

**REPORT TO THE JOINT LEGISLATIVE AUDIT COMMITTEE ON FAMILY CARE**  
**AUGUST 31, 2012**

**PROFILE OF PEOPLE WAITING FOR LONG TERM CARE PROGRAMS**

**OVERVIEW OF THE SURVEY AND SUPPLEMENTAL DATA**

- The Department completed a two-part analysis of people waiting for publicly-funded long term care programs in November 2011.
- The data used in the analysis was based on a survey of 300 people on the wait list, selected randomly, who were interviewed in October of 2011.
- The survey was complemented by a review of indicators from the adult long term care functional screen to further profile the needs of people on the wait list for assistance with activities of daily living and other long term care supports and services.
- The functional screen is the automated tool used to determine whether an individual is functionally eligible for long term care programs.
- For both the survey and the supplemental profile, the population from which was the sample was drawn represented 90% of the people on the waiting list in counties where Wisconsin's long term care reformed programs, Family Care, IRIS, PACE and Partnership are available.
- The results of the survey show that:
  - 81% of individuals live in their own home, apartment, or a relative's home
  - Most individuals want to stay where they currently reside once they enroll in a long term care program.
  - The top three services requested by those on the wait list include:
    - Laundry or chore services
    - Personal care services (bathing, dressing, eating, toileting, grooming, etc.)
    - Transportation services

# Waiting for Long-Term Care Programs

Office for Resource Center Development  
WI Department of Health Services

Analytic Insight Customer Survey  
Survey Date: October 8-11, 2011

## Q1. Are you on a waiting list for long term care programs?

		%/Frequency	Cumulative Percent
Valid	1 Yes	68.2 % (n=180)	68.2
	2 No	31.8 % (n=84)	100.0
	Total	100% (n=264)	
	3 Don't know	12% (n=36)	
Total		300	

- One third of survey participants said that they were not on the waiting list.

*(Note: This result could be due to a variety of reasons. People can be confused about the term 'long-term care programs', may have cognitive disabilities that prevent their ability to recall, or a family member may have been a survey respondent.)*

## Q2. How long have you been waiting?

	%/Frequency	Cumulative Percent
1 6 months or less	50.9% (n=84)	50.9
2 More than 6 months to 1 year	23.6% (n=39)	74.5
3 More than 1 year to 3 years	16.4% (n=27)	90.9
4 More than 3 to 7 years	3.0% (n=5)	93.9
5 More than 7 to 10 years	1.2% (n=2)	95.2
6 More than 10 years	4.8% (n=8)	100.0
Total	100.0% (n=168)	
7 Don't know	15	

- Half (50.9%) have been waiting 6 months or less.
- 75% have been waiting for one year or less.
- 80% of participants who are elderly have been waiting for one year or less.
- 90% of people with Alzheimer's Disease have been waiting less than one year.
- 1/3 (33%) of people with developmental disabilities have been waiting *more than 1* year.

## Length of wait, by client group

Client Group	% waiting less than 6 months	% waiting 6 months-one year
Elderly	64.6% (n=53)	14.6% (n=12)
Physical Disability	49.5% (n=49)	24.2% (n=24)
Developmental Disability	43.1% (n=22)	23.5% (n=12)
Alzheimer's disease	75% (n=15)	15% (n=3)
Mental Illness	53.7% (n=22)	26.8% (n=11)
AODA	25% (n=1)	50% (n=2)
Other	33.3% (n=5)	26.7% (n=4)
Chronic Disease	41.75% (n=5)	33.3% (n=4)
Total	50% (n=82)	23.9% (n=39)

\*Note: Sample includes people on the waiting list in counties where IRIS and Family Care are available.

## WHAT PEOPLE ARE WAITING FOR

### Types of Help

- The **top three** things people are waiting for are: **personal care services**, help with instrumental activities of daily living (IADLs) such as **laundry and chore services** and **transportation**.

### Q3. What kind of help are you waiting for (*open ended*)?

		%/Frequency
\$Q3 <sup>a</sup>	1 Personal care services (bathing, dressing, eating, toileting, grooming)	27.9% (n=46)
	2 Equipment (wheel chairs, communication devices, etc.)	2.4% (n=4)
	3 Laundry or chore services	30.3% (n=50)
	4 Transportation	17.6% (n=29)
	5 Employment	6.7% (n=11)
	6 Help with managing behaviors	.6% (n=1)
	7 Nursing services	4.2% (n=7)
	8 Managing a health condition or chronic disease	3.6% (n=6)
	9 Nursing home	1.2% (n=2)
	10 Assisted living	11.5% (n=19)
	11 Mental health services	1.8% (n=3)
	13 Financial assistance	13.3% (n=22)
	14 Other	12.7% (n=21)
Total		133.9% (n=221)

### Top Three Types of Help Customers are Waiting For, *by client group* Comparison of Customer Survey Responses to ADRC Director Survey Responses

Client Group	Top 3 : Customer Response (open ended)	Top 3 : ADRC Response (multiple choice) <i>Note: "Financial Assistance" was not an option</i>
<b>Elderly</b>	1. IADLs/laundry and chore services 2. Personal care services 3. Financial Assistance <i>(Note: Assisted Living is 4<sup>th</sup>)</i>	1. Help with IADLs 2. Assisted Living 3. Personal care services
<b>Physical Disability</b>	1. IADLs/laundry and chore 2. Personal care services 3. Transportation	1. Personal care services 2. Laundry and chore (IADL) 3. Transportation
<b>Developmental Disability</b>	1. Transportation 2-3. Employment & Financial Assistance (tied)	1. Employment 2. Help with IADLs 3. Transportation
<b>Alzheimer's disease</b>	1-2. Assisted Living & Financial Assistance (tied) 3. IADLs and Personal care (tied)	1. Assisted Living 2. Help with IADLs 3. Personal care services

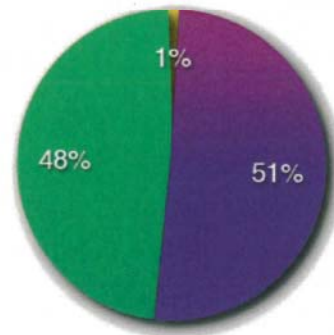
## HOW PEOPLE MANAGE WHILE THEY WAIT

About half (51%) of the individuals on the waitlist indicate that they are getting help right now. Another 48% indicate that they are not getting any help.

### Q.4 Are you (they) getting any help right now?

	%/Frequency	Cumulative Percent
1 Yes	51.0% (n=153)	51.0
2 No	47.7% (n=143)	98.7
3 Don't know	1.3% (n=4)	100.0
Total	100.0 (n=300)	

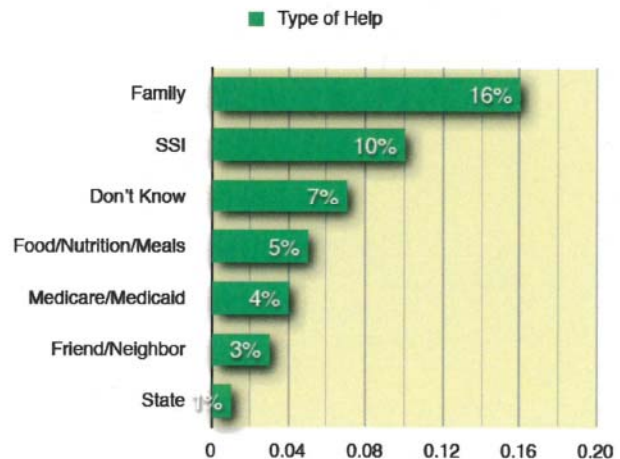
● Yes ● No ● Don't Know



- Those who are getting some help now, indicate that this help is mostly from **family, friends or neighbors** (18.3%) and other **programs** such as SSI, Medicare, Medicaid and programs that help support food, nutrition and meals (19%).
- Those who are least likely to say that they are getting help right now are those who are **60 or older** (53% said they were not getting help) and those with a **chronic disease** (57% said they were not getting help right now).

### Q5a. Are you (they) getting any help right now? If yes, what kind of help are you (they) getting?

Comment	Number	Percent of Responses
Family	24	15.7%
SSI	15	9.8%
Don't Know	11	7.2%
Food Nutrition or Meals	7	4.6%
Medicare or Medicaid	6	3.9%
Friend or neighbor	4	2.6%
State	1	0.7%



**Unduplicated customer responses (*Are you getting any help right now, if yes, what kind of help are you getting?*):**

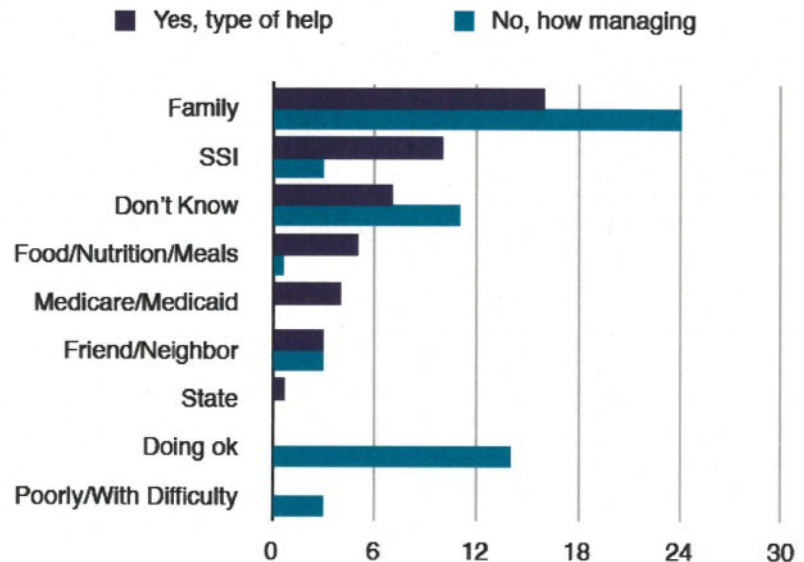
- Mother helps her
- Sister helping out
- My daughter
- Neighbor helps out
- My roommates are helping me out right now.
- My husband is living with me.
- Family is helping
- Grandson is helping
- My granddaughter moved in with me so she could take care of me.
- Help from parents
- Family and friends are helping, in nursing home now, hope to be out in a month.
- My ex-wife is helping me out.
- A friend is helping me get around.
- Home help twice a week
- I am getting home care services.
- Meals on Wheels
- Chores, shopping, and transportation, cooking, cleaning
- Helping me shower and house keeping
- Building a ramp and health care and lawn maintenance
- Getting help with personal care. Getting help to go to daycare.
- Help with my prescriptions and help with my food
- With people bathing me of some sort
- Cleaning lady comes and cleans once a month
- Got help from a grant to help purchase a sink
- Feed me and I'm living with them
- Medication, bathing, house keeping
- They help me get a bath. They serve my food. They clean my room.
- Visiting nurses. 6 hours a week from personal care services
- Nursing; aids, bathing and respite
- Personal care
- Take care of hygiene
- Constant supervisor, personal care
- Dental, physical therapy, I go to the doctor every so often
- Physical therapy, helping me showers, occupational therapy, and house keeping.
- Health care and special equipment they need
- I'm still going to the hospital, doctors, etc.
- Medical and medication
- VA pension they tell me that I should have someone coming in to help me. All my stuff from the VA.
- Just Food Stamps
- Katie Becket child care
- County, social worker
- Paying for her housing assistance
- Respite
- Senior preferred insurance
- Speech therapy, special ed, life skills, employment training
- Help finding a place and job
- Help with a driving instructor and an opportunity for a job
- Hiring outside help
- Mental help
- Assisted Living
- Nursing home
- I live in a facility with elderly people. I go eat in the dining room and my kids help me.

**Q5b. Are you (they) getting any help right now? If no, how are you (they) managing?**

Comment	Number	Percent of Responses
Family	37	24.18%
Doing okay	22	14.38%
Don't Know	17	11.11%
Poorly or with difficulty	5	3.27%
SSI	4	2.61%
Friend or neighbor	4	2.61%
Food Nutrition or Meals	1	0.65%

- One quarter of the participants who indicate that they are NOT receiving help right now, say that they are 'managing' with the help of family.
- Another 14% say that they are 'doing okay'.

- Regardless of whether a customer feels that they are getting help right now or not, there are similarities in the types of help people receive while they are waiting.
- 1/3 of the people on the list (Q7) indicated that they asked to be put on the list because they need help in the future (not now). This could be one explanation for why 14% said that they are 'doing ok'.



**Unduplicated customer responses (Are you (they) getting any help right now? If no, how are you (they) managing?)**

- With help from his daughter which is me and I am his caregiver.
- Son helps
- We take care of everything for him.
- The Ms. helped me get some stuff.
- My husband and I are working together and getting by.
- My grandkids and daughter
- My daughters are helping me. They come and give me baths and bring me food that I have to warm up.
- My children do what they can.
- Lots of family help
- Living with family
- Living with brother
- Lives at caregiver's house

- If am able to drive I do and if not, my boyfriend or someone else does.
- I, his mom, help him.
- I take care of my husband.
- I live with my daughter. We live together. I manage myself.
- I have a friend that comes once a month and helps with things that needs to be done or else I don't get help.
- I am managing through family and friend support and I have given up driving. I also have fuel assistance.
- I am getting help from my wife.
- I am doing what I can to take care of him.
- His mom is taking care of him.
- With a great deal of difficulty
- Very hard. My son takes care of me. No medical care, nothing.
- Very carefully
- Terrible and you got to pay for your doctor and your medicine and it is terrible.
- Social security barely pays bills, have difficulties with necessity.
- Poorly and she is very young
- Not very well, I would like my apartment to be a little cleaner. I had a lady who did some light cleaning and my daughter does some shopping for me.
- Not good, he needs help. He just sits at the garden.
- I can walk and everything. My right arm hurts so bad I can't use it. The pain pills don't help.
- I live in a dirty house.
- I don't manage really good because I just got over a bout of bacterial infection and I am having spinal problems. I can't walk very good.
- I am not managing. I cannot go to the doctor.
- Very well with a little help.
- He's doing good, having a good time. Every two or three months he has a downward spiral.
- Getting along slowly but surely.
- Do what I can do. Got to be careful.
- Local medicine clinic for insulin
- I have a cane and a walker. Tries not to use in the house.
- I am living on my savings account and that is gone.
- I am getting help from the VA, that is medical mostly.
- Girl in building helps me.
- They are taking care of themselves.
- The best I can. I live in a group home.
- On your own right now.
- By myself.

**Q6. What do you think will change when you are able to get into a program that you are waiting for?**

	<b>%/Frequency</b>
Don't Know	40.0% (n=40)
Transportation	12.0% (n=12)
Chores	11.0% (n=11)
Family	11.0% (n=11)
Health	7.0% (n=7)
Stay in home longer	7.0% (n=7)
Doctor or medical care	5.0% (n=5)
Way of life or attitude	4.0% (n=4)
Food Nutrition or Meals	2.0% (n=2)

## Customer Responses (what do you think will change)?

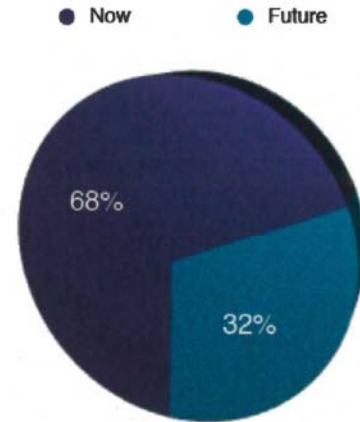
- A lot of things. The way of life, period.
- At least he will be there for life. He has been in Wisconsin for 29 years.
- Everything. I will be able to get groceries and shower myself.
- I know things would get better and I would not have to wait for people to help me and it will be on my own time.
- Meet goals for the future.
- My quality of life.
- Something better
- Assistance for housing and living accommodations
- Financial to stay at home
- Hopefully will be able to stay in my home longer, for a few more years anyway
- It will make it easier, it helps me to stay in my own home
- Move closer to family
- She need different living place. Personal care, transportation
- Assisted living to help with chores
- Well I think that I can get a lot better care. I could get better hygiene because I can't do it myself. And right now I can't even get out and about to do my errands so they would help me with that.
- Just so I can get some help getting dressed in the morning and help me get my house cleaned up
- Better health
- Help his condition. Getting insulin.
- Help to get medicine and ease pain.
- Hopefully my health gets better
- Medical and all kinds of stuff, all my medical and all my needs should change when I get into a place of my own.
- My house will be cleaner and I will feel better about myself.
- Somebody help me get in and out of the tub, cleaning up and general help
- I really need help with the stuff around the house
- Get the home more organized. Still in boxes and need help.
- Chores done, help doing personal things
- Help with chores 'til I can walk again.
- Help with my house cleaning and hoping to get an oven.
- I might get somebody to come in once a week to clean. I have no one.
- More free time as far as things go for my grandma, she needs someone with her all the time
- Get out a little bit more and take a computer class.
- I need help with her so I can go back to work
- I think he will get a job. Have a social life. That would give us a break.
- He would be able to do day services that he needs
- It'll help her get out of the house and be able to do something's. She is the only one in the house during the day.
- Manage on my own, and get an apartment, get transportation to get out more often
- He will be able to get more hands on care than I can give him. We are hoping he will be more social being around people his age.
- Helping her out with the little things
- It would be wonderful and put a bar to help me get out of the bath tub.
- Hopefully I'll be able to deal with day to day activities much better.
- Hoping I will get clothes I need, etc.
- I think that when her mother can stay home, she will be able to teach her important skills needed for survival.
- I am hoping I don't have to waste my whole paycheck for other people to drive me
- I need someone to give me transportation to the store and the pharmacy and all I have right now is transportation to the doctor.
- They will have more independence and be able to permit us to get away and to take better care of her.
- That I could depend on myself, not my children





**Q7. Did you [they] ask to be put on the list because you [they] need help now, or because you [they] need help in the future?**

Response	%/Frequency	Cumulative Percent
1 Need help now	68.4% (n=119)	68.4
2 Need help in the future	31.6% (n=55)	100.0
Total	100% (n=174)	

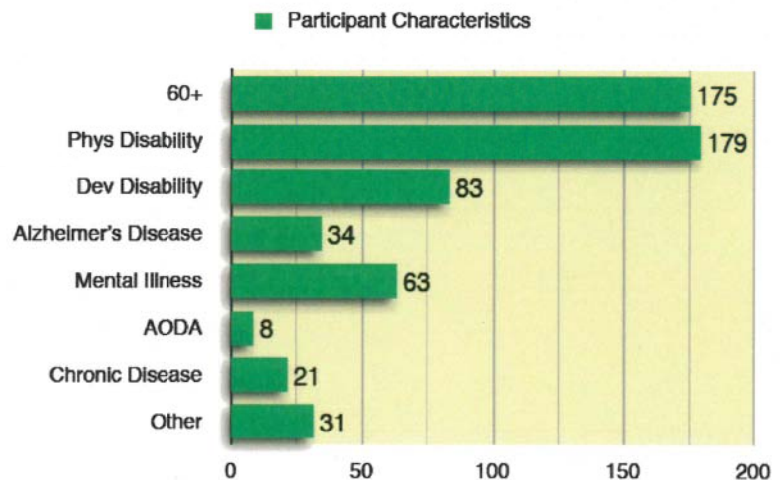


- One in three elderly (33%), people with a mental illness (32.5%) and with a chronic disease (38.5%) are on the waiting list and indicate that they need help later.

**Q8. Survey Participant Characteristics**

Which of the following apply? Are you... (read list, note all that apply)

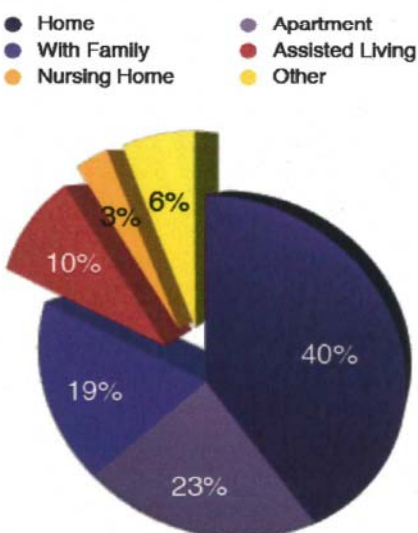
		% of cases
\$Q8 <sup>a</sup>	1 60 years of age or older	59.3% (n=175)
	2 (You/they) have a physical disability	60.7% (n=179)
	3 A developmental disability	28.1% (n=83)
	4 Alzheimer's disease or other dementia	11.5% (n=34)
	5 A mental illness (Other than Alzheimer's or dementia)	21.4% (n=63)
	6 A concern regarding alcohol or other drug dependency, or	2.7% (n=8)
	7 Some other disability or concern	10.5% (n=31)
	9 Chronic Disease	7.1% (n=21)
	Total	201.4% (n=594)



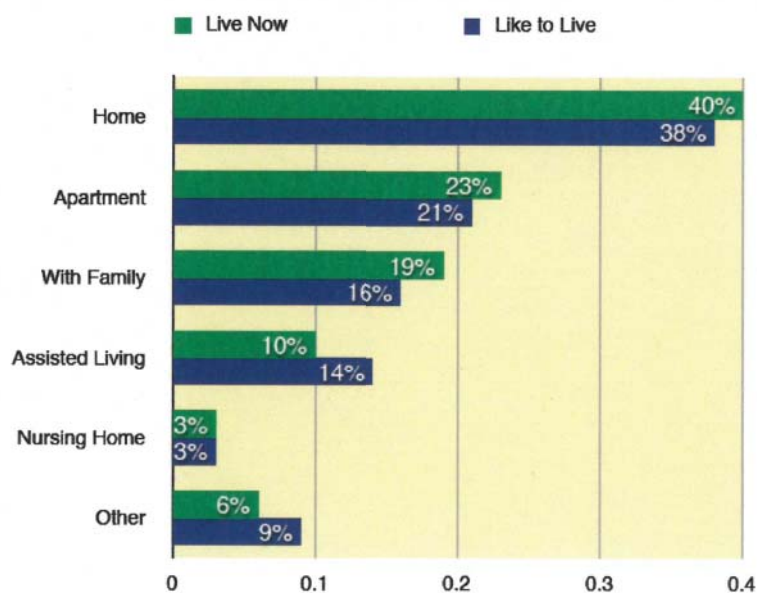
## LIVING ARRANGEMENT

### Q9. What type of housing are you [they] living in right now?

- 81% of participants currently reside in their own home, apartment, or with family.
- 13% live in an assisted living or nursing facility.



### Q10. When you [they] are able to receive services, where would you [they] like to live?



\*Note: The "Other" category includes responses such as "the same place I am in now", "in town", "a better neighborhood".

# Profile of People Waiting for Long-Term Care Programs

In November, 2011, an analysis of individuals waiting for publicly funded long-term care programs was conducted. Data derives from the long-term care functional screen; the automated tool used to determine whether an individual is functionally eligible for long term care programs. 4205 individuals were included in the sample (which represents 90% of the people on the waiting list in counties where IRIS and Family Care are available).

Ages of waitlist people	# People	% of People
17-25	446	10.6%
6-45	278	6.6%
46-65	864	20.5%
66-75	525	12.5%
76-85	980	23.3%
86-95	991	23.6%
96+	121	2.9%
Total	4,205	100.0%

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- Two-thirds of the people waiting are over age 65.
  - More than one quarter of the people waiting are over age 85.
  - 121 people are 96 years of age or older.

Hierarchical Target Group*	# People	% of People
Developmentally Disabled	728	17.3%
Elderly	2,226	52.9%
No Target Group / NA**	21	0.5%
Physically Disabled	1,230	29.3%
Total	4,205	100.0%

\*People with developmental disabilities who also meet another target group are included in the DD category.

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- One out of two are frail elders
  - One out of three have a physical disability
  - One out of five have a developmental disability

Length of time on waitlist	# People	% of People
Less than 6 months	2,053	48.8%
6-12 months	1,037	24.7%
Between 1 year & 2 years	847	20.1%
More than 2 years	268	6.4%
Total	4,205	100.0%

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- Consistent with the customer survey, half (48.8%) have been waiting 6 months or less.
  - 75% have been waiting for one year or less.

## Activities of Daily Living (ADL)

Activities of daily living include day-to-day tasks such as bathing, dressing, eating, mobility, toileting, and transferring.

- Forty percent (40%) of people waiting require assistance with **three or more** activities of daily living. People who are elderly or who have a physical disability are most likely to require assistance with three or more activities.

- About one quarter (24%) do not require any assistance.

	% with no ADL Needs	% with 3-6 ADL Needs
People with Developmental Disabilities	37.4%	26.6%
Frail Elderly People	21.6%	40.3%
People with Physical Disabilities	21.7%	46.3%
Aggregate	24.3%	39.6%

The following chart shows the percentage of people that require assistance with the specified ADL. The most common activities that people require assistance with are bathing (67%), dressing (49%), and mobility (31%).

	Developmental Disability	Frail Elders	Physical Disability	Aggregate
Bathing	56%	69%	68%	<b>66.5%</b>
Dressing	40%	49%	53%	<b>49%</b>
Eating	21%	20%	20%	<b>20%</b>
Mobility	9%	34%	39%	<b>31%</b>
Toileting	23%	30%	30%	<b>29%</b>
Transferring	7%	28%	38%	<b>27%</b>

## Instrumental Activities of Daily Living (IADLs)

*Instrumental activities of daily living include tasks such as meal preparation, medication management, money management, laundry/chore services, transportation, and access to or use of the telephone.*

- Eighty-eight percent (88%) of people waiting require assistance with **three or more** instrumental activities of daily living. People who are elderly or who have a developmental disability are most likely to require assistance with three or more activities.
- **Almost every person** waiting for long-term care programs require assistance with at least one instrumental activity of daily living.

	% with no IADL Needs	% with 3-6 IADL Needs
People with Developmental Disabilities	0.0%	91.5%
Frail Elderly People	0.4%	90%
People with Physical Disabilities	0.6%	80.6%
Aggregate	0.4%	87.5%

The following chart shows the percentage of people that require assistance with the specified IADL. The most common IADLs that people require assistance with are laundry and chores (93%), meal preparation (89%), and transportation (80%).

	Developmental Disability	Frail Elders	Physical Disability	Aggregate
Meal Preparation	84%	92%	86%	<b>89%</b>
Medication Management*	82%	77%	63%	<b>73%</b>
Money Management	96%	74%	53%	<b>72%</b>
Laundry/Chore	83%	95%	94%	<b>93%</b>
Transportation**	89%	83%	70%	<b>80%</b>

\* Indicates percentage of people who require assistance among those that take medications

\*\*Indicates the percentage of people that do not drive a vehicle at all.

## Limitations of People Waiting

*The most typical person on the waitlist is an elderly person between 76 and 95 years of age who has been on a waitlist less than six months.*

### Developmental Disabilities: Top Three ADLs and IADLs

1. Bathing (56%)
2. Dressing (40%)
3. Toileting (23%)
4. Money Management (96%)
5. Transportation (89%)
6. Meal Preparation (84%)

### Elderly: Top Three ADLs and IADLs

1. Bathing (69%)
2. Dressing (49%)
3. Mobility (34%)
4. Laundry/Chore (95%)
5. Meal Preparation (92%)
6. Transportation (83%)

### Physical Disabilities: Top ADLs and IADLs

1. Bathing (68%)
2. Dressing (53%)
3. Mobility (39%)
4. Laundry/Chore (94%)
5. Meal Preparation (86%)\*
6. Transportation (70%)