Early assessment coupled with early intervention

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

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

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

Family support networks instead of institutions

Home visits per year by Karin Dom Foundation

<table>
<thead>
<tr>
<th>Year</th>
<th>Visits</th>
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</thead>
<tbody>
<tr>
<td>2013</td>
<td>652</td>
</tr>
<tr>
<td>2014</td>
<td>801</td>
</tr>
<tr>
<td>2015</td>
<td>925</td>
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</table>
Support begins at the maternity hospital immediately upon birth through breastfeeding advice, consultations with psychologists, play groups for children and parents, home visits, play and therapist sessions, and any other activity considered beneficial for the development of the child. Karin Dom Foundation does not perform residential care but works in the natural environment of the child.

THE PROBLEM:
A medical centred approach still prevails

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

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

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

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

THE DEVELOPED SOLUTION:
A family centred approach is introduced

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

ABOUT BULGARIA
Struggling to advance in the World’s Mothers Report

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

THE MODEL:
The child’s home becomes the focal point

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

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

Playgroup and support Network
The second service is the parent-toddler playgroup. The playgroup offers an opportunity for parents and children to interact with each other, learn through play, meet new people, make friends, and have fun together. Parents and specialists work together to teach children new skills and habits (cognitive, motor, speech, social). The playgroup sessions take place at an appointed hour in a specially equipped playgroup room in the Karin Dom headquarters, including age-appropriate toys. The playgroups provide an opportunity for the children to socialize in a group environment, and thus be better prepared for inclusion in a nursery or a kindergarten. In addition, the playgroups provide an opportunity for parents to practice new models of child-parent interaction.

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

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

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

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

FACTS AND FIGURES:
Almost 1,000 home visits in 2015

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<tr>
<th>Year</th>
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<th>New cases per year</th>
<th>Closed cases per year</th>
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<table>
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<tr>
<th>Year</th>
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<th>Number of single consultations per year</th>
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<tr>
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<tr>
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<td>652</td>
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<td>78 boys</td>
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<td>120</td>
</tr>
<tr>
<td>2013</td>
<td>87 boys</td>
<td>55 girls</td>
<td>142</td>
</tr>
</tbody>
</table>
Maternity Hospital

Support

Baby-friendly practices promote breast-feeding

GOAL

SCHOOL

Inclusive
It is important to note that Karin Dom does not perform residential care. Early intervention services are provided exclusively in the child’s natural environment – his or her home, playground, kindergarten, etc. This model differs from Bulgaria’s common practice of delivering centre-based services to young children. Each Early Intervention Team consists of a physical therapist, speech therapists, special educator, psychologist, paediatrician, social worker, and breastfeeding consultant. The Foundation’s teaching staff consists of five full-time members as well as five additional members who work with the therapist team but also work as part-time trainers. If necessary, Karin Dom uses outsourcing services.

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

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

FUNDING:
Private and public funding have been secured

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

OUTLOOK:
Working on further dissemination of the program

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

OBSTACLES THAT REMAIN:
Inaccessible architecture, lack of assistance and training

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

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

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

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

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

HOW THE COOPERATION WORKS:
Karin Dom and For Our Children Foundation

• The past cooperation between Karin Dom Foundation and For Our Children Foundation has been designed to share experiences in developing an Early Intervention Programme and to combine efforts towards sustainable development and awareness-raising regarding the new early childhood intervention (ECI) services in Bulgaria. To this end, the two organizations issued a common manual on the provision of ECI services, since both organizations apply the same approach.

• The two organizations differ, however, in the variety of other services that they offer (for example, For Our Children Foundation offers the prevention of child abandonment in maternity wards, development of parental capacity, family support, and foster care, among other services), and the two operate in different locations of Bulgaria.

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ABOUT ZERO PROJECT ANALYSIS
In-depth Research of Innovative Practices

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This in-depth analysis can be downloaded for free at www.zeroproject.org and www.easpd.eu

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