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EDITORIAL

An additional approach to Down syndrome treatment

Hay algo más en el tratamiento del síndrome de Down

A. Serés

Associate Editor, International Medical Review on Down's Syndrome

In the recent IV Ibero American Congress on Down syndrome, celebrated in Salamanca between 16th and 18th March, it became clear that something further exists in the treatment of Down syndrome, something which we are all part of. When Dr. John L. Down first described this syndrome, which was later to carry his name, where a series of physical and mental traits combine, he could never have imagined that, albeit a century and a half later, the people suffering from it would achieve the levels of autonomy and self-sufficiency that they now enjoy. For years DS people have been gradually becoming a part of our difficult and complex society. It is no longer strange to see people with Down syndrome travelling alone on the bus, shopping in the supermarket and even holding down ordinary jobs. They now fall within the range of "normality" as a part of diversity. In Salamanca the congress attendees, who were experts from Europe and America, talked about their jobs and new trends in the medical treatment of Down syndrome. They were able to confirm that beyond the papers they were presenting, an additional approach was apparent: human contact with the DS person.

More than 50 years ago when the genetic origin of this syndrome was discovered, it appeared that its treatment would be basically medical. Although this has been partially true, and greater medical awareness of the syndrome has ensued, it is not the whole truth. Great inroads have been achieved into the quality of life of DS people and their life expectancy has improved. This has mainly been thanks to preventative medical therapy, with diverse health programmes and also to medical advances in general, from which people with DS have also been able to benefit. We must also not forget that apart from medical treatment early stimulation and psycho-pedagogic treatment is highly significant.

Professionals working with these people, such as doctors, therapists, family members and indeed society in general,

must always remember that there is a third side to DS treatment, and it is just as important, or indeed more so, than the other two. It is society's approach to these people. It was also stated that not all actions are valid. That people with DS are not compelled to lose their human dignity in the name of technology and scientific know-how.

Over the last few years people with Down syndrome have adopted a more major role, having turned from "surviving" to "living" and here we wish to make a clear differentiation between what is a passive object – being and nothing more – to being a participative individual who has rights and with them, obligations.

If we reflect on this process we will realise that we all have or will sooner or later have some type of disability and will require the support and comprehension of those around us. Thus as members of society who we consider "normal" we are not very different from those who, either from their development, from accidental causes or human nature itself, are not blessed with full capacity. In this sense we are all people with DS.

For over 25 years the Down Medical Centre has generated a very long series of actions, both on-site and for learning and teaching, and medical research, for the improvement in the treatment of the pathologies associated or caused by Down syndrome. The members of the DMC have actively participated in the congress with its new lines of investigation. They have also made their sensitivity towards people with DS clear, bearing in mind always that a major part of treatment is taking good care of them.

During the last few years a great many steps in medical investigation on DS have been taken, with most resources being engaged mainly in prenatal diagnosis, but very little in how to treat those who suffer from it. Despite the lack of resources a huge qualitative jump in the quality of life of people with DS has taken place and they now

enjoy good health and acceptable levels of education. However, it does not stop there. In the future they will have to involve other aspects which have been neglected up until now, the third pillar of treatment: ‘‘an additional approach to DS’’. We cannot quality everything by chromosomes or health programmes, or early stimulation, etc. The third pillar of treatment is something that ties each one of us, and is based on the care society affords these people. Notwithstanding, we cannot change society if we do not first change ourselves. We live in a highly complex society where many things are just for appearance, where the individual

predominates over the family, where the aim is to regulate and organize everything. On the other hand we are also teaching values to noble, sincere people, like those with DS, so that they can make a difference in a society which is losing these values. We are encouraging them to step out of their comfort zone and explore new territories. There is no one recipe for resolving this challenge to educate our society in diversity. We all have a mission, we all have to reflect on what we can do for them. They are not asking us for compassions, quite the contrary, they are asking us to strive for them with passion.