Editorial

Thanks to better medical care and social conditions, people with Down syndrome and other disabilities can now enjoy a longer life expectancy. With potential quality of life also on the up, the outlook is particularly bright, as we now know that with the right support they can work, have an active social life and make decisions on issues that affect them. All of these factors increase their chances to lead a normal life. The last few years have been devoted to educating children and getting young adults into the workplace, and this has yielded fruits which they, like others, should be able to enjoy.

We are now facing a situation that is new not only for families but in particular for those who work in this area. A fresh challenge lies before us: an age group until now almost entirely outside of our experience, forcing us to rethink the way we work in this field if we are to be proactive in enhancing quality of life. The Catalan Down Syndrome Foundation (FCSD) is asking itself a multitude of questions: what will happen to those who have already passed their fortieth or fiftieth birthdays when there are not enough resources for all? Are the currently available occupational and destination options for those with more severe communication challenges the most appropriate? Will they accept the choices we are offering? Do we have the right resources and good practices for this age group - particularly bearing in mind the new prospects for a group of people who are increasingly active?

In the past, residential facilities and day centers have provided a space for adults to come together giving families a bit of ‘respite’, but the activities they offer are minimal and normal social ways of relating virtually inexistent. In a nutshell, they are far from providing the quality of life that we would like to see. Are such places really up to scratch for this group of people? What about the newer generations, who are more demanding and better prepared for life? Arguably, a great deal must now change. Moreover, it is not simply a case of the options we offer and facilities we provide; we must act differently and change the way we address people with a disability. In light of their clear progress, it is now up to us relatives and professionals to rise to them. Centers where individuals can be ‘dumped’ are no longer acceptable for most clients or their families. However, concerns about making their life as safe as possible and ‘what will happen’ when their parents are no longer around are still in the foreground and shall remain so. It is down to us, the organizations that work with these people, to be strategic enough to foresee the solutions to this new situation, setting an example on how we should see and treat people with a disability, and seeking alternative resources to fit today’s reality.

The FCSD, in its constant quest for solutions and resources that improve the lives of people with a disability, believes it is time to begin reflecting upon and adapting the methodologies used for these adults. For all human beings, entry into adulthood implies a series of privileges which are the outcome of preparation during childhood and adolescence, and primarily concern independence and decision making. Broadly speaking, an attitude is thought to be more or less grown-up according to the degree of responsibility it entails. In the case of people with an intellectual disability, we know full well that this is not possible if, firstly, their actions are curtailed, and secondly, they are not given the right support to help them carve out this role. Trained staff must therefore become support ‘facilitators’ so that the clients can achieve their goals and see out their life plans. This can be a steep learning curve since it means radically shifting our vision and expectations away from the prevailing image of people with disabilities as carriers of an array of shortcomings that are commonly mistaken for an inability to choose and decide, resulting in them being deprived of responsibilities in adulthood and treated like children.

We at the FCSD have launched a pilot project for older people, many of whom are inactive and have serious communication problems and a lackluster or restricted social life. Through the range of activities that are organized to diversify and explore clients’ interests, we have once again witnessed their capacity to continue evolving and learning, as well as the extent of their self-knowledge. All of this has strengthened our belief even further that people with a disability must be treated as active individuals who in childhood must be equipped with the tools that will enable them to make decisions in the future. When they become adults it is important to make sure that their activities and occupations are still relevant to society, and, above all, that those around them help them to grow as people.

Mainstream employment has played a key role in this as these people are no longer seen merely as ‘disabled’ but as having a job that defines them. Today they work as clerks, gardeners, warehouse keepers laundry assistants, cleaning operatives, kitchen assistants, supermarket shelf stockers, catering assistants, food company operatives, concierge assistants, maintenance workers and shop assistants, to name but a few. All earn a wage and make Social Security contributions because they are productive – working in *mainstream companies* – and, as such, they are people with responsibilities who begin accruing purchasing power and pay taxes. However, all of this can crumble to dust if the individual does not have enough support to be independent when it comes to playing an active role in society and making decisions.

We need go no further than choosing a home to find an example of this problem today. Choosing and deciding where, how and with whom one wants to live and, above all, who will give support and what form this will take, are fundamental in enhancing quality of life. If, when the time comes, an individual is denied access to this level of decisions about their own life, the implication is that no social value is being attached to their other achievements. Changing this entails breaking down the cliché that portrays these people as straitjacketed by Down syndrome, or any other intellectual, physical or sensorial disability, and starting to see them as people who have a great deal to offer and, above all, are entitled to the life that they choose and decide.

From the moment a baby is born and in every direct care service we offer, the FCSD endeavors to help families create a future for their children and to show them how to make the best decisions. However, we also want parents to teach their children how to decide for themselves and to support their little ones as well as older boys and girls as they build their own identity. When they reach adulthood, we encourage and assist them in acquiring an active social role.

Currently, the Foundation is also making it possible for these people to embark upon their own Independent Living project. Since 2002, we have helped 29 individuals to move into 21 homes that we support professionally with natural support provided by their families. Many more families are now looking into this option and starting to explore how they can plan and achieve this dream. By all working together we can now make this dream come true.

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