

Climent Giné<sup>1</sup>  
Anna Balcells<sup>2</sup>  
Joana Mas<sup>3</sup>

# Early Intervention in Catalonia

## Abstract

*This paper describes the evolution of early intervention (EI) in Catalonia until its present day. The first attempts were established in the early seventies by interdisciplinary teams trying to improve the development of children with disabilities with an understanding that it was crucial to intervene as early as possible. Nowadays, EI in Catalonia consists of a well-established public network of Early Intervention Centres with specific catchment areas responsible for preventing, detecting, treating and monitoring children (and their families) with disorders in their development. The article provides an accurate description of the process that families with children with developmental delay follow from the time they discover a problem in their child's development until they reach the Child Development and Early Intervention Centre. To this end, the article is divided into two parts. The first takes a brief look at the history of the legislation regarding EI in Catalonia, while the second focuses on how the services involved were conceived and are currently organised and implemented.*

*Key words: Early intervention, policy, practice, Catalonia, target group, families.*

## Families in need for support

*Mariola woke up from her afternoon nap and started to make some movements that were completely unknown to me: her head slumped and she closed her eyes over and over again. This was repeated every time she woke up in the morning or after a nap.*

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<sup>1</sup> Ph.D., Ramon Llull University, Barcelona, Spain, (E-mail: [ClimentGG@blanquerna.url.edu](mailto:ClimentGG@blanquerna.url.edu))

<sup>2</sup> Ph.D. Student, Ramon Llull University, Barcelona, Spain, (E-mail: [AnnaBB0@blanquerna.url.edu](mailto:AnnaBB0@blanquerna.url.edu))

<sup>3</sup> Ph.D., Ramon Llull University, Barcelona, Spain, (E-mail: [JoanaMariaMM@blanquerna.url.edu](mailto:JoanaMariaMM@blanquerna.url.edu))

*Although I was a first-time mother, I knew straight away that something was not right and I would have to take Mariola to the hospital. I thought we would be a few hours waiting around in A&E and after a general examination they would tell me what was the matter and we would go home with a prescription for some medicine. But some hopes! The hours turned into days, long, lonely days in a cold room watching Mariola being submitted to tests and more tests, days without any rest, which increased the worry and the anxiety of not knowing. In the end we emerged from that period of being shut up with an answer: tuberous sclerosis, one of the so-called rare genetic disease displaying specific symptoms in various parts of the body, including the brain, but with a broad spectrum of manifestations. There then began a new life for which nobody had prepared or even warned me, full of uncertainties, thoughts, unknown words and the initials of different centres and organisations. The first and most important help I had was the calm, the vision of the positive side of things and the happiness my husband conveyed to me at all times, and which he still does every day that goes by. I take this opportunity to thank you for everything, for being by my side and supporting me in the most difficult situations.*

*The second help we received was from the Early Intervention Centre at which we arrived via Mariola's neuropaediatrician and a referral from our primary healthcare centre. From the first day we entered the centre, the treatment we received from the people there was extremely cordial, warm and friendly. It was decided that Mariola should start with one physiotherapy session a week to teach her first to crawl and then to walk, as her muscular tone was low. At the same time, she was seen, and continues to be seen, by a neuropaediatrician, to monitor the evolution of the disease, the knowledge acquired, the deficiencies, and also to explain to us in simple terms the essence of how the disease is caused.*

*When Mariola was one she started to crawl and at 16 months she took her first steps. Just when I was giving birth to my second child, Marcel, the physiotherapy sessions finished and the sessions with Dolors, the psychologist, began. For about a year we have accompanied Mariola to the sessions with Dolors. A special rapport has grown up between them. They are very fond of, and also show great respect for, each other. Between games she explains to us, the parents, the reason for that activity, the aim she wants to achieve and, depending on the response, how Mariola is developing. From time to time we also have a session with her, just the parents on our own, during which she tells us how Mariola is getting on and we also tell her about our concerns, our worries and the progress we are able to observe in everyday situations.*

*Now that Mariola is nearly 4 years old, we still go to the Centre once a week "to play with Dolors", as she says; by now she goes into the session on her own and when she comes out she tells me what they have done and whether she has behaved well or average. When we leave we always say "see you on Monday, Dolors", in the knowledge that there we have a help and a friend.*

*Noelia Pardo.  
Mom of a child with disability*

These simple words written by a mother introduce us to the reality of early intervention in Catalonia from the time the mother discovers that something is not quite right in her daughter's development until they reach the Child Development and Early Intervention Centre. Although the experience recounted here is unique, it provides us with an intimate description of the process that people go through, furnishing a neat introduction to this article whose purpose is to describe how early intervention (ECI) in Catalonia is conceived of, organised and implemented. To this end, the article is divided into two parts. The first takes a brief look at the history of the legislation regarding EI in Catalonia, while the second focuses on how the services involved have been conceived of and organised (goals, scope, family involvement, professional training, the route followed by families, referrals, etc.).

### **A brief look at the history**

To understand the current state of early intervention in Catalonia, reference must be made to the way Spain is divided into different regions and how different powers are devolved to them. Spain is made up of 17 regions, known as autonomous communities, each with its own government and parliament democratically elected by the citizens living there. In spite of the fact that the Spanish parliament and government retain a number of exclusive powers, each autonomous community has a certain legislative, organisational and financial capacity enabling it to implement its own policies in certain spheres and, in particular, in social services and education. More specifically, the autonomous communities are responsible for early intervention in Spain, as, beginning in 1981, the relevant powers have been gradually devolved to them by the central government (Ponte, 2004).

An important milestone in this process was the enactment of Law 13/1982 of 7 April, known as the Disabled Persons Social Integration Act (published in the official gazette – BOE- on 30 April 1982). This Act introduced a set of measures that had a direct effect on subsequent legislation concerning early intervention in each autonomous community. For the first time it spoke of the importance of prevention and the need to intervene at an early age in the case of children having some difficulty or deficiency. At all events, the first specific regulations concerning the early intervention did not arrive until social services laws were passed in the different autonomous communities. A first feature of early intervention in Spain to be noted is the diversification of responsibility for it resulting from the fact that the funding model and system of organisation differ considerably from one autonomous community to another. Nevertheless, from the point of view of how such intervention is conceived of and implemented, it should be mentioned that the professionals involved put a lot of effort into reaching a framework agreement for the whole of Spain which was set out in the White Paper on Early Intervention (*Libro Blanco de la Atención Temprana*) published in 2000 (Real Patronato de Prevención y de Atención a Personas con Minusvalía, 2000). This document covered the following aspects: definition, objectives, main spheres of action, relationship with the community and co-ordination among institutions.

Although Catalonia has had full powers regarding early intervention since 1985, when the central government transferred responsibility for it to the Catalan autonomous government (*Generalitat de Catalunya*), the origin of early intervention in Catalonia dates back to the mid-1960s when the first interdisciplinary teams were set up to deal with children with disability and their families during the first few years of the children's lives. Many of these teams were linked to parents' associations which were created to compensate for the absence of support and services for children that needed them (Rubert, 2010).

These early teams were the result of the enthusiasm of certain professionals wishing to address the needs of children with some sort of disorder in their development in the first few years of their lives. Those professionals had neither means, nor resources, nor official recognition, but they nevertheless believed wholeheartedly in the need to offer such a service to the population. As the years went by, various Early Intervention Centres gradually became more firmly established. These were mostly privately owned and located in hospitals, special education schools or on the parents' associations' premises, although they were not covered by any official legal framework.

The gradual growth of these services, coupled with increasing demand, led the autonomous government to publish the first legal instrument regulating early intervention in Catalonia. This was the Order, of 29 July 1985, which instituted the Sectorial Early Intervention Programme. The most important contributions made by this order have been summarised by Rubert (2010) as follows:

- Public recognition of the work done by the early intervention centres existing at that time, all of which had been set up by social and private initiative.
- Definition of the centres' catchment areas. The geographical area covered by each early intervention centre was delimited and its work in co-operation with the other children's services in the area was officially recognised. Following this Order, children's parents and/or guardians no longer had a choice of centre, but were allocated to one on the basis of where they lived.
- The creation of more centres, especially state-run centres, across Catalonia, in order to comply with the catchment area plan ensuring all areas were covered. The setting up of new centres led to the co-existence of publicly run and privately run centres.

In 1994 new legislation was introduced in Catalonia based on the experience built up, progress in regard to how the matter was conceived of and other laws passed in the social services field. Legislative Decree 17/1994, of 16, November had the effect of stimulating demand by families for early intervention and broadened the scope of such intervention. There was a shift away from a view of the service as focusing mainly on disability and prevention to a more global and ecological perspective prioritising prevention and promoting optimum development in order to avoid or minimise possible disorders (Rubert, 2010). After this there was a gradual move to expand intervention beyond children with disability to cover children with other developmental problems or at social risk as well.

The following year, Decree 206/1995, of 13 June, brought early intervention under the Social Welfare Department. This Decree also represented progress in regard to the concepts and terms employed. In particular:

- It no longer used the term *disminució* (handicap) and introduced instead *transtorn* (disorder) to refer to a feature of the population at which the service was aimed.
- The age at which intervention could be provided in exceptional cases if really necessary was extended to 6 years, although 4 continued to be the upper age limit.
- Greater emphasis was placed on interdisciplinary teams of professionals which were made responsible for the whole intervention process, providing assessment, intervention, support and guidance to the parents and collaborating with the other young children's services.

This conceptual change also influenced the name given to the centres providing early intervention. It was changed from Early Intervention Services (SAP) to Child Development and Early Intervention Centres, the name by which they are still known today. Legislation concerning early intervention in Catalonia was completed by Law 18/2003, of 4 July, on family support and the regulations for implementing it, and Decree 261/2003, of 21 October, which laid down the current guidelines for this field.

### **Early intervention in Catalonia today**

Early intervention in Catalonia comprises a well-established public network of Early Intervention Centres with specific catchment areas charged with preventing, detecting, treating and monitoring children with disorders in their development.

Basing itself on the White Paper on Early Intervention (Real Patronato de Prevención y de Atención a Personas con Minusvalía, 2000), the Department of Social and Citizen Action of the autonomous government of Catalonia defines early intervention as “all the interdisciplinary actions in the sphere of prevention, detection, diagnosis and therapeutic intervention ranging, in a broad sense, from the moment of conception until the child is six years old, encompassing, therefore, the prenatal period, the perinatal period and the postnatal period of early childhood” (Generalitat de Catalunya, 2010). This same document specifies that “early intervention is aimed at children who display (chronic or temporary) disorders in their development, have a history pointing to biological, psychological and social risk, are in a situation where they are at risk of suffering such disorders or display difficulties in rearing. Moreover, early intervention is also aimed at the families of these children”.

It should be pointed out that this conception of early intervention is in keeping with the most up-to-date views emerging from research and espoused by international bodies. We refer here to a broad conception of early intervention, the importance of the family, focus on the child's potential, emphasis on a bio-psycho-social model, etc. (Dunst, 2000; Giné et al., 2006; Guralnick, 2001; Soriano, 1999).

As already mentioned the Early Intervention Centres are responsible for early intervention preventive and support work. In particular, the functions allocated to them

include carrying out a global assessment of the problems of the child and its family (diagnosis); providing the family with information, guidance, support and advice; giving the child with disability personalised therapeutic care; offering special schools with guidance and support; monitoring the child's development; collaborating in prevention and detection programmes; and engaging in research, teaching and training.

The aims pursued by the Early Intervention Centres in accordance with their commitments are (Generalitat de Catalunya, 2010):

- Caring for children from conception to six years old
- Taking part in the co-ordination of the (detection and prevention) actions carried out in this age-group
- Participating in interdepartmental co-ordination and co-operation projects
- Providing interdisciplinary teams with special expertise in child development
- Guaranteeing individualised work and continuity of care.

The Generalitat de Catalunya (2010) has stipulated that the early intervention centres are aimed at:

- Children who in normal circumstances would not require such care or assistance, but whose family or social situation may make it necessary.
- Children who in normal circumstances fail to reach development appropriate to their age and therefore need special care to achieve it.
- Children with evident malformations, congenital defects, cerebral lesions due to any causes or any other anomalies.

In addition to these children, the scope of intervention encompasses the families as a unit of development, the natural environment in which the child lives and society in general, as all these contexts has an impact on the child's overall development. So the early intervention centres in Catalonia do not deal only with children suffering a manifest organic, permanent disability, such as Down's Syndrome or Autism Spectrum Disorder, but are aimed in general at children with disorders in their development or at risk of such disorders due to their biological, psychological or social situation. From this perspective, development is understood as the result of the child's interaction with its environment, including the people in it.

Some professionals working in this area in Catalonia (UCCAP, 2004) have estimated that, bearing in mind the extent of the population at which early intervention is aimed (children with disabilities, slight and temporary difficulties, at social risk, etc.), the proportion covered should be at least 7.5% of the infant population (0-6), as against the 4.7% actually dealt with in 2008. It should be pointed out, however, that the number of children dealt with has increased every year, going up from 11,454 users in 2002 to 24,883 in 2008, a rise of 117.24% (Generalitat de Catalunya, 2010).

Although the aim of the legislation and the desire of the professionals are clearly to involve families more, the fact of the matter is that this goal is still a long way off. Indeed, following research assessing the quality of early intervention services in

Catalonia with the collaboration of 36 professionals and 38 families, Vilaseca et al. (2004) concluded that early intervention is still heavily focused on the children and little on their families, since the predominant model over the past few decades has been the clinical model centred on the child's rehabilitation, leaving the family in second place. Nevertheless, the situation is paradoxical: whereas, on the one hand, it seems that the importance of working with families as the context for development is acknowledged, the criteria the administration actually employs to determine the amount of money to be allocated to each of the services are based on the number of children dealt with, which has a negative effect on the efforts the services have to make to deal with the families.

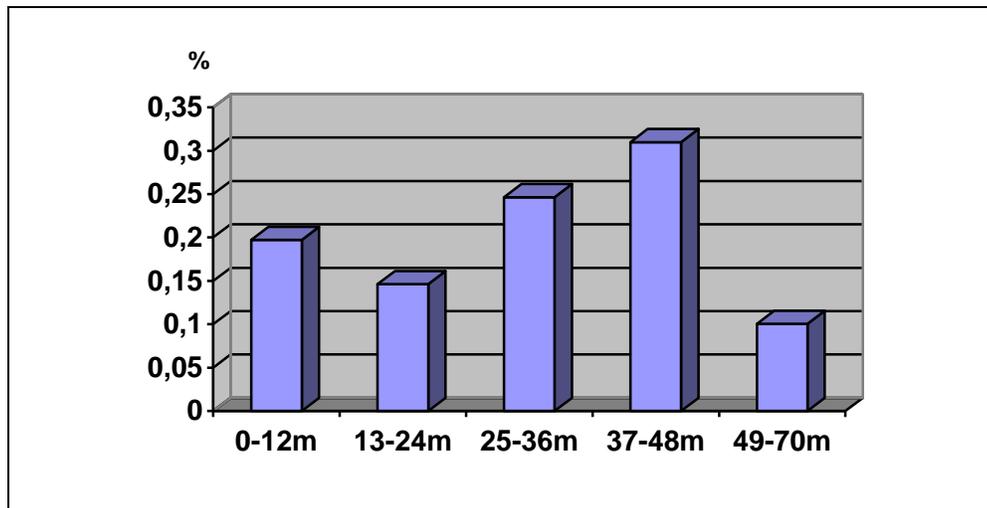
Coming back to the aims of the Early Intervention Centres, one of the requirements is that the team of professionals should be interdisciplinary, covering all the areas of the child's development and the different objects of intervention (child, family and environment). These professionals must be specifically educated and trained in physiotherapy, speech therapy, medicine, psychology and social work (UCCAP, 2004). These are the minimum areas of expertise the Early Intervention Centres have to cover, although the larger teams often include specialists in pedagogy, educational psychology and psychomotricity.

The only requirements professionals must currently fulfil to be able to work in an Early Intervention Centres are a qualification in one of the disciplines just listed. Nevertheless, the White Paper on Early Intervention (Real Patronato de Prevención y de Atención a Personas con Minusvalía, 2000) comes out clearly in favour of requiring professionals working in early intervention to possess, in addition to their basic qualification, specific education and training in early intervention to be obtained via a master's degree. In short, the White Paper calls for specialist university courses and in-service training to ensure that the professionals working in this field are sufficiently well trained (Real Patronato de Prevención y de Atención a Personas con Minusvalía, 2000).

There are currently 86 centres in Catalonia (Generalitat de Catalunya, 2010) each catering for a particular sector of the population and geographic area. The advantage of this sectorisation is that professionals have extensive knowledge of the resources available in their area of intervention and of the existing services (schools, community resources, private practices, leisure and free time resources, etc.). Some of these centres are publicly owned, while others are privately owned, but they all receive public funding and so the families do not have to pay for the services.

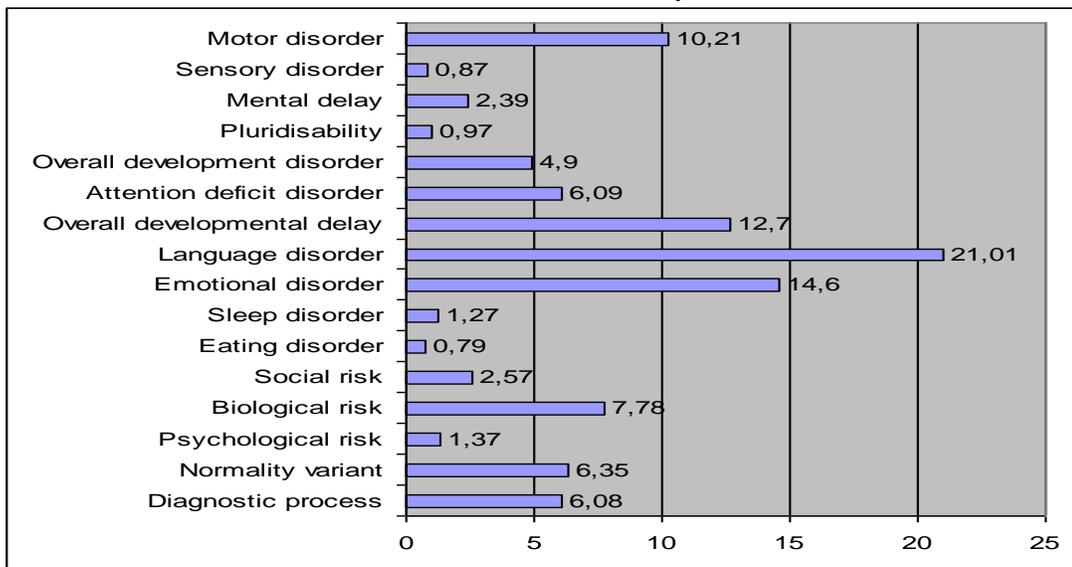
Children and their families reach the Early Intervention Centres in Catalonia in a large variety of ways. This diversification is probably due to the growing awareness among professionals and families regarding normal child development. This increased awareness has improved the detection of difficulties in infants at younger and younger ages, and of disorders with different aetiologies. As shown in Graph 1, in 2008 more than 19% of the children seen at the early intervention centres were less than a year old and 14.61 were under 2, although 4-year-olds constituted the largest age-group (30.99%) (Generalitat de Catalunya, 2010).

Graph 1. Age at which children were first seen at the early intervention centres in Catalonia in 2008 (Generalitat de Catalunya, 2010).



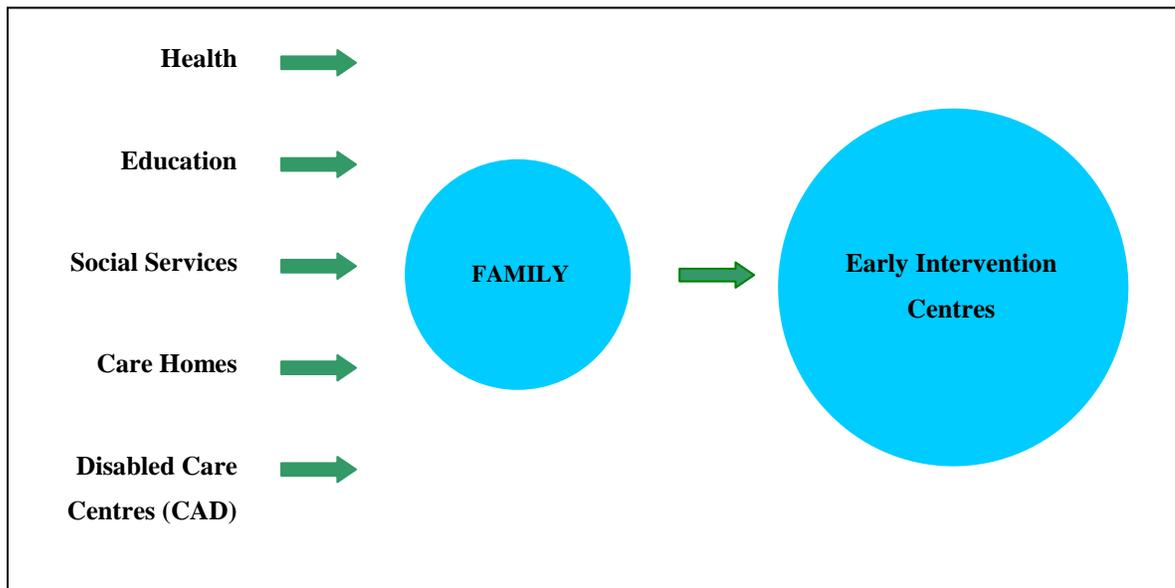
As regards aetiology, in 2008 language disorders were the most frequent reason for referral (21.01%), followed by emotional disorders (12.70%) and cognitive developmental delay (12.70%). The least frequent reasons for referral were eating disorders (0.79%), sensory disorders (0.87%) and multiple disabilities (0.97%) (Generalitat de Catalunya, 2010).

Graph 2. Main diagnosis of all the children dealt with by the early intervention centres in Catalonia in 2008 (Generalitat de Catalunya, 2010).



As already stated, not all cases reach the early intervention centres by the same route. The first symptoms are usually detected by the primary care services (health and social services), although it is often the families themselves who bring the strangeness of the development of their child to the attention of the authorities. Once the hypothesis has been confirmed, the families are informed and referred to the Early Intervention Centre. After this, it is up to the families to phone the centre for an appointment and describe their child's difficulty. Figure 1 shows the normal route taken by families to reach the Early Intervention Centres.

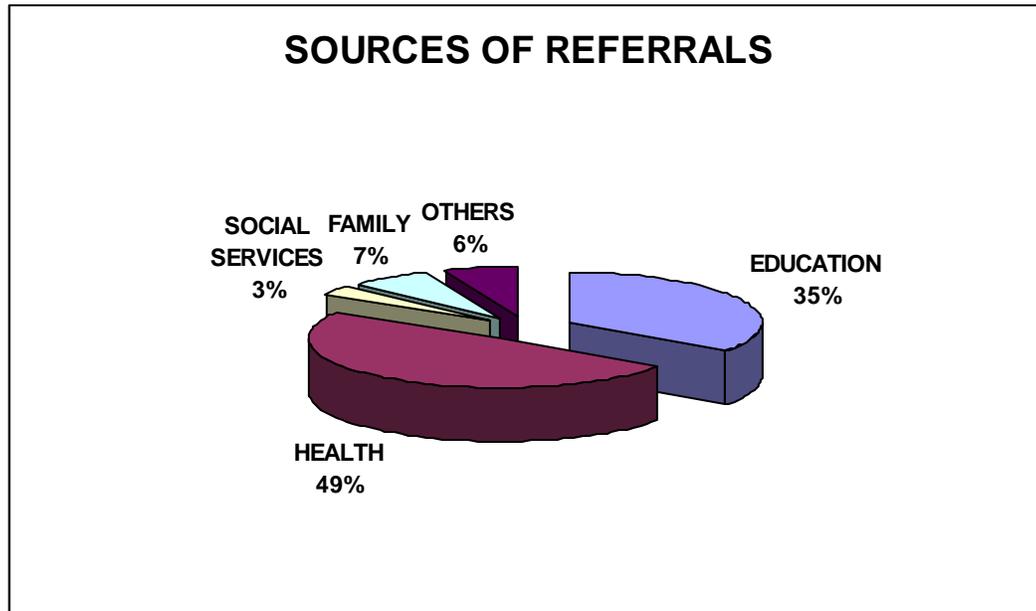
Figure 1. Referral route (Generalitat de Catalunya, 2010)



As expected, the services normally involved in referring children to the early intervention centres are healthcare (hospitals, pediatric services, etc.), education (nursery schools, infants' schools, educational psychology services, etc.) and social services, as well as the legal system, care homes and disabled care centres, (Generalitat de Catalunya, 2010; Ruiz & Zaurín, 2004).

Graph 3 shows the distribution of the origins of referrals to early intervention centres in 2008: health services (49%), education (35%), social services (3%), families (7%) and others (6%) (Generalitat de Catalunya, 2010).

Graph 3. Referral sources 2008 (Generalitat de Catalunya, 2010)



When a family phones an Early Intervention Centre, the team takes a series of steps to assess the child and its immediate environment. These steps include:

- a) a meeting of various professionals to decide who is to assess the child in view of the kind of difficulties reported and each professional's particular expertise.
- b) a meeting with the child's parents or guardians at which the case history is compiled: reason for the request, family history, reports by other professionals, the child's development, the environment in which the child lives and participates, and the parents' concerns and/or expectations regarding the child's development.
- c) an assessment of the child: the cognitive, motor, communicational, psychological and affective capabilities through observation of the infant and administration of the tests considered most appropriate in each case, usually the Bayley II, Batelle, Reynell, McCarthy, ITPA, Riviere, etc., scales (not specifically mentioned in the references).
- d) a meeting with the centre team to share the information gathered, make the assessment and decide on the most suitable intervention (the goals to be aimed at, the professionals to be involved, the frequency of the intervention, etc.). Normally at this meeting a functional diagnosis of the child is made taking into account the classifications in the DSM IV, ICD 10 and the diagnostic classification of the *National Center for Clinical Infant Programs* (Ruiz & Zaurín, 2004 ).
- e) Lastly, the family is informed of the assessment that has been made and the proposed intervention is explained to it.

The centres carry out a global intervention taking into account all the areas of the child's development (emotional, social, cognitive, communicative and motor). The intervention is almost always performed with the child on its own. In some cases, while a relationship between the child and the professional is being built up or when it is thought useful for the parents to see how the professional interacts with the child, the parents are invited to be present at the intervention sessions, although in both cases their role is generally confined to that of observers.

Most of the direct intervention sessions with the child are held at the centre and usually last 45 minutes. The frequency of the sessions varies according to the degree of the child's disorder, whether the child is attending school and its emotional status. According to Ruiz & Zaurín (2004) the different intervention modalities can be divided up as follows:

- Intensive intervention (2 or 3 sessions a week)
- Regular intervention (1 session a week)
- Follow-up intervention (every fortnight or more)

In addition to the sessions with the child, the professionals devote a large part of their work to raising the awareness of, and co-ordinating what they are doing with, the child's tutors at school, the educational psychologists, the area social workers if necessary, etc. They also put aside time for training, teaching and, to a lesser extent, research. Early intervention in Catalonia, therefore, does not consist merely of what is done directly with the child. One might say there is one type of intervention which is more direct –that performed with the child- and another which is less direct –that which is carried out with the different agents involved with infants and young children.

Even so, it should be borne in mind that according to a study of the needs of the families in Catalonia conducted by the Disability and Quality of Life research group (Ramon Llull University) in 2010, parents insist on being able to have more contact with the professionals (Disability and Quality of Life; Educational Aspects, 2010) . The families are satisfied with the attention and care they receive from this service, but not with the amount of time dedicated to them as opposed to the child on its own, which confirms the results of a previous study (Giné et al., 2001).

According to Ruiz & Zaurín (2004), from the outset, Catalonia has been a pathbreaker in Spain in the way it has managed early intervention. It can be said that Catalonia now has an early intervention service provided by the early intervention centres that is well established, well regulated and highly regarded for the quality of the care it delivers (Vilaseca et al., 2004), although certain important limitations remain in the rural areas and in regard to certain needs, as well as, as just mentioned, in relation to direct intervention with the families.

Indeed, the measures that need to be taken to improve the service in the future and bring practice into line with the new perspectives on such work include: making the service more sensitive to the families' needs (opening times, etc.) and more flexible, including

the possibility of home visits to contextualise better the advice given on child rearing; and, lastly, increasing the time devoted to the families, especially in the case of children who require it.

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