# THE EUROPEAN DAY OF DISABLED PERSONS 3 DECEMBER 1994

# REPORT OF THE HUMAN RIGHTS PLENARY MEETING

EUROPEAN PARLIAMENT BUILDING, BRUSSELS, 17-18 OCTOBER 1994

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**FOREWARD** 

Extracts from the United Nations Standard Rules on the Equalisation of Opportunities for Disabled People.

"There are disabled people in all parts of the world and at all levels in every society. The number of disabled people in the world is large and growing...

Both the causes and the consequences of disability vary throughout the world. These variations are the result of different socio-economic circumstances and of the different provisions that States make for the well-being of their citizens...

Present disability policy is the result of developments over the past 200 years. In many ways it reflects the general living conditions and social and economic policies of different times. In the disability field, however, there are also many specific circumstances which have influenced the living conditions of disabled people. Ignorance, neglect, superstition and fear are social factors which throughout the history of disability have delayed the development of and isolated disabled people...

Towards the end of the 1960s organisations of disabled people in some countries started to formulate a new concept of disability. This new concept indicated the close connection between the limitation experienced by disabled individuals, the design and structure of their environments and the attitude of the general population...

States should recognise the right of the organisations of disabled people to represent disabled people at national, regional and local levels. States should also recognise the advisory role of organisations of disabled people in decision-making on disability matters...

The role of organisations of disabled people could be to identify needs and priorities, to participate in the planning, implementation and evaluation of

services and measures concerning the lives of disabled people, and to contribute to public awareness and to advocate change."

#### BACKGROUND

At the Special Plenary Sessions to mark the end of the Decade of Disabled Persons (1983-1992) at the United Nations General Assembly in October 1992, a resolution was passed declaring that 3 December each year will be the International Day of Disabled Persons.

The United Nations Commission on Human Rights, in Resolution 1993/29 of5 March 1993: "Appeals to Member States to highlight the observance of the International Day ...with a view to the achievement of the full and equal enjoyment of human rights and participation in society by persons with disabilities."

This compliments the aim of HELIOS: 'A Community action programme to promote equal opportunities for and the integration of disabled people' and in response to the European Union's interest, Disabled Peoples' International- European Union Committee (DPI-EUC) in collaboration with the Disability Forum was awarded a subvention by the European Commission to organise a 'European Day of Disabled Persons' as an integral part of the International Day.

Last year on December 3 the Parliament of Disabled People in Brussels, in its resolution, invited the Commission to initiate legislation for the adoption and implementation of the UN Standard Rules. This resolution has been recognised by the European Commission in its White Paper on Social Policy.

To further the implementation of the Standard Rules, this meeting of disabled people and advocates from the European Union was organised to ensure that the European Commission and the European Parliament had knowledge of the views of disabled people on these important issues.

It was decided by the European Day working party acting on behalf of the HELIOS Forum that 3 disabled representatives, or parents of disabled children, should be selected from each of the Member States through the national councils on disability. In addition, one disabled representative or parent should be selected from each of the twelve European NGOs.

These representatives of 24 European and national disabled people's organisations met at the European Parliament Building in Brussels on 17 and 18 October to debate four major human rights' issues and to launch a new campaign throughout the European Union.

This report documents the proceedings of this meeting and provides a focus to the campaign with its launch throughout the Union on 3 December. The four major issues addressed are: a European definition of disability; eugenics, bio-ethics and euthanasia; Independent Living; and sexuality.

It was requested that where possible the appointed representatives should be experts on one of the topics of discussion. Furthermore, these fortyeight delegates were requested to discuss the four topics within their own countries or their own organisations in order to attend the meeting fully briefed on the stance taken by their Member State on specific issues to be raised at the plenary.

It must be recorded that this was not done in every case and therefore some of the opinions were subjective.

This report is the result of a meticulous study of the notes taken during the debates and study of the tapes of the entire proceedings in order to provide a balanced and concise overview of the opinions expressed.

Papers submitted by Mobility International and by the European Blind Union, who were unable to attend were read out to the entire assembly, to take their place in the overall debate.

DEFINITION OF 'DISABLED PERSON'

Chair: Paul Boulinier

Vice Chair of the HELIOS Disability Forum

#### INTRODUCTION

The Chair opened the proceedings by reiterating that as a way of marking the International Day of Disabled Persons it was felt necessary to highlight the importance of the autonomy, freedom of choice and independent living of disabled people through debate and subsequent declarations by disabled people themselves. To deal with such philosophies involves looking at the reflections of how we are viewed within society. Therefore these four topics were decided upon as they encompass important fundamental issues, and it was considered vital that our reflections on these issues should be heard by European and national authorities. He stressed that although these questions could not be solved or discussed in their totality during the course of two days, nor allow a definitive statement on behalf of ALL disabled people, it was an opportunity for views to be expressed which would provide a starting point for further discussion.

The Chair continued to say that it was vital for the information discussed at this plenary meeting to be taken back to delegates' organisations and countries, and highlighted the fact that this conference was only the beginning of a process whereby disabled people are setting the agenda of a discussion to be continued into the future which will influence and inform politicians, policy makers and service providers of the issues affecting the lives of disabled people.

The Chair then opened the debate on Definition of Disability stressing the importance of this issue in terms of its relevance to the rest of the agenda.

#### MAIN ISSUES

The debate began with a discussion to ensure that, should a definition of disability be decided upon, it did not exclude any person with an impairment. For example, mental health system survivors were concerned that a definition which was too restrictive would exclude them, thereby denying them access to services and resources.

The HIV and AIDS community consists of a variety of people who need to be included in a definition of disability, because of the impact of the medical world on their lives. However, many within that community would reject the idea that they are part of the disabled community. The definition agreed needs to include those with hidden impairments who are also faced with stigmatisation, segregation and discrimination.

It was generally accepted, however, that the agreed definition should include and incorporate all disabled people.

#### Medical model

Delegates unanimously rejected the medical model of disability, which divides people into groups according to their medical condition. The reasons were as follows:

- a. Collective diagnosis, labelling and medical descriptions were unhelpful and inaccurate in identifying the environmental, attitudinal and organisational barriers resulting in the discrimination and exclusion of disabled people.
- b. The medical model is unhelpful and inefficient in identifying an individual disabled person's needs.
- c. The medical model identifies the problem as that of the disabled individual. rather than society's refusal to accommodate difference(s).
  - d. The medical model is used to segregate disabled people, target services and exclude and marginalise disabled people away from mainstream society.

Impairment, on the other hand, is part of the human condition.

The medical model of disability was summed up by one delegate: "Disability is not a medical condition but a social situation created by how society responds to us as human beings." It was also stated that "Impairment is about functional loss; disability is about inequality and discrimination" and stressed that disabled people must begin to articulate the difference.

Medical intervention Participants stressed that their rejection of the medical model of disability was not a refusal to accept treatment or medical intervention but more a question of identity. Disabled people were viewed in a negative way and their identity centred around denial and an inability to have equality. Therefore our identity must be taken out of the medical model. People wished to be treated as individuals, not labelled according to their medical condition.

Full citizenship While discussing the importance of a comprehensive definition of disability, delegates suggested that society needs to accept that disabled people are entitled to have full citizenship. By doing so, the right of disabled people to playa full role in the social, economic and cultural development of society would be recognised. It was felt by

delegates that disabled people are currently often treated as sub-human because of their differences.

#### Self determination

The right to self determination for all disabled people in all aspects of life was demanded, e.g. the right to choice in education, housing, employment and public services.

Only by giving us this choice can we become full and equal members of society and make a valued contribution to the community of which we are pan, and thereby change the way we are viewed by others.

Social reaction Delegates spoke of the social reaction which bonds disabled people together as a community of people who are discriminated against and oppressed. One spokesperson said: "It is not our impairment which excludes us, it is society's refusal to remove the barriers to allow us the same civil rights which the rest of society takes for granted." Another spokesperson added that society must be seen as the disabling factor, thereby removing responsibility for the problem from the individual.

World Health Organisation Conference delegates believed that the World Health Organisation's definition of disability individualises our oppression. It does not explain how society discriminates against disabled people, and places the responsibility and onus for our exclusion from society on the disabled individual. Many of the disabled people attending the Conference rejected the WHO definition, and felt it should be replaced with the definition which was accepted at this Conference. In addition it was agreed:

"The WHO definition reinforces oppressive practices and notions, and it forces us to take responsibility for our own exclusion. It works as a continuum and does not look at the real reason for our oppression. 'Type of disability' is a term I personally do not understand. What I do understand is that the way we experience disability may vary according to the nature of the interaction involving the disabled person. This is what I understand and accept. Disability is common to us. It is about our denial and exclusion."

Disability is about more than being disadvantaged, which implies being held back, and is often a political and economic reality. It does not only disadvantage us, it denies us.

"Finally there are people who are infected or affected by HIV/AIDS, mental health system survivors and other groups who are completely excluded

from the debate. The WHO definition is not disabled people's definition and therefore we must reject it."

#### **Barriers**

There was a general feeling that European legislation was required to remove the environmental, attitudinal and institutional barriers which restrict, influence and control our lives. By removing these barriers delegates believed that the major disabling elements in society would also be eradicated, and the experience of disability could be changed positively.

#### CONCLUSION

During the course of the debate several countries and organisations drafted proposals for a definition. These were considered during the closing session and the main focus of all of the proposals showed a consensus of opinion. The debate on the Definition of Disability was concluded with the adoption, by all present, of a proposal from France which stated that:

A EUROPEAN DEFINITION OF 'DISABLED PERSON' "A Disabled Person is an individual in their own right, placed in a disabling situation, brought about by environmental, economic and social barriers that the person, because of their impairment(s), cannot overcome in the same way as other citizens. These barriers are all too often reinforced by the marginalising attitudes of society.

It is up to society to eliminate, reduce or compensate for these barriers in order to allow each individual to enjoy full citizenship, respecting the rights and duties of each individual."

By supporting this resolution this meeting on human rights expresses its non support for the current classification of impairment, disability and handicap operated by the World Health Organisation. We call upon the WHO to enter into a dialogue with disabled people's organisations to adopt a new definition in line with the above resolution.

# BIO-ETHICS, EUGENICS & E UTHANAS IA

Chair: Rachel Hurst

Chair of Disabled Peoples' International -European Union Committee

#### INTRODUCTION

The Chair introduced this issue by reminding delegates that if certain laws regarding eugenics and bio-ethics, some already in place and others being proposed, had been implemented, some of us would not be here today. Europe needed to take the lead in this area as other continents such as Africa were looking towards Europe for direction. The Chair believed it was most important to begin a European debate on these issues and she hoped the discussion would lead to agreement and the production of a policy statement.

#### MAIN ISSUES

Euthanasia It was not proposed that a coordinated suggestion for or against euthanasia should be sought but the question of quality of life had to be seen as paramount. Discussion took place regarding who actually judges the quality of life of disabled people. The question was raised as to whether it was the disabled person themselves, or a medical or legal professional. An example was given of an institutionalised disabled person who requested his physician to allow him to choose euthanasia. Upon further discussion with some disability activists, who asked him why he wished to practice euthanasia, he replied that he was in an institution with no support. When the concept of Independent Living had been explained to him however, this person stated that he did not actually want to die. One of the delegates stated that many people experiencing emotional distress wish to take their own lives. Instead they are given medication and locked away. Hence it could be argued that if quality of life has disappeared, people should be allowed to die with dignity.

It was reported that euthanasia is already being practised in different parts of Europe and elsewhere. A minority of delegates therefore felt that euthanasia should be legalised. In the Netherlands, the Supreme Court accepted that an individual in a mental health establishment could be helped by their doctor to practice euthanasia. The deciding factor for making such a decision regarding euthanasia would be whether an individual could tolerate their suffering. The spokesperson felt that the

acceptable level of suffering should be viewed in terms of the abuse of the individual's Human Rights, rather than in terms of their medical condition.

The key issue is the individual's, and not the professional's, definition of quality of life.

The Dutch experience has shown that mental health system survivors have the right to make psychiatric wills, whereby survivors state what they wish to happen to them should they be institutionalised again. The purpose of such wills is to guard against a future act whereby their rights may be taken away from them.

It was added that some people are unable to make such decisions regarding euthanasia but no consensus was reached on whether these decisions should be taken by an advocate or family member. The overall feeling was that the individual concerned was the only person who should make such decisions.

Information and advice Delegates called for extensive information and advice to be made available regarding the issues of bio-ethics, eugenics and euthanasia. This information must be provided by disabled people and their organisations to parents, doctors and other professionals. This would ensure accurate information and positive images and would enable informed decisions to be made.

Most decisions about all of these areas are made from a non-disabled view of disability as a tragedy. Disabled people feel that any of these decisions made by the medical and legal profession must be taken in collaboration with disabled people, their families and their organisations.

Eugenics Following on from discussion concerning the freedom to make informed choices about preventative treatment, a spokesperson from the Conference stated that eugenics is not about curing or preventing impairment. Eugenics is about purity of race and the removal of defects. He went on to say "It is not a medical argument about purity, it is a moral argument."

Ethics committee The suggestion was made that if national ethics committees, or perhaps a European body, were to include disabled people in their debate, certain precautions could be taken. This would allow ongoing consideration of the views of disabled people, alongside that of the medical professionals and families. It was also considered essential that these committees should be in place to discuss cases at the early stages

rather than when major decisions have to be taken. There is clearly a major difference between ridding society of the root causes of an illness, and arguing that certain disorders have to be eradicated. The two issues present very different moral questions.

The draft "Convention on Bio-Ethics of the Council of Europe" was discussed by the Council of Europe in September. Article 6 states that for research purposes, non beneficial interventions may be carried out on 'incapacitated persons'. This allows medical experiments to be undertaken on 'incapacitated persons', even if these experiments are of little value to the disabled person. The Bio-ethics Convention contains no safeguards and no definition of what constitutes a 'low risk or high risk' experiment. Delegates were horrified to learn of this resolution which they saw as a clear example of the negative way disabled people are viewed by much of society.

Genetic research A spokesperson was concerned that genetic researchers have not consulted with disabled people and therefore the voice of disabled people is not heard. As a result research into genetics has a very negative view of impairment. There are worrying motives behind such research which need to be challenged but which are currently going undiscussed. The U.S. campaign 'Right to Health' was quoted. This is not about the right to health but the right to be born with 'normal' genes. Without increased debate with disabled people such campaigns will continue to go unchallenged. Medical research should serve the aim of medicine not the aim of eugenics.

#### Parenthood

Debate continued around the question of whether, regardless of an individual's impairment, women should have the choice to either complete their pregnancy or request a termination.

# Tragedy

If disability is viewed as a tragedy, the termination of foetuses with impairments is increased. It was reported that some women having prenatal diagnosis sign a form enabling the detection of abnormalities to allow immediate termination without further consultation, advice or counselling. One spokesperson referred to the progress of medical science which, in addition to saving many lives, leads to technologies such as pre-natal diagnosis and its incumbent ethical question. Should society shoulder the responsibility of deciding the length of an individual's life?

Delegates agreed that they defend the right to life for all human beings but the right sort of advice, support and social environment is necessary to allow this to happen and for decent choices to be made.

Enforced sterilisation/contraception Evidence was provided by various delegates that disabled women -particularly those with learning difficulties - were being sterilised without their consent. In cases where women were allowed to conceive, the majority of children were immediately removed from their parents. No counselling or support was offered to these parents after this had taken place.

# Rights of the woman

It was emphasised that any policy decision made by delegates should include the right of women to choose whether they wished to continue with their pregnancy. This must be a woman's choice.

In the UK, termination of pregnancy is allowed until the twenty fourth week of gestation. However if abnormality is detected doctors will carry out abortions until term. This was considered by some delegates as murder - not abortion.

It was agreed by delegates that the woman's right to choose should not be removed, but that equality should be ensured between foetuses with and without impairments.

This was another area where information and advice was essential in allowing women to be fully aware of the choices open to them. It was argued that the tragedy model of disability has influenced individuals in their decision-making over whether or not they terminate their pregnancy. It was concluded that disabled people need to become involved in the debate on abortion.

A discussion took place as to whether people with a learning difficulty were able to make decisions for themselves on the issues of childbirth and euthanasia. A minority of delegates were of the opinion that this decision could only be made through an advocate or by a member of the disabled individual's family.

However this suggestion was strongly rejected by others because people generally agreed that such decisions of life and death could not be taken by an advocate.

Cost implications The cost implications, of, for example, continued care, continuation of a pregnancy and enabling an individual to live independently, were raised by delegates because in many countries Health Services are being rationalised. This factor is also used as a way of pressurising people into making decisions, especially in the case of pregnant women. This was felt to be dangerous. Delegates were asked to consider the replacement of questions such as 'is life useful or not?' and 'what is the cost of rejection?' with questions asking 'would this life be too costly to maintain?'.

Delegates strongly believed that cost implications of any of the issues discussed above should not be taken into account in any decision-making.

Scientific progress It was generally agreed that medical research should be stimulated and scientific progress allowed to move forward towards positive prevention of diseases. The medical professionals should be aware of natural limits however and avoid exposing disabled people to exploitation and infringement of human rights. The integrity of the individual must be upheld.

#### CONCLUSION

Debate and decisions on these issues must consider the input of disabled people. It was felt that there should be further discussions similar to this meeting, in order for the voice of disabled people to become a real presence. The Chair summed up the main points and the outcome of the discussion on Eugenics, Bio-Ethics and Euthanasia produced the following points:

Disabled people have an equal claim on life and a right to the social and economic resources which would enable them to live their life with a maximum of dignity). and self-determination and therefore we should not be seen as a tragic minority.

All ethical and medical intervention considerations regarding disabled people must be made with the full and direct co-operation of the individual involved.

Whilst supporting the right to choose abortion for all women, we consider it offensive that cost implications should be used as an excuse to terminate a disabled person's life or the life of a foetus with impairment(s). This should be outlawed.

#### INDEPENDENT LIVING

Chair: Josee van Remoortel

Chair of Disability NGOs in Consultation

#### INTRODUCTION

The Chair introduced the concept of Independent Living and stressed the need for a European dimension to Independent Living with the aim of focusing on the introduction of legislation, on a European level, to provide access to Independent Living for all disabled people. She emphasised the major problems that the definition of Independent Living represents for some disabled people. We must ensure the inclusion of people with hidden impairments e.g. mental health system survivors, people with sickle cell, people who are infected or affected by HIV / AIDS, etc. when discussing Independent Living issues. The Chair stated that a wide gap exists between legislation in the Member States as some have been more successful in achieving human rights than others. She believed that what was required in Europe was a system similar to the one in place in America (Americans with Disabilities Act).

#### MAIN ISSUES

The right to control our lives

The point was raised that Independent Living must be recognised as a fundamental right for disabled people and the economic framework must be developed to enable disabled people's access to Independent Living.

"For years, Independent Living was something which all disabled people wanted and aimed for. It was perceived that Independent Living would ensure recognition of the human rights of disabled people. Independent Living is about disabled individuals taking control, having choice, being empowered and having self determination. Independent Living is not another rehabilitation programme, it is about our own individual civil rights."

# Legal framework

Delegates discussed the importance of living independently within the community. In this instance, community was defined as the means of addressing issues of equalisation of opportunity.

If Independent Living is to be recognised as a fundamental right, it must be enforced via a legal framework which comprehensively addresses the removal of those barriers faced by disabled people, i.e. institutional discrimination. There is also a necessity for legal rights to accessible transport, housing, leisure activities and employment. It was stated that these are issues common to all disabled people and therefore a common legal objective is required. To make this legal right a reality delegates have to challenge the organisations and structures of Member States and put in place a mechanism whereby disabled people can rely on the enforcement of this legal right. It was stated that these demands for legislation are already present within the White Paper on Social Policy and it must be emphasised that we are not stipulating HOW each Member State should move forward, but saying that the processes towards implementation of legislation SHOULD be beginning in each State.

The Danish experience was discussed as, over 30 years, they have developed a high standard in this area. One spokesperson was keen to develop solidarity between the Member States to establish such a framework which would ensure provision of the basic requirements which underpin the concept of Independent Living such as housing, financial resources and assistance. Another delegate pointed out that European legislation was not the only solution and the starting point must be an increased awareness amongst policy makers, throughout the European Union as well as at national levels, of disabled people's human rights.

European Dimension Many delegates felt that the disparity between Member States in terms of legislation and development is too great to allow for harmonisation throughout the European Union and that a greater degree of convergence between the States was required -at national and local levels as well as at European Level. This point was reiterated by a spokesperson from Portugal where the concept of Independent Living simply does not exist as a choice.

Resources Discussion took place as to who controls the means of distribution of the resources which disabled people require to ensure their access to Independent Living. It was believed important that disabled people should be empowered in order for us to self determine the kind of

lifestyle we want to lead. To do this involves tackling the relationship between the state, providers of services and disability organisations. For example, it is still the case that many disabled people have to go 'cap-in-hand' in order to receive resources to live independently. The majority of organisations of disabled people are not given resources to support directly and develop services on behalf of their members.

#### Self-determination

This is therefore an issue of self determination. It is not just the opportunity to control our lives which disabled people are demanding but the means by which we do this. In Denmark, disabled people receive a pension which enables them to have a lifestyle similar to an individual earning an average wage, and the state makes additional resources available to employ staff where necessary. This applies to people with physical impairments who wish to live at home. In the case of people with learning difficulties, who live in collectives consisting of 2-5 people, they too receive a pension. In addition to this disabled people have campaigned for pension payments to be made to people living in large institutions. Payments made to people living in institutions have become the responsibility of the social, rather than the housing ministry.

The question of the provision and administration of personal budgets was discussed further and one delegate reiterated that the only way to ensure disabled people can have choice is by giving them control over the budgets necessary to access services and support. We need to determine our own needs and buy the services we know are of benefit to us. All disabled people must be included in decisions regarding which services they receive, including those individuals with learning difficulties. Appropriate advice and support services must also be in existence to enable people to manage their budgets effectively.

Autonomy Disabled people have the right to an independent life. It is not for anyone, apart from that person, to decide what they can or cannot do. Concern was shown by a few delegates that some disabled people with learning difficulties may find it difficult to live independently. However the majority of disabled people present at the conference felt that Independent Living should be an option for everyone as it provides personal fulfillment and social integration, and the resources necessary to achieve Independent Living should be made available.

Peer Counselling One of the organisations represented at the meeting raised the point of the role of peer counselling -a system whereby disabled

people act as advisors to other disabled people -as a key to Independent Living. For individuals whose sole experience has been confined to institutions, peer counsellors enable disabled people to make informed choices on the practical dimensions of how to live independently, i.e. control of budgets, employment of personal assistants and, very importantly, they help bridge the psychological gap.

The cost of independent living A number of delegates spoke of the cost benefits of Independent Living compared with those incurred by keeping people in large institutions. A spokesperson from the Netherlands said that a five-year survey had shown that Independent Living was no more expensive than placing people in institutions. A further example had proved that some institutionalised care could cost twice as much as allowing a person to live in their own home with personal assistants.

It was added that we must fight for adequate pre-conditions to programmes of Independent Living. Without adequate preparation, programmes may fail which re-inforces governments' opposition to the concept.

# Quality of Life

While discussing cost, it was pointed out that not only is there the cost benefit to society, in that it cannot afford NOT to have resourced programmes of Independent Living, i.e. in terms of the increased consumer potential afforded by allowing disabled people to be fully integrated into the economy, but there is also the cost benefit to the individual in terms of quality of life. Given the right environment and support a disabled person can develop as an individual and increase all elements of their independence. Independent Living allows individuals the freedom to determine their own lives and to become .integrated into society.

# Integration

One spokesperson raised the concern that integration should not be seen as disabled people integrating with other disabled people but that Independent Living should be considered in terms of disabled people integrating into an open society .

#### Personal Assistance

Concern was raised around a proposal to use unemployed people as voluntary assistants. This may be a cost-effective solution for the economies of all Member States but it is a worrying solution for disabled

people who should have paid assistance, not voluntary help for which they have to be grateful. Another spokesperson added that formal professional training of assistants is not always appropriate. Disabled people must decide what is appropriate, it should be a matter of individual choice and not a decision to be made by professionals.

#### CONCLUSION

The Chair thanked everyone for their contributions to an intense and frank debate and the discussion on Independent Living was able to come to the following conclusion:

We believe that independent self determined living should be a right for every disabled person.

Every disabled person should have a choice of resources to support self determination, including a personal budget paid by the state, assessed in relation to individual needs.

Member States should be made aware of the cost effectiveness of Independent Living and the integration of disabled people in their communities.

Recognising the need to raise awareness of self determination for disabled people and the need to mobilise politicians and policy makers, we believe that there should be European incentives for national comprehensive legislation to support the right to Independent Living.

#### **SEXUALITY**

Chair: Johan Wesemann

Chair of the HELIOS Disability Forum

#### INTRODUCTION

The Chair welcomed everybody to the meeting and hoped for a thorough and carefully thought out debate on a subject which, despite being an intrinsic part of our lives, is rarely discussed. Disabled people are clearly discriminated against in this area and are seldom in a position to make choices regarding their sexuality. Discussion must take place on how disabled people can have full lives in terms of sexuality with fundamental needs being met, adequate access to information and behavioural support.

#### MAIN ISSUES

#### **Attitudes**

Several delegates gave examples of attitudinal discrimination in this area. Their experiences had proved that, as disabled people, we are not expected to marry or have children and as such are not viewed as sexual beings.

#### Information and Education

There was general agreement that increased information was required on sexuality for disabled people, their parents, their partners, carers, social services and other relevant organisations.

It was generally agreed that training needed to be carried out by experienced disabled people who were able to advise others on the main issues i.e. sexual orientation, safe sex, contraception, and issues connected with HIV and AIDS. This training must be given from an impartial perspective, especially with regard to sexual preference. Disabled people should do more work to provide information which enables other disabled people to make informed choices about their sexuality. Such information should include advice on developing a positive self-image.

A representative from Portugal spoke of a project which was being developed in her country which recognised that disabled people are sexual beings. The project's main objective is to develop and provide educational

courses, which support and encourage individuals to acknowledge their sexuality. The project involves working with disabled people and their families, counsellors, and education and health personnel.

It was acknowledged by delegates that people who are infected or affected by HIV / AIDS should be welcomed into the larger disability debate. Their experience of oppression and discrimination should be utilised to educate all disabled people.

Participants considered it vital that guidelines should be established to direct people on these issues, and that these guidelines must be written and presented by disabled people.

Society needs to recognise disabled people as sexual beings. To achieve this, disabled people need to feel positive about themselves.

The Danish Experience In 1986 the Danish Parliament adopted legislation to address issues connected with the sexuality of disabled people. Provision is made for disabled people to have an active sex life. For example, there is provision of sex education in schools. The government produced guidelines in 1989 in which everyone (including disabled people living in institutions) has a right to sex education. They felt that this helps to dismiss some of the myths which exist in society and enables everyone to be more proactive in this field. An increase in frank, open discussion with carers and parents would also help to heighten understanding and further dispel these myths.

The Dutch Experience The Dutch spokesperson referred to the innovative developments in the Netherlands where there has been a certain degree of sexual emancipation for all people. The subject had been taboo in general and not just where disabled people are concerned. He spoke of the various programmes which had been set up through a variety of agencies enabling disabled people to have contact with prostitutes. Accessible rooms in hotels, etc. are available, and it is accepted that disabled people may need to use these services without stigma being attached to the individual.

Concern was expressed by some delegates that prostitution itself could be exploitation of both the prostitute and the client.

Sexual Abuse Delegates were of the opinion that adequate research and investigation had not taken place to show the true scale of the extent of abuse, particularly of disabled people, and that this research must be instigated. There is a need to recognise that in addition to people with

learning difficulties and mental health problems, people with limited communication skills are subject to sexual abuse and deprived of appropriate support, through education, to prevent such situations.

Legal Protection Greater legal protection needs to be given to disabled people who have experienced sexual abuse. This was considered especially important for women with learning difficulties, because their evidence was not admissible in the majority of lawsuits. The European Court of Human Rights needs to be challenged on the lack of action in this area by courts in some of the Member States.

# Sterilisation and Parenting

It was stated by one delegate that "Forced sterilisation constitutes rape by the state".

The issues of forced sterilisation and enforced birth control needed to be raised as a human rights issue. Discussion took place between a few of the delegates about whether forced sterilisation and contraception for people with learning difficulties was acceptable in certain situations. It was voiced by a minority of delegates that some people with learning difficulties should not be encouraged to have children, and that sterilisation may be one solution.

In Spain, for example, legislation on sterilisation for people with learning difficulties exists. This decision is taken by a judge with the consent of the individual. Before sterilisation can take place there may also be an input from a counsellor a family member and people close to the individual. However delegates felt that informed consent was always needed or such action constituted abuse.

Enforced sterilisation is an attack on the individual regardless of that individual's impairment. It is both an aggressive and irreversible act.

Examples were given of institutions in France which provide training on issues such as contraception and how to educate without attacking the individual's sexuality. This training is carried out with the consent of parents, and encourages responsibility by everyone concerned.

Delegates from the UK explained that in the majority of cases where a couple with learning difficulties become parents the child is then removed from them. It was felt generally that this was a violation of human rights. In the case of a decision as to who can or cannot have children, this must be

left to the individual and their partners. This argument was endorsed by the statement that no legislation exists in Europe giving courts the power to sterilise an individual on the basis that they could be a bad parent, unless of course you are a disabled parent. If a disabled person has a child there are other methods for dealing with this situation and appropriate support should be available.

In the case of people with learning difficulties some delegates were of the opinion that parents had the right to restrict their disabled child's sexuality to prevent unnecessary pregnancies.

The question of male responsibility in a pregnancy was highlighted and the spokesperson felt that it was time for this responsibility to be acknowledged.

#### Interference

Any interference or legal intervention in the sexuality of disabled people is unacceptable and must stop. People should be encouraged to become educated and acknowledge their sexuality. Disabled people should have the right to choose their sexual preference and all forms of sexuality must be respected. Freedom of choice must exist for all individuals. Simply because choices CAN be removed legally does not render these decisions right.

# Legislation

A representative of the Coalition of People Living with HIV and AIDS proposed that there should be an equalisation of the age of consent throughout Europe, regardless of an individual's sexual orientation.

#### CONCLUSION

The Chair closed the debate commenting that discussion alone helps to raise consciousness of the problems and the different ways of approaching this issue. He was pleased that many aspects of sexuality had been discussed at various levels and summed up the main points stressing that sexuality must be viewed positively. Some Member States have taken steps towards this with Parliamentary recognition of disabled people's rights to obtain sexual information and this has been enshrined in legislation. In addition, taboos must be broken down and there is a need for an information campaign.

Autisme Europe put forward a statement which was accepted as a preamble to the conclusion.

Disabled people, like all human beings, have sexual and emotional needs that evolve throughout their life. Only better information to the public and to disabled people and their families will enable recognition of the validity of these needs and assist disabled people to develop, protected from any abuse.

The Chair thanked everybody for their contribution to the debate and there was agreement from the delegates that the position reached through this discussion is as follows:

Sexuality must be viewed positively as a part of life. In order to project this positive image we need to provide good sexual information.

Sex information should preferably be provided by other disabled people.

Disabled people have to be actively involved, they must involve themselves in the communication of such information.

We should not simply look at the situation as it stands today, but look at improvements to the current situation through legislation.

Disabled people themselves must make the decision and control what happens to them. In order for this to happen disabled people must be provided with proper choices, especially in regard to sexual preference.

Ignoring sexual abuse and pretending it does not happen must be stopped. Sexual abuse must be addressed through appropriate legislation, to which all disabled people should have access.

Disabled people must have the right to self-determination in all aspects of their sexuality, should this be sexual preference, sterilisation or contraception.

Good communication is required at all levels. Disabled people must have the opportunity to find out their own needs, realise and express them.

Disabled people must be provided with information relating to safer sex, HIV and AIDS.

#### STATEMENT OF SUPPORT

FROM THE ALL PARTY DISABLEMENT GROUP OF THE EUROPEAN PARLIAMENT.

Mary Banotti MEP, Vice Chair of the All Party Disablement Group of the European Parliament presented a Statement of Support from the Intergroup at the European Day of Disabled Persons' human rights plenary meeting held in Brussels on 17 and 18 October 1994.

# Statement from the Intergroup

The All Party Disablement Group of the European Parliament represents approximately 100 MEPs from the different political groups and nationalities of the Parliament. The All Party Disablement Group is pleased to give its support to the plenary debate today which precedes the European Day of Disabled Persons and we look forward to having a full debate in December. The Group has pressed the Commission for more resources for the day both this year and by establishing a specific budget line in the budget for the Day and for a study of anti-discrimination legislation. Last year the All Party Disablement Group secured the use of the Parliament's hemicycle for the Day.

The topics debated today are fundamental to disabled people's everyday lives and are not debated enough. We are pleased that the results of these debates will be presented to policy makers at European level and that action will be taken in the form of a resolution. It is important that concrete action follows from these debates. I propose to make a brief statement on behalf of the Intergroup on each of the four areas you are discussing.

#### **Bioethics**

The Bioethics Convention of the Council of Europe as currently drafted can be used directly to discriminate against disabled people as it stands that non beneficial interventions can be carried out on incapacitated persons. The All Party Disablement Group has submitted an urgent protest to the Council of Europe, registering its serious objections to the draft as it strands. The current draft also permits transfer of organs between the disabled person and a family relation without the agreement of the disabled person and without proper regulation. The All Party Disablement Group considers that this is a serious violation of disabled people's human rights and can be used to justify human rights abuses particularly against people with a learning disability .

# Independent Living

The All Party Disablement Group believes that the only way to guarantee Independent living for disabled people is full anti-discrimination legislation which gives disabled people full civil rights. This is not something in our view that should be left to member states. America has anti-discrimination legislation in the form of the Americans with Disabilities Act. It is now time that Europe followed suit with full anti-discrimination legislation.

It is totally wrong that disabled people should be refused access to a cinema because they are perceived as a fire risk and outrageous that it remains lawful in today's Europe to display a sign outside a restaurant which states "no disabled people here".

The Intergroup welcomes the recently issued White Paper on Social Policy which recognises that the Treaties as they stand offer no protection against discrimination on grounds of disability and contains a commitment to revise the Treaties so that disabled people can have protection under the Treaties. We want to work both with the Commission and with NGOs to make that commitment a reality.

# **Definition of Disability**

The Intergroup looks forward to reading and discussing the contributions from disabled people on this issue. It is important to move to both a definition of disability that member states and NGOs recognise and will work with, and one that no longer relies on outmoded ideas and concepts and outmoded language. Too often definitions of disability rely on medical rather than social definitions, failing to look at the social and political consequences of the disability -the fact that it is attitudinal and societal barriers that are disabling rather than the fact that a person has a disability. It is also important that any definition recognises hidden disabilities.

# Sexuality

Too often disabled people are subjected to stereotypical assumptions about their rights to have a child or to have a sexual relationship. This is particularly true for mentally handicapped people who are sometimes sterilised without their consent.

Finally, I look forward to the I December when we will have further opportunity to debate these issues between MEPs and NGOs and to read

the report which has been produced from these debates and to formulate a plan for taking them forward at European level.

#### **CLOSING SESSION**

# Chair, Rachel Hurst

At the close of each debate the main points were summed up by the Chairpersons but the conclusive statements were arrived at during this session of the Plenary Meeting.

Prior to this session, a synopsis of the main points agreed was distributed to all the participants. In addition to these, many additional statements were received by the Chair. In order to arrive at an agreed joint statement for each topic of debate, the Chair invited participants to consider each one in turn, amend or add points where necessary in the form of brief debate and then vote. In this way consensus was reached by all present on the statements which appear on the previous pages.

The Chair thanked everyone for their contributions on behalf of the Disability Forum and Disabled Peoples International, adding that disability is moving higher up the political agenda and only in time would the importance of this event be realised as playing its part in further raising awareness of these issues.

The Human Rights Plenary Meeting was then closed.

#### LIST OF PARTICIPANTS

# ATTENDING THE HUMAN RIGHTS PLENARY, BRUSSELS, 17-18 OCTOBER 1994

#### NATIONAL DISABILITY COUNCILS

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I. ASSOCIATION DE PARENTS
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KA TOLIEKE VEREINIGUNG
 VOOR GEHANDICAPTEN - RENE VASTMANS

3. CSNH -NATIONAL COUNCIL - JEAN PAUL HERBECQ

#### DENMARK

DSI/SOCIETY FOR PEOPLE
 WITH LEARNING DIFFICULTIES - JOHN MOLLER

2. DSI/SOCIETY OF MS - NIELS ARTHUR HANSEN

3. DSI/MUSCULAR DYSTROPHY
ASSOCIATION - EVALD KROG

#### FRANCE

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2. APF/CFHE/ASSOCIATION FOR HOME SERVICES - BERTRAND BASSE-SAIGE

3. CFHE/GFPH/ADAPEI 92 (PARENTS ASSOCIATION) - DOMINIQUE RAVEL

#### GERMANY

1. BUNDESVEREINIGUNG LEBENSHILFE FUR GEISTIG BEHINDERTE

- DR THERESE
NEUER-MIEBACH

2. VDK -NATIONAL COUNCIL - DR UTE LINDAUER

3. ALLGEMEINER
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IN DEUTSCHLAND -ABID - DR DEHLEF ECHERT

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 INFO-HANDICAP - SILVIO SAGRAMOLA

**NETHERLANDS** 

I. GEHANDICAPTENRAAD

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**CARVALHO** 

3. ASSOC. PORTUGUESA PARA PROTECAO

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# EUROPEAN DAY OF DISABLED PERSONS 3 DECEMBER 1994

# SYNOPSIS OF THE HUMAN RIGHTS PLENARY MEETING 17-18 OCTOBER 1994

Supported by the HELIOS Programme Directorate General V of the European Commission, and the European Parliament

"The topics debated today are fundamental to disabled people's everyday lives and are not debated enough. We are pleased that the results of these debates:1will be presented to policy makers at European level and that action will be taken in the form of a resolution. It is important that concrete action follows from these debates."

# Mary Banotti MEP

Vice Chair of the All Party Disablement Group of the European Parliament during the presentation of a Statement of Support, 18 October 1994.

#### **FOREWORD**

Extracts from the United Nations Standard Rules on the Equalisation of Opportunities for Disabled People.

"There are disabled people in all parts of the world and at all levels in every society. The number of disabled people in the world is large and growing....

Both the causes and the consequences of disability vary throughout the world. These variations are the result of different socio-economic circumstances and of the different provisions that States make for the well-being of their citizens...

Present disability policy is the result of developments over the past 200 years. In many ways it reflects the general living conditions and social and economic policies of different times. In the disability field, however, there are also many specific circumstances which have influenced the living conditions of disabled people. Ignorance, neglect, superstition and fear are social factors which throughout the history of disability have delayed the development of and isolated disabled people...

Towards the end of the 1960s organizations of disabled people in some countries started to formulate a new concept of disability. This new concept indicated the close connection between the limitation experienced by disabled individuals, the design and structure of their environments and the attitude of the general population...

States should recognize the right of organizations of disabled people to represent disabled people at national, regional and local levels. States should also recognize the advisory role of organizations of disabled people in decision making on disability matters...

The role of organizations of disabled people could be to identify needs and priorities, to participate in the planning, implementation and evaluation of services and measures concerning the lives of disabled people, and to contribute to public awareness and to advocate change."

Last year on December 3 the Parliament of Disabled People in Brussels, in its resolution, invited the Commission to initiate legislation for the adoption and implementation of the UN Standard Rules. This resolution has been recognised by the European Commission in its White Paper on Social Policy.

To further the implementation of the Standard Rules, this meeting of disabled people and advocates from the European Union was organised to ensure that the European Commission and the European Parliament had knowledge of the views of disabled people on these important issues.

# Report Methodology

The report is the result of a meticulous study of the notes taken during the debates and of the tapes of the entire proceedings in order to provide a balanced and concise overview of the opinions expressed.

#### INTRODUCTION

Representatives of 24 European and national disabled people's organizations which are members of the European Disability forum met at the European Parliament Building in Brussels on 17 and 18 October to debate four major human rights' issues and to launch a new campaign throughout the European Union.

The main focus of the campaign will be the launch throughout the Union on 3December of a report addressing four major issues – definition of disability; bio-ethics, eugenics and euthanasia; Independent Living; and sexuality.

# A European definition of Disability

The World Health Organisation (WHO) international classification puts the definition of disability as being the 'problem' of the individual. Disabled Europeans are increasingly understanding that this medical approach is not the reality. We are learning, from our own direct experience, that disability arises from the interaction of the impairment with a society which produces barriers to integration and understanding.

For disabled Europeans to agree a collective definition of disability will be a major step towards achieving our human rights, because if disability is socially constructed then there has to be a social solution.

# Eugenics, Bio-ethics and Euthanasia

The advance of medical science has increased the many opportunities for eugenics – the practice of improving the genetic stock of a population. But there is a great difference between ridding the world of a killer disease and the assumption that an impairment, condition or functional limitation is a bad thing and should be eradicated.

Bio-ethics also underlies the concept that all physical and mental imperfection is unacceptable. There is little discussion on the value of human life, the negative attitudes of society and the social barriers which are the real cause of why society believes that certain conditions such as cystic fibrosis, spina bifida or muscular dystrophy should be genetically eradicated. These ethical judgements are so often mad by non-disabled people who, because of kindness and sometimes ignorance, cannot bear the thought of other people's suffering. But it is we disabled people, many of us with conditions that it is being suggested should be genetically mutated, who should be leaders in this discussion.

It could be argued that euthanasia is a response to the progress of medical science which keeps people alive. It could also be a response from people who do not understand that for many disabled people, the greatest suffering comes from not being able to live independently. The debate is about the quality of life.

# Independent Living

Independent Living is the name given to the concept of the empowerment of the disabled individual and their ability to control their own daily lives. Independent Living is not the name of a particular service or provision but should be the object of services and the furtherance of people's human rights.

Two issues which are unique to independent living are personal assistance and direct payments. Through hiring assistants with money provided directly by statutory authorities disabled people can retain choice and control over their own lives and cut down the considerable costs of institutional or community care provision.

# Sexuality

Negative attitudes to disabled people and the concentration on, our impairments have had a profound effect on our sexuality -not only on other people's recognition of our sexuality as valid but on our own evaluation of ourselves as sexual beings. Marriage has not been considered as an option for many disabled people, nor childbirth. Disabled people who have lived most of their lives in institutions have not received sex education and in many European countries disabled women have been encouraged to receive sterilisation, if for no other reason than that it would be easier for personal assistants. These attitudes have particularly affected ,disabled women and people with severe or learning difficulties.

# SYNOPSIS HUMAN RIGHTS PLENARY MEETING 17 -18 OCTOBER 1994

Representatives from each Member State of the European Union and ENGO (Helios Forum) met to discuss the issues of a European definition of disabled persons, eugenics, bio-ethics, euthanasia, Independent Living and sexuality, as they relate to the human rights of disabled people. The main points emerging from this meeting were as follows:

# **Definition of Disability**

Disabled people must start setting the agenda for discussions of issues relating to their lives -this meeting was only the beginning of this process.

Delegates unanimously rejected the medical model disability, which divides people into groups according to their medical condition. However this does not entail a rejection of treatment or medical intervention.

It was generally accepted that the agreed definition of disability should include and incorporate everyone with an impairment who is identified within the definition below.

It was acknowledged by delegates that people who are infected or affected by HIV/AIDS should be welcomed into the disability movement. Their expertise should be utilized to educate people in our movement about their experience of oppression and discrimination.

# Statement of Agreement

A Disabled Person is an individual in their own right, placed in a disabling situation, brought about by environmental, economic and social barriers that the person, because of their impairment(s), cannot overcome in the same way as other citizens. These barriers are all too often reinforced by the marginalizing attitudes of society.

It is up to society to eliminate, reduce or compensate for these barriers in order to enable each individual to enjoy full citizenship, respecting the rights and duties of each individual.

By supporting this resolution this meeting on human rights expresses its non support for the current classification of impairment, disability and handicap operated by the World Health Organisation. We call upon the WHO to enter into a dialogue with disabled people's organisations to adopt a new definition in line with the above resolution.

Bio-ethics, Eugenics and Euthanasia

The right to self determination for all disabled people in all aspects of life was demanded.

Delegates called for extensive information and advice to be made available regarding the issues of bio-ethics, eugenics and euthanasia.

This information must be provided by disabled people and their organisations.

A spokesperson from the Conference stated that Eugenics is not about curing or preventing impairment. It is about purity of race and the removal of defects, which includes all conditions.

A spokesperson was concerned that genetic researchers have not consulted with disabled people. Therefore the voice of disabled people is not heard. As a result research into genetics has a very negative view of impairment.

Quality of life must be determined by the individual, rather than professionals.

# Statement of Agreement

Disabled people have an equal claim on life and a right to the social and economic resources which would enable them to live their life with a maximum of dignity and self-determination and therefore we should not be seen as a tragic minority.

All ethical and medical intervention considerations regarding disabled people must be made with the full and direct co- operation of the individual involved.

While supporting the right to choose abortion for all women, we consider it offensive that cost implications should be used as an excuse to terminate a disabled person's life or the life of a disabled foetus. This should be outlawed.

# Independent Living

Many delegates believed that European legislation was required to remove the environmental, attitudinal and institutional barriers which restrict, influence and control our lives.

We must ensure the inclusion of people with hidden impairments e.g. mental health system survivors, people with sickle cell, people who are infected or affected by HIV/AIDS, etc. when discussing Independent Living issues.

Legal rights to accessible transport, housing, leisure activities and employment are required. It was stated that these were issues common to all disabled people. To make this legal right a reality delegates have to challenge the organizations and structures of the Member States. A common legal objective is required. It is also necessary to put in place a mechanism whereby disabled people can rely on the enforcement of this legal right.

It was believed to be important that disabled people should be empowered in order for us to self determine the kind of lifestyle we want to lead. To do this would involve tackling the relationship between the state and providers of services and disability organisations.

A European dimension was required, and people needed to aim for the introduction of legislation which provided access to Independent Living.

Disabled people have the right to an independent life. It is not for anyone, apart from that person, to decide what they can or cannot do.

All disabled people must be included in decisions regarding which services they receive, including those individuals with learning difficulties (mental handicap).

# Statement of Agreement

We believe that independent, self determined living should be the right of every disabled person.

Every disabled person should have a choice of resources to support self determination, including a personal budget paid by the state, assessed in relation to individual needs.

Member States should be made aware of the cost effectiveness of independent living and the integration of disabled people in their communities.

Recognising the need to raise awareness of self determination for disabled people and the need to mobilize politicians and policy makers, we believe that there should be European incentives for national comprehensive legislation to support the right to independent living.

# Sexuality

Issues such as sexuality, sexual expression and sexual practice should be viewed as a matter *of* personal choice and freedom, without interference from the legal or medical profession.

Evidence was provided by various delegates that disabled women - particularly those with learning difficulties -were being sterilised without their consent.

Conference delegates requested that a woman's right to choose should not be removed, but that equality between non-disabled foetuses and those with impairments should be ensured.

It was generally agreed that training needed to be carried out by experienced disabled people who were able to advise others on the main issues i.e. sexual orientation, safe sex, contraception, issues connected with HIV / AIDS.

It was felt by delegates that disabled people should be recognized as part of society and as sexual beings. Disabled people needed to have a positive self-image of themselves.

Issues of forced sterilisation and enforced birth control needed to be raised as a human rights issue.

Forced sterilisation constitutes rape by the state.

People felt that in the case of a decision as to who can or cannot have children, this decision must be left to the individual and their partner.

Delegates felt that disabled people had the right to experience all forms of sexual orientation.

#### Conclusions

Sexuality must be viewed positively as a part of life. In order to project this positive image we need to provide good sexual information.

Sex information should preferably be provided by other disabled people.

Disabled people have to actively involved, they must involve themselves in the communication of such information.

We should not simply look at the situation as it stands today, but look at improvements to the current situation through legislation.

Disabled people themselves must make the decision and control what happens to them. In order for this to happen disabled people must be provided with proper choices, especially in regard to sexual preference.

Ignoring sexual abuse and pretending it does not happen must be stopped. Sexual abuse must be addressed through appropriate legislation, to which all disabled people should have access.

Disabled people must have the right to self-determination in all aspects of their sexuality, should this be sexual preference or sterilisation or contraception.

Good communication is required at all levels. Disabled people must have the opportunity to find out their own needs, realise and express them.

Disabled people must be provided with information relating to safer sex, HIV and AIDS.