DPI EUROPE

A REPORT OF THE DISABILITY HUMAN RIGHTS NETWORK - Combatting Social Exclusion

DISABLED PEOPLES' INTERNATIONAL - EUROPEAN REGION

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Combatting Social Exclusion - Disability Human Rights Network

INTRODUCTION

That disabled people face discrimination in their daily lives is now well documented. The realisation that disability is an issue of rights and that there is a need for social change is now slowly being recognised by the introduction of non-discrimination legislation in some countries. However, over and above this discrimination there is a growing body of evidence of systematic violence and abuse against disabled individuals. To date, evidence of such human rights violations has not been collated or disseminated but the Human Rights Network will do this and show, through their direct experience, the reality of disabled peoples' lives.

This document works at two levels. It reports on the establishment of innovative pilot networks in 5 European Union countries, to present the first documented evidence of abuse of disabled peoples' rights within Europe. It also outlines the methods used to train a selected group of volunteers with the aim of establishing these networks, presenting a model for training and the setting up of such networks elsewhere. Reports of the contents of the database are available separately from Disability Awareness in Action (DAA) who worked in partnership with DPI Europe and received funding to manage and input to the database, although a brief summary of the database is included within this report.

Background

The aim of the project was to address social exclusion by implementing DPI-EUC's Human Rights Network Working Group's 1998 report concerning Human Rights and Violations of Disabled People based on the UN Declaration of Human -Rights. The culmination of many years' discussions with DPI Europe's Human Rights Task Force, the objective was to establish a system of collection of cases of human rights abuses and discrimination against disabled people. Collection and collation of such evidence has not previously existed and, as such, this was a pioneering exercise.

The preparatory activity of one year included - establishing a pilot national network in five member states, appointing 2 or 3 national network coordinators,. preparing and carrying out a training programme for the coordinators, setting up a standard violations, data collection system for use throughout the European Union and setting up a secure central database and verification systems.

Funding was also made available to the five partner organisations to assist with administration costs incurred by the volunteers. This funding was available only

for the duration of the project and means that, in order to continue their work, national funding will have to be sought to provide financial support for the work of the coordinators into the future. As the project drew to a close this became a real and pressing issue. Through exposure to many cases of abuse, and a greater awareness of the human rights instruments existing to protect our rights, the coordinators developed a sense of ownership of the work which they were anxious to continue in the form of training others at national level and acting as mentors.

Progress

DPI Europe has been successful in implementing each area of the aims and objectives. The project has meant a learning curve for all involved - trainers and coordinators alike - and was not without its problems. These will be discussed more fully in the analysis to follow.

As a result of the project, DPI Europe has 5 networks operating within the European Union on a voluntary basis. They have contributed to the database collection, now approaching 800 entries (March 2000), which is managed by DAA in London, UK. It is the long term effect of the project, which is to be anticipated, however, as concentration on development of long-term structures come to fruition, and the individuals continue to develop their expertise at national level. With an increased awareness of international and national legislative rights and where these are being violated, they will be able to expose the inherent discrimination existing at national level whilst continuing to contribute to the growing database whose evidence will be used for global campaigning.

The primary problem was that of insufficient time to prepare the project. The reasons for this fall with the structure of European Union contract production. Prepared after the start date of the project, and stipulating that spending cannot begin prior to signature, there is inevitably a shortening of the project programme. This has a direct and negative impact on the achievements of any given project. In this case it led to a situation where coordinators in one or two of the countries were nominated by national assemblies to attend the training without being fully aware of the long-term aims of the project. There was also the problem of language -which remains a problem as long as funding is not available for interpretation - as national assemblies felt bound to nominate individuals proficient in English, not necessarily individuals who would choose to take on a role of voluntary coordinator.

Having said that, the project was extremely fortunate in having a group of people who were committed to the network, the philosophy of human rights and who would work together as a group. By the final session, their sense of belonging to a Europe wide network of people committed to protecting disabled peoples' rights was apparent, as was their sense of responsibility to the continuity and expansion of the networks through securing of funds and the recruitment of

additional volunteers. We were fortunate that Richard Howitt, MEP, was available to attend the final evaluation session, along with members of the Human Rights Task Force, who all reacted extremely positively to the work of the group and the aims of the networks.

The lack of preparation also led to an initial training programme which did not suit the needs of all the individuals, many of whom were already working within the legal framework, the field of human rights, and/or counselling. This was resolved however through ongoing evaluation by the trainers They were able to adapt the work of the second session to better suit the calibre of the coordinators.

The successes of the project more than outweigh the teething problems experienced. The sense of responsibility on the part of the coordinators meant that instead of seeing the purely one dimensional view of rushing to collect as much data as possible, their view was more far-reaching. How to establish a network which can take on its own form i.e. using mentors, recruiting more individuals to be trained as coordinators. To this end, coordinators worked hard with national assemblies and other bodies to try to secure funding for continuity after the end of the project period; publicised the project through magazine articles and through local organisations.

The database now holds over 800 cases affecting over 1 million people and the networks are slowly contributing to this - close to 50% of all the cases entered to the database between January and April 2000 were submitted via the networks.

The database and SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis is looked at in more detail later in the report and will give a picture of the coordinators evaluation of the training project.

Activities
Setting up a standard violations data collection system

The Human Rights Network working group reconvened in February 1999 to discuss the project in detail. Long and detailed discussions took place concerning defamation, and the protection of volunteer coordinators and national assemblies.

In relation to security for the individual coordinators and the national assemblies, it was agreed that networks should be established but they must be independent of the national assemblies Coordinators should not be paid a remuneration, but act as volunteers and be reimbursed expenses only.

The working group established the conditions overleaf, which were then developed into contracts for signature by the partners and the coordinators.

Pilot National network in 5 member states

The five partner countries were Germany, Italy, the Netherlands, Finland and Portugal. The partner organisations are members of DPI. and are all self-advocacy organisations. They all agreed to establish a national network by recruiting individuals prepared to be trained and work as volunteer collectors of information relating to violations of disabled peoples' rights. It had been agreed that the networks should operate independently of the national assemblies for reasons of security but, as will be seen in the analysis which follows, there were problems inherent in this as coordinators felt that they needed more support from their member organisations during the initial phases:

Funding was given to the national assemblies to help with administration costs incurred by the networks during the project period and means will have to be sought to provide financial support if the work of the coordinators is to continue into the future.

Appointing national network coordinators

A total of ten individuals were nominated to act as national network coordinators. This grew to eleven, plus a mentor, during the project. Two countries were able to nominate only one individual due to the difficulty in finding people at once proficient in English as a second language; able to travel intermittently to attend training sessions; and able to offer enough time to the project because of pressures of work etc.

Following the first training session the coordinators in these countries decided to recruit one or two further individuals to work with them at national level. On completion of the project, it also became apparent that some coordinators aim to try and develop a wider national network by recruiting other volunteers to train as coordinators.

DPI-EUROPE - HUMAN RIGHTS NETWORK CONDITIONS

National Networks
Each participating national assembly (project partner) shall sign and abide by the conditions of a contract with DPI-Europe and should establish an independent -network under the following conditions:
a)   be pro-active
b)   be aware of local and national laws in force
c)   be prepared to publicise the network and encourage the sending in of information concerning violations

d)   be prepared to follow standard methods for measuring the accuracy and veracity of the information
e)   ensure confidentiality of personal cases and other information
f)   abide by national laws concerning data protection and freedom of information
g)   abide by project procedures for sending accredited data to the central resource body
h)   appoint three individuals as coordinators
j)   ensure reports are provided in English or French
k)   follow project accounting procedures and provide original vouchers for all allowable expenditure incurred in relation to the project

Volunteer Coordinators

There will be an operational group of two or three independent coordinators who must be prepared to travel and receive 9 days of training, and act as a volunteer for at least 2 years.

a) selection criteria

i   potential to be 'case collectors' and eventually national trainers
ii.   apolitical
iii.   trustworthy and able to maintain confidences
iv.   committed to the principle of human rights and the concept of disability as a human rights issue
v.   ensure material is provided in English or French
vi.   maturity
vii.   people skills, an ability to listen and synthesise data
viii.   good native written and presentation skills
ix.   preferably, computer skills
x.   knowledge and understanding of discrimination as it affects disabled people

b) gender balance will need to be observed

c) each coordinator will have a project contract with DPI Europe

d) tasks

i.   to provide background information on the network

ii.   collect data concerning violations in accordance with procedures concerning the collection of data, and verify the evidence

iii.   be responsible for the completion of a standardised form detailing the necessary information for inputting into the database .

iv.   provide written testament to having heard the case/received the evidence or provide the signature(s) of witness(es)

v.   where required, be responsible for translating any data into English

Training

a. Training for coordinators will be provided by DPI-Europe and subjects covered will include:

i.   The Universal Declaration, the UN Standard Rules and other relevant legal instruments concerning non-discrimination, including ways and means of obtaining information about national legislation

ii.   Definitions of violations and classification systems

iii.   Collection of evidence and the means of verifying such evidence .

iv.   Data collection - practical and technical, and data protection

v.   Interviewing and people skills

vi.   Ethics including rules of confidentiality and the protection of individual rights

b. Timetable

May - 4 days

(training to be provided by a lawyer and an expert in people skills)

September - 3 days

December - 2 days, including evaluation

c. Venue

United Kingdom

Setting up a secure central database and verification systems

We worked in partnership with Disability Awareness in Action (DAA) who made a contribution to this project of the database and their operator, based in London.

During the 1997 Human Rights Network Project, DPI Europe recruited a computer consultant to develop the model for a secure database to collate the evidence in question on an international scale.

DAA were then successful in receiving a grant to establish and operate the system. The model was transferred to a PC and set up in February 1999. Jill Brooke worked as the database operator and began work on inputting the archival material stored by DAA. She attended the training programme to outline the system to the coordinators and was part of the project in all data was submitted to her for inputting and storing. Liaison took place with the computer consultant to resolve initial problems related to data retrieval and ease of use, and to ensure security of the data.

The database can retrieve information on all fields as they appear on the form and can report at three different levels giving statistical information only or giving a full descriptive report

Based on the format of the database, the working group and Human Rights Task Force agreed the data collection form, which will be used by the Network and submitted to the database operator. Only the upper section will be returned to the central database in order to retain anonymity of the individual concerned. A cross-reference system, however, will allow for identification if this is ever required and agreed by the individual concerned. (see Annex)

Data collected by the coordinators will be verified by them and the source provided - where it is not the individual concerned i.e. press/television.

A 6 month report on the database was prepared in October 1999, followed by an annual report in April 2000. These are available on request from DAA and outline the methods of reporting and analysis made possible by the database.

National assemblies involved in the project will be able to request annual reports for national use.

Preparing and carrying out a training programme for the coordinators

The first training sessions took place in London in June and October 1999,and the evaluation session followed in January 2000.

According to the conditions set by the working group in February, the programme included sessions on human rights and legal instruments; definitions of violations; collection of evidence; data collection and interviewing and people skills.

The basis for the first part of the programme was the Universal Declaration on Human Rights and the report on Violations and Disabled People, prepared in 1997198 for the first Human Rights Network project.

The database, data collection form and experience of the database operator formed the framework for the sessions on data collection and verification.

Coordinators were also briefed on how the network would operate, their roles and National Assembly support. It was stressed that the DPI Europe Human Rights Network exists independently of the National Assembly and, as voluntary Human Rights Network coordinators, they must operate independently of the National Assemblies.

In view of this it was deemed important that individuals were approached within the National Assembly Executive boards to act as a 'mentor' and support.

For the sections on people skills and interviewing, we recruited a firm of professional trainers. Two disabled people who lead workshops and training courses on disability awareness/equality; interviewing techniques etc. They developed a varied and interesting programme of practical exercises and role-play techniques, (see below), and their input to the project was invaluable in promoting a sense of unity to the group

DPI Europe - Human Rights Network Project Co-ordinator Training

Development of 'People Skills' Module
Sunday 6th and Monday 7th June 1999, London

Aims and Objectives
The overall aim of this module is to equip volunteer human rights network co-ordinators with the appropriate communication skills to carry out their role effectively.

Objectives:
By the end of this module, co-ordinators will:

?? understand the issues which affect individual and group communication, and in particular be able to identify potential blocks and barriers

?? be equipped to apply appropriate interviewing techniques, including active listening and effective questioning

?? have gained a clear awareness of the most useful ways of presenting and recording information, arising from individual and team working

?? be able to set parameters for their own involvement, and be able to find ways of identifying and communicating boundaries

?? understand the importance of referring to other agencies, and be able to identify the points at which that may become appropriate, as well as communicate this clearly and assertively

?? have begun to develop a communication action plan for their own development and involvement in the network

Programme Outline - Day I

Welcome and objectives for the module

Effective communication:	factors affecting communication blocks barriers and pitfalls
Interviewing techniques:	access issues active listening effective questioning
Recording information:	methods of recording consistent, systematic and accurate recording
Presenting information:	getting the message across effectively basic presentation skills

Establishing the boundaries (1): introduction

Programme Outline - Day 2 (half day)

Review of day 1 and questions

Establishing the boundaries (2):	assertive communication stress and pressure resources for referrals using your own support network
Action plans:	group and individual individual communication skills audit and development action plan action plan for involvement in the network

Session/Workshop Evaluation and close

Evaluation of Training Programme - I

The first session was long - 4 days - and quite difficult in terms of the travel, cross-cultural exchange and intake of new material in a second language. However, it was very successful and coordinators were largely very happy with the proceedings. Over the course of the four days, they came together as a group, offering sources of mutual support.

The evaluation process showed that the coordinators already had good skills in this area and would have preferred more in-depth exercises, with more emphasis on practical exercises and role-playing techniques, and a programme designed more specifically to their needs. As mentioned in the introduction, lack of preparatory time prevented adequate consultation between the participants and trainers prior to the first session. However, these points were taken into consideration and DPI Europe worked with the trainers to ensure the October session was designed to meet the specific skills and weakness of the coordinators. These included exercises on interviewing and people skills. (see annex)

The calibre of the participants was very high and we were disappointed that partner assemblies were not able to submit their details earlier in order that trainers could have had the time to make contact with them and design the course accordingly. It would certainly have been to the advantage of the coordinators in order to make optimal use of the short time available.

Following the first session we contacted the national assemblies stating these concerns and also others relating to support for the network. *"It was decided that the national assemblies must remain separate from the Network coordinators but we realise now that a system of support is essential, particularly where only one, or even two coordinators are operating. The coordinators may have contacted you already, but it not, we must emphasise the necessity for a named person from the Assembly to be put forward and act as a support/mentor for the coordinator."*

In relation to this, coordinators approached individuals within their national assemblies and were largely successful in establishing support.

We were also disappointed that partner national assemblies had not been able to offer more support to the nominated coordinators prior to the training session, which meant that they all had differing views of their role. To this end we confirmed a "job description" to them.

The Human Rights Network

We wished to emphasise that outside of the agreed contract, there were no rules. This exercise had not been carried out before and, as such, the coordinators

were able to develop the networks as they wished - taking on the role of trainer at national level; taking on additional help to collect/submit data; liaising between new individuals recruited; using a mentor; using the exposure to new information related to the abuse of rights to develop as national experts/spokespeople within disability organisations and the media.

The network is the coordinators, and it will be as large or small as they make it. We hope that over time it will grow and that we will receive more funding in order to train coordinators in other countries.

Evaluation of Training Programme - 2

The October session aimed to build on the evaluations of the June programme. It included the use of cases from the database to explore interviewing techniques, and the use of a press release, which could be adapted for national promotion of the project, and serve as an exercise on presentation. It was noted that great progress had already been made in terms of additional coordinators; the use of mentors; the beginning of data collection; network sponsorship in Italy; publicity via newspaper and magazine articles; greater emotional support from national assemblies and the beginnings of a greater awareness of the project.

It was also evident from feedback that the task of the coordinators was a difficult one in the sense of explaining to individuals why they should divulge information. The overall effect database will be to influence change, and in order to do this, individuals will need to share their experience of abuse or discrimination in the knowledge that nothing can be done to help change their immediate situation. Coordinators can only explain that individual cases added to thousands of others will promote reaction and help the overall struggle to fight discrimination through presentation of concrete evidence to governments and campaigning work.

A cause of concern was also the raising of peoples' expectations that their situation can be resolved or-ameliorated by the coordinator. All that can be recommended in this case is that appropriate individuals are identified within the local disability network who coordinators can refer people to for ongoing support and information. It was stressed to coordinators that they must be clear about their role with the interviewee and to discuss cases in terms of right violations, in an attempt to isolate the personal problem from the political and social problem

Network Development

Between June and October 1999, the coordinators had the opportunity for the work of collecting and submitting data to the database to begin.

However, as organisers, we had not taken into account that the volunteers would see their role as much greater than data collection alone. They saw themselves in a position to develop formal structures at national level, and had concentrated, during this first phase, on publicising the network, establishing funding, and

negotiating with their organisations. Concerned to ensure a system with continuity which could possibly work without them in the future, through the ongoing recruitment and training of other volunteers and collectors'. They had also concentrate on pinpointing sources of information i.e. in the Netherlands, a network of 28 advice centres; in Portugal, APD's social work centre; in Germany, the newly formed human rights office; in Italy, collaboration with other human rights organisations. Only in Finland did we encounter problems in that the national organisational structure had no obvious place for the coordinators to fit into. The Finnish volunteers also experienced difficulty in accessing cases of abuse and discrimination, as they are not covered in the media, and encountered problems resulting from the vast cultural differences existing within Finland.

A hugely positive outcome of the project was that it became a true learning experience for all concerned. Through the differing approaches-in the 5 countries, problems presented themselves, which sewed to be constructive to the development of the project, thanks to the ability of the group, and the trainers, to adapt to differing needs and situations. The trainers accurately described the group as "pioneers", having to clear a path in order to set up the ' networks - and they had gone along way towards this by the end of the second session.

It was evident that all the networks had different roles with and within their national assemblies, and therefore different needs. Coordinators were encouraged to discuss future strategies with their national assemblies prior to the close of the project in order to explore support and funding opportunities. They were also invited to the final evaluation session where coordinators presented on the individual networks.

All 5 countries are at different levels of development in terms of disability politics hence political developments towards non-discrimination legislation in Germany and the Netherlands meant that these national assemblies were already using evidence collected as a political tool. In Portugal, coordinators found that much of their time was spent promoting the human rights philosophy rather than building up the network. In Finland, the lack of reporting in the media and vast cultural differences within the country makes it very difficult for a network to be sustainable or effective. In Italy, the network benefited from publicity and interest from local organisations. As in Finland however, the regional differences make it very difficult for national efforts to be effective and they wish to work on building up regional networks.

The Dutch Model - Training the Trainers
The Dutch coordinator had devised an effective model which would have the possibility of being replicated throughout the network. Effectively, the 5 coordinators trained through this project would continue to liaise with DPI Europe and their national assemblies. They may also have a mentor for support and, in the case of the Netherlands, an ongoing relationship with the regional offices which, although acting as advice centres, would benefit from being able to

document the evidence. At national level, they could then recruit additional coordinators who would be responsible for collecting data and recruiting volunteers to assist in researching cases and material.   As previously mentioned, such a model would rely on the availability of national funds and a time commitment on the part of the coordinators to train others.

To the Future

In order to maintain cohesion as a group suggestions were made as to how the networks could remain in contact for mutual support.

These included:
- maintenance of the e-group
- periodic reporting on the networks in the DAA bulletin
- a virtual internet community which could operate as a private forum for the coordinators on the DPI Europe web site; plus a public forum where articles could be posted and issues discussed. Funding would have to be sought for this.

Project Evaluation

At the final session, coordinators worked on a SVVOT analysis (Strengths, Weaknesses, Opportunities and Threats) of various elements of the project which will provide a useful tool if DPI Europe are able to develop such a network in other European countries. Evaluations from the trainers are annexed.

Analysis of the project by SWOT

STRENGTHS

Recruitment of Coordinators
- Personal Profiles were considered, and individuals chosen who were known to have the relevant skills, with good networks and close links with organisations.
- Geographical coverage was considered
- Opportunity for personal development, to learn and increase own skills

National Support and involvement
- National Assembly worked closely with the coordinators expressed interest in the work and facilitated the networks when requested (D, I)
- Personal and practical support given by the local organisation (F)
- Much encouragement given at the outset
- Accessible, knowledgeable and skillful mentors for technical and emotional support and guidance.

Data Collection/Sources
- Many cases found from different sources i.e. . press and where national reports have already been prepared and only need translation (D9 N, I)
- Cases arising from counselling sessions and Independent Living Centres
- Use of reports from national organisations
- Good support from friends and colleagues to help with reading press articles
- Use of press cutting and scanning services
- Personal Contacts/interviews

External Support & Structure
- Good training which met expectations and responded to comments and criticism -proved useful in defining the role of the coordinator
- Training timetable acted as useful deadline for fulfilling the setting up of networks
- Fruitful exchange of experience; new ideas, and new ways of working
- DPI responded positively and efficiently to comments and queries
- Sense of common international purpose
- Opportunity to feedback and promote development of own organisations

WEAKNESSES

Recruitment of Coordinators
- Lack of information and clarity of what the project entailed i.e.. the training course element was not effectively explained
- National Assembly gave too little guidance and notice about the network training, -resulting in coordinators not being fully prepared for the task
- Imbalance of coordinator skills/knowledge
- Selection limited by language , which excluded many skilled individuals
- Lack of support from the National organisation because of lack of time and difficulty with the language/terminology etc.

National Support and involvement
- Definition of national assembly's commitment was unclear
- Time constraints within the organisations. Many possible individuals within the organisation who could join the network but would need support (P)
- After initial support from the National Assembly, coordinators felt isolated \
- Where mentors had been selected by the Assembly, and not chosen personally, little support was given - due to lack of clarity of their role
- Communications sometimes difficult between national coordinators because of geographical distance

Data Collection/Sources
- Lack of voluntary support to scan newspapers

- Geographical distance between organisations and lack of DPI support at local level (F)
- Lack of time to source information (F, D)
- Time delays where cases to be translated before submission to the database (I)
- Information overload (N)
- Limited media point of view - subjective or exaggerated reporting
- Unwillingness to divulge information in cases of personal interview

External Support and Structure
- Timescale too short - lack of time to fulfil the training and develop networks. 3 training sessions in London over 6 months was hard work and very stressful. It also prevented concrete results being achieved between training sessions
- Training sessions too short. Coordinators would have preferred more time for discussion; exploration of legal issues, and a re-visiting of practical skills
- Aims of the training could have been clearer at the outset.
- Aims of the training not relevant to all coordinators 1
- No contact between coordinators outside of the courses

OPPORTUNITIES

Recruitment of Coordinators
- Preparation of a 'starter pack' for the recruitment of coordinators. This could help them to decide whether or not to become involved - to include information on DPI; the HRNW; establishment of networks etc.
- A briefing pack made available prior to the training - to include how to recruit others; guidance on establishing networks.

National Support and involvement
- Coordinators were given a chance to improve their language skills (N)
- Selection of a personal mentor, to give emotional support, not necessarily from within the National Assembly, and ideally selected by the coordinator as it is a very personal relationship. (N)
- Lack of guidance from the National Assemblies worked positively in that coordinators then had a lot of freedom to define their own role and create their own networks (N)
- National organisation is a possible source of volunteers for the networks (N)
- Develop legal and political awareness at national level - empower people in order to know how to best use the data
- Make use of people within national assembly network with good language skills to support volunteers

- Development of a disability rights glossary in several languages to support those with minimal English and/or establish funds to enable interpretation .
- Clarification of role of national assembly and the support they give
- Clarity of role of mentors i.e. technical support from assemblies or emotional support from a personal mentor. Training for mentors/supporters i.e.. national networks of mentors
- Exchange of experience, and ideas
- Networking - and incorporating new regions
- Coordinator role can work on two levels - data collection as well as exploration of human rights and legal issues
- How to develop contact amongst coordinators for problem-solving and support

Data Collection/Sources
- Coordinators can use contacts with other organisations, explore the national infrastructures to gain access to cases and use projects they are working
- Clearer guidelines on submission of data
- Move from role of coordinator to mentor to ensure continuity and look at ways of transferring skills from one coordinator to another
- Propose pilot network to existing resource centres (N)
- How to share/spread expertise and responsibilities, and support communication between -national coordinators.
- Strategic publication of data. Discuss with national assemblies how the data and reports can best be used
- Look at ways to reassure people of anonymity

External Support and Structure
- Longer project period
- Greater exploration of legal issues
- Develop contacts between coordinators for problem-solving and support
- Retain sense of common international purpose

THREATS

National Support and involvement
- Development of network not a high priority
- There is usually a key person responsible for European work and if they are not available, the support is weakened. (F)
- Potential volunteers for the networks may be difficult to source because of the training language being in English (N, D)
- Many disabled people are not qualified in the area of personal development and training, and work/support would be needed to find the right people to develop and sustain the network (P)
- Lack of resources and time(I)

- Isolation and emotional involvement with cases (I)
- Need to move beyond problem solving and look at the wider picture of discrimination (D)

Data Collection/Sources
- People may be reluctant to divulge information when they know about the database.
- How to build up trust?

External Support and Structure
- Problem of language as all course materials and cases have to be translated(I)
- Concern that the lack of coordinator contact during the project may result in total loss contact after the training programme
- Possible loss of expertise and continuity if reliant on one or two coordinators
- Lack of motivation to continue collection
- Possible inability of DPI Europe to maintain a close contact with the network because other commitments, lack of resources.

Summary

The final evaluation session is largely interpreted in the SWOT analysis. The problems identified will prove very useful to DPI Europe if we are successful in repeating this innovative work elsewhere.

Many of the problems are for DPI to solve such as the language problem and developing guidelines. However, many were unforeseen. In planning this project, the Human Rights Task Force did not expect the coordinators to take on such responsibility for the future of the networks and it was emphasised that, at its basic level, this exercise was simply about data collection. To take this further nationally would have to implicate the full support of national assemblies. It is national assemblies we must also look to for adequate briefing prior to training but we know and appreciate that these organisations are tied to national commitments and it is difficult or impossible to release individuals to support European projects without adequate funds. It is also a fact that the Human Rights Task Force were keen to keep the networks separate from the national assemblies in order to keep them removed politically. With hindsight we can see that this created a gap for the coordinators in terms of support. Developing a mentor structure could be the solution to this.

It was also emphasised that the coordinators do not have to take responsibility for deciding what is or is not a violation in terms of the Universal Declaration of Human Rights. When cases are submitted, it is up to staff at DAA to decide if they can be entered into the database or not. However, it was evident that coordinators wished to have more knowledge in this area in order to better judge the cases and testimonies found.

In terms of recruitment, the Task Force had emphasised only that coordinators should have an understanding of, and a commitment to, Human Rights issues. Other skills were a bonus, but in the future we can ensure that the trainers are fully aware of these. Additionally, where specific political or legal skills exist, these can be effectively used at national level working with national reports.

The problems which exist with direct testimony is a difficult one as an individual will often feel that they will not gain anything by discussing their case for the database. It was stressed however that coordinators need to emphasise the issues of rights and violations, promoting the political/social aspect of the problem rather than focussing on the personal.

The coordinators are a committed group but time and funding is against them - and concerns were raised about the network's freedom where funds were provided via the government. We hope that they will receive support from their national assemblies, and continue to identify interested individuals to assist them in this essential task, using the network as a means to reach disabled people and influence public opinion and the government.

Disability Awareness in Action:
Human Rights Database
As at 4 April 2001

Summary
At 4th April 2001, the DAA Human Rights Database:

? ? contained 1,285 reports, affecting 2,038,044 disabled people.

? ? recorded human rights abuses that have resulted in the death of 5,036 disabled people since 1970.

? ? shows that 423,194 disabled people (21% of victims recorded in the 3 Database) have endured the breach of Article 3 - which proclaims 1 that 'Everyone has the right to life, liberty and security of the fundamental human right.
person'

? indicates that disabled people endure systemic abuse in education. Abuse of Article 26 of the Universal Declaration affected the greatest number of disabled people (768,205 or 38% of victims) education.

? ? 415,620 recorded victims (21% of all victims) have been subjected to 'torture or to cruel,. inhuman or degrading treatment or punishment' (Article 5)

? ? shows that desk-based research of documents remains the single most prolific source of evidence (49% of reports).

? indicates that the support of representative organisations of disabled people provides a vital source of information, particularly of information that is insufficiently 'newsworthy' to be reported by the mainstream press (almost 31% of reports are received via such organisations)

Annexes

1. DPI Europe - Human Rights Network Project - Press Release

2. Data Collection Form

3. June Programme

4. October Programme

5. Interviewing Skills - Case Studies & Observation sheets - Examples

6. People Skills - Identifying Future Needs

7. Trainers' Evaluations

DPI EUROPE - Human Rights Network Project

That disabled people face discrimination in their daily lives is now well documented. The realisation that disability is an issue of rights and that there
is a need for social change is now slowly being recognised by the introduction of non-discrimination legislation in some countries. However, over and above this discrimination there is a growing body of evidence of systematic violence and abuse against disabled individuals. To date, evidence of such human rights violations has not been collated or disseminated but the Human Rights Network will do this and show, through their direct experience, the reality of disabled peoples' lives.

An 'Amnesty' Model
The Network, instigated by the Human Rights Task Force of Disabled Peoples International - Europe (DPI Europe), is currently operating in 5 European countries. It consists of a small number of volunteer coordinators collecting evidence on discrimination and abuse against disabled people from the public domain and the individuals themselves. The aim is to gradually establish an 'Amnesty' type organisation, forging a network across the European Union of disabled peoples' groups who are concerned about human rights violations against disabled people.

Evidence collected is submitted to a centralised database, managed by Disability Awareness in Action (DAA), and the production of regular reports will provide hard evidence which can be used to raise awareness of disability as a human rights issue and support proposed actions for amelioration of the situation experienced by disabled people.

Background
The Network is part of a European Commission funded project which began in 1997. A report was prepared which interprets articles of the United Nations Universal Declaration of Human Rights (1948) in relation to disability and attempts to categorise what a violation is. The Human Rights Task Force also employed a computer expert to

devise a secure and effective database, and worked with a group of European experts to set down guidelines on how violations could be collected and verified whilst protecting the identity of the individuals concerned.

The second stage of the project began in January 1999 when volunteer coordinators were selected by DPI national assemblies in Finland, Germany, Italy, the Netherlands and Portugal. EU funding is providing for training in data collection and communication skills. Once the funding period is over, contracted as volunteers for two years, the coordinators will continue to recruit additional volunteers and collect evidence for submission to the global Human Rights Project being undertaken by DAA. A further objective is that the coordinators will eventually become national human rights experts to ensure an initial base of skilled people is available to join debates on a wide range of legal medical, social and ethical issues. DPI Europe is now seeking tiding to extend the Network into other European countries.

Influencing Change

It is only with the publication of concrete evidence that current practices can be challenged and real change introduced. We will demonstrate to policy makers and the community in general the true condition of disabled people in society and from this pressure, real and lasting change can be introduced.

If you are based in one of the partner countries and would like to make contact - in your own language - with a coordinator, please contact your national DPI assembly or contact us at the DPI Human Rights Network c/o 11 Belgrave Road, London SW1V 1RB UK. Tel: +44 171 834 0477 Fax: +44 171 821 9539 E: dpieurope@compuserve.com and we will forward your details to the relevant national network.

About us

DPI Europe is dedicated to the promotion and protection of disabled peoples' human rights and committed to ensuring that disabled people are able to achieve till participation, self-determination, integration and equalisation of opportunities in the structures and services at the heart of every community.

DPI E Human Rights Task Force is small group of disabled experts and lawyers working together to monitor activities and developments in relation to the protection of disabled peoples' rights.

DAA is an international information network. A collaborative project between Disabled Peopled' International, IMPACT, Inclusion International and the World Federation of the Deaf.

DATA COLLECTION FORM

HUMAN RIGHTS NETWORK - VIOLATION OF DISABLED PEOPLE'S HUMAN RIGHTS

Reference No:

1. COUNTRY OF VIOLATION

2. DATE OF VIOLATION   3. IS VIOLATION STILL CONTINUING   YES NO

4. DATE CEASED   5. IF CEASED, WHY?   PUBLIC OPINION
                                                       LEGAL ACTION

ACTION
6. TYPE OF VIOLATION   STRUCUTRE & ORGANISATION
                         INTERVENTION
                         ATTITUDES & ACTIVITIES
                         LAW
                         DEATH
                         OTHER

7. PERSONAL DATA
We need to know details of person/people involved. If the violation concerns more than one person, please tick all the relevant boxes.

GENDER	AGE	IMPAIRMENT
Female	0-16	Physical
Male	17-64	Hearing
	65+	Visual
	All	Learning Disability
		Mental Health

8. PERMISSIONS
Permission to include this information on the database
from the individual concerned if or when appropriate   Yes

/complete details overleaf
_____

To be detached & retained at national level

NAME………………………………………………………………….

ADDRESS …………………………………………………………………….

………………………………………………………………………………

………………………………………………………………………………

………………………………………………………………………………

………………………………………………………………………………

Signed: Date:

9.   DESCRIPTION OF VIOLATION

………………………………………………………………………………

………………………………………………………………………………

………………………………………………………………………………

………………………………………………………………………………

………………………………………………………………………………

Verified by ……………   Signature …………….   Date: ………….

HUMAN RIGHTS NETWORK TRAINING COURSE

FOR VOLUNTEER COORDINATORS (PART 1)

Bonnington Hotel, London, UK

4-7 June, 1999

PROGRAMME

Part 1 of the course will be held at
the Bonnington Hotel, Southampton Row, London
where participants will be staying from 4 - 7 June 1999.

Friday, 4 June 1999

14.00-15.30 Welcome

Background to the Human Rights Network Project
Knut-Johan Onarheim, Human Rights Lawyer,
Chairperson, Human Rights Task Force, DPI-EUC

An Introduction to the Universal Declaration of Human Rights and other
Human Rights Conventions
Knut-Johan Onarheim, Human Rights Lawyer,
Chairperson, Human Rights Task Force, DPI-EUC

15.30 Break

16.00 Continuation:
An Introduction to the Universal Declaration of Human Rights and other
Human Rights Conventions
Knut-Johan Onarheim, Human Rights Lawyer,
Chairperson, Human Rights Task Force, DPI-EUC

17.30. End of day's sessions

Saturday, 5 June 1999

09.30 Identifying violations and abuses within the framework of the Universal
Human Rights
Knut-Johan Onarheim, Human Rights Lawyer,
Chairperson, Human Rights Task Force, DPI-EUC

11.00 Coffee

11.30 An Introduction to data protection legislation
        Knut-Johan Onarheim, Human Rights Lawyer,
        Chairperson, Human Rights Task Force, DPI-EUC

13.00 Lunch

14.00 Methods of collecting & verifying cases of violations and abuses
        Knut-Johan Onarheim, Human Rights Lawyer,
        Chairperson, Human Rights Task Force, DPI-EUC &
        Jill Brooke, Human Rights Project Officer,
        Disability Awareness in Action

15.00 Tea

15.30 An Introduction to the Human Rights Abuses Database
        Jill Brooke, Human Rights Project Officer,
        Disability Awareness in Action

16.30 The Role of the Volunteer Coordinator
        Relationship with national assembly, a discussion
        Julie Marchbank, Project Director

Sunday, 6 June 1999

10.00 - 17.30

The Role of the Volunteer Coordinator - development of 'People Skills', including forming one to one relationships, interviewing skills, the art .of listening, how to ask the right questions, recording information, setting parameters and working within them, referring to other agencies, confidentiality and ethics

Monday, 7 June 1999

09.30 - 12.00
        Continuation:
        The Role of the Volunteer Coordinator - development of 'People Skills', including forming one to one relationships, interviewing skills, the art of listening, how to ask the right questions, recording information, setting parameters and working within them, referring to other agencies, confidentiality and ethics.

DPI Europe - Human Rights Network Project Co-ordinator Training
Development of 'People Skills' Module
Sunday 6th and Monday 7th June 1999, London

Aims and Objectives

The overall aim of this module is to equip volunteer human rights network co-ordinators with the appropriate communication skills to carry out their role effectively.

Objectives:

By the end of this module, co-ordinators will:

- understand the issues which affect individual and group communication, and in particular be able to identify potential blocks and barriers
- be equipped to apply appropriate interviewing techniques, including active listening and effective questioning
- have gained a clear awareness of the most useful ways of presenting and recording information, arising from individual and team working
- be able to set parameters for their own involvement, and be able to find ways of identifying and communicating boundaries
- understand the importance of referring 'to other agencies, and be able to identify the points at which that may become appropriate, as well as communicate this clearly and assertively
- have begun to develop a communication action plan for their own development and involvement in the network.

Programme Outline - Day I

Welcome and objectives for the module

Effective communication: factors affecting communication blocks
                            barriers and pitfalls

Interviewing techniques: access issues
                            active listening

effective questioning

Recording information: methods of recording
consistent, systematic and accurate recording

Presenting information: getting the message across effectively
basic presentation skills

Establishing the boundaries (I): introduction

Programme Outline - Day 2 (half day)

Review of day I and questions

Establishing the boundaries (2):   assertive communication
stress and pressure
resources for referrals
using your own support network

Action plans: group and individual
individual communication skills
audit and development action plan
action plan for involvement in the network

Session/Workshop Evaluation and close.

DISABLED PEOPLES' International EUROPE

HUMAN RIGHTS NETWORK PROJECT
TRAINING FOR VOLUNTEER COORDINATORS
(PART 2)
Bonnington Hotel, London, UK
8 - 10 October, 1999

DPI-EUC, 11 Belgrave Road, London SWIV IRB, UK.

Aims and Objectives

The overall aim of this module is to build on and consolidate communication and related skills to enable volunteer human rights network co-ordinators to carry out their role effectively.

Objectives:

By the end of this module, co-ordinators will have had an opportunity to revisit a number of key issues dealt with during the initial training in June 1999, and 'address areas of current need so that they:

- deepen their understanding of the main aspects of individual and group communication and, in particular, potential blocks and barriers;
- practise appropriate interviewing techniques, including active listening and effective questioning;
- gain an awareness of the most useful ways of combating isolation and vulnerability within their role, including by effective use of key relationships;
- develop their own presentation skills in relation to disseminating information about the network / project within their own country;
- understand their own future role and continue to develop their action plan for development of and involvement in the network

PROGRAMME
The course will be held in the Derby Rooms,
the Bonnington Hotel, Southampton Row, London WC1
where participants will be staying from 8 - 10 October 1999.

Friday, 8 October 1999

Coordinators arrive
Dinner available at the hotel until 22.00

Saturday, 9 October 1999

10.30	Coffee & Welcome
10.45	Open Forum - Round table discussion. An opportunity to exchange experience/problems/concerns and to seek clarification on issues relating to data collection and violations. *Facilitator: Rachel Hurst - member of DPI E Human Rights .Task Force*
13.00	End
13.30	Lunch - will be served in the restaurant
15.30	Development of 'People Skills' Module - stage 2 *Trainers - Andrew Bruce & Jeni Price* Session 1: Welcome - Objectives Review of presentation skills and methods - DPI press release
17.00	Break - Coffee/tea will be served
17.50	Session 2: Presentation skills. 'A practical exercise based on DPI press release
19.00	Session ends
19.30	Dinner - will be served in the restaurant from 19.30

Sunday, 10 October 1999

09.0	Continuation - Development of 'People Skills' Module - stage 2 Session 3: Key learning points from presentation skills session

Review of interviewing techniques and models .
Interviewing skills practical session based on case studies

10.30   Break - Coffee/tea will be served

11.00   Session 4:
Feedback and discussion from interviewing skills session
Individual issues for co-ordinators (1):
Dealing with isolation and vulnerability

12.30   Lunch - will be served in the restaurant

13.30   Session 5
Individual issues for co-ordinators (2)
Identifying and using support effectively
Finding and working with volunteers

15.00   Break - Coffee/tea will be served

15.15   Session 6
Closing session - review, round-up and evaluation
Identification of anticipated future needs
Conclusion by DPI

16.00 Au revoir and bon voyage!

Interviewing Skills Session
Case Study 2

Interviewee Instructions

You are a 51 year old woman with learning difficulties. You want to tell the person talking to you about things that happened to you in your childhood, particular between the ages of IO and 14 when you f were sent to live at the "Provincial Training Centre for Mental Defectives".

The institution had both adults and children living there. You were made to change dirty underclothes of adults who were unable to care for themselves. You were forced to do housework, like scrubbing floors. All your food was mashed up and you had to eat from a tin bowl with a spoon. You slept on a mattress in a room with bare cement floors.

For you the most distressing thing was that at the age of 14 you were told you were going to have your appendix taken out, but you were sterilised (you might describe this as 'stopped from having a baby when I was older'). You get very upset about this as you would have liked to have children. You keep going back to this during the course of the interview and get distressed when you talk about it. You know that people in authority agreed that

you should be sterilised because they didn't believe you were capable of being a good parent.

You left the institution in 1965 and went to live independently. Someone has helped you to take legal action against the local. authority and you have been given a very large sum of money in compensation. But this won't make up for the treatment you received and the fact that you have never been able to have a baby.

Interviewing Skills Session

Observer Instructions for Case Study 2

- How did the interviewer put the interviewee at ease?

- What techniques did they use to start the interview and find out key facts?

- How did they deal with any distress that the interviewee showed?

Case Study 2 - Observer's Sheet

•What kind of questions worked well?

•What could have been done differently to improve the interview?

•Did the interviewer establish good communication at a level which could be understood by the interviewee?

•If you are comfortable with the TA model, do you have any comments about the behaviours which each person was using (parent, adult, child)? What about body language etc.?

Interviewing Skills Session
Case Study 3
Interviewer Instructions

You have at last managed to interview a homeless disabled man who has been in prison for six months. You know that he was put in prison for hitting a police officer, and that he was just given a 'suspended' sentence (not actually. put in prison, but found guilty and would only have to serve the prison sentence if he did that, or a similar, offence again).

The only other of information you have been given that he crawled into court.

You need to find out if he really did crawl into court and why. You also need to find out a bit about his history, and the circumstances around his arrest and trial. Why did he end up going to prison if he was only given a 'suspended' sentence.

Interviewing Skills Session
Case Study 3

Interviewee Instructions

You are a disabled man who has been homeless for many years. You spend a lot of time on the streets, begging. Last year a police officer arrested you for begging, but you got very angry and upset and hit him. When you were taken to the police station, your crutches were taken away. This meant you had to crawl into court a few days later when your case was tried.

You had a very difficult childhood and have been in hospital or homeless for a lot of your life. This was because your parents abandoned you when you were 9 years old, when you got polio.

You explained this in court and were given a 'suspended' sentence of one year (that means you didn't have to go to prison, as long as you assured the court you wouldn't carry on begging). There was a complaint that the sentence wasn't harsh enough so you were sent to prison for six months, although your crutches were returned to you.

You feel angry and humiliated. You can't understand how anyone expects you to live without begging, because you have little education and no chance of getting a job. You think that the Human Rights Network Co-ordinator may be able to help you sort out your problems and keep asking what they think you can do now-where you can live and how you can get enough money to eat, etc.

Interviewing Skills Session

Observer Instructions for Case Study 3

•How did the interviewer put the interviewee at ease?

•What techniques did they use in the interview to find out key facts?

•How did they keep the interview 'on track' (on the main subject)?

Case Study 3 - Observer's Sheet

•How did they deal with any anger that the interviewee showed?

•What kind of questions worked well?

•What could have been done differently to improve the interview?

•If you are comfortable with the TA model, do you have any:- comments about the behaviours which each person was using (parent, adult, child)? What about body language, etc.?

DPI Europe
"People Skills" Module - 9th - 10th October 1999

IDENTIFYING YOUR FUTURE NEEDS AS VOLUNTEER CO-ORDINATORS

Please think about any barriers that may get in the way, or stop you carrying out your role in the future. These could include things such as:

→Resources -financial and human.

→Accessible equipment/work and interview space.

→ Lack of support or financial assistance.

→Attitudes of others.

→Information and communication issues.

→Training/knowledge gap.

→Appropriate back-up/materials from DPI or own Assembly, including guidance or contracts etc.

Now, we'd like you to summarise or make a note of what specific needs you have which, if met, would successfully deal with or remove these barriers, (now or in the future). How could you get these needs addressed?

(Please work in pairs or small groups to discuss)

Trainers' Evaluation Session
January 2000

Preparation:
Didn't know enough about group
before training started: trainers
should do a Training Needs
Analysis before future course(s)

Assumptions!
Trainers had certain assumptions
that Co-ordinators would know their
roles. However it turned out that it
was an evolving understanding for all

Training Needs

Using the group:
This was a very skilled group who
could have been involved in
planning their
training/support/contact time. Need
to consider ways of achieving that
in future if appropriate

Trainers' Evaluation Session
January 2000

Expectations and Needs:
Individuals had different
expectations and needs, so not all
needs were met (which may be true
of any training). However, common
goal to some extent overcame
potential negatives of that

Skills for Role:
Needed earlier clarification of skills
required for role - person
specification at start would
design of course (and possibly
recruitment of Co-ordinators?)
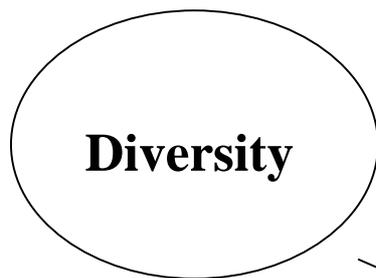
Diversity

Diversity is strength!
Very positive sharing of ideas
different approaches, cultures:
experience, skills etc. ,A
challenge at times, but also
one of major strengths of group

Language:
An issue and a challenge at
times for participants and
facilitators. Learning points for
future work here!

TRAINER'S EVALUATION
14th - 15th January 2000

Need to agree a better
balance of formal learning
and skills training
with Open Discussion

Use of examples
or content nearer
to the work of
Coordinators
would be valuable

How to best use our 'contact time' with volunteers

Trainers need to be clear
what timetable is
acceptable to participants
in order to design a
successful programme,
that will be 'owned' by
Coordinators

Balance of our
flexibility and Co-
ordinators'
commitment to
making best use
of the limited
contact time
available

TRAINER'S EVALUATION
SESSION
14th - 15th January

Perhaps we could arrange a Training 'Refresher' weekend for a year's time to review progress and share experiences!

Has been a positive learning experience for us all

Project development - Observations and future issues

Evaluation of the training has been patchy - this has close link to 'training needs analysis' for next time

We have made good progress across all areas (DPI, the database /participants and trainers)