

# Human Rights Committee Manual



South Carolina Department of  
Disabilities and Special Needs  
(Revised August 10, 2018)

## WELCOME TO THE HUMAN RIGHTS COMMITTEE

Dear Human Rights Committee Member,

Welcome! Thank you for your service as a member of a Human Rights Committee. You play a crucial role in South Carolina's disability services, and your efforts are greatly appreciated.

People with intellectual and developmental disabilities, as well as related disabilities, are entitled to the same rights available to all other citizens. When a person is unable to exercise his or her rights as a citizen, society is obligated to intervene, to safeguard these rights and to act humanely and conscientiously on that person's behalf.

South Carolina Code of Law 44-26-70, relating to the rights of people receiving services from DDSN, requires that each DDSN Regional Center and local Disability and Special Needs Board establish a Human Rights Committee (HRC).<sup>1</sup> Qualified service providers are also required by DDSN to either create their own HRC or connect with an existing DSN Board HRC.<sup>2</sup> The HRC ensures that every recipient of DDSN services is afforded fundamental fairness, protecting their rights and freedoms.

It is our greatest task to support the people we serve to lead complete and whole lives and to exercise their rights and responsibilities as citizens to the fullest.

This manual is intended to provide a solid philosophy on which to base your work as well as practical help and functional guidelines. With the help of this manual, you will be able to:

- Apply principles of People First Language
- Discover legal landmarks for disability rights
- Identify the purpose of an HRC
- Know State law concerning HRC procedure and practice
- Learn the history of the treatment of persons with disabilities
- Listen to the voices of people with disabilities
- Review common issues for HRCs
- Study current State and Federal law concerning disability rights
- Understand the balance between rights and risk<sup>3</sup>

Once again, welcome, and thanks for your service to people living with disabilities in our State!

*The South Carolina Department of Disabilities and Special Needs*

<sup>1</sup> Available at <https://www.scstatehouse.gov/code/t44c026.php>.

<sup>2</sup> DDSN. (2016). *Directive 535-02-DD: Human Rights Committee*, p. 2. Retrieved from [http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20\(040816\).pdf](http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20(040816).pdf). See also See p. 38 of this manual.

<sup>3</sup> Adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

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## SECTION 1

# The World of Intellectual Disability

*In this section....*

Voices of People with Disabilities

Introduction to Intellectual Disability

Challenges for People with Intellectual  
Disabilities

DDSN Mission, Vision, Values

Disability is a natural part of the human experience, and in no way diminishes the rights of individuals to participate in contribute to society.

*US Congress, 2015*

**VOICES OF PEOPLE WITH DISABILITIES**

**“In order for people**  
to have a  
**good life,**  
staff need to know  
what is **important** to them.

It is easy to find out...  
**JUST ASK!”**

- Doris  
*TN Advocate*

www.C-Q-L.ORG  
**CQL**™ | The Council on  
Quality and Leadership

When I’m **not** listened to,  
I feel like a  
**RUBBER BAND**  
**BEING STRETCHED**


I can only be stretched so far until I

**BREAK.**

- Anthony  
*TN Advocate*


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Quality and Leadership


**“People want**  
**JOBS**  
not to just  
**SIT**  
**AROUND**  
and be bored  
**ALL DAY.”**



- Chelsea  
*TN Advocate*

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Quality and Leadership

**“Please act with**  
**URGENCY**   
when making decisions.  
**When the system**  
gets in the way of action,  
it is **MY LIFE** that ends up

**ON HOLD.”** 

- Anthony  
*TN Advocate*

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**VOICES OF PEOPLE WITH DISABILITIES**

**“How can people build natural support networks if they **ONLY** spend time with **STAFF**?”**

We need to get out **in the community** in order to **meet new friends.**

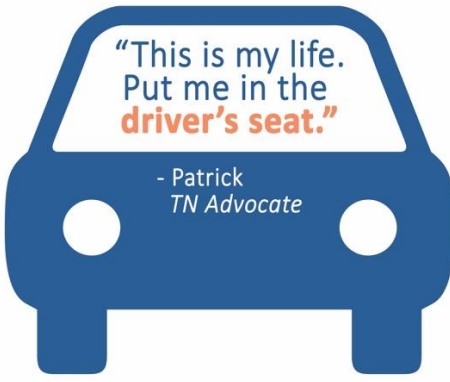
- Patrick  
*TN Advocate*



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**CQL** | The Council on Quality and Leadership

**“This is my life. Put me in the **driver’s seat.**”**


- Patrick  
*TN Advocate*



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**“How can people **exercise their rights** if they don’t know **WHAT** they are?”**

- Patrick  
*TN Advocate*




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**“When my staff leave, **IT HURTS.** It hurts me, and affects **MY LIFE.**”**

We need to work together to find a way, to **HELP THE GOOD STAFF STAY.**

- Ashley  
*TN Advocate*



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## INTRODUCTION TO INTELLECTUAL DISABILITY

### What Is an Intellectual Disability?

Intellectual disability is a disability that occurs before age 18. People with this disability experience significant limitations in two main areas: 1) intellectual functioning and 2) adaptive behavior. These limitations are expressed in the person's conceptual, social and practical everyday living skills. Many people with intellectual disability are mildly affected, making the disability difficult to recognize without visual cues.

### How is Intellectual Disability Diagnosed?

Intellectual disability is diagnosed with standardized tests of intelligence and adaptive behavior. Individuals with intellectual disability who are provided appropriate personalized supports over a sustained period generally have improved life outcomes. In fact, many adults with intellectual disability can live independent, productive lives in the community with support from family, friends and agencies.

An estimated 4.6 million Americans have an intellectual or developmental disability.

*The Arc, 2011*

### How Many People Have Intellectual Disability?

An estimated 4.6 million Americans have an intellectual or developmental disability. Prevalence studies may not identify all people with intellectual disability. Many school age children receive a diagnosis of learning disability, developmental delay, behavior disorder, or autism instead of intellectual disability.

### What Is Intelligence?

Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardized tests given by trained professionals. Intellectual disability is generally thought to be present if an individual has an IQ test score of approximately 70 or below.



**What Is Adaptive Behavior?**

Adaptive behavior is the collection of conceptual, social and practical skills that have been learned by people in order to function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect his or her ability to respond to a particular situation or to the environment.

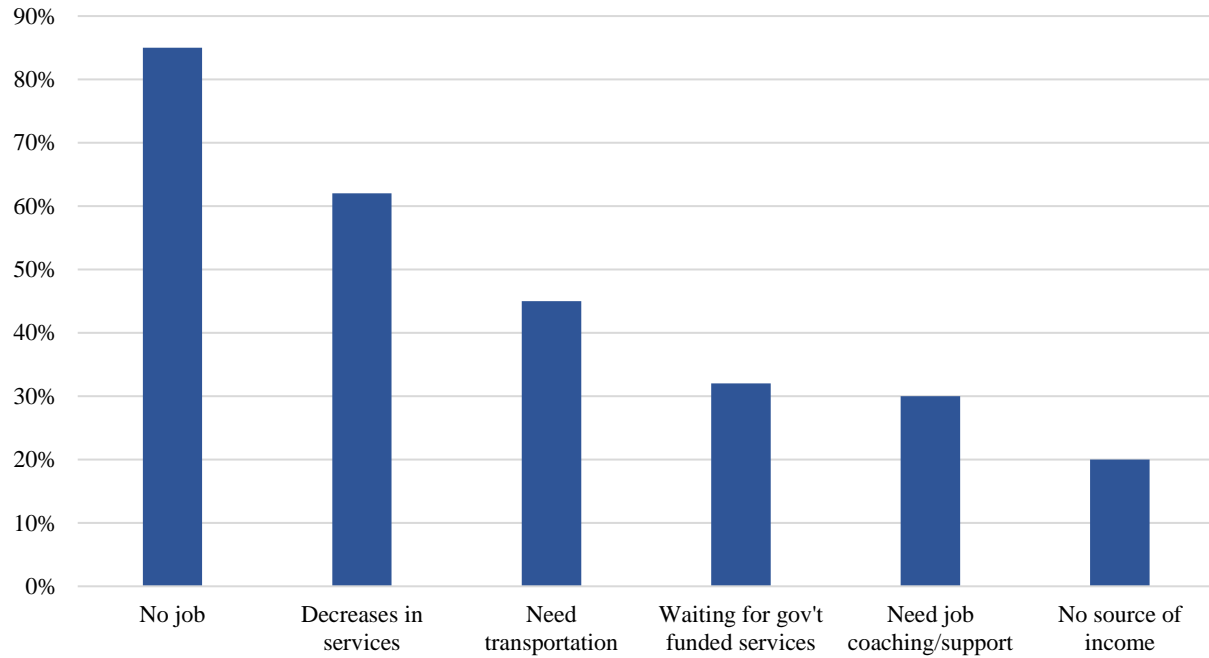
**How Does Having a Disability Affect Someone's Life?**

The effects of intellectual disability vary considerably among people who have them, just as the range of abilities varies considerably among all people. Children may take longer to learn to speak, walk and take care of their personal needs, such as dressing or eating. It may take students with intellectual disability longer to learn in school. As adults, some will be able to lead independent lives in the community without paid supports, while others will need significant support throughout their lives. In fact, a small percentage of those with intellectual disability will have serious, lifelong limitations in functioning. However, with early intervention, appropriate education and supports as an adult, every person with an intellectual disability can lead a satisfying, meaningful life in the community.<sup>4</sup>

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<sup>4</sup> The ARC. (2011). *Introduction to Intellectual Disability*. Retrieved from <https://www.thearc.org/what-we-do/resources/fact-sheets/introduction-to-intellectual-disability>

### CHALLENGES FOR PEOPLE WITH INTELLECTUAL DISABILITIES



According to a 2010 survey, people living with intellectual and developmental disabilities (IDD) and their families face very real challenges to achieving their dreams:

- 85% of people with IDD did not have a job
- 62% were experiencing decreases in services
- 45% had unmet transportation needs
- 32% were waiting for government funded services
- 30% needed job coaching or on the job support
- 20% of the people with IDD had no source of income. <sup>5</sup>

<sup>5</sup> Anderson, L.L., Larson, S.A., & Wuorio, A. (2011). 2010 FINDS National Survey Technical Report Part 1: Family Caregiver Survey. Minneapolis: University of Minnesota, Research and Training Center on Community Living. *Executive Summary*, p.iv. Available at <https://rtc3.umn.edu/docs/FINDSTechnicalReportPart1CaregiverSurvey.pdf>



## Mission

- Assist people with disabilities and their families through choice in meeting needs, pursuing possibilities and achieving life goals, and minimize the occurrence and reduce the severity of disabilities through prevention.

## Vision

- To provide the best in services to assist persons with disabilities and their families in South Carolina.

## Values

- The health, safety and well-being of each person
- Dignity and respect for each person
- Individual and family participation
- Choice, control and responsibility
- Relationships with family, friends and community connections
- Personal growth and accomplishments



## SECTION 2

# The History of Intellectual Disability

*In this section....*

Treatment of People with Disabilities

Disability Rights in The United States

Legal Landmarks for Disability Rights

Congress acknowledged that society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment.

*William J. Brennan Jr.  
Associate Justice  
US Supreme Court  
1956-1990*

## TREATMENT OF PEOPLE WITH DISABILITIES<sup>6</sup>

<b>Societal Perspective &amp; Treatment Through the Years<sup>7</sup></b>	
<b>Up to 1700s</b>	Possessed by the devil, a sinner; Tortured, burned at stake, left to die
<b>1800-1920s</b>	Genetically defective; polluting the race; Hidden away
<b>1930-1940s</b>	Genetically defective; polluting the race; Institutionalized, sterilized, exterminated
<b>1940-1970</b>	Unfortunate, object of charity, pity; Institutionalized, rehabilitated
<b>1970-2014</b>	Independent, self-determined; Civil rights affirmed and encoded into law
<b>Important Dates in Disability History</b>	
<b>1200-1700</b>	Accepted belief that mentally ill people (lunacy and idiocy) were possessed by the devil or evil spirits. As a result, they were routinely whipped, tortured and burned at the stake. Between 1400 and 1700 more than 100,000 women executed as witches. Many of these women had some form of mental illness or other age-related disability.
<b>1800</b>	Science begins to replace religion as the main authority guiding leaders in the West. Biology and science are used to explain the world. Instead of being seen as having a spiritual deficit, people with disabilities are seen as having a genetic deficit. People with disabilities placed under the care of medical professions, professional educators and social workers. Almshouses, workhouses, institutions proliferate in the U.S.
<b>1850</b>	Beginning of the Eugenics Movement. Goal to improve the quality of the human gene pool. People with disabilities were segregated and hidden (institutions, asylums, hospitals, segregated schools, sheltered workshops, attics) or placed on display as entertainment (freak shows, circuses).
<b>1861</b>	The American Civil War (1861-1865) – 30,000 amputations in the Union Army alone.

<sup>6</sup> Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 8-9. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

<sup>7</sup> For more information, see also <http://museumofdisability.org/virtual-museum/>

<b>1920</b>	German Social Darwinists feared that the degeneration of the race was due to medical care of the ‘weak’ that had begun to destroy the natural struggle for existence. Institutionalization of people with disabilities is seen as best for them and for society. People with disabilities seen as a “drag on civilization.”
<b>1924</b>	The Commonwealth of Virginia passed a state law that allowed for sterilization (without consent) of individuals found to be “feebleminded, insane, depressed, mentally handicapped, epileptic and other.” Alcoholics, criminals and drug addicts were also sterilized.
<b>1930</b>	President Franklin Delano Roosevelt’s physical disability hidden from the American public for fear that it would detract from his power and status.
<b>1935</b>	The league of the Physically Handicapped is formed in New York City to protest discrimination against people with disabilities by federal relief program. The group organizes sit-ins, picket lines and demonstrations and travels to Washington D.C. to protest and meet with officials of the Roosevelt administration.
<b>1939</b>	In Germany: End of Nazi sterilization program. Beginning of Euthanasia Program. 200,000 killed in total.
<b>1945</b>	President Harry Truman signed a proclamation creating “National Employ the Handicapped Week.”
<b>1950</b>	Laws still on the books in some states prohibiting persons “diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object” from appearing in public.
<b>1961</b>	President Kennedy appoints a special “President’s Panel on Mental Retardation”, to investigate the status of people with mental retardation and develop programs and reforms for its improvement.
<b>1970</b>	Independent Living movement begins, grass roots effort by people with disabilities to acquire new rights and control over their lives.
<b>1971</b>	The U.S. District Court of Alabama decided in Wyatt vs. Stickney that people in residential state schools have a constitutional right “to receive such individual treatment as (would) give them a realistic opportunity to improve his/her mental condition.”
<b>1990</b>	The Americans with Disabilities Act (ADA) was passed by the United States Congress and signed into law by President George H.W. Bush. The intent of the law was to end the historical isolation and segregation of, and discrimination against, individuals with disabilities.

<b>1996</b>	In <i>Helen L. v. Didario</i> , the US Court of Appeals for the Third Circuit, found that a woman with a disability who was confined in a nursing facility had the right under the ADA to receive attendant care services in the community.
<b>1999</b>	In <i>Olmstead v. LC</i> , the US Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions.
<b>2006</b>	The UN Convention on the Rights of Persons with Disabilities was adopted on at the UN Headquarters in New York. It was the first comprehensive human rights treaty of the 21st century. It was entered into force on 3 May 2008.
<b>2014</b>	The US Department of Health and Human Services Centers for Medicare and Medicaid (CMS) issues the Home and Community-Based Services (HCBS) Settings Final Rule, to “maximize the opportunities for participants in HCBS programs to have access to the benefits of community living and to receive services in the most integrated setting”.



## DISABILITY RIGHTS IN THE UNITED STATES

In the 1800s, states throughout America began to build large scale asylums for people with mental health conditions and other disabilities. By the early 1900s, many of these institutions became overcrowded and residents experienced maltreatment. Psychiatric institutions continued to grow until public policy began to change toward deinstitutionalization in the 1960s.

In the mid-twentieth century, nursing facilities became the primary institutions for senior citizens and people with physical disabilities. These facilities grew considerably with the creation of Medicaid and Medicare in the 1960s. Nursing facility populations grew rapidly throughout the 1970s and 80s. Unlike the trend with mental health hospitals, the population in nursing facilities grew to 1.4 million Americans in nursing facilities by late 2011.

The Americans with Disabilities Act was signed into law by President George H.W. Bush. Congress made a number of historical findings, which included recognition of the history of institutionalization in the United States. Congress stated, “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” In signing the law, President George H.W. Bush declared that the ADA “takes a sledgehammer to [a] wall . . . which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp.”

Historically, society has tended to isolate and segregate individuals with disabilities.

*US Congress, 1990*

Title II of the ADA prohibits public entities, including state and local governments, from discriminating against “qualified individuals with disabilities” by excluding them from services and activities due to their disability. Federal regulations were created to enforce the Act. One of the regulations created was called the “integration mandate.” The integration mandate requires public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of the qualified individuals with disabilities.” This integration mandate would become the basis of the Olmstead decision in 1999.<sup>8</sup>

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<sup>8</sup> OlmsteadRights.org. (n.d.). *Before Olmstead*. Retrieved from <https://www.olmsteadrights.org/about-olmstead/>. See p. 20.

## LEGAL LANDMARKS FOR DISABILITY RIGHTS

### Wyatt V. Stickney (1971)

In *Wyatt v. Stickney*, a federal court in Alabama held for the first time that people who are involuntarily committed to state institutions because of mental illness or developmental disabilities have a constitutional right to treatment that will afford them a realistic opportunity to return to society. The ruling led to sweeping reforms in the nation's mental health systems and the creation of minimum standards of care and rehabilitation.

After hearing arguments in the case, U.S. District Court Judge Frank M. Johnson, Jr. ruled on March 12, 1971 that thousands of patients with intellectually disabilities who had been committed involuntarily “unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition.”

Johnson proclaimed: “To deprive any citizens of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process.”

Each resident,  
regardless of ability  
or status, is entitled to  
develop and realize  
his fullest potential.

*Article 2,  
Wyatt Standards*

In a Dec. 10, 1971 opinion, the Court articulated “three fundamental conditions for adequate and effective treatment programs in public mental institutions”: A humane psychological and physical environment, qualified staff in numbers sufficient to administer adequate treatment; and individualized treatment plans. In both decisions, Judge Johnson applied what came to be known as the “Wyatt Standards,” a set of 49 minimum constitutional standards for the adequate treatment of people with mental illness and developmental disabilities.<sup>9</sup>

In four of the standards (24, 28, 29, 30) Judge Johnson created what he called a “**human rights committee**” to oversee the implementation of these standards at each institution.<sup>10</sup>

<sup>9</sup> DisabilityJustice.org. (2018). *Wyatt v. Stickney*. <https://disabilityjustice.org/wyatt-v-stickney/>

<sup>10</sup> For the complete list of standards and rights, see: <https://mn.gov/mnddc/ada-legacy/pdf/Wyatt-v-Stickney-Constitutional-Standards-and-Rights.pdf>

## The Americans With Disabilities Act (1990)

The Americans with Disabilities Act (ADA) prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life.

Modeled after the Civil Rights Act of 1964, which prohibits discrimination on the basis of race, color, religion, sex, or national origin, as well as Section 504 of the Rehabilitation Act of 1973, the ADA is an “equal opportunity” law for people with disabilities.<sup>11</sup>

To be protected by the ADA, one must have a disability, defined as a “physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment...”<sup>12</sup>

The ADA was signed into law on July 26, 1990 by President George H.W. Bush. The Title II and III regulations, including the ADA Accessibility Guidelines, were issued in 1991.

On July 15, 2016, Attorney General Loretta Lynch signed a Final Rule<sup>13</sup> revising the ADA title II and III regulations to implement the requirements of the ADA Amendments Act of 2008. Title III was again revised on November 21, 2016. The Final Rule was published in the Federal Register on December 2, 2016.<sup>14</sup>

[The ADA] takes a sledgehammer to [a] wall which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp.

*Pres. George H.W. Bush  
ADA Signing Ceremony  
July 26, 1990*

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<sup>11</sup> United States Department of Justice, Civil Rights Division. (2018). *Introduction to the ADA*. Retrieved from [https://www.ada.gov/ada\\_intro.htm](https://www.ada.gov/ada_intro.htm)

<sup>12</sup> For a helpful guide to the ADA and other federal disability rights laws, including The Fair Housing Act and The Individuals with Disabilities Education Act, see <https://www.ada.gov/cguide.pdf>.

<sup>13</sup> See p. 70-71.

<sup>14</sup> United States Department of Justice, Civil Rights Division. (2018). *The Current ADA Regulations*. Retrieved from [https://www.ada.gov/2010\\_regs.htm](https://www.ada.gov/2010_regs.htm).

## **Olmstead V. LC (1999)**

In *Olmstead v. LC*, the US Supreme Court held that people with disabilities have a qualified right to receive state funded supports and services in the community. The *Olmstead* lawsuit started with two women named Lois Curtis (known as “LC”) and Elaine Wilson who both had diagnoses of mental health conditions and IDD. Lois and Elaine went in and out of Georgia’s mental health hospitals dozens of times because they did not have help at home.

After waiting for years for their community-based supports to be set up, they filed a lawsuit. The defendant was Tommy Olmstead, the commissioner of the Georgia Department of Human Resources. *Olmstead v. LC* went all the way to the US Supreme Court.

The Court found that under the ADA, it is against the law for the state to discriminate against a person based on his or her disability. The Court said that the state discriminated against Lois and Elaine by requiring them to live in a mental health hospital. It should have instead provided services for them in the community. By confining them in the hospital, the state was segregating them by requiring them to live with others with disabilities.

The Court said that people with disabilities like Lois and Elaine have the right to receive the treatment they needed in an integrated setting if that is what they want, if their doctors agree, and if it doesn’t fundamentally change how the state provides services to people with disabilities.<sup>15</sup>

Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

*US Supreme Court  
Olmstead Ruling, 1999*

## **South Carolina’s Response to Olmstead**

South Carolina updated two sections of the State Code of Law, 44-20-20 and 44-26-140, to comply with the requirements of the *Olmstead* decision.

*Section 44-20-20:* “The State of South Carolina recognizes that a person with intellectual disability, a related disability, head injury, or spinal cord injury is a person who experiences the

<sup>15</sup>OlmsteadRights.org. (n.d.). Retrieved from <https://www.olmsteadrights.org/about-olmstead/>

benefits of family, education, employment, and community as do all citizens. It is the purpose of this chapter to assist persons with intellectual disability, related disabilities, head injuries, or spinal cord injuries by providing services to enable them to participate as valued members of their communities to the maximum extent practical and to live with their families or in family settings in the community in the least restrictive environment available. When persons with intellectual disability, related disabilities, head injuries, or spinal cord injuries cannot live in communities or with their families, the State shall provide quality care and treatment in the least restrictive environment practical.

In order to plan and coordinate state and locally funded services for persons with intellectual disability, related disabilities, head injuries, or spinal cord injuries, a statewide network of local boards of disabilities and special needs is established. Services will be delivered to clients in their homes or communities through these boards and other local providers. It is recognized that persons with intellectual disability, related disabilities, head injuries, or spinal cord injuries have the right to receive services from public and other agencies that provide services to South Carolina citizens and to have those services coordinated with the services needed because of their disabilities. South Carolina recognizes the value of preventing intellectual disability, related disabilities, head injuries, and spinal cord injuries through education and research and supports efforts to this end.

The State recognizes the importance of the role of parents and families in shaping services for persons with intellectual disability, related disabilities, head injuries, or spinal cord injuries as well as the importance of providing services to families to enable them to care for a family member with these disabilities. Admission to services of the South Carolina Department of Disabilities and Special Needs does not terminate or reduce the rights and responsibilities of parents. Parental involvement and participation in mutual planning with the department to meet the needs of the client facilitates decisions and treatment plans that serve the best interest and welfare of the client.”<sup>16</sup>

*Section 44-26-140:* “Clients to receive least restrictive appropriate care and habilitation available; exceptions.

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<sup>16</sup> <https://www.scstatehouse.gov/code/t44c020.php>

(A) Clients receiving services for intellectual disability shall receive care and habilitation suited to their needs and in the least restrictive appropriate care and habilitation available. The care and habilitation must be administered skillfully, safely, and humanely with full respect for the client's dignity and personal integrity. The department shall make every effort, based on available resources, to develop services necessary to meet the needs of its clients.

(B) In emergency admissions when the least restrictive setting is not available a client must be admitted to the nearest proper facility until he may be moved to the least restrictive setting.

(C) In judicial or emergency admissions to the department every attempt must be made by the court to ensure a client's placement in the least restrictive alternative of services available.

(D) No client may remain at a level of care that is more restrictive than is warranted to meet his needs if alternative care is available. A residential program must attempt to move clients from:

- (1) more to less structured living;
- (2) larger to smaller facilities;
- (3) larger to smaller living units;
- (4) group to individual residence;
- (5) segregated from the community to integrated into the community;
- (6) dependent to independent living.<sup>17</sup>

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<sup>17</sup> <https://www.scstatehouse.gov/code/t44c026.php>

**SECTION 3**

**Human  
Rights for  
People with  
Disabilities**

Our commitment to human rights must be absolute, our laws fair, our natural beauty preserved; the powerful must not persecute the weak, and human dignity must be enhanced.

*President Jimmy Carter  
Inaugural Address, 1976*

*In this section....*

Fact Sheet

Human Rights Approach to Disability

Position Statement: Human and Civil Rights

Rights Under US Federal Law

Rights Under State Law

Rights of People Receiving DSSN Residential Services

Dignity of Risk

Balancing Rights & Risk

Right Restrictions

## FACT SHEET

- Lack of access to civil, political and economic rights for people with disabilities – including the right to a fair hearing, to vote, marry, seek employment, and access health services – is commonplace worldwide.<sup>18</sup>
- Deprivation of legal capacity – or the right to make decisions about one’s own life – profoundly impacts people with disabilities.<sup>19</sup>
- The US Declaration of Independence (1776) captured the right to liberty and equality: "We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the Pursuit of Happiness."<sup>20</sup>
- The US Constitution (1787) and the Bill of Rights (1791) guaranteed many rights to citizens, including freedom of speech, the press, religion, and assembly.<sup>21</sup>
- No one can take away a person's constitutional rights. However, Congress can add to our constitutional rights by passing federal laws.
- State legislators can also pass laws that expand on or explain the rights and responsibilities of citizens of their states.
- The modern concept of "human rights" was born after WWII. The 1945 charter of the United Nations begins by reaffirming a "faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women".
- Three years later, in 1948, the General Assembly of the United Nations adopted the Universal Declaration of Human Rights. It is essentially a list of human rights, and establishes uniform standards for the treatment of all persons.<sup>22</sup>
- The United Nations Convention on the Rights of Persons with Disabilities was adopted by the UN in 2006. It is the first comprehensive human rights treaty of the 21st century.<sup>23</sup>

More than one billion people, or 15% of the world’s population, live with disabilities.

*Human Rights Watch*  
2011

<sup>18</sup> Human Rights Watch. (2011) *One Billion Forgotten: Protecting the Human Rights of Persons with Disabilities*, p. 3.

Retrieved from: [https://www.hrw.org/sites/default/files/related\\_material/2014\\_%20disabilities\\_program\\_low.pdf](https://www.hrw.org/sites/default/files/related_material/2014_%20disabilities_program_low.pdf)

<sup>19</sup> Ibid, p. 11.

<sup>20</sup> Retrieved from <http://www.ushistory.org/declaration/document/>.

<sup>21</sup> Retrieved from <https://constitutioncenter.org/media/files/constitution.pdf>

<sup>22</sup> Tuller, Jean E. (n.d.) *Human Rights for People with Mental Retardation*, AAMR Fact Sheet.

<sup>23</sup> United Nations. (2008). Available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>



## THE HUMAN RIGHTS APPROACH TO DISABILITY (UN)

The human rights approach to disability acknowledges persons with disabilities as subjects of rights and the State and others as having responsibilities to respect these persons. It treats the barriers in society as discriminatory and provides avenues for persons with disabilities to complain when they are faced with such barriers.

A rights-based approach to disability is not driven by compassion, but by dignity and freedom. It 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.

Instead of focusing on persons with disabilities as passive objects of charitable acts, it seeks to assist people to help themselves so that they can participate in society, in education, at the workplace, in political and cultural life, and defend their rights through accessing justice.

The human rights approach establishes that all policies and laws should be designed with the involvement of persons with disability, mainstreaming disability in all aspects of political action.

Following this model, no “special” policies should be designed for persons with disabilities, notwithstanding the particularities needed to comply with the principle of full participation.

Under this model, persons with disabilities have rights and instruments that can empower them to claim their rights. They have the tools to be in control of their lives and fully participate on equal terms with others. The human rights approach provides that persons with disabilities are closely involved in policymaking by law.<sup>24</sup>

Know me for my  
abilities, not my  
disability.

*Robert M. Hensel  
Film producer, poet,  
athlete, activist, Guinness  
World Record Holder,  
US Ambassador to  
Wheelchairs for the  
World*

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<sup>24</sup> Adapted from: United Nations, Human Rights Office of the High Commissioner. (2014). *The Convention on the Rights of Persons with Disabilities Training Guide, Professional Training Series No. 19*, p.10-11. Retrieved from [http://www.ohchr.org/Documents/Publications/CRPD\\_TrainingGuide\\_PTS19\\_EN%20Accessible.pdf](http://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTS19_EN%20Accessible.pdf)

### **POSITION STATEMENT: HUMAN AND CIVIL RIGHTS (THE ARC & AAIDD)**

All people with intellectual and/or developmental disabilities are entitled to human and civil rights.

Given that all people with intellectual and/or developmental disabilities are complex human beings with varying attributes and living circumstances, and many experience multiple risk factors for human and civil rights violations,

We emphasize that all are entitled to human and civil rights regardless of age, gender, race/ethnicity, sexual orientation, cultural, linguistic, geographic, and spiritual diversity, economic status, severity of disability, intensity of needed supports, or other factors that expose them to increased risk of rights violations.

These rights include the rights to autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, and equality of opportunity and others recognized by law or international declarations, conventions, or standards.

All people with intellectual and/or developmental disabilities must have the right to supports they need to exercise and ensure their human and civil rights.

Local, state, federal, and international governments must strongly enforce all human and civil rights.<sup>25</sup>

I don't need easy.  
I just need possible.

*Bethany Meilani  
Hamilton-Dirksis,  
professional surfer,  
Author of "Soul Surfer:  
A True Story of Faith,  
Family, and Fighting to  
Get Back on the Board"*

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<sup>25</sup> Congress of Delegates, The Arc of the United States, & American Association on Intellectual and Developmental Disabilities (2009). Retrieved from <https://www.thearc.org/document.doc?id=3634>

**RIGHTS UNDER US FEDERAL LAW (HCBS SETTINGS RULE)****Individuals participating in a Medicaid HCBS Waiver must be SUPPORTED to:**

- seek employment and work in competitive integrated settings,
- engage in community life,
- control personal resources,
- receive services in the community,
- all to the same degree of access as individuals not receiving Medicaid HCBS.

**Individuals participating in a Medicaid HCBS Waiver have the RIGHT to:**

- Choose their home and workplace/day program based on their individual needs and preferences.
- Privacy, dignity and respect.
- Freedom from coercion and restraint.
- Exercise individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.
- Choose their services and supports, and who provides them.
- A legally enforceable agreement (contract or lease) for their home, and protection from eviction that all tenants have under the applicable landlord tenant law.
- Privacy in their sleeping or living unit.
- Unit entrance doors which they can lock and unlock with their own keys, with only appropriate staff having keys to doors as needed.
- Choice of roommates, if applicable.
- Furnish and decorate their sleeping or living units within the lease or other agreement.
- Control their own schedules and activities.
- Access to food at any time.

- Visitors of their choosing at any time.
- Setting which are physically accessible for them.
- A person-centered plan which justifies any modification, limitations, or restrictions of their rights only after meeting the following criteria:
  - Identification of a specific and individualized assessed need.
  - Documentation of the positive interventions and supports used prior to any modifications to the person-centered service plan.
  - Documentation of less intrusive methods of meeting the need that have been tried but did not work.
  - Inclusion of a clear description of the condition that is directly proportionate to the specific assessed need.
  - Inclusion of regulation collection and review of data to measure the ongoing effectiveness of the modification.
  - Inclusion of established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
  - Inclusion of the informed consent of the individual.
  - Inclusion of an assurance that interventions and supports will cause no harm to the individual.<sup>26</sup>

Our long-term goal is a systematic shift in the treatment of people with mental disabilities from institutionalization to community integration.

*Human Rights Watch*

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<sup>26</sup> Adapted from, US Department of Health and Human Services, Centers for Medicare & Medicaid. (2014). *CFR-2017-title42-vol4-§ 441.530 Home and Community-Based Setting*. Retrieved from <https://www.gpo.gov/fdsys/pkg/CFR-2017-title42-vol4/pdf/CFR-2017-title42-vol4-sec441-530.pdf>. Complete Setting Rule document available at <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

## **RIGHTS UNDER STATE LAW**

### **SECTION 44-26-90. Rights of client not to be denied<sup>27</sup>.**

Unless a client has been adjudicated incompetent, he must not be denied the right to:

- (1) dispose of property, real and personal;
- (2) execute instruments;
- (3) make purchases;
- (4) enter into contractual relationships;
- (5) hold a driver's license;
- (6) marry or divorce;
- (7) be a qualified elector if otherwise qualified. The county board of voter registration in counties with department facilities reasonably shall assist clients who express a desire to vote to:
  - (a) obtain voter registration forms, applications for absentee ballots, and absentee ballots;
  - (b) comply with other requirements which are prerequisite for voting;
  - (c) vote by absentee ballot if necessary;
- (8) exercise rights of citizenship in the same manner as a person without intellectual disability or a related disability.

### **SECTION 44-26-100. General rights of clients; limitations on rights<sup>28</sup>.**

(A) Except to the extent an interdisciplinary team of a residential program determines that it is required by the medical needs, safety, or habilitative goals of the client to impose restrictions, a client may:

- (1) communicate by sealed mail, telephone, or otherwise with persons, including official agencies, inside or outside the institution. Reasonable access to writing materials, stamps, envelopes, and telephones, including reasonable funds or means by which to use telephones, must be provided;

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<sup>27</sup> South Carolina Legislature. (2011). *South Carolina Code of Laws Unannotated, Title 44: Health, Chapter 26: Rights of Clients with Intellectual Disability*. Retrieved from <https://www.scstatehouse.gov/code/t44c026.php>

<sup>28</sup> Ibid.

(2) receive visitors. A facility must have a designated area where clients and visitors may speak privately;

(3) wear his clothes, have access to personal hygiene articles, keep and spend a reasonable sum of his money, and keep and use his personal possessions, including articles for personal grooming not provided for by the facility unless the clothes or personal possessions are determined by an intellectual disability professional or physician to be dangerous or otherwise inappropriate to the habilitation regimen. If clothing is provided by the facility, clients must have the opportunity to select from neat, clean, seasonal clothing that allows the client to appear normal in the community. The clothing must be considered to be the client's throughout his stay in the facility;

(4) have access to individual storage space for private use. Personal property of a client brought into the facility and placed in storage by the facility must be inventoried. Receipts must be given to the client and at least one other interested person. The personal property may be reclaimed only by the client or his guardian as long as he is living unless otherwise ordered by the court;

(5) follow or abstain from religious practices. Religious practices may be prohibited by the facility supervisor if they lead to physical harm to the client or to others, harassment of other clients, or damage to property.

(B) The department shall determine what constitutes reasonable access for the rights provided in this section. Limitations imposed on the exercise of the rights by the client and the reasons for the limitations must be made part of the client's record. The limitations are valid for no more than thirty days. The time may be extended an additional thirty days if, upon review, it is determined the client's safety or habilitation warrants limitations of the rights. If the department restricts rights, the reasons for the restriction and why the condition cannot be resolved in a less restrictive manner must be recorded in the client's record.

## RIGHTS OF PEOPLE RECEIVING DSSN RESIDENTIAL SERVICES

The DDSN Residential Habilitation Standards require that:

People are:

1. a) Informed of their rights;
2. b) Supported to learn about their rights.
- c) Supported to exercise their rights.
- d) Due process is upheld prior to any rights restrictions.

These rights include Human rights, Constitutional rights and Civil rights.

- Rights Training includes responsibilities as well as rights.
- Training occurs a minimum of once every three (3) months.
- Wide latitude is given as to how training may occur; however, documentation such as a signed training attendance sheet must exist to verify that each person received training. Should a person refuse to sign the training sheet or refuse to attend training, this should be documented on the training attendance sheet.
- Each person's right to privacy, dignity and confidentiality in all aspects of life is recognized, respected and promoted.
- Personal freedoms, such as the right to make a phone call in private, to decide to have a friend visit, choices as to what to have for a snack, etc. are not restricted without due process.
- People are supported to manage their own funds to the extent of their capability.
- Due process is upheld, including the **Human Rights Committee** review of restriction of personal freedoms.
- People with limited knowledge and experience receive training and opportunities to explore their individual rights and the responsibilities that accompany them.<sup>29</sup>

There is no greater disability in society, than the inability to see a person as more.

*Robert M. Hensel  
Film producer, poet,  
athlete, activist, Guinness  
World Record Holder,  
Ambassador*

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<sup>29</sup> SC DDSN. (2018) *Residential Habilitation Standards, Revised February 12, 2018*, p. 10. Retrieved from [http://www.ddsn.sc.gov/about/directives-standards/Documents/currentstandards/Residential%20Habilitation%20Standards%20-%20Revised%20\(011918\).pdf](http://www.ddsn.sc.gov/about/directives-standards/Documents/currentstandards/Residential%20Habilitation%20Standards%20-%20Revised%20(011918).pdf)

## THE DIGNITY OF RISK

WHAT IF...

WHAT IF... you never got to make a mistake?

WHAT IF ... your money was always kept in an envelope where you couldn't get it?

WHAT IF... you were always treated like a child?

WHAT IF... the job you did was not useful?

WHAT IF... you never got to make a decision?

WHAT IF... the only risky thing you could do was act out?

WHAT IF... you couldn't go outside alone because you might run away?

WHAT IF... you took the wrong bus once and now you can't take another one?

WHAT IF... you got into trouble and were sent away and you couldn't come back because they always remember your trouble?

WHAT IF... you worked and got paid 86 cents a week?

WHAT IF... you had to wear your winter coat when it rained because it was all you had?

WHAT IT... you had no privacy?

WHAT IF... you could do part of the grocery shopping but you weren't allowed to do any, because you weren't able to do all of the shopping?

WHAT IF... you spend three hours a day just waiting?

WHAT IF ... you grew old and never knew adulthood?

WHAT IF... you never got a chance?

There can be such a thing as human dignity in risk. And there can be a dehumanizing indignity in safety!

*Robert Perske  
Disability Rights  
Advocate & Author*



## BALANCING RIGHTS AND RISK

An important component of the DDSN Risk Management Program is associated with balancing the goal of promoting independence and self-determination with the provider's responsibility to keep the individual safe from foreseeable harm. This area of risk management has taken on new importance over the last decade as a result of the shift in treatment/ habilitation that has empowered people supported to be more in control of their lives and decisions.

Exposure to risk is a part of everyday life, and it is largely through making choices and assuming some risk that judgment (i.e., capacity) is developed. However, the ability to distinguish between reasonable and unreasonable risks is sometimes a complex task, and people with disabilities can be vulnerable to abuse, neglect, exploitation and a variety of other dangerous situations that may be the result of their own decision making.

### Process of Determining Degree of Risk

Finding the balance between the provider's responsibility to protect people, while at the same time promoting their personal growth and autonomy always begins with the person and those who know him/her best. This would include the family, members of his/her "circle of support," and often the direct support professionals that work with the person on a regular basis.

#### A. Presumption of Full Capacity

In the eyes of the law, if a person is 18 years of age or older, and has not been adjudicated as incompetent, then there is a presumption that the person is competent to make his/her own life's decisions, and to assume the consequences of those decisions. (This presumption may be restricted by the terms of the Adult Health Care Consent Act and DDSN Directive 535-07-DD: Obtaining Health Care Consent for Minors and Adults, for decisions involving healthcare.)

The exercise of rights carries with it responsibilities. Provide opportunities for people to think about responsibilities that result from the choices they make.

*The Council on Quality and Leadership*

#### B. Factors that Reduce Capacity

There are certain factors that may be present in a person's life that reduce the validity of this presumption of competence. These factors generally exist with degrees of severity. Some of the factors that reduce the likelihood that a person is truly able to make all their own decisions and accept the risks involved include:

- Level of cognitive impairment
- Level of social adaptive impairment
- Level of expressive and receptive language impairment
- History and experience in decision making
- Presence of or degree of mental illness

- Presence of or degree of substance abuse
- Using the above mitigating factors, a determination can be made as to whether the person has a reduced capacity to make their own decisions, and furthermore, the relative degree of the reduced capacity.

**C. Potential for Harm**

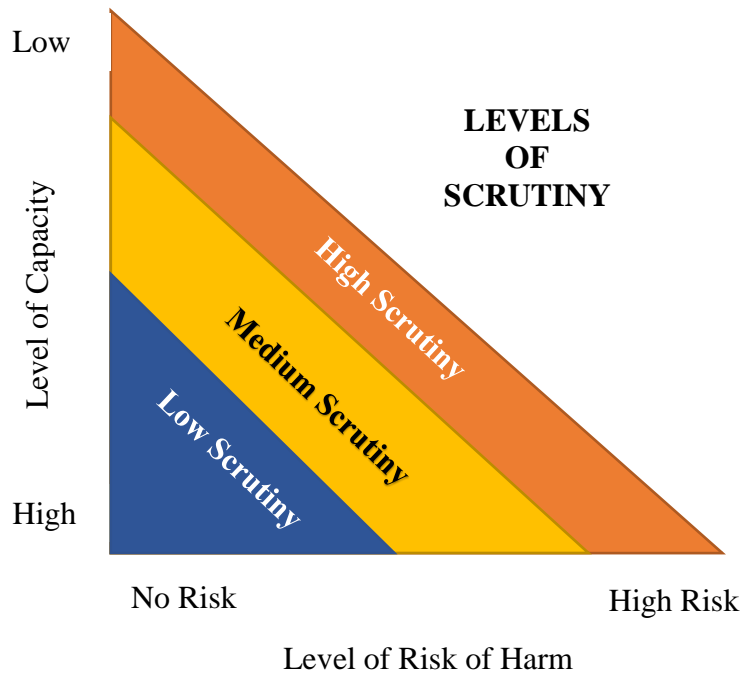
Not all decisions are of equal weight. Some decisions are of little consequence, while others may determine the quality and even the length of a person’s life. The consequences of a decision, in relation to the amount of risk that is involved, may be determined by asking:

- What is the potential that harm will occur?
- What would be the severity of the harm?
- What would be the duration of the harm?

Using the above answers, a determination can be made as to the degree of potential harm associated with the decision, choice or situation under consideration. The more likely that harm will result from a decision or choice, the more competence the person supported by the provider should possess before that decision is left fully in their hands.

**Level of Scrutiny to be Applied**

Individuals, families, teams, and providers can determine how much scrutiny should be applied to a decision by considering two factors: level of competence and the level of risk of harm.



- A. **LOW SCRUTINY** (low risk combined with high capacity) would indicate that the person can make these decisions by themselves.
- B. **MEDIUM SCRUTINY** (medium risk and/or medium capacity) would indicate that the decision or situation requires support for the person, such as consultation with the family, circle of support, treatment team, etc. before the decision is made.
- C. **HIGH SCRUTINY** (high risk and/or low capacity) would indicate that the decision should be made by the provider, or some other substitute decision maker, after consultation with the individual, family, team, professional staff, or employing other specialty consultations.

The keys to establishing the proper balance between the person's right to make his/her own decisions and the organization's duty to protect from foreseeable harm or risk are in:

- Having a rational basis for establishing any reduced capacity;
- Having a rational basis for establishing any potential for harm; and then
- Varying the degree of assistance/ support given to the person based upon these first two factors.

### Reducing Risks to The Person Supported

Just like the rest of us, a person supported by the provider's good judgment can increase with training, experience, and consultation with others. The following strategies can be utilized in order to increase the person's capacity to make good decisions, and by so doing, reduce the risk of harm to the individual.

- Additional training
- Additional experience through practice or approximating
- Family support/involvement
- Professional counseling
- Mentoring
- "Circle of Support" involvement
- Neighborhood support
- Staff supervision/shadowing/fading of supports
- Dividing a task/situation into those parts that may be done independently, and those parts where supervision/support is presently needed.

### Reducing Risks to The Provider

Service and support providers need to assure that they are on firm ground from an ethical and a liability point of view, as they turn more and more control for decision making over to the person supported. If harm does occur to a person under the providers care and supervision, then the provider will need to document the steps that it took in order to properly balance the rights of a

Support the person to experience the consequences for themselves. We learn best through our mistakes not our successes.

*The Council on Quality  
and Leadership*

person to make their own decisions with the duty of the provider to protect from foreseeable harm. Below are listed some of the steps an agency can take to accomplish this:

- Utilize a rational, defensible process in assessing when a decision can be left in the hands of the person and when graduated supports should be applied.
- Seek family involvement in decisions.
- Use a team approach in deliberations.
- Seek outside consultations, a second opinion, or an “independent clinical review”.
- Utilize the services of an ethicist or Ethics Committee when appropriate.
- Communicate with other providers or DDSN Central Office to determine what the standard of care has been in that particular area.
- Document deliberations and actions.
- Refer very difficult cases to the courts for adjudication.
- Provide regular training to staff on making balanced decisions in this area.
- When in doubt, err on the side of health and safety.
- Assure that appropriate liability insurance is in place.<sup>30</sup>

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<sup>30</sup> DDSN (2018). *Risk Management*. Retrieved from <http://www.ddsn.sc.gov/QualityManagement/Pages/RiskManagement.aspx>

## RIGHTS RESTRICTIONS

### What is a “rights restriction”?

A “rights restriction” is anything that limits or prevents an individual from freely exercising his/her rights and privileges. Something is usually considered restrictive if it impedes the enjoyment of general liberties that are available to all citizens. As described below, some rights restrictions are always illegal; others may be permitted under limited circumstance.

### What are some examples of rights restrictions?

#### Limitations on access

- To personal possessions (mail, clothing, etc.)
- To food or drink
- To activities
- To family, friends, children, significant others
- To visitors of their choice in their home at any time
- The person may not answer their phone or doorbell.
- The person must ask permission to go anywhere in their own home (rooms, refrigerator, cupboards).
- The person does not or is not allowed to make their own decisions or offered choices.

#### Limitations to movement

- Therapeutic holds
- Helmets, splints for behavior control
- Mechanical restraints (mitts, belts, vests, etc.)
- Door/window alarms
- Locked doors for which the individual has no key
- Fences and/or gates that restrict egress or exit
- One-to-One supervision

#### Limitations to privacy

- Staff enter a person’s room without permission
- Staff go through the person’s purse, pockets, drawers, etc.
- Person not given privacy with their visitors
- “Junk” mail is removed from the person’s mail before they see it.<sup>31</sup>

### When are rights restrictions permitted?

Only in specific circumstances. The law states any modifications or restrictions to the exercise of rights must be supported by a specific assessed need and justified in the person-centered service plan. The following eight requirements must be documented in the person-centered service plan:

Obviously, because of my disability, I need assistance. But I have always tried to overcome the limitations of my condition and lead as full a life as possible.

*Stephen Hawking*

<sup>31</sup> Adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 14-15. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

1. Identify a specific and individualized assessed need.
2. Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
3. Document less intrusive methods of meeting the need that have been tried but did not work.
4. Include a clear description of the condition that is directly proportionate to the specific assessed need.
5. Include regulation collection and review of data to measure the ongoing effectiveness of the modification.
6. Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
7. Include the informed consent of the individual.
8. Include an assurance that interventions and supports will cause no harm to the individual.<sup>32</sup>

### Are there alternatives to rights restrictions?

Yes. There are often other alternatives that a team can choose from when an individual's situation requires the team to intervene. When a restrictive procedure is presented to the HRC, the committee should ask certain questions to determine if the restriction is the least restrictive option. For example, the committee can ask "What right is being infringed upon?"<sup>33</sup> More than one right can be restricted at the same time. For example, imposing a medically prescribed diet may result in several rights being restricted such as: limited access to food, limited or no choice of food selections, limited or no access to money that may be used to obtain food, and limited or no free community access.

Freedom is not worth having if it does not include the freedom to make mistakes.

Mahatma Ghandi

### When should rights restrictions NOT be implemented?

1. When "it's always been done that way." There must be a rationale for each restriction and it should be clear that the restriction imposed meets the needs of the individual without being more intrusive than need be.
2. When it is for staff convenience. Anyone living with others must abide by some rules and agreed upon routines. However, when a rule is imposed on a person against their will, it must be considered a restriction.
3. When the only reason is that the ISP team proposed it. Despite the best of intentions; a team may not have proposed the most appropriate plan. The HRC serves as a safety net to ensure that rights are unjustly or excessively restricted, and needs to question team decisions.<sup>34</sup>

<sup>32</sup> US Department of Health and Human Services, Centers for Medicare & Medicaid. (2014). Retrieved from <https://www.gpo.gov/fdsys/pkg/CFR-2017-title42-vol4/pdf/CFR-2017-title42-vol4-sec441-530.pdf>.

<sup>33</sup> See p. 48, 57-58.

<sup>34</sup> Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 15. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

## SECTION 4

# The Human Rights Committee

The role of the Human Rights Committee is to safeguard and protect the rights of people receiving services to ensure that they are treated with dignity and respect in full recognition of their rights as citizens.

*DDSN Directive  
535-02-DD*

*In this section....*

Purpose

People

Policy

Flow Chart

Common Issues

Helpful Questions

## PURPOSE

According to the South Carolina Code of Laws: Rights of Clients with Intellectual Disability, Section 44-26-70, Human Rights Committees “must be established for each regional center and for each county/multicounty program.”<sup>35</sup>

Qualified service providers are also required to create their own HRC or connect with an existing Disability and Special Needs (DSN) Board’s HRC.<sup>36</sup> Their four-fold purpose is to:

1. **Review and advise** the regional center or the county/multicounty board on the policies pertaining to clients' rights policies;
2. **Hear and make recommendations** to the regional center or county/multicounty board on research proposals which involve individuals receiving services as research participants pursuant to Section 44-20-260;<sup>37</sup>
3. **Review and advise** the regional center or county/multicounty board on program plans for behavior management which may restrict personal freedoms or rights of clients;
4. **Advise** the regional center or county/multicounty board on other matters as requested pertaining to the rights of clients.

## PEOPLE

The Law states the following concerning HRC members:

1. Members “must be appointed by the Director or his designee” at each regional center and county/multicounty program.
2. Employees or former employees of the regional center or county/multicounty board must not be appointed.
3. Each committee consists of not less than the following five persons:
  - (1) a Family member of a person with intellectual disability or a related disability;
  - (2) a Client of DDSN, if appropriate;
  - (3) a Representative of the community at large with expertise or a demonstrated interest in the care and treatment of persons with intellectual disability or related disabilities.
4. Members...serve in an advisory capacity only and are exempt from liability.

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<sup>35</sup>Last update June 7, 2011. Retrieved from <http://www.scstatehouse.gov/code/t44c026.php>


<sup>36</sup> DDSN. (2016). *Directive 535-02-DD: Human Rights Committee*, p. 2. Retrieved from [http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20\(040816\).pdf](http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20(040816).pdf). See also See p. 38 of this manual.

<sup>37</sup> Available at <http://www.scstatehouse.gov/code/t44c020.php>



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Reference Number: 535-02-DD

Title Document: Human Rights Committee

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Applicability: DDSN Autism Division; DDSN Regional Centers; DSN Boards; and Contract Service Providers

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**PURPOSE**

This directive establishes policies and procedures for the establishment, and operation of a Human Rights Committee (HRC) at each Department of Disabilities and Special Needs (DDSN) Regional Center, DDSN Autism Division, Disabilities and Special Needs (DSN) Boards and Contract Service Providers, and sets forth guidelines for the authority, role, and responsibility of such committees.

**PHILOSOPHY**

Individuals with disabilities are entitled to exercise their civil, political, social, economic and cultural rights on an equal basis with others. Each individual who receives services from DDSN is encouraged and assisted to exercise his/her rights as a citizen and as a service recipient. When an individual is unable to fully exercise their rights, it is the responsibility of society to safeguard and protect those rights. The Human Rights Committee serves as society's representative to protect the due process rights of individuals receiving services from DDSN, DSN Boards, and contract service providers.

State law specifies that DDSN “shall establish policy and procedures for the operations of the committees.”<sup>38</sup> DDSN did so in “[Directive 535-02-DD: Human Rights Committee](#).”<sup>39</sup>

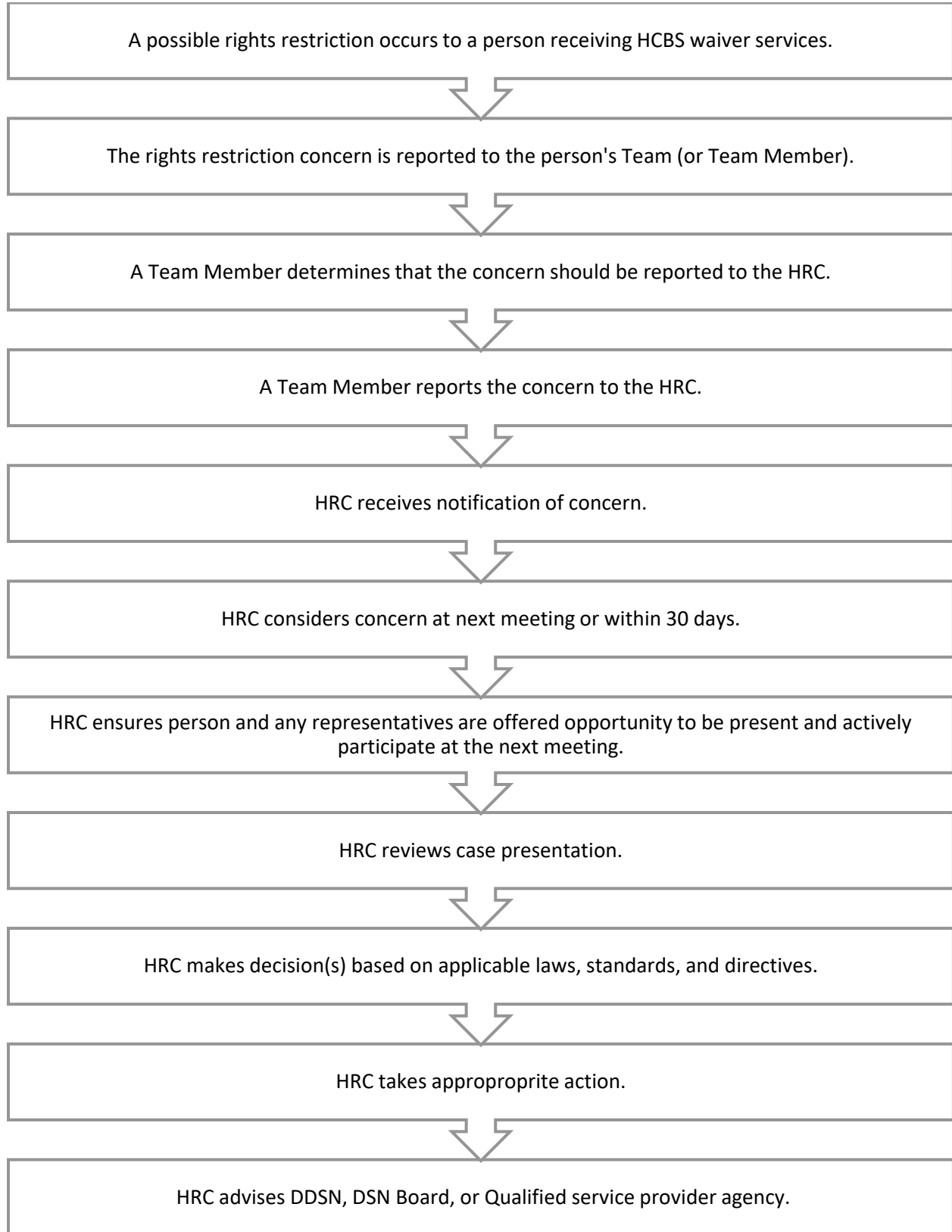
For the most current edition of Directive:

1. Go to the DDSN website, [www.ddsn.sc.gov](http://www.ddsn.sc.gov).
2. Once on the homepage, click on “About DDSN” near the top of the left sidebar.
3. Next, click the link “Current DDSN Directives” for the list of directives.
4. The list is in alphabetical order. Scroll down to “Human Rights Committee” and click on the [link](#).

<sup>38</sup> South Carolina Code of Laws. (n.d.). *Section 44-26-70, Human Rights Committees*, C. Retrieved from <https://www.scstatehouse.gov/code/t44c026.php>

<sup>39</sup> Last update April 8, 2016. Retrieved from [http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20\(040816\).pdf](http://www.ddsn.sc.gov/about/directives-standards/Documents/currentdirectives/535-02-DD%20-%20Revised%20(040816).pdf). See p. 37-44.

### HUMAN RIGHTS COMMITTEE FLOW CHART



## COMMON HRC ISSUES

While an HRC may review and advise on any number of concerns, the following are some common issues with which the Committees have been involved.

- Individual rights restrictions
- GPS tracking bracelets
- Door/window alarms
- Other environmental restrictions
- One-on-one supervision
- Restrictive behavior support plans
- Painful/aversive treatments
- Abuse, Neglect, Exploitation (ANE) allegations
- Use of psychotropic medication
- Issues regarding informed consent
- Guardianship issues
- Incident report review
- Use of emergency procedures
- Money management issues
- Smoking reduction practices
- “Do not resuscitate” (DNR) medical orders

I am different,  
but not less.

*Temple Grandin  
Professor Colorado State  
University,  
Autism Spokesperson*

### HELPFUL QUESTIONS FOR HRC

- Do our Policies and Procedures reflect the mission and vision of our organization/agency? How do we verify/incorporate?
- Are policies and procedures written in a clear, understandable manner-- preferably at a 5<sup>th</sup>-8<sup>th</sup> grade reading level? Are they “user friendly”? How could we find out?
- Are they person-centered? How could we find out? What are some “key” words?
- Do policies and procedures reflect “best practice” in the field of intellectual/developmental disabilities? How could we find out?
- Do we as a Human Rights Committee review policies and procedures for rights restrictions?
- Are policies and procedures written to clearly protect the safety and well-being of persons supported?
- How often are the policies and procedures updated and by whom? Do those who use them the most have input into their creation/revision?
- Do policies and procedures have built-in prompts for staff to adhere to certain time frames? For example: (twice yearly in January & July, etc.)
- In what ways do our policies and procedures address the requirements of monitors, surveyors, rules, mandates, etc.?
- Are any right restrictions being universally applied in a setting?
- Is informed consent issued prior to use?
- How are staff/committee members trained in policies and procedures? Do we use competency-based training materials?
- Are agency grievance and appeal processes easy to understand?
- Do we follow our own policies and procedures? Do we ever deviate or make exceptions? If so, what method of approval do we have in place?
- Do policies and procedures promote choice and independence?<sup>40</sup>

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<sup>40</sup> Adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 25-26. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf25-26](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf25-26)

**SECTION 5**

**The  
Human  
Rights  
Committee  
Toolbox**

*In this section....*

**Conducting Meetings**

**Rights Quiz**

**People First Language**

**Confidentiality**

**Scenarios for Discussion**

When you have a disability, knowing that you are not defined by it is the sweetest feeling.

*Anne Wafula Strike,  
Athlete, Author, Sporting  
Ambassador*

**Basics of Conducting HRC Meetings**

1.	The meeting is conducted by the committee chair or his designee not provider staff or consultants.
2	The committee is a stand-alone advisory group separate from the agency. All deliberations will proceed under a principle of neutrality.
3	Committee decisions are made by vote.
4	Only committee members may vote, not provider staff or consultants.
5	Committee members whose vote may represent a conflict of interest in a case must excuse themselves from voting.
6	Staff or consultants not associated with the case in presentation are to be excused from the room.
7	The person receiving HCBS services may request that any provider staff, to include the ED, not be in the room during presentation of their case and/or while they are making their refusal or appeal. The person must be informed of this right before case presentation begins.
8	Per DDSN Directive 535-02-DD, meeting agendas and minutes must be utilized, and attendance must be taken.

### RIGHTS QUIZ

The table below lists some rights that are guaranteed to individuals with intellectual/developmental disabilities. Some are constitutional, some are mandated by federal and/or state laws, others are DDSN policy, and some may be all three.<sup>41</sup> Review the list and place a check in the box in the category(s) in which you think each right might fall.

RIGHTS	US CONSTITUTION	FED/STATE LAW	DDSN POLICY	ALL THREE
To services in the least restrictive environment.				
To access the courts and legal representation.				
To vote.				
To free association.				
To privacy.				
Freedom from unnecessary medication and mechanical, chemical, or physical restraint.				
To bed, dresser, and storage area.				
To adequate nutrition.				
To manage personal funds.				
To fair and equal treatment by public agencies.				
To contract, own, and dispose of property.				
To religious worship.				
To marry, procreate, and raise children.				
To equal educational opportunity.				
To private communication.				
To seasonal, neat, and clean clothing.				
To equal protection and due process.				
To file a grievance without fear of retribution.				
To be free from discomfort and deprivation.				
To physical exercise.				
To dignity and respect.				

<sup>41</sup> Adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 12. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/ HumanRights/ HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/ HumanRights/ HRCTraineeNotebookrev030116.pdf)

## PEOPLE FIRST LANGUAGE

People with disabilities are – first and foremost – **people** who have individual abilities, interests and needs. They are moms, dads, sons, daughters, sisters, brothers, friends, neighbors, coworkers, students and teachers. About 54 million Americans -- one out of every five individuals -- have a disability. Their contributions enrich our communities and society as they live, work and share their lives. People with disabilities constitute our nation’s largest minority group, which is simultaneously the most inclusive and the most diverse. Everyone is represented: all genders, all ages, all religions, all socioeconomic levels and all ethnic backgrounds. The disability community is the only minority group that anyone can join at any time.

The language a society uses to refer to persons with disabilities shapes its beliefs and ideas about them. Words are powerful; old, inaccurate, and inappropriate descriptors perpetuate negative stereotypes and attitudinal barriers. When we describe people by their labels of medical diagnoses, we devalue and disrespect them as individuals. In contrast, using thoughtful terminology can foster positive attitudes about persons with disabilities.

One of the major improvements in communicating with and about people with disabilities is "People-First Language.”

People-First Language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person. People-First Language is an objective way of acknowledging, communicating, and reporting disabilities. It combats stereotypes by focusing on the person first. <sup>42</sup>

It is especially important that you use and promote respectful language when referring to or talking about the people that you help support.

*Illinois DHS*

Using People First Language <sup>43</sup>	
Say:	Instead of:
He has an intellectual disability.	He’s mentally retarded.
People with disabilities...	The handicapped or disabled.
She uses a wheelchair.	He’s/She’s wheelchair bound.
He has Down Syndrome.	He’s Down’s.
She needs or uses...	She has a problem with...
He receives special education services.	He’s special ed...
She needs/does not need assistance with...	She is low/high functioning.
He uses alternative communication forms.	He is non-verbal.
She is communicating through behavior.	She is having behaviors.

<sup>42</sup> The ARC. (2018). *What is People First Language?* Retrieved from <https://www.thearc.org/who-we-are/media-center/people-first-language>

<sup>43</sup> Adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 28. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HRCTraineeNotebookrev030116.pdf)



## CONFIDENTIALITY

State and Federal Law require that Human Rights Committees, like other persons and groups granted access to DDSN client records, must treat all such information with strict confidentiality.

### State Law

South Carolina State Law 44-26-130 guarantees confidentiality of communications with, and records of clients, as follows:

(A) Communications between clients and intellectual disability professionals, including general physicians, psychiatrists, psychologists, nurses, social workers, members of interdisciplinary teams, or other staff members employed in a client-therapist capacity or an employee under supervision of them are considered confidential. Certificates, applications, records, and reports made for the purpose of this chapter that directly or indirectly identify a client, as well as privileged communications, must be kept confidential and must not be disclosed by a person unless:

- (1) the identified client or his representative consents;
- (2) a court directs disclosure upon its determination that disclosure is necessary for the conduct of proceedings before it and that failure to make the disclosure is contrary to the public interest;
- (3) disclosure is required for research conducted or authorized by the department;
- (4) disclosure is necessary to cooperate with law enforcement, health, welfare, and other state agencies, schools, and county entities;
- (5) disclosure is necessary to carry out this chapter.

(B) Nothing in this section precludes disclosure:

- (1) upon proper inquiry, of information as to a client's current medical condition, to appropriate next of kin;
- (2) if the information is used in an educational or informational capacity if the identity of the client is concealed;
- (3) of information to the Governor's ombudsman office or the South Carolina Protection and Advocacy System for the Handicapped, Inc., as consistent with state law.<sup>44</sup>

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<sup>44</sup> South Carolina Legislature. (2011). *South Carolina Code of Laws Unannotated, Title 44: Health, Chapter 26: Rights of Clients with Intellectual Disability*. Retrieved from <https://www.scstatehouse.gov/code/t44c026.php>

## Federal Law

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) addressed the issue of “protected health information”. The regulation is known as the “Privacy Rule”, and it defines how health care providers can use and disclose protected health information.<sup>45</sup>

A central aspect of the Privacy Rule is the principle of “minimum necessary” use and disclosure. A covered entity must make reasonable efforts to use, disclose, and request only the minimum amount of protected health information needed to accomplish the intended purpose of the use, disclosure, or request.<sup>46</sup>

In compliance with HIPAA, DDSN has notified service recipients that their health information is typically used only to “treat you, run our organization, and bill for your services.” Since HRCs help “improve care” and “manage...treatment and services”, they may be granted access to the person’s protected health information on an as-needed basis.<sup>47</sup>

## Guidelines

Review the following guidelines concerning confidentiality:

- HRCs must be diligent in assuring their practices remain in accordance with HIPAA.
- Confidentiality is an important component of a strong HRC. Each committee member must assure that information about persons receiving services is held in the strictest confidence.
- Conversations should be kept confined to the meeting room and care must be taken to assure topics are not discussed in hallways, parking lots, etc.
- Likewise, after meeting care must be taken that papers containing identifiable information are not left lying about.
- When discussing an individual served who is not present at the meeting, use a coding system (initials, identification numbers, etc.) to keep complete anonymity even from the HRC.
- If the discussion includes someone who is not receiving services at the agency, the person’s identity must be kept confidential.<sup>48</sup>

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<sup>45</sup> Adapted from DHEC. (2014). *Public Health and HIPAA*. Retrieved from <http://www.scdhec.gov/library/ML-025080.pdf>

<sup>46</sup> Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 23. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

<sup>47</sup> <http://www.ddsn.sc.gov/PrivacyPractices/Pages/HIPAA.aspx>

<sup>48</sup> Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p.22-23. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

## SCENARIOS FOR DISCUSSION

1. Lori is receiving both residential and day services at the agency where she lives. Every morning, Monday through Friday, a bus stops at her house to take her and two other individuals to a day program, which is not very far from their home. In recent months Lori has become steadily more reluctant to get on the bus, although, once aboard, she seems fine. In the past two weeks she has had what appear to be panic attacks at the sight of the bus. Male staff are now being detailed to the home in the morning to physically carry her onto the bus. Lori seems to regard food as a very powerful reinforcer. In order to lessen the risks involved in the current staff response, it is proposed that her breakfast be withheld and served to her on the bus. Additionally, the doctor has recommended Zoloft for her anxiety. What should the HRC advise?

Potential Rights Restrictions:

Related Issues to Explore:

2. Joe has been making life interesting for the third shift staff for some time since coming here from the SODC. He has developed a habit of urinating in inappropriate places and seems to prefer his and his roommate's dresser drawers. Adequate clean clothing for both Joe and his roommate is constantly in short supply. Both sets of parents regularly complain about Joe's actions and it was recently brought to the attention of the agency's Executive Director. Staff removed the dresser and locked it in the laundry room. Each evening after the roommates go to bed, staff takes out one outfit for each roommate and hang them in the closet. Staff report that the number of instances of inappropriate urination is nearly zero since the dresser was removed. It is proposed that the clothing remain inaccessible until such time that something better is figured out. Both guardians agree to the plan. Should the HRC endorse this plan?

Potential Rights Restrictions:

Related Issues to Explore:

3. Jim is a fairly strong young man. He also seems to have experienced a life history in which he seldom was required to do anything he didn't want to do. Staff in his home often describe him, at least when their descriptions aren't unprintable, as "non-compliant." When demands are placed on him, he may become physically aggressive until the demands are eased. The doctor has prescribed Paxil for agitation, as well as to calm the physical aggression. The psychologist also recommends a behavior program in which his aggressiveness is ignored in hopes of extinguishing it. The Behavior Management Committee has approved this plan. Should the HRC agree? <sup>49</sup>

Potential Rights Restrictions:

Related Issues to Explore:

4. Kate lives in a house with four other women of similar age and temperament. The level of activity in the house is often pretty intense and staff are kept busy trying to do their jobs while coping with the rivalries, which abound. Last week Kate walked out of the house following an argument with her roommate. Staff searched the area but were unable to find her. The local police brought her back unharmed about an hour later. It turned out that Kate had walked across the busy highway outside and then to a small strip mall about a mile away. The team is worried this might happen again and want some direction from the committee. What should the HRC advise?

Potential Rights Restrictions:

Related Issues to Explore:

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<sup>49</sup> Questions 1-3 adapted from Illinois Department of Human Services. (2016). *Human Rights Committee Chairperson Training*. p. 30-34. Retrieved from [http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By\\_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf](http://www.dhs.state.il.us/OneNetLibrary/27896/documents/By_Division/Division%20of%20DD/HumanRights/HRCTraineeNotebookrev030116.pdf)

5. Mary suffers from a degenerative muscle disease. She is experiencing more and more difficulty keeping her torso upright in her wheelchair. A physical therapist has recommended a “Posey vest” for use while in her wheelchair and the addition of bed rails to keep her in her bed at night. The case has been presented to the HRC. What should the committee advise?

Potential Rights Restrictions:

Related Issues to Explore:

6. Susan has been receiving services from public and private agencies for most of her life. In recent years her health has begun to fail and her doctor has diagnosed the early stages of congestive heart failure. It is essential, he says, that Susan quit smoking or risk major, and potentially fatal, medical complications. Susan has agreed many times to stop smoking, usually after having what she describes as her “last cigarette” as she is leaving for her part-time job answering the phone at the day program site. Although she has agreed to leave her cigarettes behind at home, by early afternoon she begins to demand a cigarette. If none are forthcoming, she becomes increasingly aggressive verbally and on two occasions has hurled herself from her wheelchair by saying that she wants to die. Staff, some of whom are ardent non-smokers, are quite worried about her health problems and are reluctant to contribute to them by helping her smoke. It is proposed that she be rationed to three cigarettes per day and that her house be declared a “non-smoking” area. That will mean that Susan will have to step outside to enjoy her smoke, a fact that may be sufficiently punishing to encourage her to cut down even more. Should the HRC agree with the staff’s plan?

Potential Rights Restrictions:

Related Issues to Explore:



## SECTION 6

# Important Documents

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

*United Nations  
Universal Declaration  
of Human Rights*

*In this section....*

Universal Declaration of Human Rights

Convention on the Rights of Persons with Disabilities

Americans With Disabilities Act

HCBS Rule

## UNITED NATIONS UNIVERSAL DECLARATION OF HUMAN RIGHTS

### **Article 1.**

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

### **Article 2.**

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

### **Article 3.**

Everyone has the right to life, liberty and security of person.

### **Article 4.**

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

### **Article 5.**

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

### **Article 6.**

Everyone has the right to recognition everywhere as a person before the law.

### **Article 7.**

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

### **Article 8.**

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

### **Article 9.**

No one shall be subjected to arbitrary arrest, detention or exile.

### **Article 10.**

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

### **Article 11.**

(1) Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defense.



(2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

**Article 12.**

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

**Article 13.**

- (1) Everyone has the right to freedom of movement and residence within the borders of each state.
- (2) Everyone has the right to leave any country, including his own, and to return to his country.

**Article 14.**

- (1) Everyone has the right to seek and to enjoy in other countries asylum from persecution.
- (2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

**Article 15.**

- (1) Everyone has the right to a nationality.
- (2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

**Article 16.**

- (1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
- (2) Marriage shall be entered into only with the free and full consent of the intending spouses.
- (3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

**Article 17.**

- (1) Everyone has the right to own property alone as well as in association with others.
- (2) No one shall be arbitrarily deprived of his property.

**Article 18.**

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

**Article 19.**

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

**Article 20.**

- (1) Everyone has the right to freedom of peaceful assembly and association.
- (2) No one may be compelled to belong to an association.

**Article 21.**

- (1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
- (2) Everyone has the right of equal access to public service in his country.
- (3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

**Article 22.**

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

**Article 23.**

- (1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
- (2) Everyone, without any discrimination, has the right to equal pay for equal work.
- (3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
- (4) Everyone has the right to form and to join trade unions for the protection of his interests.

**Article 24.**

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

**Article 25.**

- (1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
- (2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

**Article 26.**

- (1) Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.
- (2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.
- (3) Parents have a prior right to choose the kind of education that shall be given to their children.

**Article 27.**

- (1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.
- (2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

**Article 28.**

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

**Article 29.**

- (1) Everyone has duties to the community in which alone the free and full development of his personality is possible.
- (2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.
- (3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

**Article 30.**

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.<sup>50</sup>

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<sup>50</sup> United Nations. (1948). Retrieved from <http://www.un.org/en/universal-declaration-human-rights/>

## **UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (SELECTED)<sup>51</sup>**

### **Article 1: Purpose**

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include 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.

### **Article 5: Equality and non-discrimination**

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.

### **Article 6: Women with disabilities**

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

### **Article 7: Children with disabilities**

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

### **Article 9: Accessibility**

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in

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<sup>51</sup> For entire document, see <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>)

urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- (b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures:

- (a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- (b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- (c) To provide training for stakeholders on accessibility issues facing persons with disabilities;
- (d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- (e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- (f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- (g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
- (h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

#### **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 17: Protecting the integrity of the person**

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

#### **Article 19: Living independently and being included in the community**

States Parties to the present 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.

## AMERICANS WITH DISABILITIES ACT (SELCTED)

### Sec. 12101. Findings and purpose<sup>52</sup>

#### (a) Findings

The Congress finds that:

- (1) physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination;
- (2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
- (3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;
- (4) unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;
- (5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;
- (6) census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;
- (7) the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and
- (8) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.

#### (b) Purpose

It is the purpose of this chapter

- (1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

### Sec. 12102. Definition of disability

As used in this chapter:

#### (1) Disability

The term "disability" means, with respect to an individual:

- (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;

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<sup>52</sup> CFR Title 42, Chapter 126, Equal Opportunity for Individuals with Disabilities (Sections 12101 & 12102). For entire document, see <https://www.ada.gov/pubs/adastatute08.htm>.

- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment (as described in paragraph (3)).

(2) Major Life Activities

(A) In general

For purposes of paragraph (1), major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.

(B) Major bodily functions

For purposes of paragraph (1), a major life activity also includes the operation of a major bodily function, including but not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.

(3) Regarded as having such an impairment

For purposes of paragraph (1)(C):

(A) An individual meets the requirement of "being regarded as having such an impairment" if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity.

(B) Paragraph (1)(C) shall not apply to impairments that are transitory and minor. A transitory impairment is an impairment with an actual or expected duration of 6 months or less.

(4) Rules of construction regarding the definition of disability

The definition of "disability" in paragraph (1) shall be construed in accordance with the following:

(A) The definition of disability in this chapter shall be construed in favor of broad coverage of individuals under this chapter, to the maximum extent permitted by the terms of this chapter.

(B) The term "substantially limits" shall be interpreted consistently with the findings and purposes of the ADA Amendments Act of 2008.

(C) An impairment that substantially limits one major life activity need not limit other major life activities in order to be considered a disability.

(D) An impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.

(E)

(i) The determination of whether an impairment substantially limits a major life activity shall be made without regard to the ameliorative effects of mitigating measures such as

(I) medication, medical supplies, equipment, or appliances, low-vision devices (which do not include ordinary eyeglasses or contact lenses), prosthetics including limbs and devices, hearing aids and cochlear implants or other implantable hearing devices, mobility devices, or oxygen therapy equipment and supplies;

(II) use of assistive technology;

(III) reasonable accommodations or auxiliary aids or services; or

(IV) learned behavioral or adaptive neurological modifications.

(ii) The ameliorative effects of the mitigating measures of ordinary eyeglasses or contact lenses shall be considered in determining whether an impairment substantially limits a major life activity.

(iii) As used in this subparagraph

(I) the term "ordinary eyeglasses or contact lenses" means lenses that are intended to fully correct visual acuity or eliminate refractive error; and

(II) the term "low-vision devices" means devices that magnify, enhance, or otherwise augment a visual image.

## HOME AND COMMUNITY-BASED SETTING RULE

### CFR-2017-title42-vol4-§ 441.530 Home and Community-Based Setting<sup>53</sup>

(a) States must make available attendant services and supports in a home and community-based setting consistent with both paragraphs (a)(1) and (a)(2) of this section.

**(1) Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan:**

(i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.

(ii) The setting is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.

(iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.

(iv) Optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

(v) Facilitates individual choice regarding services and supports, and who provides them.

(vi) In a provider-owned or controlled residential setting, in addition to the above qualities at paragraphs (a)(1)(i) through (v) of this section, the following additional conditions must be met:

(A) The unit or dwelling is a specific physical place that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord tenant law of the State, county, city or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each participant and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law.

(B) Each individual has privacy in their sleeping or living unit:

(1) Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors as needed.

(2) Individuals sharing units have a choice of roommates in that setting.

(3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement.

(C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.

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<sup>53</sup> US Department of Health and Human Services, Centers for Medicare & Medicaid. (2014). Retrieved from <https://www.gpo.gov/fdsys/pkg/CFR-2017-title42-vol4/pdf/CFR-2017-title42-vol4-sec441-530.pdf>. Complete Final Rule document available at <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>



(D) Individuals are able to have visitors of their choosing at any time.

(E) The setting is physically accessible to the individual.

(F) Any modification of the additional conditions, under paragraphs (a)(1)(vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:

- (1) Identify a specific and individualized assessed need.
- (2) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
- (3) Document less intrusive methods of meeting the need that have been tried but did not work.
- (4) Include a clear description of the condition that is directly proportionate to the specific assessed need.
- (5) Include regulation collection and review of data to measure the ongoing effectiveness of the modification.
- (6) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
- (7) Include the informed consent of the individual.
- (8) Include an assurance that interventions and supports will cause no harm to the individual.

**(2) Home and community-based settings do not include the following:**

- (i) A nursing facility;
- (ii) An institution for mental diseases;
- (iii) An intermediate care facility for individuals with intellectual disabilities;
- (iv) A hospital providing long-term care services; or
- (v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.

(b) [Reserved]

