A. Purpose
The purpose of this procedure is to establish a process for the review of human rights issues raised by or on behalf of individuals placed or treated under the direction of the DDS Commissioner in DDS operated, funded, and/or licensed facilities or programs, supports and services.

B. Applicability
This procedure applies to all individuals placed or treated under the direction of the Commissioner. This includes individuals receiving services in DDS operated, funded, and/or licensed facilities or programs including individuals receiving individual supports. This procedure applies to individuals with Individual Support (IS) to the extent that the services and supports funded by DDS and implemented by paid staff are connected to a human rights issue or complaint.

The procedure does not apply to individuals who live independently, and who live with their families, without DDS funded supports, those exempted from review by the Human Rights Committee, by the regional or training school director, or who reside in long-term care facilities, licensed, funded and/or overseen by other state agencies.

Definitions
Aversive Procedure: A procedure that contains the contingent use of an event or device that may be unpleasant, noxious, or otherwise cause discomfort to (1) alter the occurrence of a specific behavior or to (2) protect an individual from harming him or herself or others and may include the use of physical isolation and mechanical and physical restraint. This also includes the use of chemical restraints and the use of restrictive procedures such as escorts (except escorts like ‘guide along’ that are met with little or no resistance from the individual) physical isolation, over-correction, and other similar techniques.

Behavior Modifying Medications: Any chemical agent used for the direct effect it exerts upon the central nervous system to modify thoughts, feelings, mental activities, mood, or performance. These chemical agents or psychotropic medications are often categorized as follows: antipsychotics (neuroleptics), antidepressants, antimanics, antianxiety agents, stimulants, and sedatives/hypnotics. Medications that are not usually described as psychotropic are covered by this procedure when they are prescribed primarily for their behavior modifying effects such as mood stabilization and impulse control. These medications include certain anticonvulsants, some beta-blockers, and certain other drugs.

Clients/Consumers: Individuals who are placed or treated under the direction of the DDS Commissioner in DDS operated, funded, and/or licensed facilities or programs, including individuals receiving supported living services and individuals with Individual Support Agreements, to the extent that the supports and services funded by DDS are connected to an issue of rights under the law.

Human Rights Committee: A group of people who, as a committee provide review and advice to DDS Regional and Training School Directors pertaining to the protection of the rights of DDS “clients/consumers”. Each HRC shall have at least 5 members, including staff of contracted/qualified provider agencies and other community volunteers. A DDS employee shall act as liaison between the HRC and the region or training school and respective director. The HRC shall advise the regional or training school director as to matters it reviews.
Intrusive Program/Device: Program or programs or a device that provides information about an individual’s physical status, well-being, whereabouts, or activity, that is used to ensure the individual’s safety or the safety of the community, and not merely for convenience. Intrusive devices may include monitors, door alarms, bed alarms, etc. This would also include a body or room search.

Planning and Support Team (PST): A group of people that includes: the individual being served; his or her family, guardian, or advocate; those people who work most directly with the individual in each of the professions, disciplines, or service areas that provide service to the individual, including direct care staff; and any other people whose participation is relevant to identifying the needs of the individual, devising ways to address those needs, writing or revising an annual plan for services, and monitoring that plan for effectiveness.

Mechanical Restraint: Any apparatus used to restrict movement, including any device (e.g. helmets, mitts, and bedrails) used to prevent self-injury. This excludes mechanical supports designed by a physical therapist and approved by a physician that are used to achieve proper body position or balance, protective devices that are approved by a physician for specified medical conditions (e.g. helmet used to protect an individual from injury due to a fall caused by a seizure), and mechanical devices if they can be removed by the individual at their choosing (e.g., helmets, belts, mitts).

Physical Isolation: The process by which an individual is separated from others and is physically not allowed to leave (i.e., prevented through physical means such as physically blocking the door) that area until defined criteria are met. (This does not include occasions when an individual is sent to a room with verbal prompts and is not physically prevented from leaving.)

Physical Or Mechanical Restraint Employed As A Medical Restraint: There are two types of medical restraints (A and B). Type A is physical, mechanical, or chemical restraint that is used to safely administer medical or dental services. For example: physically holding a person’s arm to draw blood, suture, etc; use of a papoose board. Type B is physical, mechanical, or chemical restraint that is used to aid a healing process and prevent an otherwise acceptable behavior. For example: use of chair with tray to prevent person from walking while a sprained/broken ankle heals.

Physical Restraint: Any physical hold used to restrict individual movement or to protect an individual from harming him or herself or others. This excludes holds that are met with little or no resistance from the individual (e.g. holds that are used as guidance to teach an individual a skill).

Pre-Sedation: Medication(s) ordered by a legally authorized prescriber to be administered to an individual prior to a scheduled medical or dental appointment to assist the consumer to successfully obtain or undergo an examination, procedure and/or treatment.

Program Review Committee (PRC): A group of professionals, including a psychiatrist, assembled to review individual behavior treatment plans and behavior modifying medications to ensure that they are clinically sound, supported by proper documentation and rationale, and are being proposed for use in conformance with department policies.

Qualified Provider: Agencies certified or licensed by the Department

Restitution: The practice of having a consumer reimburse an individual or program for the misuse, overuse, and/or intentional destruction of goods or services. For example: repayment for excessive phone bills, or stolen/damaged property.
Restrictive Intervention: Any intervention that prevents the individual from having access to specific categories of objects that are likely to be dangerous for the individual or others. Restrictions may apply to knives, weapons, sharp objects, cleaning fluids, matches, lighters, etc. Restrictions may also apply to behaviors, which are considered unsafe, or harmful, for example smoking and/or dietary restrictions. Restrictions may be accomplished through the use of locks on doors, cabinets or closets.

D. Implementation

1. Regional Committees
   Each Regional or Training School Director shall establish a Regional or Training School Human Rights Committee. This committee will serve as the official Human Rights Committee for the region (Training School), which acts, independent of any other committee established by private agencies.

2. Memberships
   Regional and Training School Human Rights Committees shall consist of at least five members appointed for a two-year term who are initially selected by the Regional Director. Members are appointed for a two-year term and may be reappointed for subsequent terms. Vacancies will be filled as approved by the Regional and Training School Director.

HRC membership shall be broadly based and strive toward diversity. Committee membership may include a health care professional, a DDS employee, a lawyer, as well as a parent or legal guardian and a consumer whenever possible. Committee membership will also include a qualified person who has experience or training in contemporary practices to change inappropriate client behavior and a person with no ownership or controlling interest in the facility/agency where the consumer lives. Committee members must identify potential areas of conflict of interest (i.e., individuals, agencies, or programs with whom they are closely involved) with an understanding that they will not participate whenever a program, or an individual is reviewed that may constitute a conflict for the member.

The Regional or Training School Director, or his or her designee, shall assign a staff member to serve in a liaison and administrative support capacity to the committee.

The responsibilities of the Liaison include:
- Act as a liaison between the committee and Department or Private agency staff
- Collect, prepare and review materials for the committee
- Develop a schedule for presentations
- Prepare agendas for the committee, in consultation with the Chairperson
- Attend meetings of the committee
- Process HRC Recommendations
- Manage HRC database for the purpose of tracking, and to provide the ability to provide trends and analysis.

The responsibilities of the HRC Chairperson shall be as follows:
- Work in conjunction with Liaison to recruit members
- Facilitate Committee meetings
- Ensure documentation is taken at each meeting
- Ensure coverage by the HRC at all PRC meetings
- In conjunction with the HRC Liaison submit an annual report to the Regional Director or Training School Director summarizing the committees activities during the year.

3. Responsibilities of the Human Rights Committees:

Mandatory Reviews:
The function and duties of the Regional and Training School Human Rights Committee shall be consistent throughout the state. Committees shall advise and make recommendations to Regional or Training School Director in the following mandatory areas, which include but are not limited to:
- Restrictive Interventions
- Aversive Procedures
- Intrusive Programs/Devices
- Restitution
- Pre-sedation Medication
- Other

The Human Rights Committees shall serve as the official Human Rights Committee where and when such committees are required by statute, regulation, or department policy.

4. The Regional Human Rights Committee shall operate as follows:
   - Establish a chairperson of the committee other than the liaison.
   - Meet at least six (6) times a year.
   - Maintain documentation of the committee proceedings and file
   - Maintain the confidentiality of the individual and staff.
   - Ensure the process for bringing issues to the committee complies with the process outlined in this procedure.
   - Review packets within 90 days of receipt.
   - Provide feedback to the Planning and Support Team within 30 days of review.
   - Monitor areas of potential conflict within the committee. Members who identify an area of conflict will recuse themselves for that particular case.
   - Submit an annual report to the Regional or Training School Director summarizing its activities during the year.

HRC will review requests for individual consumers, not for addresses, with the exception of DDS Respite Centers. The committee shall review issues and concerns brought by clients, staff, administrators, parents or advocates that involve potential violations of individual rights.

A completed packet must be submitted to the Regional HRC Liaison who will schedule a review at the next available HRC meeting. A completed packet includes, to the extent minimally necessary and relevant for the matter(s) under review:

- Request for HRC Review Form (Attachment B)
- Consent For Treatment Form (for the individual and all other affected individuals) (Attachment C)
- Behavior Support Plan/Program
- Recent Data (e.g. behavioral, medical, and/or programmatic)
- All evaluations, assessments, and/or doctor’s orders that are related to the target behaviors/request
- Picture or description of item(s)/device(s) being requested
- Applicable legal documents (e.g. probation/parole)

For individuals participating in the region’s Family Respite Centers, a Safety Management Consent form (Attachment F) needs to be submitted.
5. HRC outcomes:
   - After reviewing the information submitted for review, the HRC shall
     Approve
     Disapprove, or
     Approve with qualifications.

Full approvals are granted for up to a maximum of 3 years.

6. A member of the Human Rights Committee shall attend all meetings of the Program Review Committee to determine that the following criteria have been met:
   - Proper procedures to obtain consent or approval
   - A medication reduction plan or a rationale for continuing the medication that is being proposed or is in place
   - A behavior treatment plan that contains positive strategies to enhance skills and, where possible, address target behaviors using the least intrusive/restrictive means
   - The proposed program is congruent with the department’s mission
   - The proposed program does not violate the rights of other individuals living in the same residence

HRC committee members attend PRC meetings to determine if any issues require immediate review by the full Human Rights Committee. When that occurs, the HRC member will list the issue on the PRC face sheet. The entire packet is then forwarded to the Human Rights Committee liaison for inclusion on the next HRC agenda.

7. Review of Complaints:

The Human Rights Committee may request that the Regional or Training School Director review or investigate a human rights complaint brought before the Committee. A written report of the findings of such review shall be provided to the Human Rights Committee.

If a complaint comes to the Regional or Training School Director which addresses an alleged violation of human rights, the Regional or Training School Director will assign fact finding to the most appropriate departmental staff. Once fact-finding is completed, this information will be forward to the HRC Liaison for review at the next HRC meeting. At this meeting a determination is made regarding whether a human rights violation was made, if so the case manager and as appropriate, other staff will be notified of the findings to determine next steps and/or corrective actions.

8. Annual Report:

   a. The annual report shall include a general assessment of the Committee’s impact on ensuring and protecting an individual’s rights over the year and recommendations for change in the coming year.
   b. The Regional or Training School Director or his or her designee shall be responsible for sending a copy of the report to the Commissioner by Sept 1 of each year.
E. References

Statute: CGS 19a Research with Human Subjects

Rules, Regulations, Policy-External

Federal Regulation for ICF/MR – 42 CFR Ch. IV Subpart I:
483.420, Condition of Participation, Client Protections
483-440, Condition of Participation, Active Treatment Services (f) Standard: Program monitoring and change (3) (i) (ii) (iii)
483-450, Condition of Participation, Client Behavior and Facility Practices

Rules, Regulations, Policy-DDS

DDS-1, “Client’s Rights.”
DDS-3, “Client Programs.”
DDS-I.E.PO.003, “Behavior Modifying Medications”
DDS-I.E.PR.003, “Behavior Modifying Medications”
DDS-I.E.PO.004, “Program Review Committee”
DDS-I.E.PR.004, “Program Review Committee”
DDS-I.H.1.PO.002, “HIPAA Uses and Disclosures: General rules (The Standard)”

F. Attachments

Attachment A – Guidelines to prepare for Human Rights Committee presentation
Attachment B - Request for Human Rights Committee Review form
Attachment C - Consent for Treatment form
Attachment D – DDS Human Rights Committee Flow Chart
Attachment E – DDS HRC Face Sheet
Attachment F – Respite Safety Management Consent Form
Attachment G – PRC/HRC Guidelines