

**THE PERSON WITH DOWN
SYNDROME:
ORIENTATIONS FOR
FAMILIES**

FOREWORD

Families play a key role in the education of all children and especially in that of children with Down syndrome.

This document, published by EDSA, aims to offer orientation and help for parents and families living with a child with Down syndrome.

It has been discussed and drawn up by parents and professionals from various countries who have a wealth of experience in educating and caring for people with Down syndrome. And it aims simply to propose a way forward that has proven effective: total involvement of the family in the child's education, which should be based on values, on personal autonomy and on making the most of the qualities of each individual.

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The person with Down syndrome

Orientation for families

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Presentation

Persons with Down syndrome are, above all, people.

Having a child with Down syndrome initially means that the parents enter a world of fear and questions without answers.

However, when we hold a new born baby with Down syndrome in our arms, perhaps it is our gaze, full of fear and doubt that makes it feel different for the first time.

The purpose of these lines is to contribute towards families of persons with Down syndrome seeing their son or daughter as just one more person, with the same opportunities, the same rights, the same differences, and with the help necessary to make all this possible.

1 Focussing on the person

From very early on the person with DS should receive support adapted to

their needs, from within a context of equal opportunities and a clear emphasis on personal autonomy. This means:

1. **Normalising treatment**, similar to how we treat any of our children, neither discriminating nor overprotective.
2. **Support adapted to their needs**, especially as regards health and development, making use where possible of specialised early care services.
3. A **compensatory and integrated education**, supporting the person in their areas of greatest need without this meaning the separation of the child from other children of their age.
4. Opportunities for a **normalised social life**, in the family environment, the neighbourhood, the community and at school. We will not help our children by providing them with a life that is different, together with other persons with DS and separated from the rest of the people.
5. **Attitudes that favour their autonomy**. Our fears are greater than those of our son/daughter. We must let them face their own fears and make their own mistakes, because if not, we are impeding their learning to be independent.
6. A **future with quality of life**, full of goals and dreams, in other words, with a project for the future, which the person with DS is in control of and is the centre of.

The person with DS will have greater opportunities for a happy life the better we adjust support to their needs so that they learn to be more autonomous, to develop their own experiences and to take control of their own life.

The best attitudes that parents with a child with DS can develop do not imply minimising the situation, or hiding from the world, or blaming themselves, or being scared about a future of uncertainty, but do imply facing the situation with serenity and normality, based on the certainty that

many other persons with DS and their families enjoy a life that is as happy or happier than the rest.

2. Life in the home

The family is the first and foremost reference point of the person with DS during their infancy and a large part of their future.

This means, among other things, that the attitudes of the family, the quality of cohabitation and the style of treatment received by the person with DS will favour or not their level of autonomy and self-government in adult life.

It is logical that at first we think that the person with DS has greater needs and so consequently needs more protection. However, with this attitude, we limit the opportunities the child with DS will have to learn for themselves, to make mistakes, to make decisions. Is a life without errors, without decisions being made, or without risks imaginable? Our interests as parents are often in conflict with the interests of our son or daughter with DS, and wherever possible we must ensure that he or she lives with the same opportunities as his or her siblings and the rest of the children and young people of their age. This does not mean neglecting the needs of the person, but giving them support so that they can become as autonomous as possible in the future.

Favouring autonomy and self-determination for the person with DS does not only constitute a better quality of life for the person with DS, but also for the family (greater independence for the parents, better climate for relationships, and better preparation for the future).

In this sense, we must weigh up the type of treatment we give to our child with DS in relation to their siblings, and this should be as similar as

possible in both cases. Greater overprotection towards the person with DS can easily produce feelings of injustice in siblings (especially if they are at an early age) which can damage them and family life.

If it is requested, both organisations for persons with DS and their families and centres for orientation and family therapy can provide parents with orientation and assessment regarding the management of attitudes, education and treatment of the person with DS and their siblings, in addition to facing and resolving conflicts in the home.

Finally, some key aspects of the education of the person with DS in the home are:

The teaching of self-care tasks, hygiene, dressing, etc.

Participation in basic domestic tasks (tidying up their room, making the bed, cleaning, tidying the wardrobe, folding clothes, making basic meals, etc.).

Sexual and affective education (management of emotions, guidance on appropriate sexual conduct, etc.).

The stimulation of occupational and work interests.

The stimulation of interests in recreational and hobby activities.

The facilitating of opportunities for social interaction with other persons inside and outside of the family unit.

The teaching of problem-solving abilities (describe situations, generate alternatives, evaluate the consequences and make decisions).

The teaching of values (honesty, responsibility, etc.).

In any of the aspects mentioned a greater level of autonomy can be favourably developed in the person, by providing learning opportunities and the necessary support, even with persons with a higher level of disability.

3. Health

Concern for the health of the person with DS should be inherent throughout the life of the person and not at a given period or moment.

It is known that over the last decades the health and life expectancy of persons with DS has improved greatly. This does not mean that we should stop giving them the attention they need. In fact, associated with Down syndrome are a series of factors that require special vigilance and attention from birth.

Currently, **preventative health programs** for persons with DS represent the best strategy for ensuring levels of health and physical well being for the person that will adjust their quality of life to that of the rest of the population. The most advisable for the family, is to use specialised health services right from the beginning. These will provide the parents with the appropriate guidelines regarding vigilance and care for the health of the child with DS.

In addition to using specialised services, it is desirable that the person with DS makes use of community health services in order to obtain the greatest level of normalisation possible.

4. The early years

In general, the needs of the baby with DS are as diverse as with any other child. However, several factors associated with the syndrome (intellectual disability and other associated medical problems) require that we ensure **specialised and expert care** for the person, which provides the appropriate support in terms of health and development.

This means that as soon as possible, the family should ask their primary care service or social services for **orientation concerning available resources and services**: Health programs, early care services, associations for families, specific centres, etc.

Getting in contact with an **organisation for persons with DS and their families** will not only mean receiving expert orientation concerning existing

resources, but also support, understanding, someone to listen and the experience of other families and of those professionals dedicated to improving the quality of life of persons with DS.

Early intervention services are the most appropriate resources for persons with DS in their early infancy (0 - 3 years). This first stage of life is fundamental for psychomotor development, emotional experience, understanding the environment, language, and social relationships. During this period, early care will provide the child with DS with specific support, which will favour their development at the time of greater cerebral plasticity, and consequently greater learning potential.

In addition, at this first stage it is of great importance that parents, siblings and other family members of the baby with DS learn together **to live like any other family**, with a healthy style of relationship, as stress-free as possible and with the most opportunities for a comfortable environment, with affection, and open to experiences in the community (walks, excursions, going to restaurants, cinemas, etc.) Generally, the more we live like any other family, the better it is for the person with DS, for family cohabitation and the matrimonial relationship.

5. Family and school

When the child with DS starts school, the family is frequently faced with the decision: **Integrated schooling or special education?**

Experience has taught us that – in spite of the limitations, mistakes, lack of resources, etc. education in an integrated school (with other pupils who do not have DS) is the best and most desirable choice, although this is still not possible in all European countries.

The principles of non-discrimination, normalisation and equal opportunities must be applied in the school, transforming the latter, when necessary, in order to respond to the needs of all students, whether they are disabled or not. It is a question of time and clear ideas.

The best idea for parents, is to seek orientation within the educational services and local DS associations, regarding which is the best centre, in

each case, for their child, taking into account his/her needs and the resources that exist locally.

Integrated education can be positive or negative depending on the level of adaptation of the student to his/her school environment. In contrast, schooling at a special education centre can contribute to educational success on account of the specialised resources available, but can also limit opportunities to intervene in normalised settings and with other persons without disability.

On the other hand, mixed regimes can be found in some areas that combine the benefits of both systems, and as a rule are generally preferable to both separately. Three examples of this are:

Shared schooling. The pupil with DS can attend the school of integration for a given number of hours or days and on other days go to a special education centre, where specialised learning support is provided (language, psychomotor development, socialisation, etc.).

Integrated schooling with support from MISU (Mobile Integration Support Units). The pupil with DS receives, in the school of integration, the support of a specialised team for pupils with Down syndrome, in co-ordination with the school's teaching staff.

Specific classrooms in schools of integration. These are special education classrooms within mainstream schools, which in addition to providing an educational system adapted to the needs of the pupil, ensures that at certain times they share situations with other pupils without disability, thereby facilitating the person's social inclusion (for example; at playtime, dining room, physical education classes, etc.)

Once the model of schooling the child with DS will receive is determined, the attitude of the parents and of the family in general must be one of **maximum collaboration with the school**. This means, based on an attitude of maximum respect for the job of teaching, but also on the responsibility that implies a continuous attention to the evolution and well being of the child.

Wherever possible, the collaboration of the parents with the school should extend to all levels of the educational community (teacher, tutor, support teachers, educators, language specialists, participation in meetings, etc.). This will have favourable results in:

The participation of our child with DS in school life, their social integration, etc.

Education for autonomy, applying at home what has been learned at school.

Relationships with other parents and children.

The detection and communication of needs that arise, at both school and in the home.

A better co-ordination of all educational action.

6. Transition to adult life

In the last stage of schooling for the person with DS (16 - 20), we should intensify our efforts in all that favours their achieving a greater level of autonomy.

According to their level of needs, once schooling has finished, the person with DS will require, **day services** (therapeutic and functional) or **services offering orientation, training and support for their entry into employment** (occupational services, for vocational training, self employment, and supported employment, etc.)

In any case, what we should always avoid is that when the person with DS finishes school, they stay in the family home and not attend any service - we would break their itinerary of entry into employment and make the transition to adult life and social integration more difficult.

It is of great importance at this stage to intensify **an education towards autonomous life** (habits of home life, domestic tasks, self-care habits, use of public transport, use of community resources, etc.) with the person with

DS. The more this learning is facilitated, the more we help the person to prepare for acquiring a dwelling or residence in the future.

Finally, in adolescence, **social relationships and incorporation into the life of the community** take on maximum importance. Going to clubs or leisure centres or going on holiday with friends, etc. can constitute a good opportunity for the young person to strengthen a social life outside of family life. Social relationships outside of the family are positive and necessary in order to ensure their social integration, development, and emotional well being.

7. The family of the adult person

As has already been mentioned, the attitudes and actions of the family are determining factors for the person with DS when they arrive at adulthood.

Access to employment services (protected, with support), occupational services, day, or therapeutic services, dwelling, residence, etc. will be decisions to be faced at this stage.

We can establish several keys to adapting support to the needs of the adult person and provide them with a quality of life similar to other citizens:

A life with the greatest independence possible. This implies that if the person can work to support themselves they should do so, if they can have their own home then they should have it, and if they can enjoy their own family life, they should do so. This, which can be so easily extrapolated from the other citizens and associated with fundamental rights (to work, to have a home, a family, etc.), is very often not easy for the family of a disabled person to take on. Fearing the future, the risks, the lack of protection, are barriers that can incapacitate the person with DS more than their own limitations.

See the person with DS as an adult, who chooses their own clothes, that uses and administers their money, who relates to their friends, who increasingly decides on more relevant aspects of their present and future life. Provide him or her with ever more opportunities to decide for him or herself, so that they go on building their own life.

Assisting their access to work. In some countries, the social care systems (pensions) are incompatible with earning a salary and this makes it even more difficult for persons with DS to join the job market.

If the person can develop professionally at a centre that provides preparation for work, at a special employment centre or at a regular company, we should ensure that they do so, as by doing this we are assisting with the true acquisition of an adult role, their social participation, their independence.

Assisting in their acquiring a home. To have their own home, albeit in the company of other persons with disability. This is in principle something desirable for the person with DS the same as for any other person, as this allows them to enjoy their own home. Parents often resist this, until by necessity they become faced with having to find a solution for them. It would be much better to provide this option to the person when they want it, when the learning takes place that will permit them to live with greater autonomy. Only in this way will we guarantee an old age, peaceful in the knowledge that our child with DS can live without our continuous support.

Maintaining family ties. Assisting their independence does not mean breaking ties. The person with DS who attends a day centre, or who has employment, or who lives in their own home continues to need his or her family, just as much as they are needed, and this means maintaining contact with the frequency that is mutually desirable (visits, lunch or dinner, going out, travel, etc.).

Guarantee the future. The increase in life expectancy of the person with DS means that it is now frequent for children to outlive their parents. This should urge us on so that, with their participation and whenever possible, we resolve the guardianship of our child for when the parents are no longer

there. A sibling or other family member would be the most desirable option, but if this is not possible; we can turn to other social resources that exist with different names in each country.

In any case, and by way of a conclusion, the best strategy that families can adopt in order to guarantee a quality life for our son or daughter with DS, is **to help them to be a little more autonomous each day, to give them the opportunity to take more and more decisions, to support them in everything that signifies constructing and developing their own project for life.**

