



The Indiana Family and Social Services Administration

Data Forum

Mortality Review – What does the data tell us?

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Purpose

The purpose of this webinar is to present to Bureau of Developmental Disabilities Services (BDDS) providers an overview of the annual mortality data, mortality statistics from other states, mortality recommendations, and available resources to assist in identifying and addressing prevalent conditions and illnesses.



Disclaimer

The information presented in this webinar is reflective of the data collected during the Mortality Review process. This information is for informational purposes and general guidance of best practices and is 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 the 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.



Agenda

Today's Topics:

- I. Mortality Data
- II. State comparison data
- III. Mortality Recommendations
- IV. Resources
- V. Fatal Four
- VI. Conclusion
- VII. Questions/Discussion
- VIII. Contact Information



Agenda

I. Mortality Data



Mortality Data

Mortality Rate

Calendar Year	Number of Individuals in BDDS Services	Number of deaths	Mortality Rate* (# of deaths per 1,000 individuals)
2017	32,681	389	11.9
2016	29,317	436	14.9
2015	26,474	400	15.1
2014	23,325	430	18.4

*The mortality rate is a crude mortality rate, which is an unadjusted mortality rate.

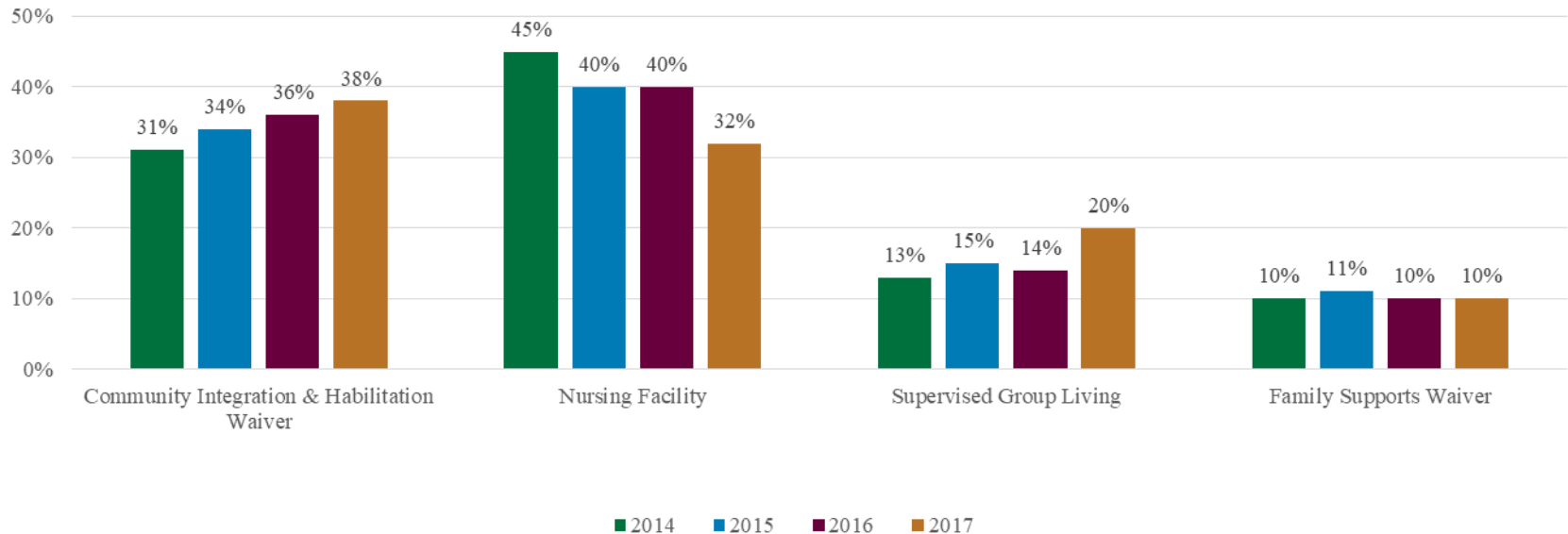


Mortality Data

Mortalities by BDDS Service, 2014-2017

BDDS Mortalities by BDDS Service: Four-year Comparison 2014-2017

Data Source: State of Indiana DART database





Mortality Data

BDDS 2017 Mortalities by Gender and Service

BDDS 2017 Mortalities by Gender and Service Total Mortalities = 389 Data Source: State of Indiana DART database					
BDDS Service	Male	Percent	Female	Percent	Total
Community Integration & Habilitation Waiver	82	56%	64	44%	146
Nursing Facility	66	52%	60	48%	126
Supervised Group Living	43	55%	35	45%	78
Family Supports Waiver	25	66%	13	34%	38
State Line Funding	1	100%	0	0%	1
Total	217	56%	172	44%	389



Mortality Data

Mortalities by Gender: 2017 BDDS Mortalities Comparison to 2016 General Population

Mortalities by Gender: 2017 BDDS Mortalities Comparison to General Population
Data Sources: State of Indiana DART database
Center for Disease Control and Prevention, National Center for Health Statistics

	Male		Female		Total
	Count	Percent	Count	Percent	
Population					
BDDS (2017)	217	56%	172	44%	389
Indiana—General Population (2016)	32,378	51%	31,095	49%	63,473
National—General Population (2016)	1,400,232	51%	1,344,016	49%	2,744,248



Mortality Data

According to the National Center for Health Statistics, people with intellectual and developmental disabilities have a life expectancy of 50.4 to 58.7 years compared to the general US population of 78.5 years.

(CDC 2011)



Mortality Data

BDDS Mortalities by Gender, 2014-2017

BDDS Mortalities by Gender: Four-year Comparison 2014-2017
Data Source: State of Indiana DART database

Year	Male		Female		Total
	Count	Percent	Count	Percent	
2014	224	52%	206	48%	430
2015	217	54%	183	46%	400
2016	231	53%	205	47%	436
2017	217	56%	172	44%	389
Combined	889	54%	766	46%	1,655

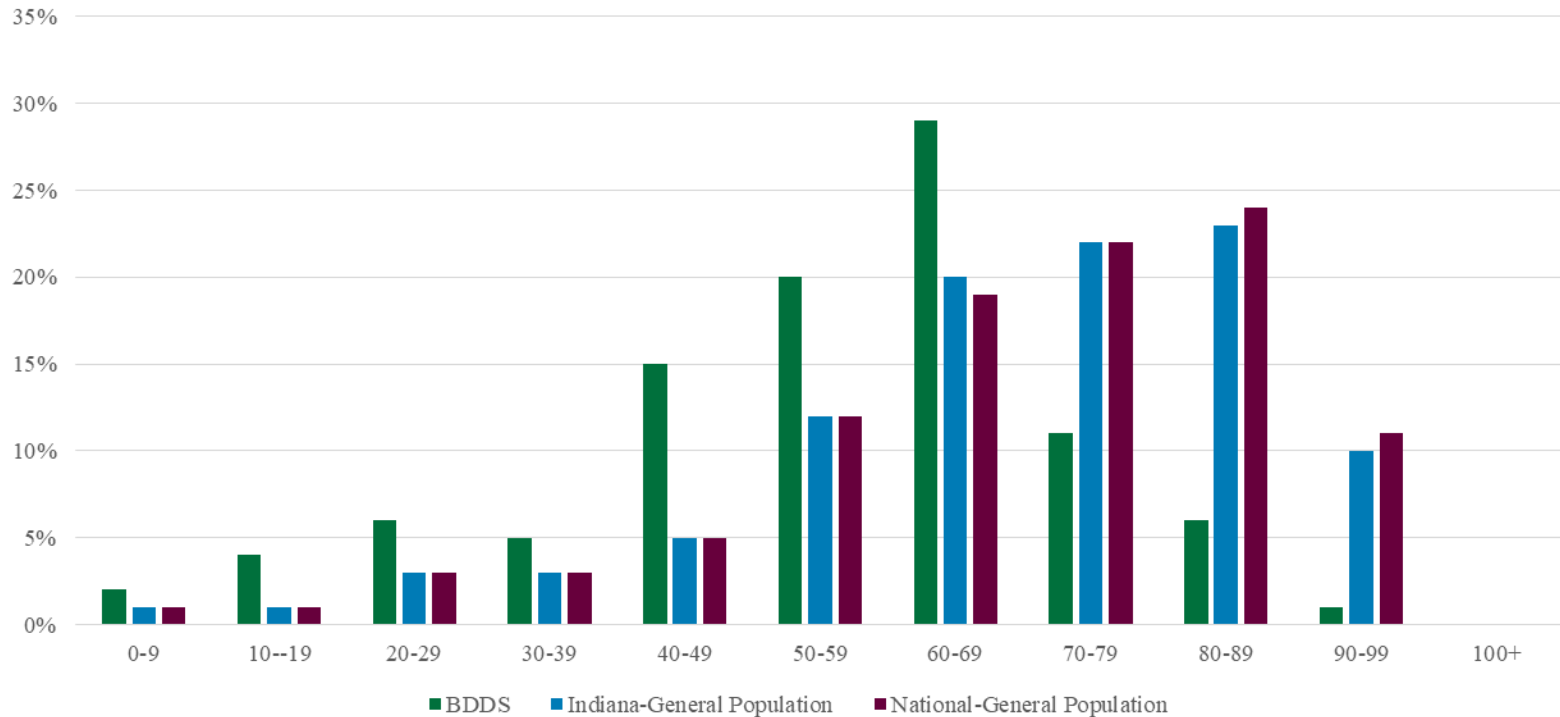


Mortality Data

Mortalities for Males: 2017 BDDS Comparison to 2016 General Population

Mortalities for Males: 2017 BDDS Comparison to 2016 General Population

Data Sources: State of Indiana DART database;
Center for Disease Control and Prevention, National Center for Health Statistics



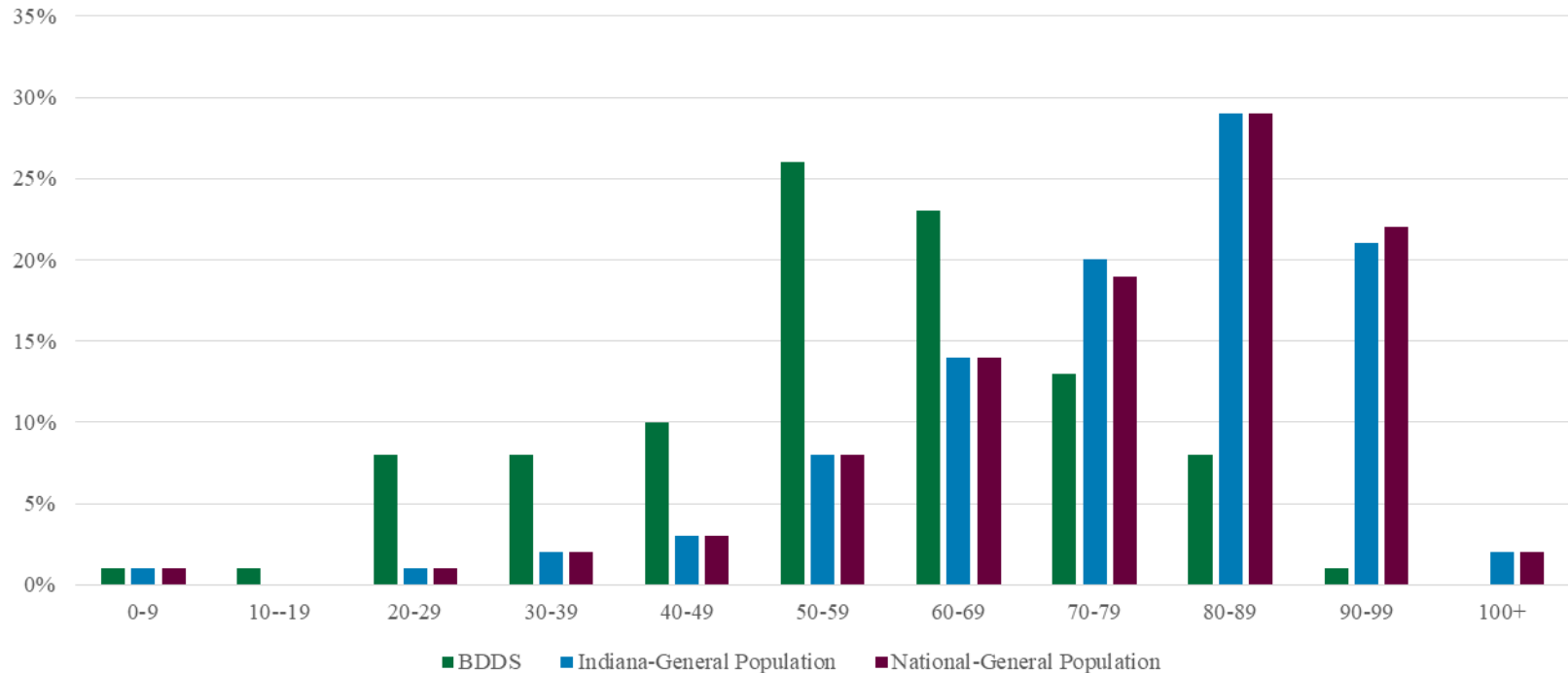


Mortality Data

Mortalities for Females: 2017 BDDS Comparison to 2016 General Population

Mortalities for Females: 2017 BDDS Comparison to 2016 General Population

Data Sources: State of Indiana DART database;
Center for Disease Control and Prevention, National Center for Health Statistics



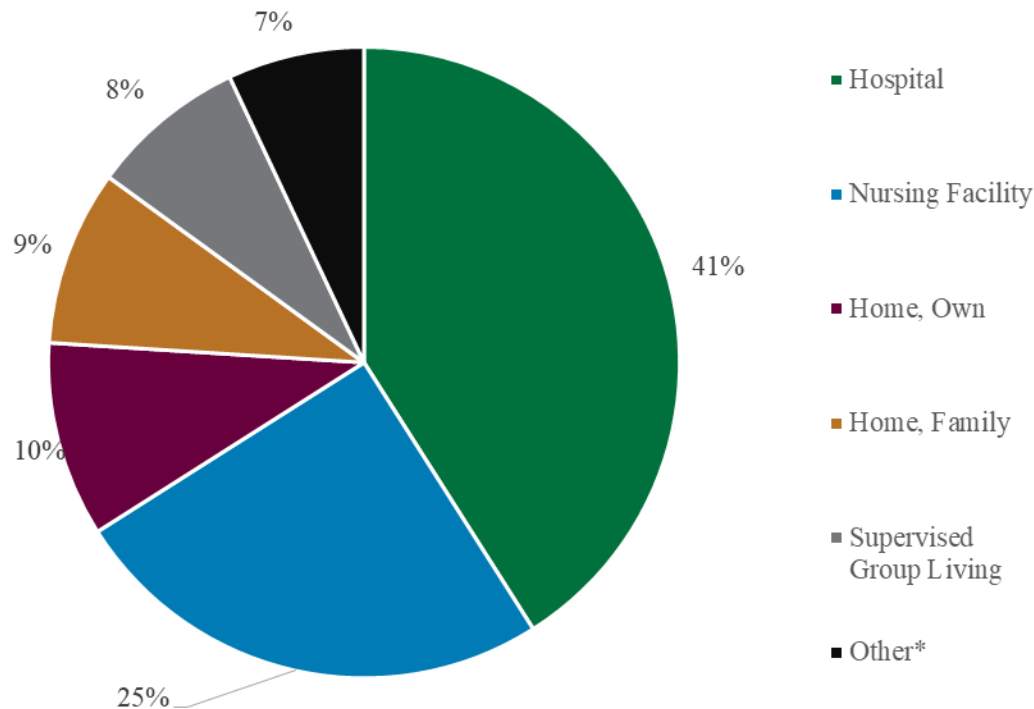


Mortality Data

BDDS Place of Death for 2017

BDDS Place of Death for 2017

Total Mortalities = 389 | Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process



*'Other' is comprised of hospice and community settings (e.g., restaurant, park), and unknown settings due to pending death certificates from Indiana State Department of Health.

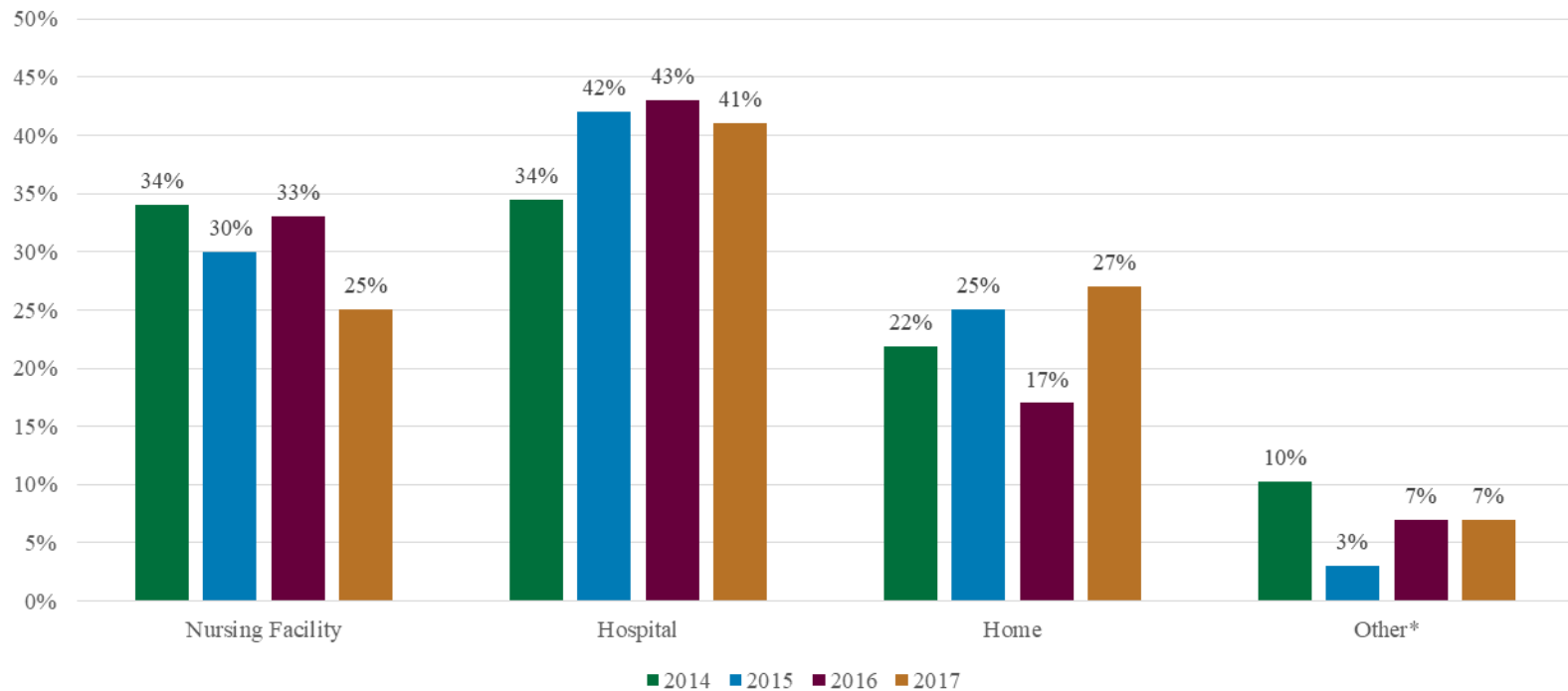


Mortality Data

BDDS Place of Death: 2014-2017 Comparison

BDDS Place of Death: 2014-2017 Comparison

Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process



“Home” includes own, family homes, and Supervised Group Living. *Other is comprised of hospice and community settings (e.g., restaurant, park), and unknown settings are due to pending death certificates from Indiana State Department of Health.



Mortality Data

BDDS Classification of Death, 2017

Mortalities are classified using a matrix:

Internal/External and Anticipated/Unexpected.

Classification is based on the source of injury/disease, past medical history, current health status, diagnoses, risk level, age, and other contributing factors.

Examples:

- Anticipated/Internal – death from a chronic disease/cancer
- Anticipated/External – individual with a history of illicit drug use and death is an overdose
- Unexpected/Internal – death due to a heart attack but individual has no history of contributing factors and is in good health
- Unexpected/External – death from a car or pedestrian accident



Mortality Data

BDDS Classification of Death, 2017

BDDS Classification of Death, 2017

**Total Mortalities = 389 | Data Sources: Indiana State Department of Health;
Provider documents submitted during the mortality review process**

	Anticipated		Unexpected	
	Count	Percent	Count	Percent
Internal	334	86%	47	12%
External	1	0%	7	2%



Mortality Data

BDDS Primary Causes of Death: 2014-2017

BDDS Primary Causes of Death: 2014-2017 Comparison 2014-2017								
Data Source: Indiana State Department of Health								
Primary Cause of Death *	2014		2015		2016		2017	
	Count	%	Count	%	Count	%	Count	%
Diseases of the Respiratory System (includes pneumonia)	130	30%	121	30%	122	28%	105	27%
Diseases of the Circulatory System (includes heart disease)	107	25%	57	14%	106	24%	97	25%
Cancer	29	7%	38	10%	19	4%	23	6%
Diseases of the Nervous System (includes seizures)	27	6%	29	7%	48	11%	39	10%
Infections (includes sepsis)	22	5%	18	5%	33	8%	31	8%
Total	315	73%	263	66%	328	75%	295	76%
Total Mortalities for the Year	430	---	400	---	436	---	389	---

*Primary Cause of Death is based on official death certificate.



Mortality Data

BDDS 2017 Top Five Primary Causes of Death: Comparison with 2016 General Population

BDDS 2017 Top Five Primary Causes of Death: Comparison with 2016 General Population

Data Sources: Indiana State Department of Health, Center for Disease Control and Prevention, National Center for Health Statistics

Primary Cause of Death for 2017*	Average Age	Number of Deaths	Percent of Deaths	Percent of Deaths in Indiana General Population (2016)	Percent of Deaths in National General Population (2016)
Diseases of the Respiratory System	57.2	105	27%	11%	10%
Diseases of the Circulatory System	59.5	97	25%	29%	31%
Diseases of the Nervous System	51.8	39	10%	8%	7%
Infections	53.6	31	8%	3%	3%
Cancer	55.4	23	6%	22%	22%
Total	---	295	76%	73%	73%

*Primary Cause of Death is based on official death certificate.



Agenda

II. State Comparison Data



State Comparison Data

Comparison of the Primary Causes of Death with Four States

Comparison of the Primary Causes of Death

As Reported by Four State I/DD Agencies and Indiana

Rank	MA DDS CY2012 (adults)	MA DDS CY2013 (adults)	CT DDS FY2013 (all ages)	OH DDD 2012 (all ages)	LA OCDD FY2012 (all ages)	IN BDDS CY2016 (all ages)	IN BDDS CY2017 (all ages)
Method	Underlying		Primary	Unknown	Unknown	Primary	Primary
1	Heart Disease 16.0%	Heart Disease 13.7%	Heart Disease 28.6%	Heart Disease 14.7%	Pneumonia 15.0%	Respiratory Diseases (includes pneumonia) 28.0%	Respiratory Diseases (includes pneumonia) 27.0%
2	Cancer 13.7%	Cancer 13.4%	Respiratory Disease 22.4%	Congenital Diseases 13.0%	Heart Disease 12.4%	Circulatory Diseases (includes heart disease) 24.0%	Circulatory Diseases (includes heart disease) 25.0%
3	Alzheimer's Disease 13.0%	Alzheimer's Disease 12.2%	Cancer 10.0%	Cancer 9.1%	Cancer 10.1%	Nervous System (includes seizures) 11.0%	Nervous System (includes seizures) 10.0%
4	Septicemia 10.0%	Aspiration Pneumonia 8.6%	Aspiration Pneumonia 7.9%	Aspiration Pneumonia 6.9%	Congenital Diseases 10.1%	Infections (includes sepsis) 8.0%	Infections (includes sepsis) 8.0%
5	Aspiration Pneumonia 9.4%	Septicemia 8.6%	Septicemia 7.9%	Pneumonia 6.8%	Septicemia 8.8%	Cancer 4.0%	Cancer 6.0%



Agenda

III. Mortality Recommendations



Mortality Recommendations

Mortality Review Triage Team and Mortality Review Committee

Mortality Review Triage Team –

- Initially reviews and synthesizes all required documentation submitted for each BDDS mortality and writes a mortality brief to share with the committee
- Comprised of a physician, registered nurse, and program staff



Mortality Recommendations

Mortality Review Triage Team and Mortality Review Committee

Mortality Review Committee –

- Reviews all mortality cases
- Refers cases to appropriate entities, when needed
- Develops and issues provider-specific recommendations
- Presents general system recommendations
- Comprised of a physician, registered nurse, the state Ombudsman, and representatives from: 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



Mortality Recommendations

Mortality Review Process

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
- all alleged abuse or neglect
- medical records
- case manager case notes
- incident reports
- staff training records
- death certificate
- autopsy (if applicable)



Mortality Recommendations

Purpose of the Mortality Review Process

The mortality review process reviews the circumstances leading up to and including the death of the individual. BQIS reviews the information and assesses if service delivery issues were present. These recommendations do not imply that the service delivery issue resulted in or contributed to the death.



Mortality Recommendations

Mortality Cases from October 2015 to December 2017

- 1,122 mortality cases reviewed
- 427 provider recommendations made on 206 cases
- 78% of the recommendations were for CIH individuals



Mortality Recommendations

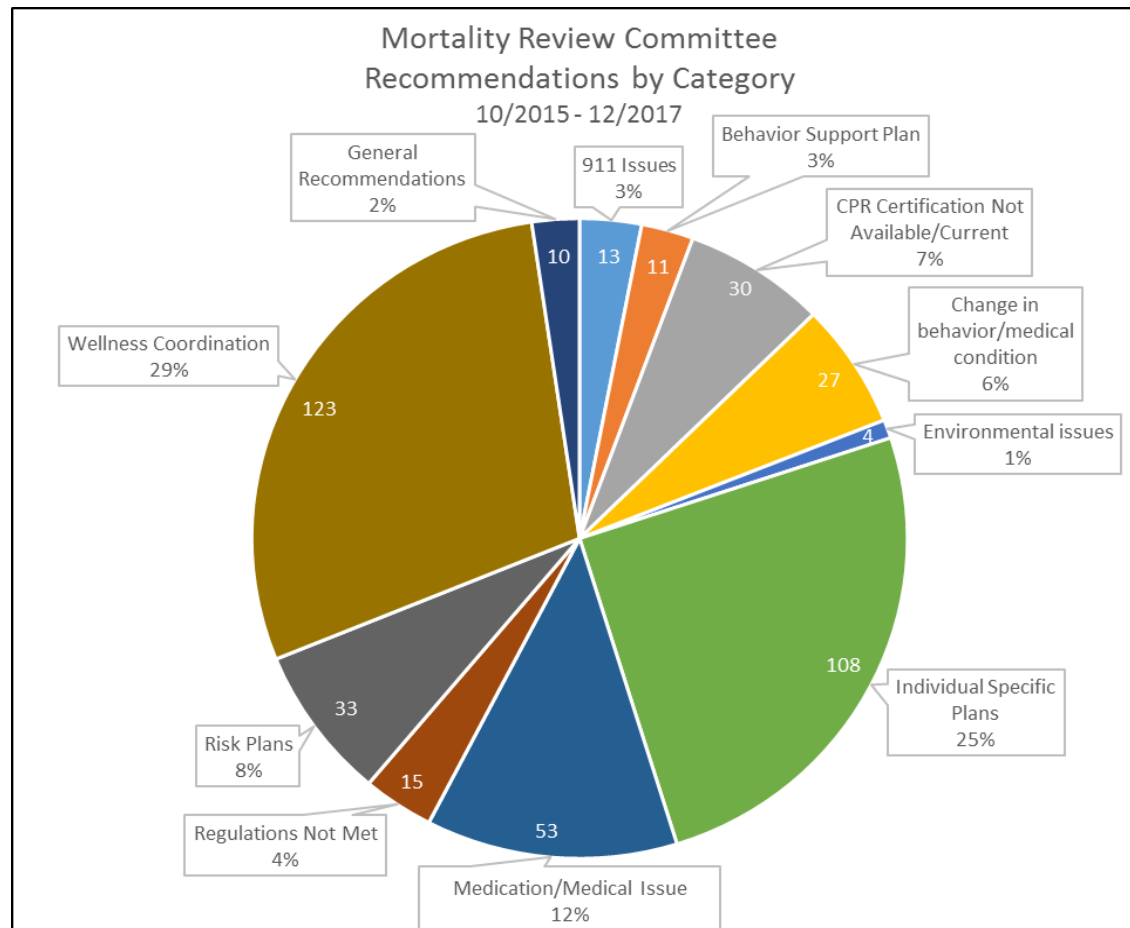
Service Areas Identified as Needing Quality Improvement

- 911 Issues
- Behavior Support Plan
- Cardio-Pulmonary Resuscitation (CPR) Certification Not Available or Not Current
- Change in Behavior or Medical Condition
- Environmental Issues
- General Recommendations
- Individual-Specific Plans
- Medication or Medical Issues
- Regulations Not Met
- Risk Plans
- Wellness Coordination



Mortality Recommendations

Recommendation by Category Distribution





Mortality Recommendations

Quality Improvement Opportunities

- Ensure agency 911 protocols are aligned with CPR training guidelines;
- Develop and implement robust training on individual-specific behaviors that includes information to assist staff in discerning when a behavior may indicate medical symptoms;
- Ensure a training tracking system is in place to track required training/certifications and identifies upcoming expirations;



Mortality Recommendations

Quality Improvement Opportunities

- Train staff on the “normal” or “baseline of the individual” in order to recognize when a change in condition occurs;
- Review documentation standards so the staff are documenting medical symptomology in progress notes to ensure continuity of care;
- Implement a procedure for identifying, documenting, and repairing broken equipment;



Mortality Recommendations

Quality Improvement Opportunities

- Establish or provide a support system for emancipated individuals when health condition declines;
- Ensure an effective system for reviewing and documenting communications between staff, management, and the Wellness nurse (or other medical personnel) is in place and implemented consistently;



Mortality Recommendations

Quality Improvement Opportunities

- Review all policies regarding service documentation to ensure 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;



Mortality Recommendations

Quality Improvement Opportunities

- 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



Agenda

IV. Resources



Resources

BQIS Fact Sheets, Checklists, and Reminders

The BQIS website has a Resource section with links to resource materials for providers.

<https://www.in.gov/fssa/ddrs/2635.htm>



Resources

BQIS Resources to Reduce Premature Mortality

- Recognizing change in status
- Responding to change in status
- Aspiration prevention – multiple topics
- Basic communication
- Emergency room – multiple topics
- Hospitalization – multiple topics



Resources

BQIS Resources to Reduce Premature Mortality

- Medical Symptoms: Recognizing a heart attack in the IDD population
- Signs and symptoms indicating a change in status
- Stroke and IDD
- Potential aspiration: Signs and symptoms to watch for



Resources

BQIS Resources to Reduce Premature Mortality

- Seizures – multiple topics
- Diabetes
- Positioning Plan Protocol
- Skin Assessment
- Bowel Management (BM) Tracking Sheet
- Managing appointments – multiple topics



Resources

BQIS Resources to Reduce Premature Mortality

- Constipation Protocol
- Dehydration Protocol
- Choking Risk Assessment
- Dysphagia – multiple topics
- Pneumonia Risk Assessment
- GERD protocol
- Intake and Output



Agenda

V. Fatal Four



Fatal Four

Fatal Four for Individuals with Intellectual and Developmental Disabilities

- Aspiration
- Constipation
- Dehydration
- Seizures



Fatal Four

Fatal Four

Why are individuals with intellectual or developmental disabilities at a higher risk?

- Posture problems
- Lack of mobility
- Certain medications
- Inability to communicate issues



Fatal Four

2017 Fatal Four in BDDS Mortalities

Primary Cause of Death	Fatal 4 included in category	Number of deaths due to Fatal 4	Percent of Primary Cause of Death	Percent of all deaths
Diseases of the Respiratory System (n=105)	Aspiration	37	35%	9.5%
Diseases of the Gastrointestinal/Digestive System (n=7)	Constipation	3	43%	1%
Diseases of the Nervous System (n=39)	Seizures	12	31%	3.0%
Diseases of the Hormone/Nutrition/Metabolism Systems (n=11)	Dehydration	2	18%	0.5%
n=389				



Fatal Four: Constipation



CONSTIPATION

Intellectually and Developmentally Disabled Fatal Four

Definition — Constipation occurs when an individual has difficult or infrequent bowel movements. Constipation can lead to a blockage in the small or large intestine which prevents stool and gas from moving through in the usual way.

Why are individuals with Intellectual and Developmental Disabilities at a high risk?

- Lack of mobility
- Diet (e.g. lack of fiber or liquid)
- Certain medications (e.g. antidepressants, antihistamines, calcium and iron supplements, narcotic pain medicine)



Signs & Symptoms

- Vomiting
- Behavioral outbursts
- Bloating or hard stomach
- Refusing meals
- Decreased bowel sounds
- Hard or small stools

Preventative Action Steps

- Increase the amount of fiber intake
- Increase liquid intake
- Increase activity
- Limit caffeine consumption
- Track and document bowel movements for individuals at risk



Fatal Four: Dehydration



DEHYDRATION

Intellectually and Developmentally Disabled Fatal Four

Definition — Dehydration occurs when the body does not have as much fluid as it needs. The severity depends on how much fluid is missing from the body.

Why are individuals with Intellectual and Developmental Disabilities at a high risk?

- Inability to obtain something to drink without assistance (e.g. wheelchair/bed bound)
- Inability to communicate the need for something to drink (e.g. non-verbal)
- Individuals with chronic illnesses (e.g. uncontrolled/untreated diabetes, cystic fibrosis)
- Certain medications (e.g. diuretics, psychotropic)

Signs & Symptoms

- Dry mouth
- Headache
- Decreased/dark urine
- Absence of tears
- Dizziness
- A lack of sweating

Preventative Action Steps

- Frequently offer fluids and foods with high water content (e.g. watermelon, oranges, jello)
- Provide extra fluids when the temperature rises or activity level increases
- Identify medications that may have dehydration as a side effect
- Track input/output





Fatal Four: Aspiration



ASPIRATION

Intellectually and Developmentally Disabled Fatal Four

Definition — Aspiration occurs when food, saliva, fluid, stomach contents, or a foreign object go into the airway and/or lungs but the person can still breathe. Silent aspiration will not have any visible symptoms.

Why are individuals with Intellectual and Developmental Disabilities at a high risk?

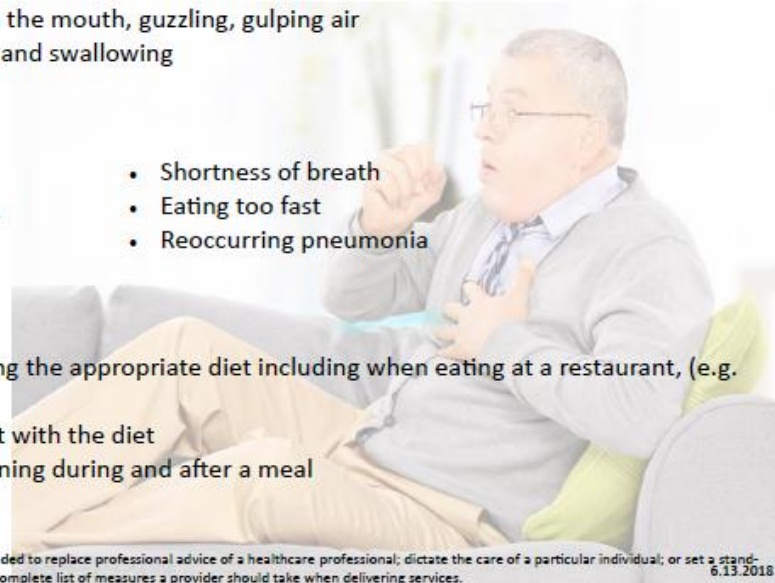
- Poor/improper positioning
- Rapid eating, stuffing of food in the mouth, guzzling, gulping air
- Poor coordination of breathing and swallowing

Signs & Symptoms

- Frequent coughing
- Loss of interest in certain foods
- Fever and/or low temperature
- Shortness of breath
- Eating too fast
- Reoccurring pneumonia

Preventative Action Steps

- Ensure the individual is receiving the appropriate diet including when eating at a restaurant, (e.g. thickened liquids, pureed)
- Ensure medication is consistent with the diet
- Implement appropriate positioning during and after a meal
- Conduct a swallow study





Fatal Four

Fatal Four: Seizures



SEIZURES

Intellectually and Developmentally Disabled Fatal Four

Definition — Seizures occur due to abnormal electrical activity in the brain. There are two types of seizures: focal (partial) and generalized seizures.

Why are individuals with Intellectual and Developmental Disabilities at a high risk?

- Individuals have an underlying brain dysfunction

Signs & Symptoms

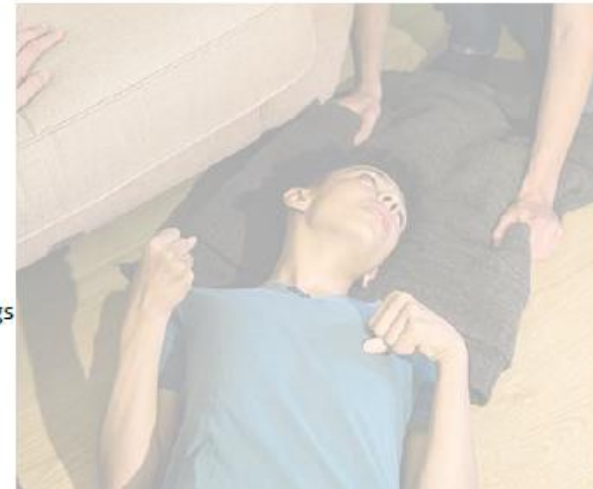
- Symptoms vary according to the individual. Some individuals may stare while others make shake violently.

How to Respond to a Seizure

- Do not leave the individual alone
- Do not restrain the individual
- Move objects away to prevent injury
- Place padding under individual's head/arms/legs

Preventative Action Steps

- Manage stress
- Take prescribed seizure medication
- Maintaining a healthy weight
- Keep record of seizure activity
- Exercise regularly





Fatal Four

Significant Contributor to the Fatal Four: Gastroesophageal Reflux Disease (GERD)



GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Significant Contributor to the Fatal Four for the Intellectually and Developmentally Disabled

Definition — A digestive disorder that affects the ring of muscle between the esophagus and stomach. When this muscle is not working properly, whatever is in the stomach flows back into the esophagus (food, fluid, and stomach acid).

Why are individuals with Intellectual and Developmental Disabilities at a high risk?

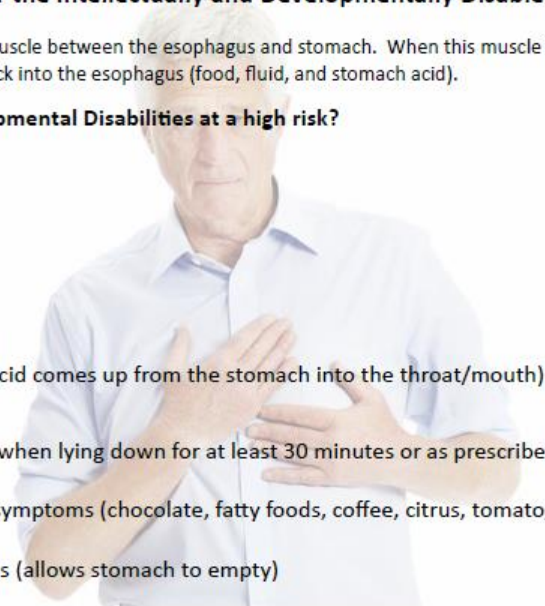
- Posture problems
- Lack of mobility
- Improper positioning
- Certain medications
- Excessive drooling

Signs & Symptoms

- Heartburn (can last as long as two hours)
- Regurgitation (partially digested food or acid comes up from the stomach into the throat/mouth)

Preventative Action Steps

- After eating, stay upright or elevate head when lying down for at least 30 minutes or as prescribed by a physician
- Avoid foods and beverages that increase symptoms (chocolate, fatty foods, coffee, citrus, tomato, spicy foods, etc.)
- Space out mealtime and decrease portions (allows stomach to empty)
- Encourage weight loss





Fatal Four

Fatal Four: Resource links available on BQIS webpage

Aspiration. Office for People with Developmental Disabilities, New York State.

<https://opwdd.ny.gov/sites/default/files/documents/HSAAspiration022613FINAL.pdf>

Constipation. Clinical Advisor. Mary Atkinson Smith, DNP, FNP-BC; Craig L. Escude, M.D.

<https://www.clinicaladvisor.com/cmece-features/cme-ce-credit-intellectual-and-developmental-disabilities/article/395169/5/>. 2/13/2015.

Dehydration and Signs of Dehydration. Illinois Department of Human Services.

<http://www.dhs.state.il.us/page.aspx?item=60229>

A Little Book about Gastroesophageal Reflux Disease. Philadelphia Coordinated Health Care.

<https://www.pchc.org/images/PDFs/Publications/Physical-Health/GERD-Booklet.pdf>

Seizure Disorder. Division of Developmental Disabilities, Arizona.

https://des.az.gov/sites/default/files/qafs_seizure_disorder_2.pdf



Agenda

VI. Conclusion



Conclusion

Individuals with intellectual and developmental disabilities present with an array of co-morbidities and are often not receiving health-related interventions in a timely manner.



Conclusion

“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. “Mortality of People with Intellectual and Developmental Disabilities from Select US State Disability Service Systems and Medical Claims Data”, 2015



Conclusion

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.



Agenda

VII. Questions/Discussion



Agenda

VIII. Contact Information



Contact Information

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