

CHAPTER 5: THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK

UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Article 10, Right to Life:

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.

Article 11, Situations of Risk and Humanitarian Emergencies:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

OBJECTIVES

The background information and exercises contained in this chapter will enable participants to work towards the following objectives:

- Define the right to life
- Define the right to protection in situations of risk and humanitarian emergencies
- Understand the interrelationship between the right to life and protection in situations of risk and other human rights
- Identify ways in which the right to life of people with disabilities and protection in situations of risk have been promoted or denied
- Describe the provisions regarding the right to life and protection in situations of risk and humanitarian emergencies in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

For disabled people like me who are constantly up against society's belief that our lives are of less quality, the right to life article is literally a matter of life and death. To participate in its development is of vital importance.

— Jane Campbell, British Disability Rights Advocate speaking about the right to life provision in the UK Human Rights Act

GETTING STARTED: THINKING ABOUT THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK

Disability is profoundly linked to the right to life. People with disabilities are frequently denied their right to life, as well as their right to protection in situations of risk in many contexts, such as natural disaster, armed conflict, and other humanitarian emergencies.

Harmful cultural practices may directly violate the right to life of people with disabilities. Where resources are limited, preferential treatment of boys in the provision of food and medical attention directly impacts girls with disabilities and their right to life. In some cultures and societies, women and girls with disabilities are, like other women, subjected to practices such as widow burning and dowry killings. The practice of female genital mutilation often results in death from hemorrhaging and can create life-threatening conditions later for women during childbirth.

Other practices likewise implicate the right to life of people with disabilities. The practice of euthanasia in many countries takes the form of withholding life-saving treatment to a newborn child with a disability. Disability organizations have exposed cases where adults or children with disabilities have died at the hands of medical personnel who unilaterally decided that their life was “not worth living.” These cases have included the imposition of a “do not resuscitate order” (DNR order) on the medical chart of patients with non life-threatening health care conditions. (See text box below). A DNR order is intended to prevent attempts at Cardiopulmonary Resuscitation (CPR) if a patient goes into cardiac or respiratory arrest.

Barriers to Enjoyment of the Right to Life

- Attitudes that life with a disability is “not worth living”
- Life-threatening conditions in institutions and orphanages
- Harmful cultural practices such as female genital mutilation, dowry killing and widow burning
- Selective abortion based on disability
- Infanticide and neglect of newborn infants with disabilities
- Imposition of “do not resuscitate” (DNR) orders
- Withholding of life-sustaining treatment for people with disabilities in hospital settings
- Domestic violence, particularly against women and girls with disabilities
- Failure to be inclusive of people with disabilities in disaster management, programs for refugees and internally displaced persons, and other humanitarian programs
- Lack of access to adequate food, clean water, shelter and basic survival needs

Disability advocates have invoked the right to life in order to oppose physician-assisted suicide. Other practices of concern include abortion on the basis of disability. In developing countries, the mortality rate of children with disabilities is frequently disproportionately high because such children may not receive adequate health care, including immunization from childhood



diseases. Health care providers frequently underestimate the quality of life enjoyed by people with disabilities. Consequently, people with disabilities are sometimes not given life-saving interventions that would otherwise be provided to patients.

The enjoyment of the right to life by people with disabilities is inextricably linked to the enjoyment of other human rights. For example, if a person with a disability has no access to health care or rehabilitation services, their right to life may well come under threat. Subjecting people with disabilities to dangerous working environments or to conditions that amount to forced labor is likewise potentially life threatening.

Access to information is another precondition to the enjoyment of human rights and, in some instances, is directly related to the enjoyment of the right to life. Thus, the failure of officials to provide important information in accessible formats (e.g., HIV/AIDS prevention programs or emergency evacuation procedures in times of natural disaster) may infringe upon the right to life of people with disabilities. These illustrations demonstrate that human rights are indivisible, interdependent, and interconnected. What is clear is that without respect for the right to life, all other human rights are without meaning.

Guiding Principles on “Do Not Resuscitate” Orders

The following Guiding Principles were developed by the British Columbia Association for Community Living to ensure that people with developmental disabilities are not subjected to the inappropriate use of “do not resuscitate” orders (DNR orders):

- A disability is not a terminal illness;
- The decision of whether someone is at the end stages of life must be made independently of the person’s disability;
- All people at the end stages of life have the right to care and comfort measures, with an emphasis on alleviating pain;
- DNR orders should only be considered when someone is in the irreversible terminal stages of an illness or when the process of giving CPR could potentially cause significant trauma to the individual;
- Physicians should seek consent for a DNR order from the individual or an authorized substitute decision-maker before the order is placed on a person’s medical chart;
- People with developmental disabilities who are receiving treatment for a treatable health care condition should be given CPR, unless the process of giving CPR could potentially cause significant trauma to the individual.¹

EXERCISE 5.1: Threats to Life

Objective: To understand threats to the right to life of people with disabilities

Time: 30 minutes

Materials: Chart paper and markers or blackboard and chalk

¹ “Do Not Resuscitate Orders Policy.” *British Columbia Association for Community Living*. <http://www.bcacl.org/index.cfm?act=main&call=788F8794>

1. Introduce:

Explain that people with disabilities face many threats to their life, not necessarily from their disability but because of it. These may include the dangers of living in institutions, decisions made by the medical profession, social attitudes, and public policies like eugenics. Endemic poverty may also threaten their quality of life and health, along with armed conflict or natural disaster.

2. Discuss:

Divide participants into pairs and ask each pair to:

- Share some examples from their own experiences or the experiences of people in their communities of such dangers to survival;
- Try to explain the cause of such threats to the survival of people with disabilities;
- Refer to “Barriers to the Enjoyment of the Rights to Life” (see text box above) or formulate a new list from responses of group.

3. Report/Analyze:

Ask each pair to report the causes they recognized for such threats to life. List these on a chart/blackboard as they are reported.

- Ask participants if these causes can be grouped into categories (e.g., poverty, cultural or societal attitudes, medical decisions, public policies);
- What actions could be taken to address these causes and protect the right to life of people with disabilities? Are there preventive measures that may be taken to reduce life-threatening situations? Are there advocacy strategies that might help?

WHAT DOES HUMAN RIGHTS LAW HAVE TO SAY ABOUT THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK?

The right to life is the most fundamental of all human rights. Article 3 of the **Universal Declaration of Human Rights** (UDHR) provides that “[e]veryone has the right to life, liberty and security of person.”² Article 6(1) of the **International Covenant on Civil and Political Rights** (ICCPR) provides:

*Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.*³

The right to life is not absolute, however. For example, the death of a combatant during a lawful act of war under international humanitarian law does not violate the right to life. In certain limited circumstances, such as self-defense, a law enforcement official may take the life of someone. Some jurisdictions permit capital punishment for serious crimes, a practice which Article 6 of the ICCPR acknowledges but also narrowly limits in those countries where the practice exists.

When a state recognizes the right to life in international law, it assumes various duties. The **UN Charter** prohibits the threat or use of force by any State against another State, except in exercise of the inherent right of self-defense.⁴ The **Human Rights Committee**, which monitors

2 See <http://www.unhcr.org/refugees/udhr/lang/eng.htm>

3 See <http://www.ohchr.org/english/law/ccpr-one.htm>

4 See <http://www.un.org/aboutun/charter>



the ICCPR, has stated in **General Comment 6** that “States have the supreme duty to prevent wars, acts of genocide and other acts of mass violence causing arbitrary loss of life.”⁵ The State’s obligations include making every effort to avert the danger of war and to strengthen international peace and security. These obligations constitute the most important condition for the safeguarding of the right to life. States may not limit the right to life during times of war or emergency and are required to provide protection and safety to persons who are non-combatants as a matter of **international humanitarian law**.

States must also refrain from action that may intentionally take away life. The **Human Rights Committee** has condemned the practice of infanticide for infants with disabilities and noted that it “is gravely concerned at reports that new-born handicapped infants have had their lives ended by medical personnel.”⁶ The **Committee on the Rights of the Child** urged States to “review and amend laws affecting disabled children which are not compatible with ...the Convention, for example legislation which denies disabled children an equal right to life, survival and development (including, in those countries which allow abortion, discriminatory laws on abortion affecting disabled children, and discriminatory access to health services...).”⁷

The Human Rights Committee has stressed that the protection of the right to life requires that States adopt positive measures designed to protect life. These may include measures to increase life expectancy, decrease infant and child mortality, combat disease, and provide rehabilitation, adequate food, clean water shelter, and other basic survival needs.

Rule 2.3 of the **UN Standard Rules** requires that “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.”⁸

The CRPD reflects these concerns about the right to life of people with disabilities. In Article 10, the CRPD recognizes the inherent right to life for people with disabilities and, in addition, requires States to “take all necessary measures” to ensure the enjoyment of that right by people with disabilities, on an equal basis with others. Article 11 of the CRPD requires positive measures of protection and safety for people with disabilities affected by situations of humanitarian emergencies and risk. Article 11 is closely connected to Article 10 insofar as war and other acts of mass violence continue to take the lives of thousands of innocent human beings every year.

In sum, States have the obligation to **respect, protect, and fulfill** the right to life of people with disabilities and their right to protection and safety in situations of risk and humanitarian emergency. In meeting their obligation to *respect* the right to life of people with disabilities, States must refrain from directly or indirectly infringing on disabled peoples’ enjoyment of the right to life. States must also refrain from policies that enforce discriminatory practices that may impact their right to life, including in times of humanitarian emergency.

The obligation to *protect* includes, among other things, the adoption of all appropriate legislative, administrative, and other measures to prevent threats to the life of people with disabilities by state officials, as well as third parties. Protective measures could include careful monitoring of all settings where people with disabilities live or receive services, whether publicly or privately operated. Transitioning people with disabilities into community-living situations with appropriate

5 See <http://www.umn.edu/humanrts/gencomm/hrcom6.htm>

6 Concluding Observations of the Human Rights Committee for The Netherlands. UN Doc. CCPR/CO/72/NET (2001). <http://www1.umn.edu/humanrts/hrcommittee/netherlands2001.html>

7 See <http://www.unhchr.ch/html/menu2/6/crc/doc/days/disabled/pdf>

8 See <http://www.ohchr.org/english.law/opportunities.htm>

supports and out of institutions would also constitute protective measures. In the context of humanitarian crisis situations, protective measures could include disaster preparedness planning with the participation of people with disabilities and the provision of services that are inclusive of people with disabilities, such as appropriate evacuation procedures and refugee assistance programming.

The obligation to *fulfill* the right to life and protection in situations of risk requires States to, among other things, adopt positive measures to ensure the enjoyment of the right to life. Such measures might include information campaigns that seek to dispel the myth that people with disabilities have lives “not worth living” or training programs for disaster preparedness and relief workers that include the care of people with disabilities in the general population.

EXERCISE 5.2: What Rights to Life and Protection in Situations of Risk Does the CRPD Affirm?

Objective: To review and understand Articles 10 and 11

Time: 30 minutes

Materials: Chart paper and markers or blackboard and chalk

1. Review:

Assign either Article 10 or Article 11 of the CRPD to small groups of participants. Ask each group to discuss and paraphrase its article in common language and give some examples of how that right could be enjoyed and make a difference for people with disabilities.

2. Paraphrase/Give examples:

Read each section of Articles 10 and 11 aloud and ask the assigned group to give their paraphrase. Discuss the meaning of the section until everyone can agree on a paraphrase. Especially ask:

- What does “inherent” mean?
- What might “necessary measures” refer to in each article?
- Ask for examples of armed conflict, humanitarian emergencies, and natural disasters, focusing on those experienced by this community.

Write the final paraphrase of Articles 10 and 11 on chart paper and post.

After each section ask for examples of how that right could be enjoyed and make a difference for people with disabilities. What “necessary measures” might be implemented by States to ensure the right to life and protection in situations of risk? Encourage participants to be as specific as possible.

3. Discuss:

How can Articles 10 and 11 of the CRPD be used to set national disability rights agendas and formulate platforms of action for submission to political parties or government decision-makers? What types of actors might disabled peoples organizations target for advocacy around the right to life and protection in situations of risk (e.g., Ministries of Health, humanitarian and disaster assistance organizations, the United Nations High Commissioner for Refugees)?



THREATS TO LIFE IN INSTITUTIONS

People with disabilities living in institutions are at high risk for human rights abuse, including infringements on the right to life. Placing people in large-scale institutions, instead of providing for living arrangements within the community, is isolating and makes close monitoring of conditions nearly impossible. Mental Disability Rights International (MDRI) has documented egregious violations of the right to life for children and adults with psycho-social and other types of disabilities who are housed in dismal and dangerous institutions. The human rights reports published by MDRI reveal unhygienic conditions of detention, excessive use of physical restraints, lack of adequate food, water, clothing and medical care, and other life dangerous and life-threatening conditions, including instances of patients freezing to death. People with disabilities face other dangers in institutional settings. In emergency situations, institutions have so often failed to take appropriate action when doing so could have averted threats to life. Recent cases in Russia and Hurricanes Katrina and Rita in the United States reveal that all too frequently, people with disabilities are simply left behind. (See text box). MDRI and many other disability rights organizations advocate for the closure of such facilities and enjoyment of the right to live independently and in the community, with appropriate supports (See also Chapter 6, “Freedom from Torture and Other Forms of Abuse,” p. 83).

Lives Lost in Minnesota Institutions: The Remembering with Dignity Campaign

Remembering with Dignity is a coalition of disability rights and advocacy organizations founded in 1994 working to honor people who lived and died in Minnesota’s state institutions. The goals of the campaign include:

- Restoring over 12,500 unmarked graves in institution cemeteries. Graves currently identified with only a numbered cement block – or with no marker at all – will be honored and marked with the person’s name, date of birth and date of death.
- Collecting and recording oral histories of people with disabilities, particularly those who have lived in institutions.
- Organizing people with disabilities to ensure full integration in community life and to prevent a return to institutionalization.
- Raising public awareness about people with developmental disabilities.
- Demanding an apology from the State of Minnesota for its treatment of people with disabilities kept in institutions.

Campaign Achievements:

- Obtained release of the names of people buried in the Faribault cemeteries by working with the Department of Human Services, Attorney General's Office, Disability Law Center and Faribault Regional Center.
- Reconstructed incomplete lists of the earliest burials at the former Faribault State Hospital. There is now a more complete record of the individuals who were buried anonymously there.
- Between 1997 and 2005, the state legislature approved the granting of \$725,000 for marking 12,500 graves of people buried in state hospital cemeteries.
- Placed over 2500 gravestones at cemeteries of former state hospitals.
- State cemetery in Cambridge was officially named the “Garden of Remembrance”.
- Introduced a resolution asking the state legislature for a formal public apology to Minnesotans who were institutionalized and apology from the Governor in recognition of harms caused by massive institutionalization.⁹

⁹ “Remembering with Dignity, Read the Apology Resolution.” 2005. *Advocating Change Together (ACT)*. http://www.selfadvocacy.com/programs_rwd_apology.htm

EXERCISE 5.3: Advocating for Community-Based Living

Objective: To consider strategies for addressing threats to the right to life of people with disabilities living in institutions and advocacy on community-based living

Time: 30 minutes

Materials: Chart paper and markers or blackboard and chalk

1. Introduce:

Explain that people with disabilities are still housed in large scale institutions in many parts of the world and that community-based living is still a new phenomenon in many places. Disability groups such as Mental Disability Rights International in the US and the Mental Disability Advocacy Center in Hungary are working to expose abuses in institutional settings and promote community-based living.

2. Discuss:

Divide participants into pairs and ask them to:

- Share examples of situations in their own community/country/region where people with disabilities are not being provided with the opportunity to live in the community;
- Identify threats to the life and survival of persons with disabilities living in institutions;
- Identify the barriers that continue to prevent people with disabilities from living in the community.

3. Report/Analyze:

Ask each pair to report on the situations identified, the threats to life/survival, and the barriers that prevent community living. List these on the chart as they are reported.

- What actions could be taken to address these issues and protect the right to life of people with disabilities?
- What type of advocacy might be most effective (e.g., education, dialogue, documenting and reporting, media campaigning, court action)?
- Who needs to be informed in order to take action?

Russian Fire Safety Failures

Russia records nearly 18,000 fire deaths a year, several times the per capita rate in many other countries. In some of the worst cases, people with disabilities are the most affected. For example, in Russia on three days in December 2006:

- On December 9, 46 women died in a fire in Moscow in a drug rehabilitation institution in southern Moscow. Doors were allegedly locked, and the metal barred windows could not be opened.
- On December 11, eight people died in a fire at a psychiatric institution in the town of Taiga, Siberia.
- Also on December 11, a fire broke out in an institution for children with psycho-social and intellectual disabilities, but all escaped serious injury.¹⁰

10 "Russia: Government must establish independent investigation into hospital fires." 12 Dec. 2006. *Disability World*. http://www.disabilityworld.org/01_07/russianfires.shtml



EUGENICS AND NAZI-ERA MASS KILLING

While people with disabilities throughout the ages and in most societies have faced stigma and discrimination on account of their differences, the rise of the **eugenics movement** in America and Europe during the late nineteenth century led to the specific targeting of people with disabilities for widespread abuses, and ultimately, mass murder in Nazi Germany. Eugenacists warned that the birthrate of the “fit” and “talented” members of society had declined to an alarming extent, while less-desirable members of society continued to multiply. In the most egregious cases, people with disabilities were singled out for mass murder, as in the Nazi genocidal programs targeting people with disabilities living in institutions. (See text box) Children with disabilities were targeted for systematic killing under a separate Nazi program that preceded the mass murder of adults with disabilities. A decree mandated the reporting of all newborns and infants under three years of age with suspected “hereditary diseases” including, among others, Down’s Syndrome, deafness, blindness, paralysis, and congenital physical disabilities. A variety of particularly horrific killing methods were used, including massive lethal injection to the heart, poison administered over an extended period of time, gassing with cyanide or chemical warfare agents, starvation, and exposure. The latter two methods were sometimes selected so that doctors could attribute the death to “natural causes” or routine illness such as pneumonia. Estimates suggest that at least 5,000 children with disabilities were killed under the euthanasia program during World War II. More recently, human rights reports have exposed eugenics-like programs in North Korea where people with disabilities are sent to dismal internment camps and are categorized and then separated according to their disability. For example, camps exist for persons of short stature who are rounded up and relocated and are prohibited from marrying or having children. People with mental disabilities are detained in camps known as ‘Ward 49’ where they endure particularly harsh and life threatening conditions.¹¹

SITUATIONS OF RISK: NATURAL DISASTER AND ARMED CONFLICT

Recent humanitarian emergencies – both natural disasters such as the Asian Tsunami and crises resulting from armed conflict such as Kosovo, Liberia, and Iraq – disclose the failure of large-scale assistance operations conducted by international agencies to respond appropriately to the needs of disabled beneficiaries. A UN commissioned review of overall humanitarian responses and the Tsunami Evaluation Coalition report found that transparency, communication, and accountability to affected populations was notably lacking in relief efforts.¹² These reviews suggest that humanitarian organizations were largely unprepared and ill-equipped to address even the most basic needs of people with disabilities in the provision of shelter, food, water, and health care services.

Likewise, Hurricanes Katrina and Rita in the United States demonstrated the failure of US federal-level disaster preparedness for meeting the needs of persons with disabilities. During Hurricane Katrina and its aftermath, people with disabilities were trapped in their homes for days and provided with completely inadequate medical care in shelters. Many disabled people died as a result. Later, they were often unable to access assistance programs. For example,

11 “North Korea Puts Disabled in Camps.” 10 Nov. 2006. *Disabled People’s International*. <http://v1.dpi.org/lang-en/resources/details?page=753>

12 Cosgrave, John. “Tsunami Evaluation Coalition: Initial Findings.” Dec. 2005. *Tsunami Evaluation Coalition*. <http://www.tsunami-evaluation.org/NR/rdonlyres/576D8E84-27DB-44DC-8663-83AB9D5BF614/0/lowresA520060221.pdf>

shelters provided to survivors were not accessible to people who use wheelchairs.¹³ Armed conflict, whether international or national in character or localized conflict involving militias and gangs, presents a major threat to human life and security. Conflict is a source of disabling conditions of all kinds and can exacerbate or create secondary disabilities for people with disabilities. There are many adverse effects of conflict on people with disabilities, including the break-up of support networks of family and community, displacement or abandonment, and destruction of health, rehabilitation, and transportation infrastructure. The devastating impact of armed conflict on the mental and psycho-social well-being of the affected population is also a major risk factor.

Operation T-4

In 1933, the German Ministry of Justice proposed legislation authorizing physicians to grant “mercy deaths” in order to “end the tortures of incurable patients, upon request, in the interests of true humanity.” The legislation was never formally enacted, yet its objectives – not euthanasia but the mass killing of people with disabilities – were implemented in the form of a program known as Operation T-4.

Under the top secret T-4 program, patients in all government- and church-run sanatoria or nursing homes with a wide range of physical, sensory, and mental disabilities perceived to be hereditary in nature were targeted for extermination. Included were those with blindness, deafness, epilepsy, intellectual disabilities, autism, depression, bipolar disorder, mobility impairments, or congenital disabilities. The pool of victims later expanded to include sick residents of poorhouses and old age homes.

The T-4 program served as a testing ground for the Nazi killing machine. At the outset T-4 victims were killed by lethal injection, but they soon became the first victims of an experimental gas chamber at Brandenburg Prison. In a test run in January 1940, patients diagnosed with mental disabilities were gassed to death in an experiment intended to show the effectiveness of poison gas over other methods of killing. Nazi techniques of outfitting killing chambers with false showerheads and bathroom tiling developed under the T-4 program were later used extensively in the notorious death camps like Auschwitz and Birkenau.¹⁴

Although many international documents recognize that persons with disabilities are a particularly at-risk population in times of humanitarian crisis, few specific policies and practices have resulted in humanitarian action. Nonetheless, international humanitarian assistance organizations, including both UN specialized agencies and large private voluntary organizations, do identify their work as “rights-based” and protection-oriented. Few of these groups have any disability-specific policies and staff members are ill-equipped to accommodate people with disabilities in their programming. Advocacy by disabled peoples organizations is an essential tool in ensuring that humanitarian assistance programs take into account the specific needs of people with disabilities in their preparation for and response to humanitarian crises. People with

13 See <http://www.nobodyleftbehind.org>

14 Lord, Janet E. “The Application of the Laws concerning Genocide and Crimes against Humanity to People with Disabilities” in *Encyclopedia of Genocide and Crimes against Humanity*, (Dinah L. Shelton, ed., Macmillan Reference USA, 2004).



disabilities and their representative organizations must participate in all programs designed to reach affected populations in times of crisis.

EXERCISE 5.4: People with Disabilities in Situations of Risk

Objective: To consider the needs of persons with disabilities in natural disasters and identify strategies to enhance the protection of people with disabilities in emergency preparedness

Time: 45 minutes

Materials: Chart paper and markers or blackboard and chalk (optional)

1. Brainstorm:

Ask participants to identify natural disasters that can take place in their community (e.g., blizzard, tornado, hurricane, earthquake). List these. Ask the group to create three profiles of people with disabilities in their communities. Encourage diverse profiles, including different ages, disabilities (including psycho-social disability), ethnic minority status, and living arrangements (e.g., living alone, in an institution, with family). Collect the profiles and select a diverse sample to use in role plays.

2. Imagine:

Divide participants into small groups and give each group a profile with these instructions: Your group is going to role play what might happen in a typical natural disaster.

- Choose one of the typical disasters identified in Step 1 to role play using the profile you have received. What really happens in your community in these crises (e.g., loss of electricity, gas or water, loss of most forms of communication, loss of assistance devices such as artificial limbs, crutches, hearing aids, eye glasses, loss of means of transportation, inability to meet basic needs such as food, water, shelter, latrines, and health care services)?
- One person should play the person with disability and others should develop support (or non-support) roles (e.g., family member, neighbor, police, relief worker, medical personnel).
- You may choose to role play a worst-case scenario, a best-case scenario, or both.

3. Present:

Ask each group to present its role play. Afterward, form a panel of those who took the role of the person with disability and “interview” them about their experiences.

- What kinds of responses were or would have been helpful in this situation?
- What kinds of responses were or would have been unhelpful?

4. Discuss:

Emphasize that although people with disabilities have a human right to life and that States must take specific measures to ensure their protection and safety in emergencies, the needs of people with disabilities are often overlooked in real crises or situations of armed conflict.

- What can be done to ensure protection of this right?
- Who is responsible to see that this protection is provided?
- Does your community have a disaster preparedness plan?
- Does it include such protections? What can you do to help first responders and aid workers to better include disability issues in their work?
- **Optional:** Have each group present a disaster preparedness plan that takes into account the needs of persons with disabilities or a checklist of tips for humanitarian

workers. (For examples of checklists, see text box below and the following website: <http://www.nobodyleftbehind.org>).

Checklist for Community Disaster Preparedness for Persons with Mobility Impairments

- Do get involved in public disaster planning in your community.
- Don't wait until a disaster, and people with disabilities are left behind.
- Do get prepared at home and then expand preparedness to public settings.
- Don't assume evacuation plans exist for people with disabilities.
- Do form an "Accessibility Committee" at work and other public places.
- Don't assume you will be evacuated with everyone else.
- Do explore evacuation options with emergency managers and others.
- Don't overlook alternatives, such as evacuation chairs.
- Do share the plan with all those in the building/area and then practice it.
- Don't wait until the disaster to raise awareness on disability issues.
- Do learn about disasters and share that knowledge.
- Don't forget to check shelter accessibility and service animal provisions.
- Do talk to local emergency managers about disability rights.
- Don't wait to train and educate others about the plan procedures.
- Do initiate talking to managers, responders and Red Cross/Red Crescent.
- Don't forget to develop a network of supporters who can assist you.
- Do remember to participate so that "Nobody is Left Behind"!¹⁵

DISABILITY ADVOCACY ON THE RIGHT TO LIFE

Disability advocacy has, in recent years, begun to address how a growing "right to die" or "assisted suicide" movement may impact the right to life of people with disabilities. These movements claim to provide people with significant and/or terminal illnesses or disabilities the right to choose death according to their own timing and place. The major question of concern for disability advocates is whether death in such cases is really a free and informed choice or merely a response to external pressure and negative messages about the "burden" of disability or assumptions about quality of life. Some disability organizations, such as the US-based group, Not Dead Yet,¹⁶ are confronting the "right to die" movement and challenging the apparent devaluation of the life of a person with a disability. Such organizations oppose attempts to legalize physician-assisted suicide and address other medical and bioethics issues. Other disability advocates are addressing the right to life in other contexts, such as working to ensure that people with disabilities have access to quality health care, including immunization programs or health education. Still others are working on ensuring that emergency preparedness addresses the needs of people with disabilities in a variety of situations of risk. In these, and many other contexts, activists with disabilities must work in cooperation with other stakeholders to advocate on right-to-life issues.

15 "Individual Disaster Preparedness, Disaster Do's and Don'ts Checklists." *Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments*. <http://www.nobodyleftbehind2.org>

16 Not Dead Yet. *notdeadyet.org*. 2005. <http://www.notdeadyet.org/docs/about.html>



EXERCISE 5.5: Making a Commitment to Promote the Right to Life and Protection in Situations of Risk

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to life and protection in situations of risk, the group members are ready to think about taking concrete action;
- Acknowledge that, although there is still much planning and information gathering to do, commitment to creating change is also very important;
- Explain that you would like to ask each participant to name one individual action, however small, that she or he is willing and able to take in the next month to promote the human right of people with disabilities to the right to life and protection in situations of risk.

To plan advocacy initiatives for the human rights of people with disabilities, see Part 3, “Advocacy! Taking Action for the Human Rights of People with Disabilities,” p. 229.

USEFUL RESOURCES ON THE RIGHT TO LIFE AND PROTECTION IN SITUATIONS OF RISK:

- *An ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*. US Department of Justice:
<http://www.ada.gov/publicat.htm#Anchor-Emergency>.
- British Columbia Association for Community Living: <http://www.bcacl.org/index.cfm?act=main&call=788F8794>
- International Disability Rights Monitor, *Disability and Tsunami Relief Efforts in India, Indonesia and Thailand* (Center for International Rehabilitation: September 2005): <http://www.disability.ws/idrm>
- Mental Disability Rights International: <http://www.mdri.org>
- National Organization on Disability, Disaster Readiness Tips for People with Disabilities Series: <http://www.nod.org>
- Nobody Left Behind Research Project, Research and Training Center on Independent Living, Lawrence, Kansas: “Final Report of the Nobody Left Behind: Preparedness for Persons with Mobility Impairments Research Project” (M.H. Fox et al. 2007): <http://www.nobodyleftbehind.org>
- Not Dead Yet: <http://www.notdeadyet.org>
- UN Human Rights Committee, General Comment No 6, the Right to Life (Article 6), 16th Session, 1982:
<http://www.unhchr.ch/tbs/doc.nsf/084ab9690ccd81fc7c12563ed0046fae3?Opendocument>