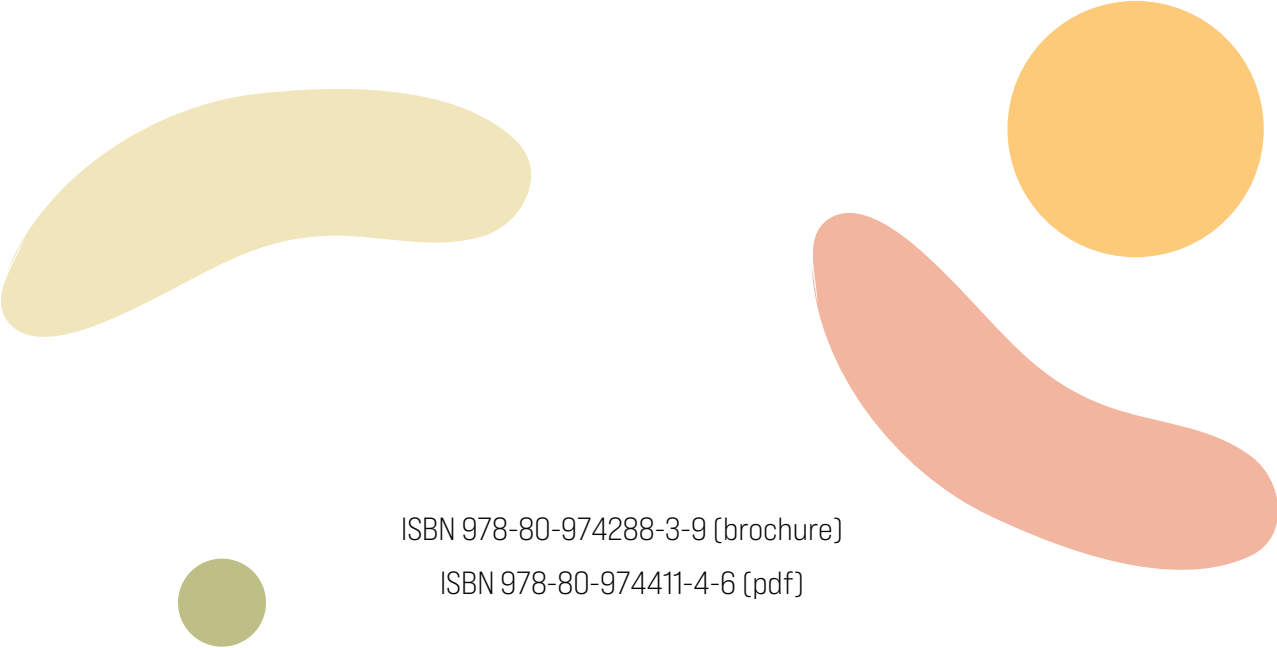
# MANUAL

for teachers in kindergartens, primary and secondary schools  
on multidisciplinary care and inclusive education for pupils  
with spina bifida and hydrocephalus



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


Authors:  
Terézia Drdulová  
Marek Krajňák



ISBN 978-80-974288-3-9 [brochure]

ISBN 978-80-974411-4-6 [pdf]

Erasmus+ Projekt 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 kindergartens and schools, developed in the framework of the Multi-IN project. The general guide, together with supplementary manuals and educational video courses, are intended to support the efforts of multidisciplinary collaboration between professionals and families in inclusive education for children with spina bifida and hydrocephalus.

All Multi-IN resources are open access articles, allowing unrestricted use, distribution, translation and reproduction in any medium, provided the original authors and source are credited. The entire series of educational materials is available at:

**[www.multi-in.eu](http://www.multi-in.eu)**

The manual contains general recommendations based on a survey of the needs and rights of students with spina bifida and hydrocephalus in the context of inclusive education and a multidisciplinary approach. The authors acknowledge that there may be differences and variations in competencies in each country school psychologists in kindergartens, primary and secondary schools based on state legislation. The legislation of a particular country takes precedence over the recommendations given in the manual.

The authors thank all parents and children from Bulgaria and Slovakia who shared their personal stories and contributed their educational experiences to our research on MULTI-IN outcomes.

# OBSAH

<b>INTRODUCTION</b> .....	3
<b>BASIC CHARACTERISTICS OF INCLUSIVE EARLY CHILDHOOD EDUCATION</b> .....	4
Tips for teachers to support the inclusion of a pupil with a difference .....	6
Creating well-being and safety in the classroom .....	7
<b>TEACHER - CREATOR OF INCLUSIVE ENVIROMENT</b> .....	9
Essential characteristics of a teacher in inclusive education .....	10
<b>WHAT A TEACHER SHOULD KNOW ABOUT SPINA BIFIDA AND HYDROCEPHALUS</b> .....	11
<b>A COMPREHENSIVE TEACHER’S VIEW OF A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS</b> ..	15
A teacher accepting the rights of a pupil with spina bifida and hydrocephalus .....	18
Questionnaire mapping the inclusion of a pupil with spina bifida and hydrocephalus .....	22
Questionnaire for classmates of a pupil with spina bifida and hydrocephalus .....	23
Tips to support teacher-pupil communication .....	24
<b>THE TEACHER AND HIS RESOURCES</b> .....	27
<b>APPLICATION OF INCLUSIVE PRINCIPLES BY PHYSICAL EDUCATION TEACHER</b> .....	28
The impact of exercise on the development and self-perception of the pupil .....	29
Recommended procedures for planning and implementing lessons .....	30
Specifics of pupils with spina bifida and hydrocephalus related to physical education .....	31
Examples of inclusion of pupils with spina bifida in physical education .....	31
<b>THE ROLE OF THE TEACHER IN A MULTIDISCIPLINARY TEAM</b> .....	33
Teacher as team coordinator.....	33
Teacher collaboration in the developement of the Individual Education Program .....	34
Teacher - advocate for a pupil with spina bifida and hydrocephalus .....	36
Preparing a pupil with spina bifida and hydrocephalus for in real life .....	37
<b>CONCLUSION</b> .....	38
<b>REFERENCES</b> .....	39

# INTRODUCTION



I have been working with children with diverse needs in inclusive education settings for over 20 years. Throughout my professional life, I have had the opportunity to observe up close the educational journey of hundreds to thousands of students with all kinds of difficulties. It was not the severity of the difficulty on the part of the pupil that was the deciding factor, but the approach taken by the pupil's teachers, assistants, special educators, psychologists, principals and others. **The most difficult experience with inclusive education is usually the first one, because it costs so much - overcoming the fear of the unknown.**

Educating a child or pupil with spina bifida or hydrocephalus is just such an experience for a teacher - full of fear and apprehension about many unknowns.

In my practice I have never met a child, pupil or young person who has not been able to move on, to overcome themselves and make some progress in one or more areas of their life. However, each pupil has made progress primarily in comparison with themselves, not with others. At the same time, I have experienced many wonderful situations and surprises from ordinary pupils, which they have thought up, prepared and organised in order to make it clear that in some way another classmate is important to them.

**Pupils know how to manage inclusive education.** Especially when they have adults around them - teachers, principals, assistants, psychologists, special educators, parents and others whose attitudes and behaviours they can emulate. What's more, they can teach us - the important adults - something alongside. This manual seeks to support teachers in knowing how to manage the inclusive education of a student with spina bifida or hydrocephalus. I hope it will help more and be a good guide.

Most children born with spina bifida and hydrocephalus in the 21st century have a chance at a full life. Provided they have access to timely and quality health care, informed parenting professionals, ample stimulation for their development and access to quality education from an early age. Together, we can do this much more easily. Let's join forces and make it happen - including with the help of this manual.

”

Inclusive education will not save the world,  
but it will transform many parts of the world into  
more beautiful places to live and  
make a major impact on the lives of pupils.

“

T. Drdulová

# BASIC CHARACTERISTICS OF INCLUSIVE EARLY CHILDHOOD EDUCATION



Inclusion means belonging to society, being able to participate in its life in any sphere. Inclusive education is inclusion in the school system and is therefore one part of the inclusive process. In time and space. According to the authors of the Index of Inclusion, inclusive education is a set of values whose purposeful introduction into life answers the question: "What should we know in order to live better together?" Schools offer a unique space and, above all, enough time for children, pupils, young people and students to get to know each other in their diversity, so that one day they can and will be able to live together in society. Never at any other time do they have more time to do this than during the term. This whole process should start at an early age for children. If ordinary children and children with disabilities or with any difference come together in kindergarten, they will experience difference as a natural part of life and with it they will receive information about the diversity of people who make up the world.

**The teacher is the mediator of this important information about the world. His role is essential.** However, he is expected to convey it to children without having experienced it himself in childhood and, above all, without his conviction that it is an important fact for children or pupils. We all know what this looks like in practice. Mostly, teachers are given the duty to pass on more important information to children and pupils. However, a research report by the European Agency for Special and Inclusive Education entitled 'Teacher Education for Inclusion in Europe - Challenges and Opportunities' states: *'Investing in early childhood education and in an increasingly inclusive education system is likely to be a more efficient use of resources than short-term initiatives aimed at 'closing the gap' or supporting some marginalised groups'* (European Agency, 2011, p. 77).

As can be seen, the importance and benefit of early support is crucial for any diverse group of children or pupils. Supporting pupils with diverse needs means recognising those needs and being able to meet them through the provision of support for pupils.

The same agency's Inclusive Education and Classroom Practice project states:

The criteria that should be used when providing special measures to pupils should be:

- (1) as timely as possible,
  - (2) as flexible as possible (if one approach doesn't work, choose another),
  - (3) as "light" as possible (without negative side effects),
  - (4) as close as possible (i.e., preferably within the regular classroom of the regular school closest to the child's home - i.e., where the child would attend if he or she did not have a disability)
  - (5) as short as possible
- (European Agency, 2003, p. 16).

Detailed information about the European Agency for Special and Inclusive Education, its materials and publications in electronic form can be found on its website <http://www.european-agency.org/>. They are available in 24 languages of the Member States of the European Union.

More about inclusive education in the context of pupils with spina bifida and hydrocephalus can be found in the General Guidelines, which is part of the Multi-IN educational materials. We recommend that you familiarise yourself with the contents of the General Guidelines before reading the Multi-IN Manual for any of the eight target groups.

If you are a teacher today and you are educating children or pupils, your core skills should include the ability to understand the importance of educating diverse learners. **An important competency for today's teacher is to be able to not only meet the needs of diverse learners, but to understand that every child has the right to a quality inclusive education.** This right brings a child hope for his or her better future. In fact, the right to education is likened to an elevator that makes it possible to fulfil the person's other rights. Conversely, without the right to quality inclusive education, it is not possible to fulfil that person's other rights. In addition to the Convention on the Rights of the Child, most states in the world have signed another United Nations international treaty, the Convention on the Rights of Persons with Disabilities, and have thereby committed themselves to the obligations contained therein. This treaty has supranational validity and therefore, even if a State does not have legislation dealing with various aspects of the lives of persons with disabilities, the State should comply with the provisions contained in this treaty.

The Convention stresses that teachers and other professionals working with pupils with disabilities need training and support from other professionals.

### ***The ten principles of a good adaptation process according to Drdulová***

1. Give emphasis to sufficient preparation.
2. **Put** the needs and best interests of the child or pupil first.
3. Plan the whole process with the active participation of the pupil's family or carers.
4. At each stage, try to invite experts.
5. Improve the inclusive process dynamically.
6. **Monitor** the sustainability of the set processes.
7. Make the point that other children are naturally inclined to inclusion.
8. Prepare and involve all pupils in each activity without distinction.
9. **Periodically evaluate** the process with rating scales.
10. **Make sure the** student's transition to a different environment is smooth.



## TIPS FOR TEACHERS TO SUPPORT THE INCLUSION OF A PUPIL WITH A DIFFERENCE

According to Berry, the most successful integration strategy is a combination of **maintaining one's own identity and characteristics along with developing contacts with members of the new group.**

1. Consciously include the pupil in class structures - not letting them sit alone, planning work in pairs or small groups in the classroom so that the pupil can interact naturally with other pupils.
2. Encourage patronage of classmates - a classmate - a volunteer - will take on a new student and help him or her navigate the school, the fabric, the structure. Pupils can take turns according to pre-agreed rules.
3. At the same time, it is important not to make the pupil a typical representative of the group, but to allow him to be an individual.
4. Make use of the new pupil's knowledge and abilities (do not focus on his/her limitations)
5. Encourage classroom activities in which all pupils can reflect their individual differences
6. It is very important to involve the pupil in leisure activities, whether long-term and regular or short-term, one-off activities, where children have more opportunities to get to know each other and informally develop their relationships.
7. It is important to note that in this process there are shifts and changes on both sides, in the pupil being included and in the group into which the pupil is included.



## CREATING WELL-BEING AND SAFETY IN THE CLASSROOM

The teacher's complex perception of the pupils fundamentally influences the teacher's view of the pupils and his/her activities with the pupils. If the teacher cares about the well-being of each pupil, it creates the basis for pupils' active participation, thereby stimulating the expression of pupils' abilities and their success both in and out of school.

When pupils have regular opportunities in school to work together and develop social skills, this increases their ability to engage in meaningful relationships with others and has a powerful impact on the environment and the community in which they live. Social skills are very closely related to the ability to name emotions, experience them and have a profound impact on the development of a sense of justice and leadership skills in students - as future citizens.

Below are some of the ways in which a teacher can help to create a safe and comfortable classroom:

- 1. Attention** - to give the pupil enough attention to feel part of the class team. This does not mean giving significantly more attention than other pupils. Creating opportunities for each pupil to present themselves in their own natural way, not in front of the blackboard. In the case of pupils with spina bifida and hydrocephalus, it is recommended that the teacher gets to know the pupil before he/she starts school, together with his/her parents. This is a good strategy to significantly reduce the fear of unfamiliar things that the teacher may read in professional reports about the pupil. During the meeting, the teacher should find out a lot of information from the parent that will clarify the pupil's situation.
- 2. Reassurance** - regularly asking the pupil how they feel, if they understand everything, if they have everything they need and if they are missing anything. A pupil's response to change can look different for each pupil. For example, it may be an inadequate response, silence, uncooperativeness, disruption or rapid changes in the pupil's behaviour. The teacher should take into account that the pupil may not initially be able to express his/her feelings, experiences and needs. Patience and empathy should be important teacher attributes. Asking the pupil is important even if the child does not show any difficulties or obviousness. It has an essential preventive character.
- 3. Peer support** - it is very important to build a culture of peer support in the classroom. Pupils should be encouraged to belong together in order to develop together as a team. If there are pupils in the class who are willing to provide support to other pupils. Teachers should divide all children into groups of two or three pupils to help and support each other from the outset and this should be done when any pupil, not just those with a disability, is in need.

4. **Communication** - thoughtfully creating simple ways of communicating with each other - how pupils can get along, understand each other and express their basic needs. This can be aided by whole class activities using communication cards, multi-lingual signs, a school plan, etc. Awareness of the concept of Nonviolent Communication, developed and refined by Marshall Rosenberg, is very helpful in this regard. Professional publications and videos are freely available to teachers.
5. **Collaboration** - by regularly incorporating activities to promote collaboration into the classroom, the functioning of the class as a team will be achieved much more quickly and effectively.

It is equally important that the teacher looks after himself and his well-being, because **the well-being of the educator means the well-being of the classroom**. Below are tips that can help teachers make a conscious effort to create well-being in the classroom:

1. **Teaching** - the teacher should not be afraid of slowing down teaching. Working on good relationships with each other is time well invested and brings benefits in many areas for the future as well.
2. **The educator's expectations** should not be too high. Working with a collective is a long distance run and requires a lot of time. Proceeding slowly - without high expectations of anyone - protects against disappointment.
3. **Emotions** - the teacher should take into account the emotions of the pupils and should not be afraid of them. It is common for some emotions to manifest over a longer period of time. Giving pupils the space to talk about emotions is important.
4. **Trust** in yourself and your students is equally important. The teacher should not be afraid in advance that he or she will not make it.
5. **Help**. The teacher should be able to ask for help and turn to someone he or she trusts, share with colleagues or with professionals. The teacher is not and cannot remain all by himself. Consciously preventing burnout brings positive results.
6. If there is an **assistant in the classroom**, the teacher and assistant need to be matched. Joint and regular planning between teacher and assistant in advance contributes to creating a sense of well-being during learning. During the planning process, they agree together on how to communicate during the lesson, the location of the assistant, and the level of support to be provided,
7. The teacher should **encourage a good relationship** between the assistant and the pupil as it facilitates the whole learning process and helps to provide more targeted support to the pupil.



# TEACHER - CREATOR OF INCLUSIVE ENVIRONMENT

The teacher is one of the primary actors of the educational process, a professionally qualified pedagogical worker who, in addition to teaching, organizes and coordinates the activities of pupils, co-creates the educational and social climate of the classroom and the environment. Much emphasis is placed on the importance of the social role of the teacher (especially the classroom teacher) in the mutual cooperation of pupils, parents, other teaching staff, not excluding assistants, but also the general public (Průcha et al. 2003).

Inclusion is often shrouded in many myths. Research shows that a large number of teachers are concerned about inclusion. The most common reason given was that children and pupils with disabilities would require much more time and so teachers would not be able to devote sufficient time to other pupils. The second most prevalent concern was the view that it is essential for the education of children and pupils with special educational needs to have 'some' minimum of specialist skills necessary for teaching these pupils. It is also evident from other research that teachers are concerned about the lack of elementary support from the school or counselling facility (Hájková et al., 2013).

As Lechta et al. (2010), the preparation of an inclusive teacher is a demanding process and it is not possible to expect that such a teacher will possess all the special pedagogical competences. **It is essential to view the inclusive teacher as a "general teacher" of both intact and medically and otherwise disadvantaged or children at-risk with a comprehensive focus and general competencies.** For this reason, effective cooperation and active sharing of information and insights of all participants cooperating in the education of a particular child, including parents, is essential. It is also important to note that inclusive teacher extends and intensifies the reach of special education.

All teachers are responsible for inclusive education. This puts the responsibility on them to educate themselves and to expand not only their knowledge, but above all their new skills. The teacher should know the answer to the question: What kind of teachers does an inclusive society need in the 21st century school? And therefore, what are the basic competences of a teacher for inclusive education, the necessary skills when working with a heterogeneous groups of pupils.

The authors of the Inclusion Index have defined three areas **that need to be developed on the path to inclusive education.** Each area is related to the teacher, he or she is directly involved in it:

## 1. Creating an inclusive culture

- In practice, this means that teachers and other staff use new language and labels for pupils, and do not differentiate between pupils on the basis of disability. Emphasis is placed on how the school and family communicate.

## 2. **Stablishing inclusive structures**

- An inclusive environment is purposefully created - primarily through good relationships, supportive communication from school staff, the school's values and vision, intensive and team-based forms of support, opening up to parents and the community.

## 3. **Creating inclusive models of education**

- Education is oriented towards the pupils' personal competences for the future (to know, to do, to be, to live together)
- Introduces teaching that does not exclude, does not separate (avoids or minimizes the creation of special groups, separate teaching)
- **Pupils are offered individual support that follows the pupil's individual developmental goals, supports their potential and strengthens them overall.**



## ESSENTIAL CHARACTERISTICS OF A TEACHER IN INCLUSIVE EDUCATION

**The European Agency for the Development of Special and Inclusive Education has defined the Inclusive Teacher Profile.** It is a set of essential skills, knowledge, attitudes and values that everyone entering the teaching profession needs, regardless of the subject, specialism or age group they will teach or the type of school where they will teach.

1. **Respecting the value of pupil diversity** - differences are seen as a resource and an asset for learning. Teachers should therefore welcome pupil difference and see it as a value.
2. **Supporting all pupils** - teachers set high targets for every pupil. At the same time, they support academic, practical, social and emotional learning for all pupils; as well as effective educational methods in such heterogeneous classrooms.
3. **Collaboration** - Collaboration and teamwork are essential parts of every teacher's approach. Areas of competence relate to working effectively with parents and families as a whole, working with a wide range of professionals from (teaching) assistants, psychologists, special educators, social educators, and other professionals.
4. **Personal professional development** - teaching is a learning activity and therefore teachers have a responsibility for their own lifelong learning. Areas of competence are related to teachers' reflection on practice and continuing teacher education as a tool for continuous professional development.

# WHAT A TEACHER SHOULD KNOW ABOUT SPINA BIFIDA AND HYDROCEPHALUS



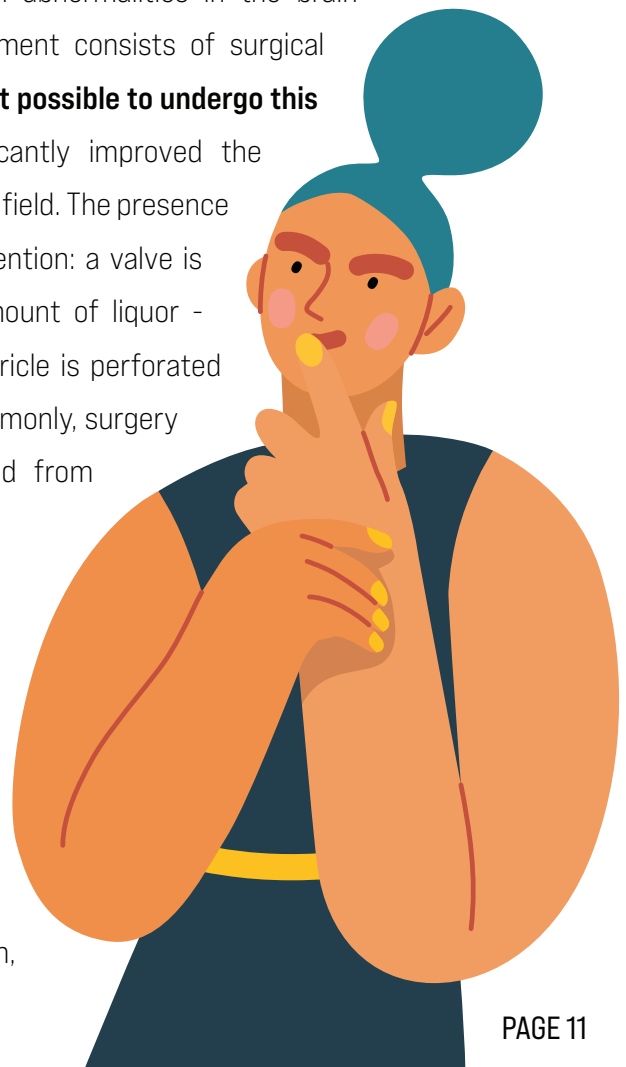
Spina bifida is a disorder of the closure of the bony arch of the vertebrae (spina bifida), which results in bulging of the spinal cord and its coverings, with impaired function of the nervous structures. It occurs by the 28th day after conception. **Spina bifida is** diagnosed in almost one tenth of people with physical disabilities, according to Melichovsky (2010).

For boys and girls, this health disadvantage occurs in approximately equal proportions. For larger malformations, the incidence ratio changes from 7:3 to the disadvantage of boys.

As mentioned by Horn (2014) spina bifida is the most commonly used term to name congenital developmental defects that affect the central nervous structures and their sheaths by impaired midline fusion.

Depending on the site of the disorder (localization of the spina bifida on the spinal cord), varying degrees of musculoskeletal impairment, defecation impairment, and sensory impairment in the affected area may be manifested. Spina bifida is also often associated with abnormalities in the brain (hydrocephalus, Arnold - Chiari malformation II). Treatment consists of surgical closure of the defect. **Advances in medicine have made it possible to undergo this operation in the prenatal period**, which has significantly improved the prognosis for children with this diagnosis in the locomotor field. The presence of hydrocephalus in a child also requires surgical intervention: a valve is inserted into the cerebral ventricle to regulate the amount of liquor - cerebrospinal fluid - or the bottom of the cerebral ventricle is perforated laparoscopically to allow the liquor to drain out. Less commonly, surgery is indicated for Arnold-Chiari malformation II (adapted from Understanding Spina Bifida).

The above interventions compensate to some extent for the consequences of malformations. However, this is a lifelong diagnosis, the care of several specialists, especially several specialist doctors, is necessary. In childhood, it places high demands on physiotherapeutic and orthopaedic interventions and, depending on the severity of the disorder, further hospitalisations. From birth,



management of urinary and bowel emptying is required by adults. In 90% of all patients, intermittent catheterisation is necessary. Due to reduced or completely absent sensitivity, preventive skin care and skin nursing is essential. More detailed information on care can be found in the MULTI IN nurses' manual or other manuals.

We have briefly summarized this information so that the teacher can visualize how the early experience of a child with this diagnosis differs from the early experience of healthy infants and toddlers. This is a developmental period during which, according to the quality of the primary relationship, a relational pattern is formed that predetermines how the child will relate to other people in challenging life situations. The teacher should be aware of the impact of early childhood on the pupil's development and how the number of operations, numerous hospitalisations and visits to outpatient doctors and other specialists have a major impact on his or her development, particularly in the social sphere. All this information should be taken into account, particularly in understanding the impact on the pupil's social integration and on his or her ability to form and maintain relationships with other peers.

Lutkenoff (1999) defined the developmental specificities of children with spina bifida and hydrocephalus in six domains: gross motor, fine motor, speech and language development, social development, and self-care activities.

The **gross motor area** involves movement and control of the body. In its development, large muscle groups of the body are involved and it includes, for example, climbing, but also walking. Due to damage to the central nervous system, the vast majority of children with spina bifida have their gross motor development affected to the greatest extent. Gross motor skills are affected more severely the higher up the lesion is located. The deficiency in this area is many times noticeable after birth - the child does not move his/her legs at all or only minimally. Head control, rolling over and sitting come later than in normal children, as do crawling and climbing, which may not develop at all. Jumping, running or climbing stairs is often beyond the capabilities of this group of children.

In **fine motor skills**, attention is focused on the smaller muscles of the hands and fingers. This includes activities such as grasping objects or controlling facial, eye muscles. Fine motor skills do not tend to be affected as much in the early years and develop in a similar way to other children. In the later period, when this kind of motor skills is already more complex, many of the children with spina bifida or hydrocephalus are slightly behind in this area. Graphomotor problems related to writing, as well as activities requiring hand-eye coordination, cause them considerable difficulties.

In the **area of speech and language development**, the focus is on the ability to communicate with others.

Equally important is the ability to understand and remember spoken language, gestures or symbols used in communication, but also to be able to pronounce words and apply communication symbols and gestures. Development in this sphere is generally similar to that of intact children. Some of these children have even more highly developed communication skills. Children are often very talkative, but their ability to understand the meaning of words may be impaired and may be a lifelong problem.

Cognition represents the **ability to learn to cognize**, reason, solve a problem, navigate the environment, understand cause-effect relationships, but also to transpose abstract ideas. In children with spina bifida, the impact of this diagnosis on the intelligence is usually minimal. Children with hydrocephalus are at risk of associating intellectual disability due to shunt problems or complications during treatment. **Children with impaired central nervous system development are more likely to have developmental disorders of learning (especially dyscalculia), attention, memory, organisational skills and orientation to the surface. Children with these diagnoses are also generally characterised by a slower psychomotor pace.**

There are no differences in **social development** and early development (social smile, perception of family members) compared to intact children. If a child shows delays in this sphere, it is the result of a lack of opportunities to play and to interact with peers. If the child is not given opportunities for decision-making, problem-solving, he/she may have problems with self-esteem, but also in interpersonal competence.

The area of **self-care activities** includes the ability to take care of oneself on a daily basis, such as the ability to dress oneself, take care of personal hygiene (including catheterisation), the ability to move from or to a wheelchair, etc. The development of these skills in children with spina bifida and hydrocephalus is greatly affected by problems with fine and gross motor skills.

The teacher also needs to know about the possible specificities of the pupil with spina bifida and hydrocephalus in the field of cognitive and executive functions, which fundamentally and often differently affect the learning process. Knowing these should help to understand the various obstacles and barriers that the pupil has in achieving his/her learning goals. It should be borne in mind that it is this specific cognitive profile that may externally appear as a **lack of motivation in the child**, or a lack of self-discipline (Fletcher, Brei 2010).

An important piece of information for the teacher is that there are different types **of memory** - visual (sight), auditory (hearing), short-term memory and long-term memory. It is important to know which type of memory the pupil has difficulty with. Deficits in prospective memory are common in pupils with spina bifida. **Prospective memory is the ability to remember what things a person intends to do in the future and later recall his or her intention at the right time.**

All this information should be known by the class teacher and communicated to other teachers in close

cooperation with the school special teacher or psychologist. Another important topic is how dealing with barriers to learning affects the child's experience. This includes experiencing success or failure, experiencing the relationship with the teacher or assistant and, last but not least, experiencing peer relationships. The Multi-IN manuals for psychologists and also for special educators offer more information on these topics.

Despite the potential difficulties in educating pupils with spina bifida and hydrocephalus, statistically it is true that:

- Most pupils with SB have average IQ values
- Verbal abilities are higher than non-verbal (spatial) abilities for most pupils. Especially if non-verbal tasks have to be performed within a time limit or are associated with movement.
- Verbal IQ scores are a better indicator of a student's learning ability than spatial or overall IQ scores.
- Word reading and spelling analysis are better developed, while reading comprehension and mathematical skills are mostly lower.



# A COMPREHENSIVE TEACHER'S VIEW OF THE PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS ● ●

The basic setting of the 21st century teacher should take into account the fact that **there is no universal pupil in the sense that such a pupil performs at an average level.** However, if the teacher's setting is geared towards bringing the pupil closer to some notion of the average pupil, this will often absorb the teacher's entire effort. A teacher's basic starting point in inclusive education should be towards purposeful exploration of pupil diversity and valuing diversity as a value that is anticipated. The teacher's holistic or integrated perception of the pupil fundamentally influences the teacher's view of the pupil and his or her activities with pupils. A holistic view of the pupil does not prevent the teacher from taking into account the specificities of any pupil. It also means setting learning goals for any pupil, not only in the cognitive domain.

Early intervention goals in the U.S. are framed in six areas of child development:

1. Personal, emotional and social development.
2. Communication, language and literacy development.
3. Development of pre-math and mathematical skills.
4. Development of the ability to acquire knowledge and understand the world.
5. Development in the field of physical fitness.
6. Development in the field of creativity.

The teacher's comprehensive perception of the pupil specifically takes into account:

- the pupil's right to quality inclusive education,
- individual characteristics of a pupil with spina bifida or hydrocephalus,
- the pupil's special needs arising from his or her disability and its consequences,
- the strengths of the pupil's personality, his talents,
- the pupil's background,
- the impact of this environment on the pupil's long-term development,
- the consequences of the different development of the pupil's central nervous system from prenatal development,
- the individual secondary consequences of a diagnosis or multiple diagnoses in a pupil,
- the unevenness of the pupil's development,
- the unpredictability of development and the impossibility of determining the pupil's prognosis,
- the pupil's family's vision of the pupil's education and the family's options,
- the interests, hobbies, acquired skills and abilities of the pupil.

Educating pupils who have disabilities is a challenge for teachers for a number of reasons. It is very likely that he or she will encounter one or the other diagnosis for the first time. It is desirable for the teacher to take these facts into account when teaching:

- A pupil with any disability has the same needs as any other pupil of their age.
- A pupil with disability has the right to a quality inclusive education.
- In most countries, a pupil with disability has formally declared accessibility to inclusive education.
- A disability brings additional needs to the pupil that must be borne in mind and taken into account in everyday life. On the subject of pupils with disabilities, the term special educational needs is used, but in some countries the term additional needs is already used to further emphasise that the diversity of needs is not only for pupils with disabilities, but applies to any pupil.
- The sooner a pupil can name his needs and how to meet them with the specific form of support he needs, the clearer the process of his education becomes for the teacher. The concept of non-violent communication, can be of concretely help:
  1. Observation without evaluation
  2. Feelings and their verbalization
  3. Needs and their verbalization
  4. Pleading.
 More information is available here:
   
<https://www.nonviolentcommunication.com/product/the-no-fault-classroom/>
- The active involvement of the pupil in the learning process brings a number of benefits to everyone involved. It requires from adults an attitude of respect and acceptance towards the pupil, open communication and cooperation. You can read more about this on page 24.

The importance of the teacher's correct internal adjustment towards pupils in general, and towards pupils with spina bifida and hydrocephalus, is underlined in the literature by the Pygmalion effect described by the psychologist Rosenthal. At the beginning of the school year, he and his colleague Jacobsen carried out an experiment at the school - the so-called "Harvard Learning Test" - which supposedly identified which pupils were bright and gifted. This information, with the identification of these children, was given by the psychologists to their teachers. In reality, however, the names of the children were chosen at random and were pupils with average IQ test scores. But the teachers did not know this. This sample consisted of 20% of the students. Rosenthal took hidden notes from observations of the teachers' interactions. He noticed that teachers consciously and unconsciously treated children who were labeled as smart and gifted differently. They **were more likely to call them out, praise them, and use nonverbal communication, facial expressions, and gestures differently from other children.** The results of the experiment were shocking. These children did indeed have **significant improvements in their academic achievement** at the end of the year and also in intelligence tests. The Pygmalion effect emphasizes that the teacher's adjustment to the students is more fundamental than the diagnosis, the difficulty, or any difference of the student. The children we expect to be capable become even better.

*"Pavol, who has spina bifida and hydrocephalus, has loved to draw since he was a child. Drawing in particular is not a very common hobby for children with physical disabilities. He would draw anything, anytime. His pictures were colorful, dynamic. He liked to give his drawings to others as a gift. A short time after he gave one of his drawings as a gift, he was approached by people from a certain company to draw a picture with a Christmas theme as a suggestion for their Christmas greeting. He flatly refused, saying that he couldn't draw. Even pleas and persuasions from his parents, who were surprised by his clear attitude, did not help. He explained to them that the teacher at school had said that he could not draw. Then the parents understood why their son had stopped drawing."*

When trying to take a holistic view of a pupil diagnosed with spina bifida and hydrocephalus, the concept of F-words, which describes 6 important aspects of the life of a child with a disability and portrays it in a holistic way, can be very helpful for teachers and other professionals. The F-words concept is the result of the work of the Can Child Research Centre at McMaster University in Canada, which aims to make a positive difference in the lives of children with disabilities.

The concept stresses the necessity of the presence of these **6 areas in the lives of pupils with disabilities:**

1. **Functionality** - The ability to be able to do things, albeit in a different way than the general population.
2. **Fitness** - Being and staying mentally and physically healthy.
3. **Friends** - The ability to form friendships and actively participate in life around you.
4. **Family** - Take into account the influence of the pupil's family environment
5. **Fun - Entertainment.** To have the opportunity to take part in activities that ordinary children and young people experience and to have the opportunity to develop their own hobbies.
6. **Future.** Finding ways in which the pupil can be included in the life of the local community not only now but also in the future.

This concept is a counterbalance to the prevailing deficit-oriented approach of professionals and often parents. It offers a framework for how to communicate about a child's disability, as well as practical tools for use in the educational process, monitoring the child's adaptation and setting intervention goals. Teachers are advised to visit the website to find original professional articles, instructional videos as well as examples of how the concept can be worked with in a school setting. Since the concept is in English, we recommend that the classroom teacher, as part of the collaboration, contact an English language teacher who is educating a student with spina bifida or hydrocephalus and together they can use this unique guide to support the student in the school setting.

<https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>

Another tool for teachers and assistants - especially in kindergartens - is the international WEL - COME IDEA app, which can be downloaded here, together with its methodology:

<https://welcome-idea.eu/#/home?lang=1>

The application and the methodology are available online in four languages - Czech, Slovak, English and Bulgarian. It is an output of international cooperation within the Erasmus plus project. The project outputs are:

1. Methodology for working with children with special educational needs in preschool education.
2. Welcome IDEA ( Interactive Digital Educational Assistant)
3. Support for work with children with special educational needs in pre-school education.

**"Child development experts emphasize that even one supportive relationship a child has with an adult can be crucial in the process of shaping his or her personality."**

For a pupil with spina bifida or hydrocephalus, the teacher is one of the most important people who can have a major impact on the pupil's life and direction. It is important for the teacher to pay attention to the development of the pupil's abilities and interests, to the formation of his/her personal qualities, and it is equally important to contribute to the improvement of the pupil's state of health by educational means.

## A TEACHER ACCEPTING THE RIGHTS OF A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

“

Respect is the bridge that makes it easier for everyone to walk across.

T. Drdulová

”

**Every pupil with a disability not only has special needs but also has his/her rights. Not only** do they need special support, but they have the right to be supported in identifying and removing existing barriers in society and to be supported to make reasonable adjustments.

Due to special needs, pupils with special educational needs are granted rights:

- to an individual approach respecting his/her abilities and possibilities, talents and state of health to the extent provided by law or other regulations,
- for the provision of counselling and services related to education and training,

- to the organisation of education and training appropriate to his/her age, abilities, interests, state of health and in accordance with the principles of psychohygiene,
- to education and training using specific forms and methods appropriate to his or her needs, and to the creation of the necessary conditions that make such education and training possible,
- a child or pupil with special educational needs has the right to use special textbooks, teaching texts, workbooks, multimedia aids and special didactic and compensatory aids in education and training; deaf children and pupils are guaranteed the right to education in the sign language as their natural form of communication; blind children and pupils shall be guaranteed the right to education and training using Braille; children and pupils with impaired communication skills shall be guaranteed the right to education and training using alternative means of communication.

More information about the rights of pupils with spina bifida and hydrocephalus can be found in the Multi - IN General Guidelines, which teachers are advised to read before reading the manuals for each target group.



If adults guide pupils, children and young people to express their views and feedback, they can benefit from it themselves. Pupils name what they expect from the teacher and can complement each other with learning content that is meaningful to all. The teacher is able to plan and design lessons more accurately so that the needs of all pupils are taken into account. Such teachers also move pupils with disabilities into the role of co-creators through shared discussion and show them appreciation and respect. If a teacher does not implement this in his or her practice, it will take a good dose of courage. It is clear that pupils will be at different levels to begin with, but they will gradually learn from each other to express their opinions, give effective feedback and thereby shape their thinking. The skill of giving constructive feedback is a skill they will use throughout later life. By offering pupils with spina bifida or hydrocephalus the opportunity to be involved in the classroom, extracurricular activities and at the same time influence what is happening, it gives them the opportunity to be active participants in the community. The following examples offer inspiration for teachers - how inclusion is imagined by pupils - including those with spina bifida or hydrocephalus.

## *ABC of Inclusion through the eyes of a pupil*

Focus on my **A**bilities.

Help me to **B**elong.

Facilitate opportunities for me to **C**onnect.

Respect the **D**iversity of me.

Treat me as an Equal and teach me **E**quality.

Respect and include my **F**amily too.

Teach me how to become a **G**lobal Citizen.

Respect that my Children's Rights are **H**uman rights.

Ensure I am Authentically **I**ncluded.

Educate me about the importance of **J**ustice for All.

Show and teach me **K**indness.

Support my communication or **L**anguage barriers.

Ensure that my experiences are **M**eaningful.

**N**urture my interests and abilities.

Create **O**pportunities for me to Thrive.

Help me to **P**articipate fully.

Embrace me in **Q**uality inclusion.

Respect my **U**niqueness.

**S**ee and support my Individual Needs.

Always look for ways to help me **T**hrive.

Ensure that I **U**nderstand you and am understood.

Support me to always have a **V**oice and be heard.

Help nurture my **W**ellbeing.

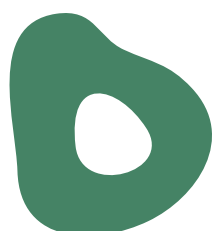
Support me to e**X**cel in everything I do.

I am **Y**oung and may need you to be my voice.

**Z**

Source: Diversity kids: The Inclusion Alphabet and Me

Translation and editing: T. Drdulová





Dominik Drdul, then a 17-year-old young man with spina bifida and hydrocephalus from Slovakia, gave a speech in Brussels in 2014 - on the occasion of the 25th anniversary of the adoption of the Convention on the Rights of the Child - on behalf of all the children of Europe. Part of his speech to policy makers from European countries was:

**"Today is the anniversary of the adoption of the UN Convention on the Rights of the Child. This Convention has changed the daily lives of millions of children around the world, including children like me - children with disabilities. Many of them still do not have these rights fulfilled,"**

**"I also see a problem in the mindset of people who consider our lives inferior. They put themselves in the role of saviours - I'll help you, I'll sort it out. They don't take us as partners. But I don't stand for feeling sorry, I stand for doing something," Dominik explained.**

In Brussels, he recalled Albert Einstein's statement that if we judge a fish by its ability to climb a tree, we will spend a lifetime believing it is stupid. He added that he agrees with this statement because he too has had many times when someone has focused only on his weaknesses and not on his strengths. He further added that the obstacles he faces in his daily life are mainly in people's minds. In practical terms, there is a lack of barrier-free access in cities, institutions and schools.

**"It doesn't take much effort to see my disability - it's obvious. Well can you discover my abilities? Can you discover the abilities of other children with disabilities? Please do. Consider me and all other children with disabilities as your partners - we long to be taken seriously,"**  
**Dominic stressed there.**

In order for pupils to feel listened to, they need to be able to express their opinions. The teacher can use a one form of gauging pupils' opinions. Below is a questionnaire for a pupil with a disability and for his/her classmates. The teacher can use it as part of the prevention process to find out about the relationships between pupils. After some time, the teacher can repeat it with the pupils and compare the results.

It is important to emphasize one of the possible preventive activities of the teacher. It is important that the teacher or any other member of the multidisciplinary team does not wait for difficulties or misunderstandings among the pupils, but that he/she carries out preventive activities to the maximum extent possible. Prevention is one of the fundamental pillars in inclusive education.

## QUESTIONNAIRE MAPPING THE INCLUSION OF A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

**Name and surname:**

**Class:**

**Age:**

### **Please read carefully the following instructions for working with this questionnaire:**

The questions in this questionnaire are about your inclusion in the class. Your answers will help us to find out how you perceive your level of inclusion at our school. Please be as specific as possible and give real examples. If you do not have enough space under the question, please continue your answer on the other side of the paper or on a new sheet of paper. However, do not forget to include the question number. In your answers we want to focus on your realistic description of inclusion/integration/inclusion (i.e. everything that you think is not going well, that you might prefer not to admit and that bothers you). Don't worry, your answers will not be published anywhere and will only serve to improve your inclusion and education. The questionnaire is not on time. Thank you for your openness and commitment to changing things. Remember, we are here for you! :)

1. Name what you think are the differences between you and other pupils.
2. How do your classmates behave towards you?
3. How do teachers treat you?
4. How do you work with your classmate(s) in pairs, triads?
5. Do you spend time together after school?
6. What do you usually do together?
7. What do you think you are good at?
8. Do you think you are more often the target of jokes, insults compared to other classmates?
9. Do you think that your presence in the classroom has changed your classmates' view of disabled people? If so, in what ways?
10. Do you think your disability gives you a different view of the world? If so what?
11. What is your dream? Where would you like to study next? What would you like to do after your education/study?

The above questionnaire was inspired by Holúbková's (2008) questionnaire, which focused on the perceptions of pupils with disabilities in the mainstream classroom. The questionnaire cannot be regarded as immutable as it is non-standardised and is primarily intended to serve as inspiration. The teacher knows his/her pupils best and can therefore make changes to it. It is also recommended to distribute a similar questionnaire to other pupils - as directly defined by the author mentioned above. This gives you the opportunity to find out how the pupil is perceived by his peers.

## QUESTIONNAIRE FOR CLASSMATES OF A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

**Name and surname:**

**Class:**

**Age:**

### **Please read carefully the following instructions for working with this questionnaire:**

The questions in this questionnaire relate to the inclusion of a pupil with a disability in the classroom. Please answer as specifically as possible (and therefore give real examples) and also as detailed as possible for each of the items. If you do not have enough space under the question, please write the continuation of your answer on the other side of the paper or on a blank sheet of paper. However, do not forget to include the questionnaire item/question number. In your answers we want to focus on your real description of inclusion/integration/inclusion (i.e. everything that you think is not going well, that you might prefer not to admit and that bothers you). Don't worry, your answers will not be published anywhere and will only serve the purpose of improving/enhancing your inclusion and education. The questionnaire is not on time. Thank you for your openness and commitment to change things. We are here for you! :)

1. Name what you think are the differences between you and an integrated classmate ?
2. Have you recently worked with an integrated classmate, e.g. in pairs or triads? How did you feel?
3. What advantages, disadvantages do you see in having this pupil as part of your class?
4. How do the teachers behave towards him/her?
5. Do you think you can learn something new from him/her?
6. Do you spend time together after school?
7. What do you usually do together?
8. What do you think he/she is good at?
9. Does this pupil become the target of jokes, insults more often compared to other classmates?
10. Do you think that the presence of this pupil in your classroom has changed the way your classmates view people with disabilities? If yes , in what specific ways?
11. What is your opinion on where this pupil could go after leaving this school?

The above questionnaire was inspired by Holúbková's (2008) questionnaire, which focused on how a pupil with a disability is perceived in the classroom in inclusive education.

## TIPS TO SUPPORT TEACHER-PUPIL COMMUNICATION

The tips emphasize those aspects of teacher - pupil communication that are conducive to a supportive relationship on the part of the teacher. They are linked to individual, group or class discussions focusing on discrimination, mental health and other topics with an impact on pupils' futures. They can be relevant in the current post-pandemic era.

In order for pupils to feel listened to, reassured that they are being taken seriously and left with a sense of hope for the future, it is important to be prepared for these discussions:

1. Study the information about the issue you want to raise with the pupils in the discussion.
2. Reflect on your own feelings and prejudices related to the topic, which may undesirably influence your communication with pupils. Ask for supervision if necessary.
3. Take into account the varied experience of each pupil, which influences their current view of the issue under discussion.
4. Accept the fact that not all pupils will be willing to engage in discussion. It is important to 'meet' pupils where they are rather than trying to push them into what you think is best for them.
5. Be receptive to the atmosphere in the classroom. Check how the pupils feel before and after the discussion. Regularly ask short questions about the pupils.
6. Pay attention to your own mental well-being, reflecting on your own stress and tension, so that you are as available as possible to the pupils when discussing with them.

Whether you are facilitating a conversation or addressing a specific issue at school, you may find the Canadian experts' framework, Listen - Trust - Act, useful. Putting it into practice will make your students feel welcome, supported and reassured in the school community.

### A. LISTEN

A key element in promoting pupils' mental health and wellbeing is **listening to understand**.

1. To create an atmosphere of acceptance, focus on active listening strategies:
  - Listen to understand, not to answer. The goal is to make the pupil feel heard, not to have an immediate solution to their problem.
  - Pay attention to your body language as the student shares their experience. Show empathy and compassion then.
  - Be physically, emotionally and mentally present. Don't be preoccupied with other things at the time of the conversation. This is how you communicate to the student your interest and concern for him/her.
  - Be understanding of the student's unique experience. Work with his/her perspective as a reality,

do not deny it.

- In group discussions, listen to the "quiet voices" but do not push them to engage in dialogue.
  - Allow sufficient time and space, do not interrupt the conversation.
2. Provide opportunities to share in the classroom, in small groups, or individually with a student.
  3. Be aware of your position, the power and privileges that you have and are determined by your position as well as your unique life experience, which may be vastly different from your student's unique experience.
  4. Be aware of your biases, prejudices, avoidance of contact, or, conversely, preferences towards particular pupils (they are always present). Look for what triggers these feelings in you. What prevents you from staying in contact with the pupil (in both positive and negative ways). Supervision can be very helpful in this self-reflection.
  5. Receive the messages that the pupil sends not just in words. Notice his body language and non-verbal expressions to understand him better.

## **B. TRUST**

Confidence in what pupils share confirms their life experience.

1. Believe what the student tells you about their experience. Respond with understanding and compassion.
2. Be careful not to deny or belittle their experiences or feelings by your reaction. During the conversation, check:
  - a) whether you understand the pupil correctly (rephrase the captured message and ask the pupil if you understood it correctly),
  - b) whether you take the pupil's experience and his/her feelings as reality (let the pupil know that it is okay to feel the way he/she feels in a given situation, whatever it may be)
3. Use neutral language when responding to the pupil. For example, "I hear that ... ", "I can see that you are upset", etc. Avoid misleading reassurances such as 'it will be fine'.
4. Be aware of the discomfort you may feel when you hear about the learners' experiences. **Be careful not to be driven to seek immediate solutions.**
5. Enquire about the situation of pupils who have some difference. Find out how inequalities in access to education, housing, employment or healthcare affect how pupils think about their future.

## **C. ACTION**

Acting with and for pupils is integral to reassuring pupils that their identity, mental health and wellbeing are worthy of attention and support.

1. Pupils who are directly affected by the topic discussed in the group may need additional care and support. We recommend that the class teacher be an informal daily part of the class community.

This will show that you really care about the pupils.

2. Be sensitive to the manifestations of mental health difficulties in your pupils. If necessary, **encourage both the pupil and their family to seek professional help.**
3. Ensure that the needs and views of the pupils themselves are taken into account when developing school action plans.
  - a) Act together with the pupils and for their benefit. Pay attention to disadvantaging (often long-established) practices and barriers that put certain pupils at a disadvantage. Give space for these to be directly named and work to remove these barriers.
4. Consult procedures and options with other institutions where necessary
5. Do not work alone in the pursuit of change. Listen to everyone involved. Involve colleagues, listen to their perspectives. Think about what all the practice (barrier) is related to and what it helps to maintain.
6. Continue to pay attention to education:
  - a) Continue to talk to pupils about equity, mental health, equality of opportunity, reflect on the options you have in making the necessary changes towards supporting all pupils,
  - b) report cases of unequal treatment of pupils. Also look for examples of good practice and take inspiration from how identified barriers can be overcome.
7. Action plans and their implementation help to bring about systemic change. But even during these processes, it is the pupils who are most important, and they need someone to be there to listen to them.

## THE TEACHER AND HIS RESOURCES

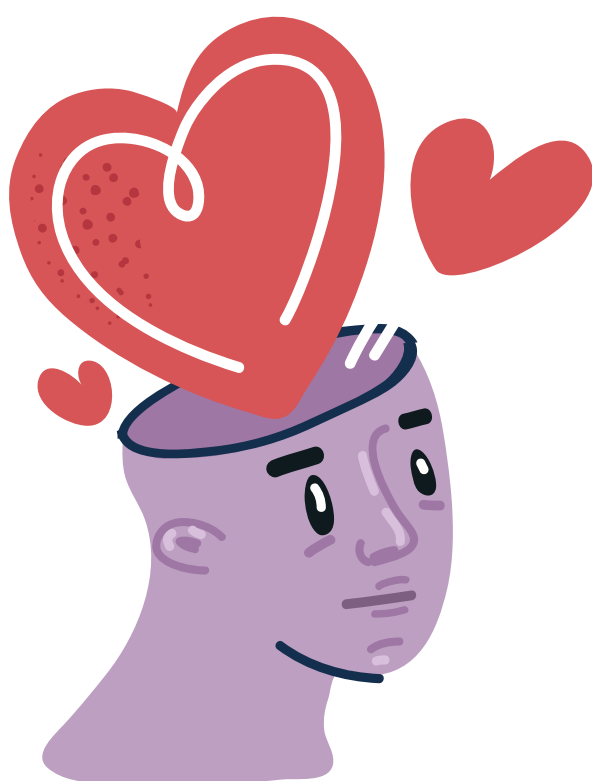


Inclusive education does not only focus on the learner, but on all those involved in the learning process and considers it important that they are supported. The teacher cannot be left alone in inclusive education. This contradicts any characteristics of inclusive education. On the contrary, the cooperation and support of the teacher is in the whole process of inclusion.

**It is extremely important for a teacher to know his or her resources and to take care of him or herself and his or her health - mental and physical - in a preventive way. They can do this by using supervision, coaching or mentoring. We strongly encourage teachers to use the services of such trained professionals.**

Quality inclusive education for pupils with disabilities inevitably implies the need for teacher support and collaboration with other professionals. The teacher has the right to request this support. Otherwise, it is not appropriate to speak of inclusive education. Above all, it is the responsibility of the school management to ensure that teachers' resources are regularly replenished.

Many pupils diagnosed with spina bifida or hydrocephalus need the support of a learning assistant. However, this form of support alone may not be sufficient for the teacher for a number of reasons.



## APPLICATION OF INCLUSIVE PRINCIPLES BY PHYSICAL EDUCATION TEACHER

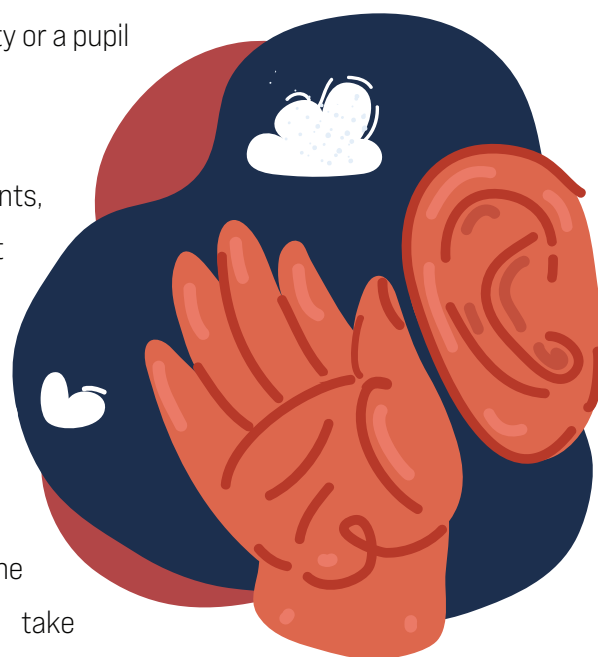


In the context of the teacher's holistic view of the pupil with spina bifida or hydrocephalus, it is important to highlight the role of the physical education teacher, which is related to overcoming obstacles, knowing one's limitations, the skill of reaching the available goals and the active approach to overcoming one's limitations within the possibilities of the given handicap. We consider it important to note that a pupil's relationship to sport can, of course, be significantly influenced by the primary family environment, but also by the secondary peer environment or the pupil's own character. (Lechta et al., 2010). An informed and holistic pupil development-focused attitude on the part of the teacher is all the more crucial.

Physical activity is essential for the social and physical development of a pupil with spina bifida, but the functional level of pupils with spina bifida and hydrocephalus may differ. There is no specific adapted physical education programme for pupils with spina bifida. It always depends on the level of spinal cord damage, the severity of the deformity and the medical devices used by the pupil with spina bifida or hydrocephalus.

Physical education for pupils with spina bifida and hydrocephalus is part of the inclusion process and cannot be separated from inclusion by a decision to exempt a pupil from taking the subject. Inclusive physical education requires adapting the content for the pupil and is primarily about the teacher's ability to be responsive and creative. It often does not place higher demands on the teacher than the inclusion of any other pupil - for example, a pupil with hyperactivity or a pupil with behavioural difficulties, discipline difficulties, etc.

It is important for the PE teacher to work with the pupil's parents, assistant, school nurse, or the pupil's physiotherapist or specialist doctor. They can guide the teacher and the pupil as to what exercises the pupil can do, what load is appropriate for the pupil and so on. It is a good idea to make a written record of the meeting of the members of the multidisciplinary team, make a copy of it and give it to those involved - including the parents. The record should include the pupil's objectives and the competences of the professionals involved - what they take responsibility for - as well as the date of the next meeting to evaluate the fulfilment of the educational objectives and the procedures implemented. The record can be part of the Individual Education Programme, as well as an evaluation of the achievement of the learning objectives.



## THE IMPACT OF EXERCISE ON THE DEVELOPMENT AND SELF-PERCEPTION OF THE PUPIL

There are many reasons why pupils with spina bifida or hydrocephalus should be included in PE lessons, but here are just a few:

1. Clearly demonstrated impact of physical activities on the overall wellbeing - physical and mental health of pupils.
2. Learning new skills affects the perception of one's own body, its possibilities, limits and consequently influences the student's self-perception.
3. To exercise, develop and improve muscle function, overall fitness can every pupil - with the support of an assistant. Otherwise there would be no worldwide Paralympic movement. Paralympic sport movement is not for the healthy people. Everyone benefits from blood circulation to parts of the body and targeted engagement of those muscle groups that perhaps the pupil does not use routinely.
4. In school, it is a subject during which cooperation and **team spirit are developed, where emotions are often expressed and one can practice regulating and expressing them to a socially acceptable degree.** In addition, sport and the emotions associated with it simply bring sports people closer together. Sport and non-competitive sporting activities bring pupils closer together and influence the group-class dynamic.
5. The experience of schools that include pupils with spina bifida or hydrocephalus in mainstream PE lessons is that these pupils are able to exercise and have the drive and motivation to overcome their limitations. **Several pupils with physical disabilities even have a talent and genetic predisposition for sport.** In addition, each pupil can improve his/her physical condition, relax, stretch stiff muscles, and explore the possibilities of his/her body while playing sport.
6. During the exercise, coordination is often practiced, the cooperation of the brain hemispheres is practiced and the brain is significantly blooded, which is fundamentally beneficial to the psycho-hygiene of the pupil.
7. Exercise is the **prevention of many secondary consequences of spina bifida** in pupils - such as decubitus, obesity, osteoporosis.
8. There is evidence that good physical fitness for children and young people with disabilities throughout their lives improves and speeds up their recovery from surgery, interventions and illnesses, and thus has a major impact on their quality of life and that of their families.

There are, of course, limits imposed by a pupil's medical condition or the absence of certain functions due to a disability. For example, a pupil with paraplegia cannot run, but he or she can run alongside other pupils in a wheelchair or on a handbike for a distance and increase the length of that distance over time, thereby

increasing his or her own physical fitness. He or she may be assigned different tasks such as checking the results of pupils, to encourage other pupils or exercising on a mat and strengthening the arms or learning new stretching exercises.

Some schools offer training in some functions, such as improving graphomotor skills, to pupils with spina bifida instead of PE lessons, regardless of the level of these skills. Such a concept does not correspond to the philosophy of inclusive education and does not reflect a holistic view of the pupil. The pupil is separated from other pupils at a time when he could be practising social skills, relaxing and developing physical activity instead of mental activity and gaining a positive relationship with it.



## RECOMMENDED PROCEDURES FOR PLANNING AND IMPLEMENTING LESSONS

1. The teacher strives to involve all pupils, using the support of a (teaching) assistant in PE lessons. If the pupil is in a wheelchair, it is useful to have his/her help in transferring him/her from the wheelchair to the mat, in transferring him/her within the school and in supervising the safety of all pupils (e.g. during ball games, when moving around the gym in a wheelchair).
2. The teacher prepares a part of the physical education lesson for all pupils in a sitting position.
3. The teacher invites a disabled athlete or coach to speak in or out of class to introduce disabled sport to all pupils. If possible, all pupils will try playing, for example, wheelchair basketball or floorball.
4. The teacher, in cooperation with the parents, the school principal, the assistant, the school health officer and other professionals, will plan extracurricular activities such as swimming and skiing courses, taking into account the needs of the pupil with spina bifida and hydrocephalus, and will arrange for an assistant to be present on the course.
5. The teacher divides the pupils into groups and each group practises different exercises - depending on which group the pupil with spina bifida and hydrocephalus is in.
6. The teacher plans activities in which every pupil can participate - according to his/her abilities. Arranges the distribution of pupils into groups so that pupils take turns. For example, with a significantly weaker pupil or so that the ratio of pupils in the groups is balanced and there are pupils in the group who can support each other - if a pupil needs more support. Care is taken to ensure that all pupils try out and practise new skills.
7. The teacher works closely with the pupil assistant in planning, implementing and evaluating activities to ensure that their activities are effective and coordinated.
8. When planning the exercise content for a pupil with spina bifida, the teacher can be inspired by an app with illustrative pictures and videos of exercises for people with disabilities or after an injury. The app is freely available and allows you to specify the extent of spinal cord damage, the age of the exerciser. Available here:

<https://bulgarian.physiotherapyexercises.com/>

in English: <https://www.physiotherapyexercises.com/>

## SPECIFICS OF PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS RELATED TO PHYSICAL EDUCATION

It is good if the teacher keeps the following in mind when doing physical activity:

- If the pupil has had surgery, it is a good idea to accept the doctor's advice on how long the pupil should not exercise.
- Because of the increased risk of latex allergy in pupils with spina bifida, pupil contact with latex exercise equipment should be avoided during non-physical education.
- During increased physical movement of the pupil, accidents may occur due to incontinence. The pupil should be able to go to the toilet at any time if necessary without explaining the situation to the teacher.
- Pupils with spina bifida may show impaired hand-eye coordination, slower response to stimuli, instructions, misunderstanding of rules, and inattentiveness of the pupil. It is necessary for the teacher to respond appropriately to these situations and to guide other pupils to do the same.
- For pupils with hydrocephalus and an implanted valve, physical touch should avoid the head and neck area and the pupil should not hang upside down for prolonged periods of time.
- Pupils with spina bifida may use a variety of medical devices - such as braces, crutches - and these may need to be taken off during the exercise and then put back on when the exercise is finished.

## EXAMPLES OF INCLUSION OF PUPILS WITH SPINA BIFIDA IN PHYSICAL EDUCATION

**"I've been teaching high school physical education for 40 years, but a class like this - with a Paralympic winner, wheeling the pupils around in wheelchairs - I've never experienced that before."**

Statement of a physical education teacher who educated a student with spina bifida and hydrocephalus in a wheelchair along with other classmates in high school.

**"A child with hydrocephalus and a behavioural disorder was afraid to be taken on a ski course by teachers because of repeated bad experiences with the pupil's behaviour in a strange environment. However, the school principal communicated with the parent, the student in an intensive and timely manner, and they wrote a written agreement about the procedure to be followed if inappropriate behavior occurred. The pupil managed the course because he really wanted to be there. At the same time, he benefited a lot - physically and mentally - he managed to control himself, he pushed his limits."**

**"As a child with congenital quadriplegic hydrocephalus, an associated mild form of quadriparesis and a rather introverted nature, I struggled in this area of movement and exercise. My father pushed me in places during physical activities and often lost patience, believing that despite the diagnosis he would change me at least a little in his image and I would simply grow out of the diagnosis. I became increasingly withdrawn around my peers and avoided physical activities because I often faced ridicule from my peers and classmates. Although my physical education teacher in second grade tried to motivate me, I refused to participate in any more activities."**

The physical education teacher, the motivational approach of the family and the cooperation of adults - all this is extremely important for the further progress of the pupil in the field of movement. The physical education teacher and his/her attitudes thus play an important role in the pupil's self-perception and influence his/her further development.



# THE ROLE OF THE TEACHER IN A MULTIDISCIPLINARY TEAM



## TEACHER AS TEAM COORDINATOR

The multidisciplinary team is a collaborative group of mostly professional and teaching staff who are actively involved in creating a respectful school culture. Its members are mainly the class teacher, the school special educator, the school psychologist, the career or educational counsellor, the school psychologist, the social educator, the principal, the school health officer and others. Professionals who work with the pupil outside the school may also be invited to join in if necessary.

The teacher works not only with the students, but also with other teachers, parents and others. Coordinated action in collaboration with each member of the teaching staff contributes to the effectiveness and comprehensiveness of inclusive education and the support of all pupils and educational stakeholders.

The teacher is one of the most important members of the multidisciplinary team. He or she often acts as a coordinator or team leader because, due to the nature of his or her duties, the teacher most often interacts with the other members and also with the student's parents.

**The class teacher is also the person who has the chance to know the pupil best, his/her strengths, any learning difficulties, his/her level of performance and individual learning outcomes. The class teacher - if necessary for the pupil - is involved in planning, adapting and modifying the curriculum to facilitate the participation of pupils with spina bifida and hydrocephalus in all classroom activities.**

Makes or participates in a number of decisions throughout the process. Multiple decisions are usually made collaboratively - as part of a team - and, at a minimum, in consultation with a special educator or psychologist. Obviously, this happens when professional matters are primarily involved. Other types of decisions can only be made by the school principal.

**It is essential that each member of the team accepts his or her own and others' competences - as defined by the relevant legislation or other regulations.**

“

No visible learning occurs without relationship.

Dr. Comer

”

## TEACHER COLLABORATION IN THE DEVELOPMENT OF THE INDIVIDUAL EDUCATION PROGRAM

As already mentioned, the starting point for the education of pupils is the assessment of the current state of the pupil in the educational process and the knowledge of any medical, psychological or special educational diagnosis. Also important is the aforementioned cooperation with the school psychologist, school special educator, external special educator, as well as cooperation with the paediatrician and the pupil's family.

**An Individual Education Programme (IEP) is one of the tools for individualised support for a pupil. It is based on the diagnostic conclusions of various experts and their recommendations for personalised education of the pupil. By defining the pupil's needs, the necessary support, through the setting of specific and measurable goals. The IEP loses its meaning if it is to be merely a formal document. On the contrary, it has the potential to be an effective and flexible tool to support the pupil. It is a flexible tool that allows for ongoing changes.**

The pupil's class teacher is often responsible for creating the IEP and may involve a special educator, psychologist or assistant. The teacher should follow the relevant regulations but should not be left out of the IEP development process. It is also desirable that the parents of the pupil may be actively involved in the development of the IEP. There is a law in the U.S. that requires the school to schedule the IEP development meeting at a date and time that is convenient for the parent.

**Later, by evaluating the IEP goals at least twice a year, the parent receives specific feedback from the teacher about the student's progress. Regular evaluation of the goals will also ensure continuity of support for the pupil - as they move from one period to the next, or if they change schools or teachers.**

It is a risk if the teacher or anyone else, when developing the IEP and its objectives, pays too much attention to the pupil's diagnosis and focuses on the pupil's weaknesses. It is empirically established that knowing a pupil's diagnosis will consciously and unconsciously influence the adults around the pupil. It is often impossible to ensure a pupil's progress in areas where the pupil has significant impairments resulting from the underlying diagnosis. With the impaired central nervous system development of pupils with both spina bifida and hydrocephalus occurring in a fundamentally different way to that of a healthy child, it is very likely that some impairment will occur in these pupils. Today's knowledge of neuroscience can empirically capture and illustrate with imaging techniques - such as EEG, CT, MRI, neurofeedback - these differences. One of these is the fact that on a number of tasks, the parts of the brain in the frontal lobe of the brain that are responsible for most of the executive (control) functions of the brain can be observed to be uninvolved in students with a disordered CNS. This can translate into a variety of learning difficulties for the pupil. For example, the literature describes a phenomenon where a pupil with spina bifida perceives or sees many trees when reading, but does not always see the forest as a whole. The pupil can build up a good vocabulary but may have difficulty linking individual words into meaningful ideas or may have difficulty retelling the text he

or she has read. The difficulties of a pupil with spina bifida or hydrocephalus may manifest themselves in the following areas:

- Memory
- Understanding
- Attention
- Impulsivity control
- The ability of the organisation
- Sequence
- Decision making and problem solving



Any combination of the difficulties listed can cause a pupil to have varying degrees of learning difficulties even if he or she has average or even above-average intellectual abilities. Difficulties may become particularly pronounced as the content of learning becomes more challenging - around the fourth year.

In the IEP, the teacher may also include cooperation with the pupil's family and with the pupil himself and list what this cooperation will consist of. The teacher should assist the family in adopting a style of education that is characterised by a balance of rational and emotional approaches. It can be characterised, on the one hand, by a rational attitude to the pupil's state of health, seeking to stimulate, encourage and help the pupil appropriately by making reasonable demands on his or her performance and, at the same time, creating a safe and pleasant environment in which the pupil feels accepted. The teacher can receive information from family members which, in turn, helps the teacher to get to know the pupil's specific needs better and thus continually improve the individualisation of his/her educational process.

The development of a pupil's abilities and interests, as well as the formation of personal qualities, is also considered extremely important. However, it is equally important to contribute to the improvement of the pupil's state of health by educational means. In particular, the pupil's IEP can be named and monitored in a specific way (for example, by regular meetings with a psychologist or special educator):

- Pupil's sense of humour.
- Building learner autonomy and independence as an important skill.
- The experience of emotions by the pupil and the pupil's ability to regulate them.
- Progress in interpersonal relationships and social skills in the pupil.
- Developing pupil's hobbies and interests and many others.

Consequently, according to the objectives set in the IEP, the teacher applies various teaching strategies such as task differentiation, universal design in education, multi-level teaching and assigning tasks to pupils according to the predominant types of intelligence of the pupil, so that pupils can achieve their maximum personal learning outcomes within the framework of common classroom activities. Each pupil can thus complete the assignment in a different way.

Within the Individual Education Programme (IEP) it is therefore necessary to work not only with the difficulties but also with the pupil's prerequisites. It is essential that other teachers are actively involved in the development of the IEP, that they are familiar with it and that it is a 'living document'. It is also important that it is not drawn up 'only' by the class teacher or the school special education teacher in order to fulfil administrative duties. The aim is for the pupil to acquire - on the basis of his or her individuality and potential - a body of skills and knowledge. The class teacher, in cooperation with the school psychologist and the special educator, should inform the other teachers of the objectives set for the pupil.

## **TEACHER - ADVOCATE FOR A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS**

If the class teacher gets to know the pupil and understands his/her specifics or learning difficulties, he/she can explain these specifics and the resulting need for a change of approach to the pupil's other teachers or other members of the multidisciplinary team. In this, they can work intelligently with the school nurse, possibly with the school psychologist or special educator, or they can invite a medical specialist to the school by agreement. One of the main issues is understanding the importance of catheterisations a pupil with spina bifida.

1. Every teacher should have an understanding that it is a procedure that fulfils one of the basic needs of the pupil and fundamentally affects the pupil's health. It requires sufficient time. The pupil may therefore arrive late for the lesson.
2. It is also important to remember that the pupil should not do the coiling during the big break - so that he/she has the same space and opportunity as the others - to form relationships with his/her classmates during the break.
3. Despite the best care, incontinence accidents can happen to a pupil, to which the teacher should respond appropriately. In order for this to happen, each teacher must be made aware of this in advance. It is a good idea for the class teacher to keep this in mind with any new teacher who may come into contact with the pupil.

For the pupil with hydrocephalus, it is about understanding the connection to the insertion of a valve into the brain that drains cerebrospinal fluid into the abdominal cavity. A valve is a technical device that can respond to a variety of external influences. With a sudden change in the weather, the pressure in the brain may change and the pupil may look drowsy or show signs of flu-like illness. A number of other things can affect the valve - such as an inflammatory process starting in the pupil's body, a sudden change in the weather and atmospheric pressure to which he or she reacts, or a mechanical impact to the head (e.g. by a ball or other object). Any sudden changes in a pupil's mood should be investigated and reported as soon as possible to parents, the school nurse or the Headteacher who is responsible for pupils in the school.

## PREPARING A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS FOR REAL LIFE

A strong, positive self-image is the best possible preparation for success.

“

Joyce Brothers

”

Experts agree that one of the most important goals of an inclusive school is to prepare pupils for a quality and successful life in today's modern society, especially through the atmosphere, the form of teaching and the environment. **The pupil's teacher, in cooperation with other professionals, can thus discover the pupil's strengths, abilities or talents. They can thus help the pupil to decide on further studies at secondary school or university.**

It is worth bearing in mind that providing careers advice to pupils with spina bifida and hydrocephalus may take longer than to mainstream pupils. It requires intensive communication with the school in which the pupil and his/her family are interested. No activity in this area should take place without the consent of the pupil's parent, or the pupil themselves - if they are an adult and legally responsible for themselves.

The education of pupils with physical disabilities requires the professional preparation of teachers, a stimulating and supportive school environment that provides support measures and enables pupils to develop their potential. It guides pupils towards lifelong learning and employment and thus promotes their social inclusion. [Chadová, 2015]

The direction of the teacher's activities should therefore take into account how his or her actions and decisions - as well as those of other adults - will affect the pupil's future, and also to have an idea of what skills will be useful for the pupil in everyday life.

**Brei (2021) defines these characteristics of a well-adapted adult:**

1. **Social skills - the ability to create and maintain relationships with other people**
2. **Respect for authority**
3. **Self-esteem as self-respect**
4. **Ability to meet challenges**
5. **Ability to accept limits or ask for help**

## CONCLUSION



“

I was given the gift of otherness  
to see the world differently.

”

Marek Krajčák

We will end this manual with a true story. The story of a boy who was born prematurely at the turn of the 32nd and 33rd week of pregnancy. A boy for whom there was no indication that he could "step out" of the shadow of his diagnoses. One of them was the diagnosis of hydrocephalus. The doctors' prognosis was: "This child will not survive." Later, "He won't be able to walk, sit up!" A question mark even hung over whether he would even be able to see and hear.

If we were to look into his documentation, we would learn that the child was in the so-called borderline range in some components of intelligence in the psychological diagnosis of school maturity...

This - once a child - to you, as a fully integrated adult - husband, father of two wonderful healthy sons, but not least a teacher and special teacher, addresses these lines, "I have been given the gift of otherness to see the world differently." Like many others...

There were people in my life who believed in me and who always supported me, but there were also people who didn't. Those who have driven me forward, but also those who have held me back. Even among teachers. There were times when everyone around me was weird, and vice versa, when I felt like the biggest weirdo. I met people who praised my achievements, even though they were never my goal. They were perhaps an inspiration, a means and a path for other parents of otherwise gifted children and for their children.

Today I thank all the people mentioned in the previous lines. For every single helping hand, encouragement, smile, but also a fall, even a mockery... Without all of this, I would not be standing where I am today.

I think we are making a mistake if we think of inclusion as a model. Inclusion should be a philosophy of thought in itself.

I wish for all of us not only to talk about inclusion, but to live it through small changes, acts of love and a change of mindset.... and thus change lives.



Co-author Marek

## REFERENCES



Babiaková a kol.: Príprava učiteľa primárneho vzdelávania na profesiu. Aby práca nebola záťažou. Belianum Banská Bystrica, 2022. ISBN 978-80-557-2005-0

Brei, T.J.: Guideline for the care of the people with Spina Bifida - 4th Edition. Spina Bifida Association. 2020. Dostupné tu: <https://www.spinabifidaassociation.org/resource/guidelinespdfull>

Brei, T.J. (2021). Help your child fly - Provide the Safety Net: Clinical Pearls to Promote Independence. Education. Day for Parents. (nepublikovaný príspevok z konferencie dňa 15.5.2021).

Čadová E. A kol.: Katalog podpurných opatrení pro žáky s potřebou podpory ve vzdělávání z důvodu tělesného postižení nebo závažného onemocnění. Univerzita Palackého v Olomouci, 2015. ISBN 978-80-244-4687-5 (pdf verzia). Dostupné tu: <http://katalogpo.upol.cz/wp-content/uploads/katalog-tp.pdf>

Drdulová, T.: Začlenenie detí so zdravotným postihnutím do prostredia materskej školy. "Aj TY si medzi nami vítaný" MPC Prešov, 2014. ISBN 978-80-565-0001-9. Dostupné tu: [https://mpc-edu.sk/sites/default/files/projekty/vystup/drdulova\\_0.pdf](https://mpc-edu.sk/sites/default/files/projekty/vystup/drdulova_0.pdf)

European agency for development in special needs education: Profil inkluzívni učiteľa. Brusel: EADSNE, 2012. ISBN 978-87-7110-317. Dostupné tu: [https://www.european-agency.org/sites/default/files/profile\\_of\\_inclusive\\_teachers\\_sk.pdf](https://www.european-agency.org/sites/default/files/profile_of_inclusive_teachers_sk.pdf)

Hájková, V. a kol.: Cesty k inkluzi. Praha. Karolinum, 2013. ISBN 978-80-2462-086-2

Holúbková, K.: Žiak s postihnutím očami spolužiakov. [rigorózna práca]. Praha: Pedagogická fakulta, Univerzita Karlova v Prahe. 2008

Horn, F.: Detská chirurgia. Bratislava: Slovak Academic Press, 2014. ISBN 978-80-8960-724-2.

Chlebničanová, A., Drdulová T., Tomovčíková M., Kubíny L.: Od najmenších po najväčších. Možnosti tvorby inkluzívneho prostredia v materských školách na Slovensku. Nadácia pre deti Slovenska. Bratislava, 2021. ISBN 978-80-89403-24-0

Inklukoalícia. 2022 Inkluzívne vzdelávanie. [online]. [cit. 2022-07-30]. Dostupné tu: <https://www.inklukoalicia.sk/inkluzivne-vzdelavanie>

Lechta, V. a kol.: Základy inkluzívni pedagogiky: dítě s postižením, narušením a ohrozením ve škole. Praha: Portál, 2010. ISBN 978-80-7367-679-7.

Lutkenhoff, R. N.: Children with Spina Bifida. Bethesda: Woodbine House 1999. ISBN 800-843-7323.

Porter, P., Obst, B., Zabel, A.: A Guide for School Personnel Working With Students With Spina Bifida. 2009, Kennedy Krieger Institute

Loudová Stralcynská, B.: Podpora práce s deťmi so ŠVVP v predškolskom vzdelávaní. Praha. Raabe, 2019. ISBN 978-80-7496 Dostupné tu:

[https://welcome-idea.eu/SK\\_WELCOME\\_WORKSHOPY\\_Podpora-prace-s-detmi-so-SVVP.pdf](https://welcome-idea.eu/SK_WELCOME_WORKSHOPY_Podpora-prace-s-detmi-so-SVVP.pdf)

Prucha, J. a kol.: Pedagogický slovník. Praha: Portál. ISBN 978-80-7178-772-3.

Stožický, F., Pizingerová, K.: Základy dětského lékařství. Praha: Karolinum, 2006. ISBN 978-80-2461-067-2.

Tannenbergerová, M.: Pruvodce školní inkluzí aneb Jak vypadá kvalitní základná škola současnosti? Wolters Kluwer ČR. Praha, 2016. ISBN 978-80-7552-008-1.

Zelina, M.: Stratégia rozvoja osobnosti. Bratislava: IRIS, 1996. ISBN 978-808-570-109-8.

Adapted Physical education. Dostupné tu:

<https://www.spinabifidaassociation.org/resource/adapted-physical-education/>

Diversity kids: The Inclusion Alphabet and Me. Dostupné tu:

[https://www.google.com/search?q=diversity+kids%3A+the+inclusion+alphabet+and+me&oeq=&aqs=chrome.0.35i39i362l6j46i39i362j46i39i175i199i362.89040246j0j15&sourceid=chrome&ie=UTF-8#imgcr=3a-l\\_66GQ3K5pM](https://www.google.com/search?q=diversity+kids%3A+the+inclusion+alphabet+and+me&oeq=&aqs=chrome.0.35i39i362l6j46i39i362j46i39i175i199i362.89040246j0j15&sourceid=chrome&ie=UTF-8#imgcr=3a-l_66GQ3K5pM)

Listen, Believe, & act: Support for students who have been disproportionately impacted in schools. InfoSheet – A Mental Health Literacy Resource for Educators.

Dostupné tu: <https://smho-smso.ca/wp-content/uploads/2021/10/Info-Sheet-Listen-Believe-Act.pdf>

Projekt WEL - COME. Dostupné tu:

[www.e-welcome.eu](http://www.e-welcome.eu)

<https://www.e-welcome.eu/?lang=bg>

<https://welcome-idea.eu/#/home?lang=1>

<https://www.minedu.sk/data/att/14971.pdf>

<https://www.teraz.sk/zahranicie/slovak-na-pode-eu/107167-clanok.html>



# MANUAL

for teachers in kindergartens, primary and secondary schools  
on multidisciplinary care and inclusive education for pupils  
with spina bifida and hydrocephalus

Authors:

Terézia Drdulová

Marek Krajňák

Graphics: Natália Krajčo

ISBN 978-80-974288-9-1 (brochure)

ISBN 978-80-974411-0-4 (pdf)

Copyright © 2022 Multi-IN



[www.multi-in.eu](http://www.multi-in.eu)

<https://www.facebook.com/MultiINeu>



Co-funded by  
the European Union

ISBN 978-80-974288-9-1 [brochure]

ISBN 978-80-974411-0-4 [pdf]

This project "Multidisciplinary care in the inclusive education of pupils with spina bifida and hydrocephalus" (Multi-IN) was financed with the support of the European Commission. This document expresses only the views of the Multi-IN partnership and the Commission is not responsible for any use of the information, which are contained in it.

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

Copyright © 2022 Multi-IN