



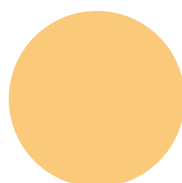
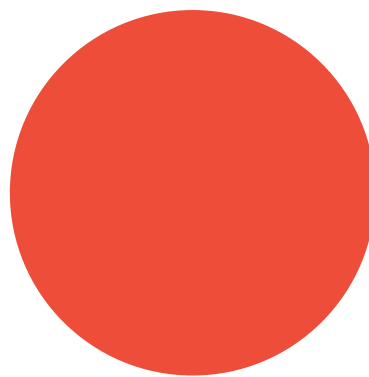
MANUAL

for parents and family members
on multidisciplinary care and inclusive education
of pupils with spina bifida and hydrocephalus



Developed in partnership between:
Spina Bifida and Hydrocephalus-Bulgaria Association
Early Intervention Centre Trnava, Slovakia

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

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INTRODUCTION



The manual for parents and family members is part of a 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.

This manual covers the key aspects of being a parent of a child with spina bifida or hydrocephalus that impact the child's education and social inclusion. A variety of important topics related to upbringing and education, such as building functional skills, promoting independence and self-care, developing resilience, etc., that strongly influence, though indirectly, the child's participation and performance at school and in the kindergarten are covered.

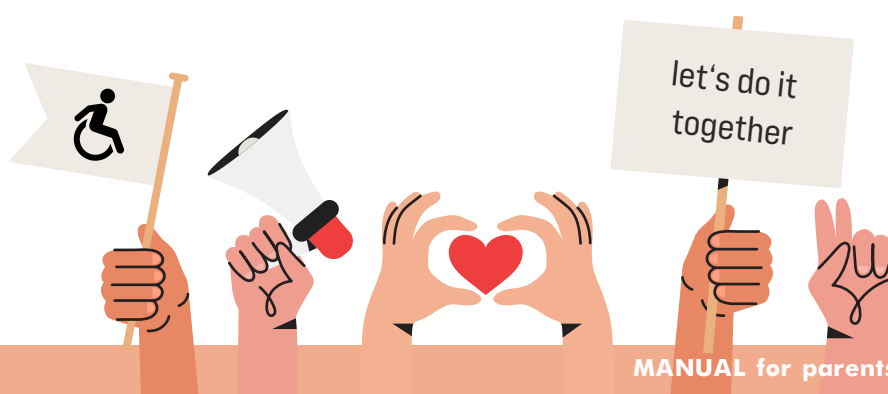
As external parties to the education system, the parents may have difficulty understanding their role in it, including some ideas, rights, functions and relationships within the educational process. This manual contains separate chapters dedicated to the child's rights in the education system, the basic principles of inclusive education, the functions of the parent in the multidisciplinary team and the interaction with the professionals in the team. Our goal is not so much to go into deep detail, but to provide basic knowledge on these topics using language that is easy to understand and to encourage parents to improve and to try to find themselves the answers they need.

We hope that this Manual will help parents to become more aware of how the way they upbringing their child at home affects the child's inclusion at school and kindergarten and to increase their knowledge and improve the skills they need in order to help their child achieve full participation in the educational process.

All materials are available on the website of Multi-IN:

www.multi-in.eu

Author's note: Parent is used as a general term for an adult who is directly involved in raising and upbringing a child with spina bifida or hydrocephalus. This term includes biological parents, adoptive parents, guardians, close relatives - grandparents, older siblings and other family members.



BEING A PARENT OF A CHILD WITH SPINA BIFIDA OR HYDROCEPHALUS



In modern culture, the birth of a child is seen as a symbol of faith and hope and carries expectations of continuation and self-perpetuation. Usually, even things like the very existence of the newborn, the baby's features and appearance become a source of pride. Parents often have expectations and make plans for their children even before born. They visualize their first steps, their kindergarten, the sport or musical instrument they will play and the school they will attend, even their profession in life. The child's achievements are perceived as the parents' success.

However, when a child is born with a disability, all these expectations and hopes often seem lost. It is difficult for parents to perceive a disabled child as their successor. From a source of pride, the child turns into a disappointment. After learning of their child's disability, parents enter a situation that has the potential of becoming a crisis, one that often accompanied involves a severe disappointment, psychological distress and a strong sense of loss or reduced self-esteem. Until recently, the traditional view was that families raising a child with developmental disorders are normally destined to go into crisis, to suffer from stress or develop a pathological condition. In recent decades, this view has evolved into a recognition that there many models for successful dealing with this problem that can act as a prerequisite for positive child development. Indeed, parents of children with disabilities go through a difficult and painful internal process involving a complete rethinking of their views, beliefs and expectations in order to bring their hopes and plans for the future in line with reality. **As a result, parents expand their competence and skills, strengthen their resilience, and grow to become better persons, which is how they are able to successfully overcome the challenges they face.** This exactly is the way we look at parents of children with spina bifida and hydrocephalus, we see them as people who successfully cope with the vicissitudes of life, not as helpless victims.

The other Multi-IN manuals which are intended for professionals working in schools include an introductory chapter on spina bifida and hydrocephalus in which we explain the implications of these medical conditions in the context of the relevant professional area. In this parent manual, we will not go into details about the development of the neural tube or the types of spina bifida, because in the context of the above, we believe that all parents are familiar with this type of information in detail. More details on these topics can be found in the General Guidelines, which are the basic Multi-IN document, as well as in the individual manuals for the target groups.

In this manual, we will focus on the most important things that a parent of a child with spina bifida or hydrocephalus probably already knows, but it is still useful to be reminded of from time to time.



SPINA BIFIDA IS A LIFELONG CONDITION WITH MANY SECONDARY CONSEQUENCES AND RISKS

The open spinal defect is closed surgically; if necessary, a valve is placed to relieve the pressure, but the developmental deficits in the nervous system result in many and varied complications that will accompany the individual throughout his/her life. Spina bifida is not a disease that can be cured. This fact, however, should not cause fear, but should be viewed as a reality that the parents have to accept in order to properly care for their child.

The good news is that the progress of science and the developments in medicine and technology make it possible to avoid the more serious risks and achieve satisfactory control over the adverse consequences of this condition so that the child be functionally and socially included. That is why, we often talk about control/management of the condition spina bifida. Here are some examples:

- If the child is not able to walk independently, the child can use walking aids (crutches, orthoses, wheelchair) that allow the child to move, to be independent, to be with friends, and to reach places that he/she could not otherwise reach;
- If the child has incontinence, a program for Clean Intermittent Catheterization (CIC) and/or a program for regular colon cleansing can be successfully put in place so that social continence (dryness and cleanliness) is achieved;
- Spinal deformities can be controlled and the risk of contractures can be reduced through regular sports activities and rehabilitation;
- If the child is allergic to latex, alternative products made of vinyl or other materials can be used.

Good care requires control over a number of secondary conditions and prevention of possible risks. Good care often requires a multidisciplinary cooperation that involves many specialists joining their efforts not only in the field of health care, but also in educational, social and other areas. The multidisciplinary support team for children with spina bifida and hydrocephalus may include a neurosurgeon, a neurologist, urologist, urology nurse, rehabilitator, social worker, therapists, a nutritionist, resource teachers, assistants and others. This dynamic community of professionals will probably change many times as the child grows and his/her condition changes, with the parent usually being the person who is constantly there, selecting and often coordinating the work of the experts. Over time, it is normal for the responsibilities to be shared with and then completely transferred to the grown-up child. Preparing their child for this moment is perhaps one of the most important tasks that the parents of children with spina bifida and hydrocephalus have.

A HAPPY AND FULFILLING LIFE OF PEOPLE WITH SPINA BIFIDA AND HYDROCEPHALUS

There are many examples on the Internet, in the media and social networks, of young people and adults with spina bifida and hydrocephalus who are successful in various fields of life such as sports, music, cinema, medicine, politics and civil society areas. Even more are the people about who you will not read in a newspaper article, but you can meet in the subway or at your workplace. These are regular employees in shops, clerks, teachers or factory workers who are also successful in their field of work, have families and friends, pay credits and live happy and fulfilling lives.



People with spina bifida and hydrocephalus can:

- attend mainstream kindergartens, schools and universities and do very well, provided that they get the support they need;
- have friends to share and have fun with;
- go to the theater, a nightclub, the beach or in the mountains;
- travel around the world;
- engage in arts and music;
- play sports;
- drive a car;
- be good professionals in the field they have chosen;
- earn enough money to support themselves and even more;
- have their own family;
- have their own, perfectly healthy biological children.

For most parents of children with spina bifida and hydrocephalus, these are achievable dreams, and the key to achieve these dreams is largely in their own hands.

FUNCTIONALITY AND QUALITY OF LIFE: IN WHAT IS IT WORTH INVESTING IN

Initially, many parents focus on achieving their child look like the other children, meeting the developmental milestones and their own ideas of success and happiness. Over time, most parents begin to understand that each child has his/her own unique path in life and that the role of the parent is to prepare the child emotionally and physically as well as socially and economically for adult life and for the time when the parent will no longer be around. As they become more and more aware of this fact, the parents change their perspective. Instead of focusing on when their child will start walking, their priorities begin to shift towards improving mobility with the help of aids, and the hours of intensive rehabilitation give way to games and sports with friends.

Parents now understand that what is worth investing time and effort in is building functional skills that help in the daily activities.

Many parents look back in time and realize that some of the surgeries that their child went through were unnecessary, because while they improved the way the child's body looked, they didn't improve the way it functioned. Many of us realize that the hours we have spent together with the child memorizing texts and formulas in order to get to the same grade level as his/her classmates have brought us unnecessary stress, but no real knowledge.

Over time, we understand that the late introduction of the wheelchair or the postponement of self-catheterization has prevented the child from being more independent and being able to build friendships. Lots of well-meaning parents go down this road and over time they all learn what their child really needs.

We would like to remind you that being in good physical shape, having good muscle strength, mental abilities and being able to move independently (not necessarily walking) are the main factors for successful everyday functioning and quality of life of children with spina bifida. They have a greater impact than other medical parameters related to this disability (Schoenmakers, 2004).

BUILDING YOUR CHILD'S INDEPENDENCE FROM AN EARLY AGE

Helping children achieve optimal independence in everyday life and build functional life skills is critical to achieving independence and self-confidence in children with spina bifida and hydrocephalus. Independence can be both physical and emotional, and it is very important that the parents help the child develop both aspects starting from an early age.

This can be achieved by:

- allowing the child to make choices and take part in the decisions about his/her life by discussing with the child the possible options and the corresponding consequences. This applies to everything - from small decisions about clothing and food, to more important ones such as choosing a school, a doctor, etc.;
- involving the child in the planning of free time and trips, taking part in ordering consumables and aids, doctor visits, etc.;
- involving the child in the process of taking care of his/her own health and maintaining personal hygiene. It is important for the parents to familiarize their children with how their bodies work and what care they need to take to stay healthy. When it comes to self-care, early mastery of functional skills such as changing clothes, washing and bathing, self-catheterization, etc., is extremely important;
- allowing the child to take part in the housekeeping, depending on his/her age and individual abilities - cleaning, tidying up, sorting laundry, caring for younger siblings, preparing a shopping list, etc.;
- paying attention to the financial and administrative literacy and purchasing skills – creating a budget, going shopping, paying with cash, a card or online, keeping and storing documentation, etc.;

- timely introduction of the necessary aids to provide maximum mobility and independence of the child, according to child's physical abilities and age - wheelchair, walker, orthoses, therapeutic chair, ergonomic writing aids, etc.;
- teaching the child to express his/her needs and to seek help when the child cannot take care of them alone;
- teaching the child to accept help from people outside the family, not just from family members;
- encouraging the child to develop social skills and build friendships with peers – attending kindergarten, going regularly to the nearby playground, welcoming his/her friends at home;
- supporting the child's interests and helping the child develop his/her strengths – taking the child to training and other activities, asking the child to try new activities.

A focused effort and a full awareness of how important independence is are required on the part of the parents. According to a research in the US, most children with spina bifida experience a delay in independence development of two to five years compared to their peers (Logan, 2020). This delay includes the development of skills such as changing clothes, planning activities with their peers, preparing pre-planned meals, etc. Because of over-parenting or just to save time, many of us choose to carry the day-to-day responsibilities of the child and to make decisions on the child's behalf. **The gradual transfer of responsibilities to the child requires awareness, time, effort and a lot of courage, but in the long run this will pay off many times over.**

The degree of physical independence that could be achieved is different for each child. There are young people and adults with spina bifida and hydrocephalus who are unable to self-care or move around without help. They also need emotional independence and the right to make independent informed decisions about their lives or to make choices about the help they need and who should give it to them.

PARENTS AS A SIGNIFICANT FACTOR IN A CHILD'S SELF-ESTEEM AND RESILIENCE

Achieving optimal independence in the daily life and building functional life skills are critical to achieving self-reliance and thereby improving the self-esteem of children with spina bifida and hydrocephalus (Schoenmakers, 2004).

A study has described young people with spina bifida and hydrocephalus as more dependent, less intrinsically motivated, more immature and more prone to depression and anxiety compared to their peers (Brei 2021).

They also show low self-esteem. At the same time, we must not forget that it is the environment that directly determines the psychosocial development of children (Holmeck et al. 2002), (Galambos, 2006), which practically means that **the people from the child's inner circle can influence the way the child perceives his/her self**, his/her personal value, competences and potential.



CHILDREN ARE STILL GROWING

Like all children, children with spina bifida and hydrocephalus are also growing, and at each stage of their development they and their families encounter new challenges that they have to deal with. Starting kindergarten, first grade, changing schools, entering puberty and the teenage years - these transitional periods bring stress to all families. For the families of children with disabilities, the challenges are even greater, but if the parents and the child are prepared, there will be significantly less stress.

Each period has its own peculiarities and the children and their parents will have to master new skills and competences as well as add to the ones they have acquired in the past. Although the exact situation may differ from family to family, the direction remains the same - to prepare the children for a fulfilling life as adults. Therefore, we must not forget that at every stage and depending on the child's abilities, it is very important to:

- encourage maximum independence and autonomy;
- develop functional skills as a primary goal;
- build a responsible attitude towards health and habits for an active and healthy lifestyle;
- encourage full participation in the community and in social relationships;
- accept the changes that the child undergoes as the normal result of the process of growing up, together with the new needs, roles and functions that arise from them;

- try to provide the child with a life that is as close as possible to the life of his/her peers, with all of the experiences and emotions that are typical for the particular age.

SUPPORT FOR PARENTS

Being a parent is perhaps one of life's greatest challenges. It brings a lot of joy, but it is also accompanied by great responsibilities. This is particularly true with regard to the parents of children with disabilities, whose lives often present one challenge after another, and calm moments are almost absent. It is overwhelming for a parent to shoulder all this burden alone, and it is quite normal to seek support within or outside the family.

The spouse is the most natural source of support. Although, in general, the presence of a disability is a factor that brings a number of negative effects on the relationship between the parents (Shan, 2003), (Mazur, 2008), the families of children with spina bifida show relatively high levels of resilience. **The quality of the relationship between the partners before the birth of the child is a major indicator for the stability and the adaptability of the relationship** (Holmbeck, 2010), (Spaulding, 1986). It is important that they continue to communicate with each other as parents, partners and friends. By sharing their thoughts, feelings, worries and joys, the parents are supporting each other and the couple should be able to find the way to family harmony. Don't be afraid to discuss your needs, plans, dreams or fears with each other. This will help you get to know your partner and yourself better.

Maintaining positive relationships and good communication is no less important for the parents who have chosen to raise their child separated. In both cases, the help of a family therapist may be necessary.

In some societies, seeking psychological support is still viewed with prejudice, which results in not seeking professional help in time. Seek professional help if you notice symptoms of anxiety or depression; if you are stuck in a negative thought pattern; if you don't feel the same person; if people who care about you tell you that you need to see a psychologist. Being a psychologist does not mean being a magician, and you may not find the right person the first time around, but it is certainly a step in the right direction.

The extended family members (grandparents) and close friends are another major source of support. It is very important for the parents to have a trusted person on whom they can rely on in raising the child. This will provide them with more time for themselves, more time for social activities or hobbies, thus reducing stress and negative thoughts.

Caring for a child with a disability has its own peculiarities, so it is very important that the parent gives clear information and precise instructions using a language that is easy to understand.

This is the only way to make helpers feel confident in their actions so they can support the child in the best possible way. Whether it is catheterization, feeding, communication or exercises, **at least two people should be able to perform the same thing so that they can replace each other when caring for a child.**

The relations with relatives have always been a delicate matter, especially when they involve the child. Conflicts caused by differences in understanding between people from different generations, excessive strictness or failure to follow the provided instructions are common. It is better for everyone when common sense prevails over the emotions; we know that this is good advice to give but it is hard advice to follow.

When they do not have the support from relatives, parents can seek the help of an external assistant, a daycare center or other support services. Professional care makes the parents more relaxed and helps them state their requirements in regard to the care of the child more clearly and directly. Along with this, getting help from external persons brings new experiences to the child and helps to overcome existing emotional dependencies more easily.

Many parents get invaluable help from formal and informal support networks of parents of children with similar conditions. These can be parent associations, patient organizations, groups on social networks, groups of active parents at local level, etc. Within these networks, in addition to emotional support, parents can also find reliable information and valuable advice. There are some topics that can only be discussed with people who have dealt with a similar problem, and who truly understand our concerns and fears. It is this kind of emotional comfort and support that the parental networks provide. The conducted studies confirmed the multiple benefits that parents get from the participation in such groups. They gain new skills, get an increased sense of power and a sense of belonging [Solomon, 2001], [Law, 2001].

In our relationships with other parents, we should never forget that although we are faced with similar challenges, we are people with different interests and views on life. Having children with a common diagnosis does not automatically make people friends, but it can start lifelong friendships. Sometimes conflicts may arise between parents and in such situations, it is important not to forget that we are all in the same boat and have one goal - the best for our children.

The local support organizations for people with spina bifida and hydrocephalus and their families are a valuable source of support and reliable information. We encourage all parents to keep in touch and take advantage of the resources and services that your local association provides. This is an invaluable opportunity for both the parents and the children to build contacts and friendships and to create their own support network on which they can rely in the future.

KNOWLEDGE IS THE KEY TO A BETTER LIFE

Knowledge is the key to a better life, so it is no coincidence that this phrase was the motto of the International Federation for Spina Bifida and Hydrocephalus (IF) for many years. Modern medicine, the development of technology and the values of our society made it possible for the today's children to have a better quality of life. Getting access to services and rights requires reliable information, understanding and developing of appropriate skills.

Carefully choose your information sources and always seek second and third opinions when it comes to making important decisions, consult established specialists and do not trust any promises of a “miracle cure”.



PARENTS AS A CHILD'S BEST ADVOCATES

In all Multi-IN resources, we have repeatedly stated that the family is the best advocate for their children. There are no other people who know their needs better and who are more devoted to fighting for the children's rights. In addition to that, the parents are the ones serving as role models in regard to how the child will assert his/her rights in the future.

In the chapter named "The Role of the Parent in the Multidisciplinary Support Team" we look in more detail at the parent's advocacy roles in the education of the child.



PARENTS' ATTENTION AND TIME FOR EACH OF THEIR CHILDREN

In many families, the child with spina bifida and hydrocephalus has brothers and/or sisters. They all grow up together, share their childhood experiences, but also their parents' time and attention. Regardless of the birth order of the children, having a sibling with a disability inevitably affects the other children in the family.

Having a loved one with a health problem is challenging for the child's mind as it creates serious concerns for the future of the loved one and of the whole family. At the same time, caring for a sick child often takes up much of the parents' time and energy. Parents do not always manage to adequately meet the needs of their other children who also compete for their attention, but do not dare to express their feelings, so as not to burden their parents further.

Although as a result of their experience, many siblings show high levels of empathy, cooperation and satisfaction, studies have shown that siblings of children with chronic illnesses are more likely to suffer from depression, anxiety or other adverse psychological conditions (Sharpe, 2002). Therefore, it is important that parents make a concentrated effort to care for all their children:

- Provide support and give time to other children in the family. Remember that it is not the quantity but the quality of the experiences that matters most;
- Work to create a stable relationships and quality communication between the children in the family. Avoid separating the children; in this way the care for them will be easier. If necessary, seek help from a psychologist;
- Try to engage the family in activities that do not focus solely on the needs or interests of the child with a disability;
- Seek to achieve a balance when it comes to family responsibilities and housekeeping by spreading the responsibilities among all household members based on their abilities and age;
- Familiarize the child's siblings with the peculiarities of the health condition and the needs of the child with spina bifida or hydrocephalus. Share this information with them using language they can understand;
- Do not burden the child's siblings with overwhelming caregiving responsibilities. It is wonderful to have your children help each other, but they are still children and have the right to enjoy their childhood, play games and pursue personal interests.



A positive attitude on the part of the family toward spina bifida, the overall family satisfaction, and levels of sibling conflict are the main factors that determine sibling resilience (Bellin, 2008).

Everything said so far about parenting may sound general and beyond the context of the topic of inclusive education and multidisciplinary care. However, **the skills of the parents, their attitude, experience and competences have a direct impact on the child's education as well as on how the child enters the system and how he/she will develop within it.** As a participant in the multidisciplinary support team, the parent has the strongest impact on the child and largely determines what part of the child's potential the professionals could develop.

Building functional skills and encouraging independence, participation, social communication, development of talents and strengths and self-assertion - all important principles and values in the upbringing and education of the child are set by the parent and transferred to the team in the school or kindergarten. **Providing education should not be viewed as end in itself. The education should support our common goal as parents** – to raise an independent, self-aware individual who is aware of his/her own worth and ability to contribute to the common good despite the difficulties caused by the disability.



THE RIGHT TO EDUCATION



The parent is their child's best advocate. He or she is the person who knows best the needs and interests of the child as well as the child's deficits and strengths, including in regard to education.

Invoking the rights of the child, the parent is able to change the environment so as to provide the best opportunities for the development of the child based on the child's particular needs.

Parents are experts when it comes to their children's needs as they have to meet them from birth and there are many aspects of the child's life about which the professionals can fully trust the observations and expertise of the parents. However, we should note that in contrast to knowing their child's needs, the parents often do not know their child's rights so well – they may have difficulty naming them, they may not always be able to spot discrimination or clearly indicate the barriers that prevent the child from accessing the necessary service or participating in a given activity. However, this does not mean that they will not notice if the child's rights are being violated. Often, parents describe the feeling as an inner feeling of injustice, harm or insult - *“Why was only my child not invited to the school trip?”*, *“It is not fair that they constantly make comments about my child's bad handwriting”*, *“The teacher does not let my child participate in physical education classes in order not to get hurt.”*, etc.

In this chapter, we will summarize in a comprehensible language the basic rights of children with spina bifida and hydrocephalus in regard to their access to education, hoping to help parents look at the educational and other areas of the life of the child in the light of the rights that their child has. This is an internal process in the course of which the parents will expand their knowledge of the human rights as well as their parenting and administrative competencies to build skills that will help them deal with the problems at a new level. These new skills will enable the parents to employ a range of legal and civil rights-based tools that have the potential of a far greater impact than the tools limited solely to the needs of the child.

The internal process we are talking about is a long process and can be built up over a lifetime. The purpose of this manual is to help the parents in their journey, and in some case even to encourage them to take this journey. It is certain, however, that this manual cannot exhaust the vast topic of the access to education for children with spina bifida and hydrocephalus.

Different countries have different educational systems with different peculiarities and operate in accordance with the local legislation and regulations, but there are two international legal documents recognized by most countries in the world that impose fundamental principles and build the framework defining the status of children with disabilities and their rights, including regarding access to education. These are the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

The General Guidelines for multidisciplinary care and inclusive education of pupils with spina bifida and hydrocephalus contain a separate chapter named “The Rights of Children with Disabilities”, where you can familiarize yourself with these documents in detail. In this manual, we provide a brief summary in order to introduce the parents to the topic of education from the rights perspective. Our advice is when reading the provided information to consider it in the context of your personal experience and the experiences of your child.

The definition of the term “disability”, established by the United Nations Convention on the Rights of Persons with Disabilities, emphasizes on the interactions between the person and the barriers in the society that make it difficult for the person to participate fully and effectively on an equal basis with the others. In this regard, **children with disabilities have the right to be supported, including in their education, in a way that takes into account the existing barriers and provides reasonable facilitations.**

The main principles on which the rights of children with disabilities are based on are:

- The interests of the child are considered most important and they should be the leading factor in all decisions related to the child.
- The conditions in which children with disabilities grow, learn, play and live must be such as to guarantee their dignity, encourage their independence and facilitate their active participation in society.
- Children with disabilities have the right to receive care and services that correspond to the condition and needs of the child and the needs of the people caring for the child, and these services must be provided free of charge or at a reasonable cost, based on the economic status of the family.

If at any point in time, you notice that these principles are not being applied in regard to your child, it is very likely that your rights have been violated.



. You are also likely to find texts in laws or regulations that describe your situation more specifically. If you live in a country governed by the rule of law, these legal texts are the tools that will best protect your child's interests. It is an important responsibility of every parent to pass to their child the knowledge of how to use these essential tools, both through personal example and through purposeful work designed to build specific skills and promote independence and civil awareness.

INCLUSIVE EDUCATION



The United Nations Convention on the Rights of Persons with Disabilities pays special attention on the need to support the right to education of persons with disabilities at all levels of the educational system. Article 24 of the Convention is devoted to Education, which in regard to persons with disabilities must be aimed at the development of their personality, talents and creative abilities as well as at the development of their mental and physical abilities to the full extent of their potential, and should be provided in accordance with the human rights, the fundamental freedoms and human diversity and by enabling people with disabilities to participate effectively in the free society.

A number of concepts of inclusive education, which review it in different aspects, are built on these principles. It turns out that inclusive education is an extremely complex concept and could hardly be described in a few sentences. What is interesting is that all these definitions do not contradict to one another, but rather complement one another and overlap to describe inclusive education in its entirety and complexity.

Summarizing some of the popular concepts, we can say that inclusive education is all of the following at once:

- A fundamental right of all students and a means of realizing other human rights;
- A path to achieving an inclusive society;
- An educational system, a process, and approach in teaching. At the same time, it is a vision and a model;
- Inclusive education is aimed at and includes all students who learn together in a common environment;
- An educational model that promotes the participation of all stakeholders and implies the reduction of all forms of exclusion and discrimination;
- In the inclusive education, diversity is a fundamental value and it is considered to be a positive aspect and a factor for development;
- As an educational strategy, inclusive education adapts to abilities, talents or deficits in order to ensure that each student uses his or her full potential while learning to communicate and cooperate with others;
- **Inclusive education includes the achievement of educational goals and is much more than physical presence at school;**

- In inclusive education, the failure to achieve the goals is viewed as a sign that additional support is needed and it is in no way interpreted as a lack of ability;
- Inclusive education supports children who have specific needs within the general educational system through a combination of reasonable facilitations, individual support and accessibility measures, both in terms of architecture and learning content;
- Inclusive education does not exclude students and does not imply the application of segregation criteria of any type;
- Inclusive education promotes comprehensive schools for all children, close to their homes;
- One of the main goals of inclusive education is to prepare students for a quality and successful life in today's modern society.

It becomes clear from all these characteristics that inclusive education is not just some specific educational model aimed at children with disabilities. It is an education for all children – with and without disabilities, children with specific 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.

The concept of inclusive education is asserting as a model recognized by all modern societies around the world. According to the UN Convention on the Rights of Persons with Disabilities (Article 24), the member states must ensure the realization of the right of persons with disabilities to education through the creation of an inclusive educational system.

Inclusive education brings many positive changes that are observed in students, both with and without disabilities, as proven by the results of long-term international studies. We already know that students with disabilities who have been educated in an inclusive environment show significantly better results in life than students who have not had this opportunity. They enjoy a better quality of life, including in terms of social connections, community participation and income. At the same time, it is now clear that there are benefits for all students. Studies conducted in Canada have shown that inclusive policies and practices lead to better performance of all children, both academic and social. (Inclusion BC, 2014).

It is important for the parent to be well familiar with the concept and the main features of inclusive education, so that the parent knows in what environment the child should learn and what support services the child can receive. Along with this, by understanding the essence of inclusion, the parent acquires another tool that could be used for protection the rights of the child and a starting point in the interaction with other stakeholders involved in the education of children with spina bifida and hydrocephalus.

Your child has the right to study in a mainstream class at the local school, together with other children from the neighborhood. There, your child should get the support he or she needs to be successful.



SPECIAL EDUCATIONAL NEEDS OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS



Children with spina bifida and hydrocephalus, along with their unique characteristics, interests and abilities, have a complex set of special educational needs that must be met in order to achieve successful inclusion in kindergarten and school. The full spectrum of these needs can vary depending on various factors and combinations thereof such as health status, degree of disability, family environment and socioeconomic status.

In the Multi-IN General Guidelines, we review the specific educational needs of children with spina bifida and hydrocephalus, using Maslow's model as a generalizing framework. In the manuals for the target groups, we dwell in more detail on the specific needs from the point of view of the relevant professional field. In this document we will not go into details, as we believe that parents are experts when it comes to their children's needs, including in regard to education. Unlike other participants such as the professionals, the challenges that the parents face are related to the successful communication of their child's needs, knowing their educational rights and how to protect them.

The needs of the children at school must first be identified, so that the educational system be able to best meet them. This can be done informally through observations, document reviews or conversations between the parent and the stakeholders - teachers, school principal, psychologist, nurse, etc. Sometimes children need supportive activities and services that can easily be provided without additional administrative burden, such as after-school activities with the teacher, consultation with the school psychologist, making modifications to the bathroom to suit the child, rearranging the furniture in the classroom, etc.

In the event that the informal assessment identifies a need for additional, more specific support, a formal assessment of the student's individual needs should usually follow. This assessment should be carried out by a team of experts analyzing strengths, difficulties, potential for optimal development, participation in the educational process and opportunities for success. Scores from IQ test, academic achievements, language skills, social/emotional functioning are all things that need to be taken into consideration. It is extremely important that the experts are familiar with the peculiarities of the cognitive and educational profile of children with spina bifida and hydrocephalus and the impact that the secondary consequences of their disabilities have on their development. Only then the experts will be able to identify the real educational needs and offer relevant support. Experts can find more information on this topic in the Multi-IN manuals for school psychologists, teachers, principals and resource teachers.

In the assessment process, it is important to take into account the opinions of the parent and the child. The parent is a source of valuable information about the child's strengths, the successful and unsuccessful educational strategies, communication style, the specific needs caused by the health condition and the vision for the future.

Based on the result of the assessment, the expert team should prepare an individual support plan, with specific goals and supporting activities, which may include: ensuring accessible architecture and specialized equipment, work with a speech therapist, psychologist, resource teacher, rehabilitator, and sometimes modification or adaptation of the learning material or making changes in the assessment criteria. Each student's plan should be different, as it should reflect the individual needs of the child. **With minor adaptations and minimal levels of support, some children manage to achieve the expected learning outcomes for their educational level/grade. Other students with more complex needs require modification of the curriculum and wider support from specialists.**

It is important for the parent that the plan is tailored to the vision for the child's development - that the goals are realistic, functional and age-appropriate, and that they will develop the child's individual potential and will prepare the child for the future. The strategies should be motivating and tailored to the child's interests and strengths, and the activities should promote personal development, independence and inclusion. The goals should be specific and measurable, and the plan should name the people responsible for helping to achieve them.

The assessment and plan are dynamic in nature and it is normal to be revised periodically.

Author's note: The information provided in regard to the assessment of educational needs is summarized. In some countries, there may be discrepancies in the procedure. Parents are advised to check the details that apply to them locally.



THE ROLE OF THE PARENT IN THE MULTIDISCIPLINARY TEAM



In order for their inclusion in school and kindergarten to be successful, most children with spina bifida and hydrocephalus need the support of a multidisciplinary team. Whether a formal assessment is carried out and an individualized plan is put in place or the support is provided informally, the efforts of experts from different disciplines are needed to meet the specific needs of the children.

The members of the multidisciplinary team work in parallel and may be experts in different fields, and the team could have a variety of compositions, according to the need for support - teachers, special educators, school administrators, health workers, social workers, psychologists, etc.

The inclusive educational model gives parents, although not professionally trained, a fundamental role in the multidisciplinary team. This role poses new challenges for parents. In order for their participation in the support team to be effective and meaningful, many of them will have to gain new knowledge and master new skills. Parents must familiarize themselves with the complex web of policies, laws and regulations in order to understand how the educational system works, and do a research on the roles and functions of the professionals within the educational system. Parents have to know and understand their child's rights and their own rights and responsibilities as parents. Along with this, they will be required to devote considerable time and resources to attend meetings with the team and perform additional work with the child outside of school. It is important for parents not to forget that **being involved in their child's education is their right, but that comes with responsibilities and requires time, commitment and efforts.**

Good teamwork requires trust, tolerance, respect, communication, cooperation, self-awareness and many other qualities that we need to demonstrate in order to achieve the common goal - the successful inclusion of the child.

As a part of the multidisciplinary team, the parent has specific and extremely important functions that are described in this chapter. To perform them successfully, **the parent will need the support of the professionals**, in the form of a feedback, counseling and particular actions. The same is absolutely true in the opposite direction as well - in order to be able to perform their functions successfully, teachers, teaching assistants, nurses and principals will all need the cooperation of the parent at some point.

THE PARENT AS AN EXPERT ON THE CHILD'S NEEDS

We often mention that the parent is the expert when it comes to the needs and care of their child. No one in the educational system understands better than the parent the child's health status, health needs and the ways to meet them. The same it is also true in regard to the needs of the child for an accessible and safe environment. Along with this, parents know their children's talents, strengths and interests and, based on previous experience, can propose successful models for communication, motivation and learning. Knowing their child best, the parent is able pick up the slightest differences in the emotional state of the child, notice possible signs of bullying, anxiety or stress.

It is very likely that the parent will be the only person with a previous experience with a child with spina bifida and hydrocephalus. This makes the parent very useful in obtaining additional information and bringing in experts from outside the school environment to support the child.

THE PARENT AS A SOURCE OF INFORMATION

In order to be of real benefit to the child's inclusion, parental expertise must be recognized by the professionals involved in education and the knowledge of the parent should be shared with the experts. Regular communication is extremely important. In addition to providing information through conversations, we advise parents to provide copies of the main available documentation - medical history, test results, reports or correspondence. Be open and share your concerns. The information provided by you will be treated as confidential in all cases.

In addition to the obligation to provide information, the parent has the right to receive feedback and the right to be informed in time about the support that the child receives as well as about the child's progress and successes during the school year, attendance and discipline, and about all other matters related to the child's life at school/kindergarten.



THE PARENT AS THE PERSON RESPONSIBLE FOR ALL IMPORTANT DECISIONS ABOUT THE EDUCATION OF THE CHILD

As the guardian of the child, the parent is responsible for his/her development and well-being. This gives the parent the right and the responsibility to make strategic decisions in regard to their child's education such as to choose a school and its type in accordance with the effective regulations, the form of education and the type of support, etc. The other members of the team have an equally important role - to actively participate in the process of inclusion of the child, to provide adequate feedback, to consult and guide the parent, thus supporting the process of making informed decisions that are in the best interest of the child. At the same time, **when such decisions fall within the competence of a professional, the parent also has the responsibility to support the process by providing his/her knowledge and opinion.**

Do not hesitate to contact the team working with your child to get the necessary information, professional opinion or clarification when necessary. At the same time, we want to emphasize that these interactions should be built on dialogue and mutual respect. The parent has the right to fully participate in the team's meetings and **the important decisions related to education require the consent of the parent in a written or a verbal form.** You have the right to disagree!

THE PARENT AS THE PERSON WHO SETS THE EDUCATIONAL GOALS AND PROVIDES THE VISION FOR THEIR CHILD'S FUTURE

As parents we all have a vision for our child's future. It is that best version of our child that we strive to achieve in our care as parents; the direction in which we want our child to develop. In parenting, the vision is what defines the values, the way of upbringing and the goals we set for the children.

In previous chapters, we have already discussed how promoting independence, developing functional and communication skills, building positive self-esteem and emotional resilience are all strategies that support the child's path to becoming an independent, capable and empowered adult. At home, the parent has the opportunity to encourage building of such skills, but cannot directly influence this in an external environment such as the school or the kindergarten. The school and the kindergarten are the places where the children spend a large part of their active day, so it is extremely important that the school team follows the same shared vision and pursues common goals.

The main task of the parent is to communicate this vision with all of the professionals in the multidisciplinary team, so that each of them can support it, within the framework of their field and competences. It is normal for classmates and their parents to become aware of this special treatment.

Compassionate looks, neglect or overcaring - give a clear sign that this attitude does not help the child!



THE PARENT AS THE BEST ADVOCATE FOR THEIR CHILD

Given that our primary responsibility as parents is to protect our children, it is natural that the family becomes the best defender of their rights.

The educational system is not perfect. Even in the most inclusive schools and classes there are children that do not receive the necessary support. **Through advocacy, parents can change the system so that their children have access to services and can protect rights that had not been observed.** This is how every advocacy process begins - from a motive that leads to an action. But what are the parents supposed to do when they find themselves in such a situation? Who to turn to for help? What exactly should they ask for? What should they do if their request is denied?

The role of an advocate, although natural, is not easy at all. It requires a set of skills and knowledge that parents of children with spina bifida and hydrocephalus must develop. It is very likely that due to the experience they accrued through the years, they have already mastered these skills without even realizing it.

Above all, in order to be an effective school advocate, **a parent must know the educational system well**, including its hierarchy, interactions between different units, roles, functions and responsibilities of the people involved in the child's education. We advise parents to familiarize themselves not only with the international conventions, but also with the more important administrative documents that apply to them locally. They can also find useful information, good practices and advice from other sources - internet groups, parent networks, friends and neighbors.

Once the parent becomes familiar with the environment, from his/her expert position, the parent can make a qualitative analysis of the current situation identifying the reasons that has led to this situation and all of the negative consequences on the child, on the other children at school, on the participants in the educational process and even on the society.

In the process of analysis, the parent may find various possible solutions to the problem, each of which could become the goal of the advocacy. Sometimes these solutions are relatively easy to achieve (installing a ramp at the school), but on other occasions they are more global and may require changes in administrative regulations or even a law (inclusion of the diagnosis in the list of diseases for reduced admission criteria at high schools). The more global the needed change is, the more likely is that you will need like-minded people to support you - other parents, local activists, NGOs, and why not politicians, especially at a time of approaching elections. Don't let such meetings scare you.

It is important to identify and contact the people who make the decisions and are responsible for bringing about the desired change. You can send a formal letter, visit them in the office during their office hours or seek informal personal contact - the choice depends on the specific case. Local media and social networks can also be useful in resolving issues related to the rights of people with disabilities.

Do not give up! Advocacy is a long-term process.

There is always a solution and there is always a higher institution to turn to.

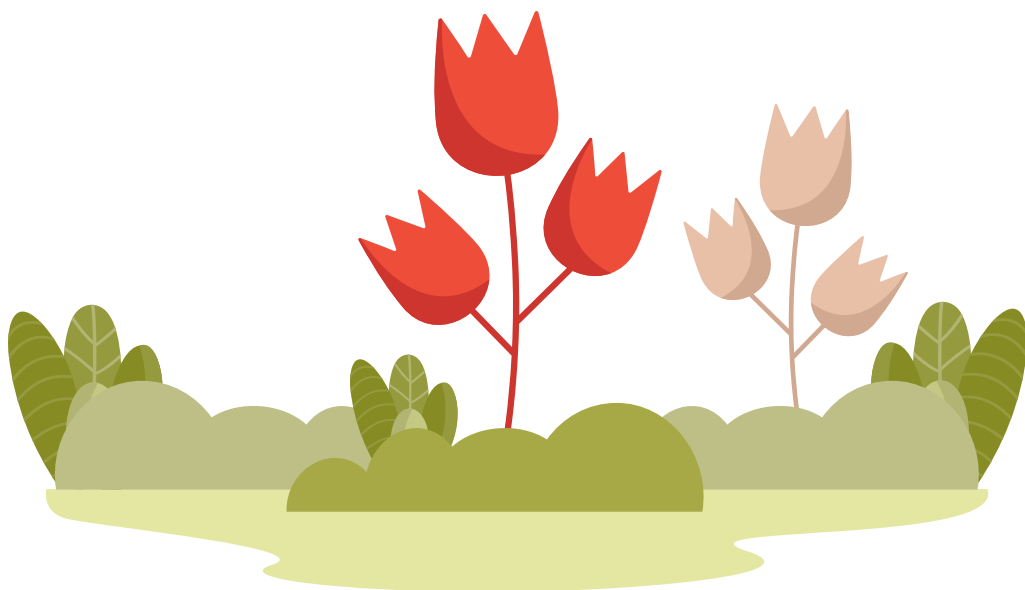
Although at times it may seem hopeless, advocacy works! One of the greatest benefits is that it leads to lasting positive change for everyone.



THE PARENT AS A ROLE MODEL FOR THE CHILD

Within the multidisciplinary team, the parent shares his/her vision for the child's future and the perspective of the parent becomes a behavior pattern for the other members. But the most powerful influence that the parent has as a role model is over their own child. The child copies from the parent both the attitude that the child will have towards himself as an adult and the attitude that the child has towards education and the professionals in the educational system. When in the contacts between the parent and the team at school the child observes respect, tolerance and willingness to cooperate, it is very likely that the child will have the same attitude. This is how a positive environment is built, which is the most suitable and stimulating environment for the student's development.

It is unacceptable to use harsh language or insults to the people who work with the child every day. If you still can't help but comment on them, criticize the behavior, not the person's personality.



INTERACTION WITH OTHER TEAM MEMBERS



As the child's representative, the parent interacts with all other members of the support team. For their joint work to be successful, it is important that the parent knows the roles, responsibilities and the rights of each of them. This will help build positive relationships and make communication significantly more meaningful and effective.

Keep in mind that most teachers and professionals working in the educational system support inclusive education, but sometimes they need additional help and knowledge. Be demanding, proactive and supportive of their efforts towards your common goal.



Teachers, including class teachers

Teachers play the main role in meeting the educational needs of children with spina bifida and hydrocephalus and are one of the most important members of the multidisciplinary team. When children experience learning difficulties, teachers are required to plan, adapt or modify the curriculum so as to ensure the participation of the children in the educational process and the in daily activities of the class. These duties of theirs may be shared with special educators, resource teachers, or teaching assistants.

The class teacher is the teacher who is closest to the child and who knows best the child's qualities and talents, strengths or learning difficulties. He or she usually takes on the role of team coordinator and is the school person with whom the parents communicate most often. When a child needs extra support or another urgent problem arises, it is normal to turn to the class teacher first. The class teacher could be used as a mediator in the communications with other teachers, participants in the team or parents of the other children from the class. Maintaining regular communication with the class teacher is very important. It is good to agree in advance how often the communication should take place and the teacher's preferred method - by phone, email or face-to-face.

The class teacher is also the main role model for the other children. When a teacher demonstrates a positive attitude, values diversity, and makes everyone feel accepted and important, regardless of their achievements, these values are more readily adopted by classmates and educators. Very often, the bad climate in the class is the result of a misunderstanding of the idea of inclusion on the part of the class teacher or his/her lack of knowledge or skills to apply it in practice. In such a case, you can support the teacher by providing working ideas from your own experience, or by seeking assistance from other members of the team, for example the special educator or the school psychologist, or by contacting the school management.



School leaders

The school leaders includes principals and other employees who are responsible for managing the activities of the educational institution. The primary role of the school leaders in the multidisciplinary team is to provide a safe, positive and accessible school environment and to promote an inclusive philosophy and attitude among all team members. This includes a number of activities such as planning, organizing and supervising the learning and administrative processes in the school, that are often invisible to people outside the school.

Parents are often worried about meetings with the principal and direct contact with the school management is rather rare. Usually, there is an initial meeting, when the child enters school or at the beginning of the school year, during which the general educational needs of the child and how they will be met in the future are the topics discussed. The reason for most follow-up meetings is often the lack of or insufficient support from the professionals in the team or another type of difficulty that the child encounters in the inclusion process. This practice is not good because it misses the moment for proper intervention or possible correction in the child support plan.

Inclusive education implies a partnership between the parent and the principal, regular contacts and joint decisions.

Special teachers

If a child has learning difficulties, the multidisciplinary team may include a special educator to support the work of the general education teacher. The role of the special educator is to support the child by providing special instructions and guidance in various formats. The resource teacher implements a variety of strategies so that students with learning disabilities pursue their personal goals within the activities shared with the class. In theory, inclusive education implies that the whole class learns together. However, taking the child out of class for additional activities with the resource teacher is a common but not a good example. If your child's activities with the resource teacher take place separately and in parallel to the curriculum, talk to the teachers and ask them to find a way to really include the child.

Special teachers often are the ones facilitating the communication among classmates by teaching students with disabilities social and communication skills and encouraging positive attitudes toward others. It is a good idea to present your child to them in the light in which you see your child, with his/her strengths, talents and interests. This will help the teacher find the common ground between the children in the class.

Maintain regular communication with resource teachers. They can help you better understand your child's learning difficulties and show you different solutions and strategies to stimulate your child's development outside school.

School psychologist

The school psychologist is responsible for the mental health and supports the personal development of students through advice and regular consultations in the school or kindergarten. In his or her work, the psychologist performs periodic assessments of the child's condition, which may include conversations with the parents. On the one hand, the parent provides information on the child's development until now and his/her behavior outside school, and on the other hand, the parent receives valuable guidance on upbringing. Don't worry about being open. The information you share will be treated as confidential.

Not all children with spina bifida and hydrocephalus visit the school psychologist regularly. However, it is important that both the child and the parents know that they can always turn to the psychologist for help or advice. In many cases, it is the parent who notices the first signs of anxiety or depression and can more easily recognize the signs showing that the child is a victim of bullying. If that happens, do not hesitate to seek the help of the school psychologist, especially in the period of puberty, which is extremely difficult for some children with spina bifida and hydrocephalus to go through.

School nurses and school health workers

School nurses are most often the health experts in the support team. They not only take care of the health needs of children with spina bifida and hydrocephalus in the educational institution, but also help teachers, special educators and psychologists to understand how the health status and health needs of the pupils may impact on their performance and behavior. In order to successfully fulfill their role, they need reliable information about the student's health status and health needs. Since spina bifida and hydrocephalus are not common diagnoses, it is normal for the school nurse not to know in detail the peculiarities of the health care for this patient group and lack practical experience with it.

Ask the nurse to read the manual for this target group and in a follow-up conversation, discuss your child's specific needs. In the Multi-IN manual for school nurses, a model of a health passport for students with spina bifida and hydrocephalus has been attached. The health passport contains the basic medical information in a systematized form and allows the nurse to quickly and easily cover the most important aspects of the child's condition. Along with this, the health passport also describes the student's basic needs, which the nurse should meet at school. We recommend that the parent and the nurse complete the health passport together based on the medical documentation provided by the parent.

Completing and keeping a health passport is not mandatory, but would significantly improve the quality of the health care at school. If the nurse at your school chooses not to use a health passport, make sure that you pass on the most important information, including contact information for you and the doctors in charge.

It is likely that the nurse will have no experience in performing clean intermittent catheterization. If the nurse will be the person performing this procedure, take time to demonstrate in practice how you perform the procedures. The Multi-IN manual for nurses contains helpful illustrations and the basic steps, which can help.

Assistant

In order to fully participate in the learning process, some children with spina bifida and hydrocephalus may require assistant support. The assistant can help them carry out a number of daily life activities, and in case of children with learning difficulties, the assistant can directly support the student by following the instructions of teachers and special educators.

Proper communication between the assistant and the parent is very important for successfully meeting the basic needs of the child in the educational institution. It is the parent's responsibility to provide reliable and comprehensive information about the child's current condition and needs. It is very likely that the assistant will have no previous experience with a child with such diagnosis, so provide the information using comprehensible language and, if possible, give demonstrations - show exactly how to lift the child, where to hold him or her, etc. The assistant will have to do some of these things for the first time. Clean intermittent catheterizations, although not sophisticated, are usually quite challenging. Be patient, explain and plan ahead for time required to master these new skills. Ask your child's assistant to read the Multi-IN manual for this target group and give specific additional guidance if needed.

As the assistant is an adult who spends much of the day with the child, he or she will often feel the need to set boundaries and enforce rules. These all should be agreed with you and should reflect your parenting style. Take the time to explain calmly and comprehensively what principles and values you want to pass on to your child and demand that the assistant implement them.

It is quite normal for a closer and even friendly relationship to develop between the parent and the assistant. In informal conversations, the parent can receive feedback about the learning process, relationships with other children and the overall climate at school. Treat this information as confidential and use it wisely so as not to discredit the assistant.

Pupil

The student is an important member of the multidisciplinary team. His/her role usually overlaps with that of the parent, with the child becoming more active and taking on more roles and responsibilities as the child grows up. The degree of participation and commitment varies according to the age and abilities of the student, but also according to how much the parent is willing to delegate rights and responsibilities to the child. Usually, the parent is the one who determines the student's role and activities in the team and prepares the child for them. This happens naturally and is part of the overall preparation for the transition to independent life that parents implement when raising and educating their children. This is a long process and begins at an early age, long before the child comes to the school door.

Discussing topics related to education in a language that the child can easily understand, respecting his/her opinion and making joint decisions; active participation of the child in the meetings with the professionals at school - these are all small steps towards empowerment. The goal is that the child becomes an expert in his/her needs, is able to communicate them, set goals, use the support and resources of the professionals, make independent decisions and stand up for himself/herself.

CONCLUSION



The concept of inclusive education gives the parent a primary role in the multidisciplinary support team. Due to parent's expertise in the care and needs of the child, the parent is a valuable partner of the educational professionals. At the same time, as the person who raises and educates the child, the parent is the one who largely determines the student's potential, which the professionals will work to develop.



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*Your children are not your children.
They are sons and daughters of Life's longing for itself.
They come through you but not from you.
And though they are with you yet they belong not to you.
You may give them your love but not your thoughts,
For they have their own thoughts.
You may house their bodies but not their souls,
For thir souls dwell in the house of tomorrow, which you cannot
visit, not even in your dreams.
You may strive to be like them, but seek not to make them like
you.
For life goes not backward nor tarries with yesterday.*

Kahlil Gibran

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MANUAL

for parents and family members
on multidisciplinary care and inclusive education
of pupils with spina bifida and hydrocephalus

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