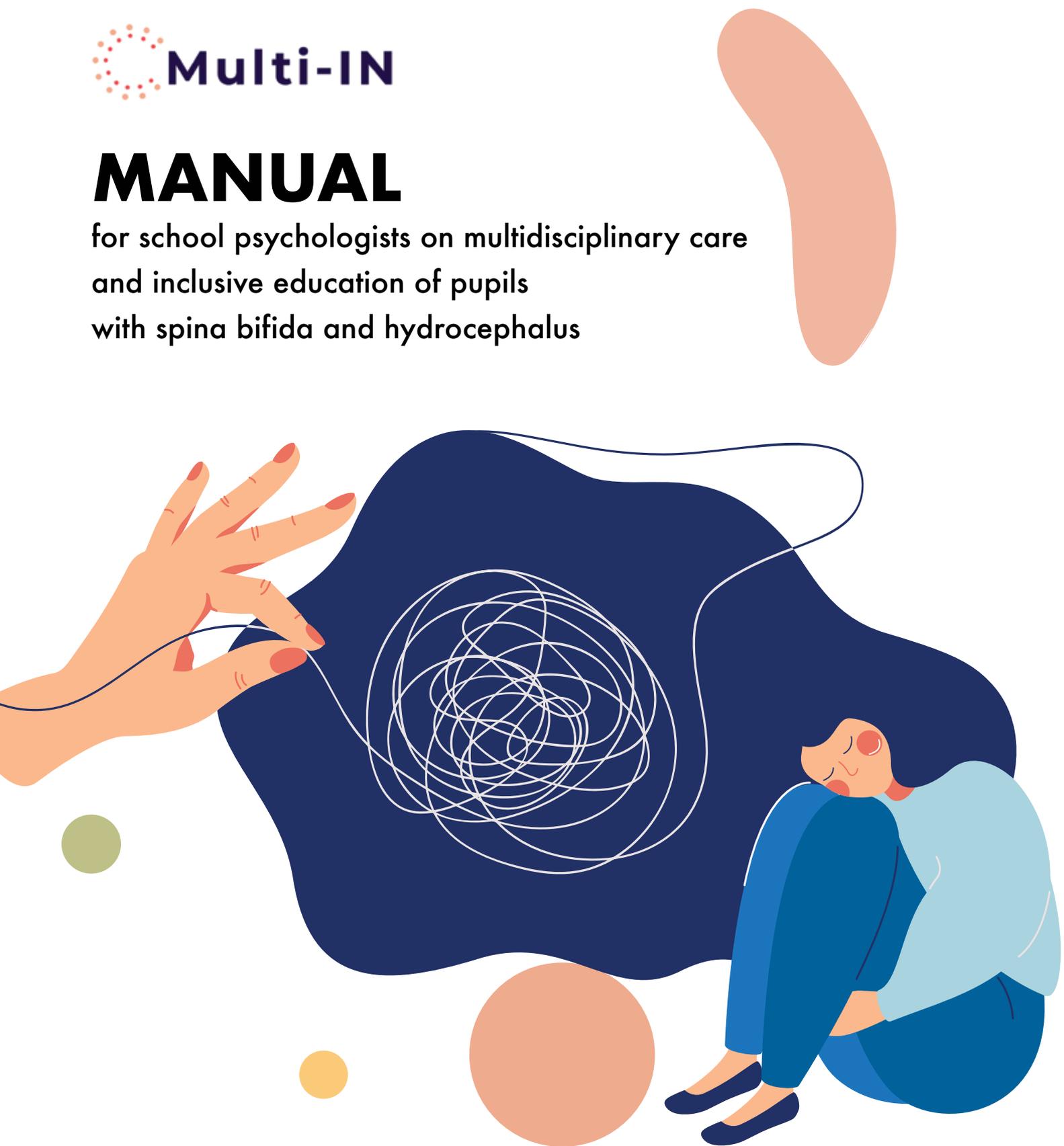




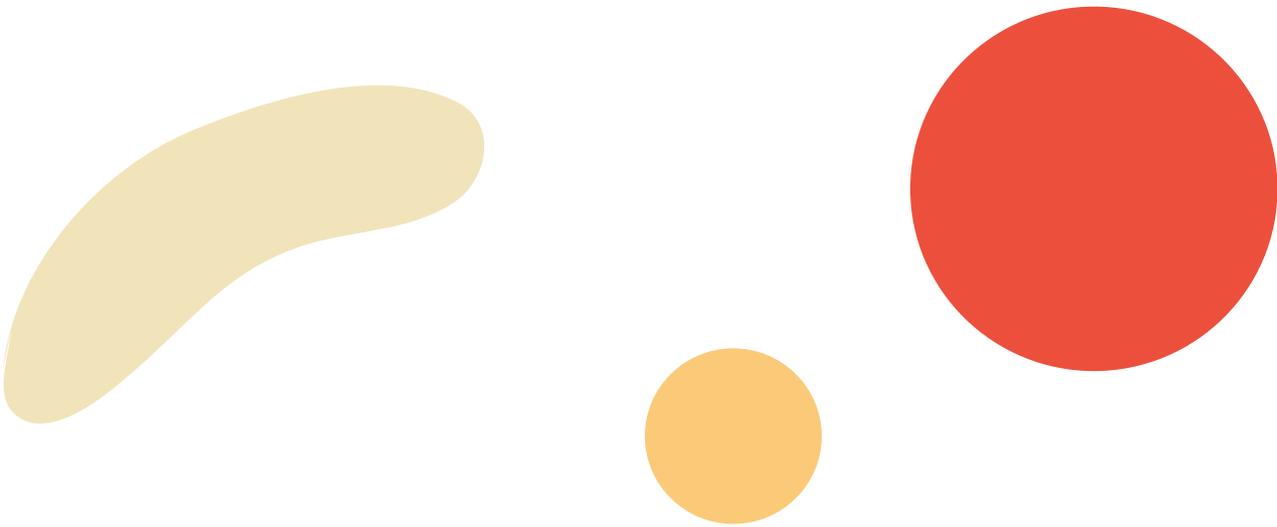
MANUAL

for school psychologists on multidisciplinary care
and inclusive education of pupils
with spina bifida and hydrocephalus



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

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This document is part of a set of educational materials to support inclusion of children with spina bifida and hydrocephalus in kindergartens and schools, developed in the framework of the Multi-IN project. The General guidelines, together with manuals and educational video courses, aim to support multidisciplinary efforts by professionals and families to promote inclusive education for children with spina bifida and hydrocephalus.

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The entire series of educational materials is available at

www.multi-in.eu

The Manual contains general recommendations based on examining the needs and rights of learners with spina bifida and hydrocephalus in the context of inclusive education and multidisciplinary approach. The authors recognize that there might be differences and variations in competences of school psychologists in kindergartens and schools in every country based on local legislation. First, you should follow your local legislation and then the Manual's recommendations.

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.

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INTRODUCTION

The manual for school psychologists in kindergartens and schools is part of a set of training materials developed within the Multi-IN project to support the provision of multidisciplinary care and inclusion for pupils with spina bifida and hydrocephalus. Its aim is to assist school psychologists in educational institutions in their efforts to provide quality professional care and create a supportive inclusive environment. School psychologists are most often present in schools, but this document is useful for all other professional staff who work in kindergarten and schools (for example, therapeutic and social pedagogues).

This manual discusses the role of the school psychologist in the multidisciplinary support team - given the unique position that the school psychologist has, by creating a supportive and safe relationship with the pupil directly in the school environment. At the same time, he or she has the opportunity to monitor the development of pupils with spina bifida and hydrocephalus, the process of their integration into the school environment and the ability to influence these processes competently in favour of the best interests of the pupils. It could be said that alongside the parents, he/she has the opportunity to become an advocate for the pupil, his/her rights and the fulfilment of his/her developmental needs in one of the most important periods of development. He/she works in an environment that is, after the family, the second most important environment that shapes pupils. For many vulnerable groups of pupils, the active presence of a supportive professional in the school environment is essential and has the potential to influence the whole of a pupil's future personal development.

In addition, the manual describes some of the specific risks arising from the results of longitudinal research on groups of pupils and young people diagnosed with spina bifida and hydrocephalus. At the same time, it provides specific tips and describes recommended practices that are helpful in preventing consequences of pupil's diagnoses.

We hope that the manual will provide practical inspiration for school psychologists in the process of creating a safe school environment for all involved, not just pupils with disabilities.

All materials are available on the Multi-IN website: www.multi-in.eu

THE BASIC FOUNDATIONS OF THE WORK OF A SCHOOL PSYCHOLOGIST

Our initial hypothesis is that disability greatly affects an individual's life, but does not primarily determine who is he/she and, in the case of a pupil, who they will become. We hold that it is the quality of interpersonal relationships that primarily influences the development of his or her personality (Landreth 2012).

The manual is prepared in accordance with the concept of mental health and the principles of positive psychology applied in the practice of a school psychologist as presented by *Gajdošová and Bisaki (2017)*. At the forefront of this approach is, first of all, primary prevention, identification of positive abilities, qualities, skills, gifts and talents of all participants of the educational process. Our focus is not on an isolated diagnosis, disorder or deficit, but on the individual, their deficit-specific situation and aspects of their mental and physical health.

Another starting point for this manual is the UN Convention on the Rights of Persons with Disabilities, including but not limited to the following articles:

"The Parties recognize the right of persons with disabilities to education. For the purpose of exercising this right without discrimination and on the basis of equality of opportunity, the Parties shall ensure an inclusive education system at all levels and lifelong learning aimed at:

- a) the full development of human potential and a sense of dignity and worth, and to strengthen respect for human rights, fundamental freedoms and human diversity;*
- b) the development of the personality, talent and creativity of persons with disabilities, as well as their mental and physical abilities to the maximum extent possible;*
- c) enabling persons with disabilities to participate effectively in a free society." (Art. 24[1])*

"The Parties shall take appropriate measures to enable persons with disabilities to develop and use their creative, artistic and intellectual potential not only for their own benefit but also for the enrichment of society as a whole." (Art. 30)

The aim of the manual is to answer the questions:

1. How can a school psychologist help fulfill the rights of children with spina bifida and hydrocephalus?
2. How can a school psychologist reflect the current needs of children and young people with spina bifida and hydrocephalus?
3. How can a school psychologist enhance and support the positive development of children and young people with spina bifida and hydrocephalus?

The birth of a child with a disability is a challenge for a family that can fundamentally affect the way it functions. Fear for the health and life of the child, frequent hospitalisations, the probable loss of income of one of the parents, increased financial demands, increased stress in the relationships between family members are just some of the challenges that the family of a child with a disability has to face. How the family copes with this challenge depends on many factors. One of the most crucial ones is what information professionals provide to the family about the lives of people with disabilities after the diagnosis has been announced. In our society, the medical approach still prevails in professional circles. This is characterised by a focus on the deficit, its correction and the pursuit of the norm. It is based on the premise that repair of a physical deficit leads to better functioning of the pupil and that the value is to achieve some normal performance of activities [Rosenbaum, P., Gorter J.W., 2011]. **Unfortunately, practice shows that "correcting" a physical deficit or function does not automatically lead to better child functioning,** because all functional aspects are influenced by a large number of other factors, with impairment, deficit in any one area being only one of them [Wright et al. 2007 & Chiarello 2011. IN: Rosenbaum, Gorter 2011]. In the same way, the idea of normality (what and how most people do) is proving useful as a kind of guide, especially in diagnosis. But it is not sufficient in a comprehensive intervention because it does not take into account the holistic development of the child [Rosenbaum, Gorter 2011]. If we consider a child with a diagnosis of spina bifida or hydrocephalus, an example might be the parents' refusal of a wheelchair for a child with SB (pressure to walk), which hinders the development of the child's autonomy (which at that age should and, thanks to the use of a wheelchair, could take place).

From a psychological point of view, it can be seen as a sign of positive coping with the reality of the child's disability that the parents themselves see in the child, above all, a child who is - like any other child - accepted, loved and allowed to **cope** to the maximum extent possible (with the use of compensatory means and support) **with similar developmental challenges to those normally faced by their peers.**

Why is it good to be a wheelchair user from birth?

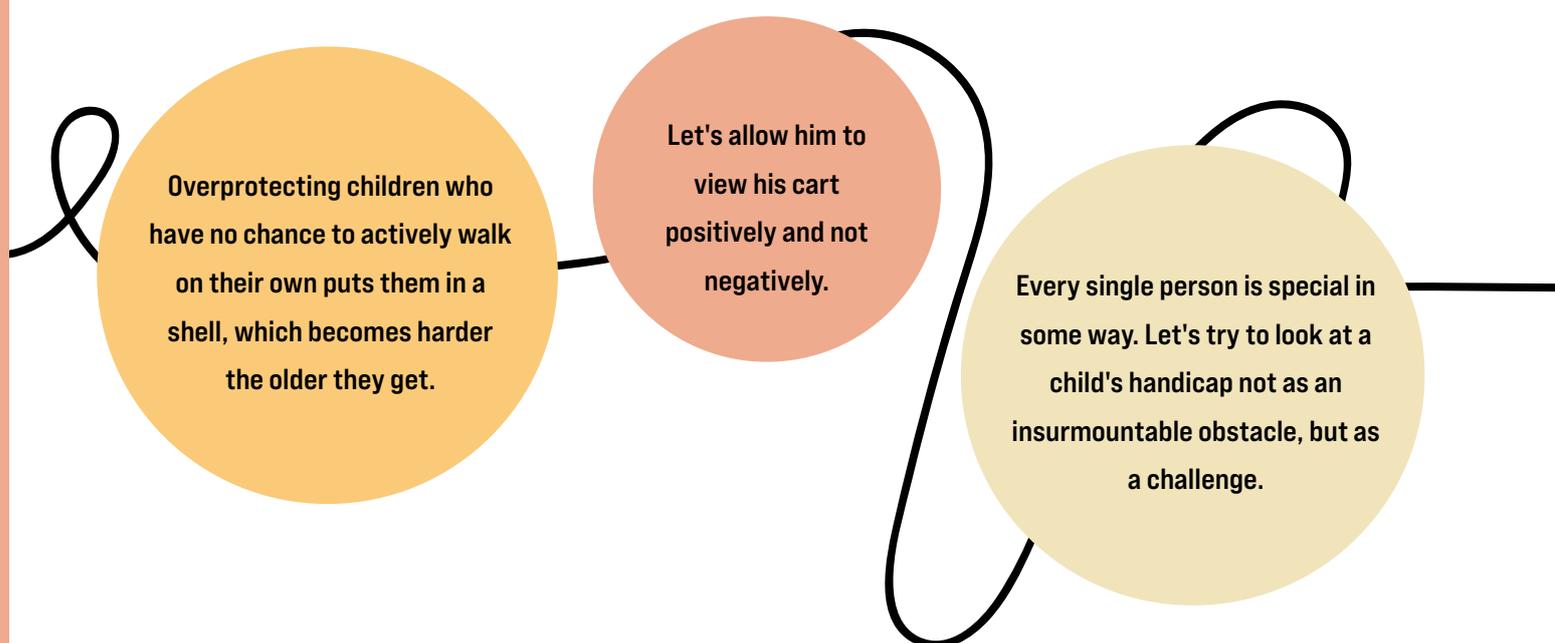
Mother experience of children with SB, H in Slovakia

If someone had asked me this question 2 years ago, I would have shaken my head and not known how to react. Today, however, I know that this is the best thing that can be for a person who has no prospect of actively walking. For a person who is partially or completely non-ambulatory.

So once again: "Why be a wheelchair user from birth?"

- 1. the child gets used to the wheelchair as part of his personality,**
- 2. the child has the freedom of movement and the ability to make choices, to choose from a number of options, to move where he wants, where he is drawn to,**
- 3. the environment gets used to a child in a wheelchair at a time when the child is not yet thinking about why he/she cannot walk.**

It is important for parents to mobilize all their forces, be honest with themselves and the child, and decide to allow the child to be independent at the earliest possible age. Freedom of movement develops the child in many areas. It builds independence in the child. It enables the child to move independently among peers and thus develops not only his or her skill in controlling the wheelchair, but more importantly, to integrate socially among peers. He develops his communication skills, intellect. On this basis, it could be said that by ensuring physical mobility (i.e. the child can move independently in a barrier-free environment), we are also building the child's mental mobility (the child can communicate among his peers, can find a friend, can assert himself). And it is on this that their future existence, their success, their autonomy and identity and the possibility of an independent life is based.



Together with other authors (Brej, Gajdošová), we conclude that the role of the school psychologist in the multidisciplinary care of a child diagnosed with spina bifida and hydrocephalus is to emphasize the aspect of holistic development of his/her personality and to co-create a supportive social environment.

Drawing attention to the milestones of psychosocial development (a suitable underpinning theory may be the theory of psychosocial development according to E. H Erikson) and together with other members of the multidisciplinary team (especially parents and educators) look for ways to support the child in overcoming them. His/her expertise should also contribute to the understanding of the experiences and behaviour of the children or students involved and their parents/carers in the context of the children's developmental changes and needs, taking into account the specificities arising from the disability.

Based on these premise, we consider it essential that the school psychologist:

1. know the diagnosis and its specific manifestations
2. know the risks of secondary aggravation of the consequences of disability and strategies to prevent these risks;

3. be able to distinguish between what is a direct consequence of the diagnosis and what is a consequence of the wider context and the specific conditions of the environment in which the pupil live;
4. influence positive personal development - on the one hand, by building and supporting resilience ; on the other hand, in cooperation with all persons involved in the upbringing and education of the child, identify his/her positive abilities, personal qualities, skills, gifts, talents *[Gajdošová 2017]*.



WHAT A SCHOOL PSYCHOLOGIST SHOULD KNOW ABOUT SPINA BIFIDA AND HYDROCEPHALUS

Spina bifida is a disorder of the closure of the bony arch of the vertebrae (spina bifida), which results in bulging of the spinal cord and its envelope, with impaired 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 perform this operation in the prenatal period, which has significantly improved the prognosis for children with this diagnosis in the locomotor field. The presence of hydrocephalus in a child also requires surgical intervention: a valve is inserted into the cerebral ventricle to regulate the amount of liquor - cerebrospinal fluid - or the bottom of the cerebral ventricle is perforated laparoscopically to allow the liquor to drain out. Less commonly, surgery is indicated for Arnold-Chiari malformation II (adapted from Understanding Spina Bifida).



The above interventions compensate to some extent for the consequences of malformations. However, this is a lifelong diagnosis, the care of several specialists is necessary, especially several specialist doctors. 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 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.

We have briefly summarized this information to give the practitioner an idea of how the early experience of a child with this diagnosis differs from the early experience of healthy infants and toddlers. This is a developmental period during which the quality of the primary relationship forms a relational pattern that predetermines how the child will relate to other people in challenging life situations. The school psychologist does not yet act as a member of the team at this stage of development, but we mention this as a cue for anamnestic inquiry. It is the psychologist's responsibility to take the information obtained into account when planning interventions.

In the context of the work of the school psychologist, it is necessary to pay attention to the possible specifics in the field of cognitive and executive functions in pupils with spina bifida and hydrocephalus, which affect the learning process. Their knowledge should help to improve the quality of psychological diagnosis and the understanding of what obstacles the pupil has in achieving his/her educational goals. It should be kept in mind that it is this specific cognitive profile that may externally appear as a lack of motivation in the pupil, or a lack of self-discipline (Fletcher, Brei 2010). How dealing with barriers to learning impacts on the child's experience is also an important topic. These include experiencing success or failure, experiencing the relationship with the teacher, teaching or personal assistant and last but not least experiencing peer relationships.

SPECIFIC FEATURES OF PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS

In *Understanding Spina Bifida - a handbook about spina bifida and hydrocephalus* (2019), the authors describe the following areas that may or may not be affected by a diagnosis of spina bifida and hydrocephalus. The source of these difficulties is the changes to the brain caused by hydrocephalus but also different early childhood experiences (e.g. differences in physical play, gaining social experiences). Frequent absences, surgeries, or associated seizures are also a challenge. The deficits listed below are common in children diagnosed with spina bifida and hydrocephalus. However, it is important to remember that each child is unique and requires a good psychological assessment, especially of the level of specific cognitive functions. The results of these examinations then need to be taken into account when interpreting the overall result of a comprehensive intelligence test.

In the spotlight	
Weakening of attentional selectivity, i.e. the ability to focus on the important information and ignore the parts that are not relevant to the task at hand.	The pupil's attention is overwhelmed by a lot of stimuli, he cannot independently determine their priority, he needs to be guided.
Impairment in the ability to keep attention focused on the task at hand.	The pupil is easily distracted, e.g. changes the topic of conversation at a moment's notice. He pays attention to what he is currently interested in.
Weakening of the ability to shift attention	It can take a child longer to withdraw attention from what he or she is currently preoccupied with and move it onto something else.
In the area of language	
Impaired understanding of abstract concepts	The pupil has difficulty in understanding abstract words, thoughts that cannot be directly seen or experienced.
Difficulties in linking information	In the course of a longer conversation or when reading a text, the child does not notice the connections.
Difficulties in understanding the content "between the lines".	The pupil has difficulty understanding ambiguous and only hinted information, impaired ability to draw conclusions.
Difficulties in processing verbally delivered information	These difficulties are directly related to understanding concepts, following instructions, understanding the text. For example, a child can learn and remember facts well but has difficulty in applying them and solving new problems.

In the field of visuoperception and spatial perception	
Recognition, integration and memory of visual stimulation	The child has difficulties with orientation, especially in a new space.
Understanding and visualising the positions of objects in space and in relation to each other	The student has difficulties in subjects that require spatial perception - mathematics, geometry, geography.
Difficulty in eye-hand coordination	
In the field of memory	
Working memory	Difficulty in holding information in short-term memory, remembering instructions, remembering the sequence of steps in a procedure (routine).
Spontaneous equipping yourself with information	The risk is isolated memorization without context.
Weakening of planning memory	Difficulty in remembering what to do - to go for a scheduled check-up or to take medication at a given time.
In the area of executive functions	
Planning and organisation	The pupil has difficulties in the implementation in the implementation of a complex project, the performance of tasks often postpones, mainly because he does not know how to start. He needs support in breaking down the task into concrete steps. May have difficulty understanding what the task is about.
Commencement of the task	
Independent work	
Completion of the task	
Monitoring the story	
In the area of psychomotor tempo	
Slower psychomotor pace	The pupil has difficulty writing papers, taking notes and completing work assignments.

Given the plasticity of the brain and the uniqueness of each child, care should be taken to look out for the so-called masked cognitive profile *[Brei 2021]*. Children with spina bifida and hydrocephalus often have good verbal abilities that mask difficulties in comprehension. The pupil may appear to be distracted, hyperactive, but in reality the restlessness in the child is due to a weakening in comprehension and an inability to adapt to a new situation. Difficulties in executive and organizational skills may look like laziness. Pupils often fail to verbalize this problem, thus taking on the role of 'lazy', 'messy', which affects his/her self-image and self-esteem. Clumsy to rude behaviour may reflect deficits in social skills. Pupils focus more on what is being said than on context or non-verbal cues; social interaction requires quick assessment of the situation and problem-solving skills, which can be very challenging for them.

RISKS OF SECONDARY AGGRAVATION OF THE CONSEQUENCES OF DISABILITY

We consider the area of the secondary deepening of the effects of disability to be one of the key themes in the work of the school psychologist. While a child is born with a diagnosis of spina bifida and hydrocephalus and, in terms of disability, the condition can largely be merely stabilized and maintained, the psychosocial development of a child with this diagnosis appears to be variable and influenced by the social environment in which the child grows up (*Holmeck et al. 2002; Friedman et al. 2004, Galambos et al. 2008 and others*). In other words, how a child or young person perceives himself, his worth, his competence and his potential depends on the attitude of the people around the child. Whether he or she will grow into a person:

1. autonomous, aware of their own worth, their ability to contribute to the common good despite the adversity of a disability, or such,
2. who lives his or her life from the perspective of a victim and whose interactions with the outside world in adulthood are determined by feelings of inferiority and demands for help from those around him or her.

The following characteristics of adolescents and young adults with diagnoses of spina bifida and hydrocephalus, as identified through studies compared to peers without disabilities, are reported in the literature (*Brei 2021*). Findings on young adults state:

- They are more dependent on their parents
- Show less intrinsic motivation in learning
- Demonstrate less independence in the home environment
- They are less involved in household chores and experience less consistency from parents
- They participate in comparatively fewer activities with their peers, while at the same time these activities do not provide many opportunities for interaction (cinema, watching TV)
- They are less mature in decision making, indicating generally higher parental involvement in most decisions
- Older age is associated with an increased risk of depression and anxiety in people with these diagnoses.

In this context, the nursery, primary and secondary school environment is a crucial part of how a child or young person perceives themselves and their diagnosis. Experiences of interactions with peers and adult authority figures leave a significant imprint on a pupil's psyche (*Vagnerová 2005*), so we consider it important that professional or educational staff are aware of this influence (*Gajdošová 2017*) and reflect on their interactions towards a pupil with a disability with this in mind.

The following attitudes and attitudes, often present (also) in the school environment, contribute to the secondary aggravation of disability. Several of these have in common that they view the disabled pupil primarily as a patient, not as a pupil with potential:

- **Overlooking, ignoring, denying, or conversely overestimating differences in cognitive processes and executive functions (Fletcher, Brei 2010).** The pupil is judged as lazy, dreamy, unmotivated, disorganized ("He has extra if he tried."). Primary disturbances in cognitive and executive processes result in negative evaluative statements towards the pupil's person, possibly interpreted as mental retardation. Negative evaluations by the adult towards the pupil have a major impact on the pupil's self-concept (Landreth 2012) and also model the behaviour of peers, thus increasing the risk of ostracising the pupil.

The other side of the coin is an approach that focuses on correcting these deficits without taking into account the possibility of compensation. Instead of compensatory aids, professionals' efforts will focus on training in the deficit areas. This can, of course, produce results over time, but it can be counterproductive in terms of overall personality development if the pupil is confronted only with his or her deficiencies in the context of special education and psychological care, without identifying and, above all, developing the pupils's strengths.

- **The natural developmental needs of a pupil with a disability are not given importance. Alternatively, other values prevail in the priority ranking.** Necessary to mention for example:
 - the need to extend social interactions beyond the family, separation from primary caregivers (late integration into the kindergarten team; situations where the parent is in the position of pedagogical or personal assistant also in the kindergarten environment);
 - the need for play and ordinary experiences. The pupil undergoes rehabilitation and therapy, but little attention is paid to how to enable a child with a motor deficit to play the way he or she wants to play, or how to provide the pupils with ordinary childhood experiences;
 - the need for peer relationships during schooling. Child is excluded from school events due to physical barriers, have fewer opportunities for informal gatherings, etc. A typical example of an inappropriate approach is the provision of supportive stimulation exercises during 'educational' lessons, when the pupil has the opportunity to interact more with his/her classmates and at the same time develop those areas in which he/she can excel;
 - the need to be involved in making decisions and influencing things that affect the pupil or young person;
 - the need for an open future - people around the pupil do not have (or have distorted) information about what life is like for people with spina bifida and hydrocephalus in adulthood. Therefore, topics about the future, job opportunities, and the possibility of starting a family are often avoided, discouraged, or outright stopped by conversations about the dreams and aspirations of a child or young person with these diagnoses.

- **Protecting and proactively helping the child** (in the sense of doing things for the child) may at first glance appear to be an exemplary acceptance of a child with a disability. However, the pitfall of this approach is that the pupil is placed in the position of a helpless victim who needs to be cared for and does not develop the skills and competences needed to overcome obstacles. Development, progress, happens through challenges and in response to those challenges. If a pupil is not confronted with obstacles, he or she does not discover new possibilities (*Brei 2021*). It is appropriate and desirable to expose the pupil to obstacles that he or she is capable of mastering, to accompany him or her in overcoming them and finding his or her own solutions. This leads both to the development of the necessary skills and to the building of self-esteem, awareness of one's own competence, resilience and autonomy.

On autonomy in accordance with *T. J. Brei (2021)*, we think of autonomy as the ability to consciously influence one's life, make decisions, and take responsibility for what happens in our lives. Even a person with a spinal impairment can do this despite remaining dependent on assistance in certain areas. It is also important to note that the development of autonomy and participation can be encouraged at any age and can be worked on by any adult who has been in regular contact with a child or young person with a disability for at least some time.

- A specific risk for vulnerable pupils is **social exclusion - ostracisation**, which can lead to bullying.



The role of the school psychologist is to prevent these risk influences, especially at school. If they do occur, he or she should be the one to recognise these risks, name them and, in cooperation with other stakeholders, take steps to correct them. His action should be directed towards the teaching and other professional staff, the child's class, the pupil's parents and, of course, the pupil himself/herself. It should be stressed that much more can be influenced by preventive action than just solving the problems that arise.

PRACTICAL TIPS FOR PREVENTING THE SECONDARY EFFECTS OF DISABILITY

a) Recommendations for cooperation with pedagogical, professional staff and school management:

- Educate teaching and other professional staff about the diagnosis of spina bifida and hydrocephalus. It is important to pass on information about differences in learning due to developmental malformations of the brain. About how these manifestations can be 'masked'.
- Together with the school management, look for opportunities to train teaching and professional staff in an inclusive, respectful approach.
- Provide not only informational but also emotional support to teachers. Appreciate even small steps in finding ways to reach your child. Encourage them to use supervision when needed. Communicate the need for supervision of teaching staff to management as an important part of effective pupil's inclusion.
- Organise a meeting around the pupil, inviting people involved in the pupil's care from both the school and out-of-school environment, so that together you can look for ways to support the pupil, have a clear definition of your role towards the pupil, and at the same time prevent a one-sided view of the pupil.
- In cooperation with teachers and parents, guide the pupil to the fact that he/she has the opportunity to influence what is happening around him/her, that he/she has the opportunity to participate in decisions that affect him/her. For example, in the context of interventions, invite the pupil to express his/her attitude towards the activities offered, to have the opportunity to reflect on his/her experience. Accept and encourage the child to express his/her own opinion.
- Seek opportunities with teachers and parents for the pupil's participation in all school activities.
- Identify appropriate strategies to build and support autonomy as a key competence for the pupil's future. And this for each role in which the child functions (pupil, child, friend). What can we do for the pupil's autonomy in a given matter that would help him/her to manage the matter without the help and support of parents?

b) Recommendations aimed at psychological and special-educational diagnostics:

- Implement and initiate a high quality psychological assessment with regard to deficits in sub-cognitive and executive functions. Interpret the results of a comprehensive intelligence test in the context of these findings .
- Regularly screen for qualities of attention that tend to mask themselves as difficulties in motivation or behaviour.
- Set aside time for a detailed anamnestic interview with the parent. Pay attention to early

relational experiences between the primary person and the child and to milestones in the child's psychosocial development. Erikson's theory of psychosocial development may be an appropriate theoretical framework. Try to integrate the information obtained from the history, from the interaction with the child, and formulate - communicate back to the parent hypotheses about the child's current psychological needs.

c) Recommendations for cooperation with parents:

- Promote effective parenting skills aimed at developing independence, skills, decision-making, participation.
- With respect to the age and cognitive capacity of the pupil, encourage the shifting of responsibility for self-management (self-care, catheterisation, skin checking) from the parents to the pupil. Seek, with the parents, aids that allow the parents to gradually 'move away' from the pupil.
- Look for age-appropriate opportunities to involve the pupil in the running of the household together with the parents. Encourage parents to allow the pupil to participate in family matters to help broaden the repertoire of experiences needed for independent living. For example: entrusting and consistently requiring the completion of appropriate household chores (this may require some adaptation of the environment, tools), involving the pupil in the planning and implementation of a major purchase, for older pupils it is appropriate to allow them to be part of the process e.g. buying a new car, opening a bank account, etc.

d) Recommendations for individual work with the child

- Offer your pupil a good quality, safe and supportive relationship, ideally as soon as possible after they arrive at school. ***Don't wait for difficulties to arise, be preventative;***
- Get to know the pupil. Identify resources based on his strengths and support his resilience. Do not limit your action to stimulating deficit abilities;
- Talk to your pupil at regular intervals about how he integrates information about his diagnosis, how he thinks about it;
- As part of individual interventions, carry out regular screening for the development of depressive and anxiety symptoms (at least once a year);
- Focus on social skills training where appropriate.

e) Recommendations for working with the class team:

- On a regular basis and in cooperation with the class teacher, carry out sociometry, activities to strengthen peer relationships, discussions on the topic of disability in the classroom. Use education suitably complemented by experiential techniques. Pupils have many questions. Understanding differences can bring a lessening of tensions and a greater willingness to cooperate.

Identify problematic relationships, work on an individual basis with pupils who define themselves negatively towards a pupil with a disability. Look for the roots of such behaviour. Aggression and negativity is often a cry for help at school age.

Inspirations for working with classroom teams:

<https://www.nonviolentcommunication.com/product/the-no-fault-classroom/>

<https://www.pacer.org/bullying/classroom/elementary/ele-quick-guides.asp>



IMPLICATIONS OF THE DIAGNOSIS VERSUS THE WIDER CONTEXT OF THE PUPIL WITH DISABILITY

Brei (2021) highlights the following based on the research conducted:

- The level of self-esteem of a young person with spina bifida and hydrocephalus correlates more with beliefs, attitudes, family satisfaction and cohesion than with health status;
- Hyperprotective parenting is linked to lower child resolve and lower self-esteem;
- Appreciative and responsive parenting (taking into account the child's emotional and developmental needs) is also linked to high expectations of the child, developed coping strategies, higher self-esteem and functional skills.

In light of these findings, it is necessary for the school psychologist to be able to distinguish between the direct effects of the diagnosis on the pupil's behaviour and the effects of the pupil's educational environment. This requires knowledge of the pupil as well as the pupils's family history, with emphasis on the parents' predominant parenting style, approach to current experiences.

Distinguishing these impacts is essential for planning interventions:

1. **For the primary consequences of the diagnosis**, interventions focus on compensating for or removing barriers (e.g., use of visual planning aids to compensate for impaired executive abilities, social skills training).
2. **In the case of secondary consequences** to create opportunities for corrective experiences (promoting resilience, self-confidence, involvement in decision-making, making demands on the pupil, accompanying the pupil in overcoming obstacles). Here it is important to remember that even one supportive relationship with an adult can be crucial for a pupil in the process of shaping his or her personality.

PROMOTING POSITIVE PERSONAL DEVELOPMENT IN PUPILS WITH SPINA BIFIDA AND HYDROCEPHALUS

The school psychologist's last but not least role, which we emphasize in this manual, is to promote positive personal development in pupil with spina bifida and hydrocephalus. We have mentioned some practical tips in the previous sections, but we consider this topic so important that we want to devote a separate space to it. At the same time, we want to summarise in it the more or less indicated information about the preferred approach to pupil with disabilities. The presence of any disability is a lifelong challenge for the pupil and his/her family. Periods of relative calm and adaptation to life with this diagnosis are interspersed with more challenging, crisis periods. This is a fact and experience of many families and people diagnosed with spina bifida and hydrocephalus themselves. For this reason, it is necessary for the school psychologist to give targeted attention to building and promoting resilience - that is, resilience to stress.

It is defined in the current understanding of the bio-psycho-social, i.e. holistic approach, as the capacity of a person to endure or recover from a complex problem that threatens his or her stability, viability, or development (*Sapienza, Masten 2011, s. 268 IN: Orosova 2017*).

According to *Bernard (1991)*, the **profile of a resilient child** consists of:

- Social competence (flexibility, empathy, caring, communication skills, sense of humour, ability to develop positive relationships with adults and peers, facilitating good connections with family, school, community).
- Problem-solving competence (ability to find alternative solutions to cognitive and social problems, planning and appropriate level of self-control, resourcefulness in seeking help from others).
- Autonomy (sense of one's own identity, ability to act independently, exercise some control over environmental conditions, ability to separate in some way from dysfunctional family).
- A sense of the future and of goal-oriented behaviour (having goals, aspirations, hope, perseverance).

In his work *Fostering Resiliency in Kids: Protective Factors in the Family, School and Community*, he identifies three areas that promote resiliency in pupils:

- Care and support.
- High expectations and demands.
- Allowing the pupil to participate in what is happening around him/her and giving him/her age-appropriate responsibilities.

If we want to support the resilience of a pupil with a disability, we cannot just focus on his/her deficits. We can only have high expectations of the pupils, leaving him or her with age-appropriate responsibilities and at the same time expect positive results if we are aware of his or her capabilities, strengths and inner resources. If we equally name these strengths and encourage the pupil to develop them. Also, if we accept that the pupil will not perform some activities, tasks, assignments "normally" but is allowed to find his own way to achieve results. This builds the consciousness of one's own competence and ability to cope even in difficult life situations in a way that is specific to that person.

One of the characteristics of an inclusive school according to the Inclusive Education Checklist is that educational priorities are set with the pupil's transfer between his/her schools in mind. In this context, we consider it crucial that the school psychologist, in collaboration with all those involved in the child's education, identifies the child's positive abilities, personality traits, skills, gifts, talents (*Gajdošová, Bisaki 2017*). *Drdulova (2022)* emphasizes to look for talents, not limits, in students with disabilities. It is this knowledge about the pupils that forms the basis of career counselling and has the potential to influence the child's quality of life now and in the future (*Gajdošová Bisaki 2017*).

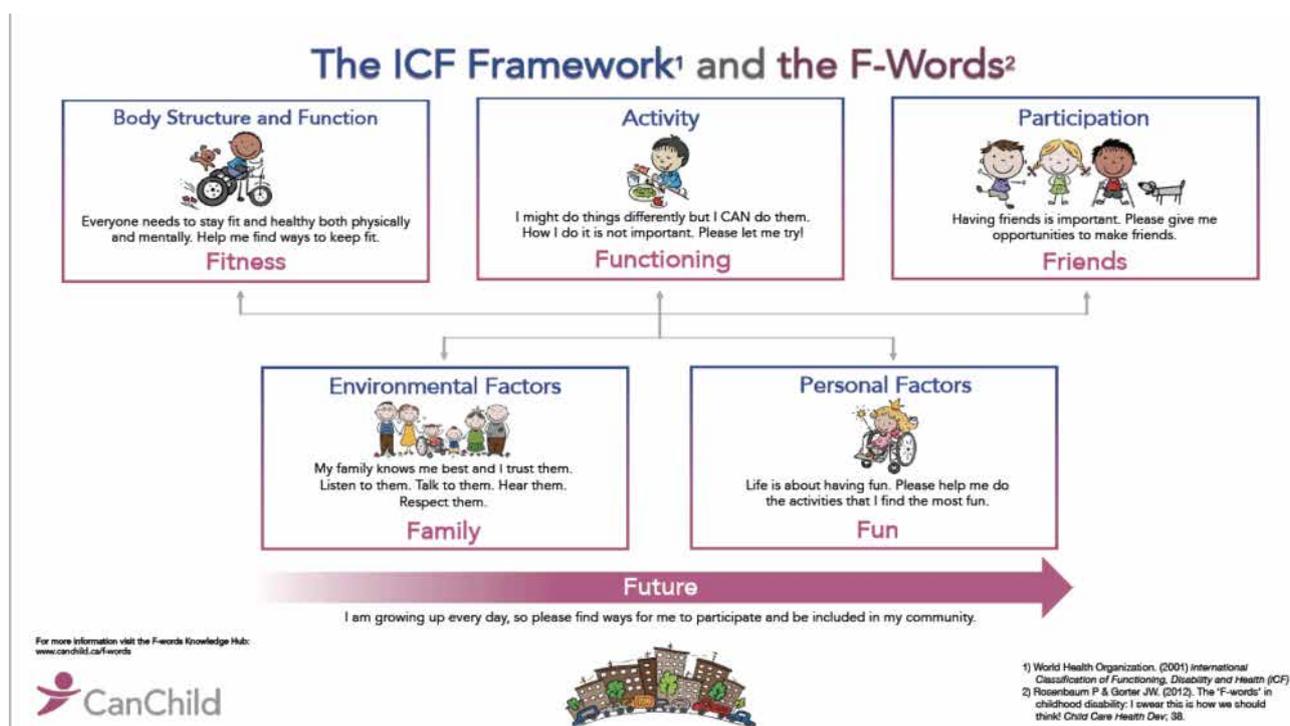


PRACTICAL TIPS TO SUPPORT POSITIVE PERSONAL DEVELOPMENT IN PUPIL WITH SPINA BIFIDA AND HYDROCEPHALUS

The concept of F-words, which describes 6 important aspects of a child's life (with and without functional limitations), can be very helpful in integrating a pupil diagnosed with spina bifida and hydrocephalus. The F-words concept is the result of the work of the Can Child Research Centre at McMaster University whose goal is to make a positive difference in the lives of children with disabilities.

This concept is a counterbalance to the prevailing deficit-oriented approach. It is based on the International Classification of Functioning Ability, Disability and Health, published by the World Health Organization in 2001 (*introduced in English in the manual by Orgonášová and Palát in 2004*). It offers a framework for how to communicate about a pupil's disability, as well as practical tools for use in the educational process, monitoring the pupil's adaptation and setting intervention goals. The scope of this manual does not allow for a detailed description of the possibilities offered by the F-words concept, but the reader is strongly encouraged to visit the website where he/she will find original professional articles, instructional videos as well as demonstrations of how the concept can be used in a school setting.

Figure: **Modified scheme of the international functional classification of disability and health, supplemented by the concept of F-words.**
Original available here: <https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability>



Another inspiring perspective is the concept of Carol Dweck, a psychologist at Stanford University, who studied how people cope with setbacks. She developed a theory of mind-set- Mindset- in which she identified the so-called **fixed mind-set** and the **growth-oriented mind-set**. Currently, this theory is very popular and provides practical ideas on how to communicate the topic of success/failure with pupil, how difficulties in achieving goals can be seen as opportunities for growth, how to manage the frustration of failure, how to support pupil intrinsic motivation, or how to recognize and develop pupil's hidden talents. This theory is reflected in the practice of other professionals who develop it and bring it to the general public in the form of courses or practical tools for working with pupils. We list some of them that we have personal experience with in our work:

<https://biglifejournal.com/>



TOOLS TO ENCOURAGE REFLECTION, POSITIVE PERCEPTION OF SUCCESSES AND FAILURES, DEVELOPING EMOTIONAL INTELLIGENCE, RESILIENCE AND SELF-ESTEEM

<https://biglifejournal.com/collections/journals>

Especially for the work of a psychologist, the following tools may be useful:

<https://biglifejournal.com/collections/journals/products/conversation-cards>

<https://biglifejournal.com/collections/printables/products/growth-mindset-challenges-resilience-bundle>

<https://biglifejournal.com/collections/printables/products/self-esteem-printables-kit>

We recommend to browse the whole site to find what the pupil in your care needs right now and also to choose an age-appropriate activity.

Suggestions for classroom work using the Big Life Journal

<https://biglifejournal.com/collections/teaching-guides/products/lesson-plans-big-life-journal>

This link also contains a sample lesson using the Big Life Journal.

Guidelines about the diagnoses spina bifida and hydrocephalus:

<https://www.spinabifidaassociation.org/resource/guidelinespdffull/>

<https://hollandbloorview.ca/sites/default/files/2019-03/Understanding%20Spina%20Bifida.pdf>

Promoting the development of life skills in children and young people with disabilities

<https://hollandbloorview.ca/sites/default/files/2022-03/LifeSkillsGuide-2022.pdf>

Inclusive education

<https://www.welcome-idea.eu/#/home>

https://www.ph-noe.ac.at/fileadmin/root_phnoe/Forschung/Migration/Index_curriculum_pages.pdf

<https://rideproject.eu/>

<https://rideproject.eu/media/practice-resources-en.pdf>

<http://worldofinclusion.com/>

<https://www.wearelumos.org/resources/inclusive-education-unit-evaluation-report/>

Best interests of the child and child protection

<https://www.wearelumos.org/resources/>

<https://www.wearelumos.org/resources/ensuring-access-treatment-children-hydro/>

https://lumos.contentfiles.net/media/assets/file/Nobody_Allowed_Harm_You_BG_-_edit2.pdf?

<https://www.wearelumos.org/resources/empowering-children-and-young-people-disabilities-improve-responses/>

Bullying prevention

<https://anti-bullyingalliance.org.uk/>

<https://anti-bullyingalliance.org.uk/tools-information/free-cpd-online-training>

http://worldofinclusion.com/res/alleq/21223_Elliott.pdf

Our belief is that a pupil can benefit from any approach that does not reduce a pupils with disabilities to a set of deficits, does not try to fit them into developmental tables, but perceives their uniqueness, potential, looks for ways to fulfill them, and at the same time perceives a pupil with disabilities as a person of value and capable of being an asset to their environment.

COOPERATION AND SUPPORT OF THE SCHOOL PSYCHOLOGIST IN A MULTIDISCIPLINARY TEAM

"The advantage of an expert - a school psychologist - is that he or she works directly in the school, is present there every day, knows the school, its system and sub-systems well, knows the teachers, the teaching staff, the school management, the pupils, the classes, even the parents of many pupils, knows the process of education in the school, that is, knows the school from the inside, so that he or she can contribute much more significantly to creating a supportive, healthy, safe and positive school environment for individuals and teams." *[Gajdošová 2017 s.11]*

If she knows the specifics of the development of pupil with spina bifida and hydrocephalus, she can influence and participate a lot in improving the quality of the inclusive atmosphere in school. In the last section of this manual, we therefore discuss the intersections of collaboration with other members of the multidisciplinary care team.

The school psychologist works closely:

With the **special teacher** in diagnosing the pupils's current needs with regard to age, current experience, current adaptation in the school environment, also with regard to specific challenges related to his/her health condition (e.g. prolonged absence from school, etc.).

With **teachers** and **teaching assistant** in the areas of:

- with the class teacher in regular assessment of the social climate in the classroom;
- supportive communication and motivation of the pupil;
- modelling appropriate behaviour towards a pupil with a disability;
- appropriate handling of the topic of disability within the classroom team with regard to the understanding of other pupils;
- providing support not help in the sense of building autonomy not dependence on others;
- identifying strengths and their targeted systematic exploitation and promotion.

With the **management of the school** at:

- submitting proposals and suggestions for improving and streamlining the inclusive school environment as a system;
- designing and implementing subsystems such as:
 - a/ personal development of pupils,
 - b/ professional orientation and career choice of pupils,
 - c/ care for gifted and talented pupils,

d/ peer and marriage counselling and parenting education,
e/ professional growth and personal development of teachers,
f/ personal and social management and organisational development (according to Gajdošová, 2017).
g/ we are also adding a sub-system of development and vision for the care and support of pupils with disabilities;

- developing a school-based bullying prevention strategy.

With **parents**:

- in assessing the child's current needs with regard to holistic development;
- provides them with advice and support in the area of child personality development, but also in the area of taking care of their own mental health;

With a **nurse** co-participating in the care of the pupils:

- in the area of supporting the pupil's autonomy in health self-management (where appropriate).

CONCLUSION



It is evident that the professionals view on the pupils with disability is primarily dominated by the pupil's deficits, shortcomings, and limits. It is rarer to encounter a professional who, almost from the beginning of their interaction with a pupil, focuses on uncovering the strengths of a pupil or young person with a disability, strengthening his or her abilities and resilience. A number of children, young people with spina bifida and hydrocephalus testify to such unpleasant experiences. Many parents name an important point - their child verbalises that this approach affects them and sees it as an injustice that they cannot cope with.

It is our hope that this manual can help professionals to view pupils with disability as having the same rights as any other pupil. To see the pupil first and foremost as a pupil who needs the same stimulation, experiences and interactions, so that from an early age his or her environment encourages the pupil's active participation in all areas of life. Thanks to a wealth of research, proven knowledge and technology, supporting pupils with more than just spina bifida and hydrocephalus should be commonplace today. We would very much like this to be the reality for the majority of children who are born not only with spina bifida and hydrocephalus, but with any more or less visible disability or impairment.

Many of the recommendations in this manual are applicable regardless of the presence of a disability. Therefore, we believe that the manual has the potential to shape the school psychologist's view of any pupil in his or her care and to promote positive development.

"An important responsibility of school psychologists is to achieve this, that teachers, school systems are aware of the significant potential of their assistance."

Liebenberg

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MANUAL

for school psychologists on multidisciplinary care
and inclusive education of pupils with spina bifida and hydrocephalus

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