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

Survey Methodology

The Division of Aging (DA) conducted an online survey of a diverse group of stakeholders to identify opportunities to modernize the home and community-based services (HCBS) system in Indiana. A total of 1,234 surveys were completed from July 18, 2017 to August 11, 2017. The table below displays the total number of survey respondents by category.

Category	# of Participants
Individuals currently receiving services (all ages)	506
Individuals not receiving services (all ages)	226
Caregivers	212
Case managers	127
HCBS provider	112
Other*	51
Total	**1,234**

*Other survey respondents included other professionals (paramedics, elder law attorneys, psychologists), options counselors, and nursing facility providers.

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?
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?

Individuals Not 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. (Non-Caregivers Only) How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for a friend or loved one in the future?

Long-Term Care Preferences and Needs

5. How important is it to you to remain in your own home as you age?
6. How important is it to you to be in a safe and secure environment as you age (even if it may not be in your own home)?
7. How likely is it that you may need help with activities, such as bathing, dressing, and walking in the next two years?
8. How likely is it that you may need help with activities, such as shopping, cooking meals, and transportation in the next two years?
9. What types of services do you think you might need in the future?
10. If you or a family member needed help with activities such as bathing, dressing, and cooking meals, how would you prefer to receive those services?
11. Thinking about when you might need help with activities, such as bathing, dressing, and cooking meals in the future, what would be the reasons why you decide to move to a nursing home rather than stay in your own home?

Access to Services and Supports

12. If you or a family member needed support with activities, such as bathing, dressing, and cooking meals, where would you be most likely to find out about services?

13. How concerned are you about being able to afford long-term care services for you or your family?

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 long-term illness or disability?
4. How would you describe your own health?
5. 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?
6. Have you ever been employed either full or part-time while providing care to your friend or loved one?
7. Thinking about the person you are providing/most recently provided care to the most, are you…
8. Where does/did your friend or loved one live at the time you provided care?
9. 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?
10. Do you/did you feel prepared to help 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 your friend or loved one?
12. 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?

HCBS Providers

1. Which of the following best describes your role within your organization?
2. Which of the following services is your organization approved to provide?
3. From your perspective as a provider, what aspects of the current Medicaid HCBS system work well in meeting the needs of the people you support?
4. From your perspective as a provider, what aspects of the current Medicaid HCBS system need improvement to meet the needs of the people you support?
5. What services are most helpful to the individuals you serve?
6. What services do the individuals you serve need that they currently do not get?
7. What is the single biggest barrier that prevents the individuals you serve from receiving the services they need?

Case Managers

1. From your perspective as a case manager, what aspects of the current HCBS provider system work well?
2. From your perspective as a case manager, what aspects of the current HCBS provider system could be improved?
3. What is the typical caseload for your organization's full-time case managers?
4. Does the number of people on your case load give you the time to meet the needs of the individuals you serve?

5. Do the individuals you serve know who to call or where to go to get information if their needs change and they need new or different services?
6. Where do the individuals you serve find information when they need services or help with their care?
7. Do you feel that the individuals you serve receive all the services that meet their needs and goals?
8. What services are most helpful to the individuals you serve?
9. What services do the individuals you serve need that they currently do not get?
10. What is the single biggest barrier that prevents the individuals you serve from receiving the services they need?

Summary of Survey Responses

Individuals Currently Receiving Services
Respondent Characteristics

1. **What is your age?**

	N	%
18-34	46	9.1%
35-44	27	5.3%
45-54	31	6.1%
55-64	101	20.0%
65-74	87	17.2%
75-84	102	20.2%
85 years or older	69	13.6%
Not sure	1	0.2%
Missing	42	8.3%

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

	N	%
Yes	408	80.6%
No	56	11.1%
Missing	42	8.3%

3. **How would you describe your long-term illness or disability? (n=408)**

	N	%
Developmental disability	20	4.9%
Blindness	21	5.1%
Deafness or severe hearing impairment	14	3.4%
Physical disability	217	53.2%
Psychological or emotional condition	26	6.4%
Chronic illness (e.g. diabetes, COPD, arthritis)	177	43.4%
Traumatic brain injury	7	1.7%
Other*	45	11.0%

*Other responses included old age, Alzheimer's, dementia, or other neurological diseases.

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

	N	%
Yes	360	71.1%
No	144	28.5%
Not Sure	2	0.4%

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

	N	%
Yes	487	96.2%
No	19	3.8%

Informal and Formal Supports

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

	N	%
Yes	381	75.3%
No	125	24.7%

7. How prepared did your family member feel to help with your daily activities? (n=381)

	N	%
Very well prepared	129	33.9%
Somewhat well prepared	177	46.5%
Not well prepared	61	16.0%
Not sure	13	3.4%
Missing	1	0.3%

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

	N	%
Yes	121	23.9%
No	372	73.5%
Not sure	7	1.4%
Missing	6	1.2%

9. How prepared did your friend feel to help with your daily activities? (n=121)

	N	%
Very well prepared	44	36.4%
Somewhat well prepared	44	36.4%
Not well prepared	26	21.5%
Not sure	6	5.0%
Missing	1	0.8%

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

	N	%
Yes	299	59.1%
No	193	38.1%
Not sure	3	0.6%
Missing	11	2.2%

11. Do you feel your support staff have the right training to meet your needs? (n=299)

	N	%
Yes	256	85.6%
No	22	7.4%
Not sure	18	6.0%
Missing	3	1.0%

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

	N	%
Yes	296	58.5%
No	183	36.2%
Not sure	12	2.4%
Missing	15	3.0%

13. How do you pay for these support services?

	N	%
Pay out of pocket	40	7.9%
Medicaid	173	34.2%
Medicare	15	3.0%
CHOICE or Older Americans' Act services managed through your Area Agency on Aging	28	5.5%
Private insurance	3	0.6%
Other (please specify)	32	6.3%
Not sure	4	0.8%
Missing	211	41.7%

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

	N	%
Extremely concerned	102	20.2%
Very concerned	64	12.6%
Somewhat concerned	50	9.9%
Not very concerned	44	8.7%
Not at all concerned	35	6.9%
Missing	211	41.7%

15. Do you have family members or friends who live nearby?

	N	%
Yes	374	73.9%
No	91	18.0%
Don't Know	2	0.4%
Missing	39	7.7%

16. How far does your family member or friend live? (n=374)

	N	%
In your household	61	16.3%
Less than 20 minutes away	218	58.3%
20 minutes to 1 hour away	84	22.5%
1 to 2 hours	11	2.9%

Residential Preferences

17. Where do you currently live?

	N	%
In my own home or apartment	337	66.6%
With other family	89	17.6%
Assisted living facility	34	6.7%
Other*	28	5.5%
Missing	18	3.6%

*Other responses included nursing facilities or other long-term care facilities.

18. Are you living where you would like to live? (n=169)

	N	%
Yes	99	58.6%
No	51	30.2%
Missing	19	11.2%

19. How important is it to you to remain in your own home as you age? (n=337)

	N	%
Extremely important	240	71.2%
Very important	80	23.7%
Somewhat important	12	3.6%
Not that important	4	1.2%
Missing	1	0.3%

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?

	N	%
Yes	356	70.4%
No	69	13.6%
Unsure	49	9.7%
Missing	32	6.3%

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

	N	%
Very easy (I am able to find information to answer most/all questions I have)	151	29.8%
Somewhat easy (I am able to find some information that is helpful)	172	34.0%
Somewhat difficult (I don't always find the right information or the right person to help me)	109	21.5%
Very difficult (I cannot locate the information I need or the right person to help me)	42	8.3%
Missing	32	6.3%

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

	N	%
My doctor's office	148	29.2%
My case manager or care coordinator	219	43.3%
My local Area Agency on Aging (AAA)	105	20.8%
My local Aging and Disability Resource Center (ADRC)	33	6.5%
INconnect Alliance	1	0.2%
2-1-1	31	6.1%
The Internet	56	11.1%
Friend/family member	211	41.7%
Media: Newspaper/TV/Radio	22	4.3%
Church or religious organization	20	4.0%
Not Applicable	8	1.6%
Other*	47	9.3%

*Other responses included home health agency, assisted living staff, other direct care staff, the VA, community centers, and senior centers.

23. Do you know who your case manager/care coordinator is? (n=390)[1]

	N	%
Yes	193	49.5%
No	33	8.5%
I don't have a case manager/care coordinator	129	33.1%
Missing	35	9.0%

24. Can you reach your case manager/care coordinator when you need them? (n=199)

	N	%
Yes	188	97.4%
No	5	2.6%

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[1] 390 out of 506 survey respondents currently receiving services were asked this question. Individuals who completed the survey with their case manager were not asked this question.

Person-Centered Services and Supports

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

	N	%
My services meet all of my needs	241	47.6%
My services meet some of my needs	199	39.3%
My services do not meet my needs	34	6.7%
Missing	32	6.3%

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

	N	%
Yes	233	46.0%
No	241	47.6%
Missing	32	6.3%

27. What services and supports do you need that you currently do not get? (n=233)

	N	%
Family/caregiver training	31	13.3%
Respite care/caregiver supports (providing help or a break for caregivers)	55	23.6%
Behavior management	19	8.2%
Hospice and/or palliative care	2	0.9%
Mental health supports	38	16.3%
Therapy (physical, occupational, speech, recreational, etc.)	53	22.7%
Attendant care – e.g., help with bathing, dressing, etc.	54	23.2%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	88	37.8%
Home-delivered meals	56	24.0%
Assisted living or housing with services	30	12.9%
Adult day service	22	9.4%
Transportation to get to medical appointments	64	27.5%
Transportation for non-medical activities	64	27.5%
Wheelchair repairs	13	5.6%
Battery replacement for scooters	11	4.7%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	32	13.7%
Disposable medical supplies (DMS) – e.g., incontinence supplies	30	12.9%
Home modifications (e.g., ramp, grab bars, etc.)	39	16.7%
Personal emergency response services (e.g. Medic Alert)	35	15.0%
Other*	42	18.0%

*Other responses included house cleaning, medication fee assistance, pest extermination, and more hours for existing services.

Individuals Not Currently Receiving Services

A total of 305 individuals not currently receiving services completed the survey. Of the 305 individuals, 79 (25.9%) provided care without pay for someone with a long-term need. Questions specific to caregivers are summarized in the next section.

Respondent Characteristics

1. What is your age?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
18-34	9	4.0%	7	8.9%
35-44	6	2.7%	8	10.1%
45-54	11	4.9%	21	26.6%
55-64	45	19.9%	25	31.6%
65-74	69	30.5%	14	17.7%
75-84	57	25.2%	3	3.8%
85 years or older	24	10.6%	1	1.3%
Not sure	2	0.9%	0	0.0%
Missing	3	1.3%	0	0.0%

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

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Yes	71	31.4%	30	38.0%
No	152	67.3%	49	62.0%
Missing	3	1.3%	0	0.0%

3. How would you describe your long-term illness or disability?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Developmental disability	1	0.4%	0	0.0%
Blindness	2	0.9%	1	1.3%
Deafness or severe hearing impairment	4	1.8%	2	2.5%
Physical disability	29	12.8%	13	16.5%
Psychological or emotional condition	10	4.4%	5	6.3%
Chronic illness (e.g. diabetes, COPD, arthritis)	52	23.0%	19	24.1%
Traumatic brain injury	1	0.4%	2	2.5%
Other*	5	2.2%	3	3.8%

*Other responses included obesity, Parkinson's and other neurological diseases.

4. **(Non-Caregivers Only) How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for a friend or loved one in the future?**

	Non-Caregivers (n=226)	
	N	%
Extremely likely	24	10.6%
Very likely	41	18.1%
Somewhat likely	65	28.8%
Not very likely	93	41.2%
Missing	3	1.3%

Long-Term Care Preferences and Needs

5. **How important is it to you to remain in your own home as you age?**

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Extremely important	140	61.9%	49	62.0%
Very important	61	27.0%	23	29.1%
Somewhat important	17	7.5%	4	5.1%
Not that important	8	3.5%	3	3.8%

6. **How important is it to you to be in a safe and secure environment as you age (even if it may not be in your own home)?**

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Extremely important	162	71.7%	63	79.7%
Very important	51	22.6%	15	19.0%
Somewhat important	12	5.3%	0	0.0%
Not that important	1	0.4%	1	1.3%

7. **How likely is it that you may need help with activities, such as bathing, dressing, and walking in the next two years?**

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Extremely likely	10	4.4%	10	12.7%
Very likely	19	8.4%	8	10.1%
Somewhat likely	47	20.8%	9	11.4%
Not very likely	150	66.4%	52	65.8%

8. **How likely is it that you may need help with activities, such as shopping, cooking meals, and transportation in the next two years?**

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Extremely likely	9	4.0%	10	12.7%
Very likely	24	10.6%	7	8.9%
Somewhat likely	52	23.0%	16	20.3%
Not very likely	141	62.4%	46	58.2%

9. **What types of services do you think you might need in the future?**

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Family/caregiver training	37	16.4%	34	43.0%
Respite care/caregiver supports (providing help or a break for caregivers)	41	18.1%	38	48.1%
Behavior management	8	3.5%	7	8.9%
Hospice and/or palliative care	29	12.8%	21	26.6%
Mental health supports	33	14.6%	23	29.1%
Therapy (physical, occupational, speech, recreational, etc.)	78	34.5%	40	50.6%
Attendant care – e.g., help with bathing, dressing, etc.	47	20.8%	29	36.7%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	95	42.0%	44	55.7%
Home-delivered meals	56	24.8%	28	35.4%
Assisted living or housing with services	44	19.5%	27	34.2%
Adult day service	12	5.3%	22	27.8%
Transportation to get to medical appointments	73	32.3%	43	54.4%
Transportation for non-medical activities	56	24.8%	32	40.5%
Wheelchair repairs	13	5.8%	12	15.2%
Battery replacement for scooters	9	4.0%	11	13.9%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	36	15.9%	31	39.2%
Disposable medical supplies (DMS) – e.g., incontinence supplies	29	12.8%	31	39.2%
Home modifications (e.g., ramp, grab bars, etc.)	43	19.0%	36	45.6%
Personal emergency response services (e.g. Medic Alert)	54	23.9%	30	38.0%
Other*	25	11.1%	9	11.4%

*The majority of other responses indicated that individuals were not sure of what services they might need. Some responses included lawn care, pet care, and medication fee assistance.

10. If you or a family member needed help with activities such as bathing, dressing, and cooking meals, how would you prefer to receive those services?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Have family and friends provide all the care at home	48	21.2%	5	6.3%
Have care provided at home by a paid helper	44	19.5%	17	21.5%
Have care provided at home by both family and friends and a paid helper	74	32.7%	44	55.7%
Have care provided in a home-like setting such as an assisted living facility where housing, food, and personal help are provided	18	8.0%	7	8.9%
Have care provided in a nursing home	0	0.0%	0	0.0%
Not sure	42	18.6%	6	7.6%

11. Thinking about when you might need help with activities, such as bathing, dressing, and cooking meals in the future, what would be the reasons why you decide to move to a nursing home rather than stay in your own home?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Need for greater support	47	20.8%	12	15.2%
Safety and security	27	11.9%	7	8.9%
Proximity to family	2	0.9%	17	21.5%
Caregiver unavailability	32	14.2%	10	12.7%
Specialized supports in nursing facilities	29	12.8%	28	35.4%
I would not move to a nursing facility	69	30.5%	5	6.3%
Other (please specify)	12	5.3%	12	15.2%

Access to Services and Supports

12. If you or a family member needed support with activities, such as bathing, dressing, and cooking meals, where would you be most likely to find out about services?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Friend/family member	94	41.6%	33	41.8%
My doctor's office	66	29.2%	20	25.3%
Hospital discharge planner	36	15.9%	19	24.1%
My local Area Agency on Aging (AAA)	80	35.4%	33	41.8%
My local Aging and Disability Resource Center (ADRC)	38	16.8%	14	17.7%
INconnect Alliance	3	1.3%	4	5.1%
AARP	24	10.6%	7	8.9%
2-1-1 or telephone book	18	8.0%	8	10.1%
Internet	47	20.8%	25	31.6%

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Media: Newspaper/TV/Radio	7	3.1%	2	2.5%
Church or religious organization	18	8.0%	8	10.1%
Not sure	37	16.4%	12	15.2%
Other*	13	5.8%	10	12.7%

*Other responses included community centers and senior centers.

13. How concerned are you about being able to afford long-term care services for you or your family?

	Non-Caregivers (n=226)		Caregivers (n=79)	
	N	%	N	%
Extremely concerned	78	34.5%	42	53.2%
Very concerned	53	23.5%	1	1.3%
Somewhat concerned	56	24.8%	12	15.2%
Not very concerned	39	17.3%	24	30.4%

Caregivers

1. **What is your age?**

	N	%
18-34	15	7.1%
35-44	21	9.9%
45-54	47	22.2%
55-64	68	32.1%
65-74	43	20.3%
75-84	14	6.6%
85 years or older	3	1.4%
Don't know	1	0.5%

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

	N	%
Yes	53	25.0%
No	159	75.0%

3. **How would you describe your long-term illness or disability?**

	N	%
Developmental disability	0	0.0%
Blindness	1	1.9%
Deafness or severe hearing impairment	2	3.8%
Physical disability	21	39.6%
Psychological or emotional condition	7	13.2%
Chronic illness (e.g. diabetes, COPD, arthritis)	32	60.4%
Traumatic brain injury	2	3.8%

4. **How would you describe your own health?**

	N	%
Excellent	20	9.4%
Very good	74	34.9%
Good	77	36.3%
Fair	36	17.0%
Poor	5	2.4%

5. **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	159	75.0%
Past	53	25.0%

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

	N	%
Yes	119	56.1%
No	93	43.9%

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

	N	%
Providing social activities or companionship	191	90.1%
Taking them shopping or shopping for them	197	92.9%
Providing transportation to medical appointments	193	91.0%
Providing transportation to non-medical activities	180	84.9%
Aiding with household chores	191	90.1%
Helping them with meals	183	86.3%
Helping them to manage finances	171	80.1%
Overseeing their medication management	164	77.4%
Being responsible for other medical or nursing tasks	142	67.0%
Assisting with bathing or dressing	138	65.1%
Other*	17	8.0%

*Other responses included household maintenance, yard work, and incontinent care.

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

	N	%
In your household	120	56.6%
Less than 20 minutes away	53	25.0%
20 minutes to 1 hour away	27	12.7%
1 to 2 hours	5	2.4%
More than 2 hours	5	2.4%
Not sure	2	0.9%

9. **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	41	19.3%
Somewhat easy	44	20.8%
Somewhat difficult	68	32.1%
Very difficult	29	13.7%
I did not coordinate care between providers	30	14.2%

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

	N	%
Very well prepared	65	30.7%
Somewhat well prepared	93	43.9%
Not well prepared	48	22.6%
Not sure	6	2.8%

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 your friend or loved one?

	N	%
Yes	110	48.1%
No	102	51.9%

12. 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	66	31.1%
No	146	68.9%

HCBS Providers

1. Which of the following best describes your role within your organization?

	N	%
I am an executive leader of my organization	59	52.7%
I supervise direct care professionals (personal care attendants, home health aides)	22	19.6%
I supervise clinical staff (nurses, social workers, therapists)	6	5.4%
I work as a clinical professional (nurses, social workers, therapists)	20	17.9%
I work as a direct support professional (personal care attendants, home health aides)	5	4.5%

2. Which of the following services is your organization approved to provide?

	N	%
Home health (nursing, PT, OT, ST, home health aide)	34	30.4%
Music or recreational therapy	41	36.6%
Physical, occupational, or speech/language therapy	32	28.6%
Personal care (attendant care, homemaker/chore services, companion services)	59	52.7%
Adult day services	36	32.1%
Assisted living	8	7.1%
Structured family caregiving	14	12.5%
Case management	11	9.8%
Home-delivered meals	4	3.6%
Pest control	1	0.9%
Transportation to get to medical appointments	29	25.9%
Transportation for non-medical activities	37	33.0%
Environmental modifications	4	3.6%
Vehicle modifications	0	0.0%
Respite care	72	64.3%
Family/caregiver training	30	26.8%
Specialized medical equipment and supplies	4	3.6%
Behavior management	37	33.0%
Residential habilitation and support	42	37.5%
Supported employment	15	13.4%
Nursing facility services	5	4.5%
Hospice	3	2.7%

3.   From your perspective as a provider, what aspects of the current Medicaid HCBS system work well in meeting the needs of the people you support?

	N	%
Amount of the service we provide is sufficient	38	33.9%
Duration of the service we provide is sufficient	58	51.8%
Scope of the service we provide is sufficient (consider how narrowly or broadly a service is defined)	60	53.6%
Sufficient professional staff (nurses, social workers, therapists)	24	21.4%
Sufficient direct care staff (personal care attendants, home health aides)	20	17.9%
Training for providers is sufficient to provide high quality services and supports	45	40.2%
Adequate supervision of direct care staff to ensure high quality services and supports	40	35.7%
Provider qualifications outlined in code are sufficient to provide high quality services and supports	56	50.0%
Quality assurance mechanisms for providers are appropriate to ensure high quality services and support	49	43.8%
Incident reporting mechanism is effective to ensure high quality services and supports	62	55.4%
Administration of services is sufficient to ensure that we have adequate capacity to provide services at the right time and in the right place (e.g. claims processing, level of documentation required)	43	38.4%
Reimbursement is sufficient to ensure my ability to provide services and supports at the right time and in the right place	18	16.1%
Reimbursement is sufficient to ensure high quality services and supports	12	10.7%
Reimbursement is provided in an efficient and effective manner to enable me to consistently and efficiently provide services to people who need them	30	26.8%
Interactions with case managers are efficient and effective	48	42.9%
Flexibility to allow for innovations in providing services	33	29.5%

4. **From your perspective as a provider, what aspects of the current Medicaid HCBS system need improvement to meet the needs of the people you support?**

	N	%
Amount of the service we provide is not sufficient	51	45.5%
Duration of the service we provide is not sufficient	30	26.8%
Scope of the service we provide is not sufficient (consider how narrowly or broadly a service is defined)	22	19.6%
Increased availability of professional staff (nurses, social workers, therapists)	52	46.4%
Increased availability of direct care staff (personal care attendants, home health aides)	70	62.5%
Training for providers is not sufficient to provide high quality services and supports	31	27.7%
Supervision of direct care staff is not adequate to ensure high quality services and supports	27	24.1%
Provider qualifications outlined in code are not sufficient to provide high quality services and supports	12	10.7%
Quality assurance mechanisms for providers	18	16.1%
Incident reporting mechanism	21	18.8%
Administration of services is not sufficient to ensure that we have adequate capacity to provide services at the right time and in the right place (e.g. claims processing, level of documentation required)	22	19.6%
Reimbursement is not sufficient to ensure my ability to provide services and supports at the right time and in the right place	77	68.8%
Reimbursement is not sufficient to ensure high quality services and supports	81	72.3%
Reimbursement is not provided in an efficient and effective manner to enable me to consistently and efficiently provide services to people who need them	43	38.4%
Interactions with case managers	36	32.1%
Flexibility to allow for innovations in providing services	43	38.4%

5. What services are most helpful to the individuals you serve?

	N	%
Family/caregiver training	45	40.2%
Respite care/caregiver supports	85	75.9%
Behavior management	50	44.6%
Hospice and/or palliative care	13	11.6%
Mental health supports	28	25.0%
Therapy (physical, occupational, speech, recreational, etc.)	49	43.8%
Attendant care – e.g., help with bathing, dressing, etc.	69	61.6%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	54	48.2%
Home-delivered meals	21	18.8%
Assisted living or housing with services	27	24.1%
Adult day service	44	39.3%
Transportation to get to medical appointments	59	52.7%
Transportation for non-medical activities	58	51.8%
Wheelchair repairs	20	17.9%
Battery replacement for scooters	9	8.0%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	33	29.5%
Disposable medical supplies (DMS) – e.g., incontinence supplies	27	24.1%
Home modifications (e.g., ramp, grab bars, etc.)	36	32.1%
Personal emergency response services (e.g. Medic Alert)	22	19.6%
Other*	7	6.3%

*Other responses included home health services, health care coordination, and case management/.

6. What services do the individuals you serve need that they currently do not get?

	N	%
Family/caregiver training	14	12.5%
Respite care/caregiver supports	25	22.3%
Behavior management	25	22.3%
Hospice and/or palliative care	8	7.1%
Mental health supports	42	37.5%
Therapy (physical, occupational, speech, recreational, etc.)	26	23.2%
Attendant care – e.g., help with bathing, dressing, etc.	15	13.4%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	13	11.6%
Home-delivered meals	15	13.4%
Assisted living or housing with services	11	9.8%
Adult day service	9	8.0%
Transportation to get to medical appointments	28	25.0%
Transportation for non-medical activities	32	28.6%
Wheelchair repairs	17	15.2%
Battery replacement for scooters	8	7.1%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	16	14.3%
Disposable medical supplies (DMS) – e.g., incontinence supplies	12	10.7%
Home modifications (e.g., ramp, grab bars, etc.)	17	15.2%
Personal emergency response services (e.g. Medic Alert)	12	10.7%
Other*	22	19.6%

*Other responses included home modifications, pest elimination, or additional direct care staff to provide services.

7. What is the single biggest barrier that prevents the individuals you serve from receiving the services they need?

	N	%
Lack of knowledge	21	18.8%
Lack of providers	27	24.1%
Lack of informal supports	3	2.7%
Caregiver burnout	13	11.6%
Insufficient coordination between providers	5	4.5%
Eligibility process takes too long	18	16.1%
Financial guidelines are too restrictive (individuals earning too much or having too much in resources to qualify for publicly-funded support)	13	11.6%
Functional needs are too great	3	2.7%
Dual diagnoses (Mental Health and/or Intellectual/Developmental Delays)	6	5.4%
Functional needs not acute enough to qualify for publicly-funded support	3	2.7%

Case Managers

1. **From your perspective as a case manager, what aspects of the current HCBS provider system work well?**

	N	%
Provider quality assurance mechanisms are appropriate to ensure high quality services and supports	46	36.2%
Training for providers is sufficient to provide high quality services and supports	32	25.2%
Sufficient professional staff (nurses, social workers, therapists) to meet the needs of the individuals they serve	23	18.1%
Sufficient direct care staff (personal care attendants, home health aides) to meet the needs of the individuals they serve	9	7.1%
Adequate supervision of direct care staff to ensure high quality services and supports	23	18.1%
System is focused on individuals' needs and preferences	68	53.5%

2. **From your perspective as a case manager, what aspects of the current HCBS provider system could be improved?**

	N	%
Quality assurance mechanisms for providers	46	36.2%
Training for providers is not sufficient to provide high quality services and supports	67	52.8%
Increased availability of professional staff (nurses, social workers, therapists)	99	78.0%
Increased availability of direct care staff (personal care attendants, home health aides)	118	92.9%
Supervision of direct care staff is not adequate to ensure high quality services and supports	78	61.4%
System needs to focus more on individuals' needs and preferences	41	32.3%

3. **What is the typical caseload for your organization's full-time case managers?**

	N	%
0-25	7	5.5%
26-50	19	15.0%
51-60	27	21.3%
61-70	45	35.4%
71-80	21	16.5%
81 or more	8	6.3%

4. **Does the number of people on your case load give you the time to meet the needs of the individuals you serve?**

	N	%
Yes	68	53.5%
No	59	46.5%

5. **Do the individuals you serve know who to call or where to go to get information if their needs change and they need new or different services?**

	N	%
Yes	115	90.6%
No	12	9.4%

6. **Where do the individuals you serve find information when they need services or help with their care?**

	N	%
Doctor's office	46	36.2%
Case manager or care coordinator	118	92.9%
Local Area Agency on Aging (AAA)	71	55.9%
Local Aging and Disability Resource Center (ADRC)	47	37.0%
INconnect Alliance	9	7.1%
2-1-1	25	19.7%
The Internet	21	16.5%
Friend/family member	79	62.2%
Media: Newspaper/TV/Radio	17	13.4%
Church or religious organization	31	24.4%
Other*	11	8.7%

*Other responses included providers or senior centers.

7. **Do you feel that the individuals you serve receive all the services that meet their needs and goals?**

	N	%
Yes	44	34.6%
No	83	65.4%

8. **What services are most helpful to the individuals you serve?**

	N	%
Family/caregiver training	39	30.7%
Respite care/caregiver supports	97	76.4%
Behavior management	33	26.0%
Hospice and/or palliative care	38	29.9%
Mental health supports	51	40.2%
Therapy (physical, occupational, speech, recreational, etc.)	54	42.5%
Attendant care – e.g., help with bathing, dressing, etc.	105	82.7%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	97	76.4%
Home-delivered meals	86	67.7%
Assisted living or housing with services	70	55.1%
Adult day service	53	41.7%
Transportation to get to medical appointments	92	72.4%
Transportation for non-medical activities	79	62.2%
Wheelchair repairs	32	25.2%
Battery replacement for scooters	24	18.9%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	69	54.3%
Disposable medical supplies (DMS) – e.g., incontinence supplies	67	52.8%
Home modifications (e.g., ramp, grab bars, etc.)	88	69.3%
Personal emergency response services (e.g. Medic Alert)	85	66.9%
Other*	10	7.9%

*Other responses included companionship, healthcare coordination, and home repairs.

9. What services do the individuals you serve need that they currently do not get?

	N	%
Family/caregiver training	29	22.8%
Respite care/caregiver supports	28	22.0%
Behavior management	32	25.2%
Hospice and/or palliative care	5	3.9%
Mental health supports	74	58.3%
Therapy (physical, occupational, speech, recreational, etc.)	28	22.0%
Attendant care – e.g., help with bathing, dressing, etc.	20	15.7%
Homemaker/chore services – e.g., help with cooking meals, housekeeping, etc.	23	18.1%
Home-delivered meals	10	7.9%
Assisted living or housing with services	26	20.5%
Adult day service	31	24.4%
Transportation to get to medical appointments	37	29.1%
Transportation for non-medical activities	65	51.2%
Wheelchair repairs	28	22.0%
Battery replacement for scooters	33	26.0%
Durable medical equipment (DME) – e.g., wheelchair, walker, oxygen, etc.	14	11.0%
Disposable medical supplies (DMS) – e.g., incontinence supplies	12	9.4%
Home modifications (e.g., ramp, grab bars, etc.)	24	18.9%
Personal emergency response services (e.g. Medic Alert)	4	3.1%
Other*	17	13.4%

*Other responses included bed bug treatment, home repairs, and companion care.

10. What is the single biggest barrier that prevents the individuals you serve from receiving the services they need? (n=116)

	N	%
Lack of knowledge	5	4.3%
Lack of providers	46	39.7%
Lack of informal supports	4	3.4%
Caregiver burnout	6	5.2%
Insufficient coordination between providers	5	4.3%
Eligibility process takes too long	14	12.1%
Income guidelines are too low (individuals earning too much to qualify for publicly-funded support)	10	8.6%
Functional needs are too great	2	1.7%
Dual diagnoses (Mental Health and/or Intellectual/Developmental Delays)	15	12.9%
Functional needs not acute enough to qualify for publicly-funded support	9	7.8%