



WRITTEN COMMENTS

submitted by

MENTAL DISABILITY ADVOCACY CENTER

European Court of Human Rights
Application no. 47848/08

Centre for Legal Resources on behalf of Valentin Câmpeanu against Romania

30 September 2011

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INTRODUCTION

These written comments are submitted by the Mental Disability Advocacy Center (MDAC) pursuant to leave granted by the President of the Third Section under Rule 44(3) of the Rules of Court. MDAC is an international human rights organisation which advances the rights of children and adults with intellectual disabilities and psycho-social disabilities. MDAC uses law to promote equality and social inclusion through strategic litigation, advocacy, research and monitoring and capacity-building. It operates at the global level as well as regional and domestic levels in Europe and Africa. It is headquartered in Budapest, Hungary and was founded in 2002. MDAC has participatory status with the Council of Europe and a special consultative status with the United Nations Economic and Social Council. MDAC has previously served as a third party intervener in the cases of *Kędzior v. Poland* (no. 45026/07) and *Gauer and Others v. France* (no. 61521/08).

I. BACKGROUND INFORMATION ON PERSONS WITH DISABILITIES AND INSTITUTIONALISATION

The 2011 World Report on Disability, produced jointly by the World Health Organization (WHO) and the World Bank, estimates that one billion people worldwide have some form of disability.¹ Among the key findings of the report are that people with disabilities are more than twice as likely to find healthcare provider skills inadequate to meet their needs, and nearly three times more likely to report being denied needed health care.²

The Court has recognised that people with disabilities, including mental disabilities, and people with HIV are vulnerable groups with a history of prejudice and stigma with lasting consequences, resulting in their social exclusion.³ The Office of the United Nations High Commissioner for Human Rights (OHCHR), WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) in their joint brief⁴ emphasised a clear link between HIV and disability, observing that people with disabilities are among all key populations at higher risk of exposure to HIV and people living with HIV may develop impairments as the disease progresses.

Stigma against persons with disabilities has resulted in their social exclusion worldwide, but has taken the form of institutionalisation on a large scale in many parts of Eastern and Central Europe. According to a 2010 UNICEF report, the number of children in residential care in Eastern Europe and Central Asia was the highest in the world.⁵ The countries in the region have traditionally relied on placing into institutions children who are abused and neglected, and those with disabilities. In 2007, more than 626,000 children lived in institutions in 22 countries of the region. More than one third of those children were children with disabilities. In many countries, children with disabilities represented as many as 60% of all children in institutions. This, according to UNICEF, was an indication of the failure of the systems to provide tailored responses to children with disabilities and their families.⁶ UNICEF identified a heavy reliance on institutions to care for children with disabilities and noted that many people were still under the misapprehension that an institution was the best place for a child with disability.⁷ Families hand over their children with disabilities to institutions due to, *inter alia*, the lack of economic support, including care and tailored services to support families to look after such

¹ World Health Organization and World Bank, *World Report on Disability*, June 2011, p. xi, http://www.who.int/disabilities/world_report/2011/en/index.html

² WHO news release, *New world report shows more than 1 billion people with disabilities face substantial barriers in their daily lives*, 9 June 2011, http://www.who.int/mediacentre/news/releases/2011/disabilities_20110609/en/index.html

³ *Kiss v. Hungary*, no. 38832/06, § 44, 20 May 2010; *Kiyutin v. Russia*, 2700/10, §§ 63-64, 10 March 2011

⁴ UNAIDS, WHO and OHCHR, *Disability and HIV Policy Brief*, p. 1, www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf

⁵ UNICEF, *At home or in a home?*, September 2010, at 8, http://www.unicef.org/ceecis/At_home_or_in_a_home_report.pdf

⁶ *Id.*, at 4 and 6

⁷ *Id.*, at 2

children at home. They might even be actively encouraged by the medical personnel or authorities to give up their children.⁸

Research has shown that residential care, as such, can be damaging to children's development. Adverse physical effects include poor health, physical underdevelopments, hearing and vision problems, and delay in the development of motor, speech and cognitive skills. In addition, children living in institutions often suffer psychologically and emotionally and they may develop further disabilities.⁹ Moreover, they are being commonly transferred from one institution to another. These moves contribute to their further seclusion because the children are prevented from developing closer ties and relationships. It is not unusual that young people, especially those with disabilities, remain in institutions even after their eighteenth birthday.¹⁰ UNICEF concluded that support and assistance to families caring for children with disabilities should be a top priority area in the ongoing reforms.¹¹ Despite reforms of the child care systems and a decrease in the overall number of institutionalised children, the total number of children with disabilities in institutions has been stable for the last 15 years (in view of the fact that the birth rate in the region has dropped dramatically, the numbers can even be higher).¹² This figure suggests that children with disabilities are largely ignored in the ongoing reforms.¹³ In Romania, the number of children with disabilities in institutions rose from 5,909 in 2004 to 10,108 in 2007.¹⁴

Lack of planning for children in institutions reaching the age of majority has resulted in large numbers of persons coming out of children's institutions becoming homeless or being placed in psychiatric institutions for want of any alternative. According to a 2005 Council of Europe Parliamentary Assembly report, "[o]ne crucial problem mentioned in the rapporteur's previous report and by all the NGOs concerned has to do with what happens to children in institutions after the age of 18. Forced to leave the institutions for minors where many of them have spent their entire lives, they usually end up on the street or in psychiatric hospitals."¹⁵

The high rate of HIV/AIDS among children, particular to Romania, has been directly tied to the high rates of institutionalisation of children.¹⁶ The failure to use adequate infection control, the practice of giving blood transfusions to malnourished children, and the frequent injection of medication and vitamins in children's institutions drove the widespread transmission of HIV.¹⁷

International bodies have specifically addressed the mistreatment of children in Romania as a form of discrimination. The United Nations Committee on the Rights of the Child (CRC) expressed concerns with regard to discrimination against three groups of children in Romania – Roma children, children with HIV/AIDS and children with disabilities – and recommended that Romania fully and effectively implement necessary measures.¹⁸ The UNICEF survey showed that these groups of children were being discriminated against in numerous aspects of their lives including their abandonment, institutionalisation, health care and education.¹⁹

⁸ Id., at 29

⁹ Id., at 19 and 29

¹⁰ Id., at 6 and 10

¹¹ Id., at 47

¹² Id., at 45, 20; UNICEF estimates that 861 children per 100,000 lived in institutions in 2000, and 859 per 100,000 in 2007

¹³ Id., at 27

¹⁴ Id., Table F

¹⁵ Council of Europe Parliamentary Assembly, Doc. 10452, 8 February 2005, Doc. 10452: The rights of children in institutions: follow-up to Recommendation 1601 (2003) of the Parliamentary Assembly

¹⁶ Report of the Special Rapporteur on the right to health, E/CN.4/2005/51/Add.4, 21 February 2005, para. 48

¹⁷ Id.

¹⁸ UNICEF, *Children on the Brink, A Focused Situation Analysis of Vulnerable, Excluded and Discriminated Children in Romania*, October 2006, http://www.unicef.org/ceecis/06-rom-sitan_en.pdf

¹⁹ Id., Chapter IV, at 72-90

Cases of life-threatening conditions in institutions, malnutrition and ill-treatment of children with mental disabilities or HIV/AIDS have been documented throughout Europe, for example in Serbia²⁰, Moldova²¹ or Bulgaria. The 2010 joint investigation by the Bulgarian Prosecutor General and the Bulgarian Helsinki Committee indicated that over the past 10 years, 238 children with disabilities had died in social care homes. The report suggested that sick children tended not to be hospitalised, regardless of the gravity of their health condition, and that they were left to die in the institution, or hospitalised too late.²² Widespread abuses of children or adults with disabilities in institutions in Romania are very well documented.²³ A 2002 study found a striking malnutrition rate among children living in institutions in Romania.²⁴ The United Nations Special Rapporteur on the Right to Health visited the Poiana Mare Hospital in August 2004 and recommended that the government make appropriate medication available, ensure that patients are able to access effective complaint mechanisms and provide human rights training for hospital staff.²⁵ The European Committee for the Prevention of Torture (CPT) has documented malnutrition, deaths, and failure to provide medical treatment to persons detained in psychiatric institutions.²⁶ The United States Department of State, in its 2009 Human Rights Report on Romania called attention to continuing poor conditions at the Poiana Mare hospital and other psychiatric institutions, including overcrowding, shortage of staff, shortage of medication, insufficient food, poor hygiene, widespread use of sedation and restraint, and lack of awareness and observance of laws and regulations related to psychiatric admissions and detention.²⁷

It is clear from the statistics and documentation of abuses in institutions for children and adults that placement in an institution may place a person with a disability at significant risk of neglect, ill-treatment, abuse, grave illness, and even death. As will be discussed below, State failure to avoid such placement; to monitor, prevent, investigate and prosecute torture and ill-treatment; to ensure access to the highest attainable standard of health on an equal basis with others for persons with disabilities; and to provide and facilitate access to effective remedies for violations of the rights of persons who are in a situation of extreme vulnerability constitute grave violations of human rights under international and European law. State impunity for such violations discriminates against persons with disabilities, debases the value of their rights and their lives, and perpetuates the very stereotypes that allow such violations to occur in the first place.

II. INTERNATIONAL STANDARDS

A. The United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations General Assembly on 13 December 2006 and entered into force on 3 May 2008. As of 28 September 2011 it was signed by 153 and ratified by 105 Parties including the European Union (the European Community). Its provisions are legally binding for most of the Council of Europe Member States - 45 Member States signed and 29 have already ratified the CRPD. Romania signed the CRPD on 26 September 2007 and ratified it on 31 January 2011.²⁸

²⁰ Mental Disability Rights International, *Torment not Treatment: Serbia's Segregation and Abuse of Children and Adults with Disabilities*. Washington, DC: Mental Disability Rights International, 2007, <http://www.mdri.org/PDFs/reports/Serbia-rep-english.pdf>

²¹ Rapport au Gouvernement de la République de Moldova relatif à la visite effectuée en Moldova par le CPT du 14 au 24 septembre 2007, CPT/Inf (2008)39, point II(C)(D), and para 99, <http://www.cpt.coe.int/documents/mda/2008-39-inf-fra.htm>

²² Bulgarian Helsinki Committee, *Submission to the Human Rights Committee regarding the consideration of the third periodic report of Bulgaria*, 3 June 2011, http://www2.ohchr.org/english/bodies/hrc/docs/ngo/BHC_Bulgaria_HRC102.pdf; relevant statistical data can be found at <http://forsakenchildren.bghelsinki.org/en/>

²³ See *inter alia*, CPT reports, 2009 U.S. State Department report

²⁴ Bulgarian Helsinki Committee, *supra* note 23

²⁵ Paul Hunt, *Addendum: Mission to Romania*, E/CN.4/2005/51/Add.4, 21 February 2005 available at <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G05/111/56/PDF/G0511156.pdf?OpenElement>.

²⁶ CPT reports on Romania (1995, 1999, 2004, 2008 and 2010) can be consulted at <http://www.cpt.coe.int/en/states/rom.htm>

²⁷ U.S. Department of State, *Human Rights Report: Romania, 2009*, available at www.state.gov/g/drl/rls/hrrpt/2009/eur/136053.htm

²⁸ Status of ratifications can be consulted at www.un.org/disabilities

The CRPD has been characterised as a major leap forward in international human rights law which represents the first serious effort to discontinue the marginalisation of disability within human rights.²⁹ It does not create new rights, but it is the first legally binding instrument to comprehensively reaffirm and reinforce existing rights in a framework specific to persons with disabilities.³⁰ The fundamental purpose of the CRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.³¹ The principles of equality and non-discrimination are among the main features of the CRPD. The general provision on equality and non-discrimination can be found in its Article 5(2). The latter expressly obliges States to “prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds ...” This general wording is further emphasised and reiterated throughout the other provisions of the CRPD. Besides the duty of the State actors to refrain from discriminatory legislation and practices, it is essential that private employers, private suppliers of goods and services, and other non-public entities be subject to both non-discrimination and equality norms in relation to persons with disabilities.³²

The Court has held on a number of occasions that the European Convention for the Protection of Human Rights and Fundamental Freedoms (“the Convention”) is a living instrument which must be interpreted “in the light of present-day conditions”³³ and must be read “in the light of the notions currently prevailing in democratic States”.³⁴ In its recent case-law the Court also took into account the wide acceptance of the CRPD provisions in the Council of Europe Member States. In the case of *Glor v. Switzerland*³⁵ it made explicit reference to the CRPD as the basis for the “existence of a European and universal consensus on the need to protect persons with disabilities from discriminatory treatment”, despite the fact that the relevant events had taken place before the adoption of the CRPD by the General Assembly in 2006 (Switzerland has not even signed the CRPD yet). In *Alajos Kiss v. Hungary*³⁶ and *Jasinskis v. Latvia*³⁷ the Court also mentioned the CRPD, even though the relevant events had occurred before the respondent States signed the CRPD.

B. Access to justice for people with disabilities

A 2007 survey, supported by the European Commission and conducted in several European countries³⁸ concluded that the access of people with mental disabilities to rights and justice was by no means guaranteed. The survey found that legal structures and proceedings were generally not accessible for the people with intellectual disabilities and that their legal representation was not very well organised. The report noted that the general legal framework applied to people with mental disabilities regardless of their specific physical, intellectual or financial needs.

A 2011 report of the European Union Agency for Fundamental Rights (FRA), focusing specifically on access to justice in Europe, noted that the level of awareness of redress mechanisms among vulnerable groups was very low. Similarly, the effective possibility to seek protection of the rights of vulnerable people at the domestic level was hindered, *inter alia*, by legal costs and a narrow construction of legal standing.³⁹

²⁹ Andreas Dimopoulos, *The UN Convention on the Rights of Persons with Disabilities* (Ashgate Publishing Limited, 2010) at 79

³⁰ United Nations, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol* (2007), at 5

³¹ Article 1 of the CRPD

³² United Nations Enable, *Convention on the Rights of Persons with Disabilities: Questions and Answers*, para 11, <http://www.un.org/disabilities/default.asp?navid=24&pid=151#iq7>

³³ See, among many other authorities, *Selmouni v. France* (GC), no. 25803/94, § 101, ECHR 1999-V

³⁴ *Van der Musselle v. Belgium*, 23 November 1983, § 32, Series A no. 70

³⁵ *Glor v. Switzerland*, no.13444/04, § 53, 30 April 2009

³⁶ *Kiss v. Hungary*, no. 38832/06, § 44, 20 May 2010; Hungary signed CRPD on 30 March 2007 and ratified on 20 July 2007

³⁷ *Jasinskis v. Latvia*, no. 45744/08, § 40, 21 December 2010; Latvia signed CRPD on 18 July 2008 and ratified on 1 March 2010

³⁸ Inclusion Europe, *Justice, Rights and Inclusion for People with Intellectual Disability*, www.inclusion-europe.org/documents/1081.pdf

³⁹ FRA, *Access to justice in Europe: an overview of challenges and opportunities*, Luxembourg, March 2011, at 37-54 http://fra.europa.eu/fraWebsite/attachments/report-access-to-justice_EN.pdf

Under Article 13 of the CRPD, States are obligated to ensure access to justice for persons with disabilities on an equal basis with others, “including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.”⁴⁰ To ensure effective access to justice, States are required to provide persons with disabilities with support and accommodations, and to identify and eliminate obstacles and barriers to accessibility.⁴¹ This support is indispensable for people with mental disabilities in order to let them effectively complain about violations of their human rights. On the contrary, the lack of support would result in the virtual impossibility of fighting against existing abuses. This conclusion is also supported by the findings of the above survey according to which especially people with disabilities living in institutions have very limited access to justice and very limited possibilities to claim their rights.⁴²

The possibility of enforcing a right is central to making fundamental rights a reality.⁴³ The FRA study emphasised that the overly restrictive domestic rules on legal standing are one of the major restrictions to effective access to justice.⁴⁴ Persons with mental disabilities are particularly restricted in this regard in that national legislation in some States does not let individuals bring a claim to a court unless they have full legal capacity – even when their rights are directly concerned.⁴⁵ Further, persons with mental disabilities may avoid becoming involved in legal proceedings, including proceedings in which their own rights are at stake, for fear of having their legal capacity restricted.⁴⁶ In many countries individuals deprived of their legal capacity may initiate judicial proceedings only through their guardians. However, it is not uncommon that persons deprived of their legal capacity do not have any guardian. For example, in the Czech Republic, the proceedings on deprivation of one’s legal capacity and on appointment of a guardian are two separate and unrelated sets of proceedings, the latter following the former. As a result, there exists a period, sometime lasting several years, when persons do not have a guardian after they are deprived of their legal capacity.⁴⁷ A similar situation exists in other countries, such as Russia and Bulgaria, where the failure to appoint a guardian after a court has restricted a person’s legal capacity can result in long gaps during which the person cannot take any legal action, including initiating legal proceedings; this legal and factual situation has been described in several cases brought before the Court.⁴⁸

The factual or legal inability of persons with intellectual disabilities to access justice can, ultimately, lead to impunity for violation of their rights. This feature prevalent in many countries has been observed by the Special Rapporteur on Disability who concluded that “[p]eople with developmental [intellectual] disabilities are particularly vulnerable to human rights violations. ... They encounter significant problems in accessing the judicial system to protect their rights or to seek remedies for violations; and their access to organizations that may protect their rights is generally limited. While non-disabled people need independent national and international bodies to protect their human rights, additional justifications exist for ensuring that people with

⁴⁰ Article 13(1), CRPD.

⁴¹ Articles 9 and 13 of the CRPD

⁴² Inclusion Europe, *Justice, Rights and Inclusion for People with Intellectual Disability*, at 31, www.inclusion-europe.org/documents/1081.pdf

⁴³ FRA, *supra* note 40, at 3

⁴⁴ FRA, *supra* note 40, at 40

⁴⁵ *Id.*

⁴⁶ For example, MDAC represents a woman, Ms V, in domestic proceedings in the Czech Republic. Ms V was diagnosed as having a mental illness. She brought proceedings concerning her parental rights to her children. In the scope of these proceedings the judge raised doubts as to Ms V’s legal capacity and openly indicated a possibility to initiate proceedings on restriction/deprivation of her legal capacity and appointment of a guardian.

⁴⁷ At domestic level, MDAC represented a client, Mr S., who did not have any legal guardian for four years after he was deprived of his legal capacity.

⁴⁸ For example, *Stanev v. Bulgaria* (dec.), no. 36760/06, 29 June 2010; Mr Stanev did not have a guardian for one year after he had been deprived of his legal capacity. MDAC represents a client, Ms. B., in domestic proceedings in Bulgaria; Ms. B. has had her legal capacity restricted for more than 10 years with no guardian appointed. See also *Lashchevskiy v. Russia*, no. 18095/11; the applicant was detained in a psychiatric hospital because he did not have a guardian, after which the detaining hospital became his guardian.

disabilities and their rights be given special attention through independent national and international monitoring mechanisms."⁴⁹

Persons with intellectual disabilities who are deprived of their legal capacity and detained in institutions have very limited knowledge, if any, about their rights and possibilities to seek protection of their rights. Moreover, their vulnerability makes them more susceptible to violations of human rights, including those fundamental ones guaranteed by Articles 2 and 3 of the Convention.⁵⁰ Many of them have no family or close relatives. In many countries, the majority of persons placed in social care or specialised institutions for persons with mental disabilities have been deprived of their legal capacity and, in some cases, the directors or other staff of the institution serve as the person's guardian.⁵¹ Having regard to the fact that abuses occurring inside institutions are unseen by and unknown to society, it is more likely that there would be nobody to assist those persons (and who would raise these issues before domestic or international organs), if they are ill-treated or if their lives are endangered. Assuming that a breach of the right to life presupposes that a death has occurred, or is about to occur, and the State is responsible for it, in the absence of any relatives or any other representatives of the deceased, it is very likely that such violations will go unpunished. For children and adults with intellectual disabilities, orphans or people deprived of their legal capacity and detained in institutions, States could "avoid" any responsibility to protect their lives by not providing them with any person who would assist them with their affairs, including protection of human rights.

The fundamental aim of the Convention is to guarantee the rights that are practical and effective⁵², not theoretical and illusory, and the Court acknowledged that several cases transcended the individual person. It noted a moral dimension of cases before it and held "[w]hile under Article 34 of the Convention the existence of a "victim of a violation", that is to say, an individual applicant who is personally affected by an alleged violation of a Convention right, is indispensable for putting the protection mechanism of the Convention into motion, this criterion cannot be applied in a rigid, mechanical and inflexible way throughout the whole proceedings."⁵³ The existence of a general interest was considered as one of the reasons to continue the proceedings after the applicant's death even though there was nobody who would pursue the application.

Cases initiated by NGOs in situations where there was no one who could assert their rights have been examined by courts throughout the world. In a landmark case of *The Canadian Council of Churches v. Canada*⁵⁴, the Canadian Supreme Court noted the complexity of society and emerging complex issues to be solved by the courts and found the need to extend the right to standing from the traditional approach which limited standing to those who possessed a private interest. Without providing a blanket approval to everyone, such a test must follow three principles: firstly, the case must concern a serious issue as to the invalidity of legislation, secondly, the plaintiff must demonstrate a genuine interest and thirdly, there must not be another reasonable and effective way to bring the issue before the court. A similar approach has been adopted by, for example, the Irish Supreme Court in a case concerning the right to life of the unborn guaranteed by the Irish Constitution. Considering the nature of the right at stake, it concluded that there could never be a victim who could sue in respect of that right. Therefore it granted standing to an NGO which had a *bona fide* concern and interest for the protection of that right. It also held that the right of access to the courts also included the right to seek to restrain breaches of the Constitution where the public interest so requires.⁵⁵ In another case

⁴⁹ Special Rapporteur on Disability, *Report by the Special Rapporteur on Disability on the Question of Monitoring*, para 2, <http://www.un.org/esa/socdev/enable/rapporteur.htm>

⁵⁰ Ill-treatment in psychiatric and other institutions detaining persons with intellectual disabilities and other issues arising under Articles 2 and 3 of the Convention have been reported in a number of Council of Europe Member States' (see part III below)

⁵¹ In a number of cases pending before the Court, the applicants were under the guardianship of the director of an institution or the institution itself. See, *inter alia*, *Stanev v. Bulgaria*, cited above, *Lashin v. Russia* (dec.), no. 33117/02, decision as to the admissibility 6 January 2011, or *D.D. v. Lithuania*, no. 13469/06 (communicated case).

⁵² *Airey v. Ireland*, judgment of 9 October 1979, Series A no. 32, § 24

⁵³ *Karner v. Austria* [GC], no. 40016/98, § 25, ECHR 2003-IX, with further references

⁵⁴ <http://scc.lexum.org/en/1992/1992scr1-236/1992scr1-236.html>, Database of the decisions of the Supreme Court of Canada

⁵⁵ <http://www.pila.ie/resources/casesummaries/the-society-for-the-protection-of-unborn-children/>, *The Society for the Protection of Unborn Children (Irl) Ltd v. Diarmuid Coogan et al.*, (1988)IR734; <http://eprints.utas.edu.au/2038/3/02whole.pdf> (at 127), *Attorney General (at the relation of SPUC (Irl) Ltd) v Open Door Counselling Ltd & Dublin Well Woman Centre Ltd*, (1988)IR593; (1988)ILRM19

concerning systematic deficiencies in the treatment of prisoners with mental health problems the Irish Supreme Court granted standing to an NGO for two main reasons – the NGO was a sincere and good faith litigant with expertise in prisoners’ rights and the case concerned systematic deficiencies which required an expert body to present the issues clearly to the court.⁵⁶ A similar position was adopted by the High Court of England and Wales when it granted standing to Greenpeace in an environmental case.⁵⁷

The recognition of persons with mental disabilities as equal to others within the meaning of international human rights standards and protection of lives of those of them who are detained in institutions, often for life-time, is no doubt an issue of general interest not limited to a particular State. The failure to create conditions recognising persons with mental disabilities as equal to others and allowing them to complain about violations of their fundamental rights (including the right to life and freedom from ill-treatment) while they are alive, cannot discharge States from their liability for the death of those persons after they pass away.

III. RIGHTS OF PERSONS WITH DISABILITIES AND PERSONS WITH HIV/AIDS

A. Right to life

The right to life is a fundamental right guaranteed by a number of international instruments⁵⁸. Article 10 of the CRPD provides that every human being has the inherent right to life and obliges States to take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

The jurisprudence of various international bodies related to the right to life has established that States’ obligations include the positive obligation to protect lives of all persons under their jurisdiction, including those who are held in institutions. The United Nations Human Rights Committee noted that protection of the right to life required States to adopt positive measures and considered that States should take all possible measures to, among other issues, increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics.⁵⁹ In this respect it is important to take into account Article 25 of the CRPD which sets obligations for States to, *inter alia*, (i) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons; (ii) require health professionals to provide care of the same quality to persons with disabilities as to others; and (iii) prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. Similarly, the Human Rights Committee stressed the importance of humane treatment and respect for the dignity of all persons held in institutions, including in psychiatric hospitals. Application of this principle cannot depend on the available material resources and must be applied without distinction of any kind.⁶⁰

Some leading cases in this area (see below) show that the right to life includes the obligation of States to make available not only adequate food and water in order to sustain life but also the duty to provide medical treatment to allow individuals to sustain life in dignity while they are detained. The Court itself recognised that “an issue may arise under Article 2 of the Convention where it is shown that the authorities ... put an individual’s life at risk through the denial of health care which they have undertaken to make available to the

⁵⁶ *Irish Penal Reform Trust Limited & Ors v. the Governor of Mountjoy Prison* (2005) IEHC 305

⁵⁷ *R v Inspector of Pollution, ex p Greenpeace Ltd (No.2)* (1994) 4 All ER 329

⁵⁸ Article 3 of the Universal Declaration on Human Rights; Article 6 of the International Covenant on Civil and Political Rights; Article 6 of the Convention on the Rights of Child; Article 2 of the European Convention on Human Rights and its Protocols Nos. 6 and 13; Article 4 of the American Convention on Human Rights; Article 4 of the African Charter on Human and Peoples’ Rights, etc.

⁵⁹ Human Rights Committee, *General Comment no. 6 (the right to life)*, para 6, 1982,

[http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/84ab9690ccd81fc7c12563ed0046fae3?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/84ab9690ccd81fc7c12563ed0046fae3?Opendocument)

⁶⁰ Human Rights Committee, *General Comment no. 21 (humane treatment of persons deprived of liberty (Article 10))*, 1992, [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/3327552b9511fb98c12563ed004cbe59?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/3327552b9511fb98c12563ed004cbe59?Opendocument)

population generally.”⁶¹ Given the fundamental nature of the rights at stake, it is important to emphasise that States are responsible to protect individuals from violation of their human rights not only by State agents but also by private entities or individuals, including those working in private hospitals and other institutions.⁶²

In the leading case of *Villagrán Morales et al. v. Guatemala*⁶³ the Inter-American Court of Human Rights found that the State was responsible for the torture and murder of five so called “street children”, that is children who lived on the streets of the Guatemala City. It explicitly held:

“144. The right to life is a fundamental human right, and the exercise of this right is essential for the exercise of all other human rights. If it is not respected, all rights lack meaning. Owing to the fundamental nature of the right to life, restrictive approaches to it are inadmissible. In essence, the fundamental right to life includes... also the right that he will not be prevented from having access to the conditions that guarantee a dignified existence. States have the obligation to guarantee the creation of the conditions required in order that violations of this basic right do not occur and, in particular, the duty to prevent its agents from violating it.”

“191. ... the Court wishes to record the particular gravity of the fact that a State Party to this Convention can be charged with having applied or tolerated a systematic practice of violence against at-risk children in its territory. When States violate the rights of at-risk children, such as “street children”, in this way, it makes them victims of a double aggression. First, such States do not prevent them from living in misery, thus depriving them of the minimum conditions for a dignified life and preventing them from the “full and harmonious development of their personality”, even though every child has the right to harbor a project of life that should be tended and encouraged by the public authorities so that it may develop this project for its personal benefit and that of the society to which it belongs. Second, they violate their physical, mental and moral integrity and even their lives.”

The case of *Lantsova v. The Russian Federation*⁶⁴ before the Human Rights Committee concerned a denial of health care in a prison. Finding a breach of the right to life of the author’s son, the Committee stated that:

“9.2 ... after the deterioration of the health of the author’s son, he received medical care only during the last few minutes of his life, that the prison authorities had refused such care during the preceding days and that this situation caused his death. ... The Committee affirms that it is incumbent on States to ensure the right of life of detainees, and not incumbent on the latter to request protection. ... [T]he essential fact remains that the State party by arresting and detaining individuals takes the responsibility to care for their life. It is up to the State party by organizing its detention facilities to know about the state of health of the detainees as far as may be reasonably expected. Lack of financial means cannot reduce this responsibility. The Committee considers that a properly functioning medical service within the detention centre could and should have known about the dangerous change in the state of health of Mr. Lantsov. It considers that the State party failed to take appropriate measures to protect Mr. Lantsov’s life during the period he spent in the detention centre.”

In the case of *International Pen, Constitutional Rights Project, Interights on behalf of Ken Saro-Wiwa Jr. And Civil Liberties Organisation v. Nigeria* the African Commission of Human and Peoples’ Rights concluded that “[t]he protection of the right to life ... also includes a duty for the state not to purposefully let a person die while in its custody. Here at least one of the victims’ lives was seriously endangered by the denial of medication during detention.” The Commission found a violation of the right to life when denying medication to a prisoner had endangered his life but had not caused his death.⁶⁵

Alongside the Court’s extensive case-law on the subject, the obligation of States to carry out an effective investigation into alleged violations of human rights, including the right to life, arises from international human rights standards. Focusing especially on persons with disabilities, Article 16 of the CRPD obliges States to take all appropriate measures to protect persons with disabilities from all forms of exploitation, violence and abuse and to ensure that all such cases are identified, investigated and, where appropriate, prosecuted. A similar obligation can be found in the International Covenant on Civil and Political Rights (ICCPR). The Human Rights Committee considered the special vulnerability of certain categories of persons and emphasised the obligation to investigate allegations of violations promptly, thoroughly and effectively through

⁶¹ *Cyprus v. Turkey* [GC], no. 25781/94, § 219, ECHR 2001-IV

⁶² See, among other authorities, Human Rights Committee, *General Comment no. 20*, 1992, para 2, [http://www.unhcr.ch/tbs/doc.nsf/\(Symbol\)/6924291970754969c12563ed004c8ae5?Opendocument](http://www.unhcr.ch/tbs/doc.nsf/(Symbol)/6924291970754969c12563ed004c8ae5?Opendocument); Report of the Special Rapporteur on torture, A/HRC/7/3, 15 January 2008, para 31; Human Rights Committee, *General Comment no. 31*, CCPR/C/21/Rev.1/Add.13, 26 May 2004, para 8

⁶³ *Villagrán Morales et al. v. Guatemala*, judgment of 19 November 1999, Series C no. 77

⁶⁴ *Lantsova v. The Russian Federation*, Communication no. 763/1997, views of 26 March 2002

⁶⁵ Icelandic Human Rights Centre, *The Right to Life, Positive obligations imposed by the Right to Life*, <http://www.humanrights.is/the-human-rights-project/humanrightscasesandmaterials/comparativeanalysis/life/>

independent and impartial bodies.⁶⁶ Furthermore, it noted that “[a] failure by a State Party to investigate allegations of violations could in and of itself give rise to a separate breach of the Covenant.”⁶⁷ The Human Rights Committee also noted that the problem of impunity of such violations may be an important element which contributes to the recurrence of the violations.⁶⁸

As regards the duty of the States to investigate alleged violation of human rights, such as the right to life, the Inter-American Court of Human Rights in the case of *Velásquez Rodríguez v. Honduras*⁶⁹ held:

“176. The State is obligated to investigate every situation involving a violation of the rights protected by the Convention. If the State apparatus acts in such a way that the violation goes unpunished and the victim’s full enjoyment of such rights is not restored as soon as possible, the State has failed to comply with its duty ... The same is true when the State allows private persons or groups to act freely and with impunity to the detriment of the rights recognized by the Convention.

177. In certain circumstances, it may be difficult to investigate acts that violate an individual’s rights. The duty to investigate, like the duty to prevent, is not breached merely because the investigation does not produce a satisfactory result. Nevertheless, it must be undertaken in a serious manner and not as a mere formality preordained to be ineffective. An investigation must have an objective and be assumed by the State as its own legal duty, not as a step taken by private interests that depends upon the initiative of the victim or his family or upon their offer of proof, without an effective search for the truth by the government. ... Where the acts of private parties that violate the Convention are not seriously investigated, those parties are aided in a sense by the government, thereby making the State responsible on the international plane.”

International law on the right to life and international jurisprudence related thereto are consistent in upholding States’ obligation to protect life, including by providing necessary medical treatment and taking other preventative measures to ensure that this right is upheld. Further, States violate this right by failing to fully investigate and allowing the acts of private parties to go unpunished.

B. Freedom from torture and inhuman and degrading treatment

The absolute prohibition against torture is enshrined in numerous international treaties.⁷⁰ The CRPD endorses this legal regime and places it in the framework relevant for persons with disabilities. Article 15 of CRPD provides:

“1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.

2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.”

The CRPD provides further authoritative guidance on the absolute prohibition of torture in respect of persons with disabilities. Article 3 of the CRPD proclaims the principle of respect of the individual autonomy of persons with disabilities. Article 12 recognises their equal right to enjoy legal capacity in all areas of life, such as deciding where to live and whether to accept medical treatment.⁷¹

Persons with mental disabilities are often placed in institutions and excluded from society, which in itself violates the CRPD, whose Article 19 guarantees the right of people with disabilities to live in the community and to choose one’s place of residence on an equal basis with others . Given their special vulnerable position, they are often totally dependent on the staff, and unaware of their rights or how to protect their rights. In these circumstances, abuses can be easily hidden from the outside world. The Special Rapporteur on Torture emphasised the concept of vulnerability, observing that “[t]orture, as the most serious violation of the human right to personal integrity and dignity, presupposes a situation of powerlessness, whereby the victim is under the total control of another person. Persons with disabilities often find themselves in such situations, for instance when they are deprived of their liberty in prisons or other places, or when they are under the control

⁶⁶ Human Rights Committee, *General Comment no. 31*, CCPR/C/21/Rev.1/Add.13, 26 May 2004

⁶⁷ *Id.*, para 15

⁶⁸ *Id.*, para 18

⁶⁹ *Velásquez Rodríguez v. Honduras*, Judgment of 29 July 1988, Series C. No. 4 (1998)

⁷⁰ Such as the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Article 2), the International Covenant on Civil and Political Rights (Article 7) and the Convention on the Rights of the Child (Article 37)

⁷¹ M. Nowak, *Interim Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, U.N.Doc. A/63/175 (28 July 2008), para. 44

of their caregivers or legal guardians. In a given context, the particular disability of an individual may render him or her more likely to be in a dependant situation and make him or her an easier target of abuse."⁷² He further stressed that "[p]ersons with disabilities are often segregated from society in institutions, including prisons, social care centres, orphanages and mental health institutions. They are deprived of their liberty for long periods of time including what may amount to a lifelong experience, either against their will or without their free and informed consent. Inside these institutions, persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. The lack of reasonable accommodation in detention facilities may increase the risk of exposure to neglect, violence, abuse, torture and ill-treatment."⁷³ He expressed his concerns about the fact that "in many cases such practices, when perpetrated against persons with disabilities, remain invisible or are being justified, and are not recognized as torture or other cruel, inhuman or degrading treatment or punishment".⁷⁴

Despite the absolute prohibition against torture and inhuman and degrading treatment, the actual situation in institutions throughout the world, where persons with disabilities are kept, often falls below these standards. For example, the United Nations Committee on Economic, Social and Cultural Rights asked States to "ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society. All such services should be provided in such a way that the persons concerned are able to maintain full respect for their rights and dignity."⁷⁵

International judicial and quasi-judicial bodies have examined a number of complaints concerning ill-treatment and lack of adequate treatment of persons with mental disabilities. For example, in the case of *Uton Lewis v. Jamaica*⁷⁶ the Human Rights Committee found that the denial of medical treatment to a prisoner on a death row amounted to inhuman treatment in violation of Article 10(1) of the ICCPR. This provision guarantees the right for all persons deprived of their liberty to be treated with humanity and with respect for the inherent dignity of the human person.

In the case of *Victor Rosario Congo v. Ecuador* the Inter-American Commission on Human Rights held that "retaining in custody and without medical treatment, a person who was suffering from cerebral edema and cholera constituted a violation of ... the prohibition of the infliction of inhuman, cruel or degrading treatment."⁷⁷ It emphasised that this specific person was in a particularly vulnerable position because he had a mental disability. It equally found that the State had been responsible for the death of Mr Congo who, while still in detention, died of malnutrition, hydroelectrolitic imbalance, and heart and lung failure.⁷⁸

The obligation to conduct effective investigations into alleged ill-treatment has been recognised by international bodies, including the Human Rights Committee, which concluded that the authorities were under the obligation to investigate complaints against maltreatment promptly and impartially, in order to make the available remedies effective.⁷⁹ Noting the cases of ill-treatment in the Bulgarian institutions (see part I above) the Council of Europe Commissioner for Human Rights concluded: "It has to be recognised that persons detained in psychiatric social care institutions are extremely vulnerable. Considering their limited possibility to communicate with the outside world, states have an obligation to set up and support truly independent national monitoring bodies, and to ensure adequate resources for such bodies. Any reports of ill treatment in

⁷² Id., para. 50

⁷³ Id., para. 38

⁷⁴ Id., para. 41

⁷⁵ The Committee on Economic, Social and Cultural Rights, *General Comment no. 18*, para. 34

⁷⁶ *Uton Lewis v. Jamaica*, Communication no. 527/1993, 18 July 1996, para 10.4

⁷⁷ *Victor Rosario Congo v. Ecuador*, Case 11.427, Report No. 63/99, Decision of 13 April 1999, para 65

⁷⁸ Icelandic Human Rights Centre, *The Right to Freedom from Torture, or Cruel, Inhuman or Degrading Treatment or Punishment*, <http://www.humanrights.is/the-human-rights-project/humanrightscasesandmaterials/comparativeanalysis/tortureorcruel/>

⁷⁹ Human Rights Committee, *General Comment no. 20*, 1992, para 14

psychiatric hospitals must be thoroughly and effectively investigated – in order to prevent and remedy torture, inhuman and degrading treatment or punishment of people in institutions in Europe today.”⁸⁰

CONCLUSION

As the UN Special Rapporteur on Disability noted: “[The CRPD] has risen from the very core of the human rights principles of the United Nations. It is founded on the principles of dignity and justice; and rooted in the concepts of inalienability, universality and indivisibility of human rights. It highlights the right to full participation, and rests upon the notion of equality without distinctions; underlines the right to enjoyment without discrimination; stresses the belief in the dignity and worth of all human being, and their right to equality and protection by the law.”⁸¹ Despite the ongoing international criticism of the ill-treatment and other forms of abuses in institutions in Romania, the government has not ensured equal rights and treatment for persons with disabilities. It has not only failed to protect their well-being and, ultimately, lives, on an equal basis with the rest of the population, it has also failed to provide them with any effective or practical possibility to seek protection of their human rights, including the right to life, and stop the existing violations while they are still alive. The failure of the State to provide these powerless and extremely vulnerable persons with such a possibility while they are alive cannot ultimately lead to the State’s impunity after their death.

⁸⁰ Thomas Hammarberg, *Inhuman treatment of persons with disabilities in institutions*, 21 October 2010, [https://wcd.coe.int/wcd/ViewDoc.jsp?Ref=PR776\(2010\)&Language=lanEnglish&Ver=original&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864](https://wcd.coe.int/wcd/ViewDoc.jsp?Ref=PR776(2010)&Language=lanEnglish&Ver=original&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864)

⁸¹ Statement by the Special Rapporteur on Disability, *Convention on the Rights of Persons with Disabilities: A Progressive Human Rights Instrument*, September 2006, www.un.org/esa/socdev/enable/srstathrc2006.html

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