

THE PATH TO INCLUSION

chronicles and personal stories

about the experience in the educational system of pupils
with spina bifida and hydrocephalus from Bulgaria and Slovakia



Developed in partnership between:

Spina Bifida and Hydrocephalus-Bulgaria Association
Early Intervention Centre Trnava, Slovakia
and
a Slovak Association for Spina Bifida and/or Hydrocephalus
as an associated partner

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INTRODUCTION



DEAR READERS,

THE PATH TO INCLUSION is part of the set of educational materials to support the inclusion of children with spina bifida and hydrocephalus in kindergartens and schools, developed under the Multi-IN project. The chronicles and personal stories complement the basic Multi-IN training materials - the general guidelines, manuals and educational video courses that aim to support the multidisciplinary efforts of professionals and families towards inclusive education of pupils with spina bifida and hydrocephalus.

And while the other Multi-IN resources summarize global experience and good practice to help stakeholders find the right direction in their work with students with spina bifida and hydrocephalus, this document contains the personal experiences of children and young people with spina bifida and hydrocephalus in the educational system in Bulgaria and Slovakia.

The eleven stories from Bulgaria are based entirely on information from in-depth interviews that our team conducted with children and their parents in the process of developing the Multi-IN general guidelines. Separate passages are included in the General Guidelines, in order to give credibility, completeness and a human face to the topics covered in the document. After writing down the stories, we realized that they were too valuable to fall into oblivion as a work file on someone's computer and needed to be displayed and shared.

The names of the main characters have been changed, but the events and cases described are quite real and as such, contain both good and frankly bad examples of inclusive education. Therefore, we decided on the chronicle as a genre that allows readers to draw their own conclusions through their views and attitudes, based on the objective presentation of facts.

The stories from Slovakia present rather good practices and a positive perspective and were collected by volunteers and team members of the Slovak Association for Spina Bifida and/or Hydrocephalus.



We believe that everyone with an attitude towards inclusive education will find something for themselves and be enriched by reading these stories. They will be even more useful for professionals in the education system who often do not have personal experience in working with students with spina bifida and hydrocephalus (due to the prevalence of these disabilities).

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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 this document and all Multi-IN outputs.



ROZA



Roza is 13 years old. She lives with her mother and her grandmother in a small district town. She was born with spina bifida and hydrocephalus. She suffers from epilepsy. She is continent, but suffers from frequent urological infections. She is entering puberty relatively early and is going through it very problematically, with bouts of dizziness and seizures.

Most of the time she uses a wheelchair to move around, managed and pushed by her mother or grandmother. This requires both women to be by her side almost all the time. Roza has been using an electric wheelchair for several months now. She likes using it because it gives her independence.

She started going to a regular group in the kindergarten when she was three. She was accompanied either by her grandmother or by her mother: they carried her, pushed the wheelchair, helped her wash up, fed her and changed her clothes. Roza went there with desire.

She continued in the neighbourhood school with most of the children from the kindergarten. There were two other pupils with disabilities in the class. The teacher made all effort to include them by shifting the seats of the students every week, so that all children in the class got to know each other better. The children got along well with Roza. They helped her in case of need, although this rarely happened because her mother or grandmother were always there.

The school had stairs to the first floor and the corridors are at levels. Her mother or grandmother took her in their arms to get her to the classroom on the first floor. Making use of an election campaign, her mother managed to obtain municipal funding for improving school accessibility. Ramps were installed at the back entrance and in the corridors, which, however, were of no help because of their steep slope. Later, at the initiative of the mother, the principal applied under a national program and received funding for an elevator to the first floor. The specialised rooms on the upper floors remained inaccessible.

The building has a toilet for disabled people, but it is too narrow for Roza's wheelchair. In order to enter, her mother or grandmother have to take her in their arms. The child avoids using it, which, according to doctors, might be the reason for her frequent urological infections.

The girl is sensitive to loud noises, changes her mood often, and sometimes has nervous crises. This has intensified after she entered puberty. When she was in the first grade, learning difficulties were identified after some examinations. A special teacher and a psychologist started working with her. This happens in individual sessions, while the other children are having physical education or music classes. Her mother is happy with such support, because it takes place in a quiet and peaceful environment and Roza is able to learn her lessons better. The psychologist is very supportive during some of her pubertal crises.

The special pedagogue makes written and oral assessments. In the final year, when the matriculation exams should take place, it often happens that other students protest against the easier test conditions that are used for children with special needs.

According to a decision of the local education authority, as a child with SEN, Roza has the right to choose a high school at her own decision without taking exams. **Her mother is researching the high schools in the town. She says that the school's profile doesn't matter as long as it's architecturally accessible.**



DONA



Dona is 19 years old, with spina bifida and hydrocephalus. She is incontinent, without infections. An urologist has never been consulted. She suffers from frequent headaches. She uses a ring wheelchair indoors and for short distances.

Dona comes from a Roma family. She lives in a big city. Her parents have no education, but they put a lot of effort into educating all their children. Her father is currently working and her mother is taking care of the girl all day, also at school.

Dona started school relatively late, at the age of nine. There are no valid medical or other reasons for this delay. Her mother says that it was difficult to find a school to enrol her in because of the wheelchair. A school principal in a remote neighbourhood agreed to admit her, in case she was accompanied by an assistant. Dona and her mother started going to school. Her father took them to the school and back by car. Her classmates and staff showed a positive attitude, but the girl found it difficult to adapt. She didn't talk to almost anyone. She closed herself off even more when the tone and noise increased. She didn't like going to school. She had difficulties with her lessons. Dona used support services: a special teacher and a psychologist.

After four years, the principal said that Dona was "no longer for this school" and they should look for something else.

Her parents moved her to another school. There, she studied as an individual student, at her own insistence. She didn't enter the classroom and had no contact with other children. The whole family, along with her little baby brother, travelled every day and waited for her in the car until her classes were over. The school had stairs and her father had to pick her up. Later two rails were installed, which made the situation a little easier, but the slope was too steep and using the rails always required at least two people. Her father stopped working for a while in order to help.

The school didn't have a separate room for individual lessons. Every day the family had to wait in the hallway for a room to get free.

Despite the poor conditions and organisation, in this school, the girl found a Bulgarian language teacher who invested time and effort and managed to teach her how to read and write. Her mother was very proud of this achievement.

Over time, Dona started trying to make contact with children and wanted to change the form of education. Two schools were changed, but the girl didn't feel well in any of them.

Her mother asked for support from the Regional Department of Education. She was referred to a nearby neighbourhood high school. They admitted Dona to a regular class. The principal found a room for the class on the first floor, which is at ground level. The building has a toilet for people with disabilities. The child can move independently in the classroom and in the corridors, go in and out of the building, and use the toilet.

Mother and daughter no longer needed a driver and her father started a better job. Her mother continues to accompany her, but waits on the benches in the yard. Dona insists on this. This makes her feel more secure.

The class teacher accepted her with the words "Being in a wheelchair doesn't mean that there should be no future." The teachers are kind to her and Dona starts going with desire. She started being friends with two girls. The whole class accepts her well. They help her with the doors, carry her textbooks, and accompany her to the shop. When a boy from the other class called her "an invalid", her classmates protected Dona immediately and almost had a fight with him.

The new school does not use a special teacher or another form of resource support. When gaps with the material appear, Dona is additionally consulted by the main teachers. She has realised that in a calm environment, face to face, she could be more concentrated and understand better.

Her mother says that Dona feels happy in her current school. ***"It's so good when there are principals who make changes even for one child."***



VICTOR



Victor is 18 years old, with spina bifida and hydrocephalus. From the age of 7, he gets around independently in a wheelchair. He does sports in his free time. He does CIC 5 times a day and takes medications. He often suffers from urological infections. He lives with his mother and father in a big city. He is graduating from high school this year.

Victor has gone through all the educational stages. His mother describes the first years as very difficult and says that it was only in high school that he began to feel included.

Victor is currently studying at a vocational high school, surrounded mainly by boys, many of them Roma. Despite the initial worries of the family, Victor has met many friends there. They help him move around in the school more easily and carry textbooks and purchases.

From the age of 14, he has been going to school alone by public transport. Sometimes, he changes several vehicles. In case of need, he is assisted by classmates, vehicle staff, police officers from metro stations or strangers. His parents are not completely at peace with this situation, but they realize that the independence and freedom he has achieved are invaluable.

The boy has an active social life with his classmates. They often go out after school, gather at parties, and train together.

There were times when some children called him “invalid”, but according to his mother, he quickly forgot about it.

Victor's family chose this high school only because of the accessible architectural environment. The boy's interests and the profile of the school were not a factor. The building is equipped with a ramp to the first floor, an elevator and a toilet for people with disabilities. Victor can go to all the rooms on his own. He does not use any adult assistance at school.

When he was three years old, a group for children with special educational needs (SEN) was opened in a nearby kindergarten. Vicky couldn't walk so he started there. He was the only child with “preserved intellect”. Most children had autism, developmental or intellectual disorders. It wasn't long before his mother noticed that Viktor stopped talking, began to imitate the sounds of the other children, and started banging his head against the bed. She asked the principal to move him to a regular group. Another reason for her request was that the room for children with SEN was on the third floor and climbing the stairs with a child in her arms was very difficult.

The principal agreed, provided Vicky is accompanied by another person. The family hired an assistant with their own funds. When the payment of the assistant's salary became impossible, his mother started to accompany the child to the kindergarten. They stayed together until the end of fourth grade.

Shortly before he turned 7, Victor received his first wheelchair. To date, his mother says that waiting for so long was a mistake. At the same time, he started his first grade in the neighbourhood school. The building had a transport ramp at the back entrance. For several years, his class stayed on the first floor for their classes.

At the beginning of the 4th grade, the principal advised his mother to look for another school because she couldn't leave the class on the first floor. The floor was intended only for young students and **“a compromise with Victor would mean discrimination against the others”**. Conflicts were brewing with the parents of younger children. **“Why should everyone suffer because of one person!”** said parents of the school board.

Victor stayed in the same school. His class room was on the second floor and his mother carried him up the stairs all year.

His mother started looking for another solution, namely: an elevator. The facility was expensive and for the principle the investment “made no sense”. His mother sent letters to various institutions at the local and national level, but did not receive a reply. This did not stop her and she started a petition among parents and neighbours. She was seeking support around parks and playgrounds. She came across a man who took the cause to heart and through him, in a year of elections, the local government allocated funds to build two elevators – at Victor's school and at a nearby high school.

6 months after the installation, the elevator was still not working and was waiting for the necessary inspections. During this period, the boy did not go to school. He studied at home. His mother had already started work and there was no one to carry him.

“I was forced to sign the document saying that since I could not come with him to school, the responsibility for using the elevator is entirely mine. He had no assistant, and I had found a new job.”

The parents signed this declaration and hoped that the issue was purely formal. A few months later, a fire drill was carried out at the school. During the last class for the day, a staff member entered the rooms and warned of a fire. The children rushed up the stairs, and 11-year-old Victor entered the elevator and pressed the button. As he went down, the electricity was turned off and the child remained in complete darkness, closed between the floors. He could only hear the excited cries of "Fire!" He managed to recover from the fear and called his father, who called the school administration. Until his father's call, no one had established Victor's absence.

It was difficult for the boy to recover psychologically. Long after the accident, he could not stay inside closed premises and his grandmother had to assist him at school for several months. His mother filed complaints with various institutions, but never got to know who was responsible for the case.

For 7 years his parents couldn't find a common language with the school management. The principal was well-intentioned and tried to help, according to her own understanding. **She refused to leave the class on the first floor and support his mother's efforts, while at the same time organised fund-raising events "so Viktor could walk" without seeking the consent or notifying the parents in advance.** This led to a number of awkward situations with neighbours who commented on the family's income and purchases at the local grocery. Another whim of the principal was for the boy to wear a white national costume in order to start walking. His parents often thought about changing schools, but the closeness to their home and the inner conviction that things had to happen in a different way kept them going.

Victor was admitted in first grade as a student with SEN without being examined. According to the management, all children in wheelchairs had SEN and needed support. He had to work with a special teacher and psychologist several times a week. While his class had a lesson, Vicky was taken to a separate room where resource support took place. The child rebelled because he wanted to be with his classmates and did not cooperate with the specialists. Eventually, the special lessons were suspended.

The class teacher failed to “handle discipline.” Worried that the child might be injured, he constantly made remarks and restricted his mobility. He went so far as to forbid him to move from the wheelchair to a seat so that he did not fall. Vicky was naughty and playful. He did not show much interest in the lessons. Studying was hard for him and took him more time than other children. This made him nervous. The diagnoses of “hyperactivity” and “attention deficit” followed soon after.

After he refused to work with the specialists at school, his mother enrolled him for consultations with external experts in private offices. They tried to work with a psychologist, speech therapists, and linguists. Viktor continued to not want to cooperate.

In primary school, Victor's favourite subject was physical education. The sports hall was on the third floor, but his mother took him up whenever necessary. The teacher included him in the sport activities by inventing games with the children or assigning him individual tasks like boxing.



BORIS



Boris is five years old, born with spina bifida. He has partial paralysis of one of his legs. He can walk on his own limping, climb stairs and even run. His mother does CIC 5-6 times a day but Boris is still incontinent. He lives with his parents in a large district city.

When Boris was 3 years old, his mother decided to return to work. She started looking for a suitable kindergarten. The family's worries were related to the need for Boris to be catheterized 2-3 times during the working hours. **His mother believed that she could seek help from the nurses that all kindergartens have. Although the regulations imposed this obligation on nurses in kindergartens and schools, his mother had heard of cases when they refused.**

At the first meeting with the nurse, his mother carried with her all medical papers and made a demonstration of CIC. The nurse agreed and started doing CIC in the health office at the kindergarten two or three times a day. She also changed the boy's diapers. Everything was going smoothly. His mother returned to work and the child feels well in the kindergarten. He has friends and goes there with desire.

A problem occurs only when the nurse is absent due to illness or is on leave. These days, his mother and father have to leave work to do CIC. They have tried several times to persuade the deputy nurse to take on this responsibility, but they face lack of understanding and reluctance. One of the nurses even offered to put an indwelling catheter "so as not to make Boris feel bad."

There are two years until Boris starts going to school, but his mother is already worried about this moment. She is already researching the nearby schools. She fears she may have to leave work. Additionally, she worries that he will be ridiculed because of the diapers. She is considering meeting the child with a psychologist to deal with the potential trauma.



STELLA



Stella is 8 years old, with spina bifida and hydrocephalus. Since the age of 2, she moves around independently with a ring wheelchair. Outside, the wheelchair has to be pushed often because of the bumps and high curbs. She does CIC on her own through a Mitrofanoff stoma. Stella lives with her mother in a big city. Her father also helps with her upbringing.

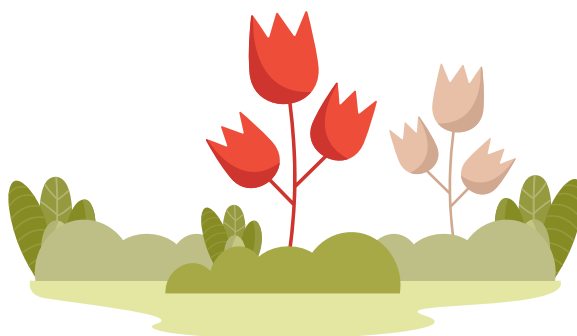
Stella started attending a preschool group at a nearby school when she was five. Classes were held until noon and children studied on desks. According to her mother, traditional kindergartens are not a suitable option for a child who actively uses a wheelchair: they have stairs, and children often go out in the yard; the toilets are shared and small; classes are held at low tables.

The child did not continue first grade in the same school because the first graders' rooms were on the second floor.

The principal of a neighbouring school made the commitment to leave Stella's class on the first floor for at least four years. The building has external stairs to the first floor. A ramp was built with the help of the city mayor, but the slope is too big to use it alone. Her mother also has difficulty using the ramp without assistance.

The school has a toilet for people with disabilities, made years ago for another student. However, the room is too narrow for the girl to use it alone with her wheelchair. Her mother has to come and help her with the CIC. She has asked the nurse for assistance, but she has refused.

Before starting first grade, her mother contacted a special educator who examined Stella. No need for resource support was identified. The girl handled her lessons well. Later, her mother noticed that **she often pushed down objects from the desk (pencils, textbooks), found it difficult to navigate well in space, and often hit walls. Her class teacher thinks that Stella does this on purpose in order to attract attention.**



Stella has no close friends at school. She communicates with one or two children. She was sometimes the object of insults and verbal abuse by a group of children in the class. One of the boys even kicked and hit her. The class teacher failed to deal with the problem. She did not take sides because these were “children's problems”. Several times, her mother alarmed the principal, the Regional Department of Education, the Ministry of Education. She contacted a lawyer and was considering filing a lawsuit. Eventually, the boy was moved to another school and the situation calmed down.

It is difficult for Stella to accept insults from her classmates. There are times when she becomes very emotional and cries. Then, her mother stops her from school for a week or two until she calms down. Her mother would like to consult a psychologist, but she is worried that there are no good specialists in the city who know the specifics of children with spina bifida and hydrocephalus and the consultations can harm the child.

Her mother takes Stella to the school and back, she stays there to do CIC. After classes, she takes her to rehabilitation and other extracurricular activities. The two spend the whole day together and this leads to additional stress.



ELIF



Elif is 17 years old. She lives with her parents and younger brother in a small mountain town. She was born with a severe form of spina bifida, which has not been operated on so far. Her family makes sterile bandages every day in order to protect her from infections. It is difficult for the girl to move, she has complete paralysis of her lower limbs. She can't sit; the wheelchair is set in a semi-recumbent position. Her fine motor skills are well developed. Her mother does CIC several times a day.

Elif can't hear or speak. She communicates with her family through hand gestures that only her relatives understand. She has a difficult puberty. She often has nervous crises and cries.

Her first four school years were in a regular class at a public school. Her parents enrolled her because they wanted her to have contact with other children. The girl couldn't learn any of the lessons because she couldn't hear. She couldn't learn how to read. She liked to draw and copy texts as pictures without knowing their meaning. She liked to be in contact with the other kids.

Both a special pedagogue and a psychologist worked with Elif.

The school was with stairs. Employees helped lift the wheelchair. During these four years, her mother accompanied her in class.

After the fourth grade, Elif continued her studies as an individual student, at school. She has lost her desire for 3 years now and refuses to attend school for any reason. According to her mother, after entering puberty, Elif began to get nervous when meeting other children and preferred to avoid them. At the same time, she stopped visiting the rehabilitation centre. She is currently working on individual materials that teachers send electronically. She has no personal contacts with them.

Elif has no friends outside her family. All other people, including teachers, fail to communicate with her.

When she was little, speech therapists from the town worked with her. They flatly refused to use the universal sign language or other communication systems. They tried to teach her how to speak, but it did not happen.



EVA



Eva is 13 years old, with spina bifida and hydrocephalus. She uses orthosis and crutches. She does by herself CIC 5 times a day and manages to achieve some control over her incontinence. She has skin problems and hard-to-heal wounds. She lives with her family in a big city.

When she was 3, Eva started using the services of a social assistant provided by the municipality.

For 8 years, only one woman held this position. Initially, she took Eva to kindergarten, helped with the stairs and the washing and dressing, took her to rehabilitation and extracurricular activities.

When Eva was 5, her parents began to catheterize her (CIC). They trained the assistant and she took on this responsibility in the kindergarten. For this purpose, they used the medical office.

Before starting first grade, her parents researched the nearby schools. Eva had an assistant and was climbing stairs, so the elevator and ramp were not so urgent. It was more important to have a wide toilet room for people with disabilities or at least a room for CIC. The school that had the necessary conditions refused to admit her because her address was outside its territorial scope. Her parents turned to the Regional Department of Education from where they were referred to another school because of the good special teachers, without the need for such support being identified. Her parents sought help from the media. After a series of articles in the local press, Eva was admitted to the requested school.

After enrolling the child, the principal provided full support. The class was located on the first floor of a building with only three steps. A room for CIC was provided. The class teacher managed to build a united class where Eva felt equal and of full value. She found good friends among the children from the school.

Her parents gave clear instructions to the assistant and often talked to her. Their goal was to keep her help only if needed in order to encourage the child to cope on her own. The assistant did not enter the classes. She catheterized Eva during the small breaks so that the girl could play with the children during the big one.

When Eva learned to do CIC on her own, the assistant's help was limited to carrying the heavy bag to and from school. Eva expressed her desire to be alone at school. Her parents talked to the school management and the class teacher and with slight reorganisations they succeeded: the principal offered a second set of textbooks to be used only in school; Eva got a key to one of the toilets, where they installed a small first aid kit for her items; the child used single sheets instead of notebooks. Her bag was significantly lighter and she continued in 6th grade without her assistant. The children in the class help her when climbing stairs and carrying purchases.



MONIKA



Monika is 15 years old, with spina bifida and hydrocephalus. She can walk alone without any aids. Sometimes she is unstable and loses her balance easily. She can climb stairs holding on to a railing. She started CIC when she was 9. Until her twelfth birthday, her family lived in a large regional city in Bulgaria. Then, they moved abroad.

When Moni was 3 years old, her parents included her in a municipal program that provided assistive care for children with disabilities in the region. **She started going to a kindergarten accompanied by an assistant** who changed her diapers, helped her move around and took care of her safety.

Monika continued going to school with an assistant until her fifth grade. For almost 9 years, more than 10 women changed. **No one agreed to be trained to do CIC. The nurse also refused to make this commitment. Her mother had to come to the school at least once a day.**

Moni started having difficulties with her lessons and her assistant had to enter classes to help. She usually stood at the desk next to Moni and explained the lesson in a more accessible way, while the teacher dealt with the other students. At the same time, a special pedagogue worked with the child after school.

Monika got along well with most of her assistants. Two of them happened to become aggressive. Her mother alerted the company providing the social services and their contracts were terminated.

Moni could walk without any aids, but was unstable. Her mother was worried that the child could fall down the stairs or be injured by running children during breaks. **The principal refused to provide additional railings on the stairs at the entrance or to move the class to the first floor because the child could walk and “there was no need”.**



All toilets in the school had squatting pans. The stalls were too narrow to be used with an assistant. The assistant often had to change Moni's diapers in the hallways while the other children were in class. Her mother repeatedly tried to talk to the principal about this problem. **After preparing a complaint to the Regional Department of Education, a suitable room was quickly found.**

The class teacher made all efforts to include Monika: she invited her mother to speak during parent-teacher meetings; explained her condition to the children and encouraged them to help her; sometimes she worked individually with her and coordinated Moni's activities with the resource teacher. Moni got along well with her classmates. She managed to build friendships with 1-2 children. There were times when she was insulted by some classmates, but her assistant intervened and eased the tension.

The deteriorating health of the child and the need of an urgent complex and expensive surgery motivated her family to immigrate abroad. Monika was 12 years old at the time.



ALEXANDRA



Alexandra is a 15-year-old girl with spina bifida and hydrocephalus. She lives with her parents and grandmother in a small district town. She can walk alone, but only for short distances. She is unstable and gets tired quickly. She can climb stairs, holding on to the railing. She does CIC every three hours to achieve dryness. She still can't do it alone. In this regard, she is completely dependent on her mother and grandmother. Her family encourages her. She has been consulted by a urology nurse during her regular urological examinations abroad, with no result. No physiological cause has been identified.

When Alexandra was 4 years old, her parents enrolled her in a kindergarten. She rarely went there and when it happened, it was only for a few hours because there was no one there to change her diapers and to do CIC. During this period, she was often treated in hospitals. Most of the time, her grandmother took care of her at home.

She started first grade at a nearby school. Her grandmother received permission to come to the school for CIC and change her diapers. At first, this happened in a small storage room used by the cleaning ladies. The building had a toilet for people with disabilities, but it was out of order. They found a solution through the school nurse who allowed them to use the medical office during the big break. The family was grateful for the understanding and thought it would be too much to ask the nurse to perform the CIC procedure.

From the very beginning, the class teacher managed to create a positive environment. The children helped Alex. There had never been any insults or conflicts. However, the girl failed to build closer friendships that went beyond school.

In the upper grades, a physical education teacher was appointed class teacher. Alexandra was allowed not to take part in these classes and the contact with her was minimised.

Alexandra did well with the study material. She made an impression of a diligent and curious student. She was often praised. At the matriculation exams, she received very good grades, which allowed her to choose among the best high schools in the city. After much deliberation, the family decided not to take this opportunity. Alex continued in her current school. It was close to home, good relations were established with the team, as well as a CIC routine. **The comfort prevailed over the interests and capabilities of the child.**

In her high-school years, Alexandra continues to be diligent. She often comes into conflict with her mother because she "learns more than necessary".

The school has specialized rooms in physics, biology, geography, computer training, etc., which are located on different floors in the building. **Going up and down the stairs is a challenge for her and takes all her time during breaks. As she can manage it, the principal does not consider it necessary to take measures and move the class to one floor.**

The whole family is involved in Alexandra's education. Her father drives her in the morning, goes inside with her and carries her bag to the room on the second floor. Her grandmother comes during the big break to catheterize her and takes her after school. In good weather, they return on foot. Her grandmother carries the heavy backpack.



MARTIN



Martin is a 16-year-old boy with spina bifida and hydrocephalus. He lives with his parents in a small town. He is a wheelchair user. He suffers from urological infections with high fever and often takes school sick leave. He is still not able to catheterize himself and his parents are helping him.

Martin used to live 200 metres from his primary school, but his father drives him every day. The sidewalk tiles were so broken that his wheelchair couldn't hardly move on. After several expensive repairs of the wheelchair, his father had taken the decision to use the car.

Martin is currently studying computer programming in high school. He does not like it much and finds it difficult, but the school has an elevator and toilets for people with disabilities. Architectural accessibility is the reason the boy studied at this school. **In fact, his interests are in chemistry, biology, and foreign languages, but such schools in his hometown are not accessible for wheelchairs.**

Martin still cannot catheterize himself. He often forgets the sequence of steps. The school toilets do not lock and he does not feel comfortable. **The principal refuses to provide a locker, so Martin's mother has to come to school and help him in CIC.** In addition to helping him with catheterization, she takes him to and from school, which takes her all day.

In his first year in school, Martin used to work with resource teachers without being examined, just because he is a wheelchair user. After several months, the teacher considers that the child does not need additional support.



KATKA



Katka is 17 years old and lives in a mountain town. She was born with spina bifida. She can walk independently with orthosis and crutches. Katka does very well in school. He has a broad field of interests in chemistry, biology, foreign languages and fine arts. All the teachers have wonderful impressions of the girl. Katka is socially confident with many friends in class with whom she spends her free time. They walk together, visit theatres and concerts.

To support Katka's school and social life, her mother is always ready to take her by car. She is happy to have a flexible job, which allows her to be available when Katka needs her help.

Despite Katka's success in school, not everything is going smoothly. The biggest challenge for her has always been the inaccessible architecture. The school has several multi-levels buildings that have no elevators. There are special classrooms in history, chemistry, geography, and computer science, situated in separate buildings. **The time during the breaks is often not enough for Katka to move from one room to another.** During the winter months, the yard is snowy and icy and the girl cannot move between the buildings. Then she usually stays in the classroom and the teacher teaches her online.

Going to school during the winter months is a real challenge for her. **The schoolyard is not cleared of snow**, and children and teachers reach the building through a small icy path. Katka can't walk on it with crutches and her mother has to lead and pick her up every day.

Now there is already an accessible toilet in one of the school buildings only thanks to Katka's parents. Few years ago, the toilet was squatting and it was impossible for the girl to use it without assistance.

In order to help Katka move between the buildings, her mother often goes to school 3-4 times a day. Few years ago, there were **no parking spaces for people with disabilities available near the school.** After a series of complaints from Katka's family, such places were marked. Currently, although available, these places are often occupied by cars of teachers or high school students who are not allowed to use them.

In the spring and autumn time, Katka prefers to walk to school. She had **problems with cars parked on the sidewalks.** Her parents gave a signal and the local government removed the cars and put pegs. The family had conflicts with their neighbours, but Katka now can go to school safely.





Experience of a special teacher with the presence of a child with spina bifida and hydrocephalus in a regular classroom.

The case study of inclusive education of a girl with a spina bifida and hydrocephalus into the mainstream kindergarten proves that **active cooperation on all sides may bring expected results**. Parent's attitude, their dedication, initiations, active early cooperation with advisory and medical institutions, the assistance of a special teacher, the cooperation with kindergarten, kindness of municipal authorities to establish a role of pedagogical assistance as well as giving support to medical services in assisting the girl with toilets – that all create the cornerstone in which success is standing. After that successful inclusion of Hanka we may also see teachers of kindergarten, her assistant, and class pupils. Everybody is accepting her with love as one of them, helping her to adapt to a new environment. **But particularly they never give her a feeling of strangeness.**

Our statement which stands on the results from special pedagogical and psychological diagnosis as well on the experiences and cooperation with parents, school management, and teachers, bring us to the results that after one year of an adaptation process the inclusive education was very successful not only on learning functions but on emotional and social processes as well. Based on the special pedagogic screening it was found out her significant improvement of cognitive functions. Tasks from the Individual Educational Plan (IEP) were fulfilled extraordinarily well. At the same time, she obtained a significant improvement in graphomotor skills and development of communication skills.

Based on that improvement it is evident that her staying in the mainstream kindergarten brings her big benefits for her further personal development. In that regard, advisory professionals are recommending to continue in her inclusion into the mainstream school, where education will further continue according to IEP which reflects the disability of the child. This example of successful inclusion of the child with a physical disability (spina bifida) may be a good example for other parents eventually other persons with disability as well.



ROMAN



Experience of a primary school teacher with the presence of a child with spina bifida and hydrocephalus in a regular classroom.

Four years ago, Roman, a boy, also came to the 1st grade among little freshmen with a physical disability - spina bifida. Maybe his gait betrayed a little that his legs didn't listen at all and it's harder in life than the rest of us, but he immediately won us over with a kind of charm of his personality. His face glowed with happiness, great curiosity, and a passion for learning.

Today, he is a "big quarter" and manages the school - also thanks to the hard work of his parents. For example, in mathematics, multiplication memory is often the fastest and becomes the "King mathematics", reads well - has a general overview of the world from the encyclopedia.

Roman is very diligent and purposeful, popular in the team for his kindness. Children accept him as he is. Even in this school year they chose him for the "chairman" of the class. Maybe we help him in the little things (carrying heavier things, keeping him okay, in the locker room), but he teaches us important skills for life. **Thanks to him, we learn more mindfulness, consideration, tolerance, to cope more easily with our little problems and that disabilities are part of our lives, they are one of us. We are also more aware of the value of health.**

Roman, with his perseverance and strong will in overcoming problems, gives us a proper lesson to life. I will not forget the situation in the children's park, when the children were slipping on a slide, he stood looking at her. I went to him to help him somehow slip too. When I did, she spoke to him, he said, "I'm just thinking I can do it." And he did in a few months. he did it himself!

His tenacity is truly admirable. He manages (thanks to his parents and old people) not only teaching, but also extracurricular events such as swimming training, trips, school stays in nature, military training, they go skating with us, he is simply one of us. We no longer perceive his handicap as a disability, but as a blessing. With his personality, friendship, he opens not only our eyes, but especially our hearts.

Although I am his teacher, he teaches me. It's a gift to me and I thank him for it!

"After all, we are not only responsible for what we do, but also for what we do not do."

Class teacher Daniela Gubková



DOMINIK**Student with spina bifida and hydrocephalus and his point of view of his education.**

Liberty and responsibility in connection with school? Two concepts, which are divided one of each other. Is there any connection between them? Are they needed for life? Inevitable? Can we acquire them? Can we rate them? Are they measurable? I understand liberty as a disposition of my unique personality to decide what to do or not, to decide in relation to someone or something. However, liberty includes big committee in itself- the committee that I'll take full responsibility for my opinions and specific decisions made by the same and still unique personality. Committee to take all responsibility and consequences in case of fault or fail. From the other angle of view, I sense liberty as a lack of forcing. The ability to decide independently and freely is preceded by very long process which includes huge number of little steps. I live for 17 years, and I realize a few of them.

I - as everyone of us - have been from my very early childhood influenced by someone or something, by the environment, that enclosed me. I cannot remember hospital as my very first home for a longer period, but my primal memories belong to my family. Here it is, where my formation process of the Human- social being - has begun. This human being should be conscious of the consequences of its doing. Just in the environment of love and acceptance I should face the first challenges. I had to learn to respect for parents, coexistence with sibs, and mainly, that there won't be everything as I dreamed about. I had had to adjust the circumstances – that often has been really challenging.



Other important steps on my way to freedom and responsibility led to private kindergarden Lienka in Smolenice. It was quite challenging, but also very important objective for the pedagogues to face my bold personality, to form me. Beside many other situations I have been every single day dependent on help of teachers to overcome huge number of stairs. Not everyone has been able or willing to help me. **My teacher's willingness to get through these barriers with me, again and again, has shown me there are problems to be overcome.** Sometime later I still appreciate their access even more and more. In spite it was no piece of cake for them at all, nor it was pleasing. That time I mainly enjoyed the kindergarden, but I have also received something what left deep mark inside me. When my early years had gone, I have joined primary school. There have been new challenges, new mates and even more stairs awaiting me. Altogether with curriculum I have acquired many competences. **Even in that time I could make many decisions freely because my vicinity always asked and often accepted my opinion.** Furthermore, it offered me to look further and made me grow personally. For example, in the second class my teacher provided me discreet option to explain my bad feelings and regarding behaviour. This small and tricky step taught me to work on my behaviour. After four years passed on this school, I have continued my studies on the 8-year form of gymnasium in Trnava. Day by day I have had to wake up earlier, travel to and come back from school, where I have often been on my own, because my parents were at work. During my childhood I have regularly exchanged school desk for hospital bed or doctor's ambulance. Omnipresent stairs became second-league problem. **Many of unforeseeable happenings gave me a lesson of deliberation's and patience's importance in complex solution of the issues that have always exceeded problems of my mates.** My very important experience is, that I sometime must ask for help, provide the helper with needed instructions, and accept the help, also not optimal one. Something what is not rated but inevitable for life.



I have been spending my time with my hobbies too. I love travelling, photos shooting and meeting new people. Along the way I use to observe people behaviour and its consequences. One of the things I have noticed is that the easier way is often not the better one. I try to adjust my acts to this. A few years ago, I have taken up strengthening and doing sport. It is not easy and not ever I want to continue, sometimes I just desire to let it go. In the cases I most often think about my primary motivation and start considering the various benefits. I realize it contributes to my will building. Beside sport and strengthening I like foreign languages. Developing in this area has brought me more benefits than difficulties. I have many friends abroad that I can communicate with using technical means. Due to language abilities, I can also share my opinions, my feelings with them. Meeting youngsters and adults with disabilities has taught me that my skills, impressions, and experiences can serve and being helpful to others. I have chosen volunteering in the 3rd sector. I have efforted to take active role in international workshop "ABC of self-advocacy". I could barely imagine what it was going to take for me. I have decided to engage in advocating of rights of people with disabilities. This act allowed me to speak on international forums that we cannot rate with mark, but they meant a lot for me. Thanks to school I could present my knowledge and experience from the area of rights of people with disabilities fluently in English. I could be equal discussor for many people from various Europe countries. I have done next step to the topic I want to study and be in charge with, in my future.

My family accepted me as I am and helped me to start off the way to freedom. I really appreciate ability to educate. Time spent in school and outside taught me a lot and tried my competence to decide. The most helpful were people, who had free mind. I am persuaded that we learn to free and responsible decision-making life-long.



THE PATH TO INCLUSION

chronicles and personal stories

about the experience in the educational system of pupils
with spina bifida and hydrocephalus from Bulgaria and Slovakia

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