

The Evolution of Human Rights for Persons with DD

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 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 Support Professionals (QSPs)
- A "Right to Treatment
- Staff to client ratios
- Physical plant features/dimensions
- Development of behavior plans
- 1971 - The United Nations 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.

- 1973 - Rehabilitation Act

This is shown as the first federal civil rights law protecting the rights of individuals with disabilities. It prohibits discrimination based on disability in the areas of:

Education, Vocational Education, college Programs, employment, health, social services programs, welfare, federally funded programs.

- 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 decertification's.
- 1990 - Americans with Disabilities Act (ADA) Congress passed this law. It is a landmark civil rights bill that extends protection against discrimination to individuals with disabilities. It addresses four main areas of potential discrimination.

Employment, Public Facilities, Transportation and Communication.

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 change the DSP's role:

Over the last 40 plus years, the role of the 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.

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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 developmental disability aide training).

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.

Discussion Activity: Client Rights and Staff/Agency Responsibilities.

- Does a client 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 client, 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 client. Where does that belief come from and what proof do you have to support it?
- A client in a group home can only eat food that is kosher. Where/how do we get that food? Do you know what 'kosher' means?
- How do we balance trying to empower a client and teach him/her self-advocacy with a client's cultural preference to defer to his/her father and let him do the speaking and decision-making?
- A client requests private, quiet time five times per day to pray. The client's service plan indicates he cannot be unsupervised. What do we do?
- Is it okay for a client to wash his hair only once per week?
- You are talking to a client about a 'behavior' that is problematic to others in the house. The client is looking at the ground and her lap, not at you, while you are talking. What are your thoughts?

It is essential that when you are representing and promoting the rights and interests of a individual, that the client's cultural background is recognized and considered. It is important that the rights and desires of the client are being represented and not those of the advocates. DSPs should be aware that within an individual's cultural context, how an advocate is perceived will vary in each ethnic and cultural group.

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.

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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 QSP 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 include:

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 ensure her safety? Things to consider:

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

Alternate Human Rights Scenario 5:

A QSP and a DSP are standing in the hallway talking about a person with a disability on the QSP's caseload. The QSP 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 QSP 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 QSP 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 QSP 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.

Guardianships

When children with disabilities reach age 18, they may have a guardian appointed. Family members are not automatically named the legal guardian for their relative with a disability. 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 the party's relation to the person.

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.
- 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 his/her records on a regular basis
- Protecting the person's rights
- Approval of psychotropic medications
- Making informed decisions for the person.

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Types of Guardianships:

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

The basic forms guardianship can take follow:

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)

Note: in some agencies, the Behavior Management Committee (BMC) is called something else. The name of this agency's BMC is: _____

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 QSP or executive director in an effort to discourage and prevent the occurrence of abuse and neglect.

Who Presents Issues to the HRC?

Typically the presenters of issues to the HRC are:

- \$ Self-Advocates
- \$ Relatives/Guardians
- \$ QSPs
- \$ Front line supervisors
- \$ Psychologists, behavior analysts

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.

Sexuality and People with Disabilities

Having a developmental disability does not alter the right of a person to express his or her sexuality. People with developmental disabilities have sexuality rights and deserve acceptance of their sexuality. There are many varying perspectives on this issue. The issues can be different in the family home than in a group home, in a work setting, or in public. Regardless of the setting and situation, DSPs should not be judgmental and try to impose their own personal values on the people. It is also important that DSPs respect the privacy of people they support to discuss and express their sexuality. DSPs can show respect and dignity for the people they support who need help with personal care activities by asking permission before assisting/touching and waiting for a response. DSPs can also listen carefully to issues that people may express, and get them to the correct person who can help them. DSPs should not try to handle sexual situations by themselves. They need to communicate with the individual's parents or guardian, their supervisor, and their agency's QSP for support and guidance on sexuality issues. Agencies may have specific policies and procedures addressing sexuality, and if they do, you should become familiar with these policies.

A good source for information on this topic is:

Indiana Institute on Disability Center for Disability Information & Referral Institute for the Study of Developmental Disabilities <http://www.iidc.indiana.edu/cedir/sexuality.html>

Activity: Read The Dignity of Risk and Discuss it in Class.

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?

Educational Rights

Direct care staff should know that students with disabilities are, as much as possible, involved in the regular education curriculum. This is required by the IDEA (The Individual with Disabilities Education Act). IDEA is a federal law enacted in 1990, reauthorized in 1997 and again in 2004. It is designed to protect the rights of students with disabilities by ensuring that everyone receives a free appropriate public education (FAPE), regardless of ability. Furthermore, IDEA strives not only to grant equal access to students with disabilities, but also to provide additional special education services and procedural safeguards.

Special education services are individualized to meet the unique needs of students with disabilities and are provided in the least restrictive environment. Special education may include individual or small group instruction, curriculum or teaching modifications, assistive technology, transition services and other specialized services such as physical, occupational, and speech therapy. These services are provided in accordance with an Individualized Education Program (IEP), which is specifically tailored to the unique needs of each student.

Go to <http://idea.ed.gov/explore/home> for more information on this act.

School Districts are required to develop an ***individualized education program***

YOU AND I

I am a resident. You reside.

I am admitted. You move in.

I am aggressive. You are assertive.

I have behavior problems. You are rude.

I am noncompliant. You don't like being told what to do.

When I ask you out to dinner, it is an outing. When you ask someone out, it is a date.

I don't know how many people have read the progress notes people write about me. I don't even know what is in there. You didn't speak to your best friend for a month after she read your journal.

I made mistakes during my check-writing program. Someday, I might get a bank account. You forgot to record some withdrawals from your account. The bank called to remind you.

I wanted to talk with the nice-looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers. You met your spouse in the produce department. He couldn't find the bean sprouts.

I celebrated my birthday yesterday with five other residents and two staff. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounds wonderful.

My QSP sends a report every month to my guardian. It says everything I did wrong and some things I did right. You are still mad at your sister for calling your Mom after you got that speeding ticket.

I am on a special diet because I am 5 pounds over my ideal body weight. Your doctor gave up telling you to lose weight.

I am learning household skills. You hate housework.

I am learning leisure skills. Your shirt says "couch potato."

After I do my budget program tonight, I might get to go to McDonald's if I have enough money. You were glad that the new French restaurant took your charge card.

My QSP, psychologist, RN, occupational and physical therapists, nutritionist and house staff set goals for me for the next year. You haven't decided what you want out of life.

Elaine Popovich, Lutheran Social Services