

# THE RIGHT WORDS

Using the right words means respecting the rights and dignity of persons with disabilities

(Article 8 CRPD)

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Contacts: nazionale@anffas.net

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### INTESA M SANPAOLO

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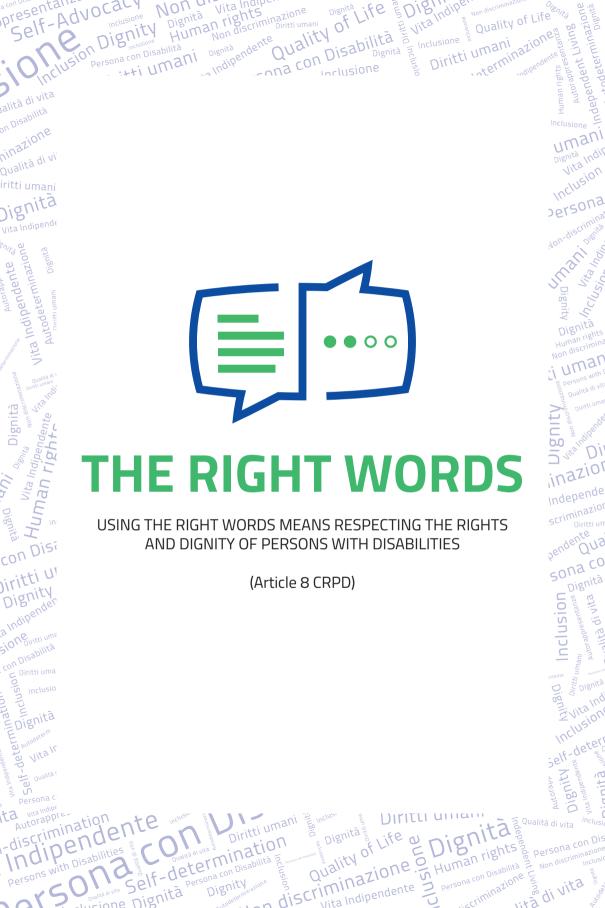


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The era in which we are living is certainly one of the most complex from a socio-economic point of view. However, I believe that it is also an important historical moment of opportunity and innovation, which must be seized and during which perspectives on the theme of inclusion are evolving. This is largely thanks to the United Nations Convention on the Rights of Persons with Disabilities and, in Italy, to the Disability Framework Law, which I have the task of fully implementing, as well as to the economic and project-based opportunities launched by the Italian National Recovery and Resilience Programme. Another factor of change is the capacity for social innovation implemented by Third Sector organisations, which manage projects and services, and the growing opportunities offered by digitalisation.

In visiting facilities throughout Italy, I am learning about interesting proposals and models of action that can be replicated and should be promoted and supported. It is now increasingly important to get institutions, third sector organisations and the private sector to join forces in order to meet citizens' needs sooner, more effectively and more extensively through shared objectives.

I am convinced that this is a moment of great potential on which we must capitalise. To do so, we also need a cultural change that puts the person at the centre, not as a mere recipient of help but by making a concrete investment in the skills and talents of each individual.

We still have a long way to go to achieve full inclusion of persons with disabilities, to ensure universal accessibility and an autonomous, independent, participatory and dignified life for all without discrimination. There are many issues to be tackled with great commitment and

seriousness: the right to education, training, inclusion at work, real integration between health, social-health and social services, and above all the life project. These are issues on which I am working hard to strengthen the national regulatory framework in line with the UN Convention on the Rights of Persons with Disabilities, ratified by Italy in 2009, and with the European Strategy for the Rights of Persons with Disabilities 2021-30.

In order for a real cultural leap to take place, we must start with the words we use and explain why some terms are preferable to others when dealing with disability issues, but also explain their meaning. The evolution of terminology, which underlies a profound change in the way we look at disability, is a global process that is fuelled by the driving force and contribution of all countries, and within them, of the whole of society. This publication is addressed to everyone and is intended as a contribution, by using "the right words", to promote, sensitise and increase knowledge and awareness on the correct approach to disability and on the rights protected by the Convention, also from a cultural and value-driven perspective.

Alessandra Locatelli Minister for Disabilities





### INTRODUCTION

The Un Convention on the Rights of Persons with Disabilities
The use of correct language increases respect for the rights and
dignity of persons with disabilities

The Convention reaffirms, promotes, protects and guarantees the full and equal enjoyment of all fundamental rights and freedoms by persons with disabilities, including persons with the greatest support needs, on an equal footing with all other persons and with respect for their inherent dignity.

The enjoyment of the fundamental rights and freedoms of persons with disabilities is implemented through specific "measures" that each State, in all its constituent units, must implement in order to ensure the full and effective achievement of this objective.

The articles of the Convention that make significant reference to the correct use of language are:

### **ARTICLE 1 - PURPOSE**

Article 1, in setting out the purpose of the Convention as described above, identifies the persons entitled to protection, namely persons with disabilities, understood as those who "have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"...

### **ARTICLE 3 - GENERAL PRINCIPLES**

Article 3 of the UN Convention on the Rights of Persons with Disabilities lists the "general principles", i.e. the overarching "values" on which the provisions of the Convention are based and to which they conform.

### These principles are:

- (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) non-discrimination;
- (c) full and effective participation and inclusion in society;

- (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity itself;
- (e) equality of opportunity;
- (f) accessibility;
- (g) equality between men and women;
- (h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

### **ARTICLE 8 - AWARENESS-RAISING**

The Convention considers "awareness-raising" to be an important means of contributing very significantly to the pursuit of the full enjoyment of all human rights and fundamental freedoms by persons with disabilities.

For this reason, States Parties must promote and increase knowledge and awareness of the correct approach to disability and the rights protected by the Convention, including in cultural and value terms, by taking action to

- (a) raise awareness throughout society, including at the family level, regarding persons with disabilities, and foster respect for the rights and dignity of persons with disabilities;
- (b) combat stereotypes, prejudices and harmful practices that affect persons with disabilities, including those based on sex and age, in all areas of life;
- (c) promote awareness of the capabilities and contributions of persons with disabilities.

The Convention already indicates the essential measures to be undertaken by States to this end:

- (a) public awareness campaigns aimed at fostering a receptive attitude towards the rights of persons with disabilities, promoting a positive perception and greater social awareness of persons with disabilities, promoting recognition of the abilities, merits and aptitudes of persons with disabilities, including in the world of work;
- (b) promotion of an attitude of respect for the rights of persons with disabilities at all levels of the educational system, especially including all children, from an early age;
- (c) encouragement for all media to represent persons with disabilities in a manner consistent with the objectives of the Convention;
- (d) promotion of training programmes to raise awareness about persons with disabilities and the rights of persons with disabilities.



### **ARTICLE 9 - ACCESSIBILITY**

Among the rights enshrined in the Convention is the right to "accessibility", which is also designated as a universal "principle" of the entire Convention. This right is portrayed in a broad sense, and is considered instrumental to the enjoyment of the right of all persons with disabilities to participate fully in all aspects of life and to live independently, like all other citizens.

This article requires States Parties to take "appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas".

Accessibility must, in particular, be ensured, not only with reference to buildings, roads, transport and facilities in general (e.g. schools, housing, health facilities and workplaces), but also "to information, communications and other services, including electronic services and emergency services".

The Convention indicates the essential measures that States Parties must adopt to this end. They must:

- (a) develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- (b) ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- (c) provide training for stakeholders on accessibility issues facing persons with disabilities;
- (d) provide, in buildings and other facilities open to the public, signage in Braille and in easy to read and understand forms;
- (e) provide forms of assistance by persons or animals and intermediary services, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- (f) promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- (g) promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- (h) promote the design, development, production and distribution of



accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

# ARTICLE 21 - FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

The Convention reaffirms the right of every person with disabilities to freedom of expression and opinion and access to information.

This right is guaranteed by ensuring that every person with disabilities is able to request and receive information and to communicate his or her views on an equal basis with others through any freely chosen means of communication within the diverse range of possible tools.

By "communication" the Convention means:

- languages;
- display of text;
- Braille and tactile communication;
- large print;
- accessible multimedia;
- written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

Language means "spoken languages and sign language" as well as "non-verbal forms of expression" in general".

The Convention indicates the essential measures that States Parties must adopt to this end. They must:

- (a) provide information intended for the general public to persons with disabilities, in accessible formats and technologies appropriate to different kinds of disabilities, in a timely manner and without additional cost;
- (b) accept and facilitate the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- (c) require private entities that provide services to the general public,



- including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- (d) encourage the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- (e) recognise and promote the use of sign language.

# ARTICLE 29 - PARTICIPATION IN POLITICAL AND PUBLIC LIFE

Participation in political and public life lastly, accessibility must also be ensured with respect to the exercise of political rights on an equal basis with others, so that persons with disabilities can effectively and fully participate in political life, directly or through freely chosen representatives, vote and be elected.

To this end, States Parties must:

- (a) ensure that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
- (b) protect the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
- (c) guarantee the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allow assistance in voting by a person of their own choice.

States Parties must also actively promote "an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs" through:

- (a) participation in non-governmental organisations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
- (b) forming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.





### **GUIDELINES**

To ensure respect for the rights and dignity of persons with disabilities, accessibility of information and communication on an equal basis by persons with disabilities through the correct use of language

The Guidelines are inspired by the model introduced by the UN Convention on the Rights of Persons with Disabilities, and provide guidance aimed at increasing respect for the rights and dignity of persons with disabilities through the correct use of language, the right to freedom of expression and opinion, and the right to fully and universally accessible information.

The Guidelines can be a useful reference for:

- the general public;
- policy-makers;
- institutions:
- those working in the mass media;
- legal practitioners;
- anyone involved in guaranteeing and/or delivering benefits and services to the community.

If you need further support or have doubts about general aspects, you can ask for help from the federations or organisations that represent persons with disabilities or contact the National Observatory on the Conditions of Persons with Disabilities in Italy directly.

#### **GUIDELINES**

1) It is not correct to use words such as "differently abled", "diversely abled", "disabled", "person suffering from a disability", "person with a handicap" or other similar words. Under the UN Convention, these words must always be replaced by the term "person with disabilities". The term "handicap" must also be replaced by the word "disability". Should it have to be used, however, for instance to cite an article of law, care must be taken to place the word in quotes. In any case, the

- use of words with a negative and inappropriate meaning, e.g. cripple, mongoloid, demented, etc., must always be avoided, as in such cases it could constitute "harassment".
- 2) Always ensure that persons with disabilities can receive information and communicate, in any place and context, through whichever means or method they prefer (e.g. sign language, Braille, CAA, Easy to Read, etc.). Where necessary, providing them with the necessary and adequate assistance to be supported in their decision-making processes, to express their wishes, expectations and preferences, to access information, to express their ideas and thoughts.
- 3) When decisions directly affecting a person with disabilities have to be taken, always involve him/her, even if he/she is a minor and/or represented by a third party (e.g. family member, guardian, support administrator, etc.), never in a fully substitutive manner.
- 4) Ensure that a person with disabilities can participate in public life and express his or her personal thoughts and opinions in any context.
- 5) Use appropriate terms correctly, particularly among media professionals, taking the human rights-based model as a reference and promoting an inclusive culture that always takes into account the fundamental freedoms of persons with disabilities.
- 6) Never use quotations that include a derogatory or inappropriate concept or term. If for any reason it needs to be quoted, the reason should be specified and the correct term proposed as an alternative. For example, if an unsuitable term is encountered, for example, the term "mongoloid", specify that this term represents disability in a derogatory way and cannot be used, whereas the correct definition is "person with Down syndrome". Should it be necessary to quote directly from a regulatory or other text that contains terms other than those described above, it is advisable to place the term in quotes and, where possible, indicate the reason why the term is not to be considered suitable, providing the correct definition.
- 7) Never identify the person with his or her "illness". The person is not his or her illness but has a name and surname.



- 8) Only mention a person's disabling condition when it is actually relevant to the narration of the facts and, when it is mentioned, use correct language that always puts the person in the foreground, e.g. "person with Down syndrome", "person on the autism spectrum disorder", "person with motor disability".
- 9) Always take care to find out the person's preference as to how he or she would like to be described as well as what specific aspects he or she feels should be reported in relation to his or her health condition or disability.
- 10) Avoid narratives that see the person with disabilities described as either a "victim" or a "hero". Therefore, both pietism and sensationalism should be avoided in all cases.





### **CONCEPTS AND KEY WORDS**

### **ACCESSIBILITY**

According to the UN Convention, States Parties must take all appropriate measures to ensure that persons with disabilities, on equal terms with other citizens and in all living environments, have access to the physical, sensory, transportation, information and communication environment, including related systems and technologies, and to other facilities and services open or provided to the public. Therefore, in accordance with the principle of "universal design", all necessary adaptations must be made so that this right is always enforceable.

Information, communication and other services, including computer and emergency services, must also conform to these principles. This also includes promoting access for persons with disabilities to new information and communications technologies and systems.

To this end, "the information sector is also obliged to make systems available to all persons with disabilities in such a way as to ensure that information intended for the general public" is provided "in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost". For people with intellectual disabilities and neurodevelopmental disorders, for example, the use of "easy to read" language and CAA is becoming increasingly popular. Similarly, sign language and subtitling for deaf people, and voice support for video systems and Braille support for writing systems for blind people etc. are increasingly widespread.

### **ADVOCACY**

This word describes the civil process through which a person or group of people seek to support a policy, whether social, economic or legislative, and to influence the related distribution of human and monetary resources.

Advocacy, thanks also to the use of social tools, can guide public opinion and, consequently, public policy.

### **ASSOCIATIONS EMPOWERED TO ACT UNDER LAW NO. 67/06**

Law no. 67/2006 "Measures for the judicial protection of persons with disabilities who are victims of discrimination" provides for the establishment of a register of associations and entities empowered to act on behalf of persons who are victims of discrimination.

Persons with disabilities who believe they have suffered discrimination on the basis of their disabling condition can contact the associations and entities listed in that register and ask them to intervene to remove the discrimination they have suffered, including by taking legal action.

The associations empowered to take action may also act directly and autonomously against a discriminatory measure, when the discrimination takes on a collective character.

The register is kept and updated by the Ministry for Disabilities.

The list is public and is periodically updated following an investigation by the Department for Policies in Favour of Persons with Disabilities.

### **AUGMENTATIVE AND ALTERNATIVE COMMUNICATION - AAC**

The Convention defines "communication" as the written, audio, plainlanguage, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

AAC (alternative/compensative/augmentative communication), is the set of symbols and equipment for the total or partial, temporary or permanent compensation of severe difficulties in speech and writing.

AAC is a communication tool that must be adapted to the individual person. States Parties are therefore obliged to accept and facilitate the use of augmentative alternative communication in official activities by persons with disabilities.

### **BARRIERS**

The International Classification of Functioning, Disability and Health (ICF) identifies "barriers" as "factors in a person's environment which, through their absence or presence, limit functioning and create disabilities". An environment may present barriers of an architectural nature (e.g. the presence of steps may be a barrier for persons with physical disabilities) but



also of another nature (e.g. the lack of information in accessible language may be an invisible barrier for persons with intellectual disabilities and neurodevelopmental disorders, or barriers of a sensory-perceptual nature may be a limitation for them or for people with sensory disabilities). Disability is an evolving concept and is the result of the interaction between people with impairments and behavioural and environmental barriers, which prevent their full and effective participation in society on an equal basis with others. For this reason, contexts in which there are barriers of various kinds assume particular importance for the disabling condition because it is precisely these contexts which, by interacting with "physical, mental, intellectual or sensory impairments", limit or prevent the full and effective participation in society by persons with disabilities on an equal basis with others, thus becoming a determining factor of the condition of disability itself.

### **BIO-PSYCHO-SOCIAL MODEL**

The bio-psycho-social model is a strategy for approaching the person that attributes the outcome of illness as well as health to the intricate and variable interaction of biological factors (genetic, biochemical, etc.), psychological factors (mood, personality, behaviour, etc.) and social factors (cultural, familial, socioeconomic, etc.). The bio-psycho-social model contrasts with the biomedical model, which attributes disease primarily to biological factors such as viruses, genes or somatic abnormalities that the physician must identify and correct. This model is the basis of the ICF - International Classification of Functioning, Disability and Health.

### **BRAILLE**

The Convention requires States Parties to take all appropriate measures to ensure that all persons with disabilities can exercise their right to freedom of expression and opinion, including the freedom to receive and impart information and ideas on an equal basis with others through any media of their choice.

Braille is a tactile relief reading and writing system that enables blind and visually impaired persons to access written texts and information by sliding their fingertips over a surface containing combinations of raised dots, each of which corresponds to an alphanumeric character.

States Parties are therefore obliged to accept and facilitate the use of Braille by persons with disabilities in official activities.



#### COMMUNICATION

By "communication" the Convention means:

- languages;
- display of text;
- Braille and tactile communication;
- large print;
- accessible multimedia;
- written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

### **COMMUNITY**

This word indicates a specific group of people, often living in a defined geographical area and sharing the same culture, values and norms, organised in a social structure based on the relationships that the community has developed over time. Members of a community acquire their personal and social identity by sharing common beliefs, values and norms that the community has developed in the past and may change in the future. They also manifest a certain awareness of their group identity. They share the same needs and commitment to meeting them.

### **DISABILITY DISCRIMINATION**

The CRPD dedicates an entire article (Article 5) to the theme of "equality and non-discrimination", recognising that persons with disabilities should not be treated differently because of their condition and that States should prohibit "any form of discrimination on the basis of disability".

In Italy, there is a specific law that prohibits discrimination on the basis of disability, namely Law no. 67/2006, which introduces forms of protection, including judicial protection, for people who are victims of discrimination, which can also be exercised with the support of associations empowered to act.

The types of discrimination identified today are:

- direct discrimination: direct discrimination occurs when, for reasons related to disability, a person is treated less favourably than a person without a disability in a similar situation is, has been or would be treated (Article 2, paragraph 2, Law 67/2006);
- indirect discrimination: indirect discrimination occurs when an apparently neutral provision, criterion, practice, act, agreement or conduct puts a



- person with disabilities at a disadvantage compared to other persons (Article 2, paragraph 3, Law 67/2006);
- harassment: harassment, i.e. undesirable conduct on the grounds of disability, which violates the dignity and freedom of a person with disabilities or creates a climate of intimidation, humiliation and hostility towards him/her (Article 2, paragraph 4, Law 67/2006) is also considered discrimination;
- discrimintion by association: the European Court of Justice and national courts have recognised the notion of discrimination by association, which occurs when a person suffers less favourable treatment through being associated with another person with disabilities. This is the case when a family member of a person with disabilities is discriminated against (in his/ her job or interpersonal relationships) because he/she is a close relative;
- multiple discrimination: this occurs when a person is discriminated against on the basis of more than one factor, but each discrimination takes place at different times and is based on different factors each time (I am discriminated against because I am female, but I am also discriminated against, at another time/place, because of my disabling condition);
- intersectional discrimination: takes place when discrimination is based on several factors that interact so that they can no longer be distinguished and separated. This is the case, for example, when disabled women are arbitrarily subjected to forced sterilisation. This type of discrimination is not experienced by women in general nor by men with disabilities;
- systemic discrimination: structural or systemic discrimination is the result
  of hidden or overt patterns of discriminatory institutional behaviour, or
  discriminatory cultural traditions, social rules and legal norms. This type of
  discrimination could include enrolling children with disabilities in special
  schools for persons with disabilities instead of including them in the general
  education system.

To learn more about combating discrimination on the basis of disability, one can consult the material produced by Anffas Nazionale as part of the project "AAA-Antenne Antidiscriminazione Attive". Information on the project is available in the "Projects and Campaigns" section of the website www.anffas.net

### **EASY TO READ**

Easy-to-read meaning language that is easy to read, is a way of communicating information that enables everyone, but especially people with intellectual



disabilities and neurodevelopmental disorders, to have access to information and therefore be able to learn, participate in society, know their rights and defend them, communicate and make their own choices. Inclusion Europe, together with other organisations, has identified a number of guidelines for translating texts etc. into language that is "easy to read and understand".

For more information on Inclusion Europe, consult the website www. inclusion-europe.eu

For more information on "easy-to-read language" you can visit the "easy-to-read language" section of the Anffas website www.anffas.net (insert direct links to reference pages only in the e-book version).

### **EMPOWERMENT**

Empowerment is the process through which people gain more awareness and full knowledge of their rights, so that they can claim and demand them for themselves. For persons with intellectual disabilities and neurodevelopmental disorders, this process must be guaranteed through the provision of adequate support in the processes to acquire awareness and knowledge and to learn about one's rights, also in order to exercise the right to self-advocacy either on an individual level or through organised self-advocacy groups.

More information on the Anffas Nazionale project "IO, CITTADINO! (I, the Citizen" and on "PIAM" - the Italian Platform for Self-advocates in Action is available in the "Projects and Campaigns" section of the website www.anffas. net. (insert direct links to the relevant pages only in the e-book version).

### **EQUAL OPPORTUNITIES AND NON-DISCRIMINATION**

The principle of equal opportunities is inherent in the Italian Constitution, which, in Article 3, enshrines the principle of formal equality among all citizens, who have equal social dignity and are equal before the law, "without distinction of sex, race, language, religion, political opinions, personal and social conditions", while also recognising the Italian Republic's task of "removing obstacles of an economic and social nature" that, by limiting the freedom and equality of citizens, prevent the full development of the human person and the effective participation of all workers in the political, economic and social organisation of the country.

The removal of economic and social obstacles therefore entails an active intervention by the State, aimed above all at promoting so-called "social rights" that guarantee equal opportunities and make it possible to remove all the unfavourable conditions that could limit enjoyment of rights and



therefore lead to discrimination between citizens.

This principle is further reaffirmed by the UN Convention on the Rights of Persons with Disabilities, which states that "States Parties ... recognise the right of all persons with disabilities to live in society, with the same freedom of choice as other persons, and shall take effective and appropriate measures to facilitate the full enjoyment by persons with disabilities of this right and their full integration and participation in society ...".

The Convention also promotes the principle of "equality between men and women", recognising that women and children with disabilities are often at greater risk, in the home environment and outside, of violence, injury and abuse, neglect, lack of care, maltreatment and exploitation.

# EUROPEAN STRATEGY ON THE RIGHTS OF PERSONS WITH DISABILITIES 2021-2030

In March 2021, the European Commission adopted the Disability Rights Strategy 2021-2030. Through this 10-year strategy, the European Commission aims to improve the lives of persons with disabilities in Europe and throughout the world.

The goal of this strategy is to make progress to ensure that all persons with disabilities in Europe, regardless of gender, racial or ethnic origin, religion or belief, age or sexual orientation, can

- enjoy their human rights
- have equal opportunities and equal access to society and the economy;
- be able to decide where, how and with whom they live;
- move freely within the EU regardless of their care needs and no longer be subject to discrimination

For more information, please visit the "Policies and Activities" section of the website www.ec.europa.eu

### **FACILITATORS**

The ICF identifies "facilitators" as "factors that improve functioning and reduce disability". For example, the installation of ramps or lifts are considered facilitators because they make an environment where there are architectural barriers accessible to people with physical disabilities; the use of "easy to read" language is a facilitator for people with intellectual disabilities and neurodevelopmental disorders, allowing better access to information; the use of appropriate language to connote disability can be a facilitator because it allows cultural barriers to be eliminated and counteracts stigma



and prejudice. At the same time, the facilitator is equally important, whether a caregiver, a professional service provider, a member of the friendship circle or family network of the person with disabilities who supports him/her in his/her activities, choices, communication, decision-making processes, etc.

### **FAMILY CAREGIVER**

Under Law no. 205/2017, art. 1 c. 255, a family caregiver is defined as a person who takes care of a person with disabilities, where there is a relationship linking that person to the person being cared for (spouse, civil union, de facto cohabitation, kinship or affinity) and the latter's conditions, which must have led to the recognition of "severe disability" pursuant to Article 3, paragraph 3 of Law 104/92 or an assistance allowance. In the first instance, those closest to the person (spouse, de facto cohabitant, civil partner, first or second-degree relative) may be considered caregivers, while third-degree relatives will only be considered when the parents or spouse of the care recipient are over sixty-five years of age or are also suffering from a disabling disease or are dead or missing.

# FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION

According to Article 21 of the Convention, States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others. Every measure, tool and means of communication must therefore be put in place to guarantee the exercising of this right, taking into account the differing needs of persons with disabilities, also due to specific forms of disability. Article 21 involves the entire community, but in particular all those who work in the world of information, both with regard to the use of adequate and correct language, and also with regard to the tools to be adopted (e.g. sign language, subtitling, Braille, Easy to Read, AAC, etc.). In addition, care must be taken to make texts and information and technology tools fully accessible, practical and usable, starting from the school context. Persons with disabilities must always be put in the best possible position to express their opinions themselves in the various contexts by providing, where necessary, the necessary and appropriate support.



### **FUNCTIONAL PROFILE**

The functional profile describes the person's functioning in his/her life context. Functioning is an interactive, evolutionary process that varies in different constructs (bodily functions and structures, activity and participation) and domains of health (safety, relationships, education, work, environment ...). The level of functioning is closely related to personal well-being. The set of functioning levels in the different constructs and domains constitutes the functional profile.

#### **HABILITATION**

Article 26 of the UN Convention distinguishes between the concept of rehabilitation and habilitation. The former is aimed at recovering lost or limited functionality. The second deals with enabling the person by focusing on functioning, always taking into account the desires, aspirations and practical activities that the person wants to and can perform.

### **HUMAN, CIVIL AND SOCIAL RIGHTS**

Human rights are the inalienable rights of human beings, that is, the rights that must be guaranteed for every person by the mere fact of belonging to the human race, regardless of the person's origin, belonging or place. Civil rights are rights that pertain to the personality of the individual, such as freedom of thought, personal freedom, freedom of assembly, freedom of religion and economic freedom. Indeed, in this area, the individual is guaranteed a measure of discretion as long as his or her actions do not violate the civil rights of others. For this reason, civil rights oblige states to adopt an abstentionist approach.

Social rights – including the right to work, to obtain care, to study, to health protection – are those rights arising from the maturation of new needs that arose in connection with the development of modern industrial society. These rights imply active behaviour on the part of the state, which must guarantee citizens practicality and certainty in their protection and in the recognition of the relevant guarantees.

### **ICF**

The International Classification of Functioning, Disability and Health (ICF) is part of the WHO Family of International Classifications, together with the International Statistical Classification of Diseases and Related Health Problems 10th revision (ICD-10), the International Classification of Health



Interventions (ICHI), and derived Classifications.

The ICF, which is based on the biopsychosocial perspective, provides both a unified, standardised language and a conceptual reference model for describing health and related states.

#### The ICF

- provides a scientific basis for the understanding and study of health as an interaction between individual and context;
- constitutes a common language for the description of health and healthrelated conditions in order to improve communication between health professionals, researchers, planners, public administrators and the population, including persons with disabilities;
- enables comparison between data collected in different countries, health disciplines, services and at different times;
- provides a systematic way to code information in health information systems.

The ICF can be used in all systems that have a connection to health, such as welfare, labour, education, insurance, economics, legislation and those dealing with environmental changes. To do this, it is necessary to define protocols for using the ICF as a language and as a descriptive model of health status.

### **INCLUSION**

Inclusion can be defined as the characteristic that makes a context suitable for all people, with or without disabilities, who can experience it on equal terms. In essence, a context is itself constantly and consciously evolving and changing to allow all its components equal opportunities and non-discrimination.

For this reason, the concept of inclusion is much broader and goes beyond the earlier concept of "integration". Integration was and still is a concept that emphasises 'diversity'. Where a person has been unable to adapt to a specific and pre-established context, this leads to exclusion and marginalisation, often being a prelude to discrimination for these reasons. Therefore, all life contexts (e.g. school, work, sports, leisure, etc.) should today tend to change and evolve in an inclusive way, initiating and supporting the necessary transition. For example, a school context is made inclusive when the entire context is modified and adapted appropriately to allow each child, pupil, student with disabilities to fully and effectively exercise his or her right to education, instruction and socialisation, on an equal footing with others.



In this case, the key factor is the right and necessary supports, both formal and informal, which must be provided within the same, appropriately adapted, context.

### INDIVIDUAL PROJECT

The individual project, previously envisaged and defined by Article 14 of Law No. 328/2000, has been further refined in Delegated Law No. 227/2021, which envisages a specific delegated decree aimed at detailing the conceptual, operational and organisational aspects for the preparation of individual, personalised and participatory projects and the corresponding project budgets.

The new regulatory provisions prescribe that personalised and participatory individual projects:

- will be implemented by means of multidimensional assessment units composed in such a way as to ensure the integration of case management, assessment and planning interventions by the competent health, social and health and social-welfare authorities;
- will follow a multidisciplinary approach to ensure the participation of the person with disabilities and of those who represent him/her;
- will identify the supports and reasonable accommodations necessary to guarantee the full enjoyment of fundamental rights and freedoms, including the possibility to choose, without discrimination, one's place of residence and a suitable housing solution, including by promoting the right to home care and social welfare support;
- will be aimed at achieving the goals of the person with disabilities in accordance with his/her wishes, expectations and choices, improving his/her personal and health conditions as well as his/her quality of life in its various spheres;
- will identify the barriers and facilitators that affect the contexts of life in accordance with the applicable principles of the United Nations Convention on the Rights of Persons with Disabilities, indicating the tools, resources, services, measures, and reasonable accommodations that must be adopted to implement the project and that are necessary to compensate for limitations to activities and to enable the participation of the person with disabilities in the various spheres of life and in the various contexts of reference, including work and school as well as cultural and sporting contexts, and in any other context of social inclusion;



- will ensure the adoption of the reasonable accommodations necessary to allow the proper identification and expression of the wishes of the person concerned and his or her full understanding of the measures and supports that can be put in place, in order to guarantee the person with disabilities, even when he or she is subject to a legal protection measure or needs very high-intensity support, full participation in the multidimensional assessment, in the drafting of the individual, personalised and participatory life project and in its implementation in a manner that guarantees the satisfaction of the person concerned;
- will provide that implementation of the project will in any case be ensured as the geographical and living context of the person with disabilities changes, through the human and instrumental resources under the respective jurisdiction of the local authorities and the regions in accordance with current legislation, as well as ensuring that, at the request of the person with disabilities or of his or her representative, the development of the individual, personalised and participatory life project will also actively involve Third Sector entities, through forms of co-planning and co-design pursuant to Articles 55 and 56 of the Third Sector Code, referred to in Legislative Decree No. 117 of 3 July 2017;
- will specify all the human, professional, technological, instrumental and economic resources, both public and private, that can also be activated within the local community and the informal support system, aimed at implementing the project in question, setting out the cases in which it can be wholly or partly self-managed, with the obligation to report on it in accordance with criteria predefined in the project itself, and stipulating that within the framework of the project, all suitable and relevant support and interventions are identified to ensure that marginalisation conditions are overcome and that fundamental rights and freedoms are enjoyed on an equal basis with others, and that their implementation is also ensured through reasonable accommodation as defined in Article 2 of the United Nations Convention on the Rights of Persons with Disabilities;
- will require the identification of professional figures whose task will be to supervise creation of the project, monitor its implementation and ensure discussion with the person with disabilities and his or her family contact persons, without limiting the right of the person with disabilities to selfmanage the project;
- will ensure social inclusion and participation, including the exercise of the rights to affectivity and sociability, and will aim to identify supports and



services for independent living and models of self-managed personal assistance that support independent living for persons with disabilities in adulthood, facilitating their de-institutionalisation and preventing their institutionalisation.

# INSTITUTIONALISATION, SEGREGATION AND DE-INSTITUTIONALISATION

The UN Convention enshrines the right of persons with disabilities to live independently and to be included in the community.

At the same time, it enshrines their right to be free to choose where, how and with whom they live without ever being forced into a specific living arrangement.

These assumptions must be the basis for planning processes for deinstitutionalisation and institutionalisation prevention.

De-institutionalisation processes should aim at putting an end to all forms of institutionalisation, isolation and segregation of persons with disabilities, both in the private and the public domain.

An institutionalising context can be defined as a place where, for example, there is significant isolation and segregation from normal life contexts, the total absence of any forms of involvement in day-to-day decisions, the lack of opportunities for the persons concerned to choose where, how and with whom they live, the rigidity of routines regardless of personal wishes and preferences, identical activities in the same place for a group of people under a certain authority, a disproportionate number of persons with disabilities in the same environments, little or no attention to respect for the intrinsic and extrinsic dignity of persons with disabilities living in institutions.

In Italy, the law aimed at avoiding institutionalisation and promoting deinstitutionalisation paths through appropriate support measures and housing solutions that reproduce the home and family of origin, is Law no. 112/2016. However, given the extent of the phenomenon, specific and more robust legislation should be issued on the matter, allocating suitable and sufficient resources for this purpose.

### **LANGUAGE**

By "language" we mean spoken languages, sign language, Easy to Read language, as well as "non-verbal forms of expression" in general, and any other form of communication that may enable all persons with disabilities to be able, as best as possible, to exercise their right of expression and access to



information. Furthermore, the correct use of language represents one of the most important ways to counter prejudice, social stigma and discrimination against persons with disabilities and to promote the right cultural approach that respects the rights and dignity of all persons with disabilities, in compliance with the paradigms referred to in the Convention.

# NATIONAL OBSERVATORY ON THE CONDITION OF PERSONS WITH DISABILITIES

The National Observatory on the Condition of Persons with Disabilities, established in Italy by Law no. 18/09, aims to promote the full integration of persons with disabilities, in implementation of the principles enshrined in the UN Convention on the Rights of Persons with Disabilities, as well as the principles set out in Law no. 104/1992.

The Observatory has the following tasks:

- a) promote the implementation of the UN Convention on the Rights of Persons with Disabilities and prepare a detailed report on the measures taken to fulfil its obligations under the Convention and the progress achieved in this regard, in liaison with the Interministerial Committee on Human Rights;
- b) prepare a three-year action programme for the promotion of the rights and integration of persons with disabilities, implementing national and international legislation
- c) promote the collection of statistical data illustrating the condition of persons with disabilities, also with reference to different territorial situations
- d) prepare a report on the state of implementation of disability policies, with reference to data on the state of implementation of disability policies in Italy, as well as on the guidelines that will be followed
- e) promote the carrying out of studies and research that can help to identify priority areas towards which actions and interventions for the promotion of the rights of persons with disabilities are to be directed.

### **NEED FOR SUPPORT**

The Convention enshrines the right of all persons with disabilities to receive adequate support, including high or very high intensity support.

This is in order for them to be fully included in various contexts, on an equal basis with other citizens. The approach based on the need for support



replaces the previous classifications used to describe conditions of disability, i.e. mild, medium-severe, severe, very severe, dependent, etc.

An individualised, customised and participatory project must therefore aim to identify the support needed in the given situation - in terms of quality, quantity and intensity - in order to be able to pursue the best living conditions and enjoy a quality life.

The need for support is to be identified by means of evidence-based tools, always taking into account the wishes, expectations and preferences of the person concerned, also supported by those who look after the person's interests.

Supports can be both formal and informal and/or geared towards supporting decision-making processes.

Once identified through a person's life project, supports, as fundamental rights, must be made practically and fully enforceable and cannot be subjected to any limitation, not even by pointing to the lack or absence of adequate resources. More information on the Anffas Nazionale "Capacity" project is available in the "Projects and Campaigns" section of the website www.anffas.ne

### PEOPLE-FIRST LANGUAGE

People-first language tends to avoid defining a person by his or her disability. In most cases, this language places the reference to disability after a reference to the person, as in the case of "person with disabilities" rather than "the disabled person".

Not all persons with disabilities prefer this approach and, in particular, some members of the autistic and deaf communities prefer identity-first language. "Identity-first" language is based on completely opposite assumptions because it mentions the disability first, e.g. "a Down (girl)" or "an autistic (boy)".

An example of "people-first" language, on the other hand, is "a girl with Down syndrome" or "a boy with autism".

To establish the most suitable terminology, the best solution is to contact the person with disabilities or a spokesperson of an organisation representing persons with the disability in question. When this is not possible, it is recommended to use "people-first" language.

### **PERSONS WITH DISABILITIES**

The Convention recognises persons with disabilities as part of human diversity and humanity itself.



The Convention recognises that disability is an evolving concept and is the result of the interaction between people with impairments and behavioural and environmental barriers, which prevent their full and effective participation in society on an equal basis with others.

The Convention states that persons with disabilities are defined as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

### THE QUALITY OF LIFE MODEL

This model indicates people's perceptions of their place in life in relation to the cultural context and value system in which they live and with respect to their own goals, expectations, standards and interests. It is a very broad concept that encompasses, in a complex way, the physical and psychological state of health of each individual, his or her level of independence, social relationships, personal beliefs and relationship with the defining characteristics of the environment.

In the meta-model proposed by Schalock and Verdugo Alonso (2002), with all subsequent developments and additions, the quality of life perspective is broken down into 8 domains:

- 1. Physical Well-being;
- 2. Material Well-being;
- 3. Emotional Well-being;
- 4. Self-determination;
- 5. Personal Development;
- 6. Interpersonal Relations;
- 7. Social Inclusion;
- 8. Rights and Empowerment.

### REASONABLE ACCOMMODATION

Article 2 of the UN Convention defines "reasonable accommodation" as "[...] the necessary and appropriate modifications and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

Reasonable accommodation, therefore, represents a right and consists of an individualised solution to be adopted with immediate effect in the event



that rights cannot be guaranteed with the ordinary means available, with the only limitation being that the measures identified are not undue or disproportionate.

It can be applied, for example, in the school context, in the workplace, in bureaucratic and administrative procedures, and in any other context or situation where there is an objective need.

It is usually requested by the person with a disability (and/or his or her representative) from the obligated party.

The denial of reasonable accommodation represents a specific type of discrimination on the basis of disability recognised by the UN Convention. In Italy, it may also be censured pursuant to Law no. 67/06.

The obligation of reasonable accommodation is subject to the limit of undue or disproportionate burden, as defined in Article 2 of the CRPD. The CRPD Committee noted that this limit should be understood as a single concept where "undue" and "disproportionate" are equivalent qualifiers. The burden of proving the undue burden of the reasonable accommodation therefore lies with the provider. Therefore, where it is necessary to provide reasonable accommodation for the reasons described above, the obliged party will have to prove that it has done everything necessary and has come as close as possible, in the given situation, to full enjoyment of the right in question.

### **SEGREGATION**

The term "segregation" indicates a set of behaviours and actions that place the person with disabilities in a condition of unjustified restriction of his or her individual freedoms, impairment of intrinsic and extrinsic dignity, total isolation and separation from the rest of society, and limitation in the exercise of fundamental rights and freedoms.

Such behaviours are rooted in processes that dehumanise people with disabilities and fail to recognise their fundamental rights.

Despite the fact that segregating behaviour and contexts have been progressively eliminated over time, e.g. the abolition of asylums as well as special schools and segregated classes, the practice of segregation in some specific contexts still cannot be considered fully eradicated.

Segregation, in fact, can occur in any context, not only within a facility or institution, but also in a family, school, or work environment. It is often



difficult to detect or rarely highlighted because, on the one hand, there is little perception of it and, on the other, there is a tendency to keep such conditions hidden.

There is quite often a tendency to believe that persons with particular forms of disability, especially highly complex forms, only need interventions to protect their own and others' health or property and, therefore, to justify segregating and institutionalising solutions, believing them to be the only and best possible solutions in the given situation.

The topic of combating institutionalisation and segregation was addressed in intervention line 2 of the Second Biennial Action Programme for the Promotion of the Rights of Persons with Disabilities, The document can be accessed in the "Documents and Regulations" section of the Ministry of Labour and Social Policies website.

Among the specific actions to be taken, this programme indicated the need to carry out a systematic and comprehensive survey of facilities with segregating characteristics. The programme also provided indicators that make it possible to recognise existing or potential situations of isolation and segregation (including in the home).

However, this programme has not produced the expected effects to date and, therefore, the issue of combating institutionalisation and segregation, reiterated in Delegated Law no. 227/2021, will have to be addressed by more incisive and far-reaching measures than those implemented to date by the Italian legislature.

### **SELF-ADVOCACY**

Self-advocacy relates to persons with disabilities exercising their right to express and/or demonstrate and reveal, in person, their thoughts, opinions, expectations and preferences and/or to assert their rights.

It is also closely related to self-determination. Furthermore, it is a right of persons with disabilities who need to access adequate support in order to be able to exercise their right to self-advocacy. This can also be exercised through the presence of facilitators, who can provide the person with disabilities with the necessary support. Here, too, great care must be taken to ensure that no one completely replaces the person with disabilities or restricts their freedom of expression. This term indicates speaking for oneself and one's own interests.

### **SELF-DETERMINATION**

This is the right for everyone to make their own choices and decisions freely



based on their own preferences and interests.

Therefore, self-determination is a set of aptitudes, abilities and opportunities available to the person to act as the primary causal agent in his or her own life and to make choices about his or her own actions, free from undue external influence or interference. This right is often denied to people with disabilities, especially those with intellectual disabilities and neurodevelopmental disorders, due to multiple prejudices around these issues. On the other hand, it is the right of persons with disabilities - even those with high support needs - to enjoy the necessary supports in their decision-making processes, without anyone ever fully replacing them. In any case, all possible efforts must always be made to achieve the best interpretation of wishes and preferences, rather limiting oneself to merely identifying the best interest, perhaps focusing exclusively on health and safety.

#### **SIGN LANGUAGE - LIS**

Italian sign language (LIS) is a natural language conveyed through the visual-gestural channel and used in Italy by members of the deaf sign language community, who may or may not be deaf, native signers or late signers. It differs from the spoken Italian language in that it is purely and distinctly visual, with its own phonological, morphological and syntactic structure. Italian sign language is made up of eight formational parameters equally divided into manual and non-manual, each having a distinctive function: in fact, like the phonemes of a linguistic system, they make it possible to identify minimal pairs.

#### **STIGMA**

Stigmatisation is the social phenomenon that attributes a negative connotation to a member (or group) of the community. The word stigma is used as a synonym for a label, a distinguishing mark, in reference to the social disapproval of certain personal characteristics. In sociology, it is used to characterise a physical or mental "handicap" or a "deviance".

The stigmatisation of persons with disabilities is often the result of ignorance, prejudice, insensitivity and outdated cultural legacies. Even today, persons with disabilities are victims of the social stigma that tends to regard them as ill, incapable, a burden, unproductive or with fewer rights. Stigma based on the disabling condition often unconsciously permeates cultural, economic, technical and political decisions, relegating persons with disabilities to the



margins of society. Combating social stigma is one of the priorities of the entire Italian movement of associations of persons with disabilities and their families, who are engaged in processes of empowerment and promotion of mainstreaming policies to work towards affirming a correct approach and view of disability.

#### **TAKING CHARGE**

This expression indicates the process in which a service, in response to an expressed or unexpressed demand, but in any case, on the basis of an institutional mandate, plans one or more interventions aimed at a person or a cohabiting unit, maintaining an ongoing relationship with that person or unit in order to review and adapt the intervention over time.

# THE UNITED NATIONS AGENDA 2030 FOR SUSTAINABLE DEVELOPMENT

The UN Agenda 2030 for Sustainable Development is a programme of action to promote human well-being, protect the planet and global prosperity signed in September 2015 by the governments of the UN member states, who committed themselves to achieving 17 Sustainable Development Goals by 2030. All the goals are very important and must commit the entire civil society, including organisations representing persons with disabilities, in order to achieve them in full. Since they are based on respect for the human rights of all the inhabitants of the planet, persons with disabilities are beneficiaries of all the goals, for example, "zero poverty", "health and well-being", "quality education", "gender equality", "decent work and economic growth, reducing inequalities", accessible cities, collection of disaggregated data on persons with disabilities etc. More information on the UN 2030 Agenda can be found in the "Agenda 2030" section of the website unric.org

# UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The UN Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty that aims to combat discrimination and human rights violations.

The Convention is part of the protection and promotion of the rights of the person, as outlined internationally since the Universal Declaration of Human Rights of 1948, and confirms the fundamental principles regarding the rights



to equal opportunities and non-discrimination for persons with disabilities. On the whole, the Convention does not recognise "new" rights for persons with disabilities, but instead aims to ensure that they can enjoy all the rights granted to other citizens.

The Convention consists of a preamble and 50 articles and aims to promote, protect and ensure the full and equal enjoyment of all rights and freedoms by all persons, including those with disabilities. Disability is recognised as a condition linked to the existence of barriers of various kinds (physical, psychological, social) that can hinder persons with physical, mental or sensory impairments, who, according to the Convention, have the right to participate fully and effectively in society.

The Convention is followed by an Optional Protocol, consisting of 18 articles. The Convention and its Optional Protocol were ratified and made enforceable by Italy through Law No. 18 of 3 March 2009, published in the Official Gazette No. 61 of 14 March 2009.

Article 3 of this Law established the National Observatory on the Conditions of Persons with Disabilities.

#### UNIVERSAL DESIGN

According to the UN Convention on the Rights of Persons with Disabilities, universal design means the design of products, facilities, programmes and services that can be used by all persons, to the widest extent possible, without the need for adaptation or specialised design. Furthermore, "Universal design" does not exclude supportive devices for particular groups of persons with disabilities where these are necessary.

In Article 4, "General Obligations", the UN Convention also requires the commitment of States to ensure and promote the full implementation of all human rights and fundamental freedoms for all persons with disabilities, without any kind of disability-based discrimination, including through "development of universally designed goods, services, equipment and facilities [...] which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines"

The principle of universal design can be applied to any context (for instance,



an urban or residential environment devoid of physical or non-physical barriers from the outset), making it flexible and fully usable by anyone, eliminating or reducing the types of negative interaction between person and environment that lead to the condition of disability.

For a person with an intellectual disability who has to use, for example, an urban service, it could be important to have clear and simple access to information (e.g. "easy to read" language and/or AAC) and to have clear points of reference to consult in case of doubt or need.





# THE RIGHT VOCABULARY

## A

#### **ABNORMAL / ANOMALOUS**

This terminology is not acceptable as an adjective to describe a person with disabilities, not even for diagnostic purposes. In fact, a definition that emphasises profiles of abnormality as opposed to those of normality is out of line with the paradigms introduced by the Convention, since there is, among other things, no universal definition of normality. Each person, regardless of the disabling condition, is in fact different from the other. The convention affirms the principle of "respect for difference and

The convention affirms the principle of "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity itself".

Therefore, where it is strictly necessary to report certain information (for example, regarding specific character or behavioural aspects, particular manners of expression or communication, etc.), one must never implicitly or explicitly express judgements referring to conditions or profiles of normality or abnormality.

At the same time, where it is necessary to emphasise differences between people, neutral language should be used (for example, by talking about "persons with disabilities" and "persons without disabilities", "students with disabilities" and "students without disabilities", etc.).

# AFFECTED BY / AFFLICTED BY / VICTIM OF / SUFFERING FROM

One should avoid using such phrases firstly because they lead to the stigmatisation of persons with disabilities by placing the emphasis

on the "illness" and/or the suffering and whatever the person may be lacking. Over time, such definitions have contributed to the social stigma surrounding disability, generating feelings of pity or sympathy.

The Convention enshrines the fact that disability is the result of the interaction between people with impairments and behavioural and environmental barriers, which prevent their full and effective participation in society on an equal basis with others.

The convention also states that "persons with disabilities" are those with enduring "physical, intellectual, or sensory impairments" which, in interaction with barriers of various kinds, may hinder their full and effective participation in society on an equal basis with others.

Therefore, one must always use the definition of a "person with disabilities", with the main emphasis on "person" rather than the person's condition. Where one has to specify the origins of the disabling condition from a diagnostic point of view, it is recommended to use neutral language, placing the emphasis first on the person and then on the diagnosis. For example, "person with Down syndrome", "person with muscular dystrophy", "person with cerebral palsy", "person on the autistic spectrum", etc.

#### **ASYLUM**

In the past, the term "asylum" was used to refer to hospitals where people with various "mental illnesses" were admitted, often for long periods of time. Now that they have been closed, the correct terminology to use is "mental health centre" or "psychiatric hospital".

#### **AUTISTIC**

The definition of "autistic" is to be avoided. Likewise, definitions such as "neurodiverse", "neurodiversity", "neurodivergent" are to be avoided in describing the person's condition.

It is preferable to use the following definitions: "autistic person", "person on the autism spectrum disorder", "person with autism spectrum disorder". One must always emphasise, first of all, the meaning of "person" rather than his or her condition or disease.

Given the variety of definitions and taking into account the diverse sensitivities and orientations, it is in any case considered appropriate, when talking to the people concerned, to ask them directly which definition they prefer to use.



B

#### BLIND / VISUALLY HANDICAPPED / VISUALLY IMPAIRED

In the case of sensory disability related to a condition affecting the visual organs, again in keeping with the person-centred model, it is advisable to use definitions such as "person with sensory disability", or "person with visual disability".

The use of the term "blind person" is also acceptable.

On the other hand, phrases such as "a partially sighted person", "a visually handicapped person", "a visually impaired person" and "a blind person" should be avoided. It is, however, appropriate to ask the person concerned which term they prefer and to adapt to their wishes.



#### **CONFINED TO A WHEELCHAIR / WHEELCHAIR-BOUND**

The expressions "wheelchair-bound" or "confined to a wheelchair" should be avoided because these expressions convey a priori an idea of suffering through stigmatising the person by emphasising the "illness" and/or suffering, thus generating feelings of pity or sympathy towards that person and therefore damaging his/her intrinsic dignity. In fact, these expressions implicitly state that a person with disabilities suffers or has a reduced quality of life, whereas the wheelchair is actually a "facilitator". It is preferable, therefore, to describe a person as "a person with a motor disability" or "a person with disabilities who relies on the use of a wheelchair" or "a person who uses a wheelchair to get around".



## **DEAF / DEAFNESS**

In the case of sensory disability related to a condition affecting the hearing organs, again in keeping with the person-centred model, it is advisable to use definitions such as "person with sensory disability", "person with hearing disability". The use of the term "deaf person" is also acceptable. While phrases such as "hard of hearing", "a hearing impaired person" and "a deaf



person" should be avoided. It is, however, appropriate to find out how the person concerned prefers to be defined and to adapt to their wishes.

#### **DEAF-MUTE**

Italian legislation abolished this term with Law 95/2006. Therefore, this term is now to be considered outdated and obsolete. The correct definition is "deaf person".

#### **DEFORMED**

The term "deformed person" should never be used. In fact, it does not conform to the new paradigms of the approach to disability, because it emphasises "impairment" in a negative sense. In all cases, therefore, it is enough to use the definition "person with a physical disability", "person with a motor disability", etc.

#### DIFFERENTLY ABLED / DIVERSELY ABLED

The term differently abled/diversely abled became fashionable in the 1990s because it was considered a more appropriate alternative to earlier terms such as "disabled", "handicapped" or "retarded", and so on. Such terms are now completely obsolete and outdated in the light of the definition introduced by the Convention, namely "person with disabilities". The terms differently abled/diversely abled, handicapped, etc. actually tend to emphasise the "diversity" rather than the person.

#### **DISABLED**

When talking about a person, it is not appropriate to mention his or her disabling condition, unless it is relevant to describe the facts. In this case, the best choice is to use language that mentions the person first and then the disability, avoiding use of the word "disabled" as an adjective to describe the person directly. Therefore "the writer with a disability" is better than "the disabled writer". In fact, in Italian, the adjective "disabile" (disabled) connotes a generic condition of incapacity that affects the person as a whole and not just the interaction between the person's condition and the environment in which he or she lives. The expression "person with disabilities" is part of the official language of the UN Convention on the Rights of Persons with Disabilities. It has the merit of putting the person first and framing disability as a condition external to the person. Where it is necessary to use collective descriptions, consider using phrases such as "movement of persons with disabilities" instead of "movement of the disabled".



#### DYSLEXIC / DYSGRAPHIC / DYSORTHOGRAPHIC / DYSCALCULIC

When referring to a person with such difficulties, it is correct to use the phrase "person with specific learning disorders", even in the school context. Dyslexia (a specific disorder that manifests itself in difficulty in learning to read, particularly in deciphering linguistic signs, i.e. in correctness and speed of reading), dysgraphia (a specific writing disorder that manifests itself in difficulty in graphic production), dysorthography (a specific writing disorder that manifests itself in difficulty in transcoding language processes) and dyscalculia (a specific disorder that manifests itself in difficulties in the automatic calculation and processing of numbers) are part of SpLD, specific learning disorders.

Together with disability and socio-economic, linguistic and cultural disadvantage, SpLDs are part of SEN (Special Educational Needs). These disorders are classified by the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) as neurodevelopmental disorders.

# F

#### FRAIL

The term frail is very vague, as it can refer to reduced resistance to any factor. All people can be frail, but not all persons with disabilities are frail or wish to be considered as such. One should therefore avoid misusing such terminology to describe a person or a group of persons with disabilities, unless one is referring to a specific context and frailty is related to a precise risk situation. For example, various laws and regulations use the criterion of "frailty", sometimes improperly, to identify a specific group of beneficiaries. One might consider persons with disabilities who were classed as "frail" arbitrarily in relation to the post COVID-19 pandemic and the associated obligation to protect the airways.



#### **GENETIC DEFECT / GENETIC DISEASE**

Terms such as "disorder", "defect" or "disease" in their negative or derogatory sense should always be avoided when describing the person's condition. It is



recommended to use the word "condition" instead and to identify the specific diagnosis wherever possible. In any case, the emphasis should always be on the person and not on the disease and diagnosis.



#### HANDICAP / HANDICAPPED / HANDICAPPED PERSON

The terms "person with a handicap", "handicapped person" or "handicapped" should not be used, as they are completely outdated and obsolete and must be replaced by the term "person with disabilities". These terms are still present in some legislative sources and, pending their elimination/replacement, it is recommended that whenever one has to reference them (e.g. citation within a text), the term used must be place in quotes.

#### **INVALID / INCAPACITATED**

Today, these terms are still linked to the recognition of certain health, social security or welfare conditions applicable to the general public that, by law, may give rise to the granting of certain benefits, including financial benefits. Persons with disabilities can also request certification of such conditions and therefore obtain "recognition of civil invalidity", "ordinary invalidity", "incapacity", etc. Therefore, when referring to persons with disabilities, these phrases should only be used where it is necessary to highlight the existence of a condition provided for by law. Outside these cases, the word "invalid", "incapacitated" etc. should not be used as adjectives to describe the person. Always prefer the term "person with disabilities".



#### LAME / LIMPING / CRIPPLED

These terms have assumed a negative and, in some cases, offensive connotation over time. They are to be considered completely outdated and obsolete. It is recommended to use the general term "person with a motor



disability" or, if necessary, the further specific term "person with movement difficulties in the lower limbs". In all cases, one must never use adjectives such as "lame", "limping" or, worse stills, "crippled".

# M

### MAD / INSANE / MANIAC / CRAZY / LUNATIC / PSYCHOPATH / DERANGED

Terms like "mad", "insane" or "deranged" that are frequently used in informal contexts to indicate emotional or mental instability, have a negative connotation and are considered offensive. When referring to a person with a disorder in the psychic area, it is recommended not to use such terminology but to prefer the term "person with a mental disability", or to specify the type of disorder using the correct phrasing, e.g. "person with bipolar disorder" etc.

#### **MONGOLOID**

This term was in common use at the end of the 19th century to refer to persons with Down syndrome. This was due to somatic traits that were considered similar to those of East Asian populations. Hence the term "Mongoloids", which has a negative connotation. In fact, the use of the term "Mongoloid" to refer to a person with Down syndrome is considered highly derogatory. The correct definition to use is "person with Down syndrome".

#### **MUTILATED PERSON / AMPUTEE**

The terms "mutilated person" or "amputee" do not conform to the new paradigms of the approach to disability, because they place the emphasis on "impairment" in a negative sense. If referring to a person with a physical disability, if it is necessary to include specific information on the disabling condition, it is sufficient to use the definition "person with a physical disability" or "person with a motor disability".



#### **PATIENT / ILL PERSON**

Except in cases where a person with disabilities is in a healthcare or hospital setting to receive treatment or therapy, the terms "patient" or "ill person",



outside the medical context, are to be avoided. Similarly, one must generally avoid classifying a person with disabilities as "ill" or to refer to his or her condition as an "illness" simply because he or she lives in a residential facility or is receiving support through semi-residential services etc., even if they are of a distinctly medical nature.

#### PERSON WITHOUT DISABILITY

"Person without disability" is the preferred term when the context requires a comparison to be made between persons with disabilities and persons without disabilities.

# R

#### **RESIDENT / USER / PATIENT**

When these terms are used to refer to persons with disabilities who attend a residential or semi-residential service, they are to be considered completely inappropriate as they are highly depersonalising.

A person living in a residential facility, for example, should be defined as a person who "lives at ..." Similarly, a person who attends a semi-residential centre or receives health, social or socio-medical services, should be defined as a "person who receives support within the ... service" or "person who uses the ... service".

# RETARDED / MENTALLY RETARDED / MENTALLY HANDICAPPED / FEEBLE-MINDED / MENTALLY DEFICIENT/ MENTAL DEFICIENCY

The terms "mentally retarded", "mentally handicapped" and "mental retard" or "feeble-minded" were once in common use but are now considered obsolete and offensive, and therefore to be avoided, whether or not one is referring to a person with disabilities.

When referring to the type of disability, the correct definition is "person with an intellectual disability or neurodevelopmental disorder". Such types of disability also include persons with Down syndrome, persons with autism spectrum disorder, persons with specific learning disorders, etc.



# S

#### **SENILE / DEMENTIA**

The term senile should never be used, whereas the term "person with a dementia condition" may be used if a person with disabilities presents a decline in memory or other thinking skills severe enough to reduce his or her ability to carry out daily activities.

Alternatively, and in the presence of a specific diagnosis, the term "person with Alzheimer's disease", "person with Parkinson's disease", etc. may also be used.

#### SEVERE / MODERATE / MILD

Under the modern approach, these adjectives should no longer be used to describe a person's disabled status.

The phrases "person with mild - moderate - severe - very severe - not self-sufficient" place the emphasis on illness and limitations in a negative light, leading to the assumption that they are inherent in the person. These phrases should be replaced by "person with low - medium - high - very high support needs".

This, in fact, makes it possible to highlight the relationship between the person and the context in a positive perspective. It reaffirms the concept on which the biopsychosocial model and the convention are based, according to which disability is to be considered as the negative result (which can be modified with the right support) of the interaction between the person's characteristics and the context in which he/she lives, works, etc.

#### STAMMER/STUTTER

This word should be avoided. When it is necessary to describe the presence of a speech or language disorder, or to refer to a person with such a disorder, it is advisable to use the terminology "person with a language disorder" or "person with a speech disorder".

In any case, when interacting with the persons concerned, it is always advisable to ask them directly which definition they prefer.



# V

# VEGETATIVE STATE / VEGETABLE / COMATOSE / UNCONSCIOUS STATE

Referring to a person in a vegetative state as a "vegetable" is considered offensive and dehumanising. It is preferable to use precise medical terminology or, if this is not possible, terms such as "minimally conscious" or "in an unconscious state". If one opts for the term "vegetative state", use language that puts the person first in the description, such as "a person in a vegetative state".

#### **VULNERABLE**

Vulnerable persons are defined as those persons whose condition is assessed as particularly critical due to particular health frailties caused by specific illnesses. Not all persons with disabilities can therefore be defined as "vulnerable" or "particularly vulnerable" per se. Instead, for persons with disabilities, apart from health-related frailty, one must refer to the concept of the "vulnerable person", bearing in mind that what makes them vulnerable are, in reality, the treatments they have undergone over the centuries and the obstacles, barriers and discrimination they encounter in their everyday lives. Therefore, in the case of disability, the term that best describes this condition is "people made vulnerable".



# DIAGNOSTIC DEFINITIONS OF DISABILITIES

#### DIAGNOSES RELATED TO MENTAL HEALTH

"Mental illness" is a generic term that describes a range of conditions of different kinds that affect the ability to act, think, feel or perceive the world. Mental illnesses are also called mental disorders. The most common forms are anxiety disorders, mood disorders and schizophrenia disorders. Due to perceived social stigma, some people are calling for the abolition of the term "mental illness", suggesting instead "a person diagnosed with a psychiatric disorder" or "a person with a history of mental illness".

The term "person with a mental disorder" can also be preferred to the term "person with a psychosocial disability", which is used by organisations of persons with disabilities, especially at the international level. Indeed, it is important to emphasise the person in this case too and to consider the impact of stigma, since a person is not his or her disorder. However, the term "mental illness" is still frequently used in the medical and psychiatric community.

A person's mental disorder should only be mentioned when it is relevant to the description of the facts and the diagnosis comes from a qualified source. Whenever possible, specify the person's disorder rather than using the generic phrase mental illness.

Use inverted commas when officials or family members express themselves to describe a person and specify, if appropriate, that the diagnosis has not been confirmed. Avoid describing a person as mentally ill. Any source making statements about a criminal suspect's mental health history should have the authority to do so. Do not use mental health terminology to describe problems of a different nature.

#### Mental health disorders include:

#### Depression

Depression is one of the mood disorders. It should, however, only be mentioned if the information is relevant in order to describe the facts and only when there is a formal diagnosis.

#### • Bipolar disorder

Bipolar disorder is a mood disorder characterised by changes in mood, energy, behaviour and activity. Episodes are usually classified as manic, hypomanic, depressive or mixed.

Bipolar disorder often develops in late adolescence or early adulthood. It is only appropriate to mention a person's "bipolar disorder" if the information is relevant in order to describe the facts and only when there is a formal diagnosis by a qualified medical professional. Do not use "bipolar" as an adjective to describe something other than a medical condition, for example to describe something that changes suddenly or dramatically.

#### Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder is an anxiety disorder usually caused by a traumatic event that has had extremely strong emotional repercussions. The events in question may include assaults, war, sexual assault, natural disasters, road accidents or imprisonment.

Symptoms may include reliving the traumatic event, avoidance of certain behaviours, negative emotions or physical symptoms such as dizziness or nausea. It is only appropriate to mention a person's PTSD if the information is relevant in order to describe the facts and when there is a formal diagnosis by a qualified medical professional.

### Dissociative identity disorder / multiple personality disorder

Dissociative identity disorder is characterised by the emergence of two or more distinct personality states or multiple identities in a person's behaviour or consciousness. It is only appropriate to mention a person's "dissociative identity disorder" if the information is relevant in order to describe the facts and only when there is a formal diagnosis by a qualified medical professional. Use the term "dissociative identity disorder" instead of "multiple personality disorder". Use language that emphasises the person, such as "a person with dissociative identity disorder".



#### Psychosis

The term psychosis is used as generic term to describe the symptoms of certain disorders involving delusions, hallucinations or other forms of loss of contact with reality. People with psychosis are referred to as psychotic. In common usage, "psychotic" is often used as a synonym for "crazy", so it can be offensive and inaccurate. Use the words "psychotic" and "psychosis" only to accurately describe a medical condition. Avoid using the adjective "psychotic" to describe a person; instead, mention a person who "has psychotic symptoms". Avoid using the term in spoken language.

#### Schizophrenia

Schizophrenia is a chronic condition and a form of psychotic disorder, characterised by a distorted perception and interpretation of reality, which affects a person's thoughts, emotions and actions.

Frequent symptoms include visual and auditory hallucinations, delusional and disorganised thinking, lack of responsiveness, inability to take pleasure in daily life and other social problems. It does not involve the presence of separate personalities. It is only appropriate to mention a person's schizophrenia if the information is relevant in order to describe the facts and only when there is a formal diagnosis by a qualified medical professional. Use language that emphasises the person in the description, such as "a person with schizophrenia", "a person living with schizophrenia" or "diagnosed with schizophrenia", rather than "a schizophrenic" or "a schizophrenic person". Do not use the word "schizophrenic" in spoken language to indicate something inconsistent or contradictory.

#### DIAGNOSES RELATED TO THE LOCOMOTOR SYSTEM

### Muscular dystrophy (MD)

The term muscular dystrophy refers to one of more than 30 genetic conditions characterised by progressive weakening and degeneration of the muscles that control movement. It is acceptable to use expressions such as "person with muscular dystrophy", together with a brief description of what the condition entails. Avoid stating that a person "suffers from" or "is afflicted by" the disease.



#### Cerebral palsy

The term "cerebral palsy" indicates several neurological disorders that appear in infancy or early childhood and permanently impair body movement and muscle coordination.

Spastic cerebral palsy is a common type of cerebral palsy. It is acceptable to use expressions such as "person with cerebral palsy", together with a brief description of what the condition entails. It is acceptable to refer to a person saying that he or she "has spastic cerebral palsy". Avoid referring to person as a "spastic". When describing specific symptoms, the best option is to ask the person or family which terms they prefer.

#### • Infantile paralysis / poliomyelitis / polio / post-polio syndrome

Infantile paralysis was the term in common use to describe polio in the past. Symptoms include muscle weakness and paralysis. The polio vaccine was introduced by Jonas Salk in the 1950s and it drastically reduced the number of polio cases worldwide. It is preferable to say "had polio as a child" or "contracted polio as an adult" or "has post-polio syndrome" rather than "suffers from polio" or "was a victim of polio".

#### • Paraplegia / quadriplegia / tetraplegia

Paraplegia is defined as functional deficiency or motor paralysis in the lower limbs and torso. The cause is usually an injury to the spinal cord or brain. Quadriplegia is defined as paralysis of the torso and all four limbs. The term is used interchangeably with "tetraplegia". It is characterised by the loss of motor and sensory function. People with this condition are often referred to as "quadriplegics" or "paraplegics", but some consider these terms offensive. "A person with quadriplegia" is better than "a quadriplegic", as the latter term implies defining the person based on their condition. Sometimes persons with quadriplegia describe themselves as "tetra", in which case one should use inverted commas.

#### **NEURODEVELOPMENTAL DISORDERS**

### Neurodevelopmental disorders include:

#### Intellectual disability

Intellectual disability is characterised by deficits in general mental abilities,



such as reasoning, problem solving, planning, abstract thinking, the ability to make judgements, academic learning and learning from experience. These deficits involve impairment in adaptive functioning to such a degree that the individual is unable to meet standards of autonomy and social behaviour in one or more aspects of daily life, including communication, social participation, school or work activity, and autonomy at home or in the community. Developmental delay is generally diagnosed when an individual fails to meet expected developmental stages in several areas of intellectual functioning.

#### Communication disorders

Communication disorders include language disorder, phoneticphonological disorder, social communication disorder and fluency disorder. The first three are characterised by deficits in the development and use of language, speech and social communication respectively, while the last one concerns an impairment in the fluency and cadence of speech. Communication disorders occur early and can produce permanent functional impairments.

#### Autism spectrum disorders

Autism spectrum disorder is part of the broader category of neurodevelopmental disorders, which arise during the developmental phase, resulting in an impairment of personal, social, academic or workplace functioning.

The DSM-5 (Diagnostic and Statistical Manual of Mental Disorders) identifies "autism spectrum disorder" as a single diagnostic category that includes four different sub-categories, corresponding to four different ways in which the disorder manifests itself (autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified - PDD NOS and disintegrative childhood disorder).

As regards diagnosis and symptomatology, the DSM-5 notes a difficulty in the area of communication and social interaction in multiple contexts, including deficits in social reciprocity, non-verbal communication used for interpersonal interactions and a "pattern of restricted and repetitive behaviour, interests or activities".

#### • Attention-deficit/hyperactivity disorder - ADHD

ADHD is a neurodevelopmental disorder characterised by disabling



levels of inattention, disorganisation and/or hyperactivity-impulsivity. Inattention and disorganisation involve the inability to stay focused on a task, an apparent lack of listening and misplacing items, at levels inappropriate for the person's age or developmental level. Hyperactivity-impulsivity involves an excessive level of activity, agitation, inability to stay seated, intrusion into others' activities and inability to wait.

#### • Specific learning disorder

Specific learning disorder is diagnosed when specific deficits are present in an individual's ability to perceive or process information efficiently and accurately. It first appears during school years and is characterised by persistent and progressive difficulties in learning basic academic skills in the areas of reading, writing and/or arithmetic. The individual's performance in educational skills is far below average for the age. In all individuals, the specific learning disorder can result in permanent impairment of those activities that depend on the skills involved, including performance at work.

#### Movement disorders

Movement disorders include coordination development disorder, stereotyped movement disorder and tic disorders. Coordination development disorder is characterised by deficits in the acquisition and execution of coordinated motor skills. It is manifested by clumsiness and slowness or inaccuracy in the performance of motor skills that interfere with everyday life activities. Stereotyped movement disorder is diagnosed when an individual exhibits repetitive, apparently intentional and apparently purposeless motor behaviours, such as shaking one's hands, rocking, hitting one's head, biting or hitting oneself. Tic disorders, on the other hand, are characterised by the presence of motor or vocal tics, i.e. stereotyped movements or sudden, rapid and non-rhythmic vocalisations.



# Easy to read Language version



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# The right words

Using the right words means respecting the rights and dignity of people with disabilities.

# Foreword by Minister Alessandra Locatelli

In these pages, the Minister for Disabilities, Alessandra Locatelli, says that we are living in a difficult historical moment but also a very important one, because there are many possibilities and opportunities for change and that this is very important regarding the issue of inclusion.

She says that **for inclusion**, **the UN Convention on the Rights of Persons with Disabilities is very important** and that as far as **Italy** is concerned **the framework law for disabilities is very important**. As Minister for Disabilities, she has the task of implementing this law.

The Minister also writes that the **Third Sector**, i.e. the world of organisations and associations, has a great capacity for innovation, that is, for creating new things, and that while visiting many facilities throughout Italy, she saw how many services and projects these associations have implemented and **that these services and projects can be repeated**, **promoted and supported**.

She says that it is important to combine the forces of Third Sector entities, Institutions and those working in the private sector because this will make it possible to reach citizens and their needs.

For the Minister, at this time, it is important to succeed in making a cultural change that is, a change in thinking, and that this change must focus on the person.

This means that the person must not be thought of only as someone who must receive help but must also be valued and we need to invest in everybody's abilities and talents.

According to Minister Locatelli there is still a lot to be done to get full inclusion for people with disabilities, to guarantee accessibility and an autonomous, independent and participatory life without discrimination.

There are many important topic that need to be addressed with a lot of commitment: the right to education, training, work, the work between health and social services and above all the Life Project.

# The Minister is working on these issues to try to make Italian laws stronger

following the UN Convention on the Rights of Persons with Disabilities and the European Strategy on the Rights of Persons with Disabilities 2021-2030.

However, to achieve a real cultural change it is also important to **start with the words that are used** and it is important to explain why it is better to use some words instead of others when talking about disability.

The change in terminology, i.e. the words we use, is also a sign of an important change in the way disability is viewed and something that needs the contribution of all Countries and all societies.

For Minister Locatelli
this publication, which is addressed to everyone,
uses the right words
to promote, foster and grow
culture, values, knowledge and awareness
about disability, about the right way
to relate to disability
and on the rights protected
by the UN Convention on the Rights
of Persons with Disabilities

Alessandra Locatelli Minister for Disabilities

#### Introduction

A convention is a list of rules and rights.

Countries that sign it promise to respect and enforce it.

Rights are those rules that are needed to get along well with others.

The UN Convention on the Rights of Persons with Disabilities is a very important document.

It says that people with disabilities have the same rights and freedoms as everyone else.

Countries that have signed the Convention must therefore guarantee all their citizens with disabilities equal rights and equal freedoms.

Countries that have signed the Convention are called States Parties.

The UN Convention does not create new rights for people with disabilities, but says that people with disabilities have human rights like all other people and must not be discriminated against

### **Article 1 – Purpose**

Article 1 of the UN Convention on the Rights of Persons with Disabilities explains who persons with disabilities are and what we means by disability.

The UN Convention explains that persons with disabilities means those people who have impairments, i.e. disabilities, of a physical type, so, for example, they have difficulty getting around, or intellectual disabilities, so for example they need more time to learn certain things, or sensory disabilities, so for example they cannot see or hear.

The Convention explains that when people with disabilities encounter barriers in society they are faced with obstacles that do not allow them to participate in the life of society on an equal basis with other people.

It then explains that disability arises from the encounter between the characteristics of a person and the environment in which he or she lives.

### **Art. 3 – General Principles**

The principles are the most important ideas on which the Convention is based.

### These principles are:

- respect for the dignity of persons, for their autonomy and independence
- do not discriminate against people, that is, do not treat them differently just because they have a disability
- full participation of people with disabilities in the life of society
- respect for disability seen as part of the diversity of humans themselves
- equal opportunities for people with disabilities
- accessibility
- equality between men and women
- respect for children and young people with disabilities

### **Article 8 – Awareness-raising**

Article 8 of the Convention says that it is very important to to raise awareness about the rights of persons with disabilities.

Awareness means **knowing and understanding something**.

In this case, the Convention says it is important to get people to know and understand what disability is and to get them to understand that everyone has the same rights and equal opportunities.

That is why the countries that have signed the Convention must work to

- make the Convention widely known
- get people to understand what disability is
- combat all discrimination towards people with disabilities and their families.
   Discrimination means treating someone differently just because they are seen as different from others.
   For example, many people with disabilities are discriminated against because of their disability.

 to get people to understand how important the contribution of people with disabilities can be in the society in which we live, in every context, including work

To do this, the countries that have signed the Convention can perform a number of activities, such as

- providing information and training on persons with disabilities and their rights
- encouraging the media, such as radio and television to represent people with disabilities correctly, i.e. as people just like everyone else and not as people who cannot do the same things as others

# **Article 9 - Accessibility**

Article 9 talks about accessibility and explains that the UN Convention refers to accessibility as the right of people with disabilities to participate in the life of society in all its aspects and to be independent.

Accessibility means being able to use something or to enter a place without encountering obstacles.

For example, it means that someone who is in a wheelchair can enter all the places they want to visit because there are no doors that are too narrow or steps.

This means that the place is accessible.

# But accessible also means, for example, having information that is easy to read for people who have reading difficulties.

For instance, this means that a book written in an easy-to-read manner is accessible and that everyone, even people with disabilities can understand what it says.

According to the UN Convention, in fact, everything must be accessible including information and communication.

Article 9 says that countries that have signed the Convention must guarantee accessibility.

They can do this in various ways, for example

- with laws and guidelines
   to ensure the accessibility of facilities
   and services open to the public.
   Accessibility must also be guaranteed
   by private facilities
   that provide services open to the public.
- providing training activities to explain what accessibility problems are, also with the participation of people with disabilities

- making sure signs are also provided in Braille and other accessible reading formats.
   Braille is a system of writing with raised dots.
   When writing in Braille, raised dots are made, which people can feel when they run their fingers over them.
   Each shape of dots has a specific meaning.
   So when you run your fingers over the dots you can read what is written
- providing people in need
  with suitable supports and aids
  to ensure accessibility.
  A suitable aid can be, for example,
  a sign language professional,
  Sign language is used by many people who cannot hear
  to communicate and to understand what is said by others.
  Sign language is the communication that takes place
  by making signs.

In sign language, every gesture has a precise meaning

 promoting access to new technologies and to information and communication systems for people with disabilities

# **Art. 21 - Freedom of expression and opinion and access to information**

Article 21 of the UN Convention on the Rights of Persons with Disabilities says that people with disabilities have the right to express their opinions and ideas and have the right to access information.

People with disabilities have the right to request and receive information and to communicate their ideas on an equal basis with others using any means of communication that they choose from the various means available.

When it says communication, the UN Convention means

- the different languages
- the display of texts
- Braille and tactile communication.
   Braille is a system of writing with raised dots.
   When writing in Braille, raised dots are made, which people can feel when they run their fingers over them.
   Each shape made by the dots has a specific meaning.
   So when you run your fingers over the dots you can read what is written
   Tactile communication is when you communicate using objects and other materials
- large print
- accessible multimedia such as DVDs etc.
- tools for alternative, written, audio and simplified communication with the support of readers and other accessible communication systems

When it says language, the UN Convention means spoken languages and sign language and also non-verbal communication, such as languages that use gestures and movements to communicate.

To guarantee this right, the UN Convention says that countries that have signed it must:

- provide people with disabilities with accessible information also by using appropriate technology at no extra cost accept and facilitate the use, in official dealings, of sign language, Braille and any other type of accessible communication chosen by people with disabilities
- ask private facilities offering services to the public to provide accessible information including through the use of the Internet
- encourage mass media, e.g. radio, television and internet operators to make their services accessible to people with disabilities
- recognise sign language.
   Sign language is the communication that takes place by making specific signs and gestures.
   In sign language, every gesture has a precise meaning

# Article 29 Participation in political and public life

Article 29 of the UN Convention says that people with disabilities have the right to participate in political and public life on an equal basis with others, to vote or be voted for and that, in this case too, it is important to to guarantee them full accessibility.

To do this, countries that have signed the UN Convention must:

- ensure that election (voting) materials, facilities and procedures, are accessible, easily to understand and easy to use
- protect the right of people with disabilities to vote by secret ballot i.e. without letting anyone know what or whom they voted for.
   They must also protect their right to stand for election
- they must guarantee the right of people with disabilities to vote also by allowing them, if they request it, to be assisted in voting by people that the people with disabilities have chosen themselves

To guarantee the right of people with disabilities to participate in public and political life, countries that have signed the UN Convention must also promote their participation in the activities of associations and organisations involved in the public life of the country and promote the establishment of organisations of people with disabilities, and participation in these by people with disabilities themselves, to represent them at national, regional and local level.

The guidelines to protect and ensure respect for the rights and dignity of people with disabilities and to ensure that people with disabilities will be able to access information and communication on an equal basis with other people using correct language.

The guidelines are a list of rules that help people to do things all in the same way and all in the right way.

These guidelines are based on the UN Convention on the Rights of Persons with Disabilities. Their aim is to get people to use correct language when talking about disabilities and people with disabilities.

## Using correct language means respecting people with disabilities.

These guidelines also aim to enforce the right to accessible information and freedom of expression and opinion.

#### The guidelines state that:

1. it is not correct to use words such as differently abled, diversely abled, disabled, person affected by a disability, person with a handicap and other similar phrases.

In fact, the UN Convention says that instead of these words one must say **person with a disability**. The word **handicap should not be used** either. Instead, we should use the word **disability**.

If it is really necessary to use these words, they must be put between two inverted commas.

Inverted commas are these two signs " ".

We must always avoid derogatory words, i.e. words that have a negative meaning and express contempt towards the person they refer to

- 2. people with disabilities must always be able to receive information and must be able to communicate with others in the way they prefer, e.g. with Braille or sign language or easy-to-read language. If necessary, people with disabilities must always be able to have support to enable them to express their their wishes and preferences and so that they can access information
- 3. the person with a disability must always be involved when decisions are made that affect him/her, even if he/she is a minor, i.e. in Italy under the age of 18, or if he/she is represented by other persons such as a family member.
  No one should ever take the place of the person with a disability, in other words, no one should ever decide or choose in their place
- must always be guaranteed participation in public life.
  The person with disabilities must always be able to express his or her own thoughts and ideas

the person with disabilities

4.

5. one must always use appropriate and correct words when talking about disabilities and people with disabilities.

This is especially important for everyone working in the mass media, i.e. in radio, newspapers, television, etc.

6. never use phrases that contain derogatory words, i.e. words that have a negative meaning and express contempt towards the person they refer to.

If it is really necessary to use these words, they must be put between two inverted commas.

Inverted commas are these two signs "".

One must also always explain that these are not the right words and that the right words are something else

7. we must always remember that the person is not his or her illness. This means that the person with a disability is a person, not his or her disability.

8. when recounting something, you can only talk about a person's disability only if it is really necessary for the story being told.
In this case, it is important to always use correct language, with words that put the person first, such as a person with Down syndrome or a person with motor disability, that is, a person who has difficulty getting around

9. it is important to understand how the person with disability wants to be described, i.e. how the person with disability prefers to be described.

It is therefore important to understand which of his/her characteristics he/she prefers to be mentioned

**10.** avoid talking about people with disabilities as victims or heroes.

This is important to avoid feelings of n

This is important to avoid feelings of pity or other inappropriate feelings towards people with disabilities.

### **Important concepts and words**

### **Accessibility**

The UN Convention on the Rights of Persons with Disabilities says that countries that have signed the Convention must ensure that people with disabilities have full accessibility in all life situations, on an equal basis with other people.

# Accessibility means being able to use something or enter a place without encountering obstacles.

Things that prevent access in places, such as steps or doors that are too narrow, are called architectural barriers.

# But accessible also means, for example, having information that is easy to read for those with reading difficulties.

For instance, this means that a book written in an easy-to-read manner is accessible and everyone can understand what it says.

This means that transport, the environment in which we live, information and communication must all be accessible.

Countries that have signed the Convention must make all the necessary adaptations to ensure accessibility.

Since information and communication must also be accessible, those working in the field of information must also provide people with disabilities with the appropriate technologies and tools for accessible information and communication.

For example, much more use is now being made of sign language, easy-to-read language and AAC (Augmentative and Alternative Communication).

Augmentative and Alternative Communication is a type of communication that is used to help people who have difficulties in communicating or talking or have language difficulties.

Augmentative and Alternative Communication can also be referred to as AAC Alternative Augmentative Communication.

In AAC, **images and symbols** can be used.

A symbol is an image that represents an abstract concept, i.e. something that exists but cannot be touched. For example, a heart symbol can represent the concept of love. Regarding accessibility, the UN Convention also talks about reasonable accommodation.

#### **Advocacy**

# Advocacy means endorsing and supporting to a social, economic or other policy.

Advocacy, therefore, is when a person or a group of people decide to endorse and support a social, economic or other policy.

Advocacy can influence public opinion, i.e. what people think about a given topic, and can also influence public policy, i.e. the political activities of a country.

Associations empowered to act on the basis of Law number 67 of 2006

Law number 67 of 2006 is an Italian law that serves to tackle discrimination against people with disabilities.

Discrimination means that the rights of a person with a disability are not respected and that person is treated differently from others because they have a disability.

This law says that it is possible to create a register, i.e. a list, of associations and organisations that can act on behalf of people with disabilities who have been victims of discrimination.

Therefore, people with disabilities who think they have been discriminated against can ask for help from the associations included in the list to take steps to eliminate that discrimination.

If there is a particular discrimination that affects a community, i.e. many people, the associations on the list can also act on their own, without a direct request from the people who are the victims of the discrimination.

The list of associations is public, i.e. everyone can see it and consult it.

The list is updated by the Department for Policies in Favour of People with Disabilities. The Department is an office that deals with all actions and interventions that protect the rights of people with disabilities and their participation and inclusion in society.

# AAC: Alternative Augmentative Communication

### **AAC** is Alternative Augmentative Communication.

Alternative Augmentative Communication is a type of communication that is used to help people who have difficulties in communicating or talking or have language difficulties.

AAC is used with people who have difficulty communicating and with all people who need to communicate with them.

In AAC, **images and symbols** can be used. A symbol is an image that represents an abstract concept, i.e. something that exists but cannot be touched. For example, a heart symbol can represent the concept of love.

### AAC is adapted to the individual person with whom it is to be used.

Therefore, when using AAC it is important to carefully consider everything about the person with whom one wants to use AAC.

The UN Convention says that States Parties, that is, the countries that have signed the Convention must make the use of AAC available to people with disabilities to guarantee the right to have accessible information.

Barriers
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# The International Classification of Functioning, Disability and Health

is a document that describes health and disability and uses a single language to describe them.

In English, The International Classification of Functioning, Disability and Health can also be written as ICF, International Classification of Functioning, Disability and Health.

According to this document barriers are elements that exist in a person's environment and which can limit that person and create a disability.

For a person with a physical disability i.e. who has difficulty getting around, a barrier could be a step.

For a person with intellectual disabilities or neurodevelopmental disorders, a barrier could be a text that is not written in easy-to-read language and is therefore not accessible.

Disability therefore arises from the encounter between the characteristics of a person and the environment in which he or she lives.

It means that in the **environment in which one lives** there can be both material and non-material **barriers**, which create disabilities.

Braille

Braille is a writing system that enables people who cannot see, or who cannot see clearly, to read written texts.

Braille is a system of writing with raised dots. When writing in Braille, raised dots are made, which people can feel when they run their fingers over them.

Each shape made by the dots has a specific meaning. So when you run your fingers over the dots you can read what is written.

The UN Convention says that States Parties, that is, the countries that have signed the Convention, must make documents written in Braille available to people with disabilities to guarantee the right to accessible information.

#### Bio-psycho-social model

The bio-psycho-social model is a model of thinking that sees illness and health as the result of the encounter and exchange of many different factors.

It therefore sees illness and health as the result of the encounter of genetic factors, i.e. the genetic inheritance of each person, psychological factors, i.e. factors such as personality and behaviour of the person and social factors, such as factors arising from society, the family, etc.

### The bio-psycho-social model is the opposite of the biomedical model.

The biomedical model sees disease as the result of viruses or abnormal genes, i.e. genes that do not work properly, and which the doctor must therefore detect in order to correct it.

The bio-psycho-social model can be hard to understand.

To really understand what it is you can ask a person you trust for help, such as a family member, a facilitator, a practitioner or a friend.

#### Communication

The UN Convention on the Rights of Persons with Disabilities says that communication means

- languages
- display of text
- Braille and tactile communication.

  Tactile communication
  is when people communicate
  using objects and other materials
  that can be touched
- large print
- accessible multimedia.
   An example of multimedia is a DVD
- alternative communication systems, tools and formats in written or audio form, including all accessible information and communication technologies.

#### **Community**

A community is a group of people who often live in the same place and who share the same culture and laws.

People who are part of a community believe in the same things and share values and laws that in common.
Beliefs, that is, the things one believes in, values and laws are formed over time and can also change in the future.

People who are part of a community also share the same needs and make the same effort into satisfying them.

Disability Manager - Employment placement manager

Article 27 of the UN Convention on the Rights of Persons with Disabilities says that persons with disabilities have the right to have a job and be accepted in the workplace. In Italy, we have **Law number 68 of 1999** which deals with employment of people with disabilities and there are also guidelines that say workplaces must have a manager in charge of the placement of people with disabilities.

This manager must create a personalised project for the person with a disability who will be employed and must work to find a solution to the problems that the person with a disability may encounter in the workplace.

The guidelines say that in public administrations, i.e. in public offices, a training course has been established for these types of managers. In private offices, this manager is called Disability Manager, (in Italian, Manager della Disabilità).

### **Discrimination based on disability**

Article 5 of the UN Convention on the Rights of Persons with Disabilities deals with Equality and non-discrimination and says that people with disabilities must not be discriminated against, i.e. treated differently from others because of their disability.

Discrimination means that a person's rights are not respected and that person is being treated differently just because that person has a disability.

There are many types of discrimination:

#### direct discrimination

direct discrimination occurs when in a given situation a person with a disability is treated differently and less favourably than another person without a disability who is in the same situation.

Here is an example of direct discrimination: when a person with a disability is not hired to do a job just because they have a disability, then they are being discriminated against.

#### indirect discrimination

indirect discrimination occurs when, for example, there is some conduct or provision that puts people with disabilities at a disadvantage even if that conduct or that provision does not seem to contain any discrimination.

Here is an example of indirect discrimination: if a notice is written about a public service that concerns all citizens but it is not written in easy-to-read language, people with disabilities are discriminated against because they may have difficulty understanding what the notice says.

In this case there is no direct exclusion of the person with a disability, but the person is still discriminated against because they cannot read the notice and therefore cannot get the updated information like all other citizens.

#### harassment

harassment means being very annoying to someone, it means being very nasty to a person.

Harassment towards people with disabilities are all those nasty and unwanted behaviours that people with disabilities suffer just because they have a disability.

Harassment does not respect the dignity and freedom of people with disabilities and it forces them to live in a hostile environment, i.e. an environment that does not respect them and can humiliate them.

discrimination by association
 discrimination by association means
 discriminating against someone without a disability
 because they have a connection
 with a person with a disability.

Discrimination by association occurs for example, when a person without a disability is discriminated against because he/she is a friend or relative of a person with a disability.

This discrimination has been recognised in Italy and in Europe.

 multiple discrimination multiple discrimination means that a person is discriminated against for different things.

For example, women with disabilities can be discriminated against because they are women and because they have a disability.

 intersectional discrimination intersectional discrimination occurs when there are several elements together that can no longer be distinguished and that discriminate against people with disabilities.

This type of discrimination happens almost automatically. For example, women with disabilities are often subjected to forced sterilisation.

Forced sterilisation is an operation force on women with disabilities to prevent them from having children. It is called forced because women are obliged to have the operation even though they may not want to.

### systemic discrimination systemic discrimination is the result of discriminatory cultural traditions or discriminatory institutional rules.

An example of systemic discrimination is sending children with disabilities to special schools for persons with disabilities instead of including them in schools where all other children go.

To further explore the issue of tackling discrimination on the basis of disability you can read the material produced by Anffas Nazionale for the **AAA project – Antenne Antidiscriminazione Attive** on the Anffas website www.anffas.net

http://www.anffas.net/it/progetti-e-campagne/aaa-antenne-antidiscriminazione-attive/

by following this link

#### Easy-to-read

Easy-to-read

is a way of communicating information that is accessible, i.e. it allows everyone and especially people with intellectual disabilities and neurodevelopmental disorders to have access to information

and therefore be able to learn, to be able to participate in society, to know their rights and defend them, to communicate and be able to make their own choices.

### **Inclusion Europe**,

which is a European association working to enforce the rights of people with intellectual disabilities, has produced guidelines, together with other organisations, for writing texts and other materials in easy-to-read language.

For more information, go to the Inclusion Europe website You can follow this link https://www.inclusion-europe.eu/

For information on easy-to-read language you can visit the Anffas Nazionale website at www.anffas.net by following this link http://www.anffas.net/it/linguaggio-facile-da-leggere/linee-guida/

#### **Empowerment**

Empowerment means being able to achieve greater awareness and knowledge about one's rights and therefore being able to personally demand them and have them respected.

Therefore, empowerment is a kind of path for knowledge and personal growth that the person can follow.

To be able to follow this path and therefore to be aware of their rights, people with intellectual disabilities and neurodevelopmental disorders must be given the right support.

With empowerment, people with intellectual disabilities can exercise their right to self-representation either on their own or in organised self-representation groups.

Self-representation means expressing in person what one's own thoughts, ideas and preferences are and claiming, i.e. demanding to have one's rights respected.

For more information on the Anffas Nazionale project **Io Cittadino (I, the Citizen)**, you can go to www.anffas.net follow this link http://www.anffas.net/it/progetti-e-campagne/io-cittadino/

For information on **PIAM**, **Piattaforma Italiana Autorappresentanti in Movimento**you can go to www.anffas.net
you can follow this link
http://www.anffas.net/it/progetti-e-campagne/piattaformaitaliana-degli-autorappresentanti/

### **Equal opportunities and non-discrimination**

**Article 3** of the Italian Constitution states that all citizens are **equal before the law**: this means that laws are the same for everyone.

No differences are made on the basis of sex i.e. no differences are made between men and women, no differences are made on the basis of **race** i.e. based on **skin colour**, **language**, **religion**, **political ideas**, or based on being **rich** or **poor**. The Italian State must **get rid of obstacles** i.e. things that limit freedom and equality. Equal opportunities are therefore part of the Italian Constitution.

The Constitution is the most important law of the Italian State.

A constitution is a list of people's rights, duties and values. Italy has written and signed its Constitution and promises to respect and enforce it.

The UN Convention on the Rights of Persons with Disabilities also says that countries that have signed the Convention recognise the right of persons with disabilities to live in society with the same freedom of choice as other people and that they must take every measure possible to promote the full inclusion and participation of people with disabilities in society.

The Convention also recognises equality between men and women and says that women and children with disabilities are often more at risk of being victims of violence, abuse, lack of care, exploitation and neglect.

### European Strategy on the Rights of Persons with Disabilities 2021-2030

The European Strategy on the Rights of People with Disabilities 2021-2030 is a document of the European Commission.

With this document, the European Commission wants to improve the lives of people with disabilities in Europe and throughout the world.

The aim of this document is to guarantee people with disabilities

- their human rights
- equal opportunities and equal access to society
- that they can decide where, how and with whom to live
- that they can move freely within the European Union regardless of their care needs and that they will longer be victims of discrimination

More information on the European Strategy is available on the European Commission website. The page is not written in easy-to-read language.

you can follow this link https://ec.europa.eu/social/main.jsp?catId=1484&langId=it

#### **Facilitators**

The International Classification of Functioning, Disability and Health says that facilitators are elements that help people with disabilities.

For example, ramps or lifts are considered as facilitators because they make a place accessible where there are stairs or steps that stop someone with a mobility disability, i.e. difficulty getting around, from being able to enter that particular place.

The use of easy-to-read language is also a facilitator because it allows people with intellectual disabilities to have access to information.

The use of correct and appropriate language when talking about disabilities is a facilitator because it makes it possible to tackle prejudices i.e. mistaken ideas about people with disabilities.

Facilitators can also be caregivers, practitioners, family members and friends of people with disabilities because they support them in their activities in their choices and in making their decisions.

The International Classification of Functioning, Disability and Health is a document that describes health and disability uses a single language to describe them.

### **Family caregiver**

Caregiver is an English word which means to take care of.

A Caregiver, therefore, is someone who takes care of someone.

Specifically, in Italy, Law number 205 of 2017 says that a family caregiver is someone who takes care of a person with disabilities when there is a family relationship between the two persons,

i.e. between the caregiver and the person with a disability, and when the person with a disability has been recognised as having severe disability under **Law number 104 of 1992** or has been granted an assistance allowance.

Law number 104 of 1992 is the law in Italy concerning the assistance and rights of persons with disabilities.

The assistance allowance is an economic benefit, that is, money received by someone who cannot manage without a caregiver or cannot perform actions of everyday life on their own.

Freedom to express opinions and access to information

Article 21 of the UN Convention says that people with disabilities have the right to express their opinions and their ideas and have the right to access information.

People with disabilities have the right to request and receive information and to communicate their ideas on an equal basis with others using any means of communication that they choose from the various means available.

# All States Parties must guarantee and protect this right.

This means that they must implement and make available to people with disabilities all the supports and tools that they need to make information accessible.

The tools and supports must be adapted to the various and specific types of disabilities.

Article 21 concerns the whole of society but particularly concerns people working in the information sector, i.e. in newspapers, television, radio, etc.

People working in the information sector must produce accessible information with the appropriate tools, such as easy-to-read language, Braille, etc., and must also be careful about the language they use when talking about disabilities and people with disabilities.

All technologies, such as computers, etc. must also be accessible

In order to be able to express their ideas and opinions, people with disabilities must have the same equal conditions and equal opportunities as others and must be able to have fair and adequate support.

#### **Functional Profile**

The Functional Profile describes how the person relates to the context, i.e. the environment where he or she lives. How a person relates to the context can change and is linked to the person's well-being.

#### **Habilitation**

According to Article 26 of the UN Convention on the Rights of Persons with Disabilities rehabilitation and habilitation are two different concepts, i.e. they have two different meanings.

Rehabilitation means trying to make the person recover some abilities or capacities that he/she had and that he/she has lost.

Habilitation means enabling the person, i.e. working with and supporting him/her, always taking account of his/her wishes and preferences, to enable him/her to get gain skills or abilities that he/she did not have and can succeed in having.

### **Human, civil and social rights**

Human rights are rights that must be granted to every person simply because that person belongs to the human race, that is, simply because they are human beings.

This means that all people have human rights, no matter where people come from or where people are.

Civil rights are, for example, the right to freedom of thought personal freedom, religious freedoms, the right to assemble with other people, etc.

All people may exercise these rights but they must not violate the rights of others. Violating the rights of others means not respecting them.

Social rights are, for example, the right to work, to study the right to health protection, etc.

Social rights must be guaranteed and protected by the State.

# ICF - The International Classification of Functioning, Disability and Health

The International Classification of Functioning,
Disability and Health
is a document that describes health and disability
and uses a single language to describe them.

This single language aims to improve communication between practitioners working in health care, researchers, administrators and the population, including people with disabilities.

The ICF also makes it possible

- to compare data from many countries, on health services and different health sectors
- to collect and sort information from different health systems

The ICF can be used in all areas that concern health for example, also employment, education, etc.

In English, the International Classification of Functioning, Disability and Health can also be written as ICF, International Classification of Functioning, Disability and Health.

The International Classification of Functioning, Disability and Health is a document written by the WHO, the World Health Organisation. The WHO works and operates to achieve better health for everyone.

The ICF is part of a series of other very important documents produced by the WHO.

**Inclusion** 

Inclusion means
succeeding in making an environment suitable
for all people
with or without disabilities,
and living under conditions of equal opportunities.

This means an environment that must constantly evolve, i.e. change to allow everyone in that environment to live under conditions of equal opportunities and non-discrimination.

The meaning of inclusion has replaced the meaning of integration.

Integration, in fact, meant and still means that the person who was seen as different had to adapt to the existing environment.

This meant that if the person could not adapt they were excluded and isolated from other people.

### This meant **having an environment that discriminated**.

# All contexts, that is, environments, should change and be inclusive.

For example, we say that a school is inclusive when the whole context of the school changes and adapts to allow students with disabilities to exercise their right to education and instruction on an equal basis with other students.

### **Individual project**

The individual project is a very important document for people with disabilities and for their right to freedom of choice because the life project lists all the wishes, needs, ideas and thoughts of the person.

The individual project is provided for in Article 14 of Law number 328 of 2000 and is also mentioned in a more recent law, Law number 227 of 2021.

The new indications say that individual, personalised and participatory projects

 are created out by a working group called the multidimensional assessment unit and that they must look at many aspects that concern the person with a disability

- ensure the participation of the person with a disability and those representing them
- identify supports and reasonable accommodations guarantee fundamental rights and freedoms, including the right to choose, without discrimination, where to live and the possibility of care at home
- are aimed at achieving the goals
   of the person with disabilities
   according to his or her wishes, expectations and choices,
   and improve the personal and health conditions
   of the person with disabilities
   and quality of life in various contexts
- identify the barriers and facilitators
   that influence the various contexts of life,
   in accordance with
   the UN Convention on the Rights
   of Persons with Disabilities,
   and indicate the tools, resources, services
   and reasonable accommodations
   that are to be used to implement the individual project
   and which enable the participation
   of persons with disabilities
   in the various contexts of life,
   including the contexts of school
   work, sport and culture

ensure reasonable accommodations
 that seek to understand the wishes
 of the person concerned
 and the supports that can be provided
 to guarantee the person with disabilities,
 even if he/she is under a legal protection measure
 or if he/she needs very strong supports,
 that he or she will have full participation
 in implementing the individual,
 personalised and participatory life project.
 A legal protection measure is, for example,
 a support administrator.

The support administrator is a person who is appointed by a judge and who helps people with disabilities when they are in difficulty or when they have to make important decisions

indicate that the project itself must be implemented even if the context of life and locality of the person with disabilities changes and also ensures the involvement of Third Sector entities in the project if requested by the person with disabilities or the person representing him/her.
 A Third Sector entity is, for example, an association like Anffas Nazionale.

- indicate the resources and the professionals,
   i.e. people who are experts in that field and on that subject,
   that may be involved to implement the project
   and says that it is necessary to identify all the supports
   and actions that can help
   to overcome the isolation of the person
   and to guarantee fundamental rights and freedoms
   and that these must also be guaranteed using
   the reasonable accommodations as specified by the
   UN Convention on the Rights of Persons with Disabilities
- indicate that experts in the field must be found who must be given the task of implementing the project, monitor the implementation of the project, and ensuring discussion with the person with disabilities and his or her contacts and family members. They also indicate that it must always be considered that the person with disabilities may be able to manage the project independently
- ensure inclusion and participation in society, and identifies the types of support and services needed to enable independent living and to counter the institutionalisation of the person with disabilities.

## Institutionalisation, segregation and de-institutionalisation

The UN Convention on the Rights of Persons with Disabilities says that people with disabilities have the right to live independently and to be included in society.

It also says that people with disabilities have the right to decide where and with whom they live and they should never be forced to stay in a place they do not want to be.

The right to decide where and with whom to live is the basis for achieving de-institutionalisation.

De-institutionalisation means
getting people with disabilities out
of institutions or facilities
where they risk not having personal
and private space
and of having to live with people
they do not want to.

De-institutionalisation must succeed in ending the isolation of people with disabilities and eliminate institutionalising contexts.

An institutionalising context is a place where people with disabilities cannot choose where and with whom they live, cannot decide about their lives and cannot decide about everyday things but are forced to do whatever other people say and decide.

In Italy, we have **Law number 112 of 2016** which aims to **eliminate institutionalising contexts**.

This law also wants to encourage the creation of other places where people with disabilities can live. These places should be like the family homes of the people with disabilities who have to go and live there.

Law 112 of 2016 is a very important law but this is a very important topic and a stronger law should be made that can be used get rid of institutionalising contexts.

### Language

The word language refers to spoken languages, sign language, easy-to-read language, as well as non-verbal forms of language, i.e. language in which body movements are used to communicate, and any other type of communication that can allow people with disabilities to exercise their right of expression and access to information.

The correct use of language can combat prejudices i.e. mistaken ideas and discrimination towards people with disabilities and can promote a culture that respects the rights of people with disabilities.

### LIS - Sign Language

Italian Sign Language, which can also be called LIS, is a language that is communicated through vision and gestures.

This language can be used by people in the community who call themselves deaf signers and which is made up of people who are deaf or who can hear, and people who use this language from birth or who started using it later.

## National Observatory on the Condition of Persons with Disabilities

# The National Observatory on the Condition of Persons with Disabilities was established in Italy by Law number 18 of 2009

and aims to **promote the full inclusion**of people with disabilities in society,
thus respecting the UN Convention
on the Rights of Persons with Disabilities
and Law number 104 of 1992.

### The tasks of the Observatory are

- to promote the implementation of the UN Convention on the Rights of Persons with Disabilities
- to write a three-year plan of action
   i.e. valid for three years,
   for the promotion of the rights
   of persons with disabilities
   and for their inclusion
- to promote the collection of data that explain the living conditions of people with disabilities
- to write a report to say whether policies and laws concerning disability have been implemented
- to promote studies and research to understand the most urgent things to be done in order to promote the rights of persons with disabilities

### **Need for support**

The UN Convention on the Rights of Persons with Disabilities says that all persons with disabilities have the right to have the right and appropriate support. In this way, people with disabilities can be fully included in society.

Individualised, personalised and participatory project is a project that must be able to understand what types of support are needed by each person with disabilities in specific situations in order to allow them to have the best living conditions and a quality life.

To understand which types support people with disabilities need, there are tools called evidence-based tools, which must always take into account the wishes, expectations and preferences of the person concerned.

There are different types of support.
Once we understand which types of support the person with disabilities needs, including through his or her own life project, these cannot be limited and the person with disabilities must be able to use them without any limitations.

### The life project

is very important for people with disabilities and for their right to freedom of choice because in the life project all the person's desires, needs, ideas and thoughts are written down. The project also talks about the Quality of Life of the person with a disability.

For more information on this topic, you can consult the **Capacity** project of Anffas Nazionale by visiting www.anffas.net

by following this link http://www.anffas.net/it/progetti-e-campagne/capacity-la-legge-e-equale-per-tutti/

## **People-First language**

People-First is language that puts people first.

This language avoids talking or referring to the person with a disability starting with his or her disability.

With this language, the person comes first.
For example, with this language
one says the person with a disability
and not the disabled person.
Some people with disabilities,
in particular people
who are part of communities of people with autism
and communities of deaf people
prefer language based on identity.

In this case, we talk about identity-first language, i.e. one that puts identity first.

When using this language, we say a **Down person**, therefore a Down girl, or an **autistic person**, therefore an autistic boy.

In contrast, in People-First language, which puts the person first, we say a girl with Down syndrome and a boy with autism.

To find and use the most suitable words and language the best approach is to contact people with disabilities or a spokesperson of an organisation representing the people with disabilities to whom the language refers.

If this is not possible, then it is better to use People-First language.

### Persons with disabilities

The UN Convention on the Rights of Persons with Disabilities says that persons with disabilities are part of human diversity.

The Convention says that disability is constantly evolving, that is, that disability is always changing, and explains that disability arises from the encounter between the characteristics of a person and the environment in which he or she lives.

It means that in the **environment in which one lives** there may be material and non-material **barriers** that **prevent people with those characteristics from having equal opportunities and equal rights.** 

The UN Convention says that persons with disabilities means those people who have impairments, i.e. physical disabilities, so for example they have difficulty getting around, or intellectual disabilities, so for example they need more time to learn certain things, and that when people with disabilities encounter barriers in society, they are faced with obstacles that do not allow them to participate in the life of society on an equal basis with other people.

## The Quality of Life Model

This model explains how people see their life in the context where they live and in relation to their own goals their own expectations and interests.

Schalok and Verdugo Alonso are two very important scholars who have developed a model where the quality of people's lives is represented through eight domains, i.e. in eight areas.

#### These areas are:

- 1. Physical well-being
- 2. Material well-being
- 3. Emotional well-being
- 4. Self-determination
- 5. Personal Development
- 6. Interpersonal Relations
- 7. Social Inclusion
- 8. Rights and Empowerment

The Quality of Life model can be hard to understand.

To understand what it actually is, you can ask a person you trust for help, such as a family member, a facilitator, a practitioner or a friend.

### Reasonable accommodation

Article 2 of the UN Convention
on the Rights of Persons with Disabilities
explains that reasonable accommodation
means all those modifications and adaptations
that must be made to eliminate
barriers and obstacles
that prevent people with disabilities
from being able to do things just like everyone else.

Reasonable accommodation is a right of people with disabilities and people with disabilities can request it if they need it.

If reasonable accommodation is not given, there is discrimination against the person with a disability who requested it.

This is discrimination based on disability, i.e. that person is discriminated against, which means that they are treated differently and their rights are not recognised, because they have a disability.

In Italy, we have **Law number 67 of 2006** which punishes those who discriminate against people with disabilities, therefore also those who decide not to give reasonable accommodation to the person with a disability who asked for it.

If someone fails to give the person with a disability the exact reasonable accommodation that he/she asked for, they still have to give the person with a disability another type of reasonable accommodation that may suit that person with a disability.

When a reasonable accommodation is given that is different to the one requested by the person with a disability, it must be shown that everything possible has been done to give a reasonable accommodation as close as possible to the one requested. Reasonable accommodation is given when it is not possible to guarantee people with disabilities the same rights using the tools available in everyday life.

**Self-advocacy** 

Self-advocacy means expressing in person what one's own thoughts, ideas and preferences are and claiming, i.e. demanding to have one's rights respected.

Self-advocacy is a word that means **speaking for yourself** and for your own interests.

Self-advocacy is linked to self-determination.

People with disabilities have the right to have the right supports to be able to exercise self-advocacy.

For example, they have the right to have a **facilitator**.

In this case too, no one should make decisions or express themselves in the place of the person with disabilities.

### **Self-determination**

Self-determination means making one's own choices and making one' own decisions freely and based on one's own preferences and interests. Self-determination is a right.

This right is often denied to persons with disabilities, in particular, it is denied to people with intellectual disabilities and with neurodevelopmental disorders because there is still a lot of prejudice against them.

Prejudice means having a wrong idea about a person an idea that has been formed without any real reason and without knowing the person.

### People with disabilities,

even those who need a lot of help and support, have the right to have the right aids and supports to be able to make their own decisions and no one should be allowed to make decisions for them.

Every effort must be made to try to better understand and interpret their wishes and their preferences.

## **Segregation**

The word segregation refers to a set of behaviours and actions that, without any reason, deprive persons with disabilities of their freedom and their fundamental rights that isolate and separate them from the rest of society

Over time, these behaviours and actions have disappeared: for example, asylums have been closed and special classes where students with disabilities were sent have been eliminated.

Unfortunately, however, segregation can still exist today.

In fact, segregation can occur in any context, such as in a family, work or school environment.

Today it can also be difficult to understand where segregation exists. **Segregation is often hidden**.

It is also often thought, wrongly, that people with severe disabilities must be protected and that the only solution is to make them live in contexts that isolate them and which are therefore institutionalising contexts.

An institutionalising context is a place where people with disabilities cannot choose where and with whom they live cannot decide about their lives and cannot decide about everyday things but are forced to do whatever other people say and decide.

Tackling institutionalisation is an issue addressed in the Biennial Action Programme for the promotion of the rights of persons with disabilities.

This programme is a document where many important things are written for the lives of people with disabilities and to promote and protect their rights.

In the Programme, it says that all facilities that can segregate must be eliminated it also describes how to recognise a segregating facility. Unfortunately, there is still much work to be done about this issue, now also addressed by Enabling Law number 227 of 2021.

The Programme can be found on the website of the Ministry of Labour and Social Policy and is available at this link https://www.lavoro.gov.it/notizie/Documents/II-Programma-di-azione-biennale-disabilita.pdf

The Programme is a difficult document to read.

Stigma

Stigma means giving a negative meaning to a person or a group in a community because of a certain characteristic that is not accepted.

People with disabilities are often stigmatised, so they are victims of stigma, and are therefore seen as sick people, incapable people and as a burden on society.

Unfortunately, stigma around disability exists and even if one is not aware of it, it influences society and isolates people with disabilities.

The entire Italian movement of associations of people with disabilities and their families is fighting against stigma and is working to achieve this goal.

### **Taking charge**

Taking charge refers to a service that project interventions to support the person or his/her family. Taking charge interventions can be changed over time.

## **United Nations 2030 Agenda for Sustainable Development**

The UN 2030 Agenda is a very important document that explains what activities need to be done to promote the well-being of human beings and protect the planet.

The UN is the United Nations Organisation. It is a worldwide organisation whose goals include maintaining peace and security in the world.

Sustainable development means allowing society to develop in a way that manages to meet the needs and requirements of present generations, i.e. of people living now, without compromising, i.e. without damaging the capacity of future generations, that is, of the people who will exist in the future, to be able to satisfy their own needs and requirements too.

The 2030 Agenda was signed in 2015 by the countries that are members of the UN. All these countries have committed to achieving **17 goals for Sustainable Development by the year 2030.** 

In this Agenda 2030 there are therefore 17 goals that seek to eliminate hunger and poverty and to achieve human rights for everyone.

All the Goals are based on respect for the human rights of all inhabitants of the planet.

Therefore, all the Goals are important and also concern people with disabilities.

The Goals to be achieved also include ensuring quality education and reducing inequalities.

## Everyone must work to achieve these goals.

You can get more information about Agenda 2030 by visiting the UN website at this link https://unric.org/it/agenda-2030/ However, the linked page is not written in easy-to-read language.

## United Nations Convention on the Rights of Persons with Disabilities

A convention is a list of rules and rights. Countries that sign it promise to respect it and to enforce it.

Rights are the rules we need to get along well with others.
All people have rights and all people must respect the rights of others.

The UN Convention on the Rights of Persons with Disabilities is an international document that aims to combat discrimination and the violation of human rights.

The Convention does not give new rights to people with disabilities. Instead it wants to ensure that all rights recognised for all other people are also respected for persons with disabilities.

The Convention has an introduction that explains how it came into being, 50 articles, i.e. 50 points into which the text is divided, which explain what the rights of people with disabilities are, and an optional protocol, that is, a document that was added to the Convention and that the countries that signed the Convention can decide to sign or not.

The Convention lists all the rights of people with disabilities and says that these rights must be respected.

The Convention explains
that we must think about disability
in a different way,
that is, not as a disease
and it explains that disability
is the result of the encounter
between a person who has a physical
or intellectual problem
and the obstacles present in their environment
that prevent the person from participating
in the life of society as others do.

Italy has signed the Convention and this became a law in the Italian State in March 2009.
Italy also signed the Optional Protocol.

With the law of 2009, Italy also created the National Observatory on the Conditions of Persons with Disabilities.

The Observatory is a body that works to protect people with disabilities.

## **Universal design**

According to the UN Convention on the Rights of Persons with Disabilities universal design means creating services, facilities, products and programmes that can be used by everyone without the need to adapt them in any particular way. This means, for example that public transport must be usable by everyone, that computers must be accessible to everyone, that training or education courses must be accessible to everyone.

Support tools for people with disabilities, if they are necessary, are included in universal design.

Article 4 of the UN Convention says that States Parties must guarantee and promote the human rights and fundamental freedoms of all persons with disabilities, including by developing services and equipment that are universally designed. It also says that States Parties must encourage the use of universal design when laws and guidelines are written.

The concept of universal design can be used in any context and by anyone and in this way can eliminate or reduce the negative relationship between the environment and the person that causes the disability.

For a person with an intellectual disability who has to use a public service in a city, for example, it may be important to have accessible information written in easy-to-read language or AAC for that service.

## The right words

The following are some terms, i.e. words or phrases that it is better not to use when talking about disabilities and people with disabilities. It also explains which words and phrases it is better to use instead of those that are not acceptable.

These terms are put in alphabetical order, so they start with the letter A.

Sometimes, in a box next to these terms, there are other terms that may have the same meaning or can be used in their place.

#### **Letter A**

### Abnormal Anomalous

When talking about a person with a disability one should never use the words **abnormal or anomalous.** 

These words do not respect what is said by the UN Convention on the Rights of Persons with Disabilities and furthermore there is no definition of normality that applies to everyone.

All people, with or without disabilities, in fact are different from each other.

The Convention says that **we must respect diversity** and respect the acceptance of persons with disabilities because they are part of human diversity and humanity itself.

Therefore, even when you have to give specific information about people, you must never use those words.

You must use fair language, without making any judgements, i.e. comments about the people you are talking about. When talking about people with disabilities you must use correct phrases, such as people with disabilities.

Affected by Afflicted by Victim of Suffers from

When talking about a person with disabilities one should not use the phrases

- is affected by
- is afflicted by
- is a victim of
- suffers from

In fact, if one uses these phrases one focuses only on the disability and suffering **without looking at the person**.

These kinds of phrases only create feelings of pity towards the person with a disability, and can stigmatise people with disabilities.

Stigma means **giving a negative meaning to a person** or a group in a community because of a certain characteristic that is not accepted.

People with disabilities are often stigmatised, so they are victims of stigma, and therefore seen as sick people, incapable people and as a burden on society.

The **UN Convention** explains that persons with disabilities means those people who have impairments, that is, **disabilities**, **of a physical type**, **so**, **for example**, **they have difficulty getting around**, **or intellectual disabilities**, **so for example they need more time to learn certain things**, **or sensory disabilities**, **so for example they cannot see or hear**.

The Convention explains that when people with disabilities encounter barriers in society they are faced with obstacles that do not allow them to participate in the life of society on an equal basis with other people.

It then explains that disability arises from the encounter between the characteristics of a person and the environment in which he or she lives.

This is why one must always use the phrase person with a disability, because the person with a disability is a person, not his or her disability.

It is important to always use correct language, with words that put the person first, such as a person with Down syndrome.

### **Autistic**

One should not use the word autistic
Instead, it is better to use the words
autistic person,
person on the autism spectrum disorder
or person with autism spectrum disorder.

In this way you always put the person first and not the disability or illness.

The subject of autism is very complex and therefore, when you have to talk about people with autism it is best to **ask them directly** how they prefer to be described.

#### **Letter B**

Blind Visually handicapped Visually impaired

When talking about a sensory disability, i.e. related to the 5 senses, for example sight or hearing, it is better to use words such as person with sensory disability or person with visual impairment if referring to a person who has problems with site.

The phrase **blind person** can also be accepted.

On the other hand, phrases such as a **partially sighted**, **visually handicapped**, **visually impaired or blind** should be avoided.

In this case too, it is better to directly ask the people you are talking about how they prefer to be described.

#### **Letter C**

## Confined to a wheelchair Wheelchair-bound

One should avoid using phrases such as wheelchair-bound or confined to a wheelchair because even in this case you are conveying an idea of suffering and you are emphasising the illness or suffering. In this way, you create feelings of pity towards the person with a disability.

In fact, using these words and phrases is like saying that the person with a disability is suffering or has a lower and therefore reduced quality of life compared to other people.

Instead, for some people with disabilities a wheelchair is **a facilitator**. Facilitators are elements that support and help people with disabilities.

In this case, a wheelchair helps people who cannot walk or have difficulty getting around.

Therefore, it is better to use words and phrases such as **person with motor disability** or **person who uses a wheelchair** or **person who gets around in a wheelchair**.

**Letter D** 

Deaf Deafness

When talking about people who have a sensory disability that affects hearing it is better to use phrases such as **person with a sensory disability** or **person with a hearing disability**.

One can also say a **person who is deaf**.

One should not use words like hard of hearing, a hearing impaired person or a deaf person

In this case too, it is better to directly ask the people you are talking about how they prefer to be described.

#### **Deaf-mute**

Italian law removed this word with Law number 95 of 2006.

The correct term to use is **person who is deaf**.

### **Deformed**

The phrase **deformed person must never be used**because it emphasises **the impairment the disability, in negative terms**.

You should always use the phrase person with physical disability or person with a motor disability, etc.

## Differently abled Diversely abled

In the past, the words diversely abled and differently abled were used very often because people thought they were better words than disabled, handicapped or retarded.

Today, the words differently abled and diversely abled should not be used anymore because with the UN Convention on the Rights of Persons with Disabilities, there is a new definition of disability.

The words diversely abled, differently abled disabled, handicapped or retarded, emphasise the disability instead of focusing on the person.

#### **Disabled**

When talking about a person it is not correct to speak about his or her disability condition.

One can talk about the disability condition, if it is an important topic, to describe the facts one is talking about.

In this case, it is better to use language where the person is always put first and then his or her disability, and without using the word disabled.

For example, it is better to say the writer with a disability instead of the disabled writer.

In Italian, in fact, the word "disabile" indicates generic incapacity of the person and therefore does not mean disability as it is described in the UN Convention on the Rights of Persons with Disabilities.

Therefore, the correct phrase is **person with a disability**.

If you have to describe situations in which there are many persons with disabilities who are part of a group, you can use the phrase the movement of persons with disabilities while you should not use the phrase the movement of disabled persons.

Dyslexic Dysgraphic Dysorthographic Discalculic

**Dyslexia** is difficulty in learning to read. **Dysgraphia** is difficulty in writing.

**Dysorthography** is the difficulty in writing the spoken language.

**Dyscalculia** is a difficulty with numbers and calculations.

Dyslexia, dysgraphia, dysorthography and dyscalculia are **SpLDs**, **Specific Learning Disorders**, i.e. they are difficulties in learning certain things.

SpLDs, together with disability and social, economic, linguistic and cultural disadvantage, are part of SEN, Special Educational Needs.

When one has to talk about people who have this type of difficulty it is correct to use the phrase **person with specific learning disorders**, even as far as school is concerned.

The **DSM-5** is the Diagnostic and Statistical Manual of Mental Disorders.

It is a document that describes many disorders and says that dyslexia, dysgraphia, dysorthography and dyscalculia are neurodevelopmental disorders.

Letter F
Frail

The word frail is not a precise word.

All people can be frail but people with disabilities are not all frail or do not want to be seen as frail.

It is therefore better **not to use this word to describe a person with a disability or a group of people with disabilities**.

You can only use this word if you are talking a specific situation where frailty is linked to a risky situation.

For example, in some laws the word frail is used, sometimes incorrectly, to indicate people who will benefit from that law.

For example, many people with disabilities were referred to as frail people when laws were made for the use of protections after Covid-19.

Letter G

**Genetic defect Genetic disease** 

When describing a person's condition, one should never use the words disorder, defect or disease.

Instead, one should use the word **condition** and indicate, if possible, **the specific diagnosis**, **for example, the type of disability**.

In this case too, one must always put the emphasis on the person and not their illness or diagnosis.

Letter H

Handicap

The terms (words)
Handicap, Handicapped person, Handicapped should not be used
because they have been replaced by the term person with a disability.

Sometimes these words are still used in the texts of laws: in this case, while waiting for the words to be replaced or eliminated, it is important to put them in inverted commas.

#### **Letter I**

Insane
Sick
Maniac
Madman
Crazy
Psychopath
Deranged

# These are all words with a negative meaning and are offensive.

When talking about a person with psychiatric disorders, i.e. mood or behavioural disorders, one should not use those words. Instead, one should use the phrase person with a psychiatric disability or specify the type of disorder, for example, person with bipolar disorder.

Bipolar disorder is a mood disorder that is characterised by changes in mood energy, behaviour and activity.

## Invalid Incapacitated

Today these words are linked to **certain health conditions of citizens**.

When these conditions are recognised by the state, people who have them can get support by receiving benefits such as money.

In fact, this is called recognition of civil invalidity or recognition of incapacity.

People with disabilities can also ask to have these conditions recognised.

When these words refer to persons with disabilities, they should only be used when talking about recognition of these conditions.

If one is not talking about these conditions or their recognition,

then these words should not be used to describe persons with disabilities.

One must always use the terms **person with a disability**.

### Letter L

Lame Limping Cripple

Over time, these terms have become negative and offensive.

The phrase **person with a motor disability** should be used or if other specifications are needed, one must use **person who has difficulty moving the lower limbs, i.e. The legs and feet**.

One must avoid using words such as **lame**, limping, crippled.

**Letter M** 

**Mongoloid** 

In the past, this word was used to refer to **people with Down syndrome**.

This word was used because certain physical characteristics of people with Down syndrome, such as their eyes, were considered almost the same as those of certain East Asian populations who lived in Mongolia.

Hence the term Mongoloid.

The word Mongoloid has a negative meaning and is a sign of contempt towards people with Down syndrome.

We must use the term **person with Down syndrome**.

#### Mutilated Amputee

The words mutilated person or amputee are not acceptable because they emphasise the impairment, the disability of the person, and therefore have a negative meaning.

When talking about a person with a physical disability and specific information must also be given about his or her disability condition, the right words to use are **person with a physical disability** or **person with a motor disability**.

#### **Letter P**

#### Patient Sick person

The words sick person or patient should not be used if the person with a disability being referred to is not in a hospital or health facility or does not have to receive treatment.

In general, one should not refer to a person with a disability as sick and one should not refer to their disability condition as an illness

just because they may be living in a residential centre or because they use health-related support services.

#### Person without a disability

When one has to make a comparison between people with disabilities and people without disabilities, the phrase **person without disabilities** should be used.

#### Letter R

Resident User Patient

These words are used when referring to people with disabilities who attend residential or semi-residential centres but they are not acceptable words.

## These words are not acceptable because they do not focus on the person.

When talking about people who attend these centres one must say **person who lives at the centre**.

When speaking about a person who benefits from, i.e. uses, certain health services one should say **person who uses supports** with the service, etc.

Retarded
Mentally Retarded
Mentally Handicapped
Mentally Weak
Mentally Deficient
Mental Deficiency

These words must not be used anymore because they are offensive.

These words should not be used anymore even if you are talking about people without disabilities.

Instead, we must say people with intellectual disabilities or neurodevelopmental disorders.

People with Down syndrome, people with autism spectrum disorder and people with learning disorders are also considered as having intellectual disabilities and neurodevelopmental disorders.

#### Letter S

Senile Dementia

The word **senile should never be used**.

If you are talking about a person with memory problems, that is, who cannot remember things properly anymore, or who has other problems that affect his or her ability to think and to perform the activities of daily life, i.e. everyday activities, one can use the phrase person with a dementia condition.

When the type of dementia condition is known, one can write, for example, **person with Alzheimer's**, **person with Parkinson's disease**, **etc.** 

Serious Moderate Slight

These words should not be used anymore to describe a person's disability conditions.

In fact, phrases such as person with mild disability person with moderate disability, person with very severe disability are often used.

These phrases emphasise the disease and limitations and suggest that the illnesses and limitations are the person.

These phrases should be replaced with other phrases such as **person with low need for support,** 

person with low need for support, person with medium need for support, person with a high or very high need for support.

These phrases

put the emphasis on the person

and make it clear that the disability arises

from the encounter

between the characteristics of a person

and the environment in which he or she lives.

Stammer/stutter

#### The word stammer/stutter should not be used.

If you have to describe a problem or a speech difficulty or you have to talk about people who have speech difficulties it is better to use the phrase **person with a speech disorder**.

In this case too, when talking to people who have difficulties or language problems it is better to ask them directly how they prefer to be described.

#### **Letter V**

Vegetative state Vegetable Comatose Unconsciousness

A person who is in a vegetative state is a person who is alive but has no self-consciousness, does not interact with others and does not respond to stimuli.

Using the word **vegetable** to refer to a person who is in a vegetative state **is very offensive and derogatory**.

Other terms must be used,
i.e. other phrases or words,
such as
person in a minimally conscious state
or person in a state of unconsciousness.
If you decide that you really have to use
the term vegetative state
then you must say person in a vegetative state.

#### **Vulnerable**

Vulnerable persons are those persons who are in a very critical condition, i.e. very difficult, due to particular health fragilities caused by specific pathologies, i.e. diseases.

For this reason people with disabilities cannot always be referred to as vulnerable or particularly vulnerable.

One might possibly describe persons with disabilities as vulnerable if referring to all the treatment they have undergone over time and to all the barriers and obstacles they encounter in everyday life.

In this case, one can speak of **persons made vulnerable**.

#### **Diagnosis of disabilities**

A **diagnosis** is an explanation of a set of symptoms, i.e. signs and signals, that a person may have. Diagnosis makes it possible to recognise **a person's health condition**.

Explanations of some **diagnoses of disabilities** are provided below.

Diagnoses can be difficult to understand: to get a clear understanding of what a diagnosis means you can ask a person you trust for help, such as a family member, a facilitator, a practitioner or a friend.

#### Diagnosis related to the psychic sphere

The psychic sphere concerns the area of the psyche, i.e. **mood or behaviour disorders.** 

#### **Mental illness**

Mental illness is a generic term used to refer to a range of different conditions that can affect people's ability to act think and feel.

Mental illnesses are also called **mental disorders**.

The most common mental illnesses are **mood disorders**, **anxiety disorders and schizophrenia disorders**.

The term mental illness can be interpreted as a term that stigmatises a person.

Stigma means giving a negative meaning to a person or a group in a community because of a certain characteristic that is not accepted.

This is why many people want to **eliminate this term** and instead to use the term **person diagnosed with a psychiatric disorder** or **person with a history of mental illness**.

Instead of person with a mental disorder, one can also use the term **person with a psychosocial disability**. This term is widely used by organisations of people with disabilities, especially on an international level.

The phrase mental illness is still widely used in medical circles.

One can use this expression only if it is really necessary and only if it is important for describing the facts and if this diagnosis has been made by qualified persons.

Whenever possible, one should specify the type of disorder that the person has and not use the generic term mental illness.

One should avoid describing a person as mentally ill.

Disorders of the mental area include:

#### Depression

Depression is part of the mood disorders.

Depression is a feeling of sadness
and loss of interest in everything.

One should only talk about a person's depression if it is really necessary in order to describe the facts and only if there is a diagnosis.

#### Bipolar disorder

Bipolar disorder is a mood disorder and occurs when there are frequent changes in energy, behaviour and activity.

This disorder often develops in late adolescence or early adulthood.

One should only talk about a person's bipolar disorder if it is really necessary in order to describe the facts and only if there is a diagnosis made by a qualified doctor.

One should not use the word bipolar to describe something other than the actual the disorder, e.g. just to describe something that changes suddenly.

#### Post-traumatic stress disorder

Post-traumatic stress disorder is an anxiety disorder that is usually caused by a traumatic event that the person experienced, i.e. a very bad event that has happened to them.

These events can be assaults, wars, violence, car accidents, etc.

Symptoms, i.e. signs, may include the feeling of experiencing that traumatic event again, the desire to avoid certain behaviours or other physical feelings such as nausea.

One must only talk about post-traumatic stress disorder of a person if it is really necessary in order to describe the facts and only if there is a diagnosis made by a qualified doctor.

#### Dissociative identity disorder and multiple personality disorder

Dissociative identity disorder or multiple personality disorder is a disorder that occurs when a person has several personalities or several identities in his or her behaviour. That is, when a person behaves as if they had many different personalities and many different identities.

One must only talk about dissociative identity disorder or multiple personality disorder of a person if it is really necessary in order to describe the facts and only if there is a diagnosis.

Even in this case, one must use language that puts the person first, and therefore one must say **person with dissociative identity disorder**.

#### Psychosis

The word psychosis refers generally to certain disorders such as hallucinations, delirium or a loss of contact with reality.

People with psychosis are called **psychotic**. However, in everyday language the word psychotic is often used to mean **crazy**.

For this reason, the word psychotic can be offensive and incorrect.

One should avoid using the word psychotic to describe a person.

One can use the term person who has psychotic symptoms.

#### • Schizophrenia

Schizophrenia is a disorder that causes the person who has it to stop recognising reality properly and that influences their thoughts, emotions and actions.

The symptoms, i.e. signs, of schizophrenia that are most often experienced are hallucinations, disorganised thoughts, not being able to be happy in everyday life, etc.

One should only talk about a person's schizophrenia if it is really necessary in order to describe the facts and only if there is a definite diagnosis made by a qualified doctor.

Even in this case, one must use language that **puts the person first**, and therefore one must say **person with schizophrenia**, or **person who has been diagnosed with schizophrenia**.

# One should not use terms such as schizophrenic or schizophrenic person.

When speaking, one should not use the word schizophrenic to describe something that contradicts itself, that is, something that indicates first one thing and then its opposite.

#### Diagnosis of the locomotor apparatus.

The locomotor apparatus means the skeleton, muscles, etc.
The locomotor apparatus enables people to move.

#### Muscular Dystrophy

When we speak about Muscular Dystrophy we mean a progressive i.e. increasingly stronger, weakening of the muscles that control people's movements.

To talk about Muscular Dystrophy one can use terms such as a **person with muscular dystrophy**.

One should avoid using phrases such as a person suffering from muscular dystrophy or a person afflicted with muscular dystrophy.

#### Cerebral palsy

Cerebral palsy is a term that indicates neurological disorders, i.e. disorders affecting the brain.

These disorders appear first in early childhood or in infants and are disorders that permanently damage (i.e. damage forever) the movement of the body and the coordination of muscles.

One can use terms such as
a person with spastic cerebral palsy,
also describing what it means,
i.e. the type of disorder,
and one can also say
a person who has spastic cerebral palsy.
The term spastic person should not be used.
In this case too,
it is better to ask
the person you are talking about
or their families directly
how they prefer to be described.

Infantile paralysis
 Poliomyelitis
 Polio
 Post-polio syndrome

In the past, the term infantile paralysis was used to refer to poliomyelitis. Polio is a serious disease that causes paralysis of the person's muscles.

The polio vaccine was created in the 1950s and since it arrived there have been fewer cases of polio worldwide.

When talking about this issue, instead of saying he/she suffers from polio or is a polio victim, one must say he/she had polio as a child or got polio as an adult or has post-polio syndrome.

# Paraplegia Quadriplegia Tetraplegia

Paraplegia is paralysis of the upper body and legs. It means that the person is unable to move their upper body and legs.

Paraplegia is usually caused by an injury, i.e. damage to the brain or spinal cord.

The spinal cord connects the brain with the rest of the body.

Quadriplegia is paralysis of the torso, legs and arms. It means that the person is unable to move their torso, legs and arms.

The term tetraplegia can also be used.

When there is quadriplegia, there is usually no more movement or feeling of the limbs, i.e. of the legs and arms.

People who have this condition are often called **quadriplegics** or **paraplegics** but some people think that these are offensive words. It is therefore better to say person with quadriplegia or person with paraplegia.

#### **Neurodevelopmental disorders**

Neurodevelopmental disorders include:

#### • Intellectual disability

Intellectual disability is characterised by difficulties in reasoning, in thinking, in learning the things they teach in school, etc. These difficulties do not allow people who have them to be autonomous or to know what to do in certain areas of daily life.

When a person fails to reach the expected stages of his or her intellectual development then a diagnosis of intellectual disability may be made.

#### Communication disorders

Communication disorders are language difficulties, difficulties in speaking fluently, i.e. without interruptions or problems, difficulties in pronouncing letters or words properly, etc.

These disorders can be recognised early and can create permanent damage, i.e. damage that lasts forever.

#### • Autism spectrum disorders

Autism spectrum disorder causes difficulties in personal, social, school and work relationships.

The DSM-5 says that autism spectrum disorder also includes other types of autism spectrum disorder, such as Asperger's syndrome, etc.

The DSM-5 says that the signs of autism spectrum are difficulty in communication, difficulty in relationships with others, certain behaviours, interests and activities that are always repetitive.

The DSM-5 is the Diagnostic and Statistical Manual of Mental Disorders.

It is a document that describes many disorders including Autism Spectrum Disorder.

## Attention Deficit Hyperactivity Disorder - ADHD

ADHD is the acronym for **attention deficit hyperactivity disorder**.

This disorder is characterised by inattention, disorganisation and hyperactivity.

Inattention and disorganisation are the lack of attention and lack of organisation.

Hyperactivity means never being able to sit still and wait and it means always wanting to move, run, etc.

When there is inattention and disorganisation, the person cannot keep their attention on a task and it seems as though they are not listening to other people.

#### Specific learning disorder

Specific learning disorder is diagnosed when the person has difficulties in understanding and processing information.

These difficulties start to appear during the school years, when the person has difficulty, for example learning to read, write or do calculations.

#### Movement disorders

Movement disorders are difficulties in movement coordination, stereotyped movements, i.e. movements that are repeated continuously for no reason, and movements such as tics.

Tics are very fast movements that are involuntary, i.e. that the person makes automatically.

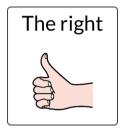
Difficulties in movement coordination occur when one is unable to make certain movements or are they are learned very slowly, and this can cause difficulties in everyday life.

#### To download this content

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# Alternative Augmentative Communication (AAC) version





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The Minister







Alessandra Locatelli



says that



the United Nations



Convention



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with disabilities

































































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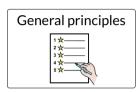










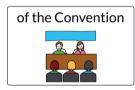








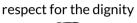














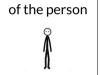




non-



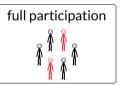






allow









in society



9





































































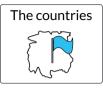










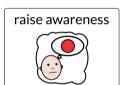


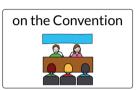
















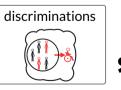




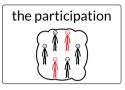


















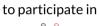


















without

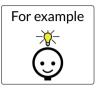


having to face



obstacles and barriers











































of expression



and opinion



and access



to information



Article



21

explains



that persons



with disabilities



have



the right



to express



their opinions



and ideas



and have



the right



to access



information



























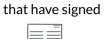






#### the countries







### the Convention



must









using











#### sign language







# and all forms









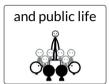














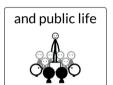






















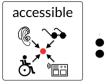


















































































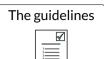
































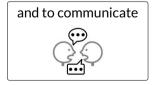




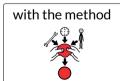
























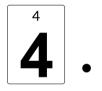
























































































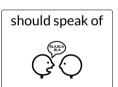
















































































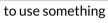














or enter a place



without



having to face



obstacles



and it means



and having



easy-to-read



information



























































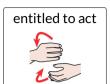
social

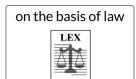


or other









number 67



number 67





















































## Augmentative and Alternative Communication

































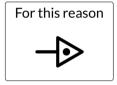






























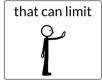


























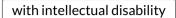














a barrier



might be



a text



which is difficult



to understand



because



it is not



written



in easy-to-read



language



The disability



arises



when



in

the environment



there are



visible



or invisible



barriers



that create



disability





























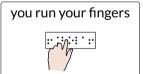


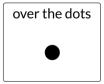




To be able to read



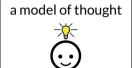
































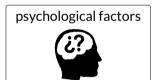




















speaking a language









































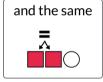






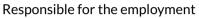












































The person









































to read



and understand



It is



a method



of communication



for accessible



information



that allows



everyone



and persons



with intellectual disabilities













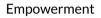


















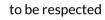
your



rights

and ask for them











with intellectual disabilities









to understand

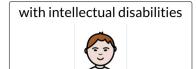


their rights









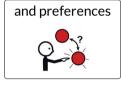












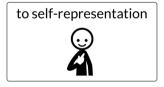
















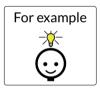




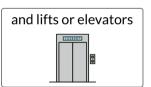




































because it allows









to have access





facilitators









and family members



of the person

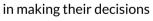




because they support























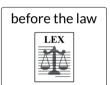










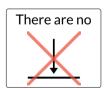




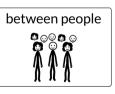
















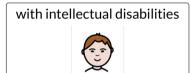






























on the Rights



with Disabilities





































,









the ability









free





































and access



to information











says that

















and have























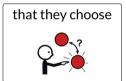














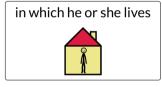














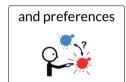






























































no matter where they come from











the right to





of thought

to personal





to freedom

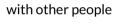


of religion



to associate











and to study



the right







ICF

**ICF** 







explaining



the correct



language to use









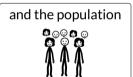


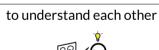


























means



making



an environment



suitable



for all



people

with disability

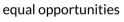


or without disability



and offering



















change



to allow



the person



with a disability



to participate



















































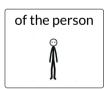








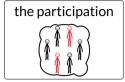












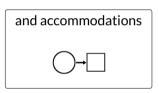
















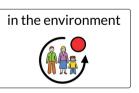








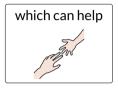




































































































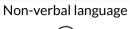




and non-verbal language



•







a language





body movements



and any other type





that can allow









to express themselves



and to understand











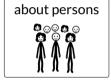














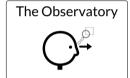










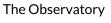














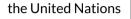






to promote









to develop



a three-







for the promotion



of the rights







to collect







and information



on the condition





















The United Nations







says



that persons







have



the right



to receive



support



In this way







with disabilities



can be fully





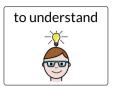


## in society





















































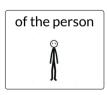






















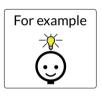






















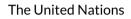


















says



that disability







the characteristics





meet



the barriers



of the environment







### in the environment



# there are



#### barriers



#### that do not allow







#### with disability



#### to have



equal opportunities



and equal rights

















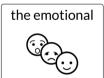


















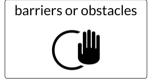






























of actions



that deprive





with disabilities

of their freedoms





isolating







with a disability



from the rest of society























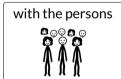


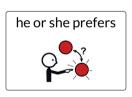














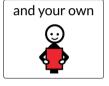
























your



thoughts



ideas



and preferences





No one



should



make decisions



in place



of the person



with a disability









making your own choices



freely



and based on your preferences



and interests



Self-determination





a right





with disabilities







the right



to get



help



to make their own decisions













and gestures



for communication





Some



from the deaf community



use sign language







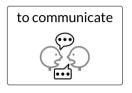




















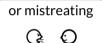


of a group or community











persons



The associations











want







stigma

















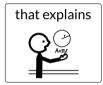


































have made the committment













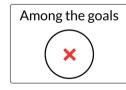














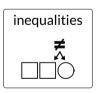




























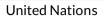
















on the Rights





with Disability



The Convention









the rights

of persons









The Convention













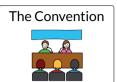


these





265







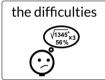
























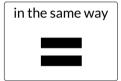












































that everybody











































an explanation

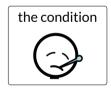




























































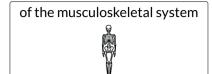


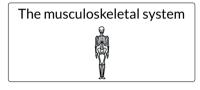


















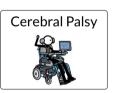


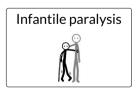




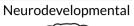
















They are



Intellectual disability



## Communication



disorders



Movement



disorders



Autism Spectrum



disorders





## **Attention Deficity**



Hyperactivity



disorder



## Specific learning



disorders



