

State of Connecticut
Department of Developmental Services
Health Standard # 09-2
Guidelines for Deferred, Limited, or Declined Health Care

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Author: Directors of Health Services

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Contact Person: David Carlow,
DMR Director of Health & Clinical Services

PURPOSE: The intent of this Health Standard is to identify the best practice guidelines that are to be applied when health care providers, individuals, and/or guardians decide to defer, limit, or decline health care.

APPLICABILITY: This health standard is applicable to all individuals for whom the department bears direct or oversight responsibility for their medical care. It is to be applied to the planning and coordination of care for persons residing in residential placements and those receiving individual supports.

DEFINITIONS:

Deferred – means the act of putting off for a future time.

Limited- means restricted scope of intervention

Declined- means rejected or refused to accept

INTRODUCTION: One of the responsibilities of the DDS Commissioner is to assure that persons placed or treated under the direction of the Commissioner receive prompt, sufficient and appropriate medical and dental treatment. With few exceptions, neither the DDS Commissioner, nor other DDS officials, have the authority to make medical decisions, the statutes vest a significant medical care oversight function in the Commissioner and DDS. Persons with intellectual disabilities are entitled to the same preventive health care and treatment considerations as non-disabled persons. Sometimes, decisions are made to defer or limit health screenings and interventions or to decline the care or treatment options that are provided for a person with intellectual/developmental disabilities. These decisions may be made by the person, the person's family/guardian, and/or the person's health care provider. The basis for these decisions may include a lack of understanding about the person or about the recommended care, fear of the process, a perceived lack of cooperation, and/or other personal reasons. It is important that the person is looked at as an individual and that choices about care are made on the basis of the person's best interest and not influenced solely on the basis of his/her diagnosis of intellectual/developmental disabilities or ability to cooperate. This standard will identify the role of the team to ensure that the person receives adequate health care while respecting the decision made by the person or his/her family/guardian, as applicable.

STANDARD: The team supporting the person with intellectual/developmental disabilities shall review all decisions to defer, limit or decline preventive and/or recommended health care and identify a plan to advocate for, educate, and/or support the person as necessary to promote his/her health and safety.

Implementation:

1. When notified that a decision has been made to defer, limit, or decline recommended health screenings and/or care, the person's support team shall ensure that the reason for this decision is reviewed.
 - a. If the decision is made by the person, the support team shall identify one or more members to be responsible for discussing this matter with the consumer.
 - The person may require more information/simpler explanation of the procedure or treatment

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that is recommended before consent is given

- The person may be fearful and require additional preparation and/or supports to assist him/her to complete the testing or treatment process (i.e., desensitization, presence of favored staff person at appointment, counseling)
 - The person may need to be assisted to understand the consequences of his/her decision.
- b. If the decision is made by the family/guardian, the team should recommend that the person's health care provider is notified and the implications of this decision are discussed if this has not already occurred. The family/guardian may need to be assisted by the team to understand other actions which could assist the person to better tolerate the procedure.
- c. If the decision is made by the health care provider, the support team shall identify a member to be responsible for making contact with the provider to determine the reason for the deferral or limitation of care
- If problems were encountered that relate to inadequate preparation of the individual for the appointment, the procedure should be rescheduled as soon as possible and the staff advised of the new appointment and the prescribed preparation.
 - If the treatment/procedure was not able to be done because of challenging behavioral difficulties or other problems encountered, the issues should be identified and the team should work with the health care provider to determine if the treatment/procedure can be rescheduled or accomplished under different circumstances, and/or with additional supports (i.e., desensitization, increased staff supports, pre-sedation, use of anesthesia).
 - The health care provider may need to be advised about the recommended preventive care guidelines of the department. Refer to DDS Health Standard # 08-1.
 - The health care provider may need for additional information about the person (i.e., health history, family history)
 - The health care provider may need assistance to understand the abilities of the person to make informed health care choices
2. Depending on the seriousness of the decision to defer, limit, or decline health screenings or care, an identified team member should notify the regional Health Services Director/ Public Service Nursing Director of this matter so that the implications can be reviewed and a plan can be recommended to the person's support team. This plan may include consideration of a second opinion by another health care provider or other possible intervention.
3. Documentation of the decision to defer or limit health care , the reason for the decision, and all actions taken to assist the person, family/guardian, and/or the health care provider with this decision should be included in the person's record. All actions by team members to advocate for the person should also be documented.

NOTE: Not all medical decisions require informed consent of the person or a guardian, i.e., routine, non-invasive medical or dental procedures. Although every effort is made to inform the person and family/guardian of such events, and obtain consent or approval, the Commissioner's obligation in assuring prompt, sufficient and appropriate medical care requires "informed consent" only when required by law, e.g., for non-routine medical treatment, invasive treatment, treatment presenting competing benefits and risks, etc.