HEALTH AND HUMAN RIGHTS RESOURCE GUIDE





HEALTH AND HUMAN RIGHTS RESOURCE GUIDE

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Health and Human Rights Resource Guide

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Fifth Edition, November 2013

Cover photograph courtesy of Sven Torfinn - Panos for the Open Society Foundations, "A paralegal nurse named Mercy and a lawyer named Johnson, both with Nyeri Hospice in Nyeri, Kenya talk with Elizabeth (center) about her health and property. She has cancer and is cared for by her granddaughter Caroline (to her left). She wants to ensure her granddaughters can inherit her property even though other relatives are trying to claim it."

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CHAPTER 9





DISABILITY, COMMUNITY LIVING, HEALTH AND HUMAN RIGHTS

Disability is a human rights issue! I repeat: disability is a human rights issue. 55

 Speech by Bengt Lindqvist, Special Rapporteur on Disability of the United Nations Commission on Social Development

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INTRODUCTION

This chapter will introduce you to key principles of the Convention on the Rights of Persons with Disabilities (CRPD) and health and human rights issues facing persons with disabilities. The chapter will also introduce you the right of persons with disabilities to live in the community as well as the human rights violations against persons with disabilities living in institutions. This chapter is based upon the Convention on the Rights of Persons with Disabilities.

Some of the issues in this chapter are also addressed in Chapter 1 on Patient Care and Human Rights.

The chapter is organized into six sections that answer the following questions:

- 1. How is disability a human rights issue?
 - 1A. How is disability and health a human rights issue?
 - 1B. How is institutional living a human rights issue and what is community living?
- 2. What are the most relevant international and regional human rights standards related to disability, health and community living?
- 3. What is a human rights-based approach to advocacy, litigation, and programming related to disability, health and community living?
- 4. What are some examples of effective human rights-based work in the area of disability, health and community living?
- 5. Where can I find additional resources on disability and human rights?
- 6. What are key terms related to disability and human rights?

1. DISABILITY AND HUMAN RIGHTS

What do we mean by disability?

Defining disability

The Convention on the Rights of Persons with Disabilities ("CRPD") does not provide a definition of disability, but instead provides a broad description intended to be widely inclusive. The CRPD establishes in Article 1 that 'persons with disabilities' includes 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.¹ This description of disability shifts the focus toward the social and environmental barriers that hinder an individual's participation in society rather than on the individual's impairments.

This approach to disability is called the "social model" of disability. The "social model" recognizes that the exclusion of a person with a disability from society is the result of a barrier or hindrance to the individual's ability to participate fully, rather than the result of the individual's inherent inability to participate. For example, if a person cannot access a health clinic because of his/her mobility impairment, it is not his/her inability to walk which is the issue, but rather the clinic's lack of accessibility.

Global prevalence of disability

Persons with disabilities constitute a significant portion of the population worldwide, yet they remain one of the most marginalized and vulnerable populations. It is difficult to obtain accurate data on the number of people with disabilities worldwide because approaches to measuring disability vary across countries and according to the purpose and application of the data. However, the World Health Survey—a face-to-face household survey conducted in 2002-2004 in 59 countries—estimated that about 650 million adults had a disability, with about 92 million of those adults experiencing very significant disabilities.² The survey also demonstrated that the occurrence of disability is higher in low-income countries where about 18% of the population has a disability, in comparison to high income countries where about 11.8% of the population has a disability.³

Human rights-based approach to disability

Over the past decade, awareness and understanding of issues related to disability rights has grown. In particular, the Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006 and entered into force on May 3, 2008, has been integral to advancing recognition of the human rights of persons with disabilities. The CRPD provides us with a comprehensive approach to realizing the rights of persons with disabilities.

¹ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 1 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

² World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

³ Id.

The CRPD is important for both outlining the rights of persons with disabilities and for changing perceptions of disability. The UN Office of the High Commissioner for Human Rights describes a human rights-based approach to disabilities:

A rights-based approach seeks ways to respect, support and celebrate human diversity by creating the conditions that allow meaningful participation by a wide range of persons, including persons with disabilities. Protecting and promoting their rights is not only about providing disability-related services. It is about adopting measures to change attitudes and behaviours that stigmatize and marginalize persons with disabilities. It is also about putting in place the policies, laws and programmes that remove barriers and guarantee the exercise of civil, cultural, economic, political and social rights by persons with disabilities.⁴

Persons with disabilities face wide-ranging human rights abuses including institutionalization, isolation, stigma and discrimination, and lack of access to health, education and employment opportunities. The CRPD sets outs a wide range of rights that address all aspects of life, such as respect for home and the family, education, employment, health, participation in political and public life, participation in cultural life, recreation, leisure and sport, the right to life, freedom from torture or cruel, inhuman or degrading treatment or punishment and the right to equal protection and equal benefit of the law. The CRPD seeks to "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." 5

The CRPD and Conflicting Law

The CRPD is a relatively recent human rights treaty. The CRPD consolidates and expands on existing international law on the rights of persons with disabilities. As the UN Department of Public Information notes, "[the CRPD] does not create any 'new rights' or 'entitlements'. What the convention does, however, is express existing rights in a manner that addresses the needs and situation of persons with disabilities."

The CRPD imposes new legal obligations on States and supersedes any prior non-binding international, regional or domestic standards. However, there are many binding regional and domestic standards that fall short of, or conflict with, the more recent and expansive CRPD standards. For example some standards and case law address forced treatment or confinement where due process was not maintained, but do not question the legitimacy of forced treatment or confinement. Likewise, some standards and case law qualify the right to live in the community, rather than protecting the right absolutely.

This chapter, including the tables, is based upon the CRPD and CRPD-aligned standards. The chapter does not include standards or case law that contravenes or diminishes the rights provided in the CRPD.

⁴ UN Office of the High Commissioner for Human Rights, Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors (2010). http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf.

⁵ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 1 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

⁶ United Nations, Convention on the Rights of Persons with Disabilities, "Why a Convention?" http://www.un.org/disabilities/convention/questions.shtml.

IA. HOW IS DISABILITY AND HEALTH A HUMAN RIGHTS ISSUE?

Introduction

Using the CRPD as a framework, this section explores a human rights-based approach to health for persons with disabilities, including the social and economic determinants of health.

The CRPD and the right to health

Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, under CRPD Article 25.7 In this context, health is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or illness." It is crucial to note that the CRPD establishes that disability is not necessarily a medical condition and emphasizes the role of environmental and attitudinal barriers, rather than an impairment (if it exists at all) in hindering full and effective participation in society on an equal basis with others. While persons with disabilities may at times need to access health services for medical conditions related to their disabilities, this should not be presumed to be their primary need for health services.

The right to health in Article 25 must be interpreted in the context of the core principles of CRPD outlined in Article 3. The core principles include non-discrimination; participation; autonomy, including the freedom to make one's own choices; social inclusion; gender equality; and equality of opportunity. These principles are overarching and should guide interpretation of other CRPD articles.

Progressive Realization and Non-Discrimination

The right to health established in Article 25 must also be read in light of Article 4(2) which requires States to progressively realize economic and social rights. Progressive realization means that "States parties have a specific and continuing obligation to move as expeditiously and effectively as possible" towards the full realization of the right to health. The Committee on the Rights of Persons with Disabilities recognizes that no State is able to realize the right to health immediately. For example, States may have to develop health care infrastructure, train health professionals, or implement health care legal reforms to begin realizing the right to health. The obligation for States to progressively realize the right to health requires them to make continuing efforts to implement the right, recognizing that it is a process achieved over time.

States are immediately obligated, upon ratifying the CRPD, to ensure non-discrimination. The obligation to guarantee non-discrimination under the CRPD is the same as required under the ICESCR and the CRC, which "all impose an immediate obligation to guarantee that economic, social and cultural rights are enjoyed without discrimination. Accordingly, measures towards the progressive achievement of rights must at all times be guided by, and comply with, the basic requirement of non-discrimination." The obligation to guarantee non-discrimination must be immediately implemented "irrespective of the level of available

⁷ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 25 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

⁸ World Health Organization, "Definition of Health." http://www.who.int/about/definition/en/print.html.

⁹ UN Nations Committee on Economic, Social, and Cultural Rights, General Comment No. 3: The Nature of States Parties Obligations, E/1991/23 (Dec. 14, 1990). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

¹⁰ United Nations Economic and Social Council (2007). "Report of the United Nations High Commissioner for Human Rights", E/2007/82, 25 June. http://ap.ohchr.org/documents/alldocs.aspx?doc_id=15584.

resources."¹¹ The Committee on Economic, Social and Cultural Rights explains that non-discrimination is an immediate obligation for all States, regardless of resources because "many measures, such as most strategies and programmes designed to eliminate health-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information."¹²

Access to Health Services

The CRPD requires that States Parties "take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation." Persons with disabilities face a range of barriers in accessing health care services, including cost, accessibility, stigma and discrimination and lack of or inadequacy of services and resources. Without equal access to health care, "people with disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation."

Both the CRPD and the Committee on Economic, Social and Cultural Rights (CESCR) provide guidance on what accessibility means and how it should be understood in the context of health. The CRPD broadly defines accessibility in Article 9 as "access, on an equal basis with others, to the physical environment, to transportation, to information and communications ... and to other facilities and services open or provided to public, both in urban and rural areas." CESCR explains in General Comment 14 on the right to health that the four components of accessibility are non-discrimination, physical accessibility, economic accessibility, and information accessibility.

Non-discrimination - Equal Access to Health Care

Non-discrimination is a central principle to the CRPD and is critical for ensuring equal access to health care for persons with disabilities. The CRPD defines in Article 2 that:

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.¹⁸

All persons with disabilities have the same general health care needs as everyone else and require access to mainstream health care services on an equal basis as everyone else. 19 Also, with the move away from institutionalized living towards community living, it is crucial that health care services and facilities are developed and accessible to all persons with disabilities.

¹¹ Id.

¹² UN Nations Committee on Economic, Social, and Cultural Rights, *General Comment No. 14*: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

¹³ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 25(a) (2006). http://www.ohchr.org/EN/HR-Bodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

¹⁴ World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

¹⁵ Tomlinson M et al, "Health care and the UN Disability Rights Convention" The Lancet, 374, (Nov. 28, 2009).

¹⁶ United Nations General Assembly, Convention of the Rights of Persons with Disabilities, A/RES/61/106, Art. 9(1) (2006). http://www.ohchr.org/EN/HR-Bodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

¹⁷ UN Nations Committee on Economic, Social, and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

¹⁸ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 2 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

¹⁹ World Health Organization, Disability and health, Fact Sheet (Nov 2012). http://www.who.int/mediacentre/factsheets/fs352/en/index.html.

Physical Accessibility

Physical accessibility is a critical component for ensuring equal access to health care for persons with disabilities. Physical barriers to accessing health care include both environmental and infrastructural barriers as well as geographical barriers, such as access to rural health centers.

The CESCR explains in General Comment 14 on the right to health that physical accessibility is defined as follows:

Health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as ... persons with disabilities ... Accessibility also implies that medical services and underlying determinants of health, such as safe and potable water and adequate sanitation facilities, are within safe physical reach, including in rural areas. Accessibility further includes adequate access to buildings for persons with disabilities.

The CRPD also focuses on geographical access to health care, establishing in Article 25(c) that States parties must "[p]rovide these health services as close as possible to people's own communities, including in rural areas." Provision of health care facilities to individuals in rural areas ensures that everyone is able to physically reach health care facilities. The provision of health services within an individual's community is critical for persons with disabilities who have a right to access health services within their community.

In addition to access to health facilities, physical access extends to accessible medical equipment and services. For example, women with mobility impairments are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable and mammography equipment only accommodates women who are able to stand.²⁰

Economic Accessibility

The CRPD provides in Article 25 that States parties must "provide persons with disabilities the same range, quality and standard of free or affordable health care and programmes as provided to other persons ..." According to the 2002-2004 World Health Survey, affordability was the primary reason why persons with disabilities, across gender and age groups, did not receive needed health care in low-income countries. In its study of 51 countries, the World Health Survey reported that 32–33% of nondisabled men and women cannot afford health care, compared with 51–53% of persons with disabilities. 22

The CRPD establishes in Article 25 that States parties must "[p]rohibit discrimination against persons with disabilities in the provision of health insurance ... which shall be provided in a fair and reasonable manner." However, persons with disabilities have lower rates of employment, making it more difficult for them to afford health insurance or less likely to covered if health insurance is usually provided by the workplace. Those persons with disabilities who are provided health insurance may be denied coverage due to their pre-existing conditions or discriminatory coverage policies.

Affordable health insurance is an important measure for addressing barriers to financing and affordability. Measures can include targeting people with disabilities who have the greatest health care need, providing general income support, reducing or removing out of pocket payments to improve access, eliminating discriminatory provisions, and providing incentives to health providers to promote access.²³

²⁰ Id.

²¹ World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

²² Id.

²³ Id.

Information Accessibility

The form or the content of information can serve as barriers to accessing information for many persons with disabilities.²⁴ For example, presenting information in Braille and sign language are two different forms of communication which make information accessible to individuals who otherwise may experience barriers. Similarly, using easy-to-read language or using pictures and cartoons are different methods for changing the content of information to make it more accessible.

In the health context, access to information is crucial for patients to engage with their health care providers and to receive and understand relevant health information. Access to information in the health context extends to accessible forms, informational brochures and communication with health care providers. Access to information is also important for navigating the health care system. Information provided through referral systems, waiting lists or booking systems for appointments should also be accessible to everyone and facilities should also be outfitted with proper signage to and within buildings.

Informed consent

The CRPD establishes in Article 25 that States parties must "[r]equire health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent ..." The UN Special Rapporteur on the right to health, Anand Grover, defines informed consent as the following:

Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.²⁵

Informed consent is supported by the general principles in CRPD Article 3 which include individual autonomy and respecting the freedom of individuals to make decisions about their life.

Violations of informed consent may, in some instances, amount to torture. In his most recent report, the Special Rapporteur on torture, Juan Méndez, called on all countries to ban all non-consensual and forced medical interventions against persons with disabilities.²⁶ He explains that "Both this mandate and United Nations treaty bodies have established that involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment."²⁷

Persons with disabilities have the right to provide or withhold consent for any medical intervention or health service and should be involved and communicated with directly about their health. Health professionals should speak directly with individual them self about their health matters and health choices, and not speak solely to their carers, relatives or proxies.²⁸

For more information on informed consent generally, please see Chapter 1 on Patient Care.

²⁴ Office of the High Commissioner for Human Rights, Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors (2010), pg. 58. http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf.

²⁵ United Nations General Assembly, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/64/272 (Aug. 10, 2009).

²⁶ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

²⁷ ld.

²⁸ Shakespeare T, Lezzoni LI, and Groce NE, "Disability and the training of health professionals," The Lancet 374, no. 9704 (Nov. 28, 2009).

Sexual and reproductive care of the same range, quality and standard of care as others

The CRPD establishes in Article 25 that States parties must provide persons with disabilities the same sexual and reproductive health care and programmes as provided to other persons. Sexual and reproductive rights must be guaranteed for persons with disabilities and yet persons with disabilities often experience gross violations of their rights and cannot access sexual and reproductive services. This quote from a guide on gender mainstreaming in public disability policies explains the content of sexual and reproductive rights respectively:

Sexual rights, understood to mean liberty to decide freely and responsibly on all questions related to sexuality, implies also the right to exercise one's sexuality safely, free from discrimination, coercion and violence; the right to physical and emotional pleasure; the right to freely-chosen sexual orientation; the right to information on sexuality; and the right to access sexual health services. Reproductive rights, taken to mean the freedom and independence each individual has to decide responsibly if she or he wants to have children or not, how many, when and with whom, encompasses also the right to access information, education and the means to do so; the right to take decisions on reproduction free from discrimination, coercion and violence; the right to access quality primary healthcare, and the right to measures to protect motherhood. All these rights must be fully guaranteed for female adolescents and women with disabilities under conditions of equality, free consent and mutual respect: to date this has not been the case.²⁹

Statistics reveal that adolescents and adults with disabilities are more likely to be excluded from sexual and reproductive health education and face stigma, prejudice, and denial of access to sexual and reproductive health services.³⁰ It is commonly and wrongfully assumed that persons with disabilities are not sexually active and therefore do not need sexual and reproductive health information and services.

Women with disabilities often have their reproductive rights denied, and some are subjected to forced marriages, forced abortions and forced sterilizations.³¹ Women with disabilities are particularly vulnerable to forced sterilizations that are performed under the auspices of legitimate medical care or the consent of others in their name.³² Sterilization is defined as "a process or act that renders an individual incapable of sexual reproduction." In his most recent report, the Special Rapporteur on torture, Juan Méndez, asserted that "forced abortions or sterilizations carried out by State officials in accordance with coercive family planning laws or policies may amount to torture."³³ Forced sterilization of girls and women with disabilities is driven by social factors, including minimizing inconvenience to caregivers, the lack of adequate measures to protect against the sexual abuse and exploitation of women and girls with disabilities, and a lack of adequate and appropriate services to support women with disabilities in their decision to become parents. The International Federation of Gynecology and Obstetrics (FIGO) issued updated guidelines in 2011, reaffirming the rule of no

²⁹ Ediciones CINCA, *Guide to gender mainstreaming in public disability policies* (Feb 2012): 246. http://www.oear.or.at/inter-national/europaeische-union/europaeisches-und-internationales-recht/GuidetoGenderMainstreaminginPublicDisabilityPolicies.pdf#page=233.

World Health Organization, Disability and health, Fact Sheet (Nov. 2012). http://www.who.int/mediacentre/factsheets/fs352/en/index.html; World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

Open Society Foundations, Sterilization of Women and Girls: A Briefing Paper (2011). http://www.opensocietyfoundations.org/sites/default/files/sterilization-women-disabilities-20111101.pdf; World Health Organization, Promoting sexual and reproductive health for persons with disabilities: WHO/UNFPA Guidance Note (2009). http://whqlibdoc.who.int/publications/2009/9789241598682_eng.pdf.

³² Center for Reproductive Rights, Reproductive Rights and Women with Disabilities (2002). http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupes_particuliers/Femmes_Genre/reproductive_rights.pdf.

Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

sterilization without informed consent of the women herself (that of a family member or guardian does not amount to consent,) and requiring both the provision of information in accessible formats and the time and support to make a decision.³⁴

Quality health care services and provision of specialized services

The CRPD establishes in Article 25 that States parties must "provide persons with disabilities with the same range, quality and standard of free or affordable health care programmes as provided to other persons." Research demonstrates that persons with disabilities receive poorer health care services and consequently experience poorer health outcomes. Persons with disabilities are also more vulnerable to deficiencies in healthcare services, which increase their risk of secondary conditions, co-morbid conditions and age-related conditions.

For example, women with disabilities receive less screenings for breast and cervical cancer than women without disabilities, and people with intellectual impairments and diabetes are less likely to have their weight checked.³⁵ The Disability Rights Commission in the UK conducted a formal investigation into inequalities in health and found "that people with mental illness and people with intellectual impairments not only experienced more ill-health, but received a poorer service from health professionals and as a consequence they had higher rates of morbidity and mortality."³⁶

People with disabilities have the same healthcare needs as everyone else, especially as they age, and require screening, preventive, and wellness-oriented care as provided to other persons. Health care providers must be taught that "having a disability is not incompatible with being healthy and it should not be assumed that the issue for which consultation in being sought is related to disability."³⁷

Measures for addressing barriers to service delivery include: targeting interventions to complement inclusive health care, including people with disabilities in general health care services, improving access to specialist health services, providing people-centered health services, coordinating services and using information and communication technologies.³⁸

Health professionals

The CRPD establishes in Article 25 that States parties must "[r]equire health professionals to provide care of the same quality to persons with disabilities as to others ... by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care." States must also address human resource barriers to quality healthcare for people with disabilities by integrating disability education into undergraduate training, providing health care workers with continuing education, and supporting health care workers with adequate resources.³⁹

³⁴ International Federation of Gynecology and Obstetrics, Female Contraceptive Sterilization (June 2011). http://www.wunrn.com/news/2011/06_27/062711_female.htm.

World Health Organization, Disability and health (June 2011). http://www.who.int/mediacentre/factsheets/fs352/en/index.html.

³⁶ Shakespeare T, Lezzoni LI, and Groce NE, "Disability and the training of health professionals," The Lancet 374, no. 9704 (Nov. 28, 2009).

³⁷ Id

³⁸ World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

³⁹ Id.

The CRPD prioritizes health care training and awareness as well as the creation of ethical standards in an effort to ensure that health professionals provide the same quality of care to persons with disabilities as to others. Health care education on disability should include a range of topics including clinical information, communication strategies and an introduction to a human rights approach to disability. Training beyond clinical information is important as explained in this article:

Doctors and other health professionals who encounter disabled people in their professional practice should be aware not only of the causes, consequences, and treatment of disabling health conditions, but also of the incorrect assumptions about disability that result from stigmatised views about people with disabilities that are common within society... it is important for professionals to understand not just disease, but also the experience of living with disability.⁴⁰

Health care professional training on the rights of persons with disabilities combats stigma and equips providers with the awareness necessary to provide persons with disabilities quality health care.

Social determinants of health and persons with disabilities

In General Comment 14, CESCR explains that the right to health is "an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health." In addition to access to services, the right to health encompasses social factors that affect health, including gender equality, health-related education and information, and adequate nutrition. Moreover, CESCR explains that the determinants of health must also be physically accessible, economically affordable, available in sufficient quantity and provided in a non-discriminatory manner.

The determinants of health, as described above, "are in turn shaped by a wider set of forces: economics, social policies, and politics." Michael Marmot explains that "material deprivation is not simply a technical matter of providing clean water or better medical care. Who gets these resources is socially determined." Persons with disabilities, as a marginalized population, are more vulnerable to the social and economic determinants of health and consequently experience poorer health outcomes. As Richard Wilkinson and Michael Marmot explain, "It's not simply that poor material circumstances are harmful to health; the social meaning of being poor, unemployed, socially excluded, or otherwise stigmatized also matters."

⁴⁰ Shakespeare T, Lezzoni LI, and Groce NE, "Disability and the training of health professionals," The Lancet 374, no. 9704 (Nov. 28, 2009).

⁴¹ UN Nations Committee on Economic, Social, and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

⁴² Tomlinson et al, "Research Priorities for health of people with disabilities: an expert opinion exercise," The Lancet 374 (Nov. 28, 2009).

⁴³ UN Nations Committee on Economic, Social, and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

⁴⁴ World Health Organization, "Social determinants of health: Key concepts." http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/index.html.

⁴⁵ Marmot M, "Social determinants of health inequities," *The Lancet* 365 (2005): 1099–104. http://www.who.int/social_determinants/strategy/Marmot-Social%20determinants%20of%20health%20inqualities.pdf.

⁴⁶ Wilkinson R and I Marmot M, Social determinants of health: the solid facts (WHO Europe, 2003). http://www.euro.who.int/_data/assets/pdf_file/0005/98438/e81384.pdf.

Persons with disabilities are "disproportionately poor, and have historically experienced diverse forms of social exclusion."⁴⁷ For example, the Special Rapporteur on Health wrote that "Services to ensure the underlying determinants of health, includ[e] adequate sanitation, safe water and adequate food and shelter. Persons with mental disabilities are disproportionately affected by poverty, which is usually characterized by deprivations of these entitlements."⁴⁸ Therefore, "Inclusive health-care models will be key tools for governments creating poverty-reduction programmes due to the link between disability and poverty."⁴⁹

The social and economic determinants of health for persons with disabilities are essential to consider. "Injustices occur when disability is overmedicalised. Seeing difficulties purely as individual problems can ignore structural issues that contribute to health status, such as poverty, environmental barriers, and social exclusion." A human rights-based approach that addresses the social and economic determinants of health, including discrimination, is required to address the persistent inequalities of persons with disabilities in health status and access to health care.

Right to Education

Education is a social determinant of health, and lack of education can limit the enjoyment of the right to health and other economic and social rights. Generally, lower levels of education are associated with poorer health outcomes including illness, malnutrition and higher rates of infant mortality. It is important to consider access to education and quality education as part of the broader picture of health.

The CRPD provides in Article 24 that persons with disabilities must not be excluded from the general education system. States parties must enact legislation and implement policies to develop inclusive education systems. The CRPD establishes that when free primary education is provided, people with disabilities may not be excluded on the basis of their disability. When developing inclusive education systems, governments must also account for additional funding requirements and allocate appropriate funds from the budget.

The CRPD establishes that State parties must provide persons with disabilities the support necessary to facilitate their effective education. However, many schools do not facilitate education for persons with disabilities, thereby creating barriers to academic and social development. Barriers to effective education are diverse and include curriculum and pedagogy issues, inadequate training and support of teachers, physical inaccessibility, and labelling, violence, bullying, abuse and attitudinal problems.⁵¹ The CRPD explains that States shall provide effective individualized support measures to maximize academic and social development. Societal attitudes of stakeholders, including teachers, school administers and other students are also an important factor in facilitating equal education for persons with disabilities.⁵²

⁴⁷ Shakespeare T, Lezzoni LI, and Groce NE, "Disability and the training of health professionals," The Lancet 374, no. 9704 (Nov. 28, 2009).

⁴⁸ United Nations Economic and Social Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, E/CN.4/2005/51 (Feb. 11, 2005).

⁴⁹ Stein MA, "Health care and the UN Disability Rights Convention," The Lancet, 374 (Nov. 28, 2009).

⁵⁰ Shakespeare T, Lezzoni LI, and Groce NE, "Disability and the training of health professionals," The Lancet 374, no. 9704 (Nov. 28, 2009).

⁵¹ World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf.

⁵² Id.

Right to Work and Employment

The right to work and employment is also a social determinant of health and must be considered in the broad picture of health. Persons with disabilities have low participation in the labor market and, when employed, are frequently employed in low-paying positions.⁵³ It is not surprising that as a result, persons with disabilities are disproportionately poor and socially marginalized. Work is a means to gain a living as well as participate in one's community. The CRPD provides in Article 27 that persons with disabilities have the right to work on an equal basis with other, including the "right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities."⁵⁴

Persons with disabilities face a range of barriers to employment opportunities, most significantly discrimination and stigma, lack of accommodation, lack of accessible transport, and denial of education and/or vocational training.⁵⁵ The CRPD guides States parties to focus on non-discrimination laws, accessibility, reasonable accommodation, and positive measures as means to implement the right to work for persons with disabilities.

Violations of the right to health

Freedom from Violence, Abuse and Exploitation⁵⁶

Persons with disabilities are vulnerable to violence, abuse and exploitation, especially when persons with disabilities are reliant upon others for support and care. Persons with disabilities are susceptible to violations within their home and by family members, caregivers, health care professionals and community members.⁵⁷ People with disabilities also experience higher rates of corporal punishment in schools.⁵⁸ Persons with disabilities are also vulnerable to sexual violence, sexual abuse and sexual exploitation, and are up to three times more likely than non-disabled people to face physical and sexual abuse and rape.⁵⁹

CRPD Article 16 on freedom from violence, abuse and exploitation provides detailed directives for countries on legislation, programs, monitoring systems and other measures to prevent and address violence against persons with disabilities. Under the CRPD, States parties must implement recovery and reintegration programs for persons with disabilities who were victims of violence, abuse or exploitation. Even though persons with disabilities are more vulnerable to violence, abuse and exploitation, they face barriers to accessing physical, cognitive and psychological rehabilitation services and legal interventions.

⁵³ United Nations Human Rights Council, Report of the Office of the United Nations High Commissioner for Human Rights: Thematic study on the work and employment of persons with disabilities, A/HRC/22/25 (Dec. 17, 2012). http://www.ohchr.org/EN/Issues/Disability/Pages/UNStudiesAndReports.aspx.

United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 27 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

United Nations Human Rights Council, Report of the Office of the United Nations High Commissioner for Human Rights: Thematic study on the work and employment of persons with disabilities, A/HRC/22/25 (Dec. 17, 2012). http://www.ohchr.org/EN/Issues/Disability/Pages/UNStudiesAndReports.aspx.

See also, O'Reilly A, The Right to decent work of persons with disabilities (International Labour Organization, Nov. 30, 2007). http://www.ilo.org/wcmsp5/groups/public/---dgreports/---dcomm/---publ/documents/publication/wcms_091349.pdf.

⁵⁶ United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 16 (2006). http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

⁵⁷ United Nations General Assembly, Note by the Secretary- General on Torture and other cruel, inhuman or degrading treatment or punishment, A/63/175 (July 28, 2008).

⁵⁸ Human Rights Watch, US: Students with Disabilities Face Corporal Punishment at Higher Rates: ACLU and Human Rights Watch Seek Ban on Physical Discipline at School (Aug. 10, 2009). http://www.hrw.org/news/2009/08/07/us-students-disabilities-face-corporal-punishment-higher-rates.

⁵⁹ United Nations Population Fund, Emerging Issues: Sexual and Reproductive Health of Persons with Disabilities. http://www.unfpa.org/upload/lib_pub_file/741_filename_UNFPA_DisFact_web_sp-1.pdf.

Freedom from Torture

In his most recent report, the Special Rapporteur on torture, Juan Méndez, writes that persons with disabilities are vulnerable to torture in the health care setting. The report affirms that involuntary and forced medical treatment in as well as involuntary commitment to health-care facilities and institutions are forms of torture and ill-treatment. He writes that "in the context of health care, choices by people with disabilities are often overridden based on their supposed "best interests", and serious violations and discrimination against persons with disabilities may be masked as "good intentions" of health professionals." The report explains that violations cannot be justified by claims of "medical necessity," and emphasizes the fundamental need for free, full, and informed consent by patients for any medical procedures. 61

The following examples have been recognized by the Special Rapporteurs on torture, Méndez and Nowak, as forms of torture in the health care setting. All of these practices are prohibited under the CRPD⁶² but may rise to the level of torture in the following circumstances:

- Forced and non-consensual medical interventions including:
 - o Forced administration of psychiatric medication without free and informed consent or against the individual's will, under coercion or as a form of punishment. Also, "[t]he administration of drugs, such as neuroleptics, which cause trembling, shivering, and contractions, and make the individual apathetic and dull his or her intelligence has been recognized as a form of torture." ⁶³
 - Medical experimentation or medical treatments without consent including abortion, sterilization, electroshock treatment and psychosurgery.
 - o The use of electroshock treatment (also a form of forced and non-consensual medical interventions). In writing about prisoners, the Special Rapporteur explained that "unmodified ECT may inflict severe pain and suffering and often leads to medical consequences, including bone, ligament and spinal fractures, cognitive deficits and possible loss of memory. It cannot be considered as an acceptable medical practice, and may constitute torture or ill-treatment." ⁶⁴

⁶⁰ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

⁶¹ Guterman L, Top UN Expert on Torture Demands an End to Abuse in Health Care (Open Society Foundations, March 2013). http://www.opensocietyfoundations.org/voices/states-must-end-abuses-health-care-demands-top-un-expert-torture.

⁶² Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

⁶³ United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175 (July 28, 2008).

⁶⁴ Id.

- o The use of restraints or seclusion for both long and short-term application (also a form of forced and non-consensual medical interventions). There have been reports of persons with disabilities tied, chained or handcuffed to their beds or chairs for prolonged periods.⁶⁵ Overmedication may also be considered a form of chemical restraint. The Special Rapporteur writes that "[i]t is important to note that "prolonged use of restraint can lead to muscle atrophy, life-threatening deformities and even organ failure, 'and exacerbates psychological damage.'" The Special Rapporteur notes that there can be no therapeutic justification for the prolonged use of restraints, which may amount to torture or ill-treatment."⁶⁶
- Deprivation of liberty through involuntary commitment to psychiatric hospitals or institutions. "Deprivation of liberty that is based on the grounds of a disability and that inflicts severe pain or suffering could fall under the scope of the Convention against Torture (A/63/175, para. 65). In making such an assessment, factors such as fear and anxiety produced by indefinite detention, the infliction of forced medication or electroshock, the use of restraints and seclusion, the segregation from family and community, etc., should be taken into account."⁶⁷

The Special Rapporteur against torture notes that all of the above practices are banned under the CRPD. States are urged to prohibit all forced and non-consensual medical treatment and to require the free and informed consent of patients prior to performing medical treatment.⁶⁸ As well, the Special Rapporteur against torture recommends that States abolish "[l]egislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent" citing to Article 14(1) (b) of the CRDP which provides that "the existence of a disability shall in no case justify a deprivation of liberty."⁶⁹ Instead, the Special Rapporteur recommends that States "[r]eplace forced treatment and commitment by services in the community" that "meet needs expressed by persons with disabilities and respect the autonomy, choices, dignity and privacy of the person concerned..."⁷⁰

⁶⁵ United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175 (July 28, 2008); Human Rights Watch, Like a Death Sentence: Abuses Against People with Mental Disabilities in Ghana (Oct. 2012). https://www.hrw.org/reports/2012/10/02/death-sentence-o; Tavanier YB, Institutions Remain Dumping Grounds for Forgotten People, Newsletter (European Coalition for Community Living, 2009). https://www.opensocietyfoundations.org/publications/institutions-remain-dumping-grounds-forgotten-people.

⁶⁶ United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175 (July 28, 2008).

⁶⁷ Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

⁶⁸ Id.

⁶⁹ Id.

⁷⁰ Id.

IB. HOW IS INSTITUTIONAL LIVING A HUMAN RIGHTS ISSUE AND WHAT IS COMMUNITY LIVING?

Introduction

This section focuses on CRPD Article 19 on the right of persons with disabilities to live independently and to be included in the community. CRPD Article 19 provides that persons with disabilities have the right to live in the community and to participate in society as equal citizens. This right is referred to as "the right to community living" within this chapter. The right to community living reinforces that persons with disabilities are not restricted in their choices and opportunities because of their own limitations, but rather are restricted as a result of social and physical environmental barriers to their full and equal participation within their communities. The focus of community living is to create an enabling social and physical environment so that all persons are able to be included and participate in their community.

This section will begin by discussing violations of Article 19 on community living, focusing on segregation in institutions as well as isolation in the community, including in group home and home living arrangements. Additional human rights violations that occur in institutions including heightened risk of exploitation, violence and abuse and will also be explored in the first section. The chapter will then examine the right to community living and how this right may be implemented. As states move away from institutionalized living, it is important to understand what alternatives are available that respect the right to community living.

The analysis in this section of the chapter is based solely upon CRPD Article 19.

How is institutional living a human rights issue?

Institutionalization violates the right to community living

Persons with disabilities are frequently segregated in institutions against their will where they are denied the opportunity to make decisions about their lives or participate in the community as equal citizens. Persons with disabilities are often deprived of their right to live independently and instead are placed in residential institutions—a process known as "institutionalization." The term 'institutionalization' is used to describe a person with a disability who has been confined to an institution, often against their will, and deprived of the ability to make decisions about their lives.

The most common conception of an institution is a large, long-term residence facility. However, rather than focus upon a set of defining characteristics of institutional residences, human rights advocates focus on the culture of institutions and their effect upon the individual as portrayed in the following description:

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and day to day decisions. An institution is not defined merely by its size.⁷¹

Parker C and Clements L, The European Union and the Right to Community Living: Structural Funds and the European Union's Obligations under the Convention on the Rights of Persons with Disabilities (Open Society Foundations, 2012). http://www.opensocietyfoundations.org/sites/default/files/europe-community-living-20120507.pdf; European Coalition for Community Living, Wasted Time, Wasted Money, Wasted Lives—A Wasted Opportunity?, Focus Report (2010): 78. http://community-living.info/documents/ECCL-StructuralFundsReport-final-WEB.pdf; Inclusion International, Inclusion International Campaign on Article 19 – Living in the Community. http://www.inclusion-international.org/home/inclusion-international-campaign-on-article-19/.

People with disabilities are frequently segregated in institutions against their will where they are denied the opportunity to make decisions about their lives or participate in the community as equal citizens.

A large number of children and adults with disabilities are institutionalized globally. The United Nations (UN) estimates that up to eight million children live in institutions.⁷² The UN figure is likely to be an underestimate, given that data collection and reporting in many countries is poor. For example, a European Commission-funded study of European Union member states and Turkey found that there are almost 1.2 million people with disabilities living in institutions in these countries alone.⁷³ The two largest groups who are institutionalized are people with mental health problems and people with intellectual disabilities.⁷⁴

Institutionalization of persons with disabilities persists, and new institutions for persons with disabilities continue to be built. The European Union seeks to promote the social inclusion of people with disabilities. However, even in countries that are members of the European Union little has been done to address the institutionalization of people with disabilities and new institutions for people with disabilities continue to be built in some EU member states.

CRPD Article 19 obligates States parties to recognize the right of persons with disabilities to live in the community with choices equal to others and to ensure that they have the opportunity to choose their place of residence, and where and with whom they live. While CRPD Article 19 does not make specific reference to closing institutions, its provisions indicate that this is required. For example, the requirement that States parties ensure that persons with disabilities have access to community services that support their social inclusion and "prevent isolation or segregation from the community" is incompatible with persons continuing to be placed in institutions.⁷⁵

Segregation in institutions isolates individuals from the community

Segregation in long-stay institutions, such as psychiatric facilities, social care homes and orphanages, is the most significant human rights violation experienced by many children and adults with disabilities. The segregation of persons with disabilities in long-stay institutions is in itself a human rights abuse because it deprives them of their right to community living and to live independently. Furthermore, institutionalization reinforces the stigma and prejudice directed towards persons with disabilities and perpetuates the misconceptions that they are incapable or unworthy of participating in community life.⁷⁶

In some countries, long-stay institutions are situated in remote rural areas. This means that residents rarely, if ever, receive visitors and have little or no communication with the outside world—in in many cases for the rest of their lives. For example, a 2004 study of residential institutions in France, Hungary, Poland, and Romania found that "[c]ontact with family, friends and community is limited."⁷⁷

⁷² United Nations General Assembly, Report of the independent expert for the United Nations study on violence against children, A/61/299 (Aug. 29, 2006): 16. http://www.unicef.org/violencestudy/reports/SG_violencestudy_en.pdf.

⁷³ Mansell J et al, Deinstitutionalisation and community living – outcomes and costs: report of a European Study, Volume 2: Main Report (Canterbury: Tizard Centre, University of Kent, 2007), (the DECLOC report). http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Volume_1_Exec_Summary_final.pdf.

⁷⁴ Id.

Parker C, A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities (Open Society Foundations, Dec 2011). http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-2011202.pdf; Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012). https://wcd.coe.int/ViewDoc.jsp?id=1917847.

⁷⁶ United States Supreme Court, Decision of Olmsted v. LC, 527 US 581 (1999).

⁷⁷ Freyhoff G et al, eds., Included in Society - Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People (European Commission, 2004). http://www.community-living.info/contentpics/226/Included_in_Society.pdf.

Segregation in institutions denies the right to make choices

Institutional living denies persons with disabilities the right to choose where they live, how they live, and with whom they associate. Institutional life is inherently a strictly controlled living and does not provide opportunities for individuals to make choices.⁷⁸

Segregation in institutions limits access to services within the community

Conditions within many institutions are poor and residents are not provided with adequate support or services, including health and rehabilitation services. For example, the 2004 study mentioned above found that "[r]esidents often live lives characterized by hours of inactivity, boredom and isolation" and that "[s] taff numbers are frequently too low to provide habilitation and therapy."⁷⁹

Segregation in institutions limits participation in the community

Institutionalized persons with disabilities face major challenges in exercising their fundamental rights to participate in the community. Particularly, institutionalized individuals are denied full and equal access to education and employment, two major methods of community participation. Institutionalized individuals are often denied educational opportunities, being either excluded from the education system or provided segregated or poor quality education. Likewise, persons with disabilities are often denied opportunities to work in the community. Some programs provide employment opportunities where persons with disabilities are grouped together and given menial tasks, disregarding the individual's choices and right to participate in the community.

Isolation within the community and isolation by improper service delivery violate the right to community living

Individuals living in a home or group home setting are also subject to violations of the right to live in the community. It is not the size of the residence that determines whether the right to live in community has been violated. Rather, the right to community is violated when an individual is denied the right to live independently, to exercise control over one's life, and to participate in one's community.

Violations of the right to community living occur when persons with disabilities living in a home or group home are isolated or segregated as a result of how services are delivered or by a lack of services available in the community. Violations occur:

... when people with disabilities who need some form of support in their everyday lives are required to relinquish living in the community in order to receive that support; when support is provided in a way that takes away people's control from their own lives; when support is altogether withheld, thus confining a person to the margins of the family or society; or when the burden is placed on people with disabilities to fit into public services and structures rather than these services and structures being designed to accommodate the diversity of the human condition.⁸⁰

⁷⁸ Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012). https://wcd.coe.int/ViewDoc.jsp?id=1917847.

⁷⁹ Freyhoff G et al, eds., Included in Society - Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People (European Commission, 2004). http://www.community-living.info/contentpics/226/Included_in_Society.pdf.

⁸⁰ Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012): 4. https://wcd.coe.int/ViewDoc.jsp?id=1917847.

This means that a person is denied their right to live in the community if he/she is prohibited from leaving the house, or faces barriers to accessing education or health services, or pursuing employment. Not only do structural barriers such as inaccessible places, technologies, or services cause isolation and segregation, but stigma and a lack of support within the community can also results in isolation of persons with disabilities from their communities. These social, physical, and economic barriers or hindrances prevent full participation in the community, and constitute violations of CRPD Article 19.

Persons with disabilities living in institutions experience additional violations of their human rights, beyond the right to community living.

Persons with disabilities living in institutions are at higher risk of torture and other cruel, inhuman or degrading treatment or punishment, in violation of CRPD Article 15. Reports have shown that residents of institutions are subjected to serious and sustained human rights violations, ranging from inadequate food, heating and clothing to barbaric treatment such as the unmodified (without anaesthesia or muscle relaxants) use of electro-convulsive therapy, the use of cage beds, sexual abuse, forced sterilisation and other forms of "treatment" without their consent.⁸²

The United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment of punishment (Special Rapporteur on Torture) explains the vulnerability of persons with disabilities in institutions to torture:

Torture, 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 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. However, it is often circumstances external to the individual that render them "powerless", such as when one's exercise of decision-making and legal capacity is taken away by discriminatory laws or practices and given to others.⁸³

Torture against persons with disabilities has been widely reported and documented within institutions. Persons with disabilities, when committed to a residential institution for long-term stay, are dependent upon the institution for their care, support and social needs. Persons with disabilities have been subjected to neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence inside institutions.⁸⁴ A lack of reasonable accommodation in detention facilities can increase the risk of neglect, violence, abuse, torture and ill-treatment.⁸⁵

Torture in institutions must be addressed by prohibiting and terminating all institutionalized living. The Special Rapporteur on Torture, Juan Méndez, writes in his 2013 interim report that "The Committee on the Rights of Persons with Disabilities has been very explicit in calling for the prohibition of disability-based

⁸¹ Id

⁸² Amnesty International, Bulgaria: Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities (Oct. 2002). http://www.amnesty.org/en/library/info/EUR15/005/2002; Amnesty International and Mental Disability Advocacy Center, Cage Beds: Inhuman and Degrading Treatment in Four Accession Countries (2003). http://www.mdac.info/en/resources/cage-beds-inhuman-and-degrading-treatment-or-punishment-four-eu-accession-countries

⁸³ United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175 (July 28, 2008).

⁸⁴ United Nations General Assembly, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, A/63/175 (July 28, 2008).

⁸⁵ Id.

detention, i.e. civil commitment and compulsory institutionalization or confinement based on disability. It establishes that community living, with support, is no longer a favourable policy development but an internationally recognized right."86

What is the human rights-based approached of community living?

Right to community living

CRPD Article 19 establishes that people with disabilities have a right to live in the community and to participate in society as equal citizens. By ratifying the CRPD, States parties make a commitment to ensuring that persons with disabilities can live and participate fully in their communities. The right to community living requires the closing of institutions and prohibiting institutionalized living.⁸⁷ Therefore, governments must provide the support and structures that enable persons with disabilities to live and participate in the community. "This will encompass a range of services and supports such as housing, including supported housing, care in the family home, social work support, and supported employment, as well as access to mainstream services such as health care."

CRPD Article 19: Living independently and being included in the community

States parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-house, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Community living is closely linked with other human rights including the right to liberty, non-discrimination, bodily integrity, privacy, and freedom from torture, violence, exploitation, and abuse. However, community living is more than the realization of these rights. "The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one's life, wrought on people with disabilities because of their need for support against the background of an inaccessible society." 89

Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf.

⁸⁷ Parker C, A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities (Open Society Foundations, Dec 2011). http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf; Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012): 9. https://wcd.coe.int/ViewDoc.jsp?id=1917847.

⁸⁸ Parker C, A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities (Open Society Foundations, Dec 2011). http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf.

⁸⁹ Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012): 8. https://wcd.coe.int/ViewDoc.jsp?id=1917847.

Article 19 establishes that States parties can ensure full inclusion and participation in the community by (a) providing persons with disabilities to opportunity to choose where and with whom they live; (b) providing a range of support services; and (c) ensuring that all public services are provided to persons with disabilities on an equal basis. These three components of community living are each important to realizing community living:

- 1. Choice. Ensuring that persons with disabilities have the opportunity to choose where and with whom they live implicates the right to equal recognition before the law (Art 12 on legal capacity). Article 12 of the CRPD affirms the right of everyone to make their own decisions. Article 12(2) states that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an on equal basis with others in all aspects of life." Therefore, current state laws on involuntary commitment and guardianship should be revisited in light of the rights articulated in Article 12 and Article 19.
- 2. Individualized support services. In order to ensure that persons with disabilities are enabled to live in the community, they must have access to a full range of services including housing and community support services, which includes personal assistance. Community support services could include a broad range of services including access to social workers, supported employment and access to health care. The CRPD establishes that access to all services necessary to "to prevent isolation or segregation from the community" is an essential component of the right to community living.
 - Many countries do not have the resources necessary to provide extensive services. However the CRPD provides in Article 4(2) that States parties are obligated to "take measures to the maximum of its available resources ... with a view to achieving progressively the full realization of these rights." Therefore, States parties must continuously strive to implement the right to live in the community by taking steps over time and to the maximum of their resources. This extends to the State's obligation to provide the resources and support services necessary to realize the right to community living for persons with disabilities.
- 3. Inclusive community services. Article 19 establishes that community services and facilities for the general population must be available on an equal basis to persons with disabilities and are responsive to their needs. This means that all public services and facilities must accessible to persons with disabilities, and reasonable accommodations should be made.

Implementing the right to community living

Governments must make a commitment to community living in order to ensure the right of persons with disabilities to living in the community. The former Council of Europe's Commissioner for Human Rights, Thomas Hammarberg recommends to "...set deinstitutionalisation as a goal and develop a transition plan for phasing out institutional options and replacing them with community-based services, with measurable targets, clear timetables and strategies to monitor progress." ⁹⁰

When implementing community living policies and programs, governments should be guided in all decisions by the CRPD, especially the CRPD general principles. There is "less clarity with regard to the mechanisms that replace institutionalisation and would constitute a human rights-based response." Effective deinstitutionalisation requires an understanding that the right to community living is more than just access to the physical placement in the community; rather, living in the community is linked to issues of autonomy and choice. 92

⁹⁰ Hammarberg T, The Right of People with Disabilities to Live Independently and be Included in the Community, CommDH/Issue Paper, (Council of Europe, 2012). https://wcd.coe.int/ViewDoc.jsp?id=1917847.

⁹¹ Id.

⁹² Id.

There are also budgetary considerations that must be accounted for in implementing the right to community living. "For living independently and being included in the community to become a reality, social policy reform is needed, which has budgetary implications, involves multiple stakeholders, and necessitates coordination across government ministries and local authorities." ⁹³

To provide guidance on key areas of work that governments will need to take to comply with CRPD Article 19, the Open Society Public Health Program has developed a checklist. 94 The ten action points from this list are:

A Community for All: A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities

- 1. Commit to transforming the system from institutional services to community- based services
- 2. Provide explicit recognition of the right to community living for all (the right of all persons with disabilities to live in the community, 'with choices equal to others')
- 3. Develop a national strategy for transforming the system from institutional placements to community-based services
- 4. Establish mechanisms to enable the participation of civil society, in particular, people with disabilities and their families
- 5. Develop links with experts (international and national)
- 6. Review legislation, policies and practices relevant to the implementation of Article 19
- 7. Review existing services for people with disabilities
- 8. Ensure transparency and accountability in the use of public funds
- 9. Establish mechanisms for data collection
- 10. Establish mechanisms for periodic review of the action plan and national strategy

Organizations are beginning to develop resources and tools to provide guidance on the process of deinstitutionalization and the transition to community living, and many of these are listed in the resources section of this chapter. For example, the European Expert Group on the Transition from Institutional to Community-based Care has published a resource that provides detailed guidance on transitioning from institutionalization to community living called "Common European Guidelines on the Transition from Institutional to Community Based Care" sa well as a toolkit on the use of European Union Funds.

⁹³ Id.

⁹⁴ Parker C, A Community for All: Implementing Article 19 – A Guide for Monitoring the Implementation of Article 19 of the Convention on the Rights of Disabilities (Open Society Foundations, Dec 2011). http://www.opensocietyfoundations.org/sites/default/files/community-for-all-guide-20111202.pdf.

European Expert Group on the Transition from Institutional to Community-based Care, Common European Guidelines on the Transition from Institutional to Community Based Care: Guidance on implementing and supporting a sustained transition from institutional care to family-based and community-based alternatives for children, persons with disabilities, persons with mental health problems and older persons in Europe (Nov. 2012). http://deinstitutionalisationguide.eu/wp-content/uploads/2012/12/2012-12-07-Guidelines-11-123-2012-FINAL-WEB-VERSION.pdf. See also, European Expert Group on the Transition from Institutional to Community-based Care, Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care (Nov. 2012). https://deinstitutionalisationguide.eu/.

2. WHICH ARE THE MOST RELEVANT INTERNATIONAL AND REGIONAL HUMAN RIGHTS STANDARDS RELATED TO DISABILITY, HEALTH AND COMMUNITY LIVING?

How to read the tables

Tables A and B provide an overview of relevant international and regional human rights instruments. They provide a quick reference to the rights instruments and refer you to the relevant articles of each listed human right or fundamental freedom that will be addressed in this chapter.

From Table 1 on, each table is dedicated to examining a human right or fundamental freedom in detail as it applies to persons with disabilities. The tables are organized as follows:

Human right or fundamental freedom				
Examples of Human Rights Violations				
Human rights standards	UN treaty body interpretation			
	This section provides general comments issued by UN treaty bodies as well as recommendations issued to States parties to the human right treaty. These provide guidance on how the treaty bodies expect countries to implement the human rights standards listed on the left.			
Human rights standards	Case law This section lists case law from regional human rights courts only. There may be examples of case law at the country level, but these have not been included. Case law creates legal precedent that is binding upon the states under that court's jurisdiction. Therefore it is important to know how the courts have interpreted the human rights standards as applied to a specific issue area.			

Other interpretations: This section references other relevant interpretations of the issue.

It includes interpretations by:

- UN Special Rapporteurs
- UN working groups
- · International and regional organizations
- International and regional declarations

The tables provide examples of human rights violations as well as legal standards and precedents that can be used to redress those violations. These tools can assist in framing common health or legal issues as human rights issues, and in approaching them with new intervention strategies. In determining whether any human rights standards or interpretations can be applied to your current work, consider what violations occur in your country and whether any policies or current practices in your country contradict human rights standards or interpretations.

Human rights law is an evolving field, and existing legal standards and precedents do not directly address many human rights violations. Through ongoing documentation and advocacy, advocates can build a stronger body of jurisprudence on disability and human rights.

Abbreviations

In the tables, we use the following abbreviations to refer to the thirteen treaties and their corresponding enforcement mechanisms:

Treaty	Enforcement Mechanism
Universal Declaration of Human Rights (UDHR)	None
Convention on the Rights of Persons with Disabilities (CRPD)	Committee on the Rights of Persons with Disabilities (CRPD)
International Covenant on Civil and Political Rights (ICCPR)	Human Rights Committee (HRC)
International Covenant on Economic, Social, and Cultural Rights (ICESCR)	Committee on Economic, Social and Cultural Rights (CESCR)
Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)	Committee on the Elimination of Discrimination Against Women (CEDAW Committee)
International Convention on the Elimination of All Forms of Racial Discrimination (ICERD)	Committee on the Elimination of Racial Discrimination (CERD)
Convention on the Rights of the Child (CRC)	Committee on the Rights of the Child (CRC Committee)
Convention against Torture and Other Cruel, Inhuman or Degrading Treatment (CAT)	Committee against Torture (CAT)
African Charter on Human and Peoples' Rights and Protocols (ACHPR)	African Commission on Human and Peoples' Rights (ACHPR Commission)
[European] Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR)	European Court of Human Rights (ECtHR)
1996 Revised European Social Charter (ESC)	European Committee of Social Rights (ECSR)
American Convention on Human Rights (ACHR)	Inter-American Court of Human Rights (IACHR)
American Declaration of the Rights and Duties of Man (ADRDM)	Inter-American Court of Human Rights (IACHR)

Also cited are the former Commission on Human Rights (CHR) and various UN Special Rapporteurs (SR) and Working Groups (WG).

Table A: International Human Rights Instruments and Protected Rights and Fundamental Freedoms

	UDHR	CRPD	ICCPR	ICESCR	CEDAW	ICERD	CRC
Non-discrimination and Equality	Art. 1, Art. 2	Art. 5	Art. 2(1), Art. 3	Art. 2(2), Art. 3	Art. 2, All	Art. 2, Art. 5, All	Art. 2
Independent Living		Art. 19					Art. 23(1,2)
Supported Decision Making		Art. 12					
Equality before the Law	Art. 6	Art. 5(1), Art. 12	Art. 16, Art. 26			Art. 5	
Health	Art. 25	Art. 25		Art. 12	Art. 12	Art. 5(e) (iv)	Art. 23 (3, 4), Art. 24
Informed Consent		Art. 25(d)					
Sexual and Reproductive Health		Art. 25(a)			Art. 12(1), Art. 14(2) (b)		Art. 24(2) (f)
Education	Art. 26	Art. 24		Art. 13	Art. 10	Art. 5(e) (v)	Art. 23 (3, 4), Art. 28, Art. 29
Employment	Art. 23	Art. 27		Art. 6, Art. 7	Art. 11	Art. 5(e) (i)	
Life	Art. 3	Art. 10	Art. 6(1)				Art. 6(1)
Liberty and Security of Person	Art. 3	Art. 14	Art. 9(1)				Art. 37(b)
Exploitation, Violence and Abuse		Art. 16					Art. 19, Art. 32(1), Art. 34, Art. 36
Torture or Cruel, In- human or Degrading Treatment*	Art. 5	Art. 15	Art. 7				Art. 37(a)

^{*}See also Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Article 2.

Table B: Regional Human Rights Instruments and Protected Rights and Fundamental Freedoms

	Africa: ACHPR	Europe: ECHR	Europe: ESC	Americas: ADRDM	Americas: ACHR
Non-Discrimination and Equality	Art. 2, Art. 19	Art. 14	Art. E	Art. II	Art. 1(1)
Independent Living			Art. 15		
Supported Decision Making					
Equality before the Law	Art. 3			Art. II, Art. XVII	Art. 3
Health	Art. 16		Art. 11, Art. 13	Art. XI	
Informed Consent					
Sexual and Reproductive Health					
Education	Art. 17			Art. XII	
Employment	Art. 15		Art. 1	Art. XIV	
Life	Art. 4	Art. 2		Art. I	Art. 4
Liberty and Security of Person	Art. 6	Art. 5(1)		Art. I	Art. 7(1)
Exploitation, Violence and Abuse	Art. 5				
Torture or Cruel, In- human or Degrading Treatment	Art. 5	Art. 3			Art. 5(2)

Table 1: Disability and non-discrimination

Examples of Human Rights Violations

- Persons with disabilities are disproportionately underrepresented in the labor market.
- Persons with disabilities are not provided an accommodation to ensure access to health care services or places of work.
- Children with disabilities are discriminated against in the classroom because teachers misunderstand the disability or consider the child 'handicapped'.

Human Rights Standards

CRPD 5 (1) States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

- (2) States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- (3) In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
- (4) Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Treaty Body Interpretation

CRPD: recommending that Argentina "incorporate the concept of reasonable accommodation into its anti-discrimination legislation and to ensure that the relevant laws and regulations define the denial of reasonable accommodation as a form of discrimination on grounds of disability. The Committee recommends that the State party take steps to simplify existing judicial and administrative remedies in order to enable persons with disabilities to report acts of discrimination to which they have been subjected. The Committee also recommends that the State party devote special attention to the development of policies and programmes for persons with disabilities who belong to indigenous peoples and for deaf-blind persons with a view to putting an end to the many forms of discrimination to which these persons may be subjected." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: reiterating to Spain that the denial of reasonable accommodation constitutes discrimination and that the duty to provide reasonable accommodation is immediately applicable and not subject to progressive realization. CRPD/C/ESP/CO/1 (2011).

CRPD: "[t]he Committee urges Spain to expand the protection of discrimination on the grounds of disability to explicitly cover multiple disability, perceived disability and association with a person with a disability, and to ensure the protection from denial of reasonable accommodation, as a form of discrimination, regardless of the level of disability. Moreover, guidance, awareness-raising and training should be given to ensure a better comprehension by all stakeholders, including persons with disabilities, of the concept of reasonable accommodation and prevention of discrimination. CRPD/C/ESP/CO/1 (2011).

CRPD: calling upon Hungary to adopt effective and specific measures to ensure equality and prevent multiple forms of discrimination of women and girls with disabilities in its policies, and to mainstream a gender perspective in its disability-related legislation and policies. CRP-D/C/HUN/CO/1 (2012).

CRPD: calling upon Hungary, Spain, Tunisia and China to take steps to ensure that its legislation explicitly prescribes that failure to provide reasonable accommodation constitutes a prohibited act of discrimination. CRPD/C/HUN/CO/1 (2012), CRPD/C/ESP/CO/1 (2011), CRPD/C/TUN/CO/1(2011), CRPD/C/CHN/CO/1 (2012).

CRPD: urging China to take measures to fight the widespread stigma in relation to boys and girls with disabilities and revise their strict family planning policy so as to combat the root causes for the abandonment of boys and girls with disabilities. CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that Peru place emphasis on the development of policies and programmes on indigenous and minority persons with disabilities—in particular women and children with disabilities that live in rural areas, as well as persons of African descent—in order to address the multiple forms of discrimination that these persons may suffer. CRP-D/C/PER/CO/1 (2012).

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Table I (cont.)

Human Rights Standards	Treaty Body Interpretation
	CRPD: urging that Peru accelerate its efforts to eradicate and prevent discrimination against women and girls with disabilities by incorporating gender and disability perspectives in all programmes, as well as by ensuring their full and equal participation in decision-making. The Committee also urged Peru to amend its legislative framework to provide special protection to women and girls with disabilities, as well as to adopt effective measures to prevent and redress violence against women and girls with disabilities. CRPD/C/PER/CO/1 (2012).
	CRPD: recommending that Tunisia act with urgency to include an explicit prohibition of disability-based discrimination in an anti-discrimination law, as well as ensure that disability-wbased discrimination is prohibited in all laws, particularly those governing elections, labor, education, and health, among others. CRPD/C/TUN/CO/1(2011).
CRC 3 (1) States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community	CRC Committee : recommending that Azerbaijan "undertake awareness-raising campaigns on eliminating discrimination against children with disabilities, and consider enacting legislation explicitly prohibiting such discrimination." CRC/C/AZE/CO/3-4 (CRC, 2012).
	CRC Committee: recommending that Australia and Azerbaijan "establish a clear legislative definition of disability, including for learning, cognitive and mental disabilities, with the aim of accurately identifying children with disabilities to effectively address their needs in a non-discriminatory manner." CRC/C/AUS/CO/4 (CRC, 2012); CRC/C/AZE/CO/3-4 (CRC, 2012).
	CRC Committee : recommending that Andorra "Increase budget allocations to provide children with disabilities with equal access to adequate social and health services, including psychological support, counselling services, parental guidance for families of children with disabilities, and tailored services for children with learning difficulties and behavioural disorders, and raise awareness about all services available." CRC/C/AND/CO/2 (CRC, 2012).
	CRC Committee : recommending that Namibia "Ensure that all legislation on children, including the proposed Child Care and Protection Bill, include a specific prohibition of discrimination on the ground of disability, and develop holistic and coordinated programmes across ministries on the rights of children with disabilities." CRC/C/NAM/CO/2-3 (CRC, 2012).

Table 2: Disability and the right to live independently and be included in the community (community living)

Examples of Human Rights Violations

- Persons with disabilities who are institutionalized.
- Dedication of resources to the reconstruction of large residential institutions.
- Lack of resources and services to help persons with disabilities live within their communities.
- A child is placed in an institution because she is diagnosed with Down Syndrome and her parents are told that there is no support available to help them raise her at home.
- A young man with intellectual disabilities is admitted to a social care home far from his home because his mother has become ill and can no longer look after him without some help.

Human Rights Standards

CRPD 19 States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- **(c)** Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Treaty Body Interpretation

CRPD: recommending that **Spain** ensure an adequate level of funding is made available to effectively enable persons with disabilities to: enjoy the freedom to choose their residence on an equal basis with others; access a full range of inhome, residential and other community services for daily life, including personal assistance; and enjoy reasonable accommodation so as to better integrate into their communities. CRPD/C/ESP/CO/1 (2011).

CRPD: encouraging **Spain** to expand resources for personal assistants to all persons with disabilities in accordance with their requirements. CRPD/C/ESP/CO/1 (2011).

CRPD: recommending that **Argentina** "implement the deinstitutionalization strategies that it has adopted in an effective manner and to develop and implement mental health plans based on the human rights model of disability, along with effective measures to promote the deinstitutionalization of persons with disabilities." CRPD/C/ARG/CO/1 (CRPD, 2012)

CRPD: calling upon **Hungary** "to ensure that an adequate level of funding is made available to effectively enable persons with disabilities to: enjoy the freedom to choose their residence on an equal basis with others; access a full range of in-home, residential and other community services for daily life, including personal assistance; and enjoy reasonable accommodation with a view to supporting their inclusion in their local communities." CRPD/C/HUN/CO/1 (2012).

CRPD: calling upon **Hungary** to take appropriate measures to enable men and women with disabilities who are of marriageable age to marry and found a family, as well as to provide adequate support services to men and women, boys and girls with disabilities to enable them to live with their families, with a view to prevent and reduce the risk of placement in an institution. CRPD/C/HUN/CO/1 (2012).

CRPD: calling upon **Hungary** to undertake greater efforts to make available the necessary professional and financial resources, especially at the local level, to promote and expand community-based rehabilitation and other services in their respective local communities to children with disabilities and their families, in order to enable children with disabilities to live with their families, as recommended by the Committee on the Rights of the Child (CRC/C/HUN/CO/2). CRPD/C/HUN/CO/1 (2012).

Table 2 (cont.)

Human Rights Standards	Treaty Body Interpretation
	CRPD: recommending that China take immediate steps to phase out and eliminate institutional-based care for people with disabilities. Further, the Committee recommends China to consult with organisations of persons with disabilities on developing support services for persons with disabilities to live independently in accordance with their own choice. Support services should also be provided to persons with a high level of support needs. CRPD/C/CHN/CO/1 (2012).
	CRPD: recommending that China develop a wide range of community-based services and supports that respond to needs expressed by persons with disabilities, and respect the person's autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health. CRPD/C/CHN/CO/1 (2012).
	CRPD: urging Peru to initiate comprehensive programmes to enable persons with disabilities to access a whole range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community, especially in rural areas. CRPD/C/PER/CO/1 (2012).
CRC 23 (1) States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.	CRC General Comment No. 7: explaining that "[e]arly childhood is the period during which disabilities are usually identified and the impact on children's wellbeing and development recognized. Young children should never be institutionalized solely on the grounds of disability. It is a priority to ensure that they have equal opportunities to participate fully in education and community life, including by the removal of barriers that impede the realization of their rights. Young disabled children are entitled to appropriate specialist assistance, including support for their parents (or other caregivers). Disabled children should at all times be treated with dignity and in ways that encourage their self-reliance." CRC/C/GC/7/Rev.1 (2006), para. 36(d).
	CRC Committee : recommending that Australia "Take measures to de-institutionalize children with disabilities and further strengthen support to families to enable them to live with their parents." CRC/C/AUT/CO/3-4 (CRC, 2012).
	CRC Committee: recommending that Egypt "[s]trengthen the availability and accessibility of community-based educational and health services for children with disabilities, in particular by strengthening inclusive education which promotes the child's self-reliance and active participation in the community in line with article 23, paragraph 1 of the Convention." CRC/C/EGY/CO/3-4 (CRC, 2011).
	CRC Committee : recommending that the Czech Republic implement of measures to provide alternatives to the institutionalization of disabled and for the strengthening of community-based programmes to enable them to stay at home with their families in. CRC/C/15/ADD.201 (CRC, 2003), para. 49.
	CRC Committee : recommending that Hungary implement community-based rehabilitation programmes, including parent support groups, to avoid the marginalization and exclusion of disabled children and children with disabled parents. CRC/C/HUN/CO/2 (CRC, 2006), para. 40.

Table 2 (cont.)

Other Interpretations

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993: "Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services."

Council of Europe Commissioner for Human Rights: "The right to live in the community applies to all people with disabilities. No matter how intensive the support needs, everyone, without exception, has the right and deserves to be included and provided with opportunities to participate in community life. Time and again it has been demonstrated that people who were deemed too 'disabled' to benefit from community inclusion thrive in an environment where they are valued, where they partake in the everyday life of their surrounding community, where their autonomy is nurtured and they are given choices." (CommDH/IssuePaper(2012)3).

Council of Europe, Recommendation (2006) 5 of the Committee of Ministers to member states on the Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015: "People with disabilities should be able to live as indepenzzdently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community. Enhancing community living . . . requires strategic policies which support the move from institutional care to community-based settings"

The Parliamentary Assembly of the Council of Europe, Report of the Social, Health and Family Affairs Committee: "The practice of placing children and adults with disabilities into institutions undermines their inclusion as they are kept segregated from the rest of society and suffer serious damage to their healthy development and obstruction of the exercise of other rights. Deinstitutionalisation is a prerequisite to enabling people with disabilities to become as independent as possible and take their place as full citizens with the opportunity to access education and employment, and a whole range of other services." Doc 11694 (August 8, 2008).

Table 3: Disability and the right to supported decision-making

Examples of Human Rights Violations

- An individual is denied the right to make decisions about their life because the court has declared them legally incapacitated and appointed a guardian.
- An individual is denied the opportunity to decide where he/she lives and with whom.
- An individual is denied the right to vote because the court has declared them legally incapacitated.

Human Rights Standards

CRPD 12 (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

- (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- (4) States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Treaty Body Interpretation

CRPD: recommending that Argentina "launch an immediate review of all current legislation that is based on a substitute decision-making model that deprives persons with disabilities of their legal capacity. At the same time, the Committee urges the State party to take steps to adopt laws and policies that replace the substitute decision-making system with a supported decision-making model that upholds the autonomy, wishes and preferences of the persons concerned. In addition, the Committee recommends that training workshops on the human rights model of disability be organized for judges to encourage them to adopt the supported decision-making system instead of granting guardianships or trusteeships." CRPD/C/ARG/CO/1 (CRPD, 2012)

CRPD: recommending that **Spain** and **Tunisia** review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders. CRPD/C/ESP/CO/1 (2011), CRPD/C/TUN/CO/1 (2011).

CRPD: recommending that Hungary use effectively the current review process of its Civil Code and related laws to take immediate steps to derogate guardianship in order to move from substitute decision-making to supported decision-making, which respects the person's autonomy, will and preferences and is in full conformity with article 12 of the Convention, including with respect to the individual's right, on their own, to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work, and to choose their place of residence. CRPD/C/HUN/CO/1 (2012).

CRPD: urging **China** to "adopt measures to repeal the laws, policies and practices which permit guardianship and trusteeship for adults and take legislative action to replace regimes of substituted decision-making by supported decision making, which respects the person's autonomy, will and preferences, in the exercise of one's legal capacity in accordance with Article 12 of the CRPD. In addition, the Committee recommended that China, in consultation with DPOs, prepare a blueprint for a system of supported decision-making, and legislate and implement it which includes:

- Recognition of all persons' legal capacity and right to exercise it.
- Accommodations and access to support where necessary to exercise legal capacity.
- Regulations to ensure that support respects the person's autonomy, will and preferences
 and establishment of feedback mechanisms to ensure that support is meeting the person's needs.
- Arrangements for the promotion and establishment of supported decision-making." CRPD/C/CHN/CO/1 (2012).

CRPD: urging **Peru** to abolish the practice of judicial interdiction and review the laws allowing for guardianship and trusteeship to ensure their full conformity with article 12 of the Convention and to take action to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will, and preferences. CRPD/C/PER/CO/1 (2012).

Table 4: Disability and equality before the law

Examples of Human Rights Violations

- Persons with disabilities are not given identity cards.
- Persons with disabilities who are declared incompetent by a court are consequently also denied civil rights such as the right to vote.
- No legal remedies and safeguards against guardianship, such as independent review and right to appeal.
- Persons with disabilities are denied the ability to exercise the right to marry.

Human Rights Standards

CRPD 12 (1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

- (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. ...

Treaty Body Interpretation

CRPD: noting that in **Peru** it is reported "that a number of persons with disabilities, especially those living in rural areas and in long-term institutional settings, do not have identity cards and, sometimes, have no name" and urging **Peru** to promptly initiate programmes in order to provide identity documents to persons with disabilities, including in rural areas and in long-term institutional settings, and to collect complete and accurate data on people with disabilities in institutions who are currently undocumented and/or do not enjoy their right to a name. CRPD/C/PER/CO/1 (2012).

CRPD: urging **Peru** to amend the Civil Code in order to adequately guarantee the exercise of civil rights, particularly with regards to the right to marry to all persons with disabilities. CRPD/C/PER/CO/1 (2012).

CRPD: recommending that **China** revise their laws to ensure that all persons with disabilities have the right to vote. CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **Peru**:

- (a) "Restore voting rights to all people with disabilities who are excluded from the national voter registry, including people with disabilities subject to judicial interdiction.
- (b) Reach out to vulnerable individuals and protect people with disabilities from such violations in the future, including through relevant training.
- (c) Guarantee the right to vote of people with disabilities in institutions, by ensuring that they are physically permitted to go to assigned polling stations and have the support required to do so, or to permit alternative options." CRPD/C/PER/CO/1 (2012).

Table 5: Disability and the right to the highest attainable standard of health

Examples of Human Rights Violations

- A person with a disability is denied care at a local health center because the physician does not know how to care for them.
- A person with limited mobility cannot access a health care facility.
- Rural citizens with disabilities cannot access health facilities because they are too far.
- A person with a disability does not have the ability to pay for needed health care services.
- Specialized health services for children with disabilities are not readily available leading to late diagnosis and/or improper treatment.
- Lack of early detection programmes of disabilities for children.
- · There are no rehabilitation services offered to individuals with disabilities in a certain city.
- A woman with a schizophrenia diagnosis is told by nursing staff that her abdominal pain is 'all in your head'. She is later diagnosed with ovarian cancer.
- Women with disabilities are denied reproductive health services.

While States parties have an obligation to move as expeditiously as possible towards the full realization of the right to health, States are immediately obligated to ensure non-discrimination in access to health care. Therefore, discrimination on the basis of disability is prohibited regardless of a State's resources.

Human Rights Standards

CRPD 25 States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall: . . .

(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

Treaty Body Interpretation

CRPD: recommending that **China** adopt measures to ensure that all health care and services provided to persons with disabilities, including all mental health care and services, be based on the free and informed consent of the individual concerned, and that laws permitting involuntary treatment and confinement, including upon the authorisation of third party decision-makers such as family members or guardians, be repealed and that **China** develop a wide range of community-based services and supports that respond to needs expressed by persons with disabilities, and respect the person's autonomy, choices, dignity and privacy, including peer support and other alternatives to the medical model of mental health. CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **China** "allocate more human and financial resources to the public medical services and arrange the cooperation of the insurance companies." CRP-D/C/CHN/CO/1 (2012).

CRPD: urging **Peru** to "elaborate comprehensive health programmes in order to ensure that persons with disabilities are specifically targeted and have access to rehabilitation and health services in general" and to:

- "Review its legal framework in order to ensure that insurance companies and other private parties do not discriminate against persons with disabilities;
- Apply budgetary resources and create skills among health personnel, in order to
 effectively comply with the right to health care of persons with disabilities, ensuring that hospitals and health centres are accessible to persons with disabilities;

Provide services of early identification of disabilities, in particular deafness, designed to minimize and prevent further disabilities, including among children." CRPD/C/PER/CO/1 (2012).

Table 5 (cont.)

Table 5 (cont.)		
Human Rights Standards	Treaty Body Interpretation	
ICESCR 12(1) The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.	CESCR, General Comment 14 , para 19: "States have a special obligation to provide those who do not have sufficient means with the necessary health insurance and health-care facilities, and to prevent any discrimination on internationally prohibited grounds."	
	CESCR, General Comment No. 5, para. 34: "States should 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. The right to physical and mental health also implies the right to have access to, and to benefit from, those medical and social services—including orthopaedic devices—which enable persons with disabilities to become independent, prevent further disabilities and support their social integration. Similarly, such persons should be provided with rehabilitation services which would enable them to reach and sustain their optimum level of independence and functioning.' 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."	
CRC 3(3) States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision. CRC 24(1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.	CRC Committee : recommending that Egypt strengthen the availability and accessibility of community-based educational and health services for children with disabilities; ensure that all children with disabilities regardless of their status, enjoy access to rehabilitation services and increase the coverage of community-based rehabilitation facilities across its territory; and review the current health insurance system in order to cover all children and to lower the cost of health services for the most disadvantaged families." CRC/C/EGY/CO/3-4 (CRC, 2011).	
	CRC Committee: recommending that Bolivia establish systems of early identification and early intervention as part of their health services; and undertake greater efforts to make available the necessary professional (i.e. disability specialists) and financial resources, especially at the local level and to promote and expand community-based rehabilitation programmes, including parent support groups to ensure that all children with disabilities receive adequate services. CRC/C/BOL/CO/4 (CRC, 2009).	
	CRC Committee: recommending that Malaysia provide children with disabilities with equal access to adequate social and health services, including psychological and counselling services, and tailored services for children with learning difficulties and behavioural disorders, and raise awareness about all services available. CRC/C/MYS/CO/1 (CRC, 2007).	
	CRC Committee: recommending that Finland "Establish a holistic legal and policy framework to guarantee the equal right of children with disabilities to access good-quality health -care services, public buildings and transportation." CRC/C/FIN/CO/4 (CRC, 2011).	

Table 5 (cont.)

Human Rights Standards	Case Law
ACHPR 16(1) Every individual shall have the right to enjoy the best attainable state of physical and mental health. ACHPR 16(2) States Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.	ACHPR: In a case against The Gambia , the Court held that the Lunatics Detention Act (LDA), the principle instrument governing mental health, is outdated for many reasons: overcrowding, no requirement for consent to treatment, no independent examination for the living conditions in units, and patients cannot vote. The Court ordered Gambia to repeal the law and develop new legislation for mental health in conformance with international norms and standards. 241/01 Purohit and Moore / Gambia (The) (May 2003).

Other Interpretations

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993: "Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of health, employment and social services."

The Declaration on the Promotion of Patients' Rights in Europe, promulgated by a WHO European Consultation: "Patients have the right to a quality of care which is marked both by high technical standards and by a humane relationship between the patient and health care provider." World Health Organization, A Declaration on the Promotion of Patients' Rights in Europe art. 5.3 (Copenhagen: WHO, 1994). Available at http://www.who.int/genomics/public/eu_declaration1994.pdf.

Charter of Fundamental Rights of the European Union, art. 35. Everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities.

Table 6: Disability and the right to informed consent

Examples of Human Rights Violations

- People with disabilities are deprived of their right to provide or deny consent to treatment.
- Women with disabilities are subject to sterilization without their full and informed consent.
- Persons with disabilities are subjected to medical experimentation without their consent.
- Persons with disabilities are subjected to forced medications.

Human Rights Standards

Treaty Body Interpretation

CRPD 25 States shall (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent ... **CRPD:** urging **Hungary** to amend Act CLIV on Healthcare and abolish its provisions that provide a legal framework for subjecting persons with disabilities with restricted legal capacity to medical experimentation without their free and informed consent. The Committee recommended to Hungary that it implement the recommendation made by the Human Rights Committee in 2010 (CCPR/C/HUN/CO/5) to "establish an independent medical examination body mandated to examine alleged victims of torture and guarantee respect for human dignity during the conduct of medical examinations." CRPD/C/HUN/CO/1 (2012).

CRPD: expressing concern to **Tunisia** about the lack of clarity concerning the scope of legislation to protect persons with disabilities from being subjected to treatment without their free and informed consent, including forced treatment in mental health services; and recommending that Tunisia incorporate into the law the abolition of surgery and treatment without the full and informed consent of the patient, and ensure that national law especially respects women's rights under article 23 and 25 of the Convention. CRPD/C/TUN/CO/1 (2011).

CRPD: urging that **China** cease its policy of subjecting persons with actual or perceived impairments to "correctional therapy" and abstains from involuntarily committing them to institutions. It furthered urged China to abolish laws that allow for medical experimentation on persons with disabilities without their free and informed consent. CRPD/C/CHN/CO/1 (2012)

CRPD: recommending to **China** that rights based approach to rehabilitation and habilitation be put in place and ensure that such programmes promote the informed consent of individuals with disabilities and respects their autonomy, integrity, will and preference. CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **China** adopt measures to ensure that all health care and services provided to persons with disabilities, including all mental health care and services, is based on the free and informed consent of the individual concerned, and that laws permitting involuntary treatment and confinement, including upon the authorisation of third party decision-makers such as family members or guardians, are repealed. CRPD/C/CHN/CO/1 (2012).

CRPD: noting that in **Argentina**, there is a "lack of clear-cut mechanisms for ensuring that persons with disabilities give their free and informed consent. for any type of medical treatment before it is administered" and recommending that **Argentina** "adopt protocols for ensuring that all persons with disabilities give their free and informed consent for any type of medical treatment before it is administered." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: recommending that **Spain** "ensure that the informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support." CRPD/C/ESP/CO/1 (CRPD, 2011).

Table 7: Disability and the right to sexual and reproductive health

Examples of Human Rights Violations

- Women with disabilities are subject to compulsory abortions.
- · Women with disabilities are subject to involuntary sterilization.

Human Rights Standards

CRPD 25 States shall **(a)** provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

CRPD 17 Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

CRPD 23 (1) States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

CEDAW 12(1) States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health

services, including those related to family

Treaty Body Interpretation

CRPD: recommending that **Spain** abolish the administration of medical treatment, in particular sterilization, without the full and informed consent of the patient; and ensure that national law especially respects women's rights under articles 23 and 25 of the Convention. CRPD/C/ESP/CO/1 (2011).

CRPD: calling upon **Peru** to abolish administrative directives on forced sterilization of persons with disabilities. CRPD/C/PER/CO/1(2012).

CRPD: calling upon **China** to prohibit compulsory sterilization and forced abortion on women with disabilities. CRPD/C/CHN/CO/1 (2012).

CRPD: regretting that, in **Argentina**, "in cases where a woman with disabilities is under guardianship, her legal representative may give consent for a legal abortion on her behalf. It is likewise concerned that persons with disabilities are being sterilized without their free and informed consent." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: recommending that **Argentina** "amend article 86 of its Criminal Code and article 3 of Contraceptive Surgery Act No. 26.130 so that they will be in accordance with the Convention and take steps to provide the necessary support to women under guardianship or trusteeship to ensure that the women themselves are the ones who give their informed consent for a legal abortion or for sterilization." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: recommending that **China** ensure that "sex education be taught to children and adolescents with intellectual disabilities." CRPD/C/CHN/CO/1 (2012).

CESCR General Comment 5, para. 31: explaining that "[w]omen with disabilities have the right to protection and support in relation to motherhood and pregnancy... The needs and desires in question should be recognized and addressed in both the recreational and procreational contexts."

CEDAW Committee: recommending that **Australia** "enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilization of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent." CEDAW/C/AUL/CO/7 (2010).

CEDAW Committee: noting that the **Czech Republic** "has not implemented the 2005 recommendations of the ombudsman, endorsed by the committee in 2006, to adopt without delay legislative changes with regard to sterilization, including a clear definition of free, prior and informed consent in cases of sterilization and to financially compensate the victims of coercive or non-consensual sterilizations performed on, in particular, Roma women and women with mental disabilities." CEDAW/C/CZE/CO/5 (CEDAW, 2010).

planning.

Table 8: Disability and the right to education

Examples of Human Rights Violations

- Parents of a child with intellectual disabilities are told that their daughter cannot go to school because she is 'uneducable.'
- No education is provided to children in an institution.
- A person with a disability is denied vocational training on the basis of their disability.
- Parents of a child with a disability are not provided adequate resources to assist them in sending their child to school.
- A child with a disability does not attend the local school because of the lack of transportation.

Human Rights Standards

CRPD 24(1) States Parties recognize the right of persons with disabilities to education . . .

CRPD 24(2) In realizing this right, States Parties shall ensure that: (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory education, of from secondary education, on the basis of disability.

Treaty Body Interpretation

CRPD: recommending that Argentina "develop a comprehensive State education policy that guarantees the right to inclusive education and allocates sufficient budgetary resources to ensure progress towards the establishment of an education system that includes students with disabilities. The Committee also urges the State party to intensify its efforts to ensure that all children with disabilities receive a full compulsory education as established by the State party, while devoting particular attention to indigenous peoples and other rural communities. It likewise urges the State party to take the necessary steps to ensure that pupils with disabilities who attend special schools are enrolled in inclusive schools and to offer reasonable adjustments for students with disabilities within the general education system." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: recommending that Spain

- (a) "Increase its efforts to provide reasonable accommodation in education, by: allocating sufficient financial and human resources to implement the right to inclusive education; paying particular attention to assessing the availability of teachers with specialist qualifications; and ensuring that educational departments of local governments understand their obligations under the Convention and act in conformity with its provisions;
- (b) Ensure that the decisions to place children with a disability in a special school or in special classes, or to offer them solely a reduced standard curriculum, are taken in consultation with the parents;
- (c) Ensure that the parents of children with disabilities are not obliged to pay for the education or for the measures of reasonable accommodation in mainstream schools;
- (d) Ensure that decisions on placing children in segregated settings can be appealed swiftly and effectively." CRPD/C/ESP/CO/1 (CRPD, 2011).

CRPD: recommending that **China** "reallocate resources from the special education system to promote the inclusive education in mainstream schools, so as to ensure that more children with disabilities can attend mainstream education." CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **Peru** "allocate sufficient budget resources to achieve advances in the progress for an inclusive education system for children and adolescents with disabilities, and take appropriate measures to identify and reduce illiteracy among children with disabilities, especially indigenous and Afro-Peruvian children." CRPD/C/PER/CO/1 (2012).

CRPD: noting that in **Tunisia** "the inclusion strategy is not equally implemented in schools; rules relating to the number of children in mainstream schools and to the management of inclusive classes are commonly breached; and schools are not equitably distributed between regions of the same governorate." CRPD/C/TUN/CO/1 (CRPD, 2011).

Table 8 (cont.)

Human Rights Standards

CRC 28(1) States Parties recognize the right of the child to education, and with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

- (a) Make primary education compulsory and available free to all;
- (c) Make higher education accessible to all on the on the basis of capacity by every appropriate means;
- **(e)** Take measures to encourage regular attendance at schools and the reduction of drop-out rates.

Treaty Body Interpretation

CRC Committee: recommending that **Australia** "Give priority to inclusive education of children with disabilities and ensure that the best interests of each child are a primary consideration in decisions concerning his/her school enrolment." CRC/C/AUT/CO/3-4 (CRC, 2012).

CRC Committee: recommending that **Bosnia and Herzegovina** "Ensure that children with disabilities enjoy their right to education, and provide for their inclusion in the mainstream education system to the greatest extent possible, including by developing a disability education action plan to specifically identify current inadequacies in resources, and to establish clear objectives with concrete timelines for the implementation of measures to address the educational needs of children with disabilities." CRC/C/BIH/CO/2-4 (CRC, 2012).

CRC Committee: recommending that **Namibia** "Ensure that children with disabilities are able to exercise their right to education, and provide for their inclusion in the mainstream education system to the greatest extent possible, including by providing teachers with special training, by increasing facilities for children with disabilities and by making schools more accessible." CRC/C/NAM/CO/2-3 (CRC, 2012).

CRC Committee: stating to **Italy** that "[w]hile welcoming efforts to integrate children with disabilities in the school system, the Committee is concerned that disability is still conceptualized as a "handicap" rather than approached with the aim of ensuring the social inclusion of children with disabilities, and that there are regional disparities in the provision of specialist teachers in schools" and recommending that **Italy** "provide sufficient numbers of specialist teachers to all schools so that all children with disabilities can enjoy access to high - quality inclusive education." CRC/C/ITA/CO/3-4 (CRC, 2011).

CRC Committee: recommending that **Cyprus** "establish a clear legislative definition of inclusive education. It further recommends that the State party adopt measures, including reasonable accommodation in all schools, to ensure that children with disabilities are able to exercise their right to education, and provide for their inclusion in the mainstream education system." CRC/C/CYP/CO/3-4 (CRC, 2012).

CRC Committee: raising concerns to **Bulgaria** about the inadequate education for children in "social care institutions" and considers these children need to be provided with mainstream education. CRC/C/BGR/CO/2, 2008.

CRC Committee: concerned about the limited inclusion of children with disabilities in the educational system in **Kazakhstan** and **Ukraine**. CRC/C/15/ADD.213 (CRC, 2003), para. 54; CRC/C/15/ADD.191 (CRC, 2002), para. 53.

CRC Committee: noting the limited number of trained teachers to work with children with disabilities, insufficient efforts made to facilitate the children's inclusion into the educational system, and inadequate resources allocated to special education in **India**, **Rwanda**, and **Zambia**. CRC/C/15/ADD.228 (CRC, 2004), para. 56; CRC/C/15/ADD.234 (CRC, 2004), para. 46; CRC/C/15/ADD.206 (CRC, 2003), para. 52.

CRC Committee: recommending that **Kyrgyzstan** integrate children with disabilities into the regular educational system and for increased resources for special education. CRC/C/15/Add.244 (CRC, 2004), para. 48.

Table 8 (cont.)

Human Rights Standards

ESC 15 ... the Parties undertake in particular (1) to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;

ESC 17(1) With a view to ensuring the effective exercise of the right of children and young persons to group up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake . . . (1)(a) to ensure that children and young persons . . . have the care, the assistance, the education n and the training they need.

Case Law

ECSR: held that France violated Article 15 and 17 because insufficient provision was made for the education of children and adults with autism. International Association Autism-Europe v. France, Complaint No. 13/2002.

ECSR: held that Bulgaria violated Article 17 "because children with moderate, severe or profound intellectual disabilities residing in HMDCs do not have an effective right to education," and "because there is discrimination against children with moderate, severe or profound intellectual disabilities residing in HMDCs as a result of the low number of such children receiving any type of education when compared to other children." Mental Disability Advocacy Center (MDAC) v. Bulgaria, Complaint No. 41/2007.

Other Interpretations

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993: States should recognize the principle of equal primary, secondary and tertiary educational opportunities for children, youth and adults with disabilities, in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the educational system. [Standard Rules, 6].

United Nations Guidelines for the Alternative Care for Children: stating that children "should have access to formal, non-formal and vocational education in accordance with their rights, to the maximum extent possible in educational facilities in the local community." (November 2009, para. 85).

Council of Europe: stating that "all children have rights, hence disabled children have the same rights to family life, education, health, social care and vocational training as all children; long-term planning involving all stakeholders will be needed to ensure that children with disabilities are able to exercise the same rights as other children and to access social rights on the same basis as other children." (CM/Rec(2010)2).

Table 9: Disability and the right to decent work

Examples of Human Rights Violations

- A person with intellectual disabilities is placed under guardianship, and the guardian does not allow him to be employed.
- An employer refuses to hire a woman even though she is the best applicant for the job because she had depression in the past.
- People with intellectual disabilities are 'employed' in a workshop where they are given menial tasks to do all day for which they receive 'pocket money' at the end of the week.

Human Rights Standards

CRPD 27(1) States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities...

Treaty Body Interpretation

CRPD: recommending that **Spain** "develop open and advanced programs to increase employment opportunities for women and men with disabilities." CRPD/C/ESP/CO/1 (CRPD, 2011).

CRPD: recommending that **Argentina** "develop a public policy to promote the inclusion of persons with disabilities in the labour market through, for example, the launch of awareness-raising campaigns targeting the private sector and the public at large which are designed to break down cultural barriers and prejudices against persons with disabilities, the implementation of reasonable adjustments in order to ensure that persons with disabilities in need of such adjustments can participate in the labour market, and the development of training and self-employment programmes. The Committee recommends that the State party reinforce its measures for monitoring and certifying compliance with the employment quota for persons with disabilities in the public sector." CRPD/C/ARG/CO/1 (CRPD, 2012).

CRPD: recommending that **Hungary** "effectively implement the disability-specific provisions of the Labour Code and develop programmes to integrate persons with disabilities into the open labour market and the education and professional training systems, and to make all work places and educational and professional training institutions accessible for persons with disabilities." CRPD/C/HUN/CO/1 (CRPD, 2012).

CRPD: recommending that **China** "undertake all necessary measures to ensure the persons with disabilities freedom of choice to pursue vocations according to their preferences" and that it "create more working opportunities and enact legislature, so that companies and State organs employ more persons with disabilities." CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **China** "introduce affirmative actions to promote the employment of persons with disabilities, inter alia, to prioritize the employment of persons with disabilities as civil servants." CRPD/C/CHN/CO/1 (2012).

CRPD: recommending that **Peru** "develop new policies that promote the inclusion of persons with disabilities in the labour market which could include tax incentives for companies and persons who employ persons with disabilities, the recruitment of persons with disabilities in public administration and the development of self-employment programmes." CRPD/C/PER/CO/1 (2012).

CRPD: recommending that **Tunisia** "Ensure the implementation of measures of affirmative action provided for in the law for the employment of women and men with disabilities" and "Increase the diversity of employment and vocational training opportunities for persons with disabilities." CRPD/C/TUN/CO/1 (CRPD, 2011).

Table 9 (cont.)

Human Rights Standards

ent Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right.

(2) The steps to be taken by a State Party . . . shall include technical and vocational guidance and training programmes, policies and techniques to achieve steady economic, social and cultural development and full and productive employment under conditions safeguarding fundamental political and economic freedoms to the individual.

Treaty Body Interpretation

CESCR General Comment 5, para 21: recognizing "[t]he 'right of everyone to the opportunity to gain his living by work which he freely chooses or accepts' (Art 6(1)) is not realized where the only real opportunity open to disabled workers is to work in so-called 'sheltered' facilities under substandard conditions. Arrangements whereby persons with a certain category of disability are effectively confined to certain occupations or the production of certain good may violate this right."

CEDAW 3 States Parties shall take in all fields, in particular in the political, social, economic and cultural fields, all appropriate measures, including legislation, to ensure the full development and advancement of women, for the purpose of guaranteeing them the exercise and enjoyment of human rights and fundamental freedoms on a basis of equality with men.

CEDAW Committee: recommending that **Italy** "mainstream the issues of ... women with disabilities, who may suffer multiple forms of discrimination, into its employment policies and programmes, and to intensify its efforts ... aimed at achieving de facto equal opportunities for ... women with disabilities in the labour market." CEDAW/C/ITA/CO/6 (CEDAW, 2011).

CEDAW Committee: recommending that **France** "undertake special measures to assist women with disabilities to enter into the labour market" CEDAW/C/FRA/CO/6 (CEDAW, 2008).

Other Interpretations

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993: States should actively support the integration of persons with disabilities into open employment. This active support should occur through a variety of measures such as vocational training, incentive-oriented quota schemes...financial assistance to enterprises employing workers with disabilities. States should also encourage employers to make reasonable adjustments to accommodate persons with disabilities. [Standard Rules, Rule 7]

Council of the Europe Resolution: asking Member States to 'continue efforts to remove barriers to the integration and participation of people with disabilities in the labor market, by enforcing equal treatment measures and improving integration and participation at all levels of the education and training system' [2003/C175/01].

Council of Europe: Action Plan to promote the rights and full participation of people with disabilities in society (Europe 2006-2015): "To promote the employment of people with disabilities within the open labour market by combining anti-discrimination and positive action measures in order to ensure that people with disabilities have equality of opportunity." (Recommendation (2006) 5 of the Committee of Ministers to member states on the Council of Europe).

European Directive on Equal Treatment in Employment, Council Directive 2000/78/EC

European Union Charter, art. 15: "Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation."

Table 10: Disability and the right to life

Examples of Human Rights Violations

- Terminating life support for persons with disabilities when such decisions are made on the basis of the person's disability.
- Creating a distinctive period under the law that permits abortions solely on the basis of disability.
- Endangering a person with disabilities' life (see the CRPD recommendation to China below).

Human Rights Standards	Treaty Body Interpretation
CRPD 10 States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.	CRPD: recommending that Hungary and Spain abolish the distinction made in the Act on the protection of the life of the fetus in the period allowed under law within which a pregnancy can be terminated, based solely on disability. CRPD/C/HUN/CO/1 (2012), CRPD/C/ESP/CO/1 (2011).
	CRPD: expressing concern to China about the abduction of persons with intellectual disabilities, most of them children, and the staging of "mining accidents" in Hebei, Fujian, Liaoning and Sichuan, resulting in the victim's death in order to claim compensation from the mine owners; urging that China continue investigating these incidents, prosecute all those responsible, impose appropriate sanctions, implement comprehensive measures to prevent further abductions of boys with intellectual disabilities and provide remedies to the victims. CRPD/C/CHN/CO/1 (2012).
CRPD 25 States shall (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.	CRPD: expressing concern that, in Spain , guardians representing persons with disabilities deemed "legally incapacitated" may validly consent to termination or withdrawal of medical treatment, nutrition or other life support for those persons. The Committee reminded Spain that the right to life is absolute, and that substitute decision-making in regard to the termination or withdrawal of life-sustaining treatment is inconsistent with that right. Requested that Spain ensure that the informed consent of all persons with disabilities is secured on all matters relating to medical treatment, especially the withdrawal of treatment, nutrition or other life support. CRPD/C/ESP/CO/1 (2011).

Table II: Disability and the right to liberty and security of person

Examples of Human Rights Violations

- Involuntary commitment to psychiatric institutions.
- Individuals living with intellectual impairments are permanently confined at home because of lack of resources for medical and social care.
- A young man is detained against his will to a psychiatric hospital after his parents raised concerns about his behaviour. He is not told why he has been admitted.
- A woman is admitted to a social care home on the authorisation of the person appointed as her guardian. She is not consulted about this decision.
- Residents of an institution are not informed about their right to apply to a court or tribunal to challenge their involuntary admission/detention.
- There is no mechanism for appealing an involuntary commitment.
- · People are institutionalized indefinitely with no review of their status or of the admission decision.

Human Rights Standards

CRPD 14 (1) States Parties shall ensure that persons with disabilities, on an equal basis with others:

- (a) Enjoy the right to liberty and security of person;
- **(b)** Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
- (2) States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Treaty Body Interpretation

CRPD: recommending that **Hungary** review provisions in legislation that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities. CRPD/C/HUN/CO/1 (2012).

CRPD: recommending that **China** abolish the practice of involuntary civil commitment based on actual or perceived impairment. CRPD/C/CHN/CO/1 (2012).

CRPD: calling upon **Peru** to eliminate Law 29737 to prohibit the deprivation of liberty on the basis of disability, including psychosocial, intellectual or perceived disability. CRPD/C/PER/CO/1(2012).

CRPD: recommending that **Tunisia** repeal legislative provisions which allow for the deprivation of liberty on the basis of disability, including a psychosocial or intellectual disability. The Committee further recommended that until new legislation is in place, all cases of persons with disabilities who are deprived of their liberty in hospitals and specialized institutions be reviewed, and that the review include the possibility of appeal. CRPD/C/TUN/CO/1 (2011).

CRPD: recommending that **Spain** review its laws that allow for the deprivation of liberty on the basis of disability, including mental, psychosocial or intellectual disabilities; the repeal of provisions that authorize involuntary internment linked to an apparent or diagnosed disability. CRPD/C/ESP/CO/1 (2011).

Table 12: Disability and protection against exploitation, violence and abuse

Examples of Human Rights Violations

- Students with disabilities experience higher rates of corporal punishment.
- State systematically fails to prosecute persons responsible for violence and abuse against persons with disabilities.
- State fails to develop a strategy to prevent violence against persons with disabilities in either private or public settings.
- · Programs and facilities servicing persons with disabilities are not monitored by independent authorities.
- Persons with disabilities are subjected to forced labor.

Human Rights Standards

CRPD 16 (1) States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the, from all forms of exploitation, violence and abuse, including their gender-based aspects.

- (2) States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
- (3) In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
- (4) States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
- (5) States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Treaty Body Interpretation

CRPD: expressing concern to **Spain** that at the reportedly higher rates of abuse of children with disabilities in comparison with other children and recommending that Spain increase efforts to promote and protect the rights of children with disabilities, and to undertake research on violence against children with disabilities, adopting measures to eradicate this violation of their rights. CRPD/C/ESP/CO/1 (2011).

CRPD: recommending that **Hungary** take effective measures to ensure protection of women, men, girls and boys with disabilities from exploitation, violence and abuse, in accordance with the Convention, amongst others, the establishment of protocols for the early detection of violence, above all in institutional settings, procedural accommodation to gather testimonies of victims, and prosecution of those persons responsible, as well as redress for victims. It also recommends the State party to ensure that protection services are age-, gender- and disability-sensitive and accessible. CRPD/C/HUN/CO/1 (2012).

CRPD: expressing concern by the reported incidents of abduction and forced labor of thousands of persons with intellectual disabilities, especially children, such as the occurrence of slave labor in Shanxi and Henan; and urging **China** to continue investigating these incidents and prosecute the perpetrators. It also asked the state party to implement comprehensive measures to prevent further abductions of persons with intellectual disabilities and provide remedies to the victims, by including data collection on the prevalence of exploitation, abuse and violence against persons with disabilities. CRPD/C/CHN/CO/1 (2012)

CRPD: expressing concern to **Tunisia** regarding their high rate of violence for discipline in the home against boys and girls (94%) and recommending that Tunisia evaluate the phenomenon of violence against boys and girls with disabilities. CRPD/C/TUN/CO/1 (2011).

CRPD: encouraging **Tunisia** to include women and girls with disabilities in the National Strategy for the prevention of violence in the family and society, and to adopt comprehensive measures for them to have access to immediate protection, shelter and legal aid. It requested Tunisia to conduct awareness campaigns and develop educational programmes on the greater vulnerability of women and girls with disabilities with respect to violence and abuse. CRPD/C/TUN/CO/1 (2011).

Table 13: Disability and freedom from torture and cruel, inhuman and degrading treatment

Examples of Human Rights Violations

- · People in an institution are kept in cage beds and are forced to eat and use the toilet in bed.
- People in an institution who have been labeled "dangerous" by staff are tied or chained to chairs or beds for hours and even days at a time.
- Persons with disabilities are subjected to "correctional therapy" at psychiatric institutions.
- · Persons with disabilities are involuntary administered psychiatric medication including neuroleptics.

Human Rights Standards

CRPD 15 (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.

Treaty Body Interpretation

CRPD: noting that in **China** "For those involuntarily committed persons with actual or perceived intellectual and psychosocial impairments, the Committee is concerned that the "correctional therapy" offered at psychiatric institutions represents inhuman and degrading treatment. Further, the Committee is concerned that not all medical experimentation without free and informed consent is prohibited by Chinese law." Urging **China** "to cease its policy of subjecting persons with actual or perceived impairments to such therapies and abstain from involuntarily committing them to institutions" and "to abolish laws which allow for medical experimentation on persons with disabilities without their free and informed consent." CRPD/C/CHN/CO/1 (2012).

CRPD: urging **Peru** to "promptly investigate the allegations of cruel, inhuman or degrading treatment, or punishment in psychiatric institutions, to thoroughly review the legality of the placement of patients in these institutions, as well as to establish voluntary mental health treatment services, in order to allow the persons with disabilities to be included in the community and release them from the institutions." CRPD/C/PER/CO/1 (2012).

CRPD: urging **Argentina** "to immediately approve the bill on the creation of a national mechanism for the prevention of torture so that institutionalized persons with disabilities can be monitored and protected from actions that may constitute acts of torture or other forms of cruel, inhuman or degrading treatment or punishment." CRPD/C/ARG/CO/1 (CRPD, 2012)

CRPD: urging **Hungary** to "amend Act CLIV on Healthcare and abolish the provisions thereof that provide for a legal framework for subjecting persons with disabilities with restricted legal capacity to medical experimentation without their free and informed consent." CRPD/C/HUN/CO/1 (CRPD, 2012)

3. WHAT IS A HUMAN RIGHTS-BASED APPROACH TO ADVOCACY, LITIGATION, AND PROGRAMMING?

What is a human rights-based approach?

"Human rights are conceived as tools that allow people to live lives of dignity, to be free and equal citizens, to exercise meaningful choices, and to pursue their life plans." 96

A human rights-based approach (HRBA) is a conceptual framework that can be applied to advocacy, litigation, and programming and is explicitly shaped by international human rights law. This approach can be integrated into a broad range of program areas, including health, education, law, governance, employment, and social and economic security. While there is no one definition or model of a HRBA, the United Nations has articulated several common principles to guide the mainstreaming of human rights into program and advocacy work:

The integration of human rights law and principles should be visible in all work, and the aim of all programs and activities should be to contribute directly to the realization of one or more human rights. Human rights principles include: "universality and inalienability; indivisibility; interdependence and interrelatedness; non-discrimination and equality; participation and inclusion; accountability and the rule of law." They should inform all stages of programming and advocacy work, including assessment, design and planning, implementation, monitoring and evaluation.

Human rights principles should also be embodied in the processes of work to strengthen rights-related outcomes. Participation and transparency should be incorporated at all stages and all actors must be accountable for their participation.

A HRBA specifically calls for human rights to guide relationships between rights-holders (individuals and groups with rights) and the duty-bearers (actors with an obligation to fulfill those rights, such as States). With respect to programming, this requires "[a]ssessment and analysis in order to identify the human rights claims of rights-holders and the corresponding human rights obligations of duty-bearers as well as the immediate, underlying, and structural causes of the non-realization of rights." 99

A HRBA is intended to strengthen the capacities of rights-holders to claims their entitlements and to enable duty-bearers to meet their obligations, as defined by international human rights law. A HRBA also draws attention to marginalized, disadvantaged and excluded populations, ensuring that they are considered both rights-holders and duty-bearers, and endowing all populations with the ability to participate in the process and outcomes.

⁹⁶ Yamin AE, "Will we take suffering seriously? Reflections on what applying a human rights framework to health means and why we should care," *Health and Human Rights* 10, no. 1 (2008).

⁹⁷ For a brief explanation of these principles, see UN Development Group (UNDG), The Human Rights Based Approach to Development Cooperation Towards a Common Understanding Among UN Agencies (May 2003), available at: www.undg.org/archive_docs/6959-The_Human_Rights_Based_Approach_to_
Development_Cooperation_Towards_a_Common_Understanding_among_UN.pdf.

⁹⁸ Ibid

⁹⁹ Ibid.

What are key elements of a human rights-based approach?

Human rights standards and principles derived from international human rights instrument should guide the process and outcomes of advocacy and programming. The list below contains several principles and questions that may guide you in considering the strength and efficacy of human rights within your own programs or advocacy work. Together these principles form the acronym PANELS.

- Participation: Does the activity include participation by all stakeholders, including affected communities, civil society, and marginalized, disadvantaged or excluded groups? Is it situated in close proximity to its intended beneficiaries? Is participation both a means and a goal of the program?
- Accountability: Does the activity identify both the entitlements of claim-holders and the obligations
 of duty-bearers? Does it create mechanisms of accountability for violations of rights? Are all actors
 involved held accountable for their actions? Are both outcomes and processes monitored and
 evaluated?
- **Non-discrimination**: Does the activity identify who is most vulnerable, marginalized and excluded? Does it pay particular attention to the needs of vulnerable groups such as women, minorities, indigenous peoples, disabled persons and prisoners?
- **Empowerment**: Does the activity give its rights-holders the power, capacity, and access to bring about a change in their own lives? Does it place them at the center of the process rather than treating them as objects of charity?
- **Linkage to rights**: Does the activity define its objectives in terms of legally enforceable rights, with links to international, regional, and national laws? Does it address the full range of civil, political, economic, social, and cultural rights?
- **Sustainability**: Is the development process of the activity locally owned? Does it aim to reduce disparity? Does it include both top-down and bottom-up approaches? Does it identify immediate, underlying and root causes of problems? Does it include measurable goals and targets? Does it develop and strengthen strategic partnerships among stakeholders?

Why use a human rights-based approach?

There are many benefits to using a human rights-based approach to programming, litigation and advocacy. It lends legitimacy to the activity because a HRBA is based upon international law and accepted globally. A HRBA highlights marginalized and vulnerable populations. A HRBA is effective in reinforcing both human rights and public health objectives, particularly with respect to highly stigmatizing health issues.100 Other benefits to implementing a human rights-based approach include:

- Participation: Increases and strengthens the participation of the local community.
- Accountability: Improves transparency and accountability.
- **Non-discrimination:** Reduces vulnerabilities by focusing on the most marginalized and excluded in society.
- Empowerment: Capacity building.
- **Linkage to rights**: Promotes the realization of human rights and greater impact on policy and practice.
- Sustainability: Promotes sustainable results and sustained change.

¹⁰⁰ Gauri V & Gloppen S, Human Rights Based Approaches to Development: Concepts, Evidence, and Policy, World Bank Policy Research Working Paper 5938 (Jan. 2012). http://elibrary.worldbank.org/content/workingpaper/10.1596/1813-9450-5938.

How can a human rights-based approach be used?

A variety of human rights standards at the international and regional levels applies to patient care. These standards can be used for many purposes including to:

- Document violations of the rights of patients and advocate for the cessation of these violations.
- Name and shame governments into addressing issues.
- Sue governments for violations of national human rights laws.
- File complaints with national, regional and international human rights bodies.
- Use human rights for strategic organizational development and situational analysis.
- Obtain recognition of the issue from non-governmental organizations, governments or international audiences. Recognition by the UN can offer credibility to an issue and move a government to take that issue more seriously.
- Form alliances with other activists and groups and develop networks.
- Organize and mobilize communities.
- Develop media campaigns.
- Push for law reform.
- · Develop guidelines and standards.
- · Conduct human rights training and capacity building
- Integrate legal services into health care to increase access to justice and to provide holistic care.
- Integrate a human rights approach in health services delivery.

4. WHAT ARE SOME EXAMPLES OF EFFECTIVE HUMAN RIGHTS PROGRAMMING IN THE AREA OF DISABILITY, HEALTH AND COMMUNITY LIVING?

This section contains **eight examples** of effective activities addressing disability and human rights. These are:

- 1. Studies on dsability-related harassment
- 2. The first decision of the Committee on the Rights of Persons with Disabilities
- 3. Challenging educational opportunities for autistic children in France
- 4. Advocating for the rights of persons with intellectual disabilities in Kenya
- 5. Advocating for the implementation of the CRPD in Croatia
- 6. Advocating for independent living for persons with disabilities in Europe
- 7. Establishing community-based supported housing in Moldova
- 8. Implementing supported decision making in Canada

Example I: Studies on Disability-Related Harassment

Project Type

Advocacy

The Organization

Established in 2007 by the British Government, the Equality and Human Rights Commission now promotes and monitors human rights across nine protected grounds. Under the Equality Act of 2006, the Equality and Human Rights Commission is charged "with a view to encouraging and supporting the development of a society in which (a) people's ability to achieve their potential is not limited by prejudice or discrimination, (b) there is respect for and protection of each individual's human rights, (c) there is respect for the dignity and worth of each individual, (d) each individual has an equal opportunity to participate in society, and (e) there is mutual respect between groups based on understand and valuing of diversity and on shared respect for equality and human rights." Equality Act, 2006, c. 3, § 3 (Eng, Wales and Scot).

The Problem

People with disabilities are often targets of harassment and violence and in many cases the violence results in death or serious injury. However, harassment and hate crimes against persons with disabilities are largely undocumented and as such and remain invisible to society. In cases where persons with disabilities are harassed to the point of serious injury, authorities have been often aware of earlier, less serious incidents of harassment but failed to take adequate precautions. Sometimes authorities disregard or disbelieve reports of violence against persons with disabilities or sometimes they fail to share information with other relevant organizations. Often authorities seek to change the victim's behavior rather than addressing the perpetrator's behavior. Also, people with disabilities do not always report violence against them for many factors including social isolation. When harassment progresses to degrading and dehumanizing treatment, authorities often fail to classify this behavior as a hate crime as they would for other protected characteristics.

Actions Taken

The Equality and Human Rights Commission conducted an inquiry into the everyday experiences of persons with disabilities who were subject to harassment. The inquiry featured ten selected cases where persons with disabilities have died or been seriously injured as a result of disability-related harassment. The inquiry utilized the ten selected cases to illustrate the key features of disability-related harassment. Each case involved an in depth examination to explore how and why disability-related harassment occurs. The inquiry engaged with authorities involved with each of the cases leading to open dialogue about the breakdown in protection of the individual. After reviewing all of the materials and analyzing the common features, the inquiry developed seven core recommendations and 79 detailed recommendations. The Equality and Human Rights Commission then published the recommendations for public consultation through which they received 81 formal responses. Based upon these, the Commission released a second report detailing 43 final recommendations under seven categories.

Results & Lessons Learned

The inquiry and report are valuable on many levels. The inquiry enabled authorities involved in cases of pervasive harassment to reflect on their role of protecting persons with disabilities and how this may best be accomplished. As well, the inquiry made public issues of disability-related harassment and the gross violations of rights that occur against persons with disabilities in Great Britain. Lastly, the inquiry and report develop positive recommendations that will be helpful in guiding further discussion and policy reform in the area of disability-related harassment.

Hidden in Plain Sight: Inquiry into disability-related harassment (2011)

Available at: http://www.equalityhumanrights.com/uploaded_files/disabilityfi/ehrc_hidden_in_plain_sight_3.pdf

Out in the open: Tackling disability-related harassment: A manifesto for change (2012)

Available at: http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-in-to-disability-related-harassment/out-in-the-open-manifesto-for-change/

The recommendations are categorize under the following seven categories:

- 1. Reporting, recording and recognition to counter that "underreporting of disability-related harassment was widespread; that disabled people often saw incidents as so commonplace as to be part of daily life and not 'hate crimes' and that those receiving reports of harassment were failing to ask about disability or see it as a potential motivation."
- 2. Addressing gaps in legislation and policy to counter "disparity in sentencing guidelines for different groups and an insufficiently robust safeguarding referral process that means people are put at risk and criminal acts are not promptly referred to the police."
- **3. Ensuring adequate support and advocacy** to counter "gaps in provision of support services, not just at the reporting stage but throughout and beyond the process of accessing justice."
- **4. Improved practice and shared learning** to prevent "problems with sharing data, failure to recognize 'incidents' and a failure to pick up incidents at an early stage."
- 5. Redress and accessing justice to counter that "very few cases of disability-related harassment go through the courts; and even when they do, sentencing does not always follow."
- **6. Prevention, deterrence and understanding motivation** to counter "a lack of investment in research into the motivation and profile of perpetrators" and the lack of "statutory requirement to conduct a serious case review for the murder of a disabled person."
- 7. Transparency, accountability and involvement to counter "that the absence of data is a major problem to identifying, preventing and tackling disability-related harassment" and that it also "makes it harder for individuals and organizations at a local level to hold authorities to account for their performance."

Equality and Human Rights Commission

Great Britain

Web: http://www.equalityhumanrights.com/

Example 2: The first decision of the Committee on the Rights of Persons with Disabilities

Project Type

Litigation: H.M. v. Sweden, U.N. Doc. CRPD/C/7/D/3/2011 (21 May 2012).

The Actor

H.M., a private litigant with a disability, brought this case.

The Problem

H.M. had disability that limited her mobility. Her doctors determined that hydrotherapy was the only option to stop her physical impairments from progressing further and improver her quality of life. However, because she could not leave her house without risk of further injury, the doctors recommended the construction of an indoor pool in her home for hydrotherapy.

H.M. applied for a permit with the Örebro Local Housing Committee to extend her house by 63 square meters so that she could build an indoor pool. The Housing Committee rejected H.M.'s application because the *Planning and Building Act* prohibited such a use.

Procedure

H.M. appealed the decision and exhausted her domestic remedies. She then filed a complaint with the Committee on the Rights of Persons with Disabilities.

Arguments & Holdings

Article 2—Definition

Article 2(3) of the CRPD prohibits "discrimination on the basis of disability." The Committee reasoned that "denial of reasonable accommodation" was included by the definition of "discrimination on the basis of disability." Furthermore, and quite importantly, the Committee found:

The right not to be discriminated against in the enjoyment of the rights guaranteed under the Convention can be violated when States, without objective and reasonable justification, fail to treat differently persons whose situations are significantly different.

The Committee found that the applicant's hydrotherapy pool was essential to prevent the advancement of H.M.'s physical impairments, which stemmed from her disability. Therefore, since a departure from the development plan under the Planning and Building Act would not be a "disproportionate or undue burden," the CRPD required that Sweden make the departure so that H.M. may build her therapeutic pool.

Disability Community Living

Articles 25 (health) & 26 (habilitation and rehabilitation)

Article 25 of the CRPD provides that persons with disabilities have the right to health "without discrimination on the basis of disability" and that "States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services . . . including health-related rehabilitation." Article 26 of the CRPD provides that "States Parties shall take effective and appropriate measures . . . to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life." In light of Articles 25 and 26, the Committee found that the denial of development plan departure permit was disproportionate and produced a discriminatory effect on a person with a disability who needed the permit for health and habilitation. Therefore, the Committee found a violation of Articles 25 and 26 of the CRPD.

Article 19(b) (Living independently and being included in the community).

Article 19 of the CRPD imposes an obligation on States Parties to "take effective and appropriate measures" to "facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community." The Article specifically states that "[p]ersons with disabilities have access to a range of inhome, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." Therefore, the Committee found that Sweden had violated Article 19(b) of the CRPD, since the therapeutic pool was the "only option that could support her living [in] and inclusion in the community."

Convention on the Rights of Persons with Disabilities (CRPD) Article 2

"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

Article 25 (health)

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

Article 26 (habilitation and rehabilitation)

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services ...

Article 19 (community living)

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community ...

Disability Community Living

Commentary & Analysis

This is the first decision of the U.N. Committee on the Right of Persons with Disabilities. It also marks a break from the medical legal model to the social legal model for disability issues. Understanding that it is not the person that is deficient, but rather the environment, the CRPD rejects a medical model in favor of a social model that puts an end to barriers that prevent participation in society by persons with disabilities.

Jurisprudence from Committee on the Rights of Persons with Disabilities

Web: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Jurisprudence.aspx

Example 3: Challenging educational opportunities for children with autism in France

Project Type

Litigation

The Organization

Autism-Europe is a European umbrella organisation whose main objective is to advance the rights of persons with autism and their families and to help them improve their quality of life. They cooperate with various other civil society organizations, such as the European Disability Forum (EDF) and the Platform of European Social NGOs to influence European decision-makers.

The Problem

At the time this action was filed, France was failing to provide education to people with autism due to (1) the lack of inclusion of people with autism in mainstream education on the one hand and (2) the dramatic shortage of specialised educational services on the other hand.

When Autism-Europe lodged the complaint, only 10% of children and adults requiring specialized education were enrolled in a special school. The other 90% were not receiving any education.

In addition, only 5% of the children with autism who could have been mainstreamed were individually integrated into schools.

Procedure

In 2002, Autism Europe submitted a collective complaint to the European Committee of Social Rights on the ground of Articles 15, 17 and E of the European Social Charter, dealing with insufficient educational provision for persons with autism in France. In 2003 the European Committee rendered its decision.

Arguments & Holding

According to Autism Europe, France failed to satisfactorily apply its obligations under the Revised European Social Charter with regard to the right to education of children and adults with autism. In this respect, Autism-Europe argued that France did not provide sufficient education opportunities, facilities and services of an adequate standard or quality to children and adults with autism. Additionally, Autism-Europe claimed that France discriminated against children and adults with autism because France did not manage to ensure that they enjoyed the right to education in the same way that all other children and adults did. This lack of action by the French government also resulted in discrimination because children and adults with autism did not enjoy the same level of education as other people.

The European Committee of Social Rights concluded that the situation in France constituted a violation of Articles 15§1 and 17§1, and of Article E of the revised European Social Charter because:

- (1) the proportion of children with autism being educated in either general or specialist schools in France is much lower than in the case of other children, whether or not disabled, and
- (2) there is a chronic shortage of care and support facilities for autistic adults.

Violations of the Revised European Social Charter

Article 15 - The right of persons with disabilities to independence, social integration and participation in the life of the community.

Article 17 – The right of children and young persons to social, legal and economic protection.

Article E – Non-discrimination principle

Committee's Application of the Charter to the Facts

"[T]he implementation of the Charter requires the State Parties to take not merely legal action but also practical action to give full effect to the rights recognised in the Charter. When the achievement of one of the rights in question is exceptionally complex and particularly expensive to resolve, a State Party must take measures that allow it to achieve the objectives of the Charter within a reasonable time, with measurable progress and to an extend consistent with the maximum use of available resources. States Parties must be particularly mindful of the impact that choices will have for groups with heightened vulnerabilities as well as for others [sic] persons affected including, especially their families on whom falls the heaviest burden in the event of institutional shortcomings"

Commentary & Analysis

Even though the decision referred specifically to the case of people with autism, its scope goes well beyond this group by reasserting the right to education for all people with disabilities, regardless of the severity of the disability. While people with autism are unfortunately the hardest hit because of the glaring lack of educational services tailored for their needs, they unfortunately are not the only ones to suffer because of France's indigence in this regard.

Autism Europe's complaint is the first collective action to defend the rights of people with disabilities in Europe. Its importance in this respect was highlighted by the Council of Europe. This action culminated in a decision that was adopted in 2003, which was the European Year of People with Disabilities. It took its place in the movement to improve the fundamental rights of people with disabilities, especially of those in need of a high level of support, throughout Europe.

The lack of education could also be challenged by the UN Convention on the Rights of Persons with Disabilities, since States Parties recognize the right of persons with disabilities to education and to effective individualized support.

Autism Europe

Brussels, Belgium

E-mail: secretariat@autismeurope.org Web: http://www.autismeurope.org/

Example 4: Advocating for the rights of persons with intellectual disabilities in Kenya

Project Type

Advocacy

The Organization

Founded in 1996 as a teacher-based organization, the Kenya Association for the Intellectually Handicapped (KAIH) is committed to the promotion of the welfare of the intellectually handicapped. The mission of KAIH is "[t]o promote the human rights of [persons with intellectual disabilities] and their families within society through education, advocacy, empowerment, and information exchange."

The Problem

Persons with intellectual disabilities in Kenya face higher incidences of sexual, physical, emotional and psycho-social abuse than the general population. As a result, they are more vulnerable to HIV/AIDS.

Only 1% of persons with intellectual disabilities in Kenya have their Kenyan National Identification Card. Consequently, obtaining benefits and asserting rights based on citizenship is quite difficult. Additionally, only 1.5-2% of persons with intellectual disabilities attend primary school, and they therefore have fewer employment opportunities than the general population that attends school at a higher rate.

Most of these problems are traceable to widespread discrimination and stigma within Kenya against persons with intellectual disabilities and the lack of knowledge that persons with intellectual disabilities have of their own rights.

Actions Taken

In 2004, KAIH began to shift its focus away from training teachers to educating parents and supporting the home life of children with intellectual disabilities. KAIH formed parent support groups to teach parents about their child's intellectual disabilities.

Disability Community Living

In addition, KAIH informs children with intellectual disabilities of their human rights. Armed with knowledge, children with disabilities can now use a rights-based approach for self-advocacy.

Finally, KAIH has worked to educate the community about intellectual disabilities to counter the prevalent stigma and discrimination that exists against persons with intellectual disabilities.

Results & Lessons Learned

There are now 42 different support groups throughout the Migori, Nyeri, Kiambu, Siaya and Nairobi counties. Each county has its own list of accomplishments, including those related to education awareness creation, advocacy, self-advocacy, economic, social and political change; HIV/AIDS and reproductive health; vocational rehabilitation and sustainable livelihoods; resource mobilization; and institutional strengthening and governance. You may find a list of each county's accomplishments here:

- Nyeri (http://tinyurl.com/b4gm6rn)
- Siaya (http://tinyurl.com/b7jbnx6)
- Migori (http://tinyurl.com/a5r4xjc)
- Nairobi (http://tinyurl.com/ax73gx9)
- Kiambu (http://tinyurl.com/bxg8pju).

In 2011, KAIH won the social inclusion category at the inaugural Ability Awards, Kenya's first awards ceremony for organizations and people advancing the rights of persons with disabilities. KAIH's work advocating for persons with disabilities was nationally recognized at the Ability Awards.

Kenya Association of the Intellectually Handicapped (KAIH)

Nairobi, Kenya

Web: http://kaihid.org/

Example 5: Advocating for the Implementation of the CRPD in Croatia

Project Type

Advocacy

The Organization

The Association for Self Advocacy (ASA), established in 2003, is the first non-governmental organization (NGO) in Croatia run by and for persons with intellectual disabilities.

The Problem

Croatia was one of the first countries to ratify the UN Convention on the Rights of Persons with Disabilities (CRPD), yet prsons with intellectual disabilities remain marginalized in Croatian society. Many persons with intellectual disabilities in Croatia are declared legally incompetent and thus denied the right to make any decisions regarding their lives. As a result, many cannot realize their right to education, employment, marriage, ownership of property, voting, or other basic rights. One in three children and adults with severe intellectual disabilities in Croatia remains institutionalized.

Actions Taken

The CRPD has the potential to introduce significant improvements in the lives of persons with intellectual disabilities. The ASA undertakes a variety of activities aimed at promoting the implementation the CRPD:

- ASA advocates for the development of community-based services as alternatives to institutionalization.
- ASA trains persons with intellectual disabilities about human rights and self-advocacy, and organizes public awareness campaigns about the human rights of people with intellectual disabilities.
- Consistent with the CRPD's guarantee of accessibility, ASA prepares and distributes easy-to-read materials on the rights of persons with intellectual disabilities.

In Focus

Although Croatia is a state party to the CRPD, its progress towards meeting its obligations under that convention and towards deinstitutionalization of the intellectually disabled has been disappointing. According to Human Rights Watch, "research in Croatia found a serious lack of progress with regard to deinstitutionalization, combined with limited investment in development and financing of community-based alternatives to institutional care and housing [T]he primary reason for the failings described . . . is not lack of financial resources dedicated to deinstitutionalization but rather lack of leadership." NGOs, like the ASA, are necessary to narrow the gap between Convention obligations and the realization of rights for persons with disabilities.

Source: Human Rights Watch, Once You Enter, You Never Leave: Deinstitutionalization of Persons with Intellectual or Mental Disabilities in Croatia 2, 51 (September 2010). Available at: http://www.hrw.org/reports/2010/09/23/once-you-enter-you-never-leave-o.

Disability Community Living

Results & Lessons Learned

- ASA, led by persons with intellectual disabilities, is recognized for its expertise in human rights and advocacy.
- Persons with intellectual disabilities in Croatia, Slovenia, Bosnia and Herzegovina, Macedonia
 and Romania who have participated in ASA's self-determination and self-advocacy training are
 equipped with the skills to advocate for their rights in their respective countries.
- ASA works with other self advocacy groups, human rights organizations and NGOs providing community based services for persons with intellectual disabilities to promote implementation of the CRPD.

Association for Self-Advocacy (ASA) Udruga za samozastupanje (Croatian)

Zagreb, Croatia

E-mail: kontakt@samozastupanje.hr Web: http://www.samozastupanje.hr/

Example 6: Advocating Across Europe for Independent Living for Persons with Disabilities

Project Type

Advocacy

The Organization

In 2005, a group of advocacy organizations established the European Coalition for Community Living (ECCL) to advocate for the development of comprehensive, quality, community-based services as an alternative to institutionalization. A Europe wide cross-disability initiative, ECCL is led by the European Network on Independent Living, the European umbrella organization run by people with disabilities.

The Problem

Over one million people with disabilities are confined to long-stay institutions across Europe, often for their entire life. Despite recognition that people with disabilities have the right to live in the community as equal citizens, the legal, financial, and other reforms necessary for community living have not been implemented. The development of a wide range of quality community-based alternatives to institutionalization is crucial to realizing community-based living for all people with disabilities.

Actions Taken

ECCL's activities include:

- *Publishing* position papers and briefings and making recommendations on the right of people with disabilities to live in the community.
- Advocating before European institutions for policies that support community-based services, and
 highlighting the crucial importance of involving people with disabilities as equal partners in this
 work.
- Supporting ECCL members in their national advocacy activities.
- Facilitating exchange of information and the promotion of best practice in the development of
 community based services, through seminars and newsletters for ECCL members and other interested organizations.
- Launching a campaign calling for recognition of the right of all people with disabilities to live in the community and for a shift in government funding from long stay institutions to community-based services.

Disability Community Living

- Publishing an investigative article and video that highlights the appalling human rights abuses
 that take place on a daily basis in institutions for people with disabilities in Bulgaria, Romania and
 Serbia. The article and video also document the lack of real progress towards developing community-based alternatives.
 - o Yana Buhrer et al., *Institutions Remain Dumping Grounds for Forgotten People*, Newsletter of the European Coalition for Community Living (Issue No. 10), Oct. 2009, at 3. Available at: http://www.opensocietyfoundations.org/sites/default/files/eccl_20091031.pdf.
- Writing a report, which found that recipients of European Union's Structural Funds maintain large, archaic institutions for people with disabilities with the funds they receive, instead of using those funds to support community-based programs.
 - o European Coalition for Community Living (ECCL), Wasted Time, Wasted Money, Wasted Lives—A Wasted Opportunity? (2010). Available at: http://www.opensocietyfoundations.org/sites/default/files/wasted-opportunity-20100325.pdf.
 - o Video: Dumping Grounds for Forgotten People (Nov. 3, 2009). Available at: http://www.youtube.com/watch?feature=player_embedded&v=R_juS3mo534.
- Contributing to the work of the European Expert Group on the Transition from Institutional to
 Community-based Care, established in 2009 at the initiative of the European Commission. Within
 this group, ECCL made a significant contribution to three policy documents, and has taken part in
 trainings on the right to community living and developing community-based alternatives to institutional care for the European Commission and national governments.
 - o Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (2009). Available at: http://ec.europa.eu/social/main.jsp?langId=ro&catId=89&news-Id=614&furtherNews=yes.
 - Common European Guidelines on the Transition from Institutional to Community-based Care (2012) and the Toolkit on the Use of European Union Funds for the Transition from Institutional to Community-based Care. Available at: www.deinstitutionalisationguide.eu.

Results & Lessons Learned

- ECCL has provided organizations with information and contacts in planning, providing or advocating for community-based services.
- ECCL has established cooperation with policy and decision makers at the European level and is
 considered to be an expert on community living and deinstitutionalization by various European
 disability organizations.
- By insisting on the central role of people with disabilities in the planning and delivery of services,
 ECCL has gained the trust of user-led organizations and is considered a legitimate representative of their interests.

European Coalition for Community Living (ECCL)

E-mail: coordinator@community-living.info

Web: www.community-living.info

Example 7: Establishing Community-Based Supported Housing and Support Services in Moldova

Project Type

Advocacy

The Organization

Keystone Human Services International (KHSI) is a family of non-profit, non-governmental organizations, including working to create environments where all people can grow, exercise self determination and be participating, contributing and valued members of their communities. Through subsidiaries in Eastern Europe, including the Moldova Association (KHSMA), KHSI advances the independence of people in vulnerable situations due to disability, institutionalization, poverty, abandonment and exploitation.

Keystone Human Services International Moldova Association (KHSIMA), a non-governmental organization that promotes the human rights and social inclusion of people with intellectual disabilities,

The Problem

In Moldova, as in many Central and Eastern European countries, many persons with intellectual disabilities are placed in long-stay institutions with little or no contact with their families or communities. A major reason for this is the lack of alternative services and support at the community level.

Actions Taken

KHSIMA has worked effectively with the Ministry of Labor and Social Welfare to establish community-based supported housing and other support services as alternatives to institutionalization. KHSIMA's work includes:

- Developing pilot community-based alternatives to institutions, focusing on supported housing, shared living, family reunification, and foster care.
- Providing technical assistance for the development of legislation and financial mechanisms for community-based services.
- Documenting the deinstitutionalization process as tool for learning and replication and developing an evidence-base for deinstitutionalization in Moldova.

Disability Community Living

Results & Lessons Learned

- KHSIMA's work has shown that it is possible for non-governmental organisations to develop good quality community based services and to have a significant influence on policy and service development.
- KHSIMA's pilot community-based alternatives have been recognized by the Ministry of Labor and Social Welfare for their quality, and have helped to make deinstitutionalization and the development of community based services a Ministry priority, with KHSIMA a key Ministry partner.
- Policy and legislation for community-based services informed by implementing deinstitutionalization was adopted.

Keystone Human Services International Moldova Association (KHSIMA)

Chisinau, Moldova

E-mail: khsima@keystonehumanservices.org

Web: http://www.keystonemoldova.md

Example 8: Implementing Supported Decision Making Through "Representation Agreements" in Canada

Project Type

Advocacy

The Organization

Founded by citizens and community groups involved in the reform of British Columbia's adult guardianship legislation, the Nidus Personal Planning Resource Centre is a non-profit, charitable organization operating in British Columbia, Canada. Nidus helps persons with disabilities engage in personal planning in the areas of health care, personal care, legal affairs and financial affairs. Their website includes fact sheets, videos, legal forms and exercises that help advance supported decision making through representation agreements, enduring powers of attorney, health care consent, advance directives, living wills, personal care, adult guardianship and the prevention of abuse.

The Problem

Most states have a system by which a court can declare a person legally incompetent. Under these systems, many persons with mental disabilities lose their legal capacity to make decisions for themselves, sign contracts, vote, defend themselves in court or make their own health care decisions. Yet, Article 12 of the Convention on the Rights of Persons with Disabilities recognizes that persons with disabilities have the right to equal legal capacity. Therefore, it is necessary for State Parties to enact legislation or provide programs to provide assistance to persons with disabilities so that they may exercise this capacity.

Supported Decision-Making

A decision making approach according to which supporters, advocates or established systems may assist an individual with disability to make his or her own decision or express his or her will, provided the supporter, advocate or system is not in conflict of interest or in a position of power or undue influence over the individual. Supported decision making, as opposed to traditional substitute decision-making or guardianship, does not imply a transfer of decision making rights to third a party.

Convention on the Rights of Persons with Disabilities (CRPD)

Art. 12(2): States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Art. 12(3): States Parties shall take appropriate measures to provide access by persons with disabilities to support they may require in exercising their legal capacity.

Actions Taken

British Columbia enacted the Representation Agreement Act, which allows disabled persons with diminished mental capacity to enter into a representation agreement with a "support network", which empowers them to make their own decisions when possible by providing them with interpretative and communicative assistance. As noted by the UN:

One of the main innovations in the legislation is that [it does not define capacity, meaning that] persons with more significant disabilities [do not have to meet specific criteria to] enter into representation agreements with a support network. A person does not need to prove legal competency under the usual criteria, such as having a demonstrated capacity to understand relevant information, appreciate consequences, act voluntarily and communicate a decision independently, in order to enter this agreement.

A number of individuals and support networks have entered representation agreements as an alternative to guardianship or other forms of substitute decision-making. A community-based Representation Agreement Resource Centre [Nidus] assists in developing and sustaining support networks by providing information, publications, workshops and advice. The Centre also oversees a registry in which a network can post an agreement for other parties to view if required before entering a contract with the individual.

Representation Agreement Act, RSBC 1996, c 405 (Can.).

http://www.canlii.org/en/bc/laws/stat/rsbc-1996-c-405/latest/rsbc-1996-c-405.html

Results & Lessons Learned

For many years, States have assumed that the mere status of having an intellectual or psychological disability provides sufficient basis to strip a person of his/her legal capacity to exercise his/her rights. This new legislation from British Columbia represents a paradigm shift away from a paternalistic-oriented substituted decision making legal scheme towards a supported decision-making which respects the legal capacity of disabled persons. It is a reflection of the Preamble of the CRPD, which recognizes "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" and that "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them."

Nidus Personal Planning Resource Centre and Registry

Vancouver, Canada E-mail: info@nidus.ca Web: www.nidus.ca

5. WHERE CAN I FIND ADDITIONAL RESOURCES ON DISABILITY AND HUMAN RIGHTS?

A list of commonly used resources on disability and human rights follows. It is organized into the following categories:

- A. International instruments
- B. Regional instruments Europe
- C. Regional instruments Other
- D. Disability and Human Rights General
- E. Health Care and Disability
- F. Disability and Reproductive and Sexual Health
- G. Education and Disability
- H. Torture, Violence and Abuse and Disability
- Women and girls with Disabilities
- J. Children with Disabilities
- K. HIV/AIDs and Disability
- L. Disability and Development
- M. Community Living Generally
- N. Community Living Europe
- O. Supported Decision-Making
- P. Resources / Periodicals
- O. Toolkits
- R. Websites General
- S. Websites Community Living

Research Tips

A good starting point for general information on the CRPD is the UN Enable website (http://www.un.org/disabilities/). This is the official website of the Secretariat for the Convention on the Rights of Persons with Disabilities located within the UN Department of Economic and Social Affairs. This website features recent events and publications from UN sources as well as information, publications and links on thematic areas relating to disability and human rights. The home page also provides an option to sign up for the UN Enable Newsletter.

The UN Committee on the Rights of Persons with Disabilities also maintains a website (http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx) with links to its latest events, reports, jurisprudence and external links.

A. International instruments

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- International Labour Organization (ILO), Convention (No. 159) and Recommendation (No. 168) Regarding Vocational Rehabilitation and Employment (2008). http://www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_103529.pdf.
- UN Committee on Economic, Social and Cultural Rights, *General Comment 5: Persons with Disabilities* (1994). http://www2.ohchr.org/english/bodies/cescr/comments.htm.
- UN Committee on the Elimination of Discrimination against Women, *Recommendation No. 18: Disabled Women* (1991). http://www2.ohchr.org/english/bodies/cedaw/comments.htm.
- UN Committee on the Rights of the Child, General Comment 9: The rights of children with disabilities (2006). http://tb.ohchr.org/default.aspx?Symbol=CRC/C/GC/9.
- UN General Assembly, Beijing Declaration on the Rights of People with Disabilities (2000).
- UN General Assembly, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, UN Document A/RES/48/96 (December 20, 1993). http://www.un.org/documents/ga/res/48/a48ro96.htm.
- UN General Assembly, *Guidelines for the Alternative Care of Children*, UN Document A/RES/64/142 (February 24, 2010). http://www.unicef.org/protection/alternative_care_Guidelines-English.pdf.

B. Regional Instruments - Europe

- European Commission, Communication from the Commission to the European Parliament, the Council, the
 European Economic and Social Committee and the Committee of the Regions, European Disability Strategy
 2010-2020: A Renewed Commitment to a Barrier-Free Europe, COM/2010/0636 (November 2010).
 http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:en:NOT.
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- Council of Europe, Recommendation of the Committee of Ministers to member states on deinstitutionalisation and community living of children with disabilities, CM/Rec(2010)2 (February 3, 2010). https://wcd.coe.int/ViewDoc.jsp?id=1580285&Site=CM.

- Council of Europe, Recommendation of the Committee of Ministers to member states on the education and social inclusion of children and young people with autism spectrum disorders, CM/Rec(2009)9 (October 21, 2009). https://wcd.coe.int/ViewDoc.jsp?id=1526657&Site=CM.
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- Council of Europe: Committee on the Rehabilitation and Integration of People with Disabilities, Recommendations and Guidelines to promote community living for children with disabilities and deinstitutionalization, as well as to help families to take care of their disabled child at home (December 31, 2007).
- Council of Europe, European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), CPT Standards: European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), CPT/Inf/E(2002)1 Rev. 2011 (2011), pp. 48-63. www.cpt.coe.int/en/documents/eng-standards.doc.
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C. Regional Instruments - Other

- Organization of American States, Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (June 7, 1999). http://www.oas.org/juridico/english/treaties/a-65.html.
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D. Disability and Human Rights - General

- Cojocariu C, Handicapping Rules: The Overly Restrictive Application of Admissibility Criteria by the European Court of Human Rights to Complaints Concerning Disabled People (London: Sweet & Maxwell, 2011). http://www.interights.org/campeanu/index.html.
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- Inclusion International, Priorities for People with Intellectual Disabilities in Implementing the United Nations Convention on the Rights of People with Disabilities: The Road Ahead. http://ii.gmalik.com/pdfs/UN_brochure_screen.pdf.
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E. Health Care and Disability

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F. Disability and Reproductive and Sexual Health

- Center for Reproductive Rights, *Reproductive Rights and Women with Disabilities: Human Rights Framework* (2002). http://www.handicap-international.fr/bibliographie-handicap/4PolitiqueHandicap/groupes_particuliers/Femmes_Genre/reproductive_rights.pdf.
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G. Education and Disability

- Human Rights Watch, Futures Stolen: Barriers to Education for Children with Disabilities in Nepal (August 2011). http://www.hrw.org/reports/2011/08/24/futures-stolen.
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H. Torture, Violence and Abuse and Disability

- Equality and Human Rights Commission (UK), *Hidden in plain sight: Inquiry into disability-related harassment* (2011). http://www.equalityhumanrights.com/legal-and-policy/inquiries-and-assessments/inquiry-into-disability-related harassment/hidden-in-plain-sight-the-inquiry-final-report/ [available in BSL and easy read formats].
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6. WHAT ARE THE KEY TERMS RELATED TO DISABILITY AND HUMAN RIGHTS?

Α

Accessibility

Accessibility describes the enabling of persons with disabilities to access, on an equal basis as others, the physical environment; transportation; information and communications, including information and communications technologies and systems; and to other facilities and services open or provided to the public, both in urban and rural areas. (CRPD Art. 9)

Accommodation - Reasonable

Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. (CRPD Art. 2)

Assistive Devices; Assistive Technology

Assistive devices or technology are designed, made or adapted to increase mobility, hearing, vision and communication capacities and enable persons with disabilities participate in society. Products may be specially produced or generally available for people with a disability. (World Health Organization)

В

Barriers

Barriers can take a variety of forms, including those relating to the physical environment or to information and communications technology (ICT), or those resulting from legislation or policy, or from societal attitudes or discrimination. The result is that persons with disabilities do not have equal access to society or services, including education, employment, health care, transportation, political participation or justice.

C

Community living

Community living is realized when persons with disabilities live in the community and participate in society as equal citizens. The focus of community living is to create an enabling social and physical environment so that all persons are able to be included and participate in a community.

Community-based services

These are the range of services and support that enable persons with disabilities to live in the community, participate in community life and to pursue educational and employment opportunities. The range of services include anything required to enable community living and include housing, supported housing, access to mainstream services such as health care, supported employment, day services and care in the family home, social work support, the provision of independent living skills such as teaching on cooking or managing personal finances.

Communication

Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology. (CRPD Art. 2)

D

Deinstitutionalization

This term is used to describe the process of closing or scaling down long-term, residential institutions. Deinstitutionalization should be coupled with the development of community living options in order to be successful by providing alternatives for former residents of institutions.

Disability

The Convention on the Rights of Persons with Disabilities ("CRPD") does not provide a definition of disabilities, but instead provides a broad description intended to be widely inclusive. The CRPD explains in Article 1 that 'persons with disabilities' includes 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. This description of disability shifts the focus towards social and environmental barriers that hinder an individual's participation in society rather than on the individual's impairments.

Ε

Education – Inclusive

Inclusive education focuses on the right of persons with disabilities to participate in the general education system and to not be discriminated against on the basis of disability. Schools must provide reasonable accommodations and the support required to facilitate the effective education of persons with disabilities. (CRPD Art. 24)

Equalization of Opportunity

Equality of opportunity is one of the general principles of the CRPD listed in Article 3. It is the "process through which the general system of society, such as the physical and cultural environment, housing and transportation, social and health services, educational and work opportunities, cultural and social life, including sports and recreational facilities, are made accessible to all."¹⁰¹

G

Guardianship

This term refers to the legal arrangement where the court may deem an individual to lack capacity to make decisions for them self and appoint a person, called the guardian, who the court authorizes to make decisions on the individual's behalf. Guardianship is also referred to as substituted decision-making. For the human rights-based approach to individual capacity and decision-making, please see "supported decision-making."

¹⁰¹ UN Enable, "World Programme of Action Concerning Disabled Persons." http://www.un.org/disabilities/default.asp?id=23.

Н

Health

Complete physical, mental, and social well-being rather than merely the absence of disease or infirmity. (World Health Organization)

I

Impairment

Any loss or abnormality of psychological, physiological or anatomical structure or function. 102

Informed consent

A process by which a patient makes informed choices about their own health care and provides consent to the provider to carry out that care. The patient must be provided with adequate and understandable information, including on the treatment's purpose, alternative treatments, risks, and side-effects, in order for the consent to be valid. Persons with disabilities have the right to provide or withhold informed consent for any and all medical interventions.

Institution

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or congregated and are denied the opportunity to make decisions about their lives or participate in the community as equal citizens. An institution is not defined merely by its size. While an institution may be a large, long-term residence facility, it is any place in which people do not have, or are not allowed to exercise control over their lives and day to day decisions.

Institutionalization

Institutionalization is used to describe the practice of confining a person with a disability to a residential institution, often against their will, and depriving them of their right to live independently and the ability to make decisions about their lives.

L

Language

"Language" includes spoken and signed languages and other forms of non-spoken languages. (CRPD Art. 2)

P

Personal Assistant

Persons with disabilities may chose to employ a personal assistant to ensure their independence. Personal assistants are employed by the person with a disability. The person with a disability manages and controls who to hire and fire, and authorizes and manages the type and method of services provided, when services are required, the work schedule, and training of the personal assistant.¹⁰³

¹⁰² UN Enable, "World Programme of Action Concerning Disabled Persons." http://www.un.org/disabilities/default.asp?id=23.

¹⁰³ Independent Living Institute, "Personal Assistance: Key to Independent Living as Illustrated by the Swedish Personal Assistance Act." http://www.inde-pendentliving.org/node/1193.

R

Reasonable accommodation

See "Accommodation - reasonable".

Rehabilitation

Rehabilitation refers to "a goal-oriented and time-limited process aimed at enabling an impaired person to reach an optimum mental, physical and/or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment."¹⁰⁴

S

Sign Language Interpretation

A sign-language interpreter is a person trained to interpret information from sign language into speech and vice versa. There are many different sign languages across the world.

Social Determinants of Health

Social determinants refer to underlying factors that determines an individual's health. Social determinants include access to safe and potable water and adequate sanitation; an adequate supply of safe food, nutrition and housing; healthy occupational and environmental conditions; access to health-related education and information, including on sexual and reproductive health; education; availability of social services; and income.

Substituted decision-making

See Guardianship.

Supported decision-making

Supported decision-making is a decision making approach according to which supporters, advocates or established systems may assist an individual with disability to make his or her own decision or express his or her will, provided the supporter, advocate or system is not in conflict of interest or in a position of power or undue influence over the individual. Supported decision making, as opposed to traditional substitute decision-making or guardianship, does not imply a transfer of decision making rights to third a party.

U

Universal Design

Universal design refers to the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. (CRPD Art. 2)

¹⁰⁴ UN Enable, "World Programme of Action Concerning Disabled Persons." http://www.un.org/disabilities/default.asp?id=23.