

Optimum care for people with multiple disability

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“We talk about their abilities, not their disabilities,” says Arantzazu de Olaortua, President of the

Catalan Cerebral Palsy Foundation, an organisation set up in 1996 by a group of parents concerned about their children’s future. A sufferer from cerebral palsy is subject to considerable physical limitations, although their intellect may be unaffected. “Intelligence trapped inside a body which does not respond,” as Ms. Olaortua explains. Cerebral palsy occurs during the final stages of pregnancy, and above all during delivery, with the newborn baby suffering a lack of oxygen causing irreversible damage to a part of the brain. “These are complex and delicate individuals, and any comment can affect them,” says Arantzazu, who has experienced the situation herself, as she has a 35-year-old son with the condition. In bringing up such boys and girls particular emphasis must be placed on physiotherapy, rehabilitation and speech therapy, making regular schooling a secondary priority. If all these problems can be overcome (physical barriers, learning methods, etc.), they may even go on to university studies.

One of the programmes receiving support is entitled “Just see what we can do. The first exhibition by women with cerebral palsy”. A number of exhibitions of paintings and clay sculptures have been organised for the past 3 years, the work of women affected by cerebral palsy who paint with their mouths or use a device attached to the forehead.

One of the key aims of the foundation now at the point of fruition is the construction of a residential home with a gym and swimming pool: Lull 163. The building, located close to the Rambla in Barcelona’s Poble Nou district, has already been completed; all that remains is for it to be fitted out before it opens next year. Ms. Olaortua explains that “the Foundation has pioneered a number of features, such as for example ensuring that the home operates like a little hotel: we are talking about adults who shouldn’t be forced to have dinner at seven o’clock every evening as if they were at boarding school”. At night the home will have space for 24 residents, and will also operate as a day centre. Families are generally reluctant to be separated from their children, but when the parents become older or one of them is no longer present, life in an adapted residence may be a positive option in dealing with adult life.

“A Mutual Breather - Are You With Me?” is another programme in which voluntary contributions play a vital role, providing services to 200 boys and girls. They have some 200 volunteers who help organise a whole range of activities at weekends: visits to exhibitions, trips to the cinema or the theatre, and five-day summer camps allowing parents to enjoy a little free time as well. The volunteers also play sports with the young people, “the only sphere of life where they can compete on equal terms,” according to Arantzazu. “A person who cannot lift a cup to their mouth can win an Olympic medal”.



The Citizens Mutual Assistance Group headed by psychologist Carme Riu, and the Saturday morning workshop Jokin (Games for Integration), intended also for siblings and friends who do not have cerebral palsy, are other services on offer.

Nexe Foundation

Two in every thousand children in Europe are born with multiple disability, a figure which is rising. An increasing number of premature babies are being born, and although rehabilitation techniques have improved, many children who would previously not have survived can now be saved. These are children with serious physical disabilities, with severe mental disability, and also health problems: impaired sight, hearing, breathing problems, difficulty swallowing, many requiring a gastric tube; they may be “still” children, in the words of writer Màrius Serra, or may suffer convulsions.

The Nexe Foundation, established over 25 years ago, has the only specialist kindergarten for children with all kinds of disability up to 6 years old, although most of them are transferred before they reach that age to the Guimbarda Special Education School, which caters for them up until adulthood. “In the afternoons we have a small induction group for the youngest children who have not yet taken up a place,” says Sònia Corpas, the family coordinator.

The foundation is divided into three sections. One focuses on infant care, with programmes to improve the children’s quality of life and provide constant monitoring in an attempt to address the disorders they suffer. Cecile de Visscher, President of the Nexe Foundation and herself a teacher and educationalist, aware that most of these children were not going to school, began to work with a group of professionals to change the situation, and those changes are quite evident. Every day 35 boys and girls go along to this kindergarten where they receive highly personal attention. There is one member of staff for every two children: educational psychologists, nutritionists, physiotherapists, nurses and speech therapists to stimulate them in the early years of life, “when the flexibility of the brain is es-



Arantzazu de la Olaortua, President of the Catalan Cerebral Palsy Foundation

sential”, explains Cecile. She shows me around the multi-sensory room, with its ball pool, colours, tactile and musical stimuli and lots of hugs and affection. The work they do can only be understood in the sense of a vocation, with considerable training and constant refresher courses required.

The Nexe Foundation works closely with families and also grandparents, who are greatly affected by the situation of their children and grandchildren. They organise workshops for siblings, the family ‘breathing space’, with leisure activities for the children, and a new activity workshop in association with the

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Catalan Guimbarda Foundation

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Guimbarda Foundation for youngsters aged between 12 and 16. Cecile de Visscher has written the story *Mimi and the Blue Giraffe*. The copyright payments will go to the Foundation, which requires considerable private resources in order to continue its work.

Horse-riding

The Guimbarda Special Education School has for the past 12 years been engaged in a wonderful and pioneering initiative: boys and girls with multiple disability go horse-riding once a week, some lying down on the horse, others in the arms of a monitor, but “for them the level of sensation is hugely gratifying, as the pelvis and the spinal column move,” explains physiotherapist and Guimbarda’s Deputy Director Mercè López.

Housed in a light-filled new building completed in 2002 (although they had been working on the same site in prefab huts since 1977), the Guimbarda Foundation has a direct grant special education school for 27 children and a day centre for those aged over 18, also with 27 places, with the youngsters heading home in the evenings after a shower.

In the Koalas class, for children age 6 to 13, there are youngsters with a higher cognitive level. Many communicate using the big mack,

a device with a button which the children can press to play back pre-recorded messages to their parents or teachers. Guimbarda deals with children suffering a range of disorders about which we still have a great deal to learn, such as the Rett’s and Moebius Syndromes, conditions which are genetic in origin and research into which will benefit greatly from the funds raised by the most recent TV3 Marató telethon. Some of the children at the school have unfortunately experienced setbacks: one girl suffered serious side-effects following two operations on a brain tumour; another was affected by an unknown virus when she was younger. All the cases are highly challenging and require constant attention. Which, complains Guimbarda Director María José Escribano, makes it “incomprehensible that we have a nurse only once every other day to care for such delicate children. Eight of them use gastric feeding tubes, some take a great deal of medication, while others require cardiac massages, their convulsions need to be evaluated, etc.”. These demands, which years later have still not been dealt with, are exacerbated by the lack of road signage at the school’s exit. “There is no pedestrian crossing, and every day we ourselves have to stop the traffic so the children can get on and off the buses,” the Guimbarda staff explained.

Catalan Cerebral Palsy Foundation
www.fcpc.cat

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www.nexefundacio.org

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