

Final Evaluation of the EU-funded project

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

By Megan Bick, October 2018

List of acronyms used in the report

BCH –Belarussian Children’s Hospice

HP - HealthProm

CWD–Children with disabilities

CWLLC- Children with life-limiting conditions

CSO –civil society organisation

SCOPE OF THE EVALUATION:

The terms of reference for this piece of work specified the following:

1. Development of evaluation methodology to measure results of the EC-funded project in Belarus. This methodology will be developed in a manner that provides the analysis of the following:
 - The impact of the project upon beneficiaries
 - Achievement of the expected results and specific objectives in accordance with the project log-frame
 - The impact of the project upon the Belarussian Children’s Hospice
2. Evaluation visit to Belarus to undertake a data gathering process in relations to this project by going to all the main areas where project work has been carried out. This will include consultation with project beneficiaries, members of the project team and regional coordinators, key stakeholders, government officials (e.g. from the Ministry of Health etc.) and other professionals and parents involved in the project.
3. Analysis of data and preparation of the evaluation report.

METHODOLOGY

Having already carried out the Organisational Assessment of Belarus Children’s Hospice and thus become acquainted with the organisation, it was decided to ask me also to carry out the final evaluation.

As the project has still a couple of months to run the approach included ex ante and interim evaluation, as well as research and assessment. The project was analysed from the perspective of the OECD DAC evaluation principles of Relevance, Effectiveness, Efficiency, (early) Impact and Sustainability.

The on-site visit took place from 15- 23rd October 2018 when most of the main sites of activity of this project were visited: Volkovuisik, Grodno, Gomel, Rigachov, Mogilev as well as the Children’s Hospice in Minsk. In addition a trustee of BCH was interviewed.

The evaluation was conducted by two independent consultants in the autumn of 2018, the local evaluator looking more specifically at the social return on investment (SROI)¹ – a principles-based method for measuring the additional financial value, not currently reflected in conventional financial accounts, relative to the resources invested. It can be used to evaluate the impact of a project on all stakeholders as well as identifying ways to improve performance. This was done by Alyona Lis, the same person who carried out the mid-term review of the project and contains more of the facts and figures.

In addition the UK project manager carried out a detailed discussion with the social workers involved to find out the impact on them, their personal reflections and suggestions for the future.

List of documents consulted as well as interviews:

1. Project Proposal
2. Logical Framework
3. EC Interim Report, HealthProm and BCH Years 1&2
4. Mid-term Independent Evaluation 2017
5. BCH Organisational Assessment, Capacity Building Plan and new Strategic Plan
6. The terms of the sub-granting scheme and application analysis.
7. The project publication *Little Book on Great Rights* (in Russian).
8. The agenda and final report from the Final Conference of the project.

This evaluation encompasses as best it can all three of the project's specific objectives:

- 1 Strengthening the 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;
2. Model of community-based advocacy service for CWD and CWLLC is piloted and established in Minsk, Gomel, Mogilev; (Grodno was added at a later stage from savings made elsewhere.)
- 3 Raising awareness of the rights and needs of CWD and CWLLC and their families.

BACKGROUND

The European Union Delegation in Belarus commissioned HealthProm and the Belarus Children's Hospice to run a project aimed at protecting and promoting the rights of children with complex disabilities (CWD) and life-limiting conditions (CWLLC) in Belarus in

¹ The SROI method as it has been standardised by the Social Value UK provides a consistent quantitative approach to understanding and managing the impacts of a project. It takes into account stakeholders' views of impact, and puts financial 'proxy' values on all those impacts identified by stakeholders which do not typically have market values. The aim is to include the values of people that are often excluded from markets in the same terms as used in markets (i.e. money), in order to enable giving those people affected a voice in resource allocation decisions. Some SROI users employ a version of the method that does not require that all impacts be assigned a financial proxy. Instead the "numerator" includes monetised, quantitative but not monetized, qualitative, and narrative types of information about value.

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.

This work was to be carried out directly through project activities as well as indirectly through capacity building of the Children's Hospice so that they can more ably broaden the scope of their work and continue to develop this direction of work after the termination of this project.

THE HUMAN RIGHTS AND ADVOCACY CONTEXT IN BELARUS

“After three years of gradual improvement, the sustainability of Belarusian CSOs stagnated in 2017, with deterioration in two dimensions—legal environment and financial viability—and improvement in three dimensions—advocacy, service provision, and public image.”²

according to the 2017 Civil Society Organisation Sustainability Index for Central and Eastern Europe and Eurasia (21st edition - Sept 2018 Developed by: United States Agency for International Development Bureau for Democracy, Conflict and Humanitarian Assistance Center of Excellence on Democracy, Human Rights and Governance)

Belarus has no recent tradition for advocacy thus making the pilot project a critically frontline initiative. The potential for impact is considerable throughout society, although 2 years is a very short time to bring about any lasting change and a longer-term sustained approach would have ensured a lasting development which could have kept Belarus at the forefront of supporting CWLLC in the region.

Freedom House commissioned a sociological study with both qualitative and quantitative components regarding public opinion towards human rights and human rights advocacy in Belarus between November 2015 and May 2016³. The results generally showed a society largely unaware of the work of human rights organisations and with only a cursory knowledge of what human rights are and why they are important.

Nearly two-thirds of survey respondents said they did not know where to turn if they find themselves in a situation where their rights are being violated. Even when recognised, few do anything to redress any human rights violations faced lacking the belief that pursuing further action would lead to a positive resolution. However in 2017 ten key CSOs in the human rights sector developed strategic plans and also value-based principles to guide human rights work in Belarus, to which more than twenty organisations committed. BCH also created their first long term strategic plan.

OTHER FACTORS AFFECTING CIVIL SOCIETY

During the period under review in this evaluation a progressively worsening situation was emerging for civil society as evidenced in a more recent report released in June 2018 by FIDH. This report⁴ criticises the increasing stranglehold the executive powers are exercising against the independence of lawyers in Belarus.

In addition cuts in international donors' funding and CSOs limited access to local funding has weakened the sector still further. The only positive from this is that CSOs have had to

² <http://actngo.info/wp-content/uploads/2018/10/CSOSI-2017-Regional-Report.pdf>

³ <https://freedomhouse.org/report/special-reports/belarus-public-opinion-about-human-rights-and-advocacy>

⁴ <https://www.fidh.org/en/issues/human-rights-defenders/belarus-controls-on-lawyers-endangering-human-rights>

develop the trust of Belarusians and this improvement is shown in the increased amount of crowdfunding success they have had as well as attracting volunteers. BCH, with its own fundraising department, has benefitted from both of these measures.

Assumptions in the log frame for the best possible outcomes for this project included: political goodwill and support for the action from key Ministries; positive EU-Belarus relations conducive to project success; policy level sustainability/legislation; better communication and cooperation between ministries; adequate budget support at national and local level to sustain local services; increased trust between government and CSOs. It also envisaged linkages being created between human rights defenders and the BCH team which given the deterioration in state relations may have been a mixed blessing if followed up and so wisely not made a priority for the time-being.

With the position at best stagnating if not worsening for CSOs in Belarus according to the reviews quoted above, it is all the more impressive the inroads the regional coordinators made into putting in place mechanisms for effective advocacy. Although this project has been focussed on the social and economic rights of the most vulnerable members of society, CWD and CWLLC, one regional coordinator mentioned feeling uncomfortable locally for having been so proactive in promoting these children's rights to have access to better services or living conditions.

EVALUATION OF THE PROJECT

Relevance

The space open to civil society in Belarus seems to be shrinking and such initiatives as this too few and far between in the regions. Two things make the EU project funding especially relevant now. Firstly, it offers independence of action, whereby social workers can promote children's rights for the full implementation of the laws which set out the many benefits which should be provided to families with CWD/CWLLC. Secondly, it committed support to a flexible innovative project which could adapt to both local and individual changing needs.

The relevance of and need for this programme can be seen by the high take up of participation in all the activities from training for parents to the final international conference having a waiting list as so many people from Belarus and neighbouring countries wanted to attend. Before this project, parents had only medical personnel to approach with their special living/feeding/access issues and have appreciated at long last having somebody to turn to for the non-medical needs so important to quality of life.

Another proof of relevance is the incremental rise in the number of requests for legal consultation on the hotline from the regional coordinators together with the parents of CWLLC from 48 in the first year to 67 in the second and 111 so far during this current year. In the regions they noted a continued rise in the number of enquiries for assistance week by week. On average the regional coordinators have contacted the hospice legal hotline 12-13 times per month, when they are tackling a new issue as they already have gained so much experience between them that they are now able to take on similar cases and already know the best approach to be used.

Changing the attitude of the public towards people with disabilities is a huge and highly relevant on-going task in all countries and an essential part of any such project. By working regionally and particularly in smaller towns where news can spread fast and wide the

community-based advocacy pilots has made a start in changing mind-sets. One of the main such events was the Children's Rights Holiday celebrated in Mogilev initially as an internal event within the "Dom Rebyonka" but in the summer also held in a public park with "Islands of Friendship". The local authority supported the event with free ice-cream and judging by photographs of the day there was plenty of interaction between children with disabilities and other children and young people.

There are not so many strong CSOs in Belarus and so to work on the capacity of BCH, not only in their ability to support advocacy initiatives for CWD/CWLLC but as an organisation itself and leader of the CSO community, was most relevant. BCH has a good reputation and host training sessions on generic subjects which could benefit other smaller CSOs.

The internal management structures of CSOs in Belarus are generally not strong⁵ and so to carry out an organisational assessment and base on its results improvement of internal management procedures and principles, including division of responsibilities, decision-making procedures and staffing policies was a wise intervention. BCH is unusual in the region for having a developed Board with a fairly clear division of responsibilities between the board and staff, but still there is room for more work to be done promoting good governance and transparency.

Effectiveness

The project runs activities on multiple levels, while tackling the issues of development. It was observed that BCH and HealthProm employed several levels of activities that intertwined swiftly: capacity building through training or individual consultations, research, publications, monitoring, advocacy.

The project had a comprehensive approach, working not only with civil society but cross-sectorally, involving health, education and social care professionals as well as BCH staff, parents and volunteers in their study visit and training sessions, conferences and forum meetings. Hence the social workers were not working in a vacuum and mutual understanding was developed between state and non-state actors.

With the training and follow up support from the legal advisor, the regional coordinators were generally effective in terms of defining and implementing their planned activities and achieving their objectives. If they faced non-typical questions they asked the legal advisor to help them to understand the legislation or to check their draft requests. Established practice has been worked out for state provision of: specific nourishment, free medicine or disability aids for CWLLC; installation of access ramps or preferential credit for those building homes with specific access; social housing for families with CWLLC.

Being such a diverse group in their age and background, they employed a wide range of methods to achieve these objectives, to implement their planned activities and to widen their outreach to their target groups. The close network of regional coordinators has enabled them to share ideas and approaches with each other, where possible providing support and complementing the work of each other.

The project established an informal network of civic actors and worked towards the development of local leaders. The manner of running training sessions was designed to be

⁵ According to the 2017 Civil Society Sustainability Index <http://actngo.info/wp-content/uploads/2018/10/CSOSI-2017-Regional-Report.pdf>

empowering, creating active rather than passive beneficiaries. Parent groups took the lead in saying what they wanted and so activities ranged from yoga lessons (with childcare provided), art exhibitions of their own work and picnics in areas of natural beauty to offering to help with maintenance work in the children's day centre.

Training for social workers and parents became ever more practical in nature and helped them develop quite original and effective approaches. The social workers and parents who have attended training days started up approaches involving active use of various internet tools for dissemination of new knowledge and provision of support to those otherwise isolated by their intense caring roles. The project is designed in a way that reflects the technological advancement and offers an original approach and solutions.

The very fact that two new projects (In Gomel and in BCH with young adults – see below under Sustainability for more details) are to some extent a continuation of actions already started during the current project is a good indication for the effectiveness of this project. These other two projects also employ similar strategies to enhance the rights of both children and young people with life-limiting conditions, at multiple levels.

Some project work concentrated on helping BCH to become a more effective organisation by carrying out a self-assessment of its strengths and weaknesses across a broad range of competencies and designing a capacity building programme to focus on the prioritised areas of the staff. A longer term strategic plan has now been written by BCH, which may be difficult to follow given the shortage of international donors, but with the increase of local fundraising by their fundraising department, many aspects of their work can continue as planned. BCH's reputation has risen over the past few years as a leading light in developing palliative care in the wider region from the Baltics to Central Asia. The final conference covered both medical and ethical issues of basic children's rights as well as promoting the role of parents' associations.

Efficiency

Overall the evaluator found good project management and very few examples of inefficiency or wasted opportunity in the course of the project work. The efficiency of the actions has been influenced by a strong partnership, inclusive participatory approach, the networks created and by the sub granting modality.

Partnership between local NGOs, and foreign NGOs eligible to apply for them, has always been fundamental to EU programming. If each partner plays to their own strength – their know-how and contacts – it is thought efficiencies will result. More than this, the EU also aspires to share core European values through partnerships between Belarussian NGOs, and NGOs from other parts of Europe. In the project under review, the evaluator found both assumptions broadly justified. It helped considerably having a UK project manager fluent in Russian, with a good understanding of local conditions and attitudes. HealthProm, the European partner, has decades of experience in the region as well as a wide pool of experts from UK from which to choose the most appropriate trainers for each project area.

A series of round-tables were organised to develop a pilot innovative model of community-based advocacy service for CWD and CWLLC, providing them with access to advocacy, legal advice and support services. The pilot model was developed efficiently by close consultation with the regional coordinators, state representatives, other relevant CSOs from different regions as well as with the ultimate beneficiaries - parents of children with

disabilities/life-limiting conditions. This participatory approach involving beneficiaries, intermediaries and state actors was effecting in raising early on weak-points and challenges to enable a smooth introduction of an effective model.

Over and above the support provided by the project managers and the legal assistant, the regional coordinators were able to benefit from a mutual support **network** created and enhanced by their regular trainings and meetings for sharing experience in Minsk. There were many instances of one phoning another to check out difficulties, find out most successful approaches or just generally having a moan about the pressure of work etc.

Similarly parents of CWLLC who also got together for training under the project shared their contact details where appropriate and had begun to share practically and emotionally through social media. With these parents often being amongst the most isolated given the nature of their caring roles, such a mutual support group has provided great benefit to all and will last beyond the duration of the project.

It is often found that projects which have specific geographic or thematic outreach can consolidate their impact efficiently through **micro-grant schemes**. At a relatively small cost, these schemes can coincidentally identify good local partners for future work with the hospice. They could also sometimes identify a fresh local issue of social welfare or human rights concern. This modality helped develop additional synergies with other organisations and initiatives in Minsk and the regions, including with one social enterprise in Bobruisk and one entrepreneur in Gomel.

Both partners went through a learning curve having made the application process for the small grants too complicated in the first year and simplifying it for 2018 which meant that there were more applications. Then, despite the small sums available (max 5000 Euros per grant) the small grant scheme appealed to a range of different organisations (women's groups, cultural/educational organisations, parent groups supporting disabled children or more generic developmental associations) with 10+ applying and four succeeding. They were scored on the relevance, effectiveness and potential sustainability of their proposed activities and innovation of approach. In addition a score was given for their proposed interaction with other CSOs and state institutions.

With 6 grants given in total, costing 30,000 Euros plus the administrative time of project staff, this has proved a highly cost-effective way of raising awareness of issues facing CWD. Three of the still on-going small projects were visited by the evaluator and showed wide outreach for example promoting volunteering amongst students (after preparing them for the special needs of working with CWLLC). The small project which it was not possible to visit at this time due to time constraints was developing a system for social contracting with the local authorities. Setting up such a successful pilot: training local authority representatives on procurement practices; bringing in specialists to clarify needs and standards; exploring different ways of reimbursement etc could have huge ramifications nationwide if the experience is accepted and disseminated.

Impact

With the project still on-going at the time of the evaluation it is clearly early days to be assessing impact. There have been a large number of outputs in the form of meetings, training, conferences and other events which have led to some impressive outcomes some of which are detailed below.

Much of the impact has been deep on individuals, but there has been a breadth of impact due to the regional coverage of this project, the rise in awareness of CWLLC and networking. The following areas of impact were identified:

Impact on CWD/CWLLC

On the whole impact has been deep and long lasting on the immediate beneficiaries who have had their lives changed, for example the small boy who now has the special food he requires provided by the state. As a result of these consultations the success rate has varied from 3 family problems being resolved in the first year to 14 during 2017 and 10 so far this year.

Impact on parents and families of CWD/CWLLC

The number of parents contacted during this project has far exceeded the numbers planned in the logframe. Initially parents were reluctant to come to meetings or join in events but gained in confidence as the project progressed to become proactive in arranging social or educational activities. Initial embarrassment of having their children seen show in a reluctance to have photographs taken of them has disappeared and films were taken of various competitions and celebrations.

The outreach to hundreds of parents throughout the country has helped many parents of CWLLC feel greater self-worth, less isolated, more empowered. The profile of parents, often single mothers, of children with disabilities and children with life-limiting conditions. One “Dom Rebyonka” has a separate room for a parents club where they can meet or socialise as a complete family as well as have separate activities for fathers, siblings etc.

Impact on the situation young people with life-limiting conditions

2018 has seen a new phenomenon of young people over the age of 18 asking for information on their legal rights for provision of care. With 4 such cases this year the hospice has decided to take this forward with a new project for those leaving the care provision for children and having to find their way in a new world. This will be funded by the Friends of the Belarus Children’s Hospice.

Impact on regional coordinators

In an important respect the impact of the project **Crowd Sourcing and the Army** has been greater than planned. The project invited the LSE as 3rd partner, to help it reach a European forum for the first time. Yet since 2013 it has unexpectedly cooperated with the OSCE, the European Committee for the Prevention of Torture, and in 2015, will submit a Shadow Report to the UN Human Rights Committee. The project has also maximised the impact of its individual legal advice, by sharing good practices and templates on its website.

Impact on implementing partners

This project helped HealthProm to gain expertise in a completely new area, namely children's palliative care - through study visits they improved their knowledge, skills and understanding of palliative care and effective support mechanisms for parents with CWLLC. They also established new contacts in Latvia and Ukraine and are currently developing a similar project in Ukraine.

Over and above the social care skills to add to their more medical focus, BCH also gained a new longer term working strategy developed with a participatory approach to help it move from short-term plans and a more hierarchical structure. This was timely given the end of a phase of development leading to the completion of the new hospice building. This project

has helped enhance their international role in developing palliative care and promoting the rights of all children.

Impact on public awareness

Several newspaper articles were shown of concerts for people who are hard of hearing, art exhibitions, sporting events etc. where CWD were taking part and all the parents and staff I talked to mentioned changing attitudes with more people with disabilities being seen in the streets. Social media has helped this change too with a greater range of people posting information, named by one project as their "Window on the World". The promotion of volunteering with CWD amongst students has had a major impact on the many students who have taken up this role.

Impact on medical practitioners

In Grodno, for example, where one doctor has 153 sick children under her care and no help from a nurse, the social worker has provided much assistance in the provision of all-round care for the family of a CWLLC. BCH has continued to provide updated information on means of palliative care to these doctors while on visits or organizing training for this current project

Impact on state structures

In some areas the social workers have organised meetings of social welfare, health and education professionals to look at gaps in the provision of services and care for CWLLC and help them work together systematically in providing an all-encompassing care package meeting the different needs of each individual child.

Monitoring of children's rights

Although not a stated objective of the project, the legal adviser at BCH, Irena Gamova has developed a database of all inquiries, which allows her to monitor all her cases and appeals to local authorities in Minsk and in the regions, the full and partial resolutions as well as cases still being processed. This is an excellent tool for understanding the needs of CWLLC and the potential for improving their quality of life, differences between the regions and what would be needed for a fully-fledged national system for improving the quality of life of this vulnerable group.

Publications

One of the most popular and long-lasting outputs of this project was to publish two editions of the "Little Book on Big Rights" written in an accessible way. In addition BCH also produced a manual to accompany this for specialists called the "Little Book on Big Rights - how to help effectively". This included sections on how to work with media and PR, local authorities and other CSOs.

Development of BCH website

Although the improved website is still in its first year of implementation one can see that BCH is now able to reach a wider audience, to interact with volunteers and civil society at large and also to communicate directly with the public. .

Sustainability

Normally sustainability is project-related only, but in Belarus next to the sustainability of the project results, the sustainability of CSOs is under some threat too. The risks to sustainability are related primarily to the external environment in which civil society operates:

- deteriorating human rights and NGO environment

- lack of understanding on the side of the public of issues facing CWLLC
- the low image of CSOs, their nature and function
- the significant government influence over the information landscape
- the withdrawal of traditional donors from the country, etc.

On the other hand, there are also some good examples of sustainability. In the majority of cases the sustainability is ensured through the pool of experts created, following the training initiatives of the grantees, the strengthened capacity of both the partner organization and the CSOs that participated in the small grants programme, or the concrete tools already created.

Sustainability depends also on the continuity of the action and finding funding from elsewhere to further embed this important initiative. The partnership between HP and BCH has worked well and so they are looking for new sources of funding to further develop this effective approach of promoting children's rights. The model guidelines for community-based advocacy services could form a good basis for a more fully-fledged national network, so it is disappointing that the funding hasn't been continued to further embed the existing pilots and extend the services to more towns throughout the country.

The popular publications are a good and long-lasting legacy of this project which will help parents long into the future with the hope that resources can be found to update them at some stage when laws may change. According to the mid-term review, who is a native speaker, all the project materials are popular and well used as they are informative, easy to read, and clearly target their specific audience. Social media networks are self-sustaining being of no/low cost and of immense value to the previously isolated parents of CWLLC. It can only be hoped that these networks will be open to invite new members and maintain the positive momentum created by this project.

Chernobyl Children's Project have just started a new project with UNICEF funding together with their partners in Gomel, 'Supporting Children Together' supporting families with children with disabilities in three districts (Rechitsa, Rogachev and the Railway District of Gomel). In each district they are employing a team of three people (Galina Fomenok from the HealthProm project is the Head of the Rogachev team). The idea is to encourage Education and Social Protection departments to work much more closely together in assessing and attempting to meet the needs of these children and their families. If it is successful, UNICEF hope to roll it out across the country.

CONCLUSIONS AND RECOMMENDATIONS

The addition of a final conference to showcase the experience and success of this project both nationally and internationally was particularly pertinent in sharing lessons learnt and the various ways of improving the quality of life of CWLLC.

The mid-term evaluation considered the project '**Developing a pilot advocacy service in Belarus to protect the rights of children with severe disabilities and children with life-limiting conditions**' as very important for Belarus, as it helps to establish the mechanism of implementation of state aid for families raising children with severe disabilities and incurable diseases.

By using a twin approach of working through professional services and promoting the worth of parents in the care of their children as they really are the "professionals" as regards their own children and what they need. This project has provided a great service in making sure

that CWLLC cannot be forgotten and left to die, but have a right to what can be provided to give them a better quality of life.

The community-based advocacy system has been piloted and proved its worth. By engaging a wide range of people (although all women they are of different ages and professional backgrounds) it has been shown that a variety of approaches can produce good effect.

As this project is unfortunately coming to an end, individual project recommendations have no place, but more generic ones for similar such projects are

- The **project duration** should have the possibility of an extension time given the loss of time in registering projects where the main applicant or co-applicant is a foreign entity delaying some project activity and thus restricting the time for dissemination at the end.
- **Sub-granting** should be preserved and even increased, as it helps extend the outreach of the project, creates ownership and sustainability. Small sub grants turned out to be quite effective now that the system has been put in place for their disbursement.
- **Synergies** should be promoted on all levels: with BCH expertise being brought into future HP projects elsewhere as well as their involvement in similar such initiatives throughout the Russian-speaking region in particular.
- The pool of knowledge accumulated till now in this arena should be preserved for future community advocacy projects, and shared with them.