

# CODE OF ETHICS



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## WHAT IS OUR CODE OF ETHICS AND WHAT IS ITS AIM?

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EDSA's mission is to promote the development of a network of associations for Down syndrome in Europe, based on respect for the diversity of cultures and nations and with the common aim of improving the quality of life of people with Down syndrome and their families.

EDSA's main objective is to promote the complete development of people with Down syndrome, regardless of racial, linguistic, religious, philosophical, or political considerations. EDSA seeks to improve the health, education and training, and integration into society of people with Down syndrome to the greatest extent possible, so that each one can lead as normal a life as possible.

EDSA's priorities may be summarised as follows:

Protection of the rights of people with Down syndrome

The provision of genetic counselling when diagnosis has been confirmed

Establishing health and early care programmes

Emphasising family support and caring for the seriously disabled

Diversity in education initiatives

Promoting access to employment and providing guidance for adult life

Ensuring integration into the community in terms of sport and leisure activities

Providing guardianship services and training specialists

Supporting research and the development and implementation of new technologies;

Promoting positive social images

Guaranteeing professional and dedicated association leadership.

The globalisation of social life, the economy, advances in modern communications and technology have made it necessary to define a code of ethics both on an international and a local scale, (i.e, from the level of ethical criteria which are widely shared to the local level of understanding specific experiences.)?

Our code aims to recommend rather than to prohibit. We have focussed on developing guiding principles to help organisations, professionals, volunteers, families and persons with Down syndrome make appropriate decisions. We will always promote a model of cooperation rather than one of conflict.

This code of ethics is therefore intended as a general guide for action, with the aim of encouraging organisations, professionals, volunteers and families to:

- carry out their professional and/or personal duties competently and in accordance with accepted principles;
- commit themselves to a series of shared responsibilities, providing the impetus for initiative and dedication;
- always be led by the guiding moral values and a socially aware moral conscience when pursuing their goals, and to understand and accommodate the contexts and consequences of each decision.

We consider this code to be an ongoing dialogue, a dynamic, living document. It must therefore be open to continuous revisions, modifications and improvements. We must collect the experiences of organisations, professionals, volunteers, families and persons with Down syndrome and allow them to inform our thinking and the presentation of our shared ideals and aims. Educational practice must inform the theory and principles of this document.

Essentially, this code is based on the following documents:

1. **The Charter of Fundamental Rights of the European Union**, dated 28 September 2000. Article 26: *“The Union recognises and respects the right of disabled persons to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.”*
2. **EDSA Identity Document**, which identifies and promotes:
  - values such as dignity, inclusion, normalisation, independence, self-determination, quality of life, individualisation and specificity with regard to persons with Down syndrome;
  - values such as solidarity, justice, specificity, social usefulness, transparency, public responsibility, efficiency, quality, client orientation and cooperation with regard to organisations;
  - the notion of the family as the basis for the full social integration of persons with Down syndrome, and recognises the individual needs of each family.

The code of ethics we present below is derived from all of the above, and has been created with the intention of ensuring the application of these and other principles relevant to the care of persons with Down syndrome.

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## **ORGANISATIONS SHOULD:**

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- Provide care services for all people with Down syndrome and their families, giving special support to those in difficult situations, adjusting the support to fit the particular needs and characteristics of each.
- Facilitate normal living and working conditions for people with Down syndrome by teaching them to be independent.
- Provide people with Down syndrome and their families with the necessary communication channels to enable them to express themselves, thereby guaranteeing a practical and efficient system of suggestions and complaints.
- Help families to accept their personal situation and create an appropriate environment for the complete personal development of people with Down syndrome, providing information, support, therapy, training, leisure and means of communication or other resources necessary to achieve this purpose.
- Promote a positive image of people with Down syndrome and their families, avoiding negative connotations, such as pity or despair, and using the media or any other appropriate form of dissemination to achieve this.
- Guarantee the exchange of information between administrators, professionals and volunteers by creating useful channels of communication (capable of gathering opinions, complaints, and suggestions), and promoting positive attitudes and encouraging new initiatives.
- Be mindful of and seek to enhance the human and physical climate surrounding people with Down syndrome, totally rejecting any physical or psychological punishment, eliminating all types of architectural, communicative barriers, etc, and creating a cheerful and pleasant environment for each and every person with Down syndrome.
- Promote the full integration of people with Down syndrome into their communities, and performing the social, legal and political actions necessary to achieve this.
- Guarantee the rights of people with Down syndrome, particularly the right to privacy, information and confidentiality, and striving to eliminate the obstacles that prevent compliance with these rights.
- Defend the rights of people with Down syndrome and their families when those rights are infringed, and doing so through peaceful means and dialogue, avoiding segregation or conflict.

- Promote the independence of people with Down syndrome through activities that increase their participation in society and their use of community services, with the final aim of full social integration.
- Promote responsible effective and competent services within all organisations which attend to people with Down syndrome.
- Recognise, in the setting up of associations, etc., that families play an essential role in the social integration of people with Down syndrome and promoting actions that serve to emphasise this role and increase the family's participation.
- Ensure that organisations do not act in their own personal, political or economic interests, This can be achieved by creating statutes that regulate their activities, by advocating frequent changes in their presidency and management, and by recommending regular external audits.
- Promote, by means of specific actions, the support, communication, cooperation and exchange between the associations and organisations that make up EDSA, paying special attention to those nations or regions which are most disadvantaged, or whose resources and possibilities are more limited.
- Guarantee the involvement of all professionals, volunteers and people with Down syndrome in the decisions and actions that are taken, always respecting and including the range of opinions expressed.
- Develop according to principles of efficiency, targeting a quality-driven management approach with regard to processes and results.
- Use economic resources cautiously, honestly, transparently and prudently, avoiding superfluous expenditure and justifying it whenever necessary.
- Revise, modify and update the code of ethics in collaboration with relevant professionals, volunteers, people with Down syndrome and their families.

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### **PROFESSIONALS AND VOLUNTEERS SHOULD:**

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- Believe in the idea that all human beings can develop and grow, can be educated and be independent and capable if provided with the right assistance.
- Train, inform and guide the families both in the acceptance of their personal situation and that of the person with Down syndrome, and in the development of their potential and possibilities on an individual and group basis.

- Empathise with the life and individual characteristics of people with Down syndrome – by “putting themselves in their shoes” – and always promoting their self-esteem and social recognition irrespective of their skills, abilities, achievements, or difficulties.
- Not discriminate against people with Down syndrome or their families for social, political, economic, cultural, racial, gender, or religious reasons, guaranteeing that they are treated in a dignified manner, with respect and equality.
- Listen to people with Down syndrome and promote platforms of self-advocacy for them, favouring their right to self-determination, including the right to say “No”.
- Promote activities, situations and methodologies which favour the autonomy, self-determination and decision-making capacity of people with Down syndrome and their families, provided that their personal circumstances and characteristics so permit.
- Allow people with Down syndrome and their families to take decisions on matters that affect their lives, consulting with them and providing them with the necessary information and training to make informed decisions.
- Help people with Down syndrome and their families take advantage of the resources in their communities and to use the existing support services and communication and exchange channels to ensure that their needs are fully met.
- Update their professional training on a continuous basis in order to be capable of providing a quality service for people with Down syndrome and their families, incorporating the scientific and technical rigour and efficiency required.
- Not carry out their professional activity in such a way that it results in personal benefit or profit, either directly or indirectly, nor carry out parallel professional activities without informing the organisation prior to commencing such activities.
- Act in accordance with the rules, principles and ideas that govern this organisation, maintaining an attitude of respect, participation, dialogue, teamwork and cooperation with clients, other professionals, volunteers and the organisation itself.
- Fight for this code of ethics to be put into practice, reporting any incidents or improper behaviour on the part of professionals and volunteer personnel, and reporting any injustices perpetrated against people with Down syndrome and their families.
- Create national and local ethics committees to analyse and resolve any conflicts that may arise.

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## **THE FAMILIES SHOULD:**

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- Promote at all times a dignified and capable image of the person with Down syndrome, as an individual with rights and duties, by means of setting an example and working to achieve as normal a life as possible.
- Prioritise first and foremost an affectionate and respectful treatment of people with Down syndrome within the family, including their right to privacy.
- Facilitate the communication and expression of the needs, interests, complaints, desires, etc, of people with Down syndrome, continually encouraging their capacity for decision-making and self-determination.
- Be aware of the key socialising and enabling role that the families play in the education of persons with Down's syndrome and in their socio-cultural integration.
- Continuously revise the educational model, checking that it is working properly and, when necessary, changing or eliminating all those attitudes, conceptions or procedures that are damaging to the complete and harmonious development of the person with Down syndrome.
- Anticipate the future of people with Down syndrome with regard to housing, economic resources, personal care and access to employment, and promoting their self-determination, autonomy and complete personal development.
- Make use of the channels of communication and expression of suggestions, criticisms, needs, complaints, condemnations and ideas, and thereby seek continuously to enhance the quality of care for people with Down syndrome.
- Use the economic, social and service resources, appropriately and honestly, so that they are always directed at satisfying the needs and requirements of people with Down syndrome.
- Act coherently with the organisation with regard to the principles, rules, procedures, attitudes, and activities, in the treatment of people with Down syndrome, thus promoting continuity and diversity in their education.
- Participate to the full in the services created to help and respond to the needs of the families, collaborating with and offering their support to other families in need.
- Offer their support and cooperation to organisations, professionals and volunteers on a continuous basis so that the role of education is truly significant, catering for all life situations of people with Down syndrome, and granting the same education principles to everyone.

- Collaborate and participate in the different activities of the organisation with interest and enthusiasm, always respecting and sharing the principles, rules and values that regulate it.
- Fight for the rights of people with Down syndrome so that they are respected in all spheres, and ensure that the organisations apply pressure on the various areas, institutions and individuals, as required.