

Heeding the Voice of Parents

**Families' experience of services for children with disabilities
and/or special needs, aged 0-4, in Ukraine, including
experience of an innovative Early Intervention Service**



Executive Summary

The Ukrainian government has taken a number of important decisions to improve the quality of life of children with disabilities and special needs, through the process of de-institutionalisation, support for inclusive education and the development of Early Intervention services.

The main aim of this research has been to study the circumstances and needs of families bringing up children with a disability and/or special needs, up to the age of four, and their experience of receiving services, including an Early Intervention service. It examines the extent to which the availability and quality of these services correspond to the needs expressed by families.

The research was conducted in two regions of Ukraine: Kharkiv region, where Early Intervention is most developed, and Dnipro region, where the service is at an initial stage of development. 238 parents who care for a child with a disability and/or special needs under the age of 12 took part in the research. The experience of families of children of four years of age or older was studied retrospectively. Eleven representatives of the healthcare, education and social protection departments of Kharkiv and Dnipro city councils and regional administrations also took part in the research.

The research was undertaken by the Kyiv International Institute of Sociology, on the initiative of the international non-governmental organisation HealthProm (Great Britain), the Institute for Early Intervention (city of Kharkiv) and the National Assembly of People with Disabilities (Ukraine), with support from UNICEF and funded by the government of Germany and the European Union.

This was a participatory research study: at all stages in the research process it drew on the expertise, through their experience, of parents of children with a disability and/or special needs, without any reduction in scientific objectivity. The parent advisors to the study received basic training in the methods and main principles of the research.

A range of methods was used to collect and analyse the data, in order to increase reliability and validity: desk research; questionnaires and a quantitative survey; structured in-depth interviews; focus group discussions and expert structured interviews with representatives of city and regional government departments.

This research will be useful for representatives of the healthcare, education and social protection sectors, non-governmental organisations, professionals who provide services to children with disabilities and/or special needs and their families, and also for those who protect and advocate for the interests of these families.

Main findings

The first section “**The impact on families of the birth and early years of a child with disabilities and/or special needs**” analyses families’ experience and the factors that have a considerable impact on their quality of life: the emotional impact of giving birth to a baby with disabilities, or realising that they have developmental problems, and how this affect personal relationships within the family; everyday challenges; financial problems and employment issues; negative community attitudes; and access or lack of access to information and high-quality services.

Assessment of the psychological wellbeing of parents in the study revealed that 40% of parents have symptoms of depression. This is over six times higher than the national average in Ukraine, and more than twice as high as the figure found in similar studies among parents of children with disabilities and/or special needs in Western Europe and the United States.

The data show that most parents experience financial difficulties and challenges managing their daily routine in caring for their child. They suffer from a shrinking circle of friends and reduced contact with the outside world - magnified by physical access barriers and poor infrastructure, lack of tolerance from other people and a bureaucratic government system of services.

The research shows that the psychological wellbeing of parents is related not just to the health of the child, but to parents’ abilities to manage day-to-day tasks, the quality of relationships within the family, the family’s financial situation, and the extent to which they are satisfied with the services they receive. The availability of high-quality and affordable services for children and their families (education, advice, emotional support) can significantly improve parents’ wellbeing and their child’s quality of life. This is critically important to the creation of an environment in which the child can reach their full potential.

The second part “**Services for children with a disability and/or special needs and their families, including an Early Intervention service**” looks at the services received by the families that took part in the research, and how satisfied they were with them.

The research shows that almost all the respondents received services designed for children with disabilities and / or special needs in early childhood: 96% of respondents received more than one type of service, and 55% received five or more.

Despite the varying difficulties and needs experienced by the families who took part in the research, the vast majority - with no significant differences between the two regions - received predominantly medical services. This indicates that the medical model dominates service provision for children with disabilities and/or special needs. This, in turn, leads parents to concentrate on seeking medical treat-

ment, without consideration for the principles of the modern biopsychosocial model, which facilitates the all-round development of the child.

Representatives of healthcare, education and social care departments articulated the view, clear also from written information they provided, that what parents of such children need most of all are treatment and rehabilitation for the child, and financial support for the family. The research shows, therefore, that the real needs of families are only partially being met.

The parents who took part in the research were critical in evaluating the current system of services provided by the state. They stated that a comprehensive, effective system to meet the needs of children and their families does not exist. Payments have to be made for services that on paper are declared to be free-of-charge.

State assistance for children with disabilities and/or special needs and their families is possible only after an application for 'disabled' status and an Individual Rehabilitation Plan (IRP). According to the parent respondents, the process of applying for this status is extremely slow and time-consuming. They state that the IRP is a formality, and that it does not take into consideration the needs of the family, or provide any real help in caring for a child with disabilities and/or special needs. In about two thirds of cases disability is acknowledged only when a child is three years old; before then children and their families do not receive any of the services or concessions that are applicable for children with disabilities.

Parents were asked to select and evaluate the service that they considered the most effective of all the services they had received. They evaluated this service according to the following criteria: their satisfaction with the quality of direct work with the child, their satisfaction with work done to assist family members and others in the child's natural environment to understand and support the child and address any relationship issues; the relationship between the parents and the professionals; the parents' experience of the way the service operates; the level of respect for parents' rights while receiving the service; the accessibility and proximity of services, and an overall score. Parents who had received Early Intervention services evaluated these services according to the same criteria.

Early Intervention is an innovative service for Ukraine that brings together medical, psychological, educational and social components. It is provided by an interdisciplinary team of professionals and is designed to support the development of children from birth to four years, with or at risk of disabilities and / or special needs, in the natural environment of the child. Early Intervention focuses on support for parents and carers, with the goal of social inclusion and to develop conditions that raise the level of participation of children and their families in everyday life.

A comparative analysis shows that Early Intervention best meets the various needs of children and families, even when compared to the service selected by parents from traditional services as the most effective. Parental satisfaction with the content and quality of work done to assist family members and

others in the child's natural environment to understand and support the child and address any relationship issues is twice as high for Early Intervention as for other services. This support is a key factor in the quality of life of families with a child with a disability and/or special needs.

Parents of children with genetic conditions who experienced Early Intervention had half the rate of depression of parents of children with genetic conditions who had not received the service. This may be because genetic conditions like Downs Syndrome are diagnosed early, and thus the parents who accessed Early Intervention services were able to do so at the earliest stage.

Parents commented that the values and ethics of Early Intervention differ from conventional approaches, and noted how much attention was paid to the needs of the child and family. They also noted the extent to which Early Intervention professionals engaged in dialogue with parents, paid attention to parents' queries, and focused both on the improved wellbeing of the whole family, and on supporting parents to find effective ways to interact with their child.

The third part "Finding useful approaches" provides a quantitative and qualitative analysis of the most important aspects of services provided for children with disabilities and/or special needs and their families.

For parents, the important aspects of services are: (1) attention to the quality of life of the family, and to the personal relationships within the family; (2) respectful partnership relationships between professionals and parents; (3) a high level of professionalism, a multidisciplinary approach and service accessibility.

The research shows that to reduce the gap between the content and quality of services and the needs of families, regular monitoring and thorough, system-wide evaluation - taking into account the views of the parents who use the services - is required.

The report also includes a section of recommendations, for those responsible for developing policy, as well as for those who design and provide services within healthcare, education and social protection departments.

Conclusions

1. The birth of a child with a disability and/or special needs means that families face a range of additional tasks, which relate to more than the child's health. Families suffer emotional difficulties, and the challenges of their day-to-day lives, and problems with employment and finances, put them under serious pressure. Access issues, poor infrastructure and intolerance from other people magnify these

problems. All these factors reduce the quality of life and functioning of the family. They can cause depression in parents and affect family relationships, which in turn can affect the child's health and development.

2. The existing system only partially meets the needs of families with a child with a disability and/or special needs. The range, content and availability of services provided by healthcare, social protection and education systems have many inadequacies, and parents of children with a disability and/or special needs face difficulties at every stage of interaction with these sectors.

3. The study demonstrates that the service that is most effective in meeting the needs of parents of children aged 0-4 is Early Intervention, as it is focussed not only on the child, but also on the quality of life of the family and the relationships within it. It provides parents with emotional support while helping them to acquire additional skills to interact with their child during daily routines, as well as facilitating the social inclusion of children with special needs and their families.

4. Cooperation between agencies is an essential condition for creating an effective system to help children with a disability and/or special needs and their families. The services provided must meet the needs of families, and parents, as the recipients of these services, must be included in system-wide and thorough evaluation of the quality of the services.

The full Russian-language report can be downloaded from the website: <http://rvua.com.ua/library-materials>