HELIOS II
Social Integration and Independent Living

The Elimination of Socio-psychological Barriers: Assistance in Daily Living

Thematic Group No. 5
1996 Report

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Acknowledgement

It would not have been possible to have researched and completed this report without the commitment, openness and honesty of all of the countries involved. The participants in Thematic Group V included representatives from disability led organisations and service providers and large voluntary and statutory organisations from almost all countries. The subject matter challenged many cherished beliefs and deeply intrenched attitudes and often involved heated debate but the spirit of co-operation and the conviction felt by all participants that disabled people must have civil rights equal to those of people who are not disabled supported our work throughout. Without exception the hosts of our study groups allowed us detailed insights into both the good and the not so good aspects of their work. It was this which enabled us to put aside our stereotypes and prejudices and concentrate on the matter in hand.

We hope that this report will contribute in some small way to the cause of disabled people throughout Europe.

This report is written to inform those who read it and not to claim that any one country is better (or worse!) than any other. We hope that it will be a useful tool to all those who wish to enable disabled people to be just like anybody else

We would also like to acknowledge the support provided by the HELIOS team of experts as a whole and particular the support provided by Mary Kyriazopoulou and Patricia Winrow.

Preface

The purpose of the Community action programme HELIOS II is to promote integration and equal opportunities for disabled people. It was established by the Council Decision of 25 February 1993 and covered the period from 1 January 1993 to 31 December 1996.

Exchange and Information Activities (E.I.A.) were one of the programme’s operational aspects. Their aim was to identify, define and disseminate innovative and effective practices regarding integration in the Member States. In addition, they tried to develop a strategy of European know-how on integration issues.

The Social Integration and Independent Living sector of the E.I.A.s consisted of 192 organisations, officially nominated by the 15 EU Member States plus Norway, Iceland and Liechtenstein. Their representatives were divided into 15 thematic groups in order to analyse at European level the different issues that constituted the official working themes of the sector: Elimination of technical and socio-psychological barriers.

The main means of European networking and collaboration between the partners involved study visits, training sessions and seminars. Within every group, the development of the working theme was approached as a three stage process involving: getting to know each other and exchange information, analysis and discussion of the issues on the basis of the different practices in the Member States and drafting conclusions.

This report is the result of the work done by thematic group No 5 on the theme "The key role of personal assistance in promoting autonomy: key principles, finance". It reflects not only the challenge of such a diverse group of disabled people, professionals, representatives of associations, service providers, managers, policy-makers etc. working together at European level but also the richness of the work achieved during the course of the Helios II programme with the presentation of conclusions and proposals that need further action.

This report is intended to help set a new agenda for improving the quality of life for people with disabilities so that their needs can be met throughout the European Union.

Mary Kyriazopoulou
Helios Team of Experts

Introduction

This report is the culmination of three years work by thematic group No 5 ’The elimination of socio-psychological barriers: Assistance in daily living Training: disabled people, assistants)’

The membership of this group is made up of Personal Assistance Users, service providers managed by disabled people, other service providers and representatives from governments, voluntary and statutory agencies.

During its three years existence the group had members from the following countries (please see appendix A for full list)

- Austria (1)
- Belgium (2)
- Finland (1)
- France (1)
- Greece (1)
- Iceland (1)
- Italy (2)
- Norway (1)
- Portugal (1)
- Spain (1)

- Sweden (1)
- UK (3)

and held 9 study visits in the UK (2), Belgium (2). Portugal, Italy, Sweden, France and Spain.

The contact persons for the group were:

Cléon Angelo (Belgium)
Angelo Paganin (Italy)
Gyles Palmer (UK)

The key elements addressed for the final year of the project were:

- Definition of the operating procedures for personal assistance in the different countries
- Exchange of information on the different experiences of training from the point of view of disabled people, professionals and service providers.
- Provision of training addressed to both personal assistance users (disabled people) and personal assistants to optimise quality of personal assistance in daily living.
- Definition of key elements which training must address (e.g. technical aspects, administrative/legal, management and relationships).
- Co ordination between service providers, professionals and disabled people.
- Main issues in the independent living movement.
- Peer counselling as a means of promoting and supporting independent living.

Throughout the life of the group (1994 - 1996) emphasis has been placed on the importance of communication between disabled people, statutory and non-statutory service providers and funders, this has been supported by formal and informal information gathering exercises which have led to the production of a number of group statements. These include the Madera Declaration (1994) (Appendix D) and the Herefordshire statement on training needs (1995) (Appendix F). The group also recognised the importance of the 1989 Strasbourg resolutions which were drawn up by disabled people from fourteen countries at a conference in April 1989 at The European Parliament, Strasbourg, France (Appendix C). Further information in the appendices include a summary of the ’Description and Evaluation of the best personal assistance services in a variety of European countries’ (Appendix B).

Our final year has focused on the training of disabled people and their assistants but we have also returned to a discussion of principles of independent living prompted by the arrival in the group this year of colleagues from the Scandinavian countries (Sweden, Norway, Finland and Iceland).

For disabled people and for those who fund and provide services for and with them the 1980’s and 90’s has seen a time of change within the public welfare sector in Europe. This change has been characterised by growing expectations and demands for autonomy and independence from individual disabled people and those who represent disability movements and decreasing resources for public welfare in general. The impact of these changes have been tempered by local conditions and attitudes in each of the countries belonging to the European Union, each country is unique and at a different stage of development, dictated by different histories, the attitudes of politicians and of ’society’, and differing geographical, social and resource conditions.

There is an increasing emphasis by many members of the European Union on the introduction of market forces to improve the quality of services to disabled people. The assumption is that service users will be empowered by having the ability to ’exit’ services with which they are not satisfied. This method of empowerment relies, however, on the ’customer’ having sufficient resources to weigh up the relative advantages of the cost of the service against its quality and having a wide variety of services from which to choose. An alternative approach is that disabled people have full control of their services and the way in which they are provided - either by directly employing personal assistants or by managing the organisations which provide them. The extent to which this form of empowerment can lead to disabled people having real control over their lives is, again, constrained (1) by the attitude of funders whether they use the medical model of disability to place the responsibility on the disabled person to ’compensate’ for their ’lack’ of ability to access society and employment or the social model of disability which places the responsibility on society to break down the barriers which disable individuals (physical or attitudinal) and (2) by the lack of resources.

Group 5 came to the unanimous conclusion that the ability of disabled people to employ their own personal assistants is an essential prerequisite to real empowerment and control. This included the responsibility of training their own staff although it was recognised that some training should be provided by specialists or professionals (e.g. lifting and First Aid). The group also recognised a tension between the need to be good employers and to meet legislative requirements when employing staff and the wish to retain full control.

Consideration must also be given to those people who may, either because they are intellectually disabled or through choice, not wish to have complete control of their personal assistants as direct employees (for example administrating pay, tax and insurance or the organisation of emergency support when regular workers leave suddenly or fall ill). Group 5 therefore concluded that disabled people should be offered a choice of system to use.

The prime focus of Group 5’s work was therefore on the opportunities that disabled people have to employ their own Personal Assistants (or to choose agencies to do so for them) and retain complete control over the choice, training, scheduling of staff and the type of support that they purchase.

Principles of Independent Living

Independent Living is a philosophy and a movement of people with disabilities who work for civil rights and equal opportunities, self respect and self-determination. "Independent Living" does not mean that persons with disabilities do not need anybody, that they want to do everything by themselves or live in isolation. "Independent Living" means that disabled people want the same life opportunities and the same choices in every-day life that their non disabled brothers and sisters, neighbours and friends take for granted. That includes growing up in their families, going to the neighbourhood school, using the same bus, getting employment that is in line with their education and abilities, having equal access to the same services and establishments of social life, culture and leisure. Most importantly, just like everyone else, persons with disabilities need to be in charge of their own lives, need to think and speak for themselves without interference from others.

To this end disabled people need to learn from and support each other, organise themselves and work for political changes that lead to legal protection of their human and civil rights. Traditionally, disabled persons have been seen as medical cases and objects of charity and care, pity and protection. These wide-spread attitudes have been obstacles on their way to self-determination, self-representation and full citizenship.

In order to reach the same control and the same choices in every-day life that nondisabled persons take for granted a number of prerequisites are necessary. For persons with significant support needs there are three key requirements: personal assistance, technical assistance and accessibility in the built environment including accessible housing. Without these three necessities persons with significant support needs can choose only between being a burden on their families or living in an institution. These extremely limited and limiting options are incompatible with the concept of Independent Living.

The Principles of Personal Assistance

Assistance from paid workers enables the user to carry out such every-day activities as bathing and dressing, and going to the toilet, household chores such as shopping, preparing meals and cleaning. Assistants help the user at work, about town and on travel. They assist in communicating or in structuring the day, as required. In brief, assistants help with those activities which the user would have done by himself or herself, had it not been for a physical, sensory, mental or intellectual disability.

People who are dependent on others for the most basic needs of life face prejudices. Given their physical dependency it is easy to reach the conclusion that they are also dependent on others emotionally and intellectually. Somebody who cannot pull up his or her pants like a small child, may be treated as a small child in other respects as well.

The result is often over-protection and custodial care where other people make the decisions for them.

It is no surprise then that the Independent Living philosophy is most easily grasped by people who are dependent on assistance in their every-day lives. This is also the reason why the Independent Living Movement emphasises the importance of the quality of assistance for users who want to achieve maximum independence. In order to provide an operational definition for quality, the Independent Living Movement coined and defined the term "personal assistance":

> ’Personal’ assistance means that users exercise the maximum control over how

services are organised and custom design their services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the individual user decides

- who is to work,
- with which tasks,
- at which times,
- where and how

Thus, the individual user must be able to recruit, train, schedule, supervise, and, if necessary, fire his or her own assistants. Simply put, "personal assistance", means that the user is the boss.

It is recognised that users with learning or mental disabilities will need support from third persons with these functions.

Personal assistance enables users to take their rightful place in family, at work and society with all the rights and duties that the general population takes for granted. With personal assistance persons with significant support needs need no longer be a burden on their families. Parents, husbands, wives and children do not need to stay at home and sacrifice their careers or education. Personal assistance users not only manage on their own, they can also take their share of household and childrearing. With personal assistance we can attend school and educate ourselves, enter the labour market and become tax-payers. When we fall in love, our partners need not fear that they are about to sign up for a life-long 24 hour job.

Most existing services cannot be called "personal" assistance, since they are not custom-made to the individuals needs and do not allow control and acceptable choices. Most often users are not in the position to recruit their own assistants. Instead. they have to accept assistance from the available staff. This is true for both stationary institutions or their "ambulatory" counterparts - the community-based services of local governments or voluntary organisations. Inherent in these solutions is their hierarchical structure with the user at the bottom. Users are forced to share the common staff which, in itself, reduces choices and freedom of movement.

Other limitations exist when assistants do not have proper employment contracts and wages. Then, users can neither demand quality work, attention and reliability nor can they feel in charge.

Direct Payments

Today, most assistance services control and limit the lives of disabled people, making them dependent and helpless. The solution is for them to take a position where they no longer have to adapt their needs to the needs of the service provider but instead shape their own services according to their own needs.

Turning into "personal assistance" requires a fundamental shift in the distribution of power between user and provider. One precondition for this change is an altered self-perception of the user of the services. Instead of seeing oneself as the passive object of other people’s interventions, the user needs to be actively in charge of his or her own life. The best help in facilitating this change is peer support. The other precondition is having access to the funds it takes to hire one’s assistants. Both requirements go hand in hand.

Direct payments must be arranged in such a way that all disabled people have equal access to them. They should be available to people of all ages and social backgrounds, and without regard to the persons income.

In order to have access to the necessary money we need to redirect the resources which are used in the disability field today. Instead of passively receiving services, the :individual user needs to have the money which these services cost. With the same amount users can achieve a better quality of life. With money in their hands, they can buy services from the provider of their choice. Or they hire, train and fire their own assistants which is the most direct and effective control over service quality.

"Services in kind control us, direct payments empower us".

Resistance to the simple idea of direct payments has been strong given the vested interests of many service providers and the wide-spread prejudices against disabled people according to which they cannot act in their own best interest and need to be "taken care of".

Direct payments are truly the state of the art when it comes to enabling persons with extensive disabilities to reach self-determination, integrity and full citizenship.

Analysis

Based on a survey of Personal Assistance services, discussions and study visits in group 5 and the ENIL (European Network for Independent Living) meeting in Stockholm 1996.

A review of the legislation in place in each of the European Countries involved in Helios shows a wide variety of funding mechanisms both between different countries and within them.

Group 5 concluded that, irrespective of the resources available to each country, their geography, history and attitude there are a number of common factors which need to be considered when eliminating socio-psychological barriers which prevent disabled people from exercising their rights as citizens.

Legislative and financial basis for the funding of PA Systems

In most countries the right to financial support depends on a combination of a medically determined level of disability which is administered nationally and which is statutory and a discretionary contribution towards ’social needs’ which is paid locally. In almost all countries the level of financial contribution is not sufficient to enable the disabled individual to lead a life as a participant in their society. In many cases discretionary contributions are reduced when the individual has other income funding is therefore not universal. Many countries have funding mechanisms which enable disabled people to employ their own Personal Assistants but legislation is variable, for example in several countries the funding available makes it difficult for PA users to cover such costs as administration, emergency cover, insurance, PA holidays etc. and an implicit assumption is made that they will be employed informally. In Sweden and Finland (amongst others) the full costs are covered but there is a growing emphasis on reducing costs by limiting the number of hours paid for. Many countries have a maximum limit to what they are prepared to pay which might be determined nationally or locally or both.

The review highlighted significant regional variations within countries which depend on geographical location, the availability of and competing pressures on local authority resources and their political makeup. This was even the case where high levels of funding were generally available in the country as a whole. In most cases there are no national guidelines or legislation which dictate how funding is to be provided (for example in the UK the new Direct Payments Bill only allows Local Authorities to decide whether they will use the system). It is often difficult for disabled people to move from one area to another as they may then lose their funding and be forced into more institutional support. This places a significant restriction on their freedom of movement and ability to choose where they live. In some countries access to personal assistance is limited to support within the home -for example Belgium - no assistance is provided outside the home.

In some countries the maximum limit on funding implies that disabled people who require more support should ’consider’ the option of institutional care.

Few countries have systems in place which take account of disabled people with intellectual disabilities - where PA systems exist for this group the role of PA employer is often taken by relatives - no country recognises the need for independent advocacy to the extent of providing significant funding for it.

The training of Personal Assistant Users and Personal Assistants

In countries where the use of Personal Assistants has become commonplace (for example Sweden) there is a requirement placed on the PA user by some agencies managed by disabled people to undertake training in the management of staff. In other countries little support, advice or training is given to PA users in managing their staff. This has negative consequences both for the PA user and for people employed as PA’s (for example the UK). Other countries do not have legislation which allows the employment of PA’s (for example Belgium). The systems that do exist are therefore informal and do not provide for the training of PA users.

Training for PA users

Group 5 agreed that it is important both that PA users (and/or their advocates if they use them) should receive training in the management of Personal Assistants both in terms of administering payroll, tax and insurance and in terms of ’people management’. Additional support should be given to PA users through peer group support.

Training for PA’s

There are a number of models. In four countries this is almost entirely done by the user. In three countries it is done by the user with help from Co-ops or a voluntary agency. In the majority of countries there is no recognised training.

PA users within the group and PA users consulted by the group feel very strongly that they should have total control over the training that PA’s receive both because they wished to avoid over professionalisation of PA’s and because they are best placed to train PA’s to meet their specific needs. At the same time all members of the group recognise that some general training is required - for example to meet Employment and Health and Safety legislation in individual countries (e.g. basic lifting training and First Aid, driving). Some members of the group feel that where PA’s may be employed through agencies and working with people with particular disabilities (deaf, blind, intellectual) more specific training may be required such as communication, disability equality or signing. Where PA users find it difficult to communicate their specific needs personally to assistants some training could, for example, be provided through the medium of a video of the PA user.

How are assistants employed?

There are two basic models of employment for personal assistants: as direct employees, hired by the user; or as agency employees, hired via a co-operative or voluntary agency. Several countries had one or both of these systems. In both cases, the user makes the choice of worker, and has day to day control over the worker. These options are not yet available in some countries in Europe.

The traditional model of employment is for the local authority (or voluntary non profit or Private for-profit organisations) to employ care staff. In this case, the user does not have the same choice or control over the workers. In some cases, the workers are "refuseniks" (Conscientious objectors), people who have opted out of national military service and who are allocated to "community work" instead. This happens in Italy and Germany, for example. In the UK some workers are volunteers, recruited by a national agency, Community Service Volunteers. None of the contributors favoured this sort of arrangement except where disabled people where able to choose the volunteer / refusenik. Even then the rapid turnover of staff can cause difficulties.

All countries have some sort of assistance provided by the local authority, although it is limited in scope in some.

Recruitment is done in various ways. Direct advertisement seems most common, word of mouth or employment agencies are also used.

Conditions of service

In countries where the money available to hire assistants is sufficient to meet full wages costs (Sweden, Norway, for example) workers have standard contracts based on national labour laws.
In several countries, the money available to hire assistants is not sufficient to meet full wages costs. People therefore work in the ’grey’ economy and do not have standard contracts. This has a detrimental effect on the quality and reliability of the service.

Many people employ family or friends as and when required, using the social security payments available to them. Because these amounts are usually small, the employment is not formal. This happens quite often in Austria, France, Italy and the UK for example.

Where assistants are employed by the local authority they have standard contracts. In some countries wages are equivalent to those paid to basic nursing staff and in others they are significantly lower.

In some countries, anyone can be employed as a PA. In others there are restrictions, for example the UK limits the employment of family members as personal assistants.

Who chooses the assistants?

This is the major issue for most users. In schemes where the user has a direct payment to employ workers, the user makes the choice. Some respondents stressed that the user and only the user, makes this choice. A few others said that the user chooses, sometimes with help from the voluntary organisation or co-op. But in several countries, there is no choice. "Assistants are sent by the services". In some schemes there may be a chance to reject a particular worker if you do not like them but choice is limited.

Consistency across one country

In several of the countries, both good and bad practice co-exist. The standard of service available may depend on where you live, your age or your impairment. Regional variations were noted in Italy, the UK and Germany. In Austria, the law was drafted to try to stop regional differences and to form a

’partnership’ between central and regional government. Even in Sweden, where one law covers the whole country, rural areas do not offer the same level of service as urban ones. Age restrictions on direct payments apply in most countries.

Resources

In most, if not all, countries the resources available for independent living are not so great as those available for supported or institutional living. In many countries the financial regulations favour institutions, for example in Germany the fee charged by residential homes can include an element of capital costs, for buildings, whereas the fee charged by a personal assistance co-op can not include any capital costs. In some countries institutional care is offered by charitable and religious organisations; these bodies do not offer money for personal assistance to support independent living. (In some countries charitable bodies are now starting to provide ’assistance’, but this is not usually under the direct control of the users.) In those countries with a well established state welfare system, the bulk of spending is on assistants employed by local government. Relatively small amounts are spent on supporting disabled people to employ their own assistants. Few countries provide funding for the initial development of user led PA organisations.

When this is added to the problem of under financing of individual care packages, so that users are forced to employ people in the "grey" economy, it is clear that the financial bias against independent living is strong.

Support for the PA user

There are three types of situation: countries with a well developed PA service in all or a part of the country (Sweden, Norway, Germany, UK, Finland) countries with a PA service at different stages of development, (Belgium, Italy, Austria, Iceland and France) and countries currently with no PA service (Greece, Portugal, Spain).

Amounts of support available correspond with the level of development of PA services .in the country. Slightly less support seems to be available in France and Austria than in Belgium and Italy. However there are always significant regional variations in all countries.

In a number of countries, there are Centres for Independent Living and/or Personal Assistance Support Services. CILs are always controlled by disabled people; PA Services are often controlled by disabled people but are sometimes run by the local authority or by a voluntary organisation (NGO). These sorts of scheme are also to be found in ltaly.

Who informs people about independent living programmes?

In five countries an organisation of disabled people (CIL or PA Services) provides information but this is mostly concentrated in urban areas. In three countries the local authority provides information. In other countries it is down to the individual to seek out the information.

What help is there for users in relationships with personal assistants

In six countries there is training available via CIL or PAS. This is also available in some regions in Italy. In other parts of Italy and in some other countries there is support from the local authority or from charitable organisations. In at least two countries there is no help at all.

Training available varies within countries too, because it is usually available only from specific local organisations.

All countries with a CIL stress the importance of peer support, not just for training but for ongoing support for users. The ability to share experience, and to support one another through difficulties, and find solutions to problems, is highly valued.

What help is there for user in legal disputes

Only four countries have formal legal help available, via the CIL. Some other countries have citizens' advice or rights offices. In most it is up to the individual to use what general legal aid is available. Several CILs reported a need for legal aid fund, to help users who get into disputes.

Help for users with intellectual impairments

Some counties use a "deputy" or "advocate" to assist. Quite often a relative will play this role. In five or six countries there are schemes serving people with learning difficulties, but these are all small in scale. In at least three countries users must be intellectually capable of managing their own schemes.

Some examples of good practice in involving people with intellectual impairments exist in the Netherlands, Sweden and the UK but this is rare.

Conclusions and Recommendations

General Conclusion

Personal Assistance as defined in this report is an essential factor for the independent living and empowerment of disabled people as active and responsible members of their local communities and society as a whole. It enables access to employment, leisure, education and social interaction.

Conclusion

Direct payments are intended to give the user autonomy and power. It fellows that the user should be able to choose how to spend the payment, including hiring family members if that is their choice.

High service quality is only possible if training for PA users and PA’s is being provided by organisations of disabled people.

Disabled people need access to information about the opportunities for independent living.

At the present time the majority of resources are devoted to institutionalised services. This disempowers disabled people and is not an effective, efficient and economical use of these resources.

Disabled people require a range of options from which to choose the best personal support system for themselves.

Countries which are still developing services for disabled people now have the opportunity to learn from good practice identified in our study.

Recommendations

- All countries must recognise the right of disabled people to user controlled personal assistance. In the same way as their citizens have the right to education and health care.
- Statutory authorities should have a legal duty to ensure that accessible information is available on independent living and the range of options available.
- The state must finance networking between disabled people and their organisations (eg. peer counselling and advocacy).
- The state must finance the development costs for Personal Assistance and Independent Living advisory services.
- Resources must be moved from institutional services to independent living services including personal assistance as defined in this report.
- Financial support should not be based on a medical definition of the disability. As far as possible it should be based on the disabled persons assessment of the support that they require in order to live the life which they want to live as responsible citizens. It should be available to reduce the barriers which prevent this.
- The funding available for the employment of Personal Assistants should be identified and paid nationally - it should not depend on local priorities or agenda.
- Funding and information should be transferable within and between European Community countries.

- The control of personal assistants should lie with the PA user (within the requirements of national / European employment legislation) or their chosen representatives.
- Any direct payment provided for the employment of personal assistants should reflect the resources required to provide formal employment (e.g. the right of the employee to have paid holidays, insurance and sickness benefit) and appropriate backup systems.
- Existing and future Direct Funding and PA systems must be widened to include all disabled people irrespective of age and disability; this may include the development of appropriate advocacy and self-advocacy.
- Training provided by disabled PA users should lead to credits towards European / National Vocational Training Qualifications.

Appendices

Appendix A:

Address list of the participants in Group 5

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Appendix B

Summary of survey of personal assistance services in Europe

Description and Evaluation of the Best Personal Assistance Service in Your Country

Stockholm 1996

Participating countries:

- Austria
- Belgium
- Finland
- France
- Greece
- Iceland
- Italy
- United Kingdom
- Sweden

Questions

A. Legislative and financial basis

1. Purpose of legislation
2. Legal basis for the funding of the p.a. program
3. Financial responsibility
4. Eligibility criteria and needs covered

5. Who assesses needs and how?
6. How much money is paid and how often ?
7. Does the amount depend on the user's/user's family income ?
8. Money flow and its control
9. What costs are covered (e.g. back wages. full wages, employer's social insurance fees. employer's administration assistants' costs when accompanying user) ?

Answers

France

1. Financial compensation of the personal help in relation with the percentage of disability.
2. Origin of the disability and no need of the person. Blueprint law 80/06/75.
3. Social Security for the general system, social support (Department) for a disability which is the consequence of an illness.
4. Recognition of the disability rate by the technical commission for the professional replacement (COTOREP). Cover of the real needs is not taken into account.
5. No evaluation of the needs. Evaluation according to medical criteria.
6. Allowance ceiling for a third party at a full rate, >4000 FR. monthly.
7. No, except for disabled workers.
8. Present trend: control of the use of those funds for the use of a third party.

9. Reduction of social contributions and the income tax of the disabled person.

Austria

1. Since approximately 350.000 persons in Austria need help or care a federal law concerning care allowance was enacted in 1993 to meet at least part of the expenses of necessary care without consideration of income to enable independent life as far as possible for persons with a deficiency.
2. ---
3. State and federal countries.
4. Seven levels (level 1:50 - 75 hours help needed per month, level 7: more than 180 hours monthly); care and help in daily life.
5. Public health officer (medical doctor).
6. Between ATS 2.635, - (level 1) and ATS 21.074, - (level 7) monthly (twelve times a year).
7. No.
8. Money goes to the bank account of the user; there is no control whether the money is used in the intended way.
9. It is not enough money to pay normal wages, social insurance, etc. It is rather like pocket-money for relatives or friends providing care in the case of a severe handicap. If the disability is not very severe part of the needed support can be financed (Social services, help with household chores, home helper services).

United Kingdom

1. ,
2. Legislation is still being developed. Currently the legal basis for funding is the NHS and Community Care Act. Since this specifically prohibits direct payments to p.a. users money has to channel through a "third party" (an organisation of disabled people). Legislation is currently going through Parliament to allow direct payments. There is also provision for a limited form of direct payments, the Independent Living Fund. This does not represent the best personal assistance service available, but it is widely used. This response does not refer to the ILF; it is based on schemes in London local authorities.
3. The financial responsibility is taken by the Social Service department of the local authority.
4. The basic eligibility criteria are that the person is in need of "community care" services, and is both willing and able to direct their own personal assistance. The best (but not most) schemes cover people with any form of impairment and all ages of adult. Needs covered are personal support, domestic support. The best schemes also cover social needs such as going out, writing letters.
5. Needs assessment is usually by a "care manager". In best schemes the user will set out her own assessment and will discuss this with the care manager. The user Will have advice from an organisation of disabled people on assessing their own need. (See also Section C).
6. Money is paid either monthly or quarterly. The amount is paid on assessed need at an agreed hourly rate. The agency rates in London are weekdays 8.00 am until 10.00 pm £6.31 per hour, weekends £6.59 per hour. Sleep-ins Weekdays £4.12 per hour, weekends £4.30 per hour.
7. Local authorities may apply a means test (there are no national criteria on this as yet). Most

authorities expect the user to contribute a portion of their disability benefits to the cost. Authorities may not take family income into account only the user’s income.

8. Users keep time sheets and wages records. Most schemes require users to open a separate bank account for direct payments, so that payments in and out are easy traced. Auditing is carried out quarterly in some schemes, annually in others.
9. No scheme covers all costs. The best ones cover national insurance, agreed wages, recruitment costs, limited holiday pay and a small amount for administration.

Belgium

1, 2, 6, 8. The Activities of Daily Life services (AVJ): Brussels, Wallonie and Flanders. The AVJ services are non profit associations and are rules on three different legislation basis:

> Brussels: 16th May 1991 Law (Official Journal - 1.8.1992), Decree of the gathered College of the C.C.C.. - 21.10.1993 (official Journal - 23.12.1993). Number of AVJ places : 50. Staff norm : 0.8 full time per service’s user and one full time coordinator. Subsidy: +/-1 .000.000 BF per user/year. Age maximum of the users : 60 years. However, the people who reach 60 years in the AVJ service could continue to benefit of it.
>
> Wallonie: Decree of the "Executif de Ia Communaute Francaiso" - 9 September 1991 (Official Journal - 24.1.1992). Number of AVJ places :165. Staff norm: Not yet fixed. Subsidy : Not yet fixed. Age maximum of the users : 60 years. However, the people who reach 60 years in the AVJ service could continue to benefit from it.

Flanders: Decree of the ’Executif Flamand" - 31 Juliet 1990, 21 November 1990. Ministerial Decree (Official Journal - 30.4.1991). Number of AVJ places: 250. Staff norm : 9 full time for 12 up to 15 users and one full time coordinator. Subsidy : +/- 1.000.000 BF per user/year. Age maximum of the users : 65 years. However, the people who reach 60 years in the AVJ service could continue to benefit from it.

8. They are granted by the regions through the Social Welfare. The subsidies are administered by the service in order to give the AVJ assistance to the disabled persons.

7, 9. In Brussels. the user financially contributes to the services (max. 3000 Bf month) but it does not cost anything for the people having incomes lower than 500.000 Bf. In Wallonie. the financial contribution is 1000 Bf max./month and the services are free in Flanders.

5. The service is addressed to disabled people being able to determine their own demand, who need a minimum of 7 hours of AVJ assistant per week and this is only a physical assistant notably in the following domains: getting-up and to bed, toilet, meals, mobility transfer, various activities, so that they could lead the same life as a valid person. A contract is signed between the user and the service, in some AVJ services, in which the user determines his AVJ demand and the frequency of it. By this contract, the service engages itself in providing this assistance.

Italy

1. The Italian Framework Law on Disability (5.2.1992, no 104) provides in its article 9 that municipalities and local health and welfare authorities have to implement services of personal assistance.

2. Regional laws and regulations plus Local Health Welfare Authorities and city/ municipality regulations.
3. Municipalities according to the economical possibilities; regional regulations.
4. All citizens in temporary or permanent severe limitation of their personal autonomy: people without any support (especially from family) or in the situation of disability or illness; live in family but in situation of uneasiness.
5. Social service of Municipality: through domiciliary visit after request made by user, his/ her family or after any indication made by voluntary organisation or any other citizen.
6. The cost of the service, depending on the Municipality can be free. When paid, usually it is done every two or three months, sometimes also yearly. The user's or family's contributions covers usually not more than 20% of the whole cost of the service.
7. In almost all cases there is a co-financing/contribution given by the user according to his/ her income. In few municipalities the cost of the service depends on the whole family income.
8. The control is made by the social service department of the municipality or who sends the invoice with all costs defined to the user.
9. Usually the service delivery system covers more than 85%of the costs. Each Municipality has its own regulation and cost rates. The user, depending on its income, covers the rest of the cost.

Iceland

1. Purpose of legislation is to ensure to the disabled, equality and living conditions comparable with those of other citizens, and to provide them with conditions that enable them to lead a

normal life.

2. ACT on the affairs of the handicapped no.59 1992 form a legal basis for funding of p.a. programs.
3. Local authorities shall, within possible means, give the disabled the option of personal assistant services and thus have the primary responsibility. In cases of special support needs, disabled people shall be according to the ACT given further personal assistance. Regional offices make decisions as to further personal assistance. Regional offices make decisions as to further personal support according to authorised budget expenditures at each given time. upon prior opinion from the Regional Board.
4. All persons who meet The National Insurance Institution's assessment criteria of disability (medical assessment). Needs covered are breaking through social isolation and various kinds of assistance concerning the multiple functions of daily life, if such assistance is needed to prevent institutionalisation.
5. Local social service assesses the needs concerning social participation. Regional offices (on behalf of the Ministry of social affairs) assesses the needs for assistance in functions of daily life.
6. The amount per hour is determined by the wage contracts of supportive assistants. Paid monthly.
7. No, it does not depend on income, it depends on the quantity and quality needed and the money the authorities are willing to put in it.
8. The control is in the case of social assistance made by each local social service. For personal assistance in functions of daily life the money flow is controlled by the Regional offices on behalf of the Social Ministry which decides the total amount for each Region. Money can be paid directly to the user, the user's family or to the user's service provider.
9. Full wages are covered but recruitment costs and administration costs are not. It is up to the different local authorities if and how much there is paid for assistant when accompanying the

user.

Finland

1, 2. Act on Services for Persons with Disabilities, which states that the local government has to provide all persons with extensive disabilities with some kind of housing and assistance. The act does not say how the assistance should be organised and one way of doing this is through the personal assistance. There are other ways but they do not have as much user control as the personal assistance scheme does.
8. According to the Act the local government has to cover the costs due to hiring a personal assistant.
4. Anyone with an extensive disability is covered in principle. There are no limitations of age or type of disability. The user can define the duties of the assistant as she/he likes. The system covers personal needs. household work, education and employment.
5. Usually the user writes an application defining his/her needs and a social worker in local government assesses those and sees how they are covered. The need for a Personal Assistant is measured in hours per week.
6. Salary paid every month according to the hours worked. It is common to set a limit of 40 hours per week although the best systems cover more.
7. Payment is not means tested.
8. In some places the money is paid directly to the user who then pays insurance, taxes and salary to lesson the administrative duties of the user some places have a system where the local

government pays the salary of the assistant directly (including insurance and taxes) but the user always remains the actual employer and retains control.

9. The local government covers full wages (inc. holiday pay), insurance and taxes. It sometimes covers the cost of recruiting and costs of the assistant when accompanying the user (e.g.. entrance fees) it does not cover higher pay for Sundays or night time work or for administrative costs.

Sweden

LSS The Law of Special Support and Service to specific disabled people, LASS - The Law of Assistance Cost Funding. Purpose is to enable persons with extensive disabilities to have a ’good quality of life’, that is to become more independent of their families, move out of institutions and become productive citizens. The law was inspired by the Swedish Independent Living Movement. LSS gives the user the legally guaranteed right to receive funds for PA.

The National Social Insurance is funding (depending on the LSS) the costs for persons who have the right to use more than 20 hours (PA) per week, it is also responsible for health insurance, pensions etc. The insurance is financed by state income taxes.

All persons up to the age of 65 who need a minimum of 20 hours per week for such basic tasks as dressing, bathing, eating, communicating etc. have the right to personal assistance. A total of 6,200 persons are entitled to benefit. Persons with fewer then 20 hours per week requirement can apply to their local government for a similar scheme but in this case the user has no legal right to receive cash payments - the services may be provided in kind instead. Local Government is also only obliged to ensure a reasonable quality of life and fewer hours of assistance may be granted.

Assessment is conducted by trained staff from the Social Insurance. They are to consider a persons total life situation including the users responsibility within the household, at work and in leisure. Need is expressed in the number of hours per week. Assessment also includes the length of the accounting period within which the user can dispose of hours, save or spend as they wish.

The maximum amount per user hour is determined each year by central government and is presently (1996) 21 ECU’s.

Benefits from Social Insurance are not means tested.

The monthly payment from the Social Insurance can be paid directly into the users bank account or, at the discretion of the user, to the service user’s provider. At the end of each month the user has to send the Social Insurance a signed statement specifying the amount of money received and spent (hours used). At the end of the total accounting period excess hours must be reported and this amount of money is subtracted from the next payment. Social Insurance can audit service providers.

Question

B- Service delivery

1. Who can work as assistant?

2. What types of employment contracts exist?
3. Who is the employer?
4. Who recruits the assistants, how?
5. Who trains assistants, how?
6. Who Schedules, supervisors assistants, how?
7. Can the individual p.a. user choose his/her assistants?

Answer

France

1. Daily life help trained for this service; untrained assistant; family members who are not particularly competent.
2. Salaried contract with providers of services or individual contract in case of a direct job;
3. Providers of services associations or individual employer, or local communities.
4. Various systems according to the situation.
5. There is a vocational training certificate for the assistance to disabled people (CAFATH).
6. Providers associations or disabled persons;
7. No, except if he is himself an employer.

Austria

a) relatives, neighbours and friends - without wages.
b) persons who are sent by home helper services, organisations which provide care and assistance, etc.

1. Full time jobs, Part time jobs, Fee contract.
2. Social Services, Private organisations.(the user would need a very high income of his own to be able to employ one or more assistants).
3. Social services, Private organisations, etc. in their usual manner.
4. Social services, private organisations, etc. in courses, or the employ nurses,
5. Social services, private organisations.
6. Assistants are sent by the services, the user may reject one or two, but then.

United Kingdom

1. Usually anyone EXCEPT close family living in the same house as you. (A few schemes allow this), but it is not encouraged as it is open to abuse by relatives and experience shows that employing a member of the family does not work.
2. Workers have a written contract: in UK law this does not give them many rights, but it sets our

hours of work, rates of pay, allowed time off, etc.

3. The user.
4. The user, either by direct advertisement or with the help of an advisor from PAS (see section C).
5. The user, sometimes with the help from PAS.
6. The user.
7. The user, sometimes with the help from PAS.

Belgium

1, 2. The staff have a secondary school diploma and an employee contract.
3, 4. The employer is the non-profit association and, through it, the disabled persons who make part of it.
5. There is no training school for the formation for the assistants. The AVJ assistants are trained directly on their entry into the service. Some demands have been made to the respective Ministries in order to put into place trainings following the scheme designed in Hereford.
6. To the minimum, the half of the governing board of the AVJ services is composed of the disabled persons, who are essentially users of the concerned services. This gives to the members a decisional power about the engagement, the work to be done, and the assessment of the assistants during a prove period, permitting them a real control on the quality of the service and on the daily and financial management. This users' involvement and responsibility meet, for a great part, the goals described in the Declaration of Madere.
7. The AVJ assistance is given 24/24 In the user's private home who lives either alone or with his family and organises his autonomy.

This is the user who decides the moment where he wishes to receive the assistance and how it will be given; however, he doesn't have the choice between the assistants of the team who are on duty.

Italy

1. Every person over 18 years of age can become an assistant.
2. According to the employer, public or private contract: full time, part time, temporary or permanent collaboration job.
3. Municipalities or Local Health and Welfare Units that manage the services directly or through an agreement with social co-operatives of services. The social co-operatives or user organisations directly. The user or his/her family.
4. Through a direct contact, after an interview or (if public), through public competition.
5. Usually the Regional Government organises two year courses of more or less 720 hours with theoretical lessons and practical stages. The organisation of such courses is made by Local Health Units or Cooperatives. User organisations are involved in the elaboration of the educational programme or to bring forward some lessons or specific themes of the courses.
6. The organisation of the services is usually scheduled by the organisation responsible for the delivery of the service. There are controls made by Local Authorities if the service is delivered by a private or voluntary organisation. The supervision is made by social workers or by any other person responsible of the service.
7. The "feeling" between user and service provider is taken into account by the responsables of the

services.

Finland

1. Anyone can work as an Assistant, including a family member although this is not encouraged.
2. A written contract. The law gives specific rights to workers such as time off, holiday pay, insurance, minimum wage.
3. The user
4. The user. Advertisements and employment agencies can be used.
5. The user while the assistants are at work.
6. The user.
7. Yes.

Sweden

Anybody. organisation, company or person can deliver services. There are no requirements as to qualifications. Only limitations relate to age (> 1 8) and the total number of hours worked during the month (Swedish labour laws).

Employment contracts (agreed between unions and employers) can be full or part time, monthly employment and severance payment at end of employment or payment per hour.

Social Insurance funding can be used to purchase services from a provider (local government, private company or user cooperative). In this case the provider is the employer of the assistant. An individual user may start up their own company which is, then, the employer.
The service provider. Often users can express their wishes as to which assistants they prefer. In some models (e.g. STIL) the individual user is solely responsible for recruitment. The individual user can advertise in any way.

In STIL's user co-operative the individual user is responsible for training assistants according to individual users need. The only common training is in ergonomics (lifting). Users either use experienced assistants to train new ones or, as recommended by STIL train each assistant themselves.

In STILs user cooperative model the individual user is solely responsible for scheduling, supervising, motivating and retraining assistants.

STIL allows the individual user full freedom over the recruitment and scheduling process. It is up to the user to decide who will work, when and with which tasks.

Questions

C. Support for the individual p.a. user

1. How are users informed about program and their rights?
2. Legal aid for users in disputes with funders, assistants, service providers?
3. Training of p.a. users.
4. Support of p.a. users in conflicts with assistants.
5. Support of p.a. users with intellectual disabilities in managing their service?

Answers

France

1. Not informed except through an individual step.
2. No.
3. No.
4. No.
5. Yes, within a continuation service.

Austria

1. They must seek information, look for advice and help themselves.
2. None known.
3. None Known.
4. Social Services, private organisations.
5. There is none.

United Kingdom

1. Usually by the p.a. advisory service (organisation of disabled people). Sometimes by the care manager (employed by the local authority).
2. No automatic legal aid; can use PA advisory service, and local authority complaints process; is possible to challenge local authority in court but it is a complicated procedure and there are only a few users to do this.
3. The best schemes are supported by a personal assistance advice and support service, (PAS) always run by organisation of disabled people. They provide training for users in self assessment, budgeting, managing workers etc. Many PAS provide payroll service (GAO).
4. PAS service will help mediate disputes, support users in managing workers.
5. PAS service will ensure advocacy available when needed.

Belgium

1. The service convention processes the rights and the duties of the users as well as the modes of the work execution. The AVJ assistants are submitted to a working regulation which puts in value, between other, the AVJ service philosophy.
2, 4. In the case of a conflict, both parties must attempt to find a solution; if it is not possible, the service responsible or else the members of the Governing Board will intervene according to the importance of the problem.
3, 5. There is no formation for the users. Every person must be capable of managing his life independently and his assistance demand to the service (no user with intellectual disabilities).

Italy

1. Each Municipality has the obligation to promote the service with any kind of resources. Many times, to avoid mistakes or lack of information, voluntary associations promote the extension of the services.
2. The largest Municipalities, but in all Province Councils there are "Right of the Citizens Offices". Usually the citizen goes directly to his/her Municipality.
3. At the moment there are few experiences (like Prisma’s independent living courses). in which in the educational programme, there is also the training of users.
4. As above and user organisations.
5. As no.3 above and user organisation.

Iceland

1. Regional offices have the role of informing all disabled people about their rights and programs available. Various disability organisation inform their members about their rights.
2. There is no built in right to legal aid. Some disability organisations provide legal aid. Low-income persons can get legal aid paid by the local social services.
3. Until now there is no special training of p.a. users.
4. Disability organisations support users. Region offices have the contradictory role of providing service and supporting the users.
5. Relatives often take the role of deputy. Disability organisations also have a strong supporting role.

Finland

1. The independent Living Centres and some other disability organisations spread information about the system.
9. The ILC in Helsinki has a lawyer who specialises in this.
8. The ILC organises courses for PA users where they are informed about their rights, shown

how to assess their needs and informed about the duties of an employer (e.g. Accounting).
4. The ILC's have various forms of peer support for this such as discussion groups and a telephone service.
5. Does not exist.

Sweden

The LASS law charges local governments with the task of informing persons who might be eligible for the payments. Also, disability organisations inform their members about the program and their rights. STIL conducts courses, distributes literature and has staff to answer questions during office hours.

According to Swedish law legal aid to low income persons cannot he granted when the persons appeal against Social Insurance decisions. Some disability organisations including STIL do have staff on hand who will assist the individual to appeal against decisions.

Is not legally required but membership of some user controlled cooperatives (e.g.. STIL) requires members to graduate from a ’supervisor course’ which prepares the user for becoming a supervisor of his/her assistants.

STIL members have access to support from staff consisting of experienced PA users. Peer group support sessions are conducted on the most frequent problem areas with assistants. There is also a ’buddy’ system where inexperienced members are linked to experienced PA users.

In STIL there are a number of members with intellectual disabilities. In most cases a legal representative (often a relative) will take on the function of recruiting, training. supervising assistants. In some cases where this support has not been strong STIL has tried to assist with a ’deputy supervisor’ the deputy supervisor is, in turn, supervised by STILs own staff.

Questions

D- Evaluation

1. What are the problems with this particular solution?
2. How can this p.a. solution be improved?

Answers

France

1. Everything has to be done in that field.

Austria

1. The "care allowance" does not enable financing all the help needed. Families still have to supply the majority of support. Users cannot choose or train their assistants.
2. By user co-operatives and peer support.

United Kingdom

The current problem is legal bar to direct payments. It is hoped this will be soon be removed. The other major problem is lack of consistent provision across the country. Each local authority can choose whether to offer a PA scheme and if so,. how to arrange it, also getting full costs of being a good employer is very hard.

Personal assistance is currently limited to a small group of users. There is a need to make the idea more well known. We need more PAS services to support independent living. Many schemes bar older people need more experience in this age group, maybe new sorts of PA service. Standards need to be set for PAS services.

Belgium

1. The problems which have been met are the following

   The personal assistant regulation is not recognised (which gives a limit into the choice of candidates : staff without qualification by lack of financial means).

   The lack of assistants training, as well as the qualification level is a difficulty for a good performance of the services in the regions of Brussels and Wallonie.

   The lack of users training does not encourage them to take responsibilities within the non profit association.

   The AVJ assistance is only given in the user's home and in the immediate environment. No assistance is foreseen to the outside, at work, during leisure time. That is why in Flanders, a complementary budget is wanted in order to benefit of an assistance outside of the dwelling. The environmental accessibility is really limited or missing (sidewalks, transport, stores).

Italy

1. At this moment in Italy, there is no service of p.a. as denied in many European countries. The description and evaluation made in the previous points are on the service of domiciliary assistance, delivered both to disabled people and the elderly. We can have many examples of a service that is very similar to a service of p.a. The problem is that the users has very little time -

some hours per day or even less (some hours per week). In fact, the services are still very far from what we consider p.a. (the user chooses directly the assistant), but more and more domiciliary care services, with its polyfunctional figures is giving an answer to the needs also of the disabled. The new Framework Law on disability takes into account the p.a. service: now it is time to start it and user organisations are planning an important role in promoting it (also managing innovative experimental services).

2. The Domiciliary Care service is guaranteed in most of the county. More and more this service is being developed in order to give more autonomy to the user of the service (elderly first, and then disabled). There is a need to start with services of p.a. on an experimental basis. In parallel training courses for the users must be developed. Some user organisations and some local authorities are moving in this direction.

Iceland

1. The personal assistance system was legislated in 1992. It is by no doubt a very important step in moving from institutionalisation towards an independent life. In Iceland local authorities and Regional offices have taken a central role in providing the p.a. service. It may be a question of how successive a "providing of independence" can be. Authorities will always stress the importance of regulations, controlled money flow, schedules being looked after and so on and thus take the responsibility from the users.
2. There are yet not many users or users Co operatives employing personal assistants in Iceland, but the opportunity is there. Because of a small population (250.000 people) in a big island with

some 300 local authorities, it will be necessary to find ’Icelandic" models that work for the benefit of users autonomy and are strong enough to deal with the bureaucracy.

Greece

Description and evaluation of the best Personal Assistance Service in our country

Relating to the report about the description and evaluation of Personal Assistance Service in our country, we would like to inform you that in Dodecanses of Greece we do not have such a kind of system.

Our experience in the past contains a visit through Horizon Programme at "Centre Studi Prisma" in Italy, where two members of our association (a paraplegic person and a personal assistant), had a week general training. We were also informed by Prisma’s representatives at a convention in Rhodes.

We provide a personal assistant model through Social Exclusion’s programme, because our needs of this kind of service are various and original. In our territory we also have to face a concrete conception about people with extensive disabilities. This conception wants these people and their families locked at their houses with any way out or opportunity for independent living, education, entertainment etc.

We believe that in Dodecanses we will succeed to adapt this system according to our needs, culture and possibilities.

Finland

One problem is inconsistency throughout the country. It is up to local government to decide how the assistance is organised - through the PA system or through more old fashioned systems. We need to spread information about the system throughout the country.

Another problem is inadequate hours. The Assistance may be given for 40 - 60 hours per week although a real need might be for 80 hours or 24 hours per day. A problem related to this is the lack of Sunday and night time pay. We must make the authorities see that Personal assistance is less expensive than institutional care.

A third problem is that it is a fairly demanding task to be the employer of a Personal Assistant. Users need more information and support.

Sweden

Social Insurance: After the age of 65 the user has to turn to local government which often entails a lower quality of life. People with fewer than 20 hours a week requirement should benefit from the scheme. Recent changes have removed the right to PA whilst at school or day centre. Those institutions must now employ staff or use ordinary staff to assist users in school or day centre hours. We see this as clear leap backwards.

User cooperative models depend on the wisdom and enthusiasm of leaders. According to its constitution the management board must be 100% PA users. The scheme may deteriorate if there are not enough committed board members. t is also difficult to find qualified PA users to employ as staff. Availability of peer support depends on good and motivated members who work in this field.

Solutions delegates a great deal of responsibility to the individual member and the cooperative is therefore quite vulnerable if some members do not live up to their responsibilities and, for example, mistreat an assistant. If / when this happens the cooperative’s reputation suffers and labour unions might take action against us.

The rapid growth of STIL has led to a shortage of ’buddies’, ’deputy supervisors’, and peer support. Since STIL respects the right of members to run their own lives without interference they cannot be forced to seek help in managing their affairs - as long as they do not violate other members rights.

There is an increasing pressure (from the government) to reduce costs against which STIL lobbies and demonstrates. STIL is still in a process of growth and its quality will always depend on the members There has to be a ’critical mass’ of members with skills, motivation and solidarity.

Appendice C:

The Strasbourg Resolutions (1989)

Preamble

We, disabled people from The Netherlands, UK, Denmark, Italy, Switzerland, Sweden, France, Austria, Finland, Belgium, USA, Hungary, Federal Republic of Germany and Norway have come together from April 12 14 1989 at the European Parliament, Strasbourg, France.

This conference has focused on Personal Assistant Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence.

We, disabled people. recognising our unique expertise, derived from our experience, must take the initiative in the planning of policies that directly affect us.

To this end we condemn segregation and institutionalisation, which are a direct violation of our human rights, and consider that governments must pass legislation that protects the human rights of disabled people, including equalisation of opportunities.

We firmly uphold our basic human right to full and equal participation in society as enshrined in the UN Universal Declaration of Human Rights (extended to include disabled people in 1985) and consider that a key prerequisite to this civil right is through Independent Living and the provision of support services such as personal assistance services for those who need them.

The recommendations of the UN World Programme of Action (115) specifically states that "Member States should encourage the provision of support services to enable disabled people to live as independently as possible in the community and in so doing should ensure that persons with a disability have the opportunity to develop and manage these services for themselves."

Resolution 1 of the 43rd UN General Assembly (1988) reaffirms the validity of World Programme of Action, and Resolution 2 stresses That "special emphasis should be placed on equalisation of opportunities"

Considering these and similar recommendations from both The European Community and the Council of Europe and to ensure that disabled people within Europe should have parity of equalisation of opportunities we stress that these objectives must be achieved.

In support of the international movement of disabled people in Disabled Peoples' International which has a special commitment to setting up a network of initiatives for Independent Living as part of the implementation of equalisation of opportunities, we call on governments and policy makers to enforce the following principles:

1. Access to personal assistance service is a human and civil right. These services shall serve people with all types of disabilities, of all ages, on the basis of functional need, irrespective of personal wealth, income or marital and family status.
2. Personal assistance users shall be able to choose from a variety of personal assistance service models which together offer the choice of various degrees of user control. User control, in our view, can be exercised by all persons, regardless of their ability to give legally informed consent.
3. Services shall enable the user to participate in every aspect of life such as home, work, school, leisure and travel and political life. These services shall enable disabled people to build up a family and fulfil all their responsibilities connected with this.
4. These services must be available long term for anything up to 24 hours a day, 7 days a week, and on a short term, or emergency basis. These services shall include assistance with personal, communicative, household, mobility, and other related services.
5. The funding authority shall ensure that sufficient funds are available to the user for adequate training of the user and the assistant, if deemed necessary by the user.
6. Funding must include assistants' competitive wages and employment benefits, and all legal and

union required benefits, plus the administrative costs.

7. Funding shall come from one central guaranteed source, and be paid to the individual wherever he/she chooses. Funding shall not be treated as disposable taxable income, and shall not make the user ineligible for other statutory benefits or services.
8. The user should be free to appoint all personal assistants, whoever he/she chooses, including family members.
9. Lack of resources, high costs, substandard or non existent services shall not be used as a rationale for placing an individual in an institutionalised setting.
10. There shall be a uniform judicial appeals procedure which works independently of the funders, providers and assessors, and is effected within a reasonable amount of time and enables the claimant to receive legal aid at the expense of the statutory authority.
11. In furtherance of all the above, disabled people and their organisations must be decisively involved at all levels of policy making including planning, implementation and development.

Appendice D:

The Madera Declaration (1994)

The Philosophy

Rights

Everybody should have the right to personal assistance, as they do to health and to education - this right should be included in The Maastricht Treaty.

By assistance we mean the following:

> Assistance given by a worker in the activities of daily life which the disabled person cannot do because of his/her disability.
> For the physical/sensorily disabled person the assistance means assistance directed by the disabled person e.g.: getting up, preparing meals, travel to work, support at work, accessing community facilities, participating in a social life.
> For a person with intellectual disabilities the assistance may also include guidance (e.g.: utilising public services, budgeting) by a person of their choice.
> The group agree that every country should include such rights in their laws or constitution.

Choice

Every disabled person should have a freedom of choice.

Should have a variety of possibilities (e.g.: institution, Assistance in daily living, agencies or others).

To be able to be free to choose and enter into mutual agreements without compromising their autonomy.

Participation

The disabled person’s participation includes:
To have his turn to speak, to witness, To communicate

To intervene and to interfere in the organisation of the services which concerns

- his body;
- his house;
- The community

To act as a citizen

Self Determination (autonomy)

Living ones own life and having personal goals

Determining and defining ones own needs

Living ones own life without being excluded by a disability

Responsibility

To accept the consequences which arise out of free choice - these consequences apply to:

- His / her body
- Family
- Community

Control

Personal assistance budget: Disabled people must be able to set the priorities, to control and to be part of the decision making process in the use of public finance.

Personal assistance: The disabled person must be able to be a responsible employer, recognising their rights and duties. This includes the right to direct the personal, the assistant, and ensure that the quality of the service is satisfactory.

The services which may act as an agency for personal assistants: the disabled person must have The power to control and to be included in the management of the service in order to ensure that the service has the quality that the disabled person requires.

The means of control need to be clear and defined in consultation with the disabled person. There need to be clear boundaries, demarcation of responsibilities and relationships between those involved.

To this end there should be clear bilateral contracts between he disabled person (the consumer) and the provider.

Disability is a social phenomenon created by inaccessible environments and negative attitudes.

Society must:

- accept and value difference
- recognise that specific needs exist
- recognise that those needs are also of positive value to society
- be inter-dependent and take responsibility
- accept that the right to dignity, for compensation for disability, to education and employment require Personal Assistance
- Provide the means to do the above:
    - material / equipment
    - people
    - finance
    - in order that the disabled person may inhabit and enjoy their bodies and minds, house and community

The group also identified three other fundamental rights:

- To have the means of being equal
- To have a private and confidential life
- To be able to take risks

Means

Recognition of role of personal assistants

Assistance which compensates for the disability and is under the control of the disabled person.

e.g.: Independent Living Fund (UK), Cellules AVJ / Fokus (Belgium), Cooperative (Sweden)

Personal Assistants must have:

- Proper job
- Proper wages and conditions
- Employment protection
- Means to pay for insurance, holidays etc.

Information

- About how to achieve independence
- About the options available
- About rights (advocacy)
- Peer counselling - disabled people providing information in collaboration with professionals
- Sharing information between countries
- Good quality of information

Training

To develop training centres for disabled people working towards independent life.

- For the disabled person
- For parents / family
- For the community
- For PA’s - by disabled person, ongoing, basic and specific (To individual employer)
- For professionals - about the philosophy of independent living as part of professional training.
- About the best way of providing a good quality personal assistance service (mutual respect, confidentiality, health and hygiene, lifting techniques)

Finance

Income to cover daily needs (from employment or benefits/subsidy) separate from:

- Income for expenses incurred as a result of disability (Not means tested, 24 hours per day if necessary and untaxed)
- Income to fulfil family responsibilities
- Should not depend on family income
- Direct payments should be possible if wanted.

The working party recommends that this allowance is treated as a high political priority and that sufficient means are assigned.

Legislation

The group agrees that a European / National / Regional "regulation" would be the best guarantee of ensuring that disabled people have access to personal assistance.
That there should be European / National I Regional commission to monitor standards and evaluate the quality and effectiveness of personal assistance.

The legislation would also clarify the workers rights and responsibilities and the different types of practices which improve the autonomy of disabled people.

The group agrees that the administration of the rules of access to personal assistance should be separated from the agencies which fund personal assistance.

That there should be a separation of functions between resources available and assessment of need

Others

This points hereafter are of main importance for an independent life in the community but haven’t been treated here as they are making subject to the working meeting of other groups of HELIOS II:

- Adapted architecture
- Equipments compensating the deficiency
- integration in the community
    - transport
    - employment
    - leisure time
    - education

Recommendations

Recognizing the personal assistance

Governments to recognise and give priority to personal assistance as a way of improving the integration of disabled people

The EEC and National governments need to recognise and prioritise the role of Personal Assistance as an essential factor for the integration and emancipation of disabled people.

Transferability

The exchange of information and examples of good practice between all member states to promote and accelerate the process of the achievement of autonomy for all the disabled citizens of the European Community.

It is accepted that the same philosophy and principles will apply but that each country will need to find different solutions (subsidiarity)

Protect and enlarge budget for services for disabled people

The working group wishes that this allowance for personal assistance is recognised as a political priority and the sufficient means are assigned.

Job creation The use of personal assistants will increase the possibility of local employment.

Strategy to Promote our Recommendations

On two levels:

- At government level - Europe wide
- Through networks of disabled people - the consumers
    - Through collaboration between disabled people and professionals
    - Use media
    - Show disabled people in active role
    - Positive images can lead to positive action e.g.: Employment opportunities
    - Role in family

Appendix E:

The Hereford Paper on Training of PA Users and PA’s (1995)

Training of PA's	Training of PA users
Handling and lifting	Handling and lifting techniques
Health and safety	Health and safety
First Aid	Self asseniveness
Food hygiene	Self assesment of needs Peer counselling
Respect of private life and confidentialty	Communication skills
Communication: to listen and to make oneself heard	Recruitment: Interview techniques Job descriptions Person specification Application forms

Training in new technologies	Employment law and legislation Payment of wages, sick pay Insurance contributions Pensions Disciplinary processes Holidays Management Contracts Polce chocks Equal opponunities
Nonmedical and elementary knowledge of different kinds of disabilities and their practical and daily consequences	Assesment of the PA target setting Independent advocacy services, self advocacy
Knowledge of the reasons for the existence of the work	Human resource management and negotiation
Definition of the boundaries of responsibility (contract)	Money management
Practical experience and training in communication skills	Use of technology Time management, rotas
Awareness of rights and obligations	Peer group support
Reflection on motivation	
Ethics	

Training for both PA users and PA’s have some common elements, these are:

- Better definition of the goals of the training in order to achieve clarity of role
- The training starts and ends with the needs of the PA user
- There should be an emphasis on good communication
- Both parties must be clear about their expectations
- Training should be evaluated regularly
- There should be a code of practice and mutual respect
- The motivation of the PA should be evaluated

Agencies should be able to provide training where PA users have learning difficulties who don’t want to take responsibility

The PA user should control his/her PA’s training scheme

The training should be part of an EEC vocational training qualification.