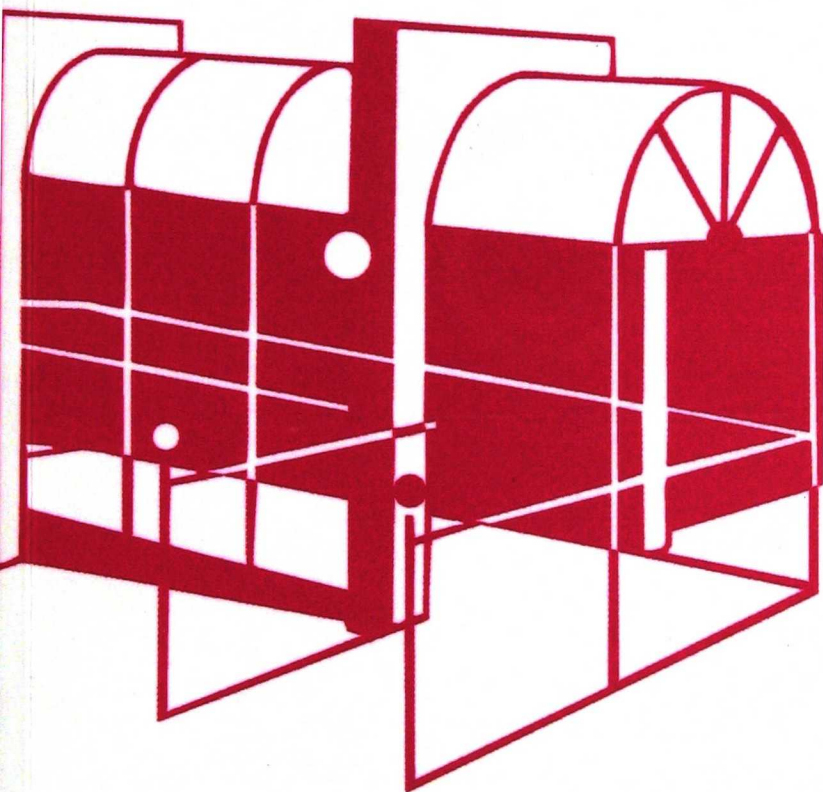


# WHITE PAPER ON EARLY INTERVENTION



MINISTERIO  
DE TRABAJO  
Y ASUNTOS SOCIALES

REAL PATRONATO  
SOBRE DISCAPACIDAD



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ON  
EARLY INTERVENTION**

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## **WHITE PAPER ON EARLY INTERVENTION**

Federación Estatal de Asociaciones de Profesionales de la Atención Temprana (GAT)

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## PREFACE

Childhood development is an extremely complex dynamic process sustained by biological, psychological and social evolution. The first years of life determine a particularly critical phase of existence in which perceptive, motor, cognitive, linguistic, affective and social capacities develop to provide the child with a balanced interaction with its surrounding world.

Early intervention, which is based on the scientific principles of paediatrics, neurology, psychology, psychiatry, pedagogy, physiotherapy and linguistics, etc., aims at offering a set of optimizing and compensating actions for children with deficiencies or who are prone to deficiencies to enable their maturation in all environments and allow them to reach the highest level of personal development and social integration.

Three decades have passed since the appearance of the first early intervention (formerly, early stimulation). It has been shown to be necessary to rely on a corresponding standard which covers the specific problems of the sector and determines adequate planning throughout the state territory.

**The Early Intervention Group (EIG)** has been constituted to draw up a **White Paper on Early Intervention**. This document is intended to be a reference for public administrations, professionals, associations and families to overcome the lack of coordination and solve deficiencies in organization and resources. The EIG relies on the representation of specialists from various autonomous regions and on the support of the Real Patronato sobre Discapacidad. At the same time, it has received support from the Spanish Confederation of Organizations in favour of the Mentally Disabled (F.E.A.P.S.) and Fundación ONCE, among others.

There are great differences in matters concerning early intervention from one autonomous region to another, caused by different competence levels transferred from central government to regional governments. While some have a consolidated network of centres, others have not yet implemented the basic infrastructure. The map of early intervention resources has to harmonize territorial differences and operating models, to determine a state sectorization that makes good use of already available centres and creates centres where they do not exist in order to reach all those in need of this type of preventive action and assistance.

The demarcation of competences and responsibilities of various levels of the state and regional governments should be defined and confined within a legal framework which determines limits to competences and directives aimed at organizing the sector. The standards determined by the European administration in this matter should serve as a reference to achieve adequate standards for this new context. Our incorporation into the European Union has brought along a decisive boost to economic and productive sectors, as well as to health care and education. This progress should be used to promote early intervention for it to achieve full approval.

Regional administrations should achieve a high degree of efficiency in planning, in the rationalisation of management and in finance, identifying regional needs for early intervention and supplying the required resources to guarantee the most adequate response for children in need. Furthermore, they should be receptive to scientific advances and to contributions from those who, as professionals, researchers, entities and parent associations, face the specific problems of early intervention in order to assimilate those solutions which improve aspects that remain inadequate.

The funds for financing early intervention centres are insufficient and the economic endowments must be increased to match the corresponding budget allowances in other European countries. We must not forget that many alterations in development can be prevented if they are treated in time. This leads to a substantial improvement of life quality not only for sufferers but also for society as a whole. For this reason, among others, early intervention has great personal, social and economical profitability.

The document refers throughout to *interdiscipline, globality, coordination and quality*. All these concepts cannot be put into practice without the monitoring and coordination of all public and private administrative organizations involved in giving attention to the child as a central topic of intervention and the child's family.

There are no technical or other kinds of arguments for interrupting an intervention due to factors as random as date of birth, economic difficulties of the family, the place of residence or dependence on one area of government or another. Children requiring early intervention have the right to these resources for treatment despite differences between having been born in one autonomous region or another, within the same region or in areas where resources of this nature do not exist. It is a question of guaranteeing the principle of equality of opportunities for a sector of the population that is particularly defenceless and sensitive to the effects of disabilities, of which children presents levels of significant prevalence.

In the current organization chart, the competent fields in the matter of early intervention are: **health care, social services and education**. *A system is needed to regulate and liaise between these three areas, creating a state and regional legislative framework to set up coordination and joint action in favour of the universalization of the early intervention centres all over the state territory*. Accordingly, the organization of early intervention should enable:

- a. The adoption of measures aimed at prevention.
- b. Early detection of risks of impairment.
- c. Intervention as a process leading to maximum physical, mental and social development.

Early intervention cannot be seen exclusively as a field of rehabilitation, of psycho-social intervention or of education, but rather it should be part of an integral process whose final objective is the harmonious development of children integrated in their environment. *To achieve this goal intervention in the sector needs to offer satisfying levels of efficiency and quality*.

The publication of this document should become a reference for all sectors involved in early intervention: institutions, associations, professionals, researchers, parents and whoever else undertakes to guarantee adequate intervention for this community. Therefore, it should be a document for reflection and progress. This is the starting point to achieve action lines that cover the corresponding needs of all children in Spain without exception.

Obviously, the adequate planning of the sector requires a political commitment which, by means of consensus, enables a decisive step towards legislation that serves as a common model which will subsequently develop and adapt to the peculiarities of each autonomous region. Accordingly, a state commission for early intervention or an institute of early intervention must be created to promote legislation aimed at overcoming this historical deficiency. It is a matter of determining the common foundation on which each autonomous region is to define its specific standard. From a first generic regulating state standard onwards, the commitment and regional responsibilities should have a marked efficient and pragmatic approach.

It is necessary to meet the costs of different social and economic sectors created by the country. However, particular emphasis needs to be placed on the need for financing early intervention sectors as it still does not have a budget. Consequently, its financial situation has been insufficiently consolidated, which differs from other neighbouring countries, as early intervention is precisely one of the most profitable long-term actions due to its efficiency, preventive nature and direct repercussion on the present and future life quality of those treated.

Society and administrative systems should be flexible so that the child who presents disabilities or is at risk of suffering them will be offered resources and necessary means for the child-family interaction and for the development of its capacities. Children with problems in their development should have all the rights our society offers and should be protected by the *Universal Declaration of Children's Rights*. Public organisms need to get involved in safeguarding health, social protection and education, coordinating activities to provide an efficient institutional response to said rights, even more so when there are conditions that indicate that those affected are unprotected and in a situation of inferiority.



The vagueness of the standards and competences maintains this strategic sector in the middle of nowhere, while it is trying to ensure that resources and suitable interventions to overcome disabilities are within the reach of the entire population of mentally disabled children. We should remember that the *Spanish Constitution* delegates in public authorities the guarantee of rights and equality for all Spaniards. In Articles 27 and 49, said authorities are entrusted to develop a policy of integration and specialized intervention for people in need due to their physical, sensorial and psychological disabilities.

Intervention in the child population at risk of suffering limitations to their process of development will be the best instrument to overcome individual inequality resulting from disability. The achievement of competences particular to the evolution process will place children in a favourable condition to understand and adapt to their social and natural environment.

The moment has come to think about and make use of experience to determine the future bases of early intervention. It corresponds to defining the rights and duties of the users of these centres, to determining the outline of organizational and functional procedures, optimizing resources, contrasting models, research, reinforcing prevention and introducing significant improvements in the treatment given to children in need. This White Paper, the result of vast and detailed work, should serve as a guide to focus efforts to pursue the improvement of early intervention and the life quality of those who need it most.

# 1. DEFINITION OF EARLY INTERVENTION

**By early intervention, we mean joint intervention, aimed at children from 0-6 years old, at the family and the environment, whose objective is to respond as soon as possible to transitory or permanent needs present in children with development disorders or who are at risk of suffering them. This intervention, which should consider the globality of children, should be planned by an interdisciplinary or trans-disciplinary professional team.**

## Early childhood development

Early childhood development in the first years is characterized by the progressive acquisition of functions as important as posture control, autonomy of movement, communication, verbal language and social interaction. This evolution is closely linked to the maturation process of the nervous system, already initiated in intrauterine life and to emotional and mental organization. It requires an appropriate genetic structure and satisfaction of the basic requisites of a human being at a biological and psycho-affective level.

Early childhood development is the result of the interaction between genetic factors and environmental factors:

- **The genetic base**, specific in each person, determines typical development abilities and until today we have been incapable of modifying them.
- **The environmental factors** modulate or even determine the possibility of expression or lack of some of the genetic features. These factors are of a biological, psychological and social nature.

Biological environmental factors include the maintenance of homeostasis, state of health, absence of factors that are aggressive to the nervous system, etc., which are necessary conditions for appropriate maturation.

The interaction of the child with its surroundings is a psychological and social environmental factor and comprises the affective links it determines from affection and stability received when being looked after, the perception of all that surrounds it (persons, images sounds, movement, etc.). These conditions, which are basic human needs, determine the emotional development, communicative ability, adaptation, and attitude towards learning.

In early childhood, the nervous system finds itself in a phase of maturation and of important plasticity. The state of maturation determines a great level of vulnerability when faced with adverse environmental conditions and aggression, where any alteration to the acquisition of typical goals corresponding to the first evolution stages can endanger the subsequent harmonious development, but plasticity also provides the nervous system with a greater capacity for recuperation and a functional and organic reorganization which decreases significantly in subsequent years.

The evolution of children with alterations in their development will depend greatly on the detection date and on the moment the early intervention is started. The shorter the period of deprivation of stimuli, the better the use of cerebral plasticity and the level of sub-normality will be less significant. In this process, family implication is crucial, it is an indispensable element for favouring affective and emotional interaction as well as the efficiency of the treatment.

## Development disorders

Development is the dynamic process of interaction between the organism and the environment resulting in the organic and functional maturation of the nervous system, development of psychological functions and the structuring of the personality.

The development disorder should be considered as the significant deviation of the "course" of development as a consequence of health or relationships which determine biological, psychological and social evolution. Certain delays in development can be compensated or neutralized spontaneously; it is often the intervention itself which determines the transience of the disorder.

### **Biological-social risk**

Children considered as exposed to biological risk are those who, during the pre-, peri- or post-natal period of early development, have been subject to situations which could alter their maturation process such as prematurity, low birth weight or anoxia at the moment of birth.

Children considered as exposed to psycho-social risk are those who live under unfavourable social conditions such as the lack of care or appropriate interactions with parents, family, abuse or negligence which may alter their maturation process.

### **Global character**

On planning intervention, we need to consider the evolution moment and the needs of the child in all fields, not only the deficiency or disability it may present. In early intervention, one should consider the child overall, bearing in mind the interpersonal, biological, psycho-social and educational aspects particular to each individual. Interpersonal aspects should be related to the child's own environment, family, school, culture and social context.

### **Interdisciplinary team**

The interdisciplinary team is made up of professionals from different disciplines where a formal space exists to share information, decisions are to be taken on the basis of this information and common goals are reached.

### **Trans-disciplinary team**

The components of the transdisciplinary team acquire knowledge from other related disciplines and incorporate their discoveries into their practice. Only one professional of the team assumes the responsibility of the intervention and/or direct contact with the family.

## 2. AIMS OF EARLY INTERVENTION

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The main objective of early intervention is for **all children who present development disorders, or are at risk of suffering them; receive everything considered preventive and care-related following a model that considers bio-psycho-social aspects. This can boost their capacity for development and wellbeing and enable them to integrate into the family, school and social environment in the most complete way. It also affords them personal autonomy.**

Early intervention should reach all children who present any kind of disorder or alteration in their development, be it of a physical, psychological or sensorial nature, or when they are considered to be in a situation of biological or social risk. All action and intervention has to consider not only the child but also the family and its environment.

From this wide framework, the following joint objectives typical of early intervention are deduced:

1. Reduce the effects of a disorder or disability in the whole global child's development.
2. Optimize, as far as possible, the child's course of development.
3. Introduce the necessary compensation mechanism, elimination of barriers, adaptation to specific or associated needs.
4. Avoid or reduce the appearance of secondary effects or disabilities produced by a disorder or high risk situation.
5. Attend to and cover the needs and demands of the family and the environment in which the child lives.
6. Consider the child as an active subject of intervention.

### 3. INTERVENTION LEVELS IN EARLY INTERVENTION

The need to determine relations with programmes and services acting within the context of the child and its family is the result of the bio-psycho-social model of early intervention. Early intervention centres and services should carry out their interventions in an attempt to coincide with the social efforts made by other sectors of administration and the community who are working in health, education and social welfare. There are three levels on which this collaboration should be based.

#### **Primary prevention in health (\*)**

Health care and intervention, aimed at the promotion of the welfare of the children and their families, correspond to primary prevention. They are universal measures whose objective is to reach the entire population. They contain rights such as health assistance, maternity leave or situations of adoption or fostering. The rights generated by the Law of Conciliation of Family and Working Life can also be included in this level.

At this level, early intervention is aimed at identifying and pointing out to social institutions, the circumstances related to the preparation of universal standards and rights in the field of promotion and protection of childhood development. The correct universalization, gratuitousness and precocity of early intervention claimed in this document, would be a very significant measure of primary prevention.

#### **Secondary prevention in health**

Secondary prevention is based on the early detection of illness, disorders or risk situations. It is complemented through special programmes aimed at identifying communities in risk situations, such as premature babies under 32 weeks old or weighing less than 1500 g, family units with adolescent pregnancies under 18 years old, at risk of relationship malfunction, family units with pregnancies from 35 years old onwards, with risk of chromosomal abnormalities, children with spastic quadriplegias and the risk of hip dislocation. The annexe details the most relevant risk factors.

Epidemiological research allows us to identify the risk communities which are to be the object of special attention, including a social alert system, such as early detection awareness campaigns for professionals of different networks and for society, as well as intervention protocols for each and every community included in the programmes. In most of these protocols, especially when the risk factors are directly related to development, the participation and intervention of early intervention services will be necessary.

#### **Tertiary prevention in health**

Tertiary prevention corresponds to actions aimed at solving situations identified as bio-psycho-social crises. Examples of these situations include the birth of a child with a disability or the appearance of a development disorder. The social implement to avoid this crisis becoming profound and to find solutions is precisely the task of an early intervention service, which assumes the maximum responsibility for activating a reorganization process working with the child, the family and the environment in which they live. In some cases, a new balance can be achieved more or less rapidly, but in others, a long time could be needed to overcome the situation where the family or personal projects are affected by limitation of the possibilities of movement, communication, and autonomy of a family member. The complexity of these situations will make the intervention of an interdisciplinary team necessary.

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(\*) Health has been defined by the WHO as a state of complete physical, mental and social wellbeing and not only the mere absence of disease or pain. (World Health Organization. Regional Office for Europe: HEALTH FOR EVERYONE, 1985)

### 3.1 PRIMARY PREVENTION IN EARLY INTERVENTION

The aim of primary prevention of disorders in childhood development is to **avoid conditions that may lead to the appearance of impairments or disorders in childhood development.**

The social competences that take priority in this action are those of health care, social services and education. Other departments such as labour and the environment also have important responsibilities in this field.

COMPETENCES OF HEALTH CARE SERVICES are programmes for family planning, pregnant women, mother-child health care, detection of metabolepathies and vaccines, information about risk factors and their prevention, primary paediatric attention and hospital and health actions in general.

It has been action in this field that has permitted the practically total eradication of poliomyelitis, a drastic reduction of certain intrauterine infections, elimination of infantile cerebral paralysis as a result from RH incompatibility, early detection and treatment of certain metabolepathies, etc. The most recent advances are avoiding HIV in the foetuses transmitted by an infected mother. Paediatric services in early intervention, used by the entire population from birth up to 14 or 18 years of age, occupy a special place in the prevention of development disorders or risk situations as they are aimed at all children, by means of regular check-up programmes and child health controls.

Monitoring programmes of children at high risk of presenting neuropsychosensory disorders, carried out from neonatal units, paediatric and child neurology services, are specifically aimed at particularly vulnerable groups of children.

The child mental health services have an important role in primary prevention, collaborating with health and family planning teams in mother-child programmes which should help to avoid, on many occasions, the appearance of risk situations. These services also participate in the preparation of recommendations and in the adoption of measures to encourage mental health in general and to reduce the child's exposure to situations of psycho-social deprivation.

COMPETENCE OF SOCIAL SERVICES. These are the interventions aimed at the prevention of social risk situations and abuse, by action or omission, affecting the minor. The action of the social services is often based on attention to the family. These programmes which consider the whole family, are especially relevant because of the prime importance of the family in the child's wellbeing and development. Said mother-child centres are orientated along these lines.

Social services also intervene in a special way in the prevention of disorders in childhood development through programmes aimed at groups in risk situations due to social conditions such as adolescent mothers, immigrant population, etc.

COMPETENCE OF EDUCATIONAL SERVICES. These are support actions aimed at the child and its family from primary schools, used by the majority of the population from the age of 3 years, some even earlier. The task of these centres in the prevention of development disorders can be fundamental for the population at high risk as they offer a stable and stimulating environment to a sector of children which often suffers from adverse conditions within the family.

An important level of preventive action from education services takes place through the formation of secondary school, further education and vocational training pupils, in the field of health care, education and society, and especially in family planning.

CHILDHOOD DEVELOPMENT AND EARLY INTERVENTION CENTRES should participate in primary prevention, collaborating with information/training campaigns for the general population in aspects related to childhood development and also as part of their work with children affected by permanent disorders, by avoiding the appearance of additional pathologies.

### 3.2. SECONDARY PREVENTION IN EARLY INTERVENTION

The object of secondary prevention in early intervention is the **detection and early diagnosis** of development disorders and risk situations.

#### DETECTION

The detection of possible alterations in childhood development is a fundamental aspect of early intervention as it will activate the different mechanisms available in the community. The sooner the detection is carried out, the greater the guarantee of preventing added pathologies, achieving functional improvement and enabling a closer adjustment between the child and its environment.

The **early detection** of disorders in childhood development represents an essential step to diagnosis and to therapeutic attention. Early detection is fundamental to a phase in which the plasticity of the nervous system is greater and therapy is at its most efficient. Childhood development disorders must be detected the moment the first indicative signs appear, if possible, before the different syndromes are completely structured. The detection of alert signals which represent possible indicators of childhood development disorders should be present in the daily work of all those who work with children.

Detection should be followed by the initiation of the diagnosis process and therapist intervention, but there is a series of circumstances which often prevents or avoids detection and diagnosis of development disorders, especially cognitive and emotional psychopathologies in the first years of life:

- Trivial and contemporizing tendencies leaving the therapist in a situation of apathy when faced with problems that deserve serious attention and assessment.
- Reduction tendencies which lead to incorrect interpretation of atypical behaviour in children, attributing them exclusively to disabilities or inappropriate parental education, or to isolated physical or biological factors.
- Fear or resistance to starting up a diagnosis and therapeutic process so as to avoid labelling too early, even if the existence of problems is admitted.
- Unawareness of the existence of early interactional or relational problems and the denial of psychological suffering of the child.
- The need to create specific detection programmes and the elimination of risk conditions.

All these factors contribute to the fact that a great number of children who present problems in their development are not being detected and that an aggravation of their dysfunctions and conflicts may occur as they have no access to the therapeutic help they need. Ignoring alert signs and early symptoms of psychopathology may lead to them organizing themselves in more structured ways such as autism, psychosis, deficiency processes, states of depression or early evolution disharmonies.

The detection of development disorders or risk situations involves various phases and agents.

#### Prenatal phase

##### Obstetrics services

Secondary prevention of disorders in childhood development should start in obstetrics services, with particular attention to pregnant women by health professionals (obstetricians and midwives), who are responsible for the detection of risk situations, and who are also expected to give information, support and orientation to future mothers. When appropriate, the derivation of or coordination with services specialized in attention to pregnant women at a high biological, psychological or social risk is applicable, providing the necessary health, social and psychological help.

In the prenatal phase, various risk situations and conditions can be detected:

- a) Presence of an alteration that will lead to a development disorder and/or subsequent disability: spina bifida, chromosomal abnormalities, phocomyelia, etc.
- b) Characteristics or circumstances present in the foetus or in the mother which are often associated with development alterations: certain structural alterations of the central nervous system, maternal infections, etc.
- c) Conditions of high biological risk: family records, maternal health factors or age, pregnancy conditions, etc.
- d) Conditions of high psycho-affective risk: adolescent mother, mental disease of parents, scarce family resources, multi-problematic families, etc.

The detection of biological disorders associated with subsequent disability, detectable in the prenatal phase is an interdisciplinary function in which gynaecologists, obstetricians, geneticists, biochemists and paediatricians collaborate closely to offer the family broad information about the situation, prognosis, prevention possibilities and possible interventions. Information to the family about possible consequences, therapy resources, etc. should be given early and be as objective and as complete as possible so that the family can decide their option freely.

When a prenatal diagnosis of impairment is made and the pregnancy is continued, psychological care must be given to the parents, especially to the mother. Owing to the alteration, the mother or child may suffer when being informed about the diagnosis. These circumstances suppose a risk factor for the parental adaptation to the newly-born in the neonatal phase.

When the prenatal deficiency diagnosis is followed by an interruption of pregnancy, preventive psychological support to the parents should also be provided about possible future pregnancies.

### Perinatal phase

#### **Neonatology services**

In Neonatology units or services, **children at high risk of presenting impairments, disorders or alterations in their development**, receive intervention in regard to certain genetic conditions or adverse biological or organic situations: intrauterus infections, low birth weight, hypoxia, cerebral haemorrhages, postnatal infections.

The necessary stay of these children in the neonatal unit, often requiring intensive care and prolonged isolation in an incubator, adds other risk factors of an environmental and psycho-affective nature. Environmental stimuli most frequently include noise excess, intensity and exposure time to intense light, immobilization, etc. In the psycho-affective field, there are also limitations and, on occasions, a lack of contact with parents, with inappropriate social stimulus due to the presence of multiple carers, hypo- or hyper-stimulation conditions associated with the needs of care, controls, tests, etc. It should be considered that even when contact with the parents is possible, the adaptation to the child's needs or possibilities is difficult or limited due to their emotional block and alteration.

During the period of permanency in the neonatal unit, it is often not possible to determine with any certainty the future evolution of the child, but it is possible to determine the risk condition and the need for evolution monitoring.

### Postnatal phase

#### **Paediatric services**

Through the child's regular visits in the first years of life and child health control programmes, the paediatric team, should be, without any doubt, the main agent in early detection. Direct observation of the child and the information provided by the parents in an interview about their concerns and aimed at obtaining the most relevant details, leave room for the confirmation of normal childhood development or to the determination of a situation suspect of deviation.



This detection level is fundamental as children with serious problems in their development have a high proportion of pre- or perinatal pathology records and there are often specific monitoring programmes they should assist. Only a minority of children with slight problems in their development have perinatal records and therefore the majority is not included in specific monitoring programmes. Detection in these cases should be carried out within the framework of regular paediatric visits.

Appropriate evolution monitoring of children in general should lead to an appropriate detection of development disorders as signs and deviations become evident and enable the identification of the corresponding disorders in the first years.

- a) During the first year, most of the more serious development disorders can be diagnosed: severe and medium forms of cerebral palsy, mental handicap, sensory deficits.
- b) During the second year, moderate or slight forms of the previous disorders can be detected, as well as those corresponding to the spectrum of autism.
- c) Between two and four years, language disorders and delays become evident. Minor motor disorders and behaviour disorders, often already present in previous phases, become more evident and are a reason for a visit.
- d) From five years old onwards, slight mental disability, slight motor malfunctions, dyspraxias, etc. become evident if they have not been detected previously, as is possible and considerable, causing learning difficulties at school.

Already from the first months and during the first years, the appearance of emotional and relational alterations is possible, together with early interactive malfunctions which are often expressed through psychosomatic alterations in sleep and nourishment.

An important function of early intervention and childhood development centres and of child mental health teams consists of their support for primary teams in the task of detecting childhood development disorders in different fields.

The coordination and development of joint programmes is important to enable health professionals to detect the disorders that often are unnoticed or misinterpreted in their first phases, such as generalized development disorders, significant interactive malfunctions in the relation between parents and children, somatic expression disorders or slight mental disability.

### **Educational services**

When the boy or girl attends school, teachers and educators are an important agent of detection. In this phase, problems in ability and basic learning behaviour can be appreciated: motor skills, socialization and language skills, attention and perception difficulties and emotional or cognitive limitations which had not been detected previously.

The conditions of nursery school and the interaction produced in the school context, different to those in the family environment, generally reveal the presence of deviations in the evolution process, maladjustments in the psycho-affective child's development and/or alterations in behaviour which, due to their own character or to the minor nature of the disorder, can easily pass by unnoticed by parents and health staff, and not be detected until the child enters the educational context.

When the educator or teacher detects the possible presence of a disorder, he communicates his concern to the family and from the information provided by the school environment and family, coordinated guidelines of observation and intervention should be determined, as well as appropriate recommendation and consultation of the

child's paediatrician and to the early childhood development and early intervention centres to determine a complete diagnosis and to initiate the appropriate therapy.

A social risk situation, inappropriate attention, lack of affection and suspicion of child abuse can also be detected in the school environment, where coordination with social services professionals is fundamental.

### **The family environment**

The family environment undoubtedly represents an important method of detection because, on many occasions, it is the parents themselves, or people close to the child, who, by daily interaction with the child in its natural environment, may observe that there is a difference or deviation between the behaviour of their child and that of other children. Greater attention and information to parents would be an element which would undoubtedly enable early detection of development disorders, as well as greater availability of time on behalf of the paediatrician who receives the parents' visits to assess the child's development and give an appropriate answer to their possible concerns.

### **Social Services**

Social services, from their relation with the families with psycho-social problems and with the community in general, find themselves in an excellent position to detect social risk factors for childhood development such as situations of very low economic family income, adolescent mothers, drug dependency, social exclusion, etc.

### **Other health services**

Frequently, children presenting unidentified development disorders make their first visit to other health services and are sent to a specialist. These visits offer the opportunity to recognize the existence of a global disorder in the child's development, of which the symptom for which he/she has been sent is an element. These health professionals will send the family to the childhood development centre and/or hospital of reference for a complete diagnosis of their problems and to begin therapy.

## **DIAGNOSIS**

The diagnosis of an alteration in development consists of the evidence of an alteration in development as well as recognition of its supposed causes, enabling the understanding of the process and the initiation of appropriate therapy.

Faced with the suspicion of a childhood development disorder, a wide diagnosis must be suggested to consider different fields and levels because the problem the child presents is, in most cases, multiple, affecting different areas and of a multifactorial origin; the interaction of genetic factors, health aspects, psycho-affective care and general environmental conditions.

The diagnosis of difficulties the child presents will be the result of considering various partial diagnoses, identifying main and secondary diagnoses.

### **Areas of diagnosis**

Diagnosis in early intervention should include biological, psychological, social and educational fields, with the collaboration of professionals from different disciplines and fields: medicine, psychology, pedagogy and social sciences.

### **Levels of diagnosis**

In the diagnosis of development disorders, 3 levels of diagnosis should be considered: functional, syndromic and etiological.

### Functional diagnosis

Functional diagnosis presents the qualitative and quantitative determination factor of the disorders or dysfunctions. It presents the basic information for understanding the child's problems, considering family interaction and that of its cultural environment, its abilities and their possibilities for development. Functional diagnosis is essential for the preparation of the aims and strategies of the intervention.

### Syndromic diagnosis

Syndromic diagnosis is presented by a set of signs and symptoms which define a certain pathological entity. Identification of a syndrome or medical profile, often allows us to know which are the responsible structures of the disorder (neurological, psychological or social) and it offers clues to its etiology.

Syndromic diagnosis offers information about the environments about which we should obtain more information to determine the etiological diagnosis and it helps to determine if we are dealing with a stable, transitory or evolution pathology, with a predominant organic or environmental base.

### Etiological diagnosis

The etiological diagnosis tells us about the biological or psycho-social causes, about functional disorders or about the identified syndrome. In any event, we will try to determine the etiology of the different identified disorders, always in consideration of their multifactorial nature, in a wide approach that considers biological, psychological, educational and general environmental aspects.

Often, and with certain problems such as disorders of the autism spectrum and language disorders, the etiological diagnosis cannot be carried out with absolute certainty, but in all cases we will try to determine a supposed diagnosis.

In most cases, the delimitation of organic etiology needs appropriate tests complementary to a diagnosed hypothesis, although it is important to consider that the normality of said tests does not indicate the absence of an organic base of the disorder.

To define relational etiology when situated in environmental conditions requires an appropriate knowledge of the social conditions, early links, family organization and expectations, etc.

Functional diagnosis presents the essential base for therapy planning: syndromic and etiological diagnoses provide the family with biomedical information and, in some cases, specific treatment.

Evolution monitoring is fundamental to confirm an initial hypothesis for a diagnosis.

### **Communication of diagnosed information**

Diagnosed information to parents when faced with a risk situation or before the probable presence of a development disorder of their child, presents a very important issue for early intervention. Informing the parents of the possibility that their child presents a disorder or disability generates a significant emotional upset, with anxiety and anguish, fears, feelings of rejection and denial, initiating a mourning process that is different in each family and for each family member.

Families stress the importance of the way in which diagnoses are communicated to them, making it necessary to be careful with the whole information process and with the ways in which they are carried out.

Good information makes it possible for the family to reach a better understanding and assimilation of their child's reality and to enable them to adjust their environment to the psychological, mental and social needs and possibilities of the child.

It is recommended that the father and the mother receive the diagnostic information simultaneously after having seen and, if possible, having had their child in their arms.

The professional or institution must have a reserved place so that the meeting can take place with the necessary privacy and where the parents can feel psychologically comfortable, share their feelings and offer each other emotional support.

It is important to provide the information, bearing in mind the child's most probable evolution, long term prognostic and therapeutic possibilities, but also considering the fact that each family is different. Different variables must be considered: the personal situation of the married couple and of other family members, aspects of the family institution, their network of relationships, economic situation, number of children, origin and cultural projection, etc. Diagnostic information must be adjusted to this reality considering not only the child's reality but also that of its family and social environment.

It is convenient to consider the information situation more as a process rather than a specific act. The diagnosis entails uncertainties towards the future, disorientation regarding the present or feelings of fault regarding their past actions. It will be necessary to offer the possibility of new interviews in which parents can clarify all their doubts and express their fears and concerns.

As far as the information itself is concerned, *a direct approach is recommended, avoiding difficult technical terms*, offering, where appropriate, a translation to terms adapted to each family. It is convenient to carry out a *global expression of the problem* profile instead of creating an exhaustive catalogue of present and future problems. The diagnostic process tends to be *descriptive and functional* and on information about a certain alteration or injury, a functional meaning of the injury will determine the implicit diagnosis.

*A well-defined diagnostic profile* reassures, even if the diagnosis and prognosis can be considered serious. Maintaining doubts about the child's future, sometimes an inevitable situation during the first years of life, when an intervention is initiated without absolute diagnostic certainty, can create anxiety, but this situation may be less harmful if specific terms for its solution are determined, avoiding contradictory information and undefined, unjustified expectations. As the prognostic or functional diagnosis settles, the family gains a more precise idea about the immediate future. This will enable their reorganization, the taking of decisions and the distribution of new roles and tasks which will make it possible to overcome the situation. Once parents know and admit the existence of an important irreversible disability, such as deafness or blindness, it will become easier for them *to find communication and relation alternatives* than when they maintain recovery expectations removed from reality. It would be good to point out the importance of resorting to good sense before making statements which may unjustifiably open or close the horizon of the child and its family.

It is convenient for there to be a *permanent professional* who fulfils the function of companion in the *diagnostic process*, although on some occasions his role is limited to being present while other professionals speak with the family. This person should be in contact with those professionals who are going to attend the child so as to follow the communication and information in a correct and coordinated way.

The information of a disorder diagnosis should always be accompanied by information to the family about the different therapeutic, social, educational, economic resources etc. available in the area and about how to access them, as well as about the existence of parent associations. It is important to guarantee the coordination between professionals and institutions and to be able to offer companionship throughout the development process.

In fact, with the diagnostic information, the first transition takes place in the family, possibly the most important one because the capacity to receive and give appropriate answers to the needs and characteristics of their new family member, depends on it to a great extent.

Great responsibility falls on the professionals who transmit the diagnostic information to the parents. He/she should have appropriate training and experience in this issue, being prepared to understand, tolerate and

restrain various feelings that may be produced in the parents as well as taking charge of his/her own feelings (anxiety of the professional before a pathological diagnosis), to be able to maintain the necessary emotional distance transmitting to the parents pondered and real information and, at the same time, understanding and support.

### **3.3. TERTIARY PREVENTION**

Tertiary prevention groups together all activities directed at the child and its environment with the objective of improving the conditions of its development. It is directed at the child, its family and its environment. With this, one should diminish or overcome disorders or malfunctions in development, prevent secondary disorders and modify the risk factors in the child's direct environment.

The intervention aimed at children who present development disorders should be initiated the moment deviation in their development is detected at a neonatology unit. Since there is a period of hospitalization in the neonatal phase, intervention is already initiated in that particular unit .

When detection is carried out through paediatric visits, at primary schools or by parents, intervention starts at childhood development and early intervention centres or at early intervention units which give continuity to intervention when this has been initiated in the neonatal unit.

Another fundamental objective of intervention is for the family to learn about and understand their child's reality, its abilities and limitations, acting as a stimulant for the child's development, adjusting its environment to its physical, mental and social needs, securing its wellbeing and facilitating its social integration.

Intervention should be planned in a global and interdisciplinary way, considering the abilities and difficulties in different fields of development, its records and evolution process as well as the possibilities and needs of the other family members and the resources available and the knowledge of and action concerning the social environment.

When the child attends primary school, this will offer important possibilities for positive influence on socialization and learning processes, acting as reinforcement to the specific therapeutic process which is why determining appropriate coordination is fundamental.

## 4. MAIN ACTION FIELDS

### 4.1. CHILDHOOD DEVELOPMENT AND EARLY INTERVENTION CENTRES

**Childhood Development and Early Intervention Centres (CDEIC)** are regional services whose aim is the intervention in children from 0-6 years with development disorders or at risk of suffering them.

These interdisciplinary centres appeared in the 1970s and have undergone constant evolution throughout their history, adjusting to increasing demands for intervention from children and their families. This process has been motivated by a better detection and diagnosis of different development disorders, and by its multifactorial origin; both factors have emphasized the capital importance of early intervention.

Creation and evolution of the CDEICs have run parallel to the existence and orientation of other services and institutions which from health, social, and educational fields in autonomous regions have given and give answers to certain groups or to their specific needs. This adjustment and the diverse administrative dependence have generated different CDEICs, even if the same objective is maintained: the provision of necessary intervention for all children with development disorders or malfunctions (without exception due to origin, type or grade) or who are in a biological, psychological or social risk situation.

The CDEIC model mainly covers intervention for children with diverse development pathologies or malfunctions, and the intervention needs for those children who have been or are in a biological, psychological and social high risk situation.

In certain communities or geographical areas, depending on their history and care resources, some groups of children with specific development disorders are attended either in CDEIC or in early intervention programmes or units constituted with other services or centres, such as certain child mental health centres, motor disorder rehabilitation centres and centres for intervention in people with auditive or visual disability. All of them with characteristics very similar to those of the CDEICs.

The CDEICs must be located near the families and situated close to other early attention services, such as health or social service centres or primary schools. This enables the relation between the different professional agents, knowledge of the children and their family's natural environment and of the social and economic reality of the families in the community.

When the CDEICs share their location or premises with other resources, it is important that they are well differentiated for correct identification.

**The CDEIC team** will be multi-professional, interdisciplinary and of holistic orientation, considering that the intervention covers biological, psychological, social and educational aspects particular to each individual, and interpersonal aspects related to its particular environment such as family, school and culture.

The team will be formed by early intervention specialists from medical, psychological, educational and social fields.

Apart from the appropriate university degree, the training of professionals will be specialized in early intervention, obtained through post-graduate training cycles. Vocational training is an essential requisite in the tasks carried out by team members.

#### **Primary and secondary prevention**

The functions of a CDEIC include *prevention, detection and awareness tasks*. The Early Intervention Centre will collaborate with institutions, associations and with other professionals of the area in drawing up pro-

grammes whose aim it is to make the general population aware of prevention aspects related to childhood development.

### **Programmes aimed at families and future parents**

All activities aimed at providing better information and orientation to families and to the general society are covered here in order to avoid the appearance of deviation of the normal child development.

- Awareness programmes aimed at the fertile population. Pregnancies among adolescents and populations identified as high risk.
- Information programmes about the normal child development to families and future parents at primary attention centres (health and family planning centres), social services, playschools and primary schools.

### **Programmes aimed at professionals**

These programmes offer practical information to the professionals in a privileged situation due to their relations with parents. The objective is that they can be the first agents to promote the health and education of the child, as well as the detection of possible alterations in normal development. They are aimed at:

- Health professionals.
- Social services professionals.
- Child education professionals.

### **Tertiary prevention**

Intervention will be planned and programmed individually, considering the needs and possibilities of each child in each development area, the situation and possibilities of its family and those of the school environment. The programme will include the temporariness of the objectives, the methodological discipline and assessment of the proposed objective or the result of the applied programme.

Intervention in the early intervention centre starts when an application is received from the family or any other professional or institution. This intervention consists of different moments: initial assessment, therapeutic intervention, monitoring, control and derivation.

### **Initial assessment process**

The initial assessment process involves a profound global study of the child's development, its individual and family record and its environment.

For correct, complete assessment, collaboration of the professionals from different disciplines in the team, or the collaboration of those who participate in exploratory or complementary tests will be needed.

In the initial assessment, we can distinguish the following four moments: collection of information, assessment of the child and its environment, preparation of diagnostic hypothesis and preparation of an intervention plan and a return to the family interview.

#### **1. Collection of information**

Undoubtedly, the appropriate collection of information represents the most important element of the diagnosis process. We obtain information through the reception, systematic collection of information and contributions from other professionals.

### 1.1. *Reception*

The first contact with the family represents the reception, a moment in which the professional, through an attitude of listening, collects the concerns, memories, projects, expectations and difficulties parents reveal regarding their child and themselves, as well as the child's personal and family records.

Apart from being a very important working tool to carry out the initial assessment, the reception interviews determines the first guidelines to intervention design.

### 1.2. *Systematic collection of information*

Based on the reception interview information, the details the family have not provided spontaneously but are necessary for an appropriate understanding of the child's development and its evolution moment, as well as for the possible alteration causes in the process, are collected on a systematic basis.

### 1.3. *Information from the professionals*

Through written reports or interviews, information from other professionals who are familiar with the child and its family are obtained. Said professionals include the paediatrician, school psychologist, educator, social workers, etc.

The information is organized into a common record so that a professional who needs to contact the family can see the previously provided information and avoids requiring information that has already been provided.

## 2. Assessment of the child and its environment

For the assessment, we have different instruments which are used accordingly with each child based on the first hypothesis in the record:

- Observation of the reactive and spontaneous conduct when faced with certain situations and stimulus. Relation to own parents and to the professional who carries out the assessment.
- Relation to other children and to the educator when the child is in school.
- Physical check-up and neurological and functional assessment of the child.
- Standardized tests.
- Observation at home.
- Complementary exams, specialized consultations.

The application of these techniques will provide us with information corresponding to the general and specific functioning of the child, at a physical, mental or emotional level. This information will reflect not only the possible limitations and disabilities presented by the child but also the whole of its abilities and possibilities.

## 3. Preparation of diagnostic hypothesis and intervention plan

When the collection of information phase has concluded, a meeting is held where each professional provides details and conclusions on his/her assessment to jointly determine, bearing in mind all bio-psycho-social factors, a diagnosis hypothesis at three levels; functional, syndromic and etiological, as defined in the previous chapter.

The needs of the child and the family are determined, together with the resources available in the community. It is important to determine action priorities, possible short-average and long-term prognoses. Objectives of therapeutic intervention are specified, ranked and temporized, determining the professional or professionals responsible for carrying them out. This first therapeutic plan will be subject to the opinion and possible new elements the family may provide in the return interview.



#### 4. Return interview

In the return interview we offer the parents the diagnostic information prepared by the team, for which all the considerations presented in the previous chapter and in the paragraph *Diagnostic information* are taken into account.

The main objective of the interview will be to offer the parents all information they need to understand the present situation of their child, possible future expectations and therapeutic means we are able to provide for them as well as for the child at the centre, offering our support and solidarity, using an appropriate language they can understand. The intervention plan will be proposed and determined in accordance with the function or functions parents can assume. The probable prognosis and the possibility of recurrence of the disorder are considered.

#### **Therapeutic intervention**

The intervention groups all activities aimed at the child and its environment to improve its conditions for development. The action field and the intervention discipline are determined regarding the age, characteristics and needs of the child, type and degree of disorder, the family, the team itself and the possible collaboration of other resources of the community.

Intervention is planned and programmed globally and individually, creating specific guidelines adapted to each child's needs and each family's needs in each development field.

The programme should include temporization of objectives as well as assessment and ways to achieve them. Therapeutic early intervention is aimed at the child, the family, the school the child attends and the general social and institutional environment.

#### Child care

Once assessment is finished, every child has an individualized and global intervention programme with contributions from various professionals in the service.

Whenever possible, this programme is carried out with the parents' participation, which allows them to discover their own resources and at the same time, reinforce the relation with their child, a very important aspect for its maturing and affective evolution.

As for the child's needs and those of the family, the intervention can be carried out at the CDEIC, at home or at other places such as the educational centre or the hospital in the case of a new-born or infant who, due to its problems, is obliged to be hospitalized for long periods. The professional or professionals in charge of the intervention count on specific training regarding the type of disorder the child suffers.

The number of sessions and the duration of each of them depends on the child's needs. In some cases, depending on age and characteristics, treatment can be carried out in reduced groups, with a maximum of three or four children.

#### Family care

One of the tasks corresponding to a CDEIC is to be aware of the family's needs (parents, brothers and sisters and other members) and to suggest what kind of intervention or interventions may be the most efficient to give a coherent answer. The purpose of intervention with the family should be to help the parents think about and adapt to the new situation, offering them the possibility of understanding the global situation better, avoiding the consideration of the problem exclusively focused on the child's disorder. All this favours the positive attitudes of helping the child, interpreting the child's conduct in regard to its difficulties and trying to re-determine feed-back in the parent-child relation. Each family should be helped to adapt their real expectations and possibilities to the inter-

vention and to correctly situate, from the beginning, the role that corresponds to the professional and the protagonist they should also assume.

The attention to the family can be carried out individually or in a group, depending on the situation and needs of the moment.

As a priority, individualized intervention has the capacity to open a space in which professionals, as well as parents, can dialogue and exchange information referring to the child's treatment, home situation and general family or school aspects. This intervention can be the appropriate way for the family to transmit feelings, difficulties regarding their child's disorder or hopes and expectations regarding achieved advances.

It is important for professionals to attend not only the aspects related to the child but also other family requests, not always easy to manifest, related to the couple's relationship and bonds with other sons and/or daughters and other family members. The purpose is to help them understand their feelings and recognize their responsibilities when it comes to the education of their children.

Parents should be informed correctly of any change related to the intervention such as objectives, methodology or different contacts determined with other health or educational professionals.

In the same way, information should be provided about all administrative resources, and the economic and legal assistance parents can receive. They will be offered the possibility to contact different associations of parents of children with difficulties, available in the community, as well as contact with other professionals or assistance devices.

For all this, plain language should be used, adapted to the social and cultural framework of each family, and respecting their differences.

Group work can be organized as an open space in which a meeting with various parents is possible, giving them the opportunity to express and at the same time, to listen to experiences, feelings and difficulties involved in this situation.

#### Attention to the school

CDEIC should inform the school about the situation of the child and its family at the moment the child starts school. Subsequently, and in collaboration with the school team and educators, spaces can be set up in which pedagogic objectives can be reviewed or discussed, as well as learning strategies and the use of sufficient material or personal resources to accomplish pre-set objectives. It is also appropriate to participate in the decision-taking process about the school category.

#### Intervention in the environment

The intervention, which seeks to overcome physical and social barriers, should be carried out bearing in mind the natural environment of the child to obtain its integration in the social environment in which it lives.

From the CDEIC, strategies are designed to adapt the environment to the child's needs acting in a coordinated way to enable socio-environmental integration. Their purpose is to overcome differences, change attitudes and eliminate physical and socio-environmental barriers to enable active participation of all society members.

#### **Assessment and monitoring**

By assessment, we understand the integral process from which changes in the child's development and its environment take place and the efficiency of the methods used is evaluated. Its purpose is to verify the adequacy and effectiveness of action programmes related to planned objectives.

Assessment should insist on all aspects of intervention and two parts can be considered:

- Continued assessment, which allows the adjustment of the programme to needs and the introduction of relevant modifications.
- Final assessment, which determines if all the objectives set at the beginning of intervention have been accomplished and also to specify if this intervention is considered as complete or if a deviation has to be carried out.

The team should determine the objective and contrastable assessment and monitoring procedures.

## Deviation

The intervention period of a child at an early intervention service finishes when it is considered that due to its positive assessment the child does not need this service any more or when for reasons such as age or competences its intervention should be continued by another care service.

In both cases, the family has the right to receive verbal information and a written report that synthesizes the child's evolution and the current situation as well as the needs considered essential.

When intervention needs to be continued by another team or care service, coordination between both is fundamental and, always with the family's knowledge, information should be transferred appropriately. The moment and form of the transfer should be evaluated and planned carefully, bearing in mind the family and child's link with the previous service.

The change of the professional team should not involve a discontinuity of intervention in the child and the family in any case. Coherence and continuity should be guaranteed from the necessary coordination among professionals and appropriately flexible administration.

## 4.2. HEALTH SERVICES

### OBSTETRICS SERVICES

The important preventive work of these professionals, basically primary prevention, is essential. It is carried out by means of:

- Detection and diagnosis of risk factors before pregnancy.
- Care to the pregnant woman at high biological, psychological or social risk, providing the necessary health, psychological and/or social help.
- The information given at birth preparation visits, where parents receive information about normal child development and needs, as well as about possible alert signs.
- Detection of possible risk situation at childbirth and appropriate attention.
- Spreading of and participation in prevention programmes and disability detection.
- In case of a prenatal impairment, psychological care for the parents, especially the mother, aimed at prevention as a result of the alteration of the mother-child bond.

### NEO-NATOLOGICAL SERVICES

In the neonatological environment, we often find children who are at **high risk** from impairments depending on its prematurity, the consequences of low birth weight or other hereditary and/or pre-natal factors. The incidence of children who at birth pass through a neo-natal care unit is of 10% to 12% and between 3% and 5% of people born are considered to be at psycho-neuro-sensory risk.

This reality converts the neonatological services into an important prevention instrument by avoiding, in many cases, the appearance of impairments in children.

The neonatology service also carries out important secondary prevention work by the detection and diagnosis of pathological conditions, already determined at birth, associated with development disorders, as well as by being one of the main detection sources of high risk biological and social conditions.

During the child's time at the neonatal units, certain signs typical of a disorder in the child's development may appear, leading to a set of actions aimed at initiating the appropriate treatment to eliminate or reduce the effects of the symptoms. Parents play a decisive role here.

It is in the service of neonatology where early intervention should start for children presumed or known to present decreases or development disorders or at risk of suffering them within the population attended in the service. This intervention will be planned, together with the neonatologist in the following fields: clinical, environmental and social.

1. Intervention in the clinical field. They are based on avoiding as far as possible situations which could generate impairments for the child, and on providing those conditions which favour the child and act "protectively".

2. Interventions in the environment. They are directed mainly at taking care of the environmental factors which favour the child's development, controlling as far as possible those supposed to be invasive of its maturity (intense light, noises, constant manipulation, etc.) and bearing in mind the doctor's prescriptions.

3. Intervention in the social field. They are addressed to help the parents or to reduce the effects of a high social risk situation which will affect the child's development.

This set of actions, at the same time, supposes a function or task corresponding specifically to the section of the service's professionals, as well as actions on the family unit, fundamentally on the parents and on the child.

### **Intervention in the family**

Intervention in the family refers to actions addressed to the parents above all. This intervention is a priority, since it is one of the factors which is going to condition the development and evolution of the child. Therefore, the neonatal early intervention programme should be determined on the following objectives:

- Assessment from the very beginning of the emotional state, social situation, needs and learning ability (referring to the care the child needs) of the parents to plan an intervention that provides the most necessary elements and resources in each case.

- Favour the parent-child bond as this will be the best guarantee of wellbeing and appropriate stimulation- This requires free entrance for the parents to the unit at all times so that they can adjust themselves to the child's needs.

- To act as an emotional bridge for the parents, which will allow them to start creating an intrapsychological space to enable them to eliminate anxiety and to start identifying themselves with their child and the delicate cares it needs, sometimes for a long time. This is always necessary due to the early separation of mother and child and the consequent emotional alteration the parents suffer.

- Assessment, at the moment of discharge from the service, of the parents' capacity to respond appropriately to the child's needs and the determined bond quality as this circumstance will determine the adaptation at home, as well as possible readmissions in case of initial anxiety and anguish regarding the child and should its care persist.

- Assessment of its socio-family needs, providing necessary help from the first moments as the socio-family situation of the parents greatly conditions its own emotional balance.

## **Intervention in the new-born**

The intervention in the newborn will be determined by always giving priority to the state of health and the possibilities this state offers in rehabilitation as well as in the preventive field. It will be the state of the child which will condition most of the actions directed at it in early intervention. Therefore, the assessment of the different states typical of the newborn, according to its age should be known by the parents and the professionals, mainly nurses who provide all the care, adapting them to its maturation and its biological and psycho-social evolution.

Basically, all parents need help to interpret internal and external sensations of their child, favouring experiences of wellbeing and satisfaction. These are the interventions considered within the early intervention framework according to the following criteria:

- All professional action on the child should adapt as far as possible to state of maturity, not only clinically, evaluating its states of disorganization, stress or wellbeing to guide the corresponding practice.
- The nursery staff should do a maternal function with the child; this involves empathy, adaptation to its corporal signs in caring (fear, discomfort, wellbeing, etc.) and mutual satisfaction.
- If we bear in mind this maternal function of the nurses, their actions should have criteria of stability and permanence. Therefore, there should be as few staff changes as possible. It is a basic aspect to bear in mind from a health organization point of view.
- Parents have to be made participants in nursing their children within the unit despite the effort and disposition this requires on behalf of professionals.

## **Service discharge**

The moment of service discharge should be programmed considering the biological, psychological and social factors of the child and its family. Clear and precise personal information will be provided to the family about the child's situation and its needs, as well as a written discharge report containing the most essential and clarifying details about the child's clinical and functional state and the intervention it requires.

Information will always be personalized, adapted to the personal and socio-cultural situation of the family for better understanding.

The importance of maintaining the criteria of early intervention within the child units, paediatrics and primary attention should be stressed to give continuity to the intervention, monitoring and control of the child and the family within the neonatology service.

## **Derivation**

When an indication of intervention in a CDEI centre exists, as well as when faced with the social (social services) or school intervention at the moment of service discharge, all determined derivation mechanisms will be used. All necessary information should be enabled for this purpose. The determination of certain collaboration agreements and monitoring programmes and control between health, educational and social institutions, enable this task.

## **Maturity monitoring development units**

The monitoring programmes of children with psycho-neuro-sensory risk in maturation units were established in Spain in 1977 by the National Plan for the Prevention of Sub-normality with the fundamental aim of controlling the development of all children with neuro-psycho-sensory risk as well as children with already determined damage of the central nervous system, to detect as early as possible anomalies in development and to initiate the appropriate treatment.

The concept of the newborn with risk is defined as the child who, as a consequence of its record during

pregnancy and/or birth, has more probabilities to present, in the first years of life, transitory or definitive cognitive, motor, sensory or behavioural development problems. Nowadays, the concept of risk should be extended to the postnatal period and infants because on many occasions the risk factor acts after birth.

For the selection of risk criteria, the guidelines given in 1982 are followed by the Perinatology Committee of the National Plan for the Prevention of Sub-normality, later modified by the Perinatology Section of the Spanish Association of Paediatricians (see Annexe).

The monitoring programmes guarantee that the babies and infants receive the intervention recommended by the Paediatric Associations of our country and by the American Academy of Paediatrics. The children with confirmed or suspected disability should receive care in a system which:

- Recognizes the need for early detection and treatment of the disorders, including the identification of profiles with the probability of causing a delay in development, providing means for early detection.
- Develops a service plan that considers the needs of the child and its family by means of regular interdisciplinary assessments.
- Provides information to parents when there is a suspicion or diagnosis of delay in development or disability and respects the fundamental role of the parents in their child's development and their right to participate in decisions that affect them.
- Promotes and develops community prevention services.

These objectives can be carried out in the hospital framework, creating monitoring units linked to the neonatology and neuro-paediatric services in childhood development and early intervention centres, or in centres from the health, education and social services network in a way in which the child and its family will have easy access to enable the monitoring. The main thing is that this type of attention exists; the situation and organization will depend on the different resources of each community.

The monitoring programmes are included in the secondary prevention of deficiencies as a whole, of activities which, when the intervention takes place in the early phases of life in risk situations or when damage is determined, favour the optimum development of the child

Primary prevention is practised by continued information to the parents, which will give rise to the fact that the action over their child improves in all aspects: knowing their needs and providing necessary help by participation in awareness programmes, which enables prevention and detection.

The monitoring programme enables the **early detection** of development disorders by regular controls and it shows the needs of each family very early, orientating them appropriately.

The monitoring should be carried out by professionals with training and experience in childhood development. One member of the team should be the reference for the family to preserve the global vision of the child, on the occasions it has to be assessed by various specialists. It should be drawn up in a protocol, covering all aspects of the child's development and the care given to the family.

The place where it is carried out has to fulfil various conditions to enable the family to fulfil all controls without having to suffer alteration in the family dynamics.

In addition to development assessment, complementary neuro-physiological, ophthalmologic exams and scanners are carried out for those children who need them. Support has to be given to the family to help them understand the problems of their child, giving them confidence in their actions, offering them true information adapted to their emotional and cultural situation, determining an atmosphere of confidence that presents an appropriate framework for taking decisions.

It is essential for the information to be fluent between the teams attending the child and those to which it is transferred.

## Coordination

Coordination is first determined with the team or centre that moves the child on to a monitoring programme. For those children who have been hospitalized in the neonatal unit, coordination should start with the planning of the hospital discharge. In those cases where the child comes from primary paediatric services, social services, playschools, etc., coordination will be with each one of them.

The fluency of information should be continued between the monitoring unit and the different professionals who have transferred the child and those to whom the child is transferred: childhood development and Early Intervention Centres, reception centres, associations, schools etc.

## PAEDIATRICS IN PRIMARY CARE

The new concept of development paediatrics is very important, dedicated to the maturation process and to three objectives: to promote mental and physical health, to be able to carry out an early diagnosis and an effective treatment and to study the causes of disorders and their prevention. Development paediatrics is an essential part of paediatric practice, carried out in health centres.

The health professionals who have a most regular contact with the children and their families are the paediatrician and the paediatric nurse, occupying a central position in the network of health services, and acting as a reference to parents and to different community services and programmes (pregnancy care and preparation for childbirth programmes, maturity monitoring, sensory screening, etc.). The paediatrician asks for complementary examinations and visits to specialists and/or hospital services, and receives different reports and transmits them to the family from a global viewpoint.

Primary prevention in paediatric care is carried out by health controls of the child health programme, in which the paediatric team acts as the consultant and educator of the families and promotes preventive attitudes to development disorders. His interventions reach the community through parent associations, schools, etc.

**Detection** is carried out through health check-ups of the child, applying screening methods to detect alert signs of development disorders. Paediatricians present an essential level for detection and appropriate derivation of the children towards diagnosis centres, monitoring and intervention. In diagnosis, alone or in collaboration with specialists, the paediatrician is in a position to carry out the first approach of the situation, contributing with the knowledge of the child and of the family to determine or rule out the presence of alterations.

To evaluate a child appropriately, there are sufficiently contrasted observation methods and screening objectives that can be used in daily practice. Observation offered by the family who know the child and are in daily contact with it should be valued and given special importance.

**Coordination** between the paediatrician and the remaining services (health, social, educational, CDEIC, etc.) attending the children in the neonatal unit should start with the planning of the hospital discharge and continue with all other teams attending the child.

Permanent training of staff who carry out detection or risk situations and alert signs of development disorders is fundamental as this concerns paediatric aspects that are still somewhat unknown. Early detection of anomalies or deviations in development and promotion of appropriate actions which enable optimum development are very important. The paediatric team is assigned the task of giving guidelines and advising the families about the most favourable attitudes for the child's development. Nowadays the attitude of "lets wait and see what happens" or "until the child has clear symptoms", cannot be accepted as it is demonstrated that early intervention, when the pathology does not show itself definitively, can improve the evolution course significantly.

A specific aspect of the paediatrician is that, being a professional of reference to the family for years, he has a wide knowledge of the child and its family, which should enable coordination between the different services.

## NEURO-PAEDIATRIC SERVICES

Neuro-paediatric services intervene in early intervention in diverse fields:

- Joint action with professionals of the neonatal unit, concerning the diagnosis and therapy care newborn risk babies need.
- They take part in development monitoring programmes, being part of the team which attends children considered of high bio-psycho-social risk.
- They carry out essential work in relation to the CDEIC to detect alert signs and the diagnosis of neurological disorders. This task can take the form of visits or support services or direct participation in the teams. Neuropaediatrics is one of the most appropriately based medical specialities to form part of the early intervention teams.

The neuro-paediatricians determine the functional, syndromic and etiological diagnosis of children with development disorders and specifically of organically based processes. Access to different complementary examinations from the hospital environment enables the preparation of the diagnosis. In addition to the global care given to the child and to the family, the neuro-paediatrician guides the medical treatment in those processes susceptible of improvement with medicine and special diets.

His active participation in training and teaching programmes to increase knowledge of childhood development and its alterations enables appropriate detection and derivation. Coordination between services that have transferred the child and the centres where the child is to be attended is important.

## CHILD REHABILITATION SERVICES

Rehabilitation services in Spain are linked to three types of experiences:

1. Hospital experience, in which physical therapy actions and treatment of acute pathologies predominate. They result from the demand for recovery of orthopaedic, traumatic and neurological after-effects, registered at hospital institutions.
2. Experiences from social services, including the psycho-social dimension, through personalized programmes as a response to social integration and regional needs of persons with disability. The scenario comprised the network of IMSERSO base centres.
3. Experience resulting from associative movement generated specialized centres of integral and intensive treatment for determined pathologies.

As far as childhood from 0 to 6 years old is concerned, teams of base centres have been a very important part of encouragement for early stimulus and primary care programmes during the last two decades. Their natural destination, in general, has been incorporation into the early intervention networks of the different autonomous regions. Accordingly, the speciality of child rehabilitation has been formed for many years. This is another medical discipline that may be appropriate for forming part of the CDEIC teams.

Where the specific association centres are concerned, in many cases they have occupied the place of intervention centres for children with disability from early childhood onwards.

Concerning health rehabilitation centres, in their actual structure, they specially represent the creation of physiotherapy at primary care health centres, a complementary resource for assessment and treatment of some situations of childhood disability. The orthoprosthesis area, particularly, is a very important competence of these services.



## MENTAL HEALTH SERVICES

The professionals who make up the children mental health units intervene in all early intervention levels.

General prevention resources from child mental health cover:

- Coordination and development of programmes with other services: health, educational, social and judicial services.
- Collaboration with preventive detection of psychological risk factors.
- Participation in training programmes and coordination with other early intervention professionals.
- Teaching and investigation about everything related to child mental health.

The diagnostic process of difficulties in psychological development should be centred basically on observation, analysis and assessment of:

- Symptoms (somatic, behavioural and psychological) of the child and of its mental functioning.
- Parent-child interaction.
- Family environment characteristics.

Therapeutic intervention in child mental health units is a priority, when required, and covers different basic attention disciplines:

- Direct intervention with the child, individually or in a small group, in cases of severe early psychopathology, basically: psychosis, autism, evolution disharmonies.
- Family intervention to enable understanding of disorders, difficulties of the child and the importance of adjustment to its needs at home.
- Coordination activities with other services and related professionals.

When faced with a possible transfer to other CDEI centres, social or school services, it will be necessary to determine collaboration criteria and monitoring control programmes with them.

## OTHER MEDICAL SPECIALITIES

There are other specialities, apart from those mentioned previously, that form part of early intervention, fundamentally in diagnosis and therapeutic intervention. Although they have not been given due importance, the detection work of some of these specialities is worthy of particular mention.

Among different specialities, the importance of **Ophthalmology** or **Otorhinolaryngology, and other orthopaedic surgery** should be stressed. They receive children transferred for specific problems and they can carry out detection of global development problems.

These specialists also take part in the monitoring of the development of newborn risk babies for which regular sensory and neuro-motor control is essential. Another aspect is diagnosis and specific

treatment of those in need. Coordination with other specialists and with the team attending the child, is fundamental and should be enabled through an interdisciplinary structure.

**Radiology, Neurophysiology, Biochemistry and Genetics** are other specialities which frequently intervene in diagnostic processes and the prevention of complications.

They are other medical specialities not mentioned previously, but they are no less important, they carry out their role in early intervention in diagnosis, treatment and transfer.

### 4.3. SOCIAL SERVICES

Bearing in mind the importance of social context and environmental conditions in the existence of a impairment in development or in the risk that it may be produced, social services have a clear function and responsibility in prevention programmes as well as in detection tasks, diagnosis and intervention in all cases where they are required.

Social services and their professionals intervene at each and every early intervention level, and their action in early intervention is considered of vital importance. It is carried out through the promotion of the families' social wellbeing and the preparation of prevention and intervention programmes.

#### **Promotion of family wellbeing**

Social services professionals should watch over the gestation, adoption, upbringing and socialization processes and ensure that they are carried out under suitable conditions for an emotional balance and the cognitive adaptation to these tasks in a way that the principles set forth in the Convention on Children's Rights are applied.

Early intervention has contributed to the acknowledgment of the importance for childhood development of the following factors:

- Affective dedication.
- Economic sufficiency.
- Labour stability.
- Family relations stability.
- Participation in social networks.
- Coherence of educational styles.

The protection of the early relation between parents and their children, should be a social priority. Therefore, it is necessary to intensify measures which, with respect to cultural diversity, encourage, form and enable parents to practise their functions, allowing them to reconcile their professional and family life by:

- a) The organization of interchanging and educational spaces for parents which serve as an alternative to isolation and grouping of the family, pre- and postnatal social networks, maternity schools for knowledge of other experiences.
- b) Support to local administrations and to associative organizations to extend and create new temporary shelter resources which enable, on the one hand, compatibility with professional life and enjoyment of leisure time for parents, and on the other, relations between children enabling their interaction and communication. Services such as maternal assistants, day-centres, home help, babysitters, children's play-centres, etc. should be made available for families who need them, stimulating participation in family networks (grandparents, brothers, etc.) and neighbours ( family carers) in the tasks of support and looking after the children.
- c) The revision of social and economic benefits, tax improvements and other ways of support to upbringing, should consider:
  - Extension of paid paternity leave days to accompany the mother at the moment of birth, to look after the children if mother and child have to remain in hospital, to reorganize family life during the first two months of life, for temporary care of children with chronic ailments, to take care of school transition periods, enable leave situations and reduction of the working day to take care of the child until it is three or six years old.
  - Extension of economic benefits per child creating an assignment for three years and an economic support framework for temporary shelter service, increase of tax reductions, etc.
- d) Education and approximation of adolescents to the realities of upbringing and then relation training in

flexible and balanced criteria. This education should have a theoretical outline but, above all, a practical one, an approach to reality, visits to maternity wards and playschools, thematic dialogue spaces, etc.

- e) Configuration of the urban environment and of audiovisual measures such as social dialogue spaces and the popularization of good upbringing practices.
- f) Promotion of equality before domestic tasks and their social acknowledgment.
- g) Offer of sufficient and decent housing.
- h) Integration and access for all children, including non-resident or temporary residents, to social protection.

All these are examples, among others, of possible guidelines for protection policies for early relations. The preparation, with the widest political consensus, of a legal provision, in which these general protection measures are updated and determined is recommended.

### **Prevention programmes**

Primary prevention can be carried out through interventions (individual support or in groups) directed at previously defined contexts such as "with difficulty/social risk" as well as through community projects directed at promoting wellbeing and global health during early childhood.

Based on the social-risk indicators, the main objective of secondary prevention programmes will be the detection of family situations and/or environmental and social factors which can lead to a development disorder of children or put them in a risk situation.

As above, these objectives can be worked out on an individual level or through community programmes in collaboration with other organizations or institutions.

They are programmes aimed at social communities whose situation is identified as a confirmed risk factor for childhood development and therefore the need to count on important support resources for family life, such as teenage maternity, poverty, multiple births, drug addictions, social, ethnic or cultural isolations, socio-family violence, among others, has to be stressed.

In these situations, the needs to count on family life-support resources must be emphasized. Prevention programmes involve selective intervention measures for risk communities. Generally, this does not imply the creation of different lines of protection for the family but the increase of the level of protection to determine a more rigorous control over their usefulness and evolution. It has to do with extending social wage programmes, socio-professional insertion, family education, support at home, rest programmes for foster families and specific parent groups. It is convenient for professionals working with this programme from basic social services or specialized indifferent public administrations for associated organisations and early intervention services to maintain a stable and regular inter-institutional coordination for the contribution of experiences, training and mutual information and if necessary, transfer due to the need for intervention.

### **Intervention programmes in psychosocial environment**

The aims of early intervention programmes in the psychosocial environment are aimed at:

- a) The reconstruction and reorganisation of the original family, if this is considered viable.
- b) Protection and companionship of transfers when a process of dissolution of family bonds occurs or others are constituted.
- c) Family reinsertion, for fostering and/or adoption.
- d) Protection and companionship of institutionalized children without perspectives and family references.
- e) Early intervention for any detectable development disorder and preparation of mourning or social estrangement processes for parents and their children.

The demand for early intervention in children between 0 and 6 years old who suffer family crisis situations finds support in the evidence that for a child, family experiences constitute a decisive component in its symbolic organisation and the separation of its family structure is such a serious problem that it can only be admitted as a transitory situation.

The organization of the early intervention actions require:

- Constitution of primary care social services as a place of reference and detection of this situation.
- Constitution of primary care social services with teams specialized in minors, childhood and adolescence and mental health.
- Coordination of minor teams with Childhood Development and Early Intervention Centres to plan an intervention project.

#### **Diagnosis and social intervention in the early intervention team**

The intervention of the social worker in early intervention is part of the global care given to the child and its family, collaborating as another member of the multidisciplinary team in its treatment and subsequent integration and socialization in the community.

From the collection of socio-family information onwards, a social diagnosis can be prepared and a work plan and necessary strategies can be determined to help the family incorporate improvements which provide a greater wellbeing to the child, its family and its environment.

These intervention strategies are directed basically at:

- Activating and to making good use of internal resources of the family itself.
- Introducing necessary external resources for the child's problems and the moments of its lifecycle.
- Orientating the family concerning existing legal and social measures, providing knowledge about rights, services, economic or other benefits, informing them about conditions and ways of accessing them.
- Working on the transfer of the family to other specific services when a particular problem cannot be solved.
- Promoting coordination with professionals from other areas and institutions to work together on intervention strategies in specific cases or situations.

#### **4.4. EDUCATIONAL SERVICES**

Based on the principle that all persons have the right to participate in society, school becomes an important milestone in the process of integration and socialization of children, especially of those with development problems.

Child education is of significant seriousness because the first years of life are determining for harmonious physical and psychological development, as well as for the formation of intellectual faculties and the development of personality. Education at this age has a stressed preventive and compensating character due to the importance early intervention has to avoid development problems in the general population and especially in those children who present special educational needs.

The intervention services for children in the phase of 0 to 6 years old have been developed under different models, with different responsibilities and purposes. From the beginning and as changes took place in our society and in the family, especially with the incorporation of women into the professional world, society meets with the problem of who attends the children in the phase prior to compulsory schooling from a purely care-related model. This is the moment when nursery schools come up as a social assistance service for families, without clear educational intentionality.

Playschool in our country, as in the rest of Europe, is developed from the evolution of nursery schools onwards, due on the one hand to social demand and on the other to its reinforcement as a public service open to children, with a stressed educational approach. Accordingly, playschool is converted into an entity that systemizes programmes and organizes formal child education.

Nowadays, according to the *LOGSE* (Law of General Order of the Education System), child education is the first level of the education system with a duration of 6 years, divided into two cycles, the first from 0 to 3 years and the second from 3 to 6 years. The second cycle is more generalized than the first, although it is a phase that remains voluntary and it therefore presents a different reality, depending on each autonomous region. However, public administrations should guarantee sufficient places for this first cycle for all children who demand them.

From the advent of this law, child education determines general objectives whose purpose is for children to develop capacities such as: knowing their own body, relating to others through different ways of expression and communication, acquire certain autonomy in activities they carry out habitually, observing and exploring their family and social surroundings.

### **Primary prevention**

It is important to stress the educational character as a mediator and facilitator of subsequent learning in this scholar period. Child education should contribute to the affective, physical, social and moral development of the child. This means a new way of interacting with children of these ages, moving away from the nursing function traditionally carried out with young children.

From this perspective, playschools become a privileged place where prevention tasks can be carried out concerning possible delays in development, and, at the same time, a lack of compensation related to the social, cultural or economic environment.

### **Secondary prevention**

Detection of possible special educational needs of children during childhood is one of the functions to be carried out by teachers in the classroom, in collaboration with psycho-pedagogical teams. These teams are in charge of the evolution of detected needs in children with the purpose of determining their nature, as well as questions related to school placements, the preparation of curricular adaptations and the technical help they may need.

In psycho-pedagogical assessment, information about the child should be collected, as well as about the scholar and family context. From the conclusions of this assessment, future action results which, within the educational area, is carried out so that the child can follow, within its possibilities, the determined goals of this educational phase.

This way, proposals and decisions about school placement will be based on psycho-pedagogical assessment, bearing in mind bio-psycho-social aspects as well as the opinion of the family and other professionals involved in early intervention treatment. In any case, these measures are of reversible character, paying attention to circumstances that may affect the pupils as well as the results of other assessments.

These psycho-pedagogical teams may receive different denominations in each autonomous region but, in general, it is their task to coordinate, supervise and enable the integration process of children with educational needs into the playschool.

### **Tertiary prevention**

Within this phase of child education, it is considered that the school placement of children with special educational needs should start within a context as normalized as possible with the purpose of helping and favouring the process of development and learning.

Practically, this means that the school placement of these children is carried out preferably in ordinary centres. Therefore, the curriculum is adapted to the needs of each child, leaving school placements in special education centres or units to those situations in which the child needs significant adaptations and in an extreme grade of the ordinary curriculum as well as the same personal and material ways uncommon in ordinary centres: the classroom is converted into a structured space that should put the child in contact with experiences, material and resources which in other ways would not be within its reach. Therefore, exceptionally and only when the psycho-pedagogical team advises, the school placement of these children will be in special education centres during the second cycle of child education (3-6 years old).

During this childhood phase, children's special educational needs should have the possibility of prolonging their school placement if this is what the psycho-pedagogical team indicates.

There are child education centres which preferably integrate children with a certain disability. This makes it possible to use the technical support these children need and, at the same time, the specialization of teachers is favoured and social relation between the children and their families is enabled.

In each case, the teams determine action plans related to the educational needs of the children and it is the tutor-teacher who is responsible, within the classroom, for putting these plans into practice, as well as for the necessary curricular adaptations to be carried out. These adaptations tend to enable the children to reach the objectives typical of child education, always within their possibilities.

Accordingly, and for the whole educational process in playschool, the psycho-pedagogical teams are an essential element for integration because they offer direct help to the child as well as to the teacher, and they coordinate the different interventions the child may need with their teachers. They also enable direct help to the child by means of specialists such as a speech therapist, a psychomotor specialist or a support teacher.

Problems in the process of integration usually appear when there is no early intervention prior to the playschool placement, and when, as age increases, school demands grow. Generally, children with special educational needs who turn to the playschool at the age of 0-3 years do so because of recommendations by the psycho-pedagogical teams or by Childhood Development and Early Intervention Centres who value the possibilities the school offers the child for its development positively although they continue with the early intervention programmes already started. In general, integration of the child into the playschool complements the tasks carried out by these services.

One should bear in mind that child education centres, because of their objectives and the special care given to social and affective aspects, are ideal places to achieve the maximum development of the capacities of children with special educational needs.

Through all that is revealed, it can be seen how important it is to maintain a close relationship between the playschool and the CDEI centres. This relationship should have the following objectives:

- a) Professionals at playschools and CDEI centres, can collaborate with preparation of intervention programmes and with the delimitation of the most appropriate objectives, materials and procedures of the teaching-learning process.
- b) Determining the educational needs of children between 0-6 years old, locating and transferring the children who present anomalies in their development, as well as contributing in the preparation of the curriculum of this period.
- c) Attempting to achieve continuity in the children's education, covering all their needs from birth onwards and acting as a link, preparation and reinforcement for their integration into playschool.
- d) Coordinating and sharing information about the child's situation when placed in school.
- e) Exchanging information about the child's activities and behaviour during the school period.
- f) Giving technical help to school placement programmes for children with special educational needs.
- g) Collaborating in guidance for the families, their knowledge and support for their needs.

The relation between the CDEI centres and playschool should aim at providing global educational care, systemized and appropriate for children between 0-6 years old, contributing to reflection and debates about organizable proposals and orientation in playschool, supporting, assessing and training the support teacher as well as the teacher of the ordinary classroom and, fundamentally, supporting and enabling the integration process and the full development of children with special educational needs.

## 5. ACTION IN THE COMMUNITY

Problems resulting from development disorders of children is not a matter to be tackled exclusively in CDEI centres or social protection services. It should involve community resources also and society as a whole as it has to do with a particularly neglected social community. Beyond the benefit and optimization of learning possibilities, reasons which justify this include the principle of equality of opportunities, improvement of life quality of the child and its family and the preparation of these children and their futures as citizens.

To develop community actions regarding the susceptible population of early intervention, on the following is required:

- Territorial delimitation.
- Location of resources which complement and/or improve the actions of early intervention.
- Determination of information flows which permit an appropriate coordination of resources.
- Actions for the popularization of interventions and training of professionals.
- Communication mechanisms with those people institutionally responsible for the intervention area.

### ACTION

1. Knowing the space and the population subject to attention, through data analyses: population pyramids, income distribution, study levels, life style, etc.
2. Identifying the area's resources and their functioning, avoiding interference in actions and achieving effort synergies.
3. Participating in the interdisciplinary preparation of "risk indicators" in the population and its surroundings so as to determine parameters which will serve as a guide for detection, moving on, intervention and monitoring of cases.
4. Participating in the preparation of intervention flows in a way that the following is formed:
  - A coordination model among professionals so that customers perceive the intervention globally.
  - Documental circuits as a support to intervention in cases: the professional who acts over a case does so aware of all available details so that the intervention reaches a high level of efficiency.
  - Meetings on of case assessments and coordination of professionals.
5. Preparing reports which manifest the intervention demands, their nature, the action and the level of achieved objectives. They help to detect the most vulnerable communities and the bio-psycho-social conditions that favour them and they serve for the planning of preventive measures.
6. Organizing and participating in debates and training forums related to early intervention and to children in general.
7. Promoting community action in favour of the high risk childhood, through investigation projects, popularization resources, publications, etc.
8. Participating in interdisciplinary and inter-institutional coordination reunions which promote debates about different aspects of childhood and, in this context, communicate the situation of early intervention in the area to the responsible institutions so that action or resources are dynamized with the purpose of optimizing their use.
9. Providing support and technical advice to professionals of educational services for children from 0 to 6 years old.
10. Making society aware of the peculiarities and needs of the high risk population and their families.
11. Disposing of necessary economic benefits to develop prevention and social awareness campaigns about development disorders in children.

## 6. INTER-INSTITUTIONAL COORDINATION

The White Paper on Early Intervention should lead to a reorganization of administrative infrastructures and of redistribution or creation of the necessary economic, material and personal resources to guarantee satisfactory efficiency in the coverage that should be given to children in need from the early intervention centres.

The malfunctions of the administrations should be overcome by introducing, in any group of professionals or levels where this is necessary, the pertinent rationalization measures to improve the management of available resources and to create those which do not exist.

The essential difficulty appears when a child with a development delay can be subject to intervention by the health service, social services or education. If its problems involve two or three of the above fields, this intervention should not be given by separate departments but the transfer of information should flow among them and all actions to be developed should have a common denominator: the child, who, unaware of administrative organization charts, lives its own reality, its specific problems and should benefit from all the care these services can give.

The child has a biological, psychological and social organization and when some of these aspects are affected, bearing in mind the interrelation, the institutions should offer an integrated answer that guarantees its health, its intellectual and emotional development and capacities for adaptation.

### COORDINATION LEVELS

In early intervention, coordination channels should be determined that enable efficient planning and which serve as information transfer channels among the agents involved. This coordination should be achieved around the following dimensions:

- **Inter-institutional and intra-institutional:** ministries involved, regional ministries, local administrations and consumer organizations.
- **Inter-professional:** this involves coordination of specialized areas and sectors. Three levels of coordination should be considered.
- **State level:** central government should promote the coordination of the ministries of health, work, social affairs and education to outline a common policy which determines inter-ministerial channels for the planning of the early intervention sector.
- **Regional level:** those autonomous regions with competences transferred regarding health, social affairs and education and the local administrations, should assume the creation and organization of those resources necessary to offer some sectorized early intervention centres which generalize free, top-quality treatment available for those in need, as an exponent of solidarity, equality and social justice.
- **Early intervention resources:** this coordination level covers those professionals in health, social affairs and education areas who are going to influence childhood development as well as the professionals of the early intervention centres in inter-rans- and multidisciplinary teams.

The complexity of approaching specific problems of children with alterations in their development of social, psychological, sensorial or physical etiology continues to be a challenge for professionals, public administrations and society. Indeed, the different areas of knowledge tend to provide their own theoretical-experimental corpus of solutions for health, social and educational problems. The purpose of all aspects of early intervention is the improvement of the life quality of the children and the consequent normalization of their capacities for adaptation. Scientific specialization makes it possible to examine in more detail the knowledge of aspects of development alterations which a few years ago showed a cryptogenesis which nowadays, in some cases, has been solved. In others, said knowledge has made it possible not only to learn of the biological and social factors that can lead to development disorders, but also of appropriate alternatives for their prevention and solution.

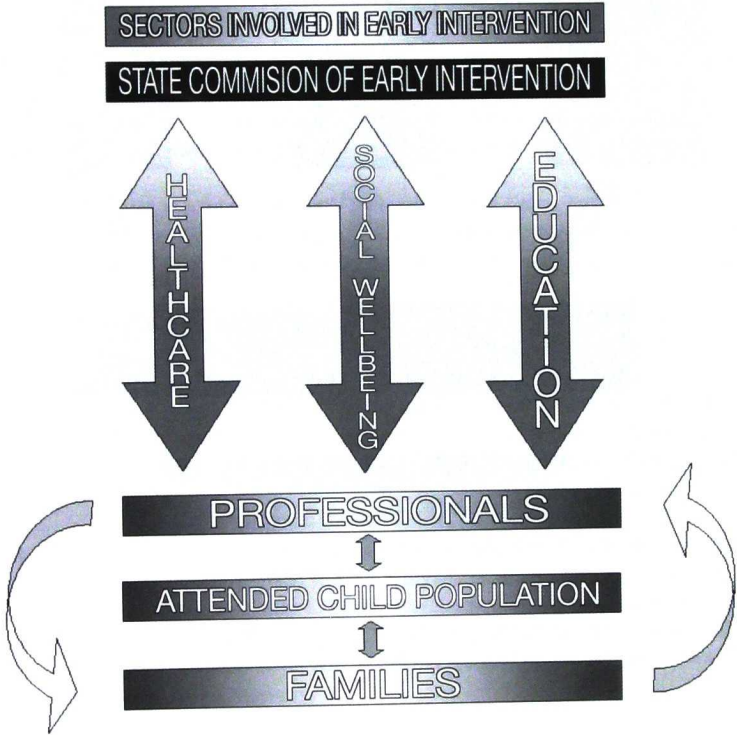


Coordination between the areas of research and the sectors that affect the child population susceptible to intervention is essential. The current structure of the State offers different situations regarding the standard, decision-taking and budgetary capacities, depending on each autonomous region. Consequently, a quality early intervention service must be provided in accordance with the social diversity of each region. The creation of a **State Early Intervention Commission or an Early Intervention Institute** would be a decisive contribution to the regulation of the sector, laying down common criteria and promoting legislative development to overcome the voids that still exist.

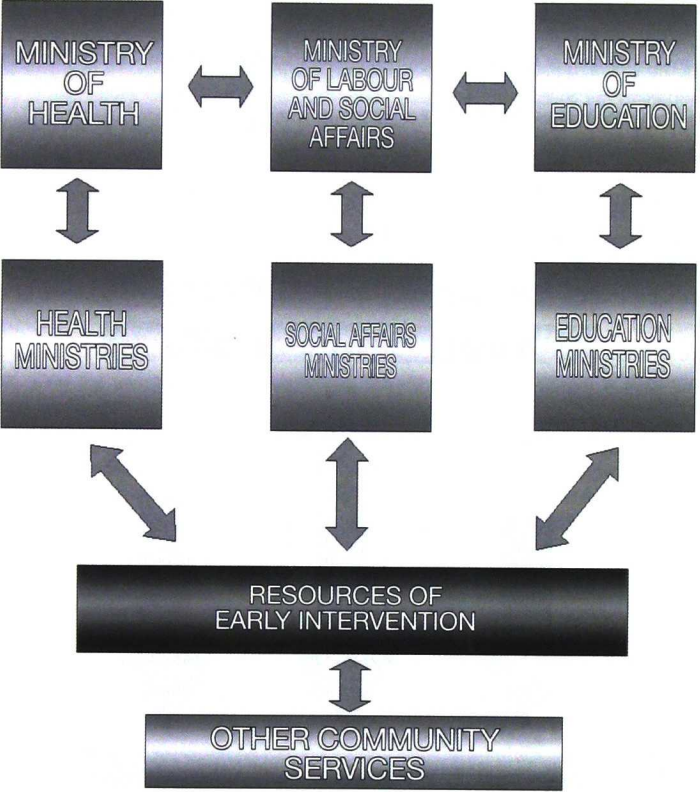
We must make mention of the need for regulating coordination, basically through the protocolization of the detection, derivation and control and monitoring programmes. Consequently, consideration must be given to the sectors involved in early intervention and to their relation and intercommunication.

### Coordination Graphs

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# COORDINATION IN EARLY INTERVENTION



## 7. RESEARCH

Research in early intervention is necessary to develop more and more efficient intervention programmes.

This research will serve to increase the knowledge about characteristics of different disabilities or development disorders, their repercussion on family dynamics, sources of stress and to evaluate which are the most efficient intervention methods. Research is also necessary for the empirical support of political or administrative decisions about the distribution of available material and economic resources to intensify approximations more effectively and with a better cost-quality ratio.

Studies in early intervention are very diverse because the current state of knowledge and discipline generates in each one of them the need to advance along different investigation lines. In some cases it is still necessary to develop epidemiological research which provides us with detailed knowledge of the etiological agents and psycho-social circumstances of problems that affect the child because only from this knowledge can real prevention programmes be planned.

In other cases, research must be developed that lead to new diagnosis methods which allow earlier detection of problems to make earlier intervention possible (general development disorders, certain sensorial disabilities or socio-environmental deprivation), and also greater possibilities of prenatal detection of problems (see results obtained in congenital errors of the metabolism, Down syndrome, spinal dysrhapisms).

Epidemiological research is important in early intervention as it helps, from the information provided, to know the risk factors and therefore the primary and secondary prevention actions that can be planned. It shows the number of children and families who need these services and adapts the resources to the needs detected.

For a long time, researching early intervention focused almost exclusively on showing the efficiency of intervention, any intervention, rather than no-intervention. From different disciplines integrated in the field of early intervention multiple empirical proof has been provided of this effectiveness in the first years of life and of the importance of its early determination. Although it will always be convenient to insist on the demonstration of efficiency of the different approaches to the child and its family context, we are in a phase where it is necessary to take one more step and dedicate efforts to analyse and understand the most appropriate and effective strategies of intervention to coordinate and organize the different services involved in global early intervention.

Nowadays, rather than insisting on the demonstration of the efficiency of intervention in opposition to no-intervention, it is necessary to demonstrate which specific intervention approaches are more effective, which certain aspects of each method of intervention leads to better results, which characteristics of programmes are more efficient and also, which characteristics of the child and the family contribute to better results. Greater practical involvement is being demanded in research in the field of early intervention; quality research which leads to direct consequences for improvement of future interventions.

The application to the field of early intervention of research on the intervention in different surroundings where the child lives (family, school, etc.) has demonstrated its efficiency for the knowledge of promoting factors or inhibitors of the child's development, according to the general systems theory, ecological theory, etc.

Accordingly, it is especially necessary to point out the importance of the development of interdisciplinary investigations which lets us carry out a mid- and long-term monitoring of the child's development, the results of which are to be known by the intervention services and programmes which initially attended the child's and/or its family's needs to value the real repercussions of these resources and also to improve the quality of all services.

It would be convenient to have channels for the communication of experiences and for access to documentation sources. It is necessary to count on forums, specialized publications and a scientific body of early intervention that encourages and channels research appropriately.

The contributions of the different disciplines lets us advance in the improvement of prevention and intervention programmes and in the availability of technical means.

Development of research in early intervention should start from the knowledge of the limitations and difficulties typical of research in this field and, generally, in the world of disabilities. Some of the problems are of a purely methodological nature and, at least theoretically, we should be able to solve them. Among other aspects, it is convenient to point out the difficulties met when it comes to putting the variables to be studied into practice.

One methodological question to bear in mind is the presence of a possible excessive multiplicity of approaches, even from different institutional contexts, which can become apparently contradictory in certain aspects. Once again, it should be the development of the investigation that makes it possible, as is being done at present, to delimit theoretical frameworks on models that lead us towards a more and more effective early intervention and greater quality.

Other methodological difficulties in research in early intervention are intrinsic to the subject to be studied; therefore, they tend to be more difficult to avoid whereas they must be considered to find the way to control them. The relevant literature refers to problems such as:

1. Heterogeneity of groups subject to treatment, of their family, social or institutional circumstances, which leads to the use of small or little homogeneous experimental samples and makes the extrapolation of results very difficult. Accordingly, only the unification of efforts and criterion, together with as exhaustive as possible knowledge of the etiology of the problem the child presents, can lead to the solution of this methodological limitation.
2. Great intra-subject variability. Again, this intra-subject variability, together with the group heterogeneity or inter-subject variability, limits the experimental and even statistical design possibilities to be used in research on the efficiency of therapeutic approaches.
3. The dynamic nature of the intervention process which, logically, force a continuous re-planning of therapeutic or evolution objectives according to the individual answer of each child or each family to the intervention programme.

Finally, we can also outline certain ethical problems that limit research possibilities in the field of early intervention and general disabilities. They centre fundamentally on the difficulty to compare groups because, if that possibility existed, it would not be ethically acceptable to deny participation of a group of children in an intervention programme, and in the impossibility of experimental manipulation. Consequently, field or natural context research must be used, where all methodological problems intrinsic to the subject to be studied, necessarily appear.

Apart from these limitations, a political, institutional and professional effort is necessary for intensification, reinforcement and development in our country, which have in fact been occurring productively for some years in different universities and early intervention centres in Spain. The need to promote the constitution of both parts in analysis, reflection and investigation tasks is evident.

Consequently, public administrations must provide and enable mechanisms and ways that permit this collaboration between university and centres and services for early intervention so that it will be possible to carry out intervention programmes, increasing the efficiency of intervention strategies, detailed knowledge of cognitive processes and emotional implications in learning and in the development of skills, all from descriptive as well as experimental points of view. It is necessary for public administrations to enable times and spaces for investigation in all centres and the disposition of appropriate instruments to promote the exchange of experiences and the determination of the economic resources that make them possible.

The different administrations must become aware of the need to create research projects in this field which consider biological, psychological and social aspects. An initial measure along such lines is the inclusion of early intervention in the priorities for economic grants and subsidies for research.

## 8. TRAINING

For the aims of early intervention to be carried out appropriately, professionals who take part in the interdisciplinary teams, must possess specialized training that provides them with a high qualification for playing their roles with maximum efficiency. At the same time, given the circumstances the children and their families are involved in when development problems exist, the profile of those who work in this field should have a special vocational predisposition and attitude, as well as the necessary scientific knowledge, because of specially complex circumstances.

Early intervention involves professionals in different training programmes, working in an interdisciplinary field. The interdisciplinary concept goes beyond the parallel sum of different specialities and for this reason, the training of this community involves academic training in a specific discipline, with qualifications, as well as in a conceptual framework common to all of them.

This dual training should have its own development space through reflection and team work, including a global vision of the child, its family and surroundings. The convergence of different fields of knowledge allows the optimum exercise of professional practice.

The special features of early intervention and the need for team work, make specific and common training necessary, to be achieved through specialization courses, accessible to graduates from university fields of health, education and social services (medical sciences, pedagogy, teaching, physiotherapy, speech therapy, social work, etc.).

The teachings that lead to obtain the official title of specialist in early intervention, after the corresponding graduation of qualifications, should provide appropriate scientific-technical training. The contents to be developed for this work can be identified, among others, as follows:

- Childhood development, including a wide knowledge of the different phases and field of development and of the factors that influence development, assessments considered typical and variations in normality, critical periods and evolution keys of different ages.
- Knowledge of the different medical profiles of disorders in childhood development, their possible etiology and causes, their nature, characteristics, evolution and prognosis as well as the most effective preventive and therapeutic measures in each case.
- Analysis and revision of philosophical and scientific trends that have historically influenced the development of different intervention models and results assessment models.
- Child psychology, the knowledge of which will allow the professionals to respond appropriately to the emotional needs and characteristics of the child in each evolution phase.
- Neurobiology of development and child neurology to provide the professional with knowledge about functional principles of the nervous system, its evolution and plasticity.
- Principles of psycho-pedagogy of learning and of applied motivation in the childhood phase.
- Principles of educational interventions, didactic and methodological bases.
- Intervention techniques in the communication area in specific intervention methodologies and systems in different disorders.
- Study of family dynamics, in its double role as facilitator of the child's development and also as a service receiver. Understanding of the family system, its cultural, economic, organizational features, etc.
- Theoretical and practical knowledge about the different professionals who make up an early intervention team, bearing in mind the distribution of roles, the dynamics of a group, strategies in decision-taking.
- Rehabilitation and bio-engineering technology.
- Approaches to investigation, methodology, search for information that generates positive attitudes towards experimentation and reinforces a critical spirit among professionals, allowing them to contrast different intervention possibilities empirically.

- Analysis of the legislative, institutional and standard reality, social and anthropologic characteristics, variables of surroundings and existing resources.

The preparation of regular training plans that cover the needs of the sector sufficiently and the demand for supervised and continuing professional experience is a *sine qua non* condition for the organization of qualified early intervention services at a level appropriate to their responsibility. Therefore, it is necessary to equip CDEICs as qualified teaching units to participate actively in applied training and supervising practices of these future professionals.

It is necessary to point out the convenience of favouring and motivating positive attitudes towards research as early as the training phase. Equally, the critical spirit that leads professionals to feel the need to contrast different possible intervention forms empirically should be reinforced, as well as the concern to know, select and put into practice the proposals whose efficiency has been demonstrated.

To develop a training programme in early intervention effectively, through specialization and postgraduate courses. These have to be accessible to various required qualifications for the configuration of an interdisciplinary team of said characteristics. Public administrations should determine lines of finance to enable access to this type of training. Universities should assume this training challenge because it is a key for offering the society quality early intervention.

# 9. BASIC PRINCIPLES OF EARLY INTERVENTION

## 1. Dialogue, integration and participation

The family, school and community integration of the child with a development disorder, implies respect for its condition as an active subject. Early intervention should enable social knowledge of the child and access its way of communicating and expressing its wishes, promoting coherent and stable educational and relation models.

Collaboration with the family is a basic attitude of early intervention, with respect to culture, values and beliefs of the parents, brothers and sisters and grandparents. The expression of their needs and interests, the right to receive information in an appropriate way and to take part in whichever decision concerns them, should be stimulated. Early intervention also has to be centred on the family, regarding the contribution of the ways required for solving their difficulties and assuming their responsibility.

Another aspect to be considered is social participation in the development of plans and programmes aimed children with development disorders. This participation should be specific through the professional associative movement and the consumers in each area or territorial district.

## 2. Gratuitousness, universality and equal opportunities, public responsibility

The presence of a disability or a development disorder implies a high risk of social marginalization. Early intervention acts for prevention and, whenever the case arises, the avoidance of said risks, facilitating equality of opportunities in access to different contexts of social life, incorporation into a family where one will be loved, co-existence and socialization in a school open to all children, the community environment designed in an understanding way towards difference.

Due to its origins and aims, early intervention must be a public service, universal, free of charge for all children and families in need. The gratuitousness must be complete and should reach technical aid and remove integration barriers.

## 3. Interdiscipline and high professional qualifications

The concept of interdiscipline goes beyond the parallel sum of different specialists. Training of professionals who participate in early intervention implies training in a specific discipline as well as in a conceptual framework common to all of them. This should have its own development space through reflection and teamwork. For this common framework, four areas can be identified:

- Specialization in childhood psycho-motor development. Understanding of typical and atypical processes, evolution characteristics of different ages, forms of relation in each one of them.
- Detailed study of the psycho-sociology of family dynamics, understanding of the family system, their cultural, economic, organizable peculiarities, life cycle, etc.
- Knowledge of the legislative, institutional and standards reality, social and anthropologic characteristics, environment and geographical surroundings of the community.
- Sufficient training and experience regarding team work, group dynamics, role-playing, decision-taking strategies, etc.

Preparation of regular training plans and the demand for supervised and continuing professional experience is a *sine qua non* condition for the organization of qualified early intervention services at a level appropriate to their responsibilities.

#### **4. Coordination**

Intervention for those children with developmental disorders and for their families is carried out within a specific institutional framework. The families tend to stress the need that the services and orientations offered by each organization or each professional must coincide and consider the whole situation when it comes to action plans. The early intervention services must promote the work in local networks to complement each other and enable family life quality. It is convenient to centre this coordination on basic protocols of transfer and exchange of information and computerized registers of equivalent contents for the whole nation. These registers should be in agreement with parent associations and consumer federations and they should contain clauses that safeguard personal privacy.

Coordination also concerns the continuity of services. The organization of the diagnostic information process or the transition to school are two inexcusable milestones. It is highly convenient for each family to have a professional reference to turn to in order to solve doubts or questions. Said reference must offer confidence and help reorganize everyday life coherently. The avoidance of fragmentation, which may occur as a consequence of the intervention of multiple agencies, organizations and professionals, is a main object of coordination.

#### **5. Decentralization**

The principle of decentralization refers to the determination of an organized system around the family's needs, in their surroundings, including the provision of home services. This involves the inclusion of early intervention in the network of primary care given by health and social services in the neighbourhood of playschools and the family.

Decentralization must be compatible with a good organization of access to and support from the most specialized services of the area or region (third-level services, resource centres, specific centres) whenever necessary. The respect for the everyday life of the family, the safeguarding and promotion of life quality should preside the organization and functioning of the services.

#### **6. Sectorization**

Sectorization refers to the need to delimit the action field of the services to guarantee a balanced correlation between proximity and knowledge of the community and environment. Operative functionality and quality of the teams and a sufficient volume of demand for the purpose of facilitating the inclusion of all kinds of health, educational and social services.



# ANNEXE

## Annexe A EARLY INTERVENTION STANDARDS

This chapter is the result of previously compiled work. From the chapter on early intervention, by José María Alonso Seco, in the document *Achievements on handicaps in Spain: balance over 20 years, from the Royal Patronage of Prevention and Intervention to People with Handicaps*, we obtained numerous legislative notes and valuable comments. From Jesús Sebastián (Zaragoza) and from the *Handbook of good practice in early intervention*, from FEAPS, many references to legislation. Finally, we would like to thank the professionals from the Spanish Centre of Documentation on Disability, from the Real Patronato sobre Discapacidad for their collaboration and contribution of suggestions, without which we would not have been able to write this Annexe.

### International standards subscribed by Spain

- Declaration of Children's Rights (UN, 1959).
- Children's Rights Convention (UN, 1989). Ratified on 30 November, 1990. (Official Gazette 30 December).
- European Social Charter. Ratified 29 April, 1980.

### General State Legislation

- Spanish Constitution of 1978.
- Royal Decree 620/1981, 5 February, on the unified system of public aid for the disabled. (Official Gazette 6-4-1981).
- Order, 5 March, whereby RD 620/1981 is developed. (Official Gazette 8-3-1982).
- 13/1982, 7 April, Social Integration of the Disabled Act. (Official Gazette 30-4-1982).
- Royal Decree 383/1984, 1 February, whereby the special system of social and economic benefits, set forth in Act 13/1982, 7 April on the Social Intervention of the Disabled is determined and regulated. (Official Gazette 27-2-1984).
- Act 39/1999, 5 November, to promote the reconciliation of family and professional life of working people. (Official Gazette 26-1-2000).

### General Regional Legislation

#### **Andalucía**

- 1/1999, 31 March, Attention to people with handicaps in Andalucía Act. (Official Gazette of the Andalucía Cabinet 17-4-1999). In particular, Title II, which refers to prevention of impairments, health assistance and medical-functional rehabilitation, and Title III, dedicated to special educational needs.

## **PUBLIC HEALTH**

### State legislation

- 14/1986, 25 April, General Public Health Act (O.G. 29-4-1986).
- 63/1995, 20 January, Royal Decree on health benefit ordinance of the National Public Health System (O.G. 10-2-1995).
- Order of the Ministry of Public Health and Consumption, 23 July 1999, whereby the Order of the 18 January 1996 on development of the R.D. 63/1995, 20 January, is modified to regulate orthoprosthesis benefits (O.G. 5-9-1999).

## **Regional legislation**

### **Andalucía**

- 101/1995, 18 April Decree, which determines the rights of the parents of children in public health during the process of giving birth. (O.G. of the A.C.). Early stimulation is determined as one of the rights of the hospitalized newborn (Art.3.j).
- 195/1998, 13 October, Decree regulating orthoprosthetic benefit. (O.G. of the A.C. 3-11-1998).

### **Aragón**

- 2/1989, 21 April, Aragon Health Act. (O.G. of Aragon 4-1989).
- 8/1999, 9 April, reform of 2/1989, 21 April Aragon Health Act, of the Aragon Health Service. (O.G. of A. 17-4-1999).

### **Canarias**

- 11/1994, 26 July, Health Ordinance Act of the Canary Islands. (O.G. of Can. 5-8-1994)
- 3/1997, 21 January, Decree adopting the Health Plan of the Canary Islands (O.G. of Can.31-3-97).

### **Cataluña**

- 15/1990, 9 July, Health Ordinance Act of Catalonia. (O.G. of the C.C.30-7-1990). Modified by Act 11/1995, 29 September. (O.G. of the 18-10-1995).
- 79/1998, 27 March, Decree laying down the standards governing orthoprosthetic benefits. (O.G. of the C.C. 30-9-1998).

### **Comunidad Autónoma de Illes Balears**

- 1/1993, 6 April, Balearic Health Service Act. (O.G. of the B.I. 15-8-1992).

### **Castilla y León**

- 1/1993, 6 April, Health System Act. (O.G. of the C.L.C.).
- 16/1998, 28 January, adopting the Socio-health Intervention Plan of Castilla and Leon (O.G. of C. and L.).
- 212/1998, 8 October, Decree adopting the 2<sup>nd</sup> Health Plan of Castilla and Leon (O.G. of C. and L.).

### **Galicia**

- 69/1998, 26 February, Decree regulating Early Intervention in the disabled in the Galicia. (O.G. of Galicia 10-3-1998).

### **La Rioja**

- 4/1991, 25 March, Act for the Creation of the Rioja Health Service. (O.G. of La Rioja 18-4-1991).
- 11/1995, 2 March, Decree regulating Health Controls in Childhood. (O.G. of La Rioja 8-4-1995).

### **Navarra**

- 17/1998, 26 January, Decree regulating the orthoprosthetic Benefits of the Navarra Health Service-Osasunbidea, related to external prosthesis, wheelchairs, orthosis and special prosthesis. (O.G. of Navarra 23-2-1998).
- 170/1998, 16 November, Order from the Health Councillor determining the programme of early detection of hipoacusias in the neonatal period. (O.G. of Navarra 30-12-1998).

### **País Vasco**

- 175/1989, 18 July, Decree adopting the letter of rights and obligations of patients and users of the Basque Health Service/Osaidetza (O.G. of P.V. 4-8-1989).
- 9/1997, 12 February, Decree regulating orthoprosthetic benefits concerning external prosthesis, wheelchairs, special orthosis and prosthesis (O.G.P.V. 21-7-1997).

## **Principado de Asturias**

- 1/1992, 26 July, Health Service Act of Asturias (O.G.P.A. 13-7-1992).

## **SOCIAL SERVICES**

### **State legislation**

- 1/1996, 15 January, Organic law for the legal protection of the youth: of partial modification of the civil code and the law of civil prosecution (O.G. 17-1-96).

### **Regional legislation**

#### **Cantabria**

- 5/1992, 27 May, Social Action Act (O.G.ofc.5-6-92).

#### **Castilla-La Mancha**

- Order of May 1998, regulating the services of the base intervention centres for people with disabilities in Castilla la Mancha (O.g.c.m 25-5-98).

#### **Cataluña**

- 17/1994, 16 November, legislative decree regulating the fusion of Acts 12/1983;26/1985 and 4/1994 governing approved social assistance and services and determining early intervention services within the specialized attention to people with mental disability (art.11.b )2.2).(o.g. of g.c.13-1-95).
- 206/1995, 13 June, affiliating early intervention to the department of social welfare (o.g. of g.c. 24-7-95).
- 96/1998, 31 March, Decree of the interdepartmental commission of coordination of administration actions from the Generalitat aimed at children and adolescents with disabilities or at risk of suffering them .(o.g. of the g.c 14-4-98) modified by Decree 211/1999, 27 July (O.G.of the G.C.4-8-99).

#### **Castilla y León**

- 16/1998, 29 January, adopting the socio-health intervention plan of Castilla and León (O.G.C.L 3-2-98).

#### **Madrid**

- 11/1984, 6 June, Social Services Act (O.G.CM. 23-6-84).

#### **Valencia**

- 8/1996, 4 June, Decree affiliating the functions related to early stimulation of disabled to the Council for Labour and Social Affairs. (O.G.V 7-6-96).
- 5/1997, 25 June, Law regulating the social services system in the Region of Valencia. (O.G.V 4-7-97).

#### **Galicia**

- 4/1993, 4 April, Social Services Act (O.G.11-5-93).

#### **Murcia**

- 8/1985, 9 December, Social Services Act (O.G.R.M. 19-12-85).

## **EDUCATION**

### **State legislation**

- 334/1985, 6 March, Royal Decree governing Special Education (O.G.16-3-85), modifications to Royal Decree 696/1995, 28 April.
- 1/1990, 3 October, Organic Law of General Ordinance of the Educational System (LOGSEJ). (O.G. 4 October) modifications: Organic Law 9/1995, 20 November.

(O.G.21-11-95): 13/1996, 30 December, Law (O.g.31-12-96); 66/1997, 30 December, Law (O.G.31-12-97); 50/1998, 30 December, Law (O.G.31-12-98).

- 1333/1991, 6 September, Royal decree determining the curriculum of child education.(O.G.9-9-91).
- 9 December, 1992, Order of the Ministry of Education and Science, regulating the structure and functions of the educational guidance and psycho-pedagogic teams,(O.G.18-12-92).
- 696/1995, 28 April, Royal Decree for the Ordinance of the education of pupils with special educational needs. (O.G.2-6-95).

## **Regional legislation**

### **Canarias**

- 286/1995, 22 September, Decree for the Ordinance of intervention for pupils with special educational needs. (O.G. 11-10-95).
- 9 April, Order of the regional Ministry of Education, Culture and Sports concerning school placement and resources for pupils with special educational needs because of disability resulting from impairment, pervasive development disorders and hospitalized pupils. (O.G 25-4-97).

### **Cataluña**

- 299/1997, 25 November, Decree governing educational intervention for pupils with special educational needs. (O.G.G.C 28-11-97).

### **Valencia**

- 39/1998, 31 March, Decree for the Ordinance of education for intervention for pupils with special educational needs. (O.G.V 17-4-98).

### **Galicia**

- 320/1996, 26 July, Decree for the Ordinance of education for pupils with special educational needs. (O.G.G. 6-8-96).
- 120/1998, 23 April, Decree regulating educational and professional guidance in the autonomous region of Galicia. (O.G. 27-4-98).

### **Navarra**

- 153/1999, 10 May, Decree regulating educational guidance in public centres in the autonomous region of Navarra. (O.G.M. 31-5-99).

### **País Vasco**

- 118/1998, 23 June, Decree for the Ordinance of the educational response for pupils with special educational needs within the framework of comprehensive and integrating schooling. (O.G.P.V. 13-7-98).
- 30 July, 1998, Order from the Department of Education, Universities and Research, determining criteria for school placement for pupils with special educational needs and assigning resources for their correct intervention in various stages of the educational system. (O.G.P.V. 31-8-98).

## **CHILDHOOD**

### **Regional legislation**

#### **Andalucía**

- 1/1998, 20 April, Rights and Intervention of Minors Act.(O.G.A.C. 12-5-98).

#### **Aragón**

- 10/1989, 14 December, Protection of Minors Act. (O.G.C. 20-12-89).

## **Canarias**

- 1/1997, 7 February, Global Intervention for Minors Act. (O.G.C 17-2-97).

## **Cantabria**

- 7/1999, 28 April, Protection of Childhood and Adolescence Act. (O.G.CA. 6-5-99).

## **Castilla-La Mancha**

- 3/1999, 31 March, Minors Act (O.G.C.M. 16-4-99).

## **Cataluña**

- 8/1995, 27 July, Intervention and Protection of Children and Adolescents Act and of modifications to Act 37/1991, 30 December governing protection measures for minors and adoption. (O.G.C.M. 2-8-95).
- 7/1995, 21 March, Preservation and Protection of Minors Act. (O.G.B.I. 8-4-95).

## **Madrid**

- 6/1995, 28 March, Guarantees of Rights in Childhood and Adolescence Act. (O.G.C.M. 7-4-95).

## **Valencia**

- 7/1994, 5 December, Childhood Act, promoting equality of opportunities. (O.G.C.V. 16-12-94).

## **Extremadura**

- 4/1994, 10 November, Protection and Intervention for Minors Act. (O.G.E. 24-11-94).

## **Galicia**

- 31/1997, 9 June, Family, Childhood and Adolescence Act. (O.G.G. 20-6-97).

## **Asturias**

- 1/1995, 27 January, Protection of Minors Act. (O.G.PA 9-2-95).

## **Murcia**

- 3/1995, 21 March, Childhood Act. (O.G.M. 12-4-95).

## **Annexe B. BIOLOGICAL AND SOCIAL RISK FACTORS**

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### **BIOLOGICAL RISK FACTORS**

#### **A. Newborn with neurological risk**

- R.N. with weight < P10 for its gestational age or with weight <at 1500 grammes or Gestational age <32 weeks.
- APGAR < 3 at the minute or <7 at 5 minutes.
- RN with mechanical ventilation for more than 24 hours.
- Hyperbilirubinemia needing blood transfusion.
- Neonatal convulsions.
- Sepsis, meningitis or neonatal encephalitis.
- Persistent neurological malfunction (more than seven days).
- Brain damage evidence by ECO OR TAC.
- Malformations of the central nervous system.
- Neuro-metabolopathies.
- Chromosomopathies and other dimorphic syndromes.
- Child of mother with mental pathology and/or infections and/or drugs that can affect the foetus.
- RN with brother with neurological pathology not clarified or with risk of recurrence.

- Twin, if the brother or sister presents neurological risk.
- Whenever the paediatrician considers it appropriate.

### **B. Newborn with sensory-visual risk**

- Prolonged mechanical ventilations.
- Highly preterm.
- RN with weight <to 1500 grammes.
- Hydrocephaly.
- Congenital infections of the central nervous system.
- Cranial pathology detected by ECO/TAC.
- Malformation syndrome with visual compromise.
- Postnatal infections of the central nervous system.
- Severe asphyxiation.

### **C. Newborn with sensory-auditory risk**

- Hyperbilirubinemia needing blood transfusion.
- Highly preterm.
- RN with weight < 1500 grammes.
- Congenital infections of the central nervous system.
- Ingest of aminoglycosydes during a prolonged period or with high levels of plasmatic elevates during pregnancy.
- Malformation syndromes with auditory compromise.
- Family records of hypoacusia.
- Postnatal infections of the central nervous system.
- Severe asphyxiation.

### **SOCIAL RISK FACTORS**

The socio-family risk is valued because it is the risk variable that most affects acute perinatal mortality and also perinatal morbidity in the long term. The criterion of socio-family risk to be monitored is as follows:

- Acute economic deprivation.
- Accidental traumatising pregnancy.
- Unsettled coexistence in the family group.
- Traumatizing separation in the family group.
- Parents with a low I.Q./non-Stimulating surrounding.
- Severe illnesses/exitus.
- Alcoholism/Drug addiction.
- Prostitution.
- Crime/imprisonment.
- Adolescent mothers.
- Suspicion of abuse.
- Children taken into homes for children.
- Families who repeatedly do not observe health controls.

**Disorder in motor development**

This diagnosis is applied when we consider the presence of a pathology affecting nerve ways, centres or circuit levels involved in motricity. Different forms and degrees of cerebral palsy, spina bifida, miopathies, etc. and different minor motor dysfunctions (motor delay, hypotonia, gross and fine motor difficulties).

**Disorder in cognitive development**

This group includes disorders concerning different degrees of mental disability, limited intellect and specific dysfunctions in cognitive processing.

**Disorder in sensory development**

This group includes visual or auditory deficiencies of different degrees.

**Disorder in speech development**

This group includes difficulties in the development of communicative and verbal abilities at speech comprehension level as well as expressive abilities or articulations.

**Pervasive development disorder**

This group includes children with simultaneous and severe alterations in different psychological development areas (autism and minor forms related to autism and psychosis).

**Disorder in behaviour**

This group includes children with forms of inappropriate behaviour, sometimes disturbing.

**Emotional disorders**

This includes children with manifestations of distress, inhibition, symptoms and mood disorders, etc.

**Development disorder of somatic expression**

This group includes children who present functional pathologies in the oral alimentary sphere, respiratory problems, sleep-wakefulness cycle, continence control, etc.

**Evolutional delay**

This group includes children with an evolution delay and who are not situated in any of the above groups. They often make up a provisional diagnosis that evolves subsequently towards normality (frequent evolution in the case of children who have suffered or suffer chronic disease, hospitalization, inappropriate care) and in other cases towards different dysfunctions, where cognitive disorder is the most frequent.

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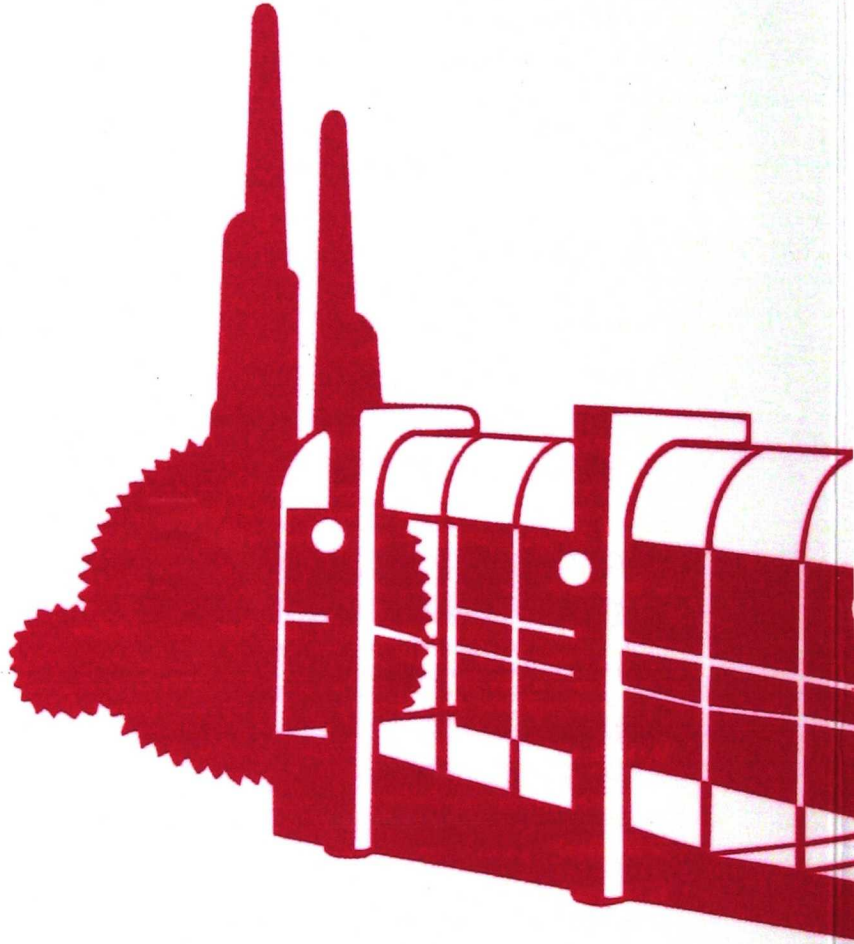
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