



MANUAL

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



Created in partnership between:

Association of Spina Bifida and Hydrocephalus - Bulgaria

Early Intervention Centre Trnava - Slovakia

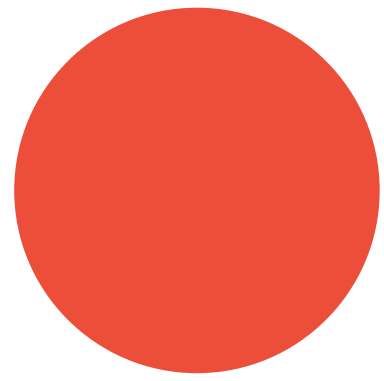
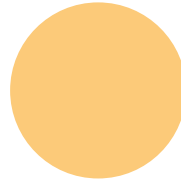
and Slovak Association for Spina Bifida

and/or Hydrocephalus as an associated partner

Authors:

Terézia Drdulová

Katarína Ondášová



ISBN 978-80-69027-9-7 (brochure)

ISBN 978-80-69027-00-8 (pdf)



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

This document is part of a set of educational materials to support the 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

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.

CONTENT

INTRODUCTION	3
INCLUSIVE EDUCATION	4
Inclusive education and early intervention in families with children with spina bifida and hydrocephalus ...	7
SPECIAL TEACHER IN INCLUSIVE EDUCATION	14
An objective view of a pupil with spina bifida and hydrocephalus.....	16
AREAS OF SUPPORT FOR PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS	20
Promoting the rights of pupils with spina bifida and hydrocephalus	22
Promoting pupil participation in school and in the community	24
Promoting mental health and wellbeing	25
Opportunities to promote wellbeing in school	28
Supporting the executive functions of the learners	30
Options and tips for stimulating pupil's executive abilities	35
Supporting the building of the pupil life skills	38
THE ROLE OF SPECIAL TEACHER IN A MULTIDISCIPLINARY TEAM	40
Special teacher as leader of a multidisciplinary team	41
Special teacher networking collaboration	42
Special teacher and the individual educational plan	44
CONCLUSION	47
REFERENCES	48

INTRODUCTION



"If someone says inclusion doesn't work, it wasn't inclusion."

Dr. Carol Quirk

To be born with spina bifida or hydrocephalus - no child has chosen this, nor in any way deserved it. However, his life is affected by various limits. Each such child is different, endowed with unique abilities - it is unmistakable. How his life develops is in the hands of the adults around him. Above all, his family, the professionals around the family, who influence what opportunities they will give the child. Every professional who enters the life of a child with spina bifida or hydrocephalus has a unique opportunity to become a co-creator of his or her life. The special educator in inclusive education can be one of those who set a positive perception and direction for the child with spina bifida or hydrocephalus towards self-acceptance, autonomy, and healthy self-presentation, enabling him/her to move successfully through life, responding in a healthy way to the challenges and difficulties that life puts in front of him/her.

The Multi-IN manual for special educators has the ambition to be a guide, advisor and mirror for the special educator in inclusive education, according to which he/she can adjust his/her activities to perceive the abilities of children and pupils from an early age, to look at them positively and to adjust his/her professional views and attitudes towards children and pupils with spina bifida and hydrocephalus. It offers tips on how you can work towards creating a positive and healthy learning environment for all pupils. It is the authors' wish that the manual facilitates the process of inclusion for all stakeholders in inclusive education and makes clear the challenges in this process. Together with children and pupils, let us join forces and create an inclusive learning environment - also with the help of this manual in our hands.

*"Blue or black cloud, water is our friend.
Flowers need it to grow nicely, to make life a little bit more beautiful.
Spring is no joke this year, Corona dropped in on us with it.
She made our tears big, she took over the streets.
There the sun will not sting us with its rays on our cheeks.
The virus is doing very well, that is the fate of this spring.
Spring is very tenacious, it is not afraid of the Corona, with its sun, ray, being, new life awakens.
Despite today's pandemic, it has opened its doors, saved us from the cold.
Spring is a very powerful lady, she will save us from the Crown.
It will give us rays, fragrance, breezes, there will be rejoicing again.
It works mighty miracles, it drives away all clouds.
The Goddess of Life makes it known that death is not to be feared, that life is to be enjoyed."*

Barbora Turčková

INCLUSIVE EDUCATION



"If a person is truly included, no one will question their presence, only in her absence."

Renee Laporte

Every person is born with the same need to belong somewhere. People with disabilities are no exception. Children with spina bifida and hydrocephalus are born with their disabilities and therefore often experience their difference as something natural, normal - given that living with impaired health is their only reality. If a child is lovingly accepted as he or she is by his or her family, he or she and his or her family expect to be accepted in kindergarten, primary or secondary school. It is we, the adults, who decide whether or not to accept people with disabilities. Most of the time, we make decisions based on our beliefs about inclusion or inclusive education. Either we have a pro-inclusion mind-set and are looking for ways to make inclusion happen in the long term, or we do not see people with disabilities as valuable enough and there is a prevailing belief that these people have nothing to contribute to us who are able-bodied and therefore we do not see the point of their inclusion.

Šuhajdová (2018) points out that each school as an educational institution has its own preferred values. *"However, if such values are competitiveness, individualism and an emphasis on achieving good results and performance, then such a school is likely to have great difficulty in successfully introducing and, above all, implementing inclusive education. The greatest risk is that the teaching staff themselves may be in some way coerced into demanding that all their pupils achieve."*

Pedagogists educating pupils with disabilities in mainstream schools should not only believe in the basic principles and goals of inclusive education, but also believe in the possibility of implementing them. Above all, they believe that they are the ones who can make a significant contribution to its successful implementation and realisation.

Ostatníková (In Šuhajdová, 2018) points out that there are still few educators with a positive attitude towards inclusive education and an educator who does not feel the need for change will find it very difficult to accept. Similarly, Lechta (2012) points out that if educators themselves are not truly convinced of possible educational success, such success is unlikely to occur. Moreover, Kudláčová (In Šuhajdová, 2018) stresses that inclusive education can only be successful if there is a change of mindset, and not only in the community of educators, but a change of mindset must occur in the whole society.

Much has been done through laws, accessibility, bringing people together, but the change of mind-set in ost people is not coming. When people with disabilities are alongside other ordinary children, ordinary citizens,

in ordinary places, in ordinary roles, it helps to remove barriers and misconceptions. People with disabilities are then perceived as primarily good classmates, neighbors, friends, athletes, employees. It is important to realise that every person can contribute to changing the inclusive mind-set of his or her own mind and thus spread this mind-set further.

The acquisition of academic knowledge alone is not enough to enable young people to play the role of active citizens and to face the socio-economic realities of their lives in order to avoid inequality, poverty, discrimination, marginalisation and exclusion. **Indeed, people with disabilities are also excluded when they cannot get somewhere, do not have access to services, do not have the opportunity to participate and do not feel welcome.**

On the contrary, the Convention on the Rights of Persons with Disabilities requires them to be fully included and to fulfil their right to a quality inclusive education:

- Non-discrimination.
- Fulfilling the best interests of the child
- Fulfilling the child's right to be heard.
- Protection from violence and child abuse.
- Opportunity for community living.
- Supporting the mobility of the child.
- Access to healthcare.
- Habilitation and rehabilitation.

The European Commission created the "EuropeanEducationArea" and issued a report in 2021 stating that it is essential to continue working in schools to create a positive and healthy learning environment for all pupils. **It goes on to say that in the 21st century, education must go beyond narrow sectoral goals such as academic achievement.** In addition, education should actively contribute to the health and well-being of children and young people, whose mental health needs are increasingly evident and challenging. The European Commission also reported on the creation of a European Learning Area by 2025 and the collaboration to identify how schools can address the educational and socio-emotional needs of their pupils - particularly those who are struggling - and how they can provide pupils with a balanced and quality education that sets them on a path to an active, productive and healthy life. **This report responds to such initiatives and to the recognised need for schools across Europe to prioritise and actively promote pupils' mental health and well-being in safe and inclusive settings.** Specifically, it seeks to develop a theoretical framework to guide the way in which the whole school system can be mobilised at different levels, in partnership with the community, to promote mental health and well-being. In addition, the report makes recommendations for the effective implementation of a system-wide, school-wide approach to promoting mental health and well-being and preventing bullying in schools across the EU. The report is available here: <https://data.europa.eu/doi/10.2766/50546>

On the contrary, the school can make a big difference with its positive approach, and it can make a concrete difference:

- A comprehensive view of the student with disabilities,
- care for pupils with disabilities,
- active cooperation with the pupil's family,
- encouraging pupils and rewarding their involvement,
- supporting people with disabilities,
- treating pupils with disabilities as equals.

If the school management, together with the staff and parents, set inclusive education as a shared vision, they can work together step by step to implement inclusive education specifically in these forms:

As an individual in school:

- Believing in inclusion.
- Appreciate diversity.
- Create options.
- Share research results.

As part of the school team:

- Collaborate.
- Seeing the invisible.
- Share a vision of inclusion.
- Ask questions.
- Brainstorm options.
- Implement a shared reflection on "What if...?"
- Asking, "How can we do this?"

For the pupil:

- Differentiate instruction and tasks.
- Introduce elements of universal design into learning.
- To compare the pupil only with himself.
- To focus assessment on pupil progress and not only in the cognitive domain.

"All children benefit from being in an inclusive environment where they can engage, collaborate in meaningful ways and create authentic, caring relationships there."

How Children Learn, 2014

INCLUSIVE EDUCATION AND EARLY INTERVENTION IN FAMILIES WITH CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS

Eurlyaid, a European umbrella organisation specialising in early intervention, introduced the Manifesto - Early Intervention for Children with Developmental Delays in 1993 (de Moor, 1993). In it, it defines that *"early intervention is for all children with developmental risks or disabilities. Family support covers the period between prenatal diagnosis and the point at which the child reaches compulsory school age. It covers the whole process from the earliest possible identification and detection of risk to the long-term stimulation of the child and accompaniment of the whole family. Although we do not currently consider prenatal diagnosis to be an integral part of early intervention, its psychological and social effects on parents are included in early intervention."*

Prenatal diagnosis is a topic that concerns families with a child with spina bifida and hydrocephalus. Worldwide, for more than 30 years, children with spina bifida have been operated on during pregnancy. The goal is to close the spina bifida to prevent further impairment of leg mobility. At the same time, in many cases these children do not develop hydrocephalus. Experts working in this field talk about a new scientific field -spinabifidology. A short demonstration video on fetal surgery can be viewed here:<https://www.youtube.com/watch?v=bLnYzCcTEEA>

It is impossible to prepare in advance for the birth of a child with spina bifida or hydrocephalus, even if the parents know that they are expecting such a child. The family finds itself in a completely new situation and only step by step discovers what it means to have a child with a disability. The doctors' predictions may or may not come true, because every child with spina bifida or hydrocephalus is unique. In such a situation, if the family has someone who can help them navigate, provide answers to at least some of the questions about what lies ahead or about the possible future, it is a great advantage for the family. Early intervention social service teams normally include a special teacher who can make a big difference with his or her approach. As a specialist, he or she should provide an objective view of people with spina bifida or hydrocephalus. The experts' views on people with spina bifida or hydrocephalus, which are part of the Multi-IN General Guidelines for Inclusive Education and Multidisciplinary Care, can be helpful in this respect.

EXPERTS' VIEWS ON PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

Authors: Andrej Drdul a Terézia Drdulová

"Knowledge is power, community is strength and a positive attitude is everything."

Lance Armstrong

1. Spina bifida or hydrocephalus does not define a child. His or her personality consists of a unique set of characteristics, only one part of which is a disability. How his disability will affect his development and future is decided at an early age and based on the right information and support his family receives at that time.
2. Many children and young people with spina bifida and hydrocephalus are now redefining the picture of these disabilities. Developments in medicine, complex stimulation and assistive devices are enabling these children to develop fundamentally differently and acquire different skills than in the recent past.
3. Parental guidance should be provided by experienced professionals. Counselling should provide access to a range of topics and issues related to living with spina bifida and hydrocephalus on an assessment basis.
4. Parents deserve the time needed to adapt to the new situation after the birth of a child with spina bifida and hydrocephalus.
5. Parents are the ones who make the decisions. Professionals should treat parents with respect. Parents should feel that they have a choice at any time.
6. The quality of life of people with spina bifida and hydrocephalus depends on many factors. Most adults with spina bifida stress that it is up to them to assess their quality of life.
7. An association of people with the same diagnosis is a rich source of information, experience, contacts and can provide support.
8. Multidisciplinary collaboration is more efficient, cost-effective and preventive.
9. Experts from different fields offer their expertise, opinions and opportunities.

At every stage of a child's development, it is important to support and develop the functional abilities, independence and high self-esteem of a child with spina bifida and hydrocephalus.

Adapted from the Multi-IN General Handbook on Multidisciplinary Care and Inclusive Education for Pupils with Spina Bifida and Hydrocephalus
Ak odborníci pracujúci s deťmi v ranom veku poznajú vývinové riziká tohto veku u detí so spinou bifidou a hydrocefalom, môžu im úspešne predchádzať

.For the first years of life, parents with children with spina bifida and hydrocephalus primarily visit doctors, rehabilitation and other specialists. During this period, there is a risk that **the family will become socially isolated and the child's entry into kindergarten will be delayed** for a variety of reasons - such as a preference for rehabilitation or waiting for the child to start walking. It is important to emphasise that delaying entry among peers will significantly increase the child's emotional and social developmental delay.

A child enters kindergarten mostly around the age of three. It is desirable that professionals consider it essential that a child with spina bifida and hydrocephalus is integrated into the collective early. However, it is a good idea to think in advance to prepare the child with spina bifida and hydrocephalus for inclusive education, and it is therefore necessary to begin to address his or her admission to kindergarten with a longer time reserve in advance. Early intervention social services can help the family to prepare for the whole process of entering pre-school, applying for an assistant. Together with the family and according to the family's requirements, professional staff can guide parents and teachers so that the integration into the kindergarten takes place as soon as possible and with minimum difficulties. **The risk of integration into kindergarten is that the child will only be tolerated in kindergarten or that the child will be seen primarily through his or her limits.**

As part of the international European project Agora, the NGO Association of Early Intervention Providers and Supporters in Slovakia has created an animated film about early intervention. The film introduces the basic principles of this service for families with children with disabilities or children at risk of developmental delay. In cooperation with partners from Belgium, the Netherlands, Hungary, Poland, Bulgaria and Romania, a six-language version of the film was produced. The video on early intervention services names specific situations that early intervention staff deal with families in the process of accompanying families. The video can be viewed here:

Video in ENG:

<https://vimeo.com/581272486>

The aim of early intervention is to provide the most effective support to the family as early as possible. **Quality early intervention or early childhood programs reflect how learning happens in early childhood and provide environments and experiences to engage children in active, creative and meaningful exploration, play and investigation.** Through them, practitioners enable children's communication to be captured, support their expressed thoughts and ideas, and stimulate further child expression. It is ideal if this happens in a mainstream nursery. If not, early intervention can at least partially replace this with a quality program that should include 4 main components:

1. Togetherness - every child perceives the need for togetherness when he or she is connected to others and **participates, contributes to their world.**
 Early intervention programs form authentic, caring relationships and connections to create a sense of belonging among children, adults, and the world around them.
 The organizations facilitate connections between the home and early intervention programs, invite families to participate in children's experiences, and build trusting partnerships with families.
2. Well-being - each child develops a perception of self, health and overall well-being - well-being. **Early intervention programs nurture a child's healthy development and support their growing sense of self.**
 Each child is active and engaged, exploring the world with his or her body, mind and senses.
3. Encounters - Early intervention programs provide environments and experiences to engage children in active, creative, and meaningful exploration, play, and inquiry.
Professionals allow the planning of environments and experiences slightly above the child's current abilities to stimulate their learning.
4. Expression - every child is a capable communicator who can express themselves in a variety of ways.
 Early intervention programs provide environments and experiences to **engage children in active, creative, and meaningful exploration, play, and investigation.** Practitioners allow the child's communication to be captured, to support the child's expressed thoughts and ideas, and to stimulate further expression.

Similar to early intervention programmes, children with spina bifida and hydrocephalus should be included in the kindergarten setting in such a way that their participation and active input is evident. Vodicka's (2022) research - in agreement with WHO and other authors - points to the need to focus on the child with developmental difficulties in kindergarten or other settings from different aspects: biological, developmental, psychological, pedagogical and social (family, school, community) and **their functionality and ability to participate in these systems.** This, according to the author, will help to **create an individualized picture of the needs of a particular child at all levels of his functioning and to set up his support in the kindergarten environment. Given the** broad and multidimensional nature of developmental difficulties in children, such an approach is in line with the ICF-CY biopsychosocial model of health (WHO 2007, 2012), **where participation is understood as an important component of health.**

This highlights the need for collaboration and coordination between the different professionals who come into contact with the child. From the child's earliest years, the special educator can be the person who initiates, consciously maintains and coordinates the multidisciplinary collaboration of professionals.

On the other hand, if a deficit definition of the child's special educational needs prevails, the causes of these needs are attributed to the child's disadvantage or disability, or to the child's family. In this regard, Vodickova (2022) points out that this diverts attention away from barriers on the part of the school or education system (Hall et al. 2019). The same author stresses that **identifying barriers on the part of the kindergarten and the collaboration of educators to remove them for the benefit of the child with developmental difficulties, supports the child in moving forward. The** author goes on to say that developmental difficulties in pre-school children, often manifesting themselves only at the time of training in an educational institution, deserve professional attention and intervention directly in the kindergarten environment, with **the aim of early intervention and enabling all children to participate in their education, socialisation with their peers, and in their lives.**

The special educator should be able to identify barriers, barriers in the kindergarten environment. As a tool for identifying barriers, the special educator can use the very specific Early Childhood Self-Reflection Tool developed by practitioners. The self-reflection tool is a set of specific questions. It focuses on early childhood settings as sites of participation and learning. It emphasises the process and structural factors within the setting that influence children's experiences. The tool addresses eight aspects:

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

The Early Childhood Self-Reflection Tool is part of the methodology available here:

<https://www.european-agency.org/resources/publications/inclusive-early-childhood-education-environment-self-reflection-tool>

If educators want to engage a child with any challenges, they should know the child's strengths. Targeted written elicitation of positive information about the child from the child's parents or caregivers at the beginning of the school year or when the child enters kindergarten can be a concrete way to help.

POSITIVE INFORMATION ABOUT THE CHILD/PUPIL

This information will help teachers to educate your child more effectively this school year:

The child's name (preferred by the child) is:

Write 3 to 5 words that best describe your child's character:

What are its strengths?

What are his favourite activities?

Who are your child's friends?

What are your child's favourite activities?

What are his least favourite activities?

Do you have any concerns about your child's progress at school?

What would you like your child to achieve this year?

Do you have other information about your child that you would like to share with us?

Thank you!

Source: Eredics, N.: Inclusion in action: practical strategies for adapting your curriculum.

Paul H. Brookes Publishing Co. Inc. 2018.

Translation. Drdulová

IDEA - AN APP FOR WORK AT SCHOOL AND AT HOME

A useful tool for special educators, teachers, assistants - especially in kindergartens - is the international application WEL-COME IDEA, which can be downloaded together with its methodology here:

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

The interactive app contains a comprehensive set of learning activities divided according to the different areas of child development (social, communication, cognitive, emotional, motor and sensory). The app is designed to work with individual children, small groups and the whole class. Using basic pedagogical diagnostics, it allows you to identify those areas that need to be developed in a child and, based on the results, directly recommends specific activities suitable for the child in question. The application and the methodology are available online in four languages - Czech, Slovak, English and Bulgarian. It is the result of international cooperation within the Erasmus plus project.

Some other risks in the development of a child with spina bifida or early-onset hydrocephalus:

- Child with spina bifida or hydrocephalus as the focus of adult attention
If a child becomes the centre of attention, his development and future are affected in a very bad way. A child should not become the centre of attention from an early age, neither in the immediate family environment nor in his wider social environment. If all the attention is focused on the child, this will ultimately do more harm than good for the child in the future.

- A child with spina bifida or hydrocephalus and his emotional attachment to his parents. It is very essential for a child to be able to detach emotionally from his parents, to go outside the family, to experience other environments, other people as a safe space.
- Uneven personality development in a child with spina bifida or hydrocephalus
- Parents after the birth of a child with serious health problems often focus on one side of the child. Often times, it is the area that is the weakest in the child. Most of the time, most energy is focused on practicing walking. Despite the fact that walking is not and will not be the most important life skill in a child and later in an adult. On the contrary, mobility and ensuring a child's mobility from the earliest age is what can move a child in all directions. In the same way, the purposeful cultivation of hobbies in a child with spina bifida or hydrocephalus from an early age. Favourite hobbies can be swimming, fishing, bicycling (on a bicycle or on a handbike), handicrafts, reading, learning foreign languages and others - according to the preference of the child and his/her parents, the family's possibilities.
- Promoting a protective parenting style and passivity in a child with spina bifida or hydrocephalus Every child at this age is naturally curious, interested in exploring the world around him. So the goal is that a child with a disability can also decide where he wants to go, what he wants to do. Various aids can be used for this, such as crutches, a walker, a walking brace - the so-called walker - and also a wheelchair. Research has shown a link between enabling a child's mobility and their cognitive development. **If we do not give this to a child from a young age, he or she will very quickly become accustomed to passivity. To the fact that he is just sitting, someone moves him and decides what the child will or will not do. On the contrary, if we give the child a chance, if we give him a choice, if we give him options - to move himself, to choose an activity - it is a very different way of being for him from a very early age, which he will acquire and which will become part of the characteristics of his personhood.**
- A parent of a child with a disability is not an expert on the child's development, so it is important that professionals around the child and his/her family are aware of the developmental challenges of such children and minimize the secondary effects of the disability through their actions. More on this topic can be found in the Multi-In Manual for School Psychologists, which is freely available and downloadable. Early intervention, working with the family of such a child, can be beneficial in many ways and will fundamentally affect the complex development of the child and the direction of the family.

„The only disability in life is a bad attitude.“

Scott Hamilton

SPECIAL TEACHER IN INCLUSIVE EDUCATION



„A man whose health is seriously impaired will never reveal his hidden sources of strength, unless others treat him like a normal human being and **abuse him, to try to shape his own life.**“

Helen Keller - blind and deaf writer

The position of a special educator in inclusive education is associated with the expectation that he/she is the professional who can provide support to pupils with special needs, as well as to parents, teachers and other persons participating in the educational process. His/her position is crucial because he/she is considered to be the one who is the source of information, procedures and tools on how to use the tools of special education to facilitate the education of diverse learners in mainstream schools. With regard to pupils with spina bifida and hydrocephalus, he should therefore get to know the specifics of a pupil with a fundamentally different development of the central nervous system, the specifics of a pupil with a physical disability - if the pupil has one. He should also have an understanding of the need for a holistic view of the pupil and accept the uniqueness of each pupil in his approach. Specific information on pupils with spina bifida and hydrocephalus is available within all the Multi-IN Project Outputs, but especially in the General Handbook and in the individual manuals for the 8 target groups. In everything, the teacher should cooperate with the school management, with the pupil's family and with other professionals involved in the pupil's care. If the special educator works in a school, he/she usually has the opportunity to work with the pupil individually, in groups and also directly in the classroom.

According to Frindrich [2015], the individual work of a special educator focuses mainly on improving perception (visual, auditory, tactile), developing the cognitive and expressive abilities of the pupil, guiding pupils to independent, cultivated, creative, preferably fluent and comprehensible communication.

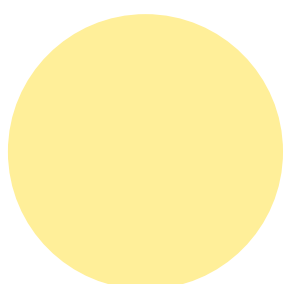
A special educator can significantly influence the pupil's development, his/her perception of self and focus on the pupil's possibilities and potential through his/her pro-inclusive attitude and professional attitudes. In this context, Covey [2012] notes that any person who is able to unleash in others their hitherto unnoticed potential, a person who inspires, encourages and stimulates them to do something noble, who sets an example for them in this regard, is a "wonder-worker" of the present, of our everyday life. The same author highlights the mission of educators in this way: *"What more can each individual educator do, what more can he contribute to the world, than by enabling each child to move successfully through life, to respond maturely to the challenges and difficulties that life places before him?"*

Covey (2012) advises those working with pupils to think about and answer questions about a particular pupil. We recommend that the special educator reflect on his or her questions, write down the answers to these questions about the particular pupil with spina bifida or hydrocephalus, and do this at regular intervals, but at least once a year.

Name and surname of the pupil:

Entered on:

1. What innate abilities does the pupil have?
2. What of his talents or character traits could be developed to a level that matches his aptitudes?
3. Which innate abilities of the pupil manifested in his early childhood have been suppressed or silenced by cultural DNA?
4. How and with what can I show this child that I respect his innate abilities?
5. What will I say to him in the next 24 hours to show him that I appreciate and admire these abilities?



AN OBJECTIVE VIEW OF A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

„Never underestimate the power and effects of sincere, positive beliefs about the value of the other person, their potential and innate abilities. By manifesting this belief, you strengthen and affirm faith in yourself“

S. R. Covey

Pupils diagnosed with spina bifida or hydrocephalus are very diverse and therefore cannot be clearly classified into one group of pupils with disabilities. In most cases, pupils with spina bifida are classified as having a physical disability. Clearly this includes some pupils with a diagnosis of spina bifida, but certainly not all. Professionals working with people with spina bifida liken them to snowflakes because no two people with the same extent of spina bifida are ever the same. The manifestations and consequences of spina bifida are highly variable from person to person. This is partly because the whole development of the central nervous system is fundamentally different from that of the normal child. The possible associated difficulties are many and their consequences are therefore very varied.

Spina bifida is a disorder of the closure of the bony arch of the vertebrae, which results in the bulging of the spinal cord and its envelope, with a violation of the function of the nervous structures. It occurs by the 28th day after conception. Depending on the site of the disorder (the location of the spina bifida), there may be varying degrees of musculoskeletal impairment, impaired voiding and impaired sensation in the affected area. 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 cerebrospinal fluid, or the bottom of the cerebral ventricle is perforated laparoscopically to allow the fluid to drain. 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 the malformations. However, this is a lifelong diagnosis and the care of several specialists, especially several specialist physicians, is required. In childhood, it places high demands on physiotherapeutic and orthopaedic interventions and, depending on the severity of the disorder, further hospitalisations. From birth, adult management of urinary and faecal emptying is required. In 90% of all patients, intermittent catheterisation - coil catheterisation - is necessary. Due to reduced or completely absent sensitivity, preventive care and skin care is essential. More detailed information on care can be found in the Multi-IN nurses' manual or other manuals.

*Adapted from the Multi-IN Manual for School Psychologists
on Multidisciplinary Care and Inclusive Education for Pupils with Spina Bifida and Hydrocephalus*

In terms of gait function, children with spina bifida are divided into three groups:

1. Children walking.
2. Children walking with aids - with crutches, using a walker. Walking is usually only functional for short distances.
3. Children moving in wheelchairs - some independently, others with the help of another person

More detailed information about the different types of spina bifida is recorded in the General Multi-IN Guide. The situation is even more heterogeneous for pupils with hydrocephalus. There are many causes of hydrocephalus in children, and as the central nervous system is affected, other diagnoses are often added. The most common are visual, gross and fine motor disorders, and epilepsy is also common. Some children with hydrocephalus may also be diagnosed with cerebral palsy from a certain age.



Assigning pupils to groups according to their limits is not very helpful. Currently, professional opinion is moving away from looking at pupils according to their diagnoses, and it is more advisable to look at pupils according to the form of specific support they need. This approach is pragmatic, takes into account the uniqueness of each person with a disability and allows them to be seen more holistically, rather than just focusing on one characteristic (usually a deficit) of the person. An approach focused on finding, adjusting and providing support accepts the individual needs of the learner and also their right to a quality inclusive education. It is much more beneficial and effective if the professionals' approach is based on the pupil's abilities, skills, interests and talents, identifying and removing barriers in the environment, access, content of education.

If someone wants to characterize in more detail persons with spina bifida and hydrocephalus, he should know that all over the world many famous personalities have lived and are living - artists, athletes, writers, doctors, lawyers and people of other professions. Finland had a woman with spina bifida in the government, and in Slovakia, a 23-year-old lawyer with spina bifida and hydrocephalus became the youngest ever member of the national parliament in 2020. The special teacher has a great responsibility to be a source of objective information about the pupil with spina bifida and hydrocephalus and to communicate this information to

others involved in his or her care. The special teacher should objectify his/her beliefs about the pupil with spina bifida and hydrocephalus. If the special teacher is a first-time experience with a pupil with spina bifida and hydrocephalus, he or she may not be able to gain insight into the pupil's situation on his or her own. We recommend that the special teacher seek out experienced professionals who have personal experience, or contact a non-profit organization for persons with spina bifida and hydrocephalus, or use the services of a mentor, coach, or supervisor.

Pupils with spina bifida and hydrocephalus may have different learning difficulties, but statistically:

Väčšina žiakov (až 90%) so spinou bifidou má priemerné hodnoty IQ.

- Most pupils (up to 90%) with spina bifida 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 in these pupils, while reading comprehension and mathematical skills are mostly lower.

Lutkenoff (1999) defined the developmental specificities of children with spina bifida and hydrocephalus in six domains:

1. gross motor skills,
2. fine motor skills,
3. speech and language development,
4. development of cognition,
5. social development and
6. self-care activities.

It is important to note that one area of personality influences the other areas and they interact with each other. A more detailed description of the developmental domains can be found in the Multi-IN Manual for Teachers. Knowing the specifics of the development of a child with spina bifida or hydrocephalus is important in order to prevent or reduce the impact of these difficulties on the child's overall development. If they cannot be prevented, we speak of secondary consequences of the disability. One important finding about people with spina bifida is that they are capable of independent living to varying degrees. However, educating a child with spina bifida and hydrocephalus to live independently should start from an early age.

For people with spina bifida or hydrocephalus to live successfully and independently, we see it as essential to talk about the need to focus on **building a child's independence from an early age. For people with spina bifida and hydrocephalus to live successfully and independently in adulthood, it is essential that education for independence starts from the earliest age.** Independence in everyday tasks includes dressing, eating, washing, mobility (not walking), using medical equipment, keeping order, doing small and age-appropriate household chores and participating in all tasks around the child - such as using equipment, coiling, medical tasks.

We see independence as a crucial and complex ability for a child to live as independently as possible in ordinary, everyday life. As a result, the child performs those self-care and activities of daily living that he or she is able to do on his or her own or with minimal help and assistance from someone else and is not supported in a passive care receiver stance. This area of development is mostly neglected by professionals. In development, different professionals look at different performances of the child and the area of the child's participation in everyday life is not considered as important.

Emphasising and motivating parents to educate their child to be independent from the earliest age is one of the basic prerequisites for a disabled child to live independently in the future. Without the support of professionals, it is very difficult for a family to navigate a new living situation and to get out of the cycle of doctors' visits and all that a disabled child requires. It is the professionals who can help the family to name and prioritise what they are looking for in a child, not only in the present but also for the future. The situation can often change due to changes in the child's health. If the family does not have named priorities that influence the child's upbringing and direction in the long term, the child's upbringing will slip into the traditional and mainstream society-supported social model of treating people with disabilities as objects of help from able-bodied people. However, this approach will ultimately magnify the child's disability and make the situation more difficult or even complicated for everyone.



Author of photo: Peter Hečko

AREAS OF SUPPORT FOR PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS



Similarly - as we mentioned in the chapter on inclusive education - the approach of any practitioner predetermines their setting and perceptions of disabled pupils. A holistic perception of a pupil with a disability does not preclude taking into account the specificities of any pupil. On the contrary, focusing on one area seems to reduce the pupil to that area alone and prevents seeing and taking into account the wider circumstances that shape and influence the pupil in the long term. The special teacher should therefore perceive the following for each pupil with spina bifida and hydrocephalus:

- the pupil's right to quality inclusive education,
- Individual characteristics of a pupil with spina bifida and hydrocephalus,
- the pupil's special needs arising from his or her disability and its consequences,
- the strengths of the pupil's personality, his talents, talents,
- the pupil's background,
- the impact of the pupil's 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 diversity of the pupil's brain manifested in many times
- 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,
- interests, hobbies, acquired skills and abilities of the pupil.

The special teacher can support the pupil in a variety of ways. First of all, he or she has the opportunity to work individually with a pupil with spina bifida and hydrocephalus, to get to know him or her very well and to influence the pupil's development and direction in life in a fundamental way. It is useful for the special teacher to make the pupil aware of the source of his or her difficulties, to help the pupil understand them and to offer him or her hope. His/her position in the school also enables him/her to work with the pupil within a group of pupils - formed with a specific purpose - or within his/her natural group - the classroom. In addition, he has the opportunity to influence the pupil through the important adults who are around the pupil - parents, teachers, school management, assistants, health professionals, as well as peers, siblings and others. If the special teacher himself has an understanding of the pupil's wider context and uses a respectful approach, he can guide others, justify his perspective and motivate others for the most optimal and pupil-developing approach to the pupil and his family.

It is worth noting that girls and women with spina bifida and hydrocephalus should be given more attention, as research shows that they are many times more vulnerable than men

Thus, various programmes for a healthy self-perception, promoting girls' self-esteem and self-worth can be of significant help to the special teacher.

English version of the manual:

<https://www.dove.com/uk/dove-self-esteem-project.html>



Author of photo: Peter Hečko

PROMOTING THE RIGHTS OF PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS

Inclusive education not only assumes, accepts, but also welcomes and values the diversity of learners. Nor does it regard the difference of a pupil with spina bifida as something inferior, but sees it as an asset for all.

Most often, the special teacher can show respect to the pupil by creating a space in which the pupil can express his/her opinion, give his/her point of view, give feedback on an event, an activity, a happening around or on a decision that adults are preparing and will affect the life of this pupil.

In all decisions about a pupil, adults should be committed to the best interests of the child, while at the same time knowing and taking into account the pupil's own views. This follows from the Convention on the Rights of the Child, which binds every adult. You can find out more about the rights of pupils with spina bifida and hydrocephalus in the Multi-IN General Handbook, which we recommend you read before reading the Multi-IN manuals for each target group. It is good if adults guide pupils to express their opinions, feedback. If pupils with spina bifida and hydrocephalus could have their say on how they imagine their education and the support they need, they would be very likely to be happy to say these thoughts:

1. I come to school to learn how to communicate, function in everyday life, understand others and live with my peers. I am not in school to get as much information as possible into my memory.
2. I am first and foremost a child, though I am clearly a different child in some ways.
3. Some of my individual needs are different from most of my classmates, but I have the same rights as everyone else.
4. I should have the same opportunities to choose, to participate, to try things and experiences as my other classmates.
5. Even though I am a person with a disability, I have unique gifts, abilities. I know how to enrich the people around me.
6. It will help me if I am only compared to myself. I have my own unique individual needs - also due to my diagnosis - and therefore it is unfair to compare me to those who are not affected by a disability.
7. My limits are obvious. Encouragement to not be afraid to ask for help will help me.
8. Maybe sometimes I can't fit in. I need support in how to create and maintain relationships with other people and appreciation of my - even if only small - progress. It will be beneficial for me to experience the beauty of working with peers in which I can be an asset.
9. Please listen to my opinion, my point of view. Together we can more easily identify the barriers that prevent me from participating and expressing my abilities.
10. It will help if I experience respect for my uniqueness, acceptance of my abilities and limits.
11. It will be helpful if you allow me to make mistakes and help me learn from them.
12. It will convince me if I experience that it pays to be grateful, kind, empathetic and understanding of others.

13. I will be glad if you can guide me on what I can control and what I can't control, so that I can better regulate my emotions.
14. You can help me build my ability to make independent decisions by giving me responsibility for age-appropriate decisions.
15. Respect me and help me to be respected by others, encourage my respect for myself and others. It will teach me to respect myself.
16. You may perceive how my family or immediate surroundings have influenced me so far. It will be beneficial to me if you offer something that moves me towards greater autonomy and the ability to make my own decisions.
17. If I can see in the people around me how they accept and deal with challenges, I can handle mine more easily.
18. In the way you communicate with me and about me, I can sense what your beliefs are, your views on people with disabilities, and whether you consider me an equal partner or someone inferior.

Thanks to her long and active collaboration with young people with spina bifida and hydrocephalus, T. Drdulová (2023).



PROMOTING PUPIL PARTICIPATION IN SCHOOL AND IN THE COMMUNITY

When trying to support the participation of a pupil diagnosed with spina bifida and hydrocephalus, professionals may find the concept of F-words, which describes 6 important aspects of the life of a child with a disability and portrays it comprehensively, very helpful. 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 need for all these 6 areas to be present in the lives of pupils with disabilities:

1. Function - 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. We encourage you to visit the website where you can find original professional articles, instructional videos as well as examples of how the concept can be worked with in a school setting.

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

One concrete and widely applicable tool based on the F-Words concept is the F-Words Life Wheel available here:

https://canchild.ca/system/tenon/assets/attachments/000/004/283/original/Favourite_F-words_Life_Wheel_for_Families_and_Children_2023.pdf

Through this tool, the special teacher can monitor, be aware of and evaluate the situation of a particular pupil with spina bifida and hydrocephalus, his family or other environment in which he lives. The tool can also help the pupil to become aware of his/her situation and decide to accept it or change it.

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

PROMOTING MENTAL HEALTH AND WELLBEING

"Pupils who are happy in school learn much more easily."

We include a chapter on mental health promotion because research has shown a higher risk of developing depressive symptoms in adolescents and young adults with diagnoses of spina bifida and hydrocephalus - compared to the general population. Good mental and physical health is essential for academic success. Research shows that students' motivation, focus and ability to learn, retain and apply knowledge are closely related to their good health at school. **Research shows that embedding social-emotional learning, mental health, wellbeing and bullying prevention programmes in schools is one of the most effective ways to promote the psychological wellbeing of children and young people - including those experiencing disadvantage and marginalisation. This is in line with a more holistic vision of education that recognises that children and adolescents need a balanced set of cognitive, social and emotional competencies to achieve positive outcomes in school and in life.** Given the high risk of possible depression in adulthood for people with spina bifida and hydrocephalus, a preventive focus on this area of personality is highly significant.

As we have already mentioned, the goal of inclusive education is not and can never be only to ensure the supply of knowledge for pupils. A special teacher - like any other school employee - has a responsibility to look after their own mental health and to assist other adults to do so. Inclusive education does not just focus on the pupil, but on all those involved in the learning process and therefore considers it important that they are provided with support. As in the Multi-IN Teacher's Manual, **we emphasise that there is a symbiotic relationship between the mental health of school staff and the mental health of pupils. If adults aim to support pupils' mental health, staff should enjoy good mental health. Classroom and school climate strongly reflects the relationships between pupils and school staff. A pro-inclusive adult climate will also transfer to pupils, their relationships.**

Unfortunately, bullying is a common phenomenon in the European Union, with more than 50% of pupils reported to have suffered from bullying in the 2018 PISA study. Given that pupils with disabilities are up to three times more likely to be bullied, special teacher, together with other school staff, should do everything possible to prevent bullying in the first place. Any signs of bullying must be closely monitored and dealt with. More information on bullying prevention can be found in the Multi-IN manual for school psychologists.

The special teacher's expertise in inclusive education should include the ability to map the pupil's state of experience, evaluate it and support the pupil preventively to learn skills that will help them cope with any difficulties. We emphasise preventative action over reactive action, that is, adults around the pupil should not wait for difficulties to arise, but given the potential risks, their intervention should be proactive and provided in a timely manner.

Globally, the prevention of survival and mental health disorders in children, pupils and young people has become highly topical during and after the COVID-19 period. During its duration, we have seen on a large scale how social isolation, the lack of opportunities for social interaction, has a fundamental impact on the psyche of pupils. The fundamental lesson from this period is that the negative effects of social isolation on mental health and survival - which we all experienced during this period - are experienced by children and pupils with disabilities as a normal reality, and this is due to social isolation during stays in hospitals, treatment, in medical clinics or as a result of exclusion. More emphasis has begun to be placed on the mental health and overall wellbeing of the children, pupils and adults around them.

Wellbeing is characterised as a state in which a person can fully develop their physical, cognitive, emotional, social and spiritual potential in a supportive environment and live a full and satisfying life with others.

Wellbeing, or mental and physical well-being at school, is seen as essential for pupils, school leaders and teachers to lead happy and fulfilling lives, manage stress and play to their strengths. A school in which most people feel comfortable and where they establish functional and supportive relationships with each other, they can develop their full potential.

The well-known pyramid of basic human needs defined by A. H. Maslow, provides a guide for how the school environment is an opportunity to contribute to the wellbeing of pupils and staff. The different levels of the pyramid correspond to the domains of wellbeing - physical, emotional, social, cognitive, spiritual - and build on the knowledge of how the human brain functions in the areas of learning and behaviour.

The less students have each area of need met, the more difficult it is for them to learn or function in harmony with others and with the whole group. This is also true for adults; without ongoing needs fulfillment, they cannot function well in life - either professionally or personally - in the long term. As part of the outputs of the Multi-IN project, a General Guide is available to adults which, in a separate chapter, discusses the different levels of needs of pupils with spina bifida and hydrocephalus. It is recommended to study the different levels, their specificities for the pupils mentioned and to apply specific measures to the pupil.

According to Brdička (2019), wellbeing expresses the subjective perception of how close our real life is to the life we would like to live. It is therefore essential to teach all pupils - even those with spina bifida or hydrocephalus - to express their needs, to ask for their opinion, their perspective.

The special teacher's expertise in inclusive education should include the ability to map the pupil's state of experience, assess it and support the pupil in a preventive way, so that he or she can acquire skills that will help him or her to cope with any difficulties....

We would like to draw your attention to Emotional Compass, an application in Slovak language - mainly aimed at working with children <http://kompaspredeti.sk/>

The use of digital tools is also a growing concern for pupils with disabilities, who are spending more time online than ever before.

The key is moderation and purposeful use of digital tools, as both non-use and overuse of screens are associated with lower life satisfaction.

Digital tools can be usefully used to promote mental health and therefore digital wellbeing is considered to be one of the important components.

Digital wellbeing is one of the components of overall wellbeing that is directly impacted by digital technologies. There are now quite a lot of online mental health apps. Thanks to digital technologies, people can relax, unwind, do enjoyable things that enhance a person's overall wellbeing.

OPPORTUNITIES TO PROMOTE WELLBEING IN SCHOOL

Research shows that embedding social-emotional learning, mental health, wellbeing and bullying prevention programmes in schools is one of the most effective ways to promote the psychological wellbeing of children and young people - including those experiencing disadvantage and marginalisation. This is in line with a holistic vision of education that recognises that children and adolescents need a balanced set of cognitive, social and emotional competencies to achieve positive outcomes in school and in life.

Schools can do much to create a healthy and safe space for all children to learn. A special teacher can be the person who looks after the physical and mental health, well-being and safety of students with spina bifida and hydrocephalus over the long term - throughout their years at school. He or she may do so in a variety of areas:

1. In the field of culture and school environment

- Promote a clear vision, ethos and culture for the school - including with regard to pupils with differences.
- To contribute to a positive climate for the classrooms and the school as a whole and for every pupil in it.
- Promote a healthy lifestyle for pupils, school staff.
- Promote the quality of the physical environment of the school and its surroundings - to make it safe and accessible for all pupils, staff

2. In the field of learning

- Quality teaching and support for all pupils.
- Improving evaluation.
- Develop wellbeing skills in yourself, pupils, staff.
- Expect success from every student.
- Personalise learning activities that spark pupils' interest (according to their preferences).

3. In the area of partnership and cooperation

- Respect relationships.
- Collaborate and share with each other inside and outside the school.
- Participate and involve all members of the school community.
- Promote the wellbeing of school staff.

At the same time, the special teacher should know where to look for help and to which help to refer those persons (pupils, adults) who need it at that time.

The World Health Organization offers an online guide called "What to do in times of stress". It's clarity and simplicity makes it well suited for many groups - parents, pupils, teaching and other school staff, and relatives of pupils.

Available here: <https://apps.who.int/iris/bitstream/handle/10665/331901/9789240003910-eng.pdf>

SUPPORTING THE DEVELOPMENT OF COPING SKILLS IN A PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

At the same time, a special teacher 's mental health care is a great support in building resilience in students with spina bifida and hydrocephalus, as well as in building coping skills for school-age and beyond. It is one of those life skills and habits that benefit a lifetime of learning.

Research shows that embedding social-emotional learning, mental health, wellbeing and bullying prevention programmes in schools is one of the most effective ways to promote the psychological wellbeing of children and young people - including those experiencing disadvantage and marginalisation. This is in line with a more holistic vision of education that recognises that children and adolescents need a balanced set of cognitive, social and emotional competencies to achieve positive outcomes in school and in life. Given the high risk of possible depression in adulthood, a preventive focus on this area of personality is highly significant.

When working with students, infographics with listed procedures, specific steps, or visualized coping skills can be very helpful for the special teacher. Many internet portals offer such possibilities. Some are in English, so they are more useful for upper grade students. We think that for use by special teacher or parents, this is a good source of support. Also (not only) for many pupils with spina bifida and hydrocephalus their use is helpful.

The special teacher, assistant or parent can write individual coping strategies on cards for the pupil, from which the pupil chooses the one that he/she thinks is most appropriate in a particular situation. It can also be supportive if the special teacher, working individually, models for the pupil situations in which the pupil either already finds himself or could find himself and together they look for which skill could be helpful to the pupil at that moment, how he would use it, what he would say or do.

Website tips - resource materials:

www.mentalhealthcenterkids.com

SUPPORTING THE EXECUTIVE FUNCTIONS OF THE LEARNER

Numerous neuropsychological studies have revealed a pattern of strengths and weaknesses in motor, cognitive, academic, and adaptive functions in people with spina bifida. This pattern is most often found in people with spina bifida who were born with the open form of spina bifida (with meningocele), usually have Arnold Chiari malformation type II, and other congenital malformations of the brain (affecting the cerebellum, midbrain, and corpus callosum). (Adapted from Understanding Spina Bifida).

In preschool, these difficulties manifest themselves as problems with attention, with pragmatic use of language and with mathematical problem solving.

On the contrary, children perform well in tasks based on making associations (understanding of mathematical facts, good vocabulary).

The special teacher or school psychologist] can greatly guide and educate parents, teachers and other professionals about the implications of a primary diagnosis that is not just an orthopedic disability, but due to the brain malformations, hydrocephalus affects especially those areas that require the generation and integration of information.

Brei (2021), in his guide to the care of individuals with spina bifida and hydrocephalus, recommends that the focus of the person conducting the psychological or special education diagnosis should not only be on assessing the general intellectual performance of the student with spina bifida and hydrocephalus, his academic knowledge, but also on the sub-skills, which are:

1. Attention,
2. Memory,
3. visuomotor coordination,
4. adaptability,
5. executive functions of the pupil.

Based on our experience and in line with the literature, we perceive that the latter area is not given enough attention in psychological and special-educational diagnoses. According to research findings, it is the executive functions that are directly related not only to academic achievement but also to the quality of social skills, mental well-being and overall quality of life.

Brei (2021) **highlights that executive functioning, along with socioeconomic status, level of intrinsic motivation, and parental support for independence, are significant predictors of successful transition to adulthood for students with spina bifida and hydrocephalus. Therefore, we consider it important for the special teacher of a particular pupil with spina bifida or hydrocephalus not only to regularly map their level, but to target their development, stimulation and support.**

Adolescents with spina bifida appear to show a clear impairment in attention and executive function, and this impairment may contribute to their well-known social difficulties.

Executive functions serve to control, regulate, and coordinate mental processes and behavior. They help the pupil to adapt to the demands of real life by enabling him/her to make effective use of cognitive skills (perception, memory, thinking) and to limit the interference of various stimuli from the external world and the pupil's inner experience - including his/her own emotions.

They come to the fore especially in new, more challenging situations and determine how flexibly the learner can respond to changing demands. They play a lesser role in familiar situations where a pupil with spina bifida may rely on a certain routine or automatic behaviour.

Executive functions are the bridge from "I know" to "I do" and significantly influence the use of the learner's intellectual potential. Brei (2021) points out that for pupils with spina bifida and hydrocephalus, it is therefore important to distinguish between skills and behaviours that the pupil knows how to do and behaviours that they actually perform independently.

Based on several studies (in Vágnerová, 2020), it is possible to define **three basic executive functions** that evolve over time and the degree to which they are interrelated also evolves:

- **Inhibition** - the student's ability to suppress irrelevant information, distracting thoughts or memories, or his or her inappropriate reactions.
- **Working memory** - allows you to retain important information in your mind and manipulate it as needed, or update it based on new knowledge. Updating knowledge requires the suppression of knowledge that is no longer relevant to the learner]
- **Cognitive flexibility** - allows the learner to switch attention and move from one activity to another as needed. It is the pupil's ability to change his/her perspective on a situation, to adapt to new conditions or demands and to use alternative strategies. The level of cognitive flexibility of the pupil is directly dependent on the quality of his/her inhibition

The development of executive functions is gradual and depends on the interconnection of the central control network in the brain with its other areas that provide individual functions.

By the third year, the so-called general executive ability develops; after the third year, the sub-functions begin not only to differentiate, but also to link and coordinate.

After the fourth year, the first two basic executive functions (inhibition and working memory) can already be distinguished.

At the end of preschool (age 6-7 years), cognitive flexibility is added to these skills.

The complex executive functions of the pupil are based on a combination of basic functions and allow

control over the course of more complex activities in the brain - such as:

- integration of lessons learned,
- creating new strategies for progress,
- monitoring your own activities,
- regulating the process of solving various problems,
- evaluating the effectiveness of the solution,
- planning future activities

Properties of executive functions

- They represent a combination of different components, they cannot be defined as a single capability.
- They are directive in nature, regulating and controlling various (not only psychological) activities: cognition, thinking, emotionality, motivation and action.
- They begin to develop in early childhood, but their development continues into the third decade of life.
- They are associated with the activation of different, (increasingly differentiated) neuronal networks, which invariably involve the frontal lobe cortex.

According to the authors Mc Closkey, Perkins and van Divner [in Vágnerová, 2020].

In order to assess a pupil at risk of executive function impairment, it is recommended that a psychologist or special teacher develop a profile of the pupil's executive functions in close collaboration with the parents or even the pupil's teacher. This will give an overview of those executive functions that are at an acceptable level and those that are not quite sufficient.

In the world and in the Czech-Slovak environment, the methodology "BRIEF: Assessment of executive functions in children", published by Hogrefe Testcentrum, is available to assess the level of executive functions. It is a questionnaire method designed to be filled in by parents and teachers of pupils aged 5 -18 years. The questionnaire items saturate eight scales - the different components of executive abilities:

1. Inhibition.
2. Shift of attention.
3. Emotional control.
4. Initiative.
5. Working memory.
6. Planning and organisation.
7. Organization of aids.
8. Behavior control.

The clinical scales are combined into two indices, the Behavior Regulation Index and the Metacognition Index, and together form what is known as the Global Executive Composite. The method contains Czech norms - including psychometric parameters of Czech standardization.

Another inspiring international publication is Peg Dawson and Richard Guare's Executive Skills in Children and Adolescents - A Practical Guide to Assessment and Intervention [available here:

<https://www.guilford.com/books/Executive-Skills-in-Children-and-Adolescents/Dawson-Guare/9781462535316>].

The publication offers useful and effective ways of qualitatively assessing a pupil's strengths and weaknesses. It also includes tips on how to create a supportive environment and promote specific skills in the pupil: organisation, time management, attention maintenance and emotional control. The publication includes 38 appendices - practical tools: questionnaires, structured and semi-structured interviews with the parent-teacher or the pupil. Also structured procedures for planning interventions.

Knowing the profile of the abilities of a pupil with spina bifida and hydrocephalus, including his/her executive abilities, as well as the patterns of their development, is important for the appropriate definition of the goals of an individual educational programme as well as for understanding the behaviour of a pupil with executive impairment.

In this context, we consider it necessary to emphasise that qualitative and pupil-oriented assessment of abilities has a more significant impact on the setting of a pupil's individual learning programme than assessment of a pupil by standardised methods. The latter, however, place the pupil's performance somewhere within the Gaussian curve and tell us something about the pupil's limits. They are less concerned with the pupil's own areas of interest, motivators and strengths, which, precisely when performance or executive functions are weakened, have a significant impact on the development of the pupil's self-esteem, self-confidence and self-worth. Pupil-oriented assessment tools can be found in the aforementioned foreign publication. A preview of these tools can be found at the following link:

<https://www.guilford.com/dawson3-forms>.

Further examples on executive functions and learner self-regulation from international publications can be found here:

<https://www.guilford.com/excerpts/kennedy4.pdf?t=1>



Author of photo: Terézia Drdulová

Knowing the profile of the abilities of the pupil with spina bifida and hydrocephalus, including his executive abilities as well as the patterns of their development is important for the appropriate definition of the goals of the individual educational program, as well as for the understanding of the behaviour of the child with these disorders. **Often the executive dysfunctions of pupils with spina bifida and hydrocephalus are interpreted as a lack of cognitive abilities, or as a manifestation of reluctance, sloppiness, lack of motivation or laziness. They are reflected in both academic and social domains. They affect the area of primary family relationships, the area of establishing peer relationships, as well as the area of personality development (identity, self-esteem and self-worth)** [Vágnerová, 2020].

According to Queally [2020], executive dysfunctions in a pupil with spina bifida and hydrocephalus are manifested in all the areas mentioned, but mainly as difficulties:

- Related to the identification of subtask requirements. This prevents the learner from starting to solve the problem and effectively directing his/her attention to the essential facts during the solution;
- Related to focusing on multiple tasks at the same time (multitasking);
- Related to the prioritization of the learner ;
- Related to the processing of a lot of information;
- Related to the organization of information. The consequence is a weakened ability of the pupil to form the bigger picture.

Weakenings in executive functions only become apparent as demands on the pupil increase.

Pre-school children and pupils in the first year of primary school benefit from routines and a relatively strong structure which ensures that demands are predictable and this gives the child/pupil the opportunity to benefit from the experience. Pri riešení úloh sú deťom často dostupné podporné pomôcky, návody ako úlohy riešiť.

When solving problems, children are often provided with support tools, instructions on how to solve the problems.

The discovery of dysfunctions in the executive domain often occurs at the mid-point between first and second grade - **around fourth grade** - when learning to read and do arithmetic is replaced by more complex tasks. Reading ceases to be a goal and becomes a means to acquire information. Mathematical tasks are equally more complex and present increased demands on the organisation and mental processing of information.

In the middle and high school period, the pupil's executive function deficiencies have an impact on the **process of his or her empowerment**. For many young people with spina bifida, their impairments must also be taken into account in the process of finding suitable employment [Zabel, Raches 2010].

OPTIONS AND TIPS FOR STIMULATING PUPIL'S EXECUTIVE ABILITIES

As we have mentioned, the contribution of dysfunctional executive abilities to the possible failure of a pupil with spina bifida can be large, so we consider it important to bring also ideas and ways in which executive abilities can be stimulated in pupils. As the issue implies, success and acquisition of these abilities is not guaranteed. Below we outline ways in which pupils' executive functions can be stimulated, following Dawson and Guare's (2010) practical recommendations and specifically to intervention at the environmental level. The authors specify the educational practices through which the relevant executive function is developed and also the pupil is motivated to use it. The tips are applicable to the work of the special teacher with the pupil, but equally to the teacher or assistant whom the special teacher can guide.

Note: Examples are selected from the text Greek Gods.

Intervention at the environmental level requires:

A) **Change the nature of the tasks in any of the following forms:**

By shortening the assignment:

- **Original:** Draw a diagram to show the family relationships between these gods: Zeus, Poseidon, Hades, Demeter.
- **After the change:** draw a diagram to show the family relationships between these gods: Zeus, Hera

By dividing the task into smaller steps:

- **Original:** What was ruled by a god whose symbol is lightning?
- **After the change:** have you seen the lightning? When can you see it? So what is ruled by a god whose symbol is lightning?

Allowing the learner to choose the task, the procedure:

- **Originally:** look at the pictures. What do you think they mean?
- **After the change:** look at the pictures. Select the pictures and see what you see in each one.

Umožnením učiacemu sa žiakovi vybrať si úlohu, postup:

- **Pôvodne:** Pozri sa na obrázky. Čo podľa Teba znamenajú?
- **Po zmene:** Pozri sa na obrázky. Vyber si obrázky a pozri sa, čo na každom z nich vidíš.

B) **Change the way the pupil is encouraged to solve**

Remind them what to do:

- **Example:** look at the symbol table. Which symbols are you still missing the names of the Greek gods and the area over which they ruled?

To guide the pupil through the learning process:

- **Example:** what did you learn about memory today? How memory helps a person while reading? What did you remember most from the reading? What should we do when we don't remember what we read about? Write three pieces of advice you can give to a classmate when he or she does not remember information from a text.

Before the task, go over with the student what will happen and how to solve the problema.

- **Example:** now you read four sentences. Two of them contain information that was in the text about the Greek gods, two of them bring new information. Your task is to determine which two sentences are "old" and which are "new".

C) **Change the way you interact with a student with low levels of executive functioning**

Directly call for attention

- **Example:** read sentences 4 and 5. In them you will find the answer to the question.

Počas úlohy vyzvať k použitiu evokovanej znalosti, skúsenosti

- **Príklad:** Poznáš mená niektorých gréckych bohov? Čo o nich vieš?

During the task, invite the use of the evoked knowledge, experience

- **Example:** do you know the names of some Greek gods? What do you know about them?

Check your to-do list, monitor your progress and provide positive encouragement after the task

- **Example:** check that you have filled in all the necessary rows in the table.

Talking about what happened, what worked and what didn't, what can be done better next time

- **Example:** you were very good at remembering the names of the Greek gods. However, you were confused by the symbol of the god of war, but the text says it is the symbol of the god of the underworld.

Below, we provide additional **tips for improving complex executive abilities in students** with spina bifida and hydrocephalus, which we briefly characterize. We note that not all of the listed executive functions need to be impaired in a particular pupil. It is helpful if the special teacher makes it clear to the pupil what is the source of his difficulties, to help him understand his difficulties and to offer him hope that by persistence it is possible to change his habits.

Emotional control - to be able to control and direct one's own feelings and emotions

- Practicing calming strategies such as mindfulness, repeating affirmations
- Working with breaks and moving the pupil to a safe place

Planning/Prioritising - knowing what to do first, making a plan and knowing which task to start with

- Recording the day's task and homework.
- Recording work in planner, calendar.

Organizing - keeping things organized and in place, keeping records of things

- Throwing away trash and unnecessary items from your backpack, from your desk.
- Sorting papers and putting away unnecessary ones.
- Prepare your clothes for the next day the night before.

Perseverance - the ability not to give up and to complete tasks, even when it is difficult

- Agreeing with parents/teachers on the rewards the pupil will receive if they complete the task.

Mindfulness - focusing on a task, a person for a time, ignoring distractions, diverting attention when needed

- Moving around, taking short breaks, walking during breaks.
- Removal of distractions.

Time management - understanding how long things take, judicious use of time to accomplish a task

- Create a "To Do" list for each day.
- Thinking through in advance how much time each task will require.
- Establish and repeat morning, afternoon and evening routines.

Flexible thinking - looking at things in a new way, thinking about something in a new way, and dealing with something that is not going the way you want it to.

- Repeating yourself - to yourself:

"Let the little things go."
 "Accept and receive support."
 "Be patient."
 "Sometimes things don't have just one solution."

SUPPORTING THE BUILDING OF PUPIL LIFE SKILLS

Life skills are sometimes difficult to find in the school curriculum, but no one working with pupils can avoid the fact that without them a young person has very little chance of succeeding in life. The skill of effective communication, cooperation with other people, naming one's needs, feelings, regulating them, following rules, agreements - all this and many other skills predestine a pupil for his long-term employment.

Several modern trends in education emphasize the importance of leadership and nurturing creativity. In the near future, AI is expected to have a huge impact on the way education is delivered and on the new demands of the labour market. While routine activities are easily automated and replaceable by robots, creativity poses a significant challenge for AI, so it is expected that people with creativity will find it easier to find employment. If the education of pupils with spina bifida and hydrocephalus is to guide and prepare them for their future employment, it must also take into account the formation of their personal qualities, and this can only be done in cooperation with family, teachers and other professionals.

The special teacher can also guide the actions and decisions of other adults by pointing out how they will affect the pupil's future and what skills are beneficial for a pupil with spina bifida and hydrocephalus. As a physician who has spina bifida himself, Brei (2021) emphasizes that a well-adjusted adult should have these characteristics:

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.

The special teacher can also work individually with the pupil to introduce him/her to the principles of successful people according to Covey's concept, which lists 7 habits that pupils should adopt.

Habit 1: **Be proactive**

Take initiative and responsibility for your behaviour, decisions and results. Focus on what they can influence.

Habit 2: Start with the end in mind

Based on a shared vision, better set measurable personal and team goals and plan meaningfully.

Habit 3: **Putting the most important first**

With clear priorities, implement the most important goals instead of frequent "firefighting" at home or at work.

Habit 4: **Think Win-Win**

Create and develop good relationships by fostering mutual trust at all levels.

Habit 5: Seek **first to understand, then to be understood**. Effectively direct your attention to understanding, listening to the other person, expressing your opinion, and giving and receiving feedback.

Habit 6: **Create synergy**

Strive to find innovative solutions that bring satisfaction to all involved.

Habit 7: **Sharpen the Saw** Increase your motivation, energy.

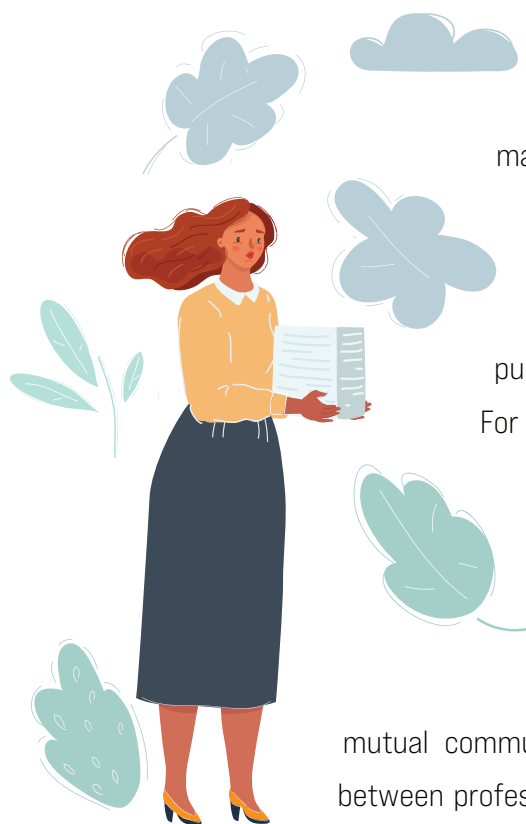
To learn more about applying the 7 Habits of Successful People to the school environment, visit:

<https://www.leaderinme.org/>



Author of photo: Peter Hečko

THE ROLE OF THE SPECIAL TEACHER IN A MULTIDISCIPLINARY TEAM



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 teacher, the school psychologist, the career or educational counsellor, the school psychologist, the social teacher, 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. For pupils with spina bifida and hydrocephalus, many professionals are involved in their care from an early age. Likewise, his inclusion in kindergarten or school involves several people. It is much easier - for both the pupil and his family - if a culture of mutual information, alignment of care goals and mutual support is set up from the beginning. Only honest mutual communication will open up the space for building mutual trust between professionals and parents, and possibly also between the pupil. The special teacher is the part of the team that can bring other professionals together, because he or she needs to communicate with all stakeholders to set up a good Individualized Education Program.

The job of a special teacher takes many forms. The most common of these include:

- Coordination of a multidisciplinary team of experts on-site at the school.
- Coordination of professional practices and close cooperation with establishments that diagnose pupils
- Providing methodological support to teachers in specific situations within the educational educational process, e.g. consultations, educational activities.
- Strengthening teachers' competence to deal with everyday challenges, such as bullying, developmental learning disabilities,
- Supporting communication with the pupil's parents (legal representatives) and other close persons.
- Providing support in creating a positive school climate by mapping the needs of all its actors.
- Implementation of targeted activities, interventions in individual or group form.
- Providing individual support for the pupil's learning.
- Monitoring the inclusion of a pupil with spina bifida and hydrocephalus in the classroom team.
- Providing advice to a pupil with spina bifida and hydrocephalus on a variety of topics.

SPECIAL TEACHER AS LEADER OF A MULTIDISCIPLINARY TEAM

To be a leader in an official capacity while also becoming an informal leader recognized by the community as a natural authority is true mastery. It requires very good communication skills on the part of the person concerned. A special teacher can become a leader of a multidisciplinary team in the sense of setting both a pro-inclusive philosophy and direction for the team. He or she can be the one who, by understanding the benefits of mutual cooperation, will motivate the other members by his or her example, way of working and form of communication. A high degree of the communication skills of the professional is also his ability to facilitate (gently guide) a group of people.

An activity aimed at mastering the facilitation of a discussion in a group of people can be a very helpful and concrete tool when working with a team, when it meets regularly. It offers practices, the mastering of which can help the facilitator considerably and move the level of conducting joint meetings towards achieving the desired goals. We have adapted it from the School Support Team Manual, which was published in 2022.

Activity: facilitating discussion

Directions for the activity: for each situation, match the letter with the answer.

It can also be repeated, or describe what else you would do (for A very helpful and concrete tool in working with the team, when it meets regularly, can be an activity aimed at mastering the facilitation of a discussion in a group of people. It offers practices that, if mastered, can help the facilitator considerably and move the level of conducting joint meetings towards the achievement of the desired goals. We have adapted it from the School Support Team manual.

You can go through this activity individually, but you can also do it at the beginning of school. In the beginning of the year (or at the beginning of a team meeting) you can observe the practices and behaviour of the team members during the discussion.

Possible situations:

1. You want to stimulate discussion.
2. You want to end the discussion.
3. You want to draw the participant into the discussion.
4. Two participants talk to each other.
5. They ask you a question you don't know the answer to.
6. You want to check the level of support for a particular opinion.
7. The discussion is between two participants only. The others look on.
8. The discussion has been going on for some time, you don't know if it is still beneficial.
9. Two people are debating with no concrete progress.
10. You would like to know how effectively you led the group.

Alternatives of possible responses of the facilitator to the situations that arise:

- a) Ask each participant to summarize the views of the others.
- b) Ask for feedback from the group.
- c) Give the group an open-ended general question.
- d) Give the participant a specific question.
- e) Ask the group a specific question.
- f) Give participants an open-ended general question.
- g) Ask the group to summarize.
- h) Ask the participant to summarize.
- i) Turn the question into a group.
- j) None of the above. I would do.....

SPECIAL TEACHER NETWORKING COLLABORATION

1. It is good to realise that you are becoming a "networker" and as a concerned member of a multidisciplinary team you are suddenly in a dual role.
2. Observe the characteristics and attitudes of the people, teams, institutions that appear in the topic you are working with (directly - by name, with traceable contact... "Mrs. XY teacher", doctor,)
3. Analyse the contacts and make a list of them - a "core network of multidisciplinary care actors". When creating its network, visually and textually prioritize, in particular, the roles of the actors in multidisciplinary care and their:
 - Relational positioning (reflecting relational security, resistance, shared values),
 - Previous themes, activities and achievements in multidisciplinary care,
 - Strategic competencies and declared skills (benefits and strengths),
 - resources for further cooperation.
4. Approach your own multidisciplinary team with the need for multidisciplinary care networking and agree on the basic starting points.

Questionnaire to assess the preparedness of multidisciplinary care actors for networking.

Source: adapted from Vlachová, I., Vlach, J., 2020.

Directions: on a scale of 1 to 5, where 1 is strongly disagree and 5 is strongly agree, indicate how much you agree with each of the statements below.

[5 = strongly agree; 4 = agree; 3 = neutral; 2 = disagree; 1 = strongly disagree]

Score

1. People will believe that this cooperation is essential.
2. People will believe that this collaboration will improve team, organizational and client outcomes and satisfaction.
3. People will understand that this cooperation needs to happen now.
4. Teams and organisations have the resources and capacity to make this collaboration happen.
5. We in the team and people in the organisations have experience of implementing networking multidisciplinary collaboration.
6. We in the team and people in the organisations have people ready to do this networking.
7. Leaders in organisations will be committed to networking this collaboration and will actively support it.
8. Networking and this collaboration is compatible with the culture of the organisation(s).
9. Relationships and communication between actors in multidisciplinary cooperation will improve as a result of this networking.
10. Multidisciplinary cooperation processes will improve as a result of this networking.
11. The system of multidisciplinary cooperation, including management and support components, will function more effectively after this networking.
12. As a result of this networking, people will have more of the relevant information they need to do their jobs.
13. As a result of this networking, people will have more of the resources, tools and tools they need to do their jobs.
14. This networking will reinforce the feeling that people are together as a team.
15. This networking will bring more qualifications, growth and appreciation of multidisciplinary cooperation actors than before.
16. People will have more powers/competences as a result of this networking.
17. As a result of this networking, actors in multidisciplinary collaborations will be better able to accept higher expectations for performance.
18. Workloads will be more accepted by people as a result of this networking.
19. Power measurement will be more objective as a result of this networking.
20. People will believe they have the right skills to make multidisciplinary collaboration happen.
21. People will have more certainty of engagement as a result of this networking.

Evaluation

84 - 105 points: you are well prepared for networking, people will support multidisciplinary collaboration if you focus on leading it. But don't rest on your laurels. Communicate the networking strengths of the multidisciplinary collaboration actors and be prepared for potential problems.

63 - 83 points: networking success is in your hands. You need to invest time and resources to gain people's support. Identify the most critical areas and work on them. Communicate the networking strengths of the multidisciplinary collaboration actors.

42 - 62 points: your networking is risky and will require ongoing resources to support people to implement and sustain multidisciplinary collaboration. Do a cost benefit analysis and reconsider whether you want to do the networking. If so, you need a very good plan that focuses on both the human and technical aspects of networking multidisciplinary collaboration actors.

21 - 42 points: your networking is on the road to failure and requires an immediate redesign or you'll throw resources and energy out the window.

SPECIAL TEACHER AND THE INDIVIDUAL EDUCATIONAL PLAN

The Individual Education Programme (IEP) is an important tool in the hands of the adults in the school to tailor education to each pupil. It should reflect the teacher's holistic view of the pupil, knowledge of the special characteristics of the pupil with spina bifida or hydrocephalus, and provide effective support for all, even if it is primarily for the pupil.

A good IEP is never a formal document but a dynamic instrument of change. It should take into account and reflect a holistic view of the pupil's situation and translate this into all aspects of education.

The fundamental question is: How to achieve this? A good starting point is to get to know the pupil as well as possible - through his/her family, professionals who have known him/her for a long time, communication with the pupil, finding out what he/she wants.

12 principles of a good IEP for a student with disabilities by Jorgensen, Schuh, Nisbet (The Inclusion Facilitator's Guide)

1. The goals of the IEP reflect high expectations for the pupil's learning
2. Family participation is expected
3. Activities and environments in which skills are taught are inclusive (in the presence of all pupils)
4. Skills, objectives and activities are age-appropriate
5. Communication, mobility, and behavior training are part of regular instruction
6. Activities are opportunities to interact with children without disabilities
7. Goals and expectations - are measurable
8. Pupil has the opportunity to choose and learn their chosen skills
9. Goals are real life skills for the pupil
10. The pupil is provided with mainstream support prior to special support
11. The skills to be acquired by the pupils can be achieved in a variety of ways
12. Assistive technology and other support is provided to enable the pupil to understand instruction and visualize learning

For pupils with spina bifida or hydrocephalus, this means that the IVP will be reflective:

1. Ensuring that all areas are accessible during and after school activities
2. Ensuring the pupil's mobility in any environment
3. Ensuring space and space for pupil toileting
4. Respecting the increased time for pupil toileting
5. Providing a safe space - including for the pupil to express his/her views
6. Providing sufficient space for socialisation and relationship building with peers, classmates
7. Involving the pupil in the process of planning and evaluating learning
8. Accepting the needs and possible difficulties of the pupil
9. Cultivating the pupil's preferences and interests
10. Providing the necessary degree of assistance in various areas - personnel, aids, technical resources,

The IVP is based on the diagnostic conclusions of various experts and their recommendations for the pupil's personalised education. The special teacher, through his/her expertise, can help other teachers, school management and other members of the multidisciplinary team to understand the conclusions and recommendations of the counseling facility and translate them into long-term effective and concrete support for the pupil.

Parents, the class teacher, the special teacher, or an expert from the guidance institution who knows the pupil should be involved in the process of developing the IEP. The special teacher can convene and facilitate meetings, clarify the context and, where appropriate, highlight risks.

The IVP allows you to flexibly record all of the pupil's progress - against themselves. If a change is necessary in a pupil's learning, it is recorded in the IVP, as well as further progress.

The IVP is a great help when changing teachers, schools, medical conditions. It captures the pupil's development, his/her abilities as well as difficulties and weaknesses.

When a pupil's difficulties arise, the special teacher can offer help in the form of consultation, setting up more effective support or modifying the content of the education. They can also work with the pupil to provide appropriate specialist interventions and effective support.

The special teacher should assist the family and the teachers in applying 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 towards the pupil's condition, seeking to stimulate, encourage and help him or her appropriately by making reasonable demands on his or her performance and, at the same time, creating a safe and comfortable environment in which the pupil feels accepted.

Through the IVP, the special teacher can provide and coordinate support for the pupil, teachers, and assistants, specifically through interventions, modifications to the environment, consultation with specialists, and curriculum adaptations, thus fulfilling his/her special education mission.



„Popcorn is prepared in the same container, at the same temperature, in the same oil, and yet the corn kernels don't pop at the same time. Let's not compare children. Everyone's time will come.“

CONCLUSION

In recent years, it is possible to observe a shift in the perception of the role of the special teacher in schools from a staff member who primarily provides administrative support for the inclusion of pupils with disabilities in mainstream schools to a professional who provides support, who holds best practice support for all pupils, especially those with disabilities. At the same time, he is more the one who contributes to building a pro-inclusive atmosphere in the school and significantly influences the current and future quality of life of pupils, their participation in society. How a pupil with spina bifida or hydrocephalus will perform in life one day is largely determined by the school he or she attended, the professionals who influenced him or her, the relationship they developed with him or her and the way they prepared him or her for life.

Experts at Harvard University say that, *"Resilience requires relationships, not rugged individualism. The ability to adapt and thrive despite adversity develops through the interaction of supportive relationships, biological systems, and the expression of genes. Despite the widespread but mistaken belief that humans need only some heroic strength of character, science now tells us that it is the reliable presence of at least one supportive relationship and multiple opportunities to develop effective coping skills that are the essential building blocks for enhancing the ability to cope well with significant adversity."*

As the authors of this manual, we hope that special teachers will find this manual - as well as other outputs of the Multi-IN project - helpful and inspire them to effectively support pupils with spina bifida or hydrocephalus and benefit from it throughout their later lives.

REFERENCES

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

Brdička, B.: Digitální wellbeing na Future Learn. Metodický portál: Články [online]. 04. 03. 2019, [cit. 2020-12-16]. Dostupný tu : <<https://spomocnik.rvp.cz/clanek/22019/>>. ISSN 1802-4785.

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).

Brigid M. Rose, Grayson N. Holmbeck: Attention and Executive Functions in Adolescents with Spina Bifida. Journal of Pediatric Psychology, Volume 32, Issue 8, September 2007, Pages 983–994. Dostupné tu: <https://doi.org/10.1093/jpepsy/jsm042>

Carvalho, L. A kol.: Odporúčané postupy včasnej intervencie: Príručka pre odborníkov. Bratislava. Asociácia poskytovateľov a podporovateľov včasnej intervencie, 2021. ISBN: 978-80-570-3013-3. Dostupná tu: https://asociaciavi.sk/wp-content/uploads/2021/10/Guide_VSK_online.pdf

Covey, R.S.:l ve mně je lídr. Praha. FranklinCovey, 2012. ISBN 978 80 260 3087-4

Čadová E. A kol.: Katalog podpurných opatření 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

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

European Commission, Directorate-General for Education, Youth, Sport and Culture, Simões, C., Caravita, S., Cefai, C., A systemic, whole-school approach to mental health and well-being in schools in the EU: analytical

report, Publications Office of the European Union, 2021. Dostupné tu:

<https://data.europa.eu/doi/10.2766/50546>

European Commission, Joint Research Centre, Sala, A., Punie, Y., Garkov, V., et al., LifeComp: The European Framework for personal, social and learning to learn key competence, Publications Office of the European Union, 2020.

Dostupné tu: <https://data.europa.eu/doi/10.2760/302967>

Executive Function and Self-Regulation. Center on the Developing Child. Harvard University. Dostupné tu:

<https://developingchild.harvard.edu/science/key-concepts/executive-function/>

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

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

Horn, F.: Detská chirurgia. Bratislava: Slovak Academic Press, 2022. ISBN 978-80-8265-001-6.

Horn, F.: Encefalokéla. Spina Bifida. Bratislava: Slovak Academic Press, 2014. ISBN 978-80-8960-724-2.

Chlebničianová, A., Drdulová T., Tomovčíková M., Kubíny L.: Od najmenších po najväčších. Možnosti tvorby inkluzívneho protredia 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.

De Moor, J. M. H., Van Waesberghe, B.T.M., Hosman, J. B. L., Jaeken, D., Miedema, S: Manifest - Early Intervention for Children with Developmental Disabilities: Manifesto of the Eurlaid Working Party, International Journal of Rehabilitation Research no 16, p. 23-31. Nijmegen. Catholic University, 1993.

OECD (2018), Equity in Education: Breaking Down Barriers to Social Mobility, PISA, OECD Publishing, Paris.

Dostupné tu:

<https://doi.org/10.1787/9789264073234-en>.

Piačková, K., Magurová B., Močiliaková, A.: Komplexný psychologický manažment detského a adolescentného pacienta s poruchou pozornosti a hyperaktivitou.

Dostupný tu:

https://www.health.gov.sk/Zdroje?/Sources/dokumenty/SDTP/standardy/15-11-2022/7_2-Klin_psych_pre-deti-a-dorast-KPM-detskeho-a-adolescentneho-pacienta-s-poruchou-pozornosti-s-hyperaktivitou-F90_0.pdf

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

Manifest - Early Intervention for Children with Developmental Disabilities: Manifesto of the Eurlyaid Working Party, by J. M. H. DE MOOR*, B. T. M. VAN WAESBERGHE, J. B. L. HOSMAN, D. JAEKEN and S. MIEDEMA, Department of Special Education, Catholic University, PO Box 9103, 6500 HD Nijmegen, The Netherlands; published in: International Journal of Rehabilitation Research 16, 23-31 (1993)

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.

Šuhajdová, I.: Ľudský faktor - kľúčová podmienka inklúzie? Typi Universitatis Tyrnaviensis. Trnava, 2018.

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

Vodičková B.: Vývinové ťažkosti u detí v materskej škole v kontexte liečebno-pedagogickej praxe. Univerzita Komenského. Bratislava, 2022. ISBN: 978-80-223-5409-7

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&aq=chrome>

e.0.35i39i362i6j46i39i362j46i39i175i199i362.89040246j0j15&sourceid=chrome&ie=UTF-8#imgrc=3a-l_66GQ
3K5pM

Kolektív autorov: Diagnostika a stimulácia kognitívnych exekutívnych funkcií žiaka v mladšom školskom veku. Vydavateľstvo Prešovskej univerzity v Prešove. Prešov, 2016. ISBN 978-80-555-1719-3. Dostupné tu: <https://www.unipo.sk/public/media/40475/Diagnostika-a-stimulacia-kognitivnych-a-exekutivnych-funkcii-ziaka-v-mladsom-skolskom-veku.pdf>

Kolektív autorov: Školský podporný tím. Teoretický a praktický sprievodca. VÚDPaP. Bratislava, 2022. ISBN 978-80-89698-32-5. Dostupný tu: https://vudpap.sk/wp-content/uploads/2023/01/MANUAL_SPT_web.pdf

OntarioHow does learning happen? ISBN 978-1-4606-3839-2. Dostupné tu: <https://files.ontario.ca/edu-how-does-learning-happen-en-2021-03-23.pdf>

Projekt WEL - COME. Dostupné tu:
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>

All children benefit from being in inclusive environments where they are able to participate and collaborate in meaningful ways and form authentic, caring relationships.
(How Does Learning Happen?, 2014, p.24-25)



MANUAL

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

Authors:

Katarína Ondášová

Terézia Drdulová

Graphic layout: Natália Krajčo

ISBN 978 - 80 - 974288 [brochure]

ISBN 978 - 80 - 974411 [pdf]

Copyright © 2023 Multi-IN



www.multi-in.eu

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



Co-funded by
the European Union

ISBN 978 - 80 - 974288 [brochure]

ISBN 978 - 80 - 974411 [pdf]

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

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

Copyright © 2023 Multi-IN