

# autisme la garriga

## 25 years of a project



congost autisme  
fundació









autisme la garriga  
25 years of a project

■ autisme  
la garriga  
25 anys  
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This book is addressed both to parents and professionals concerned about autism, as well as to non-involved people who wish to know what is autism, what kind of services exist for affected people, how autism influences the family life, etc. The history and current reality are presented, both concerning Autisme la Garriga's project and the world of autism in general, as well as the future challenges.

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# Presentation

The Right Honourable Jordi Pujol  
President of the Autonomous Government of Catalonia

It is a great pleasure for me to present the book **autisme la garriga. 25 years of a project**, since it is a demonstration of 25 years of good labour carried out with effort, dedication and esteem, looking towards the future and aiming to help the families that find themselves with the hard diagnostic of having a son or a daughter with autism.

The Autonomous Government of Catalonia has supported this initiative and many others that have come up from the will of some parents. Parents who have not resigned themselves, have not stayed passive considering their problems, but have tried to put together their capacities and the help from the rest of the society, both from professionals and individuals, as well as from public and private institutions, in order to develop determined ideas, a determined project.

The Catalan society faces up to the challenge of paying attention to people with autism and, in general, to all the people and families who need support to keep on going. We cannot allow our society to become "autistic" itself, unable to communicate and causing isolation among all of us. We need people with sensitivity, dynamism and eagerness as people in **congost autisme** Foundation, that have learnt to share their experiences, have learnt to deeply analyse their needs and foresee the needs of others in order to offer an integral answer, which allows to support people with autism and their families.

We must analyse, interpret and modulate the care that each person and family require. In these last 25 years, the situation has very much changed thanks to the involvement of many people, institutions and the Catalan public Administration. We want this situation to keep on changing and developing, since our objective is a society where each individual is valued and considered as an important and unique piece.

In this book is patently obvious the commitment and the milestone that **congost autisme** Foundation has meant in the area of people with autism. It has worked close to the people affected, their families, together with other organisations from the field of the disabled and has closely collaborated with the different departments of the Autonomous Government of Catalonia. All this work is carried out under the perspective of the social inclusion of people with autism, with all their civil and citizenship rights.

This publication strengthens the believe that the main future challenge is to be able to offer people with autism, and their families, a life that provides their wishes and needs with answers. I encourage you to keep on working from the perspective of integral and interdisciplinary actions that you have established as future challenges in this document.



Jordi Pujol  
President of the Autonomous Government of Catalonia



# Preface

The Right Honourable Joan Rigol  
President of the Parliament of Catalonia

Since long time ago, since the beginning of the seventies, I have had the chance to collaborate with **autisme la garriga's project** of **congost autisme** Foundation. This has allowed me to share with families, parents who have a son or a daughter with autism, what that fact means. I have been able to see how these parents commit themselves to face up to autism beyond the problem of their own child. The autism has not shut themselves in their problem, but given them the possibility of exerting a civic commitment towards the society.

The approach to the person with autism is an incitation, a lesson to learn the mystery that we, the people, are. The possibility to communicate through language is the acknowledgement that beyond the "ego", that each one of us are, there is "the other", who invites us to come out of ourselves.

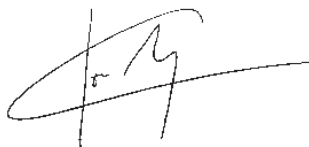
But when this "other" –as in the case of the person with autism- cannot communicate, we should make up for this lack: this is the deepest act of esteem, it is the act of "giving yourself" when it is not possible to wait for an answer. It is in that way the person with autism we love makes the most of our human possibilities.

Emmanuel Mounier –the French philosopher who formulated his thought about the "personalism" based on the acceptance of the other through the dialogue- lived this personal experience in order to be able to communicate with his disabled daughter. Through his daughter, Mounier experienced the deepest sense of the human dialogue.

It is important to remind this message to a society as ours, which instead of going into our possibilities as persons in greater depth, values and considers us for our immediate usefulness. It reduces us, through economics and consumerism, to the *do ut des*. It makes us lose the deepest sense of the person: our capacity to go beyond the immediate interest in order to be able to stand by the other, by his needs, by his feelings, by his convictions.

It is true that with people with autism we have to show our best feelings and our best attitudes, as if they were theirs; these people make us to carry out this task of making up for; faced up to their lack, we can only offer them an attitude of service, far beyond any answer.

Our world needs the witness of families that, due to the fact of having a son or a daughter with autism in their bosom, have learnt to accept the challenge of offering an answer to this reality with humanity, bearing in mind that everything a person with autism asks the society for is nothing but humanism. Actually, this is the challenge of any society.



**Joan Rigol**  
President of the Parliament of Catalonia





# ■ What is autism?

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Autism is not a disease, in the strict sense of the word, but a syndrome.

A syndrome is a group of symptoms (uneasiness, problems or impairments that the affected person or his/her relatives, in the case of children, expose to the expert) and signs (data found by the expert exploring the patient) manifested simultaneously and clinically defining a determined morbid condition.

It is more than 50 years since people started talking about autism. In 1943, the American psychiatrist Leo Kanner, from systematic observation of eleven children, established the first description of the syndrome that he designated childhood autism.

Amongst all the psychopathological features presented by that group of children, the ones Kanner considered fundamental to define the impairment were the following:

1. Deep lack of affective contact with people
2. Obsessive desire of sameness
3. Lack of speech or language without communicative purpose

Subsequently, he formulated a detailed description of a complete secondary symptomatology, also found in the behaviour of these children.

After the initial work of this psychiatrist, many studies about the autistic syndrome appeared in different places of the world, and the result was a great deal of interpretations, definitions and descriptions.

Today, one of the most accepted definitions is the one contained in the fourth edition of the book Diagnostic and Statistical Manual of Mental Disorders, the so-called DSM-IV (American Psychiatric Association, 1994), which defines the autism according to the following features:

**A.1.** A qualitative deterioration of social interaction

**A.2.** A qualitative deterioration of communication

**A.3.** A restricted repetitive and stereotyped patterns of behaviour, interests, and activities

As well, the autistic disorder is defined as that in which these developmental impairments are manifested at an age earlier than the 3 years. It is at this stage when a delay or an abnormal functioning appears, at least in one of the following areas: social interaction, language used in social communication, or symbolic or imaginative play.

Clinically, autism is a very heterogeneous frame due to the great interindividual differences regarding three aspects: core symptoms (A1, A2, A3), secondary symptoms and intelligence quotient.

Concerning core or nuclear pathology, impairment of social interaction is easily observable in any individual with autism, even at the most early ages. During childhood and contrary to normal people, they do not manifest a clear and persistent affective behaviour towards the mother and adults in general, so we could talk about a lack of establishment of the first affective relationships.

It is frequent that, during the first year of life, the child with childhood autism does not present anticipatory behaviours as raising his/her hands to be lifted up or not manifesting any happiness when seeing the feeding bottle. Afterwards, these children usually do not go after parents when they are at home, nor look for consolation when they get hurt or they do not feel well.

Visual contact –a behaviour appearing very early, at the two or three months in normal children- is also very impaired in cases of autism.

These kinds of behaviours are not exclusive from this disorder; they appear as well in abandonment frames or hospital syndromes. Nevertheless, it has to be said that for an experienced general practitioner it is not difficult to observe differential features of social isolation, manifested in those frames, from those related to autism.

The communication impairment does not only refer to the delay and the developmental degree of linguistic skills. What precisely characterises the use of language in people with autism are the disorders in its use as a communication tool.

Impairments in the development of language are already visible in childhood pre-linguistic behaviours,

as for example social imitation. These children usually do not take part in simple imitation plays, they do not say "goodbye" with their hand, do not point out with their finger. It is not frequent either the correct use of toys or the development of simulation plays.

In the cases in which there is spoken language, the appearance of echolalia is abundant (automatic repetition of words said to him/her), both immediate and delayed. It is also characteristic the pronominal reversal (when they want to say "I", they say "you") related to echolalia. Moreover, individuals who have spoken language usually speak less than normal children do.

It is important to highlight the lack of reciprocal interaction, of true conversation in the verbal behaviour of autistics. It could be said that they do not speak with a person, but "to" a person.

The fact that about 50% of individuals with this disorder do not have spoken language could give us an idea about the severity of the communication impairment. On the other hand, as happens with social interaction, we also found very different degrees of affectation. From individuals with a practically inexistent comprehension level, who do not have any kind of linguistic code; to individuals with a good comprehension level, who have an essentially correct spoken language, where impairments have to do with the pragmatic and/or suprasegmentary aspects of linguistic expression (we refer to voice tone and inflection –lacking musicality, monotone and rigid- so characteristic).

The secondary pathology of autism is very wide and, as we have stated, could vary very much from one case to another. In the most affected individuals, hyperactivity

(very restless, distracted and impulsive individuals) mainly during childhood, and stereotypes, mainly in motor functions, are frequent.

In addition, during the first years, or in the case of people with autism who have not received any treatment before, temper-tantrums, very low tolerance to frustration (responsible for innumerable tantrums), self-aggressiveness (they could hurt themselves with their hands, fists, hit their head, scratch or bit themselves, etc.), and sleep disorders appear. In individuals of a higher level, verbal stereotypes and obsessive behaviours are usual.

Regarding the intelligence of these people, and contrary to what certain myths say, most of individuals with autism present an associated mental retardation. Initially, Kanner believed that children with autism had a normal intelligence, and so their incapacities were due to the autistic disorder. Subsequently, it has been incontestably proved that this was not true, and that most of people affected with autism (about 70% and 80%) present an intelligence quotient quite lower than the average of population in general.

Currently, the problem of the etiology of autism has not been solved. Originally, that is, in the years after the first description of the syndrome, and following the ideas of Leo Kanner regarding this aspect, believes were that the causes of the syndrome had a psychogenic nature, that is, environmental. Subsequently and gradually, this theory has been refuted by biologic researches in this field that, although they have not managed to identify the concrete cause or causes of this disorder, have shown the existence of an impairment with an organic nature in the origin frame (genetic, metabolic, infectious factors, etc.).

About prognosis, it should be said that with the current knowledge we could state that the person with autism will be autistic during his/her whole life. Today, autism does not get over. The evolution of the frame will depend on the severity of the disorder.

Disadvantageous indicators are the low cognitive level, the lack of language, added psychiatric and neurological disorders (about 20% and 25% of them are epileptic), an unstructured familiar environment or the delayed therapeutic welfare intervention. The opposite factors improve the prognosis: a good intelligence, a good development of language, the lack of psychiatric and neurological disorders, a good familiar environment with informal supports (parents, neighbours and friends), and an early treatment.

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# The treatment of autism

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## Background

As exposed in the previous chapter, the history of the treatment of autism started to be written at the same time as the definition of the syndrome, that is, in 1943. Leo Kanner's references to the possible influence of psychogenic factors in the genesis of the disorder, together with certain characteristics of the cases described (lack of neurological signs and existence of evolutionary areas and/or cognitive skills little or non affected), contributed to exclude –with the study elements available at that time- its biological etiology. This fostered the psychogenic hypothesis and the implementation of therapeutic orientations based on dynamic psychology, favoured at those moments by the preeminence of psychoanalysis in psychiatry and psychology.

This situation remained so during many years, and until the middle sixties other tendencies did not start appearing. Regarding treatment, the development of operational behaviour modification techniques allowed the appearance of the first behavioural therapeutic programmes applied to autism. In this sense, and although afterwards it was proved that both the psychodynamic and behavioural paradigms regarding the etiology of autism were wrong, the results of the intervention programmes of both tendencies, as well as the perspectives opened, were quite different.

From the psychoanalysis point of view, it has always been defended that autistic frames were the clinical expression of an early psychological trauma, caused by a pathological development of the affective relationships of parents towards their children, that had led the child to get isolated from the outside world to avoid the contact with a environment perceived as aversive. In addition, it was affirmed that, behind that psychological defence, the cognitive potentials of affected individuals remained intact. Although subsequently some authors with the same orientation introduced the neurological fragility as a necessary factor (but not enough) for the development of autism, they did not modify the therapeutic guidelines and went on applying psychodynamic therapies, which made for the reconstruction of the psychic development of the person, obtaining the results we all know.

Concerning the behavioural psychology, the etiologic paradigm was referred to an erroneous learning chain during the first evolutionary stages, as a factor causing the syndrome, and the therapeutic programmes were based on the systematic application of operational behaviour modification techniques, aiming to remove erroneous learning and replace them for others more adapted. The successes of this kind of interventions, in areas like self-help skills or problematic behaviours, alternated with evident failures in the treatment of core symptoms of autism: interpersonal relationships and communication impairments. However, although

the psychodynamic orientations did not allow developing any effective therapy, operational behaviour modification techniques proved that it was possible to modify certain behaviours of people with autism through the manipulation of environmental variables. The application of the behaviour functional analysis principles, which says that human behaviours tend to fulfil a function for the subject who applies them, and those are partially conditioned by precedent and consequent factors accompanying them, represented the start-up of the treatment of autism on a scientific basis, and allowed to start new and very profitable ways of research. At the same time, the start (also in the middle sixties) of etiological studies with a biological orientation involved the generalisation of pharmacological therapies, which during the course of years have notably developed.

## Current situation

### Therapeutic programmes

Because of the huge number of empirical and experimental data accumulated during the last decades, it could be stated that the most effective therapeutic programmes are those combining the application of techniques coming from the behavioural and cognitive psychology, together –if necessary- with pharmacological therapies. As well, the available information makes possible to enumerate a group of general principles to be considered when designing intervention programmes (Cuxart, 2000):

- Plan functional objectives.
- Design a reasonable number of objectives.
- Carry out periodical and objective evaluations of individuals.
- Educate in contexts as much natural and varied as possible.

- Structure to the utmost the learning processes.
- Choose treatment centres according to their typology and particular features of the individual.
- Work together with the family.

Bearing in mind these principles, the objective of individual therapeutic programmes should be not only the development of new behavioural repertoires, but also the modification or suppression of problematic behaviours. In this sense, intervention evidently should have a psychological and/or pedagogical nature, but when the behaviours we wish to modify or eliminate are significantly modulated by endogen factors (biological), psychopharmacological interventions will be also necessary.

Nevertheless, the problem caused by a very general description of the ideal therapeutic principles for the population with autism is the great heterogeneity of this population itself. It is widely known that the level of core symptomatology, the profile of associated symptoms and the intelligence quotient are three variables contributing decisively to the definition of very different clinical frames. Therefore, apart from some very generic guidelines, therapeutic programmes should have a much-individualised nature.

### Treatment of interpersonal relationships

During last years, quite useful programmes and techniques have developed for treating surely the most prototypical impairment of autism and one of the most resistant to interventions: interpersonal relationships. An example of these programmes is the so-called TED, *Thérapies d'Échange et Développement* (Barthélémy et al., 1995), which is based on individual treatments with a behavioural nature. The programme mainly applies to young children with severe autism.

There are other programmes, which are based on relationship therapies from a cognitive perspective.

All of them have in common their individual design, as well as the fact of being based on objects and/or activities very pleasant to the child, which helps to structure interpersonal relationships. This way, they drift apart from the most classical programmes of operational behaviour modification, much more rigid and little sensitive to individual differences.

### Treatment of communication

In order to describe the treatment of communication (i.e. language), it is useful to divide the affected individuals into two groups: those who have certain spoken and purposive language, and those who have not. In this sense, it is convenient to recall here that approximately half of the population with autism never gets to develop spoken language.

For many individuals placed in the second group, the development of programmes of alternative or augmentative communication has meant the possibility to have a communicative code system. Nowadays, the firm belief exists, amongst professionals, that if a child reaches the age of 4 years and has not developed purposive spoken language, it is necessary to start a programme of alternative communication. This programme could be, depending on the features of the person, either of signs (e.g. Total Communication, Schaeffer et al., 1980) or pictographic. The breadth of the linguistic code will depend mostly on the cognitive levels of the individual. However, even for individuals with an associated severe mental retardation –who, therefore, are not able to learn more than some elements and just make instrumental demands–, it has been proved that the possession of a

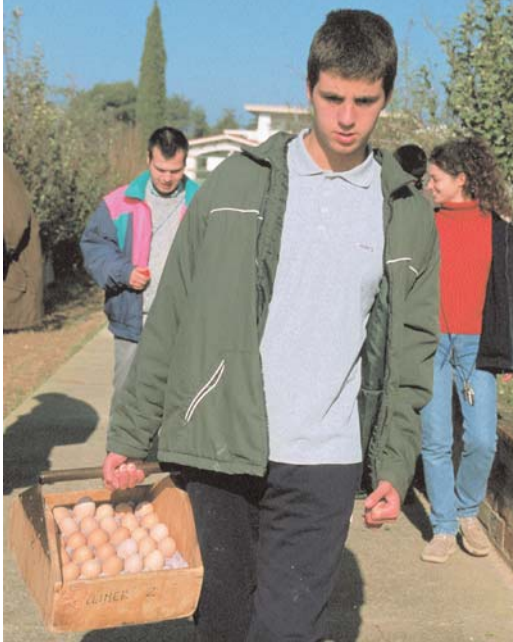
socially accepted and effective system of communication involves important benefits for the person. These benefits are not only direct due to the possibility to influence the environment of the person, but also indirect, due to the reduction of behaviours (e.g. aggressions), which although complying with communicative functions, their topography makes them problematic.

For individuals who spontaneously develop purposive spoken language, the treatment applies for improving aspects that in autism are always very impaired. For this reason, in the area of pragmatics, this is a priority objective, since the affected individuals tend to use the linguistic resources they have very little, and in a rigid and impaired way. In this sense, it is quite paradoxical, for people who are not acquainted with autism, to realize that people with a spoken language formally correct make such a poor and deviated use of it. In these cases, therapies make for improving verbal communication, from both a quantitative and qualitative point of view.

### Learning academic and work tasks

For people affected with autism, learning structured tasks is even more difficult due to different factors, consubstantial to the syndrome. The wide range of handicaps constituted by the affective-relational, communicative, cognitive and of intrinsic motivation impairments and/or deficits, together with the appearance of interfering behaviours, forces a deep study of the specific objectives and the methodology of programmes.

Regarding the methodological approach, it should be pointed out that the difficulty that many of these people manifest for the comprehension of information of a verbal nature, together with the usually well-



preserved visual-spatial abilities, has induced to the generalised use of visual supports, with a notable

success. Other techniques that have proved their usefulness to improve the learning of these people are, amongst others, the tasks analysis, learning without mistakes, modelling and back chaining. Therefore, we could state that the joint use of these tools has allowed a higher closeness of performances to individual potentials.

During adulthood, the use of these techniques has been accompanied lately with the development of working programmes coming from the concept work with support (ASEPAC, 1999). This concept includes the functionality, meaning, flexible help and election possibility principles, and constitutes a decisive element for the social and work inclusion of people with autism. Programmes of work with support consist on the development of real work tasks through the

physical or verbal aid from educators, and they contemplate a very wide range of work environments: from specific services for the most affected people, to ordinary job posts for a more capable minority. Systematic studies about the results of the application of these programmes have shown (Cuxart et al., 2000) that even the most severe adults with autism could benefit from real work tasks. In addition, it has also been evidenced that these programmes contribute to provide affected people with a better quality of life and to increase the motivation of their educators.

### Problematic behaviours

In people who present autism, behaviour disorders are usually frequent and severe. In the previous chapter of this book, the most usual are described and, it is true that, although they are not part of the nuclear pathology of the syndrome, they produce very severe distortions of the familiar, institutional and social environment. Behaviour problems contribute, in many cases, to notably worsen frames and could severely interfere in the learning processes.

The treatment of behaviour disorders requires a functional diagnosis, as the previous step to design a therapeutic programme, which, as we have already pointed out before, should have an essentially psychological and pedagogical nature. Although that, we have also stated that when there are endogen factors significantly contributing to the maintenance of behaviours, it is also necessary a pharmacological intervention. From a psychological and pedagogical point of view, the techniques used to modify or eliminate these behaviours are many: differential reinforcement, extinction, reply interruption, and time out. In addition, there is an increasingly wider consensus to eliminate all those techniques implying the presentation of aversive stimuli.

## Services

Apart from specific therapeutic programmes, the care and treatment of autism require a wide range of services:

1. Diagnosis
2. Familiar support
3. School
4. Day centre for adolescents and adults
5. Therapeutic and temporary halls of residence
6. Alternative dwelling

These services cover different needs and their use, by people with autism and their families, will depend on the period of the life cycle in which the individual is and his/her individual needs.

The specificity degree of all these services may be different but, as a general rule, we should consider that for the most severe cases, those should be very specific, while for the most capable, certain mainstream services could be appropriate, provided they have at their disposal adequate resources.

## Family

The severe consequences that involve having a child with autism for the family functioning make the existence of familiar support services necessary. The kind of support and its degree will be different from one case to another, but it is evident that during the child's whole life cycle, any family will need some kind of support and advice.

From a chronological perspective, the first thing

families ask for is a diagnosis of their child containing not only descriptive aspects, but also prescriptive. Subsequently, and apart from an adequate centre for the schooling of the child, parents need an individual programme to treat their child at home, which should include a regular advice by qualified professionals. Gradually, and as the child grows up, families should have at their disposal respite services during weekends, holidays and unexpected situations. Finally, the existence of alternative dwelling systems should be contemplated, in the cases in which the cohabitation at home is not possible anymore, due to the inability of parents to appropriately care for their child, or due to their biological disappearance.

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# ■ Etiology and scientific researches on autism

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Autism is a very wide and complex developmental disorder that has a bearing on the superior cerebellum functions. Autism is not a disease, but a range of abnormal manifestations contained under a big umbrella known as Autistic Spectrum (Rapin, 1991, 1998). It is characterised by qualitative deficiencies in the area of social interaction and communication, as well as by restricted, repetitive and stereotyped patterns of behaviour, interests, and activities (DSM IV). On the other hand, several disorders, syndromes and diseases with different etiologies could appear within the same autistic behaviour.

It appears since childhood and these children present a social isolation made evident in the action of gaze avoiding, lack of reply when calling them, lack of participation in group activities, lack of consciousness about others and lack of social and emotional empathy. Abnormalities in communication skills refer to both verbal and nonverbal, and go from a failure in the development of language expressive and receptive skills, to a repetitive language and echolalia. Patients with language have an inability to start or hold a conversation correctly. They are not able to interpret corporal language, intonation and facial expressions either. Their behaviour patterns are repetitive, stereotyped, resistant to changes, they feel very attached to objects or parts of the object, they insist in determined routines, are fascinated by moving objects and do not develop any symbolic play.

As there is a lack of biological markers, until this very moment the diagnosis of autism is limited to a clinical diagnosis. Behavioural manifestations of patients with autism could be observed in children with different clinical phenotypes, with a higher or lower cognitive deficit and several behavioural and communicative patterns. All the aforementioned constitute the great spectrum of autistic disorders (Rapin, 1997, 1998), which we found described in the international classification of diseases (ICD 10) and in the diagnostic and statistical manual of mental disorders (DSM IV). Therefore, in a child with an autistic spectrum disorder, it is essential to follow certain study guidelines and focus on the search of congenital and/or acquired brain damages, concurrent, toxic and/or metabolic diseases, epilepsy or any other medical or neurological abnormalities that could benefit from a etiologic diagnosis, an early medical and psychological treatment, and a genetic and familiar advice (Gillberg et al., 2000).

## Medical history

It is essential to elaborate a good medical dossier detailing familiar backgrounds, and to search for the existence of any relative -not only first-degree's, but also in several generations-, with autism, language delay, mental retardation, fragile X syndrome, tuberous sclerosis, etc., due to their implications and the need of a chromosomal or genetic evaluation. In addition, it is

also important to search for the appearance of affectivity and anxiety disorders, depressive, maniac disorders, schizophrenia, obsessive-compulsive disorders and tics, since it has been proved that these disorders are more frequent in families of patients with autism and might increase the family burden (Rutter, 1997; Simonoff, 1998; Fombonne et al., 2000).

We should detail the obstetrical and perinatal backgrounds, since unjustifiably it was believed the delivery was the origin of autism or mental retardation. An increase of obstetrical complications in labours of children with autism, independently of the mother's age, had been published. Although some previous studies had pointed out to a possible, but slight, association between autism and an increase of obstetrical risk factors, these signs have not been confirmed by ulterior studies (Lord et al., 2000).

It is essential to verify with the medical history any of the items of the psychomotor development, especially from the 18 to the 36 months, that is when the appearance of stagnations or jumps in development, and evolutionary regressions can be better evidenced. The social, communicative, and behavioural features, as well as the delay in language acquisition, the loss of social interaction, the obsessive behaviours, the attention deficit, the existence of epileptic seizures, the depressive conditions, the irritability, self-aggressions, the existence of disorders in the regulations of sleep and feeding should be accurately checked (Gillberg et al., 2000).

### Physical examination

The physical and neurological examination should be complete and exhaustive. In people with autism, some more time is frequently required, due to the probable

lack of cooperation of a patient with deterioration in communication and behaviour problems. You should always take into account that some severe and unexplainable changes in behaviour may be due to non-diagnosed concurrent diseases. When starting the examination, you always have to make the curve of the cephalic perimeter, since the average of cephalic perimeter in children with autism might be higher than the one of children with a normal development (Fidler et al., 2000). The same has been observed regarding the cerebral weight in post-mortem studies (Courchesne et al., 1999). Although only a little range of children with autism have an evident macrocephaly with a cephalic perimeter over percentile 98, the distribution of measurements is clearly deviated upwards, with an average in autism about percentile 75 (Lainhart et al., 1997). This macrocephaly could be detected at birth or it could appear an acceleration of the cerebral growth during the first year of life.

Macrocephaly phenomenon without a clear neuropathology in children with autism is widely recognised (Lainhart et al., 1997; Rapin, 1996).

Next, we should evaluate any dimorphic risk, special phenotype, somatic malformation or the presence of cutaneous abnormalities or organs abnormalities, to detect in any child presenting autism a neurocutaneous disease or the possibility of some syndrome known as fragile X, Rubinstein-Taybi, Smith-Lemli-Opitz, etc. When carrying out the motor examination, we will find that about the 25% present hypotonia, particularly during the first years of life. Abnormalities in fine and gross motor functions are found in many autistic patients, although it is more important in those presenting a lower IQ (intelligence quotient) (Rapin, 1996). It is very frequent the presence of stereotyped movements and behaviours, which can be observed in a 60-80% of these children.



The cognitive level should be evaluated, including the evaluation of social, play and communicative function (expressive, receptive, use of symbolic and spoken language) interactions. Deficit skills in play are independent from the intelligence quotient they present (Rapin, 1996).

### Behavioural assessment

Until this very moment, it does not exist any biological marker or laboratory analysis for the diagnosis of autism and other pervasive developmental disorders. According to that, doctors should use their clinical judgement, aid by diagnostic manuals as the DSM-IV and the ICD-10, as well as by the results of some evaluation instruments, scales or questionnaires. Tests for the detection of children with autism most widely used are: Questionnaire for autism in young children (Baron-Cohen et al., 1992; Baron-Cohen et al., 1996), Pervasive developmental disorders detection test (Siegel, 1998), the Childhood Autism Rating Scale (Schopler, 1986), the Autism Diagnostic Review (Lord, 1994), and the Autism Diagnostic Observation Schedule (Lord, 1999, 2001). For older verbal children the Australian Scale for Asperger's Syndrome is frequently used (Garnett et al., 1998). Due to the frequency of autism in child population (1/500 children), it is indispensable for the pediatrician to carry out psychomotor development monitoring, especially in high-risk population, and to exclude auditory deficits. It is essential to make the differential diagnosis with other pathologies to reach early the diagnosis of autism (Filipek, 1999, 2000). The interdisciplinary collaboration and advice is indispensable in the diagnosis and evaluation of children with autistic spectrum disorders.

### Complementary examinations

When you have a patient with autistic spectrum disorders, you should carry out complementary tests for their etiological study. Several neurological probing techniques are used: neuroimaging, biochemical analysis, neurophysiological examinations, genetic studies, etc., which will help us to trace the organic causes, today known, and that may constitute the origin of autism in some patients, and they could also help us to better know the brain functioning in these patients, in their idiopathic shapes (De Long, 1999).

### Neuroimaging

Great steps forward in radiological studies have been shown during last years, especially in the field of neuroradiology, with Computerized axial Tomographic scan (CT or CAT scan) and cranial functional Magnetic Resonance Imaging (fMRI), with volumetric studies, as well as Spectroscopy to study cerebral metabolites. In the last decades, SPECT has been added and has allowed us to visualize the hypoperfusion of the right cerebral hemisphere in a group of patients affected with Asperger's Syndrome. Studies on Positron Emission Tomography (PET) have made us easier the study of the global basal use of glucose in the brain.

In the eighties, the first studies with CT or CAT scan (Computerized axial Tomographic scan) described several abnormalities in cerebral images, but the study by Damasio et al. (1980) showed that cerebral abnormalities in CTS of individuals with autism were only associated to the existence of concurrent disorders, rather than to autism itself. In a review of more than 400 image studies in individuals with autism, a very low prevalence of focal damages or

other pathologies was found, and their variable location defined them as merely accidental data or coincidences (Filipek et al., 1992). A range of studies with CT or CAT scan and fMRI in patients with autism, previously excluded from those presenting other identifiable disorders different from autism, have confirmed a lack of detectable cerebral abnormalities which were specific characteristics of autism (Filipek, 1999). Using the functional Magnetic Resonance Imaging (fMRI), Baron-Cohen (1999) showed that in patients with autism and Asperger's syndrome an activation of the frontal-temporal region, but not of the amygdale, was produced. The studies on positron emission tomographies (PET) have shown increases of cerebral glucose in basal nucleus, frontal, parietal and temporal lobules, although other groups of researchers have not confirmed it (Filipek, 1999). A recent work of five men with a high functional level and autism showed: inverse hemisphere dominance during verbal auditory stimulation, a tendency to diminished activation of auditory cortex during auditory stimulation and a cerebellar activation, also diminished, during nonverbal auditory perception. Other studies have shown abnormalities in base ganglions and in the anterior cingulate gyrus (Haznedar, 1997). In children with autism, using the precursor of serotonin (alpha-C11 metyltryptophan), it was observed how the serotonin synthesis was more reduced in the left hemisphere than in the right cerebral hemisphere, which evidenced an abnormality in the serotonin synthesis of the cortical dental-thalamus tracts (Chugani, 1999). Other studies have described a lack of the serotonin synthesis increase period in the brain of children with autism (Filipek, 1999).

### Biochemical studies

During last years a wide range of biochemical



determinations in urine, blood and cerebrospinal fluid have been carried out trying to identify specific metabolic abnormalities in individuals with autism. Studies on congenital errors of metabolism regarding amino acids, carbohydrates, purines, peptides, are included, as well as abnormalities in the mitochondrial respiratory chain, and studies on toxins.

The concurrence of symptoms similar to autism in patients with congenital errors of metabolism makes us think in the use of the detection test as a part of the evaluation routine in patients with severe clinical frames. Metabolic tests and studies apply when there is a history of lethargy, cyclical vomiting, dimorphic or rough features, severe mental retardation, and epileptic seizures persistent to medication in regressive frames. Nevertheless, the percentage of children with autism in which an identifiable metabolic disorder has been confirmed is probably below the 5% (Shevell, 2000).

The increase of platelet serotonin levels seems consistent, but their mechanism is unknown (Cook et al., 1993), although it seems evident, that serotonergic neurotransmission in autism is pathologic (Chugani et al., 1999). The existence of antibodies against the basic protein of myelin in children with autistic behaviour (Cook et al., 1990) and the existence of partial or incomplete activation of T lymphocytes have arisen speculations about a possible involvement of the self immune system, although at the time being it has not been possible to confirm it.

There are several analytic studies on patients with autism searching for a biological marker, but they have not reached concluding results. Examples: element traces analysis, celiac antibodies, food allergy tests to gluten, casein, candida and other fungus,

micronutrients, vitamin levels, studies on intestinal permeability, feces analysis, urinary peptides, thyroid function test and, recently, studies on erythrocyte peroxidase glutathione (Page, 2000). Most of biochemical analyses are currently used to understand the physiopathology of autism (Johnston, 2000).

### Neurophysiological studies

Neurophysiological studies help us to complete and better understand the pathology of these patients.

Conventional electroencephalogram (EEG) studies in children with autism have shown that from 13 to 83% are abnormal, although the record methods and the variability in interpretation could justify the differences (Tuchman, 2000). Telemetry records with 24 hours video-EEG in children with autistic spectrum have shown abnormalities with paroxysmal downloads in a 46% (Tuchman et al., 1997). Recently, Lewin's study (1999) has shown, with magneto/electroencephalography (MEG & EEG), an epileptic-shaped activity in an 82% of patients with autistic spectrum and a likely background of convulsions and regression. The prevalence of epilepsy in a great range of pre-school children with autism has been estimated in a 7% (Rapin, 1996), in another range in a 14% (Tuchman et al., 1991), and the accumulated prevalence in adults is estimated between 20 and 23% (Minshew et al., 1997). The seizures appearance peaks occur during the pre-weaning period and the adolescence (Minshew et al. 1997).

Epileptic seizures could be of all kinds, but the complex partials seem to be the prevailing ones, while the abnormalities detected in the EEG appear more frequently in temporal lobules.

It is difficult to recognize complex partial seizures in individuals with autism, due to the tendency to interpret motor movements or strange autistic behaviours as epileptic, and this get worse due to the lack of correlation between clinical epileptic seizures and paroxysmal activity in EEG (Minshew et al., 1997). A recent study suggests that there could be a causal relationship between a subgroup of children with autistic regression and EEG defined as "benign focal epilepsies" (Nass et al., 1998). Any behaviour, as for instance staring, activity blocking, or aggressiveness seizures associated to conscience disorders should make us suspicious about complex partial seizures in children with autism. Particularly, in young and pre-school children, and in situation where there is a high rate of clinical suspicion of suffering clinical or sub-clinical epilepsy, we should apply EEG with long deprivation of sleep, searching for the existence of paroxysms and slow waves during sleep (Tuchman et al., 1997), and evaluate its therapeutic possibilities (Tuchman, 2000).

Studies on auditory evoked potentials (AEPs) of the cerebral trunk and middle latency auditory evoked potentials (MAEPs) have shown contradictory results in the different studies carried out. We have always to bear in mind that auditory problems may coexist in these patients; therefore, they have always to be excluded during the clinical examination (Rapin, 1997).

The study of visual defects is complex in patients with autistic spectrum disorders, but the examination of the eye's back, as well as the visual evoked potentials (VEPs) and the electroretinogram (ERG), could make abnormalities in their visual sharpness evident.

## Genetic studies

Considering that the autistic spectrum includes different clinical entities with several kinds of etiopathogenicity, its genetic basis is thought to be heterogeneous too. The incidence of autism is 3-4 times higher in men than in women. The recurrence risk for siblings of an idiopathic case is 3%, 50-75 times higher than that of general population (Bolton et al., 1994; Filipek, 1999). In 1976, for the first time, Hanson published that genetic factors played an important role in autism and, next year, the first publication (Folstein, 1977) about 21 couples of twins, and the concordance between monozygotes and dizygotes came out. This study confirms us that genetic factors play a very important role in the etiology of autism.

Chromosomal abnormalities have a great interest in any pathology whose origin is unknown, since they could point out to chromosomal regions containing genes involved in the pathology of autism. Many publications describe patients with autistic spectrum disorders who present numeric and structural chromosomal abnormalities. Most of them are *de novo* and, currently, involve almost every human chromosome (review: Gillberg, 1998).

One of the abnormalities of chromosomal disorders associated to autism most commonly described is the one affecting chromosome 15 (maternal interstitial duplication of region 15q11-q13), which appears between 1 and 4% of a range of cases that complied with the autistic spectrum criteria (Salmon, 1999). The detection of patients with fragile X has also been frequent. Other chromosomal abnormalities currently identifiable with karyotypes of high resolution are the incidence of cryptic deletions and microdeletions (Schroer et al., 1998; Turner et al., 2000), although the exact biological significance of the abnormalities



described is still not known.

Since then, the believe candidate genes in autism exist has gradually increased. Recently, multiple genes interacting amongst them are thought to be involved in the etiology of autism (Turner et al., 2000).

During last years, several groups of international researchers have focused their studies about the genetic basis of autism on the identification of susceptibility locus in the whole genome. This approach has need studies of great collections of familiar cases, compiled in multi-central studies, using several statistical methods of linking analysis. Amongst these studies we could highlight: the study from Pericak-Vance et al. (1997), which detected significant

linking in region 15q; and the International Molecular Genetic Study of Autism Consortium (IMGSAC, 1998), with 99 families with several affected, found 6 loci in chromosomes 7, 16, 4, 10, 19 and 22, which might contain candidate genes. Candidate genes with highest values have been recorded in chromosome 7q and 16p. Another recent study has been the Paris Autism Research International Sibpair Study (Philippe et al., 1999), in which 51 familiar cases have been studied and 11 genomic regions with significant linking have been detected by nonparametric methods. Four of these regions have coincided with other studies. In addition, in the Collaborative Linkage Study of Autism (1999), it is pointed out that regions identified with a highest linking for this group correspond to chromosomes 13q and 7q31-33. The study carried out in 1999 by Risch et al. has had a great importance.



It describes results compatible with a model of multigenic inheritance in more than 15 involved loci, through the study of 90 familiar cases. It is observed that there is little congruence between genetic results obtained by the different groups. Currently, regions with higher possibilities are 7q31-q32, 15q11-q13 and 16p13.3. This lack of concordance between the different studies is due to the great clinical heterogeneity of the studied populations and to a lack of clinical consensus in the diagnosis criteria used. The comparison of diagnosis criteria suggests that the age, the existence and/or lack of verbal communication and intelligence quotient of patients are essential variables to be deeply considered when making these studies. It is essential the subdivision and homogenisation of phenotypes to increase the possibility to detect the different genes involved in autism (Lord et al., 2001).

Another essential phenomenon to take into account in the study of genes is imprinting. It is a common mechanism of mammal silencing one of the two copies of a gene, according to its parental origin. Imprinted genes express themselves in a specific monoallelic way, depending on what their origin is (paternal or maternal), according to the tissue (brain, blood, skin, etc.) and the stage of development. They are grouped in chromosome regions making up functional domains of high genomic complexity. The genomic imprinting plays an essential role in fetal and behaviour development. The number of the imprinted genes described grows constantly. Last published records collect some 39 genes and everyday new ones appear. Recent studies show the direct involvement of imprinting in the complex subjacent mechanisms in fetal development, of brain and behaviours, as well as their influence on developmental and neurobehavioural disorders, amongst which psychiatric disorders are included (Isles et al., 2000). Imprinting

diseases are associated to non-Mendelian complex inheritance models. Often, they are *de novo* produced, but in some cases could be hereditary, due to mutations affecting specifically the imprinting centre or concrete genes, and they are only manifested when they are inherited from the progenitor who should transmit the non-imprinted active gene, as happens with the gene UBE3A, causing Angleman's Syndrome.

Studies on rats have shown that chromosomal complements, both paternal and maternal, are necessary to the embryo's viability. Recent studies (Isles et al., 2000) have evidenced that the paternal complement contributes specifically to the correct development of the placenta, the muscle and particular areas of the brain related to primary motivated behaviour (which corresponds to the areas of hypothalamus and the areas septum and pre-optic of the brain). On the contrary, the maternal genome is indispensable for the brain growth and the development of brain areas related to the social behaviour (neocortex and striatum). These studies evidence the essential involvement of imprinted genes in the brain development.

Within the autistic spectrum, it is as well included the Rett's Syndrome, and its diagnosis is clinical. However, the recent finding on mutations in the codifying region of the gene MECP2 (Amir et al., 1999) in these patients makes possible their existence help us to confirm their diagnosis. This great finding has aided us to understand that most of girls with Rett's Syndrome, who present mutations of this gene, are *de novo* mutations with dominant inheritance linked to chromosome X (Xq28), suffer the ionisation phenomenon, which is lethal in hemizygosis. This gene does not equally express itself in the different tissues of the human body, and that makes even more

difficult to know its study. The function of this gene is regulating: it inhibits the expression of other genes. This gene only acts during neurodevelopment, and that explain us the different stages of the disease that these patients present and how, from puberty, they enter a phase with stabilisation, including the recover of some of its severe clinical signs. Mutations findings in the codifying region of this gene, in an 80% of girls in its classical shape and in a 50% of the atypical forms of Rett's Syndrome, make us to think that there might be other affected genes and other involved regions, apart from the codifying region of MECP2.

The gene MECP2 encodes Methyl CpG-binding protein 2 (MeCP2) and shows a high expression in the brain during the last weeks of pregnancy and the first year of life.

Some scientists have shown, in rats affected with Rett's Syndrome, that the gene MeCP2 is necessary for the maintenance of neuronal function, mainly after birth. The different clinical manifestations in humans with mutations in MECP2 have turned out to be wider than expected. Last year, several works have been published showing the wide phenotypic spectrum of this gene's mutations, which is not only found in classical and atypical Rett's Syndrome. It is also found in asymptomatic women (carrier mothers), in men with severe congenital encephalopathy, in men with classical Rett's Syndrome and somatic mosaicism (Amstrong et al., 2001), in men with chromosomal abnormalities (XXY) and Rett's Syndrome clinical symptomatology, also in men and women with familiar mental retardation, and in a patient with autism (Couvert et al., 2001). This gene is very complex and its pathogenic mechanisms are unknown. All this clinical variability should be influenced by the regulating function of MECP2 on many other genes that have a very important role in the normal development of

central nervous system. Nowadays, studies are focused on knowing whether the MECP2 is the sole responsible gene for Rett's Syndrome or there are other genes involved, and searching for mutations, not only in codifying regions, but also in the wide regulating regions and, recently, in the gene's promoter region (Monros et al., 2001). Currently, several scientific groups of the international scene look for other genes involved in Rett's Syndrome, to get to know the function carried out by MECP2 on mental retardation and autism. For that, national and international tissues banks of patients with autistic spectrum disorders are being set up with frozen DNA's samples of different tissues (lymphocytes, fibroblasts, muscle, brain, etc.) from different patients to analyse the expression patterns of gene MECP2 and the imprinting condition of gene UBE3A and other genes imprinted in brain, which might be functional candidates for autism.

In our country, the San Joan de Déu Hospital in Barcelona, in 1999, got a grant from the Health Research Fund for genetic studies on Rett's Syndrome. This hospital is currently the reference centre for the study of the gene MECP2 in Spain. In 2002, thanks to a grant from the Fundació Marató de TV3, it has started the study and classification of patients within autistic spectrum and the implications of gene MECP2 (Xq28) and of functional candidate genes of regions 15q11-q13 in autism associated to mental retardation.

During next years, thanks to the several scientific researches with multidisciplinary and multi-central studies, a biological marker might be found which will make us easier an early diagnosis, and efficient treatment and a genetic advice to families with affected people within the autistic spectrum.

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# ■ Dr. Josep Rom. A passion for autism

**José Manuel Romacho Romero.** Doctor of Medicine, Psychiatrist.

Dr. Josep Rom was a person difficult to define. This brief biography by the fond friend has its basis on a purified friendship, indelibly for me, and that he gave me during more than three decades.

Pep was the paradigm of the intelligent man blessed with a clinical vocation, combined with a sense of humour in form of fine irony. He was a tireless reader and a live example of the phrase of Dr. Letamendi, who said, «the doctor that only knows medicine, does not know medicine either».

He was born in 1935 in a fishermen village called Cambrils, and was the second of three brothers. He was the son of an expert fisherman, and his love for the sea and his native country remained constant in his heart. For these reasons, in the prime of his life, in 1982, he came back to Cambrils to be a general practitioner until his retirement.

He got his degree in Medicine in 1960, after being a houseman student since 1954 at the Medical Clinic of Professor Dr. Pedro Pons, where afterwards he was a doctor assistant.

He was also disciple of Dr. Santiago Montserrat Esteve, at the Dispensary of Psychosomatic and Psychiatric Medicine of the Clínico Hospital, the master by whom he was most influenced due to his studious mentality

and critical objectivity. From him, he included in his own professional practice the interpretation of clinical phenomena with a scientific view.

Dr. Rom was a brilliant doctor devoted since he was very young to a patient task: to observe, orientate and help patients and their families. He always put his professional practice, in favour of patients, before the academic splendour.

His great clinical experience is based on facts as being, with only seventeen years, duty assistant at the disappeared Psychiatric Institute, where afterwards he worked as a doctor. This circumstance allowed him to study and cohabitate with many patients.

I fondly remember some summer discussions in front of the sea of his Cambrils. In them, Pep confided in me his fascination by the autistic behaviours of those patients who were at the Psychiatric Institute. His interest in the autistic world came from far away. Then, it is not strange that, after contacting Mr. and Mrs. Roca, he joined in 1975, as adviser neuropsychiatrist, the technical management of the designing of the project, which we currently know as **autisme la garriga**.

The way he approached and contacted with the autistic child, doing him/her somersaults, ticking





him/her on the ground, his great ability to observe together with his clinical sharp eye and tenacity for discovering why, remain in the mind of professionals of **autisme la garriga**.

His collaboration in the project persisted until his death, in October 2000.

As a honourable scientist, he proclaimed with courageous clarity his thoughts about autism in the congresses of the Child and Youth Psychiatric Spanish Society, of which he was the president, and in other discussion forums at the end of the 70's and at the beginning of the 80's, and he said that «the autistic child, he does want to be in the world, but he can't».

To my friend Rom liked to define himself as neuropsychiatrist. Therefore, he affirmed in 1986, at the Week of study of autism and childhood psychosis, organised on the occasion of the celebration of the tenth anniversary of the founding of **cerac**, that the neurophysiological-neurodynamic hypothesis was the true way to reach the world of childhood autism.

Josep was passionately interested in the essence of autism, but his worry about people with autism and what could be done for them here and now was even more intense.

Apart from being a great doctor, he was a honourable professional who carried out a huge assistance task in the field of autism and mental deficiency.



As on some occasions our Right Honourable President of the Autonomous Government of Catalonia has said, «that who has started a task he/she has fought for and worked with persistent tenacity, with illusion and confidence to be working to release the suffering from others, does not die. His/her work, example and path remain». All we have left then, mainly, is following his example.

The figure of Dr. Rom remains indissolubly linked to the history of general childhood psychiatry and to the therapeutic autism approach in Catalonia, through his 25 years advice in **autisme la garriga's** project.







# Autisme la Garriga

**Joan Roca.** President of Congost Autisme Foundation.

## The beginning, the reason of this initiative

In the middle seventies, the knowledge level about autism and the services of care and treatment of affected people were quite restricted worldwide.

The biological line of researches had started only ten years before, which meant the beginning of the loss of predominance of psychogenic hypothesis about the origins of autism. Regarding services, the specific treatment centres were very scarce and only existed, in a relevant number, in some countries as the United Kingdom or the United States. As for the therapeutic aspect, although it is true that about the middle sixties the principles of operational behaviour modification had started being applied to the population with autism, the results obtained until then were quite irregular. Finally, the psychopharmacology of that period, mainly concerning the disorders with onset during childhood, was relatively little developed.

In 1976, the only thing we had at our disposal to treat autism with relative efficiency were the programmes applied to the population with mental deficiency, which contained elements from the learning psychology and from the abovementioned operational behaviour modification.

In Catalonia and Spain, the situation of people with autism and their families in those years could be simply described as dramatic. The inexistence of an official recognition of the syndrome, the ignorance of professionals and society, and the lack of practically any kind of services, caused the lack of adequate replies to the most basic needs. Until then, the care to people affected with autism had been reduced, in Catalonia, to the isolated action of some professionals. An example was the neuropsychiatrist Josep Rom, who in the sixties had already an important knowledge about this disorder, and he not only made differential diagnosis, but also had started a specific unity of autism at the Fatima Centre of Terrassa.

This reality involved that people with autism, when they left childhood, went into the pavilions of people affected with severe mental retardation at psychiatric hospitals or remained at home and caused the unofficial, unknown and dramatic existence of families condemned to suffer a very hard situation in the framework of a society who did not know this disability.

In 1975, a reduced group of parents with children with autism, who did not just resign ourselves when facing up to the conflict, decided it was necessary to open new grounds, and instead of simply accepting passively the problem, we started searching for alternatives. That

way, we founded the association **apafac** (association of parents of children with autism of Catalonia). Then, with a small team of professionals, managed by Dr. Josep Rom, we designed the first lines of a *project whose aim was giving an integral answer to the needs of people with autism all through their life cycle*, what we currently know as **autisme la garrija**'s project. From this integral care point of view, we defined the following four action central themes to carry out our project:

1. *Execution of categorical diagnosis, both descriptive and prescriptive*, with the aim of defining the syndrome's affectation and the necessary treatment.
2. *Permanent communication with families*, as an indispensable element for the acceptance of the problem.
3. *Development of services for the whole life cycle of the person with autism*, including the establishment of therapeutic and temporary halls of residence, familiar support services, as differential elements of the services existing at that moment.
4. *Active participation of families in the therapeutic process*.

We tried to set up services to cover the needs of people with autism and allow their families to cohabitate with them without unbalancing the familiar core, reaching that way, their social inclusion. All these things, which seem obvious today, at that moment, were at odds with the established patterns.

With this spirit of renovating ideas, on the 6<sup>th</sup> September 1976, **cerac** opened its doors; an educative centre specialized in the treatment of children with autism. It was the first service of our integral care project.

The initial course 1976-1977 came in useful to make evident to professionals starting themselves in the

treatment of autism that the care to cases with a severe nuclear symptomatology and an important associated mental retardation was an extremely difficult task, and that progresses were slow, limited and not necessarily regular. But it also showed them that permanent observation, systematic evaluation and intelligent, flexible and imaginative application of different techniques of psychology and pedagogy, as operational behaviour modification and learning principles, led to clinically significant improvements and, therefore, to a marked increase of the quality of life of their pupils and their relatives. The experience and professional quality of Dr. Rom were decisive in those moments; because he orientated the therapeutic guidelines of the centre towards rigor, range of thinking and researcher mentality.

The start-up of our activities was already an experience of social inclusion. The centre was placed in premises located in 32 Ceramica Street, Montbau district, in Barcelona. We will always be very fond of the members of the *Cooperativa Barcelonesa de Vivendas* (Dwelling Cooperative of Barcelona), who gave us those premises with non-profit motives in mind, and all those people of the district who welcomed with absolute normality and collaboration the birth of our initiative.

From that inclusion experience, it is worth to highlight the relationship established with the School Baloo, and the possibility they offered to our children to share the recess with their pupils.

A project was born came about by the joint work of parents and professionals as a management pattern, which is still the same. A project full of efforts and uncertainties, difficult moments, but full of illusions for a better future and with the satisfaction of having found the way for our children, a project that left behind the anguish of discovering that there was nothing for them and their future.

Since the beginning, we knew that we wished to find an answer to the needs of people with autism, but also to the needs of their families. We had crossed on our own the desert of discovering the severe problem our children suffered and the future anguish that this involved. The simple fact of meeting other families, sharing the problem and starting to design a future alternative had already been a great help for us. Therefore, we also were born with this service vocation to families, to serve them as a reference point and an experience exchange forum, to offer them not only services for their children, but also information about autism and future expectations, as well as particular help that will allow them to reach, though everything, a normality in their familiar life.

### An integral answer to the needs of people with autism

The design of our project was made considering the network concept. We tried to set up *direct care services for people with autism*, but we were convinced that this was not enough, and that it will be also necessary to set up *family support services*. For these services to work with the required level of quality, *diagnosis, research and training* should be also promoted, as well as the experience exchange with other organisations, both national and international. We should not only set up services, but also set up *knowledge* in the field of autism, and we set out to do it around a flexible, effective and efficient organisation, with very specialized services, but at the same time with determined objectives and a shared way of working.

From this organisation pattern and with our own management pattern, that is, the collaboration between parents and professionals, we have worked to build up what currently is the **autisme la garriga's**

project.

We have to say that, although during the first years the parents volunteered to manage the services, the management was professional since the first moment. Each one of us contributed their knowledge and flairs to lead the development of the project, although that involved a great effort on the part of everyone, since we should combine it with our jobs.

In this framework, after founding the educative centre specialized in the treatment of children with autism, in 1977, the Orientation, Advice and Diagnosis Service started its activities. This service grew significantly in few years, and the synthesis sessions of diagnosis processes turned into open clinical sessions to professionals and students. Moreover, they constituted and constitute an essential element of the on-going training of the staff of our services. The training of professionals has always been one of the priorities of our project and, for this reason, taking apart the mentioned clinical sessions, since the very beginning, the attendance to courses or seminars, the exchange of professionals coming from other organisations through stays and work sessions, etc., has been a constant.

In 1984, the Education Department of the Autonomous Government of Catalonia endorsed this service, fact that implied changing its name. From then on, this service was called EAP **cerac-apafac, Autism Specific Psychopedagogical Advice Team**. This change of name meant that the task carried out concerning diagnosis and advice about the autistic spectrum to other centres and professionals, and to families, was now official. As well, for our service this endorsement meant to be part of the general network of psychopedagogical advice teams of the Education Department as an autism specific service covering the territory of Catalonia, and collaborated to turn it into the reference centre in our country.



The diagnosis of psychopathologies as autism, or other disorders of this syndrome, is a complex process that requires an experimental interdisciplinary team. Therefore, the EAP **cerac-apafac** consists on professionals coming from the fields of neurology, psychiatry, psychology, pedagogy and familiar advice.

As we have already said, we started our activities in premises in Barcelona. However, the development of services required new spaces. In 1980, we inaugurated the premises where the offices were, located at S. Antoni M<sup>a</sup> Claret Street in Barcelona, and in 1982, we moved the services to La Garriga. This village, about 35 km from Barcelona, offered us not only facilities giving an answer to our needs, but also a friendly and sensitive population. Since the first moment, these

people made us the execution of our activities and the social inclusion of the boys and girls cared for easier, which was a key element in the philosophy that has always inspired us.

From that moment on, our services are located at magnificent modernist villas surrounded by gardens. It is important to highlight that a very important part of these facilities (one of the modernist villas, the premises of an ancient mill and some farming lands) belong to the Foundation Cottet Mor. In 1987, this institution allowed us the use of these facilities free to place at them the Cottet Hall and Terlab, and since then, they give us stable support. During all these years, we have made different adaptations to the needs of our activities with a work that has implied the close collaboration of experts on the treatment of autism and the architect who has led the different refurbishments. This task has required much technical and creative effort. The great professionalism of the architect, Jaume Riba Romeva, together with his special sensitivity, have made us today to be pride of having adapted the facilities to the utmost minimum detail to the needs of these people. As well, we can enjoy an aesthetical frame of great beauty, that allows the boys and girls cared for to live in a pleasant environment with a very good quality of life level.

In 1983, we founded **asepac** (association pro people with autism of Catalonia), with the aim of fostering the care, treatment and social and work inclusion of people with autistic spectrum disorders. This association manages **Terlab**, the Occupational Therapy Centre, which started its activities in 1987 with the objective of giving an answer to the needs of adolescents and adults. Currently, it cares for 39 people and its facilities consist on workshops (2,534 m<sup>2</sup>), a greenhouse (256 m<sup>2</sup>), and farming lands. There

The transfer of the services to La Garriga was a key factor that allowed us to carry out the global care project, as expressed in the **following diagram**:

	Childhood	Adolescence	Adulthood
Diagnosis			
Neurological, psychiatric and psychological control			
Early treatment			
School age treatment			
Psychosocial rehabilitation			
Social and work inclusion			
Leisure			
Familiar support			
Therapeutic halls of residence			

are workshops on organic farming, poultry farming, gardening, paper recycling and paper handling, and fabrics.

The basis of the centre's methodology is:

- *Work with support*, which is the work carried out by a person with the physical and/or verbal aid from an educator.
- Supports and reinforcements *individual plan*.
- *Division of activities in elemental behaviours*.
- *Moderate length of activities*.
- *Alternation of activities and spaces*: sedentary / active; indoors / outdoors.

• *Functional analysis of behaviours*.

In 1983, the first therapeutic and temporary hall of residence started its activities: the **Cau Blanc Hall**. It was a pioneer service in Europe due to its characteristics, and deserved the recognition of the European Union, fact that was materialised in 1986 with the signature of our first agreement with the European Commission. In 1990, and considering the need for this kind of service, a second hall of residence was added: the **Cottet Hall**, which also obtained European funds. This two halls hold about 20 users each, their opening hours are complementary to those of the day centres and are open 365 days a year. As a



service model, it is important to point out that the stay could be temporary or permanent, according to the therapeutic and familiar needs of each user.

As for temporary stays, the halls of residence have three basic functions:

1. *Familiar support* with the service of temporary or permanent hall of residence, according to particular needs.
2. *Specific treatments* that require the care 24 hours a day during a determined period.
3. *Diagnosis* that require a longer and global observation than those of sessions of external visits.

Concerning the *support to families*, we have already commented that it constitutes one of the basic principles of the project. The birth of a child with such a severe disability and so specific features as those of autism means a very important impact. We can clearly talk about a before and an after in family life. The family has to go through a first period of confusion and anguish, rebuild the familiar structure based on the complete acceptance of this new member with special needs and not forget, however, those of the others who should preserve a stable cohabitation, in which the priorities of everyone are taken into account. In addition, all the abovementioned has to be done, precisely, thinking of this child, who needs to count on a solid, comfortable and permanent estimation from his/her relatives.

The couples also need to have at their disposal resources in order that the extreme care their child with autism requires does not damage the marital relationship. It is also important both the wife and the husband could be able to develop professional activities, which make them diversifying their interests, and if there are other children, being able to dedicate them the time and affection they need.

Since the beginning in 1977, the answer to these needs was materialised through the establishment of the first service of this kind, the *therapeutic holiday service*, that currently works during weekends and other holiday days, Christmas, Easter and summer holidays. This flexible respite and leisure service, which currently may hold up to 45 people, allows each family to choose the stays they require and, therefore, to organise themselves according to the need of all their members. Regarding the affected person, apart from preventing him/her to suffer any backward step in his/her usual therapeutic line due to an excessive holiday period, allows him/her to enjoy different leisure activities structured and adapted to his/her possibilities, which foster to the utmost his/her circle of relationships, activities and self-help skills.

This day service, if necessary, could be complemented with the temporary hall of residence service.

As well, in the framework of familiar support services, we should mention the *specialised accompaniment service*, which consists on providing the families with a professional to go with them when they have an appointment with the doctor or any other action related to the person with autism. This service aims to achieve that the medical appointment, tests or treatments could be carried out in appropriated conditions and, therefore, minimizing the effect of his/her behaviour impairments.

The *physical and psychomotor activity* is essential for the treatment of these people, and aims to develop and maintain their psychic and physical welfare and stimulate group activities. The facilities of **autisme la garriga** have a sports centre including a gym, a heated swimming pool, an open-air swimming pool and plenty of spaces to take physical exercises. Usually, we also



organise excursions to do trekking.

Finally, we should highlight, as a key point in our project of integral care to the needs of people with autism, the founding, in 1984, of the **Congost Autisme Private Foundation**, which is currently recognised at the international scene as the pioneer in the development of specific actions and services for people with autism. The Foundation, which has the support from the different public administrations of Catalonia, Spain and Europe, as well as from private institutions and individuals, has the following goals:

- *Promote, protect and help* the non-profit entities devoted to the treatment and care of people with autism.
- *Foster and develop scientific research, training and*

*dissemination projects*, as well as the study of work techniques and methods for their application to education, care and social inclusion of these people.

- *Exercise the guardianship* of those people who need it.

We would like to insist in the fact the Foundation is a very important element of our project, since it not only collaborates with entities devoted to autism with its technical, human and economic support, but also has boosted research and training programmes, as well as their dissemination. Moreover, the Foundation, through exercising the guardianship of those people who need it, sets itself up as an entity that could help structuring the future of our children beyond our lives. This is an essential element, since our project was precisely to cover the needs of people with autism all through their life cycle, which means, in most of cases, beyond the live of their parents.

The Foundation has developed an intense task in different fields related to autism:

- Promotion, creation, collaboration and support of specific centres, particularly those of occupational therapy services and therapeutic halls of residence.
- Organisation of training activities addressed to both parents and professionals.
- Coordination and collaboration in national and European projects.
- Advice to entities, families and professionals.
- Participation in scientific studies.
- Publications.
- Consultancy.

The existence of services of diagnosis, advice, outpatient's treatments, psychosocial rehabilitation, occupational therapy, halls of residence and familiar

support complete the direct care services framework of **autisme la garriga's** project. Together with training and research projects boosted by the Foundation, as well as the possible guardianship of those people who need it, they are the quality guarantee of the care during the whole life cycle, twenty-four hours a day, 365 days a year. This situation implies not only an essential element for the stability and improvement of people with autism, but also constitutes an essential support for the affected families.

**From first experience exchanges to international projects**

The design of a project about global care for people with autism was something new in 1975, when we started working. However, since the first moment, we were clear about defining principles to inspire the



project, establishing a services network, having an own model of organisation that will allow us to carry out everything was not enough. It was necessary to set up the basis to create knowledge about autism and its needs, together with the promotion of research and its dissemination, training of parents and professionals, and a constant innovation spirit, which is what has inspired us during these 25 years. Everything should be done with the rigour of the internal work in the organisation, but also, as we have always done it, open to the outside, and not only to our country, but also to the world. Again, it appears here the network concept, including not only services, but also organisations that exchange experiences at an international level.

The first step was the *collaboration with public administrations*, where an intense work was carried out to achieve the official recognition of autism as a specific disability.

In 1978, different departments of the *Autonomous Government of Catalonia*, which with the restoration of the institution were beginning their task, started carrying out studies about the problems of the disabled in general. The Education Department promoted several meetings to set up the basis of its knowledge. That implied the constitution of commissions, and amongst them, there was the *Commission of Care to Autistic Children and Adults*, to which were invited to participate Dr. Francesc Cuxart, at that time technical manager of the services, and myself, as the president of **apafac**.

A work group constituted by the heads of entities for the disabled was set up, where I also participated together with Mr. Jordi Oliver, the secretary of **apafac**. Subsequently, some representatives from the *Barcelona City Council* were included in this work

group that turned into the constitution of the Municipal Trust of Mentally Handicapped People, which was the origin of the current *Municipal Institute of Handicapped People*.

In 1981, the Education Department set up a work group of experts on autism to carry out a *Study to set up the basis for the care of the population affected with childhood psychosis and autism in Catalonia*. Representatives from the Education, Health and Social Security, and Employment Departments, as well as eight experts on autism (three of them were from our organisation) constituted this group. These three experts were Dr. Josep Rom, as neuropsychiatrist, Dr. Francesc Cuxart, as clinical psychologist, and Mrs. Lidia Fina, as expert on the organisation of services, who was the secretary of the group as well. This work shows the essential features that characterize this disability, its possible evolution, its needs and the necessary services to cover them. The final report of this study reflexes the assumption, by the experts, of the philosophy of our global project elaborated in 1976.

In 1983, the Special Education Service of the Education Department invited two members of our technical team, Dr. Josep Rom and Dr. Francesc Cuxart, as representatives of the autism and childhood psychosis population of Catalonia. They took part in a commission, which carried out an action programme that implied the ulterior dissemination, knowledge and improvement of the *Curricular Design for the elaboration of individual developmental programmes*. Dr. Francesc Cuxart was the secretary of this commission.

During all these years, there has been a close and very positive collaboration with the different departments

of the Autonomous Government of Catalonia. They have been particularly sensitive to the needs of handicapped people in general, and with their impetus and help, private initiatives with public vocation as ours, covering a gap in the services offer of the country, have been possible. It is important to highlight that we have regularly received support from the departments of Social Welfare, Education, Health and Social Security, and Employment, and sporadically, from the departments of Agriculture, Stockbreeding and Fisheries, Culture, Industry, Trade and Tourism and Justice, whose representatives have visited several times our services. From these visits, we would like to highlight, in 1987, the visit paid by the Right Honourable Jordi Pujol, president of the Autonomous Government of Catalonia, as well as the visit of the Honourable Joan Vallbé, counsellor of Agriculture, Stockbreeding and Fisheries, in 1992, and the visit of the Honourable Irene Rigau, counsellor of Social Welfare, in 2000.

We have also received support from the Provincial Council of Barcelona, which in 1976 awarded us with the first official grant that our services received. In 1990, Distinguished Maite Arqué visited us, who at that moment were the deputy of Social Services.

Concerning the *Spanish Administration*, we should point out to two stages. The first stage was at the beginning of our activities, before the transfer of competences to the Autonomous Government of Catalonia. During this period, it existed an intense collaboration with the Handicapped People Prevention and Care Royal Trust, with SEREM, called afterwards INSERSO, with the Ministry of Health and Social Services, the Ministry of Education and Science, the Special Education Institute and the Ministry of Culture. The features of the second stage have been the programmes carried out through the Confederación

Autismo-España (Autism-Spain Confederation), which have involved again a relationship with the Spanish Administration.

From our collaboration with public administrations we would like to mention as well, the relationship we have always hold with *La Garriga City Council*, which has been ready to collaborate at any time with our project and has make easier something very important: the inclusion into town of the boys and girls cared for.

Finally, we should mention a long and fruitful relationship with the European Union, which has led us to develop important studies and projects, and to foster the experience exchange with other foreign organisations, fact that has involved enrichment for any of us.

In 1986 and 1987, we signed our two first European agreements in the framework of a *Pilot Programme to improve the quality of life of handicapped people*, which contributed to the conditioning of the facilities included in Cau Blanc Hall and Cottet Hall.

From then on, our task at developing European projects has been a constant. We should highlight the following:

*New Focus on Autism* (1998-1999), in the framework of the Horizon programme from the European Commission, with the collaboration of the Employment Department of the Autonomous Government of Catalonia. It was carried out together with 8 entities from France, Belgium, Greece, Italy, Portugal and Spain.

This project, which had the aim of developing programmes of work with support for severely affected



people with autism, allowed professionals to share experiences and knowledge, to progress more quickly towards effective solutions validated in a transnational environment, and served as an example of good practice to other entities. This implied the design of specific programmes, as well as the organisation of training courses for trainers and people with autism.

To **autisme la garriga** this programme involved going from an experience of occupational workshops for people with autism, started in 1987, to becoming a European pilot project of work with support. The results of these works were compiled in the book *Work with support for severely affected people with autism*, published by **asepac** in 1999, in Catalan and Spanish. The most important conclusions were the following:

- Severely affected adults with autism could benefit from a real work with support.

- It is necessary a previous and accurate selection of activities.
- Programmes should include specific methodologies and techniques.
- The development of this kind of programmes increases the motivation of educators.
- These programmes constitute a very efficient therapeutic instrument for treating this group of people. Concretely, these programmes have evidenced an improvement of work basic skills and a decrease of behaviour problems associated to the autistic disorder.

*Aquatic environment teaching project for autistic adult people (1999-2000), carried out in the framework of the Socrates Programme. The goal of this project was training professionals in the field of*

*Cottet Hall and Cau Blanc Hall at the back.*



the aquatic environment, as a therapeutic instrument to improve interpersonal relationships and motor functions, as well as training people with autism regarding the development of their physical skills in this element as a mean of adaptation and social inclusion. It was developed together with partners from Spain, France

and Portugal. We should highlight the edition of a joint video, showing the philosophy and used techniques in these programmes.

*Trainautism* (2000-2001), developed in the framework of Leonardo da Vinci Programme, with the aim of disseminating the experiences of work with support obtained as a result of the project **autisme la garriga** and the Irish Society for Autism, and developing programmes adapted to the reality of countries from the Centre and Eastern Europe, particularly Slovakia, Hungary and the Czech Republic. We went to visit different services and organised scientific seminars in Bratislava, Budapest and Prague, in order to achieve the expected objectives. The programme involved a mutual enrichment and the establishment of new and solid professional relationships.

*On-line Trainautism*, which has started at the end of 2001 in the framework of the Socrates Programme, action Grundtvig 1, has the objective of training and advising affected families. The project is three-years-long and it is developed together with parents associations and universities from Ireland, the Czech Republic, Slovakia and Poland. This programme has also obtained the support from the Social Welfare Department of the Autonomous Government of Catalonia.

These European projects have been very important during the last years, and have meant an important boost to what, since the beginning, we have considered a priority: *fostering and updating our knowledge, particularly regarding scientific and therapeutic actions.*

The aim to be up-to-date concerning the newest programmes and techniques has led professionals, since the very beginning, not only to regularly take part in courses, congresses and seminars, but also to attend *training and experience exchange stays* at leader centres in the study and treatment of autism in different countries of Europe and America. When we started our activity, these stays were very important and allowed us to get in direct touch with the national autistic associations from the most advanced countries regarding the treatment of autism, as the United States and the United Kingdom. At those moments, they were already quite developed and were the undeniably leaders, regarding the rest of associations from all over the world. Thus, already in 1978, we started our contacts with the National Society for Autistic Children from United States, and agreed different stays of our technical manager at the services of those organisations, combined with visits to psychiatric hospitals and halls of residence.

**autisme la garriga** has also regularly received visits of professionals and representatives from different institutions to hold experience exchanges, which have been useful not only to widen our knowledge, but also to voluntarily and openly submit our own professional performance to the criticism of others. This method has been a magnificent system to evaluate our task and promote the on-going improvement that always has inspired us.

Equally, through the years we have advised many entities or professionals, who have asked us for, both in the technical and organisation field and in the design of facilities. From these collaborations, particularly we would like to highlight the one started in 1995 with Mrs. Aziza Bennani, High Commissioner for the Handicapped People of Morocco, for the establishment of a centre for people with autism in Tangiers, funded by the Foundation Catalana de Gas. After a previous information exchange, in May 1996, Mrs. Bennani, together with two people from her team, Mr. Abdesselam El Onazzani, the Social Inclusion manager, and Mrs. Froh Belfakir, architect, came to visit exhaustively the services of **autisme la garriga**, to see on the spot what was necessary to consider, both for the designing of the new centre and its organisation.

Later on, in July 1997, before the inauguration of the centre in Tangiers, its manager, Dr. Diori M'Hammed stayed for a week at La Garriga to complete his information concerning the start-up.

As for *associationism*, it is necessary to say that, during the eighties, the number of associations of parents with children affected with autism grew significantly, both in Spain and in the rest of Europe.

In 1980, different European associations organised an international congress on autism in Gant, Belgium. **apafac** took part in it actively, and its secretary, Mr. Jordi Oliver, gave a paper. After this congress, a small group of associations' representatives, already existent in different countries, met in Paris to constitute a European association. We hold other meetings, where the number of interested associations gradually grew. Concerning Spain, two more associations took part in this initiative.

That way, in 1983, we founded the International Association Autism Europe. I have been a continuous member of its Board of Directors. Currently, it holds 78 member institutions, from 30 different countries.

The set up of the International Association Autism Europe constituted a very relevant issue for the future of people with autism and their families. We knew that the fight to raise public administrations and society awareness, regarding the features of the disorder and the multiple needs of the affected population, was necessary to boost it from the highest spheres, that is, Europe. This task became a basic element in the radical change that took place in few years concerning the question of autism. From being an almost unknown subject, it became the most relevant childhood psychic disorder, according to the number of scientific publications, and the society started to know the problem reality.

During the eighties, the performance of the International Association Autism Europe was decisive, not only concerning the progress in the treatment of autism, but also concerning the normalisation of the affected families. It gave all its support to scientific studies, and thanks to them, the theoretical orientations about autism went on evolution, from clearly psychodynamic conceptions to more biological guidelines regarding etiology, and more behavioural and cognitive regarding therapeutic programmes. All the abovementioned involved a radical change in any field related to autism, and affected families stopped feeling guilty, as indirectly responsible for the origin of their children's affectation.

Each three or four years, Autism Europe organises an international congress, amongst which we particularly

would like to mention the congress we organised in Barcelona in 1996, *Hope is not a dream*, that gathered 1.700 people, relatives and professionals, from 50 different countries.

We have to refer as well to the magnificent relations that we have always held with the different organisations from the rest of Spain. Since the first years, there was a mutual collaboration, help and information exchange, fact that made us to be informally known as the *friends club*. This informal group led us to constitute in 1994 the *Federación de Asociaciones de Padres Protectoras de Personas Autistas del Estado Español* (Federation of Parents Associations Protecting Autistic People of Spain), whose abbreviated name was *Autismo España* (Autism Spain), that in 1997 became the *Confederación Autismo España* (Autism Spain Confederation) to be able to protect as well the federations set up in the different autonomous communities. It started its activities with 6 members, and currently it has 42. I have presided this entity since the beginning until 2001 and, now, I still collaborate as the vice-president.

We should highlight as well that, in 1997, we founded the *Federació d'Associacions de Pares de Persones amb Autisme de Catalunya* (Federation of Associations of Parents of People with Autism of Catalonia), the *Federació Autisme Catalunya* (Autism Catalonia Federation), in order to foster the links between the different autism associations of our country.

Finally, and again at the international scene, I have to refer to the constitution, in 1998, of the *World Autism Organisation*. Once again, we were in its constitution process and, since the first moment, we took part in the Executive Committee of this organisation. In 1983, the constitution of Autism Europe was a key objective,

a great step forward to boost the European policies concerning the welfare of people with autism and their families. Today, it is not necessary to say, in the framework of a Europe gradually more unified, the sense of this kind of association is more in force than ever. Nevertheless, it was necessary to take a step further, in a world that involves such a growing globalisation as ours, to promote the relations globally and gather the efforts carried out in the different continents.

We can see, then, that the two last decades, in the field of autism, have meant not only a great boost to local associationism, but also to the utmost associationism level, that is, worldwide. We understand that the fight to improve the quality of life of people with autism could only be achieved through the joint work of parents and professionals, their relations, experience exchanges and optimisation of resources. **autisme la garriga** is, then, a project in a much wider framework, in which it not only takes part actively, but has also been one of the promoters. I mean the entities just mentioned above that are the following:





Federació Autisme Catalunya  
Confederación Autismo España  
International Association Autism Europe  
World Autism Organisation

### Autisme la Garriga: A consolidated reality open to the future

Once we have exposed the history and current situation of **autisme la garriga**, the immediate question that we should consider is obvious: where are we going? where is the study, care and treatment of the autistic disorder going?

It is evident that the answer to this question is much linked to the evolution of the whole society, since the future of autism as a mental disorder, as well as that of the people directly or indirectly affected will be the result of the interrelation of multiple factors of social, ideological, philosophical, ethic and scientific nature.

Nevertheless, if we focus on the strictly scientific field, there is no doubt that the current knowledge in the field of genetics will allow, quite soon, to detect specific impairments that will open new grounds towards a very accurate comprehension of the biological origins of autism. Moreover, this will lead towards the definition of subgroups within the same

disorder, through the comparative study of *genotypes* (genetic expression) and *phenotypes* (clinical expression). On the other hand, the permanent evolution of the neuroimaging techniques will make possible the precise description of brain impairments (morphological and functional), which will be possible to correlate with genetic impairments, psychological disorders and behavioural symptoms. Summing up, we will obtain a comprehension of autism much more global and, at the same time, the possibility to carry out a description of individual cases at different levels: genetic, anatomic-physiologic and psychological.

However, in order to be able to take true advantage of the scientific and technological progresses, it is indispensable to establish a permanent, deep and generous collaboration between professionals of the different implied disciplines. It is necessary to reinforce the interdisciplinary work, the set-up and development of solid work teams formed by professionals completely convinced about the believe that the scientific future of autism is linked, as in many other cases, to a joint effort. From this point on, it will be possible to make decidedly progresses implying the highest possible performance in the way of scientific progress, which will provide with extremely important benefits all the affected people.

Although this, autism is a disorder affecting the person during his/her whole life, reason why the identification of its causes, which should lead to prevent the onset of the syndrome, is only an objective aspect of research. Detection and early treatment constitute two essential areas, because they slightly condition individual prognosis. For this reason, research should plan as one of its prime objectives the identification of biological markers of autism. This identification will allow undoubtedly detections of possible cases of



autism much earlier and more reliable.

As for early interventions, recently there has been a very important increase of the programmes based on behaviour modification techniques with an intensive nature. Their philosophy and methodology could seem generally adequate, but it is evident that it is necessary to deepen much more in the study of results in order to be able to obtain objective data about their efficiency and, therefore, about their real advantages and limitations.

The fact that autism affects the person during all his/her life implies the care services and treatment to be based on a philosophy of social inclusion. In this sense, the intervention during adulthood involves very concrete challenges, for the distance between the theoretical self-help skills degree expected from these people when they reach this stage and that which really achieve people with autism is, in many cases, extreme, apart from permanent. On the other hand, the biological aging of parents adds new difficulties to which we must give an appropriate answer. Next years, the number and range of services for adults should increase. In this sense, we firmly believe in the philosophy that has inspired our project, that is, in services including direct care centres and familiar support services. These services should take into account the several affectation degrees and the idiosyncrasy of each particular case, to bring about individualised care and a flexible utilisation. In the field of work, the concepts real work and functional tasks take root firmly. This has implied the development of adapted work programmes with a wide range of options, going from work with support in specific centres for the most affected people, of which **autisme la garriga** was the pilot project in the European sphere, to jobs in ordinary environments for

the most capable.

We should carry out our task; I would like to insist on this, open to the outside world, and once more, taking advantage of any instrument within our reach.

**autisme la garriga** goes for a future where research and new technologies have a key role. In this framework, we can talk about a future that, actually, is



**cerac  
association**

**diagnosis and advice,  
outpatient's treatments,  
psychosocial rehabilitation**



**asepac  
association**  
pro people with  
autism of catalonia

**occupational therapy  
familiar support**



**apafac  
association**  
of parents with children  
with autism of catalonia

**halls of residence  
"sports centre"  
specialized accompaniment**

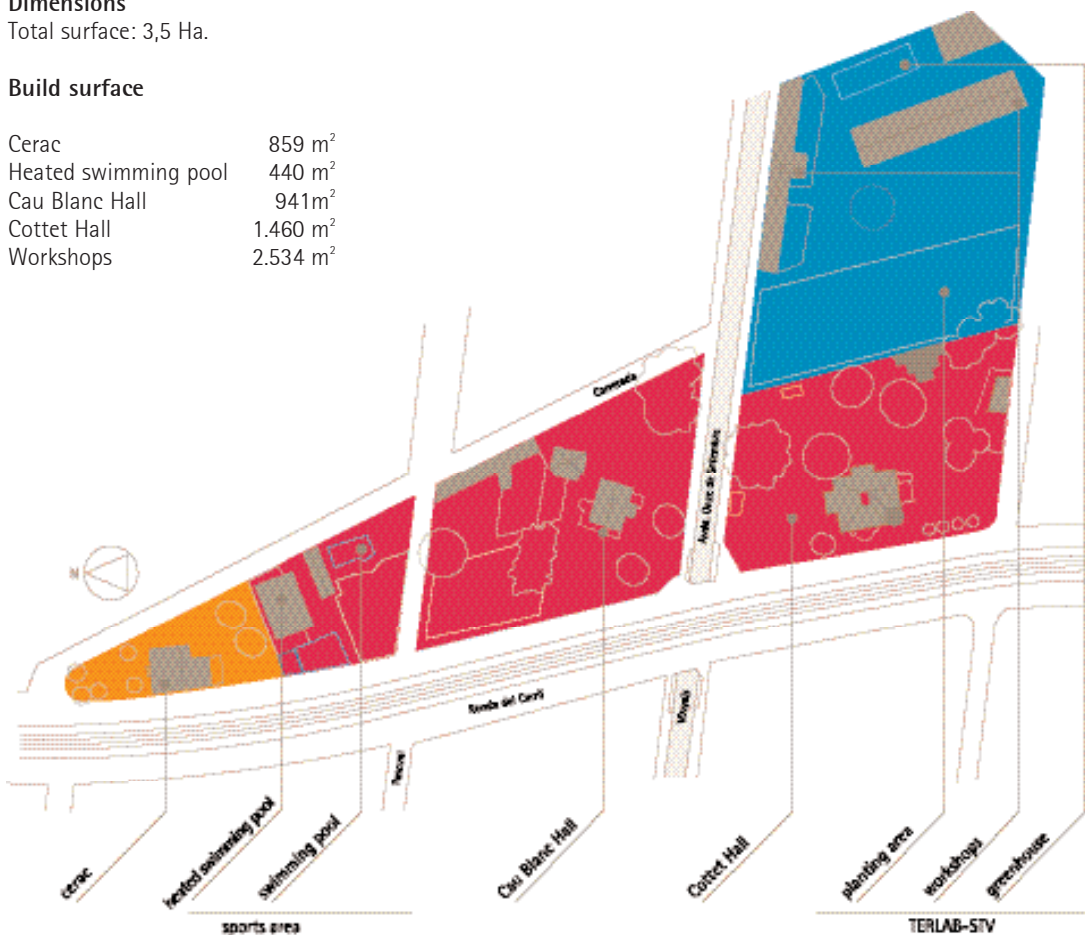
## ■ Facilities

### Dimensions

Total surface: 3,5 Ha.

### Build surface

Cerac	859 m <sup>2</sup>
Heated swimming pool	440 m <sup>2</sup>
Cau Blanc Hall	941m <sup>2</sup>
Cottet Hall	1.460 m <sup>2</sup>
Workshops	2.534 m <sup>2</sup>



Inauguration of the exhibition 25 Years for Autism

Distinguished Alfred Vilar, mayor of La Garriga,  
Mrs. Teresa Domingo, organiser of the exhibition and  
Mr. Joan Roca, president of the Congost Autisme Foundation



# ■ The Foundation. A step forward in Autisme la Garriga's project

**Luis Maluquer.** Lawyer.  
Secretary of Congost Autisme Foundation.

## From the associative concept to the foundational concept

Each one of the institutions involved in the project **autisme la garriga** has been created in different periods and under different circumstances to respond to the specific needs that have been arising through time. **apafac** has always had a pronounced generalist and welfare nature for autism, **cerac** has mainly developed diagnostic, treatment and advice aspects, and **asepac**, the social and work rehabilitation programmes. Nevertheless, as legal entities, they have a common factor: they constitute groups of people –but not resources groups– in which comes together an associative will characteristic of each project for the consecution of a specific social purpose.

At the beginning of the eighties, a fundamental fact is introduced in the legal environment. The Spanish Constitution of 1978 establishes in its article 34 the right to founding for general interest purposes, and in 1982, the Law of private Foundation of Catalonia is enacted. That way, a new legal concept is born within the reach of projects with a social nature.

We can define the private Foundation as the legal entity constituted through the will of one or several founders with the contribution of determined properties for the consecution of a specific purpose,

which must be of general interest and have an adequate organisation to allow the institution to act as a legal entity. The concept, then, is the contribution of properties, the will to allocate certain means for a determined purpose. The initial foundational estate constitutes these means and its possible increases. Therefore, in the Foundation we cannot say that there are people serving an interest, as in societies, but on the contrary, there is a set of properties serving an interest or a purpose.

Essentially, the Foundation makes easier the possibility of maintaining and preserving determined properties with a social aim independently of the person of founders themselves and with a complete dissociation of the properties from the life of donors. The concept makes the person itself an element of minimal importance, and there is a great difference regarding the associative phenomenon, which would not exist without those people who, together and as members, constitute a legal entity. However, as time goes by, people succeed each other, new members are incorporated, the reality of life makes disappear some of them because of their disability, illness or decease. The incorporation of new people into a determined associative figure will never be automatic.

From all the above, we can deduce that the associative concept, as an agglutinating element of wills lasting

through time, does not have enough consistency to ensure, along several generations, the accomplishment of its purposes, if we compare it with the inherent possibilities of the foundational model.

Currently, there are societies with a long history that show every day they are likely to remain, although as times goes by they have suffered changes concerning the will of their founders. There is something inherent related to the associative concept, which is its mobility and flexibility, either as a positive element to adapt to the current time or as a more negative aspect that implies the alteration of an initial project towards a new approach, not always successful.

### The Congost Autisme private Foundation: a guarantee of future

The enactment in Catalonia of the Law 1/1982, of 3<sup>rd</sup> March, about private Foundations, which is the first of its genre in the Spanish State, has a great importance regarding the Foundation right, consecrated by the Constitution and, subsequently, by the Autonomy Statute of Catalonia. The Autonomous Government of Catalonia has exclusive authority in Foundations with educational, cultural, charity and welfare and other aims, according to the territorial principle of belonging to the Catalan territory.

This law, together with its subsequent regulation development, implies the creation, for the first time, of a legal framework where to establish the basis of the future right to found -through the contribution of properties- a legal entity with its main scope all over the territory of Catalonia.

Just two years after the enactment of this law, **apafac** (association of parents with children with autism of Catalonia) decided to shape a project that would complete the actions carried out by the associations and, at the same time, would allow, in the long term, the definitive consolidation of what it is and should be the **autisme la garriga's** project.

In order to complement the effort already carried out and the group of people, it was considered necessary to set up a stronger and lasting structure. This structure should act as an agglutinating element of the task the societies were carrying out in the field of autism within the framework of the **autisme la garriga's** project, with the aim of providing this project with a greater consistency.

The Congost Private Foundation was established on the 6<sup>th</sup> April 1984, with the aim of providing with economic funds all those non-profit entities, whose main purpose is the treatment and welfare of people with autistic spectrum disorders. Its aim is even to act as guardianship of those people who do not have relatives with moral capacity to act in that way.

The Foundation is born with a modest estate. It is provided with some real estate located in Catalonia and it is registered at the Foundation Registry of the Autonomous Government of Catalonia with the number 38. To give oneself an idea of the situation, this registry currently contains more than 1.500 foundations. Swiftly, the Foundation becomes the leader of the **autisme la garriga's** project, as an agglutinating element of the common project.

In 1996, the Foundation adds to its name the word Autisme, and becomes the **congost autisme** private foundation. In 1997, it widens its purposes, which



include the fostering and organisation, directly or indirectly, of welfare, educational and cultural activities. The Foundation is also able to manage services related to the treatment of autism, as well as to foster, create and manage halls of residence, educational and welfare centres for people suffering this disability.

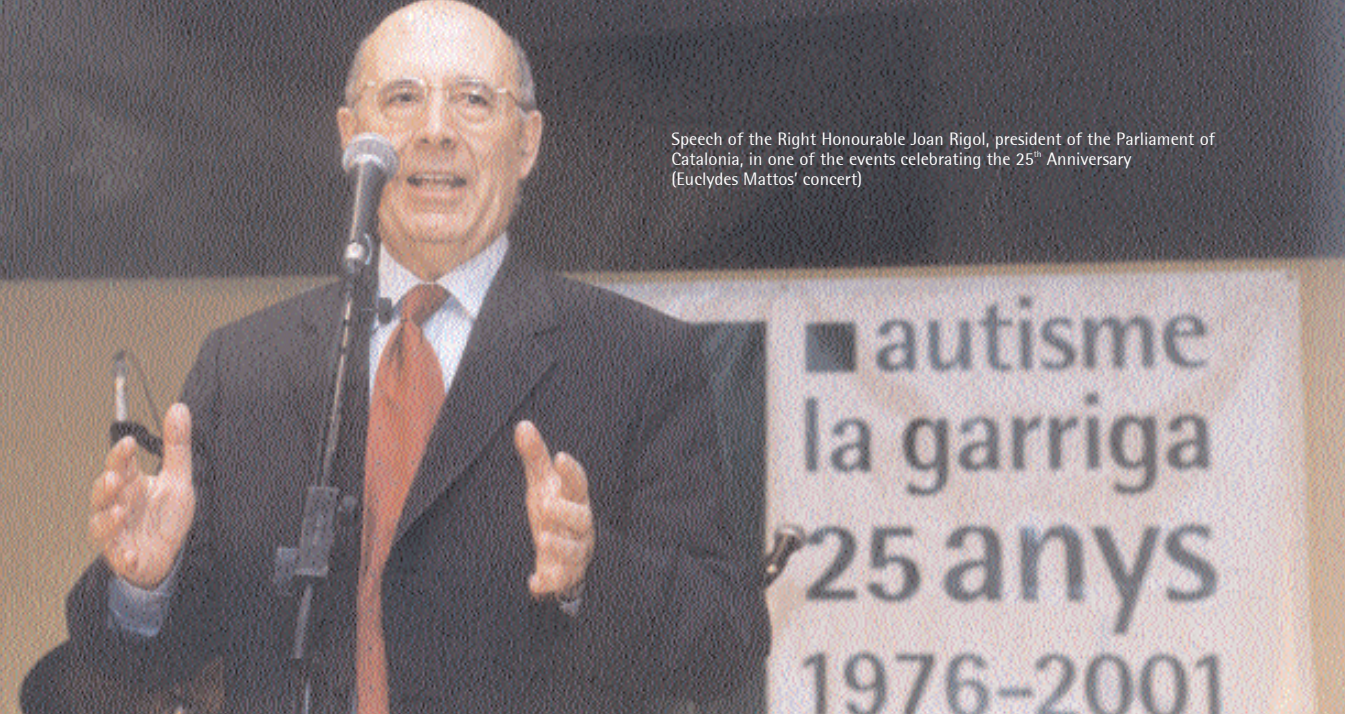
The Foundation becomes the protection umbrella of the associations related to the **autisme la garriga's** project. In 1987, the establishment of the agreement with the Foundation Cottet-Mor concerning the transfer in use of its real estate allowed incorporating the Cottet Hall and Terlab –two key services of our project- to the services network at La Garriga. Today, eighteen years after, the **congost autisme** Private Foundation, pioneer in Catalonia in the field of autism, is more than a fact.

The Council, which has been loyal since the first moment to the project and the foundational purposes, has managed the Foundation with a will of consolidation and leadership in unique and respected projects in the field of autism, opening it to research and giving it an international scope.

The incorporation of new Counsellors from different professional areas has allowed the integration of new criteria and points of view that strengthen and benefit the will of the founder entity. Today, the Foundation can see how the origin project has celebrated its 25<sup>th</sup> anniversary, and holds the commitment of acting as a catalyst, helped by civil society, to persevere through time and generations, regarding the improvement and development of autism treatments, and with the firm commitment to achieve an increase in the quality of life for people with autism and their families. We are sure that the Catalan civil society –that gradually better understands the realities and lacks of our



century and gets more involved in solidarity projects-will manage to rise to the occasion for contributing to the maintenance and expanding of this extraordinary project that the **congost autisme** Private Foundation is leading in Catalonia.



Speech of the Right Honourable Joan Rigol, president of the Parliament of Catalonia, in one of the events celebrating the 25<sup>th</sup> Anniversary (Euclydes Mattos' concert)



The Honourable Irene Rigau, counsellor of Social Welfare, gives a commemorative plaque on behalf of the Autonomous Government of Catalonia.

# Chronology of the most significant facts concerning Autisme la Garriga's project

1975

A group of parents meet to try solving the problem of their children with autism, and they design the first guidelines of a global care project for people with autism, which today we know as **autisme la garriga**.

The psychodynamic orientations regarding autism are majority in many countries. The lack of services is general.

1976

On the 6<sup>th</sup> September, **cerac** starts its activities. It is an educative centre specialised in the treatment of children with autism, located at 32, Ceramica St., Barcelona.

Constitution of **afapac**, association of parents of children with autism of Catalonia.

The associations of parents with children with autism at the United Kingdom and United States are already solid entities, which constitute a point of reference for the rest of the world.

1977

Establishment of the Orientation, **Advice and Diagnosis Service**.

Establishment of the **Therapeutic Holiday Service**.

1978

**apafac** is declared an entity of public usefulness.

Beginning of the active participation of professionals from **cerac** and **apafac** in the commissions set up by the Autonomous Government of Catalonia, aiming to define the public policies concerning the care of the population affected with autism.

The president and the secretary of **apafac** take part in the work group of heads of entities for handicapped people. This work group turned into the constitution of the current Municipal Institute of Handicapped People.

Beginning of a stage in which the organisation of international congresses about autism in different countries and other scientific discussion forums become something usual.

1979

The prestigious magazine *Journal of Autism and Childhood Schizophrenia* changes its name into *Journal of Autism and Developmental Disorders*. This fact comes from the conceptual change that would take place during those years regarding the nomenclature of the autistic disorders.

1980

Participation in an international congress in Gant, organised by different European associations, where we

expose the global care project for people with autism, which we currently know as **autisme la garriga**'s project. After this congress, the work to constitute the International Association Autism Europe starts, in which **apafac** takes part actively.

Inauguration of the offices, located at 282, S. Antoni M<sup>a</sup> Claret St., Barcelona.

The American Psychiatric Association, in the third edition of the publication *Diagnostic and Statistical Manual of Mental Disorders*, so-called the DSM-III, eliminates the word *childhood psychosis* and introduces the word *pervasive developmental disorders*.

## 1981

Acquisition of the buildings at La Garriga, *Villa Rose* (cerac) and *Villa Santo Domingo* (Cau Blanc Hall), in order to set up the services there.

## 1982

The services move to La Garriga.

## 1983

Constitution of the **International Association Autism Europe**. **apafac** is a founder member of this organisation, and its president, Mr. Juan Roca, is a member of the Board of Directors. This association sets up a Scientific Council, of which Dr. Josep Rom is one of the members and the only representative from Spain.

Foundation of **asepac**, association pro people with autism of Catalonia, aiming to foster welfare, treatment and social and work inclusion of people with autistic spectrum disorders. Inauguration of the hall of residence **Cau Blanc**.

## 1984

Establishment of the **Congost Autisme Private Foundation**.

The Autonomous Government of Catalonia endorses the Orientation, Advice and Diagnosis Service. From then on, the name of the service will be **EAP cerac-apafac, Autism Specific Psychopedagogical Advice Team**.

## 1985

Inauguration of the open-air swimming pool at the sports centre of the facilities in La Garriga.

The studies trying to identify the core disorder or disorders of autism, from a cognitive point of view start after the publication of the article from Baron-Cohen et al. Does the autistic child have a "theory of mind"?

## 1986

To mark the occasion of the celebration of the tenth anniversary of **cerac**, we organise different events, amongst which we should highlight the **Week of study about autism and childhood psychosis**, organised by the **congost autisme** Foundation. During this week, from the 3<sup>rd</sup> to the 5<sup>th</sup> November, a theoretical and practical course is carried out at the facilities of **cerac** in La Garriga, as well as different updating and perspectives workshops, on the 6<sup>th</sup> and 7<sup>th</sup> November, at the auditorium of Caixa de Barcelona, in Barcelona.

Signature of the first collaboration agreement with the European Commission, in the framework of a Pilot project to improve the quality of life of handicapped people.

The **congost autisme** Foundation publishes the book **Autisme: realitat o mite** (*Autism: reality or myth*).

## 1987

The Foundation Cottet-Mor allows us the free use of the real state where the Cottet Hall and Terlab are located.

**Terlab**, the Occupational Therapy Centre starts its activities.

Signature of the second collaboration agreement with the European Commission.

The president of the Autonomous Government of Catalonia, the Right Honourable Jordi Pujol, visits the services.

The **congost autisme** Foundation publishes the book **Aportaciones para un estudio técnico sobre los autistas severamente afectados** (*Contributions for a technical study about severely affected autistics*), written by Dr. Josep Rom and Dr. Francesc Cuxart.

## 1989

The **congost autisme** Foundation organises the **II Theoretical and practical course of study about autism and childhood psychosis**, held from 13<sup>th</sup> to 15<sup>th</sup> April at the facilities of **cerac** in La Garriga.

In the framework of support to families, we start the specialised accompaniment service.

## 1990

Inauguration of the hall of residence **Cottet**.

The deputy of Social Services of the Provincial Council of Barcelona, the Distinguished Maite Arqué, visits the services.

Celebration, at La Garriga, of the general assembly of the

International Association Autism Europe.

**apafac**, together with the International Association Autism Europe, organises the **International seminar about legal protection of people with autism in Europe and the situation in Catalonia**, in which speakers from different countries participate. Amongst other works, in this seminar, it was presented a comparative study about the legal situation of people with mental deficiency in different European countries, elaborated by Mr. Laurent Vogel, from the Sociology Centre of Social Law in Brussels. Autism Europe published this study with the support of the European Commission. The **congost autisme** Foundation publishes the Catalan version of this study, **Els sistemes de representació i de protecció jurídica de les persones disminuïdes psíquiques** (Representation and legal protection systems of people psychically handicapped).

Genetic studies about autism are general, and during this decade, the first instruments for the early detection of autism are developed. Moreover, the programmes of early intervention and the discussions about their real effectiveness increase.

## 1992

Celebration of the tenth anniversary of the establishment of the services at La Garriga. For this reason, we organise an open-door day and a technical session about autism in the premises of Caixa de Manlleu.

The Agriculture, Stockbreeding and Fisheries counsellor, the Honourable Joan Vallvé, visits the services.

## 1994

Constitution of the Federación de Asociaciones de Padres Protectoras de Personas Autistas del Estado Español (Federation of Parents Associations Protecting Autistic People of Spain), **Autismo España** (Autism Spain). Juan Roca is elected president and he holds this position until



the 2<sup>nd</sup> March 2001, when he goes on collaborating as vice-president.

The **congost autisme** Foundation organises, the 13<sup>th</sup> May, a **Seminar about autism and childhood psychosis**, at the facilities of Cottet Hall, in La Garriga.

## 1995

The **congost autisme** Foundation organises a **Course on autism and other pervasive developmental disorders**, from the 7<sup>th</sup> to the 10<sup>th</sup> February, at the facilities of **cerac**, in La Garriga

The **congost autisme** Foundation publishes the book **Aportaciones a la comprensión y el tratamiento de los autistas adultos severamente afectados** (*Contributions to the comprehension and treatment of severely affected autistic adults*), written by Dr. Josep Rom, Dr. Francesc Cuxart and Dr. Jordi Folch.

## 1996

The International Association Autism Europe, together with the **congost autisme** Foundation and the collaboration from Autismo España, organise, under the Honorary Chairmanship of Her Majesty the Queen of Spain, the 5<sup>th</sup> International Congress Autism-Europe in Barcelona. It was held from the 3<sup>rd</sup> to the 5<sup>th</sup> May, at the Congresses Palace of Barcelona, and 1.700 people from 50 different countries took part in it.

**cerac** and **asepac** are declared entities of public usefulness.

Growing importance of the brain neuroimaging techniques (structural and functional) when studying the pathogenesis of the autistic disorder. The need of increasing very slightly the resources for research and the care of adults with autism is revealed.

## 1997

Autismo España becomes a confederation.

Foundation of the **Federació Autisme Catalunya** (Autism Catalonia Federation), of associations of parents of people with autism of Catalonia.

Dr. Francesc Cuxart is elected member of the Board of Directors of ARAPI, Association pour la Recherche de l'Autisme et la Prevention des Inadaptations (Association for the Research on Autism and the Prevention of Discrimination), whose headquarters are in Paris.

## 1998

Beginning of the project **New Focus on Autism**, in the framework of the Horizon Programmes of the European Commission, with the aim of developing programmes of work with support for severely affected people with autism.

Foundation ONCE publishes the minutes of the 5<sup>th</sup> International Congress Autism Europe **Hope is not a dream**. This book is presented in Barcelona on the 12<sup>th</sup> February, at the auditorium of Caixa Catalunya, located at the building "la Pedrera". To mark the occasion of this event and the great collaboration received from Foundation ONCE with the **autisme la garriga**'s project, its executive vice-president, Mr. Rafael de Lorenzo, visits the facilities of La Garriga.

Foundation of the **World Autism Organisation**. **congost autisme** Foundation is a founder member and Mr. Juan Roca is appointed treasurer of this organisation.

Dr. Francesc Cuxart is elected member of the scientific committee of ARAPI.

The transnational programmes about autism funded by the European Commission become usual.

## 1999

Inauguration of the heated swimming pool at the facilities of La Garriga.

Beginning of the **Aquatic environment teaching project for autistic adult people**, in the framework of the Socrates Programme of the European Commission. The objective of this project is training professionals in the field of the aquatic environment, as a therapeutic instrument to improve interpersonal relationships and motor functions, as well as training people with autism regarding the development of their physical skills in this element.

**congost autisme** Foundation and the Confederación Autismo España (Autism Spain Confederation) organise a seminar-workshop about **How to establish a fund-raising plan**, held from 17<sup>th</sup> to 19<sup>th</sup> June in Barcelona, at the Cultural Centre of the Foundation "la Caixa".

**asepac** publishes the book **Work with support for severely affected people with autism**.

Dr. Mercè Pineda and Dr. Francesc Cuxart are appointed members of the Scientific Committee of the Confederación Autismo España.

## 2000

The Social Welfare counsellor of the Autonomous Government of Catalonia, the Honourable Irene Rigau, visits the services.

Beginning of the project **Trainautism**, in the framework of the Leonardo da Vinci Programme. Its aim is disseminating the experiences of work with support and developing programmes adapted to the current situation of countries in the Centre and Eastern Europe.

On the 10<sup>th</sup> October, Dr. Josep Rom deceases.

Dr. Mercè Pineda and Dr. Joan Cruells joint the **autisme**

**la garriga's** project as consultants.

## 2001

Beginning of the project **On-line Trainautism**, in the framework of the Socrates Programme. The aim was training and advising families affected by autism.

On the 6<sup>th</sup> September, we commemorate the 25 years of the beginning of the services. It is the first celebration of a series of events held during the academic year 2001-2002. From 2001, amongst these events, we highlight a concert offered by La Garriga City Council, chaired by the president of the Parliament of Catalonia, the Right Honourable Joan Rigol. This concert, performed by the singer-songwriter Euclydes Mattos, took place on the 30<sup>th</sup> November, at the auditorium of the company Honda.

## 2002

On the 15<sup>th</sup> March, the exhibition **25 years for autism** is inaugurated. Until the 31<sup>st</sup> March, it is presented in La Garriga (Exhibition Room of the City Council), from the 30<sup>th</sup> April to the 26<sup>th</sup> May in Barcelona (Room of the Football Club Barcelona Museum), and from the 6<sup>th</sup> to the 23<sup>rd</sup> June in Terrassa (Cultural Centre of the Foundation Caixa Terrassa).

On the 25<sup>th</sup> March, the Honourable Irene Rigau, the Social Welfare counsellor of the Autonomous Government of Catalonia, visits the exhibition and gives a commemorative plaque to mark the occasion of the 25 years of the services. The relatives of the boys and girls cared for at **autisme la garriga** pay a tribute to the couples Roca-Fina and Oliver-Esteller, the founders of the project.

On the 7<sup>th</sup> June, the Right Honourable Joan Rigol, president of the Parliament of Catalonia, inaugurates the exhibition in Terrassa. After the inauguration, a concert takes place, performed by the jazz group La Locomotora

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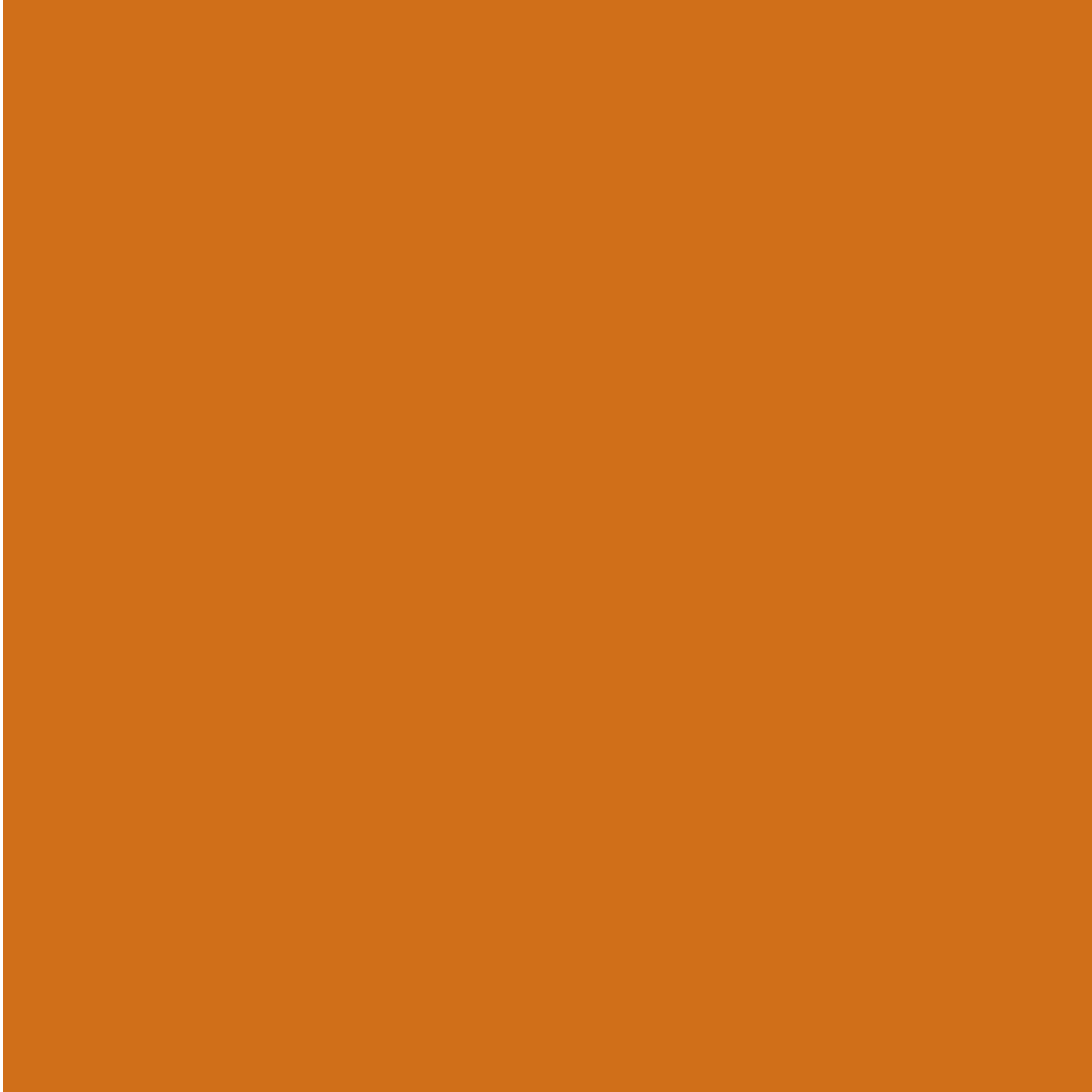
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And finally,

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In 1976, when we inaugurated the first service of what today is **autisme la garriga**, we did it with a huge illusion and great future expectations. It was the first fruit of the joint work from a small group of parents and professionals, who had designed a global project to give an answer to the needs of people with autism. Nevertheless, the project would have been quite different, and surely much more discrete, if we would not have counted on the impulse, advice and support of people of high human and professional quality, familiarly non-affected by autism. Our gratitude to all those people for devoting us, altruistically, their effort and time, and make us discover that there are many people ready to make the world where we live in better.

Thanks, many thanks to those who work or have worked at the different entities that constitute the **autisme la garriga's** project. We know that your task is very hard and requires a very high level of professionalism, but also of humanity.

Thanks to public administrations, especially to the Autonomous Government of Catalonia. We have worked with them very closely since the very beginning and they have showed us their great sensitivity towards handicapped people and, particularly, towards the problem of autism. With their stable support, we have been able to develop our activities.

Moreover, even more thanks. This time to La Garriga. Firstly, to the City Council, but mainly to the whole population that since the very first moment welcomed our project with an especial sensitivity and an open and friendly mind. They have provided us with the means to develop our activities in a frame of great aesthetical beauty and, at the same time, of great human quality. We believe that having taken the name of the town for our project, **autisme la garriga**, is the most evident sign of our gratitude, and identification with La Garriga, where we have found the ideal framework to develop it.

We also would like to express our most sincere gratitude to all those private organisations that have collaborated with our project during these 25 years. To all of them thanks to trust us and help us.

We would like to highlight the institutions and

companies that, most significantly, have given us their support all through these years, and that we list below:

AEFE Ofimàtica, S.L.

Assessoria Izquierdo

Autonomous Government of Catalonia

Presidency Department

Agriculture, Stockbreeding and Fisheries Department

Culture Department

Education Department

Employment Department

Health and Social Security Department

Industry, Trade and Tourism Department

Justice Department

Social Welfare Department

Barcelona City Council

Barcelona's International Official Trade Fair

Brunnschweiler

Ca l'Oliver

Caixa Catalunya

Caixa de Barcelona

Caixa Manlleu

Caixa Terrassa

Caja Madrid

Càritas Diocesana

Centre Excursionista la Garriga

Clarian

Colla Sardanista Sant Jordi

Construccions la Garriga, S.A.

Cooperativa Agrària del Vallès

Cooperativa Barcelonesa d'Habitatges

EAC Instal·lacions, S.L.

Eka Chemicals

El Corte Inglés

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Escola d'Art de la Garriga

Escola d'Enginyers Paperers

Escola de Música de la Garriga

Escola Tèxtil d'Arts i Oficis de Sabadell

Estebanell i Pahisa Energia, S.A.

Estudi d'Arquitectura Marrón i Riba

European Community

Football Club Barcelona

Foundation "la Caixa"

Foundation Agrupació Mútua

Foundation Antoni Serra Santamans

Foundation Arthur Andersen

Foundation Asepeyo

Foundation Carmen y M<sup>a</sup> José Godó

Foundation Catalana de Gas

Foundation Cottet-Mor

Foundation M<sup>a</sup> Francisca de Roviralta

Foundation ONCE

Foundation Ponsich

Foundation Sant Pius X

Foundation Santa Maria

Foundation Santillana

Foundation Viure i Conviure

Fusteria Garriguenca, S.L.

Gallart, S.L.

Gelsa Empresa Constructora, S.L.

Gremi de Fabricants de Paper

Handicapped People Prevention and Care Royal Trust

Honda-Greens Power, S.L.

Hoteles HUSA

Iberia Líneas Aéreas

Jordi Anglada-Pintura

Laboratori Enginyeria Paperera i Materials Polimèrics.

UPC-Girona

Laboratori Ramoneda

La Garriga City Council

Laisa - Roquette

La Locomotora Negra

Litosplai

Mafinsa

Maluquer Advocats

Mas-Serralleria, S.L.  
MB Papeles Especiales  
Medes Advocat  
Ministry of Education and Science  
Ministry of Employment and Social Affairs  
Museu Molí Paperer de Capellades  
OCE España, S.A.  
Paperera La Confiança  
Provincial Council of Barcelona  
Quod Disseny  
Red Cross  
Sati  
Seminari de Barcelona  
SEREM  
Telefónica  
Torras Papel  
TZ Asesoria, S.L.  
Vidriera Vilella  
Voluntaris Escoltes Catalans

To finish with, we would like to express our gratitude to all of you who have devoted your time to read this book. The different activities we have organised to celebrate these 25 years of the services, amongst them this publication, have been a good way to take stock of the task carried out and to define new strategies. We would not wish this celebration to be an act of self-satisfaction, but a boost for future projects. With this spirit, we are ready to face up to the challenge of next 25 years, to which you are invited to accompany us through.



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