



# **Disabled Women *And* Personal Assistance**

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**Personal Assistance as an  
instrument to guarantee  
equal opportunities  
and a life of quality**



PROGETTO  
**I CARE**



**“Disabled Women And Personal Assistance Against Violence”**

**Programma Daphne 2000 - 2003**

**Measures to combat violence against children young people and women**

n. JAI/DAP/03/207/W

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## INTRODUCTION

In all cultures and societies women have started to create a new way which is leading to a true and real equality. A way to obtain work and good life conditions, to occupy their proper place in the communities in which they live. Even if change comes slow and with big and small obstacles. The matter of gender, therefore, has taken on a considerable importance allowing, through policies and actions, to report and pursue the discrimination that women have gone through and still go through.

But at what point in this process of change are disabled woman? Disabled women are marginalised and still invisible in our society. They are discriminated against and their Human Rights are constantly violated.

The project "I Care - disabled women and personal assistance against violence" - n. JAI/DAP/03/207/W inside the Daphne Programme 2000 - 2003, Measures to combat violence against children young people and women - concentrates on disabled women in their very private sphere of their domestic life and their dependence on assistance.

This programme has given us the opportunity to focus our attention on the matter of gender linked to disability. Disabled women are subject to double discrimination: the first determined by gender as a result of influence, of prejudice, of social, political, economic and cultural injustice; the second closely connected to the conditions of disability.

Starting from this horizon with the project I Care we have analysed, using the methodology of focus groups, the relationship between personal assistant and disabled woman. A relationship that is created between two persons, who aren't two empty bodies. One who supports and one who is supported, but two psychological worlds, each one with its own emotions, fantasies, experiences, sensations and ideas, that meet during the actions of eating, drinking, going to the bathroom, etc. But what happens when these two worlds meet? Could these two worlds not recognise each other? Could a slight unconscious and hidden battle occur where both the one and the other pursue the same desire: to affirm one's own identity? Is this battle for power over the other a cause for conflict and violence inside this relationship?

In this Kit a group of disabled women and personal assistants from the three countries, Italy, France and Germany are partners in the project. They have answered questions testifying the real life experiences of women. It is necessary to reconsider and to reformulate the way of seeing this relationship. The work is definitely not complete. In fact personal assistance, that allows disabled women to live a full, free and independent life, is a matter that must be dealt with on two levels. The first

subjective and personal that is to find out the methodology and instruments of empowerment, which allow disabled women to expect Personal Assistance consciously as a right and to feel themselves equal to the other in the relationship. The second objective has a social component that involves the responsibility of society to find economical, social, political and instrumental solutions to guarantee this service to disabled persons, in particular disabled women. Personal Assistance is a service that allows disabled women to live with dignity and freedom according to Art. no. 1 of the Universal Declaration on Human Rights:

**“All human beings are born free and equal in dignity and rights”<sup>1</sup>.**

Therefore this Kit should be a resource of finding strategies and instruments, to devise solutions and positive actions that allow all disabled women who need assistance, and who live either in big and rich towns or in poor rural areas, to get out of the ghetto of invisibility and discrimination, in which they have been locked up by prejudice, by their being women and by their conditions of disability and be finally equals.

Project Manager  
**Rita Barbuto**

<sup>1</sup> Art. No.1 of the Universal Declaration on Human Rights - UN 1948.

# 1. A definition of self-determined living

The project "I Care" has four fundamental concepts as pre-suppositions: autonomy, self-determination, independence and inter-independence of persons with disability. These make up the foundation of the philosophy of Independent Living.

The philosophy of independent living of disabled people started in the United States and rapidly spread in the whole world, inspired by a model of independent living and by a paradigm of social assistance which offers equal opportunity services to guarantee full citizenship to every person.

In open contrast with the prevalent concept of disability determined by the medical model, that emphasises the importance of considerate actions and care, the paradigm of Independent Living allows the person with disability to regain her freedom and to convert herself from a passive subject to performer and protagonist of her own individual destiny, capable of self-determination, answering to their own needs and desires. The person with disability knows that she has health, social, technical and human necessities, but, at the same time, knows she is capable of controlling her own life, of taking in hand her own destiny, of making decisions with regard to matters that concern her personally.

Independent Living is inspired by the model of Human Rights, according to which every man and every woman have fundamental rights, and all Governments and International institutions have to adopt appropriate strategies to protect and guarantee them

The world has been built on the promise of the independence of the Nations. This has its mirror image in the personal freedom of each human being. The Universal Declaration on Human

Rights of United Nations of 1948 to which Constitutions and world political organisation refer to, for making societies which are equal, pluralists and respectful of all differences and minorities vindicates exactly, the respect of freedom for each single person.

**When** we talk about the meaning of independence referring to disabled people, it has the same meaning as when referred to anyone else. This concept is a fundamental principle that allows the fulfilment of the universal aims of equal opportunities, full participation in society and of individual freedom. These are elements that show how much the universal rights of personal development and quality of life have been carried out by disabled people.

Independent living is therefore fundamental in human rights. It has to be guaranteed to all disabled persons. It is important to bring out the fact that investing in independent life, means much more than just paying for personal assistance services and similar forms of practical help as well as in barrier free surroundings. In fact, the access to personal assistance, which enables a disabled person to choose and to be in charge of the service, is of crucial importance, because it is the means by which one's personal autonomy, self-determination, independence and inter-independence can be fulfilled.

D.P.I. Italy has tried to give a definition of these concepts, (written in the glossary) aware of the fact that these indicate processes that are linked to one another, because they are closely linked to one another. DPI (Disabled Peoples' International) puts a stress on the close relationship that exists between persons, their autonomy and independence, the need of self-determination, and the society. Everyone in theory can



be independent in a network of relationships. Disabled persons live this possibility with many obstacles and limitations, receiving only separate answers, that are violations of their rights as citizens, as well as their Human Rights.

DPI states, therefore, that living in conditions of equal opportunities is possible. Only an inter-independent life, only the inter-relationship between persons with their different disabilities and abilities, only a society that allows a person with disability to compete on the same level as other citizens in the planning of solutions of living together, can guarantee persons with disabilities to be born, to grow, to reproduce and to live together. This means to overcome standardisation and the normalisation that industrial and post-industrial societies impose on citizens and introduce and let live a diverse normality: a society in which normality is diversity and diversity is normality.

The wealth of a diverse normality is the contribution that we bring to the world, to transform it into a world made to measure for all.



Personal assistance is the help that a disabled woman receives for the things she's not able to do on her own during everyday life. Personal assistance is adapted to the individual needs of each disabled woman, allowing her to live her everyday life in autonomy and take part in social life like everybody else. This involves all areas of everyday life: domestic life, professional activities, education, taking part to social life and cultural meetings. It also includes many particular services, such as body care, household affairs, child care etc.

**Personal** assistance is a service that can be fulfilled in few hours, but may also take the whole day: the quantity of time is determined by the seriousness of the disability and by personal needs. It's the disabled woman who decides the modalities of the assistance: where, when and how. In the working sphere it is the disabled woman who decides on the contents, ways and hours of her working activities whilst the personal assistant carries out all the duties that the disabled woman cannot do by herself, for example type on the computer or send a fax.



Thanks to personal assistance the disabled woman can be fully autonomous, independent from family's help and live outside of institutions. The model of personal assistance sees the disabled person as a responsible and compe-

## 2. What is "personal assistance"?

tent subject, in everything regarding her life, and no longer as an object.

### 2.1 The types of personal assistance

Personal assistance is a service and must be paid for. In many European Countries there are two forms of personal assistance:

1 Self-administration<sup>2</sup> (the money granted for the payment of personal assistants chosen by the disabled person is paid directly to the person concerned by the public authorities) in which the disabled person becomes employer of her own personal assistants;

2 The public authorities transfer the money granted to a certain person for her personal assistance directly to the service provider.

A significant example of self administrated assistance is the German one, defined as "employer's model". The woman with disability has to give life to a small firm with rights and duties typical of an employer: by paying taxes and contributions to the State and wages every month to her employees. To carry out these duties she can also have the help of a tax consultant which will be paid for too. It's the disabled woman herself who conducts the job interviews and hires her assistants; organises their training, guides them, and gives orders about working time, leaves, substitutions, holidays etc. If it's the local authority or an insurance that pay the expenses, the amount depends from the type and gravity of the disability.

This form of personal assistance means great responsibilities and hard work. There are however in Europe hundreds of disabled people that use this form of assistance and they find it much more efficient and satisfying than the traditional services.

The second type of personal assistance can be used when the person with disabilities can't or doesn't want

<sup>2</sup> In Italy self-administrated assistance is defined as indirect, whilst in Germany and in many other European countries it is defined as direct.

to administrate her personal assistance herself. In Germany, in this case, the disabled woman turns to the “services of personal assistance” which normally carry out the bureaucratic procedures of financial matters, of the selection of personal assistants and of their hiring. The disabled woman together with the service of assistance chooses her own assistant, trains her and decides according to her needs, what type of duties the assistant must carry out.

The self-administrated form of personal assistance was born thanks to the movement for Independent Living, but it’s still rare in Europe. Other traditional forms of assistance are very diffused such as for example: “assistenza domiciliare” (assistance that takes place at home) in Italy, “ambulant services” in Germany and “auxilière de vie” in France. In these forms of assistance the structure that supplies the service (pre-arranged times and rotation of the staff) assumes the main responsibility and acts in a bureaucratic way. The traditional service puts aside the needs and specific requirements of persons with disabilities.



### 3. What we mean by the term “violence”

Very often disabled people are subject to episodes of violation of Human Rights, discrimination and also of physical and psychic violence. Disabled women are particularly vulnerable to violence. The person who acts with violence, usually men and sometimes women, plays on the fact that disabled women cannot defend themselves and depend on assistance and that nobody will believe them anyway. Another important fact in this context is to exercise power on others. This can go so far as to violate, sexually exploit and abuse especially disabled girls and women. This is a fact proven by statistics.

**I**t is therefore clear, that the dependence on others is also present in the model of personal assistance and it is also clear that violence can take place even in this type of relationship.

The concept of violence to which we make reference to in this work of ours is rather vast. In the relationship between personal assistant and disabled woman, we speak of violence when the dignity and self-determination of persons involved is being violated. Violence can also be induced by inside and outside factors, that puts a strain on the quality of the relationship.

These conditions may be:

- Having too little time at one's disposal. Both are under pressure because of the lack of time, because welfare does not pay enough. In reality more hours of personal assistance are necessary.
- Economic issues. Both are under pressure because financing is not always guaranteed.
- Little respect for the disabled woman's needs. Traditional services, as the “ambulant services in Germany or “assistenza domiciliare” in Italy, make decisions the disabled woman does not agree with.

The violations that could take place inside the relationship between the disabled woman and her personal assistant and that could damage self-determination, mainly regard the following situations:

- The personal assistant decides when, where and how help is necessary.

- The personal assistant ignores instructions of the disabled woman and does not attend to her needs

- The personal assistant does not respect the privacy and intimacy of the disabled woman.

- Conflicts are not talked out and put a burden on the relationship.
- The personal assistant is burdened beyond her physical and psychological limits by instructions and certain behaviour of the disabled woman.
- The personal assistant and/or the disabled woman hurt each other verbally.
- The personal assistant and/or the disabled woman hurt each other physically
- The personal assistant and/or the disabled woman blackmail each other.
- One personal assistant sows dissension between the disabled woman and the other personal assistants.
- The personal assistant is dishonest, unreliable and not punctual.
- The personal assistant takes advantage of the goodness of the disabled woman or vice versa.
- The disabled woman takes her problems and bad moods out on the personal assistant or vice versa.
- The personal assistant burdens the disabled woman with personal problems or vice versa.
- A personal assistant with a “helper syndrome”, or rather suffocating behaviour, may become a strong psychological burden for the disabled woman.

This list is considered neither hierarchic nor complete, but it is only an exemplification of the form that violence may assume in the relationship between a disabled woman and her personal assistant.

## 4.1 Italy

In Italy the main laws that provide for personal assistance services are:

- Law no. 104 of the 5th February 1992- “skeleton law on assistance, social integration and rights for disabled people”.
- Law no. 162 of the 21st of May 1998- “Modifications to law n. 104 of 5th February 1992 concerning measures of support measures for people with severe disabilities”.
- Law no. 328 of the 8th of November 2000- “Skeleton law for the fulfillment of the integrated system for intervention and social services”.

Some regional laws of local governments must be added to the main regulations:

- Law no. 104 of the 5th of February 1992- “Skeleton law for assistance, social integration and the rights of disabled persons”.

It is the first law that introduces the concept of autonomy and of personal and home assistance.

The articles that provide for home care and personal help services are: art. no. 8 comma 1, letters a) and b) and art. no. 9, comma 1.

Art. no. 8, comma 1 letters a) and b) states that the social inclusion and integration of the disabled person take place through social, psychological and pedagogical intervention, of social assistance and health care at home, of domestic and economical support. These interventions of support to the person with disability and to the family with which she lives. Personal help for disabled persons with temporary or serious permanent limitations of personal autonomy.

Art. no. 9, comma 1 states that : “The service of personal help that can be set up by the municipalities and by the local health authority within the limits of their normal budget resources, is directed to citizens with temporary or serious permanent limitations of personal autonomy that cannot be overcome with the use of technical help, informatics, prothesis or other forms of support made to facilitate self-sufficiency and the pos-

# 4. Personal assistance and legislation in Italy, Germany and France

sibility of integrating themselves, and it also includes the service of interpreters for hearing-impaired persons”.

The limit of this law is that these services are not compulsory, but

depend on the municipalities' resources. For this reason the service of personal assistance has developed in limited areas: it's present in rich towns and regions, but it's not present in poor regions.

- Law no. 162 of the 21st May 1998- “Changes in law no. 104 of the 5th of February 1992 concerning support measures in favour of persons with serious disability”.

**This** law integrates the previous one (Law no. 104/'92) and it is important because it is addressed to people with very serious disabilities. This law clarifies the types of services and sees to appropriate financing that integrate the local government ones.

With regards to assistance services the law provides for different interventions both for non self-determined people and for those who can make their own decisions.

With regards to the former, forms of home assistance and personal help are provided for, as well as institutions which give accommodation for short periods and emergencies, it also provides for the partial reimbursement of documented assistance expenses within the bounds of schemes previously agreed upon with the region's services. This regulation therefore, is of support to the families in which a disabled person who is not capable of self-determination, lives.

For persons with physical disability, and so capable of self determination, the law regulates the self-administrated personal assistance service, with the aim to guarantee their right to an independent life (for the first time a law introduces this concept), intervening on conditions of permanent and serious disabilities that limit personal autonomy.

In both cases, assistance is possible, even on a 24 hour basis, but which is very rarely enforced. However, the institution of a personalised plan is an innovative element of the law, through which a programme of help to the person is worked out, managed in a “self-administrated way” (referred to by the law as “indirect”) and depending on the needs of the person requesting this assistance. The work carried out is subjected to inspection of the service rendered and of its effectiveness.

- Law no. 328 of 8th November 2000- “Skeleton Law for achievement of the integrated system of interventions and social services.”

Law no.328/2000 creates the integrated systems of social services, and respect for disabled persons, in art. 14, comma 1 and 2, it sanctions the predisposition of an individual project that includes all the needs and services to the person, and services of care and rehabilitation which the single person necessitates with regards to full integration. To achieve the full integration of disabled people in the family and social life sphere, as well as in education, vocational training and work, The municipalities together with local health authority, arrange beforehand on personal request an individual project. This individual project includes disability diagnosis, care and rehabilitation that the person needs that are chargeable to the National Health Service. It also includes personal care service, in direct or credit form, chargeable to the Municipality. These services are aimed at recovery and social integration, as well as the necessary economical measures to overcome poverty, marginalisation and social exclusion. In the individual project potentiality and family support are defined.

**The** law also provides a fund for social expenses. This social fund is not enough for all types of service provided. Therefore the associations of old people and disabled are working to have a fund appointed for personal assistance, called “fund for non self-sufficiency”, but the bills of law regarding this are still blocked.

So, in spite of these complex laws, the service of per-

sonal assistance in Italy takes on many different aspects, which change, due to the economical resources of each Municipality and Region. So a definite standard does not exist (percentage of invalidity, type of disability etc.) if not the one of the State and local government treasury, on which to define times, modality and economical compensation for the carrying out of the service.

It's very difficult and often impossible to obtain this service in many cases.

## 4.2 Germany

Personal Assistance is generally financed by three different sources:

- Krankenversicherung, (SGB V) “health insurance”, which covers the medical/nursing part of home-care, i.g. dressing wounds, given medication, tracheostoma care.

A physician has to write a prescription for these and the health insurance has to approve it.

- Pflegeversicherung, (SGB XI) which is an insurance that covers basic care-needs like personal hygiene, nutrition, mobility and household chores. The monthly payment is limited according to three set degrees of care - needs, which usually only covers part of the actual need of support.
- Sozialhilfe, (SGB XII) “social welfare”, which supposedly covers all the needs that are not covered by the insurances above mentioned, including support to take part in leisure activities. Here the allowance also depends on personal income of the applicant and his immediate family.

The amount of support given is defined by law, with the “Pflegeversicherung” having the strictest limitations, and “Sozialhilfe” with the most leeway in interpreting the regulations. It is, however, possible to get 24 hours per day paid if the disability is severe.

Germany principally has the legal requirements for a



disabled person to finance personal assistance. But of course it is very difficult to get the actual need of support accepted by insurances and welfare. Quite often the payments are not enough to finance adequate personal assistance, and the applicants have to spend a lot of time and energy getting even that. Also, the allowance are only partly independent of income, which means that persons with a disability, who need a lot of support, are at a disadvantage.

### 4.3 France

At the moment in France, with regards to the Law of orientation in favour of disabled persons (*loi d'orientation en faveur des personnes handicapées, 1975*) every disabled person can benefit from:

1. A cheque called “Allocation Compensatrice Tierce Personne - ACTP” which is given depending on a standard decided by the State, through the Départements. The amount of the sum, from 40% to 80%, that is distributed to persons with disability is determined according to the needs of the person. However this sum allows people with disability to make use of only 4 hours of personal assistance a day. A further 20% is distributed if the person with disability works and is used to cover the expenses of personal assistance at work: it is the “Allocation Compensatrice pour frais professionnels”.

2. A cheque called “Allocation pour Tierce Personne - ATP” is of € 100,00 which is given entirely by the Sécurité Sociale.

These cheques are intended for the payment of personal assistants to help people with disability carry out essential everyday activities: hygiene, going to bed, getting up, getting dressed, going out, etc.

The “Allocation Compensatrice Tierce Personne - ACTP”, given by the Departments, must always be justified and used for hiring personal assistants.

The “Allocation pour Tierce Personne - ATP”, given by the Sécurité Sociale, must not be justified and is used for covering those extra costs that a person has to sustain because of his/her disability.

In March 2002 an experimental initiative was started for those persons with disability that need personal assistance for 24 hours a day. Starting from December 2004 from 200 to 300 disabled persons will benefit of this provision.

A Departmental Commission chosen by the Prefect, Representative of the State, makes an assessment of the personal needs. This assessment can be questioned by the disabled person, if he/she thinks that his/her needs have been under valued. In this case the person with disability has to be subjected to a reassessment, and in this case the disabled person will be assisted by a doctor he/she trusts and by an association representative.

In order to receive the “Allocation Compensatrice Tierce Personne - ACTP” the person with disability has to possess the following requirements:

- A percentage of at least 80% of permanent disability.
- Must be acknowledged as a disabled person for at least 16 years.

The request for the “Allocation Compensatrice Tierce Personne - ACTP” must be addressed to COTOOREP (Technical Orientated Commission and the Professional Requalification) that decides the sum to

be paid, and the duration of this payment.

Help to persons with disability is guaranteed by services of:

1. Personal assistance. The service was born thanks to the pressures of associations of person with disability and with the aim to guarantee that all normal everyday activities take place. The personal assistant receives certified training by a diploma that has been established with an ordinance of the 30th November 1988. To receive the service of personal assistance an economical contribution is requested of the disabled person that varies, according to his/her income (if the person with disability practises an occupational activity, only a quarter of the wage is considered in the assessment of the income) of the cost of the personal assistant, of the needs and the effective duration. This service is run by associations through an agreement with the State.

2. Home assistance. In this case you can obtain the reduction of 50% of the costs sustained by hiring the helper.

3. Help at home. To benefit from this service you must have a percentage of invalidity equal or above 80% or being unable to work because of this disability. To receive this type of help you must apply to the "County Centre of Social Action" (CCAS) or to the organisations that give home assistance. This service is limited to only 30 hours a month, and its amount is decided upon by departmental authorities.

Within January 2005 the reform of the law on personal assistance is expected that will bring on better changes instituting a compensation system of disability.



## 5.1 Object of the research

The project “I Care - Disabled Women and Personal Assistance Against Violence” n. JAI/DAP/03/207/W Programme Daphne 2000-2003, Measures to combat violence against children young people and women, comes from the need of deepening the subject of personal assistance as a means to promote an autonomous, independent and inter-independent life of women with disability.

**This** means to investigate in the relationship that is created between the disabled woman and the personal assistant during the carrying out of the service. Analysing the interacting dimension in which the people involved build a communicative relationship starting from their own identities.

In this specific case the object of study of “I Care” is the violence that could take place in the service of personal assistance, an area of investigation unknown until today. We talk about a phenomenon of potential or real violence, exercised or experienced of which we try to understand the meaning, in relation with two female universes - women with disabilities and personal assistants - that have to fix a boundary to their relationship.

In the relationship in question, we find two identities joined by the experience of professional assistance, but at the same time two identities that bring with them different life stories which determine in different ways their own deep and intimate experiences (body, emotional, fantastic, cognitive ) and it's own psychological growth.

The objective of the project is, therefore, that of letting the female worlds of disability and those of normality communicate: the women who are aware of their own life situation, and have therefore gone through actions of empowerment and the female world of personal assistants and then look at the interaction.

This is the innovative element of the project “I Care”

# 5. Results of the research

and with this we hope to start a new process of communication and exchange between groups of persons in contact with disability.

Three Nations of the European Community: France, Germany and Italy have been involved into the research.

## Areas explored

The areas that the research has explored are:

- Characteristics of the relationship in the personal assistance service.
- Type of human and professional relationship that is created in the relationship of personal assistance.
- Aspects of reciprocal violence during the service of assistance.
- Perception and meanings of violence inside the relationship.
- Forms of assistance: self-administrated and distributed by public and private organisations and incidence on type of relation.

## Target

The target chosen by the project is made up of:

Women with disabilities that have developed empowerment towards their own condition of disability, and who are on the way to emancipation have asked themselves which could be the ways for obtaining personal services that are respectful towards the privacy/intimacy of the customers. These women carry out a job of introspection, analysis and research to contribute to the growth of other disabled women and to help the women/personal assistants to improve their professional ability.

Personal assistants that offer a service to disabled women and take care of their bodies in everyday actions, are indispensable in their lives. These women, while carrying out their profession, don't always stop to analyse aspects such as respect of intimacy, and little importance is given to the body and to the relationship with the body of the disabled woman.



## Methodology

### *The focus group*

The focus group is a technique of social research used to deepen and to determine matters, themes and areas of interest. It makes use of a group of persons essentially

homogeneous that inter-

act between themselves and are guided by a moderator who plans the modality of development of the debate. The focus group has the merit to create interaction between the participants: the way in which they compare different points of view reproduces more realistically the process that presides the forming of opinions; and brings out more information regarding: products, services, programmes, communication campaigns, etc.; on coverage of complex subjects: personal reasons, habits, aptitudes, experiences, expectations. All this in short time and at rather low costs.

The elements that characterise the technique of focus group are: the centrality of the group as a source of information, interaction, focalisation on a specific theme, qualitative information and the presence of an interviewer. The paternity of this instrument of research leads to Robert K. Merton.

### *Characteristics of the Group*

The purpose being that of studying a particular phenomenon. The group is made up of researchers according to the aim of the research. The participants must have characteristics of relative homogeneity and interest in the subject to be discussed, so as to reduce as much as possible, the inclination of some subjects to

prevaricate on others, to want to prevail at all costs the discussion or deviate it towards digressions that are not pertinent. In this way everybody can feel free to express their own point of view and exchange opinions.

The subjects must participate at their own free will. Generally the number of participants varies from six to ten elements or from four to twelve.

## 5.2 Report Italy

### Focus group whit disabled women

The focus group was directed by a trainer and an observer following some guidelines:

- Type of relationship between disabled woman and personal assistant;
- Dominant components of the relationship (listening, availability, flexibility, dispute, violence, etc.);
- Instruments that can ameliorate the relationship between disabled woman and personal assistant (empowerment, advocacy, peer counselling, adequate financing, etc.);
- Typology of assistance: self-administration of assistance service (indirect assistance for Italy) and distribution of assistance service by an organisation (social co-operative, enterprise, county's service, etc.)

### *Participants*

The group was made up of 10 Roman women with motor and sensorial disabilities, ages between 18 and 55. Only a few of them have actively attended the associations, covering leader's roles; others have attended training courses organised by the same associations. One of them lives in a "casa famiglia" created by the City of Rome and managed by an assistance co-operative.

### *Description of the typology of the service used*

Some women use the service of personal assistance supplied by co-operatives, others self-administrated ones.

The experience of the girl who lives in the “casa famiglia” is particularly significant.

The “home family” is a place created as an alternative to total institution and should offer a way of a life in continuity similar to the one in one’s own family, guaranteeing a service of personal assistance geared towards independence and autonomy of the person, with the aim of a better quality of life and achievement of equal opportunity.

However, from the discussion it is clear that even in these context, the relationship that is created are relationships that deprives the person of the freedom of self-determination and self-planning his/her needs and wishes.

### *Features and criticalness of the relationship*

An important point was immediately clear from the group’s work, that is that personal assistance is a fundamental service to live freely and independently. But at the same time a series of difficulties were pointed out:

- Difficulty in having a private life, owing to the fact of constantly having a person with you from whom you cannot hide anything;
- Difficulty making sure that the assistants maintain their role;
- Lack of listening by the assistants. Being listened to during the assistance is essential and gives tranquility; not listening can bring on serious consequences both to the assistant, who could make wrong movements, and to the receiver of the service who may suffer abrupt jolts, dangerous for her physical health.



### *Instruments that can promote a positive relationship*

With regard to the instruments that can ameliorate the relationship between the disabled woman and her personal assistant, the Roman women talked about training through the methodology of empowerment, advocacy and peer counselling, that gives them a greater capability to run the service. Furthermore, they also request adequate financing.

The training is acknowledged as important even by the assistants.

Lastly, it came forth that the typology of self-administrated service gives more security, costs less and works better, whilst the mediation between the centre of responsibility of the co-operative of assistance which runs the service and the receiver of the same seems to be a problem, because the co-operative is geared towards the total planning of the service. The costs are higher, because they are not only for the assistants but also for the organising system. The main importance is given to the organisational needs, and does not respect peoples’ needs. In Rome, there is an Agency for Independent Living, administrated by people with disabilities. They do interviews at request of an interested party so as to find out the needs. Then they choose the assistants and give the administrative service, simplifying the management of all the difficult bureaucratic aspects.

## Focus group with personal assistants

### Participants

10 women took part in this group, aged from 20 to 50, each having worked as personal assistant for several years.

### Description of the typology of the service given

The institutions they work for, in most cases, are social co-operatives, to which the County hands over the management of the service of personal assistance. The duties carried out, beyond the care of the person, are: home care, family support, accompaniment, help at studying.

### Characteristics and criticalness of the relationship

To face the themes, the moderator of the group invited the participants to define their own working experience with one word. The interventions basically underlined the human character of the relationship, which is created between the woman with disabilities and the personal assistant during the carrying out of the service.

**Among** the words that were mentioned, there are many that emphasise the enriching and constructive nature of the experience of the service to the person. The women mainly underlined the aspect of mutuality of the relationship of help, the friendly and affective dimension that comes out, as well as the possibility to strengthen their capability of listening, being available towards the other and being open minded. Only two expressions - "lots of patience" and "personal involvement even after working hours" - show a more difficult aspect of the service of personal assistance. All the assistants agree on the fact that it is much more difficult to work with the family, than it is with the disabled person.

### Instruments that can favour a positive relationship

Some conditions that could make the service of personal assistance more satisfying and ameliorate the quality of the relationship were pointed out in the:

- Formal acknowledgement of the figure of personal assistant.
- Organisation of the work, that includes more working hours a week.
- The turn-over of more assistants for the same disabled person.

## 5.3 Report Germany

### Focus group with disabled women

#### Participants

6 women with physical disabilities took part in this group, aged between 35 and 50, of whom 2 work part-time, 1 is seeking a job and 3 of them were unemployed. Of these women, 5 have a professional formation or a high school degree, and 1 has no formation, but has worked for ten years in a protected workshop for disabled persons.

#### Description of the typology of the service given

4 women have benefited from a personal assistance service (procured by a Centre for Self-Determined Living) for more than ten years, 2 for three to four years.



3 women have benefited from a personal assistance service for twelve to twenty-four hours a day, 2 women for eight hours a day and 1 woman for four hours.

**One** woman has been self-administrating her personal assistants (hires her own assistants). She says that things work better now and there are less bureaucratic problems compared to those before when she had personal assistants by a competent assistance service.

The other women receive their personal assistants directly from the personal assistance service. Of these, 3 organise their own assistants however within the service: working hours, training, substitution in case of absence, etc. The assistance service only takes care of paying wages. Looking for new assistants can be done by the user/client or by the service, even through advertisements in newspapers.

### *Characteristics and criticalness of the relationship*

There are two aspects to consider in the relationship with the assistant: the personal level and the working one. Both are of equal importance: there must be understanding and also dialogue, but on the other hand, the work has to be carried out in an organised, safe and reliable way. For disabled women the most important criterion is reaching and gaining autonomy: the assistants are “the arms and the legs” of disabled women. The problems that emerge inside of this service have a negative influence on the relationship between the disabled woman and assistant and can create stress to the one who benefits from the assistance.

Protecting privacy is a learning process that if not observed changes into a violation of the Human Rights of the person.

### *Instruments that can favour a positive relationship*

The instruments identified are:

- Set up clear agreements and to define limits and possibilities;
- Support the disabled woman and not to be afraid of defending the respect of one’s own privacy;
- Inform on the meaning of autonomous life;
- Set up modalities to guarantee autonomy even for those women that are not able to be self-determined.



### **Focus group with personal assistants**

#### *Participants*

4 female assistants of women aged from 20 to 48 took part in this group.

#### *Description of typology of the service given*

The assistants are employees in the organisation of assistance of the Centre for Self-Determined Living of disabled people. Two of them have worked for the same disabled woman and the other two for another disabled woman.

### *Characteristics and criticalness of the relationship*

Two women say they work well because the disabled woman gives clear indications. The nice thing about being an assistant is having flexible working hours. Even the personal relationship has an important part. The contact with the world of disability is considered a benefit with regard to the capability of knowing how to face personal problems.

The other two women admit to having difficulty working with a disabled woman affected by a progres-

sive illness. They report that sometimes it is very hard working for this woman who is often capricious and aggressive, who vents her bad temper and her precarious physical condition on her assistants, considering them in part responsible for her own difficulties.

So it seems clear that, when the disabled woman accepts her own disability, even the relationship with her assistant is positively influenced.

If the disabled woman does not live in peace with her illness/disability then this influences the relationship with her assistants in a negative way. Acceptance is in fact more complex in a condition in which one slowly loses capabilities, one after the other, and dependence on the assistants increases.

### *Instruments that favour a positive relationship*

The identified instruments are:

- Reciprocal respect and acknowledgement of the importance of the assistants' work;
- The support of the disabled woman in difficulty with regard to the acceptance of her disability;
- Clear indications to the assistants;
- In case of problems inside the relationship, the need of serious outside supervision;
- Ability in constructing positive relationships;
- Training of both subjects involved.

## **5.4 Report France**

### *Focus group with disabled women*

#### *Participants*

10 women with motor disabilities aged from 18 to 40 years old took part in this group.

#### *Description of the typology of the service given*

3 women who attend high school, benefit from the scholastic assistant, and confess to having great hope in the new dictated French legislation on disability, which should come into effect in the year 2005. This

law should take note of the needs of disabled persons, so as to support their disability both financially and with human and technical help.

In France a disabled person can benefit from only three hours of assistance per day, which in many cases is too little. One hour of assistance costs 12 Euro and since the cheques distributed from the Institutions are not based on real needs, the disabled person is compelled to support a greater daily cost.

### *Characteristics and criticality of the relationship*

The relationship between the disabled person and the personal assistant is held up by a working contract, signed by both parties. But even though the contract clearly defines the duties to be carried out, (preparation of meals, personal hygiene, household duties, etc.) often the assistant carries out these duties in the way he/she retains most convenient, for example with delays, which consequently cause delays for the person with disability, at work or at University.

Most of the women taking part in the focus groups complain about a relationship that assumes a form of "assistant" to "assisted" (doing in the place of... instead of doing with...). So it becomes a relationship of assistantship and not a working as a team, in harmony.

This determines a situation of stress for the disabled woman, even because of the working modalities of the assistants, who normally, is believed, should do this job for vocation.

In this situation, even the non-respect of intimacy becomes a banality.

### *Instruments that can favour a positive relationship*

The identified instruments are:

- More personnel;
- Better training: no acknowledged title or diploma exists for personal assistants;
- Better wage evaluation: the cheques that disabled persons receive for their wages are insufficient, and this does not motivate the work of the assistants.

## Focus group with personal assistants

### *Participants*

5 female assistants of women, aged between 23 and 48 took part in this group.

### *Description of the typology of the service given*

The assistants look after persons with motor disabilities and persons with psychical or sensorial disabilities.

### *Characteristics and criticalness of the relationship*

The personal assistants say: "The persons that we assist can do nothing without us, but we cannot do everything". And admit to being:

- Badly trained and with a small pay
- Not acknowledged by a title-diploma and to having:
- Little time at disposal to develop the necessary personal relationship needed to create a confidential atmosphere, so as to render the service in the best possible way.



### *Instruments that can favour a positive relationship*

The identified instruments are:

- Awareness of the importance of their profession despite the lack of acknowledgement of a diploma from the French State;
- The reform expected by the year 2005 is necessary to the 5 million disabled French persons.

## 5.5 A Comparison

The results obtained from the research of the project "I Care" on both targets - disabled women and personal assistants - have put into evidence, in the three partner countries, basically homogeneous characteristics.

For this comparison it has been preferred to analyse the contents reported by each target group, in base to the following areas:

- Characteristics of relationship
- Instrument that support a positive relationship
- Forms of assistance and incidence on type of relationship.

### **Characteristics of the relationship**

#### *The disabled women's point of view*

In the group of the Italian women, as well as in that of the German women, what is mostly emphasised, is the important job of personal assistance, as a fundamental service oriented towards the independence and autonomy of the disabled person, with the aim to guarantee a better quality of life, and conditions of equal opportunity.

But this represents a condition of remarkable ambivalence, because finding yourself always with another person, means not to enjoy a completely private life. In fact, German women say that it is important to safeguard your own personal sphere and even more to outline this with precision: the assistants, sometimes, take decisions in their place, and it is important that this is discussed.

But this is not always easy, because the assistants might be offended, and object to the requests. Here arises a battle for power.

These stories make us think about the conditions of double discrimination of disabled women.

The world of women in general has tried and tries to redeem themselves from a condition in which being a woman means necessarily to carry out a female role of taking care, with little chance of developing relationships of equality on the inside of decisional areas: family, finance, politics, science, management, etc.

From here, the need to bring back inside a territory, a space, a relationship, the assertion of something that can be called “power” or, better, the chance to be and to count.

This privileged place, most of the times has become one’s own home. Here a chance has been given to women to decide and determine their own choices and to assert their personal knowledge.

But what happens when, because of a condition of disability, the woman is no longer legitimate, and she’s no longer allowed to establish herself even in these contexts?

She loses her social identity, and her reason for being. She becomes an indefinite subject, who needs to rediscover the sense of her existence.

It is in this territory that the disabled woman and her personal assistant sometimes meet and clash.

**The** two cases are brought together by the research of an identity, which asserts the right to be a person no matter the sex and disability: both, in their female itinerary, have to fight to claim their own living-space.

So it may occur, as has been witnessed many times, that these two worlds are not legitimised. A hidden, unconscious battle breaks out, wherein reality both the one and the other have the same wish: practice one’s own power to affirm one’s own identity. This struggle for power, the one over the other, is a very frequent cause of conflicts and violence inside of this relationship. The assistants, but in many cases also the woman with disabilities, trespass into in a sphere which does not belong to their relationship, with the risk of violating the intimacy of people.

On an operative plan, a main difficulty reported by Italian women is the lack of listening. They say that being listened to, while the service of personal assistance is being carried out is an essential element, because in the physical care, big errors may be made (abrupt movements, jolts, etc.) sometimes with serious consequences.

In the report we have seen that even French women complain about the existence of an unequal relationship between personal assistant and disabled woman: there’s always a relationship of “assistant/assisted”, where the first substitutes the second.

We have seen that German women focus their attention on two aspects of personal assistance: the personal one and the professional one. It is important that there is dialogue, understanding, affection, but there must also be professionalism that guarantees the woman who receives assistance, security and reliability.

Also when a personal relationship becomes more affective and friendly, it is good to keep the two levels separated. Very often, due to this type of relationship, whenever the need to seek a new assistant arises, the woman with disabilities, finds it very difficult to let go: whether for fear of not finding another valid helper, or because she worries about the economical future of the assistant she would like to dismiss.

### *The assistants point of view*

In the group of the Italian assistants, the fundamental element which has been underlined, is the humane character of the relationship, which is created, between the woman with disabilities and the personal assistant, during the carrying out of the service.

The women were invited to define their experience as assistants with one word.

Among the terms that have been mentioned there are many that emphasise the enriching and constructive nature of the experience of the service to the person. We recall some of them “great enrichment”, “exchange of experiences”, “learning together”, “empathic listening”, “friendship”, “availability”, “open-mindedness”.

With these expressions, the assistants have mainly underlined the aspect of mutuality reciprocity support relationship, the friendly and affective dimension, which is created, as well as the chance to strengthen one’s ability to listen, being available and open-minded for the other. Some of them have talked about this profession as a real choice of life.

Even the German assistants spoke about the importance of a friendly relationship, as well as the sharing of interests that may bring together the disabled woman and her assistant. Furthermore, they say that the contact with the world of disability enables them to face their own life and personal problems in a diffe-

rent way, perceiving other meanings and giving them the right importance.

Concerning this the French assistants complained that it is very difficult for them to create a confidential relationship with the person they assist because they have little time at their disposal, since the service gives just one hour of assistance per person.

Among the expression indicated by the group of the Italian assistants, only two - "a lot of patience" and "personal involvement even beyond working hours" - show a more wearisome aspect of the personal assistant. However, even if the moderator of the group tried to make the women think about the more problematic aspects of the assistance to the person, no conflict situation was brought out, detectable as a violation of human rights.

A problematic aspect reported by the assistants specially when they assist a person with mental disability, is the relationship with the family. This often opposes to the path towards autonomy which the disabled person goes through with the assistant, who finds herself forced to be mediator between the family's resistance and the needs of the person to whom she gives assistance. Sometimes the assistant becomes a model of behaviour to the family and its members, who have to learn to manage the relationship with the non self-determined disabled person with authority, without being too authoritative or too permissive.

Lastly, another difficulty which has come forth is linked to the affective sphere of disabled women.

**An** Italian assistant has testified her experience of impotence and frustration, when she compared herself with a disabled woman, who confessed her impossibility making her dream come true that of becoming a wife. In the face of such dramatic stories, the assistant can develop empathetic and stimulating listening for facing problematic situations, but she must not take charge of the life and choices because the disabled person must act in complete autonomy, self-determination and personal responsibility. Somehow she has to protect herself from emotional involvements, that can trespass into those personal and intimate spheres, which as we have already said above, do not belong to her.

## **Instruments that favour a positive relationship**

### *The women's point of view*

The instruments that allow a better quality of the efficiency and efficacy in the levels of service, favouring a positive relationship between the disabled woman and the personal assistant, are represented in the following points of the focus groups of the disabled women of the three countries:

### *Training*

The training must be directed towards both the disabled women and the assistants. With regard to women with disabilities, they, through the process of empowerment, peer counselling and advocacy, can be helped to become aware of their own desires and needs and become active in the requests and management of the assistance.

With regards to personal assistants, they have to be trained in their job, only by the women to whom the service is addressed, since the latter are the only ones able to teach them technical and practical knowledge so as to be able to satisfy the physical needs in the most appropriate and adequate way for the different needs. Besides a trial period is necessary to establish the suitability of the chosen assistant.

### *Promotion of the type of work*

The disabled women say that it is very important that this type of work is acknowledged and promoted, because the assistance is the fundamental condition which allows them to take part actively in the contexts of social life, study, work, the economic and political sphere, etc. in which they live.

### *Increase of personnel*

The disabled women declare that a greater number of assistants is needed (at least two) which work in turns with the same person, because it is a very energy con-

suming job, both on a physical and psychological level, especially with the seriously disabled.

### *Dialogue and respect*

It is important to have dialogue and reciprocal respect between the woman with disability and her assistant, because it is good to point out the role and the duties that the latter must carry out. The women declare that it's fundamental that the assistant does not replace them, but respects their capability of self-determination, even when she does not agree with their choice. On the other hand even the disabled woman must have respect for the assistant's needs, satisfy her requests, besides praising her when she has worked well.

### *The assistants' point of view*

Among the instruments that favour a positive relationship between the disabled woman and the assistant, and therefore an improvement of the service, the assistants of the three countries answer in the same way as follows:

#### *1. Regulation of the service*

The assistants declare that the service has to have regulations, starting from the formal acknowledgement of the figure of personal assistant, by a diploma or other specific title. Furthermore, they underline with insistence that the organisation of the service must be organised on a greater number of weekly working hours, and the possibility for more assistants to work in turns for the same disabled person. As it has already been mentioned in another part of the kit, there are some of conditions which could render the service to the person more effective and efficient, improving also the quality of the relationship that is established. The assistants consider the lack of rules of the service as frustrating and humiliating for their job, but also burdensome and badly paid.

Besides, to avoid conflicts, the disabled woman has to be able to give clear instructions. The assistant has to be able to ask for explanations if the instruction is not understood.

#### *2. Culture of disability*

The assistants identify the reason for the non-acknowledgement of a title, in the lack of culture of disability in the societies. There is not as yet an adequate information about issues concerning disability.

Among the common people, as in the institutional areas, there is still a lot of ignorance, which nourishes prejudices towards women with disability. People want them closed up at home, without a chance to live an autonomous and self-determined life.

**They** stress the importance that there is need of greater awareness towards the theme of disability, since they think that this would allow, in persons in general, the growth of awareness regarding issues that may concern all citizens, and stimulate the attention towards an environment still full of mental and architectural barriers.

#### *3. Support and supervision*

The assistants declare that it is important for them to have supervision meetings or team work in which they have feedback from other assistants regarding their own work. This would represent a way of protecting the assistants and avoid their burn out, avoiding also the suffering of the persons that are close to them (their partners, their family, the disabled woman with whom they work).

Supervision is necessary also in case of conflicts. For the resolution of the latter outside support is convenient, which can be identified: a) on the institutional



level, b) on the domestic one, c) in the service, and d) in trustful persons that act as mediators between the assistant and the person with disabilities.

#### *4. Family's awareness*

According to the assistants interviewed, the process towards awareness and emancipation of the family with regards to the disabled son or daughter affects the quality of the service of assistance. It is important to be acknowledged by the family in their role, especially when they assist a person with a cognitive disability, since many times it is the same assistant who sustains her emotionally in experiences of inadequacy inside the social contexts that he/ she frequents.

#### *5. Disabled woman's awareness*

The assistants affirm that the awareness of the disabled woman regarding her capability of being autonomous, affects the nature of the service, since the perception of her own limits guarantees the assistant a space of action with regard to her own functions and competences.

#### *6. Reciprocal respect and sharing of interests*

The reciprocal respect and the sharing of common interests, as well as having established a good affective relationship, are the essential ingredients to render the service of assistance dignified.

## **Forms of assistance and influence on the type of relationship**

### *The point of view of disabled women*

From the group of the Italian women it came forth that self-administrated assistance, in Italy called "indirect assistance" guarantees better results, costs less and works better. This also happens thanks to the presence of an agency for Independent Living, managed by

persons with disabilities who, on demand of the person interested, carries out the recruitment of the assistants and gives the administrative service, simplifying all the bureaucratic aspects of the difficult management.

The service of assistance mediated from the structures, defined in Italy with the term of "direct assistance" on the other hand, presents greater difficulties, because the mediation between the centre of responsibility of the co-operative of assistance which manages the service and the receiver of the same is problematic. The logic direction in this case, is aimed towards the total planning of the service. The costs are higher, because they do not concern only the assistants, but also the whole organisational system.

So, the mediated report removes the needs of the person in favour of organisational needs, favouring the logic of profit. Moreover, the assistants recruited by the co-operatives, do not have an appropriate training. A further point against direct assistance is the turnover of the assistants.

## APPENDIX “A”

### Draft of a european legislation on personal assistance

Welcome

People with extensive disabilities, i.e. those who need assistance from other persons in their daily lives constitute the group with the least education, employment, income and social contacts. The reason is not our lack of physical and intellectual capabilities but lack of access to mainstream education and training, lack of barrier-free housing in the community, lack of accessible transportation, lack of barrier-free workplaces and “reasonable accommodations”, lack of personally directed assistance in one’s natural living environment and outright prejudice and discrimination - conditions that force us into and keep us in residential institutions and parental homes for lack of acceptable alternatives, rob us of mainstream life and undermine our self-esteem and, thus, create self-fulfilling prophecies. We believe that individuals who have acquired their disability at an early age are particularly prone to get caught in this self-reinforcing downward spiral.

One of the keys for breaking the vicious circle is personal assistance, i.e. user directed assistance from other persons with those activities of daily living that the user either cannot do by herself or for which he or she would need an inordinate amount of time and energy.

An estimated number of one million disabled European citizens are warehoused in residential institutions, marginalised and invisible. For this forgotten population personal assistance is one of the keys for moving back into the community.

An the same time, community based personal assistance policies and programs enable many assistance users to become gainfully employed, allow family members to return to the labour market and provide numerous employment opportunities for personal assistants.

A voice of our own is needed to break our present dependence on service providers and other professional experts and to present facts, convincing arguments and politically viable solutions that promote self-determination in every-day life and break the culture

of dependence that our group has been exposed to far too long.

#### *Our Mission*

The European Centre for Excellence on Personal Assistance is an initiative of major Centres for Independent Living in Europe and their respective networks consisting of grassroots groups of disabled people, most of whom are users of personal assistance, with a long experience in helping each other move out or keep out of residential institutions.

ECEPA’s task is to:

- Guard the rights of persons with disability, who are users of the assistance service in Europe.
- Improve the quality of the service of personal assistance, so as to improve the quality of life of disabled persons in Europe.
- Work for national policies on personal assistance in the States that are members.
- Work for a European-wide policy for personal assistance users’ mobility across national borders.

#### *ECEPA’s Action Plan*

The activities of ECEPA will focus on personal assistance, its role in de-institutionalisation, in achieving equal opportunities and in enabling people with extensive disabilities to become contributing members of the community. To this end ECEPA will analyse existing policies and practices, document examples of good practice, develop model legislation, and impact policy makers.

In particular, ECEPA will engage in the following activities

- conduct comparative policy analysis in the area of personal assistance in Europe, including its labour market implications
- carry out comparative research on the prevalence of institutionalisation and forced parental home accommodation of persons who depend in their daily lives on personal assistance.

- document and disseminate examples of good practice
- draft model legislation for personal assistance
- disseminate the results through the partners' websites, an electronic newsletter on personal assistance, events
- building alliances with other disability organisations, service providers, policy makers impact local, regional and EU level politicians.



## APPENDIX “B”

### **Eight key demands to the European Parliament about a European wide policy on personal ENIL**

The principals that guide ENIL’s work are:

1. Independent living is a process of awareness, empowerment and emancipation. This process enables all disabled persons to achieve equal opportunities, rights and full participation in all aspects of society.
2. Disabled people must be able to control this process individually and collectively. To achieve this goal we provide peer support and use democratic principles in our work.
3. As equal citizens we must have the same access to the basics of life including: food, clothing, shelter, health care, assistive devices, personal support services, education, employment, information, communication, transportation and access to the physical and cultural environment, the right to sexuality and the right to marry and have children, and peace.
4. The Independent Living Movement must be a cross disability movement addressing the needs of all disabled persons. In order for this to occur we must rid ourselves of any prejudice we have towards persons with disabilities other than our own and encourage the involvement of disabled women and other underrepresented groups. Disabled children should be enabled by their families and society in general to become independent adults.
5. Disabled people must obtain all the requirements for equalisation of opportunities and full participation by defining their own needs, choices and degree of user control.
6. The Independent Living Movement is opposed to the development and maintenance of systems which promote dependency through institutional responses.

7. Disabled people must involve themselves in research and development, planning and decision making, at all levels, in matters concerning their lives.

These above principles were adopted at the ENIL meeting, ‘Het Timmerholt’,

Netherlands August 31 - September 3, 1990.

## APPENDIX “C”

### **Tenerife declaration. Promoting Independent Living - Ending discrimination against disabled people**

We, four hundred participants from many European countries gathered at the 1st European Congress on Independent Living, held in Tenerife in the framework of the 2003 European Year for Disabled People, urge that the Canary Islands’ and Spanish Governments take the lead in advocating for the implementation of this Declaration in European Union policy, specifically in the work for the upcoming Non Discrimination Directive on Disability, and the European Action Plan on Disability.

#### **Principles of Independent Living**

We, disabled people, must have the means to take responsibility for our lives and actions in common with non-disabled people. Most of the problems that disabled people encounter are not medical but social, economic and political.

After a history of marginalisation and exclusion, disabled people are NOW demanding the right to choose how we live our lives in the community. We demand the same opportunities and choices and the same degree of control and self-direction over our everyday lives that non disabled people take for granted.

Our full and equal participation in society will enable us to reach our maximum potential as human beings, and in so doing contribute to the economic and social life of the community. This has historically been denied us.

Disabled people must be viewed as the experts on their lives. As experts, we have the right and responsibility to speak on our own behalf. Furthermore, us disabled people need to control our own organisations.

Independent Living is a fundamental Human Right for all disabled people regardless of the nature and extent of their impairment. These include people with learning difficulties, mental health system users and

survivors, disabled children and older disabled people.

Every life and diversity should be valued. Every human being should have the right to make choices about issues affecting their lives.

#### **We Affirm**

In all activities of the public sector such as infrastructure planning, education, transportation, employment measures and other services, the needs of disabled people must be fully taken into account through Universal and Inclusive Design. Service design and implementation must follow independent living principles and centre on a person’s individual needs.

Personal Assistance enables persons with physical, sensory, intellectual, and other impairments to live a self directed life in the community, enabling fuller participation in all human activities. Examples include, parenting, sexual activities, education, employment, environmental development, leisure, culture and politics.

Disabled people should have maximum control over disability and independent living related services. These should include public financing, advocacy, training, and peer support for people who may not be able, or wish, to take full control of their lives.

It is unacceptable that European disabled citizens are still kept in residential institutions, because of the lack of appropriate living alternatives in the community.

We stress that independent living support services are essential in order for disabled people to enjoy basic freedoms and must be funded by all Governments. We, disabled people from all over Europe, do not accept any funding limitations in regards to our basic freedom. If necessary we are ready to challenge these assumptions about the lack of resources.

#### **European Union**

We urge the European Union (EU) to continue to expand its Human Rights policies to improve the qua-

lity of life of disabled people through freedom of choice and higher quality of services.

We condemn any type of segregation and institutionalisation that are a direct violation of our Human Rights. Governments must implement and enforce legislation that protects the Human Rights and equal opportunities of disabled people.

We urge the EU to adopt measures that will guarantee and prioritise community based, over institution type, solutions in the area of disability support services.

Disabled people must be given the choice to convert disability related support services, that are currently received in kind, into the equivalent amount of direct payments.

In compliance with the Treaty of Rome, we demand that EU governments adopt a minimum level of direct payment for personal assistance services in all EU countries in order to promote freedom of movement within and between EU states. Furthermore, in promoting standards for inter-operability of goods and services the needs of disabled people must be taken fully into consideration.

We demand that the EU require governments of European States fund the development and support of organisations controlled and run by disabled people to promote Independent Living.

We demand that the EU adopt the necessary measures to prevent discrimination against disabled people in future advances of genetics, science and technology.

Arona, Tenerife - April 26th, 2003



## Glossary

- Personal Assistance** All the actions carried out by an operator (personal assistant) made to support the life's development of a person with disability, with special attention to the administration of the house and person's hygiene. The assistant of help to the person must grant:  
Flexibility: answer to the needs that may change, compared to the everyday life of the person who uses the service, to his age, to the type of disability, to the demand, the environmental context in which the service takes place;  
Privacy: the assistant has to be able to respect the privacy of which every person has right; The role: the assistant has to be of support and never in substitution
- Empowerment** Empowerment can be defined as a process to reconstruct a positive evaluation of oneself and one's own self-efficiency, following experiences and/or situations that have strongly undermined self-respect. The disabled person, inside this process, is supported in his attempt to change these conditions that prevent the possibility of growth and emancipation. The acquisition of ability and capability, the widening of the self image, allow the person to feel able to influence his own existence and the social context in which he lives. Some experts of the process of empowerment have underlined how "the concept of empowerment is fundamentally built around the fact of "taking in hand one's own life".
- Advocacy** The term advocacy (...) is an English term that originates from the Latin word "advocare" (call on oneself, to take upon oneself), deed, backup action, of an idea, of a person. Literally speaking it would correspond to the concept of "advocacy" and who practices it would be a sort of "advocate/lawyer", the guardian of a cause, of a person, who has to the spokesman of the personal rights - if they are violated or in danger of being violated - and to support their reasons. In cases of defence and claim of human and civil rights advocacy is used as a methodology and/or a modality of accompaniment. This is articulated and organised with forms and types of actions that may involve either single persons or groups or movements.
- Mainstreaming** Mainstreaming means inclusion of the prospective of disability, on all levels and in every process of the actions, of policies and of economic measures of the European Union. This means that the achievement of policies and actions to promote equal opportunities for disabled persons, must not be restricted to specific measures assigned to the world of disability. It's nothing about adopting programs and financial resources, addressed exclusively to this specific group of persons, but rather to insert the question of disability on the inside of the policies and of the actions that concern all the other citizens. The prospective of mainstreaming puts into evidence that the promotion and implementation of equality of opportunities must not to be confused with the simple objective of balancing cold statistics. When we talk about equal opportunities, we mean in fact the setting off of the person in his/her diversity, the respect of differences to create pluralistic and democratic societies.
- Autonomy** All children during a certain period of their lives feel the need to become autonomous from their original family creating new spaces in their lives, social roles, interpersonal relationships, outside the family relationships, where they can have experiences of confrontation about themes that are essential for everybody's growth: friendship, affection, sex, work and so on. This process of autonomy - common to all children that become potential mothers and fathers - does certainly not have, a coherent character, but is punctuated with tension, confrontations and lacerations that each time inevitably characterise their separation from their parents.
- Self-determination** Autonomy is connected to the person's ability of self-determination, i.e. to want and to be able to choose, and to the progressive responsibility regarding the consequences that these choices entail. It is clear that this, more or less, long process, is related to the ability of building a relationship outside the family and to overcome the prejudice that considers a disabled person as someone who continuously depends on someone else. In brief we could say that autonomy and the ability of self-determination are the first steps to be able to live independent and inter-independent experiences.
- Independence** The first level of independence to obtain is that of autonomously carrying out daily life activities. In this case, there are external conditions that may allow an easier achievement of this target, such as the following: favourable economical conditions, availability of resources on the territory, etc. But it's evident that these activities depend also - and in a considerable way - on personal choices. Such as travelling (for holidays and/or free time), to obtain the driving-licence, to manage one's own house-keeping, to build a professional-skill, are some of the activities that bring and make one live situations of independence.
- Inter-independence** To work for inter-independence with society and with the human and natural habitat in which one lives, represents yet a successive stage. In this area we can include all activities with which one inter-acts with society and with many people, in the form of reciprocal dependence, inter-change and reciprocity. To seek and obtain a job, to build a space of chosen relations, to form a family, to act in society in a conscious way, through political, economical and social actions, are many faces of the same medal, in which we play the capacity of autonomy and independence, in relation with society and concrete persons, with continuity and in a structural form.