



ENIL Italia

European Network on Independent Living

Bruxelles, 15 June 2011

INDEPENDENT LIVING IN ITALY

ENIL Italia has declared the main principles of its activity in a document called "Manifesto for Independent Living". According to these principles, for people with disabilities, Independent Living is the right of living just like anyone else. This means people with disabilities should have equal rights, such as the chance of taking our decisions about our lives and about the activities we have chosen, with the only limits as people without disabilities.

This also involves the right of determining our life, the ability of facing and controlling everyday life and future life, without other people's decisions. In short it means freedom, in spite of disabilities.

THE LAWS

Since the beginning of the nineties, thanks to the steady involvement of some people with disabilities, such as Gianni Pellis, Raffaello Belli, Miriam Massari, John Fischetti, Roby Margutti, Elisabetta Gasparini, Gianpiero Gozzo etc. the principles of the Independent Living arrived in Italy, in the wake of the international movement that was born in the USA and spread mainly in Northern Europe.

Following an International Conference held in Rome in 1989, whose title was "Personal assistance as a key for Independent Living" ENIL Italia was founded in may 1991, as the Italian network of Independent Living. This laid the foundation for a more incisive action and for a legislative reform.

The first achievement with the regional law in Tuscany n. 72 in 1997, later brought to the important national law n. 162 in 1998, that introduced the possibility of direct payments. In Italy, the law 104 has been in force since 1992 and it has determined the ground rules about the rights, social inclusion and assistance of the "person with a handicap." The changes made to this law, that led to the law "2nd May 1998 n. 162" introduced the right of self-determination, control of every day life, provided by personal assistance, available for people with disabilities and not self-sufficient.

This was possible thanks to the addition of the third paragraph to article 39 that says: "the regions can provide:"..."to regulate, in order to guarantee the right of Independent Living to people with disabilities, and serious limitation of personal autonomy in performing one or more essential life functions, that are impossible to be managed by technical aids, the conditions to realize help service to individuals, managed in an indirect form, also through personalized plans for people who make request, with a further check of the supplied benefits and their efficiency"¹.

¹ in Italy we must distinguish between "DIRECT ASSISTANCE" (when the social security/ local government takes in charge the organization of the assistance) and indirect assistance person with disabilities himself takes charge of it opposing the English definition "direct payment" which is used in many countries for Personal Assistance P.A).or indirect payment



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In some Italian regions such as Piedmont, Veneto, Friuli Venezia Giulia, Tuscany, Lombardia and Lazio, the first projects of Independent Living started up. The programme S.A.V.I. ("Servizio di Aiuto per la Vita Indipendente" meaning "Help Service for Independent Living") arose in Grugliasco (near Turin), Como, Rome, Verona and Venice, aiming to help people with disabilities to achieve their own independence, their self-determination as well as the possibilities of social inclusion.

THE CURRENT SITUATION

In 2001 the reform of the "Title V of the Italian Constitution" aimed to create the basis as well as the essential conditions for a future republic based on federal principles and welfare. Each Italian region receives nearly exclusive competences in the field of healthcare and social policy, while the State keeps directing and controlling equal rights and equal distribution, along with its traditional tasks about defence, law and order, justice and foreign policy. Notice that in Italy there are 20 regions, that include a geographical area with Municipalities, Provinces and metropolitan cities and they are managed by their own statute, rules and functions conferred by the Italian Constitution. Thanks to Convention on the Rights of Persons with Disabilities, ratified in Italy by the law n. 18/2009, all the regions should include in their rules about social policies, the possibility of choosing the self-managed P.A. for people who make the request, according to the principles that are in section 19 of the Convention itself. Actually, this decentralization has also got a negative impact on direct payment and on all the social benefits: each region arranges the social services of P.A. according to its own rules and, above all, according to a policy of the available resources.

Our national anthem says "Brothers of Italy..."but actually people with disabilities are still divided as for the different regional social policies and mainly the personal assistance. The successful achievements got by the local organizations always hang in balance and they need to be preserved every year from the shattering cuts at the national budget. The dignity of the people with disability still survives only with the interventions of skilled administrators. There is still a great difference between Northern and Southern Italy: while some regions in the north and in the centre have achieved good results, in the south the situation concerning P.A. remains worse. Even the citizenship right remains unattended: it's impossible that a person with disabilities with a P.A. could change address or move to a different region keeping this allowance active.

Some regions such as Valle d'Aosta, Piedmont, Veneto, Friuli-Venezia-Giulia, Tuscany, Emilia Romagna, Marche, Abruzzo, Sardinia have made rules and specific resolutions with the available funds for direct payment of P.A.; other regions have got local rules. In Molise, a parliamentary bill for Independent Living was ratified in November 2010, starting with a little fund of 400.000€ (it is the smallest Italian region with about 320,000 inhabitants).

Doubtless, our situation is still so far from the consolidate framework (options) running in Sweden, the only country where the personal assistance directly managed is a recognized and ratified right.



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Therefore people with disabilities can be really merged on the community, enjoying equal rights. That's our goal and we are the leading experts. Somebody wrote a cold truth: a person with a serious mobility handicap and without personal assistance has less chance to survive than a homeless. In fact the last one can manage to drink water, eat or get shelter from the rain, while the disabled will be doomed.

In Italy every person with disabilities who has been certified receives a disability pension of € 256.67, an accompany allowance of € 480.47 (€ 783.60 for the completely blind people). We can get additional financial contributions in various forms as well as assistance, directly or indirectly.

By the way, the right to personal assistance with direct payments is not yet carried out all over the country, but where it is allowed, it can reach approximately € 3000.00 per month.

In general, the admission criteria to enjoy the financing for P.A. are:

- Physical and sensory disabilities for people aged over 18 years old
- Condition of gravity as stated in the art. 3 paragraph 3 Law 104/92
- Parameters of personal income (concerning the disabled person only)
- Ability to self-determination

In addition to historical federations and associations established in our country, such as FISH and FAND, DPI etc.. dealing with the rights of people with disabilities in general, in the different regions there are active associations like UILDM Venice in Veneto, Consequor for Independent Living in Piedmont, LEDHA in Lombardia, Idea Onlus in Friuli and so on that also serve as Agency for Independent Living, AVI Rome and AVI Tuscany, many groups and committees such as the Regional Committee Veneto and Committee Lombardo etc. that promote local self-managed P.A..

We can say that, at present, the National Movement for Independent Living is a collection of various people with disabilities who actually belong to different associations, committees and individuals who spontaneously collaborate to develop, as good practices, the right to choose 'self-managed PA. throughout the Italian territory.

ENIL Italy has restarted its activities after a break, due to the fact that each member has worked in its territory to strengthen local organizations. Nowadays, healthcare and assistance are almost exclusively managed by the regional administrations and thus, the idea of a national organization has been delayed. The recent campaign of witch-hunting (seeking false invalids) aiming to reduce the rights of people with a true disability, the need for a link between the various situations, first of all information, the need for a development of the movement in southern Italy along with the need for a legislation able to guarantee the same rights everywhere, led to the decision to start again the national campaigns and try to set ENIL Italy, given its history and credibility, at a national level.

LINES OF INTERVENTION

The European Union has just ratified the U.N.C.R.P.D. therefore the European Disability Forum is calling on the European commission to ensure that a proposed European Accessibility Act can become an



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effective tool to improve the lives of people with disabilities in Europe. At the same level, regarding the "Fundamental rights and citizenship" programme, without the right of the independent living possible with the personal assistance are unattended the Articles 1, 4, 6, 7, 21, 26. On these assumptions and with a renewed willingness for cooperation, we wish the involvement of ENIL in future activities, and our goal is to achieve the principles of the UN Convention, that could lead to the growth and spreading of the right to self-managed P.A., de-institutionalization, empowerment of people with disabilities in our country and the whole of Europe.

Real policies against the uneconomic increase of the institutes made for an improbable "taking-care" of the Pwd, and promoting back to front the spread of the C.I.L.s (Centers of Independent Living) directly managed, also in the Centre and the South of Europe. One of basic steps would be to set a ground rule for which the public budget is established by the necessary social amount to loan all the fundamental human rights, instead of cutting down services and allowances due to the "balance assessment" escape. People with disabilities must become aware that our life can't be overcome to the money's worth and neither transitional situations concerning personal assistance: human rights aren't "experiment test". Nothing about us without us.

Best Regards,
Segreteria Operativa ENIL Italia

