



HUMAN RIGHTS COMMITTEE CHAIRPERSON TRAINING

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Human Rights Committee (HRC) Chairperson Training

“Disability is a natural part of the human experience, and in no way diminishes the rights of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society.”

Federal Legislation and the Rehabilitation Act Amendments of 1992

Course Objectives

Participants will be able to:

- Identify the role of the HRC
- Recognize the importance of historic perspectives of the treatment of persons with intellectual disability
- Demonstrate knowledge of required committee membership
- Identify duties of the HRC Chair
- Demonstrate knowledge of rules as they apply to individual rights
- Identify components of Informed Consent
- Demonstrate understanding of philosophical considerations with regard to individual rights
- Recognize the various types of guardianship
- Apply principles of People First Language
- Understand the importance of Human Rights Policy and Procedure

Role of Human Rights Committee

The general responsibility of the Human Rights Committee (HRC) is to assist the provider in affirming, promoting and protecting the human and civil rights of individuals receiving services. The HRC monitors and reviews the activities of the agency to assure that those rights are upheld in accordance with the laws that govern them. The committee is empowered by the agency Executive Director and/or the Board of Directors.

Other responsibilities of the HRC include:

- Being held accountable to question every situation in which a person's rights are restricted for any reason
- Reviewing the means utilized by the provider/agency to inform individuals, staff, guardians, and families of individual rights
- Monitoring the way individuals supported are trained to exercise their rights
- Being proactive to ensure people have full access to their rights as citizens (as opposed to their rights as clients)
- Reviewing policies and procedures annually to assure compliance with Department regulations

The HRC...

- assures that legal counsel or advocacy is available whenever a person faces due process
- should never be a 'rubber stamp committee' that approves anything and everything that comes before it
- monitors and reviews the authorization and use of behavior modification interventions approved by the BMC
- reviews and monitors the authorization of emergency rights restrictions
- makes recommendations on ways to improve the degree to which human and civil rights are promoted
- Ensuring that rights restrictions are implemented only when necessary and are reviewed as temporary measures.

However,

The function of the Human Rights Committee is largely dependent on the role it serves within the agency. The policies of the agency will determine the exact role of the HRC.

Freedoms of Everyday Life

The HRC assures that Constitutional rights are upheld.

The **US Constitution** guarantees these 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
- Right to marry and raise children
- Privacy
- Right to vote
- Right to Self-Determination (making own choices)

The Committee also protects against violations to Illinois specific rights for people receiving supports in the Illinois support system for people with developmental disabilities. These rights include:

- Right to services in the 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 religious worship
- Right to physical exercise
- Right to manage personal funds
- Right to adequate nutrition
- Freedom from involuntary servitude
- Freedom from unnecessary medication and mechanical, chemical, or physical restraints
- Individuals or guardians shall be permitted to purchase and use services of private physicians and other mental health and developmental disabilities

professionals of their choice, which shall be documented in the person-centered plan.

Perspectives on the Historical Treatment of People with Disabilities

Historical perspectives regarding people with intellectual disabilities show that ignorance, neglect, superstition, and fear often ruled people's perceptions. People with disabilities were referred to as being "inferior" and "less than human" and the care that was provided reflected these beliefs. Common language used in the past reflected our perceptions: "fools" "idiots" and "imbeciles" were common terms used. Families of people with disabilities would hear over and over again from specialists in the field "Your child is defective, put him/her away and forget them." People with disabilities were looked upon as "broken" and needing to be "fixed". These false perceptions led to development of social policy which reflected these beliefs. This fostered use of ineffective "treatments", the effects of which still persist today.

From the late 1860s until the 1970s, several American cities had laws making it illegal for persons with "unsightly or disfiguring" disabilities to appear in public. These were called "ugly laws." One such law was the Chicago Municipal Code, Section #36034 which included an ordinance that stipulated: "No person who is diseased, maimed, mutilated or in any way deformed so as to be unsightly, disgusting or improper is to be allowed in or on the public ways or other public places in this city, or shall therein or thereon expose himself to public view, under penalty of not less than one dollar nor more than fifty dollars for each offense." Many states' and cities' Ugly Laws were not repealed until the 1970s, and Chicago was the last to repeal its Ugly Law in 1974.

Examination of these historical perspectives is important because sometimes we need to know where we have been to figure out where we are now, and what the future may hold.

In 1990, the Americans with Disabilities Act became law, and it provided comprehensive civil rights protection for people with disabilities. Closely modeled after the Civil Rights Act, the law was the most sweeping disability rights legislation in American history. It mandated that local, state, and federal governments and programs be accessible, that employers with more than 15 employees make "reasonable accommodations" for workers with disabilities and not discriminate against otherwise qualified workers with disabilities, and that public accommodations such as restaurants and stores not discriminate against people with disabilities and that they make "reasonable modifications" to ensure access for disabled members of the public. The act also mandated access in public transportation, communication, and in other areas of public life.

For more information on historical treatment of people with disabilities please go to:
<http://museumofdisability.org/virtual-museum/>

Perspectives on the Historical Treatment of People with Disabilities

Years	Societal Perspective	Treatment
Up to 1700s	Possessed by the devil, a sinner	Tortured, burned at stake, left to die
1800-1920s	Genetically defective; polluting the race	Hidden away
1930-1940s	Genetically defective; polluting the race	Institutionalized, sterilized, exterminated
1940-1970	Unfortunate, object of charity, pity	Institutionalized, rehabilitated
1970-2000s	Independent, self-determined	Independent; civil
1200-1700:	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.	
1800:	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 professionals, professional educators and social workers. Almshouses, workhouses and institutions proliferate in the U.S.	
1850:	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).	
1907:	Indiana became the first of 29 states to pass compulsory sterilization laws directed at people with genetic illnesses or conditions.	
1920:	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."	

Perspectives on the Historical Treatment of People with Disabilities

Years	Societal Perspective	Treatment
1924:	The Commonwealth of Virginia passed a state law that allowed for sterilization (without consent) of individuals found to be "feeble-minded, insane, depressed, mentally handicapped, epileptic and other." Alcoholics, criminals and drug addicts were also sterilized.	
1930:	President Franklin Delano Roosevelt's physical disability hidden from the American public for fear that it would detract from his power and status.	
1935:	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 organized sit-ins, picket lines and demonstrations and traveled to Washington D.C. to protest and meet with officials of the Roosevelt administration.	
1939:	In Germany: End of Nazi sterilization program. Beginning of Euthanasia Program. 200,000 killed in total.	
1945:	President Harry Truman signed a proclamation creating National Employ the Handicapped Week.	
1950:	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.	
1961:	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 improvement.	
1970:	Independent Living movement begins, grass roots effort by disabled people to acquire new rights and control over their lives.	
1972:	The U.S. District Court of Alabama decided in <i>Wyatt vs. Stickney</i> 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."	

1975:	All Handicapped Children Act codifies 1972 special education proposals that require students with a disability to have an individual plan.
1986:	Education of the Handicapped Act Amendments (PL 99-457) Earmarks funding for states to collaborate with families to develop plans and programs from birth forward.
1992:	Americans with Disabilities Act of 1992 is an extension of the 1994 Civil Rights Act that extends civil rights to those individuals with disabilities.
2002:	No Child Left Behind (NCLB), producing measurable gains and outcomes to increase achievement. This was the educational centerpiece of the George W. Bush presidency
2009:	Common Core State Standards are to be designed so that they will challenge and help students with disabilities in the same manner they are intended in the general education setting.

Wyatt v. Stickney

One of the most significant legal cases affecting rights of people with developmental disabilities is Wyatt v. Stickney. *Wyatt v. Stickney*, filed in the federal United States District Court for the Middle District of Alabama on October 23, 1970, it was a landmark ruling that established baseline care and treatment requirements for those who are involuntarily committed to state institutions because of mental illness or developmental disabilities. The suit was filed on behalf of the patients at Bryce Hospital in Tuscaloosa, with 16-year-old Ricky Wyatt as the main plaintiff. Wyatt had been incarcerated for "delinquency" but had never received any other diagnosis of mental disability or condition. The defendants in the case were the Alabama Department of Mental Health (DMH) and its commissioner, Stonewall Stickney. The suit initially was prompted by layoffs at Bryce Hospital, with attorneys alleging that insufficient staff at the hospital would prevent involuntarily committed mentally ill patients from receiving adequate treatment, a violation of their civil rights under the Fourteenth Amendment of the U.S. Constitution.

Because of this ruling, minimum standards were created for care of people with intellectual disabilities who reside in institutional care.

These minimum standards or 49 principles of care included:

- “Right to treatment”
- Establishment of the previously known as the Qualified Mental Retardation Professional (QMRP) Qualified Intellectual Disabilities Professional (QIDP)
- Staff to client ratios
- Physical plant features/dimensions
- Development of Behavior Plans
- Establishment of Human Rights Committees

For more information *about Wyatt v. Stickney*, please go to:
<http://www.adap.net/Wyatt/landmark.pdf>

Rules

Over the years, rules have been established to protect the rights of people receiving services within the Illinois support system for people with disabilities. Some of these rules include:

- Notice of Rights to Appeal (IL462-1202) is provided at the initiation of services, upon request, annually, and with changes or discontinuation of services as applicable.
- Each agency is required to establish or ensure a process for the periodic review of behavior intervention and human rights issues involved in the individual's treatment and/or habilitation. Agencies required to have behavior intervention and human rights review policies and procedures under licensure or certification standards shall continue to comply with those standards.
- Providers are expected to teach appropriate alternative skills/behaviors to replace undesired behaviors and use behavior intervention procedures that do not involve unnecessarily restricting the rights of participants.
- The committee shall review program policies, procedures and practices which restrict an individual's rights, whether general or specific to behavior management in all programs written within the agency (CILA, Service Facilitation, DT, ICF, etc.)
- The HRC must review all rights complaints, all restrictive interventions including those used in emergency situations, all use of psychotropic medication, any medications used to manage behaviors, any restrictive interventions used to

manage behaviors, or to treat a diagnosed mental illness. The review must occur at least annually for all individuals regardless of service/supports being provided.

- The HRC shall approve special training procedures prior to implementation and review those procedures at least every three months, except aversive conditioning procedures which shall be reviewed and approved at least every 30 days.
- The HRC shall maintain minutes, including attendance and decisions made.
- The HRC Committees must meet at least quarterly if not and more often if needed. Can meet monthly depending on the cases.

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Rules Quiz

The table below lists some rights that are guaranteed to individuals with developmental disabilities. Some are constitutional, others would be considered *best practice*, and some would be mandated by rules. Review the list and indicate in which category each right would fall. If a 'rule', please list Mental Health Code, or Rule 115.

RIGHTS	CONSTITUTIONAL	BEST PRACTICE	RULE
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.			
To contract, own, and dispose of property.			
To religious worship.			
To marry 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.			

<p>To choose purchase and use services of private physicians and other mental health and intellectual disabilities professions of their choice which will be documented in the person-centered plan.</p>			
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HRC Membership

HRC Membership should include . . .

- at least 5 members
- at least 1 person receiving services from the agency and/or his or her family member or guardian
- at least 1/3 of the members otherwise unassociated with the agency
- no more than 1/2 of members employed by the agency

To be considered “unassociated” with the agency, a member must not be a former employee, person receiving services, guardian of person formerly served by the agency or relative of present/former employee or person receiving services. Vendors providing products or services are considered associated members. Staff from other providers or programs are considered associated members.

HRC is most effective when comprised of members who will advocate for persons served and who will weigh the relative merits of restrictions versus the risk or potential harm and assess validity of procedures.

Some Common HRC Models

Stand Alone

These committees are based on the agency’s own resources. They work well in supporting the ‘culture’ of the agency; however, it may be difficult to recruit an adequate number of outside members.

Consortium

Due to size and more rural location, a smaller agency may find the consortium most beneficial. Since the HRC would be shared by two or more agencies, the problem of recruitment of outside members is lessened. The preservation of confidentiality needs special consideration here.

Combined HRC/Behavior Management Committee (BMC)

This model is generally discouraged because each committee should serve different functions. The BMC is there to examine the technical aspects of behavior programs. With the combined method, each of the important tasks of these committees may become slighted.

What is a Rights Restriction?

“Restriction” means anything that limits or prevents an individual from freely exercising his/her rights. Something is usually considered restrictive if it impedes the enjoyment of general liberties that are available to all citizens.

Rights restrictions include (but are not limited to) such things as:

Limitations on *access*

- To personal possessions (mail, clothing, phone, etc.)
- To food or drink
- To activities
- To family, friends, children

Limitations to **movement**

- Mitts
- Therapeutic holds
- Helmets, splints (all are restrictions and must be reviewed at least once per year, if behavior reviewed more often)
- Mechanical restraints
- Door/window alarms and other environmental restrictions
- One-to-One supervision

Other typical issues reviewed by the HRC

- Psychotropic medications – By rule, always considered to be “restrictive”, even if prescribed for a medically diagnosed condition.
- Guardianship issues
- Incident report review
- Money management issues

- Choice of services

The uses of psychotropic medications, physical restraint or denial of food or possessions are all easily recognized restrictions. But due to a variety of reasons, persons served may be subjected to a variety of less obvious restrictions. The HRC needs to be diligent in assessing services and supports to determine if restrictions or limitations are imposed.

Determine if restrictions are imposed. A person's rights might be restricted if...

- Staff enters a person's room without permission.
- Staff goes through the person's purse, pockets, drawers, etc.
- The person does not or is not allowed to make own decisions.
- The person is not allowed or assisted to answer their phone or doorbell.
- Junk mail is removed from the person's mail before they see it.
- The person must ask permission to go anywhere in their own home (locked doors, refrigerator, cupboards)
- Medical services provided by one physician, not having a choice.

With any program that causes a restriction of rights, it is expected that:

- Nonrestrictive interventions were ineffective according to data collected.
- The restriction is **temporary**;
- The restriction is defined with **specific criteria** (under exactly what circumstances will it be used);
- The program is **paired with learning/training components** to assist the person in the eventual removal of the restriction;
- The restriction is **removed** upon reaching clearly defined objectives;
- **Reviewed** regularly by HRC

Least Restrictive Alternatives

There are several interventions that a team can choose from when an individual's behavior is such that the team must 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. The committee must first ask "What right is being infringed upon?" More than one right can be restricted at the same time. For example, imposing a 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
- Limited or no free community access

Before a restriction is proposed, there must be documentation that other less restrictive methods have been regularly applied by trained staff and failed.

Rights Should Not Be Restricted Just Because...

It's always been done that way... Teams are to determine the least restrictive level and type of support needed on an individual basis. There should be a rationale for the restriction, and it should be clear that the restriction imposed meets the needs of the individual without being more intrusive than need be.

House rules/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. Individuals should be involved in the development of rules and routines in order to live with other and exercise control over their lives.

The 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. The HRC needs to question and evaluate team decisions.

The Guardian wants it: Despite the best intentions, rights should not be restricted because of guardian request.

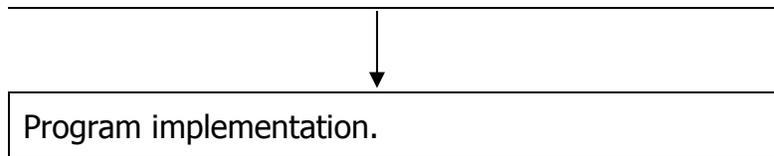
Important notes regarding restrictions

- Restrictions, when necessary, are not bad.
- Restrictions must be individualized.

- Don't think you can "identify what a restriction is" by compiling a list. Use the 'neighbor' test; if you cannot do it to your neighbor, who doesn't have a disability it is probably restrictive.
- What is restrictive for one individual may not be restrictive for another.
- The person's opinion about the restriction is important.
- There is never just one solution to a rights issue.

Typical Behavior Management Committee (BMC)/Human Rights Committee (HRC) Flow Chart





*Opportunities for informal consultation by the HRC.

Behavior Management vs. Human Rights Committees

Behavior Management Committee - The BMC is a representative body of individuals who have clinical expertise to review behavior plans and make a judgment as to whether or not the plans are clinically/technically appropriate

Human Rights Committee - The HRC, in reviewing behavioral programs, has as its focus the assurance of the rights of the individuals(s) served in agency programs. In addition to the protection of the rights of the people served, it is also the function of the HRC to assure the maximization of rights and ensure that rights limitations are temporary in nature and that they occur in very specifically defined situations.

Helpful Information

In order for the committee to fully examine requests for any restriction of an individual's rights, it is helpful to have enough information presented.

What type of information is helpful to have when discussing a submission?

- Functional Assessment of the target behavior for which restrictive program was designed
- Documentation that indicates the risks of the target behavior versus the risk of the proposed intervention
- Past efforts to replace the target behavior
- Documentation that the behavioral support plan is reviewed regularly by the person's support team
- Clear definition of the targeted behavior or behaviors
- Informed consent from the individual or the individual's legal representative
- Behavior Management Committee approval (if agency has a BMC)

HRC Endorsement Options

The committee will need to approve any restriction before it can be implemented. Some endorsement options include:

- Endorse for up to 12 months
- Endorse contingent on specific modifications by Interdisciplinary/Community Support Team
- Return for re-review by Behavior Management, or CST based on specific issues
- Rejection or failure to endorse

Resolving Issues that Emerge Between Meetings

Meeting frequency will depend on how the flow of services works at the agency. Cases that are discussed at HRC will first need to be discussed at the BMC meeting and the timeline that is established between BMC and HRC meetings must be one that will work for the agency. The goal is to ensure that reviews take place in a timely manner.

However, sometimes issues need to be approved between scheduled meeting times. The procedure for approving restrictions between meetings will depend on your agency policy and procedure for approval. After the emergency approval, the case is then discussed and noted in the minutes of the next scheduled HRC meeting.

What is your agency policy regarding resolution of issues that come up between scheduled meetings?

Agendas, Sign-In Sheets and Meeting Minutes

Agendas are very helpful in guiding meetings and keeping them on track. The agenda may list who is presenting and at what time, topics that will be discussed and any highlights that will aid in keeping the meeting running efficiently.

It is helpful to take attendance at each HRC meeting for record-keeping purposes. Each member's name, signature, title and relationship to the organization should be kept on file for regulatory bodies that may require this information.

The HRC must maintain minutes of each meeting held. Local, state, and federal regulatory bodies often request the minutes when conducting an agency review. Many times, the Chairperson arranges for someone to take notes at the meeting, since at times discussion can become intense. This will allow the Chairperson to pay full attention and can assist with the accuracy of the record. Be sure that medications

mentioned are spelled correctly and that dosages are indicated. The minutes must include who was in attendance and what decisions were made. Be sure to include information regarding any emergency reviews that have occurred since the last meeting, member education that has occurred since the last meeting, etc. The meeting minutes should then be circulated to the appropriate leadership within the organization.

Chairperson Duties

The role of the chairperson is to coordinate all of the activities of the committee, synthesize information, achieve consensus and make recommendations to the executive director. Aside from these duties, the chairperson may be responsible for a variety of other duties. These duties may include such things as membership education, recruiting new members, assuring that confidentiality is upheld, assuring due process and promoting individual rights.

Some additional HRC Chairperson Duties may include:

- Develop an agenda and sign-in sheet for HRC Committee.
- Introduce members of the committee and presenters at the HRC meeting
- Establish rapport with members on the committee
- Ensure the minutes are taken accurately and recorded
- Ensure minutes are retained appropriately
- Lead and facilitate the HRC meeting
- Ask probing questions to ascertain information
- Assist QIDPs presenting information, as needed
- Arbitrate issues at the meeting
- Ensure follow-up on any HRC issues
- Communicate with BMC as needed
- Communicate with program managers, as needed
- Reinforce the purpose of the HRC meeting
- Reinforce confidentiality with committee members
- Provide educational resources/technical assistance when needed
- Obtain group decisions and recommendations
- Handle issues in the interim
- The ability to commit to the term length of HRC Chair (2 years is typical)

Membership Education

Because rules require that a certain percentage of members of the committee must be unassociated, we must realize that some of our members may not be familiar with many subjects associated with developmental disabilities. Therefore, as chairperson, it is your responsibility to provide information to the committee. This can be done in various ways, such as having a guest speaker, providing written information that can be disseminated and discussed at the next meeting, videos, field trips, etc.

Some topics for member education may include:

- Introduction to Developmental Disabilities
- Historic perspectives of people with disabilities
- Rights
- Agency policy
- Abuse/neglect
- U.S. Constitution
- Guardianship
- Behavior Modification
- Informed Consent
- Advocacy
- Positive Behavior Supports
- Acronyms
- DHS Rules
- Waiver information

Committee members should be provided with adequate training and discussion time for members on relevant issues on personal freedom and privacy such as:

- private phone calls
- private email accounts
- smoking
- engaging in sexual behaviors

Recruiting Strategies

Recruiting new members can be a never-ending job. Many times, it is best to recruit more members than you will need because sometimes new recruits don't stand the test of time. The requirement to assure that 1/3 of members are unassociated with the agency may turn out to be more difficult than initially anticipated.

Some ways to recruit may include:

- Public Presentations (i.e., Rotary Club, etc.)
- Ads
- Personal Referrals/Word of mouth
- Exchange with another agency
- Agency web site (Facebook)
- Be present in the community

Promoting Rights

The HRC is responsible for monitoring and reviewing the means used by the agency to promote the rights of individuals served. How does your agency:

- Inform individuals, staff, guardians and families of the individual's rights?
- Train individuals served in how to exercise their rights?
- Provide individuals with the opportunities to exercise their rights to the fullest extent of their capabilities?

Informed Consent and Confidentiality

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 during the meeting, some organizations use initials, identification numbers, etc. to keep complete anonymity even from the committee members. It is agreed that if discussion includes someone who is not receiving services at the agency, the person's identity must be kept confidential.

With the enactment of the Health Insurance Portability and Accountability Act (HIPAA), HRCs must be diligent in assuring that their practices remain in accordance with federal

and state HIPAA regulations. Again, the intent of this statute is to assure that an individual's personal information is not shared without permission. 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

When records are shared, or information requested, **informed consent** must be obtained. According to the Mental Health & Developmental Disabilities Confidentiality Act, the consent should be in writing and contain the following elements...

- The person or agency to which disclosure is to be made
- The purpose for which disclosure is to be made
- The nature of the information to be disclosed
- The right to inspect and copy the information to be disclosed
- The consequences of a refusal to consent, if any
- The calendar date on which the consent expires
- The right to revoke the consent at any time

All consents should be written in plain, easy to understand language.

Due Process

The agency should have a formal policy by which persons served may formally complain. Due process, which is outlined in the Fourteenth Amendment, states no person shall be deprived of liberty without the process of law. The concept of due process is intended to protect people from undue restriction of rights.

Agencies must assure that a procedure concerning formal complaints exists and it conveys the procedures in **writing**. Further, assurances should be in place that guarantee that the action will not result in retaliation or any barrier to services. The written policy information should contain the answers to the following questions

Complaint procedures (and forms, if applicable) should be readily available to persons served and be written in a way that is understandable. An organization may have a separate policy and procedure for grievances and appeals or may include these in a common policy and procedure covering complaints, grievances, and appeals. Written guidelines for practices include procedures for levels of review and the rights and responsibilities for each party involved. These procedures are explained to personnel and persons served in a way that meets their needs.

Guardianship

Types of Guardianship under Illinois Law

There are several types of guardianship available under Illinois Law. **If guardianship is needed**, consideration should be given to obtaining the least restrictive form, based on the individual's capabilities.

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. **MUST** be stated -NO Authority is given to guardian, unless, specifically stated in guardian order.
- 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.

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

"The Guidebook of Laws and Programs for People with Disabilities"
<http://www.illinoislegalaid.org/index.cfm?fuseaction=home.dspcontent&contentID=784>

Human Rights Policies and Procedures

The HRC is responsible for keeping agency policies and procedures regarding individual rights current. It is recommended that these be reviewed at least annually. Be sure that the agency is up-to-date with applicable rules and best practice. Agency policy can cover such areas as:

- HRC Mission Statement
- Purpose of the committee
- Functions (what does the committee review?)
- Definitions
- Meetings (Frequency, procedure, quorum)
- Membership composition
- Membership education
- Approval consensus
- Participation documentation
- Emergency approval procedure
- Special duties of the committee (for example, the Executive Director may request the committee investigate incidents related to individual care)

All members should be trained about policies and procedures. Sometimes organizations have clear policies; however, many times the policies are not enacted because employees or supervisors do not understand them.

Below are some questions on Policies and Procedures. Answer the questions based on your agency's Policies and Procedures.

1. Do our Policies and Procedures reflect the mission and vision of our organization/agency? How do you verify/incorporate?
2. Are policies and procedures written in a clear, understandable manner--preferably at an 8th grade reading level? Are they "user friendly"? How could you find out?
3. Are they person-centered? How could you find out? What are some "key" words?
4. Do policies and procedures reflect "best practice" in the field of developmental disabilities? How could you find out?
5. Does your Human Rights Committee review your policies and procedures for rights restrictions?
6. Are policies and procedures written to clearly protect the safety and well-being of persons supported?
7. How often are the policies and procedures updated and by whom? Do those who use them the most have input into their creation/revision?
8. Do policies and procedures have built-in prompts for staff to adhere to certain time frames? For example: (twice yearly in January & July, etc.)
9. In what ways do our policies and procedures address the requirements of monitors, surveyors, rules, mandates, etc.?
10. Is a Restriction of Rights issued to all involved?
11. Is informed consent issued prior to use?
12. How are staff/committee members trained in policies and procedures? Do we use competency- based training materials?
13. Are agency grievance and appeal process easy to understand?

14. 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?

No policies and procedures should ever be regarded as “complete” in the sense that they will never change. The best policy/procedure manual is the one that is geared to continuous growth over time and incorporates design features that make this kind of growth possible.

People First Language – It’s not just ‘semantics’

Language is powerful. When we misuse words, we reinforce the barriers created by negative and stereotypical attitudes. When we refer to people with disabilities by medical diagnoses, we devalue and disrespect them as members of the human race. We need to recognize the power of words and carefully choose language that can positively influence and potentially change societal perceptions of people with disabilities. As Chairperson of the HRC, it is especially important that you use and promote respectful language when referring to or talking about the people that you help support.

For too long, labels have been used to define the value and potential of people who are labeled. Often, when people hear a person’s diagnosis, they automatically make assumptions. Assumptions are made about the person’s potential, what he or she can or can’t do, whether he or she can learn, be employed, or live in the community.

We must believe all people with disabilities are real people with unlimited potential, just like all people. People will live up (or down) to expectations. If we expect people with disabilities to succeed, we cannot let labels stand in their way. A person’s self-image is strongly tied to the words used to describe them. We must not let labels destroy the hopes and dreams of people with disabilities and their families. *The only label a person really needs to use is his or her name.*

Generally, in choosing words when talking/writing about people with disabilities, the guiding principle is to refer to the person first, not the disability. In place of saying “the disabled,” it is preferable to say, “people with disabilities.” This way the emphasis is placed on the person, not the disability. Disability should not be the primary, defining characteristic of an individual, but merely one aspect of the whole person.

Some General Guidelines for Talking about Disability are:

- Don't use labels! When we put a label on a person, it purports to tell us what's inside. It is as if we are labeling a can of tomatoes. The label tells us what to expect when we open it.
- Do not refer to a person's disability unless it is relevant to the conversation
- Use "disability" rather than "handicap" to refer to a person's disability
- When referring to a person's disability, use *People First Language* (such as "he has epilepsy")

Avoid negative or sensational descriptions of a person's disability. Don't say "suffers from", "a victim of," or "afflicted with."

Examples of People First Language

Say:	Instead of:
He/she has an intellectual disability	He/she is mentally retarded
Persons with disabilities	The handicapped or disabled
He/she uses a wheelchair for mobility	He's/She's wheelchair bound
He has a diagnosis of Down Syndrome	He's Down's
He/she has issues with	He/she has a problem with
He receives specialized education services	He's special ed.

Remember to always use People First Language during meeting discussions and in writing meeting minutes.

Let's Practice

Examine these statements and determine if they are stated in People First Language. If not, change the statement to be "People First".

- "He's an intellectually disabled person."

- “John had a behavior.”
- “Audrey is non-compliant.”
- “There are three tube-feeders in this house.”
- “Bob is a runner.”

Some Philosophical Considerations Personal Growth vs. Freedom from Harm

In general, people that live in community-based programs have greater freedom to direct many aspects of their lives. People having the freedom to make choices, freedom to fail and the chance to learn from experience.

However, it is important to make a risk/benefit analysis and determine the cost of absolute safety versus the benefit of interaction with the environment. The HRC can be a forum for this type of analysis. Many times, agencies have imposed lists of restrictions in the name of safety; however, this type of thinking only fosters dependence. There are certainly situational concerns regarding the right to try and the right to fail, however, an agency cannot ignore its part in supporting this “dignity of risk.”

Risk

It is vital to remember that the adults we support are fully adults. When considering the idea of risk, we may want to ask questions such as “What supports would we put in place for ourselves or friends or family who want to do things they’ve never done before?”

- Talk about those things
- Research the best safety practices and decide if it makes sense for the current situation
- Try something for a short period of time
- Try something with someone who has more experience than we do
- Evaluate the experience and make new decisions about going forward.

Sometimes things go wrong. If they do...

- Examine what happened and think about what you've learned
- Don't over-react
- Don't write another policy that applies to everyone when something happens with one person

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

Mahatma Gandhi

Scenarios for Discussion

1.

Joe recently moved to your agency from a State Operated Developmental Center. He has developed a habit of urinating in inappropriate places and seems to prefer using 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 hangs them in the closet. Staff reports 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. Will you endorse this plan?

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion

2.

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 BMC has approved this plan.

Potential Rights Restrictions

Related Issues to explore?

Scenarios for Discussion

3.

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. Lori seems to regard food as a very powerful reinforcer. Additionally, the doctor has recommended Zoloft for her anxiety.

Potential Rights Restrictions

Related Issues to Explore:

Scenarios for Discussion

4.

Marian recently moved to your agency. Ever since she arrived she has attempted to run outside on a number of occasions. Risk assessment shows that she does not demonstrate traffic safety skills and the residence is located in a busy area. The team has determined that a door alarm needs to be installed on all doors so that at the sound of the chimes, they could be sure Rhonda was safe.

Potential Rights Restrictions:

Related Issues to Explore

Scenarios for Discussion

5.

Recently one of the QIDPs came to you as HRC Chairperson for some advice. It seems that Marcus, one of the gentlemen that she helps to support, has decided that he wants to go to the barber and have his head shaved. He's seen men on TV with shaved heads and thinks that this is the look for him. The problem is that that Marcus' parents don't want him to do it. They are very involved with their son and he goes home to Chicago to visit them often. Marcus' parents are concerned about that particular hairstyle because in the neighborhood where they live, this is considered to signify gang affiliation and they are worried for their son's safety. The QIDP is worried that Marcus may not be able to visit the family if he goes through with the hairstyle choice.

What type of advice would you give to the QIDP?

Scenarios for Discussion

6.

Paul recently moved to a more active home. This home goes to a wide variety of activities, including baseball games, stock car races, and out to eat. Since Paul moved to the home, there has been incidents of money and supplies disappearing. Paul does have a history of stealing (in his younger years) but hasn't displayed any incidents recently, nor has Paul been found with the items. The agency has decided to install surveillance cameras in the home. The cameras will be placed in the home except for bath/bedrooms. The cameras will also help administration assure staff are doing their jobs and prevent abuse.

Potential Rights Restrictions:

Related Issues to Explore

Appendix A

Sample HRC Checklist*

Questions	Comments
1. Who is the person and what significant things are going on that require the committee's attention?	
2. What is at issue?	
3. What are the relevant data and what do they indicate?	
4. What is the proposed restriction?	
5. Has informed consent been obtained? From whom?	
6. What is the impact of the restriction in the person's life and lives of those around them?	
7. What alternatives have been tried?	
8. What were the results?	

Sample HRC Checklist*	
9. Why is <i>this</i> particular action being recommended?	
10. What is the person’s perspective of the restriction?	
11. Who will implement the procedure? How will they be trained?	
12. Has the program been approved by BMC?	
13. What are the criteria for reinstatement?	
14. What are teaching strategies for reaching criteria?	
15. What are the review mechanisms? Dates?	
16. What are the committee recommendations?	

*Source: High Tide Press, Human Rights Committees book by Steve Baker and Amy Tabor, “Staying on Course with Services and Supports of People with Developmental Disabilities”. To purchase this book go to the High Tide Press web site at: <http://www.hightidepress.com/titles/disabilities.php>

Resources

Baker, Steve and Tabor, Amy Human Rights Committees, Staying on Course with Services and Supports for People with Intellectual Disabilities, High Tide Press
Available at: <http://www.hightidepress.com/titles/disabilities.php>

The Council on Quality Leadership, *All About Rights*, Towson, Maryland, 2004

"Quality in Practice: Human Rights Committee" Council on Quality and Leadership. 2007
Available at: www.thecouncil.org/QIP_HRC.aspx

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