IO1: CONSOLIDATED SITUATION ANALYSIS OF THE STATE OF DE-INSTITUTIONALIZATION OF SUPPORT STRUCTURES FOR YOUNG TEDDIP
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INTRODUCTION

Disability is part of the human condition and limitations involved require adjustments in the environment, in order that persons with disabilities can exercise their rights on equal terms to other citizens. The population of persons living in institutional care belongs among the most marginalized and the least visible, which means that the human rights of these people are particularly at risk.

Given the different circumstances that limit the exercise of rights, following various recommendations and resolutions of international bodies, it has been established the need to promote the development of national strategies to improve the welfare of people with disability. The content and objectives of such documents intended to be an instrument to participate fully and actively in society and forces countries that have adopted the introduction of policies and measures promote equal rights in all spheres of social life.

Recommendation CM/Rec(2010)2 of the Committee of Ministers of the Council of Europe to member states on deinstitutionalisation and community living of children with disabilities adopted by the Committee of Ministers on 3 February 2010 very explicitly states that building of new institutions should be discouraged by refusing to approve and fund proposals for this type of project, while public authority action, strategic planning and coordination should focus on prevention of institutionalization, prevention of prolongation of initially foreseen short-term stays, deinstitutionalization of those currently in institutions, and creation of community-based services.

This Consolidated Report of TEDDIP'Europe project was produced as part of the European Commission Erasmus+ funded TEDDIP'Europe Project and presents the different stages of the normative context led by national governments of the Czech Republic, France, Spain and Italy regarding the minors with an intellectual disability and autism (in French under the syndromes called TED and DIP). The goal of this study is to present the state of Art in each partner country regarding the legal framework relevant for TEDDIP youth, existing support structures and the state of de-institutionalization of those structures.

LEGAL AND POLICY FRAMEWORK

Legislation concerning persons with intellectual disabilities involves a wide range of different legal documents, such as the Charter of fundamental human rights and freedoms, CRC, UNCPD, the Constitutions, laws regulating different aspects of life (education, health care, employment, social services, etc.) and regulatory norms (decrees), which specify in detail the rights, obligations and restrictions regarding these persons. Thus, we provide an overview of some of them in the Czech Republic, France, Spain and Italy.
Czech Republic

<table>
<thead>
<tr>
<th>Date</th>
<th>Law</th>
<th>Title</th>
<th>Description</th>
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<tbody>
<tr>
<td>2004</td>
<td>561</td>
<td>Act on Pre-School, Basic, Secondary, Tertiary Professional and Other Education</td>
<td>This act sets out the conditions under which education and training takes place, defines the rights and obligations of individuals and legal entities in education and determines the competence of state administration bodies and municipalities in education.</td>
</tr>
<tr>
<td>2004</td>
<td>435</td>
<td>Act on Employment</td>
<td>From the disability point of view, this legal framework regulates the employment situation of people with disabilities. The regulatory norms (decrees) define the active labour market policy (especially the incentives for enterprises to hire disabled people), the content of individual plan for vocational rehabilitation and forms of counselling provided by labour office units.</td>
</tr>
<tr>
<td>2006</td>
<td>108</td>
<td>Act on Social Services</td>
<td>This law regulates the conditions for providing assistance and support to individuals in unfavourable social situation through social services and care allowance, the conditions for authorizing the provision of social services, public administration performance in the area of social services, social services supervision and conditions for the performance of social services.</td>
</tr>
<tr>
<td>2009</td>
<td>198</td>
<td>Act on Equal Treatment and on Legal Means of Protection against Discrimination and on Changes of Some Acts (the Antidiscrimination Act)</td>
<td>In relation to the legal framework of European Union and the Charter of fundamental human rights and freedoms this act defines the right to equal treatment and prohibition of discrimination in following matters: access to employment and entrepreneurship, membership in professional associations and trade unions, social security, access to health care and education, etc. Discrimination is prohibited on grounds of race, ethnic origin, nationality, sex, including pregnancy and maternity, sexual orientation, age, disability, religion, faith or belief.</td>
</tr>
<tr>
<td>2011</td>
<td>372</td>
<td>Act on Health Services</td>
<td>This law incorporates the rights of patients arising from the Convention on the Human Rights and Biomedicine and the supplementary protocol to the Convention.</td>
</tr>
</tbody>
</table>

Moreover, besides the legal documents, the Government board for people with disabilities in the Czech Republic has regularly prepared and reviewed National Plans for Persons with Disabilities since 1992 with the aim to improve the conditions and quality of life of persons with disabilities and their integration into society. Besides that, the National Strategy of the Development of Social Services has been prepared that explicitly states the need of deinstitutionalisation of social services and includes also the financial plans to support the process.
France

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<tr>
<th>Date</th>
<th>Law</th>
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</table>
| 1975 | 75-534    | Guidance for persons with disabilities             | It is the first law dedicated to the social and health institutions and to disabled people. It clearly defines 3 basic rights for people with disabilities, children and adults:  
  - The right to work.  
  - The right to a minimum guarantee of resources by means of benefits.  
  - The right to school and social integration. |
| 1989 | Decree Of 27 October 1989 |                                                    | It includes the relevant annexes for the management of mentally disabled, physically disabled, for multiple disabilities, for the hearing impaired and for the visually impaired.                                  |
| 2002 | 2002-2    |                                                    | This law is aimed to reform social and medico-social institutions.  
  This is the 2nd law dedicated to the social and health institutions. The law established individual projects for users of nursing homes, taking into account their expectations and needs. |
| 2005 | Law Of 11 February 2005 |                                                    | This Law addresses equal rights and opportunities, participation and citizenship of people with disabilities. This law has also led to the creation of the Department for Disabled People. |
| 2009 | Hospital Patient Health Territory |                                                     | This law established calls for projects for healthcare and medico-social services.                                                                                                                                 |

In France, there is no specific law for young TEDDIP but there are recommendations for good professional practice issued by the National Agency for the Evaluation of Social Institutions and Social Medicine and High Authority of Health. Moreover, French government created Autism Plan that is a program with a set of measures to improve the care of people with autism at the national level.

Spain

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<tr>
<th>Date</th>
<th>Law</th>
<th>Title</th>
<th>Description</th>
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<tbody>
<tr>
<td>1970</td>
<td>14</td>
<td>General Education policy</td>
<td>It mentions for the first time the need to support students with special needs, they are called deficient and misfit according to the mainstream education.</td>
</tr>
<tr>
<td>1982</td>
<td>13</td>
<td>Law on the Social Integration of the Disabled People</td>
<td>This law enacts to remove architectural barriers to support handicapped people and their integration to job environment.</td>
</tr>
</tbody>
</table>
1990 1 The Organic Law for General Management of the Education System This law enforces the standardization and integration of students with special educational needs.

1995 9 The Organic Law for Participation, Evaluation and Government of Educational Establishments This law starts to distinguish gifted children and children with transient and permanent educational needs. Also it promotes curricular adjustments and provisions for disabled people and adds new subjects to educational programs. Since then education system also involves therapeutic teachers, social workers, psychologists and pedagogues, speech therapists, physiotherapists, nurses, educators and interpreters for the deaf and blind.

2002 10 The Organic Law for the Quality of Education This law provides schooling until the age of 21.

2006 2 The Organic Law of Education The law that speaks about social commitment of schools and the principles of equity and equality. It is intended that schools have sufficient autonomy to promote the inclusion of all the students. From this moment we can start to talk about the support for the students with special educational needs.

2011 26 Law 26/2011 This law is the regulatory adaptation for the International Convention on the rights of persons with disabilities.

2013 8 The Organic Law for the Improvement of Educational Quality Primary objective to promote personal and professional development of people. This law updates terms, definitions and content following the guidelines of the Convention of the Rights of Persons with Disabilities. It speaks about inclusive schooling and education in a single system. It produces an increased personal resources, materials and infrastructure for pupils with special educational needs.

In recent years the Plan of Action: Spanish Disability strategy 2014/2020 following the objectives set by “EU 2020 strategy” adopted by the Council of Europe, provided the guidelines for public Spanish Policy on Disability.

Italy

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<tr>
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<th>Description</th>
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<tbody>
<tr>
<td>1978</td>
<td>180</td>
<td>National Mental Health Law</td>
<td>Aimed at progressively closing existing mental hospitals that at that time were accommodating people of all ages with different mental health problems. Law 180 focused on new fully integrated support services that comprehend prevention, care and rehabilitation. Later, Law 180 was included, with minor modifications, within the General Health Law no. 833.</td>
</tr>
<tr>
<td>1992</td>
<td>104</td>
<td>Framework Law for assistance, social</td>
<td>It is the main law directly addressing rights of disable people, including children. It aims at guaranteeing the</td>
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integration and rights of the handicapped

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<thead>
<tr>
<th>Year</th>
<th>Law Number</th>
<th>Title</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>68</td>
<td>Norms for the right to work for the disabled persons</td>
<td>This law is aimed at encouraging targeted job placement, establish specific services, in addition to forms of obligation, sanctions and incentives for enterprises to hire disabled persons.</td>
</tr>
<tr>
<td>2000</td>
<td>328</td>
<td>Framework law for the creation of an integrated system of social services and measures</td>
<td>This law is not addressing directly people with disabilities, however it concerns the integrated system of social services, acknowledges and supports the role of families in the education and care system, the promotion of wellbeing and social cohesion. Moreover, it establishes for a full integration of persons with disabilities in family and social life, as well as in school and vocational education programmes, municipalities and local health units, upon request of the person involved, shall prepare an individual project (PI).</td>
</tr>
<tr>
<td>2006</td>
<td>67</td>
<td>Measures for the safeguard of disabled people who are victims of discrimination</td>
<td>It is a legal framework aiming to protect the civil and political and economic rights of disabled individuals and protect them from stigma and direct or indirect discrimination.</td>
</tr>
<tr>
<td>2010</td>
<td>170</td>
<td>New rules on specific learning disorders at school</td>
<td>The law provides for the involvement of schools which are willing to have efficient teachers and administrators (and informed parents) who are sensitive and prepared to cope with the issues related to specific learning disorders and who wish to allow teachers to know the matter and, therefore, to be able to recognize the cases they are shown and to early detect the strategies that need to be applied, case by case.</td>
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</table>

Besides the legislative framework, the Italian Ministry of Health releases every two years a National Health Plan with a special section devoted to mental health as a priority area.

The legal framework in the Czech Republic, France, Spain and Italy covering mental health problems and disabilities provides a relatively good protection of the rights of people with disabilities, focusing mainly on inclusive education, adoption and assistance. Young people with disabilities are covered by general provisions applying to children or to people with disabilities.
IDENTIFICATION OF YOUNG TEDDIP

In all countries covered by this report the professionals responsible for identification process of young TEDDIP are paediatricians, doctors, general practitioners, children psychiatrists, neurologists, psychologists, professional educators, speech and physical therapists. The final diagnosis usually comes from psychiatrist or clinical psychologist. In case of Spain there is multidisciplinary team for early intervention consisting of medical neuro-pediatrician, rehabilitation physician, psychologist, pedagogue, speech therapist, physical therapist, occupational therapist, social worker, school psychologist.

Usually in all countries the age, when the first diagnosis is given, depends on the type of disability. TEDDIP symptoms are observed during the first 3 years of the life of a child depending on the type of syndrome. The ultimate expression of symptoms, however, is observed between 3 and 6 years of the life of a child and before going to primary school to get a complex diagnosis.

The identification process is reflected in the figure below:
According to qualified estimations, 3% of population in the Czech Republic have some type of mental disorder (Pipeková 2006). According to the statistical data on people with health disabilities, there were 11 604 children with mental disorders in the age 0 – 14 and 22 964 adolescents and adults in the age 15 – 29 in the Czech Republic in 2006 (Czech Statistical Office 2008) and 15 683 children in the age 0 – 14 and 19 394 in the age 15 – 29 in 2012 (Czech Statistical Office 2014).

The majority of Pervasive Developmental Disorders belong to the group of autistic spectrum disorders. According to the data from the Czech Social Security Administration, the numbers of children with autistic spectrum disorders (ASD) has been rising very fast recently, mainly due to increased awareness of this disease and thus increased recognition and diagnosis of the disorder. In
2006, the health insurance system registered only 140 children (0-18 years) with this diagnosis. In 2010, these numbers increased to 11,193 children with PDD (Bártlová 2012).

France has 3.5 million disabled people in a population of 70 million. Among them, 2 million are carriers of a severe mental disability. 700,000 of them are having mental disability, which represents 20% of disabled people. In France, there are 650,000 people diagnosed with pervasive developmental disorder or one child in 150 births is born with autism. In France, 80% of children with ASD do not attend school.

In Spain it is estimated that approximately 1% of the Spanish population has some kind of intellectual or developmental disability. According to data collected by all the Communities, at the end of 2013 in Spain a total of 234,915 people had diagnosed with intellectual disability (with equal or greater than 33% grade). This represents 9.16% of all people with disabilities recognized in Spain. From all of these people, 134,127 men (57%) and 100,788 women (43%) have intellectual disabilities. The collected data is not entirely accurate, because it only considers those who have officially recognized disability certificate and they don’t consider other possible disorders related to development.

In Italy National data about the young people with TEDDIP syndromes doesn’t exist. Available estimates (Autism Observatory of the Lombardy Region) indicate minimal prevalence of 4.5 cases per 10,000. For example, in Piedmont the rate of prevalence in children (0-18 years) is about 2.5 persons per thousand, with a peak of 3.7 per thousand in the range of 6-10 years old children.

**SUPPORT STRUCTURES AND INCLUSION MEASURES OF TEDDIP YOUTH**

The responsibility to provide support structures for children with intellectual disabilities (or general with any kind of disability) and their families is currently divided into several ministries among all partner countries (Ministry of Labour and Social Affairs, Ministry of Education, Culture, Youth and Sports and Ministry of Health). Each ministry is responsible for different institutions, types and forms of care, which complicates the coordination of the process of deinstitutionalisation of support structures. Even if there are no specific authorities dealing specifically with matters concerning young people with disabilities, a number of institutions and bodies deal with issues affecting children and persons with disabilities.

In the case of children and young people with disabilities the following support structures exist in partner countries:

<table>
<thead>
<tr>
<th>Country</th>
<th>Support structures for young TEDDIP</th>
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<tbody>
<tr>
<td>Czech Republic</td>
<td>• daily service centres offer children and young people with disabilities ambulatory services aimed on developing their skills, independence and interests;</td>
</tr>
<tr>
<td></td>
<td>• day care centres provide ambulatory services to children and young people with disabilities, focusing on rehabilitation, acquisition of skills necessary to become independent, etc.</td>
</tr>
<tr>
<td></td>
<td>• week centres offer residential services for children and young people with disabilities to develop their skills and independence while providing</td>
</tr>
</tbody>
</table>
accommodation and meals;

- homes for persons with disabilities provide residential services for children and young people (from 3 to 26 years - Decree No. 182/1991 Coll.) with disability;
- sheltered housing to allow people with disabilities to live without their parents and gives them a whole range services like accommodation, help with housekeeping, meals and help with its preparation, mediating contacts with the social environment, etc.
- outpatient and inpatient health care facilities (type of the facility depends on the form of disability);
- hospitals, convalescent hospitals, hospices and spa facilities providing rehabilitation, including care for the terminally ill;
- Early Care Services - provided in the form of outreach services for children under 7 years of age who are disabled and their parents and for families with children whose development is at risk, the service is aimed at family support and child development (in most cases run by non-governmental organisations);
- halfway houses provide residential services for young adults leaving institutional or protective care;

Spain

- Early Care Centers (CAIT). Multidisciplinary teams that do detection tasks and early care attention.
- Guidance Equipments and Counselling Education (EOEP). They carry out assessment and detection programs within the center.
- Social Services (SS.SS). A network of social workers and family workers to help the families of young TEDDIP.
- Equipment Care for Children and Adolescents (EAIA). They take care of children and adolescents with difficult family situations.
- Special Education Centers (CEE). They serve young TEDDIP who have special educational needs and need of specific support
- Ordinary schools, with Special Education Units (USEE) and special educators.
- Mental health centers for behavioral and mental disorders.
- Hospital classrooms. The hospitals provide classrooms for teachers to give lessons to those students who are hospitalized.
- Home care. Teachers who give lessons at student’s house.
- Residences, Service homes and Support Programs of Autonomy in Own Home, who supports the independent living.
- Integration leisure centers are helping young TEDDIP to socially integrate.
- Temporary Residential Centers (RESPIR) for TEDDIP families.
- Comprehensive Support Classrooms (AIS) for students with behavioral disorders, that can be located in ordinary or special education schools, but depends of the CEE centers.
- Special workplaces (CET), occupational centers (CO), Occupational Services Insertion (SOI) or monitoring support, different alternatives to support and to insert to the regularly labour market.

France

- Hospitals and day hospitals
- Centers for Early Social and Medical Actions
- Special Education Service and Home Care centers
- Medical centers for Psychoeducation
• Medical Educational Institutes
• Nursery Teaching Units in mainstream educational institutions for children up to 6 years
• Classes for Inclusion in mainstream primary educational institutions
• Localized units for Inclusion in mainstream high school educational institutions

Italy

• Community Mental Health Centers - responsible for planning and coordinating interventions across different facilities and settings.
• Day Hospitals allow complex diagnostic assessments and therapeutic interventions on short- and medium-term bases.
• Day centers are open for at least 8 hours a day for 6 days a week and implements programmes promoting self-care and the practical and interpersonal skills required in everyday life.
• Medical or rehabilitation centres promote patients’ psychosocial rehabilitation and integration and may offer different levels of staff supervision and types of intervention in order to meet patients’ specific needs.
• Non-governmental organisations/ User/consumer and family associations aim to find and qualify the resources useful to the therapeutic and rehabilitative work, organise educational activities and ensure the inclusion of TEDDIP youth into mainstream society.

The staff working within support structures (both public and private) are characterised as being multidisciplinary. The team usually consists of psychiatrists, psychologists, teachers, nurses, social workers, educators, workers in social services, health staff, pedagogical staff, occupational therapists, matrimonial and family counsellors, physiotherapists, speech therapists and other professionals who directly provide social services that deals with the full array of mental health needs.

Czech Republic

In the Czech Republic, the first steps of deinstitutionalization of social services were made after the year 1989. The active role for implementing the process and introducing new types of services for mentally disabled was taken especially by newly formed nongovernmental organizations, often founded by the parents of handicapped children.

In the Czech Republic ensuring equal opportunities for children and young people with disabilities is one of the main objectives of the National Strategy to Protect Children’s Rights. It aims to establish special measures and legislative changes to ensure that children with disabilities could live with their families and to be educated in the mainstream schools.

A pupil with mental disability can be educated in mainstream primary school, practical primary schools (for pupils with mild mental disability) and special primary schools (for pupils with severe and profound mental disorder). The children with disabilities can be educated in mainstream schools through individual (in class with other children with the individual education plan) or group integration (special classes for children with disabilities in mainstream schools). The legislation recognizes also other forms of education of disabled minors, such as individual education (homeschooling) or the education of pupils with profound mental disorder (usually homeschooling with special education supervision) (Křžkovská 2012).
Although the right of every child to be educated in mainstream school has been promoted already, many children with disabilities are still educated in separate practical or special schools (almost 24,000 pupils educated in practical and special schools). The changes of Education act are foreseen to simplify the process of implementing the support measures to every child with special educational needs. However, the system of special schools for children with severe and profound disability will remain as an option for the families of these children even after the change of the Education Act.

France

In France there are no national guidelines for deinstitutionalization. The educational approach for TEDDIP youth is depending on the diagnosis provided. They are educated in the following structures:

- Center for Early Social and Medical Actions (TEDDIP youth aged 0-6)
- Hospitals
- Special educational institutions
- Mainstream schools

There are national organisations founded by families that form a part of structures organized based on the government scheme and in certain cases, those structures can provide education.

In France, public structures don’t have the capacity to cover all the needs of young disabled people, hence some private associations play a crucial role in providing the support for those in need. In 2012 (September data) 298,361 children with disabilities were educated in France in the following structures:

- 45% in regular schools, including classrooms for inclusive education.
- 29% in regular schools of second degree, including units for inclusive education.
- 26% in specialized institutions, such as hospitals and social health centers.

Spain

In Spain, the first signs for deinstitutionalization can be observed in 1982 with the Law on Social Integration of the Disabled and in 1985 with the Royal Decree of the Management of Special Education that established the need of educating children with mental and sensory disabilities in mainstream schools. In Spain, TEDDIP students are included in students with special educational needs (SEN) and the Equipos de Orientación y Educación Psicopedagógica (EOEP) work with families and schools to find the right school for schooling.

Schooling in mainstream schools: Special education teachers make direct attention to students with SEN and support teachers in the participation of these students in regular classrooms, but can also make individual or small classroom special education group sessions.

Schooling can be shared between Daycare Center and Special Education Center.

Schooling can also be implemented in special education centers.

Education by Family associations and private foundations for the people with disabilities. Most of them are a social initiative and nonprofit organizations.
The Young TEDDIP who have reached the post-compulsory programs, can enter special work programs (special work places, occupational center, occupational services and support at work), this type of support is mainly provided by the Ministry of Employment and Social Security. All the support programs to develop autonomous life of young TEDDIP depend on the financial aspects for social services. Even if Spanish schools begin developing diversity care plans and promote improvements in teacher training for inclusion, however special institutions are still favoured and in cases of multiple special educational needs special education classrooms in mainstream schools are limited.

**Italy**

Italy is the first country that with the Law 180 in 1978 established solely community network of health care facilities for people with special needs.

Italian Constitution and different laws establish a series of measures and services to allow people with disability to live in their family environment or, if this is not possible, to find alternative options to avoid their insertion in special institutes.

Inclusion for pupils with disabilities is highly favoured ensuring the right of children and young people with disabilities have adequate access to classes, from primary school to all education institutes. They can complete compulsory education up until 18 years of age instead of 16. Support teachers are part of the team of regular class teachers and participate in all the planning and assessment activities. Support teachers are also facilitators of all inclusion processes.

Italian services for disabled young people are also provided by non-governmental organisations that play an important role in the development of services in Italy. The nongovernmental service providers are mainly not-for-profit organisations, including user and parent associations. These organisation must be accredited on the basis of regional rules stating the requirements needed in terms of architectural features, staff qualification, programmes and local needs for services.

In Italy, there are still very few special schools. Those are public or private special schools recognised by the Ministry of Education and they often belong to medical or rehabilitation centres. The parents decide whether the student should attend a special school or a mainstream school. Special schools are mainly attended by blind students, deaf students or students with heavy intellectual or psychosocial disabilities. The number of students with disabilities that attend and spend the night in these special institutes is very limited.

**FINANCIAL ASPECTS OF SUPPORT STRUCTURES**

In the Czech Republic the state finances support structures for people with mental disabilities not only by grants, but also giving the service users financial funds to pay these services in the form of social care allowances. The process of deinstitutionalisation is mostly funded by European funds and the governmental support.

The social care institutions are usually managed and financed by local municipalities – more than 85% of all residential facilities are managed by local municipalities.
NGOs mostly provide outreach or ambulatory social services, which are financed through grants and state funds or European Social Fund (The Government of the Czech Republic 2007).

In Spain, services and resources for people with disabilities, can be public, private and semi-private. The State provides people with special needs all resources needed to ensure their care.

There are different ministries (Ministry of Education, Culture and Sport, Ministry of Health, Social Services and Equality, Ministry of Employment and Social Security) provide financing for support structures for young TEDDIP and educational structures.

Different types of scholarships are available for young people with disabilities, like educational aids (transport, books, psychological, language re-education, etc), economical support for households and residences, sheltered work and occupational centers or Social Security benefits for families.

In France Ministry of Social Affairs and Health finances all support structures (public structures and private associations) by public funds.
It is important to note that the Ministry dispenses public funds from local governments including the department through the General Council. The General Council has a social mission and chooses the actions it wishes to conduct.

In Italy the public health care sector is composed of public facilities, private accredited facilities and fully private facilities. Private accredited facilities are considered as fully public structures, as they are financed by the National Health Care System and provide services on behalf of the NHS.

Funds are allocated by the Government as a general health budget to the regions, and then the regions allocate their budget to Local Health Authorities according to their needs and priorities. Various regions have created funding mechanisms for initiatives aimed at encouraging independent life and social inclusion for persons with disabilities.

Private facilities are financed directly by the users/consumers and don't receive any direct funding from the State. People with disability has a right to a monthly allowance that allows them to approach private support-structures for people with disabilities, however the allowances are very low.
BIBLIOGRAPHY


