PROTECTION AND LEGAL RIGHTS FOR DISABLED PEOPLE

HYPERTEXT

FROM CONSTITUTIONAL RIGHTS TO FURTHER LEGAL CLAIMS

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since Rev. 2022/02

Year 15 - Rev. 2024/01







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PREFACE

In June 2009, the National Centre for Rare Diseases directed by Dr Domenica Taruscio within the ISS (Istituto Superiore di Sanità, the Italian NHS), cooperated with the Associazione Crescere in Bologna (J.D. Ernesto Stasi) and with the Associazione Prader Willi in Calabria (Dr Domenico Posterino) in order to update and enhance the **Guide** "From Constitutional Rights to Further Legal Claims", which is edited by Associazione Prader Willi and available for free download in PDF format on the website of the National Centre for Rare Diseases (CNMR): the Associazione Crescere and the Associazione Prader Willi are both non-profit organizations.

This starting project led to the issue of a **summary guide**, which provides hypertext links to legislative provisions and other related documents: is a challenging project which requires constant updating.

The hypertext "From Constitutional Rights to Further Legal Claims" is the result of this project in collaboration with the CNMR. This hypertext aims at providing user-friendly guidelines about disabilities and rare diseases, since we strongly believe that "legal instruments are also essential tools in order to defeat rare diseases", as stated by Professor Fulco Lanchester during the opening speech of the Rare Diseases Conference "Malattie Rare: la ricerca tra etica e diritto", held at the University La Sapienza in Rome on 14th February 2006.

The hypertext is divided into different sections according to different topics. Paragraphs are listed at the beginning of each section; the final section contains a full list of links to legislative provisions referred to in this text, along with explanatory notes. At the end of each section there is reference to official websites and links to other guidance documents on related subjects. This hypertext does not impose any legal obligations in itself, nor is it an authoritative statement of the law, although it makes reference to legal documents and official websites.

This hypertext applies to Italy. The hypertext was translated into English with the sole aim of facilitating a better comprehension. The translation does not have official status.

INTRODUCTORY NOTE

This hypertext provides abbreviated descriptions of some laws in order to enhance its readability. For instance, Law n. 104 of 5th February 1992 headed "Framework Law to enhance Support, Social Integration and Rights for Disabled People" is simply referred to as "Disability Framework Law".

This hypertext makes reference to NORMATTIVA, the Italian legislation website managed by the Italian Stationery Office.

The main text contains reference to the legislation in force at present, while the chronological index in the final section provides an overview of the changes in legislation, which are listed by publication date in the Italian Official Gazette.

Please notice that the current text reports only specific provisions, along with indications of the related law articles: e.g. Art. 1.1 of <u>Law 95/2006</u> (*New Regulation for people with hearing impairment*), has not been reported, as it contains generic provisions, while Art. 1.2 and 1.3 of the same Law have been referred to (i.e. <u>Law 381/70</u>), as they concern specific provisions.

The following link is to the INPS webpage (National Social Welfare Institution), dedicated to <u>ISEE</u> (Revenue Bureau's Evaluation of Financial Situation), where you can find Guidelines, Forms and FAQ.

Finally, the following link is to the INPS webpage on <u>simulation of ISEE calculation</u> according to Legislative Decree n. 109 of 31st March 1998, Legislative Decree n. 130 of 3rd May 2000, and Prime Minister's Decree n. 159 of 5th December 2013 and later modifications.

Home

ITALIAN CONSTITUTION

- Art. 2: "The Republic recognises and guarantees the inviolable rights of the person, as an individual and in the social groups where human personality is expressed. The Republic expects that the fundamental duties of political, economic and social solidarity be fulfilled."
- Art. 3: "All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social conditions. It is the duty of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality of citizens..."
- Art. 24: "All persons are entitled to take judicial action to protect their individual rights and legitimate interests..."

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HEALTH RIGHTS

- Art. 32 of the Italian Constitution "The Republic safeguards health as a fundamental right of the individual and as a collective interest and guarantees free medical care to the indigent..."
- Main Legislation
- Rare Diseases and Orphan Medicinal Products
- Assisted Reproductive Technologies
- **Transplantation**
- Informed Consent

Main Legislation

Law n. 833 of December 23, 1978 (National Health Service)

- **Art. 19** The ASL (Local Health Service) provides prevention, treatment and rehabilitation services.
- Citizens have the right to choose a doctor and to choose in which hospital to go according to the objective organisational limits of the healthcare services.
- **Art. 26** The ASL rehabilitation centres and private rehabilitation centres approved by ASL provide rehabilitation for disabled people.
- Rehabilitation services include prosthetic services. (Ministerial Decree n. 321 of May 5, 2001: "Prosthetic services provided within the National Health Service")

Legislative Decree n. 502 of December 30, 1992 (New Legislation on National Health Service)

Update List at the time of Legislative Decree n. 502/92 of 16th June 2010.

Legislation in force is reported as usual; its several amendments are reported in the Update list link issued by NORMATTIVA.

Notice Art. 3 (Paragraphs 7 and 8) on social and sanitary integration, Art. 6 on training, Art. 14 on citizens' participation, and Art. 16a on continuing training.

Prime Minister's Decree of January 12, 2017 (Definition and update of essential healthcare levels, as reported by Art. 1, Paragraph 7 of Legislative Decree n. 502 of December 30, 1992), published in the Italian Official Gazette n. 65 of March 18, 2017 - Supplemento Ordinario n. 15.

Decree of June 23, 2023 (Definition of outpatient Ministerial specialist and prosthetic care rates) in O.G. General Series n° 181 of August 4, 2023 shall be in effect starting from January 1, 2024, for outpatient care and April 1, 2024, for prosthetic care.

Law n. 104 of February 5, 1992 (Disability Framework Law)

Art. 6 – Prevention and Early Diagnosis "Prevention, antenatal screening and early diagnosis of disability are performed according to the health care plan ruled by Art. 53 and Art. 54 of Law n. 833 of December 12, 1978 and its amendments..."

See Prime Minister's Decree of July 9, 1999; Law n. 548 of December 23, 1993 (Congenital hypothyroidism, Phenylketonuria, and Cistic fibrosis); Art. 1, Paragraph 229, of Law n. 147 of December 23, 2013 (Expanded newborn screening), Law n. 167, of August 19, 2016 (Provisions on mandatory newborn screening tests for prevention and treatment of hereditary metabolic disorders) and the related Ministerial Decree of 13th October 2016 (Provisions concerning the implementation of newborn screening tests for early diagnosis of hereditary metabolic disorders) published in s.s. n. 267 of the Italian Official Gazette on 15th November 2016 and as hypertext version (pdf/a 158 kb); Legislative Decree n. 73 of June 7, 2017 (Urgent provisions on preventive vaccination, converted and modified from Law n. 119 of 31st July 2017); Ministerial Decree of September 17,

2018 (Establishing of the National Vaccination **Register**), published in the Official Gazette n. 257 of 5th November 2018.

- Art. 7 Health Care and Rehabilitation "They are performed according to plans which integrate health and social care...involving disabled people, their families and the community. The National Health Service and its approved Centres provide rehabilitation and out-patient health care services at home or in the Centres providing day care or respite services for rehabilitation and education..."
- **Art. 11 Staying Abroad for Medical Treatment** "If medical treatment does not involve going into hospital, disabled people and their carer will receive an allowance for their stay in hotels or structures approved by the medical centre, by way of derogation from Art. 7 and Art. 8 of the Ministry of Health Act of 3rd November 1989."

Legislative Decree n. 124 of April 29, 1998 (Exemptions from Payment), Art. 5 on Rare Diseases.

Law <u>n. 3 of January 16, 2003</u> (Legal Provisions concerning...) Title IX on health protection, Art. 42-53: Art. 51 on non-smokers health protection, integrated by Legislative Decree <u>n.6 of January 12, 2016</u>.

Legislative Decree <u>n. 196 of June 30, 2003</u> (Personal Data Protection Code: Section <u>7-13</u> on rights concerning personal data, Section <u>22-26</u> on sensitive data, Section <u>74-96</u> on exercising rights in specific sectors: Section 74 on car permits and access to town centres, Section 75-94 on health care sector, and Section 95-96 on education)

National Health Service Plan 2006-2008 – Notice in the chapter on strategies point 3.2 on LEA (Essential Level of Assistance), point 3.6 on networks, point 3.8 on social-health integration, and point 4.2 on the Third Sector.

UNO Convention on the Rights of Persons with Disabilities of December 16, 2006 (Italian version issued by the Ministry of Labour, Health and Social Policy), and its Ratification n. 18 of March 3,

2009 (English official version), the Decree of the Ministry of Labour and Social Policy n. 167 of July 6, 2010 founding the National Observatory, and Prime Minister Decree n°115 of July 20, 2023, containing the related Regulation on composition and functioning, and Decree of the President of the Republic of 4th October 2013 (Implementation of the biennial executive plan promoting rights and inclusion of persons with disabilities), published in the Official Gazette of 28th December 2013 - Serie Generale n. 303 and as hypertext version (Pdf/a kb 626), - presentation slides (Pdf kb 1636) and Decree of the President of the Republic of 12th October 2017 (Implementation of the Second Biennial Executive Plan promoting Rights and Inclusion of Persons with Disabilities) published in the Official Gazette of 12th Dicember 2017 - Serie Generale n.289 and hypertext version Guidelilnes (Pdf/a kb1145). **Deinstitutionalization** drawm up by te UN Committee on the Rights of Persons with Disabilities (Pdf 220 kb).

Law <u>n. 38 of March 15, 2010</u> (Accessing Palliative Care and Pain Relief)

Legislative Decree <u>n. 179 of October 18, 2012</u> converted into Law 221/2012 (Section IV, from Art. 12 to Art. 13, Paragraph 2)

Law 179/12 (*Urgent Provisions for Growth*) includes provisions implementing and increasing the effectiveness of electronic services' applications also for people belonging to categories at risk of exclusion, such as people in need of social and medical assistance. These provisions concern:

1) Electronic Health Records and Healthcare Information Systems (Art. 12 L.D. n°179/2012), regulated by M.D. of 7th Septemer 2023 (in O.G. 24/10/2023) dedicated to Digital Health Record 2.0 which has replaced Prime Minister's Decree n. 178 of 29th September 2015 (Electronic Health Records Regulation), except chapters III and IV (Processing for Research and for Government) which remain in place until a new decree (Art. 27.5).

The EHR (FSE in italian) collect electronic data and documents regarding the social and health condition of patients; these records are generated and maintained by Regions and Autonomous Provinces, complying with the privacy legislation, in order to enhance the following activities and purposes:

- Prevention, diagnosis, medical treatment, and rehabilitation;
- Scientific study and research in the fields of medicine, biomedicine and epidemiology;
- Health care programs, quality assessment of health care and assistance.

Healthcare Information systems and records (art.12 paragraph 10 and following Law Decree n° 179/2012) also assure the regular collection of personal, health and epidemiological data in order to survey and classify any source of risk to human health and safety regarding a specific disease or medical condition affecting people within a given group.

All healthcare material has been reorganised by the Ministerial Decree of September 7, 2023 and dedicated to the Digital Health Record 2.0 (in O.G. 24/10/2023).

Among the essential data is the following: the Patient Summary, made up by the MMG/PLS (Art.4), the personal notebook of the patient (art.5), their de-identified data (art.6), the preservation of patient data until 30 years after death (art.10), the access to the Digital Health Record for minor or incapacitated people (art.11.6/7), the access to the data in case of emergency (art.20), the INI platform regarding the national data exchange between different regional FSE (art.1q/r - art.29).

By Ministry of Health Decree, aiming to provide an efficient instrument for consultation, analysis and planning the same across the entire national territory, directions have been given on the essential **Data integration** which make up the FSE documents (Ministerial Decree May 18, 2022) also replaced by M.D. 7/9/2023 and have been laid down

- the <u>Guidelines</u> (Pdf/a version Kb979) for the FSE implementation and its improvement (Ministerial Decree <u>May 20, 2022</u>).
- 2) Electronic medical prescription and medical history (Art. 13) which is gradually going to replace paper documentation.
- 3) In case of generic drugs, mentioning the active ingredient in the medical prescription is mandatory (Art. 13, Paragraph 2), whereas the prescription of a specific branded medication is still possible writing a brief explanation of this choice.
- **Legislative Decree** n. 90 of June 24, 2014 converted with modifications into Law 114/14 (Urgent provisions on simplification and administrative transparency...)
- Art. 26: pending the implementation of digital prescription, up to six medicine packets can be prescribed per prescription regarding the given chronic diseases.
- **Art. 27.1bis:** every health care facility must have a third party liability insurance (RCT) and a work insurance (RCO), in order to cover both clients and members of staff.
- **National Dementia Plan** (Strategies for the promotion and improvement in the quality and appropriateness of dementia healthcare), published in the Official Gazette n.9 of January 13, 2015. Click on the following link to the <u>ISS page</u> to learn more.
- Ministerial Decree of 2nd March 2016 (Regulation on functioning and organisation of the Istituto Superiore di Sanità), published in the Italian Official Gazette n.88 on the 15th April 2016.
- Law <u>n. 24 of March 8, 2017</u> (Provisions on safe healthcare assistance, safety of assisted people, and professional liability of healthcare practitioners).
- Law <u>n. 3 of January 11, 2018</u> (Delegation to the Government on medicinal product clinical trials, provisions on rearrangement of

healthcare professions and healthcare management jobs by the Ministry of Health)

Law <u>n. 29 of March 22, 2019</u> (Establishment and Regulation of the National Cancer Registry and Analysis Network)

Ministerial Decree of 20th August 2019 (Allocation of Funds to the Regions to reduce waiting time for healthcare services (19A07081) Italian Official Gazette n. 268 of 15th November 2019)

Legislative Decree n.101 of July 31, 2020 (Implementation of Council Directive 2013/59 Euratom which laid down basic safety standards for protection against the dangers arising from exposure to **ionising radiation**, repealing Directives 89/618/Euratom, 90/641/Euratom, 96/29/Euratom, 97/43/Euratom and 2003/122/Euratom, and rearrangement of the related regulatory framework implementing Art. 20, Paragraph 1, Letter a) of Law n. 117 of 4th October 2019). (20G00121) (Italian Official Gazette n. 201 of 12th August 2020 – Supplemento Ordinario n. 29).

See **Title XII** – **Medical Exposure** (Articles 156 - 171), in which Articles 165 and 166 aim at protecting young children, pregnant women and nursing mothers. The rules described in these Articles also apply to anyone who provides non-professional care and comfort to people exposed to medical exposure (Art. 156.3).

M.D. April 29, 2022 (Approval of the organizational guidelines for the "Digital framework for the implementation of the domestic care") in O.G. General Series n. 120 of May 24, 2022) - Guidelines (Pdf/a version Kb 586)

M.D. <u>n.77 May 23, 2022</u> (Regulation for defining frameworks and standards for the development of regional assistance within the National Health Service).

Law <u>n. 62 of May 31, 2022</u> (Provisions on the transparency of the relationship between manufacturers, entities operating within healthcare and healthcare organizations).

Under art. 3 of the Law, if the donation of goods or other benefits for entities operating within the health sector or healthcare organisations, are made by institutions, including the Third Sector, that produce or trade medications, goods or services for human or animal health including those that organise meetings or conferences of the same nature, exceed:

- For operators, a unit value of 100 € or a total value of 1000 € per year
- For facilities, a unit value of 1000 € or a total value of 2500 € per year They must be communicated, or face penalties, in accordance with the manner stipulated as per the instructions written by the Health Ministry's public digital registry.

The agreements and conventions, concerning consulting relationship, teaching and research as well as participating in conferences, committees and commissions, are subject to the same disclosure.

Law <u>n.129 of August 3, 2022</u> (Delegating the Government for the reorganization of the institutional frameworks for the hospitalization and evidence based treatment, of those as per legislative decree n. 28 of October 16, 2003).

Decree by the Prime Minister of June 1, 2022 (Establishment of the National Patients Registry office) (ANA) in Official Gazette n°240 of October 10, 2022.

National Oncology Plan 2023-2027 (pg 15: primary prevention, pg 53: oncology network (and Ern), pg 49: PDTA, pg 61: National rare tumour network, pg 76: nutritional support, pg 86 and 106: Caregivers and their education); the CREA Guidelines on the Health Diet)

National Cancer Registry Decree of the Ministry of Health of August 1, 2023 in O.G. n°203 of August 1, 2023

Ministerial Decree of June 9, 2023 (Adoption of the National Health Technology Assessment Program) in O.G. n°207 of September 5, 2023

Ministerial Decree of May 31, 2023 of the Ministry of Heatlh

(Establishment of the «National Network for thalassemia and haemoglobinopathies») in O.G. n°214 of September 13, 2023

Law n°130 September 15, 2023 (Provisions regarding the establishment of a diagnostic program for the detection of Type 1 Diabetes and celiac disease in pediatric population)

Law n°193 of December 7, 2023 (Provisions for the prevention of discrimination and the protection of the rights of individuals who have been affected by oncological diseases) the law regarding the Cancersurvivor's right to be forgotten.

M.D. n. 77/2022 contains among other provisions **for regional care** by establishing community houses, community hospitals, palliative care network, telemedicine.

Domestic and Territorial Care – Digital Health Record (FSE)

As part of the planned measures by "Measure 6" (network closer to people, buildings and telemedicine for territorial health care) of the PNRR, there are organizational guidelines which include the "Digital model for the domestic care implementation", issued by Ministry of Health with Ministerial Decree of April 29, 2022.

All measures follow the principles of "home as the main place of care", to be achieved through:

- 1) The service of domestic care, which needs to guarantee the continuity of assistance;
- 2) The planning of domestic accesses, considering the clinical care and complex needs of patients;
- 3) The service of domestic care together with **Telemedicine** implementation.

The elements that characterize the domestic care reorganization are: 1) Community houses, with doctors available for 12 or 24 hours as well as other healthcare professionals;

- 2) The community or family nurse, who can use computer-based instruments and telemedicine;
- 3) A new and more concrete relationship between the patient and the General Medicine Specialist or the Family Paediatrician;
- 4) The territorial operation Center (COT)
- 5) Continuity of care Unit
- 6) Network of palliative care (cfr L.38/2010).

These are the new guidelines for the reorganization of the territorial care adopted by the next rule issued with Ministerial Decree of May 23, 2022 by the Minister of Health, together with the Minister of Economy and Finance, for the "Definition of the standards for the development of the territorial care in SSN".

The Decree defines the qualitative, structural, technological and quantitative standards of the buildings for the territorial care and for health, environment and climate prevention systems.

The rule is composed by three attached files, in the third one there is the glossary of the used acronyms, the first one describes the standards, and the second file is the prescriptive one and it is used for the reconnaissance of standards.

There is, essentially, the territorial splitting in different departments of about 100.000 residents each, and every department may have:

- 1) A COMMUNITY HOUSE **hub**, every 40/50 thousand residents, where citizens can go to for every health and social-health needs, with social workers included;
- 2) COMMUNITY HOUSE **spoke** and medical clinics for general medicine based on the territorial needs;
- 3) A FAMILY NURSE or COMMUNITY NURSE every 3.000 residents;
- 4) A TERRITORIAL OPERATION CENTER (COT) which coordinates the taking in charge of individuals in need;
- 5) An OPERATION CENTER 116117 headquarter of the Harmonised European Freephone Number (NEA), which offer a phone service for no urgent medical care;

- 6) A COMMUNITY HOSPITAL every 100.000 residents, with 20 beds, which works as a link between domestic care and hospitalization;
- 7) A CONTINUITY of CARE UNIT (UCA), which is a mobile unit of a specific area for the management of complex health issues;
- 8) DOMESTIC CARE, which is a domestic service for specific health care pathways and for personalized care plans. It is based on the principle "may home be the main place of care";
- 9) NETWORK OF PALLIATIVE CARE;
- 10) FAMILIAR CONSULTORS, which take care of minors, women, couples and family's health;
- 11) The PREVENTION DEPARTMENT in health, environment and climate matters;
- 12) The TELEMEDICINE, which is a remote health service and social-health service, for which the Health Ministry has laid down the guidelines by the <u>Decree of Settembre 30, 2022</u>.

Every territorial operation unit, combining to form the Department, must have suitable digital solutions for making digital health files that will be included in the **Digital Health Records (FSE)**. Its task and content have been updated according to the Ministerial Decree of May 18 and 20, 2022, as stated.

Please, notice the protocol of the Metropolitan City of Bologna of September 2019 on the <u>administration of medicines</u> in schools and educational facilities.

AIFA has made available the AIFA Medicinali app for smartphones, designed to offer a practical and immediate tool for citizens to obtain information, manage and receive alerts about their currently prescribed medications.

(From the AIFA website: https://www.aifa.gov.it/mobile-app-aifa)

Rare Diseases and Orphan Medicinal Products

Ministry of Health Act n. 279 of May 18, 2001

Ministerial Decree of 2nd March 2016, published in the <u>Italian</u> Official Gazette n.88 on the 15th April 2016, Art. 9.a: Mission and Establishment of the National Centre for Rare Diseases.

Prime Minister's Decree of 12th January 2017, published in the Italian Official Gazette n. 65 of 18th March 2017 Art. 52

EU Council Recommendation of June 8, 2009 on an action in the field of rare diseases and Opinion of the European Economic and Social Committee.

Legislative Decree n. 38 of 4th March 2014 Art. 13: European Reference Networks ERN

Law <u>n. 175 of 10th November 2021</u> (Provisions for medical treatment of Rare Diseases and for supporting Research and Production of Orphan Medicinal Products)

The Ministry of Health Act n. 279 of May 18, 2001 established <u>The Italian National Network for Rare Diseases</u> which concerns:

- the establishment of the Italian National Network of Centres of Reference, both regional and interregional, to tackle the problems of prevention, medical surveillance, diagnosis and treatment of rare diseases, granting specific forms of assistance for rare disease patients. (This includes the Diagnostic, Treatment, and Assistance Procedures (It. PDTA) which have already been established and implemented for certain rare diseases in some Regions, such as in Lazio and above all in Lombardia (see <u>Rare Disease Coordinating Center-Lombardia-Diagnosis, Treatment, and Assistance Procedures (PDTA) Profile</u>);
- the establishment of the National Registry of Rare Diseases at the Istituto Superiore di Sanità (ISS), which is expected to receive epidemiological data from regional centres in order to coordinate a

national health service action plan for medical surveillance and treatment of rare diseases;

- the creation of a list of rare diseases with an identification code for which patients are diagnosed and treated completely free of charge, included in Annex 1 of The Ministry of Health Act n. 279/2001, which was updated by Annex 7 of the Prime Minister's Decree of 12th January 2017 (published in the Official Gazette n. 65 of 18th March 2017), see also the database of rare diseases exempted from payment edited by the Ministry of Health. Each rare disease or each group of rare diseases is identified by an identification code. The Prader-Willi syndrome is identified by identification code RN1310, while code RN0680 identifies the Turner syndrome (see the Ministry of Health Act n. 279/2001). Each part of the code has a specific meaning: R stands for Rare, N refers to the International Classification of Diseases ICD-9 Code, in which N is the 14th letter of the English alphabet and it stands for class 14 indicating genetic disorders; if G is the third code letter the rare disease belongs to a rare disease group, as the Turner syndrome which is now identified by code RNG080 following the update implemented by the Prime Minister's Decree of 12th January 2017, otherwise it is identified by a progressive number. International Classification Diseases ICD-9 was subscribed by 43 state members of WHO World Health Organisation in 1990 and it is currently being reviewed; the reviewed list should be issued by 2014 and it should also include classification of further rare diseases and conditions which will receive free diagnosis and treatment. The current version of the list classifies 250 rare diseases. (Section 10-12 of EU Recommendation of June 8, 2009 on Rare Diseases.)

Rare Diseases National Plan (PNMR) 2013 – 2016

As provided in the above EU Recommendation of 8th June 2009, the Council of the European Union recommends that Member States establish and implement plans or strategies in the framework of the

ongoing European project for rare diseases national plans development EUROPLAN, primarily in order to achieve the following:

- Ensure that rare diseases are adequately coded and traceable in all health information systems, encouraging an adequate recognition of the disease in the national healthcare and reimbursement systems based on the ICD while respecting national procedures.
- Foster research projects on rare diseases.
- Identify appropriate centres of expertise throughout their national territory and foster their participation in European reference networks. (Legislative Decree n. 38 of 4th March 2014, Art. 13: European Reference Networks ERN); see ERN on the EU webpage.
- Consult patients on the policies in the field of rare diseases.
- Facilitate patient access to updated information on rare diseases.
- Promote the activities performed by patient organizations, such as awareness-raising, capacity building and training exchange of information and best practices, networking and outreach to very isolated patients.

Implementing this EU Recommendation, Italy drew up a Rare Diseases National Plan, which has been approved by the Italian State-Regions Conference on 16th October 2014.

This National Plan, involving patient organizations, aims at outlining the current situation, providing indications in order to tackle rare diseases by means of close cooperation between institutions and in fields relevant to patient assistance, such as primary and palliative health care, rehabilitation and home care, as well as integration at school and at work, according to the various legislation currently in force on rare diseases.

The Plan has been updated and approved by the State-Regions Conference on May 24, 2023.

The new PNMR 2023-2026 (Pdf 1.567 Kb, unofficial version, with interactive contents on the side,) is divided into 9 chapters: Primary prevention in pg. 6, Diagnosis in pg. 9, Pharmalogical treatments in pg. 13, Non-pharmalogical treatments in pg. 16, Assistance Pathways in pg. 19, Training in pg. 25, Information in pg. 29, Registers and monitoring NMR network in pg. 34, Research in pg. 37. Each chapter includes the following items: Introduction, Objectives, Actions, Tools, Indicators. The Introduction refers, with the respective links, to other related plans and documents

Law <u>n. 134 of August 18, 2015</u> (Provisions concerning diagnosis, medical treatment and rehabilitation of **persons with hearing** disorders and family assistance)

Law n. 648 of December 23, 1996 - Legislative Decree n. 536/96 (... Medicinal Products) Art. 1.4

Regulation (EC) n. 141/2000 of the European Parliament and of the Council of December 16, 1999 on Orphan Medicinal Products

Detailed information on national and European legislation on orphan medicinal products is available on the National Centre for Rare Diseases website:

www.malattierare.gov.it/malattie/terapieFarmacologiche

(National Centre for Rare Diseases – Orphan Drugs)

Law n. 175 of 10th November 2021: Consolidated Law on Rare Diseases

The Consolidated Law on Rare Disease is composed by 16 Articles which are grouped into five Chapters as follows:

- Chapter I (Articles 1-3): purposes, definition and scope;
- Chapter II (Articles 4-6): services and benefits for people with Rare Diseases;

- Chapter III (Articles 7-10): the Centre, the Committee, the Network and the National Plan for Rare Diseases;
- Chapter IV (Articles 11-14): Research and Information;
- Chapter V (Articles 15-16): financial provisions and final provisions.

See the Rare Diseases webpage which features an <u>explanation Article</u> <u>by Article</u> of the Consolidated Law on Rare Diseases.

By Ministerial Decree of September 8, 2022, the National Committee of Rare Diseases (CoNaMR) was established, ad per art. 8 of T.U., to "provide direction and coordination, defining the regional and national strategic guidelines".

Reference Website:

National Centre for Rare Diseases

Help-line Rare Diseases: 800.89.69.49

The following link is to the opening speech of the Rare Disease Day 2009, held by Dr Laura Mazzanti of S. Orsola-Malpighi Polyclinic in Bologna, which is available for free download in PDF format:

La Giornata delle Malattie Rare 2009

(Rare Disease Day 2009)

Lucilla: un viaggio nel mondo dei diritti is a web documentary by the Legislative Assembly of Emilia-Romagna which includes a part on Rare Diseases.

<u>Lucilla e le Malattie Rare</u> is an hypertext, presented at the Rare Disease Day 2013, concerning sanitary legislation, especially on drugs

and orphan medicinal products. It includes texts, images, videos and slideshows ranging from the European Union to the Emilia-Romagna Regional Health Service.

Assisted Reproductive Technologies

Law <u>n. 40 of February 19, 2004</u> (Provisions on assisted reproductive technologies*)

Ministerial Decree n. 265 of December 28, 2016 (Regulation concerning manifestation of the will to access to assisted reproductive technologies, according to Art. 6 of Law n. 40 of 19th February 2004)

Ministerial Decree <u>n. 130 August 20, 2019</u> (Regulation of... and National Register of Donors of Reproductive Cells for heterologous assisted reproductive technologies)

Couples are allowed to use assisted reproductive technologies provided that they are different-sex couples formed by living persons of age, either married or unmarried, who are sterile and of fertile age (Art. 5). Posthumous artificial insemination (from a dead donor) is therefore not allowed by law. Donor insemination is allowed by law (Art. 4), provided that it has been diagnosed a pathology causing total and irreversible sterility or infertility (Judgement of Constitutional Court n. 162 of 9/04-10/06/2014, published in s.s. n. 26 of the Italian Official Gazette on 18th June 2014).

As established by the Constitutional Court (Judgement n. 96 of 15th May - 5th June 2015, published in <u>s.s. n. 23 of the Italian Official Gazette on 10th June 2015</u>), "fertile couples having transmissible rare diseases in compliance with the seriousness criteria established by <u>Art. 6</u>, <u>Paragraph 1b of Law n. 194 of May 22, 1978</u> (*Provisions on maternity social protection and voluntary interruption of pregnancy*), and certified by a dedicated public facility" are also allowed to use

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[•] In this context, Assisted Reproductive Technologies (ART) is meant to be the equivalent to the Italian "Procreazione Medicalmente Assistita" (P.M.A.).

assisted reproductive technologies.

Along this judgement, Art. 13, Paragraph 3b and Paragraph 4 of Law n. 40, of February 14, 2004 (Provisions on assisted reproductive technologies) been declared have unconstitutional by Constitutional Court (Judgement n. 229 of 21st October-11th November 2015, published on n. 46 of the Italian Official Gazette on 18th November 2015), insofar it charged with an alleged offence the embryo selection even in those cases in which it was exclusively aimed at avoiding implantation of embryos affected by transmissible genetic disease which have been medically reported by dedicated public facilities and match the severity criteria described by Art. 6, Paragraph 1b, of Law n. 194 of May 22, 1978 (Provisions on maternity social protection and voluntary interruption of pregnancy). ART are only used in public and private health facilities approved by Regions (Art. 10), according to the guidelines of the Ministry of Health, which are issued at least every three years by ISS, the Italian National Health Service, (Art. 7). Doctors must inform couples about the risks associated with ART in order to grant their informed consent; they must also inform them about adoption opportunities (Art. 6), which are governed by Law n. 184 of May 4, 1983, and its modifications, (On adoption and custody of children and young people). More information on international adoptions are available in English on the website of the Commission for the International Adoptions.

Main website: **ISS - ART Registry**

The following link is to a fact sheet on ART and to the presentation on topic "Assisted Reproductive Technologies and Adoption" held by lawyer Maria Teresa Bettelli on 12th March 2011 during the seminar "Gli Incontri del Sabato" organized by the Associazione Crescere, which are both free downloadable:

La Procreazione Assistita e <u>l'Adozione</u>

(Assisted Reproductive Technologies and Adoption)

Transplantation

Living-donor Transplants

According to Art. 5 of the Italian Civil Code: Laws of self-deprivation and disposition are permitted if not implying permanent prejudice to the human body, and if not contrary to the law and morality.

This obligation was amended by the following legislation:

Law <u>n. 458 of June 26, 1967</u> (Kidney Donation)

Law n. 483 of December 16, 1999 (Legislation on split liver transplant)

Law <u>n. 167 of September 19, 2012</u> (Rules allowing living donor split transplantation of lung, pancreas, and intestine)

Art. 5 of the Italian Civil Code does not apply to the following:

Law <u>n. 52 of March 6, 2001</u> (Recognition of the Italian Bone Marrow Donor Registry)

Law n. 219 of October 21, 2005 (New legislation on transfusions and national production of blood products), which replaced Law n. 107 of products); Ministerial Decree of 1st August 2019 (Blood safety – blood components not aimed for transfusion) published in the Italian Official Gazette n. 226 of 26th September 2019

Ministry of Health Act n. 116 of April 16, 2010 published on 26th July 2010 in the Official Gazette n. 172 (Law on living donor transplantation)

Ministerial Decree <u>n. 130 of August 20, 2019</u> (Regulation on goals, functions and structure of the Transplantation Information System SIT, and...)

Decree of the President of the Republic n. 131 of August 23, 2019 (Regulation on the Donation of Human Tissues and Cells – technical specifications for testing)

It is also possible to make a donation of bone in occasion of prosthetic hip surgery with the donation of the femur head, that is removed to implant the prosthesis. At the Rizzoli Institute of Bologna is based the <u>Cell and Musculoskeletal Tissue Bank</u> (BTM), the most important in our Country. In its website it is possible to find every wider information.

Deceased Organ Donation

Law <u>n. 578 of December 29, 1993</u> (Law on Death Assessment and Certification)

Law n. 91 of April 1, 1999 (Law on organ and tissue transplants)

Organ and tissue transplants are authorized only with the consent of the deceased or his/her family. To ensure that the removal, storage and use of any tissue is lawful, it is important to establish clearly that consent has been given. The giving of consent is a positive act; implicit consent ruled by Art. 4 is not in force yet.

Organ donation is voluntary and free. Any form of payment for organ donation is unlawful.

Directive EU of May 19, 2010 (Standards of quality and safety of human organs intended for transplantation)

In relation to the aforementioned legal provisions, we also highlight the following:

Law n°10 of February 10, 2022 (Provisions on the disposal of one's post mortem body and tissues for studies, training and scientific researche) and its related regulation

President of the Republic Decree n°47 of February 10, 2023 (Regulation containing provisions on the disposal of one's post mortem body and tissues for studies, training and scientific research).

Art. 8 of the aforementioned law 91/99 established at the National Institute of Health:

The National Transplant Centre

which provides a comprehensive examination of the topic on its website.

Consent to Treatment

Art. 32 of the Italian Constitution: "No one may be obliged to undergo any given health treatment except under the provisions of the law."

Art. 54 of the Penal Code (Case of Necessity) "When someone has been obliged to react in order to save himself/herself or another person from a severe physical danger his/her action is not punishable."

Oviedo Convention of April 4, 1977 (Italian version from the ISS website), and its Ratification by Law n. 145 of March 28, 2001 (Official text in French)

The following Art. 5-9 of the Oviedo Convention "An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it." (Art. 5.), except "When because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned." (Art. 8, see also Art. 54 of the Italian Penal Code).

The Convention also covers protection of persons not able to consent, for whom "intervention may only be carried out with the authorisation of his or her representative or an authority..." (Art. 6), and previously expressed wishes (Art. 9).

See also the following judgments of the Court:

- judgement of the Supreme Court n. 2347/2008 in criminal matters;

- judgement of the Supreme Court n. 2847/2010 in civil matters.

Law n. 219 of December 22, 2017 (Rules concerning Informed Consent and Advance Healthcare Directives)

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LEARNING AND EDUCATION RIGHTS

Art. 34 of the Italian Constitution "Schools are open to everyone..."

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FOREWORD

Law <u>n. 104 of February 5, 1992</u> (Framework Law on Disability) Art. 12 and 13

M.I.U.R Guideline, Protocol n. 4274/09 (School inclusion of disabled pupils)

The M.I.U.R's Commitment and M.I.U.R. Directive concerning Special Educational Needs (BES) and Local Support Centres (CTS) issued on December 2012

Law n. 107 of July 13, 2015 (Law on good school) Art. 1, Paragraph 180 and 181, Letter c and f

Legislative Decree <u>n. 66 of April 13, 2017</u> (Rules on promoting school inclusion of students with a disability according to Art. 1, Paragraph 180 and 181, Letter c) of Law n. 107 of 13th July 2015), and its amendments and supplements (Legislative Decree <u>n. 96 of August 7, 2019</u>).

This Decree rules the school inclusion of students with a certified disability as established by Law 104/92 and it should have been fully implemented by 1st January 2019.

These Decrees state that school inclusion will be implemented by defining and sharing an <u>Individual Educative Plan (PEI)</u> which is part of the Individual Plan (PI) established by Art. 14 of Law <u>328/2000</u>.

New provisions concern basically the following:

COMPETENCE AND CERTIFICATION

- 1) Identifying and rearranging which competence and performance are needed by the State, Regions and Local Authorities, in order to implement school inclusion. Noticeably, technical auxiliary staff (known as ATA staff) will be allocated considering the presence of disabled students and which gender those students belong to. This regulation will also define the professional profiles of the staff members whose job is to assist students enabling their autonomy and personal communication, according to the tasks of the school staff (Art. 3, Legislative Decree 66/17).
- 2) Assessment of the school, considering the school inclusion level achieved by each school institute according to the definition of specific standards (Art. 4, Legislative Decree 66/17).
- 3) Procedures of certifying and documenting for school inclusion. Application for disability assessment aimed at school inclusion must be submitted to the INPS, which will answer within 30 days (Art. 4, Legislative Decree 96/19). New framework of the Medical Commissions, following the modification of Law 104/92, has been

established by Art .5 of Legislative Decree 66/17. Assessment by the Medical Commissions is the prerequisite for the drawing up of the **Functioning_Profile**, which is set according to the <u>International Classification of Functioning</u>, <u>Disability and Health (ICF)</u> issued by the World Health Organisation. The Functioning Profile is set in order to draw an Individual Educative Plan (PEI), which is part of the plan set by the local authority together with the ASL on demand and in collaboration with the parents or legal guardian of the disabled child (Art. 14 of Law n. 328/00).

4) **The Functioning Profile,** established by Art. 12, Paragraph 5 of Law n. 104 of 5th February 1992, including and replacing the Functional Diagnosis and the Functional Dynamic Profile, according to the amendments established by Art. 5 of the Legislative Decree 66/17. This Profile is drawn by a multidisciplinary assessment team and it defines "which kind of professional skills and support are needed in order to achieve the school inclusion".

In November 2022, the Health Ministry dictated the <u>Guidelines for</u> the drafting of disability certificates for development age, for the <u>purpose of educational inclusivity and functional profile</u> (*Pdf 1.21 Mb*).

PEI - PI and INCLUSION TEAMS

5) The **Individual Educative Plan** (PEI), (Art. 7. Legislative Decree 66/17).

It is planned in full collaboration with the family and the Inclusion Team, as established by Art. 9, Paragraph 10, "considering the disability assessment and the Functioning Profile", and, "it identifies educational goals and objectives, tools, strategies and modalities in order to achieve... the meeting of the educational needs which have been identified". Furthermore, the Plan details, "modalities of support teaching, basic assistance and hygienic care". The Profile is "drafted by June, and it is usually set in its ultimate version within October".

The Interministerial Decree n. 182 of 29th December 2020, "Adoption of the national Model of individualized educational plan and related guidelines, as well as methods for allocating support measures to students with disabilities, in accordance with article 7, paragraph 2-ter of legislative decree of April 13, 2023" as amended by Interministerial Decree n. 153 of August 1, 2023, defines new modalities in order to assign the supporting measures established by legislative decree 66/2017, as well as the Individual Educative Plans (PEI) which are to be adopted in schools along with their guidelines (www.istruzione.it/inclusione-e-nuovo-pei).

6) The Inclusion Plan (Art. 8. Legislative Decree 66/17)

It will be defined by each school and it will be included in the 3-year-school plan educational offering. The Plan details how to use resources coordinatively, following the principle of reasonable accommodation, in order to overcome barriers and identify suitable facilitators in the given situation".

7) School Inclusion Teams.

Art. 9 of Legislative Decree 66/77 has been substantially modified by Art. 8, Paragraphs 4-9, of Legislative Decree 96/19.

A **Territorial Inclusion Team (GIT)** has been established in each Italian Province, as well as in the chief towns. The Team comprises teachers who are expert in school inclusion and it is coordinated by a technical manager or by a headmaster who chairs it.

The GIT coordinates its activity with the regional school office, supporting school institutes during the definition of the PEI.

While dealing with further tasks of counselling and planning, the GIT considers the advice of: a) the main local associations for disabled people; b) Local authorities and ASL.

Each school establishes a **School Inclusion Working Team (GLI)**, comprising teachers, resource teachers and possibly technical staff, as well as ASL specialists. The Team is nominated and headed by the headmaster, its aim is to support the faculty in defining and

implementing the Inclusion Plan, it also aims at helping teachers and school councils with the implementation of the PEI.

The School Inclusion Working Team takes into account the pupils' and their parents' advice, it may also be counselled by some representatives of the main local associations for disabled people.

A **School Inclusion Working Team** is established for each pupil with a disability, in order to define the PEI and check the process of school inclusion, including the quantification of special education teaching hour proposal. Each Team comprises the faculty or the class council, with the participation of parents and specialists. Pupils with a certified disability are fully entitled to take positively part into the Team, as established by Art. 8, Paragraph 10, of Legislative Decree 96/19.

QUANTIFICATION AND TEACHERS

- 8) Methods of quantifying, requiring and allocating special education resources.
 - Since 1st January 2019 the request of special education teaching hour edited by the Headmaster, will take place according to what is determined in the preparation of the PEI by the GLO, after the evaluation carried out by each PEI and the definition of the school inclusion plan, according to an integrated planning policy. Once he had consulted with the GLI, the Headmaster submits the request to the GIT, which as technical body of the USR verifies the documentation and the consistence of the requested number of teaching staff, submitting a related proposal to the USR. This will allocate the resources within the school staff (Art. 10, Legislative Decree 66/17). The period of the teaching assignment for special education teachers is five school years.
- 9) Introduction of new procedures for those who apply for the job as special education teacher in nursery and primary schools, following to the opening of a pedagogy and special education specialization course

(Art. 12, Legislative Decree 66/17). The enforcement date will be established by decree. Teaching assignments in high schools are ruled by the legislative decree on the initial teacher training.

CONTINUITY OF THE EDUCATIONAL AND TEACHING PLAN

10) The Headmaster may also propose school staff members as special education teachers, provided that they have the proper specialization; as regards supply teachers, their temporary contract may be prorogated for the next school year, weather there is a good teacher-pupil relationship and in case of request submitted by the pupil's family (Art. 14, Legislative Decree 66/17).

PERMANENT OBSERVATORY ON SCHOOL INCLUSION

11) It has been established the Permanent Observatory on School Inclusion, which is chaired by the Ministry of Education and it is formed by all the bodies involved in inclusion, including organizations and pupils, with the task of supporting the Ministry of Education (Art. 15, Legislative Decree 66/17).

HOME SCHOOLING (Art. 16, Legislative Decree 66/17)

School Attendance

Law n. 104 of February 5, 1992 (Framework Law on Disability)

Art. 12, Paragraph 1-2 – Inclusion of disabled children in day nurseries, learning and education rights for disabled people attending schools, universities and any other education provider.

Law n. 53 of March 28, 2003 (Resolution to the Government for Education)

Art. 2, c): "...inclusion of disabled people is established by Law n. 104/92 on reasonable adjustments...".

Law n. 62 of March 10, 2000 (On School Equality)

Schools must allow access for disabled pupils. They should promote the inclusion of disabled children in their admission arrangements and in all aspects of school life, as established by law.

Financial Help

Law n. 118 of March 30, 1971 (Law protecting invalid civilians) Art. 30: "Invalid civilians in financial difficulties are totally exempt from tax, including payment of school and university fees, if their impairment affects two thirds of their physical or mental ability, according to the application of benefits for war orphans, blind persons, invalids and their children."

Legislative Decree n. 68 of March 29, 2012 (Review of legislation on education right policy...) Art. 9, Prime Minister's Decree of 9th April 2001 Art. 8, Paragraphs 1, 7 and Art. 14 et seq.

As regards university fees, total exemption for disabled students affected by a 2/3 disability has been established by art. 9 of Legislative Decree 68/2012, as well as by Art. 8 of the Prime Minister's Decree of 9th April 2001, which demands the establishment of an exemption scheme for students with a disability inferior to 2/3 to the provisions taken by each university, and includes further help measures for disabled students as established by Art. 14 and the articles thereafter.

School Accessibility

Parents should give clear and detailed information to the school about their child's special needs (e.g. transport, assistance, nutritional needs, medications and appointments and special equipment).

Privacy: information about impairment of disabled pupils is sensitive personal data by Art. 22 of Law n. 196/2003.

On the website of the Data protection Authority, you can find the vademecum <u>The Privacy- friendly school</u>, (*Pdf 42 Mb*), a handy tool for educational institutions, teachers, students and families.

In August 2009, the Ministry of Education issued the "Guidelines for the School Inclusion of Disabled Pupils". This document is divided into three sections preceded by an introduction about the importance of school inclusion. The first section deals with the legislation, the second one explains organization and function of the Institutions of reference, the final section includes practical guidance for schools and families.

The Ministry of Education issued an invitation to tender (ITT) within the project Nuove Tecnologie e Disabilità – Azione 6 (New Technology and Disability – Action 6) to schools and education providers who are interested in developing research projects for technology and didactic innovation in order to improve the school inclusion of disabled pupils. The research projects approved in June 2008, which include the participation of many Italian schools from North to South Italy, led to the development of programs and software for disabled pupils. 25 hardware and software products about many different subjects, from Mathematics to ancient Greek, are currently downloadable free of charge. The following link to the Ministry of Education, University and Research website provides information about the project and access to the free downloadable products:

Applicativi per la Scuola elaborati dalle Scuole, da Alessandria a Barletta, in favore di situazioni di disabilità

(School Applications for Disabled Pupils projected by Italian Schools)

Please notice that the following reports are to be considered as archive data referring to the previous legislation.

Caring for a Disabled Pupil

The following link is to a part of the presentation on the topic "School inclusion and support", held by Dr. Vincenzo Bellentani on 14th June 2008 during the seminar "Gli Incontri del Sabato" organized by the Associazione Crescere, which is available for free download:

La Scuola: l'inclusione e il sostegno

(School inclusion and support)

The following link is to the presentation on the topic "Functional Diagnosis, Dynamic Functional Profile and Individual Educational Plan", held by Professor Maria Cristina Silvestri on 10th October 2009 during the seminar "Gli Incontri del Sabato" organized by the Associazione Crescere, which is free downloadable:

Diagnosi Funzionale, Profilo Dinamico Funzionale, Piano Educativo Individualizzato

(Functional Diagnosis, Dynamic Functional Profile and Individual Educational Plan)

Disability Support in Education

Law n. 104, February 5, 1992 (Framework Law on Disability)
Art.13, paragraphs 3/6

Ministry of Education, University and Research <u>Departmental</u> <u>Circular n. 3390/2001</u> (General Assistance for Disabled Pupils)

Prime Minister's Decree April 9, 2001 (Equal Rights and Fair Treatment for Disabled Students) Art. 14.

Art. 47 of the National Collective Employment Agreement (CCNL) of 16th May 2003, **and Art. 32 and 36** of the National Collective Employment Agreement (CCNL) of 26th May 1999 (it will be updated

by a Regulation issued by the second half of October 2017 implementing Art. 3 of Legislative Decree 66/2017).

Schools provide general assistance through school caretakers, who "help disabled pupils accessing and leaving school environments." School caretakers also give practical help with personal care tasks, e.g. using sanitary facilities, toileting and personal hygiene for disabled pupils.

<u>Italian State-Regions Agreement of March 20, 2008</u> (Support for disabled pupils) Art. 5:

Special care, care for autonomy and communication are provided by the Comuni (the local authorities) for nursery, primary and secondary schools, they are provided by the Provinces for higher education and by the ASL (the local health service), if paramedical personnel or experts in psycho-sociology are needed.

In September 2019, it was drafted a <u>Protocol for Drug Delivery</u> within educational settings in the Metropolitan City of Bologna.

Every school has an obligation to employ specialists like learning and teaching assistants for the inclusion and education of disabled pupils. (Law n. 104/92, Art. 13, paragraphs 3/6)

Schools generally employ one specialist teacher every two disabled pupils. (Italian State-Regions Agreement of March 20, 2008, Art. 5)

DSA: Specific Learning Disabilities

Ministry of Education, University and Research Note n. 4099/2004 (General Guidance on DSA: Specific Learning Disabilities)

Ministry of Education, University and Research Note n. 5744/2009 (Baccalaureate Examinations 2008-2009: Pupils with DSA: Specific Learning Disabilities)

U.S.R. E.R. Memorandum n. 1425/2009 (Practical Advice on DSA)

Emilia Romagna Governing Council Resolution n. 108 of February 1, 2010 (Regional Plan for DSA)

Law <u>n. 170 of October 8, 2010</u> (Provisions on DSA in school environment)), and its implementing rules in the Ministerial Decree of <u>July 12, 2011</u> including the attached <u>Guidelines</u>.

Italian State-Regions Agreement of July 25, 2012 (DSA Certification)

Interministerial Decree of 9th November 2021 published in the Italian Official Gazette n. 307 of December 28, 2021 (Compensatory tools for people with DSA in public competitions)

Law <u>n.25 of March 28, 2022</u> (Business and business operators support. – Art. 7 pro DSA)

People with DSA (Specific Learning Disabilities) have specific difficulties in reading (Dyslexia), writing (Graphic Dyslogia and Dysorthography), or in computing (Discalculia or numeracy problems), although they are normally intelligent. Almost 4% of the Italian Population is affected by DSA.

After two years of discussion, the Law on DSA in the school environment was issued on 19th October 2010, it recognizes DSA specifying that people with DSA have normal cognitive capacities and they do not have neurological disorders or sensory deprivation. The diagnosis of DSA is made by the National Health Service, while the school can help detecting DSA.

The Law on DSA in the school environment aims at granting equal rights and opportunities to people with DSA both in social and professional environments. In this sense, the law plans training courses for the school staff, financing them through *ad hoc* investments, specific teaching methods and a flexible timetable for families.

The power to implement these provisions is conferred on the Ministry of Education, University and Research (MIUR).

Implementing rules have been issued by the MIUR in the Ministerial Decree n. 5669 of July 12, 2011 including the attached <u>Guidelines</u>, which have been <u>updated</u> in 2022 by the National System guidelines of the ISS.

The MIUR had already issued policy provisions concerning Regional Council Education Departments (*Note n. 4099/2004*), and specific operational guidance for Baccalaureate Examinations (*Note n. 5744/2009*).

A new section of the MIUR website has been dedicated to DSA, including related legislation, documents, publications, and projects such as project *Nuove Tecnologie e Disabilità-Azione 6* (see paragraph on School Accessibility).

Following this trend in Emilia Romagna, the Regional Council Education Department (USR) issued operational advice *(Circular n. 1425/2009)*, while the Local Council Education Department (USP) in the Province of Bologna adopted the plan described in <u>Protocol n. 12860/A36b of November 11, 2008</u>.

The Region Emilia Romagna issued a regional plan on DSA (Resolution n. 108, February 1, 2010), including one section on DSA in the Resolution n. 1 of 11th January 2010 on school certification: CTS Marconi arranged a *Survival Guide for Families* using highly readable fonts (the Guide is in Italian).

The Interministerial Decree of 9th November 2021 (*Official Gazette n. 307 of 28 December 2021*) introduced provisions concerning compensatory tools for people with DSA to be implemented in public competitions; should these compensatory measures for people with DSA not be arranged the notification of public competition may be invalidated. Similar measures have been issued for private business sector by art. 7 c.2 bis e sg. of law n.25 of March 28, 2022.

Presentation slides on DSA, which are taken from the lecture presented by Professor Maria Cristina Silvestri during the meeting on SLD on 27 November 2010 as part of the seminar "Incontri del Sabato" (Saturday Meetings), organized by Associazione Crescere, are available clicking on this link.

Reference Website:

hubmiur.pubblica.istruzione.it/web/istruzione/dsa www.aditalia.org

The following link is to the presentation on "Specific Learning Disabilities (DSA): juridical, medical, educational, and psychological aspects", held on 9th October, 27th November 2010, and 8th October 2011 during the seminar "Gli Incontri del Sabato" (text in Italian):

I DSA: aspetti giuridici, medici, psicologici e didattici

(Specific Learning Disabilities (DSA): juridical, medical, educational, and psychological aspects)

Prof. Cristina Maria Silvestri: <u>Cosa sono e come affrontarli</u>

Dr. Graziana D'Addabbo: <u>Diagnosi differenziale e interferenze emotive</u>

Dr. Vincenzo Bellentani: USR ER - <u>Risorse per i DSA</u>

Dr. Michela Cappai: Programma Pro DSA

Accessible Technology and Learning Equipment

Law n. 104 of February 5, 1992 (Framework law on disability) Art. 13 b)

Decree of the President of the Republic n. 503 of 24 July, 1996 (Physical barriers in public buildings) Art. 23, Paragraph 3.

Law <u>n. 69 of March 22, 2000</u> (Fund for the inclusion of disabled pupils)

Legislative Decree n. 63 of April 13, 2017 (Effectiveness of education rights...), Art.7, Paragraph 3 (Teaching aids, etc.)

Accessible technology products, teaching and learning equipment must be already available in schools. Special equipment for the inclusion of disabled pupils must be provided to nursery, primary and secondary schools by the Comune (the local authority), and to high schools by the Province.

Physical Barriers

Law <u>n. 118 of March 30, 1971</u> (Law protecting invalid civilians) Art. 27.

Law <u>n. 41 of February 28, 1986</u> (Provisions on the drawing up of the State annual and multiannual financial framework), Art. 32.20: Physical barriers in Public Works.

Law n. 104 of February 5, 1992 (Framework law on disability) Art. 23 and 24.

Law <u>n. 23 of February 11, 1996</u> (Law on school building) Art. 2 and 3.

Decree of the President of the Republic n. 503 of July 24, 1996 (Regulation concerning provisions for the removal of physical barriers in public buildings, space and environment)

The removal of physical barriers has been assigned to the Comuni (local authorities) in nursery, primary and secondary schools, and to the Province in high schools (Law n. 23/96, Art. 3)

Buildings which have been built or restructured since 28th February 1986 must be accessible to disabled people (Law n. 41/86, Art. 32), buildings built before 28th February 1986 must be modernized so that disabled people can have access to them (Decree of the President of the Republic n. 503/96, Art. 23 "School Building").

Transport

Law <u>n. 118 of March 30, 1971</u> (Law protecting invalid civilians) **Art.** 28:

School transport for disabled pupils has been assigned to the Comuni (local authorities). The Province must provide transport for disabled pupils in higher education and for disabled students.

Home and Hospital Education

Law <u>n. 104 of February 5, 1992</u> (Framework Law on Disability) Art. 12, paragraphs 9/10.

Ministry of Education, University and Research, Departmental Circular n. 4308/2004

<u>Prime Minister's Decree n. 185 of February 23, 2006</u> (Regulation to determine pupils with disability), enforced until 31st December 2018.

Legislative Decree n. 63 of April 13, 2017 (Effectiveness of education rights...), Art 8, (School in hospitals...)

Legislative Decree <u>n. 66 of April 13, 2017</u> (Provisions on promoting school inclusion of disabled pupils...) Art. 16 (Home schooling)

Hospitals, private practices and paediatric centres provide schoolrooms for their young patients. Disabled children, even if in day hospital, are included in these schoolrooms, as well as other children who have been hospitalised for over 30 days.

Home education will be provided using also new information technologies, for pupils who cannot attend school for at least 30 days (not necessarily consecutive) because of certified severe diseases.

Learning Visits and School Excursions

Departmental Circular n. 291/92, Art. 8, Paragraph 2:

Disabled pupils can be accompanied by a teaching assistant or by any member of the school staff (teachers and school caretakers).

A disabled pupil can also be accompanied by one of his/her classmates aged 18 and over who volunteers.

Links and Useful Documents

Reference page on the Ministry of Education, University and Research website:

<u>hubmiur.pubblica.istruzione.it/web/istruzione/disabilita</u> <u>hubmiur.pubblica.istruzione.it/web/istruzione/famiglie/alunni_disabili</u>

This link is to <u>Focus con i dati statistici</u> ("Focus on school data") a publication by the Ministry of Education, University and Research concerning school integration in the school year 2014/2015.

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DETERMINING DISABILITY Delegation Law for Disability

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Law n. 118 of March 30, 1971 (Law protecting invalid civilians)

Law n. 18 of February 12, 1980 (Disability allowance)

Law <u>n. 508 of November 21, 1988</u> (Supplementary measures supporting invalid civilians)

Legislative Decree n. 509 of November 23, 1988 (Provisions in order to determine disability)

Ministry of Health Act of February 5, 1992 (Official Gazette n. 47/92 – Tables on disability percentages)

Law n. 80 of March 9, 2006 – Decree Law n. 4/06 (Provisions ... on organization and functions of Public Administration.) Art. 6.

Ministerial Decree of August 2, 2007 (Official Gazette n. 225/2007 - Determining diseases and disorders which are exempt from assessment ...)

Law n. 102 of August 3, 2009 – Decree Law n. 78/09 (Provisions contrasting crisis ...) Art. 20.

Law n. 111 of July 15, 2011 - Decree Law n. 98/11 (Financial Manoeuvre) Art. 38 and 18.

Law <u>n. 183 of November 12, 2011</u> (Stability Law 2012...changes - Art. 27 l. f)

Law <u>n. 98 of August 9, 2013 - Decree Law n. 69/13</u> (Dispositions on economic recovery) Art. 42 Ter.

Law <u>n. 99 of August 9, 2013 – Decree Law. n. 76/13</u> (First provisions...) Art. 10.5 (Income references)

Law <u>n. 114 of August 11, 2014 - Decree Law n. 90/14</u> (Urgent provisions on simplification, administrative transparency and efficiency of judicial offices) Art. 25.

Law <u>n. 120 of September 11, 2020 – Decree Law n. 76/2020</u> (Urgent provisions on simplification and digital innovation) Art. 29 Ter.

Law <u>n. 227 of December 22, 2021</u> (Delegation to the Government on Disability)

According to Art. 1 of Law n. 227 of 22nd December 2021, the Italian Government has been delegated to revise the legislation concerning disability by means of decrees to be issued within 20 months from the 31st December 2021, the deadline has been extended to the 15th of March 2024 (art.1 c.5 L. 24/2/2023 n,14), in order to ensure to people with disability the acknowledgement of their condition, the full exercise of their social and civil rights and to promote their autonomy and their equal opportunities.

According to Art. 2 of Law n. 227 of 22nd December 2021, the Government's decrees will concern the following scopes:

- a) definition of the condition of disability, revision, rearrangement and simplification of the related legislation;
- b) assessment of disability, revision of the assessment procedures and basic criteria;
- c) multidimensional evaluation of disability, planning and implementation of individual personalized participatory life projects for disabled people;

- d) computerisation of assessment procedures and data storage systems
- e) redevelopment of public services concerning inclusion and accessibility;
- f) establishment of a National Guarantor for disability;
- g) enhancement of the Office for the policy supporting disabled people established by the Prime Minister's Office.

Procedure to assess disability

The procedure to assess disability, deafness, blindness, and invalidity has been amended since 1st January 2010 by Law 102/2009.

The INPS (National Social Welfare Institution) issued explanatory notes on the new telematic procedure within the Circular n. 131 of December 28, 2009.

The new procedure named INVCIV2010 is based upon the use of telematic systems and it is divided into the following stages:

- Certification of the pathological cause of disability made by a doctor who has been qualified by INPS. The digital certificate will be sent in a specific INPS format supported by its software to INPS. The software assigns a code ICD9 automatically on the base of the diagnosis. (INPS Form AP68). As this certification has been included in the LEA (Essential Level of Public Medical Assistance), according to Annex 1, Paragraph G of the Prime Minister's Decree of 12 January 2017 (Official Gazette n. 65, 18th March 2017)
- Request for Disability Assessment (Law n. 104/92; Law n. 68/99) must be sent to INPS using a specific software. The request can be submitted either by a benevolent fund or the disabled person, as

- well as by her/his tutor, its validity expires up to 30 days since the delivery of the digital certificate. (INPS Form <u>AP66</u> and <u>AP67</u>)
- Visit Booking: At the moment of the digital certificate delivery the software produces a receipt and gives the chance of choosing the date of the visit, which must be booked within 30 days, or within 15 days for patients with severe conditions, according to Ministerial Decree of 2nd August 2007 (Italian Official Gazette 225/2007) and for oncology patients (Law n. 80/2006). It is allowed to attach all the related medical documentation which is deemed to be useful to their request (INPS Comunication n. 3315 of 1st October 2021). If a home visit is needed, this can be requested by the doctor. The visit can also be postponed. However, according to Art. 29Ter, which has been added to Decree Law 76/2020 by the law converting the decree, the Commission may decide, even upon request by the disabled person (Art. 29Ter, Paragraph 2), to make an assessment based on the documentation which has already been provided, without any visit.
- Disability Assessment: members of the Medical Commission may vary according to the type of assessment requested, but they include a doctor of the INPS, a social worker and an expert of the ASL, and a neurologist, psychiatrist or psychologist in case of mental impairment. The person to be assessed can be supported by his/her medical officer and submit documents and certification which may be useful for the assessment. The assessment report will be issued in a digital INPS format (Format E, according to Resolution n. 189/09), with indication of the code ICD9 and Ministerial Decree of 5th February 1992, which is being amended by Art. 20 c.6 of Law n. 102/09. The table included in the Ministerial Decree of 5th February 1992 concerns how disability may affect work capacities (Legislative Decree n. 509 of November 23, 1988 Art. 1, Paragraph 3, Art. 2 Paragraph 2)

- Check: If the disability request has been accepted but it does not meet unanimous approval by the Medical Commission, the INPS Medical Centre may substantiate it within 10 days or they can appoint a check visit in order to reassess the applicant within 20 days.
- Duration of the Procedure: it should take maximum 120 days between the submission of the request and the provision of benefits related to its acceptance.
- Access to Documents: the applicant with a PIN (personal identification number) related to his/her request can follow the whole procedure online until the 1st October 2020, then it will be necessary to use his/her SPID (Sistema Pubblico di Identità Digitale, "Public System of Digital Identity"), as explained by INPS Circular n. 87 of July 17, 2020, following the guidelines as set by the AGID whenever minors are concerned, which means getting the access to the INPS portal dedicated to disabled individuals using the C.I.E or C.N.S or elDAS.
- Right of Appeal: Claims for judicial review against INPS is the only possible procedure in order to appeal for a disability request which has been rejected within 180 days, an INPS doctor must be involved in the investigation. Further application for a disability assessment cannot be submitted if there is a pending action (Law n. 69/09, Art. 56, paragraph 2).

From 1st January 2012 claims for judicial review against INPS will be compulsorily preceded by a technical expert's report according to Art. 38 Point 1 of <u>Legislative Decree n. 98 of July 6, 2011</u> and <u>Art. 27.f of Law n. 183/11</u>.

NOTICE: According to Art. 18 Point 22 of <u>Legislative Decree n. 98</u> of <u>July 6, 2011</u> Regions can delegate to INPS the assessment procedure. According to INPS (October 2020) the Italian Regions which have already implemented this delegation are the following:

Basilicata; Calabria; Campania (only in the Provinces of Avellino, Benevento, Caserta, and Salerno), Friuli Venezia Giulia (only Pordenone); Lazio; Sicilia (only in the Provinces of Trapani, Caltanissetta, and Messina); Veneto (only in San Donà di Piave, Verona, and Venezia).

The ICD classification identifies approximately 250 rare diseases. More rare diseases should be included in the reviewed version of the classification which will be issued in 2014, according to the EU Recommendation in the field of Rare Diseases of June 2009; this review is essential, as national systems of benefits and assistance are based on ICD classification. (Council Recommendation of 8th June 2009 on an action in the field of rare diseases, paragraphs 10-12 and II.2.)

It is expected a simplified procedure for submitting the application concerning minors: as in the <u>INPS message n°4212 of 22/11/2022</u> and $n^{\circ}892 \text{ del } 2/3/2023$.

The following link is to the presentation headed "The New Procedure to assess Disability", which was shown on 15th April, 29th May 2010 and 4th June 2011 and 16th June 2012 during the seminar "Gli Incontri del Sabato" organized by Associazione Crescere:

La nuova procedura per l'accertamento dell'invalidità, handicap e disabilità (The new procedure to assess disability)

Dr. Fabrizia Capitani: Presentazione dell'INVCIV2010 (Pdf 468 kb)

Avv. Renzo Cristiani: Finalità della nuova procedura (Pdf 324 kb)

Dr. M.Caterina Manca: L'INVCIV2010 in Emilia Romagna (Pdf 401 kb)

Avv. Renzo Cristiani: <u>I ricorsi</u> (Pdf 186 kb)

Dr. Fabrizia Capitani: Le problematiche emerse dopo un anno di applicazione (Pdf 499kb)

Dr. M.Caterina Manca: <u>Il punto al 2012 sull'INVCIV2010 in Emilia Romagna</u> (Pdf 487kb)

Assessment Response

The Medical Commission provides a statement which certifies the level of disability and the related rights and benefits.

This statement can be as follows:

- 1. "Not disabled" because of the absence of diseases/disorders or with a reduction in work capacity inferior to 33%;
- **2. "Disabled"** with a reduction of work capacity over 33% (*Law n.* 118/71, *Art.* 2);
- **3. "Disabled"** with a reduction of work capacity over 74% (Law n. 118/71, Art. 2 and 13; Legislative Decree n. 509/88);
- **4. "Disabled"** with total and permanent incapacity for work (Law 118/71, Art. 2 and 12);
- **5. "Disabled"** with total and permanent incapacity for work and mobility impairment so that a permanent carer is needed (*Law n.* 18/80; *Law n.* 508/88);
- 6. "**Disabled**" with total and permanent incapacity for work and in need of permanent care as impairment totally prevents normal day-to-day activities (*Law n. 18/80; Law n. 508/88*);
- 7. "Blind" with chance of vision correction inferior to 1/20 for both eyes (Law n. 82/70; Law n. 508/88);
- 8. "Blind" with total visual impairment (Law n. 382/70; Law n. 508/88);
- 9. "Deaf" (Law n. 381/70; Law n. 508/88);
- 9a. "Deaf-Blind" (Law 107/2010);
- 10. "Impaired" with long-term difficulties in carrying out normal activities (Law 118/07, Art. 2; Law 289/90 Art. 1);

- 11. "**Impaired**" with mobility impairment so that a permanent carer is needed (*Law n. 18/80*);
- 12. "**Impaired**" in need of permanent care as impairment totally prevents normal day-to-day activities (*Law n. 18/80*).

More detailed information are available in the guidance which is free downloadable on the UILDM HandyLex website:

Come leggere i verbali di invalidità e di handicap

(How to understand reports on disability and impairment)

The guidance also shows benefits and assistance related to each specific conditions, including financial help, tax relief, assistance provisions, ticket exemption, benefit at work, etc..

Disability Assessment

Law n. 104 of February 5, 1992 (Framework law on disability) Art. 3 and 4.

Impairment is assessed through the same procedure in use to assess disability. The Medical Commission (see above, point 4 of the paragraph about "Procedure") will assess:

- Impairment, that is a condition which causes difficulties in inclusion (Law n. 104/92, Art. 3, Paragraph 1);
- Severe disability, that is a condition which needs permanent care (Law n. 104/92, Art. 3, Paragraph 3).

People can be affected by both an impairment and disability.

According to Art. 25.4 of Decree Law <u>n. 90 of June 24, 2014</u>, exclusively for the purposes described by Art. 21 and Art. 33 of Law 104/92, and by Art. 42 of Decree Law <u>n. 151 of March 26, 2001</u> (working paid parental leave and long term leave), it is established the following:

- If the Medical Commission described by Art. 4 of Law 104/92 does not provide a response by 45 days from the date of the application, a temporary assessment can be carried out by a doctor of the ASL who is a specialist in the given diseases;
- As result of its assessment, the Medical Commission described by Art. 4 of Law 104/92 can provide a temporary certification upon motivated request;
- A temporary assessment response provided by a doctor of the ASL, as well as a temporary certification by the Medical Commission is valid up to the issuing of the final assessment response.

QR Code and Disability Card

According to INPS message n. 4019 of 30th October 2020, the "QR Code dell'Invalidità Civile" is the new system which has been implemented for reading every report concerning legal disability, blindness, deafness and handicap. The QR Code can be read on any mobile device by dedicated applications such as "INPS Mobile", and it can be used to certify invalidity in real time, having thus access to the help and support established by the applicable legislation. Instructions are available (in Italian) in the following INPS communication of 25th January 2021:

QR-Code INPS for people with disability

People with over 66% of disability as well as people with over 35% inability are eligible for the <u>Disability Card</u> which must be required to the INPS. The Disability Card is a valid document in all the European Union States which serves as identity card. The Disability Card supplies for all the necessary documentation with the INPS QR Code and enables the access to all the services and facilities dedicated to disabled people (*Prime Minister's Decree of 6th November 2020, published in Italian Official Gazette n. 304 of 23rd December 2021 - INPS Communication <u>n. 853 of 22rd February 2022</u> and Circular <u>n.</u>*

<u>46 of 1st April 2022</u>). The EU Disability Card is also supported even by banks and banking foundations through a <u>protocol of understanding</u> between ABI and ACRI.

Care Plan Check and Review

Law <u>n. 80 of March 9, 2005 - Law Decree n. 4/06</u> (Provisions...organization and function of the Public Administration), Art. 6.

Law n. 102 of August 3, 2009 - Decree Law n. 78/09 (Provisions contrasting crisis ...) Art. 20.

Law <u>n. 98 of August 9, 2013 - Decree Law n. 69/13</u> (Dispositions on economic recovery) Art. 42 Ter.

Law <u>n. 114 of August 11, 2014 - Decree Law n. 90/14</u> (Urgent provisions on simplification, administrative transparency and efficiency of judicial offices) Art. 25.

Disorders, diseases and impairments for which check visits are excluded are listed in the Decree issued by the Ministry of Economy and Finance in collaboration with the Ministry of Health (Ministerial Decree of August 2, 2007 published in the Official Gazette n. 225 on 22nd September 2007). Medical documentations needed in order to give evidence of a disability and its related benefits are also listed in the decree." (Cf. Art. 6 of Decree Law 4/06 – Law 80/06; Art. 42 Ter of Decree Law 69/13 – Law 98/13), provisions are updated with M.D. of April 14, 2022 (in O.G. n.125 of May 30, 2022).

Moreover, Art. 6 of Decree Law 4/06 – Law 80/06 states that "Regions must enforce provisions in order to simplify and standardise procedures of health checks ... to be taken by specific Commissions on the same date and standards for every field that requires legal investigation".

According to Art. 25.6bis of Decree Law n. 90 of June 24, 2014 converted with modifications into Law 114/2014, pending of the assessment procedure financial benefits have been valid up to the final assessment response. Moreover, the same Art. established that the summoning to the visit is a task assigned to the INPS (*Cf. INPS Circular n. 10/2015*); this Circular reminds that checking for the persistence of disabilities is also a task given to the INPS (*Art.20, Paragraph 2 of Law 102/09*).

As stated by INPS <u>information note n. 1835 of 6th</u>, May 2021, should the person concerned not show up for the check visit, his/her financial benefits will be immediately suspended and he/she will be sent a notification requiring to justify his/her absence within 90 days. Should his/her justification be considered valid, the person concerned will be notified the rescheduling of his/her check visit, while should it be considered not justified or should the person concerned desert the rescheduled check visit his/her financial benefits will be revocated.

As soon as the notification is received, the person concerned can, as in the first proceeding, transmit additional medical documents online and the Commission will decide, even on specific request of the person concerned, to formulate their opinion on the state of the proceedings, without requiring an appointment. (INPS Communication $n.926 \text{ of } 25^{th} \text{ Febraury } 2022$).

Financial Benefits

Preface

Administrative procedures for the payment of financial support and benefits will be taken for disabled people who have been assessed eligible for them. Since 2000, regions have been ruling the financial support for invalid civilians, which are provided by the INPS, according to Legislative Decree n. 112/98, Art. 130.

Disability Living Allowance

Since 1992, new tables concerning the levels of disability have been issued according to the Ministry of Health Act of 5th February 1992 and Legislative Decree <u>n. 509 of November 23, 1988</u>, which amended Law n. 118 of March 30, 1971. Invalid civilians with 74% work inability are eligible for Disability Living Allowance.

Eligibility criteria:

- Age between 18 and 65;
- Level of disability between 74% and 99%;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court Judgement n. 187/2010);
- Annual income up to: see link at the end of this paragraph;
- Unemployed or not employable;
- Being unemployed, jobless or performing a work activity yearly paid **less than 4931**€ is a necessary condition in order to be eligible for this welfare benefit (<u>Msg INPS n. 3495 of 14th October 2021</u> <u>Msg INPS n. 4689 of 28th December 2021</u> ex art. 12 ter D.L. <u>n. 146 of 21st December 2021</u>, established by the conversion law n. 215 of 17th December 2021).

Rate: see link at the end of this paragraph.

The Disability Living Allowance is also paid to eligible disabled people who are part-time employed.

The Disability Living Allowance will be converted to a State Pension at the age of 65 (Art. 19 of Law 118/71).

Invalidity Pension

Invalid civilians with total and permanent work inability are eligible for Invalidity Pension (Art. 13 of Law <u>n. 118 of March 30, 1971</u>), if they are in financial difficulties.

Eligibility criteria:

- Age between 18 and 65;
- 100% disability;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court <u>Judgement n. 40/2013</u>);
- Annual income up to: see link at the end of this paragraph;

Rate: see link at the end of this paragraph.

The Invalidity Pension will be converted to a State Pension at the age of 65 (Art. 19 of Law 118/71).

People eligible for Invalidity Pension may be also eligible for Attendance Allowance, but they are not eligible for further benefits related to the same condition.

Attendance Allowance

Invalid civilians with a 100% disability due to physical or mental impairment and blind people are eligible for Attendance Allowance by Law n. 18/80, Law n. 508/88, and Art. 1 of Law n. 406 of March 28, 1968.

Eligibility criteria:

- No age limits;
- Citizens who have been assessed and certified as totally blind;
- Citizens whose disability due to physical or mental conditions has been recognized by the medical officer and either who are in need of permanent assistance in order to carry out normal day-to day activities, or who cannot ambulate without receiving help from a permanent carer;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court <u>Judgement n. 40/2013</u>);

- Not living in a care home whose costs are already paid by public services or institutes.

Rate: see link at the end of this paragraph.

Personal income does not affect Attendance Allowance.

Employed people may also be eligible for receiving Attendance Allowance, but people receiving Attendance Allowance are not eligible for further benefits related to the same condition ($Art.\ 1\ off\ Law\ n.\ 508/88$).

Coming of age, minors receiving Attendance Allowance, as well as those receiving Communication Allowance, will become eligible for allowances and other financial benefits due to adults with no need for further medical assessment, as established by Art. 25.6 of Decree Law n. 90 of June 24, 2014, provided that they meet the eligibility criteria listed in the given legislation. (Cf. INPS Circular n. 10/2015 and Msg INPS n°1446 del 18/4/2023).

INPS with message n°3347 of 26/9/2023, has recognized the continuation of the right to the accompanying allowance as provided by Law n° 18 of February 11, 1980, even in the case of free hospitalization, if the assistance provided by the healthcare facility is not exhaustive, subject to the issuance of suitable documentation by the same public hospital.

Pension for partially sighted people

People with vision capacity up to 1/20 for both eyes even after correction are eligible for a pension for partially sighted people if they are in financial need.

Eligibility criteria:

- No age limits;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court <u>Judgement n. 22/2015</u>);

- Annual income up to: see link at the end of this paragraph;

Rate: see link at the end of this paragraph.

Partially sighted people may also be eligible for a SPECIAL ALLOWANCE which is not affected by personal income, according to Law n. 508/88, Art. 3.

Rate of the special allowance: see link at the end of this paragraph.

People who receive a pension for partially sighted people are not eligible for further benefits related to the same condition.

Blind Person's Allowance

Blind people aged 18 and over are eligible for this allowance if they are in financial difficulties, according to Art. 8 of Law n. 66/62, while blind people aged under 18 are eligible for Attendance Allowance (Law n. 508/88, Art. 5), and when they come of age there will be no need for further medical assessment (see the paragraph above on Attendance Allowance as established by Art. 25.5 of Decree Law 90/14, and INPS Circular n. 10/2015 and Msg INPS n°1446 of 18/4/2023).

Eligibility criteria:

- Aged 18 and over;
- Be certified blind;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court Judgement n. 22/2015);
- Annual income up to: see link at the end of this paragraph;

Rate (it may be reduced for blind people living in a care home whose costs are already paid by public service or institutes): see link at the end of this paragraph.

Monthly Allowance for Disabled Children

Disabled children aged up to 18 are eligible for this allowance by Law n. 289 of October 11, 1990

Eligibility criteria:

- Age up to 18;
- Be certified "impaired child with permanent difficulties in carrying out normal activities for his/her age" or "impaired child with deafness who cannot hear in his/her best ear sounds over 60 decibels";
- Attending local practices or day-care centres, either public or private, which are approved by the ISS and specialized in medical treatment or rehabilitation for disabled people. Attending schools, either private or public (this is due for the whole compulsory school attendance period, provided that leaving school must be notified, as established by Art. 6 letter *d-bis* Paragraph 3 of Legislative Decree n. 70 of May 13, 2011 which modified Art. 2 of Law 289/90), including nursery schools (See Italian Constitutional Court Judgement n. 467/2002), and training centres;
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court <u>Judgement n. 329/2011</u>);
- Annual income up to: see link at the end of this paragraph;

Rate provided for the rehabilitation period or school attendance: see link at the end of this paragraph.

Disabled children who receive a monthly allowance are not eligible for neither Attendance Allowance or Communication Allowance, as well as the Special Allowance for partially sighted people.

According to Art. 25.5 of Decree Law <u>n. 90 of June 24, 2014</u>, one can apply for financial benefits due to impaired adults six months prior to the date of coming of age. This will be provided temporarily, pending the assessment of meeting the given eligibility criteria. (Cf. <u>INPS</u> Circular n. 10/2015 and Msg INPS n°1446 of 18/4/2023).

Communication Allowance

Children aged up to 12 are eligible for the Communication Allowance if the quietest sounds they can hear in their better ear average between 500-1000 and 2000 frequency in Herz, that is over 60 decibels.

Children over 12 are eligible for the Communication Allowance if the quietest sound they can hear is over 75 decibels.

Eligibility criteria:

- No age limits (see previous indications);
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court Judgement n. 230/2015);
- Be certified deaf as previously specified;
- No income limits.

Rate: see link at the end of this paragraph.

Children who receive the Communication Allowance may also be eligible for Attendance Allowance but they are not eligible for a Monthly Allowance.

Coming of age, minors receiving Communication Allowance, as well as those receiving Attendance Allowance, will become eligible for allowances and other financial benefits due to adults with no need for further medical assessment, as established by Art. 25.6 of Decree Law n. 90 of June 24, 2014, provided that they meet the eligibility criteria listed in the given legislation. (Cf. INPS Circular n. 10/2015 and Msg INPS n°1446 of 18/4/2023)

Allowance for the Deaf

Deaf people are eligible for this allowance if they are deaf from birth or early childhood and in financial difficulties. deaf people whose disability is due either to mental disorders or war or work injury are not eligible for this allowance even if they are in financial difficulties.

Eligibility criteria:

- Aged between 18 and 65;
- Be certified deaf:
- Italian citizen or foreign citizen, either with or without residence permit (See Italian Constitutional Court <u>Judgement n. 230/2015</u>);
- Annual income up to: see link at the end of this paragraph.

Rate: see link at the end of this paragraph.

People who receive this allowance are not eligible for further financial benefits related to the same disability.

This allowance will be converted to a State Pension for deaf people aged 65 and over.

Please notice that they who have been certified as deaf-blind will receive financial support and benefits concerning their disabilities on the basis of comprehensive criteria (Art. 2 of Law 107/2010).

Allowance rates and income limits related to the financial benefits which have been previously described are regularly updated and readable clicking on the following link:

Allowance Rates and Income Limits 2014-2015
Allowance Rates and Income Limits 2015-2016
Allowance Rates and Income Limits 2017-2018
Allowance Rates and Income Limits 2018-2019
Allowance Rates and Income Limits 2019/2020
Allowance Rates and Income Limits 2020/2021
Allowance Rates and Income Limits 2021/2022
Allowance Rates and Income Limits 2021/2022

Exception to the previous legislation concerns the following:

Disabled Workers

Law <u>n. 222 of June 12, 1984</u> – (Amendments on Disability Pension legislation)

Workers, either employees or self-employed, covered by a (compulsory) INPS insurance, who have been assessed a reduced work capacity due to disability, mental or physical impairment which is not the result of civil or military service are liable to the following:

The assessment procedure is telematic, as well as the procedure named INVCIV2010, and it starts filling and filing the simplified form INPS SS3. After that, the application must be sent according to the provision stated by INPS Circular n. 91 of July 2, 2012 within 90 days.

Financial benefits are the following:

Disability Allowance (Art. 1 of Law 222/84)

Eligibility criteria:

- Age between 18 and 65;
- 5 years of creditable service, at least three of them shall be paid in the five year period prior to the date of application;
- Level of disability over 67%.

The amount of the Disability Allowance is calculated according to the contributory pension scheme since 31st December 1995, and according to the retributory (or mixed) pension scheme whether or not a 18 year creditable service has been already paid by the time of the application.

The Disability Allowance will be converted to a State Pension for people of retirement age.

The Disability Allowance is not affected by personal income

Note that as regards social security contributions, both employees who are deaf, as established by Law 381/70, and employees with a certified disability over 74% can apply for a personal credit of 2 months of social security contribution every year of certifiable work that they have done since January 2002, up to a maximum of 5 years of personal credit, according to Art. 80, Paragraph 3 of Law <u>n. 388 of December 23, 2000</u>.

Ordinary Pension of Inability (Art. 2 of Law 222/84)

Workers with total and permanent work inability are eligible for the Ordinary Pension of Inability, as the eligibility criteria, as well as the calculation of the amount, are the same established for the Disability Allowance.

The Invalidity Pension is not dependent on your annual income and, despite the Disability Allowance, any work activities are inconsistent with its payment.

Survivor's Pension to Invalid Persons

Law <u>n. 903 of July 21, 1965</u> (*Pension Reform on Social Security*) – Art. 22

Beneficiaries of a survivor's pension, provided that they are both **unable to work** and were **dependant** of a deceased retiree, and whose income is below the related income limits, are the following:

- The children, regardless their age;
- Unmarried brothers or sisters, provided that they still do not perceive a pension and only in absence of other beneficiaries.

Specific percentages of pension benefits due to each beneficiary are indicated in the same Article.

Dependant is a person who has been continually supported by the retiree before his/her death.

Unable to work are people whose impairment, either physical or mental, completely prevent them to work profitably, according to Art. 39 of Presidential Decree <u>n. 818 of April 26, 1957</u> and Art. 2 of Law 222/84.

Links and Useful Documents

Online Reference: <u>SuperAbile</u>, website managed by INAIL (the Italian Workers' Compensation Authority), see especially the webpage "*L'esperto risponde*"

The following link is to the presentation "Disability and Starting Work", held by Dr Fabrizia Capitani, S. Orsola-Malpighi Policlinic in Bologna, on 28th March 2009 during the seminar "Gli Incontri del Sabato" organized by the Associazione Crescere. The presentation is free downloadable:

L'invalidità e l'avvio al lavoro

(Disability and Starting Work)

The above presentation also deals with the following topics: assessing disability, work rights for disabled people, exemptions from payment. It makes reference to the legislation of Region Emilia-Romagna, where a law simplification by Art. 6 of Law n. 80/2006, according to Regional Law n. 4 of February 19, 2008 came into force. It does not include the new assessment procedure established by Law 102/09, which has been in force since 2010.

On 5th November 2020, the INPS has issued a guide (in Italian) on <u>RIGHTS AND PROTECTION IN CASE OF ONCOLOGICAL DISEASES</u>, (Pdf 193kb) "A short handbook which may give help and orientation to those who have to deal, directly or indirectly, with such difficult issues", it contains useful information for everybody.

The following link is to the Italian hypertext guide:

Invalidità civile. Guida pratica alla conoscenza: la procedura, i diritti, i benefici

(Disability, a practical guide to procedures, rights and benefits)

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RIGHTS IN WORK

Art. 4 of the Italian Constitution: "The Republic recognises the right of all citizens to work..."

- Social cooperatives, type b)
- Social Farming
- Special Employment Rights
- Links and Useful Documents

Main Legislation

Law n. 381 of November 8, 1991 (On cooperative societies)

Law n. 104, February 5, 1992 (Framework law on disability), Art. 17-20

Law <u>n. 68 of March 12, 1999</u> (Provisions on work rights of disabled people)

Legislative Decree n. 276 of October 9, 2003 (Implementation of delegation on Occupation and Job Market established by Law n. 30 of February 14, 2003); Art. 14 has been abrogated by Law 247/07 and subsequently reinforced by Law 133/08

Law n. 141 of August 18, 2015 (Provisions on social farming)

Legislative Decree n. 151 of September 14, 2015 (Provisions on streamlining and simplification of procedures and tasks required to enterprises and citizens, along with provisions on employment relationships and equal opportunities, enforcing Law n. 183 of 10th December 2014)

Ministerial Decree of 6th February 2018 (Establishment of a national board for integration of disabled people at work), published in the Official Gazette n. 77 on 3rd April 2018

Directive of June 24, 2019, by Prime Minister (Guidelines regarding the legally Protected categories mandatory hiring) in O.G. n. 213 of September 11, 2019

Ministerial Decree n. 43 of March 11, 2022 (Guidelines regarding disability hiring quota)

Law <u>n.78 of June 21, 2022</u> (Delegating the Government for public contracts matters) Art. 1 c. 2 l. h

Social Cooperatives, type b)

Social cooperatives which aim at including disabled workers and disadvantaged people in sectors, apart from social care, health and education, are ruled by Art. 1b) of Law n. 381 of November 8, 1991, and they are therefore called Social Cooperatives type b).

By Art. 3.4 of the same Law, disadvantaged people include alcoholics, drug-addicts, convicts who have been admitted to non-custodial measures, and so on.

As much as for the targeted employment, the invalidity percentage must be over 45% and certified by a qualified commission, according to the <u>INPS Circular n. 226/92</u>, which also includes further implementation specifications.

At least 30% members of a social cooperative must be disadvantaged people, and no contributions are due for their national insurance.

Note that as regards social security contributions, both employees who are deaf, as established by Law 381/70, and employees with a certified disability over 74% can apply for a personal credit of 2 months of social security contribution every year of certifiable work that they have done since January 2002, up to a maximum of 5 years of personal credit, according to Art. 80, Paragraph 3 of Law <u>n. 388 of December 23, 2000</u>.

Social cooperatives have specific features, their members can be:

• not more than 50% volunteers, who are only eligible for reimbursement of expenses, as well as in the Non-Profit

Organizations, and for insurance covering against accidents at work and occupational diseases;

- natural or legal persons.
- professional advisers and counsellors, such as legal advisers, by way of derogation from Art. 10 of Law n. 1815/39.

Normal members must form the majority of members having the right to vote.

Social cooperatives, as well as Non-Profit Organizations, have tax relief on inheritance and gift tax, etc. Operating profits are tax free, but members cannot share them, since they must be saved or reinvested.

Note that public societies can collaborate with social cooperatives, by way of derogation from the legislation on Public Administration, provided that they comply EU Directives on Public Procurement (Art. 5) and that they do not concern the social care, health and education sectors.

Companies can partially comply with the obligatory employment percentage established by Law 68/99 by stipulating conventions for the provision of services to Social Cooperative, type B, according to Art. 14 of Legislative Decree <u>276/2003</u>.

Social Cooperatives who comply with the legislative standards and requirements qualify to be legally considered social enterprises (Art.1.4 of Legislative Decree D.Lgs. n. 112 of July 31, 2017).

Here it is an Italian example of <u>Statute of Social Cooperative type b</u>) which includes many possible options, as well as an <u>initiative</u> (encompassing either a social cooperative type b) and a social cooperative type a)), which was presented during the Prader Willi Regional Meeting of the Emilia Romagna Region on 17th September 2011.

Social Farming

According to Law <u>n. 141 of August 18, 2015</u> social farms are those farm enterprises whose mission includes the following:

Art. 1.a) Socio-occupational integration of workers with a disability and disadvantaged workers as established by Art. 2, Paragraph 3) and 4) of Regulation (EU) n. 651/2014 of the Commission of 17th June 2014, and of disadvantaged workers as established by Art. 4 of Law n. 381 of 8th November 1991 with later amendments, and of working-age minors who are involved in rehabilitation and social support projects.

Art. 1.c) Providing supplies and services which assist and support medical, psicological and rehabilitation therapies aimed at improving the health social-functioning cognitive and emotional conditions of the interested people, also by means of rearing animals and plants.

Art. 6 defines which kind of measures are to be taken to support social farming, as giving social farms priority in invitations to tender for supply contracts of agri-food products intended for school or hospital canteens (Art. 6.1), and in the allocation of government or confiscated land (Art. 6.3).

Special Employment Rights

Target recruitment is ruled by Art. 2 of Law n. 68 of March 12, 1999.

"Target recruitment of disabled people involves technical equipment and support in order to assess fairly the work ability of people with a disability and include them at work considering their abilities. Target recruitment also involves support schemes, actions and making adjustments to the physical environment, equipment and employees' behaviour in order to improve the inclusion of disabled people in the workplace."

It is unlawful for the employer to give a task to a disabled worker which he/she cannot carry out because of his/her disability. (Law n. 68/99, Art. 10, Paragraph 2)

Art. 1 of the same Law lists categories of disabled people who are eligible for **obligatory recruitment**:

- disabled people with mental and/or physical impairment, or sensory deprivation which causes over 45% work inability certified by a Medical Commission;
- disabled people with over 33% work inability certified by the INAIL (the Italian Workers' Compensation Authority);
- blind and deaf people;
- people with a disability due to war injury and invalid civilians.

Disabled people listed above are eligible for obligatory employment by Art. 3 of the same Law. Public and private employers have an obligation to employ disabled people according to the following percentages:

- 50 employees: 7% disabled employees;
- between 36 and 50 employees: 2 disabled employees;
- between 15 and 35 employees: 1 disabled employee.

Notice:

Law n. 68/99, Art. 4 on the criteria for calculating the obligatory employment percentages; Art. 7-10 of the same Law on starting up work schemes for disabled employees, and Art. 11-13 on financial benefits for employers recruiting disabled people.

Similarly, companies redeploying workers with a disability are eligible for financial benefits provided by the INAIL (Art. 1 c.533 Law n. 145 of December 30, 2018).

As previously stated above, companies can partially comply with the obligatory employment percentage established by Law 68/99 by stipulating conventions for the provision of services to Social Cooperative, type B, according to Art. 14 of Legislative Decree 276/203.

Unlike public institutions, private companies having more than one factory/office in Italy can comply with the obligatory employment percentage by employing disabled people only in one of their factories/offices (*Art. 5 Law n. 68/99* complying with Art. 9 of Legislative Decree n. 138/2011).

The Prime Minister's Office issued, for public administrations, the **guidelines on mandatory employment** on 24th June 2019, which was published in the Official Gazette n. 213 of September 11, 2019.

By decree of the Minister of Labour, n. 43 of March 11, 2022, published on the institutional website of the Ministry, have been issued, according to the ONU Convention's principles regarding the rights of people with disabilities and to the forecast of the Legislative Decree 151/2015, the "Guidelines regarding the disability hiring quota", which concern:

- Services for active employment policies and for the disability hiring quota;
- The process that needs to be followed by the employer who hires individuals with disabilities, by law 68/1999;
- Integrated network in the activation path of the individual with disabilities;
- The local agreements;
- The bio-psycho-social evaluation of the disability;
- The analysis of the workspace's characteristics and of the reasonable accomodations;
- The director of job placement of individuals with disabilities;
- Good practices for work inclusion.

In the following link you can find the <u>presentation</u> of the guidelines (*Pdf 5744 Kb*) made by the Ministry of Labour.

As regards employment in Public Administration, eligible people with disabilities can be employed notwithstanding the amount of job places reserved in the related open recruitment, so that to cover the reserved share. (Art. 16 of Law 68/99 as indicated by Art. 25 of Decree Law 90/2014). Furthermore, disabled people with at least 80% disability are exempt from prequalification recruitment exams, in case these are scheduled. (Art. 20 of Law 104/92, as indicated by Art. 25 of Decree Law 90/2014)

In a similar way to previously established for social cooperatives, art. 1 c.2 l.h of delegated laws for public contracts (Law 78/22), it is intended to provide contracting authorities with "the ability to reserve the right to participate in the tender process as well as granting business operators whose main scope is social and professional integration of those with disabilities or disadvantages."

Disabled employees may be eligible for the **Attendance Allowance**, even if they are aged over 65 (*Law n. 508 of November 2*, 1988).

Links and Useful Documents

Ministry of Works website:

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WORKERS' RIGHTS

Disabled workers and their families share the same employment rights as other workers. However, there are some special rights for disabled workers, they may concern:

- Paid Leave
- Other Paid Leaves
- Night Work
- Occupational Pension Rights for Disabled Workers
- Place of Employment
- Links and Useful Documents

General Considerations

Telematic Application

People employed in the private sector and any worker, including civil servants (INPS Circular n. 114/2008), who receives financial assistance from the INPS (e.g. paid maternity leave, paid parental leave, daily leave, other paid leaves established by Law 104/92), must submit applications only by electronic data transmission as established by INPS Circular n. 171 of December 30, 2011.

Law n. 104 of February 5, 1992 (Framework law on disability) Art. 33.

Law <u>n. 53 of March 8, 2000</u> (Provisions on maternity support) Art. 20.

Legislative Decree <u>n. 151 of March 26, 2001</u> (Consolidated law on maternity support and protection) **Art. 42**.

Law n. 183 of November 4, 2010 (Further provisions on work...)
Art. 24.

INPS Circular n. 41 of March 16, 2009

INPS Circular n. 155 of December 3, 2010

INPS Circular n. 45 of March 1, 2011 (Including provisions for INPS employees)

INPS Circular n. 171 of December 30, 2011

Legislative Decree n. 119 of July 18, 2011 (Delegation to the Government for the reassessment of the legislation concerning paid leaves)

INPS Circular n. 32 of March 6, 2012 and its related Circular n. 1 of February 3, 2012 by the Dipartimento della Funzione Pubblica*

INPS Circular n. 159 of November 15, 2013 (Extension of the right to paid leave, as established by Art. 42 point 5 of Legislative Decree n. 151 of 26th March, 2001, for a relative up to the third degree of relationship or a legal tutor living with a person with severe disability).

Legislative Decree n. 81 of June 15, 2015 (On employment contracts)

Legislative Decree n. 105 of June 30, 2022 (Implementation of the EU directive 2019/1158 of the European Parliament and Council, of June 20, 2019, regarding the balance between professional activity and family life for parents and carers and which abrogates the directive 2010/18/EU of the Council).

Paid Leave

The enforcement of Law n. 183 of November 4, 2010 introduced new provisions on permit by Art. 24, which modified Art. 33 of Law

The Dipartimento della Funzione Pubblica is an administrative department in the Italian public administration.

104/92. These new provisions, which are specifically referred to in the next paragraphs, mainly concern the following topics:

- Reduction of persons who are eligible for a paid leave.
- Abrogation of paid leaves which are provided to parent workers alternatively, since only one parent can claim for a paid leave, apart from parents of children with severe disability. The above provision has been replaced with the introduction of Legislative Decree 105/2022 which removes the nominated *Referente Unico*.
- Abrogation of the eligibility criteria of cohabitation, continuity and assistance.
- The carers' right to choose the nearest place of employment to the home of their person in need of care.
- Abrogation of benefits in case of not eligibility according to the criteria established by the new legislation.
- Creation of a benefits database by the Dipartimento della Funzione Pubblica*.

As previously explained (see General Considerations), since 1st April 2012 applications for paid leaves and leaves of absence must only be submitted to the INPS by electronic data transmission (e.g. online, by the CAF^{**}, or by calling the Helpline 803 164).

A) Parents, Relatives and Tutors, Partners in civil union including homosexual civil unions (*Circ. INPS n. 36 of March 7, 2022*)

- 2 hours daily leave:

public administration.

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^{*} CAF is the acronym for Centro di Assistenza Fiscale, a kind of Italian service centres providing tax and accountancy advisory.

For working parents, either mother or father alternatively, of children up to three years old with a severe disability certified by an ASL Medical Commission, provided that disabled children do not live in care home or institutes (unless parental assistance has been required by the medical staff, according to Art. 3, Paragraph 1(a, and Art. 4, Paragraph 1(b of Legislative Decree 119/2011).

A daily leave is paid at 100% of a normal wage and become an alternative to the Additional Parental Leave or to further leave described below.

(Law n. 104/92, Art. 33, Paragraph 2; Law n. 53/00, Art. 20; Legislative Decree 151/01, Art. 42; Law n. 183/10, Art. 24)

- 3 days monthly leave:

For parents, and spouse with disabled people who do not live in care home or institutes (unless parental assistance has been required by the medical staff, according to Art. 3, Paragraph 1(a, and Art. 4, paragraph 1(b of Legislative Decree 119/2011), and are certified with severe disability, AND for relatives up to the second degree of relationship in case of people with certified severe disability whose parents or spouse are absent, either dead or divorced, elderly (over 65 year old) or affected by progressive conditions.

(Art. 6 of Legislative Decree 119/2011 modifying Paragraph 3 of Art. 33 of Law 109/92) and Art.3 c.1 l.b n.2 D.Lgs. 105/2022 - INPS announcement n. 3096 of August 5, 2022)

While formerly single parents, including adoptive parents, were able to benefit otherwise from these permissions, meanwhile, and in other cases, it was up to a single subject (nominated *Referente Unico*), as per Legislative Decree 105/2022, and clarified by the INPS Message n. 3096 of August 5, 2022, has amended article 33, section 3, of the Law n. 104/1992, and is made clear that, notwithstanding the maximum limit of three days, assistance for the same individual with disability in a serious situation, has the right to be recognised, upon

request, by more than one subject amongst those entitled, that can benefit from it as alternatives to each other.

The criteria of permanency and exclusiveness for carers has been abrogated by Law n. 183/10.

Should the assisted person live in a Comune which is situated farer than 150 km from the caregiver's residence, the worker is required a documentation certifying his/her arrival to the residence of his/her assisted person.

(Art. 6, Paragraph 1b of Legislative Decree 119/2011)

A 3-day monthly leave must be taken in the month of reference for three days, either consecutive or not (INPS informative notes n. 15995/2007 and 16866/2007). Should it be taken fractionated in hours, there is a limit to the number of hour leave, which results dividing the number of the working hours per week by the working days per week, multiplied with three.

A monthly leave must be taken in the month of reference for three days, either consecutive or not.

A 3 day monthly leave can be paid to one parent even if the other one is not eligible for it.

Parents of children under three years old are also entitled to take a 3 day monthly leave, which can be extended to disabled children aged over 18.

(Law n. 104/92, Art. 33, Paragraph 3; Law n. 183/10, Art. 24)

More uxorio cohabiting partner

Art. 33, Paragraph 3 of Law 104/92 has been declared unconstitutional by the Italian Constitutional Court, where it does not include the *more uxorio* cohabiting partner "among those who are eligible to a monthly paid leave in order to assist a disabled person in severe conditions" as alternative to the spouse, tutor or to relatives up to the second degree of relationship"

(<u>Judgement n. 213/2016</u> published on the Italian Official Gazette of September 28, 2016)

Paternal daily leave for fathers married to a housewife

(Legislative Decree n. 151/01, Art. 40)

B) Disabled Claimants

Disabled workers can claim a monthly leave for three days.

(Law n. 104/02, Art. 33, Paragraph 6; Legislative Decree n. 151/01, Art. 42)

In this case, if the disabled claimant receives care from a relative, they must take their monthly leave at the same time (INPS Circular n. 128 of July 11, 2003).

Monthly and daily leaves are paid 100% of a normal wage by Law n. 102 of August 3, 2009 and by art 17, Paragraph 23 of the Decree contrasting crisis, which abrogated some limits previously imposed by Art. 71, Paragraph 5 of Law n. 133/08, also known as "Legge Brunetta" (*The Brunetta Act*).

Other Paid Leaves

- Long-term Parental Leave:

Parents of children up to 12 (formerly 8) years old have the right to apply, alternatively, for a parental leave for 10 or 11 months according to different cases, as established by *Legislative Decree n. 151/01*, *Legislative Decree n. 80/2015 and related INPS announcement n.* 4576/2015).

Long-term parental leave may be taken for longer periods, up to 3 years (Law n. 104/92, Art. 4, Paragraph 1; Legislative Decree n. 151/01, Art. 33, Paragraph 1), for parents of children with severe disability certified by ASL Medical Commission who do not live in care home or special institutes (unless parental assistance has been

required by the medical staff). A 3 year parental leave includes the period of the standard parental leave (Art. 3 of Legislative Decree 119/2011, INPS Circular n. 32/212 and Circular of the Dipartimento Funzione Pubblica n. 1/2012). As an alternative to long-term parental leave, parents can take permits as established by Art. 42, Paragraph 1 of Legislative Decree 151/01 (i.e. 2 hours a day).

Parental leaves established by Art. 32 are due to working parents of children up to 6 year old (Legislative Decree 151/01, Legislative Decree n. 80/2015 and related INPS announcement n. 4576/2015). They are paid 30% of the standard wage for no longer than 6 months in all, calculated by considering the sum of parental leaves taken by both parents (Art. 34, Paragraph 1, Legislative Decree 151/01).

Instead of a parental leave or within the limits of their permits as established by Part V of Legislative Decree n. 151 of March 26,2001, workers have the right to negotiate, just once, a switch from full-time to part-time job, with a working time reduction of maximum 50% (Art. 8, paragraph 11, Legislative Decree 81/15).

Paragraph 1 of the above Legislative Decree will be implemented for the prolonged parental leave period established by Art. 33 (children with a disability).

Other parental leaves established by Art. 32 and different from those described by Paragraphs 1 and 2, are paid 30% of the standard wage to working parents of children up to 8 year old (Legislative Decree 151/01, Legislative Decree n. 80/2015 and related INPS announcement n. 4576/2015), provided that personal income does not exceed two and a half times the amount of the minimum retirement pension covered by the mandatory general insurance (Art. 34, Paragraph 3, Legislative Decree 151/01).

As previously explained (see General Considerations), since 1st October 2011 applications for parental leaves must only be submitted

to the INPS by electronic data transmission (e.g. online, by the CAF**, or by calling the Helpline 803 164).

- 2 Year Parental Leave:

Parents of a disabled child with a certified severe disability who does not live in care home or special institutes (unless parental assistance has been required by the medical staff), can get a 2 year parental leave immediately, thanks to Art. 3, Paragraph 106 of the Finance Act 2004 n. 350 of December 24, 2003 which modified Art. 43, Paragraph 5 of Legislative Decree n. 151 of March 26, 2001. Any parental leave will not be considered in calculations of vacation pay, Christmas bonus, and severance pay.

Priority for a parental leave up to 2 years is given first to the spouse of the disabled person, then, if the spouse is absent or dead, to one parent, including adoptive parents, eventually to one son or daughter, and finally to one brother or sister, living with a disabled person whose parents are dead. (Art. 4 of Legislative Decree 119/2011 which abrogated Paragraph 5 of Art. 42 of Legislative Decree 151/2001), or to the non-marital cohabitant according to Legislative Decree 105/2022 by EU directive 2018/1158.

Relatives who take a parental leave must both live with the disabled person and take up residence in the same house.

Following the Supreme Court judgement n. 19 of January 26, 2009, the INPS issued <u>Circular n. 41 of March 6, 2009</u>, and subsequently <u>Circular n. 32 of March 6, 2012</u> specifying persons entitled to take a 2 year parental leave, who are listed in priority order.

Following judgment of the Supreme Court n. 203 of July 18, 2013, the INPS, with <u>Circular n. 159 of November 15, 2013</u>, established that a relative up to the third degree of relationship or tutor living with

* CAF is the acronym for "Centro di Assistenza Fiscale", a kind of Italian service centres providing tax and accountancy advisory.

the disabled person can be eligible for a 2 year parental leave in case of absence, death or disabling disease of the person who is primarily entitled to the leave.

INPS, with message n°4143 of 22/11/23, clarified that:" while it remains that extraordinary leaves cannot be granted to more than one worker for the care of the same person with severe disabilities, it is instead possible to authorize both the use of the aforementioned leave and the use of permits under art. 33 of Law n° 104/1992 for multiple workers caring for the same person with severe disabilities, alternatively and as long as not used during the same days".

As previously explained (see General Considerations), since 1st January 2012 applications for parental leaves must only be submitted to the INPS by electronic data transmission (e.g. online, by the CAF**, or by calling the Helpline 803 164).

Parental Leave and its extension are also due in case of custody and adoption, either national or international. (Legislative Decree n. 151/01, Art. 36-37, and 45).

- Paid Leave for Healthcare treatment due to Invalid Workers

Invalid workers who have been certified at least with a 50% work impairment are eligible for a paid leave for healthcare treatment every year, for a period up to 30 days. (Legislative Decree 119/2011, Art. 7).

The application to be submitted by the invalid worker to their employer must be accompanied by the related request by a physician of the National Healthcare Service who certifies the need for medical treatment related to the invalidity of the applying worker.

Notice that any working parents are entitled to take a 2 year parental leave because of compelling grounds; this type of parental leave is not paid and not included in the calculation of occupational pension

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^{*} CAF is the acronym for "Centro di Assistenza Fiscale", a kind of Italian service centres providing tax and accountancy advisory.

rights, although it can be repaid and therefore considered in the calculation related to pension rights (Law n. 53/00, Art. 4, Paragraph 2).

Dr Matteo Naldi explained the system of parental leaves and other paid leaves on 14th June 2008, during a meeting belonging to the seminar "Gli Incontri del Sabato" organized by the Associazione Crescere. An updated and enhanced version of his presentation is free downloadable clicking on the following link:

Il Sistema dei Permessi e dei Congedi (Parental leaves and other paid leaves)

Night Work

Employees who officially care for a person with a disability recognized by Law n. 104/92 are entitled to refuse night work.

(Legislative Decree n. 151/01, Art. 53; Resolution of the Ministry of Works n. 4 of February 6, 2009)

Occupational Pension Rights for Disabled Workers

As regards social security contributions, both deaf employees, as established by Law 381/70, and employees with a certified disability over 74% are entitled to claim a 2 month personal credit in every working year they have done since January 2002. These credits will be included in the calculation of their occupational pension benefits up to a maximum personal credit corresponding to 5 years of social security contribution, according to Art. 80, Paragraph 3 of the Finance Act 2001, n. 388 of December 23, 2000. Thus, disabled employees can add up to five years of social security contribution in the calculation of their pension benefits.

Place of Employment

Law <u>n. 104 of February 5, 1992</u> (Framework law on disability), Art. 21 and 33.

Law n. 183 of November 4, 2010 (Further provisions on work...)
Art. 24.

A) Parents, Relatives and Tutors

Parents, including adoptive parents, relatives and tutors who are entitled to take a monthly paid parental leave by Art. 33, Paragraph 3 of Law n. 104/22, are also entitled to get the nearest place of employment to the home of their disabled child or person with a severe disability in need of care, by Art. 24 of Law n. 183/10. They cannot be moved from this place of employment without their consent.

(Law n. 104/92, Art. 33, Paragraph 5; Law n. 183/10, Art. 24)

B) Disabled Claimant

Disabled Claimants employed either in the public or private sector are entitled to the same rights which have been described in the preceding paragraph.

(Law n. 104/92, Art. 33, Paragraph 6)

Furthermore, by Art. 21 of Law n. 104/92:

"Employees engaged in the public sector with a 2/3 disability or with a disability listed in the first category of Table A annexed to Law n. 648/50 are entitled to choose their place of employment among possible work locations and cannot be moved from it without their consent. They also are entitled to submit a priority application for job transfer".

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Physical Barriers

Judgment of the Constitutional Court n. 167/99.: "Disabled people are entitled to a right of mobility".

Law <u>n. 118 of March 30, 1971</u> (Provisions protecting invalid civilians), Art. 27, last Paragraph: "Invalid Civilians with mobility impairments have priority in the application for social and government supported private housing which are on the ground floor."

Law n. 41 of February 28, 1986 (Provisions on the drawing up of the State annual and multiannual financial framework), Art. 32.20: Physical barriers in Public Works

Law <u>n. 13 of January 5, 1989</u> (On physical barriers in private housing): "Provisions enhancing the removal of physical barriers in private buildings". Public funds are provided by the Regional Public Work Department, once that the Comune (the local authority) has requested them according to the application of a citizen.

Ministerial Decree <u>n. 236 of June 14, 1989</u> (Technical requirements granting accessibility, adaptability and visitability of private buildings and subsidized facilitated public housing to overcome and remove architectural barriers)

Law <u>n. 220 of December 11, 2012</u> (Amendments to Condominium regulations)

Art. 27 of Law 220/2012, which is in force since 17th June 2013, has modified Art. 2 of Law 13/89, establishing that the approval by 1/3 of the shares corresponding to the total value of the building and by the majority of the people present to the condominium meeting in its second convocation is not enough in order to approve building renovations concerning physical barriers of apartment blocks.

At the same time, Art. 5 of Law 220/2012 amended Art. 1120 of the Civil Code, concerning the regulation of innovations in condominiums, by adding new provisions that include, among other things, architectural design barriers and it establishes that for the approval of such provisions the majority is now always required, as prescribed in art. 1136 c.2 (the numerical majority of those present as well as the main value of the building), and the prohibition of innovations that may damage the stability and safety of the building, without making further reference to the architectural detailing of the building, in accordance with art. 2 c.1 of L. 13/1989, as amended by art. 10 c.3 of L.D. 76/2020, while still allowing the possibility for a person with disabilities, as per art. 2 of L 13/89, to proceed at their own expense in the event of denial or inaction by the condominium.

Law n. 104, February 5, 1992 (Framework law on disability), Art. 23: "Removal of physical barriers for sport, tourist and leisure activities"; Art. 24: "Removing or overcoming physical barriers".

Decree of the President of the Republic n. 503 of July 24, 1996 (Regulation concerning provisions for the removal of physical barriers in public buildings, space and services).

Legislative Decree n. 222 of November 25, 2016 (Procedures subject to authorisation ...)

Removing physical barriers can be carried out freely, provided that it does not involve external elevators or refurbishment of the building's shapes, activities which must be submitted to the competent authorities, being subject to CILA-Comunicazione Inizio Lavori Asseverata ("Start Work Notice"), see Paragraph 93 of the Scheme n. 21 and 22. Ministerial Decree of 2nd March 2018, published in the Official Gazette n. 81 of April 7, 2018, the Glossary of Free Building Construction, provides the list of activities aimed at "removing barriers that physical do not involve external elevators refurbishment of the building's shapes", these activities do not require to be submitted or notified to the competent authorities, provided that they do not comprise activities involving hygiene and health rules, protection against earthquakes, fire, hydro geological hazards, as well as protection of cultural and environmental heritage, as established by Legislative Decree n. 42/2004 (see exemptions specified in Art. 149).

Decree of the President of the Republic n. 31 of February 13, 2017 (Regulation on the appraisal of interventions which are either exempted by environmental restrictions or under simplified authorisation procedures)

Interventions aimed at removing physical barriers are specified in Annex A, Paragraph 4, and Annex B, Paragraph 6.

Removing physical barriers in condominium buildings is subject to the above mentioned specific regulation.

Driving Licence

Legislative Decree n. 285 of April 30, 1992 (Road Traffic Regulation **Articles 115-139**)

A driving licence is required for every type of motor vehicle and it can be issued only to people without any psychophysical conditions either personal or inducted which prevent from safe driving ((Art.119 of Legislative Decree n. 285 of April 30, 1992).

People with a physical disability or mutilation can obtain a **special driving licence** (Art.116 c.4 D.L. 285/92). After having verified that the applicant meets the psychophysical requirements for driving, the AUSL Commission issues a medical certification indicating personal data, type of special driving licence (A, B, C or D) and the prescription of any necessary adjustments.

The special driving license will be issued to the applicant who passes both the written and practical driving test. The special driving licence reports any prescribed adjustment which is identified with a number code (see Annex 1) respecting the privacy policy as established by Legislative Decree n. 59 of April 18, 2011.

The Ministerial Decree of 1st June 2021 (Official Gazette n. 226 of September 21, 2021) and the Ministerial Decree of 21st June 2021 (Official Gazette n. 226 of September 21, 2021) established provisions concerning compensatory tools, e.g. audio files and extra time, for people with a certified DSA (Specific Learning Disabilities, see the chapter on Learning and Education Rights) who take the written driving test.

Mobility and Parking

Law <u>n. 104 of February 5, 1992</u> (Framework law on disability), Art. 28

Legislative Decree n. 285 of April 30, 1992 (Road Traffic Regulation)

Decree Law n. 5 of February 9, 2012 (Urgent provisions on development and simplification), Art. 4

Decree of the President of the Republic n. 151 of July 30, 2012 (Implementation rules of the New Highway Code concerning facilities, badges, signs and markings to facilitate the mobility of disabled and impaired people)

Legislative Decree n. 90 of June 24, 2014 converted with modifications into Law 114/14 (*Urgent provisions on simplification and administrative transparency...*), as established by Art. 25.2, which innovates Art. 119c.2 of the Highway Code, **driving license** renewal for disabled people with a certified permanent condition will be carried out according to the ordinary procedures and deadlines.

Legislative Decree <u>n.68 of June 16, 2022</u> codified with modifications in law 108/2022 (Urgent provisions on ... sustainable mobility ...), to the art.7 l i) it innovates art. 190.7 of the Highway Code which now let "the cars used by people with disabilities", "which are included in medical aids" (by art. 46 of the Highway Code itself), "move on the cycle paths and on the pedestrians and cycle paths".

Vehicles for the transport of disabled people have access to traffic free zones and dedicated parking places by Art. 381 of the Decree of the President of the Republic <u>n. 495/92</u> (The Highway Code Regulation) and its amendments.

Disabled people are entitled to this right, as well as **people with** reduction of mobility (Decree of the President of the Republic <u>n. 151</u> of July 30, 2012, Art. 1) and blind people (Decree of the President of the Republic n. 503 of July 24, 1996, Art. 12, Paragraph 3).

"Mobility Parking Badges" have a 5 year period of validity and can be renewed, they are issued by the Comune (the local authority), in which disabled people are residents. Application for an Orange Badge must be submitted to the Mayor, attaching to it a certificate written by the Medical Commission in charge of the procedure INVCIV2010,

[•] The Mobility Parking Badge is the Italian equivalent to the Blue Badge.

which is the same certification required to apply for tax benefits related to vehicles (*Legislative Decree* n. 5 of February 9, 2012, *Art.* 4).

The badge design is customised and it should be displayed where it can be clearly read through the windscreen of your vehicle. The front of the badge should face upwards, showing the wheelchair symbol.

The Mobility Parking badge will be enforced since 15th September 2012, it complies with the badge features established by the European Council Recommendation n. 98/376/EC of 4th June 1998 on a parking card for people with disabilities. The old "Orange Badge" will be still effective up to three years from the implementation of the new mobility parking badge (*Art. 3 of the Decree of the President of the Republic n. 151 of July 30, 2012*). The new European Blue Badge CUDE (Contrassegno Unificato Disabili Europeo), which has been created on a common national information platform, applies to the whole Italian territory (*Art. 29 of the Decree Law n.76 of July 16, 2020 and Decree of 5th July 2021 of the Minister of Sustainable Infrastructure and Mobility published in the Italian Official Gazette n. 183 of August 2, 2021*).

According to Section 74 of Legislative Decree n. 196 of June 30, 2003 (Personal Data Protection Code), the badge shall not display sensitive data, however personal data of the badge holder can be checked in case of inspection.

Art. 1.e) of Decree of the President of the Republic n. 151 of July 30, 2012 left to the Comune this optional choice, but now Art. 25.3 of Decree Law n. 90 of June 24, 2014 imposed that each Comune shall establish by its own regulation the reservation within pay and display car parks of a number of free parking spaces for disabled people larger than the amount established by Art. 11 Paragraph 5 of Decree of the President of the Republic n. 503 of July 24, 1996 (that is one every fifty or one every car park consisting of less than fifty parking spaces). This concludes the dispute over eventual free parking for disabled people within pay and display parking spaces, which are delimited by blue lines, as now each Comune can establish free parking for

disabled people within paid car parks, when no reserved parking spaces for disabled people are still available. According to Art. 188 c3bis of Legislative Decree n. 285/92 (New Road Traffic Regulation, as reported by Decree Law n. 121/21) free parking for disabled people is granted anyway even without a specific regulation by the Comune. According to Paragraph 3 of the same Article: "Vehicles authorized for transporting invalid people... are not bound to time limits in parking areas".

Dedicated Parking

According to the Highway Code, the Mayor can issue a public notice in order to assign a free parking place to an Orange Badge holder. This parking place should be identified by a parking sign which displays the identification code of the Orange Badge holder who is entitled to use it.

Decree of the President of the Republic n. 151/2012 established that a free parking place must be assigned to disabled people when there is no accessible private spaces, irrespective of weather the disabled people has a car and driving license.

Rail Transport and Bus Service

Rail Transport

Chapter V of Regulation (EC) n. 1371/2007 of 23rd October 2007 (on rail passengers' rights and obligations)), updated by EU Regulation 2021/782 of April 29, 2021, established the rights of disabled people and people with reduced mobility.

This includes the following: right to transport (Art. 21), information (Art. 22), assistance at railway stations and assistance on board (Art. 23), conditions on which assistance is provided (Art. 24),

compensation for mobility equipment, assistance devices and assistance dogs (art. 25), mandatory training for personnel (art.26).

In accordance with this regulation, RFI has made available a support service for people with disabilities along with an information service, found on this page of its website.

Legislative Decree n. 70 of April 17, 2014 which has been brought into force since 21st May 2014, provides the **sanctions** against violation of the provisions of Regulation (EC) n. 1371/2007 on rail passengers' rights and obligations. Art. 16 concerns legislation regarding disabled people.

Please note that Trenitalia shall provide disabled people in receipt of carers' or communication allowance, as well as for the Inail assisted, with a <u>Blue Card</u> by which they can travel free of charge, while their carer shall pay a reduced price train ticket. Trenitalia also offers a free video interpretation service in LIS at major train stations, accessible through smartphones.

Bus Service

Legislative Decree <u>n. 169 of November 4, 2014</u> enforced on 6th December 2014, provides sanctions against violation of the provisions of Regulation (EC) n. 181/2011, amending Regulation (EC) n.2006/2004 on bus passengers' rights and obligations.

See the third section, Art. 8-12, on the legislation regarding people with disabilities.

Ministerial Decree of 5th March 2015 (published in the Italian Official Gazette n. 84 of April 11, 2015) describes in which conditions Bus Stations must provide assistance to disabled people, i.e. in case of travel longer than 250 Km, 55 bus stops, if equipped with waiting room, reception or ticket office. This Decree is followed by Ministerial Decree of August 25, 2022 (Designating bus stations that give

assistance to people with disability or people with reduced mobility) in O.G. n. 211 of September 9, 2022.

Air Travel

Regulation EC N. 1107/2006 of July 5, 2006 (On the rights of disabled persons and persons with reduced mobility when travelling by air):

- (1) "Disabled persons and persons with reduced mobility have the same right as all other citizens to free movement, freedom of choice and non-discrimination. This applies to air travel as to other areas of life."
- (4) "In order to give disabled persons and persons with reduced mobility opportunities for air travel comparable to those of other citizens, assistance to meet their particular needs should be provided at the airport as well as on board aircraft, by employing the necessary staff and equipment. In the interests of social inclusion, the persons concerned should receive this assistance without additional charge."
- (8) "...A charge levied on each air carrier using an airport, proportionate to the number of passengers it carries to or from the airport, appears to be the most effective way of funding."

Sea Transport

Legislative Decree n. 52 of March 8, 2005 (Implementation of Directive 2003/24/EC of the European Parliament and of the Council on safety rules and standards for passenger ships):

"The ships should be constructed and equipped in such a way that a person with reduced mobility can embark and disembark easily and safely..."

See Annex III of the same Legislative Decree, applying the guidelines for safety requirements for persons with reduced mobility, including access to ships, signs, means to communicate messages, alarms, and additional requirements ensuring mobility inside the ship such as handrails, corridors, passageways, and elevators.

Law <u>n. 37 of February 14, 1974</u> (Public transport free of charge for guide dogs) and its amendments (Law 378/88 and Law 60/06)

Blind people are entitled to take their guide dog free of charge on all public transport and in **all facilities open to the public** (Law 378/88).

Reference website on transportation

For European regulations regarding passengers rights when travelling on trains, buses, ships, and airplanes:

ART – Transport regulation Authority

A section of the website is dedicated to passenger rights, complaints filing and disputes resolution.

Tourism

Legislative Decree n. 79 of May 23, 2011 (Tourism Code)

Laws concerning disabled people are included in Art. 3 and Art. 36 of the Annexes.

Please notice that **Art. 3** has been declared unconstitutional by judgement n. 80 of April 2, 2012, as its content is under the jurisdiction of the Region.

Art. 3 established as follows:

- By enforcing the UNO Convention of 2006 (Law <u>n. 18 of March 3</u>, <u>2009</u>), the State guarantees that disabled people can use services

offered by the tourist industry without paying more than other people who use the same services. (Art. 3, Point 1);

- Impeding the use of tourism services and accommodation is considered a form of discriminatory action (Law <u>n. 67 of March 1</u>, <u>2006</u>), according to Art. 3, Point 3;
- According to Art. 36, *Letter h*, package holiday agreements must specify whether tourism accommodation is equipped for disabled people.

At Point n. 4 of a two-year plan for the rights of disabled people, described by Decree of the President of the Republic of October 4, 2013 – issued on the Italian Official Gazette n. 303 of 28th December 2013 (hypertext version (Pdf/a kb 626) - presentation slides (Pdf kb 1636)), regarding promotion and implementation of accessibility and mobility, it is a strategic decision considering the full enforcement of the proposals introduced in the guide Make it Accessible (Pdf 3,5 mb) - Italian hypertext version: "Accessibile è meglio". This publication is the first White Paper on Tourism for everybody in Italy, it was introduced by the Italian Prime Minister's Office of February 2013 as a result of "a careful comparison between Institutions and Associations of disabled people, mainly within the scope of the Committee for the development of accessible tourism coordinated by the Struttura di Missione for the fresh boost for Italy's image".

Sport

Art. 33 of the Italian Constitution: «The Italian Republic acknowledges the educational, social and psychophysical well-being promotion value of sports activity in all its forms».

Law <u>n. 189 of July 15, 2003</u> (Provisions for disabled people in order to become involved in sport activities)

Law <u>n. 376 of November 16, 2000</u> (Code ruling health and antidoping in sports)

Ministerial Decree of July 26, 2011 (Italian Official Gazette n. 208 of July 26, 2011) - Ministerial Decree of April 16, 2018 (Italian Official Gazette n.128 of August 5, 2018) - Ministerial Decree of June 1, 2019 (Italian Official Gazette n. 221 of September 20, 2019) - Ministerial Decree of August 4, 2021 (Italian Official Gazette n. 264 of November 5, 2021) - Ministerial Decree of June 28, 2022 (Italian Official Gazette n. 250 of October 25, 2022) - (Revision of Medicinal Products and Substances ... considered as Doping according to Law n. 376 of December 14, 2000).

Ministerial Decree of August 22, 2022 (O.G. n. 296 of 20/12/2022) - (Provision of orthotic and prosthetic aids for the performance of amateur sport activities for people with physical disabilities).

Notice that many medicines may contain drug substances and they must therefore be prescribed by a doctor (Art. 1.4 of Law n. 376/00). Prohibited substances are, for example, the following: diuretics, hormones, substances acting on the hormonal system, corticosteroids, and beta-blockers.

As regards this topic, an overview of the presentation slides shown by Dr Gianni Russo of IRCCS (The Scientific Institute for Research, Hospitalization and Health Care San Raffaele in Milan), during the meeting organized by ArfSAG at the Policlinic S. Orsola-Malpighi in Bologna on 5th December 2009, is available for free download on the following link:

La terapia ... e lo sport anche agonistico (Therapy...and sport, even athletic)

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FURTHER LEGAL CLAIMS and OTHER BENEFITS

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Right to Vote

Art. 48 of the Italian Constitution: "All citizens, male and female, who have come of age, are voters".

Law n°180 of May 13, 1978 (Voluntary and Compulsory Health Assessment and Treatments). Art. 11: Elimination of voting restrictions for persons under guardianship or declared mentally disabled.

Law n. 104 of February 5, 1992 (Framework law on disability) Art. 29.

Law <u>n. 17 of February 5, 2003</u> (Dispositions on how to exercise the right to vote...).

Law n. 46 of May 7, 2009 (Voting rights at home).

Blind or physically impaired people could be helped in accessing polling stations only by a voter registered at the same polling station. Under Law n. 17 of February 5, 2003, any registered voter can

provide aids and help disabled people to access the service. Every person who cannot reach a polling station can apply for voting at home, by Law n. 46 of May 7, 2009.

On the 6th Decembre of 2023, the European Commission released the Guidelines of good electoral practices for citizens with disabilities (*Pdf* 850 kb En)

Single Fund for disability

In order to ensure efficient policy planning for the inclusion, accessibility, and support of people with disabilities, Law n°213 of December 30, 2023 (Article 1, Section 210) has established, effective from January 1, 2024, the Single Fund for the Inclusion of Persons with Disabilities.

In the subsequent paragraph 213, the purpose and areas of intervention are specified: school support, digitalization, employment, sport, tourism, autism, caregiving, deafness and hypoacusis, and third-sector initiatives.

Simultaneously, Section 212 has abolished, starting from January 1, 2024, the previously designated funds for:

- inclusion of people with disabilities provided by L. 41/21;
- educational support provided by L. 234/21
- caregivers provided by L. 205/17;
- Deaf people and people with hypoacusis provided by L. 145/18.

Children Fund and Nursery School Financial Support

Parents of children who are born or have been adopted **between 2012 and 2014** can apply for a \in 5,000 loan to be repaid in five years with a subsidised interest rate

(Law n. 147 December 27, 2013, Art. 1 Paragraph 201)

Since 1st January 2017 this loan has been extended by Prime Minister's Decree of 8th June 2017 ((in the <u>Official Gazette n. 213 of September 12, 2017</u>) to newborn or adopted children. Within 3 years from the childbirth or adoption, it is possible to apply for a loan up to € 10,000 to be repaid in (up to) 7 years.

For more updated information see the related <u>INPS webpage</u>. According to the criteria described by INPS Circular <u>n. 14 of January 31, 2019</u>, children aged up to three years with a severe disability who have been born since 1^{st} January 2016 are eligible for financial support and benefits concerning nursery school fees and home education. In order to apply for this kind of financial support and benefits, whose maximum amount is $\in 1,500$ per year (Law <u>n. 145 of December 12, 2018</u>), an application must be submitted following the instruction listed in the <u>dedicated INPS webpage</u>.

Universal Single Allowance for Dependent Children

Law <u>n. 46 of 1st April, 2021</u> established the universal single allowance for dependent children in order to support births, parentship and employment, especially female employment. According to this Law, within the next 12 months the Italian Government will issue decrees implementing the criteria established by the Law itself: in 2021 the Italian Government issued the Decree Law <u>n. 79 of June 8, 2021</u>, and then the Legislative Decree <u>n. 230 of December 29, 2021</u> implementing Law n. 46/21.

The Law's criteria established the provision of an allowance, whose amount is based on the family's ISEE, which will be paid from the seventh month of pregnancy to the age of legal majority of the child (18 years old), or until the age of 21 of the child who still depends from his/her parents, being either a student, a worker or in search of employment.

In case of dependent children with a disability, there are no age limits to the payment of this allowance, whose amount will be increased up to the 50% on the basis of the disability severity. This allowance can be cumulated with other financial benefits for disabled people.

Foreign parents are eligible for the dependent child allowance too, provided that they hold a residence permit.

Parents who are not subject to income taxation are not eligible for the dependent child allowance.

It has been established an organisation, including the most representative family associations, whose task is to check the enforcement of this Law.

According to the Ministerial Decree of 11^{th} October 2021 (published in the Official Gazette n. 285 of November 30, 2021) unemployed parents or single-income family who have dependent children with at least 60% disability are eligible for a financial support from \in 150 to \in 500 per month, provided that their ISEE is within the related established limits.

Telephone Expenses

AGCOM (The Communication Regulatory Authority):

Deliberation <u>**n. 314/00 of June 1, 2000/CONS**</u>

Deliberation n. 514/07 of October 3, 2007/CONS

Deliberation n. 290/21 of September 23, 2021/CONS

Deliberation n.36/23 of February 22, 2023/CONS

A 50% discharge of the monthly telephone expenses can be requested by family with at least one member belonging to one of the following categories: invalid civilians, people who receive a social

pension, people over 75 years old, unemployed heads of family. Since 2004, only people with an income up to € 6713.93 according to the ISEE (Revenue Bureau's Evaluation of Financial Situation) are entitled to receive this kind of discharge. The application should be submitted every year.

Deaf people are entitled to a 100% discharge of the telephone expenses, while discounts are applied to blind or half blind people. Furthermore, they are all eligible for 180 hours of Internet connection free of charge.

The AGCOM (Deliberation 290/21) has extended the above mentioned benefit to people with reduced physical mobility which has been certified as established by Art. 30 c7 of the <u>Financial Law 2001</u>, n. 388/2000, further extended to June 2024 with the resolution 36/23/cons of February 22, 2023.

People eligible for this benefit can have also a 50% discount on three special mobile plans offered and chosen by their mobile network provider.

Information Technology

Law <u>n. 4 of January 9, 2004</u> (Provisions to support the access to information technologies for the disabled), and Decree of the President of the Republic <u>n. 75 of March 1, 2005</u> $^{\perp}$

Ministerial Decree <u>n. 239 of November 14, 2007</u> (Regulation issued by the Ministry of Culture implementing Art. 71a of Law n. 633/41 on copyright)

Legislative Decree <u>n. 106 of August 10, 2018</u> (Implementation of Directive (EU) 2016/2102 WAD on the accessibility of the websites and mobile applications of public sector bodies)

An English translation of the Italian legislation on Accessibility is available for free download on the following link: <u>PubbliAccesso – Documents in English</u>

Guidelines on the accessibility to information technology tools and equipment (20A00464) (Official Gazette n.20 of January 25, 2020)

Legislative Decree n. 82 of May 22, 2022 (Implementation of the EU directive 2019/882 of the European Parliament and Council of April 17, 2019, regarding the requirements to access to services and the products. (OG General Series n. 152 of July 1, 2022)

Monitoring the accessibility of Public Administration websites: https://accessibilita.agid.gov.it/

Law n. 4 of January 9, 2004, also known as "Legge Stanca" (*The Stanca Act*), aims at improving access to information technologies of public services for disabled people, according to equality principles set by Art. 3 of the Italian Constitution. Notice Art. 5 "The provisions of the present law also apply to the educational and didactic materials used in all schools and at every level", and Art. 4.4 "Public and private employers must provide disabled employees with hardware equipment, software tools and assistive technologies which are suitable for their needs and enable them to carry out their duties; this also applies in the event of teleworking. Private employers are subject to the provision as referred to in article 13, subsection 1, letter c) of the law n. 68 dated March 12, 1999". (See Law n. 68 of March 12, 1999)

Ministerial Decree n. 239 of November 14, 2007 states that "People with sensory deprivation certified according to Law n. 104 of February 5, 1992 are entitled to copy and use materials protected by copyright". Copy and use of copyright materials is allowed with the previous authorisation of a Supervisory Body.

As stated on the Ministry website: "with the approval of the Accessibility Act (Legislative Decree n. 82 of May 22, 2022), computer-based products and services, such as phones, e-book, automated ticket machines in train stations and airports, ATMs will need to respect certain requirements to be accessible to all" as

explained by the Minister of Disability, Erika Stefani, sanctions, removal of the product from the market, and removal from app stores..

It should be recalled that the Ministry of Education issued an invitation to tender (ITT) within the project Nuove Tecnologie e Disabilità – Azione 6 (New Technology and Disability – Action 6) to schools and education providers who are interested in developing research project for technology and didactic innovation in order to improve the school inclusion of disabled pupils. The research projects approved in June 2008, which include the participation of many Italian schools from North to South Italy, led to the development of programmes and software for disabled pupils. 25 hardware and software products about many different subjects, from Mathematics to ancient Greek, are currently free downloadable. The following link to the Ministry of Education, University and Research website provides information to the project and access to the free downloadable products:

Applicativi per la Scuola elaborati dalle Scuole, da Alessandria a Barletta, in favore di situazioni di disabilità

(School Applications for disabled pupils projected by Italian schools)

Cinema and Video

Law n. 220 of November 14, 2016 (Cinema and Video Regulation)

Art 3g: "It promotes and fosters the broadest access to cinema and video, considering the specific needs of disabled people, according to the related international conventions subscribed by Italy;"

Art. 12-4: "In order to guarantee the achievement of the goals presented in this Article and foster the greatest development and diffusion of works, provisions include the following:

a) "Incentives and contributions for the writing, development, production, distribution and promotion of works are subject to the meeting of further terms and conditions concerning the applicants and the terms of agreement, considering also the specific needs of disabled people, especially as regards the use of subtitles and visual descriptions;"

Electric Bonus

People affected by a severe disease, which has been assessed and certified by the ASL, or their families with whom they live, are eligible for an electric bonus, i.e. a discount on electricity bills, if they need to use any of the electromedical equipment listed in the Decree of the Ministry of Health of 13th January 2019 (Italian Official Gazette n. 56 of March 9, 2011), e.g. medical ventilators.

On the website <u>ARERA</u> you can find a detailed description of the electric bonus and what to do to apply for it.

Lis and List

As established by Art. 34ter of Law n. 69 of May 21, 2021 the Italian Republic acknowledges, promotes and protects the Italian Sign Language (LIS) and the Italian Tactile Sign Language (LIST). LIS and LIST interpreters are certified as professional workers whose training is to be defined by a decree which will be issued by either the President of the Government or the Minister for Disability in collaboration with the Minister for University and Research. This decree will be implemented by 90 days from the date of the enforcement of the Law (e.g. 22nd May 2021).

All the State Institutions, including schools, universities, Regions, Provinces, Comuni, and National Health Service facilities, promote

experimental projects aimed at implementing the LIS and LIST interpretation and subtitling services (Art. 34 ter.3).

According to the Interministerial Decree of 10th January 2022 (Official Gazette n. 81 of April 6, 2022) LIS and LIST interpreter profession provisions have been laid down in reference to the practice of the profession (art.1), to the educational career (art.2) and to the professional list (art.3).

Link and Useful Documents:

Ufficio di coordinamento delle azioni del Governo per le persone con disabilità e le loro famiglie

(Coordination Office of Government actions for Persons with Disabilities and their Families)

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LEGAL PROTECTION

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Welfare Services

Law <u>n. 104 of February 5, 1992</u> (Framework law on disability), Art. 40, paragraph 1: the Comuni (the local authorities) must provide welfare services for the inclusion of disabled people: "personal care service" for people who lack autonomy, home care service, aids for cultural, sport and leisure activities which are listed under Art. 13.

Law <u>n. 162 of May 21, 1998</u> (Changes in Law n. 104/92, concerning care and assistance for people with severe disability).

Law <u>n. 328 of November 8, 2000</u> (Integrated system of aids and welfare services). "Framework Law for the creation of an integrated system of aids and welfare services". See especially:

- Art. 14 on individual plans for disabled people concerning both school inclusion and "After Our" provisions.
- Art.9 and 11 on minimal structural and organisational requirements for residential and semi-residential care facilities. This was followed by the Prime Minister's Decree <u>n. 308 of May 31, 2001</u> (Regulation on minimal structural and organisational requirements for residential

and semi-residential care facilities, as established by Art. 11 of Law n. 328 of the 8th November 2000).

By Art. 7, facilities are categorized and described according to the following types:

- a) assisted living communities (up to 20 residents with limited autonomy)
- b) residential care facilities (up to 80 partially dependent residents)
- c) residential long-term care facilities (up to 120 dependent residents, grouped by 30 if they are elderly and grouped by 20 if they are disabled people)
- d) day care centres (up to 30 people)

Furthermore, residential and semi-residential care facilities must comply with the requirements listed in Allegato A.

Group homes and residential childcare communities (up to 6 residents) are described by Art. 3.

As established by Art. 5, septies c2 of Law n. 55 of June 14, 2019, funds have been allocated up to 2024 in order to implement closed-circuit **videosurveillance** systems in "healthcare and assistance facilities, either residential and semi-residential, for elderly and disabled people".

And lastly, in accordance with the standards and requirements as indicated in articles 1 and 2 of law n°328 of November 8, 2000, concerning the *«Framework Legislation for the implementation of integrated interventions and social services system»*, it has passed into law n°33 of March 23, 2023 (Government Delegation dealing with policies supporting the elderly).

Examples concerning aids and welfare services provided by the Policlinic S. Orsola - Malpighi in Bologna are available on the following link:

Il servizio sociale ospedaliero

(Welfare services in hospital)

The following link is to a PDF version of the "Guida ai Servizi Sociali" (Guide to Welfare Services), created by the National Centre for Rare Disease under the direction of Dr Domenica Taruscio in collaboration with Federazione Prader Willi and presented during the seminar "Incontri di Parent Training nella syndrome di Prader Willi" (Prader-Willi Syndrome Parent Training), organized by I.S.S. between September 2008 and February 2009.

The Guide is available for free download:

Guida ai Servizi Sociali

(Guide to welfare services)

Attorney

Law n. 6 of January 9, 2004 (Attorney)

This Law amended Title XII and Articles 388, 414, 417, 418, 424, 426, 427, 429 of the Italian Civil Code.

Main changes in legislation concern:

- The Title XII "On Mental Impairment and Legal Decision Depriving" was modified in "Provisions for the Protection of People who partially or totally lack Autonomy".
- This Law aims at "protecting people who lack mental capacity to make their own decisions and carry out normal day-to-day activities, by means of temporary or permanent support", it should therefore limit the use of legal decision depriving.
- Under Art. 404 and following, an attorney is assigned by decree of the judge supervising a guardianship selected in the residence of the disabled person. An attorney makes important decisions for people

who are not able to make their own decisions because of mental or physical impairment, either permanent or temporary.

- An attorney has the power to make any decisions according to the conditions and restrictions set by the judge.
- "An attorney has an obligation to report regularly on the life and social conditions of his/her donor to the judge".
- An attorney is not paid, except for the reimbursement of the approved expenses.
- Testamentary dispositions in favour of an attorney are unlawful, except those concerning a relative up to the fourth degree of relationship, the spouse or civil partner.

<u>Guidelines</u>, <u>procedures and FAQ</u> are available on the related webpage of the Tribunale di Bologna (Bologna Court of Law).

Lawyer Maria Teresa Bettelli and lawyer Annalisa Caligiuri held a presentation on the role and power of attorneys on 6th June 2009, during one of the meetings of the seminar "Gli Incontri del Sabato", organized by the Associazione Crescere. Their presentation is free to download on the following link:

<u>L'Amministratore di Sostegno</u> (Attorney)

Family Caregiver

Law n. 205 of December 27, 2017 (2018 State Budget Estimate and 2018-2020 State Budget)

According to Paragraph 255 of Art. 1, family caregivers are people who provide assistance to their spouse, their civil partner or cohabitee, as established by Law n. 76 of May 20, 2016, as well as people who provide assistance to a relative up to the third degree of relationship.

In any case, the person assisted is not self-sufficient because of disease, impairment or disability, including chronic or degenerative conditions; they have been certified invalid as they are in need of global and long term assistance, as established by Art. 3, Paragraph 3 of Law n. 104 of 5th February 1992, or they are in receipt of attendance allowance as established by Law n. 18 of February 11, 1980.

According to Paragraph 254, it has been created by the Ministry of Employment and Social Security a Support Fund aimed at supporting the task and assistance of family caregivers, which starts with an annual budget of € 20 millions in 2018, 2019 and 2020. The criteria of use of this Support Fund have been established by decree on 27th October 2020 (published in the *Official Gazette n. 17 of January 22, 2021)*. This Fund has been placed in the **Single Fund for Disability** provided by art.1 paragraphs 210/216 of Law n°213 of December 30, 2023.

"After Our" Provisions

Law <u>n. 112 of June 22, 2016</u> (Provisions on assistance for severe disabled people without family support) and the related Ministerial Decree of November 23, 2016 (Eligibility criteria in order to apply for assistance, care and protection provisions supported by the Fund for severe disabled single people) published in the <u>Italian Official Gazette n. 45 of February 23, 2017</u>.

This law includes provisions for the assistance of people with a severe disability who cannot count on family support, in order to avoid their institutionalization through schemes of help at their own home.

In these cases, disability should not be derived from ageing-associated diseases and it must meet the criteria of severity established by Art. 3, Paragraph 3 of Law 104/1992, and it must be certified as established by Art. 4.

The above provisions must be consistent with the previously designed "individual plan", as established by Art. 14 of Law <u>n.</u> 328/00. The "individual plan" is mandatory for the implementation of the regulatory special education and it has been inspired by the biopsychosocial model according to the Internetional Classification ICF (*Art. 2 of Ministerial Decree of November 23, 2016, published in the Official Gazette n. 45 of February 23, 2017*).

Implementation of this law will include:

- a Fund, shared in by local authority, third sector institutions and families organized in associations (*Art. 3, and Art. 4, Paragraph 2*).
- financial benefits for insurance policies, trusts and special funds dedicated to this goal. (*Artt. 5,6- Agenzia delle Entrate memorandum* 34/E pdf, of October 20, 2022)

A public information campaign will be held by the Presidency of the Ministers' Council.

The Italian Data Protection Authority*

Legislative Decree n. 196 of June 30, 2003 (Personal Data Protection Code), Section 153 and following.

The Italian data protection authority's tasks are set forth in the law (the Data Protection Code 196/2003, which superseded the Data Protection Act 675/1996).

The Italian data protection authority (Garante per la protezione dei dati personali) is an independent authority set up to protect fundamental rights and freedoms in connection with the processing of personal data, and to ensure respect for individuals' dignity. Special importance should be attached to the provisions made in respect of health care, employment, banking, insurance, journalism,

^{*} See the English section of the data protection authority's website.

telecommunications, video surveillance, marketing, and public administrative agencies.

The description above is taken from the data protection authority's website, where you can find the Italian legislation on data protection, general information, information on procedures, and press releases.

You can also find references to the Data Protection Code in the following chapters of this Guide:

- On health rights, Section 7-13 on rights concerning personal data, Section 22-26 on sensitive data, Section 74-96 on exercising rights in specific sectors: Section 74 on car permits and access to town centres, Section 75-94 on health care sector, and Section 95-96 on education.

The Ombudsman

Law <u>n. 127 of May 1, 1997</u> (Simplification of administrative and control procedures), Art. 16 (Ombudsmen of Autonomous Provinces and Regions)

Legislative Decree <u>n. 267 of August 18, 2000</u> (Consolidated Law on Local Authorities), Art. 11 (Local Government Ombudsman and Provincial Ombudsman), Art. 136 (Commissario ad acta*)

Law n. 42 of March 26, 2010 - Decree Law n. 2 of February 25, 2010 (Urgent provisions for Regions and local authorities), Art. 1.

Law n. 24 of March 8, 2017 (Provisions on safe healthcare assistance, safety of assisted people, and professional liability of healthcare practitioners), Art. 2 (Assignation of the task to supervise health rights to the ombudsman)

^{*} The *commissario ad acta* is a special commissioner established by the Italian Administrative Procedure Code.

Regulation on internal procedures of the Agenzia per l'Italia digitale (Agency for Digital Italy) which have external relevance, during the phase of first implementation, these procedures are aimed at carrying out the tasks of the **ombudsman for the digital**. (20A00448) (Official Gazette n. 19 of January 24, 2020).

The Ombudsman is in charge of ensuring impartiality and efficiency of public administration, reporting abuses, shortcomings, and delays in administration to the detriment of citizens.

The Regional Ombudsman has the power to replace local authorities which fail to enforce mandatory acts with a Commissario ad acta (Art. 136 of Legislative Decree 267/2000)

Further specific ombudsman's tasks are established by the following legislation:

- Art. 25 of Law <u>241/90</u>: on access to public records, relating to the administration by either local, provincial or regional authorities;
- Law <u>104/92</u>: on ensuring assistance, inclusion, civil and legal rights for disabled people. Pursuant to Art. 36 of this Law, the ombudsman can decide to bring a civil action to trials for crimes set forth in Art. 527 of the Italian Penal Code, Title XII and XIII of Book 2 of the Italian Penal Code, and Law n. 75 of February 20,1958.
- Art. 2 of Law 24/17 establishes that Autonomous Regions and Provinces may assign to the Ombudsman the task of **Health Rights Supervisor**, whose task is also to manage for free complaints on malfunctioning submitted from any subject receiving healthcare.

As local government ombudsmen have been abolished by Art. 2 paragraph 186 of Law 191/09 and Art. 1 of Decree Law 2/10, they will remain in office until the end of their term of office.

On the other hand, it is established by agreement that the provincial ombudsman can also cover the tasks formerly carried out by the local government, thus having an extended territorial scope.

Legislation and tasks of local government ombudsmen before their abolition are explained in the <u>2009 Report of the Local Government</u> <u>Ombudsman of Bologna</u>, who will remain in office until 2014.

General information on Ombudsman's tasks and authority are available on the website concerning <u>The European Network of Ombudsmen</u> (versions in every European language)

Ombudsman for Childhood and Adolescence

Law <u>n. 112 of July 12, 2011</u> (Establishment of the Authority Ombudsman for Childhood and Adolescence)

Law n. 176 of May 27, 1991 (Implementation of the Convention on the Rights of the Child, New York 1989)

Law n. 46 of March 11, 2002 (Implementation of Additional Provisions set up during the Convention on the Rights of the Child, New York, 2000)

Law n. 77 of March 20, 2003 (Implementation of the European Convention on the Rights of the Child, Strasbourg, 1996)

Law 112/2011 set up an **Ombudsman for Childhood and Adolescence**. This kind of national Authority, who already provides services in many countries (see for instance the website of **ENOC**, The European Network of Ombudspersons for Children), joins the action of other administrative and judicial institutes charged with the protection and promotion of children and under 18 persons.

The Ombudsman for Childhood and Adolescence is charged with the protection of the rights of under 18 persons, as established by both the national legislation and international conventions listed above. Please, notice especially Art. 3 Paragraph e) of Law 112/2011 on health rights, establishing that the Ombudsman must assure fair opportunity in accessing medical treatment and exercising children's rights to health. Moreover, it established that fair opportunities in education must be granted to under 18 persons undergoing medical treatment and hospitalization.

The Ombudsman also promotes information on children's rights and under 18 persons (Art. 3 Paragraph m) of Law 112/2011).

Following Law 112/2011, some Italian Regions established their own Ombudsman for Childhood. Here are listed some of these Regions, including a link to their website (last update in March 2012)

• Calabria; Emilia Romagna; Friuli Venezia Giulia, Lazio; Liguria; Marche; Toscana; Veneto; Provincia autonoma di Bolzano.

The Ombudsman for Childhood and Adolescence of Region Emilia Romagna issued an *In-depth Article* (Italian language) introducing the role of his Authority and the legislation on children's rights and protection of under 18 persons with direct link to the original legal texts.

Legal Protection against Discrimination

Law <u>n. 67 of March 1, 2006</u> (Provisions on legal protection from disability discrimination)

Legislative Decree n. 216 of July 9, 2003 (Implementation of Council Directive 2000/78/CE establishing a general framework for equal treatment in employment and occupation)

Legislative Decree n. 150 of September 1, 2011 (Supplementary provisions to the Code of Civil Procedure), Art. 28.

The Law n.67/2006, which consists of four articles, provides clear and direct provisions on legal protection from direct disability discrimination and harassment, since it is unlawful for service

providers to treat disabled people less favourably because they are disabled. Under this Law, disabled people can be represented in court by <u>accredited</u> associations, who are entitled to take "class action" on behalf of their members.

See also provisions against discrimination at work in Legislative Decree n. 216 of July 9, 2003, implementing the Council Directive 2000/78/CE, which are both still in force.

Litigation concerning discrimination are judged in interlocutory proceedings, according to the procedure established by Art. 28 of Legislative Decree n. 150 of September 1, 2011.

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TAX RELIEF AND BENEFITS

- Tax Credits and Deductions
- Vehicles and Transport
- VAT
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Tax Credit and Tax Deduction

Notice the following distinction:

- <u>a tax credit</u> is a part of expenses expressed in percentage (19%) which is deduced from the gross tax;
- <u>tax deduction</u> consists of expenses which can be deducted from the gross income.

Tax Credits:

- People with dependent children get € 950 for children over three, and € 1220 for children under three years old. Tax credits increase € 400 for dependent children with a disability. A tax credit may vary according to the personal income and it becomes null for a personal income over € 95000;
- A 50% tax credit is due for expenses, incurred between 26st June 2012 and 31th December 2014, to remove physical barriers;
- Since 1st January 2007, carers with a personal income up to € 40000 can get 19% tax credits for their expenses up to € 2100;
- Tax credits for vehicles: see the paragraph "Vehicles and Transport";

^{*} ICI is the municipal tax on immovable property which is applied in Italy.

- 19% tax credit for health costs such as medical tests, surgical procedures, and specialists examinations, it is deducted from the personal income tax basis if expenses are over € 129.11; every taxpayer is eligible for this tax credit, which is independent from persona circumstances such as disability or impairment;
- 19% tax credit for the following expenses:
- 1) Ambulance transport for disabled people, while medical treatment in ambulance are considered health costs and therefore deductible over € 129.11;
- 2) Costs of wheelchairs and fabric supports such as spinal supports;
- 3) Costs of artificial limbs;
- 4) Costs of ramps in order to remove physical barriers outside or inside houses; people who get this tax credit are not eligible for 50% tax credit under Art. 1 of Law n. 449/97;
- 5) Costs of adapting lifts in order to allow access to wheelchairs;
- 6) Costs of information technologies and equipment such as touch screens, fax, computers, and hands-free telephone sets designed to improve the inclusion of disabled people and certified as listed by Art. 3 of Law n. 104/92.

Moreover, there is a 19% tax credit on transport costs for disabled people certified according to Art. 3 of Law n. 104/92.

- Since 2002, there has been a 19% tax credit on expenses paid by deaf people certified as established by Law n. 381 of May 26, 1970, for interpreting services, provided that they can show the official receipt documenting the provision of that service in case of tax inspection.
- Expenses of guide dogs for blind people. In this case, there is a 19% tax credit on the personal income tax for expenses of one guide dog up to € 18075.99. This tax credit also applies to the expenses for vehicles used to transport blind people and it can be applied only

once every four years, except in case of loss of the dog. Moreover, € 516.46 is paid as reimbursement of maintenance costs of a guide dog.

Relatives who are dependent from a disabled person are also eligible for a 19% tax credits on the expenses listed above.

Tax deductions:

- Medical costs related either to general practices and specialist practices paid by a disabled person or by his/her family (e.g. care and rehabilitation costs) in case of permanent disability;
- Medical costs of care homes, which have been certified by the care home, paid by people with a disability which has been assessed and certified as established by Art. 4 of Law 104/92, as well as people with a 100% inability and people who receive an Assistance Allowance hospitalized in care home;
- Expenses for social workers, family carers, and personal assistants can be deducted up to € 1549.37.

Vehicles and Transport

Disabled people with permanent mobility impairment listed by Art. 4 of Law n. 104/92, people with a mental disability who receive an Assistance Allowance by Art. 7, Paragraph 7 of the Finance Law 2001 n. 388/2000, amputated people and relatives who have them in care are entitled to financial benefits on the following categories of vehicles: cars up to 9 seats, goods/passengers cars, motor caravans, side cars, and special vehicles.

Since 2004, dependant people are people with a personal income up to € 2840.51; allowances, pensions and financial benefits provided to invalid civilians are not included in the taxable basis.

Vehicles which belong to companies or institutions do not qualify for financial benefits even if they are used for transporting disabled people.

Financial benefits regarding vehicles may include:

- 1. Reduced VAT (4%) 4% VAT can be applied on the purchase of either new or second-hand vehicles with engine displacement not exceeding 2000 c.c. for petrol-powered, and 2800 c.c. for diesel-powered. Reduced VAT can be applied only once every four years, except cases of de-registration from the PRA (*Italian Vehicle Register*), e.g. for end-of-life or stolen vehicles, within four years. (*Finance Ministry Circular n. 197/E of July 31, 1998; Art. 8 of Law n. 449/97*). Reduced VAT is also applied to costs of vehicle adaptation.
- **2. Income Tax Allowances** A 19% tax credit for expenses of purchase or vehicle adaptation can be deducted entirely or divided into four annual rates of equal amount. A 19% tax credit can be applied to purchase expenses up to € 18075.99, but any insurance reimbursement related to the vehicle must be deducted from this deductible amount. A 19% tax credit can be also applied to extraordinary costs of vehicle adaptation and repair. (Art. 11 of Law n. 212/2000; Art. 13a of the Income Tax Law*)
- **3. Vehicle Tax Exemption** One must submit the specific application to the Regional Tax Office in order to get an exemption from payment of the Vehicle Tax, which can be requested once at time for vehicles with engine displacement not exceeding 2000 c.c. for petrol-powered, and 2800 c.c. for diesel-powered.

The Italian income Tax Law is also known by the Italian actoryin Tolk

^{*} The Italian Income Tax Law is also known by the Italian acronym TUIR.

4. Registration Exemption Exemptions from paying vehicle registration can be claimed for the transfer of property of newly purchased vehicles, either new or second-hand.

Reduced VAT (4%)

- Purchase or adaptation of vehicles (see indications in the preceding paragraph).
- Purchase of mobility aids and equipment.
- Purchase of information technologies and equipment in order to enhance the inclusion and autonomy of people with a physical impairment or communication difficulties (Law n. 30/97).
- Purchase of prostheses and supports which are specifically used by people with a permanent functional impairment.

IMU (former ICI)* Tax Credits

As regards the IMU (former ICI), tax credits for disabled people may vary according to the dispositions provided by each Comune (the local authority). Disabled people should therefore ask for information in the Comune where their house is located.

Links and Useful Documents

Agenzia delle Entrate website:

Guide to Tax Benefits on Healthcare Costs (Update X/23)
Guide to Tax Benefits for Disabled People (Update II/23)

The following link is to the presentation of the text "Infermità e Agevolazioni Fiscali" (Disability and Tax Relief), shown by Dr Giulia Dolcetta on 27th March 2010, during a seminar organized by

^{*} ICI is the municipal tax on immovable property which is applied in Italy.

Associazione Crescere with the participation of ARAD, ANTR and ArfSAG (Non-Profit Associations). Her presentation is free downloadable:

Infermità e Agevolazioni Fiscali (Disability and Tax Relief)

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EXEMPTIONS FROM PAYMENT

Medicines and Healthcare

Ministry of Health Act n. 279 of May 18, 2001 (Rare diseases)

Prime Minister's Decree of 12th January 2017, published in the Official Gazette n. 65 of 18th March 2017 Art. 52

Law <u>n. 648 of December 23, 1996</u> - Legislative Decree <u>n. 536/96</u> (Orphan medicinal products) Art. 1.4.

Legislative Decree n. 124 of April 29, 1998 (Exemptions), Rare Diseases are ruled by Art. 5.

The Ministry of Health published a complete guide to dispositions concerning exemptions from payment. The following text reports the introduction to the guide (see the <u>complete guide text</u>).

Specialist practices, either diagnostic and therapeutic, for treatment and screening of rare diseases which have been certified are exempt from payment by Ministerial Decree n. 279/2001.

Exemption from payment is also extended to medical examinations and genetic tests which may be necessary in order to diagnose rare diseases on patient's relatives, as these are often caused by genetic disorders.

Exemptions from payment concerning rare diseases are listed in Annex 1 of Ministry of Health Act n. <u>279/2001</u>, which has been updated by Annex 7 of Prime Minister's Decree of 12th January 2017, published in the <u>Official Gazette n. 65 of March 18, 2017</u>, see also the <u>Rare Disease Exemption Database</u> edited by the Ministry of Health.

The application for any exemptions from payment must be submitted to the ASL, along with a certificate of rare disease issued by one of the Medical Centres approved by the Region where the patient lives.

If there are no approved Medical Centres in the Region of residence, the patient can apply to a Medical Centre in another Region. Medical assessments of rare diseases must be issued and prescribed in one of the approved Medical Centres, where the Medical Officer who writes the certificate should indicate the best Centre for the treatment of that specific rare disease.

One can apply for more exemptions from payment in case of more than one certified rare disease.

A list of practices exempt from payment is not currently available, as the treatment of rare diseases may vary according to each specific case. The doctor should therefore choose the best treatment among those provided by the medical centres for rare diseases, including prosthetic services needed due to mutilations caused by the disease itself (Art. 18, Paragraph H of Prime Minister's Decree of 12th January 2017).

The following is the link to the National Centre for Rare Diseases - ISS:

www.malattierare.gov.it/esenzioni

The National Centre has a **Help-line Rare Diseases**, active from Monday to Friday (9.00-13.00), which provides personalized information about Medical Centres, Associations and exemptions:

800.89.69.49

The following is the file made by the Associazione Crescere, who deals with this topic, making reference to the legislation in force in the Region Emilia Romagna:

Associazione Crescere-Normativa

Notice that the text of Decree n. 279/2001 is available on the website with explanatory notes of the related legislation.

Please note in the handbook maintained by the Region Emilia Romagna, the ticket payment exemptions are available at the link:

https://salute.regione.emilia-romagna.it/cure-primarie/ticketesenzioni/esenzioni,

which covers both the national and the regional regulation (updated february 2023)

More detailed information on the topic **Orphan Medicinal Products** either in Italy and abroad can be found clicking on the following link to the official website of the National Centre for Rare Diseases:

www.malattierare.gov.it/malattie/terapieFarmacologiche

(National Centre for Rare Disease – Orphan Drugs)

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Link List to Legislative Provisions

Presidential Decree n. 818 of April 26, 1957 (On Disability, State and Survivor's Pensions)

Law n. 903 of July 21, 1965 (Pension Reform on Social Security)

Law <u>n. 458 of June 26, 1967</u> (Kidney donation)

Law n. 118 of March 30, 1971 (Law protecting invalid civilians)

Law <u>n. 37 of February 14, 1974</u> (Public transport free of charge for guide dogs)

Law <u>n. 194 of May 22, 1974</u> (Provisions on maternity social protection and voluntary interruption of pregnancy)

Law <u>n°180 of May 13, 1978</u> (Voluntary and Compulsory Health Assessment and Treatments)

Law n. 833 of December 23, 1978 (National Health Service)

Law n. 18 of February 12, 1980 (Disability allowance)

Law <u>n. 184 of May 4, 1983</u> (On adoption and custody of children and young people

Law <u>n. 222 of June 12, 1984</u> (Amendments on disability pension legislation)

Law <u>n. 41 of February 28, 1986</u> (Provisions on the drawing up of the State annual and multiannual financial framework), Art. 32.20: Physical barriers in Public Works

Law <u>n. 508 of November 21, 1988</u> (Supplementary measures supporting invalid civilians)

Legislative Decree n. 509 of November 23, 1988 (Provisions in order to determine disability)

Law n. 13 of January 5, 1989 (On physical barriers in private housing)

Ministerial Decree <u>n. 236 of June 14, 1989</u> (Technical requirements granting accessibility, adaptability and visitability of private buildings and subsidized facilitated public housing to overcome and remove architectural barriers)

Law <u>n. 289 of October 11, 1990</u> (Further provisions protecting invalid civilians)

Law <u>n. 176 of May 27, 1991</u> (Implementation of the Convention on the Rights of the Child, New York 1989)

Law n. 381 of November 8, 1991 (On cooperative societies)

Law <u>n. 390 of December 2, 1991</u> (Equal rights and fair treatment for disabled students),

Law n. 104 of February 5, 1992 (Framework law on disability)

Ministry of Health Act <u>of February 5, 1992</u> (Official Gazette n. 47/92 – Tables on disability percentages)

Legislative Decree n. 285 of April 30, 1992 (Road Traffic Regulation)

Legislative Decree n. 502 of December 30, 1992 (New health care legislation)

<u>Update List</u> at the time of Legislative Decree n. 502/92 of June 16, 2010

Law <u>n. 548 of December 23, 1993</u> (Congenital hypothyroidism, *Phenylketonuria*, and Cistic fibrosis)

Law <u>n. 578 of December 29, 1993</u> (Law on death assessment and certification)

Decree of the President of the Republic of February 24, 1994 (Official Gazette n.79/94 - Directives ... for disabled pupils)

Law n. 23 of February 11, 1996 (Law on school building)

Decree of the President of the Republic n. 503 of July 24, 1996 (Regulation concerning provisions for the removal of physical barriers in public buildings, space and services)

Law n. 648 of December 23, 1996 - Decree Law n. 536/96 (... Medicinal Products)

Legislative Decree n. 124 of April 29, 1998 (Exemptions from Payment)

Law <u>n. 162 of May 21, 1998</u> (Changes in Law n. 104/92)

Law <u>n. 68 of March 12, 1999</u> (Provisions on work rights of disabled people)

Law n. 91 of April 1, 1999 (Law on organ and tissue transplants)

Prime Minister's Decree of July 9, 1999 (Regarding the Decree's implementation)

Law <u>n. 483 of December 16, 1999</u> (Legislation on split liver transplant)

Regulation (EC) n. 141/2000 (Orphan medicinal products)

Law <u>n. 53 of March 8, 2000</u> (Provisions on maternity support)

Law n. 62 of March 10, 2000 (On school equality)

Law <u>n. 69 of March 22, 2000</u> (Fund for the inclusion of disabled pupils)

Law <u>n. 328 of November 8, 2000</u> (Integrated system of aids and welfare services)

Law <u>n. 376 of November 16, 2000</u> (Code ruling health and antidoping in sports)

Law <u>n. 388 of December 23, 2000</u> (Finance Act 2001 – Art. 30 c7: Benefits for people with severe disability or inability - Art. 80: personal credits of social security contribution)

Ministry of Education, University and Research <u>Departmental</u> <u>Circular n. 3390/2001</u> (General assistance for disabled pupils)

Law <u>n. 52 of March 6, 2001</u> (Recognition of the Italian bone marrow donor registry)

Legislative Decree n. 151 of March 26, 2001 (Consolidated law on maternity support and protection)

Oviedo Convention of April 4, 1977, and its Ratification by Law n. 145 of March 28, 2001

Prime Minister's Decree n. 14787 of April 9, 2001 (Equal rights and fair treatment for disabled students)

Ministry of Health Act n. 279 of May 18, 2001 (RARE DISEASES)

Prime Minister's Decree <u>n. 308 of May 31, 2001</u> (Regulation on minimal structural and organisational requirements for residential and semi-residential care facilities)

Law n. 46 of March 11, 2002 (Implementation of additional provisions set up during the Convention on the Rights of the Child, New York, 2000)

Law <u>n. 3 of January 16, 2003</u> (Legal provisions concerning...) Title IX on health protection, Art. 42-53: Art. 51 on non-smokers health protection.

Law <u>n. 17 of February 5, 2003</u> (Dispositions on how to exercise the right to vote...)

Law <u>n. 53 of March 28, 2003</u> (Resolution to the Government for education)

Law <u>n. 77 of March 20, 2003</u> (Implementation of the European Convention on the Rights of the Child, Strasbourg, 1996)

Legislative Decree n. 196 of June 30, 2003 (Personal Data Protection Code: Section 7-13 on rights concerning personal data, Section 22-26 on sensitive data, Section 74-96 on exercising rights in specific

sectors: Section 74 on car permits and access to town centres, Section 75-94 on health care sector, and Section 95-96 on education)

Legislative Decree n. 216 of July 9, 2003 (Implementation of Council Directive 2000/78/CE establishing a general framework for equal treatment in employment and occupation)

Law <u>n. 189 of July 15, 2003</u> (Provisions for disabled people in order to become involved in sport activities)

Ministry of Education, University and Research, Departmental Circular n. 4308/2004

Legislative Decree n. 276 of October 9, 2003 (Implementation of delegation on occupation and job market established by Law n. 30 of February 14, 2003)

Law <u>n. 4 of January 9, 2004</u> (Provisions to support the access to information technologies for the disabled)

Law n. 6 of January 9, 2004 (Attorney)

Law <u>n. 40 of February 19, 2004</u> (Provisions on assisted reproductive technologies)

Ministry of Education, University and Research Note n. 4099/2004 (General guidance on DSA: Specific Learning Disabilities)

Decree of the President of the Republic n. 75 of March 1, 2005 (Implementation regulations for Law 4/2004)

Legislative Decree n. 52 of March 8, 2005 (Implementation of Directive 2003/24/EC of the European Parliament and of the Council on safety rules and standards for passenger ships)

Law <u>n. 219 of October 21, 2005</u> (New legislation on transfusions and national production of blood products)

Prime Minister's Decree n. 185 of February 23, 2006 (Regulation to determine pupils with disability)

Law <u>n. 67 of March 1, 2006</u> (Provisions on legal protection from disability discrimination)

Law n. 80 of March 9, 2006 – Decree Law n. 4/06 (Provisions...on organization and functions of Public Administration)

Regulation EC N. 1107/2006 of July 5, 2006 (On the rights of disabled persons and persons with reduced mobility when travelling by air)

Law <u>n. 95 of February 20, 2006</u> (New Regulation for people with hearing impairment)

Ministerial Decree of August 2, 2007 (Official Gazette n. 225/2007 - Determining diseases and disorders which are exempt from assessment ...)

Regulation EC n. 1371/2007 of October 23, 2007 (On rail passengers' rights and obligations)

Ministerial Decree n. 239 of November 14, 2007 (Regulation issued by the Ministry of Culture implementing Art. 71a of Law n. 633/41 on Copyright)

<u>Italian State-Regions Agreement of March 20, 2008</u> (Support for disabled pupils)

National Health Service Plan 2006-2008

<u>UNO Convention on the Rights of Persons with Disabilities</u>, of December 16, 2006, and its Ratification n. 18 of March 3, 2009

Law n. 46 of May 7, 2009 (Voting rights at home)

U.S.R. E.R. <u>Memorandum n. 1425/2009</u> (Practical advice on DSA: *Specific Learning Disabilities*)

Ministry of Education, University and Research Note n. 5744/2009 (Baccalaureate Examinations 2008-2009: Pupils with DSA: Specific Learning Disabilities)

<u>UE Council Recommendation</u> of June 8, 2009 on an action in the field of rare diseases and <u>Opinion of the European Economic and Social</u> Committee

Law <u>n. 102 of August 3, 2009 – Decree Law n. 78/09</u> (Provisions contrasting crisis ...)

M.I.U.R. <u>Guideline</u>, <u>Protocol n. 4274/09</u> (School inclusion of disabled pupils)

Emilia Romagna Governing Council Resolution n. 108 of February 1, 2010 (Regional Plan for DSA: Specific Learning Disabilities)

Law <u>n. 38 of March 15, 2010</u> (Accessing palliative care and pain relief)

Ministry of Health Act n. 116 of April 16, 2010 (Law on living donor transplantation)

Directive <u>EU of May 19, 2010</u> (Standards of quality and safety of human organs intended for transplantation)

Law <u>n. 107 of June 24, 2010</u> (Provisions to acknowledge the rights of deaf-blind persons)

Decree of the Ministry of Labour and Social Policy n. 167 of July 6, 2010 (National Observatory)

Law n. 170 of October 8, 2010 (Provisions on DSA: Specific Learning Disability in school environment), and its implementing rules in the Ministerial Decree of July 12, 2011 including the attached Guidelines

Law n. 183 of November 4, 2010 (Further provisions on work...)

Legislative Decree n. 59 of April 18, 2011 (Implementation of directives 2006/126/EC and 2009/113/EC concerning driving licence - Annex 1 Union Codes)

Legislative Decree n. 79 of May 23, 2011 (Tourism Code)

Law n. 106 of July 12, 2011 - Decree Law n. 70/11 (Economic provisions ...Art. 6)

Law n. 111 of July 15, 2011 - Decree Law n. 98/11 (Financial Manoeuvre, Art. 38 and 18)

Law <u>n. 112 of July 12, 2011</u> (Establishment of the Authority Ombudsman for Childhood and Adolescence)

Legislative Decree n. 119 of July 18, 2011 (Delegation to the Government for the reassessment of the legislation concerning paid leaves)

Ministerial Decree of <u>July 26, 2011</u> (Published in n. 208 of the Italian Official Gazette as "Revision of Medicinal Products and Substances considered Doping Substances by Law 376/2000)

Legislative Decree n. 150 of September 1, 2011 (Supplementary provisions to the Code of Civil Procedure ... Art. 28)

Law n. 148 of September 14, 2011 - Decree Law n. 138/11 (Financial Manoeuvre bis ... Art. 9)

Law <u>n. 183 of November 12, 2011</u> (Stability Law 2012...change - Art. 27 l. f)

Decree Law <u>n. 5 of February 9, 2012</u> (Urgent provisions on development and simplification), Art. 4

Italian State-Regions Agreement of July 25, 2012 (DSA Certification)

Decree of the President of the Republic n. 151 of July 30, 2012 (Implementation rules of the New Highway Code concerning facilities, badges, signs and markings to facilitate the mobility of disabled and impaired people

Law <u>n. 167 of September 19, 2012</u> (Rules allowing living donor split transplantation of lung, pancreas, and intestine)

M.I.U.R Commitment for School Accessibility - Inclusion and Directives on Special Educational Needs and School Inclusion of December 2012

Law <u>n. 220 of December 11, 2012</u> (Amendments to Condominium regulations)

Law n. 221 of December 17, 2012 - Decree Law n. 179/12 (Section IV, from Art. 12 to Art. 13, Paragraph 2)

Law n. 98 of August 9, 2013 - Decree Law n. 69/13 (Dispositions on economic recovery) Art. 42 Ter

Law <u>n. 99 of August 9, 2013 – Decree Law. n. 76/13</u> (First provisions...) Art. 10.5 (Income references)

Decree of the President of the Republic of 4th October 2013 (Implementation of the biennial executive plan promoting rights and inclusion of persons with disabilities), published in the Official Gazette - Serie Generale n. 303, of December 28, 2013 and as hypertext version (Pdf/a kb 626)

Law n. 147 of December 23, 2013 (Expanded newborn screening)

Prime Minister's Decree <u>n. 159 of December 5, 2013</u> (Revision regulation of ISEE)

Legislative Decree n. 38 March 4, 2014 (Art. 13: European Reference Networks ERN)

Legislative Decree <u>n. 70 of April 17, 2014</u> (Sanctions against violation of the provisions of Regulation (EC) n. 1371/2007 on rail passengers' rights and obligations)

Law <u>n. 114 of August 11, 2014 - Decree Law 90/14</u> (Urgent provisions on simplification, administrative transparency and efficiency of judicial offices) Art. 25

<u>Rare Diseases National Plan 2013 - 2016</u> (PNMR) (Approved by the Italian State-Regions Conference on 16th October 2014)

Legislative Decree n. 169 of November 4, 2014 enforced on 6th December 2014 (Sanctions against violation of the provisions of Regulation (EC) n. 181/2011 (Amending Regulation (EC) n.2006/2004 on bus passengers' rights and obligations)

National Dementia Plan (Strategies for the promotion and improvement in the quality and appropriateness of dementia healthcare), published in the Official Gazette <u>n.9 of January 13, 2015</u>.

Legislative Decree n. 80 of June 15, 2015 (Provisions on healthcare, living and working needs, implementing Art. 1, Paragraphs 8 and 9, of Law n. 183 of December 10, 2014)

Legislative Decree n. 81 of June 15, 2015 (On employment contracts), Art. 8

Law <u>n. 107 of July 13, 2015</u> (Law on good school) Art. 1, Paragraph 180 and 181, Letter c and f

Law <u>n. 134 of August 18, 2015</u> (Provisions concerning diagnosis, medical treatment and rehabilitation of persons with hearing disorders and family assistance)

Law n. 141 of August 18, 2015 (Provisions on social farming)

Legislative Decree n. 151 of September 14, 2015 (Provisions on streamlining and simplification of procedures and tasks required to enterprises and citizens, along with provisions on employment relationships and equal opportunities, enforcing Law n. 183 of December 10, 2014)

Prime Minister's Decree <u>n. 178 of September 29, 2015</u> (*Electronic Health Records Regulation*)

Ministerial Decree of 2nd March 2016 (Regulation on functioning and organisation of the Istituto Superiore di Sanità), published in the Italian Official Gazette n. 88 of April 15, 2016.

Law <u>n. 112 of June 22, 2016</u> (Provisions on assistance for severe disabled people without family support)

Law <u>n. 167 of August 19, 2016</u> (Provisions on mandatory newborn screening tests for prevention and treatment of hereditary metabolic disorders)

Ministerial Decree of 13th October 2016 (*Provisions concerning the implementation of newborn screening tests for early diagnosis of hereditary metabolic disorders*) published in <u>s.s. of the Italian Official Gazette n. 267 of November 15, 2016</u> and as <u>hypertext version</u> (Pdf Kb 158).

Law n. 220 of November 14, 2016 (Cinema and Video Regulation)

Legislative Decree <u>n. 222 of November 25, 2016</u> (Procedures subject to authorisation ...)

Ministerial Decree n. 265 of December 28, 2016 (Regulation concerning manifestation of the will to access to assisted reproductive technologies, according to Art. 6 of Law n. 40 of February 19, 2004)

Ministerial Decree of 23th November 2016 ("After Our" Provisions) published in the <u>Italian Official Gazette n. 45 of February 23, 2017</u>

Prime Minister's Decree of January 12, 2017 (Definition and update of essential healthcare levels, as reported by Art. 1, Paragraph 7 of Legislative Decree n. 502 of 30th December 1992), published in the Italian Official Gazette n. 65 of March 18, 2017 - Supplemento Ordinario n. 15.

Decree of the President of the Republic n. 31 of February 13, 2017 (Regulation on the appraisal of interventions which are either exempted by environmental restrictions or under simplified authorisation procedures)

Law <u>n. 24 of March 8, 2017</u> (Provisions on safe healthcare assistance, safety of assisted people, and professional liability of healthcare practitioners)

Legislative Decree n. 63 of April 13, 2017 (Effectiveness of education rights...), Art.7, Paragraph 3 (Teaching aids, etc.)

Legislative Decree n. 66 of April 13, 2017 (Rules on promoting school inclusion of students with a disability according to Art. 1, Paragraph 180 and 181, Letter c) of Law n. 107 of 13th July 2015).

Legislative Decree n. 73 of June 7, 2017 (Urgent provisions on preventive vaccination, converted and modified from Law n. 119 of July 31, 2017).

Prime Minister's Decree of June 8, 2017 (in the Official Gazette n. 213 of September 12, 2017)

Decree of the President of the Republic of 12th October 2017 (Implementation of the Second Biennial Executive Plan promoting Rights and Inclusion of Persons with Disabilities) published in the Official Gazette - Serie Generale n. 289 of December 12, 2017 and as hypertext version (Pdf/a kb 1145).

Law <u>n. 219 of December 22, 2017</u> (Rules concerning Informed Consent and Advance Healtcare Directives)

Law <u>n. 205 of December 27, 2017</u> (2018 State Budget Estimate and 2018-2020 State Budget – Art. 1, Paragraph 254 and 255 - Family Caregiver)

Law <u>n. 3 of January 11, 2018</u> (Delegation to the Government on medicinal product clinical trials, provisions on rearrangement of healthcare professions and healthcare management jobs by the Ministry of Health)

Ministerial Decree of 6th February 2018 (Establishment of a national board for integration of disabled people at work), published in the Official Gazette n. 77 of April 3, 2018.

Ministerial Decree of 2nd March 2018, published in the Official Gazette n. 81 of April 7, 2018, the Glossary of Free Building Construction,

Ministerial Decree of April 16, 2018, published in the Official Gazette n. 128 of June 5, 2018 ("Revision of Medicinal Products and Substances and Medical Practices considered as Doping according to Law n. 376 of 14th December 2000).

Legislative Decree n. 106 of August 10, 2018 (Implementation of Directive (EU) 2016/2102 on the accessibility of the websites and mobile applications of public sector bodies)

Ministerial Decree of September 17, 2018 (Establishing of the National Vaccination Register), published in the Official Gazette n. 257 of November 5, 2018.

Ministerial Decree of November 15, 2018 (2018 Fund Allocation to the Italian Regioni for supporting severe disabled single people), published in the Official Gazette n. 4 of January 5, 2019.

Ministerial Decree of November 26, 2018 (Social Policy Fund Allocation 2018), published in the Official Gazette n. 8 of January 10, 2019.

Law n. 145 of December 30, 2018 (2019 State Budget Estimate and 2019-2021 State Budget)

Law <u>n. 29 of March 22, 2019</u> (Establishment and Regulation of the National Cancer Registry and Analysis Network)

Law <u>n. 55 of June 14, 2019</u>, Art.5 (Videosurveillance systems protecting children and elderly people)

Legislative Decree n. 96 of August 7, 2019 ((Rules on promoting school inclusion of students with a disability)

Prime Minister's Office Directive 24th June 2019 (Guidelines on mandatory employment), published in the Official Gazette n. 213 of September 11, 2019

Ministerial Decree of June 1, 2019 (Italian <u>Official Gazette n. 221 of September 20, 2019</u> - Revision of Medicinal Products and Substances ... considered as Doping according to Law n. 376 of 14th December 2000)

Ministerial Decree of 1st August 2019 (Blood safety – blood components not aimed for transfusion) published in the Italian Official Gazette n. 226 of September 26, 2019

Ministerial Decree <u>n. 130 of August 20, 2019</u> (Regulation on goals, functions and structure of the Transplantation Information System SIT, and. and National Register of Donors of Reproductive Cells for heterologous assisted reproductive technologies.)

Ministerial Decree of 20th August 2019 (Allocation of Funds to the Regions to reduce waiting time for healthcare services) (19A07081) published in the Italian Official Gazette n. 268 of November 15, 2019)

Decree of the President of the Republic n. 131 August 23, 2019 (Regulation on the Donation of Human Tissues and Cells – technical specifications for testing)

Law <u>n°10 of February 10, 2020</u> (Provisions on the disposal of one's post mortem body and tissues for studies, training and scientific researche) and its related regulation

Legislative Decree n. 101 of July 31, 2020 (Implementation of Council Directive 2013/59 Euratom which laid down basic safety standards for protection against the dangers arising from exposure to ionising radiation, repealing Directives 89/618/Euratom, 90/641/Euratom, 96/29/Euratom, 97/43/Euratom and 2003/122/Euratom, and rearrangement of the related regulatory framework implementing Art. 20, Paragraph 1, Letter a) of Law n. 117 of October 4, 2019). (20G00121) (Italian Official Gazette n. 201 of August 12, 2020 – Supplemento Ordinario n. 29). See Title XII – Medical Exposure

Law <u>n.120 of September 11, 2020 – Decree Law n.76/2020</u> (Urgent provisions on simplification and digital innovation) Art. 29 Ter

Prime Minister's Decree of October 27, 2020 (Criteria and modalities of using the Support Fund aimed at supporting the assistance tasks of

family caregivers in 2018-2019-2020. (21A00193). (published in the Italian <u>Official Gazette</u>, general series n.17 of January 22, 2021)

Law <u>n. 46 of April 1, 2021</u> (Delegation to the Government for rearranging, simplifying and enhancing provisions supporting dependent children by means of the universal single allowance)

Law <u>n. 69 of May 21, 2021</u> (Conversion into law, with amendments, of Decree Law n. 41 of 22nd March 2021 on urgent supporting provisions...related to the COVID-19 emergency) Art. 34 ter (LIS and LIST)

Decree Law <u>n. 79 of June 8, 2021</u> (Urgent provisions on the temporary allowance for underage children)

Ministerial Decree of June 1, 2021 (Official Gazette n. 226 of September 21, 2021) and Ministerial Decree of June 21, 2021 (Official Gazette n. 226 of September 21, 2021) (Compensatory tools for people with a certified DSA who take the written driving test)

Ministerial Decree of July 5, 2021 (Establishing a common national information platform of the new European Blue Badge CUDE), in the Official Gazette n. 183 of August 2, 2021

Ministerial Decree of August 4, 2021 published in the Italian Official Gazette n. 264 of November 5, 2021 (Revision of Medicinal Products and Substances ... considered as Doping according to Law n. 376 of 14th December 2000)

Decree Law <u>n. 121 of September 10, 2021</u> (New Road Traffic Regulation)

Decree Law <u>n. 146 of October 21, 2021</u> (Urgent provisions on economic and financial matters, for the preservation of employment and for needs which cannot be postponed)

Ministerial Decree of October 11, 2021 published in the Italian Official Gazette n. 285 of November 30, 2021 (Criteria for the identification of the beneficiaries and for the presentation mode of the

requests for the monthly contribution for unemployed or single-income parents with dependent disabled children)

Law <u>n. 175 of November 10, 2021</u> (Provisions concerning medical treatment of Rare Diseases and for supporting Research and Production of Orphan Medicinal Products)

Prime Minister's Decree of November 6, 2020, published in the Official Gazette n. 304 of December 23, 2021 (Disability Card)

Interministerial Decree of November 9, 2021 published in the Italian Official Gazette n. 307 of December 28, 2021 (Compensatory tools for people with DSA in public competitions)

Law <u>n. 227 of December 22, 2021</u> (Delegation to the Government on Disability)

Decree Law <u>n. 230 of December 29, 2021</u> (Establishment of the universal single allowance for dependent children, in the implementation of the delegated powers of attorney as conferred by the Government in accordance with the law n. 46 of April 1, 2021)

Ministerial Decree of January 10, 2022 (Provisions on the Italian LIS and LIST interpreter profession) in O.G. n. 81 of April 6, 2022

Ministerial Decree <u>n. 43 of March 11, 2022</u> (Guidelines regarding the disability hiring quota)

Law <u>n. 25 of March 28, 2022</u> (Business and business operators support. -Art.7 pro DSA)

Ministerial Decree of April 14, 2022 (Amendments of the decree of August 2, 2007 on the subject of identification of the pathologies regarding those which are exempt from examinations on the permanent status of disability) in O.G. n. 125 of May 30, 2022

Ministerial Decree of April 29, 2022 (Approval of the organizational guidelines for the "Digital framework for the implementation of the awdomestic care") in O.G. n. 120 of May 24, 2022

Ministerial Decree of May 18, 2022 (Essential data integration that makes up the files of the Digital Health Record) in O.G. n. 160 of July 11, 2022

Ministerial Decree of May 20, 2022 (Adopting the Guidelines for implementing the Digital Health Record) in O.G. n. 160 of July 11, 2022

Legislative Decree n. 82 of May 22, 2022 (Implementation of the EU directive 2019/882 of the European Parliament and Council of April 17, 2019, regarding the requirements to access to services and the products)

Ministerial Decree n. 7 of May 23, 2022 (Regulation for defining frameworks and standards for the development of regional assistance within the National Health Service).

Law n. 62 of May 31, 2022 (Provisions on the transparency of the relationship between manufacturers, entities operating within healthcare and healthcare organizations)

Legislative Decree n. 68 of June 16, 2022 codified, with modifications, in law 108/2022 (Urgent provisions on ... sustainable mobility ...) Art.7 l.i

Law <u>n. 78 of June 21, 2022</u> (Delegating the Government for public contracts matters) Art. 1 c.2 l.h

Legislative Decree n. 105 of June 30, 2022 (Implementation of the EU directive 2019/1158 of the European Parliament and Council, of June 20,2019, regarding the balance between professional activity and family life for parents and carers and which abrogates the directive 2010/18/EU of the Council)

Law <u>n. 129 of August 3, 2022</u> (Delegating the Government for the reorganization of the institutional frameworks for the hospitalization and evidence based treatment, of those as per legislative decree n. 28 of October 16, 2003)

Ministerial Decree of August 25, 2022 (Designating bus stations that give assistance to people with disability or people with reduced mobility). in O.G. n. 211 of September 9, 2022

Decree by the Prime Minister on June 1, 2022 (Establishment of the National Patients Registry office) (ANA) in O.G. n. 240 of October 10, 2022

Ministerial Decree of June 28, 2022 (Revision of Medicinal Products and Substances ... considered as Doping according to Law n. 376 of 14th December 2000) in O.G. n. 250 of October 25, 2022.

Ministerial Decree of August 22, 2022 (Provision of orthotic and prosthetic aids for the performance of amateur sport activities for people with physical disabilities) in O.G. n. 296 of 20/12/2022

Ministerial Decree of September 30, 2022 (Procedures for the selection of telemedicine solutions and territorial distribution, as well as the evaluation process of the proposals for the regional requirement for the minimum service of telemedicine and for the implementation of the guidelines for telemedicine services) in O.G. n. 298 of 22/12/2022

President of the Republic Decree $n^{\circ}47$ of February 10, 2023 (Regulation containing provisions on the disposal of one's post mortem body and tissues for studies, training and scientific research).

Law $\underline{n^{\circ}33}$ of March 23, 2023 (Government Delegation dealing with policies supporting the elderly)

Rare Diseases National Plan 2023-2026 (PNMR) (Approved by the Italian State-Regions Conference on 24th May 2023)

Ministerial Decree of June 23, 2023 (Definition of outpatient specialist and prosthetic care rates) in O.G. General Series n° 181 of August 4, 2023

Prime Minister Decree n°115 of July 20, 2023, (Regulation on composition and functioning of Observatory of Persons with Disabilities)

Ministerial Decree of August 1, 2023 (*National Cancer Registry*) in O.G. n°203 of August 1, 2023

Ministerial Decree of June 9, 2023 (Adoption of the National Health Technology Assessment Program) in O.G. n°207 of September 5, 2023

Ministerial Decree of May 31, 2023 of the Ministry of Heatlh (Establishment of the «National Network for thalassemia and haemoglobinopathies») in O.G. n°214 of September 13, 2023

Law <u>n°130</u> of <u>September 15, 2023</u> (Provisions regarding the establishment of a diagnostic **program for the detection of Type 1 Diabetes and celiac disease** in pediatric population)

Law <u>n°193</u> of <u>December 7, 2023</u> (Provisions for the prevention of discrimination and the protection of the rights of individuals who have been affected by oncological diseases)

Law <u>n°213 of December 30, 2023</u> (National estimated budget for the financial year 2024 and multiannual budget for the three years period 2024-2026)

We would like to thank the Publisher Giuffrè who allowed us the free access to all legislative materials needed in order to complete this text.

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ANNEXES

Annex A: (Past Model Document for the Response of the Commission assessing Impairment)

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Annex B: (Past Model Document for the Response of the Commission assessing Disability)

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