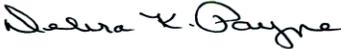


 <p style="text-align: center;">POLICIES AND PROCEDURES</p> <p style="text-align: center;">State of Tennessee Department of Intellectual and Developmental Disabilities</p>	Policy #: 80.6.1	Page 1 of 14
Policy Type: Community	Effective Date: July 11, 2018	
Approved by:  Debra K. Payne, Commissioner	Supersedes: Provider Manual Chapter 2, Section 2.9 (3/15/14)	
	Last Review or Revision: June 6, 2018	
Subject: HUMAN RIGHTS REVIEW PROCESS		

- I. **AUTHORITY:** Tennessee Code Annotated (TCA) 4-3-2708, TCA 33-1-303, TCA 33-3-103 through 115, and Rules of the Tennessee Department of Intellectual and Developmental Disabilities Office of Licensure Chapter 0465-02.
- II. **PURPOSE:** The purpose of this policy is to establish administrative procedures for local and regional Humans Rights Committees (hereinafter HRC); and describe formal human rights review procedures in order to promote and protect the individual rights of persons supported and to ensure that all rights restrictions and limitations to those rights do not occur without informed consent and/or formal human rights review.
- III. **APPLICATION:** This policy applies to Department of Intellectual and Developmental Disabilities (hereinafter Department or DIDD) employees and approved providers working with HRCs.
- IV. **DEFINITIONS:**
  - A. **Approved Provider or Provider** shall mean a provider who has been approved by DIDD to provide one or more HCBS waiver services and may include state-funded services.
  - B. **Assent** shall mean an expression of approval or agreement that may be provided by any person.
  - C. **Behavior Support Plan (BSP)** shall mean the document written by a licensed practitioner of Behavior Analysis which clearly defines the actions and steps that guide direct support professionals and other caregivers in supporting the person to build positive behaviors to replace or reduce challenging and or dangerous behaviors.
  - D. **Center for Medicare and Medicaid Services (CMS)** shall mean the United States federal agency which administers the Medicare, Medicaid, and the Children’s Health Insurance Programs.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 2 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

- E. **Circle of Support (COS)** shall mean a group of people who meet together on a regular basis to help a person supported plan for and accomplish his/her personal outcomes and actions. The person supported is the focus or the center of the COS. At a minimum, this includes the person supported, his/her family members and/or, if applicable, legal representative(s), case manager or independent support coordinator, and the providers (including direct support professionals) of any supports and services the person receives. Friends, advocates and all other non-paid supports are included at the invitation of the person supported.
- F. **Civil Rights** shall mean the rights of personal liberty guaranteed to U.S. citizens by the 13<sup>th</sup> and 14<sup>th</sup> amendments to the Constitution and by acts of Congress.
- G. **Clinician** shall mean a licensed, certified, or DIDD-approved professional who prescribes a treatment.
- H. **CMS Home and Community Based Settings (HCBS) Final Rule** shall mean the January 16, 2014 regulation that defines, describes, and aligns home and community based settings requirements and defines person centered planning requirements for persons receiving Medicaid reimbursed services in HCBS settings under 1915(c) and other specified waivers.
- I. **Dignity of Risk** shall mean recognition of the fact that a certain amount of risk is involved in all life experiences that offer the opportunity for personal growth and positive change. Supporting Dignity of Risk means honoring a person's right to make choices that may involve risks that are typically associated with these types of goals and choices, and committing to assist the person to identify, consider, and implement strategies to reduce the known potential negative consequences of these risks.
- J. **Formal Human Rights Review** shall mean the process, by which the individual human and civil rights of person supported are upheld, promoted and protected. It includes examination and critique of proposed and implemented restrictions on the rights of persons supported; and ensures that mechanisms and safeguards are in place to restore individual rights when restrictions have been implemented.
- K. **Highly Restrictive or Intrusive Behavioral Safety Interventions** shall mean techniques (i.e., supported recovery-separation, mechanical restraint, protective equipment, specialized behavioral safety interventions) that are only used in emergency circumstances and go beyond what is required to resolve the immediate crisis due to the persistent and ongoing risk of harm to the person supported or others.
- L. **Human Rights** shall mean the innate rights and freedoms to which all humans are entitled. These rights include the right to life, liberty, equality and the pursuit of

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 3 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

happiness. Human rights also refer to the basic respect and dignity that must be afforded to each individual.

- M. **Human Rights Committee (HRC)** shall mean the group of appointed persons responsible for ensuring that appropriate mechanisms and safeguards are in place to promote and protect individual rights and that any limitations of rights will not occur without informed consent.
- N. **Incident Review Committee (IRC)** shall mean the committee with a defined membership and meeting schedule assigned to monitor the reporting of incidents, review incidents and investigations reports, provide recommendations and identify trends regarding reportable incidents.
- O. **Informed Consent to Accept a Rights Restriction** shall mean a voluntary agreement made by a well-advised and well informed person supported or, if applicable, legal representative to accept a rights restriction. Well-advised and well-informed means the person or, if applicable, legal representative has been informed of and understands the assessed need for a limitation of their rights (the rights restriction) and that their condition is directly proportionate to the specific assessed need. The person or, if applicable, legal representative has also been informed and understands that positive interventions and supports and less intrusive methods of meeting the assessed need have been tried but did not work. The person or, if applicable, legal representative has also been informed and understands that the rights restriction will be reviewed at a minimum annually to evaluate ongoing effectiveness of the restriction and to determine if it is still necessary or can be terminated or made less restrictive. With all of this information provided, the person or, if applicable, legal representative can make an informed choice to either provide or withhold informed consent for a rights restriction.
- P. **Regional Psychopharmacology Review Team (RPRT)**<sup>1</sup> shall mean professional teams established in each region to provide consultation and recommendations for clinicians prescribing psychotropic medication.
- Q. **Restricted Interventions**<sup>2</sup> shall mean a restrictive behavior analytic procedure that may only be authorized by a licensed practitioner of behavior analysis, and must be approved by a behavior support committee and appears on the DIDD list of restricted procedures.
- R. **Rights Restriction** shall mean any action imposed on a person supported in response to a risk to his/her health, safety, or finances that limits or prevents the

<sup>1</sup> [http://tn.gov/assets/entities/didd/attachments/Referral\\_Process\\_Regional\\_Psychopharmacology\\_Review\\_Team.pdf](http://tn.gov/assets/entities/didd/attachments/Referral_Process_Regional_Psychopharmacology_Review_Team.pdf)

<sup>2</sup> The list of restricted interventions is available online: [http://tn.gov/assets/entities/didd/attachments/Health\\_Services-Interventions\\_Restricted.pdf](http://tn.gov/assets/entities/didd/attachments/Health_Services-Interventions_Restricted.pdf)

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 4 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

person supported from freely exercising his or her human and civil rights and privileges.

- V. **POLICY:** The Department has implemented a systemic approach to ensure that human and civil rights of persons receiving waiver services are not violated. This systemic approach includes formal human rights review that involves the person supported and his/her Circle of Support, agency Incident Management Committees, and local and regional Human Rights Committees.

The Department and providers of services and supports assist persons supported to understand their rights and the responsibilities that accompany exercising their rights. To protect people's rights, persons supported with alternate decisions makers (e.g., conservators) are supported to participate in and influence the decision making process and exercise their rights. Persons supported are guaranteed the opportunity to be heard and be treated fairly in any situation in which rights limitations are proposed and/or imposed. In order to promote and protect people's human and civil rights, a person's rights are not limited without informed consent and/or a formal human rights review. In situations in which rights restrictions are imposed, a person's rights are not limited without a plan to restore them. Regional and local HRCs serve as advisory committees to the DIDD Regional Director and provider agency executive director or chief executive officer.

VI. **PROCEDURES:**

A. Local Human Rights Committees

1. Local HRCs must be authorized by the DIDD Regional Director. The provider is responsible for administrative support of the local HRC. DIDD regional office staff is responsible for oversight of local HRCs.
2. Local HRCs may conduct HRC business for multiple providers or a single provider.
3. The provider executive director(s)/chief executive officer(s) are responsible for appointing HRC members. Local HRC members shall be individuals who are familiar with people with disabilities and have relevant professional or personal experience which contributes to their role as an HRC member.
4. To establish authorization to perform HRC functions, the provider executive director/chief executive officer responsible for operational oversight of the HRC must provide to the DIDD Regional Director sixty (60) calendar days in advance of the first meeting:

**Subject: HUMAN RIGHTS REVIEW PROCESS**

- a. The provider agency (ies) forming the HRC.
  - b. The name of the provider executive director/chief executive officer responsible for operational oversight of the HRC.
  - c. The roster of HRC membership (name, title).
  - d. Meeting frequency and location.
5. To continue authorization to perform HRC functions, the provider executive director/chief executive officer responsible for operational oversight of the HRC must obtain a signed approval letter from the DIDD Regional Director prior to holding the first meeting of the new calendar year. The provider executive director/chief executive officer responsible for operational oversight of the HRC must provide thirty (30) calendar days in advance of the first meeting of the new calendar year:
- a. The provider agency (ies) forming the HRC.
  - b. A roster of HRC membership (name, title).
6. The provider executive director/chief executive officer responsible for operational oversight of the HRC must report to the DIDD Regional Director any changes in membership, change of chairperson or change of entity responsible for operational oversight within thirty (30) calendar days of the change occurring.
7. Provider(s) involved with a local HRC are responsible for providing adequate staff to administratively support the committee.
- a. If a local HRC has been formed by a single provider, the provider executive director/chief executive officer is responsible for operational oversight and administrative support of the HRC.
  - b. If multiple providers jointly form a local HRC, the executive directors/chief executive officers shall determine which agency is responsible for operational oversight and administrative support of the HRC.
- B. Regional Human Rights Committees
1. DIDD regional office staff is responsible for administrative support of Regional HRCs. The DIDD Director of the Office of Civil Rights and DIDD

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 6 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

Director of Behavioral and Psychological Services have responsibility for oversight of Regional HRCs.

2. Members of Regional HRCs are appointed by the DIDD Regional Director. Regional HRC members shall be individuals who are familiar with people with disabilities and have relevant professional or personal experience which contributes to their role as an HRC member.
3. Upon appointment, each regional committee member shall sign a Conflict of Interest and Confidentiality Statement for Committees/Councils DIDD-6021 form. No member shall be allowed to participate in any committee business until such statement is signed.

C. Composition of Local and Regional HRC

To operate effectively, HRCs must have a balanced membership. Committees must be able to weigh various pieces of information and reach practical solutions that benefit the person supported and those who are close to him/her. It is important that the committees be comprised of individuals who will advocate for the person's right to withhold informed consent, right to be informed of potential rights restrictions and seek practical solutions to situations that threaten the person's ability to make independent choices and the person's health or safety, or the health and safety of the public-at-large. All HRCs will be comprised of at least five (5) members who have received HRC training designated by DIDD. Committees should be careful not to create a membership imbalance by adding too many members from any of the categories named below. In order to take action, at least one third (1/3) of the HRC members present at the meeting must not be employed by DIDD. HRC membership shall include:

1. A minimum one (1) person receiving waiver services or one (1) family member of a person receiving services from a provider in the region or from a provider involved in forming the committee.
2. Other HRC members shall be individuals who are familiar with people with disabilities and have relevant professional or personal experience which contributes to their role as an HRC member and have been trained on or have familiarity with the Final Settings Rule.
3. The committee shall elect a member to serve as the chairperson.
4. Each regional office shall designate an HRC liaison to communicate with local HRCs and manage the agenda for the Regional HRC.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 7 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

D. Formal Human Rights Review Process

Circle of Support responsibilities are as follows:

1. Review the individual support plan (ISP) for any restrictions of the person's rights. This includes rights restrictions that appear to benefit the person supported, e.g., limits on the number of cigarettes a person can smoke per day or prohibiting visitation with people who are believed to have a negative influence on the person supported.
  - a. If the ISP contains rights restrictions then conduct a formal human rights review. Ensure the person supported and/or, if applicable, legal representative have given informed consent for every rights restriction in the ISP. The person supported shall be given support to understand his/her rights and the responsibilities associated with his/her rights and the restriction. The person or, if applicable, their legal representative shall also be assisted to understand their right to refuse consent to the restriction. Ensure that any rights restriction that is implemented includes a fading plan for reducing or eliminating the need for the restriction. Restrictions must be time-limited and evaluated at least annually to assess continued effectiveness. The person's and/or, if applicable, legal representative's consent shall be documented in the ISP.
  - b. If the person or, if applicable, legal representative refuse to consent to the restriction then the restriction must be discontinued, the ISP amended and submitted for review per policy 80.3.4 Authorization of Services. The person's or, if applicable, legal representative's refusal to consent shall be documented in the ISP.
  - c. If there is disagreement over the restriction then the person's case manager (CM) or independent support coordinator (ISC) shall make a referral to a Human Rights Committee for further formal human rights review.
2. Review of emergency use of rights restrictions that were implemented based on an imminent risk of harm to the person supported or others by the person supported.
  - a. Convene a COS meeting which shall take place as soon as possible, within 21 calendar days, to protect the rights of the person.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 8 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

- b. Verify that the provider sought informed consent after one (1) day and that if consent was not obtained within five (5) calendar days, the restriction was withdrawn unless withdrawing the restriction would cause imminent risk of harm to the person supported or others by the person supported.
  - c. Assess the ongoing need for continuation of the rights restriction and possible less restrictive alternatives to the rights restriction.
  - d. Make recommendations regarding the person's supports and services and alternatives to the use of rights restrictions.
  - e. Documentation of the meeting shall be submitted to the Regional HRC prior to their next meeting.
3. A rights restriction may not be imposed or added to a person's ISP without formal human rights review as described in this policy. Rights restrictions that arise between COS meetings must be reviewed by the appropriate entity (e.g., COS, IRC, or local or regional HRC) prior to imposition.

The functions of the agency Incident Review Committee<sup>3</sup> are:

1. For the use of psychotropic medications (i.e., routine, not PRN or emergency) informed consent must be obtained from the person supported, or if applicable, legal representative prior to the administration of said medication.
2. Submit a reportable incident form (RIF)<sup>4</sup> to DIDD if it is discovered that psychotropic medication (not PRN or emergency) was administered without the person's or, if applicable, legal representative's consent, for follow-up by DIDD.
3. Concerns about the psychotropic medications prescribed for a person supported may be recommended for submission of an initial inquiry to the Regional Psychopharmacology Review Team (RPT). Referrals may be made to the RPT even if the person and/or, if applicable, legal representative has consented to the medication.

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<sup>3</sup> See Provider Manual Chapter 7 section 7.3.b. for a description of IRC functions.

<sup>4</sup> See Provider Manual Chapter 7 section 7.3 Incident Management Requirements and 7.4 Investigation Requirements.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 9 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

The functions of the local or Regional HRC are:

The primary functional difference between local and Regional HRCs is that regional committees resolve human rights issues that cannot be resolved at the local level and provide technical assistance and training to local HRCs.

1. Review and make recommendations regarding complaints of rights restrictions and human rights violations at the request of the person supported or other member of the person's circle of support. The person will be supported to be involved in the HRC meeting and have input on developing and implementing any recommendations that are made.
2. Consultative review of Behavior Support Plans, restricted interventions and make recommendations to resolve conflicts between those providing consent to the BSP, e.g., person supported and legal representative, if applicable. The HRC does not approve or disapprove restricted interventions or BSPs and does not have the authority to overrule or overturn a consent provided by a person's conservator. However, when the HRC makes a recommendation to change a BSP, the licensed practitioner of applied behavior analysis is bound to either make the recommended change or provide an explanation for why the change cannot be made. If changes are made to the BSP, the person and/or, if applicable, legal representative must provide consent prior to implementation of the change. At a minimum the consultative review of the Behavior Support Plan by the HRC shall include:
  - a. Review BSPs that include restricted interventions or other rights restrictions for potential human rights violations. This includes any planned action(s) that limits an individual's rights.
  - b. Determine if the person or, if applicable, legal representative has provided informed consent for the BSP and/or rights restriction.
  - c. Determine if a specific assessed need is identified and there is a clear description of the condition that is directly proportional to the specific assessed need.
  - d. Review the benefit-risk analysis completed in development of the BSP or plans for rights restrictions.
  - e. Determine if adequate documentation demonstrating all other least restrictive measures have been attempted and failed, which has led

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 10 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

- to the current restriction(s) and there is documentation of the positive interventions and supports used prior to any restriction.
- f. Determine that the restricted interventions or other rights restrictions are not used in the absence of other treatments designed to increase the likelihood of positive skills.
  - g. Determine that the BSP and/or rights restriction includes a fading plan for reducing or eliminating the need for the restricted intervention. Restricted interventions must be time-limited and evaluated on a regularly scheduled basis to assess continued effectiveness.
  - h. Determine that the proposed restricted intervention or other rights restrictions are not for staff convenience.
3. Review emergency and PRN use of psychotropic medication. See VI. D. Functions of Agency Incident Review Committee for review of routine psychotropic medications.
  4. **Regional HRC only.** Review of emergency use of rights restrictions based on an imminent risk of harm to the person supported or others by the person supported. These reviews shall occur at the next scheduled Regional HRC meeting or within 30 calendar days of the emergency use of the rights restriction. In these reviews, the HRC shall:
    - a. Verify that the provider sought informed consent within one (1) calendar day and that, if not obtained within five (5) calendar days, the restriction was withdrawn.
    - b. Verify that the Circle of Support assessed the need for the rights restriction and possible less restrictive alternatives to the rights restriction. This meeting shall take place as soon as possible (within 21 calendar days) to protect the rights of the person. Documentation of the meeting shall be submitted in time for the HRC meeting.
    - c. Ensure that all appropriate notifications were made related to the rights restriction and the event that prompted it. Reference Provider Manual chapter 7 Table 7.1-1.
    - d. Make recommendations regarding the person's supports and services and alternatives to the use of rights restrictions.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 11 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

5. **Regional HRC only.** Review and make recommendations regarding research proposals or academic projects involving persons supported receiving services through DIDD to ensure that implementation of the proposal or project will not result in human rights violations.
  6. Limitations in HRC authority
    - a. The HRC does not have the authority to overrule or overturn the consent or refusal to consent provided by a person who does not have a legal representative.
    - b. The HRC does not have the authority to overrule or overturn the consent or refusal to consent provided by a person's legal representative. The legal representative must be authorized to consent to the proposed treatment or rights restriction as stated in the order.
- E. HRC Training Requirements
1. All HRC chairpersons, and local and regional HRC members shall complete DIDD sponsored orientation and training. Training records shall be maintained in the Department's ELM (electronic learning management system).
  2. Initial and ongoing training shall be provided to all HRC members to assist them in carrying out their responsibilities. Ongoing training shall occur at least every three (3) years or sooner if there is a change in the majority (membership required for a quorum) of committee members since the last training. HRC members shall initially receive training on the following topics:
    - a. Role, responsibilities and procedures of the HRC.
    - b. Home and Community Based Settings (HCBS) Final Rule (e.g., settings requirements, modifications, person centered planning, etc.).
    - c. Intellectual and developmental disabilities (e.g., autism, cerebral palsy, and related conditions).
    - d. Personal rights of people.
    - e. Negotiating freedoms and limitations.
    - f. Benefit-risk analysis.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 12 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

- g. Imminent Risk.
- h. Dignity of Risk.
- i. Elements of consent and assent.
- j. Tennessee Code Annotated statutes pertaining to conservatorship, surrogate decision making, civil commitment, forensics, criminality.
- k. Supported decision making.
- l. Restrictive clinical treatments (including restricted interventions).
- m. Alternatives to HRC review.
- n. Protection from Harm.

F. Documentation Requirements

For each meeting of the HRC, the chairperson shall ensure the meeting minutes summarize any discussion and input from the person supported and/or, if applicable, their legal representative regarding proposed rights restrictions, restricted BSPs and recommendations for follow-up. The minutes shall be maintained by the agency providing administrative support to the HRC. Minutes must be available for review upon request by DIDD.

- 1. Name of Committee.
- 2. Meeting Date.
- 3. Members present.
- 4. Non-voting attendees.
- 5. Chair Approval Signature.
- 6. Identifying Information.
  - a. Name of person.
  - b. Name of agency.
  - c. Name/title of presenter.

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 13 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

7. Purpose of the Review.
  - a. Initial, follow-up, and annual review of restricted BSPs.
  - b. Initial or follow-up review of restitution.
  - c. Initial, follow-up, and annual review of Emergency and PRN psychotropic medications.
  - d. Initial, follow-up, and annual review of other restrictions.
8. Resolution.
  - a. Issues adequately addressed.
  - b. Issues inadequately addressed.
  - c. Issues addressed with the following recommendations.
9. Actions necessary for resolution.
10. Date of follow-up.
11. Note whether informed consent was obtained.
12. In addition, restricted BSPs and other restrictions should include what the restrictions are and their justification.

G. Local HRC Disposition Requirements

The HRC must address all business issues brought before the committee in a timely fashion. Final recommendations must be provided no later than thirty (30) business days following presentation of the issue. Local HRC recommendations may be appealed to the Regional HRC.

H. Confidentiality and HIPAA

HRC members have a responsibility to keep information discussed during meetings confidential. All individuals attending an HRC meeting must sign a confidentiality agreement. Aside from HRC members, only those individuals directly involved with the issue being presented to the committee or speaking on behalf of the person, if

Effective Date: July 11, 2018	Policy #: 80.6.1	Page 14 of 14
Subject: HUMAN RIGHTS REVIEW PROCESS		

applicable, may attend the HRC meeting. Arrangements must be made to ensure that individuals attending for issues involving other persons supported do not have inappropriate access to confidential information. All HRCs must maintain minutes of the meetings; all confidential reports disseminated to committee members must be shredded immediately after the meeting.

I. Conflict of Interest

Any HRC member who is involved in a matter under review or consideration by the HRC shall not participate in the recommendation making processes pertaining to that matter and should excuse themselves from the review discussion. If a conflict of interest involves the chairperson of the HRC, another HRC member must be designated to serve as chairperson while such matter is under review or consideration. Staff employed or contracted by providers shall not be involved in decision making or review of matters concerning persons receiving services by their employer or concerning other employees of the same agency. The licensed practitioner of behavior analysis who developed a BSP or who will be responsible for ensuring implementation of a BSP may present the BSP however, he/she shall not be involved in the process of making decisions and/or recommendations regarding that BSP.

VII. **CQL STANDARD(S):** 1

VIII. **REVISION HISTORY:** June 6, 2018

IX. **TENNCARE APPROVAL:** December 19, 2017; June 7, 2018

X. **ATTACHMENTS:**

- A. Conflict of Interest and Confidentiality Statement for Committees/Councils  
DIDD-6021