

**Delaware Health and Social Services
Division of Mental Retardation
Dover, Delaware**

Title: Consent

Approved By: *Maurice Smith*
Division Director

Written/Revised By: DMR Policy Committee

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I. Purpose

To establish standards and procedures for the protection of the rights of an individual receiving services, including: freedom of choice and self determination

II. Policy

Consent of the individual receiving services is obtained for any activity or procedure which presents significant risk to, has potentially irreversible impact on, or is physically, psychologically or socially intrusive to the client.

III. Application

Interdisciplinary Team Members
Stockley Center Superintendent
Community Services Regional Administrators
Community Services Program Directors

IV. Definitions

- A. Consent: Voluntary agreement by a person in the possession of sufficient mentality to make an intelligent choice to do something proposed by another person. The three elements of consent are: 1) the capacity to understand and make choices; 2) the information on which the consent decision is based (which must be intelligently presented to the person); and 3) the voluntariness of the decision.
- a. Direct Consent: The agreement of the person directly affected, receiving services from the Division of Mental Retardation.
- b. Substitute Consent: Agreement by a third party not directly affected.
- B. Experimental Research: Procedure and study based on hypothesis not tested or proven through controlled experimentation under reasonably similar condition.
- C. Substitute Decision-maker: a person appointed by a Court or recognized by family relationship to determine whether to give, withhold, or withdraw consent on behalf of an individual receiving services for an activity or procedure. A substitute decision-maker may be the individual's legal or natural guardian, legal custodian, or next-of-kin.
- D. Emergency Treatment: Immediate action required to preserve the life or bodily integrity of the individual receiving services or other persons.

- E. Person Initiating a Procedure/Activity Which Requires Consent: For the purpose of this policy, the Division of Mental Retardation professional responsible for the service domain in which the procedure/activity falls (for example: a Behavior Analyst of Case Manager for a behavior modification program; the Stockley Center Physician or Community Services Nurse for a medical procedure; the Activity Therapist for camp participation; etc.).
- F. Service Provider: a community based professional or agency, not part of the Division of Mental Retardation who will implement/supervise a procedure/activity for which consent is required.

V. Standards

- A. Consent shall be required for:
 - 1. Participation in experimental research;
 - 2. Release of information from individuals' records to persons not authorized by law to receive it;
 - 3. Any behavior modification program where restraints, time-out devices or aversive stimuli are used;
 - 4. Use of behavior modifying drugs, pursuant to DMR policy;
 - 5. HIV testing instances required as per Delaware Code;
 - 6. Any activity or program when consent is required by other policy;
 - 7. Contracts involving payment or exchange of value;
 - 8. Medical treatment/elective surgery/diagnostic procedures;
 - 9. Admissions to programs and residential settings;
 - 10. Educational programming;
 - 11. Legal representation.
- B. Unless otherwise specified by policy, determination of the need for consent for a particular activity/procedure shall be the responsibility of the service provider proposing the activity or procedure in coordination with the individual's Stockley Center Social Worker or Community Services Case Manager. Consent for treatment required for procedures recommended by service providers, such as community based physicians, shall be processed through this policy by the Stockley Center Physician or Community Services Nurse acting as the "person initiating a procedure/activity which requires consent".
- C. Consent shall not be required for an emergency treatment.
- D. Consent for procedures/activities shall be obtained in accordance with this policy, other DMR policies covering consent for specific procedures/activities (see references), and the policies of community based service providers who will implement/supervise the procedure/activity requiring consent.
- E. Consent shall be time limited. The duration of a consent shall be:
 - 1. The time period specified in the consent, or
 - 2. The time period implied by the objectives of the activity or procedure,
 - 3. The time period implied until completion of the activity or procedure.
- F. Unless exempt by other policies covering consent for specific procedures/activities, consent shall be renewed prior to resumption of a discontinued activity or procedure.
- G. The individual receiving services and his representative shall be appropriately involved in the decision making process for activities and procedures requiring consent.

- H. The Interdisciplinary Team shall determine the type of consent, direct or substitute, to be sought for the specific situation based upon an assessment of the risk of intrusiveness of the proposed activity/procedure, the individual's capacity to understand and make choices, the complexity of the information, and the individual's opportunity to make a voluntary decision. As the individual's mental incapacity, lack of information, or unwillingness increases, and as the risk, intrusiveness, or irreversibility of the procedure/activity increases. The effectiveness of consent shall become subject to closer scrutiny and the formality of the consent process shall increase. **(AAMD, Consent Handbook)**
- I. In the consent process the Social Worker shall serve as the individual's or substitute decision-maker's/advocate and as the agency's representative, balancing the client's substitute decision-maker's right to decide and to refuse treatment against the agency's obligation to provide treatment. The Social Worker shall be responsible for requesting and obtaining consent; and ensuring that the three elements of consent are present in any decision to give, withhold, or withdraw consent.
- J. The information regarding the proposed procedure/activity for which consent is sought shall be presented to be understood by the decision-maker. Information shall include:
1. A full, balanced, and fair presentation of the facts, risks, benefits, and alternatives;
 2. An offer to answer any questions
 3. An instruction that consent for ongoing activities/procedures may be freely withdrawn in writing at any time;
 4. And, the identification of any procedure/activity which is experimental. Other Division of Mental Retardation policies regarding consent for specific procedures/activities shall be followed, including the core of information to be provided and format of presentation.
- K. If the individual or substitute decision-maker is unable to read, the written explanation of the activity/procedure and the written consent form shall be read and explained by the Stockley Center Social Worker/Community Services Case Manager in the presence of another staff member as witness.
- L. If substitute consent is required and the decision-maker cannot appear in person to give or withhold consent, the information may be presented to him/her by personal visit or conference telephone call. In the instance of telephone contact, the information about the activity/procedure, and the consent form shall be mailed to obtain signature.
- M. Consent shall be obtained in writing and maintained in the individual's master file and record.
- N. Verbal consent may be obtained in those instances when:
1. Verbal consent is sufficient, as specified by policy;
 2. Written consent cannot reasonably be obtained in person or via mail soon enough to avoid delay of the procedure/activity which could likely result in harm to the individual or others.
- O. When verbal consent is sought to avoid delay of the procedure/activity (as in Standard 0.2 above);
1. The agreement of the service provider/and or the person initiating the procedure/activity to accept verbal consent shall be obtained before the consent is requested;
 2. The reasons necessitating the request for verbal consent shall be included in the documentation of consent;
 3. The verbal consent shall be witness by two staff persons, and their signatures included in the consent documentation;
 4. Written consent to follow-up the verbal consent shall be obtained within 30 days of receipt of verbal consent.

- P. Verbal consent shall be documented as required by specific consent policies; or in the absence of specific requirements, on the bottom of the appropriate written consent form.
- Q. If substitute consent is required and efforts to seek or involve a substitute decision-maker on the individual's behalf have failed;
 - 1. The individual's Stockley Center Social Worker/Community Services Case Manager shall document those efforts in the Interdisciplinary Notes/Data Base of the individual's record;
 - 2. As determined appropriate by the individual's team and the Division of Mental Retardation Administration, the Stockley Center Social Worker/Community Services Case Manager shall file for a Court determination of the individual's competency and the appointment of a legal guardian;
 - 3. If in the opinion of the individual's team, the individual or other persons are at risk without the immediate implementation of the proposed procedure, the matter shall be referred to the Division of Mental Retardation Administration by the individual's Stockley Center Social Worker/Community Services Case Manager.
- R. An individual or his/her substitute decision-maker shall have the right to refuse consent for a proposed activity or procedure. The Division of Mental Retardation has the right to appeal the refusal to a court of competent jurisdiction for adjudication.

VI. Procedures

| <u>Responsibility</u> | <u>Action</u> |
|---|--|
| Person initiating a procedure/ activity which requires consent | 1. Notifies the Stockley Center Social Worker/Community Services Case Manager of the proposed procedure/activity that requires consent. |
| All Staff | 2. Follows other consent policies applicable to the procedure/activity, completing documentation and forms as required. (see references) |
| Interdisciplinary Team (including Behavior Analyst) | 3. For adult individuals receiving services without a court appointed legal guardian, decides whether the individual has the capacity to understand the implication of the proposed procedure/activity and make an informed, voluntary consent decision. |
| | 4. Based upon the assessment and decision in Step 3, decides whether direct or substituted consent is appropriate. |
| Interdisciplinary Team Chairperson | 5. Records in Team minutes and in I.D. Note for the individual's record, the decisions made in Steps 3 and 4 and the participants involved. |
| Stockley Center Social Worker/ Community Services Case Manager | 6. Notifies the individual's family of the proposed procedure/activity of the plan to seek direct or substitute consent. |

Stockley Center Social Worker/
Community Services Case Manager
Initiating procedure/activity

7. If direct consent is sought:
 - a. Meets with the individual to discuss the proposed procedure/activity, in accordance with Standard J.
 - b. Facilitates/arranges discussion between the individual and the services provider who will actually implement/supervise the procedure/activity, as the individual desires.
 - c. If the individual is in agreement with the procedure/activity, obtains his written authorization on the appropriate consent form.
 - d. Ensures the individual's consent is witnessed with the date and time recorded, as required by the consent form.
 - e. Writes an I.D. Note on the discussion held with the individual and documents the individual's decision.
 - f. Notifies the individual's family of the decision.
8. If substitute consent is sought:
 - a. Meets with the substitute decision maker or holds conference call to discuss the proposed procedure/activity, in accordance with Standard K.
 - b. Facilitates/arranges discussion between the substitute decision-maker and the service provider who will actually implement/ supervise the procedure/activity, as the client desires.
 - c. If verbal consent is requested and obtained, documents the reasons necessitating the request for verbal consent and the consent if received on the bottom of the consent form or in the format required by another specific policy.
 - d. If the substitute decision-maker is in agreement with the procedure/activity, obtains his written authorization on the appropriate consent form either in-person or via the mail.
 - e. Ensures the substitute decision-maker's consent is witnessed with the date and time recorded, as required by the consent form.
 - f. Writes an I.D. Note on the discussion(s) held with the substitute decision-maker; the actions taken, including use of the mail and conference call(s), to obtain consent; and the decision made.
9. If written consent is not received via mail as expected, calls substitute decision-maker to discuss situation and facilitate receipt of written consent.
10. Upon receipt of written consent for a DMR procedure/activity, forwards original signed consent form to Central Records for the Master File and a copy to the person initiating the procedure/activity.

Stockley Center Social Worker/
Community Services Case Manager

Interdisciplinary Team*
And person initiating procedure/
activity *(including Stockley Social
Walker/Community Services Case
Manger

Stockley Center Social Worker/
Community Services Case Manager

(S.C.) Director of Social Services/
Community Services Regional
Program Director

Stockely Center Social Services
Community Services Case Manager

(S.C.) Director of Social Services
Community Services Regional
Program Director

(S.C.) Superintendent/Community
Regional Administrator

Stockley Center Social Worker/
Community Services Case Manager

11. When written consent is received for a community based procedure/activity, forwards original to the service provider implementing supervising the procedure/activity and a copy to Central Records for the Master File.
12. When consent is with held:
 - a. Notifies the Interdisciplinary Team and the person initiating the proposed procedure/activity of the decision to withhold consent.
 - b. Discussed the implications of the decision to withhold consent and identifies any concerns with warrant administration views.
 - c. Informs (S.C.) Director of Social Services or Regional Program Director of any decision to withhold consent, and of Team concerns as identified in Step 12-b.
 - d. In cases of Team concern with a decision to withhold consent, reviews with the (S.C.) Social Worker/Community Services Case Manager the information and intervention the decision-maker received to identify any additional work to be done to ensure the decision is based on a thorough understanding of all the treatment factors involved.
 - e. Works with decision-maker as directed by (S.C.) Director of Social Services/Community Services Regional Program Director and notifies this supervisor of outcome.
 - f. Informs the S. C.) Superintendent/ Community Services Regional Administrator of the continued decision to withhold consent and of the Team's concerns.
 - g. Reviews the situation and notifies the (S.C.) Director of Social Services/Community Services Regional Program Director of any decision to seek judicial review.
13. Keeps decision-maker informed of DMR's concerns and decision.

VII. References

Consent Handbook, American Association of Mental Deficiency, 1997
DMR Policies Covering Consent for Specific Procedures/Activities;

Division Policies

Consent for Elective Surgery

Client Eligibility Determination for Home and Community Based Services

Stockley Center Policies

Consent for Use of Behavior Modifying Drugs

Medical Transfers to Community Facilities

Dental Screening and Treatment

Summer Camps

Admissions

Client Funds

Infection Control

Respite Services at Stockley Center

Client Death

Community Services Policies

Individual funds

Emergency Medical Care

Behavior Management Techniques

VIII. Exhibits

None