



MANUAL

for assistants in kindergartens and schools
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
and

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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 assistants 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 Assistants in Kindergarten and Schools is part of a set of training materials created under the Multi-IN project to support the provision of multidisciplinary care and the inclusion of students with spina bifida and hydrocephalus. It supports assistants in their efforts to provide quality care and create a supportive and inclusive environment. There are different types of assistant support in European practice, that is why the introductory part draws attention to the fact that the manual is aimed at that large group of assistants who practise also in a learning environment.

The manual reviews the role of assistants in a multidisciplinary support team and their interaction with other stakeholders, with a focus on the relationship with the child and the family. In addition, the document examines the scope of assistance in meeting basic needs and risk prevention in children with spina bifida and hydrocephalus in kindergartens and schools. Special attention is paid to assistance support in the process of social inclusion and education.

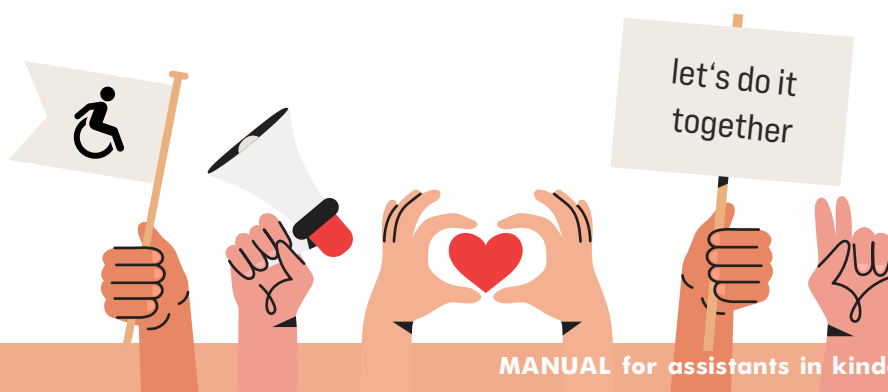
The four types of application that describe the main steps in clean intermittent catheterization, including illustrations by B. BRAUN MEDICAL Ltd., also bring direct practical benefits in child care.

The manual provides specific advice and good practices to assistants that will facilitate their work and make child care more comprehensive and inclusive. At the same time, we strive to elucidate why all these tips are important and to show how proper care can put a child's life on the path to improvement.

We hope that this Manual will help assistants realise their value in the lives of the children entrusted to them and to concentrate their efforts on achieving full participation, inclusion and independence.

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

www.multi-in.eu



ASSISTANCE CARE FOR CHILDREN WITH DISABILITIES



The Member States of the European Union that have ratified the UN Convention on the Rights of Persons with Disabilities are committed to ensuring an inclusive education system at all levels (Article 24, paragraph 1).

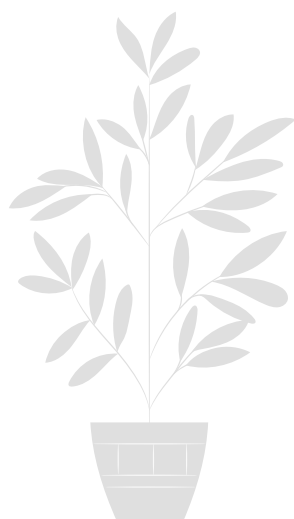
All children and young people rely on teachers and non-teaching staff to learn and be included in the education system.

For children and young people with disabilities, non-teaching staff (assistants, teaching assistants, pedagogical assistants, etc.) play an essential role in involving them in every aspect of school and pre-school education.

A study conducted in Europe in 2017 under the project "Improving Assistance in Inclusive Educational Settings"(IMAS), clearly indicated that there are no clear and consistent frameworks for the access, quality and responsibilities of assistants in the educational system. It is also impossible in some countries to provide ongoing support for children with disabilities in kindergartens and schools. For example, the type of support that an assistant provides is different as well as how they are called.

Whether this is a personal or a social assistant, a health or an education assistant, their role in the inclusion of children is crucial.

It is important to support the work of assistants of children with hydrocephalus and spina bifida, to clarify the roles of the actors in inclusive education and to provide practical guidelines for work.



THE ASSISTANTS' ROLE IN THE MULTIDISCIPLINARY SUPPORT TEAM



In order to participate fully in the learning process, some children with spina bifida and hydrocephalus need support by an assistant.

The assistant performs activities to provide daily support and improve a child's quality of life.

Assistance tasks are varied in type and depend on the level of independence of the child as well as on the disability according to the diagnosis. The assistant can help children with a number of daily activities such as eating, dressing, changing clothes, moving and positioning, as well as travelling to school. The assistant also helps with the use of aids such as a walker, a wheelchair, with putting on and taking off splints, etc. In the case of children with learning difficulties, assistants can directly support the student by following the instructions of teachers and special educators.

It is important to understand the contribution of the assistant's work, as they play an important role in the child's process of integration. An assistant's place on the multidisciplinary team is often not clearly defined. The assistant is usually a person who is not a member of the child's family, appointed by the kindergarten or school that the child attends, an employee of an external social service providing support. It is important to understand that the role of the assistant in a multidisciplinary team working with a child with spina bifida and hydrocephalus is as important as that of any other member. An assistant is usually the link between the parents and the institution, supporting not only the child but also the teaching staff. They often help the child build relationships with the other students and peers. The assistant is constantly around the child and his/her work directly supports the inclusion of the child with spina bifida and hydrocephalus.

SPINA BIFIDA AND HYDROCEPHALUS



SPINA BIFIDA

Spina bifida occurs as a result of incomplete closure of the spine and vertebrae that surround the spinal cord. This happens in early pregnancy, so spina bifida is a congenital defect. Some of the vertebrae of the spine remain open, hence the name, which literally translates from Latin as “split spine”.

This literal translation often gives a false impression that spina bifida mainly affects the skeletal system. In fact, from a medical point of view, the diagnosis is related to a malformation of the spinal cord and nervous system. In practice, this means that spina bifida can impair the motor functions and the sensitivity of the limbs, the brain function and the urinary function and the bowel function leading to incontinence (spontaneous urination and/or faecal incontinence), etc.

Spina bifida damage can be quite discreet, but it can also cause very serious consequences. This depends on the type of spina bifida – open or closed, as well as on the level of the lesion – the higher the place where the spine is affected, the more severe the damage.

Spina bifida occulta and meningocele are closed forms of spina bifida and usually have no or only mild neurological manifestations.

Myelomeningocele is the open form of spina bifida. This is the most severe form entailing damage to the spinal nerves. Newborns are operated on soon after birth. When we talk about spina bifida, we often have in mind that form which has the most serious neurological manifestations.

Spina bifida is a complex condition with many manifestations, each with a different degree of severity.

To show how different children can be and to facilitate the work of specialists, we have prepared a stand-alone edition of personal stories in addition to Multi-IN resources. We have included personal stories and real examples from the education of children from Bulgaria and Slovakia. Their names were changed, but each story involves a real child with good and not so good examples of inclusion.

We recommend that anyone who works or is about to start working with a child with spina bifida read these stories. Only some of them involve assistants, but we believe that each story sheds light on a specific aspect of child care and education and considered together they produce a good picture of the inclusion needs of children born with this diagnosis.

HYDROCEPHALUS

Nearly 90% of children with myelomeningocele also have hydrocephalus. It also occurs in children with other diagnoses such as brain tumours, complications of prematurity, congenital aqueductal stenosis, etc. (Kahle, 2015).

Hydrocephalus is a condition characterized by creation of increased pressure in the cranial cavity due to excessive collection of cerebrospinal fluid (CSF). The cerebrospinal fluid needs to circulate freely and its function is to protect the brain and the spinal cord. In hydrocephalus, the body cannot reabsorb the fluid and it accumulates in the ventricles of the brain.

It is treated surgically with the placement of a shunt/valve. The role of the shunt is to mechanically take the excess cerebrospinal fluid to the abdominal cavity or circulatory system, where the body reabsorbs it.

Subsequent surgical revisions are required for a large proportion of children who have a shunt. The most common causes are mechanical damage, infections, obstruction and need to extend the catheter; it is possible to have insufficient or excessive drainage of cerebrospinal fluid. More about the symptoms and instructions on how the assistants should react are given in the chapter “Shunt malfunction in children with hydrocephalus”.



THE ROLE OF THE ASSISTANT IN MEETING THE BASIC NEEDS OF CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS IN KINDERGARTENS AND SCHOOLS



Spina bifida is a complex condition that, along with hydrocephalus, can have a variety of manifestations, varying in severity. Most people with myelomeningocele have motor and sensory deficits below the place of the defect and use aids to move. Many suffer from some degree of urological and intestinal dysfunction, which they control with a strict regimen and intake of medications and supplements. Some have cognitive and learning difficulties. Other common secondary conditions are the development of decubitus ulcers on the skin, latex allergy, obesity, pain, poor endurance and difficulty to keep balance.

Most children with spina bifida and hydrocephalus need assistance to participate fully in all activities when staying at school and in kindergarten. The scope and intensity of this support depends on the child's condition and age, the accessibility and security of the environment, and the services available in the school. Some children may need constant care, including during classes, while others will need help mainly when moving around or using the toilet.

The main goal of the assistance in the kindergarten and at school is to provide support in the areas of deficit, so that the child can participate safely, fully, simultaneously and on an equal footing with other children in the learning process. The assistant can provide health care while supporting social inclusion, promoting the independence and the individual development of the child.



TOILET ASSISTANCE: CLEAN INTERMITTENT CATHETERIZATION (CIC)

Up to 90% of children with myelomeningocele have urological problems which include urinary retention and incontinence. A neurogenic bladder can lead to recurrent urinary tract infections, progressing to hydronephrosis and renal failure. **Many children manage to achieve social continence and reduce urinary tract infections by using a programme of clean intermittent catheterization (CIC), sometimes in combination with medication.**

CIC is a technique for draining the bladder at regular intervals using a disposable catheter. It is prescribed by a urologist who provides initial training to the parents and/or the child. A catheter is used 4-6 times a day according to the prescriptions and needs of the patient. For infants and younger children it is performed by a parent or another adult, while older children catheterize themselves.

Despite the widespread use of CIC around the world for four decades, in some countries this technique is still not well known. To support the work of the assistants, we have described the main steps of catheterization for girls [\[Appendix 1\]](#) and for boys [\[Appendix 2\]](#) in the appendices to this Manual, and in [Appendix 4](#) we have provided specific practical advice.

In some children, a catheter is not inserted into the urethral opening, but through a continent catheterization stoma located on the abdomen, below or at the waist level. It is called Mitrofanoff stoma and allows the catheter to directly access the bladder. Patients with Mitrofanoff stoma should be catheterized at strict intervals. The main steps are described in [Appendix 3](#).

Here are some basic tips for assistants to successfully apply the method in school:

- CIC is a technique that is used at home. There is no requirement to perform it in a healthcare office or by a medical person. Just as parents and even 7-8 year old children master the technique, thus any adult can also learn to apply it. This is a new skill that will expand the qualification of the assistant;
- It is recommended that the assistant be trained by a urologist or urotherapist. In practice, in most cases, parents train the assistant;
- **CIC is not a sterile technique, but it is still important to keep to high hygiene standards;**

- Catheterization can be performed in the toilet if the room is large enough, clean, lit and provides the necessary privacy;
- The catheters and other necessary supplies must be provided by the child's family. It is best to do this in advance and to have supplies for a longer period of time, for example for the next 5 to 6 days in order to avoid the risk of the child being left without catheters. It is necessary to prepare a schedule for the supply of consumables that is convenient for both parties;
- The CIC schedule should be in accordance with the physician's prescriptions and the child's schedule. In order to promote social inclusion and free communication with peers, it would be appropriate that the time of catheterization not coincide with the long break;
- teachers should be warned that the procedure is time-consuming and that the child could be late for class. This is best done by the parent or even the attending physician;
- The assistant should approach the catheterization with the necessary discretion that is in line with the perceptions of the child and the child's family. There are children who speak freely about this to their peers, but for others this topic is taboo. The assistant must respect the child's values and adhere to them.

Older children begin to self-catheterize between the ages of 9 and 14 (Atchley T. J., 2018). Every child is different, so there are quite a few children who manage to do it on their own at the age of 6 or 7 and others who still need assistance or at least supervision in adulthood. By explaining and repeating aloud the individual steps of the procedure, the assistant helps the child's transition to self-catheterization.

For some children with spina bifida it is difficult to do it on their own even at an older age due to cognitive difficulties. They often forget the sequence of steps or forget that it is time for catheterization. In this case, the role of the assistant is rather to supervise the child. To make learning easier, you can use the appendices to the manual where the basic steps are presented in pictures.



SPECIAL AIDS

Special aids radically change the life of children with motor disabilities – they make them more mobile and independent, they make the environment more accessible and daily activities less risky. For most children with spina bifida and hydrocephalus, special aids are an integral part of life, including during their stay in kindergarten and school.

In order to ensure that the support will be as effective as possible, it is important for the assistant to be familiar with the aids used by the child, including their purpose, benefits, use, placement and removal.

The child can use different combinations of aids, the purposes of which are diverse. Some of these aids support the development of specific skills, others promote independence, another group make the participation in daily learning activities effective, and still others can be used for therapeutic purposes or in training.

Below we have described the characteristic features of some of the most common special aids used by children with spina bifida and hydrocephalus:

Wheelchairs – ring and electric wheelchairs

In some countries, these are often called “invalid wheelchairs”, but we advise assistants to refrain from this definition.

Some children have been actively using a wheelchair since the age of 2-3, coping well with manoeuvres and control. Please note that not all children who use a wheelchair cannot walk. There are important advantages to using a wheelchair. It saves valuable energy that children can invest in important activities such as playing with friends.



Children spend much of their daily lives in wheelchairs and poor positioning can lead to serious consequences such as pressure sores, difficulty breathing, difficulty swallowing, severe spinal deformities, problems with peristalsis, pain and discomfort, fatigue.

When positioning the child in a wheelchair, the assistant must ensure that:

- The buttocks should be as far back as possible, resting firmly on the back of the wheelchair;
- The body should be centred in the wheelchair – the back should be centred to the backrest and the buttocks – to the seat. This allows even weight distribution and helps to avoid the appearance of decubitus ulcers;
- The pelvis should be at one level (the left side should be aligned with the right side);
- The knees should also be aligned and at the level of the thighs;
- The feet must stand firmly on the stand/footrest;
- Seat belts should be used even for short distances. They are important for both safety and proper positioning.

These are general tips that may differ in some cases from the prescriptions of the supervising physician and therapist. Above all, follow your doctor's prescriptions.

If you notice an incorrect posture, talk to the parents and/or therapist. There are various accessories such as belts and pillows that can adjust the improper sitting posture and prevent additional risks.

Due to the neurological deficit, children with spina bifida do not feel discomfort and numbness when sitting down in the same position for a long time. They need to be reminded to change their position in order to release the tension in the respective part of the body. Light exercises and wheelchair push-ups every hour are highly recommended.

The brakes must always be put on when the child has stopped, when the child is transferred from/to the wheelchair or when the wheelchair is unattended.

The assistant must be shown how to disassemble the main parts of the wheelchair, when the wheelchair has to be transported. It depends on the specific model and the parents should give the appropriate instructions to make sure that the wheelchair will then be used in a correct manner. For example, never lift the wheelchair when holding the armrests, wheels or other moving parts.

Walkers, canes, canadian crutches

They are some of the most widely used aids to support the walking of people with disabilities. They allow independent walking, climbing stairs, curbs, etc.

Orthoses/splints

The orthoses for the lower limb are often used in combination with walkers, crutches, Canadian crutches and canes. The orthoses cover the leg while fixing it in a specific position and stabilising it. At the same time they protect the bones against breaking and spraining. The child may need orthoses for both legs or for one leg only.

The main types of orthoses are divided according to the part of the leg they cover. The prescription and the selection of a specific type is determined by the type and degree of the motor impairment. The principle is that orthosis helps where there is muscle weakness. Using orthoses is a dynamic process and people may need different orthoses during the different stages of life.

For people with physical disabilities, aids are an invaluable opportunity to achieve autonomy and participate in social life. Most people do not realise that they are very expensive from a financial point of view. The process of making, ordering or repairing is difficult, and for many children this involves travelling to another city or country. **The assistant should teach the child how to be responsible and take care of the special aids** – children should not throw the crutches on the ground when sitting down and the crutches are no longer needed; when using a wheelchair children should avoid routes with bumps; children should carefully place the orthoses after removal, etc.

Bright colours and the unknown often attract younger children to special aids. Many of them think that they are for play and fun and want to touch them and play with them. Sometimes there is nothing wrong with this and it can become an occasion for meeting new people and making new friendships. In other cases however, it can be dangerous. Find out what the child thinks about the issue, discuss this topic with the parents and find an appropriate strategy in such cases.

Learning and communication aids

In addition to mobility aids, children with spina bifida and hydrocephalus can use aids of varying technological complexity to help them learn or communicate. Low-tech tools are pencil handles, timers, graphic organisers, maps and other communication systems, checklists, etc. High-tech aids are software for converting voice to text and vice versa, eye-driven communication software, reminder and daily planner applications, etc. All of them can be of great benefit to children with cognitive and learning difficulties, so it is important for the assistant to know their purpose and method of use. In some cases, additional training will be needed.

MOBILITY ASSISTANCE

For people with reduced mobility, most daily activities are a real challenge. Many public buildings, including schools and kindergartens, are not fully accessible and children with spina bifida and hydrocephalus need physical support to move in combination with aids.

The assistant can be very helpful in meeting these needs, paying attention to some details:

- Many people with disabilities have become so accustomed to the aid that they perceive it as an extension of their body. When you start working with a new child, take the time to study how the child moves and how he/she usually uses his/her aid – whether the child is active in the ring wheelchair, how stable he/she is with crutches, whether he can negotiate curbs with a walker, etc. It is important to know what the child can do on his/her own and when he/she needs help. Encourage the child to do all he/she can, even if it takes longer.
- Do not assume! Always ask before helping. In most cases, the child knows exactly how he/she wants to be helped and will tell you that.
- Always inform the child before manoeuvring or before touching the aid.
- If you can't handle a particular obstacle on your own, ask another person for help.
- If the wheelchair gets stuck, do not push or press, but check what the problem is and try to correct it.
- When descending a slope, always hold the wheelchair firmly and do not push it forward.
- When the child uses crutches or even when walking on his/her own, always go in front of him/her when climbing down the stairs and walk behind when you climb up.

HELP WITH EATING, SERVING THE DISHES, CLEARING THE TABLE, ORDERING FOOD

In addition to mobility, children with spina bifida and hydrocephalus may need help with feeding, especially with serving the dishes and clearing the table. Many children cannot carry food and drink trays without assistance. This does not mean that the assistant is solely responsible for setting and clearing the table. The child must have responsibilities depending on his/her age and ability – to set the table, hand out napkins, etc. As for the choice of food, the child should be able to choose his/her food.

Don't be tempted to choose instead of him/her in order to save time or because you think you know his/her desires.

Since eating is a social activity, give the child an opportunity and space to communicate with his/her peers.

USE OF MEDICATIONS

Most children with spina bifida and hydrocephalus require daily use of medications and supplements that target secondary conditions associated with their diagnosis. We are aware that the assistant may not be a medical professional, but he/she may undertake a commitment to give the prescribed medication if it is to be taken during the time that the assistant spends with the child.

NUTRITION AND HEALTHY LIVING

Children affected by spina bifida, and especially those who have hydrocephalus, are at high risk of obesity. Being overweight is associated with an increased risk of high blood pressure, diabetes, osteoarthritis, impaired cholesterol metabolism and heart diseases.

Along with its negative effects on the overall health, being overweight has a negative effect on a person's independence, self-care, self-esteem and mental status.

The high obesity rate in adults with disabilities makes it especially important for children and young people of this group to maintain good physical shape and healthy weight so that obesity does not negatively affect their quality of life.

When working with a child it is important to promote a body positive attitude, healthy lifestyle, healthy eating and exercise. This can be done through conversations and by presenting information in accessible language, setting good examples, providing support in sports activities and games.

The assistant should not forget that he/she becomes a role model. In this role, the assistant can set a good example by following a healthy lifestyle – choose healthy foods, avoid sugar, drink plenty of water, show a positive attitude towards exercise and sports and in no case allow himself/herself to demonstrate a bad habit (for example smoking) in front of the child.



THE ROLE OF THE ASSISTANT IN RISK PREVENTION IN CHILDREN WITH SPINA BIFIDA AND HYDROCEPHALUS



Every child may find himself/herself in a situation where he/she needs urgent support or even emergency medical care. Children with disabilities, including those with spina bifida and hydrocephalus are exposed to higher risks in this regard due to their specific health conditions. Emergencies are by no means a daily occurrence, but it is important for the assistant to know the most common risks and symptoms and how to react according to the needs and condition of the child.

The assistance is focused mainly on prevention and timely signalling, in order to avoid or reduce the risk. Ensuring the safety of the child at school is a shared responsibility of all stakeholders involved in the process of his/her inclusion.

Each party plays a specific role and functions, which contribute to avoiding risks and ensuring safe participation in the learning process. This guide is intended for assistants and the focus here is on their role. Below they will find useful tips on what to pay attention to in their work, how to identify potential risk situations and how to help the child in the best way. However, we must emphasise that this could not compensate for the commitment of the other parties – parents, teachers, principals, health workers, etc. It is important that each of them approaches the topic of safety in a professional and responsible manner.

The reaction usually consists in informing a parent/guardian, the nurse or another representative of the educational institution. **In the best case, the measures taken in due time should prevent any health emergencies.**



INJURIES RESULTING FROM ACCIDENTS

Most children with myelomeningocele have varying degrees of motor deficits. The degree is determined mainly by the level and size of the lesion. The higher the level where the defect has occurred, the greater the scope of the paresis and the more severely the motor function is affected. Hydrocephalus can also impede mobility as it affects balance and coordination in some children.

Accidents can occur when slipping on a wet floor, stumbling on stairs, manoeuvring with a wheelchair, tripping, falling or simply losing control. Such accidents can be dangerous for children with spina bifida as their bones are more fragile (Marreiros, 2018) and since they have reduced sensitivity, they may not be aware of the fracture. Injuries to the head, for example, can cause valve problems and lead to severe consequences.

Just like any other children, children with spina bifida and hydrocephalus cannot be completely and always protected against accidents. The main task of the stakeholders in the educational process is to ensure maximum safety and to limit the risks. Depending on their roles and responsibilities, each of them has different options for action in that respect. **An assistant provides direct physical assistance to the student to avoid the risk of injury.** In addition to that, knowing the needs of the child, the assistant can be a member of a team that **gives suggestions and ideas for improving the safety** of the architectural environment, can assist in the selection of aids and can promote safe behaviour.

Unsafe architecture in and around kindergartens and schools

In the General Guidelines we describe the safety and protection needs of children with spina bifida and hydrocephalus in kindergartens and schools. They occupy one of the base levels in the Multi-IN Inclusion Pyramid. The provision of safe infrastructure is sometimes neglected, especially in schools that have no previous experience with people with disabilities, and the reason may be the poor knowledge of the needs of these people.

In order to prevent an accident physically, the assistant must be especially careful and inseparable from the child, when using:

- Ramps;
- External and/or Internal stairs without handrails;
- Slippery flooring;
- Thresholds and High curbs, especially unmarked;
- Yard and adjacent sidewalks that have not been cleaned of leaves, snow and ice or that have broken tiles;
- Narrow corridors and stairs and gatherings of students on them;
- Classrooms without specified paths and manoeuvring space;
- Bags and other student belongings piled on the floor in classrooms;

These are just some of the potential dangers that the environment in kindergartens and schools can hide. If possible, the assistant should check the safety of the environment in advance. For example, he/she should walk around the building and its surrounding areas first without the child he/she will be caring for.

When the assistant notes a potential threat, he/she must report it to the management of the educational institution so that steps can be taken for its elimination. Depending on the official structure, the signal may be submitted directly to the management, the parents or the provider.

Some of the dangerous situations related to the environment can be avoided with good planning – by choosing a safe route inside and outside the building or by choosing a suitable time to move down the corridors and stairs that is different from the time when the main flow of students move around. This should be coordinated with the teachers, the management or the parents.

Improper use of aids

It is not always possible for specialists who prescribe aids to see how much such aids improve functionality in everyday life and how safely they are used. The close observations and the judgement of the assistant can be very useful in this regard both for improving security and for the overall functioning of the child. The assistant may notice that:

- The aid is not used safely and as prescribed – the child does not fasten the seat belts when in the wheelchair, forgets to release the brake or fails to manoeuvre well; leans back in posterior walkers, etc.
- The child uses the aid in a risky manner – sometimes, in order not to lag behind friends, to attract attention or for other reasons, children may undertake risky manoeuvres with the aid. These risky manoeuvres endanger both the children themselves and the others around them.

In these situations, first of all, the assistant must take action to ensure the safety of the child and the others. This can be done by prompting the child, reminding him/her of the safety rules or by directly intervening if necessary. As a next step, the assistant should share his/her observations with the parents or therapists so that they can take appropriate action.

Cognitive impairment

The increased risk of injuries and accidents for children with spina bifida and hydrocephalus is not only due to motor and sensory deficits. This can also happen as a result of poor judgement, delayed reactions, decreased attention, impaired visual-spatial perceptions or other cognitive impairments of the child.

The assistant should be especially vigilant and should not assume that the child can fully assess the risks, especially in new situations.

Safety should be one of the main topics when communicating with the child, observing the basic rules of communication with children with cognitive impairments:

- Avoid important conversations in situations with external stimuli – when it is noisy, when there are many children around or when you are pressed by time;
- Make eye contact to ensure that the child is really paying attention in the conversation;
- Summarise the rules of recommended behaviour in a specific risky situation, breaking it down to small and easy to implement steps;
- Use maps, patterns, pictures and diagrams to describe visually safe behaviour;
- Give clear and concise instructions using understandable language;
- Repeat orally together with the child.

An assistant will always be in a position to seek a balance between ensuring safety and promoting independence. **The best advice we can give is to let the child do everything he/she can do independently and to support the activities where the deficits are manifested.** There are no universal solutions.

Good communication with the family is extremely important, especially on safety issues. The assistant should feel that he/she can share his/her concerns openly, while respecting the family's perceptions and being guided by their priorities. **Some families are willing to take certain risks in the name of independence, and the assistant must respect their wishes.**

UROLOGICAL INFECTIONS

Clean intermittent catheterizations are the preferred method and “gold standard in bladder control in patients with spina bifida” [Lapides, 1972].

The symptoms of urological infections are malaise, fatigue, headache, fever. Typical abdominal pain and burning when urinating in children with spina bifida may be absent. Until recently, urine type and odour were thought to be a reliable indicator of infection, but new research suggests that this may be a misleading symptom (Midthun, 2004).

The assistant can help with the prevention of urological infections in the following ways:

- Follow strictly the prescribed schedule for catheterization and do not take long breaks;
- Observe high hygienic standards when performing catheterizations;
- Change the child's pads/diapers often enough;
- Encourage the intake of water and fluids;
- Inform the parents if cloudy, foul-smelling urine is noticed;
- Call the school nurse and inform the parents in case of the symptoms of general malaise, fatigue, headache, fever, described above;
- Give the prescribed antibiotics in the course of treatment according to the instructions of the attending physician.

HEATSTROKE

People with spina bifida often suffer from impaired heat exchange process and impaired sweat secretion. High temperatures can adversely affect their overall health and it is therefore advisable to avoid them.

The assistant can reduce the risk by:

- Avoiding sunny routes to and from school;
- Avoiding transport without air-conditioning;
- Ventilating the room;
- Taking the child out into the cool air if staying for a long time in stuffy rooms;
- Encouraging the intake of fluids;
- Carrying a water spray for face and body or a bottle of water for cooling.

SKIN INFECTIONS AND HARD TO HEAL WOUNDS

Nerve damage in spina bifida could lead to loss of sensitivity. Some children are not able to feel heat, cold, pain, pressure, abrasions or excessive moisture. Impaired blood supply and slow lymph circulation in the lower part of the body could make wounds healing extremely difficult. Therefore, prevention is the main focus of skin care for children with spina bifida.

The assistant supports prevention as follows:

- Makes slight changes in the position of children with limited mobility and encourages movement and light motor exercises during breaks;
- Places and removes the orthoses of children who stay for an afternoon nap in the kindergarten;
- Makes sure that the diapers and nappies of incontinent children are changed frequently so that their skin stays clean and dry for longer;
- Examines the child's skin for signs of redness, especially in areas covered with splints or pressure points. The assistant should inform the parents and/or the nurse in case of redness that does not fade away within 30 minutes, in case of new wounds and calluses. Do not put the splint back on in such cases! Do not rub the place!

An assistant's main task is to encourage the child's independence in self-care. It is therefore advisable for the assistant to explain the importance of each step in skin care, drawing attention to any disturbing signs that the child should be aware of.

Skin inflammation can quickly progress to an abscess, usually accompanied by fever, malaise, nausea or vomiting. If these symptoms are present, the assistant must inform the school nurse immediately.

BURNING OR FREEZING OF LOWER LIMBS

Decreased or absent sensitivity in the lower body can lead to severe burns and frostbite of the lower extremities without the child feeling pain. It is important that the assistant does not forget this and be vigilant when the child is near hot liquids or objects such as radiators, wood stoves, pipes, etc. The seats in classrooms that are next to radiators and other heating sources, as well as prolonged work with a laptop on the lap, should be avoided.

On cold winter days there is a risk of frostbitten feet. Prolonged standing and wetting of the feet should then be avoided.

In case of burns and frostbite, the assistant must seek medical help.

ALLERGIC REACTION TO LATEX

Latex allergy is a specific reaction to products made of natural rubber latex. The risk of developing latex allergy increases with repeated exposure to latex products. Even without a history of allergy, people with spina bifida and hydrocephalus should avoid contact with latex products. Instead, they should use products made of silicone, plastic, nitrile or vinyl.

Proteins contained in certain foods can cause a similar reaction of the immune system like the one caused by proteins contained in the latex. Such foods are bananas, kiwis, avocados, papayas and chestnuts.

Most often the reactions are mild and present as allergic contact dermatitis - skin redness, blisters, itching, flaking of the skin, eye burning and tearing. The assistant should seek help from the nurse.

In some children, symptoms may progress to rapid heartbeat (tachycardia), chest pain, difficulty breathing, tremor. In these cases, call immediately 112!

SHUNT MALFUNCTION IN CHILDREN WITH HYDROCEPHALUS

In children with hydrocephalus, there is always a risk of complications associated with valve malfunctioning. It is essential that the assistant is well aware of the signs of the malfunction. Timely treatment reduces the risk of possible complications and brain damage!

Symptoms can vary. Some develop more slowly and are chronic. These are:

- Irritability and other abrupt changes in the child's emotions and character;
- Deterioration in school performance;
- Headache, more pronounced in the morning; Weakness

In these cases, the assistant should alert the parents.

Other symptoms require immediate consultation with a neurosurgeon and/or neurologist and therefore the assistant must inform the parents of such symptoms in due time. These include:

- Severe, intolerable headache; Nausea and vomiting, more pronounced in the morning
- Pain in the neck and throat;

- Impaired vision; Double vision;
- Sensitivity to light; Redness along the shunt line;
- Abdominal pain if there is drainage to the abdomen; Difficulty moving due to spasticity;
- Drowsiness or inability of the child to stay awake; Loss of consciousness.

INCONTINENCE ACCIDENTS

Emergencies that require assistance are not always associated with an immediate health risk. These are the incontinence accidents that can occur most unexpectedly.

Almost all people affected by spina bifida suffer from urological and bowel dysfunction to some degree. By introducing a programme for CIC and a regular bowel washout programme, most children achieve satisfactory control and social continence.

However, cases of small or more serious incontinence accidents. The assistant must react discreetly and quickly, helping the child to clean and change clothes. It is advisable that the child has a second set of clothes and wet towels available for such cases. The toilet, the health office or another separate room can be used for cleaning.

In case of large amounts of faecal mass, it is desirable to call the parents and the child should go home to completely clean the intestines.

EVACUATION IN CASE OF DISASTERS

With regard to accidents, the assistant must keep the following in mind:

- Natural disasters and other emergencies can occur at any time;
- Familiarise yourself in advance with the school's emergency evacuation plan.
- Make sure that the bag with consumables (catheters, urological pads) is with you/on the wheelchair;
- Accompany the child on the way to the nearest exit according to the plan;
- Never leave the child alone;
- When you reach a safe place, inform the school management and indicate the location;

EMERGENCY MEDICAL CARE

Even with the best care and attention, urgent medical attention may be needed.

We remind you below of the basic rules in case of an emergency medical case in the school, valid for both the assistant and every adult:

- Call 112
- Send someone to call the school nurse immediately
- Stay with the child
- Inform the child's parents/guardians of the situation

We stimulate the assistant many times in this manual to encourage the child's empowerment and self-care. However, let us not forget that a child is not always able to adequately assess the risks and the need for help in a given situation. Trust your judgement!



THE ROLE OF THE ASSISTANT IN THE PROCESS OF SOCIAL INCLUSION IN KINDERGARTEN AND SCHOOL



The role of each participant in the process of inclusive education is crucial. Children with spina bifida and hydrocephalus have the right to education, social contacts and emotional development equal to their peers. Inclusive education is an integral part of the right to education. It is essential for the development of a child with spina bifida and hydrocephalus to participate consciously and at all levels in the process of interaction and learning in kindergarten and school. It has also been proven that social relationships have a beneficial effect on the physical and mental health of every person (Pachucki, M. C., Ozer, E. J., Barrat, A., & Cattuto, C., 2014).

We encourage proactivity and different methods of work that would acquaint the circle around the child not just with his/her deficits, but also with his/her strengths and abilities.

Be active, do not hesitate to talk to the parents of the child you are working with about the specifics of his/her needs arising from the diagnosis. Do it with respect and attention, this is not something to worry about. It is good to be prepared to answer the questions that sometimes other children may ask you. Discuss the issues with the family and the teacher on a regular basis. The topic is not taboo, and when presented in an appropriate way, it can only help other students understand. Lack of information is sometimes more dangerous and may do unnecessary harm.

At the same time, the assistant is an observer watching how the others perceive the child with spina bifida and hydrocephalus and how the child interacts with them. Using a game or the impressions of the interests of the different groups in the class, the assistant can include the child in common games and activities and why not try to help build friendships. When a relationship is established, the assistant should withdraw and let the child communicate with his/her peers on his/her own. The assistant can stay nearby if the child needs him/her, but still leave enough personal space for free interaction. Remember that interpersonal relationships are complex enough without the intervention of an assistant. The child you support is probably anxious and tense when interacting with others. You can help him/her simplify that interaction if needed. Also, your presence would be helpful in a situation of conflict or aggression. If this happens, you need to decide whether and how to inform the teacher and the family.

Barriers to architectural inaccessibility easily become social barriers. Try to provide the child with physical access to peers. Sometimes this means to draw the teacher's attention to the fact that some activities exclude some children from the class. Do it carefully and discreetly. Other times you just have to move the wheelchair closer to the rest of the children.

There are children with spina bifida and hydrocephalus who are not verbal. This does not mean that they cannot communicate and that they do not need it. They usually use sign language, card communication systems or specialised software. When an assistant starts working with such a child, he undergoes the appropriate training so that they can communicate effectively with each other. At the next stage, the assistant can pass this knowledge on to the children in class.

There are children with spina bifida and hydrocephalus who do not need help with social communication. Especially with advancing age and entering puberty, the constant presence of an adult in the company of peers can begin to embarrass and irritate them. Don't let that offend you! Encourage the natural desire for independence and try to help only where the child really needs support.



THE ROLE OF THE ASSISTANT IN SUPPORTING CHILDREN WITH LEARNING DIFFICULTIES



Some children with spina bifida and hydrocephalus cope with the learning process on their own. For the others, however, support from an assistant during classes is essential. Children with special educational needs who study together with children with typical development achieve higher results in their education and develop better social skills. The results from the meta-analysis conducted by Oh-Young and Filler (2015) clearly show that **students in a more inclusive learning environment reach higher results to those in more segregated environments, both academically and socially.**

The key to success is the use of proper educational techniques that are positive for everyone in the classroom. The good cooperation between the assistant and the teaching staff is of great importance for a child with learning difficulties. It is important to remember that the assistant is responsible for the specific child he/she works with and the teacher is responsible for the whole class. This does not mean that the assistant educates the child himself/herself, on the contrary, the assistant does not have an educational function and does not assume that role in any way. Any support he/she provides in the learning process is pre-synchronized with the teacher. Whenever possible, the teacher shares his/her plan for the day/week so that they can work together to adapt the information that the assistant is to pass on to the student. You need to coordinate in advance with the teacher how you will be introduced to the students and how they will address you to avoid awkward situations.

Whenever you need to intervene in the educational process:

- Use clear and simple language. Strive to be always properly understood and repeat, if necessary, and wait for a sign that this is so;
- If necessary, prepare pre-adapted and auxiliary materials, coordinated with the teacher, that will facilitate the explanation of the new material to the child;
- Discuss with the teacher the use of a calculator or another aid by the child during a learning situation;
- Do not worry that you will have to talk to the child during the lesson, this will not break the discipline or distract the other students so much;
- Follow the teacher, who can give you a sign to intervene, to help or may request another reaction on your part if necessary;
- If the child finds it difficult to concentrate or does not want to follow the lesson, calmly change the activity for a short time and then return to the learning process;

- Talk to the teacher about the child's activity, such as taking part in a class, preparing a presentation, working together with a classmate; This will increase the child's self-confidence and self-esteem;
- Support the child by focusing his/her attention on the educational process and explaining things that are unclear to him/her, but without answering instead of him/her or giving him/her ready-made answers to difficult questions;
- The task that is completed quickly is not always the most important, it is important that the student has perceived and understood the delivered new information, as well as how to use it later;
- Set a good example. The assistant is watched by all children, not just by the child that he/she works with. When the teacher speaks or seeks the students' attention, you should also listen and show interest, and when an assignment is given, you should be the first to prompt the performance of the assignment.

The assistant must provide promptly adequate information to the teacher about the child's understanding, progress and deficits in the learning process. If the child with whom the assistant works has an individual support plan in place, the assistant should be acquainted with it. Access to the plan can be provided by the resource teacher or the parents. Thus, it will be more than clear that the goals set will be pursued by all participants in the multidisciplinary team. Collaboration is extremely important and only in this way the support provided to the child with spina bifida and hydrocephalus would be most effective. When a good relationship is established between the assistant and the teacher, they can work together to create an inclusive classroom. An environment that does not exhaust the efforts of a child with spina bifida and hydrocephalus to adapt, but an adapted environment in which the child receives quality education on an equal footing with his/her classmates. When you are familiar with the specific condition of the child you work with, you can give suggestions on how to move the furniture in the classroom to facilitate the movement with aids, how to set up a special area for rest or a specific subject or how to create auxiliary teaching materials that would benefit everyone. Your place in the room should also be determined from the beginning, whether you will be close to the child or not, and that depends on the support that you need to provide as an assistant. This should be clarified in advance with the child's teacher and parents.

RELATIONSHIP WITH THE CHILD AND PROMOTING INDEPENDENCE



When a child with spina bifida and hydrocephalus is accompanied by an assistant, the connection between them is robust and strong. The child often relies on the assistant and this can sometimes make it difficult for him/her to become independent. Depending on the child's condition and age, the activities he/she can perform independently are different. Each case must be considered individually. It is very important to be aware of this and the assistant should adapt to such dynamics.

When an assistant starts working with a child with spina bifida and hydrocephalus, he/she receives guidance from his/her parents, as well as from the specialists who have worked with the child so far. All participants in the child's life must understand the role of his/her autonomy and its importance for its future life. In order to grow as an adequate and independent person who will be able to take care of himself/herself, the child should be encouraged to learn and perform routines related to health as well as to take responsibility for himself/herself.

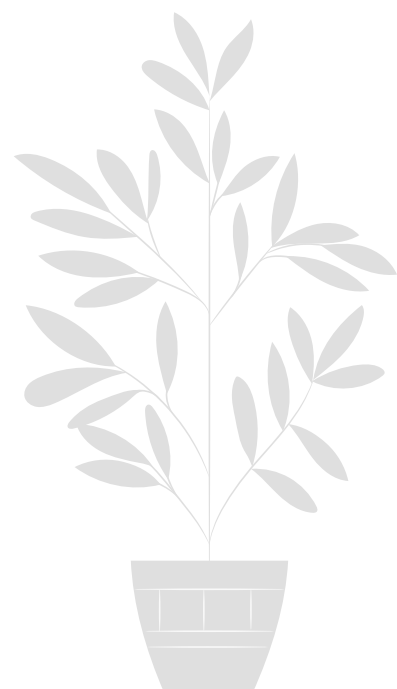
This is probably one of the most difficult roles of the assistant – to support a child with spina bifida and hydrocephalus and to stand at the same time a step aside in order to let him/her learn, build friendships, and even make mistakes.

Calculated risks could be beneficial to the child, but they should always be discussed with the parents first.

In this section we provide some specific examples of encouraging independence in a child with spina bifida and hydrocephalus:

- Interact with the child candidly and openly. Talk to him/her about his/her wishes and answer his/her questions (if necessary, after having discussed the subject with his/her parents in advance);
- You must be acquainted in advance with the method of use of each aid in order to make sure that the child handles it properly and when it is necessary you can just observe without interfering;
- Do not answer questions instead of the child, if this is not necessary – neither in his/her communication with others, nor during the educational process;
- Respect the child's space. Stay aside during breaks and group activities so that he/she can build a relationship with his/her peers;

- Do not make decisions about the child's daily life or condition that he or she can adequately make. Let the child choose his/her food, clothes, route, and friends. If you think some decisions are not good enough, you can discuss the risks and express an opinion, but let the child take the final decision. Informed choice is the way one learns about responsibilities;
- Encourage the child's independence and desire to perform certain activities on his/her own. Be patient and give him/her enough time to gain confidence in his/her actions. Accept that the results will come slowly and will not be perfect, but they will be the best for the child;
- Don't compare: "Look what that girl can do", "Why don't you try like that boy"; Let the child focus on his/her own abilities, so he/she can develop themselves without constantly feeling need to catch up with someone else;
- Praise the child you work with; In this way, you encourage his/her efforts and show him/her that they are not in vain;
- **Do not take anything personally.** Depending on the condition of the child with spina bifida and hydrocephalus, he/she may have intellectual difficulties, change his/her mood or find it difficult to accept his/her diagnosis. Moreover, children change with age, especially when they enter puberty. Sometimes this affects their interaction with others, and the closest person is usually the assistant, and he/she often is the target of the variety of these emotions.



RELATIONSHIP WITH THE FAMILY



As parents of a child with spina bifida and hydrocephalus, the families that you will work with will have gone through multiple and different difficulties in their lives. As an assistant who will spend time with their child every day, you need to approach with respect and understanding their ways of dealing with the situation. Get acquainted with their perceptions and views and try to be their representative in the general education institution. Good contact with parents is very important for the effective work of the assistant. Communication should take place every day and should be clear to all participants. Do not leave anything unclear and look for answers in a collaborative manner. Approach with confidence the desires and goals that the family sets for the future development of the child. Be flexible if you don't always understand everything or don't agree with something. Let the parents also feel your support.

Often, when working with a child for a long time, the assistant also builds a strong bond with the child's family, but he/she is still not a member of the family. If you are an acquaintance of the family, make sure that this does not affect your work or behaviour in kindergarten or school. The assistant will receive most of the information about the diagnosis and condition of a child from the parents. Be careful with the information you have access to and the trust you have been given.

Make it a habit to communicate with the parents when the child is not around. Thus, the child will not feel constantly monitored and analysed and his/her self-esteem will not be affected. Let the feedback the parents receive be complete and adequate so that they can continue to work effectively at home.



COLLABORATION WITH OTHER MEMBERS OF THE MULTIDISCIPLINARY TEAM



The most important thing to ensure the success of inclusive education, is to have teamwork. Each member of the multidisciplinary team supporting a child with a disability plays an essential role. **The involvement of non-teaching staff, such as the assistant or the parents, in setting common goals, discussing the child's development or stagnation, and synchronising the approach is also exceptionally important.**

Sometimes the presence of an assistant in a general education institution is a novelty and it is not always well received at the beginning. This is due to the lack of information, and the status of an assistant is quite versatile. For that reason, the assistant needs to be active in the process of getting to know each other, in the communication with the others, to ask questions, but also to give opinions and to be positive about getting feedback about his/her work. Good cooperation and communication skills are very useful when working in a multidisciplinary team.

As a participant in this multidisciplinary team, you may need to attend team meetings on the child's progress or make an assessment of the child's condition. Always be guided by what is best for the child, be impartial and do not hesitate to share an opinion. Often in practice, the assistant has diverse professional experience and this can mislead the others regarding the value of his/her expertise. Nevertheless, the assistant is the person who is most often and closest to the child, who observes not only specific periods of the child's day but also the child's entire stay in kindergarten or school, and is also often his/her confidant. He/She can accurately and clearly explain the interests and strengths of the child as well as notice, on the other hand, specifics that are difficult to detect.



CONCLUSION



Every child has the right to access education in order to develop and improve, to build friendships and share their daily lives with peers, to fully prepare for adult life. Children with spina bifida and hydrocephalus have their place in kindergarten and school, along with all other children. Our task, as a society, is to provide them with a supportive environment so that they can grow and learn calmly and happily.

The assistant is one of the key figures in this process of inclusion, as he/she is most often and closest to the child in daily life. By supporting the child in the school and kindergarten, the assistant not only provides the opportunity to attend education institutions physically and safely, but also makes his/her participation in the learning process full and meaningful.

To be a GOOD assistant you need to believe in what you do, be willing to constantly learn new things and not be afraid to stand behind the child you work with to protect his/her rights, interests and feelings.

You are the PERSON who can help a child make their dreams come true!

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All kids need is a little help, a little hope, and someone who believes in them



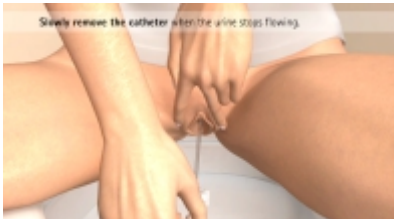


Earvin "Magic" Johnson

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CLEAN INTERMITTENT CATHETERIZATION IN GIRLS. STEP BY STEP

<p>Make sure that all equipment and materials are available. Lay them out close.</p> <p>The child removes or pushes down their underwear. Some assistance may be needed. The child takes position.</p> <p>Wash your hands.</p>	
<p>Clean the urethral opening from top to bottom.</p>	
<p>Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly.</p>	
<p>With the other hand spread the labia and pull them up slightly so that the urethra is clearly visible.</p>	
<p>Push the top of the catheter gently against the urethral opening and slowly insert it.</p> <p>Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.</p>	
<p>Once the catheter has reached the bladder, push it a little bit further and let the urine flow out.</p>	

<p>Wait in this position for the urine to flow.</p>	
<p>When the urine stops flowing, gently apply pressure above the pubis. A small portion is likely to flow out.</p>	
<p>Use the following technique to remove the catheter: Withdraw 2-3 cm by turning the catheter slowly and stop when there is no more urine coming out. Put the catheter in a little bit deeper and withdraw until the bladder is empty. When the urine stops flowing, slowly remove the catheter.</p>	
<p>Dispose of the used catheter and supplies in the trash.</p>	
<p>Dispose of the urine in case you have used a urine collector. Put on clean diapers if necessary. Wash your hands.</p>	


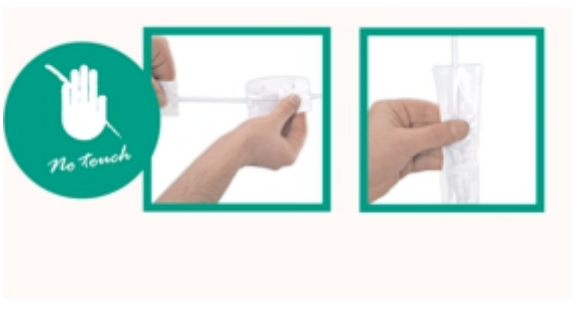



The images are provided by B.BRAUN MEDICAL Bulgaria, a partner in the Multi-IN project. www.bbraun.bg



This document is part of the Manual for assistants in kindergartens and schools on multidisciplinary care and inclusive education of students with spina bifida and hydrocephalus, developed under the Multi-IN project. More resources in inclusive education of students with spina bifida and hydrocephalus are available on the project website www.multi-in.eu

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CLEAN INTERMITTENT CATHETERIZATION IN BOYS. STEP BY STEP

<p>Make sure that all equipment and materials are available. Lay them out close.</p> <p>The child removes or pushes down their underwear. Some assistance may be needed. The child takes position.</p> <p>Wash your hands.</p>	
<p>Wash the penis. Pull back the foreskin and wash the end of the penis around the urethral opening.</p> <p>Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly</p>	
<p>With the other hand hold the penis straight out (at an angle of 45 degrees with the boy's body)</p> <p>Push the top of the catheter gently against the urethral opening and slowly insert it.</p>	
<p>Push it in further until it reaches the sphincter muscle. Now point the penis toward the boy's toes and apply light pressure. Once the catheter has reached the bladder push it a couple more cm and let the urine flow out.</p> <p>Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.</p>	
<p>Wait in this position for the urine to flow.</p> <p>When the urine stops flowing, gently apply pressure above the pubis. A small portion is likely to flow out.</p>	

<p>Use the following technique to remove the catheter:</p> <p>Withdraw 2-3 cm by turning the catheter slowly and stop when there is no more urine coming out.</p> <p>Put the catheter in a little bit deeper and withdraw until the bladder is empty.</p> <p>When the urine stops flowing, slowly remove the catheter.</p>	
<p>Dispose of the used catheter and supplies in the trash.</p> <p>Dispose of the urine in case you have used a urine collector.</p> <p>Put on clean diapers if necessary.</p> <p>Wash your hands.</p>	

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CLEAN INTERMITTENT CATHETERIZATION IN CHILDREN WITH MITROFANOFF STOMA

1. Make sure that all equipment and materials are available. Lay them out close.
2. Wash your hands.
3. Clean carefully the area around the stoma.
4. Remove the catheter from the packaging. Do not touch the part, which will be inserted. Hold it firmly.
5. Push the top of the catheter gently against the stoma and slowly insert it.
6. Make sure that the opposite end of the catheter is pointed at the urine collector or toilet bowl.
7. Once the catheter has reached the bladder, push it a little bit further and let the urine flow out.
8. Wait in this position for the urine to flow.
9. When the urine stops flowing, slowly remove the catheter.
10. Dispose of the used catheter and supplies in the trash.
11. Dispose of the urine in case you have used a urine collector.
12. Wash your hands.

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CLEAN INTERMITTENT CATHETERIZATION AND SOME PRACTICAL TIPS

The procedure is neither painful nor uncomfortable. When the basic steps and hygiene standards are followed, it is completely safe. Below three options are presented - for girls, boys and children with Mitrofanoff stoma. Discuss the steps in advance with the parents and the child, because there may be slight differences in the way they perform the procedure - they may clean the urethra with a special agent or the type of catheter may require additional lubrication. Find out which position is most comfortable for the child and follow the guidelines provided by the family.

Maximum hygiene is mandatory - clean your hands, do not touch the tip of the catheter and do not touch other surfaces before using it. If the catheter gets dirty, use a new one!

If the catheter requires additional lubrication, apply the lubricant just before the catheter is inserted.

If you use gloves, they should be latex-free.

It is advisable to use a catheter of the largest possible size [CH].

Below are some possible problems that may occur during the procedure and the way to solve them.

Necessary supplies

(indicative list)

- Sterile catheter;
- Lubricant. Boys usually need a lubricant if the catheter is not pre-lubricated;
- Running water;
- Intimate/baby wet wipes;
- Waterproof pad;
- Bactericidal hand sanitizer;
- Agent for cleaning the urethra;
- Urine collection container/bag
- Diapers/pads

Preparation for self-catheterization

To encourage the child's independence and in order to facilitate the transition to self-catheterization, allow the child to help in some of the steps of the procedure. For example, have the child hand over the supplies, take off his/her clothes, clean up, etc. Say the steps aloud together at each stage.

Possible problems that may occur during the procedure

- In case of a problem with the catheter insertion, you can try using catheters with a different size, coating, tip type or hardness.
- In case of pain or discomfort caused by the vacuum when removing the catheter, try using a catheter with a smaller width or place your finger on the opposite end of the catheter to close it before removing it.
- A few drops of blood on the catheter are usually due to a minor injury caused by a damaged surface of the catheter (factory defect). If they disappear after 2-3 procedures, they are not considered a problem.
- If the blood is more than that, it is probably due to an internal wound and in this case, a consultation with a physician is required.
- In case of a spasm, wait for it to resolve and then continue the procedure.
- It is not a problem if you happen to insert the catheter into the vagina. Discard the catheter and repeat the procedure using a new catheter.

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