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PURPOSE

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

PHILOSOPHY

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

AUTHORITY

S.C. Code Ann. § 44-26-70 (Supp. 2012) relating to the rights of people receiving services from DDSN requires that each DDSN Regional Center and DSN Board establish a Human Rights Committee. Contract service providers may either use the Human Rights Committee of the local DSN Board or establish their own Committee.

DDSN Autism Division operated programs may utilize an existing Human Rights Committee of a DSN Board or of a Regional Center or it may establish its own Committee.

The regulations governing Intermediate Care Facilities for Persons with an Intellectual Disability (ICF/ID) require the establishment of a specially constituted committee which functions as a Human Rights Committee to review, approve, and monitor programs to manage inappropriate behavior and other programs that involve risk to protection and rights. Policies and procedures of this directive are applicable to these specially constituted Committees.

ROLE

The role of the Human Rights Committee is to safeguard and protect the rights of people receiving services to ensure that they are treated with dignity and respect in full recognition of their rights, and to review and advise regarding issues which present ethical questions involving service recipients.

Members of the Human Rights Committee serve in an advisory capacity and are exempt from liability.

The Human Rights Committee is an entity separate from the service organization. It should not duplicate advocacy efforts that have been established to represent the rights and interests of people with disabilities or special needs, but shall serve in an adjunct capacity to those efforts.

Human Rights Committees shall develop bylaws for the conduct and operation of its committee that minimally include: a definition of "quorum," and the distribution of the current agenda and prior meeting minutes to the members before scheduled meetings. At the discretion of the Human Rights Committee, appropriate agency staff or an advocacy representative may attend meetings. However, information shared, obtained, or disclosed during the conduct of the meeting is confidential and must not be disclosed.

The Human Rights Committee may organize into subcommittees for specific purposes in order to meet its responsibilities (e.g., medication review, behavior support plan review, grievance appeal, ethics review, etc.). Any business conducted by the sub-committees must be brought before the full committee for review and approval.

Minutes shall be taken of each meeting and shall reflect the date and time of the meeting, those Committee members present and absent, and a record of decisions and recommendations in a manner that readily identifies the issues reviewed, the decisions reached, and the follow-up that is necessary. A tape recorder may be used for this purpose. The minutes shall also reflect the names of others attending the meeting.

RESPONSIBILITIES

The Human Rights Committee is charged with the responsibility of protecting the due process rights of people receiving services and supports and functions to provide a community perspective in advising the Facility Administrator/Executive Director/CEO on the acceptability of procedures and programs involving rights issues.

Specific responsibilities include:

1. Review and approve all agency actions, practices or policies which restrict any person's rights.

2. Review and advise on agency policies and practices pertaining to the rights of people who receive services.

3. Review and approve individual habilitation plans prior to implementation which:

   a. Restrict personal freedoms or rights.
   b. Use restrictive or intrusive procedures as part of a Behavior Support Plan (e.g., restraint, door alarms, visual or auditory monitoring devices, locked cabinets or locked rooms where items needed or used by supported individuals are kept, time out, or aversive conditioning). NOTE: Time out and aversive conditioning also require prior written approval of the DDSN State Director.
   c. Use behavior control medications for behavior management.

4. Receive notification of the use of emergency restraints. Each Human Rights Committee, in coordination with the Agency, may establish its own mechanism for receipt of such reports.

5. Review and advise on research proposals to ensure that the rights, dignity and welfare of research participants are protected and they are not used as a source for research which is not associated with disability issues.

6. Receive notification of alleged abuse, neglect, or exploitation. Each Human Rights Committee, in coordination with the Agency, may establish its own mechanism to receive such reports.

7. Ensure that prior informed consent is obtained as set forth in S.C. Code Ann. § 44-66-10 "Adult Health Care Consent Act" and DDSN Directive 535-07-DD: Obtaining Consent for Minors and Adults, when:

   a. A person considers participation in a research proposal approved by DDSN.
   b. An activity, plan or procedure that intrudes physically, psychologically, socially, or has irreversible effects is proposed.

8. Review and advise on concerns of applicants for services, service recipients, or their representative when concerns cannot be resolved through other efforts. The Human Rights Committee shall review the concern at its next regularly scheduled meeting or within 30 days from the date of appeal to the Human Rights Committee. If a more expedient resolution (less than 30 days) is required as determined by the Human Rights Committee Chairperson or the Facility Administrator/Executive Director/CEO there should be a called meeting of the Human Rights Committee. Areas that may be reviewed by the Human Rights Committee include, but are not limited to:

    a. Habilitation plans (day, residential, service coordination).
    b. Program, supports, and service placement decisions.
    c. Restriction of personal freedoms and rights.
    d. Access to medical or habilitation (treatment) records.
    e. Determination of a person's ability to give informed consent.
    f. Program, supports, or service termination.
    g. Refusal of treatment services.

9. Advise the DDSN Regional Center or local DSN Board or contract provider agency on other matters pertaining to the rights of people receiving services and other issues identified by the Human Rights Committee or Agency.

MEMBERSHIP

The DDSN State Director shall appoint members to each DDSN Regional Center Human Rights Committee upon recommendation of the Facility Administrator. Additionally, should the DDSN Autism Division choose to have its own committee, members will be appointed by the State Director upon the recommendation of the Associate State Director-Policy. The Agency Director of a DSN Board or contract service provider shall appoint members to the Human Rights Committee.

Current employees of a DDSN Regional Center, local DSN Board, or contract provider agency may not serve on their respective Human Rights Committees. Former employees may not serve on their respective agency Human Rights Committee. They may, however, serve on any other agency's Human Rights Committee at any time.

The Human Rights Committee is an independent, impartial entity.

Membership should reflect the cultural, racial, and disabilities diversity of the community in which it functions.

A minimum of not less than five (5) persons shall be appointed to each Human Rights Committee. Membership shall include:

1. A user of DDSN services from any service area, representing those receiving services or a self-advocate nominated by the local self-advocacy group.

2. A family member of a person who has an intellectual disability or related disability, autism, head and spinal cord injury or similar disability.

3. A representative of the community at large with expertise or demonstrated interest in services to people with an intellectual disability or related disability, autism, head and spinal cord injuries, or similar disabilities.

4. A community professional with expertise in behavioral or medical fields. This may include a physician, nurse, pharmacist, psychologist, etc.

5. Other community representatives (e.g., clergy, educator, lay citizen, etc.).

Exceptions to the minimum number, composition, and terms of service must be approved by the Associate State Director-Policy or her designee.

Members shall be appointed for three (3) years with terms of service staggered for the purpose of continuity. Members may be reappointed for one (1) additional consecutive term. A chairperson shall be elected annually by the membership.

An attendance log shall be maintained and when a member fails to attend three (3) meetings without excuse from the chairperson or 50% of scheduled meetings within one (1) year that member shall be removed from the committee.

Agency responsibility is one of support and resource; therefore, staff shall not serve as a member of the Human Rights Committee, but may serve in a staff capacity to the Human Rights Committee. The agency will provide clerical support to the Human Rights Committee.

The Agency shall ensure that appropriate resource staff are available to the Human Rights Committee to provide expertise and assistance. Resource staff may include a physician, nurse, pharmacist, psychologist, or other professionals.

TRAINING

All new Human Rights Committee members shall receive training and orientation before attending a meeting that requires a vote. Members shall be afforded an opportunity to tour programs and services and meet people receiving services. Ongoing training shall be provided to the Human Rights Committee members to assist them in carrying out their responsibilities. This training shall occur at least every three (3) years or sooner if there is a change in the majority of committee members since the last training. A log of training shall be maintained and the training topics should include:

1. Rights of people with disabilities and special needs;

2. Due process;

3. Role and responsibilities of the Human Rights Committee;

4. Confidentiality, Informed consent, and release of information;

5. Disabilities (intellectual or a related disability, autism, head and spinal cord injuries, and related disabilities);

6. Behavior support;

7. Medications (including dosages, interactions, contraindications, and side effects);

8. Principles of least restrictive alternatives, normalization, inclusion, protection from harm, active treatment, individualized supports, quality of life issues, etc., and

9. HIPAA - members should receive privacy notice as a part of this training.

10. Other areas that may be specified by the Human Rights Committee or Agency.

The Facility/Executive Director/CEO or his/her designee shall provide this training and shall be responsible for scheduling on-going training. A sample training manual compiled by DDSN is available on the agency website at http://www.ddsn.sc.gov/providers/manualsandguidelines/Documents/FullHRCManr.pdf.

MEETINGS

The Human Rights Committees shall meet as often as necessary, but at least every other month six (6) times a year. Exceptions to this rule must be approved by the Associate State Director-Policy or her designee.

The Human Rights Committee shall assure that people whose rights may be restricted are afforded the opportunity to be present at the Human Rights Committee meeting and that they have the opportunity to present their wishes.

The Human Rights Committee shall assure that people coming before the Human Rights Committee are offered a personal representative to accompany them to the meeting to support him/her to speak or to speak on behalf of the person.

Case presentations coming before the committee shall include a summary. The presentation shall include all of the information needed for the committee's deliberations; however, all information that might identify the person and the outcome of any discussion along with any recommendations shall be coded to protect the identity of the person. If the person and/or his/her representative attend the committee meeting, their attendance shall overrule the coding requirement.

Procedures shall be established for expedient review of emergency situations, which require a Human Rights Committee review and decision. Reviews may be accomplished through a subcommittee, telephone poll, mail, electronic mail, or other procedures established by the Human Rights Committee. The minimum number of contacts must equal the quorums defined in

the By-Laws. Emergency review procedures should be used when it is in the person's best interest not to wait until the next regularly scheduled Human Rights Committee as determined by the Human Rights Committee Chairperson or Facility/Executive Director/CEO.

At its next regularly scheduled meeting, the full Committee should be informed and the full Committee shall approve or rescind the action when emergency approval procedures have been utilized. This provision shall not apply to the review of abuse, neglect, exploitation, and critical incidents.

Case presentations should include the following:

- Statement of concerns
- History of the concern
- History of intervention
- Current data
- Tardive Dyskinesia (TD) scores when applicable
- Recommended course of action
- Informed consent
- Person's concerns
- Family concerns
- Measures for follow up and review

CONFIDENTIALITY

All information concerning people receiving services and their families and staff shall be considered confidential. All members of the Human Rights Committee shall sign a statement of confidentiality upon appointment.

QUALITY ASSURANCE

DDSN Autism Division, Regional Centers, DSN Boards, and contract service providers shall develop quality assurance/improvement procedures for implementing this directive.

These procedures shall be indicated in the Quality Assurance/Improvement Plan.

DDSN Autism Divisions Regional Centers, DSN Boards, and contract service providers shall also develop monitoring procedures to ensure compliance with this directive.

The Facility/Executive Director/CEO or his/her designee shall regularly attend the Human Rights Committee meetings to assure the proper functioning of the Human Rights Committee.

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