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BEHIND THE MASK OF CARE

A REPORT BASED ON THE RESULTS OF THE SITUATION ANALYSIS OF BABY HOMES IN UKRAINE

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2020

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ABBREVIATIONS

AIDS	Acquired human immunodeficiency syndrome
ANTHRO	WHO tool for the analysis of anthropometric data of children under the age of 5 years
ATC	Amalgamated territorial community
BMI	Body mass index
CP	Cerebral palsy
CSSFCY	Centre of social services for families, children, and youth
FASD	Fetal alcohol spectrum disorders
FTCH	Family-type children's home
GMFCS	Gross Motor Function Classification System
HCF	Healthcare facility
HIV	Human immunodeficiency virus
ICD-10	International Classification of Diseases, Tenth Revision
ME	Municipal enterprise
MF	Municipal facility
MNPE	Municipal non-profit enterprise
MOH	Ministry of Healthcare of Ukraine
NHSU	National Health Service of Ukraine
PHCC	Primary healthcare centre
RHD	Regional Health Department
RSA	Regional State Administration
TPC	Therapeutic physical culture
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

FOREWORD

Since the beginning of the last century, dozens of studies have been conducted which prove the negative impact of institutional care on children's development, quality of life and ability to adapt to living in society, as well as economic and societal consequences. They provide conclusive evidence that young children in facilities, including baby homes, are exposed to health and development risks. According to recent research in neuroscience, the first years of life (especially during pregnancy and up to the age of 3 years) are critical for the development of the brain which depends on genes, life experience, the environment (especially proper nutrition, safety and protection), stimulations involving communication and play, and care by parents or guardians. In other words, it is a period of enormous opportunities that can be lost forever if a child does not receive the love and individual care needed for survival and development.

As of early 2020, 2.756 children resided in 38 baby homes in Ukraine[1]. This report describes the findings of the first comprehensive domestic study of children in such facilities. The data indicates poor health and development of children and confirms the findings of international studies conducted in other countries. Some of the findings are shocking in the context of children's rights and their best interests, but unfortunately this is the reality and awareness of the situation should encourage the government and local authorities to take urgent action.

Our experience, and that of other organisations, demonstrates that supporting parents in their parenting role and facilitating their access to services is key to the wellbeing of children and preventing family separation. Developing adoption, guardianship, patronage families and foster families are necessary conditions for enforcing the ban on the placement of children under 3 in any facility, provided by the National Strategy of Reforming the System of Institutional Care and Upbringing of Children for 2017-2026[2].

We hope that this analysis - of the reasons why young children are placed in baby homes, the gaps in child protection and paediatrics, and recommendations for the development of medical rehabilitation, palliative care and social services in the regions - will be used by the Ministry of Healthcare of Ukraine and the Ministry of Social Policy of Ukraine for health reform and deinstitutionalisation.

This report calls on all those involved in working with children to put an end to the use of institutional care for young children, to join efforts to support families and communities, to train professionals, to develop alternative care; all that is necessary for the health and development of children and their right to family care.

Halyna Postoliuk,
Director of the Regional Office
Hope and Homes for Children

1 / URL: http://medstat.gov.ua/ukr/MMXVIII.html.

2 / CMU Resolution as of 08.09.2017 No. 526-r "On approval of the National Strategy of Reforming the System of Institutional Care and Upbringing of Children for 2017 - 2026 and the action plan for the implementation of its first stage".

SUMMARY

This report presents the findings of the 2019-2020 assessment conducted within the Pilot assessment of residential healthcare facilities for children and development of recommendations for reform (hereinafter - the Pilot)[3] with assistance from the Health Reform Support, funded by the United States Agency for International Development (USAID) and the UK Government's Good Governance Fund in five baby homes of Dnipropetrovsk, Poltava and Kherson regions. The Pilot was implemented by Hope and Homes for Children with assistance from the Presidential Commissioner for Children's Rights, in cooperation with the Ministry of Healthcare of Ukraine and the Ministry of Social Policy of Ukraine, structural subunits of three region state administrations, and the baby homes.

In addition to the findings from the assessment of baby homes, the report presents results from the region assessments regarding needs in the medical rehabilitation, paediatric palliative care, and social services for children aged 0-6 years and their families.

The assessed baby homes are region healthcare facilities providing socio-medical support, primary and secondary healthcare services to orphans and children deprived of parental care, and children temporarily placed by parents or legal representatives due to difficult life circumstances. Healthy children, children with physical and mental health problems and children with disabilities are placed in the facilities. Three baby homes in Dnipropetrovsk region are specialised and admit children aged 0-4 years. Kherson baby home is designed for children aged 0-3 years and Kremenchuk baby home admits children aged 0-6 years. As of 1 October 2019, there were 415 children aged between 1 month and 6 years 8 months in the five baby homes.

THE ASSESSMENT 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 vast majority of children (60.2 %) were admitted to facilities under the age of 12 months. At the time of the assessment, 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. 56.2 % of children in baby homes were orphans and children deprived of parental care, while the others had parents unrestricted in their rights.

ALMOST 70% OF CHILDREN IN BABY HOMES ARE SOMATICALLY/NEUROLOGICALLY HEALTHY AND ONLY HAVE A DEVELOPMENTAL DELAY DUE TO DEPRIVATION.

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

3 / The pilot is implemented under the Grant Agreement RG-1903-00320 awarded by the USAID-funded Health Reform Support (HRS) implemented by Deloitte Consulting Overseas Projects LLC (DCOP) under the USAID-DCOP Contract No. 72012118C00001, according to the International TA Project (Program) Accreditation Certificate No. 264 issued by the Ministry of Economic Development and Trade of Ukraine on 29.11.2018.

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.

ALL FAMILIES OF CHILDREN IN BABY HOMES, WHERE PARENTS ARE NOT RESTRICTED IN THEIR RIGHTS, CAN BE DESCRIBED AS "FAMILIES IN CRISIS" -

all of them at some point needed the help of a social work specialist to prevent the abandonment of the child or to promptly detect problems in the family and social support needs. Using the documents are available in the baby homes, it was not possible to analyse the extent to which families had access to social services and what assistance was provided to them before the decision was made to place the child in the facility. Many families do not keep in touch with children in the facilities, but they still remain their legal representatives. None of the children separated from their families by the authorities were visited by representatives of these bodies. Parents and relatives of children in almost 50 % of families that were visited during the assessment had experience of living in residential care facilities. Household surveys showed that only a small number of families had the capacity for reunification. All families need strong support and professional social services.

Baby homes were established in the '60s and '70s; the buildings are vast and are designed for a large number of children (from 70 to 120 beds).

CHILDREN LIVE IN CROWDED CONDITIONS WITH POOR BASIC AMENITIES, WITH AN AVERAGE OF 10 CHILDREN PER ROOM.

All facilities need to be adapted for people with special needs. Ramps to enter the main building are installed in three baby homes. Rooms for classes and health services also do not comply with the principles of inclusiveness. All buildings are two-storey, but no elevators are installed.

In general, the facilities are organised in a similar way which is typical for baby homes: children are grouped by age (up to 1.5 years and older) and health, there are offices for doctors and educators, manipulation and massage rooms, an isolation unit, quarantine areas, utility rooms, etc. Baby homes did not have a standard list of services they provide. All five facilities do not have medical information systems (MIS) and services are not accounted.

IN BABY HOMES, THE NUMBER OF ACTUAL STAFF EMPLOYED WAS LESS THAN THE NUMBER OF POSITIONS ON THE STAFFING LIST; OUT OF 838 POSITIONS, 712 PEOPLE WERE EMPLOYED.

In general, the employee structure was similar across the baby homes; approximately 23.2 % are administrative and support staff, 26.8 % are nursing staff, and 13% are educators and 37.4 % are health staff (the largest group).

Nurses and educators predominate among the health and education staff. Health staff mostly provides follow-up care rather than medical rehabilitation. Documents signalled that an individual rehabilitation plan is only developed for children with disabilities. At the time of the assessment, most health and education staff had not been trained in rehabilitation and / or palliative care services in the past 5 years.

IN THE BABY HOMES, 81.4 % OF EXPENDITURE IS ON WAGES AND PAYROLL CHARGES.

Monthly expenditure on medicines and dressings ranged from UAH 64 (Dnipro) up to UAH 412 (Kremenchuk) per child. Facilities spend between UAH 27 (Kherson) and UAH 48 (Kremenchuk) on food per child per day.

The needs assessment of children aged 0–17 years for medical rehabilitation and paediatric palliative care services, and the needs assessment of children aged 0–6 for social services, included analysis of statistics, mapping of available services, assessing demand for such services in the regions, and evaluating service recipients and providers. In addition to the overall needs assessment, the assessment calculated separately the need for symptomatic and specialised paediatric palliative care, as well as the average daily number of children and their families in need of such care. Comparison of all components of the needs assessment enabled an understanding of the relationship between supply and demand for medical rehabilitation services and paediatric palliative care, as well as social services.

During the analysis of human and other resources, and the way the facilities are organised, the experts assessed the capacity for transformation into medical rehabilitation and palliative care centres for children.

THE DATA SHOWS THAT NONE OF THE FIVE FACILITIES ARE CURRENTLY READY TO BE TRANSFORMED INTO SUCH A CENTRE;

there are not enough qualified specialists, equipped facilities with access for people with disabilities, specialised equipment, etc. In the future, local authorities should be aware that the decision to establish medical rehabilitation and palliative care centres will require significant investments, and it will be necessary to take into account healthcare facilities in the region which are contracted by the NHSU for the provision of such services.

REFORMING BABY HOMES IS AT THE INTERSECTION OF HEALTH, CHILD PROTECTION, DECENTRALISATION, AND EDUCATION REFORMS.

The development and implementation of plans for the transformation of baby homes should be supported with enhanced interagency cooperation and regulatory frameworks, development of child and family support services, family-based care, and improvements to health care and living conditions for children remaining in the baby homes during the transition period.

The assessment results demonstrate the established practice and operation of baby homes and provide an evidence base for the authorities and management to measure the ability of these healthcare facilities to serve as medical rehabilitation and palliative care centres for children; help to find balanced solutions based on children's interests about their future, in the context of reforming the health and institutional care systems of children.

METHODOLOGY

The purpose of the assessment - to measure the capacity of baby homes to serve as medical rehabilitation and palliative care centres in line with the needs of children and their families for health and social services.

The assessment consisted of two components:

1. Assessment of five baby homes, including:
   - stock and flow of children;
   - assessment of children's health and development;
   - assessment of resources of the children's families;
   - analysis of human resources, including the qualifications of baby homes health and education staff;
   - analysis of logistics.
2. Assessment of the needs of children and their families for services in Dnipropetrovsk, Poltava, and Kherson regions, including:
   - assessment of the needs for medical rehabilitation services for children aged 0-17[4];
   - assessment of the needs for palliative care services for children aged 0-17[5];
   - assessment of the needs for social services for children aged 0-6 years[6] and their families.

As part of the assessment of five baby homes **(Fig. 1)**, the characteristics of 415 children in the baby homes at the time of the assessment, and 239 children who left these facilities during October 2018 - October 2019, were analysed. Consent for the health and development assessment was obtained for 415 (98 %) children. During the assessment, 83 of 158 (53 %) families of children in five baby homes, whose parents were not deprived of parental rights, were visited. The staff assessment included a review of personal files, job descriptions, and functional responsibilities of 334 health and education staff members who provided their consent for processing their personal data; 119 of them (36 %) took part in the survey on job satisfaction and attitudes to health reform. The assessment of the baby homes premises included the analysis of documents, examination of the premises, assessment of available equipment, and a survey of management and administrative personnel.

The needs assessment of children aged 0–6 for social services, and the needs assessment of children aged 0–17 for medical rehabilitation and palliative care services in Dnipropetrovsk, Poltava, and Kherson regions, consisted of the following elements: 1) desk study by analysing documents and open sources; 2) mapping of services based on the results of requests sent to the facilities that can provide such services; 3) focus groups and in-depth interviews with providers of medical rehabilitation, palliative care, and social services to children and their families and parents / representatives of children aged 0–17 who use such services. 100 in-depth interviews were conducted in three regions, including 42 interviews with health and social care providers and 58 interviews with service recipients. Five focus groups were conducted for 36 people raising children with disabilities or developmental disorders.

4 / In fact, until the age of 18 (17 years 11 months and 29 days).

5 / The same.

6 / In fact, until the age of 7 (6 years 11 months and 29 days).

Data was collected using standardised tools developed within the Pilot. The protocol and tools of the assessment were reviewed by the Ethics Committee of the Ukrainian Institute of Public Health Policy.

Five teams were created to collect data, each of them included baby home assessment team leads; social work specialists who assessed family and community resources; paediatricians who were responsible for assessing the health and development of children; and specialists in personnel and logistical resources assessment. Team members were trained on the purpose and objectives of the assessment, methods of data collection, methods of building a sample, assessment tools, ethical principles, assessment process, responsibilities of all team members and the schedule of the field stage of the assessment. All assessment teams' members involved in the collection and processing of personal data signed a non-disclosure agreement.

Visits to baby homes to analyse documents, survey staff and families, and assess the health and development of children, were carried out between October and December 2019. During the same period, data was collected for the region assessment of social service needs of children aged 0–6 and medical rehabilitation and paediatric palliative care needs of children aged 0–17.

Sets of electronic data in MS Excel were prepared according to the paper-based forms. To verify the data, a logical control was carried out to ensure compliance of filling in the questionnaires, as well as analysis of duplicates and missing values, and comparison of electronic and paper data. The quantitative data analysis mostly included methods of descriptive statistics, calculation of frequency and percentages, averages and medians. Quantitative data analysis was performed in SPSS. The qualitative data analysis involved the preparation of interview transcripts in MS Word and the selection of topics following the prepared list of codes. MS Excel was used to encode in-depth and focus group interviews.

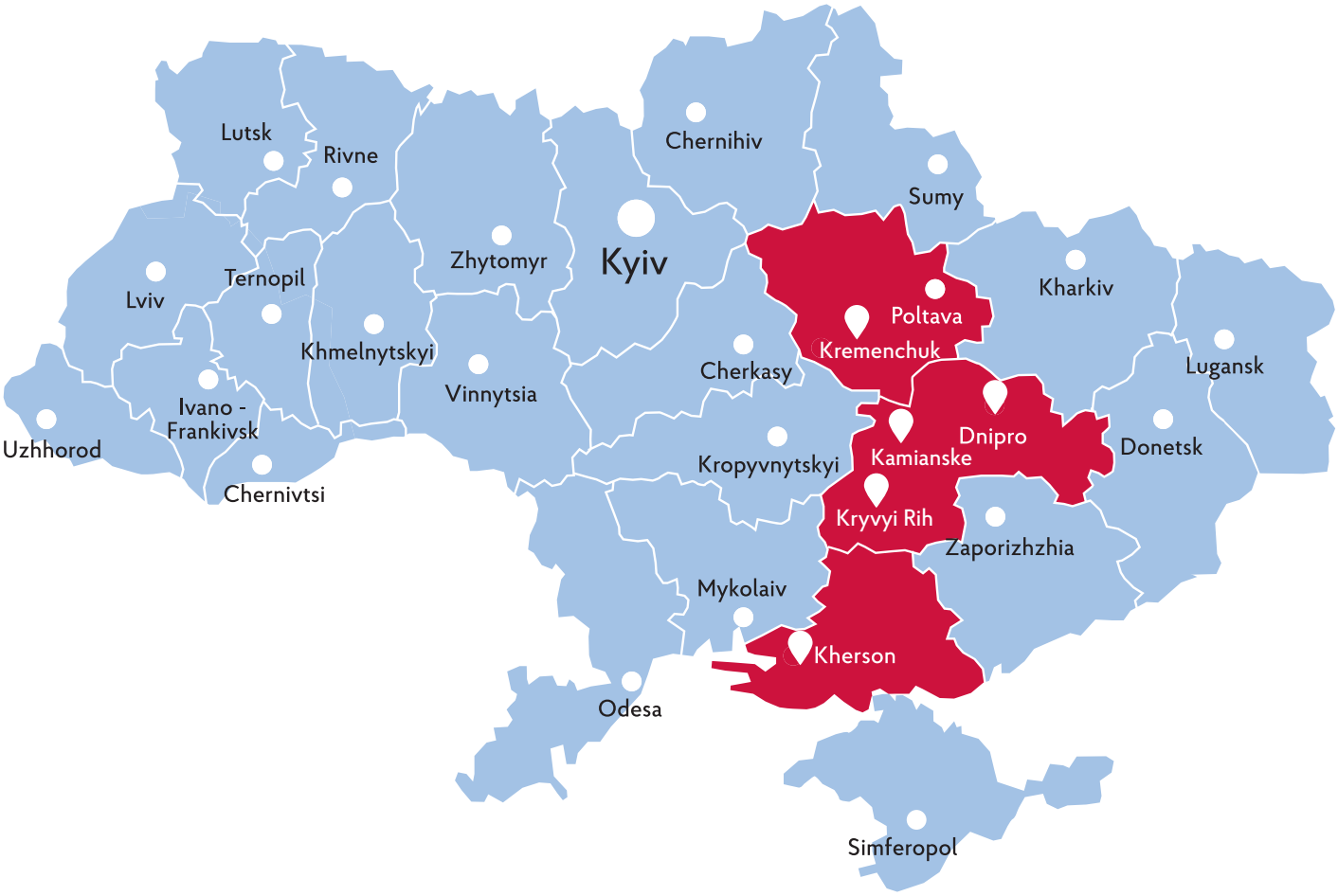


Figure 1. Geographical locations of the assessed baby homes in Dnipropetrovsk, Poltava and Kherson regions

FINDINGS

GENERAL INFORMATION ABOUT CHILDREN

This section presents the results of the analysis of personal files, visiting logs, and records of children raised in the baby homes. At the time of the assessment, there were 415 children in the five baby homes. Dnipro baby home had exceeded capacity **(Fig. 2)**. In the other baby homes, the number of residents at the time of the assessment ranged from 71 % (Kamianske) to 90 % (Kremenchuk) of the maximum number of children for which the facilities are designed.

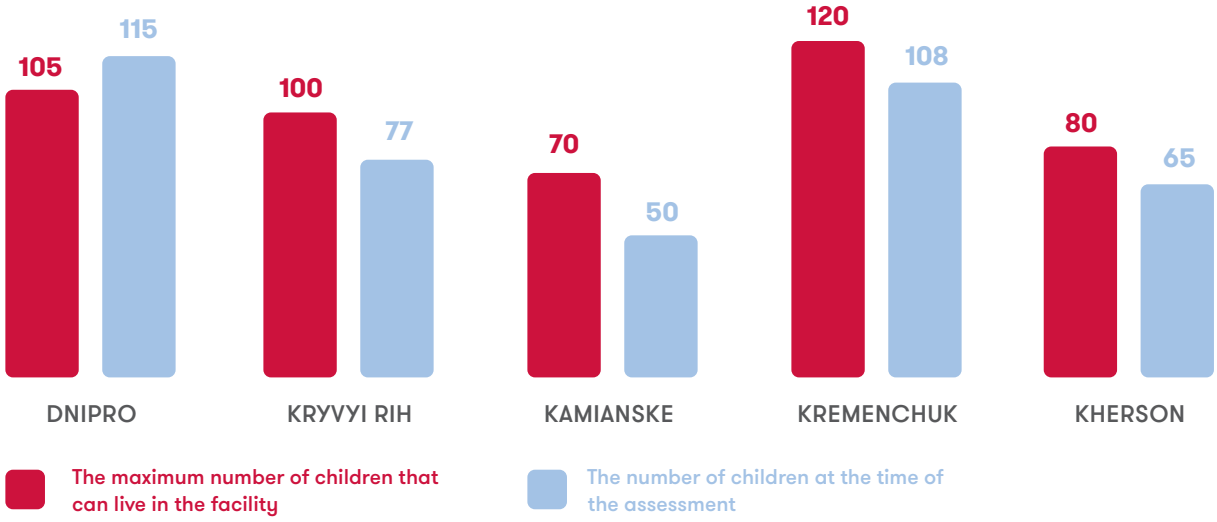


Figure 2. Number of children the facilities are designed for and the actual number of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, *persons*

DEMOGRAPHIC CHARACTERISTICS

The percentage of boys in all facilities was higher than that of girls except for the Kryvyi Rih baby home **(Fig. 3)**. The percentage of children under the age of 12 months ranged from 14 % to 25 % **(Fig. 4)**. Most of the children in all five baby homes were between one and three years old. The high percentage of children older than three years (21 %) in the Kremenchuk baby home is explained by the fact that this facility admits children up to the age of 6. In practice, children sometimes stay longer than is required by law and the charters of the facilities. For example, in the Dnipro baby home, which admits children up to the age of 4 years, at the time of the assessment six children had already turned 5 years.

7 / MOH order No. 123 as of 18.05.1998 "On approval of the Standard Baby Home Charter". URL: https://zakon.rada.gov.ua/laws/show/z0372-98.

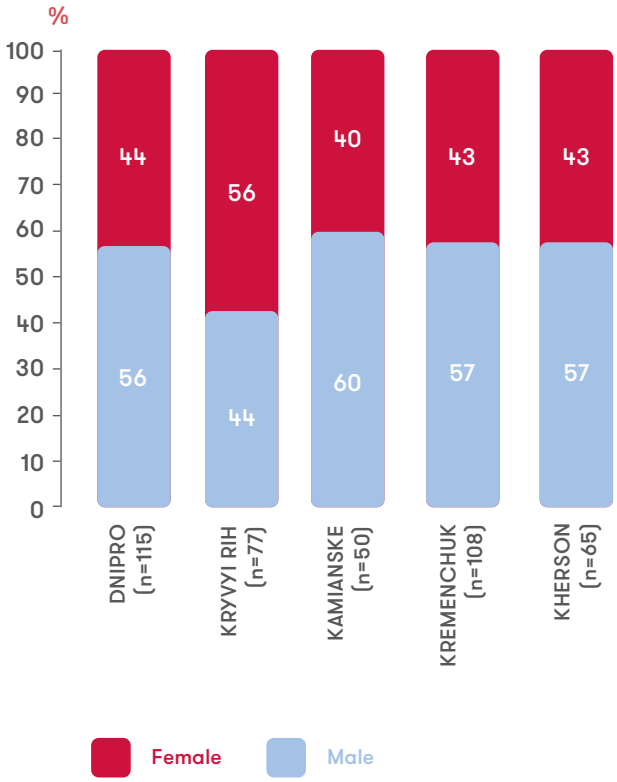


Figure 3. **Sex of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %**

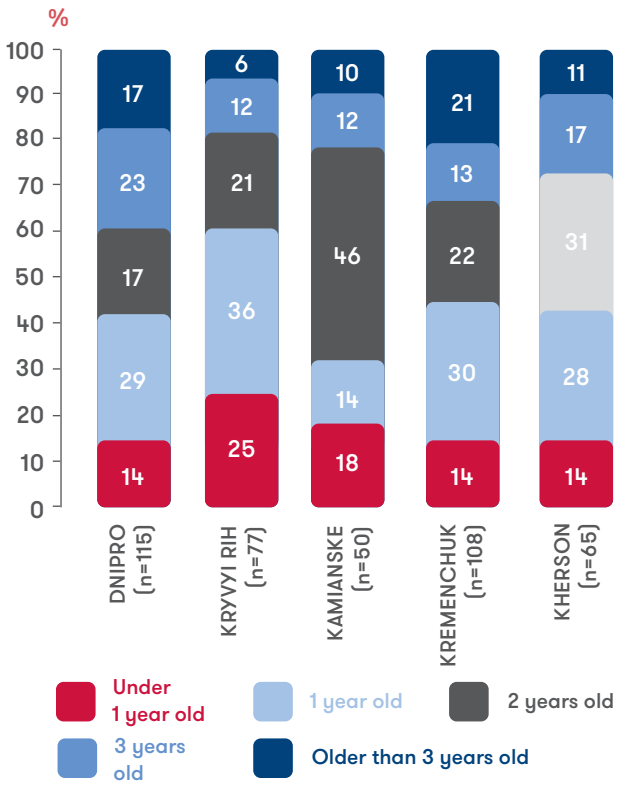


Figure 4. **Age of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %**

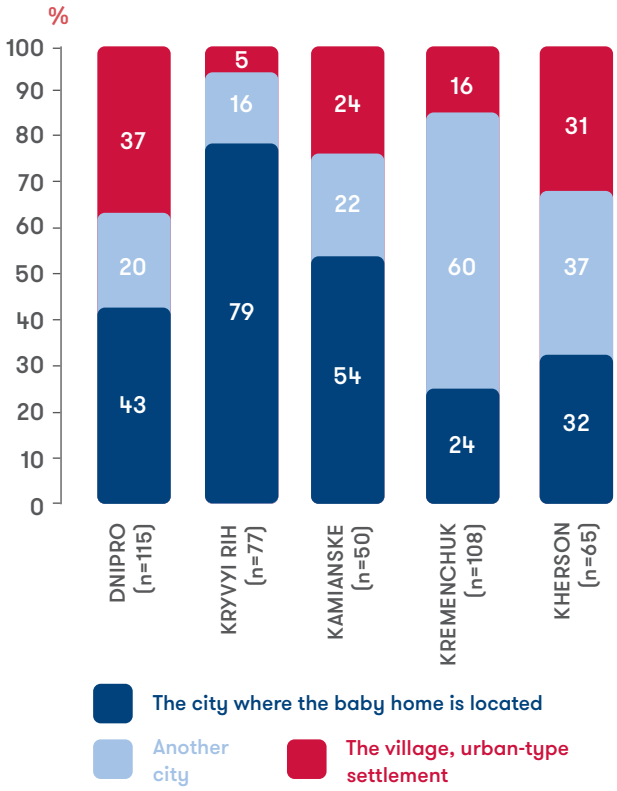


Figure 5. **Geographical origin of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %**

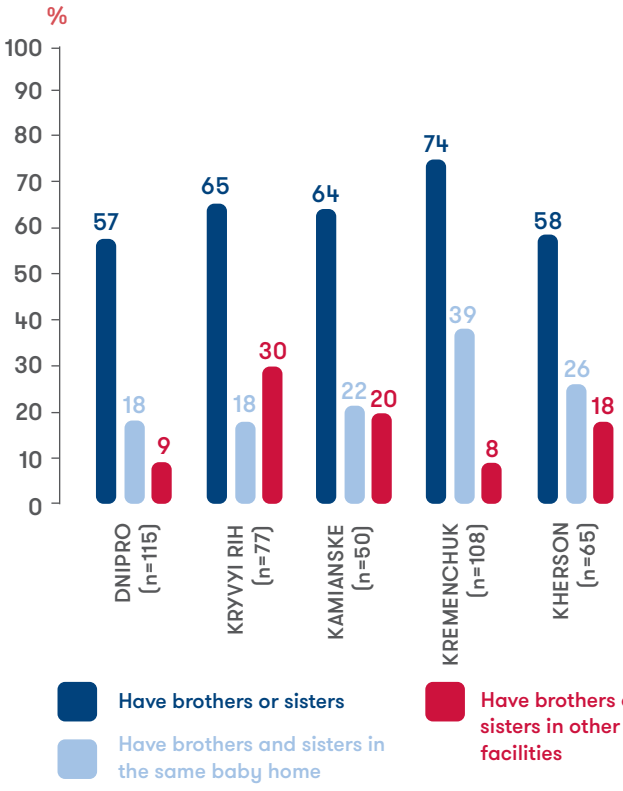


Figure 6. **Information about siblings of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %**

The geographical origin of children differed by facility. The Kryvyi Rih baby home is the only one where almost all children (79 %) come from the city where the baby home is located **(Fig. 5)**. The percentage of children from rural areas was the highest in the Dnipro (37 %) and Kherson (31 %) baby homes.

Between 57 % (Dnipro) and 74 % (Kremenchuk) of children in baby homes had biological brothers and / or sisters; of these, half of their siblings lived in the same baby home or another institution **(Fig. 6)**. Every fourth child in Kamianske and Kremenchuk baby homes, every fifth child in Dnipro and Kryvyi Rih baby homes and every tenth child in the Kherson baby home came from large families that had three or more siblings.

STATUS OF CHILDREN AND FREQUENCY OF VISITS BY LEGAL REPRESENTATIVES

In the Dnipro, Kremenchuk, and Kherson baby homes, nearly half of the children were deprived of parental care and the rest had parents with unrestricted rights **(Fig. 7, Table 1)**. The Kryvyi Rih baby home is the only one where almost all the children (82 %) were deprived of parental care. The opposite situation is in the Kamianske baby home where only about a third of the children (38 %) had such a status. Children were deprived of parental care for two main reasons: 1) the mother abandoned the child (usually in the maternity hospital) or the child was brought secretly to the facility; and 2) the parents were deprived of parental rights by a court decision for failing to perform their duties, often due to child abuse or substance abuse. With the exception of the Kherson and Kryvyi Rih baby homes, the majority of children in other facilities, within the sample of those whose parents are not restricted in their rights, were placed upon the initiative of the family.

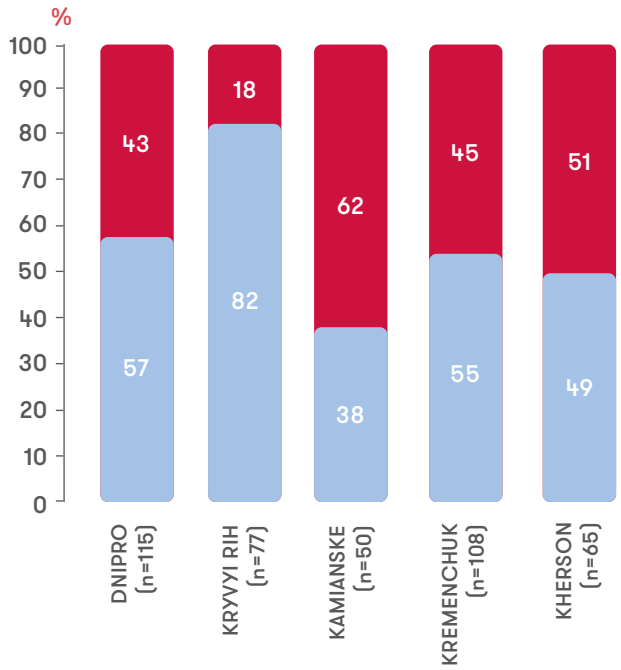


Figure 7. Status of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %

Table 1. Status of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, *persons*

	Dnipro (n=115)	Kryvyi Rih (n=77)	Kamianske (n=50)	Kremenchuk (n=108)	Kherson (n=65)
Orphans and children deprived of parental care, including:	**65**	**63**	**19**	**59**	**32**
Orphans	2	2	-	1	-
Children deprived of parental care, including:	63	61	19	58	32
Children whose parents are deprived of parental rights by the court decision	32	22	12	21	22
Children separated from their parents, but the court decided not to deprive them of parental rights	3	4	1	9	3
Children whose parents were judged incapable	1	-	-	-	1
Children whose parents are serving prison sentences	1	-	1	1	-
Children whose parents have a chronic illness which is confirmed by a certificate of the health committee	3	4	-	1	-
Children whose parents are in the temporarily occupied territory which is confirmed by the act	-	1	-	-	-
Abandoned children	23	30	5	26	6
Children whose parents are not restricted in their rights, including:	**50**	**14**	**31**	**49**	**33**
Children separated from their parents as decided by the guardianship authority	11	14	3	10	18
Children placed upon the initiative / request of the family	39	-	28	39	15

MAINTAINING CONTACT WITH THE FAMILY AND ORGANISING REGULAR VISITS TO THE FACILITY ARE IMPORTANT FOR REINTEGRATION.

Unfortunately, even when parents remain as the child's legal representatives, many children are not visited. The analysis of visits to children whose parents are not restricted in their rights, and children separated by a court decision without parents being deprived of their rights, has shown that even when a child is visited, they are usually sporadic, occurring less than once a month **(Fig. 8)**. According to the visiting logs, none of the children separated by the decision of the guardianship authorities were visited by representatives of these authorities, which contradicts the requirements of the Law of Ukraine "On Ensuring Organisational and Legal Conditions for Social Protection of Orphans and Children Deprived of Parental Care"[8].

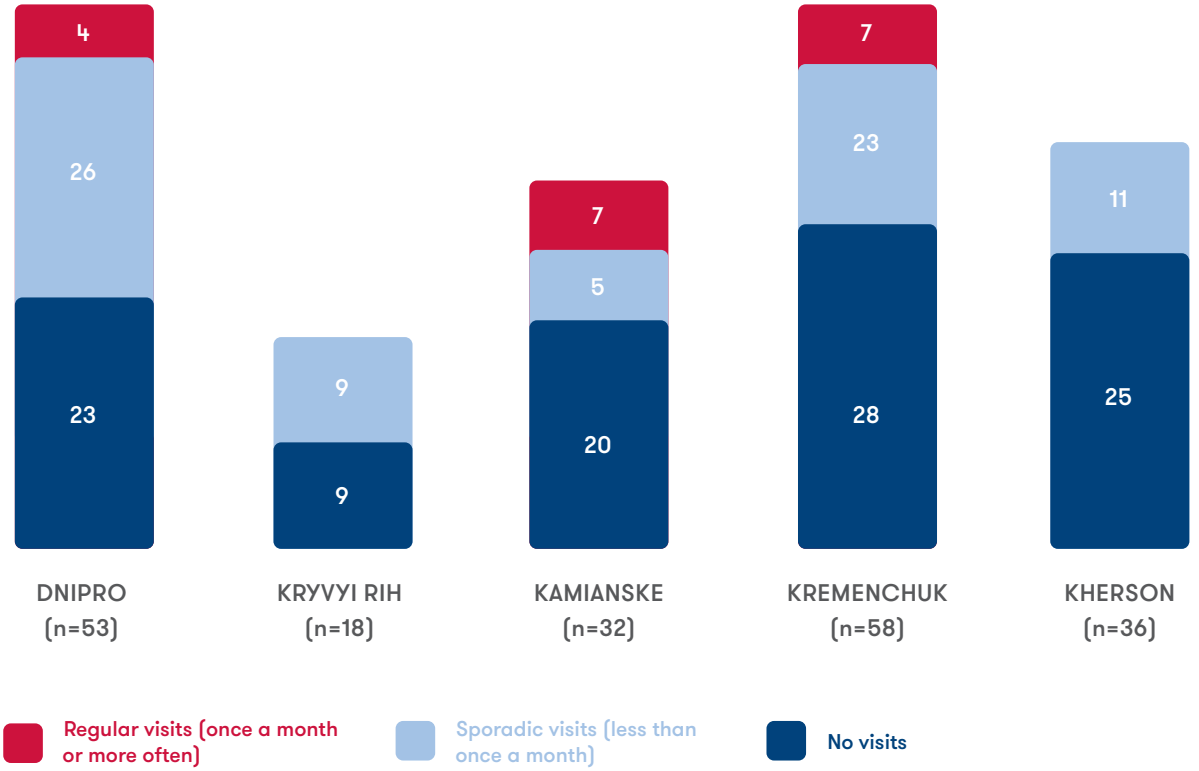


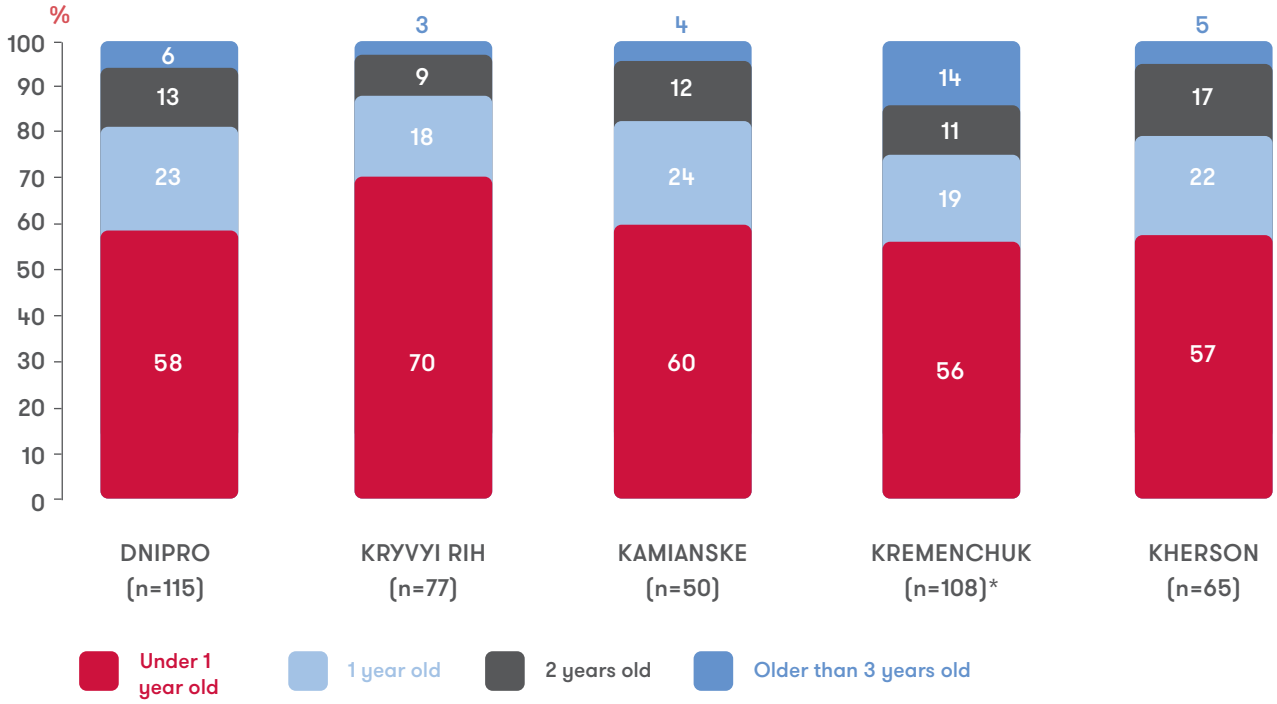
Figure 8. Visits to children whose parents are not restricted in their rights and children separated from their parents by a court decision without deprivation of parental rights, of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, *persons*

8 / Articles 5-6 of the Law of Ukraine "On Ensuring Organisational and Legal Conditions for Social Protection of Orphans and Children Deprived of Parental Care": https://zakon.rada.gov.ua/laws/show/2342-15.

LENGTH OF STAY AT THE TIME OF THE ASSESSMENT

About 60-70 % of children who are placed in the baby homes are younger than 12 months old **(Fig. 9)**. Given the age of children at the time of the assessment, they had lived in the facilities for a very long time. Only in the Kryvyi Rih baby home was the median length of stay at the time of the assessment less than a year (9 months), whereas this ranged from 12 to 15 months in the other facilities.

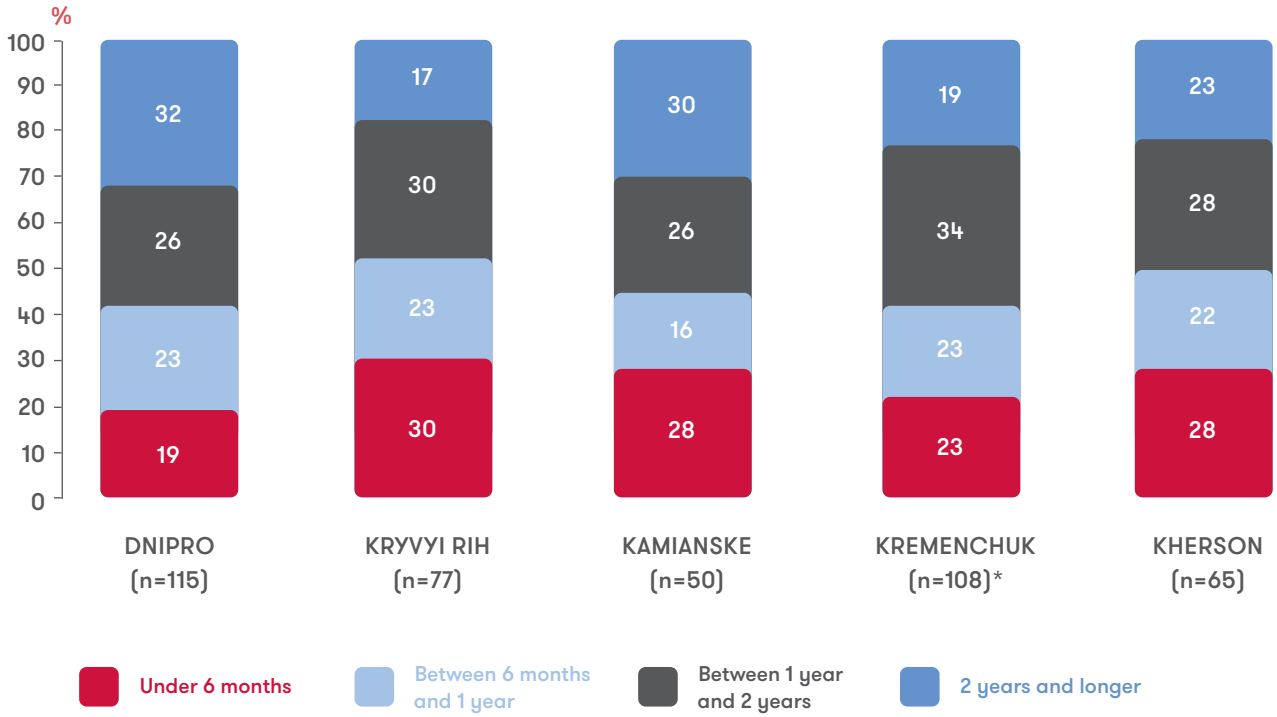
According to previous studies, staying in a facility for more than 6 months during early childhood (up to 3 years old) may have irreversible negative consequences for the rest of their life[9]. That is why it is important to prevent the separation of the child from the family, and if this is not possible and the child is in danger in the family, to initiate the process of deprivation of parental rights and try to quickly place the child in family care. The analysis of the situation in five baby homes shows that 70-80 % of children stay in the facilities for more than 6 months **(Fig. 10)**. In Dnipro and Kamianske baby homes, every third child has lived in the facility for more than 2 years, compared with every fourth child in the Kherson baby home, and every fifth child in the Kryvyi Rih and Kremenchuk baby homes.



* In the Kremenchuk baby home, there was no data on the date of placement for one child, so it was impossible to figure out the child's age at the time of placement.

Figure 9. Distribution of children by age at the time of placement in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

9 / Kreppner JM, Rutter M, Beckett C, Castle J, Colvert E, Grootheues C, et al. Normality and impairment following profound early institutional deprivation: A longitudinal follow-up into early adolescence. Developmental Psychology. 2007;43:931–946.

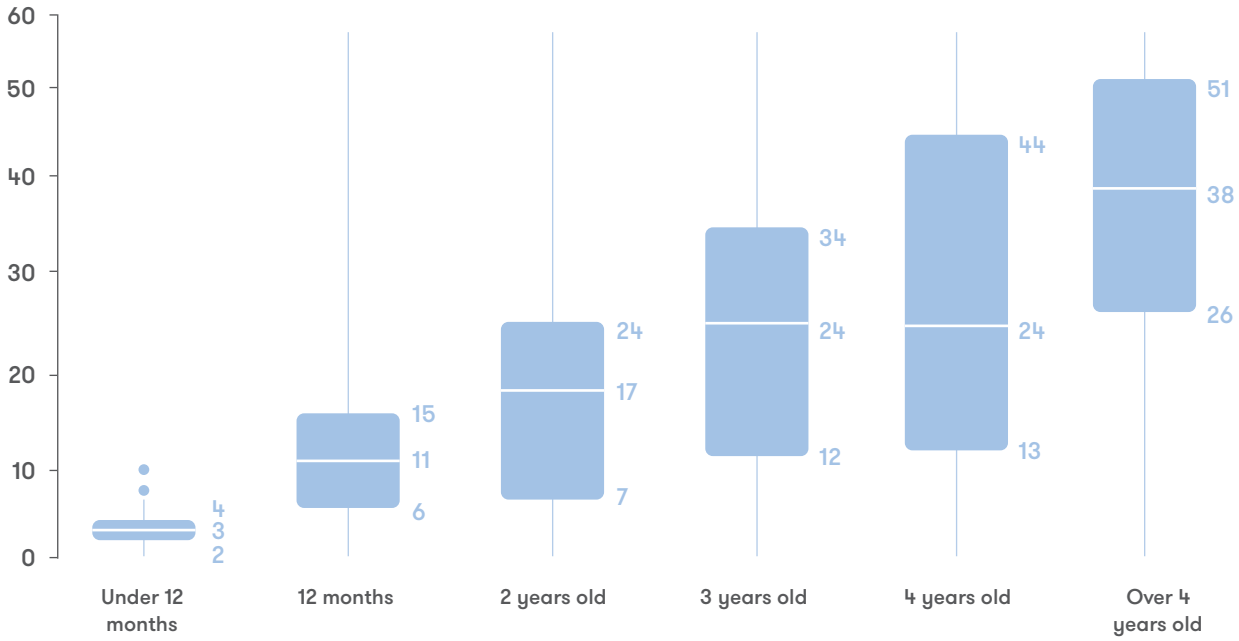


*In the Kremenchuk baby home, there was no data on the date of placement for one child, so it was impossible to measure the length of stay.

Figure 10. Distribution of children by the length of stay in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, %

In all baby homes, there is a correlation between the child's age and length of stay: older children on average stayed in a facility longer than younger ones **(Fig. 11)**. Differences in the length of stay depending on age may indicate a delay in making decisions on a child (it concerns to statutory deadlines for returning the child to the family or initiating deprivation of parental rights by a court order), both by the guardianship authorities and the administration of baby homes. According to the law, lack of parental care for six months is already sufficient grounds for depriving parents of their rights (Article 164 of the Family Code of Ukraine[10]) and this process can be initiated both by the baby home and the guardianship authority. The analysis of children's files shows that, in practice, there is no routine monitoring and analysis of the frequency of visits to children by their parents, or the initiation of the procedure to deprive parents of their rights; which is often postponed even if there are grounds for this. The length of a child's stay in a baby home is also affected by the lengthy process courts take to consider whether to deprive parents of their rights and grant the child the status, which is a necessary condition for adoption or placement in family-based care. In an interview, representatives of the Service on Children's Affairs mentioned that the trials could last more than a year. Also, deterrents may be linked to the maximum period children can stay in baby homes (according to the legislation, children can stay in a specialised baby home until they turn 4) and the correlation between a facility's budget and the number of children.

10 / Family Code of Ukraine / Newsletter of the Verkhovna Rada of Ukraine (VVR), 2002, Issue 21-22, p.135: https://zakon.rada.gov.ua/laws/show/2947-14.



Explanation: The age categories of children are calculated as full years, for example, 1 year is from 1 year 0 months and 0 days to 1 year 11 months and 29 days. The "box" shows 50 % of the most common values with a median (bold horizontal line). For example, among one-year-olds, a quarter stayed in the baby home for up to 6 months, half of children - from 6 to 15 months, and another quarter - for more than 15 months. The median duration is 11 months. The graph is based on data from five baby homes (n = 415).

Figure 11. Length of stay of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions at the time of the assessment, by the age of the child at the time of placement, *months*

REASONS FOR PLACEMENT AND LOCATION BEFORE PLACEMENT IN A FACILITY

The personal files indicated the main reasons for the placement of children in a facility, which included difficult financial situations, an inability to care for a sick child or to take care of a child alone (single mothers), abandonment, and negligence specifically because of substance abuse **(Table 2)**. There are some differences between facilities. The placement of children because of a single-parent family was more common among the children of Dnipro and Kremenchuk baby homes. Abandonment of a child in a maternity hospital or children's hospital was more often cited as a reason for placement in the Kryvyi Rih baby home than in others.

All registered reasons for placement can be described as "difficult life circumstances"; situations where the help of a social work specialist was needed to prevent the abandonment of a child by detecting early on the problems in a family and their need for social support. Unfortunately, the available documents do not allow an analysis into the history of contact between the family and the social worker before the decision was made to place the child in a facility; the extent to which families had access to social services, and what assistance was provided to them.

Table 2. Reasons for placement of children into the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

	Dnipro (n=115) %	Kryvyi Rih (n=77) %	Kamianske (n=50) %	Kremenchuk (n=108) %	Kherson (n=65) %
Single-parent family	45	-	12	49	2
Illness of parents / guardians	4	5	6	3	2
Mental disability of parents / guardians	3	-	10	4	2
Disabilities of parents	1	-	-	-	-
Elderly person caring for a child	-	-	-	-	8
The biological mother / father is in prison	2	-	2	-	-
Minor parents	2	1	2	2	2
Parents died	-	3	-	3	3
Abandoned child	30	52	18	20	17
Return of the child by adoptive parents	-	-	-	-	2
Health status of the child	9	-	16	7	22
Parental abuse / neglect of the child	30	35	56	55	37
Domestic violence	1	1	-	4	2
Parents are substance users	22	14	26	33	31
Poverty (no housing and livelihood)	30	3	36	24	28

Except for the Kherson and Kamianske baby homes, in the other facilities almost all children were in healthcare facilities before placement in baby homes (Fig. 12). This is greater than the percentage of abandoned children in a maternity hospital or children's hospital. This situation is explained by the common practice of placing children separated from their families in a healthcare facility during the period that the child registers with a baby home. Children are temporarily placed in children's hospitals because there are no other accommodation options.

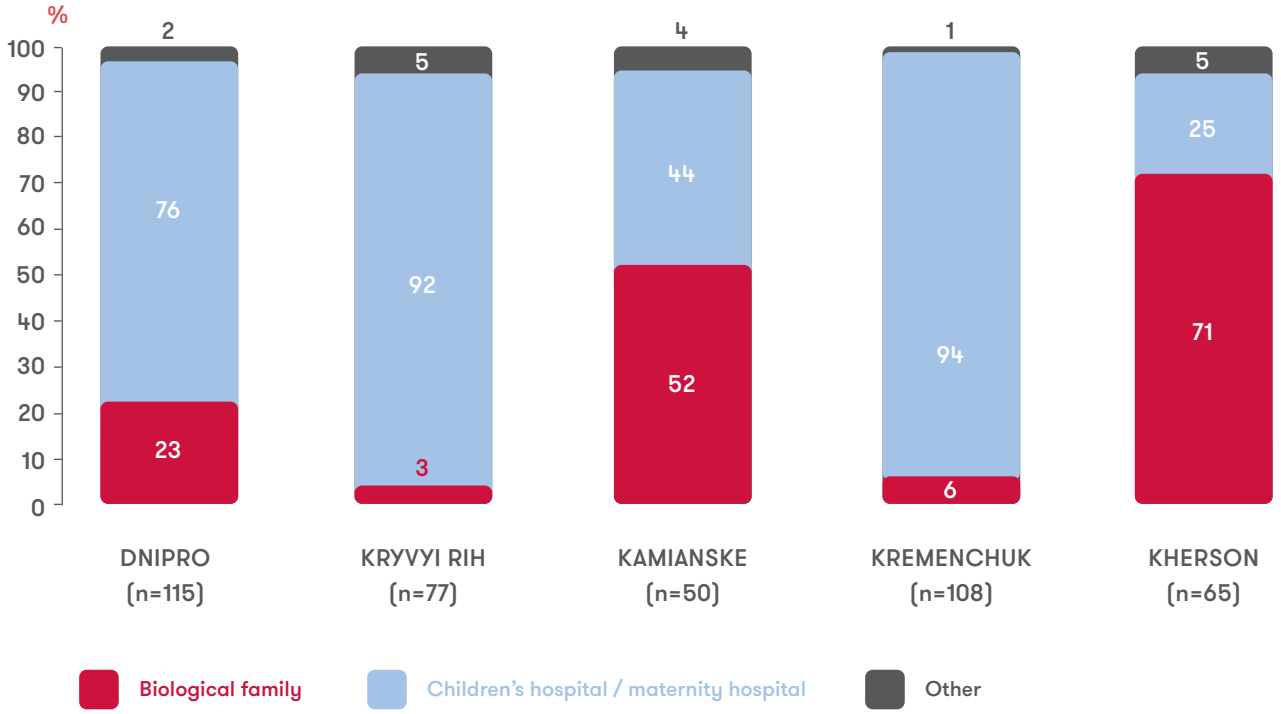


Figure 12. Location of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions before placement in the facility, %

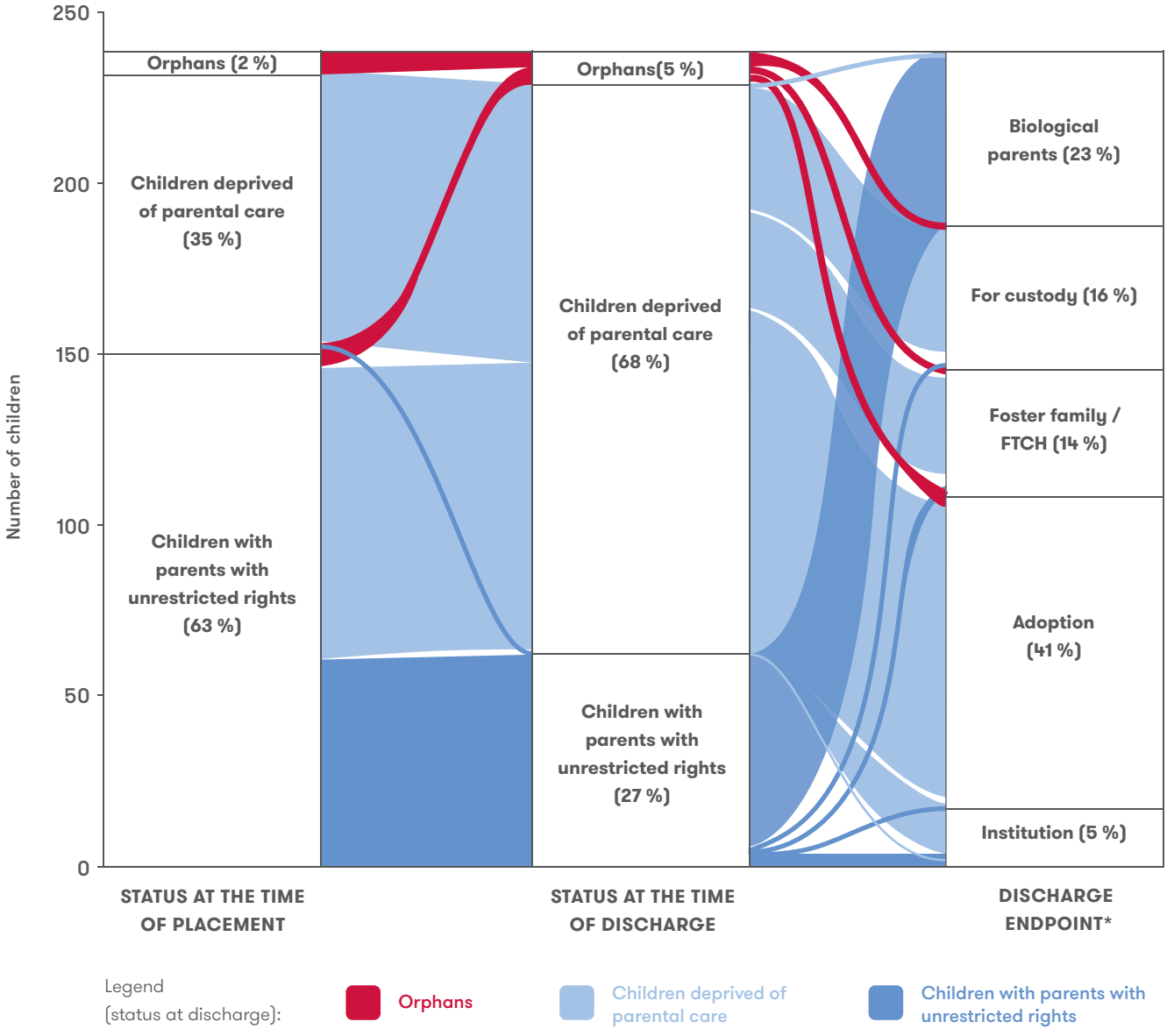
CHARACTERISTICS OF CHILDREN LEAVING BABY HOMES

To understand the changes in a child's status upon leaving a baby home, their next placement options, and length of their stay in a facility before discharge, the assessment teams analysed the personal files of 239 children who left the baby homes between October 2018 and October 2019. During this period, 54 children left the Dnipro baby home, 34 left the Kryvyi Rih baby home, 44 left the Kamianske baby home, 55 left the Kremenchuk baby home, and 52 left the Kherson baby home.

Regardless of the child's status at the time of placement in a baby home, most leave with the status of a child deprived of parental care **(Fig. 13)**. Among the total number of children who left the baby homes of Dnipropetrovsk, Poltava, and Kherson regions in the last 12 months, the percentage of children deprived of parental care almost doubled between placement and discharge (from 35 % to 68 %). Only half of children who had parents with unrestricted rights at the time of placement maintained the same status by the time they were discharged.

Where a child is placed depends on the status of the child. Children whose parents had full parental rights at the time of discharge were mostly reunited with their biological families. Conversely, orphans and children deprived of parental care were mostly placed in various forms of family-based care. Generally, in all baby homes except Kherson, nearly half of the children who left the facilities were adopted. The Kherson baby home is the only facility where children were mostly reunited with their biological families or were cared for by relatives or non-relatives. In all facilities except for the Kryvyi Rih baby home, there

were cases of discharge into another institution (between 4 and 9 % of the total number of discharged children). According to the law, these children had reached the age limit for staying in the facility. It is worth mentioning that among the children leaving for another institution, there were children who at the time of discharge still had parents with parental rights, despite the fact the children had lived in the baby homes for a long period of time (between 32 and 57 months) and their parents did not visit them.

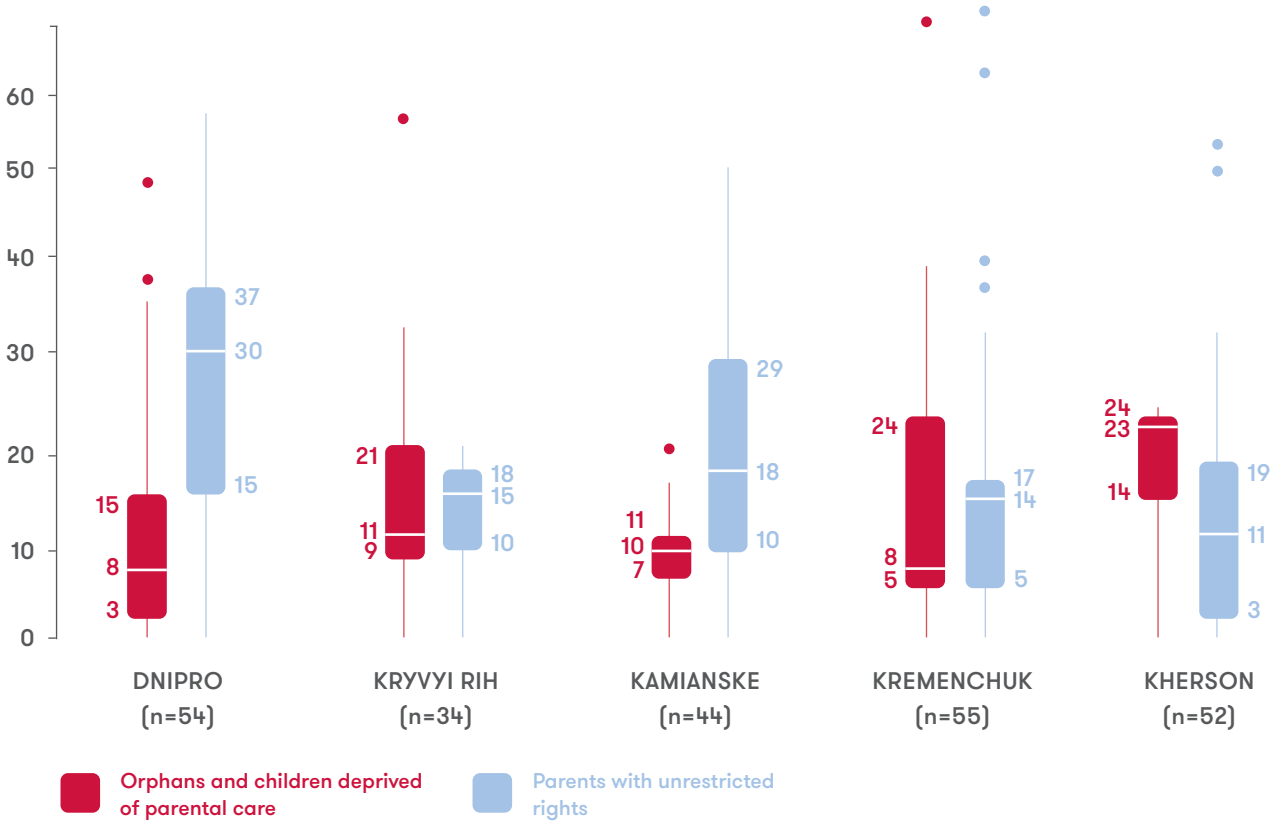


* One child among those discharged died, this is not shown in the graph. Because of this, the total percentage in the column "discharge endpoint" is less than 100 %.

Explanation: The graph is based on data from the five baby homes (N = 239). Coloured lines show "transitions" between different statuses and discharge endpoins. The thicker is the line, the more people are in that category. For example, in the five baby homes, 63 % of discharged children had parents unrestricted in their rights, and at the time of discharge there were only 27 % (blue). Most of the children, who both at the time of placement and at the time of discharge had parents with unrestricted rights, were reunited with their biological families (23 % of the total number of those discharged).

Figure 13. Changes in the status of the child and the placement of children who left baby homes of Dnipropetrovsk, Poltava and Kherson regions, from October 2018 to October 2019, %

Except for children in the Dnipro baby home, the median length of stay of discharged children was similar in all baby homes (about a year: 11-13 months). In the Dnipro baby home, this figure was twice as high (24 months). In almost all facilities, children whose parents were not restricted in their rights stayed in the facility longer than orphans and children deprived of parental care **(Fig. 14)**. The difference is particularly visible in the Dnipro baby home, where the median length of stay in the facility at the time of discharge was 30 months (2.5 years) among children whose parents were not restricted in their rights at the time of placement, and 8 months among children deprived of parental care. The opposite situation was in the Kherson baby home, where the children whose parents were not restricted in their rights, left the institution faster.



Explanation: The "box" shows 50 % of the most common values with a median (bold horizontal line). For example, in the Dnipro baby home, a 25 % of orphans and children deprived of parental care stayed in the facility for up to 3 months before discharge, 50 % for 3 to 15 months, and another 25 % for more than 15 months. The median is 8 months.

Figure 14. Length of stay in the baby home as of the moment of discharge from the baby homes of Dnipropetrovsk, Poltava and Kherson regions of children who left from the institutions from October 2018 to October 2019, according to the child's status at time of placement, *months*

STOCK AND FLOW OF CHILDREN IN THE BABY HOMES

To analyse the stock and flow of children in the baby homes, the assessment teams collected data on the number of placed and discharged children, as well as the number of children who stayed in the facility for a year between 2016 and the first 9 months of 2019 (Fig. 15). If you look at the number of children placed in the baby homes compared to the number discharged, you can see that in all facilities during 2016-2017, more children were placed than discharged, while in 2018 the situation reversed. Only in the Kryvyi Rih and Kherson baby homes was there a steady decrease in the total number of children who stayed in the facility during the year. In the Dnipropetrovsk region baby homes and the Kremenchuk baby home, the discharge rates in the first 9 months of 2019 were much lower than similar annual rates for 2018; it can be assumed that children mostly leave in the last quarter of the calendar year, and not evenly throughout the year.

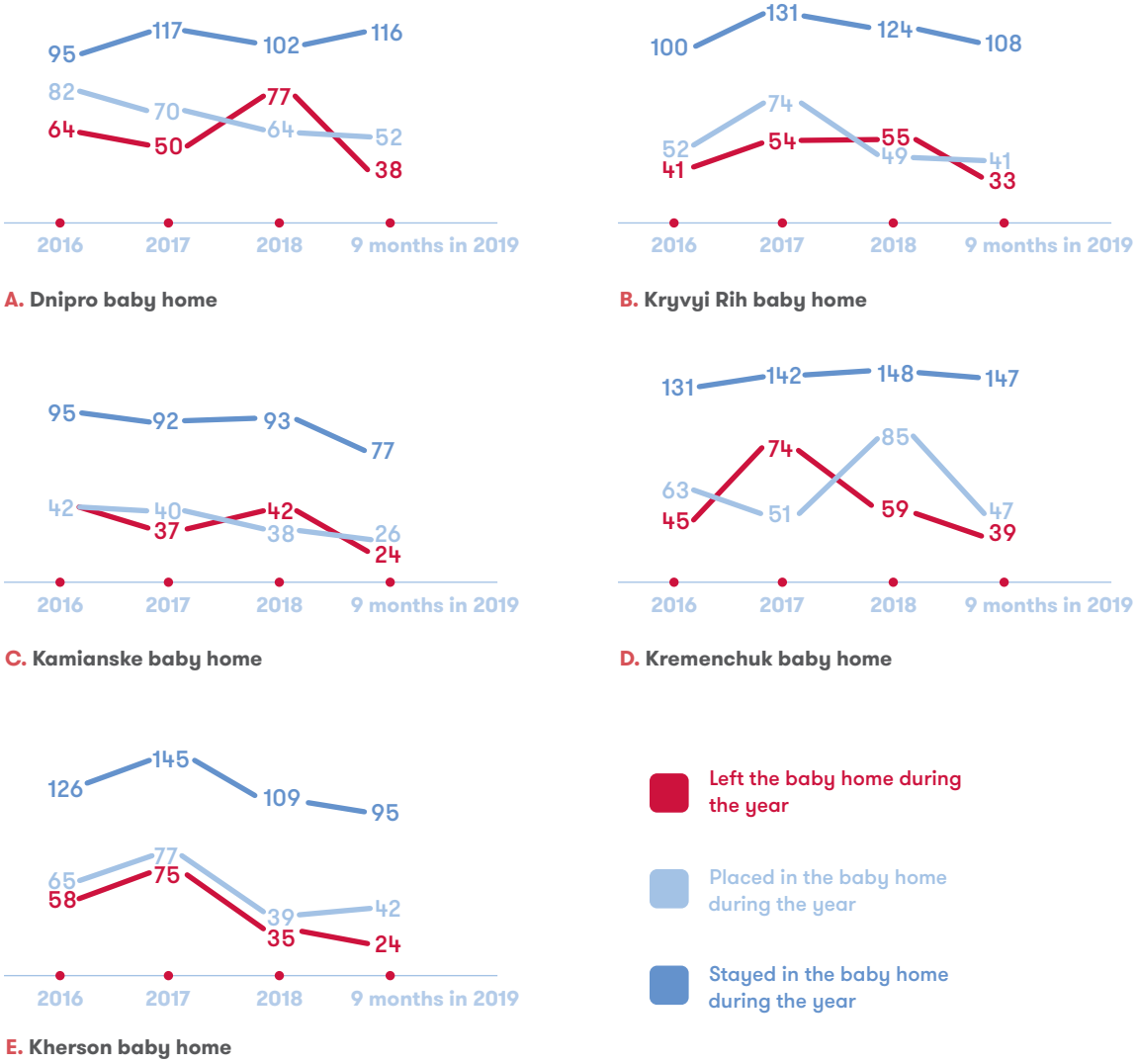


Figure 15. **Stock and flow of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions between 2016 and the first 9 months of 2019, *persons***

HEALTH AND DEVELOPMENT OF CHILDREN

The assessment of children's health and development is a key component of this report. It was based on both a careful analysis of the facilities' medical records and field observation of children in the baby homes, conducted by paediatricians who were members of the assessment teams. According to ethical principles, health assessments were conducted only with those children for whom consent was given for the processing of their personal and health data, as well as for being observed. Informed consent was obtained for 406 out of 415 (98 %) children who were in the five baby homes at the time of the assessment (110 out of 115 children in the Dnipro, 75 out of 77 children in the Kryvyi Rih, all 50 children in the Kamianske, 106 out of 108 children in the Kremenchuk and all 65 children in the Kherson baby homes).

PREMATURE BIRTH

The percentage of children born prematurely, with a gestational age under 36 weeks[11], was 28 % in the Kryvyi Rih baby home, 25.5 % in the Kremenchuk baby home, 24.5 % in the Dnipro baby home and 18 % in the Kamianske baby home. In the Kherson baby home, there were fewer children born before 36 weeks (11 %). The medical records of premature babies in the five baby homes did not specify any age-based adjustments[12] for the organisation of nutrition, the screening and development assessment of such children, the organisation of preventive, curative and rehabilitation measures.

ANALYSIS OF MORBIDITY IN CHILDREN, ACCORDING TO THE BABY HOME MEDICAL RECORDS AND ASSESSMENT RESULTS

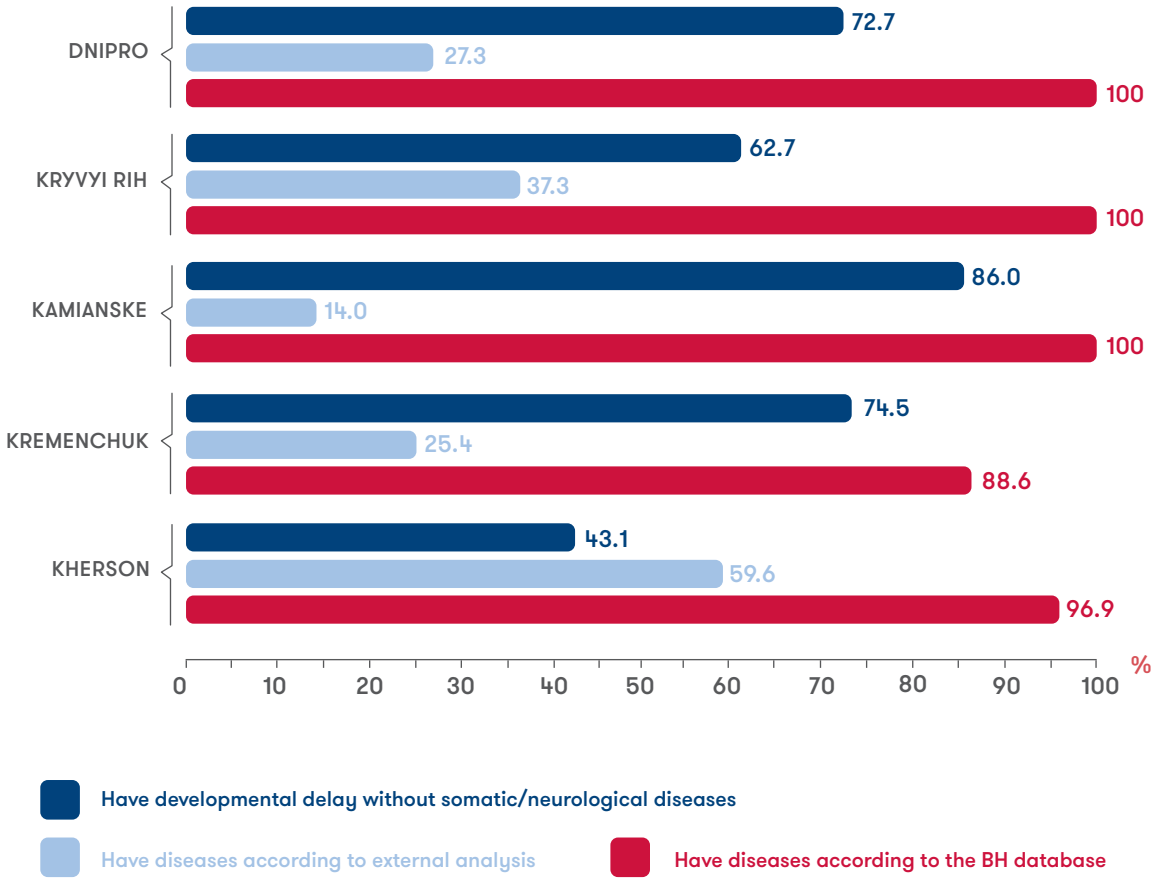
According to the baby home medical records, only 12 children (11 %) in the Kremenchuk baby home and 2 children (3%) in the Kherson baby home were diagnosed as "healthy"; but no healthy children were identified in the Dnipropetrovsk region baby homes: Dnipro, Kryvyi Rih and Kamianske **(Fig. 16)**.

An in-depth review of children's diagnoses, given the presence of "myth" diagnosis[13] and morpho-physiological characteristics that are common for young children, revealed many more healthy children with neither somatic nor neurological conditions than was indicated in the medical records. Thus, 86 % (43 children) were recognised as somatically / neurologically healthy in the Kamianske baby home, 75 % (79 children) in the Kremenchuk baby home, 73 % (80 children) in the Dnipro baby home, 63 % (47 children) in the Kryvyi Rih baby home, and 43 % (28 children) in the Kherson baby home.

11 / The gestational age of the child is the period of perinatal development which lasts from the first day of the last menstruation to the birth of the child. A baby is considered premature if it is born between 22 and 37 full weeks (154-258 full days from the first day of the last menstrual cycle, regardless of body weight and body length at birth).

12 / Adjusted age is used to describe on average children under 3 who were born prematurely, according to the following formula: chronological age (months) [(40 weeks - gestational age) / 4 weeks]. Source: Age Terminology During the Perinatal Period PAEDIATRICS Vol. 114 No. 5 November 1, 2004 p. 1362 -1364 (doi: 10.1542 / peds.2004-1915).

13 / A "myth" diagnosis is a diagnosis that is controversial in terms of both the evidence and the findings of health experts. Myth Diagnosis: Is healthcare recession-proof? URL: https://www.healthcaredive.com/news/myth-diagnosis-is-healthcare-recession-proof/567470/.



* In the Kryvyi Rih baby home, one child had a "no diagnosis" mark in the medical records.

Figure 16. Distribution of diseases and developmental delays in children, according to baby homes medical records and expert analysis, %

HOSPITALISATION

A considerable number of hospitalisations for general and acute conditions was detected, especially among children from the Kryvyi Rih and Kherson facilities **(Fig. 17)**. The Kamianske baby home is rated third in terms of the number of hospitalisations for both general and acute conditions. It should be noted that the frequency of hospitalisations due to the exacerbation of chronic diseases or complications is almost the same across all the baby homes except for Kremenchuk. The availability of satisfactory health staff in the baby homes does not eliminate the need to transport children to hospital to receive health care. On the other hand, the high incidence of acute conditions among children in the Kherson and Kryvyi Rih baby homes requires further investigation on nosocomial infections in closed children's facilities.

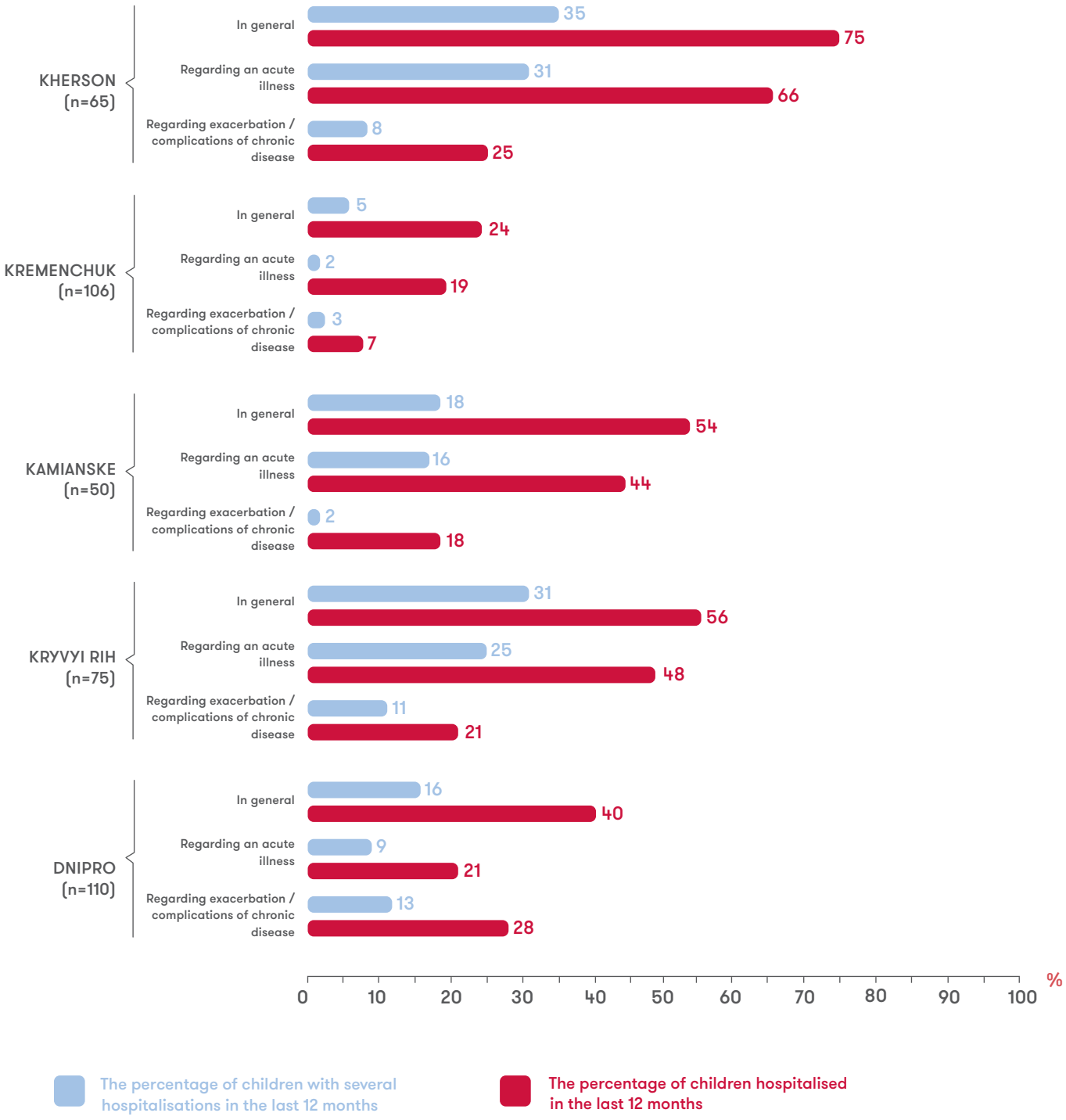


Figure 17. Percentage of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions who were admitted to hospital in the last 12 months and the percentage of children re-admitted during this period, by type of admission, %

PERCENTAGE OF CHILDREN'S HEALTH DISORDERS

In order to understand the significance of health disorders and the impact on a child's development an analysis of morbidity in children in regards to functional organ systems was conducted, taking into account the severity of the condition, the possibility for complete correction, and "myth" diagnosis. Evaluation of the incidence of congenital developmental abnormalities, chromosomal abnormalities, and genetic / metabolic disorders revealed that the smallest number of children with a congenital disorder were in the Kremenchuk baby home, whereas the largest number were in the Dnipro baby home **(Fig. 18)**. Incidences of hospitalisation are not determined by the number of conditions that may lead to complications or increased susceptibility to inflammatory diseases. For example, Dnipro baby home had the largest number of children with congenital abnormalities and chromosomal / genetic conditions, at the same time yet did not have the highest incidences of hospitalisation.

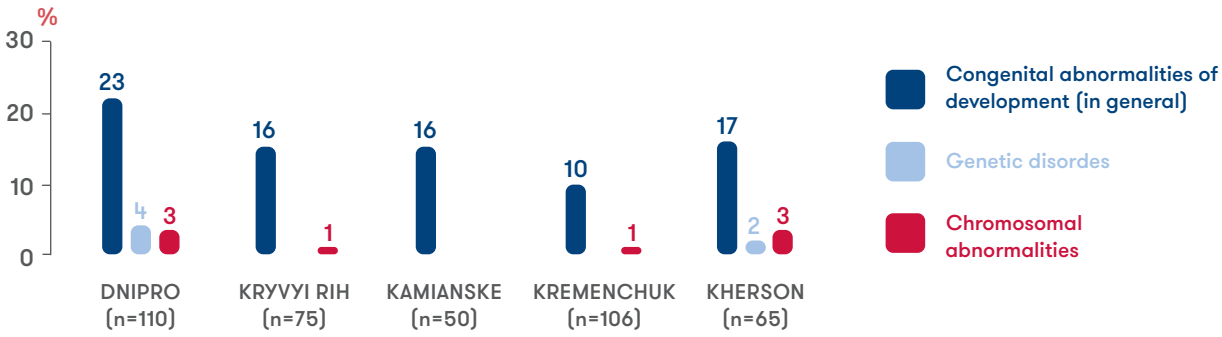


Figure 18. Percentage and type of congenital disorders in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

The analysis of the type of congenital abnormalities in children from different baby homes showed that congenital defects are mainly characterised by abnormal developments of the nervous and cardiovascular systems. Other developmental abnormalities, particularly those of the urinary system or gastrointestinal tract, are observed in a few cases. In contrast, the percentage of children in the Kherson and Kryvyi baby homes with defects of the urinary system and gastrointestinal tract, as well as abnormal facial developments, is over 30%. At the same time, 24 (37 %) children in the Kherson baby home are diagnosed with "fetal alcohol spectrum disorders" (FASD), which fully explains the range of congenital abnormalities in these children[14]. There were no children diagnosed with FASD in the other baby homes despite information indicating alcohol abuse by parents. In the Kremenchuk and Dnipro baby homes, five children aged 2 and older were diagnosed with a "patent foramen ovale"[15, 16, 17]. A condition such as Patent Ductus Arteriosus (PDA) should be corrected, especially in children over 12 months of age. There was one child with this uncorrected condition in the Kremenchuk baby home.

The most common visual impairments among children from the baby homes are refraction disorders (myopia, hypermetropia, astigmatism), strabismus, and optic nerve atrophy (partial or complete) **(Fig. 19)**.

14 / Centers for Disease Control and Prevention: Fetal alcohol spectrum disorders (FASDs). URL: https://www.cdc.gov/ncbddd/fasd/index.html.

15 / URL: https://my.clevelandclinic.org/health/diseases/17326-patent-foramen-ovale-pfo.

16 / Ghiglia S, Feslove V. Patency of foramen ovale in full term and preterm neonates. A follow-upstudy. *Pediatr Med Chir.* 2008; 30:192–196.

17 / Lin KM, Liang CD, Chien SJ, et al. Predictors for regression of large secundum atrial septal defects diagnosed in infancy. *Acta Cardiol Sin.* 2013; 29:82–87.

Medical care for such children is considered insufficient in many baby homes, except for Kremenchuk. There are many children in this baby home where the optic nerve atrophy is associated with a high incidence of strabismus and refraction disorders. On the contrary, no children in Kryvyi Rih were registered with optic nerve atrophy, however refraction disorders are most frequent as well as a high percentage of strabismus. The baby homes in Dnipro and Kamianske also have high percentages of children with strabismus and refraction disorders. In all five facilities, medical records do not contain information about the treatment and medical care for children with visual impairments, in particular concerning measures such as correction with eyeglasses, strabismus correction exercises, the method of excluding one eye in case of strabismus, and other interventions. The lack of correction to visual impairments is the reason for developmental delays in children, and delayed diagnosis and treatment for optic nerve atrophy leads to further damage. High-quality and timely ophthalmological care for children with visual impairments should be an integral part of medical care for children in baby homes.

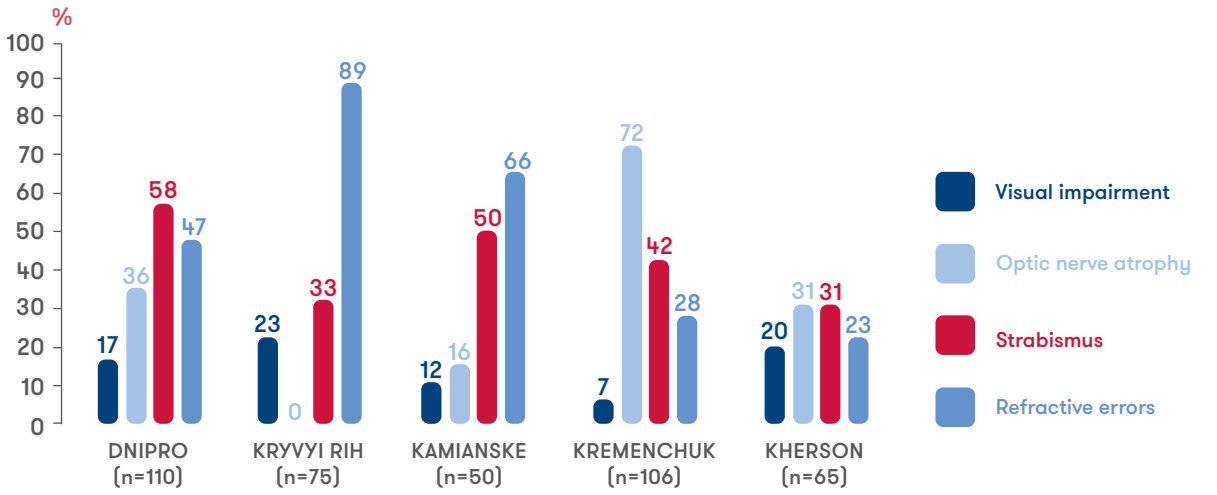


Figure 19. Percentage of visual impairments in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

Cerebral palsy (CP) (spastic tetraplegia, hemiplegia, etc.) is significantly contributing to the incidence of hospitalisations due to exacerbations / complications and developmental disorders. In the baby homes of Kryvyi Rih, Kamianske, and Kherson, every tenth child has CP **(Fig. 20)**. Except for a few cases, diagnoses of cerebral palsy and other paralytic syndromes were not supported with the Gross Motor Function Classification System (GMFCS) in the baby home medical records, which is the basis for determining the needs for rehabilitation services and medical support[18, 19].

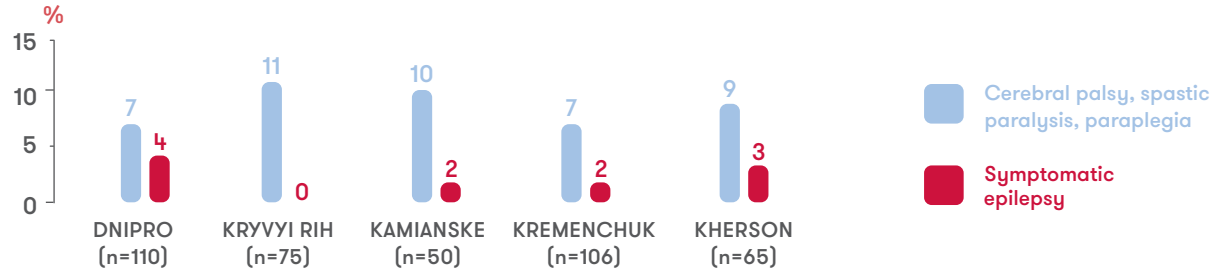


Figure 20. Percentage of nervous system disorders with cerebral palsy, spastic paresis, hemiplegia and the percentage of epilepsy in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

18 / URL: https://www.abclawcenters.com/cerebral-palsy/gross-motor-function-classification-system/.

19 / URL: https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r.

The analysis of medical records revealed that the largest number of children diagnosed with HIV / AIDS is in the baby homes in Dnipro (19), Kryvyi Rih (11), Kherson (4) and Kremenchuk (3). According to the medical records, antiretroviral therapy was provided more often for the children in the Dnipro and Kryvyi Rih baby homes and less frequently for children in the Kremenchuk and Kherson baby homes. In this regard, there is a need to clarify the diagnosis which would explain the presence or absence of treatment; further decision-making by an infectious disease specialist is required. The diagnosis of "tuberculosis" was also not described properly. Only in the Dnipro baby home did children with this diagnosis receive appropriate treatment. In the other facilities it is advisable to review the wording of the diagnosis. Hepatitis C is detected in several cases, and although children received treatment, it is also advisable to clarify stage, progress, and severity of the diagnosed disease.

ASSESSMENT OF CHILDREN'S NUTRITIONAL STATUS AND NUTRITION PLAN

Analysis of a child's nutritional status is based on the anthropometric data and the criteria for diagnosing protein-energy malnutrition (PEM)[20], according to the WHO recommendations (1999)[21, 22], and ICD-10. To assess anthropometric data, the WHO scales were used (z-score)[23, 24], as well as the WHO ANTHRO tool[25]. The assessment of anthropometric data included the individual assessment of parameters like "body weight for height", "body weight for age", "height for age", as well as body mass index (BMI). These parameters allow the chronic or acute nature of malnutrition of children to be detected, revealing common factors affecting a child's nutritional status[26].

According to the assessment results of the nutritional status of children, the percentage of children with PEM signs was over 60 % in all baby homes, and over 80 % in Kryvyi Rih **(Fig. 21)**. In addition to explicit PEM, nearly 20 % of children in all baby homes had low body weight for height (from> -2 to <-1 according to the z-score, the critical threshold before PEM).

In the Dnipro baby home, the medical records, in addition to PEM, contained reference to E45 (ICD-10) – physical developmental delays - however, no improvements to nutrition were made to correct the delays. In other baby homes, physical developmental delays (stunting) was diagnosed as "dwarfism" or simply was not documented. Linear growth retardation (E45, stunting with the z-score over -2 according to the "height for age" indicator) was most often observed in the Kryvyi Rih, Dnipro, and Kremenchuk baby homes **(Fig. 22)**.

20 / Protein-calorie deficiency - a cellular imbalance between the supply of nutrients and energy, as well as the body's need for them to ensure growth and functions, or a condition that occurs due to insufficient intake or assimilation of food which affects the body composition and leads to a decrease in lean mass and mass of body cells with the suppression of physical and mental functions and negative clinical consequences of a disease.

21 / United Nations Children's Fund, World Health Organisation, The World Bank. UNICEFWHO-World Bank Joint Child Malnutrition Estimates. (UNICEF, New York; WHO, Geneva; The World Bank, Washington, DC; 2012).

22 / URL: https://www.who.int/nutgrowthdb/en/.

23 / MOH order as of 20.03.2008 No. 149 "On approval of the Clinical Protocol of health care for a healthy child under 3". URL: http://old.moz.gov.ua/ua/portal/dn_20080320_149.html.

24 / WHO. The WHO child growth standards. [27 March 2013]. http://www.who.int/childgrowth/en/.

25 / URL: https://www.who.int/childgrowth/software.

26 / WHO, BASICS, UNICEF. Nutrition essentials: a guide for health managers. Geneva: WHO; 1999.

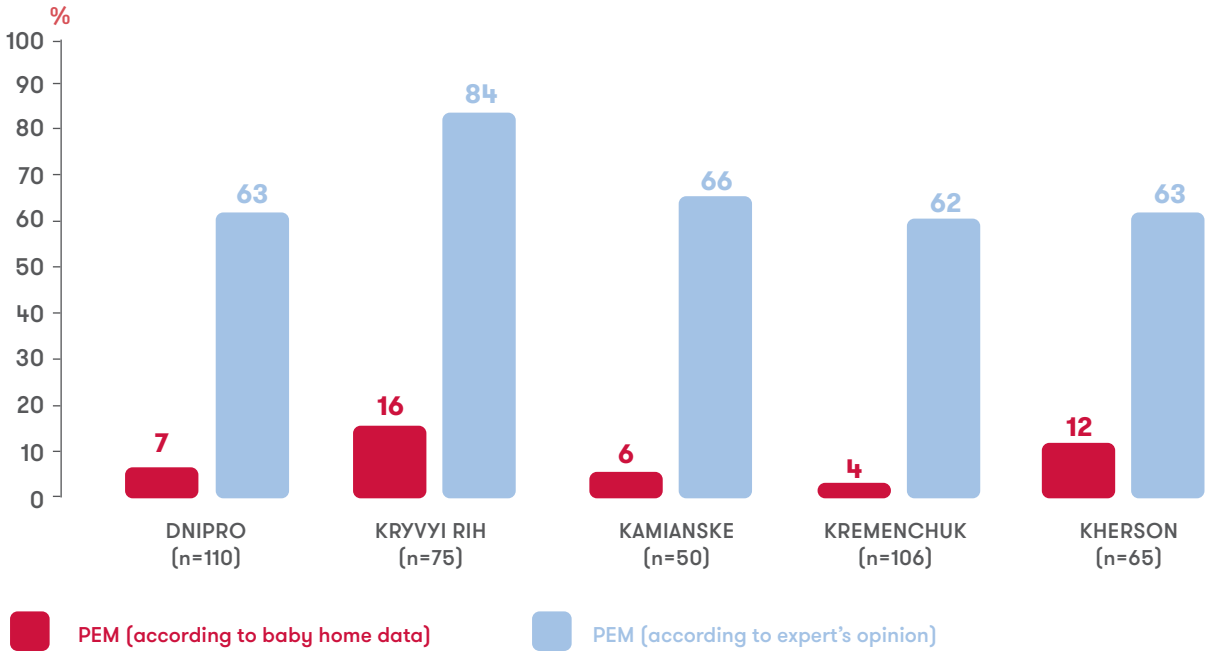


Figure 21. Percentage of nutritional disorders in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, according to medical records and expert assessment, %

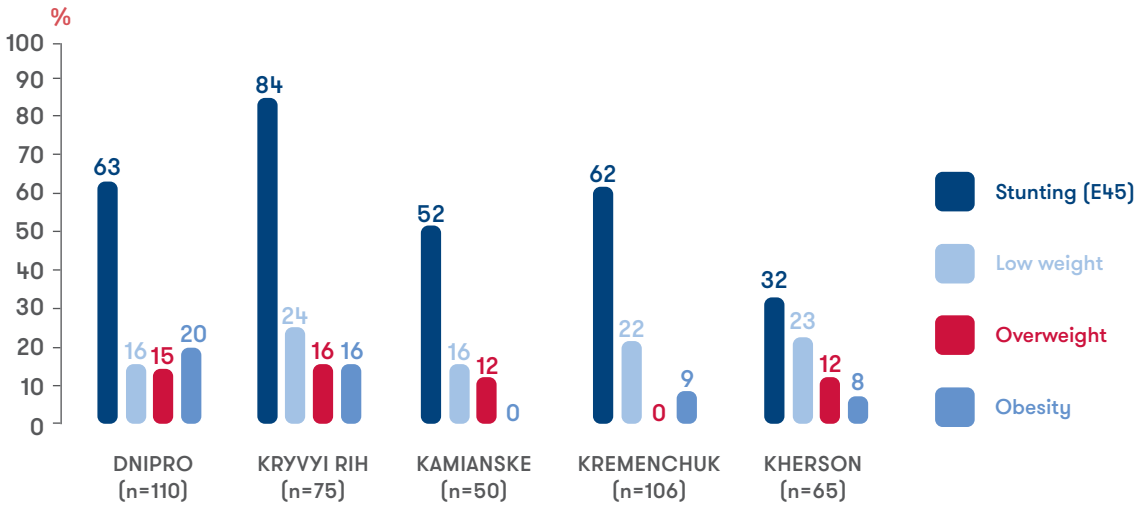


Figure 22. The type of nutritional disorders in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, according to the expert assessment, %

Analysis of the factors that lead to stunting indicates a rather terrible fact. In addition to the negative impact on the physical development of children with conditions such as Fetal alcohol spectrum disorders (FASDs), HIV / AIDS[27] and premature birth (less than 32 weeks), there is a correlation with the time a child arrives in a facility. Stunting (E45) was more likely to occur in children who were immediately placed in the baby home rather than in children aged 2-2.5 years old who, in addition to malnutrition, show negative effects of deprivation. Children who were placed in the baby homes after 2 years of age sometimes had low body weight for height and age but no linear growth retardation that is a low height for age.

27 / Cachexia in this case is coded as B22.2 or "HIV disease resulting in wasting syndrome".

Stunting in a child leads to overweightness after 3 years of age. Thus, it is among the children of Kryvyi Rih and Dnipro baby homes with the highest incidence of stunting associated with PEM that overweightness and obesity were diagnosed. Obesity in children aged 2-3 years with underlying severe linear growth retardation at an early age and / or other negative factors (including parental alcohol abuse, smoking, and premature birth) is particularly threatening for the development of a metabolic syndrome, hypertension, and type 2 diabetes. Given the fact that half of these children were born prematurely (at 28-32 weeks of gestation) this also suggests a postnatal growth restriction during the nursing stages and lack of "catch-up" growth in the first months of life regardless of international guidelines. The assessment of baby food for the first year of life namely dairy products (milk formulas) revealed only a few cases in all baby homes where children received special formula with a high protein and energy content. For example, a course of antiretroviral therapy was supported with the appropriate dietary correction (clinical nutrition with additional high-fat foods) only in the Dnipro baby home. In other cases, "Maliutka" and "Malysh" milk formulas are used which do not meet the needs of premature babies and infants with chronic diseases.

Unfortunately, linear growth retardation in children under 2 years leads to irreversible impacts on their genetic growth potential and does not meet the key principles of the WHO[28]. The artificial metabolic imprinting (1.000-day nutrition concept or Barker's fetal programming theory) is due to the additional negative impact of existing suboptimal standards in nutrition not based on increased needs or excessive losses especially in the case of severe somatic and neurological diseases[29,30].

Children's nutrition in baby homes is regulated by p.8 of the Procedure for the provision of VAT-exempt nutrition services to children in preschool facilities and students in secondary and vocational training schools, approved by the CMU Resolution No. 116 as of 02.02.2011[31], which states that the nutrition of children in preschool facilities is organised in line with the CMU Resolution No. 1243 as of 26.08.2002 "On urgent operational issues of preschool facilities and boarding schools"[32]. This matter is also regulated by the MOH order No. 112 as of 28.06.1994 "On the implementation of the CMU Resolution No. 226 as of 05.04.1994 "On improving the education, training, social protection and material support of orphans and children deprived of parental care"[33], which approved the daily diet (Annexes 1, 2, 4).

The development of a new regulatory framework for children's nutrition, or at the very least the implementation of international guidelines on the nutrition of sick and young children, is of immediate need for the Ministry of Healthcare of Ukraine. Today, the use of food products for special medical purposes (clinical nutrition)[34,35] to correct nutritional deficiencies or to cover increased nutritional needs in case of severe diseases, as well as to optimise the growth of young children, not to mention special milk formulas for premature babies, is considered to be the standard.

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28 / URL: https://www.who.int/maternal_child_adolescent/child/nurturing-care-framework/en/.

29 / Ellison, Peter T. 2010. Fetal programming and fetal psychology//Infant and Child Development 19(1): 6-20. doi:10.1002/icd.649. http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-ofuse#OAP.

30 / Koletzko B, Poindexter B, Uauy R (eds): Nutritional Care of Preterm Infants: Scientific Basis and Practical Guidelines. *World Rev Nutr Diet*. Basel, Karger, 2014, vol 110, pp 4–10. doi: 10.1159/000358453.

31 / URL: https://zakon.rada.gov.ua/laws/show/116-2011-%D0%BF.

32 / Official newsletter of Ukraine (Офіційний вісник України), 2002, Issue 35, p. 1650: https://zakon.rada.gov.ua/laws/show/1243-2002-%D0%BF.

33 / URL: https://zakononline.com.ua/documents/show/106400___106400.

34 / Bushell C, Ruthsatz M. "Foods for Special Medical Purposes. Fundamentals of EU Regulatory Affairs." Chapter 37, 8th ed., 2017; 2018. RAPS, US, 451–457.

35 / Cederholm T. et al. ESPEN guidelines on definitions and terminology of clinical nutrition. *Clin Nutrition*, 2017; 36:49–64.

If the child suffers from a severe condition with no prospects for adequate oral nutrition in the near future a gastrostomy tube is recommended. According to the expert assessment within the Pilot 18 children in Kremenchuk, Kamianske and Kherson baby homes (6 children in each facility) and 5 in Dnipro need a gastrostomy tube. No children in the Kryvyi Rih baby home need a gastrostomy tube.

Half of the residents of the Kamianske baby home (26 children, 52 %), 39 children (37 %) of the Kremenchuk baby home, 28 children (25.5 %) of the Dnipro baby home and 21 children (28 %) of the Kryvyi Rih baby home need clinical nutrition.

All baby home staff immediately need to be trained on the standards for anthropometric assessments of children, nutritional needs assessments, and creating a nutrition plan based on their health status and existing international practice for the organisation of evidence-based nutrition[36,37].

ANALYSIS OF THE FREQUENCY OF SCREENING AND ADDITIONAL TESTS

Screening frequency of visual, audio, haemoglobin levels and dental services were estimated. In Dnipro and Kamianske baby homes no children underwent audiometry tests. Only 4 children (3 %) in the Kremenchuk baby home were examined. In the other facilities the number of unscreened children is also extremely high: 73 % in the Kryvyi Rih and 72 % in the Kherson baby homes **(Fig. 23)**.

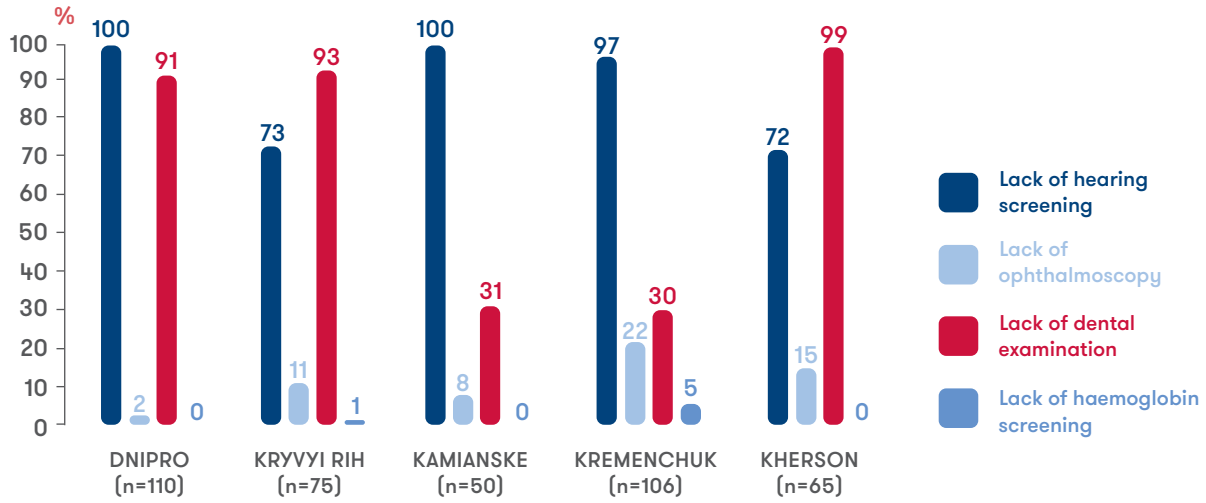


Figure 23. Percentage of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions who were not screened for audio, visual impairments, haemoglobin concentration, and dental health, %

36 / Defining Pediatric Malnutrition: A Paradigm Shift Toward Etiology-Related Definitions: Special Report/N.M. Mehta, and the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) Board of Directors//*J Parenter Enteral Nutr.* 2013;37:460-481. doi:10.1177/0148607113479972.

37 / WHO. Guideline: Updates on the management of severe acute malnutrition in infants and children. Geneva: World Health Organization; 2013. URL: https://apps.who.int/iris/handle/10665/95584.

There are no regulations on the frequency of mandatory audio screening for children in Ukraine. The critical age for hearing and speech development is up to the age of 3 years. For this reason, it is very important to conduct audio screening in time and compensate for delays before they become irreversible[38] as well as to make every effort to engage speech development professionals.

The situation with ophthalmoscopy is somewhat better. However, 23 children (22 %) in the Kremenchuk baby home, 10 children (15 %) in the Kherson baby home and 8 children (11 %) in the Kryvyi Rih baby home were not examined by an ophthalmologist. Early detection of myopia and timely referral to specialists for adequate treatment reduce the risk of amblyopia and visual malfunctions and prevent early disability. A follow-up examination should take place within 2-3 months after the initiation of treatment but the duration of this period may vary depending on the intensity of treatment and the age of the child[39]. According to the baby home data, a regular ophthalmological examination was not provided. As there is an ophthalmologist in the Dnipro baby home observations may have been conducted there however there is no information in the medical records about such treatment and its effectiveness.

Regular dental health check-ups are an integral part of a child's medical care. More than 90 % of children in the Dnipro, Kryvyi Rih and Kherson facilities had not had a dental health check-up. According to the MOH order No. 149[40] as of20.03.2008 (Annex 3), a child from the age of 6 months is to be examined by a paediatrician to record the presence or absence of teeth and re-examined again when they reach 9 months of age. Healthy children should be examined by an orthodontist at the age of 1, 1.5, 2, and 3 years to detect signs of teething problems (Annex 9), pathological changes, or occlusion peculiarities. These requirements apply to healthy children. For children with chronic diseases or developmental delays there are neither regulations related to the frequency of examination by a paediatric dentist / orthodontist nor recommendations for oral health care. According to the American Dental Association, the American Academy of Paediatrics and WHO dental health is a key indicator of overall health, well-being and quality of life. Dental examinations should be performed monthly during the first year of life from the moment the child has its first tooth and then subsequently at 18, 24 and 30 months of age[41].

Universal screening for anaemia must be provided for all children in accordance with the MOH order No. 709 as of 02.11.2015[42]. Screening is at a high level in all facilities (in the Kremenchuk baby home it was slightly lower, where 5 % of children were not examined). At the same time medical records from the baby homes often indicated that children were diagnosed with anaemia even though they did not meet the criteria and haemoglobin levels for this diagnosis in line with the MOH order. The frequency of anaemia screening was often illogical; children with normal haemoglobin levels could be examined up to 12 times a year, whereas another child with haemoglobin levels below normal might only be examined once per year. There are also reservations about the effectiveness of treatment using iron supplements and concomitant supplementation therapy.

38 / URL: http://search.ligazakon.ua/l_doc2.nsf/link1/NT1868.html, http://old.moz.gov.ua/ua/print/dn_20151026_2.html.

39 / MOH order as of 8.12.2015 No. 827 "On approval and implementation of medical and technological documents for standardization of the health care at refraction and accommodation disorders" which approved the Unified clinical protocol of primary, secondary (specialised), tertiary (highly specialised) care for refraction and accommodation disorders. URL: http://old.moz.gov.ua/ua/portal/dn_20151208_0827.html.

40 / URL: https://zakon.rada.gov.ua/rada/show/v0149282-08.

41 / Bright Futures/AAP. URL: https://brightfutures.aap.org/Pages/default.aspx.

42 / The MOH order as of 02.11.2015 No.709 "On approval and implementation of medical and technological documents for standardisation of health care for iron deficiency anaemia": URL: https://ips.ligazakon.net/document/view/moz25195?an=18ed=2015_11_02.

NEEDS FOR PAEDIATRIC PALLIATIVE CARE SERVICES

Palliative care is provided to a patient from the moment the incurable disease is diagnosed. It can improve the quality of life of a terminally ill patient and help alleviate their suffering. The Pilot assessed the needs of children in baby homes for paediatric palliative care using the criteria based on:

Appendix A – the criteria for identifying a paediatric patient in need of palliative care (the MOH draft Order[43] "On improving the organisation of palliative care in Ukraine", developed to replace the current MOH Order No. 41 as of 21.01.2013 "On the organisation of palliative care in Ukraine"); and

Appendix B – the list of conditions associated with diseases that can limit the life of a child (used additionally during the assessment, as the abovementioned criteria are not approved by the MOH)[44].

The largest number of children in need of such services, according to Appendix A, are in the Kryvyi Rih and Kherson baby homes, and according to Appendix B, in the Kherson and Dnipropetrovsk ones **(Table 3)**. As a rule, paediatric palliative care services were needed for children with severe congenital and neurological pathology, and infections (AIDS, meningitis).

Table 3. Percentage of children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions in need of paediatric palliative care according to Appendixes A and B

	Criteria for assessing the needs for paediatric palliative care			
	Appendix A (criteria)		Appendix B (list of conditions)	
	persons	%	*persons*	%
Dnipro (n = 110)	8	7	18	16
Kryvyi Rih (n = 75)	26	35	8	11
Kamianske (n = 50)	5	10	6	12
Kremenchuk (n = 106)	7	7	7	7
Kherson (n = 65)	13	20	18	28

43 / Within the implementation period of the Pilot, the draft Order was publicly discussed. At the time of preparing this report, the MOH Order "On improving the organisation of palliative care in Ukraine" was approved (No. 1308 as of 04.06.2020): https://zakon.rada.gov.ua/laws/show/z0609-20#Text. When approving the order, the criteria of Appendix A were partially changed.

44 / ACT/RCPCH. A guide to the development of children's palliative care services. 1 ed. Bristol and London: ACT/RCPCH; 1997.

Hain et al.: Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. BMC Palliative Care 2013. URL: http://www.biomedcentral.com/1472-684X/12/43.

ASSESSMENT OF CHILDREN'S PSYCHOMOTOR DEVELOPMENT AND NEEDS FOR REHABILITATION SERVICES

Timely assessment of children for developmental delays and autism spectrum disorders is necessary to initiate rehabilitation and / or include a child in early intervention services.

To improve early detection of children with developmental delays and behavioural problems the American Academy of Paediatrics recommends that all infants and young children should be screened for developmental delays. Development assessments using standardised screening tools should be performed for all children aged 9, 18 and 24 (or 30) months. Children should be screened for autism spectrum disorders at 18 and 24 months of age. Today none of the 38 screening tests and scales for children developed by the Centres for Disease Control and Prevention (CDC, USA) have been translated or approved in Ukraine.

Developmental disorders can be identified using the MOH Order No. 149 as of 20.03.2008, but it is not widely used by paediatricians, as in Ukraine there is no undergraduate and postgraduate education in "developmental paediatrics" and no monitoring of the quality of care for children. Besides, the Order envisages assessments to measure the development of healthy children up to the age of 3 years. All children from the perinatal risk group (premature babies and children with perinatal disorders) are subject to a mandatory developmental assessment, which is why three-year follow-up programmes are established for newborns after discharge from hospital by many countries in order to monitor the child's development.

Within the framework of the Pilot, children were assessed using the MOH Order No. 149 as of 20.03.2008) and the Red Flags tool[45]. Experts assessed 5 areas of development:

- **Cognitive development** - problem-solving skills, learning, short-term and long-term memory. Language and its comprehension (expressive and receptive language) - the ability to communicate and be understood by others, conversation skills, the ability to understand words, commands, phrases, and passages.

- **Gross and fine motor skills** – using large muscles of the neck, arms, legs, back, and torso for effective movement, using hands, fingers, and wrists to perform complex tasks: eating from utensils, drawing, writing, and using tools such as scissors, keyboards, etc.

- **Socio-emotional development and mental health** – a sense of wellbeing and self-respect (for example, a positive attitude to life with a more realistic understanding of one's own strengths and weaknesses), treatment of siblings, parents, friends and close relatives with joy and love, compassion for others, learning to cope with complex emotions such as anger, frustration, and sadness.

- **Adaptive development** – skills necessary for hygiene, dressing, housekeeping, cooking, cleaning, etc.

45 / URL: http://rvua.com.ua/media/136/9b4bed4e2b3c62b08fecf4b0cac6fb20.pdf.

According to the Pilot's assessment, almost all children in the five baby homes had developmental delays: more than 90 % in the Kryvyi Rih, Kremenchuk, and Kherson baby homes, 86 % in the Kamianske baby home, and 77 % in the Dnipro baby home **(Fig. 24)**. The analysis of children's somatic and neurological health helped to distinguish between those with developmental delays and health disorders and those whose developmental delays were solely because of deprivation.

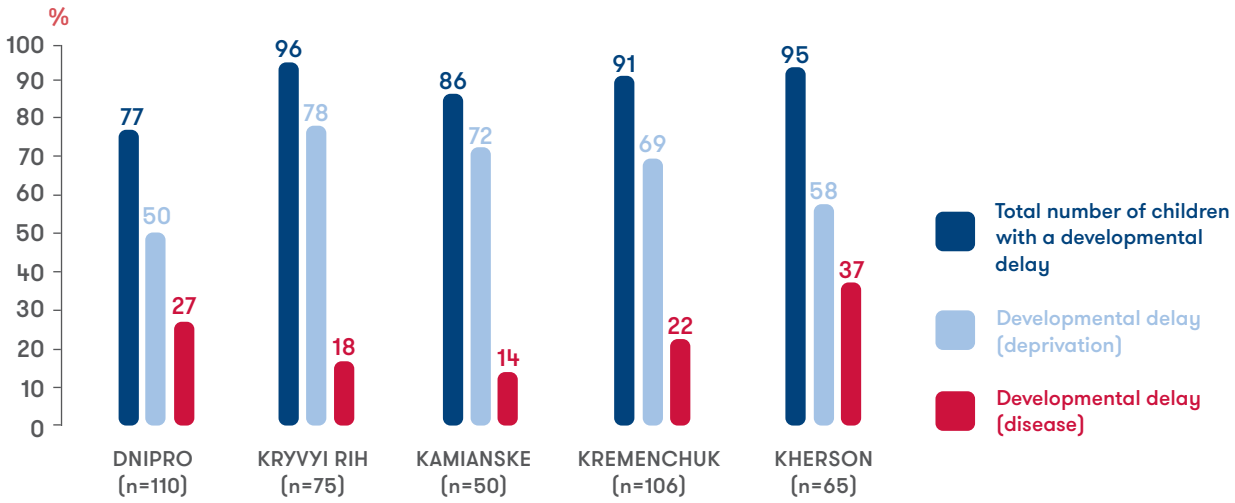


Figure 24. Types of developmental delays in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, depending on somatic / neurological pathology, %

Assessing the incidence of developmental delays by type provides an opportunity to plan the services required for rehabilitation of children in the baby homes affected by deprivation. According to the analysis, developmental delays in children are commonly linked to negative environmental impacts: socio-emotional development, communication, and cognitive development **(Fig. 25)**.

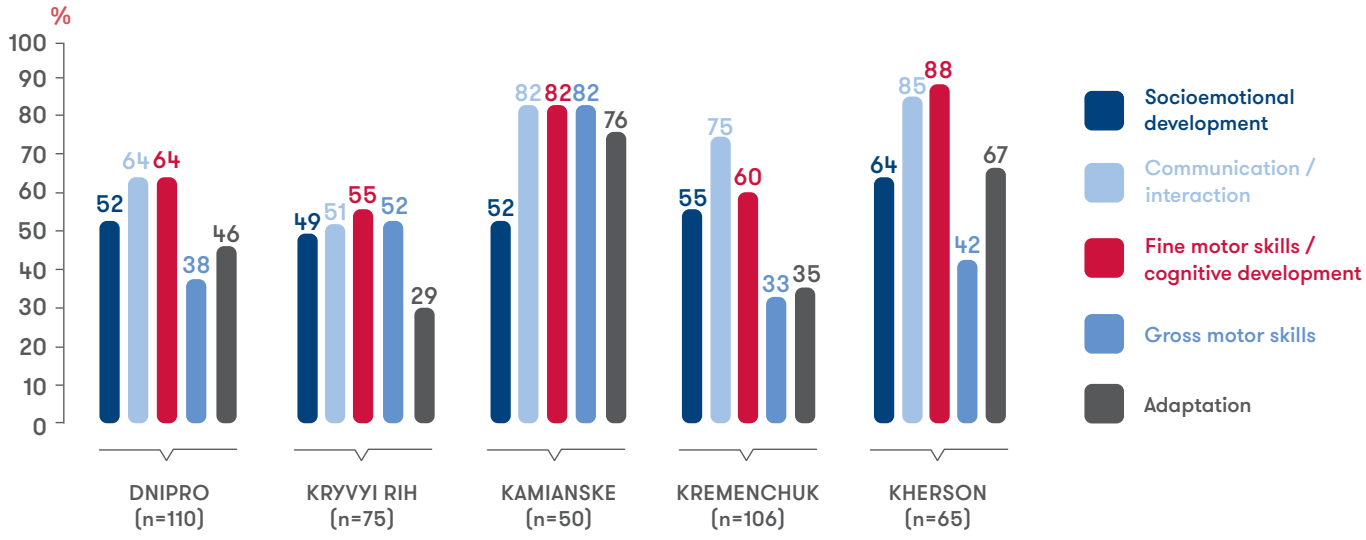


Figure 25. Types of developmental delays in children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, by key areas of development, %

There is a trend of greater developmental delays as a child grows indicating that the environment in which the child grows up in is unfavourable. A high percentage of children with a cognitive impairment may show signs of progressively irreversible changes in brain function due to deprivation. Deprivation especially impacts socio-emotional and communication developments. Routine screening for autism spectrum disorders regulated by the MOH Order No. 341 as of 15.06.2015 is not provided in any baby home despite delays in these developmental areas.

Identifying developmental disorders in children helped to empirically determine the services young children in baby homes need from specialists (physical therapist, occupational therapist, speech and language therapist, pedagogue, paediatric psychologist, etc.). Many children require services of three or more specialists at the same time **(Table 4)**.

Table 4. Needs of baby homes children for rehabilitation services

	Dnipro (n=110)		Kryvyi Rih (n=73)		Kamianske (n=50)		Kremenchuk (n=106)		Kherson (n=65)	
	persons	%	*persons*	%	*persons*	%	*persons*	%	*persons*	%
Number of children who need the services of various rehabilitation specialists										
Physical therapist	49	58	51	70	37	74	68	64	49	75
Occupational therapist	40	47	25	34	30	60	59	56	34	52
Speech and language therapist	66	78	69	95	43	86	77	73	57	88
Pedagogue	85	100	73	100	45	90	82	77	52	80
Paediatric psychologist	12	14	22	30	30	60	67	63	39	60
Frequency of children's need for the services of different rehabilitation specialists at the same time										
1 specialist	2	2	2	3	5	10	5	5	4	6
2 specialists	27	25	4	5	3	6	14	13	6	9
3 specialists	65	59	34	47	9	18	11	10	16	25
4 specialists	14	13	17	23	16	32	10	9	12	18
5 specialists	-	-	16	22	17	34	48	45	22	34

A common trend across all baby homes in terms of rehabilitation is the application of non-evidence-based medical techniques (ultraviolet irradiation, massage, electrophoresis, d'Aarsonval, earth wax, paraffin, electrically induced sleep) and medicines (Cognum, Cinnarizinum, Cortexinum, Agvantar, Noobut, Piracetam, Aminalon, Eleutherococcus, Valeriana, Neuroxon).

IT SHOULD BE NOTED THAT THE MAJORITY OF CHILDREN (86 %) IN THE FIVE BABY HOMES CAN RECEIVE OUTPATIENT CARE;

only 57 children (14 %) may need respite services, and inpatient paediatric palliative care due to complex diseases.

PARENTS OF CHILDREN, FAMILY AND ENVIRONMENTAL FACTORS

Raising a child in a biological family has priority over all alternative care, especially institutions. At the same time, it is necessary to understand the extent to which the families of children in baby homes can take care of a child and what problems and needs these families have. This information is important for planning the social services system, early detection of families in difficult life circumstances, prevention of separation and further institutionalisation of children, and ensuring the reintegration of children from the baby homes.

VISITS TO FAMILIES

Within the framework of the assessment, the plan was to visit all families of children whose parents were not restricted in their rights, as well as families where children were taken from their parents by a court decision without deprivation of parental rights. In total, the plan was to visit 158 families of the 190 children from the baby homes of Dnipropetrovsk, Poltava, and Kherson regions. We managed to reach a little more than half: 83 families of 105 children **(Table 5)**. In cases where it was not possible to visit the family, this was mainly because the baby homes had outdated contact details, and the available data on parents in the children's personal files were no longer relevant. The second reason why families were not included in the assessment was the refusal of legal representatives to participate. Seven families lived outside the assessment area, and in three families the child's legal representative was in prison.

Table 5. Characteristics of the sample of assessed families of children from the Dnipropetrovsk, Poltava and Kherson regions' baby homes

	Dnipro		Kryvyi Rih		Kamianske		Kremenchuk		Kherson	
	families	*children*	*families*	*children*	*families*	*children*	*families*	*children*	*families*	*children*
Planned number	50	54	12	15	27	32	42	55	27	34
Reached number	26	29	7	10	14	19	22	29	14	18
Reasons of failure:										
Lack of up-to-date contact details of legal representatives	20	21	2	2	7	7	9	12	11	13
Unwillingness of the child's legal representative to be interviewed (avoiding a meeting or direct refusal to talk)	3	3	2	2	3	3	6	7	1	1
Respondent lives outside the region / country	1	1	1	1	-	-	5	7	-	-
Respondent is in prison	-	-	-	-	3	3	-	-	-	-
Legal representative is in a rehabilitation centre	-	-	-	-	-	-	-	-	1	2

CHARACTERISTICS OF HOUSEHOLDS

Many families of children from the Kryvyi Rih and Kamianske baby homes lived in the same locality as the facilities (6 out of 7 families and 9 out of 14 families, respectively) **(Fig. 26)**. The opposite situation is in the Kremenchuk and Dnipro baby homes, where significantly more families lived in other localities (18 out of 22 families and 18 out of 26 families, respectively), mainly in rural areas.

All families were mostly represented by biological mothers, biological parents who lived with a permanent partner unrelated to the child, or together with other relatives **(Fig. 27)**. Families with both parents were more common among the children in the Dnipro and Kherson baby homes. For a third of the families with children in the Dnipro, Kryvyi Rih and Kremenchuk baby homes, there were other minors living in the households – the child's biological siblings or the biological mother / father's partner's children **(Fig. 28)**. Half of the assessed families with children from the Kamianske baby home and all the families with children from the Kherson baby home had minor children living in the households. Large households with three or more adults and minor children living together more often occurred in the Dnipro and Kremenchuk baby homes (nearly a third of families) **(Fig. 29)**. The sample of families of children from the Kryvyi Rih baby home differs from others in that almost half of the assessed families (3 out of 7) consisted of only one adult.

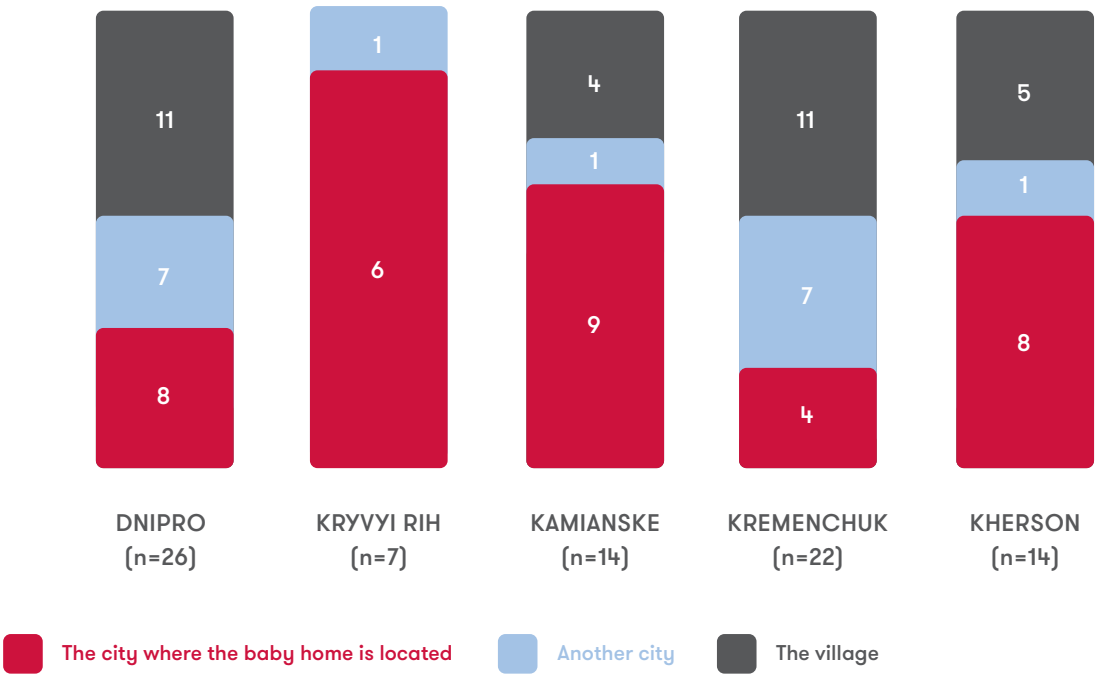


Figure 26. Type of locality where the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions lived, *families*

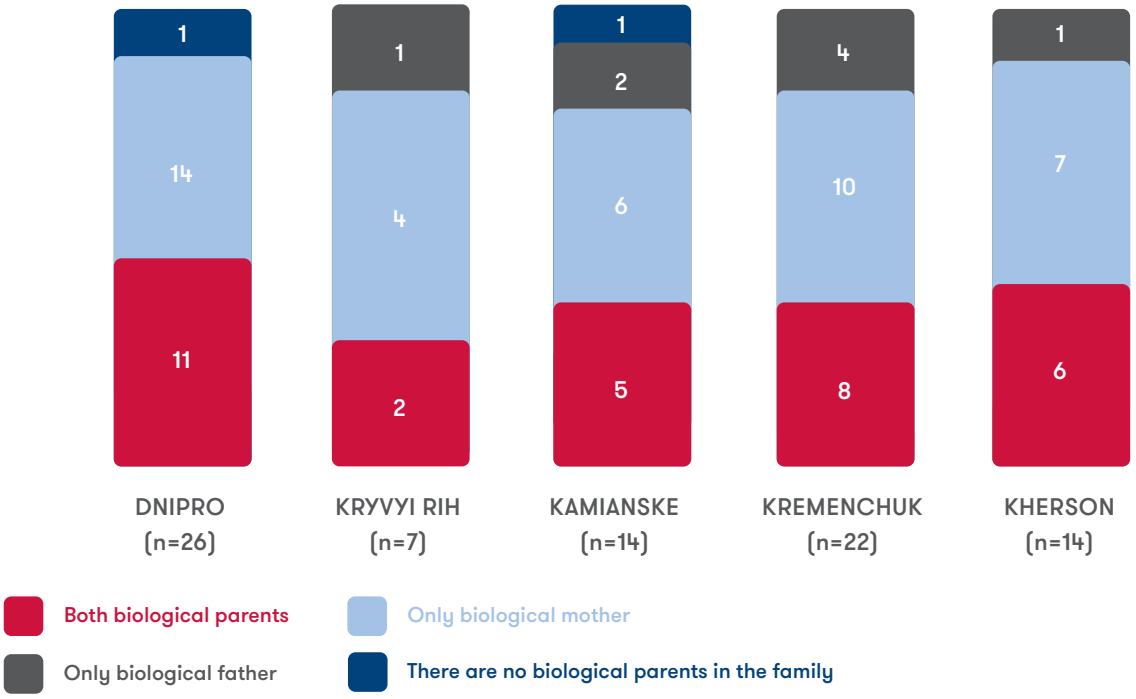


Figure 27. Presence of biological parents in the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

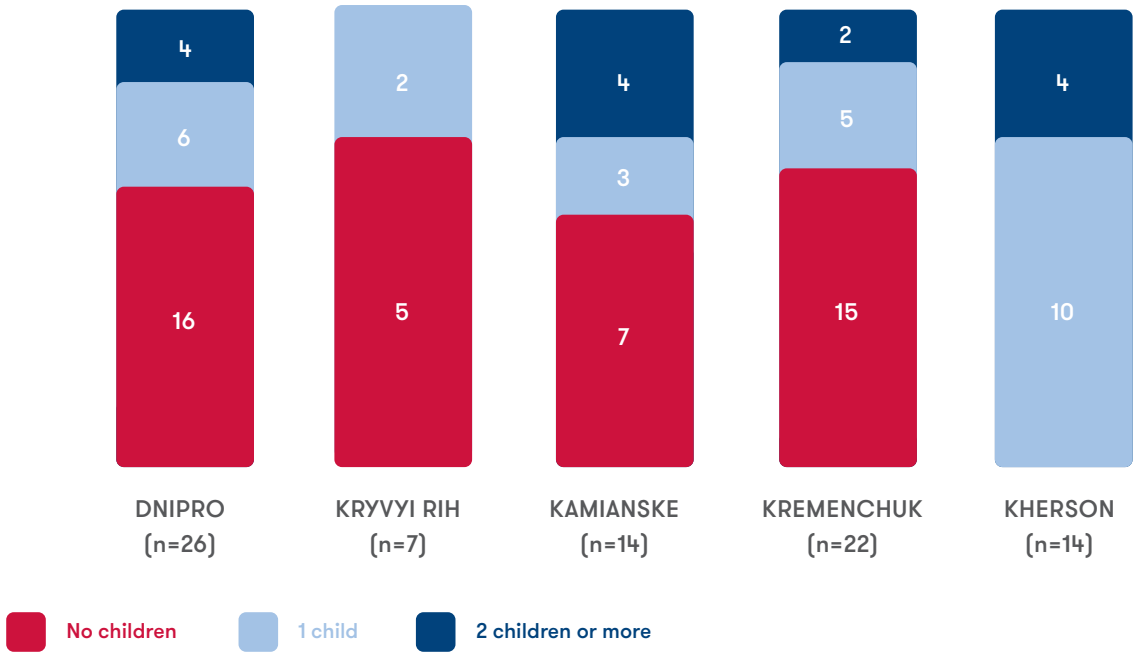


Figure 28. Number of minor children – siblings of the child in the baby home – in the household structure of assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

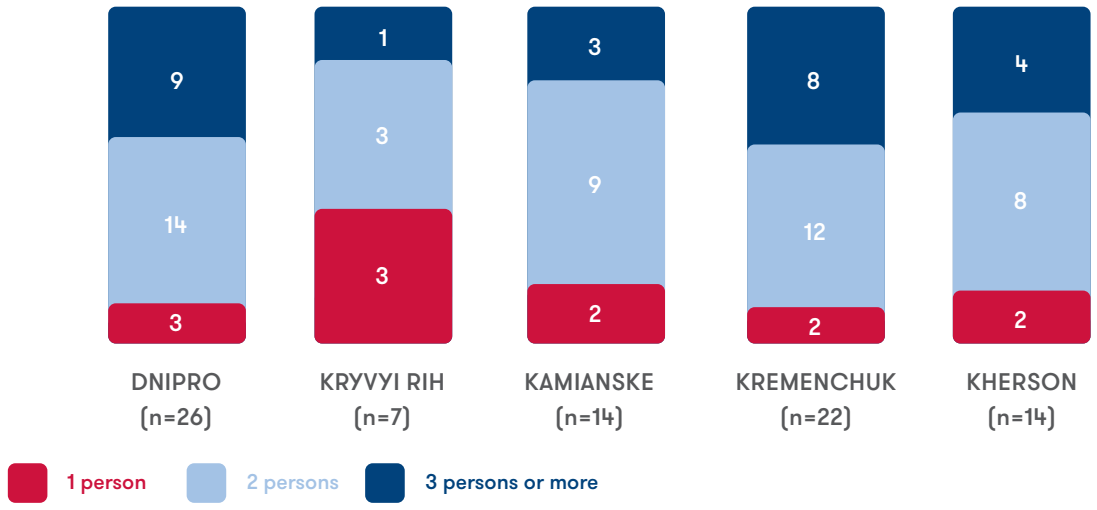


Figure 29. Number of adults in the household structure of assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

CHARACTERISTICS OF HOUSING

According to the children's files, a lack of acceptable living conditions is one of the main reasons for placing a child in a facility. Visits to families have shown that this problem is critical, especially among the families of children in the Dnipro, Kryvyi Rih, and Kherson baby homes. The majority of families of children in these facilities did not have their own housing so lived in the houses or apartments of relatives, friends or partners, dormitories, social housing, or rented housing (Fig. 30). Among the rented housing, renting of rooms was more common than the renting of apartments or houses. Only families of children in the Dnipro baby home lived in social housing or temporary accommodation, such as mother and child centres; this can be explained by the greater availability of such services in the region capital.

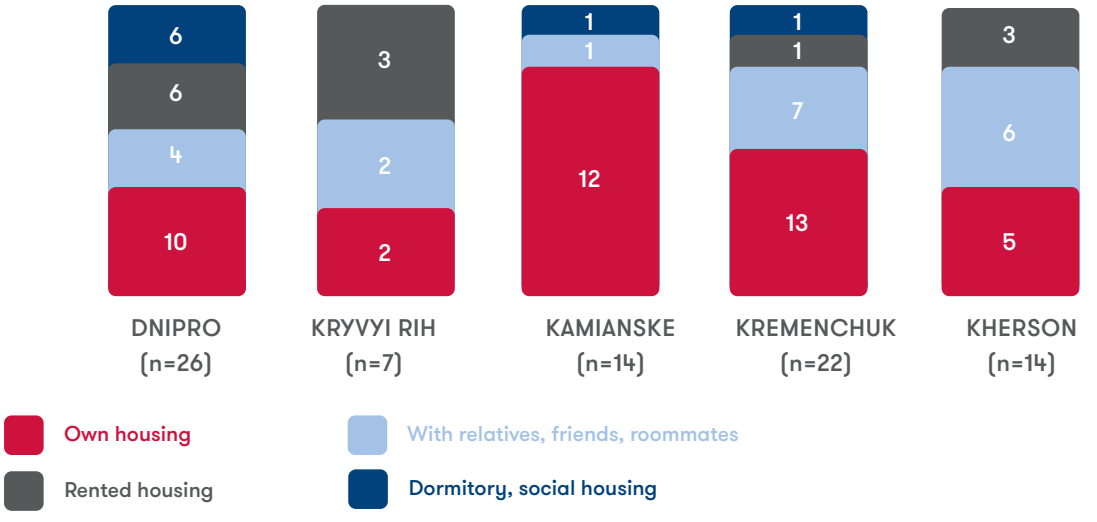


Figure 30. Type of housing where assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions lived, *families*

During the family assessments, not all places of residence were visited. It was possible to inspect the housing of almost all families of children from the Kamianske and Kherson baby homes (13 out of 14 and 11 out of 14 families, respectively). For families with children in the other facilities, experts gained access to half of the houses. Families living in rented accommodation, dormitories, or relatives' homes were less willing to provide consent for a visit. In general, nearly half of the inspected premises were inappropriate for living with a child. The families of children from the Kamianske and Kherson baby homes had a better situation, with nearly two-thirds of the inspected dwellings considered appropriate for children. The most common problem was poor sanitary conditions, and, in some cases, the dwelling was damaged, required major repairs, looked dangerous, or there were no facilities for cooking and storing food.

> "The child's biological mother does not have her own home. After the birth of the child, she lived with her female friend for some time, then she was asked to leave. She was taken to the hospital with the child, from there the child was taken to the baby home."
>
> Description of the situation by a social work specialist based on the results of a visit to the mother of a child from the Dnipro baby home

> "The biological mother lives in an old house provided by relatives. Nobody lived in this house for a long time, there is no water, gas, heating, stove, or refrigerator, and the windows and doors need to be replaced. She does not receive any benefits from the state and has no job. The biological father lives separately and has another family, they are divorced."
>
> Description of the situation by a social work specialist based on the results of a visit to the parents of a child from the Kryvyi Rih baby home

> "The apartment is dirty, with old dilapidated furniture. The refrigerator has no door. One window is missing. The mother smokes in the apartment, she can smoke right in bed. In the past, the family was helped by volunteers who came to tidy up, but over time it became dirty again, so they stopped helping. The woman has no addictions, but she is not able to keep her house clean."
>
> Description of the situation by a social work specialist based on the results of a visit to the biological mother of a child from the Kamianske baby home

EMPLOYMENT AND FINANCIAL SITUATION

All the visited families had a difficult financial situation and faced the problem of unemployment. Thus, it was common for only one adult in a large household to be working (Fig. 31). Among the respondents, there were families where none of the household members had an income during the last year and they completely depended on social welfare or help from friends or relatives (4 families from the sample of the Dnipro baby home, 2 from the Kryvyi Rih baby home, 1 from the Kamianske baby home, 3 from the Kremenchuk baby home). Even among rural families, not all of them had a plot of land where they could grow fruit and vegetables and in this way to reduce the burden of poverty. Some families had a plot but did not use it or do any gardening. For example, among rural families of children from the Dnipro baby home, only 6 out of 11 families had a garden and took care of it.

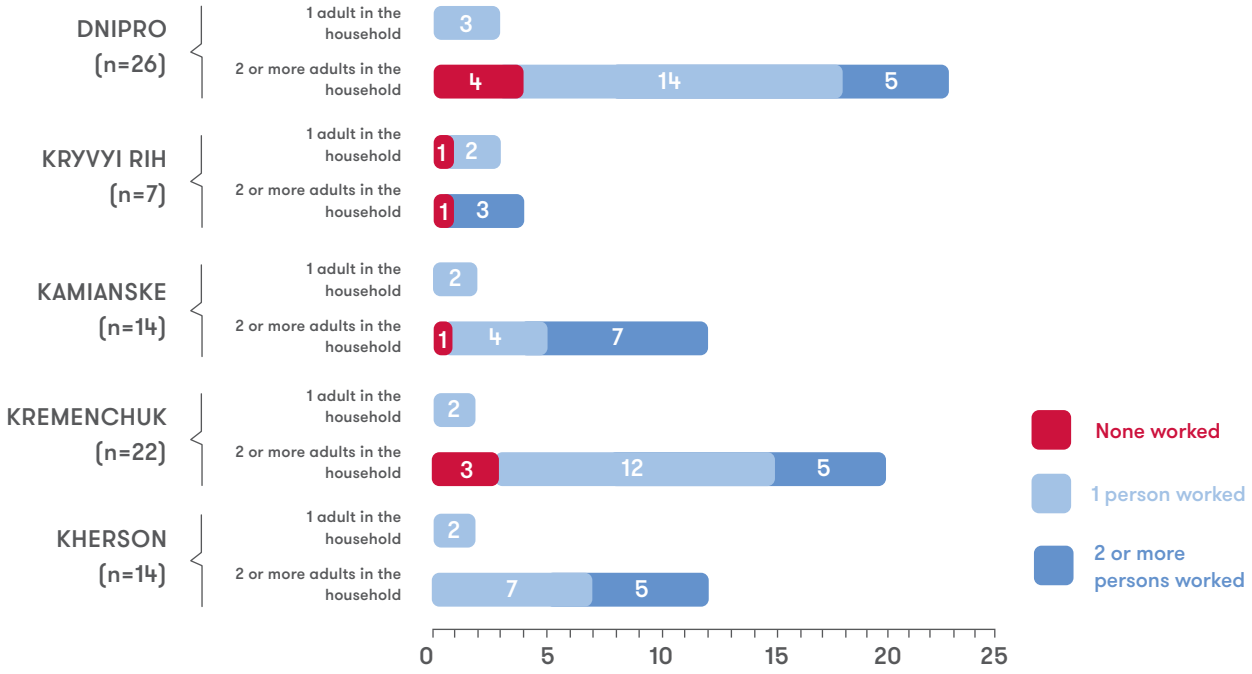


Figure 31. Number of household members who worked and earned in the last 12 months, based on the number of adult members of the household, in the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

Even in the absence of loans and timely payment of utilities, families still had debts so borrowed money from relatives, friends, or neighbours. In the sample of families of children from the Kryvyi Rih baby home, only one family out of six reported being debt-free (Fig. 32). Among the families of children from the Dnipro, Kamianske, and Kremenchuk baby homes, between a half and two-thirds of the assessed families were in debt. In cases where families took out several loans and did not repay them, the amount of debt exceeded hundreds of thousands of hryvnias. This situation was observed in families who used alcohol or drugs and did not fully understand how they were supposed to pay the loans off.

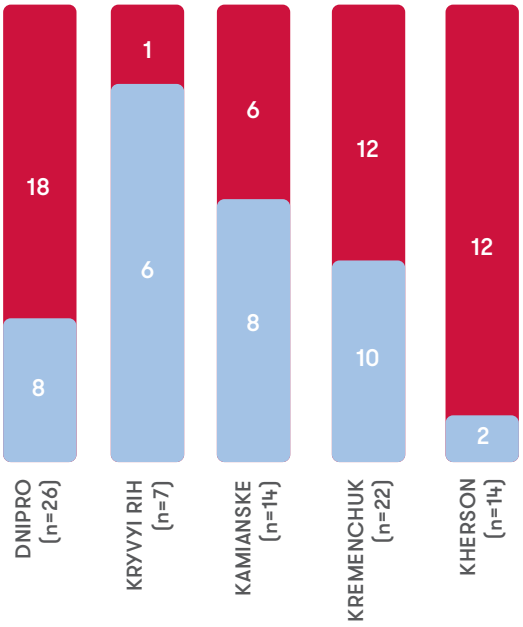


Figure 32. Presence of debts in the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

Have no debts

Have debts

Social welfare is one of the main sources of income for many families, especially for families of children from the Kamianske, Dnipro, and Kherson baby homes **(Table 6)**. Common social benefits included old-age and disability pensions, childbirth allowances, and childcare allowances for single mothers. Parents who did not receive social welfare were often unaware of the benefits and allowances available or did not know how to apply for them.

Table 6. Types of social benefits received during the last 6 months by the assessed families of children from the Dnipropetrovsk, Poltava and Kherson regions' baby homes, *families*

	Dnipro (n=26)	Kryvyi Rih (n=7)	Kamianske (n=14)	Kremenchuk (n=22)	Kherson (n=14)
Received social benefits, including	**17**	**3**	**13**	**13**	**10**
Pregnancy and childbirth allowance	1	2	4	5	2
Childbirth allowance Childcare allowance for single mothers	6	2	2	2	5
Allowance for a child whose breadwinner died	5	1	2	2	2
	-	-	1	-	1
Allowance for families with many children	1	-	2	-	-
Allowance for low-income families	2	-	1	2	2
Old-age pension	6	-	1	4	2
Disability pension	7	1	3	1	1
Unemployment benefits	-	-	1	1	1
Subsidies for utilities	-	-	1	2	-
Scholarship	-	-	-	1	-

Some families reported on receiving donations (mainly food and clothing for children) from public or religious organisations in the last six months: 6 out of 26 families of children from the Dnipro baby home, 3 out of 7 families of children from the Kryvyi Rih baby home, 2 out of 14 families of children from the Kamianske baby home and 3 in 14 families of children from the Kherson baby home. It should be noted that according to the results of the assessment, despite the difficult financial situation and dependence on social welfare, there were almost no families who believed that this situation influenced to refuse caring for a child and was the reason for placement in a facility. Only a few parents stated that their financial situation did not allow them to care for their child.

PARENT/GUARDIAN HEALTH STATUS AND BEHAVIOURAL RISK FACTORS

Visits to the families revealed that some of the parents / guardians could not take care of their children because of their health status. In general, between one-third and a half of the families of children from the baby homes of Dnipropetrovsk, Poltava, and Kherson regions had adult household members with physical or mental disabilities, chronic illness, or an injury **(Fig. 33)**.

There were cases when one or both parents / guardians had mental disorders (mainly mental retardation) and were not fully aware of the problems. In two families from the Kamianske baby home sample (one family with a single mother, the other family with a single father), the children were placed in the facility because their parents contracted tuberculosis and were hospitalised for a long period. Families facing the problem of tuberculosis said that they had to submit a certificate to the service on children's affairs following successful completion of treatment and only then could they take their children back; contradicting the WHO principles on the implementation of outpatient models of tuberculosis treatment and the prevention of long-term family separation due to tuberculosis[46]. After two weeks of successful treatment, a person with active tuberculosis does not produce bacteria and does not pose a threat of infection to others.

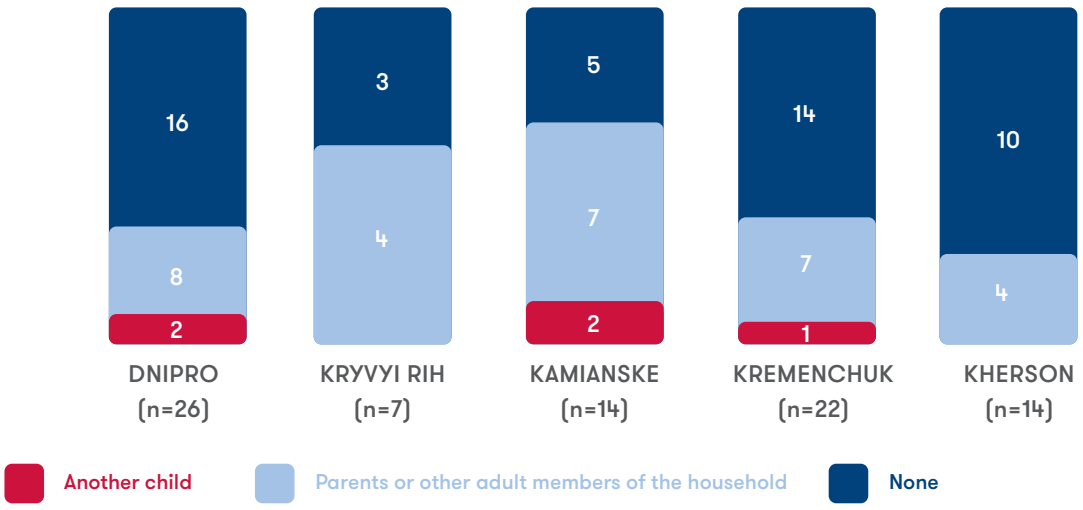


Figure 33. Presence of a physical / mental disability, chronic illness or injury in a household member (s) among the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

46 / WHO (2018). Ambulatory care and infectiousness in tuberculosis.
URL: http://www.euro.who.int/__data/assets/pdf_file/0004/388039/ambulatory-care-eng.pdf?ua=1.

> “The biological mother of the child is 25 years old and she has a disability due to mental retardation. The woman grew up in an institution. According to the personnel of the Service on Children's Affairs, her disease is periodically exacerbated so she is treated in a mental hospital. In total, the woman has three children. She placed her eldest daughter in a baby home following the advice of the Service on Children's Affairs at the age of seven months, as the girl needed an expensive surgery at a time and it could be done at the expense of the government. The mother brought her second child to the Service herself: “Take it because I will lose it.” The woman also handed over the third child to the Service immediately after birth. She now lives with a partner who is the father of two younger children. The partner periodically beats the woman. He also takes loans using her ID.”
>
> Description of the situation by a social work specialist based on the results of a visit to the parents of a child from the Kamianske baby home

> “The children arrived in the baby home when their father was in the hospital and the mother went to nurse him after the surgery. The grandmother looked after the children; she went to work in the morning before the mother returned home from the hospital. For a while the children were alone at home, crying and going outside. This situation was reported by neighbours to the Service on Children's Affairs. Now the parents have seasonal jobs, they want to get official employment. The family wants to take the children back as soon as possible, they are afraid that children may be adopted.”
>
> Description of the situation by a specialist based on the results of a visit to the parents of children from the Kherson baby home

Alcohol abuse was the dominant behavioural factor, which in some cases was combined with violence against other members of the household including children. Only one family of a child from the Kryvyi Rih baby home showed signs of substance use (the mother), according to a social worker who conducted family visits. Interviews with family members showed that more families than was noted in the personal files of children, or reported by respondents themselves, might have alcohol abuse problems. For example, among the families of children from the Dnipro baby home, 8 out of 26 families in the sample were identified as families where alcohol abuse was the reason for the separation of the child. Many families said that such a problem still exists, however, according to the social work specialist, 11 families had at least one household member who abused alcohol **(Fig. 34)**. According to social experts, a third of families in the sample from five baby homes had household members who abused alcohol.

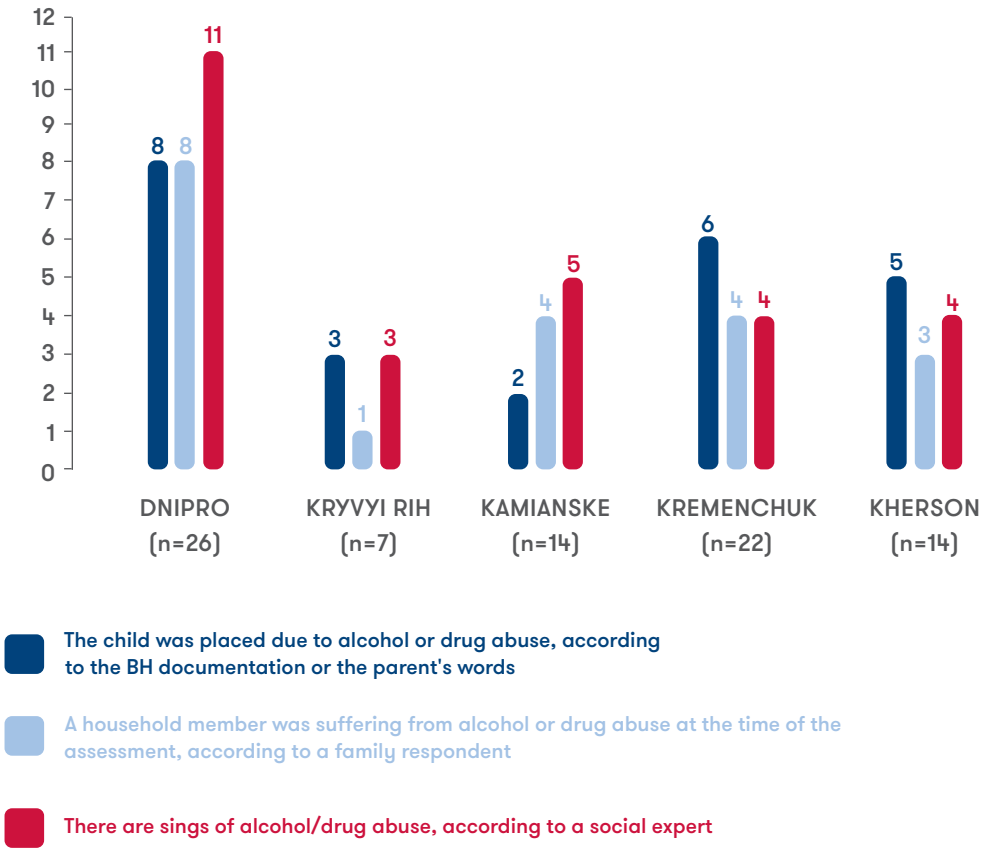


Figure 34. Number of families where substance abuse by parents was the official reason for placing children in the facilities, and the number of families where this factor was observed at the time of the assessment, among the assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

> “
>
> The family did not have the right conditions to live with the child. The mother and child were admitted to the hospital for a month and a half until the living conditions improved. Social workers helped with paperwork for the child. The community helped with the housing rent. Conditions improved and the child lived with the parents for about a month. After they received the first allowance, they started drinking. One day, the drunk mother stabbed the father who was holding the child in his arms at the time. The child fell and fractured its skull, concussed. The mother did not call anyone for help. The father was able to call the landlord and he called an ambulance. In the hospital, the mother abandoned the child and later the child was placed in a facility.
>
> ”
>
> Description of the situation by a social work specialist based on the results of a visit to the parents of a child from the Dnipro baby home

> “The father tried to cope with alcohol abuse but failed. The mother periodically leaves the family, being on the booze. As it turned out, the girl who remained in the family did not live at home for several days because her father had evicted her. She was staying with a neighbour who is the deputy headmistress of a local school. The Service on Children's Affairs plans to prepare documents for the deprivation of parental rights. According to the representative of the Service, this was not done before, as there was no facility to place the children.”
>
> Description of the situation by a social work specialist based on the results of a visit to the parents of children from the Kamianske baby home

> “The biological mother was annoyed, she said, ‘Why did they take our children? Others drink even more, they do not look after children at all, and nothing. Nobody does anything. My mother drank, my grandmother drank. No problem! I somehow grew up.”
>
> Description of the situation by a specialist based on the results of a visit to the parents of a child from the Kremenchuk baby home

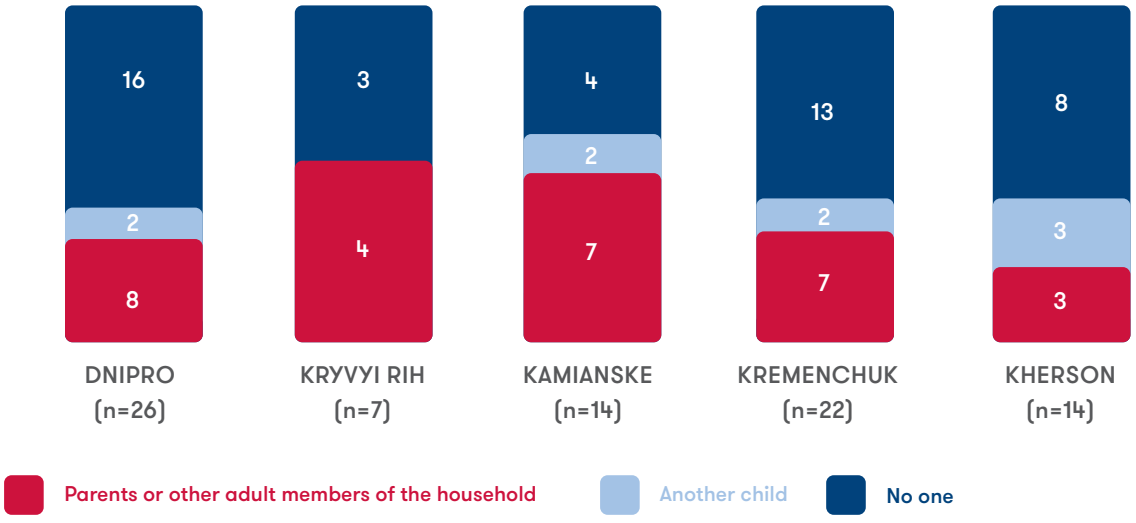
> “The child’s father still has problems with alcohol, he abuses the mother. He also has mental retardation. The child’s grandmother proposed to take the child and daughter to another region. However, under pressure from the father, the mother refused. The father has three more children, all of them deprived of his care.”
>
> Description of the situation by a specialist based on the results of a visit to the parents of a child from the Kherson baby home

The results of the assessment show that many parents of children from the baby homes themselves had experience of living in an institution. Thus, in the sample of families of children from the Kryvyi Rih and Kamianske baby homes, half of the families had adult household members with such experience, compared to a third of families of children from the Dnipro and Kremenchuk baby homes **(Fig. 35)**. There is evidence that children who grew up in facilities find it difficult to set their own life goals and do not always acquire all the necessary skills for social integration; the absence of an important person in the child’s life and lack of support can negatively affect the development of an emotional connection[47]. Some members of the household who had experience of living in a facility, and placed their child there, saw this as the only choice, especially in the absence of housing or when the child needed expensive health care. Sometimes members of a household with past experience of living in a such facility expressed a “consumer” mentality: that a child would be better off in a state-run institution that can provide for the basic needs rather than an under-resourced family.

47 / Browne K, Hamilton-Giachritsis C, Johnson R, Ostergren M. Overuse of institutional care for children in Europe. *Child-Care Health and Development*. 2006; 32(4):502.

> “
>
> O. lived in a children’s home from birth to 18. She had ten siblings, her parents abused alcohol and died. She also had problems with alcohol, now she has not been drinking for a second year. She is sorry that her childhood was spent in an institution. Now she lives with her husband and second child with her husband’s relatives. At first glance, she worried about the child. However, she brought the children to the Service on Children's Affairs several times herself and left them there
>
> ”
>
> Description of the situation by a social work specialist based on the results of a visit to the parents of a child from the Dnipro baby home

> “
>
> The biological parents are 20 years old and are married. According to a specialist of the Service on Children's Affairs, while the woman’s mother worked in another country, the couple sold their house in Kamianske and moved to the village. As the conditions were bad, the woman’s mother advised her to place the child in a facility. Now the couple has a bad relationship with the wife’s mother, they accuse her of making them abandon the child. Instead, the child’s grandmother accuses her daughter’s husband of selling the house and losing money. The woman’s sister was brought up in this baby home and her mother doesn’t see anything wrong with it: “The state keeps it – it should be used.
>
> ”
>
> Description of the situation by a social work specialist based on the results of a visit to the mother of a child from the Kamianske baby home



* Among the families of the children of the Kamianske baby home, one family did not know whether their household members had such experience.

Figure 35. Experience of living in an institution among household members of assessed families of children from the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *families*

REASONS FOR PLACING CHILDREN IN FACILITIES

In about half of the cases, the reasons parents gave for placing children in facilities matched the reasons indicated in the children's files. The official documents indicated that the most common reasons were lack of housing and poor living conditions, lack of support (single mothers), alcohol/drug abuse by one or both parents or other household members, physical illness of the child, violence, and abuse of the child. As a rule, parents talked about several reasons, not one. Families who faced physical illness or disability of the child or other members of the household also spoke of poverty, no housing or poor living conditions, and unemployment. Thus, in the Dnipro baby home, 10 files stated that the child was placed in a facility because of poverty and a lack of proper living conditions, although during the visits the parents said that they placed the child because of his / her physical illness or due to the physical / mental disability of parents; the lack of resources was a consequence of this. In the Kamianske baby home, 3 out of 14 families reported that their children were placed in a baby home due to domestic violence, but this was not reflected in personal files where instead the official reason was poverty. If there were cases of alcohol abuse in the family, household members also reported violence against children or other family members and neglect of children as a result of alcohol problems.

AWARENESS OF CHILDREN'S HEALTH

If we compare the parents' answers about children's illnesses to the available medical records, we see a difference. Parents who admitted that the child was ill were not always fully informed of his / her condition. In one of the interviews, the biological mother of a child from the Kryvyi Rih baby home said that the child had HIV, whereas the child's medical records only mentioned a developmental delay. Another mother of a child from the Kryvyi Rih baby home said her child often suffered from acute respiratory viral infections, and in general he / she was healthy, while the medical records included several serious diagnoses, from mental illness to tumours. For many children who were considered healthy by their parents, medical records indicated neurological and / or cardiovascular diseases and developmental delays. It cannot be said that all parents were wrong about the health of their children as, according to expert opinion, baby home medical records often contained "myth" diagnosis.

In general, awareness of a child's health status depended on how often the child was visited; the more often the parents visited, the better informed they were about their child's diagnosis.

SOCIAL INCLUSION AND ATTITUDE IN THE COMMUNITY

Families assessed the level of their social capital (relations with neighbours and the community) differently. In general, between half (Dnipro, Kamianske) and two-thirds of families (Kremenchuk) believed that, if needed, they could count on the help of neighbours. Usually, families who had problems with alcohol, drugs, or mental disabilities were less likely to rate their relationships with neighbours highly. For families where poverty and poor living conditions were the main problems, they tended to rely more on neighbours. In Dnipro and Kamianske, only a third of families felt that people in the community treated them well. Families who were dissatisfied with the attitude of the community also negatively assessed the level of comfort they experienced living in the community.

VISITING CHILDREN IN FACILITIES

Many visited families reported that they regularly (monthly or more frequently) visited their children in the baby home (17 out of 26 families in the Dnipro baby home, 5 out of 7 families in the Kryvyi Rih baby home, 10 out of 14 families in the Kamianske baby home, 11 out of 22 families in the Kremenchuk baby home and 7 of 14 families in the Kherson baby home). At the same time, data from the facilities' visiting logs indicate that such figures may be inflated. Parents often provided socially acceptable responses by saying they often visited their children, although in reality they visited them less often or not at all.

According to families, the main barriers to visiting children included their schedule or format of work (seasonal and far away from home), the inconvenient location of the facility (far from home, poor transportation), needing to care for other household members, and health problems. The problem of the facility's location was more frequently mentioned in the sample of families of children from the Dnipro baby home, as many families were living outside the region capital. Need to take care of other members of the household was mentioned as the reason for not visiting children mainly by the families of the children from the facilities in Dnipro and Kamianske.

REINTEGRATION / REUNIFICATION POTENTIAL AND NEEDS OF FAMILIES

During family visits, the experts assessed the potential for reintegrating children into their biological families. The main assessment criteria were as follows: whether the factor that resulted in the child being separated or placed in the facility still had an impact on the family; the extent to which parents were motivated to return the child and whether they took the necessary steps; what the condition of the dwelling was and whether it was suitable for the child to live there; whether parents worked and would be able to provide for the family; and whether there were risk factors in the family related to behaviour or health, such as alcohol or drug abuse, violence, or incapacity due to mental illness.

The results of such visits were disappointing. Although reintegration is a priority over other alternative care options such as adoption and family-based care placements (family-type children's homes, foster care), very few families were prepared for their child to return home. In many families, the main reason for placing a child in a facility had not been removed. Approximately one-third of the families of children from the Kryvyi Rih, Kamianske, Kremenchuk, and Kherson baby homes had a high probability of reintegration, compared to only 1 in 10 families of children from the Dnipro baby home **(Table 7)**. The remaining families had serious problems that required the involvement of a social worker. In 35 out of 83 families of children from the five baby homes where there were other children at risk in the household, circumstances required action from the services on children's affairs and potential deprivation of parental rights.

Table 7. Biological family reunification opportunities, according to the results of the expert assessment of the assessed families of children from the Dnipropetrovsk, Poltava and Kherson regions' baby homes, *families*

	Dnipro		Kryvyi Rih		Kamianske		Kremenchuk		Kherson	
	families	*children*	*families*	*children*	*families*	*children*	*families*	*children*	*families*	*children*
Visited, total	26	29	7	10	14	19	22	29	14	18
High probability of reintegration	3	4	2	2	5	5*	6	7	5	7
High probability of placement in the custody of an uncle	-	-	-	-	1	2	-	-	-	-
Have serious or very serious problems that require actions	23	25	5	8	8	12	16	22	9	11
Including: the situation is critical and it will probably be necessary to initiate the deprivation of parental rights	13	14	4	7	6	9	8	12	4	4

* One child from these five baby homes was reintegrated into their family during the assessment.

It should be noted that, according to the results of the survey, almost all families voiced their intention to take the child back from the facility (19 out of 26 families of children from the Dnipro baby home, 7 out of 7 families from the Kryvyi Rih baby home, 12 out of 14 families from the Kamianske baby home, 20 out of 22 families from the Kremenchuk baby home and 13 out of 14 families from the Kherson baby home). However, far fewer of them cooperated with social workers and the Service on Children's Affairs to try to resolve the difficult life circumstances that had led to the placement of the child in the facility. Many families had not been in touch with their children for a long time and have remained legal representatives only on paper. According to the experts, there were also families whose expressed wish to have the child returned seemed insincere; with parents seeming more interested in receiving social benefits for the child than the actual return of the child.

> “
>
> The family has 5 children, one of them was placed in a foster family, two live with their biological father who lives separately from the mother, they study in a boarding school. The mother did not know anything about the fourth child. The fifth child is in the baby home. The mother is very aggressive, she said she wanted to return the child provided she would be paid for it. She doesn't care about the fact that older children are in other people’s families. She doesn’t remember when she saw them.
>
> ”
>
> Description of the situation by a social work specialist based on the results of a visit to the mother of a child from the Dnipro baby home

> “
>
> In connection with the physical disability of the child and the death of the mother, the father placed the child in a facility. The grandmother cares about the child and visits it. The father works all the time, so he visits rarely. He believes that together with the grandmother he will be able to take care of the child but does not take any steps to prepare the documents needed to have the child returned. He has little information about the legal aspects of the case.
>
> ”
>
> Description of the situation by a specialist based on the results of a visit to the father of a child from the Kherson baby home

In general, family members tended to voice three main needs: financial support, access to professionals, including health professionals and educators, and solutions to housing problems. The level of awareness among families about the available services was very low. Not everyone knew what social benefits were possible, despite them being vital for many families. Few families understood the options of non-financial assistance. When families were asked about the services they need to take care of a child at home, most of them talked about the services of a family doctor, other health workers, and kindergarten services, including day nurseries, in their communities **(Table 8)**. Very few families mentioned a rehabilitation centre, inclusive kindergarten/school, support groups, parents’ clubs, and psychological and legal support, despite these services being identified as very relevant for families.

Families with alcohol problems barely mentioned the need for treatment. Families who reported conflict between members of the household or close associates did not feel that they needed mediation services. It can be concluded that many families are unaware of their needs or simply had not encountered such services so were unaware they existed.

Table 8. Responses to the question: "Which of the following services would be most useful to your family in the future to provide the child with proper care?", according to the results of the assessment of families of children from the Dnipropetrovsk, Poltava and Kherson regions' baby homes, *families*

Service	Dnipro (n=26)	Kryvyi Rih (n=7)	Kamianske (n=14)	Kremenchuk (n=22)	Kherson (n=14)
Healthcare facility	19	3	5	5	11
Family doctor	19	4	7	9	11
Kindergarten	18	3	8	9	2
Kindergarten with a nursery	6	5	5	6	-
Social worker	4	2	5	3	-
Rehabilitation centre	3	-	-	2	1
Inclusive school	2	-	1	1	-
Inclusive kindergarten	2	-	-	-	-
Support groups	1	1	1	2	-
Daycare for children with disabilities	1	-	-	2	-
Courses / club for parents	1	2	-	2	-
Municipal nanny	1	-	-	-	-
Early intervention service	1	-	-	-	-

THE CAPACITY OF BABY HOMES TO BE TRANSFORMED INTO MEDICAL REHABILITATION AND PALLIATIVE CARE CENTRES FOR CHILDREN

This section provides general information about baby homes, available buildings, their condition, the structure of rooms and offices, funding, personnel, equipment, and so on. This section also presents the results of the assessment of available logistical and human resources and services compliance of the baby homes with the requirements for the medical rehabilitation and palliative care centres for children aged 0-17 years[48]. As noted earlier, the Ministry of Healthcare of Ukraine considers the transformation of baby homes into such centres as part of the health reform.

GENERAL INFORMATION ABOUT BABY HOMES

The premises of all five baby homes were built during the Soviet era, mainly in the 60s and 70s **(Table 9)**. The Kamianske baby home, built in the 30s, is the oldest one, and at the time of the assessment, had the most urgent need for major repairs, including repairs to the roof, walls and installation of insulation.

Table 9. Characteristics of the baby homes premises in Dnipropetrovsk, Poltava and Kherson regions

	Dnipro	Kryvyi Rih	Kamianske	Kremenchuk	Kherson
Year of construction	1970	1977	1932	1979	1961
Year of the last major repairs	2000	2007	1979	2020*	2020*
Premises area	**1 main building – 1.803 m²**	**The total area is 2.448 m², incl.;** • main building – 2.211 m²; • 7 pavilions – 126 m²; • premises with a cellar – 49 m²; • housekeeping premises – 35 m²; • garbage kiosk – 26 m²	**The total area is 1.774 m², incl.:** • main building – 1.610 m²; • garage – 44 m²; • vegetable storage – 42 m²; • 3 sheds – 78 m²	**The total area is 4.603 m², incl.:** • 2 buildings for children – 3.939 m²; • housekeeping premises – 664 m²	**The total area is 1.643 m², incl.:** • main building – 1.089 m²; • laundry, boiler room and mini boiler room – 216 m²; • 4 summer pavilions – 91 m²; • 5 garages – 247 m²

* Major repairs are planned for 2020.

48 / CMU Resolution as of 10.07.2019 No.675 "On approval of the Regulations for the medical rehabilitation and palliative care centre for children": URL: https://zakon.rada.gov.ua/laws/show/675-2019-%D0%BF.

	Dnipro	Kryvyi Rih	Kamianske	Kremenchuk	Kherson
Yard area	10.346 m^2	7.830 m^2	5.800 m^2	1.877 m^2	6.930 m^2
Number of beds for children	105	100	75	120	80
Total number of rooms, including:	48	96	104	241	47
Administration and utility rooms	9	30	31	122	8
Rooms for the provision of health services	3	11	14	10	3
Classes for children	12	28	32	78	13
Bedrooms for children	11	8	7	12	14
Combined showers and WCs	13	2	-	10	5
Separate shower rooms	-	8	9	1	-
Separate WCs	-	9	11	8	4

All facilities are designed for a very large number of children; 100 or more in three baby homes (Kremenchuk, Dnipro, and Kryvyi Rih) and 70-80 in two baby homes (Kamianske and Kherson). At the time of the assessment, only the Dnipro baby home had exceeded capacity (by 10 children).

The area of each facility varies from 1.643 m^2 (Kherson) to 4.603 m^2 (Kremenchuk). Although the Kremenchuk facility is designed for approximately the same number of children as the Dnipro one (120 and 105 children, respectively), the total premises area is 2.5 times larger. At the same time, the Dnipro baby home has the largest yard area of the five facilities, which includes a garden.

All facilities had a small number of bedrooms for children, with an average of 10-12 children per room. In this context, the Kherson baby home stands out with one bedroom designed for an average of 6 children. According to the Regulations for the Medical Rehabilitation and Palliative Care Centre for Children, there should be no more than two children in one room for medical rehabilitation and one child for palliative care, in addition to an accompanying legal representative or caregiver. The age, sex, health, and needs of children and their families should be considered when arranging the premises. Currently, none of the five facilities meet such requirements, as they were not provisioned for in the Baby Home Regulations.

All facilities need to be adapted for people with special needs. Ramps to enter the main building are installed in three baby homes, however there is no equipment to enter the main building in the Kremenchuk and Kherson baby homes. No shower or WCs are adapted for people in wheelchairs as there was not enough space for height-adjustable sinks and special WCs. Rooms for classes and health services also do not comply with the principles of inclusiveness. All buildings are two-storey, but no elevators are installed. None of the current renovation plans for all the baby homes include plans to create an inclusive space.

THE WAY THE FACILITIES ARE ORGANISED

In general, the facilities are similarly organised, which is typical for baby homes; children grouped by age (up to 1.5 years and older) and health, an admission and diagnosis department, offices for doctors and education specialists, procedure and massage rooms, and utility rooms, etc. As the personnel structure differed by facility, the list of specialist offices differed also.

The Kryvyi Rih and Kamianske baby homes had additional departments that provided services to children not residing there. The Kryvyi Rih baby home has an inpatient department for parents and children, with 10 beds set aside for parents. There is a day rehabilitation department in the Kamianske baby home. These additional departments were not included in the assessment as they were not the subject of the Pilot.

According to the Regulations for the Medical Rehabilitation and Palliative Care Centre for Children, the main structural units of the Centre should be the admission and diagnosis department; special departments for medical rehabilitation (neurological, sensor, musculoskeletal, physiotherapeutic and others); palliative care departments, including mobile palliative care services, respiratory support services, counselling services, day hospital (hospice), etc.; and administrative and management department, utilities and other units. The assessment team made a list of 50 offices and departments that could be used to provide medical rehabilitation and palliative care services to children, according to the Regulations.

The Dnipro baby home least complied with the how a facility of Medical Rehabilitation and Palliative Care Centre for Children should be organised, with only a third (18) of the offices / departments from the requested list. The other facilities had approximately 50-60 % of offices /departments that could be used to provide medical rehabilitation and palliative care services to children: 27 out of 50 in the Kamianske baby home, 28 out of 50 in the Kremenchuk baby home, 29 out of 50 in the Kryvyi Rih baby home, and 31 out of 50 in the Kherson baby home. It should be noted that the assessed capacity of premises / departments refers only to the presence of such premises / departments in the way a facility is organised, not their condition or readiness to provide services in line with the Regulations for the Medical Rehabilitation and Palliative Care Centre for Children (a combination of inpatient and outpatient care, availability of offices and services for children from birth to including 17 years old, inclusive space, etc.). According to the charters, all baby homes work only with children up to the age of 4 (in Kremenchuk Baby Home with children up to the age of 6) and only in inpatient settings, so the way facilities are currently organised is not designed for a broader age range of recipients for services, and outpatient services.

SERVICES PROVIDED IN BABY HOMES

Particularly in the context of the health reform and the transition from maintaining a network of healthcare facilities to developing specific services, it was important to assess the capacity of baby homes to provide rehabilitation and palliative care services. The Pilot assessed the availability of 55 common rehabilitation services, including physical, medical and psycho-educational rehabilitation, palliative care services, and outpatient services in baby homes. The packages of rehabilitation and paediatric palliative care services were developed by the Pilot team before the requirements (specifications) for such packages were approved by the National Health Service of Ukraine (NHSU)[49]. Thus, the medical rehabilitation and palliative care services defined by the NHSU and the Pilot are different. At the same time, the NHSU emphasises that its requirements are minimal, and providers only need to comply with certain important for the programme of medical guarantees working conditions that are not healthcare industry standards to be able to work under their contract.

In addition to the list of services, the assessment team collected data on the provision levels of rehabilitation and paediatric palliative care services through self-assessment of staff involved in such services. The results of the assessment are shown in **Table 10**. It should be noted that at the time of the assessment, the facilities did not have a standard list of services they provided. All five baby homes do not have medical information systems (MIS) and services are not accounted for. Therefore, it was impossible to objectively assess the demand for such services, levels of usage, and the frequency of their provision.

In general, only one-third of rehabilitation and paediatric palliative care services were provided from the requested list in four baby homes; 17 out of 55 in the Dnipro baby home, 18 out of 55 in the Kremenchuk baby home, 19 out of 55 in the Kamianske baby home and 21 out of 55 in the Kherson baby home. In this context, the Kherson baby home stands out by providing half (29 out of 55) of the requested services on the list.

49 / Specifications and conditions for the purchase of health services lots approved by MOH on 21.01.2020; URL: https://nszu.gov.ua/likar-2020.

Table 10. Average monthly usage of rehabilitation and palliative care services by children in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, according to the staff reports

	Dnipro (n=115)*		Kryvyi Rih (n=77)*		Kamianske (n=50)*		Kremenchuk (n=108)*		Kherson (n=65)*	
	persons	%	*persons*	%	*persons*	%	*persons*	%	*persons*	%
Massage therapy	41	36	77	100	22	44	36	33	35	54
Physiotherapy	34	30	77	100	21	42	-	-	47	72
Physical therapy (kinesitherapy)	67	58	77	100	12	24	20	19	18	28
Occupational therapy	95	83	12	16	-	-	-	-	-	-
Training sessions on physical culture and sports	32	28	-	-	35	70	-	-	-	-
Counselling for parents	-	-	77	100	3	6	-	-	-	-
Preventive measures	115	100	-	-	50	100	108	100	23	35
Substitution therapy	-	-	-	-	-	-	8	7	-	-
Mental health care	-	-	-	-	-	-	HB	-	-	-
Follow-up care (by a doctor or a nurse)	115	100	77	100	50	100	108	100	60	92
Hearing aid maintenance	-	-	2	3	-	-	-	-	1	2
Maintenance of cochlear implants	-	-	2	3	-	-	-	-	-	-
Orthopaedic correction	-	-	77	100	2	4	8	7	-	-
Clinical nutrition	-	-	10	13	-	-	-	-	2	3
Psychological and educational counselling	13	11	77	100	12	24	30	28	21	32
Psychological and educational diagnosis	18	16	77	100	22	44	60	56	65	100
Psychological and educational correction	60	52	77	100	45	90	60	56	65	100
Group training (integrated / inclusive)	78	68	30	39	45	90	15	14	4	6

* Number of children in the facility at the time of assessment.

	Dnipro (n=115)*		Kryvyi Rih (n=77)*		Kamianske (n=50)*		Kremenchuk (n=108)*		Kherson (n=65)*	
	persons	%	*persons*	%	*persons*	%	*persons*	%	*persons*	%
Individual training	115	100	70	91	50	100	15	14	-	-
Distance learning	-	-	30	39	-	-	-	-	-	-
Speech therapy	115	100	60	78	42	84	44	41	16	25
Psychological and educational support	75	65	-	-	-	-	-	-	-	-
Assessment and treatment of pain in palliative patients	-	-	5	6	2	4	-	-	-	-
Coordination and communication on palliative care	-	-	30	39	-	-	-	-	4	6
Treatment of symptoms of palliative patients	-	-	30	39	3	6	4	4	4	6
Music therapy for palliative patients	-	-	30	39	-	-	4	4	4	6
Play therapy for palliative patients	-	-	30	39	-	-	4	4	4	6
Aromatherapy for palliative patients	-	-	30	39	-	-	-	-	3	5
Siblings support of palliative patients	-	-	20	26	-	-	-	-	2	3
Specialised counselling for palliative patients	-	-	20	26	-	-	-	-	4	6
Special feeding (tube)	8	7	20	26	-	-	4	4	4	6
Round-the-clock healthcare for children with palliative conditions	8	7	30	39	3	6	4	4	4	6
Education for parents of children with palliative conditions	-	-	20	26	-	-	-	-	-	-
Physical therapy for palliative patients	8	7	30	39	3	6	4	4	-	-
Spiritual support for palliative patients	-	-	-	-	1	2	-	-	-	-

* Number of children in the facility at the time of assessment.

It is worth noting that fewer children received rehabilitation and palliative care services than was required, according to the Pilot assessment. For example, in the Dnipro baby home, the need for palliative care was observed in a maximum of 18 children, whereas the service records indicated only 8 children received such support. According to the staff of the Kryvyi Rih baby home, up to 30 children received paediatric palliative care services: symptomatic treatment and therapy (music therapy, game therapy, aromatherapy); however, a pain assessment was only conducted with 5 children. Contradictory data was obtained on the frequency that psychological and educational diagnosis and correction services in the Kamianske baby home are conducted: according to the staff self-assessment, the number of children to undergo correction is double the number of children needing such interventions according to their diagnosis. In the Kherson baby home, more than half of the children needed speech therapy services, whereas only a quarter actually received speech therapy.

The results of the assessment show that facilities do not fully understand exactly what is included in certain services. Some services were not always consistent with available human resources and equipment. For example, in all five baby homes, there was respiratory support equipment (non-invasive ventilators, cough stimulator, suction unit, oxygen concentrator), however, the facilities did not indicate that they provided such services. All facilities noted a wide range of physical rehabilitation services, yet none had physiotherapists, physical therapists, occupational therapists, or medical rehabilitation specialists. Many services were provided by nurses and only a small proportion of them were trained in medical rehabilitation and palliative care. Apart from the Kryvyi Rih and Kherson baby homes, paediatric palliative care in the other facilities consists of round-the-clock care and tube feeding.

EQUIPMENT AND SUPPLIES

Within the Pilot, a standard list of equipment and supplies that a medical rehabilitation and palliative care centre would need to obtain was developed. It is important to understand that the Pilot did not assess the extent to which a facility's supplies meet the standards of the baby home. Instead, it was estimated what equipment the baby home would need in the event of its transformation into a medical rehabilitation and palliative care centre. What equipment was available and what was missing was determined for the provision of respiratory support, physical rehabilitation, occupational therapy, speech therapy, orthopedic care, psychological care, training, and equipment for movement, lifting and personal space. An inventory of existing rehabilitation and palliative care equipment in baby homes, and the desired amount to be fully equipped, is shown in **Table 11**.

Table 11. **Supplies of rehabilitation and palliative care equipment in the baby homes**

	Number of equipment types in the requested list, units	Number of available types of equipment in facilities, *units*				
		Dnipro	Kryvyi Rih	Kamianske	Kremenchuk	Kherson
Equipment for physical and occupational therapy	**15**	11	8	9	11	10
Equipment for orthopaedic care	**5**	0	5	0	1	1
Equipment for hydrotherapy	**3**	0	2	0	3	1
Equipment for integrative (complementary) therapy	**6**	3	5	2	2	3
Equipment for speech therapy	**7**	3	5	3	3	1
Equipment for psychological care	**12**	8	11	8	8	4
Respiratory support equipment	**10**	8	5	6	5	5
Training equipment	**6**	3	4	3	3	4
Feeding equipment	**8**	2	6	2	2	3
Equipment for personal space / use	**21**	5	10	6	4	7
Equipment for movement and lifting	**4**	3	3	3	3	3
Equipment for patients	**11**	1	5	0	3	1
Manipulation room equipment	**4**	1	3	1	3	3
Equipment for a cold room	**3**	0	0	0	0	0
Total	**115**	**48**	**72**	**43**	**51**	**46**

The equipment most lacking in all facilities is for patients and individual space / use. It should be noted that the available equipment is designed exclusively for the age category of children served by each facility. In the case of transformation into a medical rehabilitation and palliative care centre, facilities will need equipment for children up to the age of 17 years.

HUMAN RESOURCES

Expanding the range of medical rehabilitation and paediatric palliative care services in baby homes is impossible without adequate human resources. To understand the current staffing situation, an assessment of available human resources was conducted. This section provides data on full-time positions and the total number of staff, as well as detailed characteristics of health and teaching staff. The analysis of health and teaching staff was based on official documents including employees' personal files and job descriptions.

Staffing list and staff employed

In the baby homes, the number of staff employed was fewer than the number of positions on the staffing list **(Table 12)**. Vacant positions do not necessarily mean a shortage of staff. Like other healthcare facilities that were not reorganised, the staffing lists of baby homes were aligned with the MOH Order No. 33[50] as of 23.02.2000, which was based on the potential number of children (or rather, the number of beds), regardless of how many children received services. In practice, this led to a large percentage of administrative and support staff employed, regardless of a real need for them. Order No.33 was cancelled in 2016[51] but it did not result in the revision and optimisation of staff, as the funding system did not allow flexible planning of staff positions. The Director could change the staffing list of a facility only within the estimated budget for remuneration and payroll charges. Because of this, the staffing lists do not always reflect true staffing needs.

The total number of staff across the five baby homes was 712, including 358 persons who delivered health and educational services.

50 / MOH Order No. 33 as of 23.02.2000 "On model staffing standards of health care facilities". URL: https://zakon.rada.gov.ua/rada/show/v0033282-00.

51 / MOH Order No. 928 as of 02.09.2016 "On invalidation of the Order of the Ministry of Healthcare of Ukraine as of February 23, 2000 No. 33". URL: https://zakon.rada.gov.ua/rada/show/v0928282-16.

Table 12. Number of staff, according to the staffing list (positions) and actual employees (persons) in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, by responsibilities, 2019

	Dnipro		Kryvyi Rih		Kamianske		Kremenchuk		Kherson	
	Positions, according to the staffing list	Actual employees	Positions, according to the staffing list	Actual employees	Positions, according to the staffing list	Actual employees	Positions, according to the staffing list	Actual employees	Positions, according to the staffing list	Actual employees
Management and administrative staff	10.5	11	4.5	4	4	4	14	14	8.5	10
Support staff	28.75	25	27.75	24	20.25	16	40.5	36	22.5	21
Health staff	71.5	58	56	39	52.25	39	94.5	84	48	47
Education staff	21.5	19	17	13	18.25	16	27.5	25	14.5	16
Childcare staff (nursing staff)	35.5	25	43	28	37.25	28	65	58	55	52
Total	**167.75**	**138**	**148.25**	**108**	**132**	**103**	**241.5**	**217**	**148.5**	**146**

The number of staff in the five baby homes primarily reflects variations in the number of children for which the facilities are designed: the more beds in the baby home, the more positions and actual employees. Thus, in the Kremenchuk baby home which has 120 beds for children, there were 217 staff members, and in the Kamianske baby home with 75 beds there were 103 staff members.

The largest group of employees, in all facilities except the Kherson baby home, is health staff (from 36 % in the Kryvyi Rih baby home to 42 % in the Dnipro baby home), whilst the second largest group is nursing staff (from 18 % in the Dnipro baby home to 26-27 % in the Kryvyi Rih, Kamianske, and Kremenchuk baby homes) **(Fig. 36)**.

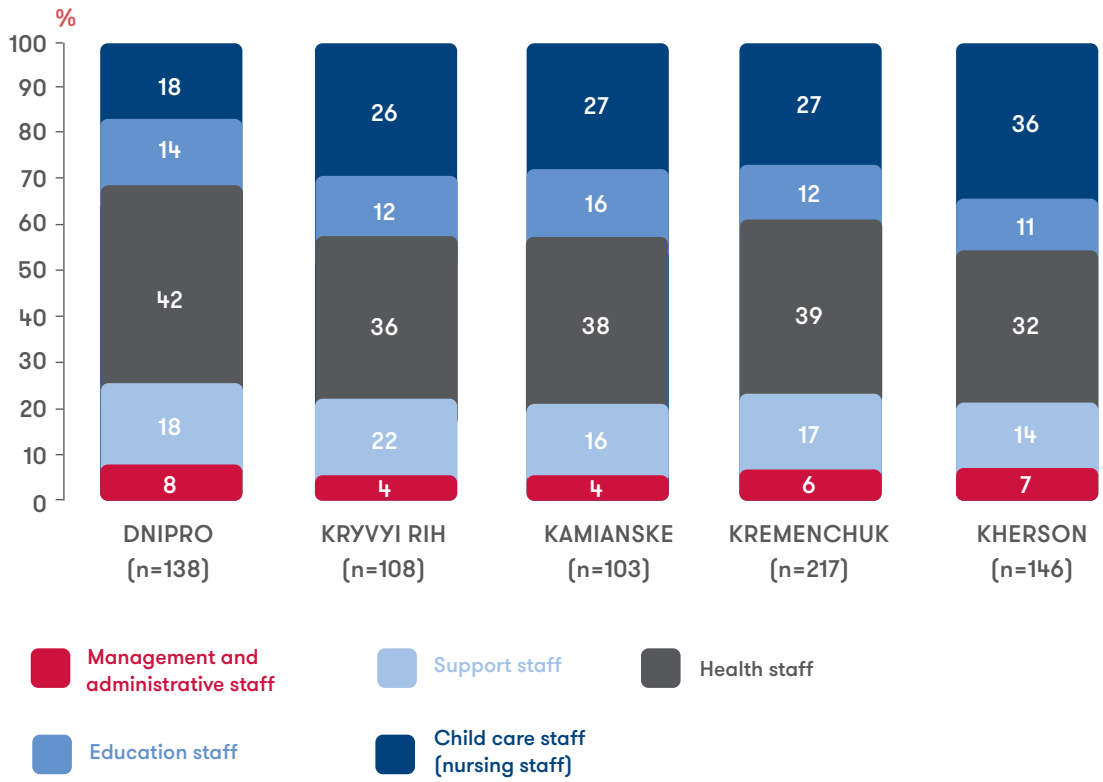


Figure 36. Groups of actual staff employed in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, as of October 2019, by responsibility, %

The structure of education and health staff

The assessment of health and education staff included only those employees who provided informed consent and agreed to the processing of their personal data: 74 out of 77 persons in the Dnipro baby home, 45 out of 52 persons in the Kryvyi Rih baby home, all 56 persons in the Kamianske baby home, 95 out of 109 persons in the Kremenchuk baby home and all 64 persons in the Kherson baby home.

In all facilities, the ratio of education staff to health staff was 1:3. The health staff is mostly represented by nurses; from 74 % (Dnipro) to 94 % (Kremenchuk) of total staff in this group **(Table 13)**. Among the education staff, educators are the most numerous; accounting for half of all education staff in the Kryvyi Rih and Kherson baby homes and over 70 % in the other facilities.

Table 13. Number of health and education staff, by position, in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, *persons*

Position	Dnipro (n=74)	Kryvyi Rih (n=45)	Kamianske (n=56)	Kremenchuk (n=95)	Kherson (n=64)
Health staff, including:	**54**	**34**	**40**	**71**	**49**
Specialists, including:	10	3	4	2	8
Paediatricians	6	3	2	1	5
Physiotherapists	-	-	-	1	1
Paediatric neurologists	2	-	2	-	1
Paediatric otolaryngologists	1	-	-	-	1
Paediatric psychiatrists	1	-	-	-	-
Nurses (including matron)	40	28	35	67	39
Chief physician	-	1	1	1	1
Other administrative health staff	3	1	-	1	1
Other health staff	1	1	-	-	-
Education staff, including:	**20**	**11**	**16**	**24**	**15**
Practical psychologists	1	1	-	-	1
Special needs experts	1	2	-	2	3
Speech therapists	2	1	3	2	2
Musicologist	1	1	1	1	1
Educators (including senior educator)	15	6	12	19	8

The list of available doctors and education staff specialists is small. Of the five baby homes, the Dnipro and Kherson facilities are best equipped with doctors; both facilities employ paediatricians, neurologists, and paediatric otolaryngologists. There is a paediatric psychiatrist in the Dnipro baby home and a physiotherapist in the Kherson baby home.

Continuous professional development

The education levels of the health and education staff were aligned with job descriptions; specialists and education staff (except educators) had higher educational qualifications whereas nurses and educators mostly had a school or college education.

Almost all health staff in the five baby homes has received additional work-related training over the past 5 years, which is a mandatory requirement for the certification of employees in healthcare facilities **(Fig. 37)**. Indication of continuous professional development among education staff is lower, especially in the Kamianske, Kremenchuk, and Kherson baby homes.

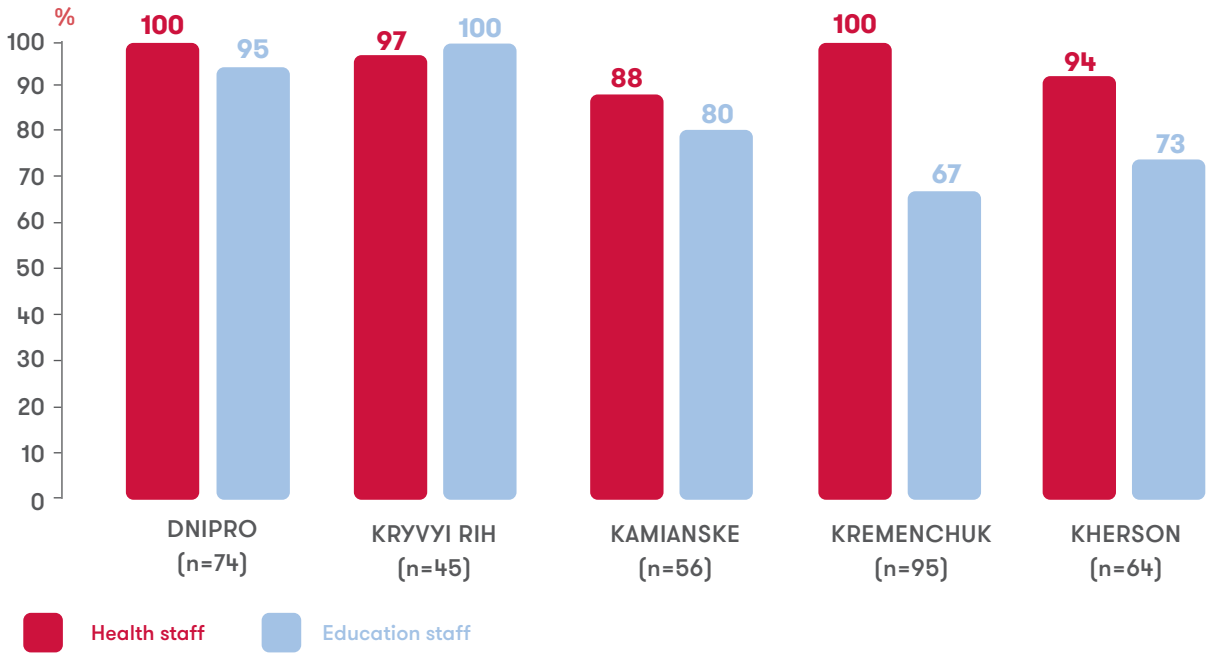


Figure 37. Percentage of health and education staff in the baby homes of Dnipropetrovsk, Poltava and Kherson regions who received additional professional training during the last 5 years, %

Health and education staff mostly received the usual advanced training courses in their specialty (short-term specialty courses, etc.) **(Table 14)**. It should be noted that until recently, advanced training courses had been the only type of training for health professionals recognised by certification standards. Since 2019, the procedures of continuous professional development for doctors have changed[52]. Physicians are now required to gain 50 points of continuous professional development during each calendar year, although previously the assessment of continuous professional development had been done every 5 years as per certification cycles. Not only the pre-certification training at a postgraduate education facility was considered, but also other types of training and/or professional activities of formal and informal education. Currently, these innovations have been implemented only for doctors.

52 / CMU Resolution as of 28.03.2018 No. 302 "On approval of the Regulations for the system of continuous professional development of specialists in the field of health care". URL: https://zakon.rada.gov.ua/laws/show/302-2018-%D0%BF.

MOH Order as of 02.22.2019 No. 446 "Some issues of continuous professional development of doctors". URL:http://moz.gov.ua/article/ministry-mandates/nakaz-moz-ukraini-vid-22022019--446-dejaki-pitannja-bezperervnogo-profesijnogo-rozvitku-likariv.

Compared to the other baby homes, a greater percentage of staff from the Kryvyi Rih baby home have participated in professional development training: 16 % of health and education staff were trained in the provision of rehabilitation services, 11 % in palliative care, 31 % in early intervention programmes, and 30 % in the early childhood development. In the Dnipro and Kherson baby homes, none of the health and education staff members have been trained in rehabilitation / habilitation or palliative care service provision in the last 5 years. In the Kremenchuk baby home, only 2 health staff representatives have been trained in palliative care during this period; no health or education staff members have received training on the provision of rehabilitation services.

Table 14. Different types of continuous professional development training among health and education staff of the baby homes of Dnipropetrovsk, Poltava and Kherson regions during the last 5 years, %

Type of training	Dnipro (n=74)	Kryvyi Rih (n=45)	Kamianske (n=56)	Kremenchuk (n=95)	Kherson (n=64)
Advanced training courses	99	93	86	91	89
Trainings (courses) on rehabilitation / habilitation services	-	16	18	-	-
Trainings (courses) on palliative / hospice care	-	11	4	2	-
Trainings (courses) on early intervention programmes	-	31	2	-	-
Trainings (courses) on the early children development	11	30	9	-	2
Trainings (courses) on enforcing children's rights	2	4	2	-	5

Staff survey: level of satisfaction, needs, and attitudes towards reform

In addition to analysing the personal files of the health and education staff, one third of staff were surveyed on job satisfaction, needs, and attitudes towards health reform. 26 persons in the Dnipro baby home, 15 persons in the Kryvyi Rih baby home, 19 persons in the Kamianske baby home, 33 persons in the Kremenchuk baby home, and 26 persons in the Kherson baby home took part in the assessment.

The results of the survey show an unsatisfactory level of basic knowledge about children's rights and the recognition of child abuse cases. More than half of the interviewed staff in the Kryvyi Rih baby home (8 out of 15 persons) did not feel competent in their knowledge of children's rights.

In the other facilities, the number of surveyed staff with limited knowledge about children's rights was also high; a third in the Dnipro baby home (9 out of 26), and a quarter in Kremenchuk (8 out of 33) and Kherson (7 out of 26) baby homes. Only in the Kamianske baby home all health and education staff considered themselves competent in matters of children's rights. More than half (11 out of 19) of the surveyed health and education staff in the Kamianske baby home considered their level of knowledge insufficient to be able to identify potential cases of abuse, exploitation, neglect and violence against children; compared to approximately a third of surveyed staff in other facilities, (10 out of 26 in Dnipro, 6 out of 15 in Kryvyi Rih, 10 out of 33 in Kremenchuk and 7 out of 26 in Kherson). Poor computer skills can be a deterrent to transformation, as cooperation with the NHSU stipulates the use of medical information systems (MIS). For example, in the Kremenchuk baby home, only 4 of the 33 health and education staff members who took part in the survey considered themselves as confident computer users, compared to approximately half of staff in the Kamianske and Kherson baby homes (9 out of 19 and 12 out of 26, respectively), and two-thirds in the Dnipro and Kryvyi Rih baby homes (17 out of 26 and 9 out of 15, respectively).

In all facilities, salary levels are the main reason for personnel dissatisfaction. The only exception is the Kamianske baby home, where four out of five health and education workers surveyed (16 out of 19 people) were satisfied with their earnings. Almost all health and education workers in the other facilities were dissatisfied with their salaries: 19 out of 26 in Dnipro, 13 out of 15 in Kryvyi Rih, 32 out of 33 in Kremenchuk, and 20 out of 26 in Kherson. In contrast, high satisfaction levels were recorded in other aspects of work related to personal impact and an opportunity for professional growth.

The number of baby home staff expressing support for health reform was quite low (11 out of 26 in Dnipro, 9 out of 15 in Kryvyi Rih, 8 out of 19 in Kamianske and 12 out of 33 in Kremenchuk). Only in the Kherson baby home three-quarters (19 out of 26) of the staff expressed support for the reform. At the same time, support for plans to transform baby homes in Ukraine into medical rehabilitation and palliative care centres was high in all baby homes except Kremenchuk. In the Dnipropetrovsk and Kherson region facilities, approximately 80 % or more of the staff agreed with the transformation option (20 out of 26 in Dnipro, 13 out of 15 in Kryvyi Rih, 17 out of 19 in Kamianske and 22 out of 26 in Kherson). Instead, in the Kremenchuk baby home, only half of the health and education staff (18 out of 33) supported the idea of transformation into a medical rehabilitation and palliative care centre for children. All respondents who support for transformation also expressed their readiness to receive additional training for the provision of medical rehabilitation and palliative care services.

Socio-demographic characteristics of health and education staff

The health and education staff of baby homes is almost exclusively female, except in the Dnipro and Kryvyi Rih facilities where there was one male employee in each baby home. The age structure of personnel reflects the general problem of aging in the health sector. This problem is critical in the Dnipro and Kamianske baby homes where more than 20 % of staff was aged 60 years or older **(Figure 38)**. In general, the median age of health and education staff was 51 years in the Dnipro and Kremenchuk baby homes, 49 years in the Kryvyi Rih baby home, 48 years in the Kherson baby home, and 46 years in the Kamianske baby home.

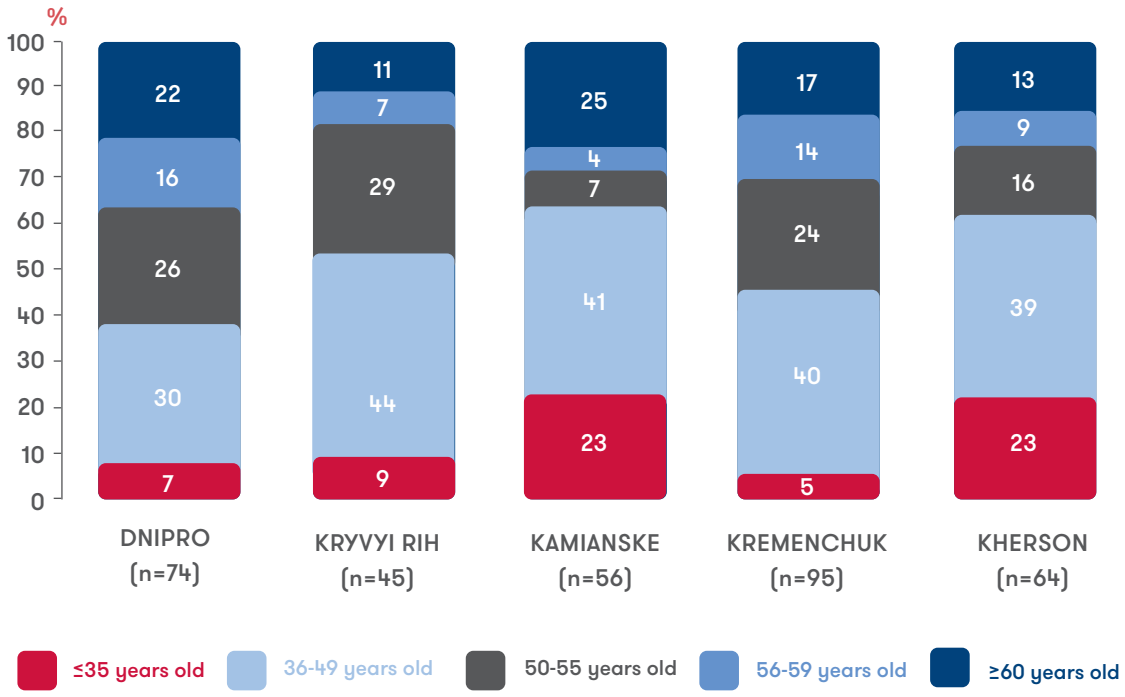


Figure 38. Age of health and education staff in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, by age groups, %

More than a quarter (27 %) of health and education staff in the Kryvyi Rih, Kamianske, and Kremenchuk baby homes was of retirement age compared to 41 % in the Dnipro baby home (Fig. 39). In this context, the Kherson baby home stands out, with only 14 % of health and education staff being of retirement age.

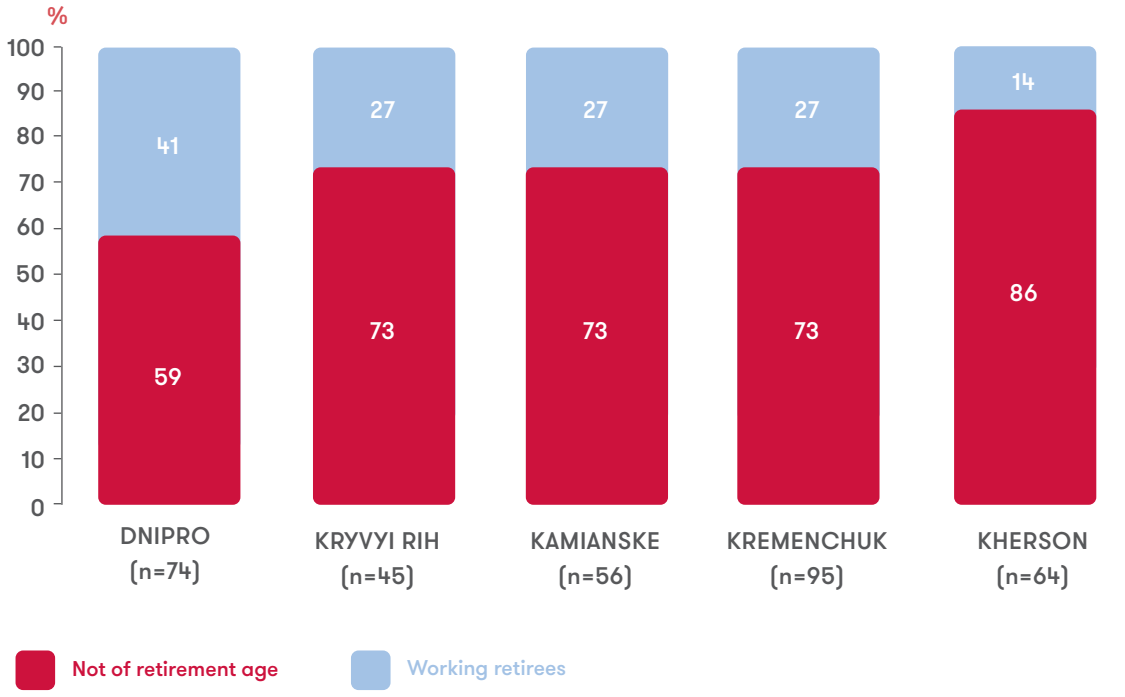


Figure 39. Percentage of working retirees among health and education staff of the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

In the Dnipro and Kherson baby homes, half of the health and education staff has been working in these facilities for more than 10 years, compared to two-thirds in the Kamianske baby home and almost all staff in the Kremenchuk baby home (Fig. 40). For many, this facility was their first and only place of work. The median years of service of health and education staff in the baby home were 10 years in the Kherson baby home, 16 years in Dnipro, 17 years in Kryvyi Rih and 19 years in the Kamianske and Kremenchuk baby homes.

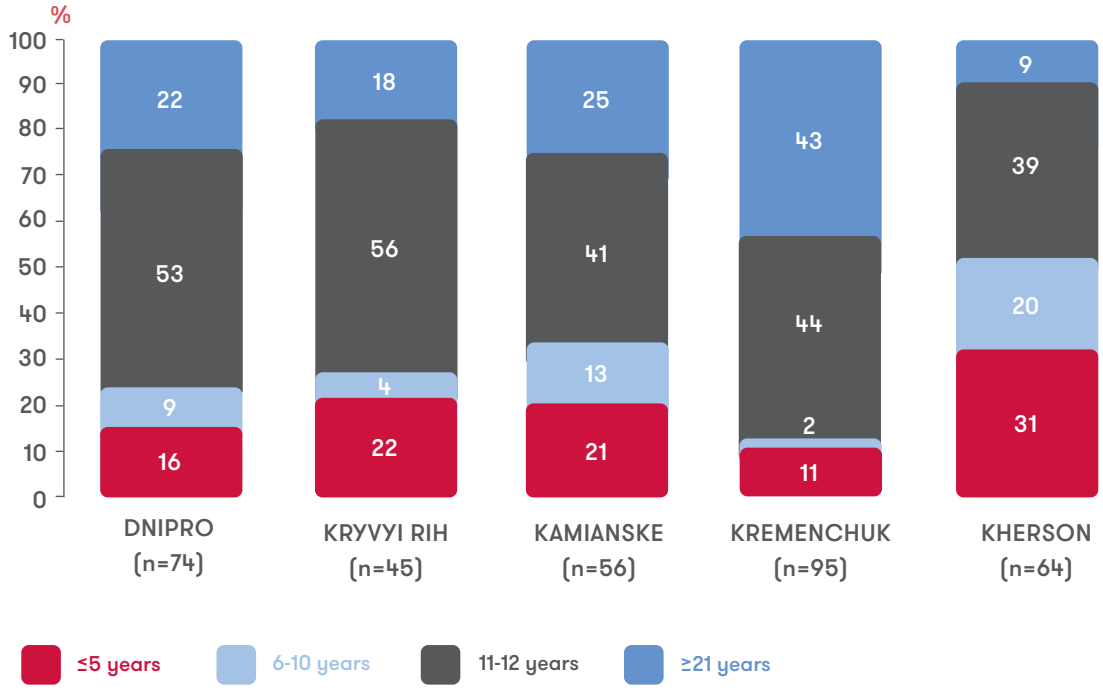
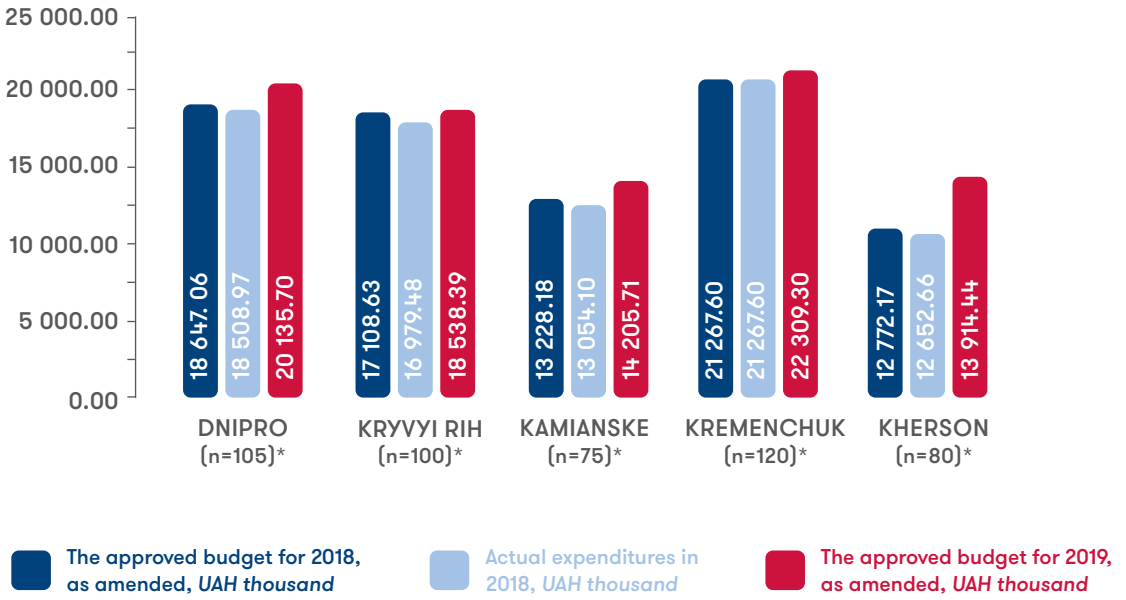


Figure 40. Years of service by health and education staff in the baby homes of Dnipropetrovsk, Poltava and Kherson regions, %

FINANCING

Of the five baby homes assessed, the largest budget was in Kremenchuk which can be explained by the greater number of beds and full-time positions: the main indicators for the distribution of budget funds in the absence of service-based financing (Fig. 41). In 2018, actual expenditures were either equal to the approved budget (Kremenchuk) or accounted for 99 % of the planned budget (other facilities). All facilities' planned budgets for 2019 exceeded the actual expenditures of the previous year by 5-10 %.



*Number of beds for children in the baby home

Figure 41. Budget of baby homes of Dnipropetrovsk, Poltava and Kherson regions, 2018-2019
UAH, thousands

At the time of the assessment, the main source of funding for facilities was the medical subvention. The share of region funds in a facility's budget was the largest in the Kremenchuk baby home (24 %) compared to the Dnipro baby home (14 %), the Kryvyi Rih baby home (6 %), and the Kamianske baby home (4 %). The Kherson baby home was 100 % financed through the health subvention.

Cost categories

In the baby homes of Dnipropetrovsk and Kherson regions, more than 80 % of expenditures were on wages and payroll charges, which is typical for all healthcare facilities that have not been transformed into a municipal non-profit enterprise, and therefore do not have flexibility in the formation and distribution of budget funds through line-item financing **(Table 15)**. In this context, the Kremenchuk baby home stands out with HR costs at 71 %. At the same time, it is the facility with the highest utility costs (10 %) as it has two large buildings for children and a housekeeping building.

Table 15. Costs breakdown of the baby homes of Dnipropetrovsk, Poltava and Kherson regions in 2018, %

Cost category	Dnipro	Kryvyi Rih	Kamianske	Kremenchuk	Kherson
Remuneration	66.8	66.8	69.9	61.9	71.2
Payroll charges	14.7	14.6	15.3	13.3	15.4
Items, materials, equipment and supplies	0.7	1.4	1.1	4.0	0.6
Medicines and dressings	0.4	0.6	0.5	2.0	0.6
Food	6.9	6.0	6.1	8.0	5.0
Utilities	5.6	6.2	4.8	9.6	5.3
Other	4.9	4.4	2.3	1.2	1.9

Average **food costs** per child per day in the 2018 budget:

- Dnipro – UAH 33
- Kryvyi Rih – UAH 37
- Kamianske – UAH 34
- Kremenchuk – UAH 48
- Kherson – UAH 27

Average monthly expenses **for medicines and dressings** per child in the 2018 budget:

- Dnipro – UAH 64
- Kryvyi Rih – UAH 114
- Kamianske – UAH 78
- Kremenchuk – UAH 412
- Kherson – UAH 104

Calculations were based on 2018 data, considering the average number of children (day / month). Donations not included.

In all facilities except the Kremenchuk baby home, less than 1 % of the budget was spent on medicines and 5-7 % on children's nutrition. In the Kremenchuk facility, expenditures on these items are slightly higher (2 % for medicines and 8 % for food). Meals per child per day cost from UAH 27 (Kherson) to UAH 48 (Kremenchuk). Given the fact that between a quarter and a half of children need clinical nutrition (high-protein and high-calorie food), the cost of nutrition should be much higher. Facilities have a wide range of monthly expenses for medicines and dressings per child: from UAH 64 (Dnipro) to UAH 412 (Kremenchuk).

Donations

Among the five facilities, the Dnipro baby home attracts the most donations; the total amount of donations, grants, gifts, and humanitarian aid amounted to over UAH 1.7 million. Facilities in Kremenchuk and Kherson raised more than 1.2 million UAH in 2018 whereas donations in the Kryvyi Rih and Kamianske baby homes were 3.5 times less. In all baby homes, donations were mainly spent on the purchase of diapers and nappies, food, medicines, and durable goods. The exception is the Kryvyi Rih baby home, where, in 2018, more than a third of donations received was invested in the renovation of the facility.

THE RESULTS OF THE NEEDS ASSESSMENT OF CHILDREN AND FAMILIES FOR MEDICAL REHABILITATION AND PALLIATIVE CARE SERVICES

There is no quick solution for assessing the need for health-related services, including medical rehabilitation and palliative care services. In the field of health care, the term "need" includes: desire – informed needs (or what services and to what extent patients need them at their discretion); demand – expressed needs (or requests for services from healthcare facilities); actual needs – both informed and non-informed needs for services; and supply – the share of actual needs that are satisfied by available health services[53]. Typically an epidemiological approach is used to assess needs using quantitative data to estimate the number and composition of the population that could potentially be a consumer of the service, including information on geographical distribution, dynamics, and key groups. The level of need is determined by the distribution of illness, disability, or harsh life circumstances and the current level of service provision to meet these needs. This approach is combined with qualitative methods to understand the current needs, priorities and views of various stakeholders, such as patients, the community, and decision-makers.

The Pilot assessed the need for medical rehabilitation and palliative care services for children aged 0–17 years and the need for social services for children aged 0–6 years in Dnipropetrovsk, Poltava, and Kherson regions. The assessment included a statistical analysis of morbidity and disabilities among children to assess the demand for such services; mapping region services through inquiries made to the Health Departments and Services on Children's Affairs of the Region State Administrations to evaluate the available supply, and both in-depth and focus group interviews with recipients and service providers to understand personal experience of medical rehabilitation and palliative care. The results of the assessment allow us to understand the supply and demand ratio for paediatric medical rehabilitation and palliative care, as well as social services.

NEEDS FOR MEDICAL REHABILITATION SERVICES

There is no legally established methodology in Ukraine to calculate the need for medical rehabilitation services. In general, the list of children who need medical rehabilitation services should be calculated to include both people with disabilities and those who need rehabilitation services but do not have a "disability" status, according to the treatment protocol of their diagnosed disease. Unfortunately, the available statistical reports and studies do not allow us to estimate the proportion of children in need of medical rehabilitation without a registered status of "disability". Data on the number of children with disabilities, which is a minimal estimate of such needs, determines the need for medical rehabilitation services.

In each region, there is an annual increase in the number of children with disabilities **(Fig. 42)**. As of 2018, there were 13.296 children with disabilities aged 0-17 years in Dnipropetrovsk region, 5.331 in Poltava region, and 3.973 in Kherson region. The rise in the number of children with disabilities is linked to the most common diseases: defects and abnormalities, mental and behavioural disorders, and diseases of the endocrine system **(Fig. 44)**. In comparison to Poltava and Kherson regions, Dnipropetrovsk region is characterised by high rates of disability due to eye disorders and infectious and parasitic diseases.

53 / Wright J, Williams R, Wilkinson JR. Development and importance of health needs assessment. *BMJ.* 1998 Apr 25;316(7140):1310–3.

We can see that the number of disability cases per 10.000 children increases rapidly with age (Fig. 43). The dynamics of disabilities by age groups follows the dynamics of the distribution of diseases in children – the latter also increases with age. Further, this may be due to the lack of access to early intervention, rehabilitation, and habilitation services at an early age which further leads to disabilities developing.

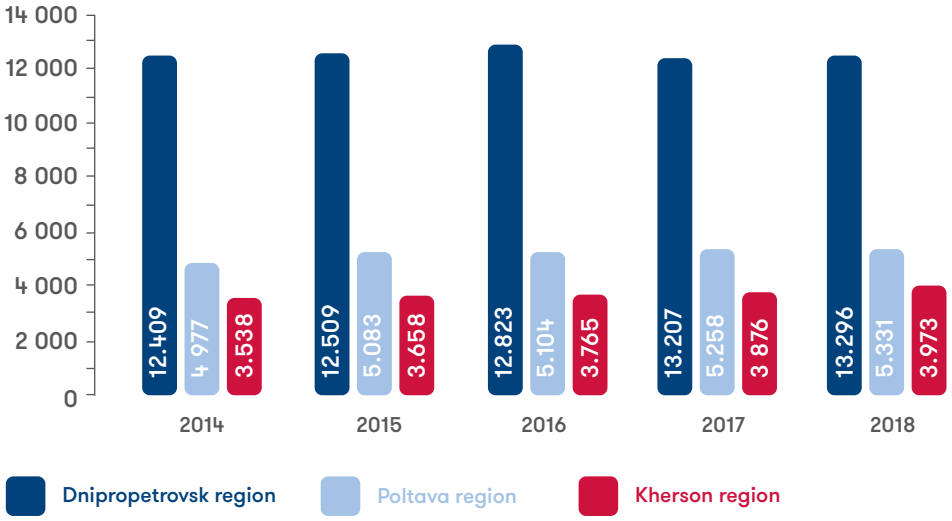


Figure 42. Number of persons with disabilities aged 0–17 years in Dnipropetrovsk, Poltava, and Kherson regions, according to the Centre for Health Statistics of the Ministry of Healthcare of Ukraine, 2014-2018, *persons*.

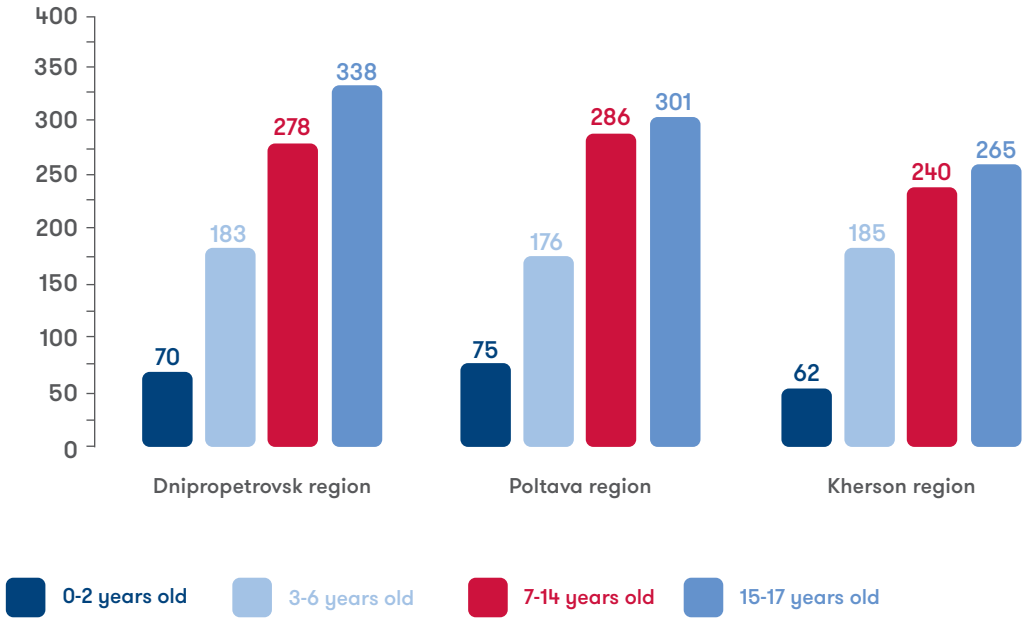
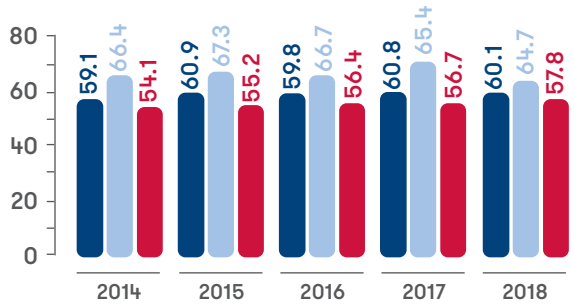


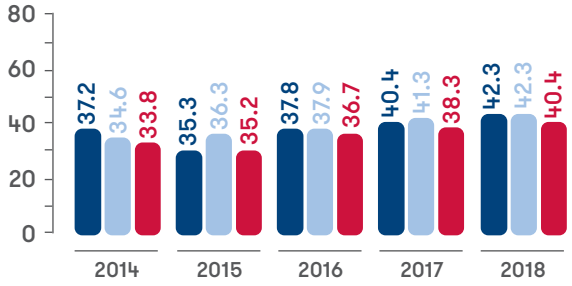
Figure 43. Number of children with disabilities per 10.000 children by age group in Dnipropetrovsk, Poltava and Kherson regions, according to the Centre for Health Statistics of the Ministry of Healthcare of Ukraine, 2018, %

High prevalence (3rd tercil: ≥10 per 10.000)

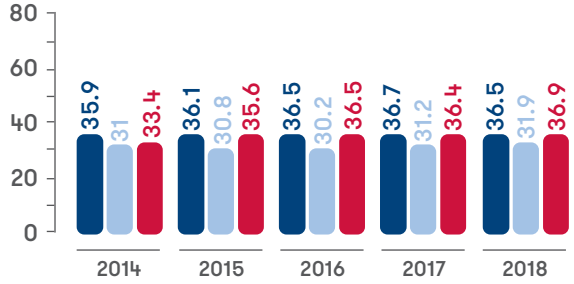
Congenital malformations (deformations), Q00-Q99



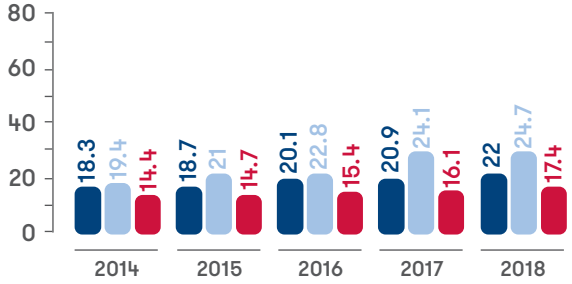
Mental and behavioural disorders, F00-F99



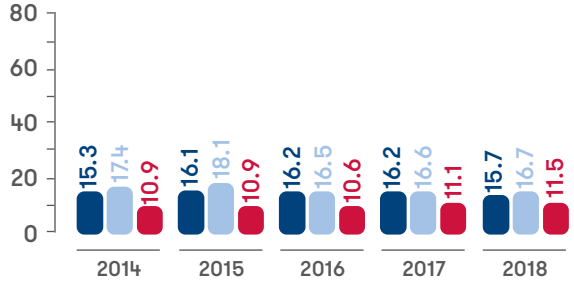
Diseases of the nervous system, G00-G99



Diseases of the endocrine system, E00-E90



Diseases of the ear and mastoid process, H60-H95

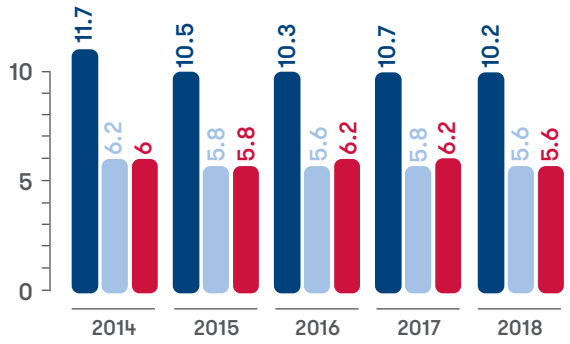


Dnipropetrovsk region Poltava region Kherson region

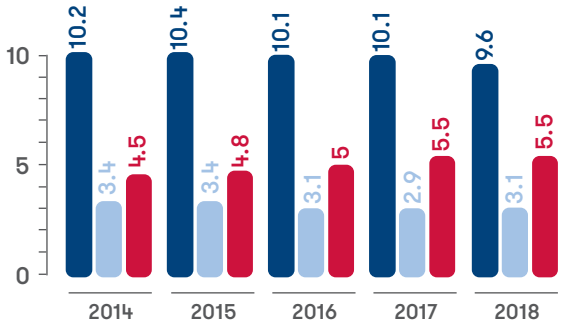
Prevalence per 10.000 children

Medium prevalence (2nd tercil: 3-9 per 10.000)

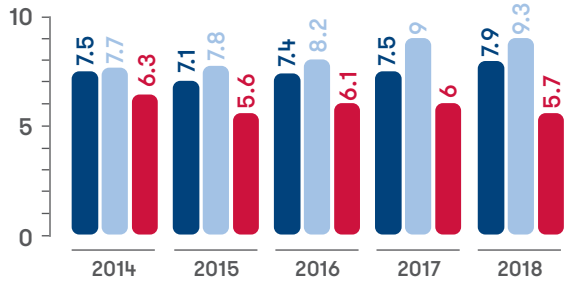
Diseases of the eye and adnexa, H00-H59



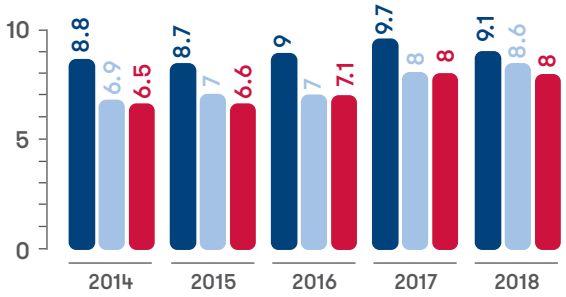
Certain infectious and parasitic diseases, A00-B99



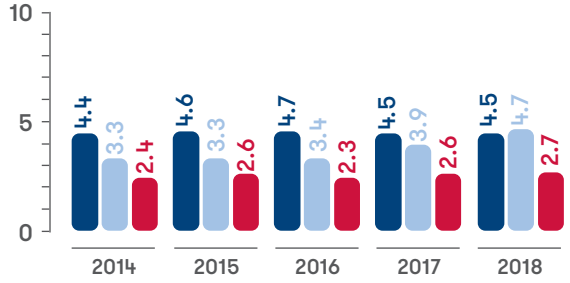
Neoplasms, C00-D48



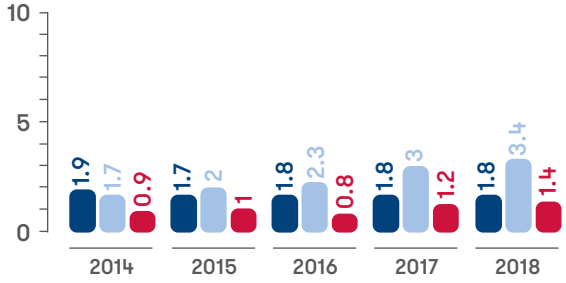
Diseases of the musculoskeletal system and connective tissue, M00-M99



Diseases of the genitourinary system, N00-N99



Diseases of the circulatory system, I00-I99

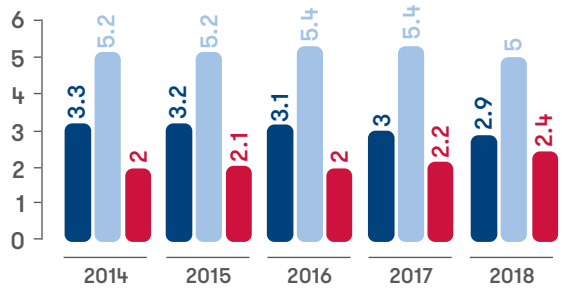


Dnipropetrovsk region Poltava region Kherson region

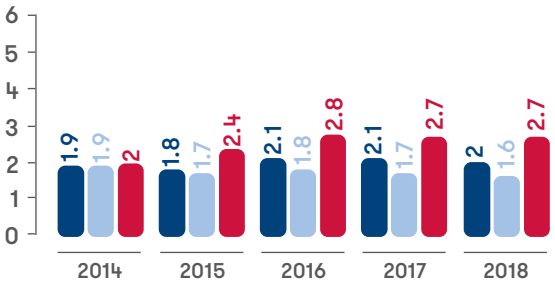
Prevalence per 10.000 children

Low prevalence (1st tertile: <3 per 10.000)

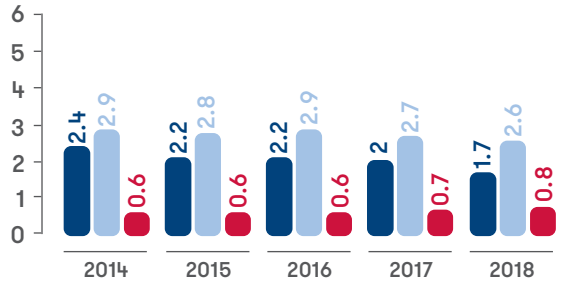
Injury and poisoning, S00-T98



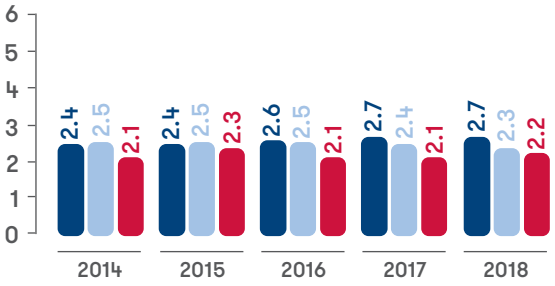
Diseases of the blood and blood-forming organs, D50-D89



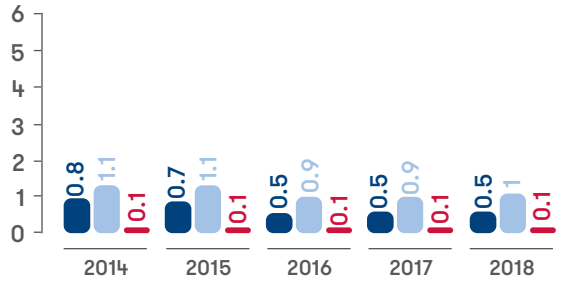
Diseases of the respiratory system, J00-J99



Diseases of the digestive system, K00-K93



Diseases of the skin and subcutaneous tissue, L00-L99



Prevalence per 10.000 children

Figure 44. Disabilities among children aged 0–17 years in Dnipropetrovsk, Poltava and Kherson regions, 2014–2018, according to the Centre for Health Statistics of the Ministry of Healthcare of Ukraine, *per 10.000 children*

NEED FOR PAEDIATRIC PALLIATIVE CARE

To calculate the need for paediatric palliative care the population risk assessment method used by Xavier Gomes-Batiste and Stephen Connor[54] and the assessment developed by the UNICEF and the International Children's Palliative Care Network (ICPCN)[55] based on the distribution of certain diseases and mortality from them were selected.

In addition to the general assessment of paediatric palliative care needs, the assessment also separately calculated the need for symptomatic and specialised palliative care, as well as the average daily number of children and their families needing such care. The following coefficients were used for this purpose:

- **Symptomatic load factor.**

  Because not all diagnosed patients need palliative care at a point in time, the symptomatic load factor is used, i.e. the severity of symptoms, especially pain. It is reported that pain in progressive non-malignant conditions occurs at an average rate of 67 %, so the average factor is 0.67[56]. The factor is 0.8 for cancer and 0.6 for HIV / AIDS.

- **Specialised palliative care factor.**

  A factor of 0.375 was used to determine the need for specialised palliative care[57].

- **Average daily census (ADC).**

  Some children need palliative care for a short period of time (for example, only one day), while others may need care for up to 365 days each year. To calculate the average projected daily need, this figure is calculated by applying an average length of care for children in need of palliative care (about 70 days for adults and 100 days for children)[58].

- **Patient's family members.**

  In addition to children with incurable diseases palliative care services are also provided to at least two members of their family. Therefore, according to the method developed by Thomas James Lynch, the indicator "average daily number of children in need of specialised palliative care" was multiplied by 3 to take into account their family members[59].

54 / Xavier Gomes-Batiste & Stephen Connor. Building Integrated Palliative Care Programs and Services. First Edition: May 2017, Liberduplex, 2017. p. 384

55 / Ibid. UNICEF, ICPCN. Assessment of the Need for Palliative Care for Children. Three Country Report: South Africa, Kenya and Zimbabwe. 2013. p.71.

56 / World Health Organisation. (2016). Planning and implementing palliative care services: a guide for program managers. World Health Organisation. URL: https://apps.who.int/iris/handle/10665/250584;
Xavier Gomes-Batiste & Stephen Connor. Building Integrated Palliative Care Programs and Services. First Edition: May 2017, Liberduplex, 2017. p. 384
UNICEF, ICPCN. Assessment of the Need for Palliative Care for Children. Three County Report: South Africa, Kenya and Zimbabwe. 2013. p. 71.

57 / Ibid.

58 / Ibid.

59 / Lynch, Thomas James. Palliative care needs assessment. Translated from English. 2013
URL: https://www.soros.PI/wp-content/uploads/2018/02/Palliative_care_needs_assessment.pdf.

To determine the need, based on the distribution of certain diseases and mortality from them, inquiries were sent to the Health Departments of Region State Administrations to assess the distribution of diseases and conditions threatening or limiting life among children. According to the 2018 data obtained, 6.802 children in Dnipropetrovsk region had diseases and conditions that needed palliative care, compared to 2.891 children in Poltava region, and 1.664 in Kherson region. The most common conditions that necessitated palliative care were congenital abnormalities and neonatal conditions, cancer, and HIV / AIDS. To assess the need for the "end-of-life" service ("EoL"), data on the absolute number of children who died from life-threatening diseases was collected.

The two methods of the needs assessment were applied: the population risk assessment method and assessment based on the distribution of certain diseases and mortality from them. Based on these methods, the following needs for paediatric palliative care were calculated **(Table 16)**:

- **Dnipropetrovsk region:** 5.794 to 8.111 children or 117 persons per 10.000 children. The need for specialised palliative care was 1.774 persons. The ADC of children in need of palliative care was about 1.900, and 5.591 persons if we include their family members. The need for EoL palliative care was 191 children.
- **Poltava region:** 2.328 to 3.260 children or 124 persons per 10.000 children. The need for specialised palliative care was 750 persons. The ADC of children in need of palliative care was 792 persons, and 2.376 persons if we include their family members. The need for EoL palliative care was 43 children.
- **Kherson region:** 1.963 to 2.748 children or 84 persons per 10.000 children. The need for specialised palliative care was 430 persons. The ADC of children in need of palliative care was 456 persons, and 1.368 persons if we include their family members. The need for EoL palliative care was 33 children.

In total, in three regions the need for paediatric palliative care was 102 persons per 10.000 children.

It should be noted that the study of paediatric palliative care needs had some limitations. The calculation was based on the data obtained from the heads of the healthcare facilities. In some cases, the information indicated that managers and physicians were unaware of paediatric palliative care matters, so clarification of data was needed. In addition, it was not possible to compare the information obtained due to a lack of national statistics data.

Table 16. Calculation of need for paediatric palliative care in Dnipropetrovsk, Poltava, and Kherson regions, according to 2018 data

Index	Population risk assessment			
	Calculation	Dnipropetrovsk region	Poltava region	Kherson region
A. Number of children aged 0–17 years, persons	–	579.371	232.841	196.286
B. Number of children aged 0-17 years who need palliative care	A*1 % - A*1.4 %	5.794 – 8.111 (average: 6.953)	2.328 – 3.260 (average: 2.794)	1.963–2.748 (average: 2.355)
Index	**Assessment based on the distribution of certain diseases and mortality from them**			
	Calculation	**Dnipropetrovsk region**	**Poltava region**	**Kherson region**
A. Number of children aged 0–17 years, *persons*	–	579.371	232.841	196.286
B. Number of children aged 0-17 years who need palliative care	Дані від ДОЗ	6.802	2.891	1.664
C. Need for palliative care per 10.000 children	(B/A)*10.000	117	124	84
D. Number of people in need of symptomatic support*	B*0.67	4.651	1.996	1.145
E. Number of people in need of specialised palliative care	D*0.375	1.744	748	429
F. Average daily census of children in need of palliative care	(B*100)/365	1.864	792	456
G. Average daily census of children and their family members in need of palliative care	F*3	5.591	2.376	1.368
H. Average daily census of children in need of specialised palliative care	(E*100)/365	478	205	118
I. Average daily census of children and their family members in need of specialised palliative care	H*3	1.433	615	354
J. Calculation of the need for EoL palliative care	-	191	43	33

* The following factors were used for diseases and conditions that require palliative care: 0.6 for AIDS, 0.8 for cancer, 0.67 for others. The number of persons in need of symptomatic support is calculated as the sum of persons who had certain diseases and conditions, adjusted by appropriate factors.

THE NETWORK OF FACILITIES PROVIDING MEDICAL REHABILITATION AND PALLIATIVE CARE SERVICES FOR CHILDREN

MEDICAL REHABILITATION AND PALLIATIVE CARE

A service map showed the existing network of healthcare facilities could not meet the needs of children and families for medical rehabilitation and palliative care services. Medical rehabilitation services were provided by 16 facilities in Dnipropetrovsk region, 11 in Kherson region, and 8 in Poltava region **(Table 17)**. In all three regions, most of these facilities are located in the region capital, and the accessibility to medical rehabilitation services in the districts is low.

According to the data received, as requested within the Pilot, the facilities reported that they were less likely to provide medical rehabilitation services to older children than those aged 0 to 3 years. This does not mean that these facilities did not have rehabilitation services for young children, but rather that this is a consequence of the limited use of early development diagnostics. Thus, less than half of the facilities that provided medical rehabilitation services in Dnipropetrovsk (7 out of 16) and Kherson (5 out of 11) regions reported the availability of assessment services using screening or developmental scales for children under 3 years, while in Poltava region two-thirds (5 out of 8) were reported. Only four facilities in each region had a follow-up service. Respite (rest) services were not mentioned by any facility. Among other services, the prescription of drugs and medical devices for individuals (special beds, prostheses, wheelchairs etc.) was mentioned.

Dnipropetrovsk region has the greatest number of beds (481) for children undergoing medical rehabilitation, compared to 399 beds in Kherson region. In this context, Poltava region stands out by having only 37 beds for the inpatient medical rehabilitation of children. In all regions, there are very few beds for parents who accompany children during inpatient rehabilitation.

Regarding human resources, all PHCCs that reported the provision of medical rehabilitation services noted that such services were provided by general practitioners such as family doctors. Medical rehabilitation specialists, physical therapists and physiotherapists were only in specialised facilities. There were very few psychologists, speech therapists, occupational therapists, and social workers.

Table 17. Results of mapping medical rehabilitation services for children aged 0-17 years in Dnipropetrovsk, Poltava and Kherson regions (according to the data received, as requested within the Pilot)

	Dnipropetrovsk region	Poltava region	Kherson region
Provided feedback, as requested within the Pilot, *facilities*	45	43	35
Provided medical rehabilitation services, *facilities*	16	8	11
Geography of facilities that provided medical rehabilitation services, *facilities*			
In the region capital	11	5	4
In districts	5	3	7
The level of healthcare of facilities that provided medical rehabilitation services, *facilities*			
Primary	6	1	1
Specialised / highly specialised	10	7	10
Availability of selected medical rehabilitation services, *facilities*			
Medical rehabilitation of children aged 0-3 years	10	6	5
Medical rehabilitation of children aged 3-17 years	12	8	8
Assessment of the development of a child under 3 years using screening or developmental scales	7	5	5
Follow-up care	4	4	4
Number of beds for patients in need of medical rehabilitation services			
For children	481	37	399
For adults accompanying paediatric patients	43	2	12
Personnel providing medical rehabilitation services to children, *persons*	154	101	63
Medical rehabilitation specialist	6	4	1
Physical therapist, physiotherapist	7	3	5
Occupational therapist, assistant occupational therapist	3	-	-
Speech therapist	19	4	5
Psychologist	12	4	6
Social worker	-	2	1
Other specialists	107	84	45

The network of facilities providing paediatric palliative care in the three regions is even smaller and is mainly represented by the primary level of health care **(Table 18)**. Thus, in Poltava region, only 4 out of the 43 facilities that responded to the Pilot's request provide palliative care services to children, and 2 of them were PHCCs. In Kherson region, 7 out of the 10 facilities involved in the provision of such services belonged to the primary level of health care, and 17 out of 18 in Dnipropetrovsk region. Accordingly, a very small number of facilities in each region provide inpatient palliative care. Only 2 facilities in Dnipropetrovsk region and 1 facility in Kherson region reported palliative care at home / a mobile palliative care team.

Table 18. Results of mapping paediatric palliative care services for children aged 0–17 years in Dnipropetrovsk, Poltava and Kherson regions (according to the data received, as requested within the Pilot)

	Dnipropetrovsk region	Poltava region	Kherson region
Provided feedback, as requested within the Pilot, *facilities*	45	43	35
Provided paediatric palliative care services, *facilities*	18	4	10
Geography of facilities that provided paediatric palliative care services, *facilities*			
In the region capital	9	2	2
In districts	9	2	8
The level of health care of facilities that provided paediatric palliative care services, *facilities*			
Primary	17	2	7
Specialised / highly specialised	1	2	3
Availability of selected services of paediatric palliative care, *facilities*			
Outpatient palliative care	17	3	8
Inpatient palliative care	1	2	3
Palliative care at home / mobile palliative care team	2	0	1
Number of beds for patients in need of paediatric palliative care services			
For children	11	11	20
For adults accompanying paediatric patients	3	3	11
Personnel providing paediatric palliative care services, *persons*	273	97	86
Paediatrician familiar with palliative care	15	33	17
Nurse familiar with palliative care	24	1	2
Psychologist or paediatric psychologist	1	1	2
Other specialties	233	62	65

According to the results, the number of available beds for paediatric palliative care in both Dnipropetrovsk and Poltava regions were only 11 for children and 3 for accompanying adults compared to 20 for children and 11 for adults in Kherson region.

Although only 4 facilities in Poltava region reported providing palliative care to children, they employ 33 paediatricians who are familiar with such services; this is twice as many as the number of staff employed in Dnipropetrovsk and Kherson regions despite there being many more facilities (18 and 10, respectively) involved in the provision paediatric palliative care. There are very few nurses trained in paediatric palliative care, especially in Poltava and Kherson regions. In general, the mapping of paediatric palliative care services showed a lack of necessary specialists and types of care available. Primary care usually provides screening and prescriptions, but there are almost no options for receiving palliative care at home. There are a lack of community nurses and mobile teams.

ASSESSMENT OF THE PROVISION OF MEDICAL REHABILITATION AND PALLIATIVE CARE SERVICES

Service providers, parents of children with special needs, and participants of in-depth interviews and focus-group interviews confirmed the lack of medical rehabilitation and palliative care services, emphasising the poor availability of palliative care. As for palliative care, most service providers mentioned a high demand for outpatient services and a need to develop this area. Service providers believe it might be more appropriate to provide palliative care services in specialised departments for certain conditions, rather than open a separate department.

In interviews, service providers reported on the availability of hospital-based palliative care units and private palliative care centres, but not for children.

According to the respondents, the list of region facilities providing medical rehabilitation services is more extensive than the network of palliative services. At the same time, rehabilitation facilities often do not have the necessary personnel to provide comprehensive services. There is lack of medical rehabilitation specialists, physical therapists, psychologists, speech therapists, and occupational therapists. Service providers felt that even specialised facilities set up to care for children with disabilities were currently unable to provide a quality range of medical rehabilitation and paediatric palliative care services.

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> The family receives social support. The boy with special needs is already 14 years old, he has a very high level of intelligence, but he has a such severe cerebral palsy that he can neither eat nor go to the toilet. He learns extremely well through the computer. The mother is in such a condition that the child must be taken away urgently, but where to? If he goes to an institution, he will be given shots and pills, and in six months he will become a “vegetable”. It's just a stalemate situation.
>
> ”
>
> A representative of the NGO service, Poltava region

The existing facilities and specialists cannot meet current demand. Parents of children with disabilities often have to wait a long time for free services. “***We should have a free massage. Only the waiting list is for 3-4 months. The same is with free prescriptions. The child fell ill today, I was given a prescription today, but will receive the medicine six months later***”, the mother of a child with special needs, Kherson region.

Service recipients spoke of geographical, administrative, and financial constraints, the unsatisfactory quality of services, including medical errors, and the needs of children and their families being ignored in the provision of medical rehabilitation services. In terms of the accessibility of services, respondents reported difficulties trying to reach the facility from another settlement or from another location within the city due to transport and streets not being adapted for inclusiveness. ***“The older she [child]becomes, the less she goes out, because barriers are everywhere. I need to ask someone to bring her in, take her out. And she grows, develops. Mentally she is healthy”***, the mother of a child with special needs, Poltava region). Parents remarked that public transport drivers sometimes do not want to take passengers who are exempt from paying the fare, and in some cases still demand payment from the accompanying person. ***“I cannot ride with my child despite my special ID. Drivers start arguing with me. And my child can’t stand swearing: shortness of breath, crying and anxiety”***, the mother of a child with special needs, Kherson region. One of the parents of a child with a palliative condition in Dnipropetrovsk region said that he had to call an ambulance with oxygen to transport the child, as this was the only safe way for them to be transported. Each time a request call is made for an ambulance he must again explain the child’s situation and why they need transportation.

Administrative constraints arise because facilities can only provide services free of charge to persons living in the vicinity, whereas other service recipients must pay for them. ***“There is a rehabilitation centre in Kakhovka. When I tried to apply, they said that they accept only Kakhovka people, not the people from the village”***, the father of a child with special needs, Kherson region.

Parents mentioned the need to seek paid services due to the low quality or total lack of a similar free service and highlighted the practice of so-called “donations” or “pocket-money” informal payments for free services. ***“We go to a private health centre to receive ozone therapy. We don't have it anywhere else”***, the mother of a child with special needs, Poltava region. Some parents expressed distrust towards the quality of rehabilitation services which public facilities provide free of charge. ***“We went to a medical rehabilitation centre. There are inadequate people there. Always dissatisfied with my child. They need the children to just sit and do nothing”***, the mother of a child with special needs, Dnipropetrovsk region.

Another problem when providing services is ignoring the needs of children and their families. There is not always targeted assistance, an individual approach or specialised rehabilitation programmes. For example, sanatorium treatment or inpatient palliative care in most cases are designed only to accommodate children, not their parents. Such facilities are often visited by children living in other towns. ***"I have a 14-year-old child taller than me. If he is hospitalised, we sleep in the same bed. Good if there is a settee or if someone is discharged, leaving a free bed"***, the mother of a child with special needs, Kherson region. In Dnipropetrovsk region, an interviewed mother reported receiving a free camp voucher for her child with deafness, but the child could not be accompanied, and there were no specialists (speech therapists) in the camp who could take care of hearing aids and provide relevant treatment to the child. Parents reported that medical devices, equipment, or services provided free of charge could not always be used. Thus, in the Dnipropetrovsk region, the mother reported that she could receive free diapers, but they were the wrong size and could not be exchanged.

Even facilities providing rehabilitation and / or palliative care services are often not inclusive; they do not have ramps, special elevators for wheelchairs, or appropriate WCs. ***"Our region rehabilitation centre for children with disabilities is a three-storey building. And to reach the groups of children we need to move from one building to another using several staircases. We have to carry our children"***, the mother of a child with disability, Kherson region.

Another problem relates to incomplete individual rehabilitation plans (IRP) for children with disabilities, and the impossibility to receive free rehabilitation services. Rehabilitation centre personnel claimed that providing services free of charge that were not listed in the IRP was an abuse of authority and punishable by law. Parents and rehabilitation providers have shared that doctors do not always complete the IRP for various reasons, for example, due to the lack of necessary additional certificates. The situation is worse among children who do not have up-to-date documents confirming their disability. Despite their need for free rehabilitation programmes, such children cannot apply. At the same time, especially in rural areas, parents cannot access the service or simply do not have the opportunity to prepare all the necessary documents without additional support. In one interview, social workers spoke of a girl with a cleft palate and mild mental retardation who had lived in the facility for four years and had not been granted a disability status during that time.

> "I knew about the rehabilitation centre, but my child did not have a disability status until the age of five so we could not cross the threshold."
>
> The mother of a child with special needs, Kherson region

Service providers and recipients expressed opposing views on the availability of information about services. Representatives of facilities and services believe information is transparent and fully informs parents. ***"It all depends on the parents. A lot of information is publicly available"***, a representative of the CSSFCY, Kherson region.

Instead, parents argued that it was very difficult to obtain information. Social welfare and social services often do not announce changes in procedures, laws and relevant services; the information is unclear. Parents of children with special needs claimed that they learned much more in their community or from representatives from NGO services than from government agencies. The human factor is important; in isolated cases, parents praised social workers. For example, in a district of the Kherson region, a social service representative created a group for parents of children with special needs, and regularly updated them via Messenger.

> “We learn by word of mouth. I accidentally learned about the genetic centre in Kharkiv. I came to our geneticist and asked: “Is it possible to go to this Kharkiv centre?” - “Yes, of course.” “Why didn't you tell me?” “Well, all moms say it's expensive, so I'm silent.” It's your job to tell us! And we shall decide whether it is expensive or not. As a result, it turned out that it was not a mental disability, but a metabolic disorder. And we started all over again.”
>
> The mother of a child with special needs, Kherson region

The process families with children in need of rehabilitation services encounter can hardly be regarded as patient oriented. Parents face bureaucracy, a lack of electronic services, and due to the fragmentation of services, they are required to fill out the same documents and obtain the same certificates for each and every service, and often visit a large number of facilities without a clear understanding of the referral process. As there are no specialists to babysit a child at home or facilities where parents can leave their child for a few hours, single parents are forced to bring their child along with them. If the child is less mobile, this process is further complicated by transport barriers. District residents of the region who received rehabilitation services outside their place of residence reported that their children had to undergo the same health tests at each facility.

> “I have a child with cerebral palsy, every two years you have to confirm the diagnosis. I come to a neurologist who confirms the diagnosis. Then I go to the children's region hospital where I have to stay a certain amount of days. It does not always have a bed, so we go to the day hospital for 10 days. Then with the certificate, I return to my neurologist. Based on this certificate, the neurologist refers us to the special committee. They issue another certificate. I have to go to a mental hospital where they issue their certificate. I also have to go to the tax agency, request a certificate of income, because without it, social welfare will not accept my documents. I have to get a certificate from the pension fund, the employment centre that I am not registered there. The certificate of family composition and certificate of the place of registration is issued in the most terrible place. And all my documents confirming that I do not work. All these photocopies, piles of documents I bring to social welfare, there I am given a slip for a certain day to see a specialist (in two or three days). I give all these documents, and within three months the disability is confirmed again. That is, for three months I do not receive social benefits. Yes, they will be paid, but in three months. And what am I supposed to do for these three months, if I am alone with two children, no one cares.”
>
> The mother of a child with special needs, Kherson region

One of the key problems in the system of medical rehabilitation and palliative care is the lack of support for parents at the community level, especially for families without relatives. This is also one of the main factors for placing children in a facility. In the interviews, the parents said they could not get sick because there would be no one to take care of their child; they do not have time for themselves: ***"Once I fell ill. I had money, but no service in the city of Kherson could bring me medicines. One child is small and sick. The other child has epilepsy. It was awful"***, the mother of a child with special needs, Kherson region. Medical rehabilitation and palliative care needs are not met in a day hospital and at home. There are no respite / rest services for parents of children with special needs, although there is demand for it. Parents need help with paperwork to receive services, to collect documents and arrange temporary care for children when visiting different institutions; this problem is urgent for single mothers and fathers. ***"There must be a social worker who can help with the documents or stay with children"***, the mother of a child with special needs, Dnipropetrovsk region.

All parents expressed the opinion that there was a lack of interventions aimed at reducing stigma and discrimination against children with special needs, including their peers and relatives: ***"My mother calls her [child] a fool and a moron. The family does not support us"***, the mother of a child with special needs, Dnipropetrovsk region. According to parents, if facilities had psychological services, they were more for children than their family members; there was a lack of psychological support services for family members: ***"It would be important for a mother and child to immediately attend courses where they would be told how to live with the disability or special needs"***, the mother of a child with special needs, Dnipropetrovsk region. Parents also noted that they lacked social housing benefits and support in equipping their home in line with their children's needs. There was a lack of quality counselling on how to care for a child given their health status, physical and / or mental levels of development.

ACCORDING TO THE INTERVIEWS, THE TOP PRIORITY IN BUILDING A SYSTEM OF MEDICAL REHABILITATION AND PALLIATIVE CARE FOR CHILDREN SHOULD BE BRINGING SERVICES AS CLOSE AS POSSIBLE TO FAMILIES — THROUGH THE INTRODUCTION OF MODELS WHEREBY CHILDREN WILL NOT BE SEPARATED FROM PARENTS AND FAMILIES FOR A LONG TIME. THIS WILL PROMOTE THEIR HEALTH AND DEVELOPMENT AND IMPROVE THEIR QUALITY OF LIFE.

THE RESULTS OF THE NEEDS ASSESSMENT OF CHILDREN AGED 0-6 YEARS AND THEIR FAMILIES FOR SOCIAL SERVICES

The social services system is expected to provide for children and families in crisis, to help them solve their problems and minimise negative consequences. The needs assessment involved collecting data on the number of families and children in need of social support and the extent to which available social services meet the needs of children and families. To answer these questions, statistical analysis of children's data and available services was conducted, along with a qualitative study comprised of in-depth interviews with providers and recipients of social services.

DATA ON CHILDREN IN NEED OF SOCIAL SERVICES

The social services system for children in Ukraine includes two main areas: prevention of separation of families, and assistance to children in difficult life circumstances such as disability, serious illness, homelessness, conflict with the law, substance use, abuse, parents or their substitutes neglecting their responsibilities, natural disaster or armed conflict[60].

There is no registry of children in need of social services in the country. The Service on Children's Affairs keeps records of children deprived of parental care, children in difficult life circumstances, the network of facilities providing social services for families, children and youth, and families in difficult life circumstances that have been supported by such services. As a result of such record keeping, we were only able to obtain aggregated data on children deprived of parental care and children in difficult life circumstances.

Orphans and children deprived of parental care

According to the information requested within the Pilot from the Service on Children's Affairs of the three region state administrations, as of the end of 2018 there were more than 13.500 first-registered orphans and children deprived of parental care under 18 years, in particular 8.649 children in Dnipropetrovsk region, 2.122 children in Poltava region and 2.778 children in Kherson region.

As of the end of 2018 and 2019, more than 1.100 orphans and children deprived of parental care resided in the institutions of three regions that report to the Ministry of Education and Science, the Ministry of Healthcare and the Ministry of Social Policy **(Table 19)**.

Children in difficult life circumstances

As of the end of 2018, there were more than 5.200 children aged 0 to 18 years in difficult life circumstances registered with Service on Children's Affairs in three regions: 3.514 children in Dnipropetrovsk region, 1.178 children in Kherson region and 571 children in Poltava region. These are mainly children living in families where the parents / guardians neglect their parental responsibilities. Not all children registered with Service on Children's Affairs received social support. In 2018, between a half and two-thirds of children were covered by CSSFCY social support; 53 % (514 out of 966) in Kherson region, 56 % (1.913 out of 3.436) in Dnipropetrovsk region and 64 % (359 out of 559) in Poltava region. **(Fig. 45)**.

60 / CMU Resolution "Some issues of social protection of children in difficult life circumstances, including those that may threaten their lives and health" as of 03.10.2018 No. 800. URL: https://zakon.rada.gov.ua/laws/show/800-2018-n.

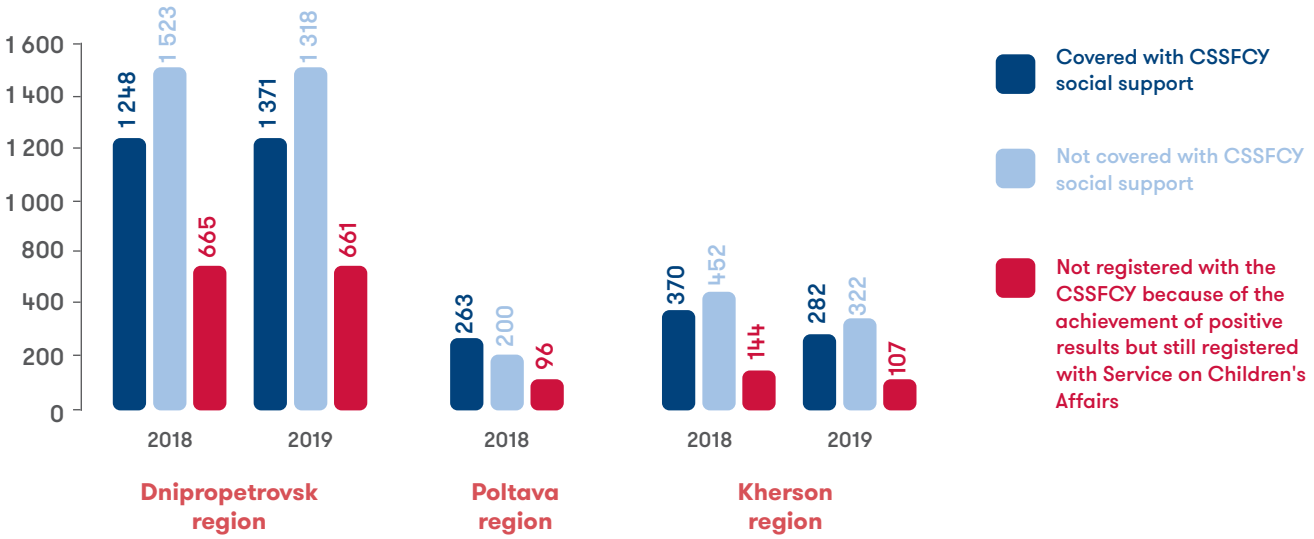


Figure 45. Number of children registered for social support services with the Services on Children's Affairs of Dnipropetrovsk, Poltava and Kherson regions, 2018-2019, *persons*

Table 19. Number of orphans and children deprived of parental care who used to reside in institutions, and who during the year moved from these facilities to family-based care, Dnipropetrovsk, Poltava and Kherson regions, according to Services on Children's Affairs of Region State Administrations, *persons*

	Dnipropetrovsk region				Poltava region*		Kherson region			
	residents as of the end of 2018	residents as of the end of 2019	moved to families during 2018	moved to families during 2019	residents as of the end of 2018	moved to families during 2018	residents as of the end of 2018	residents as of the end of 2019	moved to families during 2018	moved to families during 2019
Facilities managed by the Ministry of Education and Science, including:	538	520	61	78	85	3	24	25	3	7
Children's homes and boarding schools of general education	129	107	39	41	20	3	3	11	3	-
Sanatorium boarding schools	45	55	-	-	2	-	1	5	-	4
Specialised boarding schools of general education	2	1	-	-	18	-	-	2	-	1
Special boarding schools of general education for children in need of correction of physical and (or) mental development	11	7	1	13	31	-	6	6	-	1
Education and rehabilitation centres	344	328	17	19	14	-	1	1	-	-
Other types of facilities which provide long-term inpatient stay for children	7	22	4	5	-	-	8	-	-	1
Baby homes managed by the MOH (specialised baby homes)	121	123	136	107	42	28	13	22	4	8
Facilities managed by the Ministry of Social Policy (children's care homes of profiles I-IV)	94	88	9	3	20	-	40	35	1	3
Total	**753**	**731**	**206**	**188**	**147**	**31**	**201****	**226****	**8**	**18**

* In Poltava region, only 2018 data is available.

** The total figure does not match the totals from facilities managed by the three Ministries. This is stated in the information provided by the Service on Children's Affairs.

THE NETWORK OF FACILITIES PROVIDING SOCIAL SERVICES FOR CHILDREN

Mapping of social services for children aged 0-6 years was carried out with the support of Services on Children's Affairs of the region state administrations. 135 facilities and units (sectors) of the subdivisions of local government executive bodies in the three regions reported the provision of services in 2019, including 61 facilities / units in Dnipropetrovsk region, 43 in Poltava region, and 31 in Kherson region **(Table 20)**.

The vast majority of facilities in all regions are CSSFCY or units / sectors of social facilities. There are very few social and psychological rehabilitation centres or crisis centres for mothers and children to temporarily stay in, and most are located in the region capital or large cities.

Among the assessed families, social services were provided by 328 specialists in Dnipropetrovsk region, 132 specialists in Poltava region, and 91 specialists in Kherson region. The lion's share of all specialists who provided social services to children and their families are social work specialists. They are concentrated primarily in the CSSFCY and structural units of the executive committees of the ATC / city / village councils. Social rehabilitation centres and mother and child centres had a wider range of specialists, including doctors.

Table 20. Mapping of social services for children aged 0-6 years in Dnipropetrovsk, Poltava and Kherson regions (according to the data received, as requested within the Pilot)

	Dnipropetrovsk region	Poltava region	Kherson region
Number of facilities that reported the provision of social services, including:	**61**	**43**	**31**
CSSFCY	41	30	15
Centres for social services	3	1	6
Territorial centres of social services	-	-	2
Territorial centres of social services for families, children and youth	-	-	5
Structural subdivisions (social welfare, social and humanitarian aspects, health, etc.) of ATC / city / village councils' executive committees	7	-	-
Centres of social support for children and families	2	-	-
Mother-and-child social centres	-	1	1
Centres for social and psychological assistance	1	-	-
Centres for social and psychological rehabilitation of children	5	2	1
Centres for integrated rehabilitation of children / people with disabilities	-	5	-
Training and rehabilitation centres	-	2	-
Day care centres	1	-	-
Children's care homes	1	2	-

	Dnipropetrovsk region	Poltava region	Kherson region
Geographical location of facilities			
Region capital	17	5	3
Districts	44	38	28
Average monthly number of children supported by services (in 2019), *persons*, including:	**772**	**851**	**562**
Aged 0-3 years	329	364	235
Aged 4-6 years	443	487	327
Bed availability, beds, including:	**154**	**364**	**80**
Number of inpatient beds for children	126	199	70
Number of day-care beds for children	10	155	-
Number of beds for adults accompanying children	18	10	10
Human resources, *persons*, including:	**432**	**298**	**103**
Social workers	328	132	91
Psychologists	43	28	8
Teachers, educators	39	31	3
Education and health workers for rehabilitation	13	89	-
Other specialists	9	18	1

All facilities that responded to the request are municipal. Sources of funding to pay for the positions of social work specialists include region, city, and district budgets, ATC budgets (as well as ATC co-financing), and village councils.

During the mapping process, data on the provision of three types of services was requested **(Table 21)**:

1. services provided near the place of residence;
2. assistance to a child in crisis;
3. services aimed at supporting children with developmental disorders and children with disabilities.

Among the services provided near the place of residence, the most common were social support (250-300 families / children per month) and psychological support and counselling (600-700 families / children per month). In comparison to Dnipropetrovsk and Poltava regions, more facilities in Kherson region reported counselling services for pregnant and postnatal women, reaching approximately 150 children / families each month.

The most common service aimed to help a child in crisis was providing shelter to children in life / health-threatening situations (about 10 children per month in Poltava region, about 20 in Kherson region and about 80 in Dnipropetrovsk region). Such services are provided by centres for social and psychological rehabilitation of children and mother and child centres.

In Poltava region, provision of services aimed at supporting children with developmental disabilities and children with disabilities was higher. Facilities that provided such services mainly organised classes delivered by specialists (a psychologist or speech therapist) and provided social and psychological rehabilitation in a day-care and inpatient setting. Each month, the approximate number of children to receive early intervention services was only 50 children in Dnipropetrovsk and Poltava regions, and even fewer in Kherson region; approximately 30 children per month.

Table 21. Type of social services available for children under the age of 6 years and their family members in Dnipropetrovsk, Poltava and Kherson regions and the number of persons receiving services, 2019 (according to the data received, as requested within the Pilot)

	Average monthly number of children / families receiving services		
	Dnipropetrovsk region	Poltava region	Kherson region
Services provided near the child and family's place of residence, including:			
Social support near the child and his / her family's place of residence	259	306	297
Psychological support and counselling of parents on the care and development of children	603	715	734
Development of parenting skills (courses / clubs for parents on early development)	66	10	-
Counselling for pregnant women and mothers with newborns to prevent abandonment	34	-	152
Support to family-based care	-	30	-
Social prevention	14	-	12
In-kind support	-	-	11
Providing a range of social services to families in difficult life circumstances lacking support	-	7	-
Assistance to a child in crisis, including:			
Providing shelter to children in life / health-threatening situations	82	13	21
Providing shelter to mothers with children	8	7	9
Crisis and emergency intervention	7	-	10
Provision of social and psychological services	-	-	9
Care and education of children in alternative family care (inpatient)	-	-	8
Promoting the return of children to the biological family	-	-	4
Patronage care of a child in a patronage parent's family	1	4	6

	Average monthly number of children / families receiving services		
	Dnipropetrovsk region	Poltava region	Kherson region
Services aimed at supporting children with developmental disorders and children with disabilities, including:			
Classes of a psychologist with children	205	445	22
Classes of a speech therapist with children	83	336	8
Classes of a special education teacher with children	-	97	-
Socio-psychological rehabilitation of children with disabilities in day care	73	232	-
Early intervention service	45	49	29
Palliative care of children (inpatient)	5	-	-
Socio-psychological rehabilitation of children in day care	2	116	-
Socio-psychological rehabilitation of children (inpatient)	153	89	18
Socio-psychological rehabilitation of children with disabilities (inpatient)	2	58	-

ASSESSMENT OF THE STATUS AND PROSPECTS OF PROVIDING SOCIAL SERVICES TO CHILDREN

In the context of the reform of baby homes, it was important to determine the capacity of the existing network of social facilities to meet the social services needs of children aged 0-6 years, including the possibility of providing round-the-clock care to children separated from families due to life and health risks or those abandoned by their parents. The results of the mapping and qualitative assessment show that currently there are very few alternatives to baby homes for children aged 0-3 years.

Services for children separated from the family due to a threatening environment

The ideal option would be to place such children in patronage families. With the adoption of Law No. 936-VIII[61] as of 26 January 2016, patronage care was introduced in Ukraine at state level. The process to create patronage families requires special training and resources to promote, recruit and train potential patronage carers.

Four years have passed, but still there are very few patronage families in the country; only 1 in Dnipropetrovsk region, 4 in Poltava region, and 6 in Kherson region. Representatives of social welfare bodies reported that the patronage care development process is very difficult due to few applicants, a long training process, and bureaucratic procedures. According to the law, patronage families can take children only from their area. Therefore, if there is no patronage family or social and psychological rehabilitation centre in the city / ATC of the region, the only option for a separated child is to be placed in a baby home.

61 / Law of Ukraine as of 26.01.2016 No.936 "On amendments to certain legislative acts of Ukraine concerning strengthening of social protection of children and supporting of families with children". URL: https://zakon.rada.gov.ua/laws/show/936-19#Text.

> “
>
> There are no patronage families in our district. The children of this age are placed in the Kremenchuk baby home. There is a centre of social and psychological rehabilitation in the Kyiv district territory, but it is for children of 4 years and older. Children need to be somewhere.
>
> ”
>
> A representative of the Service on Children’s Affairs, Poltava region

Centres of social and psychological rehabilitation can act as alternatives to baby homes. There are seven such centres in Dnipropetrovsk region where a child can stay for up to 9 months for inpatient care or up to 12 months for day care. There is one centre of social and psychological rehabilitation in Kherson region and two in Poltava region, however, they admit only children aged three years and older. There are other restrictions; the centre does not admit children who are mentally ill or have symptoms of a disease during the acute stage. In Dnipropetrovsk region, the Centre of Social Support for Children and Families “It is Good at Home” / ***“Dobre Vdoma”***, has an emergency placement unit designed for 15 children aged 0-18 years, however one such centre cannot meet all needs. Urgent placement into family-based care, such as FTCH and foster care, is not possible as the law stipulates that a separated child must first be given the status of a child deprived of parental care; this process can take months or even years. ***“There may be very long court proceedings on deprivation of parental rights, the sessions may be very long, they can be postponed, it can take more than 6 months”***, a representative of the Service on Children’s Affairs, Dnipropetrovsk region.

The problem of temporary placement in most cases is solved at the expense of healthcare facilities. Children may stay in a hospital for months while they wait for the guardianship authorities to make a decision and for the paperwork to be sorted. ***“After the call to the police, such children are hospitalised to us. Then we send a message to the Service on Children's Affairs, and they decide where to place this child. Our part is providing health care for the child during his / her stay in the hospital: feeding, washing, changing clothes”***, a representative of a healthcare facility, Dnipropetrovsk region. In fact, hospitals provide temporary placement rather than health care. Given the health financing reform, hospitals will not be provided with the same financial benefits that other services providing temporary placement receive, so will not be able to cover such hospitalisations in the future.

Services for children who acquire the status of orphans or children deprived of parental care

The results of the assessment show that even after acquiring the status of an orphan or a child deprived of parental care, it may take a long time before discharge form the baby home to family-based care. In Dnipropetrovsk region, as of early Q IV of 2019, there were 175 FTCH and 341 foster families with 1.863 children[62]. In Poltava region, as of Q II of 2019, there were 134 foster families with 237 children and 39 FTCH with 248 children[63] while in Kherson region there were 122 foster families with 275 children and 67 FTCH with 444 children[64]. Currently, alternative family-based care cannot meet all needs.

62 / Portal of the Ministry of Social Policy of Ukraine "Development of family-based care", tab "Regional statistics on family-type children’s homes (FTCH) and foster families (FF)". URL: https://www.msp.gov.ua/content/rozvitok-simeynih-form-vihovannya.html.

63 / Ibid.

64 / Ibid.

Services for children who are registered with services on children's affairs due to problems in their families

As a rule, such families are referred to the CSSFCY for social support. The "pathway initiated by the organisation" – the Service on Children's Affairs, healthcare facility, or educational facility - is the main one in their work, according to CSSFCY representatives. Most of the families that received CSSFCY social services were referred by the Service on Children's Affairs. At the same time, according to Service's representatives, they reach the family quite late, when the situation is critical, and it is necessary to remove the child. ***"The Service does not always arrive on time to keep the family intact. Often when it is too late to change something"***, a representative of the Service on Children's Affairs, Kherson region. Therefore, in pathways such as this, problems are not detected early enough and assistance to prevent the removal of the child is not appropriately provisioned. Active screening of families who may potentially need social services is almost non-existent. ***"I think 40 % of children are not supported with social assistance, and in rural countryside areas, probably 90 %"***, a social worker, Dnipropetrovsk region. There is a lack of information and counselling in the community. According to CSSFCY social workers, this is due to a lack of available human resources and a large catchment area, as well as a large amount of paperwork. ***"I'm the only one in ATC. I have three thousand children. We need more personnel. There must be a psychologist, lawyer"***, a social worker, Poltava region.

Active social work specialists said that it was difficult for them to motivate parents in crisis to seek help, particularly those with addiction problems who were unaware of their needs. ***"We now conduct trainings "ABC for parents", "School of married life", other activities on responsible parenting once a month. But the interest from service recipients is very low. If you take families in crisis, it is very difficult to convince them that they need this service"***, a social work specialist, Kherson region. On the other hand, this may be due to logistical problems, inconsistencies in the format of activities with the target audience, or other barriers faced by families.

Parents who had experience of receiving social services complained about the quality of the information provided by social workers, referencing in particular the poor explanations of their rights, available services, and benefits. ***"Social welfare professionals do not explain much, do not suggest that I should apply for benefits such as a special mattress to avoid bedsores, etc.; you should go there being legally prepared"***, the mother of a child with special needs, Dnipropetrovsk region. Gaps in communication between service recipients and providers have been a major problem in the quality of available social services.

Services for families who abandon a child in a maternity hospital

The list of CSSFCY services includes work with mothers who intend to abandon their child in the maternity hospital. In practice, this means that in such cases, representatives of the healthcare facility should call a social worker from the CSSFCY or other social service centres to advise the mother, assess her needs, and motivate her to not abandon the child. During the assessment, parents of children with disabilities reported cases when doctors themselves advised them to abandon a child with disabilities regardless of the mother's choice and did not provide social or psychological support. ***"Once he was born, I was immediately told – Down's syndrome. I turned to the wall and started crying. The midwife came and said: "Why are you crying? You have two healthy children and this one will be placed in the institution"***, the mother of a child with special needs, Poltava region. Such data indicates gaps in cooperation between healthcare and social protection services to prevent abandonment of newborns. Maternity hospitals and antenatal clinics lack psychologists and social workers who can motivate

mothers not to abandon their children. In Kherson region, there are positive instances when an NGO for families with Down's syndrome children cooperates with healthcare facilities: ***"In every maternity hospital, in every antenatal clinic, there is a poster about our organisation and brochures about how to bring up such a child. It is provided immediately at the birth of a child with Down's syndrome, and parents have complete information about us, about our activities, and how to find us. We are known in all hospitals and social welfare units"***, a representative from an NGO service provider, Kherson region. At the same time, such initiatives may not be effective if health professionals themselves are uninterested in motivating mothers not to abandon the child. Both service providers and parents expressed the view that there is a lack of mother-and-child centres where mothers can live with their newborns and receive the necessary material and socio-psychological support to solve problems.

Service providers said that after the removal or abandonment of children, cases of reintegration into the family are very rare. At the same time, not all services providers understood the hierarchy of child placement options, particularly the priority to reintegrate a child into the biological family compared to family-based care. In one interview it was suggested that child abandonment and subsequent adoption was a better option than prolonged work with the mother where there had still been potential for the child to be removed once again from the family due to difficult life circumstances. ***"We had a negative experience when the mother anyway abandoned the child. The child has already been adopted. In this case, it is better that she abandoned the child, and we did not have to separate the child from the mother later"***, a representative of CSSFCY, Dnipropetrovsk region.

Services for families who place a child in an institution due to a disability, chronic physical illness, or other health problems

One of the main reasons for placing children in a baby home is the inability of parents to provide proper care and nursing. In such situations, families who place children in institutions lack the support from a social work specialist to inform them about options and available services and facilitate regular communication with the child.

Parents reported cases when social service representatives advised them to place a child in a facility during the decision-making period, saying that this was the only possible solution and source of free health care for a child. This contradicts the basic principle of social services for children; to prevent separation from the family when there is no threat to the child's life: ***"I had a situation when I was alone with two children. I asked for help here in Kherson. I was told that the help could be provided only in the institution. The facility told me that they would make concessions: "You may not abandon your child, you can leave it here for five days a week"***, a mother in difficult life circumstances, Kherson region.

CONCLUSIONS

Practices worldwide and the National Strategy of Reforming the System of Institutional Care and Upbringing of Children for 2017-2026 approved by the Government of Ukraine envisage the creation of a care and protection system where children are raised in a family or family-like environment. This includes the reintegration of children into their families, placement in other families (adoption, guardianship, foster families, etc.), as well as the creation of support services for children and families in communities that will prevent the referral of children to institutions. The main proposition is to transform MOH' baby homes for children aged 0-4 years into medical rehabilitation and palliative care centres. The results of the needs assessment and analysis of the baby homes confirmed the need for such changes, but they also revealed many problems and dilemmas along the way. The Pilot tried to summarise the existing challenges and obstacles and suggest practical steps to address them.

CHARACTERISTICS OF BABY HOME RESIDENTS

EVERY SECOND CHILD IN A BABY HOME HAS PARENTS WHO ARE NOT DEPRIVED OF PARENTAL RIGHTS.

In the Kamianske baby home, more than half of the children are placed upon the request of their parents. The exception is the Kryvyi Rih baby home where more than 80 % of orphans and children are deprived of parental care. A significant number of children who enter the facility upon the initiative of their parents may be an indication of the lack of rehabilitation, palliative care and early intervention services, untimely social support at community level, as well as a misconception that institutionalising children in difficult life circumstances is the best option.

THE GEOGRAPHICAL ORIGIN OF CHILDREN IN A BABY HOME IS EXTENSIVE, MANY COME FROM OTHER CITIES AND TOWNS.

This situation does not promote regular visits between children and parents who are not restricted in their rights. Many families live in difficult financial situations and even if they are motivated to visit their children, they may not be able to travel to another locality regularly.

CHILDREN STAY FOR UNSATISFACTORILY LONG PERIODS OF TIME IN A FACILITY.

Many children were admitted to a baby home facility under the age of 12 months and had remained there for approximately a year or more at the time of the assessment. The median length of stay in a facility ranged from 9 months (Kryvyi Rih baby home) to 15 months (Kamianske baby home). Up to a third of children have lived in a baby home for 2 or more years. The younger a child at the time of placement to a baby home is, the less likely the child will be transferred to family-based care quickly. The long stay may be the result of delays by both the guardianship authorities and the baby home administration to make decisions about the child. The long time taken in court to consider whether to deprive parents of their rights, which is a necessary condition for the child's adoption or placement into family-based care, only extends the time a child spends in a baby home. Also, as children can stay in a baby home up to the age of 6, and a facility's budget is determined by the number of children, these factors may act as deterrents for rapidly reintegrating children.

THE MEDICAL AND PSYCHOLOGICAL SUPPORT OF CHILDREN IS NOT DIFFERENTIATED, INDIVIDUAL, OR COMPREHENSIVE.

Although a baby home, as a healthcare facility, aims to provide adequate health care to children, staying in a facility exacerbates existing health problems, and deprivation leads to developmental delays in healthy children. According to doctors consulted within the Pilot, most children in facilities are somatically / neurologically healthy and only have developmental delays due to deprivation: 63 % in the Kryvyi Rih baby home, 73 % in the Dnipro baby home, 75 % in the Kremenchuk baby home, and 86 % in the Kamianske baby home. The exception is the Kherson baby home, where less than half of the children (43 %) were somatically / neurologically healthy, according to the expert assessments.

THOROUGH EVALUATION OF EACH CHILD'S DIAGNOSES HAS REVEALED "MYTH DIAGNOSIS" IN CHILDREN AND, IN SOME CASES, INCOMPLETE INDICATION OF ALL COMPONENTS OF THE DIAGNOSIS, AND INADEQUATE ICD-10 CODING, ESPECIALLY FOR NEUROLOGICAL DIAGNOSES.

A diagnosis does not always determine the severity of a disorder or the stage of disease progression. The baby home personnel are not always guided by the protocols and orders of the Ministry of Healthcare of Ukraine when providing health care.

THE TIMELINE AND SCOPE OF PREVENTIVE AND DIAGNOSTIC SCREENING AND EXAMINATION OF CHILDREN DO NOT COMPLY WITH THE MOH ORDERS.

In the Dnipro and Kamianske baby homes, no children underwent audio screening. In the Kremenchuk baby home, only 3 % of children underwent such examination, compared to approximately 30 % in the Kryvyi Rih and Kherson baby homes. More than 90 % of children from the Dnipro, Kryvyi Rih, and Kherson baby homes were not examined by a dentist, although less than a third of children in the Kamianske and Kremenchuk baby homes were examined by a dentist. Despite the prevalence of speech delay in children in the facilities, screening for early detection of autism spectrum disorders is not performed in baby homes. The lack of such examinations makes it impossible to promptly identify problems and provide the necessary rehabilitation programmes to prevent disorders.

TWO-THIRDS OF THE CHILDREN IN THE DNIPRO, KAMIANSKE, KREMENCHUK AND KHERSON BABY HOMES, AND MORE THAN 80 % OF CHILDREN IN THE KRYVYI RIH BABY HOME, SUFFER FROM CHRONIC MALNUTRITION, HOWEVER, ACCORDING TO MEDICAL RECORDS OF, IN MOST CASES THE "PROTEIN-CALORIE DEFICIENCY" DIAGNOSIS IS NOT DOCUMENTED AND APPROPRIATE TREATMENT IS NOT PROVIDED.

This indicates a lack of awareness of the anthropometric assessment; how to interpret the results and understand the criteria for determining physical developmental problems. A vicious circle develops, consisting of a physical developmental delay not being detected (failure to diagnose "protein-calorie deficiency"), failure to establish an optimal nutrition plan in the presence of increased needs, and the impact of deprivation on the child's physical development.

There is no systemic individual approach to anthropometry which allows for children with an early nutritional deficiency to be identified and their diet timely adjusted. A new regulatory framework for the organisation of nutrition interventions for children at risk of malnutrition needs to be developed. The effective CMU Resolution[65] refers to nutrition standards for children of different age groups without regard to their health status and existing international evidence-based nutrition practices (for children with neurological disorders, congenital developmental abnormalities, premature children)[66,67]. In the absence of a course for undergraduate and postgraduate students on nutrition for acute and chronic diseases, it is impossible to equip health staff with relevant theoretical knowledge and practical skills.

ALMOST ALL CHILDREN IN BABY HOMES NEED COMPREHENSIVE REHABILITATION SERVICES.

According to the Pilot's assessment, almost all children in the five baby homes had developmental delays: more than 90 % in the Kryvyi Rih, Kremenchuk, and Kherson baby homes, 86 % in the Kamianske baby home and 77 % in the Dnipro baby home. Most of these children concurrently need the services of three or more rehabilitation specialists. At the same time, in none of the three facilities the personnel structure includes the position of a physiotherapist, occupational therapist or a rehabilitation specialist.

AROUND A THIRD OF CHILDREN NEED PALLIATIVE CARE.

The maximum need for paediatric palliative care services, according to expert estimates, was 7 % in the Kremenchuk baby home, 12 % in Kamianske, 16 % in Dnipro, 28 % in Kherson and 35 % in the Kryvyi Rih baby homes. 14 % (57) of children in the five baby homes may need respite services and inpatient paediatric palliative care due to severe illness.

65 / CMU Resolution as of 22.11.2004 No.1591 "On approval of nutrition standards for education and recreation facilities" (Official Newsletter of Ukraine, 2004, Issue 47, p. 3107) URL: https://zakon.rada.gov.ua/laws/show/1591-2004-%D0%BF#Text.

66 / Defining Pediatric Malnutrition: A Paradigm Shift Toward Etiology-Related Definitions: Special Report/N.M. Mehta, and the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) Board of Directors//J Parenter Enteral Nutr. 2013;37:460–481. doi: 10.1177/0148607113479972.

67 / WHO. Guideline: Updates on the management of severe acute malnutrition in infants and children. Geneva: World Health Organisation; 2013. URL: https://apps.who.int/iris/handle/10665/95584.

CHARACTERISTICS OF FAMILIES OF CHILDREN FROM THE BABY HOMES AND THE POTENTIAL FOR REINTEGRATION

ALL FAMILIES OF BABY HOME CHILDREN, IN WHICH PARENTS ARE NOT RESTRICTED IN THEIR RIGHTS, CAN BE DESCRIBED AS "FAMILIES IN CRISIS".

Many families do not own a house, or they live in unsatisfactory living conditions. Housing problems were more common among the families of children in the Dnipro, Kryvyi Rih, and Kherson baby homes than in the Kamianske and Kremenchuk baby homes. Almost all families are in a difficult financial situation, such as debt, and depend on a social allowance. More than half of the families of children from the baby homes of Kryvyi Rih and Kamianske had household members with physical or mental disabilities, chronic illness, or injury. According to the Social Specialist from one of the project teams, almost half of the families in the sample from the Dnipro and Kryvyi Rih baby homes had household members who abused alcohol. Given these circumstances, there is always more than one reason why families place children in a facility.

THE EXPERIENCE OF LIVING IN AN INSTITUTION IS COMMON AMONG PARENTS OR OTHER ADULT FAMILY MEMBERS OF BABY HOME CHILDREN.

Half of the families of children from the Kryvyi Rih and Kamianske baby homes that were visited had adult members of the household who themselves had lived in an institution at some point in their lives, compared with a third from the Dnipro and Kremenchuk baby homes, and a fifth from the Kherson baby home. This assessment does not make it possible to establish a causal link between the experience of parents and their decision to place their child in a facility. At the same time, the prevalence of such experiences is striking and worrying. Prolonged institutionalisation, especially in the first three years of life, has irreversible consequences for the child in terms of its socio-emotional development, ability to build an emotional attachment, social integration skills, and parental instincts. Parents who were brought up in institutions, may be more inclined to place their own children in them.

MANY FAMILIES DO NOT KEEP IN TOUCH WITH THEIR CHILDREN IN FACILITIES BUT REMAIN THEIR LEGAL REPRESENTATIVES.

Although a facility has the right to initiate the process of establishing the child's status as deprived of parental care so that the child can be placed into family-based care, this is often delayed. None of the children removed by the custody and guardianship authorities were visited by representatives of these bodies, which contradicts the requirements of the Law of Ukraine "On Ensuring Organisational and Legal Conditions for Social Protection of Orphans and Children Deprived of Parental Care"[68]. There are no procedures and practices for periodically updating the contact details of parents who remain legal representatives, or analysis of the child's visits. Across the 5 baby homes, 60 children do not have the status of being an orphan or deprived of parental care; their families could not be visited due to a lack of up-to-date contact details and home address.

THE POTENTIAL FOR REINTEGRATION INTO THE BIOLOGICAL FAMILY IS VERY LOW IN ALL ASSESSED BABY HOMES, AS RISK FACTORS CONTINUE TO EXIST.

68 / Articles 5-6 of the Law of Ukraine "On Ensuring Organisational and Legal Conditions for Social Protection of Orphans and Children Deprived of Parental Care": URL: https://zakon.rada.gov.ua/laws/show/2342-15.

Out of 83 visited families (105 children), only 21 families (24 children) show a high probability of their child being reintegrated from a baby home. All others need serious support and professional social services. In 35 families with other children, circumstances required the intervention of Services on Children's Affairs and the potential deprivation of parental rights.

THE CAPACITY OF BABY HOMES

ALL FIVE BABY HOMES ARE FACILITIES BUILT DURING THE SOVIET ERA AND ARE DESIGNED FOR A LARGE NUMBER OF CHILDREN.

Children live in crowded conditions, with an average of 10 children in one room with poor basic amenities. At the time of the assessment, the Dnipro baby home was overcrowded, whereas the other baby homes were 70-90 % full.

ALL FIVE BABY HOMES NEED TO BE ADJUSTED FOR PEOPLE WITH SPECIAL NEEDS.

Almost the only adjustment is the presence of ramps to enter a building. The showers and WCs, rooms for round-the-clock stay, and classes are not adjusted for people with special needs. It is problematic to move between floors in the absence of an elevator (baby homes are two-storey buildings).

THERE ARE NO COMPREHENSIVE INDIVIDUAL REHABILITATION PROGRAMMES IN BABY HOMES.

Health staff largely provides follow-up care, not medical rehabilitation. An individual rehabilitation plan is developed only for children with a documented disability, although in reality many more children need rehabilitation services with the involvement of several specialists. The provision of psychological and educational rehabilitation services is better (except for the Kamianske and Kremenchuk baby homes where there is no psychologist) than the provision of medical services.

THE LEVEL OF STAFF INVOLVEMENT IN THE PROVIDING OF PAEDIATRIC PALLIATIVE CARE DIFFERS FROM FACILITY TO FACILITY.

Although all facilities do not have a separate palliative or hospice unit, the Kryvyi Rih and Kherson baby homes provide a wider range of such services than the other facilities. These baby homes provide assessment and treatment of pain, symptoms, special nutrition, round-the-clock medical supervision, support services, and integrative and physical therapy for palliative patients. At the same time, the methods of palliative care used today in all facilities lag behind the current level of medical science development, and partly are not grounded on the methods of evidence-based medicine. Staff is not trained for multidisciplinary coordinated work.

NURSES AND EDUCATORS ARE MOST NUMEROUS AMONG BABY HOME HEALTH AND EDUCATION STAFF.

In fact, many services are provided by these professionals. Globally, nursing homes are a common form of palliative and rehabilitation service. It should be noted that in Ukraine, nurses mostly have a professional education and their job descriptions detail few responsibilities; they perform significantly fewer clinical functions than their peers in European countries. If the structure of staff in the facilities does not change, the responsibilities of nurses will need expanding and additional training in long-term paediatric care and rehabilitation services will need to be provided.

Within the process of transforming baby homes into medical rehabilitation and palliative care centres, the list of health and education specialists will need to expand, nurses will need to be trained on individual rehabilitation programmes and areas of palliative care, or where this is not possible, specialists with such skills should be involved. All five baby homes need a physical rehabilitation specialist, occupational therapist, physical therapy assistants (like a physical therapy nurse, non-health physical rehabilitation specialists), rehabilitation nurses, prosthetic specialist, rehabilitation psychologists and psychotherapists, and a social work specialist.

THE CURRENT COST STRUCTURE IN BABY HOMES DOES NOT ADEQUATELY ALLOW FOR THE BASIC NUTRITIONAL AND MEDICAL NEEDS OF CHILDREN TO BE MET.

In the baby homes, wages / salaries and payroll costs account for more than 80 % of expenditure. The exception is the Kremenchuk baby home where staff costs accounted for 71 % of the budget. At the same time, this facility has the highest utility costs due to the vast size of its buildings. Monthly expenses per child for medicines and dressings ranged from UAH 64 (Dnipro) up to UAH 412 (Kremenchuk). Facilities spent between UAH 27 (Kherson) and UAH 48 (Kremenchuk) on meals per child per day. Given that between one third and a half of the children need clinical nutrition (products with high protein and calorie content), costs related to nutrition should be much higher. The current size of donations does not solve this problem. The transformation of facilities into municipal non-profit enterprises should be supported with a revision of the staffing list and reallocation of expenditures to really meet children's needs.

TRANSFORMATION INTO MEDICAL REHABILITATION AND PALLIATIVE CARE CENTRES WILL REQUIRE REORGANISATION OF SPACE (ESPECIALLY CHILDREN'S INDIVIDUAL SPACE) AND INVESTMENTS IN HUMAN RESOURCES IN ALL BABY HOMES. THE CAPACITY OF FACILITIES TO TRANSFORM INTO MEDICAL REHABILITATION AND PALLIATIVE CARE CENTRES DIFFERS.

Of the five facilities, the Kryvyi Rih, Kremenchuk, and Kherson baby homes provide a wide range of, and are better equipped for, rehabilitation and palliative care services. The Dnipro baby home is best equipped with specialists compared to the other facilities, despite more than 40 % of the health and education staff being working retirees who have not received training on medical rehabilitation and palliative care in the last 5 years.

In all five facilities, there are no rooms for children designed for 1-2 persons; the space is not suitable for children with special needs despite this being a requirement of the Regulations for medical rehabilitation and palliative care centres for children. The transformation into such centres will require the organisation of outpatient care, provision of services to children over 4 years old, and work familiarisation with medical information systems. This will affect a facility's management decisions in relation to flexible budget planning, human resources, and the promotion of services. Since most staff of these facilities has never worked under such conditions, this can be a deterrent.

It should be noted that several specialised healthcare facilities in all three regions, including children's hospitals and district hospitals which are better supplied with human resources than baby homes, have already been contracted by the NHSU for the provision of medical rehabilitation and palliative care for children[69]. Therefore, if transformed into medical rehabilitation and palliative care centres, baby homes will have to compete with these facilities.

NEEDS FOR MEDICAL REHABILITATION AND PALLIATIVE CARE SERVICES FOR CHILDREN AGED 0-17 YEARS

THE EXISTING NETWORK OF FACILITIES DOES NOT MEET THE NEEDS OF PAEDIATRIC MEDICAL REHABILITATION AND PALLIATIVE CARE.

Almost 13.300 children with disabilities aged 0–17 years live in Dnipropetrovsk region, more than 5.300 in Poltava region, and almost 4.000 in Kherson region. These numbers are growing every year. Most of these children are not in facilities and so need outpatient rehabilitation services. This is the minimum number of children who will need rehabilitation services, as there is no data on children who have psychophysical disorders and need early intervention and rehabilitation to prevent a disability developing. Rehabilitation specialists, physical therapists, and physiotherapists work only in specialised facilities: 26 persons in three regions. There is also a lack of psychologists, speech therapists, and occupational therapists. It is estimated that approximately 5.794 – 8.111 children, or 117 persons per 10.000 children, in Dnipropetrovsk region; 2.328 – 3.260 children, or 124 persons per 10.000 children, in Poltava region; and 1.963 – 2.748 children, or 84 persons per 10.000 children, in Kherson region need palliative care. There are no palliative care centres for children in any of these regions. Needs are not met for medical rehabilitation and palliative care services in the day care hospital, mobile palliative care, parental respite services, assistance with paperwork, and temporary childcare. There is a lack of interventions aimed at reducing stigma and discrimination against children with special needs in their environment.

NEEDS FOR SOCIAL SERVICES AND FORMS OF ALTERNATIVE CARE FOR CHILDREN AGED 0-17 YEARS

THE EXISTING NETWORK OF SOCIAL SERVICES FOR CHILDREN UNDER THE AGE OF 6 IS ALSO UNABLE TO MEET ALL NEEDS. CRITICALLY, THERE ARE ALMOST NO ALTERNATIVES TO BABY HOMES FOR THE TEMPORARY PLACEMENT OF SEPARATED CHILDREN UNDER THE AGE OF 3.

In Dnipropetrovsk region, on average 150 children under the age of 4 are removed annually from a life-threatening environment and need urgent placement due to the loss of parental care, compared to 70 children in Poltava region and 60 children in Kherson region. The problem of temporary placement in most cases is solved at the expense of healthcare facilities, such as hospitals, where children can stay for months before being transferred to a baby home or another institution.

69 / According to the NHSU electronic data, as of 22.04.2020, 17 specialised healthcare facilities in Dnipro, 10 facilities in Kryvyi Rih, 5 facilities in Kamianske, 1 facility in Kremenchuk, and 10 facilities in Kherson have already been contracted by the NHSU for the provision of medical rehabilitation and palliative care services for children. URL: https://nszu.gov.ua/e-data/dashboard/smd-contracts.

ANNUALLY, UP TO 1.250 CHILDREN IN DNIPROPETROVSK REGION, 250 CHILDREN IN POLTAVA REGION, AND 400 CHILDREN IN KHERSON REGION ACQUIRE THE STATUS OF ORPHANS OR CHILDREN DEPRIVED OF PARENTAL CARE

so need to be placed into family-based care or adoption. The results of the assessment show that even after acquiring the status of an orphan or a child deprived of parental care, it can take a long time to transfer a child into a family-based care from a baby home as there are a lack of foster families and FTCHs.

DUE TO FAMILY PROBLEMS, ANNUALLY UP TO 1.300 CHILDREN IN DNIPROPETROVSK REGION, 400 CHILDREN IN POLTAVA REGION AND 360 CHILDREN IN KHERSON REGION ARE REGISTERED WITH SERVICES ON CHILDREN'S AFFAIRS

and need intense social support in their area of residence. Active screening of families that may potentially need social services, and early detection of families in crisis are almost non-existent.

EACH YEAR, NEARLY 2,700 CHILDREN IN DNIPROPETROVSK REGION AND 1,500 IN POLTAVA REGION ARE PLACED IN INSTITUTION

for developmental delays, a disability, and the inability of families and communities to provide support, rehabilitation or habilitation in their area of residence. According to information received from parents of children with disabilities, there were cases when mothers were motivated to abandon a child with congenital abnormalities in the maternity hospital. Maternity hospitals do not always involve a social work specialist or psychologist when there is a risk of abandoning the child.

RECOMMENDATIONS

Reforming baby homes in Ukraine is at the intersection of several reforms:

- health reform which provides the distribution of the budget for health services
- reform of the child protection system - deinstitutionalisation of the system of childcare and upbringing
- decentralisation reform, particularly the transfer of responsibility for the development of social services to the level of territorial communities
- education reform - development of inclusive education

Given the progress of these reforms and international recommendations[70], there is a need to develop and implement activities to reform baby homes and develop health and social services in the regions. The Pilot recommendations are based on four objectives:

- **Strengthening interdepartmental cooperation, advocacy and streamlining the regulatory framework** – national level recommendations that include coordinated efforts of three ministries - the Ministry of Healthcare, the Ministry of Social Policy, the Ministry of Education and Science - and local authorities.
- **Implementing educational programmes and strengthening human resources in the areas of medical rehabilitation services, paediatric palliative care and social services –** national level recommendations that include the development of policies for the systematic development of education for staff of health and social spheres.
- **Transforming baby homes and removing children** – the selection of the direction for transformation and development of a strategic plan with input from subunits of region state administrations, particularly health departments, social welfare departments, services on chidren's affairs, and education and science departments.
- **Developing services to support children and families at the community level, including family-based care –** regional level activities to strengthen the network of rehabilitation services, early intervention, paediatric palliative care and social services for children and their families to prevent the institutionalisation of children, as well as support services and the development of family-based care.
- **Improving the quality of health care and lives of children who remain in the baby homes –** short-term operational decisions are designed to be implemented during the year; focused on improving the quality of health care for children in baby homes particularly during the period when the transformation plan is developed and during its implementation.

It should be emphasised that the reform of baby homes should be linked to the implementation of activities to develop rehabilitation services, paediatric palliative care, and community-based social services to prevent the institutionalisation of children and restrict their admission, as well as the removal of children from a facility. The development of a transformation plan and the introduction of a moratorium on the placement of children by the health sector only, without developing services, is dangerous. The assessment proves that it will be hardly possible to see an end to children under the age of 3 years being placed in institutions in 2021, as alternatives for children of this age category are currently almost non-existent.

70 / WHO Regional Office for Europe (2007). De-institutionalizing and transforming Service on Children's Affairss, A guide to good practice. – Birmingham, UK.

Therefore, decisions should be comprehensively considered, and consistent deadlines established, for achieving certain targets. The "theory of change" principle - a description of steps that will lead to the realisation of long-term goals - should be applied when planning actions[71]; for example, increasing the number of patronage and foster families (goal 1) to a level that meets the needs of the region allows for a moratorium on the placement of children in a baby home and prevents institutionalisation (goal 2), which in turn will increase the number of children raised in families (goal 3) and improve the health, development and quality of life of children (long-term goal).

STRENGTHENING INTERDEPARTMENTAL COOPERATION, ADVOCACY, AND STREAMLINING THE REGULATORY FRAMEWORK

The National Strategy of Reforming the System of Institutional Care and Upbringing of Children for 2017-2026 and the implementation plan, particularly the first stage[72], provided several measures for the development of services and alternative forms of childcare, including the introduction of a moratorium on the placement of children under 3 years in institutions, starting in 2020. Unfortunately, many of the plans remained on paper. The recommendations below outline the steps that, according to the Pilot results, should be taken at national level to prevent the institutionalisation of young children and to ensure their wellbeing and development.

IMPROVE MECHANISMS OF INTERDEPARTMENTAL AND INTERSECTORAL COORDINATION OF DEINSTITUTIONALISATION MEASURES AT THE NATIONAL LEVEL.

Currently, the main advisory body is the Coordinating Council for Reforming the System of Institutional Care and Upbringing of Children which is expected to facilitate the coordination of actions of central and local executive bodies on the implementation of the relevant National Strategy. Within the Coordinating Council, it is expedient to establish a standing committee to co-ordinate the transformation of baby homes.

ENSURE MONITORING AND EVALUATION OF DEINSTITUTIONALISATION MEASURES, INCLUDING THE TRANSFORMATION OF BABY HOMES, AT NATIONAL LEVEL.

For the Coordinating Council to work effectively, it is necessary to develop and approve a plan for monitoring and evaluation of the 2017-2026 National Strategy implementation. Such a plan should contain a list of indicators of the effectiveness of the Strategy's activities implementation, taking into account short-term and long-term expected results, the procedure for monitoring and evaluation, identification of sources, frequency of data collection by indicator, and people responsible for data collection and analysis. An evaluation of the effectiveness of the activities implementation should be conducted at least once a year.

71 / Theory of changes in strategic planning in amalgamated territorial communities. Practical Guide / UNDP Recovery and Peacebuilding Programme. Kyiv, 2020. URL: https://www.ua.undp.org/content/ukraine/uk/home/library/recovery-and-peacebuilding/theory-of-change-in-strategic-planning-in-ATCs.html.

72 / The plan of the second stage of the National Strategy Reforming the System of Institutional Care and Upbringing of Children for 2017-2026 has not been published at the time this report was prepared.

RAISE AWARENESS OF THE CONSEQUENCES OF INSTITUTIONALISATION, ESPECIALLY FOR YOUNG CHILDREN.

Running a nationwide communication campaign on the negative consequences of institutional care and the importance of raising a child in a family is one of the activities of the National Strategy Plan. According to the assessment, such a communication campaign should also include raising public awareness of disabilities, strengthening respect for children's rights and dignity, encouraging positive perceptions and a deeper understanding in society, and informing people about social services, rehabilitation services, and paediatric palliative care that is available. Within the communication campaign, it is important to develop messages not only for the all population in general but also for target groups (relevant local authority units, health workers including family doctors, staff of maternity hospitals, children hospitals, etc.) that may participate in the decision-making process on whether to place a child in a facility.

ENSURE THE COLLECTION OF STRATEGIC INFORMATION:

- Create a general registry of children in need of medical rehabilitation and / or paediatric palliative care, possibly as part of e-Health.
- For children in institutions, create a registry with information about their legal representatives, family, health and development data, and dates of placement and discharge. Forms developed by the Pilot can be used to build data sets on children in baby homes.

PROMOTE THE PREVENTION OF CHILD ABANDONMENT IN HEALTHCARE FACILITIES.

- Develop guidelines for the early identification of mothers at high risk of abandoning their children, and monitor all pregnancies based on these guidelines. Ensure continuity of social support, medical rehabilitation, early intervention and paediatric palliative care services for the mother and her child in the community at their place of residence.
- Analyse the performance of mother and child centres, counselling points at maternity hospitals, and antenatal clinics to plan strategic steps for their further development (format of work, training of specialists, etc.).

EMBED INTERNATIONAL EXPERIENCE INTO THE NATIONAL PRACTICE OF SUPPORTING PREGNANT WOMEN AND FAMILIES WITH CHILDREN FROM VULNERABLE POPULATIONS VIA THE COMBINED SUPPORT OF A NURSE AND SOCIAL WORKER.

Practice the methodology of providing such support as part of the experiment in certain areas and, based on the results, prepare regulations for the dissemination of the experience gained.

DEVELOP EFFECTIVE SOLUTIONS FOR THE DEVELOPMENT OF PATRONAGE FAMILIES FOR INFANTS.

Provide for a broad communication campaign to recruit patronage care candidates, improve their training curriculum with a focus on short-term care and early childhood development, training and state certification of trainers.

STREAMLINE THE LEGAL FRAMEWORK FOR HEALTH CARE OF YOUNG CHILDREN TO ENSURE EARLY DEVELOPMENT AND TO PREVENT DISABILITY:

- Approve the tools (screening and scales) for assessing the development of children from 0 to 5 years to be used at the primary and specialised levels of care.
- Approve the regulatory framework for follow-up monitoring of infants and young children at risk of developmental disorders and chronic diseases.
- Approve the procedure of systematic assessment of anthropometric indicators of children, with the nutritional status log, particularly the needs assessment and define the nutritional needs (including special clinical nutrition) of a child based on indicators.
- Develop a new regulatory framework for delivering nutrition interventions for children with health problems. The effective CMU Resolution[73] refers to nutrition standards for children of different age groups without regard to their health status and existing international evidence-based nutrition practices[74, 75].
- Develop requirements for the mandatory creation of a development space for children in healthcare facilities.
- Review procedures for establishing a disability status, develop an individual rehabilitation plan and appropriate rehabilitation services and medical devices to simplify the patient pathway - optimise the set of documents, minimise referrals and expand electronic services.

STREAMLINE THE REGULATORY FRAMEWORK FOR THE INTRODUCTION OF REHABILITATION SERVICES AND PALLIATIVE CARE FOR CHILDREN AT ALL LEVELS AND STAGES OF HEALTHCARE PROVISION:

- Develop standards for the provision of general and specialised medical rehabilitation with the possibility of providing inpatient and outpatient services.
- Ensure the implementation of evidence-based clinical guidelines for the diagnosis and treatment of diseases in children. Approve clinical guidelines and standards of early diagnosis of FASD in children.
- Develop and implement common criteria for calculating the need for paediatric palliative care and medical rehabilitation.
- Develop and approve interdepartmental programmes on follow-up care, paediatric development, early intervention, medical rehabilitation and paediatric palliative care jointly with social services, healthcare facilities (MNE), and educational facilities.

REGULATE THE INTRODUCTION OF THE POSITION OF SOCIAL WORK SPECIALISTS AT THE ATC LEVEL:

- Unify the procedure for introducing the position of a social work specialist (a structural subdivision of the executive body of local government, social service facility) and estimate his/her workload.

73 / CMU Resolution as of 22.11.2004 No.1591 "On approval of nutrition standards for education and recreation facilities" (Official Newsletter of Ukraine, 2004, Issue 47, p. 3107). URL: https://zakon.rada.gov.ua/laws/show/1591-2004-%D0%BF#Text.

74 / Defining Pediatric Malnutrition: A Paradigm Shift Toward Etiology-Related Definitions: Special Report / N.M. Mehta, and the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) Board of Directors//J Parenter Enteral Nutr. 2013; 37:460–481. doi:10.1177/0148607113479972.

75 / WHO. Guideline: Updates on the management of severe acute malnutrition in infants and children. Geneva: World Health Organisation; 2013. URL: https://apps.who.int/iris/handle/10665/95584.

- Introduce specialties: working with families in difficult life circumstances and patronage families, developing and supporting family-based care.
- Regulate the remuneration procedure and provide incentives (performance-based indicators, accrual points).

IMPLEMENTING EDUCATIONAL PROGRAMMES AND STRENGTHENING HUMAN RESOURCES IN THE AREAS OF PAEDIATRIC DEVELOPMENT, MEDICAL REHABILITATION SERVICES, PAEDIATRIC PALLIATIVE CARE AND SOCIAL SERVICES

Developing state policy on the training of highly qualified personnel and their continuous education is a key condition for providing children and families with quality and affordable services:

DEVELOP EDUCATIONAL PROGRAMMES FOR CONTINUOUS PROFESSIONAL DEVELOPMENT

on the principles of medical rehabilitation, paediatric palliative care, and early childhood development for specialists in all levels of healthcare.

PROVIDE TRAINING FOR SPECIALISTS

for the provision of medical rehabilitation and paediatric palliative care, in particular, family physicians, paediatric development specialists, physical therapists, rehabilitation specialists, occupational therapists, assistant physical therapists, assistant occupational therapists, psychologists, and speech therapists, by increasing the state order for their training.

DEVELOP AND IMPLEMENT SOCIAL WORK EDUCATIONAL PROGRAMMES IN COMMUNITIES.

To improve the training of social workers and social managers to be able to work in ATC, the possibility of introducing specialties like “social work in communities”, “social work with children / families”, “social work with family-based care”, and “social work with palliative patients” should be considered. Also, it is important to develop and implement short-term courses to train social work specialists in various community social services.

DEVELOPING COMMUNITY-BASED SERVICES FOR CHILDREN AND FAMILIES TO PREVENT INSTITUTIONALISATION

The main priority in reforming the institutional care system should be bringing services as close as possible to families and ensuring the development of family-based care (Fig. 46).

It is recommended to:

APPROVE TARGETED REGIONAL PROGRAMMES

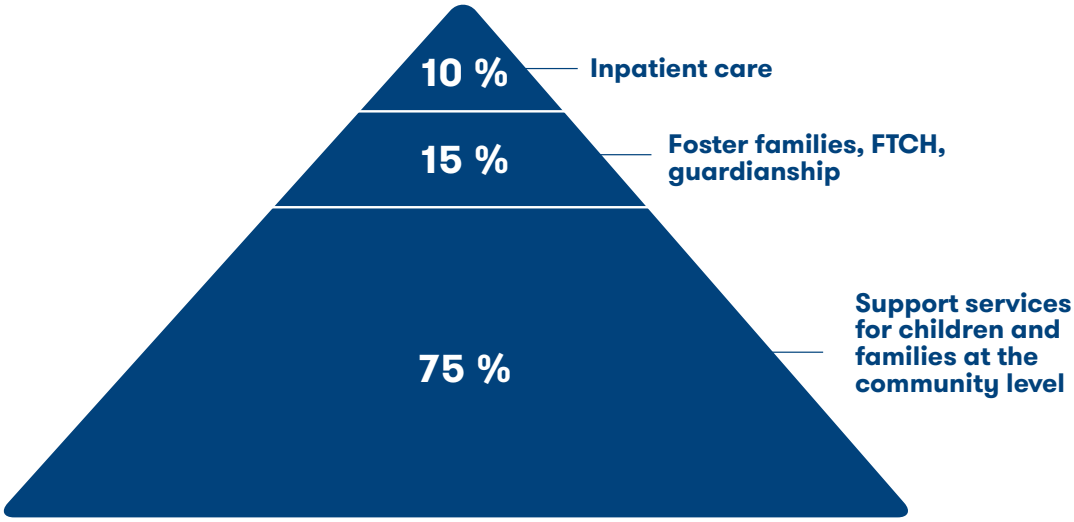
of early childhood development and follow-up care of newborns and young children at risk of developmental disorders as well as early intervention, medical rehabilitation and paediatric palliative care. Create monitoring groups to monitor programme implementation and services creation.

ESTABLISH COORDINATING GROUPS (INTERDEPARTMENTAL CENTRES) IN THE REGIONS

to organise transparent and understandable processes of children and families referral for services.

INTENSIFY THE CREATION OF PATRONAGE FAMILY SERVICES (SHORT-TERM FOSTERING).

According to the Pilot, to halt the placement of children under the age of 4 (6) years into baby homes by providing a suitable short-term alternative, Dnipropetrovsk region needs at least 135 patronage families (there is currently 1), Poltava region needs 50 families (there are currently 4), and Kherson region needs 35 families (there are currently 6). Patronage families should be established in each ATC / city, as the placement of children is territory based. This task should become a priority for ATC / cities and be accompanied by the establishment of specific quantitative indicators and methodology guidance for implementation by the relevant structural units.



Source: Adapted from the European Commission Daphne Programme, WHO Regional Office for Europe (2007). De-institutionalising and transforming Services on Children's Affairs, A guide to good practice. - Birmingham, UK.

Figure 46. **Pyramid of services for children and families**

PROMOTE FURTHER DEVELOPMENT OF ADOPTION AND FOSTER FAMILIES.

There is a need for at least 80 foster families in Dnipropetrovsk region, 30 families in Poltava region and 25 families in Kherson region to ensure children under the age of 4 (6) years can be placed out of baby homes, and children after acquiring the status of an orphan and a child deprived of parental care also has a family to be placed into.

DEVELOP A NETWORK OF SERVICES AIMED AT PREVENTING THE INSTITUTIONALISATION OF CHILDREN:

day care services and social support services for families; respite (rest) services; family support services; early intervention service; services for mothers and children in crisis; and community nurses or social work specialists in the network of maternity wards who would assess the risk of child abandonment and provide support services to mothers in high-risk groups and to families. In general, the child protection system should change the focus from emergency response to preventing early family separation. The main interventions in this regard may involve creating integrated centres of social services in communities and expanding the network of social work specialists:

- Integrated centres of social services need to support children with disabilities or health and development problems, such as early intervention services, day care, family support services, and shelters for children and mothers. On average, one centre can be created to support a population of 50-80.000, or 10-15.000 children. Thus, in Dnipropetrovsk region, it is expedient to create 50 centres, in Poltava region, and 15-20 in Kherson region. Since ATCs will not need all services (especially round-the-clock stay services), it is advisable to plan for the creation of integrated centres in line with the Law of Ukraine "On cooperation of territorial communities"[76].

- Introducing social work specialist positions in each ATC to work with children and families is recommended at the rate of 1 position per population of 1.500-2.000. In Dnipropetrovsk region it is necessary to ensure the introduction of at least 1.880 specialist positions (currently there are 232), 750 positions in Poltava region (currently there are 121), and 620 positions in Kherson region (currently there are 72). Possible options for introducing social work specialist positions: a centre for social services created by the decision of the ATC councils, a centre of social support for children and families, the creation of departments for social services or family support services in existing social facilities, or social contracting by purchasing services from NGOs.

TRANSFORMING BABY HOMES AND REMOVING CHILDREN

The transformation of baby homes into medical rehabilitation and palliative care centres for children will require investment due to a lack of necessary equipment, unsuitable premises, and the inadequate way departments and human resources are organised.

76 / Law of Ukraine as of 17.06.2014 No.1508 "On cooperation of territorial communities". URL: https://zakon.rada.gov.ua/laws/show/1508-18#Text.

In addition to the transformation into medical rehabilitation and palliative care centres for children, other options should be considered, such as: 1) transformation into a hospice / respite service; 2) merging with other healthcare facilities as a special department (outpatient, inpatient, specialised, etc.); 3) transformation into a social facility to provide rehabilitation services during the day, early intervention, training on responsible parenting or creating a centre for pregnant women, mothers in crisis or abused women and children to temporarily stay in; 4) transfer to a private owner to become a private day care centre or an inclusive preschool educational facility; 4) close the institution and transfer available resources to other healthcare, social or educational facilities.

In any case, the decision to transform a facility should take into account the needs of target groups in certain services across the region / city, available resources (human, financial), territorial accessibility, and other important factors.

PREVENTING THE PLACEMENT AND REMOVING OF CHILDREN FROM THE BABY HOME.

Regardless of the transformation option, a plan to reduce the number of children in facilities, and plan to transition them out, should be developed as part of the reform. According to the assessment findings, at least 24 children[77] could be reintegrated with their biological families so the process should be started. 84 children need an additional family assessment and 306 children need to be placed in family-based care and adoption.

PLANNING THE REMOVAL OF CHILDREN FROM THE FACILITY

should involve the baby homes, Services on Children's Affairs, and social facilities doing the following actions:

- A detailed assessment of a child's health, development, and needs. During the Pilot, experts assessed the health and development of 406 out of 415 children in the Dnipropetrovsk, Poltava, and Kherson region baby homes. The results of this assessment can be used to prepare relevant individual rehabilitation plans based on the child's identified needs.
- Data to be collected on family circumstances and livelihoods of families of children whose parents are not restricted in their rights. According to the results of the Pilot, such data is available for 105 out of 415 children in the Dnipropetrovsk, Poltava and Kherson region baby homes, while the remaining families need to be assessed.
- Determine the placement options for a child (reintegration, guardianship, adoption, foster care, FTCH), assess the ability of each to meet the child's needs, discuss the options with the child and socially and psychologically prepare the child to leave the facility in accordance with the individual plan developed.
- Determine the approximate date of when the child may be placed out of the baby home, and intermediate milestone dates required for this (for example, in the process of depriving the parent of their rights) to minimise the child's length of stay in a facility.
- To prevent the referral of new children into a facility, it is advisable to introduce a mechanism which involves the service on children's affairs of region state administrations when placing children; a single procedure for analysing each case and considering options that will meet the best interests of the child.

77 / One child (from the Kamianske baby home) was reintegrated into the family during the assessment so only needs social support.

IMPROVING THE QUALITY OF HEALTH CARE AND LIFE OF CHILDREN IN THE BABY HOMES

The results of the Pilot show that regardless of the chosen transformation option, there are actions that need to be taken in the baby homes to ensure the quality of life of children and implementation of international early childhood development standards[78].

TO STANDARDISE HEALTH CARE IN BABY HOMES,

develop and approve the internal policy of a facility with forms, scales, examination schedules, a list of MOH orders, local guidelines and document when staff are acquainted with the content of the policy.

DEVELOP AND IMPLEMENT INDIVIDUAL DEVELOPMENT/REHABILITATION PLANS FOR EACH CHILD AND THEIR FAMILIES,

not just for children with disabilities confirmed by official documents. Following the Pilot's assessment, provide access to services delivered by a physical therapist, occupational therapist, speech therapist, teacher, and paediatric psychologist - for all children who need support. In the presence of diseases, an individual plan for diagnosis and treatment interventions and rehabilitation measures involving specialists should be developed, and it is advisable to regularly revise this plan, detailing the effectiveness of interventions, their scope and schedule.

PROVIDE PALLIATIVE CARE FOR THOSE RESIDENTS WHO NEED IT,

according to the Pilot's assessment. The minimum package of palliative care services should include systematic assessment and treatment of pain, special nutrition, respiratory support, management of basic symptoms, rehabilitation interventions, and integrative medicine measures (aromatherapy, game therapy, music therapy, etc.), and end-of-life services.

IMPROVE THE QUALITY OF NUTRITION, CONSIDERING A CHILD'S AGE AND HEALTH STATUS,

and provide access to specialised clinical nutrition for children in need. Introduce a systematic in-depth assessment of the nutritional status of children with the nutrition plans formulated and organised in line with age and calculated needs.

REVISE THE STRUCTURE OF EXPENDITURES

and increase the budget for nutrition, purchase of medicines and clothes, etc. This can be done by optimising the staff of a facility, as it is personnel costs that eat the lion's share of the budget. Optimisation of the staffing list will allow the introduction of necessary specialists to participate in rehabilitation and palliative care programmes.

78 / Improving early childhood development: WHO guideline. Geneva: World Health Organization; 2020.

REVISE STAFF POSITIONS AND RESPONSIBILITIES

of health professionals in the baby homes to detail individual work with the child and introduce the work of multidisciplinary teams to organise the planning and implementation of individual plans for working with the child.

ENSURE MANDATORY ASSESSMENT OF THE CHILD'S DEVELOPMENT

through screenings and developmental scales and, if necessary, counselling from members of the multidisciplinary baby home teams.

INTRODUCE ACCOUNTING OF SERVICES PROVIDED BY FACILITIES TO CHILDREN AND THEIR FAMILIES, SYSTEMATICALLY AUDIT THE DELIVERY OF SUCH SERVICES.

Develop indicators and regularly monitor the quality of healthcare for young children (via an internal and external audit).

DEVELOP AND IMPLEMENT PROCEDURES FOR MONITORING CONTACT BETWEEN CHILDREN IN BABY HOMES AND MEMBERS OF THEIR FAMILY WHO REMAIN THEIR LEGAL REPRESENTATIVES.

Heads of facilities are recommended to check the contact details of parents on a monthly basis and update the records with changes whilst monitoring situations where contact with parents is lost. In situations where communication is lost for more than a month, the heads of facilities should immediately inform the guardianship authorities to check on the family and make a decision regarding the child.

BEHIND THE MASK OF CARE

A REPORT BASED ON THE RESULTS OF THE SITUATION ANALYSIS OF BABY HOMES IN UKRAINE

2020

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