

**MODEL ON THE
PROTECTION OF
THE RIGHTS OF
CHILDREN**

**with Severe Disabilities
and Children with Life-
limiting Conditions**



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HealthProm
Ensuring vulnerable children have the best start in life



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INTRODUCTION

At present Belarus has an extensive legal framework on the rights of families raising children with severe disabilities, their interaction with society and the state as a whole.

However, quite often the legal framework does not function properly and all services guaranteed by the legislation of the Republic of Belarus are not fully rendered in the best interests of families raising children with disabilities. It is especially typical of the families living in rural areas with no access to the Internet.

In many cases families do not know what they are entitled to, have no access to a competent lawyer to advise them about their rights and entitlements, e.g. housing rights, rights to benefits and medication. Families are often taken up with day to day survival and may not have the physical or emotional capacity to analyze the current legislation. Quite often they have negative experience in communicating with representatives of state bodies.

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In some cases, local communities oppose the idea of barrier-free environment for children with severe disabilities. People do not agree with the installation of ramps and special stairlifts and even demand to dismantle them.

Furthermore, education establishments, teachers and parents are not ready to implement inclusive education for children with disabilities and voice their disagreement with the fact that a child with a disability will become part of the mainstream education.

One of the highlights of the model developed by the Belarusian Children's Hospice is to raise awareness of the current legislation to families raising children with severe disabilities as well as to general public in terms of the barriers faced by such families and services needed.

The Belarusian Children's Hospice renders palliative care services by providing families with high quality services, guaranteeing equal access to services and resources in the capital and rural areas of Belarus. However, few NGOs and regional palliative care units bear the burden of palliative care services, while there is an extensive legal framework on the issue. Palliative care units do not function in all regions. They are subject to the Ministry of Health. Thus, their services are mainly of medical nature. As far as NGOs are concerned, they are funded by charities. There is no legislation on the involvement of individuals. All these factors impede the provision of palliative care.

The state guarantees families raising children with severe disabilities support and free of charge assistive devices, such as wheelchairs, special bicycles, medical equipment. However, parents complain on the quality and comfort of these devices and purchase assistive devices on their own, with the funding from donors, religious and other organizations.

So, whereas the legal framework of entitlements and benefits is developed, society faces inefficient use of funds.

The reality is that sponsor funding is subject to tax, in particular, a sponsor company pays a tax on the goods donated. Furthermore, the organization recipient pays a tax on the same goods while delivering them to families in need.

The Model will allow protecting the rights of vulnerable families, giving access to legal and information support, and involving parents raising children with disabilities and local communities into problem solving. The Model is based on the best international and national practices on the protection of the rights of children with severe disabilities. Moreover, it has a great potential for good practice replication in Belarus and other countries with similar state management system.

While developing Model on the Protection of the Rights of Children with Severe Disabilities and Children with Life-limiting Conditions, we have analyzed international and national practices. It should be mentioned that the national expertise on the issue is not widespread.

Meanwhile, we realized that our work is very similar to [advocacy](#), an activity which aims to influence decisions within political, economic, and social systems and institutions by boosting civic participation in the promotion of goals or public interests.

Furthermore, we'll refer to this notion, as it reflects the essence of our activities.



However, working with children with severe disabilities and life-limiting conditions in Belarus has its peculiarities:

+ Families raising children with disabilities are burdened by daily care and they may not have the physical or emotional capacity to scrutinize the relevant legislation and exercise their rights;

+ In the Republic of Belarus the system of individual applications and requests to the state bodies is well-developed, and it is possible to take control over the law enforcement, especially on the local level;

The Republic of Belarus has a vertical state management system, which has led to the lack of quality inter-agency communications on the state level and the lack of proper communications of state bodies with public organizations;

Personal contacts and communications with key executives from different state bodies make it possible to organize timely consultations and achieve results in this or that state body;

There is an essential gap in quality and accessibility of services between cities and distant rural towns;

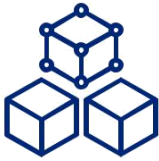
Belarusian society opposes the idea of living side-by-side with children with disabilities. Families raising children with disabilities react to that by isolating themselves from society. The situation is worsened by the lack of well-developed barrier-free environment both in big cities and distant rural areas.

We have considered the aforementioned peculiarities by adapting international advocacy tools to the current state management system in Belarus.

ANALYSIS OF INTERNATIONAL ADVOCACY MODELS

While analyzing best international advocacy models, we have realized that there is a range of advocacy models with their peculiarities. A public advocate of family interests must have the relevant skills that determine the efficiency of advocacy.

Advocacy fosters confidence and the feeling of the ability to make a difference for those whose interests are advocated. The key aspects of advocacy cover being independent of services, enhancing rights and opportunities, supporting people whose interests are advocated to raise their civic awareness, challenging inequalities, fostering social justice and supporting those who have access to help (Boylan and Dalrymple, 2011). In fact, advocacy activities help people get the necessary information, understand their rights, make their choice, and finally express their opinion.



In various regions there are different models and methods of advocacy. On the other hand, it is possible to single out key models:

SELF-ADVOCACY

Individuals represent and speak up for themselves.

Key features include:

- Securing services and supports for individuals.
- Promotes confidence, skills and knowledge and protection of individual rights (Lawton, 2009).

PEER ADVOCACY, OR 'EXPERTS BY EXPERIENCE'

The advocate and the person have a common background, for example, they may have shared experience of service provision (Monaghan, 2012).

Peer advocacy can be conducted on an individual or collective basis and often develops spontaneously, for example in care homes or day centres.

Key features include:

- Focused on common problem solving.
- Lessens the imbalance of power between the advocate and their advocacy partner as they have shared experiences. Most effectively used with specific groups and closed communities, when people are reluctant to handle issues outside of their communities.

VOLUNTEER CITIZEN ADVOCACY

Based on unpaid volunteer services.

It involves a one-to-one relationship over an extended period. The partnership is independent, not influenced by the advocacy organisation.

Key features include:

- The relationship continues regardless of any presenting issue.
- In spite of its advantages, the relationship between the advocate and the individual is viewed as an outcome in and of itself and is based on moral mutual agreements.

PROFESSIONAL ADVOCACY

A partnership between a paid advocate and a person who accesses support.

The advocate provides support and information and representation, with the aim of empowering their partner. This type of advocacy can be undertaken on a short-term or long-term basis. Long-term advocacy work may be required due to changing needs over time and the complexity of issues.

Key features include:

- Separation from other forms of direct service provision, eg social work
- Independent governance
- Independent funding arrangements (eg services are not funded by public bodies but via other indirect means, such as foundations and public organizations)
- Individual rather than group advocacy

INTERNATIONAL STANDARDS FOR ADVOCACY SERVICES

In order to ensure that advocacy services are provided in a way that effectively meets the needs of people who access support and operate in a way that is underpinned by an evidence base, standards for generic advocacy services have been developed.

These standards relate to:

- clarity of purpose
 - independence
 - empowerment
 - equal opportunity
 - accessibility and accountability
 - supporting advocates
 - confidentiality
-

FEATURES OF GOOD PRACTICE

Taking these models together, it has been possible to identify a number of common features that are important for an advocate to exhibit.

These include:

- A calm thoughtful and sensitive disposition
- Good at building relationships with people
- Competent in the relevant advocacy domain
- Independence
- Ensure the person's views are discussed and incorporated
- The ability to be succinct, articulate, thorough and offer alternative ways of thinking
- Facilitate understanding among other professionals of the person's situation.

DEVELOPING THE MODEL

Taking into account international experience and advice from the British partners, we have identified the key points of the Model on the protection of rights of our target group in Belarus.

When we initially considered the situation, we realized that the most relevant and efficient advocacy model applicable in Belarus is professional advocacy. We have made use of its key features while developing the Model.

Due to the fact that professional advocacy is not implemented on a permanent basis in Belarus, the Belarusian Children's Hospice organized a range of trainings for its lawyer and regional specialists with the participation of international and local experts as well as organized a week-long training visit to Great Britain.

In summer of 2016 a group of experts made a preliminary needs assessment of families raising children with severe disabilities in the pilot regions of the Republic of Belarus. The assessment criteria featured children's conditions, intellectual capacities, place of residence (regional city, district city, village). Having distinguished a range of problems, the Belarusian Children's' Hospice have defined its further activities to handle them.

From the onset of the action implementation, of the uppermost importance was to build a constructive dialogue with officials who take legally important decisions. In a majority of cases, we found areas of common interest and solutions that were supported by all interested parties. The specialists of the Belarusian Children's Hospice did their best to encourage officials to take part in the problem-solving.

With a view to gaining more experience in different towns of Belarus, the Belarusian Children's Hospice have introduced a new region – Grodno oblast. Advocacy groups were established in accordance with the following principle: each group included a regional specialist as well as a district specialist.

Of crucial importance was to raise awareness of the target audience's rights and opportunities.

Having considered the legal framework for people with disabilities, we published a clear and simple guide on rights, benefits and opportunities. Moreover, the target audience accessed our regional specialists and lawyer via personal visits, by phone, and on the web.

The Belarusian Children's Hospice initially focused on the work in the regions. So, our specialists teamed up with the relevant professionals in the regions. Moreover, every specialist has an individual work plan in accordance with the families' needs.

Closer to the end of the first year of the action implementation, we have defined three key tendencies:

There is an essential gap in quality and accessibility of services between cities and distant rural towns.

A lot of problems faced by the families are caused by the lack of quality inter-agency communications on the state level and the lack of proper communications of state bodies with public organizations.

While working with the families in the regions, the specialists identified a low interest of the parents to improve their life. It primarily results from a lot of declined requests from state bodies, poor knowledge of the legislation, and complicated system of state support.

COMPARING INTERNATIONAL ADVOCACY MODELS WITH PRACTICES IN BELARUS

While comparing international advocacy models with the current Belarusian experience in the domain of the protection of the rights of children with severe disabilities and children with life-limiting conditions, we have come to the conclusion that to a greater or lesser degree all models are represented in Belarus. As a result of the work done, we have found out that our future model most closely meets the requirements of Professional Advocacy. However, other elements can be included.

Why is it really Professional Advocacy?
What about other advocacy models?



Self-advocacy in Belarus

There are examples of self-advocacy when parents raising children with severe disabilities represent and speak up for themselves in Belarus. However, the model is not efficient, as individuals are not very much competent, the Belarusian legislation is complicated. Parents may not have the physical or emotional capacity to analyze the current legislation, make requests, and implement other activities. As a rule, parents' requests to state bodies are very emotional and contain little factual information, are often sent to incorrect addressees.

As a result, it delays replies and quite often official replies are formalistic. When this or that activity is in the media, the results can be contrary to what has been expected. Negative results often discourage parents and they erroneously believe that fighting for their rights is pointless. However, when the right advocacy strategies are selected, good results can be easily attained. In this case, those who succeeded become experts by experience and share experience of successful advocacy with other parents in similar situations.



Peer advocacy, or 'experts by experience' in Belarus

Components of this model are scarce in Belarus, as parents' communities and groups are inactive. There are few parents' associations working in the domain on a professional basis. On the other hand, we see a high potential in this respect, because an individual competent request to a state body in Belarus can be efficient and fruitful. Our experience confirms that. When a mother of a child with severe disabilities became a member of our regional team, despite all hardships in the regional work, she has made great progress. She did succeed thanks to consultations, personal motivation and her own experience in advocacy.



Volunteer citizen advocacy in Belarus

This model as well as peer advocacy is rarely implemented in Belarus. The reason is that there is not enough support for volunteer services among the population. Volunteers regard their advocacy as an activity aimed at helping people in need. Moreover, their help is short-term as a rule. Volunteers are frequently discouraged when there is no support. Quite often volunteer advocacy is limited to legal advice and then it ends. Nevertheless, when properly supported and managed, volunteer citizen advocacy as well as peer advocacy has huge potential.



Professional advocacy in Belarus

Making use of its key features as well as our own experience in working with families raising children with disabilities, we realized that it is the most relevant and efficient advocacy model applicable in Belarus. The key criterion is that we have achieved goods results over a short span of time. The key components will be considered later.

MODEL ON THE PROTECTION OF THE RIGHTS OF CHILDREN WITH SEVERE DISABILITIES AND CHILDREN WITH LIFE-LIMITING CONDITIONS

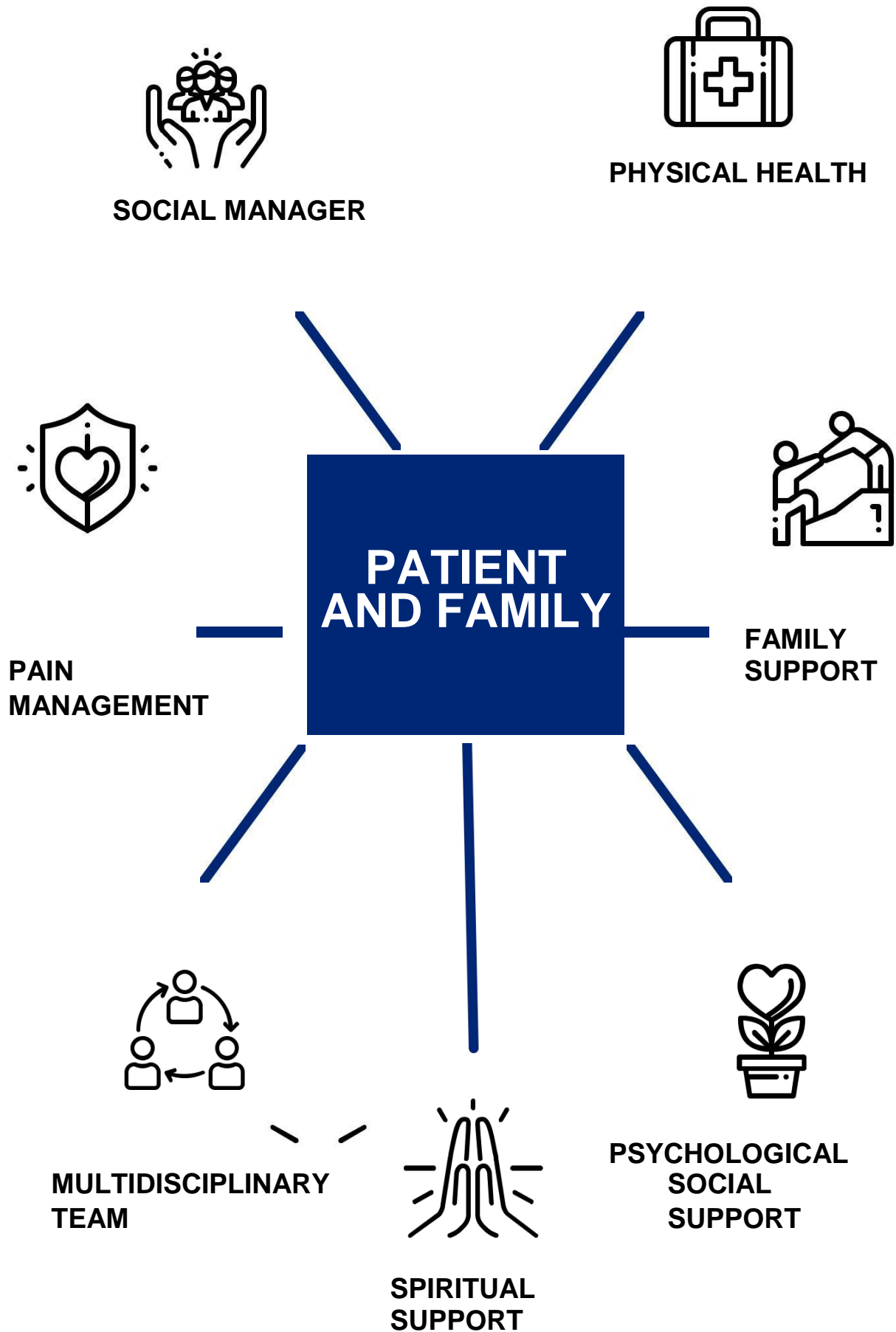
KEY FEATURES OF THE MODEL

1) PROTECTION OF THE RIGHTS OF FAMILIES raising children with severe disabilities as a component of children's palliative care. The model developed is a constituent part of holistic palliative care. See the red arrow on Diagram 1.

2) INDEPENDENT ADVOCATE AS A KEY FIGURE

An independent advocate plays a key role in the protection of rights and interests of families. Of key importance is being independent of any organization, state bodies and other individuals.

Diagram 1. Structure of palliative care



A specialist must act in the best interests of families. This is why, he/she is singled out in the diagram. Independence makes it possible to avoid conflict of interests. Efficient performance should be supported by a multidisciplinary team. Moreover, an organization that a specialist collaborates with should be independent and professional. Of the key importance is to **act in the best interests of a very sick child**. While developing the Model, we have followed these principles. That is why, we have attained good results.

3) EDUCATIONAL COMPONENT

The Belarusian education has no curriculum on the protection of rights. Thus, the model must include an educational component. The component should cover:

- Needs assessment in a family using the same methods;
- Awareness of the legislation linked to people with disabilities and their rights. Understanding responsibility, competencies and structures of various organizations and agencies;
- Communications skills with families raising children with disabilities, representatives of state bodies;
- Management and planning;

- Principles of working with media and PR-specialists.

4) COLLABORATION

An advocate is a link between organizations and families, families, specialists, such as lawyers, doctors, etc, and regional agencies – palliative units, rehabilitation centres, etc. Good communications lead to successful problem solving.

5) ENHANCING QUALITY OF SERVICES RENDERED

An advocate spots drawbacks in the provision of palliative care services in terms of advocacy tools and influences their work (Diagram 2). Advocacy is implemented in cooperation with families. If a family is not motivated properly to work in partnership, there will be no tangible results.

6) INFORMATION

An advocate provides expert information not only to families raising children with severe disabilities and also to professionals working in different agencies and organizations, which lack the necessary information.

ADVOCACY TOOLS

PLANNING ADVOCACY CAMPAIGN

Planning an advocacy campaign should correspond with the scale of the issue. Helping a family in a big city on a short-term basis will be dramatically different from handling an issue with a lot of resources in a rural area on a long-term basis. That is why, an advocate and a family should answer the following questions: What is our goal? Who is a key person that will help handle an issue? How are we going to tackle an issue? If we are supported by people, why does it take place? What should be done by people who support us? When should we start?

If we follow a plan and correct it depending on the circumstances, we have more potential to succeed.

REQUESTS, COMPLAINTS

In the Republic of Belarus these are the most efficient tools. They are especially efficient if a person whose interests are advocated make them. We should bear in mind the competencies of state bodies and agencies considering requests and complaints. It is crucial to put the matter clearly, use the right details and send requests and complaints to the right agencies and bodies.

WORKING WITH MEDIA

In some cases, it is necessary to raise the awareness of the case. The work should be approached with caution, as media can have a dramatic impact on the issue, and the results can be unpredictable and different from what has been expected.

ATTRACTING PARTIES INTERESTED

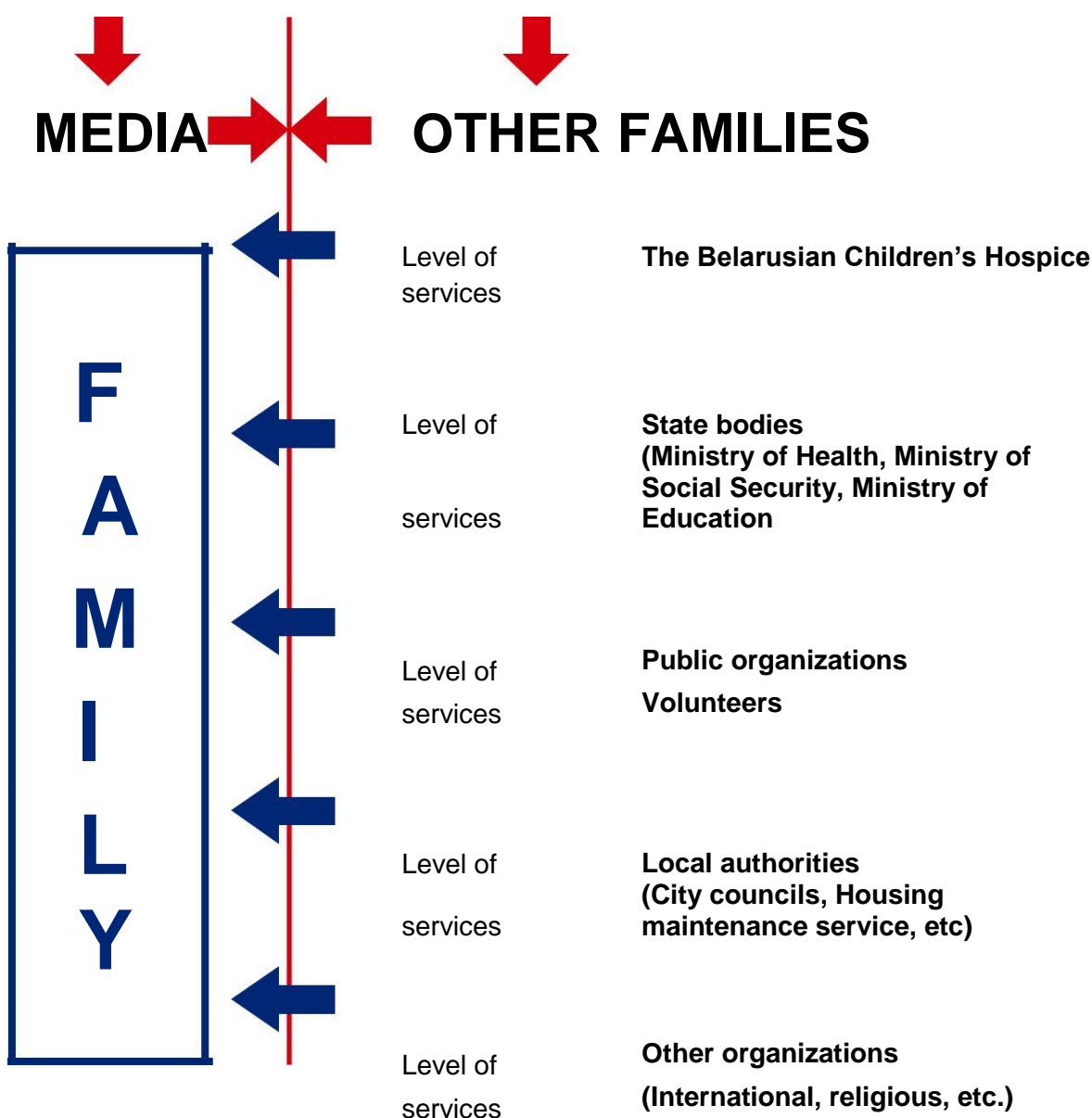
The parties interested can be extremely different. In case of families raising children with disabilities, there can be public organizations, parents' communities, bodies and inter-agency councils related the issues faced by the family.

LEGAL ISSUES

We have not initiated any legal proceedings, because we have managed to tackle issues without court proceedings. However, in Minsk oblast our lawyer advised two families with legal claims. One of them focused on the legal capacity of a family's 18-year old daughter. The other was about terminating parental rights of a family that did not take care of their child with a disability.

Diagram 2. Model on the Protection of the Rights of Children with Severe Disabilities and Children with Life-limiting Conditions

A specialist of the Belarusian Children's Hospice in the region + a lawyer



OVERVIEW OF THE MODEL (Diagram 2)

An action plan for an advocate of a family raising children with severe disabilities and life-limiting conditions is defined by the results of their needs assessment.

Needs assessment helps a specialist identify which services or the qualities of services are insufficient. Needs assessment should determine the following: what did a family do to tackle the issue and how was it implemented?

Then an advocate identifies a state body or an agency in charge of these services or in charge of improving the quality of services. Taking into account advocacy tools, a specialist, a family and a lawyer can draw up an action plan to handle the issue. The key principles include objectivity, legality and acting in the best interests of a child. If an action plan does not work and there are similar in other families, it is more reasonable to involve other interested parties and team up. Other interested parties can be represented not only by families, but also by state agencies, nongovernmental organizations, etc.

In some cases to quickly and efficiently tackle the issue and involve the public, officials and other decision-makers, it is reasonable to highlight the situation in the media. However, it should be done with caution at proper time and most importantly bearing in mind the goal.

An advocate must analyze the situation and if necessary adapt the action plan to circumstances.

Of the uppermost importance for advocacy activities are communications. If communications are successful, a lot of issues can be easily handled. Communications can be grouped into two categories. The first category is represented by communications with parents, namely what should be discussed, what should not, how to talk and when to talk, with a view to successfully handling the issues and keeping partnership relations. The other category is communications with officials and decision-makers. It is important to speak the same language with officials, to make one's message objective, clear-cut and easy-to-understand and make one's interlocutor interested.

KEY FUNCTIONS AND COMPETENCIES OF AN ADVOCATE OF RIGHTS OF CHILDREN WITH SEVERE DISABILITIES

- + Being able to work in team with parents and other specialists in the same domain, for example, the centre for children's palliative care
- + Home visits to families raising children with disabilities with a view to defining their needs and drawing up an action plan
- + Developing an individual program of social support for a family covering all social and legal needs of a child based on an individual needs assessment. The goals should be meaningful and feasible, and the resources should be versatile
- + Holistic support of a family: social, medical, educational, psychological and legal
- + Providing for inter-agency cooperation while delivering services to families, monitoring and taking control over cooperation
- + Rendering different types of help and supporting families in terms of benefits and services: financial support, health resort treatment, housing issues, etc.
- + Productive cooperation with state bodies and different agencies

WORKING MECHANISMS OF AN ADVOCATE OF RIGHTS OF CHILDREN WITH SEVERE DISABILITIES

1. Creating a databank of families raising children with disabilities
2. Needs assessment of families and analysis of quality of services rendered
3. Analyzing information on organizations and institutions both state and private, singling out the leading institutions
4. Examining the peculiarities of the organizations, their competencies and
5. Searching organizations and making contact with them
6. Informing families of the legislation, their rights and benefits, as well as supporting services, and of contact details of officials from state and nongovernmental bodies and agencies
7. Defining goals and tasks in cooperation with families to improve the quality of services
8. Detailed planning and activities for the support of families

REGIONAL SPECIFIC FEATURES OF ADVOCACY OF RIGHTS OF CHILDREN WITH SEVERE DISABILITIES:

**Minsk and Minsk oblast,
Grodno, Mogilev,
Bobruisk (Mogilev oblast),
Gomel, Rogachev (Gomel oblast)**

MINSK AND MINSK OBLAST

In Minsk and Minsk oblast the Belarusian Children's Hospice renders children's palliative care. This feature has a crucial importance for the region. Rendering holistic palliative care, including legal advice and support, compensates for families' reluctance to advocate for their rights to benefits and services from state and other organizations. Requests to advocate for the rights of families were usually sent by the Belarusian Children's Hospice. They were considered and further steps were taken. It is attributed to a good reputation of the Belarusian Children's Hospice and to the fact that requests were correctly prepared and sent.

In Minsk and Minsk oblast the state bodies replied quicker than in other regions. As a rule, it took a week. In other regions it could take a month. Sometimes there was no feedback at all. The online portal 115.бел is used to report a problem and city agencies do their best to timely tackle the issue. Our specialists made use of the portal. The quality of services rendered is higher in Minsk than in the regions.

GRODNO

The specialist working in the city of Grodno has close contacts with the state palliative unit of the Ministry of Health of Belarus. On the one hand, it makes it possible to handle medical issues in a quick and effective way. On the other hand, the specialist is dependent on the medical workers and has to seek a compromise between parents and medical staff. There are also a range of nongovernmental organizations in Grodno. They render various services to families raising children with severe disabilities, which leads to a decrease in the activities of parents' communities in the region.

MOGILEV

Like in Grodno, the specialist working in the city of Mogilev has close contacts with the state palliative unit of the Ministry of Health of Belarus. In this case it is also a matter of compromise. Parents' communities are poorly developed. The palliative care unit is in charge of rendering services and successfully renders them.

BOBRUIISK (MOGILEV OBLAST)

In contrast to the aforementioned regions, parents' communities are rapidly developing in Bobruisk.

Our specialist helps parents acquire the necessary competencies in their advocacy practices. The specialist successfully establishes contacts with parents thanks to her experience in raising a child with a disability and her self-advocacy. Efficient state palliative care system is not developed in Bobruisk. There is no support from nongovernmental organizations either. Thus, parents who are aware of better services in other regions have to advocate for their rights on their own.

GOMEL

In Gomel a range of nongovernmental organizations help families raising children with disabilities. The state palliative unit of the Ministry of Health of Belarus successfully functions in the region. In addition, our specialist has found a happy medium between the relevant agency or organization and families taking into account the needs of the latter. Moreover, the specialist makes use of the image of the Belarusian Children's Hospice. So, a lot of issues are handled through personal meeting and consultations with officials.

ROGACHEV (GOMEL OBLAST)

The situation in the region is very close to Bobruisk. The specialist has been working for a long time and has made a database of contacts and organizations, which efficiently help tackle issues. In general, the specialist collaborates with parents' associations. Holistic palliative care services are poorly developed in Rogachev.

HAVING CONSIDERED THE FEATURES OF ADVOCATING FOR CHILDREN WITH DISABILITIES IN THE REGIONS, WE CAN IDENTIFY THE FOLLOWING TENDENCIES



Proactive attitude of parents raising children with disabilities and their advocacy practices depend on their access to quality services from different organizations. The more services are rendered, the less active parents are.



Under various circumstances in different regions, the application of the aforementioned key principles of the Model leads to positive results in all regions of Belarus.



The advocacy of interests of families raising children with disabilities is more developed in big cities rather than in small cities.



The reputation of the Belarusian Children's Hospice and its image of an authoritative organization have a positive impact on advocacy practices.

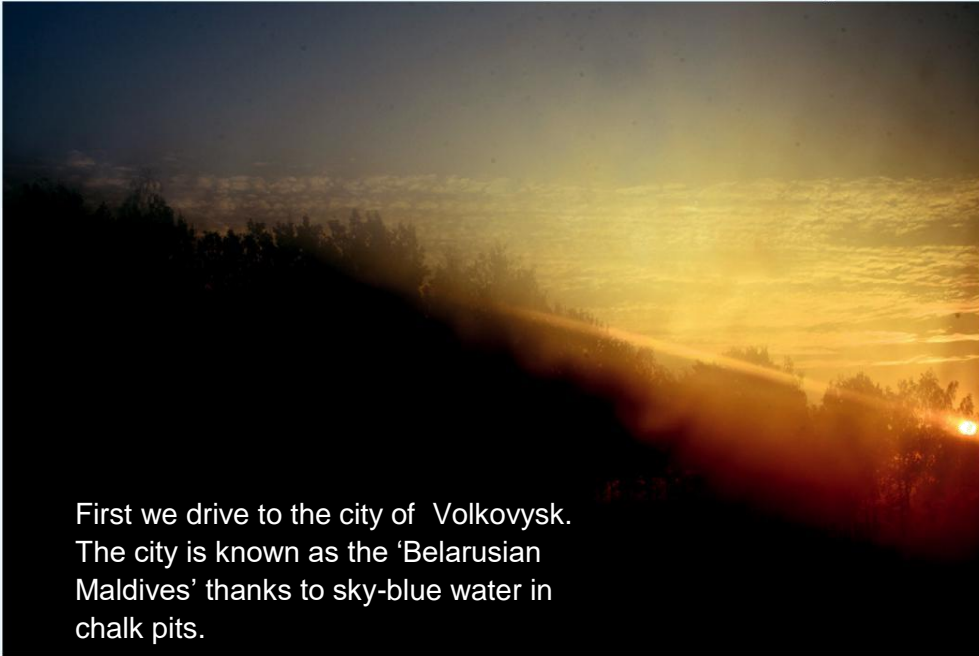
CASES



The Belarusian Children's Hospice has implemented the action Developing a Pilot Advocacy Service in Belarus to Protect the Rights of Children with Severe Disabilities and Children with life-limiting conditions for three years. The action is funded by the European Union and is implemented together with HealthProm. The key task is to lay the foundation for improving services in the regions. We travelled to all cities in the action to meet with the families who received care under the action and find out what has changed in their lives.



We are driving out of Minsk early in the morning. It is unusually warm for mid-October. It seems like it is close to May, not November. We are in high spirits, active but all of us cannot but stop at the petrol station to have a morning coffee. We agree that we have to stop there to refresh ourselves. Moreover, this morning coffee gives us a feeling of travel, a small one, but promising.



First we drive to the city of Volkovysk. The city is known as the 'Belarusian Maldives' thanks to sky-blue water in chalk pits.



No swimming, on the other hand. Moreover, it is prohibited to go to the shore, but dozens of tourists visit the place every year. We discuss all this on the way to Volkovysk and regret that we cannot do the sights. But work is work and we make our first family visit.

We are going to Alina. She is 13. The girl is diagnosed with Werdnig-Hoffmann spinal muscular atrophy. Approximately 1 in 6-10 thousand newborns have such a disease. It is characterized by degeneration of nerve cells within the lowest region of the brain and certain motor neurons in the spinal cord leading to muscle weakness of the truncal. Sensitivity and intellectual activity are up to the standard. Quite often children are communicative and vivid. Alina is dressed in a fine pink dress and her nails are also pink. The girl is a little embarrassed, but is looking at us and starts to talk.



Alina is sitting on her favorite chair. The chair is really favorite, but the posture is incorrect and it can worsen the girl's condition. But sitting properly is painful for the girl. It can be corrected by physiotherapy. Alina's mom opposes the idea, as she had negative experience in communicating with a rehabilitation specialist. Now she does not want anything new in order not to deteriorate the condition.

'We used to put on our pantyhose.



Later on we went to massage sessions. And Alina could not sleep for a fortnight. Moreover, we cannot put on our pantyhose now'

It should be mentioned that good rehabilitation cannot cause pain in children. If a child is scared or uncomfortable, it is pointless to visit it. The abilitation team of the Belarusian Children's Hospice provides physiotherapy services while playing with children without pain and fear. Our doctor persuades Alina's mom to come to Minsk. Well, it will be later. What can be done here in Volkovysk?

Thanks to the effort of our regional coordinator Yanina, the children under hospice care are provided with wheelchair ramps at their blocks of flats.

Some of them are not so easy to use, but it is a considerable step in the right direction. Now families with children with severe disabilities are not cornered in blocks of flats and can take a walk in the open air. A lot of families were consulted by different specialists, came to know about new drugs and got prescriptions. What is more important is that parents have started to communicate.

They have realized that they are not alone with their problems. It is always possible to ask a question and get an answer. So, one can rely on others and get support

Then we are leaving for **Grodno**. We arrive there late in the evening. The city is impressive. It is the only city in Belarus where the historic centre was not completely ruined. We have little time left, so we talk to our regional coordinator and go to a family while enjoying the scenes from the window.



In Grodno we meet Zakhar (5 years old) and his family. The boy meets us together with his granny. His mom will be back home from work later. The boy's granny tells us his story. Zakhar is diagnosed with clinically unconfirmed Li syndrome. The most unpleasant aspect of the syndrome is that its onset is delayed. Zakhar was born a healthy child. Up to three years old, the boy lived a normal life of his age. He ran, learnt to count, recited poems, like news and even knew who the president of the state was. The granny recollects those times with a smile, but now her eyes are full of tears and her voice is trembling. When the boy was three, the disease started to progress. When Zakhar was taken to hospital, he could recite poems, but his state started deteriorating.

'On January 25, the boy was taken to intensive care unit in Grodno. Tracheostomy was used. When the family asked the doctor when it could be removed, the doctor replied that if they got out of hospital, it would be a miracle'





The doctor provided us with a separate chamber. An extra bed for the mom was placed next to Zakhar's bed. The mom spent all time with the boy.

In April 2016 the boy was transferred from intensive care unit to hospital. Zakhar did not move and express his emotions, but all of a sudden started to smile and frown.

Zakhar came back home, tracheostomy was removed, though doctors did not believe it would happen. The boy learns letters, tries to walk without a wheelchair, and learns to talk.

'He says 'mom, dad, granny, give' and learns more complicated words. A psychologist offered games where one odd element should be removed. We do it successfully.'

Positive dynamics is so great! We wish patience and strength to Zakhar. However, the disease exhausts all members of the family – both emotionally and financially.

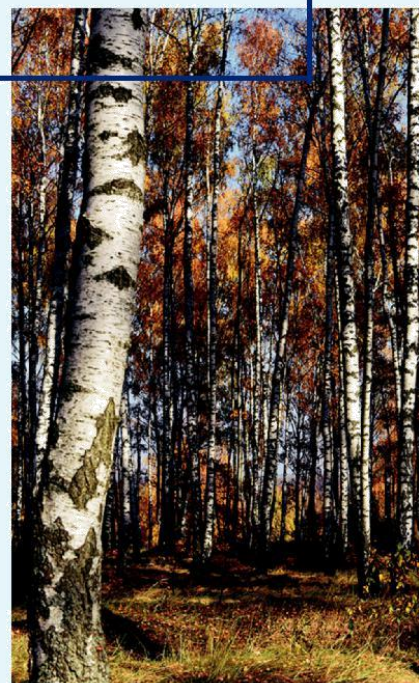
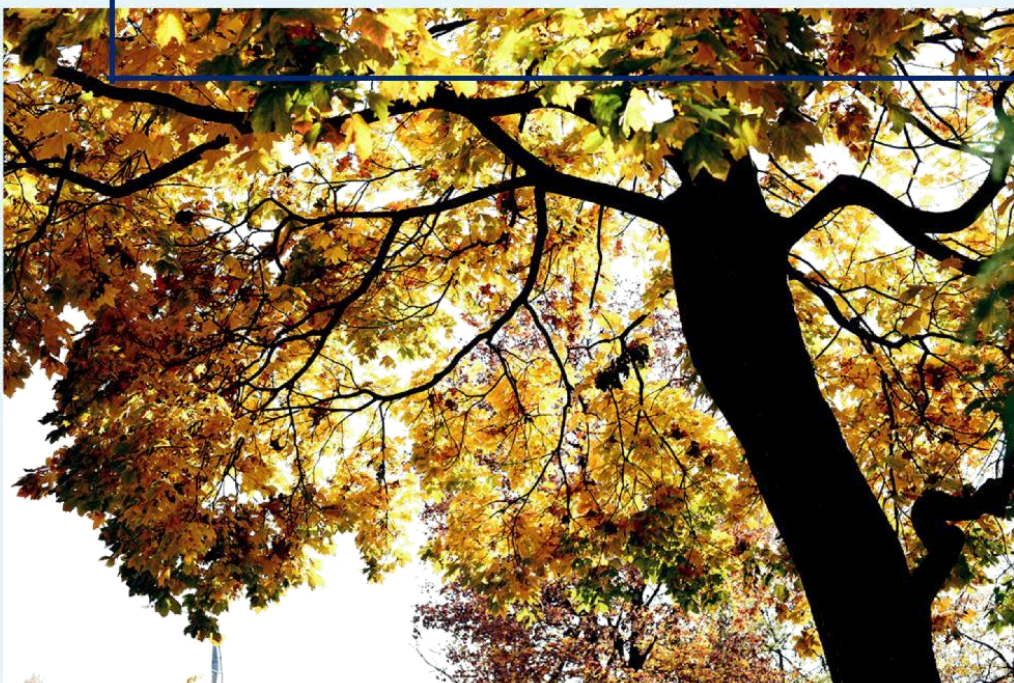
'All this time the boy is intellectually active. Even in intensive care unit. We came to him and said, 'Zakhar, if You can hear us, please, raise our hand'. And he raised it! Later on, when the boy could not raise his hand, he gave us a wink. Then Zakhar could not wink, but the doctor said that the boy's blood pressure was higher when we visited him. So, the boy reacted'.



'The provision of care is expensive. We are thankful to Oksana for her help. We would not have gone so far without her. She provided us with supplies, helped up with electric suction. Then a baby-walker, a special chair. Also, Oksana helped us find a psychologist'.

We were tired out on our first day, so we had supper and went to sleep. Tomorrow we are to cover as many as 430 kilometers.

It is 8:30 AM and we are leaving for **Bobruisk**. It will take up 5 hours to drive there. We spend this time quickly, talking and enjoying the nature.



In the city of Bobruisk **Nastya Borbut** welcomes us. She is a regional project coordinator. Over three recent years, Nastya has actively advocated for families raising children with disabilities.

Together with Nastya we make a visit to **Lisa**, a fifteen-year-old girl. Lisa is diagnosed with Dandy-Walker syndrome, a rare congenital malformation that involves the cerebellum and fourth ventricle. The girl was born with a hematoma and was operated on a month later. In course of the operation, the girl's eyeground was damaged. Now Lisa cannot see. Later on, after seizures, the bone incorrectly healed. Now Lisa cannot sit.

The neighborhood doctor does not visit the family. He says the parents know their child best of all. Sometimes, a nurse visits the family, when the doctor visits a family in the neighborhood. Nastya has worked with the family for more than 2 years.



Nastya's contribution is not only a Viber group for parents. Nastya has managed to create a social taxi in the city of Bobruisk. It has taken her a year and a half, but it is worth it. People with disabilities can use this service once a week and leave their flats.

'Nastya is ready to help us at any time. I can call her at night, for example, and she is ready to reply and help. Nastya helped us create a group on Viber for parents. Before that, we could not hear each other. Now we can act together'.

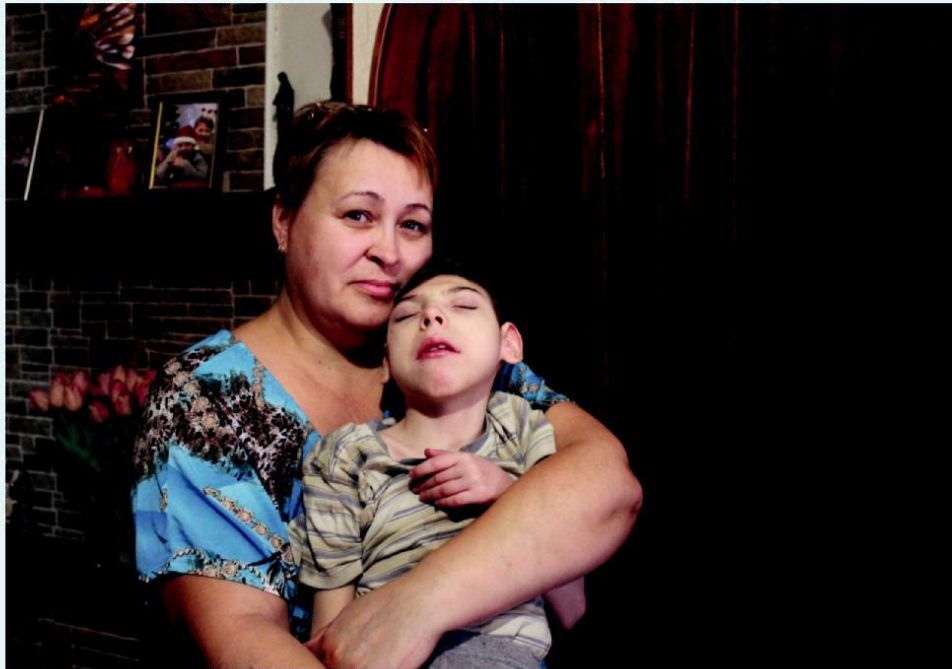


We said good-bye to Nastya and go to **Gomel**. This part of our journey is spent mostly in silence. We are well on the way. Everyone has a lot to think about.

Next morning we are going to visit **Kirill**, a seven-year-old boy diagnosed with cerebral palsy. Alyona Garai, our regional coordinator, introduces us to the family. Alyona has been working with Kirill for about two years. The parents remark that little, though very important, progress has been made so far.

It is not surprising, as the family follows all recommendations from doctors. After trainings on alternative communications, the family started to express his emotions better by means of cards. The abilitation team also advised on the right positioning and postures. The boy became more active than he used to. Moreover, the specialists recommended to use a verticalizer, a device that helps to keep a body in an upright position. Such a position helps internal parts of the body properly function. Thanks to Alyona's effort, a local charity gave the family this device. Besides, Alyona advises families as a psychologist.





‘Alyona is always ready to help us. I can call her even 20 times a day and she always replies and helps’.

Thanks to Alyona’s effort, the parents’ community of Gomel and the local palliative care unit have started cooperating. Now parents know that they can rely on the services by professionals.

So, thanks to the help of the professionals, the parents have managed to provide for the dentist’s services for children with severe disabilities. When such requests are made by mothers, they are full of emotions. Thus, instead of a well-grounded reply, state agencies can send a formal reply. Now parents know how to correctly send requests and attain results.



We are leaving for the city of **Rogachev**. The more places we visit, the more we are looking forward to new places and regions. There were no similar visits in the previous regions. Every regional coordinator sets up their priorities and follows their action plan. It is really important. Any service should be patient-oriented. The provision of care to children with severe disabilities should be flexible and should tackle real issues. Only in this case it is really efficient.



While pondering over these ideas, we arrive in the city of Rogachev. The city is very comfortable and peaceful with carved window aprons and wandering cats.

We meet with **Galina**, our regional coordinator, and make a visit to **Masha**.

It is a very difficult time for the family. Masha is in intensive care unit. Her mother tries to keep back her tears, but it is hardly possible.

‘Today is the seventh week in intensive care unit. The girl had decompression, cardiac failure, liquid in pleural and abdominal cavities. We overcame that. Now Masha has obstructive pneumonia. I guess they want to take Masha to Gomel. But I do not want to drive my daughter there. I want my child to have proper care’

A child’s mother is admitted to intensive care unit only two minutes a day. And it is even more difficult.

‘What can be done in two minutes? It seems to be humiliation’

Masha has Edwards’ syndrome. Usually children do not live up to six years old. Thanks to mother’s care, the girl is eighth and a half years old and is still living.

Nursing services are provided by the state, but are not available in all cities of Belarus. Moreover, people do not know about such an option. On the whole, nursing services are provided on a fee basis (about \$20 per month at the time of writing). On the other hand, single-parent families and children under three years old can get it free of charge.

We have to move on to the city of Mogilev, as we have a busy schedule. Our doctor copies Masha’s files and we are leaving for Mogilev.

We arrive in the evening and have little time left to take a walk. We are tired out, and decide to take a walk in the morning, except for a few minutes along the pedestrianized street. We opt out for sleep and promise that we’ll come back to [Mogilev](#) to take a walk next time.

In the morning we are going to [Polina](#) and her mom Natalya. Polina is diagnosed with Spinal muscular atrophy type 2.

Polina is a talented girl. She has good and excellent grades. The girl is keen on hand-made things and the family has a lot of them at home. Polina is also fond of music and dreams about becoming a musician. However, the girl faced an obstacle. She used to attend music classes several times a week, but now the family cannot afford this. The girl’s mother took measures and negotiated private classes at home on a free basis. It seemed great and it was only a matter of effort to do music classes.

‘It was difficult to do everything on my own, but Galina managed to organize nurse services. It is really helpful’.



‘I can rely on Oksana’s assistance and services of the palliative care unit. I do not know how I used to live without them. I used to believe that I had to do everything on my own’.

A paper on the girl’s inability to go to a music school on her own was needed from the local hospital. However, the doctor decided that music was a luxury and did not consider the family’s request. Luckily, a copy of the document was submitted and the girl has music classes. Teachers do understand that children with disabilities have the same needs as other children. Doctors do not understand.

It is not the only hardship that families face. Thanks to Oksana, a social worker of the Belarusian Children’s Hospice, the family was helped with mold in their flat, a wheelchair ramp was installed and Polina made a lot of friends from Germany.

Expenses on the provision of care for children with severe disabilities are massive. In fact, families need financial, moral, and human resources. Such families need help. But somehow when a child with disabilities is born, families are faced with hardships, not with support.

We got acquainted with only few families supported within the frames of the action Developing a Pilot Advocacy Service in Belarus to Protect the Rights of Children with Severe Disabilities and Children with life-limiting conditions. The action is funded by the European Union and is implemented together with HealthProm. Overall, thanks to the action implementation, there are six regional coordinators on six cities in Belarus. They help families raising children with disabilities. Taking into account the results of the travel, we can state that the action has laid a solid foundation for the system of the provision of care to children with severe disabilities.

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The image features a dynamic, abstract composition of geometric shapes. A large, vibrant orange shape dominates the right side, extending from the top to the bottom. On the left, a dark blue shape, resembling a stylized arrow or a folded piece of paper, points towards the center. This blue shape is layered over a smaller orange shape. The background is a clean, bright white. The overall effect is one of modern, minimalist design.

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