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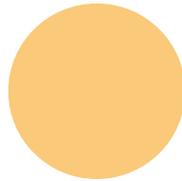
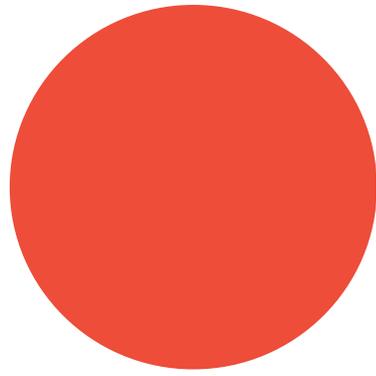
for school leaders

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



Developed in partnership between:
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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 schools and kindergartens, developed under the Multi-IN project. The General Guidelines, together with the complementary Manuals and Educational video courses, aim to support the multidisciplinary efforts of professionals and family towards inclusive education of children with spina bifida and with hydrocephalus.

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The full set is available on
www.multi-in.eu

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

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 principals in kindergartens and schools in every country based on local legislation. First, you should follow your local legislation and then the Manual's recommendations.

CONTENT



INTRODUCTION	2
THE ROLE OF THE LEADERS IN THE SUPPORT OF INCLUSIVE EDUCATION	3
WHAT THE PRINCIPAL SHOULD KNOW ABOUT STUDENTS WITH SPINA BIFIDA AND HYDROCEPHALUS?	5
THE ROLE OF THE PRINCIPAL IN THE MULTIDISCIPLINARY SUPPORT TEAM. PRACTICAL ADVICE.	8
RECOMMENDATIONS FOR PROMOTING INCLUSIVE PHILOSOPHY.	8
RECOMMENDATIONS FOR CREATING A POSITIVE ENVIRONMENT AND A FAVORABLE CLIMATE FOR COOPERATION	11
RECOMMENDATIONS FOR CREATING A SAFE AND ACCESSIBLE SCHOOL ENVIRONMENT	15
CONCLUSION	21
APPENDIX 1: BELIEFS OF PROFESSIONALS ABOUT PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS	22
REFERENCES	23

INTRODUCTION



The manual for kindergarten and school principals is part of the set of training materials created under the Multi-IN project to help the multidisciplinary care and inclusive education of pupils with spina bifida and hydrocephalus. It is intended to help the leaders of inclusive childcare centers and schools in their efforts for providing quality education, ensuring a supportive environment, and helping children with disabilities take part in the school life on an equal basis and together with their peers.

This paper provides an overview of the spina bifida and hydrocephalus conditions and the effects they may have on pupils. Along with that, the manual reviews the role of the principals in the inclusion process and in the multidisciplinary support team and gives practical recommendations on how to achieve a safe and accessible school environment, how to promote an inclusive philosophy, and create a positive and supportive climate for collaboration between the team members.

Authors' note: In this manual, the terms "principals" and "other employees responsible for the activities in a school or a kindergarten" are considered the same. This also applies to other school administrators and leaders such as vice-principals, head teachers, etc.



THE ROLE OF THE LEADERS IN THE SUPPORT OF INCLUSIVE EDUCATION



In their work, principals take on the important responsibility of leading schools and childcare centers in a way that allows all students, including the students with disabilities, to achieve the educational standards set out in the curriculum. Indeed, the latter group of students brings more challenges, but without a doubt, when success is achieved, the sense of satisfaction that comes with it is huge. Despite the fact that the responsibilities of the principals are part of their professional duties, in many cases, the quality of the support depends to a large extent on the degree of understanding and the attitude towards people with disabilities, the inclusive culture, and the inclusive education.



Our initial hypothesis is that **disability greatly affects an individual's life, but does not primarily determine who they are and, in the case of a child, 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). Encouragement, positive attitude, understanding, and support from others form the best environment and stimulate the development of children and young people with disabilities, including in regard to education. This approach brings to the forefront things like primary prevention and avoidance of risks, identification of positive abilities, qualities, skills, gifts, and talents of the students. The focus is on the child with his or her specific characteristics and needs, some of which may be the result of the disability, rather than focusing on the diagnosis, the disorder, or the child's deficits.

The United Nations Convention on the Rights of Persons with Disabilities is another important starting point for all educational professionals who work with children with disabilities. The Convention pays special attention to the need to uphold the right to education of people with disabilities at all levels of the educational system. According to Article 24, dealing with education, the education should be 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."

CRPD Art. 24(1)

Following the positive model and the principles set out in the United Nations Convention on the Rights of Persons with Disabilities, we can clearly outline the primary role of the principal in supporting the inclusion of children with spina bifida and hydrocephalus, namely providing a safe, positive and accessible school environment, promoting an inclusive philosophy and attitude among all members of his or her team, and creating favorable conditions for cooperation aimed at providing the child with the best support so that the child can achieve his/her goals and develop his/her personality within the educational system.

With this manual, we hope to help the leaders of schools and childcare centers in fulfilling their role in the best possible way within the current educational system, and give answers to some basic questions they are likely to have when they encounter a student with spina bifida and hydrocephalus:

1. How can the principal help in the implementation of the rights of children with spina bifida and hydrocephalus?
2. How can the principal meet the current needs of children and young people with spina bifida and hydrocephalus?
3. How can the principal support the positive development of children and young people with spina bifida and hydrocephalus?



WHAT THE PRINCIPAL SHOULD KNOW ABOUT STUDENTS WITH SPINA BIFIDA AND HYDROCEPHALUS?



Spina bifida is a rare congenital abnormality, so the principal is very likely to have no previous experience with a child with this diagnosis. Also, previous experience is not always an advantage, because being so different from one another, students with spina bifida may have very different needs, but their right to an inclusive education remains the same.



Administrative leaders usually have no pedagogical interaction with the student, do not provide direct care as the assistant or the nurse do, and direct contact is rather limited. However, their leadership creates the environment in which the child functions daily and is no less important for the child's development. **One of the things that are important when it comes to identifying barriers and developing strategies to overcome them is to know the needs and the specific condition of the child.**

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 - coil catheterisation - is necessary. Due to reduced or completely absent sensitivity, preventive care and skin care is essential.

From Multi-IN MANUAL for school psychologists on multidisciplinary care and inclusive education of pupils with spina bifida and hydrocephalus

To get around, many of the children use a different combination of aids, including handrim-drive or electric wheelchairs, crutches, walkers, splints, or walking sticks. Even those who move independently tend to get tired quickly and often have problems with coordination and balance. More detailed information on the health needs can be found in the Multi-IN manual for nurses and in our other manuals.

Children with spina bifida have various cognitive difficulties both because of the common brain abnormalities in this group of patients and because of the differences in early childhood experiences of these children compared to their peers (physical play, social experience, frequent absences, and hospitalizations). The Multi-IN manual for school psychologists describes in detail the aspects that could be impaired due to spina bifida and hydrocephalus, including attention, memory, speech, spatial visual perception, executive function, and psychomotor abilities. However, it is important to keep in mind that each child is unique and an appropriate psychological assessment of the child's cognitive functions should be performed. Often, these specific characteristics remain hidden behind the mask of sluggishness, laziness, or absent-mindedness, but in fact, these are cognitive needs that can be met with the help of specialists in the educational system.

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.

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From what has been described so far, it is clear that spina bifida is a complex condition that has many variations, some of which are determined by the diagnosis itself while others are due to interactions with the environment and interpersonal relationships or lack thereof. Professionals often describe this as “the Snowflake Phenomenon” because snowflakes are seemingly the same, but in fact, are so different from one another. No two children are affected in the same way by this diagnosis. There are always differences, peculiarities, and nuances. The above also applies to the diagnosis of hydrocephalus, which also may have different manifestations. Therefore, the support that students with spina bifida and hydrocephalus need in order to overcome the barriers in their education is different for each student. Providing an accessible and safe built environment, special pedagogical support in case of learning difficulties, support for social inclusion with the other children in the class, and help with the intermittent catheterization - the full range of support can be wider or narrower, according to the current needs of the child.

The combination of medical terminology and listing of possible complications and difficulties, lack of preparation and experience with students with disabilities often create an unrealistic image of children with spina bifida. You can study the child's history, review the basic documents or talk to the parents, but above all, you have to meet the child in person and get to know his or her personality.

THE ROLE OF THE PRINCIPAL IN THE MULTIDISCIPLINARY SUPPORT TEAM. PRACTICAL ADVICE



RECOMMENDATIONS FOR PROMOTING INCLUSIVE PHILOSOPHY

According to UNESCO (2008), "Implementing a rights-based approach to education, with a view to moving towards greater inclusion, will require a comprehensive reform of education, including adjustments to constitutional guarantees and attitudes, curricula, teacher training systems, materials, learning environment, methodology, resource allocation, etc. Above all, however, it will require a change in the attitude of all people in the system so that they enjoy diversity and difference and perceive them as an opportunity rather than a problem" (p. 29).



The need to emphasize the inclusive philosophy and focus on the students with disabilities as part of a shared vision for the future development of the educational institution is the common topic of all studies dealing with inclusive education. Many studies emphasize the leadership role of the principal in the successful implementation of inclusiveness as a core school value (Fisher et al., 2000; Guzman, 1997; Hoppey & McLeskey, 2013; Mayrowetz & Weinstein, 1999; Salisbury, 2006, etc.).

In practice, the concept of inclusive education is often perceived in an imprecise or different way by the different stakeholders in the educational process. An important task of the principal is to provide a clear definition and guidance to all of the people involved - teachers, parents, and students. Full understanding and acceptance of this concept by everyone involved in the educational institution is a fundamental step and a precondition without which management would hardly be able to create teams or work to provide access and a positive environment. Therefore, to achieve real change, the principal must first ensure that all stakeholders understand and practice inclusiveness in the same way.

The implementation of inclusive models requires targeted and planned work. **You need to introduce both a long-term and a short-term plan for inclusive education** that include resourcing, specific activities, roles, and areas of staff development. The plan should be developed, discussed, and accepted by the entire team so that everyone is aware in advance of the direction of development and the expected challenges and changes. Principals must set high goals, but they should also admit that change takes resources and time. Above all, they must address the mindsets that continue to segregate and stigmatize students with disabilities.

Start discussions within the team about how everyone views the inclusive school/kindergarten. Be specific and include in these discussions an analysis of the school structures, cultures, and practices and provide guidance for identifying inequity and preparing strategies for counteraction. Encourage self-reflection and sharing of personal experience.

Make inclusive education the central focus of the plan for the professional development of the staff. **Organized thematic training courses aimed at increasing the competencies** of the pedagogical team are an excellent opportunity for theoretical preparation and familiarization with the inclusive philosophy. Along with this, parallel forms of learning such as group discussions, mentoring, coaching, experience exchange groups for teachers, and peer coaching for effective learning and practices are also appropriate (Deshler & Cornett, 2012; Desimone, 2009; Elmore, 2004).

Involve the school in **projects and programs aimed at inclusive education**. This will allow you to exchange experiences and get access to the good practices of other institutions. Use financial means to stimulate the initiative of individual teachers to participate in such projects together with their students.

Use formal occasions, speeches, documents, and interviews to **state how much you and your team value the inclusive philosophy**. Personal conversations do not have the same weight as an officially stated position. Fostering an inclusive vision in the community is essential for setting the direction of schools, and acts as a strong motivator for the teachers and the whole team (Leithwood et al., 2008).

Do not allow a high concentration of children who face barriers in their education in a single class/group. Even if it seems like a good solution in terms of resource allocation and provision of special services by qualified educators, this results in segregation and has a lasting negative effect on the inclusion process. Make sure **that all students, without any exception, participate in all class activities under the curriculum**, including physical education, and that they achieve their personal goals by following the general education plan. In order to ensure the student's full participation in school life, the best time to organize the work with the special educator is the class time.

Ensure the **participation of students with disabilities in all extracurricular activities and events** such as trips, concerts, celebrations, visits to exhibitions, etc. Parents can give valuable advice on organizing events and ensuring maximum safety for the students.

UNESCO and UNICEF (2007) warn that “**getting children to school is not enough**. It is not a guarantee that they will receive an education that will enable them to achieve their economic and social goals and to acquire skills, knowledge, values and attitudes that lead to responsible and active citizenship.” Several studies demonstrate that the quality of inclusive schools is largely determined by the high academic expectations they set for all students, including those with disabilities (Dyson et.al. 2004; Farrell et.al. 2007; Waldron et al., 2011). Make sure that everyone in your team embraces inclusive education in such a way and supports all students with disabilities, even those with moderate or more severe disabilities, in their efforts to meet the state educational standards for their grade level.

Provide **equal access to educational services and assessment of all children** by minimizing the impact the disability has on their academic performance with the help of specialized software, alternative forms of testing, longer testing time, providing homework via email, etc.

Pay **special attention to the social inclusion of children with disabilities**, including children with spina bifida and hydrocephalus. Due to their frequent hospitalizations and relatively limited social experience, these children often feel excluded from their peers at school. Principals are often focused primarily on the physical and academic aspects of the inclusion process, and the need for providing support to achieve social inclusion may remain unidentified. It is assumed that social inclusion will occur automatically in the inclusive school environment but, in practice, often the school team should purposefully plan the development of these relationships.

Support your **team in their effort to promote acceptance of children with disabilities** by taking particular actions within the class and countering negative comments about these children.

Part of the positive change is minimizing the categorization of children and **excluding from the vocabulary words such as** “children with special educational needs”, “invalid children”, “sick children”, etc.

The recommendations we provide in this manual are intended to shed light on some of the aspects of the inclusion of children with spina bifida and hydrocephalus and to improve the support that principals provide in overcoming the educational barriers faced by this group of students. Most of the problems reviewed here have been identified by parents and children in personal interviews conducted under the Multi-IN project. As the authors of this manual, we are fully aware that this manual cannot be used by itself as the main tool in such a large undertaking as the introduction and implementation of an inclusive philosophy in the educational institution is. We fully agree with the understanding that inclusive education is a never-ending process, with many opportunities for improvement, and we believe that it is never too late to push in this direction.

ic talents and abilities, children with special needs as well as education for children who may face exclusion due to their ethnicity, social class, gender, culture, religion, etc. In an inclusive educational system, all students learn alongside their peers in inclusive and accessible schools within the local communities, where they all receive the support they need, in a way that corresponds to the culture and values of the society, the adopted good practices and their personal preferences. We would like to ask all visionary principals to familiarize themselves with the Index for Inclusion, including the version that is specially adapted for schools and childcare centers, where they can find valuable practical tools for creating an inclusive culture, for developing inclusive policies, and for implementing inclusive practices.

Link to the Index for Inclusion:

<https://www.eenet.org.uk/resources/docs/Index%20English.pdf>

RECOMMENDATIONS FOR CREATING A POSITIVE ENVIRONMENT AND A FAVORABLE CLIMATE FOR COOPERATION



It is the authors of the above-cited Index for Inclusion who view inclusive education as a never-ending process that involves the participation of individuals, the creation of systems and environments, and the promotion of inclusive values. Inclusion implies increasing the participation of all concerned people and reducing all forms of exclusion and discrimination. It encourages listening to the voice of children, families, and the professionals in the schools and childcare centers and assigns equal value to all of them.

As a leader, the principal has the important task of not only promoting inclusive philosophy among the members of his or her team, but also creating a positive collaborative environment where everyone matters, everyone participates, and everyone is heard and accepted. This is not an easy task as it involves interaction with various stakeholders some of whom are not part of the school administration, such as parents, healthcare professionals, and assistants.

It is important that the principal provides not only opportunities for training and obtaining a qualification, but also real support at the workplace. Perhaps the most critical component of creating an inclusive environment is the work of the principals with teachers in order to ensure that they support inclusion and are motivated to develop and implement successful inclusive programs. Some teachers may not feel confident that their preparation or qualifications will allow them to meet the needs of students with disabilities and may resist their inclusion (Avrimidis & Norwich, 2002; Idol, 2006; Scruggs & Mastropieri, 1996). The most serious concerns shared by teachers relate to the nature and the severity of students' disabilities; the availability of classroom support (e.g. an assistant, teaching assistant, and special education teacher) and the commitment of the management to support the work of the team with the necessary time and resources. Make sure that every person in your team has been provided with the necessary information and that everyone receives the support needed for performing the work.

Attracting capable and effective educators is very important because teachers are “the best resource for maximizing student achievements” (Hitt & Tucker, 2016). Retaining these teachers is even more important, especially in the field of special education, where there is a persistent shortage of teachers (Billingsley, 2004). Research shows that **good working conditions directly affect the quality of teaching and teacher effectiveness and retention** (Hirsch et al. 2007; Johnson, Kraft and Papay, 2012).

According to the summaries in one of the studies (Bettini et.al 2016), the preconditions that the principals must provide to their teams are:

- School culture that promotes high expectations in regard to students and shares the responsibility for achieving them;
- Administrative and peer support aimed at providing opportunities for cooperation and exchange of experience with other qualified colleagues;
- Useful and appropriate work materials;
- Opportunities to work with students in a group environment;
- Sufficient work time;
- Time to plan the work and provide support to students.

Create the opportunity for regular meetings between the members of the support team by providing a convenient place and time that fits the schedule of all people taking part in the meetings. Some members such as the head teacher and the special education teacher may need more frequent work meetings so that they can distribute the teaching responsibilities between themselves. Others do not need to interact so often, but advance planning is always desirable.

Acknowledge not only the value, but also the expertise of the individual team members, including the assistant, the parents, and the student himself. Each of them has specific experience and knowledge on specific issues with which he or she can support and greatly facilitate the work of the other members. Encourage the exchange of experience and consultations among team members. The psychologist can provide helpful advice on how to overcome cognitive challenges; the parent can share training models that have been successful so far, and the nurse can advise on the purchase of ergonomic furniture as a means of preventing spinal distortions.

When **making decisions** related to inclusive schools, principals often **share their leadership** with a variety of stakeholders, including teachers and parents. Research shows that this is a good practice that yields positive results in regard to the development and maintenance of inclusive schools (Billingsley, 2004; Hoppey & McLeskey, 2013). The parents, who, with their experience and expertise, can support decisions in the schools and advocate for the development of inclusive programs at a higher level, play a very important role. We will discuss the collaboration with parents in more detail in "Recommendations for Creating a Safe and Accessible School Environment".

Search for opportunities **to include in some of the training courses those stakeholders who are not part of the administration of the school**. This will further promote collaboration and informal communication within the team. Make sure that **each team member has clear and realistic expectations regarding** everyone else's **roles and responsibilities**. If necessary, discuss this topic during regular meetings. Often these roles are defined by law or in the job description. Clear definition and transparency regarding powers and responsibilities will greatly reduce the risk of conflicts.

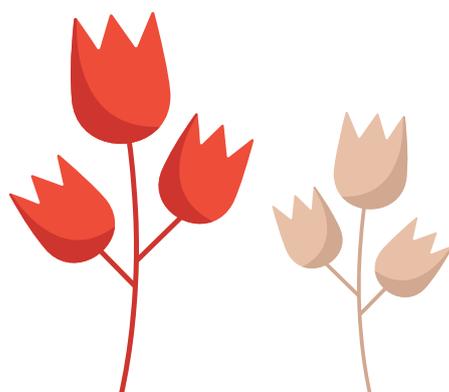


Establish **cooperation and respect** as the core principles for the work of the team.

Encourage educators to avoid punitive methods and reactive techniques in controlling student behavior. These have no proven long-term benefits in regard to discipline and behavior and often lead to labeling of children with disabilities (Lane, Cook, & Tankersley, 2013). **Encourage the promotion of positive behavior throughout the school.** Research shows that the successful implementation of this approach results in a number of benefits, including improved achievements and fewer disciplinary actions (Horner et al., 2009).

In their work to support the inclusion of students with disabilities, principals often have to manage tensions and conflicts at institutional, school, or even personal levels. The sources of conflict within the team can have their roots in misunderstandings regarding the distribution of roles, responsibilities, or resources, but most often conflicts arise due to differences in the understanding about students with disabilities and due to ignorance in regard to the principles of inclusion (Adams, 2008). As part of the General Guidelines for Multidisciplinary Care and Inclusion of Students with Spina Bifida and hydrocephalus, we have included a short list of **“Beliefs of Professionals about People with Spina bifida and Hydrocephalus”, which we think are important for members to consider and apply in their practice with this group of children.** This list is attached at the end of this document. Please, share this list with the members of the team providing support to a student with spina bifida and hydrocephalus and initiate a discussion on the individual points.

When conflict occurs within the team, principals usually find themselves placed in a situation with multiple stakeholders and are often considered the authority that must make the final decision. When making such decisions, **you should always be guided by what the best for the child is.**



RECOMMENDATIONS FOR CREATING A SAFE AND ACCESSIBLE SCHOOL ENVIRONMENT

According to the UN definition, accessibility means equal access to everyone, adding that without access to facilities and services in the community, persons with disabilities will never be fully socially included (UN, n.a.). The lack of an accessible environment is one of the main barriers to the education of children with spina bifida and hydrocephalus and one of the most serious challenges for principals in their efforts to implement inclusive models in their work.



Providing architectural accessibility, including elevators, ramps, adapted toilets on the floors, wide doors, and space to maneuver in the classroom is associated with serious financial investments. The sources of funding for public schools and kindergartens are largely limited, and the funds are pre-allocated according to the budget lines. Expenses related to improving accessibility are unplanned costs and may jeopardize the implementation of the annual budget. In addition, the construction of an elevator and the rest of the construction and repair works require the team to have specific knowledge and administrative capacity in order to prepare the project documentation and obtain the relevant permits. Financially and in terms of the school's priorities, providing an accessible environment can come into direct competition with other urgent needs such as a roof repair, a new gym, or replacement of windows. And choosing in favor of accessibility can become a source of conflict with other stakeholders - students, parents, teachers, hygienists, etc. A team that does not value inclusion may strongly resist any attempt to improve accessibility because of the concerns that the school will become a magnet for children with disabilities from the local area, worrying that they require more effort, time, and attention at work.

Providing a safe and accessible inclusive environment is a serious challenge even for the most experienced and motivated professionals. It is often too tempting to informally refer the child to a neighboring school or kindergarten that already has an elevator or an established team of specialists. Although sometimes they seem like the only possible choice, such decisions should be considered a measure of last resort as they discriminate against the child and also signal to the team and society about the values of the management, nullifying the efforts made so far in the direction of inclusion.

The educational system is not perfect and a significant part of the school and childcare centers do not provide a fully accessible environment. However, we believe that there is a solution and that every school and every kindergarten can become inclusive. We hope that in the lines below, principals will find useful ideas that will help them provide the best environment for all students, with a focus on children with spina bifida and hydrocephalus:

Depending on their particular motor deficiencies, **children with spina bifida and hydrocephalus need different architectural improvements**. Most often, these improvements come in the form of ramps, an elevator, handrails on stairs, a toilet for people with disabilities, removal of obstacles in the classroom, wide doors, and enough space to maneuver a wheelchair. They not only give the student physical access to the educational process but are also important for the independence, social inclusion, and personal development of the child. Be sure to talk to the child and the parents to determine what level of accessibility the child needs.



Providing an adapted toilet or a room for catheterizations is extremely important since a large number of patients with spina bifida are catheterized. In general, the catheterization room should be kept clean and should be wide enough to accommodate an adult assistant and provide enough space for the child to maneuver the wheelchair. The room should be lockable in order to ensure privacy and security. An adapted toilet, the healthcare office, or another room with plumbing can be used as a catheterization room.

In order to successfully implement a project related to the improvement of the architectural environment, **inclusion must be established as a shared value among all stakeholders** in the educational institution - pedagogical and non-pedagogical teams, parents, and students. This is an important condition, without which it will be extremely difficult to plan and implement any improvements related to accessibility or facilities that require funding. Misunderstanding and resistance can cause even the best ideas and projects to fail.

Do not wait until the need for an accessible environment arises to start working on providing it. It will be too late to take particular actions if you wait until there is a child in a wheelchair waiting at the doorstep. Large investments usually require time and planning. Start in advance, so that the school you manage can become accessible to everyone - students, teachers, parents with mobility disabilities, students with fractured legs, or parents with a baby in a stroller.

Be flexible when looking for alternatives to finance your projects. Do not limit to public sources like state or municipal programs. You can plan and organize long-term fundraising campaigns that include a wide range of activities such as rummage sale, cultural and sports events with the participation of students, fundraising for the cause using online donation platforms, etc.



You can get support from the parent council, local activist groups, local media, NGOs, teachers, and students active in civic engagement. When conducting such campaigns, it is important to address the rights of people with disabilities and emphasize the benefits of diversity and inclusion for all members of society. It is inappropriate to focus on the deficits and portray children or young people with disabilities as vulnerable victims and you should avoid doing this in your campaign message.

The parent is a valuable partner in your advocacy efforts to improve school and kindergarten accessibility. The parent is an expert in the needs of his or her child and has a much stronger personal motivation, so the parent can be much more influential during meetings with the city administration, politicians, or the media. Along with this, parents of children with mobility difficulties have extensive practical experience and can advise you in regard to the planning and implementation of architectural improvements. They can also point out valuable budget solutions to specific accessibility issues.

Architectural accessibility is a prerequisite, but not the most important thing in the inclusive education that principals must provide. Much more important are the attitude and the mindset they demonstrate. That is why both the students with disabilities and their parents tend to make compromises and accept an architectural environment that is far from the most accessible as long as they face understanding, acceptance, and a desire to find a solution. We can give many examples of temporary solutions that are not ideal but become useful alternatives when inclusive values are embedded in the culture of the school/ kindergarten. Such are moving the classroom to the first floor; providing manpower to compensate for the lack of elevators and ramps (people available to assist with stairs); providing a key for the teacher's toilet, etc.

When the student's physical access to specific premises such as the library, cafeteria, specialized office, etc. is difficult, the **services should be made available in a place that is accessible to the student**. This may mean remote online participation in certain classes or individual work after school hours; it may require assigning a person to supply the student with books from the library or bring snacks from the cafeteria.

The lack of architectural accessibility is often compensated by manpower. Provide support from the members of the school/ kindergarten staff and make sure that they are available when the student needs them.

Pay attention to small details that do not require much funding but planning and organization, and which can qualitatively improve the safety and accessibility of the environment, such as regular cleaning the yard from leaves and snow, placing board signs at a suitable height for people in wheelchairs, removing the lecturing desk in front of the blackboard, moving the desks in the classroom to provide space for maneuvers, etc.

Liaise with the local authority, report and **demand maintenance of the areas around the school** so that they are safe and accessible, free of cars parked on pavements, broken tiles, or high curbs. Provide parking spaces for disabled people.

Always have **accessibility in mind when organizing concerts, celebrations, or other events outside the building of the school**. Make sure that the room is physically accessible and that every student can attend the event. When arranging chairs, provide empty spaces for people in wheelchairs.

When preparing the **emergency evacuation plan**, make sure to **include clear procedures and assign responsibilities regarding those who need special assistance** in the event of an emergency. Provide emergency chairs and stretchers as part of the plan as they will help facilitate the evacuation of people with reduced mobility, especially from the higher floors of the building. If such means are not available, it is recommended that the classroom in which the class with a child with reduced mobility studies is on the first floor, as this is the most accessible and safest option. Conduct regular drills and training.

Provide an extra set of textbooks for children, even if they have only mild motor impairments. This will significantly lighten their school bag and make them much more independent from the help of an adult.

Allow the **school uniform to be adapted** so that it is comfortable and safe for the sensitive skin of children with spina bifida.

Accessibility is not just about physical access. **All materials and information provided in the classes should be accessible**, understandable, and usable by all children. Students with spina bifida and hydrocephalus may need some special materials such as gadgets and assistive technology for classroom work or speech-to-text and text-to-speech software or devices. Make sure that the students use the aids they need and that the team is trained on how to work with them.

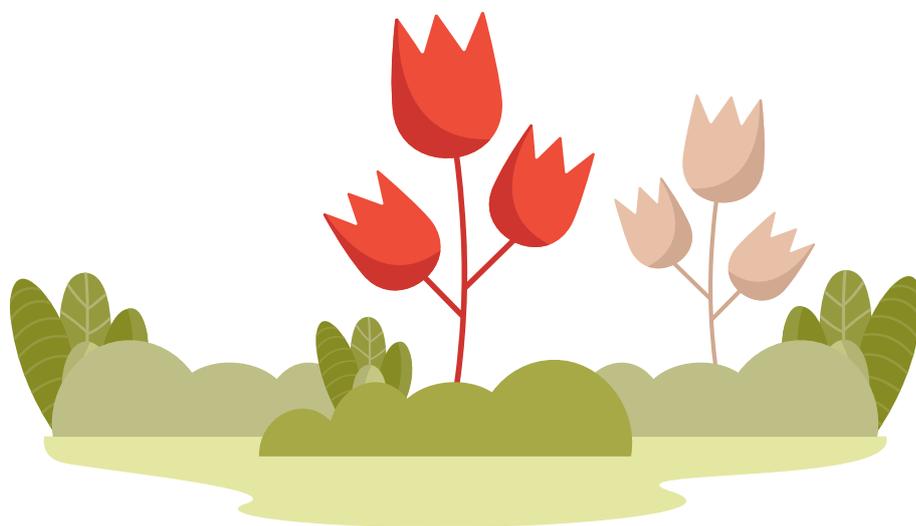
Pay **attention to children with a milder motor impairment** who, at first glance, do not need special improvements in the environment in order to participate in the educational process. Very often such children, even if they can walk without aids, have difficulties with the balance going up and down stairs independently, carrying heavy bags, using the toilet, or walking longer distances. Small improvements in the environment such as installing handrails on stairs and grab bars in the toilet can make a great difference in regard to their safety and independence. Some schools have toilets for people with disabilities that are not used daily. Do not let these rooms become storage rooms. There can always be a person who needs an adapted toilet and the room should be in the best condition.



It is very important that all improvements to the architectural environment are made in accordance with the accessibility standards so that they are of real benefit to children and adults with disabilities. Unfortunately, there are many examples where large sums were invested in ramps that are too steep or in other unusable facilities. The management of the school/kindergarten, as the body directly responsible for providing an accessible and safe environment, must observe compliance with the accessibility standards, both when installing specialized equipment and when renovating or repairing the building and its adjacent areas. Familiarize yourself with the national accessibility standards and monitor their observance. Make sure that the builders also know and follow these standards. Closely monitor the progress of the repairs and installation of the facilities. If you notice a discrepancy during construction, it is important to intervene before the work is completed, as it is best to make changes during construction, not after it. As far as your authority allows, make sure that the provisions based on which the contractors are paid contain a mandatory clause for compliance with the accessibility standards.

Below are some basic accessibility standards:

- Non-slip flooring should be installed on all ramps, elevators, and toilets for people with disabilities;
- Ramps: minimum width 120 cm, inclination between 5%-8% (recommended 5%, 1:20), horizontal surfaces at the turns with dimensions of at least 150 cm by 150 cm;
- Easy open doors with a minimum width of 90 cm;
- Stairs with handrails installed on both sides;
- Information signs should be placed at a height of 120 to 160 cm in places that are clearly visible for people sitting, standing, or walking;
- Accessibility symbols placed in front of toilets for people with disabilities and accessible routes;
- Faucets installed at a height of 90 cm with space for a wheelchair underneath;
- A toilet cubicle with minimum dimensions of 150 cm by 150 cm, with an access point in front of the cubicle with the same dimensions, equipped with a cubicle door that opens outwards. A side horizontal handle should be installed next to the toilet bowl.



CONCLUSION



The leaders of schools and kindergartens have taken on the important role of providing quality educational services and the support that students need in the context of general education so that all students be able to reach their full social and academic potential. In order to support the work of principals with children with spina bifida and hydrocephalus, in this document, we have summarized the main barriers that this group of children face when it comes to education and have provided recommendations on how to overcome those of them **that are within the competencies of the management**. Many of these represent small details in the overall picture of the inclusion process. It is the inclusive school/kindergarten that can guarantee education for every student, including students with spina bifida and hydrocephalus.

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Start by doing what's necessary; then do what's possible; and suddenly you are doing the impossible.

Francis of Assisi

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BELIEFS OF PROFESSIONALS ABOUT PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

Andrej Drdul and Terézia Drdulová

”

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

Lance ARMSTRONG

“

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

Source: Multi-IN GENERAL GUIDELINES for inclusive education and multidisciplinary care of learners with spina bifida and hydrocephalus

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MANUAL

for school leaders

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

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