02.03.03.050 Human Rights Committee

Number: 02.03.03.050

Effective: 09/15/06

Section: Developmental Disabilities

Subsection: Behavior Intervention

Authority: Mental Health and Developmental Disabilities Code [405 ILCS 5]; Mental Health and Developmental Disabilities Confidentiality Act [740 ILCS 110]

Reference: Program Directive: 02.01.06.020, Reporting and Investigating Incidents and Allegations of Abuse and Neglect.

Policy Statement

It is the policy of the Illinois Department of Human Services (DHS), Division of Developmental Disabilities, to establish a specially constituted committee to be known as the Human Rights Committee (HRC), at each State-Operated Developmental Center (SODC), which exists to support individuals who live at the Center to ensure that the programs and services provided do not infringe upon their human, civil, and legal rights

Definitions

"Center." A State-Operated developmental disabilities facility as defined by Section 1-107 of the Mental Health and Developmental Disabilities Code [405 ILCS 5/1-107].

"Center Director." The chief administrator of a State-Operated Developmental Disabilities Center or his or her designee.

"Individual." Any person receiving developmental disabilities services in a Center operated by DHS.

"Rights." The term as used in this Directive shall mean civil, human or legal rights.
"SODC Executive Committee." A committee appointed by the SODC Center Director to develop, review and approve policies, procedures and activities of the Center.

1. **Purposes**
   1. The HRC is one of several mechanisms established in SODCs to safeguard the rights of individuals by maintaining high programming standards.
   2. The HRC works in cooperation with the Center Director and the staff at each SODC, to ensure that all individuals served are treated with dignity and respect, to determine whether any right has been denied, and to make recommendations to prevent future violations.
   3. While the HRC reviews all Restrictive Programs (designed to manage inappropriate behavior) approved by the Behavior Intervention Committee (BIC), it also serves a separate and distinct function. The BIC reviews programs to ensure technical adequacy and that restrictive procedures are only used when clinically indicated.
   4. The HRC's role in the system is to ensure that individuals' rights are protected, and to ensure that adequate informed consent is obtained when rights are being restricted as part of an on-going program.
   5. The HRC ensures that the Interdisciplinary Team (IDT) has reviewed each individual's rights and established supports that enable the individual to gain/re-gain his or her rights. In addition, the HRC also reviews all policies, procedures and practices which affect the rights of individuals living in the SODCs.
   6. The HRC is to be informed of complaints of rights violations presented to the Center Director, and outcomes of corrective actions. It discusses measures which the Center has established or could establish to prevent future rights violations.

2. **Composition**
   1. Committee Membership
      The Center Director shall appoint members to the HRC. The HRC will consist of at least five (5) members, appointed for a term of three (3) years. The HRC shall consist of at least one (1) consumer. At least one-third (1/3) of the HRC members must not be affiliated with the SODC and one (1) person must have experience in civil, human or legal rights.
      2. The specific disciplines and professions of the remaining members of the HRC include, but are not limited to the following:
         1. Physician, Nurse and/or Pharmacist;
         2. Clergy;
         3. Educator, Psychologist, Clinical Social Worker or Habilitation Program Coordinator;
         4. Community Representatives;
         5. Individuals who reside at the Center or consumers from the community;
         6. Parents/guardians of individuals who reside at the Center;
         7. A representative from the Behavior Intervention Committee (BIC). This person is a non-voting member; his or her participation is to present the programs which have been approved by BIC and to answer any questions raised by the members.
3. SODC staff and individuals served may attend Committee meetings at the invitation and/or request of the HRC or if they have a professional, personal, clinical or administrative responsibility regarding issues being addressed by the HRC. These persons may attend with the approval of the individual and consent by the guardian to provide relevant information to the HRC, but may not otherwise participate in the decision-making of the HRC. Following the discussion and decision regarding the issue, the guest(s) will be excused prior to a new case review. Arrangements for attendance should be made through the HRC Chairperson.

4. Chairperson's Role
The Chairperson shall be appointed annually by the Center Director. His or her primary responsibilities include but are not limited to the following:
   1. To ensure that the HRC composition and function is in accord with applicable standards and DHS policies.
   2. To elicit opinion from each member present about each program or proposal. Consensus decisions are preferred. However, dissenting views shall be noted.
   3. To ensure that HRC meeting minutes reflect discussion and reasons for decisions and are issued in a timely manner. These minutes shall protect the anonymity of individuals served in the HRC and discussed during the meeting.
   4. To inform the Center Director of HRC membership vacancies for which an appointment of a new member is warranted.

5. Meetings
   1. The HRC shall meet at least once a month or more often, if needed. The Chairperson or designee, one person other than Center staff and a community member not affiliated with the Center shall constitute a quorum. No HRC member who has been involved in the development, review, or approval of a proposal before the HRC, shall be included in decision-making relative to that program or proposal.
   2. The HRC shall be provided necessary information for review without identifying information unless the individual or his or her guardian has consented to the release of such information.
   3. If an unplanned event arises requiring that a Behavior Intervention Procedure (BIP) must be reviewed, approved and implemented prior to the regularly scheduled HRC date, the IDT may seek approval for a program which may include restrictive techniques or psychotropic medication from a quorum of the HRC Committee.

6. Committee Policies and Procedures
Each SODC HRC shall establish policies and procedures which must be approved by the Center Director. These policies and procedures shall serve as the by-laws for the HRC and shall include, but not be limited to, the following:
   1. Procedures to fulfill all responsibilities in accord with this Program Directive;
   2. Procedures for the removal of members for failure to fulfill duties;
   3. Procedures for members to resign from the HRC;
4. Procedures for individuals who reside at the Center to file complaints;
5. Procedures for members to follow up and report on complaints; and
6. Procedures, if applicable, for using standing sub-committees to conduct specific reviews and other business.

3. **General Responsibilities**

   1. The HRC members shall be knowledgeable of the policies, procedures, and practices of the SODC that may affect or restrict individuals' rights.
   2. The HRC must review and approve prior to implementation those individual programs, designed to manage maladaptive behaviors, which include the use of restrictive procedures. The HRC shall review the use of any SODC behavioral intervention guideline for programs or practices either in use or proposed, separate from the individual's BIP, that raises questions as to the infringement of an individual's rights. The HRC shall ensure that such programs and practices are implemented with regard for the dignity and respect of the individual and contribute to his or her personal development.
   3. The HRC shall recommend termination (or temporary discontinuance) of any program or procedure whenever a violation of human rights is detected, until such time as the violation is corrected.
   4. The HRC shall review all rights restrictions that are communicated via a Notice Regarding Restricted Rights of an Individual form (IL462-2004D) that are not part of an approved BIP.
   5. The HRC will conduct periodic site reviews of residential homes, on-campus day program/vocational work sites, and off-campus day program/vocational work sites.
   6. The HRC shall thoroughly review all resolutions to complaints or grievances submitted by individuals, relatives, staff, or other interested parties to the Center.
   7. The HRC shall review the Center's individuals' rights training curriculum.
   8. The HRC shall review and approve all proposals for research, to ensure that the potential risks to the individuals involved are clearly outweighed by the potential benefits. This review shall be completed prior to the initiation of the project.
   9. The HRC of an SODC with a locked area shall review, at least annually, the status of locked living areas.
   10. The HRC shall review and approve the use of all protective devices.
   11. The HRC shall monitor the following to guard against and check for possible violations of individuals' rights, which may include:
       1. Individual injuries;
       2. Use of restraint(s);
       3. Investigative reports regarding allegations of abuse and neglect;
       4. Restriction of rights;
       5. Informed consents;
       6. Appeal of agency decisions;
       7. Anxiolitic medications and medication used for sedation prior to medical procedures; and
       8. Medical Immobilization Devices used five (5) or more consecutive days and every thirty (30) days, if continued.

4. **Functions of the Committee**
1. Review of Policies
The HRC shall review and make recommendations to the SODC Executive Committee regarding the SODC's policies and procedures that may affect the rights of individuals who live at the Center.

2. Review of Behavior Intervention Program Procedures
   1. Requests for approval of programs containing restrictive intervention techniques must include documentation that informed consent has been obtained from the individual or guardian, as applicable. When reviewing requests for restrictive programs, the HRC should consider the following questions:
      1. Was the consent informed?
      2. Is the consent legally adequate?
      3. Could the procedures (how and where they are implemented) cause the individual harm or humiliation?
      4. Would it be viewed as abusive or unacceptable by the general public?
      5. Are the proper safeguards contained in the program?
      6. Is the monitoring sufficient to ensure timely intervention if problems arise?
      7. Has the individual's team documented the less restrictive techniques that were used, their duration, and their results?
      8. Does it include a provision for staff trained to carry out the program?
      9. Have staff been trained to recognize problems that could arise with the use of a particular procedure?
   2. The HRC may reach one of the following decisions regarding a BIP submitted for review:
      1. The HRC may approve the BIP;
      2. The HRC may approve the BIP pending incorporation of required changes as specified by the HRC;
      3. The HRC may disapprove the proposed BIP; or
      4. The HRC may defer reaching a decision on the BIP for the purpose of procuring more information needed to reach a decision. Every reasonable attempt shall be made to obtain the pertinent information prior to the next regular meeting date.
   3. Following receipt of the HRC response to the reviewable BIP, the Psychologist/Behavior Analyst will ensure that all required changes are completed.
   4. For each behavior intervention program which the HRC approves, it establishes an approval renewal date not to exceed six (6) months. BIPs containing the use of psychotropic medication must be reviewed three (3) months after the initial approval and every six (6) months thereafter. BIPs containing the use of restraint must be reviewed every three (3) months.
   5. Should the HRC's decision regarding a BIP or response to a concern or complaint be disputed, the individual(s) who disagree with the
determination may appeal the decision to the Center Director and may be assisted in obtaining advocacy services.

6. The Center Director’s decision, based on the findings and recommendations of the HRC, may be appealed by the complainant to the Division of Developmental Disabilities Director. The decision of the Director shall be considered a final administrative decision.

3. Rights Review
   1. The HRC will review the SODC’s "Rights" section from each individual’s annual Service Planning Meeting upon admission, as well as any revisions during the year, to certify that rights restrictions occur only in accord with required procedures.
   2. The Chairperson of the HRC will provide the Residential Unit Director documentation certifying the HRC’s Rights Review. If a rights violation or potential rights violation is noted, immediate action is to be initiated by the Unit Director to correct the violation or potential violation.
   3. The Unit Director is to confirm in writing to the Chairperson of the HRC the status of corrective action within one (1) week of receiving the notification by the Chairperson of the HRC.
   4. The HRC Chairperson will also notify the Center Director of any rights violations or potential rights violations as soon as feasible.
   5. The HRC shall review the training curriculum of staff regarding individual rights and assure that rights and the process for filing complaints are posted in living areas. As part of the rights review process, the Chairperson of the HRC will validate that the services of interpreters have been used, when necessary, when the individual was provided with a summary of his or her rights and responsibilities and when a rights restriction was explained to him or her.

4. Protective Devices
   1. The HRC shall review the use of protective devices used to prevent an individual from causing accidental physical injury to himself or herself, i.e., protective helmet, toilet tray, etc.
   2. Approval for the use of protective devices must be obtained from the HRC prior to use. The Chairperson of the HRC will provide the Residential Services Director documentation certifying approval.

5. Review of Research Proposals Involving Individuals who Reside at SODCs
   1. The HRC shall review all proposals for research approved by the Research Review Committee, to ensure that the attendant risks to the individuals involved are clearly outweighed by the potential benefits.
   2. The HRC shall make recommendations to research investigators where changes in format or protocol are necessary for the protection of the rights and welfare of the individual(s) involved.
   3. The HRC shall ensure that federal regulations regarding research are adhered to.
   4. The HRC shall require compliance with DHS Rules, DHS Program and Administrative Directives, relevant DHS guidelines and policies, as well as compliance with the Illinois Mental Health and Developmental
Disabilities Code, the Centers for Medicaid and Medicare Services (CMS), Intermediate Care Facilities for Persons with Mental Retardation Standards, and the standards of necessary accrediting bodies.

5. The HRC shall devise a means to ensure that all policies and procedures of the SODC which are pertinent to the protection of human rights of individuals participating in research are adhered to.

6. The HRC shall ensure that appropriate procedures for obtaining informed consent have been executed by the principal investigator or his or her representative for the individual(s) involved.

7. The HRC shall receive on a quarterly basis, from the principal investigator of each ongoing research project, a written statement of progress so that approval for continuation may be granted. Approval for continuation will be based on the following criteria:
   1. Rights of individuals involved are not being violated;
   2. There have been no changes in the research protocol or program procedure without prior approval by the Research Review Committee and the HRC;
   3. There has been no change in the potential risks, or new problems which have arisen.

8. The HRC shall require that the principal investigator, upon completion of each research project, submit a typewritten statement of the outcome of results of the research. The HRC Chairperson shall maintain copies of the results.

6. Review of On-Going Activities
   The HRC shall have the option to evaluate activities at the Center which have been outlined above. That is, the HRC, individually or as a group, may inspect current activities to ascertain whether rights of individuals who reside in SODCs are being violated. Access to individuals, records, personnel and programs or research data may be limited only by federal or state law or DHS rules or policies.

5. Referrals to the Committee
   1. Any individual, employee, guardian, parent or interested party may refer any activities that might be considered to be violations of the human, civil and/or legal rights of an individual who lives in an SODC, to any member of the HRC. If the activity is determined by the Chairperson not to be a rights violation, the Chairperson will refer the issue to the appropriate SODC staff person for follow-up.
   2. Complaints, concerns, or proposals for HRC review shall generally be presented in writing to the Center Director, who in turn will provide the information to the Chairperson of the HRC. If the complaint is determined by the Chairperson not to be a rights violation, the Chairperson will refer the issue to the appropriate SODC staff person for follow-up. Should an individual, or interested party, have a concern to present before the HRC, they may be afforded an opportunity to do so by presenting themselves at the HRC meeting and receiving a consensus approval of the members in attendance to hear the complaint. The Center Director's decision (based on the findings and recommendations from the Center HRC) may be reviewed by the Deputy Director for SODC Operations, or this person's
designee, as appropriate. The decision of the Deputy Director may then be reviewed by the Director for the Division of Developmental Disabilities or his or her designee. The decision of the Director of the Division of Developmental Disabilities shall be considered final.

6. **Training of Center Human Rights Committee Members**
   Center staff, as appropriate, shall provide HRC members with adequate training to carry out their responsibilities. Documentation of such training shall be retained by the Center Staff Training Coordinator. The Center Director shall be responsible for assuring that each HRC member is given a statement of, and receives the training necessary to carry out his or her role and responsibilities. Training shall be offered in such areas as the Mental Health and Developmental Disabilities Code, Confidentiality Act, Center programs and services, use of medications, behavior intervention, etc.

Authorized by: *(Signature on File)*

Carol L. Adams, Ph.D.

Secretary