



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

**RESPONSES OF PARTICIPANTS TO CONSULTATION ON THE  
STAKEHOLDER ENGAGEMENT STRATEGY**

European Union Agency for Fundamental Rights (FRA)  
September 2010

**Disclaimer: the views expressed in the report are those of participants of the initial networking meeting on the FRA project on the fundamental rights of persons with disabilities and persons with mental health problems and do not in any way represent the views of the FRA.**

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## INTRODUCTION

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The European Union Agency for Fundamental Rights (FRA) launched its project on the Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems in 2009. The protection of the fundamental rights of persons with disabilities is a high priority for the FRA. Discrimination based on disability is one of the thematic areas of the FRA's [Multi-annual Framework](#) (2007-2012).

The FRA decided to start its work in the area of disability by focusing on two specific groups of individuals: persons with intellectual disabilities and persons with mental health problems (hereafter referred to collectively as persons with disabilities). Although the groups differ, these individuals face the same reaction from society: stigma and social exclusion. The disability project is framed by the [UN Convention on the Rights of Persons with Disabilities](#) (CRPD), which embraces the “social model” of disability. The CRPD asserts that it is society that must adapt to accommodate the needs of persons with disabilities, not persons with disabilities themselves who must be “fixed”.

**The purpose of this document is to provide an overview of the responses of participants to the initial networking meeting on the project to a questionnaire**

**on their priorities, needs, and identification of key stakeholders.**

On the basis of the responses provided, the FRA has developed a stakeholder engagement and communication strategy, which will guide the Agency over the next few years in working towards improving fundamental rights situation of persons with intellectual disabilities and persons with mental health problems.

This document provides information about the stakeholders of the FRA disability project, key issues, various stakeholders' needs and suggestions for contribution that can be made by the FRA to the ongoing work on the rights of persons with disabilities. Responses have been grouped according to the specific objectives of the FRA Disability Project, which were adjusted in a follow up to the consultation. The first Section of this paper is dedicated to the stakeholders' feedback within the context of the project, while the second section focuses on feedback which falls outside the scope of the FRA Disability Project.

## PROJECT PURPOSE, OBJECTIVES AND METHODOLOGY:

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The overall objective of the FRA disability project is that persons with intellectual disabilities and persons with mental health problems fully enjoy their fundamental rights.

In order to achieve this objective the FRA will:

- ✓ Support the proper implementation of the Convention on the Rights of Persons with Disabilities (CRPD) in the EU,
- ✓ Promote the process of moving from institutional to community care (de-institutionalisation) in the EU Member States,
- ✓ Contribute to raising awareness about the challenges faced by these groups of individuals in their everyday lives.

The project consists of three components:

- ✓ Research activities consist of two parts conducted over the period 2010-2012. The legal research includes a collection of data on anti-discrimination and equality, the protection of specific fundamental rights, involuntary placement and involuntary treatment, and competence, legal capacity and guardianship. Through the social research, primary data is collected regarding the situation on the ground (personal experiences and the views of main actors obtained through in-depth interviews and focus groups). Self-advocates and user-researchers are involved in the project design, implementation and evaluation stages. The thematic focus of the

research is on the right to independent living, legal capacity, the fundamental rights situation in long-term care institutions and access to justice.

- ✓ In terms of networking and stakeholder engagement, the FRA will identify and engage with a wider range of disability stakeholders, with a view to supporting them in the implementation of and raising awareness of the CRPD. As a result of this engagement, networks of actors may arise, bringing together a wide range of stakeholders around key thematic issues within the project. A particular challenge will also be to achieve a vertical link between actors at various levels of governance (European, national and local). The FRA will target research towards the stakeholders' needs to ensure that the findings are useful and relevant to them.
- ✓ Communication with stakeholders of the project will be tailored to the needs of the different groups. Research findings will be presented in a format that is useful to the different target audiences, with accessibility requirements and dissemination strategy at the core of all communication activity. Awareness raising activities will also be undertaken in the context of the project.

Using connection with others to achieve a mutually agreed objective, the stakeholder engagement and communication strategy methodology promotes the participation and ownership of stakeholders in all stages of the project. Partnership with stakeholders and their ownership of the project results ensures relevance, effectiveness and sustainability of the project outcome.

In light of the project objectives, the Stakeholder Engagement, Networking and Communication Strategy (hereafter Strategy) outlines the process of implementation of a combination of anti-discrimination, equal

opportunities and inclusive measures, as enshrined in the CRPD. It analyses who needs to be included in the project and which stakeholders are likely to need to adapt the way they work in light of the CRPD. The document outlines where the FRA wants to be at the end of the process as well as what we are trying achieve. The Strategy also outlines the methodology of stakeholder engagement and stakeholder communication.

#### **COMMENTS ON THE PURPOSE OF THE PROJECT:**

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The stakeholders provided the FRA with the following comments on the draft purpose and objectives of the project.

Since persons with intellectual disabilities and persons with mental health problems were identified as direct beneficiaries of the project, the purpose of the project in the broadest sense should therefore be to improve their lives.

The FRA should involve persons with intellectual disabilities and persons with mental health problems in the project, and also the stakeholders connected to them.

The data collected by the FRA should shed light on the everyday lives of persons with intellectual disabilities and mental health problems with close reference to the CRPD. The social study should also show the gaps between law, policy and practice of human rights enforcement for persons with intellectual disabilities and persons with mental health problems.

It is also crucial that the project is evaluated against its objectives and indicators and that the FRA work on disability develops further and continues after the project is completed.

The project deliverables could be helpful in advocating for the re-organisation of service provision by providing analysis and good practices examples.

The stakeholders would be interested to use the reports resulting from the FRA disability project to support users and survivors of psychiatry and persons with intellectual disabilities and to generate broader moral support for the rights-based approach to disability.

The reports may also be used as a basis for informing decision-makers and helping them to take decisions based on evidence, thereby increasing the effectiveness of their work on disability issues.

## STAKEHOLDERS OF THE PROJECT

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Responding to a questionnaire concerning the project outreach and stakeholders mapping, participants of the initial networking meeting agreed that the FRA disability project needs to reach out to the following stakeholders:

Persons with intellectual disabilities and persons with mental health problems; who are also the primary beneficiaries of the project:

- Persons with intellectual disabilities and persons with mental health problems should be empowered to submit complaints to relevant complain mechanisms, such as Equality bodies and Ombudsmen. They need to shift from passive acceptance to a pro-active claiming of their rights.

Support services, residential/community centres for persons with intellectual disabilities.

- Persons with intellectual disabilities need both information about their fundamental rights , but also hands-on guidance about what these rights mean in practice. Support services should play a 'frontline' role in detecting discriminatory situations and handling complaints.

Complaint mechanisms, such as Equality bodies and Ombudsmen, at national as well as local and regional level:

- These bodies must develop the capacity to provide appropriate support and take on a mediatory role in situations of alleged rights violations.

Professional Bodies and community

facilitators:

- Teachers, carers and social workers, doctors, nurses, psychiatrists, psychologists, hospital administrators, pharmacists, the police, business-persons, religious leaders; these are all vital players in contacting and communicating with persons with intellectual disabilities and persons with mental health problems. They will also be useful in developing and conducting the study and vital in disseminating and implementing results. In general, institutions for persons with disabilities are closed to the public (and human rights organizations), and it can therefore be difficult to gain access to institutions

Teachers:

- Most mental health problems and discriminatory attitudes emerge from childhood (there is clear data on this) and therefore prevention and resilience work with children is vital.

Employers' organisations.

The media.

Legal professionals and courts,

Psychiatric institutions, advocates/associations for those with mental health problems/intellectual disability.

Statutory bodies such as Mental Health Commission/Regulator, NHRIs.

- ☑ Social services (as a part of local authorities).
- ☑ Regional (most institutionalization is built on a regional basis) and local authorities.
- ☑ Lobbyists, NGOs/associations who lobby, professionals/experts, self-advocacy (group or individuals).
- ☑ Scientists focusing on qualitative social research.

- ☑ European Commission

Stakeholders aggregated at local level are important, and were identified as hard to reach. Some respondents felt that the number of stakeholders identified is too high for the FRA to be effective. For example, stakeholders such as employers/employees, teachers/students, health professionals and the staff of institutions could be addressed more effectively by organisations active at the local or national level.

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## CONSULTATION ON THE PROJECT OBJECTIVES

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### **Participants gave advice on the actions that the FRA should take to achieve its objectives**

Respondents pointed out that while it is explained what activities will be undertaken by the FRA during the project, the objectives of the project have not been set out yet. When it comes to objectives, the most obvious, is supporting the implementation of the UN Convention on the Rights of Persons

with Disabilities, within the remits of the FRA's mandate and capacity. Given that the FRA is carrying out a legal study and will have the results of a social study as well, it would be useful to look at which objectives these two activities can best contribute to.

## OBJECTIVE 1: ASSIST THE EU AND EU MS IN IMPLEMENTING THE CRPD IN THE EU

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In a follow up on the initial networking meeting and consultation, two objectives of the project were identified. This section of the report groups suggestions made by stakeholders under the two objectives of the project.

Under the Objective 1 of the project to assist EU and EU Member States in implementing the CRPD, the FRA received the following feedback:

The FRA should encourage the effective application of the CRPD by providing evidence-based advice resulting from both the legal and the social studies. This advice can be presented to the EU Member States, policy makers at national and local level, national and regional parliaments, and specialised agencies.

The FRA should interlink various levels of governance on the implementation of the CRPD. The role of local authorities is essential in implementing equal treatment for persons with disabilities in service provision.

In many Member National Human Rights Institutions (NHRIs) are likely to be appointed part of the national framework under Art. 33 of the Convention, which will be tasked to promote, protect and monitor the implementation of CRPD and will therefore play an important role in the effective application of the Convention.

The FRA should address possible cultural differences between Western and Central and Eastern European countries, where users don't have the same notions of discrimination and exclusion. Those organisations in Central and Eastern Europe

need support and capacity-building to develop a stronger voice. The project should be spread between old and new EU Member States.

The FRA should encourage the reform of outdated guardianship laws, a review of legislation to establish the level of compliance with the CRPD, and should make recommendations where reform is needed, supporting access to justice for persons with disabilities. Respect for rights in the psychiatric ward is essential and processes of compulsory admission and coercive treatment should be scrutinised. Hospital orders deprive psychiatric patients of legal capacity.

To support the move from institutional to community care, from a welfare to a rights-based approach to disability, the use of EU structural funds for building new institutions should be prevented. Instead, individuals should be given the opportunity to lead independent lives. Non-discrimination and equality should be promoted. Exchange on good practice examples in respect of surveillance and prevention of involuntary admittance and coercive measures should take place, by implementing the European

Pact for Mental Health and Well-being.

With regard to the legal capacity of persons with intellectual disabilities and persons with mental health problems, the FRA could contribute to developing specific guidelines for the implementation of relevant articles of the UN Convention on the Rights of Persons with Disabilities. The Agency could establish cooperation on this issue, for example, with the Council of Europe's European Committee on Legal Co-operation (CDCJ) (e.g. its current work on the Draft Recommendation on principles concerning continuing powers

of attorney and advance directives for incapacity).

Developing indicators to illustrate how to follow up the implementation of the rights enshrined in the CRPD at the national level was considered useful by several respondents.

In the immediate period, the Agency should focus its project activities on the substantial Articles of the Convention (Art 12, 24, 27, 32, 33).

## **OBJECTIVE 2: CONTRIBUTE TO RAISING AWARENESS ABOUT CURRENT CHALLENGES IN EVERYDAY LIFE SITUATION & PROVIDE SOLUTIONS**

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Under the Objective 2 of the project, to assist the EU and EU Member States in implementing the CRPD, the FRA received the following feedback.

It is crucial that the FRA raise awareness in the area of disability, in particular among the **legal profession**.

Legal professionals need a greater understanding of the challenges faced by persons with mental health problems to see how legal instruments should fit into the reality of their situations. In particular, lawyers and judges need to increase their knowledge of human rights, their knowledge of the CRPD and be able and willing to implement it. The FRA should raise awareness of the protection of the human rights of persons with intellectual disabilities and persons with mental health problems

provided for in national law and highlight the shortcomings in this area, with a view to preventing human rights abuses (involuntary treatment, lack of information about treatment, sexual abuse, poor health monitoring, torture etc).

Legal professionals should become familiar with the situation of persons with intellectual disabilities and mental health problems when coming into contact with the criminal justice system.

Some respondents pointed out that most cases of mistreatment do not go to trial, but are handled throughout a conciliation

process, often with positive results. Therefore, **Equality Bodies and other ombudsmen** offices play a crucial role at this level. There is a need to promote the presumption that mental capacity is always present unless proved otherwise. Equally important in the awareness-raising context is the need to give the opinion of service-users the same weight as that of experts.

Legal professionals should be empowered to identify forms of discrimination against persons with mental health problems and persons with intellectual disabilities. The FRA should develop awareness-raising and tools/ resources to assist legal professionals in implementing the Convention in their every day professional activities.

There is a need to raise awareness among **healthcare and intellectual disability professionals** about the paradigm shift from the welfare to the rights-based approach to disability as enshrined in the UN CRPD.

The above responses imply raising awareness about the **right to healthcare** of persons with intellectual disabilities (as set out in the CRPD) and about inequalities in access to health care (and what the consequences of these are). It would be useful for the FRA to refer to the draft WHO Europe Declaration on Children and Young Persons with Intellectual Disabilities and their Families, when identifying actions to be taken by healthcare and disability professionals.

The FRA should encourage health care and intellectual disability professionals to give proper, respectful care and treatment in line with the Convention and illustrate on practical examples and a follow up training on how it could be achieved in practice in line of raising awareness of the health care professionals about responsibilities vis-à-vis proactive fundamental rights implementation.

The FRA should also raise awareness about fundamental rights issues among mental health professionals and help them develop guidelines for the respect of human rights of their patients.

Establishment of discussions and partnerships between patients and mental health professionals should be a core objective of the project.

The FRA should raise awareness of relevant medical professionals and pharmaceutical companies, medical agencies etc. about human rights aspects of the issue of over- and under-drugging / access to medication, by providing them with good practise examples.

The need to change the practices of professional groups and attitudes among professionals was considered important. Project deliverables should be used for shifting professional behaviour. Therefore professional bodies must be involved in the networking strategy.

In terms of **employment**, awareness should be raised on the rights of persons with mental health problems and intellectual disability to be heard and respected in working environments and not to be discriminated against in access to employment and internal mobility. Relevant material describing good practices and the rights of persons with disabilities could be disseminated.

As previously mentioned, many mental health problems and discriminatory attitudes emerge from childhood, and therefore it is crucial to raise awareness of the need to combat stigma, discrimination and social exclusion from an early age, using relevant educational material and campaigns targeted at **teachers and students**.

The **media** can act as an important multiplier and influencer of general public opinion. The Agency should foster communication with key journalists very early on in the project, preparing them for the ethos and issues behind any breaking or developing news story. The [Fundamental Rights Platform](#) could aim at increasing the membership of journalist organisations. A link between the FRA and the BBC was proposed. Further mapping of relevant public broadcasters at national level should follow in order to develop a targeted communication strategy of the project.

The Agency should also increase membership of professional bodies (legal and medical) within the Fundamental Rights Platform.

ECHR judgments, such as *Schtukarov v Russia*, *HL v UK*, *Storck v Germany*, *Glor v Switzerland* should be highlighted with a view

to raising awareness of them among legal professionals. Article 12 of the International Covenant on Economic, Social and Cultural Rights and General Comment 14 on national health strategies, disaggregated data requirements, non-discrimination on disability ground, would be useful to guide the FRA's analysis.

Last but not least, the project should multiply its activities in all of the EU countries at the same time. The results of the project should be picked up by the media and broadcasted to the population at large. Networking and contacts with others working with these questions are always important. Associations of persons with intellectual disabilities could disseminate the results of the project actively to assist them in campaigning and lobbying activities. Future networking and communication work could a toolkit for multipliers and training courses.

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## OTHER COMMENTS

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The respondents identified some thematic areas that the Agency could follow. In general, the respondents felt that the Agency should expand its work into other areas of disability.

- In the context of migration and asylum, research on the situation of persons suffering from posttraumatic stress disorder (PTSD) would be a valuable inclusion to the project.
- Access to culture and sports for persons with disabilities was identified as worthwhile of further research.
- The issue of accessibility, and more generally an application of Universal Design principles in all the FRA work ensuring access to information in alternative formats ("Easy-to-Read") for persons with intellectual impairments, was

considered a possible follow up on the project in the coming years.<sup>1</sup>

- The right to education, legal capacity and conflicts with other equality grounds such as religion could be explored, as well as non-discrimination and promoting equality for persons with mental health problems and persons with intellectual disabilities.
- [Multiple discrimination and multiple disadvantage](#) – specific issues relating to persons with mental health problems and persons with intellectual disabilities who are members of vulnerable ethnic, religious or socio-economic groups and who experience aggravated forms of discrimination was identified as a possible future focus.
- Suicide-prevention of persons with mental health problems and persons with intellectual disabilities would be another important area of research to cover.
- The FRA should also look at the implementation of the Committee for the Prevention of Torture (CPT) standards, particularly in institutions and standards/conditions/methods of treatment.
- It was suggested that mental health should be mainstreamed in health care, with closer collaboration between primary care and specialised mental health care actors, for example by creating of mental health units in primary healthcare centres as an integral part of primary health care.

<sup>1</sup> See Recommendation CM/Rec(2009)8 on achieving full participation through Universal Design See Recommendation CM/Rec(2009)8: <https://wcd.coe.int/ViewDoc.jsp?id=1526681&Site=CM&BackColorInternet=C3C3C3&BackColorIntranet=EDB021&BackColorLogged=F5D383> , and accompanying report: “Achieving full participation through Universal Design” (2009), ISBN 978-92-871-6474-2: [http://book.coe.int/EN/ficheouvrage.php?PAGEID=36&lang=EN&produit\\_aliasid=2410](http://book.coe.int/EN/ficheouvrage.php?PAGEID=36&lang=EN&produit_aliasid=2410)

In addition, the focus should be on the overall access of persons with intellectual disabilities and persons with mental health problems to health care. Particularly in relation to persons with intellectual disabilities, there is a growing body of evidence about discrimination in access to health services, which often results in premature death.

- It will be more effective if the FRA gives professional organisations the necessary tools to work with all the relevant stakeholders in their community/country, rather than trying to do all the work by itself.
- The geographical focus of the project should be balanced and include Western, Central and Eastern (CEE) and Southern EU countries. In many countries, institutionalisation is still the prevalent model of care. One respondent cited an example of France, where in 2008, President Sarkozy announced the opening of 50,000 more places in institutions for persons with disabilities. It is therefore important that the FRA’s strategy is directed both at Western European and CEE countries.
- There was a wide agreement that the deliverables should be available in English, French, and German and in languages of the Central Eastern Europe Member States (CZ, SK, HU, PL, RO, BG). There was also a relatively broad consensus that the executive summary of the final report/conclusions of the study must be available in all EU languages. The materials should also be available in easy read format. Certain project deliverables, such as training manuals, handbooks and info sheets should be available in the languages of the study’s focus with brief information on the deliverables in remaining EU languages.

- It was suggested that the FRA should collect examples of collaboration models across various level of governance and promote models, which contribute best to the improvement of implementation of the CRPD. Particularly in relation to Article

33 (implementation and monitoring), the FRA could provide an overview of independent mechanisms and focal points, detailing how they contribute to implementation of the CRPD.

Stakeholders provided examples of processes and structures, which could be used by the Agency to reach out to relevant stakeholders.

**SWEDEN:** In terms of structured approach to reaching stakeholders, the Swedish example of engaging with variety of stakeholders provides a useful guidance on how to reach to relevant stakeholders in other countries:

- ✓ **Ministry of Health and Social Affairs**
- ✓ NSPH (National Association for Mental Health)
- ✓ FUB (The Swedish National Association for persons with Intellectual disability)
- ✓ HSO (The Swedish Disability Federation)
- ✓ **SKL (Swedish Association of Local and regional Authorities)**
- ✓ The National Board of Health and Welfare
- ✓ Swedish Agency for Government Employment
- ✓ The Swedish National Agency for Education
- ✓ FHI Swedish National Institute of Public Health
- ✓ Network Anti discrimination offices

**BELGIUM:** Some Equality bodies already have a model of cooperation with disability organisations, trade unions and local authorities in place. For example, the Belgian Centre for Equal Opportunities and Opposition to Racism (CEOOR) has established collaboration agreements with the main Belgian organisations that help and represent persons with intellectual disabilities and their families, and with actors in the mental health sector. Collaborations involve the exchange of expertise and information, and the development of training programs with professionals and families and disabled persons. The organisations play a front-line role in detecting discriminatory situations. In the employment sector, the CEOOR has also developed collaboration agreements with three Belgian trades unions. The legal services departments of the Trade Unions handle cases of discrimination in the workplace. However, respondents suggested that anti-discrimination legislation, especially the concept of reasonable accommodation, is insufficiently used in union interventions in the workplace, and in defending their members.

In a federal state such as Belgium, local authorities are important stakeholders with regard to the implementation of regional anti-discrimination legislation. Finally, with regard to disability issues, the CEOOR collaborates with the Belgian Disability Forum and the National High Council of Disabled Persons (advice and recommendation commission on disability federal matters), with whom the FRA has recently signed a convention of collaboration.

**United Kingdom:** In the UK the 'Care Services Commission' has a statutory duty to audit the quality of care provided by all organisations (businesses, hospitals etc) offering care and treatment (defined in a very broad way). In the UK, the Care Quality Commission is actively discussing the audit of fundamental rights protection in this context. There are also several Statutory Regulatory bodies - in the UK the General Medical Council (regulating doctors, including psychiatrists - this is different to the Royal College of Psychiatrists, which is the professional body, advocating FOR psychiatrists, the GMC independently regulates their practice) the Nursing and Midwifery Council (nurses), the Health Professions Council (for various professions, including psychologists) and the General Social Care Council (for social workers). These bodies are absolutely vital as they set rules for the medical professionals in their respective field of specialty. Professional groups tend to instantly comply, otherwise they would not be allowed to practice their profession. Related professional bodies include the Royal College of Psychiatrists, the Royal College of Nursing, the British Psychological Society (in the UK).

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## IDEAS FOR A JOINT COOPERATION

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The respondents identified possible joint activities:

- NHRIs/ Equality Bodies proposed a joint project on improving the implementation of the Convention on the Rights of Persons with Disabilities.
- DG SANCO would be interested in including the FRA in the conference on stigma and social exclusion, which is to be held at the end of 2010.
- DG SANCO would appreciate future exchange of knowledge and good practice on preventing stigmatisation and social exclusion; this was identified as an important element of a follow up.
- The Council of Europe proposed that the FRA could organise a conference devoted specifically to networking and co-ordination. This could facilitate the creation of links between governments, NGOs, public and private service providers so that the roles and responsibilities of the respective actors can be discussed and co-ordination improved for the benefit of persons with intellectual disabilities and persons with mental health problems.
- The Equal Rights Trust suggested organising a joint Roundtable on the issue of discrimination and legal protection against discrimination for persons with intellectual disabilities and persons with mental health problems.
- The European Commission / Belgian Presidency will hold conference on disability and the CRPD on 18-19 November 2010.
- The Belgian Equality body will organise both a workshop and a conference on reasonable accommodation, with all actors concerned. **The FRA could provide input from its legal study findings, emerging from the disability project.**

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## FOLLOW-UP AND SUGGESTIONS FOR ACTION

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Respondents identified the close collaboration between international organisations (Office of the High Commissioner for Human Rights and the Council of Europe, for example) as beneficial for advancing disability rights agenda.

The data collected by the FRA in the legal and social parts of the project could be used as evidence for European Network of Users and Survivors in Psychiatry members at national level in order to work more specifically on human rights issues linked to the mental health area.

It would be useful to support our efforts to promote the right to live in the community and facilitate the implementation of Art.19 of

the CRPD.

In the context of networking it would be useful to develop work on common themes with the NHRIs – e.g. the ratification/ implementation of CPRD standards in compliance with the European Convention for Human Rights/ European Charter of Fundamental Rights.

Stakeholders would be very interested in the development of indicators on the social exclusion of persons with intellectual disabilities and mental health problems. Exchange of good practice on anti-stigma activities was also suggested.

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## ANNEX: LIST OF PARTICIPANTS

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### Initial Networking Meeting on the Project on Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems

Vienna, FRA premises 25 November 2009

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