



Mortality Review Committee Recommendation Report

**Indiana Division of Disability and Rehabilitative Services
Bureau of Quality Improvement Services**

Dates of Review: October 2015 – December 2017

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Introduction

The Indiana Division of Disability and Rehabilitative Services (DDRS) Bureau of Quality Improvement Services (BQIS) monitors the providers and organizations that administer services to individuals with intellectual and developmental disabilities. As part of the ongoing monitoring, BQIS reviews the deaths of all individuals receiving services through the Bureau of Developmental Disabilities Services (BDDS). The mortality review process includes an in-depth review by the Mortality Review Triage Team (MRTT) followed by a review by an interdisciplinary Mortality Review Committee (MRC). For each mortality review, documentation is obtained and reviewed for the 30 days preceding the death or preceding a nursing facility/hospital admission. In each case, the documentation includes, but is not limited to, the following: provider documentation, provider's internal investigation of the death, all alleged abuse or neglect incidents, medical records, case manager case notes, incident reports, staff training records, death certificate, and autopsy (if applicable). The MRTT may request additional documentation if determined necessary. The MRTT synthesizes the information and produces a mortality brief of each case which is shared with the MRC. During the monthly MRC meeting, the MRC has the opportunity to make provider recommendations on any mortality case reviewed.

The MRTT is comprised of a physician and registered nurse as well as staff educated in program expectations and service delivery. The MRC encompasses professionals from various entities who represent individuals with intellectual or developmental disabilities. The professionals include a physician, a registered nurse, the state Ombudsman, Indiana Disability Rights, Adult Protective Services, Indiana Department of Health, the Attorney General, the Office of General Counsel for the Indiana Family and Social Services Administration, the Bureau of Developmental Disabilities Services, and the Bureau of Quality Improvement Services. The purpose of the mortality review process is to identify trends, develop and issue provider-specific recommendations, present general recommendations, and bring about improvement in both provider-specific and system-wide service delivery.

The information presented in this report is reflective of the data collected during the MRC recommendation process. These recommendations are for general guidance of best practices and are not intended to replace professional advice of a healthcare professional; dictate the care of a particular individual; or set a standard of care. Nor are these recommendations a complete list of measures a provider should take when delivering services. For information regarding provider requirements, see 460 Indiana Administrative Code (IAC) 6 and 42 CFR 483, Part I, as applicable.

For the timeframe of October 2015 through December 2017, the MRC was presented with 1,122 mortality cases. The MRC made 427 recommendations on 206 of the mortality cases. The number of recommendations per mortality ranged from one to seven with an average of two recommendations per mortality case. Over 78% of the cases with recommendations involved individuals on the Community Integration and Habilitation Waiver.

The following BDDS services¹ were included in the review process:

- Family Supports Waiver
- Community Integration & Habilitation Waiver
- Caregiver Supports
- Large Private Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities
- Nursing Facilities Omnibus Budget Reconciliation Act (OBRA)
- Supervised Group Living
- State-operated Care Facilities

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¹ BDDS service definitions are located in the glossary

Background

This report is the result of the review of provider's service delivery to individuals with intellectual and developmental disabilities receiving services through the Bureau of Developmental Disabilities Services (BDDS) at the time of death. Through this review, prominent categories have been identified that may assist in the prevention of service delivery issues and treatment of certain illnesses and conditions that may lead to death or other complications in the future.

In 2011, the crude adult² mortality rate for individuals with intellectual and developmental disabilities in Connecticut, Ohio, Louisiana, and New York was 9.37 compared to 7.87 in the general population of the same states. The disparity between the two populations was even greater in 2009. The intellectual and developmental disabilities population in those same states had a crude adult mortality rate of 14.96 compared to 10.02 in the general population of the same states (Lauer, Emily and McCallion, Phillip, page 398). "Individuals with intellectual disabilities... often present with a variety of potentially complex comorbidities (secondary health and behavioral conditions) that can elevate their relative mortality risk compared to the general population" (Center for Developmental Disabilities Evaluation and Research, 2014). According to the National Center for Health Statistics, people with intellectual and developmental disabilities of all ages have a life expectancy of 50.4-58.7 years compared to the general US population of 78.5 years (CDC 2011).

In many of the mortality reviews, the staff's lack of knowledge and understanding of the individual's disability and needs resulted in a late diagnosis of illness which can have an impact on the success of treatment (Care Quality Commission, 2016). Signs and symptoms related to an injury or illness in individuals with intellectual disabilities are often missed due to the individual's difficulty in communicating. "Special skills of observation, together with a close knowledge of what is normal behavior for an individual with intellectual disabilities, are needed to pick up signs and symptoms related to the illness" (University of Hertfordshire, 2017). The lack or poor quality of staff training on individual-specific information is also a contributing factor to a late diagnosis of injury or illness (Commonwealth of Massachusetts, Department of Developmental Disabilities, 2014). Training of staff, especially identifying changes in condition and seeking medical intervention, was a consistent issue in the mortality reviews and was addressed within each category.

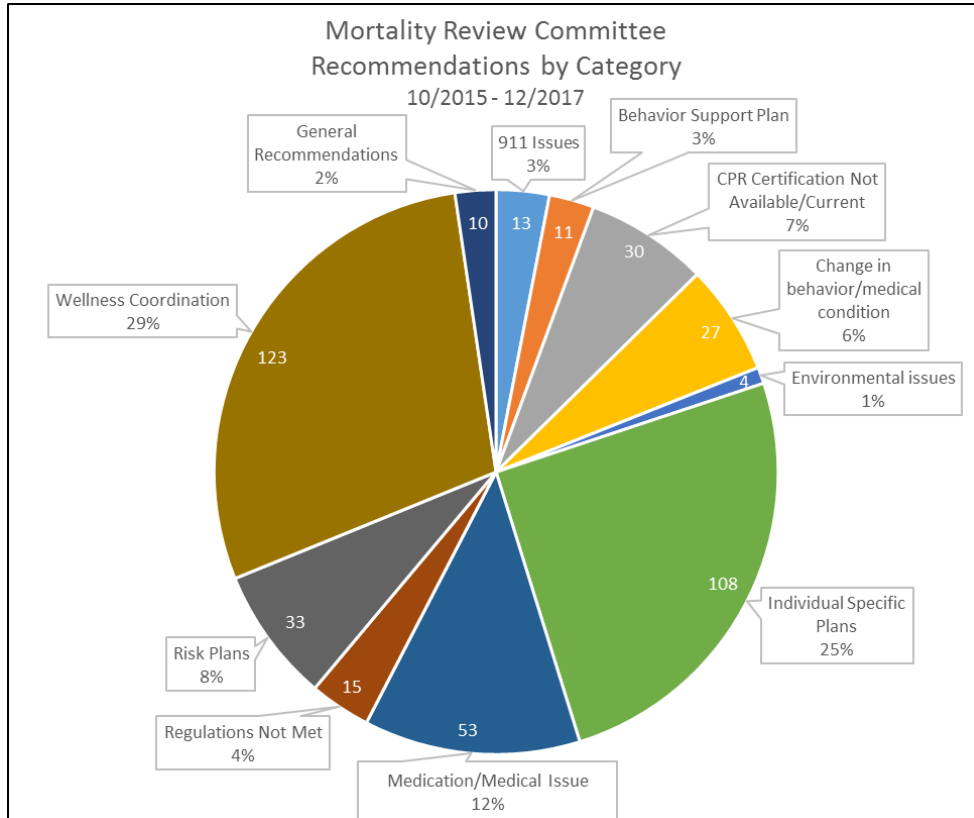
The following ten service areas were identified by the Mortality Review Committee as areas needing quality improvement to assist in the prevention of service delivery issues.

- 911 Issues
- Behavior Support Plan
- Cardiopulmonary Resuscitation (CPR) Certification Not Available or Not Current
- Change in Behavior or Medical Condition
- Environmental Issues
- General Recommendations
- Individual-Specific Plans
- Medication or Medical Issue

² Crude mortality rates are calculated using the number of deaths divided by the estimated size of the population. Adjustments are not made for risk factors.

- Regulations Not Met
- Risk Plans
- Wellness Coordination

Figure 1-Recommendations by Category



Mortalities Reviewed by BDDS Service

Figure 2-Mortalities Reviewed by BDDS Service

Mortalities Reviewed by BDDS Service: October 2015-December 2017	Count	Percent
Nursing Facility (OBRA)	490	44%
Community Integration & Habilitation Waiver	367	33%
Supervised Group Living	160	14%
Family Supports Waiver	102	9%
State Operated Facility	3	0%
Total	1122	100%

Data was compiled by Advocare, LLC.

Recommendations by Service Area

The categories presented in this document are areas of service delivery that should be reviewed by all providers serving individuals with intellectual and developmental disabilities. If policies and procedures that align with law or the waiver are not in place, providers should implement a Quality Improvement Process to address deficiencies. A sample Quality Improvement Process is located at the end of this document (See Appendix A).

911 Issues

Recommendations from the Mortality Review Committee regarding 911 issues were due to the staff calling a colleague instead of calling 911 immediately when an individual was experiencing an emergency medical situation.

For quality improvement and ensuring a timely medical emergency response to a situation, all Providers should:

- Ensure 911 protocol and agency policy are aligned with Cardiopulmonary Resuscitation (CPR) training guidelines; and
- Staff are properly trained on agency procedure to call 911 in emergency medical situations.

The following are real-life examples of issues resulting from 911 not being contacted in a timely manner during the dates for review. These examples illustrate the problem and the importance of calling 911 immediately during a medical emergency.

Situation: Per documentation, an individual was found on the floor face down and shaking. The staff called another team member and did not call 911 until the individual was unresponsive.

Recommendation: Provider should implement a process where CPR guidelines are followed in the event of a medical emergency.

Situation: Per documentation, the individual complained of chest pains and dizziness and was extremely weak. The staff called the nurse first when the individual complained of chest pains, dizziness, and weakness. The nurse then instructed the staff to call the ambulance.

Recommendation: Provider should implement a process where CPR guidelines are followed in the event of a medical emergency.

Situation: Per documentation, an individual asked for staff's assistance to call an ambulance to be taken to the hospital. Further, documentation on the same date states the direct support professional was unsure about what to do because the individual was not feeling well.

Recommendation: Provider should ensure all staff working with an individual are trained on how to respond when an individual's health status changes.

Behavior Support Plan (BSP)

During the Mortality Review Committee's review, many cases were presented where the staff were not following the Behavior Support Plan (BSP) or where the Behavior Support Plan lacked sufficient detail to provide staff with positive supports and concrete methods to address identified behaviors.

These issues may not have been a contributing factor to the death; however, for quality improvement and reducing BSP issues, all Providers should:

- Ensure BSP training is comprehensive and includes a demonstrated assessment of the training;
- Develop and implement a process, which includes management oversight, to ensure staff are following the BSP protocols;
- Provide options in the BSP that support safe living while respecting an individual's right to make personal choices;
- Develop and implement robust training on individual-specific behaviors that includes information to assist staff in discerning when a behavior may indicate medical symptoms; and
- Ensure protocols are clearly defined that entail when staff are to contact the behaviorist for additional support.

The following are real-life examples of common instances where BSPs were not followed or available during the dates of review. These examples illustrate the problem and the importance of training and adherence to BSPs.

Situation: Per documentation, the individual was given a choice of food for breakfast. After eating, the individual indicated a desire for additional breakfast including foods that his peers had eaten. When the staff denied the individual his request, the individual began exhibiting behaviors.

Recommendation: Provider should review the DDRS' policy on respecting individual choice in regards to the individual choosing what to eat and develop a strategy to respect choice while maintaining portion control to avoid unwanted behaviors.

Situation: Per documentation, the individual's medical condition had deteriorated and the individual was no longer verbal. However, the individual's documented replacement behaviors included using code words to express wants/needs.

Recommendation: Provider should ensure the BSP is updated to reflect appropriate replacement behaviors that the individual is capable of doing. Additionally, the Provider should develop more robust training on individual-specific behaviors and then retrain staff to discern what the individuals behavior is communicating (e.g., crying as a behavioral issue versus crying as a result of medical symptoms).

Situation: Per the BSP, the individual was non-compliant regarding meals and insulin. After 30 minutes of giving the individual some space and attempting every five minutes to gain compliance, the staff were to notify the nurse if compliance was not achieved. The individual refused to take all of the prescribed medications and refused to eat. Blood sugar was taken and registered extremely high throughout the day. The individual became angry because blood sugar did not come down, but repeatedly refused insulin and food; however, the nurse was not notified.

Recommendation: Provider should implement supervisory verifications of staff competency (e.g., staff following the BSP as written). Provider should develop and utilize a tool to monitor and track competency verifications. Provider should ensure established protocols are followed.

Cardiopulmonary Resuscitation (CPR) Certification Not Available or Not Current

Cardiopulmonary Resuscitation (CPR) Certification is a 460 IAC 6 requirement of all direct support professionals. The Mortality Review Committee identified several cases in which CPR certifications were not available to the committee or were not current for the staff working with an individual. Subsequently, the Committee made recommendations to the Providers in those specific cases.

For quality improvement efforts to reduce the lack of CPR certification or documentation, all Providers should:

- Establish an effective system for tracking required training and/or certifications;
- Ensure the training tracking system identifies upcoming expirations; and
- Ensure the training tracking system prohibits a staff member from providing services without the required training and/or certifications.

The following are real-life examples where lack of CPR certification or training was evident during the dates for review. These examples illustrate the problem and the importance of ensuring CPR certification is current and training is documented.

Situation: Per documentation, several staff members' CPR certification were not current at the time of the individual's death. In one instance, individual-specific training was also missing.

Recommendation: Provider should implement a system to ensure all certifications and trainings are complete, current, and documented appropriately, as required by 460 IAC 6.

Situation: Per documentation, of all staff on the schedule, CPR certification was outdated for one staff member and individual-specific training was not found for one staff member.

Recommendation: Provider should implement a system to ensure all certifications and trainings are complete, current, and documented appropriately, as required by 460 IAC 6.

Situation: Per the training documents submitted, two staff members' CPR certifications were not current at the time of the individual's death.

Recommendation: Provider should implement a system to ensure all certifications are complete, current, and documented appropriately, as required by 460 IAC 6.

Change in Behavior or Medical Condition

The majority of recommendations from the Mortality Review Committee regarding Change in Behavior or Medical Condition were due to Providers not recognizing that behavior changes were related to a change in the individual's medical condition.

For quality improvement and reducing issues with identifying a change in behavior or medical condition, all Providers should:

- Ensure an effective system is in place for tracking changes in behaviors;
- Review documentation standards so the staff are documenting medical symptomology in progress notes to ensure continuity of care;
- Develop and implement an internal system to track what actions are taken when staff identify issues that need attention to ensure there is appropriate follow-up;
- Train staff on the "normal" or "baseline of the individual" in order to recognize when a change in condition occurs; and
- Train staff to recognize physical symptoms that relate to a change in medical condition (e.g., shakiness, agitation, food refusal, blood sugar levels, lethargy, etc.).

The following are real-life examples of common instances of behavior issues indicating medical conditions that occurred during the dates for review. These examples illustrate the problem and the importance of awareness of each individual's baseline behavior.

Situation: Per documentation, the individual had health issues for two months that indicated blood sugar levels were out of normal range.

Recommendation: Provider should train staff on diabetes management including awareness of the impact of other physical conditions on blood sugar levels that indicate the need for medical intervention.

Situation: Per an incident report, the individual was exhibiting abnormal behaviors. A subsequent incident report dated two days later stated the individual was diagnosed with pneumonia.

Recommendation: Provider should retrain staff on how to recognize and respond to changes in condition; the combination of physical and behavioral changes may indicate that a higher level of intervention may be needed.

Situation: Per documentation, the individual had multiple falls with injuries during a two month timeframe.

Recommendation: Provider should develop and implement a procedure to ensure risk plans are being followed by staff. The Provider should develop and implement a procedure to intervene when there are patterns of falls identified for an individual.

Situation: Per documentation, staff identified new health issues and behaviors but it was unclear what actions staff took in regards to these issues.

Recommendation: Provider should ensure there is adequate documentation and training on how to report new or worsening medical conditions to the appropriate person.

Environmental Issues

Recommendations from the Mortality Review Committee regarding Environmental Issues were due to medical or mechanical equipment not working.

For quality improvement in reducing Environmental Issues, all Providers should:

- Implement a procedure for identifying, documenting, and repairing broken equipment;
- Ensure back-up equipment is available or can be easily obtained in emergency situations; and
- Ensure equipment to support an individual's medical condition is available and in good working condition in the environment.

The following are real-life examples of common instances where environmental factors contributed to issues during the dates for review. These examples illustrate the importance of assessing environmental factors on a standardized basis, and ensuring staff are trained accordingly.

Situation: Per documentation, the individual did not go to day service on one occasion due to an issue with the van. It is unclear how long the situation with the van had existed.

Recommendation: Provider should have a system to track maintenance on vehicles, and have an alternative plan for transportation when required.

Situation: Per documentation, the individual's breathing machine was not working and the individual was unable to receive his breathing treatment.

Recommendation: Provider should implement a process for reporting and replacing broken equipment, and have an alternative plan to ensure the individual has the necessary equipment.

Situation: Per documentation, CPR was not performed due to bodily fluids on the individual's face.

Recommendation: Provider should retrain staff in CPR so they understand chest compressions can be done without breaths, if necessary. Provider may also wish to have CPR masks available in each house or vehicle for staff to use in cases such as this.

Situation: Per the documents submitted, only the nurse was recording oxygen saturation levels.

Recommendation: Provider should obtain an oximeter to keep in the home with an individual who is diagnosed with chronic respiratory conditions for staff to monitor oxygen saturation levels. Provider should train staff on the oxygen saturation levels and when the nurse or management should be notified.

General Recommendations

General Recommendations from the Mortality Review Committee are areas where the Committee identified opportunities for changes or improvements that are not directly linked to existing requirements.

For quality improvement, all Providers should:

- Establish or provide a support system for emancipated individuals when health condition declines;
- Clearly document what services have been offered to and refused by the individual; and
- Format staff narratives in a chronological format.

The following are real-life examples of common instances where various factors contributed to issues during the dates for review.

Situation: Per the documents submitted, the individual was emancipated, self-administered medications, and also had a diagnosis of dementia. Because a Medication Administration Record was not maintained, it is unknown if the individual received the appropriate medication at the appropriate time.

Recommendation: The provider may wish to establish or provide a support system for this type of individual to ensure appropriate medication administration.

Situation: Per the progress notes submitted by the Provider, there were several instances where staff documented for an individual with the phrase 'wants and needs were met'.

Recommendation: Provider may wish to train staff on writing progress notes that reflect an individual's daily medical concerns, risk issues, goal progress, behaviors, and other descriptive information which would assist other staff in understanding the individual's past and current status.

Situation: Staff member working in an individual's home was found unresponsive with a needle and syringe. The staff member admitted to using illicit drugs while on duty.

Recommendation: Provider should consider drug screens for potential employees and random drug screening for current employees. Provider should involve police when illegal activity occurs.

Situation: Individual was not able to utilize community habilitation services as desired due to pressure ulcers that limited the individual's amount of time in the wheelchair.

Recommendation: Provider should consider alternative methods to assist an individual with skin integrity issues who wish to do things in the community.

Individual-Specific Plans

The most common issue resulting in a recommendation from the Mortality Review Committee with Individual-Specific Plans involved Providers not ensuring the required documentation was on file for staff being trained on current individual-specific plans.

For quality improvement and reducing individual-specific plan issues all Providers should:

- Establish an effective system for tracking required individual-specific trainings that includes management oversight;
- The established system should identify upcoming expirations; and
- The established system should prohibit a staff member from providing services without the required training.

The following are real-life examples of common individual-specific plan situations that occurred during the dates for review. These examples illustrate the problem and the importance of Providers following the individual-specific plan training requirements as established in 460 IAC 6.

Situation: Per the investigation, hospital discharge instructions were passed verbally to staff rather than documented.

Recommendation: All discharge instructions for an individual should be documented and all impacted staff informed and trained appropriately.

Situation: Per documentation, the individual's condition had deteriorated and the individual was no longer verbal. However, the individual's documented replacement behaviors included using code words to express wants and needs.

Recommendation: Provider should ensure the behavior support plan (BSP) is updated to reflect appropriate replacement behaviors that the individual is capable of doing when needs change. Additionally, Provider should develop more robust training on individual-specific behaviors and then retrain staff to discern what the individual's behavior is communicating (e.g., crying as a behavioral issue versus crying as a result of medical symptoms).

Situation: Per documentation the pulse rate for the individual was reported to be in the 50s, which was low for the individual in light of previous documentation of the individual's pulse rates.

Recommendation: The Provider should develop staff training on normal ranges for each vital sign and how to take into account individual-specific ranges.

Situation: Per the documentation provided, one staff member's individual-specific training and medication administration training could not be located.

Recommendation: Provider should ensure all training is current and documented prior to providing staff to an individual.

Medication or Medical Issue

Medication or Medical Issue recommendations from the Mortality Review Committee to Providers covered several topics including not identifying changes in medical conditions, not documenting critical information, not understanding possible drug interactions, and not contacting a physician when required.

For quality improvement and reducing medication or medical issues, all Providers should:

- Ensure an effective system is in place for tracking physician follow up visits;
- Ensure an effective system is in place for reviewing and documenting communications between staff, management, and the Wellness nurse or other medical personnel;
- Conduct an evaluation of documentation protocol in terms of monitoring conditions; drug interactions; and understanding the individual's baseline and identifying any changes to that baseline to ensure continuity of care.

The following are real-life examples of common Medication or Medical issues that occurred during the dates for review. These examples illustrate the importance of training and awareness of signs of medical issues.

Situation: Per the Medication Administration Record submitted, an order was listed to notify the physician if the blood pressure was over or under specific readings. Per the blood pressure tracking log, the individual's blood pressure was over the specified range on two separate occasions with no notation the physician was notified.

Recommendation: Provider should document any physician-related communication when symptoms outside normal limits are noted. In addition, the Provider should develop a protocol to ensure ongoing staff competency in understanding of blood pressure thresholds, process, and purpose of contacting the physician.

Situation: Per documentation, the individual fell and was not evaluated by a physician despite having a documented blood clot.

Recommendation: Provider should ensure a protocol is in place that states an individual should be evaluated by a physician under these circumstances. Provider should ensure staff are trained to implement the protocol after an individual falls.

Situation: Per documentation, the individual had symptoms of chest pain, indigestion, and vomiting, which are often symptoms of a heart attack in women.

Recommendation: The Provider should train staff on gender-specific signs of a heart attack.

Situation: Per documentation, the individual had identified risks of constipation and dehydration, yet input/output tracking was not consistently tracked.

Recommendation: Provider should minimize these risks by implementing a consistent input/output tracking system which includes maximum and minimums that need to be reported to the nurse or management.

Situation: Per Medication Administration Record, the gastro-intestinal tube residuals were to be checked prior to feeding and nurse called if over a set amount. Staff were to check placement of the gastro-intestinal tube prior to introduction of fluids, medications, and nutritional support. Residual amounts and staff initials were missing from the Medication Administration Record on several dates for each month.

Recommendation: Provider should ensure Medication Administration Record is monitored to confirm staff are following orders and documenting correctly.

Regulations Not Met

Recommendations from the Mortality Review Committee regarding Regulations Not Met were due to the Provider not following established Health Insurance Portability and Accountability Act (HIPAA) rules, 460 IAC 6, the Division of Disabilities and Rehabilitative Services' policies, current Community Integration and Habilitation and Family Supports waivers, and 42 CFR 483, Part I, as applicable.

For quality improvement in ensuring all regulations are met, all Providers should:

- Review policy, procedure, and training regarding HIPAA to ensure compliance with regulations;
- Ensure all staff are appropriately trained on HIPAA regulations; and
- Review all policies regarding service documentation and ensure they are in compliance with 460 IAC 6, the Division of Disabilities and Rehabilitative Services' policies, current Community Integration and Habilitation and Family Supports waivers, and 42 CFR 483, Part I, as applicable.

The following are real-life examples of common instances where HIPAA, DDRS' Policies, Waiver requirements, or 42 CFR 483, Part I were not followed during the dates of review. These examples illustrate the problem and the importance of training and adherence to all regulations.

Situation: Per documentation, in the Structured Family Caregiving home monthly visits by the home manager were not conducted or documented as required.

Recommendation: Provider should review and implement the requirements regarding home manager visits for Structured Family Caregiving, as referenced in Community Integration and Habilitation Waiver.

Situation: Provider was contacted for initial submission of the mortality review and contacted again for follow-up on missing components of the Provider's internal investigation. The final submission did not contain all the required components.

Recommendation: Provider should review its internal investigation policy/procedure for mortalities to ensure compliance with DDRS Policy: Mandatory Components of an Investigation (BQIS 460 0316 043, eff. 3/16/2012) and DDRS Policy: Mortality Review (BQIS 460 0530 029, eff. 5/30/2011).

Situation: Per the training documents and Provider explanation of current training procedures, staff were not assessed for demonstrated competency via observable performance and written test as required by DDRS Policy: Personnel Policies & Manuals (BDDS 460 0228 019, eff. 2/28/2011) and DDRS Policy: Requirements & Training of Direct Support Professional Staff (BDDS 460 0228 027, eff. 2/28/2011).

Recommendation: Provider should ensure all policies and procedures regarding staff training are in compliance with DDRS Policy: Personnel Policies & Manuals (BDDS 460 0228 019, eff. 2/28/2011) and DDRS Policy: Requirements & Training of Direct Support Professional Staff (BDDS 460 0228 027, eff. 2/28/2011).

Situation: Individual was minimally responsive and would open eyes to look at staff if name was called, but then closed them again. Staff called nurse to request authorization to call 911 because staff did not know the preferred hospital to refer Emergency Medical Technician personnel.

Recommendation: Provider should ensure emergency information as required by 460 IAC 6-29-8 (i.e., emergency numbers, hospital of preferences, and emergency protocols) is posted in a visible location to ensure staff are familiar with content of emergency protocols and information prior to a life-threatening event.

Risk Plans

Risk Plans are in place to assist staff in addressing critical situations with an individual. In the cases reviewed by the Mortality Review Committee, the recommendations surrounding the topic of Risk Plans were focused on the staff not following a Risk Plan or not identifying that an issue was related to a Risk Plan.

For quality improvement and reducing Risk Plan issues, all Providers should:

- Ensure Risk Plan training is comprehensive and includes a demonstrated assessment of the training;
- Develop and implement a process (which includes management oversight) to ensure staff are following Risk Plan protocols;
- Ensure staff have a clear understanding of warning signs of chronic issues and how to address and communicate concerns in a timely manner;
- Review all Medication Administration Records and Risk Plans to ensure they are consistent with one another; and
- Develop Risk Plans with clear guidelines of preventive measures for risk issues.

The following are real-life examples of common instances where Risk Plans were not followed or available during the dates for review. These examples illustrate the importance of training and adhering to Risk Plans.

Situation: The Medication Administration Record and Risk Plan had contradictory information for handling constipation.

Recommendation: Provider or Wellness Nurse, should ensure that the Medication Administration Record matches the Risk Plan.

Situation: A diagnosis of breast cancer was confirmed and the individual was started on chemotherapy. However, a Risk Plan was not developed for this new diagnosis and the possible side effects from the chemotherapy.

Recommendation: Provider should implement a protocol to review a new diagnosis to ensure an evaluation of risks is completed, documented, and any new Risk Plans are developed and implemented, as applicable.

Situation: Individual was diagnosed in the hospital with aspiration pneumonia and subsequent cause of death was listed as aspiration pneumonia. The Risk Plan for pneumonia dated after the initial diagnosis stated the individual had a history of repeated hospitalization for pneumonia. Although it had not been formally diagnosed as aspiration pneumonia, the Provider did not ensure appropriate training of staff on signs and symptoms of aspiration pneumonia and supervision was provided during

all meals. The Provider did not have a procedure in place for support staff to report to a supervisor any concerns of increased coughing at meals, increased mucous secretions, change in respiratory status (wheezing, gurgling, etc.), or fever as potential signs of aspiration.

Recommendation: The Provider should ensure staff receive preventative training on the signs and symptoms of aspiration pneumonia and provide supervision during all meals. The Provider should have a procedure in place for support staff to report to a supervisor any concerns of increased coughing at meals, increased mucous secretions, change in respiratory status (wheezing, gurgling, etc.), or fever. Provider should update applicable Risk Plans when there is a confirmed diagnosis to include symptoms specific to the diagnosis.

Situation: The Individualized Support Plan and Risk Plan for blindness stated that staff would guide the individual by holding an arm or shoulders while walking. A separate Risk Plan for unsteady gait/falls stated the individual was able to walk alone in familiar surroundings with constant supervision.

Recommendation: Provider should ensure the individual's Individualized Support Plan and Risk Plans are consistent and accurately reflect the needs of the individual.

Situation: The individual's Risk Plan addressed petite mal seizures. The individual had three grand mal seizures but the Risk Plan for seizures did not specifically address what should be done if the individual had grand mal seizures.

Recommendation: Provider should review seizure Risk Plans to ensure they cover all types of seizures an individual may experience.

Wellness Coordination

Wellness Coordination recommendations from the Mortality Review Committee primarily resulted from Providers not following the Wellness Coordination requirements established in the Community Integration and Habilitation (CIH) Waiver. Wellness Coordination was approved as a new waiver service by the Centers for Medicaid and Medicare on 1/31/2014. Subsequent waiver amendments (6/1/2014, 10/1/2014, 7/1/2015, 7/1/2015, and 10/1/2017) maintained the same requirements for the service as when it was initially established. The Wellness Coordination nurse is responsible for writing and updating an individual's Wellness Plan and Risk Plan(s), training the staff on the Wellness Plan and Risk Plan(s), and conducting and documenting face-to-face visits and consults with the individual according to the Wellness Tier.

For quality improvement and reducing Wellness Coordination issues, all Providers should:

- Review policies and procedures when an individual has Wellness Coordination to ensure the training requirements of Wellness Coordination are followed;
- Review with the Wellness Nurse the procedure for record review and revise accordingly;
- Implement a system for reviewing and documenting communications between staff, management, and the Wellness Nurse; and
- Ensure if the Provider is unable to provide the service, Case Managers are contacted to transition individuals to another Provider to receive the service (if desired) or to have the service removed. The Provider should also contact Provider Services to remove the Provider from the pick list.

The following are real-life examples of common Wellness Coordination situations that occurred during the dates for review. These examples illustrate the problem and the importance of providers following the Wellness Coordination requirements, as established in the CIH Waiver.

Situation: The Medication Administration Record submitted included: One Touch Ultra Blood- Use to test blood sugars four times daily and as needed. There are no recorded blood sugars on the Medication Administration Record or on a separate log. The high risk insulin dependent diabetic risk plan did not mention the checking of blood sugar levels. There was no documentation that the individual's blood sugar was checked as required. Nor did documentation reflect routine checks of the individual's blood sugar. An investigation revealed that staff members were not trained by the Wellness Nurse on the requirements of the high risk plan.

Recommendation: The provider should review protocols, training, and documentation for caring for individuals with insulin-dependent diabetes to ensure staff are properly prepared to care for individuals with this condition.

Situation: Per the medications listed on the Medication Administration Record, Eliquis and Divalproex have an increased bleeding risk when taken together. Divalproex and Mirtazapine have an increase central nervous system depression and motor impairment risk when taken together.

Recommendation: The Wellness Nurse should review Medication Administration Records for individuals with multiple medications for possible medication interactions.

Situation: Per the Medication Administration Record, Milk of Magnesia was to be taken at bedtime as needed for constipation. The nurse was to be notified if a bowel movement did not occur for six consecutive nights. However, the risk plan for constipation states: Consumer should evacuate soft formed stools at least every three days, stools will be monitored on a tracking form, and an absence of stool for six shifts is to be reported to the nurse.

Recommendation: Provider should develop a procedure to ensure there is consistency between the orders on the Medication Administration Record and the risk plan guidelines.

Situation: Per Case Manager's case note, the Case Manager had discussed the individual's health condition and a potential heart issue with the Provider. The Provider asked if Wellness Coordination could be added to the individual's plan and the Case Manager was to submit a budget review. It is unknown if any further discussion occurred between the Provider and the Case Manager regarding adding Wellness Coordination. Two months later, another Case Manager case note indicated the individual did not have Wellness Coordination.

Recommendation: The Provider and Case Manager should ensure timely follow up to discuss Wellness Coordination as an option for the individual and document the results of the follow up, including the reason why the individual did not have Wellness Coordination on the plan.

Conclusion

Individuals with intellectual and developmental disabilities present an array of co-morbidities and are often not receiving health-related interventions in a timely manner. While “significant progress has been made in life expectancy for people with intellectual and developmental disabilities over the past 50 years ... this population still experiences life expectancies that are approximately 20 years lower than the general population” (Lauer, Emily and McCallion, Phillip, pg. 400). The service delivery issues identified throughout this report are areas in which substantial quality improvement could be made. Providers should analyze this information and determine how service delivery can be improved.

Additionally, Providers should seek out resources on the chronic conditions of individuals in services to adequately prepare staff to identify changes in status and ensure issues are timely addressed. The Bureau of Quality Improvement Services has a dedicated resource webpage to support providers, including fact sheets, checklists, and information on the fatal four. The resource webpage is available at www.in.gov/fssa/ddrs/2635.htm.

These findings represent only mortalities in Indiana and caution should be taken when comparing this information to other states or populations. These findings should not be generalized to represent all individuals with intellectual and developmental disabilities.

Appendix A: Sample Quality Improvement Process

For each area of concern identified, Providers may wish to do the following:

Perform a Root Cause Analysis: Decide who in the organization will participate in the analysis (those directly involved and those that will implement and monitor solutions). The basic Root Cause Analysis steps are:

- Identify issue(s)
- Collect and analyze information/data
- Determine preceding cause or human error
- Determine root cause

Create the Quality Improvement Plan:

- List the current level of performance
- Identify organizational goals to address an identified root cause
- List strategies to prevent reoccurrence
- Establish timelines and who is responsible for communicating the plan to others and implementing, monitoring, and evaluating the plan

Implementing and Monitoring the Quality Improvement Plan:

- Execute the plan
- Monitor the plan according to the goals and timelines identified

Evaluate the Quality Improvement Plan:

- Compare the actual results of the plan to the initial goals
- Determine what changes to the plan may be needed to meet goals
- Implement and monitor revised plan

Glossary: BDDS Services

Caregiver Supports

A short-term relief period for the primary caregiver, which can be provided in the primary caregiver's home and individual's home or a non-private residential setting. The individual chooses a provider from an approved pick list, who provides the trained staff to supervise and provide assistance with personal care, daily living activities, meal preparation, and medication administration.

Reference: http://www.in.gov/fssa/files/Caregiver_Supports_FAQ.pdf

Community Integration and Habilitation (CIH) Waiver

This waiver provides Medicaid Home and Community-Based Services (HCBS) waiver services to participants in a range of community settings as an alternative to care in a Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities or related conditions. The waiver serves persons with a developmental disability, intellectual disability or autism and who have substantial functional limitations, as defined under the paragraph for "Persons with related conditions" in 42 CFR 435.1010. Participants may choose to live in their own home, family home, or community setting appropriate to their needs. Participants develop a Person-Centered Individualized Support Plan (ISP) using a person centered planning process guided by an Individualized Support Team (IST). The goal of the CIH Waiver is to provide access to meaningful and necessary home and community-based services and supports, seeks to implement services and supports in a manner that respects the participant's personal beliefs and customs, ensures that services are cost-effective, facilitates the participant's involvement in the community where he/she lives and works, facilitates the participant's development of social relationships in his/her home and work communities, and facilitates the participants independent living.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>

Family Supports (FS) Waiver

This waiver provides Medicaid HCBS waiver services to participants in a range of community settings as an alternative to care in a Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities or related conditions. The waiver serves persons with a developmental disability, intellectual disability or autism and who have substantial functional limitations, as defined under "Persons with related conditions" in 42 CFR 435.1010. Participants may choose to live in their own home, family home, or community setting appropriate to their needs. Participants develop an Individualized Support Plan (ISP) using a person centered planning process guided by an Individual Support Team (IST). The IST includes the participant, their case manager and anyone else of the participant's choosing but typically family and/or friends. The participant, with the Team selects services, identifies service providers of their choice and develops a plan of care and is subject to an annual waiver services cap of \$16,545. The FS provides access to meaningful and necessary home and community-based services and supports, implements services and supports in a manner that respects the participant's personal beliefs and customs, ensures that services are cost-effective, facilitates the participant's involvement in the community where he/she lives and works, facilitates the participant's development of social relationships in his/her home and work communities, and facilitates the participant's independent living.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>

Glossary: BDDS Services—continued

Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities

This facility is a health facility that provides active treatment for each resident. A facility is only for intellectually and developmentally disabled residents, and is designed to enhance the development of these individuals, to maximize achievement through an interdisciplinary approach based on development principles and to create the least restrictive environment. These facilities are licensed and governed by state and federal regulations and have an annual recertification for Life Safety by the Indiana State Department of Health.

Reference: <https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>

Nursing Facility

Medicaid-certified nursing homes for individuals who received OBRA services through the Division of Disability and Rehabilitative Services and primarily provide three types of services: skilled nursing, rehabilitation, or long-term care. Nursing facilities are governed by state and federal regulations and monitored by the Indiana State Department of Health. (OBRA stands for Omnibus Budget Reconciliation Act of 1987, a federal law setting forth regulations for Medicare and Medicaid conditions of participation in long-term care facilities.)

Reference: <https://www.medicaid.gov/medicaid/ltss/institutional/nursing/index.html>

State-operated Care Facility

State-operated care facilities are institutions providing services to individual with developmental or intellectual disabilities who need long-term and intensive care.

Reference: <https://www.medicaid.gov/medicaid/ltss/institutional/nursing/index.html>

Supervised Group Living (SGL or Group Home)

A Group Home or Supervised Group Living (SGL) is a residential option and alternative to waiver placements for eligible individuals with intellectual/developmental disabilities needing services. There are almost 500 Supervised Group Living homes in the State of Indiana with a capacity to serve over 3,000 individuals. Homes are licensed and governed by state and federal regulations and have an annual recertification for Life Safety by the Indiana State Department of Health.

Reference: <http://www.in.gov/fssa/ddrs/2639.htm>

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