Every Minute Matters:

Oversight and Emergency Response Failures in DD/ID care

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the disAbility Law Center of Virginia

Executive Summary

The disAbility Law Center of Virginia has done an extensive, multi-year review of unexpected deaths of individuals with Intellectual and Developmental Disabilities (IDD) receiving services licensed by the Department of Behavioral Health and Developmental Services (DBHDS). Concerns about the lack of autopsies and inaccurate death certificates motivated this work with the goal of identifying preventable patterns and strengthening protections for this vulnerable population. Ultimately, dLCV identified several concerning trends, including misleading death certificates, inadequate emergency response, preventable choking deaths, and staffing and compliance concerns. dLCV recommends that DBHDS amend its regulations to require emergency medical drills, and that the Commissioner of DBHDS issue stringent sanctions, including punitive civil sanctions, where life-threatening violations are discovered.

In this report we will

- Review the history of reform efforts
- Identify the focus of dLCV's study
- Describe dLCV's data collection
- Demonstrate what the data reveals
- Recommend critical life-saving measures needed

History: Autopsy Workgroup

In the 2022 session, the General Assembly passed a bill requiring DBHDS to convene a workgroup, to include dLCV, to look into cases of unexpected and sudden deaths among people with intellectual and developmental disabilities (IDD). The goal was to come up with guidelines on when autopsies should be done if someone with IDD who was receiving services licensed by DBHDS passes away.

The final workgroup report was written by staff at DBHDS and submitted to the Secretary of Health and Human Resources in October 2022 but was not approved for publication until February 2023, thus not in time for the 2023 legislative session. The report was not shared with the workgroup until months after it was sent to the Secretary for approval and only after repeated requests from dLCV to share the report. The workgroup members did not have any say in what was included in the final report and did not review it before it was officially submitted.

The report mainly discussed the history and current work of the Developmental Disabilities Mortality Review Committee (MRC). **The last page of the report does list four recommendations from the Autopsy workgroup**:

1. Establish policies and procedures and identify resources and funding for hospital autopsies of selected individuals with developmental disabilities receiving a DBHDS licensed service, with authorization by next-of-kin.
2. DBHDS and the Office of the Chief Medical Examiner (OCME) should prepare training on appropriate reporting of deaths to law enforcement and OCME regarding individuals receiving services from DBHDS at the time of death or immediately prior to admission to another hospital. This training can be required for DBHDS providers and shared with law enforcement agencies. There would also be a need for alignment in the DBHDS incident reporting system to track the number of deaths referred to law enforcement/OCME and the outcome of that referral.
3. Conduct a retrospective data review of the DD MRC to determine the number and types of deaths that could be medical examiner cases. This would review cause of death as a reason for referring to the medical examiner (e.g. aspiration, pneumonia).
4. Establish a structure and process for ensuring individuals with IDD in Virginia Department of Corrections (DOC) facilities are identified to determine mortality prevention strategies.

DBHDS did not support the first and fourth recommendations. According to DBHDS, the first and fourth recommendation are "not in the Scope of DBHDS." DBHDS claimed that they thought these recommendations were to be "assigned to another Autopsy Workgroup member's facility"—possibly the Virginia Department of Health for recommendation 1, and the "Ombudsman's office" for recommendation 4.

The Autopsy Workgroup's second and third recommendations garnered more consideration from DBHDS. As for the second recommendation, DBHDS has developed training that is currently being implemented. DBHDS has reported that they intend to add a requirement for this training in upcoming amendments to their licensing regulations. Finally, the DBHDS response for recommendation three: "Retrospective review has not been initiated to date as more information is needed to determine specific measures of the data in order to define the search parameter."

dLCV believes that the adoption of these recommendations would add better protection for individuals in DBHDS-licensed facilities. However, based on the findings in this report, there are

other more pressing concerns that should be prioritized which are addressed in dLCV's recommendations below.

One key issue discussed by the DBHDS Autopsy Workgroup and also identified in dLCV's investigations is the **quality and reliability of death certificates**. DBHDS and the Office of the Chief Medical Examiner (OCME) agreed during workgroup discussions that the reliability of cause of death listed on death certificates is a problem. This problem is discussed in greater detail below.

There can be no meaningful discussion of how to prevent future deaths if we do not have accurate information about why an individual died suddenly.

dLCV's Study: Updated Focus

During the first year of this three-year project, dLCV's analysis focused on the issue of autopsies and thus reviewed cases where an autopsy may have potentially provided vital information in meeting the goal of reducing preventable deaths. After the completion of the workgroup, dLCV changed the focus of review to sudden unexpected deaths.

Through the review of deaths in the first year of the study, dLCV gained insight into the investigative process of DBHDS' **Mortality Reviews and Specialized Investigation Unit**. dLCV and its predecessors have been conducting death investigations for more than 40 years and have thus seen the evolution of the system and its response to deaths in state facilities and licensed community-based programs. dLCV applauded the creation of the Specialized Investigation Unit and Mortality Reviews and has found that the investigations they do to add great value to the mission of creating a safer community for people with IDD. Their investigations and the reports are thorough and informative, which has supported a collaborative approach to identifying systemic issues, protecting individuals, and enhancing service quality.

However, we also identified limitations of the system, especially in determining the cause of death for IDD individuals who die with no known health conditions that could attribute to their sudden death, and in breakdowns at the provider level that could lead to preventable deaths. The first issue could be addressed by implementing the recommendations of the Autopsy Workgroup and the second issue is addressed in dLCV's recommendations in this report.

Collecting Data

dLCV reviewed deaths that were reported by providers in the Computerized Human Rights Information System (CHRIS). We used selective sampling to choose which cases to pull for further

investigation. Selective Sampling is a non-probability sampling technique that involves selecting participants based on specific criteria. In this study, cases were chosen based on deaths being sudden and unexpected.[1]

dLCV ultimately reviewed the records of 181 IDD individuals.

dLCV requested Mortality Review documents from the Specialized Investigation Unit (SIU) for every sudden and unexpected IDD death identified in CHRIS. In most cases, dLCV received the death certificate, the final investigative report, and the Corrective Action Plan if available. When an autopsy was performed, dLCV either received the report from SIU or directly from the OCME. Throughout the study, dLCV identified trends and issues of concern to track and analyze.

Findings: what does the data reveal?

Cause of Death

As background, when a death is deemed to be from natural causes, there is generally no review from a medical examiner or other forensic pathologist. In short, every death comes with a death certificate, but not every death comes with an autopsy.

TABLE 1: WAS AN AUTOPSY DONE?

Yes	9
No	83
Unknown	10
No, but ME contacted	53[2]
No, but ME signed death certificate	26[3]

Every death certificate must include a medical certification by a licensed medical professional such as a Medical Doctor, Physician's Assistant or Nurse Practitioner.[4] The death certificate is not

[1] For data on all IDD deaths in any given fiscal year, refer to the Annual Mortality Report. https://dbhds.virginia.gov/clinical-and-quality-management/

[2] The Autopsy Workgroup recommended training for providers and law enforcement on when to notify the OCME when a death occurs in a DBHDS-licensed program.

[3] The OCME does external views of certain cases and completes the death certificate even though they did not perform a full autopsy.

[4] Virginia Code § 32.1-263C.

always signed by a health care provider who has treated the person or has even *met* the individual before death. There is also no requirement that the medical professional certifying the death certificate have any history with or expertise in death investigations. The provider signing the death certificate must "determine the most likely cause of death to the best of their ability. If they are uncertain about the cause of death, they should use their best medical judgment to certify a reasonable cause of death."[5] The death certificate lists an immediate cause of death, underlying conditions that led to cause of death, and contributing factors.

dLCV found that, in 49 cases, a developmental disability or mental illness was listed on the death certificate as the immediate cause of death or the underlying condition that led to death. dLCV reviewed death certificates that list primary causes of death such things as intellectual disability, autism, and even "mental retardation." **None of these conditions are fatal**. By ascribing the individuals' deaths to non-fatal conditions, the medical professionals made it impossible to determine whether the death was preventable, or if further lessons could be learned.

TABLE 2: NON-FATAL CONDITIONS LISTED AS "CAUSE OF DEATH" OR CONTRIBUTING TO DEATH

Total cases	**49**
Cerebral Palsy	23
IDD	17
"Mental Retardation "	4
Down Syndrome	2
Mental Illness	5
Autism	2
"Long-term cognitive dysfunction"	1

In another 29 cases, the cause of death listed on the official death certificate conflicted with the medical information included in the DBHDS investigation reports. Examples include listing coronary artery disease as the cause of death when the medical records show the individual had no heart conditions, or where the cause of death was listed as seizure disorder when two neurologists had determined in the weeks before death that the individual was NOT having seizures.

[5] Medical Certifier Guide (https://www.vdh.virginia.gov/vital-records/electronic-death-registration-system/medical-certifier-guide/). September 24, 2025

Although the official cause of death is documented on the death certificate, during their investigation, DBHDS investigators look at the IDD individual's medical record and speak to staff who cared for them in order to gain a more complete picture of the individual and their possible cause of death. This added layer of investigation and attention enhances the ability to identify issues of concern and address them for other individuals receiving services.

More reliable information on the cause of death could significantly enhance staff's ability to recognize signs and symptoms of specific diseases and disorders in order to prevent future deaths.

For example, if an IDD individual dies unexpectedly and the provider later learns the individual died of a certain type of cancer, staff can be trained to look for signs and symptoms indicative of that disease and report them to health care providers early in order to get the best course of treatment for others in the future. In many cases (82 in this 3-year sample), individuals receiving DBHDS-licensed services were nonverbal or had low verbal skills. For people who cannot describe pain or other symptoms, recognizing the nonverbal signs becomes vital to their health and safety. In the years that dLCV has been reviewing reports of deaths and serious injuries, we have seen perhaps thousands of cases where staff have been keen to recognize subtle differences in behavior that led to diagnosis and treatment of illness or injury. Adequate and accurate death certificates could give staff a powerful tool to enhance their ability to recognize signs of distress and respond as early as possible.

Inadequate Crisis Response

Our most disturbing finding was that providers often did not respond appropriately when they found someone who was unconscious or unresponsive. Not only do these failures have serious consequences, but this has been an ongoing issue of concern known to DBHDS for several years.

In its 2018 Annual Mortality Review Report, DBHDS stated that *more than half* of the deaths they reviewed involved a failure to adhere to established emergency protocols (29 deaths). In both the 2019 and 2020 reports, the findings were even more dire with *82% of deaths* both years classified as potentially preventable involving a failure to adhere to established protocols.

Also, in the 2020 Annual Mortality Review, DBHDS identified that the most significant way in which staff neglect led to preventative deaths was by failing to follow their own 911 procedures. DBHDS attempted to fix compliance on this issue. In the latest report from 2024, they say they are still looking into different proven methods to improve how well providers stick to the rules. DBHDS has put some actions and guidelines in place and continues researching new strategies.

dLCV identified four distinct issues with providers' emergency response to an unresponsive individual: failing to provide CPR, delayed CPR, delay in calling 911, and ineffective communication with 911.

TABLE 3: FAILURES IN RESPONSE TO FINDING UNRESPONSIVE INDIVIDUAL

No CPR	46
Delayed CPR	33
Delayed 911	25
Issues during 911 call	34

Failing to give CPR

When a person is found unresponsive without a pulse or breathing, the only hope they have for successful recovery is immediate life-saving care including CPR. According to the American Red Cross, when a person has an out-of-hospital cardiac arrest, their chance of survival is about 10% even with immediate CPR. For every minute that CPR is delayed, their chance decreases by 10%.[6] A person who never receives CPR in these situations has a 0% chance of survival.

In the reports we reviewed, some reasons providers gave for failing to conduct CPR included:

- Staff could not move the individual to a solid surface due to the size of the individual and there only being one staff present;
- Belief that the individual was beyond saving;
- Concern about contracting a communicable disease such as COVID-19;
- Ignorance of how to do CPR or use AED[7]; and
- Outright refusal with no reason given

DBHDS Licensing Regulations require that there is always at least one person on duty who has a certificate in CPR and first aid.[8] A person certified in CPR is to perform life-saving acts including CPR and using an available AED until trained EMS arrives. Only a qualified licensed professional

[6] https://www.redcross.org/take-a-class/resources/articles/cpr-facts-and-statistics#:~:text=For%20the%20past%2020%20years,inside%20or%20outside%20the%20hospital, 09/24/2025

[7] In the course of their investigation, DBHDS reviews CPR certifications for the staff involved in the incident. In the vast majority of cases, DBHDS reports that CPR certifications are up-to-date. Therefore, staff have the knowledge needed to conduct CPR, but panic may play a part in their inability to perform. Drills could significantly improve staff's ability to perform under the pressure of an emergency situation.

[8] 12VAC35-105-460.

is permitted to declare death. Therefore, staff who discover an unresponsive individual must perform basic life-saving acts until trained EMS arrives regardless of their belief that the individual is deceased and beyond saving. The only exception to this rule is if the unresponsive person has a Do Not Resuscitate Order on file with that provider.

Delayed CPR

As noted above, any delay in initiating CPR significantly decreases any chance of survival. Even if staff immediately call 911 but wait for the dispatcher's instruction to conduct CPR, that delay can be fatal. Additionally, some dispatchers in Virginia are not trained to give CPR guidance.

dLCV found that, in the cases we reviewed, CPR often did not start until several minutes into 911 calls. Reasons for delayed initiation of CPR included:

- Calling other staff or a supervisor first[9];
- Taking time to "pull themselves together;"
- Waiting for instruction from the 911 dispatcher;
- Inability to determine if individual was breathing; and
- Not being able to locate or use the AED[10].

Delay in calling 911

In addition to immediate CPR, getting trained EMS to the person as soon as possible is vital to giving the individual the best chance of survival. Just as with CPR/AED, every minute counts and any delays decrease the chances of survival.[11]

The most common reason we found for a delay in calling 911 was staff calling their supervisor first when finding an unresponsive individual. In some cases, the off-site *supervisor* then called 911 rather than the person at the scene with the individual making the call.

Ineffective communication with 911

Even if staff call 911 immediately, care can still be delayed when staff fail to effectively communicate with the 911 dispatcher. Providers need to ensure that their staff know how to

[9] In two cases, staff actually left the home to run to another area seeking another staff or supervisor.

[10] In one case, the AED was locked in a closet and staff wasted several minutes searching for the key and calling other staff for direction.

[11] In one extreme case, staff found an unresponsive individual at 6:00 but did not call 911 until 6:51 with no explanation except that staff called a supervisor first.

communicate basic information to the dispatcher such as the address of the incident, details about the individual, and details about the incident.

Staff also need to listen and follow the instructions of the dispatcher. Unfortunately, when panic sets in, the ability to speak and listen are often negatively affected.

Some of the problems with 911 communication that we identified included:

- Staff talking to others (either in the room or on another phone line) rather than giving the dispatcher their attention;
- Inability to remember the address of the program[12];
- Inability to remain calm and allowing emotions to override listening;
- Inability or refusal to answer dispatcher's questions;
- The staff calling the dispatcher being in another location and relaying second or third-hand information; and
- Leaving the individual **and** the dispatcher to complete other tasks such as taking another call or talking to others on the scene.

Choking Despite Having A Food Safety Plan

dLCV identified 14 cases in which the person choked to death, even though they had a food safety plan to address choking hazards. In most of these cases, the circumstances involved a failure of supervision that led to an unfortunate, but preventable, accident. These cases are disturbing given the fact that these individuals had a known danger of choking and the providers still failed to keep them safe.[13] However, even more disturbing are the three cases where staff *deliberately* gave the individual food known to present a risk of choking and death. In these cases, staff made the conscious choice to put the individual at risk and that risk led to their death.

In one case, a sponsored residential provider (SRP) had two choking deaths occur under her care and was fired by the licensed provider after each incident. However, she told the DBHDS

[12] Given the fact that most people now use cell phones, the dispatcher no longer has the ability to determine the address from the phone number as in the past.

[13] There has been a decrease in the number of choking deaths in the past 3 years as noted in the SFY 2024 Annual Mortality Report from 8 cases in SFY 2023 to 1 in SFY 2024. However, even one preventable choking death is too many. There are accidental choking deaths that are not preventable, but advocacy and improvement must continue until there are zero preventable choking deaths.

investigator that being an SRP was her "calling" and she intends to keep finding new licensed providers to hire her.

There is currently no database where a provider may search for such prior incidents when making hiring decisions.

One Staff Present During Incident

Helping a person who is having a medical emergency is far more challenging when only one staff is on-site, as we saw in 91 of the cases we reviewed. It is not uncommon for a group home to only have one staff present on-site, especially at night, and there are no regulations requiring more than one staff member on any shift. However, it is imperative that providers recognize and prepare for the issues that may occur when there is only one person on shift.

Some common concerns that we saw in our investigation included:

- Caring for both the person in immediate need and the other recipients of services;
- Providing eye-sight or arm's length supervision for one recipient while being responsible for multiple people;
- Physically moving people when necessary for such things as CPR to a hard surface;
- Conducting CPR, locating and using the AED; and
- Communicating with the 911 dispatcher while being responsible for other recipients.

These and other issues can be identified, addressed, and practiced during emergency drills.

Repeated Violations

The DBHDS investigator in several cases identified repeated violations of the same regulatory requirement within the same year.

One provider in our sample appeared four times, repeating serious violations each time. This provider violated the regulation requiring providers to comply with their own policies 26 times. This is the regulation that often captures the provider's failure to appropriately respond to unresponsive individuals. This same provider violated the regulation requiring a working knowledge of all individuals' service plans, including health and safety protocols, 38 times in a year.

Another provider instituted a corrective action plan for staff not providing CPR for an unresponsive individual and, the next month, failed to give a second person CPR.

Another provider was *not* cited for failure to implement the Crisis Intervention Policy because they were cited for the same violation in a prior case and they were still in the same Corrective Action process.

Recommendations

Medical emergency drills

dLCV strongly recommends that the DBHDS Licensing regulations be amended to include a requirement to conduct and document emergency medical drills regularly. These drills should take place monthly or at least quarterly. This recommendation is not new as dLCV reported it to members of DBHDS leadership repeatedly in the past. DBHDS states that they intend to add requirements for emergency medical drills in upcoming amendments to their licensing regulations. Unfortunately, this process is in the initial stage of Notice of Intended Regulatory Action (NOIRA) and the full process to approve new regulations could take years.

DBHDS Licensing regulations require licensed providers to have a written emergency preparedness plan including an analysis of potential emergencies.[14] The regulation only requires drills for fire and evacuation and they must be done monthly.[15] Thus, there is no current requirement for emergency medical drills.

In 40 cases reviewed by dLCV, the DBHDS investigator specifically recommended emergency medical drills to providers. The DBHDS Offices of Licensing and Integrated Health have also released guidance on the importance of emergency planning and practice.[16] In its Sample Emergency Medical Drill Form released in October 2024, it highly recommends that "providers conduct a drill involving simulated calling of 911 and performing CPR at least quarterly."[17]

[14] 12VAC35-105-530

[15] 12VAC35-105-530-A.6

[16] https://dbhds.virginia.gov/wp-content/uploads/2024/07/Medical-Emergency-Drills-HS-Alert-combine.pdf; https://dbhds.virginia.gov/wp-content/uploads/2024/08/Common-Medical-Emergencies-HS-Alert-August-2024.pdf; https://dbhds.virginia.gov/wp-content/uploads/2024/06/July-2024-Newsletter.pdf; https://dbhds.virginia.gov/wp-content/uploads/2024/10/Emergency-Preparedness-PowerPoint-SIU-OIH-October-2024.pdf

[17] https://dbhds.virginia.gov/wp-content/uploads/2024/10/Sample-Medical-Emergency-Drill-Form-Oct-2024.pdf

In its Health & Safety Alert entitled "Emergency Preparedness: Medical Emergency Policies, Plans and Drills," the DBHDS Office of Integrated Health lists benefits of conducting medical emergency drills:

- Uncovering gaps in staff knowledge and time to review needed competencies;
- Reducing the risk of panic during an actual emergency event;
- Helping a licensed provider to find out if the Medical Emergency Response Plan actually works;
- Improve recall of skills, understanding of procedures and response time of staff members;
- Promoting communication, collaboration, and cooperation among staff; and
- Building confidence and strengthens the relationships among team members so they can better handle emergency situations.[18]

Despite these benefits, the repeated recommendations of the Offices of Licensing and Integrated Health and dLCV, and the years of dismal data around emergency response to unresponsive individuals, medical emergency drills are not yet required.

Conducting emergency medical drills would also address another issue identified by dLCV—response to a medical emergency when there is only one staff present. In the course of conducting drills, providers and staff can identify the limitations, and ultimately the solutions, faced when one person must respond to an emergency while also managing the other responsibilities of their job. For example, staff can discuss how to handle moving an unresponsive individual; handling the needs of other recipients while also dealing with the emergency needs of one individual; and how to initiate emergency medical treatment, including CPR/AED, calling 911, and getting support from management.

Sanctions

dLCV recommends the use of enhanced sanctions, including monetary fines, in cases of neglect that may contribute to an individual's death or decrease an individual's chance of surviving a medical emergency and in cases of repeated violations.

[18] https://dbhds.virginia.gov/wp-content/uploads/2024/07/Medical-Emergency-Drills-HS-Alert-combine.pdf

Under Virginia Code §37.2-419, the DBHDS Commissioner has the authority to issue a special order imposing sanctions to licensed providers who violate Virginia Code or Regulations related to the offices of Licensing and Human Rights.[19] Sanctions could include:

1. Place any service of any such provider on probation upon finding that it is substantially out of compliance with the licensing or human rights regulations and that the health or safety of individuals receiving services is at risk.
2. Reduce licensed capacity or prohibit new admissions when he concludes that the provider cannot or will not make necessary corrections to achieve compliance with licensing or human rights regulations except by a temporary restriction of its scope of service.
3. Require that probationary status announcements and denial or revocation notices be of sufficient size and distinction and be posted in a prominent place at each public entrance of the affected service.
4. Mandate training for the provider's employees, with any costs to be borne by the provider, when he concludes that the lack of training has led directly to violations of licensing or human rights regulations.
5. Assess civil penalties of not more than $500 per violation per day upon finding that the licensed or funded provider is substantially out of compliance with the licensing or human rights regulations and that the health or safety of individuals receiving services is at risk.
6. Withhold funds from licensed or funded providers receiving public funds that are in violation of the licensing or human rights regulations upon finding that the licensed or funded provider is substantially out of compliance and that the health or safety of individuals receiving services is at risk.

Certain violations by providers create obvious risks to the health and safety of individuals receiving services. Providers who *repeatedly* violate the same regulations mandating these actions are clearly placing the health and safety of individuals receiving services at high risk. Drafting and following Corrective Action Plans may be sufficient in many cases of regulatory violations, but egregious and repeated violations call for a more drastic response.

When a violation is so egregious that it may have led to an individual's death or decreased their chance of surviving a medical emergency, there must be a punitive response from the State.

Corrective action is, of course, a critical part of the licensing process. However, if all providers have to worry about is a slap on the wrist and a warning of “don’t do it again,” we can be certain

[19] §37.2-400; 12VAC35-105; 12VAC35-115; §§37.2-403 to 422

that unscrupulous providers will continue violating the same regulatory requirements again and again…up to 38 times in one year, as the data demonstrates

Failing to provide emergency medical treatment, delaying such treatment, failing to call 911 immediately upon discovering a medical emergency, and failing to follow food safety protocols should be addressed as substantial noncompliance and handled accordingly: **either with a civil penalty or withholding funds as authorized in Virginia Code §37.2-419.** dLCV is not aware of DBHDS ever instituting a civil penalty against a licensed provider.

When dLCV asked DBHDS about the use of civil penalties, the Director of the Office of Licensing provided the following response:

> *"DBHDS recognizes the importance of accountability. While corrective action plans remain our primary enforcement tool, The Office of Licensing will convene an internal workgroup to review whether expanded use of sanctions, including civil penalties, is appropriate in egregious or repeated cases where health and safety risks are severe."*

Conclusion

The findings of this report highlight critical and alarming deficiencies in the care provided to IDD people receiving DBHDS-licensed services, particularly in relation to emergency medical responses, cause of death documentation, and food safety protocols. The failure to adhere to established protocols for medical emergencies identified by DBHDS and dLCV, including delayed or absent CPR and ineffective communication with 911, presents serious risks to the health and safety of vulnerable Virginians. Repeated violations of regulatory requirements by some providers only exacerbate the problem, demonstrating a pattern of neglect and lack of accountability.

In order to address these issues and protect those IDD individuals receiving licensed services, it is essential that DBHDS implement stronger measures immediately, including the requirement of emergency medical drills and the imposition of serious sanctions on noncompliant providers.

The recommendations outlined in this report aim to close gaps in staff preparedness, ensure quicker and more effective responses in medical emergencies, and foster a culture of accountability within DBHDS-licensed providers. By taking these steps, DBHDS can better safeguard the health and well-being of those under its care and prevent or decrease preventable deaths.

Appendix A: Table of Findings

Age

Average	50
Range	19-83
Median	54

Place of death

Group Home	**79**
Hospital	48
Supported Residential Home	28
Emergency Room	18
Home (supported living)	4
Day Support	1
Other—vacation/out of state	3

Licensed service being provided when death occurred

Group Home	**129**
Supported Residential Home	39
DD Supportive in-home	5
Day Support	4
Intermediate Care Facility	4

Autopsy Done?

Yes	9
Unknown	10
ME contacted	53[20]
ME signed death certificate	26[21]

[20] The Autopsy Workgroup recommended training for providers and law enforcement on when to notify the OCME when a death occurs in a DBHDS-licensed program.

[21] The OCME does external views of certain cases and completes the death certificate even though they did not perform a full autopsy.

Licensing violations found	98
Former Training Center residents	30

Cases where deceased was with provider for short time[22]

0-1 month	11
1-3 months	8
3-6 months	13

Reported cause of death or conditions leading to death are non-fatal IDD or MH diagnosis[23]

Total cases	**49**
Cerebral Palsy	23
IDD	17
Mental Retardation	4
Down Syndrome	2
Mental Illness	5
Autism	2
"Long-term cognitive dysfunction"	1

Cause of death conflicts with medical information in investigation	29

Inadequate response to finding unresponsive individual

No CPR	46
Delayed CPR	33
Delayed 911	25
Issues during 911 call	34

[22] In a small number of cases, the individual was moved into a new home because their medical needs were too great for their former home. In these cases, the individual was in a poor medical state when moving into the new home, but the death was still unexpected.

[23] The number of individual diagnoses does not add up to the total because some death certificates listed more than one non-fatal IDD or MH diagnosis.

Other general findings

Nonverbal or low-verbal	82
Choked despite having a food safety plan	14
Person found already cold/stiff	33
Recent procedure or med change	25
Provider had multiple violations for same regulation	8
One staff present during incident	91