

In Italy a person with disability<sup>1</sup> can find specific support services from early years to adulthood mainly thanks to the Framework Law 104/92<sup>2</sup> and consequent related laws and decrees. Despite this innovative framework, the structure managing social care and support services for persons with disabilities is highly complex and different all across the country.

First of all, there are several policy sectors involved in the provision of services for persons with disabilities, in particular, healthcare, education, long-term care, justice, employment, culture, public works and social services: the Ministries of Healthcare, Education and Employment (Ministero della Salute, dell'Istruzione e del Lavoro) offers a range of essential services for persons with disability.

Second, the National government, the twenty Regions and the Municipalities have different powers on this issue. Decentralization that has been under way in the last two decades meant that the Regional (and Local) Authorities take on a strategic role for the planning / programming / governance of resources, services and actions in favour of the inclusion and education of disabled pupils. The Regional authorities are responsible for providing most of the services, they can create specific laws and decrees dedicated to disability services and they are autonomous in budget administration. However, this autonomy developed differently across the Country: the most recent reports on scholastic inclusion, residential services and employment show that the Northern Regions provide better services for individuals with disability.

Municipalities have specific competence in matters of social assistance, in particular as regards the economic and logistical support to families with members having social needs of various kinds, including those related to the care and the social inclusion of individuals with disability. The Municipalities deliver many services thanks to the National Fund for Social Policies (FNPS): this is a fund dedicated to the Regions for the development of the integrated network of social interventions and services, as required by Law 328/2000; a portion of the Fund is also attributed to the Ministry of Labor and Social Policies for National Interventions. An annual structural budget of 300 million was established from 2015<sup>3</sup>.

In short, there are many services integrating health and social care and this has improved the system of care and support to people with disabilities and their families. However, there is room for improvement – for example the care system is difficult to navigate due to its complexity and wide territorial differences based on good (or bad) local administration.

In order to facilitate access to information on services for persons with disabilities, most of the Local Health Agencies (ATS - ex ASL) have activated a service called "Sportello Integrato" (Integrated Help Desk) to serve as an information point on all services under the disability support system. Some Regions have also promoted the Case Manager (or Disability Manager): a professional assigned personally to individuals and families to provide customized support.

To support the public service provision there is a wide range of non-profit and private organisations: social cooperatives, family associations, foundations, health & research institutes (IRCSS), NGOs and volunteering associations among others. These organisations must be accredited to the Local Authorities (Region, Province and/or Municipality) in order to be eligible to deliver specific services to individuals with disability backed by public funding. These organisations, in different amount and ways, are also supported by private funding (e.g. fundraising, donors, private fundations).

<sup>&</sup>lt;sup>1</sup>The "persons-first" wording perspective is not common in the Italian normative framework. The words "disabled", "handicapped", "non self-sufficient" are the most used in the Italian laws. For each definition, Italian law has identified single or multiple benefits, allowances, facilitations, service access criteria and assessment modalities.

<sup>&</sup>lt;sup>2</sup>Law 104/92 ("Framework Law for assistance, social integration and rights of the handicapped") aims – among other things - at guaranteeing respect for human dignity, as well as the rights to freedom and autonomy of persons with disabilities, while promoting their integration in families, schools, work and society, preventing and removing negative conditions that stop the human development, the highest possible level of autonomy and participation in social life, as well as the enjoyment of civil, political and patrimonial rights; achieving a functional and social rehabilitation of people with physical and sensory impairment, while ensuring adequate services and prevention, care and rehabilitation measures, as well as a legal and economic protection; preparing adequate initiatives to overcome marginalization and social exclusion.

#### SUBSECTORS OF SOCIAL CARE & SUPPORT SERVICES AND THEIR CHARACTERISTICS

### **Early Childhood Intervention**

Services for children with disability are generally managed within the Local Health Agency (ATS – Distretto Sanitario Locale) and in the local Municipalities. The access to dedicated services and the activation of early interventions are based on the efficiency of the so-called "taking-care process" ("presa in carico"), divided into the following important steps:

- 1. Diagnosis and attestation of disability: the attestation provides for documentation, by the specialist doctor and by the psychologist of the Health District who attests the disability.
- 2. Drafting of a functional diagnosis (diagnosi funzionale DF): the doctor who has proceeded to diagnose and attest the disability is in charge of activating the further assessments deemed necessary (e.g. speech therapy, physical therapy, social assessments, psychological evaluations,...)
- 3. Activation of the functional multi-disciplinary team (EMT): this team involves all the different professionals working on the case with the aim of defining the different psycho-educational health care of social and scholastic inclusion and in general the Child's life project. The EMT support the connection with the network of social and health services and guarantees the continuity of interventions in the age of development and in adulthood through the formulation of specific life projects for the person in accordance with Law 104/92. It is a team with tasks of planning, coordination, taking charge and definition of the "life project" of disabled people. The EMT is composed by social, health and educational workers involved in the child with disability's life project.
- 4. Drafting of the life project: the EMT, involving the family, writes the life project taking into account the child's strengths, needs and development goals. The different objectives are declined together with the wide team around the child.

The "Taking-care process" in mainly managed and delivered by the Child and Adolescent Neuropsychiatry Operative Unit (UONPIA)<sup>4</sup>: this is interdisciplinary operative public service and it is responsible for the prevention, diagnosis, treatment and rehabilitation of neurological, neuropsychological and / or psychiatric diseases of infancy and adolescence (from 0 to 18 years) and of all disorders of child development in its various expressions (psychomotor, linguistics, cognitive, intellective and relational). The UONPIA units are spread throughout the country and are allocated per specific number of inhabitants. Multidisciplinary territorial teams are mobilized at the request of paediatricians or family doctors and facilitated by a given hospital or emergency room.

This service is the most important for children with disability and it deals with local authorities, schools and associations, promoting and consolidating the Team Around the Child; it operates in ways that guarantee continuity between each service, necessary to ensure appropriateness and completeness in the diagnosis, accuracy and adequacy of the therapeutic project, coherence and continuity of possible care interventions and verification of outcomes over time.

This service is free and supported by the National Health System (SSN), however the waiting lists can be very different from region to region and depending on the severity of disability: the problem of waiting lists for the evaluation and then the stepping in of the UONPIA and even more for the start of rehabilitative therapies (in the UONPIA or in the accredited rehabilitation service) is very acute at the time of preparing this factsheet in 2018. Even once the UONPIA is on a given case, it cannot always meet demand. According to regional indications, waiting lists have been differentiated according to priority levels, so as to guarantee timely interventions at least to the most urgent situations. As a result, less urgent patients find themselves with particularly long waiting lists (which can extend for 12-18 months).

Due to the waiting lists, many accredited private health centers are delivering similar services (e.g. diagnosis and "taking-care process") paid by families or supported by the SSN fund (it depends on the service and on the center itself).

The following services are available for Early Childhood Intervention (in addition to UNOPIA). NB: many serve both preschool age and compulsory school age children.

- Child-care and Preschool Services: children with disability from 0 to 6 years-old have a guaranteed a position in preschool and child-care services with priority over other children, in particular if they have a severe disability. Local authorities can provide the adaptation of the organization and functioning of these services to the needs of children with disabilities, also with the support of operators, assistants and specialized teaching staff; this support is financed with public funds. The municipalities, therefore, must provide this child-care service and private services must meet the same requirements as public ones if they want to be accredited. The kindergarten (students from 3 to 6 years old) is integrated into the national scholastic system and it can benefit of the same services (see next paragraph).
- Service for School and Social Integration (Servizio per l'Integrazione Scolastica e Sociale SISS): this service is managed by Local Authorities and it is dedicated to students with pre-school and school-age disabilities5 attending schools of all levels and that are in a situation of medium, severe or very severe deficit in the psychomotor, psychorelational, personal and social autonomy areas. The Municipality and the Local Health Agency (ATS) assigns weekly assistance hours based on the annual available budget and considering each individual's need and this service is free for families and financed with National Social Fund.

Considering the individual's needs, this service is carried out by educators and/or socio-health operators (Operatore Socio-Sanitario - OSS), employed by accredited private organizations (social cooperatives, foundations, NGOs, family associations). These professionals have access to the school attended by the pupil for: physical help and personal care; the development, strengthening and maintenance of personal, social, communication and emotional skills; the support in behavioural management and environmental / tools management.

- Educational Home Service (Servizio Educativo Domiciliare): this is an individualized home care service for children up to 18 years old with disability, aimed at acquiring personal, social and relational autonomy. This service is promoted by the Municipality and it is supported by public fund, so it is free for families. The number of hours assigned to each pupil are based on the fund itself, on disability severity and on the familiy's needs (for an average of 4 weekly hours). For children up to 13 years, the aims are development of personal autonomy and support in social interaction also in other local agencies (e.g sport activities, leisure time, local association).
- Socio-Educational Center for Children (Centro Socio-educativo per minori CSE piccoli): this is an integrated service for the daytime reception of children with disability. Attendance at this service can replace school attendance or integrate it according to a program defined with the school itself, the reference rehabilitation service and the family. It welcomes pupils with disability who require a socio-educational space as an alternative to school attendance or who, attending school for a reduced number of hours, need to complete their path with specific educational / qualifying interventions. This service is usually managed by private/non profit social companies (e.g. associations, fundations, cooperatives) financed as described in the introduction.
- Day service (Servizio Diurno Minori CDD Minori): this service offers educational and rehabilitative interventions in the afternoon and it can integrate the school attendance. This service welcomes minors from 3 to 18 years-old with disability; it is run by accreditated social cooperatives/agencies or by the Municipality and it is supported by public funds, as described in the previuos bullet point (CSE). The service aims are to accompany and encourage integration between (educational, rehabilitative, educational) paths; guarantee proposals through which to learn and develop communication, relational and autonomy skills; offer recreational opportunities for leisure time management; support families through interventions of parent training and relief; designing support measures during the transition to age, also in collaboration with local services.



### **Education Support**

The right to education of students with disabilities is enhanced by the Italian Constitution and dedicated laws, establishing prerequisites, conditions and instruments for school inclusion and ensuring the right of children and young people with disabilities to have adequate access to classes, from primary school to all education institutes and universities.

ISTAT (National Institute of Statistics), in cooperation with the Ministry of Education, University and Research (MIUR), in the annual survey declares that in the scholastic year 2016-2017 (most recent available report) there were almost 160.000 students with disabilities (3.5% of the total number of students), of which more than 90.000 in primary school and about 69.000 in first level secondary school, with an increase of 2% compared to the previous year.

The following services are available for inclusion of students with disability as per the Law 104/92:

- a) Coordinated plan of school services, social services, cultural, leisure and sport activities with other activities on the Italian territory managed by public or private organizations;
- b) Supply of didactic tools and assistive technology to schools, as well as other forms of technical assistance;
- c) Measures to accommodate the special needs of students;
- d) Supply of sign language interpreters in order to facilitate the learning process of deaf students.

The specific services should take into account the Functional Diagnosis (DF) drawn up by the health services (ATS/UONPIA), the Dynamic Functional Profile (PDF) with the same health services and family and the Individualized Educational Plan (PEI), which indicates the aims and objectives of the student. Size of classrooms with at least one student with disability cannot exceed 20, and a maximum of one student with severe disability per class is allowed.

These are the key services for students with disability in Italy:

• Mainstream school for all: The Inclusive Path that started from Law 118/1971 defined the principle of integration of pupils with disability into regular classes, at the request of families: the children with disability were no longer obliged to attend special classes/schools. After this law, most of special school and mental institutions have been closed: in 2017, as declared by the Ministry of Education, there are 21 special schools in Italy, all dedicated to students with sensory disability (blind and/or deaf students) but a recent study conducted by the University of the Sacred Hearth of Milan (2012) underlines that there are 24 special schools that welcome students with severe disabilities (only considering the Lombardia area<sup>7</sup>).

Education of students with disability is guaranteed even if they are temporarily unable to attend school: the legislation recognizes home-schooling and the creation of detached sections of state-controlled schools for hospitalized minors.

• Support Teacher: With law 517/1977 support teachers with specialized training on the subject of disability support the implementation of a specific plan assigned to specific class teams. The support teacher is assigned to classes to support the inclusion of students with disability.

In the scholastic year 2016/17, there were over 88,000 support teachers, 6,000 more than the previous year – about 1 teacher for every 2 students with disabilities. South Italy is shown to have the highest number of average weekly support hours. Officially, there is no waiting list to have a support teacher, but the assigned hours are decided by the Local Scholastic Authority and managed by the Headmaster. According to INSTAT, 41.1% of pupils in primary school and 37.2% in secondary school graduates changed their support teachers in the new scholastic year (2016-17): turnover of support teachers is one of the main obstacles to effective inclusion in mainstream education.

Ministerial decree 139/11 introduced for the first time courses on inclusion of children with disability in education that are mandatory and free for all teachers; these courses are paid by the school with internal public funds or with municipality social funds.

• Service for School and Social Integration (Servizio per l'Integrazione Scolastica e Sociale - SISS): The service for school and social integration as mentioned in the section on early childhood intervention and care, provides the same services that fall under education support for children enrolled in public and private accredited schools.

It is estimated by INSTAT that a student with disability can have about 12.5 hours per week with an SISS operator in primary schools and about 11.5 hours in secondary schools. In the South this support is drastically reduced with a gap of over 3 hours compared to the schools in the North.

• Educational Home Service (Servizio Educativo Domiciliare): as for the previous bullet point, this service provides the same support described in the section on early childhood intervention and care. For individuals aged between 14 and 18 years, this service can have a professional goal, as well as the development of personal autonomy, for the support towards work inclusion through the deputy services (e.g. Job Placement Service - SIL – see section on employment).

Service for the Inclusion of Students with Disability and Learning Difficulties (Servizio per l'Inclusione di alunni con disabilità e dislessia – SISD / SAISD): most of the Italian universities (public or private) have this dedicated service for students with disability and learning difficulties. This service is financed by the university itself (free for studens); the professionals involved in this process can be curricular professors and special professors, enrolled directly by the university, who are co-coordinators of classes and participate in the didactic planning. Students have guaranteed the access to university studies thanks to technical and didactic tools, specialized tutoring services and personalized services for exams.

### **Employment Support**

In Italy the framework law 68/99 "Norms for the right to work of the disabled" aimed at encouraging targeted job placement, establishes specific services, in addition to forms of obligation, sanctions and incentives for companies to hire persons with disability.

The most recent available data show that in Italy, 18% of persons with disability aged 45-64 years are employed (2013), of which 23% are men and 14% women.

To support the employment of individuals with disability, the Italian system has activated the following services:

• Employment Center (Centro per l'Impiego): At the age of 18, a young person with disability looking for employment should contact the Employment Center, a public provincial service which generally provides a help desk (or simply a person) responsible for registering as employment seekers new people with disability according to the law 68/99. Only persons with 45% disability as designated by the Civil Invalid Committee of the Local Health Agency (ATS) of residence, are eligible for this service. The decision takes up to 4 months since the application, and comes with a profile of the worker indicating their capabilities, any need for reinforcement through targeted training and or the impossibility to be placed in a job position. The people not enrolled in the Employment Center can be employed directly by a company (direct connection or through associations or social support in Municipality) or are assumed to be able to be competitive in the open labour market.

A follow-up interview is planned with the applying person: this is fundamental to understanding whether the individual is already able to work or if they require further training (see following bullet point). If, instead, they are not able to carry out any profitable work, they will be redirected to local welfare services for different solutions.

- Job Placement Service (Servizio di Inserimento Lavorativo SIL): In order to implement a targeted placement in a company, the provincial local Municipality (or a consortium of municipalities) run Job Placement Services, that consist in operators trained to support the person with disability to be included in a company, from early stages to dealing wth specific issues that arise; this service cooperates with the Emplyment Center. The Educational Home Service (Servizio Educativo Domiciliare described in the section on early childhood intervention and education) can support young persons with disability in accessing this service too.
- Vocational Training Center (Centro di Formazione Professionale CFP): these centers are open to students who have completed Middle School education; the main goal is to train young people and adults professionally and to facilitate their labour market entry. The CFP are managed and financed by the Region of competence (public funds) but they are organised by accredited training agencies or social cooperatives (private/non-profit).

For students certified as having a disability and under the age of 18, the CFP has specific programs, called "Personalized path". This programme lasts three years and it can be integrated with a fourth year, for a total annual number of hours

of 600 min and 990 max. The main goal is developing professional skills and the possibility of social-work inclusion with a particular focus on strengthening transversal job skills.

They are characterized by a flexible and personalized training proposal in response to personal learning methods: each student receives training and educational goals related to a broader personal project shared with the student, their family and the services of the territory, so as to facilitate student placement for training in local companies.

• Autonomy Training Service (Servizio di Formazione all'Autonomia – SFA): This service welcomes persons with disability above the ages of 16 and supports the individual in the process of personal, social and emotional growth in order to achieve the degree of autonomy required in the social and working field, encouraging the acquisition of skills useful for professional integration, in close connection with the provincial Job Placement Service (SIL). This service is usually managed by social companies (e.g. cooperatives or associations) and financed in part with public funds through accreditation and calls, in part with attendance fee - the fee is calculated in proportion to the hours attended, and the municipality of residence (that may require families to participate in the expenditure) pays it.

Duration of attendance is from 1 to 5 years (training module: 3 years max / consolidation module: 2 years max): during these years all the activities are carried out to achieve the objectives of the individualized plan. The intensity is expected to be from a minimum of 12 hours per week (part-time) to a maximum of 24 (full-time).

After the SFA, the individual is expected to be able to take care of themselves, organize their time and move independently in the territory, recognize and respect the main family, social and work rules.

- Targeted Placement Methodology (Collocamento mirato): The real innovation of the law 68/99 consists the introduction of the National targeted placement methodology, which allows companies to recruit persons with disability through specific projects that allow people to be appropriately assessed based on their actual work abilities and to place them in an appropriate job position through the *modification of the workplace*, the *supply of particular aids*, etc., so as to enable the person to carry out profitable work activity. In the case of those with an intellectual disability, targeted placement involves the presence of a *reference operator*, with the initial task of "preparing the work environment", encouraging interpersonal relationships, facilitating the learning of tasks so as not to create damage to the general production trend and help the young person with disability to enter the company organization. This methodology is mandatory by law for any Italian for profit company with more than 15 workers; employers of persons with disability receive tax discounts and service supports (see previous bullet points). The waiting list depends on availability and type of support needed and varies considerably across the country.
- National Contact Center and Call Center INAIL "Superabile": The National Institute for Insurance at Work (INAIL) has created a public website (<a href="www.superabile.it">www.superabile.it</a>) and a national call center to support the employment and the quality of life of individuals with disability.

### **Day Care**

The notion of non-autonomy has been widely discussed in Italy over the last fifteen years, especially on the regional level, in particular after the approval of law 328/00 "Framework law for the creation of an integrated system of social services and measures". The [multi-dimensional] assessment of non-autonomy is used to grant economic benefits in order to cover fees for personal assistance, access to home care, partial or total reimbursement for hospitalization in dedicated facilities according to the needs of the persons concerned.

This assessment is carried out through a system regulated by the regions with their own norms and usually applied by means of territorial teams made up of social operators and sanitary staff. Its multidimensional character means that it takes into account not only the psychophysical condition of persons but also their activities, their family context and environment. Assessments are aimed at evaluating assistance needs (referred to as assistance load or assistance intensity) in a way that is often influenced by the amount of resources available to the grant "provider" or by the "level of functional loss". A negative terminology (non-autonomous) is also used to describe situations of persons with disabilities who need appropriate instruments for an independent life.

Various studies on the notion of non-autonomy have stressed that the Italian Law does not provide a clear and shared definition. Even though all definitions in use refer to difficulties encountered in "daily activities", the list of "activities" is

different from Region to Region. Policies for "non-autonomy" that should design and guarantee a system of "long-term care" similar to other European countries are based on different evaluation instruments and resources on a regional basis. There are huge differences in other disability-related fields, because of a strong system of regional autonomy; often the need for convergence has been stressed in order to overcome difficulties and gaps in the way citizens are treated.

The two types of services described below (CDD and CSE) welcome individuals with full or partial disability of all kinds in the post-school age and adults, between 15 and 65 years. The persons enrolled in these services are not employed.

These services provide specific activities based on different age groups and implement each Individualized Plan (PI) as defined by the Local Social and Health Service. The PI plan is the consequente plan of PEI, usually used for an individual with disability in scholastic age (see education section). Both of these services can involve their users in small incomegenerating activities, leisure activities, every-day life activities and training; they are mainly run by accredited private organizations (social cooperatives, foundations, NGOs, family associations).

- Day Center (Centro Diurno Disabili CDD): this is a territorial service that provides educational, rehabilitation and assistance interventions. These centers are managed by accredited social companies (e.g. associations, social cooperatives, fundations) that are supported by public funds through Local Municipaliets (free for the users).
- The CDD is a non-residential facility open for at least eight hours a day for six days a week, with educational and rehabilitative functions aimed at preventing and / or stopping processes of marginalization and preventing and containing long-term institutional care. These centres promote autonomy and re-socialization of each person through occupational programs aimed at mastering specific skills that can be used in a professional way (possible employment) and social leisure programs. In addition to the internal activities, meetings of support for families and connection with the territory are widely promoted. Medical support is available all day long (medicines, medications) and health professionals are in the regular team. There are only some regional data on this service: for example in the Lombardia region there are 268 CDDs that can welcome from 15 to 35 persons each (median=25), for a total of almost 2,700 positions.
- Socio-educational Center (Centro Socio Educativo CSE): this is a territorial service that mainly provides educational and assistance interventions. Like Day Centers (CDD), CSEs are financed by public funds through the Municipality and managed by accredited companies. It is a non-residential facility open for at least eight hours a day for six days a week, with educational functions aimed at preventing and / or stopping processes of marginalization and preventing and containing long-term institutional care. This service is very similar to CDD but there is a key difference: these centers target only individuals with light disability, mental illness, relational problems and not certified difficulties that don't have any medical need but only social and intellectual difficulties that are obstacles to their employment capabilities.

Local Authorities (Municipality and Local Health Agency) provide financing for the family to the day center or residential service of choice (see *Living support* and *Long-Term Institutional Care* sections) based on the type of need and severity of disability.

The Waiting List of Day Care services depends on the Municipality funds and the Local Services organisation: it can range from under a month to many months. As for previously described services, the local authority can drive good or bad service delivery.

### **Living Support**

The current development of regional policies and the implementation of local planning (Zone Plan and Local Disability Plan) are enhancing the skills and potential of the individual and their family. Each Italian region, with specific dedicated regional laws, directly manages the provision of assistive technology, supportive equipment, domestic automation and home mobility. For example, the Lombardia Regional Law 23/99 supports interventions for individuals with disability and students with learning difficulties, dedicating € 2.000.000,00 for the year 2017 for the purchase of these tools. The purchase of supportive equipment, in particular for individuals with sensory and/or motor disability (e.g. provision of wheelchairs, walking sticks, blind dog support, interpreters, etc.), can be also tax deductible (from 4% to 19% of the cost incurred).

The living support services available across Italy are managed by different authorities: home and personal care services are managed by the Local Authority whereas all the accommodation services (e.g. Accommodation communities, Autonomy Services and Apartment Groups) can be directly managed by the Local Authority or by accredited organizations (social cooperatives, foundations, NGOs, family associations self-founded or privately founded).

The framework law 112/2016 "After Us" (Dopo di Noi) specifically regulates living support services delivered by each Municipality and financed with public money through the FNPS (as described in the introduction).

- Home Care Services (Servizi di Assistenza Domiciliare SAD): The Home Care Service is a social-assistance service aimed at the prevention, maintenance and recovery of residual potentials that allow the person to stay in their home and in their relational context. It is a service provided by the Municipalities free of charge in order to assist individuals with all kinds of disability or non self-sufficient people with different levels of dependency at all ages, who live alone or with their family members and includes services such as the provision of meals, laundry, home help in personal care and hygiene.
- Integrated Homecare Assistance (Assistenza Domiciliare Integrata ADI): this service offers the possibility to use together with home care also the medical, nursing and / or rehabilitative care necessary for the person's home. Persons with disability that interferes with their possibility to be self-sufficient can thus be adequately treated at home avoiding the inconvenience and costs of inappropriate institutionalisation. The Service is aimed at people with disability with different levels of addiction living alone or with their family members.
- Personal Care (Aiuto Personale): this is an intervention aimed at supporting persons whose disability can not be overcome through the provision of technical, IT, prosthetic tools with the view of helping them remain in their environment. This intervention includes specific actions to support the person, home care interventions, educational interventions (the intervention at home of operators with specific qualifications such as: educator, speech therapist, rehabilitation therapist, who prepare the person with disability and his family to carry out specific activities) and accompaniment of the individual.

Living support services delivered by accredited social companies (e.g. associations, cooperatives, fundations): the following services are financed with public money through the accreditations, public calls and municipalities support; sometimes the family is supposed to pay a reduced fee based on their income.

- Housing Communities (Comunità Alloggio): this service has the characteristics of a normal apartment and attempts to recreate an individual's environmental and family milieu. The staff (educational and / or welfare) performs diversified functions based on the assigned roles and needs of people in the household (e.g. food preparation, educational initiatives, socializing activities, social inclusion, personal care and maintenance of the premises). A person can stay there for as long as need or temporarily, as needed.
- Autonomy Services (Servizi per l'Autonomia formerly co-housing) are aimed at individuals with disability over the age of 18 with slight intellectual or mobility difficulties, coming from the local area. Self-management is prevalent, with the presence, at certain hours of the day, of assistance personnel for help around the house. It is characterized as a service aimed at meeting specific individual's needs, maintenance of skills and levels of autonomy acquired, the path of personal growth and social inclusion. It provides low-welfare services to disabled people with sufficient autonomy but with the need for support, with sufficient economic independence to meet their maintenance needs and to participate in covering their costs like utilities (light, gas, telephone). These services pay particular attention to the individual networks to best structure support networks for the individual and the group of guests. With this in mind, promotion and integration activities with groups of volunteers are encouraged. The guests, in some cases, can attend a day service or be included in employment or work activities. In the event that the income of the individual is insufficient, the Public Administration provides for integration. "Apartment Groups" (Gruppi Appartamento) offer similar services, targeting adults with disabilities.

The waiting list for each service described in this section is varies considerably across the country and can be from few days to one year, based on the given Local Authority's management capabilities. These services are not specialised on a specific disability but there are some experiences of residential services dedicated to individuals with Autism or Down Syndrome. Positive regional and local examples include:

- Tuscany region: info point for independent living (<a href="http://open.toscana.it/web/toscana-accessibile/sostegno-alla-vita-autonoma">http://open.toscana.it/web/toscana-accessibile/sostegno-alla-vita-autonoma</a>)
- Emila-Romagna region: A.S.P. REGGIO EMILIA People's city (Palestra di vita e di autonomia <a href="http://www.asp.re.it/">http://www.asp.re.it/</a> Struttura.jsp?id=35) promotes territorial welfare and co-housing
- Independent living examples: "Casa Ponte" (Down syndrome Padova), "Condominio partecipato" (Bologna), "Condominio sociale" (Cassano d'Adda), "Foresteria per i lavoratori con autismo" (Pordenone) <a href="https://www.superabile.it/static-rivista/2017/08/superabile\_magazine\_201708.pdf">https://www.superabile\_it/static-rivista/2017/08/superabile\_magazine\_201708.pdf</a>

### **Long-Term Institutional Care and Respite Care**

The Italian law 180/78, establishing the closing of mental hospitals and the creation of a network of alternative services on a regional basis marked a switch from services aimed at protecting society from persons with disability to an approach that entrenches the right of persons with disability to be cared for and integrated in society through a territorial service network for prevention, care and rehabilitation. However, in relation to deinstitutionalization, the Italian normative framework lacks an explicit reference to the right of persons with disabilities to choose a place to settle, where to live and the persons to live with.

• Assitential Health Protection Facilities (Residenza Sanitario-Assistenziale - RSD): this is the key service for long-term Institutional care. It is a residential service for persons with disability who are not self-sufficient and in a situation of severe difficulties, and who can not be assisted at home and require specialized medical treatment. The management of RSA is mainly entrusted to private organizations (70% of cases), especially non-profit organizations (48%); 13% of the residences are managed by religious bodies; about 16% of the supervisors are responsible for the public sector (INSTAT, 2015). There are significant territorial differences: the RSD is most readily available in the northern regions and least so in the South. The Northern regions also have the highest share of social and health care positions: for example in the Lombardia Region there are 103 RSD that can welcome from 15 to 290 persons each (median 44) for almost 2200 positions in total (2018 data).

The expenses, established by the bodies that manage the RSD in agreements with the Municipality, are in part covered by the National Health Service, partly by the Municipality and partly by the user and his family, according to the income (ISEE). The eligibility is checked by the Local Health Agency and the social service of the district of residence.

• Respite Care Services Italy offers a wide range of opportunities under the broad heading of respite care that are divided into non-residential, residential and economic interventions aimed at supporting the welfare burden resulting from the disability of a family member.

Non-residential services are mainly free or with a very reduced attendance fee and they are managed by non-profit associations active in the local community, involving volunteers and professionals in leisure activities for a few hours a week (often on the weekends and on holidays).

Residential services include: a) Scheduled Reception (Accoglienza Programmata in Servizio Residenziale) that offers the possibility for the person with disability and his family members to plan temporary accommodation in one residential facility for one or more periods) and b) Prompt Reception (Pronta Accoglienza) which ensures timely intervention within 24 hours to accommodate a person with disability in a residential structure in the event of an emergency situation due to the inability of the family members to provide needed care These services are delivered by the same social companies that deliver *living support services* (see previous section).

### **Leisure and Social-Life Support**

Promoting proper leisure time to children, teenagers and adults with disability i is mainly done by non-profit associations with the support of Local Municipalities. These services are usually locally based and supported by public funds, by admission fees and by private donors. The following services are the most relevant:

• Accessibile public playgrounds: in the last years many municipalities and provincial/regional authorities have promoted the adaptation and/or the building of public playground with equipment accessible to children with disability (e.g. in 2018 the Lombardia Region devoted a fund of 1 million euro to implement public playgrounds in Municipalities from 10.000

to 30.000 inhabitants). Few family associations have promoted a quality leisure time as a key aspect for the growth of a child with disability organising dedicated play spaces accessible to any type of disability (e.g. L'Abilità – www.labilità. org). These spaces are locally based (in main cities), promoted by private social organisations and supported by local Municipalities through public calls. However, on this issue in Italy there is still a lot of confusion because there is no reference legislation applicable to play equipment: the initiatives are undertaken by public or private administrations and companies sensitive to the problem but there is not a national promotion.

- Leisure Center for persons with disability (Centro di Aggregazione Disabili CAD): This is a leisure time and socialization service. It also addresses all adults with disabilities who are not in day-care services and need to be integrated into their social territory. The service, accredited by the Municipality, is free for users and it is open every day from Monday trough Saturday. The service can provide the following activies: creative workshops and support for relationships led by educators and/or specialists; unstructured meeting and sharing space for playful moments supervised by an educational figure whose task is to mediate relationships; discussion groups for subjects of interest to the participants and a psychological support desk able to offer an initial response to users' leisure time needs.
- Sports services targeted at people with disabilities: the key national sport organisation targeted at people with disabilities is the Italian Paralympic Committee (CIP), that works together with the National Olympic Commette (CONI) on the accessibility of sport facilities and promoting sports. On a local level, there are many sports association but often not specialised in welcoming persons with disability. There is a national association (e.g. SportABILI onlus <a href="http://www.sportabili.org">http://www.sportabili.org</a>) that supports other sports associations in delivering free consultancy services on how to become more accessible to persons with disability. The local municipality can provide to local sport associations specialised educators to support inclusive activities.
- Transportation and mobility services on local and national level: the National Railway Company (RFI) is also managing railway services for persons with reduced mobility and persons with disabilities while coordinating a workgroup<sup>8</sup> that involves the main associations of disabled customers. The services available free of charge include: mobility assistance, no-fee "blue-pass" on all national territory, dedicated seats on cars, silent cars on long distance trains, list of accessible stations and trains, sensory paths for blind people. Similar services are delivered by the *subway companies* in the main Italian cities.
- Also the *National Organisation for Civil Aviation* (ENAC) in 2009<sup>9</sup> defined specific guidelines implementing the airspace regulation and concerning quality standards for assistance to people with reduced mobility and staff training in cooperation with the associations of persons with disabilities and aviation operators. Many national airports (e.g. Milano Linate<sup>10</sup>) have created the following free services: silent rooms, sensory paths for blind people, dedicated seats and assistance in the airport and on board.
- Cultural site accessibility (heritage sites, museums)<sup>11</sup>: the guidelines for the elimination of architectonic barriers in cultural sites (2008) have been drafted by the Commission for the analysis of disability-related problems, in particular in the field of cultural heritage and museum activities: elimination of physical and sensorial barriers, accessibile information written in augmentative communication, dedicated labs to understand the exhibition in accessible ways (videos, images). Nowadays there are accessible museums in every important cultural city, the complete list of accessible museums organised by region is available at <a href="https://www.disabili.com/viaggi/musei">https://www.disabili.com/viaggi/musei</a>.
- Travel / holiday support services for accessible tourism: many touristic services dedicated to persons with disability have been promoted all across the country, e.g. the "Likehome" project promoted by National Association for Multiple Sclerosis (AISM), or online dedicated travel agencies (e.g. <u>Viaggiaredisabili.it</u> or <u>Nobarrier.it</u>). In 2009 the Ministry of

<sup>&</sup>lt;sup>8</sup>This group has drafted some documents concerning standards and measures to adopt; among them, there are specific guidelines concerning railway infrastructures, drafted in 2011: <a href="http://www.trenitalia.com/tcom/Informazioni/Assistenza-alle-persone-con-disabilità-o-mobilità-ridotta">http://www.trenitalia.com/tcom/Informazioni/Assistenza-alle-persone-con-disabilità-o-mobilità-ridotta</a>

<sup>9</sup>https://www.enac.gov.it/passeggeri/diritti-dei-passeggeri-mobilita-ridotta-prm/passeggeri-con-disabilita-mobilita-ridotta

<sup>10</sup>https://www.superabile.it/cs/superabile/accessibilita/trasporti/aereo/20180223e-milano-aeroporto-milano-linate.html

<sup>11</sup>http://www.beniculturali.it/mibac/multimedia/MiBAC/documents/1311244354128\_plugin-LINEE\_GUIDA\_PER\_IL\_SUPERAMENTO\_DELLE\_BARRIERE\_ARCHITETTONICHE.pdf



Tourism created a Commission for the Promotion and Support of Accessible tourism<sup>12</sup> that promotes funding for making more accessible touristic public and private locations.

• Sexual support services: in Italy there are very rare services dedicated to sexual support. Some associations (e.g. LoveGiver - <a href="https://www.lovegiver.it">https://www.lovegiver.it</a>) provides a "sexual operator" to support the affective education of persons with disability. This services are not common in Italy.

#### **FUTURE TRENDS**

- In March 2018 a new Ministry for Disability matters was created, under the management of the Ministry of Family: the minister's intention is is to reorganise the so-called Code of disability in order to simplify it<sup>13</sup>.
- The broad SCSS sector is taking the direction of decentralised services for individuals with disability, promoting a wider regional/local autonomy and sharing with the third sector (social cooperatives, associations, foundations, volunteers) the responsibility of promoting a better quality of life for persons with disability. However, this path might compromise the equality of services across the country, making people change their location in search of better support.
- The dialogue between social, scholastic, health and employment sectors is key to really implement support to individuals with disability. The local and regional structure is trying to fill gaps between these sectors but this model is struggling to become nation-wide: it is still based on the quality of local management.
- Finance Projections: in the last economic report<sup>14</sup> the expenditure of the Municipalities for social services (net of the contribution of users and of the National Fund for Social Policies) amounted to about € 7 billion (0,42% of national GDP).

#### **CONDUCTED INTERVIEWS**

Luigi d'Alonzo, full professor on Special Education, university deputee for the inclusion of students with disability and dyslexia, Director of the Research Center on Disability and Marginality, Università Cattolica del Sacro Cuore, Milano

Silvia Maggiolini, researcher on Special Education and teachers' trainer, Università Cattolica del Sacro Cuore, Milano Cristina Biollo, municipality social worker in the area of Monza and Brianza

Alessandra Ballarè and Alessia Cattaneo, Psychologists, Center for Autism, Associazione Cascina San Vincenzo Onlus Maristella Colombo, Disability referee for the Provincial Scholastic Office of Monza and Brianza

<sup>12</sup>http://www.infoaccessibilita.it/documenti/turismo-accessibile-commissione.pdf

<sup>&</sup>lt;sup>13</sup>http://www.politichefamiglia.it/it/il-ministro/il-ministro/attivita/

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- Contact Center integrato per la Disabilità INAIL <a href="https://www.superabile.it/">https://www.superabile.it/</a>
- Dati Regione Lombardia <a href="https://www.dati.lombardia.it/">https://www.dati.lombardia.it/</a>



- Dipartimento per le politiche della famiglia e della disabilità www.politichefamiglia.it/
- <u>Disabili.com</u> <u>www.disabili.com</u>
- Disabilità in cifre www.disabilitaincifre.it
- Federazione italiana per il superamento dell'handicap www.fishonlus.it
- Federazione Nazionale Sindrome di Prader Willi http://www.praderwilli.it/
- Il portale Nazionale per il cittadino dei servizi di assistenza socio-sanitaria <a href="http://www.italia.gov.it/servlet/">http://www.italia.gov.it/servlet/</a> ContentServer?pagename=e-
- INAIL (da info regione per regione sui servizi socio-sanitari) http://www.superabile.it/
- Informazioni sulla disabilità in Lombardia http://www.personecondisabilita.it
- Istituto Nazionale di Statistica https://www.istat.it https://www.istat.it/it/archivio/disabili
- Ministero del Welfare <a href="http://www.welfare.gov.it/default">http://www.welfare.gov.it/default</a>
- Ministero del Lavoro <a href="http://www.lavoro.gov.it/">http://www.lavoro.gov.it/</a>
- Ministero per le pari opportunità <a href="http://www.pariopportunita.gov.it/">http://www.pariopportunita.gov.it/</a>
- OHCHR | Committee on the Rights of Persons with Disabilities https://www.ohchr.org
- Osservatorio Nazionale Disabilità Reporting e statistiche www.osservatoriodisabilita.it
- Sportello Telematico Unificato <a href="http://lombardia.master.globogis.eu">http://lombardia.master.globogis.eu</a>



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