



# INTERNATIONAL MEDICAL REVIEW ON DOWN'S SYNDROME

www.elsevier.es/ sd



## EDITORIAL

### A human rights issue

**K. Trias Trueta**

*General Director, Fundació Catalana Síndrome de Down, Barcelona, Spain*

When a financial crisis arrives accompanied by a crisis of values as important as the one we are living in today, there are many questions we must ask in order to optimise available resources.

The demands of society make the priorities clear. However, the cut-backs affect the most basic needs of the civil society and, it is precisely the civil society that is “leading” it, as the Universal Declaration of Human Rights proclaims, the defence of the *respect for the inherent dignity of all members of the human family and the equal and inalienable rights for all that constitute the foundation of freedom, justice and peace in the world.*

To raise awareness of the rights of people with disabilities has been a constant concern of the Foundation. From the beginning we realised that, to create the conditions so that people with intellectual disabilities should be in, and live in, a situation of real equality like the rest of the population, where their opinion counts, was a question of human rights.

The Commissioner for Human Rights, Thomas Hammarberg, highlighted that people with intellectual disabilities should not be deprived of their individual rights. Thus they must be given more support so that they can exercise their rights, and other types of support that gives them equal opportunities to create their life projects.

We have opened a series of training and mutual skills spaces on human rights for young people and adults who increasingly feel like citizens in their own right. Because to speak about human rights simply means accompanying and helping to reflect on our role in society. To help put our particular situation in the world into context, to be aware of other realities –difficult and complicated– that also co-

exist with us. A diverse society requires that its members are educated in human rights in order to help build a better society, based on fraternity, solidarity and equality.

Knowledge provides us with the means to develop a more coherent discourse on our needs and, thus, to give more confidence to the parents, caregivers, guardians or therapists due their yearnings for independence. The interest of the individual must be taken into account and to make the most of their level of maturity and understanding, whatever it is. And when the skills of the individual are not sufficient –due to not being able to assess danger and the protection of their safety–, their rights will have to be defended by their representatives, but always trying to involve the individual to take part. To work for individuality of the person involves helping them understand better so that they can grow with personal security and develop their own opinion that will enable them to make decisions to achieve their life projects. Hence the importance of a service like that of an Independent Life offered by the Foundation, in which its principles are based on making these projects a reality, and where the secret is the support that, besides being individualised and respectful to the person, must be based on accompanying to ensure that it is the centre of all planning.

Because to accompany is not to walk instead of the other, nor to advance it, however good is the intention. To accompany is to support, to know how to act so that the individual advances and progresses. It is not to teach how to live, but to help to live. We all learn from one another.

We have self-managing groups in the Foundation that meet to debate and defend their rights. We have created the EXIT21 blog as a platform to give them a voice and to announce their decisions.