KARIN DOM FOUNDATION

CENTER FOR CHILDREN WITH SPECIAL NEEDS
TRAINING AND RESOURCE CENTER

Early Childhood Intervention Services for Children with Disabilities in Bulgaria: an alternative to institutional care for 0-3

Research Report

Apostol Apostolov, Veselina Vasileva, Hollie Hix-Small,
Dessislava Kuznetsova, Rouzha Pancheva

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Apostol Apostolov, PhD	Karin Dom Foundation
Veselina Vasileva	Karin Dom Foundation
Hollie Hix-Small, PhD	Open Society Foundations, London
Dessislava Kuznetsova	Open Society Institute, Sofia
Rouzha Pancheva, MD, PhD	Medical University of Varna

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Karin Dom Foundation is committed to seeing a better quality of life and equal opportunities for people with disabilities in Bulgaria. Our mission is to support the social inclusion of children with special needs and their families through professional services, advocacy, and raising public awareness.

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Sveti Nikola
P.O.B 104
Varna 9010
Bulgaria
Tel: +359 (0)52 302517
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Abbreviations

BFHI	Baby Friendly Hospital Initiative
CDI	Child Development Inventory
CEE	Central and Eastern Europe
CIS	Commonwealth of Independent States
CRC	Convention on the Rights of the Child
CHD	Congenital Heart Defect
CRPD	Convention of the Rights of Persons with Disabilities
DMSGD	Dom za Mediko-Socialni Grizhi za Detsa (in Bulgarian): Home for Medical and Social Care for Children
ECD	Early Childhood Development
ECI	Early Childhood Intervention
EII	Early Intervention Institute, St Petersburg
KID	Kent Infant Development Scale
NABS	National Association for Breastfeeding Support
NGO	Non-Governmental Organisation
PPP	Positive Parenting Programme
UNICEF	United Nations Children's Emergency Fund
WHO	World Health Organization
WHO ICF-CY	World Health Organisation's International Classification of Functioning, Disability and Health for Children and Youth

Executive Summary

Early Childhood Intervention is a multidisciplinary, coordinated developmental service for children between birth and three years of age for whom there are developmental concerns.

Good support during the first three years of any child's life is vital to ensure good health, physical and intellectual development, and social skills. This is even more important for children with disabilities. ECI services can help children reach their full potential.

This report serves to highlight the situation of early childhood intervention (ECI) in Bulgaria and how this can be taken forward in the future. ECI should be a key component in the support of children between the ages of 0 and 3 and their families, especially those with disabilities, which can be physical, mental, or a combination of both. The interventions are customised to the needs of the child and their situation and address any developmental issue the child may have through a family-centred approach to ensure good health, physical and intellectual development, and social skills and emotional well-being. One of the most important benefits of ECI for Bulgaria is to avoid the abandonment of infants by biological parents because of their child's physical or mental impairments. Currently, significant numbers of infants with disabilities are abandoned and taken care of by State institutions with detrimental effects on the development of the child and significant long term care costs to the State. By expanding and mainstreaming ECI into the healthcare and social support systems, the number of child abandonments can be substantially reduced. ECI services in combination with early breastfeeding support promote attachment and family well-being, thereby reducing abandonment. Currently breastfeeding is not encouraged in Bulgarian hospitals, especially in cases where the new-born has disabilities, and there is a lack of professional training for healthcare workers. Breastfeeding helps create a strong emotional bond between mothers and their babies that can form the basis for an important relationship, in addition to benefiting the infant's overall health and development.

The key policy recommendations of the report include the following: **collaboration** between those working on the *Social Inclusion Project*, and the *National Strategy* "Vision for deinstitutionalization of children in the Republic of Bulgaria" Action Plan with ECI as a common ground for shared work; the creation of **mobile teams** to overcome the resource gap between municipalities; **budgets** should be designed according to ECI guidelines or methodologies developed specifically for ECI services; **breastfeeding** should be mainstreamed into policy, training, and practice; **existing models** of good ECI practice should be used and supported as the basis for **scaling-up** ECI as a national service in Bulgaria; the

family-centred approach should be mainstreamed widely. NGOs should be partners in the **deinstitutionalisation process**, specifically in relation to developing and implementing community-based and ECI services; ECI **awareness-raising campaigns** should be organised for both the general public and local and national governmental institutions.

The report is divided into five main sections. First, following an introduction is the methodology, which details the research scope and methods. Second is a description of ECI, including the legal framework at an international level, examples of practice in Europe, and international good practice on breastfeeding. Third is a description of ECI and breastfeeding policies in Bulgaria. The fourth section details the existing ECI practices in Bulgaria and the current challenges. Finally, the fifth section of the report discusses the financial aspects of ECI and breastfeeding support development and sustainability.

Introduction

This report outlines the current development, role and challenges of Early Childhood Intervention (ECI) services in the context of the Bulgarian policies, services and practices for children with disabilities. The purpose of this research project was to: (a) document Bulgarian stakeholder knowledge and review existing practices in the area of ECI; (b) identify existing links between ECI and current social inclusion and deinstitutionalization policies in Bulgaria in relation to governance and funding mechanisms for services for children with disabilities.

ECI recognizes the developmental period from birth to three years as a critical period for the timely identification of a developmental delay or disability in order to maximally address the child and family's needs in order to optimize outcomes and meaningful participation in family and community life (Nelson, Zeanah, & Fox, 2007). Although the field of Early Childhood Intervention for children with disabilities has a long history internationally, spanning more than 50 years, and is supported by a strong foundation of research demonstrating child and family outcomes, ECI is relatively new to Bulgaria. A considerable part of services for children with disabilities in Bulgaria are focusing on children above the age of 3 and therefore fail to address the early needs of the child (age 0-3) and the family. Furthermore, there is lack of information about the need of early support among many parents and professionals. Many people from both groups believe that the child is "just a late bloomer" and he/she will eventually grow out of the developmental delay. Another reason for ECI not being well-established in Bulgaria is the lack of higher education and other training programs in this field and the prevailing medical model and institutional approach to care in the country.

The context of the development of ECI services in Bulgaria is the on-going process of deinstitutionalization of children in Bulgaria through which the Bulgarian government is determined to close State-run institutions for children and prevent the abandonment of children. Many new-born babies in Bulgaria who are identified with a developmental delay or disability are abandoned in state-run institutions for children aged 0 to 3 (DMSGD)[1]. In addition to disability as a decision-making factor for abandonment, other reasons for abandonment include poverty, poor parental or child health, social exclusion, homelessness, food insecurity and the lack of basic necessities needed for raising a child (The University of Nottingham: 2012). These institutions, as well as some of the new, alternative services

[1] A DMSGD is a residential type of institution for children, aged 0 to 3, which offers medical and social care. In 2011- 2 508 children were placed in DMSGD (National Statistical Institute, www.nsi.bg/EPDOCS/DMSG2011.pdf, accessed on 18.01.2013)

established to replace institutional care, tend to apply a medical model of diagnosis and treatment focused on the disability rather than the strengths of the child and family. The medical model predicts developmental outcomes on the basis of a medical diagnosis, of a disease or disorder, and determines the level of impairment or handicap. This model lacks parental involvement and support, resulting in family isolation and immediate or subsequent child abandonment. It is also a model that runs contrary to international best practice standards and law. For example, the Convention of the Rights of Persons with Disabilities (CRPD) and the WHO's International Classification of Functioning, Disability and Health for Children and Youth (WHO ICF-CY), understand disability in relation to a child's social participation and functional capacity – this is known as the social model.

One of the important factors influencing the existing high child abandonment rate in Bulgaria is the practice in maternity hospitals connected with delayed mother and child contact after birth and practices for communicating child disability with mother. When a child is born, he or she is usually separated from the mother who is discouraged from breast-feeding, providing breast-fed milk or developing any attachment to the child. This is especially true for children with disabilities. In cases of disability or any signs of abnormality at birth, hospital staff are inclined to accept that parents would not be able to look after that child and often suggest to the mother to give the child to the DMSGD where, arguably, the child will be better taken care of. International research evidence has shown that supportive breastfeeding practices after birth can lead to a tightening of the relationship between mother and child - and thus a crucial factor in the prevention of abandonment at the level of maternity hospitals (Lvoff et al., 2000)[2]. However, although the Bulgarian government has a policy to encourage supportive breastfeeding practices, many maternity hospitals do not see this policy as a priority for the services they provide.

This report argues that ECI can be used as an instrument in efforts for the prevention of abandonment of children with disabilities and for overcoming developmental challenges through providing holistic services for the whole family. Unlike institutional care and medical-based services, ECI 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. Breastfeeding support, when integrated into ECI services

[2] For details on supportive breastfeeding practices, see appendix 6- the WHO and UNICEF's Baby Friendly Hospital Initiative.

can also contribute to prevention of abandonment and lead to better developmental outcomes for children.

This report begins by explaining what methods have been used to undertake the research project on ECI practices in Bulgaria on which the report is based (section 1). It then provides an overview of the field of ECI, thus elaborating on the meaning and importance of ECI for supporting children with disabilities and their families. International examples of ECI are also provided (section 2). Sections 3, 4 and 5 provide an insight into the findings of the research project, drawing on data from the fieldwork process and from documentary sources. The report finishes by providing the conclusions from the research project and offering recommendations about the development of ECI in Bulgaria and the implementation of additional measures for supporting small children with disabilities and their families in Bulgaria in the context of de-institutionalisation and inclusion actions.

1 Methodology

1.1 Objectives, Research Questions and Limitations of the Study

The research project, on which this report is based, was intended as a small-scale, descriptive ethnographic study. The research took place in two periods – September 2011 - May 2012 and November 2012 – January 2013. The research project used qualitative methods of data collection, which insured validity of the research findings. This research project was designed when Early Childhood Intervention was becoming a key topic for the Bulgarian Government in relation to the development of new community-based services to increase social inclusion and prevent institutionalization. Preliminary information-gathering efforts indicated that only a few available ECI providers were operating in the country as a result of NGO sector pilot projects. Therefore, given the widely recognized need for ECI services, the aim of the project was to look at existing governance and financing possibilities for developing such services in Bulgaria. As the research treats ECI and breastfeeding support as intrinsically connected topics in relation to the needs of young children with disabilities in Bulgaria, it uses a common methodological frame, which is outlined below.

The project set out to answer two research questions:

(1) What are the current developments, roles and challenges of ECI (including breastfeeding support) among other services for children with disabilities in Bulgaria?

(2) What are the financial and governance opportunities for integrating ECI into the Bulgarian Government's package of services for children with disabilities and their parents?

The first question meant to unpack the circumstances related to ECI development and delivery in order to understand how stakeholders understand ECI (e.g. educational and social service providers, hospitals, Municipal administration, child protection, community NGOs)[3]. Additionally, through this question, the research explored the opportunities for financial and governance sustainability of an ECI service. The second question focused on ECI at the level of national policies and programs in relation to providing support for children with disabilities and their families.

[3] For a list of all institutions and organizations, participating in the research, see appendices 2, 3, and 4.

Although the study was able to address the above questions, it had some limitations. It was conducted for a short period of time (a total of 8 months of data collection), thus providing only a snapshot of the situation of ECI in Bulgaria. In order to address this limitation, further, longer-term research is needed in order to capture the rapidly developing processes of service development and de-institutionalisation in Bulgaria. Another limitation of the study was the fact that interviews and focus groups were conducted only in Sofia and Varna. This limitation was to some extent overcome by the fact that an e-mail based survey was conducted in 14 other locations, thus incorporating data from all key ECI providers known to the research team in order to document ECI practices in Bulgaria.

1.2 Research Instruments

The research methodology included 5 main types of instruments:

(1) Desk review and analysis of existing documents;
(2) Focus groups with relevant stakeholders;
(3) Individual, semi-structured interviews;
(4) Survey completed by organizations delivering ECI services;
(5) Case study of one ECI service delivery organization in Bulgaria;

The combination of the above research instruments allowed for a more in-depth understanding of ECI practices and policies in Bulgaria. An intentional convenience sample of potential respondents was drawn. The methodology aimed to gather data from different sources through multiple methods from diverse stakeholders in order to allow for 'triangulation' and 'diversification' of data in order to achieve a fuller picture of the context in which ECI services and finance and governance are being planned (and in some cases delivered). Table 1 below presents a summary of the fieldwork data collection instruments and what participant numbers they generated.

Research instrument	Number of Respondents
Semi-structured Interviews	21
Focus Groups	52
Survey	14
Case Study	5

Table 1. Summary of fieldwork data collection instruments and number of respondents.

A short description of the process of implementing all research instruments is presented below.

1.2.1 Desk Review

The desk review included documents related to the development of ECI service provision and financial and governance opportunities for integrating services into the social care system. Documents related to deinstitutionalization, social inclusion and breastfeeding support were also reviewed given Early Child Intervention services are necessary for successfully supporting prevention of abandonment and the inclusion of all children in family and community life.[4]

1.2.2 Semi-Structured Interviews

Interviews were carried out in two Bulgarian cities, Varna and Sofia. The city of Varna was selected because it houses an operating city-wide Early Childhood Intervention service - Karin Dom's Early Intervention Program. Sofia was selected because it is the capital city where the decision-making government institutions and international organizations are located.

The purpose of the semi-structured interview questions was to gather information related to the case study in Varna and to gather more general information about stakeholder understanding of ECI and related activities. Some of the questions covered topics such as family home visits and breast-feeding support to new mothers at the maternity hospital. These two topic areas were considered pertinent given these are two key components of the existing ECI service in Varna (Karin Dom Foundation's ECI program) and are recognized as important elements of family-centred practice and family preservation within the ECI and social protection fields, internationally. Respondents were also asked to comment on their perceived need for ECI services in Bulgaria as well as funding and governance needs for these services. Depending on respondent familiarity with ECI services in Varna, he/she was invited to respond based on knowledge of ECI in Varna or Bulgaria as a whole. Questions were also asked about the deinstitutionalisation process in Bulgaria and the relationship (if any) between this process and ECI.[5]

[4] The documents which were found relevant to the study are referred to throughout the current report, and full references for them are provided in the bibliography at the end of the report.

[5] See appendix 1 for the interview schedule used in the research.

Respondent involvement in the planning or delivery of children's services was the main criteria for selection. In relation to the topic of breastfeeding, there was an additional criterion for respondent selection: knowledge of the Government's policy on breastfeeding or nutrition. Interviews were conducted by a team of four Bulgarian researchers – one based in Sofia and three based in Varna. Interviews were face-to-face and were negotiated with respondents in advance in order to identify suitable locations and times. On average the interviews took 60 minutes and went smoothly although some interview schedules could not be followed strictly due to the limited amount of time interviewees were prepared to give.[6]

1.2.3 Focus Groups

Three focus groups were conducted – two in Varna and one in Sofia. Each focus group was led by a member of the research team. Participants were made aware of the purpose of the focus group and how the data would be used. Focus group participants in Varna represented municipal administration, maternity hospitals, the local agency for child protection, the Regional Inspectorate for Education and NGOs. In Sofia, the focus group included representatives from the municipal administration, government consultants, representatives of NGOs from Sofia and other cities in Bulgaria, and UNICEF.[7] The selection criteria for the focus groups were the same as for the semi-structured individual interviews: involvement in planning or delivering children's services was a requirement for participation.

The purpose of the focus groups was to collect information about ECI funding and service provision structures. All focus groups were asked to answer the following key questions:

- **How can ECI services be funded in Bulgaria?**
- **Can ECI become a Government-funded service? If so, how?**
- **What structures will be most suitable for providing ECI services?**

1.2.4 Survey

Fourteen organizations were identified as ECI service providers and were invited to complete the survey[8]. Ten of these organizations were NGOs who had received training and support between September 2010 and March 2012 in order to provide ECI services. These activities were financially supported by the Tulip and Oak Foundations and methodologically supported

[6] See appendix 2 for a list of NGOs and Institutions interviewed.

[7] See appendix 3 for a list of institutions and NGOs participating in the focus groups.

[8] See appendix 4 for a list of participating NGOs.

by Karin Dom Foundation. The other four organisations were identified as providers of ECI during the collection of additional information for the study (e.g. information from the Internet). The services provided by 3 of them had been funded by other private donors, and one had been funded by an EU structural funds operational program. Questionnaires were prepared by the research team[9]. The survey was sent to all 14 organisations with the request to fill it out and return it within a period of one week. The completion of the questionnaire was expected to take no more than half an hour. It contained 8 questions. The survey was carried out via e-mail and had a response rate of 93%. On receiving the completed questionnaires, the research team carried out additional phone calls with some of the respondent organizations if clarification was required. The purpose of the survey was to identify the development of ECI services in Bulgaria beyond the case study in Varna (Karin Dom Foundation). The survey was also used to gather data on how these organizations were financing their ECI services, the capacity of these services (e.g. number of children served), the structure of the service provider and the service-delivery environments (e.g. home or centre-based). The survey was limited by the fact that it was conducted only among organisations which were known to the research team, or were identified during the research process. It is possible, therefore, that there were other organisations in Bulgaria delivering ECI services which were not identified at the time of research.

1.2.5 Case Study

The research team decided to conduct a small case study of one Early Childhood Intervention service provider, Karin Dom Foundation. Karin Dom was selected for the case study because of its significant experience and expertise in providing services for children 0-3. It had been applying ECI practices since its establishment as a centre for children with special needs in 1996 and implementing a distinct ECI service since 2010. The organization offers both home-based and centre-based services. For children under three years of age, home visits are made by Early Intervention Service Consultants along with a parent-toddler playgroup at the centre. Additionally the organization provides services to prevent child abandonment in collaboration with maternity hospital staff. Finally, Karin Dom has been engaged in providing ECI training to organisations from other municipalities in Bulgaria in an attempt to expand service provision in the country. Ten of the organizations trained by Karin Dom were also involved in the research survey previously mentioned.

[9] See appendix 5 for the questionnaire used in survey among ECI service providers.

2 Early Childhood Intervention – Key Facts

This section will provide a definition of ECI and will outline some key ECI approaches. It will then position ECI in the context of children's rights and international law. Finally, this section will provide some examples of international ECI practices.

2.1 Definition and Approaches of Early Childhood Intervention

Early Childhood Intervention is a multidisciplinary, coordinated developmental service for children between birth and three years of age for whom there are developmental concerns due to identified disabilities (e.g. Down syndrome) or whose optimal development is at-risk due to certain biological or environmental circumstances experienced before or after birth (e.g. infants exposed in utero to alcohol, or born with a cleft palate) (Guralnick, 2011). ECI is a response to the need to address various forms of delays or disabilities in a child's development. Although there are various definitions of delay and disability, as well as the factors determining such conditions, there are some internationally recognised criteria used to establish certain ECI approaches. This is how a study commissioned by UNICEF defines developmental delay and disability and the categories of children prone to be affected in that way:

> "….Children who are **at risk of developing delays and disabilities** include those with poor birth outcomes, biological or genetic risks, or whose parents live in poverty, have low levels of formal education, or suffer from domestic violence, substance abuse, violent conflicts, famine, diseases, poor sanitation or other negative situations. A child is considered to have a **developmental delay** when he or she is assessed to have atypical behaviour or does not meet expected normal development for actual or adjusted age in one or more of the following areas: perceptual, fine or gross motor, social or emotional, adaptive, language and communication, or cognitive development. A delay is measured by using validated developmental assessments. The delay may be mild, moderate or severe. Poor birth outcomes, inadequate stimulation and nurturing care from birth onward, organic problems, psychological and familial situations, or environmental factors can cause delays. A child is considered to be **disabled** if he or she has a physical, health, sensory, psychological, intellectual or mental health condition or impairment that restricts functioning in one or more areas, such as physical movement, cognitive and sensory functions, self-care, memory, self-control, learning, or relating to others ….." (Vargas-Baron & Janson 2009: 8)

Developmental domains such as gross motor, fine motor, social, communication, adaptive, and cognitive are recognized as being interdependent with a delay in one area often affecting

another area of development and children's development is understood as affecting and being affected by proximal relationships (e.g. mother and father), distal relationships (e.g. community members), the physical environment, social services, working conditions and available health services (Ertem, 2011). This interdependency between developmental domains and areas of delay require "**integrated approaches** that include basic services for preventive health care, nutrition, early nurturing, stimulation and child development activities, home and community sanitation, and in cases of special need, juridical protection and protective services" (Vargas-Baron & Janson 2009: 8).

Historically, Early Childhood Intervention has undergone a process of adaptation, overcoming social and institutional barriers and learning new ways of supporting children with disabilities and their families. The approaches of ECI, over a period of more than 50 years of development, can nowadays be roughly described as 'old' and 'new'. Table 2 below outlines some old and new approaches to Early Childhood Intervention.

Old Approaches	**New Approaches**
Parents excluded	Parents as partners
One size fits all system	Individualized services
Child only focused	Child & Family focused
Deficiency focused	Strengths focused
Fragmented services	Collaborative teams
Clinic only setting	Natural environment

Table 2. Old and New Approaches to Early Childhood Intervention (Lucas, Barton, Hurth & Russell, 2010)

ECI services are generally provided by a multi-disciplinary team made up of individuals with training in disciplines such as physical and occupational therapy, speech and language therapy, and special education. Some team members bring additional specialized knowledge in areas such as sign language, Autism, assistive communication, sensory integration, and

infant mental health. The rationale for adopting a team-based approach includes: (1) some children have multiple, complex, specialized needs that require more knowledge and skills than can be expected from one individual or discipline; (2) cross –disciplinary services are required; and (3) shared ownership of the service plan necessitates a team-based format where disciplines collaborate, share and encourage and support one another to best support the child and family (Bricker & Widerstrom, 1996).

Early Childhood Intervention has been shown to be highly effective for children with biological and environmental risk as well as for children with Autism (Scheffer, Didden, Korzilius, 2011) and Down syndrome (Guralnick, 2005). Evidence-based practices are recommended (Guralnick, 2008, 2011). Evidence-based practice includes the use of rigorous and practice-based findings to develop and modify policies, procedures and practices to ensure appropriate personnel training and high quality practices. Several principles of ECI have achieved international consensus, including: (a) the adoption of a family-centred approach[10], (b) individualized interventions, (c) coordinated service delivery and (d) methods based on research (Guralnick, 2008, 2011).

Research evidence on the brain's neuroplasticity indicates optimal malleability during infancy and early childhood, a time when the brain is often able to compensate for problems when paired with intervention. In turn, ECI capitalizes on the rapid development in the early years by providing multiple, individualized, specific, and functional interactions between the child and other individuals (e.g. parent, other caregivers, children, specialists) in order to reduce or ameliorate the areas of delay. If delays are not addressed early, they may begin to affect other areas of development and increase in severity. In essence:

[10] A family-centred approach "is a set of values, skills, behaviours and knowledge that recognises the centrality of families in the lives of children and young people. It is grounded in respect for the uniqueness of every person and family, and a commitment to partnering with families and communities to support children and young people with a delay or disability to learn, grow and thrive. It puts family life – and the strengths, needs and choices of people with a disability and their families – at the centre of service planning, development, implementation and evaluation." (Department of Human Services and Department of Education and Early Childhood Development, 2011)

> "…ECI programmes provide a system of early childhood services and support for:
>
> 1) vulnerable children at high risk for developmental delays or with confirmed developmental delays or disabilities, and
>
> 2) their parents and families.
>
> The primary goal of ECI programmes is to support parents in helping their children to use their competencies to achieve their full developmental potential and attain expected levels of development, to the extent possible…" (Vargas-Baron & Janson 2009: 9).

2.2 Early Intervention – A Tool for the Prevention of Institutionalisation

There is a wide consensus in the ECI community that ECI is a powerful tool for child development. As most of the brain development occurs in the first three years of life, the earlier a child and his/her family are supported, the less damage there will be to the child-parent attachment, their communication and the developing neurological system of the child. Institutional care deprives children of a nurturing parent-child relationship. Studies show that children in institutions are affected negatively in terms of physical and mental developments (Browne, 2009). They are also affected in terms of social integration. They tend to be isolated, receive poorer quality education – especially children with disabilities - and are often unable to form social ties later in their lives (Sammon, 2001). It is well established that early environments can have lifelong effects on children's development and mental health. Developmental science has demonstrated the value of predictable and stable settings, respectful and stimulating care, the formation of sensitive and responsive relationships, and other important supportive factors in promoting young children's development and well-being. All children need these supportive factors regardless of where they live, their biological status or medical condition.

Research in Romania has compared the development of children residing in institutional care without an opportunity to develop a meaningful relationship with a care provider with children moved from the institution to ECI-focused foster care services and a group of children who had never been institutionalised. The study showed that "…the cognitive outcome of children who remained in the institution was markedly below that of never institutionalised children and children taken out of the institution and placed into foster care. The improved cognitive outcomes were most marked for the youngest children placed in foster care. These results point to the negative consequences of early institutionalization…and

underscore the advantages of family placements for young abandoned children…." (Nelson et al., 2007).

Research evidence also shows differences in brain development between children cared for in an institution and those raised in a natural environment. Neglect, which is a typical feature of institutionalised way of life, has been proved to impede brain development. Figure 1, shows the differences in brain activity of two children – one raised in a family (left image), and the other raised in an institution (right image). The right image clearly shows the effects of institutional depravation – the diminished activity of the temporal and front lobes (the brain areas connected to the regulation of the emotional and cognitive processes).

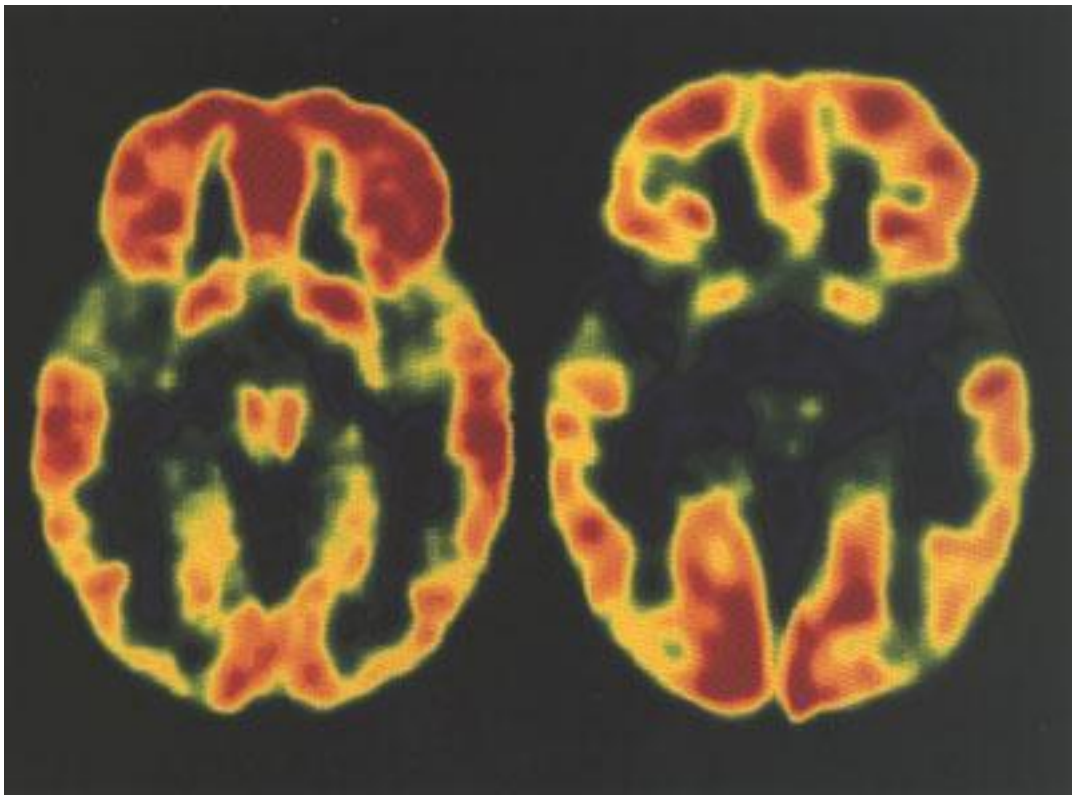

Figure 1, Brain activity of a normal 5-year-old child (left) and a 5-year-old institutionalized Romanian orphan who was neglected in infancy (right) (Source: Freund, L)

Despite the devastating effect of institutionalization on child development, however, UNICEF estimates that in the countries from Central and Eastern Europe and the Commonwealth of Independent States, 1.5 million children live in institutions. Of these children, at least 317,000 have disabilities (UNICEF, 2005). According to an estimate by Jonsson and Wiman, in Eastern Europe, 60% of all children placed in institutions are disabled (2001, p. 9). Although in many countries in the region there is a process of de-institutionalisation underway, there are

still many children living in institutions. According to recent statistics, in 2010 in Bulgaria there were 2046 children 0-3 institutionalized in DMSGD. Of these 994 were with a disability or chronically ill (State Agency for Child Protection, 2011a).

It is a positive fact that the de-institutionalisation plan in Bulgaria envisages the development of early intervention services for children 0-3 that will support families of young children and act as a preventative measure against institutionalisation. In other countries, ECI is also linked to preventing child abandonment. A study on Belarus revealed that NGO work has contributed to the prevention of abandonment of 11 % of children receiving services from an early childhood programme for 90 children with psychophysical disorders of mild or moderate degrees (Vargas-Baron & Janson 2009: 52-53). Similarly, in the Czech Republic, the Association of Early Intervention is promoting home-based ECI in the country as an "effective service…for the prevention of institutionalized care" (Association of Early Intervention, 2004).

2.3 Early Childhood Intervention and Child Rights / Legal Basis in International Law

Early Childhood Intervention, as a field of integrated services focusing on early childhood of children with developmental delays and disabilities, is recognized as a mechanism for addressing the requirements of key international disability rights acts. In particular, the UN Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) have direct implications on ECI services. It has been recognised that the CRC and the CRPD provide both the theoretical human rights for the provision of early intervention and the concrete reporting and monitoring mechanisms to ensure that governmental attention is directed towards compliance (Brown & Guralnick, 2012: 271).

The CRC requires that a child with a disability should "enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (Article 23(1)). It also states that "Early childhood is the period during which disabilities are usually identified and the impact on children's well-being and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realisation of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers)" (UN, 2005, paragraph 36 (d)).

The CRPD (UN, 2006) calls for the enjoyment of all human rights and fundamental freedoms by children and adults with disabilities. Article 19 emphasises the importance of alternatives to institutional care and the CRC's General Comment 9 "urges States parties to use the placement in institutions only as a measure of last resort, when it is absolutely necessary and in the best interest of the child." In addition, Article 23(3 & 4) of the CRPD urges States parties to provide "early and comprehensive information, services and support to both children with disabilities and their families… that such separation is necessary for the best interests of the child". At the same time, the importance of early intervention is addressed in Article 25, focussing on health, that requires the States parties to "provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services, designed to minimise and prevent further disabilities, including among children".

Thus, Early Childhood Intervention is a necessary component to ensuring the realization of these two international laws. Evidence from the literature suggests that one in three children who received ECI services no longer require special education in a preschool or disability classification (Jones, L. 2009). In addition, ECI has led to the successful inclusion of children within the formal school system (Hodes, 2007). According to the CRPD, all children have the right to education in mainstream schools. Unfortunately, without early services, children are less likely to realize this right and are more likely to require more specialized services. In fact, without ECI service provision in countries with regular practices of institutionalisation, like Bulgaria, the placement of young children in institutions at birth is quite likely. As a counter measure to institutionalisation, ECI works to ensure family preservation through supporting parent-child attachment and the promotion of parenting satisfaction.

2.4 Early Childhood Intervention Practices in Europe

2.4.1 Common Features of ECI in Europe

The European Model of ECI has developed several core principles for ECI (European Agency for Development in Special Needs Education, 2010):

Availability – as a priority to make quality ECI services universally available to all, regardless of location, social or ethnic background, or economic status etc.

Proximity – in relation to the availability aspect it is important that services are available as close as possible to families in a family-centred approach.

Affordability – services should be at minimal cost to the families and preferably free. Financing can be through public health funds, social or education authorities, or by NGOs.

Interdisciplinary working – as the range of situations covered by ECI is wide there is a strong need for greater interdisciplinary work by all those involved in the sector.
Diversity of services – ECI involves at least three services – health, social services, and education – the way these combine will vary across countries.

2.4.2 ECI in Central and Eastern Europe and the Commonwealth of Independent States

In Central and Eastern European (CEE) and Commonwealth of Independent States (CIS) countries there is a growing realization that children between the ages of 0 and 3 are not solely the responsibility of the parents and that there is a need for ECI to help support families more appropriately (Vargas-Baron & Janson, 2009). Recognition of and understanding of disabilities and what they entail is also improving, with an increase in identification of children with disabilities in the 27 CEE/CIS countries increasing from 500,000 to 1.5 million between the fall of the Soviet Union and 2005 (UNICEF, 2005). However UNICEF also estimates that there are over 1.5 million children in CEE/CIS countries that live in "institutions or other out-of-home care arrangement", over 20% of which have disabilities and lack access to basic ECD or pre-school services. Other estimates by Jonsson and Wiman place the proportion of children in institutions with disabilities at 60% (Jonsson & Wiman, 2001). The following are some examples of approaches taken in a variety of CEE/CIS countries.

Belarus

In Belarus there are around 7,000 children between the ages of 0 and 3 who have disabilities or developmental delays, a rate of around 6% of children (Vargas-Baron & Janson, 2009). Identification of infants who might benefit from ECI service provision is made possible by the universal health coverage in the country. However the problem of children without parents is significant with around 33,000 orphans or children without parental care, many of whom have disabilities. Currently ECI services are being expanded in conjunction with various other initiatives. For example the Positive Parenting Programme (PPP), developed by UNICEF, and the "Successful Childhood Development Centre", opened in 2007 in the Belarusian State University. There are also plans to start a post-graduate university programme in ECI.

The authors of the current report have been in correspondence with representatives of ECI service providers in the following three countries, therefore the information below is obtained

through personal contacts with Maguli Shaghashvili (for Georgia), Elena Kozhevnikova (for Russia), and Anna Kukuruza (for Ukraine).

Georgia

Currently Georgia is working to develop their ECI system and service delivery models. At this time, the Ministry of Health issues vouchers for ECI services. Eligibility for the vouchers is determined according to the income of the family and is related to the state poverty line. The voucher covers eight, one hour ECI sessions per month, the equivalent of 2 sessions per week. The cost of the voucher is 135 GEL (80 USD) which is not enough to cover all the associated costs, so there is a need for the family to co-pay. The state provides vouchers for children aged 0-7. In those cases in which parents need to pay, because they are above the poverty threshold, a sliding scale fee might be used incorporating financial and social status. Service providers are not yet licensed but this is expected in the future. There are, however, registration procedures and the Ministry of Health is responsible for registering providers. The parents are given the vouchers so they choose the provider that best meets their needs. Inspection is not in place but this is also being developed. At the time of writing some centre-based provision is available, as well as home-based practices. However, the legal framework for ECI has not been established yet.

Russia

The Early Intervention Institute (EII) in St. Petersburg with the help of colleagues in the United Kingdom, USA, Sweden, Norway and Finland helped the Institute move from a medical to a social model of ECI in the 1990s. Traditionally, parents felt ashamed of their children with disabilities and institutional care was common. The Institute sought to challenge the attitudes of professionals and parents. "According to defectological science, diagnostics have a scientific purpose, or at least the diagnosis is scientifically grounded. In reality, the diagnostic systems are crowded with negative values and prejudices regarding people with disabilities; they do not look for potential, only for the person's impairments. When it comes to children with disabilities, defectology's intention is always to reach the final point of the diagnosis – the differentiation between those children who are able to learn and those who are 'uneducable'" (Kozhevnikova, 1998). Even children with mild speech difficulties were sent to logopedic preschools for children with articulation problems.

EII introduced the social model and used interdisciplinary knowledge and approaches and in 2000 they were accepting 400 to 500 new families every year. Families could receive help at

polyclinical units and at the centre. Children could be referred from hospitals for children or by the family directly. The model they established included collaboration among physicians, special education teachers, psychologists, speech-language pathologists, physiologists of vision and hearing, and speech therapists. They worked to keep the child within the family and set up screening using the Kent Infant Development (KID) Scale (Reuter and Bickett, 1985, Reuter and Reuter, 1990) and the Child Development Inventory (Ireton, 1992). The scales are a type of screener/assessment hybrid that is completed by parents and is used to determine the overall developmental status of the child. It has 250 items which are entered into a computer and scored. They also check children for hearing and vision.

At one time many polyclinics had facilities connected to EII where children could receive assessment and centre-based services. Although the number of children policlinics has been reduced, currently some of the policlinics still exist, and early intervention units are opened in district social care centers for children with disabilities. The St Petersburg Department of Education is planning to open in 2014 'early support' units at city preschools. Now the EII serves a small number of families and children and conducts training for other NGOs and physicians and other professionals.

Ukraine

The development of ECI in Ukraine has been significantly influenced by the St. Petersburg model, referred to above. However, Ukrainian specialists also used American, Dutch, Hungarian and others experiences to create their own model. The Academy of Medical Science of Ukraine also contributed to this process by conducting research on different aspects of ECI in the past 10 years.

The essential feature of the Ukrainian model is a particular attention to partnership with parents and a big emphasis on parent-child relationships. Initially, ECI services were provided in centres, based on practices of NGOs. Currently, ECI services are provided in municipal policlinics. Referrals can be made by any specialist, or parents who have concerns about the development of their child can self-refer by visiting the policlinic. Recently home-based ECI programs were initiated. These are based on the belief that services should be provided in the natural environment of the child.

The services are provided by an ECI team. The team makes an assessment of the child's development and his/her needs (using scales such as KID and CDI) and creates an individual development plan, in close cooperation with parents, and focusing on the functional abilities of the child.

The strategic focus in Ukraine is on the development of regulations to implement ECI services at both municipal and national levels.

2.5 International Good Practices on Breastfeeding

There are a number international documents and programmes which highlight the importance of breastfeeding for the optimal growth, development and health of the child and set recommendations concerning breastfeeding practices. One of these programmes is the Baby Friendly Hospital Initiative (BFHI), launched in 1991 by UNICEF and the World Health Organization (WHO). This programme sets a number of criteria (10 steps) to ensure that all maternity services become centres of breastfeeding support[11]. At the European level, there is the *WHO European Action Plan for Food and Nutrition Policy 2007 – 2012* (WHO, 2008) which incorporate issues for protection, promotion and support of breastfeeding. In addition, there is a European Commission report *Protection, Promotion and Support of Breastfeeding in Europe: A Blueprint for Action* (European Commission, 2004), which acts as a recommendation for Governments and institutions which work for protection, promotion and support of breastfeeding in Europe. This report sets a framework for developing plans for breastfeeding support.

One of the areas in which breastfeeding support is internationally recognized as having a positive effect is children's health and development, especially for children with disabilities. Although there are many challenges in breastfeeding a child with certain types of disability, the positive effects of breastfeeding prevail over those challenges. For example, the benefits of breastfeeding for a child with a congenital heart defect (CHD), cleft defect, or hypotonia/Down syndrome (which are the most common birth defects) are enormous. Breastfeeding provides efficient nurturing, which influences the growth of the child and lowers the risk of developing otitis media, middle ear effusion, and respiratory infections (McCain, 2005). Furthermore, a recent trial has shown that 'early initiation of breastfeeding can reduce neonatal mortality by 22 % (Mallik et al. 2013: 25).

Another area positively impacted by breastfeeding is the relationships between mother and child. The importance and contribution of breastfeeding for early and healthy bonding between mother and infant is emphasised in many studies (Yngve, A & Sjostrom, M, 2001). Bonding at an early age is recognised as a foundation for the development of positive parental caring behaviours, and possibly as a prevention of abuse and neglect. In addition, as noted

[11] See appendix 6 for details (WHO/UNICEF, 2009).

earlier, bonding through breastfeeding can contribute to prevention of abandonment of children.

A study in St. Petersburg's maternity hospital compared the infant abandonment rates 6 years before and 6 years after implementing the 10 steps of the BFHI. The results showed that after applying the requirements of the BFHI, the infant abandonment rate dropped drastically from 50.3% per 10 000 births to 27.8 % per 10 000 births. The study had also reviewed data from other countries. In Thailand, for example, the implementation of the BFHI led to the decline of infant abandonment from 33 to 1 infant per 10 000 births. Similarly, in Costa Rica, as a result of BFHI, there was a decrease in infant abandonment from 9 to 1.5 infants per 10 000 births. Particularly beneficial has been the early contact with suckling and rooming-in. The conclusion from the study was that "…the first hours and days of life are a sensitive period for the mother when she is especially psychologically prepared to accept her infant as her own...and encouraging the early mother-infant contact with suckling and rooming-in may provide a simple, low-cost method for reducing infant abandonment" (Lvoff et al., 2000).

The above studies clearly show the links between breastfeeding, healthy child development, and child-parent bonding. Breastfeeding support, therefore, can be a valuable contribution to ECI practices and should be integrated in ECI services in Bulgaria.

3 Policies for Early Childhood Intervention Service and Breastfeeding Development in Bulgaria

3.1 Early Childhood Intervention and Policies for Children and Deinstitutionalization

Although there is evidence that ECI was first discussed in public forums in Bulgaria in the early 1990s, nothing was done at that time to introduce ECI services for children with disabilities and their families. Residential institutions were seen as places where a child could be fully looked after. People believed in the benefits of institutional care and did not suspect the ill-effects of placing a child in such care and the damages that this could cause on the child's development. Medical professionals were also contributing to maintaining this belief by providing "professional" advice to parents of children born with disabilities to place their child in an institution for children 0-3 because it would be difficult for them to look after such a child.

In 2003 the Bulgarian Government took a political decision to start lowering the number of institutionalised children in Bulgaria in accordance with the partnership agreement for EU accession between Bulgaria and the European Union (European Council, 2003). In 2008 a National Children's Strategy 2008-2018 was adopted (National Assembly, 2008). The strategy sets out measures and actions for improving children's welfare in Bulgaria. It sets out a number of key areas in which actions should be taken (e.g. family environment, living standards and social support, alternative services, health care, education, leisure and development of skills, and child participation). The document can be seen as a basis for taking actions at a national level in these areas. The document a) recommends the adoption of standards for early childhood development; b) requires the adoption of measures for the prevention of child abandonment; and c) recommends the development of appropriate community-based services.

Although the above-mentioned Strategy does not propose specific measures for children aged 0-3, it places a special emphasis on children with special needs and the early inclusion of such children in educational services. It is a positive development that the Strategy recommends the adoption of standards for early childhood development. Such standards can provide a practical support for both parents and professionals by ensuring quality child-care and services. In addition, such standards can be the foundations for achieving integrated services for children 0 to 3 as they will provide comprehensive information about early childhood development.

In 2010 the Bulgarian Government adopted a National Strategy, called 'Vision for deinstitutionalization of children in the Republic of Bulgaria', which sets out a plan for closing institutions for children and for the establishment of community-based services including for children with disabilities (Council of Ministers, 2010a). In accordance with the Action Plan of this strategy, regional and municipal strategies have been developed to facilitate the process of closing the institutions for children and the development of alternative services. Regional units for implementation and monitoring of the deinstitutionalization process have been set up within the Regional Governments' structures.

The closure of DMSGD[12] is guided by an additional document called 'Concept for Deinstitutionalization of Children 0-3' (Council of Ministers, 2010b), developed by the Ministry of Health, which is an integral part of the Action Plan. In agreement with this concept, 8 DMSGD will be closed by 2016 in a pilot phase. The closure of all DMSGD is expected to take 15 years. The pilot process is implemented through a project called "DIRECTION: family". The main funding for closing the DMSGD will come from the European Social Fund and the European Regional Development Fund with national co-funding. Since the financial framework of the project is tied to existing or predicted EU funding, it is not clear how the financial sustainability of the services will be maintained by the municipalities (the services will be decentralized for provision by municipalities) after EU funding ends. This is particularly risky because, based on evidence until 2012, the money saved from the closed DMSGDs is not re-invested back into developing services in the community for children 0-3 but is incorporated in the general State budget (National Network for Children, 2012).

The Bulgarian Government has been criticized by the Bulgarian NGO sector for being too slow in implementing measure for developing alternative services for children 0-3. For example, the **National Network for Children** – comprising more than 100 NGOs – issued a statement which argued that "the services for the prevention of abandonment of children 0-3 in the country are weakly developed…and the process of setting up services for supporting children with disabilities 0-3 is delayed" (National Network for Children, 2012).

[12] In 2009 there were 32 DMSGD (children 0-3 are placed in the institutions, called DMSGD) in Bulgaria. Although the data shows that there is a slight decrease in the number of children in DMSGD in 2010, compared to 2009, it cannot be argued that this is entirely due to deinstitutionalization measures, as in 2010 there is also a 7 % drop in the birth-rate in Bulgaria.

According to the Action Plan of the Vision for Deinstitutionalisation, ECI and breastfeeding are envisaged as part of the services to be developed as alternative services to the DMSGD institutional care aiming at supporting parents of new-born children with disabilities or children born underweight and the prevention of abandonment.

Early Childhood Intervention is envisaged as part of a package of services called 'services for support and prevention'. These will be delivered by a *Family Consultation Centre*. Early Childhood Intervention will include the provision of services and activities to support parents of newborn children with disabilities and low weight. *The Family Consultation Centre* will allow for short-term shelter for mothers and babies, and will provide psychological, social, health and rehabilitation services. Early Childhood Intervention will also be provided at the level of maternity wards in hospitals in order to prevent abandonment of babies. The services for children with disabilities will be provided by multidisciplinary teams.

In addition, another package of services will be established for children 0 to 3 and above – the *Mother and Child Health Center*. This package will offer 'early health intervention' for children with disabilities, consisting of medical rehabilitation, consultation and training of parents. Some of the services will be mobile services. The number of *Family Consultation Centers* and the number of *Mother and Child Health Centers* that will be set up in Bulgaria is 32, equal to the number of DMSGDs which will be closed.

The above services, which will be developed in place of DMSGD, certainly constitute a good basis for ECI for children 0-3 in Bulgaria. These are services which will incorporate the whole family and will thus offer more comprehensive support. There are some risks, however, that the new services may not apply new approaches to family support. For example, as the reform is being driven by the Ministry of Health, there is a risk that the 'medical model' will remain dominant, thus the services may focus on the deficits of the child, rather than on his or her strengths. Another risk is to implement the new services with the same personnel from the DMSGD. If the Government decides to employ the DMSGD personnel to deliver the new services, training will be needed to prepare them to offer comprehensive services according to internationally recognized best practice. It is unclear, however, what training will be provided to the personnel involved in developing or providing the new services. As there are no official guidelines or methodologies on ECI in Bulgaria, the personnel in the new services may be unprepared to deliver quality services. As early childhood intervention is not taught as a main subject by Bulgarian Universities, there is lack of specialists equipped with ECI knowledge and skills, and respectively with skills for training. The few organisations which

currently implement ECI services in Bulgaria have been trained by international trainers or by other Bulgaria NGOs, themselves trained by international trainers. If appropriate training is not provided, old practices may continue to operate in the new services.

Another key document for the development of ECI services is the draft of the new Child's Law (State Agency for Child Protection, 2011b). This law is still in the process of public debate, but is expected to bring a considerable improvement to the existing Child Protection Law and will assist with the implementation of the de-institutionalization process. The law specifically stipulates the provision of early intervention services for children with disabilities. It also legislates against abandonment of children and the placement of children 0-3 in specialized residential type institutions.

As a whole, the proposed measures in the Child's Law in the area of supporting children 0 to 3 appear reasonable and seem to guarantee reform in the child-care system in Bulgaria. However, before it can be enforced, the Law needs to be preceded by a good network of community services for children. Without such services being developed, the law is at risk of being difficult to implement. It is particularly encouraging that for the first time early childhood intervention is legislated as a service which can support children 0-3.

Since 2008, in parallel to the de-institutionalisation measures, the Bulgarian Government is implementing the so-called 'Social Inclusion Project'[13], the concept of which was developed before Bulgaria joined the EU in 2007, and also contains measures for developing ECI in Bulgarian municipalities. The project's primary aim is the prevention of social exclusion and the reduction of poverty among children through investment in early childhood development. This project will allow for Community Centres to be built in more than 69 Municipalities in Bulgaria.[14] The Community Centres will have two categories of service – services for children age 0-3 and services for children aged 3-7. The services for children 0-3 include: a) early intervention centers for children with disabilities (in 44 Municipalities); b) developing parental skills; c) family consultations and support; d) health consultations; e) day care for children; f) costs for attending a nursery. The early interventions services have an option for being mobile.

The Social Inclusion Project is a considerable step in the direction of developing family-centred services for children and supporting the inclusion of disadvantaged children in

[13] http://www.worldbank.org/projects/P100657/social-inclusion-project?lang=en

[14] This figure is subject to change because the Social Inclusion project has recently entered into a second phase, where more Municipalities may be funded.

mainstream education. It is especially encouraging that the Project is piloting early intervention services for children with disabilities 0-3. The main risk for the development of the ECI services by the municipalities under the project is related to the fact that these services are not methodologically specified in the project. It is not clear what approaches will be adopted by different Municipalities, what staff will be employed, how the services will be financially managed, and what impact is expected. As funding for the Project is secured only for establishing the infrastructure and piloting the new services for one year, there is a risk similar to the risks for the project for closure of DMSGD that the majority of Municipalities in Bulgaria will not be able to sustain the new services, unless there is additional Government or EU funding.

The strategic policy and legislation documents described above make it clear that there are efforts on behalf of the Bulgarian Governments to introduce early childhood intervention services and other measures which support early childhood development and children with disabilities, aged 0-3. Early Childhood Intervention Services, however, remain vaguely defined in these documents. This makes it difficult for service providers to develop such services and effectively contribute to deinstitutionalization measures. In addition, the development of ECI in Bulgaria is currently dependent on EU and World Bank funding, which poses a risk for their sustainability in the future. The fact that two years after the beginning of the process of de-institutionalisation in Bulgaria, early childhood intervention services for children with disabilities, which have been planned by the Government, are still not launched is problematic. This makes the efforts for prevention of abandonment of children with disabilities in Bulgaria even more difficult.

3.2 Policies on Breastfeeding

The topic of promoting breastfeeding was introduced in Bulgaria in 1996 by UNICEF and the World Health Organization through the Baby Friendly Hospital Initiative. Since then several steps were taken to improve breastfeeding practices in Bulgaria. In 1998 a pilot model of a baby-friendly hospital was introduced in Vratsa, a town of 60,000 inhabitants in the North-West of Bulgaria, by UNICEF. Later, in 2005, the Bulgarian Government adopted a National Action Plan Food and Nutrition 2005-2010[15] (Council of Ministers, 2005), which was the main policy instrument that addressed breastfeeding support in Bulgaria. To support the

[15] The National Action Plan Food and Nutrition 2011-2016 has also been developed by the Bulgarian Government, but has not been introduced for implementation due to lack of resources.

implementation of this Action plan, a National Breastfeeding Committee was established as a structure of the Ministry of Health in 2006. Its responsibilities were to a) implement the policy for protection, promotion and support of breastfeeding that is incorporated in the "Food and Nutrition" plan; b) to enlarge the network of baby-friendly hospitals in Bulgaria; and c) to provide training to medical personnel. The Committee, however, is in a rather weak position to implement effectively the policy on breastfeeding because it has no funds or resources to implement any activities.

One of the main problems outlined in the National Action Plan Food and Nutrition is "the low prevalence of exclusive breastfeeding, short duration of breastfeeding and improper feeding of babies" (Council of Ministers, 2005). According to this Plan, mothers breastfeed for very short periods of time. One of the reasons for this is the lack of social, emotional and educational support from family, society, health organizations or health workers. The analysis in the Plan reveals that "the current practice in most of the maternity, neonatology and children's wards, as well as the organization of the work there, do not establish conditions for the early start of breastfeeding and its successful process." The main aim of the Plan was to increase the number of babies exclusively breastfed up to the age of 6 months by 20%. It also aims to increase the number of babies who are breastfed up to the age of 1 year by 15% (Council of Ministers, 2005)[16]. The National Action Plan Food and Nutrition has not become operational because funding was not secured for it.

Research evidence shows that breastfeeding can build a strong emotional attachment and bonding between the mother and her child. Supportive breastfeeding practices are recognized as having a preventative role in the abandonment of children and influencing the health of premature babies. Unfortunately, the ratio of breastfed babies in Bulgaria is low – only 4.6% of infants are breastfed in the first hour after birth; 13.3% of the infants aged 0-1 months are exclusively breastfed (National Centre for Public Health Protection, 2009). In Bulgaria, breastfeeding support is considered as part of the duties of midwives, although midwives often do not have appropriate training to provide such support.

Breastfeeding support and promotion are also part of the activities in the Action Plan for the Vision for de-institutionalisation. Breastfeeding there is seen as a way of "development and introduction of a modern approach to healthcare". The Plan requires a renewed accreditation for hospitals which will guarantee rooming-in of mother and child, appointment of a social

[16] See section 4.4 for a correlation with rates of breastfeeding in Bulgaria.

worker in the maternity wards, and training of medical personnel for encouraging breastfeeding. Due to the voluntary character of this accreditation, however, the proposed measures remain unfulfilled. As countermeasure, the Ministry of Health has obliged hospitals to introduce "Rules for the organization of activities for the prevention of abandonment of children". These rules are in accordance with the *Methodological guide for prevention of abandonment of children at the level of maternity wards,* ratified by the Ministry of health (State Agency for Child Protection, 2010).

This methodological guide emphasizes as a main task for medical personnel to promote breastfeeding and to ensure that psychological support is provided to the mother and the baby. The medical personnel have to support the mother to initiate breastfeeding, pointing out the benefits of breastfeeding. Psychological support should be provided at the level of maternity wards. Although this guide provides a link between the risk of abandonment of children and the need for support for breastfeeding and psychological support, evidence shows that these measures are usually not fulfilled at the level of the maternity hospitals.[17]

The National Programme for guaranteeing the rights of children with disabilities 2010-2013 proposes measures specifically for supporting parents when a child with a disability is born. The Programme proposes the introduction of "standard procedures" in all neonatology wards that inform parents about the diagnosis of their child. Parents should also be informed about the opportunities for early counselling and support. A special team should be built for that purpose, consisting of a paediatrician, psychologist, and social worker. These procedures, however, are also not functional because there are no measures to regulate the implementation of the programme.

3.3 Existing Services for Children with Disabilities 0-3 in Bulgaria

The Law for integration of people with disabilities states the right for medical and social rehabilitation for people with disabilities in Bulgaria. The existing services for children with disabilities 0 to 3 in Bulgaria can be categorized into two types according to the institutions which regulate their provision – social services and medical rehabilitation services.

The social services are regulated by the Bulgarian Law for social support and the Regulation

[17] The conclusion is made on the basis of shared practice experience of volunteer breastfeeding consultants and NGOs working in the social area of prevention abandonment at the level of the maternity wards (Focus group Varna and Sofia).

for Implementing the Law for Social Support (Council of Ministers, 1998)[18]. These services could be provided either by municipal structures or other providers including NGOs. Financing for these services is provided by the National Government to Municipalities which can, at their discretion, delegate these services to other providers. According to local needs and opportunities, municipal authorities can also set up additional services and provide funding for them from municipal budgets. In most cases, public funds are not sufficient to finance these services and cover the needs of all children with disabilities across the country. Thus, although all of the above services should be available, when funding is limited, some services rarely prioritize children 0-3 as their target groups, with the exception of the Mother and Baby Unit Service which supports pregnant women and mothers with new-born babies in crisis situations.

There are two types of services – services in the community and services provided by specialized institutions. The specialised institutions provide residential-type services, while the community services can be provided in the home or in various types of non-residential centres. The following community based services can directly support child development and family capacity:

a) Personal assistant – a service for a disabled person who needs constant care. The service is provided as a support mechanism for the family;
b) Social assistant – a service to help meet the daily needs and organize the free time of people with disabilities and to implement activities for their social inclusion;
c) Center for Social Rehabilitation and Integration – provides a package of social services which include: rehabilitation, social and legal consultations, educational and professional training and counselling, and implementation of individual programmes for social inclusion;
d) Mother and Baby Unit – shelter and support are provided for single mothers and pregnant women. This is a package of services, aimed at the prevention of abandonment, involving the extended family;
e) Center for community support – provides a package of social services for children and families at risk. These include family consultation, family planning, prevention of school dropouts, supporting victims of violence, and individual work with children with disabilities.

[18] The Regulation for Implementing the Law on Social Support was passed by the council of ministers on 5.11.1998 and published in the State Gazette on 11.11.1998. It has been amended several times since.

In addition to social services, children with disabilities 0 to 3 have access to medical rehabilitation services, which are also meant to support their development. These services are under the Law for Medical Establishments and the Health Insurance Act and should be available to all people with disabilities. The services include physical therapy, occupational therapy, kinesitherapy, speech and visual therapy, psychotherapy, supportive medicine therapy, provision of supportive aids and other medical supplies.

These services could be provided by medical centers, specialized institutions (DMSGD), or private providers, specializing in such kind of medical support. They are paid for by the National Health Insurance Fund or the Ministry of Health but there is a lack of priority policies for those services and there is a lack of funding for these services, meaning parents often have to pay for the services privately.

DMSGD provides specialized support for children with disabilities through a Day Centre service. The services include diagnostics, treatment, rehabilitation, psychotherapy, speech therapy, and educational and social support. The beneficiaries are children with disabilities from the community.

The social and medical rehabilitation services together provide a good basis for supporting children with disabilities and their families. These are community-based services, and target the needs of either a child with disability or the whole family. However, children 0 to 3 are often referred to medical rehabilitation services which mainly focus on the physical health of the child, do not focus on the other developmental areas of the child, and pay less attention to the child-parent interaction.

There are only 3 types of services which provide real opportunities for involving both the child and the family and thus follow a comprehensive approach to meeting the needs of the whole family. These are the Center for Social Rehabilitation and Integration, the Center for community support, and the Day Centre, operated by DMSGD. Although all social services are available for children with disabilities 0 to 3, in practice many of them are not developed by service providers to support early childhood needs, or only support children and families in crisis situations. In reality, this deprives the 0 to 3 children with disabilities and their families from receiving appropriate services. In many places in Bulgaria, there are no services for children with disabilities at all. Similarly, qualified personnel for working with children with disabilities 0-3 are also lacking in many municipalities in Bulgaria.

Often as soon as a child with a disability is born in maternity hospitals, medical personnel still direct the attention of parents to the disability and the deficits their child will have in later life. This is the first precondition for many parents to want to abandon their children to institutional care. In addition, the fact that children 0-3 are primarily referred to medical rehabilitation services where the focus of intervention is also on the disability of the child, the risk of child abandonment on the grounds of disability is heightened. This clearly highlights the need for services which support the whole family by developing their capacity to address the needs of their children, rather than abandon them. Early Childhood Intervention Services build on existing social and medical services in Bulgaria, but provide a sharper focus on the strengths of the child and on child-parent interaction.

4. Existing Early Childhood Intervention Practices in Bulgaria – Challenges and Current Development

4.1 Early Childhood Intervention – Confusion between the Name and Expectations

All the plans for developing ECI services presented in the policy documents are in a stage of development and initial pilot implementation by the government in 2013. The existing practice of ECI services targeting young children with disabilities (0-3) in Bulgaria were developed by NGO organizations following models provided mainly by international organization along with further replication in Bulgaria.

In recent years, the civil society sector in Bulgaria has started developing various programmes targeting young children, called Early Childhood Intervention or just Early Intervention. These are based on the growing need for effective, supportive services for children with disabilities in the community, and in response to the unresolved problem of child abandonment in the country. These programs are trying to influence and advocate for the development of community based services targeting young children and families by the Bulgarian Government under the deinstitutionalisation process.

The focus groups and individual interviews carried out by Karin Dom and the Open Society Foundation among NGO representatives, experts, municipal representatives and stakeholders active in children policies development and implementation in Bulgaria showed that often the term 'early intervention' was interchangeably used with terms, such as 'early diagnosis', 'early prevention', and 'early childhood development'. This meant that the participants associated early childhood intervention with a wide range of issues and needs – from screening of pregnancies to universal support service for all children (focus group 1, Varna and focus group 1, Sofia). The term 'early childhood intervention' was not used as such. This suggests that there is a need for stakeholders to make explicit the association of 'early intervention' with a service targeting children in early years.

As can be seen from the quotation below, a representative of municipal administration closely associates ECI with medical diagnosis and preventative measures:

> *"…Early intervention is a reformative and innovative approach for children with disabilities. In fact, early diagnosis is key for prevention. We need to implement measures which effectively diagnose children, so that parents know what to do. Just like*

> *there are modern technologies in medical care of early diagnoses for adults, so we need to have early diagnoses for children, even pre-natal diagnoses…"* (Representative of municipal administration, interview, Varna)

At the other end of the spectrum, ECI was seen as part of a wider social and material support that can be provided to families of children with disabilities. The quotation below suggests, for example, that housing, material and financial support should be inseparable from ECI services. Children and families at risk were seen as the main beneficiaries of ECI services:

> *"…Parents should be supported in different ways. Material support is also very important. Housing, for example, is a problem for many families at risk. Clothes and financial support is also needed by families, because usually it is poor families which abandon their children, especially Roma families. Early Intervention should be part of a more complex support for families…"* (Representative of municipal administration, interview, Varna)

In line with the research questions of the project, the respondents were asked specifically to comment on how they saw the development and delivery of ECI in Bulgaria. One NGO respondent had a concrete suggestion of how ECI should be operated:

> *"…Early Intervention should consist of different implementing units. There will be a unit for early diagnosis or screening, a unit for therapy for children with diagnosed conditions, and a unit for children without diagnosed conditions, but when parents are still concerned. The team at the first unit should assess the needs of the child and refer it to appropriate services at the other units. The team can also refer the child to services outside the centre, depending what services are available in the community – for example a day care centre..."* (NGO representative, Sofia)

The above quotation describes a 'model' for ECI service structure and delivery. It clearly suggests that ECI is a centre-based service, consisting of several units. While links with other services outside the centre were suggested, it is not clear if ECI will include services delivered in a home setting or another 'natural environment' for the child. In fact, the dominant perception of ECI among the respondents was for a centre-based service. Home-based or 'mobile' services were always seen as complementary services to centre-based services.

4.2 Early Childhood Intervention Service in Varna

Varna has a population of 424, 893 people. In 2011 there were 4273 births (National Statistical Institute, 2011 census). In the same year there were 74 children placed in DMSGD Varna, 25 of which were children with disabilities or illnesses. Of these children, 46 were placed in DMSGD directly from the maternity hospitals. There is no official statistics about the number of children with disabilities in Varna. The only existing information is based on the number of families who have received benefits for having a child with disability. In 2011 there were 896 such cases (Child Protection Department, 2012)[19].

In addition to services funded through state-delegated budgets, the Municipality in Varna is also providing funding for social services, based on local needs. These include 'social patronage' (delivering meals to the homes of elderly people) and pensioners' clubs. The municipality is also co-funding various services, such as centres for community support, family-type residence centres, and a Mother and Baby unit.

However, there are only two providers of services for children aged 0-3 with disabilities – DMSGD Varna and the Karin Dom Foundation. In addition to caring for abandoned children, one of the services in the DMSGD is a Day Center service provided to children and families from the community. Karin Dom Foundation, on the other hand, is a charitable foundation, running a Centre for Rehabilitation and Social Integration of children with disabilities.

Karin Dom's early childhood intervention programme is offered on a voluntary basis for the families and is free of charge. The programme allows easy access of parents and children. Enrolment is preceded by an assessment of the needs of the family and a screening of the child. It is flexible and adapts to the needs of the families. The service is financed through the project "Early intervention for prevention abandonment of children with disabilities", with funding from the Open Society Foundation, Early Childhood Program-London for the period Sept 2010 – August 2013. The total amount of the project is USD 299,624. This includes

[19] The statistics are for the period January-November 2011, and refer to the age group 0-18.

financing of training, development of the early intervention services, promotion activities, implementation of the services and their monitoring and evaluation. In the period April 2011 – March 2012, additional funding of USD 41,594 was provided by the Open Society Foundation, Mental Health Institute - Budapest for the development of the service parent-toddler play-group.

The origins of ECI in the Karin Dom Foundation date back to 1996 when it was founded to support children with disabilities and their families through providing therapy and counselling. At that time ECI in Karin Dom was primarily a centre-based service. Home visits were occasionally also practiced. In 2009 Karin Dom officially launched its ***Early Intervention Programme for children aged 0-4***, in partnership with the Municipality of Varna, the local Child Protection Department, the maternity wards in two hospitals Varna (MBAL "St.Anna" and SBAGAL "Prof. Dr D. Stamatov"), and Association Colourful Future. The Programme provides services to children, who are either with disability, delay in one or more of the developmental areas or are at risk of developmental delay (e.g. when a child is born prematurely).

The Programme applies a family-centred approach and includes the following services – home visits, parent-toddler play groups, family-support network and breastfeeding support. The multidisciplinary team of the Programme consists of a physiotherapist, a psychologist, a speech therapist and a social worker. The team is led by a paediatrician. Training to the team was provided at the Karin Dom Foundation by ECI specialists from Canada, the USA, and Russia. Members of the team also went on study visits to ECI service providers in Belgium, the USA and Ireland.

The core service of the programme is the **home visit**. The home is seen as the natural environment of the child. During the 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 home visits, the specialist gives practical demonstrations to the parents on how to teach their child various skills through play or routine activities such as dressing, eating, having a bath, etc. The specialist considers the family's needs and beliefs and builds on their strengths, knowledge and skills. In addition to home visits, the specialists can also make visits to other natural environments, such as nurseries, kindergartens, playgrounds, etc.

The second service is the **parent-toddler play group**. The play group 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 and teach children new skills and habits (cognitive, motor, speech, social). The play group sessions take place at an appointed hour in a specially equipped play group room in Karin Dom's building, with age-appropriate toys. The play groups 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 Karin Dom's programme is the **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 service provides information and psychological or material support. 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. This group is called the 'parent-on-call' group. Other components of the Network are a resource library (containing toys, special aids and books), and formal and informal parent support group meetings.

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 new-born children in maternity hospitals, especially to women who are at risk of abandoning their children. Breastfeeding consultants are permanently based in the two maternity hospitals and assist the work of midwives. The service also includes regular group-meetings of pregnant women and parents of infants. The meetings are facilitated by a breastfeeding consultant and provide an opportunity for the participants to share knowledge and skills about effective breastfeeding practices and challenges in the breastfeeding process. Breastfeeding is seen as a supportive mechanism for the prevention of abandonment of children. Through supporting the bonding process between mother and baby, the breastfeeding consultants significantly reduce the risk of the baby being abandoned. They also play a mediatory role between the personnel at the maternity hospitals and the home-visit service.

Karin Dom's Early Intervention Programme is undergoing an on-going external evaluation. The evaluation is in essence an impact study, guided methodologically by the Realist Evaluation (Pawson and Tilley, 1997). One of the key instruments of the evaluation is gathering user satisfaction data and data from service providers (multidisciplinary team) and partner organisations, involved in the implementation of the programme. Data is gathered through semi-structured interviews and questionnaires, designed to reflect all services of Karin Dom's programme. There are three main areas on which feedback from parents has

been crucial for evaluation of the programme and planning its development: child development, available services, and programme impact.

One of the ways of evaluating the impact of the programme is through parent's self-assessment of progress achieved with their child and satisfaction of the services. Parents saw progress in a) the physical development of their children, b) the development of communication skills, and c) cognitive and social-emotional areas of development. Parents also thought that progress with their child was made because they were actively involved in all activities undertaken to improve the development of their children. Through being involved in the Programme parents established a better understanding of their child's needs and became better equipped to respond to those needs. They became more confident that they could cope with the challenges of raising their child. Home visits were particularly valued by parents because they could interact with ECI specialists in a natural environment and observe how the specialist engages the child in everyday activities, such as play. Providing advice to parents on how to interact with their child was also seen as beneficial.

Below are abstracts from interviews with parents involved in Karin Dom's ECI Programme, illustrating parents' perceptions of how the programme works for them:[20]

"…We did not understand him at the beginning [name of child]. When he was little, he had epilepsy and he was behind his peers. When he was two, he started walking, but with difficulty. We found out about Karin Dom's service [early intervention] from the social services (Child Protection Department). He has made a huge improvement now. He communicates, walks up the stairs alone, and plays with the toys. Now he is calmer, watches TV, we understand each other…" [Mother of a 3-year old boy]

"I am happy that the consultants visit my home during the week. They show different plays, bring toys and puzzles along, and observe how children are reacting. They help me with my own behaviour with the children. I like it that they provide advice on what I should do, so they are really useful to me. I think it is productive when I do what they advise. The result is that [name of a child] made progress with his speech – he already puts words together. They helped me with my other child, too. She had trouble sleeping, but now this is changed – she sleeps calmly." [Mother of a 2 and a half year old boy and a 4-year old girl]

[20] See also appendix 8 for two cases from the Early Intervention Programme – one presented by an early intervention team member and the other by a parent of child enrolled in the programme.

The evaluation of the programme also took into consideration how members of the partner organisations saw the purpose and progress of the programme. The partners believed that the programme was beneficial in three major ways – complementing other services and health care activities for young children, building capacity in parents, and contributing to the prevention of abandonment of children. Below are abstracts of interviews from programme partners:

> *"…Karin Dom's Early Intervention Service is a good addition to what we do. When a child is born underweight, we do everything we can to stabilize the child in the neonatal ward. After that, the Early Intervention team takes over. They have rehabilitators, speech therapists, psychologists. This is very helpful for the family because they feel supported, they can receive information and advice…"* [Representative of a maternity ward, Varna]

> *"….As partners to Karin Dom, we fully support the Early Intervention Programme. It is a big step forward, although there is much more that we can do together to support families at risk. Placing babies in institution should be a last resort. Families should be supported to keep their babies. A programme like this shows that babies should not necessarily go to an institution – there is another way…."* [Representative of the Child Protection Department, Varna].

> *"…We had a child which was previously receiving a service from another agency, in a centre for community support. There they only provided therapy to the child without involving the parents. As a result, when the child stopped attending the services, it had a regress in its development. With Early Intervention it is different – the family is also supported and parents can work with their child at any time…"* [Representative of the Child Protection Department, Varna]

In the maternity hospitals breastfeeding support was instrumental for mothers to develop closer attachments with their babies. The provided support led to improvement in breastfeeding practices in the hospitals – starting breastfeeding earlier, encouraging mothers to express breastfed-milk for premature babies, providing adequate information to mothers

about breastfeeding process. This is how a volunteer breastfeeding consultant presents the achievements of her work in maternity wards:

"….The breastfeeding consultations make parents feel more comfortable. They are more confident when they know that there is someone who could help – they feel secure. Mothers want to give the best for their child as they know that breastfeeding is the natural way of stimulating the physical and psychological development of the child. Many doctors in hospitals think mothers will abandon their children but when mothers breastfeed, it rarely happens… " [Volunteer breastfeeding consultant]

The tables below shows the number of children and families served for the period 2011-2012, and the ratio of children according to age group at the time of entering the programme.

Beneficiaries of Early Intervention Programme – Karin Dom	Number
Children enrolled in the 'home visits' service	184
Children enrolled in the parent-toddler play groups	64
Families in the Family support Network services	110
Mothers receiving breastfeeding support	4160

Table 3,Number of children and families supported by Karin Dom's Early Intervention Programme, 2011-2012.

Age of the children at the time of enrolling in the Early Intervention Programme – Karin Dom	Percentage
0 to 1	34%
1 to 2	19%
2 to 3	31%
3 to 4	16%

Table 4, Ratio of children according to age group at the time of entering Karin Dom's Early Intervention Programme, 2011-2012.

4.3. Existing ECI Services Managed by Non-governmental Organizations

The questionnaire survey of NGOs providing services for children 0-3 identified 13 organizations in Bulgaria involved in delivering of ECI services.[21] The organizations covered by the survey are based in 11 cities situated in 9 of the 28 regions: Varna, Burgas, Aitos,

[21] 14 organisations were contacted for the questionnaire survey, with responses from 13.

Dobrich, Targovishte, Ruse, Pleven, Stara Zagora, Plovdiv, Bjala Slatina, Vidin.[22] Below is a map of the location of these cities and the number of children who received ECI services for the period, in which the respective organization has been providing such services.

Map 1, Locations where ECI services have been developed with the number of children served.

The data reveals that the majority of the organizations providing ECI are social service providers – Centres for social rehabilitation and integration and community support centres. There is one Day Centre at a DMSGD with medical focused services and one organization of parents of children with disabilities. ECI seems to be most easily integrated in the structure of community organizations, where there are trained personnel and access to state funding or sustainable project funding.

The services in Vidin, Burgas and Varna have the highest number of children served. In the case of Burgas this is due to the fact that in the Day Center at the DMSGD has more personnel involved from different disciplinary backgrounds and larger financial opportunities due to the direct state subsidy and the additional funds through projects and donations. In the case of Vidin the services were provided with European funding and after that a state-delegated budget was secured for the municipalities. In the case of Varna, the services were funded by a private donor (see case study of Karin Dom – 4.2).

[22] In Ruse, Dobrich and Stara Zagora there were two service providers in each city included in the survey.

The ECI services of the surveyed organizations have been initiated in roughly the same time period – 2010 - 2011. This is the period when the deinstitutionalization process began, which meant that most of the services initiated in this period were focussed on prevention of abandonment of children and providing support in the community, in line with the National Strategy 'Vision for deinstitutionalization of children in the Republic of Bulgaria'.

The age span of the target group varied between 0 to 7 years. Most of the organizations reported that the main target group of their services is children above 3 years of age. With the development of ECI services and partnerships with maternity hospitals, however, they had gradually started to introduce services to infants and toddlers. This suggests that there is a growing understanding that ECI should be supporting children 0-3, in alignment with international practice.

The table below summarizes the data provided by these organizations - financing the ECI services, the capacity of the services (e.g. number of children served), the structure of the service provider, and the service-delivery environments (e.g. home or centre-based).

Location	Type of service provider	Period	Type	Target group according to age and risk-factor	No. of children served	Funding source	Estimated service cost per child per year in BGN
Varna	Centre for social rehabilitation and integration		Home & Centre Based	Children with developmental delays and special needs 0-4	185	Projects – private donors	1704
Bjala Slatina	Community support centre	03/2011 – 02/2012	Home-based	Children with special needs 0-7	5	Projects – private donors, EU funding	2160
Aitos	Community support centre	06/2011 – present	Home & Centre Based	Children with special needs 0-5	4	Projects – private donors, volunteers	1167
Targovishte	Community support centre	2011 - 2012	Home-based	Socially disadvantage children 0-5	7	Projects - private donors, volunteers	Not available
Pleven	Centre for social rehabilitation and integration	06/2011 – 10/2012	Home & Centre Based	Children 0-7	17	Projects – private donors, donations	703
Ruse (a)	Day centre for children with physical and mental impairments	06/2011 – 02/2012	Home-based	Children with developmental delays 4-5	3	Projects – private donors	3500
Ruse (b)	Community support centre	2010 - present	Home & Centre Based	Premature babies, children 0-6 with physical / mental impairments	15	State-delegated service, Projects – private donors	Not available
Dobrich (a)	Community support centre	06/2011 – present	Home & Centre Based	Children with special needs and developmental delays, 3-6	31	Projects – private donors, donations	2400
Dobrich (b)	Parents organization	2010 - 2011	Home-based	Children with disabilities, 3-6	10	Projects – private donors	Not available
Stara Zagora (a)	Community support centre	2010 – present	Home & Centre Based	Premature babies, children with disabilities, 0-7	45	State-delegated service, Projects – EU funding	1620
Stara Zagora (b)	Centre for social rehabilitation and integration	2011 – present	Home & Centre Based	Children with developmental delays, 0-6	23	State-delegated service, Projects – private donors	2500
Plovdiv	Community support centre	2011 – present	Home & Centre Based	Children with developmental delays, special needs 0-5	14	State-delegated service, Projects – private donors	Not available
Burgas	Day centre at DMSGD	03/2010 – present	centre-based	Premature babies, children with developmental delays, 0-7	338	Projects – private donors, donations, DMSGD-budget	
Vidin	Centre for social rehabilitation and integration	06/2011 – present	Home & Centre Based	Children, 0-5	112	State-delegated service, projects – EU funding	4200

Table 5, Details of ECI service providers in Bulgaria

Five of the surveyed organizations reported that they had secured sustainability of their services by including the ECI activities in the budgets of the state-delegated services they are running or through direct State financing. The other 3 service providers secured sustainability of their services through other projects or volunteers. Four of the organisations had ceased to provide early intervention services because their financial resources were exhausted. The required funding needs estimated by the organizations for running ECI in the future ranged from 700 to 4500 BGN per child per year. The large variation is due to the fact that the organizations used different methods of calculating service costs. Some used as a baseline the existing state-delegated services, while others calculated on the basis of project costs. As there is no standard for calculating ECI service costs in Bulgaria, each service provider included different types of costs in their budgets. For example, costs for public and or private transport, part-time or full-time staff, administrative staff, and costs for diagnostic or theraputic services. With the exception of the Day Center at the DMSGD, all the surveyed organizations offered home-based ECI-services. The organizations reported in the survey that the home visiting service was well received by different communities, especially in remote areas and among socially disadvantaged groups who did not have access to other services or trained specialists. The surveyed organizations believed that the family-centered approach was beneficial to parents and children with disabilities because it allowed a wider spectrum of needs to be addressed. The family-centred approach was also seen as a way of involving the whole family.

Some of the survey respondents expressed apprehension that the costs of their ECI services are higher than the standards for State delegated service because of higher transport costs, intensive mobile work and the need to include more specialists. Such apprehensions can be overcome, however, by introducing a methodology by the Government and integrating the service in the health, education and social system through collaboration and through combining resources. One of the surveyed organisations provided a case example of such a joint initiative. It was about a boy with cerebral palsy whose family could gain a better understanding of his needs through the early childhood intervention services and gain skills and knowledge on how to develop his cognitive and communication abilities:

> *"The family was consulted and supported to use the available benefits of the social system. Because of lack of rehabilitation services at their local community, the family was referred*

> *through the health system to use a package of rehabilitation services for 10 days in the nearest centre providing such medical services. In order to benefit from this package, the early intervention service provider covered the transport costs of the mother to the centre. The short-term plan for this child included integration in a kindergarten whereby the role of the early interventionist is to consult the teachers and collaborate with the so-called resource teacher and social assistant in order to achieve a better inclusion of the child in an adapted environment".* (Extract from survey respondent)

This case represents the flexibility needed for the early intervention services in order to respond to the specific needs of the families and through integration and coordination by combining social, educational and medical resources. The case reveals the need for applying a family-centred approach where the family is at the centre and the early intervention service provider delivers consultation, therapy, psychological support and builds the connections of the family with other community resources.

The main identified needs and areas of focus of the ECI services were identified by the respondents as follow:

- *"The early intervention services should have an easy accessible entrance and to have the opportunity to be referred not only by the Child protection Department but also by other institutions as medical professionals, nurseries and the parents themselves";*
- *"The early intervention teams have to have the opportunity to provide support at the maternity hospital to parents of children born with disabilities, premature or at-risk in order to be more effective in the prevention of abandonment of children";*
- *"The work with the child should be planned together with their family and all the family and community resources should be considered";*
- *"All the activities with the child should happen in their natural environment as much as possible";*
- *"Mediators can be used for work with families from marginalized communities";*

- *"There should be an inter-sectoral collaboration in the community with representatives of the social, educational and medical sectors."*

- *"Funding for early intervention should be provided by the Government as a state-delegated service".*

4.4 Breastfeeding Support Practices in the Context of ECI in Bulgaria - Development and Challenges

Although the de-institutionalization process is in force in Bulgaria, the percentage of abandoned babies directly from the maternity wards is still high. Of the 2000 children who annually enter DMSGD, about half of them come directly from the maternity hospitals (State Agency for Child Protection, 2011a). This fact shows that entry to DMSGD from maternity hospitals is common practice and that preventative measures are needed at the level of the maternity wards.

According to the Child Protection Law, the parents of a new-born child with a disability are supported by social workers from the Child Protection Department, who are required to consult them within 24 hours of receiving a signal from the maternity hospital. As the social worker is not part of the hospital's team, in most of the cases, the support is provided relatively late. The parents are often negatively influenced by the "medical" information about the child's condition provided by medical personnel and the existing societal stigma and attitudes around having a child with a disability in Bulgarian. . As a result, the mother is separated from her baby during her stay in the maternity ward, which is seen by the medical personnel as normal, and is even sometimes recommended.

Maternity hospitals do not usually employ psychologists or other support staff whose services could be accessed by pregnant women or parents of newborn babies. It is not the current practice in Bulgaria for the mother to be accompanied by a family member during the delivery of the child. In these difficult moments for the mother and the whole family of a new-born child with a disability or at-risk of developmental delay, the provision of efficient support and conditions for establishing attachment between the child and the parents is especially needed.

Thenational strategy, Food and Nutrition, launched in 2005, includes measures for improving the breastfeeding practices in Bulgaria. The Action Plan for De-institutionalization also recommends that breastfeeding should be encouraged in maternity hospitals. However, there are still no nationwide changes in maternity hospitals which could lead to increasing the percentage of breastfed babies in Bulgaria. There is a need for efficient collaboration in

maternity hospitals between the medical personnel, who are concerned with health issues, and the social worker and psychologist, who are concerned with the entire well-being of the child and the family.

In spite of WHO and UNICEF's recommendations to encourage breastfeeding, only 4.6% of infants in Bulgaria are breastfed in the first hour after birth. A national survey, published in 2009, showed that 13.3% of the infants aged 0-1 months and 2% of those aged 4-5 months were exclusively breastfed (National Centre for Public Health Protection, 2009). Among children aged 1 to 5 years, 19% were breastfed up to one month, 15% – up to 2 months and 10% – up to 6 months. Only 26% of infants were breastfed for more than 6 months (ibid.). The rate of early initiation of breastfeeding within the first hour in maternity units which are both BFHs and not BFHs is 2 %. For comparison, the rates of early initiation of breastfeeding in Eastern Europe and Central Asian countries are 17%, and 33% in Asia-Pacific. The average rate for the world is 43% (Petrova, 2007). A similar representative study for the city of Varna concluded that the rate in Varna is 1.8 % (Usheva et al., 2011).

In Bulgaria currently 12 out of 150 maternity wards are certified according to the standards of the BFHI. However, according to an assessment commissioned by UNICEF, the practices in most of these wards do not correspond to those recommended by the Initiative (Chalmers, 2011). For example, hospitals do not fully recommend exclusive breastfeeding until 4 months; training for breastfeeding support was not provided in half of the assessed hospitals; early initiation of breastfeeding was not recommended; only in some hospitals were mothers shown how to express milk; only in 1 hospital did mothers stay together with their babies 24 hours immediately after birth (including those delivered by a caesarean section).

As a response to the ineffective application of the BFHI standards and the level of breastfeeding support in maternity wards in Bulgaria as whole, several parents'/mothers' organizations of voluntary breastfeeding consultants were set up in the period 2005-2012. These make up the National Association for Breastfeeding Support (NABS), the Colourful Future Association (also a member of NABS), and the La Leche Liga, an international organization with peer counsellor groups in 71 countries. None of these organisations receive government funding. The volunteer breastfeeding consultants (who can be either a mother with breastfeeding experience or a medic) must first obtain special training in how to provide breastfeeding support and undertake an exam. The training to NABS consultants is provided by the National Breastfeeding Committee. The breastfeeding support is provided via Internet, telephone, home visits and occasionally through visits to the maternity wards. However, the

support of the volunteer breastfeeding consultant to the mothers is not accepted by the majority of maternity wards, even though the provision of such support is encouraged by the BFHI. Additionally, the above-mentioned organizations organize lectures and meetings for pregnant women and mothers on the subject of breastfeeding, distribute informational materials and initiate awareness-raising events and campaigns. There are over 70 NABS volunteer breastfeeding consultants in Bulgaria, the majority of which are in the cities of Varna and Sofia. There is a rising interest among medical professionals in training provision on the topic of breastfeeding support. For example, in 2010, 54% of the participants in training courses in Varna were medical professionals. The training was part of the development of Karin Dom's Early Intervention Programme. In 2010, 68 people were trained by the Colourful Future Association, Karin Dom's partner organization.

Indeed, the respondents from the medical community were keen to point out the importance of breastfeeding specifically for the health status and development of children with disabilities:

> *"Breastfeeding is the best way for nutrition, especially for children at risk."* (Interview with a senior Government Official, Ministry of Health, Sofia)
>
> *"Breastfeeding plays an enormous role for the right nutrition, good neuro-psychological development of the child, the immunity status, growth and development of the children".* (Interview with Representative of the National breastfeeding committee, Sofia)
>
> *"Breastfeeding is the best form of nutrition, especially for children at risk. It is important to have a team member who is responsible for supporting lactation. Breastfeeding support is crucial for catching up and prevention of problems with the nerve system. With such children there are usually problems with breastfeeding. One of the reasons is the concerns of the mother."* (Interview with a nutrition expert, Ministry of Health, Sofia)

Although the role of breastfeeding for the prevention of abandonment of children is recognized in international literature (Lvoff et al., 2000), and in Bulgarian national strategic

documents, it is not directly linked with the prevention of abandonment among the medical society in Bulgaria. Indirectly, however, the medical profession accepts that breastfeeding can have such a role by linking it to the development of the psychological connection between mother and child and building a lasting attachment between them. As can be seen from the quotes below, respondents emphasized the role of breastfeeding in the development of the mother-child bond:

> *"The psychological connection is one of the priorities of breastfeeding and this is well known in the international society."* (Interview with a representative of the Parliamentary Health Commission, Sofia)
>
> *"Breastfeeding is the basis for building of attachment between mother and child. Breastfeeding, usually, does not happen for these children [children with disabilities], but it is most needed for them."* (Interview with a breastfeeding consultant and trainer, Varna)

The challenges of providing breastfeeding support were well expressed by the respondents of the survey. Breastfeeding support was seen as crucial in the first days after birth, and the need for support for mothers of children with disabilities was particularly highlighted:

> *"Mothers experience the need for support most during the first days, especially when they are stressed after the delivery…"* (Interview with a representative of the National Breastfeeding committee, Sofia)
>
> *"Among these children, usually, there are the biggest problems with the lactation of the mother – one of the reasons is the stress of the mother…"* (Interview with a nutrition expert, involved in the development of the National plan "Food and Nutrition", Sofia)

Unfortunately, there is no nationwide analysis on how breastfeeding support contributes to the prevention of abandonment of children in Bulgaria. The data from Karin Dom's Early

Intervention Programme, however, shows a positive result in this respect. In one of the hospitals with which the Programme works - MBAL "St.Anna" – in 2012 there were no abandoned children. This is a result of the good collaboration between the breastfeeding consultant, based there, Karin Dom's ECI team, and the Child Protection Department (Apostolov, 2013).

The overall situation of breastfeeding support in Bulgaria shows there is a need for improving the skills and raising the expertise of the medical staff in maternity wards. It is a positive development that in recent years parents' organizations have responded to community needs and have developed links with the medical profession. The activities of the volunteer breastfeeding consultants correspond fully with the strategic documents on breastfeeding reviewed above. From this point of view, they make a significant contribution to the implementation of the Bulgarian Government's policy on breastfeeding, although they are not supported with any resources. The data reveals that breastfeeding consultants who are members of the medical profession are best accepted in the maternity wards, unlike breastfeeding consultants without medical backgrounds (Apostolov, 2013). The main challenge is the lack of political will for the Bulgarian Government to finance its own political strategies. There is a serious need for investment in promotional activities and funding for further implementation of the national plans for Foods and Nutrition. Those issues seem to remain unaddressed by the government policies and actions.

5 Financial Aspects of ECI Development and Sustainability

ECI in Bulgaria is secured through 4 main funding sources – the de-institutionalization projects targeted at the closure of institutions for children and provision of community based services, the existing community based services secured by the national and municipal budgets, the Social Inclusion Project, and other sources secured by service providers.

The project that provides public information to be used for preliminary assessment of the opportunities and risks for the development and sustainability of the ECI services in Bulgaria is the Social Inclusion Project where 44 Community Centres will be supported to provide ECI. At the time of writing this report the closure of DMSGD advanced enough to bring information regarding the scope and financial framework of the ECI services that will be provided.

According to government representative, the Community Centres are seen as a pilot for ECI services in Bulgaria:

> *"The Social Inclusion Project will be a pilot for Early Intervention….The services will not be only for children aged 0-3, but also aged 3-7. Municipalities will have to first make capital investments and will then develop services…The Social Inclusion Project is a good opportunity for sustainability of these practices.…The project is targeted at all children at risk. This is an opportunity for children with disabilities to go to school, to have real early intervention…"* (National Government representative).

The new social services that will be developed through the Social Inclusion Project will put a priority on achieving a holistic and integrated approach of service provision for children 0-7. One of the main requirements to the municipalities is to prepare collaborative services where the social, health and education experts and systems will work together in the best interest of the child. However, the lack of experience in the public services delivery to create horizontal collaboration creates a risk for achieving the holistic and collaborative approach of work in children's services. Currently, the services are at risk of being fragmented and based on separate disciplines, for example physiotherapy, psychology, etc. The medical model is also

very popular, which means that the new services are at risk of following that model (i.e. placing the focus of intervention on the child's disability, rather than on their strengths and functional skills). In addition, early childhood intervention is a new field of work for professionals in Bulgaria, and there is a clear need for sharing know-how, providing supervision, establishing a peer support system, etc. It is not clear, however, how these support mechanisms will be provided.

The Social Inclusion project envisages 37.39 million EUR for children 0-7.[23] It is not stated what proportion of the available funding will be for early childhood intervention services. In principle, Municipalities have two options for managing the funding and the services which will be set up in the new Community Centres. They can either manage these themselves or outsource them to independent providers.

As far as the municipalities will be responsible for securing future funding for services, the existence of early childhood intervention will be dependent on the municipal financial capacity and vision about the provision of such services. While bigger municipalities will be more likely to be able to afford to finance early childhood intervention services from their own budgets, for smaller municipalities this will be very difficult, if not impossible. Usually smaller municipalities have poorly developed social services, and their financing depends entirely on the national Government budget through state-delegated services or grant schemes.

As explained by a Municipal representative, in the context of the financial hardship currently facing the Bulgarian economy, most of the municipalities administering a grant from the Social Inclusion Project will probably prefer to keep the early childhood intervention centres and other services for children 0-7 at risk under their management, thus keeping workplaces and personnel within their administrations:

> *"Municipalities have an interest to manage the services themselves. In this way they secure work places in their structures. Especially now when the administrative personnel in the municipalities has been reduced. In practice, municipalities take a political decision not to delegate services. The biggest problem for small municipalities is that they don't have capacity and people."*
> (Interview with a municipal representative, Sofia)

[23] Information accessed October 2012, from the Agency for Social Support.

This situation would be most likely in municipalities which have not developed practices of outsourcing services to external providers. This scenario will automatically exclude from participation NGOs with experience in service provision for children. However, the practice of bigger municipalities is to delegate most of the social services to external providers, most likely from the NGO sector. Municipalities will be relying on the Bulgarian Government to secure funding for sustaining the services developed through the Social Inclusion Project from EU funding:

> *"Our municipality has a big grant from the Social Inclusion Project. We are not only developing services but having an infrastructural component as well – we are building a Community Centre. The contract stipulates that we will have to secure funding for at least 5 years after the end of the project. Our Municipality has a practice of funding social services, but we actually expect that there will be EU funding for these services. The Government is trying to secure this funding through the Operational Programme for Human Resources."* (Interview with municipal representative, Varna)".

During the preparation process of the Social Inclusion Project, the municipalities had to plan the new services for children at risk without knowledge about the specifics of the services that would be provided - some of the services were simply new for Bulgaria. In reality, they have planned the services according to the project framework, which is close to the state-delegated services in terms of logic of costing, but with different financial parameters. Most service providers and social commentators agree that this is not a good model for calculating the cost for social service provision. Unfortunately, however, this model was also used by the municipalities to calculate and plan the early childhood intervention services from the social inclusion project. This means that the financial planning of the new early childhood intervention services was not based on the real needs of children or professionals, but on a financial framework provided by the project.

This entails at least two drawbacks. First, the early childhood intervention services will have to be delivered according to a financial framework that does not necessarily reflect the specific requirements for these particular services. The methodologies that are due to be developed will have to reflect the existing budget, rather than the other way around. Secondly,

the municipalities which will administrate the services (and respectively the external service providers) will have to comply with the existing approach to planning, accounting, and delivering social services, thus having little or no opportunities to learn new forms of work or advocate for a different logic of service provision.

Chart 1 below shows a comparison of budgets (for one child per year) for social services which could incorporate ECI services. According to their financing source these services are state-delegated services, municipal funded services, and planned services as part of the Social Inclusion Project in Varna Municipality[24].

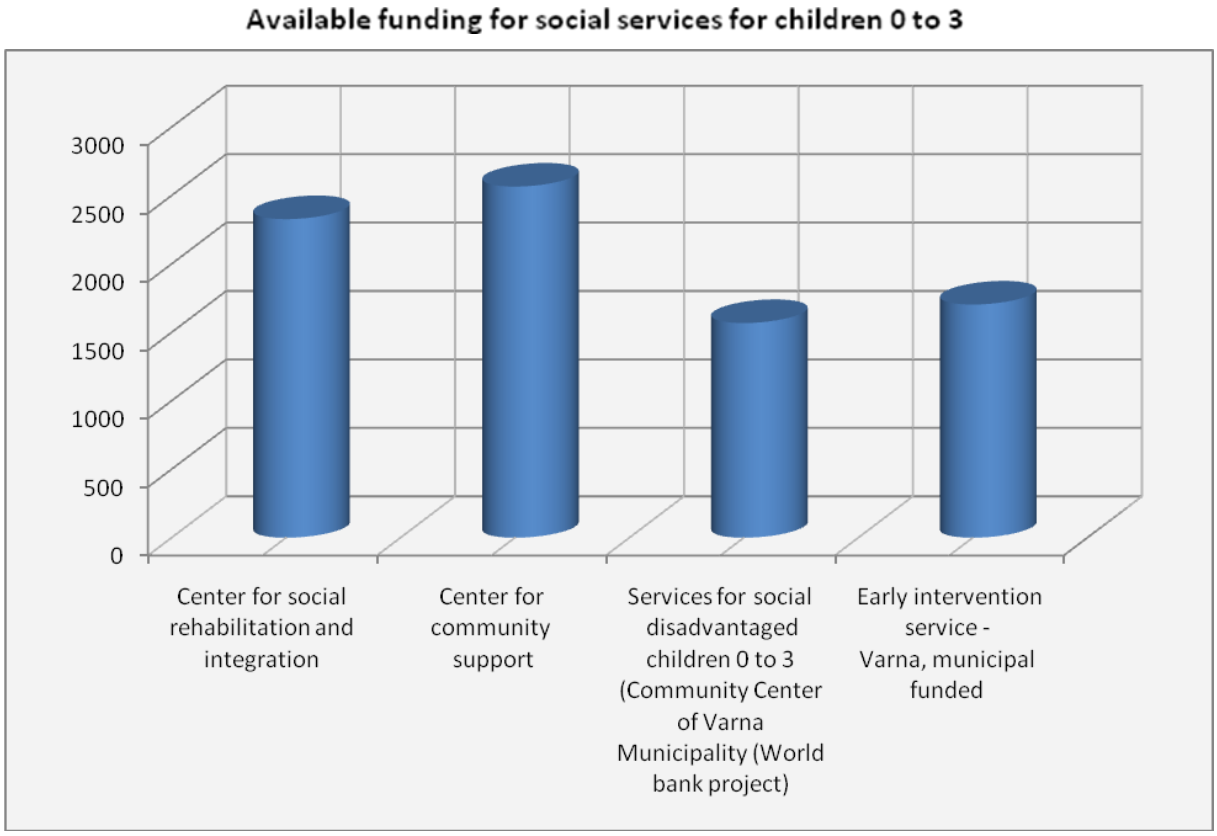

Chart 1, Disparities in funding for social services for children 0 to 3 in BGN (1 EUR ≈ 1.96 BGN)

The chart presents the budget of different types of services which are used by service providers as a way of funding early childhood intervention services. For example, ECI services in Vidin are financed through a Center for Social Rehabilitation and Integration, and in Stara Zagora through a Centre for Community support. Although there is variation between

[24] See appendix 7 for description and details of the exact cost of state-delegated services in Bulgaria.

the budgets for both service providers, the delivered early childhood intervention services are similar.

The chart above shows a bigger difference between the costs of the current State delegated services (Centre for Social Rehabilitation and Integration and Centre for Community Support) and the proposed costs for services for ECI services in Varna – the services for disadvantaged children 0 to 3 in the Social Inclusion Project and the municipal funded ECI service. The reasons for that could lie in the different approaches of calculating the services or the type of services. The variety of costs confirms the need of official State standards that provide a budgetary framework. The expectation of the service providers, confirmed also in the focus group (Sofia), is that:

> *"The budget for early intervention services should assure flexibility depending on the needs and resources of every local area".*

In the bigger regional cities the offer of a variety of services already exists or could happen within the Social Inclusion Project or de-institutionalization process. However, the provision of mobile ECI-services should be considered for smaller and remote local areas where Municipalities cannot provide municipal delegated services or where there is no capacity and/ or resources (e.g. qualified professionals). Good planning and combination of resources from the local and regional level is necessary in order to achieve not only good quality but also cost-effective services.

A possible example of financial planning for ECI is the attempt of municipal authorities in Varna at setting up municipal-funded ECI services in the city. Based on consultations with Karin Dom, the Municipal Administration has proposed the following budget for ECI services for a capacity of 40 children and their families:

	Description of budget line	Total per month BGN	Total per year BGN
A.	**Specialists remuneration**		
1.	Home visits - 4 specialists – physiotherapist, speech therapist, psychologist, social worker	2,400	28,800
2.	Family support groups - 1 psychologist	480	5,760
3.	Parent-toddler play-groups–2 specialists (teacher, speech therapist)	360	4,320
4.	Maternity hospital consultations - 1 psychologist, 1	450	5,400

	certified breastfeeding consultant		
5	Transport - 1 driver	600	7,200
6	Accountant - 0,5 (half time)	300	3,600
7	Technical assistant - 0,5 (half time)	200	2,400
B.	**Material costs**		
1.	Materials – special aids, toys, literature, etc.	150	1,800
2	Consumables	35	420
3	Transport – fuel, maintenance	257	3,084
C.	**External services costs**		
1	Telephone, electricity, water, etc.	208	2,496
2	Promotion activities	240	2,880
	TOTAL:	**5,680**	**68,160**

Table 6, Proposed budget by Municipality of Varna for ECI services with a capacity of 40 children.

The presented budget brings out an amount of BGN 1,704 per child per year.[25] The budget is based on calculations from the experience of running Karin Dom's Early Childhood Intervention Programme. However, this budget reflects only the amounts allowed by the Municipality for specialists' remuneration, which would cover neither the remuneration of experienced specialists nor the additional costs for professional development and supervision needed for applying these services. This could be a significant sum because in Bulgaria the education system does not provide a target for education of early childhood intervention. During university education of special teachers, speech therapists, and psychologists, work with children 0 to 3 and their families is not a focus. The education provided by medical universities for physiotherapists includes training for work with children 0 to 3. However, the graduate students need additional knowledge, skills and practical experience in order to be competent in providing ECI for children 0 to 3 with special needs. The budget also does not cover the infrastructural costs needed for preparing and maintaining the buildings in which some of the ECI services are provided (e.g. the parent-toddler play groups).

The focus groups and the semi-structured interviews in Varna suggested that Karin Dom's model of early childhood intervention needs to be sustained and further developed. Respondents from the medical community, psychologists, and social workers from the Child Protection Department argued that the family-centred approach that Karin Dom's service has

[25] See Appendix 7 for a comparison with the costs of state-delegated services in Bulgaria.

adopted fills in the gap in the social, education, and medical services. The family-centred approach has the advantage of supporting not only the development of the child but also of focusing on the whole family by building on the parents' knowledge and skills and connecting it with the community resources. This was pointed out by representatives from the Child Protection Department as an approach that assures the sustainability of the positive effects achieved for the child development because the parents have acquired the knowledge of how to take care of and work with their child.

5.1 Breastfeeding Support – Sustainability and Finding Needs

Currently, the provision of breastfeeding support is not funded by State or municipal budgets because it is considered as part of the midwives' duties. However, the low rates of breastfed children in Bulgaria and the large number of children abandoned at the level of the maternity wards, set as a priority the improvement of breastfeeding support and encouragement of breastfeeding. The research identified two main types of possible directions for this problem: 1) providing training for medical personnel, especially midwives, for acquiring more skills and experience about successful breastfeeding, and 2) incorporating breastfeeding in medical standards, and thus including costs for breastfeeding consultants in the health budget lines for maternity wards.

The first type of measures is also envisaged in the national strategic documents concerning breastfeeding, although as mentioned before have not been implemented because of a lack of finance. However, a common opinion among respondents was that the training for breastfeeding support for medics should be part of their education and an additional qualification / specialization:

> *"…It is good to include a module on 'breastfeeding support' in the programme for GPs 'Children's health care'. It is possible in the specialization of GPs to have obligatory several training hours for breastfeeding support. It will be also good if the Medical Association, which provides postgraduate training for medics, incorporates breastfeeding support in its training programmes …"* (Interview, with nutrition specialist involved in the development of the National plan "Food and Nutrition", Sofia)

These are steps that the medical authorities could undertake based on well-recognised needs. Such steps towards the improvement of the education of medics in the area of breastfeeding

support have been made by the Medical University in Varna. Although most of the introduced training forms on breastfeeding are facultative, the interest among the students is high. Training modules for graduate midwives and doctors are also envisaged. All these trainings sessions are on the basis of the developed training by the National Breastfeeding Committee. This fact confirms the important role of the medical authorities in Bulgaria for the improvement of breastfeeding practices and support.

The second measure in this area, pointed out by respondents, is to incorporate breastfeeding in the medical standards and thus ensure the possibility of receiving financing for provision of breastfeeding support at the maternity wards:

> *"The first step for securing funding for breastfeeding support should be changing the neonatology and obstetrician standards. The information from them is transferred to the clinical paths.*[26]*"* (Interview with former Senior Government Official from the Ministry of Health, Varna)

This measure could financially encourage the maternity wards to allocate resources for breastfeeding consultants, which together with training provision, c ensure a good quality of breastfeeding support.

Respondents also suggested that the accreditation of the hospitals, in accordance with the BFHI, could be used for increasing the financing of these hospitals. However, the analysis in the above sections shows that the Bulgarian BFHI hospitals do not meet the necessary requirements.

Some of the respondents believed that breastfeeding support, like early childhood intervention as a whole, should be developed and delivered by non-governmental organizations. The situation in Bulgaria shows that the parents' organizations of volunteer breastfeeding consultants have the resources to provide such support and promote breastfeeding but mainly in their communities. The fact that they are growing very fast in the last years and involve more medical professionals in their training, confirms that they could play a significant role in the development and provision of breastfeeding support in Bulgaria.

In relation to breastfeeding support in Varna, the Municipality of Varna is inclined to perceive breastfeeding support as part of the early intervention programme which has been proposed

[26] 'Clinical paths' are the way money is transferred from the National Health Fund to hospitals.

for municipal-funding. This means that some funding may be allocated to breastfeeding consultants in Varna as part of the whole ECI budget. This will set a precedent in Bulgaria, because currently no other municipalities in Bulgaria provide such funding.

6 Conclusion

Several key conclusions from the research can be made. Firstly, the early childhood intervention services are envisaged to be developed and implemented through the Social Inclusion Project, financed by the World Bank. With funding from the World Bank for two years and pledged funding from municipalities for at least another five years, the social inclusion project appears to be a good opportunity for scaling up early childhood intervention in Bulgaria. The fact that there will be over 60 community centres opened in Bulgaria, and most of them will provide ECI services, suggests that both in terms of host structures and financing, early childhood intervention services will be secured for a relatively good period of time. During this time, services can take shape, relationships with local communities can be developed, and the personnel can gain the necessary skills to provide the service. The key will be making these services financially sustainable in the long term with financial frameworks that reflect the reality of ECI service provision rather than the financial framework dictating what ECI services can be provided.

Another development that needs attention is the fact that as part of the plan for de-institutionalisation, the Bulgarian Government is planning to set up another early childhood intervention service as one of the services in the restructured DMSGD. This is an entirely separate activity from the Social Inclusion Project. It is not clear if the two early childhood intervention services will share common methodologies, who their target groups will be, and if their planning will be coordinated. While the Social Inclusion Project is under the Ministry of Labour and Social Policy, the DMSGD is the responsibility of the Ministry of Health and under the supervision of the Agency for Child Protection. Thus, while in theory, the three governance structures are supposed to be coordinating the creation of new services, it appears that there is very little scope for flexibility in terms of joint actions because, in practice, the Social Inclusion Project is not part of the national de-institutionalisation plan. There is a risk that the ECI services, in place of the DMSGD, will apply the 'medical model' of support.

Karin Dom's ECI Programme clearly shows that such a service is most needed and suitable for the 0-3 age group. This is particularly true if early childhood intervention is understood as a home-based service or a service provided in the natural environment of the child. While the community centres will have a mobile team for home visits, it is not clear if the mobile services will be the main form of support.

Similarly, the family-centred approach – so crucial to early childhood intervention practices – may not necessarily be integrated into the work of the community centres. It appears that although both children and families will be supported in the community centres, this support is envisaged to be provided separately to children and parents. For example, children will receive therapy in the centre, while parents will be included in trainings, school for parents, etc. It is not clear how the child and the parents will be involved in a single support process, which would lead to the greatest improvements in the development of the child. In other words, the principle of partnership between parents and early childhood intervention consultants – so crucial for the family centred model – may not necessarily be applied.

Finally, the analysis on breastfeeding support is indicative of a rather unclear situation about what the role of breastfeeding can be in the early childhood intervention service. Clearly, the medical community is supportive of the idea of encouraging breastfeeding in maternity wards, but rarely is breastfeeding understood as an instrument for the prevention of abandonment of babies. There is over-reliance on the expectation that either legislation or government policy will regulate breastfeeding practices, and only then can support for breastfeeding become a key component of services for children. At the same time, the fact that breastfeeding support is not clearly integrated in any de-institutionalisation services, albeit mentioned in documents, suggests that it is given very little priority by policy-makers. If this situation is to change, the medical community will need to develop this field of intervention from within their system.

This report revealed that t ECI, as a multidisciplinary service, is gradually taking shape and gaining popularity among service providers in Bulgaria. Although there is no common understanding of what ECI should include as a service package, there is a shared understanding that both children and parents should be supported. Slowly, but progressively, stakeholders in Bulgaria begin to think of ECI as a service supporting children 0-3 and their families in an integrated way both through focusing on the child's functional development and by helping parents to support their child.

7 Policy suggestions

- Early Childhood Intervention Services in Bulgaria should be planned both through the Social Inclusion Project and as part of the Action Plan for the implementation of the National Strategy "Vision for deinstitutionalization of children in the Republic of Bulgaria". The research evidence revealed, however, that these two mechanisms are separate in nature and under different governance bodies. In order to arrive at a common vision for the development of early childhood intervention services in Bulgaria, it is necessary to achieve better coordination between these two mechanisms and their governance bodies;
- In order to overcome the financial imbalance between smaller and bigger municipalities, regional early childhood intervention centres should be planned, with a focus on mobile teams serving municipalities without resources for developing their own ECI services.
- The early childhood intervention centres for children with disabilities that will be financed through the national projects are at risk of not having adequate budgets for such services. Budgets should be designed according to early childhood intervention guidelines or methodologies developed specifically for ECI services.
- The research evidence revealed that breastfeeding is seen as an important part of child development and children's services, but there are no concrete measures for providing mechanisms for supporting breastfeeding as part of the deinstitutionalization process. There is a need for the Government to produce a strategic document concerning the effect of the Baby Friendly Hospital Initiative on infant abandonment and to raise awareness about this issue among social and health workers;
- Targeted financial support should be provided for breastfeeding support in accordance with the strategic Government documents and policies. In this process, medical personnel should take responsibility for implementing breastfeeding practices in accordance with BFHI.
- The National Government authorities should use examples of ECI best practices from Bulgaria to develop a national model and guidelines for providing early childhood intervention services. Developed ECI services should be supported with Government funding to ensure long-term sustainability.
- The process of de-institutionalisation will lead to the closing of DMSGD. While early childhood intervention services are envisaged for children 0 to 3, it is not clear how

funding will be allocated. Government policy needs to ensure that the funding stream to the existing structures will be preserved for children's services (not merged with the overall State budget), and adequate finances will be allocated to developing ECI services. Non-governmental organizations should be included as partners in the management of the de-institutionalization process, specifically in relation to developing and implementing community-based services, including early childhood intervention services.

- More awareness-raising for early childhood intervention is needed. Awareness-raising campaigns should be organised for both the general public and local and national governmental institutions.

APPENDICES

Appendix 1. Semi-structured interviews: interview schedule

Introductory questions

1. In your view, what is early intervention, and who is it for?
2. Is there a need for early intervention services in the community? If so, what is this need based on?
3. Do you know of any early intervention services in Bulgaria? Who are the services provided by? Please provide an example of an early intervention service.
4. The 'family-centred' approach is key to early intervention service provision. How do you understand the 'family-centred approach'? Does this approach relate to the needs of the parents who might be using early intervention services?

Questions relating to Karin Dom's Early Intervention Programme

5. Early intervention includes services provided by a mobile team making home visits. In your view, what should be the role of the specialists providing home visits to parents and children?
6. In your view, what is the benefit of providing services in the home of the family?
7. 'Breastfeeding support' is an additional service in early intervention. What do you think its role is? (Specifically relates to Karin Dom's service).
8. In your view, is there a need for a breastfeeding consultant at maternity hospitals? Why?

Questions relating to the environment in which early intervention services can operate

9. In your view, how can the maternity wards and the hospitals become involved as partners in early intervention services?
10. Do you think early intervention needs additional services to accompany its core services (e.g. in addition to home visits). What would these be?
11. In addition to the family-centred approach, what other approaches would be useful in providing services (for children 0-4)?
12. In your view, how can early intervention services be managed in the community? What structure would be suitable for providing early intervention services (e.g. an NGO, Municipal structure, etc.)? Why?
13. How can early intervention be funded, and by whom?

a) in relation to a mobile team, providing home visits;

b) in relation to breast-feeding support;

c) in relation to another service for children 0-4 (please specify).

Questions relating to the system of social services and the process of deinstitutionalization in Bulgaria

14. What are the challenges in front of the providers of services for children and families in Bulgaria?
15. What are the main issues related to financing social services?
16. What are the main issues related to delegating social services to independent providers?
17. Does the de-institutionalisation process provide opportunities for community-based early intervention and other services for children? What are these?
18. What is the role of early intervention in the de-institutionalisation process?

Appendix 2. List of institutions and NGOs interviewed

Chair of NGO 'Sauchastie', Varna

Government consultant 'Social Inclusion Project', Sofia

Representative of 'National Association of Municipalities in the Republic of Bulgaria', Sofia

Head of Bulgaria Country Office, World Health Organisation, Sofia

Coordinator of 'Social Inclusion Project', World Bank, Sofia

Dean of Department of Public Health, Varna Medical University, Varna

Rector of Varna Medical University, Varna

Chair of Parliamentary Commission on 'Health', National Assembly, Sofia

Member of Parliamentary Commission on 'Health', National Assembly, Sofia

Breastfeeding Consultant, National Association 'Support for Breastfeeding', Sofia

Representative of De Pasarel Bulgaria Foundation, Sofia

Chair of the Permanent Commission on 'Social Support', Municipal Council, Varna

Minister of Health (2009-March 2010), Sofia

Coordinator of 'Food and Nutrition' Project (2005-2010), Ministry of Health, Sofia

Head of 'Social Activities and Housing Policy' Department, Municipality of Varna, Varna

Representative of the National breastfeeding committee, Sofia

Head of Department of Neonatology, Maternity Hospital, Varna

Head of Maternity Department, 'Sveta Anna' Hospital, Varna

Head of Child protection Department, Varna

Director of Directorate 'Social Activities and Health Development', Municipality of Varna, Varna

Representative of NGO 'Tsvetno Badeshte', Varna

Representative of Parent Support Network, Varna

Appendix 3. List of institutions and NGOs participating in focus groups[27]

Municipality of Varna, Varna

Municipality of Sofia, Sofia

Child protection Department, Varna

Club of Non-Governmental organisations, Targovishte

NGO 'Ekvilibrium', Ruse

UNUCEF-Bulgaria, Sofia

FICE-Bulgaria, Sofia

National Network For Children, Sofia

NGO 'Samaryani', Stara Zagora

National Centre for Public Health and Analyses

NGO 'Sauchastie', Varna

Karin Dom Foundation, Varna

Maternity Hospital, Varna,

Hospital 'Sveta Ana', Varna

NGO 'Tsvetno Badeshte', Varna

Lumos Foundation, Varna

Social Support Directorate, Varna

Regional Inspectorate for Education, Varna

[27] Some of the listed organisations participated in the focus groups with more than one representative.

Appendix 4. List of NGOs participating in survey among ECI service providers

NGO ‘Club of Non-Governmental Organisations’, Targovishte

Rousse Association for Persons with Intellectual Disabilities – BAPID, Ruse

NGO ‘Parvi Juni’, Bjala Slatina

NGO ‘Alternativi’, Aitos

NGO ‘BALIZ’ - Pleven, Pleven

Helping Hand Foundation, Dobrich

Bulgarian Association for Persons with Intellectual Disabilities, Sofia (service based in Vidin)

NGO ‘Sveti Mina’ of Families of Children with Special Needs, Dobrich

NGO ‘Alternativa 55’, Stara Zagora

NGO ‘Samaryani’, Stara Zagora

NGO ‘Ekvilibrium’, Ruse

DMSGD ‘Vyara, Nadezhda, Ljubov’, Burgas

‘Nacionalen Alians za rabota s Dobrovolci’, Plovdiv

Karin Dom Foundation, Varna

Appendix 5. Questionnaire used in survey among ECI service providers

EARLY CHILDHOOD INTERVENTION SERVICES IN BULGARIA **Questionnaire**
Organisation: **Correspondence address:** **Tel:** **E-mail:**
1. How long have you been providing Early Intervention services for? Where are the services provided? (Please, provide information about the period of provision, location, and if the services are centre- or home-based).
2. What is the main approach you are using in your work: diagnostics/child therapy/family consultations/other? (Please, provide a brief description)
3. What training or qualifications has your team received for providing Early Intervention services? What are your training needs?
4. Who are the beneficiaries of the Early Intervention services offered by your organisation (Please, provide information about the age of the children and the main criteria for including children and families in the services).
5. What is the total number of children who have received Early Intervention services from your organization? How many children do currently receive Early Intervention services from your organisation?
6. How do you finance your Early Intervention services? (Please delete as appropriate. You can choose more than one option.) **A) Projects B) Municipal Funding C) Donations D) As part of a State-delegated service. E) Other (please explain).....**
7. Based on your practice, please provide information about the cost of your early Intervention services on a 'per child' basis, and the main type of expenditure for applying the services. Please specify if the information is calculated on an yearly, monthly or other basis of expenditure.
8. Please provide any other information or commentary in relation to the Early Information services your organization is providing. **Thank you for your assistance!**

Appendix 6. The BFHI's Ten Steps to Successful Breastfeeding

"Ten Steps to Successful Breastfeeding

Every facility providing maternity services and care for newborn infants should:

1. Have a written breastfeeding policy that is routinely communicated to all health care staff.
2. Train all health care staff in skills necessary to implement this policy.
3. Inform all pregnant women about the benefits and management of breastfeeding.
4. Help mothers initiate breastfeeding within a half-hour of birth.
5. Show mothers how to breastfeed, and how to maintain lactation even if they should be separated from their infants.
6. Give newborn infants no food or drink other than breast milk unless *medically* indicated.
7. Practise rooming in - allow mothers and infants to remain together - 24 hours a day.
8. Encourage breastfeeding on demand.
9. Give no artificial teats or pacifiers (also called dummies or soothers) to breastfeeding infants.
10. Foster the establishment of breastfeeding support groups and refer mothers to them on discharge from the hospital or clinic."

Source: WHO / UNICEF (2009) *Baby-Friendly Hospital Initiative.* Geneva, Switzerland

Appendix 7. Description and cost of state-delegated services in Bulgaria

Residence family-type Centre – residential type of institution for children with disabilities – provides food and shelter. Implements social, psychological and rehabilitation work with children with disabilities. Year's standard per child – BGN 7.255,00

Mother and baby unit – provides complex of social services aiming at prevention abandonment; support and shelter for single mothers and pregnant women; work with relatives and the extended family when there is a risk of abandonment. Year's standard per child – BGN 6.257,00

Center for community support - provides a complex of social services for children and their families at risk – family consultation, family planning, services for prevention the dropout from school, prevention and support of children – victims of violence, work with children with disabilities. Year's standard per child and family – BGN 2 566.

Center for social rehabilitation and integration for children with disabilities and their families - provides a complex of social services, individual work with children, psychological-pedagogical work, programme for children with autism and children with hyperactivity and attention deficit; therapy-rehabilitation work with children with cerebral palsy; swimming, music and art therapy; preparation for inclusive education; parents' support groups. Year's standard per child – BGN 2 328.

Appendix 8.

Karin Dom's Early Intervention Programme – a case presented by ECI specialists

M.P. (child initials) is 3 years and 2 months old girl from a Roma family. She was referred to Karin Dom EI programme by a relative of the family in June last year (2012). The reason for the referral was developmental delay. M.P. is a child from first normal pregnancy with a motor delay. Shortly before the referral she suffered from Acute Viral Encephalopathy.

The initial assessment showed that M.P.'s walking was still unstable. She did not always understand people talking to her and used limited number of words herself. She was unwilling to interact with strangers and other children according to her parents. M.P. was still using diapers.

After initial conversations and assessment the child was included in the programme. A physiotherapist and a speech therapist started visiting the family twice a month. One of the first steps taken were to develop some self-help skills to make M.P. more independent. Parents were advised to speak one language because bilinguism added to her communication difficulties. The consultants gave mum plenty of ideas of activities and games to develop the child's fine motor and problem solving skills.

They also helped the family to consult a neurologist and present the child to a medical commission. This helped the family access additional support and recourses.

M.P.'s mother helps a lot with the therapy and the girl is demonstrating good improvement. She enjoys running and jumping, plays with variety of toys and is getting better with nesting and stacking. She attempts to draw and to match pictures. She also makes simple sentences and feeds herself independently with her favourite foods. Her parents are trying to provide opportunities for her to play with other kids.

In this case the EI program is contributing with small steps to attain her father's target: "I want for her to be literate".

Karin Dom's Early Intervention Programme – a case presented by a parent

"The Early Intervention Program is a project which teaches parents in the best possible way how to fully communicate and play with their children and how to stimulate their physical, psychological and mental development. I am delighted with the results for the period from December 2011 [when my daughter and I joined the program] up to present - May 2012. There is a huge change in a positive direction.

"Home visits by specialists who provide guidance and advice on ways of communicating and educating the child, are extremely helpful to us personally. In the beginning, when we sought

help from the consultants at Karin Dom, my daughter [1 year and 3 months then] could not stand upright, could not walk alone, was not able to say words, she was not used to communicating with people other than her parents, she was frightened of strangers. The first results came after several meetings with experts from Karin Dom [therapist, psychologist, speech therapist]. We were following closely the advice on stimulation of the motor development, resulting in the child beginning to stand upright without assistance, at 1 year and 4 months she was already making separate steps, and at 1 year and 5 months she was walking quite freely. After she learned how to walk, a very important positive change in psychological term occurred - my daughter was much more relaxed and talkative. This great change was noticed also by the consultants during the next home visit. I am very pleased with the way they work with her. She enjoys being with them as well, going alone to them, looking for them, bringing them toys, smiling at them, allowing them to take her in their arms, which was previously unthinkable. They set her at ease so much and she is relaxed enough to interact with them without problems. For several months she has learned many new things - how to recognize and show animals in a booklet, to make their sounds, to execute commands [come here, give an object], to put her toys in order after a game; she began to concentrate for a long time on a certain activity; she started to become absorbed and play games which were boring to her before – stringing up rings, building towers, embedding forms, arranging children's puzzles, sorting objects; she became more self-dependent – started to drink from a cup, tries to feed herself on her own, to climb stairs with assistance; started to say and use many words, she has even said his first sentence; helps with dressing and undressing, learns and shows body parts and many more skills.

“Specialists who conduct the games each week with children in Karin Dom played a large role in this progress. During the very first visit there, my daughter really liked the atmosphere and activities, and as soon as we take the rucksack with shoes and she realizes that we are going to play, she starts to rejoice. The method of structuring and conduct of activities is very cleverly established. The participants in the games are children of 1 to 2 years of age. In classes, children learn to salute, sing songs, participate in group games, and listen to short stories. In addition, there are individual games and activities through which every child stimulates the development of fine motor skills or acquire new skills. Thus, in the form of play children have fun on one hand, and on the other acquire knowledge and skills, learn how to communicate among themselves and to respect order and discipline, such skills that are extremely useful in the future [for example when visiting a nursery and a kindergarten].

"As a result of the regular attendance of the games with children at Karin Dom and the strict implementation of the advice and recommendations of the experts in the home visits, my daughter fully made up for the retardation in terms of motor development which was the reason for us to join the program. After persistent pursuits, her skills in other areas of development-cognitive, speech, social, are now relevant to her age. As of today, I reckon that in no way she is inferior to their peers, which would hardly be so if we were not included in this program.

"In this line of thought I believe that there is public demand for such services as provided by the Early Intervention Program, and it is of great importance for it to continue over time both as regards children who are already involved and children who are yet to benefit from it. I think that Varna municipality must do everything possible to ensure the future funding of the program so that many people who need it can take advantage of the services it provides. So I think the Early Intervention Program should continue after August 2012, in the same form in which it has been conducted until now - with home visits by specialists, with the play groups, with parental support groups, with support for breastfeeding [for parents of younger children].

"In conclusion, once again I would like to say that I am impressed by the work and approach of the consultants working on the Early Intervention Program. They teach parents how to be helpful to their children, how to communicate with them, how to learn new skills, how to stimulate their development. The work of specialists under this program gives great results, so it's crucial for it to continue. I would like to express my sincere gratitude to all experts from the Karin Dom team, participating in the program for their dedication and successes."

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KARIN DOM
Sveti Nikola P.O.Box 104
Varna 9010, Bulgaria
Phone No.: +359 52 302 517
Fax: +359 52 302 516
e-mail: karindom@karindom.org
www.karindom.org
www.facebook.com/karindom.org