# Editorial

## People with Down syndrome: A New Profile

2009 is a year of celebration for Fundació Catalana Síndrome de Down (FCSD), as we commemorate 25 years of leading the struggle for integration of people with Down syndrome and other intellectual disabilities and thus enabling their inclusion in society and achievement of the utmost reaches of dignity, respect, self-determination and wellbeing.

The FCSD is committed as an organization to keep fulfilling all the aims it has set itself so far: to expand its services following up on the growth and development of the persons for whom it works, and to devote its efforts to every stage of life for individuals with disabilities and ensure the necessary support is in place while providing the resources needed for the person in question to be involved in the whole process.

The FCSD places a high value on the use of its carefully selected methods to improve the treatment and care it provides. Within the ethical framework that applies in dealing with every human being, it works to advance the individual while protecting his or her dignity and privacy. Over the years, the Foundation has been involved in internationally significant biomedical and psychosocial projects, and sometimes led them; it has published or copublished over 40 books and other publications; it has held biennial international conferences covening the world's best-known specialists; and it has operated its unique Down Medical Center which, for 22 years, has not only cared for its patients but also collected and digitized all the information contained in its almost 2,000 clinical history repository comprising 18 medical specialties.

These 25 years have also been a meaningful period for the disabilities sector as a whole: over this period, the new prospects opened by Spain's unanimously voted 1982 LISMI Act, which explicitly protected individuals with disabilities, began to unfold.

This is therefore an excellent opportunity to analyze the state of our society after all this time. The first thing to strike us these days is the high media profile of people with Down syndrome: we see them in documentaries, or asking questions of the prime minister, or acting in television commercials, or leading awareness campaigns... but crucially and most importantly, we see them in the streets, alone or in small groups; we see them at their workplace, fulfilling their duties; we run into them at the movies, in museums, and so on. We can see new families strolling about and proudly showing off their newborns with Down syndrome.

All of this is very different from our recollections of 25 or 30 years ago. Back then people were more upset; the capabilities of the people termed "mentally retarded" were insufficiently known. Specifically, people who were born with Down syndrome traits were up against a devastating prognosis: it was literally believed that they were unable to learn at all intellectual disability was thought to entail a whole series of added circumstances that determined and explained all of a person's behaviors. This deterministic view was conveyed from the very start through social reactions and, above all, in terms of the possibilities remaining open to the new human being. This was a considerable burden on the child's parents and made it extremely hard to get over the grief involved in mourning the loss of the expected child and accepting the actual newborn. Many family members of people with Down syndrome now in adulthood will recall how hard it was to get the doctor to see their child, since every illness or condition was laid at the feet of the syndrome. It was a terrible prognosis, with life expectancy thought never to reach beyond adolescente, and seldom beyond puberty. Still, there were always some families and individuals who blazer their own trails and proved the possibilities that organitzations such as ours strive to make happen. Specifically, we are talking about individuals with Down syndrome who are over 40 years old today, working in jobs where they are seen by the public, and leading stable social lives.

Granted, they are few and far between, but they are very much to be considered. By the time the FCSD was started, thanks to groundbreaking work in countries such as the United States, new glimpses of a potential different present and future began to open up for people with Down syndrome. To begin with, schooling and training began to be seen as possible and necessary. A number

of methodological schools and trends arose as a result. Schools and techniques became more and more specialized, and people with disabilities began to receive therapy, treatment, life plans, and so on, moving along from one resource to the next. People with Down syndrome came to be targeted by all sorts of interventions and referrals.

Real change began to come about when the FCSD and other organizations that gradually joined up into a vast network encompassing all of Spain started to demand the rights of people with intellectual disabilities and to strive for the best medical and psychoeducational care for their children. By offering an increasing array of opportunities, letting them attend mainstream schools and letting them work in mainstream employment settings - the two key core settings in social terms - they have been able to prove what they could do in and for society.

Employment was a key step in this process. An individual with an intellectual disability who starts working and playing a specific role as a waiter, kitchen helper, or any other job, can afford, at last, to move from a passive role such as the one described in the preceding paragraph to a more active role.

This change is borne out by the emergence of a new kind of service launched in Catalonia in 2002. For the first time, an individual with an intellectual disability could choose where and with whom to live, and receive funding to cover the requise individually tailored support. This was a point of no return in the process of conquering dignity for people with intellectual disabilities. Gaining access to this level of decision making (choosing one's own lifestyle) entails a significant leap forward in terms of quality of life.

For all these reasons, we can be proud of many of the achievements of the past 25 years. However, we cannot rest on our laurels. There is still a long way to go. School integration needs to be fine-tuned to ensure its success across the board; mainstream employment needs to become a matter of course, and ordinary employers need to be dealt with consistently; natural inclusion or integration is much easier if people just naturally go to school or work in their own geographical area or place of birth. And improved quality of life has brought about a rise in life expectancy, so we will have to help ensure that old age is a time for people with disabilities to reap the fruits of their lifetime, along with everybody else, and enjoy a full and healthy life surrounded by those they love.

Many young people today are aware of their situation and demand that we, their families, place more trust in them so they can prove what they can do - and do it!

*Katy Trias Trueta*
*Director General of the FCSD*