



# Partners for Better Policies: A Manual for Mainstreaming

Developed by the European project  
“Mainstreaming Mental Disability Policies”

**Policies matter!**

**Words into action!**

**We are citizens too!**

**Together we can do it!**

**Nothing about us, without us!**

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## Information about the Partners

This project, which is supported by the European Commission, has been organised by:

- **Inclusion Europe**, the European association of societies of persons with intellectual disabilities and their families. Inclusion Europe campaigns for the rights and interests of people with intellectual disabilities and their families throughout Europe, co-ordinates activities in many European countries, responds to European political proposals and provides information about the needs of people with intellectual disabilities, advises the European Commission and members of the European Parliament on disability issues.  
[www.inclusion-europe.org](http://www.inclusion-europe.org)
- **The Open Society Mental Health Initiative** supports initiatives within Central and Eastern Europe and the former Soviet Union that seek to develop community-based services as an alternative to institutionalisation and to address the social exclusion of people with mental health problems and/or intellectual disabilities.  
[www.osmhi.org](http://www.osmhi.org)
- **Global Initiative on Psychiatry** aims to promote humane, ethical and effective mental health care throughout the world, and is in particular active in the countries of Central and Eastern Europe and the Newly Independent States, where mental health care is still usually substandard and service users' human rights are frequently violated. It also campaigns against political abuse of psychiatry wherever it occurs.  
[www.gip-global.org](http://www.gip-global.org)

In each of the eight countries two organisations (one working with people with intellectual disabilities and one working with people with mental health problems) have been responsible for the implementation of the project activities in their country.

The eight organisations that worked on issues relating to people with intellectual disabilities:

- **Inclusion Czech Republic (ICZ)** is an independent and voluntary association for people with intellectual disabilities and their families. ICZ supports initiatives which seek to improve the lives of people with intellectual disabilities and enable them to live as equal citizens.  
[www.spmPCR.cz](http://www.spmPCR.cz)
- **Estonian Mentally Disabled People Support Organisation (EVPIT)** represents Estonian organisations working on behalf of people with intellectual disabilities. EVPIT's mission is to improve the situation of people with intellectual disabilities in Estonia. Our main goal is to represent the interests of people with intellectual disabilities and, through our activities, ensure that they can participate in society as equal citizens.  
[www.vaimukad.ee](http://www.vaimukad.ee)

- **Hand in Hand Foundation** was founded in 1993 in Hungary. It is a national organisation that aims to improve the lives of people with intellectual disabilities and their families. We work with those professionals who work with people with intellectual disabilities and who share our values. International and Hungarian experts, parents and people with intellectual disabilities help us by contributing their ideas, opinions and expertise to the development and implementation of our far-reaching programmes. The main areas of our work are advocacy, supporting individuals, raising public awareness, providing an information service and service development.  
[www.kezenfogva.hu](http://www.kezenfogva.hu)
- **Rupju Berns** (Latvia) is an organisation that works in the field of policy development and seeks to promote more positive attitudes towards people with intellectual disabilities within society. In recent years we have focused on developing a network of self-advocates. These activities are linked to our work in establishing a supported employment agency and promoting lifelong learning for independent living and self-determination. These projects were initiated in 1999 with the support of Phare Lien programme and have been developed as local projects over the last few years. This has resulted in the establishment of a subsidiary organisation (NGO “Saule”) which specialises in working with the self-advocacy network. .  
[www.latvijasrupjuberns.lv](http://www.latvijasrupjuberns.lv)
- **Lithuanian Welfare Society for Persons with Mental Disability “Viltis”** is an association of Lithuanian organisations working to promote rights of people with intellectual disabilities and their families and the development of community-based services. We also advise public authorities on the development of laws and regulations concerning disability issues. We work closely with professionals from other Central and Eastern European countries - helping them to develop appropriate and accessible services for persons with intellectual disabilities and their families.  
[www.viltis.lt](http://www.viltis.lt)
- The **Polish Association For Persons With Mental Handicap** is a non-governmental, non-profit organisation. It represents the interests of people with intellectual disabilities and their families in Poland. The goal of the Association is to create equal opportunities for people with intellectual disabilities, to ensure respect for their human rights, to guide them towards active participation in social life and to support their families.  
[www.psouu.org.pl](http://www.psouu.org.pl)
- The major aim of **The Association for Help to People with Mental Handicap (ZPMP)** in Slovakia is the integration of people with intellectual disabilities into society. We want to ensure that basic human rights become a natural attribute of life for people with intellectual disabilities: the rights to work, education, leisure, family life and friends and to be accepted as they are. The activities of ZPMP in Slovakia include: the provision of social counselling and support to people with intellectual disabilities and their parents and ensuring respect for the rights and interests of people with intellectual disabilities. We publish various materials such as a magazine, a self – advocates magazine “It’s Us”, leaflets, and professional manuals. We also provide professional training and educational activities such as lectures and seminars, and organise events for self-advocates.  
[www.zpmpvsvr.sk](http://www.zpmpvsvr.sk)

- **Zveza Sožitje** is the Slovenian association of societies of people with intellectual disabilities and their families. Our goal is to provide support to people with intellectual disabilities. Our organisation has over 14, 000 members and is associated with 50 local societies and the Special Olympics of Slovenia. Zveza Sožitje was established in 1963. Since then we have developed a range of programmes for people with intellectual disabilities and their families, such as weekend seminars, life-long learning seminars and a four-year education and training programme for families. We work with national and international organisations with similar interests and objectives.  
[www.zveza-sozitie.si](http://www.zveza-sozitie.si)

The eight organisations that worked on issues relating to people with mental health problems:

- **Centre for Mental Health Care Development** is a non-governmental non-profit organisation that focuses on promoting reform and developing mental health care in the Czech Republic. The Centre was founded in 1995. We seek to protect the rights of people with mental health problems and improve mental health care. All our activities, many of which are supported by professional and financial help from abroad, focus on working with mental health care providers, public policy makers at all levels (ministerial, regional, and local) and health insurance companies.  
[www.cmhcd.cz](http://www.cmhcd.cz)
- **Iseseisev Elu** is a non-governmental organisation which provides services to people who have mental health problems and/or intellectual disabilities. Iseseisev Elu provides supported living (housing), supported employment and day care services.  
[www.iseseisev-elu.ee](http://www.iseseisev-elu.ee)
- **Soteria Foundation** (Hungary) was established by professionals and relatives in 1995. The purpose of the organisation is to provide community-based services for people with mental health problems in Hungary. Soteria has established the first day care centre in Budapest, a café as a social non-profit enterprise and a mobile case management team. It has also started vocational rehabilitation and vocational training programs.  
[www.soteria.hu](http://www.soteria.hu)
- **Global Initiative on Psychiatry** (GIP – Lithuania) is active in promoting mental health reform in the former Soviet Union. The organisation's main activities are: policy development and the promotion of evidence based practice in mental health; the improvement of mental health service delivery and building capacity of mental health non-governmental organisations.  
[www.gip-global.org](http://www.gip-global.org)
- **The Brotherhood of Hearts** (Poland) enables users and ex-users of mental health care to provide support to each other, for example in relation to hospitalisation. Its activities include: self advocacy supporting people with mental health problems in seeking employment and accommodation. We are also involved in policy development, working with public authorities and the media to raise awareness about the rights of people with mental health problems. For example we were involved in the preparation of the Mental Health Act 1993/4, the first of its kind in Poland. We are also involved in anti discrimination and anti social exclusion activities and participate in conferences and seminars.  
[www.enusp.org/braterstwo/index.htm](http://www.enusp.org/braterstwo/index.htm)

- **The Association for Mental Health Integra** (Slovakia) was established in October 1994. Its goal is to promote respect of the rights of people with mental health problems and enable them to live as equal citizens. Integra is establishing a new mental health care system based on tetralogue (mutual communication between clients, relatives, professionals and public) derived from needs of the clients. Currently, Integra operates four types of community-based services for people with mental health problems: case management, rehabilitation centre, sheltered workshops and sheltered housing.  
[www.integradz.sk](http://www.integradz.sk)
- **Latvian Nurses Association** – Psychiatric Nurses Unit (PMA) NGO, was founded in 1994 and has 515 members. PMA activities include policy development and public awareness – seeking to promote more positive attitudes towards people with mental health problems. PMA organises seminars on establishing self-help groups for clients and their relatives and prepares educational programs for professional, service providers and users. In October 2005 PMA organised a public awareness campaign focusing on the human rights of people with mental health problems in Latvia. PMA also participated in trans-national meetings, organised national conferences and training workshops.  
[www.masas.lv](http://www.masas.lv)
- **Association for Mental Health VEZI**, Štorje near Sežana, Slovenia, was established in 1998. It aims to help those people with mental health problems who live in Carst, in the west part of Slovenia. Both the number of people involved with the organisation's work (people with mental health problems, professionals and non-professionals) and the range of services it provides (education, advocacy, day centres and rehabilitation) has grown over the years. Today Association VEZI has four Day-Centres in different parts of the region, two group homes (with two new group homes about to be established) and a social enterprise project.  
[www.drustvo-paradoks.si](http://www.drustvo-paradoks.si)



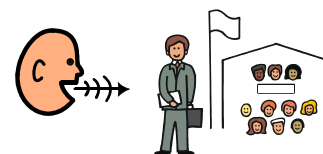


## Introduction

This manual gives information to everyone who wants to have a say in policies that are written about them.



This manual gives information on important topics. It gives ideas about how to speak with politicians and other people who make decisions about policies.



This manual can be used by trainers working with people with intellectual disabilities or with people with mental health problems.



This manual can also be used by people with intellectual disabilities and by people with mental health problems.



## Introduction

This Manual has been produced as part of the project “Mainstreaming Mental Disability Policies”.<sup>1</sup> Its purpose is to provide materials that are relevant to people with mental health problems and/or intellectual disabilities and that can be used in training events on mainstreaming policies. The Manual is also intended to help self advocates and other individuals and groups who wish to become involved in the development of policies that affect them by providing information on relevant topics, making practical suggestions on how to engage with policy-makers and raise issues of concern and by giving details on where to obtain further information.

<sup>1</sup> The term “mental disability” includes people with mental health problems and people with intellectual disabilities. Information on “mental health problems” and “intellectual disabilities” is provided on page 19.



## 1. The Mainstreaming Mental Disability Policies Project

This manual was written as part of a project called “Mainstreaming Mental Disability Policies”.

The word “mainstreaming” is very difficult to translate. When we speak about “mainstreaming”, it means that policies should not forget people with intellectual disabilities or people with mental health problems.



Politicians are responsible for different areas of work. For example social affairs, employment, culture or sport. When writing new policies or programmes for these areas, all politicians should also have in mind people with intellectual disabilities and people with mental health problems.



Partners from 8 countries worked on this project: The Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia.

The project partners organised national conferences and group discussions.

They also organised seminars and workshops for people with intellectual disabilities and with mental health problems.



The aim of the project was to show these people how they can speak with politicians about policies that affect them.



The European Union also believes that politicians must think about disabled people when they write new policies.



The European Union is a group of European countries that work together.

The European Union is very important for everybody in Europe.

# **1. The Mainstreaming Mental Disability Policies Project**

## **1.1. Purpose of the Project**

The purpose of the “Mainstreaming Mental Disability Policies” project is to increase the opportunities for people with mental health problems and people with intellectual disabilities to participate effectively in the development and implementation of policies and measures that affect them.

This project is being implemented in the eight new EU member states from Central and Eastern Europe (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia). The project activities seek to:

- increase the awareness of politicians and policy makers of the existence, needs and capacities of people with mental health problems and people with intellectual disabilities;
- increase the capacity of people with mental health problems and people with intellectual disabilities and non governmental organisations working with one or both these groups of people to engage in policy development at local, national and European levels;
- achieve change in policies and legislation so that people with mental health problems and people with intellectual disabilities have better access to education and employment;
- disseminate best practice for mainstreaming policies relevant to people with mental health problems and people with intellectual disabilities.

## **1.2. What We Mean by “Mainstreaming” and Why It is Important**

We use the term “mainstreaming” to describe the process of ensuring that all policies and measures of government and other decision makers take account of, and are responsive to, the needs of people with mental health problems and people with intellectual disabilities. This should apply to all policy and measures not just those that focus on specific mental health or intellectual disabilities issues. This approach reflects both European Union policy and international human rights standards. For example, the European Commission states that in its policies for “disadvantaged groups” (people with disabilities are included in this category):

*“...the Commission follows the approach of mainstreaming. Mainstreaming means that the needs of disadvantaged people need to be taken into account in the design of all policies and measures, and that action for disadvantaged people is not limited to those policies and measures which are specifically addressing their needs.”*



The United Nations thinks that it is very important that people with disabilities should have a say in the development of policies.



The United Nations is an international organisation. 191 countries are members of the United Nations. This means that nearly every country of the world is a member of the United Nations.

## **2. Scope, Purpose and Contents of the Manual**

### **2.1. Scope and Purpose**

This manual is for trainers, with or without intellectual disabilities or mental health problems. It is also for any trainers working with people with intellectual disabilities or with people with mental health problems.



Other people can also use this manual. It can be used to make politicians more aware of the needs of people with intellectual disabilities and people with mental health problems.

This manual covers several topics. Because it cannot cover everything, this manual only gives summaries of these topics. It also gives website addresses where you can get more information.



There is a leaflet that goes with this manual. The leaflet is about the difference between intellectual disability and mental health problems. This leaflet can be given to politicians, to help them understand the difference.



There is also a CD Rom with this manual. This manual and the information on the CD Rom can be photocopied. For example, trainers may want to use some material from this manual. They can do that and photocopy whatever they need.

The United Nation Standard Rules on the Equalization of Opportunities for Persons with Disabilities stress that the needs of each and every individual are of equal importance and that those needs must be made the basis for the planning of societies. Furthermore these Standard Rules state:

*“States should establish ongoing communication with organisations of persons with disabilities and ensure their participation in the development of government policies”.*<sup>2</sup>

Mainstreaming is underpinned by human rights principles such as equality, respect, dignity and participation.

Thus mainstreaming is of great importance. It also has a very practical benefit – if the views of people with mental health problems and people with intellectual disabilities are taken into account in their development and implementation, the resulting policies and measures are likely to be more relevant and effective.

## **2. Scope, Purpose and Contents of the Manual**

### **2.1. Scope and Purpose**

The Manual is intended to be a useful resource for those training people with mental health problems or people with intellectual disabilities on how to engage with policy makers. It should also be useful for individuals seeking to make politicians and other policy-makers more aware of the issues relating to people with mental health problems and/or intellectual disabilities. Given the scope of the areas covered, it cannot provide comprehensive information on every topic. Rather the Manual provides a summary of key issues and provides details on where further information can be obtained.

The Manual and accompanying materials (the documents on the CD Rom and the brochure outlining the differences between mental health problems and intellectual disabilities) can be copied. For example trainers may want to photocopy parts of the Manual to use as handouts for participants at training events. The brochure could be given to politicians and other policy makers.

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<sup>2</sup> See Introduction and Rule 18, A/RES/48/96, 20<sup>th</sup> December 1993, available at: [www.un.org/esa/socdev/enable/dissre00.htm](http://www.un.org/esa/socdev/enable/dissre00.htm)



## 2.2. Overview of Contents

There are 4 parts in this manual.



Part 1 has some general information.

For example, it explains how the European Union is organised.

It is accessible for people with intellectual disabilities and for people with mental health problems.



Part 2 has information

just for people with mental health problems.

This section is not in easy-to-read.



Part 3 has some ideas for trainers

who work with people with intellectual disabilities.

For example, it tells you about self-advocacy,

how to hold a meetings

and how to have a say in policies.

It also gives website addresses where you can find more material.

Part 3 is meant for people with intellectual disabilities.

Therefore, it is only in easy-to-read.



Part 4 has information, which is just for your country.

To influence policies, it is important to know

- who is responsible for what in your country;
- which organisations exist and what they work on;
- how your country is organised.

Part 4 was written for the project's countries.

Therefore, there is no part 4 in this English version.

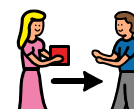


## 2.3. Future Use of the Manual

All countries should have good “mainstreamed” policies.

The partners in this project think that this manual can help.

Therefore, they want to make sure that lots of people see it.



You can help them by telling people about this manual.



## **2.2. Overview of Contents**

The manual is divided into four parts.

- **Part 1: General Information:** this is relevant and accessible to both people with intellectual disabilities and people with mental health problems. It includes, for example, a summary of how the European Union is organised and an overview of international human rights standards.
- **Part 2: Issues Specific to People with Mental Health Problems:** this provides information that will be of relevance to people with mental health problems such as information on key policy areas and suggestions for raising awareness about mental health issues, and how to organise events e.g. workshops and self advocacy groups. This section is not in an easy-to-read format.
- **Part 3: Ideas for Trainers Working with People with Intellectual Disabilities:** this provides trainers, with or without intellectual disabilities, suggestions on how to deliver training on various topics (such as self-advocacy, holding meetings and how to influence policies) and where they can find additional materials which will help to make their training participative and interesting. The information will also be useful for self-advocates wishing to become involved in the development of policies that affect them. Therefore, this information is provided in an easy-to-read format.
- **Part 4: Country Specific Information:** This Manual will be available in the languages of each of the eight countries partners in this project (Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia). Policies are developed and implemented at local, national, European and international levels and therefore, in order to be able to influence policy, it is important to know who or what organisations are responsible for, or have an interest in, in the particular policy that needs to be developed or improved. In other words it is crucial to know who the “key players” are in policy development. Part 4 which has been researched and written by the project’s national partners provides such information for each country.<sup>3</sup>

## **2.3. Future Use of the Manual**

The Manual will be available in French and German as well as Czech, Estonian, Hungarian, Latvian, Lithuanian, Polish, Slovak and Slovenian. By disseminating this Manual as widely as possible, the partners of the “Mainstreaming Mental Disability Policy” project aim to ensure that the work to promote self-advocacy and the mainstreaming of policies that are relevant to people with mental health problems and intellectual disabilities will continue beyond the life of this project.

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<sup>3</sup> Given that this section has been prepared in the national language of each of the eight countries, Part 4 is not included in the English version of the Manual.





# Part 1. General Information



There are 6 topics in part 1.

- Understanding the differences between mental health problems and intellectual disabilities.
- The European Union.
- Human rights.
- Employment.
- Education.
- Further information.

## Part 1. General Information

### Summary

Part 1 covers the following areas:

- Understanding the Differences Between Mental Health Problems and Intellectual Disabilities: if policies and other measures are to be relevant and appropriate to both people with intellectual disabilities and people with mental health problems, policy makers and other stakeholders involved in policy development will need to understand the particular issues relating to both these groups of people;
- The European Union (EU): this section provides a brief summary of the purpose and activities of the EU and provides sources for further information;
- Human Rights: this section provides an overview of some key human rights instruments. It also considers some areas of particular relevance to people with intellectual disabilities and/or mental health problems living in Central and Eastern Europe;
- Employment: this section gives examples of human rights instruments, which set out the right to work and it also provides information on the EU Directive on Equal Treatment in Employment and Occupation;
- Education: this section gives examples of human rights instruments, which set out the right to education and provides information on EU activities in relation to education;
- Further Information: this section provides you with a list of European-wide organisations working on topics that can be of relevance for people with intellectual disability and/or mental health problems.



# 1. **Understanding the Differences Between Mental Health Problems and Intellectual Disabilities**



People with intellectual disabilities and people with mental health problems have some things in common.

- They are the most excluded amongst disabled people.
- They are the most discriminated against.
- They face big barriers to their social inclusion.
- Many of them still live in long-stay institutions.



But there are also many differences between people with intellectual disabilities and people with mental health problems. It is very important that everyone understands these differences. If people do not understand these differences, they will create services that do not meet the needs of these people.



If politicians understand these differences, they will make better policies. They will also be able to take actions to stop discrimination.



## 1.1. People with Intellectual Disabilities

What is meant by “intellectual disabilities”?



When people have intellectual disabilities, they have it from birth and for the rest of their life. It is called a “life-long” condition.

The reasons for intellectual disabilities can be:

- problems during the pregnancy or at birth;
- other reasons, for example a result of an infection or injury.



People with intellectual disabilities have lower intellectual abilities. This means that they might have some problems with things like

- reading;
- counting;
- finding their way around;
- or remembering things.



However, people with intellectual disabilities also have abilities that must be respected.

## **1. Understanding the Differences Between Mental Health Problems and Intellectual Disabilities <sup>4</sup>**

The “Mainstreaming Mental Disability Policies” project focuses on both people with intellectual disabilities and people with mental health problems because they are the most discriminated and excluded groups amongst disabled people and thus the most likely to be excluded from the policy-making process. While there have been some significant improvements in attitude towards disabled people generally, there remain significant and widespread barriers to the social inclusion of people with mental health problems and/or intellectual disabilities. These barriers are particularly severe in Central and Eastern Europe (CEE) where both these groups of people continue to be excluded from mainstream society and denied their rights. This is because given the lack of community-based services, many people with mental health problems and many people with intellectual disabilities are still placed in long-stay institutions. Those people who have not been institutionalised are also likely to be excluded from community life because there are little or no services in the community and their relatives often keep them at home in order to protect them from abuse and/or to avoid bringing shame on the family.

Although these groups of people face similar barriers to their social inclusion - such as widespread and deeply rooted stigma and prejudice and serious human rights abuses - there are significant differences between them. A failure to understand these differences is likely to lead to the provision of inappropriate services and perpetuate the negative attitudes, which lead to stigma and discrimination. An understanding of these differences will help politicians and other decision-makers in their work to ensure that the steps taken to promote the social inclusion people with mental health problems and people with intellectual disabilities are both relevant and effective. It will also help them to ensure that policies and other measures are relevant and appropriate to individuals in each of these groups. Accordingly, this section explains what is meant by the terms “intellectual disabilities” and “mental health problems” and provides some information on some key differences between these two groups of people.

### **1.1. People with Intellectual Disabilities**

#### **What is meant by “intellectual disabilities”?**

This term refers to a lifelong condition, usually present from birth or that develops before the age of 18. Intellectual disabilities can be caused by genetic factors, or by environmental factors, such as infections, or by a lack of oxygen supply to the brain during pregnancy or at birth or due to abuse of alcohol during pregnancy or an injury to the brain or head. It is a permanent condition that is characterised by significantly lower than average intellectual ability and results in significant functional limitations in intellectual functioning and in adaptive behaviour. Thus people with intellectual disabilities may have permanently impaired skills in areas such as cognition, language, motor and social abilities.

However, people with intellectual disabilities also have a wide range of skills and abilities. Some people can live independent lives and will need help only in some very specific areas of life (for example some people can read but have difficulties with numbers, some people can count and calculate but have difficulties telling the time, etc).

Although there is a difference between intellectual disabilities and mental health problems, people who have intellectual disabilities can also experience mental health problems.

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<sup>4</sup> This section has been written on the basis of a brochure published by Inclusion Europe and Mental Health Europe.



### What kind of support do people with intellectual disabilities need?

People with intellectual disabilities want the same things as everybody else. For example they want to be happy, to have friends and to have a good life.

All people with intellectual disabilities also have abilities.

They can all play a role in society.

It is important, therefore, that

all services for people with intellectual disabilities focus on this.

All services should promote inclusion into society.

This is why inclusive education, vocational training and community-based services are so important.



Another very important thing for people with intellectual disabilities is accessible information.

Information is very important in society.

It is also important for people with intellectual disabilities.

Texts giving important information on people with intellectual disabilities should always be available in an accessible format, for example in easy-to-read or recorded on tapes.



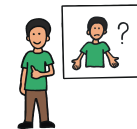
In lots of countries, people with intellectual disabilities have started groups.

These are called “self-advocacy groups”.

The people in these groups work together.

They make sure that they are asked what they think when decisions about them are taken.

Only people with intellectual disabilities can make decisions in these groups.



## **1.2. People with Mental Health Problems**



### What is meant by “mental health problems”?

People with mental health problems have, for example, problems such as anxiety or depression.

When people have mental health problems, they might find it difficult to sleep, to think clearly or to speak with other people.



There are many reasons why a person may have mental health problems. For example, a person may develop mental health problems after a stressful life event, like the death of a close friend or losing a job.

People with intellectual disabilities can also have mental health problems during their lives.

### What kind of support do people with intellectual disabilities need?

Most people with intellectual disabilities have the same needs as other people, such as having somewhere decent to live, opportunities to receive an education, obtain meaningful employment and choosing who to spend time with. However, they may need additional support to enable them to achieve these. The type of support required will depend on each individual and the nature and degree of that person's intellectual disabilities. People with mild intellectual disabilities may need some additional education (often life-long education), but can generally live independently with a small amount of support. People with more severe disabilities often need much more social support, for example personal support.

All services for people with intellectual disabilities must be geared towards maximizing both their abilities and their participation in society.

Services that facilitate and support individual development can greatly improve the abilities and promote the independence of people with intellectual disabilities. Early identification of disability and early intervention services are important in promoting optimal development of the capacities and self-determination of the individual. Access to quality inclusive education, vocational training and employment, as well as community-based living services all work to enhance the ability to lead an independent life and to promote social inclusion.

For people with intellectual disabilities, access to information is of central importance. They need information in easy-to-understand format to participate fully in society.

Increasingly, people with intellectual disabilities are claiming the right to speak for themselves and to be recognised as equal partners in discussions about decisions that affect them. This is called self-advocacy. In many countries people with intellectual disabilities have established groups of "self advocates" who support each other and others with intellectual disabilities to make their views known and to ensure that they are consulted on all decisions that affect their lives.

## **1.2. People with Mental Health Problems**<sup>5</sup>

### What is meant by "mental health problems"?

The term "mental health problems" describes a broad range of mental and emotional conditions and diagnoses such as anxiety, stress, depression and schizophrenia. Mental health problems are different from other conditions such as intellectual disabilities. The term "mental health problems" is used when an individual's mental condition significantly interferes with the performance of major life activities such as thinking, communicating, learning, and sleeping. Someone can experience mental health problems over many years. The type, intensity, and duration of symptoms vary broadly from person to person. Symptoms can come and go and seldom follow a regular pattern, sometimes making it difficult to predict when symptoms and functioning will worsen.

In some cases where individuals experience severe and/or enduring mental health problems they may be described as having a "mental illness" or being "mentally ill". However, many people with mental health problems find such terms offensive and stigmatising.

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<sup>5</sup> For further information see Mental Health Foundation: [www.mentalhealth.org.uk/page.cfm?pagecode=PM](http://www.mentalhealth.org.uk/page.cfm?pagecode=PM) and Mind: [www.mind.org.uk/Information/Factsheets/#M](http://www.mind.org.uk/Information/Factsheets/#M)



## What kind of support do people with mental health problems need?

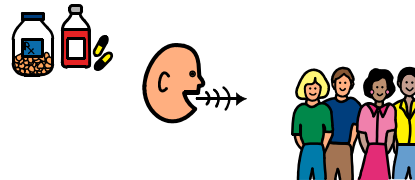


1 in 4 people in the world have mental health problems at some time in their life.

However, many people still have a good life if they get good support at the right time.

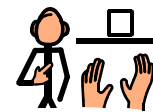
This support can be given in 3 ways:

- medication;
- psychotherapy;
- social support.



People with mental health problems should decide themselves what support is best for them.

To do that, they need good information, for example about what medication they should take and how it might affect them.



Sometimes a person with mental health problems may need to be cared for in hospital.

But it should always be for the shortest possible period of time.



Services and support should also be available outside the hospital for people with people with mental health problems so that they can live in the community.



People with mental health problems should be able to take part in society, just like people with intellectual disabilities.

This is why more community-based services should be developed.

Meeting other people with mental health problems can be very helpful.

People with mental health problems have created groups where they can meet and share their feelings and experiences.

These groups are called “self-help groups”.



But people with mental health problems can also find other ways of dealing with their mental health problems.

This could be things like doing some physical activities or relaxation exercises.



It can also be unhelpful because referring to individuals as being “mentally ill” suggests that mental health problems are caused by medical or biological factors alone whereas there are a range of reasons why a person may develop mental health problems, for example a stressful life event such as the death of a close friend or losing a job. Although mental health problems may give rise to distress and cause disruption to the person’s life, many people are able to develop ways of managing such feelings and experiences and are able to lead fulfilling and active lives.

### *What kind of support do people with mental health problems need?*

One in four people develop mental health problems at some stage in their life. Many people who experience mental health problems can learn to cope with them, especially if they receive help at an early stage. However, some people with mental health problems may not get the support that they need. Others may not seek the support that they need because, due to the stigma attached to “mental illness” they may feel ashamed or fearful of being labelled as “mentally ill”. Thus, addressing the stigma and discrimination attached to “mental illness” is an important factor in improving the mental health of the population.

Mental health problems are typically treated through some combination of medication, psychotherapy, and social support. While sometimes hospital care may be appropriate, it is important that in-patient treatment is limited to the shortest possible period of time. High quality community based mental health care services that are appropriate, accessible and affordable should be developed so that individuals are able to receive the support that they need while living in the community. However, in Central and Eastern Europe the range of treatments available are often limited or are inappropriately used and it is still common individuals to be subjected to long-term hospitalisation.

People with mental health problems should be given the opportunity of deciding for themselves what treatment works best for them. In order to do this they need sufficient information on the treatment options available, for example in relation to medication, the person will need to know the likely side effects of the treatment and what alternatives are available. This requires professionals to listen to the views of their clients so that together they can agree on a plan of treatment that is appropriate to that individual. Unfortunately such practice is still unusual in many countries across Europe.

Self-help groups can also be of great support, enabling individuals to share their feelings and experiences. People with mental health problems may also find it helpful to develop their own personal strategies for alleviating, or preventing a recurrence, of their mental health problems, such as diet, exercise and relaxation techniques. Making agreements beforehand with their relatives and those professionals who are providing treatment and care, of what to do in a crisis situation is also helpful for some people.

A leaflet on the differences between mental health problems and intellectual disabilities can be found at the back of this Manual.



## 2. The European Union



### 2.1. Overview

Countries can become members of the European Union.  
To be a member of the European Union, a country must agree with the laws and policies of the European Union.

Therefore, if you want to influence policies in these countries, it is important to know the policies of the European Union.



### 2.2. Purpose and Membership of the European Union

The European Union was founded in 1957.  
The European Union is a group of European countries that work together.  
Some people often use “EU” in short for European Union.

In 2006, there are 25 member states of the European Union:

- |                  |               |                  |
|------------------|---------------|------------------|
| • Austria        | • Greece      | • Poland         |
| • Belgium        | • Hungary     | • Portugal       |
| • Cyprus         | • Ireland     | • Slovakia       |
| • Czech Republic | • Italy       | • Slovenia       |
| • Denmark,       | • Latvia      | • Spain          |
| • Estonia,       | • Lithuania,  | • Sweden         |
| • Finland        | • Luxembourg  | • United Kingdom |
| • France         | • Malta       |                  |
| • Germany        | • Netherlands |                  |

These countries have some common aims.  
For example, they want everybody to have a good life.



Member states give some of their powers to the European Union so that all the countries can work together to reach their common aims.  
The European Union is then responsible for reaching these common aims.

This means that, for some things, it is the European Union that makes a decision.  
The member states then have to follow this decision.  
The European Union makes decision about a lot of things, for example things like human rights and public health.





## 2. The European Union

### 2.1. Overview

Individuals and organisations wishing to influence policy in their country need to have an understanding of the role of the European Union (EU). This is because by joining the EU, the governments of Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia have committed themselves to complying with policies and legislation that have been decided upon by the EU in a range of areas, some of which will be of direct relevance to people with mental health problems and people with intellectual disabilities.

This section provides a brief summary of how the EU works. This is based on information available on the EU website<sup>6</sup>, where further details can be obtained.

Inclusion Europe has published an easy-to-read brochure, “What is the European Union?”<sup>7</sup>

### 2.2. Purpose of and Membership in the European Union

Europa, the EU website describes the EU as:

*“...a family of democratic European countries, committed to working together for peace and prosperity. It is not a State intended to replace existing States, nor is it just an organisation for international cooperation. The EU is, in fact, unique. Its member states have set up common institutions to which they delegate some of their sovereignty so that decisions on specific matters of joint interest can be made democratically at European level.”*  
([http://europa.eu.int/abc/panorama/index\\_en.htm](http://europa.eu.int/abc/panorama/index_en.htm))

The EU’s activities are widespread, for example they include: economic and monetary affairs, foreign and security policy, human rights and public health. Under a series of treaties member states have delegated some of their national sovereignty to institutions of the EU.

The beginnings of the European Union date back to the 1950s but its remit and membership has evolved over the last 50 years and as from 1<sup>st</sup> May 2004 there are 25 Member States:

- |                  |               |                  |
|------------------|---------------|------------------|
| • Austria        | • Greece      | • Poland         |
| • Belgium        | • Hungary     | • Portugal       |
| • Cyprus         | • Ireland     | • Slovakia       |
| • Czech Republic | • Italy       | • Slovenia       |
| • Denmark,       | • Latvia      | • Spain          |
| • Estonia,       | • Lithuania,  | • Sweden         |
| • Finland        | • Luxembourg  | • United Kingdom |
| • France         | • Malta       |                  |
| • Germany        | • Netherlands |                  |

You can find out more about the EU in your country at:  
[http://europa.eu.int/euinyourcountry/index\\_en.htm](http://europa.eu.int/euinyourcountry/index_en.htm)

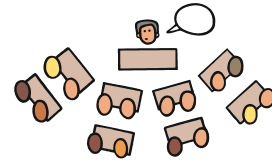
<sup>6</sup> <http://europa.eu.int/>

<sup>7</sup> Copies of this brochure can be obtained from Inclusion Europe:[self-advocacy@inclusion-europe.org](mailto:self-advocacy@inclusion-europe.org)



## 2.3. The Main Bodies of the EU

There are 3 main bodies which carry out of the EU.



### The European Parliament

Like your country, the EU has a Parliament.  
All European citizens are represented in the European Parliament.  
Our representatives are called “Members of the European Parliament”.

There are 732 Members of the European Parliament.  
They are elected every 5 years.  
Countries with more people have also more MEPs.  
The European Parliament makes laws.  
It also decides how the European Union spends the money.



### The Council of the European Union

The Council of the EU is made up of Ministers from each Member State.  
For example, when the Council speaks about social affairs,  
the meeting is made up of all the national Ministers for social affairs.

The Council of the EU decides about actions  
regarding the main policies of the EU.  
It makes the laws with the European Parliament.



### The European Commission

The European Commission makes sure that everything works well in the EU.  
The Commission makes sure that everybody respects European laws.  
The Commission organises the work of the institutions.  
It writes laws and passes them to the Parliament.

The members of the Commission are called “Commissioners”.  
Each commissioner is responsible for one area.  
For example, there is a Commissioner for social affairs.  
All the commissioners are independent people.  
They are chosen every 5 years.



The European Commission makes decisions.  
The European Parliament approves the decisions of the Commission.  
The European Parliament can also change the Commissioners.

## 2.3. The Institutions of the EU <sup>8</sup>

The main institutions of the EU are the European Parliament, the Council of the European Union, the European Commission, the Court of Justice, the Court of Auditors, the European Economic and Social Committee, the Committee of the Regions, the European Central Bank and the European Investment Bank. Set out below is information on the first three institutions, which are the main decision-making bodies. Further information can be found at:

[http://europa.eu.int/abc/panorama/howorganised/index\\_en.htm#council](http://europa.eu.int/abc/panorama/howorganised/index_en.htm#council)

- **The European Parliament:** Members of the European Parliament (MEPs) are elected every five years. The last election was in June 2004 and there are 732 MEPs from all 25 EU countries (222 of them are women). The Parliament's main role is to pass European Union laws. It shares this task, and the responsibility for approving the EU's €100 billion annual budget with the Council of the European Union. Proposals for new laws come from the European Commission. There is a cross party group of MEPs who are interested in disability issues (European Parliament Disability Intergroup):  
<http://www.edf-feph.org/apdg/index-en.htm>
- **The Council of the European Union:** This is the EU's main decision-making institution. The Council consists of ministers from the national governments of all the EU countries. It shares the responsibility for passing laws and making policy decisions with the Parliament. The Council also has the main responsibility for the EU's activities in common foreign and security policy and on some issues relating to justice and freedom. Every Council meeting is attended by one minister from each of the member states. Which ministers attend a meeting depends on which topic is on the agenda, for example, if the topic is on foreign policy, the Foreign Affairs Minister from each country will attend.
- **The European Commission** represents and upholds the interests of Europe as a whole. It is independent of national governments. It drafts proposals for new European laws, which it presents to the European Parliament and the Council. It manages the day-to-day business of implementing EU policies and spending EU funds. The Commission is also responsible for ensuring that Member States abide by the European treaties and laws and can take those that fail to do so to them to the Court of Justice. The Commission consists of 25 individuals "Commissioners", one from each EU country, and each of them has responsibility for a particular EU policy area.

Note: Individuals who are living in, or are citizens of a Member State, can make a complaint about the maladministration by a European body or institution to the European Ombudsman (see "*What can the European Ombudsman do for you?*")

[www.euro-ombudsman.eu.int/guide/en/default.htm](http://www.euro-ombudsman.eu.int/guide/en/default.htm))

## 2.4. The Directorates General of the European Commission

The European Commission is assisted by a civil service made up of 36 "Directorates-General" (DGs) and services, based mainly in Brussels and Luxembourg. These include:

- Employment, Social Affairs and Equal Opportunities (activities include: "*drawing up legislation and running programmes to counter discrimination, promoting fundamental rights and by enhancing the integration of disabled people*");
- Health and Consumer Protection (the work is divided into 3 areas: public health, food safety and consumer affairs);
- Justice, Freedom and Security (activities include: citizenship and fundamental rights).

For further information about the work of the DGs see: [http://europa.eu.int/comm/dgs\\_en.htm](http://europa.eu.int/comm/dgs_en.htm)

<sup>8</sup> The Treaty establishing a Constitution for Europe will introduce changes to the EU institutions but it will not take effect until it is ratified by all 25 Member States: [http://europa.eu.int/scadplus/constitution/index\\_en.htm](http://europa.eu.int/scadplus/constitution/index_en.htm)

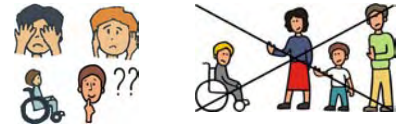


## 2.4. The Directorates General of the European Commission

The European Commission is divided in 36 different areas. They are called “Directorate General” or “DG”. Each Directorate General is divided in several Units.

For example, there is one DG for employment, social affairs and equal opportunities.

This DG is divided in Units like the “Disability Unit” or the “Anti-discrimination Unit”.



## 2.5. The European Union Disability Strategy

This is a very important document for disabled people. It explains what the EU wants to do for disabled people.

One of the main goals is to have a society open and accessible for everyone.

To do that, this text focuses for example on

- cooperation between the Commission and the Member States;
- full participation of people with disabilities.



The most important Unit for disabled people is “The Unit for the Integration of People with disabilities”.

They are responsible for making sure that every person working at the European Commission thinks about disabled people when writing new programmes.



## 2.6. Anti-Discrimination and Civil Relations

The European Commission has a website that speaks about non-discrimination:

[http://europa.eu.int/comm/employment\\_social/fundamental\\_rights/index\\_en.htm](http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm)



This is the only Commission website that has an easy-to-read section. You can visit this section by clicking on the European easy-to-read logo in the upper right corner.



This website gives you information, addresses and names of organisations that fight against discrimination.

## **2.5. The European Union Disability Strategy**

The goal of the EU Disability Strategy is to have a “*society open and accessible to all*”. This approach has been stimulated by the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities. The strategy focuses on three main areas.

- Cooperation between the Commission and the Member States: for example the Commission seeks to promote the collection, exchange and development of comparable information and statistics and good practice and raise awareness of disability issues.
- Full Participation of People with Disabilities: For example, when the Commission creates or changes a policy it aims to consider the needs and rights of people with disabilities. The Unit for the Integration of People with Disabilities is responsible for mainstreaming disability matters within the Commission and it seeks to raise awareness on disability matters and to facilitate and encourage co-operation on disability matters among Directorates-General.
- Mainstreaming Disability in Policy Formulation: The Commission considers that people with disabilities should be involved in the planning, monitoring and evaluation of changes in policies, practises and programmes. The Commission both encourages others to do so and seeks to do so itself. For example, the EQUAL initiative (2000-2006) in which a key players including representatives of groups who are discriminated in relation to the labour market are involved in developing and testing out new ideas on job creation.

Details of the EU’s Disability Strategy and key documents relating to it can be found at:  
[http://europa.eu.int/comm/employment\\_social/disability/strategy\\_en.html](http://europa.eu.int/comm/employment_social/disability/strategy_en.html)

## **2.6. Anti-Discrimination and Civil Relations**

The European Commission has a website dedicated to its work to address discrimination:  
[http://europa.eu.int/comm/employment\\_social/fundamental\\_rights/index\\_en.htm](http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm)

This website has been established by the Anti-Discrimination Unit of the Directorate-General Employment and Social Affairs. As at 2006, this is the only European Commission website that provides information in an easy-to-read format. This easy-to-read section can be visited by clicking on the European easy-to-read logo which can be found in the upper right corner of the first page of this website.

The website focuses on all aspects of the European Community Action Programme to combat discrimination (2001-2006) and Community legislation related to fighting discrimination. The website provides links to, and information on, agencies and bodies across the EU that can help both employers and employees to learn more about their rights and obligations in obtaining and ensuring equal treatment under European law. For example, the section on “Your rights and obligations” provides a link to a range of factsheets that advise on how organisations and individuals can avoid and combat discrimination.

Details of the EU anti-discrimination campaign, “For Diversity. Against Discrimination” are available at: <http://www.stop-discrimination.info>.

The EU has decided that 2007 will be the European Year of Equal Opportunities for All (2007). The aim of this initiative is to make people in the EU more aware of their rights to enjoy equal treatment and a life free of discrimination. The activities undertaken during the Year will focus on the discrimination some individuals suffer owing to their race or ethnic origin, religion or belief, age, gender, sexual orientation or disability, all of which are grounds for discrimination that may be addressed at European level. Details of the European Year of Equal Opportunities for All (2007) can be found at:

[http://ec.europa.eu/employment\\_social/equality2007/index\\_en.htm](http://ec.europa.eu/employment_social/equality2007/index_en.htm)



## 2.7. Ending Poverty and Fighting Social Exclusion



All the member states of the EU agree on a very important thing: that no citizen of the EU should be living in poverty. This should be done by 2010. They also want to fight against social exclusion.



## 3. *Human Rights*

The word “rights” describe the way people should be treated and what people are allowed to do.

Human Rights apply to everyone. However, in many countries, the rights of disabled people are not respected.



### 3.1. What are Human Rights and Why are They Important?

There are lots of documents that say what your rights are. The laws written by the government tell you about your rights. There are also European and international documents that say what your rights are. The Universal Declaration of Human Rights is the most well known document. It was the first document to say what people’s human rights are.

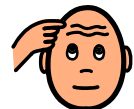


Since then other human rights documents have been written. By signing these documents, governments have agreed to respect and promote people’s human rights. When governments sign a document, we say that they “ratify” it.



These human rights documents are important. When a government ratifies (signs) them:

- they have to respect these human rights;
- they have to keep these rights in mind when writing new policies;
- organisations can remind them about their duty to respect these rights;
- organisations or individuals can complain if their rights are not respected.



Governments of all European countries have ratified several human rights documents. Therefore, all European countries should respect the people’s human rights.

## **2.7. Eradication of Poverty and Combating Social Exclusion**

In March 2000 Member States agreed on the need to take steps to make a decisive impact on the eradication of poverty by 2010 and that their policies for combating social exclusion should be based on a co-ordinated approach. The ten new Member States submitted their first National Action Plans against poverty and social exclusion (NAPs/inclusion) in July 2004. The action plans for each country can be found at:

[http://europa.eu.int/comm/employment\\_social/social\\_inclusion/naps\\_en.htm](http://europa.eu.int/comm/employment_social/social_inclusion/naps_en.htm)

## ***3. Human Rights***

### **Introduction**

Human rights apply to everyone. However in many countries the rights of people with disabilities (including people with mental health problems and people with intellectual disabilities) are often unrecognised or ignored. This section provides a brief overview of some important international and European human rights documents. It also provides details of how to get further information on human rights.

### **3.1. What are Human Rights and Why are They Important?**

In 1948, the Universal Declaration of Human Rights (UDHR) was adopted by the United Nations (UN). The UDHR was the first document to set out a range of “civil and political” rights (such as the right to life and the freedom of expression) and “economic, social and cultural” rights (such as the right to work and the right to education). Since then numerous and wide-ranging international human rights treaties have been introduced. The rights set out in these treaties are important because:

- by ratifying human rights treaties Governments commit themselves to respect and promote the human rights of their citizens;
- governments should consider human rights when developing, implementing and reviewing laws, policies and practice;
- individuals and organisations (such as non-governmental organisations) can refer to Governments to their obligations under human rights treaties when seeking to persuade them that reform is necessary;
- in some cases (depending on the treaty and whether the State has agreed to this) individuals who believe that their rights under the treaty may complain to the body responsible for monitoring States’ compliance with the treaty obligations. In other cases, where the treaty has become part of national law, individuals may be able to pursue legal action in their national courts. Under the European Convention on Human Rights, individuals may complain to the European Court of Human Rights if they believe that their rights have been violated and there is no effective remedy for this in their own country.

Governments of all countries in Central and Eastern Europe have ratified a range of international and European human rights instruments. For information on what human rights documents States have ratified see: [www.unhchr.ch/pdf/report.pdf](http://www.unhchr.ch/pdf/report.pdf) (for UN treaties).

Information on Council of Europe treaties can be found at:

<http://conventions.coe.int/Treaty/EN/v3MenuEtats.asp>

See also: <http://www.whatconvention.org/>



### 3.2. The United Nations and Human Rights



The United Nations is an international organisation.

We call it “UN” for short.

191 countries are members of the UN.

This means that almost every country in the world is a member of the UN.

The United Nations fights for peace  
and for good relations between countries.



The UN also promotes respect for human rights.

This is why, since 1993, they chose a person to be the  
“High Commissioner for Human Rights”.



This person’s job is to check that

- governments of UN member countries respect their human rights duties;
- people do not abuse the human rights of other people in any country.

#### United Nations human rights treaties

Treaties are international laws.

There are 6 very important United Nations treaties about Human Rights.

Governments from all UN member states  
were asked to ratify these treaty

This means they were asked to sign the treaties  
and to respect everything that is written in them.



The countries that have signed these treaties have to send a report to the UN,  
every 2 to 5 years.

These reports must show how the government makes sure  
that human rights are being respected.



### **3.2. The United Nations and Human Rights**

#### **Background: Role of the United Nations**<sup>9</sup>

The United Nations (UN) was established in 1945 by 51 countries. Today almost all nations are members of the UN (there are 191 members). Members must accept the obligations set out in the UN Charter. This document provides that the purpose of the UN is to:

- maintain international peace and security;
- to develop friendly relations among nations;
- to cooperate in solving international problems and in promoting respect for human rights;
- and to be a centre for harmonising the actions of nations.

A key area of the UN's work has been to set international human rights standards but now with over 80 international conventions and declarations on human rights, it is now shifting its emphasis to the implementation of human rights laws. In 1993 the UN appointed the first High Commissioner for Human Rights whose responsibilities include working with governments to improve their compliance with human rights and seeking to prevent violations of human rights. More details of the Office of the High Commissioner for Human Rights are available at: [www.ohchr.org/english/](http://www.ohchr.org/english/).

#### **United Nations human rights treaties**

There are six core UN human rights treaties all of which are legally binding on the States that have ratified them. States must submit a report, every two to five years (how often varies between the treaties) to the bodies established under the treaties to monitor whether States are complying with their treaty obligations. The treaty bodies may also receive information about the human rights situation in the countries from other sources, including non-governmental organisations. The treaties are set out below (with the name of the treaty monitoring body in brackets):

- Convention on the Elimination of All Forms of Racial Discrimination, 1965 – (Committee on the Elimination of Racial Discrimination (“CERD”));
- International Covenant on Civil and Political Rights, 1966 – (Human Rights Committee (“HRC”));
- International Covenant on Economic, Social and Cultural Rights, 1966 - (Committee on Economic, Social and Cultural Rights (“CESCR”));
- Convention on the Elimination of All Forms of Discrimination against Women, 1979 – (Committee on the Elimination of Discrimination against Women (“CEDAW”));
- Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, 1984 (Committee against Torture (“CAT”));
- Convention on the Rights of the Child, 1989 (Committee on the Rights of the Child (“CRC”)).

For further information, on the work of the human rights treaty bodies, including any reports submitted by your country see: <http://www.ohchr.org/english/bodies/treaty/index.htm>

#### **The United Nations works on human rights and disability**

One of the areas of work of the Office of the High Commissioner for Human Rights is to increase the promotion and protection of the human rights of people with disabilities (including people with mental health problems and people with intellectual disabilities). The UN considers the following core values to be of particular importance:

- the *dignity* of each individual, who is deemed to be of inestimable value because of his/her inherent self-worth, and not because s/he is economically or otherwise “useful”;
- the concept of *autonomy* or self-determination, which is based on the presumption of a capacity for self-directed action and behaviour, and requires that the person be placed at the centre of all decisions affecting him/her;

<sup>9</sup> This section provides a brief overview of United Nations (UN) and is based on information available on the UN website, where further information can be obtained: <http://www.un.org/aboutun/index.html>

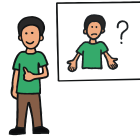
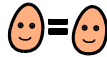


### The United Nations works on human rights and disability

The United Nations also wants to protect the human rights of disabled people.

The United Nations says it believes that people with disabilities should have:

- dignity for each individual person;
- autonomy and self-determination;
- equality for all;
- solidarity.



The United Nations has created a new group.

It is called an “Ad Hoc Committee”.

This group is working on a document about the rights of disabled people.



### Additional UN human rights standards

The United Nations has prepared many documents and laws.

If governments ratify these documents, they have to respect them.

To see which document your government has signed and has to respect, look at the website [www.unhchr.ch/pdf/report.pdf](http://www.unhchr.ch/pdf/report.pdf).

This website is not easy-to-read.

People with intellectual disabilities

might need the help of a support person to use this website.



The United Nations can also write recommendations.

Recommendations are not as strong as treaties.

They explain what governments should do in order to protect human rights.

Governments do not have to do these things, but they are encouraged to do so.



For example, in 1993, the UN wrote a text called “Standard Rules on the Equalisation of Opportunities for Persons with Disabilities”.



This text asks governments to make sure that disabled people can participate fully in society.



Again, this is not a law.

But it can be very useful guidelines for the governments.

- the inherent *equality* of all regardless of difference;
- and the ethic of *solidarity*, which requires society to sustain the freedom of the person with appropriate social supports.

For information on the Office of the UN High Commissioner for Human Rights' work on disability see: [www.ohchr.org/english/issues/disability/index.htm](http://www.ohchr.org/english/issues/disability/index.htm)

The UN has established an "Ad Hoc Committee" consider an international human rights treaty specific to disability, which will include people with mental disabilities. The Committee has not as yet completed this work. For further information see Enable, the UN's website on disability issues: [www.un.org/esa/socdev/enable/disabout.htm](http://www.un.org/esa/socdev/enable/disabout.htm)

### Additional UN human rights standards

The UN has adopted declarations and recommendations which although not legally binding provide clear guidance for Governments on what measures they should take to protect and promote the rights of people with mental disabilities:

- **The Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care** (the MI Principles) were adopted by the UN in 1991. They provide guidance on areas such as the procedures for involuntary admission to mental health care facilities, the provision of treatment and the standards of care. Although some of their provisions have been criticised for offering less protection than other human rights treaties,<sup>10</sup> they are significant because they identify some key areas that need to be considered by policy makers and emphasise the need to enable individuals with mental health problems to live in the community wherever possible (see rules 3 and 7). Although this document refers to "persons with mental illness" the principles are intended to cover all people in mental health facilities and therefore may also include people with intellectual disabilities who are placed in such facilities.
- **The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities** ("the Standard Rules") were adopted in 1993. They call upon States to take action to remove the obstacles which prevent disabled people (including people with mental disabilities) from exercising their rights and freedoms and make it difficult for them to participate fully in the activities of their societies. The Standard Rules are divided into four areas:
  - \* **Preconditions for equal participation:** this covers raising awareness, medical care, rehabilitation and support services.
  - \* **Equal participation:** this covers accessibility, education, employment, income maintenance and social security, family and personal integrity, culture, recreation and sports, and religion.
  - \* **Implementation Measures:** this covers information and research, policy-making and planning, legislation, economic policies, coordination of work, organisations of persons with disabilities, personnel training, national monitoring and evaluation of disability programmes in the implementation of the Rules, technical and economic cooperation, and international cooperation.
  - \* **Monitoring mechanism:** a Special Rapporteur reports to the Commission for Social Development.

Although neither the MI Principles nor the Standard Rules are legally binding, they can provide useful guidance for policy makers. For example, the European Union's Disability Strategy is based on the Standard Rules:

[http://europa.eu.int/comm/employment\\_social/soc-prot/disable/strategy\\_en.htm](http://europa.eu.int/comm/employment_social/soc-prot/disable/strategy_en.htm)

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<sup>10</sup> Report to the General Assembly of the United Nations, July 2003, A/58/181, *Progress of efforts to ensure the full recognition of the human rights of persons with disabilities*  
<http://daccessdds.un.org/doc/UNDOC/GEN/N03/443/22/PDF/N0344322.pdf?OpenElement>



### 3.3. Council of Europe and Human Rights

The Council of Europe is an organisation founded in 1949.  
46 European countries are members of the Council of Europe.

This Council is not the same as the European Union.  
It is a separate organisation.

The Council of Europe also defends human rights.  
It has prepared 3 important documents.

#### The European Convention on Human Rights

This document includes many human rights,  
like the right to marry and have a family.



If people think that their rights are not respected,  
they can complain to the European Court of Human Right.  
The Court can agree that the government did not respect  
the person's human rights.

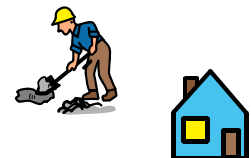


Then the government will have to take action to improve the situation.  
In some cases, governments have to pay money to the person  
whose rights have not been respected.



#### The European Social Charter

This document is about economic, social and cultural rights.  
For example, it is about the right to work  
or the right to housing.



Each year, governments have to write a report.

This report must show what the government is doing to respect this Charter.

The Council of Europe also wrote other important documents.

These documents can help if you think that you are being discriminated against  
or if you think that your rights are not respected.



You can find them on the website of the Council of Europe: [www.coe.int](http://www.coe.int)

This website is not accessible for people with intellectual disabilities.

You might need the help of your support person to visit it.



Both these documents and a wide range of other international and European human rights instruments that relate to people with disabilities can be found at:

[www.un.org/esa/socdev/enable/compendium.htm](http://www.un.org/esa/socdev/enable/compendium.htm)

The Swedish Cooperative Body of Organisations of Disabled People has developed guidance, “*Agenda 22 – Local Authorities – Disability policy planning instructions*”, for local authorities on how to draw up disability plans based on the Standard Rules. This can be obtained at:

[www.programmavcp.nl/agenda22/agenda22engels.doc](http://www.programmavcp.nl/agenda22/agenda22engels.doc)

### **3.3. Council of Europe and Human Rights**

*This section gives a brief overview of the Council of Europe and its work. Further information is available on the Council of Europe’s website: [www.coe.int](http://www.coe.int).*

#### **Background: role and purpose of the Council of Europe**

The Council of Europe was founded in 1949 and now has forty-six countries are members including 21 countries from Central and Eastern Europe. It is a separate body from the EU although no country has ever joined the EU without first belonging to the Council of Europe. One of the core functions of the Council is to defend human rights, parliamentary democracy and the rule of law.

#### **Council of Europe and human rights**

The key human rights instruments of the Council of Europe are as follows:

- **European Convention on Human Rights** (1950): this sets out a range of civil and political rights, such as the right to liberty and the right to marry and found a family. Individuals have the right to complain to the European Court of Human Rights if they believe that their rights have been violated. If their complaint is upheld, States are required to take action to remedy the breach and in some cases pay compensation to the complainant.
- **European Social Charter**, (1961, revised 1996): this sets out a range of economic, social and cultural rights such as the right to work. The revised Charter includes the right to housing. Each year States must report on their compliance with the Social Charter obligations.
- **European Convention on the Prevention of Torture and Inhuman or Degrading Treatment or Punishment** (1987): this establishes the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (the CPT) which undertakes country visits and inspects premises where individuals are detained and reports on its findings. The CPT has published a report which sets out its views on the manner in which persons deprived of their liberty ought to be treated (referred to as the CPT Standards).<sup>11</sup>

#### **Additional Council of Europe human rights standards**

- **Recommendation No. REC(2004)10** was adopted in September 2004. This document sets out guidelines “concerning the protection of the human rights and dignity of persons with mental disorder”. It recommends that Governments should adapt their laws and practice to these guidelines and also to review the allocation of resources to mental health so that the provisions of these guidelines can be met. The guidelines cover a range of issues such as non-discrimination, confidentiality, procedures for involuntary placement, procedures for treatment without consent and the requirements for the monitoring of compliance with the standards set out in the guidelines.
- **Recommendation No R(99)4, Concerning the Legal Protection of Incapable Adults**, was adopted in February 1999. It sets out principles for establishing a legal framework for substitute decision-making where such action is required while protecting the rights of those individuals who may lack capacity.

<sup>11</sup> European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment 2001, “Substantive” Sections of the CPT’s General Reports, Council of Europe. See: [www.cpt.coe.int/EN/about.htm](http://www.cpt.coe.int/EN/about.htm)



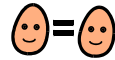
### 3.4. The European Union and Human Rights



One of the main value of the European Union is to respect human rights. When new countries want to become member of the European Union, among other things, they have to show that they respect human rights.



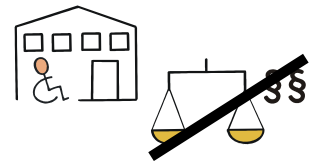
The European Union also wrote an important text about human rights. It is called the Charter of Fundamental Rights. For example, it says that everybody has the right to life, to equality and to non-discrimination.



### 3.5. Particular Issues Concerning People with Mental Health Problems and/or Intellectual Disabilities in Central and Eastern Europe

#### Institutionalisation

In many countries, there are still a lot of institutions. Governments need to take action to create community-based services. This is especially true in Central and Eastern Europe. This is because too many people are still living in institutions. Many of these institutions do not respect the human rights of the people who live there.



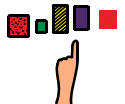
2 years ago, a study on institutions in different countries was done. The results of the study showed that people living in institutions do not have as good a life as those living in the community.



The study also said that 8 key points have to be followed for human rights to be respected in these institutions.

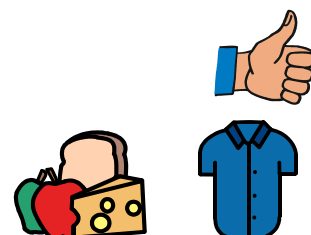
#### 1. Protection from arbitrary detention

An arbitrary detention is for example when you are being forced to stay somewhere you do not want to stay and there is no good reason for this. People should be able to choose where they want to live. A person can only be forced to stay in an institution in very special cases. These special cases must be listed in the law of that country.



#### 2. Proper living conditions

Governments must make sure that people living in institutions have a good life. That means that they are given basic things such as good food, heating and clothing.



### **3.4. The European Union and Human Rights**

Respect for human rights is one of the core values of the EU and is a prerequisite for countries seeking to join the Union. Links to key human rights sites are provided at: [http://europa.eu/pol/rights/index\\_en.htm](http://europa.eu/pol/rights/index_en.htm). Details of the EU human rights activities can be found at: [http://europa.eu/pol/rights/overview\\_en.htm](http://europa.eu/pol/rights/overview_en.htm)

The European Union Charter of Fundamental Rights (2000) sets out a range of civil, political, economic and social rights such as the right to life, to privacy, to freedom of expression, to equality and to non-discrimination. The provisions of this Charter are addressed to the institutions and bodies of the Union. They only apply to Member States when they are implementing EU law. ([www.europarl.eu.int/charter/pdf/text\\_en.pdf](http://www.europarl.eu.int/charter/pdf/text_en.pdf)).

The European Commission has proposed that a new body - a European Union Agency for Fundamental Rights – should be established. This Agency is to be an independent centre of expertise, which will advise the EU institutions and Member States on how best to prepare or implement fundamental rights related Union legislation. For further information see: [http://ec.europa.eu/justice\\_home/fsj/rights/fsj\\_rights\\_intro\\_en.htm](http://ec.europa.eu/justice_home/fsj/rights/fsj_rights_intro_en.htm)

### **3.5. Particular Issues Concerning People with Mental Health Problems and/or Intellectual Disabilities in Central and Eastern Europe**

#### **Institutionalisation**

Governments across Central and Eastern Europe (CEE) have yet to implement policies that promote the development of comprehensive community-based services as an alternative to institutional care. Although in some parts of CEE high quality community-based services are being provided, such services are few and far between. Tens of thousands of people with mental health problems and people with intellectual disabilities are still living in long-stay institutions such as psychiatric facilities, social care homes and orphanages and are segregated from society. The serious human rights violations that occur within such closed institutions have been highlighted by a number of reports.<sup>12</sup> *Included in Society*, the report of the results of, and recommendations arising from, a study of institutions in a number of countries in Europe demonstrated that institutional care has a significant negative impact on the quality of life of the residents.<sup>13</sup> This report identified a series of relevant key human rights standards, which as these reports highlight, are not being adhered to in many institutions. These standards are set out in the box below.

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<sup>12</sup> See for example, Amnesty International *Bulgaria, Far from the eyes of society: Systematic discrimination against people with mental disabilities*, Amnesty International, 2003

<sup>13</sup> Available at: [www.community-living.info](http://www.community-living.info)



### 3. Proper care and treatment

Everybody who lives in an institution must be given proper care. They must be treated well.

### 4. Individualised cared plans

In the institutions, there are often lots of people living together. However, the staff should take care of each person individually. Each person should be cared for in a way that meets his or her individual needs.



### 5. Protection from harm

People living in institution must be protected. Other people should not be able to harm them. And they should not harm others or themselves. To do this, there should be enough staff present at all times. Physical restraints should not be used unless this is necessary to protect the person or other people. Physical restraint is for example holding people so they cannot hit others or themselves. If physical restraint is used, it should be done as it says the law. It should also be for the shortest time possible.



### 6. The right to private and family life

This means that letters of people living in institution should not be opened.

It means that these people should be able to keep in contact with their family.

It also means that nobody should be made to share the bathroom, especially not with someone of the opposite sex.



### 7. Privacy

This means that people living in institutions should have a space which can be locked and where they can put their personal things.



### 8. Contact with family

People living in institutions should be able to receive visits from family. They should have access to a telephone.

They should be able to send and receive letters.





## **Institutional care and human rights (extract from “Included in Society” report)**<sup>14</sup>

**Protection from arbitrary detention:** A person's right to liberty may only be restricted in limited circumstances and in accordance with a procedure prescribed by law. (See for example Article 9 ICCPR and Article 5 ECHR.)

**Adequate living conditions:** The CPT Standards<sup>15</sup> state *“the provision of certain basic necessities of life must always be guaranteed in institutions where the State has persons under its care and/or custody. These include adequate food, heating, clothing as well as – in health establishments - appropriate medication”*

**Adequate provision of care and treatment:** *“All persons who are deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.”* (See Article 10, ICCPR).

**Individualised care plans:** Both the UN Principles for the Protection of Persons with Mental Illness and the CPT emphasize that treatment should be based on an individualised approach, so that individuals should have their own treatment plan.

**Protection from harm:** appropriate procedures must be in place to protect patients from other patients whose actions may cause them harm. There should also be adequate numbers of staff present at all times (the CPT Standards). Physical restraint should not be used unless this is the only means available to prevent harm to the person or others and when it is used, it must be carried out in accordance with approved policies or procedures and for the minimal time necessary.

**The right to private and family life:** This right can cover a wide range of issues which will be of crucial importance to residents such as receiving and sending correspondence, the provision of single sex washing facilities, access to health and personal records, the administration of medication and contact with family and friends. (See article 8 ECHR and article 17 ICCPR which both prohibit the arbitrary interference of individuals' private and family life.)

**Privacy:** The CPT Standards highlight the importance of creating a “positive therapeutic environment”. This will involve not only providing sufficient living space per patient and maintaining the state of repair and hygiene requirements of the premises, but also ensuring respect for the privacy and dignity of patients. Thus patients should be allowed to keep their personal belongings and should be provided with lockable space in which to keep these.

**Contact with family:** Many institutions are situated in remote areas and residents lose contact with their families and local communities. The CPT standards state that patients should be able to send and receive correspondence, to have access to a telephone and receive visits from family and friends.

<sup>14</sup> Key: CPT = the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment; ECHR = European Convention on Human Rights; ICCPR = International Covenant on Civil and Political Rights; ICESCR = International Covenant on Economic, Social and Cultural Rights

<sup>15</sup> These are standards that have been produced by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment. See [www.cpt.coe.int/EN/about.htm](http://www.cpt.coe.int/EN/about.htm)



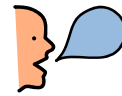
## The promotion of community based services as alternatives to institutionalisation

High-quality community-based services should be developed.

This should be done following 4 key values:

respect, choice, participation and independence.

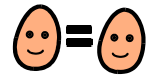
- Respect: The rights of everybody should be respected.  
Everybody should be able to say what they think.  
Everybody should be listened to.  
Everybody should be treated fairly.



- Choice: Everyone should be able to make choices about their lives.  
For example choosing where they want to live or what they want to eat.



- Participation: Everyone should have the chance to take part in society.  
Everyone should be seen as equal people.



- Independence: Everyone should make their own decision.  
For example choosing how they want to live.



## Guardianship

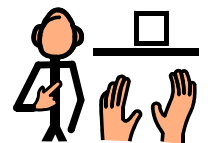
Everybody has the right to make their own choices.

This means that you can decide what you want.

But sometimes you do not really know what is the best decision.

There are many ways to protect you from making a decision that is not right for you.

When the choice is difficult, there should be someone to help you.  
In many countries, this person is called your guardian.  
You should have the right to choose this person yourself.



However, in some countries, people with intellectual disabilities do not have the right to make their own choices.

They cannot choose their guardian.

Their guardian makes all decisions for them even if the people can make these decisions themselves.

## The promotion of community based services as alternatives to institutionalisation

Paul Hunt, the United Nations' Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, has highlighted the importance of developing community-based services as an alternative to institutional care:

*"Deriving from the right to health and other human rights, the right to community integration has general application to all persons with mental disabilities. Community integration better supports their dignity, autonomy, equality, and participation in society. It helps prevent institutionalization, which can render persons with mental disabilities vulnerable to human rights abuses and to damage their health on account of the mental burdens of segregation and isolation. Community integration is also an important strategy in breaking down stigma and discrimination against persons with mental disabilities [this term includes both people with mental health problems and people with intellectual disabilities]."*<sup>16</sup>

The Included in Society report<sup>17</sup> suggested some key values to support the work to develop high-quality community based services.. The key values are: respect, choice, participation and independence.

- **Respect:** Everyone should be given the opportunity to use their rights, to say what they think, to be listened to and to be treated fairly, without being treated differently just because of their sex, age, race, or disability.
- **Choice:** Everyone should have the right to make choices about their lives, such as where they live, who they want to be friends with and the type of services that they use.
- **Participation:** Everyone should have the chance to take part in community life as an equal citizen.
- **Independence:** Everyone should be given the chance to make their own decisions about how they live and have the same freedoms as everybody else, with the support and assistance that helps them to do so.

Such values could be applied to the development and implementation of all policies and measures that impact upon individuals, including people with mental health problems and people with intellectual disabilities.

## Guardianship<sup>18</sup>

In many parts of Central and Eastern Europe people with mental health problems and people with intellectual disabilities are placed under "guardianship", by a court order, on the grounds that they considered incapable of making decisions for themselves. Some countries maintain a system of "plenary" or "full guardianship". This means that the person appointed to act as the "guardian" is given wide-ranging powers while the people made subject to plenary guardianship is prevented from making any significant decision for themselves. For example, in some countries individuals placed under plenary guardianship do not have the right to get married or to vote in parliamentary elections. In some countries a less intrusive form of guardianship, "partial guardianship", is available. Under this system the guardian is appointed to make decisions only in connection with specific issues and individuals subject to partial guardianship can make decisions for themselves about other matters.

Both these forms of guardianship can give rise to serious human rights violations on a number of grounds. In general there is a lack of procedural safeguards, lack of legal representation, inadequate assessment of a person's capacity to make decisions for him or herself and also a lack of periodic review. Furthermore, the extensive powers of the guardian can lead to abuse and exploitation of the individual deemed to lack capacity, for example the guardian requiring

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<sup>16</sup> Report of 11<sup>th</sup> February to the United Nations General Assembly, E/CN.4/2005/51  
<http://daccessdds.un.org/doc/UNDOC/GEN/G05/108/93/PDF/G0510893.pdf?OpenElement>

<sup>17</sup> [www.community-living.info](http://www.community-living.info)

<sup>18</sup> The Mental Disability Advocacy Program is undertaking research on guardianship. For further information see: [www.mdac.info/projects/guardianship.htm](http://www.mdac.info/projects/guardianship.htm)



This is wrong. Guardians should not do whatever they want.  
It is important that a judge decides about the rights of the guardian.  
It is also important that the judge checks  
that the guardian does the right things.  
And it is important that the decision is checked again  
after a few years.

Everyone should keep their rights to make decisions.  
When people need help and support,  
they should have a right to get it.  
The support should be free.



## 4. Access to Employment

We explained before that there are lots of laws protecting human rights.  
Many of these laws talk about the right to work.

For example the EU Charter of Fundamental Rights says  
that everyone has the right

- to work;
- to have other activities.

Everybody should choose these activities freely.



Another example is the United Nations Standard Rules  
on the Equalization of Opportunities for Persons with Disabilities.  
In this law, the rule 7 says that people with disabilities  
should have equal opportunities to get a job in the labour market.

### 4.1. Employment and the European Union



In 2000, the European Union wrote a very important text.  
It is called  
the “Directive on Equal Treatment in Employment and Education”.



This text fights discrimination in employment and education.



It says that people with disabilities  
should be able to work and go to school  
like everybody else.



the person subject to guardianship to move into an institution.<sup>19</sup> In particular, plenary guardianship undermines a fundamental principle that any restriction on an individual's right to be recognised before the law should be *"based on a specific finding that the individual lacks the capacity to make decisions by himself or herself with regard to that specific activity"*.<sup>20</sup>

A report to the General Assembly of the United Nations in July 2003 highlighted major concerns about the use of guardianship in some countries, pointing out that guardianship is frequently used improperly to deprive individuals with mental disabilities of their legal capacity, so that they are unable to make some of the most important and basic decisions about their life, without proper procedural safeguards such as fair hearings or periodic reviews by a competent judicial authority. The report also noted that guardianship may be used in order to circumvent the laws relating to admissions into mental health institutions and:

*"the lack of procedure for appealing or automatically reviewing decisions concerning legal incapacity could then determine the commitment of a person to an institution for life on the basis of actual or perceived disability"*.<sup>21</sup>

The Council of Europe's Commissioner for Human Rights has also highlighted similar concerns about and has called for the implementation of **Recommendation No R(99)4, Concerning the Legal Protection of Incapable Adults** (see above at page 37).<sup>22</sup>

## 4. Access to Employment

The right to work is included in many human rights instruments. For example:

- Article 15 (1) EU Charter of Fundamental Rights – *"Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation"*;
- Article 6(1), Covenant on Economic, Social and Cultural Rights recognizes *"the right to work, which includes, the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right"*;
- Article 1 European Social Charter sets out steps to be taken by States *"with a view to ensuring the effective exercise of the right to work"*, including *"to provide or promote appropriate vocational guidance, training and rehabilitation"*;
- Rule 7 United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities – *"States should recognize the principle that persons with disabilities must be empowered to exercise their human rights, particularly in the field of employment. In both rural and urban areas they must have equal opportunities for productive and gainful employment in the labour market"*.

### 4.1. Employment and the European Union

*"Employment and occupation are key elements in guaranteeing equal opportunities for all. They contribute strongly to the full participation of citizens in economic, cultural and social life, and to realising their potential."* (European Commission, Anti-discrimination & relations with Civil Society)

Article 13 of the Treaty of Amsterdam authorises the EU to take action to combat discrimination based on a range of grounds, including disability. This has led to the introduction of the EU Directive on Equal Treatment in Employment and Occupation which prohibits discrimination on a number of grounds, including disability in the areas of employment and occupation ([http://europa.eu.int/comm/employment\\_social/news/2001/jul/directive78ec\\_en.pdf](http://europa.eu.int/comm/employment_social/news/2001/jul/directive78ec_en.pdf)).

<sup>19</sup> Office of the Commissioner of Human Rights, *The Protection and Promotion of the Human Rights of Persons with Mental Disabilities, Conclusions*, CommDH(2003)1, February 2003, paragraph 11

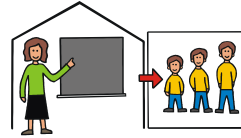
<sup>20</sup> *Progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities*, Report of the Secretary-General, United Nations, General Assembly, A/58/181, July 2003, paragraphs 20 & 21 ("the UN Report") <http://www.un.org/esa/socdev/enable/disa58181e.htm>

<sup>21</sup> <http://daccessdds.un.org/doc/UNDOC/GEN/N03/443/22/PDF/N0344322.pdf?OpenElement>

<sup>22</sup> *The Protection and Promotion of the Human Rights of Persons with Mental Disabilities*, February 2003: [http://www.coe.int/T/E/Commissioner\\_H.R/Communication\\_Unit/CommDH%282003%291\\_E%20.doc](http://www.coe.int/T/E/Commissioner_H.R/Communication_Unit/CommDH%282003%291_E%20.doc)



## 5. Access to Education



Education means going to schools,  
but it also means training for a job and life long learning.

The right to education is also included in many laws on human rights.

For example the EU Charter of Fundamental Rights says  
that everyone has the right

- to education;
- to have access to training for a job.

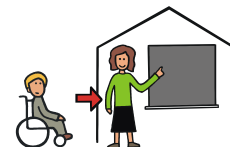


Another example is the United Nations Standard Rules  
on the Equalization of Opportunities for Persons with Disabilities.  
In this law, rule 6 says that people with disabilities  
should have equal opportunities to education.

This is not only for disabled children,  
but also for young people and adults with disabilities.



It also says that the education of disabled people  
should be part of the general education system.  
This is also called inclusive education.



The Employment Equality Directive for “establishing a general framework for equal treatment in employment and occupation” was adopted by the European Union in 2000. It requires all Member States to introduce laws prohibiting discrimination on the grounds of religion or belief, disability, age or sexual orientation in the areas of employment and occupation. The new Member States were expected to have fully transposed the Employment Directive by the date of their accession to the EU (1<sup>st</sup> May 2004), although Member States have been allowed to request a three year extension to this deadline in the relation to the introduction of laws prohibiting age and disability discrimination.

Further information can be obtained from the European Commission’s website on non-discrimination in the European Union:

[http://europa.eu.int/comm/employment\\_social/fundamental\\_rights/index\\_en.htm](http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm).

A project called “Fighting for our rights” and led by Inclusion Europe is reviewing how the concepts relevant to people with intellectual disabilities that are included in the European Employment Equality Directive have been transposed and defined in the national laws of the EU member states. The project activities include the preparation of information and guidance on the Directive and the provision of training for disability activists and advocates at local, national and European level on the use of non-discrimination legislation. This will lead to the identification and support of potential plaintiffs with intellectual disabilities in defending their rights. More information can be found at <http://www.inclusion-europe.org>.

Latest issues: in April 2006, a big fair was organised in Austria by Atempo and Inclusion Europe. These organisations had selected the 15 best European projects that working in issues relating to the employment for disabled people. The activities of these projects were presented during this fair. They provide some good examples of best practice in employment. They can be found at

<http://www.atempo.at/index.php?node=496&id=426&size=2&lang=5&>.

## **5. Access to Education**

The right to education is included in many human rights instruments. For example:

- Article 14(1) EU Charter of Fundamental Rights – *“Everyone has the right to education and to have access to vocational and continuing training”*;
- Article 13, International Covenant on Economic, Social and Cultural Rights – recognises *“the right of everyone to education”*;
- Articles 28, Convention on the Rights of the Child – recognises the *“right of the child to education”*;
- Article 2 of Protocol 1 of the European Convention – states *“No person shall be denied the right to education”*;
- Rule 6, United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities – *“States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system”*.

The Committee on Economic, Social and Cultural Rights (which oversees States’ compliance with the International Covenant on Economic, Social and Cultural Rights) has commented that education is not only a human right in itself but is also “an indispensable means of realizing other human rights”.<sup>23</sup> In the Committee’s view technical and vocational education forms part of both the right to education and the right to work and that this includes “retraining for adults whose current knowledge and skills have become obsolete owing to technological, economic, employment, social or other changes”.<sup>24</sup>

<sup>23</sup> 08/12/99. E/C.12/1999/10. (General Comments), paragraph 1

<sup>24</sup> Paragraph 16



## 5.1. Education and the European Union

The European Union has 3 goals for education:

1. to improve the quality of education;
2. to make life-long learning accessible to everyone;
3. for education courses to look at issues relating to the rest of the world.



It is the member states themselves that are responsible for the content of their education courses. They are also responsible for the organisation of their education system.

But the European Union wants to make sure that their education system is of good quality. Therefore the European Union encourages cooperation between member states on issues about education.



Furthermore, while the right to education under the International Covenant on Economic, Social and Cultural Rights is a “progressive right” (this means that governments are required to work towards achieving this right) there should be a right of access to public educational institutions and programmes on a non-discriminatory basis.<sup>25</sup>

### 5.1. Education and the European Union

Although Member States retain responsibility for the content of teaching and the organisation of their educational systems, the EU seeks to contribute to the development of quality education by encouraging cooperation between Member States. Such work has increased since the Lisbon European Council in March 2000 when the EU set out its objective for the next decade: to become “*the most competitive and dynamic knowledge-based economy in the world capable of sustainable economic growth with more and better jobs and greater social cohesion*”. This was followed by the “Report on the concrete future objectives of education systems” which set out the EU’s overall approach to national education policies, based on the following three objectives:

- improving the quality and effectiveness of education and training systems in the EU;
- making lifelong learning accessible to everyone;
- making our education and training systems more outward-looking as regards the rest of the world.

On 30<sup>th</sup> November 2002 education Ministers of 31 European countries (Member States, candidate countries and EEA countries) adopted the “Copenhagen Declaration” on enhanced European cooperation in vocational education and training. The declaration states:

*Over the years co-operation at European level within education and training has come to play a decisive role in creating the future European society... Strategies for lifelong learning and mobility are essential to promote employability, active citizenship, social inclusion and personal development. Developing a knowledge based Europe and ensuring that the European labour market is open to all is a major challenge to the vocational educational and training systems in Europe and to all actors involved. The same is true of the need for these systems to continuously adapt to new developments and changing demands of society. An enhanced cooperation in vocational education and training will be an important contribution towards ensuring a successful enlargement of the European Union and fulfilling the objectives identified by the European Council in Lisbon.*

The Council of the European Union issued a Resolution on Life-Long Learning:

[http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/c\\_163/c\\_16320020709en00010003.pdf](http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/c_163/c_16320020709en00010003.pdf)

Latest issues: in May 2006, Inclusion Europe convened its annual congress on “Life-long learning education”. The conclusions and the presentations that were made during this congress can be found at: <http://www.inclusion-europe.org/europeinaction>

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<sup>25</sup> Quinn, G., and Degener, T. with Bruce, A., Burke, C., Castellino, J., Kenna, P., Kilkelly, U. and Quinlivan, S., (2002) *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability* [www.unhchr.ch/disability/hrstudy.htm](http://www.unhchr.ch/disability/hrstudy.htm)

## **6. Further Information**

Below, we provide you with a list of European-wide organisations working on topics that can be of relevance for people with intellectual disability and/or mental health problems.

Autism Europe: [www.autismeurope.org](http://www.autismeurope.org)

European Association of Service Providers for persons with Disabilities: [www.easpd.org](http://www.easpd.org)

European Coalition on Community-Living (ECCL): [www.community-living.info](http://www.community-living.info)

European Disability Forum: [www.edf-feph.org](http://www.edf-feph.org)

European Down Syndrom Association: [www.edsa.info](http://www.edsa.info)

European Federation of Associations of families of people with Mental Illness: [www.eufami.org](http://www.eufami.org)

European Network of (ex-)Users and Survivors of Psychiatry: [www.enusp.org](http://www.enusp.org)

European Network on Independent Living: [www.independentliving.org](http://www.independentliving.org)

Mental Disability Advocacy Center [www.mdac.info](http://www.mdac.info)

Mental Health Europe: [www.mhe-sme.org](http://www.mhe-sme.org)

The Platform of European NGOs: [www.socialplatform.org](http://www.socialplatform.org)

## Part 2 – Mental Health

Part 2 will be of particular interest to people using mental health care, individuals seeking to develop and implement policies that are relevant to people with mental health problems and those developing mainstreaming training events with a focus on mental health issues.

It covers the following areas:

- information on key policy areas;
- suggestions on how to raise awareness about mental health issues;
- practical information for trainers.

### 1. Information on Key Policy Areas

This section provides a brief overview of some key mental health documents. It is intended to provide a guide for people on where to find further information, rather than a detailed analysis of the issues.

#### 1.1. Mental Health Policy and Legislation

- *European Commission (Health & Consumer Protection Directorate-General) Green Paper, Improving the mental health of the population: Towards a Strategy on mental health for the European Union, October 2005* (Responses were sought by 31<sup>st</sup> May 2006):

[http://europa.eu.int/comm/health/ph\\_determinants/life\\_style/mental/green\\_paper/mental\\_gp\\_en.pdf](http://europa.eu.int/comm/health/ph_determinants/life_style/mental/green_paper/mental_gp_en.pdf)

This document puts forward a proposal for a European Union (EU) wide strategy on mental health, which would focus on the following four areas:

1. promote mental health for all (such as promoting health in the working population);
  2. address mental ill health through preventative action (such action to reduce depression and prevent suicide);
  3. improve the quality of life of people with mental ill health or disability through social inclusion and the protection of their rights and dignity (such as work to identify best practice for promoting the social inclusion and protecting the rights of people with “mental ill health and disability”);
  4. develop a mental health information research and knowledge system for the European Union.
- *WHO Resource Book on Mental Health, Human Rights and Legislation stop exclusion, dare to care, World Health Organisation, 2005:*  
<http://whqlibdoc.who.int/publications/2005/924156282X.pdf>  
This document provides comprehensive information on the key issues and principles to be incorporated into mental health and related legislation. For example, it covers guardianship, involuntary admission and treatment, access to personal information, confidentiality and complaints. Key human rights standards and their relevance to mental health are also examined.
  - *“Facing the Challenges, Building Solutions”:* Mental Health Declaration for Europe and Mental Health Action Plan for Europe, Helsinki, Finland, January 2005. On behalf of their countries, the Ministers of Health of the Member States of the World Health Organisation (WHO) European Region (which include Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia) adopted the Mental Health Declaration and Action Plan for Europe.

The Declaration and Action plan are important documents because by adopting them, the governments of these countries have committed themselves, over the next five to ten years:

*“...to develop, implement and evaluate policies and legislation that will deliver mental health activities capable of improving the well-being of the whole population, preventing mental health problems and enhancing the inclusion and functioning of people experiencing mental health problems.”*

There are a wide range of activities proposed in the Action Plan, many of which will be useful to individuals and groups seeking to be involved in the development and implementation of policies. Set out below are some examples of the range of actions that governments are being asked to consider:

#### *Demonstrating the centrality of mental health*

- *“Incorporate a mental health perspective and relevant actions into new and existing national policies and legislation”*
- *“Give special consideration to the relative impact of policies of people already suffering from mental health problems and those at risk”*

#### *Tackling stigma and discrimination*

- *“Introduce or scrutinize disability rights legislation to ensure that it covers mental health equally and equitably”*
- *“Develop and implement national, sectoral and enterprise policies to eliminate stigma and discrimination in employment practices associated with mental health problems”*
- *“Develop a coherent programme of policy and legislation to address stigma and discrimination, incorporating international and regional human rights standards”*
- *“Set standards for representation of users and their carers on committees and groups responsible for planning delivery, review and inspection of mental health activities”*
- *“Establish vocational training for people suffering from mental health problems and support the adaptation of workplaces and working practices to their special needs, with the aim of securing their entry into competitive employment”*

#### *Offering effective care in community-based services for people with severe mental health problems*

- *“Plan and implement specialist community-based services, accessible 24 hour a day, seven days a week, with multidisciplinary staff, to care for people with severe problems such as schizophrenia, bipolar disorder, severe depression or dementia”*
- *“Provide crisis care, offering services where people live and work, preventing deterioration or hospital admission whenever possible, and only admitting people with very severe needs or those who are at risk to themselves or others”*

## **1.2. Stigma, Discrimination and Social Exclusion**

People with mental health problems experience severe and widespread stigma and discrimination. Addressing the stigma and discrimination attached to mental ill health is recognised as a crucial factor in improving the mental health of the population. This section provides some further information on steps to challenge stigma and discrimination.

- **The European Commission’s consultation document *improving the mental health of the population. Towards a strategy on mental health for the European Union (October 2005)* states:**

*“Stigma increases personal suffering, social exclusion and can impede access to housing and employment. It may even prevent people from seeking help for fear of being labelled... There is also a need to for a shift in the attitudes of the public, social partners, public*

*authorities and Governments: improving public awareness about mental ill health and treatment options, and encouraging the integration of mentally ill and disabled people into work life, can create greater acceptance and understanding across society.”<sup>26</sup>*

- **“Facing the Challenges, Building Solutions”: Mental Health Declaration for Europe and Mental Health Action Plan for Europe, Helsinki, Finland, January 2005** identifies ten areas of action that governments should consider in order to tackle stigma and discrimination (some of these are set out in section 1 above).
- **Open Up Mental Health Media’s Anti-Discrimination Toolkit:** Mental Health Media: an organisation in the UK has a specific website designed to assist people in working to challenge stigma and discrimination. It is targeted at people working in the UK but includes information that would be helpful to people working outside the UK such as information on projects that are challenging stigma and discrimination and suggestions on “what works” - how to challenge stigma and discrimination:  
[www.openuptoolkit.net/home/index.php](http://www.openuptoolkit.net/home/index.php)

## **2. Action to Raise Awareness about Mental Health Issues**

*This section provides information on activities that will help you raise awareness about mental health issues. The term “campaigning” is used to describe the various activities that are used to raise awareness, for example getting media coverage and contacting politicians.*

### **2.1. Information on Campaigning**

*Although the following websites are not focused on mental disability issues, you may find them useful as they provide a range of suggestions and ideas on campaigning.*

The Millennium Campaign: Voices Against Poverty website includes a “Campaigning Toolkit”:  
<http://www.millenniumcampaign.org/site/pp.asp?c=grKVL2NLE&b=403123>

Although the aim of the toolkit is to help individuals and civil society organisations in campaigning for the Millennium Goals (see [www.un.org/millenniumgoals](http://www.un.org/millenniumgoals)) much of the information and suggestions on how to run successful campaigns will also be relevant to raising awareness on issues relevant to people with mental health problems. The section on “campaigning skills” includes advice on how to prepare a press release, writing to editors of newspapers, giving media interviews, public speaking and organising public events.

Ask About Medicines, an independent UK based campaign to increase people’s involvement in decisions about their medicines use has produced a toolkit to assist individuals wishing to raise these issues with the local media:

[http://www.askaboutmedicines.org/Homepage/AAMW\\_2005/Materials/Media Tool Kit/default.aspx](http://www.askaboutmedicines.org/Homepage/AAMW_2005/Materials/Media_Tool_Kit/default.aspx)

“Community Newswire”, a UK website, run by the Media Trust and the Press Association provides advice and information for community and voluntary groups wishing to gain coverage in the media: [http://www.mediatrust.org/community\\_newswire/index.htm](http://www.mediatrust.org/community_newswire/index.htm)

### **2.2. Holding Meetings to Discuss Awareness Raising Activities**

If you want to raise issues of concern and get involved in policy development you will need to discuss what issues you want to focus on and what action you need to take so that you can achieve the changes that you want to see. It will therefore be important to arrange times for your group to meet so that you can agree on a plan of action and update each other on progress. In order to get the best out of these meetings, they need to be planned carefully. Set out below are a few suggestions on how to organize a meeting:

<sup>26</sup> Daugiau: [http://ec.europa.eu/comm/health/ph\\_determinants/life\\_style/mental/green\\_paper/mental\\_gp\\_en.pdf](http://ec.europa.eu/comm/health/ph_determinants/life_style/mental/green_paper/mental_gp_en.pdf)

- **Setting up the meetings:** Try to make the meeting place easy to get to by public transport. Make sure that the meeting room is situated in a relatively quiet place and that it will be available for the length of time that you want to meet (so that you are not interrupted). If you are planning to meet regularly, try to find a time that suits everyone and then keep to this time (although you may need to change this as the group gets bigger). If possible, arrange the room so that people can sit in a circle, facing each other.
- **Agenda:** Make sure that the purpose of the meeting is clear. If possible send out the agenda before the meeting so everyone knows what is going to be discussed. Keep more or less to the times on your agenda: people will appreciate this.
- **Facilitating the discussions:** your group may start off with just a few people but as more people join, it will be important to give everyone a chance to speak. It would therefore be helpful to appoint a person to chair the meeting. This person will be responsible for ensuring that all the agenda items are discussed, that everyone has an opportunity to speak and that the outcomes of the discussions are clear. You could take it in turns to chair the meeting or decide between you who would be the best person to do this. The person would need to be a good listener, be able to keep the discussions focused and have the authority to ensure that members of the group treat each other with respect.
- **Include regular breaks:** be aware that people get tired and find it difficult to concentrate after a while so you should plan to hold breaks at least every 1 & ½ hours but also ask the person chairing the meeting to suggest more breaks if necessary.
- **Getting the work done:** make sure that everyone is clear on what needs to be done before the next meeting and who has agreed to do this. Ask someone to take a note of what has been agreed, for example a list of actions to be taken, and send this to all the participants as soon as possible after the meeting.
- **Evaluation:** after the meeting think about how the meeting went, what you could improve on and what was successful.

## 2.3. Preparing a News Release

*The following suggestions are based on the Media Trust's online guide "Writing a News Release" ([www.mediatrust.org](http://www.mediatrust.org)). A sample news release is also available online.*

- **Format and Style**
  - \* Use A4 letterhead and an agreed format, double-spacing or one-and-a-half line spacing, all on one page, or two at the most.
  - \* Put "News release" and the date in large print at the top.
  - \* Include the name and title of the person who you want to see this news release .
  - \* The style throughout must be concise and intriguing as possible. Imagine that you know nothing about your organisation – do you think that this story will be of interest to readers/viewers?
- **Heading**
  - \* The heading of the news release should be short, grab the reader's attention and give a sense of the story in very few words.
  - \* Use headings for subsequent paragraphs if appropriate although they are not essential.
- **First Paragraph:** This must be short, to the point and newsworthy. It must clearly state the "five w's": who, what, where, when and why (in any order). This paragraph must be able to stand on its own as a concise piece of information.

- **Second Paragraph:** This should provide the next piece of information: either more details about the information in the first paragraph above, or new information.
- **Third Paragraph/Additional Paragraphs:** Use only if you have more new information. This paragraph could be a quote from someone involved who is willing to talk to the press if requested. The quote must add a new dimension, such as the personal side of the story. Alternatively it could be a quote from your spokesperson explaining the importance of the story in strong, authoritative language.
- **Contact Details:** Your name, title, telephone number and home or mobile phone should be included in clear, bold print at the bottom of the document. Provide a contact number for when you are out of the office. This can make the difference between your story being covered or not.
- **Additional Information for Editors:** Include the word count. Describe your charity in a few words. Give any relevant basic information and statistics. Include your website address if you have one.
- Have you circulated a copy to everyone from the campaign whom the media might contact?
- Have you made follow-up calls to journalists you know?

## **2.4. Contacting Political Representatives and Policy Makers**

The Millennium Campaign: Voices Against Poverty “Campaigning Toolkit” includes a chapter on “lobbying”. This term is used to describe *“persuading individuals or groups with decision-making power to support your position”* and this activity is aimed at shaping public policy in arenas of influence at the local, national or global level. The toolkit states:

*“When doing your organisational planning, it is important to identify other stakeholders whose co-operation or influence you need. You can then lobby people with power to act in support of the needs and interests of those who do not have direct power and influence. Lobbying can be used to influence anyone with power.”*

The toolkit sets out some “Critical success factors”:

- Be clear about your issue, your facts and your position.
- Use lobbying only for important issues that will improve life in the community and make very sure that your position is the right one before you start lobbying.
- Be careful not to speak “on behalf of” people unless you have consulted them and involved them in developing your lobbying strategy. Target the right people – analyse who has the power to make a decision on your issue and target your lobbying at these people.
- Build a lobby group – analyse who (individuals and organisations) can influence the decision-makers and try to mobilise them to support your issue – never try to lobby alone. People with political power are often most sensitive to grassroots mobilisation that represents their voters.

## **2.5. Writing to Policy Makers**

Sending a letter is one way of raising an issue of concern with a policy maker or petition. Such letters should set out clearly and concisely why you are writing to the person and what you would like him/her to do (remember the person you are writing to is likely to be busy so sending long letters which do not keep to the point are unlikely to get a positive response). Set out below is an example of a letter to a politician:

- **Who to:** Make sure that you have the correct name of the person you want to contact and that person’s proper title (e.g. Professor, Doctor, Mr., Mrs., Ms) and the person’s full address

- **Who from:** State who you are and the name of the organisation that you are representing. If your organisation does not have headed note paper, make sure that you include your contact details
- **What this is about:** Set out the particular issue that you want to raise with this person.
- **Why you are concerned:** Explain why this is a matter of concern to you and what you know about this issue. This could include very personal facts, if so, make sure you it enforces the issue you want to raise and keep it short.
- **What you would like done about it and why:** state what action you would like to be taken and why you think this action is necessary
- **Welcome the opportunity to meet or provide further information.**

## **2.6. Meeting Policy Makers**

Meeting with a politician or other policy maker is a great opportunity to present your case. It is therefore important to prepare for these meetings. Set out below are a few suggestions on how to get the best out of such a meeting:

- Be clear on why you are attending this meeting – what you want to achieve
- Be on time but do not get impatient if you are kept waiting for a while.
- If there are a number of you attending the meeting, decide between yourselves what each of you will talk about and who will start off the discussions by thanking the person meeting with you, setting out the reason for the meeting and introducing each of you and your organisation.
- Make your points clearly and concisely.
- Where you have identified problems, suggest solutions
- If you are asked a question and are not sure of the answer, suggest that you will respond later in writing
- At the end of the meeting provide a summary of the issues or a fact sheet (no more than 2 pages) with your contact details.
- Follow-up the meeting with a letter of thanks (and provide any further information you agreed to send).

Although at first these meetings may seem difficult and daunting and sometimes you may feel that you are not achieving much, do not give up. Remember you have a lot of expertise, which could help policy makers in their work to make policies relevant and effective.

## **3. *Practical Information for Trainers***

This section provides some practical information for those who are involved in running training sessions on mainstreaming policies that are relevant to people with mental health problems (also referred to in this section as “users of mental health care”).

It will be important for those individuals who wish to become involved in the development of policies that affect them to know where to find, and how to use, relevant information. They will also need to develop advocacy and presentation skills so that they are confident in raising



issues with politicians and other relevant stakeholders. This section suggests ideas on how to run training sessions that will help participants to put in practice the issues described in the above section (Action to Raise Awareness about Mental Health Issues). It includes the following Information

- Preparing for and delivering a training session.
- Ideas on how to establish a relaxed atmosphere so that the participants feel able to discuss issues with each other.
- Some examples of how to work and how to evaluate activities in order to improve knowledge and skills of both the participants and the trainer.

### **3.1. Preparing for, and Delivering, a Training Session**

The best people to run training events are people who have experience of using mental health care. This section will help the trainer to set up a useful training seminar to train his/her peers.

There are many different ways of running training sessions. However, there are some key points that will help in making the training sessions interesting and enjoyable for both the trainer and the participants. For example:

#### **i. Goal: be clear about the purpose of the training event**

Make sure that you, as the trainer are clear about the purpose of, the training event:

- What do you want the participants to have learned?
- What should they be able to as a result of the training you have given?
- For example: your objective for the first seminar may be that you want the participants to have a general understanding of the relevant legislation in your country, be aware of their rights, and have improved their presentation skills which will help them in future meetings with policy makers.

#### **ii. Methods: know how you are going to provide information and enhance skills**

Think about what training methods you are going to use for each subject that is covered in the training day. For example, informing people of the legislation is very different from teaching presentation skills.

- **Handouts:** If you just want to give information, you can use handouts, or even copies of the relevant text. If you want to discuss the information during the training session the handouts should not be very long and you will need to give the participants time to read the handout. In your own words explain what is in the handout and its relevance. For example it may be important to understand an area of law before meeting with a policy maker.
- **Exercises:** Sometimes a simple exercise will help people understand the text better. For an example see paragraph 3.4 on the Agenda 22. When teaching practical skills it is best to give a task to the participants and ask them to practice in front of the group. An example of a presentation exercise is given below at paragraph 3.6.

#### **iii. Selecting participants**

In selecting the participants you will need to consider the goals of the training so that the people who attend the training event are those who you think are interested in, and will benefit from, the training. These training sessions are targeted to individuals who use mental health services but you may find it helpful to develop additional criteria. Make sure that you have a clear and transparent policy on who you want to invite. For example: that the participants are not afraid to talk in public, they have some experience of advocating for themselves or others, or they are a member of a user organisation. It would be helpful to think about how to ensure that there is an equal gender balance among the participants and also whether you should aim to attract participants from just one region or from different regions.

#### iv. Preparing the training programme

Different people will be interested in different issues and will enjoy different training methods. It is therefore important to ensure that the training programme covers different topics and includes different activities.

- For example in addition to sessions on theory and law, include other issues that have a more practical focus.
- Keep the sessions short because it's quite exhausting to be in a training workshop. People also need time to socialise with each other. For example you could break the training programme so that for each day you have two sessions, each running for two hours. You will probably need to include a break in the two-hour sessions.
- The programme should include a range of training methods – if you have a whole afternoon of theory, people will doze off.
- The session after lunch is especially challenging as many people find it difficult to focus around that time. This would be a good time, therefore to include a session in which the participants are asked to give some input, or you could include some short exercises.

#### v. Organisation: practical issues

- **Venue and refreshments:** You need to arrange a venue to hold the training session. When deciding on the venue you should consider whether it is accessible by public transport. (You will need to give participants clear directions on how to get to the venue). You will also need to arrange for refreshments to be available for the participants. This will not only be for lunch but also for coffee breaks and in some cases you may also want to organise dinner for the participants. If the training session is for more than 1 day, you will also need to consider accommodation if participants do not live locally.
- **Equipment:** You will need to prepare the training and presentation material. Make sure you have enough handouts if you want to give materials to the participants. If you need presentation material (flip chart and pens, projector, beamer, etc.) – make sure that these are available and, for the electrical equipment, are working, in good time before the training is due to start.
- **Support for you:** Although very rewarding, preparing and delivering training can be hard work and stressful so make sure that you have some support in doing this work. If there are members of an organisation that you work with who have experience in running training events they may be able to help. You could also ask a friend or peer to help you. Some people will organise everything with a co-trainer, others will only ask for support during the coffee breaks. That is entirely up to you, but make sure that you have the help that you need.
- **Budget:** You will have to work out how much money you have to spend on the training event, prepare a budget and ensure that you stick to this.

#### vi. Delivering the training

Try to get all the participants into the room on time so that you can start promptly. It is important for both you and the participants that you create a safe environment, in which people are able to trust each other and feel comfortable in expressing their views.

Whether participants know each other already or not, it is always a good way to start the training with an “icebreaker”. These are exercises designed to help the participants get to know one another. Some examples of “icebreaker” are set out below in 3.2.

Follow the training programme, using the training methods that you have prepared. Try to keep to the agenda. If you feel that it would be helpful to do something different, explain this to the participants.

### vii. Group interaction

Try to be responsive to the needs of the group or people that you are training. The better prepared you are the easier it is to be flexible. Involve the group. Part of your program can be based on the participants' input. Don't forget to ask the participants about their specific knowledge. You might be able to learn from them and let them teach something to the group. However, make sure they don't take over. It is your training programme and you need to focus on achieving the goals you have set for the training session!

Set out how you expect members of the training group to behave in your training session. Example of the rules that you might want to establish include: listen to each other, don't talk when another is still talking, show respect to each other even if you have different views and opinions. You can either guide the group using the rules, or explain the rules to them before you start your training session.

### viii. Feedback on practical exercises

Participants may find it helpful to receive feedback from each other on how well they have performed in the practical exercises, for example, a presentation to the rest of the group. It will be important to set out some clear rules on how to feedback to each other, for example you could explain that the feedback should include 2 good points and 2 areas that could be improved. If you do not want to set rules you will need to guide the process closely to ensure that feedback is not too negative or personal. Another means of feedback for a practical exercise that focuses on information being passed from one person to another would be to ask some of the participants to watch how others convey information to each other and feed this back to the rest of the group. You could ask some to watch the non-verbal actions and others to watch the timing.

It is also important that these feedback sessions are carried out in a safe environment that shows respect for the individuals involved. Keep a close watch on the process and keep in mind that the person receiving the feedback should feel that the process has been helpful by confirming what s/he does well but also highlighting the areas that s/he needs to improve.

## **3.2. Using Icebreakers**

An icebreaker is a type of "social game" that can be used at the beginning of a meeting, training or workshop to get to know each other and "to break the ice". They can also be used at times when the trainer thinks that the group needs a period of relaxation.

### Examples:

1. Give everybody a blank piece of paper. Ask them to write on the paper:

- a) their name;
- b) where they come from;
- c) what they expect from the workshop.

Then you ask all participants to fold the paper into a little aeroplane and throw it in the air. Everybody picks up the nearest aeroplane. One person starts reading what is on the paper (aeroplane) - the paper will describe a person from the group. That person will then read the paper/aeroplane that he/she picked up from the ground, and so on until everyone has read from the piece of paper they are holding. At the end of this session the participants will know a little more about each other.

2. Take a ball. Ask all participants to stand in a circle. You throw the ball to one person and ask him/her to say his/her name. This person will throw the ball to another participant who will then say his/her name. After the first round, participants will throw the ball to a person and at the same time say the name of that person. After a while all participants will know each others name.

3. Ask everyone to sit in a circle. “Take” an imaginary rabbit. Pet it, kiss it somewhere on its imaginary body (tell the group where and remember where it was) and give it to your neighbour. He/she will pet the rabbit and kiss it somewhere and will then give it to the next person in the circle. Tell the group that they must remember where the rabbit has been kissed because it cannot be kissed in the same place twice. Everybody takes a turn in kissing the “rabbit” until the “rabbit” comes back to you. Then you explain to the group that the exercise will be repeated but this time each person will kiss their neighbour on the same place as they had just kissed the imaginary rabbit... This is a really nice game, which will give the participants something to laugh about! However, you can only do it, when you trust that the participants will be relaxed enough to enjoy it.
4. Split the group in subgroups of about 3 people. Ask them to tell each other about what they like, e.g. their hobbies. Give sufficient time (about 6-10 minutes) and make sure everybody gets the chance to talk about their favourite hobbies. Ask them to sit in a big circle. Each person will tell the rest of the group about the most interesting hobby/ies of one of the persons from his/her subgroup – this has been agreed upon within the small groups beforehand. Make sure that everybody is asked to talk about another person’s hobbies. You can keep track of all hobbies by writing them on a flip chart and categorize them. You will then see that most people have similar hobbies (like dancing, fishing and reading). This will help people relate to each other – and some will have a more or less unique hobby (maybe playing “go” – Japanese chess).
5. A relaxing icebreaker could be something with music. Ask people to sit in a very relaxed way. Then ask them to make basic singing sounds like “uuuu” or “mmmm” at different pitches. Then you could, for example, sing a melody all participants know. You could even write your own text describing the group’s situation on a melody and sing it together.

Only use the kind of icebreakers that you, as the trainer and facilitator, feel comfortable with and think will work with the particular group.

### **3.3. Thinking about Rights**

The following exercise can help participants think about their rights:

Split the group in several small groups and give them 15 to 30 minutes to make a list of the 10 rights they think they have or they would like to have. Start every sentence with “I have the right to...” Ask them to prioritise them. In the plenary afterwards ask them to name the 5 most important rights to the group. Another exercise to help raise awareness about rights is provided on page 66.

### **3.4. Agenda 22 and Practical Exercises on the UN Standard Rules**

Agenda 22, developed by the Swedish disability forum, is a comprehensive document explaining the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which was adopted by the General Assembly of the United Nations in 1993. The following exercise, using Agenda 22, is intended to make participants aware of the UN Standard Rules and how they can be used. (This simple but effective exercise was provided by one of the mental health experts involved in this project)

Show the participants the Agenda 22 document and give a short introduction to the UN Standard Rules and Agenda 22. Explain that Agenda 22 can be used by participants to see which of the UN Standard Rules their government has complied with (by for example,

introducing policies or legislation) and which rules have not been addressed. There may be cases where although policies and/or legislation have been introduced, they have not been implemented.

Ask the group to read the introduction and go through the rest of the Agenda 22 generally. Then go to chapter “Questions concerning the UN Standard Rules”.

You can divide the group in subgroups and you will provide each subgroup with one UN Standard Rule. You could choose e.g. for Rule 7: Employment.

Each group will get the same three questions, which have to be answered for the questions given for the chosen UN Standard Rule (Rule 7: Employment):

- What laws and policies exist in our country?
- What is missing?
- What do we need?

For example “Employment” has 8 subrules: 7:2 to 7:9. For each subrule the participants should ask themselves the 3 questions above. E.g. “7:2 What does the local authority do to encourage the integration of persons with disabilities into open employment?”

- What does the local authority do for disabled persons in general, then focus only on people with mental health problems – is it the same or is it different?
- What activities are missing to encourage integration in the open labour market at local authority level?
- What activities are needed to encourage integration in the open labour market?

This exercise will help your participants analyse the situation in your country on the issues that are important.

If you have a series of trainings, you could ask the participants to consider one of the UN Rules and consider whether this rule is being met in their region or location and prepare a presentation on this for the next training session. For example, if the theme of the following training session is to be on awareness raising you could ask them to consider Rule 1.

### **3.5. Identifying Key Decision-makers**

In order to influence policy development it is essential to know what individuals or organisations are the key decision makers in relation to the issue in question. It is therefore important to make participants aware of the need to identify these individuals or organisations who have the ability to initiate the changes that are being sought. For example, if there is a concern about a local hospital it will be important to find out what organisation is responsible for managing the hospital - is it the Ministry of Health or the local government? If individuals are unhappy with their treatment while in the hospital, usually the best person to approach first of all will be their doctor but if they are still unhappy with their treatment, they should then complain to the director of the hospital.

It is also important to remember that terms may mean different things to different people. It is therefore important to make sure that before you enter into a discussion about influencing policies during your training that you know and explain to your participants, quite precisely what you mean, when you use particular terms. . For example the term “local government” may be used by policy makers in the UN to mean the government of a country, whereas in a town the “local government” might be referring to the mayor.

### **3.6. Presentation Exercise**

Presentation skills are often useful, for example when presenting information to a large group. Such skills are also important for meeting with policy makers, for example if meeting with the local mayor to raise concerns about mental health issues, those attending the meeting will need to be able to explain clearly what their concerns are and what needs to be done to address these concerns.

As an exercise you can give your participants time to think about a subject, for example user values and to prepare a 5-minute presentation to give to the rest of the group. Allow the participants 10 minutes to prepare the presentation speech. Make sure everybody feels comfortable with presenting in front of the group.

After each presentation the person should be given some feedback both on the content of and delivery of the presentation. This exercise gives participants the experience of presenting information in a short space of time. This exercise will be good practice for meetings with policy makers because such meetings are usually very short so the ability to present the issues and arguments for change concisely and clearly will be very important. They will also be able to receive feedback in a safe environment from people they trust.

You may want to refer to or give as handouts, the suggestions about preparing for meetings with policy makers on page 56 above.

### **3.7. Evaluation**

At the end of your training session it is important for you and the participants of the training group to understand what they have learned and how they feel about the way you have run the training programme. You can either prepare an evaluation form for participants to complete or you can lead a discussion on this at the end of last training session. Make sure that participants follow the same rules as with the feedback session (raise points that were good and suggest areas for improvement) - the evaluation session must allow you to make the training even better next time.

Part 3, which has been written for the trainers of people with intellectual disabilities, provides further practical information and ideas on running training sessions.

## Part 3. Training ideas for trainers working with people with intellectual disabilities



### Introduction

It is important that people with intellectual disabilities are included in all policies and programmes.

We want to make sure that people with intellectual disabilities are not forgotten

when new policies and programmes are made.

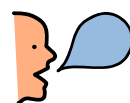
We call this “mainstreaming”.



To achieve this, people with intellectual disabilities have to be trained.

They must be trained in order to be able to:

- speak with decision-makers;
- speak up when they do not agree with something.

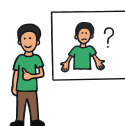


This section gives some ideas

on how to train people with intellectual disabilities.

It looks at 5 themes.

- Rights and Citizenship.
- Self-advocacy.
- Arranging Meetings for Self-Advocates.
- Easy-to-read information.
- Lobbying and information.



When you train people with intellectual disabilities, you should

- help them realise how good they are;
- help them realise that they can change the things they do not like;
- give them confidence to speak (in particular with politicians);
- give them material that they could use to raise awareness about people with intellectual disabilities.



People who have already been trained on these things are now making decisions for themselves.

They have created groups of self-advocates.

They are in contact with politicians about things they find important.

They are making changes in policies and decisions that are important for their everyday life.



**If you want, you could do that too!**





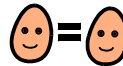
## 1. Rights and Citizenship



### 1.1. What are my Rights—I am a Citizen

It is very important for participants to realise that

- they are a person first;
- every person has the same rights.



We use the word “rights” to describe the way people should be treated and what people are allowed to do.<sup>27</sup>

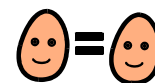
There are lots of documents that say what your rights are. Laws written by the government tell you about your rights. There are also European and International documents that say what your rights are.



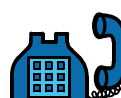
The Universal Declaration of Human Rights is the most well known document.

It explains for example that every person has the right to be treated equally. This means that you cannot be treated in a different way because of your

- race;
- religion;
- gender (male or female);
- political views;
- disability;
- or any other status.



It also explains that you have the right to be respected in your private life. This means for example that no one except you should open your letters. It means that nobody should listen to your phone calls.



<sup>27</sup> This definition comes from the information pack “My voice My choice” that you can find at order at <http://www.inclusionireland.ie>





There are lots of other rights that you have and that should always be respected. This means that other people also have lots of rights that you have to respect.

Another example of a human rights document is the European Convention on Human Rights.

These documents are not easy to understand. This is why associations for people with intellectual disabilities are trying to make them more accessible.

Easy-to-read versions exist for the following documents:

- the Universal Declaration of Human Rights;
- the European Convention on Human Rights;
- the Standard Rules of the United Nations.



To get these documents in easy-to-read or to get more information about rights, you can contact [self-advocacy@inclusion-europe.org](mailto:self-advocacy@inclusion-europe.org)



In the following pages, you will find a list of simple questions.<sup>28</sup> You can ask the participants to answer these questions. Then you can discuss their answers. There are no right or wrong answers. What is important is that they are able to say what they think.



The aim of the “Yes and No” questionnaire is to make people understand that they are important. The aim of the “True or False” questionnaire is to make people understand that they have rights.

You can make a list of those rights together.



### Tips for Trainers:

- At the beginning of this session ask people which rights they think they have.

<sup>28</sup> This document was made from a Quiz created by Ms Liza Kelly, Advocacy Officer, Inclusion Ireland <http://www.inclusionireland.ie>



## Tick YES if you Agree – NO if you disagree

**YES NO**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| Can you do something you can be proud of?                | <input type="checkbox"/> | <input type="checkbox"/> |
| Is there one thing you have done you are proud of?       | <input type="checkbox"/> | <input type="checkbox"/> |
| Is everybody good at everything they do?                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Can everybody learn something new?                       | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think other people should take decisions for you? | <input type="checkbox"/> | <input type="checkbox"/> |
| Is every person different?                               | <input type="checkbox"/> | <input type="checkbox"/> |
| Do you think that everybody needs help sometimes?        | <input type="checkbox"/> | <input type="checkbox"/> |
| Is it important to listen to what other people think?    | <input type="checkbox"/> | <input type="checkbox"/> |

## Answer TRUE or FALSE to the following statements

**TRUE FALSE**

- |  |                          |                          |
|--|--------------------------|--------------------------|
| All human beings have the same basic rights.                   | <input type="checkbox"/> | <input type="checkbox"/> |
| Staff or parents have the right to tell you when to go to bed. | <input type="checkbox"/> | <input type="checkbox"/> |
| If you live in a centre, you are not allowed to vote.          | <input type="checkbox"/> | <input type="checkbox"/> |
| The right to make choices is a basic human right.              | <input type="checkbox"/> | <input type="checkbox"/> |
| If you have a disability, you cannot get married.              | <input type="checkbox"/> | <input type="checkbox"/> |
| People can take away your rights whenever they want to.        | <input type="checkbox"/> | <input type="checkbox"/> |
| It is important to know what your rights are.                  | <input type="checkbox"/> | <input type="checkbox"/> |



## 1.2. How to Stand Up for your Rights

If someone does not respect your rights, you should complain about this person.



How to complain:<sup>29</sup>

1. look at what the problem is;
2. find out if there is a way to complain (a complaints procedure);
3. explain what happened (when it happened, where and who was involved);
4. explain what you want to happen;
5. if you write a letter, keep a copy of your letter of complaint;
6. ask when you will get an answer and make a note of the date;
7. follow up - if the date for the reply has passed, ask for an answer;
8. get as much support as you can.



Here are some tips to give people to help them stand up for their rights.



### a. Work with others

When you are standing up for your rights, it helps to do it with other people. Together we are strong!

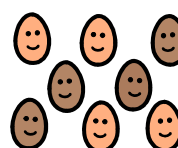


Other people will give you confidence.  
Other people may have good ideas.  
Other people will have different skills.  
When lots of people are asking for something, it is harder for them to be ignored!



### **Who can you get to work with you?**

People in the place where you live.  
People in the place you go to during the day.  
People in any groups you belong to.  
Other groups who want the same things as you.

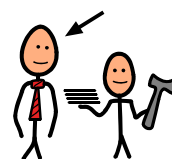


<sup>29</sup> This list comes from the information pack "My voice My choice" that you can find at order at <http://www.inclusionireland.ie>



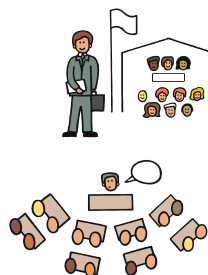
## **b. Find the right person to talk to**

If you think that your rights are not respected,  
 you have to decide who you will write to or talk to.  
 Who is responsible for the things you want to change?  
 Who has the power to change things?  
 Who can influence the important people?  
 Who can help you?



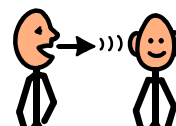
### **These are examples of people you can talk to or write to:**

The people who run the place where you live.  
 The people who run your day centre.  
 Important people in your local community.  
 Local town or region councillors.  
 Members of your parliament.  
 Members of the European Parliament.



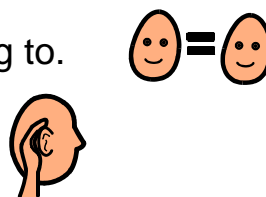
## **c. Have a clear message**

You must be clear about what you want to happen.  
 The people you are asking to change something  
 must know what you want.  
 Everyone you are working with must ask for the same thing.



### **When you ask for something, remember**

You are as important as the people you are talking to.  
 You have the right to ask for things.  
 You have the right to be listened to.  
 You have the right to be treated with respect.



### **When you are asking for things,**

Do not be rude.  
 Give other people the respect they should give you.  
 Be strong and firm.  
 Be confident and speak out.



## **d. You may not get what you want at first...**

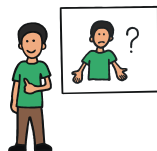
Be prepared to try again.  
 Look at how you asked and what you did...  
 You may have to do something differently.  
 Do not give up!

### **A few more tips:**

- A fun activity is to ask participants to mime their rights – by doing this each participant is showing how they can express their rights!
- The link between rights and self-advocacy is then simple:  
 when you express your rights,  
 when you speak up for yourself and ask that other people respect you,  
 you are a self-advocate!



## 2. Self-Advocacy



### 2.1. What We Do Not Want

Who is the best person to say what you want or what you need?  
You are!



Sometimes, parents  
and staff working with persons with intellectual disabilities  
think that they know better.  
But this is not true.



Let's take an example:

You have always liked to go on holidays with a group of old friends.  
But one day, you want to go on holidays with some new friends.  
Your parents or staff at your day centre  
want to send you on holidays with your old friends.  
But they should not take this decision for you.  
You know better than anyone else  
what you want to do for your holidays.



Often, people with intellectual disabilities  
find it difficult to express their wishes.  
Or people with intellectual disabilities  
find that their wishes are ignored.  
Sometimes, people think that they have a good reason  
for ignoring your wishes.  
For example they might say:



*"He has an intellectual disability,*

*he does not know exactly what he is saying..."; or*

*"I am her mother, I lived with her for 20 years, I know what she needs..."; or*

*"We live together in this centre. You have to do the same as everybody else..."*

Many people with intellectual disabilities have heard these reasons a lot.  
Parents or staff were not paying attention  
to their wishes and feelings.  
But some are now saying:  
"Stop! I have had enough! I know what I want for my life."



This is what we call self-advocacy.

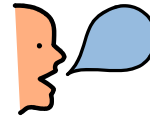




## 2.2. What is Self-Advocacy?<sup>30</sup>

Self-advocacy is not made of dreams or unreal situations.  
It starts with the really small choices that everyone can make for themselves.  
Even people with severe disabilities can make choices for themselves  
if they are given a chance!

Self-advocacy is about being a person first!  
Self-advocacy is about speaking up for yourself.  
It is about telling other people what you think.  
It is about telling other people what you need and how you feel.



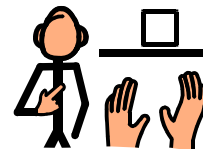
Self-advocacy is about asking questions.  
It is about speaking up... even if you are not asked what you think!  
Self-advocacy is about having your own identity.



Self-advocacy is about listening and about being heard.



Self-advocacy is also about doing things for yourself.  
Self-advocacy is about making your own decisions.  
*"I choose my clothes. I choose what I want to eat.  
I choose the people that will represent me."*



It is about having the control over your life.  
It is about starting to become independent.  
It is about asking for help when you want it  
and saying when you do not!!!



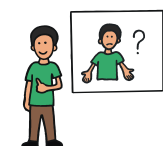
Self-advocacy is about knowing your rights.  
It is about standing up for your rights.  
It is also about knowing your responsibilities.  
It is about sharing information between each other.



Self-advocacy is about getting stronger.  
It is about confidence in yourself.  
It is about having other people believing in you as a person.  
It is about other people giving you more confidence in yourself.



Self-advocacy is about participation in family, in society, in policy.  
It is about getting involved.  
Self-advocacy is knowing what you can do.  
It is about developing confidence.  
It is about being treated with dignity.



People who speak up for themselves are called self-advocates!

<sup>30</sup> This definition comes from the brochure of the European Platform of Self-Advocacy (EPSA) that you can find and order at <http://www.inclusion-europe.org>



*“Being a self-advocate helped me to speak for myself.  
And make choices...”*

**Jean Menzies, Scotland**

*“Being a self-advocate helped me be independent and responsible.”*

**Sonia Carvalho, Portugal**

*“Self-advocacy is living by myself and taking my own decisions.  
It is breaking the silences and being heard.”*

**Andrew Forbes, Scotland**

Key self-advocate slogans are:

- “Nothing about us without us”;
- “Our lives, our choices”;
- “Who is in control?”.

### **Tips for Trainers:**

To help participants learn how to become self-advocates:

- Ask them to speak and present their views to the group on as many things and as often as possible
- Remember however that for some participants this might be the first time that they have ever been asked to give their opinion, so it is important to give them time, and support, to say what they think

## **2.3. Self-Advocacy Groups**

It is very important not to stay alone.

If you work with other people, you can:

- speak about your rights and your needs;
- express yourself and be heard;
- raise awareness of people.



It is important to create groups of self-advocates.

You and the other members of your group can talk about

- the good and bad things in your lives;
- whether our society is good at including people with intellectual disabilities;
- what can be done to make things better.

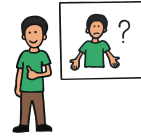


Together we are stronger!





## 2.4. How to Start a Self-Advocacy Group



When a new group is starting, it is important for the members to have control. The group should belong to the members only.

Here are some steps to start a self-advocacy group.<sup>31</sup>

1. Make sure everyone understands what self-advocacy is.  
Make sure everyone understands why people want to meet as a group.
2. Decide on what needs to be done to get the group going  
(a place to meet, a way to get there, publicity, agenda, etc.).
3. Find out how other groups work and learn from them.
4. Decide on the rules for how the group is going to work together  
(chairperson, votes, fees, etc.).
5. Develop “team spirit”  
and good working relationship between members.
6. Decide on the goals for the group.
7. Decide on ways to reach your goals.
8. Develop connections with the community.
9. Evaluate how well the group is working and make changes.



## 2.5. The Importance of Good Support

Like everybody else, self-advocates need support. Without help, self-advocates can find it hard to

- attend a meeting;
- plan the travelling;
- read the papers;
- remember what has happened.



Therefore, supporters are really important for self-advocates. Part of the challenge in self-advocacy is to find good supporters and to make sure that the self-advocates and supporters work well together. Self-advocates and supporters need to trust each other. They need to get on well. Supporters need to know the self-advocates' interests, abilities and difficulties to be able to help in the best way.

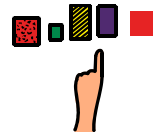


<sup>31</sup> This list comes from a brochure called “Starting a self-advocacy group” that you can find and order at <http://www.inclusionireland.ie>

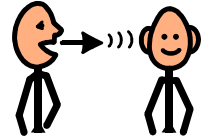




Self-advocates must always have the right to choose their supporter.  
Of course, supporters have the right to refuse  
when they do not want to do it.



Good support relies on good communication.  
Self-advocates and supporters should always say what they think  
so that they can work well with each other.



In general, supporters should make sure that  
self-advocates are as independent as possible.  
They should help self-advocates become more confident.

Self-advocates should also always respect their supporter's limits  
and need for a time to relax.  
They should not think that supporters are responsible for everything.



### **Tips for Trainers:**

To improve the relation between self-advocates and supporters:

- Prepare some games on communication  
between self-advocates and their support person.  
The games should show that there are lots of differences  
between what a person may want to say, what he or she does say  
and what the other person might hear.
- Give the supporters some time together to discuss their role.  
Being a support person is a very special role.  
Supporters doing this for the first time might need to work with others  
who have more experience of providing support.
- At the same time, self-advocates can have a session on their own.  
This will show them that they can work without their supporter.  
This has often proved to be a very interesting session for them.
- Give the self-advocates the opportunity to tell the supporters  
what is helpful support and what is not helpful support.



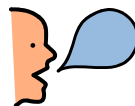
### 3. Meetings



#### 3.1. How to Get the Best out of Meetings

When you or your self-advocacy group want to change things, you will have to go to some meetings

- to get some information; or
- to say what you think.



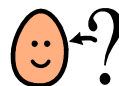
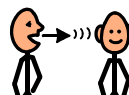
Here are some tips to take the best out of the meetings you attend.<sup>32</sup>

#### Choose the right meetings

- According to your needs and interests.

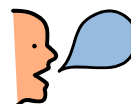
#### Prepare yourself.

- Read the papers if you receive any.
- Talk about the paper with your supporter.
- Think about the topic and the questions you have.



#### During the meeting

- If you do not understand what any of the speakers says you should ask them to explain what they mean.
- Do not speak during a presentation.
- Do not interrupt other people when they are speaking.
- Speak only about the topic that is on the agenda.
- Try to speak slowly and clearly.
- You can complain when other people do not respect these tips.



#### 3.2. Accessibility of Meetings

Unfortunately, meetings are not always accessible for people with intellectual disabilities.

This should not happen anymore.

Meetings about people with intellectual disabilities should be accessible for them.

There are several things that organisers can do to make their meetings accessible.<sup>33</sup>



<sup>32</sup> This list comes from the brochure “Rules for meetings” that you can find and order at <http://www.inclusion-europe.org>

<sup>33</sup> The following tips come from a brochure called “Recommendations for organisers” that you can find and order at <http://www.inclusion-europe.org>



They can organise a preparation meeting for people with intellectual disabilities. This will help people to understand what the meeting will be about.



During the meeting, it is often not possible to make all the sessions accessible for people with intellectual disabilities. However, there should always be some sessions that are accessible. These sessions should be clearly marked on the program.



Things like small regular breaks or working groups make it easier for people with intellectual disabilities to follow the discussions.



Programs and invitations should all be available in easy-to-read. Presentation from speakers should be easy to understand. This means that they should not be too long, and they should have visual support, with lots of examples, etc.



### 3.3. Organising a Meeting



When you or your self-advocacy group want to change things, you might even have to organise meetings yourself.

Here are a few ideas to organise a good meeting.



#### How to get people to come to a meeting?

- Choose a suitable time and place.
- Tell the people :
  - \* what the meeting is about;
  - \* where and when it is to be held;
  - \* why you want them to be there;
  - \* why it is important for them to come.
- Make sure that refreshments are available.



#### The place where you hold the meeting should be

- Easy to get to and get into.
- Comfortable.
- A suitable size.
- Have the facilities you need.
- Not too expensive.





### **About running a meeting**

- Decide who will be the “note-taker” (the person who will write the minutes).
- Decide who will be the chairperson.
- Prepare an agenda.
- Make sure the chairperson is prepared (e.g. has seen and agrees the agenda, knows what issues are likely to be raised at the meeting).
- Have the information you need ready.



### **The chairperson should**

- Introduce yourself and ask other people to introduce themselves.
- Explain the rules that will be applied for that meeting.
- Make sure that everyone can take part in the discussions.
- Have breaks when necessary.
- Keep control of the discussions (for example make sure that participants stick to the topic being considered).



### **At the end of the meeting, make sure people know**

- What decisions were made.
- What is expected of them.
- The things they have to do.
- What happens next.

### **After the meeting, make sure that**

- Someone writes up the minutes of the meeting.
- The minutes are sent to everyone.
- The minutes are sent as soon as possible after the meeting.



## ***4. Accessibility of Information: the Easy-To-Read Language***

Everyone has a right to know things.  
Everyone has the right to get information.  
Important information should always be accessible for people with intellectual disabilities.



When materials are not in easy-to-read, some people do not understand them.  
When this happens, people can feel excluded and left out.  
This is discrimination!  
We should fight to get more information in easy-to-read.



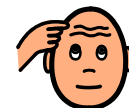
Inclusion Europe developed the European easy-to-read logo.  
This is useful because every time you see this logo on a document, you know that it will be easy-to-read.

You can download this logo for free at <http://www.inclusion-europe.org/etr>





## 4.1. Five Steps to Write an Easy-To-Read Document



### a. Think about why you need to write this

2 questions will help you decide why you are writing the document.

- What is the message you want to give?
- Why is it important for persons with intellectual disabilities?



Answering these questions, you will be able to be clear about your target audience and what information they need.

### b. Think about your message

Look at what you need to say.

- What is essential information?
- What are unnecessary details?



Only include the information that is needed.

### c. Write your document

Write the easy-to-read information following these guidelines:

- Use easy-to-understand language.
- Avoid difficult words or difficult concepts  
If you use difficult words, explain them.
- Explain with concrete examples.
- Use one idea per sentence.
- Address yourself directly to your readers.
- Address yourself to adults!
- Use short sentences (about 10 words per sentence).



### d. Prepare the layout

Avoid putting too much information on one page in your lay-out.

- Use a large and clear font (Arial 14).
- Print your text on a pale background.
- Try to put one sentence per line.
- Use drawings and pictures.
- Have less text on your pages (about 150 words per page A4).
- Avoid italic or capital letters.
- Avoid splitting up words at the end of a line.

### e. Test your document

Before publishing your easy-to-read information, test it with people with intellectual disabilities.

They are likely to suggest some changes to make the information more accessible.



You can also download the guidelines on how to write in easy-to-read at <http://www.inclusion-europe.org/documents/99.pdf>



There may be times when you receive a letter from a politician or other policy-maker that you do not understand.

This should not happen.

They should write to you in a way that is easy to understand.



Below, you will find an example of letter that you can send back when someone writes you an important letter that you cannot understand.

Mr Smith  
Prime Minister  
Avenue de Tervuren, 13B  
1040 Brussels  
BELGIUM

Brussels, 13 September 2005

**O/ Ref: IE/05-188**

Dear Mr Prime Minister Smith,

Thank you for your letter of the 28 August 2005.

We tried to read the letter but unfortunately, we could not understand it.

Could you please send it to us again in an easy-to-read format?

Together with this letter, you will find some rules that explain how to make a letter accessible for people with intellectual disabilities.

Yours sincerely,

Ulla Topi

President of  
the European Platform of Self-Advocates



## 5. How to Influence Policies

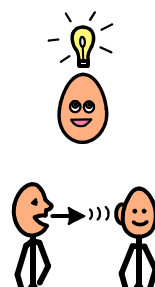


### 5.1. Lobbying

#### What is lobbying?

When you want to change something, you have to work for it!

Sometimes, you want to change things.  
Sometimes, you have new ideas about how things should work.  
To make these ideas happen,  
you have to speak to the people who can change these things.  
You have to make them support your idea.



This is called lobbying.

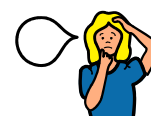
Lobbying means that you will have to write to important people.  
Lobbying means that you will have to talk to them.  
Lobbying means that you will have  
to make them understand that you are right.  
Lobbying also means that you might have to use the media!



Politicians have lots of important responsibilities.  
They have to take care of lots of things and lots of people.  
Politicians know a lot about different subjects.  
But they do not know everything.  
That is why people try to meet them,  
to give them information about their group.



If you do not meet the important people in your government,  
they might forget that people with intellectual disabilities exist...  
For example, not many politicians know about the lives  
of people with intellectual disabilities.  
We need to give them information about this.







Each government is divided into different departments  
They are usually called Ministries.

You have to find out who is responsible  
for people with intellectual disabilities.

You should write or talk to this person or even try to have a meeting.

Explain to this person how you live and what progress you would like to see.



This is what “lobbying” is about.

### A few tips:

- You can ask the participants to write a letter to an “important person”.
- You can develop a role play where they meet someone important.
- You can visit your Parliament and even meet some members.

## 5.2. Writing to Policy Makers



Lobbying can involve different things,  
for example, holding a conference or writing letters.

If you write a letter, make sure it is clear and not too long.

Make sure it is straight to the point.

In your letter, you should mention the following points.

- **Who to:** Make sure that you have the correct name of the person, the person’s proper title (e.g. Professor, Doctor, Mr., Mrs., Ms), and the person’s full address.
- **Who from:** Say who you are and the name of your organisation. Make sure to include your contact details.
- **What this is about:** Explain the problem that you have.
- **Why you are concerned:** Explain why this is a problem for you and what you know about this problem.
- **What you would like to be done about it and why:** Explain what action you would like to be taken and why you think this action is necessary.
- **Write that you would like to meet this person and that you can give further information if necessary.**







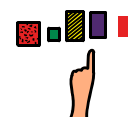
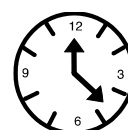
### 5.3. Meeting Policy Makers



Meeting policy-makers can also be a good way to make them understand your view and to get what you want. If you have a chance to meet them, you should not miss this opportunity.

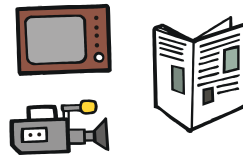
Here is a list of tips to get the best out of such meeting.

- Be clear and make sure you know:
  - \* why you are attending this meeting;
  - \* what you want to achieve.
- Be on time, but do not get impatient if you have to wait.
- You might go to the meeting with some other people. If you do this, you should decide who will say what.
- You should start by thanking the person meeting with you. Then you should explain the reason for the meeting and introduce each of you and your organisation.
- Make sure your points are clear and not too long.
- Where you have problems, suggest solutions.
- If you are asked a question, you might not be sure of the answer. If this happens, you can say that you will send a letter with an answer after the meeting.
- At the end of the meeting, give to the person you met a summary of the issues (no more than 2 pages) with your contact details.
- Follow-up the meeting with a letter of thanks and provide any further information you agreed to send.





## 5.4. Media



Meeting politicians can be a good way to make them understand your views and to get what you want. But sometimes, an even better way is to speak to the media. The media is the TV, radio, magazines and newspapers.

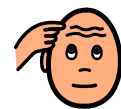
Getting into the media is important because:

- it helps people with intellectual disabilities get their voices heard;
- it helps other people hear stories about people with intellectual disabilities;
- it helps to change the way other people behave.

### How to get your story in the media <sup>34</sup>

Before contacting the media:

- think about whether your story would be best on TV, on the radio or in the newspaper;
- try and link your story to something that the media is talking a lot about or some thing that they will be talking about soon - the media are not interested in old news;
- if a journalist says no, ask them why they are not interested;
- ask them who they think may be interested in your story.



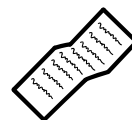
Start to make a list of people to contact.

Keep a note of the people who are helpful.

Build a good relationship with your local media.

Get to know your local media

and try to find out if anyone has a special interest in intellectual disabilities.



When you have made the first media contact, they may ask you to send them your story with a photograph.

- Make sure you send your story on time.
- Send a good photograph.

If journalists are interested in the story, they may also want to interview you.

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<sup>34</sup> These paragraphs are a summary of the resource pack called “Real Live Media” that you can find at [www.realivemedi.org](http://www.realivemedi.org)



This manual is for everyone who wants to be involved in making policies that concern them.

This manual gives information on important topics. It makes suggestions on how to speak with politicians and other people who make decisions about policies.

This manual can be used by trainers working with people with intellectual disabilities or with people with mental health problems.

This manual can also be used by people with intellectual disabilities and by people with mental health problems.

This Manual has been produced as part of the project “Mainstreaming Mental Disability Policies”. Its purpose is to provide materials that are relevant to people with mental health problems and/or intellectual disabilities and that can be used in training events on mainstreaming policies. The Manual is also intended to help self advocates and other individuals and groups who wish to become involved in the development of policies that affect them by providing information on relevant topics, making practical suggestions on how to engage with policy-makers and raise issues of concern and by giving details on where to obtain further information.

[www.inclusion-europe.org/mainstreaming](http://www.inclusion-europe.org/mainstreaming)

**We are citizens too!**

**Policies matter!**

**Nothing about us, without us!**

**Words into action!**

**Together we can do it!**

