



HUMAN RIGHTS

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Introduction from Self-Advocates

We would like DSPs to remember that we have rights. Some of the rights that are most important to us include the following:

I have the right to speak up for myself.

I have the right to eat whatever I want.

I have the right to sit where I want at lunch.

I have the right to use the microwave!

I have the right to talk to whomever I want.

I have the right to go where I want to.

I have the right to date who I want.

I have the right to go to school.

I have the right to look at my own files.

I have the right not to be abused and to call the police if I am abused.

Submitted by: Stephanie W., self-advocate, Melissa R., self-advocate, Sean J., self-advocate, Cindy T., self-advocate, Judy D., self-advocate, and Donald J., self-advocate

My name is Glen and I am 57 years old. I lived at home until I was 7 then I moved to Dixon State School. I was there for 21 years. Then I moved to the state hospital at Anna. I lived in a bunch of different places including Elgin State Hospital and Howe. Ten years ago I moved into a CILA [Community Integrated Living Arrangement]. I like to shop. When I was young I did not get to leave to go shopping. I got to go to a few parties but that was it. I did not get to pick what food I ate. Now I do. Now I get to go to church. A man from my church picks me up every Sunday. I go shopping a lot. I like to buy CD's and word search books. I like to listen to all kinds of music. When I was younger I was not allowed to talk on the phone with my family. Now I talk to my mom every week. When I was young I was not allowed to visit my family. Now I visit on holidays and my birthday. When I was young I slept in a room with a bunch of other people in bunk beds. Now I have my own room with a TV, CD player, cable and a VCR. I have lived in my home for ten years.

Submitted by: Glen M., self-advocate

Rights Guaranteed to Persons with Disabilities

The U.S. Constitution guarantees the following rights to each citizen, regardless of ability:

- Access to the courts and legal representation
- Free association
- Right to contract, own, and dispose of property
- Equal educational opportunity
- Equal employment opportunity
- Equal protection and due process
- Fair and equal treatment by public agencies
- Freedom from cruel and unusual punishment
- Freedom of religion
- Freedom of speech and expression
- Privacy
- Services in the least restrictive environment
- Right to vote



Division of Developmental Disabilities Mission Statement:

The Division of Developmental Disabilities in Illinois will provide quality, outcome-based, person-centered services and supports for persons with developmental disabilities and their families. The system of services and supports in Illinois will enhance opportunities for persons to make real choices and receive appropriate, accessible, prompt, efficient, and life-spanning services that are strongly monitored to ensure individual progress, quality of life and safety.

Source DHS website direct link: <http://www.dhs.state.il.us/page.aspx?item=29761>

Rights of Individuals Receiving Support in Illinois:



- Right to services in least restrictive environment
- Right to normalized living conditions
- Right to dignity and respect
- Right to freedom from discomfort and deprivation
- Right to appropriate clinical, medical and therapeutic services
- Right to vote
- Right to religious worship
- Right to private communication
- Right to free association
- Right to physical exercise
- Right to seasonal, clean, neat clothing
- Right to manage personal funds
- Right to bed, dresser and storage area
- Right to privacy
- Right to public media (i.e. newspapers, television, radio, magazines)
- Right to adequate nutrition
- Freedom from unnecessary medication and mechanical, chemical or physical restraints

Source: Developing Staff Competencies for Supporting People with Developmental Disabilities. Gardner and Chapman.

The Evolution of Human Rights for People with Developmental Disabilities

Historically, society has tended to isolate and segregate people with disabilities. Many early institutions were simply warehouses where people were sent for a variety of reasons; not all of which were related to mental illness or mental retardation. Very few ever received any form of individualized treatment or habilitation.

People with disabilities were considered to have no rights up until the early 1960's when a series of landmark declarations, court decisions and legislative acts began to make a crucial difference in the civil rights of persons with developmental disabilities. Some of these are summarized below:



- 1963 - The enactment of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), conceived by President Kennedy, Eunice Kennedy Shriver, and Dr. Robert Cooke. This Act resulted in better understanding, professional education, access and safety in institutional facilities. Later, changes were made to the DD Act, as conceived by Dr. Elizabeth Boggs, Dr. Elsie Helsel, and others. These changes focused on the efforts of families, professionals, and state agencies to improve supports for all people with developmental disabilities. Today, the programs emphasize legal services, advocacy, and capacity building at the state and local levels. The focus is on listening to people with developmental disabilities as self advocates, and helping people with developmental disabilities and their families obtain the information, assistive technology, and supports they need in order to make more informed choices about how and where to live and work, and be active and involved citizens in their communities.

As a result of the landmark court decision in 1970, **Wyatt vs. Stickney**, we recognized that persons with mental retardation are citizens who have "rights" under the constitution. This case resulted in the establishment of 49 Principles of service, which include the requirement to establish a seven-person Human Rights Committee to review all habilitation plans to ensure that the human rights of the residents were preserved. It also resulted in the establishment of:

- Qualified Intellectual Disabilities Professionals (QIDPs)
- A "Right to Treatment"
- Staff to client ratios
- Physical plant features/dimensions

- Development of behavior plans

In 1971, the United National issued its "Declaration of the Rights of Mentally Retarded Persons." This declaration provided expectations for higher standards of living, principals of dignity, and worthiness of persons with developmental disabilities.

- 1974 - A televised documentary made by journalist Geraldo Rivera exposed the living conditions of children and adults at the Willowbrook School in New York City. The fallout from this scandal set in motion a major deinstitutionalization program across New York State. Plymouth Center for Human Development was the first institution in the country to close under federal court order because of the deplorable conditions and abuse. It also brought about needed repairs and reforms at the institutions that continued to operate.
- 1984 - The Health Care Finance Authority (HCFA) is ordered to begin in-depth surveys in Intermediate Care Facilities for People with Mental Retardation (ICF/MRs) to see if the level of care mandated by Medicaid rules was actually being provided. The findings of these surveys brought about a wave of closures and decertifications.



Note: Although there have been major improvements in the last 45 years, discrimination against persons with disabilities continues to be a serious social problem. Discrimination continues in such critical areas as employment, housing, public accommodation, education, transportation, communication, recreation, institutionalization, health services, voting and access to public services. It is our responsibility to make sure these rights are protected for the persons we support. This is especially true when it comes to providing an environment that is free from abuse and neglect and free from the fear of abuse and neglect.

Sources: http://www.mncdd.org/dd_act/dd-act.html Connecticut Developmental Disabilities Council, Ed Preneta, Executive Director, and the Texas Developmental Disabilities Council, Roger Webb, Executive Director.

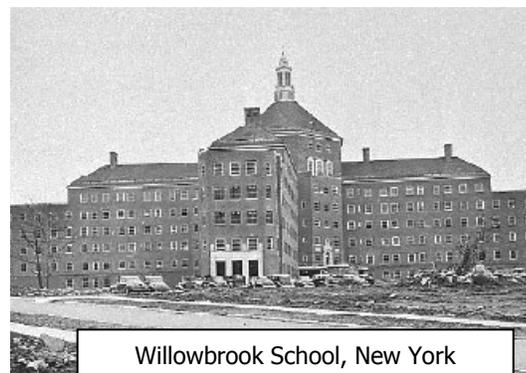
Baker, Steve and Tabor, Amy *Human Rights Committees*, High Tide Press, Homewood, Illinois, 2006

How this evolution of rights for people with developmental disabilities has changed the DSP's role:

Over the last 40 plus years, the role of direct support persons has changed as the disability movement succeeded in bringing about higher quality services for people with developmental disabilities.

During the institutional era, there were usually too few DSPs to provide the individual attention to people that would allow them to learn skills for independence. In many cases, there was only one staff to 40-50 people. Workers were not expected to teach people skills; they were simply expected to be passive caregivers. It was sometimes difficult for DSPs to just keep people clean and fed.

People moving away from institutions and group settings has resulted in the DSPs' role evolving to include emphasis on recognizing and supporting the talents, choices and preferences of people as the key to a satisfactory lifestyle. DSPs now create and ensure people have community connections and assist them in living their lives as citizens with human rights. This requires the DSP to provide supports that teach people the skills needed to participate in their community, as independently and fully as possible.



Rules and Codes

There are now laws that ensure that people with developmental disabilities have the right to considerate, safe, and respectful supports that are free of mental, physical, sexual, and verbal abuse, neglect, and exploitation. They also have the right to be free from seclusion and only put into restraints if they are an immediate danger to themselves or others.

Laws are required to ensure that individuals with developmental disabilities never again experience abuse and neglect as they did in the past. Human rights are required by various rules and codes, while others are specified by agencies. Major rules and codes protecting the rights of persons with disabilities are:

- Mental Health & Developmental Disabilities Confidentiality Act
- Mental Health & Developmental Disabilities Code
- Rule 115 (Community Integrated Living Arrangements)
- Rule 119 (Developmental Training)
- Rule 120 (Medicaid Home and Community-Based Waiver Program for Individuals with Developmental Disabilities)
- Rule 50 (Abuse & Neglect Reporting)
- Department of Human Services Regulations (e.g., requirements in grant funding contract)
- Department of Public Health Regulations (e.g., 77 Illinois Administrative Code which requires DSP training; formerly known as "developmental disability aide" training).

Role of an Advocate

What is an advocate?

An advocate is someone who helps others speak up for themselves, or listens carefully to what another person says, and speaks up for that person's needs and wants.

DSPs should act as advocates for the people they support. Ways that DSPs should be advocates are as simple as encouraging the person to be as independent as possible; helping the person shop for his/her own clothes; deciding on a weekly menu; choosing the Friday night video; increasing opportunities for community socialization and encouraging him/her to personalize their living area. Allow people additional time to do things for themselves rather than doing it for them. As an advocate, you actively work to ensure the protection of the human rights of the individual you support.



Some other ways that you can help support people's rights are:

- Assist people in understanding their rights
- Honor the choices that people make
- Always communicate in a respectful manner
- Protect people's privacy (For example, knocking before entering the bedroom)
- Recognize that people who victimize people with disabilities must be held accountable for their actions
- Represent the best interest of people who cannot speak for themselves by working hard to find an alternative way of understanding desires/needs

There are a number of advocacy groups in Illinois and across the nation that provide assistance and information to people with disabilities in a variety of settings: mental health facilities, residential programs, community placements, and nursing homes. Issues addressed by advocacy groups can include, but are not limited to: help with admission and discharge from hospitalization, adequate treatment, and refusal of unwanted services and confidentiality of records. Illinois' advocacy groups as well as other nationwide advocacy groups are listed in the Appendix section of this curriculum.

The Right to Dignity and Respect through Positive Interactions

Agencies should use positive approaches when providing services. Dehumanizing practices are prohibited. Personal freedoms should not be unduly restricted. When necessary to ensure health, safety, and welfare, limitations on personal freedom are subjected to careful ethical review through a Human Rights Committee.

The types of interactions that are used when providing support must convey dignity and respect. No one should have to live or work with someone who curses, yells, mocks, or otherwise treats him or her cruelly. The basic rule of thumb is “treat others as you would want to be treated.”

Likewise, it is not the role of the DSP to **make** someone perform a task. The role of the DSP regarding programming that is specified in the ISP (Individual Service Plan) is to provide gentle teaching and **not to let any interaction become a power struggle.**



Sample Empowerment Worksheet

Rephrase the statements below to reflect positive interaction:

1. Go take a bath.

2. That is how things are done here.

3. Why would you waste your money on . . .

4. Because I said so!

5. I told you that you wouldn't like that job!

6. Those clothes don't match . . . go change.

7. You have behaved so badly lately that you don't deserve to do to the . . .

8. Time for you to go to bed.

9. This isn't a goal you want to work on, but the team wants you to.

10. These are the people I am inviting to your team meeting.

The Right to Intimacy



Having a developmental disability does not alter the right of a person to express his or her desire to have intimacy. Intimacy is very personal. It is often a reflection of a person's need for closeness with others. It is particularly difficult to judge the "appropriateness" of another's social choices. The person's desires for social relationships, marriage and potential parenthood should be understood by the organization.

People with developmental disabilities have the right to and deserve acceptance of their sexuality. The people involved in a sexual relationship must both be consenting adults. Consent is always seen as informed consent. Some people may need support to deal with unwelcome sexual behaviors and to report this when they need assistance.

The organization should understand what sexuality means for the person. What opportunities exist for this expression? What supports are needed? (education, counseling, privacy). The person should receive sexuality education that will help them understand and be prepared for the risks, and possible results of sexual behavior. Results and risks of sexual behavior include pregnancy, sexually transmitted diseases, emotional attachment, etc. Staff should listen and watch carefully for issues that people may express, and help them get appropriate help as needed. Staff should also not be judgmental and try to impose their own personal values on people. It is also important that staff respect the privacy of people they support to discuss and express their sexuality. Most agencies have specific policies and procedures addressing sexuality. As a DSP you should ensure that these policies are followed while also ensuring that the person remains safe and their rights are protected.

A high percentage of people with developmental disabilities experience sexual abuse in their lifetime. A main factor contributing to the high prevalence is sexual abuse is the lack of sexuality education provided to them.

The Right to Privacy

The reasonable expectation for privacy is a constitutional right. All citizens have the right to keep certain parts of their lives private. The right to privacy includes having time alone and keeping certain possessions private. Each person has their own preferences for privacy. Some people like to be alone when upset or when they just want to relax. Others like to be with people much of the time and don't like much time alone. For people who live in group settings, being able to respect this right may be a challenge. The first step in supporting people's privacy is to get to know the person and what their individual preferences are and then help support those preferences.

Another important aspect to privacy is **confidentiality**. Remember, whenever you speak or write about someone's personal information, you should be concerned about sharing information with those that do not need to know.

Free Access to the Telephone

The telephone is often the person's usual way to maintain contact with friends and family. People's homes should include access to a telephone that offers privacy. People have the right to make and receive phone calls privately. People who experience disabilities which make it difficult to use the telephone should be able to use alternative types of communication. Some people may need a telephone with larger buttons for calling, telephones with pictures of the people they typically call on each pre-set dial pad key, or pre-set phone numbers for each dial pad key and a corresponding directory; i.e. 2 = mom; 3 = brother Don, etc.



The Right to Freedom of Movement

Each person has the right to move about in their environment and this freedom should be the same as all citizens. If, however, this freedom is restricted due to safety reasons, due process rights should be given. Freedom of movement can be limited in many ways.

Some examples of limitations of freedom of movement are: "one-to-one" supervision, door buzzers to monitor movement, etc.

The Right to Free Association

As a Constitutional right, people with intellectual disabilities are free to choose with whom they want to spend time. They should be encouraged to seek relationships with coworkers, neighbors and others they may meet in the community. Supporting a person's right to have relationships also provides opportunity to learn how to interact in social situations.

Cultural Competency and Client Rights Information

From The Cultural Dimensions Guide for Providers of Services for People with Developmental Disabilities (Advocacy Center for the Elderly and Disabled, New Orleans, Louisiana):



The word “culture” is used to refer to a group of people who have experiences in common, whether the group is a nation, a community, or a small group within a community. Within the broad “American culture” of the United States, there are separate cultural groups; even within local communities there are cultural differences. “Culture” is composed of aspects of life which are human-made: skills, tools, folkways, and customs. The effects of culture on a person are pervasive; one’s tone of voice, even choice of words may be influenced culturally.

It is essential that when you are representing and promoting the rights and interests of someone, that the person’s cultural background is recognized and considered. It is important that the rights and desires of the **person** are being represented and not those of the advocates.

Reminders:

- Seek to understand your own culture as well as other cultures.
- Remember the diversity of different cultures.
- Remember the extent of cultural influence on individual behavior and perceptions.

Discussion Activity: Client Rights, Cultural Competency and Staff/Agency Responsibilities

- Does a person have the right to include 20 family members in a service plan meeting, even if a staff member doesn't think it is necessary or appropriate?
- Does a person, or his/her family, have the right to refuse certain aspects of service or treatment that conflict with their religious beliefs?
- Think of an area where you have some beliefs related to a certain population or person. Where does that belief come from and what proof do you have to support it?
- A person in a group home can only eat food that is kosher. Where/how do we get that food? Do you know what 'kosher' means?
- A person requests private, quiet time five times per day to pray. The person's service plan indicates he cannot be unsupervised. What do we do?
- Is it okay for a person to wash his hair only once per week?
- You are talking to a person about a 'behavior' that is problematic to others in the house. The person is looking at the ground and her lap, not at you, while you are talking. What are your thoughts?

Source: Clearbrook

The Choice Making Process and Personal Freedoms

Giving people the opportunity to make choices in their lives is one way the DSP can help people achieve **self-determination or personal freedom**. The issue of choice and control over one's life are vital aspects of the quality of life for all people.

Many individuals with developmental disabilities have lived in environments where options for making choices are limited and where they had little exposure to an assortment of experiences that can make a basis for decision making. **Real choices** are significant when the person has **experienced** the options from which to choose.

Like other people, individuals with developmental disabilities deserve the opportunity to make choices in a graduated fashion. No one should be put in situations which allow the person to make major risky decisions, without the benefit of previous experience and learning. They should be exposed to and assisted in making small choices with small amounts of risk. Then the person can gradually make bigger and bigger choices that involve more risk when provided with the appropriate training and assistance. Remember, when risk increases, so does the need for support.

Here are some tips that can help you assist with choice making:



- Get to know the person.
- Identify opportunities for choice or preference.
- Assist the person in developing a range of choices.
- Recognize the health, safety, financial and risk parameters associated with the choice.
- Offer opportunities for choice.
- Show you value the person's choice.
- Educate and negotiate when choices are outside of the parameters.
- Process the choice experience with the person.
- Document the choice experience.
- Offer alternative means to express choice, if needed.

Individuals cannot achieve the outcomes they want unless they are given opportunities to make choices. Making a choice can be broken down into a three-tiered process:

1. The individual must first be exposed to a variety of situations & events.
2. The individual is then allowed the opportunity to indicate preference.
3. S/he then makes a choice.

Guardianship

Family members are not automatically named the legal guardian for their relative with a disability. When children with disabilities reach age 18, they may have a guardian appointed. In all cases, the court will make a determination as to the need for guardianship and who should serve as guardian. A family member may petition the court to be named guardian or the person may express a preference as to his/her guardian. If the person expresses a preference, the judge will give consideration to the person with a disability. However, the judge appoints whoever will make the best guardian and act in the best interest of the person with a disability, regardless of how they are related to each other.

Copies of guardianship papers must be in the person's file.

Guardianship is needed when a person is unable to make and communicate responsible decisions regarding his or her personal care or finances due to a mental, physical or developmental disability. A mental, physical or developmental disability and nothing more is not sufficient cause for the appointment of a guardian. The fact that a person is elderly, mentally ill, developmentally disabled, or physically disabled does not necessarily indicate the need for guardianship. The extent to which a guardian is allowed to make decisions for a ward is determined by the court based on a thorough clinical evaluation and report.

Duties of a guardian include:

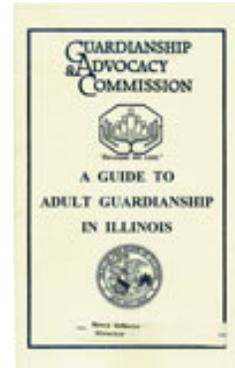
- Advocate for the person's wants.
- Visiting the individual
- Ensuring appropriate residential placement
- Being a part of the Interdisciplinary Team Process
- Approving the ISP/IPP/IHP
- Giving informed consent for medical treatment
- Monitoring supports the person receives
- Visiting the person and reviewing their records on a regular basis
- Protecting the person's rights
- Approval of psychotropic medications
- Making informed decisions for the person.

Types of Guardianships

There are several types of guardianships available under the Illinois Probate Act.

Guardianships can take following forms:

1. **Limited Guardianship** - used when the person with disabilities can make some, but not all, decisions regarding his/her person and/or estate. "Guardianship shall be ordered only to the extent necessitated by the individual's mental, physical and adaptive limitations." A limited guardian makes only those decisions about personal care and/or finances which the ward cannot make. **The powers of a limited guardian must be specifically listed in the court order.** The ward retains the power to make all other decisions regarding his/her person or estate. Limited guardianship may be used to appoint a limited guardian of the person, a limited guardian of the estate, or both.
2. **Plenary Guardianship** - used when the "individual's mental, physical and adaptive limitations" necessitate a guardian who has the power to make all important decisions regarding the individual's personal care and finances. Plenary guardianship may be used for the person, the estate, or both.
3. **Guardianship of the Person** - used when a person, "because of his disability, lacks sufficient understanding or capacity to make or communicate responsible decisions regarding the care of his person." The guardian of the person makes decisions regarding the "support, care, comfort, health, education . . . maintenance, and . . . professional services" (such as educational, vocational, habilitation, treatment and medical services) for the person under guardianship who is called a ward.
4. **Guardianship of the Estate** - used when the person "because of his disability...is unable to manage his estate or financial affairs." A guardian of the estate makes decisions about management of the ward's property and finances.
5. **Temporary Guardianship** - used in an emergency situation. Temporary guardianship can last no longer than 60 days and is a means to assure that the person who evidences need for guardianship receives immediate protection.
6. **Successor Guardianship** - used upon the death, disability, or resignation of the initially appointed guardian, when guardianship is still needed.
7. **Testamentary Guardianship** - used by parents of a person with disabilities and designates, by will, a person who assumes the guardianship appointment upon the death of a parent. The designated person must still be appointed by the court before he/she can serve as guardian. The court will consider the designated



person but is not bound by the testamentary designation. It can appoint someone else if the proposed guardian is found to be inappropriate.

Source: <http://gac.state.il.us/guardfaq>

Behavior Management Committees (BMC) and Human Rights Committees (HRC)

What Is a Behavior Management Committee (BMC)?

The BMC serves important functions within your agency. The people who serve on this committee may include self-advocates, professional staff, and board members, and other people who know the person the best. The committee has responsibility for reviewing behavior plans for technical effectiveness. These plans must then be reviewed by the HRC to ensure that the behavior management plan does not unduly restrict an individual's rights. A summary of BMC duties are:



- Review behavior plans for technical effectiveness.
- Provide impartial, professional reviews of completed plan.
- Reinforcement of schedules, functional analysis, treatment integrity, etc.
- After a behavior plan is reviewed and approved by the BMC and informed consent obtained from guardian, it then goes to the Human Rights Committee for review.

What is a Human Rights Committee (HRC)?

The HRC may include a group of individuals with a diversity of backgrounds and a broad range of experiences-- both from within and outside of the agency/facility. They should not be all of the same people who are on the BMC. These people are charged with the responsibility of protecting the rights of the individuals whom the agency/facility supports. Behavior plans must be endorsed by the HRC before implementation.

One of the issues the HRC faces is the prevention of abuse and neglect.

Staff and persons supported are encouraged to inform the HRC chair of questionable situations that could lead to abuse and/or neglect. The HRC may then decide to contact to the QIDP or executive director in an effort to discourage and prevent the occurrence of abuse and neglect.

BMC and HRC Role Related to Behavior Treatment Plans

1. After a plan is reviewed by the BMC and approved, the plan then goes to the HRC for rights review. Plans which do not receive approval from the BMC should not go to the HRC.
2. The HRC can endorse the plan as written, send it back to BMC for revisions, or endorse the plan with conditions.
3. Plans must be approved by the BMC and endorsed by the HRC before implementation.

There is a definite process that must take place before someone's rights are restricted. Your agency has policies and procedures which address the process for implementing a restrictive program; however, there is generally a similar chain of approval that is followed. First, a meeting is held by the person's Interdisciplinary Team (IDT). If the team determines that no other less restrictive measure can be found, the restrictive program is recommended. The team then requests approval of the program/restriction from the Behavior Management Committee. This committee examines the technical aspects of the restrictive program. If approved by the Behavior Management Committee, approval is finally sought from the Human Rights Committee. The Human Rights Committee may approve the program; however it is only approved for a limited amount of time because any restriction of rights should always be considered as a temporary measure. The team must continually attempt to use other programmatic/behavioral measures which would take the place of the restriction that was posed.

Documentation which supports the continued need for restriction must be presented to the Human Rights Committee at regular intervals to prove that they continue to be necessary. Documentation is a very important part of this process and that is a very important part of your role as a DSP. The restrictions must also be a part of the person's record and be found in the Individual Service Plan (ISP). We will learn more about this plan in a future module.

Activity - Losing an Important Thing in Your Life

Your instructor will guide you through the next activity. When completing the activity think about:

- Human Rights Issues
- Human Rights Violations
- Human Rights Questions
- Human Rights Situations

A Few Words about Risk

The world in which we live is not always safe, secure and predictable . . . Every day that we wake up and live in the hours of that day, there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the way the real world is. We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further cripple them for healthy living.

- Robert Perske

In working with young people and/or people with a disability there is a need, through planning, to minimize possible harm. It is not possible to eliminate risk, only to formulate strategies to minimize it. Allowing someone to undertake or engage in a risky activity does not make you negligent. Failing to take any steps to minimize foreseeable harm could be. This is called '**dignity of risk**'.



The ideal for individuals with a disability is to live a life which is as typical as possible to their nondisabled peers. All people take risks.

When a staff member is uncertain, they should discuss the situation with other staff, a supervisor or seek guidance from management.

From "Duty of Care, Critical Thinking and Ethics"

Facilitated by Dr Caroline Ellison

New Mexico Developmental Disabilities Supports Division- Meaningful Day

Please visit the below web site to read "And Yet More Information - *A FEW WORDS ABOUT DIGNITY OF RISK*."

<http://www.health.state.nm.us/DDSD/meaningfullife/documents/AYMAFEWWORDSABOUTDIGNITYOFRISK.pdf>

The “**Dignity of Risk**” recognizes that:

- The world is not always safe and secure.
- Learning new things is an important part to being human and having a full life.
- The main way people learn is to try new things.
- When people try new things, they take risks, including the risk of emotional and physical pain.
- Keeping people from experiencing risks keeps them from learning and therefore from full lives.

Respecting people requires providing them with opportunities to have choices, take chances, and make mistakes. Of course we need to start out with **small** risks. After learning has taken place, we can increase the amount of risk in a graduated fashion.



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

Mahatma Gandhi

Activity: Read and Discuss The Dignity of Risk:

The Dignity of Risk

What if...

- ...you never got to make a mistake
- ...your money was always kept in a envelope where you couldn't get to it?
- ...you were always treated like a child?
- ...your only chance to be with people different from you was with your own family?
- ...the job you did was not useful?
- ...you never got to make a decision?
- ...the only risky thing you could do was act out?
- ...you couldn't go outside because the last time you went out, it rained?
- ...you took the wrong bus once and now you can't take another one?
- ...you got into trouble and were sent away and couldn't come back because they always remembered that you were "trouble"?
- ...you worked and got paid \$0.46/hour?
- ...you had to wear your winter coat when it rained because it was all you had?
- ...you had no privacy?
- ...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?
- ...you spent three hours each day just waiting?
- ...you grew old and never knew adulthood?
- ...you never got a chance?

Human Rights Scenarios for Discussion

Directions: Read the scenarios below. Then identify and discuss which rights may have been violated. **Review agency/facility rights, identify and document which specific agency right(s) were violated.**

Human Rights Scenario 1:

Three staff members from the accounting department at an agency that serves people with developmental disabilities are sitting in the staff lunchroom. A DSP enters the lunchroom and while she is heating up her lunch begins to talk about Joe a person in her work group. She tells the people from accounting that Joe has been “acting up” all day long, cussing her out and throwing work and that she can’t wait for the day to end.

Human Rights Scenario 2:

The QIDP was visiting a residential site when he observed the afternoon shift staff watching the Super Bowl and ignoring an individual who was trying to get their attention. When the Q asked the person what was going on, he said he wanted someone to take him to church but nobody would even talk to him about it.

Human Rights Scenario 3:

When the Q asked staff why they were not helping this individual, they responded that he attended a Catholic Church across town. No one wanted to take him because they would miss part of the football game. They wondered why he didn't go earlier in the day with everyone else to the Lutheran Church down the block. One staff stated that he couldn't tell the difference anyway.

- **Which rights were violated?**
- **How can we correct this situation?**

Human Rights Scenario 4:

Susan has lived in your agency for several years. Her current service plan does not allow her to leave the facility unescorted. She has requested that she be allowed to leave the facility without staff to go to a local store for a soda each day.

The team is concerned for her safety because she has never been out on her own and the store is several blocks away. Also, she would have to cross two busy streets.

Safety Issues in this Scenario:

This scenario demonstrates the challenge between balancing high quality supports, keeping people safe, teaching people to access their community and ensuring individual rights protection. How do we find the balance between allowing Susan to exercise her rights but at the same time ensuring her safety? Things to consider:

- What safety issues are there?
- Do we know if she is able to cross street safely?
- Do we know if she can count change for purchases?
- What are her socialization skills with strangers?
- What additional supports may she need?
- How do we prepare her to exercise her choice while minimizing the risks?

Human Rights Scenario 5:

A QIDP and a DSP are standing in the hallway talking about a person with a disability on the QIDP's caseload. The QIDP is informing the DSP that the person is on a new medication and may be experiencing some side effects.

- **Which rights were violated?**
- **How can we correct this situation?**

Human Rights Scenario 6:

The QIDP was supervising the agency's fun day carnival when she observed a staff member sliding on the giant inflatable slide and ignoring an individual trying to get her attention. When the QIDP asked the person what was going on, he said he wanted to go to the library and read but nobody would even talk to him about it.

When the QIDP asked staff why they were not helping this person, they responded that the library was on the other side of the field inside the building and they didn't want to miss part of the carnival. They wondered why he didn't go to the library earlier in the day with the rest of his group. One staff stated he didn't know what he wanted to do and he couldn't read anyway.