

# **DISABILITIES AND THE INDIVIDUAL**

## **By Angela De Giorgio Domenico Massano**

### **Focus on Facts.**

#### *UN Convention and action programme*

The fourth “National Conference on Disability Policies” - organized by the Ministry for Labour and Social Policies, together with the Municipality of Bologna - took place on 12 and 13 July 2013, four years after the previous one, organized in Turin in 2009. The conference provided a forum for dialogue between institutions, individuals and associations, as well as being the occasion for the presentation of the “Action Programme for the Promotion of Rights and Integration of Persons with Disabilities”. The Programme had already been approved in February 2013 by the National Observatory on the Condition of Persons with Disabilities, was then adopted by the Council of Ministers in September, and, following the relevant Decree of implementation issued on 4 October by the President of the Republic, it was published on the Italian Official Journal on 28 December.

The Programme highlights the interventions and measures to be adopted in the next two years to promote the rights and integration of persons with disabilities; said interventions and measures are divided into seven different fields of action: review of the system for recognizing and certifying disabilities; employment; independent life and social inclusion; accessibility and mobility; education and school inclusion; health, right to life, empowerment and rehabilitation; international cooperation.

The fundamental reference and common thread of the Programme is the UN Convention on the Rights of Persons with Disabilities, ratified by Law No. 18 of 3 March 2009. The Convention is the first

binding international instrument on disability, and is the first major treaty on human rights of the new millennium. It was signed by 158 States and ratified by 139.

In its General principles, the Convention recognizes the value of human diversity, reiterates that persons with disabilities are an integral part of society, and commits the Italian State to ensure they can fully enjoy the human rights it enshrines, so as to ensure “their full and effective participation in society on an equal basis with others”. In particular, the Convention focuses on the centrality of persons with disabilities, on their dignity and on the barriers hindering their own fulfilment in all contexts of life: “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1).

This inherent dignity - to be intended as the synthesis of freedom and equality, as rightly underlined by Stefano Rodotà - is the prerequisite and the driving force of a process in which persons with disabilities see their rights concretely recognised, “ [...] including the freedom to make one’s own choices, and independence [...]” (Article 3) and are, therefore, put in a condition to exercise said rights.

The Convention and the Action programme, therefore, trace a political-legislative path of undeniable relevance and importance, which seems to give us a general picture of progressive advancement of the inclusive perspective of our society, starting from the recognition of rights and the promotion of the opportunities for participation of persons with disabilities.

### *Suspended rights?*

Unfortunately, as is often the case, the commitments undertaken with the Action programme only have a programmatic character and “can only be funded within the limits of the relevant appropriations”, as

stated in the Programme's explanatory report presented to the Italian Council of Ministers. The risk, therefore, is that the Programme could become yet another declaration of intents and that it could have the paradoxical effect of guaranteeing the rights and dignity of persons with disabilities only if these are financially sustainable.

The risk becomes even more concrete when taking into account the crisis our economy is going through, which is especially affecting persons with disabilities and their families. According to the data collected for the "Statistics on Income and Living Conditions" (EU-SILC), processed by ISTAT and relating to the years 2004-2011, in Italy, more than 21% of the "families with disabilities" are at risk of poverty, compared to about 18% of families without members with disabilities. There seems to be a close relationship between disability and poverty, caused by a number of factors that are not always adequately taken into account. Not only are pensions and allowances often not enough to cover the human and economic costs of disability, but, at the same time, as the crisis grew, so did the obstacles and difficulties in receiving said allowances.

The relationship between poverty and disability is compounded by the difficulties relating to work integration. According to the survey "Limitations on the discharge of employment tasks in persons with disabilities" (by ISTAT, the Italian National Institute of Statistics), only 16% of persons with disabilities between 15 and 74 years of age are employed, compared to 49% of the total population. The inactivity rate almost doubles: 81.2% compared to 45.4%. The European Court of Justice denounced yet another discrimination for persons with disabilities: with Judgment C-312/11 of 4 July 2013, the Court ruled that the Republic of Italy had not implemented all the necessary measures to ensure a general framework of equal treatment in employment and occupation.

It is possible, therefore, to detect a fracture, a gap between the legislative framework, the rights and programmes that often run the risk of remaining on paper, and the actual situation that persons

with disabilities have to face. In this situation, some rights - and the relevant legislation - are blithely ignored (as is the case with Section 32 of Law 41/86 on the adoption of plans for the elimination of architectural barriers by Competent administrations, or Section 14 of Law 328/00 on the drafting of “Individual projects” by Municipalities in agreement with ASL, the Italian Local Health Authorities); in other cases, said rights are constantly under attack and, more and more often, they are made conditional upon economic evaluations that run the risk of becoming an alibi to justify non-compliance as well as, sometimes, the implementation of ostracizing and stigmatizing measures and policies.

### *INPS and false certifications of disability.*

In this regard, the case of INPS (the Italian National Institute for Social Security) is emblematic. Over the past few years there was the launch of a fight against the so-called “benefit cheats” - people feigning their disability or, rather, people swindling INPS - which resembles more and more a witch hunt. Based on the headlines on TV news and newspapers, and the figures and percentages spreading around, it seems that one of the reasons behind the current crisis is to be found in this area: this fosters doubts and general distrust, and justifies the impressive measures for prevention and control that have been progressively adopted. The latter, in fact, have gradually increased, going from 300,000 controls by INPS in the years 2009-2010 to 500,000 in the years 2011-2012 (pursuant to Article 10 of Law No. 122/10, “Reduction in spending for disability”). However, when analysing the data of the Italian Financial Police on the activities of 2012, it can be seen that only 1047 “benefit cheats” were caught: this amount only represent 0.4% of the controls carried out, and 0.04% of the total of people entitled to disability benefits - considering that, in Italy, there are 2.800.000 individuals with disabilities. The data of the Financial Police on the fight against fraud affecting the social security and welfare system in 2012 show that the 1,047 “benefit

cheats” were overtaken in number by the 3,297 “fake farmhands” and the 1,619 people feigning to be poor: they represent, therefore, less than one fifth of the total of swindlers. It is thus easy to see a disproportion between the measures adopted and the results obtained.

A further analysis needs to be carried out on another element which, otherwise, might be misleading: the data regarding the percentage of pensions revoked by INPS, which, for example, amounted to around 10% for the years 2009-2010. This percentage does not take into account the high number of appeals against INPS’ measures - 60% of which are successful - as well as the fact that said revocations are often related to a reduction in the percentage of invalidity determined by the competent committees. These revocations, therefore, involved genuinely disabled individuals, who were forced to appeal so as to re-obtain the benefits they were entitled to receive, and/or who saw their invalidity percentage reduced and were denied the right to receive said benefits. In October, the President of the National Association of Parents of Autistic Persons (*Associazione Nazionale Genitori Soggetti Autistici - ANGSA*) of La Spezia, reported that, in the previous months, three youths of his association, suffering from autistic spectrum disorders, saw their certification reviewed and their invalidity percentage lowered. One of them lost the right to his school attendance benefit, and two of them lost their right to their attendance benefits. In particular, a girl who had just turned of age, who had always been certified as 100% invalid, had her percentage invalidity lowered to 91%, and thus lost all rights to her attendance benefit. These three controls were the only ones carried out by INPS on members of the Association: as a result, its record of reduction of the invalidity percentage following these controls reached 100%, thus giving rise to bitterness and doubts - as shown by the President’s considerations: “We would have all been happy if the diagnosis of those three guys with autistic spectrum disorders had been re-written, in the light of actual, concrete, clinically proven improvements. However, we all know that this is not the case.” The media uproar caused by these events might result, among other

things, into losing sight of the additional difficulties and, sometimes, humiliations caused by these decisions.

The situation becomes even more complicated and raises many doubts when considering that, in the face of the constant and elevated percentage of appeals granted against INPS' decisions (in 2011, on a total of 349,595 proceedings, INPS won 40% of the appeals, thus losing 60% of them), Section 38 of Law No. 111 of 2011 amended the procedure for disputes on certified invalidity, blindness, handicaps and disability, as well as on inability pensions and invalidity benefits: the Article makes the preventative technical control mandatory, thus rendering the procedure more complex for prospective appellants. Moreover, all resulting judgments are final.

Moreover, as well underlined in the "First National Report on Invalidity and Bureaucracy" by *Cittadinanzattiva* Association, the implementation of control activities and the use of resources to address the appeals against the decisions taken (Determination No. 91/12 of the Italian Court of Auditors mentions 325,926 pending civil cases) caused a slowdown in INPS ordinary activities: according to the 2012 Report by the Italian Court of Auditors, the timing for verifying disability has increased, rising from 120 to 278 days, and to 325 for blindness and 344 for deafness.

The fact that the procedure has become longer and more complicated, together with the alleged "benefit cheats hunt" - with the consequent stigmatization - have resulted in "human costs" for persons with disabilities. This is compounded by the economic costs caused by the intensification of control measures, amounting to €58 million for 2012. The costs for "external" doctors alone went from €3.2 million in 2008 to €25.4 million in 2011, with a 794% increase (Determination No. 91/2012 of the Italian Court of Auditors).

In the face of this situation, the 2013 Stability Law (Law No. 228 of 24 December 2012) surprisingly ordered INPS to carry out 450,000 more verifications in the years 2013-2015 (Article 1, paragraph 109).

Finally, an almost paradoxical feature of this issue should be pointed out: “benefit cheats” do not act alone. They need doctors, officers and, sometimes, politicians to support and certify their disability claims. For every unduly granted benefit there ought to be targeted measures undertaken by the State, INPS and Professional orders, aimed also at these abettors. Nevertheless, little is known about this control activity, whose results cannot be traced easily. In this sense, it is encouraging to know that, in August last year, the Financial Police reported nine politicians and seventy-four doctors and officers, who swindled the State by certifying 114 false disabilities: this is almost a one-to-one ratio, not to mention that a person feigning disability will remain one person, whereas the officers, doctors and politicians acting as abettors can potentially enable false certifications of a much higher number of people.

### *Home Care vs. Institutional Care*

The latest ISTAT Report on social inclusion of persons with limited personal autonomy shows that only one fifth of them benefit from home care. As also underlined by the data presented in 2013 by the *Cresce il welfare, cresce l'Italia* network, persons with functional limitations mostly rely on family help. It is mainly women who take on the needs relating to care and assistance, with all the attending constraints in particular as regards their participation in the labour market. This family support is also made possible by paid leaves for assisting persons with severe disabilities – even though the State is paradoxically looking with disfavour at such situations. In fact, as reported by different associations, the pensions reform of Minister Elsa Fornero (Law No. 14/12, Section 6, paragraph 2-*quater*) excluded these parental leaves for assisting relatives with severe disabilities from the calculation of pensionable service. It is clear that not enough attention is paid to the human and social costs - in addition to the economic ones - entailed by providing care and assistance to a relative with disabilities: partial or total forgoing of

work, isolation, diseases, etc. Moreover, no consideration is given to the fact that the capacities of the family network are not unlimited - if only for chronological reasons - and that the “After us” issue - often addressed via emergency measures - should be fostered and supported in advance with the help of shared projects capable of taking into account the evolution of the different situations.

Moreover, it is pertinent to note that the measures to support home care, indirect assistance and independent life courses would appear to still play a residual role compared to pre-defined interventions, which are binding and directly handled by public bodies such as, for example, institutionalisation. This is happening regardless of the considerable limitations that often affect these measures, especially as regards respect for people’s dignity and rights, and for the choices available to them. This is all the more evident if one considers the demonstrations and fights relating to these matters that are waged by many individuals and associations.

Raffaele Pennacchio, 55, died on 23 October, during one of these initiatives: he was a doctor affected by ALS, and a member of the non-profit organization “*Comitato 16 novembre*”. He died after participating, with courage and determination, in a sit-in under the Ministry of Economy and Finance, to ask for a reduction in the funding for institutional care and assistance and an increase in the funding of home care for persons with severe or very severe disabilities – so as to enable them to remain at home with dignity and to receive loving care whilst saving 50% on the costs for institutionalisation. These costs, in many cases, end up funding institutions and contexts that turn out to be the set for unjustifiable violence, as is the case of the “*I cedri*” Residence, in Liguria, for which 7 workers were arrested in January, or the case of Meta di Sorrento where, in July, episodes of segregation involving 37 persons with disabilities were reported. Following these events, the Minister of Health, Lorenzin, put in place verifications on the whole National territory, which led to the closure of a number of institutions.

As recalled by M. Foucault, already in the XVIII century - namely at the time of the French revolution - there was a heated debate between those in favour of institutional care and those in favour of home care. “If the system of home care was to prevail - with all its advantages, including that of delivering benefits to the families of the patients, of letting patients be surrounded by what is dear to them, and of consolidating natural bonds and relationships through public assistance - there would be noticeable savings: in fact, less than half of the sum necessary for attending to a patient in the paupers’ hospital would be enough to support care for a home-assisted person.”

It is clear which side prevailed, but it is just as clear that, now as then, the decision on where and when to allocate the resources is mainly one of a political/institutional nature which, however, impacts directly on the life of persons with disabilities, and in particular on their freedom and on the choices available to them (and their families).

### *School*

The ISTAT report “Integration of students with disabilities in schools”, relating to the School year 2012-2013, signals the presence of around 149,000 students with disabilities in Italy (3.2% of the total of students), around one fourth more than the previous year: this confirms the trend towards an increase in registered students, distinctive of the last decade. ISTAT also signals that, albeit with differences between the different geographical areas, less than 30% of school buildings are fully accessible, considering both internal and external passages. Special needs teachers are about 67,000, two thousand more than the previous year.

The same report - after underlining the importance of teaching continuity throughout the school year, as well as throughout the whole course of studies - indicates that 44.2% of students in primary school and 37.9% in lower secondary school no longer have the same

special needs teacher they had the previous year; moreover, for 14.5% and 12.5% of them respectively, the change occurred during the school year. Moreover, it emerges that, often, students with disabilities attend educational activities outside their classrooms, often in dedicated rooms, and that half of them do not take part in extracurricular activities.

The situation is critical and detrimental, and is made worse by the fact that many students with disabilities are not granted enough dedicated support hours and that, when this is done, it is only because of a judgment by the TAR (a Regional Administrative Court), obliging schools and the Ministry of Education to guarantee or reintroduce the necessary hours. In this regard, two judgments are especially important: one by the TAR of Latium (224/13) regarding sixty-six schools, and the other one by the Civil Court of Milan, against the Ministry of Education, following a complaint lodged by LEDHA (the Italian Association for the Rights of Persons with Disabilities) and sixteen families. In some cases, moreover, the subject of the complaint was the exclusion from the possibility of using school transportation services.

These difficulties, discriminations, penalizations, not only demonstrate that the inclusive perspective of our schools is still far from being implemented, but also that the consequences are very often borne by students with disabilities and their families, with the risk of leading to alternative pathways that were deemed outmoded.

In September 2013, some websites published the letter by a father, Claudio, which began with these words: “After four years in a normal school, we decided to register our son Giulio (affected by Down’s syndrome) in a special school... “. The decision was difficult and hard-fought, and it cast light on a situation that is often negated and/or ignored, but that still exists in Italy. In fact, in spite of the inclusive approach set forth by Law No. 517 of 1977 - which eliminated “Dedicated classes” - “special schools” keep operating pursuant to Law No. 118 of 1971, which has never been formally repealed.

A research carried out by ISTAT in 1999 indicated the presence of seventy-one “special schools”, while data relating to the year 2005/06 suggested the presence of eighty-three of them attended by 2.302 students; the website of the Ministry of Education still displays the classification lists of teachers assigned to the 22 “special schools for deaf-mute and blind people” for the school year 2011/2012. A more recent research, published in 2012 and carried out in cooperation with the Regional School Bureau of Lombardy, gives us a more detailed and articulated picture: in Lombardy, there are 24 Special schools, of which 5 are Nursery schools, 17 are Primary schools, and 2 are Secondary schools. As many as nineteen of these are State schools, hosting slightly less than a thousand students often within institutions dealing with accommodation, care and rehabilitation of persons with disabilities. They operate thanks to specific agreements between the individual institutions and the Regional School Bureau; most of them have entered agreements with the Italian National Healthcare Service. Most families have chosen these schools following a difficult experience in a “standard” school, and half of the families have been referred to these schools by teachers themselves and/or social workers.

This latter fact is especially significant: in most of the cases, “Special schools” were not the first choice but, rather, a mandatory makeshift because of the inadequacy of the school system to make room for students with disabilities. It is difficult to imagine a society that does not discriminate its citizens and promotes their participation – a truly inclusive society - if school cannot lead the way in this sense.

## **Discrimination and violence**

**18/12/2012 Lavagna (SP). Violence against persons with disabilities.**

Seven nurses were arrested for acts of violence and humiliation

on some of the persons with disabilities housed in the “I Cedri” Residence - operating under an agreement with the ASL - in Reppia, Valgaraveglia. In January, the Residence’s management changed, while in May 2013 a new chapter was added to the story, with six more people reported to the Police.

### **28/12/2012 Rome. INPS on Disability pensions.**

With Circular No. 149/2012, INPS announced that, as of 2013, the income limit for granting the invalidity pension would take into account the spouse’s income as well. The decision was suspended in January and then, in June, a provision by the Government finally clarified the situation: the income limit for those who are granted a disability pension is to be calculated on the basis of the personal income, rather than the family one.

### **03/01/2013 Busto Arsizio (VA). Sexual harassment of persons with disabilities.**

A 75-year-old man of Busto Arsizio was arrested on charges of persecuting and sexually harassing a 19-year-old person with disabilities.

### **11/01/2013 Ancona. TAR Marche on the lack of school transport.**

Final judgment No. 32/13 of the TAR of Marche, found the Municipality of Cartoceto guilty of not having guaranteed access to school transport to a student with disabilities. The Municipality was ordered to pay damages and to reimburse all costs borne by the family.

### **15/01/2013 TAR Latium on the lack of school support**

Following a group appeal lodged by several families, the TAR Latium ordered 66 schools to provide additional special needs teaching hours by its judgment No. 224/13. .

**06/03/2013 Naples. Maltreatments on persons with disabilities.**

Three institutional care centres located at viale della Resistenza, in Calvizzano (Napoli), hosting 150 persons with disabilities and elderly individuals, were seized by NAS (the Italian Department for the Prevention of Food and Beverages Adulteration). The criminal offences at issue were committed in the years 2007-2012, and range from neglect of incapable persons to maltreatment and unauthorised practice of medicine.

**09/04/2013 Barbarano (Rome). Maltreatments on persons with disabilities.**

In a *scuola media* (lower secondary school) in Barbarano, a special needs teacher and a social worker were arrested in the act (*flagrante delicto*) on charges of repeated maltreatment and battery on a 14-year-old autistic student.

The two teachers used to take the student out of the classroom to bring him to a dedicated room, where he suffered the violence, all alone.

**17/04/2013 Rome. Extortion against persons with disabilities.**

In Rome, an INPS officer was arrested on charges of extortion: some persons with disabilities were requested to pay bribes to ensure the successful outcome of the respective proceedings.

**10/05/2013 Rome. Architectural barriers.**

The *Luca Coscioni* Association supports the complaint of a woman with disabilities against *Poste Italiane*, which were found guilty of discriminatory behaviour. The Court's judgment ordered *Poste Italiane* to eliminate all architectural barriers blocking the entrance to post offices, and to pay €3,000 to the complainant as compensation for non-material damage.

**10/05/2013 Zerbolò (PV). Discrimination of students with disabilities.**

Article 9 of the rules of the new municipal nursery school of Zerbolò prevented children with disabilities from entering the building, stating that "Only those children who are self-sufficient in all their physiological functions may attend school." The Councillor and the Mayor justified this choice by affirming that they "had to protect the municipal school section, even against persons with disabilities". The discriminatory article was only cancelled after the intervention of the Prefecture.

04/06/2013 Rome. Citizenship right granted to a person with disability.

By its judgment No. 5568/2013, the TAR of Latium declared a decree by the Ministry of the Interior to be null and void on account of flawed preparatory acts. The decree had failed to grant the Italian citizenship to a mentally disabled person that had been born in Italy by non-Italian parents.

**19/06/2013 Rome. Citizenship right granted to person with disabilities.**

Thanks to the Decree on the granting of citizenship - signed by the President of the Republic - a youth with Down syndrome, Cristian

Ramos, whose mother is Colombian, may take the relevant oath, after a long battle to obtain the recognition of this right, which he had been denied because of his mental disability.

**04/07/2013 Italy sentenced by the European Court of Justice in a case concerning employment and persons with disabilities.**

The European Court of Justice, by its Judgment C-312/11, found the Republic of Italy to be in breach of EU law in relation to employment for persons with disabilities, establishing that not all the necessary measures had been taken to ensure a general framework for equal treatment in employment and working conditions.

**06/07/2013 Milan. Judgment on the reduction of funds to school support.**

On 6 July 2013, following an appeal presented by LEDHA and sixteen families with children with disabilities, an order by the First Section of the Civil Court of Milan established the discriminatory character of the conduct held by the Ministry of Education, who had reduced the number of special needs teachers compared to the requirements applying to students with disabilities.

**13/07/2013 Meta di Sorrento (NA). Maltreatment on persons with disabilities.**

In Meta di Sorrento, the NAS seized a nursing home where people suffered abuses, and were kept in inhuman conditions, with severe health and hygiene shortcomings. The accredited nursing home is worth around €2 million and in 2012 has been granted a Regional funding of around €1.5. After the seizure, the Minister of Health - Beatrice Lorenzin - initiated a series of verifications in the whole National territory.

### **30/07/2013 Milan. Maltreatment of persons with disabilities.**

Seven people were convicted by the Judge for the Preliminary Hearing of Milan, on charges of criminal association for the purposes of human trafficking and reduction to slavery - a trafficking of persons with disabilities, which were “bought” from very poor Romanian families and forced to beg on the streets.

### **06/09/2013 Casamicciola (NA). Discrimination against persons with disabilities.**

A notice posted in a nursing school in Casamicciola (near Ischia) - run by a religious body - read as follows: “Please be informed that tomorrow the school will be closed, because it is the Day dedicated to disabled persons. They are very ill and, therefore, the children get upset when seeing them. The management.” The stigmatizing and discriminatory content of the notice sparked protests, to which the nun responsible for the communication reacted by affirming: “We acted in good faith, with the idea of protecting both the children of the school and the disabled people, who visit us once a year.”

### **23/09/2013 Mugnano (NA). Parents against the presence of students with disabilities.**

In a primary school in Mugnano, after the headmistress had denied them the authorization to move their children to another class, six families out of twenty obtained the permission to move their children to other schools because of the presence of an autistic child in the class. According to the fleeing families, this was not a case of discrimination but, rather, it was due to their concerns for the possible impact on teaching caused by the presence of the autistic child. A totally different view was held by the Director of the Regional School Bureau: “School means integration, living together.”

**30/09/2013 Mileto (VV) Maltreatment of students with disabilities.**

Six teachers of a public nursing school in Mileto were committed for trial on account of maltreatment of a child with disabilities, perpetrated in 2011.

**16/10/2013 Città di Castello (PG). Mother murders her autistic son.**

In Città di Castello, a woman was arrested for having stabbed her 11-year-old autistic son, who was then hospitalized in serious condition. The episode was unanimously condemned but, at the same time, the focus was also on the isolation these families are often left in.

**01/11/2013 Turin and Palermo. Murders and suicides in families with children with disabilities.**

Two family tragedies against a background of solitude and desperation. In Turin a father stabbed his quadriplegic son, who was then hospitalized in serious conditions. In Palermo, a 58-year-old man killed his 62-year old disabled sister, who had begged him to, and then committed suicide.

**09/11/2013 Belluno. Architectural barriers.**

A Swedish tourist on a wheelchair stopped a train in Belluno by clinging to one of the handles: the train was not accessible to disabled persons. The tourist was reported to the police on a charge of causing hindrance to a public service.

## 20/11/2013 **Italy, inspections in healthcare structures.**

The results of the checks carried out in the previous months by NAS on 1,000 structures - aimed at verifying whether they had the necessary authorizations and were complying with health and hygiene requirements - led to the closure of eighteen nursing homes for persons with disabilities and elderly persons.

Moreover, 102 persons were reported to Judicial authorities and 174 to Health care authorities; 142 criminal violations and 251 administrative violations were found.

## **Legislation and policies**

### *The UN Convention*

The UN Convention on the Rights of Persons with Disabilities was concluded on 13 December 2006, was opened to ratification on 30 March 2007, entered into force on 30 May 2008, and, in Italy, it was ratified and implemented by means of Law No. 18 of 3 March 2009. The Convention represents the first binding International instrument on disabilities, and it is the first major treaty of the new millennium on human rights. The Convention is the final step of a course that began with the adoption of instruments such as the Declaration on the Rights of Mentally Retarded Persons (1971), the Declaration on the Rights of Disabled Persons (1975) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993).

The UN Convention on the Rights of Persons with Disabilities acknowledges that disability is “an evolving concept” that “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”.

Persons with disabilities, therefore, are “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 1). This is the legal-cultural framework of reference of the whole legislative system protecting persons with disabilities, and it is the first major treaty on persons with disabilities in the new millennium.

First of all, the terminological change is to be noted, given its significant relevance: the wording “persons with disabilities” focuses on the idea of being a person, in positive terms, thus overcoming the fragmented and stigmatizing terminology often used by society and by the legal system. In particular, the Convention focuses on the centrality of persons with disabilities, as well as on their dignity and the barriers hindering their full participation and realization in all contexts of life: “The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” (Article 1).

This inherent dignity of persons with disabilities is to be intended as a synthesis of freedom and equality, a prerequisite for and the driver of a process in which people see their rights concretely acknowledged and are, therefore, put in a condition to exercise them.<sup>1</sup> Recognising that the condition of disability does not depend on the subjective characteristics of individuals but, rather, on the relationship between their characteristics and the way society ensures their participation and organizes the access to and enjoyment of rights, goods and services entails a radical change of perspective, since it is now society that creates the conditions for discrimination and lack of equal opportunities that penalize persons with disabilities.

The General Principles of the Convention (Article 3), therefore, do not refer to specific conditions but, rather, they stress some universal values: respect for inherent dignity; individual autonomy, including

the freedom to make one's own choices; personal independence; non-discrimination; full and effective participation and inclusion in society; respect for diversity and acceptance of persons with disabilities as part of human diversity and humanity itself; equal opportunities; accessibility; equality between men and women; respect for the development of the capacities of children with disabilities; respect for the right of children with disabilities to preserve their identity.

The Convention represents an important result for the international community, since it is the most modern and direct international instrument on this subject, and it is binding on Signatory States. These, by ratifying the Convention, commit themselves to ensuring and protecting, in every institutional field and competence, the human rights of persons with disabilities by means of adequate policies, legislation and resources. In this sense, the concept of "reasonable accommodation" is of particular relevance: it means resorting to the necessary and appropriate modifications and adjustments without imposing a disproportionate or undue burden (with reference to the adequacy of the means in relation to the proposed objective) - where needed in a particular case - to afford persons with disabilities the enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms (Article 2).

Moreover, it is important to note how the focus is on the fact that all general policies need to take care of persons with disabilities, and have to do so by using standard resources and through an approach based on mainstreaming: this confirms the importance of defining political and economic strategies with a universal and inclusive character, by overcoming sectorial logics that are often ghettoizing and by allowing persons with disabilities to exercise and have full access to everyone's rights.

## *European Disability Strategy 2010-2020*

The European Union has dedicated the year 2003 to persons with disabilities, after having passed - the previous year - the Declaration of Madrid, representing the European cultural manifesto of persons with disabilities. This declaration marked a change of perspective, from a mainly medical-scientific point of view to one mainly social and based on rights, thus giving rise to a change in EU strategies, which were to be based on four pillars: non-discrimination, affirmative actions to ensure equal opportunities, accessibility to goods and services, involvement of the organizations of persons with disabilities in the decisions they were part of. The new “European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe” was adopted on 15 November 2010, and it indicates eight main fields of action: accessibility, participation, equality, employment, education and training, social protection, health, external action.

The strategy focuses on the elimination of barriers of different nature that hinder the effective participation and inclusion in society of persons with disabilities, and is based on the adoption of targeted EU measures to complete those adopted at National level, based on the implementation of the following legal premises:

- “Charter of Fundamental Rights of the EU”, which was signed in Nice in December 2000 and became legally binding thanks to the Treaty of Lisbon in 2009. It contains, in Article 21, an explicit reference to the prohibition of discrimination against disability, and, in Article 26, it declares the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.
- “Treaty on the Functioning of the EU (TFEU)”, which provides that the Union should combat discrimination based on disability when defining and implementing its policies and activities (Article 10), and

empowers the Union to legislate so as to combat said discrimination (Article 19).

- “United Nations Convention on the Rights of Persons with Disabilities.”

### *National legislative and policy framework*

In Italy, Law No. 104 of 5 February 1992, entitled “Framework law for the assistance, social integration and rights of handicapped persons”, is the fundamental text for reference and comparison, through coordination, not only of previous, but also of future legislation and any possible review deemed necessary by the National legal order.

More recently, Law No. 67 of 1 March 2006 - entitled “Measures for the judicial protection of persons with disabilities that are the victims of discrimination” - was meant to provide additional tools for protection by envisaging the absolute prohibition of discrimination against persons with disabilities, to encourage as much as possible their full enjoyment of civil, political, economic and social rights, thus implementing the Principle of substantive equality enshrined in Article 3 Paragraph 2 of the Italian Constitution. This same Article was referred to in full by Section 1 of law No. 67/06, as regards both formal and substantive equality, so that any action by the Administration (including inaction) that does not seek to eliminate, wherever reasonably possible, the obstacles encountered by persons with disabilities throughout their lives, is to be necessarily connected to the aforementioned notion of indirect discrimination (that is to say, when an apparently neutral provision, criterion or practice can cause particular disadvantages to a whole category of persons). Moreover, a special procedure is envisaged for the judicial protection against discriminatory actions and behaviours, and the Law in question expressly provides for the right to financial compensation for non-

pecuniary damage deriving from said forms of discrimination.<sup>2</sup>

Law No. 328 of 8 November 2000 (Framework legislation for the implementation of the integrated system of social interventions and services) was enacted in between the two aforementioned fundamental pieces of legislation. Sectorial norms, both at National and at Regional level, are grounded in this Law. Section 14 is especially important, as it describes a services model based on a project of “Global care” for persons with disabilities; this is aimed at a unitary vision of their needs and rights (by means of the so-called “Individual project”) so as to implement their full integration in family and society as well as in school, professional training and labour. As provided for by this law, upon request of the person concerned, Municipalities, together with ASL, are entitled to elaborate the Individual project: this is an actual contract between competent public bodies and the beneficiaries, and is signed by both the individuals responsible for the provision of services and the beneficiaries. Said individual project, therefore, codifies a direct relationship, without any conditional obligation, between the applicant (a person with disabilities and/or a representative) and the recipient of the application (that is to say, the Municipality where the person resides). The recipient, in turn, has to activate a complex and multipronged procedure which, when linked to Section 2 of the Prime Minister’s Decree of 14 February 2011, becomes a veritable Instrument of guidance and coordination for socio-medical integration, representing the essential element for the adoption of primary levels of protection relating to persons with disabilities.<sup>3</sup>

The State and the Regions are jointly competent to implement the individual enhancement and development policies for the full enjoyment of human rights, in compliance with the partition envisaged by the current Title V of the Italian Constitution. Moreover, the Constitutional Court has recently reiterated that the prohibition against discrimination is to be especially implemented in the fields

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2 See TAR Latium, Rome, Section II *Quarter*, 4 June 2013, *Judgment No. 5568*.

3 See TAR Calabria, Catanzaro, Section II, 12 April 2013, *Judgment No. 440*.

relating to social security, healthcare, welfare, and education. Any specific limitation on the enjoyment of the fundamental rights of the individual, or on the services aimed at giving people some “sustenance”, is in breach of the principle of non-discrimination enshrined in Article 14 of the Convention for the Protection of Human Rights and Fundamental Freedoms, and in Article 1 of the Additional protocol, as interpreted by the European Court of Human Rights.<sup>4</sup> More specifically, the Italian Constitutional Court set aside a Regional law (of a Region with special statute) for breaching the limit of reasonableness imposed by the observance of the principle of equality (Article 3 of the Constitution): that law provided that the access to the integrated Regional system of interventions and services for the promotion and protection of the rights of social citizenship was granted exclusively to EU citizens and, secondly, only to European citizens that had resided in the EU for at least thirty-six months. The Court underlined that the arbitrary elements of distinction - that is to say, based on citizenship or on a specific type of residence - contrast with the function and the legislative *ratio* of the measures forming the welfare system.<sup>5</sup> The methods for removing discrimination are set forth by appropriately reconciling the interests of the parties.<sup>6</sup> The implementation of said principles has thus allowed affording rights and economic benefits to persons with disabilities, and the lack of the relevant legislative provisions was considered as non-compliant with the Constitutional Charter because it resulted in an inadmissible obstacle to effective assistance and integration.<sup>7</sup>

Law No. 18 of 3 March 2009 (Ratification and implementation of the United Nations Convention on the Rights of Persons with Disabilities, and its Optional Protocol, signed in New York on 13 December 2006, and Establishment of the National Observatory on the Condition of Persons with disabilities), together with the

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4 See Constitutional Court, 30 July 2008, Judgment No. 306.

5 See Constitutional Court, 9 February 2011, Judgment No. 40.

6 See Constitutional Court, 4 July 2008, Judgment No. 251.

7 See Council of State, Section V, 23 July 2013, Judgment No.3954; id. 3 October 2013, Judgment No.5194.

ratification of the Convention, set up the National Observatory on the Condition of Persons with disabilities, “so as to promote full integration of persons with disabilities, in implementation of the principles enshrined in the Convention [...] as well as the principles set out in Law No. 104 of 5 February 1992” (Section 3, Paragraph 1). The Observatory is chaired by the Minister of Labour and Social Policies and has different tasks (Article 3, Paragraph 5), including: promotion of the implementation of the Convention, setting-up of a biannual action programme for fostering and developing the rights and integration of persons with disabilities, drafting of the report on the implementation status of policies on disabilities. Inter-ministerial Decree No. 167/2010, moreover, defined the Observatory as the advisory and technical and scientific support body for the development of National policies for disabilities. In November 2010, the Observatory published and delivered to the United Nations its first report on the implementation of the Convention. On 12-13 July 2013, during the “Fourth National Conference on Disability Policies”, the first “Biannual National Action Programme on Disability” was presented: this is the result of the coordinated work carried out by the Observatory and by different associations and federations of persons with disabilities, and it was adopted by means of a Presidential Decree on 4 October, and published on the Official Journal on 28 December. The Programme is the first integrated system of proposals and actions that focus on persons with disabilities and their full and effective participation in society, and it is divided into seven areas of intervention: 1) review of the system of access and recognition/certification of the condition of disability, and model of intervention for the socio-medical system; 2) work and employment; 3) policies, services, and organizational models for independent life and inclusion in society; 4) promotion and implementation of the principles of accessibility and mobility; 5) educational paths and school inclusion; 6) health, right to life, empowerment and rehabilitation; 7) international cooperation. Said actions, however, “may only be funded within the limits of the relevant appropriations.”

## *Employment*

EU law punishes any form of discrimination based on religion or personal beliefs, disability, age or sexual preferences, since it could jeopardise the achievement of the objectives of the EC Treaty, namely the achievement of a high level of employment and social protection, the improvement of life standards and quality, social and economic cohesion, solidarity, free movement of individuals. In this regard, it is worth recalling that there are doubts on the compatibility of domestic legislation with the obligations imposed at supranational level; the Italian legislation (which is mainly grounded in Law No. 68/99) shows several shortcomings especially as regards imposing and enforcing the obligation to adopt efficient and practical measures, in relation to different aspects of occupation and working conditions: the latter, in fact, should allow persons with disabilities to access employment, perform their job, get promoted and be trained, on equal terms (said inadequacy was confirmed by Judgment No. C-312/11 of the European Court of Justice, condemning Italy for not having implemented all necessary activities to ensure a general framework for equal treatment in employment and working conditions). The Italian legislation, therefore, does not ensure the correct transposition and complete implementation of Article 5 of Directive No. 78 of 2000, which obliges Member States to pass legislation including efficient and practical measures to allow persons with disabilities to exercise their fundamental rights, as is the case in the most different fields of administrative and legislative activity, at both National and Supranational level. Public measures for promotion and support are not enough: it is up to Member States to oblige all recipients to adopt concrete and adequate provisions for all persons with disabilities, according to the actual needs and situations relating to different aspects of their lives, also by guaranteeing a “reasonable accommodation” (Article 27 of the UN Convention).

## *Health*

Similarly, as regards the right to health, Article 32 Paragraph 2 of the Italian Constitution, Article 3 of the Charter of Fundamental Rights of the EU, and Section 1 of Law No. 180 of 1978, provide that each individual has the right not to be obliged to undergo a specific health treatment (except under the provisions of the law).

The right to refuse health treatments is grounded on the control exercised by the individual concerned over “health” as an asset, so that patients’ informed consent is required to a specific health treatment.

Given this premise, patients who are not able to express their wishes regarding the treatments they are - or will be - undergoing must not be discriminated compared with other patients who can do so and therefore, if their wishes can be described, they must be enabled to prevent specific health treatments from being practised on them.

As a consequence, the verification of whether a health treatment is mandatory, even if it was ascertained that the patient is against it, is related to the respect for human dignity, which has to be protected pursuant to Article 1 of the European Convention on Human Rights.

Indeed, the prescriptive part of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol provides that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”, to “prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.” All persons have not only the right to be treated, but also a constitutionally-qualified claim to be treated under their own terms: they are, in fact, the only ones who can decide which treatment to undergo or, when needed, which facilities to confide in for a quick and safe recovery.

After all, time and time again the Italian Constitutional Court has noted, in relation to the rights of persons with disabilities, that the need to protect the weak is met not only with care and rehabilitation, but also by ensuring their full and effective inclusion in the social context they belong to, as well as in the family, school and the workplace.<sup>8</sup>

### *Education*

As well as by the Italian Constitution (Article 28), the right to education is prescribed by Law No.118/71, No.517/77, and No.104/92, which set the premises, the conditions and the instruments for school integration of students with disabilities, and ensure the right of children and youths with disabilities to access standard classes of nursery schools, educational institutions at all levels, and academic institutions.

In Judgment No. 215 of 1987, the Italian Constitutional Court had already affirmed that “the participation of persons with disabilities in the education process together with teachers and able-bodied classmates is a significant socialization factor, and can be decisive in stimulating the potentialities of disadvantaged students”: hence the irrationality, that often results in unlawfulness, of the creation of two “separate” paths, and the consequent duty for the State (Article 38 Paragraph 4 of the Constitution) to make the right to education concretely enjoyable, by means of “adequate integration and support measures to guarantee that persons with disabilities can attend educational institutions.” Coherently, the provisions of Law No. 244 of 2007 - which strictly limited the number of special needs teachers - were declared unconstitutional by the Constitutional Court via Judgment No. 80 of 26 February 2010: they were, in fact, in conflict with the “international legal framework [...], constitutional and other laws, as well as with the consolidated case-law of this Court

for the protection of persons with disabilities.”

Presidential Decree No. 81 of 20 March 2009 - entitled “Provisions for the reorganization of the school network, and the rational and efficient use of human resources in schools” - provides pursuant to Section 64 Paragraph 4 of Decree-law No. 112 of 25 June 2008, confirmed, with amendments, by Law No. 133 of 6 August 2008, that first-year classes including students with disabilities will have a maximum of 20 students, whereas Ministerial Circular No. 63 of 2011 recommends that at most one student with disabilities should be present in a class. In order to improve the integration of students with disabilities, on 4 August 2009 the Italian Ministry of Education issued the “Guidelines for school integration of students with disabilities.”

Subsequently, Law No. 170 of 8 October 2010 - entitled “New provisions concerning specific learning disabilities in the school environment” (after which the guidelines of 12 July 2011 were issued) - established a new protocol for the different forms of Specific learning disabilities (SLD), namely for dyslexia, dysgraphia, dysorthography, and dyscalculia. The Ministerial Directive on Special Educational Needs (SEN) of 27 December 2012 - entitled “Policy instruments for students with Special Educational Needs and territorial organization for school inclusion” - further increased the number of students who can benefit from customised courses, by extending the right to the customisation of education to all students with difficulties (whereas in the past it was reserved exclusively for those with a certified disability, or with SLD); in doing so, the Directive recalled the principles enshrined in Law No. 53 of 28 March 2003 (entitled “Empowering the Government to define general norms on education and minimum level of services in education and professional training”).

Special Educational Needs (SEN) mean: students with disabilities, students with SLD, students with a socio-economic, linguistic, cultural disadvantage. All the compensatory and

dispensatory measures envisaged by the abovementioned Law No. 170 of 2010 are extended to these categories.

Ministerial Circular No.8 of 6 March 2013, aside from further outlining the results and the implementation of the Ministerial Directive, envisaged the implementation of an Annual Inclusiveness Plan (PAI - *Piano Annuale di Inclusività*), which should be prepared by the Working Group on Inclusion (GLI - *Gruppo di Lavoro per l'Inclusione*), approved by the teaching body of each school by June of each year, and become an integral part of the Educational Offer Programme (POF - *Piano dell'Offerta Formativa*). Nevertheless, since the date of the Decree and that of the approval of the first PAIs were very close, a specific note issued by the Ministry (Protocol No. 1551 of 27 June 2013) entrusted Regional School Bureaus with setting the date by which PAIs were to be approved and sent to them.

A specific problem, rarely addressed, is that of the so-called “Non-state schools”: Section 1 Paragraph 14 of Law No. 62 of 10 March 2000 (“Provisions for equality between State and Non-state schools, and on the right to study and education”) envisages, as from the year 2000, support measures for schools with students with disabilities and generically refers to “school institutions”. Administrative case-law, therefore, held that the abovementioned Section refers to both State schools and Non-State schools<sup>9</sup>, which are part of the National Education system in their full right. Paragraph 3 of the single Section making up said Law provides as a fundamental rule that, since they are providing a public service, Non-state schools have to accept anyone’s application for enrolment along with their educational project, including students with disabilities. Coherently, Paragraph 4 Letter e) of the abovementioned Law provides that one of the essential conditions for the acknowledgment of equality between State and Non-state schools is the fact that the latter have to ensure the application of the provisions in force on the integration of students with disabilities or at a disadvantage. As is well known,

Section 12 of Law No.104 of 1992 provides that the right to education of persons with disabilities is to be granted in nursery schools, in standard classes of school institutions at all levels, and in academic institutions: it is clear, therefore, that Non-state schools are to be included in the comprehensive notion of “school institutions at all levels”, as an integral part of the National system of education. In order to do so, these schools have to commit themselves to implementing current legislation on the integration of students with disabilities, as provided for by Section 3 of Ministerial Decree No. 83 of 10 October 2008, which sets forth the procedures for acknowledging equality between State and Non-state schools. The legal order does not oblige Non-state schools to bear all the economic burden deriving from the implementation of support interventions for students with disabilities. In fact, general and specific regulations provide that the State covers part of the costs in question via specific funding. The poor financial resources the State usually allocates to this end brings about insuperable difficulties in providing an adequate reception and integration of students with disabilities within the school or academic environment.

### *Access and mobility*

Law No.4 of 9 January 2004, “Provisions to promote the access of persons with disabilities to IT tools”, was adapted to the EU standards by means of a Decree by Minister Profumo on 20 March 2013. Said Decree updates the requirements for accessibility of the websites of Public Administrations referred to in the Ministerial Decree of 8 July 2005.

Law No. 220 of 11 December 2012 - entitled “Amendments to Regulations for joint tenancy in buildings”, which entered into force in June 2013 - provides that, as regards the removal of architectural barriers in jointly owned areas, any deliberation of the tenants’

meeting is to be approved by the majority indicated in Section 1136 Paragraph 2 of the Italian Civil Code: that is, it will be necessary for half of the attending tenants to vote in favour (50% majority), which must also amount to at least one-half of the joint tenancy shares. The quorum was thus raised, as it was 1/3 of both in the past.

Law No. 35 of 4 April 2012 - entitled “Conversion into Law, with amendments, of Decree-Law No. 5 of 9 February 2012, containing urgent measures on simplification and development” and the Draft Presidential Decree approved by the Council of Ministers on 25 May 2012 amended the implementing regulations of the Italian Highway Code, by envisaging the adoption of a single model badge identifying persons with disabilities, consistent with the EU model, so as to adequately ensure the privacy of the persons concerned.

## Reccomendations

1. Promoting initiatives in different fields (education, training, society, etc.) to foster the achievement of the cultural, scientific and legal vision introduced by the UN Convention and increase the awareness, in persons with disabilities and their families, of their own rights and choices (empowerment).
2. Subject to compliance with privacy legislation, improving and updating the systems for the collection of data and regular statistics on persons with disabilities, so as to have an actual picture of their situation, in particular as regards obstacles, barriers and discriminations they have to face every day.
3. Overcoming the cultural approach that reduces the rights of persons with disabilities to a mere cost, thus subordinating their respect to the availability of financial resources, also bearing in mind that “the creation of a society that includes all its citizens creates commercial opportunities and boosts innovation.”<sup>10</sup>
4. Strengthening the efficacy of the instruments for removing architectural barriers in existing public spaces and buildings, such as the Plan for the Elimination of Architectural Barriers (PEBA) and the Integrated Plans for Urban Spaces (PISU). Promoting the drafting of guidelines for “universal planning”.
5. Ensuring that persons with disabilities can fully participate in society, in particular by defining common guidelines for the implementation of Article 19 of the UN Convention (Independent life and inclusion in society). Ensuring that persons with disabilities have the chance to choose, on an equal basis, their place of residence.
6. Defining methods for certifying invalidity, so as to simplify the current bureaucratic procedure and ensure a reduction in waiting times. Reviewing and monitoring the overall verification system of

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10 “European Disability Strategy 2010-2020: A Renewed Commitment towards a Barrier-Free Europe”, Brussels, 15.11.2010, COM(2010)636 final.

INPS, by paying particular attention to the internal verifications of the body itself and the way to collect and disseminate data on false invalidity certifications.

7. Updating the current employment legislation and making it more efficient in offering job opportunities and following workers along their career path, by linking the legislation on affirmative actions for persons with disabilities in the field of employment with the legislation on non-discriminatory protection and equal opportunities, with special regard to women with disabilities.

8. Arranging truly inclusive processes in the fields of education and training, to be planned together with all the stakeholders (families, special needs teachers, other specialised services, etc.), also by way of the collaboration with other specialised services, the drafting of guidelines and quality indicators for school inclusion.

9. Promoting and supporting knowledge and implementation of the rights of persons with disabilities, along with the duty of the socio-medical system to agree upon and jointly draft customised programmes. Acknowledging and defining by law the rights and the role of the “in-family caregiver”, and timely developing shared perspectives and solutions for the “After us” issue.

10. Ensuring accessibility and availability of all health services and the relevant structures also by way of the specific training of practitioners.