COMMONWEALTH of VIRGINIA

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COMMISSIONER

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December 1, 2025

To: The Honorable Glenn A. Youngkin, Governor of Virginia
The Honorable Winsome Earle Sears. Lieutenant Governor
The Honorable Louis L. Lucas, President pro tempore, Virginia Senate
The Honorable Don Scott, Speaker, Virginia House of Delegates

From: Nelson Smith, Commissioner, Department of Behavioral Health and Developmental Services

RE: §37.2-314.1, Code of Virginia

Code of Virginia §37.2-314.1 directs the Department of Behavioral Health and Developmental Services (DBHDS) to report annually to the Governor and the General Assembly on activity of the Mortality Review Committee. The language reads:

F. The Committee shall report its activities annually to the Governor and the General Assembly by December 1. Such report shall include statistical and other data on the deaths of persons with a developmental disability who were receiving services from a provider licensed by the Department or in a training center or other state facility at the time of their death and recommendations developed by the Committee to address the conditions that led to such deaths. Any statistical compilations prepared by the Committee shall be public record and shall not contain any personally identifying information.

Please find enclosed the report in accordance with Code of Virginia §37.2-341.1. DBHDS Staff are available should you wish to discuss this request.

Cc: The Honorable Janet V. Kelly, Secretary of Health and Human Resources

DBHDS
Virginia Department of Behavioral Health and Developmental Services

FY 2025 Annual Mortality Review Report

(§37.2-314.1, Code of Virginia)

December 1, 2025

DBHDS Vision: A Life of Possibilities for All Virginians

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Preface

Code of Virginia §37.2-314.1 directs the Department of Behavioral Health and Developmental Services (DBHDS) to report annually to the Governor and the General Assembly on activity of the Mortality Review Committee. The language reads:

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§37.2-314.1 Mortality Review
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This report provides the 11th Annual Mortality Report of the Virginia Department of Behavioral Health and Development Services' (DBHDS) Intellectual and Developmental Disabilities (IDD) Mortality Review Committee (MRC or Committee). The information contained in this report is based on compilations of reviews; committee determinations, findings, recommendations; and quality improvement initiatives generated by the IDD MRC of the deaths of individuals with IDD. This report is derived from records of mortality reviews that occurred during state fiscal year (FY) 2025, as reported in the DBHDS incident reporting systems, and defined as the period of time from July 1, 2024 to June 30, 2025.

As of January 5, 2025[1], there were 18,034 individuals enrolled on one of Virginia's Developmental Disability Home and Community Based Services waivers[2]. DBHDS provides specialized services to thousands of individuals on Community Living, Family and Individual Supports, and Building Independence waiver in the Commonwealth.

Key Findings

- DBHDS IDD MRC reviewed 324 deaths in FY 2025, a 12 percent decrease from FY 2024 when 370 deaths were reviewed.
- The median age at time of death was 59 years old, an increase of one year from the previous FY. The mean age at death was 55.5 years old.
- The leading cause of death in FY 2025 was sudden cardiac death.
- The MRC determined both less expected deaths (256 deaths, 79 percent) than FY 2024 (77.8 percent) and unexpected (67 deaths, 21 percent vs 21.9 percent in FY 2024). One death was determined to be unknown, which is similar to FY 2024.
- The top cause of death for expected deaths was pneumonia, with the top cause for unexpected deaths of sudden cardiac death.
- Six deaths (2 percent) were determined to be potentially preventable (PP), a slight increase from four deaths in SFY 2024. The top cause of PP deaths was choking (two deaths).

Background

The DBHDS conducts mortality reviews of individuals with IDD who died while receiving a licensed service or support through the DBHDS agency. The purpose of this mortality review process is to contribute to system of care improvements by identifying opportunities to improve quality of care and supports through; integration of clinical evidence, data driven determinations, and evidenced-based quality improvement recommendations.

Deaths of all individuals with IDD who were receiving a DBHDS licensed service 90 days before the time of their death are reviewed in detail and discussed by the IDD MRC monthly. This includes an assessment and review of all aspects of care, any perceived deficiencies, and other factors that may have impacted the mortality, morbidity and quality of life of that individual with IDD. Identifying the strengths, weaknesses and gaps in existing evidence-based standards, policies, practices, and procedures through case specific reviews leads to recommendations that are then communicated to the appropriate internal offices and external entities.

At each meeting, the MRC:

- Performs comprehensive clinical mortality reviews utilizing a multidisciplinary approach that addresses relevant factors (e.g., medical, genetic, social, environmental, risk, susceptibility, and others as specific to the individual) and quality of service.

[1] January 5th was selected as a snapshot date for the middle of the FY.

[2] Virginia Waiver Management System. Accessed by DBHDS in October 2025.

- Evaluates the quality of the decedent's licensed services related to disease, disability, health status, service use, and access to care, to ensure provision of a reliable, person-centered approach.
- Identifies risk factors and gaps in service and as appropriate, specifies whether these are systemic recommendations or recommendations to specific providers, to promote safety, freedom from harm, and physical, mental, and behavioral health and wellbeing.
- Reviews citations issued by Office of Licensing related to required recommendations, to determine whether further action is required and for inclusion in meeting minutes.
- Refers any required recommendations not included in the initial citation and Corrective Action Plan (CAP) to the Office of Licensing for further investigation, and/or other divisions represented by members, when appropriate.
- Assigns recommendations and/or actions to DBHDS IDD MRC member(s) as appropriate.
- Reviews and tracks the status of previously assigned recommended actions to ensure implementation and completion.

The MRC convenes at least monthly and as frequently as necessary, to ensure that deaths are reviewed within 90 days of the date of death. Attendance by specific subject matter experts is required at each meeting. During FY 2025, the MRC met 23 times, and both quorum and membership requirements were met at each meeting.

Within 90 calendar days of death for an IDD individual who received a DBHDS licensed service, the Mortality Review Office (MRO) compiles a clinical sequence of events summary leading up to that individual's death, based on specific and required documentation from the preceding three months prior to the date of death. For each IDD mortality case review, the MRC identifies and determines:

- The cause of death
- If the death was expected or unexpected
- Whether the death was potentially preventable
- Any relevant factors impacting the individual's death
- Any other findings that could affect the health, safety, and welfare of these individuals
- Whether there are other actions that may reduce these risks of mortality, to include provider training and communication regarding risks, alerts, and opportunities for education
- If additional actions or measures are needed based on the case review, the MRC will then make and document relevant recommendations and/or interventions

Quality Improvement

One primary purpose of the DBHDS IDD MRC is to identify quality improvement opportunities in the provision of individual, provider and system levels of care and supports provided to individuals with IDD who received DBHDS licensed services.

Analysis of the mortality trends, patterns, and problems helps to identify opportunities for system quality improvements that can reduce mortality and morbidity risks to all individuals with IDD receiving behavioral health and/or developmental services. Data analysis guides system enhancement through process improvement and is the foundation for recommendation development based on findings.

DBHDS seeks to prevent instances of abuse, neglect, exploitation, and unexplained or unexpected death by identifying and addressing relevant factors during mortality reviews on a continuous basis. Case specific mortality review determinations are utilized to develop quality improvement initiatives focused on reducing IDD mortality rates to the fullest extent practicable.

System-focused quality improvement initiatives *(QIIs*) based on trends identified from case reviews on an ongoing basis, will ensure safe, effective, person-centered, timely, efficient, and equitable care for all IDD individuals.

The following were the MRC QIIs for FY 2025:

QII #1: *The MRC initiated an IDD Emergency Department (ED) Utilization QII to track repeat ED visits by individuals with IDD for the same (repeated) health issue/concern. Through data analysis and working in collaboration with external stakeholders, educational materials on the role of Managed Care Organization Care Coordinators were developed in an effort to improve continuity of care for individuals with IDD receiving DBHDS licensed services and reduce those repeat ED visits. The draft version of educational materials remains under review by the DBHDS Office of Integrated Health (OIH) in preparation for distribution to licensed providers.*

QII #2: *The Preventive Screenings QII was completed and noted a lack of preventive screening and risk factor documentation in individual's with IDD service plans (ISPs). The MRC investigated inclusion of preventive screenings documentation in the Individual Service plan (ISP) of individuals with IDD receiving a licensed DBHDS service. Interventions including educational materials and an Annual Exam toolkit for distribution to DBHDS licensed providers was developed.*

QII #3: *The MRC completed the Medical Emergencies QII which included a medical emergency toolkit (MET), educational materials, and a training module. Findings indicated that adherence to established medical emergency (911) protocols continued to be a factor. Since the MET was adopted and remains available to DBHDS licensed providers, the MRC will continue to monitor medical emergency protocol adherence for PP deaths as surveillance data.*

Mortality Review Process Enhancements for FY 2025

- The MRC continues to monitor use of the electronic Mortality Review Form's data elements for collection, tracking and analysis to ensure continued data reliability and validity with ongoing enhancements to the back-end data load
- Maintaining collaboration with the Virginia Department of Health and the DBHDS data warehouse related to identifying IDD deaths that occurred outside of Virginia (which in SFY 2025 included Tennessee and West Virginia) requiring mortality review. These efforts were undertaken to address and decrease gaps in available demographic data and other information required by the MRC to make accurate determinations.
- More prompt and vigorous mortality review timeline has occurred due to a combination of prompt submission of required documents, timely completed investigations by the Special Investigations Unit, and diligent work by MRC members. These efforts have decreased the time required between the death of a person with IDD, compilation of the electronic Mortality Review form, and review by the MRC.
- Expanded and consistent data tracking by the Clinical Nurse Reviewer team has added reliability and validity to the development and implementation of quality improvement actions and MRC recommendations.

Key Definitions

- Expected Death denotes a death that occurred as a result of a known medical condition, anticipated by health care providers to occur as a result of that condition and for which there is no indication that the individual was not receiving appropriate care. Clear evidence that the individual received appropriate and timely care for the medical condition exists.
- Unexpected Death denotes a death that occurred as a result of a condition that was previously undiagnosed, occurred suddenly, or was not anticipated. Deaths are considered unexpected when they are not anticipated or related to a known terminal illness or medical condition; are related to injury, accidents, inadequate care; or are associated with suspicions of abuse or neglect. An acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s) may also be determined to be an unexpected death. An unexplained death is also an unexpected death.
- Unknown may be used in two distinct contexts - If there is insufficient information to classify a death as either expected or unexpected OR there is insufficient information to make a determination as to the cause of death.
- Other (Cause of Death) denotes a cause of death that is identified but not attributable to one of the major causes of death used by the MRC for data trending.
- Potentially Preventable (PP) Deaths denotes deaths in the opinion of the MRC that might have been prevented with reasonable valid intervention (e.g., medical, social, psychological, legal, educational). If the individual was provided with known effective medical treatment or public health intervention and died despite this provision of evidenced based care, the death is not considered PP. A death may be determined to be PP regardless of whether the death is actionable by DBHDS or within the control of DBHDS. Deaths that occur in settings that are not licensed by DBHDS may be PP deaths. Deaths that do not indicate a violation of a licensing standard may be PP. Deaths determined to be PP have identifiable actions or care measures that should have occurred or been utilized. When the MRC determines a death is PP, the MRC then categorizes factors that might have prevented the death. For a death to be determined PP, the actions and events immediately surrounding the individual's death must be related to deficits in the timeliness or absence of, at least one of the following factors: (more than one factor may be identified)
    - Coordination and optimization of care
    - Access to care, including delay in seeking treatment
    - Execution of established protocols
    - Assessment of and response to, the individual's needs or changes in status

- Tier 1 case criteria - A case is categorized as Tier 1 when any of the following criteria exists:
    - Cause of death cannot clearly be determined or established, or is unknown
    - Any unexpected death (such as suicide, homicide, or accident). This includes any death that was: not anticipated or related to a known terminal illness or medical condition, related to injury, accident, inadequate care nor associated with suspicions of abuse or neglect. A death due to an acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s), may be determined to be an unexpected death.
    - Abuse or neglect is specifically documented
    - Documentation of investigation by or involvement of law enforcement (including forensic) or similar agency
    - Specific or well-defined risks to safety and well-being are documented

- Tier 2 case criteria - A case is categorized as Tier 2 when all the first 4 criteria exist:
    - Cause of death can clearly be determined or established

- No documentation of abuse or neglect
- No documentation of investigation by or involvement of law enforcement (including forensic) or similar agency
- No documentation of specific or well-defined risks to safety and well-being noted.
- An expected death that occurred as a result of a known medical condition, anticipated by health care providers to occur as a result of that condition and for which there is no indication that the individual was not receiving appropriate care.
- An unexpected (unexplained) death that occurred as a result of a condition that was previously undiagnosed, occurred suddenly, or was not anticipated. This includes any death that was: not anticipated or related to a known terminal illness or medical condition, related to injury, accident, inadequate care or associated with suspicions of abuse or neglect. A death due to an acute medical event that was not anticipated in advance nor based on an individual's known medical condition(s) may also be determined to be an unexpected death.

For actions recommended by the MRC, the MRC shall consider if one of the following Mortality Prevention Strategies[3] may be utilized: (more than one strategy may be identified)

- Primary Prevention Strategies - Educational and changes to services designed to help prevent a condition or event from taking place, that have been found to contribute to morbidity or mortality, such as education on reducing falls.
- Secondary Prevention Strategies – Focus on early detection and timely treatment of conditions or injuries to minimize harmful effects and prevent further morbidity or mortality, such as interventions that support and promote cancer screening.
- Tertiary Prevention Strategies – Optimization of the treatment and management of conditions or injuries, such as ensuring access to evidence-based treatment.

Deaths in Virginia

The MRC determined a cause of death in 323 out of 324 (99.7 percent) of cases, with only one death classified as having an unknown cause. This is consistent with the previous two years. The number of unknown deaths from FY 2017 – FY 2025 is shown below.

Table 1: Number of Deaths Classified as Unknown

Year	Unknown
FY 2017	31
FY 2018	34
FY 2019	42
FY 2020	16
FY 2021	2
FY 2022	1
FY 2023	1
FY 2024	1
FY 2025	1

[3] [3] Staugaitis, S., Lauer, E. (2015). *Risk Management Mortality Review & Reporting in Developmental Disabilities*. Univ of Mass Press, (69).

Legislation passed by the General Assembly in 2020 (SB482) continues to grant the MRC increased access to information and records relevant to all deaths of individuals with IDD reviewed by the MRC. This includes access to Virginia state death certificates through the Virginia Department of Health and autopsy results through the Office of the Chief Medical Examiner.

Number of deaths by cause are displayed in Table 2. The decrease in number of deaths classified as Unknown are still related to the detailed cause of death classification, versus the broader category of deaths utilized in previous year.

The most common cause of death for FY 2025 was Sudden Cardiac Death, and the number of deaths caused by Covid-19 remained stable from FY 2024 to FY 2025 (eight deaths in both years).

Table 2: Number of Deaths by Cause, FY 2025

Cause	Number
Sudden Cardiac Death	25
Pneumonia	23
Cancer w/metastasis	15
Cerebral Palsy	15
Failure to Thrive/ Slow Decline	15
Sepsis	15
Congestive Heart Failure	11
Dementia	11
Cancer w/o metastasis	10
Down Syndrome	10
Coronary Artery Disease	9
Covid-19	8
Epilepsy	9
Aspiration	7
Aspiration Pneumonia	7
Intestinal Obstruction	7
Stroke	7
Alzheimer's disease	6
Seizure	5
Accident	4
Acute Respiratory Failure	5
Cardiac Arrythmia	4
Choking	4
Lennox Gastaut Syndrome	4
Myocardial Infarct	4
Intracranial Hemorrhage	3
Muscular Dystrophy	3
Parkinson's disease	3
Renal Failure	3
Rett Syndrome	3
Angelman syndrome	2
Cardiomyopathy	2
Dandy Walker Syndrome	2
Gastrointestinal Bleed	2
Leukemia	2
Multiple Myeloma	2

Cause	Number
Perforated bowel	2
Prader-Willi Syndrome	2
Protein calorie malnutrition	2
Williams Syndrome	2

The following causes of death were found only once in FY 2025: Agenesis of corpus callosum, complications of; Anemia; Aqueduct of Sylvius malformation; Birth Injury *(TBI)*; Bowel Ischemia; Campomelic Dysplasia; Cerebrovascular Disease; Chromosome 2q24 deletion syndrome; Chronic Kidney Disease; Congenital Heart Disease; Congenital Hydrocephalus; COPD; Cornelia de Lange syndrome; DiGeorge syndrome; Distal Trisomy 15q; Edwards Syndrome; Encephalomalacia; End Stage Senile Degeneration of the Brain; Endocarditis; End Stage Renal Disease; Harm to Self/Suicide; Holoprosencephaly *[Genetic malformations, deformations, and chromosomal abnormalities]*; Homicide; Huntington's Disease; Influenza; Kearns-Sayre Syndrome; Leukodystrophy *(Genetic malformations, deformations, and chromosomal abnormalities)*; Lissencephaly; Metachromatic Leukodystrophy; Multi-Organ Dysfunction *Syndrome (AKA Multi-System Organ Failure*); Necrotizing Fasciitis; Neuroendocrine cancer of duodenum; Occipital Encephalocele *[Genetic malformations, deformations, and chromosomal abnormalities]*; Perforated appendix; Perioperative Mortality; Phelan-McDermid Syndrome; Pneumonitis; Post Operative Complications; Post Procedure Complications; Progressive Supranuclear Palsy; Pulmonary Fibrosis; Rubenstein-Taybi; Sanfilippo Syndrome; Spina Bifida; Spinal Cord Injury; Trisomy 13 Syndrome/Patau Syndrome; Unknown; Vader syndrome; and Volvulus.

Table 3 displays trend data by cause of death category. These categories will be used throughout the report. Current and historical causes of death are coded into categories so that trend data can be tracked more easily.

Table 3: Number of Deaths by Category, FY 2018 – FY 2025

Category	FY18	FY19	FY20	FY21	FY22	FY23	FY24	FY25
Accident	2	1	2	3	4	2	5	4
Birth injury						1	1	1
Cancer	23	30	34	33	33	29	40	30
Cardiovascular Disease	41	39	71	67	53	48	56	56
Congenital malformations, deformations, and chromosomal abnormalities	2	13	5	18	28	30	28	25
Drug Toxicity/Overdose	1		1	7		1		
Endocrine, Nutritional, & Metabolic Disease	31	15	27	17	35	37	27	24
Gastrointestinal Disease	11	10	12	13	15	16	14	13
Genetic malformations, deformations, and chromosomal abnormalities	11	9	16	18	29	35	51	41
Harm to self/Suicide				1				1
Hematological Disease	3	1		2	1		1	
Infectious Disease	17	19	41	23	26	26	28	18
Mental, Behavioral and Neurodevelopmental Disorder						1		
Multiple Medical Problems*	10	8						
Musculoskeletal and Connective Tissue Disease	2	1	8	2	2			
Neurodegenerative Disorder	5	18	7	21	10	8	9	11
Neurological Disorder	9	19	24	36	41	25	40	38
Perioperative mortality								1

Category	FY18	FY19	FY20	FY21	FY22	FY23	FY24	FY25
Post-Operative Complications	6	3	3	3	3	3		1
Post-procedure complications								1
Renal Disease	9	11	6	8	7	4	1	5
Respiratory Disease	43	72	79	132	120	65	67	52
Traumatic Disorder	1	1	2	2	8	4	1	1
Unknown	34	42	16	2	1	1	1	1
Total	**261**	**312**	**354**	**408**	**416**	**336**	**370**	**324**

*Discontinued in FY 2020

The number of deaths by category for individuals who were not receiving a waiver service are reported in Table 4. Cardiovascular Disease was the top category for this group.

Table 4: Number of Deaths by Category for Non-Waiver Individuals, FY 2025

Cause of Death Category	Deaths
Cardiovascular disease	9
Respiratory Disease	6
Genetic malformations, deformations and chromosomal abnormalities	5
Neurological Disorder	4
Congenital malformations, deformations and chromosomal abnormalities	4
Infectious Disease	3
Cancer	2
Endocrine, nutritional & metabolic disease	2
Total	**35**

End of Life Care

The American Association for Individuals with Intellectual and Developmental Disabilities updated their end-of-life position statement in January 2020 on caring for individuals with IDD. The MRC acknowledged that this choice is related to the type of end-of-life care for individuals with IDD as it can be reflective of interventions and actions related to contributing mortality factors. Data capture for reporting purposes was initiated in FY 2021 and will continue.

Do Not Resuscitate *(DNR)* Status

The MRC does not make determinations *(such as expected, potentially preventable, relevant findings and/or other factors)* based on DNR status. The number and percentage of individuals who had a DNR in place is displayed in Table 5. The percentage increased over time, but after reaching a high of 75 percent in FY 2023, the number dropped back down to 65 percent in FY 2024 and remained stable in FY 2025.

Table 5: Number and percent of deaths with DNR by FY

State Fiscal Year	DNR	No DNR	Percent with DNR
FY 2020	148	206	42%
FY 2021	224	184	55%
FY 2022	251	165	60%
FY 2023	222	114	75%
FY 2024	240	130	65%
FY 2025	209	116	65%

Table 6: DNR by Residential Setting, FY 2025

Residence	DNR	Total	Percent
Group Home	105	152	69.08%
Private Residence w/ Family	47	84	55.95%
Sponsored Placement	22	40	55.00%
Private Residence Other	10	18	55.56%
ICF/IID	13	16	81.25%
NF/SNF/ALF	7	8	87.50%
State Facility	5	6	83.33%
Total	**209**	**324**	**64.51%**

Individuals who lived in a group home, ICF/IID, NF/SNF/ALF, or state facility, were most likely to have a DNR in place as shown in Table 6 above.

Hospice

Of the 324 individuals with IDD whose deaths occurred in FY 2025, 125 were receiving hospice services (39 percent), which is a proportion consistent with previous years.

Table 7: Hospice Services by FY

FY	Receiving Hospice
FY 2020	35%
FY 2021	34%
FY 2022	34%
FY 2023	39%
FY 2024	38%
FY 2025	39%

Hospice services by residential setting are displayed below in Table 8. Individuals who lived in a group home or NF/SNF/ALF were most likely to be receiving hospice services.

Table 8: Hospice Services by Residential Setting, FY 2025

Residence	Hospice	Total	Percentage
Group Home	69	152	45.4%
Private Residence w/ Family	30	84	35.7%
Sponsored Placement	12	40	30.0%
Private Residence Other	3	18	16.7%
ICF/IID	5	16	31.3%
NF/SNF/ALF	5	8	62.5%
State Facility	1	6	16.7%
Total	**125**	**324**	**38.6%**

The number and percentage of individuals receiving hospice services by age group is shown in Table 9. As in previous years, older individuals were more likely to receive these services.

Table 9: Hospice Services by Age Group, FY 2025

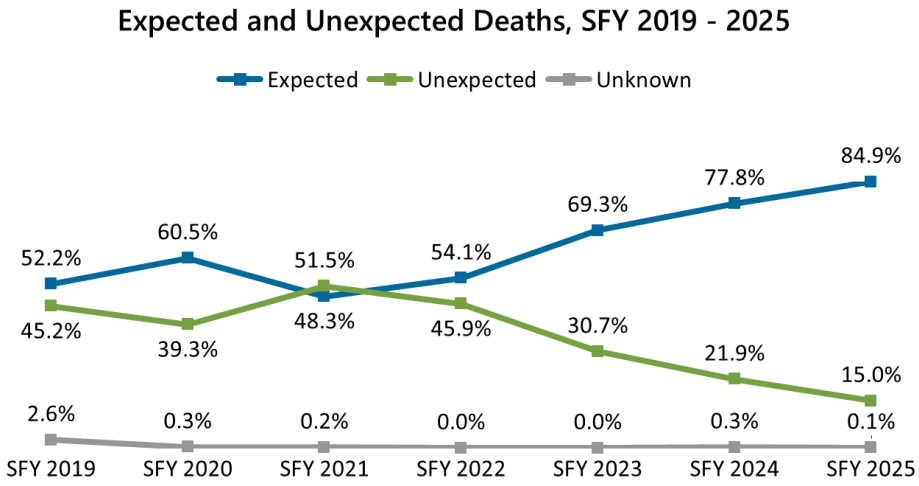
Age Group	Hospice	Total	Percentage
0-17	1	4	25%
18-30	5	39	13%
31-40	7	32	22%
41-50	12	29	41%
51-60	30	72	42%
61-70	33	81	41%
71-80	30	52	58%
81+	7	15	47%
Total	**125**	**324**	**39%**

Expected and Unexpected Deaths

The number of expected and unexpected deaths by year is shown in Table 10. In FY 2025, 256 out of 324 deaths (79 percent) were determined to be expected. This is the highest percentage in the past seven years.

Table 10: Expected and Unexpected Deaths, FY 2019 – 2025

Year	Expected	Unexpected	Unknown	% Expected
FY 2019	163	141	8	52%
FY 2020	214	139	1	61%
FY 2021	197	210	1	48%
FY 2022	225	191	0	54%
FY 2023	233	103	0	69%
FY 2024	288	81	1	78%
FY 2025	256	67	1	79%



Expected and unexpected deaths over time is displayed in the figure above. The decrease in unexpected deaths is proportional to the increase in expected deaths, which is attributed to more informed MRC determinations. Legislation passed by the General Assembly in 2020 (SB482) allowed the MRC to request and receive additional information and records relevant to specific IDD deaths in order to make more thorough determinations. The process to obtain these documents through access to external third-party entities was established in FY 2021.

The top categories for cause of death in expected and unexpected deaths are shown below in Table 11. The top category for expected deaths was 'Genetic malformations, deformations, and chromosomal abnormalities.' The top category of unexpected deaths was cardiovascular disease. These were also the top cause categories for expected and unexpected deaths in FY 2024.

Table 11: Top cause categories of expected and unexpected deaths, FY 2025

Expected	
Category	Deaths
Genetic malformations, deformations and chromosomal abnormalities	41
Respiratory Disease	38
Neurological Disorder	32
Cancer	30
Cardiovascular Disease	29
Congenital malformations, deformations and chromosomal abnormalities	24

Unexpected	
Category	Deaths
Cardiovascular Disease	27
Respiratory Disease	14
GI disease	6
Neurological Disorder	6
Endocrine, nutritional & metabolic disease	3
Infectious Disease	3

Potentially Preventable *(PP)* Deaths

In FY 2025, the MRC determined 316 out of 324 (97.5 percent) of deaths were not PP. This is a slight decrease from the previous year, when 98.9 percent were determined to be not potentially preventable. Table 12 below shows PP deaths from FY 2019 – FY 2025.

Table 12: PP Deaths, FY 2019 – 2025

FY	Not PP	PP	Unknown	% PP
FY 2019	258	11	43	3.5%
FY 2020	328	17	9	4.8%
FY 2021	365	39	4	9.6%
FY 2022	392	22	2	5.3%
FY 2023	325	11	0	3.3%
FY 2024	365	4	1	1.1%
FY 2025	316	6	2	1.9%

The causes of the six PP deaths are listed in Table 13, with the top cause of death as choking.

Table 13: Top Causes of PP Deaths, FY 2025

Cause of Death	Number
Choking	2
Accident	1
Cerebral Palsy	1
Epilepsy	1
Necrotizing Fasciitis	1
Total	**6**

When the MRC determines a death to be PP, the committee categorizes which four factors might have prevented the death. The frequency of these four factors for PP IDD deaths are displayed in Table 14 below. Cases may have more than one factor identified, and in some cases all four factors were identified. All six PP deaths involved a failure of assessment of the individual's needs or change in status.

Table 14: Factors in PP Deaths, FY 2025

Factor	Deaths
Access to care	4/6
Assessment of and response to, the individual's needs or changes in status	6/6
Coordination and optimization of care	5/6
Execution of established protocols	5/6

Findings from IDD mortality reviews may have recommended actions to prevent future events that result in avoidable negative consequences or even death. Mortality prevention strategies are focused on positive practice changes to support individuals with IDD and enhance their quality of life. For the six identified PP deaths, the MRC determined that specific case-related actions and/or interventions to mitigate risk associated with morbidity and mortality were contained in these strategies, as shown below. Primary prevention strategies are educational and make changes to services that are designed to help prevent conditions such as education on reducing falls. Secondary prevention strategies focus on early detection and timely treatment of conditions such as interventions that promote cancer screening. Tertiary prevention strategies focus on optimizing the treatment and management of conditions such as ensuring access to evidence-based treatment.

Table 15: Mortality Prevention Strategies, FY 2025

Factor	*Number of PP Deaths
Primary	4/6
Secondary	4/6
Tertiary	5/6

*Cases may have multiple strategies

Population Demographics

Methodology

The demographics for the population receiving DD Waiver services is determined from a mid-year snapshot accessed by DBHDS from the Virginia Waiver Management System (WaMS). The population used for this year's report includes individuals who were in the database on January 5, 2025, accessed in October 2025.

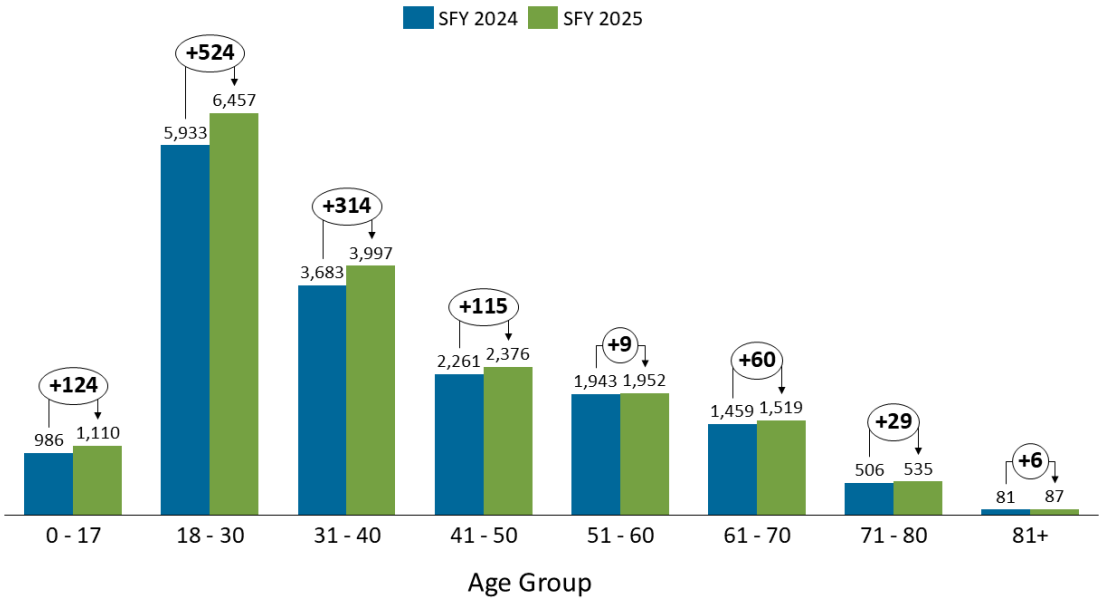
Crude Mortality Rates (CMR) are calculated per 1,000 individuals by dividing the number of deaths reviewed by MRC in certain demographic groups by the number of deaths in the waiver population for the corresponding groups and multiplying by 1,000.

Change in Waiver Population

The number of waiver recipients in the January snapshot increased from 16,852 to 18,034 in FY 2025, an increase of 1,182 (7 percent).

Most of the population increase was among younger age groups, which causes the overall population to skew slightly younger in FY 2025 than it did in FY 2024. Figure 1 on the next page shows the difference for each age group by year.

Figure 1: Waiver Population by Age Group, January 5th Snapshots



The slightly younger skew should be kept in mind when comparing the FY 2025 CMR to the previous year's CMR for various groups, especially when age is not included in a specific demographic breakdown.

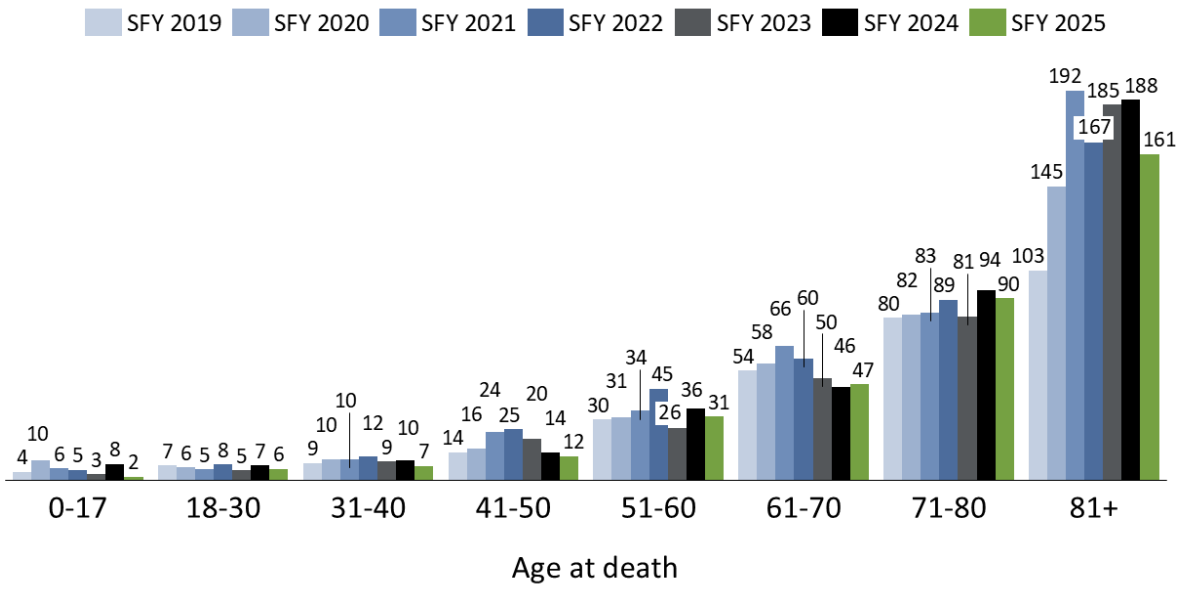
Table 16 displays CMR by age for individuals receiving waiver services. As in previous years, the rates were higher among older age groups, with the highest CMR found for individuals aged 81 or older.

Table 16: Crude Mortality Rates by Age per 1,000 population, FY 2025

Age Group	Waiver Deaths	Waiver Population	Crude Mortality Rate
0 - 17	2	1110	**1.8**
18 - 30	36	6457	**5.6**
31 - 40	28	3997	**7.0**
41 - 50	28	2376	**11.8**
51 - 60	61	1952	**31.3**
61 - 70	72	1519	**47.4**
71 - 80	48	535	**89.7**
81 or older	14	87	**160.9**

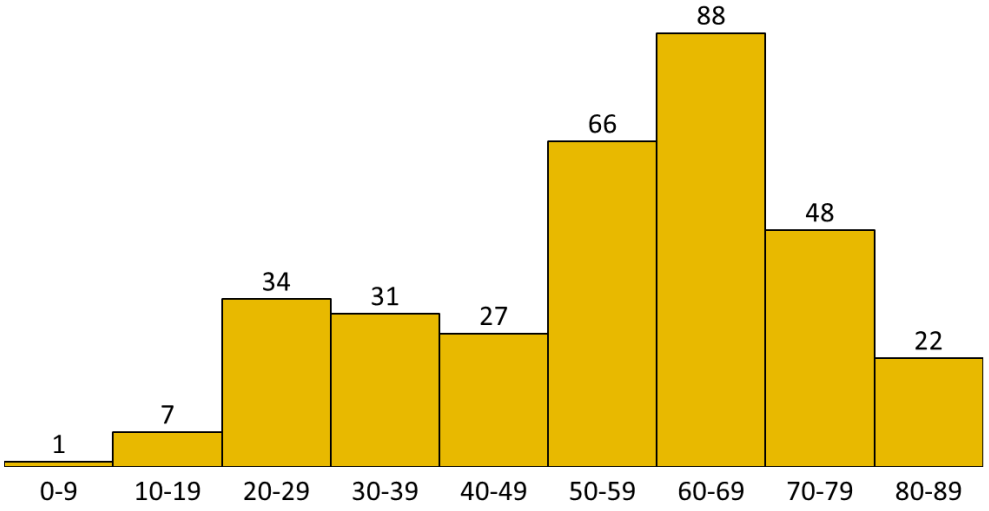
Figure 3 below demonstrates CMR by age over time. The rates for all age groups have remained roughly consistent in recent years.

Figure 3: CMR by Age Group, FY 2019 – FY 2025



The number of deaths by age group for all deaths reviewed by the MRC is shown below in Figure 2. For both the age group 50-59 and 60-69, the decrease in numbers from FY 2024 may be related to the decreased number of deaths that occurred this fiscal year.

Figure 2: Age at Death, FY 2025



Gender

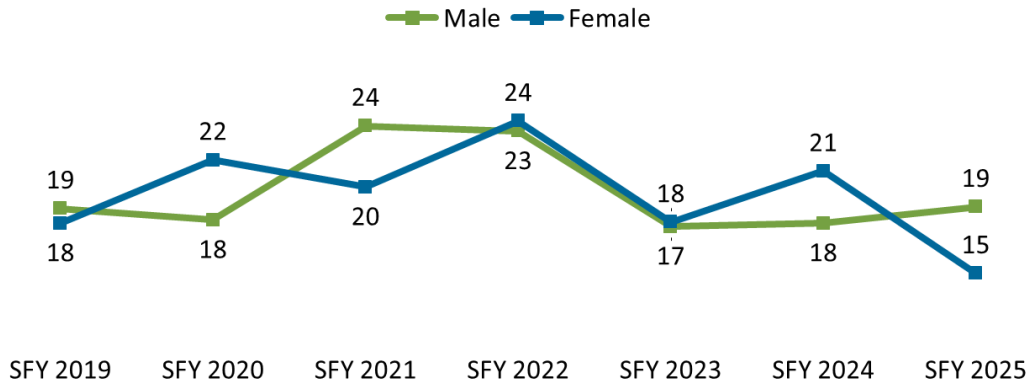
The CMR by gender for waiver recipients is displayed in Table 17. Out of the 289 deaths of individuals receiving waiver services in FY 2025, 66 percent were male. This number is consistent with the distribution of the waiver population, which was 62.5 percent male at the time of the January 2025 snapshot.

Table 17: Crude Mortality Rates by Gender per 1,000 population, FY 2025

Gender	Waiver Deaths	Waiver Population	CMR
Female	126	6761	**18.6**
Male	163	11270	**14.5**

The CMR by gender over time is displayed in the figure below. The rates have been consistent over the years, with the rate for males higher in some years and lower in other years, most likely due to the small number of deaths and random variation.

Figure 4: CMR by Gender, FY 2019 – FY 2025



The top causes by gender are shown in Table 18. Respiratory Disease was the top category for female individuals with IDD, while Cardiovascular Disease was the top category for male IDD individuals.

Table 18: Top Cause of Death Categories by Gender, FY 2025

Female	
Category	Deaths
Respiratory Disease	24
Cardiovascular Disease	21
Genetic malformations, deformations and chromosomal abnormalities	18
Cancer	18
Neurological Disorder	17
Congenital malformations, deformations and chromosomal abnormalities	13

Male	
Category	Deaths
Cardiovascular Disease	35
Respiratory Disease	28
Genetic malformations, deformations and chromosomal abnormalities	23
Neurological Disorder	21
Endocrine, nutritional & metabolic disease	13
Infectious Disease	13

Race

The number of deaths reviewed by race for FY 2025 is shown in Table 19 below. The average age at death for all White/Caucasian individuals was 56.6 years old, while the average age for Black/African American individuals was 55.8 years old. The numbers for the additional racial categories are too small to calculate a meaningful average.

Table 19: All Deaths by Race, FY 2025

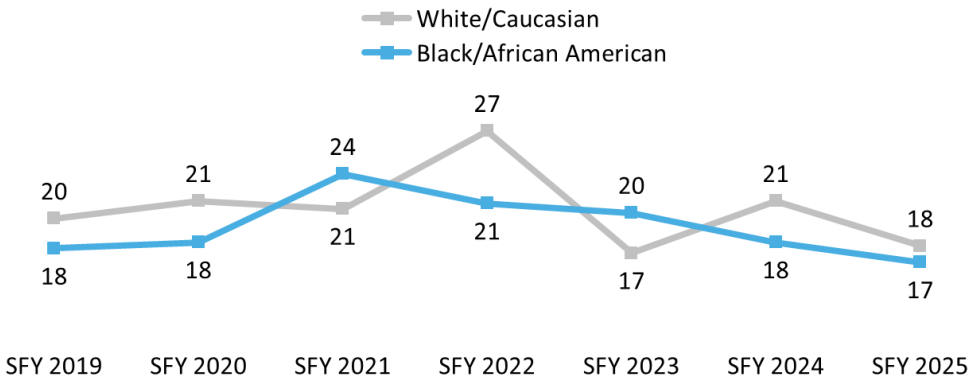
Race	Number	Percentage
White/Caucasian	217	66.98%
Black/African American	97	29.94%
Asian	5	1.54%
Multi-Race	3	0.93%
Other	2	0.62%
Total	**324**	**100.0%**

Table 20 indicates the CMR numbers by race for Black/African American and White/Caucasian individuals.

Table 20: Waiver Deaths by Race, FY 2025

Race	Waiver Deaths	Waiver Population	CMR
Black/African American	84	5084	16.5
White/Caucasian	196	10994	17.8

Figure 5, below, shows the trend in CMR by race over time. As with gender, the group with the higher rate fluctuates from year to year. This is related to the small number of deaths and random variation.**Figure 5: CMR by Race, FY 2019 – FY 2025**



The top cause of death categories by race for White/Caucasian and Black/African American IDD individuals is shown in Table 21. Respiratory Disease was the top category for White/Caucasian individuals, while Neurological Disorder was the top category for Black/African American individuals.

Table 21: Top Cause of Death Categories by Race, FY 2025

White/Caucasian	
Cause	Deaths
Respiratory Disease	39
Cardiovascular Disease	38
Genetic malformations, deformations and chromosomal abnormalities	30
Neurological Disorder	21
Cancer	21
Endocrine, nutritional & metabolic disease	20

Black/African American	
Cause	Deaths
Neurological Disorder	17
Cardiovascular Disease	16
Respiratory Disease	11
Congenital malformations, deformations and chromosomal abnormalities	11
Cancer	9
Genetic malformations, deformations and chromosomal abnormalities	7

Services and Supports

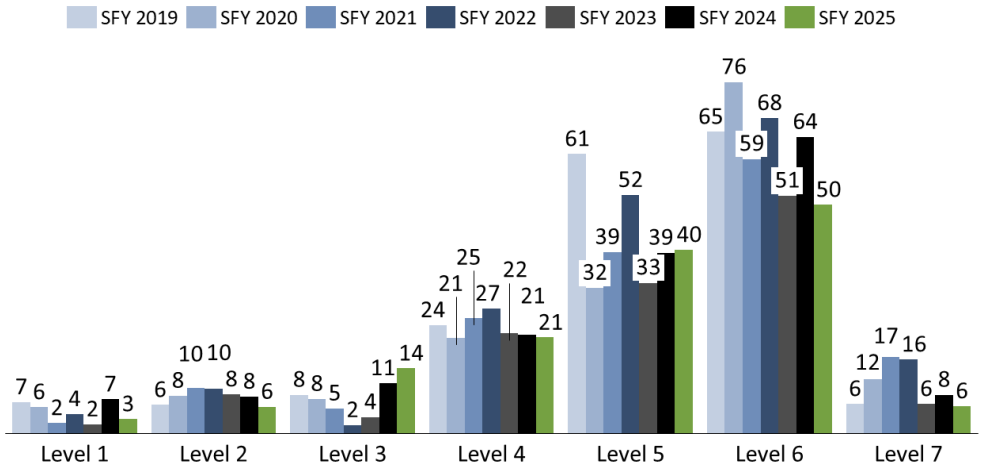
CMR for individuals with IDD receiving waiver services by Supports Intensity Scale *(SIS*) level is shown below in Table 22. The CMR was highest for IDD individuals with a SIS level of 6 similar to FY 2024.

Table 22: Deaths and CMR by SIS level, FY 2025

SIS Level	Waiver Deaths	Waiver Population	CMR
1	3	958	3.1
2	39	6716	5.8
3	8	566	14.1
4	135	6481	20.8
5	21	528	39.8
6	71	1431	49.6
7	8	1351	5.9

CMR by SIS level is displayed in Figure 6. IDD individuals with SIS Level 6 have typically had a higher CMR than those individuals at other SIS levels.

Figure 6: CMR by SIS Level, FY 2019 – FY 2025



Residential Setting

Table 23 indicates the total number of IDD deaths by residential setting and is similar to the settings in previous years.

Table 23: Deaths by Residential Setting, FY 2025

Residence	Deaths	Percent
Group Home	152	38.69%
Private Residence w/ Family	84	27.82%
Sponsored Placement	40	12.83%
Private Residence Other	18	6.57%
ICF/IID	16	3.42%
NF/SNF/ALF	8	4.17%
State Facility	6	6.49%
Total	**324**	**100.00%**

CMR for individuals receiving waiver services in a congregate or institution setting, versus those living independently *(including with family)* is shown in Table 24. As in the previous year, the CMR for individuals in congregate or institutional settings was higher.

Table 24: CMR by Living Situation for DD Waiver Recipients, FY 2025

Residential Living Situation	Deaths	DD Waiver Population	CMR
Congregate or institution	159	4965	32.0
Independent	130	13069	9.9

FY 2024 Status

<u>Recommendation 1:</u> The MRC should increase implementation of specific interventions for individuals with Failure To Thrive (FTT)/Slow Decline and Protein Calorie Malnutrition (PCM) in an effort to impact mortality prevention strategies for the IDD population. FTT and PCM accounted for 21/370 deaths in FY24.

RESULT: Completed data analysis related to FTT and PCM revealed >70 percent of individuals diagnosed with FTT and/or PCM were receiving end of life *(EOL)* care. Given the high proportion of those receiving EOL care, the MRC elected not to pursue this QII further as mortality prevention strategies were unlikely to have an impact on individuals with IDD already receiving EOL care. Data will continue to be collected and monitored to identify any additional trends should they arise.

Recommendation 2: The MRC should determine if there are patterns of similar or correlating environmental and/or medical components (i.e., medical conditions, residence type, supports, dietary protocols/restrictions, etc.) that may be contributing factors or areas of targeted interventions for individuals with a Supports Intensity Scale (SIS) Level 6, as Crude Mortality Rate remains highest (64.3 percent) among these individuals with IDD in Virginia.
RESULT: The Committee continues to collect and track data related to SIS Level 6 deaths. If ongoing data analysis reveals correlating environmental and/or medical components, the committee will develop and recommend strategies to address findings.

Recommendation 3: The MRC should attempt to decrease repeated emergency department (ED) visits for individuals with IDD related to the same health issue/concern, as MRC members noted an upward trend in ED utilization (based on DBHDS incident reporting data) during multiple case reviews.
RESULT: As a result of the MRC's ED Utilization QII, educational materials on the role of Managed Care Organization Care Coordinators were developed in an effort to improve continuity of care for individuals with IDD receiving DBHDS licensed services and reduce repeat ED visits. The draft version of educational materials remains under review by the DBHDS Office of Integrated Health in preparation for distribution to licensed providers.

Recommendation 4: The MRC should explore the incidence of pressure injuries (PIs) in IDD individuals with increased risk factors for developing serious infection as a result of PIs (i.e., non-ambulatory and non-verbal) in an effort to decrease risk for Sepsis, as Sepsis accounted for cause of death in 26/370 deaths in FY24. Of the 26 Sepsis deaths (N=370), the number of PIs as a factor can be explored as PI cases are denoted during case composition.
RESULT: The Committee continues to collect and track data related to the role of PIs in Sepsis. If ongoing data analysis identifies trends related to PIs and Sepsis, the committee will develop and recommend strategies to address findings.

FY 2025 Recommendations

Analysis and review findings of mortality review data in this report relate to actions, interventions, and/or activities that the committee determined were warranted to bring about improvement or changes in; support delivery (such as adherence to existing standards, technical assistance and training/education), and/or service or support gaps (such as medical care, access to other care and pharmacy/medication concerns).

Since the IDD MRC serves as a reviewing committee, it is usually not the primary entity with the authority to implement recommended activities, but communicates with internal agency Offices, and external collaborating partners to consider enacting.

- The MRC should focus on making end-of-life recommendations not only to impact mortality rates, but also to increase quality of care and quality of life regardless of health status.

- The MRC should further evaluate the top cause of sudden cardiac unexpected deaths in individuals with IDD to determine risk factors that may be impacted by interventions and/or early actions.
- The MRC should consider the benefit of standardized death data statewide and nationally, that may ensure data consistency for longitudinal analysis, while aiding with the committee's death determinations.

Conclusion

Individuals with IDD in Virginia and across the country continue to experience health disparities compared to those without IDD. Addressing existing or potential health risk factors through early recognition and intervention by DBHDS licensed providers for all individuals with IDD that we serve is a priority. The DBHDS IDD MRC recommends and supports efforts focused on including individuals with IDD in disease prevention, health promotion, and emergency response activities, while identifying barriers to care in order to ensure the health, safety and wellness of these individuals. This report makes an important contribution towards these efforts.