

## CHAPTER 11: LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

### UN Convention on the Rights of Persons with Disabilities

#### **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-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;
- (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.

#### **Article 28, Adequate standard of living and social protection:**

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
  - (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
  - (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
  - (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counseling, financial assistance and respite care;
  - (d) To ensure access by persons with disabilities to public housing programmes;
  - (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

#### **Article 12, Equal recognition before the law:**

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.
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.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

## OBJECTIVES

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

- Define the right to live independently and with dignity in the community
- Explain the importance of living independently and with dignity in the community for people with disabilities
- Understand the interrelation between living independently and with dignity in the community and other human rights
- Identify ways in which the rights of people with disabilities to live independently and with dignity in the community have been promoted or denied
- Understand the provisions on living independently and with dignity in the community in the UN **Convention on the Rights of Persons with Disabilities** (CRPD).

## GETTING STARTED: THINKING ABOUT LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

Very few people in the world live completely by themselves without any contact with other people! All of us rely to some extent on other people, to provide us with advice, friendship, goods, services, and a variety of other kinds of support. What then does “living independently” mean if not living solely by yourself? In essence, the right to live independently means the right to choose how you live, where you live, with whom you live, and to what degree you wish to interact with your community. It also means having access to any support you might need to realize those choices and to achieve an adequate standard of living.

A critical component of the right to live independently in a manner that respects inherent human dignity is the opportunity to make one’s own decisions and to have those decisions be respected and acted upon. Many people with disabilities have been denied this right, even with respect to the most basic of decisions, such as what to wear or eat or drink. In some cases, national legislation has expressly barred people with disabilities (especially people with intellectual or psycho-social disabilities) from making their own decisions by depriving them of the **legal capacity** needed to do so. In other instances, people have ignored the decisions of family members or friends with disabilities because they do not believe the person has the capacity to make “sensible” decisions.

Information and communication barriers can also negatively impact the ability of people with disabilities to make decisions. For example, the lack of accessible information can deprive people with disabilities of the information they need to reach a decision. The lack of communication accommodations (e.g., computer-aided real-time transcription or CART) or sign language interpreters) may make it difficult for people with disabilities to express themselves and make their opinions and decisions understood.

Violations of other human rights can create barriers to the ability of people with disabilities to live independently and with dignity in the community. For example:



- Disability-based discrimination in employment settings may deprive people with disabilities of the means to earn an income to support themselves;
- The lack of accessible transportation not only deprives people with disabilities of the right to liberty of movement, but also harms their ability to access work, education, healthcare, and shops, as well as to interact fully with the community;
- Services such as medical care or rehabilitation that are available to others locally in a general hospital or on an outpatient basis may only be available to persons with disabilities in an institutional setting;
- The lack of an adequate standard of living may force people with disabilities to live in a segregated institutional setting or with family members merely for survival reasons, such as access to food and shelter;
- The lack of accessible housing may greatly reduce the choices available to people with disabilities who want to live in a particular community;
- Negative and discriminatory attitudes towards people with disabilities may make persons with disabilities feel uncomfortable or unsafe among other community members and in turn encourage them to avoid such interactions. Such attitudes may even encourage family members to hide their family members with disabilities from the community.

Violations of the right to live independently in the community also frequently lead to violations of other human rights. For example, forcing people with disabilities to live in segregated settings deprives them of the opportunity to participate fully in the social, cultural, and political life of their community. Children with disabilities who must live apart from their families are deprived of the opportunity to grow up in a family setting, and often are denied quality inclusive education. Institutional settings can often expose people with disabilities to a higher risk of violence, sexual abuse and even death, especially women and girls with disabilities and people with intellectual disabilities. Segregated settings may also deprive people with disabilities of the opportunity to exercise their right to marry and have a family of their own. These examples illustrate that human rights are **indivisible**, **interdependent**, and **interconnected**. Above all, violation of the right to live independently in the community disrespects the basic dignity of people with disabilities that is inherent in all human beings.

## EXERCISE 11.1: What Does it Mean to Live Independently and with Dignity in the Community?

**Objective:** To understand what it means to live independently and with dignity

**Time:** 30 minutes

**Materials:** Chart paper and markers or blackboard and chalk

### 1. Brainstorm/Discuss:

Brainstorm, listing responses:

- What does “living independently” mean to you? To your community?
- Where and how do most people with disabilities in your communities live?
- Who in your community is typically placed in an institution? What kinds of disabilities do they typically have?
- Do you know people with disabilities who live independently according to your definition?

## The Ten Principles of “Independent Living”

In some countries “independent living centers” provide supports, services and other assistance to empower people with disabilities to exercise their right to live independently and with dignity in their communities. Many of these centers subscribe to common principles that reflect the “philosophy of independent living.” These principles are:

1. Human rights: equal rights and opportunities for all; no segregation by disability type or stereotype.
2. Consumerism: a person (“consumer” or “customer”) who is using or buying a service or product decides what is best for him- or herself.
3. De-institutionalization: no person should be institutionalized (formally by a building, program, or family) on the basis of disability.
4. De-medicalization: people with disabilities are not “sick,” as prescribed by the assumptions of the medical model and do not necessarily require help from certified medical professionals for daily living.
5. Self-help: people learn and grow from discussing their needs, concerns, and issues with people who have had similar experiences. “Professionals” are not the source of the help provided.
6. Advocacy: systemic, systematic, long-term, and community-wide change activities are needed to ensure that people with disabilities benefit from all that society has to offer.
7. Barrier removal: in order for human rights, consumerism, de-institutionalization, de-medicalization, and self-help to occur, architectural, communication and attitudinal barriers must be removed.
8. Consumer control: the organizations best suited to support and assist individuals with disabilities are governed, managed, staffed and operated by people with disabilities.
9. Peer role models: leadership for living independently and disability rights is vested in individuals with disabilities, not parents, service providers, or other representatives.
10. Cross-disability: activities designed to achieve the first five principles must be cross-disability in approach, meaning that they work to be done must be carried out by people with different types of disabilities for the benefit of all persons with disabilities.<sup>1</sup>

<sup>1</sup> Adapted from “The Independent Living Philosophy: Ten Principles.” *Rockland Independent Living Center*. <http://www.rilc.org/principles.htm>



## 2. Brainstorm/Discuss:

Emphasize that all human beings have a right to live in dignity and equality. Brainstorm, listing responses:

- What does “living with dignity” mean to you?
- Do you think people with disabilities would give the same definition as people who do not currently have a disability?
- Do you think most people with disabilities in your community live in dignity? Who in particular do you think *does* live in dignity? Who does not?

## 3. Discuss:

What can be done to ensure that all people with disabilities in the community can live in dignity? Can live independently?

### Examples of Barriers to Living Independently and with Dignity in the Community

- Physical barriers to places of work, shops, health care facilities, and public buildings.
- Lack of accessible transportation to places of work, shops, health care facilities and public buildings.
- Legislation, regulations, policies, or practices that force people with disabilities to live in segregated and institutional settings against their will.
- Lack of accessible information about services to support living independently and what the rights and responsibilities of persons with disabilities are with respect to accessing those services and supports.
- Lack of accommodations to facilitate communication by people with disabilities, especially blind, deaf, deafblind, people with intellectual disabilities, and people with learning disabilities.
- Attitudes about the ability of people with disabilities to live where and with whom they choose and to make decisions for themselves.

## EXERCISE 11.2: Understanding Barriers to Enjoyment of the Right to Live Independently and with Dignity in the Community

**Objective:** To understand barriers to living independently and with dignity

**Time:** 30 minutes

**Materials:** Chart paper and markers or blackboard and chalk

### 1. Introduce:

Ask for people to give examples of barriers that prevent some people with disabilities in the community from living independently and with dignity. List these.

- Are some groups of people with disabilities especially prevented from living independently and with dignity? Why?

## 2. Discuss:

Divide participants into small groups of two or three. Ask each to make up a short fictional but typical biography of a person with disabilities in this community, describing how he or she was denied the right to live independently or with dignity.

Alternative: Present these “biographies” as role plays.

## 3. Report/Analyze:

Ask each group to present its “biography.” After each, discuss what specific human rights were violated in this fictional person’s story. List these.

## 4. Analyze/Discuss

Discuss with the group what it would take for each of these fictional people to achieve the right to live independently and with dignity. You might frame this as how to reverse the negative biographies and violations reported in Step 3.

- Consider the various supports guaranteed in Articles 12, 19, and 28.
- What could be done to obtain these supports?
- Would it help to advocate for these supports in terms of human rights?

## WHAT DOES HUMAN RIGHTS LAW SAY ABOUT LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY?

A number of human rights law instruments are relevant to the right to live independently and with dignity in the community. For example, the **Universal Declaration of Human Rights** (UDHR) discusses the right to an adequate standard of living (Article 25), and the right to recognition before the law (Article 6), which is relevant to the ability to make one’s own decisions.<sup>2</sup> The **International Covenant on Civil and Political Rights** (ICCPR)<sup>3</sup> also contains provisions relevant to decision-making, such as Article 16, which recognizes everyone as equal before the law, and Article 17, which recognizes the right of everyone to freedom of expression. General Comment No. 5 of the **Committee on Economic, Social and Cultural Rights**, which monitors implementation of the **International Covenant on Economic, Social and Cultural Rights** (ICESCR),<sup>4</sup> states that governments must adopt policies “to enable persons with disabilities to live an integrated, self-determined and independent life,” and that “[d]isability policies should ensure the access of [persons with disabilities] to all community services.”<sup>5</sup> The ICESCR itself also contains provisions in Article 11 that relate to the right of everyone to an adequate standard of living, “including adequate food, clothing and housing, and to the continuous improvement of living conditions.”

The **Convention on the Rights of the Child** (CRC) emphasizes throughout its provisions the need to support the ability of children to live with their families (where it is in the best interests of the child to do so), and the right of children with disabilities to “participate in the community” (Article 23). The Committee on the Rights of the Child has further encouraged States to –

*...make every effort to provide assistance for children with disabilities and support services for their families, to the maximum extent possible on an out-patient or*

2 See <http://www.unhchr.ch/udhr/>

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

4 See [http://www.unhchr.ch/html/menu3/b/a\\_ceschr.htm](http://www.unhchr.ch/html/menu3/b/a_ceschr.htm)

5 See [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/CESCR%20General%20comment%205.En?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/CESCR%20General%20comment%205.En?Opendocument)



*community basis, thereby avoiding removal of children with disabilities from their families for placement in institutions.*<sup>6</sup>

The 1993 **UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities** (Standard Rules) addresses a number of issues directly relevant to the right of people with disabilities to live independently in the community, including:

- Awareness-raising of the rights, needs, potential and contributions of people with disabilities in society (Rule 1);
- Medical care and rehabilitation services available in the local community (Rules 2 and 3);
- Support services to promote independence and facilitate the exercise of rights by people with disabilities (Rule 4);
- Physical, informational and communication accessibility (Rule 5).
- Personnel training (Rule 19).<sup>7</sup>

The Convention on the Rights of Persons with Disabilities (CRPD) expands upon the issues addressed in earlier human rights documents and helps to clarify how States can respect, protect, and fulfill the right to live independently in the community. Because of the **interrelated**, **interdependent**, and **indivisible** nature of human rights, there are many articles in the CRPD relevant to the enjoyment of this right. However, Articles 19, 28, and 12 are especially important to issues of living independently and with dignity in the community.

Article 19 of the CRPD explicitly addresses the right of people with disabilities to live independently and be included in the community. Specifically, Article 19 emphasizes the right of persons with disabilities to “have choices equal to others,” including the opportunity to choose where and with whom they live, and to not be forced to live in a particular living arrangement. Article 19 also requires States to ensure that people with disabilities have access to the kinds of supports and services they may need to enable them to live independently and avoid segregation and isolation from the community. Such supports might include personal assistance and/or other in-home or community services. Article 19 also requires that community services and facilities that are available to the wider population are also available on an equal basis to people with disabilities and that those services and facilities are also responsive to the needs of people with disabilities.

Article 28 of the CRPD addresses the right to an adequate standard of living and social protection. Article 28 recognizes the right of people with disabilities to have an adequate standard of living, “including adequate food, clothing and housing, and to the continuous improvement of living conditions,” and to be able to enjoy this right without discrimination on the basis of disability. States must also ensure that people with disabilities enjoy social protection without discrimination on the basis of disability. For example, people with disabilities (particularly women and girls with disabilities and older persons with disabilities) need to be assured equal access to clean water, social protection and poverty reduction programs, public housing, and retirement benefits and programs.

States’ obligations with regard to the right to live independently and with dignity in the community include:

1. Obligation to respect the right by ensuring that State actors such as government officials do not interfere with the exercise and enjoyment of the right by people with disabilities;
2. Obligation to protect the right by ensuring that non-State actors such as businesses and

<sup>6</sup> See <http://www.unhcr.ch/html/menu2/6/crc/doc/days/violence.pdf>

<sup>7</sup> See <http://www.un.org/esa/socdev/enable/dissre00.htm>

- families do not interfere with the exercise and enjoyment of the right;
3. Obligation to fulfill the right by taking action to ensure that people with disabilities are able to exercise the right.

In short, international human rights law strongly supports the right of people with disabilities to live independently and with dignity in the community, not only as a right in itself, but also so that people with disabilities may better enjoy their other human rights and fully assume their responsibilities as members of society.

Article 12 of the CRPD addresses the right to equal recognition before the law, and confirms that people with disabilities “enjoy legal capacity on an equal basis with others in all aspects of life.” Historically many people with disabilities have been subjected to laws and practices that deprived them of their legal capacity and, consequently of their autonomy and freedom to choose how and where to live their lives.

Of particular concern is the fact that people with disabilities are often subjected to the substituted decision-making of other people. Even when substitute decision-makers act in good faith and with good intentions, such practices still deny people with disabilities the right to make their own decisions. Article 12 seeks to correct this approach, by recognizing the legal capacity of persons with disabilities and providing measures to support their right to *exercise* their legal capacity. Some people with disabilities require no support in making decisions, and others may need a lot of support. Regardless of the level of support needed, States must ensure that this support is not abusive and does not infringe the person’s human rights.

Lastly, States must ensure the equal right of people with disabilities to “own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit,” as well as not be arbitrarily deprived of their property. These measures are important because living independently in the community can be difficult to achieve without the ability to access and control financial and property resources.

### EXERCISE 11.3: Understanding the Right to Live Independently and with Dignity in the Community

**Objective:** To review and understand the right to live independently and with dignity affirmed by the CRPD

**Time:** 45 minutes

**Materials:** Chart paper and markers or blackboard and chalk; handouts

#### 1. Paraphrase and Discuss:

Divide participants into three groups and assign each one of the CRPD articles: 12, 19, and 28. Because of its length, you may want to divide Article 19 among three groups, with items 4 and 5 being considered by separate groups. Give each group copies of its respective article and the additional questions about the article.

#### Assignment:

- a. Paraphrase all parts of the article into everyday language. Write your paraphrase on chart paper.
- b. Answer the following questions about your article:



### **Article 12**

- What do you think is meant in Part 1 by “recognition everywhere as persons before the law”?
- What do you think is meant in Part 2 by “enjoy legal capacity”?
- What kind of support do you think is intended in Part 3 by “support they may require in exercising their legal capacity”?
- What are some examples of “the exercise of legal capacity” mentioned in Part 4?

### **Article 19**

- What do you think is meant by “independent living”? Give some examples.
- What do you think is meant by “full inclusion and participation in the community”?

### **Article 28**

- What do you think is meant in Part 1 by “adequate standard of living”?
- What do you think is meant in Part 1 by “continuous improvement of living conditions”?
- What do you think is meant in Part 2 by “social protection”?
- What “services, devices and other assistance” do you think are meant in Part 2(a)?

## **2. Report:**

Ask each group to post their paraphrase and read it aloud with the whole group, pausing at each phrase to ask if participants have questions or alternative language. Ask them to explain their answers to the questions that come with each article. Try to arrive at a clean and clearly understandable version of each article.

## **3. Give examples:**

Ask for examples of how these rights could be enjoyed and make a difference for people with disabilities.

## **4. Discuss:**

How can these articles be used to set national disability rights agendas and formulate platforms of action for submission to political parties of government decision-makers?

## **EXERCISE 11.4: Making a Commitment to Promote Living Independently and with Dignity in the Community**

Emphasize that human rights involve both rights and responsibilities.

- Ask if after learning about the human right of people with disabilities to live independently and with dignity in the community, the group is 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 exercise their right to live independently and with dignity in the community.

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

## Supported Decision-making for People with Disabilities

Increasingly, people around the world are moving away from *substituted* decision-making models, where other people make decisions on behalf of people with disabilities, to *supported* decision-making where people with disabilities themselves make their own decisions, utilizing the support of others if and when they request it. This approach attempts to respect the inherent dignity of people with disabilities and avoid paternalism. Though potentially useful for anyone requiring help to make decisions, it is particularly relevant for people with psycho-social or intellectual disabilities, who historically have been forced to comply with substituted decision-making.

Though there are as yet no internationally agreed upon standards or guidelines regarding supported decision-making, the following may be helpful for those interested in ensuring that supported decision-making activities respect the rights of people with disabilities:

- People with disabilities have the right to be respected for their inherent decision-making abilities;
- People with disabilities have the right to develop authentic decision-making voices;
- People with disabilities have the right to receive support where they request it;
- People with disabilities have the right to genuine choices and options and to make decisions based on those options;
- People with disabilities have the right to be able to make mistakes.

Can you think of other helpful standards or guidelines for meaningful supported decision-making activities?<sup>8</sup>

## USEFUL RESOURCES ON LIVING INDEPENDENTLY AND WITH DIGNITY IN THE COMMUNITY

- Access Living center for independent living: <http://www.accessliving.org>
- Canadian Association of Independent Living Centers (CAILC): <http://www.cailc.ca>
- Committee on the Rights of the Child, Report on the twenty-fifth session, Sept./Oct. 2000, CRC/C/100, paras. 688.17, 20-22, 24-25: <http://www.unhcr.org/home/RSDCOI/3f4782b74.pdf>
- Disability Rights and Independent Living Movement in the United States. University of California: <http://bancroft.berkeley.edu/collections/drilm>
- *The Independent Living Philosophy: Ten Principles*. Rockland Independent Living Center: <http://www.rilc.org/principles.htm>
- *Supported Decision-making*, Planned Lifetime Advocacy Network: [http://www.plan.ca/Programs\\_Decisions.php](http://www.plan.ca/Programs_Decisions.php)

8 Adapted from "Supported Decision-making." *Planned Lifetime Advocacy Network*. [http://www.plan.ca/Programs\\_Decisions.php](http://www.plan.ca/Programs_Decisions.php)

