



# Mortality Data Review

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

Date of Death: January 1, 2017—December 31, 2017

Report issued June 13, 2018

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## Purpose

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, BDDS, and BQIS. 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 compares 2017 mortality results to data collected in previous years.

*The information contained within this report is based on deaths during the timeframe January 1 through December 31, 2017 as reported to the Bureau of Developmental Disabilities Services through January 26, 2018 via a death-of-person incident report. Not all information was available at the time of this report. Data compiled by Advocare, LLC.*

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## Individual Population

### BDDS Waiver and Non-waiver Programs

The Bureau of Developmental Disabilities Services (BDDS) administers programs to more than 32,500 individuals with intellectual or developmental disabilities. The overall mortality rate for both waiver and non-waiver individuals in 2017 was 11.9 deaths per 1,000 individuals.<sup>1</sup> The 2017 mortality rate is lower than the three previous years: 2014—18.4 deaths per 1,000 individuals; 2015—15.1 deaths per 1,000 individuals; and 2016—14.9 deaths per 1,000 individuals.<sup>2</sup>

Figure 1: BDDS Waiver Services

BDDS Waiver Services Data Source: State of Indiana INsite database	
Individual Population as of December 31, 2017	Individuals
Family Supports Waiver	16,132
Community Integration & Habilitation Waiver	9,073
<b>Total</b>	<b>25,205</b>

Figure 2: BDDS Non-waiver Services

BDDS Non-waiver Services Data Source: State of Indiana DART database	
Individual Population as of January 2, 2018	Individuals
Supervised Group Living	3,185
Nursing Facility	1,585
Caregiver Supports	1,080
State-operated Care Facility	65
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	56
State Line	1,505
<b>Total</b>	<b>7,476</b>

<sup>1</sup> The mortality rate used in this report is a crude mortality rate, which is an unadjusted mortality rate.

<sup>2</sup> Disclaimer: Use caution when comparing mortality rates with other states and populations as the same parameters may not be utilized for inclusion criteria. Furthermore, states have different eligibility criteria that makes a comparison unreliable.

# BDDS 2017 Mortalities by BDDS Service

January 1 through December 31, 2017

Figure 3: BDDS 2017 Mortalities by BDDS Service

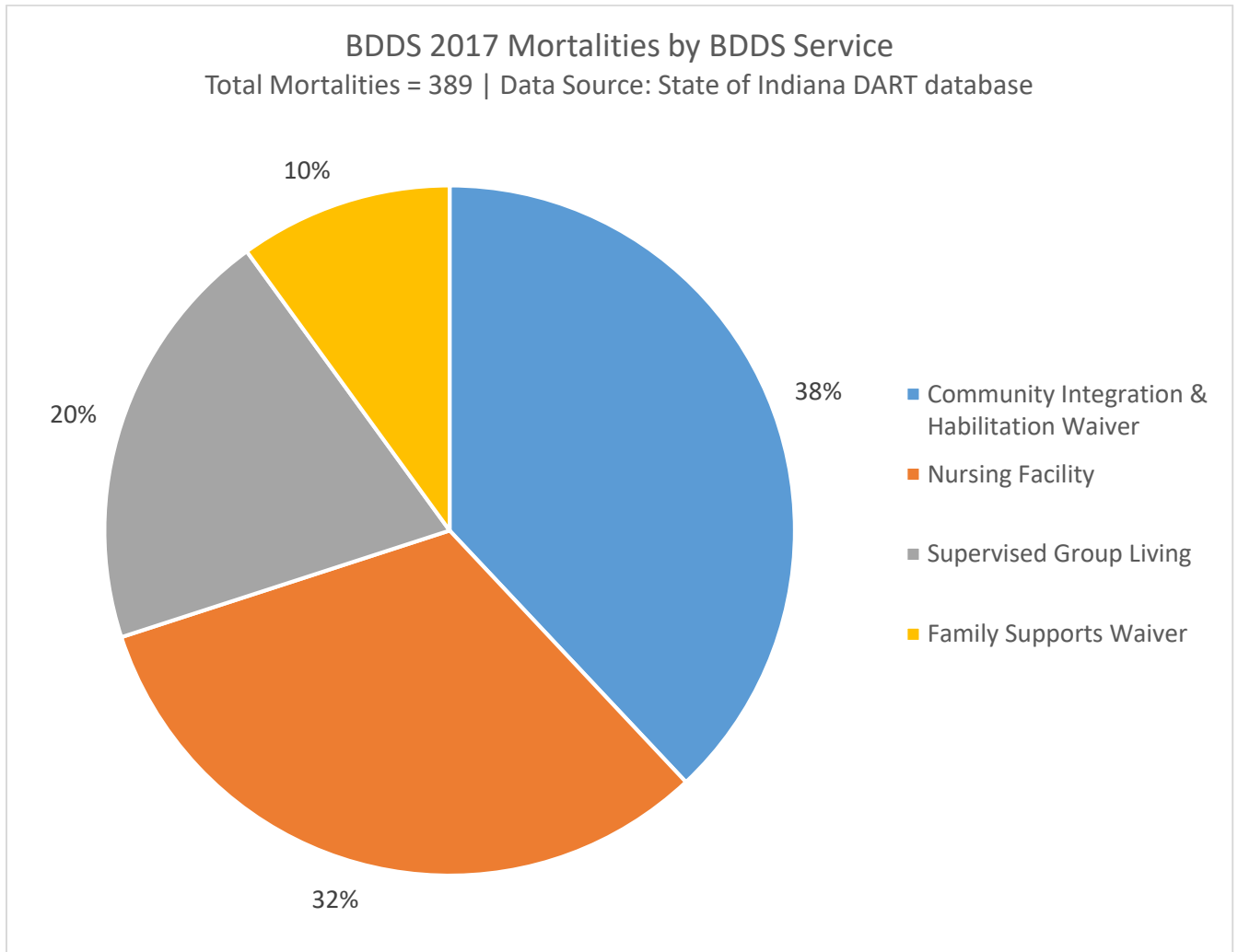
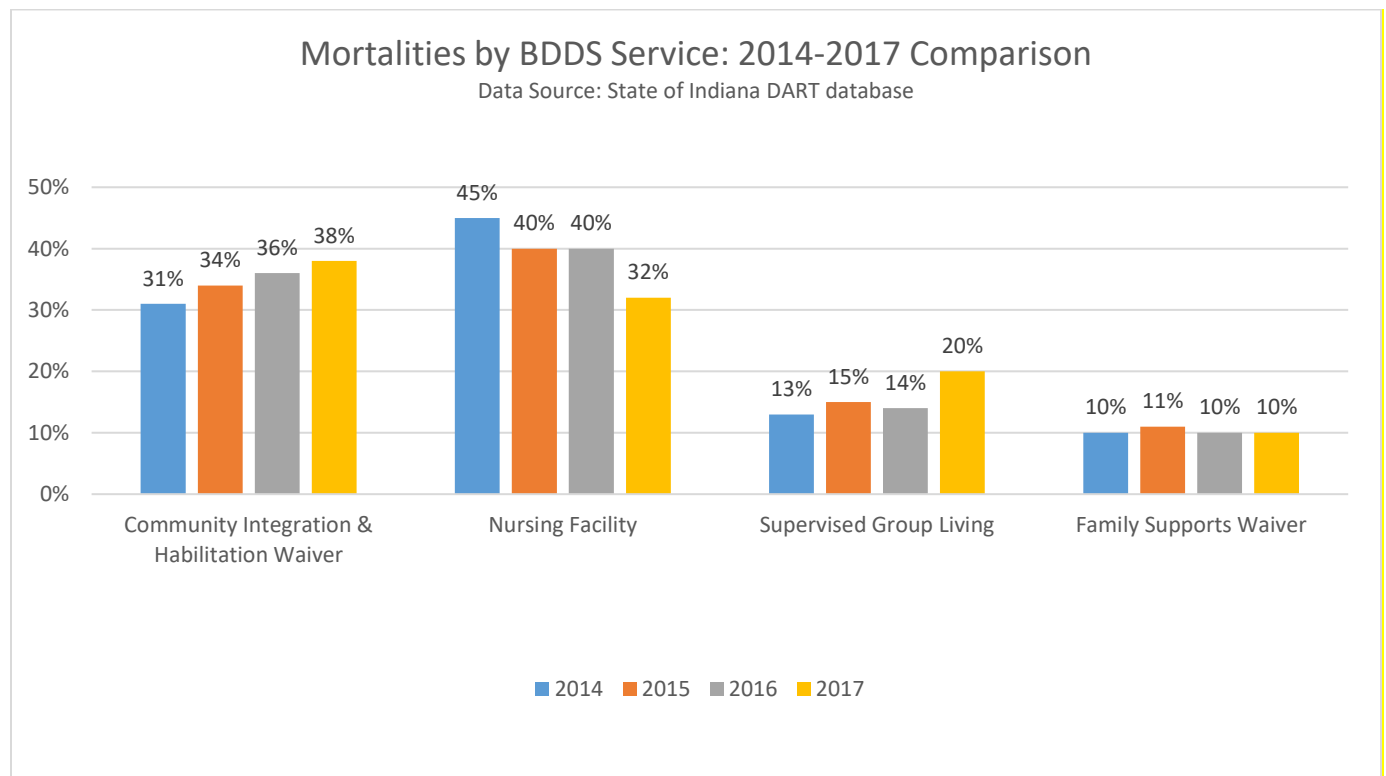


Figure 4: Mortalities by BDDS Service: 2014-2017 Comparison

Mortalities by BDDS Service: 2014-2017 Comparison								
Data Source: State of Indiana DART database								
Funding Source	2014		2015		2016		2017	
	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Community Integration & Habilitation Waiver	133	31%	137	34%	158	36%	146	38%
Nursing Facility	192	45%	159	40%	172	40%	126	32%
Supervised Group Living	56	13%	58	15%	63	14%	78	20%
Family Supports Waiver	41	10%	44	11%	42	10%	38	10%
Caregiver Supports	1	0%	0	0%	1	0%	0	0%
Large Private Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities	6	1%	1	0%	0	0%	0	0%
State Line	0	0%	0	0%	0	0%	1	0%
State-operated Care Facility	1	0%	1	0%	0	0%	0	0%
<b>Total</b>	<b>430</b>	<b>100%</b>	<b>400</b>	<b>100%</b>	<b>436</b>	<b>100%</b>	<b>389</b>	<b>100%</b>

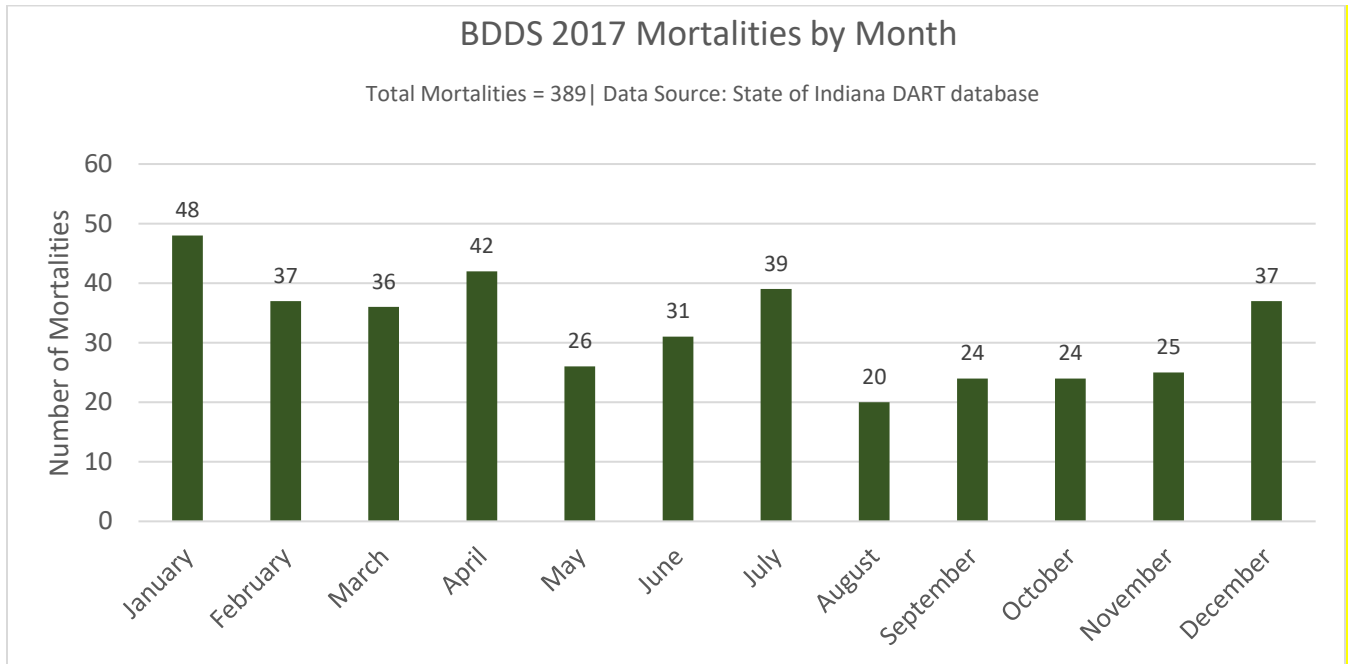
Figure 5: Mortalities by BDDS Service: 2014-2017 Comparison



## BDDS 2017 Mortalities by Month

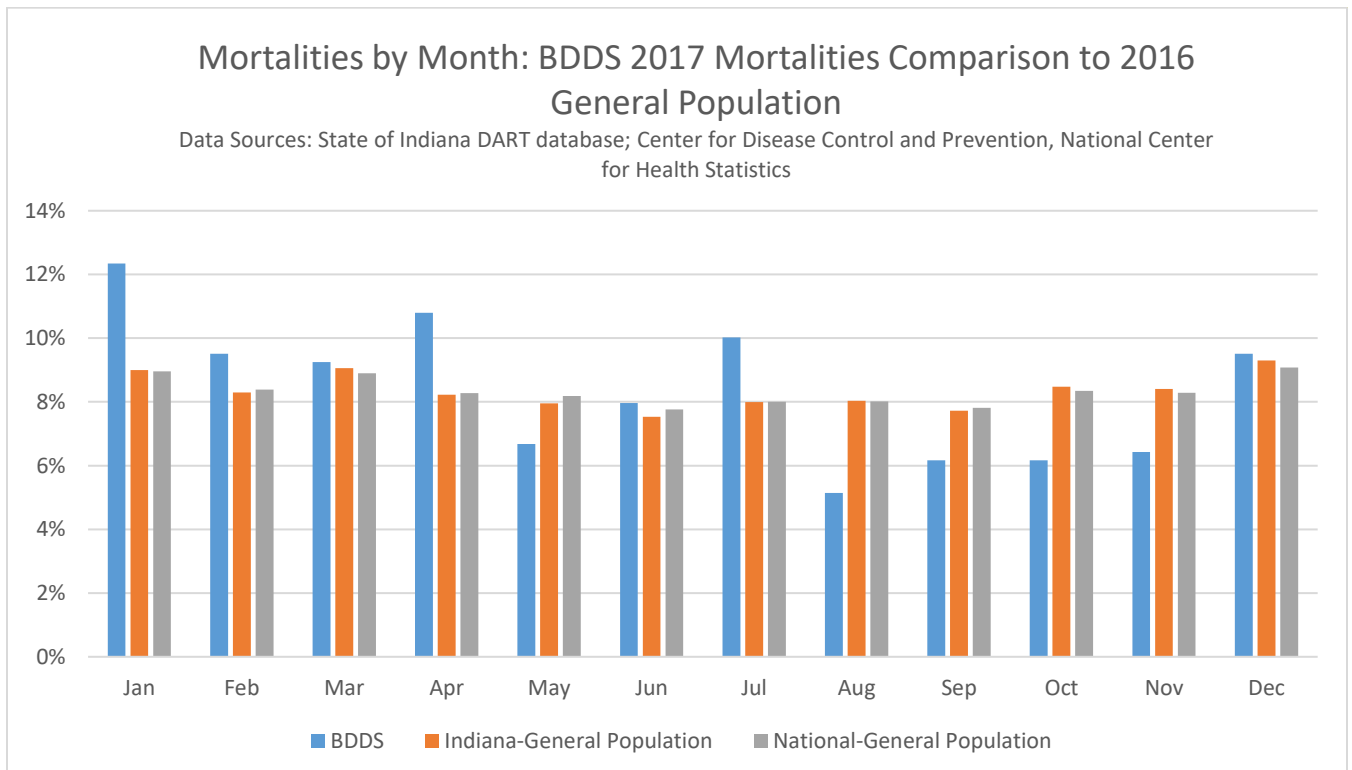
January 1 through December 31, 2017

Figure 6: BDDS 2017 Mortalities by Month



Mortalities in the BDDS population were noticeably higher than in the general population (2016) in the months of January, February, April, and July. (Note: Based on 2016 Indiana and national general population data. Data reports for general populations are not yet available for 2017.)

Figure 7: Mortalities by Month: BDDS 2017 Comparison to 2016 General Population





## BDDS Mortalities by Month: 2014-2017 Comparison

January 1, 2014 through December 31, 2017

There was a decrease in the number of reported mortalities in 2017 when compared to the trend of previous years (2014-2016).

Figure 8: BDDS Mortalities by Month: 2014-2017 Comparison

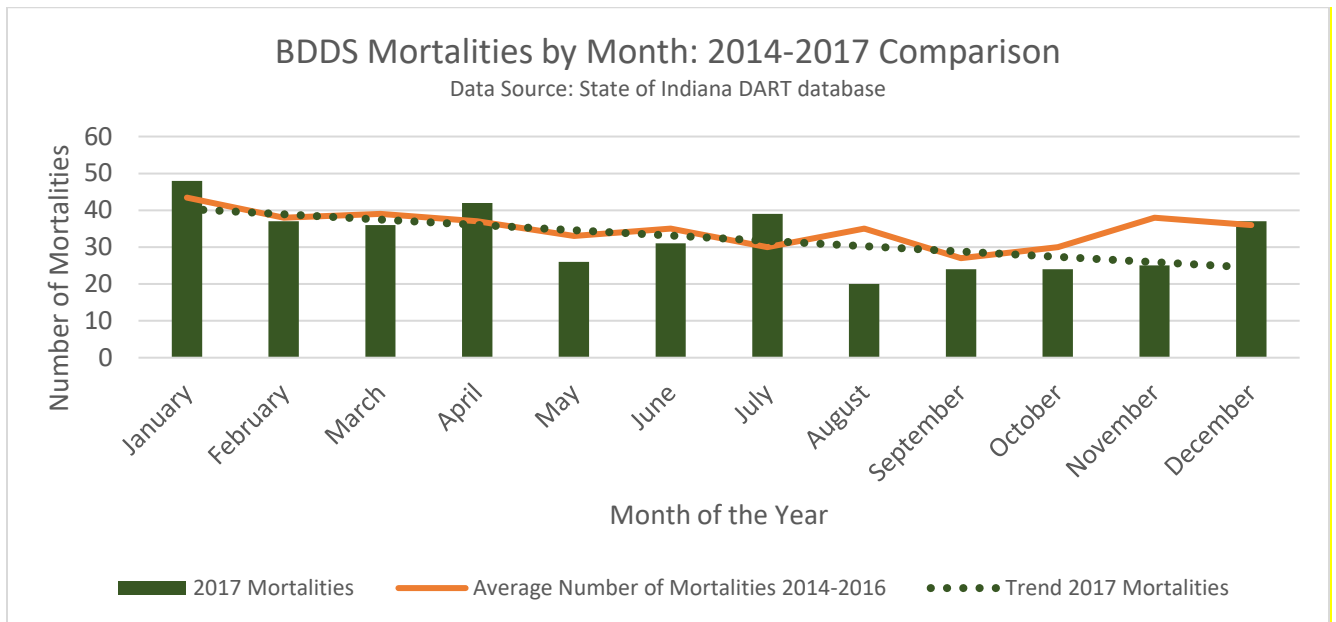


Figure 9: BDDS Mortalities by Month: 2014-2017 Comparison, Percent of Individuals Served

BDDS Mortalities by Month: 2014-2017 Comparison								
Percent of Individuals Served								
Data Source: State of Indiana DART database								
Month	2014		2015		2016		2017	
	Count	Percent of Individuals Served	Count	Percent of Individuals Served	Count	Percent of Individuals Served	Count	Percent of Individuals Served
January	53	0.23%	44	0.17%	33	0.11%	48	0.15%
February	37	0.16%	36	0.14%	40	0.14%	37	0.11%
March	42	0.18%	35	0.13%	41	0.14%	36	0.11%
April	36	0.15%	32	0.12%	43	0.15%	42	0.13%
May	24	0.10%	38	0.14%	38	0.13%	26	0.08%
June	32	0.14%	32	0.12%	40	0.14%	31	0.09%
July	30	0.13%	31	0.12%	30	0.10%	39	0.12%
August	33	0.14%	33	0.12%	38	0.13%	20	0.06%
September	30	0.13%	31	0.12%	21	0.07%	24	0.07%
October	26	0.11%	28	0.11%	36	0.12%	24	0.07%
November	37	0.16%	27	0.10%	51	0.17%	25	0.08%
December	50	0.21%	33	0.12%	25	0.09%	37	0.11%
<b>Total mortalities</b>	430	1.84%	400	1.51%	436	1.49%	389	1.19%
<b>Total served</b>	23,325	--	26,474	--	29,317	--	32,681	--

## BDDS 2017 Mortalities by Gender and Service

January 1 through December 31, 2017

The overall percentage of mortalities for males and females was approximately 50% in 2017, which is the same as the trend for previous years (2014-2016). (Note: Based on 2016 Indiana and national general population data. Data reports for general populations are not yet available for 2017.)

Figure 10: 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	Female	Total
Community Integration & Habilitation Waiver	82	64	146
Nursing Facility	66	60	126
Supervised Group Living	43	35	78
Family Supports Waiver	25	13	38
State Line	1	0	1
<b>Total</b>	<b>217</b>	<b>172</b>	<b>389</b>
	56%	44%	100%

Figure 11: BDDS Mortalities by Gender: 2014-2017 Comparison

BDDS Mortalities by Gender: 2014-2017 Comparison					
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

Figure 12: Mortalities by Gender: 2017 BDDS Mortalities Comparison to 2016 General Population

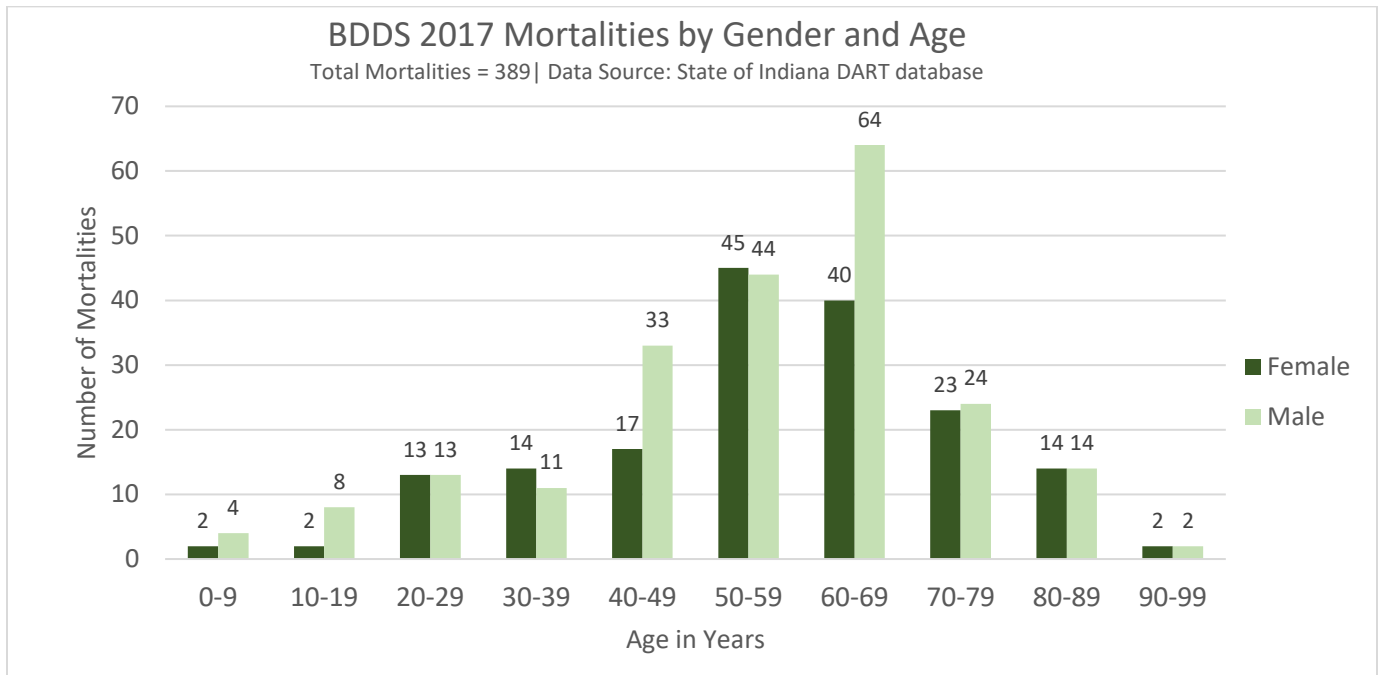
Mortalities by Gender: 2017 BDDS Mortalities Comparison to 2016 General Population					
Data Sources: State of Indiana DART database					
Center for Disease Control and Prevention, National Center for Health Statistics					
Population	Male		Female		Total
	Count	Percent	Count	Percent	
<b>BDDS (2017)</b>	217	56%	172	44%	389
<b>Indiana—General Population (2016)</b>	32,378	51%	31,095	49%	63,473
<b>National—General Population (2016)</b>	1,400,232	51%	1,344,016	49%	2,744,248

# BDDS 2017 Mortalities by Gender and Age

January 1 through December 31, 2017

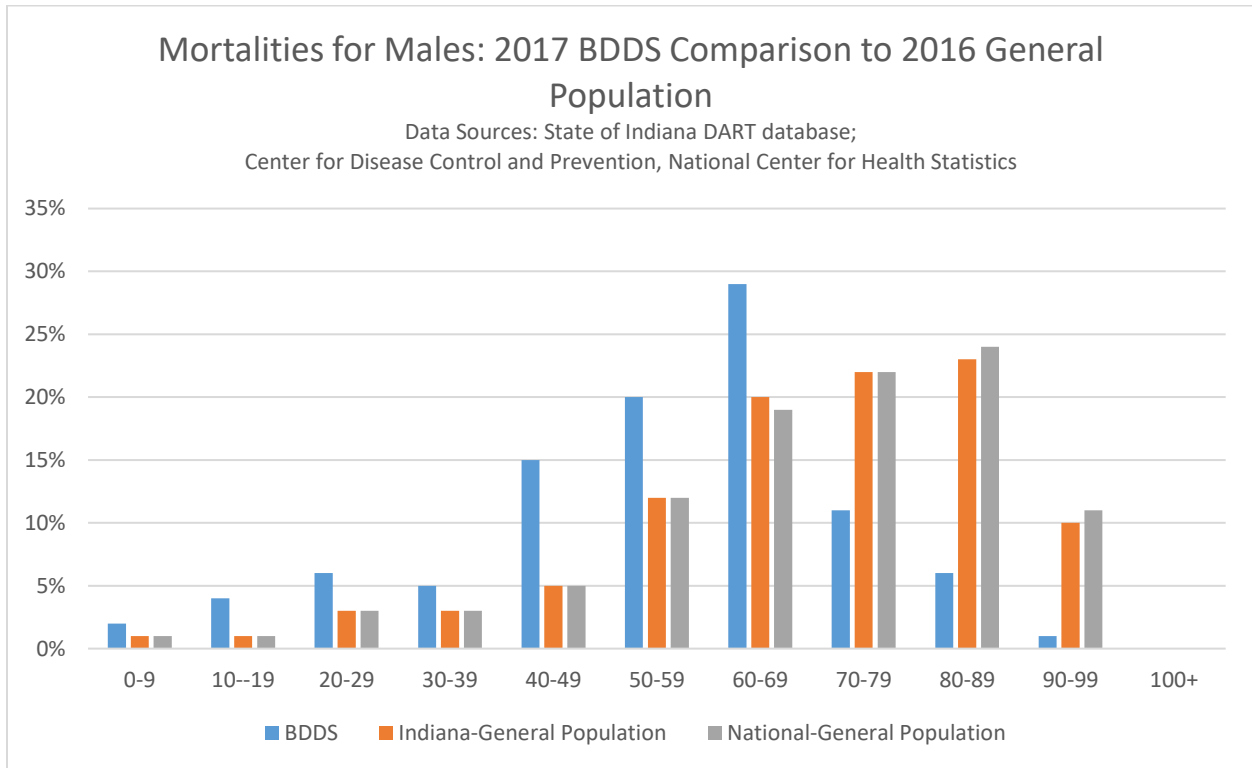
In 2017, male deaths were prominent between ages 40 and 69, while female deaths were prominent in ages 50 through 79.

Figure 13: BDDS 2017 Mortalities by Gender and Age



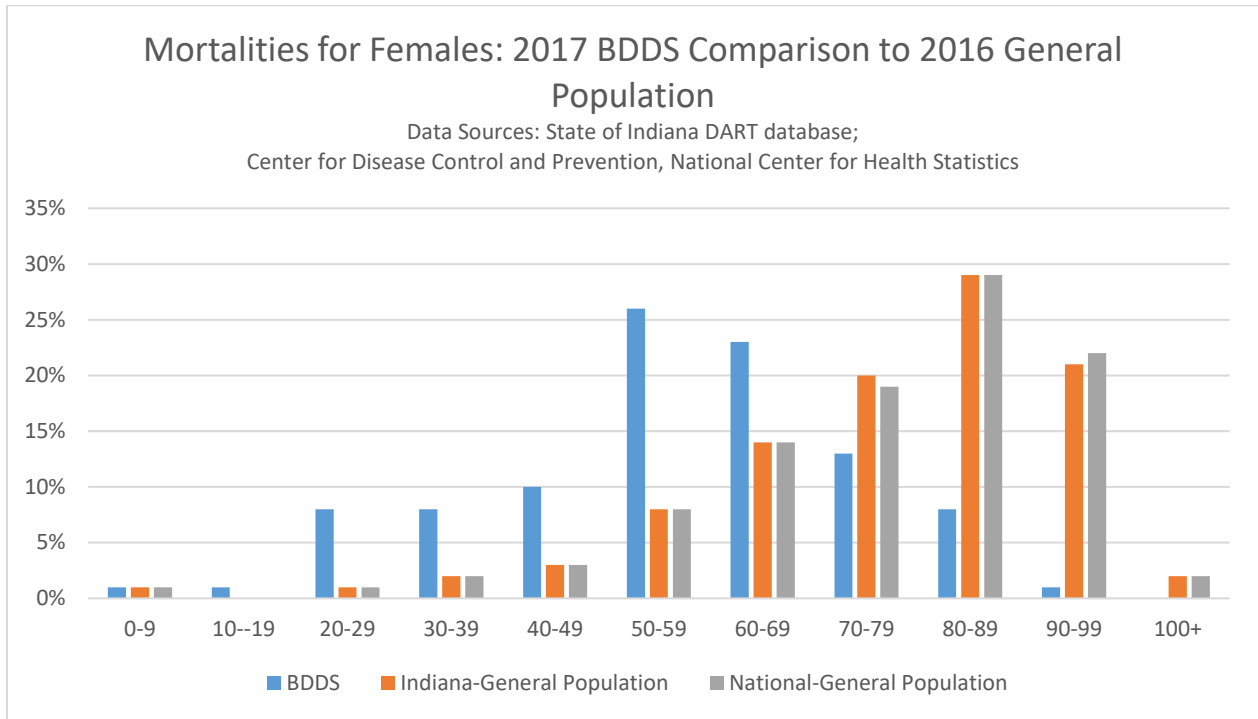
When compared to the 2016 general populations of Indiana and nationally, male mortalities in the BDDS population for 2017 were highest in the age groups ranging from 40 to 69, while the Indiana and national general population were higher in ages 60 to 89. (Note: Based on 2016 Indiana and national general population data. Data reports for general populations are not yet available for 2017.)

Figure 14: Mortalities for Males: 2017 BDDS Comparison to 2016 General Population



Female mortalities in the BDDS population for 2017 were highest in the age groups ranging from 50 to 79. In comparison to the Indiana and national general populations, female deaths were highest in the age groups of 70 to 99.

Figure 15: Mortalities for Females: 2017 BDDS Comparison to 2016 General Population

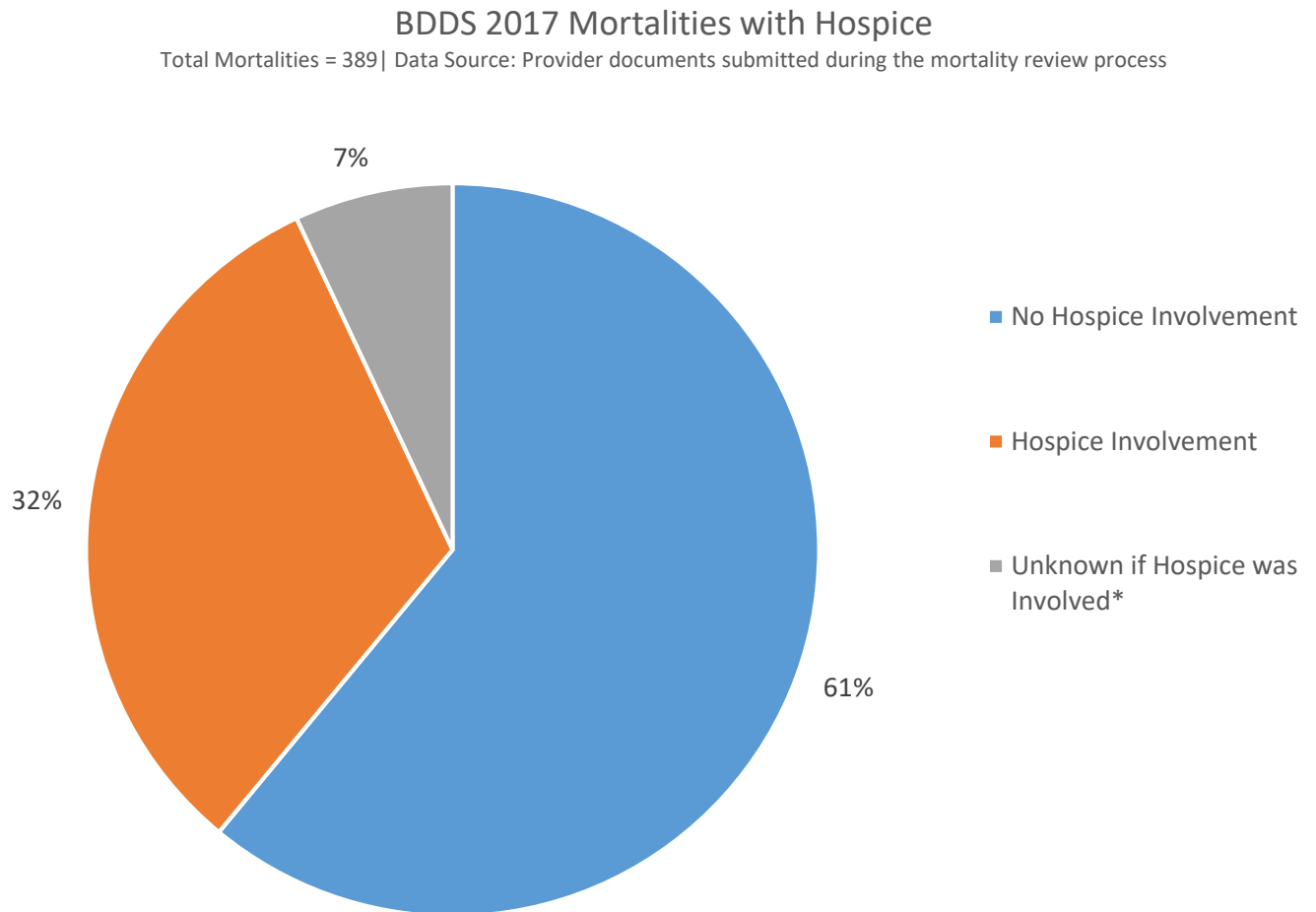


## BDDS 2017 Mortalities with Hospice

January 1 through December 31, 2017

Mortalities with hospice involvement in 2017 (32 percent) remained consistent when compared to previous years (2014-2016).

Figure 16: BDDS 2017 Mortalities with Hospice



\*Hospice status could not be determined from available documentation.

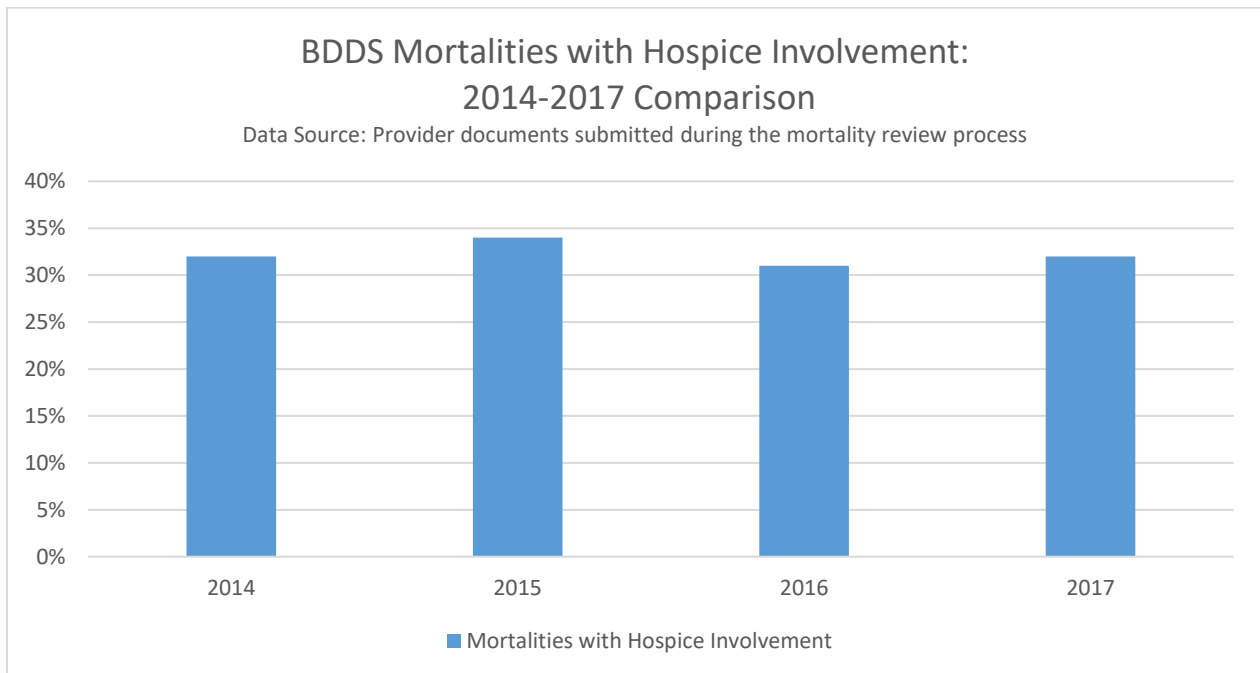


Figure 17: BDDS Mortalities with Hospice: 2014-2017 Comparison

BDDS Mortalities with Hospice: 2014-2017 Comparison								
Data Source: Provider documents submitted during the mortality review process								
	2014		2015		2016		2017	
	Count	Percent	Count	Percent	Count	Percent	Count	Percent
<b>No Hospice Involvement</b>	199	46%	236	59%	263	60%	238	61%
<b>Hospice Involvement</b>	135	32%	135	34%	135	31%	124	32%
<b>Unknown if Hospice was Involved*</b>	96	22%	29	7%	38	9%	27	7%
<b>Total</b>	430	100%	400	100%	436	100%	389	100%

\*Hospice status could not be determined from available documentation.

Figure 18: BDDS Mortalities with Hospice Involvement: 2014-2017 Comparison

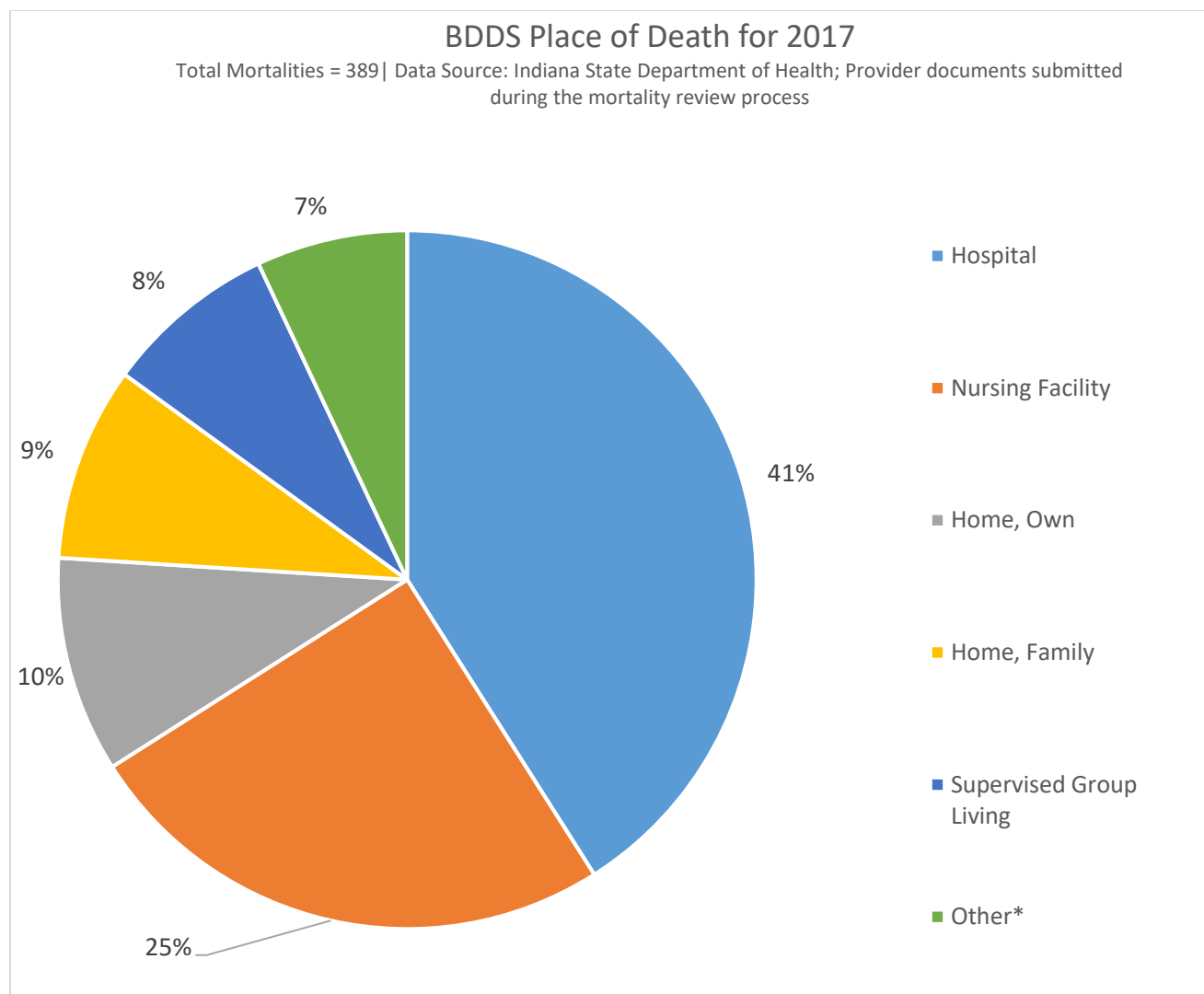


## BDDS Place of Death for 2017

January 1 through December 31, 2017

Of the 2017 mortalities for individuals served by BDDS, the 41 percent of deaths in a hospital setting is slightly higher than the 36 percent in the Indiana general population and national general population. Twenty-five percent of the individuals in both the BDDS population and the Indiana general population died in a nursing facility compared to 19 percent of the national general population. The percentages of mortalities at home were similar across all three populations—27 percent for the BDDS population, 29 percent for the Indiana general population, and 30 percent for the national general population. (Note: Based on 2016 Indiana and national general population data. Data reports for general populations are not yet available for 2017.)

Figure 19: BDDS Place of Death for 2017



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

Figure 20: Place of Death: 2017 BDDS Comparison to 2016 General Populations

<b>Place of Death: 2017 BDDS Comparison to 2016 General Populations</b>						
Data Sources: Indiana State Department of Health; Provider documents submitted during the mortality review process Center for Disease Control and Prevention, National Center for Health Statistics						
<b>Population</b>	<b>BDDS</b>		<b>Indiana-General Population</b>		<b>National-General Population</b>	
<b>Place</b>	<b>Count</b>	<b>Percent</b>	<b>Count</b>	<b>Percent</b>	<b>Count</b>	<b>Percent</b>
<b>Hospital</b>	158	41%	22,546	36%	996,647	36%
<b>Nursing Facility</b>	99	25%	16,136	25%	529,775	19%
<b>Home</b>	103	27%	18,684	29%	836,348	30%
<b>Other*</b>	29	7%	6,101	10%	381,478	14%
<b>Total</b>	389	100%	63,467	100%	2,744,248	100%

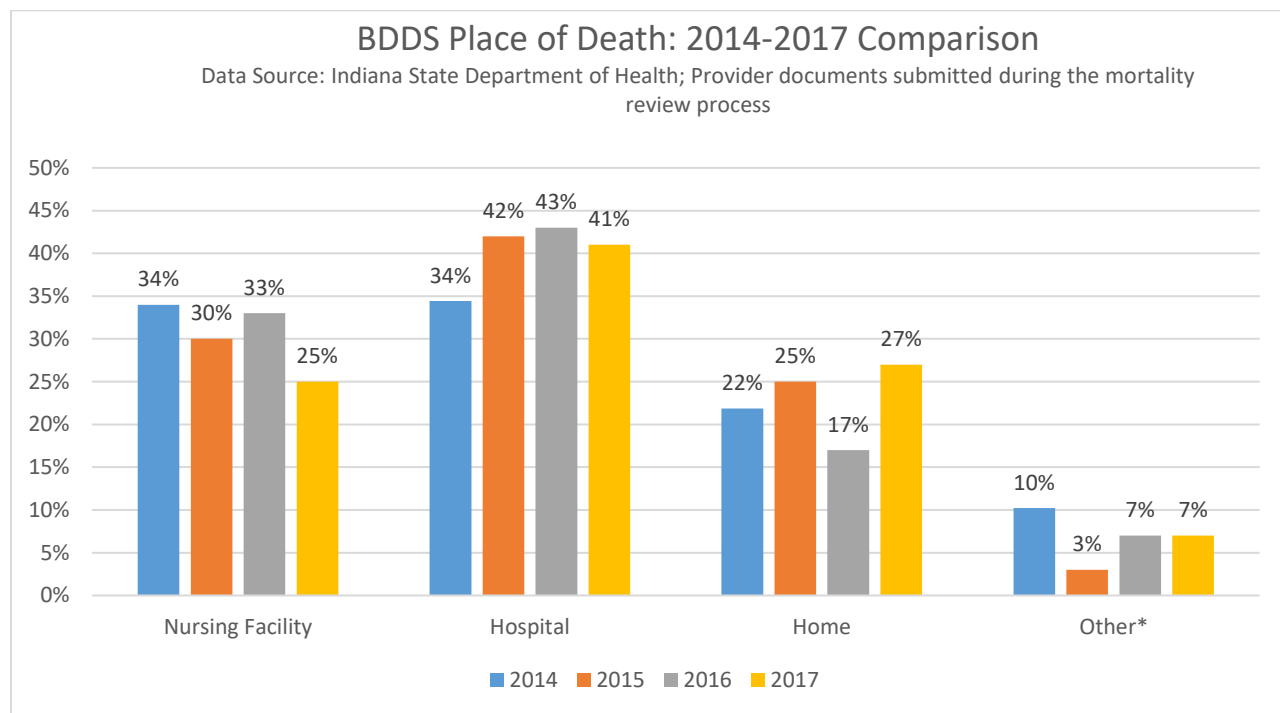
\*'Other' is comprised of hospice and community settings (e.g. restaurant, park, etc.) and unknown settings are due to pending death certificates from Indiana State Department of Health.

## BDDS Place of Death: 2014-2017 Comparison

January 1, 2014 through December 31, 2017

From 2014 to 2016, hospitals and nursing facilities were the most frequent places of death. In 2017, there was an increase in deaths in home settings (27 percent) from previous years. Deaths in nursing facilities in 2017 (25 percent) were a decrease from previous years. In all four years, hospitals remain the most frequent place of death when compared to other settings.

Figure 21: BDDS Place of Death: 2014-2017 Comparison



'Home' includes own and family homes and Supervised Group Living.

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

## BDDS Classification of Death

January 1 through December 31, 2017

Each death is classified by the Mortality Review Triage Team (MRTT) on two dimensions based on the available information: whether the death was anticipated or unexpected (given the specific individual's history, current health status, diagnoses, risk level, and age) and whether the death was due to internal or external causes (based on source of injury, disease, or cause of death). For example, a death due to cancer would be classified as 'Anticipated/Internal' but a death due to aspiration during hospital medical intervention would be classified as 'Anticipated/External'. Alternatively, an example of an 'Unexpected/Internal' death would be a healthy individual with no prior history of heart issues or contributing factors who died of a heart attack. Trauma, such as a car accident, would be classified as 'Unexpected/External'.

Figure 22: BDDS Classification of Death, 2017

<b>BDDS Classification of Death, 2017</b>				
Total Mortalities = 389   Data Sources: Indiana State Department of Health; Provider documents submitted during the mortality review process				
	Anticipated		Unexpected	
	Count	Percent	Count	Percent
<b>Internal</b>	334	86%	47	12%
<b>External</b>	1	0%	7	2%

## BDDS Primary Causes of Death, 2017

January 1 through December 31, 2017

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<sup>1</sup>.

In the respiratory, circulatory, and nervous systems, BDDS deaths related to aspiration, heart failure, and seizures were three of the top five primary causes of death for 2017. Of the 105 respiratory deaths in 2017, 37 deaths (35 percent) were related to aspiration. Sixty-two or 64% of the 97 circulatory system deaths were related to heart failure. Of the 39 nervous system deaths in 2017, 12 deaths (31 percent) were related to seizures. Aspiration, bowel obstruction, dehydration, and seizures are considered the ‘Fatal Four’ for individuals with intellectual and developmental disabilities.

Figure 23: BDDS Primary Causes of Death: 2014-2017

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

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

A comparison between deaths in the BDDS population and with deaths in the Indiana and National general populations indicates deaths of individuals in BDDS services suffer from more respiratory deaths than those in the general population. (Note: The comparison is between BDDS data for 2017 and 2016 general population data. Indiana and national general population data is not yet available for 2017.)

Figure 24: BDDS 2017 Primary Causes of Death: Comparison to 2016 General Population

<b>BDDS 2017 Primary Causes of Death: Comparison to 2016 General Population</b>					
Data Sources: Indiana State Department of Health, Center for Disease Control and Prevention, National Center for Health Statistics					
<b>Primary Cause of Death for 2017*</b>	<b>Average Age</b>	<b>Number of Deaths</b>	<b>Percent of Deaths</b>	<b>Percent of Deaths in Indiana General Population (2016)</b>	<b>Percent of Deaths in National General Population (2016)</b>
<b>Diseases of the Respiratory System</b>	57.2	105	27%	11%	10%
<b>Diseases of the Circulatory System</b>	59.5	97	25%	29%	31%
<b>Diseases of the Nervous System</b>	51.8	39	10%	8%	7%
<b>Infections</b>	53.6	31	8%	3%	3%
<b>Cancer</b>	55.4	23	6%	22%	22%
<b>Total</b>	---	295	76%	73%	73%

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

## BDDS 2017 Primary Causes of Death by Decade of Life

January 1 through December 31, 2017

Except for the age group of 0-9 and 90-99, conditions of both the Circulatory and Respiratory systems comprised two of the top three causes of death in every age group of individuals in BDDS services.

Figure 25: BDDS 2017 Causes of Death by Decade of Life

BDDS 2017 Primary Causes of Death by Decade of Life			
Total Mortalities = 389   Data Source: Indiana State Department of Health			
Age	Primary Cause of Death*	Number of Mortalities	Percent of Deaths for Decade of Life
<b>0-9</b>	Congenital Conditions	1	17%
	External Causes	1	17%
	Diseases of the Hormone/Nutrition/Metabolism System	1	17%
<b>10-19</b>	External Causes	3	30%
	Diseases of the Respiratory System	3	30%
	Diseases of the Circulatory System	2	20%
<b>20-29</b>	Diseases of the Respiratory System	6	23%
	Diseases of the Circulatory System	4	15%
	Infections	4	15%
<b>30-39</b>	Diseases of the Circulatory System	6	24%
	Diseases of the Nervous System	5	20%
	Diseases of the Respiratory System	4	16%
<b>40-49</b>	Diseases of the Circulatory System	12	24%
	Diseases of the Nervous System	11	22%
	Diseases of the Respiratory System	7	14%
<b>50-59</b>	Diseases of the Respiratory System	31	35%
	Diseases of the Circulatory System	19	21%
	Cancer	7	8%
<b>60-69</b>	Diseases of the Respiratory System	31	30%
	Diseases of the Circulatory System	29	28%
	Infections	10	10%
<b>70-79</b>	Diseases of the Respiratory System	12	26%
	Diseases of the Circulatory System	12	26%
	Diseases of the Nervous System	5	11%
<b>80-89</b>	Diseases of the Circulatory System	11	39%
	Diseases of the Respiratory System	10	36%
	Infections	3	11%
<b>90-99</b>	Diseases of the Circulatory System	2	50%
	Diseases of the Nervous System	1	25%
	Diseases of the Gastrointestinal/Digestive System	1	25%

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



Figure 26: BDDS Primary Causes of Death: 2014-2017 Comparison by Decade of Life

BDDS Primary Causes of Death: 2014-2017 Comparison by Decade of Life				
Data Source: Indiana State Department of Health				
Age	Primary Cause of Death*			
	2014	2015	2016	2017
<b>0-9</b>	Unknown	Diseases of the Circulatory System	Diseases of the Circulatory System	Congenital Conditions
	Congenital Conditions	----	Diseases of the Respiratory System	External Causes
	----	----	Diseases of the Nervous System	Diseases of the Hormone/Nutrition/ Metabolism System
<b>10-19</b>	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Nervous System	External Causes
	Diseases of the Gastrointestinal/ Digestive System	Diseases of the Circulatory System	Diseases of the Respiratory System	Diseases of the Respiratory System
	Diseases of the Nervous System & Circulatory System	Diseases of the Gastrointestinal/ Digestive System	Infections	Diseases of the Circulatory System
<b>20-29</b>	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System
	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Nervous System	Diseases of the Circulatory System
	Infections	Diseases of the Nervous System	Diseases of the Circulatory System	Infections
<b>30-39</b>	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Circulatory System
	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Nervous System
	External Causes	Diseases of the Nervous System	Diseases of the Nervous System	Diseases of the Respiratory System
<b>40-49</b>	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Circulatory System
	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Nervous System
	Diseases of the Nervous System	Cancer	Diseases of the Nervous System	Diseases of the Respiratory System
<b>50-59</b>	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Circulatory System	Diseases of the Respiratory System
	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Respiratory System	Diseases of the Circulatory System
	Cancer	Cancer	Diseases of the Nervous System	Cancer

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

**BDDS Primary Causes of Death: 2014-2017 Comparison by Decade of Life**

Data Source: Indiana State Department of Health

Age	Primary Cause of Death*			
	2014	2015	2016	2017
60-69	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System
	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System
	Cancer	Cancer	Diseases of the Nervous System	Infections
70-79	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Respiratory System
	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Circulatory System
	Cancer	Cancer	Infections	Diseases of the Nervous System
80-89	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System
	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Respiratory System
	Diseases of the Nervous System	Cancer	Diseases of the Urinary/Genital System	Infections
90-99	Cancer	Diseases of the Circulatory System	Diseases of the Circulatory System	Diseases of the Circulatory System
	Diseases of the Respiratory System	Diseases of the Respiratory System	Diseases of the Urinary/Genital System	Diseases of the Nervous System
	Diseases of the Circulatory System	---	Diseases of the Respiratory System	Diseases of the Gastrointestinal/Digestive System

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

## Comparison of the Primary Causes of Death with Four States

Figure 28 displays a comparison of Indiana’s mortality data for 2016 and 2017 with Massachusetts (MA), Connecticut (CT), Ohio (OH), and Louisiana (LA) for the intellectually and developmentally disabled populations. The Indiana State Department of Health classifies death under a major category as defined by the International Statistical Classification of Diseases and Related Health Problems-10th Revision. The classification process for the other states is unknown.

In 2017, 12.5% of all deaths were due to pneumonia which is slightly lower than Louisiana’s 15% in 2012. In contrast, the other three states have less than 10% of deaths due to pneumonia.

Of the 97 deaths in the category of diseases of the circulatory system, 62 deaths (64 percent) were due to heart failure. The 62 deaths equates to 15.9% of all deaths in 2017 within BDDS services. Indiana is slightly higher than Massachusetts and Louisiana but far below Connecticut.

Figure 27: 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%

Note: CY = calendar year; FY = fiscal year

Center for Developmental Disabilities Evaluation and Research (CDDER). “2012 & 2013 Mortality Report Commonwealth of Massachusetts, Executive Office of Health & Human Services, Department of Developmental Services”, 2014. <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/newsroom/quality-assurance/mortality-reports.html>. (Accessed on 10 May 2018).

## Glossary: Category of Death

Category	Definition	Examples
<b>Abnormal Findings Not Classified</b>	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, multiple organ failure
<b>Before/After Childbirth Conditions</b>	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
<b>Diseases of the Blood Organs and Disorders of the Immune System</b>	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	Anemias, blood clots, hemorrhaging, immune disorders
<b>Cancers (Neoplasms)</b>	Diseases in which abnormal cells divide uncontrollably and destroy body tissue.	Prostate cancer, breast cancer, lung cancer, colon cancer, leukemia, lymphoma
<b>Diseases of the Circulatory System</b>	Diseases of the circulatory system including cardiopulmonary	Hypertension, heart disease, heart failure, stroke, hemorrhage, atherosclerosis, arteriosclerosis, rheumatic fever, cardiac arrest, cardiopulmonary arrest
<b>Congenital Conditions</b>	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
<b>Diseases of the Ear</b>	Diseases of the ear and mastoid process	Ear infections, hearing loss
<b>External Causes</b>	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
<b>Diseases of the Eye</b>	Diseases of the eye and adnexa (accessory structures of eye)	Conjunctivitis, blindness, glaucoma, cataracts

## Glossary: Category of Death—continued

Category	Definition	Examples
<b>Diseases of the Gastrointestinal/Digestive System</b>	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
<b>Diseases of the Hormone/Nutrition/Metabolism System</b>	Diseases of the endocrine and metabolic systems and nutritional disorders	Thyroid, diabetes, obesity, malnutrition, cystic fibrosis, dehydration, immune syndromes, acidosis
<b>Infections</b>	Diseases generally recognized as communicable or transmissible	Sepsis, diarrhea, tuberculosis, Lyme disease, measles, rubella, hepatitis, HIV
<b>Diseases of the Muscle/Bone</b>	Diseases of the musculoskeletal system and connective tissue	Rheumatoid arthritis, lupus, arthritis, osteoarthritis, osteoporosis
<b>Diseases of the Nervous System</b>	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
<b>Other</b>	Conditions not elsewhere classified	Raynaud's syndrome, antibiotic resistance, altered mental status
<b>Psychiatric/Emotional Disorders</b>	Disorders of psychological development	Developmental disorder, intellectual disorder, dementia, substance abuse, mood disorders, schizophrenia, personality disorders
<b>Pregnancy/Childbirth/Postpartum Conditions</b>	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
<b>Diseases of the Respiratory System</b>	Diseases of the respiratory system	Hypoxia, asphyxiation, choking, influenza, pneumonia, aspiration pneumonia, viral pneumonia, bacterial pneumonia, bronchitis, emphysema, asthma, bronchiectasis, pneumonitis, aspiration, respiratory arrest, upper airway obstruction
<b>Diseases of the Skin</b>	Diseases of the skin and subcutaneous tissue	Skin infections, dermatitis, eczema
<b>Diseases of the Urinary/Genital System</b>	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: Based on International Statistical Classification of Diseases and Related Health Problems 10th Revision. World Health Organization. Retrieved March 15, 2018 from <http://apps.who.int/classifications/icd10/browse/2016/en>

## Glossary: BDDS Service

### 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](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 \$17,300. 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 Service—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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<sup>i</sup> International Statistical Classification of Diseases and Related Health Problems-Vol. 2, 10th Revision, 2010 Edition, World Health Organization, accessed at [http://www.who.int/classifications/icd/ICD10Volume2\\_en\\_2010.pdf](http://www.who.int/classifications/icd/ICD10Volume2_en_2010.pdf) on 6/1/2018.