I. **AUTHORITY:** Tennessee Code Annotated (TCA) 4-3-2708, Code of Federal Regulations (CFR) 42 § 483.420.

II. **PURPOSE:** The purpose of this policy is to establish a process for conducting systematic reviews of deaths of persons with intellectual or developmental disabilities for whom the Department of Intellectual and Developmental Disabilities (DIDD) and private ICFs/ID provide services in Tennessee; to identify factors which may have contributed to the death; to recommend necessary preventive measures; and, to improve supports and services for all persons in the system.

III. **APPLICATION:** This policy applies to all DIDD staff, service providers, and individuals who are responsible for reporting deaths or participating in the systematic review of the death. Deaths of individuals participating in all programs operated by DIDD which are funded by the State of Tennessee or by the Title XIX Medicaid Program are covered by this policy.

IV. **DEFINITIONS:**

A. **Class Member** shall mean an individual meeting the requirements in the definition of the class specified in the People First of Tennessee, et al vs. the Clover Bottom Developmental Center, or The United States of America vs. State of Tennessee, et. al. (Arlington Developmental Center).

B. **Clinical Death Summary** shall mean a written report by a qualified registered nurse regarding the circumstances surrounding an individual’s death that includes information such as services received or omitted, significant events, healthcare and medication histories, cause of death and autopsy findings (if available), and other information relevant to the death.

C. **DIDD Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID)** shall mean Department of Intellectual and Developmental Disabilities (DIDD) state owned and operated facilities for persons with intellectual disabilities.

D. **Health Insurance Portability and Accountability Act** (HIPAA) Privacy Rule establishes national standards to protect individuals’ medical records and other personal health information and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. The Rule requires appropriate safeguards to protect the privacy of personal health information, and sets limits and conditions on the uses and disclosures that may be made of such
information without patient authorization. The Rule also gives patients rights over their health information, including rights to examine and obtain a copy of their health records, and to request corrections.

E. **Home and Community-Based Services Waiver or Waiver** shall mean a Home and Community Based Services waiver for persons with intellectual disabilities that includes the following:

1. Home and Community-Based Services Waiver for the Mentally Retarded (now referred to as Intellectual Disabilities) and Developmentally Disabled (0128.R04) and any amendments thereto;

2. Home and Community-Based Services Waiver for Persons with Mental Retardation (referred to as Intellectual Disabilities) (0357.R02) and any amendments thereto; and

3. Tennessee Self-Determination Waiver Program (0427.R01) and any amendments thereto.

F. **Independent Review by a Qualified Physician** shall mean a medical review of a death covered under this policy through which a qualified physician unaffiliated with treatment of deceased individual will conduct a detailed medical review of the records to render evidenced based, objective determinations as to the cause of death and associated contributing factors.

G. **Preliminary Death Review Team** shall mean a designated group of persons in the DIDD Regional Office that includes the Regional Office Director of Nursing or designee, Regional Office Director or designee, and the Regional Office Compliance Director or designee who review initial information about a death to determine if it meets criteria for a death review.

H. **Private Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID)** shall mean intermediate care facilities for persons with intellectual disabilities that are owned and operated by entities other than the state.

I. **Unexpected or Unexplained Death** shall mean any death that did not result from the normal progression of a known medical condition or disease, including but not limited to healthcare or emergency intervention that is inappropriate, untimely, or inconsistent with physicians’ orders, advance directives, or applicable policies or standards governing withholding of medical treatment.

V. **POLICY:** Entities serving persons with intellectual and developmental disabilities who are supported by HCBS waiver or other community programs funded through DIDD, by DIDD ICFs/ID and by private ICFs/ID are responsible for reporting the death of such supported persons to DIDD and for complying with the DIDD Death Review process.
VI. PROCEDURES:

A. Reporting a Death

1. Death incidents shall be reported in accordance with the following:

a. Deaths in HCBS waiver programs or other DIDD community programs and private ICF/IDs are reported in accordance with the DIDD Provider Manual Chapter 18 Protection from Harm. Notifications include:

1) Within four hours of awareness of the death:
   a) For private ICFs/ID: Notice to the private ICF/ID Director or designee and Regional Office Administrator of the Day.
   b) HCBS Waiver programs/community programs: Notice to the Regional Office Administrator of the Day.
   c) If the death is suspicious (alleged abuse or neglect involved), unexpected or unexplained, notice to the DIDD Investigations Hotline.
   d) Notice to the person’s family, next of kin, and/or legal representative as soon as possible.

b. Deaths in DIDD ICFs/ID are reported in accordance with Policy #100.1.1 Protection from Harm in Public Intermediate Care Facilities for Persons with Intellectual Disabilities. Notifications include:

1) Within one hour of awareness of the death:
   a) For DIDD ICFs/ID: Notice to the DIDD ICF/ID Director or Chief Officer or designee or Administrator of the Day.
   b) If the death is suspicious (alleged abuse or neglect involved), unexpected or unexplained, notice to the DIDD Investigations Hotline.
   c) Notice to the person’s family, next of kin, and/or legal representative as soon as possible.
Subject: Death Reporting and Review Policy

2) By the next business day:
   a) Reportable Incident Form to the DIDD Central Office, Regional Office Director and the person's Independent Support Coordinator Agency or Support Coordinator.
   b) Notice of Death Form to the Regional Office Director.
   c) Commissioner.

3) If the death is the result of a suspected crime, the DIDD IFC/ID Director or Chief Officer shall contact local law enforcement and the Department of Health within one hour of awareness of the death.

2. Where the deceased individual had more than one provider, the priority order for determining the agency responsible for reporting the death, from highest to lowest, would be as follows, if applicable:
   a. The provider of Residential Services.
   b. The provider of Day Services.
   c. The provider of Personal Assistance services.
   d. The Independent Support Coordinator.
   e. The DIDD Regional Office.

3. Notification of law enforcement or the medical examiner: Regardless of setting, the designated staff at the DIDD Regional Office or private ICF/ID shall notify law enforcement or the medical examiner immediately if the death occurred suddenly when the person was in apparent good health, if the death occurred in a suspicious, unexpected, or unexplained manner or if the death is the result of a suspected crime.

B. Preliminary Death Review

1. If the decedent is a class member and residing at Clover Bottom Developmental Center or Green Valley Developmental Center at the time of death, a Death Review will be conducted. Therefore, a Preliminary Death Review is not applicable.

2. Within five (5) business days of receipt of a Notice of Death, the Preliminary Death Review Team shall conduct a Preliminary Death Review to determine if the death meets criteria for Unexpected or Unexplained under the following circumstances:
   a. The Death was of a Class Member in a DIDD ICF/ID (e.g., 4, 6, or 8-person home).
b. The Death was of a person receiving residential services through a Home and Community-Based Services (HCBS) waiver program, other community program administered by DIDD or was residing in a private ICF/ID.

3. A Clinical Death Summary by a DIDD or contract registered nurse and a DIDD Death Review by the Death Review Committee shall be completed for any death determined to be unexpected or unexplained. Once the process of preparing a Clinical Death Summary and initiating a Death Review has begun, the Preliminary Death Review Team has completed its responsibilities and shall not consider any additional information.

C. Clinical Death Summaries

1. A Clinical Death Summary shall be completed for the following deaths:

   a. Any death of a Class Member.

   b. Any Unexpected or Unexplained death as determined by the Preliminary Death Review Team.

2. The Clinical Death Summary shall be completed within thirty (30) calendar days of the death by the DIDD Regional Nurse (registered) or a qualified, independent registered nurse. This time period may be extended for good cause with the approval of the Central Office (CO) Director of Nursing. The DIDD CO Director of Nursing is responsible for making arrangements with the independent registered nurse, when applicable.

3. Clinical Death Summaries shall be distributed by the regional mortality nurse or designee immediately upon completion to the following:

   a. The DIDD Central Office Nursing Director.

   b. The DIDD Regional Office Director.

   c. The DIDD Regional Compliance Director.

   d. The Executive Director of the provider agency primarily responsible for serving the individual, if applicable.

   e. The Chief Administrator/Chief Officer of the DIDD ICF/ID, if applicable.

   f. The Chief Administrator of the private ICF/ID, if applicable.
D. **Initial Agency Death Review**: The purpose of the Initial Agency Death Review conducted by the agency is to identify any preventable and systemic conditions or practices that may have contributed to the death of a person that requires immediate intervention in order to protect other individuals from similar untoward events. The review must include a review of events surrounding the death, identification of known or likely contributing factors, and review of any other required information. Examples of such conditions or practices might include environmental hazards, a delay in emergency response or in seeking medical intervention, or abusive or neglectful conduct on the part of staff or others. The Initial Agency Death Review conducted by the agency is not expected to resolve all outstanding issues but may be used to identify questions or concerns to be addressed in subsequent investigations and proceedings.

1. When the death involves an individual receiving a residential service, the residential provider agency shall immediately initiate an Initial Agency Death Review.

2. When a death involves a resident of a DIDD developmental center, a medical review or physician peer review of the death may be conducted as part of the Initial Agency Death Review or at any time thereafter.

3. The Initial Agency Death Review shall be completed within five (5) business days of the individual's death. The Initial Agency Death Review Form shall be submitted electronically to the appropriate DIDD Regional Director.

4. The DIDD Regional Director or designee shall review the form for completeness and transmit it to the DIDD Commissioner or designee.

5. The Commissioner or designee shall review the Notice of Death Forms, the Reportable Incident Forms, and the Initial Agency Death Review Forms upon receipt and shall determine whether immediate intervention is necessary to protect other individuals who are receiving services.

6. An independent review of any death may be conducted by a qualified physician either as part of the Initial Agency Death Review or at any time thereafter.

E. **DIDD Death Reviews**: The purpose of a DIDD Death Review is to conduct a comprehensive analysis of the relevant facts and circumstances, including the healthcare provided, to identify practices or conditions which may have contributed to the death and to make recommendations to prevent similar occurrences. It is not intended to be an investigative, fault finding process.
1. Death Reviews shall be performed by the Regional Death Review Committee.
   a. Death Review Committee:
      1) The chair of the Death Review Committee shall be the Regional Office Compliance Director or designee.
      2) The Death Review Committee must include the following members:
         a) A qualified physician unaffiliated with treatment of deceased individual and who was not associated with the provider agency, DIDD developmental centers, DIDD ICF/ID, or private ICF/ID, as applicable, within a year of the individual's death. However, a DIDD physician shall, upon request of the Chairperson, serve as the independent physician on the Death Review Committee.
            For deaths occurring in community settings, a developmental center physician meeting the above requirements may serve as the independent physician member of the committee.
         b) The registered nurse or designee who completed the Clinical Death Summary.
         c) The Executive Director or designee of the provider agency primarily responsible for serving the individual through an HCBS waiver program or other DIDD community program, the administrator of the DIDD ICF/ID or designee or the administrator of the private ICF/ID or designee, as applicable.
         d) At least one program staff person selected by the provider agency, the DIDD ICF/ID, or the private ICF/ID who is familiar with the individual's health status and history and the course of events prior to death.
         e) The Independent Support Coordinator or equivalent, assigned to the individual.
      3) The Death Review Committee may also include the following members by invitation of the Chair:
         a) The primary care physician, nurse practitioner, or physician assistant who coordinated or provided health care to the individual.
b) The Agency Director of Nursing or the nurse who provided care to the individual while receiving services through an HCBS waiver program or other DIDD community program in a DIDD ICF/ID, or in a private ICF/ID.

c) One or more health specialists (e.g., psychiatrist, neurologist, occupational therapist, physical therapist or other specialists as needed) as determined by the Central Office Director of Nursing in consultation with the DIDD Director of Health Services.

d) The parent of a person with a disability unrelated to the deceased individual.

2. Timeline for Conducting a Death Review: Death Reviews shall be conducted within forty-five (45) business days of the individual's death. However, this time period shall be automatically extended for thirty (30) business days when the autopsy report or investigation report is not completed. Any extensions beyond thirty (30) business days shall require approval of the DIDD Commissioner or designee.

3. A death review may be requested by the Commissioner at any time on the advice of the Office of Health Services.

4. Death Review Committee Chair Responsibilities:

a. The Regional Office Compliance Director or designee shall be responsible for arranging the Death Review Committee meeting, selecting a time and location that takes into consideration the participants' schedules, and notifying the Death Review Committee members and the DIDD Central Office Nursing Director in writing of the meeting. The Regional Office Compliance Director or designee shall determine who, in addition to standing Committee members, can be included on the Committee for the particular Death Review.

b. Requests by additional persons (e.g., non-committee members) to attend the Death Review must be submitted in writing in advance of the meeting to the Death Review Committee chair and Central Office Director of Nursing. The chair will be responsible for notification that the request has or has not been granted.

c. Preparing Death Review Packets for all Death Review Committee members.
1) Death Review Packets for all Death Review Committee members must include:
   a) Notice of Death form.
   b) Reportable Incident Report.
   c) Initial Agency Death Review Form.
   d) Current and recent medication history.
   f) DIDD Investigation Report (if applicable).
   g) Autopsy Report (or preliminary report if applicable).
   h) Death Certificate, if available.
   i) Clinical Death Summary.

2) Death Review Packets for the DIDD Central Office Nursing Director, independent physician and other specialists, as applicable, on the Committee must also include:
   a) Hospital and other discharge summaries.
   b) Medication histories and other relevant health care information.
   c) Any emergency services or 911 records.
   d) Any relevant psychosocial or other information relating to the deceased individual.

   d. At least five (5) calendar days prior to the Death Review meeting, distribute the appropriate Death Review Packet to each Death Review Committee member.

4. Death Review Committee Responsibilities
   a. Committee members shall review Death Review Packets prior to the meeting.
   b. The Committee may make recommendations for improvement by the appropriate community agency, DIDD ICF/ID or private ICF/ID as follows:
      1) Recommendations will be made by members present at the meeting and will be agreed upon by the committee.
2) The recommendation must be realistic and achievable.

3) The recommendation must be measurable.

4) There must be written rationale for the recommendation.

c. In instances when an autopsy is conducted but the final report is not available at the time of the Death Review Committee meeting, the registered nurse or designee who wrote the Clinical Death Summary shall be responsible for attempting to obtain a preliminary oral or written autopsy report for discussion at the Death Review Committee meeting.

d. The Death Review Committee may reconvene to consider additional information that is pertinent to the death (e.g., autopsy, death certificate or investigation report) that is submitted subsequent to the initial Death Review Committee meeting.

e. The Death Review Committee, in consultation with the DIDD Central Office Nursing Director, shall determine from a review of the minutes whether any aspect of the death should be referred to any licensing or regulatory agency or to law enforcement officials, if referrals have not already been made.

5. Records of Death Review Committee Meetings

a. Confidentiality: Records of Death Review Committee meetings are confidential.

1) A Death Review Meeting Attendance Form containing a statement of confidentiality must be signed by all participants at the beginning of each meeting.

2) The proceedings of the Death Review Committee, including discussions among the members and any documents reviewed, shall be treated as confidential.

b. Minutes: Formal minutes shall be maintained for each Death Review Committee meeting.

1) Draft minutes shall be prepared by the Chair and made available to all Committee members for comment within eight (8) business days after the meeting.

2) Committee members shall have four (4) business days to review the draft minutes and submit corrections and comments to the Chair.

3) Following the comment period, the Chair of the Committee shall finalize the minutes within three (3) business days.
4) These timeframes may be extended by the DIDD Commissioner or designee for good cause.

5) The minutes shall include:
   a) Date of the meeting.
   b) List of names and titles of committee members in attendance.
   c) Name of the deceased.
   d) Age of the deceased at the time of death.
   e) Place of residence of the deceased at the time of death.
   f) Date, time, and place of death.
   g) Cause of death.
   h) Brief summary of the circumstances surrounding the death.
   i) Full summary of issues discussed by the committee.
   j) The Committee’s specific findings with regard to the care and treatment provided to the individual.
   k) Identification of any factors which may have contributed to the death in question.
   l) Any recommendations for improvement agreed to by the committee. The minutes must clearly indicate the basis for all such recommendations.

6) Distribution and maintenance of Death Review Committee minutes.
   a) Copies of the final minutes shall be distributed to the following:
      (1) DIDD Commissioner or designee.
      (2) DIDD Central Office Nursing Director.
      (3) DIDD Director of Health Services.
      (4) DIDD Regional Office Director.
      (5) The Director/Chief Officer of the DIDD ICF/ID, if applicable.
(6) The director of the private ICF/ID, if applicable.

(7) The executive director of the provider agency primarily responsible for serving the individual, if the death involved an individual receiving services through an HCBS waiver or other community program.

(8) The Bureau of TennCare.

b) Individuals authorized to receive the minutes shall maintain their copies in a secure location in accordance with state and federal confidential privacy statutes, rules and regulations.

c) DIDD Office of Health Services shall be responsible for maintaining a complete file of all relevant documents (including those reviewed by or made available to the Death Review Committee) in a secure location for at least ten years, in accordance with Tennessee Code Annotated 33-3-101. Records of Class Members shall be maintained until the lawsuit is dismissed, which, for some, may extend beyond the ten year requirement.

d) The DIDD Commissioner, in consultation with the DIDD Central Office Nursing Director, shall determine whether the death review findings should be disseminated more widely.

F. Follow-up of Death Review Committee recommendations:

1. Response to Death Review Committee recommendations: The Executive Director or designee of the community provider agency, the Director / Chief Officer of DIDD ICF/ID or designee, or the administrator of the private ICF/ID or designee, as appropriate for the particular death, shall provide a written response to any Death Review Committee recommendations within thirty (30) calendar days of the receipt of the recommendations. The response shall include a complete plan with time frames for implementing each recommendation or an explanation of proposed alternative actions that will be taken to address the problem(s) identified. The response shall be submitted to the DIDD Regional Compliance Director who shall submit the response to the DIDD Regional Director for review.

2. The DIDD Regional Office Director or designee shall be responsible for tracking and monitoring the provider’s implementation of the Death Review Committee recommendations. Monitoring may include on-site review of records and the provider’s practices.

3. The DIDD Regional Compliance Director or designee shall submit implementation status reports to the DIDD Central Office Nursing Director on a quarterly basis.
G. **Additional quality improvement activities**

1. **Annual review of death data:** At least annually, the Central Office Director of Nursing or designee shall review and analyze death data to determine possible patterns or risk factors in areas such as:
   a. The demographic, medical, mental health and service provision profile of the deceased individuals.
   b. The immediate and root causes of death.
   c. The issues, problems, and deficient practices or procedures identified in death reviews.
   d. The implementation of recommendations issued as a result of the death reviews.

2. **Quality Reviews**
   a. The Central Office Nursing Director will facilitate an annual quality review of Death Reviews.
   b. A standard review instrument will be used to review required components of the Death Review records:
      1) Clinical Death Summary.
      2) Death Review Minutes.
      3) Death Review Packets.
   c. The random record sample for the Review shall include 10 percent of death reviews conducted in each region.
   d. The instruments used for scoring will be retained by the Central Office Nursing Director or designee who will prepare a Quality Review report. The Central Office Director of Nursing shall submit the Quality Review to the Director of Health Services for review and distribution it to Regional Office Directors, Regional Compliance Directors and Regional Nursing Directors.
   e. The Director of Health Services or designee will work with appropriate Regional Office Compliance Directors to address the findings in the Quality Review.
      1) For indicators scoring 85% or below, the responsible entity or entities shall develop an improvement plan and submit it to the Director of Health Services or designee for approval.
      2) The Director of Health Services or designee may propose recommendations for improving consistency and quality of Death Reviews based on results of the Quality Review.
VII. **ATTACHMENTS:**

A. Reportable Incident Form

B. Initial Agency Death Review Form

C. Death Review Attendance Form

D. Notice of Death Form