

# A Greek Home Visiting Program of Early Child Intervention for Visually Impaired Infants and Preschoolers with and without additional disabilities: Present Reflections and Visions

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## ABSTRACT

Although it is widely accepted that Early Child Intervention (ECI) has valuable effects in child development and quality of life of children and their families, it still remains a lot to be done in Greece for the access of Greek visually impaired infants, preschoolers and their families to early support services. This paper discusses the context of a small scale Greek Home Visiting Program of Early Intervention for Visually Impaired babies and preschoolers aged 0-6 years with and without additional disabilities. The origins, process and methods of intervention of the program are presented in the context of a broader discussion about the needs of visually impaired babies, toddlers & preschoolers and their families in Greece. Present problems regarding the field of visually impaired and multiply handicapped children in Greece as well as future needs and visions are also discussed.

## 1. INTRODUCTION

Early Childhood Intervention (ECI) is widely recognized as a promising approach to both improving the well-being of participating children and their families and reducing the demand for social services across the life course. It is often described as an “investment,” while it has been proposed by decision makers as a prevention policy [1]. ECI is a composite of services for very young children and their families, covering any action undertaken when a child needs special support to ensure and enhance the child’s personal development, strengthen the families’ own competences, and promote the social inclusion of the child and family. These supports are to be provided in the child’s natural setting, preferably at a local level, with a family-oriented and interdisciplinary teamwork approach [2].

Visual impairment is vision loss (of a person) to such a degree as to qualify as an additional support need through a significant limitation of visual capability resulting from either disease, trauma, congenital or degenerative conditions that cannot be corrected by conventional means, such as refractive correction or medication [3].

According to the World Health Organization (Fact Sheet N282) and the ICD-10 [4] there are four levels of visual function: normal, moderate, severe visual impairment and blindness. The term ‘low vision’ refers to moderate and severe visual impairment. In Greece children with severe visual impairment fall under the Special Education Act and the laws for persons with disability. The first law for special education, implemented in 1981(L1143/1981, FEK 80/31.03.1981), established the mandatory education of children with disabilities from the 6<sup>th</sup> till the 17<sup>th</sup> year of their age in special education units. According to the 958/79 Act (article 1) “Blind is every person, who is devoid of the perception of light or whose visual acuity is less than one twentieth (1/20) of normal’.

Visually impaired children are considered as a broad category with different and often complex needs. The spectrum of visual problems in infancy is extensive and includes both peripheral disorders due to receptor problems (e.g. strabismus, refractive errors and retinopathy) and central visual disorders, which can interfere with basic visual functions (e.g., visual acuity, visual field and ocular motility), as well as with higher visual functions (known as cognitive visual functions) [5]. In many cases perinatal brain damage or genetic syndromes may affect the visual system, while additional disorders, such as cerebral palsy, mental retardation and pervasive developmental disorder may coexist.

Visual function is one of the main sensory channels of the child in order to process information and to construct mental representations. Vision deficiency decreases the ability of integrating such information. Children with visual impairment may present limitations on functional performance of their daily routine activities, related to language development, self-care and mobility.

The visual impairment of the child, as well as in case of multi-handicapped children, can have serious impact on parents and on their interactions with the child. Mothers of children with visual impairments report the emotional impact their situation can generate, as they are overwhelmed with feelings of despair, anger and sadness, when they discover the visual difficulties of their children. Most of these mothers express fear and little understanding of the diagnosis [6]. Moreover, families challenged by various combinations of environmental and

psychosocial stressors or risk factors often establish family patterns of interaction that are far from optimal with respect to their development-enhancing features [7,8].

Evidence suggests that early learning is cumulative and that basic early childhood skills are a necessary foundation for learning other skills [9, 10] This inference is supported by research on brain development in young children and the idea of sensitive periods for developmental growth [10, 11, 12, 13]. If learning begets learning, then interventions at younger ages have the potential to generate cumulative benefits by altering a child's developmental trajectory [9]. Early support programs have been shown to have positive influence on the visual development of severely visually impaired babies [14].

In support of the above, Unesco declares that the access to Early Intervention Services is considered a right of every child and a basis for 'sustainable human development' [15].

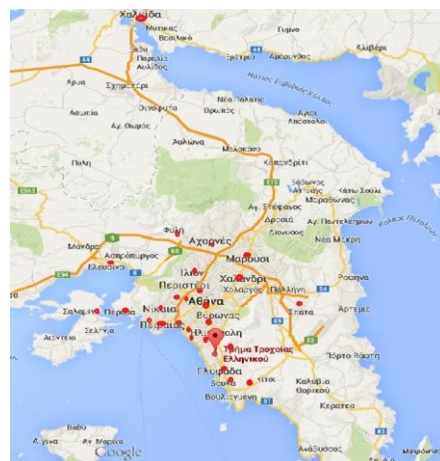
In Greece, the concept of early intervention was introduced for the first time in the Special Education Act of 2008 that allowed preschool special educational units to implement early intervention programs for children till the 7<sup>th</sup> year of their age (L3699/2008). In addition, the institution for diagnosis and support of special education needs (KEDDY) can suggest the implementation of early intervention programs where needed.

Unfortunately, despite the Special Education Act legislation (L3699/2008, articles 8 & 32), ECI is not systematically applied in Greece [16]. There are still few early intervention services for children with visual impairment, operating in the two biggest cities of Greece. Apart from two special educational units for blind children in Athens and Thessaloniki, including a pre-nursery school for children 0-5 years operating in Athens by the Centre for the Education and Rehabilitation of the Blind [17], there is a lack of ECI services in the public sector that systematically support the newborns and young children with visual impairment and multiple disabilities under the age of 3. There is also a lack of early support services for visually impaired children outside urban regions [18]. Non-Governmental Organizations for visually impaired persons try to compensate for the lack of public services, but so far they have not developed early intervention services, with the exception of a small scale program which operates from 2006 by "Amimoni-Association of Thessaloniki" in Northern Greece. Thus, the unequivocal right of access of this specific population to early education is severely impeded.

## 2. THE PROGRAM

From 2004 the PanHellenic Association of Parents & Friends of Visually Impaired Children with additional disabilities, "AMIMONI" has been offering services for up to 70 families in the area of Attiki and Chalkida (see map in Figure 1), implementing an ECI Program, with the support from the Blindeninstitut of Germany. The program treats visually impaired infants and young children from birth up to the age of six. These children

may have low vision or blindness caused by visual disorders such as retinopathy of prematurity, congenital glaucoma, cataract or Cortical Visual Impairment (CVI), whereas children may also have additional clinical conditions, such as cerebral palsy, perinatal brain damage, genetic syndromes or brain tumors that affect the visual system. Today the program caters for the needs of 25 families with systematic, weekly-home visits by professionals trained to support visually impaired and multiply handicapped children. A part of the home visit consists of intervention with the child, whereas a second part is devoted to the caregiver's counseling and support. The primary goal of the intervention is to support the development and emotional well-being of the child, as well as to support the caregiver-child interaction and to promote their 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.



**Figure 1.** The main geographical area (Attiki and Chalkida) that the program covers.

**The process of integrating a family in the program:** When dealing with a new request, the following process takes place: 1. Intake, meeting the family and listening to their history: After the telephone intake, two members of the early intervention team meet the child and its family in their residence in order to take the child and family history, including a review of the child's medical and surgical history. 2. A review of the child's ophthalmological assessment and the residual visual functions assessment provided by an optometrist is also made in order to better understand the visual needs of the child. 3. Contract and meeting of the early intervention team: After the review of the child and family needs, a contract is made between the early intervention team and the family, explaining the function of the program. Afterwards, the family visits the day center of AMIMONI, where they meet the rest of the early intervention team, such as the social worker and the child-psychiatrist. 4. Functional Vision Observation of residual vision and Observation of Developmental Functions (Instrument for Observation of the Functional

Vision and Instrument for Observation of Developmental Functions for children with visual impairment, adapted by the original scales “Funktionales Sehen” and “Beobachtungsbogen zur Erfassung des Entwicklungsstandes mehrfach behinderter sehgeschädigter Kinder” of Blindeninstitutsstiftung Würzburg of Germany, with their support and collaboration), that are provided by two members of the early intervention team. These observations are done in the house of the child with the presence of his/her caregivers and they can take a couple of visits to be completed. 5. Formulation and Implementation of an “Educational Plan”: After the Functional Vision Observation, a discussion is made with the family for the educational needs of the child and an formulation of an ‘Educational Plan’ is proposed in accordance with the family priorities. During the review process and throughout the intervention, discussions and visits to the other specialists treating the child can be made by the professional team in order to better comprehend the various needs of the child.

### **3. THEORETICAL AND SCIENTIFIC ORIGINS OF THE PROGRAM**

The aim of early intervention is to compensate for the various factors that place children at risk of poor outcomes, with additional support for the family as a unit, who can affect the child, directly, through structured experiences, or indirectly, by enhancing the caregiving environment [13]. The program is influenced by a number of theoretical traditions, concerning the factors that affect child development as well as neuropsychological findings concerning the visual functions and their role to development.

#### **3.1 Home Visiting ECI and Networking: Ecological and Transactional Influences from Child Development Theories**

It is claimed that systems features such as adopting a family-centered approach, requiring individualized interventions, generally agreed-upon values and principles, have now achieved international consensus [19]. Whereas preschool ECI programs focus almost exclusively on the child, home visitation ECI is viewed as a two-generational approach in which professionals work with parents to help them support their infants and young children in their natural environments. Bringing the intervention into the home also provides opportunity for a whole family involvement, personalized service, individual attention, and rapport building [20]. Such an approach is in accordance with the Bioecological Theory of human development [21, 22, 23]. This theory highlights the importance of understanding a person’s development within environmental systems in which both the person and the environment affect one another bidirectionally. The environmental systems involve five interconnected systems: Environments such as home or school in which children spend significant time

interacting (microsystem) and their interrelations (mesosystems), events that have important indirect influence on development (exosystem), any group, such as culture, that shares values and belief systems (macrosystem) and the historical circumstances that affect the contexts previously mentioned (chronosystem). The program is also influenced by a transactional model of development [24, 25], in which development is regarded as the product of a continuous dynamic and bidirectional interaction between the child and the experience provided by his or her social setting. Thus, it enhances the supple character of the individual and the environment. Building on this model, in the Developmental Systems Approach, Guralnick [19] defines ECI as a system designed to support family patterns of interaction that best promote child development, while the focus is placed upon parent-child transactions, family-orchestrated child experiences and on the help provided to parents in order to maximize their child’s health and safety.

#### **3.2 The Crucial Role of Early Environmental Stimulation on Brain Development**

The beneficial role of early and proper environmental stimulation is claimed to have positive effects on animal and human brain development [26, 27].

Child development is an interaction of nature and nurture [13, 28]. Hence, it is widely argued that connections that receive stimulation tend to be reinforced, while unstimulated connections tend to be eliminated. Although in early life, there are sensitive periods [26] when neurodevelopmental plasticity has greater capacity for alternative adaptations [13], the plasticity of human brain remains active throughout the life cycle since it is interlinked with the experiences of each person. As being part of the brain, the visual system also possesses a level of plasticity [29].

Increased knowledge in the field of brain development highlights the importance of early experiences in influencing the actual growth and development of neural pathways [30]. What is more, the quality of the environment in which young children spend their early years has a critical influence on their capacity to develop an adequate foundation for later learning, as well as emotional regulation [31]. Recent research on brain development seems to prove that positive rich experiences during early childhood can have positive effects on brain development [32].

#### **3.3 The Crucial Role of Visual Function in Cognitive Child Development and the Importance of Visual Rehabilitation Programs**

In the field of rehabilitation for children with visual impairments there is a wide acceptance that ‘they can learn to see better’ [33]. A number of ECI programs supporting visually impaired children use visual stimulation at visually enhanced environments, claiming to do rehabilitation of residual vision. However over the

years there has been a long debate on which intervention is more effective. Apart from medical interventions and optical aids, there is a debate on whether there is any usefulness for visually impaired children to use their residual vision and which method is more effective. Visual stimulation or visual skills training is addressed to educationally prompt and promote children to use their residual vision in situations that are contingent and concern their everyday routine or their interests according to their age. The visual material is presented in the appropriate light situation, in an accommodated distance for the child, with the manipulation of contrast and color (high contrast) and multi sensorily enhanced [14] in an organized situation that interests and motivates the children.

The method of visual stimulation was long ago criticized by a number of authors, such as Ferell and Muir as cited in Vervloed [34] regarding the ambiguous effectiveness findings of research in visual stimulation programs, while questioning scientific evidence of the practices of such programs.

However, recent studies of magnetic resonance demonstrate a relation between visual function and developmental outcome in infants with brain damage, marking the importance of early support programs for visual functioning to infant development [35, 36]. What is more, research shows that severely visually impaired children are at higher risk of poor developmental outcomes and neurodevelopmental delay [37,38] and that early intervention programs can affect positively all the aspects of development and have a preventative role for secondary disabilities [39, 5].

Apart from that, attention is driven to the context of the visual stimulation. According to Sonkensen the purpose of the visual training is not seeing but looking, making the distinction between a passive process and an active process of cognitive attention. Considering that looking is paying attention and understanding what is being seen, this skill can be acquired by experience and training [14].

#### 4. CONTEXT AND METHODS OF THE INTERVENTION

After the discussion of the ‘educational plan’, the intervention begins. The general principle of the intervention is the contingent stimulation of sensory channels by enhancing the stimulus with multi-sensory elements that interest the infant or child. Non-Invasive “offers” are presented to the child by the early interventionist in order to process different kinds of stimulants, which are multi-sensorily enhanced. In this context, the child is encouraged to actively seek the stimulus in interactive and individually planned games.

##### 4.1 Visual Stimulation-Functional Vision Training and its Context

Following the ophthalmological, optometric and Functional Vision Observation, visual ‘offers’ are given

to the infant/child according to his/her needs and the ‘educational plan’. These offers are provided along with the appropriate light and contrast conditions according to his/her needs, as the appropriate context is believed to facilitate visual attention and learning. The ‘offers’ are stimuli that are presented to the child in the right position to interact with them. The offers can be various visual stimuli from lighted material (see Figure 2) to high contrast toys (see Figure 3). In this context the child is encouraged to actively interact with the stimulus, exhibiting problem solving orientated behaviour, according to the level of his/her development. Special attention is given to the verbal and non-verbal reactions of the child in order to modify the “offer” or to avoid overstimulation.



Figure 2. The early interventionist presents a light stimulus, while the child is trying to reach it.



Figure 3. Hand made toys of high contrast crafted by the early intervention team.

Visual rehabilitation entails all kinds of interventions aimed at recovery of visual abilities, improvement of visual functioning and coping with visual disabilities. Following the inconsistent use of visual rehabilitation terms such as vision stimulation, visual stimulation and visual training, we need to specify the term of visual

stimulation and its context in our program. In this paper, we refer to visual stimulation as a method of stimulating the residual vision of children with visual impairment, aiming at altering their behavior (using their residual vision) and not their physiology. We also refer to visual training as a structured way of training basic visual skills, such as fixation, pursuit movements and saccades, for children with functional vision, in developmentally appropriate ways [34].

In children with low functional vision and other difficulties, the visual stimulation may be at the beginning more passive with artificial material, e.g. high contrast images in a computer or high contrast slides projected in front of the child, lighted material, lights and artificially enhanced toys (see Figure 2). In these conditions the stimuli are presented with the participation of the caregiver (e.g. high contrast slide projections are presented as a story). The long-term aim of this kind of stimulation is to facilitate visual attention to appropriate visual stimuli that could be gradually replaced by more natural interaction. In addition, this kind of stimulation can be combined and integrated with other activities pertaining to body awareness, such as vestibular and tactile and proprioceptive stimulation.

For children with functional vision, the intervention may include meaningful and developmentally appropriate games in order to encourage the child to exercise specific visual skills, such as visual fixation, tracking, scanning and eye-hand coordination. Figure 4 shows a child practicing eye-hand coordination with an adaptive high contrast puzzle.



**Figure 4.** The child plays with adapted puzzle under the guidance of the early interventionist.

Children with higher functional residual vision are encouraged to use their visual and other skills, according to the educational plan, in more natural conditions, during individually planned games which may range from symbolic play and preschool activities to mobility activities and support in daily routine tasks. In Figure 5 a child is trying to balance while she is walking on specific colored path.



**Figure 5.** The child plays a symbolic game where she has to step upon colored cardboards.

#### 4.2 Basic Stimulation and Body Awareness

Tactile, vestibular and proprioceptive stimulation is offered to the multi-handicapped child according to the principles of Basic Stimulation Approach [40] through meaningful activities for him/her in order to ameliorate his body awareness as a context of better perception of visual, auditory and tactual sensory input (see Figures 6 and 7). The caregiver is encouraged to participate in these activities, especially in those that promote caregiver-child communication, such as baby massage. If appropriate, networking is done with the occupational therapist or physiotherapist of the child, or a referral for sensory integration assessment is made in order to better understand the sensory needs of the child.



**Figure 6.** Vestibular and proprioceptive stimulation is offered to the child by the early interventionist.



**Figure 7.** Material for basic stimulation and body awareness employed during activities like baby massage. Objects include tactual balls, vibrated massager, bracelet with bells, and heavyweight pillow amongst others.

### 4.3 Tactual and Auditory Stimulation

Tactual and auditory stimulation and training is also provided in structured activities to the children as means of enhancing other sensory channels of information process, especially in children without functional vision. As in visual perception, the stimulation can take more passive forms for multiply handicapped children, whereas in more functional children it can take the form of structured games with the active participation of the child, such as games of tactual and auditory discrimination, along with principles of orientation and mobility support.

### 4.4 Ergonomic Intervention

The house of the child is considered to form the context of his or her everyday routine, so special attention is given to ways that it could be modified in order to facilitate perception and new learning. The intervention can take the form of suggestions and guidance given to caregivers for creating house modifications, such as forming appropriate light conditions, “crib transformations”, forming of “play corners and spaces visually and tactually enhanced, or implementing transformations that could facilitate orientation and mobility (see Figure 8). Apart from the visit intervention, hand-made toys are also offered to the family, as an opportunity for the child to generalize learning in meaningful and ecologically appropriate ways in his or her daily routine.



**Figure 8.** Ergonomic intervention as applied to a child's playroom. This view shows the wall coating of a special 'hook and loop' textile (for adjusting various toys) and of high contrast appearance. Moreover, a bar is fitted for balance purposes, and a soft floor tiles for safety.

### 4.5 Support of the Caregiver-Infant relation

Apart from the focus on the child, the relation of child-caregiver is considered an important dimension of development. Accordingly, support is given to the caregivers in order to better understand the behavior and the signals of their child and to provide them with emotional support in their parental role. This support can take the following forms: During the visit, the early

interventionist provides the caregiver with the possibility to participate in the intervention's structured activities and to interact with the child in order to better understand its strengths and needs. In these activities the caregiver can observe the structured play of his/her child and to understand his/her needs, with the help of the professional. He can also participate in the activities with the modeling and the guidance of the professional, especially in activities that facilitate their communication. These experiences can be thoroughly discussed later, during the counseling discussion, where additional information is given regarding the strengths and needs of the child as well as the present and the next developmental steps. In the discussion, support is also provided to the caregiver in order to solve problems faced in everyday life due to the child's difficulties. The caregiver support may also take other forms such as accompanying visits to other specialists in order to facilitate their communication (when appropriate). Finally support from a social worker and external psychological support are available by the early intervention team to parents in need.

### 4.6 Networking with other Professionals and Facilitation of School Adaptation

In such a multi-dimensional area such as the visual impairment, interdisciplinary communication is considered essential for understanding the needs to the children. Telephone conversations or visits to the other professionals who treat the child, such as the child neurologist, ophthalmologist, optometrist, physiotherapist, speech therapist etc, are regarded as essential. What is more, facilitation for the inclusion of the child in kindergarten, when needed, can be offered by visits to the school and by collaboration with teacher. The family of the child is considered a central part in this network. The possibility of networking among parents for solving special problems is also provided with informed consent.

## 5. REFLECTIONS ON PRESENT PROBLEMS AND VISIONS

Still, there are a number of problems associated with the lack of legal acknowledgement of the rights of visually impaired children and the under-funding of related programs. What is more there is a lack of professional education in early intervention with visually impaired and multiply handicapped children in the level of undergraduate and postgraduate university degrees. For a home visiting program of ECI with visually impaired and multiply handicapped babies and preschoolers, a wide range of knowledge and skills are required, from different scientific areas such as developmental psychology, optometry, physiotherapy, occupational therapy and counseling. So staff training depends on an ongoing education scheme delivered inside the related departments.

A number of reasons limit the potential research in the field: First of all, it cannot yet be proved via a quantitative research approach that the improvement observed is due to the effectiveness of the program, the maturity of the children or the interaction of other therapies. Second there are methodological problems in designing research due to the very different factors related with the specific population. Nevertheless, an evaluation process of the program, based on parental subjective opinion is being designed for the period 2014-2015.

With the Special Education Act limited referring to ECI (L3699/2008, articles 8,32), Greece still remains far from providing access to the visually impaired infants. Yet, following the recent rise of attention in promoting ECI in Greece, importance must be given to legally acknowledge the rights of visually impaired infants and their parents for free access to supporting services as early as possible, based on availability, proximity, affordability, interdisciplinary working and diversity [2]. What is more, program evaluation needs to be done, concerning the quality of implementation and effectiveness in promoting children's functional vision and other educational targets, while it is also important to evaluate levels of caregiver-child relationship reinforcement with standardized measures. A unifying theory about ECI with visually impaired children needs to be formed along with a consensus on the kind of appropriate early intervention practices that better address their needs. Finally there is a lot to be done for the consolidation of ECI in the field of visually impaired infants with multiple disabilities, namely continuous training of related professionals, establishment of professional standards and the need of relevant inter-service consensus and cooperation, regarding the appropriate support of the visually impaired children and their families.

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