

Indiana Long-Term Care Transformation Stakeholder Survey Compendium of Phone Survey Responses

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Survey Methodology

The Division of Aging (DA) conducted a phone survey of individuals currently receiving services, aged 85 and older, as well as their caregivers to better understand their experiences with receiving home and community-based services (HCBS) in Indiana. A total of 998 surveys were completed from July 24, 2017 to August 11, 2017. The table below displays the total number of participants interviewed by category.

Category	# of Participants
Individuals currently receiving waiver services living in an assisted living facility, Age 85+ (<i>Waiver AL</i>)	166
Individuals currently receiving waiver services living in their own home or another community setting, Age 85+ (<i>Waiver Non-AL</i>)	166
Individuals currently receiving non-waiver (CHOICE or Older Americans' Act) services, Age 85+ (<i>Non-Waiver</i>)	332
Caregivers of individuals receiving services age 85+	333
Total	998

Survey Questions

Individuals Currently Receiving Services

Respondent Characteristics

1. What is your age?
2. Do you consider yourself to have a long-term illness or disability?
3. How would you describe your long-term illness or disability?
4. Does anyone currently help you with activities like bathing, dressing, or walking?
5. Does anyone currently help you with activities like shopping, cooking meals, and transportation?

Informal and Formal Supports

6. Does a family member help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?
7. How prepared did your family member feel to help with your daily activities?
8. Does a friend help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?
9. How prepared did your friend feel to help with your daily activities?
10. Do professionals, workers, or staff help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?
11. Do you feel your support staff have the right training to meet your needs?
12. Do any of the individuals who help you with activities such as bathing, dressing, cooking meals, or transportation get paid to help you?
13. How do you pay for these support services?
14. How concerned are you about being able to continue to afford these support services in the future?
15. Do you have family members or friends who live nearby? Do not include family members you live with.
16. How far does your family member or friend live?

Residential Preferences

17. Where do you currently live?
18. Are you living where you would like to live?
19. How important is it to you to remain in your own home as you age?

Access to Services and Supports

20. Do you know who to call or where to go to get information if your needs change and you need new or different services?
21. How easy or difficult is it to find the information you need to help you get the care and support you need?
22. Where do you find information when you need help with activities such as bathing, dressing, walking, shopping, cooking meals, and transportation?
23. Do you know who your case manager/care coordinator is?
24. Can you reach your case manager/care coordinator when you need them?

Person-Centered Services and Supports

25. To what extent do the support you currently receive meet your needs and goals?
26. Are there services and supports you would like to receive that you currently do not get?
27. What services and supports do you need that you currently do not get?

Caregivers

1. What is your age?
2. Do you consider yourself to have a long-term illness or disability?
3. How would you describe your own health?
4. Are you currently providing help to a relative or friend with activities, such as bathing, dressing, and cooking meals, or was this something you did in the past?
5. Have you ever been employed either full or part-time while providing care to your friend or loved one?
6. Thinking about the person you are providing/most recently provided care to the most, are you...
7. Where does/did your friend or loved one live at the time you provided care?
8. Please think about all of the health care professionals or service providers who give/gave care or treatment to your relative/friend. How easy or difficult is/was it for you to coordinate care between these providers?
9. Do you/did you feel prepared to help your friend or loved one?
10. In your experience as a caregiver, have you ever had: a doctor, a nurse, or social worker ask you what you need/needed to help take care of your friend or loved one?
11. In your experience as a caregiver, have you ever had: a doctor, a nurse, or social worker ask you what you need/needed to help take care of yourself?

Summary of Survey Responses

Individuals Currently Receiving Services

Respondent Characteristics

1. What is your age?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
18-34	0	0.0%	0	0.0%	0	0.0%
35-44	0	0.0%	1	0.6%	0	0.0%
45-54	0	0.0%	0	0.0%	0	0.0%
55-64	2	0.6%	0	0.0%	1	0.6%
65-74	4	1.2%	0	0.0%	0	0.0%
75-84	7	2.1%	45	27.1%	0	0.0%
85 years or older	319	95.8%	119	71.7%	163	98.2%
Don't know	1	0.3%	0	0.0%	2	1.2%
Missing	0	0.0%	1	0.6%	0	0.0%

2. Do you consider yourself to have a long-term illness or disability?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	252	75.7%	160	96.4%	162	97.6%
No	73	21.9%	2	1.2%	3	1.8%
Not sure	8	2.4%	4	2.4%	1	0.6%

3. How would you describe your long-term illness or disability? [open-ended question]

	Non-Waiver (n=252)		Waiver AL (n=160)		Waiver Non-AL (n=162)	
	N	%	N	%	N	%
Developmental disability	2	0.8%	0	0.0%	10	6.2%
Blindness	15	6.0%	9	5.6%	12	7.4%
Deafness or severe hearing impairment	7	2.8%	14	8.8%	7	4.3%
Physical disability	198	78.6%	121	75.6%	149	92.0%
Psychological or emotional condition	11	4.4%	9	5.6%	0	0.0%
Chronic illness (e.g. diabetes, COPD, arthritis)	86	34.1%	73	45.6%	26	16.0%
Traumatic brain injury	1	0.4%	3	1.9%	0	0.0%
Other*	26	10.3%	29	18.1%	42	25.9%

*Other responses included Alzheimer's Disease, dementia, surgery recovery, difficulty walking, and old age.

4. Does anyone currently help you with activities like bathing, dressing, or walking?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	177	53.2%	139	83.7%	152	91.6%
No	156	46.8%	27	16.3%	13	7.8%
Not sure	0	0.0%	0	0.0%	1	0.6%

5. Does anyone currently help you with activities like shopping, cooking meals, and transportation?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	294	88.3%	163	98.2%	160	96.4%
No	38	11.4%	2	1.2%	5	3.0%
Not Sure	1	0.3%	1	0.6%	1	0.6%

Informal and Formal Supports

6. Does a family member help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	242	72.7%	150	90.4%	148	89.2%
No	90	27.0%	15	9.0%	18	10.8%
Not Sure	1	0.3%	1	0.6%	0	0.0%

7. How prepared did your family member feel to help with your daily activities?

	Non-Waiver (n=242)		Waiver AL (n=150)		Waiver Non-AL (n=148)	
	N	%	N	%	N	%
Very well prepared	179	74.0%	46	30.7%	108	73.0%
Somewhat prepared	53	21.9%	60	40.0%	37	25.0%
Not well prepared	10	4.1%	43	28.7%	2	1.4%
Not sure	0	0.0%	1	0.7%	1	0.7%

8. Does a friend help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	49	14.7%	136	81.9%	7	4.2%
No	283	85.0%	30	18.1%	159	95.8%
Not Sure	1	0.3%	0	0.0%	0	0.0%

9. How prepared did your friend feel to help with your daily activities?

	Non-Waiver (n=49)		Waiver AL (n=136)		Waiver Non-AL (n=7)	
	N	%	N	%	N	%
Very well prepared	27	55.1%	11	8.1%	6	85.7%
Somewhat prepared	19	38.8%	12	8.8%	1	14.3%
Not well prepared	3	6.1%	7	5.1%	0	0.0%
Not sure	0	0.0%	0	0.0%	0	0.0%
Missing	0	0.0%	106	77.9%	0	0.0%

10. Do professionals, workers, or staff help you with activities such as bathing, dressing, shopping, cooking meals, and transportation?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	236	70.9%	160	96.4%	151	91.0%
No	96	28.8%	6	3.6%	15	9.0%
Not Sure	1	0.3%	0	0.0%	0	0.0%

11. Do you feel your support staff have the right training to meet your needs?

	Non-Waiver (n=236)		Waiver AL (n=160)		Waiver Non-AL (n=151)	
	N	%	N	%	N	%
Yes	223	94.5%	156	97.5%	144	95.4%
No	8	3.4%	3	1.9%	7	4.6%
Not Sure	5	2.1%	1	0.6%	0	0.0%

12. Do any of the individuals who help you with activities such as bathing, dressing, cooking meals, or transportation get paid to help you?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	216	64.9%	162	97.6%	152	91.6%
No	104	31.2%	3	1.8%	13	7.8%
Not Sure	13	3.9%	1	0.6%	1	0.6%

13. How do you pay for these support services? [open-ended question]

	Non-Waiver (n=216)		Waiver AL (n=162)		Waiver Non-AL (n=152)	
	N	%	N	%	N	%
Pay privately	45	20.8%	4	2.5%	13	8.6%
Medicaid	35	16.2%	152	93.8%	125	82.2%
Medicare	67	31.0%	107	66.0%	103	67.8%
CHOICE or Older Americans' Act services managed through your Area Agency on Aging	41	19.0%	1	0.6%	1	0.7%
Private insurance	4	1.9%	2	1.2%	14	9.2%
Other*	18	8.3%	0	0.0%	0	0.0%
Not sure	63	29.2%	0	0.0%	12	7.9%

*Other responses included caregivers, Angel Corp, Home Instead, Social Security and the VA.

14. How concerned are you about being able to continue to afford these support services in the future?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Extremely concerned	111	33.3%	7	4.2%	95	57.2%
Very concerned	17	5.1%	2	1.2%	9	5.4%
Somewhat concerned	38	11.4%	30	18.1%	8	4.8%
Not very concerned	29	8.7%	103	62.1%	20	12.1%
Not at all concerned	21	6.3%	20	12.1%	20	12.1%
Missing	117	35.1%	4	2.4%	14	8.4%

15. Do you have family members or friends who live nearby? Do not include family members you live with.

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	298	89.5%	162	97.6%	156	94.0%
No	35	10.5%	4	2.4%	9	5.4%
Not sure	0	0.0%	0	0.0%	1	0.6%

16. How far does your family member or friend live?

	Non-Waiver (n=298)		Waiver AL (n=162)		Waiver Non-AL (n=156)	
	N	%	N	%	N	%
Less than 20 minutes away	225	75.5%	78	48.1%	139	89.1%
20 minutes to 1 hour away	65	21.8%	79	48.8%	16	10.3%
1 to 2 hours	3	1.0%	4	2.5%	1	0.6%
More than 2 hours	2	0.7%	1	0.6%	0	0.0%
Not sure	3	1.0%	0	0.0%	0	0.0%

Residential Preferences

17. Where do you currently live?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
In my own home or apartment	271	81.4%	1	0.6%	119	71.7%
With other family	33	9.9%	0	0.0%	44	26.5%
Assisted living facility	8	2.4%	154	92.8%	1	0.6%
Other*	21	6.3%	11	6.6%	2	1.2%

*Other responses included memory care facilities and nursing homes.

18. Are you living where you would like to live?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	310	93.1%	156	94.0%	162	97.6%
No	15	4.5%	6	3.6%	4	2.4%
Not Sure	8	2.4%	4	2.4%	0	0.0%

19. How important is it to you to remain in your own home as you age? (only individuals living in their own home or apartment were asked this question)

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Extremely important	202	74.5%	--	--	114	95.8%
Very important	53	19.6%	--	--	2	1.7%
Somewhat important	13	4.8%	--	--	2	1.7%
Not that important	2	0.7%	--	--	1	0.8%
Not at all important	1	0.4%	--	--	0	0.0%

Access to Services and Supports

20. Do you know who to call or where to go to get information if your needs change and you need new or different services?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	248	74.5%	158	95.2%	152	91.6%
No	67	20.1%	8	4.8%	11	6.6%
Not sure	18	5.4%	0	0.0%	3	1.8%

21. How easy or difficult is it to find the information you need to help you get the care and support you need?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Very easy	182	54.7%	155	93.4%	144	86.8%
Somewhat easy	75	22.5%	8	4.8%	8	4.8%
Somewhat difficult	46	13.8%	3	1.8%	4	2.4%
Very difficult	30	9.0%	0	0.0%	10	6.0%

22. Where do you find information when you need help with activities such as bathing, dressing, walking, shopping, cooking meals, and transportation? [open-ended question]

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
My doctor's office	28	8.4%	5	3.0%	3	1.8%
My case manager or care coordinator	113	33.9%	142	85.5%	70	42.2%
My local Area Agency on Aging (AAA)	86	25.8%	0	0.0%	7	4.2%
My local Aging and Disability Resource Center (ADRC)	16	4.8%	0	0.0%	2	1.2%
INconnect Alliance	0	0.0%	0	0.0%	0	0.0%
2-1-1	1	0.3%	0	0.0%	0	0.0%
The Internet	2	0.6%	10	6.0%	0	0.0%
Friend/family member	163	48.9%	146	88.0%	140	84.3%
Media: Newspaper/TV/Radio	1	0.3%	3	1.8%	0	0.0%
Church or religious organization	2	0.6%	5	3.0%	0	0.0%
Not Sure	32	9.6%	0	0.0%	2	1.2%
Not Applicable	5	1.5%	0	0.0%	3	1.8%
Other*	10	3.0%	2	1.2%	0	0.0%

*Other responses included the Council on Aging, nursing home or other facility staff, the VA, and the Yellow Pages.

23. Do you know who your case manager/care coordinator is?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	220	66.1%	148	89.2%	156	94.0%
No	87	26.1%	16	9.6%	9	5.4%
Not sure	26	7.8%	2	1.2%	1	0.6%

24. Can you reach your case manager/care coordinator when you need them?

	Non-Waiver (n=220)		Waiver AL (n=148)		Waiver Non-AL (n=156)	
	N	%	N	%	N	%
Yes	209	95.0%	148	100.0%	154	98.7%
No	4	1.8%	0	0.0%	2	1.3%
Not sure	7	3.2%	0	0.0%	0	0.0%

Person-Centered Services and Supports

25. To what extent does the support you currently receive meet your needs and goals?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
My services meet all of my needs	234	70.3%	161	97.0%	123	74.1%
My services meet some of my needs	91	27.3%	4	2.4%	37	22.3%
My services do not meet my needs	8	2.4%	1	0.6%	6	3.6%

26. Are there services and supports you would like to receive that you currently do not get?

	Non-Waiver		Waiver AL		Waiver Non-AL	
	N	%	N	%	N	%
Yes	88	26.4%	12	7.2%	19	11.5%
No	236	70.9%	154	92.8%	136	81.9%
Not sure	9	2.7%	0	0.0%	11	6.6%

27. What services and supports do you need that you currently do not get? [open-ended question]

	Non-Waiver (n=88)		Waiver AL (n=12)		Waiver Non-AL (n=19)	
	N	%	N	%	N	%
Family/caregiver training	0	0.0%	0	0.0%	0	0.0%
Respite care/caregiver supports (providing help or a break for caregivers)	5	5.7%	0	0.0%	0	0.0%
Behavior management	0	0.0%	0	0.0%	0	0.0%
Hospice and/or palliative care	0	0.0%	0	0.0%	0	0.0%
Mental health supports	0	0.0%	0	0.0%	0	0.0%

	Non-Waiver (n=88)		Waiver AL (n=12)		Waiver Non-AL (n=19)	
	N	%	N	%	N	%
Therapy (physical, occupational, speech, recreational, etc.)	4	4.5%	0	0.0%	1	5.3%
Attendant care – e.g., help with bathing, dressing, etc.	21	23.9%	2	16.7%	9	47.4%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	27	30.7%	1	8.3%	2	10.5%
Home-delivered meals	3	3.4%	2	16.7%	2	10.5%
Assisted living or housing with services	2	2.3%	0	0.0%	0	0.0%
Adult day service	0	0.0%	0	0.0%	0	0.0%
Transportation to get to medical appointments	1	1.1%	0	0.0%	1	5.3%
Transportation for non-medical activities	14	15.9%	0	0.0%	0	0.0%
Wheelchair repairs	0	0.0%	0	0.0%	0	0.0%
Battery replacement for scooters	0	0.0%	0	0.0%	0	0.0%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	3	3.4%	1	8.3%	0	0.0%
Disposable medical supplies (DMS) – e.g., incontinence supplies	0	0.0%	0	0.0%	1	5.3%
Home modifications (e.g., ramp, grab bars, etc.)	1	1.1%	0	0.0%	1	5.3%
Personal emergency response services (e.g. Medic Alert)	1	1.1%	0	0.0%	0	0.0%
Other*	16	18.2%	6	50.0%	3	15.8%

*Other responses included Medicaid, additional hours for unspecified services currently received, dental care, pest control, and recreational activities to avoid boredom.

Caregivers

1. What is your age?

	N	%
18-34	4	1.2%
35-44	12	3.6%
45-54	23	6.9%
55-64	97	29.1%
65-74	150	45.1%
75-84	30	9.0%
85 years or older	11	3.3%
Don't know	1	0.3%
Missing	5	1.5%

2. Do you consider yourself to have a long-term illness or disability?

	N	%
Yes	122	36.6%
No	203	61.0%
Not sure	5	1.5%
Missing	3	0.9%

3. How would you describe your own health?

	N	%
Excellent	38	11.4%
Very Good	84	25.2%
Good	125	37.5%
Fair	63	18.9%
Poor	20	6.0%
Missing	3	0.9%

4. Are you currently providing help to a relative or friend with activities, such as bathing, dressing, and cooking meals, or was this something you did in the past?

	N	%
Currently	273	82.0%
Past	60	18.0%

5. Have you ever been employed either full or part-time while providing care to your friend or loved one?

	N	%
Yes	150	45.0%
No	183	55.0%

6. Thinking about the person you are providing/most recently provided care to the most, are you:

	N	%
Providing social activities or companionship	314	94.3%
Taking them shopping or shopping for them	314	94.3%
Providing transportation to medical appointments	286	85.9%
Providing transportation to non-medical activities	259	77.8%
Aiding with household chores	258	77.5%
Helping them with meals	259	77.8%
Helping them to manage finances	279	83.8%
Overseeing their medication management	241	72.4%
Being responsible for other medical or nursing tasks	134	40.2%
Assisting with bathing or dressing	155	46.6%
Other	37	11.1%

7. Where does/did your friend or loved one live at the time you provided care?

	N	%
In your household	99	29.7%
Less than 20 minutes away	153	46.0%
20 minutes to 1 hour away	61	18.3%
1 to 2 hours	8	2.4%
More than 2 hours	12	3.6%

8. Please think about all of the health care professionals or service providers who give/gave care or treatment to your relative/friend. How easy or difficult is/was it for you to coordinate care between these providers?

	N	%
Very easy	108	32.4%
Somewhat easy	104	31.2%
Somewhat difficult	59	17.7%
Very difficult	25	7.5%
I did not coordinate care between providers	33	9.9%
Not sure	4	1.2%

9. Do you/did you feel prepared to help your friend or loved one?

	N	%
Very well prepared	129	38.70%
Somewhat prepared	131	39.3%
Not well prepared	67	20.1%
Not sure	6	1.8%

10. In your experience as a caregiver, have you ever had: a doctor, a nurse, or social worker ask you what you need/needed to help take care of your friend or loved one?

	N	%
Yes	199	59.8%
No	119	35.7%
Not sure	15	4.5%

11. In your experience as a caregiver, have you ever had: a doctor, a nurse, or social worker ask you what you need/needed to help take care of yourself?

	N	%
Yes	61	18.3%
No	266	79.9%
Not sure	6	1.8%