



ANED country report on the implementation of policies supporting independent living for disabled people

Country: Italy

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PART 1: EXECUTIVE SUMMARY AND CONCLUSIONS

It is very difficult to synthesize the varied framework of the work done for **Independent Living** in Italy. Certainly **Independent Living** is still something to be achieved. An independent life is a process full of complexity and difficult to achieve mostly at a cultural and political level, because it relies on a totally new concept of disability, which is no longer seen as an attribute of a particular person, but as a complex set of skills and activities, operational and health, relationships and contexts, many of them created by the social environment. This concept only in recent years is spreading even among people with disabilities; they have experienced, indeed in most cases, conditions related to an inverse process of progressive restriction of **Independent Living**, we could say with a paradox, a process of dependent life.

As for the work on the promotion of **Independent Living** in Italy the first thing to highlight is the great disparity between different regions. The inequality stems from often different social systems and laws, the ability of the movement of people with disabilities and their families to be strong on some aspects and weak on others, the resources invested, but even more by culture and by the way the conditions of persons with disabilities are read. Different Italian Regions organize it in very different ways. In some reality we find the presence of good models, based on the concept of **Independent Living**, this is mainly due to the great work done by the associations (FISH, DPI Italy, ANFASS, etc.), and the will of more progressive local administrators. In the work that follows you can find an overview on **Independent Living** in Italy, the main features of which follow some specific legislative directives, and a discussion of some innovative projects conducted in different Italian regions. Good practice relates to the development of **Centres for Independent Living**, which are the cornerstone of a draft law submitted on December 3rd 2008.

It is, therefore, a long road both for people with disabilities, to be sensitized and encouraged to leave home and to try to create their own autonomy, (with the advantages and disadvantages that this may involve), and for local administrators who may be confronted with financial and cultural problems.

The changing process toward the promotion of Independent Living are focusing on the transition from the support of models of large residential institutions, where people lived and still live, especially if they have mental disabilities. Many of these have been transformed into RSAs (Assisted Health Residences), so that they house at most seven or eight people. In such environments the institutions work with a predominantly medical and supportive approach. From these types of residences we have moved to home care interventions, where people with disabilities are assisted for a certain amount of time in their homes. In most cases people live with their families, who take care of them for the remaining time. The further step that is being promoted in some Italian areas is the promotion of free choice of disabled persons concerning assistance and for the assistants to be involved in promoting a process of empowerment.

The funds for assistance (direct or indirect) are still low, well below the real needs of hundreds of thousands of people, although transition to this type of assistance would be better for the institutions in terms of savings. The increase of national and regional allocations, therefore, can no longer be neglected, beyond the demand for it. It is for these many reasons that today the Associations of persons with disabilities deeply feel the need for cohesion concerning the very diversified national provision, and the necessity of a unified movement that can develop initiatives aimed at recognition of rights and the spread of services and tools that allow all people with disabilities that seek to, to live in an autonomous and independent way. The work to be done is to find a way of implementing projects of **Independent Living** which, inspired by examples of good practice, adopt uniform quality standards throughout the country, while allowing more prudent management of available resources.



PART 2: LEGAL AND POLICY CONTEXT

The *legislative* competences concerning social services, schooling and health have been transferred exclusively to the Regions. The State retains responsibility for the determining basic levels of civic and social services and those related to school and health. Moreover the Municipalities have administrative competences in such fields, with the exception of specific cases where the law attributes such competence to the Province (e.g. law 67/93, concerning the school attendance of blind and deaf people). Municipalities have financial autonomy, in conjunction with State control. The State takes part directly in cases of non compliance in matter of respect of the essential levels of civil and social performance.

Concerning individual life plans, art.14 of law 328/00 has instigated the principle of taking care of the total life plans of persons with disability. This is a competence of the Municipality that has been put into effect thanks to the networking of integrated services, agreed in the zone plan (art. 19)¹.

Law 180, *Detection and voluntary and mandatory medical treatment* of 13 May 1978, better known as Law Basaglia (from its promoter in the field of psychiatry, Franco Basaglia), is a well-known and important framework law that imposed the closure of psychiatric asylums and regulated compulsory health treatment, by setting up public mental health services. Subsequently the law was merged into Law 833/78 of 23 December 1978, which established the National Health Service.

The law represented a real cultural and medical revolution based on new (and more human) psychiatric concepts, promoted and carried out in Italy by Franco Basaglia. Previously, asylums had been little more than places of physical confinement, where methods of restraint, heavy and invasive medication or electroconvulsive therapy were applied.

The intention of the Law 180 was to reduce drug therapies and physical containment, by building relationships with staff and renewed human contact, fully recognizing the rights and the need for quality of life of patients, who were monitored and treated by local clinics. The implementation of the law 180 was delegated to the Regions, which are responsible for legislation in their areas, producing varied results. In 1978, in only 55% of the Italian provinces had a public psychiatric hospital, while in the rest of the country there were private hospitals (18%) or services provided by other provinces (27%). Indeed, only after 1994, with the Project Objective and the national rationalization of mental health care system, were mental hospitals actually closed in Italy, and the law has not yet been fully implemented throughout the country.

Concerning the right of disabled people to live in the community or in an institution, a fixed and general rule does not exist. In fact the decision about the possibility of “institutionalization” is left up to the interested person, to relatives or the support administrator (this was instituted by law 6/04). Instead, regarding the kind of assistance supplied, it depends on the person’s needs, verified through an integrated approach, in agreement with the resources available by the local agencies.

Even if usually the person with disability with his own directly interested relatives is included, there is little or nothing stated with regard to personal or living assistance preferences. Law 162/98, which modified the previous law 104/92, reviews measures in support of persons with serious handicap, through appropriate financing for implementing interventions with regard to the “support of the daily life” and “independent life”.

¹ Legal and political References: **State:** art. 9 law 328/00; art. 129 decree n.112/98. **Regions:** art. 117-20 law 3/01; art. 8 law 328/00; art. 131 and 132 decree n.112/98. **Municipalities:** art. 6 and 14 law 328/00; art. 131 decree n.112/98.



In Italy to date, Independent Living has been considered a life practice and an attitude.

From a normative point of view, the first reference to Independent Living of disabled people is in article 39, section 2, of the law 104/92 “law for the assistance, the social inclusion and the rights of handicapped disabled people” (published in the Ordinary Supplement of G.U. 17th of February 1992, n.39) and subsequently in the Law 162/98 “Modifications of the law 5 February 1992, n.104, concerning support measures towards people with serious handicap” (published in G.U: 29th of May 1998, n.123). This considered in particular the “discipline, with the scope to guarantee the right to have an independent life for disabled people with a grave and permanent personal autonomy in the performance of essential functions of living, not surmountable with assistive technology, the way of realization of programs for helping people, managed in a direct way, also through customized plan for people who ask for, with the audit of the services distributed and of their efficacy”.

Approval of the Law 328/00 “Law for the realisation of the integrated system of interventions and social services” (published on the Ordinary Addition to the G.U. 13 November 2000, n. 265) has introduced individual projects (art.14) aiming to define the needs and services which have to be supplied to guarantee the rights of disabled people.

Both the law 162/98 and the article 14 of the law 328/00, mostly in the southern regions of Italy, were literally neglected and ignored by regional government, most of whom have not recognised them. In some situations, national funding designed to this aim, has been amalgamated in Area Social Plans (established by the Framework Law No 328/00 in order to implement the “integrated system of interventions and social services”) or in other projects which almost always have nothing to do with Independent Living.

Today, indeed, it is a priority to go beyond the real inequality between the various regions which determine rights to services, resulting in great variation.

It is very difficult to synthesize the varied framework on the territory. It varies, in fact, from a situation as surprising as that of Sardinia, where year after year, Projects for Independent Living have been put into practice, to very different situations (Piedmont, Valle d' Aosta, Veneto, Friuli Venezia Giulia, Province of Trento, Marche, Tuscany and Rome) where there are some positive pilot projects that are now being consolidated, to others (Liguria, Emilia Romagna, Province of Bolzano, Abruzzo, Puglia) where there are “intermediate” services based on older care allowances, which seek to ensure greater flexibility and customization of simple and traditional home care services. Other variations are evident in Lombardia, where there is a “mixed” model based on the network of Municipalities and the Plans of the Area, to large areas (Basilicata, Umbria, Calabria, Campania, Molise, Sicily) in which little is done, sometimes even without a proper regional regulatory framework having been produced.

It should be emphasized that where there are good models based on the concept of “Independent Living”, this is due to the work done by the disabled people’s associations, and the effort of more sensitive local administrators.

It is, therefore, a long road both for people with disabilities, to become aware and encouraged to leave home and to try to create their own autonomy, with the advantages and disadvantages that this may involve, and for the local administrators for whom the problems and the limits are not so much economic, as many associations of disabled people find in their direct experience, but mainly cultural.

Certainly the funds for assistance (direct or indirect) are low; in fact, the Fund for non-self-sufficiency, set up by the State Economic Planning in the law 244, 24/12/2007, is well below the real needs of hundreds of thousands of people.



The need for an increase in national and regional allocations, therefore, can no longer be neglected, above and beyond the assistance solutions that need to be adopted.

For these many reasons it is deeply felt by the Associations of persons with disabilities, that there is a need for cohesion in relation to the very diversified national provision, to create a unified movement for a strategy of initiatives aimed at recognition of the rights to independent living and for the development of services. On the 3 December 2008 a group of parliamentarians of the Chamber of Deputies submitted a proposal of law n°1978 *“Disposizioni per il finanziamento di progetti di assistenza personale autogestita in favore delle persone con disabilità grave”* in the field of severe disability and self managed personal assistance, which interprets the commitment of the National Movement for Independent Living.

This law, once approved, should provide that the people in the condition of serious handicap, (within the meaning of Article 3, paragraph 3, of the law 104/92), can use self-managed personal assistance and this will enhance and extend the current rules for implementing home care.

Self managed assistance involves an allocation of annual funding that may be used for the organisation of an individual welfare project, by establishing a legal employment relationship with one or more assistants selected directly by the person with disabilities, or, in the case of non self-determination, by the family. Under the new law, the disabled person or the family will be able to establish direct contract with a personal assistant, without the intervention of a cooperative financed by the Municipality that sends the assistant. The Municipality will be able to arrange an individual welfare project

The new law, if approved, would not only guarantee persons could stay in their environments of origin, but people will be able to move to other areas with the assistance. Persons with disability would be able to manage the funds in an autonomous way so they can arrange the assistance in whatever place they are.

Also, this law, envisages the creation of Centres for Independent Living (it has not yet been defined how many and where they should be developed), managed directly by organisations of persons with disabilities. Their task will be to provide assistance to recipients of this funding, guidance and information on rights, the use of equipment, services and aids for autonomy, the realization of self empowerment programs, peer counselling, help with searching for assistants and administrative support in the management of personal assistance.

Legislation on local and regional levels:

Valle d’Aosta:

Deliberations of the Regional Board n.3111, 25 August 2003

Establishment of an experimental service for assistance for independent living for a period of one year with effect from 2 September 2003. Financing of expenditure.

Piedmont:

Deliberations of the Regional Board n.32-6868 (5th August 2002)

Criteria for distributing to the local authorities managing the social-assistance functions, the funds in accordance with Law 104/92, art. 42, paragraph 6, letter. q) and Law 162/98 on serious or very serious handicap

Deliberations of the Regional Board n.22-8775 (25th March 2003)

Definition of guidelines to use in all the Region for the testing of projects of Independent Living support of people with severe motor disabilities.

Deliberations of the Regional Board n.48-9266 (21st July 2008)



Approval of Guidelines for the preparation of projects for Independent Living.

Liguria:

Regional Law 12/2006

Promoting the integrated system of social and social health services

Deliberation of the Regional Council n.35 dated 1st August 2007

Integrated Regional Social Plan 2007/2010.

Lombardia:

Regional Law 3 / 2008.

Reorganisation of social services with the involvement of disabled people.

Autonomous Province of Bolzano:

Provincial Law 91/2007;

Standards on welfare, employment and competitiveness in order to promote equity and sustainable growth

Social Plan 2008/2011.

Autonomous Province of Trento:

Provincial laws 14/1991 and 6/1998.

Ordering of social assistance services in the province of Trento

Measures to assist the elderly and persons with severe disabilities

Veneto:

Deliberations of the Regional n.2824, 18th September 2003 and n.3279, 22nd October 2004; 10th January 2005

Guidelines for the preparation of individual projects of independent living

Single founding for domicile assistance,

Friuli Venezia Giulia:

Regional Law 6 / 2006;

Social Fund for the implementation of interventions and social services, which helps to financially support the management of social welfare services.

Deliberation of the Regional n.286/2007

Fund for Independence Possible.

Emilia Romagna:

Regional Laws 2 / 2003 and 27/2004: *social and health regional plan;*

Deliberations of the Regional n.1122/2002 n.2068/2004 and n.1230/2008, *finalised programme for health checks for the elderly and persons with disability.*

Tuscany:

Regional law 72/1997, 41/2005 and 66/2008, *Organisation and promotion of a system of citizenship rights and equal opportunities: reorganization of integrated social and health services.*

Deliberation of the Regional n.794/2004 *guidelines for the program of experimentation of the personal assistance finalised to the independent life.*

Statute of the Region of Tuscany in 2005.

Marche:



Deliberations of the Regional n.1489/2004, n.1460/2006 and n.831/2007, *Independent life project for persons with severe physical impairment*

Umbria:

Deliberations of the Regional n.374/2001, n.305/2006 and n.1211/2007.

Lazio:

Deliberations of the Regional Council n.877/2002 *Program and approval of the modalities of institution of the services for persons with disability and for the allocation to the local authorities of specific contributions*; n.601/2007 *law for the support to dependent persons*.

Abruzzo:

Deliberation of the Regional Council n.57/2006 (*Regional Social Plan 2007-2009*);
Regional Law 5 / 2008 (*Regional Health Plan 2008-2010*).

Molise:

To date there are no local references.

Campania:

Regional Law 11/2006 *improvement of the quality of life to the persons with epilepsy and their families through an effective social and sanitary assistance*.

Basilicata:

Deliberation of the Regional Board n.3263/1999.

Puglia:

Regional Laws 16/1987 and 19/2006, *law for the school integration of disable students*.

Deliberation of the Regional Board n.1104/2004 (*Welfare Regional Plan*);

Regional Regulation n.4/2007, *Law for the Integrated System of social services for the dignity and wellbeing of women and men of Puglia*.

Calabria:

Deliberations of the Regional n.3597/1999, n.1012/2000, n.332/2002 and n.237/2003.

Institution of support services for person with severe disability.

Sicily:

Regional Framework Law 22/1986.

Reorganization of the social and support services and activities

Sardinia:

Sardinia Region decree of 2 August 2000;

Regional Laws 6/2001 7/2002, 23/2005 and 2/2007;

Deliberations of the Regional from n.26/16 of 20 June 2000 to n.69/20 of 10 December 2008.

Fund for non self-sufficiency: financing of personalised plans in favour of children, young people and adults with severe disability and of personalised plans in favour of non self-sufficient old persons.



PART 3: PROGRESS TOWARDS INDEPENDENT COMMUNITY LIVING

Certainly over the last ten years or so, the situation has changed radically in Italy. There is more understanding about how important Projects for Independent Living are for people with disabilities, through both very active groups in the area, and through national and international legislation. The UN Convention on the Rights of Persons with Disabilities has been ratified by the Italian Parliament with Law No. 18, 3 March 2009: this fact provides an additional impetus.

Although today it is impossible to construct an accurate picture of the funds currently allocated to Projects for Independent Living, as a result of regional and provincial autonomy and different sources of financing, it is evident that major benefits result from this type of care. On the one hand, indeed, it has the benefit of not removing the person from their life context, preventing the obliteration of their personality and ensuring social integration within their own communities, on the other, it represents a financial saving in terms of resources

It is estimated that provision of the minimum traditional daily home care service, for two hours a day, five days a week, can cost up to 5,000 euros a year. The cost of a long hospital stay is estimated to be between 1,500 and 3,000 euros per month (research by Onlus Association Consequor for Independent Living - www.consequor.it). It is estimated that a project to support Independent Living for a person with disabilities needs funding of about 20,000 euros a year, while the same person within an institution would cost about three times more- in this case the funding needed would be approximately 60,000 euro (research by Onlus DPI Italy - Disabled People International www.dpitalia.org).

Certainly the biggest fear resulting from the closure of residential institutions is among staff who rely on the institutions for work, but on the other hand Independent Living also creates employment, through contracts for personal assistants. Also the person with disabilities may be more easily inserted into the labour market, thus becoming productive too.

Unfortunately, today, there are still services based on institutionalization throughout Italy². Research on European deinstitutionalisation (Mansell et.al, 2007), shows that we have still 117.241 places. 14.514 have a size of less than 30, and 81.428 a size of more than 30, with 21.299 places not classified.

In such structures we find persons with different disabilities: some of the places are for persons with mental disabilities (32.806), others are reserved for persons with physical and sensory disability (3.258), most of the places (72.906) are for persons with a mixed kind of disability, and other places are not classified (8.271).

Often within these residential structures there are adults of 60/70 years of age, who would be very difficult to place in other kind of institutions. Obviously, the types of disabilities most commonly encountered in these contexts are mental disability, for which there are no procedures or precautions to ensure that such persons are not placed in institutions against their will.

Such data shows that the reform of mental health, Law 180, legislated for the closure of psychiatric hospitals, and for the creation of a network of new mental health facilities on a regional basis, with the person at the centre of care, has still not been completely applied. The prohibition of new admissions led to a decrease in hospital beds: from 60,000 in 1978 to 2,500 in 1998. New mental health structures were created including outpatient clinics, new departments in general hospitals, mental health centres, and residential settings designed to provide differentiated kinds of treatment aimed at reducing the need for hospitalisation, and reducing the duration of time spent in treatment. Some hospitals remain partially open and district-based services have been slow to develop.

² http://www.kent.ac.uk/tizard/research/research_projects/DECLLOC%20Volume%20%20Report%20for%20Web%20.pdf



There are some important factors that seem to be tied to difficulties in the spread of the reform, although there has been some change in the direction in recent years. The administrative decentralisation of Italy favoured local initiatives but provided an obstacle to the implementation of the new law – at local and regional level, partly due to the political situation: it was difficult to agree national standards and there are wide disparities in resources, levels of institutional provision, professional staffing, degrees of dependency on charity or private initiatives, political cultures between North to Centre to South and the islands of Sicily and Sardinia that make it hard to judge the full impact.

Today, however, there is effort not to develop or to continue to support models of large residential institutions, but many of these have been transformed into RSAs (Assisted Health Residences), that may contain at most seven or eight people, in an environment that becomes more familiar.



PART 4: TYPES OF SUPPORT FOR INDEPENDENT LIVING IN THE COMMUNITY

4.1: PERSONAL ASSISTANCE SERVICES

There is absolutely no uniformity in Italy in the types of support available to people with disabilities in order to let them live in their homes within the community. We find very different scenarios depending on the region of residence.

In most cases the municipality of residence provides a kind of direct assistance, through the payment for a specified number (minimum) of hours of home care for an assistant to the person with disabilities who lives at home (alone or with his family).

To decide the number of hours to give the person with disabilities, the Municipality performs a dual investigation, by a commission specially convened (“Integrated Evaluation Unit”). On the one hand there is a social worker who investigates the situation at a social level (trying to answer questions such as: Does he/she live with the family? Does he/she already have an assistant “his own expense”? Does he/she have a job? What kind of life does he/she lead?). On the other hand ASL (Azienda Sanitaria Locale-Local Health Authority) doctors explore the issue regarding the specificity of the impairment by establishing the capacity and the specific needs of the person. This assessment sets the hours to be allocated to each person with a disability residing in the municipality.

Based on these recommendations, the Municipality should prepare a list, while taking into account the resources available. In so doing, criteria by which to make a selection are chosen, for example the level of income. Considerations such as trying to distribute the resources as fairly as possible, ensuring a minimum number of hours for each person, for assistance for all applicants, are taken into account. However assistance is often limited and almost always insufficient.

Usually the work involved is contracted to a cooperative of the territory, which then contracts with their staff, selected and managed according to a national collective agreement, in relation to the type of professional employed. A major problem of this type of assistance is the fact that it can not ensure the continuity of the service. Disruption often happens following the ending of an employment relationship between the cooperative managing the service, and an assistant. It then takes time to reorganise care for the disabled person, to ensure stability and continuity of the service.

Unfortunately with this type of assistance, the person with disabilities, as well as his family has no say and is not personally involved in the management of their care. Not only the person with disability almost never can choose the people who will be employed, but most often can not decide which sex the worker should be.

Beyond this, voluntary associations are very active in the community and they help in two ways. First, they are called on by local institutions to participate in the planning, management and control of the services offered by the City and by the ASL (Local Health Company) under Article 4 of Law 328/00. Secondly, they often provide support and integrate these services, offering practical support to the person, through its volunteers, thanks to contracts with the Civil Service.

Unfortunately, this direct assistance does not offer an appropriate, practical and permanent response for people with disabilities because they do not take charge of the person. It also represents only a temporary stopgap and limited help because there is not an overall project of autonomy for the person with disability. In many cases, the persons with disability are supported by the family that surround them, sometimes by their family of origin: parents who become elderly and brothers or sisters who can leave permanently, or by the spouse who sees their life radically changed by the arrival of some disability.



There are not specific services designed for families and people living with to disabled people, even if home care also supports their daily work, primarily within the home, thus easing the load burden on families.

There are some important pilot projects with regard to indirect assistance to the person with disabilities. Even if they are few in number, for a few years there have been increasing instances of good practice. This type of assistance has its basis in the legislative framework law 104/92 and subsequent changes, in particular law 162/98.

Often the implementation of these laws takes the form of allocation of budgets for health care through vouchers or other kinds of financing such as a therapeutic cheque or cash payments to families who agree to attend at home. This money may be spent on the costs of the service requested. People with severe disabilities who are not self-sufficient would otherwise have to rely on hospital facilities. The purpose of this form of assistance is to promote people staying at home and to reduce the use of residential facilities. The Regions that have adopted this measure have also determined the means of access, because the amount of care is variable and is usually related to the income and need of the person and his family.

Another more recent concrete translation of this legislation is the provision of grants for Independent Living; they are ideally based on the ability to organise and manage personal autonomy and are provided on the basis of an individual project and the calculation of the financial commitment. All the money spent has to be justified and an employment contract has to be given in the case of personal assistants. Even in this case, much depends on the will of Regions regarding the financing, managing and regulation of this form of assistance.

The possibility of assistance for 24 hours is almost a utopia. There are not sufficient resources for this, even for only a limited portion of people with disabilities. There is no data available to show what people do get at the moment because of the large differences between the Regions in the policy and funding for personal assistance.

A serious problem that must be emphasised is the fact that, when moving to a different Municipality or even in another Region, the same services cannot be guaranteed. In that instance, another evaluation committee for a new definition of needs is convened, establishing new services available, according to local resources. It should also be highlighted that a person can avail themselves of services only in the Municipality of residence - in the case of temporary transfers no kind of service is available to the person.

As regards the measurement and assessment of quality of care and services to people with disabilities, unfortunately there are no methods that guarantee impartiality (e.g. independent inspections, etc.). As regards home care, cooperatives or associations that manage the services are called on to prepare final reports, describing the work year and highlighting any problems identified, these may be based more on questionnaires in the form of anonymous surveys of general approval, but it appears that actions are an end in themselves, as they do not affect in any way the management of assistance. With regard to indirect assistance, usually to control and verify the budget allocated to the person with disabilities for Independent Living, the Municipality or Region requires the production of an employment contract for the personal assistant in order to monitor how the money paid is used.

A separate note must be made about assistance in schools. The guaranteed presence of a support teacher support is limited to classes in which there is a student with disabilities. The support teacher is provided by the State, while the Municipality or the Province, depending on the level of school, ensures the presence of an assistant for autonomy, communication and socialisation for students with disability. Again, however, the presence of the support teacher and of the autonomy assistant is not always ensured for all hours of the student's attendance, but according to available resources.



The same area of jurisdiction applies to the purchase of equipment to assist teaching and to structural adaptations to school buildings.

Concerning assistance in employment, the person with disability can take advantage of the support of his personal assistant, but there is no specific assistance provided in the work place.

Finally, assistance for persons with psychological and mental disabilities or severe disability, often involving interpersonal communication, should be discussed. In this case, disabled persons are not acknowledged to have the ability of choice and freedom to manage the way in which their assistance is organised. In instances where the person does not have the ability of choice, a judge assigns to him/her a support administrator who evaluates his/her needs for care and support and works in cooperation with social services. In most of these cases, the only alternative possible seems to be institutionalisation.

4.2: ASSISTIVE EQUIPMENT AND ADAPTATIONS

A second important aspect of Independent Living is the possibility of using assistive technologies. Everything concerning aids is a responsibility of ASL. Following medical assessment (by, for example, a physiotherapist, orthopaedic physician, neurologist etc., specific help is allocated for the disorder and to overcome a particular difficulty (e.g., an electric wheelchair to move independently, a bathroom hoist for personal hygiene or an alphabetic communicator for interpersonal communication, etc.). The cost of any technology is determined by the State through the Tariff Nomenclature, extended to all the Italian regions.

Usually, the ASL pays for the basic version of the device wanted (e.g. ASL pays for a mobile lift, rather than a complete lift system). Anything exceeding the contribution is payable by the disabled person, who can request reimbursement from the Municipality or the State, within the law n.13/89 which promotes the removal of architectural barriers inside ones home. In other words, the person with disability can ask the

Municipality or State to refund the extra money spent for the device.

Unfortunately in all the Regions there are many delays in this type of reimbursement, due to insufficient resources allocated for such purposes.

Employers who hire people with disabilities can get refunds from the Municipality or the State for any changes to the location of work or for expenses incurred for the purchase of specific equipment, within the law n .13/89 or n.68/99 the "Regulations for the right to work of disabled people".



PART 5: EVIDENCE OF GOOD PRACTICE IN THE INVOLVEMENT OF DISABLED PEOPLE

There is a great deal of evidence of good practice in Italy, despite the fact that instances are spread out nationally without continuity and are due to the willingness of individuals and to the capacity of certain municipality or regional administrations. The reason for this can be found in the system of regional autonomy that has produced different legislation and different availability of resources from region to region.

Periodically, FISH (Italian Federation to Overcome Handicap), one of the biggest organizations that represents a large number of associations dealing with disability, publishes an informative paper (see FISH, Vita Indipendente, 2006, Turin), on different projects of independent and autonomous life realised in Italy. Among the different associations that FISH represents, it's worth underlining the presence of DPI Italy (Disabled People International Italia) that works towards the realization of Independent Living throughout the country. In one paper published (FISH, Turin, June 2006), evidence of good practice is provided.

Most projects have common features. All underline the importance of involving the disabled person and his family in the training of his personal care worker. Most of the time, the first step is to build and organise a Centre for Independent Living. In Italy there are 10 CILs, a single unit structure that offers different services within a common framework: promoting autonomy and independence for people with serious or very serious disability. It must be able to offer consultancy and services related to every aspect of life: personal, housing and work autonomy.

The project's implementation is usually focused on personalised interventions. Aid services to support disabled people are necessarily individual, specific and suitable to the person and his environment.

The intervention is complex and it has to establish social relationships with people who have been in institutions, leading to plans for personalised projects. Furthermore, it is necessary to respect the wishes of the person and his system of values. The disabled person has to be involved in the project and is co-responsible for his own life project. Finally, there has been an attempt to promote independence according to service quality, where the person plays an important role in choosing the type of service, rather than determining the amount.

Some of the projects worth mentioning are:

"Vita Indipendente" project, Municipality of Venice and local health system (ASL 12, Veneto Region)

The project grants an amount of money to cover the employment costs of one or more personal care workers. The beneficiaries of the project are people with severe physical impairments (who have a certificate of total disability). The aim is to reduce the dependence of the disabled person and his family on external structures. A personal care worker is the best aid that can be given to disabled people to live their own lives: the personal care worker allows the person to live in his own house so that it is not necessary to turn to expensive institutional services or hospitals.

The disabled person employs the care worker directly and provides training according to his needs. The service's quality is guaranteed by the users: if he is not satisfied with the service, he can dismiss the care worker and choose another one, according to the law (162/98; 284/97) DR. The care worker can decide to work where and with whom he wants and when to resign as with every free employment contract. The main results, reported after several years of work, are:

- The importance of extending the services beyond primary needs
- A focus on expectations and interests that were not considered before



- An increase in activities and interests
- Improvement of social relationships and of the opportunity to socialise
- Re-evaluation of the relationship with family members, especially if they are living together (mother, father, sons etc.)
- Improvement of self-esteem and quality of life
- Concrete possibilities to access jobs.

S.A.V.I (aid service to Independent life) project, promoted by C.I.S.A.P (Consortium of Municipalities for Social Services, municipality of Collegno and Grugliasco (2001, Province of Torino, Piedmont)

www.cisap.to.it/progetto_savi.htm

www.independentliving.org/ceil/italian-good-prac.pdf

This project has been realised thanks to Piemonte Region. It started in 2000 and it has been continued because there has been an increase in the number of users over the years. The first regional funding amounted to 41.316 Euros against the total project cost of 70.768 Euros. It increased in the following years (to nearly 50.000 Euros per year) against a total cost of 150.000 Euros.

The project aims to supply disabled people with services, eventually guaranteeing a 24 hour care services. ENIL Italy (European Network on Independent Living) joined the project to discuss its way of working and its aims. This collaboration continued over the project's subsequent phases.

"Casa alla Fontana" project (www.casaallafontana.org)

This project was promoted by different non-profit organizations, which joined together to form a temporary consortium of associations: "I Care, ancora" Foundation (www.fondazioneicare.org), "Idea Vita" Foundation (www.ideavita.it), Social Cooperative "La Cordata" (www.lacordata.it) and "Mondo di Comunità e Famiglia" Association (<http://www.comunitaefamiglia.org>) (Milan, Lombardy Region).

It has been funded by Lombardy Region and Milan Province and by some private companies such as Cariplo Bank.

The "Casa alla Fontana" is a residence that offers new housing solutions to improve the quality of life without the costs of healthcare structures. It is addressed to disadvantaged groups such as disabled people, young students or workers and young mothers. The project includes the restoration of a residential building (the priest's house of S. Maria alla Fontana) to be turned into a residence suitable for disabled people and to their need to establish good relationship with the neighbourhood. It is not a collective residence because each person has his own space but there are open spaces to allow for socialisation among the users. The residents have to pay a low rent in order to guarantee the project's continuation.

"Modello per la costituzione di un'Agenzia per la vita indipendente" project.

Promoted by Vita Indipendente Association (AVI) Onlus (Tuscany Region) www.avitoscana.org

The project has been funded by the European Union and Tuscany Region, the total sum amounted to 98.127 Euros.

The project aimed at spreading information about the Principles of Independent Living Italy. The aim was mainly promotional. Two activities were organised: a training course for care workers and a seminar aimed at to disabled people looking for an independent way of living. The project lasted two years (2003-2005) and it managed to establish good relationship between disabled people and care workers.



“Casa Famiglia” Project by Centro per l’Autonomia di Roma (Centre for Autonomy, Rome) and by Associazione Paraplegici (Paraplegic Association)-Lazio Region-

www.apromaelazio.org

www.centroperl'autonomia.it

The project aims at improving individual autonomy and access to jobs and social life in order to give the same opportunities to disabled people with spinal injuries. The community-residence follows a model of care residence: it offers services to paraplegic or tetraplegic people with economic or social problems and who consequently do not have full access to social or work opportunities. Often, at the end of a period of hospitalisation, disabled people do not have the possibility to go back to their houses because they cannot afford the cost of their disability, they do not have the support of their families or because their houses are no longer suitable.

For users who run their residences autonomously, although some care workers who usually look after the most seriously affected, help is also provided. They choose the best way to get a job, while the service tries to create concrete job opportunities. The community makes use of consultancy and of the services provided by the Centre for Autonomy. Requests differ between users. Activities for socialisation are promoted inside and outside the service.

In the community-residence there is a temporary flat for those people who are living in Rome but receive medical assistance by the Unipolar Spinal Unit, C.T.O hospital of Rome.

“Abitare in autonomia” project completed by the “Associazione Comunità Progetto Sud – Onlus (Lamezia Terme, Catanzaro Province, Calabria Region).

www.c-progettosud.it

www.dpitalia.org

This project was promoted by the Welfare Ministry (law. Number: 162/98) and by Calabria Region. The work plan includes the selection of personnel, the organisation of mini flats and the individuation of the local service network. The project’s activities began in March 2002 and it is still working only for those who have already joined the project, because of funding problems. During the first year the project cost was 175.000 Euros.

The project offers an integrated service to promote an independent and autonomous life. Disabled people live in mini - flats suitable for the disability. They run the flats independently and there are open spaces to allow the establishment of social relationships among them and with other people.

At the beginning, the beneficiaries of the project were 6 people with serious disability, who are able to make decisions for themselves but who need suitable, structured assistance. Each one of them utilises the services according to his needs.

The inhabitants of the flats are directly involved in the training of the care workers and in the management of the project. Meetings between residents and the care workers concerning the running of the place have been held.

The project also runs an Information Centre on Disability that provides information about the rights of disabled people, a consultancy service that aims to create an independent life projects and a Job Agency that offers services to support access to job opportunities.

The project also includes social activities (meetings, workshops, cultural and sport events) with the aim of promoting disability issues. The objective is to help citizens to overcome cultural barriers.



The following project represents a good practice example of Independent Living in the South of Italy, which is one of the least active Italian regions in the field of disabilities.

“Vivere in autonomia” project, promoted by the Social Cooperative “Anche Noi” (Sicignano degli Alburni, Salerno Province, Campania Region).

The project was accepted in January 2009. Work includes the restoration of a building, which amounts to a total of 320.000 Euros. It has been co-financed for 244.000 Euros by the Campania Region. In following years the funding (which will be limited to management costs) will be met by a local plan fund and from charitable organizations (such as banking foundations).

The project will restore a property of the Municipality so it can regularly host four disabled people, plus another two people either in case of emergencies or so they can try out Independent Living for limited periods of time. The restoration plan includes: three double rooms, two accessible toilets, a kitchen and common “relaxation room” with a TV set, a PC connected to the Internet, and a small library. The whole house will feature adequate technologies to open and close doors, windows and roller blinds and to switch lights on and off.

The small dimensions of the house will allow disabled people to live in a family context. The guests will be involved in a number of activities both inside and outside the house (e.g. cultural events and expositions). The Cooperative will also offer a dedicated mobility service. All the activities will be optional and left to individual choice.

The distinguishing feature of the project consists of a set of personalised care services (from social to sanitary services). The project also includes “empowerment activities” for disabled people and their families. These activities will be operated through professional psychologists and care workers. The project will also offer:

- training services
- activities to raise awareness of related issues
- legal consultancy services

Disabled people are involved during the whole life cycle of the project (from defining the project idea to evaluation of the proposal). The project is coordinated by a disabled person, who is at the moment not living in the house. In the near future coordination may be entrusted to one of the inhabitants of the house.

We would also like to describe the experience of the Sardinia Region, which has been highly innovative regarding personalisation of activities, collaborative planning, and progressiveness. The Sardinia Region promotes a coordinated set of activities for people with severe disabilities, their relatives and caregivers.

The actions are oriented to strengthening public support for people who are not self sufficient, to help them to continue living in their homes (by enhancing in-home care), to support relatives and families. Programmes and actions are defined as “long term assistance” because they are supplied for long time frames without a pre-defined end date. All the programs and actions are inspired by a set of principles:

- Personalisation of interventions by guaranteeing flexibility in supplying services and by planning them around the specific needs of the beneficiaries;
- Progressiveness of the interventions in relation to the degree of self-sufficiency of the beneficiaries;
- Multidimensionality in the evaluation of the interventions, which are intended to be dynamic and continuous processes that follow the beneficiary along its path through the health and social service network;



- Uniqueness of entry points to the services and promotion of integrated social and health interventions;
- Cooperation with the beneficiaries and their families in planning the interventions and selecting the staff.

In recent years, the number of personalised interventions has grown. This growth is due, on one hand, to the correspondence of the program with the needs of the beneficiaries, and on the other to a growth in the number of people who meet the requisites to access the programme. At the moment there are 19.722 people (41% males and 59% females) who are eligible to access the programme. The eligibility assessment is a multi-dimensional analysis that takes into account the beneficiary, his family and the local institutions involved. The total funding amounted to 84.707.550 Euros in 2008.

For more information and news on projects by the Sardinia Region, see www.abcsardegna.org and ww.regione.sardegna.it/argomenti/sanita/servizi_sociali.html.

There are also a vast number of projects excluded by any network. Unfortunately it is not always easy to be aware of those projects. In order to find them it is often necessary to make detailed searches on the web by visiting the web sites of the most relevant organisations, foundations and cooperatives. An interesting source of information is represented by specialised news portals such as www.superando.it.



PART 6: REFERENCES

National and regional laws and regulations utilised for the data within this document

www.parlamento.it – Official website of the Italian Parliament

www.handylex.org – Database of laws and regulations, news and articles on legal aspects of disabilities.

All the websites of the local administrations (Municipalities, Provinces and Regions) that publish local regulations and call for bids on assistance for disabled people.

Studies on indirect assistance

Borgato Stefano e Narduzzo Crizia “Disabilità e assistenza indiretta” in HandyLex Press n.1-09, pp.12-23. – www.handylexpress.org, journal about the rights of disabled people and their families.

Galati M., Barbuto R., Coppedè N., Meduri M. e Napolitano E. “Una possibile autonomia”. Rubbettino Editore, 2003. – published by DPI Italia (Disabled People’s International) in the context of the “Alba – nuove occasioni di cura e sostegno offerte alle donne a contatto con la disabilità” EU project, www.dpitalia.org.

Barbuto R., Ferrarese V., Griffo G., Napolitano E. e Spinuso G. “Consulenza alla pari”. Comunità Edizioni, 2006. – published by DPI Italia (Disabled People’s International) in the context of the “Walking Root – methodologies and means against violence on women with disabilities” EU project, www.dpitalia.org.

European report on Deinstitutionalisation

Mansell J, Knapp M, Beadle-Brown J and Beecham, J, (2007) Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent.

Best Practice

We suggest periodically visiting the web sites of the most important national and local associations for people with disabilities and their families. Below we list some of these, which we have used while writing this report as sources of information.

FISH (Federazione Italiana Superamento Handicap). www.fishonlus.it.

DPI Italia – Italian section of Disabled People’s International. www.dpitalia.org, www.dpi.org.

ABC Sardegna – Associazione Bambini Cerebrolesi della Sardegna www.abcsardegna.org.

ANFFAS – Associazione Nazionale di Famiglie di Persone con Disabilità Intellettiva e/o Relazionale. www.anffas.net.

Thematic news portals

www.superando.it – Publishes news from Italy and abroad. It's organised in several categories, including one called “Sono autonomo”, which is dedicated to Independent Living.

Agencies and associations for Independent Living.

www.enil.it – European Network on Independent Living based in Northern Italy (Torino)

www.vitaindipendente.net – Agency based in Rome.

www.avitoscana.org – Agency based in the central Italy (Tuscany).

www.consequor.it – Charitable association for Independent Living in Piedimont.