

**THE EDSA ESSENTIALS 1**

**IDENTITY DOCUMENT  
OF THE  
EUROPEAN DOWN  
SYNDROME ASSOCIATION  
(E.D.S.A.)**

## **FOREWORD**

This document describes the mission, values and other characteristics that constitute the identity of the European Down Syndrome Association (EDSA).

EDSA's priority objectives include promoting national, regional and local associations in all countries of the European Union. This document aims to provide guidelines that will help to draw up the by-laws of those new associations that are created and give strength and cohesion to the associative movement in Europe by focussing on points of capital importance: mission, values and objectives.

This document has been drawn up by a multinational and multi-disciplinary team with the participation of parents, professionals and individuals with Down syndrome.

Our thanks to all of them for their work.

Prof. J. Perera ph D.  
EDSA President

# **IDENTITY DOCUMENT OF THE EUROPEAN DOWN SYNDROME ASSOCIATION (E.D.S.A.)**

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## **1. Identity**

EDSA is the European Confederation of legal entities representing persons with Down Syndrome and their families in countries of the European Union.

## **2. Mission**

The mission of EDSA is to promote the development of a network of associations for Down Syndrome in all European nations, respecting the diversity of cultures and peoples, the common denominator being the improvement of the quality of life for persons with Down Syndrome and their families.

## **3. Values**

The **values** that orientate EDSA's activities and its member entities revolve around 3 central points: the persons with Down syndrome, their families and the associative movement.

### **3.1. Persons with Down syndrome**

Article 26 of the CHARTER OF FUNDAMENTAL RIGHTS OF THE EUROPEAN UNION (28th September, 2000) establishes that ***The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.***

**In addition,** EDSA adopts, defends and promotes of the following values:

**1. Dignity:** the recognition of an individual's intrinsic value as a person, irrespective of sex, race, origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation.

**2. Inclusion.** The disability is not in the person but in the relations between the person and his or her environment. Inclusion, which is understood as full social acceptance of the individual with Down syndrome in the community, is the only way for his/her effective social integration and recognition of his/her rights as a citizen.

**3. Normalisation.** Normalisation is the acknowledgment of the right of each individual to a life as normal as possible, which should not differ from anyone else, notwithstanding the right to the support, necessary to meet individual needs. The consequences should be integration in the community, individual adaptation of services and education towards autonomy.

**4. Autonomy.** Education and rehabilitation should be directed towards fully developing the potentials of the person with Down syndrome in order to reach a maximum degree of autonomy and the full enjoyment of rights.

**5. Self-determination.** The ultimate consequence of autonomy is self-determination, i.d. the right to decide on one's own life. This is intrinsically related to the enjoyment of quality of life. This right transcends the person's disability and the support of individual needs which should be guaranteed; it should be reinforced in all areas of life.

**6. Quality of life.** The quality of life of persons with Down syndrome and their families is the point of reference in all actions and areas.

**7. Individualisation and specificity.** Persons with Down syndrome have the right to receive support according to their needs, their individual characteristics and to the medical, educational and social problems related to the syndrome.

### **3.2. The families**

**8. The family as a base of integration.** The family is the primary affective and learning environment of the person with Down syndrome. Family life, especially during the first stages of the child's development, will determine the lifespan development. Help conceived for the person with Down syndrome should always include the participation of the family.

**9. The needs of the family itself.** Special needs are attached to having a

family member with Down syndrome. Restructuring expectations concerning the son or daughter immediately after the diagnosis (“Down syndrome”) has been established, the need for information and advice, an increased number of crucial decisions, greater dedication and exhaustion, all this requires the support of professionals and other families who have lived through the same experiences. Specific actions that address information, support, stress therapy, leisure, communication, training, exchange or any resources related to the presence of a family member with Down syndrome are increasingly based on the specific needs of these families which should always be a central concern of all organisations.

### **3.3. The associative movement**

**10. Solidarity.** This is understood as the will to provide solutions for the needs of the community as a whole, with special attention to persons and groups experiencing greater disadvantages.

**11. Justice.** The approach of the associative movement for people with Down syndrome shall be based on the principle of and the right to equal opportunities, if necessary through positive discrimination.

**12. Specificity.** Specificity is a consequence of specialisation and involves giving a correct scientific answer to the limitations which in each person are derived from the presence of the extra chromosome 21. Without specificity, there is no sense in having the association movement for the Down syndrome.



**13. Social usefulness.** All legal entities for persons with Down syndrome must be non-profit organisations. Their social objective must be measured in terms of quality of life for persons with Down syndrome and their families.

**14. Transparency.** Social vocation, honesty and ethics in management must be principles adopted by all organisations.

**15. Public responsibility.** Down syndrome organisations, whether publicly or privately managed, must carry out actions or render services that are linked to socially recognised needs, to basic rights of the individual and must be accessible to all citizens who require them.

**16. Efficiency.** The organisations shall be developed according to principles of efficiency, with management procedures and results directed towards quality.

**17. Quality.** The commitment to quality involves continuous improvement of all activities of the organisations, which in turn are directed towards improving the quality of life for their clients.

**18. Client orientation.** Including the client's voice in the services is a precondition for quality. Persons with Down syndrome and their families should be consulted or take part in the development of activities, programmes and services.

**19. Cooperation.** The associative movement for people with Down syndrome in Europe must be constructed and strengthened through cooperation and the exchange in areas which promote actions aimed at giving everyone with Down syndrome the same level of opportunities. In this respect, special attention will be given to nations or regions that are socially at a greater disadvantage or which resources and possibilities are more limited.

## **4. Principles**

On the basis of these values, we declare the following **general principles for all actions.**

**1. Persons with Down syndrome are persons who have the same rights as other citizens:** their capabilities must take precedence over their limitations or differences. The principle of equal rights between persons with or without a disability means that the needs of all individuals have the same importance; they must constitute the basis of social planning. All resources must be used in a way to guarantee equal opportunities for everyone.

**2. We demand normalisation and inclusion at all levels and in all services,** especially with respect to the community's ordinary resources (*health, education, work, social services, housing, culture and leisure, etc.*). Support must be provided for persons with Down syndrome in order to

ensure the same quality of service which the rest of the population enjoys.

**3.** The orientation of our organisations towards **quality of life for persons with Down syndrome and their families** means: **a)** that their needs and expectations are covered, **b)** that they can develop all their potentials, and **c)** enjoy their full rights as citizens.

**4.** We defend the **respect of diversity**, understanding this to be full social acceptance of persons with Down syndrome as active members of the same society.

**5.** We opt for specificity, that is to say, **individualised and specialised attention** (prevention, education, health, rehabilitation, work...). Centres, services or ordinary resources of the community should cover the specific needs of persons with Down syndrome.

**6.** We understand our **association leadership as a respectful form of collaboration and participation** with all the organisations that respect

the rights of persons with Down syndrome, avoiding competition or confrontation at any time.

## **5. Objectives and priorities**

Consistent with our principles, we advocate programmes and plans of action based on the following strategic courses of action:

**1. Early Diagnosis and Genetic Advice.** Appropriate information and advice will help parents to take responsible decisions and to face the birth of their child with Down syndrome.

**2. Defence of rights.** EDSA will promote the defence of equal rights of persons with Down syndrome in Europe and the rest of the world.

**3. Health programmes.** Good health is fundamental for social and cognitive development, as well as for a better quality of life and longer life expectancy. Specific medical problems must be diagnosed and addressed as soon as possible. National health programmes for persons with Down syndrome must be widely diffused and adopted.

**4. Early intervention programmes.** Early specific and well applied intervention programmes have proved to be efficient as they rely on the brain's plasticity during the first years of life. Children who have taken part in them have been shown to improve their cognitive and adaptative skills.

**5. Diversity in schools.** Schooling in Europe must meet the educational needs of all its pupils, with or without a disability. No effort must be spared to supply schools with the necessary supports and resources, including special teacher training. We promote an inclusive education that sets out to reconvert special schools into centres of resources and support for the integration of pupils with Down syndrome.

**6. Access to work.** Professional training should be directed towards the effective preparation for employment, by providing the necessary support so that persons with Down syndrome can obtain employment and,

therefore, be economically independent. Within this framework, job insertion shall be understood as a continuum that includes different stages or levels of insertion: rehabilitation, training, occupational activities, protected occupation, supported employment and ordinary work.

**7. Support for the families.** As the first natural environment of the person with Down syndrome, the family must receive support and correct information for full acceptance of the situation and integration of the newborn child in the family, as well as proper training and effective involvement concerning intervention and education in order to achieve maximum autonomy of the child.

**8. Attention for serious disabilities.** Some persons with Down syndrome have a serious additional psychological or physical disability or specific needs which call for special support. Their possibilities of social integration and autonomy may be very limited; caring for them may represent a serious burden for their families. Once the particular characteristics of each individual case have been established, their care can be entrusted to specialised centres, ensuring the highest level of normalisation possible.

**Orientation towards adult life.** Longer life expectancy and the adoption of the principle of normalisation mean that all services must be directed towards adults with Down syndrome, recognising them as adults persons beyond their disability and fully respecting their right to self-determination.

**10. Leisure and sport integrated in the community.** Persons with Down syndrome should also receive the necessary support for effective social participation as far as leisure and sports activities are concerned.

**11. Tutelage services.** The establishment of Tutelage Foundations and other similar instruments should be supported; these will attend to persons with a disability and guarantee his or her well-being when the family is unable to do so.

**12. Training of specialists.** Special training of professionals (doctors, psychologists, educators, speech and language therapists, job trainers, physiotherapists, etc.) is fundamental in order to ensure adequate attention to persons with Down syndrome, according to their specific needs.

**13. Support for research, development and implementation of new technologies.** State of the art programmes concerning health care and integral attention to the person with Down syndrome will be subject to continuous adaptations in order to achieve a permanent adjustment of services to new knowledge, resources and methods.

**14. Social image and associative leadership.** The following basic objectives are stipulated:

- a) **Promotion of a positive image of persons with Down syndrome in Europe**, in order to achieve their social inclusion as citizens in their own right. Encouraging attitudes and

behaviours that strengthen their autonomy and improve their quality of life is a condition preliminary to social acceptance.

b) **Diffusion of the mission of EDSA in Europe and the world**, its principal actions and its members.

c) **Constitution of a forum of information, training and research resources**, based on the permanent exchange

between organisations attending to persons with Down syndrome and their families.

**We are convinced that actions based on these principles will have a positive effect on the recognition of the values, rights and needs of persons with Down syndrome and their families; this recognition will rebound on the development of actions directed towards improving their quality of life.**

## **6. Good practices**

When developing actions, programmes or services directed towards the needs of persons with Down syndrome, the following criteria should be adhered to:

1. All support adapted to the needs detected must be provided.
2. This support must be consistent with the values, principles and priorities established in the EDSA identity document.
3. Support meeting the needs of persons with Down syndrome shall be integrated in ordinary community services; only when this is

not possible will individuals be attended to in “special” public or private centres.

The associations or services must be regarded as companies providing services to clients. The client concept implies the right to claim services. Persons with Down syndrome are not mere users or beneficiaries, but persons in their own right.

The ultimate aim of the services is to produce quality of life. The terms under which the improvement of the quality of life of

persons with Down syndrome can be achieved will have to be defined and regularly reevaluated.

6. These terms will be subject to the criteria of quality and progressively adapted to the parameters established in the EFQM Excellence Model.

They must be based on criteria of a socially oriented economy, however, without having profit-making as an objective; they must be submitted to the economic controls established by the competent public bodies.



## **WHAT IS EDSA?**

EDSA is a non-profit international Association whose goals are:

to promote all actions and efforts which contribute to the welfare of persons with Down Syndrome according to the rights awarded to them by their own constitution, the Declaration of Human Rights and rights of persons with disabilities by the United Nations, and the European convention relating to the protection of fundamental rights and liberties.

Promote the well-being of persons with Down Syndrome in every possible way and area, and in every aspect of life: health, education, personality, autonomy and integration in the society according to the individual's aspirations and capabilities.

To encourage all scientific efforts towards advances and improvements in medical care, education, rehabilitation, vocational training, employment, leisure and independent living.

To further the interests of persons with Down Syndrome by securing all necessary resources, support and services to that end.

To create a bond among all persons with Down Syndrome, their families, friends and associations.

Article 3. EDSA BY LAWS

