For the attention of:

Mr Craig Mokhiber

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cc: Mr Facundo Chávez Penillas and Ms Krista Orama (disability@ohchr.org); Mr Jan Jarab, Regional Representative, OHCHR Regional Office for Europe

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**Subject: Contribution to the study on the right to live independently and to be included in the community**

Dear Mr Mokhiber,

I am delighted to provide you with the EU Agency for Fundamental Rights’ (FRA) contribution to the above-mentioned study.

FRA’s work on the rights of persons with disabilities has focused intensively on the right to independent living. In 2012, the FRA published the report ‘[Choice and control: the right to independent living](http://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living)’, which provides extensive evidence of some of the obstacles to independent living encountered by persons with disabilities. FRA has also published in depth reports bringing together legal analysis and evidence of the lived experience of persons with disabilities with regard to [involuntary placement and involuntary treatment](http://fra.europa.eu/en/publication/2012/involuntary-placement-and-involuntary-treatment-persons-mental-health-problems), and [legal capacity](http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems).

Based on the data collected for these and other reports, FRA identifies the following as particularly relevant to the study.

## Reviews of legislation:

## Denying or restricting the exercise of legal capacity

Several EU Member States have acknowledged that they need to harmonise their legislation with current international and European standards and some have recently reviewed their national legislative framework on legal capacity, such as England and Wales (2005), France (2007) and Germany (2009). Sweden abolished total guardianship in 1989. The Czech Republic reformed its legislation and a new Civil Code entered into force on 1 January 2014. Likewise, the Hungarian parliament amended legal capacity provisions dating back to 1959 with a new Civil Code. In Malta, the Civil Code was amended in December 2012 to introduce a system of guardianship providing that “a major who has a mental disorder or other condition which renders him incapa­ble of taking care of his own affairs may be subject to guardianship”. ([Legal capacity of persons with intellectual disabilities and persons with mental health problems](http://fra.europa.eu/en/publication/2013/legal-capacity-persons-intellectual-disabilities-and-persons-mental-health-problems), p. 28)

On 15 July 2013, the Irish government published the Assisted Decision‑Making (Capacity) Bill, which aims to provide a statutory framework that maximises individual autonomy. The bill also pro­vides for the establishment of a new statutory office, the Office of the Public Guardian, which will supervise those who provide support for decision making. The bill is expected to be passed in 2014, paving the way for ratification of the CRPD. In Finland, the working group set up to prepare for the convention’s ratification was, at the end of 2013, preparing a report outlining the revisions needed to bring existing legislation into line with the CRPD. The report, currently out for consulta­tion, will incorporate the consultation’s comments into the legislative proposal for ratification, to be presented to parliament during 2014. ([FRA Annual Report 2013](http://fra.europa.eu/en/publication/2014/fundamental-rights-challenges-and-achievements-2013), p. 242)

In Croatia, legal reform in December 2012 abolished the exclusion of persons without legal capacity from the right to vote. Similarly, amendments to the Latvian Civil Code, which came into force in 2013, end the denial of the right to vote for those deprived of legal capacity, although relevant electoral legislation has not yet been amended. ([The right to political participation for persons with disabilities: human rights indicators](http://fra.europa.eu/en/publication/2014/indicators-political-participation-persons-disabilities), p. 38)

## Allowing for forced institutionalisation

Many EU Member States have recently amended legislation in the area of involuntary placement and involuntary treatment of persons with mental health problems, triggered in particular by the entry into force of the CRPD. See Annex 1 for further details of the most recent legal reforms in this area. ([Involuntary placement and involuntary treatment of persons with mental health problems](http://fra.europa.eu/en/publication/2012/involuntary-placement-and-involuntary-treatment-persons-mental-health-problems), section 2.1.)

## Establishing a presumption of danger to self or others on the basis of disability

In 12 EU Member States, the existence of a significant risk of serious harm to oneself or others and a confirmed mental health problem are the two main conditions justifying involuntary placement. The need for a therapeutic purpose is not explicitly stipulated. See Annex 2 for further information regarding the existence of a significant risk of serious harm to oneself or others. ([Involuntary placement and involuntary treatment of persons with mental health problems](http://fra.europa.eu/en/publication/2012/involuntary-placement-and-involuntary-treatment-persons-mental-health-problems), section 2.2.1.)

## Programmes or plans to promote the implementation of services enabling independent living such as: personal assistants, home assistants or other community-based services regardless of the kind of impairment?

Sweden is the only country of the nine covered in the research that has developed legal provisions on the right to living arrangements and support (Law on Special Sup­port and Services for Persons with Disabilities, LSS). In Latvia, the Disability Law promotes community living and includes a right to a personal assistant. Bulgaria has also introduced legislation on personal assistance in the form of the Social Assistance Act. The Regulations for the Implementation of the Social Assistance Act, adopted in June 2010, entitle persons with mental health problems or intellectual disabilities (assessed with at least 71 % reduced labour capacity) to an assistant. Such assistance is limited to 10 hours per year. In Romania, under Law 448/2006 people with severe disabilities, as assessed through social and psycho‑medical evaluation, have the right to a personal assistant. An amendment to this law in 2010 stipulated that people with a severe degree of disability will no longer be entitled to a ‘meas­ure of special protection’, in other words a personal assistant.68 Instead, they receive a monthly allowance from the city council.

In Greece, municipalities offer a social welfare programme named ‘Help at Home’ designed specifically to help the elderly and people with disabilities living alone. In France, support for meaningful community par­ticipation is provided by the Support Services for Social Life (*Services d’accompagnement à la vie sociale,* SAVS) and the Medical‑social Support Services for Disabled Adults (*Services d’accompagnement médico‑social pour adultes handicapés,* SAMSAH).

In Germany, personal budgets have been legally possible since 2001 and a legal right since 2008. Under this system, benefits are paid as sums of money or vouchers, which can be used by the claimant as they see fit. By 2009 around 10,000 recipients had used this form of benefit, according to official data.70 An evaluation conducted as part of the federal Multi‑provider Personal Budget Pilot Project (*Modellprojekte ‘Trägerübergreifendes Persönliches Budget’* (2004–2007)) found that 31 % of budget recipients within the project (from a sample of 845 respondents) were people with intel­lectual disabilities (the percentage of people with men­tal health problems was 41%). In the United Kingdom, direct payments became legal with the passing of the NHS and Community Care (Direct Payments) Act in 1996. ([Choice and control: the right to independent living](http://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living), sections 1.3. and 2.3.)

In July 2012, the United Kingdomgovernment published a draft Care and Support Bill117 designed to implement reforms outlined in the policy paper *Caring for our future: reforming care and support* in England*.* The draft bill would oblige local authorities to ensure that a person receiving care and support can move to another local authority without interruption to the support they receive. The Finnish government has continued to implement pro­grammes to provide individual housing and community services for persons with intellectual disabilities and has set a deadline of 2020 for the full deinstitutionalisation of persons with disabilities. ([FRA Annual Report 2012](http://fra.europa.eu/en/publication/2013/fundamental-rights-challenges-and-achievements-2012), p. 152)

## Effective mechanisms that persons with disabilities could successfully employ in case of denial of access to services enabling independent living and inclusion in the community including access to facilities for the general population on an equal basis with others? If so, do those mechanisms guarantee reasonable accommodation when necessary services or support are not in place?

There are a variety of measures in place across the EU to enhance the opportunity for persons with men­tal health problems to access justice. In Germany, for instance, the Federal Network of Independent Offices for Complaints on Psychiatric Services (*Bundesnetzwerk unabhängiger Beschwerdestellen Psychiatrie*) estab­lished in 2010 operates in nearly 50 regions. These offices investigate grievances and complaints regarding psychiatric services, provide assistance and mediation services and try to find remedies.

Overall, the number of respondents who had formally complained against unfair treatment was in general low among those with intellectual disabilities. In the United Kingdom, though, most of the respondents had made official complaints about their treatment in a wide range of situations. An important barrier to obtaining redress was lack of awareness about complaints procedures combined with lack of formal support. ([Choice and control: the right to independent living](http://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living), sections 1.5. and 2.3.)

In Germany, the Federal Anti‑Discrimination Agency (*Anti‑Diskriminierungsstelle des Bundes*) developed a ‘Signing Question and Answer Tool’ allowing persons with hearing impairments to communicate with the agency in sign language using a webcam. ([FRA Annual Report 2012](http://fra.europa.eu/en/publication/2013/fundamental-rights-challenges-and-achievements-2012), p. 153)

For information on the availability of complaint mechanisms concerning access to healthcare, see chapter 5 of the report ‘[Inequalities and multiple discrimination in access to and quality of healthcare](http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare)’.

## International cooperation programmes related to ensuring the right to live independently and to be included in the community?

The [European Disability Strategy 2010-2020](http://eur-lex.europa.eu/legal-content/en/ALL/;ELX_SESSIONID=yzJhTP5ftX8XLkkMXBcnQQNLJN12p12WMHm4wK6T642xcpr0fK1K!1449012933?uri=CELEX:52010DC0636) covers issues of independent living and deinstitutionalisation extensively: Area 2 on participation notes that “There are still many obstacles preventing people with disabilities from fully exercising their fundamental rights […] and limiting their participation in society on an equal basis with others. Those rights include the right […] to choose where and how to live, and to have full access to cultural, recreational, and sports activities.” As such, the Commission commits to work to: “promote the transition from institutional to community-based care by: using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people”. Moreover, EU action in this area will support national activities to: “achieve the transition from institutional to community-based care, including use of Structural Funds and the Rural Development Fund for training human resources and adapting social infrastructure, developing personal assistance funding schemes, promoting sound working conditions for professional care workers and support for families and informal carers”.

Following the adoption of the structural funds regulation for the period 2014-2020, deinstitutionalisation is closely linked to the distribution of EU funds, particularly the European Social Fund and the European Regional Development Fund. The new regulation requires that a number of ‘ex ante conditionalities’, related to legal and policy instruments and measures, be met before EU Member States can apply for funding. Prior to allocating funds, the European Commission must assess that a number of criteria attached to each conditionality have been fulfilled. One of the criteria under the objective of promoting social inclusion, combating poverty and any discrimination, is that proposals include “measures for the shift from institutional to community based care”. Linked to this requirement, many of the partnership and cooperation agreements governing spending of the structural funds which are currently being drawn up between the Commission and Member States specifically include the issue of deinstitutionalisation. ([FRA Annual Report 2013](http://fra.europa.eu/en/publication/2014/fundamental-rights-challenges-and-achievements-2013), section 5.5.)

## Collect statistics and disaggregated data on services provided to ensure independent living and inclusion in the community?

FRA is now implementing a multiannual project focusing on the transition from institutional to community-based care. The project will be divided into three stages, each providing focused legal and policy analysis on the situation with regard to this transition across the EU:

* Developing a typology of institutions in the EU and developing indicators on the right to independent living (Article 19 of the CRPD)
* Research on legal and policy measures at the EU and national levels to promote independent living
* Fieldwork research/case studies in a small number of localities to understand the drivers of and barriers to deinstitutionalisation at the local level.

We would very much welcome the input and expertise of the OHCHR in the implementation of this project, and will share interim findings in 2014 and 2015. I attach a short handout on the project for your information.

Should you need any further information, please consult the [thematic page on our website](http://fra.europa.eu/en/theme/people-disabilities) and do not hesitate to contact me.

Yours sincerely,

Martha Stickings

Equality & Citizens’ Rights Department

European Union Agency for Fundamental Rights (FRA)

Annex 1: Legislation on involuntary placement and involuntary treatment (civil law)

Figure 1: Date of EU27 adoption of legal framework on involuntary placement and involuntary treatment, including latest significant reforms

Source: FRA, February 2012

| **EUMS** | **LEGISLATION** | **LAST SIGNIFICANT AMENDMENT** |
| --- | --- | --- |
| **AT** | Compulsory Admission Act (CAA) ([*Unterbringungsgesetz*](http://www.ris.bka.gv.at/Dokumente/BgblPdf/1990_157_0/1990_157_0.pdf), UbG), BGBl 155/1990  | BGBl I 18/2010 (17 March 2010) |
| **BE** | Act concerning the protection of the person of the mentally ill (26 June 1990) ([*Loi relative à la protection de la personne des malades mentaux*](http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&cn=1990062632&table_name=loi))Patient’s rights Act (22 August 2002)([*Loi relative aux droits des patients*](http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=fr&la=F&table_name=loi&cn=2002082245)*)* | No significant amendments affecting the civil commitment, while the criminal commitment was amended in 2007 (the reform entered into force in 2012) |
| **BG** | Chapter II [Health Act](http://www.mh.government.bg/Articles.aspx?lang=bg-BG&pageid=380&currentPage=3&categoryid=1058) (*Закон за здравето*) (1 January 2005) | Although it has been amended several times, the provisions in Chapter II concerning involuntary placement and treatment have not changed |
| **CY** | Law No. 77(1) of 1997 Providing for the Establishment and Operation of Psychiatric Centres for the Care of Mentally-Ill Persons, the Safeguarding of such Persons’ Rights and the Determination of Duties and Responsibilities of Relatives | [Amended between 2003-2007](http://mentalhealthcommission.org.cy/en/law/) |
| [A Law providing for the safeguarding and protection of the patients’ rights and for related matters N° 1(I)/2005](http://www.bioethics.gov.cy/Law/cnbc/cnbc.nsf/All/6960B7A5AA76C4A3C22571C9002B99F0/%24file/Patients%20Rights%20Law-English%20translation.pdf) (7 April 2005) | No amendments |
| **CZ** | Healthcare Act([*Zákon č. 20/1966 Sb., o péči o zdraví lidu*](http://www.helcom.cz/download/integrace/099pece.pdf))(1 July 1966) | 2004 |
| Civil Procedure Code ([*Zákon č. 99/1963 Sb., občanský soudní řád*](http://www.podnikatel.cz/zakony/zakon-c-99-1963-sb-obcansky-soudni-rad/)), Act No. 99/1963 Coll. | 2011 |
| **DE** | § 1906 Civil Code (BGB) introduced by the *Betreuungsgesetz* (BtG) (Custodianship Act) of 12 September 1990, (enforced 1 January 1992) | Amended in 2009 |
| Placement under public law governed by states (*Länder*) laws |  |
| **DK** | Act No. 331, 24 May 1989 on deprivation of liberty and other coercion in psychiatry | Consolidated act on the coercion in psychiatry (*om anvendelse af tvang i psykiatrien*)*,* No. 1111 of 1 November 2006 |
| **EE** | §§ 19-20 [Social Welfare Act](http://www.legaltext.ee/et/andmebaas/tekst.asp?loc=text&dok=X1043K9&keel=en&pg=1&ptyyp=RT&tyyp=X&query=sotsiaalhoolekande+seadus) (SWA) (*Riigikantselei* (6 March 1995) *Riigi Teataja I*), 21, 323, (8 February 1995) | 15 June 2005 |
| §§ 533-543 [Code of Civil Procedure](http://www.legaltext.ee/indexen.htm) (CCP) (*Tsiviilkohtumenetluse seadustik*),20 April 2005 |  |
| §§ 10-14 [Mental Health Act](http://www.legaltext.ee/text/en/X1050K3.htm) (MHA) (12 February1997) | 19 June 2002 |
| **EL** | Article 1687 Civil Code |  |
| Law 2071/1992 (*regulates involuntary treatment by mental health services*) |  |
| **ES** | Article 763 [Civil Procedure Act](http://noticias.juridicas.com/base_datos/Privado/l1-2000.html) (*Ley 1/2000, de 7 de enero, de Enjuiciamiento Civil)*, State Official Journal No. 7 of 8 January 2000 | Following the decision of the Constitutional Tribunal of 2 December 2010, Dec. 132/2010 |
| Act of the Autonomy of the Patient Law 41/2002 (14 November 2002) | Under Law 2/2010 of 3 March 2010 and Law 26/2011Normative Adaptation to the United Nation Convention on the Rights of Persons with Disabilities, 11 August 2011 |
| **FI** | Section 8 – 20 [Mental Health Act](http://www.finlex.fi/en/laki/kaannokset/1990/en19901116.pdf), No. 1116/1990 | Law 1066/2009 of 11 December 2009  |
| **FR** | [Public Health Code](http://www.legifrance.gouv.fr/affichCode.do?cidTexte=LEGITEXT000006072665), Articles L.3212-1 to L.3213-11 | Law No 2011-803 of 5 July 2011 on the rights and protection of persons under psychiatric care and arrangements for their care ([*Loi n° 2011-803*](http://www.legifrance.gouv.fr/affichTexte.do;jsessionid=AB682AF632F51C7BE51FD4666504F92B.tpdjo07v_1?cidTexte=JORFTEXT000024312722&dateTexte=20110707) *du 5 juillet 2011 relative aux droits et à la protection des personnes faisant l'objet de soins psychiatriques et aux modalités de leur prise en charge*) |
| **HU** | Healthcare Act *(*[*1997. évi CLIV. törvény az egészségügyrõl*](http://net.jogtar.hu/jr/gen/hjegy_doc.cgi?docid=99700154.TV)*)* (15 December 1997)  | Although it has been amended several times, the provisions concerning involuntary placement and treatment have not changed  |
| **IE** | [Mental Health Act](http://www.irishstatutebook.ie/2001/en/act/pub/0025/index.html) 2001 (1 November 2006) |  |
| **IT** | Article 33-35 [Law](http://www.handylex.org/stato/l231278.shtml) n. 833/1978 (23 December 1978) |  |
| **LT** | [Law on Mental Health Care](http://www3.lrs.lt/pls/inter2/dokpaieska.showdoc_l?p_id=259559&p_query=&p_tr2=)/1995, Nr. I-924, (*Psichikos sveikatos priežiūros įstatymas, Žin., 1995, Nr. 53-1290*). Available in EN (without amendments: [www3.lrs.lt/pls/inter2/dokpaieska.showdoc\_e?p\_id=39589](http://www3.lrs.lt/pls/inter2/dokpaieska.showdoc_e?p_id=39589)) | Law of 5 July 2005 |
| **LU** | [Luxembourg law on hospitalisation without their consent of persons with mental disorders](http://www.legilux.public.lu/leg/a/archives/2009/0263/a263.pdf) (*relative à l’hospitalisation sans leur consentement de personnes atteintes de troubles mentaux)* (10 December 2009) |  |
| **LV** | Article 68 Medical Treatment Law *(*[*Ārstniecības likums*](http://www.likumi.lv/doc.php?id=44108)*)* (26 February 1998) | 2008 |
| **MT** | [Mental Health Act](http://justiceservices.gov.mt/LOM.aspx?pageid=27&mode=chrono&p=8) Chapter 262 of the Laws of Malta (adopted in 1976) |  |
| **NL** | [The 1992 Psychiatric Hospitals (Compulsory Admissions) Act](http://english.minvws.nl/en/artikelen/gvm/the_psychiatric_hospitals_compulsory_admissions_act.asp) (enforced January 1994) | 2008 |
| **PL** | Law on Protection of Mental Health, (*Ustawa o wychowaniu w trzeźwości i przeciwdziałaniu alkoholizmowi*) Dz. U. 1994 No 111 Item 53519 (19 August 1994)  |  |
| **PT** | Article 12 [Law on mental health 36/98](http://www.gddc.pt/legislacao-lingua-estrangeira/english/lei-da-saude-mental.html) (24 July 1998) |  |
| **RO** | [Mental Health Law](http://vechi.ms.ro/fisiere/pagini_virtuale/114_163_Law_on_Mental_Health.pdf) (Law 487/2002) (11 July 2002) |  |
| Law on Patient’s Rights No. 46/2002 (*Legea drepturilor pacientului Nr. 46/2002*) |  |
| **SE** | [Compulsory Psychiatric Care Act](http://www.notisum.se/rnp/sls/lag/19911128.htm) (SFS: 1991:1128) | 2009 (SFS: 2009:809) |
| **SI** | Mental Health Act 77/08 (28 July 2008) |  |
| **SK** | Article 191a-191g Civil Procedure Code ([*Zákon 99/1963*](http://www.vyvlastnenie.sk/predpisy/obciansky-sudny-poriadok/)) (4 December 1963) |  1994 by Act No. 46/1994 Coll |
| 11 6 and 8 Health Care Act ([*Zákon 576/2004*](http://www.zdravie.sk/sz/content/464-20817/zakon-5762004-zz-o-zdravotnej-starostlivosti-sluzbach-suvisiacich-s-poskytovanim-zdravotnej-starostl.html))(21 October 2004) | Article 6 was amended in 2009; Article 8 was amended in 2011 |
| **UK** | [Mental Health Act 1983](http://www.legislation.gov.uk/ukpga/1983/20/contents) c. 20 | [Mental Health Act 2007 c. 12](http://www.legislation.gov.uk/ukpga/2007/12/contents) |
| [Mental Health (Care and Treatment)](http://www.legislation.gov.uk/asp/2003/13/contents) (Scotland) Act 2003 asp. 13 | 2008 |
| [Mental Health (Northern Ireland) Order 1986](http://www.legislation.gov.uk/nisi/1986/595) No. 595 (N.I. 4) |  |

Source: FRA (2012), Involuntary placement and involuntary treatment of persons with mental health problems. Correct as of February 2012.

Annex 2: Criteria for involuntary placement and involuntary treatment, by EU Member State

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| EU MS | **Mental health problem** | **Significant risk to oneself or others** | **Therapeutic purpose** | **Priority of less restrictive alternative included in the law** |
| AT | **✓** | **✓** |  | **✓** |
| BE | **✓** | **✓** |  | **✓** |
| BG | **✓** | **✓** |  |  |
| CY | **✓** | **✓** |  |  |
| CZ | **✓** | **✓** |  |  |
| DE | **✓** | **✓** |  | **✓** |
| DK | **✓** | **✓** | **✓** | **✓** |
| EE | **✓** | **✓** |  | **✓** |
| EL | **✓** | **✓** | **✓** |  |
| ES | **✓** |  | **✓** |  |
| FI | **✓** | **✓** | **✓** | **✓** |
| FR | **✓** | **✓** | **✓** | **✓** |
| HU | **✓** | **✓** |  | **✓** |
| IE | **✓** | **✓** | **✓** |  |
| IT | **✓** |  | **✓** | **✓** |
| LT | **✓** | **✓** |  |  |
| LU | **✓** | **✓** |  | **✓** |
| LV | **✓** | **✓** | **✓** |  |
| MT | **✓** | **✓** |  | **✓** |
| NL | **✓** | **✓** |  | **✓** |
| PO | **✓** | **✓** | **✓** | **✓** |
| PT | **✓** | **✓** | **✓** | **✓** |
| RO | **✓** | **✓** | **✓** | **✓** |
| SE | **✓** | **✓** | **✓** | **✓** |
| SI | **✓** | **✓** | **✓** | **✓** |
| SK | **✓** | **✓** | **✓** |  |
| UK | **✓** | **✓** | **✓** | **✓** |

Source: FRA (2012), Involuntary placement and involuntary treatment of persons with mental health problems. Correct as of February 2012.