Country brief

Deinstitutionalization for children with disabilities

Ukraine

Marianna Onufryk¹

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¹ Head of NGO “Social Synergy”, Chairman of the board of NGO “Family for persons with disabilities”
Background

This paper is one of the county briefs which have been developed in the aftermath of the regional conference “Deinstitutionalization of children with disabilities” organized by Center for European Studies in partnership with Right Livelihood Foundation and Global Campus of Human Rights. The goal of the conference was to broaden the empirical knowledge and develop strategic skills in effective management of the deinstitutionalization programs for children with disabilities in 5 countries of the post-communist countries, namely Armenia, Georgia, Tajikistan, Ukraine, and Bulgaria. The experts form the mentioned countries pointed out the benefits, challenges and drawbacks of the policies and programs on the national level. To disseminate the main experts points on the topics, country briefs had been developed.

General Policy and legal framework on DI in the Ukraine

In 2017, the Cabinet of Ministers of Ukraine approved the National Strategy to Reform the Institutional Childcare System for 2017–2026 (DI Strategy) and its Stage I Implementation Plan\(^2\). The Stage I Implementation Plan that was due to be completed in July 2019 is barely 30% implemented, while the Stage II Implementation Plan was approved with a one-year delay\(^3\). Selective monitoring of the implementation of the regional DI plans has shown that the reform has come to a standstill: services are not created, and residential care facilities are being filled with new victims of such care and upbringing. Specifically, one of the expected outcomes of the DI Strategy was to “stop placing children under the age of three in institutional care facilities from 2020”, but to date, no such moratorium has been established and 38 baby homes of the Ministry of Health system continue to accept children of this age.

As of early 2020, 2,756 children resided in 38 baby homes in Ukraine. A study was carried out in 2019–2020 as part of the project titled “Pilot Assessment of Baby Homes and Development of Recommendations for Reform”\(^4\). The study discovered that the main reasons for children entering baby homes are the difficult financial situation of families, the inability of parents to care for the child, neglect, careless treatment of the child due to substance abuse, and abandonment of the child. Almost all children were in children’s hospitals during the process of their registration with the baby homes due to the lack of other emergency placement options. The majority of children (60.2% of 415) were admitted to facilities under the age of 12 months. At the time of the study, up to one-third of children had been living in baby homes for 2 or more years. In all baby homes, there is a correlation between the child’s age and length of stay: on average, older children stayed in the facilities longer than the younger ones. Differences in length of stay depending on age may indicate a delay in making decisions about the child (meeting the statutory deadlines for returning the child to the family or initiating deprivation of parental rights by court order) by both the guardianship authorities and the institution.


\(^3\) [https://zakon.rada.gov.ua/laws/show/703-2020-%D1%80#Text](https://zakon.rada.gov.ua/laws/show/703-2020-%D1%80#Text)

\(^4\) The Project was implemented with the support of the Health Reform Support Project funded by the United States Agency for International Development (USAID) and the UK Government’s Good Governance Fund Programme in 2019–2020 in five baby homes in Dnipropetrovsk, Poltava and Kherson Oblasts. The pilot was implemented by the Hope and Homes for Children with the assistance of the Commissioner of the President of Ukraine for Children’s Rights, in cooperation with the Ministry of Health of Ukraine and the Ministry of Social Policy of Ukraine, structural units of three oblast state administrations and baby homes.
administration. 56.2% of children in baby homes were orphans and children deprived of parental care, while the others had parents that do not have restrictions on their rights in their rights⁵.

Almost 70% of children in baby homes are somatically/neurologically healthy and only have a developmental delay due to deprivation of family-like environment or/and parental care. A child’s stay in a facility exacerbates existing health problems, and deprivation leads to developmental delays in healthy children. Almost all children in baby homes need comprehensive rehabilitation services. The analysis revealed “myth diagnosis” in children and, in some cases, incomplete lists of all diagnosis components and inadequate ICD-10 coding, especially for neurological diseases. With a significant number of health staff providing health supervision, children do not receive all necessary services, including adequate nutritional support, screening for health disorders and developmental delays, and timely correction. Regulations on the nutrition of children in baby homes do not meet their needs, especially in the presence of a disease. Baby homes are part victim to outdated norms and/or the lack of regulatory and legal mechanisms for the organisation of medical and psychological support for children.

As of 1 January 2020, there were 96,577 children (42% are girls and 58% are boys) in 697 institutional care facilities. 54,859 children stay there overnight, with 88% of them having at least one parent⁶. In terms of subordination, 89,387 (92.56%) children receive care in facilities of the Ministry of Education and Science, 2,819 (2.92%) of the Ministry of Health and 4,371 (4.52%) of the Ministry of Social Policy. 17,258 children raised in institutional care facilities have disabilities, 2,046 of whom have disabilities of subgroup A.

A 2018 monitoring of children’s rights in inpatient health and social care institutions conducted by the Ukrainian Helsinki Human Rights Union with the support of international partners⁷ found the following: such institutions do not respect the privacy of patients when using toilets, showers or bathrooms; children have limited visiting time with their relatives; staff read patients’ correspondence; they practice fine art classes with children, making various items as rehabilitation and sometimes use elements of physical rehabilitation, but there is the lack of rehabilitation activities aimed at acquiring skills for independent living and staying in society; no conditions have been found for involving children in decision-making; “We can’t go out for air, use the fridge and take food freely, make calls, turn off the lights. We have to ask and agree on everything, even going to the toilet”; an insufficient number of care staff (e.g. 2 social workers per group of 21 children with complex developmental disabilities); often a lack and sometimes a shortage of remedial specialists (speech therapist, psychologist, special education teacher); bars on windows and iron beds with a wire mesh base that are still in use; a barrier environment that makes it impossible for children with physical disabilities to walk; medical services are mainly limited to the administration of medication and additional therapeutic measures are rather the exception.

Sexual abuse, particularly of children with disabilities, in institutional care facilities is not uncommon. In early September 2020, the rape of 3 girls aged 5 to 7 by the director of a children’s homes was reported⁸. Activists question the fairness of the case, as the director has many political and family connections in the region. Cases of sexual abuse of children with disabilities have also been reported in Mykolaiv⁹.

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⁶ The data is available at diplatfrom.org.ua, the URL is available at: https://drive.google.com/file/d/1E7Y-AWKHt65y3QPtVlhdVLv9Hkya_H0I/view
⁸ https://zn.ua/ukr/UKRAINE/direktora-ditbudinku-na-odeshchini-pidorzrujuot-u-rozbeshchenni-vikhovanok.html
⁹ https://mk.depo.ua/rus/nikolaev/u-nikolaevi-nareshti-rozsliduvannya-seksualnogo-24092016103700
In addition, there are cases of employment of children with disabilities, including in an orphanage in Zhytomyr Oblast\textsuperscript{10} and the City of Kyiv\textsuperscript{11}. In the latter institution, a case of a severe beating of pupils was established at the end of September 2020\textsuperscript{12}. The fact that children are practically deprived of the right to education in institutional childcare facilities of the Ministry of Social Policy is of concern, as such services are not provided even by the model regulation on residential care facilities\textsuperscript{13}, although children claim that they want to study\textsuperscript{14}.

The observance of the rights of children with disabilities during COVID-19 is of particular note. In April 2020, 42 thousand children, including children with disabilities, were returned home from residential care facilities without prior verification of the families’ ability to provide adequate care, resulting in some children having to be returned to these facilities\textsuperscript{15}. In 2020, the Ukrainian Child Rights Network, with the support of international donors, implemented the project called “Assessment and Response to Child Protection Challenges during COVID-19 Pandemic” to assess the needs of 3,053 families where children were returned during quarantine. The monitoring results fully or partially support the following hypotheses about the reasons for the institutionalisation of children in the pilot regions:

- “The lack of proper quality services for families and children in communities” was confirmed in all regions: among the reasons for placing children in residential care facilities, 86 to 99\% of families in the regions mentioned that their child had special needs in education, medicine, rehabilitation or social care, which could not be met in other institutions, and alternative solutions were not offered to them. Appropriate help and support are not available in the community.

- “Inclusion in kindergartens and general educational institutions is formal or absent at all”: 44\% to 66\% of parents in different regions reported that the reason for placing children in residential care facilities was the child’s special educational needs. Moreover, 23\% to 62.4\% of families reported that they were recommended to seek educational services in residential care facilities exactly by educational institutions, such as inclusive education resource centres (formerly psychological-medical-pedagogical commissions), schools, kindergartens, etc. The school’s assistance in adapting the child is among the conditions under which families are able to take care of the child and not place him/her in such facilities.

- “Families who intend to or have already placed their children in residential care facilities do not receive timely and appropriate support from Children’s Services and Centres of Social Services for Family, Children and Youth”: only 4.6 to 9.4\% of families in the regions reported that they received social support services. Most families did not receive any support. The share of family groups in institutions (more than one child with a family in an institutional care facility) is 12.7\% to 30.4\% in the regions, mainly indicating the choice of facility for reasons of convenience rather than a real need for the child.

- “Parents are interested in residential care facilities”: 6.8\% to 28\% of families in the regions confirmed that they had independently decided to place their child/children in an institutional care facility. In most cases, this was due to a desire to give their children a better education, including industry-specific one in special educational institutions. Parents are interested in residential care facilities mainly because quality services according to needs are not available in the community.


\textsuperscript{11} https://vechirniy.kyiv.ua/news/skandal-nyy-internat-na-svyatoshyno-klychkono-itsyiuvav-sluzhbove-rozliduvannya

\textsuperscript{12} https://www.youtube.com/watch?v=4aKV_i-r-KE

\textsuperscript{13} https://zakon.rada.gov.ua/laws/show/978-2016-%D0%BF#Text

\textsuperscript{14} https://www.radiosvoboda.org/a/28087813.html
“Residential care facilities recruit children”: it was a staff of residential care facilities who recommended parents from dozens of families in the regions to place their children in a facility.

“Most children are placed in residential care facilities for social reasons (unemployment, poverty, difficult life circumstances, etc.)”: in Volyn, Dnipropetrovsk, Mykolaiv and Poltava Oblasts, 57 to 67% of parents are not officially employed, and the main income they get is social assistance. In 12 to 37% of the cases in these regions, multidisciplinary teams did not confirm the proper conditions for children’s recreation and education. In addition, 19.5 to 55.7% of families in these regions openly stated that they placed children in residential care facilities for social reasons (poverty, unemployment, financial disadvantage, etc.)

There are several types of DI or forms of alternative care in Ukraine:

- foster caregiver family (“patronate family”) - families that provide temporary care, upbringing and rehabilitation of a child for the period of overcoming by the child, his parents or other legal representatives of difficult life circumstances. As of the 20 June 2021 there were 205 foster caregiver families (“patronate families”) in Ukraine;

- adoption – acceptance by an adoptive parent into his family of a person with the rights of a daughter or a son, carried out on the basis of a court decision. In 2020, 1,239 orphans, children deprived of parental care were adopted, in 2019 – 1,810 children. According to Maryna Lazebna, the Minister of Social Policy of Ukraine, the decrease in adoptions in 2020 took place due to the fact that on 2 April 2020, an amendment in the Civil Procedure Code of Ukraine entered into force, which provided that the deadlines for appeals lasted for the duration of the quarantine. In total, 2,047 children were adopted during 2020, and in 2019 – 2,878 children;

- trusteeship/guardianship – established by the trusteeship and guardianship body, which are district, district in the cities of Kyiv and Sevastopol, state administrations, executive bodies of city, district in cities, rural, settlement councils, over orphans and children deprived of parental care. Trustee is established over the child under the age of fourteen, and guardianship is established over children between the ages of fourteen and eighteen. A guardian or trustee is appointed mainly from persons who are in family, kinship relations with the ward, taking into account the personal relations between them, the person's ability to perform the duties of a guardian or trustee. As of 1 January 2021, there were 49,016 orphans and children deprived of parental care, which is 608 less than last year;

- foster family – a family that voluntarily took in upbringing and living together from one to four orphans and children deprived of parental care. In late 2019, there were 3,346 foster families; in late 2020, their number was 3,172;

- family-type orphanage – a separate family, which is created at the request of spouses or an individual who is not married to provide family education and cohabitation of at least five orphans and children deprived of parental care. In late 2019, there were 1,153 family-type children's homes; in late 2020, their number was 1,235;

- small group home – a social protection institution, designed for long-term (stationary) residence of orphans, children deprived of parental care, including children with disabilities, and their number in conditions close to family ones. The number of children who can simultaneously live in a small group home is up to ten people. According to the number of small group homes operating today, the National Social Service did not provide relevant information, but according to the Ministry of Social Policy, as of 4 May 2021 such homes are under construction.

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17 https://www.ukrinform.ua/rubric-society/3249668-torik-v-ukraini-usinovili-1239-ditej.html
General Policy and legal framework on managing the issues of children with disabilities in the given country

It is safe to say that residential care facilities still exist mainly due to the lack of educational, medical, social, rehabilitation and other services for children with disabilities in their place of residence. No early intervention service has been introduced at the state level, despite numerous international projects and approved strategic and conceptual documents—there is no standard service and no budget support. State standards for the provision of social services are based on the functioning of institutional care facilities, do not consider the needs of children, thus making it impossible for NGOs to provide such services. Those NGOs that provide day-care service for children with disabilities operate through international donor aid and charitable contributions of businesses and private benefactors, most of whom are parents of children with disabilities. In other words, the guaranteed free basic social services for children with disabilities do not work.

In 2017 in Ukraine the law “On Education” was adopted, which normalized the obligation of the educational institution to form an inclusive group or class in case a person with special educational needs or his/her parents applies. So, the reform on providing inclusive education accelerated 4 years ago.

The Ministry of Education and Science of Ukraine provided information that a total of 79,316 children with SEN were enrolled in general educational institutions in 2021/2022, representing 1.89% of the total number of children enrolled in general secondary educational institutions. Specifically, 36,461 children study in special schools and education and rehabilitation centres, 5,844 children in special classrooms, 25,078 in inclusive classrooms and 11,933 in individual education. Thus, the proportion of children with SEN who attend general secondary educational institutions under terms of inclusive education is 0.6%.

Unfortunately, recent statements and actions of the Ukrainian government suggest that inclusive education reform is being scrapped. There are messages and decisions on the need to maintain special and sanatorium educational institutions at all levels of government, beginning from the President, Prime Minister and MPs, while inclusive education is not a state priority. In particular, in May 2022, the Minister of Education and Science said, “blind, deaf children, children with intellectual disabilities and complex (combined) developmental disorders should receive highly specialised educational services in institutions with appropriate specialists, educational environment, facilities and resources, i.e. in special schools and education and rehabilitation centres.” That is, the Minister supports the exclusion of children with disabilities from the general secondary education system under inclusive education and the segregation of such children in specialised institutions.

Day-care service in Ukraine is a basic social service provided to children with disabilities or children with severe diseases, disorders, injuries, conditions (including before disability confirmation) from the age of 3 years. That is to say, in the Ukrainian context, this concept has a very specific and narrow connotation, which differs considerably from the context of this concept as used in the ESC. Most of the territorial social service centres have established day-care units, but they provide services for adults, mostly elderly people.

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18 http://rvua.com.ua/
24 https://zakon.rada.gov.ua/laws/show/z0643-20#Text
As for the social day care service for children with disabilities, 1,568 children with disabilities in Ukraine received this service according to the Ministry of Social Policy\textsuperscript{25} as of 1 January 2021. It is worth noting that this information received raises doubts, because we know of several more institutions that provide day care services, but this information is not displayed in the Ministry of Social Policy data. Since the Register of providers and recipients of social services has not yet been launched in Ukraine, there is no reliable information about services at present. As of 1 January 2021, over 16,000 children\textsuperscript{26} with subgroup A disabilities (persons with an exceptionally high degree of loss of health, extremely dependent on permanent nursing care, assistance or follow-up care and unable to care for themselves) live in Ukraine. These children mostly stay at home with one of the parents who is unable to work and self-actualise or are in institutional care facilities. Both options do not provide the socialisation of such children, their inclusion in society on par with other children. Day-care is a worthwhile alternative for children with complex developmental disorders, including intellectual and psycho-social developmental disorders. According to the Law of Ukraine “On Social Services” entered into force on 1 January 2020, the day-care service became the basic, which means it is provided by the Kyiv and Sevastopol city state administrations, raion, district state administrations in the cities of Kyiv and Sevastopol, the executive authorities of the city councils of cities of oblast status, as well as the executive authorities of village, settlement, city councils of amalgamated territorial communities (ATC). However, the day-care social service for children with disabilities is developing very slowly. For example, in the City of Kyiv with over 1,100 children with subgroup A disabilities, the territorial centres of social services and some non-governmental organisations provide the day-care service only to about 200 children. That is, the total supply does not cover even half of the need for the service in Kyiv. However, in hundreds of ATC, such service does not exist at all. This means that thousands of families in Ukraine, who raise children with disabilities, are left alone to face difficult life circumstances, are in constant physical and psycho-emotional strain and are excluded from active participation in social life on par with others.

The development of day-care service for children with disabilities is hampered by the lack of an appropriate state standard of social service; imperfect Procedure for determining the needs of the population in social services\textsuperscript{27}, which does not allow to determine the real need and make decisions on the development of the service; the lack of responsibility of local authorities for non-fulfilment of their powers in terms of providing day-care service; outdated, including morally, Model Regulations on the day-care unit for children with disabilities\textsuperscript{28}; the lack of methodological recommendations on equipment, including rehabilitation and remedial one, for premises of the social service provider; very slow introduction of the practice of social service contracting and/or procurement from non-state (including communal) providers. It is worth mentioning that the standard of social day-care service for children with disabilities and the new version of the Procedure for determining the needs of the population in social services have already been developed and are waiting for piloting and are under public discussion.

In addition to the regulatory uncertainties, there is an acute problem of seed funding for the establishment of day-care services, as the premises must meet certain building and sanitary standards, and appropriate equipment, furniture and remedial materials are required. UNICEF reports that the cost of establishing a day-care service for children with disabilities in the community is at least USD 60,000, which includes renovation of the premises in accordance with universal design, purchase of furniture, rehabilitation equipment, remedial materials and training of specialists. Discussions are now underway with all stakeholders on the introduction

\textsuperscript{25} https://dostup.pravda.com.ua/request/87225/response/331828/attach/3/CCE14062021%200001.pdf?cookie_passthrough=1

\textsuperscript{26} Unfortunately, no reliable data are available from the Ministry of Health or the Ministry of Social Policy

\textsuperscript{27} https://zakon.rada.gov.ua/laws/show/z0253-14#Text

\textsuperscript{28} https://zakon.rada.gov.ua/laws/show/z2057-13#Text
of a state budget subvention to partially fund basic social services for children with disabilities, including day-care service.

The lack of educational, social and rehabilitation services for children with disabilities in the community leads not only to the institutionalisation of such children but also to tragic cases. In October 2020, a mother drowned her son with autism and tried to commit suicide because she could not cope with the psycho-emotional stress and received no support. A similar case occurred in Dnipro in 2019, when a father poisoned his son with autism and then killed himself. The state has not even begun to talk about providing support and appropriate services for members of families raising children with disabilities.

**Coordination and monitoring of the DI processes for children with disabilities**

According to the DI Strategy, the coordinator of DI reform implementation is Ministry of Social policy.

Starting in 2021, the annual monitoring of the implementation of the DI Strategy should be introduced according to certain indicators, in particular:

- the number of children covered by inclusive education in preschool and general secondary education institutions compared to the previous year;
- the number of children who are provided with basic social services in the local community compared to the previous year;
- the number of territorial communities in which the positions of social work specialists have been introduced;
- the number of orphans, children deprived of parental care who are brought up in family forms;
- the number of orphans, children deprived of parental care, who are brought up in family-like environment;
- the number of children with special educational needs who are (live) in institutions around the clock.

**The specific cases of the given country, ‘best practices’ or ‘unique DI system treats**

Over the last few decades, many innovative projects were implemented across Ukraine to replace institutions with a range of prevention and quality alternative care services in the community. Hope and Homes for Children Ukraine successfully assisted local authorities to close two institutions respectively in the Dnipropetrovsk oblast, create a centre of social support for children and families and build a small group home. The institutions were under the management of the Ministry of Education. The Lviv Education Foundation successfully implements a number of programmes related to the DI reform in the Lviv oblast (5 communities are supported for the creation of social services and one of them also for the closure of an institution). The Training and Rehabilitation Centre “Dzherelo” is a training and rehabilitation centre that provides rehabilitation, educational, psychological and other family-centred services to children and young people with special needs in the Lviv oblast, amongst several other oblasts. There are some other civil society’ and donor’s initiatives that lead to development of social services at the community level and transformation of childcare institutions.

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31 https://zakon.rada.gov.ua/laws/show/526-2017-%D1%80#Text
What could have been worked better in the given formats?

The government should continue implementing the National Strategy to Reform the Institutional Childcare System for 2017-2026 in accordance with the approved principles and goals and in compliance with its international commitments, in particular:

- development of financial mechanisms to ensure the DI reform and development of services to support children and families with children;
- development and implementation of regional DI plans for reforming the system of institutional care;
- development and implementation of a system for monitoring and evaluating the process of reforming the system of institutional care and upbringing of children at the national and local levels;
- formation of a system of early detection of families with children in the early stages of family vulnerability, early intervention and support of the child's biological family;
- network development and provision of educational, cultural, medical, social, rehabilitation services (including early intervention, inclusive education) at the territorial community level, taking into account its financial capabilities and needs of residents;
- accessibility of services for children with special educational needs, in particular with disabilities, at their place of residence;
- improving the quality of educational services in special institutions of general secondary education or special classes (groups) of educational institutions with the creation of conditions for students (pupils) with special educational needs of education in an educational environment close to their place of residence;
- quality organization of inclusive education, individualization of the educational process for children with special educational needs, in particular by providing them with additional services;
- raising the professional level of specialists who provide services for children and families with children;
- development of alternative care forms in families or family-like environment for children who for some reason cannot live with their biological parents.

Conclusion

There is no use in rejoicing at the previous successes of deinstitutionalisation based only on the reduced number of children in institutions, as the number of the child population in Ukraine is also decreasing, which makes the situation not so optimistic in relative terms. Moreover, an analysis by the UCRN in 6 regions has shown that the number of children in residential care facilities in most of these regions has not changed or is even increasing. For example, according to the monitoring of institutional childcare facilities conducted by the Commissioner of the President of Ukraine for Children’s Rights, as of 1 January 2020, there were 34,947 children in special schools and education and rehabilitation centres. If we compare this with the data from the MES for 2020/2021, the number of children in such schools and centres has increased by over 4%, indicating the failure of deinstitutionalisation reform, as they are equated with institutional care facilities according to the National Strategy to Reform the Institutional Childcare System for 2017–2027.

We believe that all the previous experience on development social services for children and their families and efforts of local authorities, civil society, donors and other stakeholders will lead to revival of political will to provide DI in Ukraine according to the assumed international obligations and in order to ensure best interests of the child.

References
2. Моніторинг закладів інституційного догляду і виховання дітей (презентація): [https://drive.google.com/file/d/1E7Y-AWKHt65y3QPFV1hdVLv9Hkya_H0l/view](https://drive.google.com/file/d/1E7Y-AWKHt65y3QPFV1hdVLv9Hkya_H0l/view).