



Social Innovations in Early Childhood Intervention

Eight European case studies ready to be scaled-up

This first edition of the Zero Project Analysis covers eight outstanding Innovative Practices on Early Childhood Intervention, with a focus on Central and Eastern European countries.

- **Armenia:** Save the Children International
- **Bulgaria:** For Our Children Foundation
- **Bulgaria:** Karin Dom Foundation
- **Croatia:** Mali Dom
- **Greece:** Theotokos Foundation
- **Ireland:** National Federation of Voluntary Bodies
- **Moldova:** Lumos Foundation
- **Slovakia:** SOCIA – Social Reform Foundation



The eight case studies work in areas like
assessment, parent support networks



Since no child is like any other, individualized
education programmes are of key importance

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For more information on the report, to download versions, and for further analysis of the Zero Project, visit www.zeroproject.org

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Content

Foreword

Michael Fembek, Programme Manager of the Essl Foundation 2

Foreword

Luk Zelderloo, Secretary General of EASPD 3

Glossary 4

Armenia: Save the Children International

Access to ECD centres in rural communities 5

Bulgaria: For Our Children Foundation

Supporting families to focus on abilities and not deficits 13

Bulgaria: Karin Dom Foundation

Early assessment coupled with early intervention 21

Croatia: Mali Dom

How parents learn to raise their children at home 29

Greece: Theotokos Foundation

Step by step into inclusive kindergarten and school 37

Ireland: National Federation of Voluntary Bodies

Informing families sensitively about their child's disability 45

Moldova: Lumos Foundation

Reducing infant mortality in Europe's poorest country 53

Slovakia: SOCIA – Social Reform Foundation

A growing network of private support centres 61

A new approach to present Innovative Practices

FOREWORD BY MICHAEL FEMBEK

Programme Manager of the Essl Foundation and Director of the Zero Project



It is universally recognized that the period of early childhood is one of the most important phases for the development and well-being of any child. The intimate contact between mother and child will significantly shape the child's future disposition, and early diagnosis of any deviation becomes paramount for dedicated care.

The importance of Early Childhood Intervention (ECI) for the development of children with disabilities (as for all vulnerable children) has gained considerable recognition since the 1990s. Early age is also mentioned four times in the UN Convention on the Rights of Persons with Disabilities. Several ECI support services have been developed in recent years, such as diagnosis and assessment, home-based care and family support models, tools and toolkits, and Early Intervention Centres.

The wide gap

Still, Early Childhood Intervention is far from being mainstreamed into national policies and financial support mechanism for children with disabilities. There are many reasons for this wide gap, and arguably one of the most prominent is the fact that the period of early childhood (in most countries aged 0–6) is not covered by national education systems. Education comes later, and so do government attention and budgets.

Finding innovative solutions

The Zero Project, an initiative of the Essl Foundation, focuses on the rights of persons with disabilities globally. It provides a platform where the most innovative and effective solutions to problems that persons with disabilities face are shared. Its sole objective is to assist in creating a world without barriers. The Zero Project takes a solutions-based approach to its work. Together with its continuously growing network of over 3,000 disability experts in more than 150 countries, we seek to identify

the most effective “Innovative Policies and Practices” that improve the lives of persons with disabilities.

In-depth analysis

The Zero Project has identified more than 300 Innovative Practices and Policies over the last year, in four distinct areas: employment, accessibility, independent living/political participation, and education. For the first time, with this first edition of the Zero Project Analysis, we take our work one step further to an in-depth analysis of Innovative Practices. Eight case studies have been carefully selected in a three-step selection process that has involved dozens of experts with and without disabilities.

We have developed a model of analysis that focuses on a clear and replicable description of the solution that has been put forward by each Practice. A key element of this description is the graphic facilitation that is an integrative part of our “storytelling.”

We hope that this innovative format will prove inspiring for everyone working in the field of Early Childhood Intervention. The full Zero Project Analysis as well as all individual case studies can be downloaded from the Zero Project website (www.zeroproject.org) as well as from the website of the European Association of Service Providers for Persons with Disabilities (EASPD) at www.easpd.eu.

Cooperation with EASPD

All of us at the Essl Foundation are delighted about this first cooperation with EASPD, and we wish to express our special thanks to Franz Wolfmayr, Luk Zelderloo, and Sabrina Ferraina.

The Zero Project Analysis will be presented at the Annual Conference of the EASPD, which will take place this year in Chisinau, Moldova.

Michael Fembek, April 2016

Improving services to improve lives

FOREWORD BY LUK ZELDERLOO

Secretary General of EASPD



Since its creation in 1996, the European Association of Service Providers (EASPD) has been working to promote equal opportunities for people with disabilities through effective and high-quality service systems in the fields of education, employment, and individualised support. We represent over 12,000 support service provider organizations across Europe, and we are convinced that the realisation of the principles enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) can bring benefits not only to persons with disabilities but to society as a whole.

In order to build an effective inclusive society, persons with disabilities have to be included throughout their lives. From the very early stages of life, we must build on the capabilities, skills, and resources of the person and their family, not their deficits. Early Childhood Intervention (ECI) services are designed to support young children (and their families) who are at risk or have been identified as having developmental delay or disabilities during the most critical stage of human development – from prenatal period to eight years of age. Given the importance of this period of life for any child, it is vital to ensure access to interventions that can help children with disabilities in reaching their full potential. Under these premises, EASPD established in 2014 an Interest Group on Early Intervention. This working group was joined by several EASPD member organizations across Europe that were currently providing ECI services or were willing to develop their expertise and knowledge on the topic.

In 2016 we decided to take action on several fronts to address the situation of ECI services in Europe. First, EASPD in cooperation with the Zero Project launched a call for and selected Innovative Practices in the ECI field. Those Innovative Practices have been included in this publication and can provide a source

of inspiration for other support services, decision-makers, and professionals willing to develop or improve ECI services and programmes in their communities.

Second, EASPD believes that the implementation of the principles and rights recognised in the UN treaties also needs the involvement of society at large. Since the adoption of its multiannual strategy in 2014, EASPD is reinforcing its cross-sectorial cooperation. All partners and stakeholders must understand the societal challenges and barriers to persons with disabilities, and together we can then identify the necessary tools to solve them. To that end, EASPD is organizing its annual cross-sectorial conference – “Growing Together” – on the state of play of ECI services in Europe. This event, to be held 21–22 April in Chisinau, Moldova, represents an extraordinary opportunity to bring together all the relevant stakeholders to work and pull in the same direction: promote and secure the right to early intervention services and programmes that are affordable, available, accessible, and adapted to individual needs.

This effort is not only about people with disabilities, but also about the inclusiveness of the society we want to live in. And this requires one essential element: the involvement of society as a whole.

On behalf of EASPD, I would like to thank the Zero Project for their top-level cooperation and to congratulate the promising Innovative Practices presented in this publication. Each one of them has proven its capacity and effectiveness. Hopefully, participants of the conference in Moldova as well as members of colleges, think tanks, and organizations around the globe will be inspired by these excellent models.

Luk Zelderloo, April 2016

Glossary

Assessment, Evaluation, and Programming System for Infants and Children (AEPS). The AEPS® Test developed by Prof. Bricker et al., at the University of Oregon - allows professionals to gather assessment data for one child or a group of children in home- or center-based settings. The primary purpose of the AEPS is to assist professionals and parents/caregivers in identifying and monitoring children's developmentally appropriate educational targets and planning individualized intervention.

Ages & Stages Questionnaires (ASQ) has been developed in the 1970ies by Prof. Diane Bricker, Ph.D., at the University of Oregon. It is a developmental screening tool designed for use by early educators and health care professionals. It creates the snapshot needed to catch delays in development, highlights a child's strengths as well as concerns.

Early Childhood Care and Development (ECCD) is a field of endeavour that focuses on supporting young children's development. Early Childhood encompasses the period of human development from prenatal through the transition from home or ECCD centre into the early primary grades (prenatal – 8 years of age). Based on research, ECCD links the young child's cognitive, social, emotional, and physical processes with the Care (by families, communities and the nation) required to support that development.

Early childhood development (ECD) is the key to a full and productive life for a child. Early childhood (defined as between 0 and 8 years old) is a critical stage of development that forms the foundation for children's future well-being and learning.

Early childhood intervention (ECI) is a support and educational system for very young children (aged birth to six years)

who have been victims of, or who are at high risk for child abuse and/or neglect. Early childhood intervention came about as a natural progression from special education for children with disabilities in the 1990. Many early childhood intervention support services began as research units in universities (for example, Syracuse University in the United States and Macquarie University in Australia) while others were developed out of organizations helping older children.

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains, established by the WHO in 2001. As the functioning and disability of an individual occurs in a context, ICF also includes a list of environmental factors.

Individualized Education Program (IEP). An IEP defines the individualized objectives of a child who has been found with a disability. The IEP is intended to help children with special needs to reach educational goals more easily than they otherwise would.

Family support network. The role of this service is to empower the parents to stand up for their rights and the rights of their children. The Family Support Network includes a group of parents who have been trained to provide early support to families who have just found out about their child's disability. The service provides information and psychological or material support.

Makaton is a language programme using signs and symbols to help people to communicate. It is designed to support spoken language and the signs and symbols are used with speech, in spoken word order. With Makaton, children and adults can communicate straight away using signs and symbols.

Literature

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The Path to Inclusive Education for Children with Disabilities in Bulgaria, Ms. Blagovesta Troeva, 2014

The State of the World's Children 2013 – Children with Disabilities, UNICEF, 2013

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Access to ECD centres in rural communities

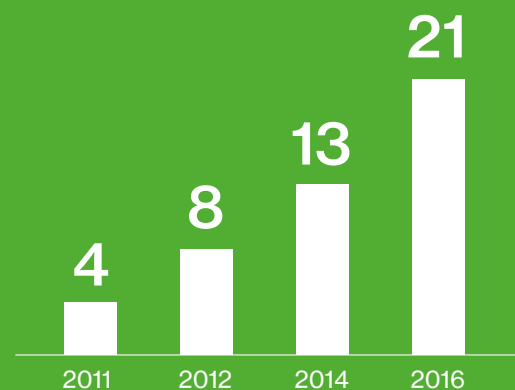
Country: Armenia Organisation: Save the Children International

MANAGEMENT SUMMARY: Save the Children, which has been active in Armenia since 1993, has established a number of Early Childhood Intervention centres, which offer Inclusive Pre-school Education for all children. The organization cooperates closely with local and federal governments and has focused on rural areas, where poverty and lack of infrastructure are the most severe. Between the years 2011 and 2015, Save the Children has provided access to Early Childhood Development (ECD) services for more than 3,600 children in 19 rural communities of Armenia.

- In Armenia Children with disabilities live predominantly with their families and have few opportunities for social inclusion and integration
- Save the Children focused on Early Childhood Development in rural areas
- The Armenian government has implemented Inclusive Education regulations



Supporting children and families by building centres in rural areas



Numbers of Early Childhood Development Centres of Save the Children

Save the Children is recognized by the Armenian authorities as a leading agency and is a pioneering agency on inclusive Early Childhood Development. Together with the Ministry of Education and Science, the organization has co-led the development of the Pre-school Education National Strategy for 2016–2025.



THE PROBLEM:

Lack of development centres

In Armenia there is a serious lack of specialized ECD centres for disabled children, since the concept of inclusive ECD centres has not yet been introduced.

In order to ensure the sustainability of ECD intervention and to promote the establishment of inclusive ECD centres, it is crucial to get an initial commitment from national and local governments for the inclusion of ECD costs in the state budget. Currently, as school-based centres are established, the Armenian state allocates per capita funding to the schools – a process that was achieved through the advocacy of Save the Children.



THE DEVELOPED SOLUTION:

Early childhood centres are built

ECD Centres, known as kindergartens, pre-schools, and nurseries, are the focal points through which children aged 3–6 years are given access to early development and learning. These centres serve to promote the overall age-appropriate development of children through a cheerful and child-friendly environment outside the home.

The objectives of Save the Children in Armenia is to increase access to ECD services and pre-school education for the most deprived and marginalized children, including children with disabilities, and to support policies to create a children-centred inclusive ECD system in the country.

Save the Children starts with a needs assessment in every target community in order to understand the specific needs of children and their communities.

ABOUT ARMENIA:

A small, landlocked country fighting poverty

- The Republic of Armenia covers an area of 29,743 square kilometres that is mountainous and partly volcanic. Its population of approximately 3 million inhabitants is divided into 10 provinces, while the capital, Yerevan, hosts approximately a third of the entire population. Armenian mines produce copper, zinc, gold, and lead, and a large part of the working population is employed in the agricultural sector.
- The 2015 UNDP Human Development Index shows Armenia in 85th place together with Albania and Bosnia Herzegovina, with a gross domestic product) of \$8,124 per capita and 38.5 percent of the population below the poverty line.
- There are approximately 207,000 children aged 0–4 years and 180,000 children aged 5–9 years, representing 13 percent of the entire population. Currently, 27 percent of children of six years and younger are enrolled in kindergartens.



THE MODEL:

All stakeholders come together

The first step is the identification of target communities, which is performed through a three-level approach:

- At the community mapping level, the team sends an official enquiry to province municipalities and requests data for all communities in the targeted provinces. Next, all data received are reviewed, including such factors as demographic information, number of pre-school children, availability of kindergartens or alternative ECD services, remoteness from the regional centre, and the socio-economic profile of communities. Lack of any pre-school services is a primary factor for the preliminary selection of communities.
- The field-level assessment seeks to verify the received data and to assess conditions in the local schools, particularly the feasibility of transforming one classroom into an ECD centre. During this assessment, the project team also meets with the mayors and members of village councils to introduce the project and discuss the possibility of a community contribution of 15 percent to the



Children enjoy Early Childhood Development classes in newly established inclusive centres

Through a specially structured educational curriculum, children practice basic mathematics, literacy, amplify hand motility, arts and crafts

renovation cost. With the participation of Save the Children's construction engineer, project staff conduct this assessment in order to see the conditions on the ground and to judge the feasibility of renovation activities. Thereafter, the Save the Children's team identifies a number of target communities for their project intervention.

- Final results of the mapping and field assessments are presented to the Republic of Armenia Ministry of Territorial Administration, Ministry of Education and Science, and province-level authorities in the target provinces to secure their approval for interventions and to get their commitment for further support to the selected schools.

Performing a thorough assessment

Immediately after the selection of target communities, the Save the Children project team – led by a Project Officer and Construction Coordinator – conducts a needs assessment. This assessment is aimed to introduce the project, assess the local needs, and understand the perceptions of community members about problems related to ECD. Community mayors, school principals, as well as schoolteachers and parents participate in the needs assessment.

The assessment explores various data collection methods, including in-depth interviews with community mayors and school principals, as well as focus group discussions with teachers and parents.



Each classroom is provided with books, developmental games, toys, and other necessary supplies (scissors, crayons, paints, paper, play dough, etc.)

In order to set priorities, the following selection criteria are used:

- Lack of ECD services in the community, i.e., no kindergarten or any alternative services.
- Number of children aged 4–6 with and without disabilities.
- Availability of premises within existing school buildings and feasibility to transform 1–2 classrooms into ECD centres.
- Willingness of the community municipality and the school management to participate in the project and support intervention (there is a need for a 15 percent local contribution for renovation activities per project).

There are no transport issues in rural communities because the distances are short and people usually walk their children to the ECD centre.

Providing a standard layout and furniture

The premises allocated by a school administration are entirely renovated, with plastering of walls and the replacement of doors, windows, and floors. Each classroom is provided with a set of furniture specifically designed for interactive education, which includes sets of so-called “chamomile” desks and chairs, with each set consisting of six movable tables and seats, thus allowing various configurations for group and individual work. The furniture sets also include a bookshelf, a large and small cabinet for toys and shoes, a teacher's desk and chair, a blackboard, and a coat rack. A play corner is organized in each classroom with two mats. Additionally, each classroom is provided with books, developmental games, toys, and other necessary supplies (scissors, crayons, paints, paper, play dough, etc.).

Each ECD classroom is provided with a separate bathroom equipped with sanitary appliances specifically adjusted for children aged 4–6 years, and the bathrooms are provided with 24/7 running water and a sewerage system. All ECD centres are provided with electrical heaters to ensure uninterrupted education in winter.

Each day consists of a four-hour class for children aged 4–6 years, with some 20–25 children per group. If there are more children in the community, the classes are organized into two shifts.

The education is provided by a teacher and a teacher's assistant with a pre-school education degree. These two professionals are carefully monitored and guided by Save the Children's project staff during the first year.



FACTS AND FIGURES:

21 centres all over the country

The project achievements in the period of 2011–2015 were the followings:

- Save the Children provided access to ECD services for more than 3,600 children in 19 rural communities of Armenia and 2 centers in the capital Yerevan; the children completed a 10-month pre-school programme and were successfully enrolled in primary school.
- Capacity-building was provided to 48 ECD teachers on ECD and parental education methodology, resulting in enhanced knowledge and skills of 2,452 parents and caregivers on child health and development.
- 21 Parental Resource Centres were established and parental classes conducted for parents/caregivers of children aged 0–6 years.
- The Armenian Government subsidized the operational costs of newly established school-based ECD centres, providing per capita funding.
- A parents' manual was published addressing early childhood development, health, and violence against children.

The course runs for 10 months, during which time children practice basic mathematics, literacy, and arts and crafts. The classes are conducted in an interactive manner using play as the main learning tool.

To evaluate the effectiveness of ECD classes, Save the Children assesses the children's knowledge and skills both before and after the 10-month period. The assessment is conducted by ECD teachers through performance observation based on the indicators provided by the National Institute of Education, including: gross and fine motor skills; emotional, personal, and social development; cognitive and speaking skills; safe behaviour; and attitude towards learning/studying.

To date, the model has been piloted and scaled-up in 19 rural communities of Armavir, Aragatsotn, Gegharkunik, and Lori provinces and of the capital, Yerevan

city. As noted above, since the model is school-based, the state takes over the established ECD classes, providing per-capita funding for children aged 5–6 years (based on the Preschool Education National Strategy). However, there is still a need for advocacy with the government for inclusion/targeting of smaller children (aged 3–4) in this strategy, including appropriate budget allocation. At this point, Save the Children provides on-going guidance and monitoring of established services while moving on to other communities for the establishment of new ECD centres.



FUNDING:

Involved for more than two decades

Save the Children Switzerland and Medicor Foundation fund the project in Armenia. Save the Children has been working in Armenia since 1993, earning a high reputation for delivering quality programmes for children and establishing strong and influential relationships with government and civil society networks. During this time the organization has managed over \$60 million in aid programmes to support the most vulnerable populations of Armenia.

The Armenian Government contributes 124,000 AMD (app. EUR 227) to schools per child/per year (high mountain regions receive 20 percent more). There is no state regulation to provide a separate budget allocation for children with disabilities in kindergartens and ECD centres, because as yet there is no institutionalized Inclusive Preschool Education in Armenia.



OUTLOOK:

High transferability

In recent years the Government of Armenia has taken important steps to legislate Inclusive Education, which became a national policy in 2005. The Law on Mainstream Education (which has merged previous laws on special education and mainstream education) stipulates that by 2022 all mainstream schools in Armenia will be inclusive.

In November–December 2015, Save the Children was involved and co-led the process to develop the Education Development National Programme for 2016–2025, and Inclusive Pre-school Education was one of the priority recommendations outlined by Save the Children.

The approach of low-cost, school-based inclusive ECD can be adapted to any country context both for rural and urban settings.

Community Mapping



Field-level Assessment



Presentation to Authorities



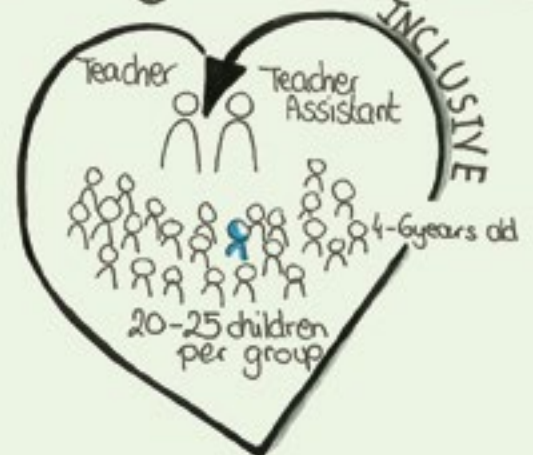
Needs Assessment



Renovating & furnishing



Working with the children





ABOUT THE ORGANISATION:

Save the Children

Save the Children International is an independent organization caring for children. Founded in 1919, today it operates in more than 120 countries throughout the world, reaching some 55 million children in 2014. Save the Children International aims for a world in which every child attains the right to survival, protection, development, and participation. Their mission is to inspire breakthroughs in the way the world treats children and achieve immediate and lasting change in their lives.

Save the Children has been operating in Armenia since 1993, delivering relief and development programmes to the most vulnerable children and their families for more than two decades. Their vital health, education, and social initiatives have helped improve basic conditions of the poorest populations through community-based projects and the capacity-building of local partners and institutions.

There are approximately 65 non-governmental organizations working in Armenia, and Save the Children Armenia works in close collaboration with them. At the beginning of every intervention, Save the Children meets with other organizations working in education to discuss way of collaboration/joint activities and to avoid overlap.

ADDITIONAL INFORMATION:

Publications readily available

For further information, Save the Children has developed the following tools:

- Information flyers for parents and caregivers on child nutrition, hygiene, first aid, anaemia, intestinal worms, and posture disorders.
- A pre-school education and development handbook provide guidance for community leaders on how to establish cost-effective pre-school education services.
- The “Inclusive Early Childhood Care and Development in Armenia Concept,” describing a proposed inclusive ECD model for Armenia.
- A guide for ECD teachers and parental education facilitators
- “I know my child, what about you”: Guide for parents
- Hand washing Poster for children
- Healthy Teeth Poster for children



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ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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Supporting families to focus on abilities and not deficits

Country: Bulgaria, Sofia and Plovdiv Organisation: For Our Children Foundation/Open Society Foundation

MANAGEMENT SUMMARY: In the period 2012–2014 For Our Children foundation developed and implemented an Early Childhood programme within its “I Deserve Childhood” project, funded by the Open Society Foundation. The programme targets children aged 0–3 years, the prematurely born, and children with disabilities, at risk of developing a disability, or with developmental difficulties, as well as their families. At the end of 2015, the programme has supported the development of 352 young children in Bulgaria.

- The approach does not focus on deficits, but rather works with the strengths of the children and with their abilities.
- The child is measured against herself/himself by monitoring pre- and post-programme development and noting what has changed during the period of support and intervention
- Activities are planned and implemented based on an assessment of the child’s development and progress of the individual child’s development.



Parents are not excluded
but partners



Empowering families to have a better
understanding of their child

The “I Deserve a Childhood” programme provides services to children with disabilities, developmental delays, or deviations and their families in order to stimulate the development of the child. The Early Childhood Intervention (ECI) specialists use a family-centred approach focused on the strengths of the child and the family, rather than on their deficits.



THE PROBLEM:

Early Childhood Intervention is almost unknown

When the project started in 2012, the Early Childhood Intervention approach was unknown in Bulgaria, with the exception of one region of the country where a local organization was piloting a similar service (Karin Dom Foundation – see page 21 for details). Most people did not understand the need for continuous monitoring of a child’s development or for the provision of professional consultations.

The government did not recognize the fact that children in the youngest age group who have disabilities or developmental problems need support, and thus it did not provide any services for children in this target group. Support only began when a child entered the education system, which is similar to most of the former communist countries.

One of the most important barriers to be overcome was related to the changing of the attitudes and thinking of parents with whom the programme has been working. They were convinced that a specialist

is better suited to care for a child with disabilities as they know and understand more about the condition of their children.



THE DEVELOPED SOLUTION:

A family-centred approach

With the implementation of the “I Deserve a Childhood” programme, For Our Children Foundation provides an innovative and professional service that supports the specific target group of children aged 0–3 years, the prematurely born, and children with disabilities, at risk of developing a disability, or with developmental difficulties, as well as their families. The programme empowers families to care for their own children by helping them to have a better understanding of the needs of their children, by improving their parenting skills, and by supporting them to develop better relationships with their children. In some cases, this programme is the only support to the families of children with developmental difficulties in the period between birth and their third year.

The main objective of this ECI programme is to support parents to help their children to develop skills as much as possible within their home environment. The advantages of this approach can be described in terms of the differences between the old and the new approaches of interventions, as presented in the following table:

Old approach	New approach
Parents are excluded	Parents are partners
One approach for the entire system	Individualized services
Focused only on the child	Focused both on the child and the family
Focus on deficits	Focus on strengths
Fragmented services	Multidisciplinary teams
Intervention takes place in a clinical environment	Intervention takes place in the family environment

Early Childhood Intervention in Bulgaria can also support society to prevent the abandonment of infants. Currently, a significant number of young children with

ECI PRACTICE:

A proven methodology introduced from Oregon/United States

- For Our Children Foundation developed the ECI practice supported by Early Childhood CARES – an outreach unit of the College of Education, Oregon, USA. The Open Society Foundation, London, funded this initial project from 2012 to 2014.
- Early Childhood CARES has experience in providing early childhood intervention and early childhood special education services to children who have developmental delays or disabilities. The methodology and approach implemented and developed within the “I Deserve Childhood” project has been practiced in various organizations, but was new to the Bulgarian context.



Hippotherapy sessions are part of the educational programmes

By integrating the early intervention programme into the health and social systems, the number of abandoned children can be significantly reduced

disabilities are abandoned and are consequently cared for by institutions, which are detrimental to their development and carry significant and long-term costs for the state. By integrating the early intervention programme into the health and social systems, the number of abandoned children can be significantly reduced. This development model helps children to achieve better results, protects their human rights, supports families, and saves precious resources for the community.



THE MODEL:

Intense cooperation with families

The provision of early intervention services is realised in the following stages:

Initially, the ECI specialist provides the parents with information about the child's situation and condition in friendly and understandable language. They are also informed about the prospects of the child's development. For example: "Every child is born with a different potential and it is difficult to make precise forecasts, but when you love, support, and stimulate your child, they will progress." Parents are also informed about the availability of relevant services in the community, if any. Often, however, there are no other support services.



Each new activity is shown by the specialist and then tried by the parent to make sure they will be able to continue with it afterwards.

Assessment tools are used as an entry to the service. One of these is a screening test for emotional development called an ASQ-3 (Ages & Stages Questionnaire) which evaluates a child's development compared to their age standard. It is a developmental screening tool designed for use by early educators and health care professionals. Another tool is the ASQ-SE, which assesses emotional development and is used mostly by parents in the home when a child has not had a professional diagnosis.

Yet another tool is the Assessment, Evaluation, and Programming System for Infants and Children (AEPS) test. The purpose of the AEPS is to assist professionals and parents/caregivers in identifying and monitoring children's developmentally appropriate educational targets and for planning individualized intervention. Moreover, regular re-testing is conducted (in six-month intervals) with both tools (ASQ and AEPS) to measure the child's progress in various areas.

The re-testing shows the achieved results against the defined goals in the individual development plan. All the information from these tests, medical documentation, observations, other expert opinions, and the resources of the family are taken into account, and an individual development plan is developed together with the parents. This plan includes goals and tasks within a certain period, which is revised and amended at three to six-month intervals. Importantly, the goals are realistic and achievable in the everyday environment.

The ECI sessions are conducted in the child's natural environment – at home or at the playground – which is why the services are mobile and are provided through home visits. The purpose of the home visit is that the ECI specialist can support and guide the family on how to use available resources/objects at home for stimulating the child's development. In this way, the development process is continuous and does not depend on the presence of the specialist. All members of the family are encouraged to participate. Parents can become their child's best therapists, since they know the child best and are with the child for the most time.

During each home visit, the specialist and parents discuss the child's progress, concerns, difficulties, and everything that has happened since the previous visit. New activities or approaches might be suggested. Each new activity is shown by the specialist and then tried by the parent to make sure they will be able to continue with it afterwards. This individual approach is applied to each child and family, and the everyday activities are adapted to the specific condition of the child.



We Deserve a Childhood...



observe children at their familiar environment



provide materials to support ECD at home



FACTS AND FIGURES:

Steady progress over the years

- The For Our Children Foundation's ECI programme has supported 352 children (152 girls, 200 boys) in the following age groups:

Up to 1 year: 145

From 1 to 3 years: 169

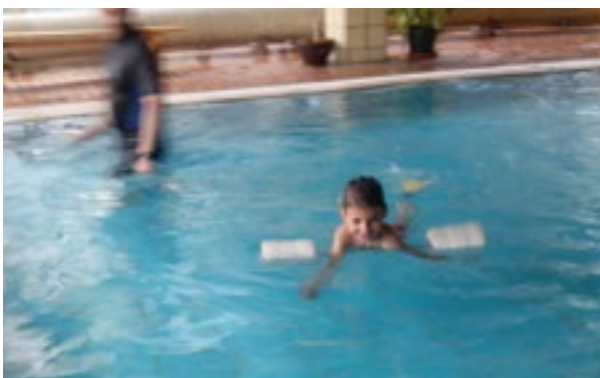
From 3 to 4 years *: 41

*Children older than four years are included in the programme if they joined the service comparatively late or if continuing support is necessary in order to develop the child's full potential.

- The total number of Foundation employees is 74, five of whom formed the ECI team.
- The Foundation has 22 support staff, a significant increase over the last three years.
- Five members of the staff conduct trainings for children and their parents, for other employees of the organization, and for external clients.

When necessary, the work of the ECI specialist is supported by a multidisciplinary team, including physical therapist, speech therapist, neonatologist, and others. The ECI specialist actively interacts with other specialists in order to respond to the complex needs of the child.

The teaching materials are specialised play items, as well as common household items such as bowls, boxes, balls, beans, and many other objects from



Hydrotherapy session: Parents are encouraged to work with the strengths of the children and with their abilities.

the home environment that can be used as support materials for training and skills development.

This early childhood intervention is the first integrated social-health service that is operating at the national level, and it is in sharp contrast to the traditional medical model that focuses on the child's deficits.



FUNDING:

Initial funding from the Open Society Foundation

In the period 2012 to 2015, the Open Society Foundation, with additional co-financing from For Our Children Foundation, funded the programme with the sum of \$181,350. Currently, there is no state funding or financial standard for the ECI services. There is funding available under a national EU-funded project, which will end in 2018, and state funding is expected to begin at that time. However, the direct beneficiaries of EU funding are municipalities and the service centres managed by them. NGOs need to rely to other sources of funding.



OUTLOOK:

Continue to grow and improve

For the period 2015 to 2017, the focus of the Foundation's work will remain on early childhood development. The organization will continue working in the same locations, trying to reach more children. Recently, the organization launched a specialised study of the impact of its services on children, seeking to measure the effectiveness of the services and to analyse the achievements and progress of the children.

Despite the progress made, there are still problems to overcome. One of these is the rigidity of the health system and its reluctance to recognize the importance of integrated social and health services, such as Early Childhood Intervention, as well as its tendency to view the Foundation's work as competition rather than as a supporting medical service. Another issue is the lack of state recognition for the need for early childhood development services and for financing them through the state budget.

The effectiveness of investment in early childhood development is seen through the visible differences in children who have been a part of an early intervention programme, both in the short and long term. They are more successful in school, their social and emotional adjustment is better, they experience fewer problems with the law, their physical health is better, and they are more able to find employment.

Children



- + with disabilities
- * prematurely born
- * risk of disability



0-3 years old

+ Parents support



- + Parents are partners
- * children & parents are focus
- * See strengths of children
- * children remain in families





ABOUT THE ORGANISATION:

For Our Children Foundation

For Our Children Foundation is a successor to the British organization for protecting children's rights, EveryChild, and has been working in Bulgaria since 1992. It is the first Bulgarian non-governmental organization to introduce foster care, starting as early as 1997. Today, the Foundation is working to make sure that no Bulgarian child spends the first years of his or her life in the isolation of an institution, but lives safe and loved in a family environment.

The services for children are provided in several specialized community support centres in the two largest cities of Bulgaria, Sofia and Plovdiv. The services are intended for children in the early age groups, specifically children 0–3 years, the prematurely born, and children with disabilities, at risk of developing disabilities, or with developmental difficulties. Over the last three years, For Our Children Foundation has provided a variety of services to more than 2,300 children. In 2015 alone, the organization worked with 1,095 children and their families, including 148 children in the Early Childhood Intervention programme.

The For Our Children Foundation offers more services, which are linked to the Early Childhood Intervention programme. These include the prevention of child abandonment in maternity wards, development of parental capacity, family support, and foster care. The clients of all the services provided by the Foundation have the opportunity to make use of the ECI services, if needed.

DEINSTITUTIONALISATION IN BULGARIA: A long way to go

- Current deinstitutionalisation policies – for both children and adults with disabilities – provide for care in small group homes (SGH), which does not significantly improve the quality of life that disabled people live.
- SGH are managed as residential institutions. As such, residents are not in control of their daily activities and are not offered the opportunity to move to a community arrangement.
- The European Social Fund is helping municipalities to provide community residential services, such as monitored housing, protected housing, day-care centres, and centres for social rehabilitation and integration.



For Our Children Foundation

Bulgaria

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ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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Zero Project Analysis

In-depth Research of Innovative Practices

presented by:

**EASPD and
Essl Foundation**

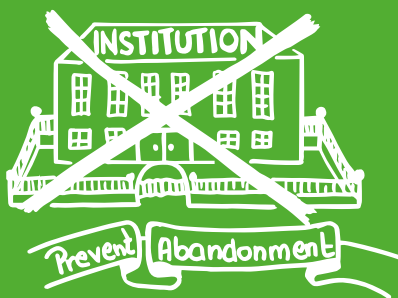
Edition #1, April 2016

Early assessment coupled with early intervention

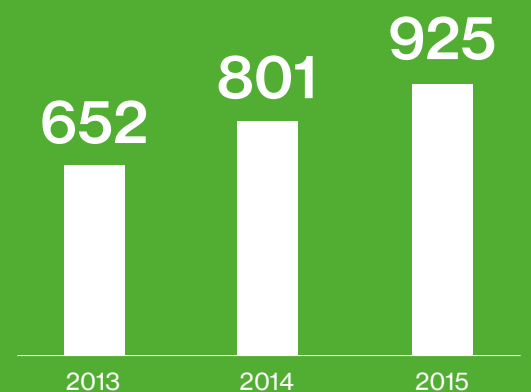
Country: Bulgaria, City of Varna Organisation: Karin Dom Foundation

MANAGEMENT SUMMARY: Since 2010, Karin Dom Foundation has supported 473 children and their families through an Early Intervention Programme. The Foundation offers support to children aged 0–4 who are at risk of a developmental delay or have special needs – that is, those who have a diagnosed condition or impairment that restricts functioning in one or more developmental areas. Operating in Varna, in eastern Bulgaria, the Foundation's objectives are:

- To provide high quality services to children with special needs and their families in order to prevent children from being abandoned in institutions and support the successful social integration of children and their families.
- To disseminate good practices by providing trainings and consultations to parents and professionals working with children with special needs in Bulgaria, while adhering to international standards.
- Work for advocacy and policy changes for children at local, regional and federal level.



Family support networks instead of institutions



Home visits per year by Karin Dom Foundation

Support begins at the maternity hospital immediately upon birth through breastfeeding advice, consultations with psychologists, play groups for children and parents, home visits, play and therapist sessions, and any other activity considered beneficial for the development of the child. Karin Dom Foundation does not perform residential care but works in the natural environment of the child.



THE PROBLEM:

A medical centred approach still prevails

In Bulgaria only a few services are available for children with special needs from 0 to 3 years. The support is based on medical models of care, and parents of infants and young children with serious disabilities are often advised by medical staff to institutionalize their children because, they are told, it will be difficult to care for them within the family environment.

Furthermore, families are discouraged from being involved in the rehabilitation services of their children. In this “expert model,” the participants depend on “professional expertise” to solve problems for the children, rather than taking the needs of the entire family into account. (Please refer to the second Bulgarian case study on page 13.)

During the first implementation period of the Early Intervention Programme in the Municipality of Varna, it became clear that there is very little awareness about early intervention services as such. Moreover, it became necessary to establish an Early Intervention Programme that helps children to overcome developmental challenges, since both parents and medical authorities tended to ignore the need for targeted support for the development of young children with disabilities aged from zero to four years.

Another significant problem was the lack of higher education and other training programmes on early childhood intervention and the application of family-centred practices in Bulgaria.



THE DEVELOPED SOLUTION:

A family centred approach is introduced

Unlike institutional care and medical-based services, this model works to support and strengthen parent-child interactions and relationships as well as child outcomes, and offers parents considering child abandonment an alternative to institutionalisation. Through early assessment coupled with intervention, there are increased chances that children with disabilities can participate and flourish in inclusive mainstream educational settings. One crucial element of early intervention is breastfeeding support, given its important role in preventing abandonment and its strong influence on better developmental outcomes.



THE MODEL:

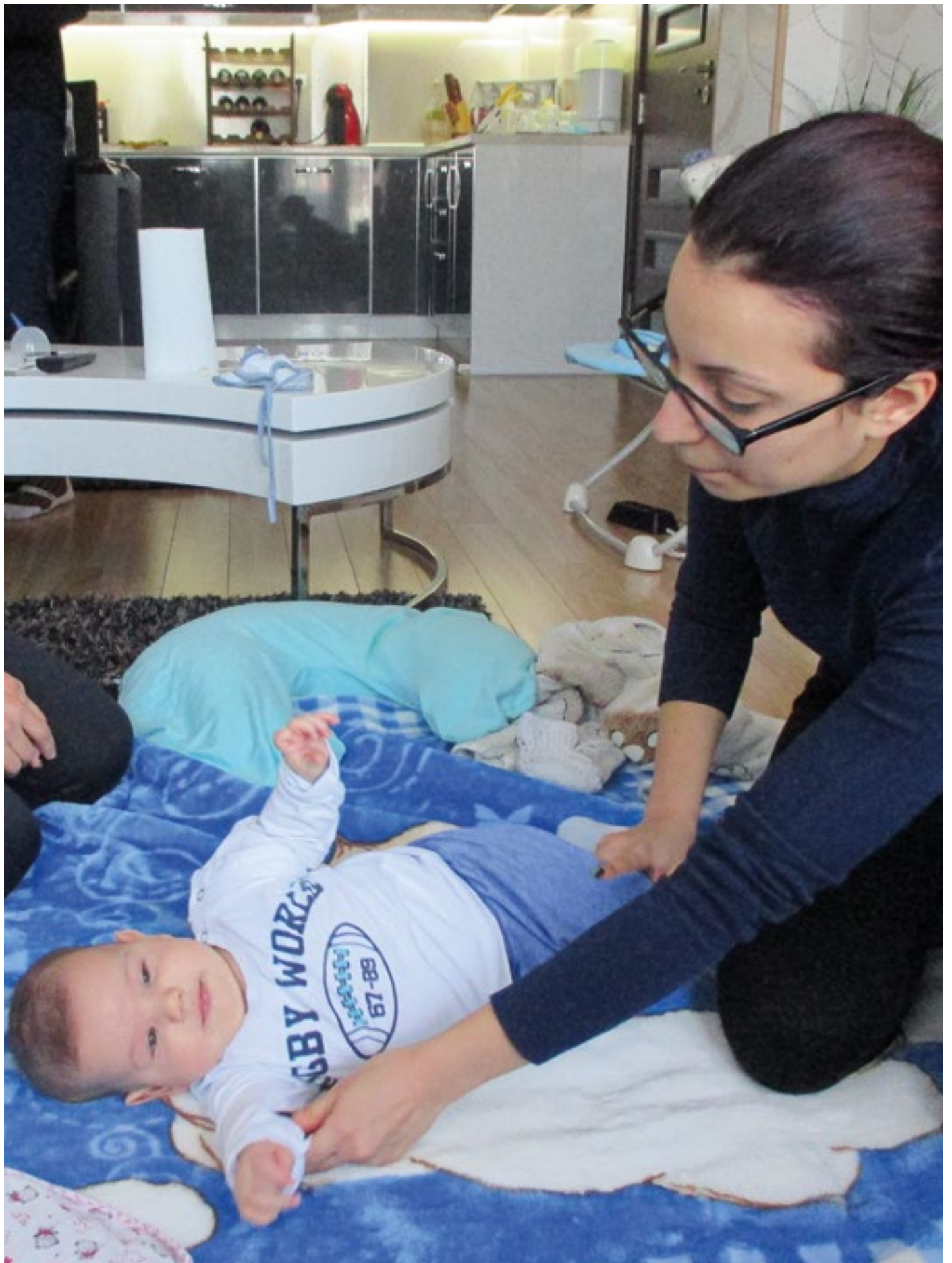
The child’s home becomes the focal point

The Early Intervention Programme includes home visits, parent-toddler playgroups, family-support networks, and breastfeeding support. Because the home is considered the natural environment of the child, the core service is the home visit. During home visits, the specialist works with the family on assessment of the child, setting of goals, and preparing an individual plan for a six-month period. Through a series of follow-up visits, the specialist gives practical demonstrations to the parents on how to teach their child various skills through play or such routine activities as dressing,

ABOUT BULGARIA

Struggling to advance in the World’s Mothers Report

- Bulgaria, a country of 28 provinces, is a parliamentary republic with a high degree of political, administrative, and economic centralization. It is a member of the European Union, NATO, and the Council of Europe. Bulgaria’s population of 7.4 million is predominantly urban. Most commercial and cultural activities are centred in the capital and largest city, Sofia. The strongest sectors of the economy are heavy industry, power engineering, and agriculture, all of which rely on local natural resources.
- The 2015 Human Development Index ranks Bulgaria 59th, with a gross domestic product) of \$15,596 per capita. Median age is 43.4 years (data from 2014), with approximately 300,000 children under five years. According to Save the Children, Bulgaria ranks 43rd in the State of the World’s Mothers Report – one of the last among EU countries, followed only by Malta, Hungary, and Romania.



Through a series of visits, the specialist gives practical demonstrations to the parents on how to teach their child various skills through play or such routine activities as dressing.

The Early Intervention Team also advises on organizing the child’s environment, on developmentally appropriate and activities, and on interaction with other children and adults

eating, bathing, etc. The specialist considers the family’s needs and beliefs, and builds on their strengths, knowledge, and skills. In addition to these home visits, the specialists can also make visits to other natural environments, such as nurseries, kindergartens, playgrounds, etc.

Playgroup and support Network

The second service is the parent-toddler playgroup. The playgroup offers an opportunity for parents and children to interact with each other, learn through play, meet new people, make friends, and have fun

together. Parents and specialists work together to teach children new skills and habits (cognitive, motor, speech, social). The playgroup sessions take place at an appointed hour in a specially equipped playgroup room in the Karin Dom headquarters, including age-appropriate toys. The playgroups provide an opportunity for the children to socialize in a group environment, and thus be better prepared for inclusion in a nursery or a kindergarten. In addition, the playgroups provide an opportunity for parents to practice new models of child-parent interaction.

The third service in the programme is the family support network, which is designed to empower parents to stand up for their rights and for the rights of their children. The service provides information and psychological/material support. The network includes a group of parents (the “parent-on-call” group) who have been trained to provide early support to families who have recently learned about their child’s disability. Other components of the network are a resource library (containing toys, special aids, and books) and formal and informal parent support group meetings.

The starting point of this service is when Karin Dom’s Early Intervention Team receives a referral and schedules a home visit. A screening tool is used to assess the eligibility of the child for the Early Intervention Programme; and during this first visit the team explains the programme and discusses the family’s concerns and expectations. During the following visits the team performs a developmental assessment of the child and records the specific needs of the family. Based on this data, the family – together with the team – decides on prioritized goals for the child and for the family. The team then determines the objectives for goal accomplishment. An “Individualized Family Service Plan” is thus developed. Normally, the plan is for a period of three to six months and answers the questions “what, when, who, and how often” regarding the services to be provided.

The Early Intervention Team also advises on organizing the child’s environment, on developmentally appropriate toys and activities, and on interaction with other children and adults. Toys and books are left at the family’s home from the resource library for a short time, as well as specialized readings upon the parents’ request.

Importance of home visits

In the home visit programme, readily available toys and other household resources are used so as not to make parents dependent on equipment and materials that are highly specialized and/or expensive. The intervention team offers ideas and strategies on how to use a particular toy, game, or routine in order to

FACTS AND FIGURES:

Almost 1,000 home visits in 2015

Early Intervention Service Users

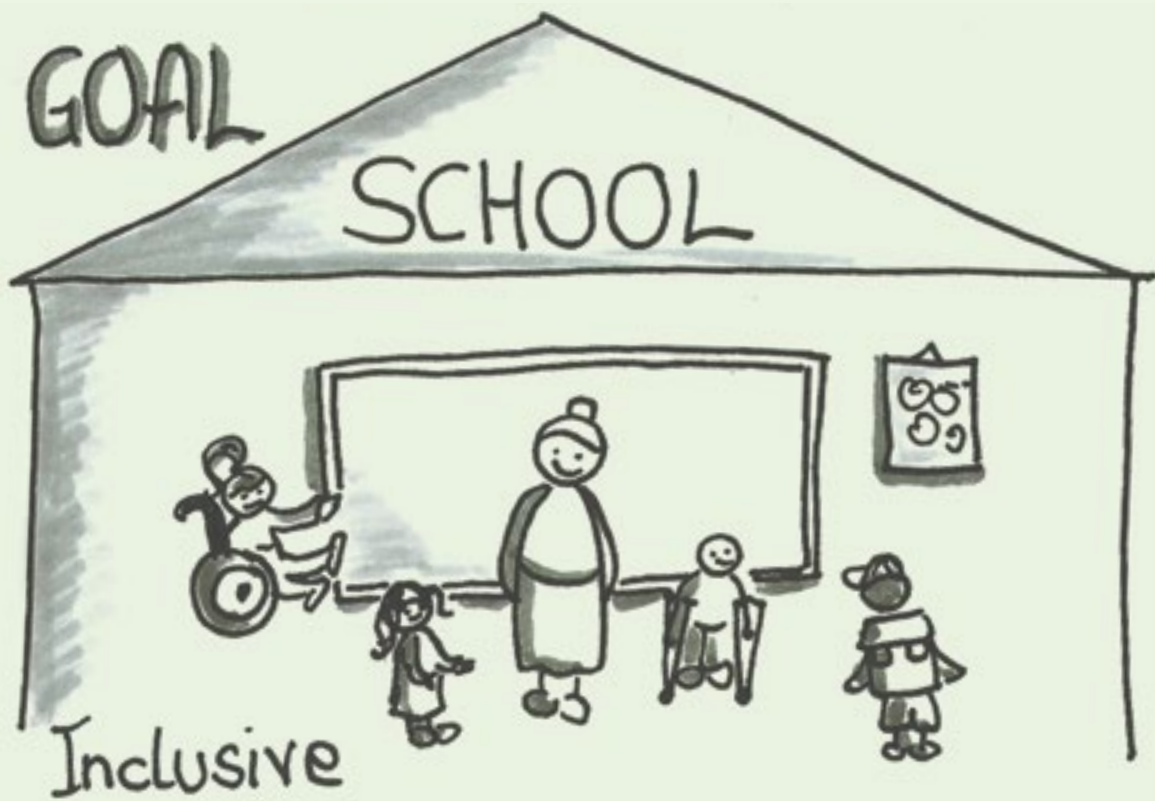
Year	Number of users per year	New cases per year	Closed cases per year
2015	149	80	52
2014	121	64	70
2013	142	87	68

Home visits

Year	Number of home visits per year	Number of single consultations per year
2015	925	27
2014	801	21
2013	652	8

Children supported by the EIP

2015	95 boys	54 girls	149
2014	78 boys	42 girls	120
2013	87 boys	55 girls	142



OBSTACLES THAT REMAIN:

Inaccessible architecture, lack of assistance and training

There are still several obstacles that hinder Inclusive Education for children with disabilities:

- Research shows that having a child with a disability can lower the potential income of parents, since social assistance is hardly available and families will have the additional expense of caring for their children.
- Inaccessible architectural environment and transport are other factors that seriously affect school and kindergarten attendance. The Country Report on Accessibility (2012) of the Academic Network of European Disability Experts revealed that only 5 out of 176 schools in the capital of Sofia are totally accessible.
- There is a lack of extensive training for teaching personnel on children with disabilities and their special needs.
- Furthermore, there are still negative attitudes among some teachers and parents regarding the enrolment of children with special educational needs in mainstream settings, especially regarding children with intellectual disabilities

create an optimal learning situation based on a child's particular interests. Parents are actively involved in the planning and delivering of their child's intervention, which maximizes its positive effect.

It is important to note that Karin Dom does not perform residential care. Early intervention services are provided exclusively in the child's natural environment – his or her home, playground, kindergarten, etc. This model differs from Bulgaria's common practice of delivering centre-based services to young children.

Each Early Intervention Team consists of a physical therapist, speech therapists, special educator, psychologist, paediatrician, social worker, and breastfeeding consultant. The Foundation's teaching staff consists of five full-time members as well as five additional members who work with the therapist team but also work as part-time trainers. If necessary, Karin Dom uses outsourcing services.

In addition, the programme includes breastfeeding support, which is provided by Karin Dom's partner association "Colourful Future." Breastfeeding support is provided to mothers of newborns while still in maternity hospitals, especially to women who are at risk of abandoning their children.



FUNDING:

Private and public funding have been secured

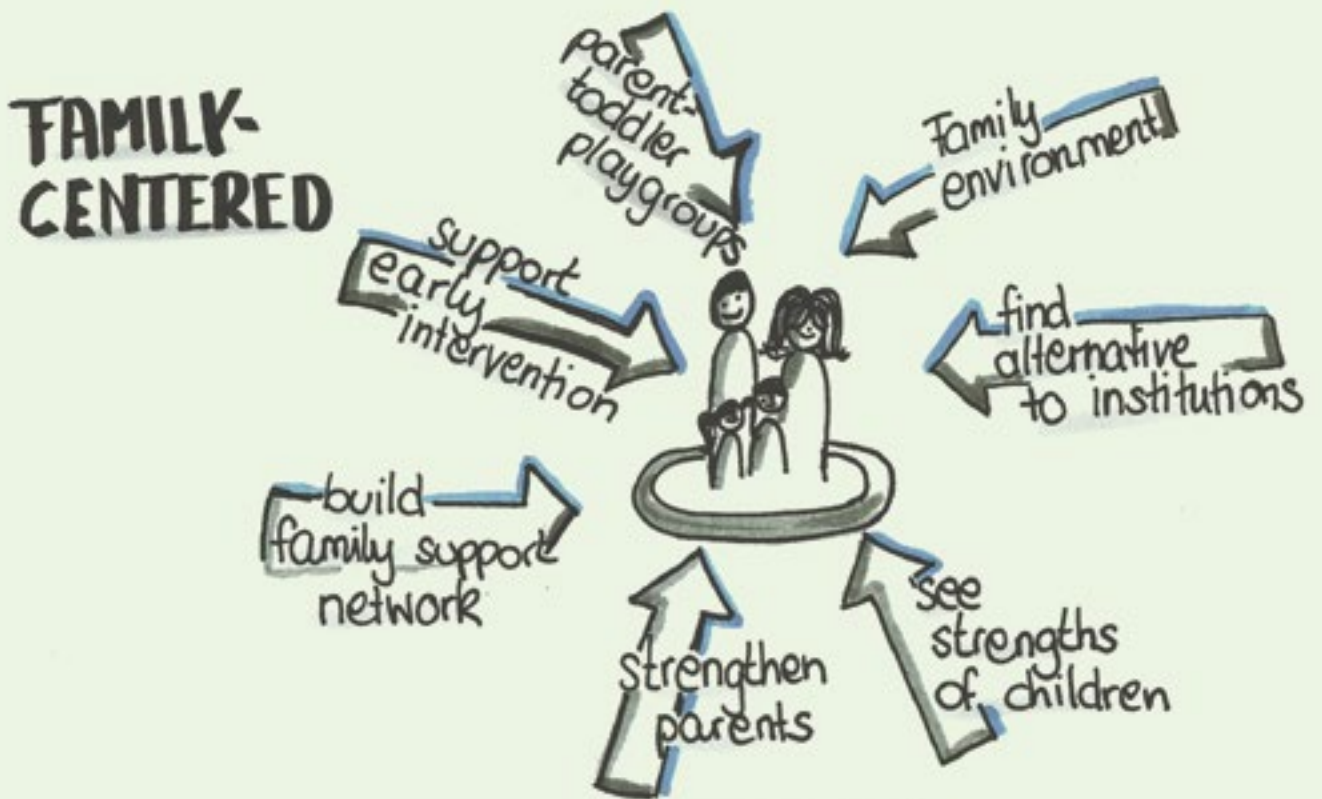
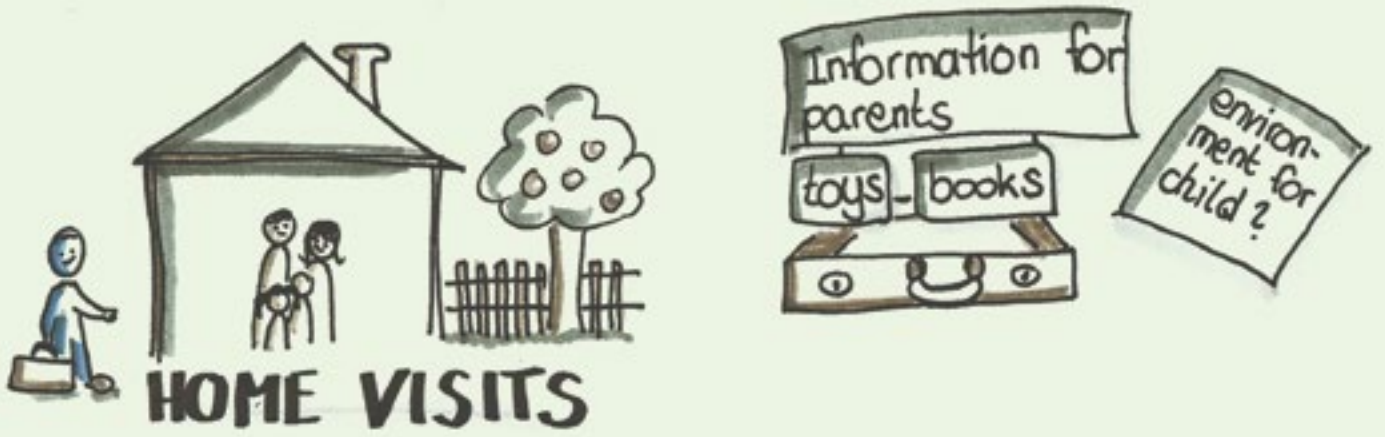
The London-based Open Society Foundation has been funding the Early Childhood Programme since its inception. In addition, starting in July 2013 the Municipality of Varna has been providing financing to the centre for early intervention to prevent the abandonment of children with disabilities. Because of the close collaboration and open dialogue between Karin Dom and the Municipality of Varna, the future sustainability of the Early Intervention Centre appears to be secure. Currently, however, the Municipality of Varna is the only municipality in Bulgaria financing early intervention services from its own budget. Finally, the Foundation was pleased to obtain funding for its "Family-Centred Approach: An instrument for the prevention of institutionalization of children with disabilities." This is a continuing project within the Early Intervention Programme, which is financed by the Tulip Foundation and the OAK Foundation.



OUTLOOK:

Working on further dissemination of the program

The positive experiences of the provision of early intervention services by Karin Dom Foundation have led to the recognition and active participation of policy-makers at the local and national level. In 2014 the Foundation signed a contract with the Ministry of Social Affairs for the development of a methodology and the provision of trainings to 47 Early Intervention Centres. Karin Dom's perspective is to further support the development of early intervention services in Bulgaria through the provision of trainings and the dissemination of good practices and approaches.





ABOUT THE ORGANISATION:

Karin Dom Foundation

After the restitution of democracy in 1993, the Stancioff family provided its summerhouse in Varna, a city in eastern Bulgaria, for the purposes of the Karin Dom Foundation. "Karin Dom" means "Karin's home" – in memory of Karin Guepin, a cousin of the Stancioff family who had cerebral palsy.

Karin Dom Foundation is an active civil organization with a leading role in providing professional services for children with special needs and in building a tolerant society in which they live.

In Bulgaria, Karin Dom is the first organization to have initiated, developed, and applied an Early Intervention Programme on a regional and, later, on a national scale. Its specialists have attended many meetings, training, conferences, and sessions led by pioneers in early childhood intervention programmes in Canada and the USA. Currently, there are ongoing consultations with specialists and professionals regarding the further development of the offered programme.

HOW THE COOPERATION WORKS:

Karin Dom and For Our Children Foundation

- The past cooperation between Karin Dom Foundation and For Our Children Foundation has been designed to share experiences in developing an Early Intervention Programme and to combine efforts towards sustainable development and awareness-raising regarding the new early childhood intervention (ECI) services in Bulgaria. To this end, the two organizations issued a common manual on the provision of ECI services, since both organizations apply the same approach.
- The two organizations differ, however, in the variety of other services that they offer (for example, For Our Children Foundation offers the prevention of child abandonment in maternity wards, development of parental capacity, family support, and foster care, among other services), and the two operate in different locations of Bulgaria.



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ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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How parents learn to raise their children at home

Country: Croatia, City of Zagreb Organisation: Mali Dom (Little Home)

MANAGEMENT SUMMARY: Mali Dom (Little Home) operates in the Croatian capital of Zagreb and offers its services throughout the country. This public institution has developed an early intervention programme for children aged 0–3 with disabilities or a high risk of developing disabilities, which is family centred and mostly practised in the child's home. Based on an initial assessment, the method is ongoing and individualized for each family. Short- and long-term goals are set by analysing results from the initial assessment and by consulting parents about what they think is important for the child to learn.

- Early intervention services are provided to some 60 children and their families each year in the Zagreb area and to an additional 150 children nationally through transdisciplinary assessment and counselling.
- Overall, the organization offers regular services to 150 persons per year and to an additional 350 persons nationally through assessments and counselling.



The key is to empower families

180 children have attended regular early intervention programmes

450 children have participated in transdisciplinary assessment and counselling

320 parents have participated in the programme

during the last three years

Mali Dom establishes collaborative partnerships with families in order to empower them. The offered services provide the necessary conditions for a child to fully develop his or her potential and a basis for future learning. By building the competences of family members, their involvement with the child and their participation in the community on behalf of the child is increased.



THE PROBLEM:

No services existed before the start of Mali Dom

Prior to the Mali Dorm initiative, there were no established and recognized home-based early intervention services in Croatia, and there was either no or very low early identification of children at risk of developmental delay. The few practices that did exist were usually deficit-oriented, which gave the child and parents a negative impression regarding disabilities. Doctors and other professionals determined the child's needs and made decisions for the family. Worse, the fragmented and specialized services started later than they were actually needed.



THE DEVELOPED SOLUTION:

Collaboration with children and parents

The mission of Mali Dom is to provide comprehensive, accessible, and responsive home-based early intervention services that support families in raising a child with a developmental disability or the risk of developing a disability from birth until three years of age. The goal is to reach developmental milestones in the first years of life.

The primary focus of the programme is to build the confidence and competence of parents and other caregivers by promoting the child's development and participation. This includes participating in "experience groups," which consist of parents and their children together with professionals (psychologists, social workers, etc.) who function as moderators. The goal of these groups is to provide experience to parents and their children through moderated activities and discussions. In addition, there are support groups whereby parents meet with other parents twice a month for discussion and role play, again guided by a moderator.

By working as a transdisciplinary team, the likelihood of confusion for the family is reduced since the number of people and disciplines with which they need to interact is very low. This model is less intrusive than a conventional institutional model because parents only need to build one key relationship and only one service provider visits the home. Such enhanced and streamlined communication is considered a key benefit for the family.

The Mali Dom model also provides greater service efficiency: more children can be served because fewer providers routinely see a child. Further, on each visit families receive guidelines for the next 2–4 months, including written materials tailored to the specific needs of the child and family.



THE MODEL:

It is important to start as early as possible

The Early intervention Team created this method based on their knowledge and experience as well

ABOUT CROATIA:

One of the few countries that offer fully inclusive education

- The Republic of Croatia declared independence on 8 October 1991 leading to the break-up of Yugoslavia, and the country was internationally recognized by the United Nations in 1992. Since 2000 the country has had a parliamentary system, and in 2013 it joined the European Union. With 4.3 million inhabitants, of whom approximately 200,000 are under five years, Croatia had a gross national income per capita of \$19,409 in 2015. The economic output is dominated by the service sector, which accounted for 66 percent of gross domestic product, followed by the industrial sector with 27.2 percent and agriculture accounting for 6.8 percent.
- Croatia offers all children and young people – including those with developmental disabilities, who are members of national minorities, the gifted, and those who are disadvantaged – full inclusion in the education system on all levels, as well as further education through adult education and lifelong learning programmes.



The primary focus of the programme is to build the confidence of parents by promoting the child's development and participation.

After six weeks, the primary therapist develops the Individualized Family Service Plan (IFSP), based on assessments and family priorities

as their insight into other programmes (consulting research and literature concerning early childhood education). The model follows a step-by-step approach, which consists of the following activities:

1. Establishment of a home-based model with developed methodology protocols and referral at the earliest possible time following birth.
2. The model is strength and resource based, enhances competence and positive functioning, and decisions are made together with family – not for them.
3. All services are well coordinated and integrated among various disciplines and sectors.
4. The model provides services for children in a natural environment – that is, settings in which the child would participate if he or she did not have a disability, such as the home and kindergarten – to the maximum extent.
5. The model has embedded natural learning opportunities and intervention strategies into the daily activities.

6. There is a strong focus on parents as the primary implementers of intervention within family routines. Families are empowered as agents of change in promoting their child's development and meaningful participation.

7. There are support and experience groups whereby parents come with their children to the Mali Dom centre to build their competences and where they can meet with a range of professionals. Here they can experience a variety of activities, games, and play that later will be embedded in their everyday routine in order to achieve set short- and long-term goals in a nonintrusive, play-oriented way.

8. To ensure quality of service and especially the interaction between team members involved in working with a specific child, the organization has designed a software application that ensures that all communications, goals, reports, and protocols are recorded.

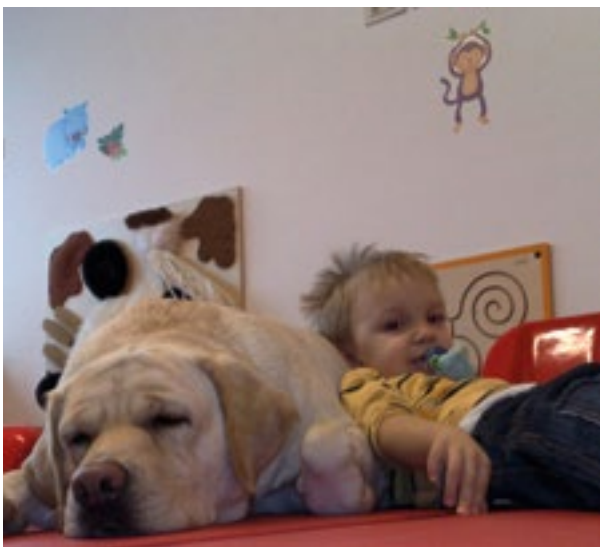
9. All children referred to the centre start with a transdisciplinary assessment, which helps to better understand the child's strengths and needs and how early intervention can help. Following the assessment, the team discusses with the family their priorities and concerns, and together they outline the next steps and answer specific questions that the family may have.

10. This is followed by an initial conversation with a social worker and psychologist. In the subsequent debriefing process the team moves to identify and support the primary therapist who will be working with the family. During the first home visit, the team explains what the parents can expect from home-based service in order to alleviate possible anxieties.

11. After six weeks, the primary therapist develops the Individualized Family Service Plan (IFSP), based on assessment information and family priorities. It includes outcomes for the child and family, and describes the learning methods and approaches that will be used. It also explains what kind of services they will receive, who will provide them, as well as where, when, and how often.

Evaluation every three to six months

At this point the IFSP is implemented, and the evaluation of defined goals is performed three to six months thereafter. –At that time old outcomes that have been reached or that are no longer relevant are discarded, and new learning strategies and activities to help meet new outcomes are initiated, as are any necessary changes in the type of service provided.



Session with the therapy dog

PROBLEM



GOAL



FACTS AND FIGURES:

180 children treated over three years

The following services are offered:

- Transdisciplinary assessment of each child, involving 2–3 professionals and 1–2 family members (usually both parents).
- Home visits by a dedicated professional who works with the individual child and family members.
- Extra support at the Mali Dom centre when needed, such as sensory integration, physiotherapy, swimming, vibro-acoustic therapy, etc., with at least one family member present (usually a parent).
- “Experience groups” composed of 4–5 children, at least one family member per child (usually a parent), and 4–5 professionals.
- Altogether, the organization has 26 teaching staff members.
- Over the last three years 180 children and 320 parents participated in regular early intervention programmes, and 450 children benefitted from transdisciplinary assessment and counselling.

Learning materials include non-standardized didactic materials, such as shoe-box activity for sorting and matching, beads or small balls for visual stimulation, and visual calendars. The therapists also select play materials suited to their intervention strategies. These include many different objects – some already in the family home and some brought by the therapists –



Therapy session can be performed with household items and everyday playtools

such as toys, games, instructional materials, everyday objects, and construction pieces.

These services are performed at the child's home primary by a therapist/service provider, who is a key member of the Early Intervention Team. Home-based practice includes regular visits (once a week) from a special teacher who works with the child and the family according to the IFSP, having first defined outcomes and short and long-term goals with all team members and the family.

Centre-based activities are provided when there is the need for professional support from some other specific field or when services cannot be carried out at home, such as physical/occupational therapy, sensory integration, swimming, psychologist consultations, and parent groups and experience groups (parents with children). In all those activities parents are present, and all are carried out in coordination with the key staff person and all other team members.



FUNDING:

Public funding is available

The practice is funded by the local government. Moreover, there is an agreement with the Ministry of Social Welfare for providing listed services. The actual budget is calculated per service: for example, home visit once a week, physiotherapist once a week, moderated experience group meetings once every two weeks, etc. Parents agree upon this plan, and it is re-evaluated – together with the child's development and the IEP – every three to six months and changed accordingly, if required.

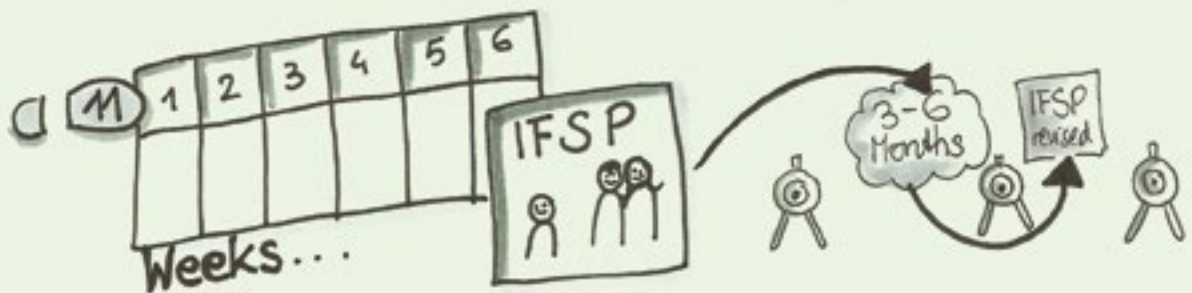
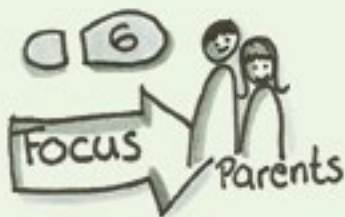


OUTLOOK:

No common standard for early intervention programmes yet

Mali Dom observes that there is still not adequate cooperation among the various stakeholders when it comes to the transition from early intervention services to other services, such as kindergarten and schools. The process functions only by an initiative of the organization, since there is as yet no legislative solution or standardized protocol.

In order to expand particular programmes, the organization needs a larger budget to employ more professionals. Another obstacle to overcome is for the Ministry in charge to standardize this methodology and ensure the service quality of other early intervention service providers. Currently, the Ministry only provides recommendations.





ABOUT THE ORGANISATION:

Mali Dom

Mali Dom (Little Home), founded in 1997, is a public institution of the City of Zagreb that provides regular daily services to more than 100 children and youth who are visually impaired, have other additional disabilities, or are deaf and blind. It operates its services in new and spacious premises, which offer the possibility of further expansion of the organization's programmes. Through further development, Mali Dom aims to become a role model in the field of care for children with multiple disabilities.

In addition to its activities directly on behalf of children, the organization offers assistance to families to help them understand each child's positive qualities, thus building stronger family ties and greatly improving each child's opportunities in life.

To date, more than 1,000 children from across the Croatia have benefitted from this programme.

EXAMPLE OF AN INDIVIDUAL EDUCATION PLAN:

Long-term goals as agreed with the parent/guardian

- Extending the tactile experience
- Capturing small objects
- Repeating double syllables with meaning
- Games of handing specific item
- Using isolated finger movements
- Pointing details on the object / image with a finger
- Imitation of movement / gesture
- Turning the pages of a book
- Standing independently
- Walking while holding onto the trolley



Mali Dom

Croatia

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ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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Step by step into inclusive kindergarten and school

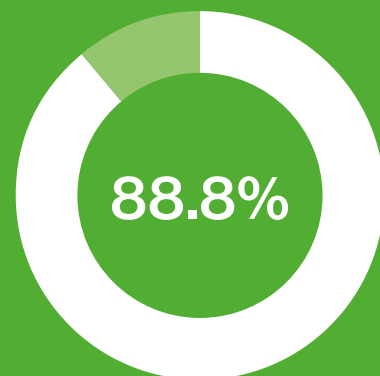
Country: Greece, Athens (Illion) Organisation: Theotokos Foundation

MANAGEMENT SUMMARY: The Theotokos Foundation provides support for children with intellectual or other developmental disabilities and their families. The goal of the Early Intervention Programme is to support the inclusion of as many children as possible in mainstream kindergartens and elementary schools. Parents are actively involved in their child's daily programme, and they regularly exchange information about their child's activities, progress, and any other concerns.

- From 2000 to 2014 a total of 117 children have used the service.
- 87 of these children were integrated into the mainstream schooling system.
- 81 children are being supported through follow-up services.



Including children in kindergartens and actively involve their parents



Parent satisfaction rate in the school-year 2014/2015 with the project

Essential to the child's development is the empowerment of the parents through active engagement in therapy sessions. Parents attend regular counselling and training sessions with all disciplines. Further, there are two meetings per year with all members of the interdisciplinary team. Throughout the week, all children attend individual sessions with the occupational therapist, speech therapist, special educationalist, or psychologist.



THE PROBLEM:

Limited availability of Early Intervention Programmes

In Greece there are very few public welfare and education services that cater to pre-school-aged children with special educational needs, and the availability of parent-counselling services is limited. For-profit service providers offer only very expensive early intervention programmes. The few programmes that are available do not offer an integration support service to ensure a smooth transition from the special setting into the mainstream schooling system.

During the last five years public services in Greece have been inadequately funded due to the country's

financial crisis in general and to a lack of specialized staff members. Consequently, fewer children with disabilities are diagnosed at an early age. In addition, the waiting lists for diagnosis through the national health system can be as long as six months – a critical waiting time for young children with difficulties who need immediate care.



THE DEVELOPED SOLUTION:

A careful preparation for inclusion

The goal of the Early Intervention Programme is to support the inclusion of as many children as possible in mainstream kindergartens and elementary schools by providing intensive intervention from an interdisciplinary team – both on-site in groups and individual programmes, and offsite with integration support.

The target group is children two to six years with diagnoses such as developmental delay, immaturity, language disorder, attention deficit hyperactivity disorder, autistic spectrum disorder, and/or other learning difficulties. The children must have a valid diagnosis from a government service. The children's parents should be subscribed to the national social security system, but this is not mandatory since a certain number of children from disadvantaged families without social security are admitted per year. Members of these families are usually long-term unemployed or are uninsured by the social security system. Over the years, the Foundation has accepted children from a nearby orphanage.

An interdisciplinary team covering all areas of development (behaviour, speech, communication, movement, daily living skills, cognitive skills, emotions, play) assesses each child. Once the child has enrolled and attended the programme for a short while, the interdisciplinary team prepares the Individual Education Program. Long- and short-term goals are set, based on internationally recognised developmental milestones for young children. The goals are worked upon during both classroom and one-to-one sessions. They are frequently assessed and, if completed, new goals are set. If there is a lack of progress, the issue of how to adapt methods and techniques in order to help the child achieve the desired goals is discussed in detail.

ABOUT GREECE:

The crisis is not over yet

A member of the European Union, Greece is a parliamentary republic in which the President, elected by Parliament every five years, acts as a Head of State. The Prime Minister is the Head of Government, and the Ministerial Council is the collective decision-making body that constitutes the government. Greece has a population of approximately 11 million people, and the main industries are tourism and shipping. The latest Human Development Index ranks Greece in 29th place, with a per capita gross domestic product of \$24,524. During the global financial crisis the Greek economy collapsed, and by 2013 the economy had contracted 26 percent compared with the pre-crisis level of 2007. Under intense pressure from the EU and international market participants, the government accepted a bail-out programme that forced Athens to cut government spending; to decrease tax evasion; to overhaul the civil service, health care, and pension systems; and to reform the labour and product markets. This process is still ongoing.



The Early Intervention Programme is performed on the 52-acre grounds of the Theotokos Foundation in Ilion, located in the north-western suburbs of Athens.

The children participating in the programme come mostly from the surrounding suburbs of Ilion, and access the site using the Foundation's bus service or by their parents' private transportation



THE MODEL:

A team of experts works with children and family

The Early Intervention Programme is performed on the 52-acre grounds of the Theotokos Foundation in Ilion, located in the north-western suburbs of Athens. The programme takes place in a dedicated building with the capacity to host four groups, while individual sessions are held in separate rooms for speech therapy, occupational therapy, and psychology support.

The children participating in the programme come mostly from the surrounding suburbs, and access the site using the Foundation's bus service or by their parents' private transportation. The site is situated close to local shops, a park, and a cinema-shopping complex, making community excursions easily accessible.

Within the framework of a bio-psycho-social model, individualised programmes are created based on a child-centred approach. The rooms are structured based on a kindergarten simulation along with supportive play and educational materials to foster development in a natural environment. Throughout the day, all children attend individual sessions with the occupational therapist, speech therapist, special educationalist, and psychologist. All disciplines are in close collaboration with the group teacher. Goals and progress are recorded daily in the child's Individual Education Programme.

The transfer of skills is an important part of the programme – both among staff and among the children – and this is accomplished through regular co-teaching programmes at which two staff members are present in the group. For example, the co-teaching programmes and staff address the following topics:

- Communication skills (teacher and speech therapist)
- Play skills (teacher and speech therapist/occupational therapist/psychologist)
- Sherborne Developmental Movement (occupational therapist and speech therapist)

- Phonological awareness (teacher and speech therapist)
- Alternative augmentative communication systems (e.g., photos, Picture Exchange Communication System, Makaton). These are introduced in the classroom with the occupational therapist and speech therapist.
- Autism Programme (in the classroom with the speech therapist, occupational therapist, or psychologist).

The above co-teaching programmes involve sharing the planning, organization, delivery, and assessment of the programmes. Planning includes the short-term goal(s) of the day's programme as well as the long-term goals. Goals may include group goals referring to a common expectation of achievement and individual goals according to the level of each child.

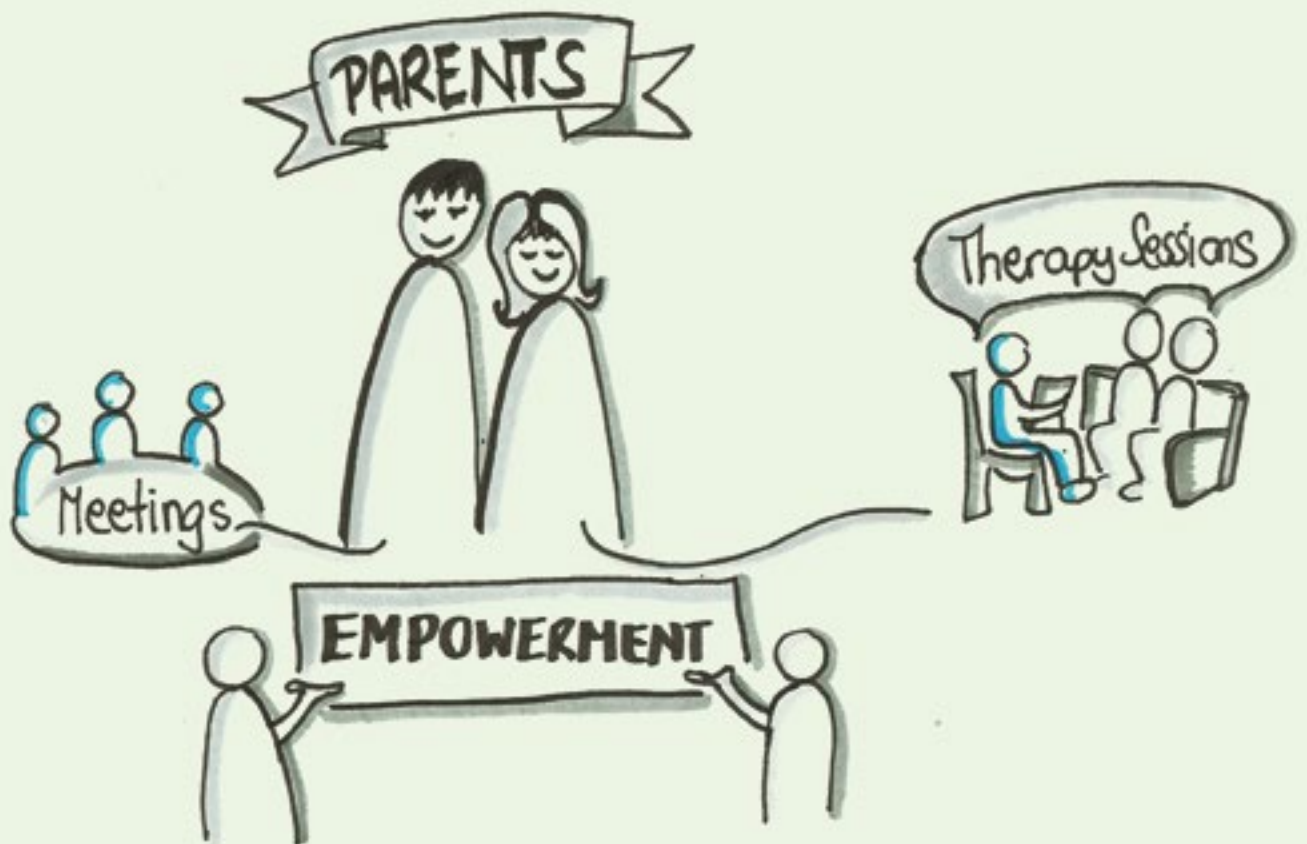
The delivery of the programme varies according to the experience of the teacher and the type of programme. For example, the therapist takes on the lead role in the first few sessions acting as a model for the teacher. The teacher gradually increases the involvement of the children (e.g., giving instructions, prompts, cues, correcting). In some cases, the goal is for the teacher to be able to deliver the programme on his/her own. In other cases, the therapists' methods and techniques act as models for the teacher to use throughout the day.

Step by step integration

Parents attend a meeting with the interdisciplinary team at which the strengths and needs of the child are discussed, as well as the structure and functioning of the service. When the interdisciplinary team, which regularly assesses the students' developmental level, decides that a particular child has reached the developmental milestones required for mainstream inclusion, a meeting with the parents is arranged. The process of inclusion is explained as well as the expectations (the child's strengths and weaknesses) regarding the inclusion process.

In the beginning, the child attends the kindergarten usually for only two days, and during the rest of the week he/she continues to attend the programme. This arrangement is performed for two reasons:

- To avoid side-effects of a sudden and stressful change in the child's daily routine.
- To allow discussion – with the child's support person and kindergarten teacher – of possible difficulties the child might face, and to work on them systematically during the days he/she is still attending the programme.



FACTS AND FIGURES:

Regular monitoring shows high rates of satisfaction

- Currently there are two groups of six children each.
- Each group has one pre-school teacher.
- There are eight therapy staff members and three enrichment programme staff members.
- Individualized Education Programme goal achievement success rates:
2012–2013 89.3%
2013–2014 72.5%
2014–2015 82.5%
- The monitoring mechanisms in place are based on ISO 9001:2008 and on the European Platform for Rehabilitation EQUASS Quality Assurance Certifications. As an organization, the Theotokos Foundation is evaluated every two years by an external ISO auditor.

The Foundation uses all the teaching material and toys that are traditionally used in mainstream pre-schools plus materials recommended for children with developmental disabilities, such as communication boards/books, visual schedules and rules, sensory integration equipment, and computer-based educational games. The teaching programme is supported by various visual aids, depending on the level of the child: for example, object symbols, photographs, drawings, Makaton symbols.



FUNDING:

Foundation funding supported by public budgets

The Early Intervention Programme is one of the programmes of the Theotokos Foundation, and all Foundation expenses are covered by the same funding sources. These are:

- An annual government grant from the supervising Ministry of Labour, Social Security, and Welfare, covering 15 percent of total expenses.
- The National Health Services Provider Organization, which covers a daily rate per service user, as well as the disability benefits from the parents' social security.

Together, this covers 56.5 percent of total expenses. The remaining costs (approximately 30 percent) are covered by donations from charities and private individuals. Children attending special schools/centres receive a government grant of €40 per day of attendance (€8,690 per year).

If a child with special needs attends the general schooling system, the cost per student in pre-school and primary school is €3,763 per year. For secondary school it is €5,009 per year (Hellenic Statistical Authority, 2011). During schooling, a child with disabilities would need to be supported by afternoon therapy programmes, which triggers an additional cost of €4,680 per year, to be covered by the government (until the age of 18), for which the government pays a maximum of €440 per month for all therapies.



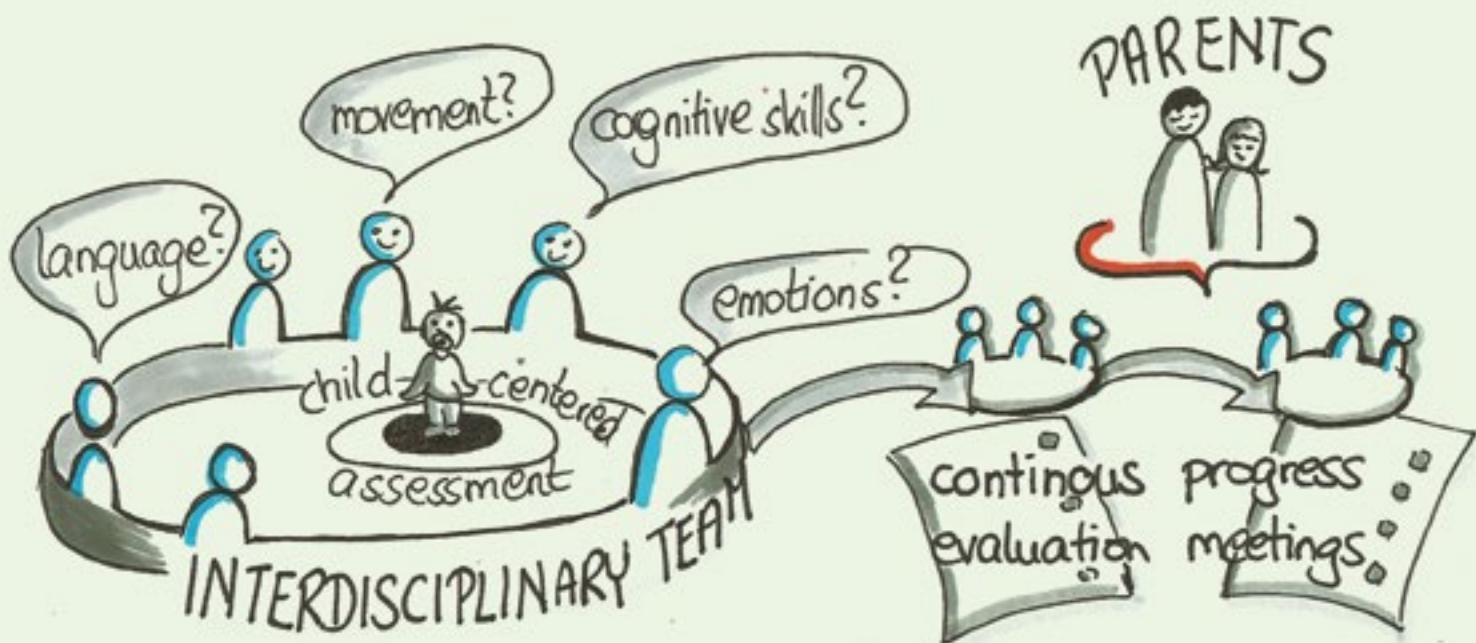
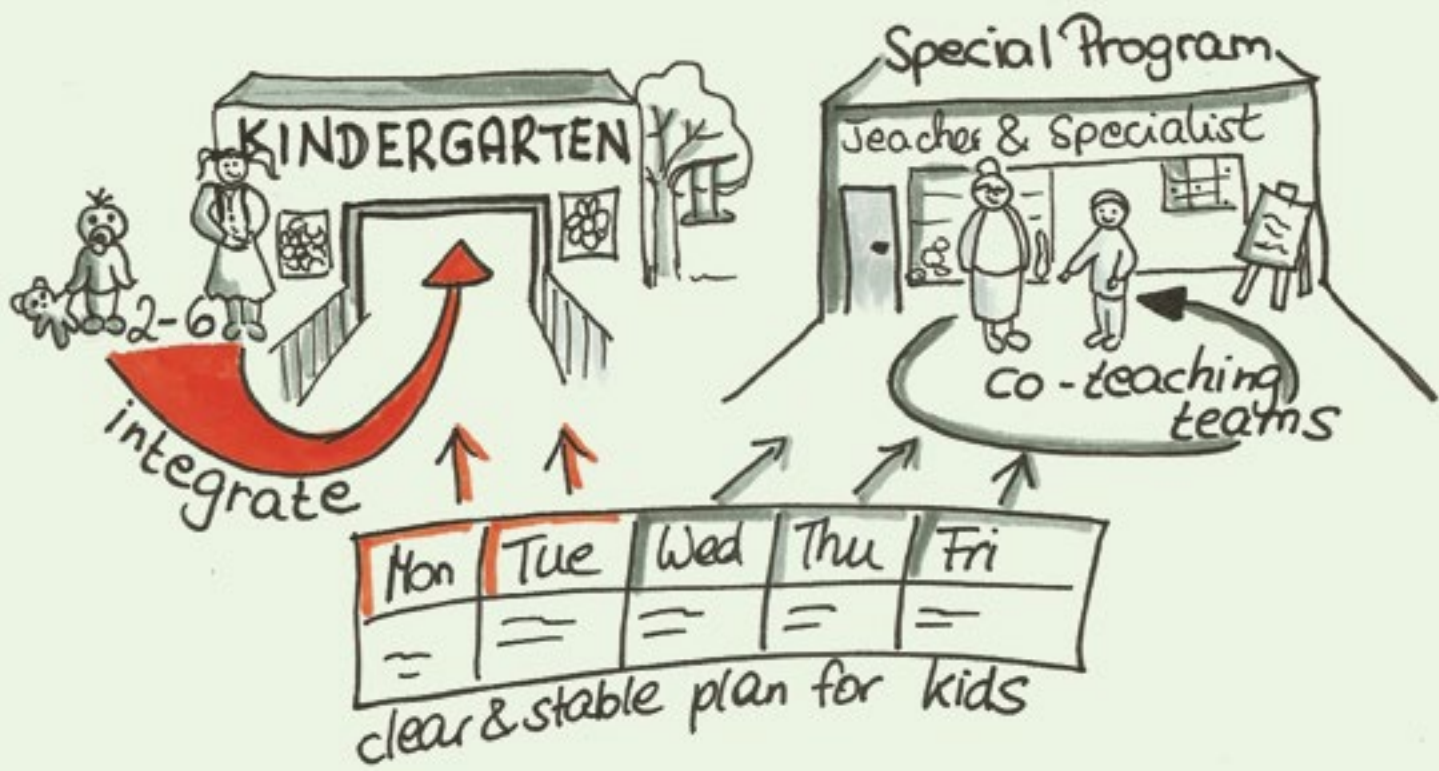
OUTLOOK:

Further cooperations are desired

Due to the overall economic situation of Greece in general, funding continues to be a barrier for the future development of the Early Intervention Programme. The annual government grant from the supervising Ministry of Labour, Social Security, and Welfare has been severely reduced in recent years; and since the Theotokos Foundation is a non-profit organization, its sources of income are restricted to the government grant, some coverage from social security payments, and from parents and donations.

In order to grow, the Foundation hopes to establish a collaboration with the neighbouring municipality of Ilion as an ongoing practice. The Foundation aims to conduct screening tests in all of the municipality's childcare centres on a yearly basis. In this way, the Foundation can ensure the earlier detection of children at risk and will increase the number of children in the offered programmes.

The Foundation believes that its practice can be readily adopted by other organizations and by other countries.





ABOUT THE ORGANISATION:

Theotokos Foundation

The Theotokos Foundation is a private, non-profit organization serving children and young adults with intellectual and other developmental disabilities, as well as their families. The Foundation seeks to provide these children and young adults with the opportunity to learn how to communicate, to function adequately in their everyday life, to care for themselves, and to be able to work so as to become autonomous and active adults. Theotokos has also developed a supported employment service called "Ergaxia," which creates opportunities for people with mental disabilities to participate in the open labour market.

The Theotokos Foundation was established in 1963 and at that time had a Pedagogical Department for children aged 6 to 12 years. Over time, the management of the Foundation realized that applications and referrals of children younger than six years were increasing. Therefore, the Early Intervention Programme was created in 2000.

THE SITUATION OF CHILDREN IN GREECE:

Only 15 percent of children with disabilities have access to education

- There are approximately 576,000 children under the age of five in Greece.
- The number of children reporting that their family's economic situation is "not well off" doubled from 7.2% in 2006 to 14.5 % in 2014.
- In 2000 the Special Education Law established 54 Diagnostic, Assessment, and Support Centres in the capital cities of each prefecture in Greece, providing diagnosis, assessment, and support to all children. However, the reduced economic capacity at both the state and the family level prevents children from fully enjoying their right to Inclusive Education and the right to have access to quality health services and social care support structures.
- According to the NGO ActionAid, only 15 percent of the estimated 200,000 children living with a disability have access to education.



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Informing families sensitively about their child's disability

Country: Ireland Organisation: National Federation of Voluntary Bodies

MANAGEMENT SUMMARY: The activities of the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation) focus on ensuring that member organizations are supported to provide high-quality, person-centred services and support to people with an intellectual disability. The National Federation has developed the Informing Families Project, the goal of which is to ensure that the communication process of informing families that their child has a disability is undertaken appropriately, sensitively, and using a family-centred model.

- Information for families who have recently received their child's diagnosis with a disability is available in seven languages on the website: www.informingfamilies.ie
- This includes information on how parents might feel about the diagnosis, how to tell other people about the diagnosis, how to search for reliable information on the Internet, descriptions of what early interventions are available, and who the relevant professionals are that families may wish to consult.



Trusting relationships between families and professionals are built right from the beginning



Education sessions for doctors and nurses create understanding for families needs

The goal of the project is to support professionals who communicate the news of a child's disability to families by providing them with evidence-based best practice guidelines and training. Positive parent-professional relationships are central to a family-centred approach to early intervention, and the disclosure process can be seen as the very first opportunity for good practice in early intervention.



THE PROBLEM:

Negative messages prevail

Before the development of the "National Best Practice Guidelines for Families of Children with Disabilities," there was no known comprehensive, evidence-based best practice guidance available in Ireland to support professionals in positive and appropriate family-centred disclosure practice.

Many families had told the National Federation of Voluntary Bodies that the news of their child's disability had been communicated to them in an insensitive,

inappropriate, or overly negative way that did not take account of the individuality of their child or of the child's full potential.

Without evidence-based best practice to guide them, many professionals have previously believed that providing the worst-case scenario was the most appropriate communication. The Informing Families Steering Group directed the undertaking of a comprehensive consultation and research programme in order to ensure that the guidelines would be informed by wide-ranging consultation and partnership with all key stakeholders and would be grounded in evidence-based research.

ABOUT IRELAND:

After drastic spending cuts, getting ready for an economic comeback

- The Republic of Ireland is a parliamentary democracy with a written constitution. The country has a population of approximately 6.3 million, including some 400,000 children under five years.
- A period of rapid economic expansion from 1995 onwards that became known as the Celtic Tiger period ended in 2008 with an unprecedented financial crisis and an economic depression in 2009. This has led to steep cuts in Social Budgets: "Since 2008, there has been a steady erosion of the kinds of flexible supports that facilitate choice, autonomy, and independent living for people with disabilities." After drastic spending cuts and with the help of the European Union and the International Monetary Fund, Ireland is once again showing positive economic growth.
- The Human Development Index of 2015 shows that Ireland's per capita gross national Product was \$39,568, ranking it 6th worldwide.



THE DEVELOPED SOLUTION:

An appropriate, evidence-based practice is established

The overall goal of the Informing Families Project is to ensure that the communication process of informing families that their child has a disability is undertaken appropriately and sensitively, using a family-centred model and in line with evidence-based best practice. This initial disclosure is the first step in building a family's understanding of their child's disability, and thus it is central to how the family initially adjusts to the information and to how they view disability itself.

The communication that takes place at the time of a child's diagnosis is also the first step in the building of a trusting relationship between the family and the professionals with whom they will interact. Positive parent-professional relationships are central to a family-centred approach to early intervention, and therefore the disclosure process can be seen as the very first opportunity for good practice in early intervention.



THE MODEL:

Thorough testing led to an adequate method

The project was developed at the National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation), which is an umbrella group of intellectual disability service



Katherine O'Leary, Chairperson of Informing the Families Cork Project, with her son Diarmuid

According to a recent study, parents as well as professionals want to have positive, but also realistic messages at the time of diagnosis

providers in Ireland. This umbrella group collaborated with organizations supporting children with physical disabilities and sensory disabilities to develop cross-disability guidelines.

The National Federation undertook a national quantitative and qualitative research project, distributing a representative survey questionnaire to 184 families and professionals along with conducting 22 focus groups (7 with families and 15 with individuals from medical, nursing, and allied health backgrounds). The results were as follows:

- A set of evidence-based best practice guidelines for informing families of their child's disability.
- A consultation and research report describing the development of the guidelines.
- A DVD ("Words You Never Forget") providing parent stories and professional guidance based on evidence found in the consultation and research report.
- A one-hour online-accredited training course for professionals.

- An informational website (www.informingfamilies.ie) for families immediately following the diagnosis of their child's disability (in seven languages).
- A report on the outcomes of a pilot implementation of the guidelines in the southern region of Cork.
- A pilot implementation project for the guidelines across hospital, community, and disability service settings in Cork from 2008 to 2010.

An evaluation was carried out on training that was delivered to 235 participants, including 80 fourth-year medical students, 130 second-year nursing students and post-graduate public health nurses, and 25 paediatric and neonatal non-consultant hospital doctors (junior hospital doctor). Participants were chosen for the study using an opportunistic, purposive sampling process.

A training programme is established

Conclusion: The improvements in levels of confidence and knowledge reported by participants of the training programme demonstrated the potential benefits of providing communication skills training that specifically addresses the needs of families at the time of their child's diagnosis. The wide range of professionals and the broad range of experience levels involved in the disclosure process indicate the need for training to be delivered across medical, nursing, and allied health disciplines.

This project has received the "Award for Public Service Excellence in 2010" by the Irish Prime Minister. Implementation of the developed guidelines includes the following actions:

- Half-day "training of trainers"
- 2 hour on-site training course (e.g., in hospitals, community health care settings, and universities)
- 1 hour e-learning module
- Tailored training where required

Further, the curriculum includes detailed teaching on the research findings and resultant best practice guidelines. A DVD has been produced depicting the personal stories of two families and their children as well as 45-minutes of input from a mother of two children with disabilities on her experiences of being told the news and her recommendations for how professionals can best support families at the time of diagnosis.

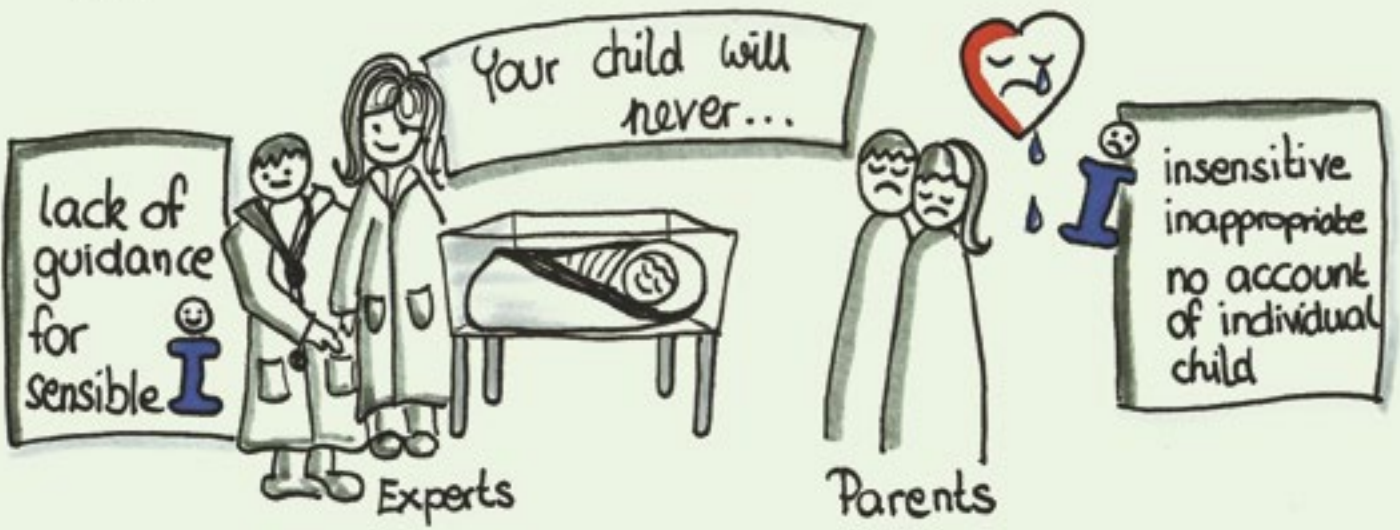
Results have improved

Finally, a study on the project's best practices traced the convergence between the guidelines and the UN Convention on the Rights of Persons with Disabilities, in particular with regard to the provision of positive, realistic, and hopeful communication. The study employed a mixed methodology, involving 22 focus groups and a questionnaire survey of 1,588 profes-

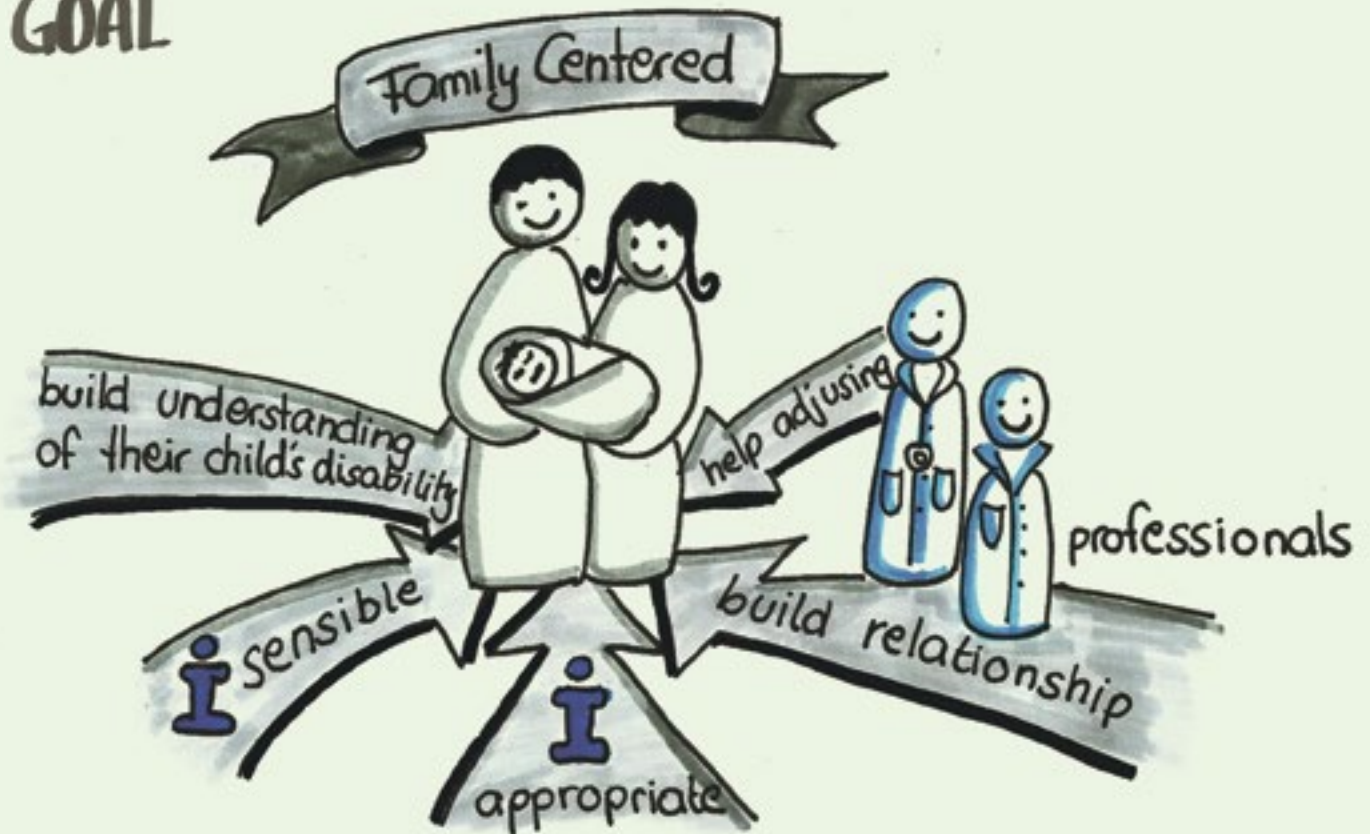


Families cutting the ribbon for the opening of a private room in Cork University Hospital where they can receive difficult information and discuss news

PROBLEM



GOAL



FACTS AND FIGURES:

A mandatory course for paediatricians how to inform families

All paediatricians in Ireland who wish to become consultant doctors must provide a certificate of completion of the Informing Families e-learning training with their application. The Royal College of Physicians of Ireland introduced this measure in 2013.

Training has been provided to:

- Trainee paediatricians at the Royal College of Physicians of Ireland
- Fourth-year medical students in University College Cork
- Second-year nursing, midwifery, and post-graduate public health nurse students in University College Cork
- First-year post-graduate medical students in University College Limerick (since 2009)
- Post-graduate nursing students on the Children's Palliative Care module in Trinity College Dublin (since 2007)

sionals and 584 families. The study found that a large majority of parents and professionals supported the recommendation of providing families with positive, realistic, and hopeful messages at the time of diagnosis, but fewer than half of the parents surveyed reported receiving communication of this type. The findings indicated that some professionals struggle with fears of providing 'false hope', a fear of litigation, and a lack of training when communicating with parents about their child's condition. However, the research also identified positive and hopeful messages that are not in conflict with providing honest and realistic communication. These include acknowledging the dignity and worth of the child as an individual, indicating that there is help available for parents, and informing families about the spectrum of possible outcomes for their child rather than the worst-case scenario.



FUNDING:

Public funding has been obtained

The Health Services National Partnership Forum and the Health Services Executive in Ireland funded the original project to develop the evidence-based best practice guidelines for informing families of their child's disability. Moreover, funding has been provided by the Department of Health to support and facilitate the future national implementation of the guidelines through a National Lottery Funding grant scheme.



OUTLOOK:

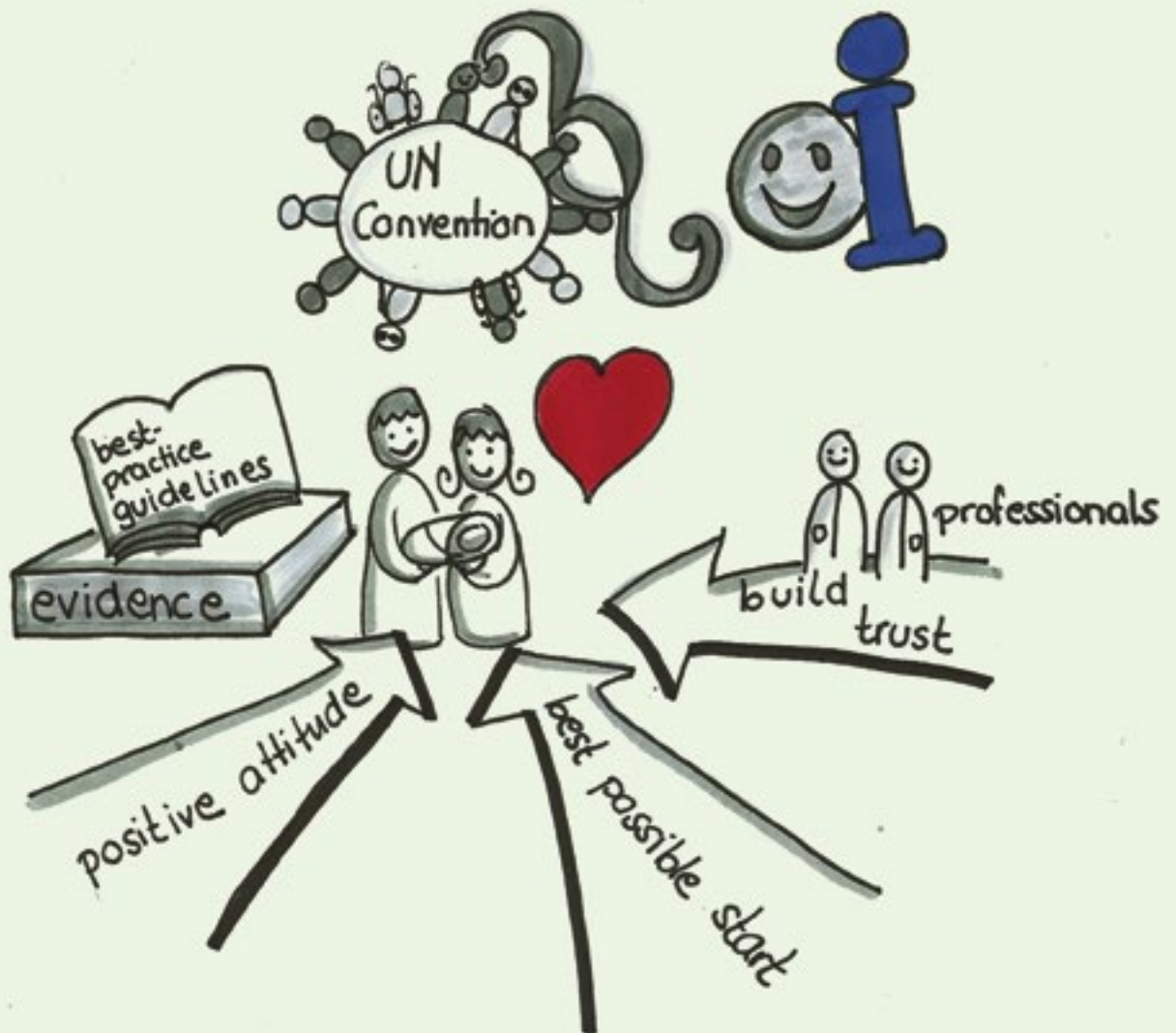
Ready for further dissemination

The guidelines are available for further dissemination in any country for which they are deemed useful and there has already been significant interaction with organisations in Finland, Austria and Germany in relation to these best practice guidelines. There is no charge for use of any of the materials as it is the intention of the National Federation of Voluntary Bodies to share this evidence-based guidance as widely as possible in order to promote supportive experiences for families everywhere.

Going forward, it is expected that professionals who inform families about their child's disability will have access to evidence-based best practice guidelines, and that families will have the most supportive possible experience. This will establish strong parent-professional trust, which will in turn support engagement with early intervention supports.



How doctors, nurses and staff are trained





ABOUT THE ORGANISATION:

National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation) is a national umbrella organization for voluntary/non-statutory agencies providing direct services to people with intellectual disabilities in Ireland. The organization and its 60 members account for more than 85 percent of this country's direct service provision to people with an intellectual disability.

The National Federation has developed initiatives to ensure that staff and volunteers in their services are equipped to meet the many challenges ahead, initiatives to promote the inclusion of people with an intellectual disability in their own communities, and key policy development initiatives. Another key function is the sharing of information among member organizations.

The National Federation is proactive in developing and contributing to policy initiatives that have a positive impact on the lives of children and adults with an intellectual disability. Working closely with various subcommittees, the organization develops policy positions on a wide range of topics for consideration by and approval of its Board. It also contributes and responds to initiatives developed by statutory authorities, including government representatives, the health service industry, and an extensive range of advisory and expert groups.

The National Federation of Voluntary Bodies also contributes to the development of various EU directives and to the implementation of the Council of Europe's Disability Action Plan.

BROAD DISSEMINATION:

Online courses available for download

The Royal College of Physicians of Ireland has adopted the National Federation's online training course – developed through the research of the Informing Families pilot implementation programme – nationally for all paediatric trainees. The course is similarly under current consideration for formal adoption by the Institute of Obstetrics following positive feedback from the Executive Council of the Institute in 2015. Funding has been provided for the national implementation of the guidelines by the Department of Health. The funding required is for a project coordinator to facilitate the roll-out of regional "training of trainers" courses and to provide printed copies of the guidelines and copies of the DVD "Words You Never Forget" to professionals. The project website provides information to families in the early stages following their child's diagnosis. This information has been translated into seven languages with financial support from the Health Services Executive.

Find more: www.informingfamilies.ie/about-the-project/support-and-training-materials.257.html



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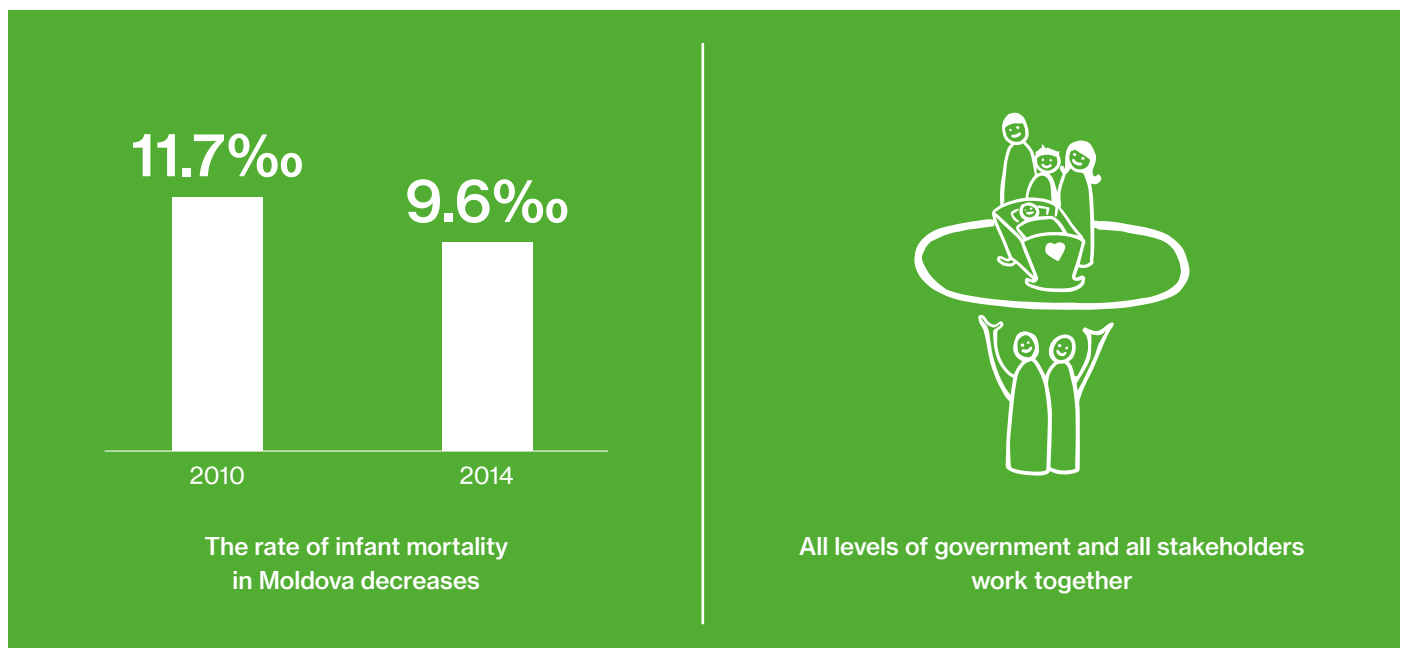


Reducing infant mortality in Europe's poorest country

Country: **Moldova, Districts Floresti and Laloveni** Organisation: **Lumos Foundation**

MANAGEMENT SUMMARY: Lumos Foundation, an international non-governmental charity organization, collaborates with governments (at all levels), various professionals and caregivers, other NGOs, faith-based groups, as well as communities, families, and children to help transform outdated systems that arbitrarily separate children from their families. Among its activities, Lumos in Moldova has supported the Government to establish an inter-sector medical-social cooperation mechanism to prevent and reduce infant and under-five mortality rates at home, and has offered assistance in implementing this mechanism in two districts (Floresti and Laloveni).

- Annually, around 11,000 children under-five years from families at risk across the country are identified, examined, and assisted by both a doctor and a social worker.
- By the end of 2015, Lumos had assisted more than 1,500 at-risk children under five years in the pilot regions.



Lumos aims to reduce infant and under-five mortality at home and to prevent the abandonment of babies and infants in institutions in two dedicated regions of Moldova. By involving all levels of government as well as other stakeholders, Lumos has been able to pioneer a successful model, which is greatly appreciated by children and their families.



THE PROBLEM:

High infant mortality rates among the poorest

Mortality rates disproportionately affect vulnerable children from rural areas, children with disabilities, families of lower socio-economic backgrounds, those living in the country's southern region, and those from minority backgrounds, including Roma children.

There are several factors that contribute to the severe problem of childhood mortality in Moldova:

- Elevated rates of at-home child mortality, largely attributable to respiratory diseases.

- Reliance on out-of-date practices for childhood illness detection and treatment.
- Over-reliance on clinical assessment and limited appreciation for a child's home environment.
- Only limited education provided to new parents on infant care and identifying signs of childhood illness.

While child mortality rates of infants and children under five have decreased significantly over the last 15 years, encouraged by the Millennium Development Goals, the rates continue to be high compared to other European countries.



THE DEVELOPED SOLUTION:

Inter-sector cooperation

In 2010, Lumos supported the Government of Moldova to undertake an evaluation of the causes of infant and under-five mortality at home. Based on the results of the evaluation, Lumos assisted the government in developing an inter-sector cooperation mechanism between the health and social sectors, which was approved in December 2010.

Lumos supports the government at all three administrative levels, based on a cooperation agreement signed with the relevant ministries (central level) and the raion (district) councils from the two pilot regions (local level). Furthermore, Lumos has established effective cooperation with international organizations, such as UNICEF. The main areas of collaboration with UNICEF are:

- Organizing an annual national conference on preventing and reducing infant and under-five mortality in the home, in partnership with the Ministry of Health and the Ministry of Labour, Social Protection, and Family.
- Supporting the implementation at the national level of the inter-sectoral cooperation mechanism aimed at preventing and reducing infant and under-five mortality at home.

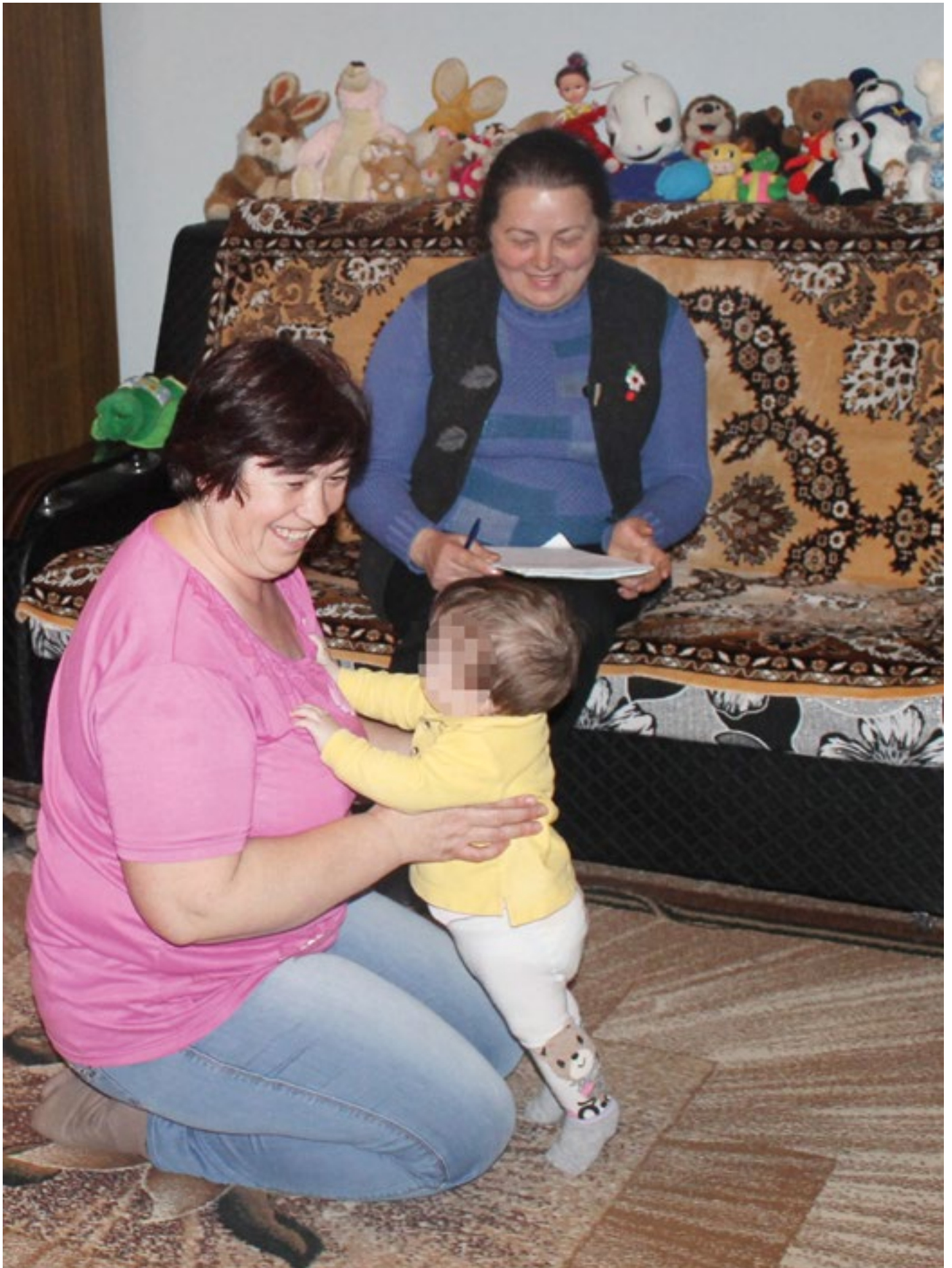
Lumos has also identified other NGOs in the field – such as CCF Moldova, Early Intervention Centre “Voinicel,” and Tony Hawk Foundation – and they work together on the development of the early intervention project for children at risk and children with disabilities in the Republic of Moldova.

The inter-sector cooperation mechanism is user-cen-

ABOUT MOLDOVA:

Still the poorest country in Europe

- The Republic of Moldova is a parliamentary republic with a President as Head of State and a Prime Minister as Head of Government. The current Constitution of Moldova was adopted in 1994. A strip of Moldovan territory on the east bank of the river Dniester has been under the de facto control of the breakaway self-proclaimed government of Transnistria since 1990.
- Due to a decrease in industrial and agricultural output following the dissolution of the Soviet Union, the service sector has grown to dominate Moldova's economy and currently accounts for over 60 percent of the nation's gross domestic product. However, Moldova remains the poorest country in Europe, with a per capita gross national income of just \$5,223 and with 38.4 percent of the population living in poverty. The 2015 Human Development Index ranks Moldova at 107 among all countries.
- At the beginning of 2015, Moldova had approximately 3.5 million inhabitants, of which some 200,000 are children five years or younger.



Specialists from the local multidisciplinary teams provide assistance and guidance to families on how to ensure child development and avoid risks to child's life and health at home.

At the district level, two specialists coordinate the work: the medical specialist and the social worker

ted, as it works directly with families with children under five who are at risk. The work of the local multidisciplinary teams is focused on prevention, early intervention, and assistance to reduce all risks to children's lives and health. This means that an individualised approach is used for each child, from planning the assistance to delivering the necessary services to the child and family.

Before the project started, institutionalisation of the child was the usual method to respond to these child protection risks. This study and project have focused on how best to support families in caring for their children at home, and thus reducing the risk of institutionalisation.



THE MODEL:

Close cooperation of all stakeholders

The assessment of children under-five is conducted in accordance with existing health care protocols, which provide for home visiting in the pre-natal period. The first visit from the family doctor occurs three days after the mother is discharged from the maternity ward; and this is followed by visits from the community nurse – twice a month during the first three months, then monthly until the age of 12 months.

When an assessment raises concerns about the well-being of a child or when concerns about the social situation of the family are identified, the medical staff inform the local authorities. At that point the community team – including the family doctor, community nurse, community social worker, representative of the guardianship authority, and other specialists as required – carry out an assessment of the situation of the child and his/her family. Depending on the level of urgency, the assessment is carried out immediately or within 24 hours after the concern has been reported. During the next seven days a

more complex assessment is conducted. As a result, the multidisciplinary team develops an Individual Assistance Plan (IAP) for the child, which is implemented and revised according to procedures of case management. The child's parents are involved in all stages of the IAP implementation.

Multidisciplinary teams cooperate

According to the data provided by the Ministry of Health, in 2015 there were 4.6 family doctors per 10,000 people registered at the national level, which equates to approximately one family doctor per 2,174 persons. In the pilot regions, the number of family doctors per 10,000 was 4.1 for Floresti and 5.0 for Ialoveni.

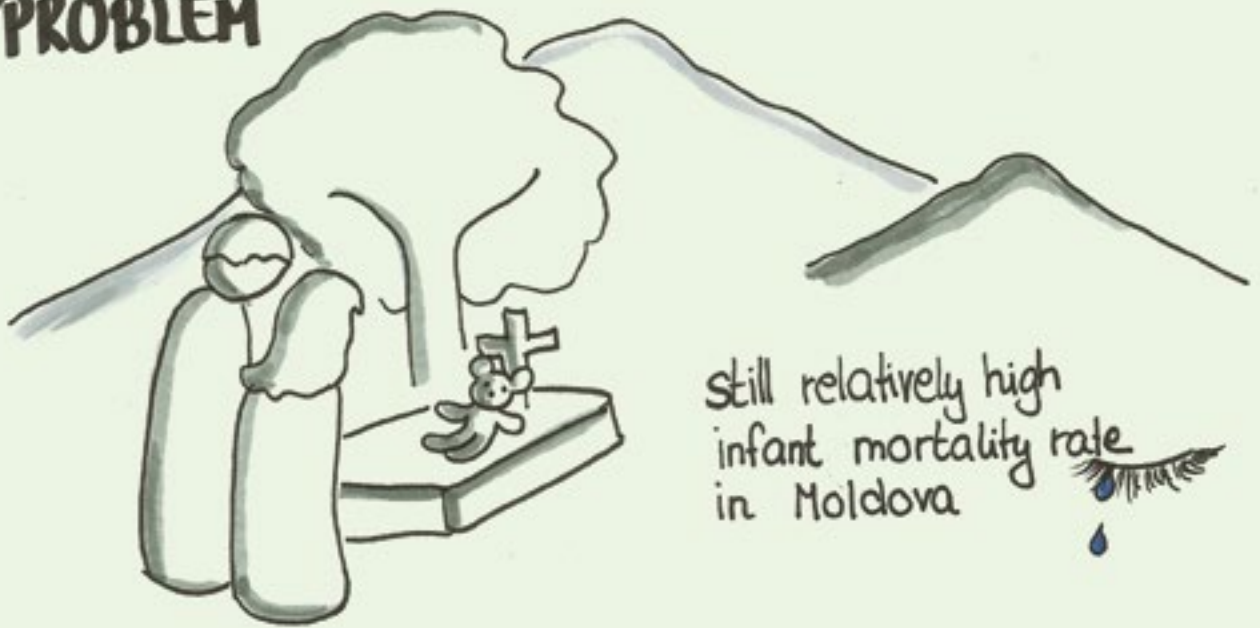
However, the situation for paediatricians is very different. In 2015 there were only 1.2 paediatricians per 10,000 people at the national level, a slight increase from 1.0 in 2012. This lack of human resources has a negative effect on access to services for remote rural populations, on monitoring quality, and on the efficient involvement of multidisciplinary teams aimed at preventing and reducing infant and under-five mortality. While the project is implemented at the community, district, and central level, the most intensive work is realised at the community level through the direct involvement of health specialists (general practitioners, medical assistants, community nurses) and social protection specialists (community social workers). These specialists are part of the local multidisciplinary teams, which may also include other specialists, depending on identified needs.

At the district level, two specialists coordinate the work: the medical specialist who supports the mother and child and works within the districts medical institution; and the social worker who works with families and children at risk, assigned by the district Social Assistance and Family Protection Department. These two specialists monitor the implementation of the mechanism at the community level and offer methodological assistance to members of the local multidisciplinary teams in the process of intervention.

Various levels of government are involved

At the central level, the Moldovan Ministry of Labour, Social Protection, and Family and the Ministry of Health coordinate the activity of territorial structures responsible for the medical and social sectors. The process is monitored via an annual report on the implementation process of the inter-sector cooperation mechanism at the national level. Based on this report, the ministries further develop the normative framework.

PROBLEM



GOAL



FACTS AND FIGURES:

Infant and child mortality rates decrease

- Over the project period, the rate of infant mortality decreased nationally from 11.7 ‰ in 2010 to 9.6 ‰ in 2014.
- The rate of mortality of children under five decreased from 13.6 ‰ in 2010 to 11.6 ‰ in 2014.
- As part of the project, Lumos has been building the capacity of medical staff and social workers regarding identification, referral, assistance, and intervention to reduce and prevent under-five mortality at home.
- During the project implementation some 1,500 professionals in the health, social, police, and public administration sectors – both from the pilot regions and non-pilot regions – received training.
- The quality of the training is ensured by the use of the training materials developed and approved by the key ministries, with Lumos support.

The initial training of specialists was carried out by Lumos in coordination with the key ministries. Initial training includes all specialists from the health and social sectors within the pilot regions, both at the community and district level, as well as specialists from other districts around the country. Annually, a nationwide seminar is organized for specialists from both sectors working at the district level in order to analyse the impact of the inter-sector cooperation mechanism, and to disseminate the practices and experiences of districts in this field. Moreover, the specialists involved benefit from individual methodological assistance and participate in roundtable activities where interactive approaches are used.



FUNDING:

Presently under evaluation

Lumos is currently conducting an in-depth analysis of the history of the European Structural and Investment Funds and how civil society worked together to convince EU member states to divert funding away from institutions to family and community-based

care. Unfortunately, at this moment it is not possible to provide a clear answer as the investigation is ongoing.



OUTLOOK:

A scalable model for other districts

Prospects for the network mechanism include:

- Strengthening of the inter-sectoral cooperation between staff from health care and social assistance systems to prevent and reduce mortality of children under five.
- Development and approval of normative frameworks, e.g.: strategy on health, development, and welfare of children and adolescents; strategy on parental education; provision of comprehensive medical, social, and educational services for early child intervention.
- Development of an early childhood intervention system at the national level.
- Development and expansion of inter-sectoral cooperation practices to prevent and reduce maternal mortality rate.

The practice of inter-sector cooperation for preventing and reducing infant and under-five mortality at home is applied at the national level and can be adopted or adapted by other organizations or countries. The implementation of the mechanism has positively influenced the well-being of children in Moldova by improving the quality of social and medical services through a unique, inter-sector system of monitoring and assisting families and children at risk. Further, it has enhanced the capacities of multidisciplinary teams to identify, evaluate, refer, assist, and monitor child victims and potential victims of violence, neglect, exploitation, and trafficking.

National & International cooperation



Levels of involvement

- Ministries
- Provinces
- Districts
- Communities



Family-Centered

District Teams



Multi-Disciplinary team



family doctor



IAP
individual assistance plan

for the child & its family

support in teams on all levels and at all steps along the way...



ABOUT THE ORGANISATION:

Lumos Foundation

Lumos Foundation is an international non-governmental charity organization and is registered in England and Wales.

Lumos is dedicated to helping to transform the lives of those disadvantaged children who live in institutions and so-called orphanages around the world. Lumos uses the phrase “so-called” because the vast majority of children are not orphans but are in institutions because their parents face extreme poverty; because the children have physical and intellectual disabilities, and their parents cannot afford treatment; or because they are from socially excluded groups. When parents are not supported in the community, these factors often lead to the break-up of families.

Lumos and several other organizations have worked to encourage the European Commission to establish regulations that state that funding to EU member states must be used for community services, not to build or renovate residential institutions. This regulation has been in place since 2014.

At the moment Lumos has teams in Bulgaria, Czech Republic, Moldova and Haiti with projects in Greece, Serbia and elsewhere. It has also opened a US office and is setting up a presence in the Latin America and Caribbean region. As part of its global focus on children in orphanages, it has also opened a US office and is currently scoping work in Latin America and the Caribbean.



Lumos Moldova

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LEGAL SITUATION OF CHILDREN IN INSTITUTIONS: Situations that lead to the separation of children and families

According to national legislation (Law 140 of 14.06.2013 on Special Protection of Children at Risk and Children Separated from their Parents), children are separated from families and placed within alternative services in the following situations:

- Children who are subject to violence
- Children who are neglected
- Children who are involved in vagrancy, begging, prostitution
- Children who are deprived of parental care and supervision due to their absence from home due to unknown reasons
- Children whose parents have died
- Children who live on the streets, or escaped or were chased from their homes
- Children whose parents refuse to perform their parental duties in bringing up and taking care of their children
- Children who were abandoned by parents
- Children whose parents were declared incompetent by a court judgment

Child placement within services (family-type or residential) is based on local or territorial guardianship authority provisions. In cases where there is an immediate danger to the child's life or health, the local guardianship authority in whose jurisdiction the child is placed shall issue an ordinance on child separation from parents or caregivers. In cases when parents have gone abroad for work, the local guardianship authority shall issue, with the consent of the parents, the order to establish a guardianship/trusteeship in line with the legal provisions.

ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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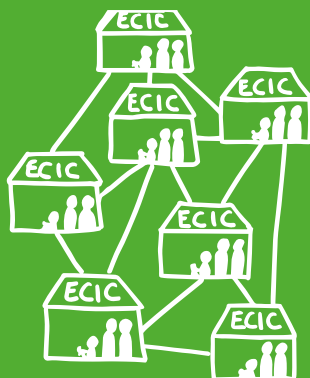


A growing network of private support centres

Country: Slovakia, Bratislava and four other cities Organisation: SOCIA – Social Reform Foundation

MANAGEMENT SUMMARY: The private SOCIA Foundation is establishing Early Childhood Intervention (ECI) centres to support families in Slovakia, located in 5 regional cities and the capital, Bratislava (Slovakia is divided into eight regions). SOCIA aims to open another three centres to cover the entire Slovak territory and thus create a network of early childhood intervention centres on a regional level. The services of SOCIA are open to all families with children aged seven and under, both with and without disabilities and irrespective of ethnic background.

- The SOCIA foundation has invested 1,237,000 Euro to establish five ECI centres and to cover their operating costs for two years (2015 to 2017).
- Early intervention as a social service is now defined in the national “Act on Social Services,” and came into effect on 1 January 2014, due to the lobbying efforts of SOCIA.



Developing a network of
ECI centres



In-home services are preferred, with most services being delivered in the child's natural surroundings.

An individual support plan is created with family input identifying key child-oriented requirements, but also targeting the needs of the entire family at the same time. Multiple tools can be used to define family needs, but experience shows that a good individual plan must be written in the family's 'language', using their own words and indicating their needs in very concrete and specific ways.



THE PROBLEM:

Scarce availability of Early Childhood Intervention centres

Families whose child is born with a disability or shows development delays need immediate support. According to national statistics, families without support are at high risk of divorce or of their children being placed in a "children's home" (previous known as an "orphanage"). In 2015 there were 4,350 children

placed in this child social-legal protection system. Of these, 1,500 were placed with foster families, while 2,850 were distributed among 85 institutions. Most of these children have special needs (for example, children with challenging behaviour), are disabled, or are Roma children.

Another problem is the division of responsibilities for services for families with disabled children among three ministries – Social, Health Care, and Education. Further, the financing of the ECI centres is uncertain because there is no direct access to public financial resources. Integration and inclusion of disabled children into pre-school and school facilities are still rare, and a dual system persists at all levels of education. Finally, there is a lack of support services for families and for rehabilitation opportunities for children in the public health care system.

ABOUT SLOVAKIA:

Slow improvements for people with disabilities

- Slovakia is a parliamentary democratic republic with a multiparty system. The Slovak Head of State is the President, elected by direct popular vote for a five-year term. The executive power lies with the Prime Minister, who is usually the leader of the winning party, but he/she needs to form a majority coalition in the Parliament. The President appoints the Prime Minister.
- Before the global financial crisis of 2007–2008, Slovakia was the fastest growing economy in the European Union. Slovakia had a per person gross national income of \$25,845 according to the United Nations Human Development Index, ranking 35th worldwide. Concerning the status of persons with disabilities in relation to economic activity, in 2012-2014, the majority of them have still remained economically inactive (contrary to the total population). On the other hand, there have been several positive developments in employment of this target group: their employment rate is slowly increasing (currently being at about 31%); and so is the number of employers preferring employment rather than other quota options - by 10%.
- Slovakia has approximately 5.4 million inhabitants and 300,000 children under the age of five.



THE DEVELOPED SOLUTION:

Children are educated in their natural environment

SOCIA has been inspired by a model in the neighbouring Czech Republic, where a system of early childhood intervention centres was started 25 years ago and where today there are now 47 specialized centres.

The goal of the SOCIA initiative is develop a functioning network of ECI centres that will serve as a pilot model, which would then lead to comprehensive, transdisciplinary services for families with children with disabilities throughout Slovakia, funded and run by SOCIA.

A network of trained transdisciplinary staff addresses all the various needs of families and children based on the following principles:

- An individual family service plan is the key instrument for providing services.
- Partnerships among the various professionals are essential.
- All staff are trained in a person-centred planning approach
- In-home services are preferred, with most services being delivered in the child's natural surroundings.
- The centre acts as the primary resource for families, and plays an important role in the networking of additional services



In the beginning, an individual family support plan is created. The plan is in the family's 'language', using their own words.

EXAMPLE OF A SIX YEAR OLD BOY WITH EPILEPSY:
**How physiotherapists, social workers
and families work together**

A six-year-old child who has had epilepsy since he was four has been stabilized and started to walk five months ago. Until he was four years he could only lay down without significant motoric and mental progresses. Now that he has begun to walk, to communicate nonverbally, and to use his specific sounds and gestures, his family needs support to help him to progress and develop his potential. He is not yet attending school, though one school has offered him one hour per week individual consultation with a psychopedagogue worker. This child does not have any opportunity to get community services or to visit child groups and learn from other children.

SOCIA has initiated its services and the family has identified actual needs and has shared ideas on how to stimulate the child's development at home. During the first consultation, the attendance and support of a psychologist, a physiotherapist, a social worker, and a special needs educator will be offered. The psychologist will identify the child's actual psychometrical degree of development and will continue to monitor the child for a period of six months. The psychologist will identify ways to motivate the child, will test what is working or not working, and will focus on the behaviour of the child. The special needs educator and the parents will look for the best options for organizing a playing area, how to use toys that they have at home according to the child's actual development degree, and suggest forms of play to stimulate the child's cognitive skills.

Careful integration into School

The physiotherapist will cooperate with the organization of the playing area; practice with parents on how to support the child with changing positions during some activities, especially during play; how to support the child with physically suitable sitting positions; etc.

The social worker will offer the family information about what financial support they could apply for from the Office of Labour, Social Affairs, and Family; will help the family with administrative tasks; and will accompany them to the Office of Labour, Social Affairs, and Family when they make their application.

The psychologist and the social needs educator will organize support meetings with an educator from the local school, and they will try to find a solution and suitable support for the child when he/she actually starts visiting the school (e.g., in September 2016).



THE MODEL:

Intense cooperation among experts, children and their family

The organization provides services for families with children aged seven and under. In the beginning, an individual family support plan is created together with family input identifying key child-oriented requirements. The plan is in the family's 'language', using their own words.

The individual plan (IP) consists of:

- Information about the family
- Starting date of IP
- Frequency of family visits
- Needs identified by family
- Goals family would like to achieve
- Each goal includes a description of the actual situation and the degree of skills of the child.[
- Often, a video is used at the beginning of the plan and after a six-month period when the IP has been completed (see more on the use of video below).
- At the end of the IP there is a conversation among the team and the family about which goals were achieved.

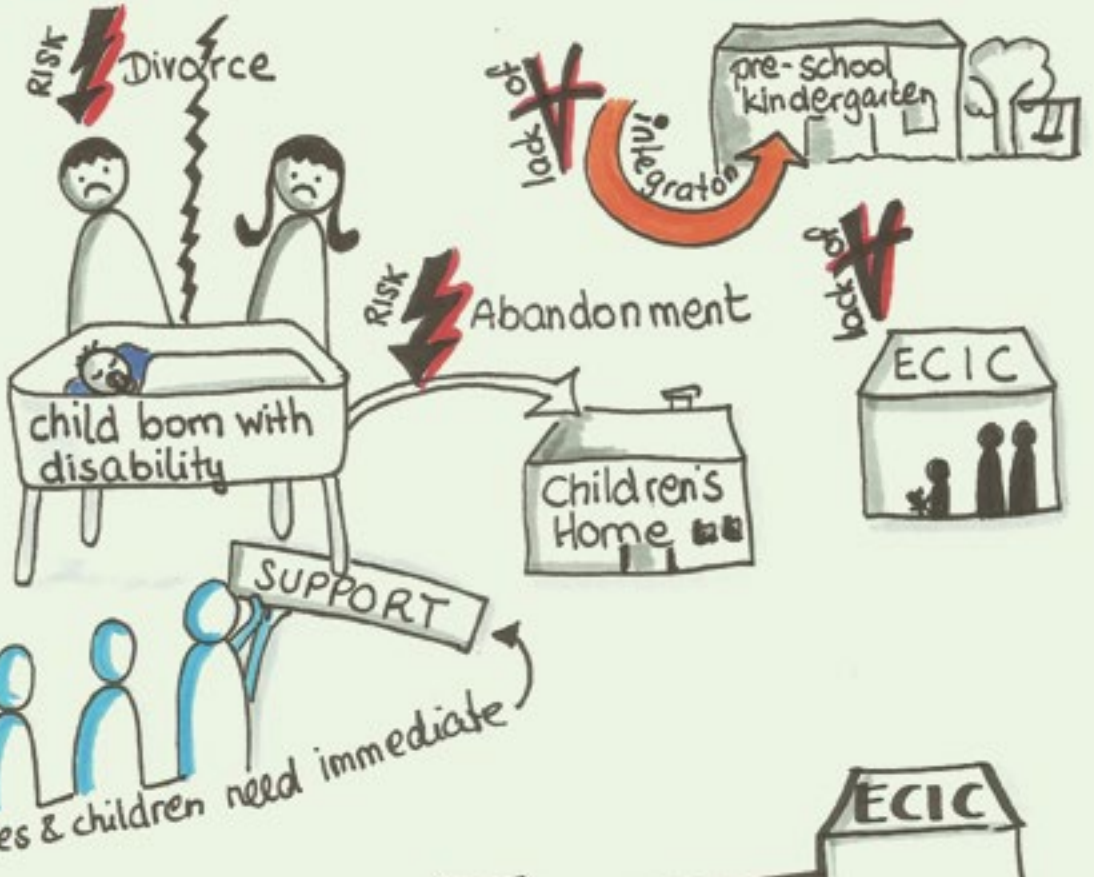
SOCIA uses the following tools to train children and to evaluate their progress:

- Developmental scales describe the actual skills of the child and suggest the next steps in supporting the development of the child in different areas (communication, gross motor, fine motor. etc.).
- Special tools for sensorial and sensomotorical stimulation.
- Conversation as a basic tool for supporting and empowering parents.
- Video – for evaluating progress, for identifying strengths and needs, and for training of parent-child interactions.
- Other tools and devices according to actual situations and the specific needs of the child and his/her family.
- Special interview techniques for identifying actual problems and needs.

The staff of an ECI centre typically include: a psychologist, a physiotherapist, a speech therapist, social workers, special needs educators, and an occupational therapist.

The team works in a transdisciplinary way. Each expert gets to know the child and his/her parents, and the team cooperates (in accordance with the parents) to suggest the best way of supporting the child and family.

PROBLEM



GOAL



FACTS AND FIGURES:

A network has been started

- Currently, there are five Early Childhood Intervention centres with a total of 25 full-time staff members
- The centres have a total capacity to serve 250 to 300 families on a regular basis.
- Five regional cities/communities were involved in the development of the project.
- Besides the 25 full-time staff members, there are 15 additional staff trained in preparation of the programme's further expansion.

Example: How an prematurely born child is taken care of

The child is born prematurely (e.g., in the 28th week of pregnancy) and three months later mother and child are in hospital again. The mother is concerned about the health and the development of the child and is looking for help. A physiotherapist and a psychologist (or a social worker) come to the family (home visit). They talk to the mother, observe the child, and suggest the best course for going forward so that the baby can develop in an optimal way.

The physiotherapist trains the mother on how best to play with her baby, which toys to use and how to use them, etc. The psychologist supports the mother



The team works in a transdisciplinary way. Each expert gets to know the child and his/her parents

in her intuitive mothering, helping her to manage her own feelings and supporting mother-child interaction. The professionals also talk to other members of the family (father, older children), and together they try to identify the actual needs of all family members and ways to meet them. This becomes the basis for an individual plan. For example: What is the next step? What would be best for the older children? If they need some help from grandparents, how can the ECI centre help them? How often should the centre's staff visit the family?

If needed, other members of the professional team will visit, such as a special needs educator when visual stimulation is needed.

All centres cooperate closely with hospitals, paediatric units, or more specifically neonatology departments in their region. This cooperation is formalized through the Executive Committee of Neonatology Society, which has issued a recommendation for doctors to cooperate with ECI centres. In this way, parents/children leaving medical treatment have a follow-up service. The centres are also cooperating with pre-school services, but there is still high resistance regarding such inclusion.



FUNDING:

Private money prevails

SOCIA is a private foundation without public subsidies or regular state donations. The establishment and financing of the three ECI centres was funded by SOCIA, with direct financial involvement from the VELUX Foundation, which is based in Denmark. Two additional centres will be opened later in 2016, funded from the proceeds of a charity ball.

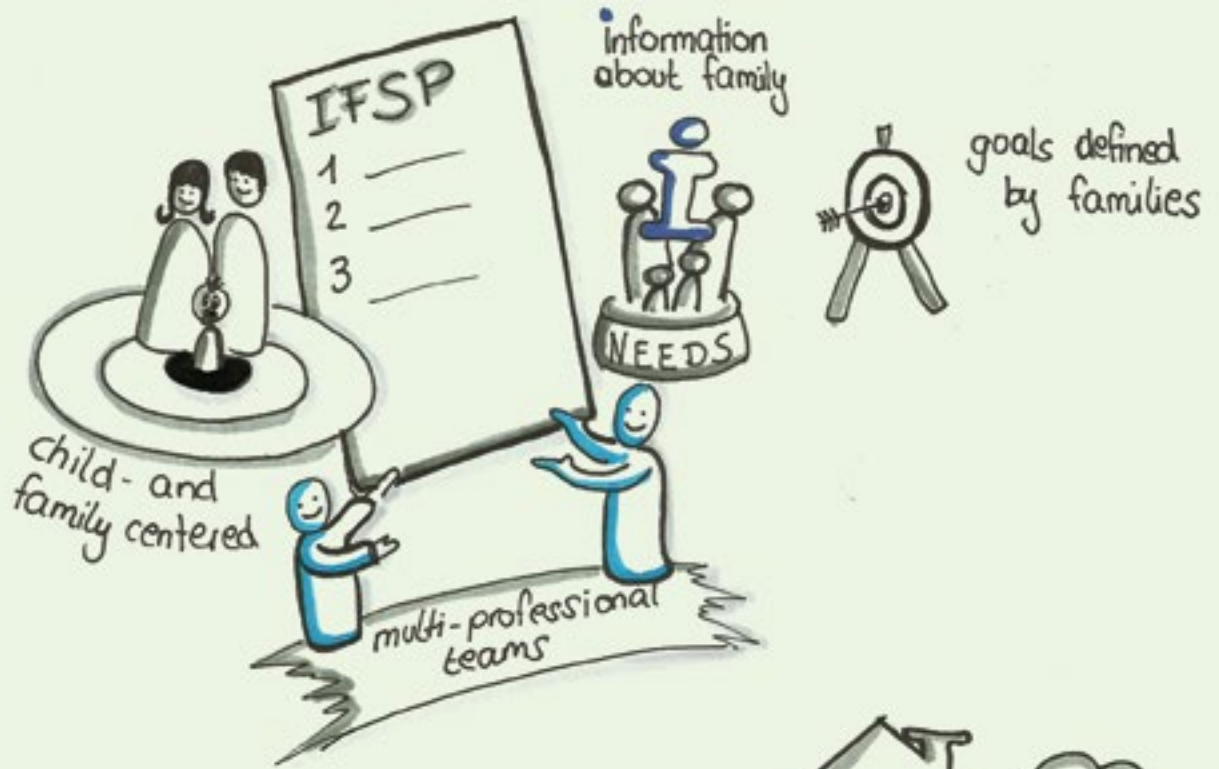


OUTLOOK:

The network should be completed next year

Slovakia requires 20 to 25 Early Childhood Intervention centres to offer an ideal accessible network for all families with disabled children. To reach this goal, SOCIA has initiated negotiations with representatives of all eight regional governments, which are the main stakeholders in developing and financing social services on the regional level.

Such a flexible and accessible network would undoubtedly contribute to the creation of a stronger and more confident group of parents, which in turn would be better able to advocate for the real inclusion of their disabled children into society.





ABOUT THE ORGANISATION:

SOCIA – Social Reform Foundation

The private SOCIA Foundation is one of the largest non-profit agencies in Slovakia. Eight full-time staff members cooperate with 50 experts who are involved part-time in various projects and initiatives of SOCIA (National Disability Forum, SOCIOFORUM, WHO, Ministries and regional governments, Social Work Advisory Board, and others).

The SOCIA Foundation aims to facilitate changes for the benefit of social groups that are most at risk by providing financial support and a variety of services. To this end, in 2015 the Foundation established five Early Childhood Intervention centres as part of a project called “Development of Early Intervention in Slovakia,” which was launched in April 2014.



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ABOUT ZERO PROJECT ANALYSIS

In-depth Research of Innovative Practices

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More than 3,000 experts from all sectors of society are part of the Zero Project Network.

More than 300 Innovative Policies and Practices have been awarded from 2013 to 2016.

More than 2,500 persons have participated in Zero Project Conferences since 2013.

More than 160 countries have been covered by the Zero Project Indicators.

www.zeroproject.org



About EASPD

EASPD (European Association of Service providers for Persons with Disabilities) is a European NGO network representing over 12,000 social and health support provider organisations across Europe and across disabilities. The objective of EASPD is to promote equal opportunities for persons with disabilities through effective and high-quality service systems. EASPD works towards ensuring the full implementation of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and is accredited to the Conference of States Parties to the Convention on the Rights of Persons with Disabilities.

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