



# PROJECT FUNDAMENTAL RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES AND PERSONS WITH MENTAL HEALTH PROBLEMS

**STAKEHOLDER MEETING REPORT**  
**4-5 NOVEMBER, 2010**

European Union Agency for Fundamental Rights (FRA)  
January 2011

# FRA Stakeholder Meeting Report

On the FRA project  
“Fundamental Rights of Persons with Intellectual Disabilities  
and Persons with Mental Health Problems”

*"Eventually the folly of this will dawn on people and we shall all joyously realise that we are all abnormal, disabled, impaired, deformed and functionally limited, because truth be told, that is what it means to be a human being."*

Jerome Bickenbach, meeting participant

**DISCLAIMER: The views expressed in this meeting report do not necessarily reflect the official position of the FRA.**

# FRA Stakeholder Meeting Report

<b>Project:</b>	The Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems
<b>Project aim:</b>	To facilitate the effective implementation of the <a href="#">UN Convention on the Rights of Persons with Disabilities</a> (UN CRPD).
<b>Meeting type:</b>	Stakeholder meeting
<b>Date/Location:</b>	4-5 November 2010 / FRA premises, Vienna
<b>Participants:</b>	Service-users; medical and legal professionals; NGO representatives; Council of Europe, UN Office of the High Commissioner for Human Rights, National Human Rights Institutions and European Union institution representatives; and disability experts (see annex two for list of participants).
<b>Why these participants:</b>	The FRA strives to engage and reach out to all stakeholders identified during its first <a href="#">disability stakeholder meeting in 2009</a> , in particular medical and legal professionals identified as playing a crucial role in implementing the fundamental rights of persons with mental health problems and persons with intellectual disabilities.
<b>Countries represented:</b>	Bulgaria*, Denmark, France*, Germany*, Greece*, Hungary*, Latvia*, Romania*, Sweden*, the United Kingdom*, etc.
<b>Meeting aim:</b>	To explore ways through which the different stakeholder groups can contribute to the protection and promotion of the fundamental rights of the two target groups, and to identify how FRA research findings can feed into this.
<b>Focus areas:</b>	Political participation (Article 29 UN CRPD); Involuntary treatment and involuntary placement (Articles 14 and 15 UN CRPD); Legal capacity (Article 12 UN CRPD) <i>(as per current FRA research focus areas)</i> .

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\* Country in which primary research will be carried out with and by service-users, and with people who impact heavily on their lives, such as carers.

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## Opening session and presentations

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Summary of key points:

- **FRA is keen to listen and learn new perspectives** on its work in the area of disability.
- The disability movement slogan **“Nothing about us without us”** guides the work of the Agency as was evidenced by the inclusive nature of the meeting.
- The following **primary stakeholders** of the disability project were identified through an initial stakeholder consultation:
  - ✓ Persons with intellectual disabilities and persons with mental health problems
  - ✓ Their family members, carers and personal assistants
  - ✓ Policy makers at EU level (European Commission, European Parliament)
  - ✓ Policy makers at national level
  - ✓ Legal and medical professionals
  - ✓ National Human Rights Institutions, Equality bodies and Ombuds offices
  - ✓ Service providers and social workers\*
- According to previous stakeholder feedback successfully harnessing social support and programmes to achieve change and independence as individuals was identified as a key challenge for persons with disabilities.
- Participants spoke about their desire to broaden perspectives, learn about promising practices and develop a network to explore follow-up activities among themselves or in partnership with the FRA.

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\* For more information please see opening remarks from [Eva Sobotka](#) and [FRA's Stakeholder Engagement Strategy of the project 'Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems'](#).

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## Plenary session on political participation (Article 29 UN CRPD)

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### Presentations:

[‘The right to political participation of persons with mental health problems and persons with intellectual disabilities’](#)

Mario Oetheimer (FRA)

[‘Participation of people with intellectual disabilities in European elections’](#)

Katrina Ward (Inclusion Europe)

[‘The implication of recent judgements for legal and medical practitioners’](#)

Jan Fiala (Disability Rights Centre)

### Summary of key points:

- Participants were generally in agreement that since the UN CRPD recognises that persons with disabilities have legal capacity on an equal basis with others, **states are obliged to provide the required support for individuals to exercise their legal capacity.**
- The lack of research material available or tools developed in the area of assessing a person’s capacity to make voting-related decisions was noted.
- Many participants agreed that since **voting decisions are entitled to be based on any criteria the voter sees fit**, tools to assess a person’s capacity to make voting-related decisions are undesirable, also noting that an individual’s ‘capacity’ to vote may change.
- Possible assessments could therefore focus on **gauging the support level needed for people to exercise their right** to vote, and not to test peoples’ entitlement to this right.
- The **integrity of the voting system and the desire to avoid electoral fraud** were discussed as reasons for preventing people from voting but **participants considered these separate issues** to that of whether or not persons with disabilities have the right to vote.
- The need for **persons responsible for assistance and/or care to assume an assistive, rather than supervisory, role** in this context was stressed.

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## Plenary session on involuntary treatment and involuntary placement (Articles 14 and 15 UN CRPD)

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### Presentations:

[‘Legal capacity, Article 12 UN CRPD and the paradoxes of beneficence’](#)

Jerome E. Bickenbach (Swiss Paraplegic Research)

[‘The preliminary results of FRA research on involuntary placement and treatment’](#)

Mario Oetheimer (FRA)

### Summary of key points:

- A relevant document in this context is the [2009 report of the UN Special Rapporteur on torture](#), Manfred Nowak.
- According to the report, **intrusive and irreversible medical treatments lacking a therapeutic purpose or aimed at correcting or alleviating a disability may amount to torture** if they are performed without the consent of the person concerned.
- There was disagreement whether the UN CRPD prohibits forced treatment, with some participants of the opinion that it is prohibited only if applied solely on the ground of disability, thus being discriminatory.

## WORKSHOPS ON INVOLUNTARY PLACEMENT AND INVOLUNTARY TREATMENT

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### Summary of key points:

- It was highlighted that the UN CRPD distinction between involuntary placement and involuntary placement is reflected to varying degrees in legislation at national level.
- Some participants mentioned the importance of assessing involuntary placement and involuntary treatment on a **case-by-case basis**, whereas others were **firmly against any type of involuntary placement or treatment**.
- The **lack of community-based alternatives** to resorting to involuntary placement was noted and offered as a partial explanation for involuntary placement being used as a first choice option rather than a last resort.
- **Awareness-raising** among the general public about alternatives to involuntary placement and involuntary treatment was considered to be important.

- The need for **dialogue between medical professionals, patients and their carers** was stressed.
- Some **good practices in psychiatry** were quoted, including examples of involving family and close friends earlier in the process of treatment.
- The need for **regular review and appeal mechanisms** to be in place, once involuntary placement has occurred, was underlined.
- The concept of acting in the **best interests of the person/patient** was discussed, with some participants emphasising the value of a user-focussed approach, which provides for the patient's own assessment of his/her response to treatment.

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## Plenary session on legal capacity (Article 12 UN CRPD)

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### Presentations:

#### ['Legal capacity'](#)

Jamie Bolling (the European Network of Independent Living (ENIL))

Testimonies – living with assistance

Monica Tornevik and Erik Lindgren (JAG)

#### ['Legal capacity'](#)

Tina Minkowitz (the Centre for the Human Rights of Users and Survivors of Psychiatry)

#### ['The right to legal capacity: guardianship at the ECHR'](#)

Jan Fiala (the Disability Rights Centre)

### Summary of key points:

- There is a need to change the interpretation of Article 12 UN CRPD, so that **supported decision-making (as opposed to substituted decision making) becomes the norm.**
- Sweden was cited as a good practice example, where **guardians are 'educated' and 'trained'** so that they know exactly what is expected from them – they cannot take any decision without the consent and agreement of the individual.
- Participants commented that persons with mental health problems are no more likely to harm others than any other group of individuals, but that they might be more likely to harm themselves.

## WORKSHOPS ON LEGAL CAPACITY

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### Summary of key points:

- Participants elected to treat **guardianship and legal capacity as two distinct concepts**.
- The variation between approaches taken to guardianship in the different EU Member States was noted, as well as the different types of guardianship that exist in the different jurisdictions.
- Balancing the **right to autonomy** and the **right to life** emerged once again and tools enabling practitioners to carry out this balancing act were called for.
- Participants suggested that traditional psychiatric assessment should not be the only way of depriving someone of his/her legal capacity, stating that psychiatrists are more oriented towards diagnosis and treatment than assessment.
- A collection of good practices was suggested for development, as a tool that could assist practitioners tasked with making assessments about individuals' legal capacity.

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## Conclusions

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### Summary

- There is a **need for increased dialogue** between medical professionals, national policy makers and legal practitioners.
- **More awareness-raising about a rights-based approach to disability is needed** among all actors – from legal and medical professionals, policy makers and national level actors to carers and family members.
- See Annex one for a list of **suggestions for future FRA action** from participants.

The stakeholder meeting was part of a process of engagement with stakeholders of the disability project and the process will continue in 2011, allowing for building on this meeting and further reach out to stakeholder groups identified in the FRA Stakeholder engagement, networking and communication strategy.

## Annex One: Suggestions for future FRA action from participants

### Awareness raising and education

- The FRA could provide a list of promising practices for community care.
- The FRA could encourage and support awareness raising activities at national level, aimed at bringing forward and promoting a new rights-based mind-set towards disabilities among the general public.
- The FRA could engage in providing support and advice to decision makers and practitioners with regard to the obligations deriving from the UN CRPD.
- The FRA could consider developing a step-by-step implementation package for certain rights.
- The FRA could, in collaboration with EU Member States, create material that envisages a medical system where involuntary hospitalisation is not permitted, giving practical examples of alternatives and their benefits.
- The FRA could develop material for, among others, medical and legal professionals encouraging them to take a rights-based approach to people with intellectual disabilities or mental health problems.

### **Stakeholder Engagement**

- The FRA could invest in making itself and its work better known to stakeholders.
- The FRA could engage with, assist and support government representatives that are willing to bring about change in their countries. This support would prevent them from being marginalised because of their views within their government. The FRA could provide these government representatives with specific advice and solutions that have been proven to work in the past, examples of promising practices in other countries or similar.
- The FRA should encourage and provide assistance to states that are willing to implement changes in their policies or plans to fulfil their new obligations under the UN CRPD.
- The FRA should further develop stakeholder relations with psychiatric associations and the judiciary.

## **Annex Two: List of participants**

ARVIDSSON, Linnéa  
Human Rights Officer, Office of the High Commissioner for Human Rights

BICKENBACH, Jerome E.  
Head of Disability Policy Unit, Swiss Paraplegic Research

BOLLING, Jamie  
Executive Director, ENIL – European Network on Independent Living

BRUNET, Sara  
Senior Lawyer, Equality and Human Rights Commission

CHRISTENSEN, Dorrit Cato  
Chairperson, Death in Psychiatric Care

CLARKE, Patrick  
Representative of the European Disability Forum and the European Down Syndrome Association, and Executive Board Member/President of the EDF – Down Syndrome International

COLDHAM, Tina  
Health and Social Care Advisory Service

ENGSTRÖM, Johanna  
Legal Officer, DG EMPL, European Commission

FIALA, Jan  
Legal Director, Disability Rights Center

GELDOF VAN DOORN, Lisette  
Member, Council of Europe Steering Committee on Bioethics (CDBI)

GERGELY, Dezideriu  
Member of the Steering Board, Romanian National Council for Combating Discrimination

GRIFFITHS, Raza  
Joint Network Coordinator at SPN, and Regional Coordinator for Open Up at MIND

HARANGOZO, Judit  
Psychiatrist, Board Member of the Awakening Foundation

JESPERSON, Maths  
Board Member, ENUSP – European Network of (ex-) Users and Survivors of Psychiatry

KINDERMAN, Peter  
Representative of Mental Health Europe

KOUVARITAKI, Janine  
Senior Investigator, Children's Rights Department, Greek Ombudsman

LAUCENIENE, Liene  
Legal Advisor, Office of the Ombudsman of the Republic of Latvia

LEWIS, Oliver  
Executive Director, MDAC – Mental Disability Advocacy Centre

LINDELL, Kerstin  
Psychiatrist, Swedish Psychiatric Association

LINDGREN, Erik  
Member of JAG

MEGIES, Stephanie  
Administrator, CPT Secretariat, Council of Europe

MINKOWITZ, Tina

President of the Center for Human Rights and Survivors of Psychiatry, and International Representative of the World Network of Users and Survivors of Psychiatry

PALLEIT, Leander

Legal research and policy advisor, German Institute for Human Rights

RENEMANE, Lubova

Psychiatrist, Assistant Professor at the Department of Psychiatry in Riga Stradins University, Latvian Psychiatric Association

ROZKALNS, Ronalds

Attorney at Law, Latvian Council of Sworn Advocates

RUSHBROOK, Ronald

Mental Health Act Policy Manager, Care Quality Commission

SPASOVA, Margarita

Communications and Project Officer, Bulgarian Commission for Protection Against Discrimination

TORNEVIK, Monica

Member, JAG

TÖRÖK, Ágnes

President of the Advisory Board of the Protective Network for Mental Health Foundation, Hungarian Psychiatric Association

TUDOSE, Catalina

General Secretary of the Romanian Psychiatric Association, and President of the Romanian Alzheimer's Society

WARD, Katrina

Project Officer, Inclusion Europe

WEINBERG-KRAKOWSKI, Stefan

Committee Member, CPT – European Committee for the Prevention of Torture or Inhuman and Degrading Treatment, Council of Europe

## Personal assistants

BENGTSSON, Ingela, JAG

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GUSTAFFSON, Erik, JAG

LINDGREN, Ingrid, JAG

LINDQUIST, Madeleine, JAG  
SYLVAN, Cecilia, JAG  
TORNEVIK, Ann-Christine, JAG

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