



Mortality Data Review

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

Date of Death: January 1, 2016—December 31, 2016

Table of Contents

Purpose	2
Individual Population	3
Mortalities by Funding Source for 2016	4
Mortalities by Month for 2016	5
Mortalities by Month: Seven-year Comparison.....	6
Mortalities by Gender and Funding Source for 2016	7
Mortalities by Gender and Age for 2016	8
Mortalities with Hospice for 2016	9
Place of Death for 2016	10
Place of Death: Seven-year Comparison.....	12
Top Five Primary Causes of Death for 2016.....	13
Top Three Primary Causes of Death: Decade of Life	14
Glossary: Category of Death	15
Glossary: Category of Death--continued	16
Glossary: Category of Death—continued	17
Glossary: Funding Sources	18
Glossary: Funding Sources--continued	19

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.

The information contained within this report is based on deaths during the timeframe January 1 through December 31, 2016 as reported to the Bureau of Developmental Disabilities Services through January 11, 2017 via a death-of-person incident report. 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 BDDS administers programs to approximately 29,000 individuals.

Waiver Funding Sources	
Individual Population as of January 11, 2017	Individuals
Family Supports Waiver	14,575
Community Integration & Habilitation Waiver	9,072
Total	23,647

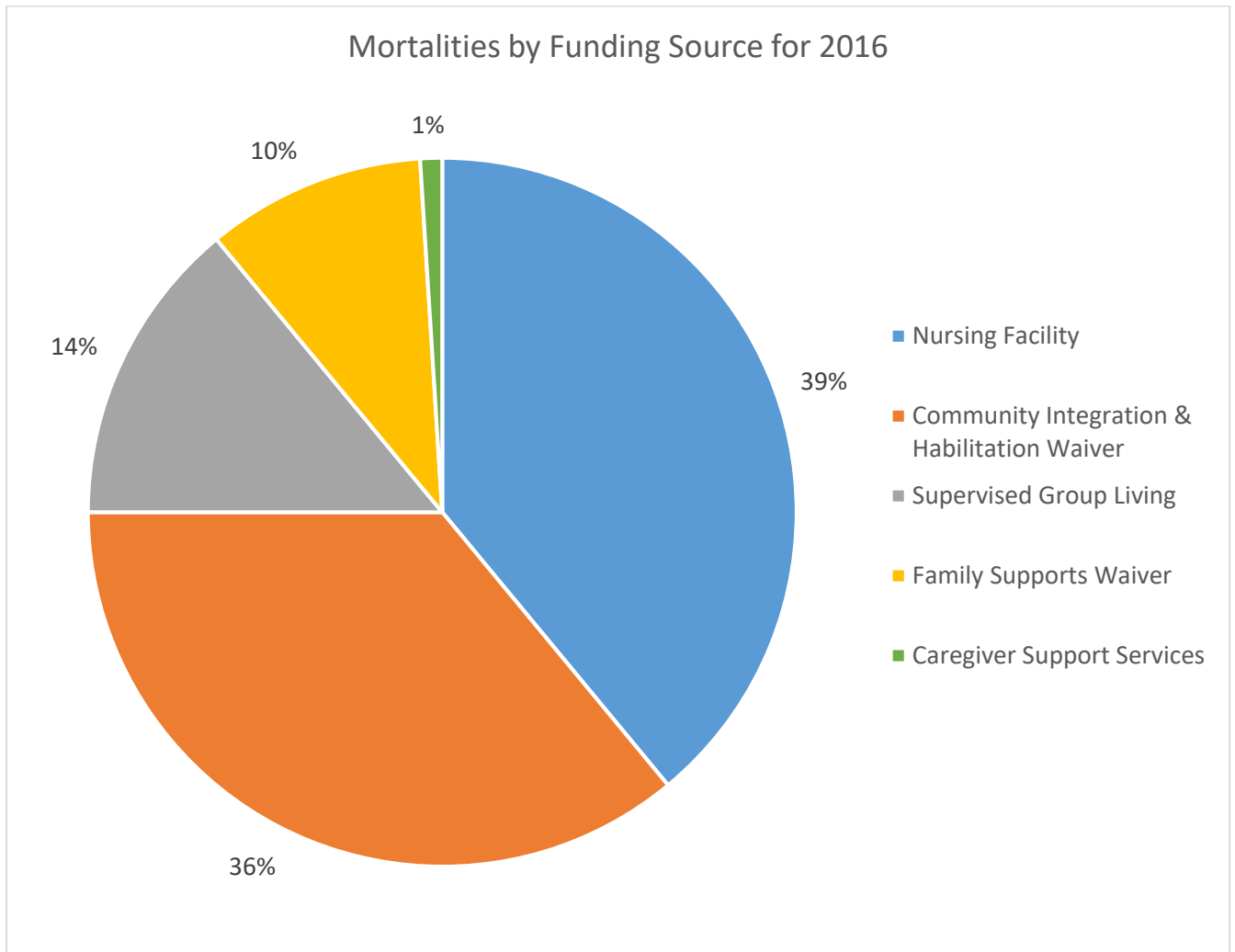
Data Source: State of Indiana INsite database

Non-waiver Funding Sources	
Individual Population as of January 11, 2017	Individuals
Supervised Group Living	3,181
Nursing Facility	1,320
Caregiver Supports	1,057
State-operated Care Facility	63
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	49
Total	5,670

Data Source: State of Indiana DART database

Mortalities by Funding Source for 2016

January 1 through December 31, 2016



Total Mortalities = 436 | Data Source: State of Indiana DART database

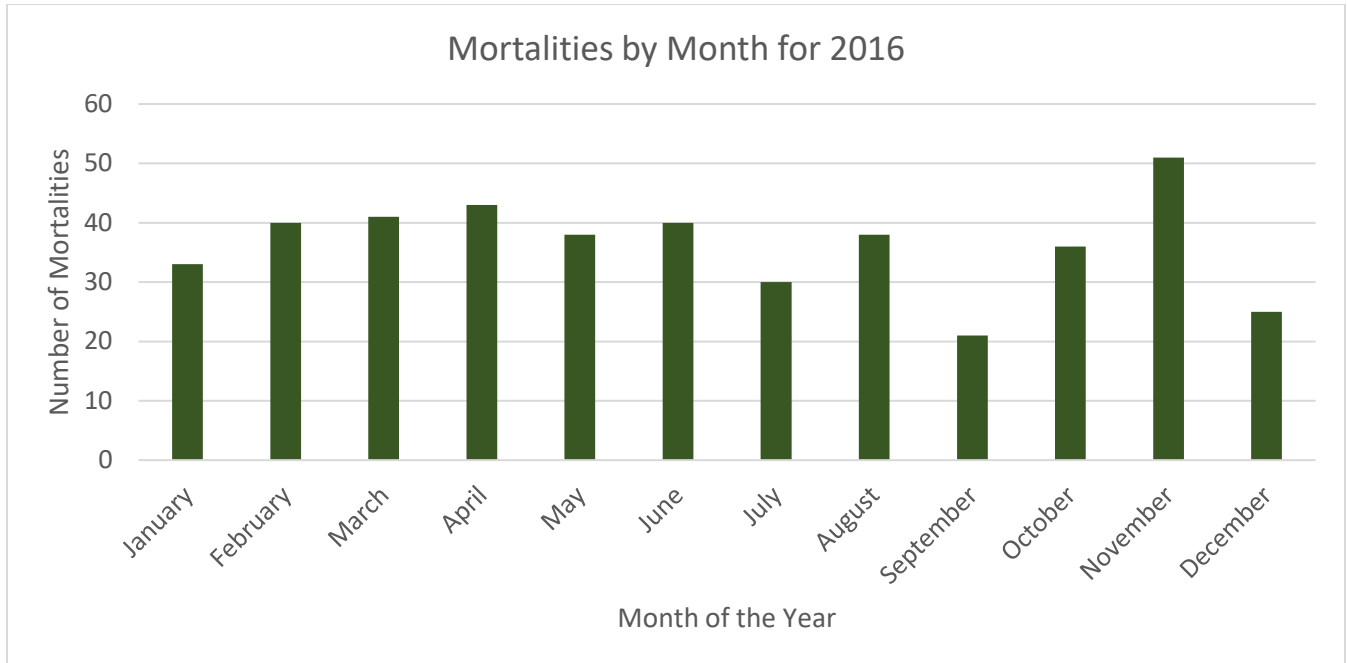
Mortalities by Funding Source for 2016	Count	Percent
Nursing Facility	172	39%
Community Integration & Habilitation Waiver	158	36%
Supervised Group Living	63	14%
Family Supports Waiver	42	10%
Caregiver Support Services	1	1%
Total	436	100%

Total Mortalities = 436 | Data Source: State of Indiana DART database

Mortalities by Month for 2016

January 1 through December 31, 2016

Compared to the national and the general population for Indiana for 2015, the rate of mortalities for individuals receiving services through the BDDS were lower in January and September yet higher in November. (Note: Data reports for general populations are not yet available for 2016.)



Total Mortalities = 436 | Data Source: State of Indiana DART database

Mortalities by Month for 2016			
Month	Count	Month	Count
January	33	July	30
February	40	August	38
March	41	September	21
April	43	October	36
May	38	November	51
June	40	December	25
		Total	436

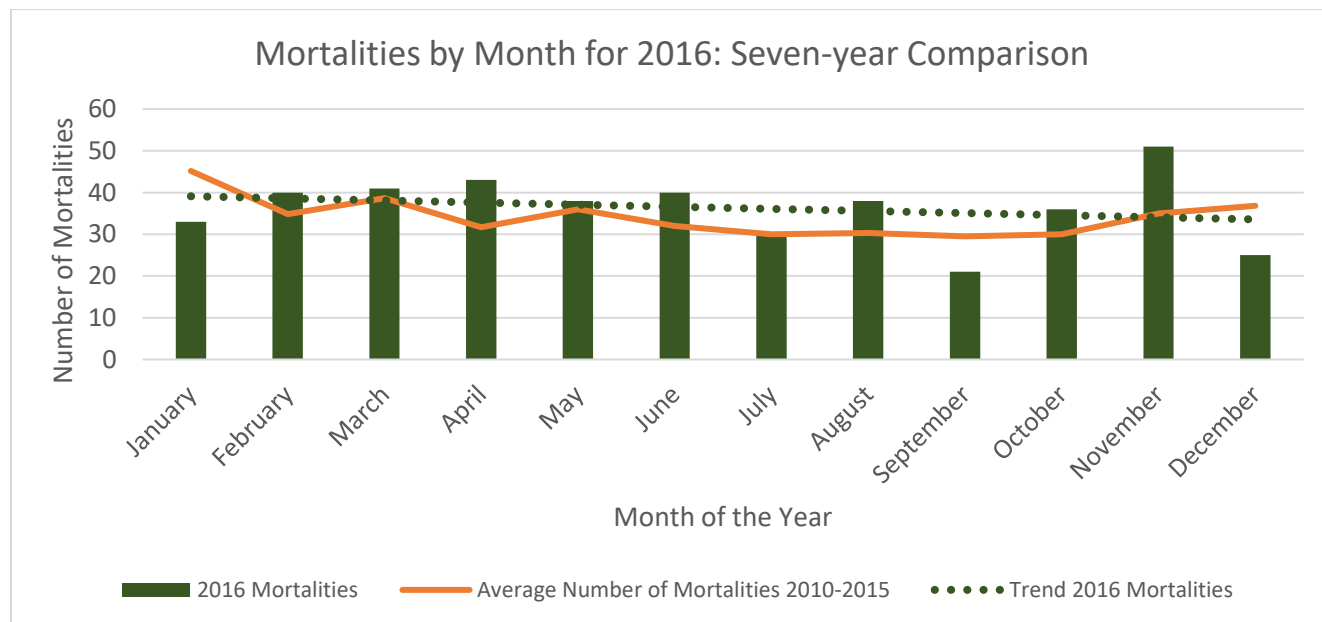
Total Mortalities = 436 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2015 on CDC WONDER Online Database, released December, 2016. Data are from the Multiple Cause of Death Files, 1999-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on March 10, 2017 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Month: Seven-year Comparison

January 1 through December 31, 2016

The mortality data for 2016 for individuals receiving services through the BDDS stayed relatively constant throughout the year similar to the general populations at the national and Indiana levels of mortalities in 2015. (Note: Data reports for general populations are not yet available for 2016.)



Total Mortalities = 436 | Data Source: State of Indiana DART database

Mortalities by Month: Seven-year Comparison							
Month	2010	2011	2012	2013	2014	2015	2016
January	49	43	33	49	53	44	33
February	41	34	30	31	37	36	40
March	37	44	37	37	42	35	41
April	34	31	29	28	36	32	43
May	31	36	44	43	24	38	38
June	31	26	32	39	32	32	40
July	27	30	37	25	30	31	30
August	28	27	37	24	33	33	38
September	28	28	28	32	30	31	21
October	37	26	34	29	26	28	36
November	37	43	33	33	37	27	51
December	29	41	30	38	50	33	25
Total	409	409	404	408	430	400	436

Total Mortalities = 436 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2015 on CDC WONDER Online Database, released December, 2016. Data are from the Multiple Cause of Death Files, 1999-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on March 10, 2017 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Funding Source for 2016

January 1 through December 31, 2016

During the years 2010-2015, females and males each comprised approximately 50% of the mortalities in both the national and Indiana general populations. In 2016, the overall percentages of mortalities of females and males in the population of individuals served by the BDDS were similar to the percentages of mortalities of females and males in national and Indiana general population data. (Note: Data reports for general populations are not yet available for 2016.)

Mortalities by Gender and Funding Source for 2016			
Funding Source	Male	Female	Total
Nursing Facility	74	98	172
Community Integration & Habilitation Waiver	91	67	158
Supervised Group Living	40	23	63
Family Supports Waiver	25	17	42
Caregiver Support Services	1	0	1
Total	231	205	436

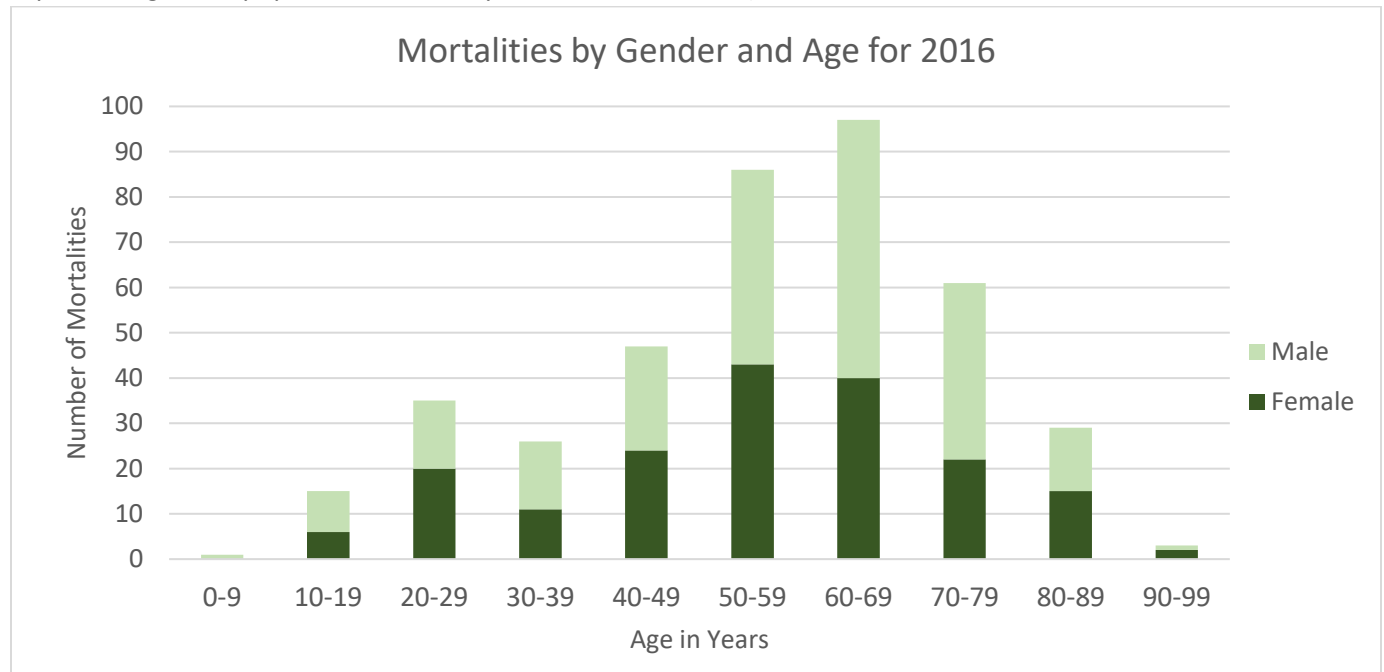
Total Mortalities = 436 | Data Source: State of Indiana DART database

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2015 on CDC WONDER Online Database, released December, 2016. Data are from the Multiple Cause of Death Files, 1999-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on March 10, 2017 at <http://wonder.cdc.gov/ucd-icd10.html>

Mortalities by Gender and Age for 2016

January 1 through December 31, 2016

In 2016, mortality trends by gender and age of the individuals in the population served by the BDDS were similar to national and Indiana general population trends in 2015 for all age groups. (Note: Data reports for general populations are not yet available for 2016.)



Total Mortalities = 436 | Data Source: State of Indiana DART database

Mortalities by Gender and Age for 2016			
Age in Years	Male	Female	Total
0-9	1	4	5
10-19	12	3	15
20-29	23	14	37
30-39	15	14	29
40-49	25	25	50
50-59	55	45	100
60-69	64	46	110
70-79	27	38	65
80-89	8	12	20
90-99	1	4	5
Total	231	205	436

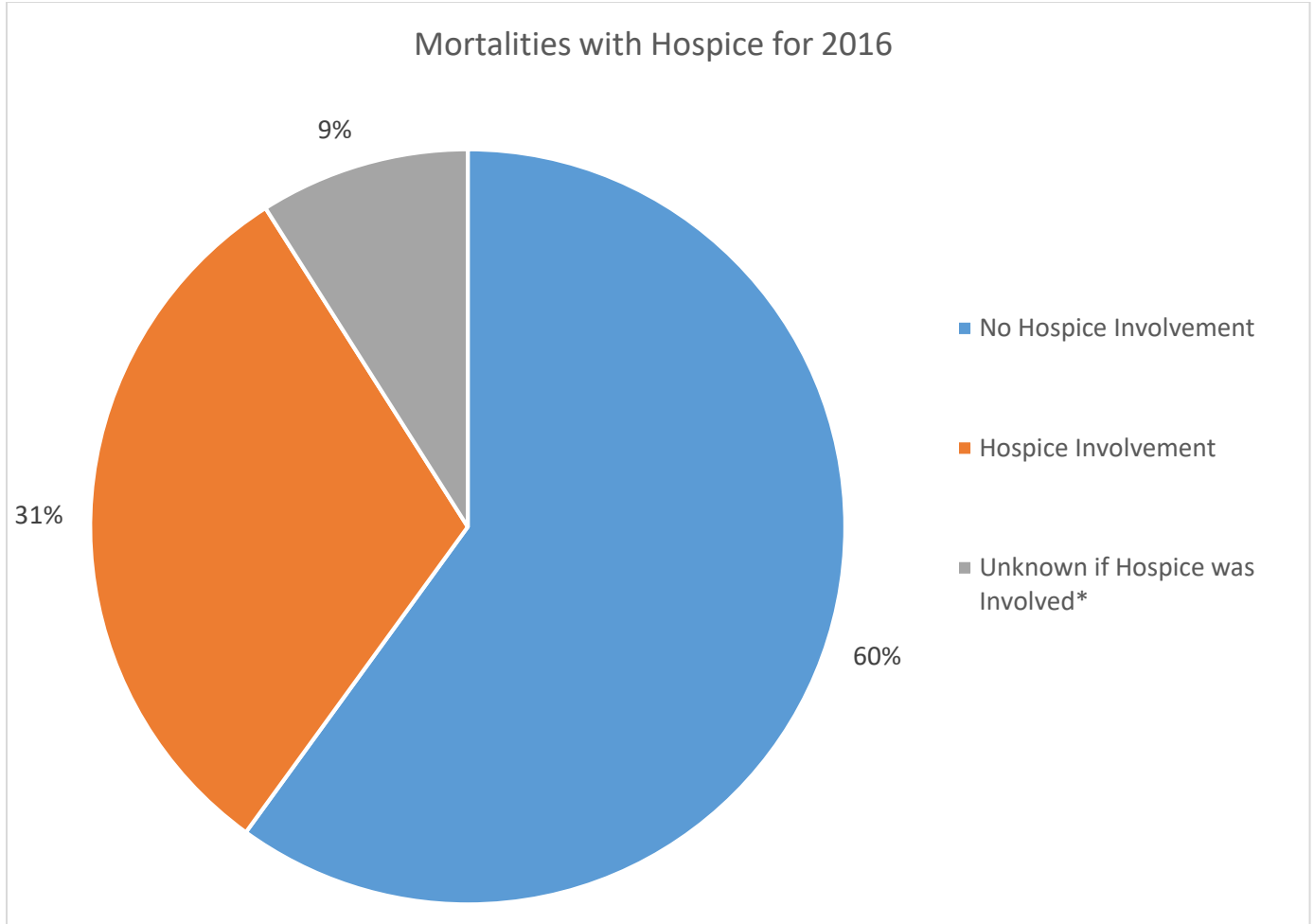
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Mortalities with Hospice for 2016

January 1 through December 31, 2016

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 status could not be determined from available documentation.

Total Mortalities = 436 | Data Source: Provider documents submitted during the mortality review process

Mortalities with Hospice for 2016	Count	Percent
No Hospice Involvement	263	60%
Hospice Involvement	135	31%
Unknown if Hospice was Involved*	38	9%

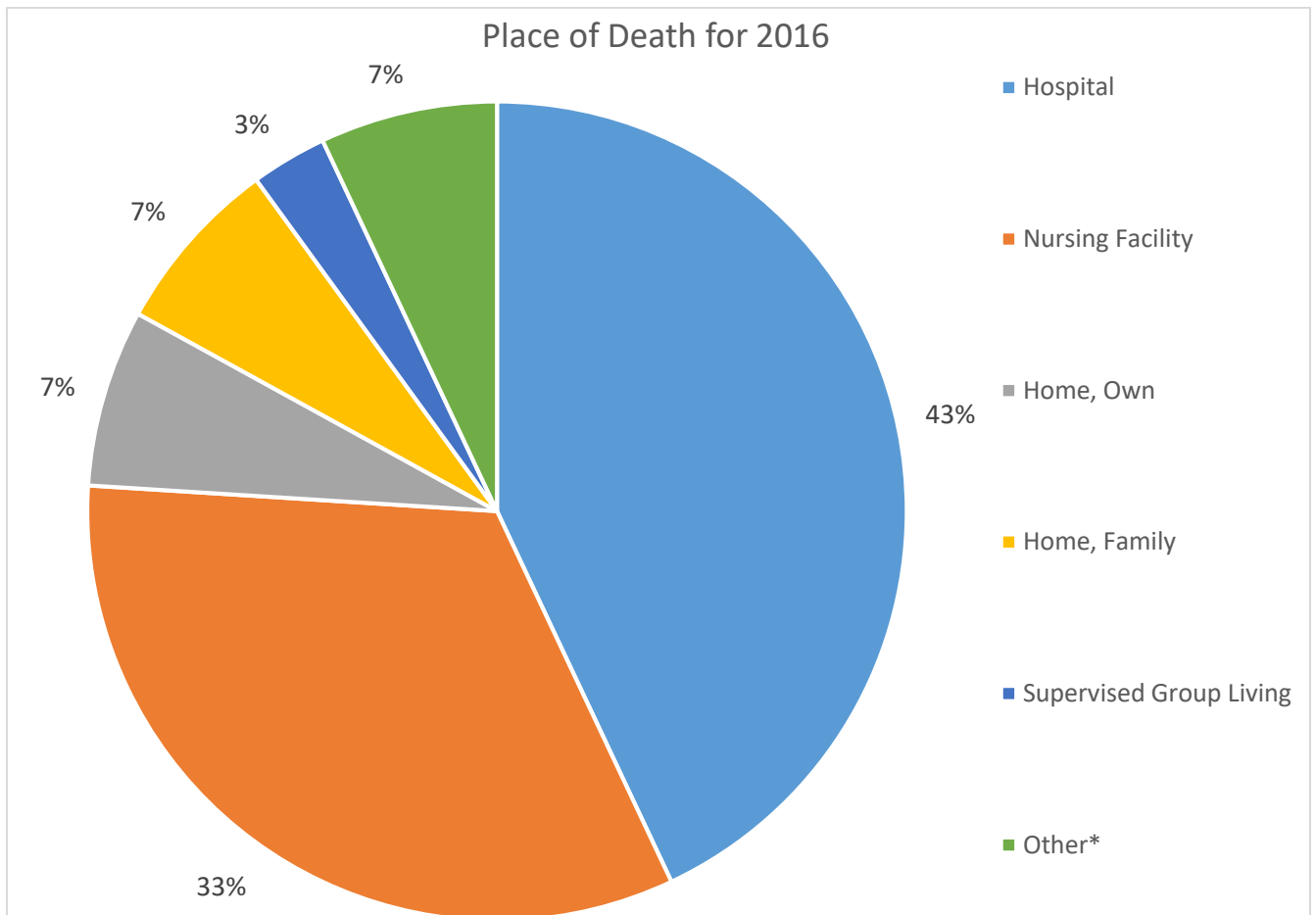
Total Mortalities = 436 | Data Source: Provider documents submitted during the mortality review process

Reference: Accessed on March 10, 2017 at <http://www.cms.gov/Medicare/Medicare-fee-for-service-payment/hospice/index.html>

Place of Death for 2016

January 1 through December 31, 2016

Of the 2016 mortalities for individuals served by the BDDS, the 43 percent of deaths in a hospital setting is slightly higher than the 37 percent in the Indiana general population and 36 percent in the national general population. The 33 percent of mortalities in a nursing facility of individuals serviced by the BDDS is higher than the 26 percent in the Indiana general population and 20 percent in the national general population. Alternatively, the 17 percent of mortalities at home for individuals receiving services from the BDDS is lower than 29 percent in the Indiana general population and 30 percent in the national general population. (Note: Based on 2015 Indiana and national general population data. Data reports for general populations are not yet available for 2016.)



*Other is comprised of hospice, community, and unknown settings.

Total Mortalities = 436 | Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Place of Death for 2016		
Place	Count	Percent
Hospital	187	43%
Nursing Facility	142	33%
Home, Own	32	7%
Home, Family	30	7%
Supervised Group Living	14	3%
Other*	31	7%
Total	436	100%

*Other is comprised of hospice, community, and unknown settings.

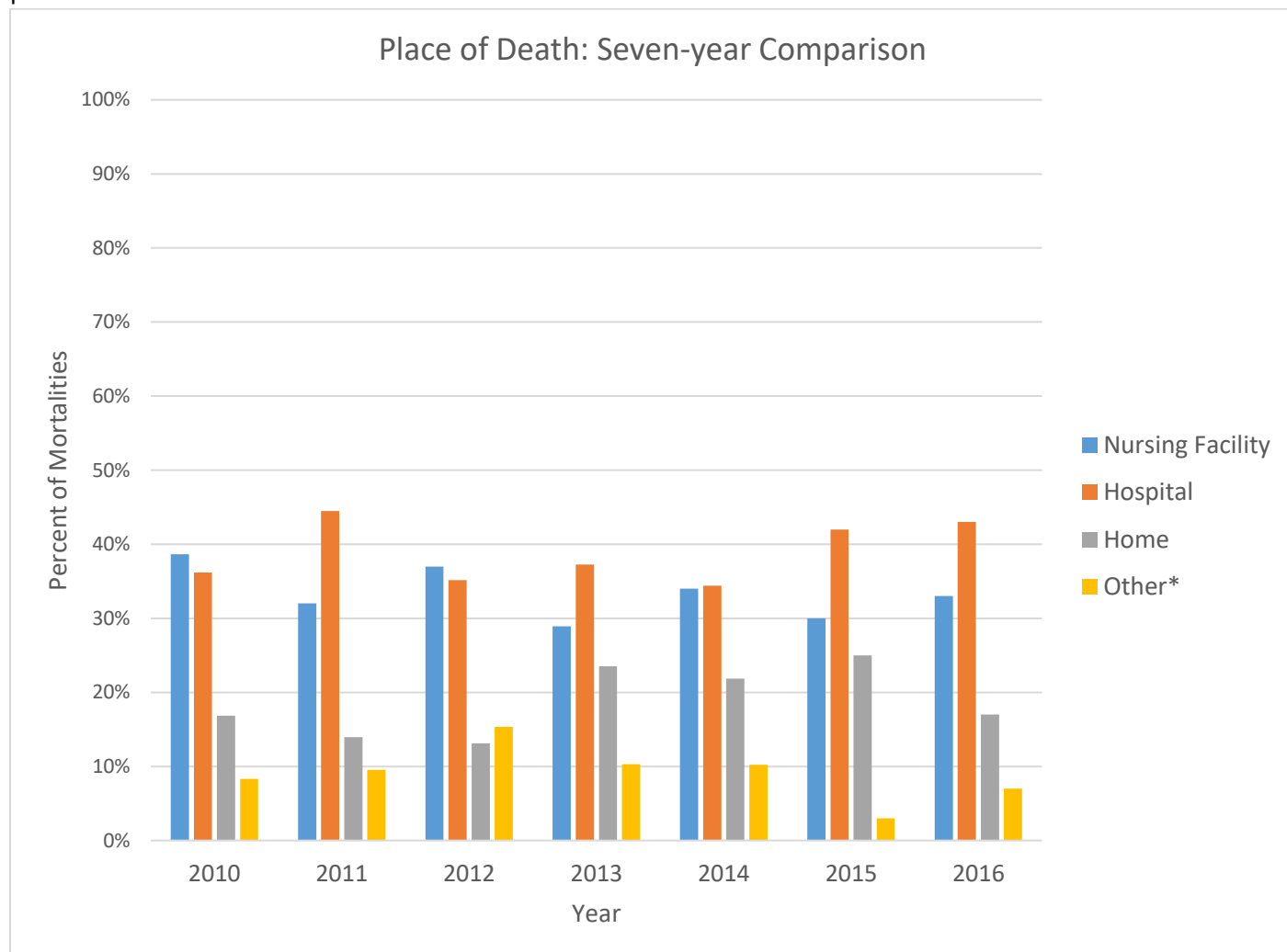
Total Mortalities = 436 | Data Source: Indiana State Department of Health; Provider documents submitted during the mortality review process

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999-2015 on CDC WONDER Online Database, released December, 2016. Data are from the Multiple Cause of Death Files, 1999-2015, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on March 10, 2017 at <http://wonder.cdc.gov/ucd-icd10.html>

Place of Death: Seven-year Comparison

January 1, 2010 through December 31, 2016

Over a seven-year time frame from 2010 to 2016, hospitals and nursing facilities were the most frequent places of death.



“Home” includes own and family homes and Supervised Group Living. *Other is comprised of hospice, community, and unknown settings.

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

Place of Death: Seven-year Comparison							
Place	2010	2011	2012	2013	2014	2015	2016
Nursing Facility	39%	32%	37%	29%	34%	30%	33%
Hospital	36%	44%	35%	37%	34%	42%	43%
Home	17%	14%	13%	24%	22%	25%	17%
Other*	8%	10%	15%	10%	10%	3%	7%

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

Top Five Primary Causes of Death for 2016

January 1 through December 31, 2016

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 2015 Indiana general population data. Data on general populations is not yet available for 2016.)

Top Five Primary Causes of Death for 2016				
Primary Cause of Death for 2016	Average Age	Number of Deaths	Percent of Deaths	Percent of Deaths in Indiana General Population (2015)
Respiratory System	54.0	122	28%	11%
Circulatory System	58.1	106	24%	29%
Nervous System	45.5	48	11%	7%
Infections	58.2	33	8%	3%
Cancer	59.9	19	4%	22%
Total		328	75%	72%

Total Mortalities = 436 | Data Source: Indiana State Department of Health

Top Five Primary Causes of Death for 2011-2016												
Primary Cause of Death for 2011--2016	2011		2012		2013		2014		2015		2016	
	Count	%	Count	%	Count	%	Count	%	Count	%	Count	%
Respiratory System	85	21%	77	19%	86	21%	130	30%	121	30%	122	28%
Circulatory System	77	19%	100	25%	81	20%	107	25%	57	14%	106	24%
Cancer	35	9%	31	8%	36	9%	29	7%	38	10%	19	4%
Nervous System	27	7%	25	6%	29	7%	27	6%	29	7%	48	11%
Infections	30	7%	30	7%	40	10%	22	5%	18	5%	33	8%
Total	254	63%	263	65%	272	67%	315	73%	263	66%	328	75%

Total Mortalities = 436 | Data Source: Indiana State Department of Health

Reference: International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved March 10, 2017 from <http://apps.who.int/classifications/icd10/browse/2016/en>

Reference: Centers for Disease Control and Prevention, National Center for Health Statistics. Underlying Cause of Death 1999- 2014 on CDC WONDER Online Database, released 2015. Data is from the Multiple Cause of Death Files, 1999-2014, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed on March 10, 2017 at <http://wonder.cdc.gov/ucd-icd10.html>

Top Three Primary Causes of Death: Decade of Life

January 1 through December 31, 2016

Except for the age groups of 10-19, 70-79, 80-89, and 90-99, conditions of the Circulatory, Respiratory, and Nervous systems comprised the top three causes of death.

Top Three Primary Causes of Death: Decade of Life			
Age	Cause of Death	Number of Mortalities	Percent of Deaths for Decade of Life
0-9	Circulatory System	1	20%
	Respiratory System	1	20%
	Nervous System	1	20%
10-19	Nervous System	4	27%
	Respiratory System	3	20%
	Infections	3	20%
20-29	Respiratory System	10	27%
	Nervous System	7	19%
	Circulatory System	7	19%
30-39	Respiratory System	12	41%
	Circulatory System	5	17%
	Nervous System	5	17%
40-49	Respiratory System	15	30%
	Circulatory System	13	26%
	Nervous System	7	14%
50-59	Circulatory System	27	27%
	Respiratory System	24	24%
	Nervous System	12	12%
60-69	Respiratory System	37	34%
	Circulatory System	24	22%
	Nervous System	9	8%
70-79	Circulatory System	19	29%
	Respiratory System	15	23%
	Infections	9	14%
80-89	Circulatory System	7	35%
	Respiratory System	4	20%
	Urinary/Genital System	3	15%
90-99	Circulatory System	2	40%
	Urinary/Genital System	1	20%
	Respiratory System	1	20%

Total Mortalities = 436 | Data Source: Indiana State Department of Health

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, failure to thrive, septic shock, multiple organ failure
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
Circulatory Diseases	Diseases of the circulatory system including cardiopulmonary	Hypertension, heart disease, heart failure, stroke, hemorrhage, atherosclerosis, arteriosclerosis, rheumatic fever, cardiopulmonary arrest
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, (e.g. acute bowel rupture), choking/asphyxiation on food
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, acute bowel rupture (unless caused by surgery, then external), peritonitis
Hormone/Nutrition/Metabolism Diseases	Diseases of the endocrine and metabolic systems and nutritional disorders	Thyroid, diabetes, obesity, failure to thrive, malnutrition, cystic fibrosis, dehydration, immune syndromes, acidosis
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, anoxic brain death/injury, encephalopathy, cerebral edema, Reye syndrome
Other	Conditions not elsewhere classified	Raynaud's syndrome, antibiotic resistance, altered mental status
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, aspiration, upper airway obstruction
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 March 10, 2017 from <http://apps.who.int/classifications/icd10/browse/2016/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.

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>