



Mortality Data Review

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

Date of Death: January 1, 2014—December 31, 2014

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Purpose

The Division of Disability and Rehabilitative Services (DDRS) Bureau of Quality Improvement Services (BQIS) works with providers and organizations that administer services to individuals with intellectual and developmental disabilities. BQIS reviews the deaths of all individuals receiving services through the Bureau of Developmental Disabilities Services (BDDS). The purpose of the mortality review is to identify trends, develop 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 mortality review process.

Based on death-of-person incident reports received by The Bureau of Developmental Disabilities Services through May 27, 2015. Data compiled by Advocare LLC.

Please submit questions or comments to the Bureau of Quality Improvement Services at BQISHelp@FSSA.IN.gov.

Individual Population

Waiver and Non-waiver Programs

The Bureau of Developmental Disabilities Services administers programs to approximately 22,000 individuals.

Waiver Funding Sources	
Individual Population as of 12/31/2014	Individuals
Family Supports Waiver (Active)	9,157
Community Integration & Habilitation Waiver (Active)	8,183

Data compiled by Advocare, LLC

Non-waiver Funding Sources	
Individual Population as of 7/9/2015	Individuals
Supervised Group Living	3,281
Nursing Facility	1,469
Caregiver Supports	1,118
State-operated Care Facility	65
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	52

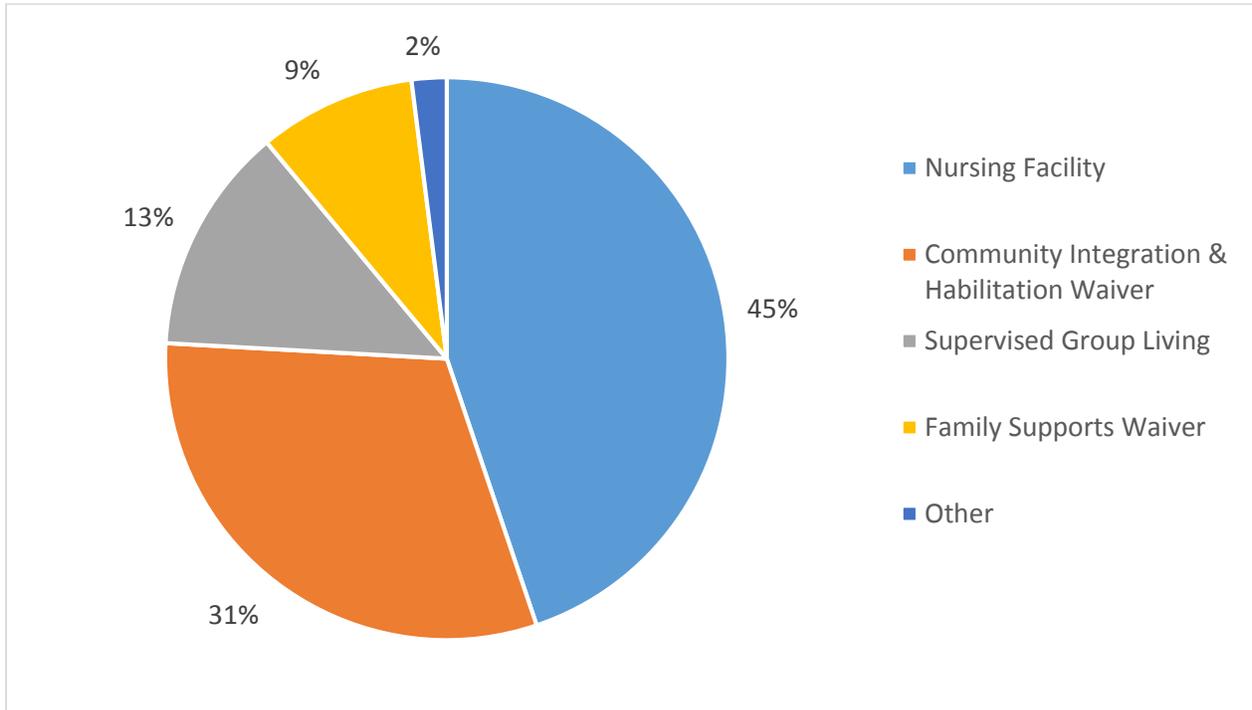
Data compiled by the Bureau of Developmental Disabilities Services

Mortalities by Funding Source for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: State of Indiana DART database

The category “Other” is comprised of Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities, State-operated Care Facility, and Caregiver Supports



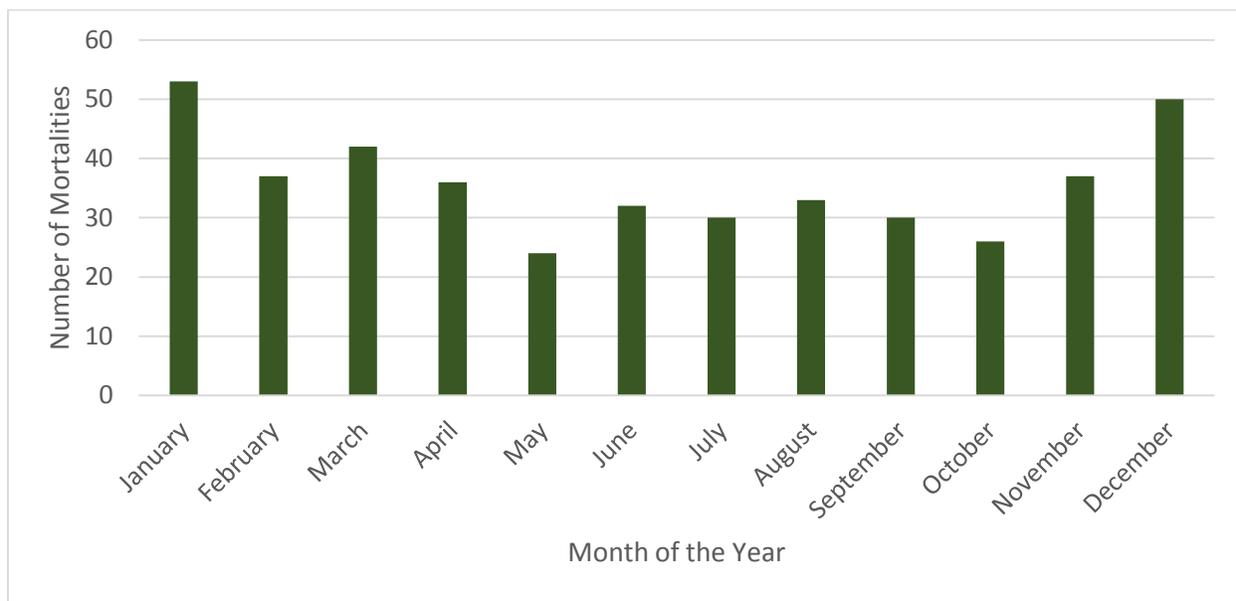
Funding Source	Count	Percent
Nursing Facility	192	45%
Community Integration & Habilitation Waiver	133	31%
Supervised Group Living	56	13%
Family Supports Waiver	41	9%
Other	8	2%

Mortalities by Month for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: State of Indiana DART database

The noted high mortality rates for January, March, and December are consistent with the 2013 mortality rates for both the national and Indiana general populations. (Note: Data reports for general population are not yet available for 2014.)



Month	Count
January	53
February	37
March	42
April	36
May	24
June	32
July	30
August	33
September	30
October	26
November	37
December	50

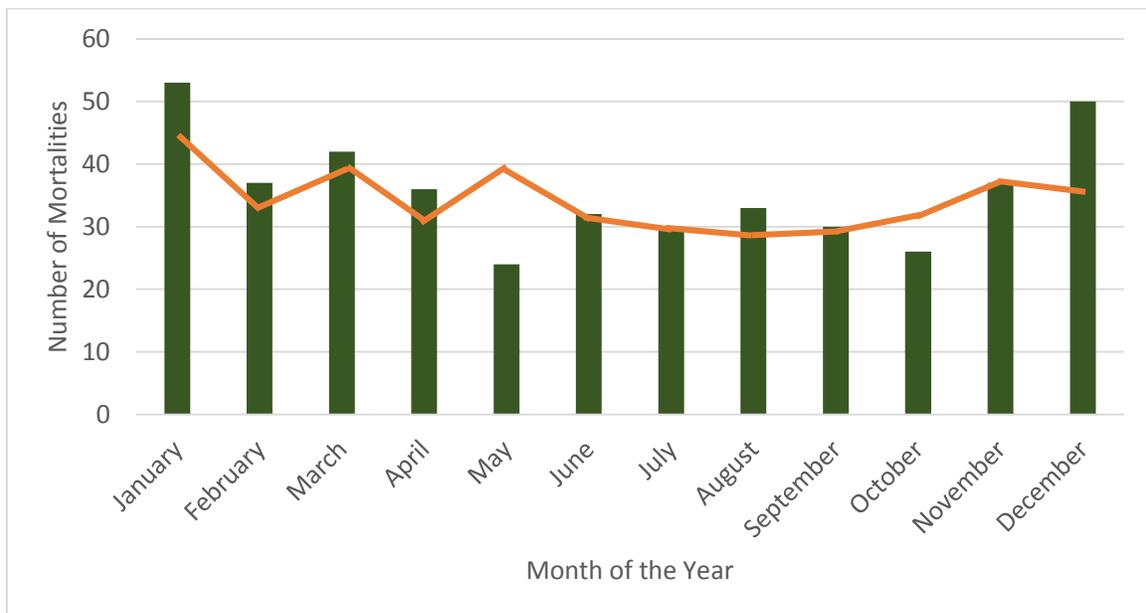
Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2013 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on July 9, 2015 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Month for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: State of Indiana DART database

For nine of the twelve months, the mortality data for individuals receiving services through the Bureau of Developmental Disabilities Services follows the same pattern as the general populations at the national and Indiana levels of mortalities in 2013. (Note: Data reports for general population are not yet available for 2014.)



Line graph: Four-year average of number of mortalities per month for the years 2010-2013

Bar graph: Number of mortalities per month for 2014

Month	2010	2011	2012	2013	2014
January	49	43	33	49	53
February	41	34	30	31	37
March	37	44	37	37	42
April	34	31	29	28	36
May	31	36	44	43	24
June	31	26	32	39	32
July	27	30	37	25	30
August	28	27	37	24	33
September	28	28	28	32	30
October	37	26	34	29	26
November	37	43	33	33	37
December	29	41	30	38	50

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2013 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on July 9, 2015 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Funding Source for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: State of Indiana DART database

During 2010-2013, females and males each comprised approximately 50% of the mortalities in both the national and Indiana general populations. Mortalities in this 2014 population of individuals served by the Bureau of Developmental Disabilities Services did not differ significantly by gender compared to national and Indiana general population data. (Note: Data reports for general population are not yet available for 2014.)

Funding Source	Male	Female	Total
Nursing Facility	93	99	192
Community Integration & Habilitation Waiver	69	64	133
Supervised Group Living	36	20	56
Family Supports Waiver	21	20	41
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	4	2	6
Caregiver Supports	1	0	1
State-operated Care Facility	0	1	1

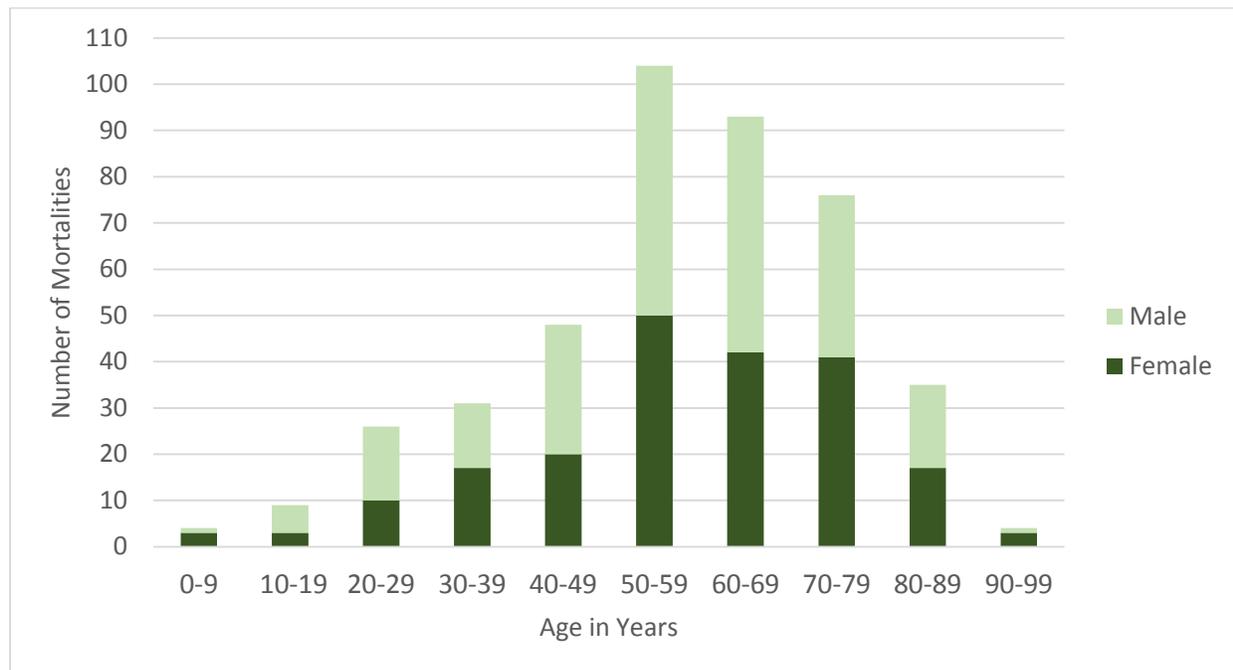
Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2013 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on July 9, 2015 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Age for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: State of Indiana DART database

In 2014, mortalities by gender and age of the individuals in the population served by the Bureau of Developmental Disabilities Services were similar to national and Indiana general population trends in 2013. (Note: Data reports for general population are not yet available for 2014.)



Age in Years	Male	Female	Total
0-9	1	3	4
10-19	6	3	9
20-29	16	10	26
30-39	14	17	31
40-49	28	20	48
50-59	54	50	104
60-69	51	42	93
70-79	35	41	76
80-89	18	17	35
90-99	1	3	4

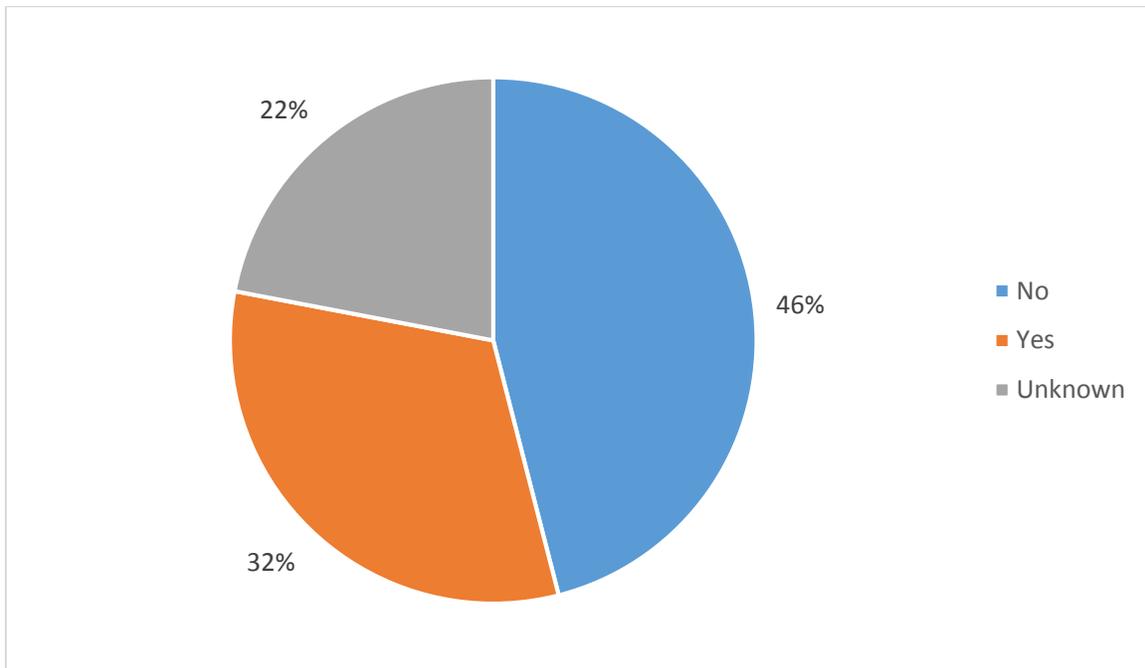
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Mortalities with Hospice for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: Provider documents submitted during the mortality review process

Hospice care is a comprehensive set of services described in Section 1861(dd)(1) of the Social Security Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members as described in a specific patient plan of care.



Hospice	Count	Percent
No	199	46%
Yes	135	32%
Unknown*	96	22%

*Hospice status could not be determined from available documentation.

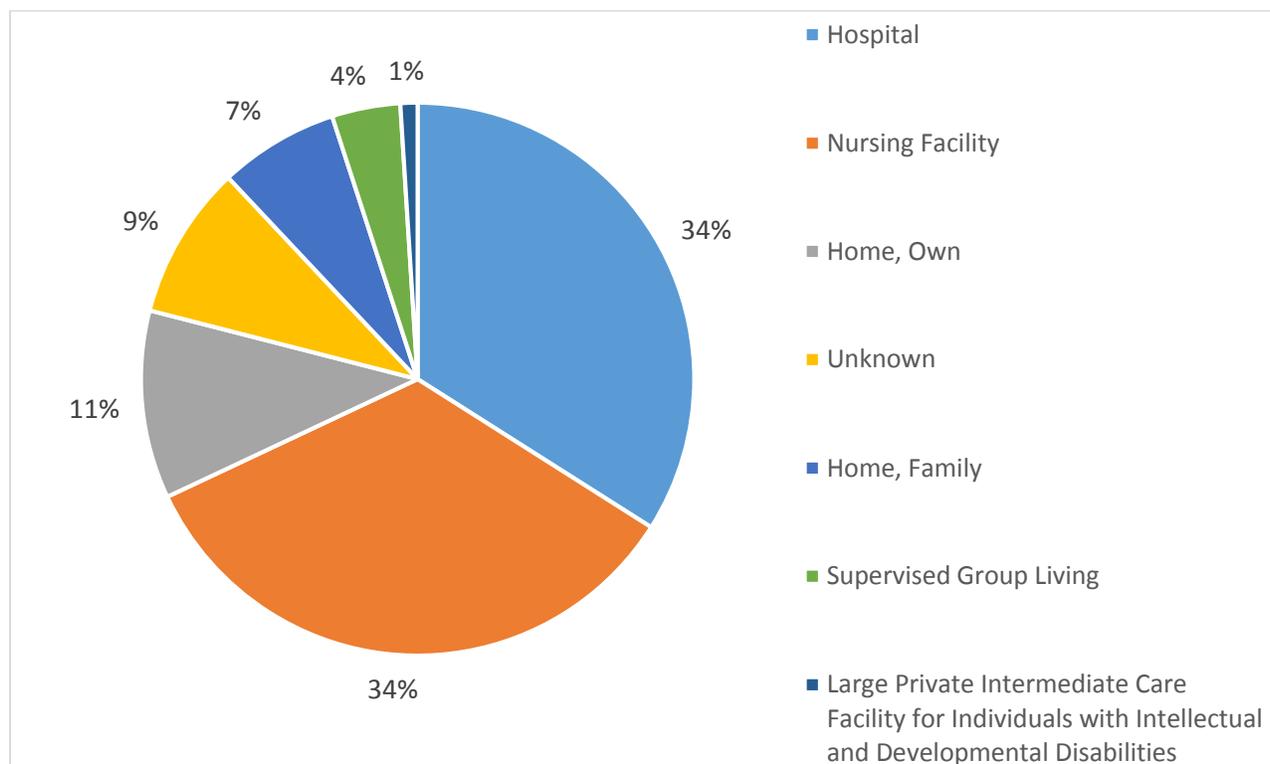
Reference: Accessed on July 9, 2015 at <http://www.cms.gov/Medicare/Medicare-fee-for-service-payment/hospice/index.html>

Place of Death for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: Indiana State Department of Health

Of the 2014 mortalities for individuals serviced by the Bureau of Developmental Disabilities Services (BDDS), 34 percent of deaths in a hospital setting is comparable to 37 percent in the Indiana general population and 38 percent in the national general population. Alternatively, the 34 percent of mortalities in a nursing facility of individuals serviced by BDDS is higher than the 26 percent in the Indiana general population and 20 percent in the national general population. Finally, the 11 percent of mortalities at home for individuals receiving services from BDDS is lower than 28 percent in the Indiana general population and 29 percent in the national general population. (Note: Based on 2013 Indiana and national general population data. Data reports for general population are not yet available for 2014.)



Place	Count	Percent
Hospital	148	34%
Nursing Facility	144	34%
Home, Own	48	11%
Unknown*	40	9%
Home, Family	31	7%
Supervised Group Living	15	4%
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	4	1%

*Place of death was not specified

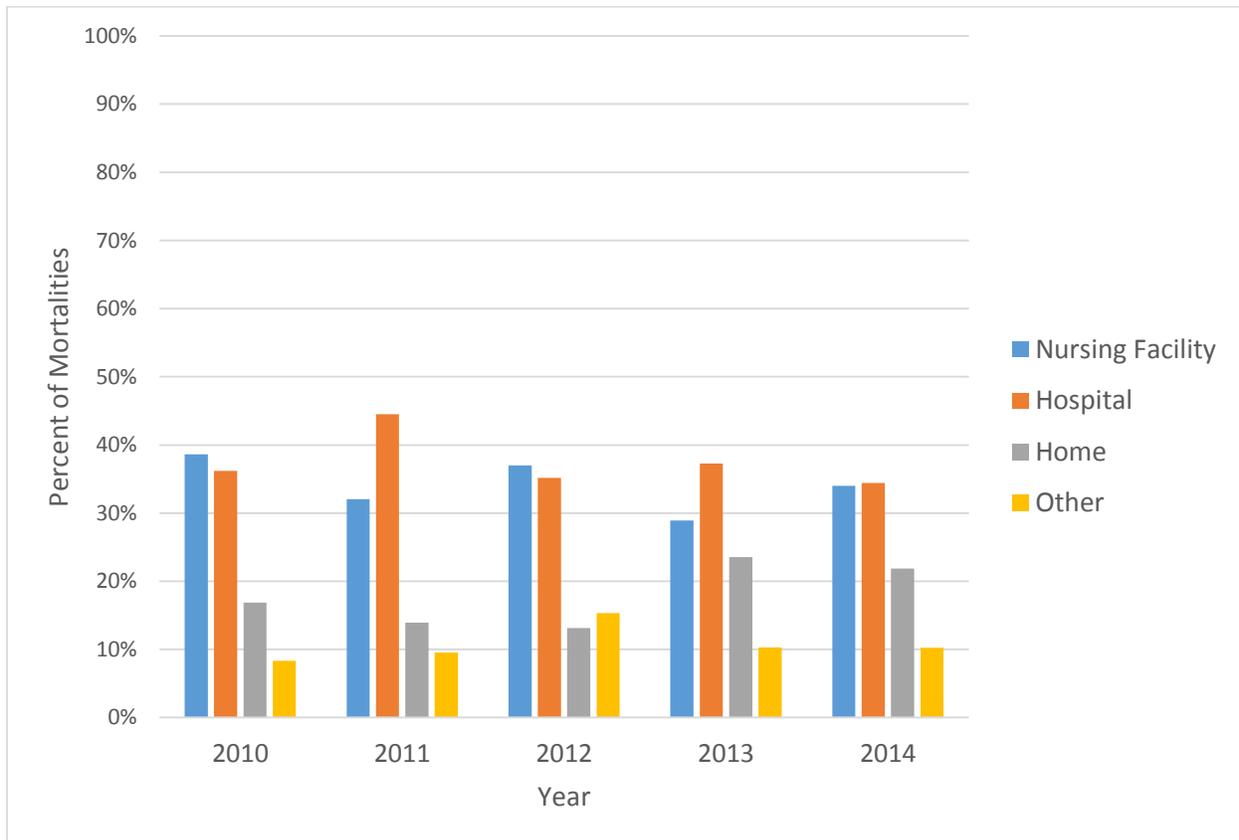
Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2013 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on July 9, 2015 at <http://wonder.cdc.gov/ucd-icd10.html>

Place of Death: Five-year Comparison

January 1, 2010 through December 31, 2014

Data Source: Indiana State Department of Health

Over a five-year time frame from 2010 to 2014, hospitals and nursing facilities were the most frequent places of death.



Place	2010	2011	2012	2013	2014
Nursing Facility	39%	32%	37%	29%	34%
Hospital	36%	44%	35%	37%	34%
Home	17%	14%	13%	24%	22%
Other	8%	10%	15%	10%	10%

“Home” includes own and family homes. “Other” includes Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities, community, hospice, ambulance and unknown locations.

Top Five Primary Causes of Death for 2014

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: Indiana State Department of Health

Each specific cause of death as reported by the Indiana State Department of Health is grouped under a major category of death as defined by the International Statistical Classification of Diseases and Related Health Problems-10th Revision. (Note: Based on 2013 Indiana general population data. Data on general population is not yet available for 2014.)

Primary Cause of Death for 2014	Average Age	Number of Deaths	Percent of Deaths	Percent of Deaths in Indiana General Population (2013)
Respiratory System	55.9	130	30%	11%
Circulatory System	61.4	107	25%	30%
Cancer	65.1	29	7%	22%
Nervous System	54.7	27	6%	6%
Infections	54.5	22	5%	3%
Total	58.3	315	73%	72%

Primary Cause of Death for 2010--2014	2010		2011		2012		2013		2014	
	Count	%								
Respiratory System	71	17%	85	21%	77	19%	86	21%	130	30%
Circulatory System	79	19%	77	19%	100	25%	81	20%	107	25%
Cancer	51	12%	35	9%	31	8%	36	9%	29	7%
Nervous System	18	4%	27	7%	25	6%	29	7%	27	6%
Infections	25	6%	30	7%	30	7%	40	10%	22	5%
Total	244	58%	254	63%	263	65%	272	67%	315	73%

Reference: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved 06/24/15 from <http://apps.who.int/classifications/icd10/browse/2015/en>

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2013 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2013, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on July 9, 2015 at <http://wonder.cdc.gov/ucd-icd10.html>

Top Three Primary Causes of Death: Decade of Life

Total Mortalities = 430 | January 1 through December 31, 2014

Data Source: Indiana State Department of Health

Respiratory system conditions are identified as a primary cause of death across most age groups, followed by circulatory system conditions. From ages 50-99, cancer is a primary cause of death.

Age	Cause of Death	Number of Mortalities	Percent of Deaths for Decade of Life
0-9	Unknown	3	75%
	Congenital Conditions	1	25%
10-19	Respiratory System	2	22%
	Gastrointestinal/Digestive System	2	22%
	Nervous System and Circulatory System	1	11%
20-29	Respiratory System	10	38%
	Circulatory System	7	27%
	Infections	2	8%
30-39	Respiratory System	11	35%
	Infections	3	10%
	External Causes of Mortality	3	10%
40-49	Respiratory System	17	35%
	Circulatory System	14	29%
	Nervous System	7	15%
50-59	Respiratory System	36	35%
	Circulatory System	23	22%
	Cancer	8	8%
60-69	Respiratory System	24	26%
	Circulatory System	21	23%
	Cancer	8	9%
70-79	Circulatory System	24	32%
	Respiratory System	19	25%
	Cancer	7	9%
80-89	Circulatory System	14	40%
	Respiratory System	10	29%
	Nervous System	3	9%
90-99	Cancer	2	50%
	Respiratory System	1	25%
	Circulatory System	1	25%

Glossary: Category of Death

Category	Definition	Examples
Abnormal Findings Not Classified	Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified	Abnormal findings on blood, urinary, tissues, or diagnostic imaging without diagnosis
Before/After Childbirth Conditions	Conditions originating in the perinatal period (before and after childbirth)	Disorders related to length of gestation and fetal growth, birth trauma, infections specific to the perinatal period
Blood/Immune Diseases	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	Anemias, blood clots, hemorrhaging, immune disorders
Cancers (Neoplasms)	Diseases in which abnormal cells divide uncontrollably and destroy body tissue.	Prostate cancer, breast cancer, lung cancer, colon cancer, leukemia, lymphoma
Cardiopulmonary Diseases	Diseases of both the cardiovascular and respiratory systems	Cardiopulmonary arrest, cardiopulmonary disease
Circulatory Diseases	Diseases of the circulatory system	Hypertension, heart disease, heart failure, stroke, hemorrhage, atherosclerosis, arteriosclerosis, rheumatic fever
Congenital Conditions	Conditions existing before or at birth, e.g., congenital malformations, deformations, and chromosomal abnormalities	Spina bifida, congenital heart, Down's syndrome, congenital nervous system conditions, congenital respiratory conditions
Ear Diseases	Diseases of the ear and mastoid process	Ear infections, hearing loss
External Causes	External causes of death	Vehicle accidents, suicide, falls, self-injurious, poisoning, assault, complications of medical surgical care
Eye Diseases	Diseases of the eye and adnexa (accessory structures of eye)	Conjunctivitis, blindness, glaucoma, cataracts

Glossary: Category of Death--continued

Category	Definition	Examples
Gastrointestinal/Digestive System Diseases	Diseases of the digestive system	Dysphagia/swallowing, esophagus, stomach ulcers, small intestine ulcers, gastrojejunal ulcers, peptic ulcers, hernia, Crohn's disease, vessel/vascular disorders, diverticulitis, diverticulosis, liver disease, alcohol related liver disease, hepatitis, gallstones, gallbladder disease, pancreatitis
Hormone/Nutrition/Metabolism Diseases	Diseases of the endocrine and metabolic systems and nutritional disorders	Thyroid, diabetes, obesity, failure to thrive, malnutrition, cystic fibrosis, dehydration
Infections	Diseases generally recognized as communicable or transmissible	Sepsis, diarrhea, tuberculosis, Lyme disease, measles, rubella, hepatitis, HIV
Muscle/Bone Diseases	Diseases of the musculoskeletal system and connective tissue	Rheumatoid arthritis, lupus, arthritis, osteoarthritis, osteoporosis
Nervous System Diseases	Diseases of the nervous system	Medication/antipsychotic drug interactions (neuroleptic malignant syndrome), Alzheimer's, Parkinson's, epilepsy/seizures, cerebral palsy, meningitis, multiple sclerosis, mini-stroke, muscular dystrophy
Other	Conditions not elsewhere classified	Multiple organ failure, Raynaud's syndrome, antibiotic resistance
Psychiatric/Emotional Disorders	Disorders of psychological development	Developmental disorder, intellectual disorder, dementia, substance abuse, mood disorders, schizophrenia, personality disorders
Pregnancy/Childbirth/Postpartum Conditions	Conditions during pregnancy, childbirth and the puerperium (post-partum)	Complications of labor and delivery, maternal care related to the fetus and amniotic cavity

Glossary: Category of Death—continued

Category	Definition	Examples
Respiratory Diseases	Diseases of the respiratory system	Hypoxia, asphyxiation, choking, influenza, pneumonia, aspiration pneumonia, viral pneumonia, bacterial pneumonia, bronchitis, emphysema, asthma, bronchiectasis, pneumonitis
Skin Diseases	Diseases of the skin and subcutaneous tissue	Skin infections, dermatitis, eczema
Urinary/Genital Diseases	Diseases of the genitourinary system	Acute kidney disease, chronic kidney disease, renal failure, kidney stones, urinary tract infections, benign prostatic hypertrophy (BPH), other prostate conditions, breast disorders, male genital disorders, female genital disorders, pelvic inflammatory disease, cystitis

Reference: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved 06/24/15 from <http://apps.who.int/classifications/icd10/browse/2015/en>

Glossary: Funding Sources

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 an 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 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 FSW 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: Funding Sources--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.

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: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/nursing-facilities-nf.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: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/nursing-facilities-nf.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>