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INTRODUCTION

It is with great pleasure that I write an introduction to Karin Dom's Early Childhood Intervention (ECI) evaluation report. I have had the privilege of working with Karin Dom's Early Intervention Program for four years, as a consultant for an initiative funded by Open Society Foundations, to develop a best practice systems framework and high quality services to support vulnerable children with developmental delays and disabilities, and their families to enable them to keep their children at home and in the community. The ECI model is based on the principles and system of services implemented in the United States, Canada and some European countries. These principles and systems have been developed and refined in those countries with research and practice over the last 40 years and have been formalized in laws, rules and implementation policies. The models are based on ECI principles that have been proven to be essential components of a cost effective and outcomes based system which results in an impressive return on public investments over a child's lifespan. The first principle is that services must start as early as possible (at birth is best) in order to maximize the potential effects of intervention and minimize the impact of neglect and nonaction as brain science demonstrates. The second principle is that services are provided in the child's natural environment (usually home) to ensure skills are functional and will be generalized and easily implemented. The third principle is that services are provided in a family centred approach to maximize follow-through and buy-in from caregivers. The fourth ECI principle is that successful implementation of services includes the development of partnerships across sectors, programs and individuals. Karin Dom has developed broad based, cross sector community partners who have provided support for this critically important work. From the medical community they have engaged physicians and hospitals, and from the social sector they have engaged child protective services and some nurseries and from professional training programs they have engaged representatives from several different universities and disciplines. Karin Dom has continuously expanded and disseminated the ECI practices across the country and it is time to make these critical and proven services available to all children and families in Bulgaria who are in need of them by standardizing and formalizing them in local, regional and national laws, policies and practices. ECI services fit into the current national plan but need an implementation and funding plan. Karin Dom has the technical skills, vision and experience to take a leadership role to assist with these next steps of policy, implementation and training. It has been an honour for me to work with and be associated with them professionally.

Judith Newman, M.S.

Associate Clinical Professor, University of Oregon ECI Consultant with Open Society Foundation

Judy Newman is Co-director and Co-founder of Early Childhood CARES, the early intervention and early childhood special education program for Lane County, Oregon. She is Senior Policy Advisor for the Early learning Alliance for Lane County, the early learning system hub for a region in Oregon. Her over thirty years of experience includes direct service provision, administration, university teaching, participation in numerous research activities, and extensive work on state and local councils, committees, task forces and boards related to policy, systems and funding for education, human services and specifically early childhood concerns. Over the past 10 years, she has worked for Open Society Foundations, Holt International and /or the University of Oregon as an international consultant with several countries on the development and implementation of legislation, policies and practices related to early Childhood intervention systems.

AKNOWLEDGEMENTS

Karin Dom would like to thank Open Society Foundations' Early Childhood Development program, London for their financial and consulting support, as well as trainings and exchange of experience and ideas! With their help and that of our partners, we managed to widen the Early Intervention Program at the local and national level, with respect to methods and sustainability.

We thank the Municipality of Varna for opening a municipal-delegated activity for early intervention services in 2013, to meet the needs of young children and their families!

Karin Dom thanks all its partners and donors for the open dialogue, mutual support and trust!

SCOPE AND AIM OF THE REPORT

The present report introduces results from the assessment conducted on Karin Dom Foundations' Early Intervention Program for the period from January 1st, 2011 to December 31st, 2015. The assessment is intended for use by state and municipal institutions, and partners. Furthermore, it aims to prove the advantages and significance of the Early Intervention Program in Bulgaria, in terms of prevention of deinstitutionalization of children with special needs, their development, as well as social and educational inclusion. The assessment includes qualitative and quantitative research methods. Data is collected through a software system, developed by Karin Dom, which summarizes the information for the services provided; interviews and inquiry surveys with program partners, parents and specialists; and documents analysis.



CHAPTER 1 KARIN DOM AND EARLY INTERVENTION

AT KARIN DOM "WE HELP OUR LITTLE SUNSHINES RISE"

Karin Dom opened in 1996 in the city of Varna to support one of the most vulnerable groups in our society – children with special needs – and to help them develop their potential: to learn and play with peers, to grow up surrounded by the love and care of their families, and aspire for a better future.

Karin Dom was founded by Mr. Ivan Stancioff – diplomat and philanthropist – as an alternative service to institutions. Today Karin Dom has a leading role in providing social services for children with special needs and their families, and prepares them for their inclusion in kindergarten and school.

The organization adapts proven effective working principles and approaches, and disseminates its experience through trainings, seminars, conferences, and work with students and volunteers. Karin Dom actively works for change of policies on local, regional and national level regarding children with special needs.

In 2001, Karin Dom received an award by the European Commission for its good practices.

Funding for Karin Dom comes from donations and implementation of projects, as well as by statedelegated activity programs - 50 children for the Centre for Social Rehabilitation and Integration (CSRI) and municipal-delegated activity - 40 children for the Early Intervention Program.



KARIN DOM'S EARLY INTERVENTION PROGRAM

Implemented in partnership with Varna Municipality, maternity wards at Prof. Dimitar Stamatov Hospital and St. Anna Hospital, Child Protection Department in Varna, and breastfeeding consultants of Colourful Future Association. Launched in 2010 with the support of Open Society Foundations' Early Childhood Development Program, London.

DEFINITION

Interdisciplinary coordinated service in support of families of infants and children 0-3, who have concerns about their child's development. Services aim to improve child's progress and family's life, and to prevent further abandonment of children born with disabilities.

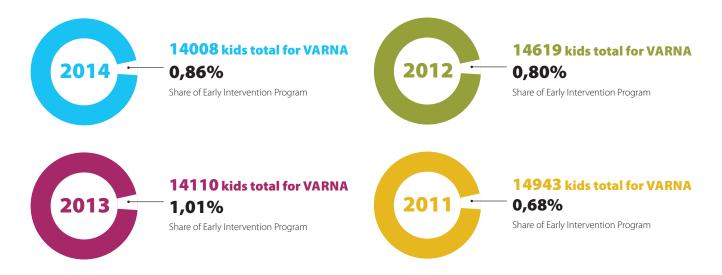
TEAM

Early intervention consultants provide services, who besides their specialization have developed additional competences through teamwork. These specialists include physiotherapist, speech therapist, special teacher, social worker, paediatrician, and administrative staff. Every year, team members take part in internal and external trainings as part of their professional development and periodical supervisions.

Key moments in the development of Karin Dom's Early Intervention Program

1996 2010 2011-12 2013 2014-15 Services in Karin dom Family-centered Early intervention Municipal-delegated Training of 47 early Centre for children and early intervention trainings to 10 NGO's activity Early Intervenintervention centres in tion"- 40 children families service the country based on agreement with the Ministry of Labour and Social Policy.

Scope of the Early Intervention Program compared to the total number of children in Varna Municipality



EARLY INTERVENTION PROGRAM'S SERVICES

HOME VISITS are the main service delivered in the child's natural environment (home, playground, nursery, kindergarten). Consultants provide the family with guidelines, suggestions, and recommendations for activities to stimulate child's development.

Complementary services:

Maternity hospital intervention:

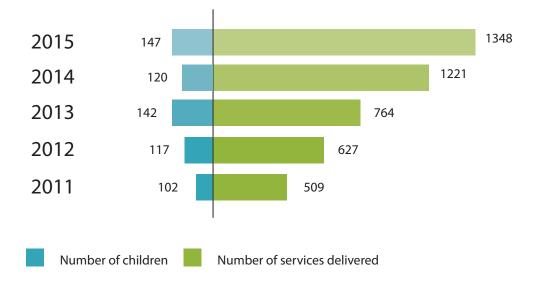
Breastfeeding support for optimal baby feeding and building relationship between mother and baby;
Social and psychological support to families with children with special needs and those at risk of institutionalization.

Group for children and parents:

• For socialization and preparation to integrate the child in a mainstream nursery or kindergarten;

• For development of functional communication and adaptive skills (including children with Autism spectrum disorders and speech and language developmental delay.

Parent support network – "contact parent"; mutual help and support groups; Resource library with literature, toys and supportive facilities; Subject meetings, seminars and trainings for parents, teachers, etc.



SERVICES DELIVERED IN THE PERIOD 2011-2015

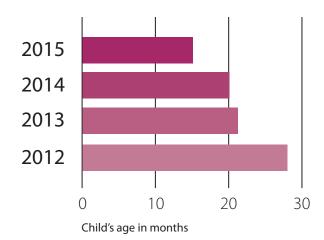
*On an average monthly basis, the program works with 65 children. Annually 10% of the children are included for progress monitoring (in 2-3 months).

WHY DO WE PROVIDE THE SERVICES IN THE CHILD'S NATURAL ENVIRONMENT?

The natural environment of the child consists of its home, playground, nursery, kindergarten and other public places. Services include family trainings, provided as part of the family's daily activities that allow the child to practice and develop new skills.

FAMILY-CENTERED APPROACH

Family-centered approach supports the whole family by focusing on strengths and resources instead on deficits and problems. Apart from the expert model, this approach allows the active participation of the family in the intervention process. Infants and toddlers spend their first years of life at home with their families, thus the family has the greatest impact on their development and education.



AVERAGE AGE OF CHILDREN ENTERING THE PROGRAM

In spite of the general public attitude, which places emphasis on postponing intervention until children grow up and overcome developmental problems, we report earlier inclusion of children in the Program. Our medical partners contribute to this success by expressing their active attitude and recognizing the Program. Social networks and media also popularize the advantages of early childhood development.

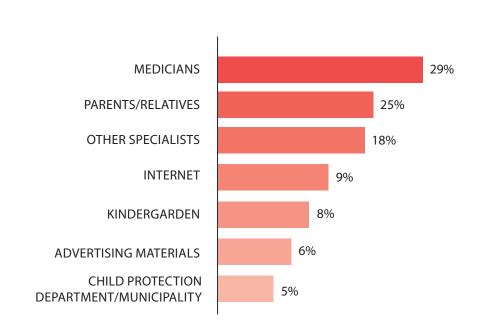


CHAPTER 2 HOW THE EARLY INTERVENTION PROGRAM WORKS

All references and information in the present report are generated by the Early Intervention Program's software system. Based on the model used in Early Childhood CARES, an early intervention program in Oregon, the software database collects and processes information and data about the Program. It serves as an ongoing monitoring of services and assures the accuracy of the reports.

PROGRAM REFERRALS

Parents declare their willingness to take part in the Program. In most cases, they are referred to by Karin Dom's partners or have received information about the Program through Internet, relatives, other parents, or friends.



CHILDREN INCLUDED IN THE PROGRAM BY SOURCE OF REFERRAL

ELIGIBILITY:

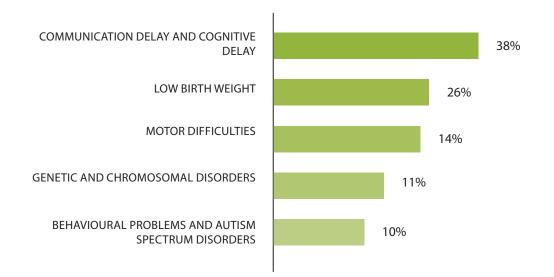
Children aged 0 to 3 who meet one or more of the following criteria:

- Risk of abandonment in institution of a child with special needs;
- Diagnosed disability or risk of developmental disability;
- Delay or risk of delay in one or more areas of development including low birth weight babies.

Karin Dom applies "Ages and stages questionnaires" (ASQ-3) – screening tool filled in by parents based on examination of five areas of development: communication, gross motor, fine motor, problem solving, and personal-social development. Results indicate if the child has delay in any particular area compared to its age norm. The tool gives parents ideas about practicing activities that stimulate child development.

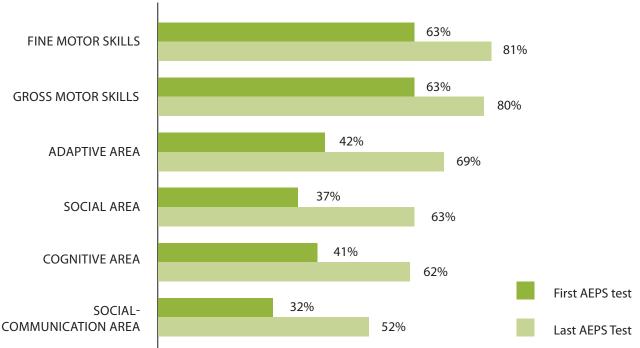
*In 2015-2016 Karin Dom conducted research for standardizing the screening in Bulgaria.

Distribution of children according to their conditions and based on the initial concerns of the parents while entering the Program:





Within the Early Intervention Program, a tool for thorough functional assessment is used – the AEPS (Assessment, Evaluation and Programming System for Infants and Children). This system evaluates and reveals the strengths of children in various developmental areas. It helps to determine the current skill level of the child and plan next steps, i.e. the functional purposes and tasks in the Individual Family Service Plan. Assessment can be re-applied every six months to observe and track the progress of the child.



RESULTS OF APPLYING THE AEPS TOOL (0-3) TO 46 CHILDREN FROM THE EARLY INTERVENTION PROGRAM.

Average value in percentages indicates the skills children have demonstrated while entering the Program and the progress made in 6 months after second testing.

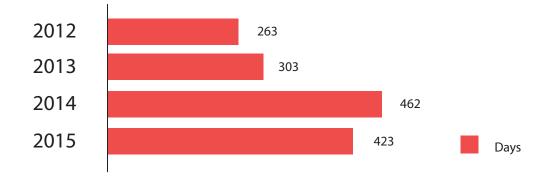
Advantage of this tool is that assessment, goal setting, intervention, and desired outcomes are directly linked, thus leading to greater efficiency. It also shows the impact on the child's development and supports the current evaluation of the service. In this way, parents and professionals can easily monitor the progress in child's development. It is an approachable tool for monitoring the results of the service.

INDIVIDUAL FAMILY SERVICE PLAN – family members define goals they consider important to themselves and their child. Based on goals the team sets individual tasks, strategies, support and services required for their successful accomplishment.

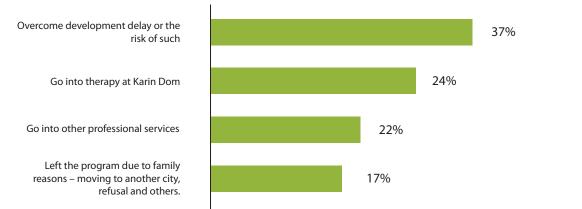
LEAVING THE PROGRAM

Upon transition to other services, Karin Dom's consultants support family to make informed choice for suitable services. Trust and cooperation among the Early Intervention team, the family and other service providers is a key to the success of moving child towards the next stage of its life

AVERAGE DURATION OF STAY IN THE PROGRAM



DISTRIBUTION OF REASONS FOR LEAVING THE PROGRAM



CHILDREN STORIES

IVAN

"The road to Karin Dom begins with the awareness of the need of professional help. We entered the Program when my son was 2 years and 7 months old. He did not speak and avoided people; did not allow anyone to touch him; his sleep was short; he was still wearing diapers and ate as much as a 10-month baby; he always ran away from children and had never reached out to me to take him; he hit his head in the door; screamed and cried for everything....l was so scared!...The diagnosis was Pervasive developmental disorder!

At each visit, the consultant advised me to use approaches and behaviour my child was able to understand, and I saw that every week we were one-step closer to the goals.

I learned how to be in favour of my child and his development. It is true that I also put many efforts in working with him. My gratitude is huge! My child is successfully adapted to kindergarten, he speaks and plays with other children...change is complete."

Ivan's mother

SASHO

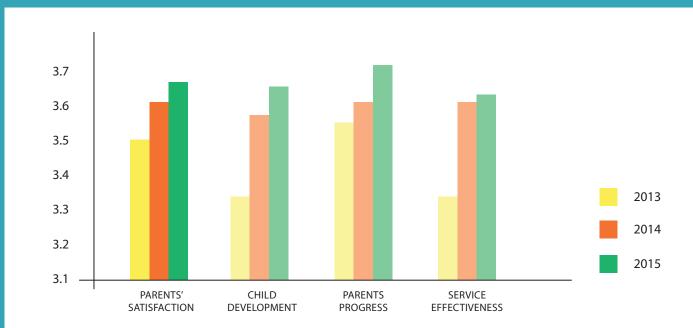
- Born 950 grams with a complicated health status;
- Abandoned in Home for Medical and Social Care -Varna;
- At 3 months old, he was placed in a foster family and entered the Early Intervention Program;
- Assessment showed deviation from the norm in all developmental areas;
- The foster family followed the guidelines and worked diligently on the goals set. The result was that Sasho progressed step by step;
- Adopted at eight months old;
- At one and a half, he compensated for existing developmental challenges and as a result reached his peers;

CHAPTER 3 PARENTAL VIEW

Between 2013 and 2015, Heat Company, an independent consultant, performed interviews and surveys, which were then summarized in five separate reports, allowing to keep track of service development. Researchers conducted interviews with 296 parents in the Early Intervention Program during that period.

RESEARCH RESULTS

Responses were scaled from 1 to 4, 1 meaning least desirable and 4 meaning greatest satisfaction.



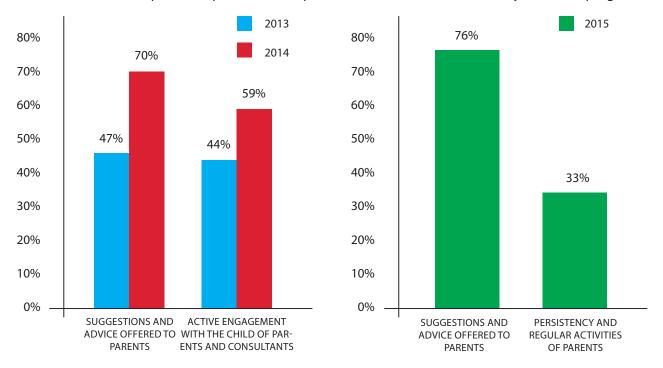
Parents' satisfaction is determined through research on the impact of the Program in three main areas:

1) Child development - progress in child development

- 2) Parents progress participation, self-confidence and skills related to their child's activities
- 3) Service effectiveness acquiring knowledge and skills, flexibility, service duration and frequency

Results of the analysis show that the highest values refer to "Parents progress". This is the positive impact of the applied family-centered approach.

"Our consultants give guidelines on how to work with the child and what is important for its development. They help us assess objectively the child's behaviour and take steps to eliminate challenges. They provide particular examples of how to play with the child so it can acquire new skills." Below are summaries of parent responses to the question, "What are the reasons for your child's progress?"



Reasons indicated by parents are evidence about the family-centered approach and its successful implementation by the experts. In 2015 a new trend emerged – "persistency and regular activities of parents." However, this does not mean that the consultants' role has been undervalued. On the contrary, they have strengthened the power of the family. Parents are confident and competent in implementing tasks designed in their individual plan as well as recommendations formulated as part of in home visits.

"In my opinion improvement is due to the fact that we were involved in the program at the onset (two months after birth). Work shows good results and this motivates us even more. Interaction with other parents also contributes to the emergence of ideas for launching new activities. We can say there is an amazing progress in past year since our daughter started attending the nursery group."

THE OPINION OF THE EARLY INTERVENTION CONSULTANTS

SERVICE ADVANTAGES:

- Accessible; short waiting period.
- Delivered in child's protective environment
- Based on home environment and family resources. For instance, it is important for parents and their child to know how to move about at home by using available resources.
- Reduced stress of parents.
- Program methodology responds to family needs. Parents set measurable and achievable goals and focus on their efforts. The Program provides activities for parents to try out until the next home visit and after that, they share the outcomes.
- Parents are satisfied by the family-centered approach due to its advantages.
- Complex and flexible service. On-site consultations are performed prior to transition to nursery or kindergarten.
- Work with families moving to other services is easier because they already know what they can expect; they are active and open for partnership.
- Families save time and resources.

SERVICE CHALLENGES:

- Perception of family-centered approach initially, parents assume that someone else will work with their child and they are not convinced of the approach's success.
- One never knows what to expect from an in-home visit, but you get used to it.
- Good time management the home visit goal needs to be followed through; all documents have to be completed.
- Overcoming challenges when visiting a nursery or kindergarten where experts are unknown; building partnerships.

CHAPTER 4 PARTNERS' SATISFACTION WITH THE EARLY INTERVENTION PROGRAM

Study of partners' satisfaction about their collaboration with Karin Dom's team shows high results (86%). Surveys (42 representatives) and feedback from the regular partner meetings informed the analysis.

Program's advantages according to partners:

- Flexibility of consultants (opportunities to provide services in different places and to support families meeting their needs);
- Work with the whole family and in all developmental areas of the child;
- The service is successfully completed by the partner's services providing a complex support for children and families.

We observe the following trends regarding representatives of different areas:

- Social sphere partners (Child Protection Department, Social Department of the Municipality of Varna, NGO) express their high satisfaction: "Parents share the presence of trust between them and the specialists", "To the present moment the early intervention social service is adequate to users", "The approach contributes to the sustainability of the achieved results, because parents actively participate and gain new skills and knowledge."
- Health sphere partners (neonatologists, paediatricians, neurologists, psychiatrists, etc.) were very sceptical in the beginning about the applied family-centered approach, as it does not emphasize on intensive therapy but on family support. Gradually, the number of families directed by medical specialists increased. "I steer parents to Karin Dom as I see the positive change for both children and families...they associate the family with other services as well.", "I direct parents to Karin Dom and vice versa. We support each other with regard to nutritional concerns."
- Education sphere partners they share that Karin Dom helps them feel more self-confident while working with children with special needs; they highly appreciate practice-oriented consultations in the kindergarten: "We changed the environment; we introduced visual schedules, symbol pictures and ges-tures. This had a positive impact on children we noticed improvement in their communication and social interaction skills. We are grateful for the cooperation!"- kindergarten teacher



CHAPTER 5 EARLY INTERVENTION TRAININGS

SERVICE PROVIDERS TRAINED BY KARIN DOM IN EARLY INTERVENTION



 2011-2015 – Karin Dom conducted trainings with 14 NGOs, including the Centre for Public Support, Complex for Social Services for Children and Families, Centre for Social Rehabilitation and Integration, Centre for Maternal and Child Health (piloted by UNICEF) and other social service providers. In support of the trained professionals, Karin Dom designed a manual, further developed in partnership with For Our Children Foundation. Results show that organizations with expertise in the work of children with special needs or such providing mobile social services, apply sustainable early intervention practices. Therefore, further trainings and supervisions are desirable.

- 2014-2015 Under a contract with the Ministry of Labour and Social Policy of the Republic of Bulgaria, Karin Dom developed methodology of the early intervention services and trained staff from 47 municipal early intervention centres. Previously trained specialists from NGOs with existing experience in the implementation of early intervention service, joined Karin Dom's training team. Results show that the majority of specialists employed in municipal centres do not have experience in working with young children with special needs. On the other hand, they are familiar with the expert approach. Working together in teams and practicing beyond their narrow specialty, is a relatively new concept for majority of Bulgarian experts as is the overall philosophy of the family-centered approach.
- Since 2016, Karin Dom has searched for opportunities for the creation of a university program in Early Intervention. The School of Public Health at the Medical University in Varna is highly interested in the idea due to existing longterm partnership between the two organizations. Expertise of the Training Centre of Karin Dom combined with the availability of opportunities for internship and practice of students, influences the interest in a partnership with other universities from around the country and abroad.

CHAPTER 6 PREVENTION OF ABANDONMENT OF CHILDREN WITH SPECIAL NEEDS

In the Central and Eastern Europe region, UNICEF estimates that a child with a disability is almost 17 times as likely to be institutionalized if suffering from a disability.¹

Statistics for Bulgaria shows that despite the started process of closure of the Homes for Medical and Social Care for Children (HMSCC) aged 0-3 years, the percentage of children bellow the age of one, who continue to enter HMSCCs is unchanged – 80% (2001-2015) when compared to the overall number of incoming children². For the most part, children aged 0-3 years enter institutions directly from the maternity ward and are rarely put up for adoption or taken in by foster families. In the meantime, these children begin to experience significant developmental delays, and higher mortality rate.

Early family support – the way families receive information and support about their child's condition – is an important step in the successful prevention of abandonment of children with special needs. Of key importance in such cases is the partnership between maternity wards and Early Intervention Program. Experts may offer psychological support, information about a specific condition, to connect families with experienced parents, or with breastfeeding experts:

"I remember the words of the doctor: 'Your life will be hell. Leave the child in an institution. Society does not accept such people.' Fortunately, at the hospital we met a wonderful person, who we will always remember, an angel – Karin Dom's Eli Todorova. She was the only person who did not ask us, 'What did you decide? Will you abandon her?' She provided us with support, advice, as well as information about Karin Dom, where there were people to assist us in the care and day to day battle..."

In 2014, Karin Dom, together with a team of psychologists, was commissioned by the Ministry of Labour and Social Policy to conduct trainings for 290 medical specialists from 36 maternity wards around the country on the topic of New Approaches to Imparting Parents with News of their Child's Disability. Assessment of the 290 medical specialists showed that over 70% of them were of the opinion that a best practice guidelines for informing families of their child's disability, would improve their work. Their recommendations included the establishment of a private room for discussions with families, the employment of psychologists, team trainings, and partnership with community non-profits.

KARIN DOM'S CONSULTATIONS WITH FAMILIES, WHOSE CHILDREN ARE AT RISK OF INSTITUTIONALISATION

	2013	2014	2015
Consultations for children at the maternity wards	8	8	13
Children who stayed with the family	8	5	10
Adopted children	0	2	0
Children placed in foster family	0	1	0
Children placed with their mother in Mother and Baby Unit	0	0	2
Deceased child	0	0	1

¹ Children and young people with disabilities, UNICEF, May 2013

² Data from the National Statistical Institute (April 2016)

Thanks to the referrals from our partners, since 2014 Karin Dom started to include in its Program foster families, who receive assistance with care and stimulation important to the development of the child. Foster parents receive individualized suggestions for their child, so that they gain confidence, understand and communicate more easily with their child, and manage effectively with everyday care. In this way, through the application of family-centered approach, a more stable and emotional connection is created between the foster family and the child. Results show:

- 1. preventing the risk of the child being send back into institutional care, because of the parent's inability to manage difficulties in raising a child with special needs;
- 2. overcoming developmental delays and better prospects for adoption.

COMPARISON OF THE COSTS IN BGN FOR STATE GOVERNMENT AND MUNICIPAL DELEGATED SOCIAL SERVICES AND EXPENSES FOR EARLY INTERVENTION³



The idea behind the Family Type Placement Centres (FTPC) is so that children may have access to services in the community, which would offer therapy and integrated environment. This means that the upkeep for one child placed in an FTPC will increase with the cost of therapy, kindergarten, school, resource assistance, and others. The table clearly shows how many times lower the costs of the Centre for Early Intervention are.

The cost of the Early Intervention Program is based on real costs for all types of services part of the Program for 2015. Initial cost and professional development trainings with international expert are not included. The above mentioned trainings were integral to the successful implementation of the family-oriented approach, as well as screening materials, assessment, and service development. Also not included are the costs of material provisions, which is need dependent. The main elements are salaries, transport, materials, trainings and supervisions, and administrative costs. Administrative and material base costs are minimal for this type of service, because of the mobile nature of the service and the applied method – maximum use of family resources. This has further influence on the achievement of family self-assurance, and in its power to manage in the best possible way the growth of their child.

CHAPTER 7 EARLY INTERVENTION IN BULGARIA: PROJECTS OR POLICIES

European funds and the World Bank are the two major sponsors for state-delegated services for early intervention in Bulgaria. Although project financing creates opportunities for piloting new services, there are also long-term disadvantages. The absence of legal regulations, standards, methodology, rules and procedures, licencing providers, and staff training requirements for the implementation of a particular service, creates certain risks that have direct influence on the quality and results.

As of yet, a university program in early intervention is not in existence in Bulgaria. Knowhow in the development of expertise for children with special needs aged 0-3 years is predominantly concentrated in big cities and is a result of additional trainings and professional exchange with foreign experts. An example of a common practice is for speech therapists to work with children 4-5 years old, as well as to wait until the child "outgrows" any developmental delay.

There is a need in Bulgaria for access to universal instruments for screening and assessment of child development, which can guarantee clear criteria for the available service and track its quality. The only widespread methodology for developmental research is from the 70s by Manova-Tomova.

The practiced model, which places the focus on the disability and not on the development of the child's strengths and functional skills, is widely popular. The family-centered approach on the other hand is a new philosophy, which to be successfully implemented requires mindset change, and new competences for attracting parents as partners.

Among the principles of early intervention, which enhance long-term results in children, are teamwork, knowledge sharing, and the coordination of support with medical specialists, teachers, social services, and ensuring the transition into mainstream education.

90% of the brain's development occurs in the first three years of life. Family is the most important resource for a child's development! Early intervention provides family support and is the best community investment!

⁴ Implemented by the Ministry of Health, project "Posoka Semeistvo," operates five centres for early intervention, that were created as an alternative service to the closure of eight HMSCC for children aged 0-3 years. Implemented by the Ministry of Labour and Social Policy, project "Social Inclusion," operates 47 centres for early intervention in municipal community centers.

EVERY CHILD DESERVES A HAPPY CHILDHOOD! LET'S MAKE THIS POSSIBLE!



This document is created with the financial support of the Open Society Foundations' Early Childhood Program. The entire responsibility for the contents of the document lies by Karin Dom Foundation.



CENTRE FOR CHILDREN WITH SPECIAL NEEDS TRAINING AND RESOURCE CENTRE

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