

29th November 2010

Dear NGO,

As you may already know, five European NGOs have nominated a representative to be part of the Advisory Board to the **study on Fundamental Rights of People with Mental Health Problems and People with Intellectual Disabilities**.

This 16 months international study, contracted by the European Union Agency for Fundamental Rights (FRA), started in July of this year.

The first part of our investigation involves collecting information about the laws and policies which affect the lives of people with mental health problems and people with intellectual disabilities in all 27 member states of the European Union. Our focus here is the analysis of what is actually being done to protect the rights of people with mental health problems and people with intellectual disabilities in the four areas of concern to our project. The four main areas of our interest are **Community living, Fundamental rights in institutions, Legal capacity** and **Access to justice**. Please see the Annex to this letter for background information on the study.

Country researchers in all 27 countries are drafting a country report, based on the law and policy analysis, as well as the analysis of any other publicly available information. In the first drafts **we have noticed a lack of NGO materials**. It is very much in the interest of this study not to look only at the theory but also at concrete practices and the way peoples' rights are being dealt with in reality.

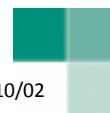
If your organization or any of your member organizations has conducted any research, published any reports, statements, press releases or any other material related to the topics above, **we would very much appreciate if you could provide the country researcher in your country** (see annex for contact details) **with sources of such information**. Those can include any publicly available material (also websites and blogs; newspaper articles etc). We are interested in any publicly available material that we can refer to, in particular from the last five years (since 2005).

We would greatly appreciate if you could provide this information to the country researcher in your country **by 22 December**. Once the report has been written, you will receive the draft version for comment.

Thank you very much in advance,

On behalf of the Research Team
(Edurne Iriarte, Anna Lawson, Oliver Lewis, Jasna Russo, Rachel Stevens and Rannveig Traustadottir),

Piet Leunis
Director Human European Consultancy



Background information study

The study "[Fundamental Rights of People with Intellectual Disabilities and People with Mental Health Problems](#)" is the first research in this field, carried out under contract with the European Union Agency for Fundamental Rights (FRA) and the outcomes should provide evidence of what countries still need to do to make sure that people with mental health problems and people with intellectual disabilities can live freely and safely in the community.

Being fully aware of the importance of language and self-definition and that there will not be terms acceptable for everybody, in the context of this particular project, we are using the terms *people with mental health problems* and *people with intellectual disabilities*, as chosen by the FRA. Nevertheless, during the course of this study we hope to suggest more appropriate and suitable terms and are looking very much forward to your input on this issue.

The study is focussing on four areas:

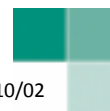
1. **Community living** (including the right to decide where to live, to have access to all the services available to general population; involvement in decision making regarding design and provision of support as well as services imposed on people and forced treatment in the community)
2. **Fundamental rights in institutions** (circumstances of detention; coercive treatment and the right to challenge and review it; autonomy, privacy and relationships; physical conditions of institutional living and general health care)
3. **Legal capacity** and
4. **Access to justice** (routes and remedies in both institutions and community; self-advocacy, complaint and support mechanisms).

The study has two parts, the drafting of so called desk study reports on the situation in the 27 EU Member States and field study (research into the lived experience of these two groups as well as into their perspectives on their fundamental rights) in 9 selected countries: Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden and the UK.

The study is jointly conducted by [Human European Consultancy](#) (Utrecht, the Netherlands), [Centre for Disability Studies](#) at Leeds University (UK), [the Centre for Disability Law and Policy](#), National University of Ireland, Galway and the [Mental Disability Advocacy Center](#) (Budapest, Hungary).

The study is guided by an Advisory board, coordinated by a Research Team and carried out by country researchers in the 27 EU Member States.

The project design has been developed in collaboration with the leading EU organisations of people with mental health problems and people with intellectual disabilities (including yours) and their advice and input throughout our work will be decisive for the quality and accountability of our reports. Our investigation focuses separately on the two groups and we are taking an emancipatory research approach.



The following organisations (in alphabetical order) are represented on our Advisory Board:

- European Coalition for Community Living, represented by John Evans
- European Disability Forum, represented by Carlotta Besozzi
- European Network of (ex) Users and Survivors of Psychiatry, represented by Mary Nettle
- European Platform of Self Advocates, represented by Senada Halilcevic
- Inclusion Europe, represented by Geert Freyhoff

The Research Team consists of six people, responsible for the methodology, researchers' training and producing final reports.

People who have experienced psychiatric treatment and people who describe themselves as having learning difficulties are working collaboratively in our research team and Advisory Board.

The researchers in the EU Member States are:

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