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*The purpose of the project is to inform the general public, government institutions and local governments of the need for early intervention and a family-centred approach in support of young children with developmental difficulties and disabilities and their families, as well as to promote the existing good practices of social service providers in this field.*

*The end goal of the National Network for Children is to ensure the existence of a fully regulated and operational National System for Early Childhood Intervention, offering excellent personalised and intensive support services to parents and young children who are at risk, have developmental difficulties, disabilities or behavioural problems, or need mental health support.*

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# I. Core definitions

## 1. What is Early Childhood Intervention?

**Early Childhood Intervention (ECI), Early Intervention for short, is a set of coordinated, interdisciplinary services provided to young children at risk, children with a developmental delay or disability, and their families, in order to support and stimulate the child's development and assist with their social inclusion.** An important part of the services is focused on early identification of the disability and support to the family to accept the news and adjust to the child's special needs.

The services target both the child and his/her family, support to the family being of key importance. A child develops within and via the family by means of daily contacts and interactions with the environment and the people around him/her. In this sense, an important part of the early intervention process is aimed at support for parents to acquire knowledge and skills, and gain confidence in order to facilitate and stimulate their child's development in the latter's typical environment.

## 2. Aims and objectives of early childhood intervention services

Early intervention seeks to provide, as early as possible, support to children with developmental difficulties or a disability and to their families so that children can develop their full capacity and be included in the social life of their community.

### The main objectives of early intervention are:

- ✓ early identification of children at risk for developmental issues or disability;
- ✓ support to parents to take the news of their child's diagnosis and adjust to their child's needs;
- ✓ support to family members to develop knowledge and skills to facilitate and stimulate the child's development;
- ✓ support to children at risk, children with developmental difficulties or a disability by provision of individualised services – psychological, rehabilitation, social, medical;
- ✓ support for developing a stable and secure parent-child relationship in the long term and for preventing abandonment;
- ✓ maximum use of neuroplasticity and sensitive periods in early childhood development to make up for the disability and to develop the child's potential.

## 3. Karin Dom Foundation's Early Childhood Intervention – mission, objectives, principles

Karin Dom has been developing its Early Intervention Programme since the autumn of 2010, having adapted a model of ECI services used in Canada and the USA. The Programme was launched with the financial support of the Open Society Institute, London. Karin Dom has been using the expertise of Canadian trainers, who delivered a three-week training for the team, and of American volunteers working in ECI services. Judith Newman, Founder and Director of the Early Childhood CARES program in the University of Oregon, USA, has been our consultant for many years now.

In July 2013 Varna Municipality was the first Bulgarian municipality to recognise the Early Intervention Service as a municipal-delegated activity and to sign a contract with Karin Dom Foundation for the provision of social services in the *Centre for Early Intervention for Prevention of Developmental Delays in Children with Disabilities* with a capacity of 40 places and the respective financing.

**In this text “Early Intervention Programme” and “Early Intervention Centre” are used interchangeably.**

**The Mission of Karin Dom’s Early Intervention Programme is to:** provide timely support to parents of children with special needs so that the parents can acquire knowledge and skills enabling them to support and stimulate their child’s development for a more meaningful life.

The objectives of the Programme are to:

- ✓ provide services at the home of infants and young children with developmental difficulties or a diagnosed disability;
- ✓ provide home-based early support and intervention via and together with the family;
- ✓ disseminate good practice.

**A distinctive feature of this service is adopting two underlying principles:**

### **1. Family-centred approach**

This is a philosophy adopted in all aspects of our organisation. The family-centred approach to ECI is defined as a set of values, attitudes and approaches to services for children with special needs and their families. The family-centred approach acknowledges the uniqueness of each family; the permanency of the family in the life of the child; that family members are the experts on their child. The family-centred approach takes account of the strengths and needs of all family members. In this partnership a trusting relationship is built; the objectives to work towards are set by the family and, in this way, parents and professionals work together, in agreement and in the same direction.

The benefits we witness with the adoption of this approach are both for the children and for the family. Children show progress in their development, achieve set objectives and develop useful daily living skills. Parents learn more about their child’s development; the level of their stress and anxiety is reduced; they feel more competent as parents and gain confidence and a sense of control over their lives. Another important aspect is that when we work like this with families, they get used to this approach and are ready to cooperate with therapists and pedagogues and participate actively in the therapeutic and training process when the children move on to other services.

## 2. Work in the child's natural environment

Natural environment means the child's typical setting coupled with their peers with no special needs; it includes the home, nursery and kindergarten, leisure activity centres, playgrounds and other settings where children interact and play together. Home-based service delivery for children allows aligning the Service to the setting, the daily routine of the child, their toys and favourite pastimes. Children learn through play, daily activities and through interaction with the people who take care of them every day. In this way we build on the child's strengths and enable the acquisition of skills useful to the individual child in his/her daily life.





## II. Organisation of the services in Karin dom's early childhood intervention programme

### 1. Target group, capacity and users

#### 1.1. Target group

The social service *Early Intervention Centre* is meant for children aged 0 to 3 years who have a disability or are at risk for developing one or have another special need affecting their development.

The Service focuses on the following target groups:

- ✓ Families with children aged 0 to 3 years who are at risk for developmental difficulties or a disability, including low birth weight and premature infants;



- ✓ Families with children aged 0 to 3 years who have developmental delays in one or more developmental domains (cognitive, motor, speech, social-emotional development);
- ✓ Families with children aged 0 to 3 years diagnosed with a disability.

## 1.2. Capacity

**The social service *Early Intervention Centre* was launched with a capacity of 40 places.**

The service is provided pursuant to a Varna Municipal Council decision, and based on an order by the Mayor of Varna and a contract between the provider and the Municipality of Varna awarding social services provision.

## 1.3. Service users

A “user” is any child and his/her parents/legal guardians with whom a service contract is signed.

This includes self-referred users who have agreed directly with the service provider, without having to declare their need to the Child Protection Department.

# 2. Service Staff

The number of staff, their qualifications and experience must ensure quality and timely delivery of the early childhood intervention services. **A team was set up comprising of professionals referred to as *Early Intervention Consultants*.**

### Consultants:

- ✓ Social worker – 1
- ✓ Psychologist – 1
- ✓ Rehabilitator/kinesiotherapist – 1
- ✓ Speech therapist – 2

### Other staff:

- ✓ Accountant
- ✓ Driver

### External Experts:

- ✓ Psychologist facilitating parents' groups for mutual assistance and support (from Karin Dom)
- ✓ Psychologist providing individual counselling to parents (from Karin Dom)
- ✓ Certified breastfeeding consultants (outside Karin Dom)

The staff structure and staffing levels in the Early Intervention Centre ensure the implementation of the support activities. In order to guarantee the quality of the services provided, external specialists can be used by the hour to join with their expertise, depending on users' needs.

The team has been working in close cooperation with professionals from various municipal and government structures, social services providers and medical professionals.

### 3. Service delivery standards

#### ✓ **Family-centred approach.**

Early intervention services focus on strengthening the family's potential and resources to stimulate the development of the young child. They are planned and implemented with the active participation of parents and are aligned with their expressed needs, expectations and values. Throughout the process parents and families, including the extended family, are an active, leading player and equal partner alongside professionals. The partnership between the family and professionals is the most important success factor for the service provided. The relationship between providers and the family is based on mutual trust, respect, honesty, open communication and joint decision-making. Professionals respect and support family decisions.

#### ✓ **Interdisciplinary approach.**

Early intervention means involvement of various professionals, working in an interdisciplinary team and coordinating their efforts to meet the complex needs of the child and the family in accordance with the individual programme. In an interdisciplinary approach, parents and team members with different professional backgrounds work together, beyond the confines of their concrete specialities and traditional professional roles.

#### ✓ **Mobility of services.**

Early intervention services come closest to the families and children and are delivered exclusively in their own natural environment. Outreach work has a leading role; it allows for an individualised approach to every child and family, taking account of their specific needs and resources.

#### ✓ **Accessibility.**

The services are open to all, with no regard for their ethnic origin, religion or social status. Services are accessible – at zero or minimal cost to the family.

#### ✓ **Flexibility.**

Services are adjusted based on the individual needs of children and families. Professionals are flexible about:

- time – services are provided within flexible time slots and with different frequency;
- roles – professionals replace and complement each other, going beyond their narrow specialisms in order to meet the complex needs of children and families;
- choice – professionals are flexible as to the choice of means and ways of support.

## 4. Main support activities provided by the Early Intervention Service

### 4.1. Home visiting by a mobile team of Early Intervention Consultants

The service is provided by a multidisciplinary team in the natural environment of the child. Visits are focused on supporting the family to use the recommended strategies facilitating the child's learning and development as part of their daily life. For this reasons during visits it is of key importance that the parent or main caregiver is present and actively involved.

Home visits take place twice a month or more frequently, if required. At the end of each week the Early Intervention Consultants prepare a schedule of planned home visits.

During home visits the consultants:

- ✓ Introduce the family to the *Early Intervention* Centre service and the activities it offers;
- ✓ Make a specialised assessment of the child's needs and strengths by means of questionnaires on the child's family and development. Together they set joint objectives for working in partnership;
- ✓ Complete a home visit form; with the participation of the family, develop an individual service plan in line with the child's specific needs and the parents' objectives;
- ✓ Demonstrate, train and propose to the family strategies and activities relevant to the achievement of the objectives. The family always tries out the activities with the child during the home visit;
- ✓ Provide toys and books from the resource library corresponding the child's individuality and development level and help the family to use these in a suitable, functional way;
- ✓ Link the family to a support network: other parents, medical professionals, agencies and service units, nurseries and kindergartens, other community-based services.



#### Parents share

“Just the information by doctors of their suspicions that my child has Down syndrome came as a shock to me. I have been given many reprehensible looks; one of the paediatricians even asked me (...) why I chose to give birth to the baby having already known the findings of the screening? I was shocked, very confused and upset. I was crying all the time and wondering what was going on in our life. ‘Why us? What shall we do now? How will we go on with our life from now on? Will we cope?’

I told myself it was time I pulled myself together. Life goes on and our young child depended on us. He was a baby like all the rest; (...) he was healthy; he could see and hear everything and he needed me. I started looking for information on Down syndrome and what I could do for our little baby. I learned about Karin Dom from a friend and I decided to turn to them for help and advice. My son was 23 days old at the time. As early as the next day, they contacted me and we agreed on a home visit. I could not believe that it all happened so quickly. This is how I met the Early Intervention Consultants – a rehabilitator, a speech therapist and a psychologist – who I still believe are the best specialists.

We got on the Early Intervention Programme and changes started to happen. I believe they are extremely kind-hearted and highly dedicated people. They treat my little sunshine very well – they cuddle him, play with him, teach him lots of things. They referred us to medical specialists for screening and provided information of other families with a child like ours. They pointed us to a nearby childcare centre where they could help with our child's development.

Rossen started to make progress in many aspects and is now not very different from the rest of the kids. He is about to start walking, is able to say several words and is an inquisitive and naughty child. Every single day he has been showing us his love and giving us this beaming smile of his. Not for a single moment are we sorry that he came into our life. For us he is a treasure; he makes us more patient and shows us the world through his eyes. He and his older brother are our happiness and they give our family a sense of completeness and unity.”

Rossen's mother

#### **4.2. Parents' groups for mutual assistance and support**

Their meetings are facilitated by a qualified psychologist/psychotherapist. They provide opportunity for:

- ✓ Provision of information needed by families in order to take informed and open-minded decisions concerning their children;
- ✓ Encouraging the family to lead a meaningful, healthy life by revisiting emotional experiences related to their concerns about their child's development;
- ✓ Putting an emphasis on available resources and capacity of the family to achieve the desired outcomes;
- ✓ Encouraging parents to be active partners to the Early Intervention Consultants, their skills to meet their child's needs being developed.



### Consultants share

“In order to accept the pace of their child’s progress, the parent needs to overcome their anxiety, answer their inner questions concerning their acceptance of their child’s condition. I had this case where the mother went to two specialists and the child was diagnosed with Generalised Developmental Disorder. But she still fails to understand what this diagnosis means. This is a good example of psycho-emotional adjustment of the parent to the diagnosis, to the reflection of what it means for her and if she is able to accept it emotionally and rationally or she refuses to. This is a long process of accompanying, supporting the parent. Referring her to medical professionals, translating into understandable language why her child cannot speak or does not understand her, what to do to improve communication in their daily life.”

Karin Dom’s ECI Programme Consultants

### 4.3. Individual counselling for parents by a psychologist

The purpose of counselling is to:

- ✓ Improve the understanding of specific children’s behaviours and identify causes and coping options;
- ✓ Improve understanding of age-specific characteristics or manifestations connected with the health status and mental health condition of the child and identify ways to meet needs;
- ✓ Motivate parents to cooperate better with the therapeutic process;
- ✓ Offer support to families during life crises through assessment of their potential and activation of coping resources;
- ✓ Guidance and support for coping with the challenges in children’s upbringing, education and therapy;
- ✓ Monitor the dynamics in the child’s condition and behaviour in the community and in the family, and get feedback.



### Consultants share

“Often enough parents do not expect such rapid progress with their child. But they see the progress; they register and share it at the next home visit. They are highly satisfied and happy. They share that they never expected the child to make so many steps ahead in their development. This is the case when progress is easy to achieve. However, there are other cases too, where results do not come as easily and spontaneously, where parents need to set themselves realistic objectives. P’s mother could only see how her child was different from the remaining kids on playgrounds and this discouraged her a lot. We set specific objectives.

When the objectives are realistic and achievable, the parent feels satisfied. We focused our efforts on the mother-child bond; she gave some thought to what she wanted to achieve with the child, what she believed important for her at this stage. The mother became highly committed; she focused on the child and in 1 or 2 months achieved her objectives. This helped her greatly to feel happy and experience in a different way their mother-child bonding. When she became active and started working with the child, things happened. It is very important for parents to realise that they need to muster up their willpower, have some extra things on their to-do list, put additional efforts at home so that their child can make progress.”

Karin Dom's ECI Programme Consultants

#### 4.4. Informal parents' network

- ✓ Provides the opportunity for families to liaise, exchange useful information, form new contacts, protect their children's rights;
- ✓ Support Parent – an experienced parent whom other parents can turn to for advice or experience sharing;
- ✓ Parents included as Support Parents are specially trained in the most suitable way to support other parents in caring for their own children.



#### Consultants share

“For support parents we use personal contact. I turn to the mothers when there is a similar case in terms of the child's condition or parents' difficulties and I ask that particular mother if she would agree to provide support to another mother, if she would call her. Because we have built a trusting relationship, in most cases parents agree. Parents themselves, on the whole, are well-disposed and when they have good experience and a good outcome in their early-intervention work with us, they gain the self-confidence enabling them to serve as an example to someone else. This also helps them see where they are and how far they have travelled.”

Karin Dom's ECI Programme Consultants

#### 4.5. Parent-child playgroups

Their meetings are facilitated by the Early Intervention Consultants.

- ✓ Provide opportunities for joint activities for parents and children facilitated by specialists;
- ✓ Prepare children for the social environment by developing relevant skills in children;
- ✓ Children get a chance to play and study the world together with their parents;
- ✓ Information, experience and ideas are exchanged, contacts and friendships are developed.



### Consultants share

“Children come to playgroups with their parents and siblings and learn in a small group effective social interactions. They learn to separate from their Mum and make their first steps in a social environment. Very often we recommend a playgroup when the child is soon to undergo an adaptation process in a childcare establishment. The child is taught to greet, take turns in joint activities, follow group rules, wait for their turn when they want a particular toy, know how to ask for it, develop motor skills. For parents it is very useful too; they can see for themselves how their child is developing compared to other kids. We suggest what they can do at home with the child in order to assist in one or other area of development. The playgroup helps them acknowledge the need for socialisation. Once the parent joins, this means they are ready and make the first step towards the child’s socialisation. In addition, the playgroup provides the child and parent with structure and rules. The parent can see that these structure and rules provide a sense of security for the child, the latter is more relaxed, and when they know what comes next and things are predictable, they learn and develop.”

Karin Dom’s ECI Programme Consultants

#### 4.6. Breastfeeding support

Breastfeeding support is included in the services of the Early Intervention Programme since breastfeeding provides the newborn and young baby with the best start to a full and healthy development. The breastfeeding process also contributes to the attachment between mother and baby, which is of great importance in the event of risk of abandonment.

Breastfeeding support is provided by Certified Breastfeeding Consultants who hold individual counselling sessions at the maternity ward, on the phone or in the family’s home. Karin Dom’s ECI consultants have completed training in breastfeeding counselling, some of them being Certified Breastfeeding Consultants. This enables them, if necessary, to provide this kind of support too, as part of home visiting.

#### 4.7. Toy library

The toy library is equipped with toys supporting child development and guaranteeing the right of all children to play. In the library parents and children can play together, tapping on useful advice and guidance from specialists. Toys in the library are selected based on high safety standards, as well as their contribution in five different domains: recognition, orientation, social-emotional area and communication.

#### 4.8. Resource library of books and toys

Parents can borrow specialised books and toys from the Resource Library at Karin Dom to help them with the upbringing of their children.

## 4.9. Information and training activities

This strand of the work has to do with promoting this social service among providers of other community-based services, as well as with the general public. Information activities are implemented in the form of internet publications, media publications, publication and dissemination of brochures, etc. Trainings include organising meetings and workshops with partners, parents, professionals to inform and raise their awareness about the activities that are implemented under this social service. These are aimed at organising training and experience sharing to disseminate good practice. The team takes part in initiatives such as School for Parents, Day of Premature Children; it also holds information meetings on child development and promotion of early childhood intervention. We conduct trainings and advocacy campaigns in order to assist the development of early childhood intervention services across the country.



### Partners share

“The Daycare Centre for Children with Disabilities (DCCD), Svishtov has been in operation since 2008. I have had the honour and pleasure to head this service from the very beginning. As early as then, in those initial years when my colleague experts and I worked in the Centre, we became aware of how much we needed an Early Intervention Programme in the community-based services we provide in Svishtov Municipality. We all know that the first 7 years in a child’s life are highly important. On the other hand, we face challenges arising from attitudes of parents but also of many colleague professionals who, even today, still claim that it is important for the child to visit a professional and this professional is to “correct” the things that are outside the norm with this child. Whereas, one of the valuable things in the Early Intervention Service is the fact that it invests in parenting capacity, in the parent’s ability to understand the child, be their closest and first-port-of-call helper. And this is precisely what we have been missing in the DCCD service.

We have been studying, reading additional information for years and what we saw in Karin Dom’s Programme showed us even more definitively that we are on the right track, we are thinking in the right direction. We have had the opportunity to be part of different trainings at Karin Dom, watch sessions, group meetings and we got this hands-on experience of the huge benefit from this service. All of this has been motivating us over the years always to look for opportunities and options to launch such a programme. Even though we were not included in the MLSP project, when early intervention was launched in Bulgaria, this was no reason for us to give up. We told ourselves: “We will look out for our right time to launch it.” Here it is important to point out the huge role the Mayor of Svishtov Municipality, Mr. Gencho Genchev, and our Deputy Mayor in charge of social services, Ms. Dimitrova, that they both played; thanks to them, last year we managed to submit a proposal and get approval for a project aimed at working with the families of babies and young children up to 6 years of age; we are currently implementing this project, where the Municipality of Svishtov is a partner to the ECIP Foundation, Sofia. All activities are implemented on the territory of the Municipality. None of us ever doubted that the service will be sought after and desired; but what we witness up until now exceeds our expectations. Many families with a variety of problems, issues and challenges look for our help, our support.”

Temenuzhka Todorova, Head of DCCD, Svishtov



## 5. Location and facilities

### 5.1. Service delivery location

The service is provided on the territory of Varna Municipality, primarily in the field – in the home of the families, in maternity wards, neonatological wards, public places, childcare establishments, at Karin Dom. The scope and type of the activities included correspond to the specific needs of the children and families. **Outreach work, where services are provided in the families' homes or another typical setting, has a leading role since it allows for an individualised approach to each child and family, taking account of their specific needs and resources, and helping build a trusting relationship between the family and the professionals.**

The complementary services of the Early Intervention Programme are provided in the main building of Karin Dom Foundation.

### 5.2. Facilities and equipment for service delivery

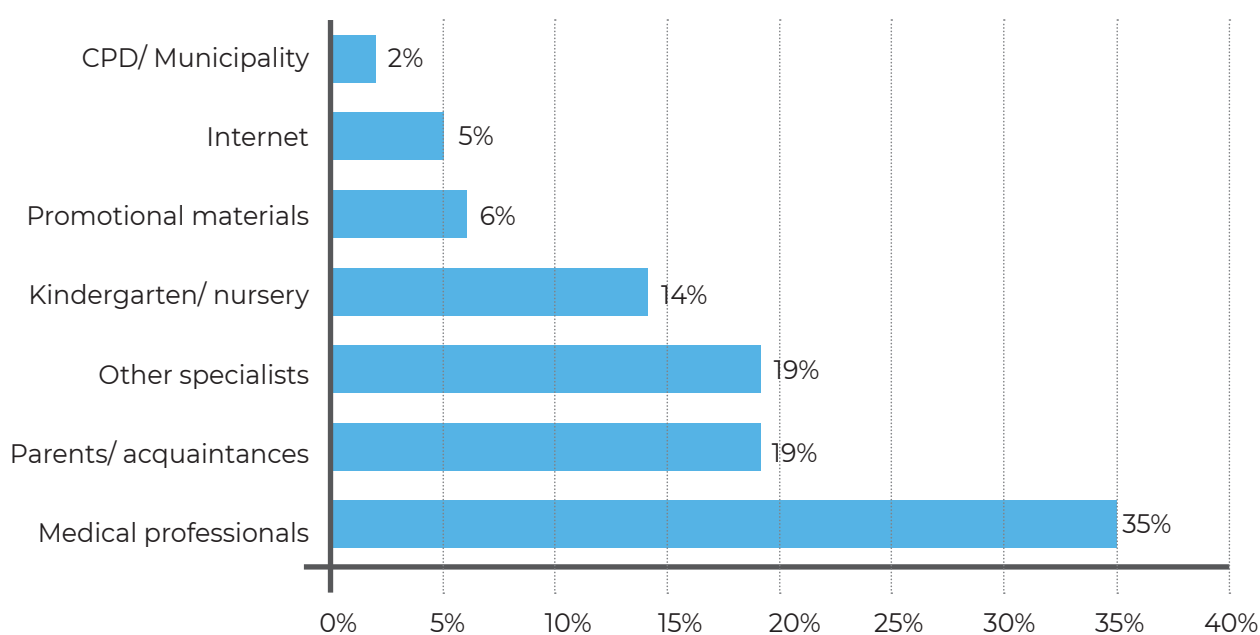
The facilities include an office for the team, a room for group work with children, a parent club and a toy library. The equipment consists of the resource library with children's books and specialised literature for parents; technical means and equipment – computers, printer, mobile phones. Transport is provided for activities.

## 6. Terms and procedure for using the Early Intervention service

### 6.1. Referral to the Early Intervention service

Reporting a child with a disability, developmental difficulties or at risk for abandonment is the first step in the early intervention process. It requires developing an operational 'reporting system' within the community, which should include all stakeholders and institutions (including organisations, individuals and institutions) in contact with children in their early childhood, including parents and relatives, medical establishments and medical professionals in out-patient and in-patient medical care (GPs, paediatricians, medical professionals in maternity wards, etc.), social workers, childcare establishments, social services providers and NGOs.

## Children in services by referral source



This system must also see to keeping families and the community at large informed with a view to facilitating access. Breaking the news about a disability to parents is an important moment in the early intervention process and plays a key role in preventing the abandonment of the child by parents. In many cases parents learn about their child's disability from the medical professionals in the respective medical establishment immediately after the child's birth. In other cases developmental issues can be registered later by the parents themselves, or by medical or other professionals. The provision of psychological counselling to parents at maternity-ward level at the time of breaking the news about the child's disability or risk of possible developmental difficulties is of particular importance. It is highly important for reducing the emotional stress of parents and their adjusting to the new situation.



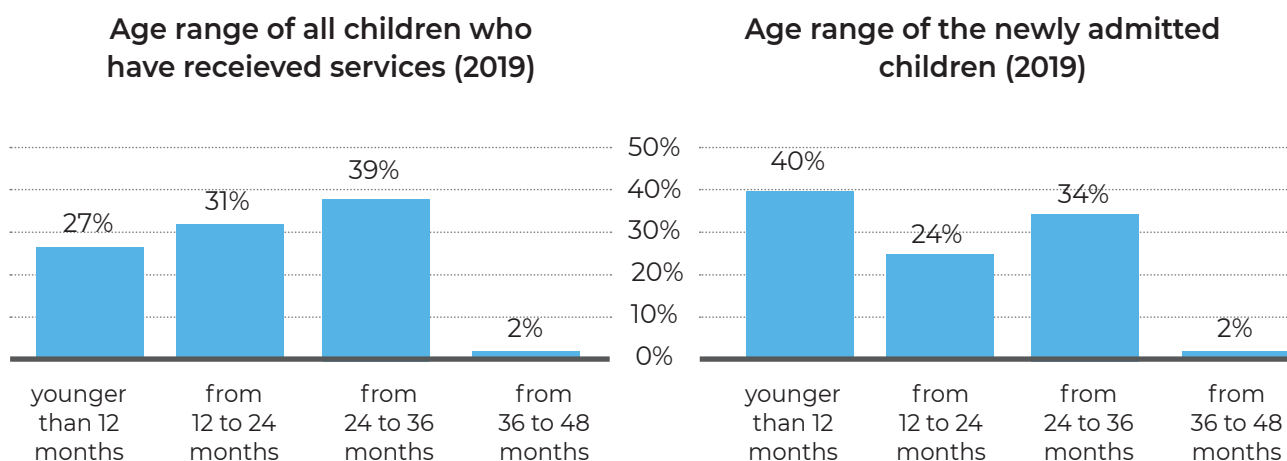
### Consultants share

“A prevailing concern is that the child does not speak, doesn't respond when called by name, doesn't follow instructions – this is common in many requests for the service. In addition, if there is delay in motor development, some parents call us, sharing: “He/she still does not roll from back to front, does not sit without support, does not walk alone, although he/she is already old enough.” Parents do notice when huge developmental milestones get delayed. Also we have a lot of children with syndromes, where they were diagnosed at birth and parents are concerned. We work with extremely premature babies born prior to Gestation Week 30. Another source of referral are psychologists from kindergartens who find, at the admission point, children with atypical development.”

Karin Dom's ECI Programme Consultants

In order to get optimal outcomes from early childhood intervention, it is recommended that when a developmental issue is detected, it is addressed at the earliest possible time.

Below is some statistics on the age of children upon admission into Karin Dom's Early Intervention Programme, as well as on the average age of all children having received services under the 2019 Programme.



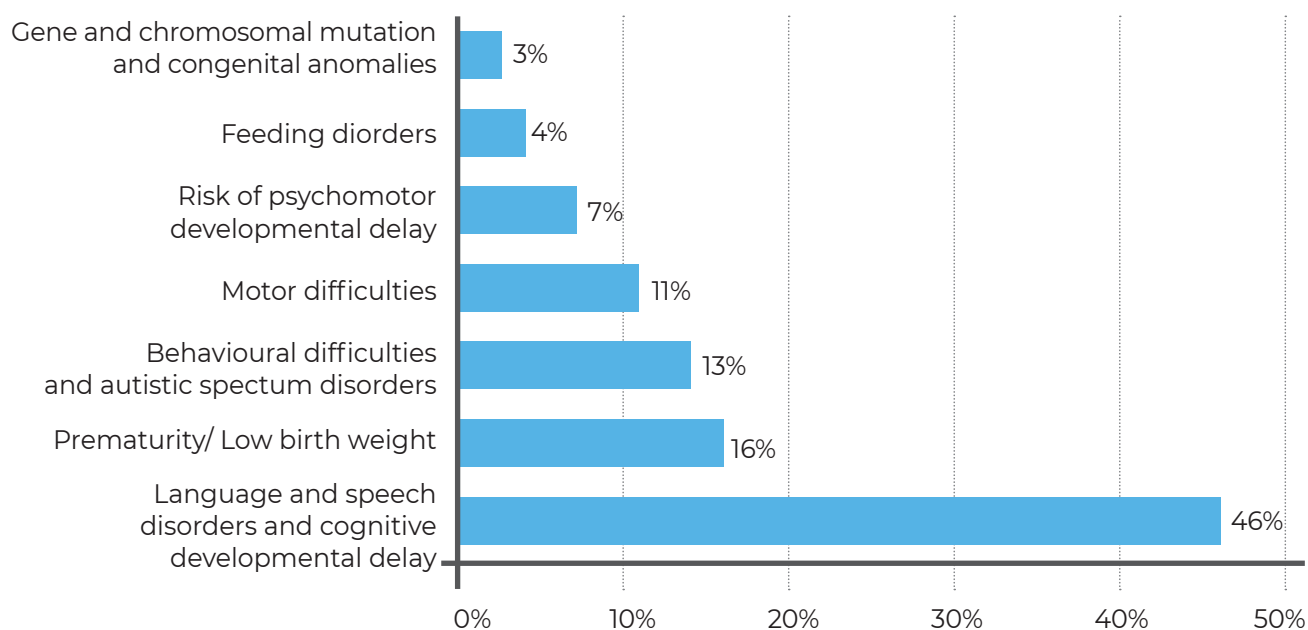
## 6.2. Enrolment in the Early Intervention Programme

The families use the social service on a voluntary basis. Enrolment for early intervention happens when the child's parents express before the provider their own desire to use the service **Early Intervention Centre**. The professionals make a specialist assessment of the needs of the child and the family and draw up a service delivery schedule. A service contract for the provision of the social service **Early Intervention** is signed with the family.

## 6.3. Eligibility criteria for using the service

- ✓ Child's age: 0-3 years, periodic counselling sessions aimed at support for the transition to kindergarten or other services being provided between 3 years and 3 years and 6 months;
- ✓ Risk of abandonment by parents and placement in an institution;
- ✓ Disability or at risk for developing one;
- ✓ Delay in one or several developmental domains – cognitive, motor, speech, social, emotional;
- ✓ Place of residence – the family resides in Varna Municipality where it is possible to make regular home visits.

## Breakdown of children by conditions according to the concerns expressed by parents upon admission into the programme



## 7. Organisation of the Early Intervention Programme

### 7.1. Casework

Following a parent's/ legal guardian's expressed desire to be included in the Programme by telephone, letter or email, it is necessary to collect the following information:

- ✓ Name and age of the child;
- ✓ Name of parent;
- ✓ Who referred the family;
- ✓ Reason for referral/ parental concerns;
- ✓ Address and telephone.

Within 7 working days following the parent's call, the Consultant informs the family by telephone about the date and time of the first home visit.

### First home visit

The first home visit takes place within 2 weeks of the declaration of desire to use the early intervention service. The purpose of the home visits is to get to know each other, to exchange information and to build trust with the family.

### **Documents filled out by the Consultant:**

- ✔ Completes the social situation questionnaire, the personal data consent declaration, and the declaration of refusal/consent of photography.
- ✔ Provides a questionnaire on the child and the parents in order to conduct a specialised assessment of the child's needs. The questionnaire stays with the family and the information provided is discussed with the consultant during the next home visit.
- ✔ The consultant provides the parents with an Ages & Stages Questionnaire for initial screening of the child's development, which is left with the family for completion, but which also allows them to try out the activities outlined in the questionnaire with the child. The results are discussed during the next visit.

Karin Dom implements as a pilot the Ages & Stages Questionnaire (ASD-3) – a screening test to be completed by parents, which studies development in five domains: communication, gross motor skills, fine motor skills, problem-solving, and social-emotional development. The screening findings show if the child experiences a delay in the respective domain compared to the age-specific norm. In 2015-2016, Karin Dom conducted a research study for re-norming ASQ for Bulgaria. Despite this, its official publication is still pending.

- ✔ The parents fill out a service use application and sign a contract with the service provider.
- ✔ The consultant completes the home visit form, leaving one copy with the family.
- ✔ If possible, agrees a date and time for the next visit or specifies a time frame.
- ✔ Leaves an information pack with the parents, which includes: brochures on the remaining activities provided as part of the social service.
- ✔ The consultant drafts a social report on the user's needs.

### **During subsequent home visits, the following takes place:**

- ✔ The Consultant discusses the child's progress and any parental concerns that might have emerged.
- ✔ New activities for the child are proposed. They are demonstrated by the Consultants and then tried out by the parents.
- ✔ A Home Visit Form is completed, a copy of which is left with the family, and another copy is filed in the child's dossier.
- ✔ The Consultant might provide new information, books, information about parent support group meetings that could be useful to the family.
- ✔ The date and time for the next visit are decided on.
- ✔ A Functional Assessment of the Child's Development AEPS – a Assessment, Evaluation, and Programming System, for Children aged 0 to 3 years, is completed. The system is used to assess and determine the strengths of children across different developmental domains. It helps determine the child's current level of skills and plan next steps i.e. the Functional Aims and Objectives in the Individual Service Plan. The assessment exercise may be redone in about 6 months, which helps track the child's progress.

The advantage of this tool is that it links assessment with intervention, which leads to greater effectiveness. It demonstrates the impact on the child's development and helps in the on-going evaluation of the service. In this way it allows parents and professionals to track easily the child's progress, while for funding parties it serves as a monitoring tool to track intervention outcomes.

- ✓ Within 2 months of signing the contract, an Individual Plan for Provision of Services to the Family is developed.

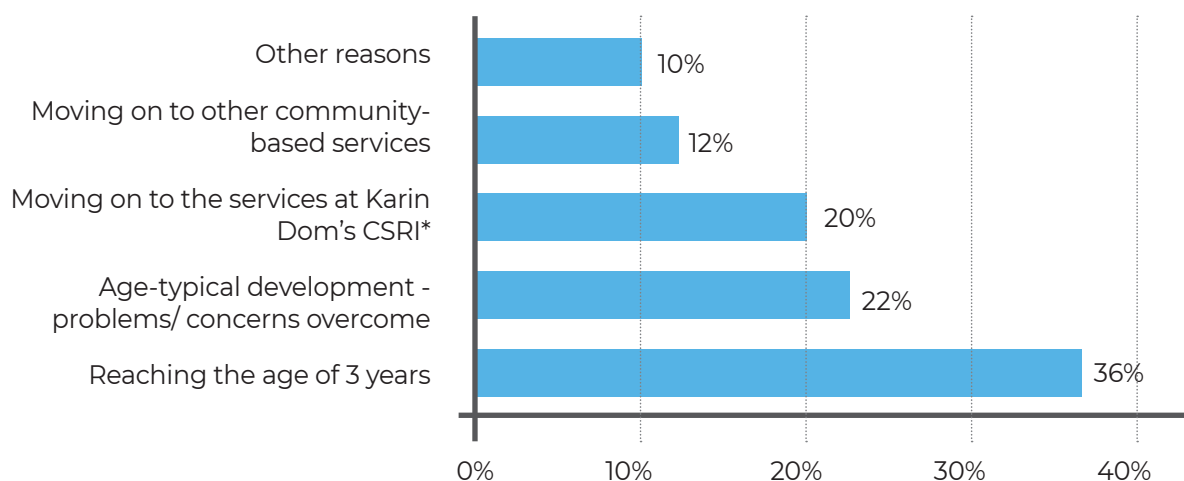
## 7.2. Frequency of service provision

The frequency of the follow-up home visits is customised in accordance with the child's and family's specific skills and interests, resources, priorities and needs, including the need for family guidance in connection with the development of the child and their long-term family goals. **The usual frequency is one or two visits per month, or more if necessary.** At the start, usually visits are more frequent, later to become less frequent.

## 8. Exit of the Programme

On average children stay in the Programme for 1 year.

Breakdown of children by reason for leaving the Programme



On transition to other services, the Consultants prepare an Individual Plan for the family to work on in the next 6 months and support the parents in their choice of services suitable for the child.

\* CSRI – Centre for Social Rehabilitation and Integration

Upon entry to kindergarten, the child might need resource support. The Consultants informs the family how to apply for resource support. The choice of appropriate kindergarten is important too. In addition to the convenient location of the childcare establishment, other factors to bear in mind are accessibility in the built environment and suitable setting, number of children in the group, experience of the teaching staff to work with special-needs children, opportunities to use additional resource support.

**Continuity is important when the child moves on to other services.** In the process of transition, efforts should be focused on team work and communication between the ECI Consultants and the kindergarten staff who will be working with the child. The family and the Consultants visit the kindergarten together; they meet the future teachers of the child and the resource support specialists. They familiarise them with the child's Individual Plan, the work undertaken up until now, the child's current skills and needs. They can offer support to the teachers in the kindergarten, especially when the latter do not feel sufficiently prepared to take on a child with special educational needs in their mainstream education setting. Sometimes a few meetings are enough; other times transition proves a continuous process. Visits from, discussions with and proposals by the Consultants can do a lot for a smooth transition and for making teachers feel more confident and parents more reassured that their child will receive quality care. Trust and cooperation among the early intervention team, the family and the kindergarten is key to the child's successful transition to the next stage in his/her life.

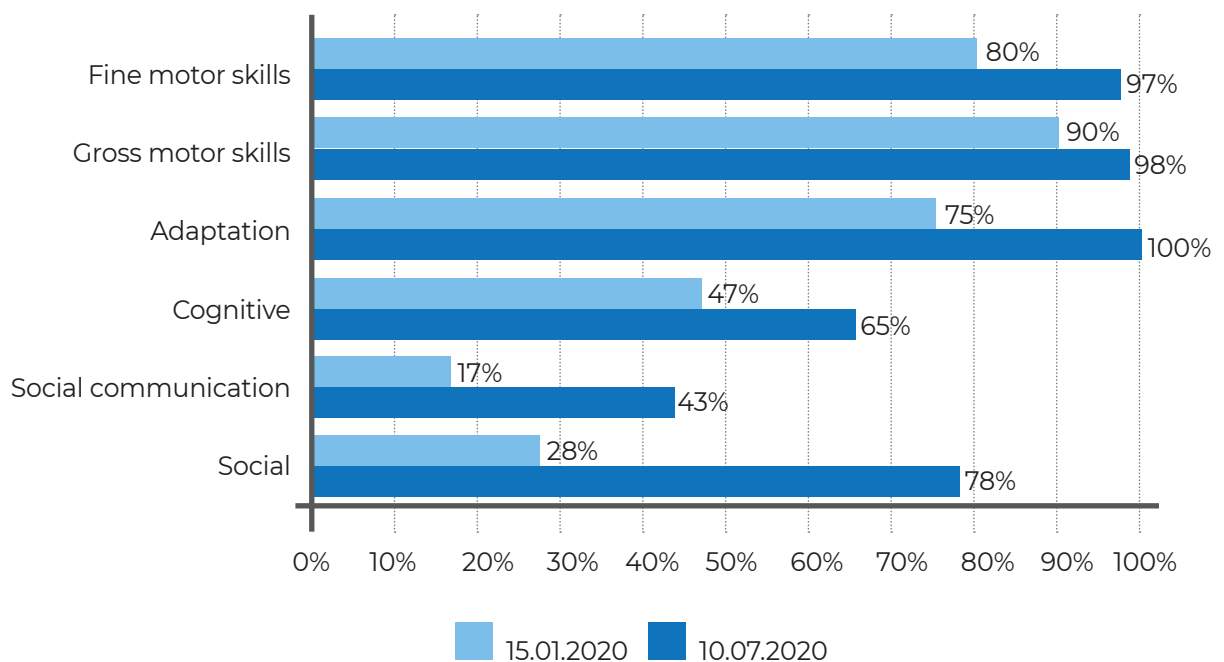
Thanks to the established trust, families and consultants stay in touch. Families call on important occasions, holidays; they inform consultants about the child's progress and the milestones in their life, such as starting Grade 1 at school.

## 9. Documentation

- ✓ Electronic Register of Child Users of the social service – specifically designed for the purposes of Karin Dom's Early Intervention Programme, allowing quick and easy references and production of information reports, statistical extracts for accountability and monitoring purposes;
- ✓ Rules of Operation of the Early Intervention Centre social service;
- ✓ Methodological Guidance on the Terms and Procedure for the Provision of the Early Intervention Centre social service;
- ✓ Rules for Working with Parents in the Early Intervention Centre;
- ✓ Service Planning Schedule;
- ✓ Monthly reporting forms;
- ✓ User Dossier, containing:
  - Service request by telephone form – to be completed at the time of the parent's first call;
  - Initial counselling session form;
  - Personal data consent declaration – during first meeting with parents;
  - Declaration of refusal/consent of photography of the child – during first meeting with parents;

- Birth certificate;
- Medical documentation – maternity ward discharge summary, reports from appointments with medical professionals, results from tests and scans, statements by the Medical Advisory Committee (LKK), the Territorial Expert Medical Board (TELK), etc.
- Ages & Stages Questionnaire (ASQ) – to be completed at the first meeting, bearing in mind the precise age of the child. In the course of joint work the Ages & Stages Questionnaire is to be completed regularly;
- Questionnaire for parents to identify the child's needs – to be handed to the parents during the first home visit and discussed together with the consultants at the second meeting;
- Home visit form – to be completed for each individual home visit;
- Application from parents to use the social service – during the second meeting with the family;
- Service contract for the provision of the social service – during the second meeting with the family;
- Initial assessment – social situation questionnaire, social report on the family's needs, medical case history and individual assessment report on the needs of the child – during the second meeting with the family;
- Assessment, Evaluation, and Programming System (AEPST™) by Developmental Domains;

**Reporting on the progress by developmental domains of a three-year-old child over a 6-month period based on AEPST™**





- ✓ Individual plan for provision of services to the family tailored to the child's individual needs – within 2 months of signing the contract;
- ✓ Team opinion (if necessary);
- ✓ Case discussion minutes (if necessary);
- ✓ Final report/ Exit assessment.

## 10. Building a partnership network

Over the years of operation of Karin Dom's ECI Programme, alongside results achieved in the work with children and their families, efforts have been made towards establishing partnerships with different institutions – local and central. There are many examples of good practice of cooperation and interaction with healthcare establishments for referring families to the Programme as early as maternity-ward level – the maternity wards of *Prof. Dr. Dimitar Stamatov* Specialised Gynaecology and Obstetrics Hospital for Active Treatment, Varna and *Sveta Anna* Multi-Profile Hospital for Active Treatment, Varna. At the start of the Programme information meetings were held on the spot and partnership agreements were signed with hospitals, in which the joint commitments of the parties were specified. Neonatologists refer premature babies to the Programme and, thanks to the joint work, these children quickly catch up with their peers. We also liaise with paediatricians and GPs who refer children to us and together we monitor the development of children with developmental difficulties or disabilities.

There are also in place good practices of partnership with local institutions working with children: the Child Protection Department, the Directorate for Social Assistance, the Mother and Baby Unit, partnerships with municipal structures: the *Social Activities* Directorate, the *Education and Youth Activities* Directorate, the *Healthcare* Directorate.

Good partnerships and practices as part of joint projects have also been developed with mainstream childcare establishments – nurseries and kindergartens, as well as partnerships with other NGOs. Karin Dom's team provides trainings and supervisions to teams in kindergartens in Varna and across the country. Thanks to the partnerships built, colleagues from kindergartens turn to the team and seek advice on appropriate strategies in the work with individual children. At the end of 2019, at the request of Varna Municipality, a training of staff from nurseries in the city of Varna was also planned. The process of inclusion of children with special needs in the mainstream education system is a continuous and multi-faceted process; for us it is important to continue with our work and contribute to this cause.



## Partners share

“Parents share that trust is built between them and the professionals”, “As at today, the social service *Early Intervention* corresponds to the needs”, “The approach contributes to the sustainability of the outcomes achieved with the child, since the parent takes an active part and has been acquiring knowledge and skills”.

Partners from the social sector (Child Protection Department, the Social Directorate at Varna Municipality, NGOs)

“I refer to Karin Dom because I can see the positive change in children and families, (...) they also link the family to other services.”, “I refer to Karin Dom and they refer to me so we help each other when it comes to adequate nutrition.”

Partners from the healthcare sector

“We modified the environment, introduced visual schedules; we use pictures of symbols and gestures. This had an effect on the children – we witness their improved ability to communicate and social interaction. We are grateful for the cooperation!”

Partners from the education sector (kindergartens)

“I’m happy to say that this is one of our best partnerships with colleagues working in the education system and we managed to reach out to the settlements in Svishtov Municipality, to the villages where professionals hardly ever get. And this is the other great benefit of this service, the outreach work, so that specialists are where the child and their family is, where their kindergarten, group or nursery is. Svishtov is a municipality where for years now we have been having very close contacts with the mayors of the various settlements, with the Child Protection Department, with colleagues from the other social services. We have been using the contact network we have established and maintained very well over time. We use local and regional media, conferences, any channels to make sure the information reaches out to the largest possible number of families. This is how this network built over many years appears very useful to make sure the information reaches the families.”

Temenuzhka Todorova, Head of DCCD, Svishtov, where Early Intervention services are also developed

## 11. Budget and sources of funding

The main source of funding of the Early Intervention Programme is through the municipal-delegated activity mechanism with funds allocated from the Varna Municipality Budget. The monthly funding by the Municipality of Varna for 40 children includes the following budget items:

### A. Remuneration for professionals:

1. Home visits
2. Individual counselling sessions for parents with a psychologist
3. Parent-child playgroups
4. Breastfeeding sessions at maternity-ward level
5. Transport – 1 driver

### B. Expenses for materials

1. Special aids, toys, books
2. Consumables
3. Transport – fuel, maintenance

### C. Expenses for external services

1. Telephone, electricity, water
2. Activities and materials for promotion of the service

Some costs, such as transport, are partly covered. For them and the other activities in the programme, project funding is sought; charity campaigns, fundraising events are organised or support from private and corporate donors is encouraged. Each activity is sustainable over time, different options for its financial provision being sought.

## 12. Quality control and supervision in the service

Quality control over the services of the ECI Programme is internal and external. The internal control is performed by Karin Dom's management, while the external – by Varna Municipality.

One of the service consultants acts as the team manager. The manager is in charge of: organising weekly team meetings, on-going case discussions as part of the work with children and families; the cases of newly admitted children; teamwork, observance of the core principles and standards of the Early Intervention Programme, sharing of successes and challenges and support to consultants; coping with professional burnout; dealing with communication at the management level with the other units in Karin Dom Foundation.

Internal control includes review of documentation – home visit forms, individual plans, exit assessments. These documents are informative of the way home visits happened, what activities were proposed, what developmental aims and objectives were set in relation to the child and what progress was made towards their achievement. The AEPS assessment made through comparison of the results at the start and end of a given period shows the child's progress by developmental domains.

Control over the quality of the service is exercised by means of interventions and supervisions. The Team Manager and the Director of Services for Children and Families hold supervisions for consultants on a monthly basis. Their findings are recorded in individual protocols. External supervisions are undertaken by Bulgarian and international consultants (supervisors), the findings of which are discussed with the management team and the Early Intervention Centre team and measures are undertaken to raise the effectiveness of the service.

Every week the Consultants join the in-house training sessions for therapists at Karin Dom Foundation. They attend Bulgarian and non-Bulgarian trainings, seminars, conferences to enhance their knowledge and skills. They share their practices with other organisations. This is how they upgrade, build on their knowledge and skills, which affects the quality of the offered service.

Another instrument to monitor Programme results is the electronic register used to obtain statistical information. This information serves as the basis for developing the technical monthly report for the social service.



### III. Effectiveness of implementing Karindom's ECI model

The early intervention model to support parents of children with developmental difficulties or disabilities is based on the **family-centred approach**. The family-centred approach centres around work not only with the child but with the entire family. The model consists of support to parents to care for their child themselves, based on the conviction that parents know and can identify best their child's needs. This approach is different from the expert approach to work, where professionals, be they doctors or therapists, diagnose and prescribe treatment or specify the area of intervention. The family-centred approach is about equal cooperation between parents and professionals. Parents can set the priorities for their family and their child's development, while professionals are there to help them work towards the achievement of the objectives they have identified.

**With this model, admission into the service is open; parents can seek advice if concerned about their child's development without any need to wait or get a referral. The service is accessible and due to its dynamics there is no long waiting time.** Integrated and flexible services are provided in compliance with the individual needs and capacity of the child and the family. There are time and funds savings for the family due to the mobile nature of the service. In addition, the family gets guidance on the required medical tests, and consultations, which saves them the stress, disorientation and going from one specialist to another.

The Early Intervention Consultants provide support in the child's natural environment – at home, where the child feels safe and protected. This lowers the level of stress in parents too. The home setting and the resources available to the family are used. For example, parents might consider it important that their child learns how to move around the house, using the furniture. The consultants propose to the parents strategies for coping with the challenges in caring for their special-needs child and support them in all activities related to bringing up their child – feeding, positioning, creating an appropriate environment in the home, etc. The consultants demonstrate games and exercises that parents and child can do together to improve the communication between them or to assist the child's development in one area or another. The service methodology corresponds to the family's needs. Parents come up with objectives and focus on their own efforts. Measureable and achievable in short time objectives are set. Activities are proposed to be tried out by parents prior to the next visit and then they share the results.

Consultants have another role too – to assist the family to liaise with other, complementing community-based services. These services could be therapy in a specialised centre, an examination by a doctor, enrolment in a nursery or kindergarten, visiting a daycare centre, use of statutory social benefits, among others. This is why establishing and maintaining a contact and partnership network with other organisations and institutions in the community is particularly important for the success of early intervention. The early intervention model is, by nature, a model of **integrated services for children and families**, early intervention being placed as the main support unit.



## IV. Achieved outcomes for children and families. Two examples from practice.

**One of the advantages of applying Karin Dom's ECI model and the family-centred approach is family empowerment.** A survey seeking to evaluate Karin Dom's ECI Programme studied the level of satisfaction of 296 parents in the 2013-2015 period. The comparative analysis over the three-year period showed great parental progress as regards their involvement and confidence about putting in practice the proposed activities. The data analysis demonstrated to us how parental confidence, competence and self-awareness about the importance of their own role for the child's development have increased. Towards the end of the survey a lot of the parents responded that their child's progress is due to the persistence and regular activities at home. This is a positive tendency because it demonstrates how the Consultants managed to activate the power of families.

**Independent, confident parents are better advocates for their children in the subsequent stages of children's lives. Their positive early parental experience also makes them better advocates for changing the policies, which is the road to building a single national early childhood intervention system.**

The two stories below, as told by Karin Dom's ECI consultants, illustrate best the programme outcomes.

#### **VYARA'S STORY\***

We met Vyara's parents at the Child Protection Department in Varna. The reason for our meeting was the risk of the child being placed in an institution and the possibility of her parents giving up their parental rights. The Department asked us to join the meeting because they relied on our experience with children with special needs and their families. Vyara was born in Gestation Week 28, weighing 600 grams. Her father tended to believe that she might not make it and was unwilling to own the child. Being hesitant, the mother received advice only from her own mother not to give up on Vyara.

A psychologist and a social worker from Karin Dom's Early Intervention Programme met the two parents, together with social workers from the CPD. At this meeting the parents voiced their concerns and shared that the prospect of taking care of an extremely low birth weight child in their view was "full of risks". Together we discussed the health status of the child and the possibilities for her to be brought up in a family environment in the future. At the time, Vyara's discharge from hospital was forthcoming and she was about to be transferred to the House for Medical and Social Care for Children to be further cared for there. We proposed to the family not to lose touch with Vyara but keep visiting her in the maternity ward instead. We talked about the fact that in general terms early childhood development can hold risks for every child. But sometimes the resilience and will to live of a tiny human being can indeed surprise us. We ended our meeting by wishing that each day brought decreasing risk for the baby.

This is how we managed to put up the definitive inclination of these parents to abandon the child. We were getting news of Vyara developing very well – being bottle-fed instead of tube-fed, crying with a clear voice, demonstrating very good reflexes. The mother and father were encouraged with their child's progress. The happy ending of this story is that the father owned Vyara and she is already in a family environment taken care of by both her parents.

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\* Names are changed with a view to preserving anonymity.



## **NELLY'S STORY**

A partner association turned to Karin Dom's Early Intervention Programme with regard to an at-risk child placed in a foster family. Weighing 1000 grams, Nelly was born in Gestation Week 28 and developed post-natal complications. I made the first home visit as a rehabilitator, together with the Programme's psychologist. We met the three-month-old Nelly, talked about the family's expectations, needs and priorities and planned the future support. I started visiting the family twice a month to work for the child's motor development. She had quite a few neurological complications and I referred the family to different medical specialists. We helped the family get a pram in which to take Nelly out. Our partners monitored the case too, making sure all tests and scans happened on time, while the foster family cooperated and followed the recommendations seeking to assist the proper development of the child.

When Nelly became 9 months old, we got the news that she was soon to be adopted. Our visits continued in her new family too; they responded with understanding and enthusiasm to the information and advice provided by us. Nelly quickly got used to her new family; her motor deficits were remedied. After she started walking, the home visits began to include also a speech therapists, and the family joined a playgroup at Karin Dom.

Less than a year has passed by since Nelly was adopted but her development is excellent. If you do not know her social and medical history, you would not believe that she belonged to the so called at-risk-children category. Recently, her family announced that they were about to adopt a little boy. We are happy that, supported by us, the parents feel motivated and ready to embark on another adoption so soon after the first. We keep visiting Nelly's first home too. Her foster family gained valuable experience and confidence and they are now taking care of a third premature child.



## V. Benefits for the community

Leaving childhood problems unresolved affects not only the life of the children and families concerned; it also has an effect on society, undermining the welfare of communities and reducing people's chances to live good and successful lives. Building healthier, happier and more productive communities can happen only if we support children to develop their potential.

Many of the potential benefits of early intervention are manifested only in the long run and are wide-spread in society – from individuals and families to local communities, and at all levels of management.

For example, reduced behavioural problems in childhood will lead to children having less destructive behaviour in school and requiring less additional support from teachers. This has the potential to bring about improved academic achievements and income over their lifespan both for the child receiving early intervention and for their peers, due to the smoother education process. This can also reduce the likelihood for school dropout, as well as reduce the chance for involvement in criminal activity, lowering in turn the burden on the justice system. This can also lead to less risky behaviour on the part of children and young people, such as alcohol and drug abuse, which can in turn affect health insurance costs and lead to improved welfare throughout their life.

The following short-term and long-term benefits can be observed with children who got early intervention:

- ✓ academic achievements;
- ✓ social and emotional adaptability;
- ✓ physical health;
- ✓ better employment and higher incomes;
- ✓ fewer cases of institutionalisation or ending up in detention or prison.

The development of a young child is sometimes affected by a number of risk factors such as poverty, poor diet, a mental condition or disability of parents, institutionalisation, placements in different families to receive care, substance abuse, violence and neglect, as well as parental low level of education.

When early intervention services are provided, these risks are counterbalanced by defence factors. As a result of support through ECI, parents cope easier with the challenges of daily life and the stress of parenting, receive support from the extended family and friends, their basic needs are met. Parents understand the child's development and acquire knowledge of parenting. The child can demonstrate how he/she feels, and can also interact with others in a positive way. The more the risk factors in the child's life, the more hampered their growth and development. The more defence factors, the more likely the progress with the child's growth and development.

Children getting early childhood intervention show better levels of school readiness. Many of these children, upon entering kindergarten, need fewer services. They have developed social-emotional skills, ability to communicate and they adapt more easily to the group environment. Also, one out of three children does not need resource support when they go to school.

Investing in early intervention pays in the long run, over the lifespan of the individual. The economic benefits of early intervention for society will, over time, exceed the early intervention costs. The benefits for the community are reduced future costs for healthcare, education and social security. Early childhood intervention contributes to building a more equitable, mature and harmonious society.



## VI. Challenges to early childhood intervention in Bulgaria

- ✓ The still existing social stigma on children with disabilities and their families leads to parents' unwillingness to share their concerns and seek professional support for their children. The benefit of early intervention is ignored both by parents and specialists – the tendency is to wait until the child is 3 or 4 years old.
- ✓ No standard mass screening is applied in Bulgaria for rapid assessment of child development by paediatricians, GPs and other specialists working with young children in order to identify and refer children to services.
- ✓ The main processes for introduction of ECI – screening, referral, diagnostics, monitoring – are not widely recognised. The provision of services in many cases is tied to a diagnosis, very often the latter being made after the age of 3 years. This leads to skipping the most sensitive period of early childhood development.
- ✓ The location of ECI service delivery is still usually at centres with professionals applying an expert model without parental involvement.
- ✓ The model shift, from expert to family-centred, is found challenging. Despite the difficulties in introducing the family-centred approach, it produces the best outcomes in

terms of shared responsibility and professionals and parents trusting each other, sharing a common view and working in synergy for the child's progress.

- ✓ Staff recruitment, retention and training are problematic. The level of staff turnover hampers continuity and reduces the quality of services. In many settlements the number of specialists is insufficient. There is no training of professionals in working with young children and applying the family-centred approach.
- ✓ Differences in the quality of the services provided and the availability of community-based support systems in urban versus rural areas, as well as in large versus small settlements, which widens the social inequality gap.
- ✓ There are still no unified state standards in place for financial provision and service quality for ECI.

## VII. Recommendations on developing early childhood intervention services

- ✓ Use universal child-development screening to enable early identification of children at risk or with developmental difficulties and their referral for further assessment.
- ✓ Provide easy access to the service, work towards changing the tendency for waiting, in order to ensure timely intervention.
- ✓ Promote community-based fieldwork/identification of children in order to make sure that the 'hidden' at-risk children are identified and offered developmental screening, and if necessary, they are referred to ECI services to guarantee that no child will be left behind.
- ✓ Establish contacts with paediatricians, GPs, hospitals with maternity and neonatological wards, nurseries and kindergartens, Child Protection Department, Mother and Baby Unit and other community-based services working with children and families to ensure referrals to early intervention programmes. It is important to track back referral sources in order to be able to plan for identification and inclusion of children in need of ECI services.
- ✓ Hire specialists with various professional qualifications in the teams providing ECI services to share and integrate knowledge across the team. ECI professionals should gain knowledge also in other areas and disciplines, in addition to their own narrow specialist area, so as to be useful to the families and support them in the best possible way.
- ✓ Provide professional induction training, upskilling and supervision for ECI professionals and other specialists working in interdisciplinary teams.
- ✓ University programmes either as a post-graduate qualification or a master's degree programme, for training of early childhood intervention specialists.
- ✓ Mentoring programmes for newly appointed and young specialists in ECI services.
- ✓ Build competences in experts performing controlling functions to monitor the quality of ECI services not only by desk checks but also by reviewing the direct work with children and families.
- ✓ Provide training to medical staff, more specifically midwives, to improve their skills and experience to support successful breastfeeding.
- ✓ Breastfeeding to be included in medical standards, thus providing for incorporating breastfeeding counselling costs in healthcare budget lines for maternity wards.





Karin Dom

### **About *Karin Dom* Foundation**

Karin Dom is a non-governmental organisation founded in 1996 by the hereditary diplomat and philanthropist Ivan Stancioff. It is one of the first centres in Bulgaria providing services for children with special needs using an entirely new model. The foundation is a dream come true both for its founder and for parents, children and professionals, who, in the course of time, have been joining forces for the benefit of children. Karin Dom not only offers therapy services, but it also provides an environment for the development, training and emotional growth of children, all of which based on the family-centred approach. The organisation advocates for changes in policies for children at local and national level, and is a member of prestigious national and international organisations.

Further information about our activities, services and resources can be found at

[www.karindom.org](http://www.karindom.org)



NATIONAL NETWORK FOR CHILDREN

### **About the National Network for Children**

The National Network for Children is an alliance of civil society organisation and like-minded individuals working with and for children and families throughout the country. Promoting, protecting and respecting children's rights are some of the key principles that bring us together. Each year, our member organisations provide support to over 110,000 children, over 26,000 families and around 5,000 professionals.

[www.nmd.bg](http://www.nmd.bg)