

## Contexts of child disability in Belarus, Moldova and Ukraine

Background Analysis:

Contexts of child disability in Belarus, Moldova and Ukraine

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## **1. Introduction**

This report summarises background research undertaken as part of a multi-country project aimed at promoting regional exchange amongst multi-sector professionals working in the area of child disability from three target countries: Belarus, Moldova and Ukraine. Background research was carried out in order to provide a baseline understanding of the disability-related contexts and 'climates' in each country. This includes current legislation, policy and major initiatives focused on disability within each country, as well as the extent to which the topic of disability is prioritised at the national Government level. To provide some comparative analysis, a brief summary of current disability policy in the United Kingdom and the wider European Union is also included.

Each of the target countries completed a questionnaire designed by the lead applicant, HealthProm. This 'Country Context Questionnaire' (see Annex) supplemented the background contextual analysis for each country. It used a range of questions designed to obtain a picture of the local policy context and 'climate' on the ground regarding child disability, as perceived by senior staff from local partner organisations, who are themselves professionals working for civil society organisations related to child disability. It was originally designed in English and translated into Russian for implementation.

The larger project of which this report forms a part is entitled *Communities, Classrooms and Civil Society: Sharing experience and developing regional approaches to addressing the rights and needs of children with disabilities in Belarus, Moldova and Ukraine*. It was generously supported by the Eastern Partnership Civil Society Forum in collaboration with other funders.

### **1.1 Limitations of this exercise**

This brief analysis was carried out solely for the purposes of supporting the larger project of which it is a part. It was therefore not an exhaustive research exercise, and findings should be considered accordingly.

## 2. Belarus

### 2.1 Background

There are currently 1.7 million children under the age of 18 in Belarus<sup>1</sup>. As of 2010, an estimated 25,867 of these were children registered with disabilities<sup>2, 3</sup>. Until recently, formal national policy in the area of disability has been limited. Whilst the Government has, in recent years, implemented a number of national initiatives aimed at providing services and support to children and adults with disabilities— such as the National Programme to create a “barrier-free environment for people with physical disabilities, 2011-2015”— the absence of a cohesive national strategy on disability resulted in many of these programmes remaining fragmented. Yet significant developments have taken place very recently. In November 2016, Belarus ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Until then, they remained one of the only countries in Eastern Europe that had signed, but not officially ratified, the Convention. A new social protection strategy was also adopted by the Government in 2016, which for the first time outlines a formal commitment to the social integration of people with disabilities. Despite these advances, societal and cultural awareness of disability remains a challenge in Belarus. People with disabilities, including children, remain highly marginalized due to persistent social stigma.

### 2.2 Disability-related policy summary

Belarus’ recent ratification of the UNCRPD is a critical step towards implementing the principles laid out in the Convention, as the process of ratification requires not only a notional commitment to its agenda but also the designation of a State budget towards its implementation. The concurrent recent adoption of the new “State Program on Social Protection and Employment Promotion, 2016-2020” is a testament to this process. This new national strategy formally prioritises the social integration of people with disabilities for the first time. Of the strategy’s five sub-programmes, three are specifically dedicated to disability: “Prevention of Disability and Rehabilitation of Persons with Disabilities”, “Developing a Barrier-Free Environment”, and “Social Integration of Disabled and Senior Citizens”<sup>4, 5</sup>.

At the service level, the Government entitles children with disabilities to free medical care, and also grants certain benefits such as housing allowances to families of children with disabilities. However, civil society organisations remain the main providers of services for children with disabilities and their families. The services and support they provide are often perceived to be of higher quality than those provided by the Government<sup>6</sup>.

### 2.3 Main themes from questionnaire

The country context questionnaire that was completed by senior staff of local partner the Belarusian Children’s Hospice, highlighted the following themes:

- Access to services for families caring for children with disabilities in rural areas is particularly poor.
- The area of advocacy for the rights of children with disabilities is very new and not yet developed in Belarus.

### 2.4 Focus topic: palliative care for children with severe disabilities and terminal conditions

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<sup>1</sup> UNICEF Country Statistics, Belarus. 2012.

<sup>2</sup> Improving disability-related data collection in Belarus has been identified as a priority by both the Government and multilateral bodies such as UNDP and UNICEF.

<sup>3</sup> UNICEF Annual Report for Belarus, 2010.

<sup>4</sup> PowerPoint presentation by Anna Zakrevskaya, Head of Department of Social Protection at the Research Institute of Labour under The Ministry of Labour and Social Protection of the Republic of Belarus. Zero Project Conference, Feb 2015.

<sup>5</sup> Official Website of the Republic of Belarus.

<sup>6</sup> Source: Belarusian Children’s Hospice.

Of the estimated 25,867 children registered with a disability in Belarus, the number of children who require palliative care for severe disabilities and terminal illnesses is estimated at 3,000 per year<sup>6</sup>. The Belarusian Children's Hospice is the main independent provider of comprehensive palliative care services in the country. It also works actively with the Government to support the development of the national system of palliative care. However, the combined efforts of the Belarusian Children's Hospice and the State system are still not currently enough to ensure the provision of quality care for all children in need. The Hospice is only able to support 300 families annually, mostly located in Minsk and surrounding areas. The need for such support is constantly rising, in part due to the long-term consequences attributed to the Chernobyl accident, which affected parts of Belarus particularly heavily. These include a reported increase in the number of children with life-limiting conditions such as cancers, genetic, metabolic and neurological diseases. The evidence from international agencies is mixed on the scale of the relationship between the radiation exposure during Chernobyl and long-term disease outcomes, and as a result their estimates of disease outcomes attributed to the event are consistently lower than those maintained by local scientists in many of the affected countries<sup>7</sup>. For example, the Belarus National Academy of Sciences maintains higher estimates of cancers directly related to the Chernobyl incident, which is correlated with the significant rise in the number of children with particular types of cancers registered in Belarus since the 1990s<sup>8</sup>.

The Belarusian Children's Hospice conducted extensive consultations with families of children with disabilities and terminal conditions for its large European Commission funded project (2015-2018), and identified key challenges faced by these families:

1. Families are often unaware of their legal rights and entitlements, such as benefits, housing and free medication. This is particularly pronounced for families who live in rural areas. Most families also do not have access to legal assistance.
2. Even if families are aware of their rights, the day-to-day burden of caring for their severely disabled or terminally ill child results in low uptake of services they may be entitled to.
3. Families in need of assistance with full-time care for their ill children frequently cannot find qualified nurses, and cannot afford such assistance privately.
4. Families report strong resistance and stigma from local specialists and service providers.
5. Families frequently encounter difficulties of physical access both in and outside their homes such as narrow doors to allow the use of wheelchair at home, no lifts, long/steep staircases, etc. Although there is a national programme aimed at the creation of a "barrier-free environment" for people with physical disabilities, it is not effectively realised in practice.

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<sup>7</sup> WHO, 2006. Health effects of the Chernobyl accident: an overview.

<sup>8</sup> Belarus National Academy of Sciences, as cited by *the Guardian*, 2010. In *Chernobyl nuclear accident: figures for deaths and cancers still in dispute*.

### 3. Moldova

#### 3.1 Background

Moldova is one of the poorest countries in Europe, currently ranked 167 out of 187 countries in the United Nations Development Programme (UNDP) Human Development Index. Equitable access to health and social services remains a challenge throughout the country, with rural populations and vulnerable groups facing the most significant barriers to services. There are currently an estimated 13,349 children with disabilities under 18 in Moldova<sup>9</sup>. Despite recent progress— particularly in the area of education— these children still face numerous barriers to accessing health, social and education services. This is largely due to persistent weaknesses in government policies, lack of training amongst health and social care professionals and teachers, and physical accessibility issues. Stigma and discrimination against people with disabilities remain persistent issues. As a result, children with disabilities are amongst the most vulnerable groups in Moldovan society, marginalised and frequently isolated at home.

#### Disability-related policy summary

Moldova has both signed and ratified the UNCRPD. A government “Strategy for the Social Inclusion of Persons with Disabilities” (2010-2013) was also successfully implemented. Significant reforms of health care, social protection and education systems have been underway since 2000. A particular achievement has been the closure of the majority of the state orphanages for young children, and the subsequent strengthening of alternative care services within the community. With the closure of state orphanages and the appearance of large numbers of children with disabilities in the community, the National Education Strategy (2004–2015) identified inclusive education as a priority area for the first time (inclusive education refers to making education in mainstream schools accessible to all children, including those with disabilities). In 2012, the government drafted new legislation on inclusive education at the primary and secondary school levels, as a result of which a national Psychological-Pedagogical Assistance Service (PPAS) was established to ensure that each child receives support in order to attend and integrate into regular school.

Despite this progress, challenges remain. Changes in the laws and regulatory frameworks are not always backed by political will at all levels, and have not yet led to pervasive changes in attitudes towards people with disabilities. Services for people with disabilities continue to operate based primarily on the medical model, and specialised training for practitioners is still needed.

#### 3.2 Main themes from questionnaire

The country context questionnaire that was completed by senior staff of local partner Partnerships for Every Child, highlighted the following theme:

- Access to services for families caring for children with disabilities in rural areas is particularly poor.

#### 3.3 Focus topic: pre-school education and support services for children with disabilities

In recent years, the number of children with disabilities has tripled in mainstream schools in Moldova, which reflects both a shift towards more robust policy regarding inclusive education, as well as improved screening and assessment practices<sup>10</sup>. However, inclusion is not necessarily synonymous with integration. Whilst they may be enrolled in a school, children with disabilities may not be fully integrated due to a lack of necessary support facilities, poorly trained staff or discrimination from staff, students and parents.

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<sup>9</sup> UNICEF, 2013. Children of Moldova.

<sup>10</sup> Moldovan National Bureau of Statistics: Education in the Republic of Moldova 2015/2016, Statistical Publication.

Although legislation now states that these children must be included in mainstream schools, in practice, social stereotypes and stigma restrict their integration and participation. Many parents and caregivers still believe that children with disabilities should either stay at home without receiving an education or be sent to a residential institution or special school. Many children with disabilities and special needs continue to be placed in institutions. In 2012, 59% of the children living in residential institutions in Moldova were those with disabilities<sup>9</sup>.

A comprehensive mapping exercise was undertaken by the lead applicant, HealthProm, and Partnerships for Every Child in 2016 as part of a large European Commission funded project (2016-2019). Educators, social service professionals, local authorities and parents of children with disabilities were interviewed. Key findings from this exercise are below:

- A high proportion of the children with disabilities enrolled in inclusive pre-schools have communication difficulties, a finding that is consistent with recent figures from the Moldovan National Bureau of Statistics. Simultaneously, speech therapists comprise only a small proportion of educational staff available in schools across the five regions surveyed.
- PPAS and Mobile Outreach Teams highlighted a need for additional expertise in communication difficulties. Both expressed the desire to add speech therapy services to their remit in order to meet demand.
- Only a small proportion of schools surveyed have adequate physical facilities to support children with disabilities.
- Only a small proportion of parents and carers of children with disabilities reported attending support groups, although those that did access such groups found them positive and useful.
- Findings suggest that children with severe disabilities and complex needs remain excluded from pre-school education, due to a range of factors including limited physical facilities to meet their needs, and unwillingness to do so perpetuated by stigma and discrimination. This remains a highly vulnerable group of children in the Republic of Moldova.

## 4. Ukraine

### 4.1 Background

2004 World Bank data estimates the prevalence of disability within the total population of Ukraine at 14.8%<sup>11</sup>. As of 2002, 153,000 children under 16 were officially registered with a disability<sup>12</sup>. This highlights the need for more recent disaggregated data on disability, which remains a challenge in Ukraine. A high proportion of children with disabilities in Ukraine live in residential institutions, where their rights are often ignored or violated in systems that cannot respond to their needs or promote their development<sup>13</sup>. Of the 101,819 children living in institutions in 2009, 42,668 were those with disabilities<sup>14</sup>. The risks of harm from institutional care exist for any child, but the consequences can be even more serious for children with disabilities. Despite these challenges, Ukraine has more recently been emerging as a leader within the region for promoting the development of Early Intervention and parent-led advocacy for the rights of children with disabilities.

### 4.1 Disability-related policy summary

Ukraine has both signed and ratified the UNCRPD. The Government of Ukraine has in place several national policies and laws pertaining to individuals with disabilities such as: “Social Protection of People with Disabilities in Ukraine” and “Rehabilitation of People with Disabilities in Ukraine”. A National Plan of Action for Children (2010 - 2016) was adopted in 2009, which has been instrumental in developing a national framework on child rights, with a particular focus on highly vulnerable groups of children including children with disabilities<sup>14</sup>. More recently, Early Intervention has been prioritised within the national reform agenda. Early Intervention refers to the delivery of a system of services to young children at the earliest point that an issue with development or a potential disability is identified, in order to support the child and their family as early as possible.

### 4.3 Main themes from questionnaire

The country context questionnaire that was completed by senior staff of local partner the Charity Fund Early Intervention Institute, Kharkiv, highlighted the following theme:

- Parents of children with disabilities are often regarded by professionals as passive recipients of care and services, rather than being actively engaged in the care of their children.

### 4.4 Focus topic: Early Intervention and parent advocacy

Early Intervention promotes a social model of disability that addresses the needs of both children and their parents or caregivers. It works in close partnership with parents and in collaboration with health, social care and education sectors, rather than treating the child medically in isolation as is often the case where a medical model of disability persists. The Charity Fund Early Intervention Institute, Kharkiv, has played a leading role in developing Early Intervention nationally in Ukraine.

Lead applicant, HealthProm, and the Charity Fund Early Intervention Institute, Kharkiv carried out a small project in 2015 designed to understand and progress the Early Intervention agenda in the country, and to develop a strategic approach to parent advocacy and peer support for families of children living with disabilities. A Parents Advocacy Strategy Meeting was held in Kiev for parent leaders from a range of organisations including civil society organisations and Early Intervention centres across ten regions of Ukraine. This event catalysed strong commitment to the development

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<sup>11</sup> World Bank and WHO. World Report on Disability, 2011.

<sup>12</sup> UNICEF and Statistical Office of Ukraine, 2002. Children and Disability in Ukraine: MONEE Country Analytical Report 2002.

<sup>13</sup> UNICEF, 2005. Children and disability in transition in CEE/CIS and Baltic States.

<sup>14</sup> UNICEF, 2011. Ukraine: Country Programme Document 2012-2016.

of Early Intervention from all participants and led to the creation of the All-Ukrainian Parents Forum for Early Intervention (AUPFEI), which brings together parent advocates to support the development of Early Intervention across Ukraine, and enables dialogue with key stakeholders. Consultation with the parent advocates demonstrated a demand to develop their capacity to more effectively liaise with policy makers.

## 5. United Kingdom and Wider European Union

The **United Kingdom** has been a leader in the promotion of the rights of people with disabilities. Since 1995, several laws have been integrated into national legislation that shape the disability related policy context in the country, as well as specific areas related to disability such as inclusive education.

Key legislation:

- **Disability Discrimination Act (1995 and 2005):** Made discrimination against disabled people illegal, and promoted the rights of individuals with disabilities in various sectors.
- **Education Act (1996):** Issued a Code of Practice for identifying, assessing and providing educational services for children with Special Educational Needs (SEN).
- **Special Education Needs and Disability Act (2001):** Amended the Education Act by further outlining the right of children with SEN to mainstream education. Also introduced statutory advice and information for parents.
- **Disability Discrimination (Public Authorities) Regulations (2005):** Holds public authorities accountable for upholding the Disability Discrimination Act.
- **Equality Act (2006 and 2010):** Brings together over 100 separate articles of legislation pertaining to various forms of discrimination into a single act. Strengthens and provides a unified legal framework for promoting equal rights for all individuals.
- **Ratification of the UNCRPD (2009):** Commits the United Kingdom to implementing internationally mandated standards of practice with regard to promoting the rights and needs of individuals with disabilities.
- **Children and Families Act (2014):** Outlines greater protections for vulnerable children, including children with disabilities. Makes changes to the system for children with disabilities to access mainstream education, including promoting a greater degree of choice for families.

In addition to legislation, the UK also has a long history of independent entities ranging from advisory bodies, civil society organisations and advocacy groups that support and promote the rights and needs of individuals with disabilities. Examples include the British Council of Disabled People's Organisations, which was established in 1978, and the Disability Rights Commission, which was created in 2000 and included amongst its founding team several Commissioners with disabilities.

The wider **European Union** has a significant history of promoting the rights and needs of people with disabilities. It has an obligation to adhere to international human rights law in this area. The EU Charter of Fundamental Rights shapes all EU law. It specifically mentions the protection of the rights of individuals with disabilities, and states that discrimination on the basis of disability is prohibited in all spheres. The EU ratified the UNCRPD in 2009, which was the first time that the EU as a body itself ratified an international human rights treaty. Progress towards meeting the goals of the UNCRPD is regularly monitored at the EU level. In 2010, the European Disability Strategy 2010-2020 was adopted, which provides a strategic framework to facilitate and support the implementation of the UNCRPD by both the EU itself and its Member States. It specifically sets out to 1.) empower people with disabilities to enjoy their full rights, and 2.) create a barrier-free Europe for all. The progress of individual Member States with regard to the UNCRPD is monitored through regular data collection and the generation of country reports. The EU also monitors EU-wide law through the Academic Network of European Disability Experts (ANED). This body conducts annual reviews of EU laws and policies with reference to disability. This information, combined with country reports from Member States is compiled in the European Commission's online data resource called "DOTCOM". This is a valuable data resource accessible to the public here: <http://www.disability-europe.net/dotcom>.

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## 7. Annex: Country context questionnaire completed by local partners

### **Country Context Questionnaire: Belarus, Moldova Ukraine**

*Communities, Classrooms & Civil Society: Sharing Experience & Developing Regional Approaches to Addressing the Rights and Needs of Children with Disabilities in Belarus, Moldova and Ukraine*

Funded by the Eastern Partnership Civil Society Forum

The aim of this brief questionnaire is to contribute to the background research we wish to carry out in each country as part of our new multi-country grant. We wish to get your local input on current initiatives, activities and relevant policy/legislation in your country so that we can get an accurate picture of the local context and how it relates to the rights and needs of children with disabilities and their families. In particular, it will also allow us to compare the contexts of each country, and to learn from each other in order to develop shared approaches to common challenges where possible.

Your responses will be used only for the purposes of this project. They will be shared in reports and a regional event, and only the name of your organisation will be used. If you have any questions, please contact either Lauren Foster Mustardé ([lauren@healthprom.org](mailto:lauren@healthprom.org)) or Tanya Buynovskaya ([Tanya@healthprom.org](mailto:Tanya@healthprom.org)).

Thank you for your participation.

## **SECTION 1**

**1. In your opinion, how would you rate the general context in your country with regard to addressing the rights and needs of children with disabilities and their families?** Please consider different sectors, such as health, education and social services.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Very restrictive				A combination of both					Very supportive

**2. Can you please explain your rating?** (Please limit your response to no more than one page).

**3. In your opinion, to what extent do professionals working in different sectors related to child disability in your country communicate with each other?** For example, education professionals, health professionals, social service professionals.

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Not at all				Some communication & information exchange					Regular collaboration & exchange

**4. Can you please provide an example of professionals from different sectors communicating or working together?** Please limit your response to no more than one page.

## **SECTION 2**

### **5. To what extent does your organisation work in the following areas?**

#### **General child disability**

<b>1</b> Not at all	<b>2</b>	<b>3</b> A bit	<b>4</b>	<b>5</b> A lot
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#### **Early education for young children with disabilities**

<b>1</b> Not at all	<b>2</b>	<b>3</b> A bit	<b>4</b>	<b>5</b> A lot
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#### **Advocacy related to child disability**

<b>1</b> Not at all	<b>2</b>	<b>3</b> A bit	<b>4</b>	<b>5</b> A lot
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#### **Support for children with severe disabilities (including those with palliative care needs)**

<b>1</b> Not at all	<b>2</b>	<b>3</b> A bit	<b>4</b>	<b>5</b> A lot
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*Thinking of the wider context in your country, we would now like to ask you about current initiatives and policies related to these areas. You may not be able to provide a response for every area, but please provide as much information as possible.*

**6. Please list current or recent INITIATIVES you are aware of related to childhood disability for each area.** By 'initiatives', we mean large projects or activities in your country designed to address the needs of children with disabilities and their families, or to improve access to basic services. These may be in different sectors, such as health, education or community-based services. These may also be supported by bodies such as the local Government, or international organisations.

- General child disability initiatives
- Early education initiatives
- Advocacy initiatives
- Initiatives to support children with severe disabilities (including those requiring palliative care)

**7. Please list current or recent POLICIES you are aware of related to childhood disability for each area.**

- General child disability policy

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- Early education policy
- Advocacy policy
- Policy related to supporting children with severe disabilities (including those requiring palliative care)

### **8. Other Areas**

Other areas or current trends you wish to mention which have not been covered. For example, developments in service delivery or professional training.

### **SECTION 3**

#### **STAKEHOLDERS**

In addition to national and local government, please list below any other organisations active in your country that work in the area of child disability. These can be from different sectors, for example, international organisations, private service providers, research institutions, advocacy groups. (Please limit your response to one page).