

Author: Alena Lis

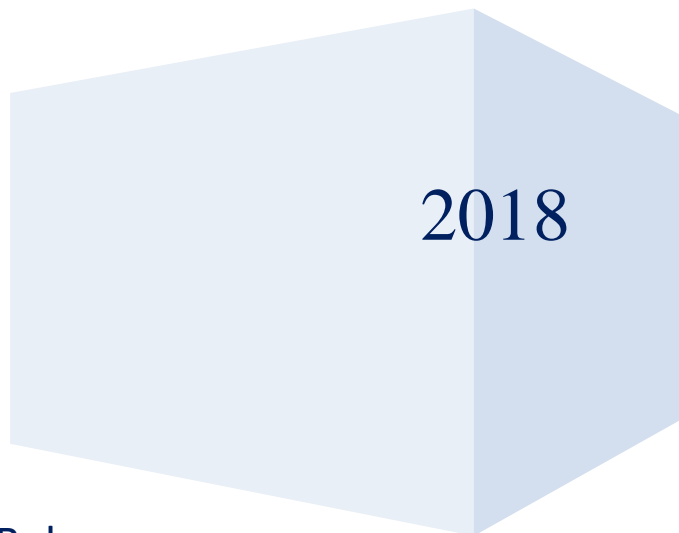
phone: +32474254750 (Belgium)

phone: +375293529468 (Belarus)

e-mail: alyona@odb-office.eu

Qualitative External Analysis of the results of the Project:

“Developing a pilot advocacy service in Belarus to protect the rights of children with severe disabilities and children with life-limiting conditions”



Minsk, Belarus

Content

List of acronyms	2
Introduction	2
Executive summary	4
Management of the project	5
Target groups and final beneficiaries of the project	8
Conclusions	12

List of acronyms:

BCH – Belarusian Children’s Hospice

CWD – children with disabilities

CWLLC – children with life limiting conditions

UNCRD – United Nations Centre for Regional Development

UNCRPD – United Nations Convention on the rights of people with disabilities

Introduction

This is a qualitative evaluation study on the implementation of the project *‘Developing a pilot advocacy service in Belarus to protect the rights of children with severe disabilities and children with life-limiting conditions’* which is conducted by Healthprom (London, the UK) in partnership with the Belarusian Children’s Hospice (BCH) and financed by the European Union. The evaluation was conducted by Alena Lis, specialist in project development, management, monitoring and evaluation in the period between 1 August and 31 November 2018. The conclusions of the analysis apply to the results of the entire project period. It is seeking to assess the outcomes of partners’ activities, as well as measure the impact it had on the target groups and its final beneficiaries¹. Additionally, the study is providing a rough estimation of the monetised and non-monetary social effects the project has had on stakeholders under review.

Particularly, it focuses on achieving expected results for three specific objectives of the project:

¹ The target groups of the project are
The final beneficiaries of the project are families raising children with disabilities and children with life-limiting conditions.

- 1) strengthening organisational capacity of Belarusian Children’s Hospice (BCH) to better protect and advocate for the rights of CWD and CWLLC at local, regional and national levels, and raising awareness of the rights and needs of CWD and CWLLC and their families (partly);
- 2) piloting community-based advocacy service for CWD and CWLLC is in Minsk, Homiel, Mahiliou and Hrodna regions;
- 3) increased understanding and support for the rights and needs of CWD and CWLLC and their families among public in Belarus.

This study bases itself on the analysis of the background materials provided by the project staff, face-to-face interviews with its stakeholders including final beneficiaries and project partners, feedback received by the subgrantees of second call for projects, as well as external trainers. Please see a detailed list of materials used below:

- 1) background materials provided by the Belarusian Children’s Hospice (project proposal (including narrative, LFA, two interim reports, events agendas’, manuals and publications produced under the project;
- 2) face-to-face interviews conducted with Pavel Burykin, Project Manager in Belarus, Iryna Hamova – the Project’s Lawyer;
- 3) face-to-face interviews with final beneficiaries of the project at the training with UK expert conducted at the training in August 2018 Homiel and Mahiliou cities;
- 4) face-to-face interviews with families receiving support in each of the targeted by the project region;
- 5) face-to-face interviews with regional coordinators of the project from Hrodna, Vaukavysk, Homiel, Mahiliou, and Babruisk;
- 6) face-to-face interviews with partner organisations in Hrodna, Mahiliou, Rahachou and Babruisk, Homiel;
- 7) Face-to-face interviews with two subgrantees of the project from Homiel and Mahiliou (second call for applications);
- 8) Skype interview with Tatiana Buynovskaya, Project Manager with the leading applicant organisation – Healthprom (UK).

To assess the initial and expected impact the activities of the project could have had on final beneficiaries, the study relies on the methodology developed by **Ashoka Foundation** to evaluate the results of activities by social innovators and adapted to the current project.

In the period of 01.08.2018-30.11.2018, the external consultant assessed the following:

- implementation of recommendations provided during the first external evaluation of the project;
- project's impact on the main stakeholders (organisation's staff, state institutions representatives) by the end of implementation period;
- project impact on the situation of final beneficiaries (families with CWD and CWLLC);
- relations with third party – subgranting scheme beneficiaries;
- synergies created by the project with the representatives of local communities in the targeted regions including representatives of business circles and state-affiliated entities;
- communication of the project's results by Belarusian Children's Hospice;
- sustainability of the project results after the project implementation period and the possibility by the local partner to build on its results including fundraising

Executive summary

After three years of project implementation, the BCH and HealthProm team managed to achieve its specific objective – strengthening the rights of children with CWD and CWLLC and their families and increasing the opportunities for them by establishing ***a pilot model of community based advocacy services involving parents raising children with disabilities, representatives of non-governmental organisations, volunteers, entrepreneurial community and public institutions.***

While working on the achievement of this objective, the Project team greatly contributed to protection and promotion the rights of children with complex disabilities (CWD) and life-limiting conditions (CWLLC) in Belarus in accordance with EU Guidelines for the Promotion and Protection of the Rights of the Child guided by the general principles of the UNCRC and UNCRPD. Apart from planned activities under the project additional consultations, round-tables and informal meetings were organised to promote children's rights. The media outreach was **20.229** of unique readers of articles about the project on the Hospice webpage and in the social networks, as per 01.12.2018. The Project's materials were reposted by other media and social network users as many as **101** times contributing to better understanding of the rights and needs of children and families in focus.

While aiming at meeting the objectives' indicators the following quantitative and qualitative results were achieved:

1. Strong synergies were built with state institutions in Hrodna (the cabinet of palliative care) and Mahiliou ('Children's House'); local business community in Babruisk, and non-governmental organisations in Minsk, Homiel, and Rahachou.
2. As of 01.12.2018, the social workers in the region jointly with the project lawyers and managers have delivered **654 face-to-face** consultations to families raising children with disabilities; **928 online** consultations and **50** consultations to medical workers. As a result –

167 cases (appeals of families were satisfied). An average price for legal assistance for each case if ordered from state or private legal companies would cost a family from 445 to 1000 euros depending on the complexity of a case. Thus, rough monetized equivalent of this assistance can be estimated **at 74.000 euro** The calculation based on the assumption that preparation of each case takes on average 10 hours and the average price for consultation with a private lawyers is 44,5 EUR (167 X10 X44,5=74315,00 EUR)

3. **226 consultations** were delivered by the project lawyers Iryna Hamava in Minsk. **27 appeals** prepared jointly with parents of children with disabilities and filed to different public institutions were satisfied (**or 12015,00 EUR** – in monetized equivalent);
4. Altogether **12 legal algorithms** were developed to protect interest of families raising children with disabilities. Among them a list of steps to be taken to receive free enteral nutritional therapy, to apply for a soft loan for housing, to receive social housing, technical rehabilitation tools, create barrier-free environment by installing a ramp, receiving free medicines, etc.). Having such algorithms developed and ready to be used by parents and social workers in the region upon the completion of the Project, is an important step for ensuring sustainability of the **developed community-based advocacy service model**;
5. An approximate cost of services (babysitting services for families raising children with disabilities, massage for children), and equipment (ramps, wheelchairs, ventilators, preferential housing etc.) that the project staff helped to receive the families in focus either from the state or from local business communities, for example in Babruisk is equal to **78267,7 EUR**. While the overall monetized equivalent of the assistance provided thanks the Project in three Belarusian cities Hrodna, Babruisk, and Vaukavysk equals to **172974 euro**. A detailed calculation of the assistance received can be found in the attached filed to this evaluation.
6. **8926 copies** prepared under the project publication – *Little Book on Great Rights* was distributed to families and specialists raising awareness about rights of children with disabilities and life limiting conditions.
7. Two calls for subgrants were successfully launched and completed increasing the project direct outreach by **1281 people** (6 projects in two years).

Management of the project and capacity building of the Belarusian Children’s Hospice (specific objective 1)

The first analysis of the administrative management of the project proved its effectiveness. In the third project year, the implementing team managed to maintain regular effective communication between London, Minsk, Babruisk, Mahiliou, Homiel, Rahachou, and Hrodna using variety of tools. Among recommendations given to the project team in the first evaluation document was

introduction of Gant Graf or any other suitable instrument that would contain the indicators foreseen in the project LFA, point out resources necessary for their achievement and staff members responsible for the implementation of each component of the Action. The two project managers chose to monitor number of consultations and working hours performed through time sheets system and direct reporting from coordinators. The workload of the staff was distributed equally, with the lawyer receiving 12-13 request from regional coordinators per month additionally to phone or skype calls from families.

Regional coordinators claimed they received 4-5 calls daily including during the weekends but organized less (1,5 visit) to families per week. The number of family visits declined naturally since by the end of second implementation period the needs' assessments had been completed and good contacts with parents established. The distribution of tasks is equal between all project coordinators. The Minsk-based project manager Pavel Burykin keeps track on the working hours.

The project staff underwent all training planned including on human rights, advocacy, teambuilding, and fundraising. During each visit to Belarus, the project coordinator, Tatiana Byinovskaya, conducted trainings on the project management involving regional team members to planning activities and relying on their expert opinion and knowledge of their clients. Later on, the project staff in the regions received plenty of opportunities to apply received knowledge on practices when dealing with families, improved their performance under the guidance of the project manager from Minsk and the project lawyer.

When approached by the evaluator all regional coordinators were able to describe the steps they are taking to access the needs of families raising children with disabilities and life limiting conditions. They noted that in the project maintained its good reputation among families and rather had families contacted its staff than vice versa. Additionally, information about its services spread through word of mouth.

All regional coordinators admit that they have increased their knowledge in human rights based approach thanks trainings with the British experts, some of them said they even started to change their mindset. Besides, they stressed they had established strong horizontal contacts in this project and were able to solve certain issues thanks peer-to-peer advice without additional consultations with the project lawyer in Minsk. At least three social workers will continue their activities in the area after the project is over – in Rahachou, Homiel, and Mahiloiu where local partners, one non-profit organization and one state-run institution, offered them jobs.

The workload of the project team remained high through entire implementation period, despite well-organised procedure of processing applications from families. This fact is linked to greater visibility of the project and positive feedback from those who had already received support. The

project staff continued to take calls outside working hours dedicating time to the Project on a pro-bono basis. For instance, in Homiel, social worker organized additional yoga classes for mothers and their children with disabilities during the days off strengthening this emerging community. Project management however regularly warned its staff about overwhelming activities and did not insist on any additional work outside the schedule. Moreover, taking into account emotionally challenging situations the project staff had to deal with, the Belarusian Children Hospice offered professional psychological support to the regional coordinators. At least 50% of them used it once or repeatedly during the project's implementation. Those local coordinators who had strong external support, like social worker in Mahiliou (working in cooperation with a local boarding school) felt more confident in continuing or building on the work, they started under the project. Others said they would like to switch to something less demanding emotionally. Both, social workers in the regions and 'their clients' admitted the importance of family-centered approach of providing assistance developed and tested by the Project. It would be a great gain of the project if this model becomes part of institutionalized system. To achieve it however, further advocacy measures are needed after Project is over.

In the third reported period one of the key indicators of LFA – the development and approval the BCH Strategical Plan was achieved. BCH had never had a strategical planning document before that caused defocusing of their programming development to some extent. For instance, projects by BCH ranged from environmental and cultural to social. After the development of the long-term strategy, the BCH clearly focused on protection of rights of families raising children with disabilities, children living in life limiting conditions in families as well as older children in need of palliative care. Another important priority of the BCH that started to shape the organisations' approach towards organizing the activities was – the focus on strengthening its presence in the regions, and the work with parents. The last one became especially evident during the concluding conference of the Project when the important role of shaping its agenda was given to parents raising children with disabilities.

One of the concerns voiced by external auditor in 2017, was lack of preconditions for organization's leadership continuity. According to Healthprom project manager Tatiana Buynovskaya, the situation persisted through 2018. In her view, one of the solutions to this challenge can become development of new projects with different autonomous leaders coordinating them. During the implementation period, as many as **five project applications** for different international calls for proposals were prepared and submitted by BCH in consortium with other organisations. Moreover, Healthprom is planning on attracting the BCH experts trained under the project to implementing similar activities in Ukraine as consultants. That will ensure that the expertise gained under the project will remain and continue improving the situation in other regions. It is also worth mentioning that the project lawyer, Iryna Hamova, visited London on the EU-funded programme MOST to receive additional training and knowledge. The fact that

her position will be preserved upon the Project completion will contribute to the sustainability of its results from one hand, and steadily rise if horizontal leadership in the organization – from the other.

Project impact on the situation of final beneficiaries (families with CWD and CWLLC)

Developing a model of community-based service became the central activity and the most expected result of the entire project that had direct impact on the final beneficiaries.

Interviewed families raising children with severe disabilities and children in life-limiting conditions (12 families altogether) praised the work of the regional coordinators of the Project (social workers) and admitted improvements in the condition of their children as well as of their own. All of them claimed that counselling support under the project had been delivered in time and upon request. The project staff was attentive, professional and provided psychological support to families' members in most difficult situations. All parents mentioned that their social life became more active due to increased communication with other parents with whom they managed to establish contact during the trainings organised under the Project. They apply skills received at the trainings with British and Belarusian experts. They also started to feel more confident about their situation. Thanks the Project, parents in targeted families learnt about their rights, understood on what kind of support they could count and what steps needed to be taken to receive it from the state. Among the improvements in the conditions of their children the parents interviewed named: ***decline of apathy, better communication and emotional response from them (smiles, gestures, other.), improvement in overall health conditions (!), fewer hospitalisations, less visits to the doctors, gaining weigh in the situations when it was badly needed.*** Apart from counselling and legal assistance, many families received material support, such as wheelchairs, had their apartments' blocks equipped with ramps, received special expensive nutrition, medicines, services of babysitters covered by the state as well as medical ventilators, orthopedic mattresses, verticalizers, social taxi service established and not only. All that was possible due to coordinated activities of the project team who were able to mobilise local communities (SMEs, charity organisations) that increased the outreach of the Project by engaging new groups in solving the problems of the target groups. One of the positive outcomes of the activities of regional coordinators and trainings on human rights has become regular and result driven communication between families and the local authorities.

In Hrodna and Mahiliou strong partnerships have been established with cabinet of palliative care, and the local boarding school (orphanage home). Local coordinators, managed to integrate the activities of the project into the work of these two state-run institutions enriching them with expertise, network of contacts of the local charity organisations, socially responsible entrepreneurs from one hand, and receiving better access to the target groups themselves from the other. In Hrodna, **Klaudzia Krauchy**k, the pediatrician of the palliative care cabinet noted that

she received a lot of new knowledge that helped her tremendously in her everyday work, this information was further passed on to colleagues during regular policlinic staff meetings. Currently, she gives master-classes to her colleagues on a biweekly basis. The local coordinator helped to reveal the needs of the families, and correctly prioritize them. Additionally, thanks cooperation with the Project they managed to organize working meetings on palliative care issues involving different stakeholders to discuss possible solutions of the situation in the region. These efforts are believed to have indirect impact on the Project stakeholders in the longer run. Already within the implementation period, they demonstrated more understanding of the topic and declared readiness to develop palliative care in Hrodna. The health care officials recognized that family-and child-centered models of providing assistance were a lot more efficient and cost effective. There were a number of intersectoral advisory meetings between healthcare officials, representatives of social services, and educational authorities inspired by joint efforts of local coordinator and palliative cabinet pediatrician. Thanks this interaction, for instance, two children with no access to education in the area were identified. Their parents refused to deal with the issue being overwhelmed with their children's condition. The BCH psychologist worked with them and offered social respite in Minsk to which they agreed and improved their psychological condition. As a result, 100% of children with disabilities in Hrodna received access to home schooling.

In Mahiliou on the basis of one of the boarding schools, local coordinator **Aksana Aliaksandovich**, helped establishing a club of parents who organize indoor and outdoor activities together, conduct awareness raising campaigns about problems of families with CWD and CWLLC. This kind of time together help them to become more active in solving their own problems and engaging with local communities including the authorities and conducting various advocacy measures. In September 2018, the club jointly with the Boarding School organized an open-air event in the city park. An added value of this initiative is that mothers help and support each other, invite fathers and siblings of children with disabilities to the meetings where they learn to cope with their life situations. One of the innovations the parents of the club introduced is attracting volunteers who accompany mothers and fathers with children with CWD at a walk stressing the normality of such situations in the eyes of other people. In Belarus, people with disabilities remain highly stigmatized. Their relatives in majority cases prefer to keep their problems to themselves, hiding their unfortunate children and isolating themselves from the rest of the society. Such joint walks contribute to destroying harmful stereotypes.

In Babruisk, the local coordinator managed to mobilise the local community of parents from scratch. Establishing community based advocacy model in this Belarusian town became the most challenging task for the Project team. The city had no preconditions for the models of assistance to families with CWD and CWLLC to be established at all. **Anastasija Borbut**, the local coordinator, managed to mobilize parents to take regular advocacy measures, causing the change in status quo in the second and third implementation period. Parents, jointly with local coordinator and Project

lawyer managed to establish a social taxi service for transportation of children with reduced mobility to physiotherapy, training and other important for their condition activities that would have been impossible before. Ms Borbut stressed that she learnt a lot from the trainings on human rights and even had her views and position changed to more proactive. According to her, her work in the Project encouraged to start interact with the Local Council deputies. Another important outcome of the activities have become attracting several local businesses to support of families in difficult life situation. This support has become regular during the reported period, several businesses now organise collection of products and goods at their workplaces involving their clients in this activity. Interviewed social Entrepreneur **Natallia Khalanskaya** who provides premises of her time-out club anti-café 1380 to groups of targeted by the Project parents free of charge, noted that for her it was important to give voice and provide opportunities for different representatives of local community. She also helped spreading information about the Project and its outcomes to the visitors of her Club.

An important role in attracting the representatives of local business communities in each of the targeted by the Project cities and towns played management trainings including trainings on fundraising conducted with the assistance of Healthprom. Thus, one can see how planned activities directly influenced the communities' behaviour.

Implementation of subgranting scheme as widening outreach to the target groups

The project implementers took on board the recommendations provided in the interim external evaluation and used diversified channels for distribution information about call for subgrants. As a result, 11 applications were received – 5 times increase if compared to 2017.

After evaluation of the received application, projects from Homiel, Rahachou and Mahiloiu were awarded grants. The three projects focusing on organizing public awareness campaigns, assessing the needs of families with children with disabilities, attraction and training of new volunteers and providing services for children with disabilities and their families – directly targeting **956 people** that with the subgrants of 2017 makes the total direct outreach – **1281** people in total. The awarded under grant mechanisms project have contributed to raising awareness about the rights and needs of children with disabilities and their families and showed the ways how the communities can contribute to solving their problems.

The evaluator managed to speak to representatives of two organisations receiving grants who praised the subgranting procedure. At the same time, both of them mentioned that more time was needed for the implementation of the projects. Please find below the social impact staircase model that illustrates the non-monetised effect of the project.

Social impact staircase model

New life of the communities (of the society): Recommendations how to assist families with CWD and CWLLC were partly taken on board by the officials in charge and will become part of the official procedures.

New life of the final beneficiaries: targeted by Project CWD and CWLLC as well as their families enjoy better quality of life, better access to medical and social services, improved their health and psychological condition, became less isolated in the society.

New behaviour by the target groups: **1)** BCH developed organization's strategy and started to implement it, actively cooperates with other human rights defenders, started to apply more proactive approach in dealing with its target groups; **2)** Representatives of state institutions participate in the organized by BCH activities (round-tables and conferences), became more open towards recommendations offered by independent experts and CSOs, seem more willing to listen to parents and recognize the effectiveness of family and child centered approach to the problems of CWD and CWLLC. **3)** Parents of CWD and CWLLC in focus started to communicate with each other and provide support for each other; with the support of the Project's lawyer and consultants conducted a number of advocacy activities; they changed their communication strategies towards their children and actively apply new knowledge. **4)** Local communities representatives in targeted cities remain involved in solving the problems of CWD and CWLLC either through charitable actions or through volunteering.

New perception of the situation by the target groups: **1)** BCH is capable to offer different strategies for advocacy of the rights of CWD and CWLLC and sees the important role of parents in these activities; BCH staff began to see great need and potential in development their programmes in the regions of the country; finally, BCH staff recognizes the importance of participatory management and planning when local coordinators contribute to the development of the projects' strategies and fundraising; **2)** State institutions began to recognize the role of CSOs and other stakeholders in solving social problems, they started to see inter-sectoral cooperation as key element for insuring better life standards of the families in focus; **3)** Families raising CWD and CWLL managed "to step out of their shell" and see more space for action.

Satisfaction of target groups and final beneficiaries: **1)** BCH staff increased their competences in advocacy, project management and fundraising, and trained their skills on practice, developed strategic plan, established and maintained contacts with charities, relevant state institutions, other human rights organisations and journalists. **2)** Representatives of state agencies learned about UK experience, built horizontal interaction for providing services for CWD and CWLLC. **3)** Families raising CWD & CWLL increased knowledge about their rights, had their needs assessed and received material and advisory support under the project, had additional services for them established **4)** Local community members learnt about families with CWD and CWLLC and engaged in helping them.

Target groups outreach: **1)** BCH staff, representatives of relevant state institutions; **2)** BCH staff; **3)** BCH staff, regional coordinators (social workers); **4)** Families raising CWD and CWLLC, local regional coordinators, BCH staff; **5)** relevant state institutions, partner human rights organisations, journalists, families raising CWD and CWLLC; **6)** local communities' members (volunteers, schools, commercial companies, entrepreneurs via awarded CSOs'); **7)** Families raising CWD and CWLLC.

Activities conducted: **1)** Study visits of the Project team and representatives of the state to London for professional exchange and peer-to-peer learning; **2)** Strategic planning session for Hospice; **3)** trainings on project management, human rights based approach, advocacy and assessing the needs of the target groups; **4)** trainings for families and local coordinators on communication with CWD and CWLLC, argotherapy, other; **5)** developing awareness raising tools (publications including online, leaflets, round-table and public events); **6)** subgranting scheme implementation (advocacy and awareness raising projects); **7)** providing consultancy services to the project target groups.

The project '**Developing a pilot advocacy service in Belarus to protect the rights of children with severe disabilities and children with life-limiting conditions**' was successfully implemented by its partners who managed to organise all planned activities and achieve qualitative and quantitative indicators foreseen. The project greatly contributed to improving situation of its main target group and the final beneficiaries – *children with disabilities and children with life limiting conditions* as well as their families' members. The project team managed to build successful cooperation with the representatives of relevant state institutions, mobilised local communities for successful advocacy actions. The Belarusian Children's Hospice along managed to improve their organisational capacity and outreach to the Belarusian regions. The organisation outlined new directions for its activities in the 5-years development plan. During three years of their activities, the Project partners ensured international flow of expertise to Belarus in the area of palliative care and ensuring the rights of children with disabilities. Please find below a short list of recommendations developed while interviewing the target groups and preparation of this report:

- All surveyed partners noted that the same trainings that had been offered by the Project to the regional coordinators and families should also be conducted for doctors dealing with children on the regular basis. Should this project continue, or its implementers secure additional funding – training for medical workers would be a must;
- 12 algorithms on how to receive assistance from the state developed by the project lawyers and its regional coordinators should be distributed among human rights defending organisations in different Belarusian regions and cities;
- More activities aimed at the development of horizontal intersectoral cooperation should be conducted in the future;
- More study visits to the countries that are more advanced in terms of assistance to families raising CWD and CWLLC should be organised under future projects of both partners. Such visits proved their effectiveness not only in peer-to-peer learning but also un building cooperation and better understanding between state and non-state actors;
- More focus on empowering parents of CWD and CWLLC and families should be made in the future BCH products – as parents are the driving force in the advocating the rights of their children;
- Publicising success stories of the project for more awareness of the problems of CWD and CWLLC and the ways to tackle them in the society would be an additional value of the project.