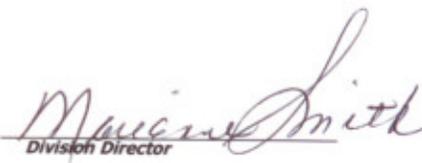


**Delaware Health and Social Services
Division of Developmental Disabilities Services
Dover, Delaware**

Title: Human Rights Committee

Approved By: 
Mavis Smith
Division Director

Written/Revised By: DDDS Records & Policy
Committee

Date of Origin: September, 1991

Revision Date: October 2008

I. PURPOSE:

To establish the roles and responsibilities of the Human Rights Committee (HRC).

II. POLICY:

It shall be the policy that the Stockley Center and Community Services Human Rights Committees (hereafter referred to as "the HRC"), shall serve in an advisory capacity to the Executive Director of Stockley Center and Directors of Community Services/Adult Special Populations.

III. APPLICATION:

- All DDDS staff
- All DDDS Contractors
- Human Rights Members (HRC) Members
- Individuals who live in a permanent DDDS supported residence (CS & SC)
- Individuals who attend DDDS supported day programs

IV. DEFINITIONS:

A.	<u>Advisory Capacity:</u> The status of the HRC function which does not have the authority or the responsibility to take definitive actions or render decisions, rather they advise or suggest action steps.
B.	<u>Consent:</u> A legal concept which has three elements: capacity, information, and voluntariness. Capacity is the ability to acquire or retain knowledge and the legal qualification or authority to perform an act. Information is full and effective disclosure of the nature of any procedure, its importance, and possible consequences. Voluntariness implies that the person understands they have the right to give consent, withhold consent or withdraw consent.
C.	<u>Level II behavior interventions:</u> Interventions which are considered to be more intrusive to the individual and may be imposed in ways that would (1) restrict or limit an individual's access to or interactions with others, items, or activities; (2) attempt to decrease excessive behavior that is either harmful or limits their meaningful interaction with the environment; (3) restricts their freedom of movement (e.g.: personal or mechanical restraint); or (4) use medication for the sole purpose of behavior management in the absence of a psychiatric diagnosis.
D.	<u>Liaison-</u> a representative of the DDDS who serves in an adjunct capacity to the members of the HRC and whose role is to provide support and technical assistance regarding the operations, philosophy and practices of the agency. The HRC liaison is responsible for reviewing the agenda for the meetings.
E.	<u>PROBIS (Peer Review of Behavioral Intervention Strategies):</u> Any of the Division-

approved peer review committees charged with the review and approval of multi-component Behavioral/Mental Health or Essential Lifestyle plans.
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- F. Surrogate a surrogate may only include the following individuals, in descending order of priority:
1. A legal guardian of person or other legally recognized agent assigned to make decisions for an individual in that individual's best interest when he/she is not competent or otherwise unable to give informed consent.
 2. A person identified by a mentally competent individual receiving services, to his/her supervising health care provider, in the presence of a witness. Such designation shall be documented by the physician and signed by the witness and such designation is documented in the person's record.
 3. Any member of the following classes of the individual's family who is reasonably available, in the descending order of priority, if the individual receiving services has been determined by his/her attending physician to lack capacity and the individual has no agent or guardian.
 - a. The spouse, unless a petition for divorce has been filed, or unless the patient has filed a petition or complaint alleging abuse, as defined in § 1041(1) of Title 10, of the patient by the spouse;
 - b. An adult child;
 - c. A parent;
 - d. An adult sibling;
 - e. An adult grandchild;
 - f. An adult niece or nephew.
- (Title 16 Del.C. §2507 and §1121-1122)*

V. STANDARDS:

- A. The HRC responsibilities shall be to:
1. review Level II Behavior Support Plans, subsequent to the PROBIS review, to ensure that appropriate informed consent has been received, due process has been afforded, the Human Rights Review Questions have been comprehensively answered, the proposed intervention reflects respect and dignity and the restrictions of rights or risk to protections are justified
 - a. **Stockley Center only**- reviews all restrictive procedure plans and psychotropic medication plans, in accordance with applicable facility policies.
 2. review, monitor and make recommendations to the DDDS about its practices and programs as they relate to protection of individual rights;
 3. review Individual Rights Complaint and DDDS findings to evaluate whether rights were violated and if appropriate action was taken, in accordance with the DDDS Rights Complaint policy;
 4. review individual rights restrictions, for people who are supported in a DDDS residential program and/or in a DDDS funded day program, after such restriction has been approved at the interdisciplinary team level, in accordance with the DDDS Individual Rights Review policy;

5. review, no less than annually, the restriction of an individual's right(s), in accordance with the DDDS Individual Rights Review policy and #6, above;
 6. focused reviews requested by the Executive Director of Stockley Center or Directors of Community Services and Adult Special Populations Programs.
- B. The HRC shall not be responsible for the clinical mechanics of a Behavior Support Plan, rather, that responsibility shall be assumed by the PROBIS committee due to their membership expertise.
 - C. The HRC shall operate under the immediate direction of the Director of Community Services or Executive Director of Stockley Center. The DDDS shall provide clerical support to the HRC.
 - D. The HRC members shall safeguard and protect all information shared within the context of HRC. The HRC shall not release information to outside agencies or person. Unauthorized disclosure of any confidential information gained within the context of the HRC shall be reason for immediate dismissal from the committee.
 - E. The HRC liaison shall ensure that all members sign the Human Rights Committee Confidentiality Statement (exhibit A) prior to his/her involvement with HRC and yearly, thereafter. The confidentiality statements shall be maintained by the HRC liaison.
 - F. The HRC member who represents the Disability Law Program (Protection and Advocacy) may disclose information in accordance with applicable Federal and State statutes.
 - G. A non-voting DDDS staff person shall be designated to serve as the HRC liaison, by the Director of Community Services or Executive Director of Stockley Center, as applicable, to advise on matters of regulation, agency philosophy and duties and responsibilities. He/she shall provide the HRC with the documents necessary to complete their assigned review.
 - H. The HRC shall be composed of a minimum of four (4) members. The Disability Law Program shall be extended the opportunity to serve as a member on each HRC. The remaining membership shall include individuals who are not directly employed by the DDDS; however, contractors or subcontractors to the DDDS may be considered for membership. Each member shall be appointed by the Stockley Center Executive Director or the Director of Community Services. NOTE: refer to ICF-MR regulations # 483.440 (f) (3) for limitations.
 - I. The presence of at least fifty-one percent (51%) of the HRC members, including the chair shall constitute a quorum for the official conduct of business.
 - J. The HRC chairperson shall be chosen by the HRC membership.
 - K. Any member of the HRC who does not attend three (3) consecutive meetings may be requested to resign from the Committee. This will be at the discretion of the Stockley Center Executive Director or the Director of Community Services.

- L. The HRC may adopt a position statement or resolution and make formal recommendations to the Executive Director of Stockley Center or the Directors of Community Services/Adult Special Populations regarding human rights.
- M. The minutes of the HRC shall be the official record of all business transactions and shall be distributed to all attending members for approval, at each subsequent meeting. Copies of the minutes shall be forwarded to the Director of Community Services/Adult Special Populations or the Executive Director of Stockley Center, as applicable.
- N. The minutes of Committee meetings shall be prepared by a DDDS clerical support staff person and include: 1) the date, place, and time, of the meeting; 2) the person presiding; 3) the names and titles of all members and guests as present or absent; 4) all motions (unless withdrawn) with the names of the persons making and seconding the motion; 5) the names of members voting in the minority (including all abstentions) and a synopsis of their position, and the names of attending member(s) not present during the vote; 6) all transactions, summaries of reports and appointments; 7) the time of adjournment; 8) signature of the chairperson; and 9) if available, the agenda for the next meeting.
- O. Any member, other than the HRC liaison may make or amend a motion. All motions, unless withdrawn, shall be considered by the HRC.
- P. The HRC shall make decisions by vote. Votes may be a show of hands, if general consensus is apparent, or by roll call of members. The approval of fifty one percent (51%) of the present membership shall be required to adopt a motion. The decision to limit an HRC member's participation in a particular review, based on a conflict of interest, shall be made by the HRC Chairperson in consultation with the liaison.

VI. PROCEDURES

Rights Restriction Review

Responsibility	Action
HRC Liaison	1. Receives Restriction of Rights form following team approval to restrict a right.
	2. Includes Restriction of Rights review on the next scheduled HRC agenda.
HRC	3. Endorses the restriction if due process was afforded, the rationale for the restriction is clearly stated, alternatives were attempted to avoid a rights restriction (if appropriate), plans are identified to help the person regain his/her right and the criteria is developed that defines when a right can be restored. OR
	4. Decides not to endorse a rights restriction and offers rationale for the decision and recommendations on how to better address the situation.
	5. Forwards non-endorsed Restriction of Rights Form to the Director of Community Services or the Executive Director of Stockley Center, as applicable, for his/her review and

	decision.
Rights Complaints Review	
HRC	1. Reviews sections A and B of the Rights Complaint form and prepares an opinion statement to include if the corrective/preventive action taken was appropriate and any further recommendations, as applicable.
	2. Forwards written opinion statement to the designated DDDS Rights Complaint Designee.
Review of Level II Behavior Support Plans	
HRC Liaison or Administrative Support Staff	1. Receives Level II Behavior Support Plan for initial review and schedules review at the next HRC meeting. a. Stockley Center only- receives all restrictive procedure plans and psychotropic medication plans
HRC Clerical Support	2. Notifies the assigned Case Manager/Social Worker/QMRP and Psychological Assistant/Behavior Analyst of review date and time.
HRC	3. Copies all related documents and distributes to members, at the HRC meeting.
HRC	4. Reviews Behavior Support Plan, the corresponding consent and the answers to the HRC questions (refer to V.A.1. and V.B. of this policy). a. Stockley Center only- also reviews all restrictive procedure plans and psychotropic medication plans with the corresponding consent and answers to the HRC questions.
HRC Chairperson	5. Sends written communication and the Behavior Support Plan Review packet, to the Director of Community Services or Executive Director of Stockley Center to advise of the recommendations/outcome/endorsement of the plan, by the HRC. 6. If Behavior Support Plan Review is endorsed, schedules a re-review within 365 days. 7. Presents Behavior Support Plan Review to the HRC, if re-presented with initial recommendations implemented.

VII. SYNOPSIS:

This policy establishes the roles and responsibilities of the Human Rights Committees. It aligns the committees directly with the applicable Executive Director of Stockley Center, Director of Community Services or Director of Special Populations. The HRCs serves in an advisory capacity to each of the aforementioned administrators.

VIII. REFERENCES:

Title 16 Del C. §1121-1123
 DDDS Administrative Policy Manual, Consent Policy
 DDDS Administrative Policy Manual, Individual Rights Review, revision date January 2003 or the most current policy revision

DDDS Administrative Policy Manual, Individual Rights Review policy
DDDS Administrative Policy Manual, Rights Complaint policy
DDDS Administrative Policy, Behavior/Mental Health Support Policy
Stockley Center Policy, Health Related Protection
Stockley Center Policy, Programming and Medication Review Committee (PMRC)

IX. EXHIBITS:

- A. Confidentiality Statement
- B. Guidelines for Establishing Informed Consent for Behavior/Mental Health Support Plans
- C. Human Rights Committee Questionnaire
- D. Restriction of Rights Form

EXHIBIT A

Human Rights Committee
Confidentiality Statement

I, _____, understand that all information discussed within the context of the Human Rights Committee (HRC) is confidential in nature. I further understand and agree that it is my personal responsibility to protect and safeguard against the disclosure of the said information outside the boundaries of HRC business.

I further understand that information that is disseminated for the purpose of HRC business shall not be duplicated in any form. HRC documents, with the exception of HRC meeting minutes, shall be returned to DDDS upon completion of the associated task.

Signature of HRC Member

Date of Signature

Signature of HRC Liaison

Date of Signature

08/Admin
PARC Approved- February 01, 2003

**Guidelines For Establishing Informed Consent
for Behavior/Mental Health Support Plans**

The process of establishing informed consent involves significantly more than simply obtaining a signature on a document. A signature on a document, which is void of any of the elements of informed consent, merely represents an accountability procedure. While it is true that a person can never be totally informed and consent is a matter of degree, a good faith effort must be exerted in an attempt to obtain informed consent. "The issue of informed consent is central; without it, empowerment cannot be achieved and the client's best interest is only approximated, if not jeopardized." (Social Work, 1991, p. 126).

The Division of Developmental Disabilities Services strongly believes that mere accountability procedures cannot and should not serve as a replacement for an individual's right to make an informed decision (or be represented for such), consequently restricting their right to empowerment. It is for this reason, therefore, that the Division of Developmental Disabilities Services embraces the following definition and explanation of informed consent.

"Three conditions must exist before informed consent can be given (1) The person must be capable of understanding the circumstances and factors surrounding a particular consent decision; (2) information relevant to the decision must be forthrightly and intelligibly provided to the person; (3) the person must be free to give or withhold consent voluntarily." (Understanding the Law- An Advocate's Guide to the Law and Developmental Disabilities, 1980, p. 10).

The first condition of informed consent, capacity, involves the individual's ability to engage in the process of rationale decision making skills (i.e., evaluate information and respond in accordance to that evaluation). Issues that need to be considered when determining if capacity exists include the person's age, degree of legal competency and the potential ramifications of the particular situation.

The second, yet, equally important condition of informed consent includes the information offered. Consent is ultimately uninformed if the decision maker does not have complete and understandable information relative to the matter for which consent is sought. The Division of Developmental Disabilities Services is committed to extending a concerted effort to deliver information which is both comprehensive and understandable in nature.

The final condition of informed consent includes an individual's voluntariness to consent, withhold or rescind their consent to a proposed or active procedure/program. "Voluntariness consists of the absences of overbearing coercion, duress, threats or inducements, and undue influence. In all cases, the test is whether the person whose consent is sought has been obliged to act against his will because of external persuasion or compulsion." (Consent Handbook, 1977, p. 11).

The Division of Developmental Disabilities Services acknowledges that there are no absolute measures of informed consent, however, they also recognize the need for professionals to extend a good faith

effort to meet all three conditions; capacity, information and voluntariness. So as to facilitate the effectiveness of obtaining informed consent, the Division of Developmental Disabilities Services requires that interdisciplinary teams implement the following procedural guidelines:

- I. The team must first determine if the individual receiving services has the ability to give consent for the proposed procedure/program. Refer to the three elements of informed consent on the previous page to determine if all of the requirements are met. It is important to remember that informed consent is relative to the situation at hand. A person may not be able to understand the complexity of a health care directive, yet, can demonstrate adequate understanding of their Behavior/Mental Health Support Plan.
- II. The individual's inability to consent to the particular procedure/program must be documented in the Client Oriented Record (COR) or Therap document by both the ID team chairperson and the prescribing or primary physician.
- III. The team must identify a surrogate if it has been determined that the individual receiving services lacks the ability to consent to a particular procedure/program and he/she does not have a guardian of person or other person legally authorized to make decisions. Pursuant to the Delaware Code, Title 16, section 2507, the following shall apply relative to the identification of a surrogate:
 - (2) In the absence of a designation or if the designee is not reasonably available, any member of the following classes of the patient's family who is reasonably available, in the descending order of priority, may act, when permitted by this section, as a surrogate and shall be recognized as such by the supervising health-care provider:
 - a. The spouse, unless a petition for divorce has been filed;
 - b. An adult child;
 - c. A parent;
 - d. An adult sibling;
 - e. An adult grandchild;
 - f. An adult niece or nephew.

Individuals specified in this subsection are disqualified from acting as a surrogate if the patient has filed a petition for a Protection From Abuse order against the individual or if the individual is the subject of a civil or criminal order prohibiting contact with the patient.
- IV. If none of the aforementioned relatives are reasonably available or if they are unwilling/uninterested to assume the responsibility of a surrogate, specific supporting documentation must be entered into the individual's COR/Therap document.

- V. If the individual receiving services has a legally appointed guardian of person, informed consent must be sought from that person rather than the individual receiving services or a surrogate.
- VI. If the individual receiving services lacks the ability to give informed consent and he/she has no surrogate, the Office of the Public Guardian should be contacted and an application for guardianship initiated.
- VII. The Case Manager/Social Worker and the Nurse Consultant and/or the Behavior Analyst shall make telephone or personal contact with the person from whom consent is being sought. All of the information contained in the Behavior/Mental Health Support Plan is explained to the person whose consent is sought, in laymen's language. The explanation shall minimally include a complete description of the dynamics of the proposed procedure/program, benefits to be expected, possible side effects and risks, alternatives to the proposed procedure/program, the rationale for the proposed procedure/program, the duration of the proposed procedure/program, and instruction that the individual is not bound to submit to consent and may freely, without consequence to themselves or others, rescind the consent. An offer shall be extended to answer any concerns or questions from the individual from whom consent is sought. Arrangements shall be made to provide other educational materials to the person from whom consent is sought, as requested. Verbal consent shall be documented in the person's COR/Therap document.
- VIII. If the person from whom consent is sought is agreeable to the proposed restrictive procedure/program, the entire Behavior/Mental Health Support Plan, as submitted to PROBIS, is provided to them for their review. A cover letter shall be attached, which serves as a synopsis of the plan and the telephone conversation/personal contact (refer to VII above). If the use of medication is involved, the applicable information from a laymen's text shall accompany the cover letter and Behavior/Mental Health Support Plan.
- IX. In approximately one week from the date that the aforementioned information is mailed/delivered to the person from whom consent is sought, the Case Manager/Social Worker shall again make contact to re-confirm that the individual possesses understanding of the proposed procedure/program and continues to be in agreement with it.
- X. The Case Manager/Social Worker shall ensure that the dated, time limited Informed Consent Agreement is returned with the appropriate signature.

REFERENCES:

Social Work, National Association of Social Workers, Vol. 36, Number 2, March 1999

Understanding the Law- An Advocate's Guide to the Law and Developmental Disabilities, Syracuse University and the Mental Health Law Project, 1980

Consent Handbook, American Association on Mental Deficiency, 1977

Title 16 Del. C. Section 2507



Exhibit C

**DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES
Human Rights Committee Questionnaire**

1. Will any of the individual's human rights be restricted by the proposed support approach? If so, what efforts are being taken to return control of the right(s) to the individual? (Please be specific)
2. If the individual is unable to give informed consent, what necessary condition(s) did not exist? What efforts are being made to assist the person to satisfy the said condition(s)? (Please be specific)
3. In your best professional judgment, did the surrogate/guardian meet all three (3) conditions of informed consent as defined in exhibit B of the Human Rights Committee policy?
4. What alternative support approaches were offered if the surrogate/guardian declined the initial proposal?
5. How does the proposed support approach incorporate personal choice/preference?
6. What mechanism will be implemented to ensure that the decision-maker, either direct or substitute, will be periodically advised of progress, problems, etc. relative to the support approach?

Signature: _____
Presenting Team Member

Date: _____

HRC endorsement date: _____

endorsed

not endorsed

recommendations offered

Rationale for not endorsing and/or recommendations offered by the HRC: _____

HRC signature: _____
Chairperson

Date: _____



EXHIBIT D

**DELAWARE HEALTH & SOCIAL SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES**

RESTRICTION OF RIGHTS FORM

Name: _____ **MCI Number:** _____

Date: _____ **Residence:** _____

I. Right(s) Being Restricted:

II. Reasons For Restriction:

III. Past Efforts To Support The Individual To Exercise This Right Without Restriction:

