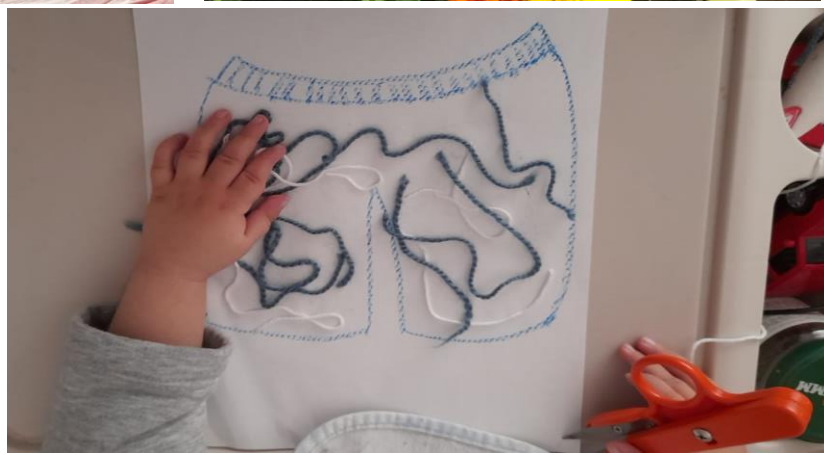


# ErISFaVIA

## Early Intervention Services for Families with Children with Vision Impairment and Additional Disabilities

### IO2

### Literature Review and Needs Assessment Study



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# Literature Review and Needs Assessment Study

## Intellectual Output 2 (IO2)

ErISFaVIA

Early Intervention Services for Families with Children with Vision Impairment and Additional  
Disabilities



Early  
Intervention  
Services for  
Families with Children with  
Vision  
Impairment and  
Additional Disabilities



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10	Mali dom-Zagreb dnevni centar za rehabilitaciju djece imladezi	



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## Contents

I. General framework of Early Intervention. Policies and legal support for early intervention programs .....	7
I.1. Legislation and human rights. Fundamentals of early intervention. ....	7
I.2. Scope of current EU policies and programs .....	8
I.3. Effective policy making for universal and targeted early intervention programs .....	9
I.4. Implications on training curricula.....	10
I.5. Early intervention programs with empirical/ scientific/ theoretical support. Examples of Early Intervention Programs .....	12
II. Literature review. Effectiveness of early intervention programs on child development. ....	21
III. Early childhood development. Characteristics, implications of VI and MDVI on development, assessment and intervention. ....	27
III. 1. Characteristics of Early childhood development .....	27
III.2. Developmental implications of vision impairment, MDVI and dual sensory impairments .....	32
III.3. Assessment in infancy and early childhood.....	34
III.4. Examples of assessment instruments .....	39
III.5. Limits of early assessment and identification .....	43
III.6. Strategies used in the approach of children with hearing and/or vision loss .....	43
III.7. Interventions for Children with Sensory Disabilities.....	44
IV. Best practices in the field of early intervention in partner countries from ErISFAVIA. Policies and legal support for Early Intervention Erasmus+ ErISFaVIA project partner countries. Scope of current and previous EU programs and other research regarding early intervention in your country. ....	50
IV.1. CROATIA.....	50
A. Policies and Legislation .....	50
B. Early Intervention Programme - MALI DOM -Zagreb .....	55
IV.2. CYPRUS.....	64
A. Policies and Legislation .....	64
B. Early Intervention Programme – St. Barnabas School for the Blind.....	64
C. Screening and assessment instruments .....	67
IV. 3. GERMANY .....	68
A. Policies and Legislation .....	68
IV.4. GREECE.....	75
A. Policies and Legislation .....	75
D. 1. Early Intervention Program (E.I.P.) – AMIMONI .....	85



Protocol of entering the program (Conditions and procedures for participating to the program)	86
The Early Intervention Multidisciplinary Team (EIMT) – role and functions	87
Assessment tools used by the E.I.P. of Amimoni.	88
Collaboration with the family.	90
Intervention with the child	90
Surveys/Research on the E.I.P. of Amimoni for children with vision Impairment.	91
IV.4. ROMANIA	98
A. Policies and Legislation	98
IV.6. TURKEY	109
A. Policies and Legislation	109
C. Early Intervention programs	115
V. REFERENCES	117



## I. General framework of Early Intervention. Policies and legal support for early intervention programs

### I.1. Legislation and human rights. Fundaments of early intervention.

Early intervention needs to be considered the centerpiece in our society's efforts on behalf of children at risk and their families. A coherent system of evidence-based interventions has to emerge in response to the needs of young vulnerable children. Previous research in the domain of early intervention shows that if early intervention programs are properly organized they can prevent or minimize the implications in cognitive development that typically occur in the absence of any type of intervention during the first 5 years of a child's life. Moreover, the early intervention system can not only contribute directly to children's development but also can reduce the stress factors associated with the family at risk or child disability. Short-term benefits of early intervention have been highlighted in the past 25 years for children at risk and those with diagnosed disabilities. In order to achieve longer-term benefits, it requires highly intensive interventions that need to be regulated by national policies and they need to be of sufficient duration to extend over various transition points in the children's lives.

From a historical point of view, the Convention on the Rights of the Child (CRC) is the first globally recognized legal document that focuses on the unique needs and vulnerabilities of children (<https://www.unicef.org/child-rights-convention>). The CRC is based on four principles: nondiscrimination, devotion to the best interests of the child, the right of life, survival and development, and respect for the views of the child. Respecting the above-mentioned principals it endorses the idea that a nurturing environment is essential for a child to develop to his or her fullest potential, and this environment is created and supported by social, cultural, political, economic, and civil rights (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2009).

Although international legislation specific to early intervention is rare, one can use the principle of universal human rights to judge the policies and programs available in individual countries. For example in 1948 the Universal Declaration of Human Rights Article 25(2) states that childhood is a period that requires special care, assistance, and protection (<https://www.humanrights.com/course/lesson/articles-19-25/read-article-25.html>). Acceptance of the Universal Declaration shows political support for equality for all people of all countries, religions, ethnicities, and socioeconomic backgrounds who should be respected for their essential worth as human beings.

One policy that refers mainly to children with disabilities is the "Declaration on the Rights of Disabled Persons adopted in 1975 and specifies the rights of persons with disabilities to receive tailored interventions and services considering their particular needs, the right to receive the appropriate treatments. On the other hand, there are many international policies regarding children that focus on their right to education. The main reason for this focus is the consideration that



education represents the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty and obtain the means to participate fully in their communities (UNICEF, 2007). Similar approaches appear in the United Nations Educational, Scientific, and Cultural Organization's (UNESCO) Convention against Discrimination in Education (1960), the International Covenant on Economic, Social, and Cultural Rights (1966), and the United Nations Convention on the Rights of the Child (1989) (UNICEF, 2007). These policies show the international community that education is a human entitlement to which children with special needs should not be excluded; indeed, education may be the only available mean through which vulnerable or marginalized children can achieve a better quality of life.

A more recent international policy is the Convention on the Rights of Persons with Disabilities (the Convention) and its Optional Protocol (a related document that outlines procedures that may be used by countries adopting the Convention) and was adopted in December 2006 by the United Nations. It is the first comprehensive human rights treaty of the twenty-first century and considers individuals as members of the society who are knowledgeable of their rights, capable of claiming those rights, and active members.

Each of the policies described here outlines principles that countries should strive to follow and not contradict through national-level laws or actions. The policies have wide-ranging goals with vast differences in implementation and the level of achievement reached in supporting countries. Some of them include qualifications, such as being subject to available resources, which provide countries a necessary means to show support, but not meet, the ideal described by international standards. Even with their limitations, these policies are advantageous because they draw global attention and coordination action to meet the educational, health, social, and other needs of all children.

## 1.2. Scope of current EU policies and programs

The European Commission Commission for the following years sets the issue of tackling poverty and social exclusion as one of the EU's key priorities. Statistics show that out of 80 million people in the EU who were at risk of poverty, 19 million of them were children. Although the reduction of child poverty and exclusion was not made a specific target, it is considered to be an integral part of the overall target of reducing poverty and social exclusion. In order to address their priorities, a key aspect of the European Semester process which implements the Europe 2020 Strategy is the adoption of some country-specific recommendations by the European Council. In 2014 twenty-six Member States received recommendations relating to children covering: income support, efficiency/effectiveness of Early Childhood Education and Care (ECEC)/ childcare (access, affordability, quality), inclusive education/early school leaving, affordable housing, financial disincentives, reconciliation, youth activation, health, and Roma. Regarding the ECEC, **acknowledges the crucial importance of going beyond the earlier conceptualizations of children's services purely as child care for working parents and embraces the importance of integrating care and education and addressing children's needs holistically.** A focus on child





well-being emphasizes the importance of high-quality ECEC to foster the development of the child, regardless of the work status of the parent(s).

EU leaders have recently established ECEC as one of the core social rights of European citizens. One of the 20 key principles of the European Pillar of Social Rights states that 'children have the right to affordable early childhood education and care of good quality'. Moreover, it emphasises that “*children from disadvantaged backgrounds have the right to specific measures to enhance equal opportunities*’. The call to move towards a European Education Area by 2025, however, recognised that there are deficiencies with respect to access, quality, and affordability of ECE. On average, 34 % or approximately 5 million children under age 3 attend ECEC. Only seven European Member States (Denmark, Germany, Estonia, Latvia, Slovenia, Finland, and Sweden), as well as Norway guarantee a place in publicly funded provision for each child from an early age (6 to 18 months). Good quality ECEC for children under age 3 is not yet available in many European countries. Clear educational content for all children, delivered by highly qualified staff and supported by consistent policies is mostly found in the Nordic, Baltic, and Balkan regions. These countries provide integrated ECEC services for all children under primary school age. Nevertheless, some of them still struggle to guarantee access for every child and have low participation rates.

Limited availability of early childhood education, access, affordability, and quality remain major obstacles and impact in a negative way for children’s development. The access of children from disadvantaged backgrounds to these services also remains challenging. Therefore, the main goals of ECEC are . access to quality and affordable childcare services, provided by adequately qualified professionals, and b. assuring early stage and preventive approaches, including specific measures to encourage attendance of children with disadvantaged backgrounds. Regarding the existing services in the partners’ countries of the project, below we describe some particularities for each country.

### 1.3. Effective policy making for universal and targeted early intervention programs

The issue of how to ensure good quality services for all children was raised, while also ensuring that those children who are at most at a risk are reached. It can be a challenge, particularly at times of economic austerity, to convince policymakers that services should be available to everyone rather than just focus on those most in need. Experts in the domain of early childhood intervention mentioned three ‘levels’ of interventional support for child development: a. universal programs, delivered by society more broadly which address all the children from 0 to 5 years old; b. ‘targeted’, intervention programs for children at risk of developmental delay or with disabilities, and c. specialized interventions for children with specific additional needs (e.g. community-based groups for caregivers of children with disabilities). It is obvious that universal services can attract more public support and that this helps to ensure the quality of services provided. However, mainline services must identify and reach out to those children and families who may be less likely to access those services or who may need additional support. Child protection services can play a



key role in identifying those children who are at risk. An area-based approach which concentrates on disadvantaged communities can also be another way of reaching those at risk.

When it comes to policymaking, everybody agrees that using the best available evidence to develop accessible, affordable, and good quality services is key to lifting children and families out of poverty. However, an important issue is how to decide what constitutes good quality evidence. There is a need for research reports to be rigorously assessed for their quality and it is important to peer review research. There is a general agreement that the evaluation of programmes needs to be rigorous and programmes that are clearly not working should be stopped, although even these can offer useful learning. However, there are several literature reviews with mixed results regarding the effectiveness of different programs, and that is due to difficulties in conducting randomized clinical trials in this domain. This has enhanced the attention being given to the monitoring and the evaluation of programmes. The challenge is to find which programs are most cost-effective. One possible solution is involving all stakeholders in the development and assessment of research and evaluation studies and vice-versa involving researchers in the process of policymaking. Taking into account the situation in different countries, four issues require particular attention: a. families and professionals need policy measures that are carefully coordinated in terms of strategies for implementation, objectives, means, and results; b. policy measures should aim to support and ensure coordination of the education, social, and health services involved, c. overlapping or contradictory measures within or across the services should be avoided; and d. policy measures might include developing regional and national Early Childhood Intervention support centers, acting as a link across the policy, professional, and user (family) levels.

#### I.4. Implications on training curricula

Young children develop abilities and learn skills through a universal set of principles and operations. Research in early childhood intervention strives to operationalize those principles so that professionals and parents can understand young children more sensitively and can plan treatment programs more effectively. Many early intervention programs merge two sets of principles and methods to promote gains for infants and preschoolers with delays and disabilities: *developmental* and *behavioral*. A combined *developmental-behavioral approach* recognizes that children's capabilities emerge in an invariant, sequential manner that is directly linked with neurophysiological factors. However, developmental capabilities, particularly for children with disabilities, emerge only when specific environmental opportunities to practice, learn, and generalize these skills in interaction with others are provided. Thus, various early intervention programs hold that developmental principles provide the *content* (e.g., developmental curricula and toys) of their program whereas behavioral principles provide the *methods* of teaching complex patterns of skills.

Analyses of early intervention program components found in increasingly larger numbers of communities indicate that this system comprises three major features: resource support, social support and the provision of information, and services (Guralnick, 1997). In terms



of the contents of the curricula that needs to be implemented by the practitioners, their purpose is the prevention, and remediation of developmental delays, recognition of risk factors in the immediate environment of the child, and the limiting of the consequences of the delays. Programs in the domain can vary in intensity, the degree of structuring, and the mode of implementation. Some of the training curricula restrict themselves to providing learning experiences (developmental enrichment programs), while others aim at the training of selected skills (e.g. cognitive-developmental protocols, and programs for behavioral training). The setting of the program can range from the home-based service to regular or specialized daycare. Moreover, it may be necessary for the child to receive individual therapy that can help the child improve in some specific areas of development.

Therefore **ECEC - Early Childhood Education and Care** is a composite of services/provision for very young children and their families, provided at their request at a certain time in a child's life, covering any action undertaken when a child needs special support to ensure and enhance her/his personal development; strengthen the family's own competences, and promote the social inclusion of the family and the child. These actions are to be provided in the child's natural setting, preferably at a local level, with a family-oriented and multidimensional teamwork approach.

One important element that appears in different definitions is the idea of prevention as part of the intervention work. Simeonsson (1994) lists three levels of prevention and intervention considering *when* preventive action should take place:

*Primary prevention* aims to reduce the number of new cases of an identified condition or problem in the population (incidence). For example, this aims to reduce new cases by identifying children at risk. Primary prevention includes measures preventing disorders or circumstances that might lead to disability (WHO, 1980). Primary prevention refers to interventions that occur before the initial onset of a disorder. These actions may be: a) *universal*, such as health measures addressed to all children and families, e.g. immunization programs for all population; b) *selective*, addressed to a fixed population, e.g. high-risk groups; c) *indicated* to a population, e.g. individuals with an identified risk.

*Secondary prevention* aims to reduce the number of existing cases of an identified problem by acting after the onset of the problem, but before it is fully developed (prevalence).

*Tertiary prevention* aims to reduce the complications associated with an identified problem or condition, to limit or to reduce the effects of a disorder or disability by acting when these are already present.

These three levels can be identified in a broader context, taking into account the 'bio-psycho-social' model of functioning and disability published by WHO (World Health Organization, ICF, 2001). According to this approach, prevention in the field of ECI cannot only take into account the health condition of a person; it should also take into account his/her social environment: "*an individual's functioning in a specific domain is an interaction or complex relationship between the health conditions and contextual factors (environmental and personal*



factors). *There is a dynamic interaction among these entities: interventions in one entity have the potential to modify one or more of the other entities* (p. 19). “

To measure the impact - the effectiveness - of ECEC, all actors involved in intervention have to be taken into account: *the child*: the progress made and self-perception by the child her/himself, whenever possible; *the family*: the level of satisfaction of the family; *professionals*: their level of satisfaction and competence; *community*: the level of satisfaction, benefits, cost/ effect investment, etc.

A research-based early childhood curriculum is consistent with research on how children develop and learn. It provides rich content and teaching practices that are shown to support children’s learning and development. It focuses on domain-specific, developmentally appropriate content and skills that contribute to children’s later development in that domain. It has rich content, meaning that it provides broad and varied experiences and activities that promote children’s learning and development. Moreover, a research-based curriculum offers a sequence of learning experiences based on children’s developmental progressions.

### 1.5. Early intervention programs with empirical/ scientific/ theoretical support. Examples of Early Intervention Programs

A series of solid arguments have been formulated for the efficacy of early intervention programs for: a. the stimulation of physical and psychomotor development of the child, b. the increase of family well-being, c. long-term benefits for the society, and d. the prevention of disabilities due to environmental and social deprivation. Early intervention programs contribute to the prevention of secondary disabilities (Beirne-Smith, Ittenbach, & Patton, 2002).

Child-centered education is tailored to the child’s needs and skills and acknowledges the right of each child to benefit from intervention outside the family. The child-centered approach is individualized, due to the high diversity of children with multiple disabilities.

Family-centered interventions focus on the family and the professional teaches the family certain skills that they can use with their child. Usually, the family-centered approach is employed in early intervention programs and home-based programs. A family-friendly approach is one that attempts to put the student’s needs first while considering the needs of the family as a whole (Durando, Chen, & Petroff, 2017).

Several countries, such as the US, fostered national initiatives in the field of early intervention, that underscored the importance of “evidence-based” decision making for education and early intervention, improve outcomes for children (Smith & Kelly, 2014).

Visual impairment is considered a low incidence disability in childhood, with approximately 1 in 1000 school-aged children being identified with visual impairments, and even smaller numbers with blindness. There is high diversity among children with VI, and even more so among children with DB and MDVI, with many having additional disabilities (Parker & Ivy, 2014). Within this disability category, there is great heterogeneity in terms of degrees of sensory



loss, for both vision and hearing, as well as the types of additional disabilities that are present. Medical causes of intellectual disabilities or various syndromes may also be associated with significant VI and DB. Very often, local service providers may not identify the sensory losses at an early age, and they may not recognize the impact of sensory loss on development. Significant communication delays and impairments within this diverse group are a common feature.

From a developmental perspective, intervention should begin as early as possible. Services can be offered in center-based schools or special education settings, but also in inclusive or home settings.

The efficacy of communication intervention is influenced by having highly preferred activities, topics, or treats as a part of the conversation, offering intervention in a playful way or involving self-care activities. Parental involvement is highly important and mothers and fathers need to be partners in the intervention, to adopt strategies they see during therapy so that they can be successful with their children (Parker & Ivy, 2014).

Family-centered education shifts the primary intervention from the child to the parents or caregivers. Therapists teach the families skills that they use with their child, an approach that is commonly employed in early intervention programs and home-based education. The best interests of the child are also the best interests of the family as a whole. A family-friendly approach is one that attempts to put the student's needs first, while considering the needs of the family as a whole. It may be important for all the team members in an early intervention program with a significant home-based component to visit the home. Some families may find a meeting in their home to be intrusive, whereas others may be much more comfortable meeting in their home.

Child-centered education is tailored to a student's unique set of needs and abilities and recognizes that children have individual rights independent of their families. A high degree of individualization is required, which is consistent with a child-centered approach because students with severe and multiple disabilities differ greatly from one another and from other students.

Some examples of widely used, empirically and theoretically supported early intervention programs, destined to children with developmental delays and disabilities are:

- Fit for Me: Activities for Building Motor Skills in Young Children (Karnes, 1992)
- The Carolina Curriculum for Infants and Toddlers with Special Needs (Johnson-Martin, Attermeier, & Hacker, 2004)
- Play and Learn: A Motor-Based Preschool Curriculum for Children with All Abilities (Coleman, Sullivan, & Krueger, 2002).

Early intervention programs for at-risk groups help the prevention of associated secondary problems in vulnerable families. One such program is „*Nurse Family Partnership*” (Zeanah, Stafford, & Zeanah, 2005), centered on the relationship between child and caregiver, attachment, training of family mediators that can foster the child's well-being, helping parents to care for their child, improvement of child's behavior, school readiness, improvement of school achievements, as well as work skills and mental health of parents.

Other examples of family-centered programs are:

- 1) „*Steps Toward Enjoyable, effective Parenting*”;



- 2) „Promoting First Relationships”
- 3) „Sensitivity Coaching”
- 4) „Home Visiting Family Support Program”
- 5) „UCLA Family Development Project” (Zeanah, Stafford, & Zeanah, 2005).

The efficacy of parent-focused early intervention programs for high-risk families is higher if the program approaches, besides the parent-child relationship, parental problems such as poverty, unemployment, lack of or poor housing, substance abuse. The approach of relationships between caregiver and other family members, caregivers, and partners is also necessary. The intervention needs to be started as early as possible so that the parent can form a therapeutic relationship with the specialist. The services are usually intense, long-lasting so that the family can benefit from a constant, strong, and healthy relationship in order to grow and improve functioning.

**The CAPEDP** (*Compétences parentales et Attachement dans la Petite Enfance: Diminution des risques liés aux troubles de santé mentale et Promotion de la résilience*) is a home visiting program developed in France, and is based on attachment theory (Bowlby, 1982), self-efficacy theory (Bandura, 1977), and human ecological systems theory (Bronfenbrenner, 1979). The policy of the program is that families have free access to extensive, comprehensive, and longstanding health care systems. The program included families from different categories: low income, low educational level or intending to bring up the child alone.

CAPEDP project involved 440 women and their families from France from 2006 to 2011. To be eligible for inclusion, women had to be at maximum 26 years of age old, and presenting at least one of three risk factors: low income, low educational level or intending to bring up the child alone. The intervention program consisted of 44 home visits starting weekly at the third trimester of pregnancy and ending with decreased frequency at the child’s second birthday (Saias et.al., 2013). During the postnatal period (0-3 months) the home visitors were reminded to pay particular attention to symptoms of maternal depression and to use active listening approaches with any mother presenting initial symptoms of depression. After the child’s birth psychologists worked with video-feedback using at home daily sequences to enhance mother sensibility and reduce maternal disruptive behavior. The attrition rate was 17% at three months of child’s age and rose constantly up to 63% until the end of the intervention at 24 months. Several variables were associated with attrition early during the program (e.g. previous abortions, attachment insecurity) and later attrition (e.g. control arm, parental loss before the age of 11 years) (Foulon et. al., 2015). Different topics were assessed at six different times at inclusion and at 3, 6, 12, 18 and 24 months after birth. Child’s mental health, maternal depression and quality of the caring environment were considered as the major mediating variables for infant mental health. Additionally, mother-infant attachment was assessed during home visits. In a subsample of 120 randomized families, attachment style, and disruptive maternal behavior were measured in a laboratory (Perkins et al., 2002).

Taken together, the CAPEDP failed to demonstrate an overall effect on postnatal maternal depression. However, post-hoc analyses reveal that the intervention was effective in terms of primary prevention and in subgroups of women without risk factors (Dugravier, et al.,



2013). Nevertheless, the CAPEDP intervention has been proven to be effective in significantly reducing infant disorganization, and maternal disruptive behavior in a subsample of 120 families (Tereno, et. al., 2017). In the intervention group, the percentage of disorganized attachment was 7.7% compared to 21.2% in the control group. In the intervention group, the percentage of disrupted maternal behavior was 31.7% compared to 51.9% in the control group.

A similar program was applied also in Germany named **Pro Kind**, which was based on the same theories of self-efficacy, attachment, and human ecology. The program aimed to enhance maternal and child's health, child development, maternal life-course, as well as at the reduction of the risk for child abuse and neglect. The visits were structured by guidelines that provide the home visitors with teaching materials and topics to discuss across the different domains. From 2006 to 2009, the Pro Kind project enrolled 755 first-time mothers between their 12th and 28th week of pregnancy with economic risk factors (e.g. unemployment, over-indebtedness >5.000 €), and at least one social risk factor (e.g. social isolation, being under age) in western, and eastern federal states of Germany. The 94 women in the intervention group received regular home visits during pregnancy up to the child's second birthday varying between weekly and monthly home visits. The attrition rate rose constantly up to 50% at 24 months postpartum (346 out of 755 families remained in the study). A younger age, a lower income, and experienced foster care placement at baseline significantly predicted program attrition until 24 months postpartum (Foulon, et.al., 2015). The third part of research is the cost-benefit analysis aiming at the assessment of the economic efficiency of the program (Sandner, 2013). Assessments of family environment and maternal competencies were based on self-reports in regular interviews. Child development was assessed with gold standard tests and a follow-up study is currently running at child's primary school age. Intervention effects were detected in the domains of social support, postnatal stress, parental self-efficacy, knowledge on child rearing and maternal attachment feelings. Intervention effects were not found for partnership satisfaction, number of further children or educational achievement. In the domain of child development, only children of high-risk mothers showed superior mental development compared to their control group counterparts. No effects were found on child language and social-emotional development (Sierau, et.al 2016; Jungman, et.al. 2015).

A limitation of both intervention programs (CAPDEP and Pro Kind) was that, although the home-visiting team had received specific instructions for the intervention implementation, a qualitative analysis of home-visiting case-notes in the CAPDEP showed little evidence of the major theme of depressed symptoms actually being addressed as a priority (Saias, et.al., 2012). The same holds true for quantitative analyses of time spent on the domain maternal health during pregnancy and parental role, including a special focus with the curriculum on child development during the first year of child's life in the Pro Kind program. Implementation fidelity in both programs seems to have taken second place with regard to more pressing issues around supporting mothers to resolve social, financial or practical problems. The home visits were structured by guidelines that provide the home visitors with teaching materials and topics to discuss across the different domains, mainly covering the following sections: child health & safety, child development, parent-child relationship, family health, and development.

Table 1. The content of Early Intervention Programs (Jungman et.al.2017)

Child Health and Safety	Child Development
Prenatal health and well-being Preparing for labor and delivery Immunization Breastfeeding and nutrition Physical activity Basic care: sleep, bathing, dressing child Hearing/Vision Monitoring growth Recognizing signs of illness Promoting well-care visits Dental hygiene Monitoring for signs of child maltreatment Child injuries, ingestion/poison Home safety review	Parental development Physical/motor development Cognitive development Language development Social-emotional development Temperament/emotional regulation Brain development Emergent literacy Play
Parent-child relationship	Family Health and Development
Recognizing signs of attachment Reading child cues Parent (realistic/unrealistic expectations) of child Promotion of positive parent-child interactions	Caregiver stress and mental health Caregiver physical healthy postpartum care Domestic violence & family violence Caregiver substance use Social support Connection to community resources Parent life course development

**ZEPPELIN 0-3 with the Program Parents as Teachers (PAT)** implemented in Switzerland was based on bio-ecological model of human development, self-efficacy theory and the concept of parental sensitivity and responsivity. The idea of the intervention program was to make usage of the community service infrastructure to reach high-risk families. Moreover, the emphasis was on the network of early intervention, and education (medical, psychological and professionals). The longitudinal study ZEPPELIN 0-3 applies a German adaptation of the home visiting program “PAT – Parents as Teachers” (PAT) and aims at interdisciplinary early recognition of child at risk for developmental delays for psychosocial reasons and at strengthening early parental support. Research is theoretically founded in a framework based on the Process-Person-Context-Time (PPCT) model (Bronfenbrenner, 2006). Thus, parental, child, interactional, and contextual characteristics (e.g., process quality, resource network) represent the core of the concept. A trained parent educator (i.e., mostly a pediatric nurse, who is professionally trained and





well experienced in parent counseling) visits families regularly at their homes every two or three weeks. Additionally, ZEPPELIN 0-3 offers monthly group meetings. The target population of ZEPPELIN 0-3 has a low socio-economic status.

Migrant families were also explicitly addressed and included if they meet the criteria regarding risk factors, for example, limited social support, financial distress, unemployment, or family difficulties. 248 families were recruited and equally randomized to the intervention or control group. Of those, 38 participants gave up by the fourth measurement time point (child age 3 years) due to moving away, lack of time, illness, or unreported reasons. With an attrition rate smaller than 5% per year, the ZEPPELIN 0-3 is more successful in retention than comparable PAT evaluation studies conducted in the US or in Germany (Neuhauser, 2014).

The effectiveness of the early intervention is rigorously assessed in a longitudinal experimental design. Framework and data material allow for a broad analysis of the proximal processes and of their mid-term and long-term effects including cost-benefit analyses. The primary outcome domains are cognitive, language and social development of the children aged 0 to 3, as well as the parental quality of caregiving. Additionally, the relation of further influencing factors of the program (like intensity), family and context factors (like social network and the use of alternative treatments) on the effects are considered. Data collection started with the baseline assessment when children were between 3 and 4 months old, and continued at 12, 24 and 36 months (Lanfranchi & Neuhauser, 2013). Preliminary analyses show the greatest impact on measures of child development. Significant small to moderate treatment effects on child language, cognition and behavior were registered. However, advantages in language and cognition decreased towards the end of the program. By contrast, differences in behavior increased towards the end of the program. At 36 months, children in the target group showed less problematic behavior and higher scores in effortful control. Finally, PAT positively influenced parent-child interaction.

**The Intensive Care Program for Vulnerable Families to Prevent Institutionalization - P.I.P.P.I.** is a program implemented in Italy which addresses positive parenting and the holistic development of the child by proposing new ways to respond to problems connected to poor parenting and child neglect (Lacharité, 2010). In accordance with the bio-ecology of human development (Bronfenbrenner, 2005) it aims to respond to children's needs with a collective action. The collective action to respond to child neglect encompasses (1) home-care intervention, (2) parent groups, (3) family helpers, and (4) cooperation between schools, families and social services. First, during home-visits practitioners spend a minimum of four hours approximately twice a week in order to address their problems and try to modify their behavior. Second, parents are involved in weekly or bi-weekly group activities to enhance reflective practice, and to encourage exchange and interaction between parents. Third, each family is provided with a volunteer support family or family helper whose aim is to offer support in concrete aspects of daily life, and to reinforce goals identified by care planning strategies. Fourth, the educational institution of the child (kindergarten, nursery, or primary school) is invited to be a full member of the multidisciplinary team. Teachers and other involved professionals outline actions (both individualized and classroom based) that will favor a positive school environment where children



can learn social and emotional competencies. Overall, 320 children from 233 families between 0 to 14 years of age were included. Children were eligible if the "team around the child" shared the presence of child neglect problems that could lead to a future placement outside the family. The study used a quasi-experimental pre-post-test design incorporating both quantitative and qualitative assessments (questionnaires and documentation analysis) to compare the families' situation before the intervention and after the intervention (Serbati, 2013). The Italian adaptation resulted in a new tool, The Child's World Questionnaire (CWQ). It is utilized to conduct a comprehensive assessment of the child's conditions, and needs, to plan further activities and to document changes over time. Usually, it is depicted as a triangle with the three sides representing the child's developmental needs, parenting capacity and up to 17 family and environmental factors (Milani, et. al., 2011). Final results monitor the program's accountability and highlight any changes in child functioning and his/her world like parenting practices. Encouraging, positive changes between pretest and posttest obtained by the CWQ occur in all three dimensions. In the dimension Family Competencies, important changes are observable in parents' self-realization and guidance and boundaries. For the Child's Needs dimension, the most important changes involve social skills, identity, self-esteem and social presentation, as well as family and peer relationships. The Environmental Factors with an improvement are support from families, friends, and other people, belonging to and participation in the community, as well as employment and income. One limitation of the study is atypical sampling of children and families since it was linked to the practitioners' recruitment. It is therefore impossible to generalize the results to the population normally referred to the Child Protection System. The second limitation is the quasi-experimental design. In the first implementation, a control group that followed the mainstream activities offered by Child Protection Services was used. The results demonstrated a significant improvement only for the P.I.P.P.I. group (Serbati, et. al., 2016). In the subsequent implementations, it was impossible to apply an RCT due to the need to involve practitioners in the research activities.

**The CARE programme** (Browne et. al., 2006) is a universal home visiting program implemented in England and designed to prevent child abuse and neglect. It was developed in response to a need for community health workers (including health visitors, midwives and community physicians) to be aware of and assess more accurately the emotional needs of all families with babies. It is focused around a child centered assessment of need and development that is completed in partnership with the parent.

CARE incorporates parent report and direct observation of parent and child. Home visits occur in a specific time frame and are fairly structured. The curriculum includes assessing the family risk of child maltreatment and abuse using the Index of Need assessing and discussing maternal mental health using the Edinburgh Postnatal Depression Scale observing and discussing infant attachment behaviors and parental behaviors, identifying additional services required, and a child development and hearing test. In total, five home visits are conducted. These are: a. newborn assessment/home visit (10–15 days after birth) 2) home visit (4–6 weeks); b. home visit (3–5 months), c. clinic assessment/home visit (7–9 months), d. home visit (12 months). There are no



published, peer-reviewed research studies for the CARE Programme, although the CARE Programme Book includes details of its evaluation.

**The Healthy Child Programme** (Department of Health, England, 2009) is an e-learning project and curriculum that aims to improve the health and wellbeing of children as part of an integrated approach to serving children and families, integrating child development and child health concerns. The e-learning project supports the implementation of The Health Child Programme–Pregnancy and the First Five years of Life (HCP) and describes a standard for service delivery. The HCP model is based on progressive universalism and seeks to provide services for all children, with additional services for children and families with particular needs and risks. The programme focuses on public health priorities such as obesity, breastfeeding and social and emotional development.

The HCP schedule includes universal guidelines (for all families) and additional guideless for women and children with risk factors. The core components of the HCP curriculum are: early identification of need and risk, health and development reviews, screening, promotion of health and behavioral change, prevention of obesity, promotion of breastfeeding, and any other appropriate prevention programs for families. The e-learning curriculum includes various modules and topics including: program basics, communication and record keeping, family health, safeguarding, positive parenting and parenting issues, development and behavior, speech, language and communication needs, growth and nutrition, immunization, health promotion, screening, and health visiting model of practice. It uses the Personal Child Health Record (PCHR) to help parents and health visitors track content of home visits.

Regarding his efficacy, the HCP Manual description notes that it is outcome-driven (provided a clear set of outcomes for children that can be measured) and evidence based (based on meta-level reviews of evidence, including the publication Health for All Children. The program is reviewed and updated by an Advisory Committee. The manual also notes that outcomes are and should be collected by local providers, however, outcome reports have not been published and are not available online.

**SafeCare Program** (SafeCare, Lutzker & Bigelow, 2002) is a home visiting model that was developed to prevent child abuse and neglect. It is designed for families with a history of child maltreatment or those with risk factors for maltreatment including young parents; parents with multiple children; parents with a history of depression or other mental health problems, substance abuse, or intellectual disabilities; foster parents; parents being reunified with their children; parents recently released from incarceration; parents with a history of domestic violence or intimate partner violence; and parents of children with developmental or physical disabilities.

SafeCare involve 1–2 hour home visits ever week over a period of 18–20 weeks. Home visitors follow structured protocols and provide parent training in three modules: 1) infant and child health care, 2) home safety, and 3) parent- child/parent-infant interactions. Each module is designed to be implemented in 5–7 sessions. Assessments utilized include the Home Accident Prevention Inventory-Revised (HAPI-R) and the Planned Activities Training (PAT) Checklist. All modules involve baseline assessment, intervention (training) and follow-up assessments to



monitor change. Home visitors guide families through seven steps to address target behaviors in each module. These steps are 1) describing desired target behaviors, 2) explaining the rationale or reason for each behavior, 3) modeling each behavior, 4) asking parents to practice the behavior, 5) providing positive feedback, 6) providing constructive feedback, and 7) reviewing parents' performance. An international version of SafeCare is currently being piloted in Belarus under Child Fund International. The international model is a stripped-down version of the curriculum to which culturally-relevant components are then added. In randomized trials and quasi-experimental designs, programs using SafeCare have been shown to reduce recidivism with currently maltreating parent, but outcomes regarding children's development aren't presented.



## II. Literature review. Effectiveness of early intervention programs on child development.

There are several ways in which early intervention can be defined, among the most comprehensive ones is the one offered by Rutter, Shonkoff & Meisels (2000) in the Handbook of Early Childhood Intervention as “*multidisciplinary services provided to children from birth to 5 years of age to promote child health and well-being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration and promote adaptive parenting and overall family function*” Starting from this definition several programs or interventions were developed to improve children’s outcomes and promote adaptive parenting and overall family function.

Several reviews (Kohli-Lynch, Tann & Ellis, 2019, Peacock, Konrad, Watson, Nickel, & Muhajarine, 2013, Jungmann et.al., 2017, Hanson & Lynch, 1995; McCollum & Maude, 1993) have tried to investigate the effectiveness of different early intervention programs (EIP) and all of them emphasized the major benefits of early intervention for children with disabilities and children at-risk. However, not all of the studies and programs investigated yielded statistically significant results in terms of the effectiveness of the interventions. Among the most frequent arguments that support the idea of EIP is the belief that early environmental stimulation can positively facilitate later development and readiness for learning (Gargiulo & Kilgo, 2004). Moreover, the idea of early environmental stimulation is also supported by the fact that it is known that there are some critical periods in early childhood when the intervention is vitally important if the child is to acquire more complex skills later on (Walker et. al., 2011). Another important assumption is that early intervention can minimize the impact of a particular disabling condition like the effect of a severe hearing loss on the development of speech and language and possibly prevent or attenuate the occurrence of comorbidities. Almost every EIP targets also the family of children with special needs or children at-risk because these children present many new challenges and responsibilities for parents or caregivers and that impacts the entire structure of the family. That represents another reason for the implementation of EIP; the professionals can develop partnerships with parents and can assist them by providing factual information, social and emotional support, and specific training if needed. From the societal point of view, EIP was proven to be cost effective, meaning a reduced need for special education services or other types of intervention services at an older age.

All in all, early intervention for children with disabilities and children at risk has definite advantages primarily for the child and then for family and society. EIP can make a significant difference in the quality of life for young children with special needs. In fact, early intervention as a strategy to prevent later problems has almost become conventional wisdom (Kammerman, 2000). Gomby (2005) analyzed twelve meta-analyses regarding home visiting early as early intervention programs in a very comprehensive review. The studies that investigated the effectiveness of home visiting have typically assessed children’s development using standardized tests and therefore their results can be compared using a statistical approach. The results were mixed and the major conclusion was that center-based early childhood education services combined with home visiting



yield larger and more long-lasting benefits in cognitive development than do home visiting services alone. Regarding the outcomes of the mothers only three of the twelve analyzed meta-analysis (Geeraert, Van den Noortgate, Grietens, & Onghena, 2004; Layzer, Goodson, Bernstein, & Price, 2001; Sweet and Appelbaum, 2004) find significant positive effects at least in one domain of maternal life course.

In the systematic review developed by Peacock et. al. (2013) they analyzed the effectiveness of paraprofessional home visiting programs in 21 studies. Their results have shown that early intervention home visiting programs that utilize paraprofessionals often do not have significant effects on socio-economically disadvantaged families when it comes to maternal outcomes, there were some improvements in decreased harsh parenting. However, it does show that young children show modest improvements in language, cognitive, and motor areas. Nevertheless, findings that were not statistically significant were much more common than significant ones.

Sweet and Appelbaum (2004) include in their meta-analysis exclusively 60 home visiting programs conducted in the United States since 1965. All included studies are experiments or quasi experiments. Their conclusion was that the utility of home visiting programs as a whole couldn't be clearly stated; mainly because of the difficulties in assessing the utility of individual home visiting programs. The studies included in the meta-analysis showed a significant impact on maternal education with the largest effect on teenage mothers. 5 of the 60 studies included in the meta-analysis present results on maternal education, seven on employment and three on public assistance and 41 studies investigate child cognitive development, and 37 studies search for effects on parenting child rearing.

Researchers have been able to consistently demonstrate that well- designed EIP produces modest positive outcomes according to their intended purpose (Yousafzai, Lynch, & Gladstone, 2014; Zigler, 2000). Recent systematic reviews (Jungmann et.al., 2017; Kohli-Lynch, Tann & Ellis, 2019, Peacock et. al., 2013,) show significant but small positive effects of the early intervention programs for children's outcomes. The most investigated approach is the home visiting programs that attempt to address the needs of at-risk families by offering services and support that they might not otherwise access. Usually, their outcomes of the studies that measure the effectiveness of early EIP are split in two different categories: maternal outcomes and child outcomes. In our review, we will mostly focus on more recent studies that show the effectiveness of EIP and on children's outcomes, such as: language, cognitive, behavioral, and motor level.

In terms of developmental outcome, the psychomotor development, cognitive development, child behavior, and language development are referred to. Disadvantaged families are considered socially high-risk families who live in poor economic circumstances, receive social assistance, or have inadequate income to meet the needs of the family. Children with disabilities according to IDEA (1997) include the following categories: children with autism spectrum disorders, intellectual disabilities, hearing impairments (including deafness), vision impairments (including blindness), orthopedic impairments, multiple disabilities, emotional disorders, learning disabilities, speech or language impairments, traumatic brain injury and developmental delays.

PubMed, Ebsco, ProQuest and Google Scholar for studies on early intervention for children at high risk or with developmental disabilities were investigated and snowball referencing to identify further relevant studies was used. Articles were included if they were randomized controlled trials or quasi-experimental studies including a control group that evaluated an EIP. Terminology used for the articles search was: *early intervention AND children with disabilities, early intervention, AND children at risk, home visiting, AND children with disabilities, home visiting, AND children at risk*. We looked for all the clinical trials that tested the effectiveness of early intervention for children at risk or with disabilities in which children's outcomes were presented. The studies had to analyze the effectiveness of an EIP that lasted at least 1 year, was a national program, and was implemented in US or in European Countries.

The following inclusion criteria were considered: a. study design b. purpose of the problem c. sample details d. intervention type e. outcomes f. results of the study. Data extraction included the characteristics of the participants, intervention (theoretical model, duration and structure), outcomes (language, psycho-motor, child-behavior) and quality of the studies.

United States							
Author	Sample	Population	Intervention Program		Outcome	Duration	Results
Caldera et al. (2007)	325	At-risk Families	Healthy	Families	Language Psychomotor Child Behavior	2y	Better results on internalizing and externalizing scale
Kartin (2002)	78	Substance abusing mothers	Seattle	Birth to 3	Psychomotor Cognitive Child Behavior	3y	Non-significant differences
Nair et al. (2003)	161	Substance abusing mothers	Based on Health Development	Infant and	Language Psychomotor Cognitive	2y	Better results on psychomotor development
Love et.al. (2005)	3001	Socio-economically disadvantaged families	Early Head Start		Language Psychomotor Cognitive Child Behaviour	3y	Significant results
Drotar et al. (2014)	464	Socio-economically disadvantaged families	BTL (Born to Learn)		Language Psychomotor Cognitive	3y	Non-significant differences



Europe						
Author	Sample	Population	Intervention Program	Outcome	Duration	Results
Cupples et. al. (2011)	343	Socio-economically disadvantaged families	No name	Psychomotor Cognitive	1y	Non-significant
Dugravier et. al. (2013)	440	Women with multiple risk factors	CAPEDP	Child Behavior	2y	Non-significant
Jungman et.al. (2015)	755	Socio-economically disadvantaged families	Pro Kind	Language Cognitive Child Behaviour	2y	Significant results on mental development
Lanfranchi & Neuhauser (2012)	248	Socio-economically disadvantaged families	ZEPPELIN (Zurich Equity Prevention Project with Parents Participation)	0-3 Language Psychomotor Cognitive Child Behavior	2y	Significant results on language, cognitive & child behavior
Serbati et.al. (2016)	322	Socio-economically disadvantaged families	P.I.P.P. (Program of Intervention for Prevention of Institutionalization)	Child Behavior	1y	Better results on child development
Cote et.al. (2019)	233	Socio-economically disadvantaged mothers	PFL (Preparing for Life)	Language Cognitive Child Behavior	4 y	High level trajectories for language and cognition
Schaub et.al., (2019)	73	High risk families	PAT (Parents as Teachers)	Language Psychomotor Cognitive Child Behavior	3y	Significant results

When analyzing the data from the 12 selected studies we have discovered that the results were mixed both in the US programs and in the Europe programs. All the selected studies are large





clinical trials in which the effectiveness of the early intervention was investigated. The programs were implemented for at least one year to a maximum 3 years, however, we could not link the positive outcomes with the lengths of the studies. Therefore, we can say that our review revealed contradictory results. Considering our work and the other published reviews (Gombi, 2005; Hanson & Lynch, 1995; Jungmann et.al., 2017; Kohli-Lynch, Tann & Ellis, 2019; McCollum & Maude, 1993; Peacock et. al., 2013), as a whole, the papers indicate positive outcomes for early interventions especially when the distinction is made between statistical significance and clinical significance. Meaning that in almost all the cases there were some improvements in children's abilities, but due to small samples, non-standardized measurements, and a high rate of attribution, that effect could not have been statistically proven.

Another important aspect that should be considered when assessing the effectiveness of early intervention programs is the fact that there are three 'levels' of interventional support for child development: a. universal programs, delivered by society more broadly which address all the children from 0 to 5 years old (e.g., through policy); b. 'targeted', intervention programs for children at risk of developmental delay or with disabilities (e.g., home visits to young mothers) and c. specialized interventions for children with specific additional needs (e.g. community-based groups for caregivers of children with disabilities). The majority of clinical trials target the first level, therefore it is more difficult to find evidence for the second and third level type of intervention. On the one hand, there are several obstacles to conducting methodologically sound experiments. Potential problems in interpreting the research literature have to do mainly with the appropriateness of the dependent measures; the absence of control groups; small sample sizes; improper sampling procedures; inappropriate statistical techniques; inadequate documentation of the treatment; the validity of the assessment instruments; and the variability within specific subject populations. On the other hand, there is a bigger problem with programs that target early child development, because the contextual adaptation of this programs is more complex than for most health programs as the determinants of child development span multiple sectors (Cavalerra, et. al., 2019). Accordingly, human resources are seen as critical for successful design and implementation; the curricula, the implementation policies, and assessing the effects are important pillars of every EIP. All the above mentioned highly influence service quality at scale and outcomes for children and makes it difficult to answer to all the pragmatic questions of the researchers. However early intervention research is not static, but rather an ongoing process; this kind of studies can guide researchers, policymakers, and educators in their quest to develop new models, programs, and services that benefit infants, toddlers, and preschoolers with special needs and their families.

Despite the chronic problems in conducting efficacy evaluations, it is our opinion that early intervention does make a difference in the lives of young children with special needs. It would appear that the field of early childhood special education has moved beyond the global question of whether early intervention works (we believe it does) to more precise avenues of inquiry: for whom, under what conditions, and toward what outcomes. Therefore, as previous researchers stated, we believe that the debate will no longer be whether to provide early intervention "*but*



*rather how much and what kind of intervention are children and families entitled to”* (Bailey, 2000; p. 74). A major task confronting the field will be to identify which early intervention programs work best and what elements are clearly essential to achieve maximum benefit (Zigler, 2000).

### III. Early childhood development. Characteristics, implications of VI and MDVI on development, assessment and intervention.

#### III. 1. Characteristics of Early childhood development

At birth, the number of neurons is about the same as the number of neurons that the human being will have during his or her lifetime. During the first months of life, the number of synapses increases dramatically in the context of a stimulating environment (Tavris & Wade, 1997), the presence of social and emotional stimulation and in the absence of distress factors and. The first two years of life are essential in a child's development, as they are marked by a high receptivity to environmental stimulation and a high neural plasticity.

Besides brain development, an increased physical development of all body structures is characteristic of the early years. Each child has his own developmental pace, depending on his particularities and the context in which development occurs.

#### **Perceptive development**

At birth, the eyes, like the brain, are well developed and they grow in size only 3 to 4 times, compared to other segments that can grow up to 20 times their size from birth to adult age (Slater, 2004). At birth, the peripheral retina is well developed, while the central part (macular region) is less developed and goes through important changes. Several visual skills are present at birth: edge detection and discrimination, early visual discrimination of size and color, distinction of contrast, shades, complex patterns, depth perception (Tavris & Wade, 1997). The world of the newborn is far from total confusion, several perceptive skills are already present at birth, such as: the detection of a sound and startle reaction to sound, turning toward the source, distinction of the human voice from other auditory stimuli, olfactory discrimination, differentiation of tastes (salty and sweet), preference for certain tastes. The development of these skills holds adaptive value for the human being during lifetime, so in the case of vision and/or hearing impairments, child development may be severely affected in a negative way.

*Table 1. Milestones in the development of object perception skills ( Kellman, 1996)*

<b>Perceptive skill</b>	<b>Sources of information</b>	<b>Age</b>
<i>Contour detection</i>	-light, chromatic discontinuities;	newborn
	- texture development/suppressions	12 months
	-visual expansion;	7 months



<i>Contour classification/ limit setting</i>	-texture development/suppression ; -relative movement -depth discontinuities	12 months
	-brightness, chromatic discontinuity;	16 months
<i>Unity formation</i>	-usual movement;	16 months
	-edge combination;	36 months
<i>Perception of three dimensional shape</i>	-determination of structure through	16 months
	-biological motion	20 months
	-singular or multiple static perspectives;	after 40 months
<i>Size perception</i>	-depth; -size in accordance to distance;	newborn
<i>Substance perception</i>	-rigid and non-rigid movements;	12 months
	-texture.	36 months

Auditory perception develops from birth when the human auditory system is anatomically and physiologically fully developed even before birth (Fernald, 2004). Intrauterine exposure to human voice is beneficial for early social development and language development. Auditory information is used for language comprehension and early experiences with language contribute to the early organization of auditory information, preparing the child's mind for later language comprehension.

*Table 2. Hearing and language development*

<b>Hearing and comprehension</b>		<b>Verbal language</b>	
<b>Age</b>	<b>Characteristics</b>	<b>Age</b>	<b>Characteristics</b>
<i>0 – 3 months</i>	Startles to loud sounds; Smiles when spoken to; Seems to recognize parent voice and silent when spoken to; Increases or decreases sucking, in response to sound.	<i>0 – 3 months</i>	Makes pleasurable sounds (cooing); Cries differently to signal different needs; Smiles when he/she sees a familiar person;



4 – 6 months	Moves eyes in the direction of sounds; Responds to modified voice tones; Observes toys that make sounds; Attentive to music.	4 – 6 months	Babbling similar to spoken language, including many different sounds: p, b m; Vocalizes joy and unpleasure; Makes sounds when left alone and when playing with a person.
7 months – 1 year	Enjoys peek-a-boo games; Turns and looks in direction of sound; Listens when spoken to; Recognizes words that denote familiar objects: shoe, cup, juice; Begins to respond to requests.	7 months – 1 year	Babbling includes long and short groups of sounds: mama, babababa; Uses speech and sounds to draw attention; Imitates different verbal sounds; Pronounces one or two words: dada, mama, bye, although sometimes not clear.
1 – 2 years	Indicates images from a book when named; Shows body parts when asked; Follows simple instructions and understands simple questions (Give kiss, Where is mamma?) Listens to simple stories, songs and poems.	1 – 2 years	Utters more words; Formulates one-two questions (Mama where?); Attaches two words, meaningfully: daddy no, Amy bye; Pronounces many consonants, at the beginning of the word;
2 – 3 years	Understands meaning differences (up/down, on/in, small/ big); Follows two simultaneous instructions (take cup, put on table).	2 – 3 years	Has a word for any object or action; Formulates 2-3 words propositions in order to talk about and ask for things; Speaking is intelligible for close people most of the time; Often asks or directs attention to objects, naming them.

### Language development

The complexity of human language is widely acknowledged and the importance of social-emotional context holds a significant role in the acquisition of language.

Veneziano (2000) underlines the importance of social context and interaction between the child and the significant people around him for the development of language. Several experiences are important in the acquisition of language:

1. *Joint attention* – common focus on an object, the mother can direct, through looking and pointing, the child’s attention to an object while she speaks about it, allowing the child to extract the meaning of the words;
2. *Conversational interaction* – contingent conversational patterns established between mother and child contribute to reciprocal interactions, the establishment of a dialogue between mother and infant, with important effects on the development of the first lexical elements through imitative play;
3. *Child directed language* – mothers use a articulated language to address to their children, with a high pitched voice, exaggerated intonation, limited simple vocabulary (less third person pronouns, short utterances, few composed forms), focused on present tense, containing more repetitions, rephrasing, extensions of the child’s utterances. Mothers adapt their language to the level of the child’s comprehension, anticipating his competences.

Conversational and interactional phenomena contain various characteristics that support the child in the acquisition of language. Mothers’ semantically contingent responses to child’s verbal utterances are the basis of the interaction between the two, with an important role in the acquisition of language (Veneziano, 2000).

The perceptual skills contribute to language development from the beginning of the child’s life and the perceptual processing mechanisms, if functional from birth, are organized in a system modulated by typical prosodic and phonologic properties of language (Bertoncini, de Boysson-Bardies, 2000). Word learning is based on innate perceptive capacities, that allow the child to structure the acoustic signal of words, to group these signals into functional unities of each language, to segment words.

The production of first vocal sounds begins in the first weeks after birth, but only at about 5 months of age, the child manages to control phonation, while articulatory control is acquired during the second half of the first year of life. According to Bertoncini & de Boysson-Bardies (2000) the milestones of verbal production during the first year of life are as presented in table 3, but interindividual differences are profoundly marking these stages.

*Table 3. Verbal utterances during the first year of life (Bertoncini, de Boysson-Bardies, 2000, p. 116)*

<b>Month</b>	<b>Characteristics</b>
1	Uninterrupted phonation, crying, vegetative sounds;
3	Cooing, glottal productions, laughing;
4	Various vocal games, velar productions;
5	Phonation control, vocal productions;
7	Babbling, canonical forms duplicated;
10	Various syllable combinations;
11	Proto-words;
12	First words.



Babbling is connected by the perception of sounds, so it does not appear in deaf children. The acquisition of language is based on cognitive capacities, as prerequisites, is dependent on language and social-cultural context, on social routines, on affective indices from others. The pragmatic and discursive contexts hold an important role in the acquisition of first words (Bassano, 2000).

### **Cognitive development**

Infants and toddlers spend a lot of time exploring and learning from their environment, a process that occurs rapidly starting from intrauterine life. According to Piaget (1929, 1960, 1952, in Tavriss & Wade, 1997), infants and toddlers are in the stage of sensory-motor intellectual development, characterized by the coordination of sensory information with body movements and learning through concrete actions: looking, touch, hearing, exploration with the mouth, sucking, prehension. In time, movements become goal directed, as the child actively explores the environment and discovers the causal relations between certain movements and their results.

One of the most important acquisitions during this stage is object permanence, beginning around the age of 6 months and being stabilized around age 1. After the acquisition of this ability, the child understands that an object or a person continues to exist, even if it disappears from the visual field or from the reachable area.

During the preoperational stage (2 to 7 years), the increasing use of symbols and language in the play, by the imitation of the adult's behavior, magical thinking, egocentrism are being developed. Empathy and perspective taking begin to emerge at 3-4 years.

### **Social and emotional development**

During the first years of life, the child's development is rapid, and at the end of the first two years, he possesses a rich repertoire of emotional expressions and feelings. Emotions are adaptive, organizing intrapersonal and social processes, while affective relations between child and adult, emotional security determine the establishment of healthy relationships between the child and his/her environment.

Emotions are relational and transactional, originating from the relationship between child and environment and communicating messages through which the behaviors are regulated. Perceptive differentiation and integration hold a significant role in emotional development. Between 4 and 6 weeks of life, the social smile is acquired, as a reaction to auditory stimulation, then visual stimulation (scanning of object contours, of the human faces, then scanning of the interior of objects following habituation). After this age, the child becomes able to process more facial characteristics, to establish prototypes of facial gestalts of emotional expressions, and to distinguish them (Bargh & Chartrand, 1999).

The sensitivity to emotional expressions of others manifests from the first hours of life when the child can imitate facial expressions. Given the role of imitation in the relationship between child and adult, Gopnik & Meltzoff (1997, in Witherington, Campos, & Hertenstein,



2004) considered it “meeting of minds”, basis for the development of empathy, morality, and prosocial behavior.

Initially, the newborn is able to manifest a single emotion, a diffuse state of excitement. Around 4 weeks, the distress is differentiated from excitement, at 6 weeks joy is manifested through social smiling directed toward any stimuli similar to the human face, at 4 months anger is differentiated from distress, at 6 months disgust from anger and at 8 months fear is acquired. From the initial undifferentiated state of the newborn, through a process of gradual differentiation, emotional development unfolds (Witherington, Campos, & Hertenstein, 2004).

Mother-child interaction, by offering the needed protection, plays an important role in emotional development. The main functions of the mother-child interaction are:

- Intersubjectivity – understanding of social relations, anticipation and expectancies for the behavior of others in relation to oneself (Trevarthen, 1993);
- Attachment development – the sense of security, mother’s ability to react to the child’s emotional signals, to fulfill affective and physiological needs (Bowlby, 1969);
- Acquisition of language – sharing of affective expressions, shared experiences, joint attention (Butterworth, 2004);
- Emotional development – mother’s support for the child’s emotional expressions, through facial expressions, vocalizing, touch, playful interactions, emotional regulation.

Physical contact is essential for the social and emotional development of the child, as well as general development and even the rehabilitation process for children with disabilities (Stack, 2004). Also, physical contact is important in the development of a secure attachment between child and caregiver. The sense of attachment security represents a basis for cognitive development, as well as trust in oneself and others. Insecure children have paradoxical reactions: they may cry in order to be held, but they protest when their need is accomplished, they may become aggressive with their caregivers, they may resist the efforts to be comforted (Tavris & Wade, 1997).

### III.2. Developmental implications of vision impairment, MDVI and dual sensory impairments

A young child’s social interactions and early relationships have a profound influence on early social-emotional development, communication/language development, and cognitive development. The natural course for developing social relationships and engaging in experiences may be disrupted when a child has vision impairment and/or hearing loss alongside additional disabilities. In such circumstances, specific consideration must be given to interventions that promote the child’s healthy social-emotional, communication, and concept development.

Vision plays a critical role in every child’s development and learning process. A person whose vision is affected or dysfunctional must rely on the other senses in order to benefit from using strategies and tools to accommodate. The environment should be evaluated to ensure that it provides the child who is blind or visually impaired optimal access to information using hearing,





touch, and movement. The child with multiple disabilities who is blind or visually impaired must be given the same access to learning as their peers without disabilities through methods such as braille, auditory description, orientation and mobility instruction, and tactile representations of learning concepts (Durando, Chen, & Petroff, 2017).

Vision impairment affects social and emotional development, language development, cognitive development and mobility, and orientation. Therefore, a child with vision impairment is most probably exposed to problems in adaptation, learning, as well as the interactions with the surroundings. Sensitivity for the child's needs in terms of environmental adaptation, as well as adapted interactions with peers, adults and surroundings, are crucial for the child's optimal development (Farrell, 2009).

An inability or diminished ability to hear can have a significant impact on a child's development and learning. The development of speech and language is dependent on consistent, reliable, and accurate auditory information; Even, a unilateral hearing loss (only in one ear) can negatively affect the language development of a young child. Children who are deaf need special considerations to develop appropriate literacy skills and often demonstrate reading/writing abilities below their peers. Hearing loss will further affect communication, literacy, and social success when combined with the presence of additional challenges such as intellectual and motor disabilities (Durando, Chen, & Petroff, 2017).

An essential aspect of multiple disabilities is the interaction of the disabilities and the combined impact on the child's development. Communication is a major challenge for children with complex needs if they have severe vision impairment. Hearing impairment, vision impairment, physical disability, and motor difficulties may have been identified by staff in the maternity hospital or by the health home visitor or parents. Other disabilities/ disorders such as moderate to severe cognitive impairment or communication disorders may be noticed only later.

The curriculum for children with multiple disability and vision impairment includes a flexibly interpreted general curriculum, a developmental curriculum (which concerns areas of early development which may include motor development, communication, cognition, and personal/social development) and additional curriculum provisions such as physiotherapy, mobility education, and motor development programs.

For some pupils with multiple disabilities and vision impairment, communication may not be primarily through spoken language or writing. Non-verbal skills may be used, including a manual signing system. Signing can be used to give visual/gestural support to aid a child's comprehension of spoken language. A switch with a voice input system may be used. Other means of communication may be objects of reference or tactile symbols. For pupils who are unable to understand and use formal communication systems such as speech and manual signing systems, their potential communication signals may be non-intentional or unconventional. A communication partner may be helpful to seek to relate such signals to meaning and more generally ensuring that stimulation that is structured and suitable is provided in an interactive context (Farrell, 2008).



### III.3. Assessment in infancy and early childhood

Assessment is *defined* as a systematic and rigorous collection and evaluation of information used to design, select, apply, and evaluate the intervention plans. Assessment can be conducted in a variety of settings and can be performed in different ways (professional ratings, observational data collection, standardized testing, etc.), whereas the results can be used in determining the right course of action in intervention, by monitoring the outcomes of the child.

Several purposes of the assessment in early childhood can be identified:

- 1) Determining the eligibility for early intervention services;
- 2) Informing professionals in the design or evaluation of instructional or other services of child's progress;
- 3) Describing groups for program planning and evaluation, policy analysis and development, communication with the public.

Most children with ages between 0 and 3 three years are often assessed by medical doctors and complex assessment is often impossible due to the lack of time. Gabovitch and Wiseman (2005) list a number of behaviors that children manifest during this period, that can be used in order for the parents to identify the “red flags” and alarming signals in the developmental areas.

- lack of social smile or any other expression that shown warmth, joy until 6 months of age and afterward;
- lack of response to sounds, smiles or other facial expressions at 9 months and afterward;
- lack of vocalizations at age 12 months;
- does not use gestures such as pointing, reaching, other gestures that show interest, hand fluttering at age 12 months;
- does not say any word at 16 months;
- does not use two sentence verbal constructions, without imitating or repeating at age 24 months;
- loss of verbal communication or proto-communication or social skills at any age.

The assessment of infants and toddlers at risk should be conducted in multidisciplinary teams and the results of the assessment are used to build the individualized intervention plans for each child.

The main purposes of the assessment of at-risk children are the identification of those who need specialized early intervention services, the increase of the level of understanding of skills, competencies, personality characteristics of the child. Thus, Greenspan and Meisels (1993, cited by Wyly, 1997) enumerate the following goals of assessment: identification of children at-risk for developmental delays; diagnosis and assessment of developmental problems; identification of the child's skills and resources; determination of the right intervention strategies.

The general purposes of assessment and diagnosis are:

- differential diagnosis – determining the specificity of the disorder, excluding the possibility that this is better explained by another disorder;
- determination of the areas and assessment modalities;



- diagnosis
- intervention.

The comprehensive assessment needs to offer information about the nature of the child's difficulties; child's capacities; general adaptation capacity; child's functioning in main developmental areas (social-emotional, relational, cognitive, language, sensory-motor); the contribution of different areas to child's difficulties and competencies and the prevention/intervention plan in order to approach the other aspects (Zero to Three, 1999).

#### *Steps in the assessment of infants and toddlers*

*The Systemic approach* of the assessment in early childhood involves screening conducted by the parents. The focus is on the developmental level of the child and the behavior is the main target in the assessment process. The identification of children with mental health problems, as well as those with developmental delays and atypical development is in the center of the assessment. All the components of the continuous assessment process are connected (Bricker, Schoen Davis, & Squires, 2004).

The main components of the assessment are:

- screening
- eligibility determination
- intervention
- assessment.

Other models of assessment in early childhood (eg., Wyly, 1997) emphasize the higher role of the specialists, compared to parents.

Each specialist needs to establish a diagnostic and to set the goals for an intervention plan that considers all the relevant areas of the child's functioning:

- presentation of symptoms and behaviors;
- developmental history: past and present affect functioning, language, cognitive, motor, sensory development, family and interactional functioning, pregnancy and birth history;
- family, community functioning, medical and psychosocial family history;
- assessment of each parent;
- interactional parent-child patterns;
- maturational and constitutional characteristics;
- affective, language, cognitive, motor and sensory patterns;
- present environmental stressors (Zero to Three, 1999).

Multiple sources of information, among which case history intake, direct observation, standardized testing, direct assessment of the child's sensory reactivity, and processing, motor planning and tone, language, cognitive development, emotional expressiveness are the gold standard in the assessment of infants and toddlers (Zero to Three, 1999).

*The Neuropsychological assessment* reflects the relationship between brain development and psychological development, allowing the early detection of brain damages in children. At birth, the newborn demonstrates astonishing capacities and during the first two years of life the



neonate's nervous system is in a state of rapid development. The brain of the infant has an immense potential of recovery and compensation (Dubowitz & Dubowitz, 1981).

Difficult labor does not necessarily prove the existence of brain damage, but the child who has gone through perinatal problems, such as prematurity, hypoxia, needs special assessment conditions and increased attention, given his vulnerability. The child's state of arousal should be carefully monitored, as well as the child's reactions to manipulation, irritability, fatigue. The assessment is centered around skills that emerge during the first years of life: spontaneous and provoked motor reactions, sensory skills, social, communicative, and cognitive skills (Majnemer & Snider, 2005). In the case of children with severe disabilities, standardized assessments may not be very useful, as their scores are very low and the estimation of the severity of disability problematic. Therefore, the qualitative interpretation of the scores might be a more useful alternative (Johnson & Marlow, 2006).

### *Screening and complex assessment*

Screening refers to a brief, broadscale evaluation, used to identify those cases in which more information is needed, as well as children who are not developing age-related skills so that these children can receive help to improve their achievement. Diagnosis refers to the formal evaluation of individual children for special education eligibility or program enrollment (McConnell & Rahn, 2016). Two main categories of assessment instruments can be useful in the process of identification and complex programming of the intervention process in case of risk and disabilities:

- *developmental screening instruments* – used in the identification of children at risk and children presenting deviations from typical development. The main purpose of screening is the identification of delays in various developmental areas, namely: motor, cognitive, executive functioning, attention, language, and behavior. Language and communication assessment is usually underrepresented in various assessments, although its development in early childhood, in connection with cognition, social interaction, is critical in the identification of various disabilities and developmental problems (Lipkin & Allen, 2005).
- *standardized assessment tests* – used for the detailed assessment of children (Johnson & Marlow, 2006). The main criteria for the test selection are: the child's age and the psychometric properties of the test mentioned in the manual.

For the early identification of children with vision impairments, *visual screening* begins immediately after birth. Newborn screening includes the assessment of the eye structures, responses to visual stimuli (for example, eye closure to bright light), and alignment. The ability to fix, follow objects and alignment are in the center of the assessment process in the first few months. Ideally, this should be evaluated for each eye independently. The ability to see and obtain small objects (e.g., a piece of lint on the carpet) is appropriate for children in the first half-year of life (Shapiro, 2011, p. 87).

Criteria for referral for additional evaluation include:

- structural abnormality at any age,



- failure to show light appreciation in either eye at any age,
- misalignment of the eyes,
- visual acuity of 20/50 or worse or more than two lines difference between the eyes in 3-year olds,
- visual acuity of 20/40 or worse or more than two lines difference between the eyes in 4-year olds (Shapiro, 2011).

Assessment of visual acuity that uses behavioral methods begins at age 3, although estimates of visual acuity can be measured earlier. Techniques that measure pursuit of novel stimuli of graded sizes, or preferential looking, yield reliable measures of visual acuity but have not been widely adopted in the primary care setting. Such test are the Teller cards, Cardiff cards and Lea tests.

The following tests can be used for children 3 to 5 years of age: Snellen letters, Snellen numbers, Tumbling E, HOTV, and the Allen or LH test. The Tumbling E test requires the child to show which way the E is pointing. The HOTV tests use letters that are more easily distinguished by preschool children because they are not affected by rotation. The Allen and LH tests are presented in a picture format for children who do not know their letters. Asking younger children to match the stimuli they see to a testing board that contains all of the stimuli may increase their performance (Shapiro, 2011).

Besides the assessment of acuity, field restrictions, and other objective measurements of losses and deficits, it is important to also assess a child's ability to use residual vision in daily activities, namely functional vision. While one child can feel comfortable to move around in familiar environments, another child with the same acuity can be frightened and unable to move around. Vision teachers and interventionists need to assess the manner in which a child is able to use the existing visual skills, as well as the nature of accommodations that the child needs. Children with undiagnosed conditions may show behaviors (approaching visual material to eyes, tilting the head while performing certain activities, staring at lights, eye poking/ pressing, light sensitivity, inconsistent visual responses, etc.) that suggest the need for further assessment. Sighted children receive around 80% of the information through vision, while around 40% of the brain is devoted to visual processing. Therefore, vision plays a critical role in both learning and development, so various strategies need to be implemented in order to reduce the impact of visual loss on the development of cognition, language, and communication, motor skills, social-emotional development, as well as concept development (Durando, Chen & Petroff, 2017).

The methods used for *evaluating hearing* are dependent on the ability of the child to cooperate. Physiologic measures, such as auditory brainstem responses or otoacoustic emissions, do not require the child's cooperation. Impedance audiometry provides useful information about the status of the middle ear and is used most often in the evaluation of conductive hearing loss. Visual reinforced audiometry may be used in children as young as 6 to 9 months to approximate hearing acuity. For those children who can be conditioned for visual reinforcement audiometry (VRA), the American Speech-Hearing-Language Association (ASHA) recommends screening with earphones to test each ear with 1,000, 2,000, and 4,000 Hz tones at 30 dB HL. If the child



cannot be conditioned to earphones, evaluation in sound field conditions may provide sufficient information to answer the question of whether the child has sufficient hearing for the development of language. Conditioned play audiometry and the use of headphones may be used in somewhat older children. For those children who can be conditioned for play audiometry (CPA), screening each ear (with 1,000, 2,000, and 4,000 Hz tones at 20 dB HL) is recommended. Referral should be made for children who show no response or no reliable response at a level at 30 dB for VRA or 20 dB for CPA at any frequency in either ear. Failed hearing screens are frequently seen in preschool children (Shapiro, 2011, p. 89).

### *Conventional and authentic assessment of vulnerable children*

Several authors argue for the use of adapted assessment in the case of children with disabilities. Neisworth & Bagnato (2004) consider a *conventional assessment* by using standardized tests, as having limited value for children with special needs. The authors suggest that *authentic assessment* of children with disabilities should be focused on observing the child's behaviors in the natural environment, with assessment procedures, context, and contents that are adequate for the child's developmental level, in cooperation with the primary caregivers. Direct observation, recordings, interviews, scales, and observation of play episodes or during daily routines can be useful in the assessment process.

The specialists that conduct the assessment should have a *family-oriented* attitude, to listen to the parents' perspective on the child's problems, to face their worries, uncertainty, helplessness regarding the child's problems. The assessment of the child developmental level, as well as the identification of those children who need more detailed assessment, can be performed using questionnaires for parents. These are useful tools that help the reduction of costs and time needed for the assessment process (Johnson & Marlow, 2006, Gabovitch & Wiseman, 2005). Some of these measures are:

- Ages and Stages Questionnaires (ASQ, Bricker & Squires, 1999);
- Parents' Evaluation of Developmental Status (PEDS);
- Minnesota Child Development Inventory (MCDI);
- Kent Inventory of Developmental Skills (KIDS);
- Parent Report of Children's Abilities Revised for Preterm Infants (PARCA-R);
- Parents Evaluation of Developmental Status (PEDS; Glascoe, 1997)
- Other useful instruments that can be used to identify several early signs for severe disorders in infancy and early childhood are:
- Child Development Inventories (GDIs; Ireton, 1992);
- Infant-Toddler Checklist for Language and Communication (Wetherby & Prizant, 2002);
- Temperament and Behavior Scales (TABS; Bagnato, Neisworth, Salvia & Hunt, 1999);
- Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ; Frankenburg, 1985).

Several arguments have been mentioned for the parental involvement in the assessment of infants and toddlers (Bortolus, Parazzini, Trevisanuto, Cipriani, Ferrarese, Zanardo, 2002): parents

know their children best, they have an interest in fostering their children’s health and development, they are the first to identify developmental risks. The assessment using parental reports cannot completely replace the children’s detailed assessment conducted by specialists, especially in the cognitive, language, and social-emotional developmental areas.

In depth analysis of the child’s problems and needs can be accomplished using various techniques, such as observation, assessment instruments for cognitive, behavioral, emotional functioning, and mental health. Besides the child’s assessment, obtaining information on environmental influences is necessary.

In order to conduct an accurate assessment, Wilmshurst (2005) recommends the multimodal assessment, using multiple sources of information, while the specialist’s task is to integrate the various information. This model of assessment includes an interview, behavioral observation, and the use of clinical tests in order to gather as much information as needed for the design of the most appropriate intervention goals, with ecological validity, as well as the determination of eligibility for special early intervention services.

The basic features of assessment in early childhood special education are: (1) eligibility and identification for specialized intervention, (2) program planning, (3) intervention and fidelity assessment, and (4) progress monitoring.

### III.4. Examples of assessment instruments

Neurobehavioral assessment of the neonate is focused on several spontaneous behavioral sequences of the neonate and the notable responses to environmental stimulation. It is usually a standardized assessment and can be conducted by medical doctors and different therapists. It includes: (1) passive and active movement patterns, (2) primitive reflexes, (3) orientation toward auditory and visual stimuli (Majnemer & Snider, 2005). The neuropsychological assessment of the neonate has the goal to detect the degree of integrity and maturation of the nervous system, especially in the case of children at-risk. One example of a useful instrument is the Neurobehavioral Assessment of the Preterm Infant (Korner, Brown, Thom, & Constantinou, 2000), assessing motor development and vigor, scarf sign, popliteal angle, activism/ orientation, irritability, percentage of the sleep time and the quality of crying of the premature children, that needed special care in the neonatal intensive care units.

Complex assessment from birth to preschool or school age can be conducted using several instruments (Andreassen et al., 2007; Johnson & Marlow, 2006, Nadelman, 2004.). Table 1 presents some instruments useful in this process.

<b>Test</b>	<b>Age interval</b>	<b>Assessment areas</b>	<b>Scores</b>	<b>Observations</b>
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<i>Mullen Scales of Early Learning (MSEL)</i>	birth – 68 months	<ul style="list-style-type: none"> <li>- fine motor</li> <li>- visual perception</li> <li>- receptive language</li> <li>- expressive language</li> <li>- gross motor</li> </ul>	<ul style="list-style-type: none"> <li>- standard scores for each domain</li> <li>- global standard score (“Early Learning Composite”)</li> <li>percentiles, equivalent age</li> </ul>	<ul style="list-style-type: none"> <li>- easy to administer</li> <li>- needs developmental assessment course</li> <li>- offers an accurate profile of strong and weak points in cognitive areas, but less detailed in motor area</li> <li>- low utility for children with motor disorders</li> <li>- standards are not recent</li> </ul>
<i>Battelle Developmental Inventory II (BDI-II)</i>	birth – 8 years	<ul style="list-style-type: none"> <li>- personal – social</li> <li>- adaptative</li> <li>- motor</li> <li>- communication</li> <li>- cognition</li> </ul>	<ul style="list-style-type: none"> <li>- standard scores for sub-domains, domains and global</li> <li>- z scores, percentiles, equivalent ages</li> </ul>	<ul style="list-style-type: none"> <li>- can be administered by a large array of professionals, but interpretation is done by specialists</li> <li>- relatively low costs, but high bias risk</li> <li>- useful for planning and monitoring the intervention efficacy</li> <li>- possibility to adapt to assessment of children with disabilities</li> </ul>
<i>Griffiths Mental Development Scales—Baby Scales (Griffiths Scales 0-2)</i>	birth – 23 months	<ul style="list-style-type: none"> <li>- locomotor</li> <li>- personal – social</li> <li>- hearing and language</li> <li>- eye-hand coordination</li> <li>- performance</li> </ul>	<ul style="list-style-type: none"> <li>- standard scores for each domain</li> <li>- equivalent ages, percentiles</li> <li>- standard score for global functioning</li> </ul>	<ul style="list-style-type: none"> <li>- offer the developmental profile and the analysis of weak and strong points in the child’s development</li> <li>- can be administered only by specialists with experience in developmental assessment and needs special training</li> <li>- low costs, but scarcely detailed psychometric properties</li> </ul>
<i>Bayley Scales of Infant Development II (BSID-II)</i>	1 – 42 months	<ul style="list-style-type: none"> <li>- mental (MDI);</li> <li>- psychomotor (PDI): coordination and motor skills</li> <li>- behavior during testing (BDT): level of activism, tendency of approach/ avoid,</li> </ul>	<ul style="list-style-type: none"> <li>- standard scores for MDI and PDI, percentiles and equivalent ages (17 age groups), but the subscales are not standardized</li> <li>- good psychometric qualities, but</li> </ul>	<ul style="list-style-type: none"> <li>- individually administered, needs long time for assessment</li> <li>- needs special training and experience in assessment for the examiner</li> <li>- high costs</li> <li>- limited in the assessment of children with disabilities, but good instrument for the identification of developmental delay</li> </ul>





		energy, emotional regulation etc.	limited predictive value	- one of the most popular assessment instrument of the infant, toddler and preschooler
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Table 1. Examples of standardized assessment tests used for assessment in early childhood

The assessment of parent-child interaction can be conducted using standardized procedures, such as the *Strange Situation* (Ainsworth, 1969).

For infants and toddlers with disabilities and risks, the focus of the assessment should be on supporting the family to maximize outcomes of the intervention (McConnell & Rahn, 2016). The *Assessment Evaluation and Programming System Family Report* (Bricker, 2002) provides a format to gather information about the child’s daily routines and activities (e.g., meals, bathing, and dressing) and family preferences regarding intervention targets. This assists the team in identifying desired outcomes important for the child’s functioning during everyday activities.

Intervention strategies can then be embedded within authentic activities and routines using toys and materials available in the home. AEPS items are clustered in developmental areas and arranged hierarchically, from earlier to later developing skills. Each item includes a subset of objectives that develop earlier than the goal and generally precede it. This allows teams to identify where a child lies in the developmental sequence and which skills need focus. Information gathered from both teacher and parent reports are used to identify and set priorities for skills to address in the intervention. These skills are taught using evidence-based teaching strategies selected based on the skills being taught and the child’s strengths, needs, and preferences, with instruction and practice embedded across various activities. The AEPS is an assessment modality conducted in the child’s natural environment, an assessment system that is comprehensible, based on functional strategies. AEPS creates the link between screening, assessment and intervention in children between 0 to 6 years, with disabilities or risks for developmental delays. The system is focused on six developmental areas: (1) fine motor, (2) gross motor, (3) cognitive, (4) adaptive, (5) social-communication, and (6) social. AEPS fosters the identification of purposes in the intervention for each child, the formulation of adequate objectives, the pre and posttest assessments, while the family is constantly involved in both the assessment and the intervention processes.

The purposes of AEPS are:

- the identification of the child’s skills on various developmental areas;
- the identification of functional goals and objectives for the personalized intervention plans;
- the planning and guidance of the intervention;
- the monitoring of the children’s progress.

AEPS assessment can be conducted by therapists, teachers, specialists, and parents/ caregivers, a multidisciplinary team. Validity and fidelity have been tested in several studies, starting from 1984, concurrent validity with Bayley Scales, interrater agreement, and test-retest fidelity are given in the manual.

*Assessment of the family environment and the quality of stimulation*



The quality and quantity of parental support that the child receives from parents/ caregivers in the natural environment is a reflection of the psychosocial risk that the child is subjected to. One instrument assessing the risks that the child has in the family is HOME (*Home Observation for Measurement of the Environment*, Caldwell & Bradley, 1984, in Thompson et al., 1998), that combines the semi-structured interview and the observation methods. The questionnaire is completed at home, in the presence of both the child and the caregiver. The instrument is focused on the child's experience in the family environment, where the child interacts with objects, events, and transitions. The instrument is destined to both practitioners and researchers and its purpose is the description of the child's family environment and its impact on the developmental outcomes, in relation to a type of intervention that is being conducted (Totsika & Sylva, 2004). The version destined to infants and toddlers (0 to 3 years) is formed of 45 items with dichotomous responses, grouped in six subscales:

- 1) maternal emotional and verbal responsiveness;
- 2) child acceptance and avoidance of punishment;
- 3) organization of the environment;
- 4) appropriate play material;
- 5) maternal involvement in child care;
- 6) variety of daily stimulation.

Scores can be computed on all of the six subscales, as well as a global score, representing the psychosocial risk that the child has, due to maternal distress, other proximal factors, that contribute to the cognitive development. The quality and amount of stimulation, as well as the support that the child receives, are very important especially for children at risk (with birth accidents, very low birth weight, fetal suffering, etc.). The score can be a predictor for the cognitive functioning, the attachment relationship, the typical development of the child on medium and long term (Thompson et al., 1998; Totsika & Sylva, 2004)

Another measure that investigates the quality of the parental care, parental adjustment in children with high risk is the Clinical Interview for Parents of High-Risk Infants, CLIP, Meyer, Zeanah, Boukydis, & Lester, 1993). The instrument assesses parental perception, affective responses and understanding of their current situation. The interview investigates the parents' story on the pregnancy, birth, child, current situation, and anticipation of the future and it is a basis for the development of an intervention plan for dyads at risk (Meyer, Zeanah, Boukydis, & Lester, 1993). The interview focuses on the whole family and the parents' skills and needs concerning the child's care are investigated, so that intervention can be planned. The sections of the interview are:

- Current state of the child;
- Pregnancy;
- Labor and birth;
- Relationship with the child and the feelings around parenting;
- Reactions toward the intensive care unit and the relation with the personnel;
- Relationship with family and social support;
- Hospital discharge and follow-up;



- Wrap-up, reflection on the experiences in the intensive care unit.

CLIP is a useful tool for the identification of family skills, coping, worries, essential for the planning of psychosocial intervention and the other interventions needed for the child and the family.

### III.5. Limits of early assessment and identification

The goal of early identification of children with developmental disabilities is far from perfection and several limitations have been identified such as the need to have multiple evaluations, to detect all disorders of interest, the limited ability of instruments to classify children, the insufficient efforts in the service of identification of children who need early intervention services. Moreover, early identification does not always lead to the inclusion of a child in early intervention programs. Families can be difficult to motivate and they can sometimes underestimate the importance of early intervention and the costs of programs can be too high for a family to afford them. The research around the efficacy of early identification and intervention is still insufficient to prove the important role of these services.

### III.6. Strategies used in the approach of children with hearing and/or vision loss

Sensory loss influences a child's social interactions and access to everyday information at home, school, and in the community, potentially delaying the development of the interdependent areas of social, communication, and language skills. The strategies identified and implemented should provide access to information, promote social interactions, and address learning needs.

Some of these strategies are:

- *Developing a Universal Design for Learning* - applied to curriculum design of instructional activities, supports, and materials to provide functional and cognitive access to instruction and meet the variability among learners. UDL comprises three principles—multiple means of representation (sensory modalities and learning needs), multiple means of action (encouragement of responses, demonstration of understanding, verbal expressions, emotional communication) and expression, and multiple means of engagement (flexible and varied learning opportunities, that facilitate attention, curiosity, and motivation);
- *Ensuring Accessibility of Visual Information* – organization and monitoring of visual information (lighting, position, glare reduction, high contrast);
- *Ensuring Accessibility of Auditory Information* – *the acoustics* of the environment should be tailored and monitored to enhance the ease of hearing the adult's voice or other auditory sounds (reducing competing ambient sounds, using rugs and window coverings, proximity to the sound source);
- *Embed Instruction within Routines* - targeting specific learning opportunities during the learner's daily routines and activities (eg. meals). It involves ecological assessment of environments at home, at school, and in the community. An ecological assessment involves



observing the learner's interaction, participation, and behaviors in different situations and activities. It allows for a predictable sequence of activities, provides repeated opportunities for learning, and supports learner participation and generalization of skills to everyday contexts. Tactile symbols can be offered as clues for various routines (Durando, Chen, & Petroff, 2017).

### III.7. Interventions for Children with Sensory Disabilities

Several accommodations and adjustments to the learning environment, as well as to the way the information is presented can be highly useful in approaching children with vision impairments and additional disabilities:

- *Corrective Lenses and/or Magnification*: the family should be supported in obtaining them and the child should be encouraged to wear them. Visual images should be easier to discriminate, recognize, and understand when a child wears prescribed corrective lenses.
- *Amplification*: most children with a hearing loss may benefit from the use of an amplification device, such as a hearing aid, to improve their discrimination, recognition, or comprehension of auditory information. The family should be supported in obtaining the device and the learner should be encouraged to wear it.
- *Cochlear Implants*
- *Acoustic Highlighting*
- *Hand-over-Hand Guidance*: placing an adult's hand over a learner's hand to show the child an object or how to do something by guiding his or her hands through an action. Hand-over-hand guidance used to physically guide the learner's hand(s) to produce a sign or a sequence of signs is called *coactive signing*. Some children, particularly those who have a significant vision loss, may dislike having their hands manipulated and are threatened by the lack of control. Others may become passive or prompt dependent, waiting for the adult to place a hand on theirs as a signal to initiate an action. This approach is commonly used, but it may interfere with a child's development of independent skills.
- *Hand-Under-Hand Guidance*: involves placing an adult's hand under a child's hand to encourage action or exploration of materials. Children with significant vision loss do not have access to the natural cues in the environment that can promote independent behavior. For this reason, the hand-under-hand strategy, which is less intrusive than hand-over-hand guidance, allows the learner to follow the adult's hands to gain access to the action being demonstrated. Although this method may easily be used with children who have experience with this strategy, it may be more challenging to use with young children or children who may not keep their hands on top of the adult's hands. In these cases, the adult may use a finger or some other physical prompt to help keep the learner's hand in place. The adult may also need to execute the activity more slowly or even pause between steps in the activity to allow the child's hands to explore in greater detail. Sometimes resistance to this strategy occurs if the child has yet to develop trust with the adult. In this case, attracting



the child's interest by holding highly preferred objects and inviting the child to explore can encourage the concept that following the adult's hands will lead to interesting, positive experiences. Hand-under-hand guidance provides the learner not only with a safe opportunity to experience the targeted action or explore an unfamiliar material, but also with the option of how much to participate in a learning activity. The use of hand-under-hand guidance or tactile modeling by placing the learner's hands on the adult's to feel the movements of the sign being produced is called *interactive signing*.

- *Mutual Tactile Attention*: gently placing the adult's hand beside the child's, without interrupting the child's focus, to share in the focus of attention. Using mutual tactile attention with individuals who are blind or visually impaired is the tactile analogy to joint visual attention, a key developmental target for children with autism. Over time, the child may follow the adult's hands to share the adult's focus of attention. Mutual tactile attention promotes social interaction, shared attention, and communication skills in learners with severe visual loss.
- *Tangible Symbols*: three-dimensional (e.g., objects) and two-dimensional (e.g., photographs) symbols that can be manipulated by the learner as a means of expressive communication. The term refers to concrete items (e.g., object, picture, textured form) that are initially used to 1) promote the learner's understanding of the daily routine, activity sequences, or options or to refer to people, places, events, or things (receptive communication); and 2) provide a means by which the learner can make requests, refusals, or choices (expressive communication). The use of tangible symbols has been found to increase the communication of learners with sensory and additional disabilities (Durando, Chen, & Petroff, 2017).

Caregivers and teachers should identify ways to help the child recognize and discriminate them from other people by using a special greeting (e.g., visual, tactile, auditory) or identification cue (e.g., watch, ring). Furthermore, the establishment of predictable routines for everyday activities and the use of objects or pictures to represent these activities are likely to facilitate the child's feelings of security through anticipation and participation in these activities. "Learning through play" is common in early childhood education, and it is essential that young children with sensory and multiple disabilities have many opportunities to engage in a variety of play activities, particularly with typically developing peers. Young children with vision loss and multiple disabilities may have restricted play skills. Based on a child's interests and preferences, parents, teachers, and other service providers may create and structure activities that motivate the child's interest and participation in play. Six different stages of play that children may demonstrate depending on their age, abilities, interests, and the setting were described. The table below provides a description of each stage of play, the possible influence of multiple disabilities, and suggestions for intervention (Durando, Chen, & Petroff, 2017).



Stages of play	Specific of children with multiple disabilities	Suggestions for intervention
Unoccupied behavior – random actions, no purpose, usually in infants	Repetitive behavior Self stimulation (tapping, waving hands etc.)	Identify preferred materials, toys, actions Redirect, shape behavior Engage child in adaptive behaviors (e.g., use of musical instruments)
Solitary play – plays alone, entertains self, 2-3 years	Limited repertoire	Imitate child play Extend play actions by adding movements, elements, combining actions (e.g., combination of music and actions)
Onlooker play – watches others play, common when language develops	Lack or diminished ability to observe and communicate with others	Create opportunity to be close to children, activities, so that the child can touch, see, hear them Communicate what other children are doing in a intelligible way
Parallel play – playing alongside others; transition to later stages	Lack or diminished ability to observe and communicate with others	Opportunities for parallel play with child and peer (e.g., play in a sand tray, play with water)
Associative play – separate play, but sharing of materials, problem solving, cooperation	Lack or diminished language or social skills	Interaction with peers Prompting to request, share materials (e.g., ask for objects, cooperation in actions and play activities, such as pouring water together)
Cooperative play – play together, older pre-schoolers, may involve physical, constructive, dramatic/fantasy play, games with rules	Lack or diminished ability to observe the skills learned by peers	Development of appropriate skills (e.g., riding tricycle) Turn taking in activities (e.g. building together) Simple dramatic scripts Pretended play

Sensory and multiple disabilities have a significant impact on a child’s language development, interfering with the usual means of receptive (input) and expressive (output) communication. Interventions to support the child’s communication development should be derived from gathering information through observations of familiar and structured activities, conversations with the family and service providers, and consideration of the child’s individual characteristics, strengths, and needs. Multiple modes of symbolic representation may be

considered to determine the method(s) of receptive communication that a child is most likely to understand, and multiple modes of expression may be identified to determine the expressive communication means that is easiest for an individual child to produce and most likely for the listener to understand. The table below outlines various means of receptive and expressive communication that may be considered in designing a communication program for a young child with multiple disabilities (Durando, Chen, & Petroff, 2017).

<b>Receptive communication</b>	<b>Expressive communication</b>
Touch cues: tactile signals, preparing the child for the next activity	Body movements: elicited by emotional responses in order to show feelings, preferences, dislikes
Object cues: objects as representations for activities	Object cues: objects as indicators for preference for touching, picking ups, pointing, looking at/ away, pushing away objects
Tangible symbols: two/ three-dimensional objects/ images as representations for persons, places, activities	Tangible symbols: use of objects, pictures, representations to indicate need, preference, to refer to persons, places, activities
Gestures: conventional actions made with hand, head, body to send a message	Gestures: head, hand, body movements, as conventional gestures or idiosyncratic movements
Vocalizations: vocal sounds with meaning	Vocalizations: sound imitation/ production, recognizable by familiar adults
Manual signs: symbolic system of manual communication	Manual signs: communicate, request, comment, answer, engage in conversation
Speech: spoken words/ propositions	Speech: spoken words to make requests, comments, answer questions,

Selected communication means should then be used systematically and consistently in everyday interactions to support a child's communication development. The literature has identified evidence-based input strategies for supporting receptive communication and output strategies for supporting expressive communication in young children with disabilities.

*Receptive communication* can be fostered by:

- the use of child-directed speech (intonation, repetition, slow rate, simple phrases): reading children books with facial expressions, gestures and props for items in the story;
- comments on the child's focus and interest: commenting the child's actions with objects, play activities;
- the use of parallel talk to describe actions: verbalizing the child's play behaviors;
- the use of self-talk to describe own actions: verbalizing adult's actions while doing them;
- repetition and emphasis on key words: reading tactile books, using simple words, interjections, for images and actions;

- the use of a variety of verbal and object cues to increase understanding of words: doubling words with actions until child understands and reacts;
- expansion of own utterances: simple propositions for sequence of actions;
- expansion of child’s utterances with syntactic and semantic expansions: play with words related to familiar objects (brown dog, good dog).

Several strategies to foster expressive communication are:

- interpretation, response to child’s gestures and vocalizations
- imitation of child’s vocalizations and actions to promote turn-taking
- provide language and communication models for expression
- use of interrupted routines, pause and wait procedure to interrupt familiar and preferred movement activities or action songs;
- use wait time delay to motivate child’s initiation of a request of a favorite activity;
- offer choices in daily activities;
- provide natural reinforcers for child’s communication efforts;
- create a need to ask for help;
- establish joint attention with child and object that is of interest;
- encourage back-and-forth interactions and two-way conversations;
- use completion prompts to encourage child to complete rhymes, chants, refrains;
- planned mistakes.

Strategies that support communication and language development also promote early literacy development; these include using fingerplays or action songs, interacting with print-rich materials, telling stories, recognizing letters, and having conversations (Durando, Chen, & Petroff, 2017). Children with sensory impairments and additional disabilities benefit from multiple opportunities to engage in accessible early literacy activities that build on their interests, including books with tactile and auditory components.

Young children develop concepts of ways of organizing and understanding experiences through everyday interactions. Young children with sensory and additional disabilities benefit from repeated opportunities to interact with real objects in meaningful situations (e.g., learning about the characteristics of a banana by peeling and eating a banana for a snack). Predictable daily routines provide learning opportunities about many concepts, including 1) language or symbols associated with activities (e.g., labels and explanations through speech, signs, gestures, objects, or pictures); 2) the sequence of activities (e.g., first, second, and so forth; first do this, then do this; go home after lunch); and 3) a sense of time (e.g., five more minutes to play, then clean up the toys). The table below outlines selected early concepts and provides suggestions for promoting them (Durando, Chen, & Petroff, 2017).

<b>Concept</b>	<b>Interventions</b>
Object permanence	Peek-a-boo Seek and find objects Finding musical objects in other rooms





	Calling child's name from another room
Use of symbols to identify and label	Identify and label common objects, people through interactions Uses models of representation as to identify and refer to objects and people
Identification and definition of objects and people, recognition of differences	Play with objects with a variety of textures Defining features that distinguish objects Encouraging interactions with people, pointing to their characteristics
Identification of spatial concepts	Opportunities to engage in physical activities Manipulation of objects

Early intervention has a crucial role in the child's development and the functioning of the family in the presence of a disability. Complex feelings are notable in the family system: disappointment, frustration, hopelessness, social isolation, major stress. Fundamental principles that lay the foundation of the healthy development of infants and young children are:

- growth and development take place in stimulating relationships;
- the birth and care of a child offers family opportunities for development and change;
- the first years influence the development over the life span;
- early attachments can be distorted by the parents' life histories of trauma;
- the presence of a therapist can reduce the risk of failure in early relationships and can offer opportunities for change (Weatherstone, 2005, p.6)

Responsive caregiving promotes children's attachment to caregivers, a sense of trust, and the development of autonomy and further influences communication and other areas of development. Studies with children with disabilities indicate that a caregiver's responsiveness to a child's signals is associated with the child's security of attachment and early social, communicative, and cognitive development; and it promotes the caregiver's sense of confidence and competence. Every effort should be made by significant caregivers, family members, and teachers to identify, interpret, and respond to subtle, nonverbal, and sometimes idiosyncratic signals from young children with sensory and additional disabilities. Familiar adults recognize the child's communicative efforts through this process, and the child learns he or she can influence caregiver responses and develops a sense of competence.



IV. Best practices in the field of early intervention in partner countries from ErISFAVIA. Policies and legal support for Early Intervention Erasmus+ ErISFaVIA project partner countries. Scope of current and previous EU programs and other research regarding early intervention in your country.

## IV.1. CROATIA

### A. Policies and Legislation

As of 2017, there are 32,101 (Croatian Institute for Public Health, 2017) children with disabilities in Croatia. The term ‘child with developmental difficulties’ is used in Croatia to describe all types of disabilities children might have and to express the possible variability and development of the disability over time (Znaor, et al., 2003). The biggest number of children registered with disabilities, 46%, are in the age group between 10-14 years suggesting inadequate early intervention and only later discovery of disabilities (UNICEF, 2015). In 2013, Croatia added Early Childhood intervention to its legal system through the Social Care Act as a direct result of the Project carried out by UNICEF, Mali dom- Zagreb, and City of Zagreb. The project’s goal was to set up a model for Home-based Early childhood intervention for children with additional needs and their families, that will be replicable in all Croatia on the local level. It was based on a model already in use in Mali dom for Early intervention but was further developed in cooperation with 135 professionals across all sectors. It did include all relevant stakeholders and Governmental representatives from all sectors (Health, Social Welfare and Education) and that resulted in finally getting **Early Intervention Services in the Legislation under within the Law of Social Welfare** that ensured not only the right to receive EI services that are home-based and timely but to be timely, they are granted to be provided before children go through a usual medical examination, diagnostic and paperwork, but just upon the referral by the doctor in the neonatal unit, or later others who are specified in referral protocol to the ECI service provider, so the child can receive and is entitled to full ECI service based on the needs assessment of the ECI service provider and not upon usual long lasting administrative procedure. That is the case when children are under the age of 3, particularly if under age of 1, so they are really entitled to receive appropriate services granted by the state just based on ECI providers needs assessment and then once they already started receiving the support and service, they can gather all other needed documents through Center of social welfare and other administrative and health institutions.

Although there were all representatives of all main sectors included, a joint decision was to put ECI as a comprehensive service under the Social Welfare. Of course, some of the services like separate therapies or inclusion in preschool is under Health and Education, but they are not legally addressed as comprehensive ECI services



### **Social Welfare Act (2013)**

#### Early intervention - Article 84

- (1) Early intervention is a social service encompassing stimulating professional assistance to children, as well as professional and counseling assistance to their parents, including other family members and foster parents, when there is an established developmental risk or a developmental difficulty of the child.
- (2) Early intervention shall be provided to children and parents or foster parents, to children living with their families or at a service provider, with the aim of integrating the children into the wider social network when this service is not ensured within the healthcare sector.
- (3) Early intervention shall be provided to a child with an established developmental challenge, a developmental risk or developmental difficulties at an early age, typically up to the age of three, and no later than the age of seven.
- (4) Upon a prior opinion of a medical doctor -neonatology specialist or a pediatrician, and exceptionally a medical doctor with another adequate specialisation, the social welfare centre shall request an assessment of the service provider regarding the duration and frequency of the provision of the service from paragraph 1 of this Article, and shall grant the right to that service by a decision.
- 5) Early intervention may be provided by a welfare home, a community services centre, and by other service providers from Article 169 of this Act, under conditions prescribed by this Act.
- (6) Early intervention may be provided in the beneficiary's family or in the foster family, as well as with the service provider from paragraph 5 of this Act, and may be granted up to five hours a week.
- (7) The beneficiary granted early intervention shall not simultaneously receive psychosocial support service

The National Strategy for Rights of Children 2014-2020 established a strategic goal support for the rights of vulnerable children, including children with disabilities (UNICEF, 2015). Medical staff determine whether a child needs early childhood intervention, and they direct parents to Centres for Social Care that subsequently give them a referral based on which they can access the needed early childhood intervention and/or to recognize the right to social care to the person who applies for the care. But also parents themselves can contact service providers (ECI) send Center for Social Welfare the Opinion to determine the need for the ECI service and its frequency. Based on that Center of Social Welfare issues the document that grants that childfree ECI service. The Ministry for Demography, Family, Youth, and Social Policy has a directory for all the social care institutions, including the Centres for Social Care, which allows users to search for the institutions and their addresses, with the Centres for Social Care being available across Croatia in all the counties Ministry for Demography, Family, Youth and Social Policy, 2019.

Pre-school programmes such as kindergartens and other institutions are particularly important as part of early intervention support. These are available for children from 6 months of age until they start compulsory school attendance (UNICEF, 2015 The Office of the



Ombudsperson highlights that there is no legal regulation regarding the question of assistants in kindergartens and kindergartens struggle to offer adequate support to children with disabilities (Office of the Ombudsperson for Persons with Disabilities, 2018). While children with disabilities always have a priority when enrolling to kindergartens, they might still face obstacles accessing the service as in some parts of Croatia there are not enough kindergartens to include every child and the Office of the Ombudsperson says that there have been instances of discrimination based on disability.

According to the Office of the Ombudsperson, Early Intervention Services based on are not systematic and it they functions on project support with experts from the fields of education and rehabilitation. Many services remain inaccessible to children in rural and less developed areas that there are parts of Croatia where the early childhood intervention is practically non-existent he waiting lists are especially long for public and third-sector services, which are free for all regardless of their income. While the waiting lists are much shorter for private services, parents need to pay to access them

*The historical background of early childhood intervention in Croatia was understood as a primarily health-care area of work taking place in health-care institutions. Such connection to medicine has had good and bad consequences which will be discussed in the chapter. Changes have been initiated in the past ten years or so in both parent associations and university circles. Changes are connected with practice (sociocognitive approach and improvement of parent-child communication), with the training of experts through post- graduate university courses and with legislation and social inclusion*

Changes have been initiated in the past 15 years or so by both non-governmental organisations in the civil sector (i.e. parents' associations) and university circles – not only as a result of their own scientific research but also thanks to the close ties between Croatian academics and their foreign counterparts, which has led to the awareness of more recent international research and calls for evidence-based practice. The parent movement started to demand new programmes for their young children that focused on the development of their communication and ability to learn based on the home environment, as well as on the possibility of their inclusion into infant nurseries and preschools. The goal of numerous initiatives has been to create conditions that enable the parent to let go of their role of 'co-therapist' and become a parent again.

Croatia has a well-developed system of pre-school settings, and the vast majority of mothers are employed, so the mothers of young children with special needs have begun to look for opportunities to include their children in mainstream nursery or preschool programmes so that their children can socialize. In their efforts to do so, parents have obtained specialist support from university institutions. Parents now have an improving understanding that although each child is born with a unique biology, this does not mean the child's future is predetermined. Parents are a



force that permanently influences the improvement of the early childhood intervention system in Croatia.

Positive:

- ECI services is regulated and incorporated in the law so it has a basic framework.
- It is defined broadly in the content; service providers; the age of the child; place of service.
- The service is free for the child and the family.
- There is no need to go through administrative procedure of the Expert Body to be approved for the right to service so children can be included immediately into the ECI.

Negative:

- The disparity in law – not everyone implements it.
- Reduced number of service providers
- Lack of coordination between service providers and between sectors (health and social welfare) and therefore services themselves.
- Lack of appropriate education of Professionals and paraprofessionals - inability to advise and empower parents when choosing.

### **The current state of early childhood intervention**

When describing the contemporary state of early childhood intervention in Croatia, it must be emphasized that the picture is very erratic, depending upon the region in which a family lives, and the kind of developmental disorder their child has. Families from the Zagreb region are in a far better position than those living elsewhere, as the majority of both traditional treatment settings (i.e. medically-based programmes) and new programmes in family environment settings are concentrated in this area. The further east or south one goes, the less favorable the situation becomes. Regarding the type of developmental disorder, families of children with sensory impairments are in a better position than others. Reasons for this lie in the medically clear diagnosis and the great efforts made by individuals who are making advances in this area, but also in the decades of specialised training of medical doctors regarding the importance of prevention. The worst situation is faced by young children with complex health and developmental difficulties, the reasons for this are tied to the very fact that the medically based philosophy of early childhood intervention still prevails. More specifically in the approach to a young child, which still predominantly takes place in a medical setting, we recognise two very different treatment approaches. Children with high neurological risks or problems established at birth (e.g. Down syndrome, brain malformations or lesions) are included in medical follow-up with many different check-ups and therapeutic programmes taking place in specialised centres under the name of the early multidisciplinary approach. Although parents are listed as team members in name, in effect they are not. Many experts regularly see the child, but multiple professionals do not work together, and services are not team based. As parents come to the centre, the child enters clinical or



medically based programmes instead of procedures that are developmentally supportive and that promote children's participation in their family environment.

Treatments focus on the child and their deficit, resulting in the routine implementation of intensive, mostly motor exercises involving a parent as a co-therapist. Doctors are often insufficiently selective in the application of therapeutic procedures. This means that, from an early age, all children are included in baby exercises that are implemented by parents on a daily basis, and also in sensory integration therapy. As parents do not have the proper psychological support and are convinced of the truth of 'the more exercise, the better', they often take the initiative of hiring therapists to exercise with their young children. However, this overexposure to various therapeutic procedures destroys daily routine and normal family life and requires additional financial input by parents. At the same time, this approach has undesirable psychological consequences for children, often leading to negative or passive attitudes and learned helplessness. Parents of young children at neurodevelopmental risk ask themselves 'How do I motivate my child to exercise?' The understanding that children can learn through participating in their everyday activities and meaningful fun experiences with their family and caregivers is slowly getting to be a familiar concept. Its full implications have not yet been accepted – this is unfortunately even more true for service providers in medical settings than of parents.

However, it must be emphasized that through the efforts of some individuals, certain programmes with young children and families have developed good practice and are more and more regularly implemented. Parents have accepted these programmes exceptionally well, and there is a reason to believe that in the near future the programmes will be able to meet the needs of all families with young children who have developmental difficulties, and will also become a part of the early childhood intervention system in Croatia. After having ECI in the Law during the deinstitutionalization process lot of Social welfare institutions could choose if they would provide that service. Most of them clicked on yes, so they are providing it on the paper. Some of them make it reality but untrained staff is the biggest problem.

We do have Postgraduate study on the Education rehabilitation Faculty now on ECI and a one year training in Mali dom for ECI practitioner. But neither of it is prerequisite for providing ECI services. Therefore, quality and intensity of services really vary throughout the country. However the situation is improving, but way too slow. Also sometimes data reported is not really the representation of the real picture of the services. The best services are still in Zagreb, Mali dom and others follow in now in the northern part of the country. Those few programs are really based on Ecological model, and rest is still struggling with the medical model. The outside medical model only Mali dom at the moment consequently provides services for children at a very young age – meaning really from birth till 1 year of age. That is improving too because 10 years ago most of organizations claimed they provide ECI services, but most of their beneficiaries were older than 3 years of age. Now it is much better, but still children 0 – 1 age is very rare to find in the programs



that are not medically based. And we do have to change that because that is the biggest window of opportunity for children.

However, there is a growing interest from neonatologist for the ECI and ECI providers like Mali dom is regular guest on their conferences whicj is good in raising awareness. Also, cooperation is really good with them as well.

#### Quality risks of providing ECI in Croatia

- Insufficient resources - sporadic service delivery / no continuity.
- Providing only certain components of the RI model / lacking comprehensiveness.
- Medical model / multidisciplinary approach.
- Insufficient education of network providers and associates.
- Large number of private providers / offline providers / offline / beyond the ability to evaluate and control standards and quality.
- “Gray” market for service providers.
- Duplication of services / overlap between providers and number of services and no coordination between them.

#### Recommendations:

- Legislative changes - no children below three years in institutional care existent, but implementation is not adequate.
- Developing comprehensive ECI systems based on legal frameworks throughout the region.
- Appropriate budget allocation and services for supporting.
- Training maternity and pediatric hospital staff to discourage institutionalization and to support parents of newborns with disabilities.
- Awareness raising on inclusion and importance of ECI.
- Breaking prejudices and stereotypes continue to contribute to the institutionalizations.
- Integrate the science of ECD as a fundamental component in all pre and in-service training of specialists working with children and families.
- Children in vulnerable groups need equal access: additional funding, staff and material is needed.

#### **B. Early Intervention Programme - MALI DOM -Zagreb**

Mali dom has been providing ECI services more than 20 years and has developed a comprehensive model based on home-based services and transdisciplinary approach. It also provides services since the day child is born up to 3 years of age. Criteria for inclusion of children in the RI program have been defined, namely: neuro-risk factors, sensory impairments, developmental abnormalities,



post-natal trauma, malformation syndromes, and more. **Referral to the Early Childhood Intervention Program** is based on the aforementioned criteria, the form is submitted by health professionals: a neonatologist, a neuro-pediatrician, a pediatrician, etc., but also since certain developmental difficulties can be detected later, the child can be referred to the RI program: psychologist, rehabilitator, speech therapist, etc.

### **Transdisciplinary assessment:**

- Comprehensive, advisory in nature, consisting of basic and additional assessments.
- Basic assessments are those that are mandatory in Mali dom based on the age of the child so that we can create a program and those are:
  1. Assessment of General (spontaneous) movements ((GM) from birth to 4 months),
  2. Assessment of motor functions through analysis of the quality of movement and movement (GMFM );
  3. Educational rehabilitation assessment.
  4. Functional vision assessment.
- If there is a need for additional assessments, some of the following are performed: Assessment of early development of communication, Assessment of socio-emotional development, Assessment of development of sensory integration, Occupational therapy assessment. Assessments are performed using standardized and non-standardized tests, and data collection through conversation with parents.
- Such an assessment provides insight into the child's current capabilities in all areas, family dynamics, abilities and expectations for the child. The aim of the assessment is not only to identify potential disabilities but also to identify the child's strengths and ways of learning. A successful, complete assessment is the first step in forming an intervention program. On the basis of a comprehensive assessment, the expert team establishes a classification of the child's development and, together with the parents and guardians, defines therapeutic goals and activities.

### **Development of the Individual Family Support Plan (IOPP) and within it the Individual Education Plan (IEP)**

- IOPP documents the early intervention process and serves as a guide for the child's provider and family. Through the creation of this document, family members and early intervention professionals work as a team to plan, implement, and evaluate services tailored to the specific needs, priorities and resources of the family.
- The Individual Education Plan (IEP) is a document that contains long-term and short-term goals, approaches and resources, and who and under what conditions carries out activities determined by the set goals. It monitors and evaluates user progress. The difference between IOPP and IEP is that the first is directed at the family as a whole and the second at the service user (child).



### Early Intervention activities through Home Based Family Support –

- Early Intervention practitioner is assigned to the family and implements integrated professional family support and coordinates any other IOPP services. The safe and relaxed family environment enables the full implementation of educational and rehabilitation procedures in the daily life of the child. Established confidence and empowered parents of his competence by family professionals are the main foundation of successful ECI.

### Early intervention activities through support at the Center (Center based)

- The Center carries out, as needed, individual or group activities, such as: Physiotherapy models, Sensory integration, Vibro-acoustic therapy, Occupational therapy, Speech therapy, Experience groups, Therapeutic swimming

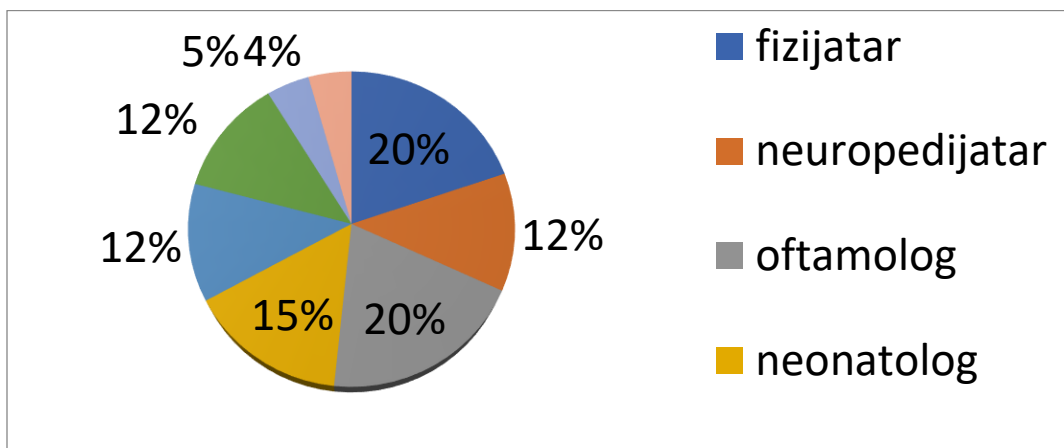
### Evaluation an re-assessment

- Re-assessment is carried out after 3 to 6 months in order to evaluate the progress of the services offered. The results of the initial and reassessment are compared and the results are compared with the age of the child.

### Continuation of Early Intervention Services

- After the assessment and opinion of the expert team for early intervention, professional support in the family for up to 3 years will continue according to the needs of the child.
- If the reassessment shows the optimal development of the child in all developmental areas, then the RI program is more necessary but parents are advised to come for follow-up through reassessments every 3 to 6 months, if necessary especially for children with high risk.

All activities are based on Transdisciplinary approach and whole ECI team meets once a week.  
Referall to Malio dom ECI services.





### **Description of ECI development model in Mali dom :**

The mission of the practice is to provide comprehensive, accessible, and responsive home-based early childhood intervention (ECI) service model that will support families in raising their child at risk or with a developmental delay or disability from birth till 3 years of age to enhance support to reach developmental milestones.

The goal is to establish a collaborative partnership with families and to empower them in identifying and achieving child and family level outcomes that are relevant and that are also meaningful for them. That way we would provide conditions for the child to fully develop its potential and provide a basis for further learning. Through empowering and building competencies of family members their involvement and participation in the community would increase.

The goal is that with the developed and appropriate approach, methodology and with established roles and responsibilities of all participants and stakeholders in the process of ECI we provide support through our Transdisciplinary team at the earliest possible stage, preferably after dismissal from the neonatal unit or at least within the first year of life of the child at risk or with developmental delay when most of the desired outcomes in child's developments and families support can be achieved.

### **Problems that are addressed by developing Mali dom model**

1. There were no established and recognized home-based EI services in the first years of life.
2. None or low awareness of early identification of children at risk or developmental delay and practically no early referral of children to any services that existed.
3. The existent practice was scarce and professionally centered.
4. Existent models were deficit-based, expertise-based and service-based models.
5. Services were carried out as remediation of a disorder, problem, disease or its consequence.
6. Professionals determined the needs and make decisions FOR the family.
7. Existent services were fragmented and specialized and started later than needed by the child and family.

### **The solution that has been developed through Mali dom model:**

1. Established home-based EI model with developed methodology protocols and referral at the earliest possible time right after birth.
2. Model is strength and resource-based, it enhances competence and positive functioning and decisions are made together **with** family, not **for** them.
3. Services are well coordinated and integrated between different disciplines and sectors – it uses a transdisciplinary approach and is also cross-sectoral.
4. It enabled providing services for children in the natural environment to the maximum extent - the term natural environment refer to settings in which child would participate had he or she not had a disability.
5. Within our model, we have embedded natural learning opportunities and intervention strategies into daily activities.



6. We have also focused on parents as primary implementers of intervention within family routines. Families are empowered as agents of change in promoting their child's development and meaningful participation.
7. Support and experience groups where parents come with their children to the centre are designed to build their competences and where they can meet with a range of different professionals other than key worker and with their support go through different activities, games and plays that later will be embedded in their everyday routine to achieve short and long term goals in a nonintrusive play oriented way.
8. To ensure the quality of service and especially interaction between team members included in the work with specific child we designed **software application** that ensures communication, goals, reports, following the protocols developed, etc.

### **Why this solution is better than other existing solutions**

Working as a transdisciplinary team reduces the likelihood of confusion for the family by reducing the number of people and disciplines with which they need to interact. This model is less intrusive because parents only need to build one key relationship and only one service provider visits the home. Enhanced and streamlined communication is considered to be a key benefit for the family. Since no discipline is more effective than another in providing early intervention services, particularly for children younger than 1 year of age, this cross-discipline work ensures that we all are working on the same comprehensive outcomes and strategies and so they are more likely to be realized. In terms of service efficiency, more children can be served because fewer service providers routinely see a child. Instead of each child receiving direct assessment and intervention, thus freeing other team members to see other children, and giving families more time in their family environment, rather than running around to get certain service during which both family and child are often too exhausted to benefit from it. Families do get also support through guidelines for the next two, three, or four months, getting written materials tailored to meet their individual and specific needs. Embedding natural learning opportunities throughout the day within a familiar environment ensures that intervention is acceptable, functional and relevant to families, encouraging the child's generalization when it comes to learning.

### **How ECI is organized**

The EI service program is performed at the child's home by primary EI therapist/service provider who is a key worker. Home-based practice includes regular visits (once a week) from the special teacher, who works with children and families according to the IFSP after defining outcomes and short and long term goals with all team members and family. Center-based activities are provided as a support when it is needed from professionals from other specific field or services that could not be carried out at home like physical therapy, occupational therapy, sensory integration, swimming, consultations with psychologist, parents' groups and experience groups (parents with children). In all those activities parents are present and all activities are carried out in coordination with key workers and all other team members. Experience groups are provided as additional



support for parents from professionals and from other parents which is very important as well. The method is ongoing and individualized for each family according to the initial assessment. The long term goals and short term goals are set combining results from initial assessment and consulting parents about what they think is important for the child to learn through the next stage. Experts use information obtained from the family and from developmental profiles in planning EI service.

Mali dom method is focused on establishing natural environments that provide context of the everyday activities of the family and the interactions between the child and the significant adults.

Some of the main principles that we follow are:

1. Family-centered: Families are the primary caregivers and educators of their young children.
  2. Promoting family competence and positive functioning.
  3. Building capacity: helping children and families use existing abilities and develop new skills.
  4. Strengths-based content.
- 
1. All children referred to our center have the right to a **transdisciplinary (arena) assessment**. Assessment helps us better understand the child's strengths and needs and how early intervention can help. Following the assessment, the team discusses with family their priorities and concerns, outline the next steps, and answer specific questions that family may have.
  2. An initial conversation with the social worker and psychologist.
  3. Debriefing process – team engages in a debriefing process intended to identify and support the primary therapist in working with the family.
  4. First home visit - describing what parents can expect from home-based service in order to alleviate anxiety.
  5. Developing the Individualized Family Service Plan (IFSP) - after six weeks primary therapist develops an IFSP in partnership with parents, based on assessment information and family priorities. It includes outcomes for a child and family, describing learning methods and approaches that will be used. It describes what kind of services they will have, who will provide it, where, when, and how often.
  6. Implementation of the IFSP.

Evaluation of defined goals refers to 3 to 6 month reviews and meetings are conducted to reevaluate IFSP and IEP. This may include new outcomes - old ones might have been reached or are no longer relevant, changing learning strategies and activities to help meet new outcomes along with changing the type of service needed.

Teaching materials



EI providers select play materials suited to their intervention strategies. They include many different objects, some already in the family home, and some brought by the therapists—toys, games, instructional materials, everyday objects, and construction pieces.

Selecting and preparing play materials to represent a major component of the service, while these materials affect many stages in the intervention process, including planning, budgeting, interacting with the children and their families, and teaching parents how to continue the therapeutic play after the visits.

In home visits, therapists are encouraged to use play materials in the family home, especially everyday objects. If a therapist brings the play materials, the program requires that the family has access to similar materials.

### **How are the needs of the children assessed?**

After decades of assessing what children cannot do, there has been a shift toward focusing on what children can do.

This strength-based approach involves **functional assessment of all developmental areas**. We use both clinical observations and various assessment tools. Such positive approaches to assessment are thought to be helpful in viewing the child as an individual with unique characteristics and abilities rather than disabilities. Children's needs are assessed mostly with curriculum-based checklists.

As professionals, such an approach also help us maintain more positive attitudes about the issues related to child development, and our role in modifying environments and/or providing intervention.

### **How are families involved in the service?**

The methodology is developed on evidence-based practice in Early Intervention and it includes:

- (a) focusing on contextualized learning in family routines;
- (b) supporting the child's participation in interest-based activities;
- (c) promoting the parent's responsiveness to the child.

Throughout the EI program, the team of experts is combining different methods to meet the child's current needs that will enhance development. Families and their priorities are unique depending on many factors that are internal and external. A very important part of our method is in depth planning of each stage, from the assessment, home visiting, creating and implementing IFSP, evaluation, and transition towards other programs.

The following issues are resolved with our methods:

1. lack of competency and responsiveness in parents,
2. better adjustment of the families to the present situation;
3. appropriate stimulation to enhance the child's development;
4. high-level quality communication with the EI team, and
5. cooperation in creating individual goals for the family and the child.



The problems that are tackled are ones that involve transition planning for children and families when they are ready to go. There is a well-tailored approach to the specific needs of each child and family. It is based on the concept that the child is integrated as a whole and can be best served through coordinated services delivered by the primary therapist with support and consultation from a team of different disciplines through a transdisciplinary approach. This is possible due to good orchestrated communication between a member of the early intervention team and families.

The program builds its foundation through **home visiting support, which is routine-based, relationship-focused, and parent-implemented intervention.** It utilizes supportive, empowering practice to recognize the family's existing interactions and activities as sources of intervention.

1. The methodology is based on evidence-based practice in Early Intervention.
2. Principles and Practice are conducted in the context of natural environments.
3. Family partnership.
4. Transdisciplinary assessment that uses both formal and informal tools for gathering information on an ongoing basis.
5. Service planning and evaluation are continuous activities throughout the process.
6. Team of experts is accepting and implementing principles of the transdisciplinary approach.

## ADMINISTRATIVE PROTOCOLS

After assessment and request for admission into the ECI program:

### **ENTRY PROTOCOL:**

1. Commission on Admissions into the program meets Decision of admission into the Program.
2. Initial telephone conversation - by a social worker; information about the decision of Commission and agreement to discuss under the Entry Protocol.
3. Initial interview - social worker; informing parents about the RI program, the content, the way and the frequency of its implementation; taking basic socio-medical history; completing a stress event questionnaire.
4. As a service provider, we send our official decision for Admission to the Center of Social work that needs to administrate (social worker).
5. Initial interview - psychologist; family needs; current situation; the adjustment process; filling in the Parental Stress Scale.
6. First home visit family; the suggestion is that a social worker/psychologist accompanies the therapist – key worker.
7. Expert support in the Center (assignment of other services according to plan and program).
8. Development of IOPP - psychologist and social worker.
9. Meeting the members of the Team around the child to exchange the information gathered so far.



## **PROTOCOL DURING PROVIDING ECI**

### 1. The first meeting

- 3 months after the first visit to the family; psychologist and the social worker together;
- verification of legal status (whether the decision of the competent Center for Social Work has arrived; documentation - whether all required documentation has been collected); monitoring of the provision of services (whether it started with professional support in the family; what frequency; whether there were any difficulties in organizing the reception of the therapist in the family, etc.; whether the services started in the Center and which ones);
- monitoring according to TOD issues (with individualization for each family); are you happy with how things are going?; what is your need for additional support?; what do you foresee / think / estimate that might be important to you in the next 6 months and what would you like to do as a family then?;
- presenting the IOPP and checking with parents whether they agree with the set goals; to change, add, delete;
- joining support groups (checking the ability of the parent organization to come to the next group (the first after the checkpoint), arranging the date and the way of additional notification;
- in the event that they could not arrange a more frequent appointment with a psychologist / social worker - individual counseling and support;
- announcement of next interview / checkpoint depending on involvement in support groups / experiential (IOPPs planned).

### 2. Second encounter

- Families not attending GPs and / or experiential families continue at a frequency of monitoring every 3 - 6 months.
- For families who have become involved in some form of support at the Center and that we see through the GP and / or experiential, another encounter would be 12 months from the 1st meeting.

### 3. Third encounter

- Transitional (depending on the age of the child, this would be another meeting somewhere).
- 6 months before leaving the RI program or after 12 months from the 2nd meeting.

## **EXCLUSION PROTOCOL**

1. Final assessment.
2. Final interview with a social worker - one month before dismissal (3 year of age).
3. Final home based visit / last experience group in the center.
4. Drafting the decision on discharge and official letter to the Center for Social Work.



## IV.2. CYPRUS

### A. Policies and Legislation

The Ministry of Education and Culture serves the needs of children with disabilities as provided in The Education and Training of Children with Special Needs Laws of 1999 113(I)/1999 ([http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia\\_N%2013\(I\)\\_99.pdf](http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia_N%2013(I)_99.pdf)) – 2001, and in The Education and Training of Children with Special Needs Regulations of 2001 ([http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia\\_N%2013\(I\)\\_99.pdf](http://www.moec.gov.cy/eidiki/nomothesia/Nomothesia_N%2013(I)_99.pdf)). This legislation provides children with disabilities with all the opportunities for equal education to develop their skills to the highest level. According to the basic provisions of the above law, the State completes an evaluation of the needs of children by a multidisciplinary evaluation team and provides special education and training from the age of three until the completion of their studies. The evaluation of the needs of each child which is deemed likely to have special needs, is done by District Committees of Special Education and Training of each province, with a multidisciplinary team. The only policy that applies in Cyprus for children with disabilities under the age of three was taken in 2001. After a decision of the Council of Ministers, in 2001 the Coordinating Service of Early Childhood Intervention was established, under the monitoring of the Committee for the Protection of the Rights of Persons with Mental Retardation, being a consultative committee of public law, that addresses preschool children (under the age of 6) who face developmental disabilities or disorders. The Service supports and guides families on how to use the services available to them, which enhance the development of the child in fields such as speech, perception and self - care.

The first Report of the Republic of Cyprus on the implementation of the Convention on the Rights of Persons with Disabilities was submitted to the UN Committee on the Rights of Persons with Disabilities on 2013. On 22-23 March 2017, the first Report of the Republic of Cyprus on the implementation of the Convention on the Rights of Persons with Disabilities was examined by the UN Committee on the Rights of Persons with Disabilities and a dialogue between the Committee and Cyprus Delegation was held. On 8 May 2017, the UN Commission on the Rights of Persons with Disabilities issued its concluding remarks and recommendations. Among the Commission's recommendations was the Improvement of early intervention services for children with disabilities.

Despite this, and numerous interventions by organisations working with children with disabilities, during the negotiation period, the new special education law that will come into force in December 2020 does not refer to children under the age of three.

### B. Early Intervention Programme – St. Barnabas School for the Blind

Since its establishment in 1929, the St. Barnabas School for the Blind, the only educational institution of its kind in Cyprus, has been offering support and services to persons with vision impairments of all ages all over Cyprus. Over the years, the nature of the School's programmes and services changed quite significantly firstly to accommodate various changes within the school that were happening to meet the education and social policy system of Cyprus and secondly to keep up to date with the trends in the education of people with vision impairments worldwide. In





the early 1980s, the School made its first attempts to organize and run an Early Intervention Programme for children with vision impairments. The early intervention programme is among the few services that not only remained intact over these years but more emphasis was given to it since we believe that when intervention is offered early and right then we can aim high for our students. The fact that Cyprus is a small island with a population of less than a million habitants and has a small geographical surface allows for an early identification of the cases of children with vision impairments and for support and services to be provided on a very personal basis, giving an insight into individual needs.

The program is offered on a ‘voluntary’ basis as implementing programs for children below the age of three is foreseen neither in the legislation nor in the work plan of the educators. Recognizing the important role that a family plays in the life of a child, the program is family based. Parents and caregivers are not only the recipients of services but are active members in the planning and implementation of the intervention program. Nowadays, our early intervention program provides ongoing, individualized, one-on-one rehabilitative services to children with vision impairments and those with additional disabilities from the time of identification. Our program includes activities such as:

- training and support to parents or caregivers who in many cases are the grandparents, to enable them to enhance their child's growth and access needed services and resources,
- training professionals who work with visually impaired youngsters in mainstream settings such as nursery schools, pre-schools or therapy centers to increase their capacity in meeting the needs of these children,
- working directly with the children to provide vital learning, literacy, and socialization experiences,
- offering supportive groups where children, parents and caregivers all benefit in an effective way as these formal and informal groups set an environment in where participants can share ideas, experiences and similar concerns for the development of their children.

The main concern of the program is to work towards the better care and development of the child. Therefore the program is characterized by a fruitful cooperation among all people involved as well as the respect towards each child's environment.

The program is addressed to any child who is considered to be legally visually impaired, meaning, whose visual acuity is below 1/10 in the best eye even with the use of any corrective lenses or spectacles.

These children and their families usually are referred by:

- child neurologists,
- the Clinical Genetics Department, of the Children's Hospital,
- pediatricians,
- relatives and friends or other parents in the programme,
- other associations that run early intervention programmes,



- own their own while searching the internet.

### **Upon referral:**

1. The first contact with the family is done with the School's social worker. This communication is either performed by phone or at her office, usually without the presence of the child. During this first communication, there is a mutual exchange of information. The family provides information regarding the child's history of the child as well as the current developmental milestones achieved, the benefits and allowances the family receives and the therapy programme of the child and the school setting if he/she attends any. The social worker also gathers all available documentation regarding the disability of the child. The social worker afterward liaises with the multidisciplinary team and a teacher of the visually impaired is assigned to the specific child.
2. The second visit usually takes place at the St. Barnabas School for the Blind. Present are the social worker, the psychologist and the teacher for the visually impaired. The social worker assists the family to complete all necessary paperwork in order for the family to obtain available benefits and allowances. The psychologist interviews the parents in order to complete the history of the child (a document developed by the Ministry of Education and Culture that seeks to collect information about the child, the medical history, habits, medication and developmental milestones). The teacher of the visually impaired works directly with the child in order to make a first assessment of the child's functional vision and developmental level. The team also meets with the family and provides some information about the early intervention programme of the School. If the child is approaching the age of three, then the team informs the family of their rights in regards to free public education and assists them in completing all necessary paperwork in order to begin the assessment process by the Ministry.
3. The team performs a home visit in order to observe the child in his/her natural environment. These visits also provide the opportunity to meet with other caregivers such as grandmothers or nannies in order to provide some guidelines in caring for the child. In case the child attends a daycare or a nursery school the team might visit the setting and provide support to those involved in the education/care of the child.
4. Based on a number of factors (child attending other settings, parents working, the severity of disabilities, child's age) the team presents a proposal to the family that might include weekly, fortnightly or monthly visits to the School of the Child and at least one of the caregivers.
5. Assessment – The teacher of the visually impaired in close cooperation with the occupational therapist and the physiotherapist performs a thorough assessment of the child.

Based on the outcomes, the team plans the Individualized Intervention Plan which later on is presented and discussed with the family. The team consists of a social worker, a psychologist, teachers of the visually impaired, occupational therapist, physiotherapist, orientation and mobility specialist, music therapist.



## C. Screening and assessment instruments

- Wechsler Preschool & Primary Scale of Intelligence – WPPSI, Author(s): David Wechsler, Publication Year: 2013  
WPPSI™-IV Wechsler Preschool & Primary Scale of Intelligence™ | Fourth Edition is an innovative measure of cognitive development for preschoolers and young children, rooted in contemporary theory and research. Age Range: 2 years 6 months to 7 years 7 months. The test has been standardised in the Greek language.
- A' (Alpha) Test for School Readiness (2007). Ideal for children 5 years of age to check their school readiness. Check whether or not a child has the skills and the maturity needed to begin primary school.
- Cardiff acuity test, (Keeler). The Cardiff Acuity Test, designed by Dr J Margaret Woodhouse, is a selection of preferential looking pictures designed to measure acuity in toddlers aged 1-3 years and in individuals with intellectual impairment. The test combines the principles of preferential looking and vanishing optotypes. It is based on the premise that a child, when presented with two different patterns, will fixate on the picture rather than on a plain stimulus. The test uses pictures that will interest a child (house, car, duck etc) positioned either at the top or at the bottom of an otherwise grey card. There are eleven visual acuity levels, with three cards at each level.
- The Kay Picture Test vision testing system to enable earlier visual acuity measurements of very young children and those with learning disabilities.
- Observation of functional vision: drafted by teachers of the visually impaired at the School as it was adapted from » Vision for Doing - Assessing Functional Vision of Learners who are Multiply Disabled«.
- Tactual Profile (Royal Visio). Tactual Profile is an observation instrument for charting the tactual functioning in children from 0 to 16 years of age who have a severe vision impairment. ([www.tactualprofile.org](http://www.tactualprofile.org)). This tool is based on observation and structured activities as well.
- Sensory Profile Assessment provides an overall picture of a child's sensory processing patterns. Results of the Sensory Profile are used to consider how these patterns might be contributing to or creating barriers to a child's performance in daily life. Eight main areas of sensory input are examined, including auditory, visual, activity level, taste/smell, body position, movement, touch and emotional/social.



## IV. 3. GERMANY

### A. Policies and Legislation

#### **The Federal Participation Law BTHG**

- The BTHG is the implementation into German law of the UN Convention on the Rights of the Handicapped.
- Its aim is to improve the lives of handicapped people.
- It defines a way to move from the concept of welfare to leading a life determined by the handicapped person him/herself.
- It ensures the continued development of integration assistance centred on the individual concerned.
- It offers every recipient of the service services tailored exactly to individual needs
- It optimises cooperation with the rehabilitation centre.

#### **Federal Participation Law and early Intervention**

- Claim to services from birth to the beginning of the school.
- Definition of the interdisciplinary complex support service.
- Combination of medical and remedial educational services.
- Services to ensure interdisciplinarity.
- Stronger binding involvement of health insurers in the complex support service early intervention.
- The provision of medical-therapeutical services as part of the complex support service early intervention not based a priori on the provisions of the guidelines on curative remedies.
- State framework contracts.
- State law may provide for other rules, e.g. admission of other institutions offering a comparable range of intervention and treatment, e.g. day-care centres for children.

#### **Directive Concerning Early Detection and Early Intervention of Handicapped Children and Children Threatened by Disability (Early Intervention Directive – FrühV).**

Date of issue: 24.06.2003,

“Early Intervention Directive of June 24<sup>th</sup> 2003 (German Laws I S. 998) which is amended by article 23 of the Law of December 23<sup>rd</sup> 2016 (German Laws I S. 3234)”

**Note:** Amended by article 23G of 23.12.2016 I 3234 (no. 66), textually proven but not yet completed processed from a documentation point of view.

#### **Preamble**

The German Federal Ministry of Health and Social Security orders the following on the basis of § 32 no. 1 of the Ninth Volume of the Social Code – Rehabilitation of and Participation by Handicapped People – (article 1 of the Law of June 19<sup>th</sup> 2001, German Law I S. 1046, 1047), most recently amended by article 1 no. 3 of the Law of April 3<sup>rd</sup> 2003 (German Law I S. 462):

#### **§ 1 Scope of application**



The demarcation between services performed by inter-disciplinary early intervention centres and social pediatric centres in accordance with § 46 paragraphs 1 and 2 of the Ninth Volume of the Social Code relating to the early detection and early intervention for handicapped children and children threatened by disability not yet attending school, the assumption and the division of costs between the rehabilitation authorities involved as well as the agreement of fees is governed by the following regulations:

## **§ 2 Early detection and early intervention**

Services in accordance with § 1 include

1. services for medical rehabilitation (§ 5)
2. remedial educational services (§ 6) and
3. additional services (§ 6a).

The required services will be carried out by professionally suitable inter-disciplinary early intervention centres, by institutions authorised in accordance with state law with a comparable inter-disciplinary intervention, treatment, and advisory range of services and by social pediatric centres taking account of the children's social environment.

## **§ 3 Inter-disciplinary early intervention centres**

Inter-disciplinary early intervention centres or institutions authorised in accordance with state law with a comparable inter-disciplinary intervention, treatment and advisory range of services within the meaning of this Directive are services and institutions focused on the family and the place of residence, which serve the early detection, treatment and support of children in order, in inter-disciplinary cooperation with qualified medical-therapeutical and pedagogic experts, to detect a threatened or already existing disability at the earliest possible time and to compensate for and mitigate the disability through targeted intervention and treatment measures. The services of inter-disciplinary early intervention centres and institutions authorised in accordance with state law with a comparable inter-disciplinary intervention, treatment and advisory range of services are generally provided in an ambulatory, including mobile, form.

## **§ 4 Social-pediatric centres**

In accordance with § 119 paragraph 1 of the Fifth Volume of the Social Code, social-pediatric centres within the meaning of this Directive are the institutions entitled to provide out-patient social-paediatric treatment of children. The early detection, diagnosis and treatment of by social-pediatric centres is focused on children who, due to nature, severity or duration of their disability or threatened disability, cannot be treated by suitable doctors or suitable inter-disciplinary early intervention centres or institutions authorised in accordance with state law with a comparable inter-disciplinary intervention, treatment and advisory range of services (§ 3). The services of social-pediatric centres are generally provided in the out-patient form or, in justified individual cases, in mobile form or in cooperation with early intervention centres.

## **§ 5 Medical rehabilitation services**

- (1) The medical services to be provided as part of services for medical rehabilitation in accordance with § 46 of the Ninth Volume of the Social Code for early detection and early intervention include in particular:



1. Medical treatment including required medical work for the purposes of early detection and diagnosis
2. Non-medical social-pediatric services, psychological, remedial educational and psycho-social services.
3. Medical-therapeutical services, particularly physical therapy, physiotherapy, voice, speech and language therapy as well as ergotherapy, as long as they are required on the basis of the intervention and treatment plan in accordance with § 7.

The provision of medical-therapeutical services as part of the complex support service early intervention is not based as a matter of principle on the provisions of the remedial measures guidelines issued by the Joint Federal Committee. Medical-therapeutical services are provided as part of the complex support service early intervention in accordance with the provisions and on the basis of the intervention and treatment plan.

- (2) Services in accordance with paragraph 1 also include advice to the parents or legal guardians, particularly
1. Initial discussion
  2. Anamnestic discussions with parents and other contact persons
  3. The communication of the diagnosis
  4. Discussion and advice on the intervention and treatment plan
  5. Exchange of opinions on the child's development and intervention process including behavioral and relationship issues
  6. Guidance and assistance on designing routine daily life
  7. Guidance on involvement in intervention and treatment
  8. Assistance in supporting contact persons in dealing with the illness or disability
  9. Communication of additional offers of help and advice.
- (3) Additional agreements at state-level are not affected

## **§ 6 Remedial educational services**

Remedial educational services following § 79 of the Ninth Volume of the Social Code includes all measures which promote the development of the child and its personality with educational methods, including the relevant required social and special educational, psychological and psychosocial assistance as well as advice to the parents or legal guardians; § 5 paragraphs 2 and 3 will apply as appropriate.

### **§ 6a Additional services**

Additional services as part of the complex support service early intervention are in particular:

1. Advice, support and encouragement of parents and legal guardians as a medical-therapeutical service following § 5 paragraph 2.
2. Non-binding low-level consultation for parents who suspect a risk to their child's development. The offer of discussions should take place before an initial assessment is carried out.
3. Services to ensure the interdisciplinarity; these are in particular:



- a) Regular inter-disciplinary team and case discussions, also through cooperation with employees involved,
  - b) Documentation of data and findings,
  - c) Coordination and exchange of opinions with other institutions attending the child,
  - d) Advanced training and supervision
4. Mobile forms of providing remedial educational and medical-therapeutical services outside the inter-disciplinary early intervention centres or institutions authorised in accordance by state law with a comparable inter-disciplinary intervention, treatment and advisory range of services and social pediatric centres.

The mobile form of inter-disciplinary early intervention may be provided for both technical and organisational reasons, for example intolerable travel distances in rural area. A medical indication is not therefore a required condition for the mobile provision of the complex support service early intervention.

### **§ 7 Intervention and treatment plan**

- (1) The inter-disciplinary early intervention centres, the institutions authorised by state law with a comparable inter-disciplinary intervention, treatment and advisory range of services and the social pediatric centres prepare in writing or electronically the services probably required following the individual need for intervention and treatment by §§ 5 and 6 in cooperation with the parents or legal guardians in an inter-disciplinary developed intervention and treatment plan and submit this to the rehabilitation authorities involved following § 14 of the Ninth Volume of the Social Code for their decision. The intervention and treatment plan is adjusted dependent on the course of intervention and treatment, at the latest after twelve months have elapsed. In doing this, the rehabilitation authorities ensure continually that the procedure is by the relevant requirements. The intervention and treatment plan will be signed by the doctor and educational specialist responsible for carrying out the diagnostic services following § 5 paragraph 1 no. 1. The parents or legal guardians receive a copy of the intervention and treatment plan.
- (2) The required service components must be named in the intervention and treatment plan and justification is required as to why this can only be provided inter-disciplinarily in the particular form of complex support service.
- (3) The intervention and treatment plan may also recommend intervention and treatment in a different institution, by a pediatrician or the provision of curative remedies.

### **§ 8 Provision of the complex support service**

- (1) The services required for intervention and treatment following §§ 5 and 6 will be provided by the rehabilitation authorities concerned based on the intervention and treatment plan with overall responsibility as a holistic complex support service. An application for the required services may be submitted to all the rehabilitation authorities involved. The rehabilitation authority to whom the application is submitted informs the rehabilitation authorities involved in the complex support service immediately. The rehabilitation authorities involved consult



amongst themselves and decide on the service within two weeks of the intervention and treatment plan being submitted.

- (2) Unless the rehabilitation authorities involved decide anything to the contrary, the rehabilitation authority responsible for the services following § 6 decides on complex support services by inter-disciplinary early intervention centres as well as on the institutions authorised by state law with a comparable inter-disciplinary intervention, treatment and advisory range of services, and on the rehabilitation authority responsible for the services following § 5 decides on complex support services by social-paediatric centres.
- (3) Should the rehabilitation authority provide services as part of the complex support service for which some other rehabilitation authority is responsible, the responsible rehabilitation authority is required to reimburse the costs. Agreements on flat-rate reimbursement are permitted.
- (4) Inter-disciplinary early intervention centres, institutions authorised by state law with a comparable inter-disciplinary intervention, treatment and advisory range of services and social paediatric centres work together. Moreover, they work together with doctors, organisations providing curative remedies and other centres involved in early detection and early intervention, such as the public health service. Should other agencies be involved in the complex support service by state law, they should also be involved in the working groups of involving bodies concerned with early detection and early intervention.

### **§ 9 Allocation of the costs of the complex support service**

The payment or sharing of costs between the rehabilitation authorities involved in services to be provided following §§ 5, 6 and 6a will be dealt with in the manner laid down in § 46 paragraph 5 of the Ninth Volume of the Social Code.

### **§ 10 Effective date**

This Directive will come into effect on the first day of the calendar month following its announcement.

### **Concluding comment**

The upper house of parliament (“Bundesrat”) has given its consent.

The basic principles and framework terms and conditions of early detection and early intervention are stipulated in § 46 SGB IX (until 31.12.2017 § 30 SGB IX) and in the Early Intervention Directive – FrühV. These were also amended with the Federal Participation Law (“BTHG”). New are particularly the contents of the complex support service early intervention in § 6a FrühV, to which, amongst other things, the low-level offer of an advisory discussion as well as, the assurance of inter-disciplinarity also belong.

## **B. Educational program – BLINDENINSTITUT MUNICH, GERMANY**





Each early intervention offer consists generally of three sections:

### **1. Non-binding consultation (Offenes Beratungsangebot)**

The early intervention team informs you about the services it provides and determines if further assessment is necessary.

### **2. Initial assessment (Eingangsdiagnostik)**

Various specialist disciplines usually cooperate in their fields.

A specific support need for your child is determined in collaboration with the attending physician and you.

This can result in the following recommendations:

- Reintroduction at a later time.
- Acceptance of the child into the early intervention program.
- Recommendation for another early intervention program or resident medical/therapeutic practice.
- No intervention necessary.

### **3. Support and treatment (Förderung und Behandlung)**

The necessary intervention and supportive measures are coordinated individually to the needs of the child and the family. The implementation of the goals worked out together includes both the support of the child as well as the continual reflection of specific services and development steps from all specialists from the interdisciplinary early intervention team, who are involved in the support of the child to varying degrees.

### **Support and treatment plan (Förder- und Behandlungsplan) (FBP)**

The FBP is a foundation for the guarantee of curative education and psychological measures by the social welfare administration as well as medical/therapeutic services through the health insurance organizations. The necessary measures and their extent are determined in collaboration with the attending doctor and the relevant employees from the early intervention center in consultation with the parent.

The FBP is generated during the initial assessment stage or directly thereafter. Usually, the FBP is re-worked after a maximum of 12 months. Should changes occur in regards to the prescribed Services or the health insurance organization be changed during the appropriation period, a new FBP must be issued immediately. This assures the financial compensation of all Services.

The FBP includes the form (individual or group support) as well as the frequency of the treatment units.

### **Complex support service (Komplexeleistung)**

In addition to curative education and psychological early support services, medical/therapeutic services will also be prescribed for the children if necessary and rendered by the interdisciplinary early intervention team so that families receive all services from one entity.



Due to supra-regional catchment areas, special rules for sensory-impaired children could be agreed upon for early intervention centers (Framework contract/Attachment 9).

In addition to the curative education services, there are varying opportunities for your child to receive the medical/therapeutic portion (physiotherapy; ergotherapy; logopedics) of the complex support service:

- through therapists from the Blindeninstitut;
- through resident therapists nearby;
- through therapists in the local early intervention center;
- through therapists in the social pediatric centers;
- as part of the daycare center support of your child.

“Isolated“ curative education service (isolierte“ heilpädagogische Leistung) without medical/therapeutic treatment)

In individual cases, it's possible to offer you and your child solely curative education service if your child does not need any medical/therapeutic treatment.

### **Number of treatment units (Anzahl der Behandlungseinheiten)**

Each year, there are commonly 72 treatment units available. The treatment units comprise of 60 minutes, 45 minutes of which are made up of the necessary child and parent related tasks. The other 15 minutes include preparation and postprocessing, external discussions as well as documentation of procedural and closing diagnostics. That also means that the necessary procedural diagnostics and their evaluation are included as part of the 72 treatment units. If, for example, video analysis and/or the creation of individual support material are/is necessary, this will be recorded as part of the remaining treatment units available. The same applies to telephone consultations.

### **Medical/therapeutic treatment units (Medizinisch-therapeutische Behandlungseinheiten)** (logopedics, ergotherapy, physiotherapy)

This can take place in the Blindeninstitut practice/Local early Intervention center/social pediatric center/daycare center (ambulatory) or if necessary in your home (mobile) and includes treatment, parental meetings, preparation and postprocessing. The drive time is also included for mobile cases with a flat time of 60 minutes used.

**Visiting a special needs pre-school facility (Schulvorbereitende Einrichtung, SVE) Or a daycare center.**

The framework contract also allows the child to be served by our early intervention specialists upon enrollment in a daycare center or special needs pre-school facility if your child does not visit any special facility for children with vision impairments or blindness.

**Complementary measures such as individual integration (Einzelintegration, EI)**  
in daycare centers.

Framework agreement - social welfare institutions and health insurance companies finance the complex of medical and therapeutic services  
Federal participation law - implements UN Disability Rights Convention of 2009 in Germany  
- Inclusion, Participation  
Early intervention regulation - legal requirements



Education curative teacher (approx. 6 years)  
+ Induction concept  
Further training 10 modules (approx. 60 days)  
teachers, educators, orthoptists,  
physiotherapists, speech therapists)

**Early Intervention**  
interdisciplinary team (curative



Initial diagnostic  
- Anamnesis  
- orthoptic finding  
- Perm and other developmental neurological findings  
pediatric centres

Parent information  
- Consultation  
- Contacts to Kindergarten,  
Schools, doctors, socio-



Annual development reports

#### IV.4. GREECE

##### A. Policies and Legislation

1. The Ministerial Decision 16065/17-04-2002 (Government Gazette of the Hellenic Republic 497/τ.Β'/22-4-2002) mentions that children aged 6 months to 5 years can attend nursery school. However, the present ministerial decision points out that the existence of programs is not mandatory.
2. Law 3699/2008 (Government Gazette of the Hellenic Republic 199 -A- 2-10-2008) entitled "Special Education of individuals with disabilities and/or special educational needs". This law refers to the notion of early intervention programs in public senior kindergarten for the first time in Greece. Kindergarten (nipiagogeio) in Greece is the first formal pre-primary



educational stage which provides services for children 4–6 years of age and, since 2006, is compulsory for children aged 5–6 years old.. According to this law, students from 4 to 7 years old may attend these programs. Also, the present law establishes Centers for Differential Diagnosis, Diagnosis and Support (KE.D.D.Y) and defines its obligations in order to develop proposals for the implementation of early intervention programs. The law in question underscores that inclusion is doable through: a. medical diagnoses at early years and, b. systematic early intervention programs.

3. The Ministerial Decision 211076/ΓΔ4/13-12-2018 (Government Gazette of the Hellenic Republic 5614/B/13-12-2018) replaced the previous “Centers for Differential Diagnosis, Diagnosis and Support into “Educational and Counseling Support Centers” (KESY) giving emphasis on early intervention programs. The 5614 Law clarifies that special education preschool teachers, psychologists and social workers are responsible for the implementation of early intervention programs. The special education preschool teachers – including sign language teachers-, in collaboration with the staff of the Educational and Counseling Support Centers (KESY), are in charge to design and implement early intervention programs aiming to support their students as well as their families. The psychologist, in collaboration with the staff of the Educational and Counseling Support Centers (KESY), the special education preschool teachers and members of the families, proposes implementation programs taking into account issues of continuous evaluation and reflection on students’ progress and effectiveness. On the other hand, the social worker, in collaboration with interdisciplinary teams, contributes to the development of tailored personalized or group psychoeducational and didactic support programs or contributes to the design and implementation of early intervention programs. It is worth mentioning here that despite the fact that the role of speech therapists, occupational therapists and physiotherapists is significant in early intervention programs, 5614 Law do not mention them as indispensable members of the KESY interdisciplinary teams regarding programs. Finally, 5614 Law gives an emphasis on sensory disabilities (i. e. blindness, low vision, deafness and hard of hearing) stressing the importance of sign language and braille.
4. The Ministerial Decision 47305/12.12.2018 (Government Gazette of the Hellenic Republic B’5571/12.12.2018) refers that the state may subsidize the attendance of children in early intervention programs that fall into four categories based on ICD 10 (i. e. R46.3: Overactivity; R46.4: Slowness and poor responsiveness R62.8: Other lack of expected normal physiological development and, R62.9 Lack of expected normal physiological development, unspecified) (ICD-10 Version 2016. <https://icd.who.int/browse10/2016/en#/R50-R69>). Finally, according to the aforementioned Ministerial Decision, if the State Law refers a child to specific experts such as: psychiatrists, pediatricians (developmental pediatrics), and neurologists, then subsidy is offered to the family for a limited number of early interventions sessions (four in total).

It may be highlighted that although early intervention services are mainly between 0 months to 3 or 4 years old, the greek legislation make no reference to ECI services for children with



disabilities only from the age of 3. According to Human Rights and Persons with Disabilities/Alternative report Greece 2019, by the National Confederation of Disabled People (NCDP) a basic weakness of the Greek educational system is the very limited access to early intervention and pre-school services for children with disabilities, services that in fact are provided by a few non-governmental agencies. The development of public early intervention structures as foreseen by the Law 3699/2008 has not been released yet (Government Gazette 2008b). According to CRPD report the Greek state lacks of a harmonized human rights based approach to disability in the legislation and the existing legislative framework for disability assessment mechanism and that data collection on persons with disabilities in the State still associates with the medical model of disability (Health Survey 2019) thus it is fragmented, unsystematic and incomplete. CRPD explicitly highlighted the lack of a comprehensive legislative framework guaranteeing equal treatment, protection from discrimination and individualized supports. Few public hospitals that offer early intervention support follow the medical model, meaning that they offer rehabilitation services such as physiotherapy, occupational therapy or speech therapy centered based in hospital environment. Parents have to search from themselves what kind of services and support they can offer their child. That has as a result that parents may find these services at a late stage, after the age of two or three years old As mentioned, early intervention services can be found in urban areas and mainly in the two biggest cities of Greece, Athens and Thessaloniki. Unfortunately rural areas and especially in Greek islands have no availability of services not only concerning early intervention but even rehabilitation services from private sector

### Main challenges

In Greece at the present time, the following challenges are faced as depicted from official surveys and particularly for family centered, home visiting ECI service for more than 15 years: There is an absence of official mapping at the State level of the services provided from private and public institutions (per age and type of service) so that the so that any gap is highlighted, the institutional gap for services targeting families and children with disabilities under the age of 2.5 is particularly noticeable. There is also a lack of information to community social care staff on the services available and consequently limited guidance to families, especially in reference to home visiting services

Furthermore, structural shortcomings of the welfare system relate to:

- No funding / uncertainty for the sustainability of the services which are mostly funded by private institutions
- Lack of objective/common system for quality assurance, control, impact measurement and evaluation of the services provided. The lack of such a system exposes family and the vulnerable child to great risk.
- The situation is particularly burdensome in the province, where the social stigma and the access to any service is either limited or absent.



The daycare centers or nursery schools provide mainly custodial care and some educational services 5 days a week (Doliopoulou & Kontoyianni, 2003). The daycare centers and nursery schools are under the auspices of Ministry of Health and Social Solidarity in conjunction with corresponding local authorities.

In total, early intervention programs in Greece, are designed and implemented by several organizations such as: a. public sectors, b. private institutions, c. non-profit organizations, d. associations of parents of children with disabilities, and e. non-governmental organizations (Tavoulari, Katsoulis, & Argyropoulos, 2014). Each of the above organizations provide early intervention programs for different age range (i. e. 0-4 or 2-6 or 0-6 years old) mainly because there is a type of flexibility regarding this matter in relevant legislation. Furthermore, special services for infants are offered by the neonatal and developmental departments of pediatric clinics. These sections provide early diagnoses and deliver early intervention programs but this takes place only in urban areas.

The procedure of screening and assessment, in Greece, is performed according to the medical model and only by medicine doctors such as geneticists, developmentalists and neurologists. After the diagnosis takes place, children are usually referred to private professionals such as speech therapists, psychologists, psychiatrists etc. for therapeutic intervention (Tzouriadou, Vouyoukas, Anagnostopoulou, & Michalopoulou, 2015).

Children who are less than 4 years old usually do not participate in assessment procedures. The assessment is mainly related to the performance of pupils within the formal education system, which in Greece concerns children from the age of 4 years and above. As a result, the initial children's educational evaluation was supposed to be conducted by kindergarten teachers or by Educational and Counseling Support Centers (KESY) with parental consent.

In Greece the home based intervention program which offers early intervention services to children with vision impairment and multiple disabilities is by two non-profit organizations: a. "Association of Parents and Friends of People with Visual Impairments and Additional Disabilities, Amymoni" and, b. "Parents and Friends of visually impaired children with additional disabilities, Sizoi". In addition, there is a Department of Infant - Nursery Education and Support operating in the frame of Center for Education and Rehabilitation for the Blind and "ELEPAP-Rehabilitation for The Disabled".

## **B. EU programmes and other research**

**European project "Promoting Effective Communication for Individuals with a Vision Impairment and Multiple Disabilities" (PrECIVIM).** The project is implemented by the University of Thessaly and financed by the European Social Fund (Erasmus + Programme, KA2), (Project Agreement Number 2017-1-EL01-KA201-036289).



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### C. Training of professionals Undergraduate Programs

As mentioned above, early intervention programs in Greece, are designed and implemented by organizations such as: a. public sectors, b. private institutions, c. non-profit organizations, d. associations of parents of children with disabilities, and e. non-governmental organizations (Tavoulari, Katsoulis, & Argyropoulos, 2014). These intervention programs refer to day care centers, nursery schools, and kindergartens (Doliopoulou, & Kondoyianni, 2003; OECD, 2018; Petrogiannis, 2010) and a big variety of professionals is involved composing many interdisciplinary teams. More specifically:

Day care centers and nurseries have three main categories of professionals: a. kindergarten teacher (nipiagogos), b. nursery and childcare teacher (vrefonipiagogos/vrefonipiokomos) and, c. Nursery and Childcare Teaching Assistant (voithos vrefonipiagogou) (Doliopoulou, 2017). Nursery and



childcare teachers are graduates of one of the three relevant departments of Higher Technological Institutes around the country (see below), whereas nursery nurses' assistants normally hold a post-secondary education college diploma following a 2-year training course.

1. Department of Early Childhood Education, Technological Education Institute, Athens. The year 2019 the department was upgraded and renamed to Department of Education and Care in Early Childhood, University of West Attica. \*
2. Department of Early Childhood Education, Faculty of Health & Medical Care, of Alexander Technological Educational Institute of Thessaloniki.
3. Department of education and Care in early childhood, University of Ioannina

**\* Department of Education and Care in Early Childhood, University of West Attica.**

**The syllabus consists of courses relevant to early intervention, as follows:**

**1. Early interactions**

During this course, students study the communicative skills for children from 0 up to 2 years old as well as the development of relations between adult intimacy. In addition, students have the opportunity to trace the factors that may have an impact on parents' expectations regarding their child. Finally, many issues are discussed through this module such as cultural factors, the nature of developmental disabilities and ways of shaping early interactions.

**2. Infant Education I & II**

“Infant education” provides students the opportunity to study the needs of children aged 1-3 years old and the factors that may influence and shape the content of Infant Education.

**3. Systematic observation of infants and toddlers.**

During this course, students a. become familiar with different types and methods of observation and, b. realize that observation skills are considered to be very important because via them professionals identify any changes to an individual's health conditions or patterns of behaviour. As a result, they are able to organize effective pedagogical frameworks that respond to the needs of a group or to the need of an individual.

**4. Daily care for infants and toddlers**

Through the course “daily care for infants and toddlers”, students realize the significance of daily care and analyze the notion of “quality” in the settings of education and care.

**5. Language Development and Communication**

Students study the principles of communication and language development, as well as relevant milestones in this field. In addition, students are invited to study and investigate the influence of factors - such as disability (sensory and developmental) - on communication and language development.



## **6. Collaborating with families**

The purpose of the course is on one hand, to understand the importance of the child's family relationship with the professionals, and on the other, to enhance student's understanding regarding families' structure and function.

## **7. Early intervention and inclusion**

During this course, students discuss early intervention programs and analyze their components. In turn, the students discuss actions and activities that take place in order to support children and their families in terms of equity and inclusion.

## **8. Pedagogical Environment for Infants and Toddlers**

This course aims to provide basic knowledge on the significance of a well-organized educational environment for infants and toddlers.

## **9. Transition Management in Preschool**

This course aims to provide knowledge and experience on management transitions in the life of a preschooler (i.e. from home to nursery or from home to kindergarten).

For more information: <https://ecec.uniwa.gr/>

The Nursery and Childcare Teaching Assistants work as qualified auxiliary staff. They have to do a course in a public or in a private Vocational Training Institution or Vocational High School, and after that they are authorized to work with children aged 2 months to 6 years (Doliopoulou, 2017). Early intervention programs are included and applied in the programs of the Special Kindergartens within which special kindergarten teachers work, construct, implement and evaluate them, based on their studies and experience (Kydoniatou, et al., 2009). The staff is mainly fully qualified preschool teachers who have been graduated from the 12 university departments of preschool education in the country.

1. Department of Special Education, University of Thessaly\*
2. Department of Early Childhood Education, National and Kapodistrian University
3. Department of Early Childhood Education, University of Thessaly
4. Department of Educational Sciences and Early Childhood Education, University of Patras
5. Department of Preschool education, University of Crete
6. Department of Early Childhood Education, University of Western Macedonia Faculty of Education\*\*
7. Department of Education Sciences in Early Childhood, Democritus University of Thrace
8. Department of Pre-school Education and Educational Design, University of the Aegean
9. Department of Primary Education, University of the Aegean
10. Department of Early Childhood Education, University of Ioannina
11. Department of Educational & Social Policy, University of Macedonia



## 12. School of Early Childhood Education, Aristotle University of Thessaloniki\*\*\*

Even though the above university departments upgrade their courses at a constant basis, the courses which are relevant to early intervention programs are still small in number.

### **\*Department of Special Education, University of Thessaly**

The syllabus of Department of Special Education includes 2 modules regarding early intervention. More specifically:

#### **1. Early detection and early intervention.**

Within this module students have the opportunity to study: the stages of children's cognitive and motor development, the biological and environmental factors of "high risk" regarding the development of neurodevelopmental disorders, the design and implementation of intervention programs, types of interdisciplinary teams and collaborative network, services which deliver early intervention programs as well as types of family support.

#### **2. Language development of deaf and hard of hearing children: The role of early intervention**

The aim of the current module is to enable students develop knowledge and skills in relation to the language development of children who are deaf or hard of hearing (DHH) and the role of early intervention. The following topics are addressed within this module: a) the language heterogeneity of DHH children, b) the meaning and features of early family intervention, c) the main principles of communication with deaf and hard of hearing children in Greek or Greek Sign Language, d) the use of functional hearing among DHH children, e) the role of emergent literacy in the language development of DHH children in Greek or Greek Sign Language.

### **\*\*Department of Early Childhood Education, University of Western Macedonia Faculty of Education**

The syllabus of Department of Early Childhood Education includes 1 module regarding early intervention. More specifically:

#### **Early detection and prevention of learning difficulties in kindergarten**

Students study different types of assessment procedures for children with learning difficulties and language impairments.

For more information: <https://uowm.gr/>

### **\*\*\*School of Early Childhood Education, Aristotle University of Thessaloniki**

The syllabus of School of Early Childhood Education includes 1 module regarding early intervention. More specifically:

#### **Prevention and psychological support to infants and toddlers with disabilities.**



Students study models of early intervention in conjunction with individual differences and cultural elements of the familial environment. Within this module student learn the basics on developmental psychology as well as basics on early childhood mental health.

More information: <https://www.nured.auth.gr/dp7nured/>

Taking into consideration the aforementioned, it can be argued, that early intervention in Greece is not systematically developed and therefore early intervention programs cannot cover adequately the real contemporary needs (Drossinou & Kaderoglou, 2005). Some potential reasons of this inadequacy are: lack of specialized centers and professionals, lack of professionals' training, and lack of productive network amongst different services and organizations (Tavoulari, Katsoulis, & Argyropoulos, 2014).

### **D. 1. Early Intervention Program (E.I.P.) – AMIMONI**

“Early Child Intervention (ECI) for visually impaired children” has been offering services in Attica since 2004, to more than 150 families, implementing an ECI program. It is a family-centered, educational, home visiting program that supports visually impaired children from birth up to the age of six **with or without** additional disabilities and their families. The program takes place on every week. Moreover, there are sometimes when the program takes place every fortnight, according to the needs of the child and family.

Since 2016 we have developed a distant service for supporting families in remote regions of Greece. This consists of an assessment of the child's functional vision and development that takes place either in our organization in Athens or their home in the county and it's followed by support via telecommunication to the family or the child's educators/ therapists.

Additionally, early intervention services are being offered through flexible services. Specifically, the Early Intervention team may offer specific or limited (in terms of frequency, content, or duration) services according to the requests and needs of families. One of those services might be an evaluation of the child's functional vision, tactile perception and the child's developmental status/stages. This assessment might take place in the day carecenter and/or the home of the family and it is followed by written evaluation and educational activities suggestions. Another service might be a specific number of home visits of the Early Intervention team to families either in the region of Attica or in the suburbs out of Attica that will take place in a specific time frame. Flexible services might also be given in cases that the child has some serious health problems and cannot follow the weekly program.

The aim of the Early Childhood Intervention Program is to promote child developmental potential and skills, to encourage his/her self-reliance and to closely support the family and the caregivers. Weekly – home visits to families take place, where the primary goal of the intervention is to support the development and emotional wellbeing of the child, as to support the caregiver-child interaction, to empower the family on its role and to promote its social inclusion. The



promotion of functional residual vision skills in the child's natural environment, along with body awareness, tactual and auditory perception and support of orientation and mobility, gross and fine movement, as well as self-care daily activities are some of possible target domains of the intervention.

The session consists of the activities the educator performs with the child (up to one hour) and conversation (counseling and support) with the parent. During the intervention with the child, parent's presence and involvement are required. The parent or care-taker is meant to observe the activities, how the child responds to them, and understands the child's communication cues and capabilities. We then invite the parent to get involved in the activity and to try to repeat the way of "playing" in daily life. During the conversation with the parent, various topics may arise, such as child's development, understanding of visual difficulty, home adjustments, health issues, parent's difficulties or emotions, parent's priorities, daily routines, needs and aspirations for their family life, etc.

Parallel to the weekly support from the early interventionist, the families receive parent counseling support from the psychologist, child-psychiatrist, or social worker of the program. The frequency of those sessions is planned according to the family's needs. What we try to implement is that every family that enters the program, has five sessions during their first year in the program. Our experience has shown that this is the most challenging period and most parents benefit from that support. After this period the parent counseling sessions occur more sporadically and according to their needs.

In addition, our program's social worker is available to facilitate families with information on the laws concerning the rights of children with disabilities, financial support available and respective procedures and facilitating networking and connection to other welfare services or institutions offering services to persons with disabilities. The social worker also may inform parents of other services that are available for their child, may communicate or escort families to health services if necessary and will communicate with other educational institutions (public schools, special schools, public educational evaluation services) that the child attends to.

The families are additionally supported, if needed, by the orientation and mobility specialist, the physiotherapist and the speech therapist of Amimoni.

### [Protocol of entering the program \(Conditions and procedures for participating to the program\)](#)

A child is entitled to receive services from our program when he/she has a diagnosis of a visual problem. The families are referred to our program usually by neurologists, pediatricians, optometrists, special schools and other parents. The protocol for entering the program has the following steps:

1. Step 1 Intake: It is performed via communication by telephone from the team's social worker. In this initial phase of the E.I.P., we gather the necessary information about the



child and the family concerning basic information about the child's medical history, developmental milestones (sitting, walking, eating, speaking, etc.), the current situation (playing, sleeping, behavior, etc.), therapy or school program and of course the expectation of parents from our program.

2. **Step 2 Introductory Session:** Takes place on the family's home. In this session, the social worker and an early interventionist visit the family with the purpose to inform about the Amimoni, the function of the E.I.P. and to take a full medical history of the child. The team also gathers information about the child's everyday life and routines. In this session, parents have the necessary time to tell their story and express their feelings. Parents are also presented with the Framework Agreement with the Early Intervention Program of Amimoni, which describes the structure and the function of the program, as well as the rights and obligations of both parties.. Our team has the opportunity to meet with the child and observe him/her in a natural situation. A detailed medical history form is completed from the interview with the parents and the medical record. This information is essential for the preparation of the assessment (step four). Afterward, our social worker writes the social report for the family's file. From this procedure, the team can have an initial idea about the family's needs to develop a family plan.
3. **Step 3 visit to Amimoni:** The family pays a visit to Amimoni's premises to meet the Association, and members of the Team. A discussion will take place with the Program Manager and the Scientific Director of Amimoni/Child Psychiatrist and meet the Chief of the Board. In this visit, parents sign the Framework Agreement with the program and if they wish to, they enroll as members of Amimoni
4. **Step 4 Assessment:** The assessment takes place in the home environment and might be conducted in one or two sessions. Two early interventionists always conduct the first assessment and the parents are always present.

Upon completion of those steps, the family enters the program. On the early sessions we introduce the parents to the concept of assessing the functional vision of their child and which are his/hers developmental needs. Following these early sessions, that allow a more thorough assessment of the child, we set our initial goals (educational plan) which are comprised in the Educational Plan in co – operation with the parents.

### **The Early Intervention Multidisciplinary Team (EIMT) – role and functions**

After the assessment, the early interventionists discuss their findings with the multidisciplinary team. The Early Intervention Multidisciplinary Team (EIMT) consists of a the Program Development Manager, two psychologists, one social worker and two Occupational therapists, a special educator and the Scientific director-child psychiatrist. Amimoni's Head of Coordination may also attend these meetings. The EIMT decides on the early interventionist and the consultant who will undertake the family, based on various criteria aiming at better cater with the family needs. This decision may also have taken place after the introductory session if the EIMT has all the necessary information.



The EIMT may ask consultation on specific issues from the orientation and mobility specialist, the physiotherapist and the speech therapist of the day care center of Amimoni, if needed.

Lastly, the EIMT and specifically the early interventionist have constant communication with the other therapists who work with the child or with the child's school. Often joint sessions are conducted with the other therapists. If the child attends school, our team visits the school in order to have the closest co-operation and to give suggestions about adjustments that would be helpful for the child. The team also has communication with the doctors and the optometrist, with whom the family cooperates.

Our team meets every week for two hours. In each meeting 1) the team may present a case (educational plan and family plan), 2) discusses intakes and assessments, 3) express difficulties and emotions, 4) exchange expertise on specific matters, 5) make decisions about interventions concerning a family in difficulty or in crisis and 6) solve administrative issues. Every fortnight, our team has external supervision from a child psychotherapist-special educator.

### Assessment tools used by the E.I.P. of Amimoni.

1. **CVI Range** - Roman Lantzy, C. A. (2018) Cortical Visual Impairment: An Approach to Assessment and Intervention. New York: American Foundation for the Blind.

The CVI Range is an "instrument used to perform a functional vision assessment...and is constructed with a specific purpose in mind: to determine the degree of impact or extent of effect, of CVI" (Roman-Lantzy, 2018). It's implemented when there are signs (medical history, observation, interview with parents) that the child may have cerebral visual impairment.

2. **The Oregon Project for Visually Impaired & Blind Preschool Children: Skills Inventory 0-6 years** - Anderson, S., Boigon, S., Davis, K., & deWaard, C. (Eds.). (2007). The Oregon project for preschool children who are blind or visually impaired. Southern Oregon Education Service District.

The Oregon Project for Preschool Children who are Blind or Visually Impaired (The OR Project) is a skills inventory (checklist) and curriculum designed for use with children birth to six who are blind or visually impaired. It can be used by parents, teachers, vision specialists, or counselors in the home or in the classroom setting. (<https://www.pathstoliteracy.org/resources/oregon-project-preschool-children-who-are-blind-or-visually-impaired>). Usually it's implemented in children that are above the age of four and when we want to see the overall abilities and difficulties of the child.

3. **Lea Tests**

The LEA Vision Test System is a series of [pediatric vision tests](#) designed specifically for children who do not know how to read the letters of the [alphabet](#) that are typically used in [eye charts](#). There are numerous variants of the LEA test which can be used to assess the visual capabilities of near vision and distance vision, as well as several other aspects of occupational health, such as [contrast sensitivity](#), [visual field](#), [color vision](#), visual adaptation, [motion perception](#), and ocular function and [accommodation \(eye\)](#) ([https://en.wikipedia.org/wiki/Lea\\_Vision\\_Test\\_System](https://en.wikipedia.org/wiki/Lea_Vision_Test_System))





Lea test). We mostly use Lea Gratings, Lea symbols, Heiding Heidi, Lea symbols Low contrast test, Heidi fixation targets, Heidi expressions test, cone adaptation test, 3D-puzzle.

These tests are used according to our needs for a better understanding of the child's vision and not with the purpose of determining visual acuity.

#### **4. Observation of Functional vision.**

It is a qualitative observation tool developed by I. Vonnikaki, psychologist-early interventionist of the E.I.P. of Amimoni. Its main purpose is to record data regarding the functional vision of the child based on practical factors acquired during the assessment and intervention. It's the main form we use during the early sessions of assessment.

#### **5. Observation scales of the development of children with vision impairment.** (Translated from the Observation Tool of the E.I.P. in Blindeninstitut stiftung Resource Center).

It is a tool based on observation of the child and structured activities with specific material. It contains all the main areas of development (gross motor skills, fine motor skills, cognition, language and independency skills concerning feeding, toilet, and dressing). It's addressed to children till 4 years of age and it's implemented in all the children participating in the program.

#### **6. Assessment tool of functional vision for up to 1-year old infants.**

(Based on the corresponding assessment tool of the Blindeninstitut in Wuertzburg).

It is also a tool based on observation of the child and structured activities with specific material. It focuses on basic functional vision skills. We use it for children up to 1 year old but also with children who have severe visual, motor and intellectual impairment. We use this tool for most of our children.

#### **7. Assessment tool of functional vision for children with vision impairment.** (Based on the corresponding assessment tool of the Blindeninstitut in Wuertzburg).

This tool is used for children more than 1 year of age who usually have good functional vision and do not have other severe disabilities. It is also a tool based on observation of the child and structured activities with specific material. Its purpose is to explore more complex visual skills.

#### **8. Tactual Profile (Royal Visio).**

A Tactual Profile is an observation instrument for charting the tactual functioning in children from 0 to 16 years of age who have a severe visual impairment. ([www.tactualprofile.org](http://www.tactualprofile.org)).

This tool is based on observation and structured activities as well. We use this toll with children who have severe vision impairment but do not have other severe impairments. They may have cerebral palsy, autism, mild intellectual disability or other.

#### **9. Bielefeld Observation Scales (BOS- BLIND).** Michael Brambring., (2006). Early Intervention with infants and preschoolers who are blind, volume 2, Edition bentheim.

This empirical study compared the average ages at which four congenitally blind children acquired 29 gross motor skills with age norms for sighted children. The results indicated distinct developmental delays in the acquisition of motor skills and a high degree of variability in developmental delays within and across the six subdomains that were analyzed.

This is a tool based on observation of the child and it is rarely used, as all the tools described above cover our needs of evaluation.



### Collaboration with the family.

Concerning the family involvement in the intervention, several aspects need to be outlined since their involvement is important and fundamental for accomplishing the established goals.

First, during the intervention, the parent(s) is/are present in order to be able to observe the educational activities. Specifically, the games that are organized in terms of visual skills (visual attention, concentration, etc.), the materials, toys and tools which are used for each activity and additionally how and when the child responds to each activity.

Furthermore, the last part of the session (30-40 minutes) is devoted to discussion with the parents. This is the time to discuss with them whatever concerns/questions, thoughts they might have concerning their child and his/her visual skills. Suggestions are made on how these activities could be integrated into their everyday life and subsequently how they can play and have fun with their child. Relevant to the aforementioned, there are suggestions concerning ergonomic adjustments either in their whole house -in order to facilitate the functional vision or/and the movement of the child around the house- or in the child's personal space (room, little room-corner).

Consequently, at the end of the educational year, we conduct the concluding assessments of the child and we document everything in an Evaluation Report, which we send to the family after making final discussions with them. Specifically, we discuss with the parents all the established educational goals along with the results of our assessment. This gives an overview of what has been accomplished and in which aspects the child has improved. In that framework, the parents are able to clearly see what has been done and how their involvement has benefited their child and most importantly they can realize the means that they have acquired in order to further bond with their child and have a functional and happy everyday life. Furthermore, we discuss the future goals for the next educational year, the aspirations of the parents and how they can be integrated within the intervention. One important note is that within the year parents are entitled to ask for an assessment, after submitting a request to the educator and defining the reason(s) for it.

### Intervention with the child

The domains of intervention with children with visual impairment and additional disabilities are:

- Visual skills : **1)** visual stimulation in a dark room with light toys and specific visual educational programs (V.E.S.) presented in a tablet or pc, **2)** visual stimulation in natural light conditions with lights and specific visual educational programs (V.E.S.) presented in a tablet or pc, **3)** use of various toys of different sizes (2cm to 30cm) for basic visual skills (see in attachment no1 for the categorization of visual skills to basic and complex) in simple or complex background, **4)** visual attention to faces, understanding of facial expressions and imitation using masks, glasses, bracelets, gloves, mirror, etc., **5)** visual exploration in medium and long distance using toys, balls, balloons or cards of various sizes in simple or complex background, **6)** visual-motor coordination using hand-crafted



toys and educational toys, 7) recognition, matching and discrimination of colors, shapes, objects, toys, etc. (3D) through various hand-crafted toys and educational toys, 8) recognition, matching, discrimination of colors, shapes, symbols, numbers, letters, flashcards of objects, animals, activities (simple or complex background) (2D) etc., and 9) spatial visualization through various games

- Auditory orientation and discrimination: musical instruments, sounds of nature or city life
- Tactile strategies of exploration and discrimination: 1) fabrics, different textures, objects, toys, natural materials, texture boards, tactile dominos, temperature, weight, etc., and 2) boards, boxes, pillowcases, cupcake pans, etc. For exploration within.
- Body perception using 1) vibration, tactile toys, brushes, body lotion or oils, etc., and 2) name body parts and movement imitation.
- Vestibular and proprioceptive perception: vibration, handling, body pressure, licra swing, etc.
- Communication skills: verbal or alternative communication through flashcards, symbolic games, support in peer interaction.
- Orientation and mobility using visual, auditory, or tactile cues in home, schools, playgrounds or other spaces.
- Psychomotor games using obstacles, steps, cones, rings, etc.
- Personal autonomy skills: feeding support, dressing support, personal hygiene.
- Concept development.

### Surveys/Research on the E.I.P. of Amimoni for children with vision Impairment.

The E.I.P. has conducted so far three surveys on parent satisfaction for the services provided. The first was conducted in 2015, the second in 2016 and the third in 2018. The two first surveys were anonymous and the last one was conducted via the internet (Google forms), and participants who replied were known. Here we will present briefly what parents expressed in the last survey.

From 33 families, 15 parents answered the questionnaire the majority of whom were mothers (64, 3%). The majority of parents (86, 7%) were very satisfied with the E.I.P. as a whole. The majority of parents were very satisfied with the information they received from the program concerning functional vision, overall development of the child, ergonomic adaptations at home and activities. They were also very satisfied with the support they received in order to better understand and communicate with their child. They were fairly satisfied with information concerning tactual perception and orientation and mobility. The majority of parents (86, 7%) were very satisfied with their co-operation with the early interventionist, while 6,7% were fairly and less satisfied. Also, the majority of the parents (73, 3) were satisfied by other services they received from the early intervention specialists (psychologists, social worker and child psychiatrist). 57, 1% of parents believe the program met their initial expectations. 66, 7% of parents believe the program helped a better understanding of the educational needs of their child while 53, 3% felt the usually



participated in the early intervention session. 78, 6% of parents believed that they were quite satisfied with how easy it was to follow the program's suggestions.

Here we present some statements about their opinions and feelings in answer to the question "what you most liked about the intervention":

*"The child is learning and is happy at the same time".*

*"What i most liked is the interaction you helped me have with my child".*

*"The happiness of my child".*

*"The expertise in vision and the answers I was able to have in questions that occupied my mind for years. Also the guidance I had on how to handle my child's disability."*

*"Excellent response of the service to appointments and phone calls, the people were friendly, they had a warm approach and an immediate help in our problems."*

*"Guidance and information were given in order to ameliorate P.'s daily life and perception. Support of the family."*

#### Findings:

Here we will present the findings of the postgraduate thesis of Lioni Diamanto "Early intervention in babies and children of preschool age with blindness, low vision or other diagnosed disability of visual perception and additional disabilities: The experience of Parents" (Lioni, D. 2019, Faculty of Medicine, Aristotelion University of Thessaloniki).

The research was conducted with parents of children who attended the E.I.P. of Amimoni for more than 6 months. The goal of the survey was to present the experience of parents that attended our program. Data collection through semi – structured interviews concerned the following topics:

- Before the intervention: early experiences, daily life, difficulties, information, sentiments.
- During the intervention: experience, sentiments, changes.
- Co – operation with the experts of the program: ways of support, emotions, difficulties.
- Self-development and family relationships.
- After the intervention: level of satisfaction, difficulties, unmet needs, future goals.

Seven Interviews were conducted at the parent's homes, only one of which was carried out with a father. Four out of seven families mentioned their co-operation with the E.I.P.

Miss Lioni's research findings that are considered to be worth- mentioning and useful for our project are:

- Concerning the period before intervention

It was a difficult period for parents both practically and emotionally. There was a lack of information and guidance. What they found very useful was the network that parents created themselves, where they found information and support. The information and guidance from experts came gradually. Parents expressed their need for further support by experts in order to fulfill their child's needs.

- During their participation in the IEP

Apart from the positive feelings they had during their first contact with the E.I.P. staff, they mentioned that they found it useful that a variety of experts assessed their child's and the



family's needs (multidisciplinary approach. They also expressed their satisfaction with the support they received. They liked the non- judgmental approach and the notion that “life goes on”. Furthermore, they concluded that their participation in the program was needed and within this framework, they familiarized themselves with suitable activities to do with the child. Half of them also mentioned that after a while they chose not to be present during the intervention and felt free to use that time to do something else. Some parents mentioned that they liked the participation of the siblings during the intervention. Apart from the improvement of visual skills, they expressed their satisfaction with their child being happy.

- After the intervention

Suggestions of parents concerning the program: a larger age range.

Examples of parents' statements:

*Now, as a mother, my dominant feeling is for her to do things that make her happy, and then things that are beneficial for her.*

*For many things, we need a specialist, because we need a little bit of help to see some things from a different perspective.*

*I liked the intervention, how can I say it? For the first time, I had a strong feeling that the team of Amimoni was here to support me.*

*Whichever time I called the office of Amimoni there was always somebody who would be there and help me with what I needed.*

*They observe the child, understand his/her needs, they discuss with each-other (in their interdisciplinary group) and finally they decide how they could help the child.*

*Specialists of Amimoni come together in the house until they define the (functional) level of X. What kind of (activities) games they can do with X. To see the needs of X.*

*I think that there was an assessment of the overall potential, of the family, the home environment, the availability, right? On what we can do.*

*Amimoni might have suggested ten activities (things), but we could do one. However, this one was not badly criticized. They didn't make you feel guilty, comparing, let's say, with your neighboring family, where they do a lot of things, why don't you do too? There was no doubt about their understanding. They told us: One? One. It's still beneficial. Half of it? As much as you can do.*

*So, Amimoni said: Oh ok. In essence, they said that you will learn to live with that. It's not even the end of the world. In fact, they did not say it like this, but this is the feeling I had after all. That those things happen, are part of life. Families face those issues, just happened for you to be within this category of families, it's not a big issue. Eventually for me this is how I feel, that you will learn how to live with this...Hope, you know. Life goes on. They were not like the doctors...they told us: Ah ok now, this poor kid... For Amimoni there was no poor kid.*



*What I most liked about Amimoni was that there was hope, that not everything is black in life, you know. We might encounter black lights, other black things, but there is always color in life. That's it.*

*Amimoni listened to all of our concerns; we discussed many issues concerning the child, but also at the same time irrelevant things apart from visual and behavioral matters.*

*Yes, Amimoni is a o program, they bring activities, handmade games. They give us materials and stuff in order to work with them on our own. Always. Since the beginning, they told me that those lights might help my child.*

*We have been analyzing the issues in order to figure out what to do and we found more things that we could do. Moreover, we could add something because they asked us if they could contribute more. "If you have an idea please tell us in order to incorporate it in the intervention".*

*It was just more pleasant, because whatever (the child) could do, he/she did it with joy. In essence whatever he/she could do, they did it pleasantly*

*I feel good, because my child reacts and has a good time. You try to help your child to feel a little bit better. Therefore, when she/he does things towards that direction, you cannot feel bad*

*We have learned more regarding the proper approach, intervention, what to take care of, during everyday life, to do stuff without considering them therapeutic.*

*We had the incentive to give more than that we used to give every day. Within this (early intervention) program we managed to give a little bit more.*

*Definitely we were (positively) affected, because look. As I told you before, from the moment that this program invests on your child but not only on him/her, but also on the family itself. Specifically, they ask us to do things and get involved.*

*Changes were made, after the improvement of the child's visual issues. Because he/she has more interests, he/she can observe, does not cry constantly, and does not feel so insecure, therefore our life is a little bit calmer.*

*Yes, definitely. Because they were explaining to us what they did, how and why they did it. And our role was assistive and we helped when we could.*

*With this program, we have found was to play (with our kid).*

In conclusion, the findings of Lioni's research were:

1. Parents faced grave difficulties during the first period after the child's birth.
2. Parents had positive feelings for their child, but negative feelings in regard to the child's difficulty.
3. The everyday life of the family was difficult, as the child's care was constant and demanding. The parents had to adapt to different roles in order to cope.
4. Extremely valuable was the support from the other parent (husband/wife).
5. Parent's experiences with doctors were negative. Also, parents had unpleasant feelings about the situation in the social services in Greece.



6. Parents had positive feelings about the existence of the parent's network (personal contact, media, etc.).
7. Parents wanted support from experts as well as from relatives and friends.
8. Parents were engaged in a constant search for a way to support their child.
9. Parent's priority was their child happiness.
10. Parents had positive feelings about entering the E.I.P.
11. Parents had positive feelings during their first meeting with the experts.
12. Parents felt positive about the program's experts, about the way they were approached by the experts and the co-operation with them.
13. The educational plan was created by the experts.
14. Parents desired to participate in the program, so as to see their child respond to the activities and learn how to implement those activities themselves.
15. Parents and children felt contentment during their participation in early intention's activities.
16. Parents tried to implement the expert's suggestions. Sometimes though they did not succeed due to daily programs or the family's limits.
17. Parents and children had positive feelings about the participation of other members of the family in the early intention program.
18. The program had a positive effect on parents, mainly because of the knowledge it offered.
19. Parents mentioned that their child had made progress due to the intervention.
20. Parents mention positive changes in family relationships due to their participation in the program.
21. Parents also mention that their everyday life had improved due to E.I.P.
22. Parents had positive feelings for the NGO "Amimoni" and for the E.I.P. They felt satisfied with the services that were available.
23. Parents believed that the program was useful.
24. Parents felt satisfied with the level of their participation in the program.
25. Parents felt that the program paid attention to their needs.
26. Parents felt sad about the termination of the program due to the age limit (till 6 years old).
27. Parents desired that the program had a longer duration.

## **D.2. Educational programme- SYZOI**

Syzoi was founded in Thessaloniki of Greece in 2007 from parents of people with visual impairments and additional disabilities (motor or sensory discrepancies, developmental disabilities). It is a non-government, non-profit organization. The Early Intervention Program of Syzoi started in 2007 and it is the only organized integrated educational program for visually impaired infants and children in all Northern Greece. Its structure is based on the similar program of Amymoni of Athens and of Blindeninstitutstiftung of Munich. Amymoni and Blindeninstitutstiftung are the organisations that inspired and support this specific program in all the ways (structure of the program, supervision and education of the staff).



Syzoi's early intervention (EI) program is a composition of services for infants and preschool children (0-6 years) and their families. It refers to children with visual impairment (partial or total blindness). The program refers also to children with visual impairments and additional disabilities (intellectual disability, autism, neurological disorders, motor or sensory discrepancies, neurometabolic syndromes).

The EI program takes place at the home of each child once a week, at a fixed time and is one and half an hour long. During the sessions, educational activities are carried out with the child in the form of play, with the presence and participation of the parents. The main areas of a child's support are vision, perception, orientation, mobility and daily skills. In addition, guidance is provided to parents with the aim of managing and resolving problems with their children and finding solutions to their autonomy.

For families who live outside the prefecture of Thessaloniki we have developed a different service in order to support these families and their children. Families visit the day care center of Syzoi as often as they can and meet the members of the early intervention team in order to be provided with our early intervention services. These consist of an assessment of child's functional vision, observation of child's development, educational activities, counseling of the parents in order to support their child and communication with child's doctors, therapists and teachers. Moreover, the early intervention educators visit these families twice a year with the aim to suggest adaptations in their environment.

#### Basic principles of the Early Intervention program

- The holistic approach to the child, adjusted to his needs and interests.
- Parent's participation in educational activities.
- Adaptation and appropriate enrichment of the child's environment (development of educational material appropriate for each child's developmental needs).
- Collaboration with all the experts who provide services to the child (doctors, therapists).

#### The Staff of the program

A multidisciplinary team:

- Child psychiatry. The child's psychiatry is responsible for the medical history of each child, family counseling and supervision of the whole team.
- Social worker. The social worker is responsible for the social history of each child and family counseling in issues relative to parent's rights and family needs.
- Special educators. The special educator in collaboration with the whole team organizes and implements home sessions. The educators of early intervention are graduate scientists with bachelor or post-degree in the field of a special education (special education teacher, special physical educator).





### Program objectives

- Observation of functional vision and support for making the best use of it.
- Observation and support of all the development areas: cognitive, behavioral, emotional, social, communication, motor development.
- Support the family to understand and respond to the needs of the child.

### Parental involvement

- One of the parents is always present at the home sessions. He/ she participate in the intervention session by holding or supporting the child, by observing its reaction, by discussing any suggestion or concerns that may have. With the guidance and collaboration of the early intervention teacher, parents decorate the room that child spends most of its times or make toys suitable to their needs.
- Parents participate in the design of their child's educational plan and they are welcome to suggest ideas. The aim of the whole intervention program is parents to be active members and feel able to implement the early intervention program in their daily life.

**For each child and family there is an individual, personal archive which contains the medical and social history, the results for the assessment protocol, the record forms from each early intervention session and the yearly educational report.**

### Medical history

According to the medical history, child psychiatry takes information from the parents about the pregnancy, the complications during birth and neonatal period, eye diseases and other organic complications, type and duration of medication.

### Social history

According to the social history, the social worker takes information from the parents of the child such as how many children there are in the family, the full name, age and educational level of all the members of the family, the socio-economic status of the family, their health and the relationship between the members of the family and their relatives. Especially, about the child, the social worker records the child's growth, the nutrition, the sleep, the ability or disability to complete the tasks of everyday life, the communication, the emotions and behaviour, the child's personality and the school life (depends on the child's age).

### Screening and assessment protocol

Our assessment protocol is based on specific observation tools of Blindeninstitutstiftung of Munich which are translated in Greek language.

More specifically, for visual perception assessment, we used the follow:

- Elementary Visual Perception Assessment Scale for children aged up to 1<sup>st</sup> year old and for children with multiple disabilities (Blindeninstitutstiftung, Munich).



- Advanced Visual Perception Assessment Scale for children with visual impairment (Blindeninstitutstiftung Munich).

For development assessment we use the following:

Developmental Observation Tool for Children with Visual Impairments (0-4 years) (Blindeninstitutstiftung of Munich).

- Early intervention for infants and preschoolers who are blind with visual impairment Bielefeld observation scales test (Michael Brambring).

For parental satisfaction, we use a modified version of Project Dakota. The specific instrument provides a complete picture of parental satisfaction and the effectiveness of the EI services rendered to their child. Project Dakota was used in previous studies to examine the effectiveness of EI services in meeting the needs of families (Iversen, Shimnel, Ciacara, Prabhakar, 2003; Kjerland & Kovach, 1990, Neofotistou et al. 2014).

#### Educational plans

Our educational plans are individualized to each child's needs and capabilities. Twice a year we use the observation tools in order to develop and evaluate the educational plans. After each early intervention session, we use a record sheet in order to record our intervention and document child's developmental progress.

The record sheet contains:

- The early intervention activities (activities and material);
- Child's responsiveness (responsiveness, attitude and mood);
- Parental involvement (parents' concerns, parents participation), and
- Climate of the home visit (tense, relaxed).

## IV.4. ROMANIA

### A. Policies and Legislation

In Romania, early intervention is part of the national policy and the strategy for early education, started in 2007, when the Romanian Government started a national program design to reform and reorganise early education service. One of the main objectives of this national project was to create educational opportunities for children from birth to 3 years old, to train the specialists and to design special programs for children with special needs as well as ensuring equal access to child care and early education services for children in vulnerable social groups. This reform project aims to change the focus on the medical care model, to a holistic approach based on child development, which, in addition to health care, involves stimulating cognitive and socio-emotional skills in infants and young children. Since 2007, an early intervention program as part of a national coherent policy and a structured and clearly defined early intervention process, governed by educational laws is not very well defined.



Educational and social policies as the national strategies are directed to different types of disabilities and to the population on risk.

In Romania, the identification of the new-borns and toddlers with different types and levels of developmental delays, the screening process and the therapy programs, as part of the early intervention is not part of a methodology or a national policy as the national Early Intervention Program for infants and toddlers with disabilities and their families.

At the moment, early intervention services are offered by special schools as part of the national education system and by different NGO's usually using foreign funds or with parents' contribution.

An early intervention program for visually impaired or/ and MDVI children is one of the major project implemented in 1998 by the Special High School for Visually Impaired, Cluj-Napoca, Romania, which is still developing year after year even the law in Romania is still very unclear and is not very explicit through the procedure and methodology concerning the implementation of this services. The early intervention programme is an important part of the services offered by the school, centred on visual rehabilitation, consisting of visual stimulation and visual training.

Early intervention is a process of providing services, education and support to young children who are evaluated and deemed to have a diagnosed visual condition (with a high probability of resulting in an associated developmental delay), an existing delay or a child who is \*at-risk of developing a delay or special need that may affect their development or impede their education. The purpose of early intervention is to lessen the effects of the disability or delay. Services are designed to identify and meet a child's needs especially in visual functioning and eye functionality or neurological development associated with a visual dysfunction five developmental areas, including physical development, cognitive development, communication, social or emotional development, and adaptive development.

Services such as parent education, support services, developmental therapies and other family-centred services that assist in child development are included in a family's early intervention program. These services are provided at no cost to families

National and international priorities are imposing to establish forcefully, a policy and a system of early education in the general framework of the ECD program. In this area, there are a number of laws and regulations to protect the rights of children under the age of three. However, all refer to child care, health, nutrition, and special protection. Many GD regarding in particular the protection of children at risk and children's rights, but there is no specific law for education and early intervention.

Education Law.

This Education Law refers to the educational needs of children aged between 3 and 6/7 years are enrolled in preschool. There is an education policy for children between 0 and 3 years or institutions dealing with this age group.

Order **5555** Article 9 provides as follows:



- c) multidisciplinary teams' early intervention is designed to make the assessment of all children, monitoring, early detection and appropriate assistance to those with special needs or at risk to develop personal skills;
- d) proposes ISJ/ISMB (Romanian ofsted) homeschooling for children homebound or establishing classes or groups in hospitals as a framework methodology developed by the Ministry of Education, Youth and Sports, according to Art. 52 para. (3) of Law no. 1/2011;
- e) provides comprehensive evaluation and diagnosis of the degree of deficiency for children, students and young people with special educational needs in special education, special integrated in mainstream education through the assessment and school and professional orientation and school centers for inclusive education.

Order 5573/2011 regarding the organization of special education and integrated special, Article 22 paragraph (1) (a) which states that special education units that have kindergarten groups may include early intervention.

Law on maternity leave / parental childcare.

Law on maternity leave (paternity) childcare 1997 states that mothers (or fathers) are able to take two years of parental leave. This led to a decrease in the number of children in nursery and as a result, many nurseries were closed.

Improving the legal framework for the establishment, as national priority, the Early Childhood Education System (ECES).

Education Act and other regulations must be revised to address the following issues:

- introduction of Early Childhood Education (0-3 years) to connect with the fact that child's education begins at birth and should be provided by institutions that address the multiple needs of the child as~: education, health and protection (for children from 0-6 years);
- introduction of a medical perspective concerning child's psychosocial testing in the context and concept of Early Childhood Education, to ensure a healthy learning environment for a positive emotional and mental development of the child and give him the opportunity to work in the society as a healthy and balanced adult;
- extending compulsory education to 12 years, age of onset being five years;
- preparing the necessary resources (human and material) for the early education system (e.g. adequate space, equipment, furniture, teachers, aid teachers, full-time nurses, speech therapists, counselors, teaching and learning aids, etc.);
- ensure training of personnel for early education institutions;
- designing and developing a dual, both ways training program including health, nutrition, and early education, replacing the current program vertically: - ensuring flexibility alternatives to early education institutions.

For successful implementation and full involvement of public authorities on Education Law revised, it is important to initiate a public awareness campaign, on the importance of early education, which would include:



- implementing a campaign to promote the issue of early education and informing the public about it (e.g. video spots, posters, press conferences, interviews);
- informing parents on early childhood education through educational programs;
- creating and developing a system of information exchange and communication on issues of education / early childhood development (e.g. website, specific publications, brochures, etc.).
- sharing knowledge and information in this area by the staff of the public / private sector and ONGs to develop a network in the Early Childhood Development field and at the same time, increase awareness in the field. Also, ONGs could be used in training, the establishment of social supply and other contracted services.

Another aim is to improve access to education, starting from education in the context of Early Intervention. As a starting point, the Ministry of Education should provide specific training to all staff by creating training institutions, design and develop training programs and courses, especially for the staff working with children under three years.

Multidisciplinary teams are needed in maternity and early education settings and institutions, to ensure equal access, support and opportunities for the children with special needs. A very welcome initiative, are mobile caravans, initiated in Botosani County by multidisciplinary teams of Mavromati pediatric hospital and Mental Health Center, with the support of pediatrician's team, psychiatrists and speech therapists. This mobile caravan's program, could be extended to the whole country for early detection of children with special

The educational needs from the rural areas, with very poor accessibility, where the population has no access to information and education need to be approached. Better cooperation and communication between parents, teachers and community members should be initiated by other programs such as the school mediators training. Provide financial support, facilities and/or benefits for children from the most disadvantaged groups, as increasing the chances and have access to education. This could be achieved through effective community solutions.

Quality of services for early education institutions should be ensured by:

- developing / reviewing and adopting of institutional standards for early education services (children aged 0-6 years) and tracking how they are ensured;
- establishing links between early childhood education and primary education programs to ensure a smooth transition from preschool to compulsory education
- reducing the number of children in the classes and improve performance through a better teacher training and supervision thereof;
- developing of a research department as a branch of the Institute of Education Sciences, for the needs of parents, children and teachers in early childhood education;
- developing programs to identify and prevent mental health problems of children between 0 and 6 years and creating an environment in which the child's mental and emotional development to be provided.

Developing / revising the curriculum for early childhood education (0-6ani) should be achieved by:



- reviewing the existing curriculum for preschools and designing curriculum for children under 3 years while ensuring socio-emotional health and their physical;
- improving and monitoring curriculum for children under three years and reassuring a continuity between this and that for children aged 3 6/7;
- developing and writing a Practice Guide for early education.

In the document of educational policies - Guidelines for the design and updating of the National Curriculum (ISE, 2016), the following are mentioned: the curriculum for the early education of the child, from birth to 6 years, is based on a set of finalities, formulated in the document of educational policies The fundamental landmarks in early learning and development (RFIDT, approved by OM no. 3851/2010). This document is a set of statements that reflect expectations about what children should know and be able to do. These expectations are defined to support the normal and full growth and development of children from birth to school.

According to the mentioned document, the aims of early education have in view a holistic approach, targeting the five areas of child development:

- o physical development,
- o health and personal hygiene;
- o socio-emotional development;
- o cognitive development and knowledge of the world
- o speech and communication development, and reading and writing;
- o learning capacity and motivation in learning.

This curriculum also applies in early education units that integrate children with disabilities, in which case more attention will be paid to waiting for a response from the child and spontaneous participation in activities with other children, and less to the number of activities per child, which it carries out. At the same time, we mention the fact that, in the case of groups in special education or/and specially integrated education, in addition to these types of activities, children also benefit from specific therapies, activities that are not included in this curriculum.

Children Multifunctional Centers could be established, particularly in poor accessibility and isolated areas, where health and education services are not available. They could function as Center for Early Childhood Development in rural areas and at the same time, they could provide training for parents and community members. However, the activity of such institutions should be monitored on the basis of predetermined criteria to ensure that the standards of education and health of children are respected. The team will be responsible for evaluating, monitoring and support of child development from birth to 3 years.

A feature of the existing early education in Romania is that the absence of legislation on the education of children of 0-3 years, a number of nurseries / kindergartens have developed without a consistent structure and without clear educational standards. There are a variety of early education institutions, some of which are listed below:

- Day care centers for children under 6 years are at risk, coordinated by the County Department of Social Services and Child Protection;



- Day care centers or private nurseries-preschools/kindergartens for children under six years, approved by the Ministry of Education and Research, which provides examples of good practice in the field;
- Nurseries/Kindergarten with childcare for children in the same age group as those in day care centers (under 6 years);
- Pre-schools/Kindergarten for children from 3 to 6/7. These local councils are funded and coordinated by the Ministry of Education and Research;
- Day care for children from 4 months to 3 years, receiving children and over three years in order to maintain staff. They are financed and coordinated by local councils, without supervision from a professional point of view and without educational standards or otherwise.
- Special schools, with early intervention classes/groups, with children with sensory impairments, hearing and sight.

Services for children aged 0 to 3 years are provided through the nurseries, which offers some form of medical care without early education component.

#### **B. Early Intervention Program – School for the Visually Impaired in Cluj Napoca**

In Romania, the early intervention services offered by The Special High School for Visually Impaired are designed to identify, prevent, or remediate existing problems related to the vision loss and enhance development through individual and family intervention strategies. Because this is a major project implemented in 1998, the programme is developing year after year due to the effort of the local authorities which are involving to find the best solutions for the different problems that may occur and to finance the program so this goes on even the law in Romania is not explicit concerning the procedures and methodology for the implementation of the early intervention. The programme is developing also due to the effort of the managerial team and specialists who are really involved in the early intervention programme implementation.

The Early Intervention Project for visually impaired children started in September 1998 in the same time in Cluj-Napoca, Arad and Timisoara thanks to Institute Teofaan/Sensis International from The Netherlands which offered financial and logistic support.

The first E.I. Team from Cluj-Napoca included:

- 2 early intervention workers (Roxana Cziker (1998 – 2008 and Aurora Petrut 1998 - 2012)
- 2 ophthalmologists (eye-specialists) – one eye specialist from our school – Rodica Medesan and one eye specialist from the Polyclinic for children from Cluj-Napoca – Angela Opincariu,
- The Director of the School for Visually Impaired Children, Cornelia Codreanu
- Head of Department for Psychopedagogy from Faculty of Psychology and Educational Sciences from “Babes-Bolyai” University- prof. Vasile Preda

The early intervention workers from Cluj-Napoca, Arad, and Timisoara were trained in Grave, The Netherlands by Institute Teofaan/Sensis International two times: 14.06 – 04.07.1998 and 18.06. – 29.06.2001. The directors of the schools for visually impaired children from Cluj-Napoca,



Arad and Timisoara and the representatives of “Babes-Bolyai” University were trained in Grave, The Netherlands in April 1998. In September 2001 a team from School for visually impaired children from Oradea and the representative of The West University from Timisoara joined the Early Intervention Programme. During 1998-2000 the Early Intervention Project was entirely supported by Teofaan/Sensis International. 2001-2002 The director of the school for visually impaired children from Cluj-Napoca and the representative of “Babes-Bolyai” University had established contacts with the Local Inspectorate of Cluj, local Authorities, national Government to continue the Early intervention project in Romania and to support 25% salaries for two early intervention workers. In January 2002 the Local Authorities by the permission of the Local Inspectorate according to the agreement established between our Ministry of Education (Mr. Andrei Marga) and Director of Sensis International (Mr. Peter Beijers) paid 25% of salaries for the two early intervenors from school.

From 2003 the activity as early intervention workers was implemented as a part of our school and the salaries for two early intervention workers were paid entirely by the Local Inspectorate. In September 1998 thanks to Teofaan/Sensis International was founded in our school the Center for Early Intervention for visually impaired children with or without associate disabilities. Our center has an Early Intervention room which was completely renovated and modernized along these years. Along these years (almost 22), the early intervention team has developed thanks to Ramona Muresan who worked as an early intervention worker from 2008, Dorina Marchis, Lavinia Dascalu.

At the beginning, the process of the identification of children was very hard because of the lack of trust in the benefits of the early intervention services, the lack of doctors’ confidence for the programme’s results and because of the fact that parents didn’t found out about the programme or the information were minimum. Due to these reasons, the number of children involved in the programme was low, the parents were registering the infants in the programme at a rise age, usually after 3 years from birth, so the period for children can benefit from the early intervention rehabilitation programme and to lessen the effects of the visual disability or delay was short. Since 1998, the programme known a spectacular growth and during 12 years of implementation more than 240 children benefit trough the services and more than 480 parents were part of the early intervention team. Home visits are an important part of the intervention because they help parents better understand their child’s development, the intervener communicates permanently with parents about their child’s progress and guide parents when there is a concern about their child’s development

#### ➤ **Mission Statement**

The mission of the Early Intervention Program is to identify and evaluate, as early as possible, those infants and toddlers whose visual development is compromised and to provide for appropriate intervention to improve child and family development.

The principle is to minimize the delays and maximize the chances of reaching typical milestones in development. It also supports and implements screening procedures to increase the early identification of difficulties and provide family support as early as possible to families.





### ➤ Service Objectives

- Helps children with visual disabilities or MDVI children develop and learn to their fullest potential.
- Enhances each family's capacity to meet the developmental needs of their child in the settings where children would be if they did not have a disability.
- Respects the family's strengths, values, diversity and competencies and answers families' questions about their child's development.
- Family training counseling and home visits.
- Support parents in meeting their responsibilities to nurture and enhance their children's development.
- It can have a **significant impact** on a child's ability to learn new skills and overcome challenges and can increase success in school and life.
- **Enhance child development and functional outcomes and improve family life** through the delivery of effective, outcome-based high-quality early intervention services.
- Provide specific intervention strategies to encourage the child's development of compensatory skills (alternatives to using vision) or use of remaining functional vision (to support the child's ability to use vision in a variety of situations).
- To promote the services of early intervention at local community and at a national level.
- To make known the existence of early intervention for children with visual impairment with/without multiple disabilities.
- Identify the children with visual impairments < 6/7 years old with/without multiple disabilities.
- Develop partnerships with Blind Association from Cluj, Polyclinics for children from Cluj-Napoca, NGO – Romanian Foundation for Children, Community and Family, World Vision, orphanages, etc.
- To draw up the activity plans for psychological age /chronological age taking into account the stage of development and the visual abilities. To improve our plans of activity with children involving the parents as well.
- To involve more the parents in activities with their children.
- Early intervention worker must be a support for the children and their families.

Visual rehabilitation entails visual stimulation and vision training aimed at the recovery of visual abilities, improvement of visual functioning, and coping with visual disabilities. Visual stimulation is aimed at improving the visual system by enhancing and changing the functionality of the eye, improving visual motor skills, visual acuity and enhancing visual field. The process is concerned with stimulating the development of children with visual impairments using visual material, to improve visual functioning.

Vision training consists in a long term process of teaching the child proper skills for using at maximum the residual vision in daily living activities, or school specific activities, applying specific methods aimed at improving visual abilities, e.g. visual perception, spatial localization, heterophobia, hand/eye coordination, etc. to achieve optimal visual performance and comfort.



## - Target group

Children with visual impairments aged 0 – 6/7 years old with or without associate disabilities and their parents who lived in Romania.

Based on the brain plasticity and the sensitivity period theories that stipulate the fact that there is an optimum period for the child stimulation so he can benefit at maximum for the rehabilitation process, early intervention programme in Romania start from the moment the parent demand for early intervention services. So most of the children start the programme at 3 months which coincides with the moment that parents agree that their child has a problem and they and their child needs help from a specialist.

The early intervention project includes children with visual impairments or MDVI with one or more from the following diagnosis: Refractive errors: near-sightedness or myopia , far-sightedness or hypermetropia , presbyopia, and astigmatism, Cataracts, Cloudy intraocular lens, Aphakia after the cataract is removed, Glaucoma, Diabetic retinopathy, Childhood blindness,Cortical visual impairment,Periventricular leukomalacia,Optic nerve's Atrophy,Optic nerve's Hypoplasia,Diabetic retinopathy,Corneal opacity, Corneal scarring, Keratoconus, Trachoma, Aniridia, Retinopathy of prematurity, Maldevelopment of the iris,Retinal dystrophies retinoblastoma,Microphthalmos,Colobomas,

## - Eligibility for the program

Eligibility for early intervention services is based on a visual and neurological screening, and evaluation of the child's skills and abilities. This evaluation must include an ophthalmologist diagnostic. To be eligible for services, children must be under 3 years of age or up to 7 years old but not benefit for others services and have a confirmed visual disability or established developmental delay in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and/or adaptive associated with a visual pathology.

There are three categories of children involved in the early intervention programme:

- Children with visual impairment or MDVI children under 3 years old who benefit from visual simulation and training, psychomotricity, cognitive stimulation and speech therapy;
- Children with visual impairment or MDVI children from 3 to 6/7 years old from mainstream kindergarten who benefit from visual simulation and training, psychomotricity, cognitive stimulation and speech therapy;
- Children with visual impairment or MDVI children from 3 to 6/7 years old who benefit only from visual simulation and training, the rest of therapies are provided as services offered by the kindergarten

## - Evaluation



Even the vision tests should be performed before leaving the hospital when a child is first born, not all the hospitals offer this services, so the parents demand an optometrist advise for a clear diagnostic when they realize that their child may have vision problems. Additional checks are performed during well-baby checks (when the baby is 6-8 weeks old), provide opportunities to detect potential delays. Early identification and treatment of certain visual challenges before age three can lead to a 95% recovery of vision. Every specialist from the multidisciplinary team makes his own evaluation.

The first evaluation is made by the optometrist who checks the vision and the specific aspects of the child's visual function and eye health. Preliminary tests can include evaluations of depth perception, color vision, eye muscle movements, peripheral or side vision, and the way that pupils respond to light. A wide variety of microscopes, lens, and digital technology is used to assess the health of all the structures of the eye and the surrounding tissues. The intervener make his own evaluation including specific tests for determination of the vision functionality: measurements of the vision field and vision-motors skills and what are the visual perception strategies used by the child to perform everyday tasks. Checking vision functionality is correlated always with important information about other levels of cognitive, communication, motor or psychomotor development. Interventionists use specific test like The Oregon Project For Visually Impaired & Blind Preschool Children, Portage Scale, The Griffith Mental Development Scales. This evaluation form helps the intervener in making a clear overview of the child abilities and developmental level, and the fields where is a need for specific intervention.

#### - **Case management**

A member of the early intervention team will contact the family by telephone or in person to plan the meeting time and place which is convenient for the family. This applies for both home visits and school visits. In case of school visits the first meeting take place with the parent/s or carer/s to establish the initial contact with family members. At the beginning of the programme, the role of the parents is essential so the interventionist can understand what are the child needs, how he interact with family members, what the parents understand the need of the child and how this needs are fulfilled. Based on the approach that the parents know the best the child, and that every child is unique, early intervention programme must apply on every family and every child needs to maximise the success.

So the interventionists have two important instruments to elaborate and work with: The individualized family service plan and the child individualized early intervention plan. After the process of the evaluation of the entire family's needs, the interventionist outline the family's early intervention plan with include: strengths and weaknesses of the hall family specific objectives to achieve during the early intervention programme and also specific activities so the main goal of the intervention is fulfilled. One guiding principle of the individualized family service plan is that the family is a child's greatest resource, that a young child's needs are closely tied to the needs of his or her family. The best way to support children and meet their needs is to support and build upon the individual strengths of their family.



**Family centered-ness** refers to principles and practices that are individualized, flexible, respectful of, and responsive to each family. Family – centered practices involve sharing information and guideless so parents make an informed decision about intervention and services, using the family’s priorities to guide the focus and goals of intervention, promoting collaboration between interventionists and families, bound their connection, their communication and relationship in the rehabilitation process and helping parents to obtain access to resources that facilitate positive results for both the child and family. The family intervention plan is a good instrument that also entails viewing the child within the context of the family system and applies all the intervention starting with family needs and child needs within the context of a family system.

### - **Multidisciplinary approach**

Early intervention services in Romania are based on a multidisciplinary approach both in the evaluation process and in the rehabilitation and intervention process.

The multidisciplinary team includes the early intervention worker, optometrist, psychologist, paediatrician, social worker and it realizes:

- A multidisciplinary assessment of the child’s strengths and needs and identification of the appropriate services to meet these needs
- Family directed assessment in which the parents play an active role throughout the assessment process to identify the family’s concerns resources and priorities and appropriate supports to promote the family’s ability to meet the child’s development needs
- A psychoeducational evaluation form, demand in the process of enrolling the child in the early intervention programme by the local authorities. It’s an important part of the evaluation in which the multidisciplinary team has a big role, to describe the real level of the development at cognitive, motor and psychomotor, visual, emotional, independence and communication level of functionality.
- A written early individualised family intervention plan and the individualized early intervention plan

### **Individualized early intervention plan**

The information gathered from the evaluation process made by the multidisciplinary team represents the based for the individualized early intervention plan which include:

- Target behaviours.
- Specific, measurable goals.
- Intervention description and method.
- Start and frequency of intervention.
- Specific activities of the intervention.
- Method of evaluation.
- Persons responsible for each part of the intervention and evaluation.
- Data from the evaluation.



The IEP is a written document that, among other things, outlines the early intervention services that the child and family will receive. The planning activities in early intervention are in a relationship with the results of the assessment, they depend on the diagnosis of the child, on the child's level of development, taking into account the characteristics of the psychological and chronological age, the preferences of children for some materials and activities, the recommendation of the eye-specialists and other specialists like the psychologist and speech therapist.

#### - **The partnership with the parents**

A child's needs cannot be separated from the needs of his or her family. For this reason, early intervention services are designed to help the family to feel comfortable and confident as they raise their child and benefit from the services outcomes. Caregivers, usually family members play a significant role in a child's early learning experiences at the same time they are like to be grappling with different difficult situations and emotions such are: Parents usually don't know what the visual disability or other disabilities mean, what the diagnostic implies or what different problems may occur during child development. Some of the parents found out later that their child has a disability or a visual delay, usually when they ascertain that the child doesn't make eye contact with the mum, or don't react properly to visual or auditory stimuli. Additionally, it is important for the parents to be involved in all the services their baby receives, to be present, to learn, to ask, to understand the process and to trust the process of teaching and learning.

At the beginning of the programme, they need to know and to learn how to interact properly with their child who may not respond in a typically way, how to recognize their children's individual needs and support their development and how to identify and advocate for the services their children needs. After they are confident with the child needs and they are ready to be part of the rehabilitation plan, parents are counselled to continue working with their child at home to reinforce lessons and skills that the early intervention team members may have introduced. This is an important part of the educational contract, so parents are responsible also for the child progress and the success of the rehabilitation of their child during the early intervention programme.

## IV.6. TURKEY

### A. Policies and Legislation

Early intervention includes the services which are offered to children (0-36 months and 36-72 months) who are at developmental risk or with special needs. With the systematic and qualified services offered in the early period, these children can exhibit significant progress in development areas (Bayhan & Taştekin, 2015; Birkan, 2002; Blackman, 2002; Doğru Yıldırım, 2019). In the context of early intervention, each country creates its early intervention systems and legal regulations based on various differences (cultural, political, resources, etc.) (Guralnick, 2008).

Services on the basis of early intervention are conducted by Ministry of National Education in Turkey and the Ministry of Family, Labour and Social Services. Even though early intervention services particularly accelerated in quantity and quality terms in last 10 years, studies in the context



of practice and regulations extends to previous years (Yıldırım Doğru, 2019). Within the scope of early childhood, there are initiatives related to preschool education starting from the 1930s and various legal arrangements in the coming years, but there is no outstanding practice within the scope of individuals with special needs. In the context of early intervention, it was stated that children with special needs should receive early education within the scope of "Children in Need of Special Education Law" in 1983. After this law, "Circular on Preschool Education of Children with Special Needs", came into force in 1987 and it stated that children with special needs should take preschool education in special education preschools and kindergartens on the basis of various adapted programs, and guidance for families with children under four and five years of age should be provided (Birkan, 2002; Yıldırım Doğru, 2019; Güven & Efe Azkeskin, 2010; Sazak Pınar, 2006).

Looking at the following years, preschool education has become a part of compulsory education for children with special needs with the Decree Law No. 573, which entered into force in 1997 (Ministry of National Education [MEB], 1997; Yıldırım Doğru, 2019). After this decree, with the "Special Education Services Regulation", which was published in 2000 and reconsidered in 2006 and 2018, "The Regulation on Preschool Institutions and Primary Education Institutions" in 2014 and the "Circular on Practices for Inclusion/Integration" in 2017, preschool education has been made compulsory for children between 36-72 months and legal arrangements have been made in inclusion/integration practices. For children of 0-36 months with special education needs ; (a) early childhood education services are carried out in special education institutions, preschool education institutions, educational institutions with a kindergarten, and homes in line with the needs of the child and family, with the decision of the special education services of the province or district, (b) the services for these children also includes the informing and supporting families, (c) preschool education is compulsory for children with special needs who have completed 36 months, (d) the duration of preschool education may be extended, taking into account the developmental characteristics of the children (Although in Turkey the preferred term is "integration" instead of "inclusion" in recent years, inclusion/integration is used in this text because the term "inclusion" is still widely used. The difference in philosophy between these two terms is also not fully understood and accepted. So these terms are used interchangeably).

In line with the above-mentioned legal regulations and the results of the educational evaluation and placement performed in the Guidance and Research Centers affiliated to the Ministry of National Education, children with special needs are directed to inclusion/integration education in public or private preschool institutions. Children who are not eligible for inclusion/integration education are directed to Early Childhood Special Education Centers or special education classes where children with special needs are educated. In these institutions, the main responsible people in the education of individuals with special needs are special education teachers and preschool teachers, however and a team of other branch teachers, assistant trainers and professional staff such as language and speech therapist can be assigned when necessary. Legal regulations emphasize making necessary educational adaptations for children in inclusive practice, preparing an individualized education program (IEP), providing necessary support services,



making necessary physical arrangements in schools and classrooms, and taking necessary measures for family participation. In addition, there should be a maximum of two students in the inclusive classrooms with 10 children, and one student with special needs in classrooms with 20 children. Legal regulations also include articles in the context of different types of disability. For example, separate classrooms can be opened for students with more than one disability, as well as home education services for those with health problems as well as special needs (Akalin, Demir, Sucuoğlu, Bakkaloğlu & İşcen, 2014; Bozarıslan & Batu, 2014; MEB, 2000, 2006, 2014, 2017, 2018; Richardson-Gibbs & Klein, 2014; Sucuoğlu & Bakkaloğlu, 2018).

As can be understood from the above information, in Turkey, there is not any legal requirement for children between 0-36 months with special needs. In Turkey, the education of 0-36 months children with special needs are provided in nurseries and day-care centers under the responsibility of the Ministry of Family and Social Policies General Directorate of Children Services. In addition, under the responsibility the Ministry of National Education Special Education and Guidance Services, education of these children are provided in institutions and homes with an emphasis on supporting the family of these children (Ekinici & Bozan, 2019). However, for children older than 36 months, early intervention in separated and/or inclusion/integration environments is carried out as a legal requirement by providing necessary precautions and educational arrangements.

Education opportunities for children with more than one disability are very limited, because it is not an accepted medical diagnosis in Turkey. Especially for children who have multiple disabilities with visual impairment, the early intervention services are vital. Since these children have severe and complicated obstacles and health problems, it is important to use special methods in their education. Therefore, it is very important to create programs specially designed for these children and to train teachers who have the ability to work with them (Ayyıldız, 2007; 2016).

### **Prenatal and Postnatal Screening and Assessment Protocols used in Turkey**

Turkey began to pay particular attention to maternal and child health through the Health Transformation Program carried out since 2003. Such studies carried out in this framework include the follow-up of pregnant women and newborns as well. In this regard, all pregnancies are monitored in hospitals affiliated to the Ministry of Health, and even if the pregnant women attend the private hospitals, the results related to their control are collected by the Ministry of Health through the Family Health Centers (Ministry of Health, 2014).

Some chromosomal anomalies can be detected with screening tests performed in certain weeks and ultrasound scanning tests performed almost every month during pregnancy. Interventions such as amniocentesis and chorionvillus biopsy are more risky interventions, although they allow definitive diagnosis (Aka, 2013).



The required interventions are made in the intensive care units of the hospitals after birth, when necessary. Even if it is a mature and healthy birth, babies are followed up after leaving the hospital. According to the program applied to all babies in Turkey are:

1. Newborn Screening Program (NTP)- Phenylketonuria, Congenital Hypothyroidism, Biotinidase deficiency, Cystic Fibrosis
2. Newborn Hearing Screening Program (YİTP)
3. Developmental Hip Dysplasia (GKD) Screening Programs.

Thus, it is possible to start preventive services for various problems that may pose risks and possible to treat. As a result of the examinations, the relevant Public Health Directorates are informed about the situations that are confirmed to be at risk, and each directorate is obliged to check the results of their infant records every day. It is necessary to enter the clinical diagnosis in the system within three months at the latest by monitoring the infants referred properly. The Ministry of Health continues its studies on detailed screening for vision screening, congenital heart diseases and immune system problems in the future (Turkish Public Health Institution).

Educational evaluation and diagnosis of special needs situations are carried out by the Guidance and Research Centers (RAM) affiliated to the Ministry of Education (MEB, 2018), while the medical diagnosis are performed by specialist doctors in full-fledged state hospitals (Ministry of Health, 2019).

#### **B. Training of professionals. (undergraduate, postgraduate and in-service programs, description of curricula)**

There is not any separate program for the training of teachers of children with multiple disabilities in the undergraduate /postgraduate/in-service education in Turkey. Thus, there is lack of theoretical and practical education of teachers of children with MDVI (multiple disabilities with visual impairment). Practitioners/teachers of children with MDIV take education in undergraduate/postgraduate programs of Special Education in general. Specifically, teachers who can provide education for students with visually impairment receive education only in Gazi University, Department of Education of the Students with Visually Impairment. It is possible to mention two main institutions responsible for teacher education in Turkey. One of these institutions is Council of Higher Education and the other is the Ministry of National Education. While teacher candidates are trained with undergraduate programs within the scope of higher education institutions, in-service training is provided for the development of teachers in the context of Ministry of National Education.

A change has recently been experienced in the field of special education in the year of 2014. The Ministry of National Education started to assign graduates of Programme in Education of the Mentally Disabled, Programme in Education of Hearing Impaired and Programme in Education of Visually Impaired as "Special Education Teachers". Based on this change, Council of Higher Education decided a new and one undergraduate program under the name of "Special Education Teaching" by combining separate programs which are Programme in Education of the Mentally Disabled, Programme in Education of Hearing Impaired and Programme in Education of Visually





Impaired and also added the areas of learning disability and autism spectrum disorder (MEB, 2014). The Education Faculties of the Universities train the teacher resource of the Ministry of National Education. As a result, changes within the Ministry of National Education in 2014 resulted in changes in Council of Higher Education in 2015. The curriculum was prepared as a core program by combining separate special education teaching programs within universities. Thus, when the teacher candidates become teachers, they are supposed to know how to teach students with different disabilities whether they are visually impaired, hearing impaired or with a mental disability.

Graduates of Special Education Teaching Programme are employed as special education teachers by public or private special education institutions affiliated with General Directorate of Special Education Guidance & Counselling Services, the Ministry of Education in Turkey.

Special Education Teaching Program is a 4 year program. The courses in the program are Professional Knowledge, General Culture and Field Education courses. 59% of the program is comprised of Field Education, 28% is Professional Knowledge and 13% is General Culture. In addition, students are required to take 12 elective courses. Graduates of the Special Education Teaching Program receive the “Special Education Teacher” title and they can work at state or private schools and rehabilitation centers affiliated with the Ministry of National Education.

Currently in Turkey, at public universities, there are 29 special education teaching undergraduate programs, and at private universities there are 7 special education teaching undergraduate programs.

In Special Education Teaching undergraduate programs, domain-related required courses are:

- Special Education
- Intellectual Disabilities and Autism Spectrum Disorder
- Hearing and Visually Impairment
- Child Development
- Early Childhood Special Education
- Turkish Sign Language
- Applied Behaviour Analysis
- Inclusion in Special Education
- Assessment in Special Education
- Supporting Language and Communication Skills
- Technology-Assisted Teaching in Special Teaching
- Preparation of the Individualized Education and Transition Plan
- Reading-Writing with Braille
- Observation at the Special Education Institutions
- Reading and Writing Instruction in Special Education
- Teaching Science and Social Study in Special Education
- Mathematics Instruction in Special Education
- Teaching Art Skills in Special Education



- Physical Education and Sport for Special Education
- Teaching Social Skills in Special Education
- Turkish Instruction in Special Education
- Special Education at Play and Music
- Family Education in Special Education
- School and Institution Experience in Special Education
- Teaching Practicum
- Instructional Technologies Material Development in Special Education

In Special Education Teaching undergraduate programs, elective courses are;

- Children with Multiple Disabilities and Their Education
- Adulthood and Sexual Education
- Early Intervention Programs
- Teaching Work and Vocational Skills
- Interdisciplinary Working and Collaboration
- Teaching of Concept in Intellectual Disability
- Instructional Modification in Intellectual Disability
- Teaching of Social Skill in Intellectual Disability
- Technology-Supported Teaching in Intellectual Disabilities
- Transitions to Adulthood in Intellectual Disability
- Natural Teaching Process and Practice
- Education of Children with Autism Spectrum Disorder
- Alternative Communication Methods in Autism Spectrum
- Behaviour Management in Autism Spectrum Disorders
- Interdisciplinary Working and Collaboration in Autism
- Teaching of Social Skill in Autism Spectrum Disorder
- Technology Supported Teaching In Autism Spectrum
- Teaching Basic Skills In Autism Spectrum Disorders
- Errorless Teaching Methods
- Teaching High Functioning Autism Spectrum Disorder
- Attention Deficit And Hyperactivity Disorder
- Math Disability: Diagnostic and Intervention
- Reading Disability: Diagnostic And Intervention
- Learning Strategies for Learning Disability
- Learning Disability and Behaviour Disorders
- Supporting Non-Academic Skills in Learning Disability
- Support Training Programs in Learning Disability
- Interdisciplinary Working and Collaboration in Learning Disabilities



- Intervention and Assessments in Early Childhood
- Writing Disability: Diagnostic and Intervention
- Critical Thinking Education
- Family Participation in Gifted Education
- Interdisciplinary Working and Collaboration in Gifted Education
- Sensory Education in Gifted Education
- Special Education and Diagnostic in Early Childhood
- Learning Problems and Education in Gifted Education
- Development Program in Gifted Education
- Social, Emotional and Academic Guidance in Gifted Education
- Diagnosis Models and Tests in Gifted Education
- Creative Thinking Education
- Advanced Turkish Sign Language
- Nature of Hearing and Assistive Technologies
- Family Participation in Education of Hearing Impairment
- Hearing Impairments and Language
- Lesson Plan Development for Individuals with Hearing Impairment
- Interdisciplinary Working and Collaboration in Hearing Impairment
- Early Intervention for Individuals with Hearing Impairment
- Supporting Communication Skills for Individuals with Hearing Impairment
- Special Teaching Methods for Individuals with Hearing Impairment
- Cochlear Implant and Listening Education
- Supporting Vision Skills
- Family Participation in Education of Visual Impairment
- Assistive Technologies for Individuals with Visual Impairment
- Education of Adults with Visual Impairments
- Interdisciplinary Working and Collaboration in Visual Impairments
- Early Intervention for Individuals with Visual Impairment
- Development Program for Individuals with Visual Impairment
- Teaching Social Skills to Individuals with Visual Impairments
- Advanced Braille Literacy
- Orientation and Mobility Skills

### **C. Early Intervention programs**

In the Special Education Services Regulation, which is an important legal regulation that regulates the special education services in Turkey (the latest revision of this regulation was released in 2018) states that, it is essential to start the education of the individuals with special needs earlier. Accordingly, early childhood education services of children with special needs



between 0-36 months are carried out at home -depending on the needs of the child and family- with special education schools, pre-school education institutions and educational institutions with a kindergarten. It is essential for children who are over the age of 36 months, to benefit from pre-school education. All services provided for such children and their families are free. The Individualized Education Plans (IEP) are prepared for such children to be applied in the educational institution where it continues after the guidance report regarding the need for special needs from the Guidance Research Centers (MEB, 2018).

Children with special needs, who have sensory losses and neurodevelopmental problems or problems due to various causes before birth, during and/or after birth (Ayyıldız, 2019), have a chance to get free individual, group or physiotherapy services in the Special Education and Rehabilitation Centers, which are special organizations affiliated to the Ministry of National Education. The content of such education will be described in the RAM's report. (MEB, 2012). Some institutions and programs aiming to serve children with special needs and their families between the ages of 0-6 are:

### **Foundation of Mother & Child Education (AÇEV)**

The foundation, which is established with the objective to increase the quality of education of parents (especially mothers) and children and to support disadvantaged groups, the aim of creating equal opportunities in pre-school education and education of children with special needs come to the forefront. (<http://www.acev.org>).

### **RİBEM (Early Support Center for Risky Babies and Children)**

It is a special center where physiotherapy and other support education services are given to infants and children between 0-6 years of age and children who have various physical, neurological or genetic problems or at risk (especially children with Cerebral Palsy) (<https://ribem.com.tr/>).

Also, early intervention studies of Research Institutes of Individuals with Disabilities of some universities are continuing (eg. Anadolu University). (<https://eae.anadolu.edu.tr/enstitumuz/hakkımızda>).

### **Core Holistic Development Center (Çekirdek Bütünsel Gelişim Merkezi)**

The center is established at 2019 for the purpose of performing developmental and educational evaluation and follow-up studies of children with visual impairment and additional disabilities age between 0-6 and their families. The child's family is especially included in the process, and support is given as to what they can do at home, too (<http://test.cekirdekgelisim.com.tr>).

Because the children with multiple disabilities cannot be diagnosed in Turkey (since the multiple disability is not defined as a formal special education category), necessary training services for such children and their families are so limited. It is known that by most of the children with multiple disabilities have also sensory losses (especially vision loss) (Ayyıldız, 2016). The



first educational services efforts/works which held in Turkey for children visual impairment and additional disabilities (multiple disabilities with visual impairment-MDVI) and their families was started at Türkan Sabancı School for the Blind. These services started within the early intervention program (so called “Baby Groups”) and the preschool classes established for such children. Over the years, as the children who served in the baby groups grow older, more preschool classes, primary school classes, and even middle school classes have been established for these children. Early intervention program at Türkan Sabancı School for the Blind ended after the assistant manager of the school at that time left her position in 2011. Early intervention services for children with visually impairment and additional disabilities (MDVI) and their families restarted after 10 years later, at the Core Holistic Development Center under the ErIsFaVIA project. It is the greatest wish of the project staff and families of the children with MDVI, to be a model for such studies to public and private institutions throughout the country.

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