

ANNEX VII 2: ITALIAN REPORT

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DEFINITION OF INTELLECTUAL DISABILITY

In Italy there is no official definition of the term ‘intellectual disability’ (ID). According to Italian Law No. 104/92, article 3, paragraph 1, *“a person with a handicap is a person with stabilized or progressive physical, mental or sensorial impairment, causing such learning, relationship and working integration difficulties that give rise to social disadvantage or isolation”*. As for the clinical definition of ID, in Italy the term ‘mental retardation’ (MR) is mainly used as defined in the two most currently used Diagnostic and Statistical Manuals of Mental Disorders, namely the ICD-10 and the DSM IV-TR. ICD-10 characterizes *“mental retardation as a condition resulting from a failure of the mind to develop completely where cognitive, language, motor, social, and other adaptive behaviour skills should all be used to determine the level of intellectual impairment”*. The DSM IV-TR defines MR as *“significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning, which onset must occur before age 18 years”*. Currently, the term ID is used more and more in scientific papers, while the term MR is mainly used in the clinical context because of nosographical reasons related to the two above mentioned manuals.

HISTORICAL BACKGROUND

The main health services for the care and treatment of people with ID have been generated by the Italian Government since the 1970s. Law No. 180/1978 (Legge Basaglia) guarantees the “guardianship” of people with disabilities and psychiatric pathologies, and began the process of deinstitutionalisation from psychiatric institutions. The social-educational approach, which stayed at the heart of the clinical and care philosophy at that time, aimed at avoiding the stigmatization of a person with disabilities supported by the “medical model”. The model focuses on meeting the needs of individuals with ID to reach their potential.

Thanks to the Law dated March 30th 1971, the Italian Government guaranteed *‘indennità di accompagnamento’* (a monthly attendance benefit for invalidity pensioners who need help to move around or who need permanent attendance to accomplish daily tasks) to people with ID. The law is similar to that provided to people with physical disabilities, who experience reduced working ability and are considered unable to autonomously provide for their own subsistence.

Such theoretical background is the basis of the current Italian regulations that, considering the limited working ability of many people with disabilities, affirm the

need for social security contributions provided by national Institutions, such as the INPS, Italian National Social Security Institute, and the INAIL, the National Institute for Industrial Accident Insurance.

With the introduction of the "biopsychosocial model", the approach to the person with ID altered from a focus on his/her pathology to his/her personal history with targeted healthcare interventions.

From the 1970s to 1980s up to the promulgation of the Law 1992, according to the aforesaid cultural background about ID, rehabilitation, research and prevention centres were established; new jobs for people with disabilities were created, structural adjustments for the removal of architectural barriers were carried out and above all, a deep revolution in the field of education occurred.

The legislative decrees of 1974 ruled the administrative autonomy of schools, while the Law 517/1977 abolished the differential classrooms and set up compulsory education for children with disabilities, promoting their integration and providing them with special aids teachers.

ITALIAN LEGISLATION

The legal and cultural framework about the ID is wide and complex, both at national and regional level. After many years of legislative silence, Law 118/1971, dealing with the education system, the institution of rehabilitation, research and prevention centres, architectural barriers elimination, job market for disabled, pension or Disability Living Allowance, developed the social benefits system for the disabled, thus promoting their integration. After the Law 118, the first decrees regarding education were introduced and Law 517 on Right to Education and inclusion of disabled children in ordinary classes was issued. This Law promoted social and working integration of disabled people.

Law 180/1978, abolished the ‘institutionalization’ of people with psychiatric pathologies and ID, resulting in the closure of mental hospitals. Law 104/1992 is concerned with care, social integration and rights of people with ID (further amendments to the Law 104/1992 are the Law 53/2000 and the legislative decree 151/2001). Law 104 represented a revolution in the history of social policy in Italy, because it promoted the civil rights and integration of people with ID in social life. According to these aims Law 162/1998 on further healthcare interventions and social integration for people with severe disabilities was issued. This regulation, aiming at the amendment and integration of the Law 104/92, promoted new forms of domiciliary care, daily assistance, welcome and emergency services, and projects aimed at promoting self-sufficiency in the disabled. Law 68/1999 aimed at promoting inclusion and working integration of “*people at working age suffering from such physical, psychological or sensorial disorder, and people with intellectual disabilities that involve a reduction in working ability over 45%, recognized by qualified experts, through support services and targeted employment*”.

The general policy Law 328/2000 “for the realization of the integrated system of interventions and social services” was addressed to both people with disabilities and

to their families. Its aim was the integration of rehabilitative interventions with social issues such as equal opportunities, right of citizenship, removing or reducing awkwardness in situations arising from financial difficulties and/or physical/mental disorders that limit the self-sufficiency of the person. The main aims of this law were individual projects for people with severe disability (art.14), domiciliary support for elderly people lacking self-sufficiency (art.15), and the promotion and support of family responsibilities (art.16). Law 388/2000 introduced a number of innovative regulations on severe disability issues, such as:

- leave of absence for parents of severely disabled children with pay for up to two years;
- two-month notional income for every working year up to a maximum of 5 years for the pension of severe disabled (over 74%) and deaf-mute workers;
- extension of the deductions for the elimination of the architectural barriers, and also for the realization of elevators and good lifts;
- financial resources.

ESTIMATED PREVALENCE FIGURES

At present, few national epidemiological surveys aiming to identify the number of people with ID in the Italian population have been published. A national study, published in 1999 by the Italian National Institute of Statistics (ISTAT), did not specifically address ID in adults, but determined that 700,000 people of about 3,000,000 had a disability categorised as a ‘mental disorder’ (including ID). As such, national-wide epidemiological data about ID is not available, and even less about adults with ID. The following few surveys, at a narrow territorial level, have been carried out:

1. Epidemiological survey on adults with ID, resident in the territorial Zone no. 9 of Macerata, from 1992 to 2004;

Population	No.
General population of every age	134.808
General population - adults	8.1614
General population – adults with disabilities	1.478
Adults with ID	316

Therefore the percentage of the adults with ID is 23% compared to the total number of the treated population; 0.38% compared to the assisted adults in the general population; while it corresponds to the 21% of the adults with disability.

2. Epidemiological survey on a sample of 96 adults with ID (56 with MR - 58.3%). The 4.08% of this percentage suffered from dementia (data related to a sample of people hospitalised in the “Istituto Sacra Famiglia” in Lombardy).

3. In a sample of 3,683 in-patients admitted to the Oasi Institute for Research on Mental Retardation and Brain Aging - IRCCS "Oasis Maria SS" in Troina (En), throughout the year 2005, 1.438 people (39%) aged over eighteen, suffered from MR.

SOURCES AVAILABLE (ESTIMATES, SERVICES AND PUBLICATIONS)

The source of reference for the estimate of ID in Italy is represented by the ISTAT - Italian National Institute of Statistics, a public research body that has been working since 1926.

ISTAT is the main supplier of official statistical information in Italy. ISTAT produces and disseminates reliable, impartial, transparent, accessible and pertinent information, able to describe the social, economic and demographic conditions of the country, in full compliance with the regulations pertaining to the privacy of respondents (www.istat.it). Under Law 162/98 (Art.41 bis), from Jan 2000 the Dept of Social Affairs of the Presidency of the Council - today the Ministry of Labour and Social Policy- has charged ISTAT with the compilation of a coordinated and integrated statistical database on disability, which will enable future planning to be on the basis of complete and reliable data (www.disabilitaincifre.it).

The Project will give a deeper knowledge of the "world" of the disabled, setting in motion a reorganisation of existing data and coordination - where possible - of real-time information channels. It should also stimulate new investigations in sectors and thematic areas where data is currently lacking. The Project is complex and involves not only ISTAT, but also other Institutions working in this field and producers of statistical information relating to the problems connected with disability.

Even though the way in which the Project was established clearly demonstrates that the main end users will be policy makers, the opportunity has been taken to identify other potential users of the database and thus exploit the Project to the full. The system is therefore aimed at state officials of various levels but also at associations and organisations supplying services in this field, to people with disabilities and their families, and at any other interested parties. For this reason one of the Project's main goals is to make the website accessible to the disabled themselves. The website is constantly updated and deals with disabilities in general, not specifically with the ID.

The main themes on ID have been discussed in various national conferences, such as: 6th National Congress "Disability, Treatment, Integration" Università di Padova, June 8-10, 2006;

Conference: "The adult with mental retardation - assessment, treatment and rehabilitation", Milan, November 20-21, 1997;

Conference: "The adult Mental Retardation in hospital: treatment and rehabilitation", Milan, November 30th, December 1st, 1995.

SERVICE PROVISION

CRITERION FOR ELIGIBILITY FOR INTELLECTUAL DISABILITY SERVICES

At present, according to the Italian legislation, people with ID receive certification of their disability from the local medical team of the AUSL (Local Health Authority). This certification aims at recognizing the disability (according to the Law 118/1971 and Law 104/1992)

SERVICES CURRENTLY PROVIDED TO ADULTS WITH ID

People with ID benefit from the same services of the general population. The services are provided from:

AUSL – Local Health Authorities

Public and private hospitals

IRCCS – Research Institutes

Furthermore, people with ID can benefit from the rehabilitation services provided by territorial networks:

day service

rehabilitation and/or occupational therapy centres

To support families, specific accommodations have been established, such as:

residential structures (RSA) or community lodging

“Hotel-Houses”

“Family Houses or Apartments”

At the IRCCS Oasis Maria SS., a two-year project funded by the Italian Ministry of Health addressed to adults with severe and profound ID, has been carried out.

The aim of the project, called “Day Habilitation” was to validate a rehabilitative and “non-welfare model” specifically addressed to adults with ID. It is divided into three phases:

1. learning predisposition
2. adaptive skills acquisition
3. learning generalization and keeping

The program is based on the structuring of a therapeutic environment and on a positive approach. Particular attention is given to the quality of the environments, to a series of continuous interventions, to the integration of humanistic approaches and behavioural techniques and to the specific training of health professionals. The two-year project contributed to an improvement in adaptive skills and reduction of challenging behaviour. Day Habilitation is one of the few rehabilitative programs specifically developed for adults with severe ID. The service is currently provided to 56 individuals at Oasi Institute.

SOURCES OF INCOME FOR PEOPLE WITH ID

Traditionally in Italy, the welfare system is based on a pension scheme as the main economic support for people with ID. Furthermore the Italian Government provides

healthcare services for people with disabilities. All Italian citizens with congenital or acquired progressive disabilities, including ID, who “*suffer a permanent reduction in the working ability or disabled under 18 with persistent difficulties performing skills and activities of their age (L. 118/1971)*” are entitled to a pension or an injury benefit. Their disability is verified by the Local Health Authorities and the Italian National Social Security Institute, who give a pension or an injury benefit according to the degree of disability. In 2006, the monthly amount of the aforesaid benefits for people with severe ID was the following:

1. Total invalidity pension	€ 238.07
2. ‘ <i>Indennità di accompagnamento</i> ’	€ 450.78

HEALTH SERVICES & UTILIZATION

HEALTH SERVICES CURRENTLY OFFERED TO ADULTS WITH ID

The available data on public healthcare expenditure do not describe a specific and detailed picture of the share of the resources that the National Health Service uses for the attendances of people with disabilities. The only data available concerns the expenditure for specific services for people with disabilities, such as rehabilitation for people with physically and mentally disabilities (including ID), rehabilitative services (ex art. 261) and prosthesis. These data come from a survey carried out by the Italian Ministry of Health, in cooperation with the Regions, on the Levels of Assistance (LEA). It deals with the health expenditures of the AUSL during the year 2001.

The rehabilitative services provided are regulated by the Law 833/1978 “Institution of the National Health Service”, art. 26: “*the healthcare services aimed at the functional and social rehabilitation of people with physical, mental or sensorial impairments, whichever is the cause, are provided from the Local Health Authorities through their own services*”

During 2001 the expenditure for the assistance of people with general disability represented 4.2% of the total health expenditure in Italy, with a regional distribution revealing a moderate variance. The Southern Regions produced the higher expenditure (4.6%) compared to the other Italian regions, while the lowest amount was recorded in the Northern Regions (3.1%).

The services provided by the National Health Service for people with general disability has been divided into four groups by the ISTAT:

1. rehabilitative assistance (residential and not-residential)
2. specialist examinations
3. check-up
4. hospitalizations

Three quarters of the total health expenditure is funded from public health expenditure. However, despite the public service, a number of citizens apply to private institutions, thus sustaining an expenditure that represents about a quarter of the whole health expenditure. Such figures highlight the fact that assistance to a person with disability is more expensive compared to the general population and involves not only the Government, but also the families financial resources.

Furthermore, since exact data on the effective amount of the social-health expenditure for people with disabilities does not exist, the role of the policy maker is hampered by a lack of information.

ITALIAN BODIES OF SEARCH ON THE HEALTH IN ADULTS WITH ID

In Italy no single official body of research exists on the health in adults with ID. However, different studies have been carried out, at territorial level, by Scientific Institutes for Research, Hospitalization and Health Care, namely, IRCCS, placed in the whole Country and financed by the Italian Ministry of Health.

In particular, the research at IRCCS Oasis Maria SS., in Troina is mainly focused on Mental Retardation. Oasi has promoted and developed (with the contribution of the Italian Ministry of Research) a computer network involving different national research bodies in order to evaluate and compare knowledge and experience on psychopathological and behavioural phenotype profiles related to the main syndromes associated with mental retardation (in particular Autism, Fragile X, Prader-Willi, & Angelman syndrome).

The main IRCCSs that focus their research on adults with MR are the following:

IRCCS Associazione Oasi MARIA SS., Troina (EN), www.oasi.en.it

Istituto Auxologico Italiano, Milano, www.auxologico.it

Istituto Stella Maris, Calambrone (PI) www.inpe.unipi.it

Ospedale Burlo Garofolo, Trieste, www.burlo.trieste.it

Fondazione Istituto Neurologico “Mondino”, Pavia, www.mondino.it

Fondazione Salvatore Maugeri, Pavia, www.Fsm.it

San Raffaele Pisana, Roma, www.sanraffaele.it

Other institutes that develop activity within the intellectual disability are:

Fondazione Sacra Famiglia ONLUS, www.sacrafamiglia.org

Fondazione Don Carlo Gnocchi ONLUS, www.dongnocchi.it

La Lega del filo d’oro – Osimo, www.legadelfilodoro.it

The main Italian journals on ID are:

Ciclo Evolutivo e Disabilità, Lifespan and Disability, www.lifespan.it

Handicap grave, www.erickson.it

Giornale Italiano delle Disabilità, www.edizionijunior.it

Handicap Risposte

Abilitazione Riabilitazione

The main Italian publishing houses that publish series on disability issues are:

Centro Studi Erickson, www.erickson.it

Edizioni Junior, www.edizionijunior.it

ERIP, www.unilibro.it

Città Aperta Edizioni, www.cittapertaedizioni.it

The most important Italian Societies dealing with disabilities are:

SIRM, Società Italiana Studio Ritardo Mentale, www.sirmonline.it

Fondazione PierFranco e Luisa Mariani, www.fondazione-mariani.org

Main websites on disabilities:

1. www.ritardomentale.it (mental retardation, rehabilitation, education)
2. www.handylex.org (legislation, rights and public services for people with disabilities)
3. www.ausilioteca.org (website of the Ausilioteca CAT - AIAS Bologna, a public service providing consulting activities regarding technical aids for disabled)
4. www.asphi.it (website of ASPHI Foundation: Development of projects to reduce handicap with IT)
5. www.disabili.com/content.asp?L=1&idMen=134 (list of firms producing aids for people with disabilities)
6. www.handimpresa.it (work supply/demand in the field of disability and other resources)
7. www.disabililavoro.it (site supervised by ANMIL and INAIL. Supply/demand, disabilities rules, help enterprises, teleworking)
8. www.form-azione.it/form-azione/disabili.htm
9. [www.labitalia.com/topics/Diversamente% 20Abili/34 .htmls](http://www.labitalia.com/topics/Diversamente%20Abili/34.html) (news on disabled and work)
10. www.sport-disabili.com (handicap and sport)
11. www.specialolympics.it (sport activities for people with intellectual disabilities)
12. www.handicapincifre.it/indicatori/trasporto/trasporto.asp (mobility and means of transportation for people with disabilities)

DATA ON LIFE EXPECTANCY AMONG POPULATION WITH ID

No studies on life expectancy among the population of people with ID are available.

COMPARATIVE INFORMATION FOR PEOPLE WITH ID AND GENERAL POPULATION

Recent studies on the population of people with ID and epilepsy reveal that 18% of people with mild ID and 30-36% of people with severe ID have epilepsy; conversely 31-41% of people with epilepsy suffer from ID. In the general population the prevalence of epilepsy is below 1%.

In a sample of 453 people with ID - 236 men and 217 women - the obesity percentage is the following:

BODY MASS INDEX(BMI)	Men %	Women %
Normal BMI < 25	64.4	56.29
Pre-obese BMI 25/30	14	12
Obese I degree BMI 30/35	11.4	17.1
Obese II degree BMI 35/40	4.2	11.1
Obese III degree BMI > 40	5.1	3.7

A survey carried out at Oasi on a sample of 355 long-stay inpatients showed that the main obesity-related pathologies are: hypothyroidism (above all in people with Down Syndrome), constipation and infantile hypotonia-related comorbidities such as scoliosis, valgus and flat feet. Only a small percentage (2%) presents hepatitis markers. Heart malformation, rheumatoid arthritis and Steven-Johnson syndrome, due to antiepileptic, can also occur.

As for difficulties in work participation and engagement in people aged between 17 and 70, we noticed the following values:

Percentage	Degree of difficulty
8,5%	minor
21,3%	medium
25,6%	great
19,9%	absolute

As for the degree of limitation in working ability in a sample aged between 17 and 60 results are as follows:

Percentage	Percentile
29,1%	0-30

In a sample of people aged between 17 and 40 (it is expected a major working integration), a similar pattern was revealed.

Furthermore 3.32% of people with ID have no relatives and 6.63% have serious family problems. Thus, about 10% of the whole sample cannot rely on family.

SPECIFIC TRAINING FOR HEALTH PROFESSIONALS DEALING WITH ID

Specific training for health professionals working with people with ID in Italy is mainly provided by Universities, public and private Institutes working in the Healthcare field:

1. Degree courses specific for ID with subjects regarding disability issues.
2. Master's degrees on ID, such as:
 - II Level Master's in "Evaluation and intervention in Intellectual Disabilities", Università Kore di Enna and IRCCS Oasi Maria ss. Troina,
 - I Level Master's in "Handicap and intellectual disabilities: handicap psychopathologies and infantile autism" Università degli Studi di Udine,
 - Masters's in "Disability and integration in the territorial Institutions" Università degli Studi di Padova

Among the postgraduate schools we would like to mention "Psicologia del ciclo della vita" that deals with Psychological Interventions in Developmental disorders in handicap.

CONCLUSIONS

On the whole a heterogeneous situation emerges where a lack of epidemiological data on people with ID and their utilization of public and private healthcare services is typical. There are no specific programmes for physical and psychological health prevention addressed to adults with ID. There are very few financial resources that can guarantee the essential needs of this population. Services provided for people with ID are also delivered in an uneven manner: in the Northern part of the Country there are more services and institutions for people with disabilities in comparison with Southern Italy. However, there are specific and updated regulations for healthcare and work integration albeit for disabilities in general. From a scientific point of view, few studies on this issue have been carried out, while in the last few years more congresses and conferences on ID have been organizing and more websites devoted to the issue of disability have been created. Nationally, there are Excellence Institutes (IRCCS), for the study of disabilities and in particular IRCCS Oasi Maria SS., has expertise specific to ID.