

EXECUTIVE SUMMARY

EARLY CHILDHOOD DEVELOPMENT AND DISABILITY IN UKRAINE

LESSONS LEARNED AND FUTURE RECOMMENDATIONS

SOFT Tulip, 2014



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BACKGROUND

Currently, out of almost 10 million children in Ukraine, approximately 167.059 have different forms of disabilities, including multiple disabilities, from which more than 62.000 live in deplorable conditions in the state-run institutions. The majority of children who stay in their families have also little chance of a normal life, given that adequate medical and rehabilitation services are scarce or unavailable, especially in the rural areas.

The main public services – health care, education, and social welfare – involved in the support of children with disabilities have been seriously affected by the transition from the Soviet system, and the economic crisis in Ukraine. Due to the lack of alternative services for children with disabilities since the early 1990s, a range of non-governmental organizations have emerged to provide services for children with special needs. In the past decades NGOs accumulated substantial experience as well as a variety of good practices that are successful, innovative, sustainable, and have a possible multiplying effect.

At the same time, Ukraine has signed the key treaties and international agreements governing children's rights and reflecting worldwide standards of inclusion, protection and (health) care for children, such as UN Convention on the Rights of the Child (CRC), UN Convention on the Rights of Persons with Disabilities, Millennium Developmental Goals, World Fit for Children Plan of Action, Council of Europe Disability Action Plan 2006-2015. These treaties drive the national agenda to diminish child institutionalization, reduce disparities and achieve equity in the Early Childhood Development (ECD) programs and policies and ensure access to appropriate support, such as Early Childhood Intervention (EI), Inclusive education, and family-centred care in order to fulfill the rights of children with disabilities and promote their development and contribute to a reduction of the number of children being placed in institutional settings.

Therefore the **purpose** of this study is to provide a comprehensive review and analyze the situation around ECD and disability in Ukraine. A group of local and international experts in the field of ECD, Early Childhood Intervention and Disability have put together and analyzed the data regarding existing system of services for children with special needs, discussed the regulatory framework and good practices and provided further recommendations with regard to the development of services and programs for young children with special needs.

ABBREVIATIONS AND ACRONYMS

WHO	World Health Organization
ChEI	Children education institution
IRP	Individual rehabilitation program
NGO	Non-government organization
UNO	United Nations Organization
PMPC	Psychological, medical and pedagogical counseling
MoSE	Ministry of Science and Education
MoH	Ministry of Healthcare
MoSP	Ministry of Social Policy
EI	Early Childhood Intervention
CSSFChY	Center of Social Services for Family, Children and Youth

STUDY DESCRIPTION

GOAL/OBJECTIVES:

The *main goal* of this study is to describe and better understand existing policy and services that specifically target, include or address the rights and needs of children with disabilities, developmental disorders or signs, symptoms or risks of arrest, alteration, delay, in any developmental area including physical, fine and gross motor, cognitive, behavioral, psycho-social (further referred to as *children with special needs*) from birth up to 6 years of age in Ukraine in order to provide a basis for further policy and service development for young children with disabilities.

The *objectives* of the study are:

- to review national policies and regulations in relevant sectors, such as health, social protection, education, recreation and leisure;
- to describe existing programs and services for young children with special needs and their families,
- to conduct a comparative analysis with respect to the number, structure and sequence of services for children with special needs in three regions: Kharkiv, Lviv, Odessa
- to identify good practices;
- to provide recommendations for policy development, service design, and standards of quality.

STUDY DESIGN AND RESEARCH METHODS:

In order to conduct the study a variety of sources were involved. An extensive review of relevant studies and documents, site visits, and interviews with parents and children, program directors and professionals were conducted. Most recent statistical data on children with disabilities were obtained from the National Statistical Office, Ministry of Health, Ministry of Finance and Ministry of Social Policy, Ministry of Education and Science as well as from relevant scientific studies.

OUTLINE OF CHAPTERS

The body of the review comprises four chapters.

Chapter I provides a brief summary of most relevant demographics, the existing system of care in different sectors, such as:

- Health care services
- Social services
- Education
- Recreation and Leisure
- Residential Care
- Non-governmental service providers
- Parents' organizations

Chapter 2 deals with the regulatory framework and provides brief historical overview as well as the analysis of the current national legislation related to ECD and disability.

Chapter 3 provides relevant background statistics and facts about three oblasts (Kharkiv, Lviv, Odessa), as well as comparative analysis with respect to:

- rates of disability and number of children with special needs in the regions;
- brief overview of how the services are provided in different regions;
- mapping of medical, educational, social services and NGOs for children with special needs in the regions;
- “Road map” of services

The opinions, experiences and satisfaction levels of parents of children with special needs with the service provision in different sectors, based on structured interviews with 72 parents, is presented. Good practices from the three regions are presented.

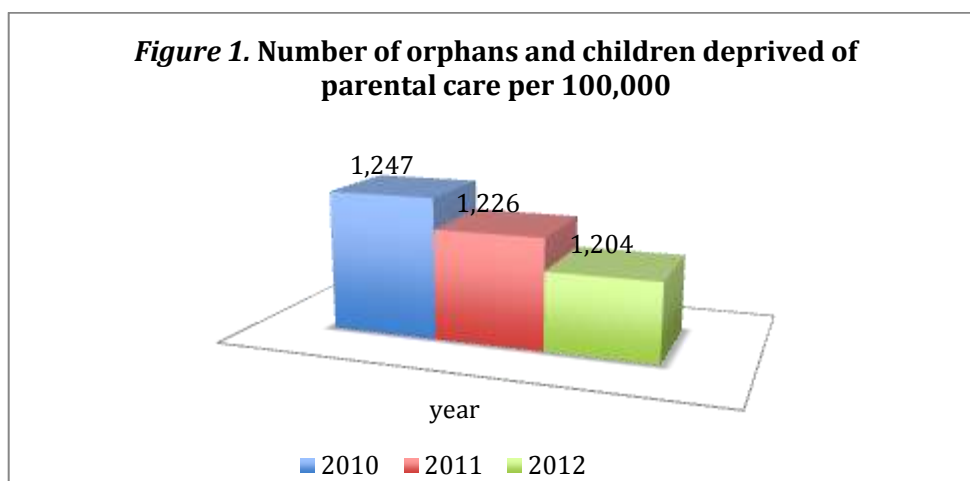
Chapter 4 summarizes the experiences in the field of ECD and disability in Ukraine, presents the conclusions and analyzes precautions and limitations. In this chapter recommendations for further policy development and service design are provided.

MAIN FINDINGS: LESSONS LEARNED

DEMOGRAPHICS

On the basis of the analysis of data on children with or at risk for disabilities and developmental disorders² from birth up to 6 years of age as well as research data on services provided to these children by institutions from different sectors, i.e., social protection, health care, education, non-government institutions (see. Appendix 1), the following conclusions can be drawn:

1. According to the State Statistics Service of Ukraine as of 01.01.2013, the number of children under the age of 6 years was 3,443,808 (40.5% of the total child population). Among them, 2,283,324 children (66.3%) live in urban areas, 1,160,484 children (33, 7%) live in rural areas.
2. Recent years have shown the deterioration of the health condition of children in Ukraine, as demonstrated in:
 - the increasing prevalence of disease by 5.4% of children from birth through 17³ years of age (from 1,879. to 1,980.5 per 1000 in 2007 and 2011, respectively);
 - the increasing number of children from birth to 17³ years of age diagnosed with a disease for the first time by 8.5 % (from 1,326.3 to 1,440.1 per 1000 in 2007 and 2011, respectively).
3. As of 01.01.2013, according to the Ministry of Health, **there are 167,059 children with disabilities living in Ukraine, representing 2.0% of the total population of children.** Compared with 2011, the total number of disabled children has increased by 0.5%. Disability index per 10,000 children increased during the last 3 years by 4.0%.
4. During the period 2010-2012 a gradual decrease of the number of orphans and children (0-17 years of age) deprived of parental care can be observed (see Figure 1)



² Further referred to as children with special needs

³ Data on children from birth up to 6 years of age was not available

4. During the period 2000-2011 a gradual decrease of the number of orphans and children (0-17 years of age) deprived of parental care in institutional care can be observed (see Table 1)

Table 1. Number of orphans and children deprived of parental care in institutional care*

	2000	2005	2007	2008	2009	2010	2011
Children's homes MoSE, youth and sports **	4764	5090	4653	4212	3873	3573	2914
Children's homes MoH	3438	3606	2959	2679	2281	2165	2068
Institutions\internats of MoSP	2989	3210	3044	2137	2336	1936	1865

*Notes: *According to the data from MoSE, MoH, MoSP.*

***Till 2009 — including children from private children's homes.*

At the end of 2011 there were 4041 clients in 598 children's homes of family type.

5. Health condition of children is often one of the main reasons for child abandonment. **94,6% of children admitted to institutional care suffer from delays in physical and mental development.**

REGULATORY FRAMEWORK AND CURRENT SYSTEM OF CARE

1. Ukraine has signed the key treaties and international agreements governing children's rights and reflecting worldwide standards of inclusion, protection and (health) care for children, such as UN Convention on the Rights of the Child (CRC), UN Convention on the Rights of Persons with Disabilities, Millennium Developmental Goals, World Fit for Children Plan of Action, Council of Europe Disability Action Plan 2006-2015.
2. Legal basis for harmonization of the National legislation with the International standards, as well as for their implementation that will guarantee the right to timely access to appropriate services for young children with special needs already exists.
3. Regulations requiring the development of the system of early multidisciplinary comprehensive services for young children, prevention of their institutionalization, and deinstitutionalization of children in institutional care are present.
4. Allegedly, there is a wide network of agencies that provide services to children with special needs in Health Care, Social Protection and Education sectors.
5. Diversity of services, their quality, proximity, and affordability do not meet the needs of clients and modern international standards of quality and require further development and improvement.
6. Mechanisms of implementation of the legislation need to be further developed and put into practice.

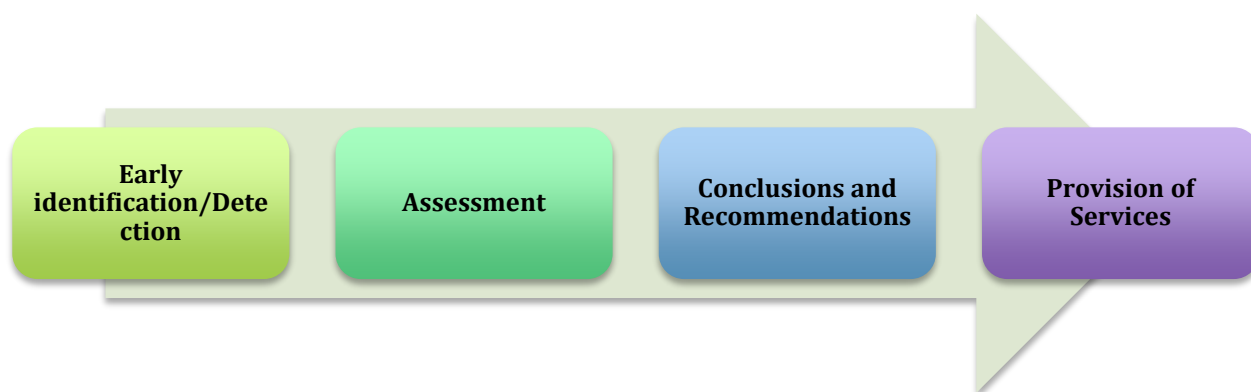
Laws are in force but not enforced

Existing services do not meet the needs of clients and international standards.

SYSTEM OF SERVICES FOR CHILDREN WITH SPECIAL NEEDS IN KHARKIV, LVIV AND ODESSA REGIONS

Analysis of the data regarding provision of services to children from birth to 6 years of age with special needs in different agencies and institutions from Health Care, Social Protection and Education sectors and in non-governmental organizations in Kharkiv, Lviv and Odessa regions revealed that families raising a child with special needs usually have to go through several stages (*Roadmap*) from identification and assessment of the health condition and special needs of the child to receiving a diagnosis and/or conclusions and recommendations that usually determine the provision of services (see Appendix 2 and Scheme 1). Below we will examine these stages in more detail.

Scheme 1. „Roadmap” for families raising children with special needs



Identification and Assessment Stage

1. In Kharkiv, Odessa and Lviv regions Health Care institutions are most actively involved at the stage of identification and assessment of children with special needs (see Appendix 2).
2. In Health Care sector there is a number of specialized screening instruments evaluating children's health condition (e.g., screening for phenylketonuria, infantile hypothyroidism, Apgar scale, etc.), however general developmental screening tools encompassing multiple areas of development are not applied. Moreover, despite the Protocol No. 149 of the Ministry of Health, which regulates the assessment procedure of the development of children up to 3 years of age, it is not used in practice in a systematic way. There is no approved or recommended list of screening instruments in Education and Social Protection sectors.
3. It has been identified that the rates of children with special needs, according to official sources are:
 - 3,5 % in Kharkiv Region
 - 3,6 % in Odessa Region
 - 2,8 % in Lviv Region

4. Obtained data on the rates of children with special needs in the three regions significantly differs from the findings of international studies, demonstrating that already in the first years of life from 10% to 13% of children have developmental delays and need appropriate services (e.g., Rosenberg et al., 2008).
5. Consistent data on the number of young children with mental disorders is lacking in all three regions, which also demonstrates the failings of early identification system. At the same time according to epidemiological studies in different European countries, 18% of children under the age of 1.5 years may suffer from mental illnesses that are associated with influence of risk factors in pre- and perinatal periods of development that can be identified in the first ten months of life (e.g., Skovgaard, 2010).
6. Deficiency of early identification system, i.e., lack of appropriate screening instruments, lack of (inter-sectoral) protocols of early identification and systemic monitoring of the development of the child, inconsistency in classification and definitions of special needs in different sectors negatively affect timely detection of special needs of young children and, consequently, opportunities to prevent delays in reaching developmental milestones, avoidable secondary conditions and, at worst, preventable death.
7. Considerable difficulties were encountered in collecting information about children affected by social risk factors. Data obtained from various sources is inconsistent and even contradictory.
8. Children in the so called social risk group often remain unidentified or unnoticed, as their parents themselves usually need help due to various psycho-social problems, and may not always play an active role in the process of timely detection and identification of special needs of their children.
9. Interviews with the parents of children with special needs confirm the shortfalls at the stage of early identification. In general they are dissatisfied with the level of professionalism of service providers, and point to a lack of modern diagnostic equipment in clinics (especially in rural areas), disregard of their own opinion and suspicions of developmental problems of their children by specialists.
10. NGOs providing Early Childhood Intervention Services in Kharkiv, Lviv and Odessa implement innovative and pro-active forms of identification of children and families in need of further assistance, using, for example, pre-screening instruments, outreach visits of experienced parents to maternity/perinatal centers and counseling of families with new-born children with special needs, dissemination of information materials for parents, professionals and the general public, as well as establishing parents' self-help groups.
- 11.** NGOs providing Early Childhood Intervention Services in Kharkiv, and Lviv often apply innovative diagnostic instruments that meet international standards, are evidence-based, and allow of comprehensive examination of general development of the child.

Conclusions and Recommendations Stage

1. In the three regions the situation appears to be comparable (see. Appendix 2): the initial diagnosis and/or disability status is established by the Health Care sector, the recommendations regarding specialized educational and *correctional* programs are issued by the Educational sector. At this stage the involvement of the Social Protection sector is very limited. At the same time the Social Protection sector is involved at the previous stages of identification and assessment, and therefore, may have potentially important conclusions and recommendations for further service provision.
2. Practically all parents, who participated in the study, emphasized the complexity of the time-consuming process of obtaining the so called *disability status* of the child, which often delays the admission to rehabilitation or other relevant programs available for children with this status. Parents can chose to refuse to apply for the disability status for their child due to the fear of stigmatization.
3. The interviewed parents noted that (medical) professionals usually do not provide sufficient information and explanations regarding the diagnosis, prognosis and recommendations about how to create opportunities and conducive environment for the development of their children with special needs in home settings, facilitate their socialization, and help them reach their full developmental potential.
4. Individual Rehabilitation Program (IRP) is developed after disability status of the child with special needs is established. As a rule, IRP is formulated by Health Care professionals, often without the involvement of experts from other sectors. The lack of knowledge of medical specialists about rehabilitation programs and services in other sectors limit the use of existing resources and the referral of the child to other relative services.
5. According to the interviewed parents, IRP appear to be formal, it exists mainly “on paper”, is dominated by medical model and do not address all developmental domains of the child.
6. There is no clearly regulated cooperation between Psychological Medical Pedagogical Commission (further referred to as PMPC) of Educational sector, providing recommendations regarding specialized educational and *correctional* programs, and institutions of Health Care and Social Protection sectors. Communication with and transition between different organizations belonging to different sectors have to be accomplished by parents who usually lack comprehensive information about existing services and organizations, their functioning, location, etc.
7. PMPC are very unevenly distributed across regions. Their distribution in cities and district centers is more favorable in comparison with rural (especially remote) areas (see Annex 3).
8. Unlike other services PMPC can conduct multidisciplinary field meetings and provide consultations for children with special needs and their parents on the basis of organizations from other sectors, which creates a positive precedent. At the same

time, some PMPC work on a voluntary basis and do not have enough personnel and (technical) means to cover the existing needs.

9. Recommendations of NGOs providing Early Childhood Intervention services in Kharkiv and Lviv are usually based on the principles of biopsychosocial model and are aimed at improvement of the quality of daily life of the child and family.

Recommendations of Health care professionals do not address all developmental domains of the child; do not correspond to the needs of families and existing resources

Service Provision

1. Health Care sector

- 1.1. As the service provision is concerned, in the three regions the network of Health Care institutions is the most ramified in comparison with Educational and Social Protection sectors (see Annexes 1, 2).
- 1.2. Dominance of the "medical model" in the institutions of the Health Care sector narrows down the choice of services to medical treatment of children without taking into consideration the modern principles of biopsychosocial⁴ model of care.
- 1.3. The range of rehabilitation services for children with special needs is usually limited to a standard set of programs or short-term rehabilitation courses that do not always correspond to the individual needs of children and families.
- 1.4. The interviewed parents note the lack of multidisciplinary services, and programs that allow learning the best ways to care for their children, support and promote the child's development and help to include the child in family and community life. According to parents, children and their families need ongoing support by specialists from different fields, and not just short-term rehabilitation courses.

Medical model of services in the Health Care sector is still dominating over the biopsychosocial model

2. Educational sector

⁴ Implementation of the bio-psycho-social model encourages the full development of different developmental domains of the child (motor, linguistic, communicative, perceptual, social, and self-care), and is aimed at improving the quality of life of the child and the family.

- 2.1. The number of institutions providing educational services to children with special needs is insufficient in all three regions, with Lviv region having the lowest number of specialized kindergartens and specialized pre-school groups (see Annex 3).
 - 2.2. According to the interviewed parents, inclusive kindergartens and (preschool) education for children with special needs is largely undeveloped.
3. Social Protection sector
- 3.1. In the three regions the number of social rehabilitation centers for children with disabilities varies considerably: there are nine centers in Lviv region, three in Odessa region and only one in Kharkiv region.
 - 3.2. Most of the social rehabilitation centers for children with disabilities work with children from the age of two years and younger children and children who do not have a disability status and/or belong to a risk group are not covered sufficiently by the services.
 - 3.3. In the three regions the network of Centers for Families, Children and Youth (CFSchY) are most ramified within the Social Protection sector (see Annex 4). However, service provision for young children with special needs and their families is not a priority direction for CFSchY. There is no available information about the number of children with special needs and their families that receive services in CFSchY, or about special programs for this target group developed or offered in CFSchY.
 - 3.4. At the same time, wide net of CFSchY and its proximity to children and families even in rural areas can be seen as a potential resource for the development of services for families raising children with special needs from birth to 6 years of age.
4. NGOs and provision of services
- 4.1. In all three regions there is a number of parents' organizations as well as NGO service providers that work with children from birth up to 6 years of age and their families.
 - 4.2. Innovative multidisciplinary family-centered Early Childhood Intervention services for families with young children with special needs have been initiated and are being actively implemented by NGOs in Kharkiv and Lviv.
 - 4.3. According to the interviewed parents, NGOs providing Early Childhood Intervention services offer most innovative programs that meet the needs of children with special needs. The NGOs offer information, psychological support for parents and families, which help to improve the quality of their lives (see Annex 2).
 - 4.4. NGOs providing Early Childhood Intervention in Kharkiv and Lviv cooperate successfully with local authorities and receive (financial) support of their innovative services that have been recognized by the state as *good practices* and recommended for further dissemination.

5. Deinstitutionalization and reform of institutional care

5.1. The reform of institutional care is carried out most actively in Kharkiv region. Over the past 8 years the number of children in institutional care decreased almost by 4 times. This positive trend can be explained by a comprehensive approach comprising

- development of the Early Childhood Intervention network of services. Unique to Kharkiv network of Early Childhood Intervention services created on the basis of NGOs and children's clinics helps to prevent the institutionalization of children with special needs by providing appropriate support to both children and their families;
- development of alternative forms of family-based care;
- transformation of residential care institutions into medical and social rehabilitation centers for children with disability status and children from the risk group and their families;
- reintegration of children into biological and foster families.

6. General aspects of service provision: Availability, Proximity and Cross-sectoral work

6.1. Institutions providing highly specialized medical services, inclusive kindergartens, rehabilitation centers are mainly concentrated in urban areas (see Annex 3).

6.2. Poor transportation system and economic difficulties make services for families of children with special needs living in rural areas inaccessible. At the same time, more than 30% of children under the age of 6 live in rural areas.

6.3. The interviewed parents confirm that there is a substantial disparity in availability, proximity and quality of services for children living in urban and rural areas.

6.4. Analysis of services that are provided by institutions in Health Care, Educational, Social Protection sectors and by NGOs demonstrates that early identification, assessment, provision of recommendations and services for children with special needs can be carried out in all the above mentioned sectors. This forms the basis for inter-sectoral cooperation in creating continuity, equity, and quality of services for children with special needs.

For children with special needs in rural areas access to services is significantly more limited

RECOMMENDATIONS AND POSSIBLE SOLUTIONS OF IDENTIFIED PROBLEMS

The study, along with positive experiences, and innovative practices, reveals serious gaps and weaknesses at different stages of the "Roadmap" which require both systemic changes and concrete practical solutions of identified problems.

SYSTEMIC CHANGES

The body of research as well as documented practical experience in different countries, including Ukraine, demonstrates that Early Childhood Intervention (ECI) system promotes the child's age-appropriate growth and development and supports families during the critical early years most effectively. ECI is intended for all children who are subject to a developmental risk, or developmental disability; covers the period between prenatal diagnosis and the moment that the child reaches school age; includes the entire process from the earliest possible identification and detection up to the moment of transfer to an educational setting; focuses not only on the child but also the family and the community; helps to strengthen vulnerable families, to normalize and improve the quality of their lives and contributes to the prevention of children's institutionalization. ECI involves broad coordinated multidisciplinary efforts in different sectors.

Differences between the traditional model of services for children with special needs and ECI are presented in Table 2

Table 2. Comparative characteristics of Early Childhood Intervention model and Traditional model of services

Characteristics	Traditional model	Early Childhood Intervention
Target group	Children with disabilities and the signs of developmental disorders	Children with disabilities and signs of developmental disorders, as well as children at risk of developmental disorders
Early identification	The responsibility is on the specialists. Delayed in time.	Shared responsibility of professionals, parents and the community. As soon as possible.
Classification	Describes disorders	Describes abilities of the child with disorders, his/her participation in society
Focus	The child in the context of "disabilities"	The child in the context of family
Goal	"Normalization" of the child, "removal" of defects	Normalization of the life of the child and family
Interaction "experts - parents"	Hierarchical relationship "specialist - patient." Professionals are the experts.	Partnership between parents and professionals. Both parents and professionals are experts

Interaction "experts - experts"	Disconnected, "through papers"	Coordinated interaction of specialists from different disciplines. Sharing "common goal".
The duration and frequency of services	Short-term rehab courses	Regular ongoing support
Services	Depending on the institution, the standard set of programs	Depending on the needs of the child and family, flexible approach, use service coordination model /Case Management
Program exit	The lack of support in the transition to the next program.	Planning and support during the transition to the next program
Financing	Institution is financed	The service is financed according to the principle "money follow the child"

According to the UN Committee on the Rights of the Child (2011) Ukraine was recommended to **“develop and strengthen Early Childhood Intervention services for children with disabilities and support to their families to prevent institutionalisation of children”**.

Importantly, research demonstrates that government funds invested early in the lives of children with special needs result in compensating decreases in government expenditures. Accumulating body of research documents a return to society between \$1.80 and more than \$17 for every dollar invested in the early care and education program, depending on the nature of the early childhood program (e.g., Barrett, 2000, Heckman, 2006). Heckman et. al. (2010) found that “every dollar invested in high quality early childhood education produces a 7 to 10 percent per annum return on investment.”

For further development of Early Childhood Intervention system in Ukraine the following steps shall be taken:

➤ *Development of public, regulatory, and legal framework; establishing intersectoral foundation of the Early Childhood Intervention system*

1. To inform the general public, policy makers and specialists about the importance, philosophy and principles of Early Childhood Intervention;
2. To develop national policy for the implementation of Early Childhood Intervention system in accordance with International obligations, legislation of Ukraine, and principles and philosophy of Early Childhood Intervention.
3. To establish the cooperation among various agencies and sectors. To create interagency/ intersectoral commissions at different levels (national, regional, municipal) for the development and coordination of Early Childhood Intervention services. Intersectoral commissions shall also include representatives from public organizations and organizations of parents of children with special needs.

4. To assign coordination role to one of the sectors depending on its degree of involvement in the work with young children (0 to 6 years of age) with special needs, ramification of its network of institutions, and the availability of human and financial resources.
5. To develop mechanisms for intersectoral cooperation at all stages of Early Childhood Intervention (identification, assessment, conclusions and recommendations, provision of services).
6. To guarantee equal rights and privileges to specialists of different professions (doctors, teachers, psychologists, physical therapists, etc.) working in the Early Childhood Intervention system, regardless of the sector in which they work.
7. To calculate the costs and cost- effectiveness of Early Childhood Intervention services.
8. To develop flexible mechanisms of financing for Early Childhood Intervention services, including those provided by NGOs. To involve resources of various ministries, regional and municipal budgets, etc. To implement the principles "money follows the child", "financing services and not institutions".
9. To actively implement the mechanism "social demand" and the purchase of Early Childhood Intervention services from NGOs.

➤ *Development of a common conceptual framework, definition of criteria, standards and protocols of Early Childhood Intervention*

1. To create a common conceptual framework for Early Childhood Intervention specialists working in different sectors to reach common understanding of the terminology, definitions and requirements.
2. To develop and define quality standards for Early Childhood Intervention services in accordance with the basic principles of Early Childhood Intervention philosophy and International and Ukrainian experience in the field of Early Childhood Intervention.
3. To develop and implement evidence-based protocols of screening, assessment and service provision
4. To develop mechanisms for licensing and quality control of Early Childhood Intervention programs and services.

➤ *Development of a National system of Early Childhood Intervention services*

1. To establish a network of community based services, especially in rural areas. In places where such services are not possible, Early Childhood Intervention mobile teams, regularly visiting families with special needs children, shall be created.
2. To use already existing resources in each region. To conduct regular mapping of services and institutions, which can be potentially involved in the Early Childhood Intervention.

3. To provide/ensure financial affordability of Early Childhood Intervention services for **all families** which need such services.

➤ *Development of professional expertise, training of Early Childhood Intervention specialists*

1. To develop and implement educational programs, training courses for professionals working in Early Childhood Intervention teams (medical doctors, psychologists, speech-language pathologists, physical therapists, etc.). To provide practical training in the field of Early Childhood Intervention (in-service trainings, study visits, supervision, job shadow trainings in the leading Early Childhood Intervention services in Ukraine and abroad).
2. To create educational-methodological centers of Early Childhood Intervention in every region in order to provide methodological support, supervision, and assistance to Early Childhood Intervention specialists to ensure adequate level of quality of services.
3. To create National Association of Early Childhood Intervention which will unite organizations, professionals, and parents of children with special needs in order to promote the principles, values, philosophy and prevent the misapplication of Early Childhood Intervention approaches; advance knowledge and competence of specialists; monitor the content and quality of Early Childhood Intervention services; ensure licensing of Early Childhood Intervention programs and services.

POSSIBLE PRACTICAL SOLUTIONS AT DIFFERENT STAGES OF THE "ROADMAP"

Identification and Assessment Stage

Implementation of effective system of early identification and screening of children with special needs will allow to lay a foundation for effective prevention of delays in reaching developmental milestones, avoidable secondary conditions, child institutionalization, and, at worst, preventable death. It will also help to prevent economical disadvantages both for the child, the family and lower the costs for subsequent support and treatment. Early identification system must comply with the International standards and identify **all children** who need help, including children at biological and psycho-social risk.

In order to improve early identification and assessment of children with special needs it is necessary:

1. To ensure cross-sectoral approach, which requires the involvement of Health Care, Social Protection, and Educational sectors, as well as the parents of children with special needs and the community.
2. To develop and implement evidence-based protocols of screening, assessment and monitoring of children.
3. To train specialists to use modern screening and diagnostic tools and provide them with the necessary instruments and equipment.

4. To introduce International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) recommended by WHO (2007).
5. To use more pro-active approach in identification of children from the so called social risk group. To maximize the use of all available resources from different sectors, to conduct awareness raising campaigns among the general public about developmental risk factors. To use home visits and patronage system with a shift of emphasis from control and monitoring to provision of support for the family.
6. To improve protocols of identification of families in difficult circumstances with a special focus on young children. To improve data collection and registration, update the database.
7. To involve parents more actively in screening and early identification of developmental problems; to provide them with early screening instruments of developmental disorders; to distribute such instruments in perinatal centers, maternity centers, children's clinics
8. To introduce in each region a single register of public and private institutions and organizations that provide services to children with special needs (service mapping) that will be available to policy makers, specialists and parents of children with special needs

Conclusions and Recommendations Stage

Conclusions and recommendations should be based on a biopsychosocial model of care and encompass all aspects of child development, including the family and the community; promote the child's age-appropriate growth and support families during the critical early years most effectively; take into consideration the demands and needs of parents as active partners at all stages of service delivery. Therefore it is necessary:

1. To ensure more active involvement of data of Social Protection sector especially what developmental environment of the child is concerned (e.g. living conditions, financial situation of a family, etc.), to take this information into consideration in the formulation of recommendations.
2. To appoint an individual coordinator (the so-called case-manager) for each family from the Social Protection sector. Case-manager will accompany and support the family and the child at all subsequent stages; provide information and, when necessary, represent the interests of the child and his or her family in different institutions and sectors.
3. To determine the timeframe between the identification of a child with special needs and the beginning of services delivery. Absence of diagnosis and/or disability status should not preclude the provision of services to the child and his or her family as quickly as possible.
4. To develop a map of services in different sectors, including NGOs, that will also include information on the rights, financial subsidies and governmental programs for children with special needs and ways to obtain them.

5. To develop a procedure for informing parents about the child's diagnosis according to modern standards of medical ethics; to create/provide opportunities for peer information exchange and support for the parents; to provide parents with the map of services.
6. To ensure that the development of IRP is carried out by a cross-sectoral commission with the involvement of the case-manager, and with active participation of the parents. IPR should correspond to available resources in different sectors, taking into account the desires and possibilities of the family. Evaluation of the IRP of young children should be done regularly (at least every 6 months).
7. To ensure that the recommendations of PMPC and other responsible entities are clear to parents; formulated in the best interest of the child and the family; based on the principles of inclusion and understanding that every child has the potential to develop regardless of the severity of disorders or disabilities
8. To ensure that recommendations reflect all efforts to provide an opportunity for a child to develop in a family environment.

Service Provision

Service provision should be based on the principles of Early Childhood Intervention, therefore it is necessary:

1. To create multidisciplinary teams that include different specialists depending to the needs of the child and the family
2. To ensure proximity of services, especially in rural areas. This can be achieved through:
 - a. Mobile teams of specialists, which will provide regular support and supervision to the family in home setting;
 - b. Existing most proximal structures (e.g., central district hospitals, primary health care centers, PMPC, ChEI and CSSFChY centers for social rehabilitation for disabled children) where Early Childhood Intervention services should be created
3. To provide a wide range of different programs within the Early Childhood Intervention system: they should correspond to the needs of the child and his/her family, promote getting functional skills, and focus on solving the problems of everyday life, be realistic and feasible.
4. To ensure the provision of services in natural environment of the child as the most efficient way of Early Childhood Intervention and to implement home visits.
5. To develop intersectoral mechanisms and routes of transition of the child to preschool and other programs as integral part of Early Childhood Intervention.
6. To create special and/or inclusive groups within existing preschool educational institutions

7. To develop and provide services for the reintegration of institutionalized children with special needs into the biological and foster families.
8. To conduct training of personnel of residential care institutions in order to improve the quality of services for orphans and children deprived of parental care who remain in residential care.
9. To use NGOs that have experience in providing Early Childhood Intervention services, practical and theoretical expertise, as educational and methodological centers; to involve them in the development of training programs for professionals who work in the Early Childhood Intervention system.
10. To use the experience of Kharkiv and Lviv in the development of network of Early Childhood Intervention services and cooperation with governmental agencies in other regions.

CONCLUSIONS

Development and implementation of Early Childhood Intervention system in Ukraine will:

- Improve early identification and screening of children with special needs necessary for effective prevention and reduction of delays in reaching developmental milestones, avoidable secondary conditions, child institutionalization, and, at worst, preventable death. .
- Strengthen families raising children with special needs and improve their parenting skills, especially what vulnerable families and families in difficult circumstances is concerned;
- Help prevent and reduce child neglect, abandonment and institutionalization and mitigate its effects on the development of the child;
- Improve the child's developmental, social, and educational gains;
- Reduce the future costs of special education, rehabilitation and health care needs;
- In the long run help to alleviate poverty and contribute to achieving social and economic equity

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