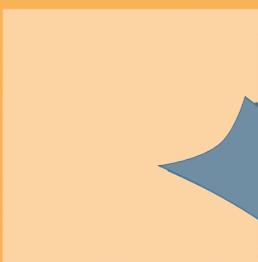
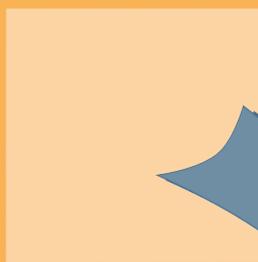


**GUIDE TO
STANDARDS**



**OF QUALITY
IN EARLY
INTERVENTION**



GOBIERNO
DE ESPAÑA

MINISTERIO
DE EDUCACIÓN
POLÍTICA SOCIAL Y DEPORTE

REAL PATRONATO
SOBRE DISCAPACIDAD



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SOBRE DISCAPACIDAD



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Edited by: Real Patronato sobre Discapacidad (The Royal Board on Disability)

Original Title: Guía de estándares de calidad en Atención Temprana

Available from: Centro Español de Documentación sobre Discapacidad, Real Patronato sobre Discapacidad. Serrano, 140. 28006 Madrid (Spain). cedd@furnet.es - www.cedd.net

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November 2008

Printed: Industrias Gráficas Caro S.L.

NIPO: 214-08-016-4

Depósito legal: M-35798-2008

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P R E S E N T A T I O N

PRESENTATION

In the last few years the global conception of Early Intervention as an integral operation of support for families of children with disabilities has been spreading throughout the whole of Europe to the point of constituting an increasingly solid network of services and benefits.

In this task, in our country, the pioneer work of IMSERSO must be highlighted with the creation in 1981 of the first Early Stimulation Services in new base centres and their subsequent extension. The experience accumulated by these services and by those created in a simultaneous manner in the health or educational ambits proved decisive in setting in motion the idea of Early Intervention as a set of actions positively oriented towards the prevention, autonomy, quality of life and personal development of all the family.

With the sponsorship and impetus, firstly of IMSERSO through the Plan of Action for Disabled people and, subsequently, the Royal Patronage for the Disabled, these ideas have been taking shape in the form of various documents of professional consensus which have served as reference in the updating of Early Intervention resources and personnel deployment throughout the whole of Spain.

In this way new, specific measures have been promoted in support of families of children with disabilities such as, among others, the extension of maternity and paternity leave and the conciliation of family and work commitments, among which may be highlighted the inclusion of disabled children between the ages of 0-3 years and their families as beneficiaries entitled to the benefits deriving from the Law of Dependence through the specific EVE scale.

One of the fruits of this support to professional collaboration has been the elaboration through the “Early Intervention and Detection” group and with the support of the State Federation of Early Intervention Associations of the “Guide to Standards of Quality in Early Intervention” which, since its first publication in 2004 has constituted a source of reference in the assessment and improvement of Early Intervention in Spain and in the countries of our sphere of activity.

For all of the aforementioned reasons, without doubt, we have great satisfaction in presenting its re-edition in English incorporating the CEGAT computer application which will multiply the possibilities in the use of self-assessment forms, the participation of professionals and users, work within a network system and communication between Early Intervention personnel teams and resources in a trans-national ambit, strengthening a common, coherent and quality culture.

AMPARO VALCARCE
General Secretary
Real Patronato sobre Discapacidad



PROLOGUE

PROLOGUE

It is certain that the terms QUALITY and INDICATORS OF QUALITY come from the business world and that there is still a lack of culture in respect of this range of themes within the world of services and human resources directly involved in work with people. We are referring in particular to the ambits of health, education and social services. However, we must consider that quality in the lending of services to people, be they public or subsidised by public authorities, has to be a right for all citizens.

Politicians want to and must know the real utility of the services which they create. The administrators of the selfsame laws want to know about their efficacy. The professionals wish to have recognition for their work and, finally, the families seek services which respond to their necessities.

The indicators of quality must be instruments for measurement which enable us to assess quantitative and qualitative aspects of relevance to direct attendance to the child and his/her family, the internal organisation of the service and its management. All of this will allow us to identify problems and introduce the necessary modifications in the intervention process, always with the aim of achieving a continued improvement in quality in welfare work in Early Intervention.

From within the State Federation of Early Intervention Associations we believe that the way of working in our ambit must bear in mind the perspective of being able to improve more and more the attention given to children and their families and in this way to satisfy the real necessities of the population which we are attending to

The White Book, which was produced by this Federation, with the support of Royal Patronage, has gradually been achieving the objective of designing specific plans in EC in the different Autonomous Communities of Spain, bearing in mind various essential principles which respond to the real necessities of all the infant population which suffers from some type of developmental disorder in its initial phases, the family and its environment. The current document, already presented in its first edition in 2004 and now revised, highlights the necessity of having a reference guide to count on which stimulates and guarantees the quality of the services provided and the activity carried out in their provision.

We believe that all the professionals and all the Child Development and Early Intervention Centres in our country will feel enriched by all the contributions which this new, revised edition offers and that they are going to hold in high esteem the work carried out by these authors, given that the quality of our work and the quality which we can offer from our centres has no other mission than to improve the quality of life of the children and of the families which they attend to.

FÁTIMA PEGENAUTE LEBRERO
President of the State Federation of Associations of
Early Intervention Professionals (GAT)



AUTHORS' NOTE

AUTHORS' NOTE

Since publication of the first edition of the “Guide to Standards of Quality in Early Intervention” notable changes have occurred in the response of Spanish society to the necessities of families with children with developmental problems or disorders.

To legislative improvements, in leave time for fathers and mothers, in economic help or in work flexibility, must be added the growing awareness (visible in new normative developments in the majority of the Autonomous Communities in Spain) that the children and their families need an inclusive environment, regular professional services and, primarily, consideration which enables them to feel like fully-fledged citizens and free protagonists in the making of decisions which affect their lives.

These advances lend a certain sepia-toned hue to the data furnished or the reflections shared in the text which introduces the Battery of Standards but we have preferred to maintain the original version as it offers a certain perspective and, within its contents, readers can verify that most of the standards of quality and their indicators remain in force and still maintain a depth and range of coverage. We hope that their availability at present in a computer format like CEGAT, thanks to the generous work of Maravillas Calviño Cid, may prove useful to the professionals, to the families and to the entities and institutions within the sector.

Readers who are already familiar with the Battery of Standards will realise that we have made slight alterations to some standards and indicators. These changes focus on the drawing of the standards and indicators in dimension 4, which is to say, those referring to the organisation and functions of the Child Development and Early Intervention Centre. This is due to the desire to facilitate the use of the standards in autonomous communities, countries and different realities. With this objective in mind, we have tried to outline more clearly functional aspects and processes over and against structural requirements in the organisation of Centres. As a consequence the number of indicators in this dimension has been reduced from 42 to 29 and these changes are also reflected in the textual presentation of the standards in dimension 5 (Programme Assessment).

As far as the rest of the Battery is concerned, the changes are unappreciable. In standard 1.7, one of the indicators has been split into two for the purposes of a better understanding and one of the indicators of standard 2.2 has been relocated for reasons of organisational coherence in standard 2.3.

We have had the satisfaction of verifying that the Guide has fulfilled its function as a source of reference in many Autonomous Communities and countries in our sphere of activity. We hope that the possibility of utilising the Standards through a computer application like CEGAT will serve to encourage reflection and practice within the sector in such a way that, in the near future, we find it necessary to review them.

It is obvious that many challenges still lie ahead in the field of Early Intervention but it is a sector which is alive and full of people who are committed to their work.

Our thanks to The Royal Board on Disability and to the Spanish Centre for Documentation on Disability for their warm reception and invaluable support, to all the professionals within the sector for their comments and contributions and to our GAT colleagues for their support and friendship.

B A C K G R O U N D

BACKGROUND

The quality of services and programmes which an organisation sets in motion in order to attend to the specific needs of particular collectives with special difficulties is one of the most important challenges to be faced nowadays.

In this direction the programme INTER was organised, encouraged by IMSERSO, to promote a training system based upon the interchange of knowledge and experience with the aim, as indicated in the minutes (BOE n° 281, 24th Nov 1998) of furthering knowledge regarding the various initiatives and models of each autonomous region, of identifying efficacious projects and good practice, in order to make them known and, if it is the case, to generalise them by means of technical or legislative norms.

From this meeting onwards, diverse groups were set up at the heart of the INTER programme with the purpose of defining a network for the interchange of knowledge and experience concerning people with handicaps. One of the groups constituted was that of “Detection and EI” composed of five organisations belonging to five autonomous regions.

Through meetings which it has held since the coming-into effect of the INTER programme, this group has tackled different aspects related to EI: information, family training and participation; coordination of the different services linked to EI, the process of schooling; new technologies; norms in different autonomous regions, etc.

Throughout the different sessions, all the participants have emphasised the convenience of advancing in the definition of standards of quality as a necessity to be given priority within the sector. The initial outcome of this reflection was the drawing up of an internal document regarding a standards guide in EI, structured on five levels: community, child development and early intervention centre, family, child and programme.

The interest shown by the group concerning the quality standards, was later given more concrete form with the presentation of an initial paper in the course of the meeting organised by AGAT (Asociación Galega de Atención Temperá) in Ferrol o 6th and 7th of October 2000 and with the examination of its methodological aspects in the meeting which was convoked by ASPACE (Asociación de Padres de Niños con Parálisis Cerebral) in Santander on 15th June 2001. Dr. Samuel Fernández, from the University of Oviedo, lends his support to this review. Dr Fernandez, an expert in evaluation, was called in his capacity as director of the quality standards guide in integration at work as promoted by IMSERSO

Throughout the last four years, the group has served as a nucleus of mediation in order to facilitate wide-ranging social interchange in which have participated EI experts and professionals belonging to different disciplines, units, programmes and regions; parents' associations from diverse ambits or with different sets of problems and experts in evaluation. The meetings, workshops, and congresses which have marked the successive phases in the elaboration of this guide (see appendix A) have enabled us to verify the

intensity which the practical culture of EI has in Spain and the widespread agreement demonstrated between professional groups and parents. There is extensive agreement when identifying the main aspects of these practices and in the understanding that the definition of quality is an open-ended process which implies both self and external assessment within a continuous process of reflection and improvement.



INTRODUCTION

INTRODUCTION

Throughout the last twenty years EI has been undergoing a gradual process of consolidation as a reference service in attending to the needs of children with developmental disorders or in risk situations, in supporting the reorganisation of family life and in coordinating the work of the different social services in order to satisfy those needs in a coherent manner.

Since its origins, the world-wide development of EI has been very unequal: the differentiation of objectives, functions and resources which have been assigned to EI historically, legal directives, administrative developments, territorial implementation and distribution, training and experience of human resources, the intensity of help lent and activity, the personalisation of certain services, have created an extraordinarily varied panorama in almost every country. Moreover, the coincidence between the implementation of early stimulation and the long process of political transition and change in state organisation in Spain, situates us among the prototypes of this diversity. The profound political and legislative changes, which have transformed the aims and organisation of the state and the distribution or administrative organisation of resources, should not be forgotten. Spain is a country which is made up of seventeen autonomous regions, each with wide-ranging powers while, at the same time, forming part of the European Union. Throughout the prolonged political transition in Spain services and resources for handicapped people have been transferred and modified in each part of the country and this diversification has been particularly noticeable in the case of EI.

The definition of the field of action of services rethinking, in so doing, objectives and assessment procedures has been the object of many rationalisation initiatives, especially after incorporation within the European Union, which acted as a catalyst in gathering and synthesising all the work experience of parents, professionals and the administration. The adhesion to Europe has strengthened and stimulated the principles of non-discrimination regarding handicapped people which were already present in each country's legislation. As a consequence of political directives concerning childcare and equal opportunities, programmes of interchange between professionals and families from different countries and the most varied of backgrounds was promoted from the European Community. The programme HELIOS II, particularly, which was developed in an itinerant manner over a period of three years (1994-1996), enabled an unprecedented process of analysis and dialogue. The experience and documents which emerged out of HELIOS and, almost directly afterwards, the publication of the plan of action for handicapped people (1997-2002), were the basis for stimulating the production of the Early Intervention White Book (2000), the FEAPS manuals of good practice (1999) or the ONCE (2000) the FIAPAS or ASPACE recommendations, the FEISD health guide and other similar documents from parents' federations and associations.

The Early Intervention White Book (1995-2000), a document produced by GAT, the federation of associations of Spanish professionals, with the support of the Royal Patronage of Handicapped, underlines the need to implant a homogeneous system of child

development and early intervention centres in all the autonomous regions whose objective is autonomy and socialisation based upon an inter or “transdisciplinary” model of high quality. A model which is broken down into sectors, decentralised and contextualized. With the Early Intervention White Book, supported by professionals’ associations and parent’s of handicapped people’ federations, EI is intended as a series of joint actions directed towards **the child, the family and the immediate environment**.

It is too soon to assess the extent to which a common consensus built around the White Book may reach, whatever the case may be, it has served to update EI in each and every one of the autonomous regions of the state. However, according to the findings of the survey promoted by IMSERSO concerning “The needs, demands and situation of families with handicapped children from 0 to 6 years of age”, in many parts of the country there still exists a certain distance between EI theory, generally considered, and reality. Complaints vis a vis shortcomings in education or prevention programmes, the existence of gaps in sensitive areas, such as diagnostic information or derivation, and the sensation of precariousness in help offered to contain the impact of assuming responsibility for a handicapped child are registered in a high percentage of families. Although the functioning of EI services is rated highest comparatively by families, the demands with respect to the global functioning of the system blur the achievements and projection of EI centres or units, making clear the advisability of revising and updating the range of social, economic and technical resources which are offered to families.

An important area of the review is concerned with the need to be able to count upon a reference guide which makes concrete and guarantee some basic parameters of intervention, which puts into practice the contents of the White Book and the manuals of good practice and serves as an element of contrast and assessment of results for all the parties involved in EI procedure.

This guide seeks to fill this vacuum by creating an instrument of reference which supports those services and professionals most directly involved in EI and which helps to invigorate the coordination and collaboration of the different social, health and educational services. The original statistical indicators of the implantation and offer of Early Stimulation in the Base Centres of the IMSERSO (as obtained in 1980) are still being used nowadays in many units. They concern, as is well-known, a summational formula of evaluation which basically reflects the number of children attended in each area of treatment, the sessions carried out and their duration.

But as is clearly indicated in the EI White Book or the good practice manuals, since then Early Stimulation has undergone a profound shift in focus. Currently, success of professional practice tends to be measured by outcomes in terms of levels of integration, participation and autonomy of children in social environments, the quality of life and the satisfaction of families, accessibility to different contexts or coordination of distinct institutions. Furthermore these variables cannot be accommodated within a purely quantitative assessment of professional processes that are carried out nor can they be measured only by using decontextualized parameters of activity, such as I.Q, degree of spasticity or language emission capacity in isolation. These formulas have already been called into question by modern theories and research, to the point of being downgraded in value as the main or only instrument of control regarding the efficacy of intervention.

The desire to introduce quality criteria, regulations and common objectives that enable one to contrast professional practices beyond the theories attached to them or the statistics indicating hourly dedication, seems to be a wish shared by the majority of people involved in EI. Legislators want to know more about the utility of services, administrators and suppliers, their efficacy; professionals want recognition for their work as well as training and research incentives; parents, whose participation proves decisive, seek objective, concrete elements of guidance concerning that which they can and must expect of EI.

This standards guide is intended as both a resource and stimulus in beginning to create a culture of self and external evaluation in the field of EI throughout the whole of Spain. In this sense, the standards are not intended as a close system of demands but rather as a catalogue of quality factors open to the contribution of different agents. This is an essential working principle to bring the diversity and participation of multiple entities and administrations into line with the coherent regulation of basic offers of help. In this way, the guide will be able to serve diverse objectives:

- ❖ To generate a **culture of quality criteria** which enable the contrast of professional practices
- ❖ To make available distinct **nuclei of evaluation** of procedures and outcomes at the level of community, family and child
- ❖ To introduce instigators and professionals in the culture of **procedural and service management** into the field of EI
- ❖ To offer the **opportunity to demonstrate** that the work carried out is useful and efficacious for those at whom it is aimed and its sponsors
- ❖ To serve as a **stimulus to the initiative for change**, training and research
- ❖ To offer **coherence and collaboration** among the initiatives of varied origin or responsibility
- ❖ To facilitate families with a **formula of identification and participation** in key processes. .

PHASES, PROCEDURES AND
ACTION IN THE ELABORATION
OF THE STANDARDS GUIDE

3. PHASES, PROCEDURES AND ACTION IN THE ELABORATION OF THE STANDARDS GUIDE

From the meetings held by the group onwards the experience surrounding “Quality Standards in Work Integration” has been chosen as a reference point, in the technical aspect, together with assessment and self-assessment formats used in other EI programmes, basically those derived from Head Start in the U.S.A. As far as professional consent is concerned, a Catalogue of Good Practices based on the proposal of the most representative documents of the sector (see section 4.1) has been taken as a starting point. An initial listing of standards selected in accordance with their interest and capacity to provide answers to new social necessities was extracted (see section 4.2). This listing has subsequently been submitted to consultation and assessment by associations of EI professionals, parent’s federations, experts and teams from different areas and communities. With the results of this consultation the final selection of standards and indicators that make up the Set of Quality Standards in EI has been made. (See section 6)

The particular phases and the action proposed in each of them in order to carry out the project were

3.1. Generation of standards

- The configuration of a Catalogue of good practice (section 4.1) as a basic background for generating the standards
- Analysis and development of the initial standards listing, bearing in mind new needs deriving from social change (section 4.2).
- The design of a standards questionnaire for the carrying out of a preliminary consultation (section 5)

3.2. Survey concerning the standards

- Connection with a group of experts and professionals from different fields of EI and who belonged to different organisms, centres and associations of the various autonomous regions.
- Sending of the initial questionnaire to the group of experts and professionals (1st consultation)
- Qualitative and quantitative analysis of the information gleaned from the first consultation and reworking of the questionnaire in accordance with contributions received.

3.3. Production of the set of standards and assessment form

- The establishment of indicators that make the action expressed in each standard concrete, pointing out for each indicator the measures and actions to be contracted with the activity of the programmes.
- Analysis and assessment of the indicators and definitive measures for each standard (A phase in which the EI Group is present)
- Design and elaboration of self-assessment form
- Review and final report



BASES AND CRITERIA OF ELABORATION

4. BASES AND CRITERIA OF ELABORATION

The work of early social insertion of handicapped children, the reinsertion of those who find themselves in situation of exclusion and the collaboration with other social networks in the minimising of risks and the stimulation of factors of protection are central to policies of equal opportunity and non-discrimination regarding the family and infancy within the European Union.

The elaboration of this Standards Guide has been carried out in adherence to a strategy of absolute quality. That is to say, a strategy that regards EI as the influential intervention of networks of people and groups (stakeholders) whose interests and involvement should be taken into account. Thus, care of the child with developmental disorders is the nuclear element in a broader process of needs satisfaction and, in each region or area of integrated services, the structural relationships that may be formed with these standards should be open, as a starting point, to their concrete participative and contextualized development.

From this point of view this guide has been produced with three main criteria as its starting point:

- ❖ Firstly, to bear in mind, as a structural base, the need to incorporate the accumulated experience in the culture of EI, which in the form of **objectives and good practices** contributed by experts and professionals organisations, by parents and their federations, constitutes an outstanding social asset.

To this end, a detailed analysis of the main documents of consensus on the part of professional experts and the associative movements has been carried out, and a generic base of objectives and good practice, organised around the most important fields or dimensions activity in EI, has been extracted:

Principles and objectives, good practice towards the community, cases by casework methodology, good practice with regard to the child the family and the programme itself.

This set of recommendations has subsequently been phased in, sequentially to the point as which a **General Catalogue of Good Practice** has been constituted. With this organisational formula a set of guides has been shaped and laid out which has served as a reference point in the generative process of the initial standards.

- ❖ Secondly, starting from the dynamics of social change, to assess and analyse in each field, what the outstanding risk and opportunity factors are in the evolutionary itinerary of children with developmental disorders and the parties involved in this itineraries (Children, families, community resources). Through the analysis of this emergent tendencies a set of additional needs has been detected which has served as a guide in the appreciation of sensitive points in the selection of the initial group of standards and which are set out as a complementary, orientative element with respect to the meaning of each standard. In this regard, the following necessities have been identified:

- The need to strengthen the child's presence in the new conditions of life, efficaciously protecting thereby her condition of active subject
 - The need to generate stability and sufficiency with greater intensity and within new spheres of family life enabling the family to fulfil their social function
 - The need to sensitise, orient and co-ordinate, community resources toward the child and the family
 - The need to conserve, improve and make competitive the heritage of complexity which the interdisciplinary culture represents in "case by case" methodology
 - The need to promote the culture of self-assessment through "step by step" examination of work procedures and routines.
- ❖ Thirdly, to value the necessity of gathering together in the final guide up to date opinion which is representative of the culture of EI in Spain. To this end a wide-ranging, final process of consultation and revision has been undertaken whose phases and procedures are detailed in the respective section.

4.1. The catalogue of good practice

4.1.1. Background

Since its beginning, as early stimulation, EI has undergone profound changes in orientation in its objectives, in procedures and in fields of intervention. It is impossible herein to offer an exhaustive history of the process of encounter between children, parents and professionals which gave rise to the idea of EI, intervention which has been term of "two generations EI", in the sense that care of the child means achieving the possibility of the carers love for and understanding of the child and of their involvement in a day by day process of active dialogue and negotiation until mutual recognition within the family is attained. But this idea has in recent years formed a main axis in the work of professionals. As the White Book indicates: **"The main objective of EI is that children who reveal developmental disorders or are at risk of suffering such disorders should receive, in accordance with a model which takes into account bio-psychosocial aspects, all of that which from a preventive and welfare point of view might foster her capacity for development and well-being, making possible in the family sense her integration within family, scholastic and social spheres as well as the attainment of personal autonomy"**.

For this reason, in signalling the objectives of EI the White Book emphasises that these objectives are 1) **integration** and 2) **autonomy**, which is to say, two dialectically entwined objectives given that the autonomy, presence and self-esteem of the child in a social context must be met by a climate of sensitive open and responsible acceptance in this selfsame context.

This strategic orientation, based on experience and observation has recently been endorsed by studies that has researched contextual importance in child development and which place the quality of interaction between the child and his carers as the most relevant question in infants care in general and in EI in particular.

The results of the research being carried out in the U.S.A. by the National Institute of Child and Development (NICHD) affect, in this sense, the core of any system of infant services and moreso, if possible, those services for children with developmental disorders. The recognition of the extraordinary value of **carer sensitivity** in constituting a **secure attachment**, and the importance of the relational asset as the basis for the participation of the child in the social world and her exploration of its surrounding, becomes an **inevitable point of departure in any programme of quality**.

As far as the study on infants care by NICHD is concerned, it should be pointed out that it is the most complete research concerning child development that has been carried out to date. In 1991, a team of researchers included 1.364 children in this study and the team has monitored their progress exhaustively since then.

Since 1998 the research team has presented its conclusions regarding the relationship between early care in childhood and development to the age of three, and is currently continuing the analysis of information being gathered from ten study centres scattered throughout the U.S.A. The results of the NICHD study sanction and confirm conclusions that form the core of thinking regarding the experience of EI throughout the last twenty years.

Boxes 1 and 2 reflect some results of the aforementioned study.

BOX N.º 1

NICHD STUDY ON CHILD CARE (FIRST RESULTS) (1998)

- 1) Higher quality child care (positive provider-child interaction) modestly predicted greater involvement and sensitivity by the mother (at 15 and 36 months) and greater positive engagement of the child with the mother (at 36 months). Low-income mothers using full-time higher quality care had higher positive involvement at 6 months than low-income mothers not using care or those using lower-quality full-time care.
- 2) The researchers found that more hours of care in the first 6 months of life were associated with lower maternal sensitivity and lower child positive engagement at 36 months. However, a combination of family and home characteristics, including income, maternal education, two parent family status, maternal separation anxiety, and maternal depression, predicted the quality of mother-child interaction more than the children's experiences in child care
- 3) The quality of childcare over the first three years of life is consistently but modestly associated with children's cognitive and language development. The higher the quality of child care (more positive language stimulation and interaction between the child and provider), the greater the child's language abilities at 15, 24, and 36 months, the better the child's cognitive development at age two, and the more school readiness the child showed at age three

BOX N.º 2

NICHD STUDY. SOME CONCLUSIONS (1998)**Higher quality care was found to be related to:**

- Better mother-child relationships.
- Lower probability of insecure attachment in infants of mothers low in sensitivity.
- Fewer reports of children's problem behaviours.
- Higher cognitive performance of children in child care.
- Higher children's language ability.
- Higher level of school readiness.

The converse is also true. Lower quality care predicted:

- Less harmonious mother-child relationships.
- A higher probability of insecure mother-child attachment of mothers who are already low in sensitivity to their children.
- More problem behaviours, lower cognitive and language ability and lower school readiness scores

Higher quantity of care or a history of more hours in child care was associated with:

- Less harmonious mother-child interaction.
- Mayor número de problemas de conducta cuando los niños alcanzaron los dos años.
- Mayor probabilidad de apego inseguro en los niños de madres bajas en sensibilidad.

Lower quantity of care is associated with:

- Better outcomes for mother-child interaction.
- Lower probability of insecure attachment of infants of mothers low in sensitivity.
- Fewer problem behaviours at 24 months.

4.1.2. Good practice

If, on the one hand, the differentiation of formal structures or the adoption of diverse models or techniques has led to significant deregulation and blurring of the original profiles of early stimulation, on the other hand its utility as an enriching and invigorating factor within the experience of EI must be recognised. It is impossible to enumerate the courses, conferences, congresses, symposia and meetings, of a primarily interdisciplinary character, which have been held in Spain over the last twenty years, having as their central axis of reference aspects relating to children with disabilities. Such has been the mobilisation in the area of work training on the part of Spanish professionals, the sustained interest in the learning of techniques, in the understanding of every kind of model of intervention, in the grasping of family and group dynamics, in innovation in the technology of disability, among other themes, that it would be tedious to recount in detail. The meetings, the accrued experience with the passing of the years, everyday working relationships with children and parents, access to other ideas and research, have changed the perspective and foci of Spanish professionals who have spent many hours with children and families in wards, in EI centres, in households and schools. The doubts, the questioning and restlessness which these hundreds and thousands of daily situations have generated, is reflected in the vigorous motivation toward the interchange of knowledge and ideas which we have already indicated. The meetings and conferences of every kind have always taken place with one common denominator in mind: the multitudinous participation of professionals and increasingly of parents in these forums. Extensive agreements has been generated by this “practical culture”, whose empirical nature does not detract from its interest or applicability and which, as we have seen, goes beyond the limits of local experience.

With early stimulation the path of social integration of children with deficiencies was initiated in Spain, as was their incorporation into networks and common resources of health, education, leisure and free time. In a sense, with the advent of early stimulation a prolonged historical period was brought to a close. In the preceding period, (up to 1980) deficiencies meant stigmatisation and social exclusion. Children with poor eyesight, hypoacusis, paralysis or cognitive handicaps were to be slotted into the category of subnormal and destined, in general, to be institutionalised in special centres. Subsequently, in accordance with social change, with the application of the principles of the Spanish Constitution, and integration in European Union, new ambits of participation in daily life have been opening up, multiplying family experience and the awareness of factors which, in each context, facilitate or impede their access and intervention. The presence of children with distinct syndromes and developmental disorders in ordinary educational centres especially, but also in the street, in parks, in general practitioners’ consulting rooms and in leisure and “free time” centres, has been changing the perspective of families and society in general. An initial achievement of early stimulation may have seen, precisely, the instigation of this contextual plurality, the furthering of mutual knowledge, the uprooting of prejudices and the social acceptance of handicap. Through these daily relationships new social images of handicapped children have been woven, images charged with positive symbolism and which attribute possibilities and abilities to those who were previously merely the object of rejection and discrimination.

The new relationships and possibilities for their sons and daughters led to an enormous development in parents associations, both specific and general, and the constitution or strengthening of federations or their presence in handicapped peoples organisations and

other non-governmental organisations (ASPACE, COCEMFE, CNSE, CRECER, FEAPS, FIAPAS, FEISD, FESPAU, ONCE etc.) many of which, subsequently grouped together in CERMI. From this associative movement was gathered, over time, the particular testimony of each family, their aspirations, the difficulties and facilities specific to each community, the extraordinary necessities which not only disabled children, but also their parents and brothers and sisters have to face. In general the day-to-day significance of living as a disabled, the encountering of demands and cultural barriers or marginalising social attitudes: all this flow of information has been channelled from the encounters with parents, stored and filtered and finally distilled into the identification of shortcomings and solutions in public context and the discrimination of sufficiency of the community's contribution.

4.1.3. Integrating experiences

The great European programmes involving interchange of experience and good practice formed the framework which during the nineties, facilitated the convergence of professional and associative experience and the elaboration of a set of documents, which due to the extent of collaboration, the wide-ranging nature of debate, and the level of agreement reached, nowadays constitute an essential reference point in the professional activity of EI

A detailed analysis of its content has been carried out in order to identify those aspects that achieve a greater level of agreement or consensus, an essential prerequisite in any project of standardisation. Accordingly, a set of objectives, procedures and organisational formulas has been grouped together which make up a representative catalogue of the culture of EI and which has served as a procedural base on the initial generation of standards and their grouping together in terms of areas or dimensions of action:

- Principles and objectives.
- Good practice toward the community.
- “Case by case” work methodology.
- Good practice with regard to the child.
- Good practice with regard to the family.
- Good practice with regard to programme itself.

In Box 3 some documents which have contributed towards the reflection and contrast in defining the aforementioned points, have been gathered together.

BOX N. °3

DOCUMENTS

Functional Rehabilitation. Thematic group n° 3.7 of European Programme Helios II (1996)

Early Intervention. Information, Orientation and Guidance of Families. Thematic group 2.1 of European Programme Helios II (1996)

Grupo de Atención Temprana-GAT (2000) :Libro Blanco de Atención Temprana.White Book on Early Intervention. Real Patronato sobre Discapacidad

Manuales de Buenas Prácticas. Handbooks on Good Practice. Guidelines and recommendations of Spanish Federations of Parents Associations :

- **Manual de Buenas Prácticas de FEAPS.**
- **Manual de Atención Temprana a niños con ceguera o deficiencia visual. ONCE.**

In the following charts we have summarised the practices and principles of actuation which are recommended in these documents.

BOX N. 4

HELIOS. REHABILITATION AND FUNTIONAL ADAPTATION (1996)

Principles and objectives	Good practice towards the community	“Case by case” work methodology	Good practice with regard to the child	Good practice with regard to the family	Good practice with regard to the program itself
<p>1. To give support in order to facilitate integration in the the family, the school and the society</p> <p>2. Developing child autonomy</p> <p>3. Promoting equal opportunities</p> <p>4. Prevention of risk factors</p> <p>5. Prevention of secondary disabilities or side effects</p> <p>6. Promoting decentralisation, district and local services</p>	<p>7. Early detection and referral</p> <p>8. Coordination with health networks</p> <p>9. Coordination with the educational resources</p> <p>10. Coordination with social services</p>	<p>11. Assessment and intervention cannot be considered separately</p> <p>12. Inter/transdisciplinary approach</p> <p>13. Understanding family dynamics</p> <p>14. Developing an integrated individualised report</p> <p>15. Key person working with parents</p> <p>16. Flexibility</p>	<p>17. To prevent isolation and provide services in normalised settings</p> <p>18. Early provision of technical aids</p> <p>19. Providing learning experiences and self-regulation activities</p> <p>20. Monitoring child development</p> <p>21. Facilitate integration into regular schools</p> <p>22. Barriers elimination, specialised equipment, curriculum adaptation</p> <p>23. Provide therapy at school or immediate surroundings</p>	<p>24. EI should be cost-free</p> <p>25. Parents partnership</p> <p>26. Enhancing morale, decreasing stress, helping parents to express their feelings</p> <p>27. The family must be thoroughly informed about the nature of impairment</p> <p>28. Support to the family adapted to cultural and individual characteristics</p> <p>29. Facilitate access to self-help groups</p>	<p>30. To evaluate quality and effectiveness of teamwork practices</p> <p>31. To evaluate teamwork dynamics</p> <p>32. To evaluate transfer of knowledge to and from the family, the team and the society as a whole</p> <p>33. To promote ongoing training in specific and global techniques, teamwork dynamics, child development</p> <p>34. Need of standardised postgraduate training</p> <p>35. Prevention of burn-out syndrome</p>

BOX N. ° 5

EARLY INTERVENTION. HELIOS II (1996)

Principles and objectives	Good practice toward the community	“Case by case” work methodology	Good practice with regard to the child	Good practice with regard to the family	Good practice with regard to the program itself
<p>1. Holistic approach</p> <p>2. Supporting families in everyday situations</p> <p>3. Integration of children in pre-primary and primary schools</p> <p>4. Preventive measures to avoid secondary disabilities</p> <p>5. Stimulating child development at an early age</p> <p>6. Supporting transition to pre-primary and primary schools</p>	<p>7. Early intervention should start as early as possible</p> <p>8. Decentralisation Network of local services</p> <p>9. Changing social perceptions with regard to children with disabilities</p> <p>10. Cooperation between early intervention and other child-oriented facilities</p>	<p>11. Interdisciplinary teams</p> <p>12. Cooperation parents-professionals</p> <p>13. Cooperation children-professionals</p> <p>14. Assess abilities and possibilities not just deficits</p> <p>15. Setting short and long term objectives</p>	<p>16. Services should be placed close to the child's living area</p> <p>17. Encouragement of child self-initiative</p> <p>18. Giving the child a language to communicate (verbal and non-verbal)</p> <p>19. Mainstream schools</p>	<p>20. Special attention when communicating “bad news”</p> <p>21. Being respectful with parents as primary decision-makers</p> <p>22. Strengthening parents competencies</p> <p>23. Dealing with personal and family dynamics</p> <p>24. Information and counselling</p> <p>25. Cooperation between parents and experts in fostering the child</p> <p>26. Rebuilding social networks</p> <p>27. Parents groups</p> <p>28. Services should be close to the living area</p> <p>29. Supporting economic and organisational issues</p>	<p>30. Supplementary training and postgraduate education for specific areas</p> <p>31. Team-oriented supplementary training and postgraduate education</p> <p>32. Supplementary training for the head of the team</p> <p>33. Encouraging research into topics such as: Diagnosis, intervention, counselling,...</p> <p>34. Longitudinal studies</p> <p>35. Cooperation at local, regional and European level</p> <p>36. Cooperation between professionals and parents associations</p> <p>37. Define quality standards</p> <p>38. Parents questionnaires</p>

BOX N. ° 6

WHITE BOOK ON EARLY INTERVENTION (2000)

Principles and objectives	Good practice towards the communityd	“Case by case” work methodology	Good practice with regard to the child	Good practice with regard to the family	Good practice with regard to the program itself
1. Integration in the family, the school and the society	8. Collaborative network of primary and specialised services	12. Functional, syndromic and ethiological diagnosis	16. Developmentally appropriate intervention	20. Appropriate information regarding diagnosis	24. “Second generation” Research
2. Encouraging child autonomy	9. Early detection and referral of developmental disorders and risk situations	13. Interdisciplinary assessment of the child and his/her context	17. Protecting mother-child relations	21. Provide ongoing support in upbringing practices	25. Ongoing training in specific and global aspects
3. Optimising Development	10. Network of Child Development and Early Intervention Centres (CDEIC)	14. Individualised early intervention plan	18. Encouraging child self-initiative	22. Protect and support transition periods	26. Ongoing training in group dynamics
4. Providing appropriate aids	11. Interagencies networks	15. Follow-up	19. Providing technical, educational and therapeutic support.	23. Provide family with resources, information and support according to their needs	27. Ongoing training in contextualised knowledge
5. To prevent undesirable secondary effects					28. Working out risk indicators
6. Delivering early intervention through decentralised cost-free services					
7. Encouraging children as active subjects of their own life					

BOX N. ° 7

HANDBOOK ON EARLY INTERVENTION - FEAPS (2000)

Principles and objectives	Good practice towards the community	“Case by case” work methodology	Good practice with regard to the child	Good practice with regard to the family	Good practice with regard to the program itself
1. Quality of life	7. Coordination for prevention and early detection plans	14. Interdisciplinary assessment	19. Encouraging self-esteem and self regulation skills	29. Active family involvement	35. Quality criteria
2. Holistic approach and development of relational, functional and leisure-related aspects	8. Community action plans	15. Assessing needs	20. Promoting child autonomy	30. Cooperation parents-professionals	36. Confidentiality Privacy Dignity
3. Family active involvement	9. Inter-agencies agreements with regard to “bad news” and early referrals	16. Individualised Plan	21. Acknowledging of the child as a subject	31. Encouraging parents participation	37. Systematisation
4. Social integration and adaptation of environments	10. Coordination of community resources	17. Family active involvement	22. Learning social skills	32. Giving help for parents welfare	38. Planning
5. Equal opportunities	11. Shared agenda for meetings and main events	18. Unified forms for case records	23. Developing school skills and readiness	33. Giving help for everyday routines	39. Continuous training.
6. Prevention of side-effects	12. Early Intervention Centres Network		24. Encouraging self-care	34. Giving help for upbringing and educational practices.	40. Self-assessment and ongoing evaluation
	13. Community actions to increase social awareness about EI		25. Home based activities		41. Research into evaluation
			26. Health and safety		42. Research into cost effectiveness
			27. Leisure activities		43. Staff stability
			28. Home-based, school-based and centre-based support		

BOX N.º 8

**HANDBOOK ON EARLY INTERVENTION OF CHILDREN WITH
BLINDNESS OR VISUAL DEFICIENCIES –ONCE (2001)**

Principles and objectives	Good practice towards the community	“Case by case” work methodology	Good practice with regard to the child	Good practice with regard to the family	Good practice with regard to the program itself
1. Help children and families to adapt to new situations 2. Promote child development socialisation and integration 3. Prevent side effects 4. Family support group	5. Coordination with community resources 6. Early detection of developmental disorders and risk situations 7. School support and help to curriculum adaptations 8. Develop training and supervision 9. Develop social awareness	10. Gather information 11. Interdisciplinary assessment 12. Ongoing assessment of child, family and environment 13. Individualised plans	14. Facilitate child global development 15. Offer the required technical aids 16. Give individualised attention, taking into account overall situation 17. Peers groups integration	18. Support mourning and bereavement processes 19. Give information and counselling 20. Help to take on children 21. Induce self-generation of resources 22. Parents self-help groups	23. Analysis of clinical and psychopedagogic tools 24. Facilitate information regarding statistical data

In this way, a large set of good practices (n=166) could be listed. Afterwards, this set was synthesised and grouped together according to dimensions of action and subsequent phasing in until making up a basic framework (n=106) in the generative process of the initial standards (n=37)

Early Intervention Principles and Objectives

- Thinking of child as the active subject of early intervention
- Active involvement of families
- Quality of life
- Equal opportunities
- Preventing risk factors
- Early detection and immediate referral
- Preventing secondary effects
- Holistic approach
- Promoting and encouraging development
- Helping child and family to find out new ways of adaptation
- Giving support to the whole group
- Facilitating developmental progress, autonomy and socialisation in overall contexts of life
- Providing the aids needed to facilitate accessibility or adaptive skills
- Facilitating smooth transitions to pre-primary and primary school.

Good practice towards the community

- Early detection and intervention in neonatal services
- Special attention to the impact of diagnosis
- Promoting early detection at paediatric centres, pre-primary and primary schools, social services

- Promoting early detection and immediate referral of developmental disorders and risk situations
- Improving primary and specialised services collaborative work
- Coordination with health services
- Coordination with educational system
- Supporting school and individualised curriculum
- Coordination with social services
- Promoting community awareness and non-discriminatory social attitudes
- Ongoing training and supervision.

Good practice with regard to the family

- Family involvement
- Attaching special importance to diagnostic information
- Protecting transition phases
- Giving support to mourning and bereavement processes
- Giving support to the process of taking on children
- Giving support to the process of personal adaptation
- Providing stability for upbringing practices
- Providing accurate information
- Being respectful with parents as primary decision-makers
- Partnership
- Encouraging self-esteem and sense of competence
- Delivering services in normalised, natural settings
- Delivering services nearby family dwelling
- Facilitating resources for the reorganisation of family routines

- Providing help in everyday situations
- Self-help groups
- Parents' groups
- Parents' schools
- Building up social relationships
- Cost-free services
- Providing resources, information and orientation on request

Good practice with regard to the child

- Spending life in normalised, natural settings
- Encouraging self-initiative
- Encouraging self-esteem
- Developing a language (verbal, non-verbal) to facilitate social relations
- Developmentally-appropriated intervention
- Providing stimulation in all areas of development
- Encouraging adaptive, functional skills
- Empowerment practices
- Supplying technical and educational aids
- Eliminating barriers
- Providing learning and autonomy-oriented experiences
- Integration into mainstream schools
- Providing therapeutical aids in natural settings
- Taking part in peer's activities
- Protecting transitions phases

- Ensuring health condition and safe surroundings
- Living at dwelling
- Providing play and leisure opportunities

“Case by case” work methodology

- Collecting and gathering information
- Joining assessment and intervention
- Dialogue parents-professionals
- Dialogue children-professionals
- Evaluating abilities and possibilities, not just deficits
- Inter and transdisciplinary assessment
- Interdisciplinary assessment of the child and his/her context of life
- Functional, syndromic, etiologic diagnosis
- Ongoing assessment
- Dealing with personal and family dynamics
- Drawing up individualised programmes
- Key worker or case coordinator
- Flexibility
- Setting targets and monitoring outcomes
- Unifying case records

Good practice with regard to the programme itself

- Guaranteeing confidentiality, privacy
- Systematisation, planning

- Evaluating teamwork performances
- Assessing teamwork dynamics
- Transferring knowledge among stakeholders
- Evaluating families' satisfaction
- Self-evaluation practices
- Promoting EI training, in-service training, with particular attention to wide-ranging topics
- Encouraging cultural sensitivity
- Deep-rooting into contextual knowledge
- Staff stability
- Highly qualified staff with postgraduate training
- Preventing burn-out
- Encouraging “second generation” research
- Studying diagnostic effects, group dynamics ...
- Evaluating early intervention outcomes
- Evaluating criterion-referenced tools
- Local, regional, national and international cooperation
- Cooperation between parents associations and expert groups
- Facilitating information regarding summative evaluation
- Elaborating indicators

Good practice in delivering services

- Creating Child Development and Early Intervention Centres (CDEIC)
- Developing Child Development and Early Intervention Centres networks
- Decentralising functions

- Improving collaborative work among local services
- Sectoring
- Cost-free services

4.2. Social change and new necessities

The formation and development of families guided by methods of upbringing and educational models that are coherent is recognised as one of the pillars of social well-being. Over and above any typological diversity or range of cultural values, parental function proves vital in the balanced development of the children and their responsible participation in social life. However, it must be borne in mind that children and parents are formed through their **internal relations**, within the family, and **externally** through contact with other families, institutions and activities in the community of which they form part. These are principles that have filtered down through the most disparate societies and cultures as a kind of historical legacy. However, in order that they should be functional in each epoch or at each historical moment, they require adaptation that takes into account the decisive traits in social life.

As society changes, the evolutionary itineraries to be found regularly throughout the life of the child and the transverse alternatives that present themselves in her proximity at each phase of development undergo modification or transformation. In the previous historical period, the hegemony of the family meant that it represented the first step on a path which led to obligatory schooling at the age of six. In the traditional patriarchal family, the father worked away from home while the mother stayed at home occupying herself with the tasks “proper of a housewife”. There existed a strong connection with networks of relatives of the families of origin and relative independence from other social resources. The upbringing and education of the child was settled with the passing on of a traditional culture and socialisation was a natural product of life in the extended family which rested upon:

- *The passing on of a supervised method of practice from mothers to daughters*
- *Anticipation of the mother role: “girls games”, dramatisation games with dolls...*
- *Experience with the upbringing of brothers and sisters and other relatives.*
- *The assessment and care regarding feelings from infancy.*
- *The inseparability of woman/mother/housewife in the patriarchal model*
- *The oral transmission of remedies and empirical observations*

In fact, the period up to the age of 6 has even been talked of as that of primary socialisation and the subsequent period as secondary socialisation.

But this reality has been undergoing modification during the last few years. The incorporation of women into the labour market, the difficulty in conciliating family life with work, geographical mobility, nuclearisation and the loss of networks of relatives in the families of origin, the weakness of matrimonial ties or the loosening of bonds between couples in general, generate new kinds of family and the home is not always the stable and exclusive stage in the infants itinerary, nor the place where a child can find herself with other children or be cared for by other relatives, that it used to be. Her life unfolds from a very early age, in different care centres, in the so-called non-places of globalisation, in contact with people other than her parents and with the continued presence of video and television (up to three hours daily on average).

The itineraries which await children born nowadays are much more open but probably more fragile than those which existed in the “immediate past”. Previously, situation of deficiency or shortcoming were concentrated in certain social sectors but these problems are becoming widespread. Nowadays, we have **greater social mobility**, with more opportunities but also with a wider distribution of risks. Spain is one of the countries in Europe in which because of its “starting conditions” one might expect greater social mobility, both upwards and downwards. This social opening-up has potentially positive effects as far as infancy is concerned, but its effects may be also negative, among them the creation of an extensive **backdrop of social fragility in early childhood**.

- *The risk of deficit in the socialisation of the child, due to the growing tendency towards nuclearisation and the diminution of centres of coexistence, the loss or absence of social networks or because of distance from or the cost of alternative resources which may render them inaccessible during periods or at times of the day when they are really required. At the time of upbringing situations of isolation, neglect, non-places, hours of video and television increase.*
- *The risk of overburdening upon one of the members of the unit of coexistence, the one who spends most time with the child, usually the mother due to the lack of democratisation in the family; situations of single parenthood originating from common law or legally married couples, the difficulties produced when both parents work...*
- *The risk of instability as a consequence of the weakening in the ties of coexistence and the demands of the work mobility or the excesses of and defects in parent’s expectations and their styles of upbringing. There is a lack of continuity in routines of people in charge or responsible, educational models...*
- *The risk of insecurity vis a vis the sensation of not controlling changes and the increasing ignorance regarding the content of parental function. There is growing confusion of priorities and values in early socialisation that accompanies anything which smacks of domesticity or welfare, which contrasts with the search for educational specialisation or early exposure to high technology (music, English, computer studies, etc). The first child which some late parents know is their firstborn...*

The existence of this extensive backdrop of risk manifests itself in symptoms as the sharp decrease in the birth rate (up to 20% of the European women do not even contemplate the idea of having children), in the difficulty in lowering the rate of prematurity

(7%) and very low weight (0'6%), the increase in so-called “invisible handicaps” in early childhood and the very urgency with which the political and technical demands within the European union propose laws or recognise **the need for a sustained strategy of support for the family and infancy which facilitates:**

- Responsible motherhood and fatherhood
- Support of economic stability and sufficiency
- The establishment of obligatory and optional periods of parental leave
- The availability of nearby networks of substitute care (formal and informal) which guarantee the reconciliation of safety with freedom of choice
- The offer of training programmes and opportunities for setting up the social networks
- The design and stimulation of new spaces of coexistence for families, young children and adolescents

This widespread recognition of obligation regarding children and families as a whole must alert EI units and centres as to the presence of **additional necessities** for children with developmental disorders and their families. Necessities that are different from those existing previously. In this direction it is as well convenient to remember that for years EI programmes have been pioneering the provision for handicapped children of those elements which nowadays are seen as necessities to be attended to in children with no handicap and, in this sense, the spread of the culture of quality in EI among the new professionals, who are going to share the care and upbringing of the children with their families, could represent a very significant contribution in the process of substitution of the traditional culture of upbringing by a scientific culture which is adapted to the new society.

4.2.1. The need to strengthen the child's presence in new contexts

In the last few years there has been an appreciable, progressive growth in sensibility and responsibility in Spanish society in all that concern wellbeing in childhood. After the passing of the Constitution in 1978, the Convention of the Child's Rights was ratified on 26th January 1990. It promotes protection against any form of discrimination (article 2), defends the best interest of the child as a prime consideration (article 3), the right to life and development (article 6) or the right to express her opinions freely in the matters that concern her (article 12).

At present, in a context of social change and cover of necessities in health, education or protection against manifest abuse, knowing how to interpret and respect the opinions of children, even those very young or with greater difficulties in communicating their wishes or promoting their active presence in social situations, is becoming a fundamental concern in policies of social inclusion aimed at childhood, in the more advanced countries.

In the traditional family, when the mother undertook, totally and sustainedly, to take charge of upbringing, education and early socialisation, the active presence of boys and girls in social life during the first and most delicate months of life was the sine que non of mothering. Becoming mothers and daughters, beyond the purely biological sense, was, in effect, the

culmination of a long and continued period of dialogue between both parts. By protecting the health of each, enough was done to facilitate this outcome. Nowadays, however, as we know, the situation is different. The development of a secure attachment is recognised as a process which is influenced in a far-reaching manner, not only by the presence of sensitive carers, but also, as experience with premature babies or handicapped children makes us aware, by the ability to understand and recognise these alternative ways of being, their peculiarities of expression, states of irritation, sleepiness or tranquil wakefulness.

In the newly emergent conditions of social life, Child Development and Early Intervention Centres will have to increase the support they offer to parents, hospital nursing staff and alternative child carers in some essential aspects of child development which form part of their cultural baggage:

- **With respect to health**, to know that the presence of serious illness, of pain and suffering are not satisfactory conditions in which to demand that the child exert himself in heeding his setting or surroundings. Critical perinatal situations, chronic illnesses or operations that involve hospitalisation bring them to face with situations of prolonged stress, carer instability, separations, isolation, loneliness... This are situations in which everybody who looks after the child must do his utmost to take care of the ecology of the child's environment, of his protection and to make him feel accompanied while his organism makes the effort to recuperate.
- **With respect to immaturity**, as in the very premature, the children have to devote a great deal of time to the regulation of visceral and sensory phenomena which accompany this lack of maturity: pain, cold, lack of sleep, hunger, thirst, excess of stimuli, the inconvenience and discomfort of technical apparatuses and sanitary routines may put his precarious equilibrium and control to the test. It is essential that parents and hospital staff know how to keep him in a protective environment ecologically-speaking, one which is relatively unaggressive sensorially in order to avoid overstimulation, to maintain a stable staff and to facilitate the presence of and contact with relatives, etc.
- Great immaturity, acute illness, periods of want and lack (sleep, hunger, thirst...) are examples of situations in which biological demands- state of health or maturational frailty of the child – must take precedence over any other demands or social considerations. When a child cries, out of hunger or due to sleepiness or pain, this is the issue that has to be shared and, if possible, solved.
- **With regard to biological otherness**, being different due to deficiency or handicap, the understanding must be extended that this otherness means a further limitation in the child's adaptive capacity, that it may hinder the expression and recognition of her needs, that it may create difficulties in orientation or anticipation regarding the actions of others or in feedback with respect to her own. However, her status as subject actively present in social situations must not be diminished
- **Regarding the status and competence of the child**. the outdated idea that, from a relational point of view, the very young child neither feels nor suffers has been discarded. However, in professional circles and in society in general, there are still sectors which are unaware of the child as a competent individual who is sensitive to social reflection. This occurs with greater frequency if the child has an unexpected

or strange appearance owing to his handicap. The protection of status makes reference to this acknowledgement of the child as a subject with the right to be recognised and respected. The protection of status is a fundamental premise in the quality of relationships which must figure in the forefront of EI programmes and in the formation of new parents, alternative carers and community resources professionals. These must learn to recognise and prevent the wide range of hidden forms of abandonment or neglect and rejection which they may end up lending themselves to, very often due to ignorance or lack of knowledge:

- It is important, for example, to recognise the difference between being integrate in the family, school or society with being physically present. The child is into these places but does not participate in the respective situation. Her opinion is not expected or asked for, nor are her initiatives reflected. The distancing may find expression not only in physical withdrawal and isolation but also in a symbolic sense: disregard, not taking her into account, not asking her, leaving her initiatives to fall onto “stony ground” to remain unfulfilled.
- Neglect of the child’s right to a private space, characterised by the oblivious invasion of her personal space in very direct ways or through overstimulation. Excess of care or stimulus may prove as detrimental as the lack thereof. This risk factor must be kept very much in mind as far as preterminal premature or ill children are concerned. These are children who need to devote a great deal of energy to self-regulation, children with motor functional or sensorial limitations who have fewer resources for self-protection.
- The maintenance of an open or concealed institutionalisation with excessive timetables nurseries, hospital and residential centres. The NICHD findings urge the study of formulas and alternatives to periods of stay in care centres.
- Giving prevalence to the interest of family or professionals over those of the child. A farreaching question insofar as children may be victim of any excesses or deficiencies surrounding a treatment at the whim of an unassessed technique, statistical reviews and so on

To sum up, the quality of EI and other social services and structures which deal with infants depends, in large measure, on the consideration of the child as an active subject who builds his knowledge, perceptions, values and feelings in close interaction with the context in which he lives or with those to which he relates, be at school, family, his peer group or the media. The need to be attentive to and to ensure respect for his biological condition, state of maturity or his different way of adapting to social life is paramount. By attending to this need the child’s liberty and opportunities for decision-making may be protected.

4.2.2 The need to generate stability and adequacy in new spheres of social life

80% of mothers of children under the age of six, in the Community of Madrid, on being asked about the implications for them of the arrival of a newborn child, stated that it had reduced the amount of time available for other things and fundamentally, time for personal care. This characteristic of permanent availability which assuming responsibility for the care of a child implies, strengthens the parallelism in degree of dependency between little children and ill people, situating homes with young children as those with a greater demand for care.

It has been calculated that the amount of time spent on care in homes with children is 5 times greater than that which devolves upon an active adult, if the child is under 4; and 4.7 times if the child is between 4 and 14 years of age

To have time available in quantity is to reckon with an asset that may be used in varying degrees and with different intensities for relating to the child:

- As time lived and shared in emotive interaction which constitutes one of the main factors in the quality and sensibility of care.
- As a time of affectionate devotion in which, although there is no direct interaction, the carer is aware of and attentive to the child, ready to cater for her needs or to interpret her demands, to take her out for a walk and so on.
- As a time of reflection upon experiences which have been lived through and the course of development.
- As a time of provision and distribution of food, medicine, nappies or toys
- As a time of rest for necessary separation and the regaining of strength and availability.

The lack of leisure or free time possibilities is a concern which still occupies a minor place in the panel of resources and alternatives which are on offer to the families of children with developmental disorders but it proves to be the most common complaint among the majority of those polled in the wide-ranging sociological study on the “Needs, demands and situation of families with handicapped children up to the age of “, recently published by IMSERSO. This poll offers a panoramic survey of opinions and data which reveal the consequences of the confluence of parent-day life conditions with the assuming of responsibility for a handicapped child.

Some findings of this study, which are detailed in tables I and II, arranged in terms of temporal phases and the context involved, highlight the substantial imbalance between resources offered and the repercussions and needs which are felt by parents who take on the responsibility of caring for a handicapped children. Although a great majority (80%) claim to have “assimilated” his presence, 58,6% said that they felt a negative repercussion, which indicates that assimilation does not diminish awareness regarding the poor evolution of their projects in life as a whole.

It is interesting to note that, in its qualitative and quantitative phase, this survey confirms the identification between the process of mourning and the “taking on“ of a handicapped child, with **comparable psychosocial aspects of other processes of social exclusion**. The feeling of guilt, frustration and despair, the feeling of rejection and social isolation, the mistrust on the future and the impotence... These are the experiences which characterise exclusion and lack of social recognition which also bound up with the intensity of the dynamics of pre-existing social mobility.

There are three aspects which, in accordance with experience gained in EI and in turn corroborated by this survey’s findings, require **urgent** consideration as fields of intervention: appropriate communication of diagnosis, stability in the transition to family life and help against exclusion.

TABLE I

**NEGATIVE IMPACT OF “TAKING ON”
A HANDICAPPED CHILD**

THEMATIC FIELD	WORSE	MUCH WORSE
Family relationships	16'6	1'2
Family relationships	16'6	1'2
Friends relationships	21'1	3'4
Adaptation to new environmental conditions	33'9	4'8
Working or professional status	31'7	5'0
Personal well-being	42'7	5'4
Economic situation	47'8	7'6
Possibility for free and leisure time	59'6	16'8
Total	58'6	

Source: Based on published data from the survey “Necesidades, demandas y situación de las familias con menores discapacitados 0-6”. IMSERSO. Madrid 2000.

TABLE II

**NEEDS AND DEMANDS IN FAMILIES OF HANDICAPPED CHILD UP
TO AGE 6**

DEMANDS	%Total	Grave
Prevention and communication of diagnosis		
Lack of appropriate information regarding preventive measures	58'9	
Delay in diagnosis	47'0	
Subjective assessment of child disability	43'8	
Diagnostic disparity	36'3	
Waiting lists, delays in appointments	48'8	
Lack of sensitiveness in the passing on “bad news”	49'9	
Inadequate background of staff	40'0	
Orientation and Early Intervention		
Delay in referral to early intervention	69'8	31'2
Delay in starting orientation processes	66'1	33'9
Inadequacy of child development after orientation	27'8	8'4
Lack of influence of orientation on families' activities	24'3	9'6
Social Integration		
Attitudinal and physical barriers against social integration	81'4	25'6
Lack of appropriate expectatives	38'0	15'0
Insufficient support for free time and holidays	44'2	
Shortage of subsidies for special transportation	62'6	
Inadequacy of psychological support	42'2	
Shortage of subsidies for technical aids	63'5	
Insufficient home-based support	64'5	
Economic deprivation	48'0	30'0

Source: Based on published data from the survey “Necesidades, demandas y situación de las familias con menores discapacitados 0-6”. IMSERSO. Madrid 2000

A) The communication of diagnosis in an appropriate manner

Parents recount that this is one of the most important moments in the process of assimilation of handicap. However, despite the recognition of this fact by EI professionals there is still a serious gap in the social services regarding this matter. Care in the passing on of “bad news” is one of the touchstones of the child’s inclusion in the family as, in the act of communication, society is “represented” by the professional who passes on the information. In table 9 several factors to be borne in mind are detailed, notably:

- That the information should be offered in the presence of the parents and the child in a straightforward and serious manner, given that the news denotes bereavement.
- That always addressing the child by her first name seems the simplest way of underlining the fact that the child is their son or daughter over and above any other consideration
- That, at the moment when parents ask for guidance, continuity in the chain of social responsibility must be forthcoming. It is the moment at which to refer them to other professional opinions –if required- and to EI, as a meeting point and place of refuge for the family, thereby ensuring that society does not appear to lack alternatives, leaving parents in the wilderness.

BOX N.º 9

**COMMUNICATION DIAGNOSIS:
FACTORS OF RISK AND PROTECTION**

FACTORS OF PROTECTION	FACTORS OF RISK
Sensibility	Indifference
Interprofessional coherence	Interprofessional disparity
Phased timing	Abruptness
Chain of social resources: offer of the right to consult other professional opinions	Lack of alternatives
Emphasis of the uniqueness and ability of the child	Offering only a uniform and negative image of deficiency
Calling the child by her name	Labelling the child with the name of the syndrome “these children”
Giving the news face to face with the parents	Giving the news separately
Using comprehensive language	Using opaque language
Giving time to come to terms with the situation and to put forward questions	Not offering space, time or opportunity to the family for dialogue or questions

FACTORS OF PROTECTION**FACTORS OF RISK**

Serious and respectful treatment	Trivialised and dramatic treatment
The accompanying of parents who are alone by a person whom they know	Lack of consideration for parent's solitude
Flexible criteria which may be adjusted to each situation	Rigid or prejudged formulas
Offer the EI consultation	Leaving no alternatives
Limiting oneself to one's own field of knowledge and area of intervention	The setting up of governing bodies which can plot the family itinerary

Source: Authors

B) Provide stability in the transition to the new family setting

The presence of almost 70% of families who report a certain delay in being referred to EI and some 31% who recount serious delay, is another of the blackspots which the survey highlights. Furthermore they concern delays which could be avoided, given that the capacity for detection and diagnosis on the part of the Spanish health network is well proven. It may be deduced therefore that there exists a problem of incomprehension regarding the critical importance of effecting referrals at the appropriate moment, that is to say, when a diagnosis of deficiency or handicap is carried out, and without directive meddling which conditions and confuses parent's expectations: "She requires a great deal of stimulation" placing EI resources in the category of dependent or second level services.

BOX N.º 10

THE TRANSIT TO FAMILY LIFE**FACTORS OF PROTECTION****FACTORS OF RISK**

Knowing and listening the family preoccupations, distinguishing issues which they think as being open to our opinion and those which they consider closed	Advancing matters and anticipating issues without considering the family's position on the basis of pre-established ideas
Coordinating services towards the family so that daily life can be resumed	Fragmenting the family towards services impeding the return to normal life
Decentralising and subdividing services in order to bring them nearer to the family and its surroundings, including home help	Institutional concentration of services isolating families from their surroundings generating unnecessary costs and journeys

FACTORS OF PROTECTION**FACTORS OF RISK**

Carrying out only essential outside appointments	Repeating tests, going over records, check-ups
Emphasising coherent aspects and avoiding rejection or dismissal	Emphasising disparity or dismissing the family or other professionals
Offering flexibility stability and availability on request	Waiting lists, delays in appointments, ...
Dealing with doubts at the right time harmoniously and care in prognosis	Prolonging of situations of doubt or advancing dubious or uncertain results
Clarifying the meanings of reports or comments when they prove opaque	Taking it for granted that things are understood
Opening spaces for parent' reflections and internal dialogue regarding issues of daily life	Meddling in matters in which the family has not sought mediation, even with one of the parents consent
Offering emotional support: parent's groups	Establishing "alliances" or informing only one part of the family as if it were a privilege
Active dialogue and negotiation of conflicts	Surreptitious dismissal of one of the parents (lack of attention, gestures, comments...
Economic and d work support, time, networks	
Accompanying transit to school	

Whatever the case may be, it is necessary to undertake the search for solutions which facilitate, from the first moment, the setting in motion of psychosocial support tasks, the appreciation of the child's abilities and the reorganisation of family life, which are characteristic of the work of EI and which, in this phase, are decisive in the drawing up of future itinerary of the child and the family. It is as well to remember in this respect, that the urgency of referral does not stem, at this moment, from the urgency in offering treatment to the child (that which by simple association, may be deduced by parents and many social sectors), but rather because this is the period in which parents get to know and assume responsibility for the child, assess information, work out feelings and plan arrangements and adaptations. Hence the importance of:

- Avoiding interferences which breaks up the family nucleus
- Providing information and accredited prognosis
- Facilitating spaces for dialogue between parents in which the sense of joint plans or projects can be redrawn
- Providing resources in the face of stress factors, support groups, respite care ...

C) Providing and increasing help vis-à-vis exclusion

The poor evolution perceived implies situations of hardship of economic necessity in 30% of the families, which if we recall that the percentage of low income families in pain is situated at 18%, indicates the probable confluence of two factors: firstly that the rate of birth of handicapped children is higher among low income families; secondly that the process of socialisation a handicapped child is particularly expensive

In the United Kingdom study on the impact of handicapped childhood on family life, the families studied revealed an expenditure of 20% extra of their total income, excluding food. In the case of children with severe handicaps this expenditure is double that which families with children who have no handicap make, and the majority consider that they would have to spend more still in order to satisfy the child's needs. It should be borne in mind that the average cost of bringing up a child in Spain is estimated at some 6000 euros for the first year.

Bearing in mind the economic impact of and the lack of free time, which is the majority complaint, it can be deduced that a significant percentage of families just live from day to day and, in a certain sense, in situation of extreme stress, whose repercussions on personal relationships, on job maintenance, on collective or personal projects must be significant, given that all those functions which revolve around care of children within the home involve an extra burden of domestic time which has to be assumed by members of the family when the baby is born, IF we orient ourselves in relation to studies like those carried out on informal care (which reveal that in more than a half of homes the responsibility for looking after the other members of the household considered as beneficiaries is assumed by one person only⁹, It may be supposed that in families with handicapped children these percentages are even greater. As far as is known, in EI centres, this extra load is usually taken on (for the most part) by mothers who, in many cases, give up their jobs or renounce their work expectations

The sensation of economic difficulty and temporal asphyxia or lack of leisure is complemented by the high percentage of families who give importance to the existence of physical and attitudinal barriers (80%) and those who have few or no expectations of social integration (38%), who consider leisure and vacational help insufficient (44,2%) help with taxis or transport (62,6%), technical help (63,5%) or help in the home (64'5%)

In conclusion, the survey reveals the existence of a heavy imbalance between perceived needs and contributions received which would call for:

- A thorough review of the range of resources
- Economic support
- Financial accessibility of services
- Comfortable habitat
- Accessibility of custodial and care facilities
- Greater opportunity of parental leave
- Increased opportunity for conciliation of family life and work
- Greater commitment toward community action in integration which appears as a priority field in EI

- Sensitisation, coherence and coordination between services
- Basic and continuous training of formal and informal networks
- Reinforcement and recognition of care work and social support
- Home-based services
- The creation and development of support and encounter groups
- Respite care, welcoming families...
- Contextual elimination of barriers, campaigns of sensitisation...
- Help with transport, holidays...
- The bringing closer of technical support services: physiotherapy, stimulation, psychomotor skills, development, and adaptation of dwelling, nursing...
- Basing of back-up services in the home during the first few months

4.2.3. *The need to orient community resources toward the interest of the child and the family*

The lack of coordination of community resources in health, educational and social regions is one of the most outstanding issues in the newly emergent daily life. During the last twenty years, in Spain an extensive network of hospitals, health centres with paediatrics and paediatric nursing, infants schools and nurseries, children's houses services, EI teams, mental health teams, teams of educational psychologists, teachers of hearing and language and practitioners of therapeutics pedagogy, social service centres, parents associations and volunteer's associations, have been set up. We are dealing with a new generation of experts who have entered a world in flux, in which it is difficult to orient oneself, to differentiate functions and professional roles and particularly to coordinate efforts. In the experience shared by the majority of services, the most important phenomena are:

- *Fragmentation*, which is to say, the dispersion of families towards services
- *Parallelism*, which is to say, the acting within a "regime" of isolation of each one of the services with respect to the others which share the same territory

In relation to EI experience, the problem of lack of coordination between services has as a consequence:

A) For parents

- The establishment of multiple appointments by different professionals and services, both inside and outside hospitals, lack of hospital coordination, delays, hours of waiting in unsuitable rooms...
- Repetition of physical examinations and case history
- Exposure to unnecessary situations of stress due to disparity between or contradiction in diagnosis and attitudes

- Disorientation regarding present or future life as, in many cases, certain issues of concern to parents are dismissed without further ado, or undervalued as a result of not knowing how to classify or situate them according to their place
- Loss of time in travelling
- The development of a feeling of negativity towards professionals
- The incurrency of unnecessary expenses
- The preoccupation with fitting into place and arranging in order of importance the puzzle of information which the different services present
- The dedication of their free time to dealing with professional directives, requesting appointments, applying for help, obtaining permits, looking for special toys and so on

B) For the children

The breaking down of family routines implies a significant risk, above all for the smallest. It should not be forgotten that during the first months, the establishment and development of these routines plays a major role in the emotional adjustment of the children, it facilitates the hastening and the learning of behavioural habits, the security and feeling of control which encourages the exploration of the milieu.

Loosing security feelings and the sensation of control of circumstances may be another consequence. It is well known that the younger the child, the more must parents, carers and services subordinate themselves to the needs and models of interaction which drive the baby. Subordination to these needs and initiatives must be to the utmost during the first months so that the child may mature emotionally and adjust her behaviour little by little. To expect that, who must be on hand and flexible regarding social routines, should be precisely the handicapped child, proves a sure, not to mention, absurd risk

For parents the breakdown in routines is an added element of stress and disorganisation that makes adaptation to the baby's needs difficult. Parental disorientation may lead then to changes of dwelling, pilgrimages or unaccredited therapeutical processes which converge upon the process of socialisation and personal development of the child, who may enter upon dead-end or inconvenient paths in life.

Taking on the reality of the multiplicity of services, which have the child and the family as the object of intervention, implies assuming the challenge of giving a coordinated interdisciplinary and interinstitutional answer, so that it is not the child or the family who have to renounce their routines, customs and normalised surroundings in order to disperse themselves towards services, but, on the contrary, it must be the services who direct their efforts towards and converge upon the family. It is necessary, except in critical situations of severe illness that the child and family stay within their habitual surroundings. To this end, visits and the provision of home help at the earliest ages must be coordinated; health and child development centres must be available as well as social-educational centres in the area or in the vicinity of the dwelling.

The coordination of services implies advancing progressively through the opportunities for relationships which the supervision of each case offers and the initiatives of cooperation which are promoted within the setting:

- Formalising structures of coordination
 - Sharing information
 - Changing one's own routines to arrange the coordination of one's own tasks with those of others
 - Formalising stable structures of cooperation
 - Working together and collaborating towards common aims

The Standards Guide has paid special attention to cooperation in integrated zones in which it would be important to create and consolidate **childhood observatories** which act as a revitalising element upon resources, facilitate the interchange of knowledge and experience the organisation of forums, proposals of formulas and protocol...

In this respect, it would be of great utility to establish a **network of indicators** which signal the situation of child protection and the declining or emerging tendencies when enable the intelligent orientation of the resources. The following indicators are considered essential at state level, at the level of autonomous region and at the level of integrated services zones for their obvious value in prediction:

- Infants mortality rate (perinatal and in the first years)
 - Rate of prematurity and low weight (neonatal)
 - Rate of very low weight (neonatal)
 - Rate of congenital malformations (neonatal)
 - Rates of infant development (to be developed)
 - Rates of scholarisation (to be developed)
- Sensitising oneself as to the importance of **normalising the social life** of the children and their families procuring the smooth flow of their lives along "natural courses": among their family, their social group, their town or neighbourhood, their school, friends, teachers and companions, during their holidays...Supporting the freedom of choice and decision concerning personal affairs. This social normalisation has to be take in place in a flexible manner because the contact and encounter with other companions with similar handicaps proves useful to many handicapped children and their parents in the development of their identity, communication and so on
 - Giving importance to **socialisation and the emergence from isolation** or situations of solitude, the involvement on dialogue, the emotional importance of organising a shared and open life in the company of other adults or children of any gender, situation or culture, thereby avoiding situations of isolation or prolonged institutionalisation, excessive dependence on monologic television or the use of toys

which only stimulate aspects of perception or manipulation, exclusion toward special itineraries or artificial and tangential contact in crowded centres institutionalisation,

- Bearing in mind the necessity of giving **opportunities and time for play**, so that the child can express herself and explore that which interests her demonstrate and expound her knowledge or achievement, fears or failures.
- Sensitising oneself regarding the importance of stimulating **autonomy and ability in decision-making**. This autonomy, which implies self-esteem, must be considered as being anterior hierarchically to purely functional autonomy. This also must be facilitated through the provision of technical aids as required at each moment. The utility of the protocol of screening for sensorial alterations, motor dysfunction and of social risk finds one of its clearest justifications here.
- Understanding that the coordination of resources and the flow of information between entities, professionals and services must be effected from a position of **multilateralism** and respect for the ideas and opinions of all parties

4.2.4. *The need to open up the target groups of early intervention safeguarding its complexity*

With the weakening of the traditional family, the demand for alternative formulas of support in the socialising of children is growing: within the context of daily practice in EI Centres, the presence of requests for assessments in matters of child development or early stimulation, which have nothing to do with situations of crisis or handicap, but rather with the needs for guidance of parents who wish to educate and stimulate their children better or who seek advice when the time comes to make concrete decisions, is more and more frequent. In this respect the opening up of the fields of team intervention helps to meet the new families' demands for assessment, facilitating optimum exploitation of the experience acquired in early care and offering a system of services with a guarantee of quality. The widening of areas of intervention, work in the social setting and the attention to new demands must not, however, mean the loss of the interdisciplinary work model which constitutes the guarantee of quality in EI. The development of flexible formulas of care must respect the systematic "case by case" exercise of interdisciplinary care procedure. This safeguard must be emphasised in contradistinction to the appearance of offers of early stimulation which do not always comply with the minimum requisites of quality. Simplified formulas are often used which attempts to compensate for their structural weakness by attaching an additionally high value to the objectives offered to parents. Although these offers may prove tempting for some, on many occasions they carry with them high risks of disorientation. In this respect, special emphasis should be placed upon "interdisciplinary" and "transdisciplinary" aspects of procedures

"Case by case" care

As the FEAPS "Manual of good practice" indicates: in order to improve the quality of life of handicapped children and of their families, one has to work with each person taking into consideration her needs and life setting.

However, the apparent simplicity in formulating these aims hides a great complexity because, as FEAPS indicates, any initiative must take into account many dimensions in the life of a person: His plans, feelings, economic situation, work and social relation. Not all children have the same needs, neither can uniform recipes of intervention be applied, nor should they be.

This social complexity implies not only bearing in mind the name and biological characteristics of a syndrome or disorder, but also the culture and projection of the family and each one of its members, their origin and provenance, the more or less conscious desires which they wanted to “deposit in the child, the social networks they count upon, economic sufficiency or lack, the need to respect their beliefs, values and decisions, the attitudes and organisational forms of the society into which they are born and in which she will have to become her parents’ daughter, a sister or brother, as well and an integral part of her community. In its origins, EI represented a form of generic intervention of diagnosed cases (Down’s syndrome, deafness, cerebral palsy) in which personal or social differences were considered trivial against the weight of uniform or standard aspects, whereas nowadays EI is conceived as an intervention of **“this child”**, who is real and present, intervention of a “unique case”, in which, to begin with there are few theses and many hypotheses, and in which the field or area of presentation of symptoms does not always correspond to the origin of the problems. EI experience, the debates and seminars among professionals, provide examples of errors from which we must all learn:

- Hypotonia in a baby, for example, does not systematically correspond to an acquired motor or neurological problem but may rather have its origin in a genetic alteration or in an upset in social relations. This possibility should be borne in mind in psychomotor or language deficiency, in disorders brought on by lack of attention or hyperactivity, in avoidance behaviour and so many other manifestations of developmental disorder.
- When the child present diverse (motor, relational or cognitive) problems or the families have to confront multisectorial needs (sentimental, economic, work related, social), the efforts in identifying and integrating each one of these dimensions is the basis of an appropriate orientation.
- The tendency to treat the part as the whole, without going beyond the immediate, the symptomatic, without tackling the situation in its entirety, may lead to grave errors. For example: the assessment of development exclusively by means of scales which do not provide a comprehensive panorama of the child’s global situation. Always treating hypotonia with physiotherapy; or language deficiency always or exclusively with speech therapy; prescribing a technical aid which cannot then be used in every day life; overstimulating the prematures and so on.
- On occasions, and with the best of intentions guidance is offered which can “mark” the families when it is interpreted as a prescription to be followed. For example, the orientation toward “plenty of early stimulation” may become transformed into an unsuitable demand with respect to the reality of a particular child.
- It is important to exert the utmost caution in order not to focus intervention in the direction of unviable aims. The maintenance of unwarranted expectations of

rehabilitation or even cure, beyond the appropriate length of time required for the emotional adaptation of the family to its new situation, may be an insuperable obstacle in the socialising and normalising process of family life.

- It must be borne in mind that in the quest to recuperate their desires and fantasies families are capable of anything: travelling around on the track of supposedly miraculous therapies, the incurring in exorbitant expenses, the paralysis and suspension of family projects, of journeying for months or years to obtain treatment whose long term profitability in neither accredited nor assessed.
- Sometimes, overzealousness or lack of practical training may lead to meddling in family life, albeit unconsciously. For example, imparting information selectively to one part of the family may incline events toward situations of privileged information, the establishment of complicity or alliances between one another, the invasion of other professionals spaces or those of other services, the dismissing of parents or other professionals.
- It is necessary to maintain one's guard against the possibility of discretionality or arbitrary ways of proceeding: judging in accordance with personal beliefs, abandoning guidance with respect to legal rights, assuming thereby a paternalistic function as to that what is best for the family, the suspension of care of the child due to negligence on the part of his family...
- It is as well to be alert to the ease with which the focus of intervention may be displaced toward matters which are not directly related to EI and which rightly correspond to other services. The process of acceptance of the handicapped child, for example, may inadvertently get diverted towards therapy for the couple or the family, "pathologising" a non pathological process or assuming the functions which correspond to mental health, educational or sanitary services.
- It is important to be aware of the limitations of one's knowledge and the possible significance of that which is not known. To understand, for example, that parents, in order to be "good parents" vis a vis society and its representatives, have to attend all the healthy checks, tests, etc. which are proposed to them, even though they may often be a matter of protocol or examination of whose utility they are not convinced.

The safeguarding of complexity implies the development of corresponding factors of protection. Those following may be highlighted:

- **An Interdisciplinary Team**, which functions as such, gathering different angles or points of view, including the categorisations or opinions which the members of the family contribute. In short, it should function as a real team and not as a merely rhetorical formula. In EI, the relativization of judgements is a guarantee for the child. For this reason, in any process of assessment, observation or interview, at least two team professionals should participate. It is not necessary for everybody to do everything, but rather that everyone should get to know the child directly and contribute with his or her way of seeing. The systematic presentation of cases and the utilising of video is a formula which enables participation and assessment.

- **A Contextualised Team**, which is to say with training in the knowledge of the milieu, the scenarios and social agents of the community, the history, events, social changes. Contextualisation facilitates the understanding of social discourse and projection strategies, the significance of dwelling, places and spaces, of the children's value for their parents. Contextualisation allows great economy on professional performance which derives, not so much from the immediate saving of time, but rather from the precise understanding of situations. In this way, accurate work strategies may be made available which, in the medium term may prove much more profitable than the multiplicity of unnecessary processes which lack orientation.
- **A Child Development and Early Intervention Centre** thought of, not only as an interdisciplinary team base, but also as a space for initiative in the promotion of the programme within the community as a whole, as an institutional interface and a point of encounter with the families.
- **UA constant concern with training and research**, so that other techniques and realities are known, one's own experience is reflected upon, an in depth analysis of the characteristics of the child, the family and the environment is carried out.

4.2.5. "Step by step" evaluation of early intervention

The need to maintain a very open position when facing different aspects or unknown factors which each case presents, the necessity for caution and flexibility in hypotheses, is a merit which does not exempt one from methodological regularity in the earliness and phased timing of intervention, in the critical examination of different perspectives (including one's own, and herein lies one of the decisive argument for the exigency of the interdisciplinary approach) or in the need for rigour in data gathering, the appraisal of the dimensions of development, the study of patterns of interaction or the implementation of rights which society offers to each family.

The complexity of EI has always been an obstacle to the formalising of structures capable of collating the wealth of professional experience. There is a lack of shared, easy-to-use, formats for documenting performance, for expressing or measuring the effect of intervention, for transferring judgements and impressions through regular procedures, for observing the evolutionary dynamics of the children, for awareness of families' satisfaction or for gathering statistics which enable deeper penetration into the reality of each team. These instrumental shortcomings impair, in no small measure, the expression of the difficulty of the task, the capacity for self-assessment and for perfecting one's work, the creation of a shared team culture, and the recognition of outside understanding of its worth, even for the parents, thereby creating imbalances in expectation between one and another, not only between teams and parents, but also between the associations or administrations which promote services

a) The **"step by step" standardisation of early intervention**, introducing temporal axes and spatial structures which join the different procedures together in order to obtain the greatest yield from professional work, to facilitate self-assessment and avoid

discretionality, arbitrary or negligent action which may jeopardise children or families, is a task which is pending. In order to fill the current vacuum or the excess of informal routines, it is necessary to reorganise EI (recovering in this regard, the funding impulse of IMSERSO) as a regulated loan facility or benefit subject to protocols and documents of organisation and function, backed-up institutionally and unprecariously, in consonance with the rights of children and the demands of the training of the professionals who assist them. In this way, specifying the phases and the courses of each procedure is a determinant factor in the quality of EI.

A phased timing of the “case by case” methodology must be effected in the process of standardisation distinguishing, in so doing, two kinds of situation:

- Those which are urgent and coincide with immediate intervention in face of the diagnostic impact
- Those which are ordinary, which means to say all others

This distinction is not capricious. The accompaniment during the immediate post-diagnostic process facilitates the family’s first period of transition and, though it may last for months, means the gaining of time later. In other demands we will encounter either sealed off processes or intervention which require long-term support, as for example, those which derive from situations of social exclusion. The general scheme to which dates and times must be added would be as follows:

BOX N.º II

PHASED TIMING OF PROCESSES

PROCESSES	Deadline
Detection, Derivation	
Request for early intervention	Day 0
Case presentation	
Admission (“welcome”) interview	
Interdisciplinary assessment and general project of aims and methods	
Counselling interview and specific programme (IFSP) of objectives and methods	
Process of coordination, application of programme and handing over of written programme	
Meeting of review or closure	
Monthly/Three-monthly review	
Annual review	

b) And **a formalisation of action**• **Regular keeping of records and case-histories of the children:**

- Details of the person concerned, date of birth, institution and place, contact telephone numbers.
- Details of legal representation or guardian.
- Registry of access to confidential information, identification of case coordinator.
- Application for EI, details of the applicant and informed consent.
- Definition and organisation of confidential information and locked files.
- Relevant correspondence.
- Phased register of action and demands: assessment interviews, observations, sessions, contacts, and so on.
- Form detailing health, maturity and physical well being.
- Form with details of dwelling indicating the name, relationship, education, occupation, income contribution and language of each household member. Genogram.
- Form assessing psychomotor development, detailing observations regarding attitudes, initiatives, joint attention, language in all its forms, play, cognitive strategies, motor and sensorial functions, criterion-referenced tests applied.
- Sheet detailing daily activities and carers.
- Form detailing coordination of protection services network: health centre, hospital, school, basic or specialised social services, support groups, respite care.
- IFSP folder with three levels objectives, methods and deadlines: child, family, surroundings.
- Closure or annual review form.

• **Preparation of plan of action in the community**

- Annual project of action, specifying aims and methods.
- Register of centre/team initiatives in which a record is kept of interinstitutional relations, matters dealt with, participants, and agreements...

— Register of requests received in the centre.

● *Family satisfaction*

— Annual survey form to assess work carried out, information received, rating of and treatment by technical staff, participation and procedures.

— “Adhesion index”, which reflects the percentage of families who drop out of the program.

● *Management plan for centre*

— Having available a structure of direction and administration, a clear definition of roles and work procedures, staff with adequate training, experience and dimension according to needs.

— Definition of times and spaces for self-assessment and assessment shared with families and with providers, establishment of space for the preparation of the plan of action, the drawing up of the annual report and the administration of available resources.

**T E C H N I C A L A S P E C T S O F
E A R L Y I N T E R V E N T I O N
S T A N D A R D S**

5. TECHNICAL ASPECTS OF EARLY INTERVENTION STANDARDS

In section 3, with regard to phases and procedures we have advanced that in making the guide we can distinguish three different stages: a) A first one, which corresponds to the initial generation of standards and whose basis he have just described; b) A second one , which is aimed to make a consultation to both professionals and consumers who are more immediately implied into EI; and finally c) A third one, which is devoted to making up the set of standards and the self-assessment-form and which most relevant issue consists of defining the indicators which should measure the functionality of each standard.

In this section we will provide a brief description of the technical work that has been undertaken to come across these three distinct phases.

5.1 Organisation of standards

5.1.1 Standards organisation

As we mentioned earlier, the starting point of the first list of standards (see appendix A of Spanish version) was the Catalogue of good practice, the analysis of additional needs which are emerging nowadays from children's life itineraries and, finally, the experience of the team itself as EI practitioners. To facilitate that the standards could be easily identified and used in teamwork, we looked for an organisational formula which, taking into account our limited culture of evaluation, could put in order both quality and simplicity within evaluation procedures. In accordance with these objectives the following plan was proposed:

a) Firstly, grouping together the standards into five distinct **“Levels”** or dimensions in order to highlight the main fields of Early Intervention:

- The community
- The family
- The child
- The Child Development and Early Intervention Centre
- The programme of Early Intervention

b) Secondly, clarifying within each Level the overall **“Aims”** and **“Programmes”** which should give sense to the standards. According to the basis aforementioned in the last section, the following aims and programmes has been defined for each Level:

Level 1 (Community)

Aim: Coordination of interinstitutional networks

Programme: Prevention, detection and early intervention

Level 2 (Family)

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

Level 3 (Infancy)

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

Level 4 (Child Development and Early Intervention Centre)

Aim: Guarantee well-organised services

Programme: Child Development and Early Intervention Centre management and administration

Level 5 (Early Intervention Programme)

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

- d) Thirdly, providing each standard with a “**Descriptor**” or label that could ease their identification
- e) Fourthly, extracting from professional experience some key “**Indicators**” to monitor the quality of a given process
- f) Fifthly, designing a “**Self-evaluation form**” to facilitate the analysis of current practices and simultaneous reworking of new aims and action plans

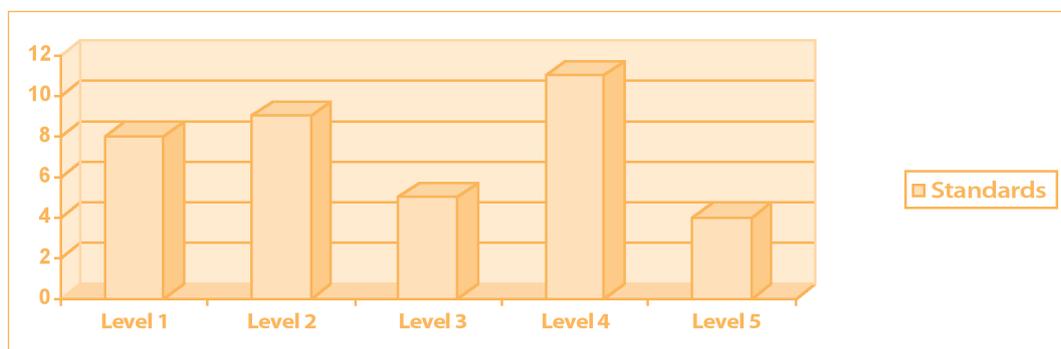
5.1.2 Standards listing

Bearing in mind this organisational diagram each standard was assigned to its corresponding Level until completing the initial set as follows:

—Level I - Community – 8 standards

- Level 2- Family – 9 standards
- Level 3- Infancy – 5 standards
- Level 4- CDEIC – 11 standards
- Level 5- Programme – 4 standards

Graphic n. ° 1 - Initial standards



5.2 Analysis of the standards survey

5.2.1 Standards questionnaire

A self-administered questionnaire was prepared and submitted to the group of experts who were selected to participate in this study

The participants were asked to qualify each standard by filling in this questionnaire. A range of five possible options was offered in order to qualify each standard

- Score 1 - The standard is very inappropriate
- Score 2 - The standard is inappropriate
- Score 3 - The standard is appropriate
- Score 4 – The standard is quite appropriate
- Score 5 - The standard is very appropriate

Additionally all participants were asked to report opinions, suggestions and modifications with regard to each standard or group of standards

5.2.2 Participants

The survey was offered to a sample of 120 early intervention experts recruited among federations of parents associations, professional associations, directors of university postgraduate studies and experienced practitioners from all over the country.

The questionnaire was attached to a letter of the groupwork introducing the purpose of the study and the procedures to fill in the questionnaire.

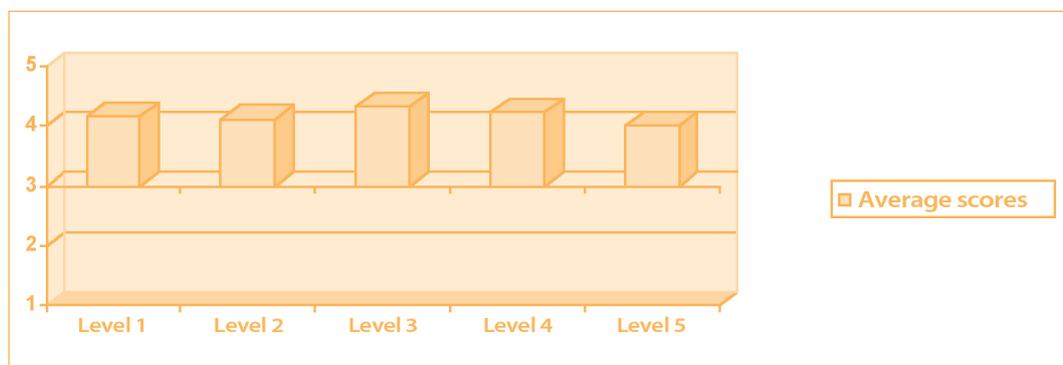
5.2.3 Results

41,6 % (n=50) of the selected participants returned the questionnaire. All the standards (37) achieved the score level qualified as “appropriate”. Twenty six (26) surpassed the score level qualified as “quite appropriate”. Overall average score was 4.17 which indicates a very high level of agreement with the statements proposed (a complete list of the initial standards and the obtained scores can be consulted in the Spanish original version)

The average score obtained by the overall group of standards of each level was as follows:

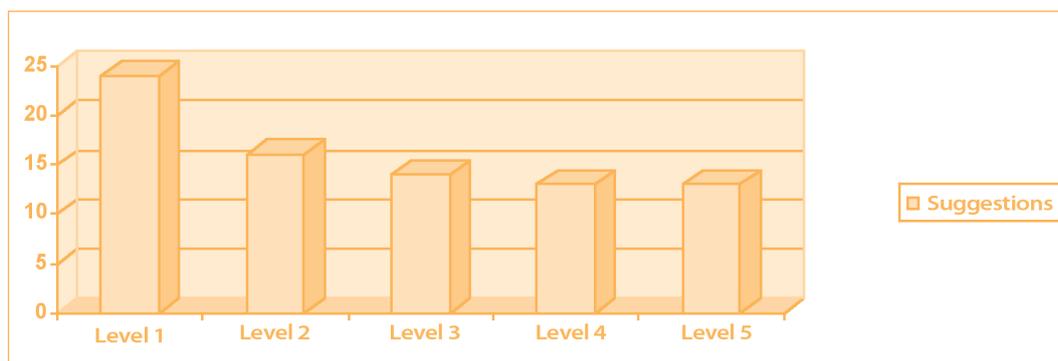
- Level 1 (community): 4,15
- Level 2 (family): 4,11
- Level 3 (infancy): 4,33
- Level 4 (centre): 4,22
- Level 5 (programme): 4

Graphic n.º 2 **Average scores**



Eighty (80) suggestions were received most of them proposing writing modifications or the necessity to take into account complementary aspects (a complete list of these suggestions can be consulted in the Spanish original version of this Guide)

- Level 1 (community). 24 suggestions.
- Level 2 (family). 16 “
- Level 3 (infancy). 14 “
- Level 4 (centre). 13 “
- Level 5 (programme). 13 “

Graphic n. ° 3 **Suggestions**

5.2.4 Final set of standards

Based on quantitative and qualitative data the final set of standards (36) was produced. 10 standards were rewritten, 5 were deeply changed, 3 (those with lowest scores) were eliminated and other 2 were rewritten and transferred to another level. 2 new standards were added to the list.

5.3 Elaboration of indicators and measures

Throughout this stage the indicators and measures that make concrete the actions expressed by each standard were established. Delphi techniques were unfolded to develop this work phase.

The indicators were produced according to technical specifications from evaluation experts. Individualised elaboration and group analysis were carried out with their support. The statements corresponding to each standard were selected under the following guidelines:

- To be clearly outlined and easy to understand what is considered particularly important, on the one hand, to avoid overlapping or misinterpretation and, on the other hand, to facilitate accurate self-administration practices and stakeholders agreement.
- To be realistic and/or achievable in existing services what is thought to be a necessary condition to encourage staff and families participation.
- To be feasible in practical terms, that is to say, easily observable and recordable taking into account staff everyday routines.
- To be reliable with regard to identifying the improvement or worsening of expected outcomes.
- To be easily measurable, that is to say, full of sensitiveness in showing trends over time or measuring participants satisfaction.
- To be meaningful for wide-ranging services.
- To combine summative and formative aspects in order to evaluate effectiveness and provide new directions toward improving services in the future.
- To be flexible, that is to say, ensuring that results are available in a variety of formats such as questionnaires, group interviews or observations.

BOX N.º 12

INDICATORS

STANDARD	N.º OF INDICATORS
1.1.- Catalogue	3
1.2.- Childhood observatory	4
1.3.- Screening protocols	5
1.4.- Early information	4
1.5.- Referral	1
1.6.- Unified application form	2
1.7.- Data protection	4
1.8.- Child Development and Early Intervention Centre	2
2.1.- Multidimensional approach	3
2.2.- Interdisciplinary assessment	3
2.3.- Family involvement	7
2.4.- Individual Family Support Plan	7
2.5.- Case coordinator	3
2.6.- Social inclusion	6
2.7.- School information	3
2.8.- Health support	4
2.9.- Parents' rights and duties	4
3.1.- Child protection	5
3.2.- Child autonomy	4
3.3.- Context and socialisation	3
3.4.- Case review	4
3.5.- Annual review	5
4.1.- Organisational flow chart	4
4.2.- Multiprofessional team	5
4.3.- Management unit	3
4.4.- Staff satisfaction	2
4.5.- Evaluation and research	2
4.6.- Accounting systems	4
4.7.- Safety requirements	2
4.8.- Information	4
4.9.- Prevention and early detection	3
5.1.- Action plan	3
5.2.- Annual report	3
5.3.- External evaluation	3
5.4.- Staff training	5
5.5.- Families satisfaction	3
TOTAL	133

In drawing up the indicators the elaboration of the set of standards came to its end



SET OF EARLY
INTERVENTION
STANDARDS

6. SET OF EARLY INTERVENTION STANDARDS

STRUCTURE OF THE STANDARDS

LEVEL - Dimension where the processes to be analysed are taking place.

The following dimensions has been defined:

- **Community**
- **Family**
- **Infancy**
- **Centre**
- **Programme**

PROGRAMME - Set of processes which are synergically interrelated

Level 1 (Community)

Aim: Coordination of interinstitutional networks

Programme: Prevention, detection and early intervention

Level 2 (Family)

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

Level 3 (Infancy)

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

Level 4 (Child Development and Early Intervention Centre)

Aim: Guarantee well-organised services

Programme: Child Development and Early Intervention Centre management and administration

Level 5 (Early Intervention Programme)

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR – Word(s) that are used to identify each standard.

STANDARD – Statements proposed as quality criteria.

INDICATOR – Performance measure of its corresponding standard .

LEVEL 1 – COMMUNITY

Aim: Coordination of interinstitutional networks.

Programme: Prevention, detection and early intervention

DESCRIPTOR 1.1

Catalogue

STANDARD 1.1

A ***Catalogue*** details the developmental disorders or risk situations that should be referred to Early Intervention services.

INDICATORS 1.1

1.1a. Families with children aged 0 to 6 years included in one of these situations or categories are referred to Early Intervention services.

1.1b. The *Catalogue* is reviewed and analysed every five years in order to update the eligibility criteria.

1.1c. The *Catalogue* is a guidance tool. Any child may be assessed on demand.

LEVEL I – COMMUNITY**Aim: Coordination of interinstitutional networks****Programme: Prevention, detection and early intervention****DESCRIPTOR 1.2*****Childhood observatory*****STANDARD 1.2**

A ***childhood observatory*** has been established within the area of integrated services under appropriate legal statements.

INDICATORS 1.2

1.2a All community resources concerned with child and family well-being take part in this observatory.

1.2.b Relevant data regarding social, health and educational circumstances of children supported by EI services are systematically registered..

1.2.c A community action plan to develop EI is elaborated every four years. This plan is reviewed every year.

1.2d Childhood health, educational an social well being is monitored through appropriate indicators.

LEVEL I – COMMUNITY

Aim: Coordination of interinstitutional networks

Programme: Prevention, detection and early intervention

DESCRIPTOR 1.3

Screening procedures

STANDARD 1.3

Community resources use *screening procedures* for early detection of children with developmental disorders or risk situations.

INDICATORS 1.3

1.3a There are screening procedures for early detection of hearing loss.

1.3b There are screening procedures for early detection of low vision.

1.3c There are screening procedures for early detection of language and psychomotor delay.

1.4d There are screening procedures for early detection of psychosocial risk situations.

1.5e There are screening procedures for early detection of metabolopathies.

LEVEL I – COMMUNITY

Aim: Coordination of interinstitutional networks.

Programme: Prevention, detection and early intervention

DESCRIPTOR I.4

Early information and support

STANDARD I.4

All families involved in diagnostic procedures receive ***early information and support*** .

INDICATORS I.4

I.4a Early information and support begin when any family have to face “bad news”.

I.4b Early information and support guidelines include time and place specifications.

I.4c Early information and support guidelines include taking into account all worries and concerns as expressed by families.

I.4d Early information and support guidelines include information about Early Intervention services.

<p>LEVEL 1 – COMMUNITY</p> <p>Aim: Coordination of interinstitutional networks</p> <p>Programme: Prevention, detection and early intervention</p>
<p>DESCRIPTOR 1.5</p> <p><i>Early referral</i></p>
<p>STANDARD 1.5</p> <p>Professional background and sensitiveness ensures early referral of eligible children towards Early Intervention services.</p>
<p>INDICATORS 1.5</p> <p>I.5a. All eligible children are immediately referred to Early Intervention services.</p>

LEVEL I – COMMUNITY**Aim: Coordination of interinstitutional networks****Programme: Prevention, detection and early intervention****DESCRIPTOR I.6*****Unified application forms*****STANDARD I.6**

Regarding Early Intervention referrals, community networks are linked through ***unified application forms***.

INDICATORS I.6**I.6a.** Application forms include:

- Child personal data
- Data of applicant(s)
- Family's informed consent

I.6b. Applications forms include the eligibility criteria that have been identified.

LEVEL I – COMMUNITY

Aim: Coordination of interinstitutional networks

Programme: Prevention, detection and early intervention

DESCRIPTOR I.7

Data protection

STANDARD I.7

All kind of registered information regarding child and family issues is considered under *data protection* regulations.

INDICATORS I.7

- I.7a.** Early Intervention activities follow the confidentiality principle.
- I.7b.** Records are kept in locked files.
- I.7c.** An appropriate register keeps track of all staff with access to case records.
- I.7d.** Families' consent is needed to transfer child information among services.

LEVEL 1 – COMMUNITY

Aim: Coordination of interinstitutional networks

Programme: Prevention, detection and early intervention

DESCRIPTOR 1.8

Decentralised district services

STANDARD 1.8

Early Intervention is delivered through ***decentralised district services***.

INDICATORS 1.8

1.8a A Child Development and Early Intervention Centre (CDEIC) is available in every district or area of integrated services.

1.8b The CDEIC meet the Level 4 required standards.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.1

Multidimensional approach

STANDARD 2.1

Early Intervention services provide a ***multidimensional, holistic approach*** which is directed towards knowing the needs of the child, the family and the environment .

INDICATORS 2.1

2.1 a. Child assessment aims to gather relevant information about personal history and relevant events (health and relations), kind of attachment with main caregivers, risk and protection factors, self-initiative, social attitudes and patterns of interaction, main interests and concerns as shown in daily routines, language modalities, play activities, cognitive background and strategies, self-regulation skills, sensorimotor functions.

2.1 b. Family assessment aims to gather relevant information about: needs and concerns as expressed by families, parenting and upbringing practices, coexistence unit, family history (genogram), risk and protection factors, internal and external relations.

2.1 c. Environment assessment aims to gather relevant information about family habitat and surrounding circumstances, other relevant people, resources or social agents involved in child development or well being, social and institutional networks, risk and protection factors.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.2

Interdisciplinary assessment

STANDARD 2.2

Early Intervention services provide ongoing ***interdisciplinary assessment***.

INDICATORS 2.2

2.2a. Assessment procedures include team sessions to evaluate case records, child observations and qualified results of criterion-referenced tools.

2.2b. Assessment procedures include team sessions in which at least two professionals take part.

2.2c. Interdisciplinary assessments first of all identify the needs of the child, the family and the environment. The assessment conclude roughing out the Individual Family Support Plan (IFSP).

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.3***Family involvement*****STANDARD 2.3**

Early Intervention services promote ***family involvement*** and participation.

INDICATORS 2.3

2.3a. Early Intervention assessment begins with a “welcome” (admission) interview.

2.3b. Family's appointments are flexibly scheduled in order to facilitate parents or caregivers participation.

2.3c. Family's needs or demands are considered in their own words.

2.3d. Early Intervention services are fully respectful with family believes, standpoints, cultural practices or privacy requirements.

2.3e. Families are considered as the primary decision-makers.

2.3f. Family's decisions are always accepted provided they are not detrimental to the child interest.

2.3g. IFSP proposals are always oriented to the normalisation of family life.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.4***Individual Family Support Plan*****STANDARD 2.4**

The ***Individual Family Support Plan*** is drawn up with the participation of family through a counselling interview.

INDICATORS 2.4

2.4a. The parents or main caregivers, the case coordinator and at least, another member of the team, take part in the counselling interview.

2.4b. The IFSP sum up the methods, deadlines and reviewing periods established for each aim.

2.4c. The IFSP summarizes the procedures designed to promote social inclusion.

2.4d. The IFSP summarizes the procedures designed to support learning experiences and smooth transitions to dwelling, preprimary and primary schools.

2.4e. The IFSP summarizes the procedures designed to provide health support in children's natural settings.

2.4f. Informed consent to undertake IFSP procedures is signed by parents.

2.4g. The IFSP is written down within 30 days since the "welcome" interview.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.5

Case coordinator

STANDARD 2.5

A team member is appointed to each family as a **case coordinator**.

INDICATORS 2.5

2.5a. A team member is appointed provisionally as a case coordinator to conduct the welcome interview. Her or she may remain as a permanent coordinator when the ISFP has been defined.

2.5b. The case coordinator takes on the family demands and promotes coherent support from community resources.

2.5c. Each case coordinator has an agenda of 15 families maximum.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.6

Social inclusion

STANDARD 2.6

Social inclusion aspects of the IFSP aims at strengthening the internal and external relations of the family.

INDICATORS 2.6

2.6a. IFSP is designed to enhance family skills and upbringing practices. Actions such as the "parent to parent" programme may be contemplated under this heading.

2.6b. IFSP is designed to improve interaction patterns between parents and children. Actions such as the participation of parents in training or video sessions may be contemplated under this heading.

2.6c. IFSP is designed to facilitate parents meetings. Actions such as regular interviews or participation in self-help groups may be contemplated under this heading.

2.6d. IFSP is designed to help families in keeping their previous works or employment projects. Actions such as the coordination with employment services may be contemplated under this heading.

2.6e. IFSP is designed to increase families' opportunities of enjoying free time. Actions such as the coordination with cultural services, respite care or home-based help services may be contemplated under this heading.

2.6f. IFSP is designed to facilitate the access to statutory aids.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.7***School information*****STANDARD 2.7**

The IFSP includes ***school information*** aspects which are drawn up with the collaboration of educational services.

INDICATORS 2.7

2.7a. Accessibility, safety and overall school environmental conditions are checked up in coordination with educational resources.

2.7b. Appropriate information regarding IFSP, aims and methods is transferred to school staff.

2.7c. Transition to school is planned in coordination with educational resources.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.8

Health support

STANDARD 2.8

The IFSP includes **health support** aspects which are drawn up with the collaboration of health services.

INDICATORS 2.8

2.8a. The IFSP is designed to attend health special needs in everyday life routines.

2.8b. When necessary, the IFSP includes information about special treatments.

2.8c. When necessary, the IFSP includes information about special aids.

2.8d. When necessary, the IFSP includes information about possible secondary effects and their prevention.

LEVEL 2 - FAMILY

Aim: Support families's special needs and protect parents-child early relationships

Programme: Family resources

DESCRIPTOR 2.9***Rights and duties*****STANDARD 2.9**

Users' ***rights and duties*** are clearly specified.

INDICATORS 2.9

2.9a. Case coordinator duties include information on family rights.

2.9b. Family complaints and suggestions are registered. They are evaluated and included in the annual report.

2.9c. Ethic principles, CDEIC mission and working statements are included in a reference book.

2.9d. The need of mediation mechanisms to solve ethic dilemmas has been considered.

LEVEL 3 - INFANCY

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

DESCRIPTOR 3.1

Full participation

STANDARD 3.1

All children with developmental disorders or risk situations have the right to achieve ***full participation*** in social life.

INDICATORS 3.1

3.1a. CDEIC team take charge of enhancing attachment relationships and child upbringing practices.

3.1b. CDEIC team take charge of providing ongoing opportunities for joint attention development and language learning experiences.

3.1c. CDEIC team take charge of promoting play-based exploration and meaningful symbolic activities.

3.1d. CDEIC team take charge of facilitating high-quality relationships with peers group.

3.1e. CDEIC take charge of keeping children away of any kind of discrimination or neglecting practices.

LEVEL 3 - INFANCY

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

DESCRIPTOR 3.2***Autonomy*****STANDARD 3.2**

According to their needs, all children with developmental disorders or risk situations have the right to receive developmentally appropriate aids (education, technical or therapeutic aids) in order to strengthen their **autonomy**.

INDICATORS 3.2

3.2a. When necessary, the IFSP provides sessions of global stimulation, functional skills acquisition, psychomotor therapy, speech therapy or physiotherapy.

3.2b. When necessary, the IFSP provides mobility or sensorial aids, sign language education, augmentative or alternative communication support and computer aids.

3.3c. When necessary, the IFSP provides developmentally appropriate learning experiences.

3.3d. All necessary aids are provided cost-free, including training and maintenance.

LEVEL 3 - INFANCY

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

DESCRIPTOR 3.3

Contextual changes

STANDARD 3.3

Appropriate **contextual changes** are implemented in order to satisfy children's special needs.

INDICATORS 3.3

3.3a. When necessary, the IFSP provides information, training and psychological support to parents and childcarers.

3.3b. When necessary, the IFSP promotes barriers-elimination or appropriate environmental arrangements.

3.3c. The CDEIC team take charge of promoting child inclusion in his/her natural settings.

LEVEL 3 - INFANCY

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

DESCRIPTOR 3.4

Case reviews

STANDARD 3.4

Case reviews, with particular attention to IFSP outcomes, child development progress and social inclusion status, are conducted regularly.

INDICATORS 3.4

3.4a. Relevant events or meaningful changes in child situation and developmental progress are systematically reviewed.

3.4b. Three-monthly a case review is carried out with the participation of two team members at least, being one of them the case coordinator.

3.4c. Case review tasks include updating of parents and caregivers narratives, examining the IFSP results and reworking of aims and methods.

3.4d. Case reviews are recorded in normalised forms which have been designed to monitor ongoing changes.

LEVEL 3 - INFANCY

Aim: Protect children's rights, ensure objective non-discriminatory assessments and provide appropriate resources

Programme: Equal opportunities

DESCRIPTOR 3.5

Supervised case reviews

STANDARD 3.5

Supervised case reviews are conducted every year.

INDICATORS 3.5

3.5a. Supervised case reviews are carried out with the participation of the early intervention team and the community resources involved in a particular case.

3.5b. Supervised case reviews may be conducted by an external supervisor when requested by families or team members.

3.5c. Supervised case reviews are prepared by the case coordinator.

3.5d. Annual case reviews follow the same framework as three-monthly ones.

3.5e. Annual reviews results are summed up and presented to families at counselling interviews.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.1**Organisational flow charts****STANDARD 4.1.**

The CDEIC 's programme administration has available ***organisational flow charts*** which show functional units, management strategies and reporting lines.

INDICATORS 4.1

4.1a. The organisational flow charts outline a management unit with clearly defined guidelines and post descriptions.

4.1b. The organisational flow charts outline an intervention unit with clearly defined guidelines and post descriptions.

4.1c. The organisational flow charts outline an information unit with clearly defined guidelines and post descriptions.

4.1d. All units have adequate settings and equipment.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.2

Multiprofessional team

STANDARD 4.2

CDEIC 's ***multiprofessional team*** work collaboratively to carry out community and "case by case" EI programmes.

INDICATORS 4.2

4.2a. Staff ratios are based on current research findings and professional recommendations.

4.2b. Staff are optimally qualified for their positions and CDEIC-related tasks.

4.2c. Staff selection guidelines are based on training background and appropriate experience.

4.2d. Teamwork includes planning of regular meetings where team members share information, analyse case records and evaluate the outcome of EI programmes.

4.2e. Teamwork performance is regularly evaluated.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.3

Management unit

STANDARD 4.3

The **management unit** take on the outlining of new projects, the monitoring of current programmes and the evaluation of overall results.

INDICATORS 4.3

4.3a. The management unit provide guidance, motivation and ethic leadership.

4.3b. The management unit promote professional awareness regarding CDEIC mission, aims and programmes.

4.3c. The management unit encourage teamwork.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.4

Staff surveys

STANDARD 4.4

***Staff surveys* provide effective input from professionals.**

INDICATORS 4.4

4.4a. Taking into account staff standpoints and aspirations is part of the CDEIC culture and statements.

4.4b. The following topics are surveyed: professional position, working conditions, relations with users and team members, CDEIC's operating procedures and aims.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.5

Evaluation and research

STANDARD 4.5

Staff are encouraged to participate in *evaluation and research* activities.

INDICATORS 4.5

4.5.a. The management unit encourages staff participation in case reviews and CDEIC overall programme evaluation.

4.5.b. The management unit encourages staff participation in research activities.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.6

Accounting systems

STANDARD 4.6

Appropriate ***accounting systems*** accurately reflect CDEIC 's financial resources and budget distribution.

INDICATORS 4.6

4.6a. Detailed descriptions of private or public financial resources and budget distribution are available to staff, users and providers.

4.6b. Calculations of cost-benefit rates or other appropriate measures of the programme efficiency are used.

4.6c. Audited financial statements are regularly produced.

4.6d. Financial annual reports are produced.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.7

Safety requirements

STANDARD 4.7

CDEIC's settings observe **safety requirements** for childcare centres.

INDICATORS 4.7

4.7a. CDEIC settings are accessible and fulfil accident prevention requirements.

4.7b. CDEIC evacuation plans have been supervised by security authorities.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.8***Information*****STANDARD 4.8**

The CDEIC provides written ***information*** regarding mission statements, target population, services delivered, institution and place, timetable and contact telephone numbers.

INDICATORS 4.8

4.8a. A complete catalogue of delivered services is available.

4.8b. Complaint policy provides all families with details of how to lodge a complaint as well as information about external complaint entities.

4.8c. Operating procedures are encouraged to change in accordance to systematic analysis of users needs.

4.8d. The CDEIC promote operational agreements with other agencies in order to facilitate smooth referrals and collaborative networks.

LEVEL 4 - CENTRE

Aim: Guarantee well-organised services

Programme: Child development and early intervention centre management and administration

DESCRIPTOR 4.9

Community-based programmes

STANDARD 4.9

CDEIC promotes ***community-based programmes*** to improve prevention and early detection of children with developmental disorders or risk situations.

INDICATORS 4.9

4.9a. The CDEIC promotes community-based programmes in order to improve family planning.

4.9b. The CDEIC promotes community-based programmes in order to expand parent education and quality childcare.

4.9c. The CDEIC promotes community-based programmes in order to improve childcare and education networks.

LEVEL 5 - EARLY INTERVENTION PROGRAM

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR 5.1

Action plan

STANDARD 5.1

*Every year the **action plan** is updated and reviewed by the management unit.*

INDICATORS 5.1

5.1a. The action plan gather relevant information regarding human and material resources, target population, organisational charts and draft agenda.

5.1b. The action plan specify aims and methods.

5.1c. The action plan is drawn up with staff participation.

LEVEL 5 - EARLY INTERVENTION PROGRAM

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR 5.2

Annual reports

STANDARD 5.2

Annual reports provide clear statements with regard to CDEIC 's action plan.

INDICATORS 5.2

5.2a. Annual reports gather and analyse quantitative data regarding funding, community activities, training and research.

5.2b. Annual reports gather and analyse statistical data regarding case records.

5.2c. Annual reports include a written statement evaluating the EI programme overall results.

LEVEL 5 - EARLY INTERVENTION PROGRAM

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR 5.3

External evaluation

STANDARD 5.3

Appropriate statutory authorities provide enough funds to carry out **external evaluation** of the EI programme.

INDICATORS 5.3

- 5.3a.** External evaluations are carried out by licensed agencies.
- 5.3b.** External evaluations go through all programme levels.
- 5.3c.** External evaluations are made every three years maximum.

LEVEL 5 - EARLY INTERVENTION PROGRAM

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR 5.4

Professional training

STANDARD 5.4

The management unit encourages ongoing ***professional training***.

INDICATORS 5.4

5.4a. The CDEIC maintain up-to-date records of staff qualifications, curriculum vitae and professional development.

5.4b. Training plans are drawn up with staff participation.

5.4c. Staff training and development cover both specific and wide-ranging topics (child development, family dynamics, teamwork, community -based activities...) .

5.4d. Specific funds are allocated for staff training plans.

5.4e. Time allocated to training plans and professional development is considered as working time.

LEVEL 5 - EARLY INTERVENTION PROGRAM

Aim: Monitor the quality of Early Intervention overall practices

Programme: Evaluation

DESCRIPTOR 5.5

Families's satisfaction

STANDARD 5.5

Families' satisfaction is regularly surveyed.

INDICATORS 5.5

5.5a. Surveys are anonymously conducted.

5.5b. Surveys are written in language that families can readily understand.

5.5c Surveyed topics include:

- Involvement and partnership.
- Quality of life.
- EI effectiveness.
- Teamwork and interagency co-ordination.
- Self-help groups.
- Parents in-service-training.



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GLOSSARY

GLOSSARY

Catalogue. Listing of developmental disorders types and risk situations that require Early Intervention

CDEIC Programme. Early Intervention and Evaluation Guidelines drawn up by CDEIC's staff.

Child Development and Early Intervention Centre (CDEIC). Service that outline and carries out community and individualised early intervention programmes making use of own resources or working collaboratively with other services.

Childhood observatory. Interinstitutional teamwork which has been organised to improve children quality of life by means of increasing social knowledge and awareness regarding childhood wellbeing and emerging or declining trends.

Community action plan. Action plan that has been drawn up by a childhood observatory.

Counselling interview. Family and team members meeting where Individual Family Support Plan takes shape.

Early Intervention. Set of actions, targeted towards children aged from 0 to 6, their family and environment, which are aimed to give response, as soon as possible, to the permanent or transitional needs that children with developmental disorders or in risk situations may present. These actions are carried out by a multiprofessional team working on interdisciplinary or transdisciplinary basis.

Early Intervention Register. District book where, under appropriate norms, records are kept to provide quantitative data regarding children enrolled in EI Programmes.

Interdisciplinary team. Multiprofessional team whose members share and discuss information in order to converge on common decisions and goals.

Individual Family Support Plan. Individualised programme produced for a particular child and family. It includes situation diagnosis, intervention plan and periodical reviewing or evaluation.

Key worker/Case coordinator. Team member who conducts the mediation processes that each family requires.

Multidisciplinary team. Multiprofessional team whose members share information but not necessarily to converge on common decisions and goals.

Multiprofessional team. Teamwork which consists of professionals coming from different fields.

Psychomotor development. Developmental progress expected from the interaction child-environment.

Screening procedure Operating protocol used to facilitate early detection of specific biological impairment or biopsychosocial risk situations.

Social exclusion. Status of objective or subjective involuntary isolation with regard to social life.

Social inclusion. Status of objective or subjective free participation in social life.

Standards. Quality criteria which provide guidelines to evaluate services' procedures and outcomes.

Transdisciplinary team. Multiprofessional team whose members share information and role-specific responsibilities. Any of team members may assume transdisciplinary tasks on her own.

“Welcome” interview. Initial meeting between family and team members, where child needs and parents demands are collected.

A P P E N D I X

APPENDIX A – GROUP WORKSHOPS

1999 – June	Madrid	Group Inter.- IMSERSO
1999 – November-	Burgos	Workshop on early intervention
2000 – May	Huesca	Workshop on early intervention
2000 – October	Ferrol	Workshop on early intervention standards
2001 – February	Villena	Workshop on early intervention standards
2001 – June	Santander	Workshop on technical aspects of standards
2001 – November	Madrid	Design of the standards guide
2002 – July	Burgos	Generation of standards
2002 – September	Vigo	Phase of consultation
2002 – October	Burgos	Establishment of indicators
2002 – November	Madrid	Early Intervention Standards Guide
2002 – December	Burgos	Self-Evaluation Form

APPENDIX B – LIST OF CONTRIBUTORS

Name	Profession
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Adelaida Echevarría	Psychologist
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Antonia Márquez Luque	Psychologist
Antonio Mériz Piedrafito	Psychologist
Beatriz Núñez	Educational Psychologist
Belén Cavero	Physiotherapist
Carmen Ascaso	Physiotherapist
Carmen Bonilla Ariza	Physician
Cristina Elósegui Larrañeta	Psychologist
Elena Cabeza Pereiro	Speech therapist
Elena Ruiz Vesga	Psychologist, Educational Psychologist
Elisa Martínez Palacios	Educational Psychologist
Estela Alastruey Alpín	Early Intervention Therapist
Esther Cevallos Moroso	Teacher, Therapeutic Pedagogy
Eugenia Lara Quesada	Psychologist
Eva Lacambra	Speech Therapist
Felipe Retortillo	Psychologist
Fernando Martínez	Speech Therapist
FIAPAS	Federation of Parents Association
Francisco Ratia Sopena	Physician
Gloria Calcerrada	Psychologist
Luisa M. Cid Domínguez	Psychologist
M ^a Angeles Orús	Social Worker
M ^a Concepción Meneses Aragón	Social Worker
M ^a Esperanza Coloma Rentero	Psychologist
M ^a Gracia Millá Romero	Educational Psychologist
M ^a Isabel Casbas Gómez	Psychologist
M ^a Isabel Hervella Ramos	Speech Therapist
M ^a José Sesa	Educational Psychologist
M ^a José López Dóriga	Educational Psychologist
M ^a Luisa Poch Olive	Neuropaediatrician
M ^a Rosa Mayo Tagarro	Teacher, Special Education
M ^a Victoria Diéguez Camba	Educational Psychologist
Mayte López Bitrian	Speech Therapist
Mercedes Sús	Speech Therapist
Mercedes Valle Trapero	Psychologist, Educational Psychologist
Pilar Otal	Psychologist
Pilar Cortés	Physician
Xuntos	Parents Association
Ruth Jiménez	Speech Therapist
Sonia Sanz Nogués	Social Worker
Teresa Busto Domínguez	Educational Psychologist
Teresa Jiménez	Rehabilitation Doctor
Victoria Labadie	Educational Psychologist
Victoria Soriano	Psychologist, Educational Psychologist
Xoana Balado Fernández	Psychomotor Development Specialist
Yolanda Hervera	Teacher Special Education

