



National Core Indicators
Aging and Disabilities Adult Consumer Survey

2018-2019 Kansas Results



Preface

The State of Kansas has a number of publicly funded long-term services and supports (LTSS) available to older adults and adults with physical disabilities who have significant health care needs. LTSS provide a wide array of health and social supports that enable these individuals to avoid placement in facilities and to live in a setting of their choice. Specifically, the Kansas Department for Health and Environment (KDHE) administers Medicaid funding for LTSS that provides a variety of program options in both facility-based and home and community-based services (HCBS) settings. The Kansas Department for Aging and Disability Services (KDADS) oversees and administers the Medicaid waiver programs. KDADS administers funding from the federal Older Americans Act and State Funding for Senior Care Act Services, making additional supports and services available to help older adults remain in the community of their choice.

Because our population is rapidly becoming older and more diverse, this is a particularly critical time for Kansas to assess the quality and impact of its existing LTSS. An element that cuts across all parts of Kansas' LTSS system is the importance of measuring quality and reporting the results to stakeholders. Participation in the National Core Indicators for Aging and Disabilities (NCI-AD) project continues Kansas' efforts to evaluate the quality of life and quality of services that persons receive. Over the next decade, Kansas will experience a demographic shift that will create new demands for the LTSS system. The findings from NCI-AD are crucial information for Kansas to better understand and support the growing and shifting population.

This report highlights the results for Kansas from its fourth year of NCI-AD Adult Consumer Survey implementation. State departments and planning groups can utilize this information to make improvements in programs and services, and more effectively meet the needs of older adults and adults with physical disabilities who have significant health care needs.

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List of Abbreviations Used in This Report

AAA – Area Agency on Aging

ADRC – Aging and Disability Resource Center

BI Section – Background Information Section of NCI-AD Adult Consumer Survey

CIL – Center for Independent Living

CPAP – continuous positive airway pressure

FE – Frail Elderly

HCBS – Home and Community-Based Services

HSRI – Human Services Research Institute

KACE – Kansas Adult Care Executives

KDADS – Kansas Department for Aging and Disability Services

KDHE – Kansas Department for Health and Environment

LTC – Long-Term Care

LTSS – Long-Term Services and Supports

N – Number of respondents

N/A – not applicable

NASUAD – National Association of States United for Aging and Disabilities

NCI-AD – National Core Indicators for Aging and Disabilities

OAA – Older Americans Act

ODESA – Online Data Entry Survey Application

PACE – Program of All-Inclusive Care for the Elderly

PCA – Personal Care Assistant

PCP – Person-Centered Planning

PD – Physical Disabilities

TBI – Traumatic Brain Injury

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What is NCI-AD?

The National Core Indicators for Aging and Disabilities© (NCI-AD) are standard measures used across participating states to assess the quality of life and outcomes of seniors and adults with physical disabilities—including traumatic or acquired brain injury—who are accessing publicly-funded services through the Older Americans Act (OAA), Program of All-Inclusive Care for the Elderly (PACE), Medicaid, and/or state-funded programs. The program is coordinated by ADvancing States¹ (formerly the National Association of States United for Aging and Disabilities (NASUAD)) and Human Services Research Institute (HSRI). NCI-AD data are gathered through yearly in-person Adult Consumer Surveys administered by state Aging, Disability, and Medicaid Agencies (or an Agency-contracted vendor) to a sample of at least 400 individuals in each participating state. NCI-AD data measure the performance of states' long-term services and supports (LTSS) systems and service recipient outcomes, helping states prioritize quality improvement initiatives, engage in thoughtful decision making, and conduct futures planning with valid and reliable LTSS data. The program officially launched in the summer of 2015 with 13 participating states². The 2019-2020 project cycle marks its fifth year of implementation, with more than twenty states expected to participate. For more on the development and history of NCI-AD, refer to the [*National Core Indicators Aging and Disability Adult Consumer Survey: 2015-2016 National Results*](#) report, available on the NCI-AD website (www.NCI-AD.org).

NCI-AD Adult Consumer Survey

Survey Overview

The NCI-AD Adult Consumer Survey is designed to measure outcomes across nineteen broad domains comprising approximately 55 core indicators. Indicators are the standard measures used across states to assess the outcomes of services provided to individuals,

¹ ADvancing States (formerly NASUAD) is the membership organization for state Aging, Disability, and Medicaid directors. www.ADvancingStates.org

² Colorado, Delaware, Georgia, Indiana, Kansas, Maine, Minnesota, Mississippi, New Jersey, North Carolina, Ohio, Tennessee, and Texas.

including respect and rights, service coordination, care coordination, employment, health, safety, person-centered planning, etc. An example of an indicator in the Service Coordination domain is: “Proportion of people who receive the services that they need.”

While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator “Proportion of people who get needed home modifications, equipment, and assistive devices” in the Access to Needed Equipment domain is addressed by several survey questions that ask about the person’s need for various types of home modifications and assistive devices. Figure 1 below details NCI-AD domains and corresponding indicators.

Figure 1. 2018-2019 NCI-AD Domains and Indicators

Domain	NCI-AD Indicator
Community Participation	Proportion of people who are able to participate in preferred community activities
Choice and Decision-Making	Proportion of people who are involved in making decisions about their everyday lives
Relationships	Proportion of people who are able to see or talk to their friends and families when they want to
Satisfaction	Proportion of people who are satisfied with where they live
	Proportion of people who are satisfied with their paid support staff
	Proportion of people who are satisfied with what they do during the day
Service Coordination	Proportion of people finding out about services from service agencies
	Proportion of people who have access to information about services in their preferred language ³
	Proportion of people who can get in contact with their case manager when they need to
	Proportion of people who know whom to contact with a complaint or question about their services
	Proportion of people who use a relative as their support person
	Proportion of people whose support staff come when they are supposed to
	Proportion of people who have a backup plan if their paid support staff don’t show up
Proportion of people who have an emergency plan in place	

³ Indicator previously reported in the “Access” domain.

Domain	NCI-AD Indicator
	Proportion of people who receive the services that they need
	Proportion of people whose case manager talks to them about their unmet needs
	Proportion of people who want help planning for their future service needs
Care Coordination	Proportion of people who had someone work with them to reduce risk of falls ⁴
	Proportion of people who feel comfortable going home after being discharged from a hospital or a rehab facility
	Proportion of people who have adequate follow-up after being discharged from a hospital or a rehab facility
	Proportion of people who know how to manage their chronic conditions
Access to Community⁵	Proportion of people who have adequate transportation ⁶
Access to Needed Equipment⁷	Proportion of people who get needed home modifications, equipment, and assistive devices ⁸
Safety	Proportion of people who feel safe around their paid support staff
	Proportion of people who are able to get to safety quickly in case of an emergency
	Proportion of people who feel safe at home
	Proportion of people who feel that their belongings are safe
Health Care	Proportion of people who have access to mental health services
	Proportion of people who can get an appointment with their doctor when they need to
	Proportion of people who experience potentially preventable emergency room visits
	Proportion of people who have needed health screenings and vaccinations in a timely manner
Wellness	Proportion of people who have access to healthy foods ⁹

⁴ Indicator previously reported in the “Safety” domain.

⁵ New domain in 2018-2019.

⁶ Indicator previously reported in the “Access” domain.

⁷ New domain in 2018-2019.

⁸ Indicator previously reported in the “Access” domain.

⁹ Indicator previously reported in the “Everyday Living” domain.

Domain	NCI-AD Indicator
	Proportion of people in poor health
	Proportion of people with uncorrected poor hearing
	Proportion of people with uncorrected poor vision
	Proportion of people with unaddressed memory concerns
	Proportion of people who often feel sad or depressed
Medications	Proportion of people who take medications to help them feel less sad or depressed
	Proportion of people who know what their prescription medications are for
Rights and Respect	Proportion of people whose paid support staff treat them with respect
	Proportion of people whose basic rights are respected by others
Self-Direction	Proportion of people who can choose or change the kind of services they receive and who provides them
Work	Proportion of people who have a paid job
	Proportion of people who would like a job
	Proportion of people who receive job search assistance
	Proportion of people who volunteer
	Proportion of people who would like to volunteer
Everyday Living	Proportion of people who have adequate support to perform activities of daily living and instrumental activities of daily living
Affordability	Proportion of people who have to cut back on food because of money
Control	Proportion of people who feel in control of their life
Person-Centered Planning (OPTIONAL MODULE)	Proportion of people who are involved in making decisions about their service plan
	Proportion of people whose service planning meetings take place when, where and with whom they want
	Proportion of people whose preferences and needs are discussed in their service planning meetings
	Proportion of people who receive a copy of their service plan after their service planning meetings

Domain	NCI-AD Indicator
	Proportion of people whose service plan reflects what is discussed during their service plan meetings
	Proportion of people whose service plan includes their preferences and choices
	Proportion of people whose supports and services help them live a better life

Survey Organization

The NCI-AD Adult Consumer Survey tool consists of the Pre-Survey form, the Background Information Section, the Full In-Person Survey, and the Interviewer Feedback Form. An alternative Proxy Version of the In-Person Survey is available for those interviews that need to be conducted with proxies of service recipients instead of the service recipient themselves. Each part of the tool is described below.

Pre-Survey form: The Pre-Survey section is an optional form intended to collect information that may be helpful for surveyors to prepare for and schedule the survey meetings. The Pre-Survey form is for surveyor use only; Pre-Survey information is not submitted or used for any data analysis or reporting.

Background Information (BI) Section: The BI Section collects demographic and service-related information about the service recipient. To the extent possible, data for the BI Section are derived from states' existing administrative records. BI items not available from state administrative data sources may be collected by surveyors at the end of the survey meeting. Surveyors may collect any missing BI information with the exception of five BI items that must be completed using administrative data sources (person's primary source of LTSS funding/program, LTSS services received through that program, length of receiving services, participation in a self-directed supports option, and legal guardianship status). Each BI item tracks whether data were derived from existing administrative records or collected by surveyors as part of the survey meetings.

In-Person Survey: The Full In-Person Survey consists of approximately 90 questions, with related questions grouped together by theme or topic (e.g., a series of questions about employment, a series of questions about support staff, etc.); another 10 questions

comprise the optional Person-Centered Planning module. The Full In-Person Survey is completed face-to-face with the person receiving services. The respondent may ask their proxy (e.g. a family member or a close friend) for assistance with answering some of the questions, if needed. The Full In-Person Survey includes both subjective and objective questions; proxy assistance is only allowed for a defined subset of more objective items.

Proxy Version: The Proxy Version is an alternative version of the In-Person Survey. It is used in place of the Full In-Person Survey when the person receiving services is unable or unwilling to provide valid responses or has asked their proxy to complete the survey on their behalf. The Proxy Version includes only the subset of more objective questions from the Full Survey that allow for proxy assistance. Questions in the Proxy Version are rephrased to be in third person, making it clear their subject is the person receiving services and not the proxy respondent. Surveyors must meet with the service recipient face-to-face and attempt to interview them; only after the in-person attempt has been made can the proxy be surveyed instead of the service recipient.

Interviewer Feedback Form: The Interviewer Feedback Form is completed by surveyors after the survey meeting is concluded. It collects information about the survey meeting itself, such as when/where the meeting took place, who was present, the respondent's level of comprehension, etc. Surveyors are also asked to provide any feedback they may have about the survey tool itself or the survey process overall.

NCI-AD in Kansas

The Kansas Department for Aging and Disability Services (KDADS) implemented the 2017-2018 NCI-AD Adult Consumer Survey in Kansas. KDADS recognized the need for an assessment of the state's publicly-funded home and community-based services (HCBS), including the HCBS/Traumatic Brain Injury (TBI), HCBS/Physical Disabilities (PD) and HCBS/Frail Elderly (FE). The NCI-AD was identified by KDADS as a valuable tool that will allow comparisons to other States in the nation when it comes to community-based services. Data from the project will be used to support efforts in Kansas to strengthen LTSS policy, inform quality assurance activities, and improve the quality of life of LTSS participants.

Sample

The total number of NCI-AD Adult Consumer Surveys conducted in Kansas in 2018-2019 and included for analysis was four hundred and three (Total N=403). Three program populations were included in the survey sample and are detailed below.

Frail and Elderly (FE) Waiver: This program provides assistance to individuals ages 65 and older who qualify to receive Medicaid and require LTSS in order to remain in a community setting, as determined through a state level of care assessment. Services include Adult Day Care, Assistive Technology, Comprehensive Support, Enhanced Care Service, Financial Management Services, Home Telehealth, Medication Reminder, Nursing Evaluation Visit, Oral Health Services, Personal Care Services, Personal Emergency Response, and Wellness Monitoring. The option for individuals to self-direct their care is made available for the following services: Comprehensive Support, Enhanced Care Service, Financial Management Services, and Personal Care Services. One hundred seventy-three people (N=173) from this program were interviewed and included for analysis.

Physical Disability (PD) Waiver: This program provides LTSS to those individuals between the ages of 16 and 64 who have a qualifying physical disability, qualify to receive Medicaid, and require LTSS in order to remain in a community setting, as determined through a state level of care assessment. Services include Assistive Services, Enhanced Care Service, Financial Management Services, Home-Delivered Meals Service, Medication Reminder Services, Personal Care Services, and Personal Emergency Response. The option for individuals to self-direct their care is made available for the following services: Enhanced Care Service, Financial Management Services, and Personal Care Services. Two hundred thirteen people (N=213) from this program were interviewed and included for analysis.

Traumatic Brain Injury (TBI) Waiver: This program provides assistance to those individuals between the ages of 16 and 65 who have a documented and traumatically-incurred brain injury, demonstrate the capacity for progress in rehabilitation and independent living skills, qualify to receive Medicaid, and require LTSS in order to remain in a community setting, as determined through a state level of care assessment. Individuals who receive services through this waiver may continue to do so up to four years until it is determined that they are no longer making progress in rehabilitation and improved living

skills. Exceptions to this timeframe are subject to a standardized review process at the state level. Services include Assistive Services, Behavior Therapy, Cognitive Rehabilitation, Enhanced Care Service, Home-Delivered Meals Service, Medication Reminder Services, Occupational Therapy, Personal Care Services, Personal Emergency Response, Physical Therapy, and Transitional Living Skills. Seventeen people (N=17) from this program were interviewed and included for analysis.

Figure 2 below summarizes programs included in Kansas’ NCI-AD survey sample, the number of survey-eligible service recipients in each and the corresponding number of conducted surveys included for analysis. Also included are calculations of margin of error for each program under two scenarios: assuming a very conservative 0.5 distribution of responses and assuming a somewhat less conservative 0.7 distribution of responses. Using the 0.5 distribution of responses is the most conservative distribution assumption for calculating margins of error that can be made and is usually used when no prior information is available about true population response distributions. When some prior information about distributions of responses in the population is available, it can be used for calculating less conservative margins of error. Based on distributions observed in previously collected NCI-AD data, it is reasonable to assume a somewhat less conservative population response distribution of 0.7 for calculating margins of error. Calculations in both scenarios use the total number of analyzed surveys in each program. It is important to note that the actual number of valid responses to an individual survey item may be smaller than the total number of analyzed surveys. This is explained in more detail in the “Organization of Results” section below.

Figure 2. Number of survey-eligible service recipients, number of analyzed surveys, and calculations of margins of error by program.

Program	Number of analyzed surveys	Number of eligible participants	Margin of error (MoE) and confidence level (CL), assuming 0.7 distribution	Margin of error (MoE) and confidence level (CL), assuming 0.5 distribution
FE Waiver	173	4,600	6.7% MoE, 95% CL	7.3% MoE, 95% CL
PD Waiver	213	5,800	6.0% MoE, 95% CL	6.6% MoE, 95% CL
TBI Waiver	17	400	21.3% MoE, 95% CL	23.3% MoE, 95% CL

Program	Number of analyzed surveys	Number of eligible participants	Margin of error (MoE) and confidence level (CL), assuming 0.7 distribution	Margin of error (MoE) and confidence level (CL), assuming 0.5 distribution
Total	403	10,800	4.4% MoE, 95% CL	4.8% MoE, 95% CL

Survey Process in Kansas

KDADS utilized agency resources to provide random samples of program participants and conduct the interviews. Samples were provided via a secure web-based application to survey staff. The process included consulting with service providers, reviewing system records, and in-person interviews with individuals receiving services. Information obtained by QMS staff was entered into the ODESA database (NCI-AD’s data portal).

Kansas used NCI-AD’s optional module on person-centered planning (PCP) in all three of its programs surveyed. In addition, Kansas chose to add 10 state-specific questions to the standard NCI-AD Survey.

Stakeholders

KDADS provides ongoing NCI-AD engagement activities through various stakeholder groups and organizations within the state. These stakeholders include HCBS Participants, HCBS Providers, Kansas Health Care Association, LeadingAge, Kansas Adult Care Executives (KACE), LTC Ombudsman, Area Agencies on Aging (AAAs) and InterHab. KDADS meets with the stakeholders through various committees and settings each month to engage in discussions related to findings from surveys on client experience as well as reaction to data from completed surveys.

Organization of Results

The following pages of the report presents findings from Kansas' 2018-2019 NCI-AD Adult Consumer Survey data collection cycle. Results are grouped by domain and are presented in chart format. Charts show results for individual survey items broken out by each program. The number of people (N) in each program that gave valid responses to that survey item are also shown. The number of valid responses to an item may be smaller than the total number of analyzed surveys, for the following reasons:

- Certain questions in the survey can only be asked of the service recipient – i.e. proxy respondents for these questions are not allowed. These questions have a smaller number of responses because they are contained only in the full In-Person Survey, whereas the total number of analyzed surveys also includes cases when the Proxy Version was used.
- Only valid responses are included in both the denominator and the numerator when calculating proportions. Unclear, refused and, for most items, “don't know” responses are excluded.
- The survey contains several skip logic patterns. This means that depending on the response to a previous survey item, a question may or may not be asked, as appropriate. When an item is skipped due to skip logic, the survey case does not contribute to the calculations for the item.

Please note: Extreme caution should be used when interpreting results where the number of valid responses is small. Each program's valid number of responses (valid Ns) is shown in every chart and table in this report. In addition to displaying valid number of responses, charts also use an asterisk to indicate Ns smaller than 20. Responses smaller than 20 should not be used as a basis for firm conclusions and should be treated as suggestive and informational only.

Each chart also contains Kansas' weighted state average, as well as the total number of observed valid responses for that survey item. A weighted state average takes into account whether the sampling strategy proportionally oversampled one or more of the state's programs; its calculation effectively “re-balances” the oversampled programs to produce an average one would expect if they were represented proportionally relative to the populations they serve. Kansas' sampling design did include oversampling of some of its programs – i.e. some programs constituted a larger proportion of the survey sample than they did as proportion of total

population of survey-eligible service recipients. To account for these programs being proportionally over-represented in the state's survey data, statistical weights were developed and applied to calculate Kansas' weighted state averages presented in the charts. For exact calculations of weights, please contact the NCI-AD project team.

Charts present results using binary data indicating presence or absence of the outcome. For the purposes of analysis, most survey items with three or more possible response options were recoded to form binary variables (i.e. responses were collapsed, for example, an "always" response combined with a "most of the time" response). For details about recoded items and the rules on collapsing response options, please refer to Appendix A. Unless otherwise stated, "don't know" and unclear/refused responses were excluded from both the numerator and denominator.

Un-collapsed and unweighted data showing frequencies of all response options by program are shown in tabular format in Appendix B. These tables contain all response options, including "don't know" and unclear/refused/no response categories. Tables also contain Kansas' unweighted overall sample averages for all response options. Please note that the "sample averages" in tables in Appendix B are simple (unweighted) averages that didn't employ weights in their calculations and may therefore be slightly different from the corresponding weighted state averages shown in the charts.

Data from state-specific questions that Kansas chose to add to the standard NCI-AD Survey are shown in Appendix C. Kansas' data from NCI-AD's optional PCP module are shown in Appendix D.

Limitations of Report

This report contains survey results related to the quality and outcomes of LTSS in Kansas. However, it does not provide benchmarks for acceptable or unacceptable levels of performance. Rather, it is up to state staff, leadership, and other stakeholders to assess information contained in this report and establish priorities. This report is intended to be one mechanism to assess the current state of Kansas' LTSS system and identify areas that are working well and areas that could use improvement. The charts in this report allow the reader to compare average outcomes between Kansas' programs and the state overall. State leaders, public managers,

policy-makers and community stakeholders can use this information to decide whether a program's result relative to another program or to the state average suggests further investigation or intervention is necessary. However, discretion should be used when comparing a program's result relative to another program, as it is important to keep in mind the potential differences as well as similarities amongst program participants and the programs themselves.

Results

Community Participation

People are able to participate in preferred activities outside of home when and with whom they want.

There is one Community Participation indicator measured by the NCI-AD Adult Consumer Survey:

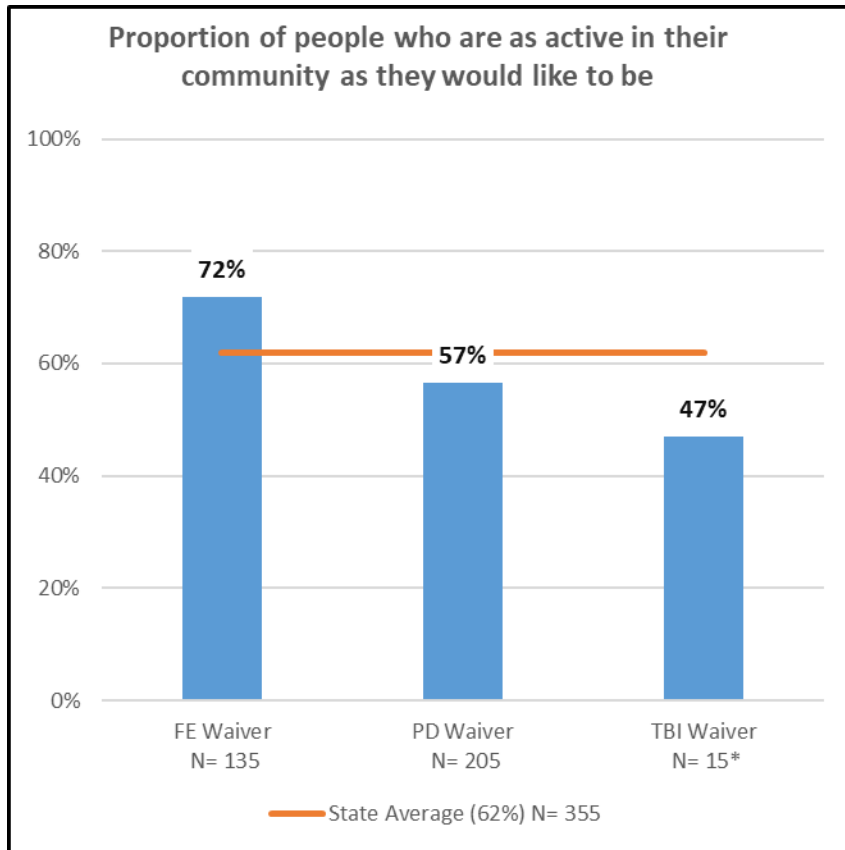
1. Proportion of people who are able to participate in preferred community activities.

There are three¹⁰ survey items that correspond to the Community Participation domain.

Un-collapsed data are shown in Appendix B.

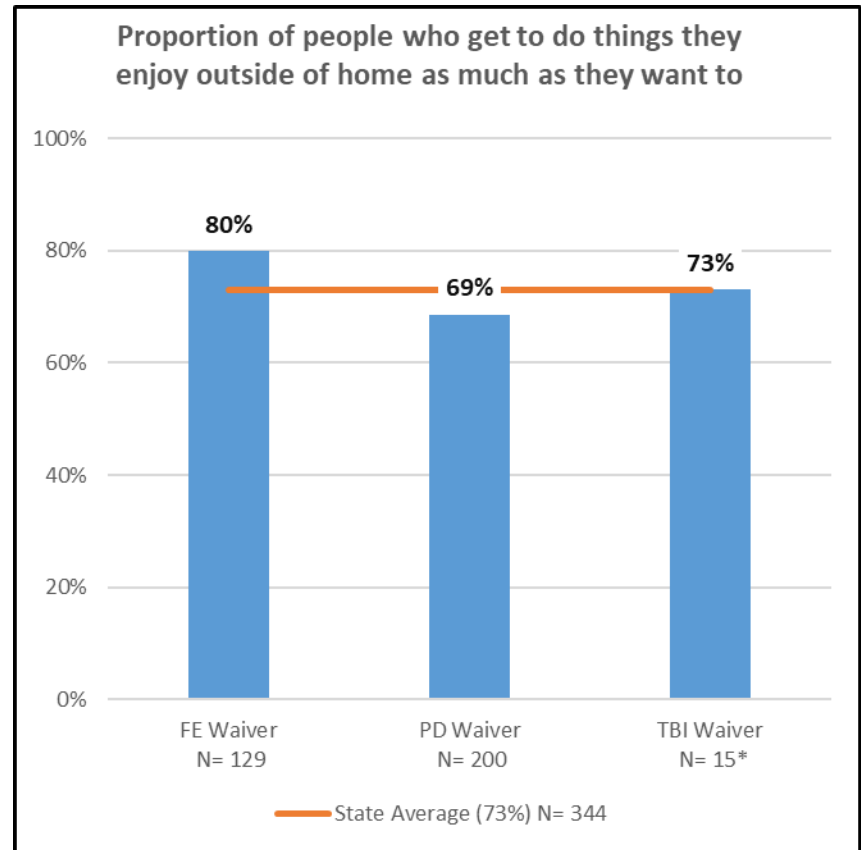
¹⁰ Data for one item are presented in Appendix B only.

Graph 1. Proportion of people who are as active in their community as they would like to be



* Very small number of responses

Graph 2. Proportion of people who get to do the things they enjoy outside of their home as much as they want to



* Very small number of responses

Choice and Decision Making

People are involved in making decisions about their everyday lives and with whom they spend their time.

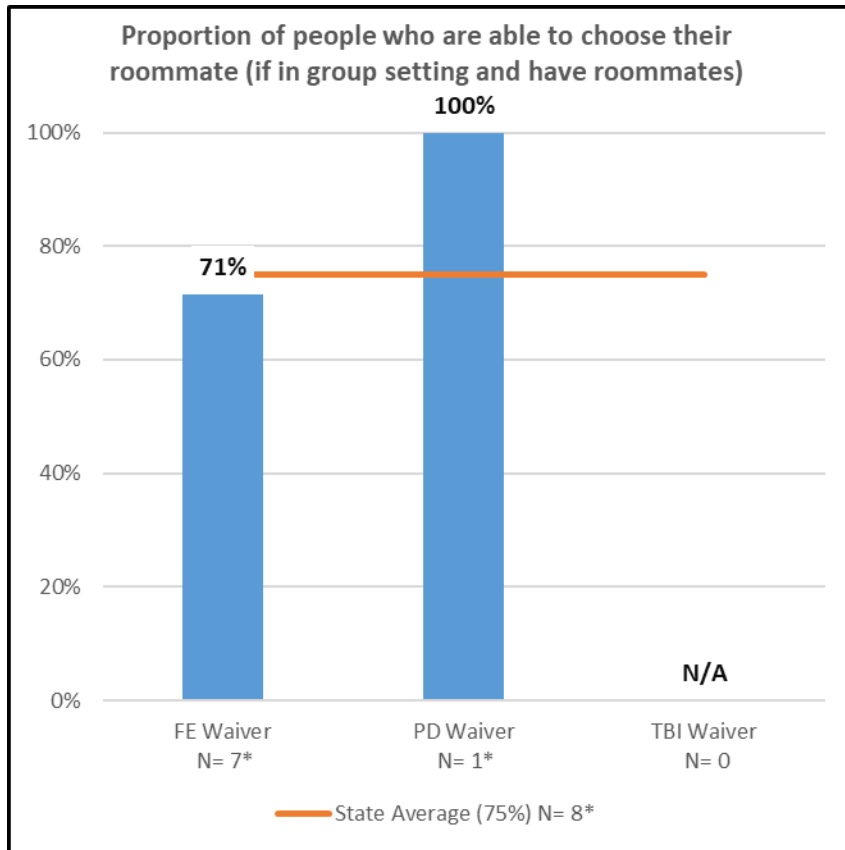
There is one Choice and Decision-Making indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who are involved in making decisions about their everyday lives.

There are four survey items that correspond to the Choice and Decision-Making domain.

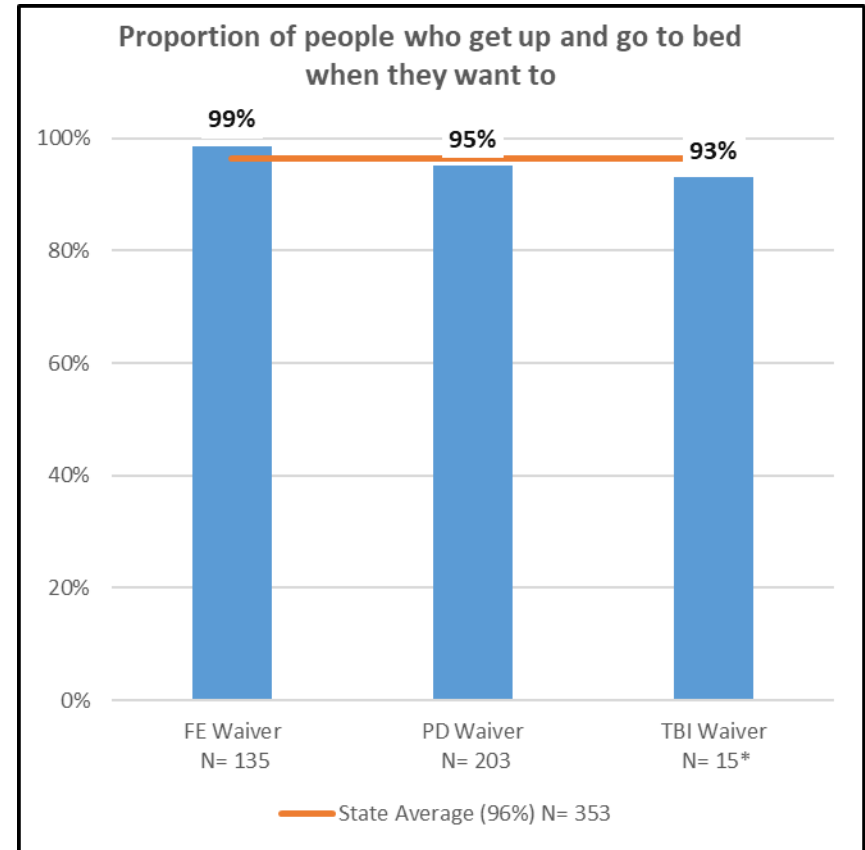
Un-collapsed data are shown in Appendix B.

Graph 3. Proportion of people who are able to choose their roommate (if in group setting¹¹ and have roommates)



* Very small number of responses

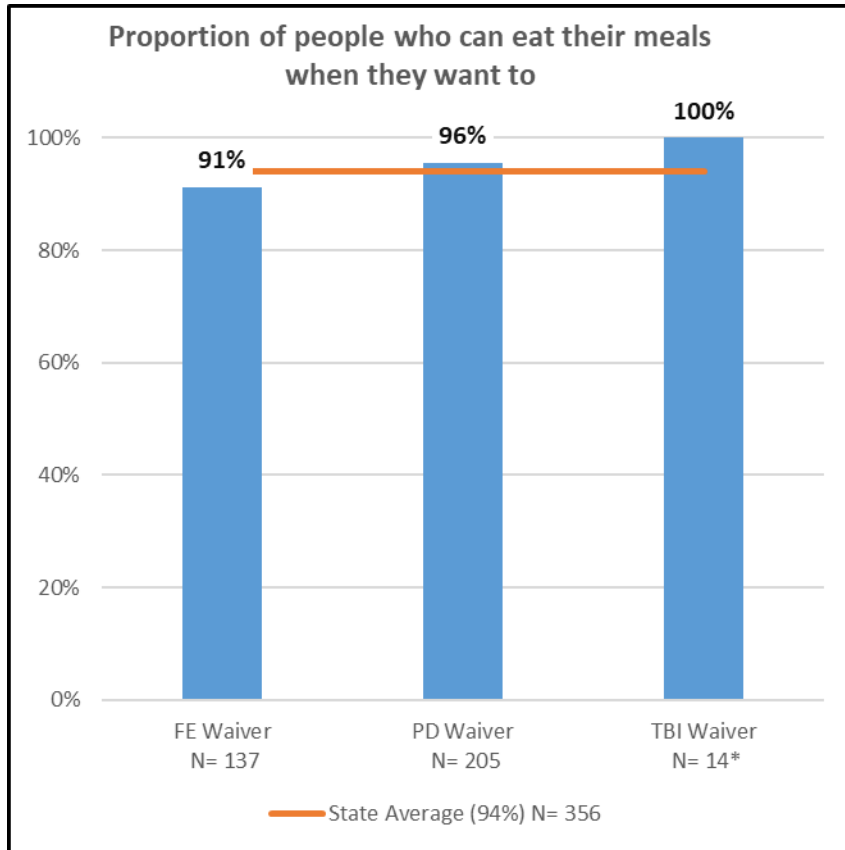
Graph 4. Proportion of people who get up and go to bed when they want to



* Very small number of responses

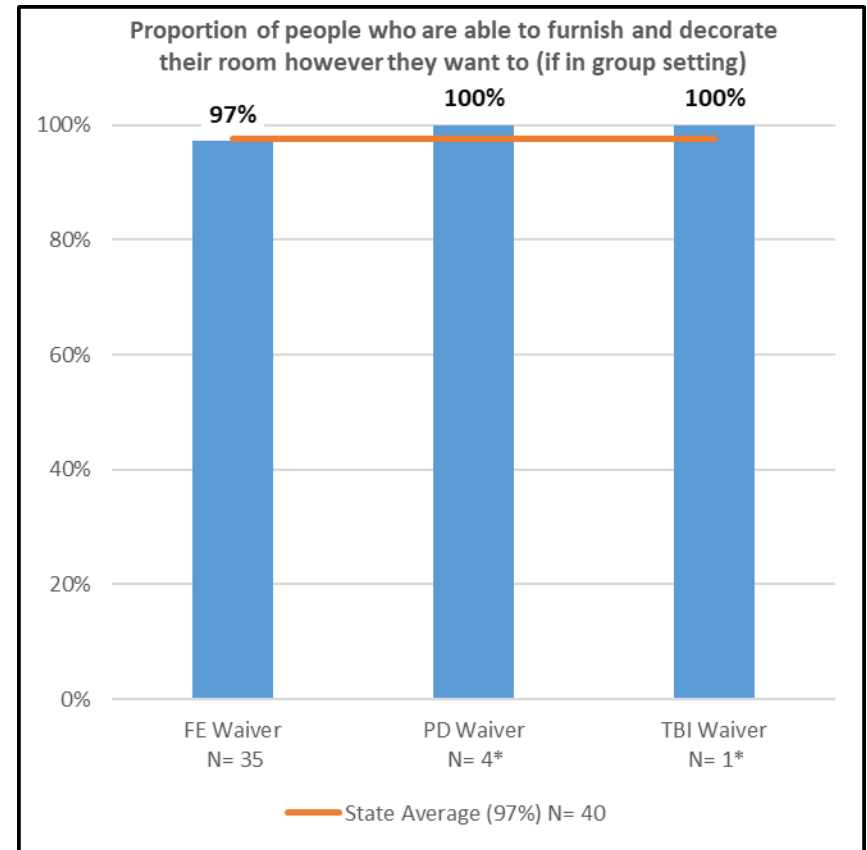
¹¹ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Graph 5. Proportion of people who can eat their meals when they want to



* Very small number of responses

Graph 6. Proportion of people who are able to furnish and decorate their room however they want to (if in group setting)¹²¹³



* Very small number of responses

¹² Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

¹³ Analysis changed in 2018-2019 – “in all ways” is now combined with “in most ways”

Relationships

People have friends and relationships and do not feel lonely.

There is one Relationship indicator measured by the NCI-AD Adult Consumer Survey:

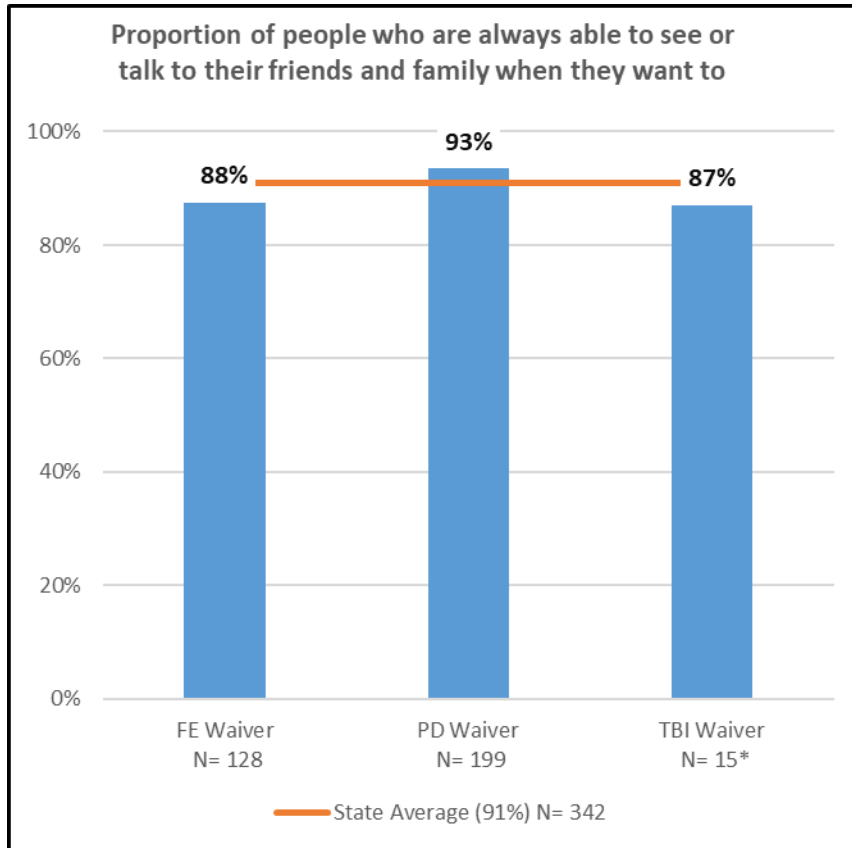
1. Proportion of people who are able to see or talk to their friends and families when they want to.

There are two¹⁴ survey items that correspond to the Relationship domain.

Un-collapsed data are shown in Appendix B.

¹⁴ Data for one item are presented in Appendix B only.

Graph 7. Proportion of people who are always able to see or talk to friends and family when they want to (if there are friends and family who do not live with person)



* Very small number of responses

Satisfaction

People are satisfied with their everyday lives – where they live, who works with them, and what they do during the day.

There are three Satisfaction indicators measured by the NCI-AD Adult Consumer Survey:

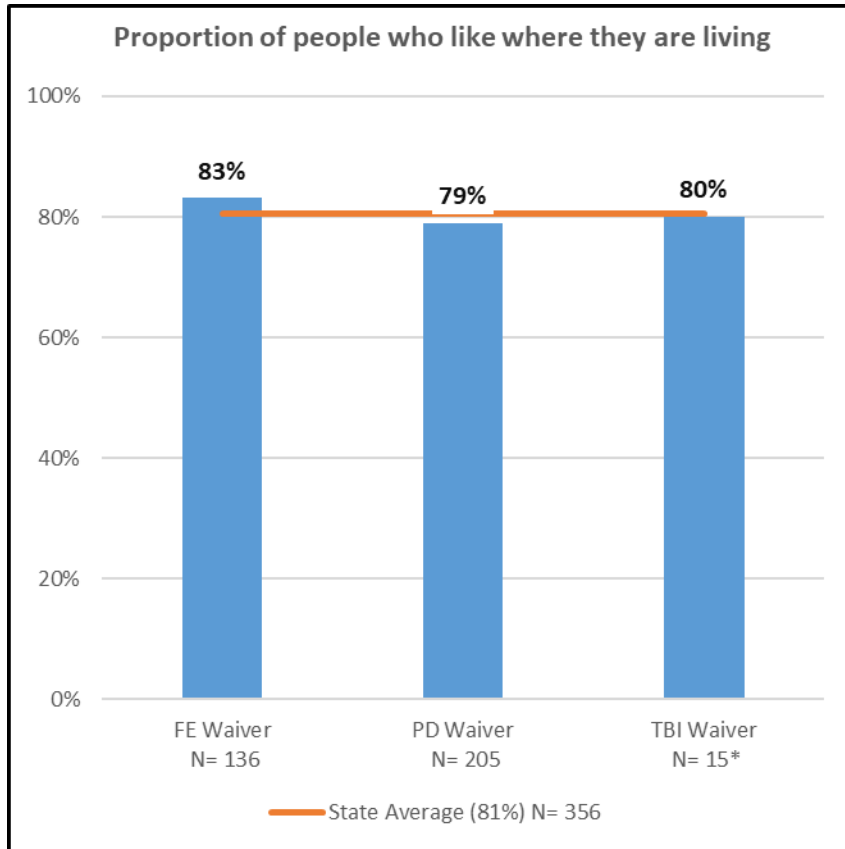
1. Proportion of people who are satisfied with where they live.
2. Proportion of people who are satisfied with what they do during the day.
3. Proportion of people who are satisfied with their paid support staff.

There are seven¹⁵ survey items that correspond to the Satisfaction domain.

Un-collapsed data are shown in Appendix B.

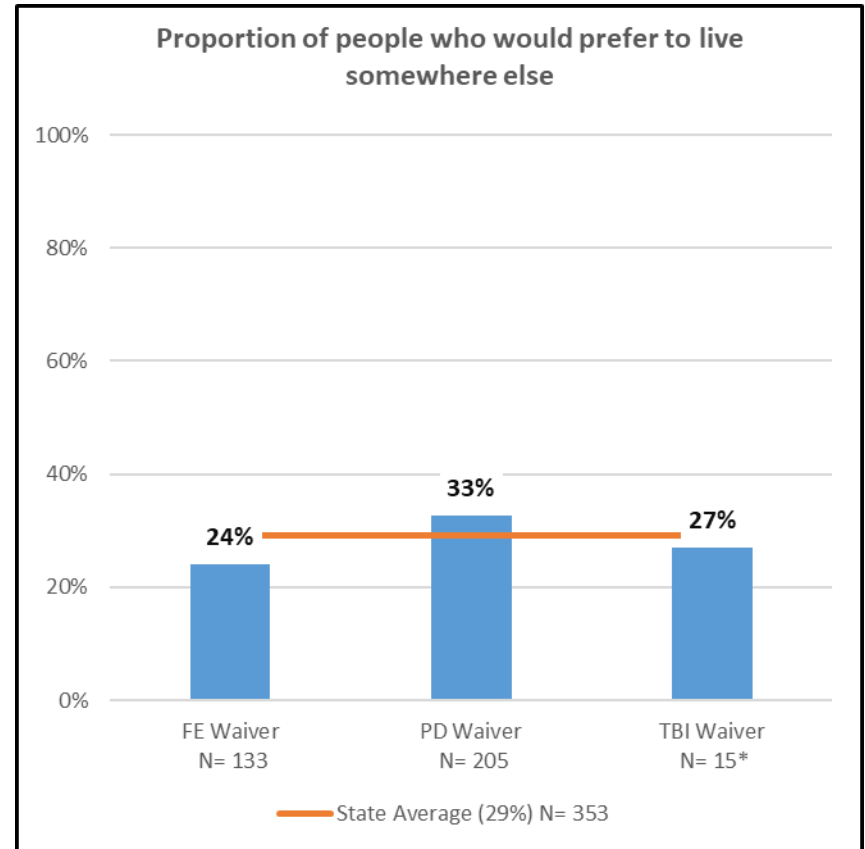
¹⁵ Data for two items are presented in Appendix B only.

Graph 8. Proportion of people who like where they are living



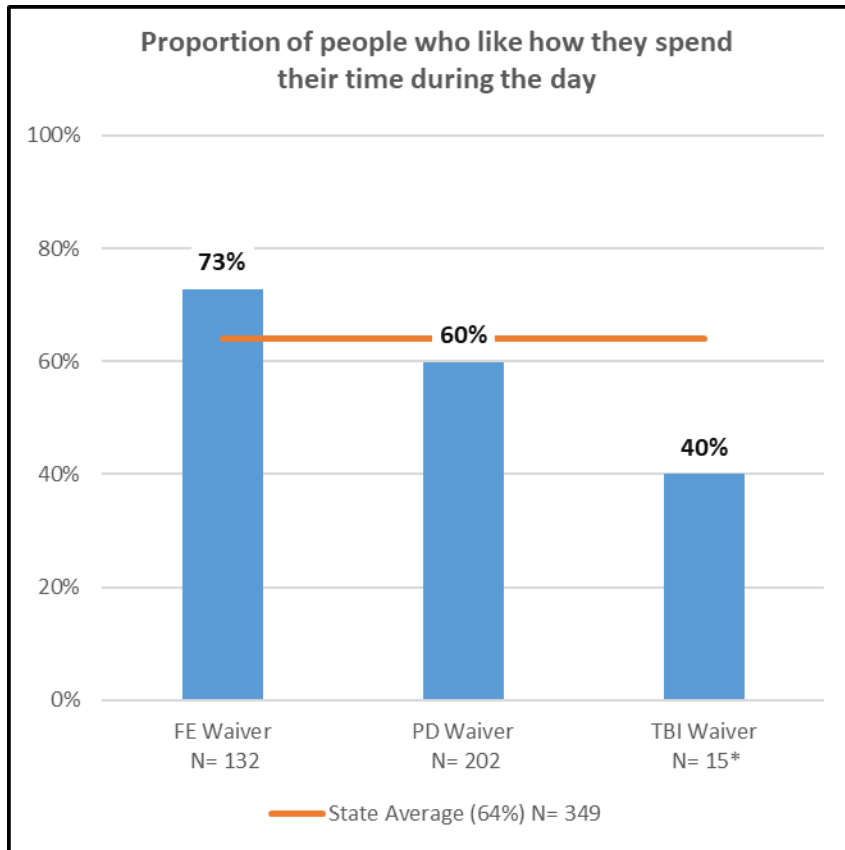
* Very small number of responses

Graph 9. Proportion of people who would prefer to live somewhere else



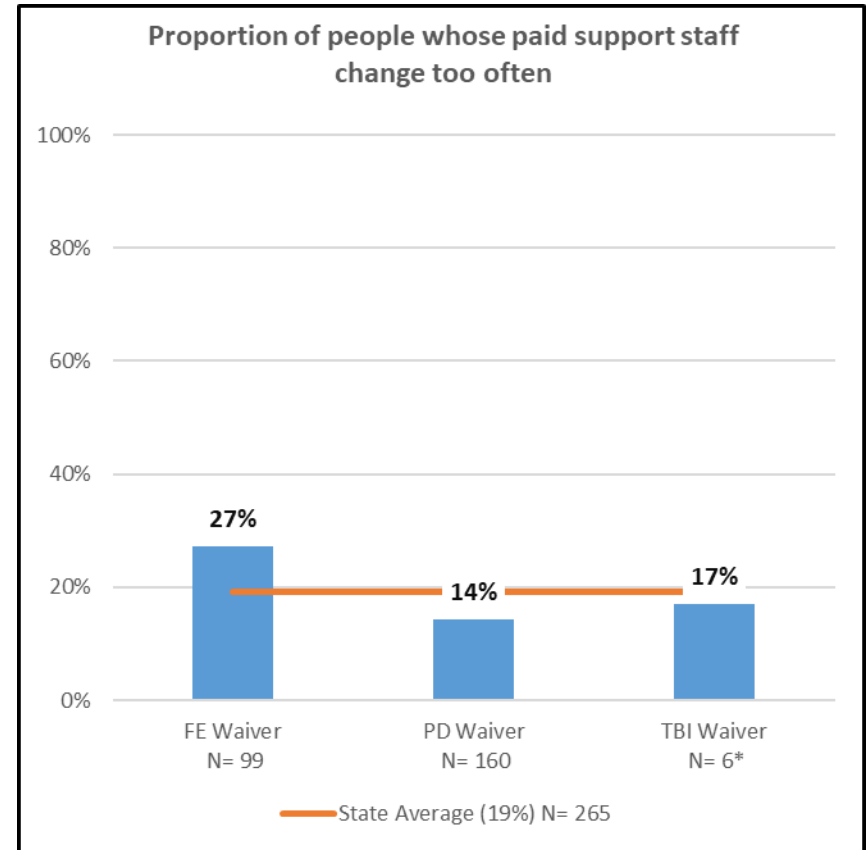
* Very small number of responses

Graph 10. Proportion of people who like how they spend their time during the day



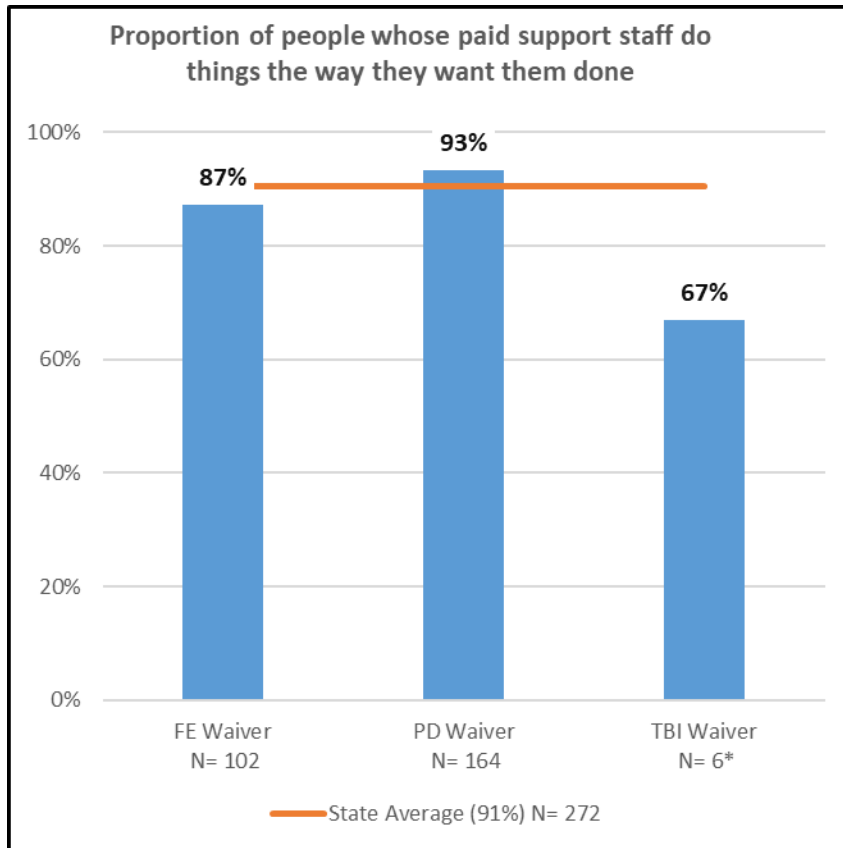
* Very small number of responses

Graph 11. Proportion of people whose paid support staff change too often



* Very small number of responses

Graph 12. Proportion of people whose paid support staff do things the way they want them done



* Very small number of responses

Service Coordination

Service coordinators are accessible, responsive, and support the person's participation in service planning and the person receives needed services.

There are eleven Service Coordination indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who know whom to contact with a complaint or question about their services.
2. Proportion of people whose case manager talks to them about their unmet needs.
3. Proportion of people who can get in contact with their case manager when they need to.
4. Proportion of people who receive the services that they need.
5. Proportion of people finding out about services from service agencies.
6. Proportion of people who want help planning for their future service needs.
7. Proportion of people who have an emergency plan in place.
8. Proportion of people whose support staff come when they are supposed to.
9. Proportion of people who use a relative as their support person.
10. Proportion of people who have a backup plan if their paid support staff don't show up.
11. Proportion of people who have access to information about services in their preferred language¹⁶.

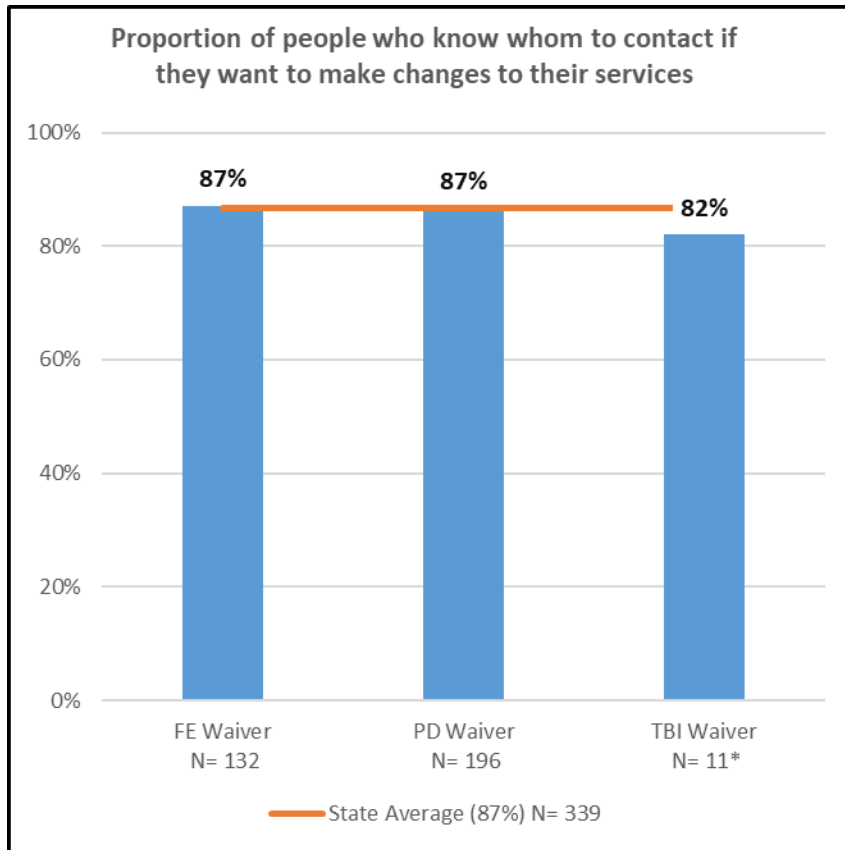
There are sixteen¹⁷ survey items that correspond to the Service Coordination domain.

Un-collapsed data are shown in Appendix B.

¹⁶ Indicator previously reported in the "Access" domain.

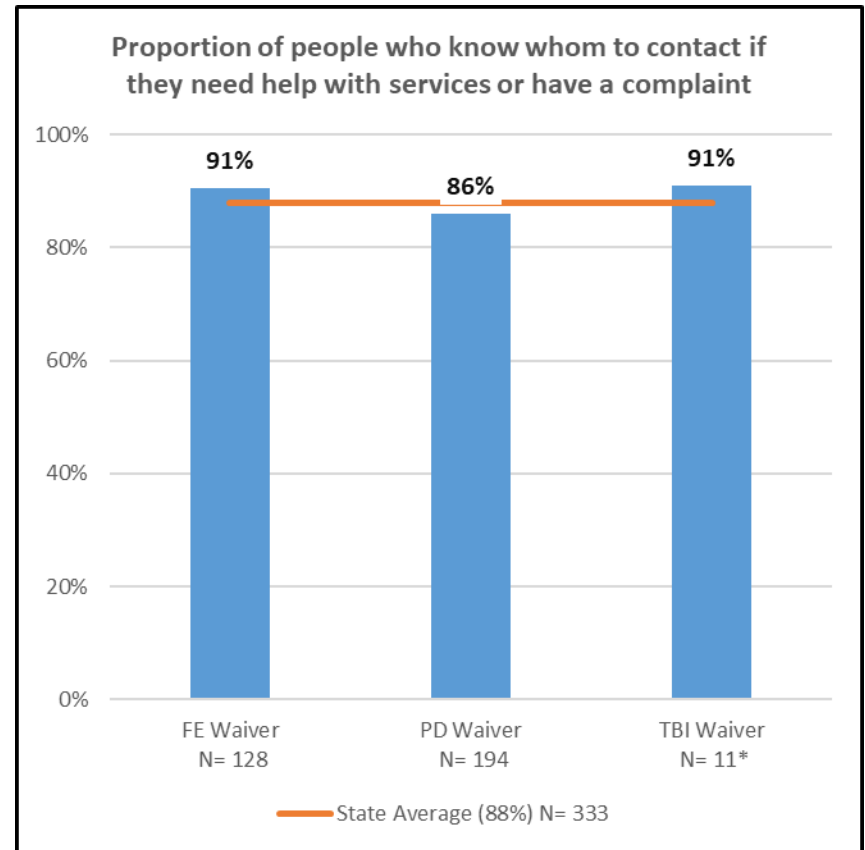
¹⁷ Data for four items are presented in Appendix B only.

Graph 13. Proportion of people who know whom to contact if they want to make changes to their services



* Very small number of responses

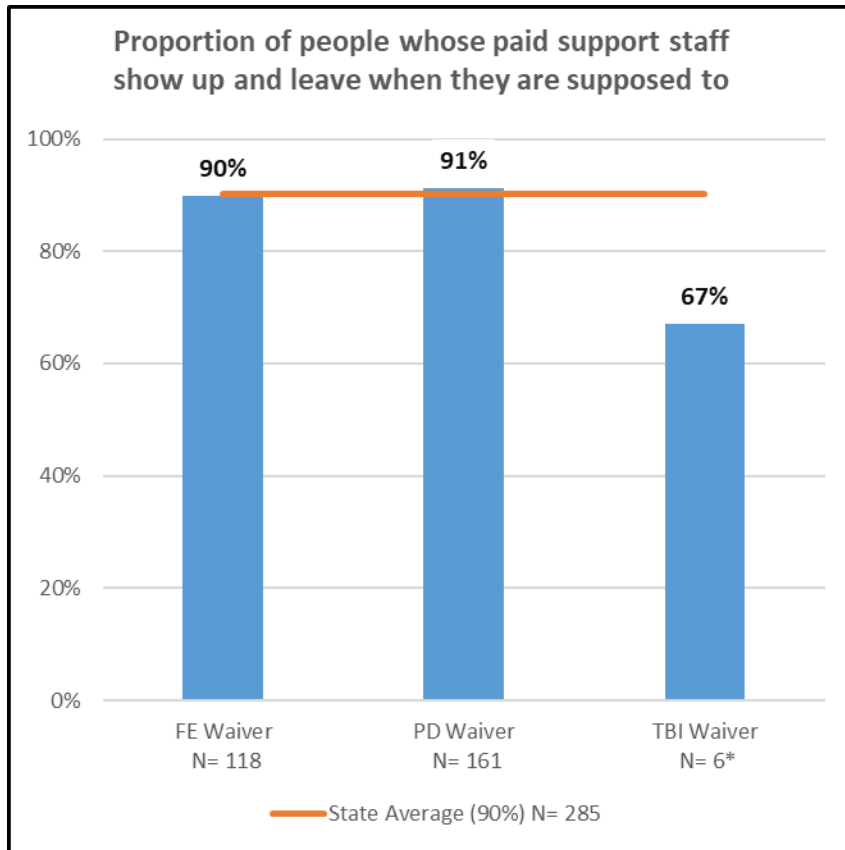
Graph 14. Proportion of people who know whom to contact if they need help with services or have a complaint¹⁸



* Very small number of responses

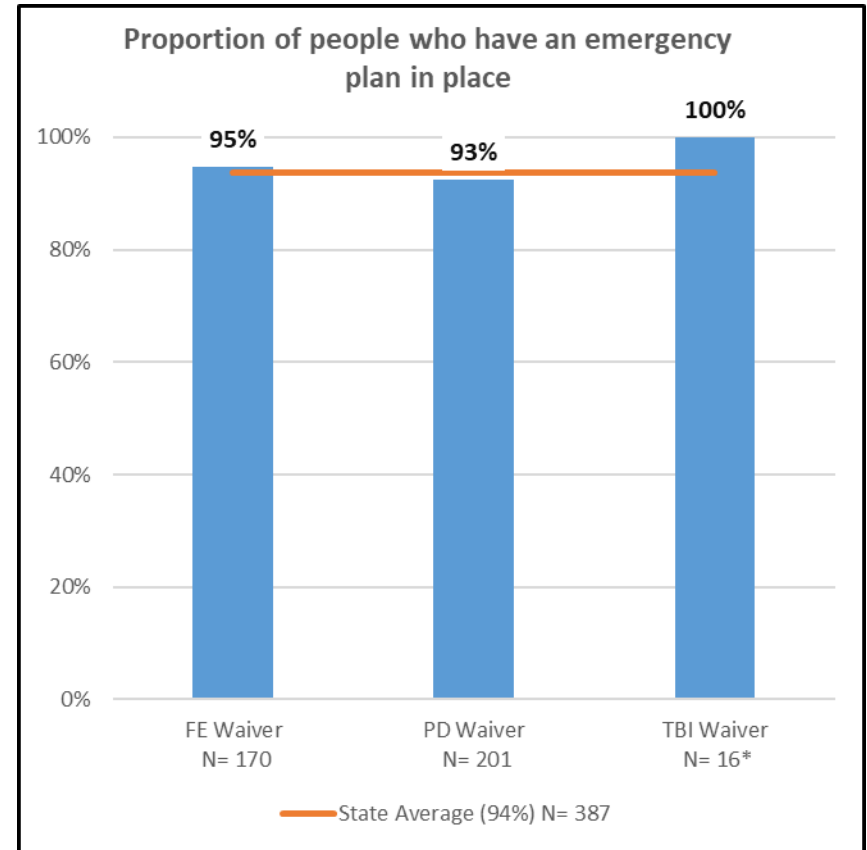
¹⁸ New item added in 2018-2019.

Graph 15. Proportion of people whose paid support staff show up and leave when they are supposed to



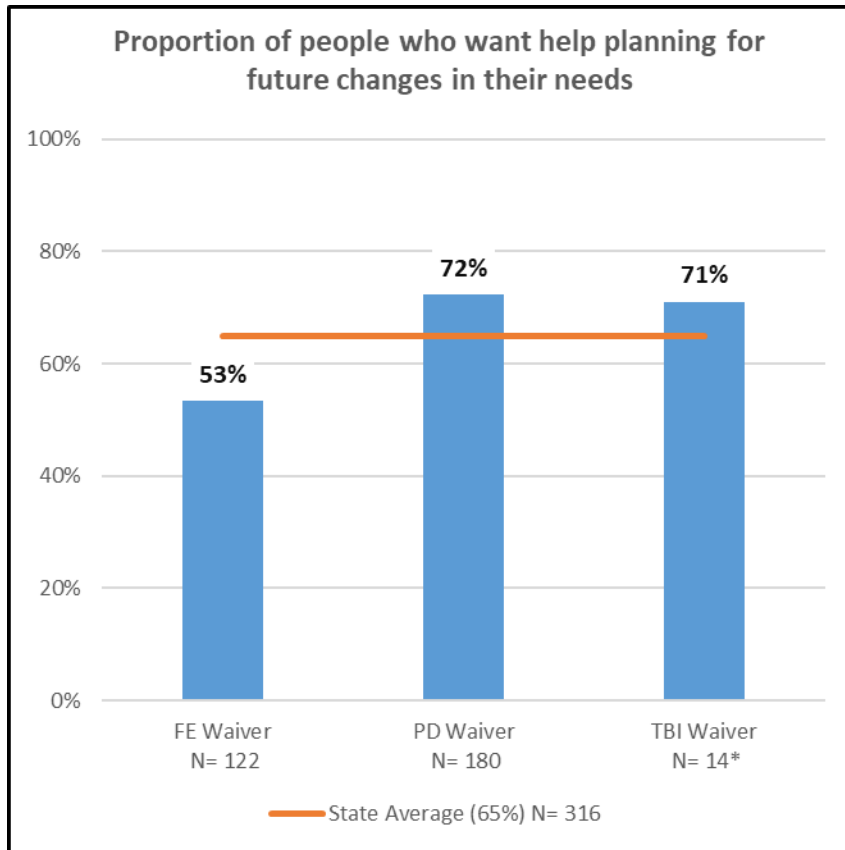
* Very small number of responses

Graph 16. Proportion of people who have an emergency plan in place



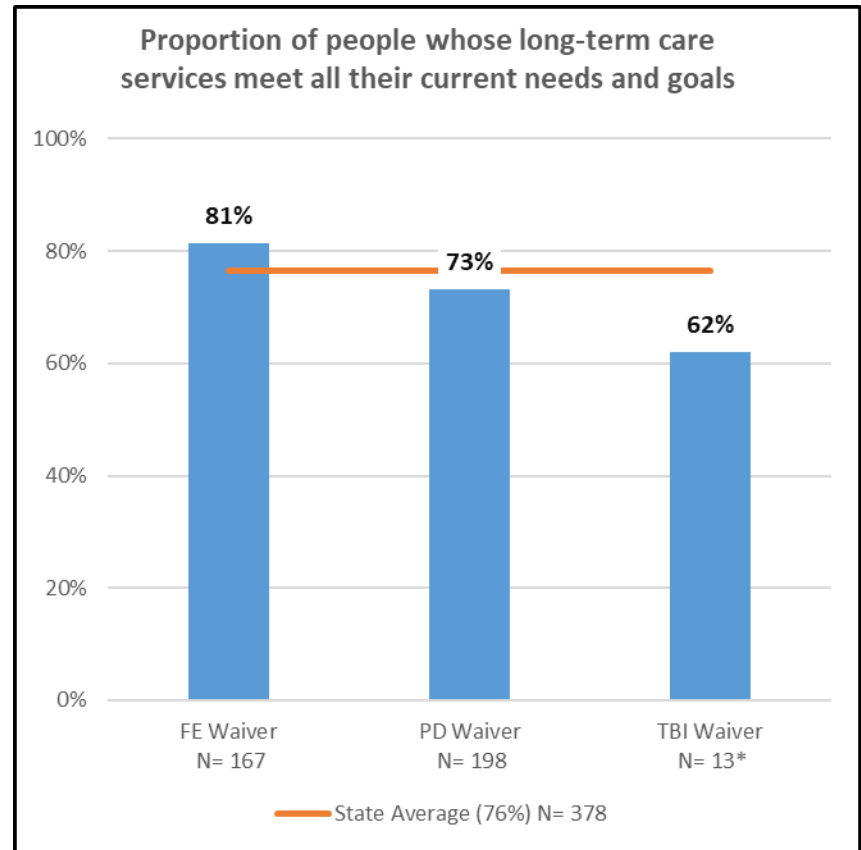
* Very small number of responses

Graph 17. Proportion of people who want help planning for future changes in their needs



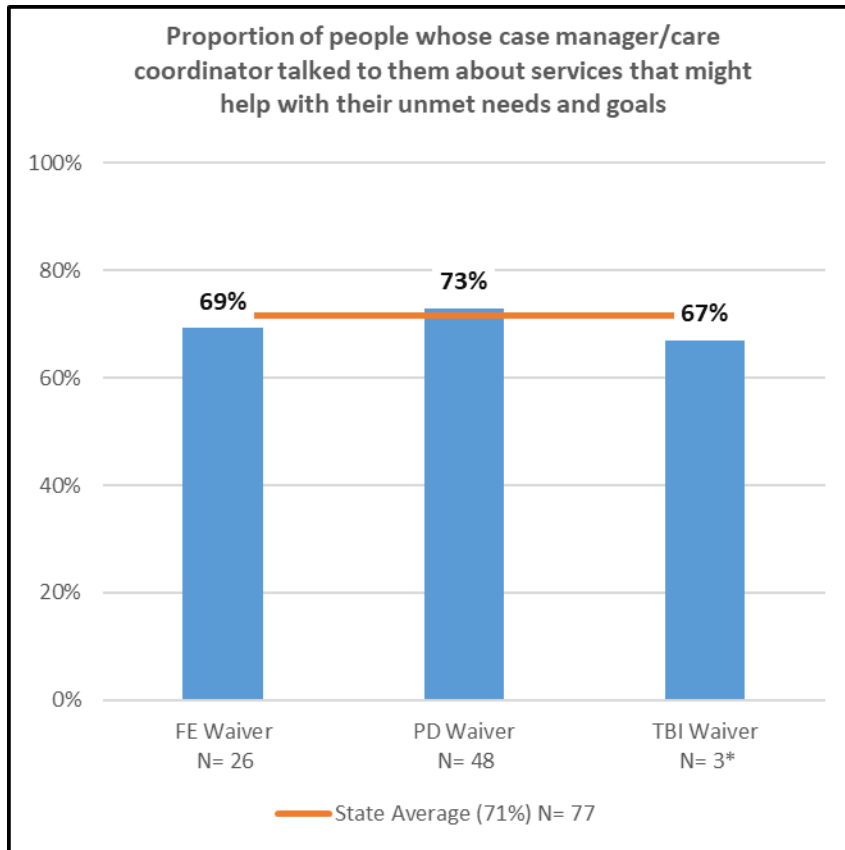
* Very small number of responses

Graph 18. Proportion of people whose long-term care services meet all their current needs and goals



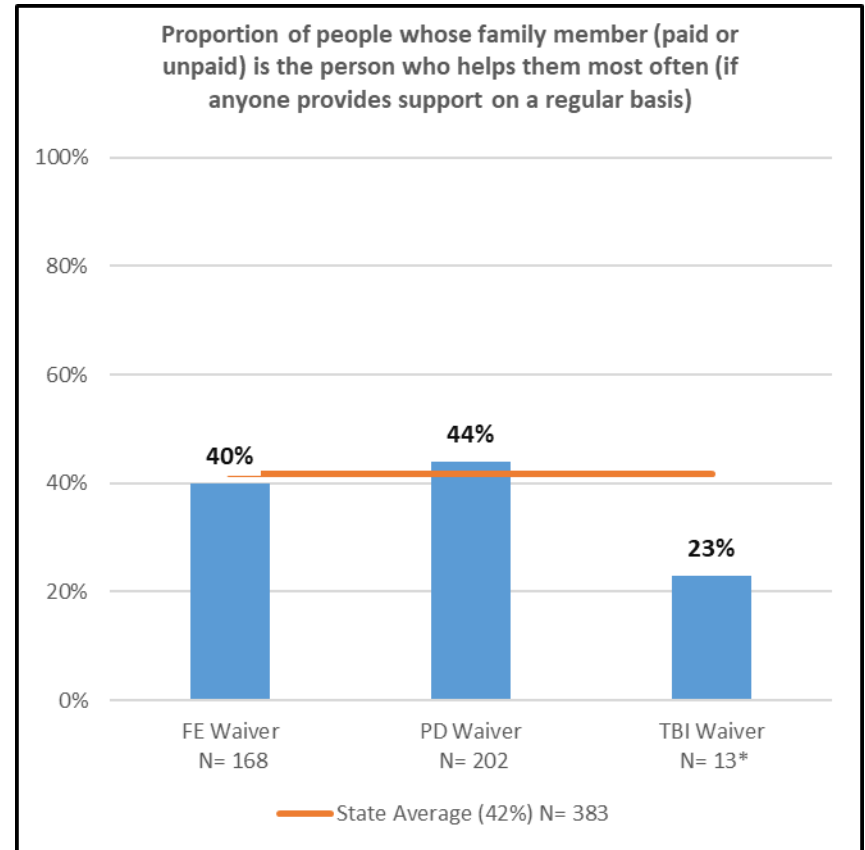
* Very small number of responses

Graph 19. Proportion of people whose case manager/care coordinator talked to them about services that might help with their unmet needs and goals (if have unmet needs and goals and know they have case manager/care coordinator)



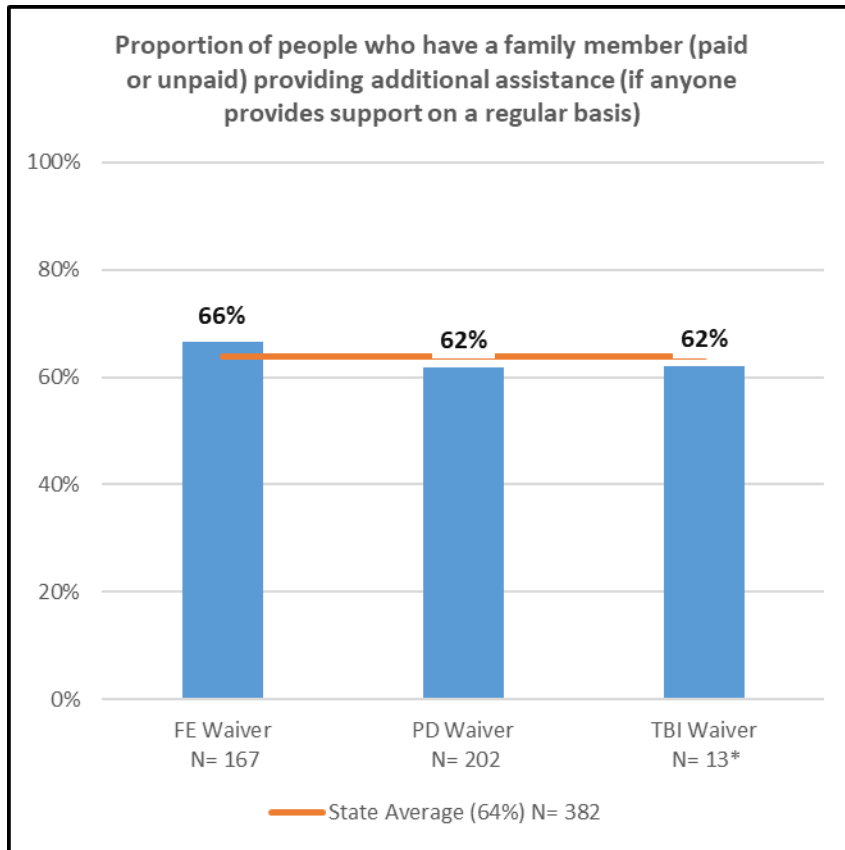
* Very small number of responses

Graph 20. Proportion of people whose family member (paid or unpaid) is the person who helps them most often (if anyone provides support on a regular basis)



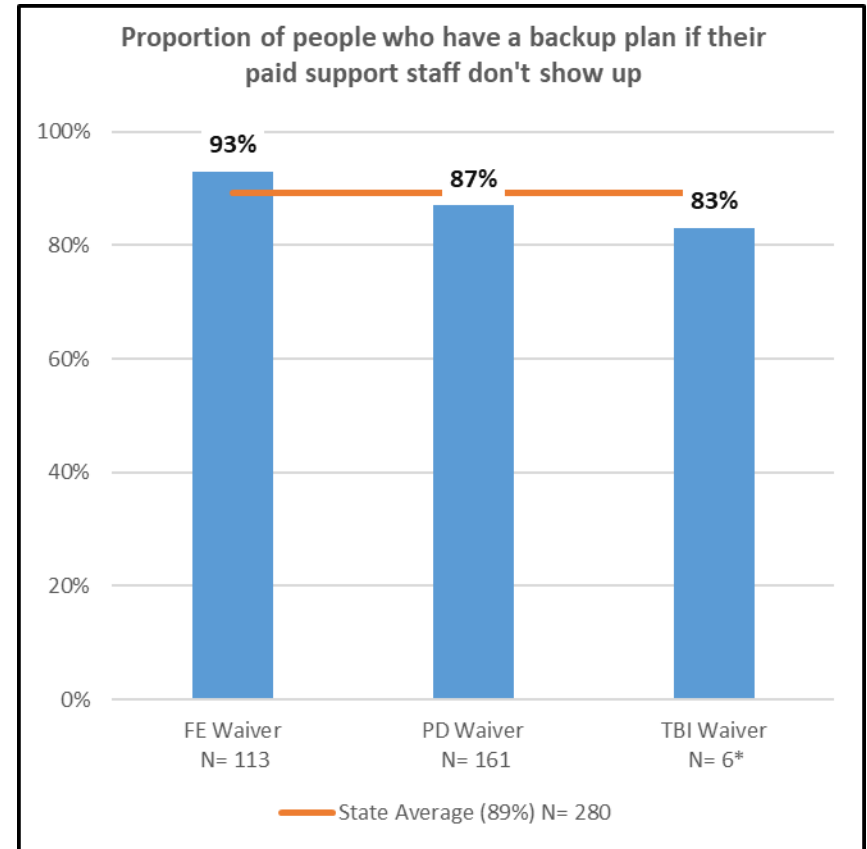
* Very small number of responses

Graph 21. Proportion of people who have a family member (paid or unpaid) providing additional assistance (if anyone provides support on a regular basis)



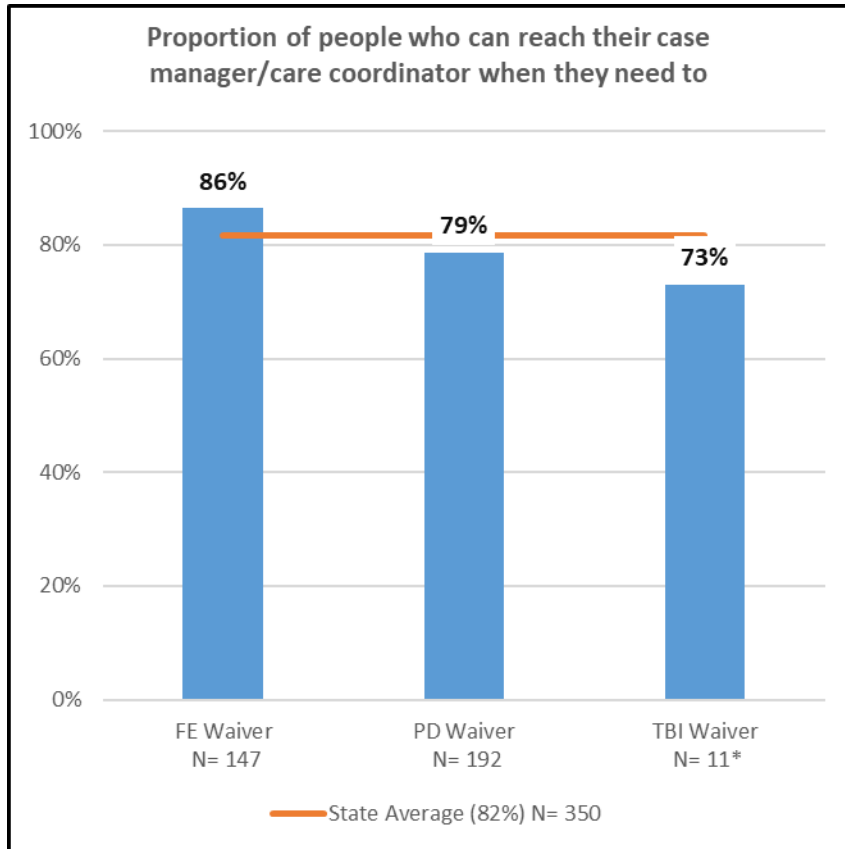
* Very small number of responses

Graph 22. Proportion of people who have a backup plan if their paid support staff do not show up



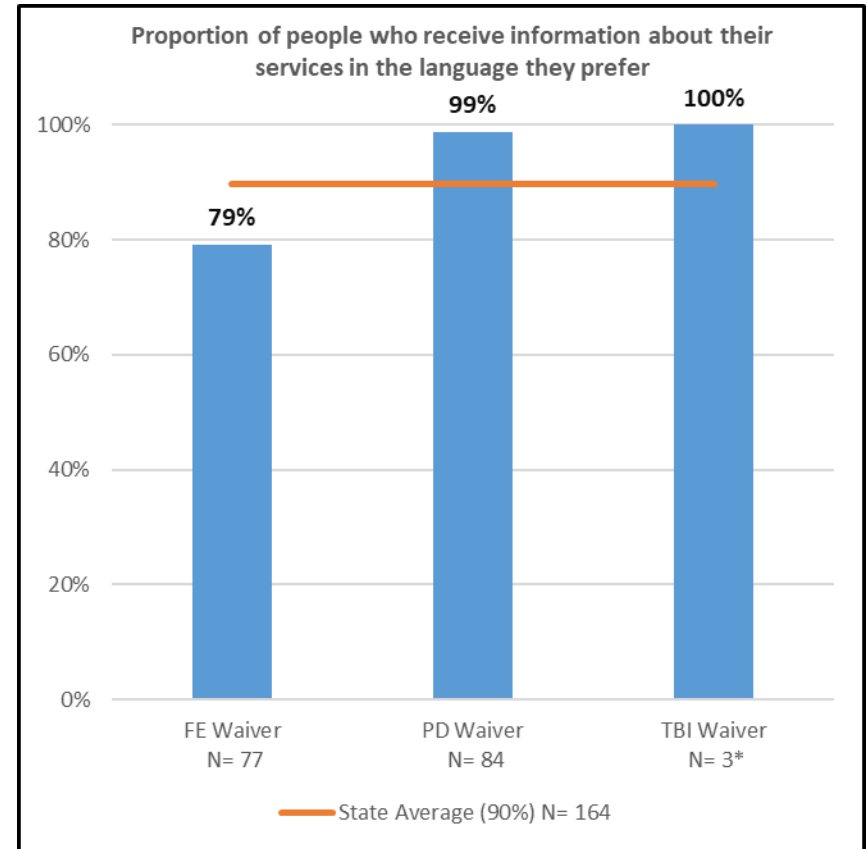
* Very small number of responses

Graph 23. Proportion of people who can reach their case manager/care coordinator when they need to (if know they have case manager/care coordinator)



* Very small number of responses

Graph 24. Proportion of people who receive information about their services in the language they prefer (if non-English) ¹⁹



* Very small number of responses

¹⁹ Item previously reported in the "Access" domain.

Care Coordination

Individuals are provided appropriate coordination of care.

There are four Care Coordination indicators measured by the NCI-AD Adult Consumer Survey:

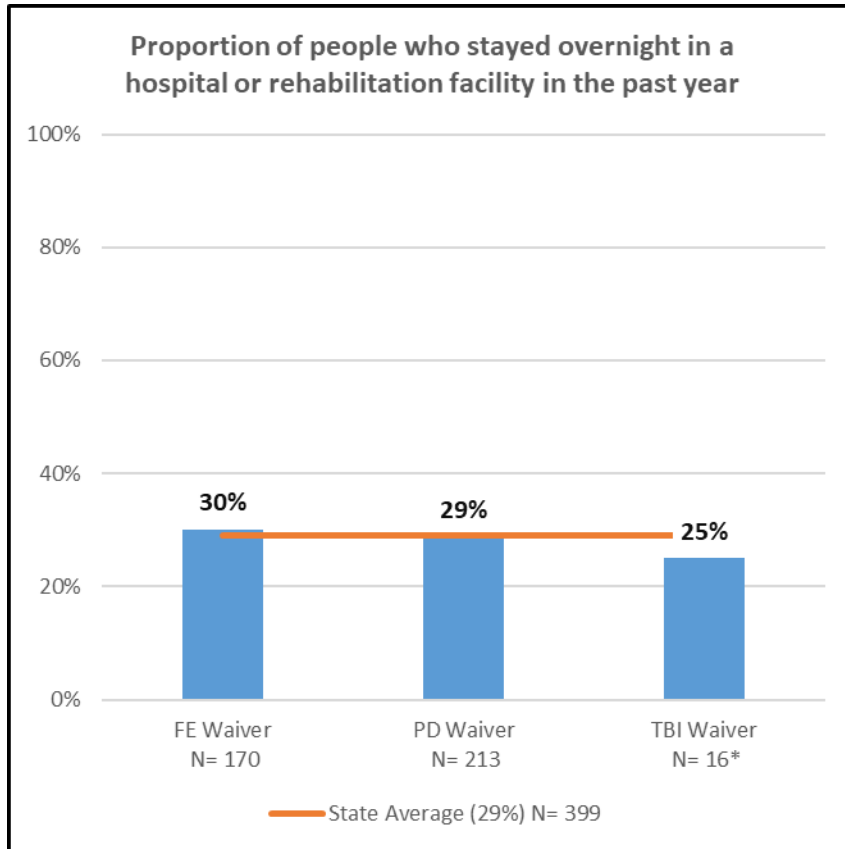
1. Proportion of people who feel comfortable going home after being discharged from a hospital or a rehab facility.
2. Proportion of people who have adequate follow-up after being discharged from a hospital or a rehab facility.
3. Proportion of people who know how to manage their chronic conditions.
4. Proportion of people who had someone work with them to reduce risk of falls²⁰.

There are six survey items that correspond to the Care Coordination domain.

Un-collapsed data are shown in Appendix B.

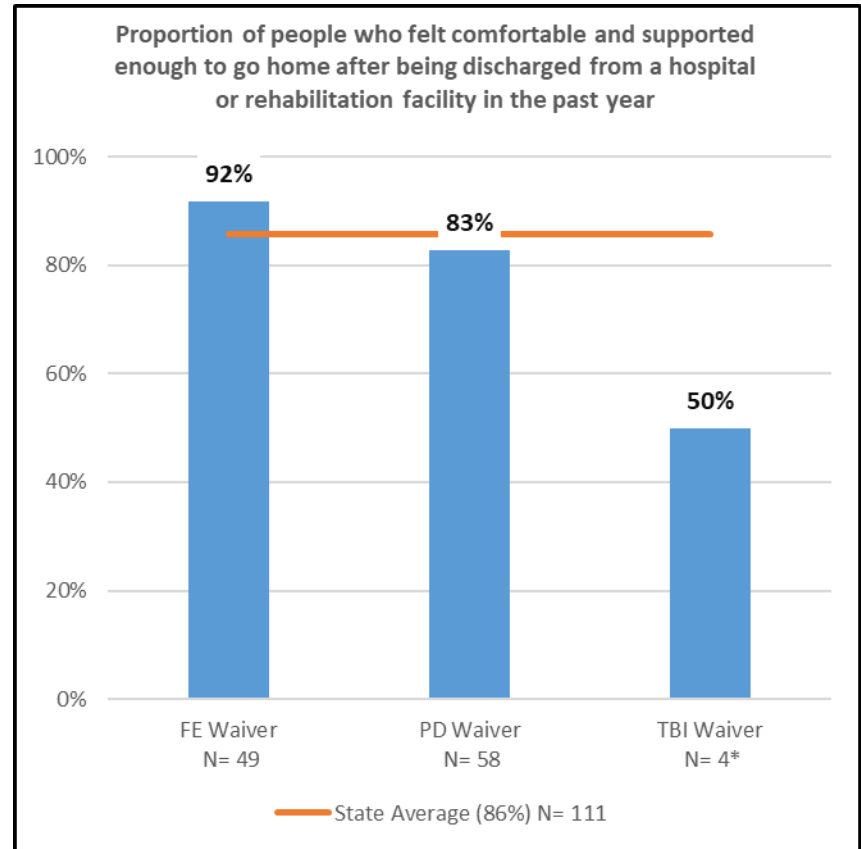
²⁰ Indicator previously reported in the “Safety” domain.

Graph 25. Proportion of people who stayed overnight in a hospital or rehabilitation facility in the past year (and were discharged to go home or back to where they live)



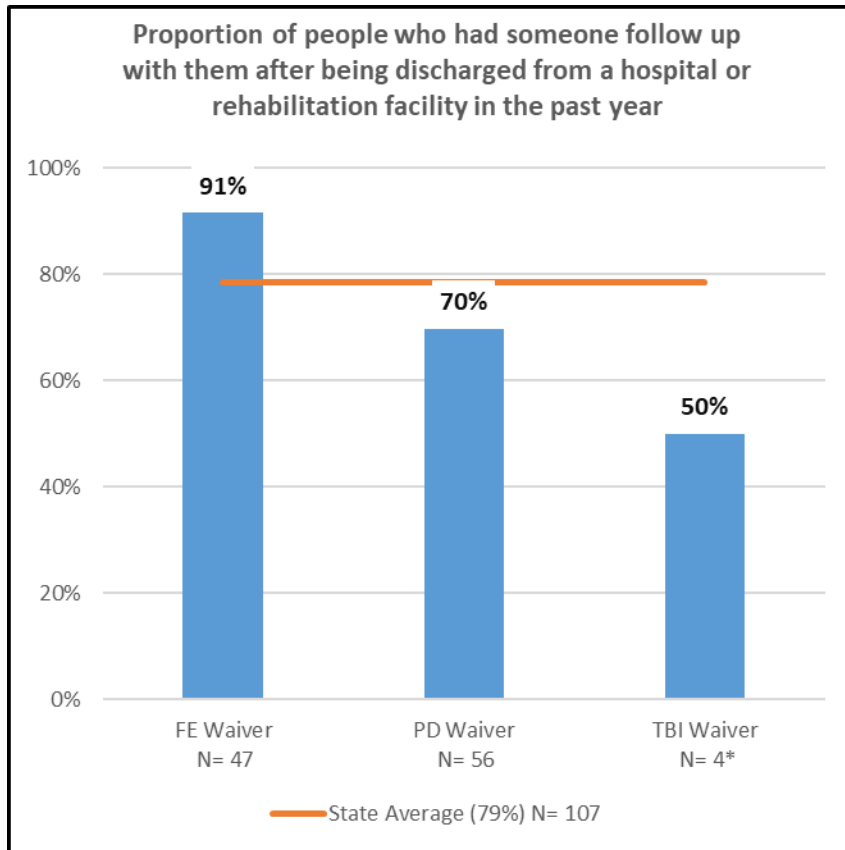
* Very small number of responses

Graph 26. Proportion of people who felt comfortable and supported enough to go home (or where they live) after being discharged from a hospital or rehabilitation facility in the past year



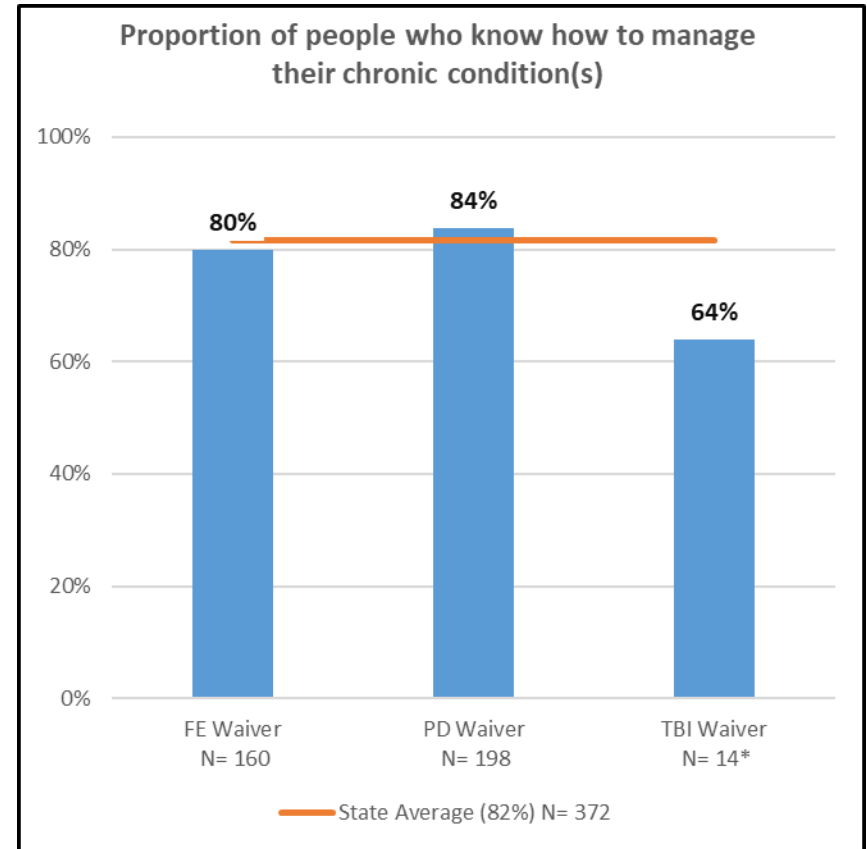
* Very small number of responses

Graph 27. Proportion of people who had someone follow up with them after being discharged from a hospital or rehabilitation facility in the past year



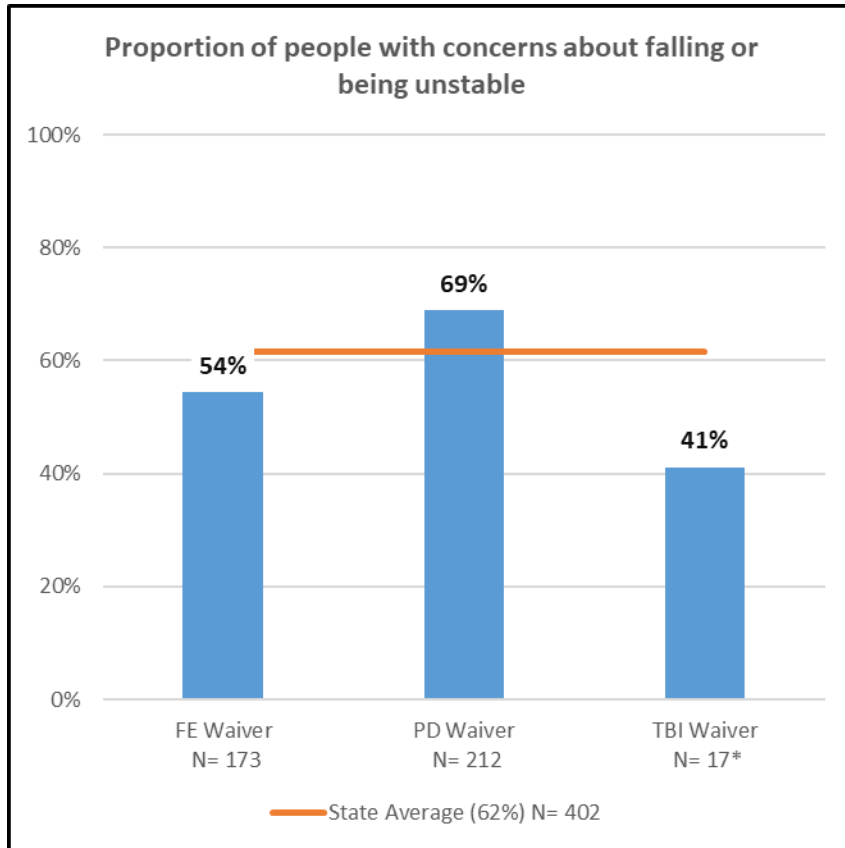
* Very small number of responses

Graph 28. Proportion of people who know how to manage their chronic condition(s)



* Very small number of responses

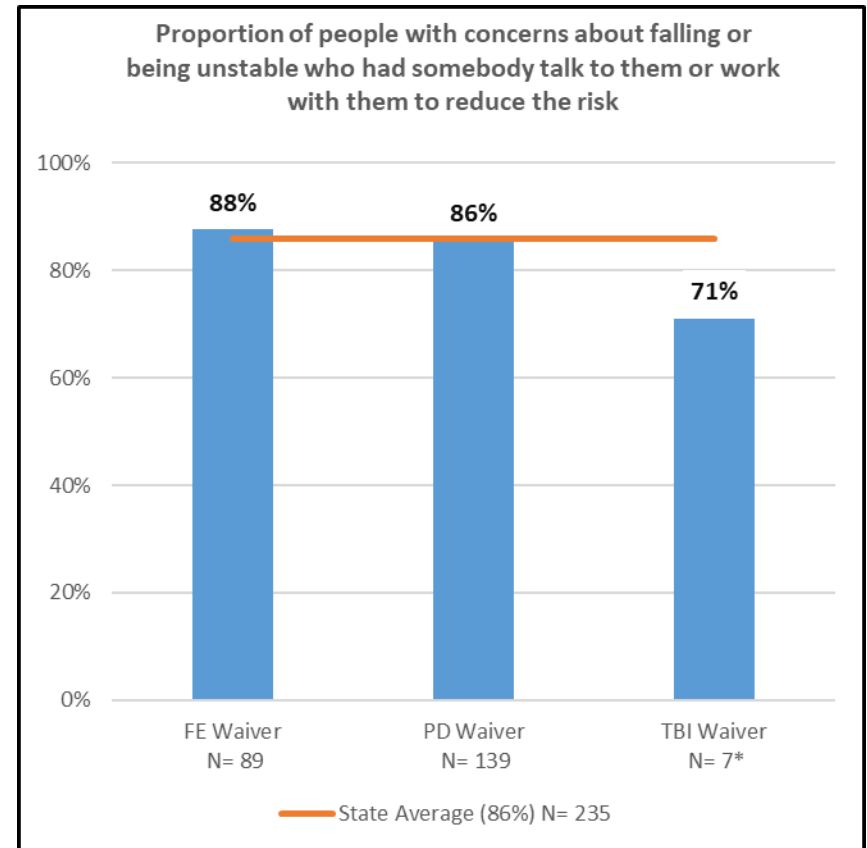
Graph 29. Proportion of people with concerns about falling or being unstable²¹



* Very small number of responses

²¹ Item previously reported in the "Safety" domain.

Graph 30. Proportion of people with concerns about falling or being unstable who had somebody talk to them or work with them to reduce the risk²²



* Very small number of responses

²² Item previously reported in the "Safety" domain.

Access to Community²³

Publicly funded services facilitate individuals' access to community.

There is one Access to Community indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who have adequate transportation²⁴.

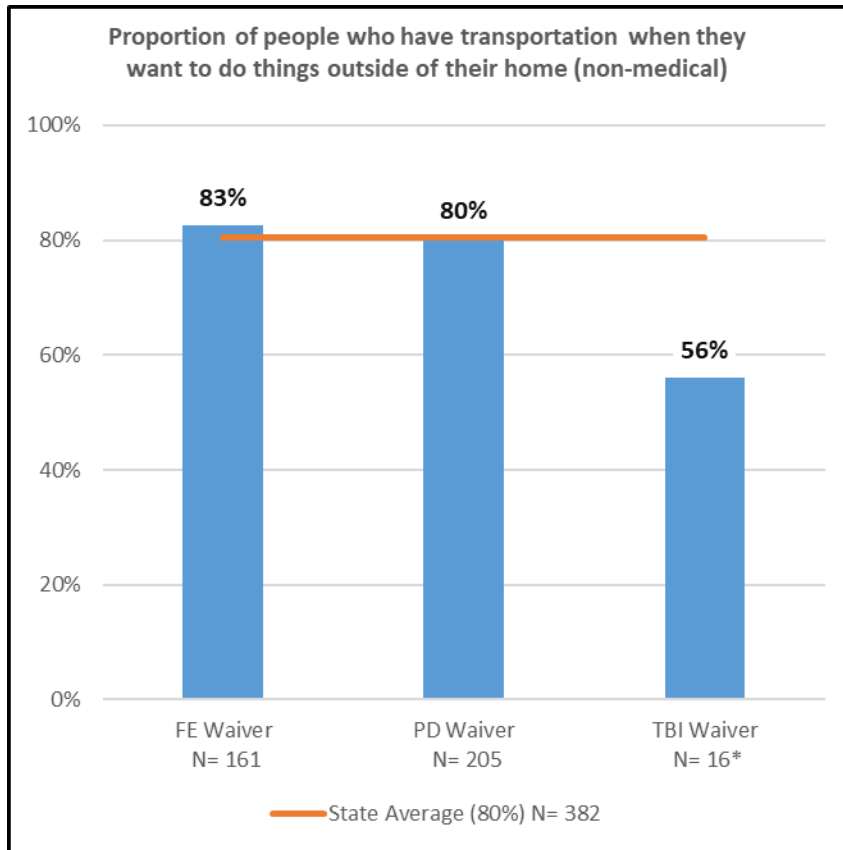
There are two survey items that correspond to the Access to Community domain.

Un-collapsed data are shown in Appendix B.

²³ New domain in 2018-2019.

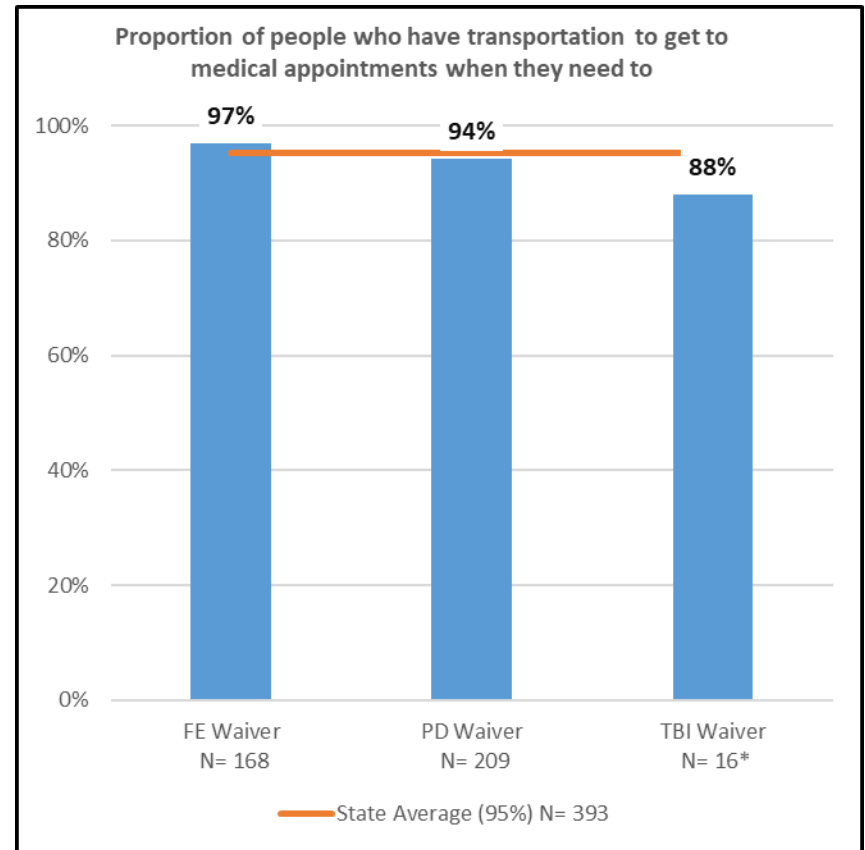
²⁴ Indicator previously reported in the "Access" domain.

Graph 31. Proportion of people who have transportation when they want to do things outside of their home (non-medical)²⁵



* Very small number of responses

Graph 32. Proportion of people who have transportation to get to medical appointments when they need to²⁶



* Very small number of responses

²⁵ Item previously reported in the "Access" domain.

²⁶ Item previously reported in the "Access" domain.

Access to Needed Equipment²⁷

People have access to needed home modifications and assistive equipment.

There is one Access to Needed Equipment indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who get needed home modifications, equipment, and assistive devices²⁸.

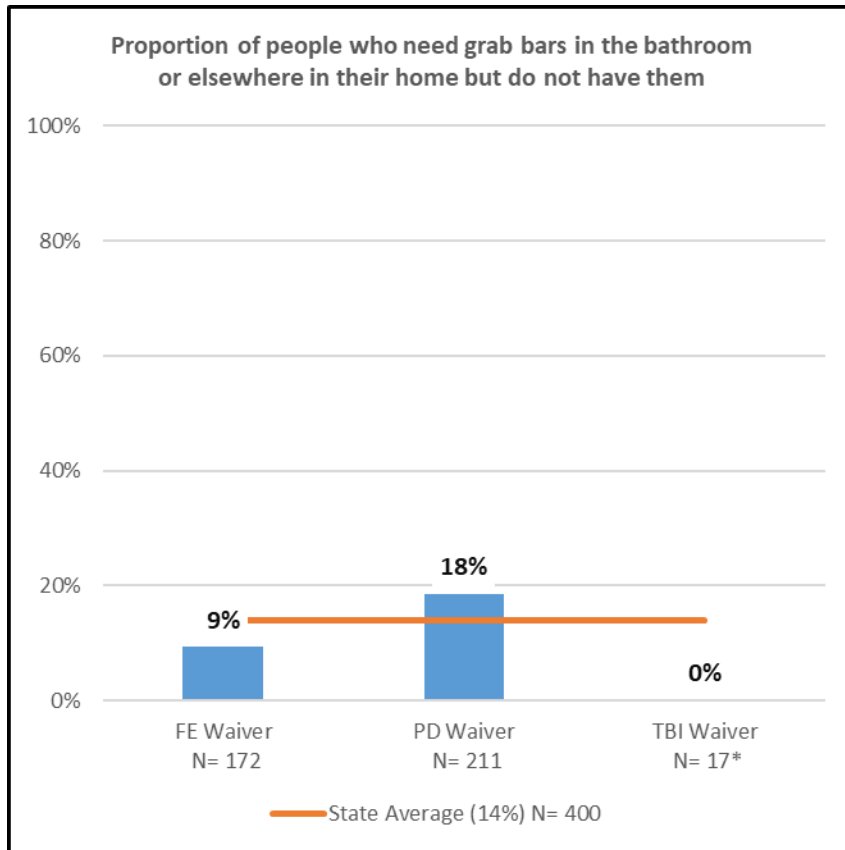
There are two survey items that correspond to the Access to Needed Equipment domain.

Un-collapsed data are shown in Appendix B.

²⁷ New domain in 2018-2019.

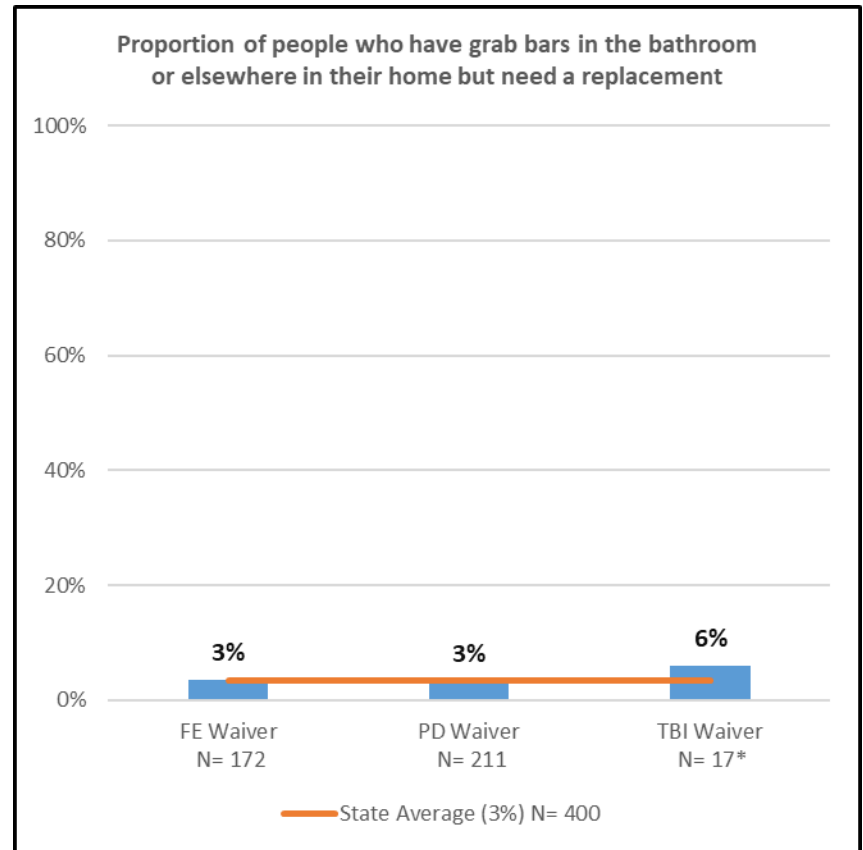
²⁸ Indicator previously reported in the “Access” domain.

Graph 33. Proportion of people who need grab bars in the bathroom or elsewhere in their home but do not have them²⁹



* Very small number of responses

Graph 34. Proportion of people who have grab bars in the bathroom or elsewhere in their home but need a replacement³⁰

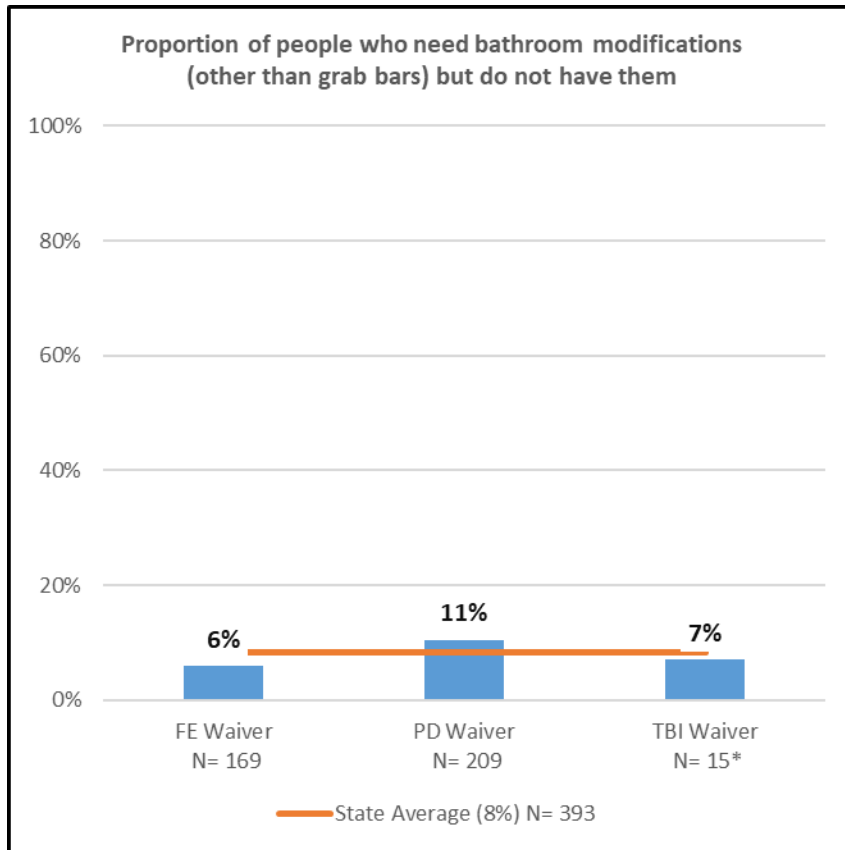


* Very small number of responses

²⁹ Item previously reported in the "Access" domain.

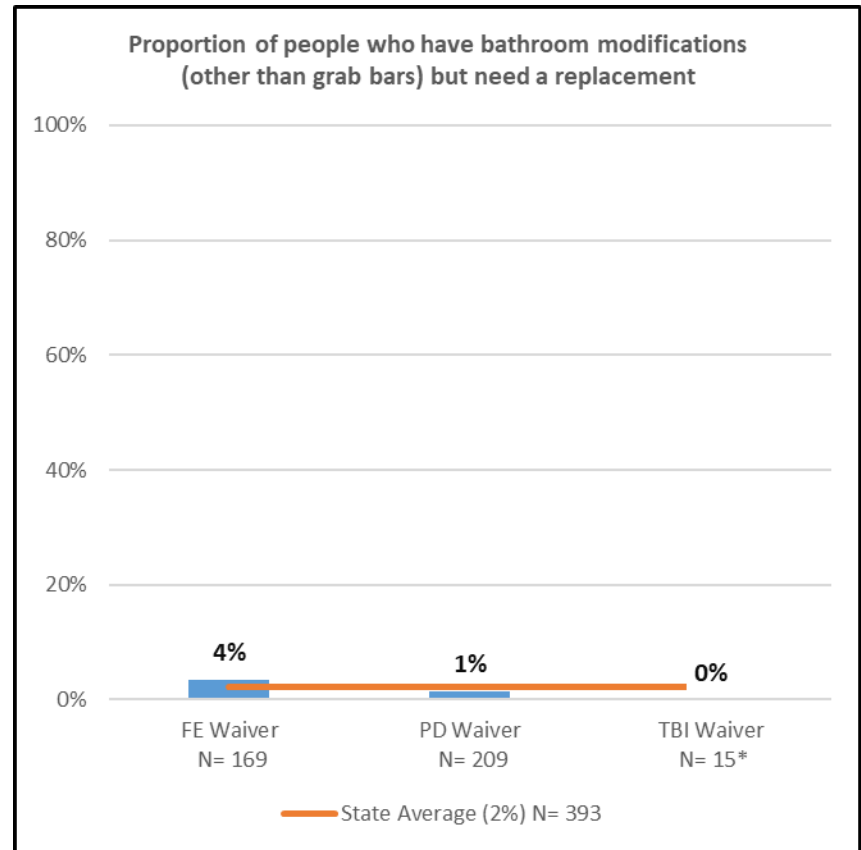
³⁰ Item previously reported in the "Access" domain.

Graph 35. Proportion of people who need bathroom modifications (other than grab bars) but do not have them³¹



* Very small number of responses

Graph 36. Proportion of people who have bathroom modifications (other than grab bars) but need a replacement³²

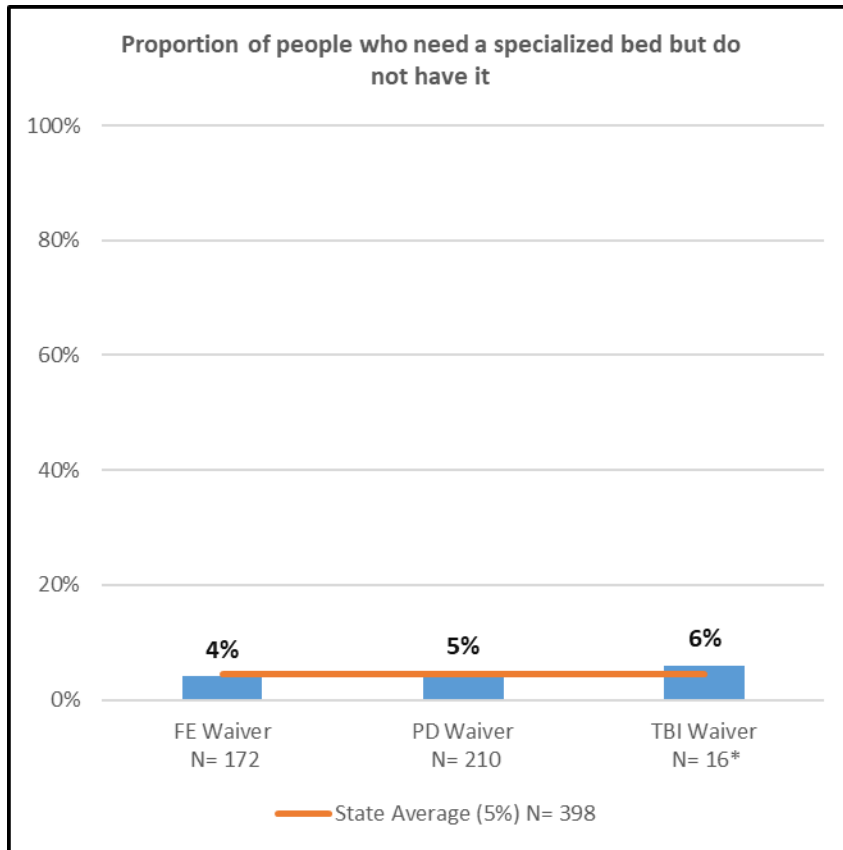


* Very small number of responses

³¹ Item previously reported in the "Access" domain.

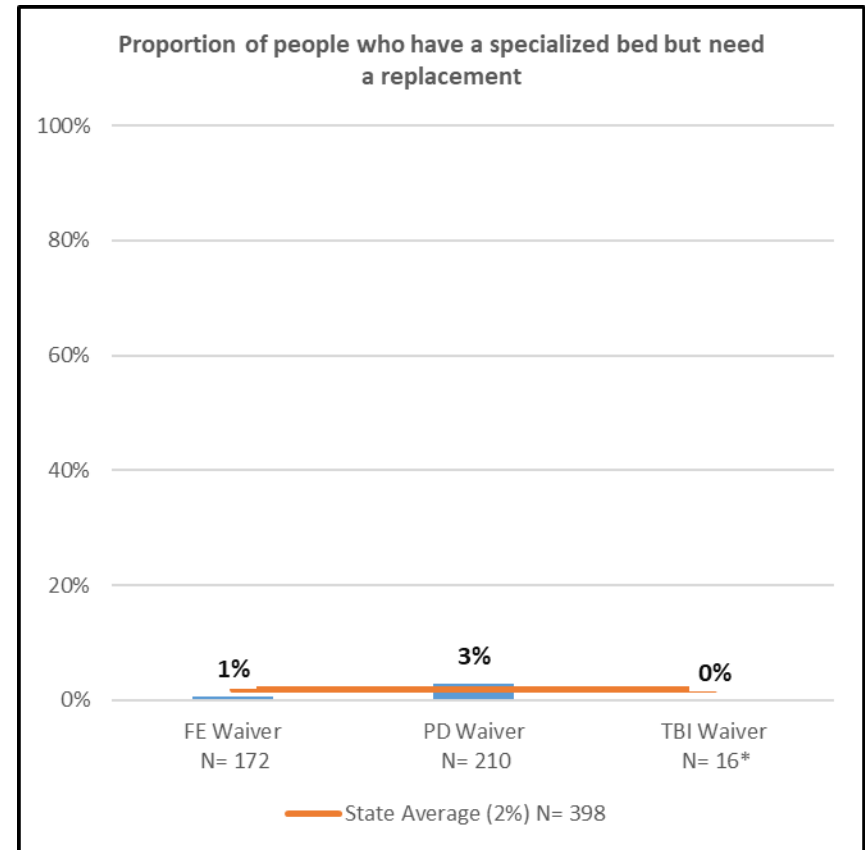
³² Item previously reported in the "Access" domain.

Graph 37. Proportion of people who need a specialized bed but do not have it³³



* Very small number of responses

Graph 38. Proportion of people who have a specialized bed but need a replacement³⁴

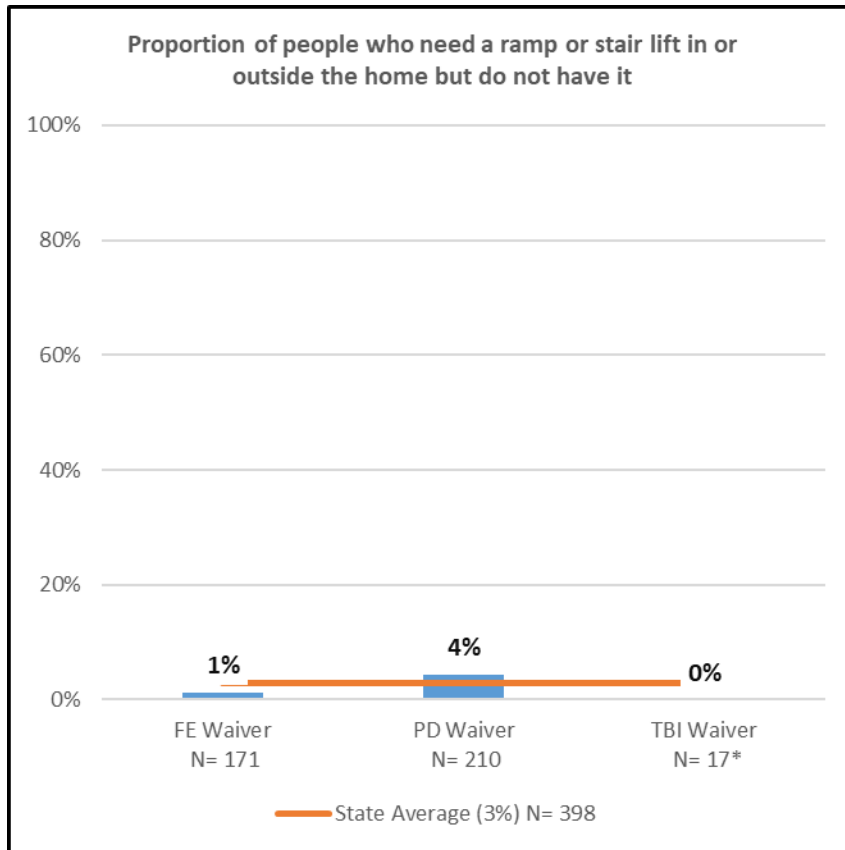


* Very small number of responses

³³ Item previously reported in the "Access" domain.

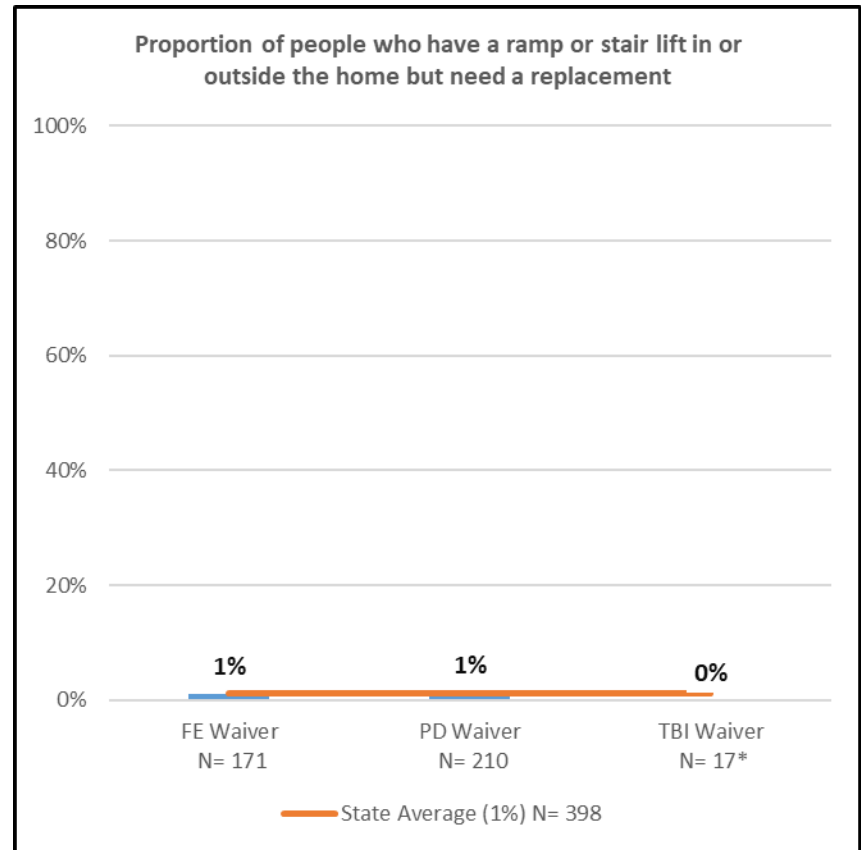
³⁴ Item previously reported in the "Access" domain.

Graph 39. Proportion of people who need a ramp or stair lift in or outside the home but do not have it³⁵



* Very small number of responses

Graph 40. Proportion of people who have a ramp or stair lift in or outside the home but need a replacement³⁶

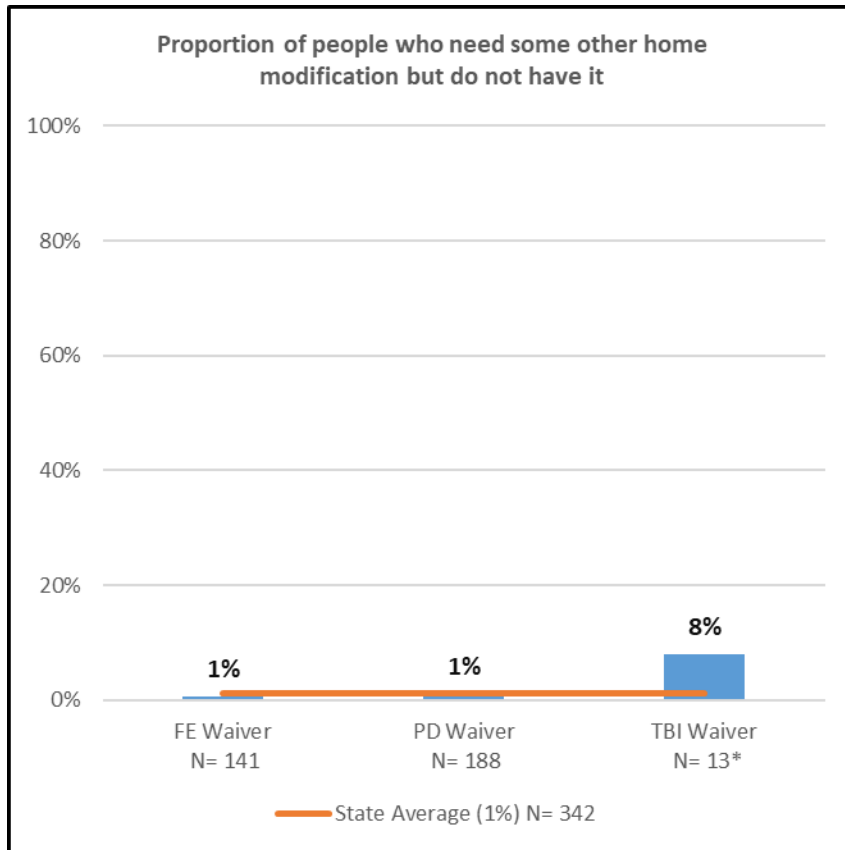


* Very small number of responses

³⁵ Item previously reported in the "Access" domain.

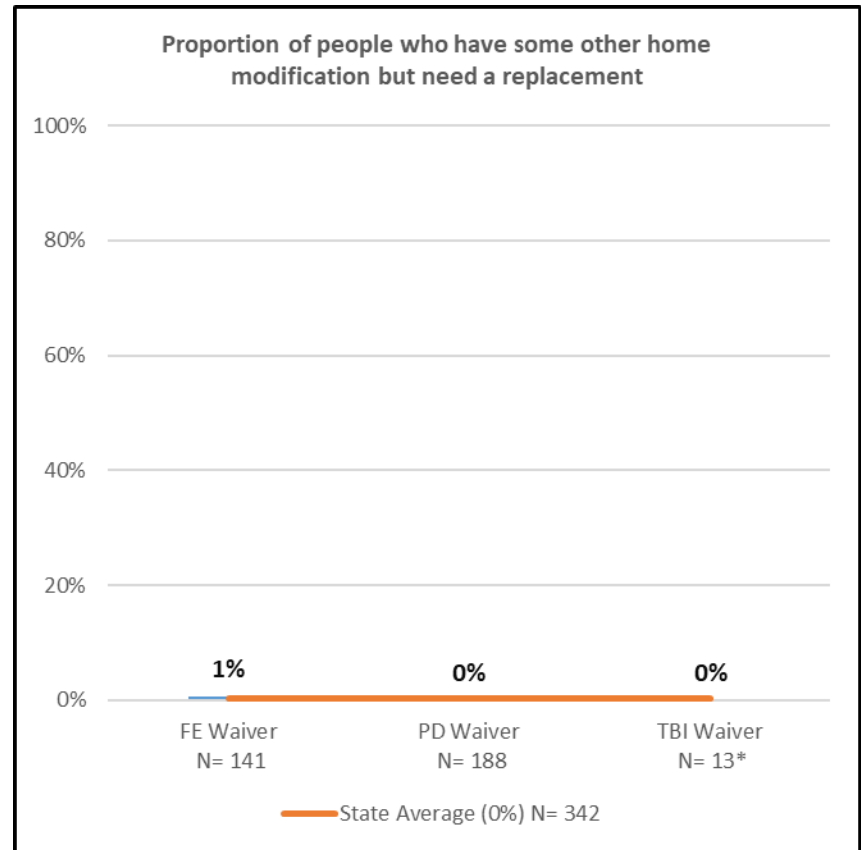
³⁶ Item previously reported in the "Access" domain.

Graph 41. Proportion of people who need some other home modification but do not have it³⁷



* Very small number of responses

Graph 42. Proportion of people who have some other home modification but need a replacement³⁸

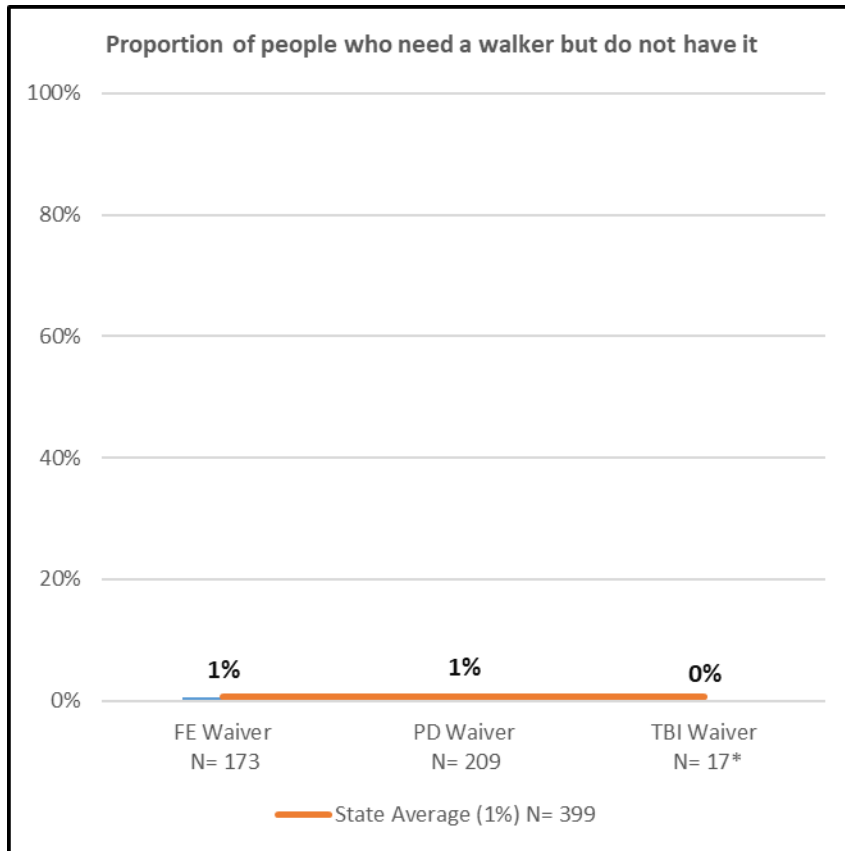


* Very small number of responses

³⁷ Item previously reported in the "Access" domain.

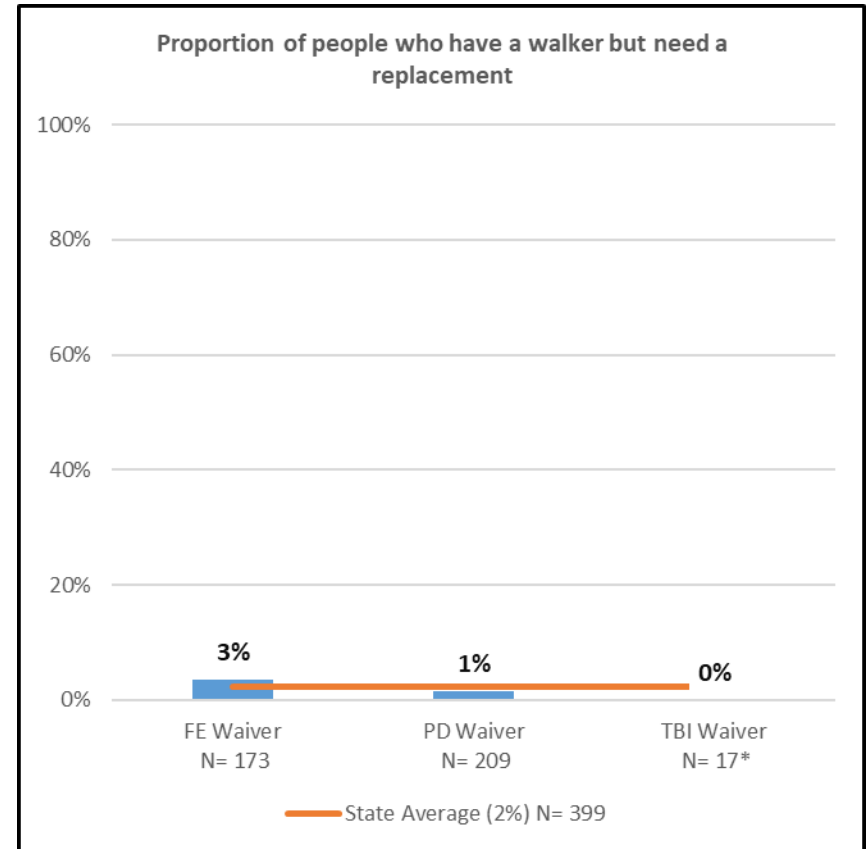
³⁸ Item previously reported in the "Access" domain.

Graph 43. Proportion of people who need a walker but do not have it³⁹



* Very small number of responses

Graph 44. Proportion of people who have a walker but need a replacement⁴⁰

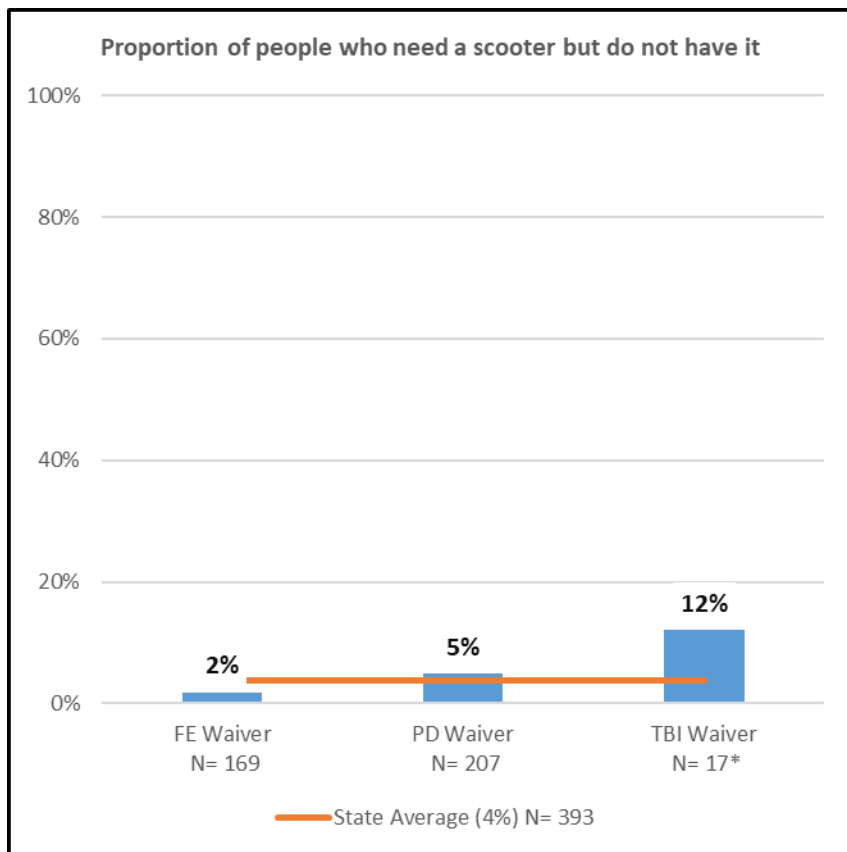


* Very small number of responses

³⁹ Item previously reported in the "Access" domain.

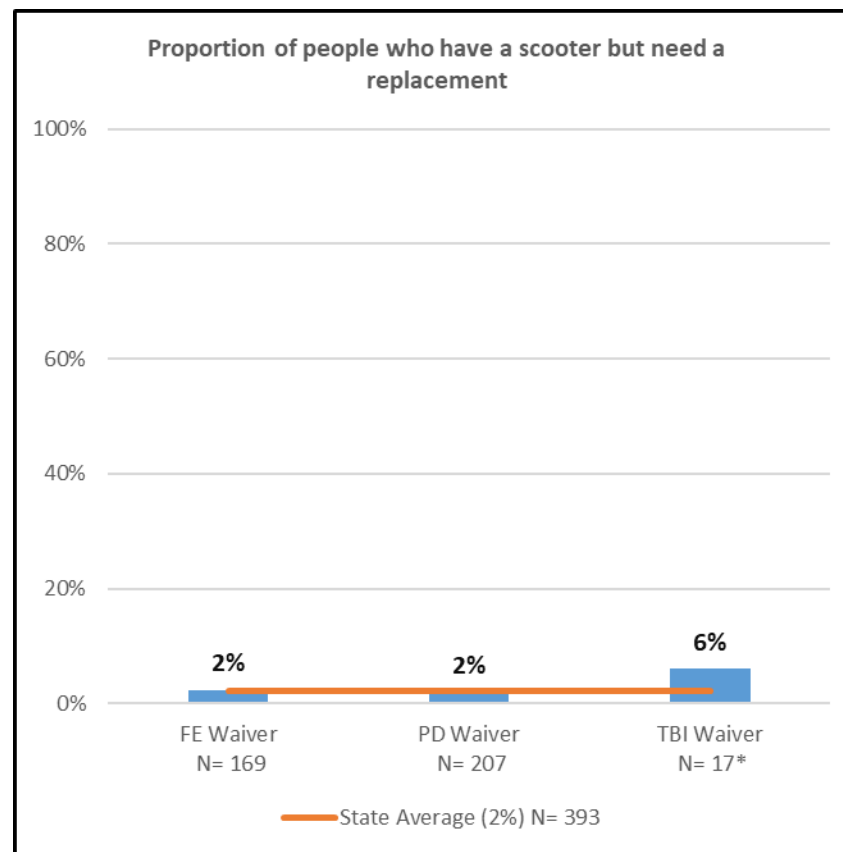
⁴⁰ Item previously reported in the "Access" domain.

Graph 45. Proportion of people who need a scooter but do not have it⁴¹



* Very small number of responses

Graph 46. Proportion of people who have a scooter but need a replacement⁴²

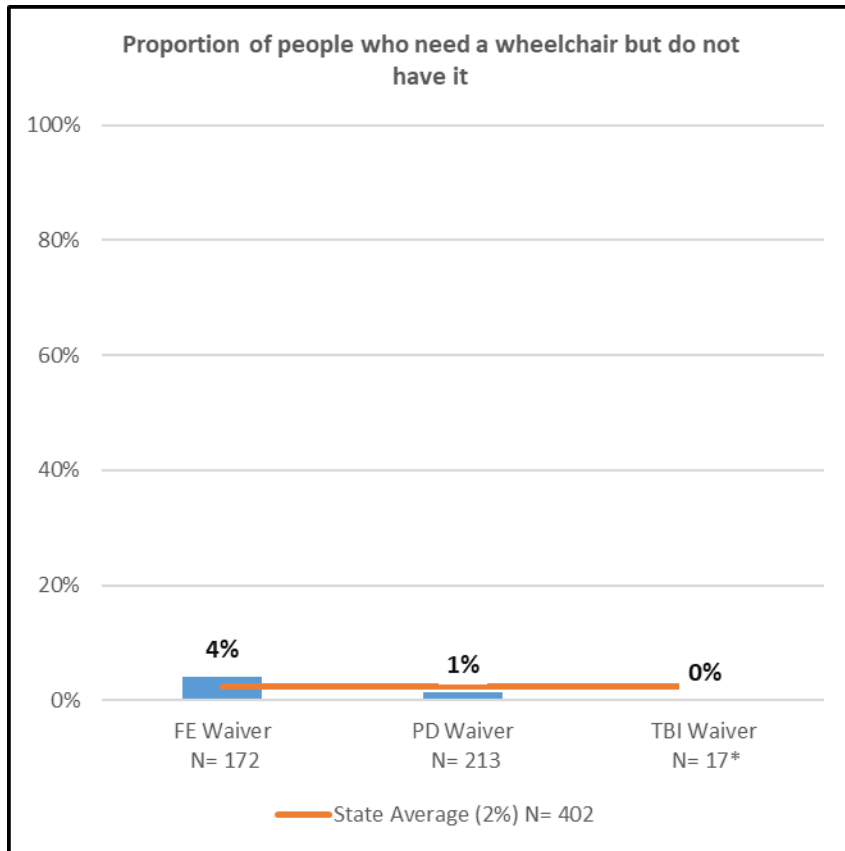


* Very small number of responses

⁴¹ Item previously reported in the "Access" domain.

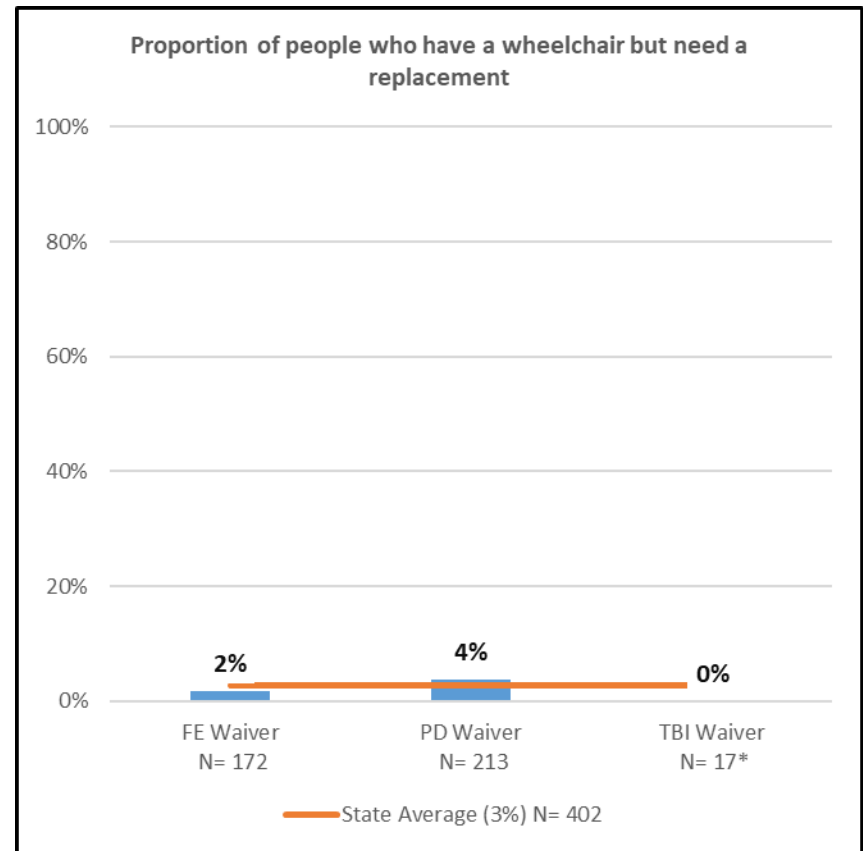
⁴² Item previously reported in the "Access" domain.

Graph 47. Proportion of people who need a wheelchair but do not have it⁴³



* Very small number of responses

Graph 48. Proportion of people who have a wheelchair but need a replacement⁴⁴

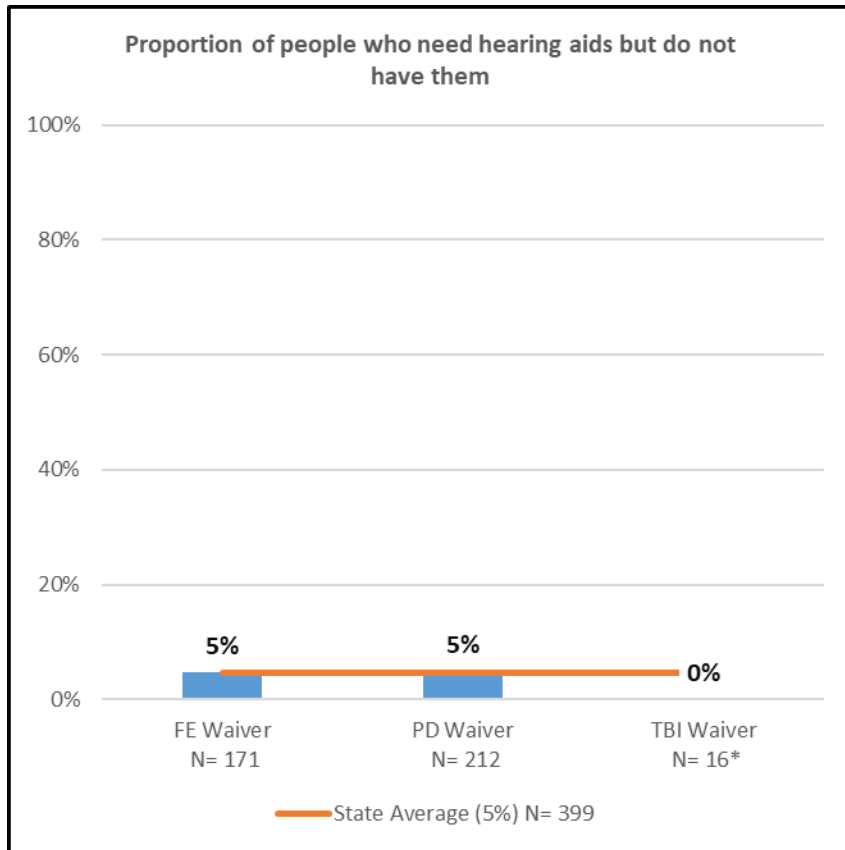


* Very small number of responses

⁴³ Item previously reported in the "Access" domain.

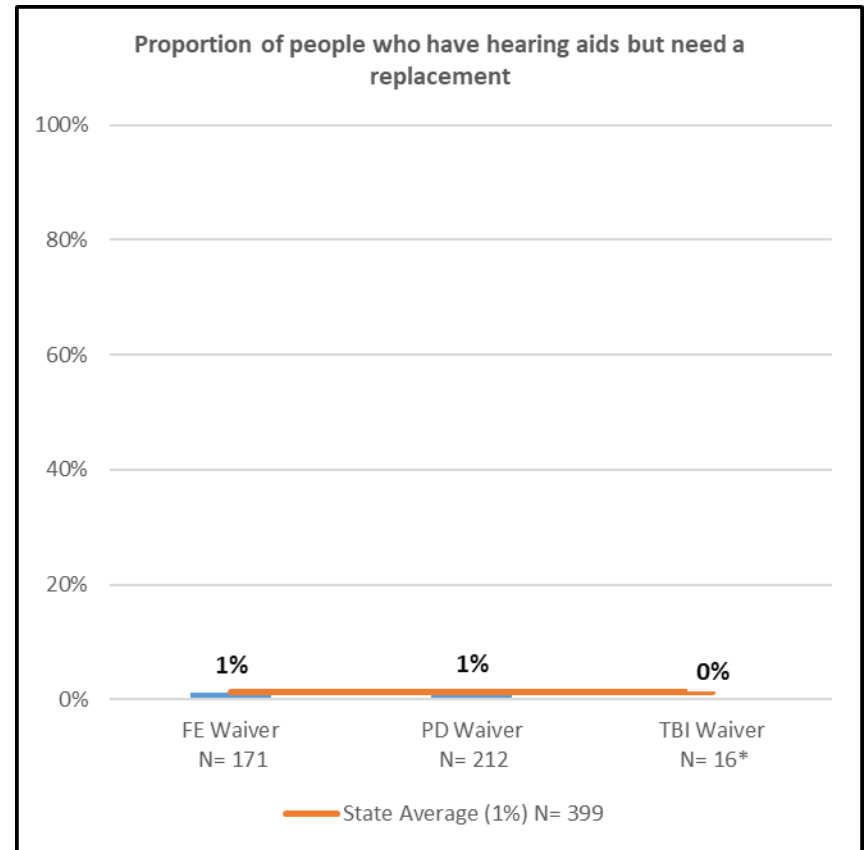
⁴⁴ Item previously reported in the "Access" domain.

Graph 49. Proportion of people who need hearing aids but do not have them⁴⁵



* Very small number of responses

Graph 50. Proportion of people who have hearing aids but need a replacement⁴⁶

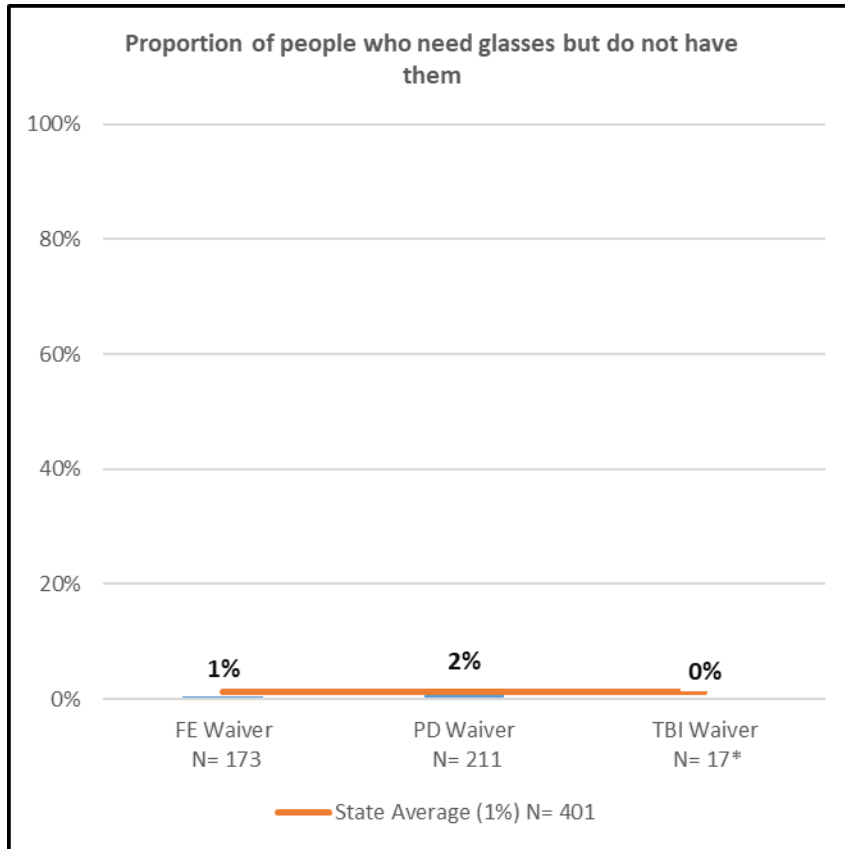


* Very small number of responses

⁴⁵ Item previously reported in the "Access" domain.

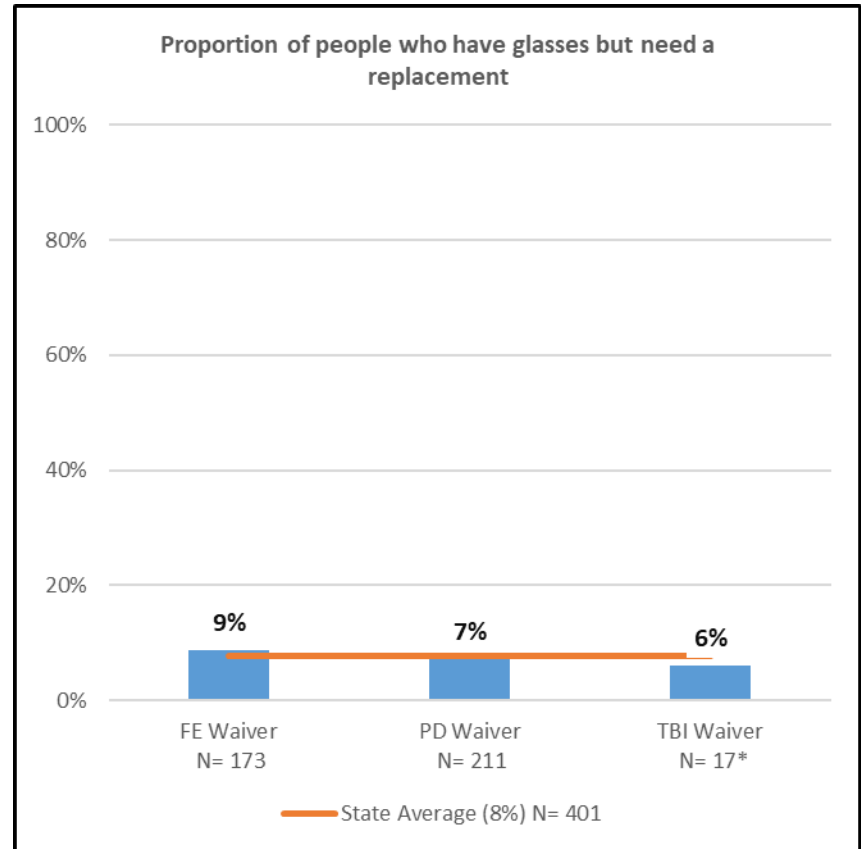
⁴⁶ Item previously reported in the "Access" domain.

Graph 51. Proportion of people who need glasses but do not have them⁴⁷



* Very small number of responses

Graph 52. Proportion of people who have glasses but need a replacement⁴⁸

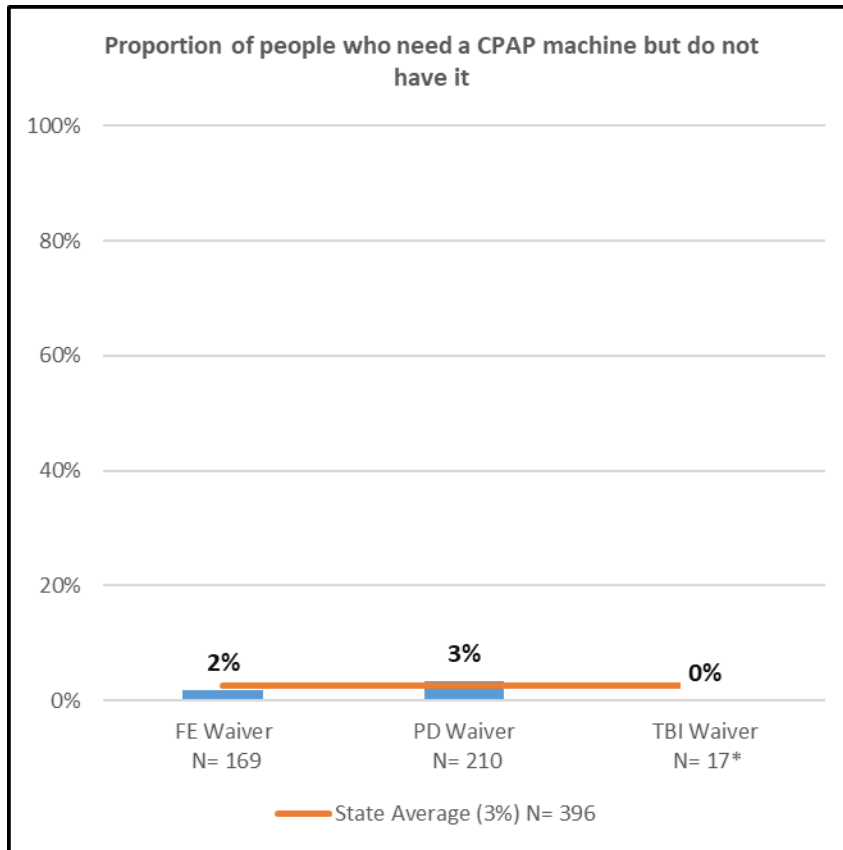


* Very small number of responses

⁴⁷ Item previously reported in the "Access" domain.

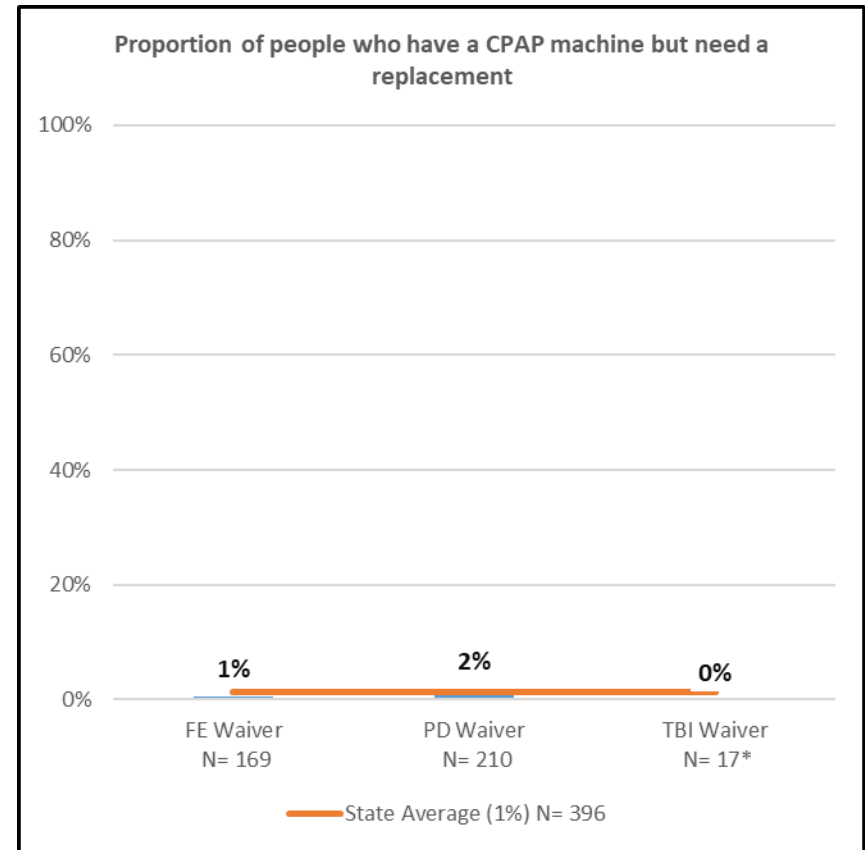
⁴⁸ Item previously reported in the "Access" domain.

Graph 53. Proportion of people who need a CPAP machine but do not have it⁴⁹



* Very small number of responses

Graph 54. Proportion of people who have a CPAP machine but need a replacement⁵⁰

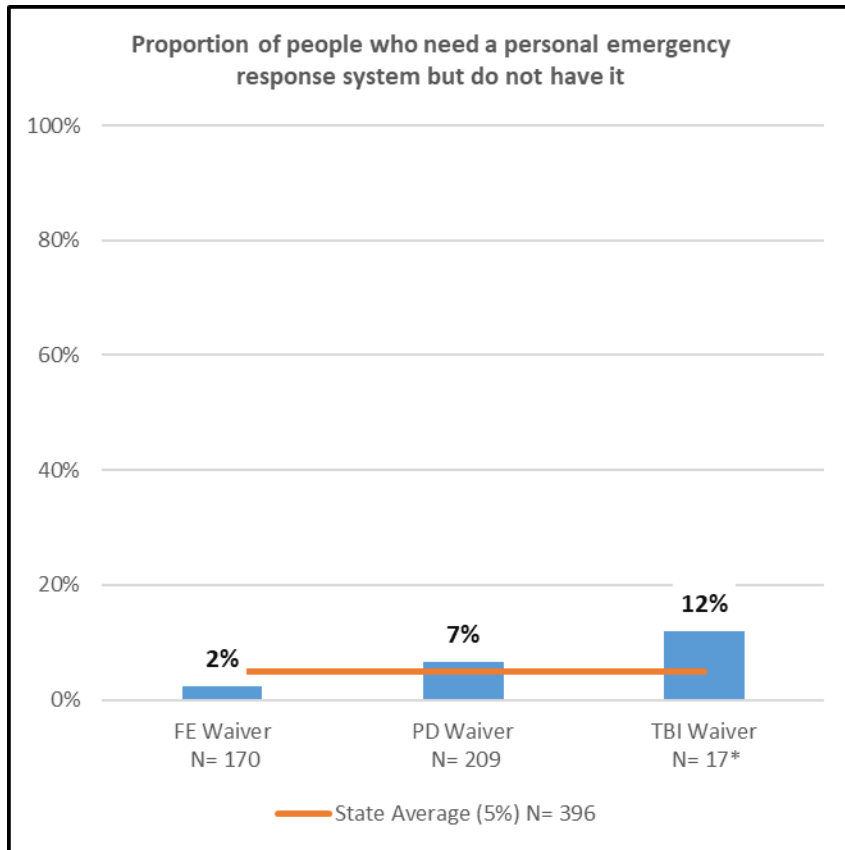


* Very small number of responses

⁴⁹ Item previously reported in the "Access" domain.

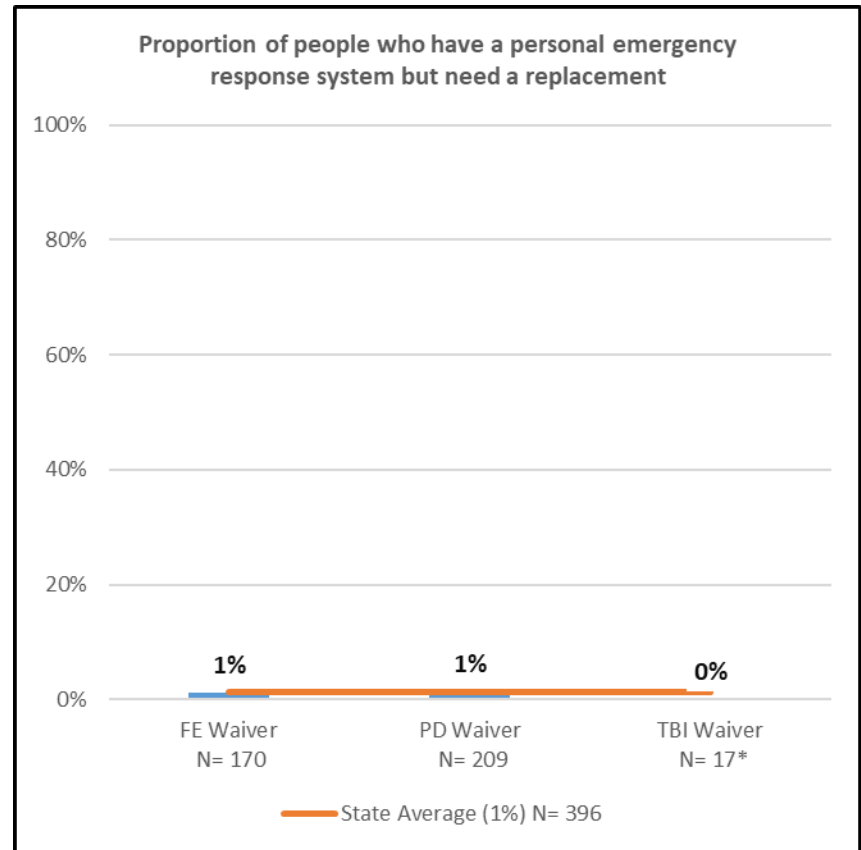
⁵⁰ Item previously reported in the "Access" domain.

Graph 55. Proportion of people who need a personal emergency response system but do not have it⁵¹



* Very small number of responses

Graph 56. Proportion of people who have a personal emergency response system but need a replacement⁵²

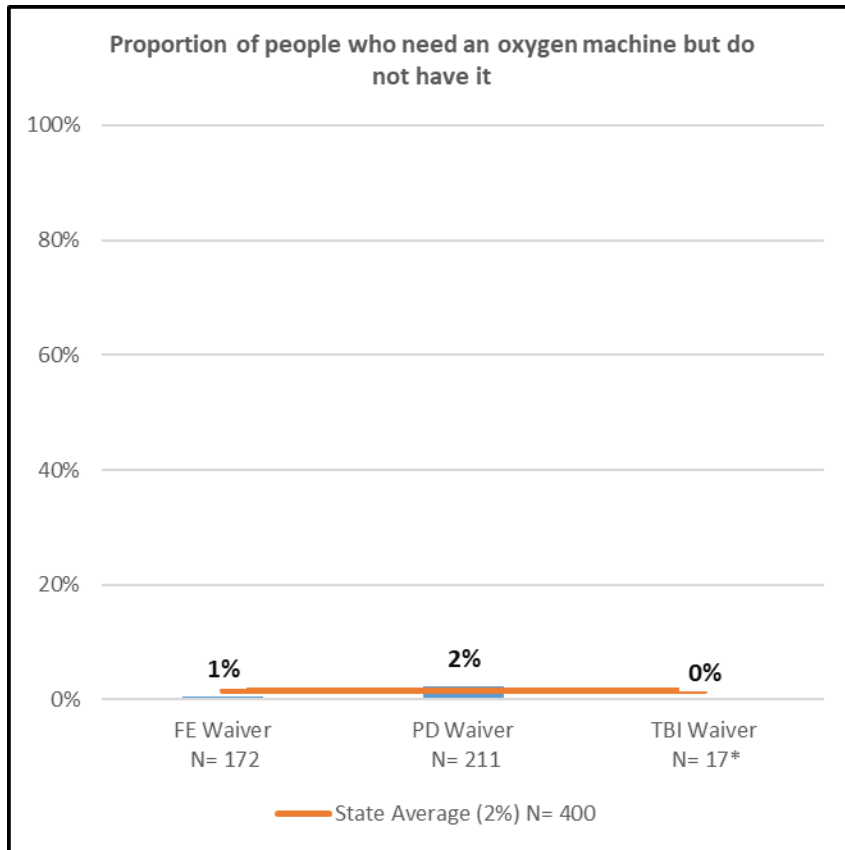


* Very small number of responses

⁵¹ Item previously reported in the "Access" domain.

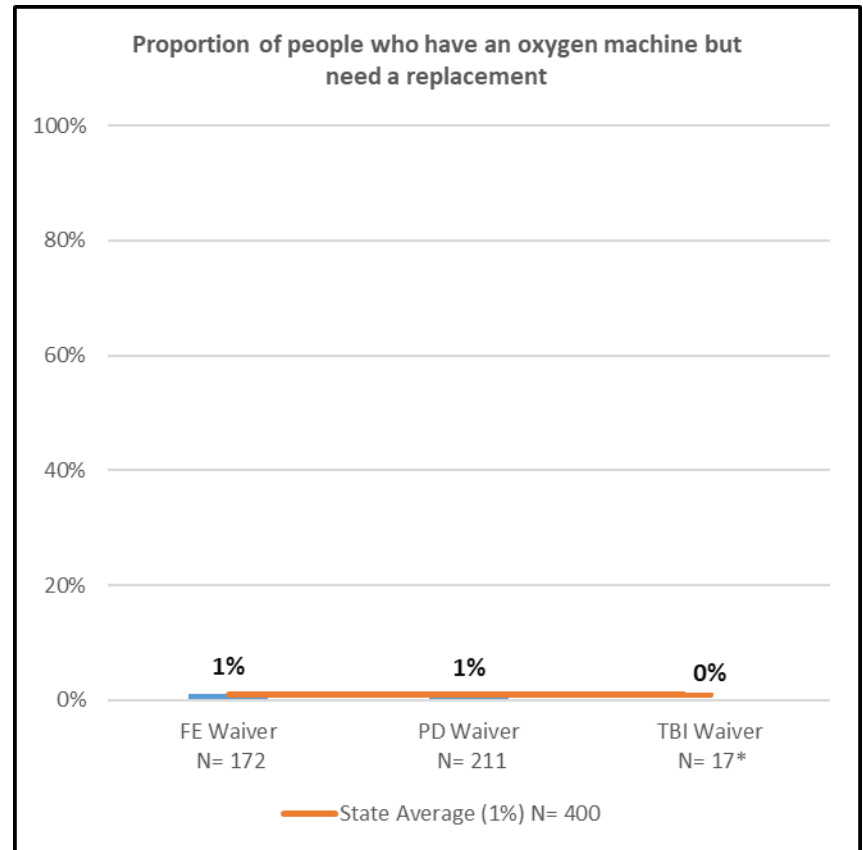
⁵² Item previously reported in the "Access" domain.

Graph 57. Proportion of people who need an oxygen machine but do not have it⁵³



* Very small number of responses

Graph 58. Proportion of people who have an oxygen machine but need a replacement⁵⁴

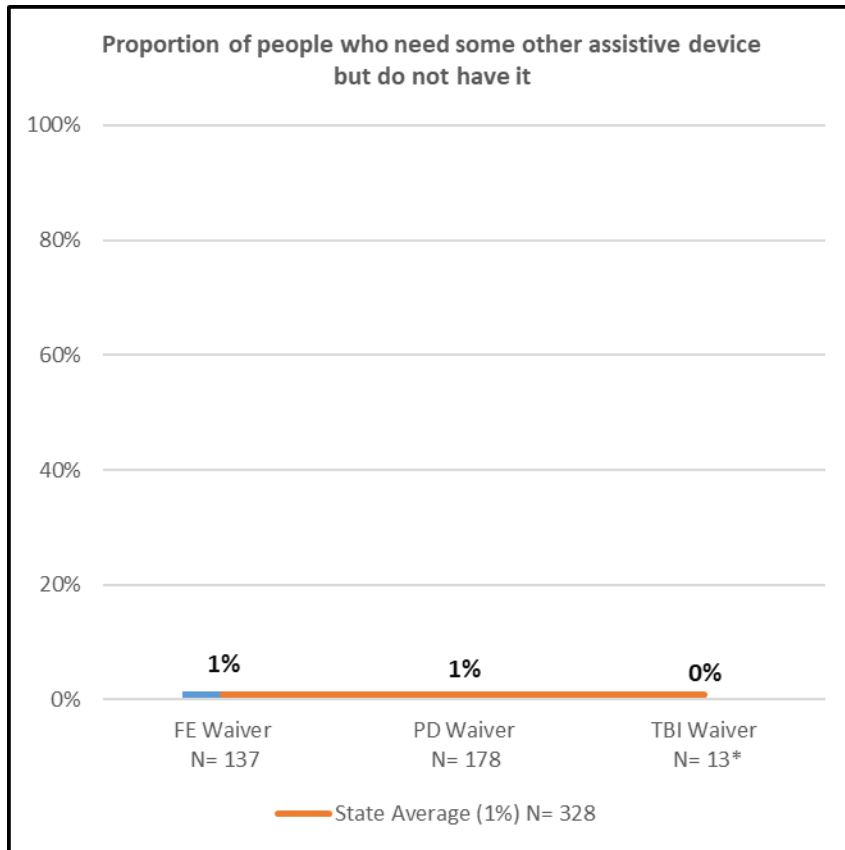


* Very small number of responses

⁵³ New item added in 2018-2019.

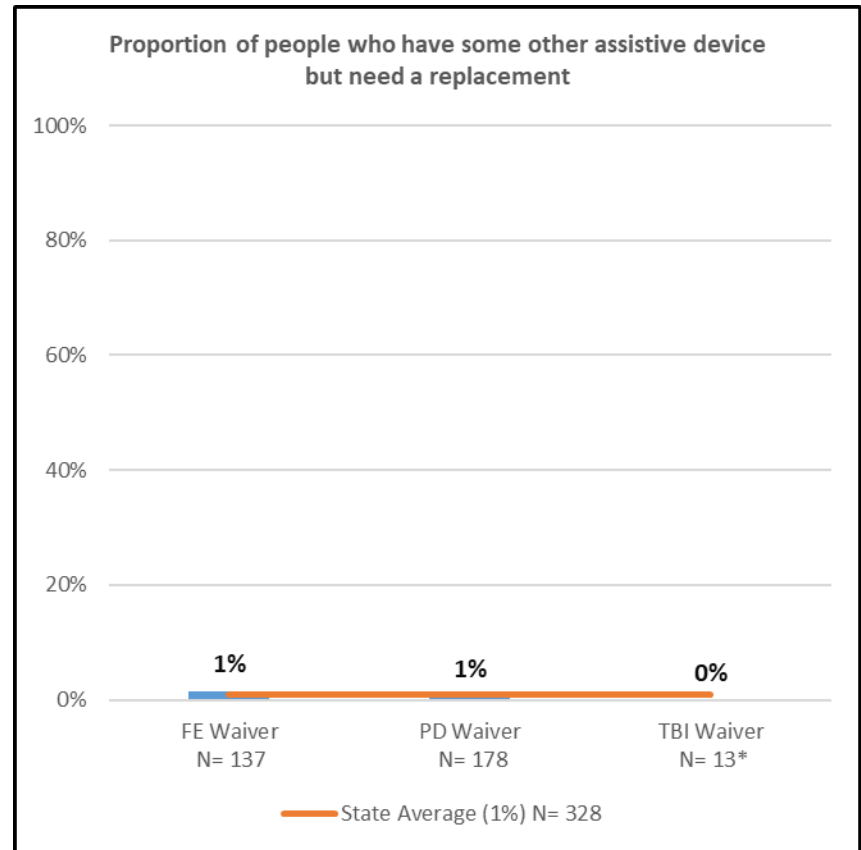
⁵⁴ New item added in 2018-2019.

Graph 59. Proportion of people who need some other assistive device but do not have it⁵⁵



* Very small number of responses

Graph 60. Proportion of people who have some other assistive device but need a replacement⁵⁶



* Very small number of responses

⁵⁵ Item previously reported in the "Access" domain.

⁵⁶ Item previously reported in the "Access" domain.

Safety

People feel safe from abuse, neglect, and injury.

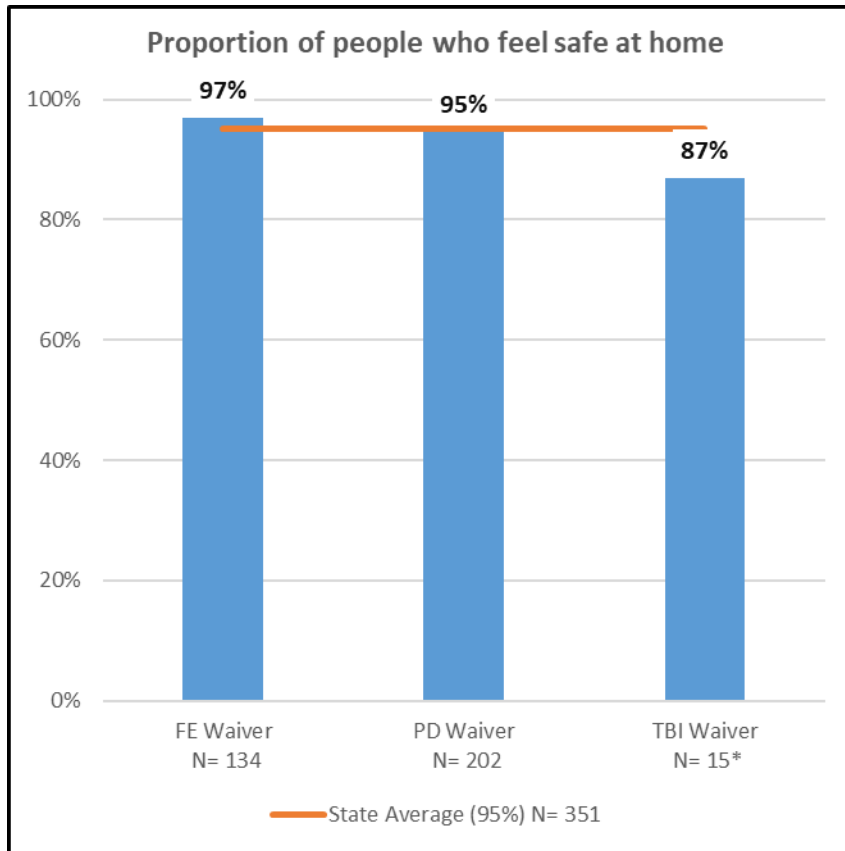
There are four Safety indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who feel safe at home.
2. Proportion of people who feel safe around their paid support staff.
3. Proportion of people who feel that their belongings are safe.
4. Proportion of people who are able to get to safety quickly in case of an emergency.

There are five survey items that correspond to the Safety domain.

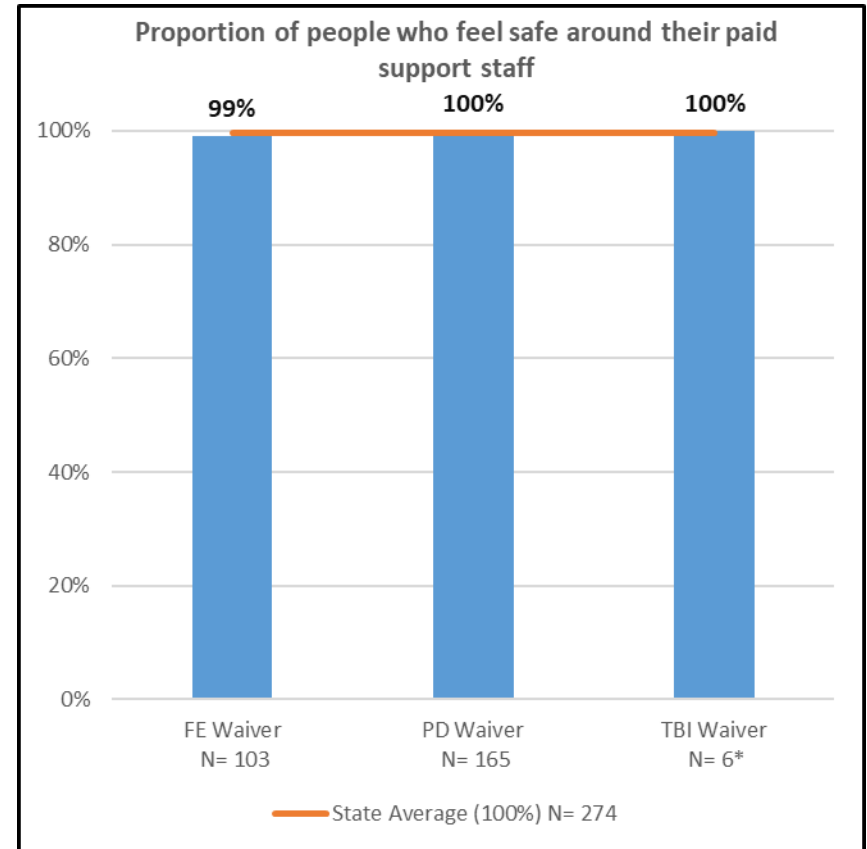
Un-collapsed data are shown in Appendix B.

Graph 61. Proportion of people who feel safe at home



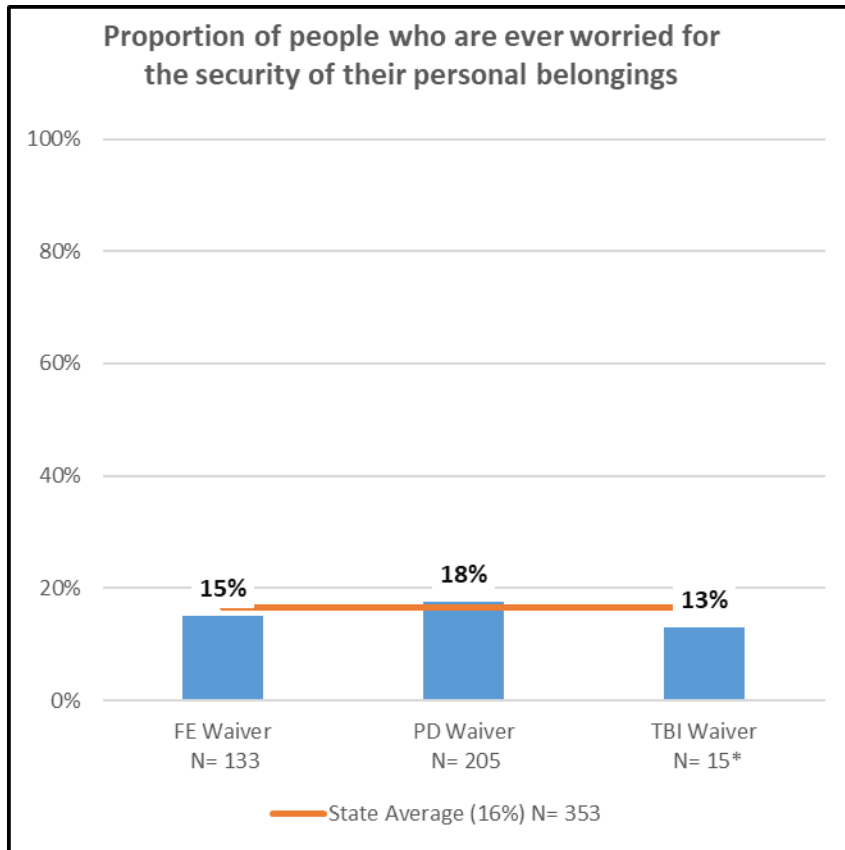
* Very small number of responses

Graph 62. Proportion of people who feel safe around their paid support staff



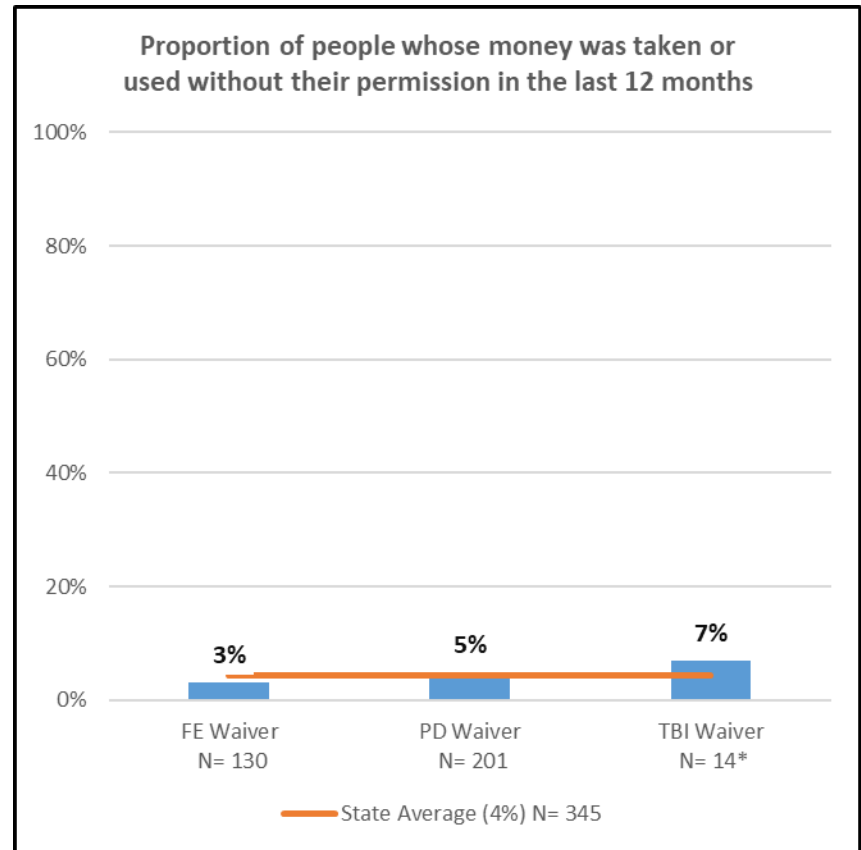
* Very small number of responses

Graph 63. Proportion of people who are ever worried for the security of their personal belongings



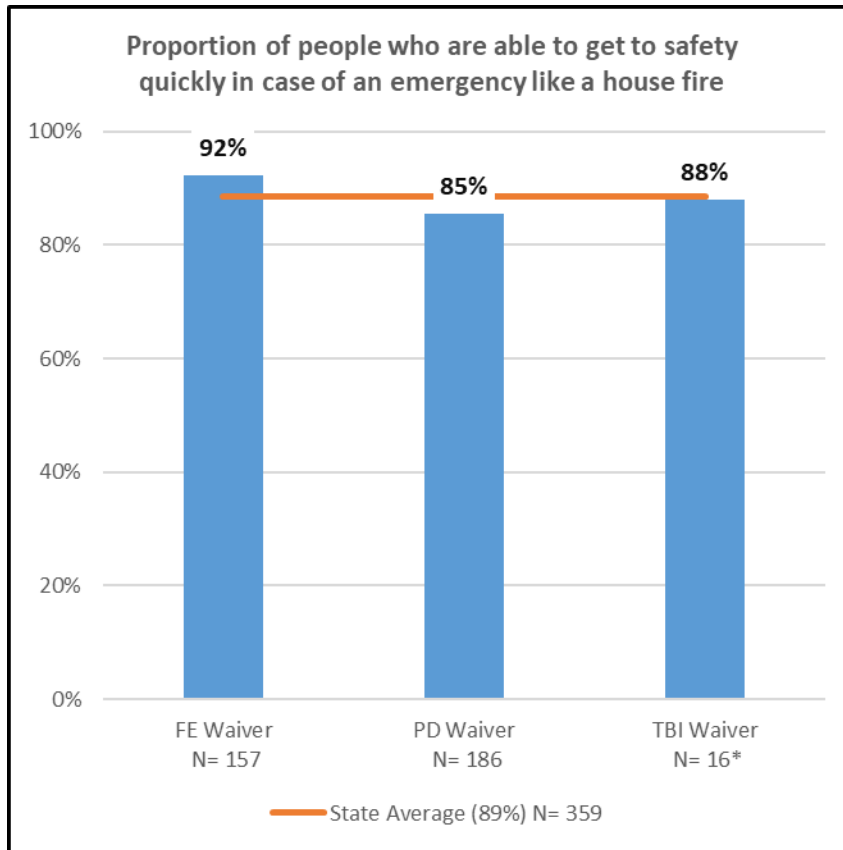
* Very small number of responses

Graph 64. Proportion of people whose money was taken or used without their permission in the last 12 months



* Very small number of responses

Graph 65. Proportion of people who are able to get to safety quickly in case of an emergency like a house fire



* Very small number of responses

Health Care

People secure needed health services.

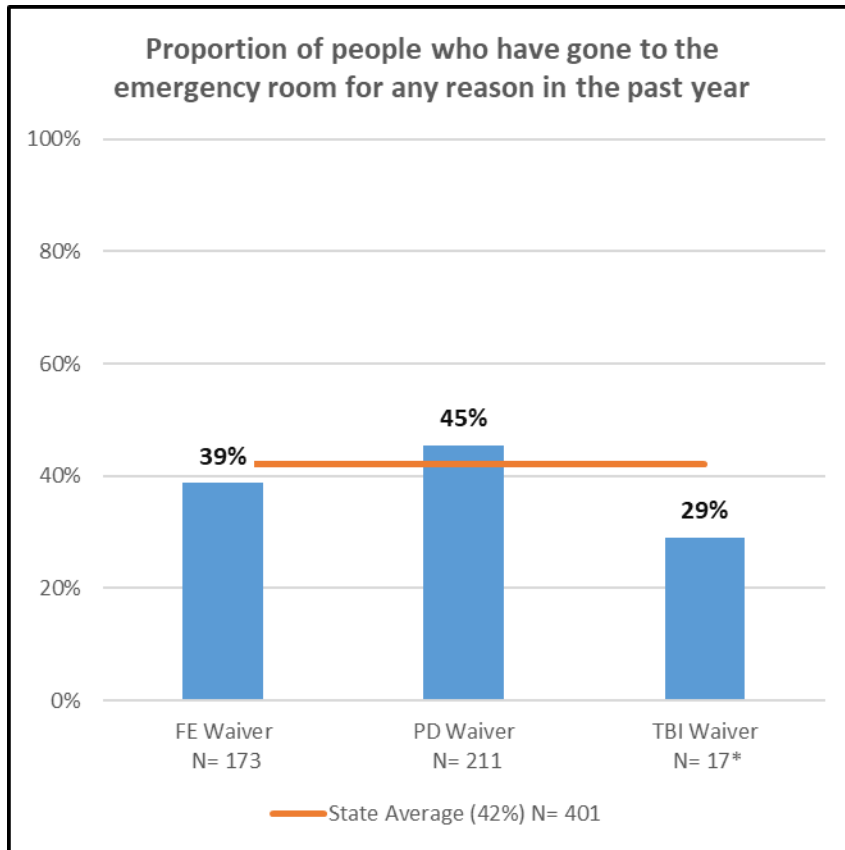
There are four Health Care indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who experience potentially preventable emergency room visits.
2. Proportion of people who have needed health screenings and vaccinations in a timely manner.
3. Proportion of people who can get an appointment with their doctor when they need to.
4. Proportion of people who have access to mental health services.

There are five survey items that correspond to the Health Care domain.

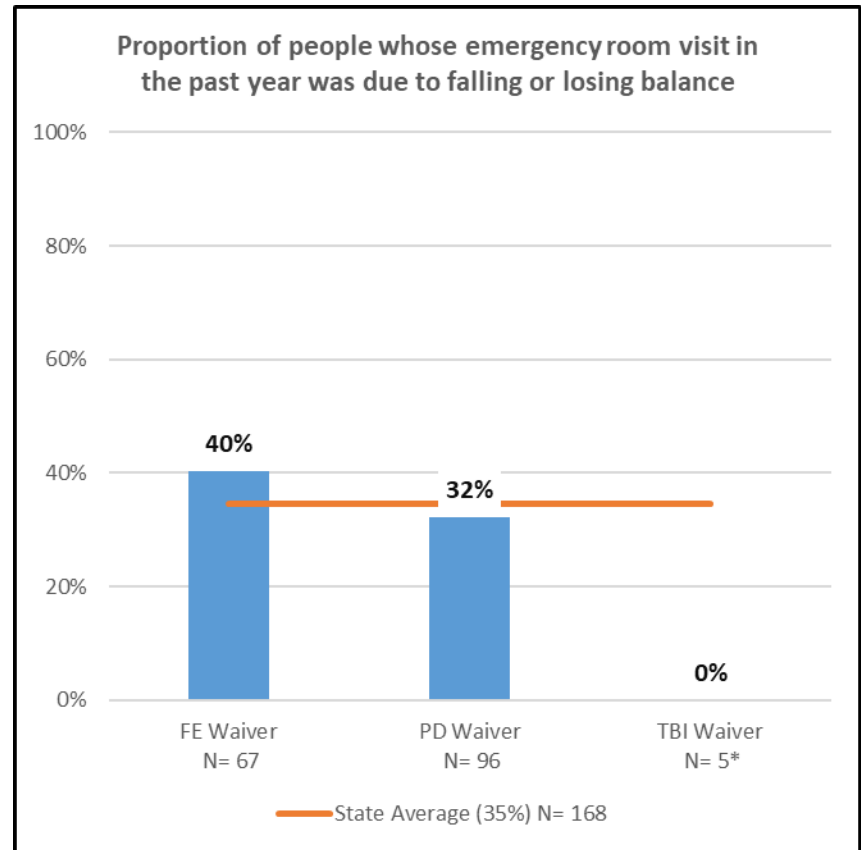
Un-collapsed data are shown in Appendix B.

Graph 66. Proportion of people who have gone to the emergency room for any reason in the past year



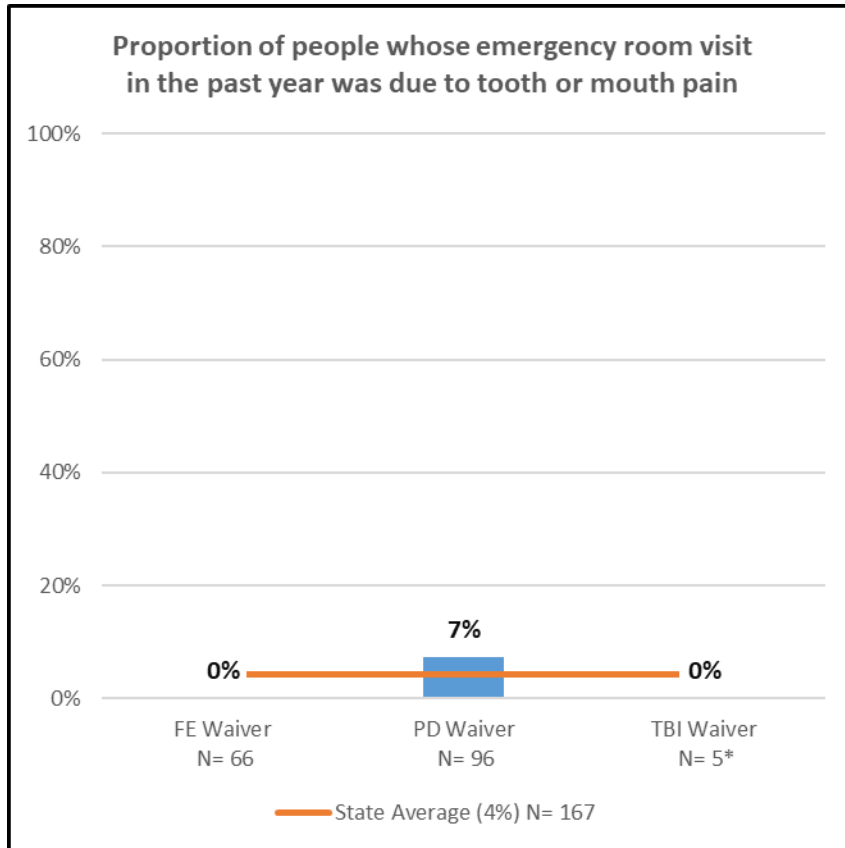
* Very small number of responses

Graph 67. Proportion of people whose emergency room visit in the past year was due to falling or losing balance



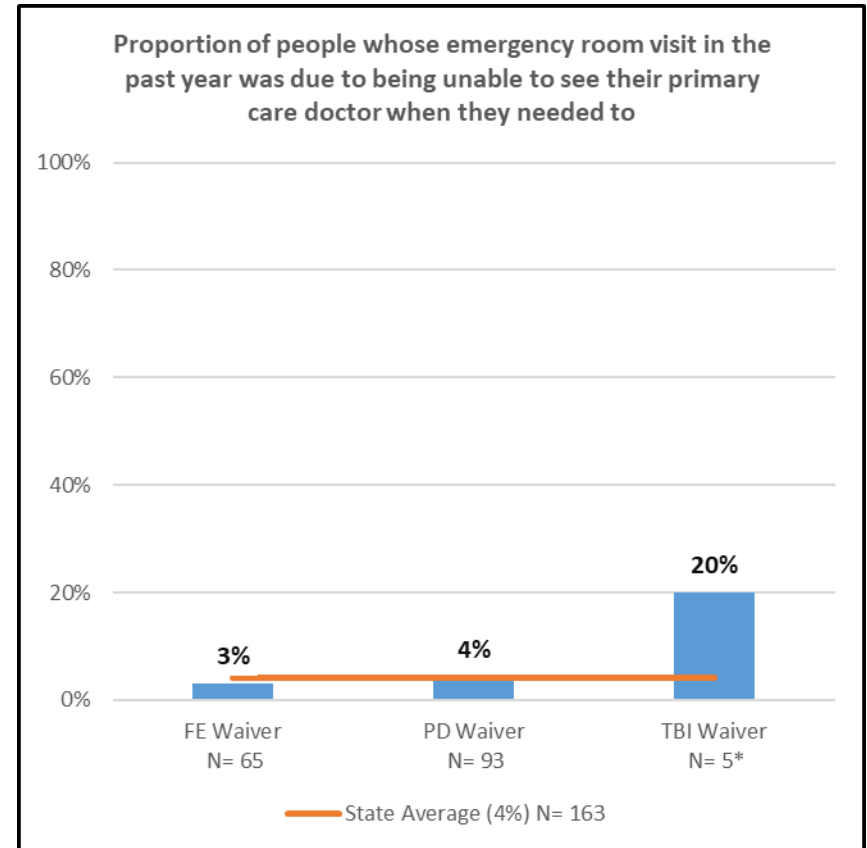
* Very small number of responses

Graph 68. Proportion of people whose emergency room visit in the past year was due to tooth or mouth pain



* Very small number of responses

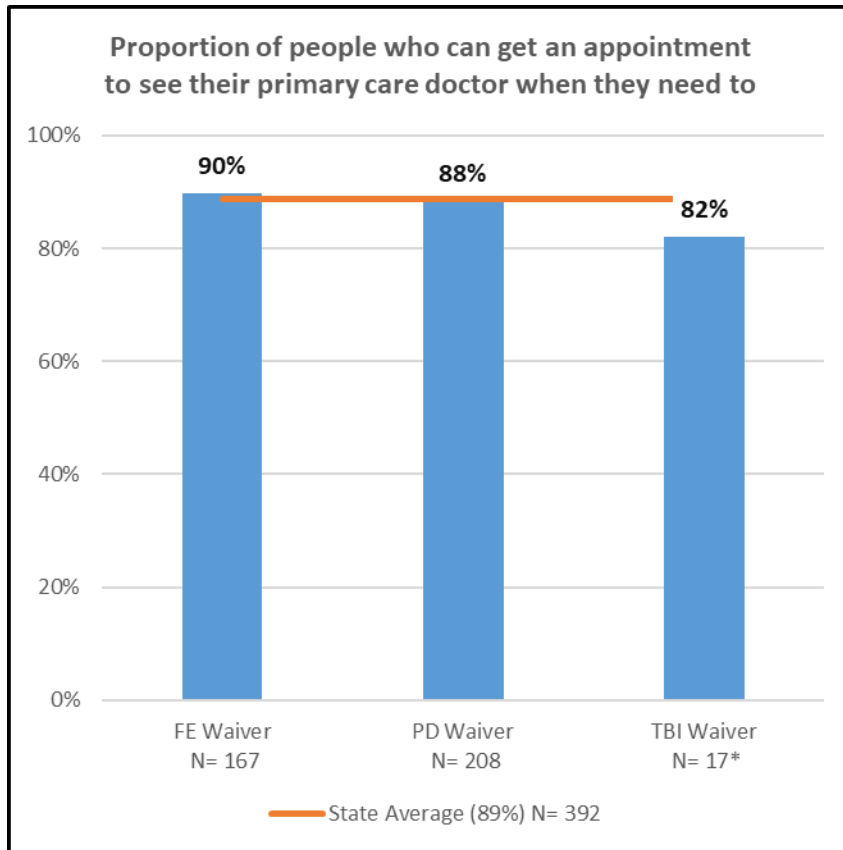
Graph 69. Proportion of people whose emergency room visit in the past year was due to being unable to see their primary care doctor when they needed to⁵⁷



* Very small number of responses

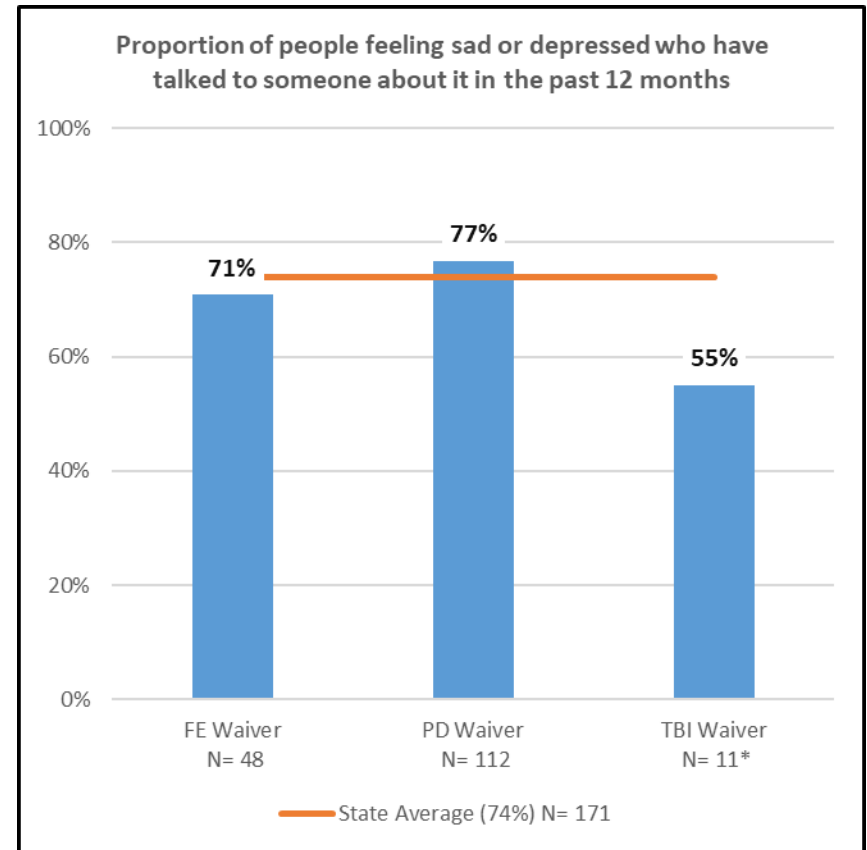
⁵⁷ New item added in 2018-2019.

Graph 70. Proportion of people who can get an appointment to see their primary care doctor when they need to



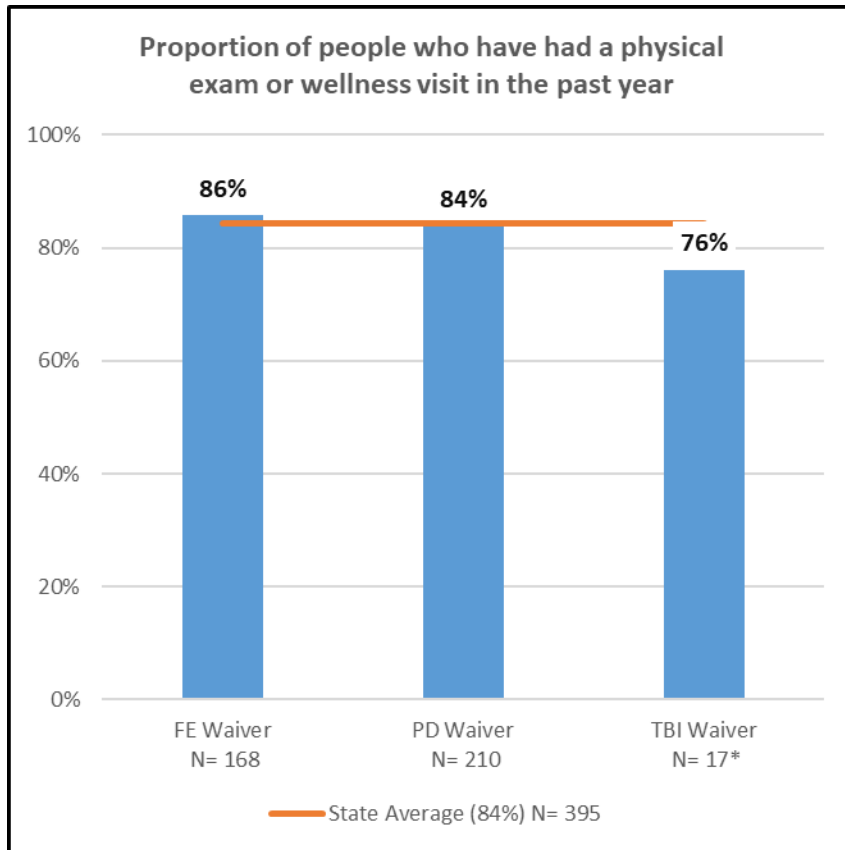
* Very small number of responses

Graph 71. Proportion of people feeling sad or depressed who have talked to someone about it in the past 12 months



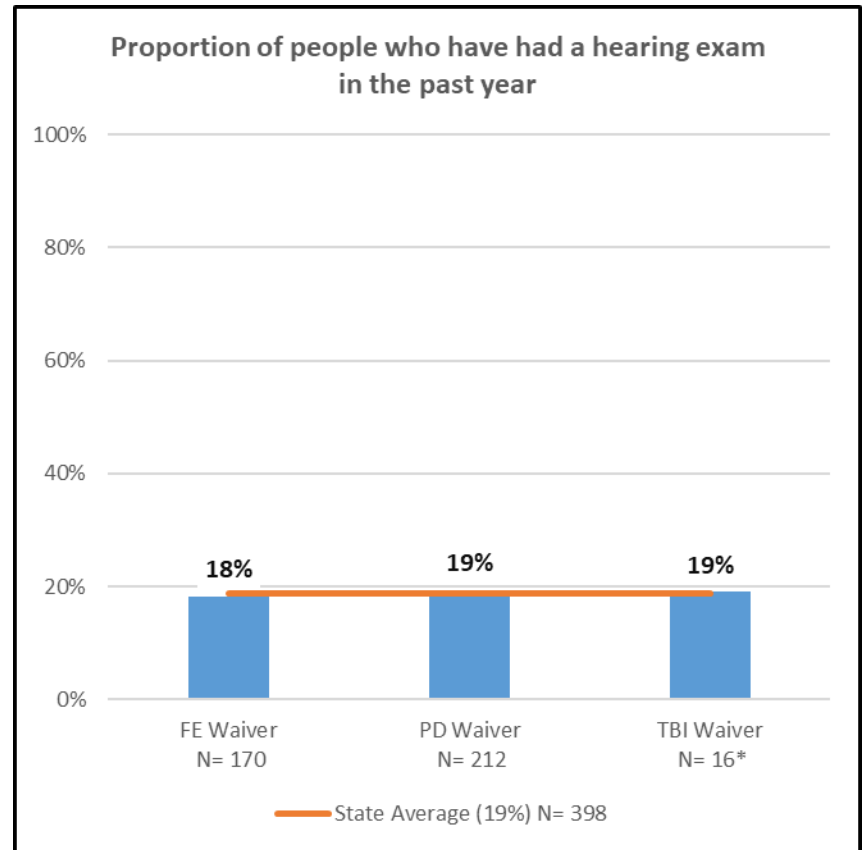
* Very small number of responses

Graph 72. Proportion of people who have had a physical exam or wellness visit in the past year



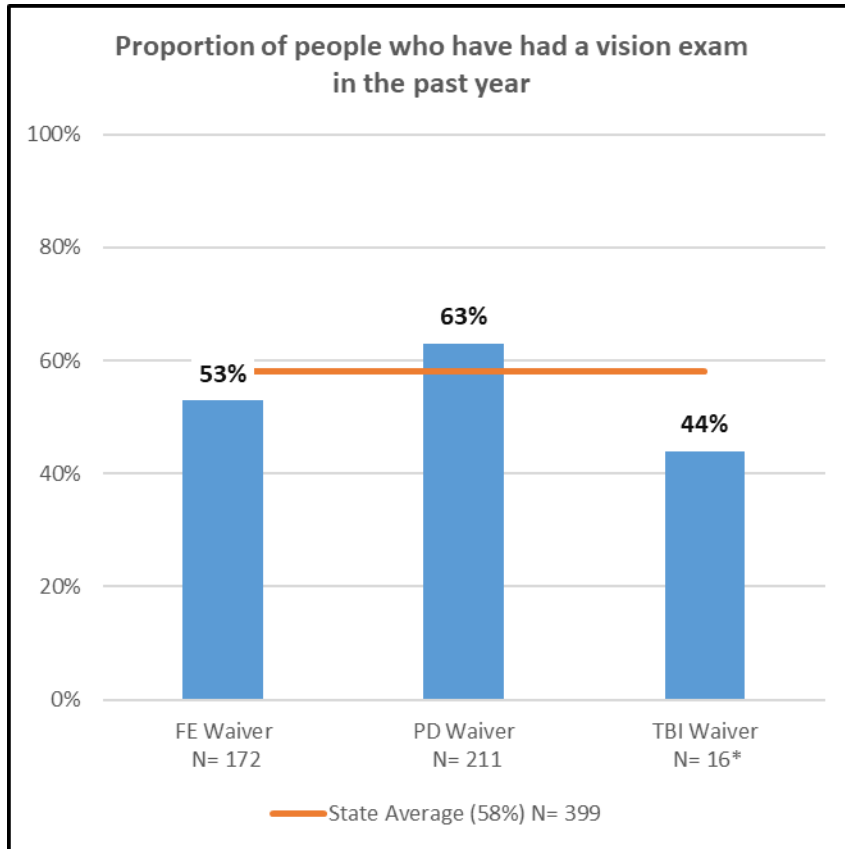
* Very small number of responses

Graph 73. Proportion of people who have had a hearing exam in the past year

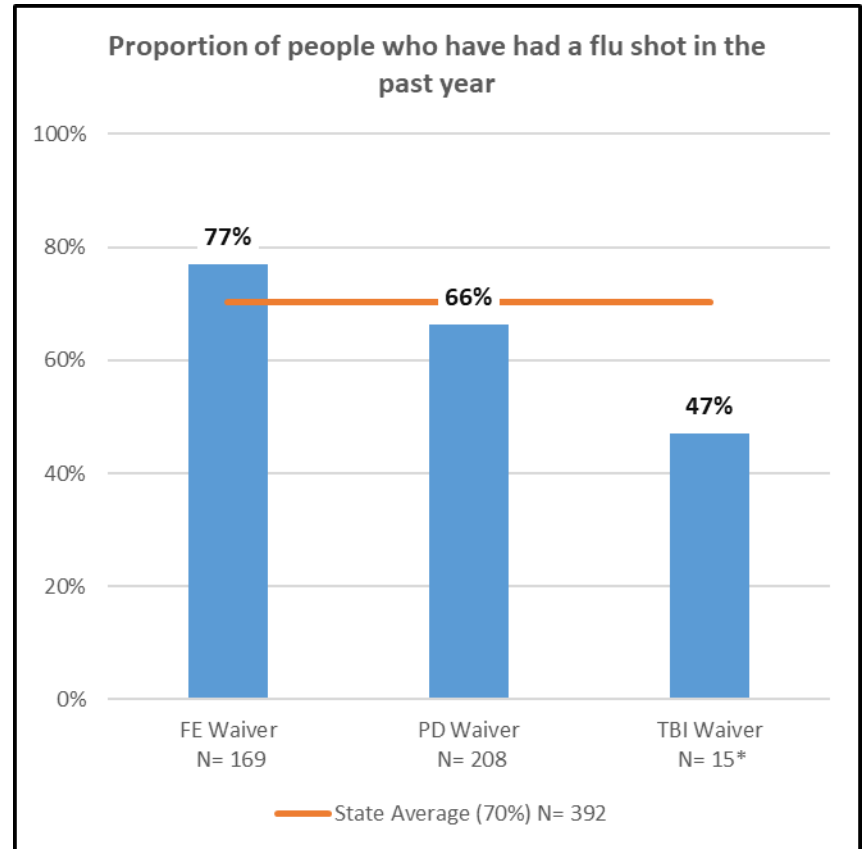


* Very small number of responses

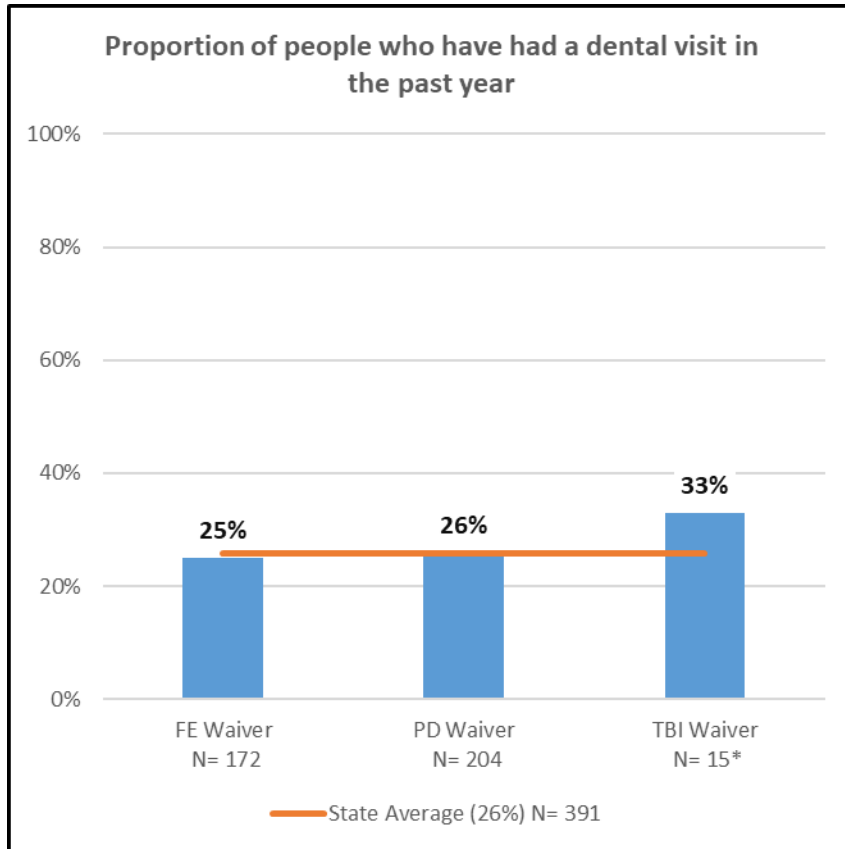
Graph 74. Proportion of people who have had a vision exam in the past year



Graph 75. Proportion of people who have had a flu shot in the past year



Graph 76. Proportion of people who have had a dental visit in the past year



* Very small number of responses

Wellness

People are supported to maintain health.

There are six Wellness indicators measured by the NCI-AD Adult Consumer Survey:

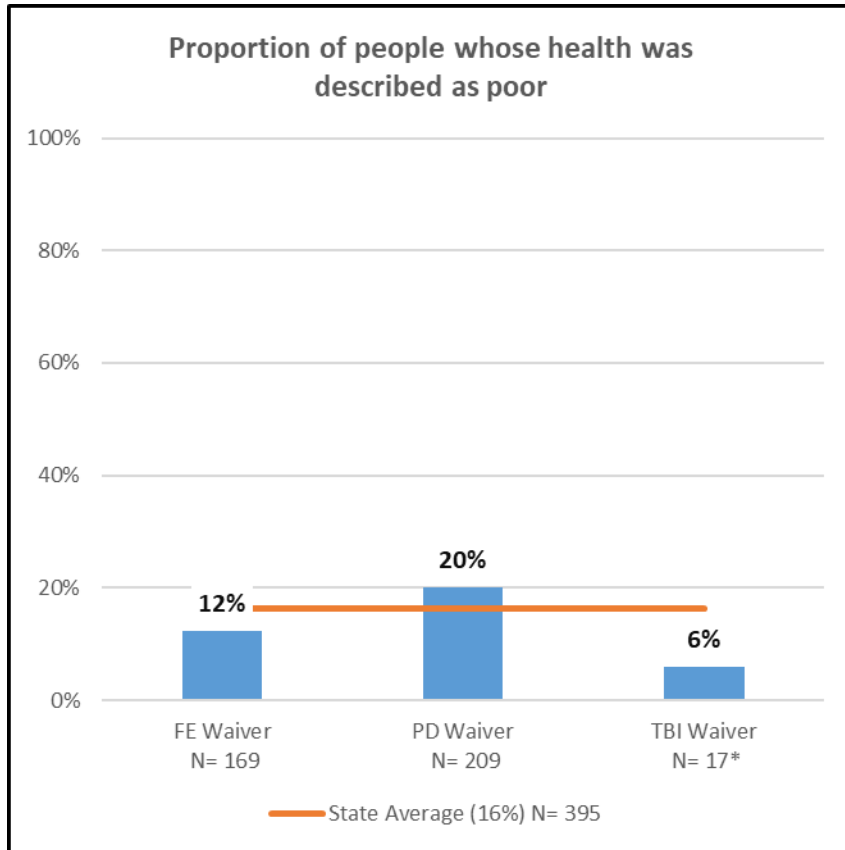
1. Proportion of people in poor health.
2. Proportion of people with unaddressed memory concerns.
3. Proportion of people with uncorrected poor hearing.
4. Proportion of people with uncorrected poor vision.
5. Proportion of people who often feel sad or depressed.
6. Proportion of people who have access to healthy foods⁵⁸.

There are eight survey items that correspond to the Wellness domain.

Un-collapsed data are shown in Appendix B.

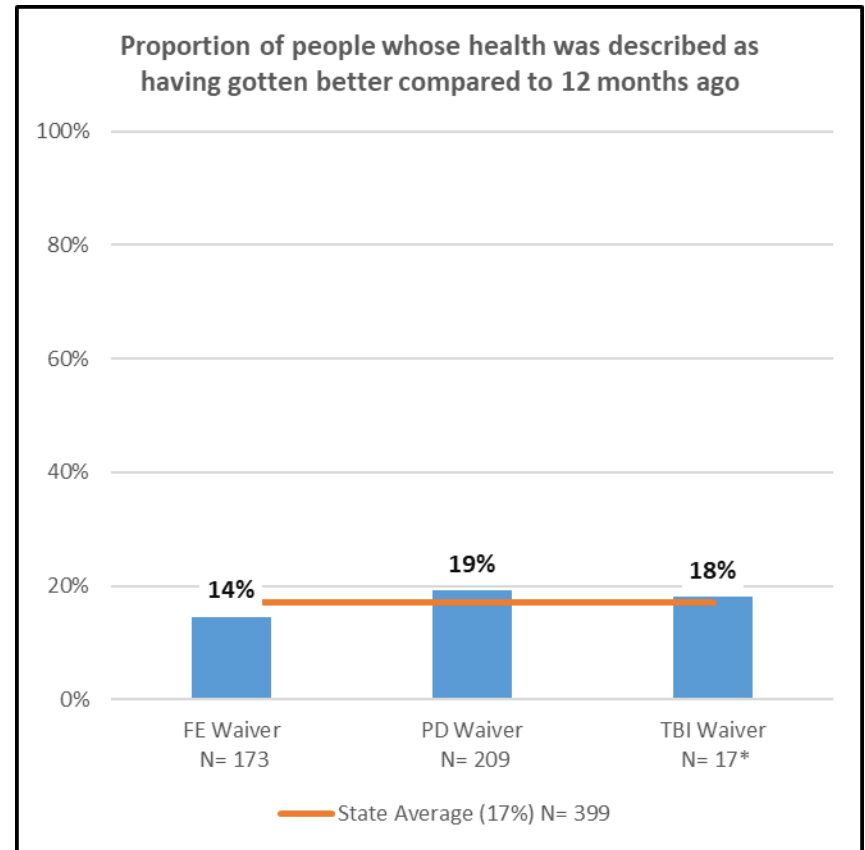
⁵⁸ Indicator previously reported in the “Everyday Living” domain.

Graph 77. Proportion of people whose health was described as poor



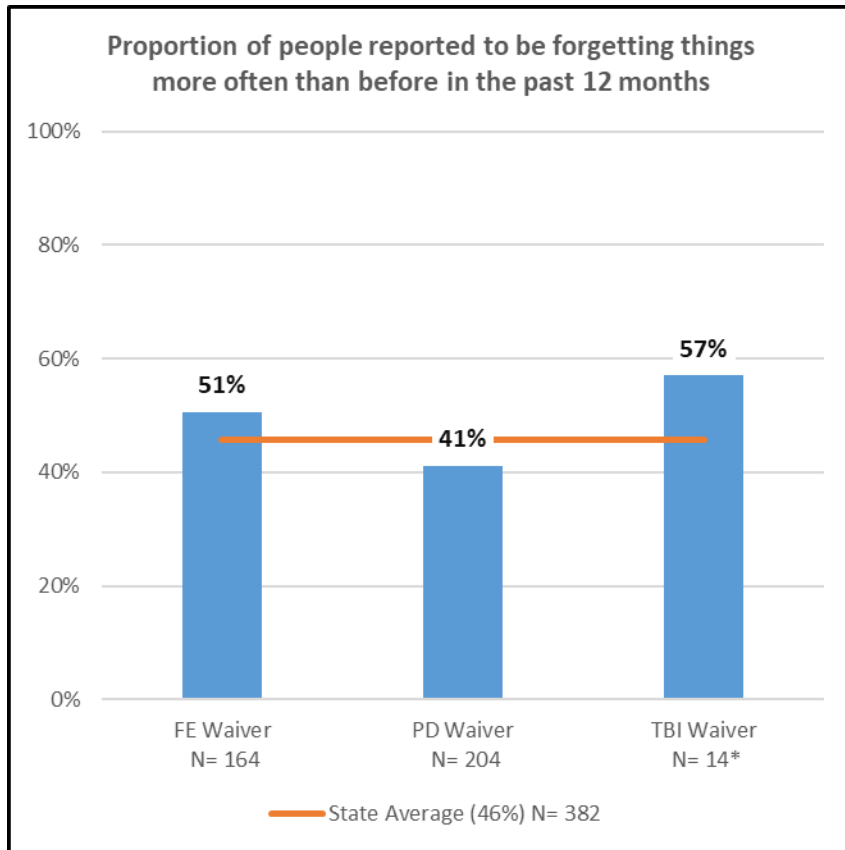
* Very small number of responses

Graph 78. Proportion of people whose health was described as having gotten better compared to 12 months ago



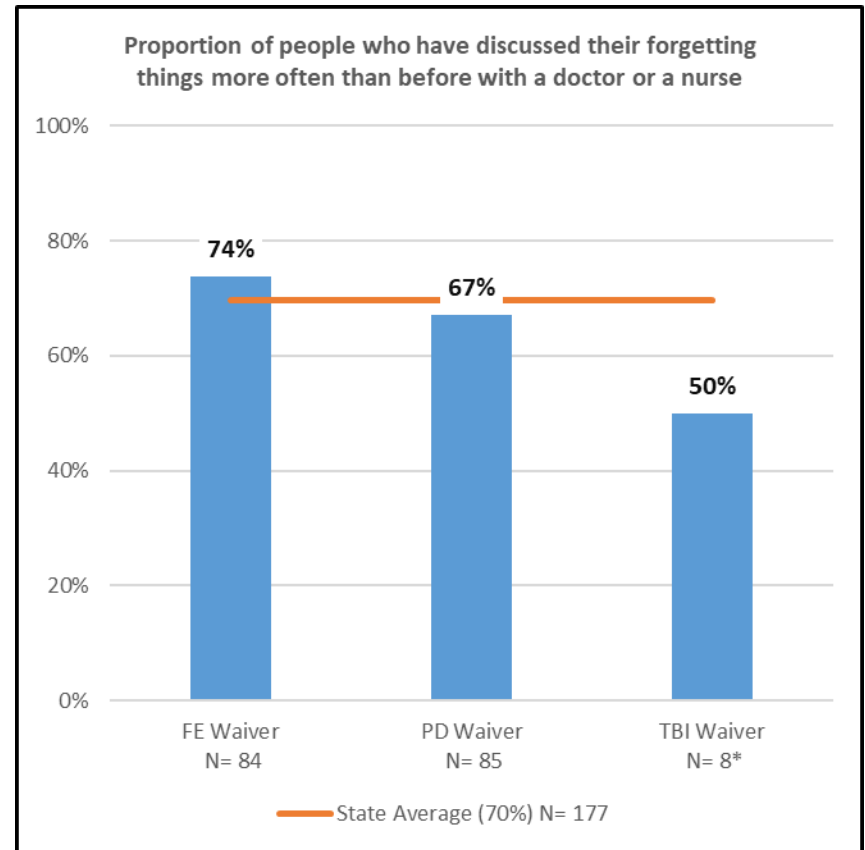
* Very small number of responses

Graph 79. Proportion of people reported to be forgetting things more often than before in the past 12 months



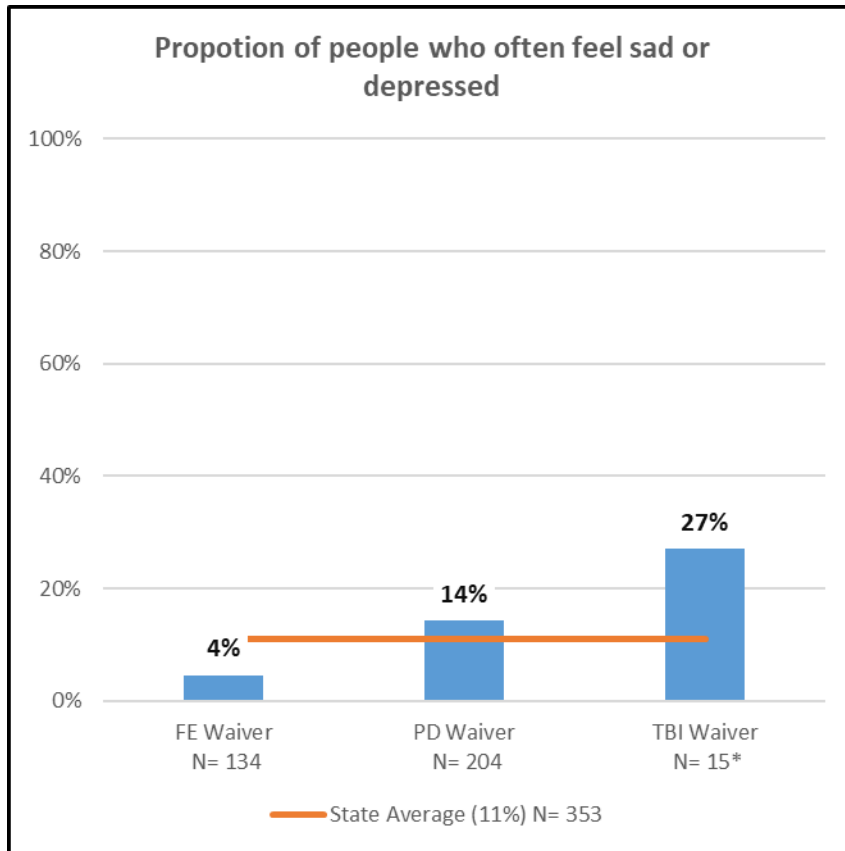
* Very small number of responses

Graph 80. Proportion of people who have discussed their forgetting things more often than before with a doctor or a nurse



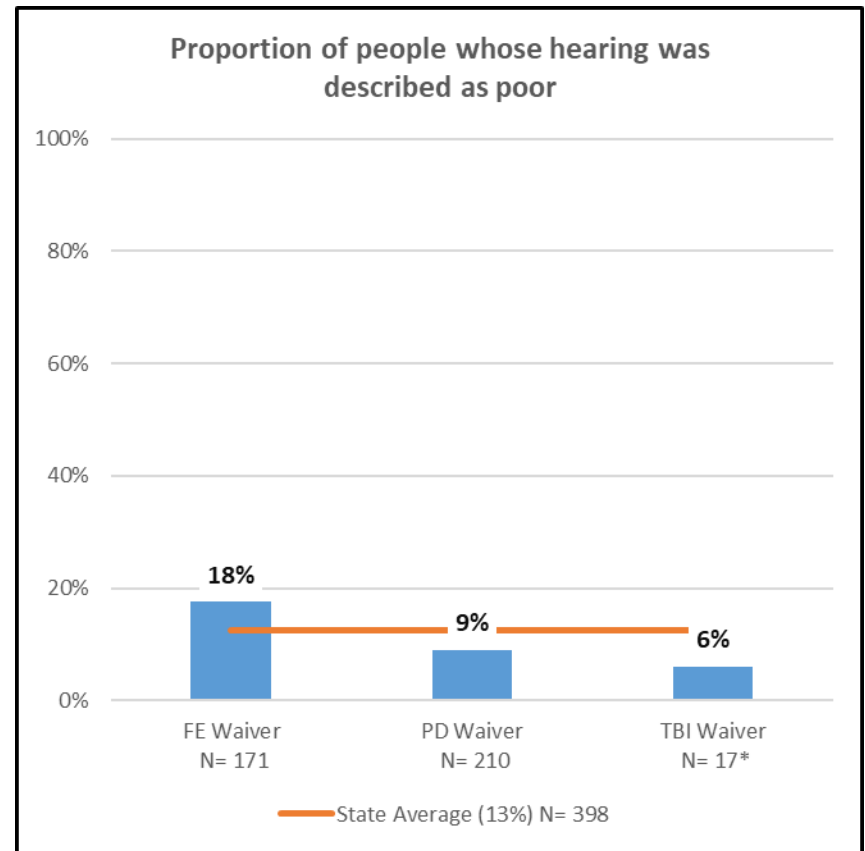
* Very small number of responses

Graph 81. Proportion of people who often feel sad or depressed



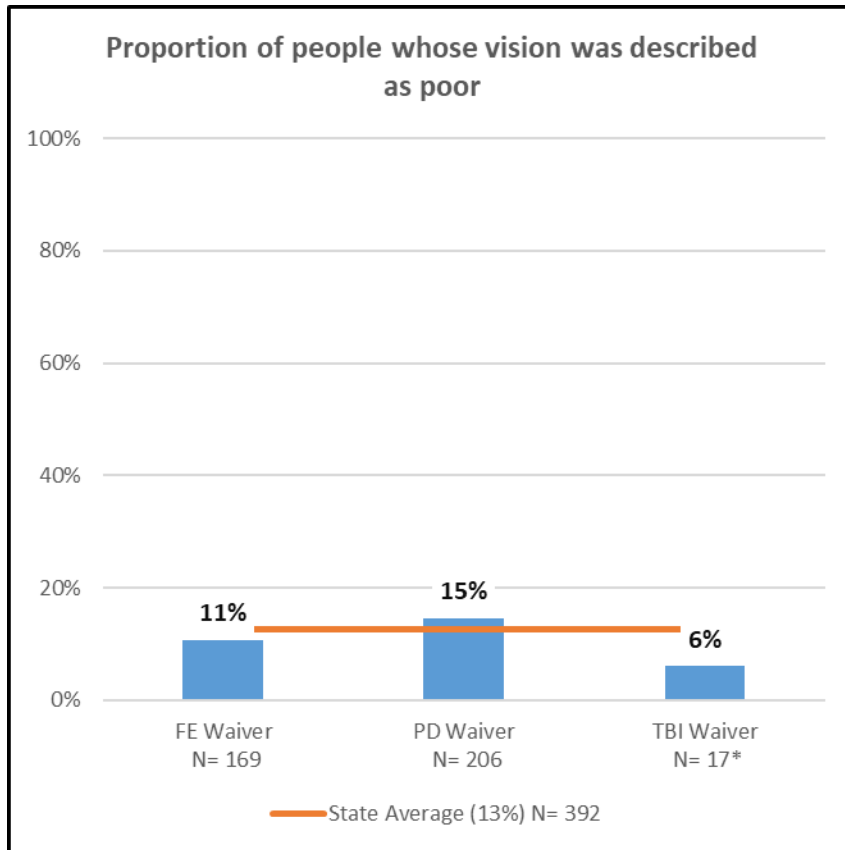
* Very small number of responses

Graph 82. Proportion of people whose hearing was described as poor (with hearing aids, if wears any)



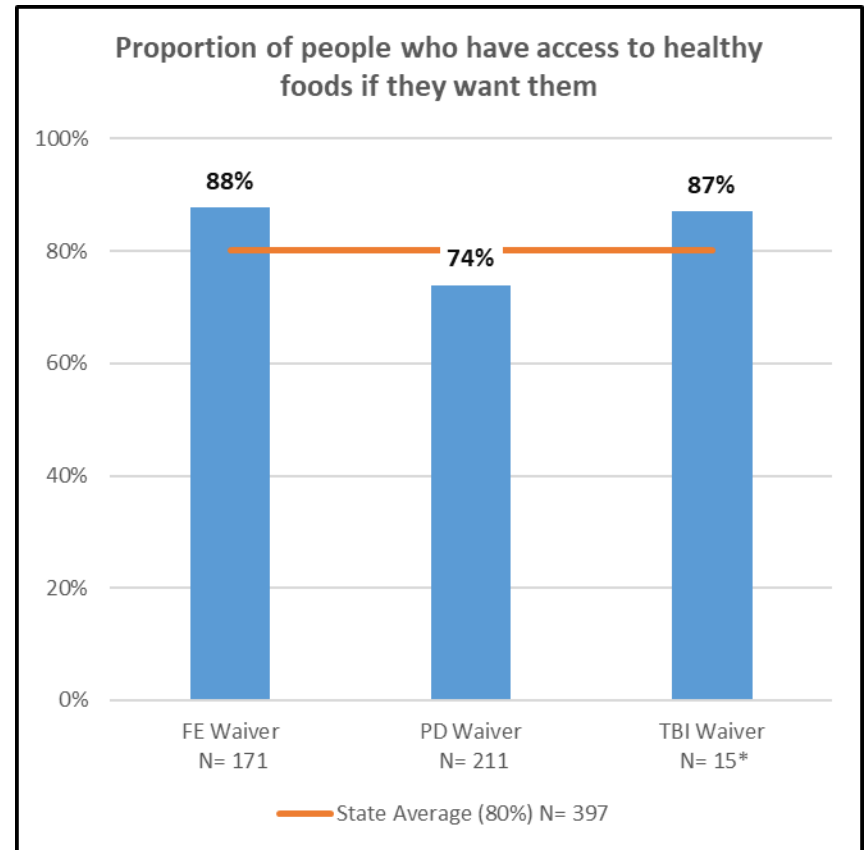
* Very small number of responses

Graph 83. Proportion of people whose vision was described as poor (with glasses or contacts, if wears any)



* Very small number of responses

Graph 84. Proportion of people who have access to healthy foods if they want them⁵⁹



* Very small number of responses

⁵⁹ Item previously reported in the “Everyday Living” domain.

Medications

Medications are managed effectively and appropriately.

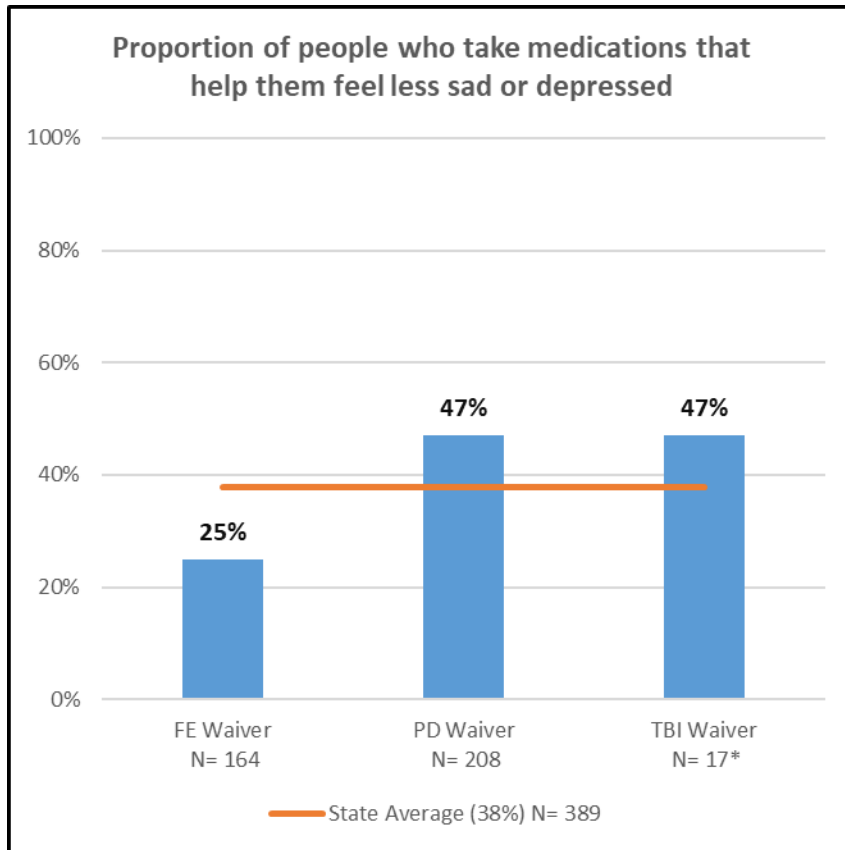
There are two Medication indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who take medications to help them feel less sad or depressed.
2. Proportion of people who know what their prescription medications are for.

There are two survey items that correspond to the Medication domain.

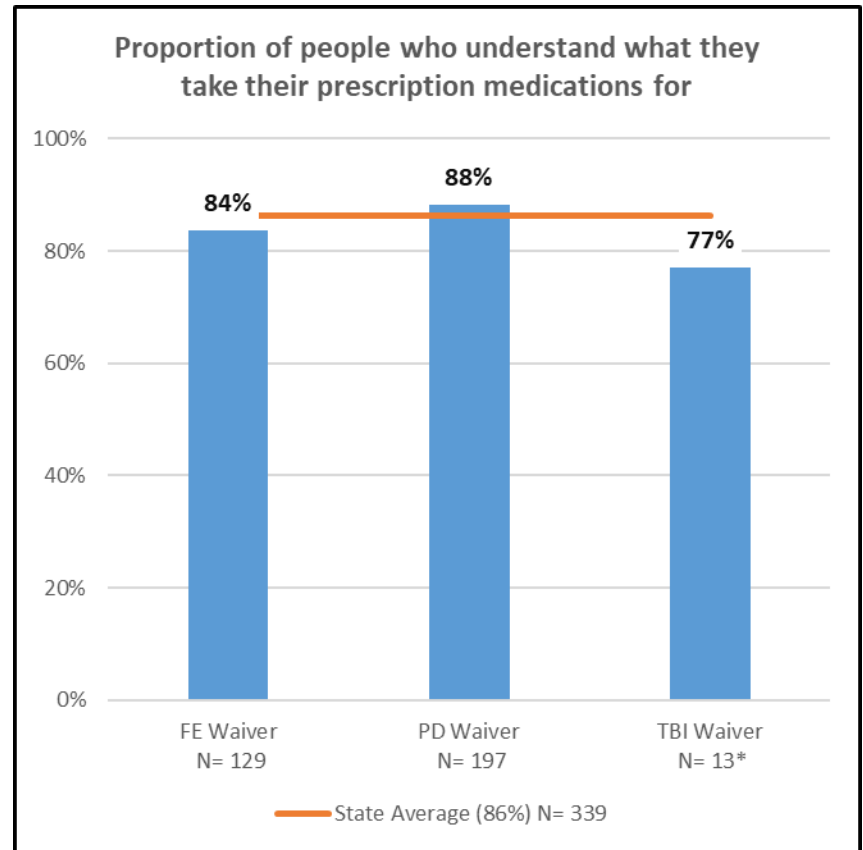
Un-collapsed data are shown in Appendix B.

Graph 85. Proportion of people who take medications that help them feel less sad or depressed



* Very small number of responses

Graph 86. Proportion of people who understand what they take their prescription medications for



* Very small number of responses

Rights and Respect

People receive the same respect and protections as others in the community.

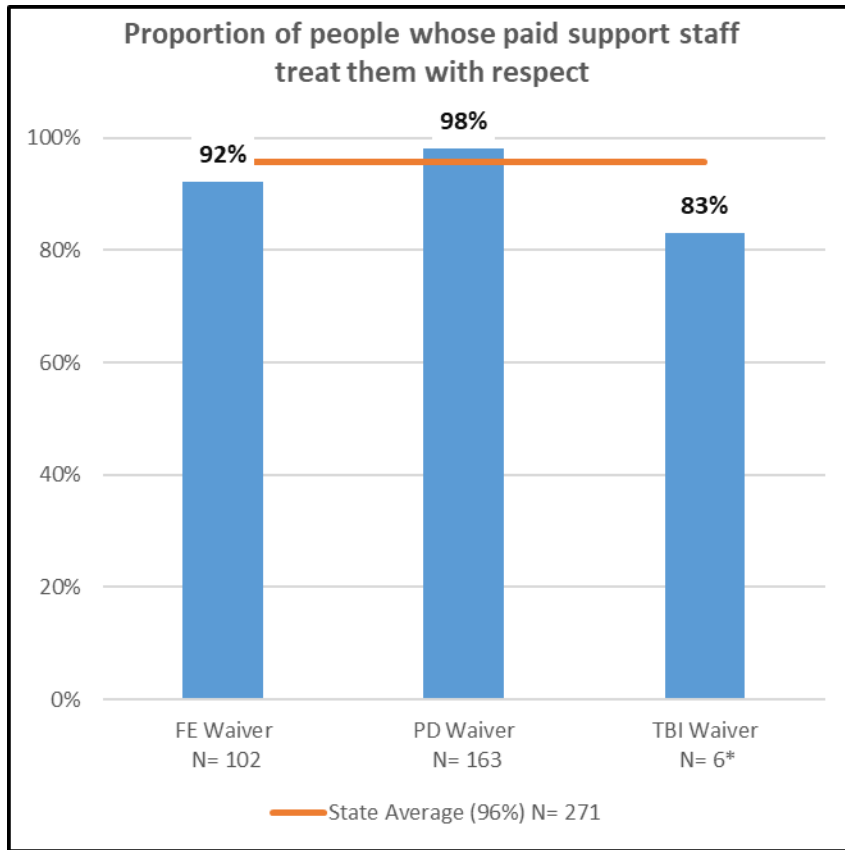
There are two Rights and Respect indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people whose basic rights are respected by others.
2. Proportion of people whose paid support staff treat them with respect.

There are six survey items that correspond to the Rights and Respect domain.

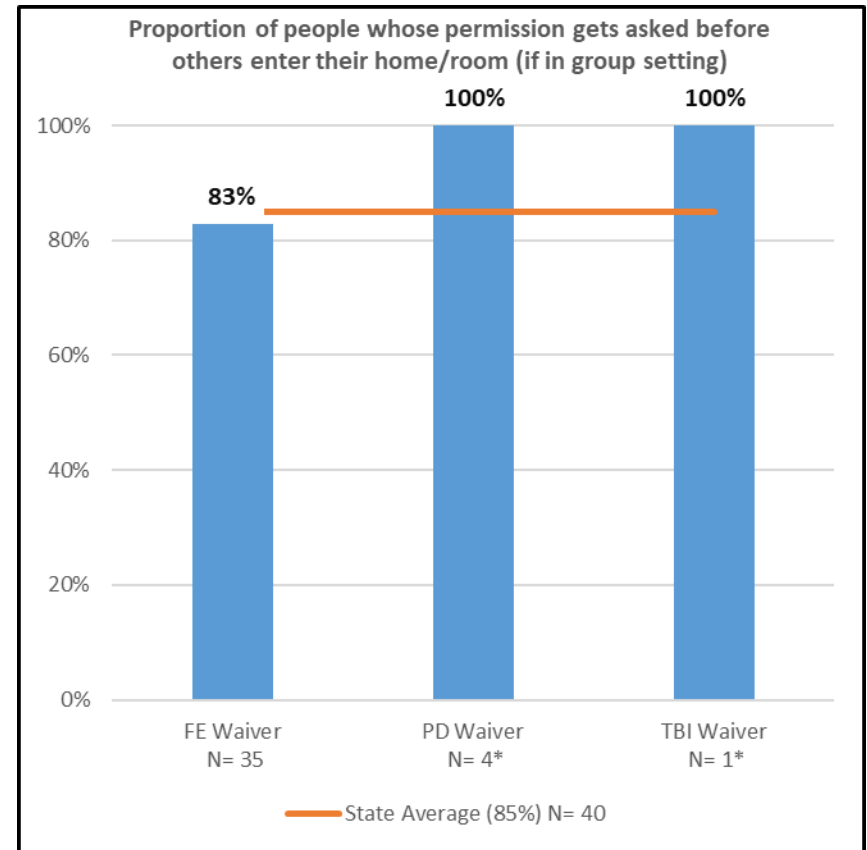
Un-collapsed data are shown in Appendix B.

Graph 87. Proportion of people whose paid support staff treat them with respect



* Very small number of responses

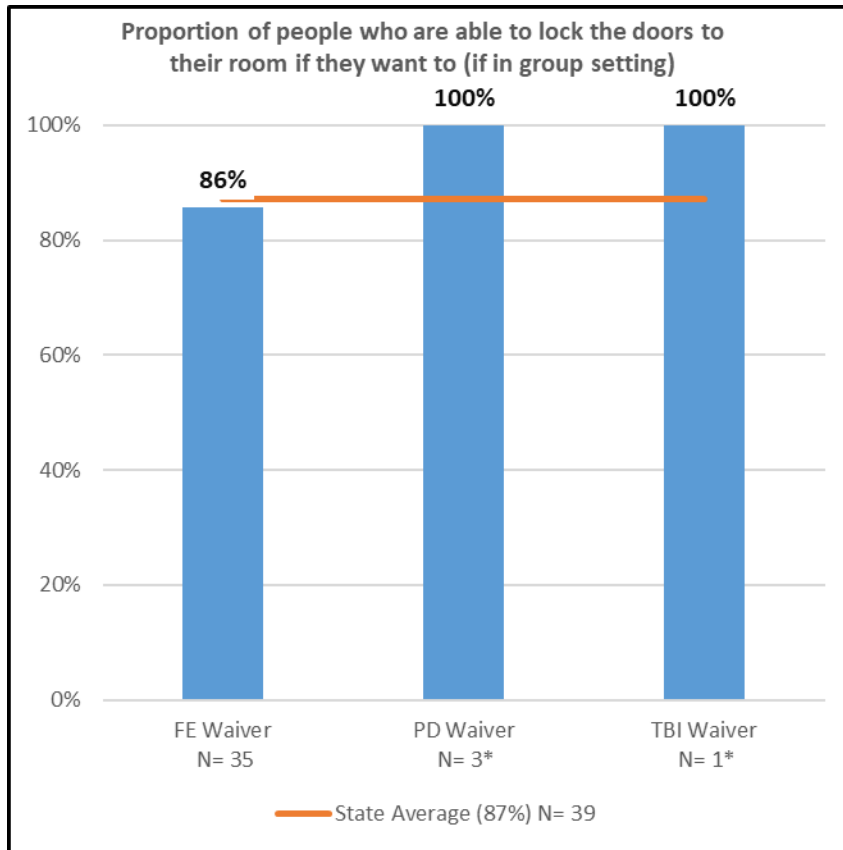
Graph 88. Proportion of people whose permission is asked before others enter their home/room (if in group setting)⁶⁰



* Very small number of responses

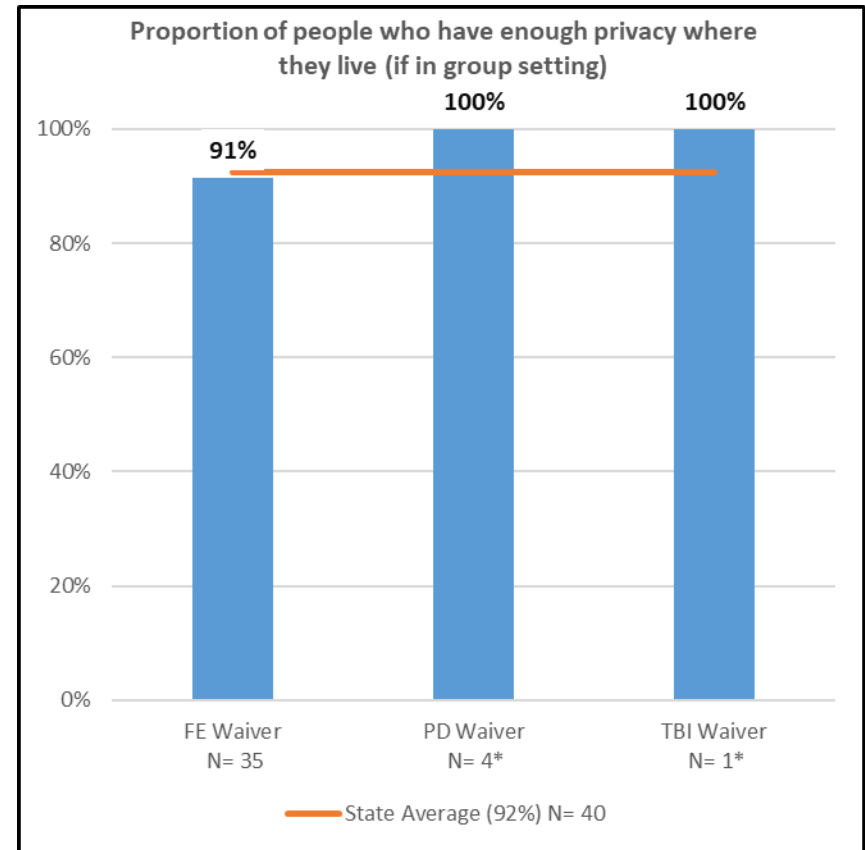
⁶⁰ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Graph 89. Proportion of people who are able to lock the doors to their room if they want to (if in group setting)⁶¹



* Very small number of responses

Graph 90. Proportion of people who have enough privacy where they live (if in group setting)⁶²

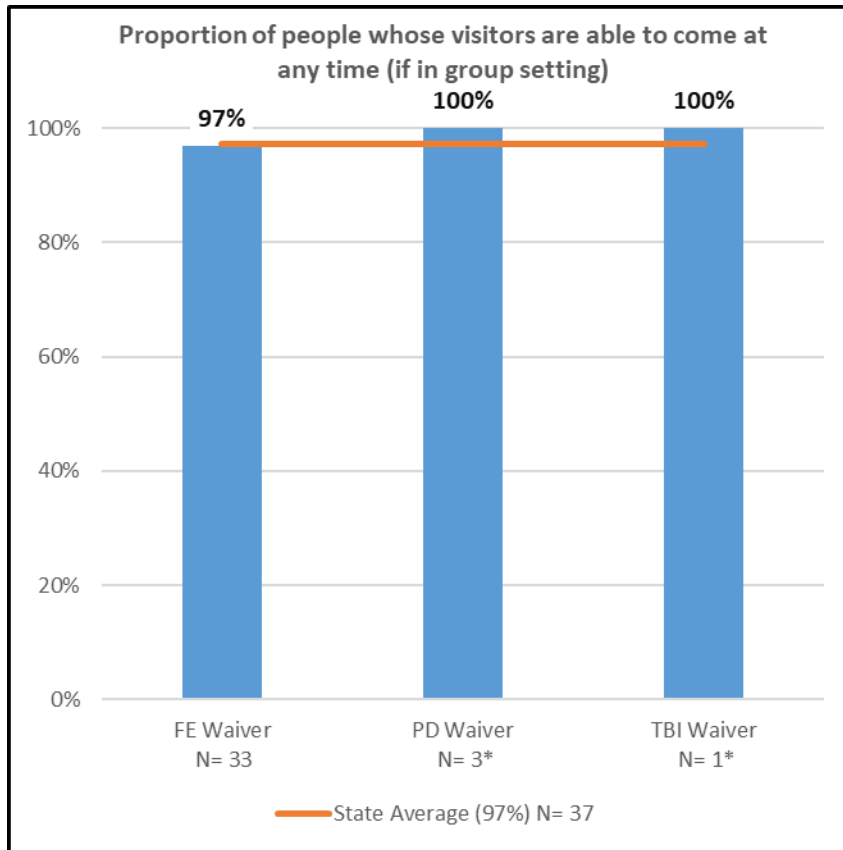


* Very small number of responses

⁶¹ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

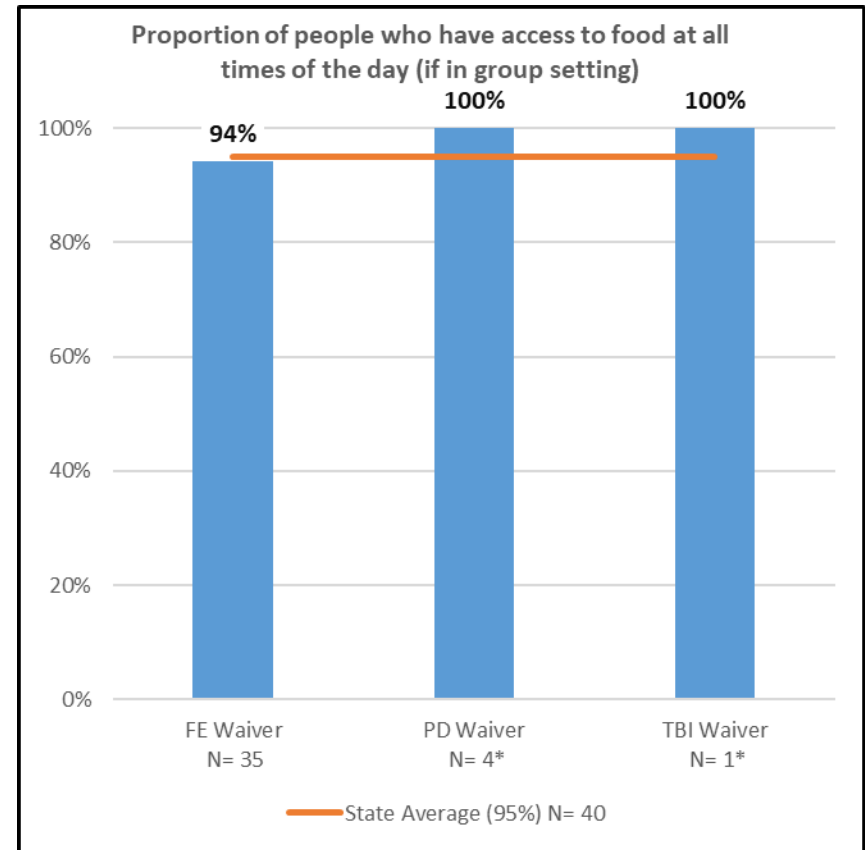
⁶² Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Graph 91. Proportion of people whose visitors are able to come at any time (if in group setting)⁶³



* Very small number of responses

Graph 92. Proportion of people who have access to food at all times of the day (if in group setting)⁶⁴



* Very small number of responses

⁶³ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

⁶⁴ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Self-Direction

People have authority and are supported to direct and manage their own services.

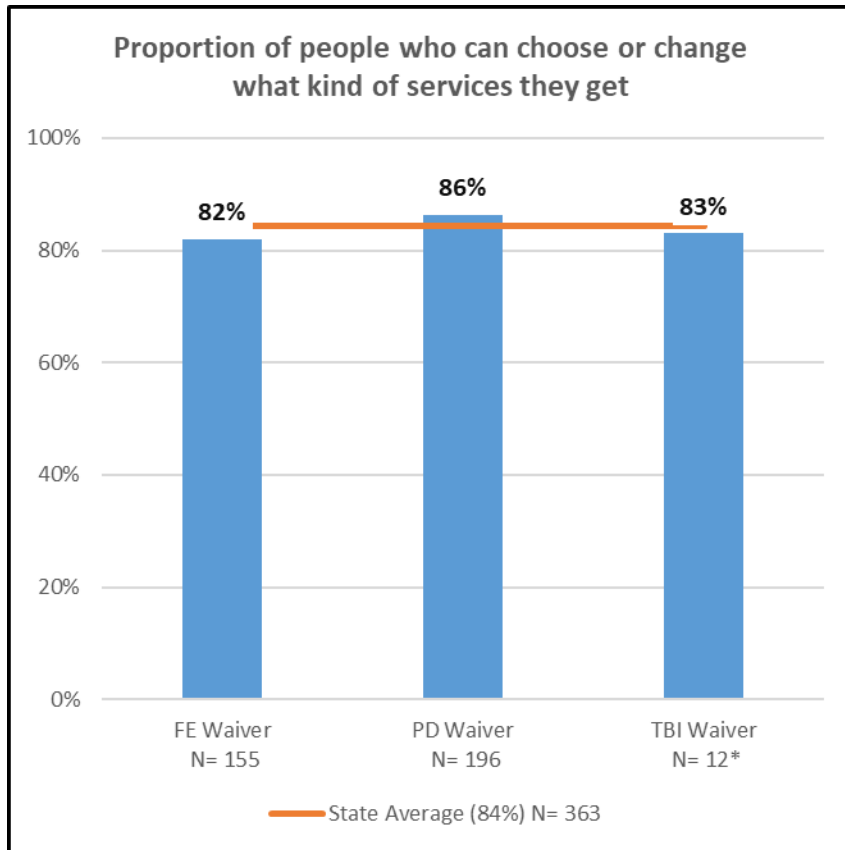
There is one Self-Direction indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who can choose or change the kind of services they receive and who provides them.

There are three survey items that correspond to the Self-Direction domain.

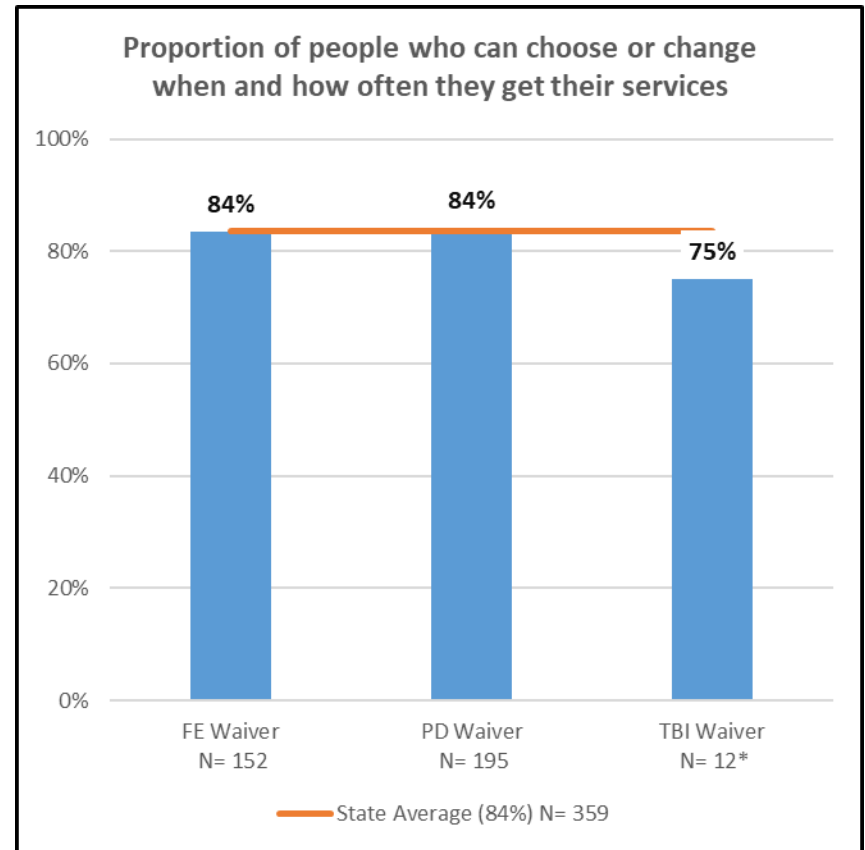
Un-collapsed data are shown in Appendix B.

Graph 93. Proportion of people who can choose or change what kind of services they get



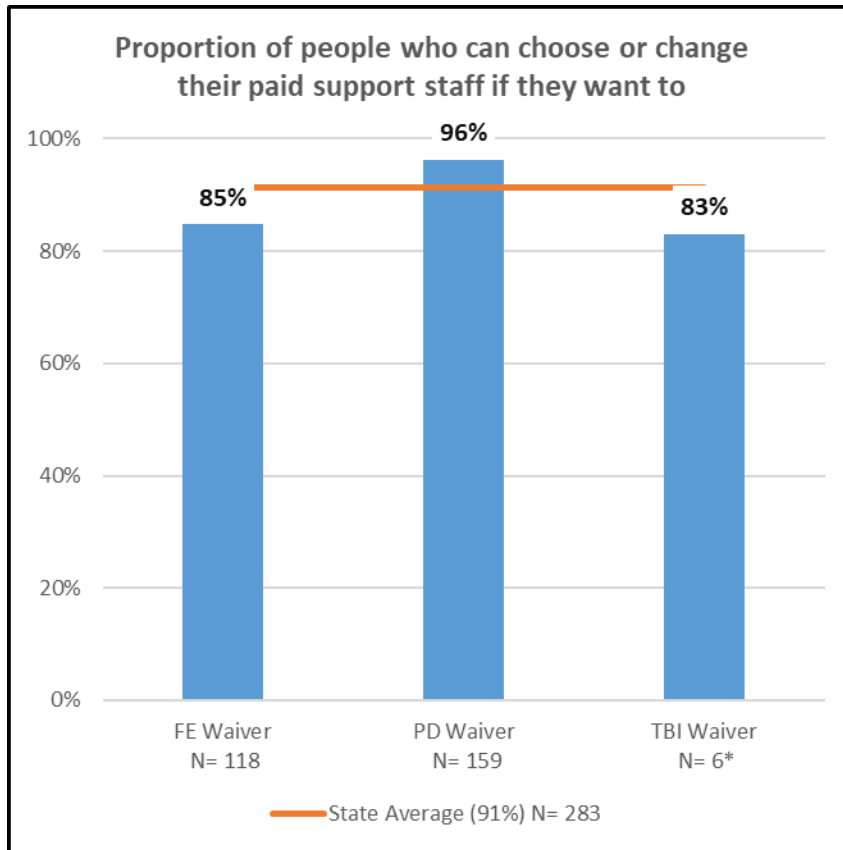
* Very small number of responses

Graph 94. Proportion of people who can choose or change when and how often they get their services



* Very small number of responses

Graph 95. Proportion of people who can choose or change their paid support staff if they want to



* Very small number of responses

Work

People have support to find and maintain community integrated employment if they want it.

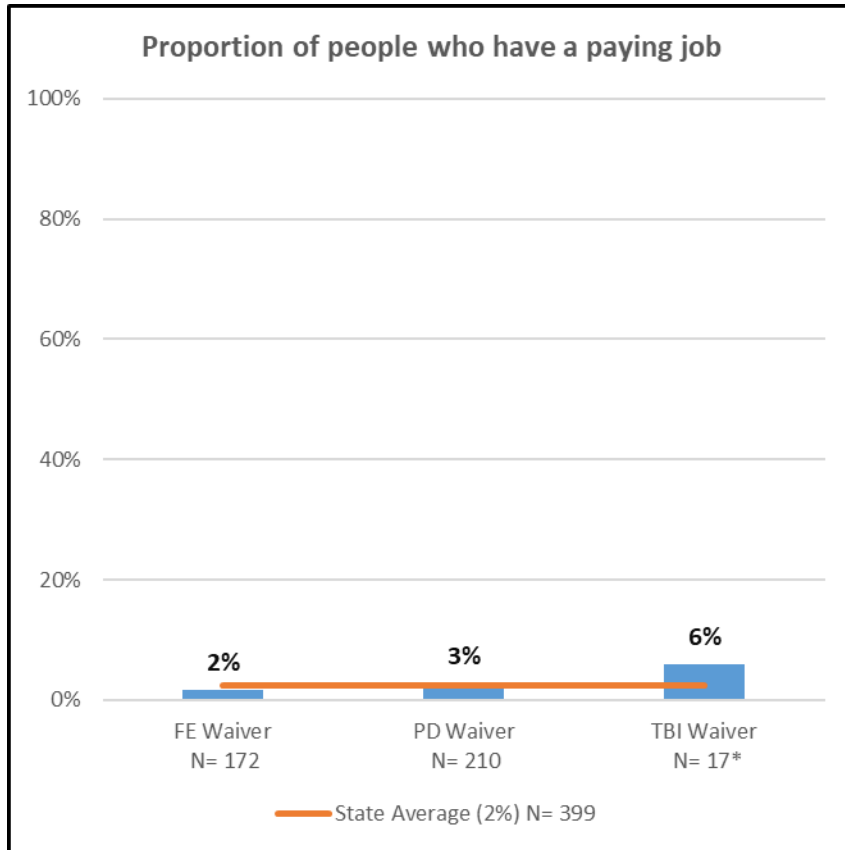
There are five Work indicators measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who have a paid job.
2. Proportion of people who would like a job.
3. Proportion of people who receive job search assistance.
4. Proportion of people who volunteer.
5. Proportion of people who would like to volunteer.

There are five survey items that correspond to the Work domain.

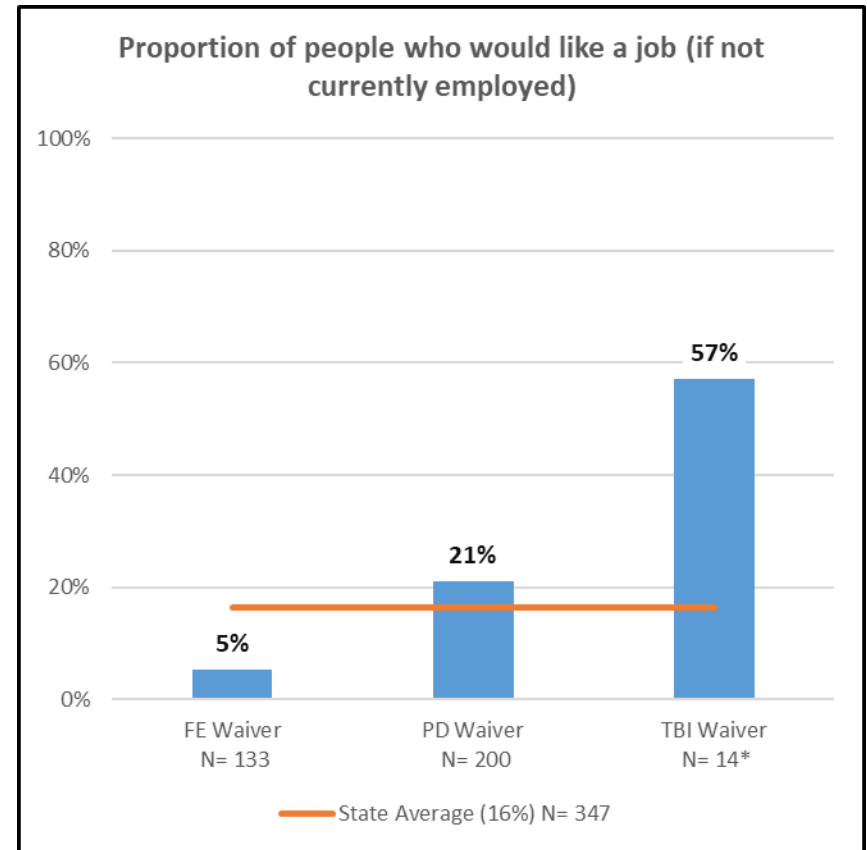
Un-collapsed data are shown in Appendix B.

Graph 96. Proportion of people who have a paying job



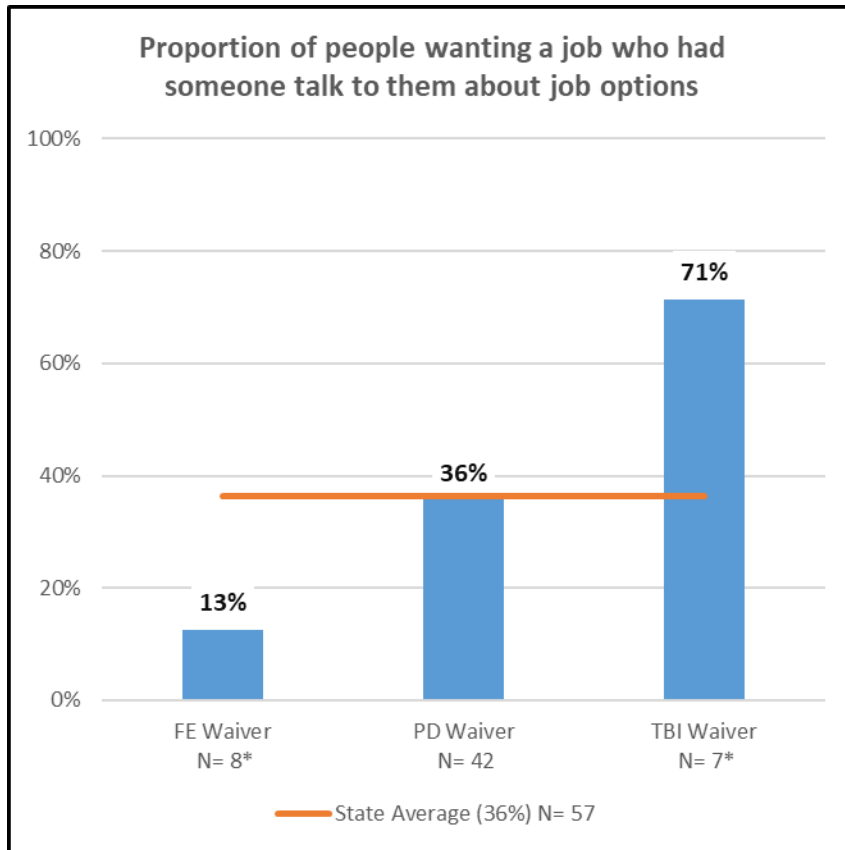
* Very small number of responses

Graph 97. Proportion of people who would like a job (if not currently employed)



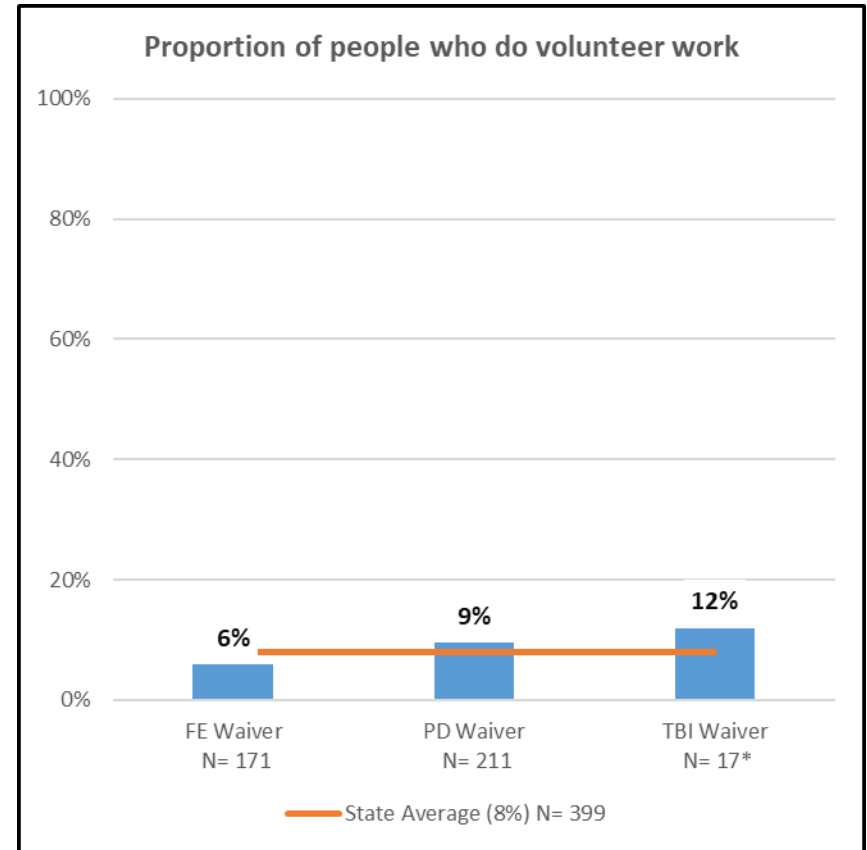
* Very small number of responses

Graph 98. Proportion of people wanting a job who had someone talk to them about job options



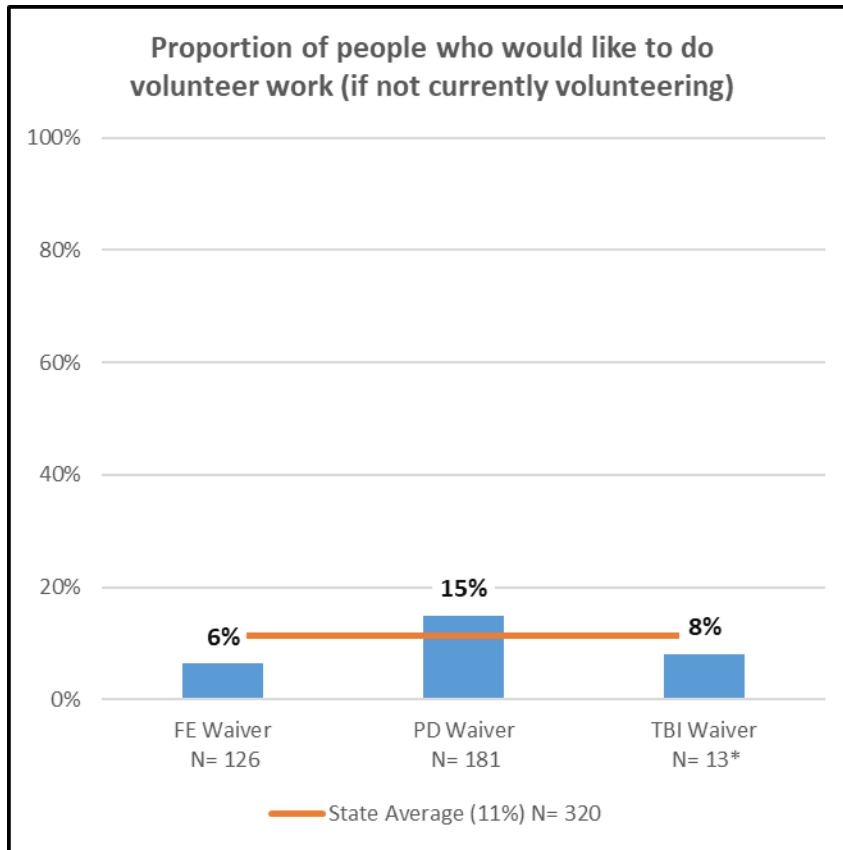
* Very small number of responses

Graph 99. Proportion of people who do volunteer work



* Very small number of responses

Graph 100. Proportion of people who would like to do volunteer work (if not currently volunteering)



* Very small number of responses

Everyday Living

People have enough supports for everyday living.

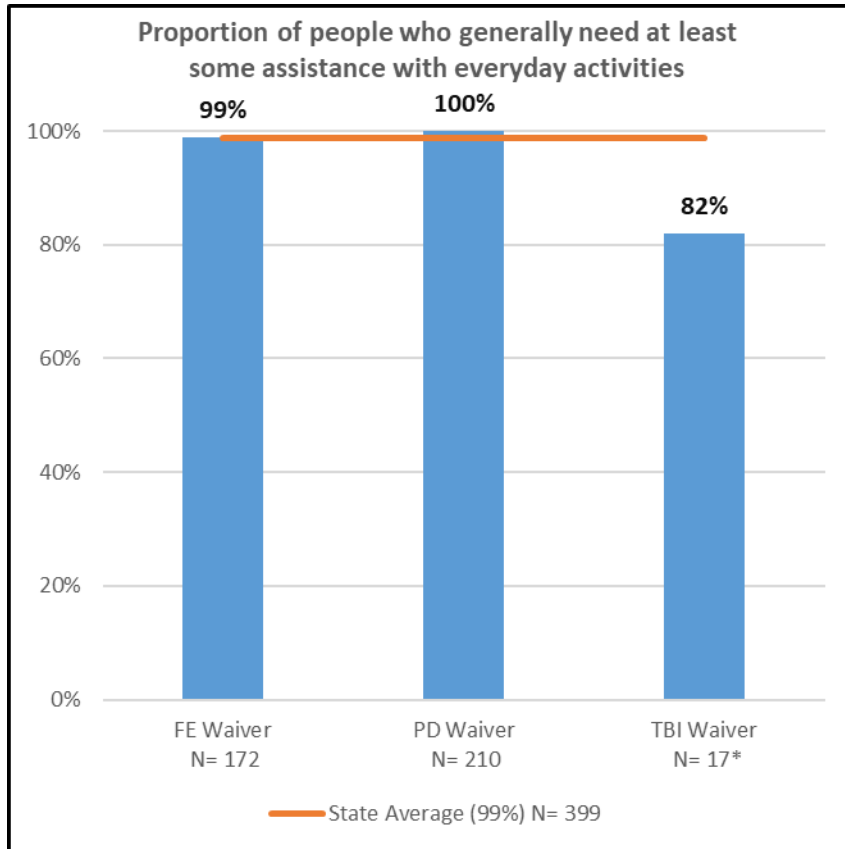
There is one Everyday Living indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who have adequate support to perform activities of daily living and instrumental activities of daily living.

There are four survey items that correspond to the Everyday Living domain.

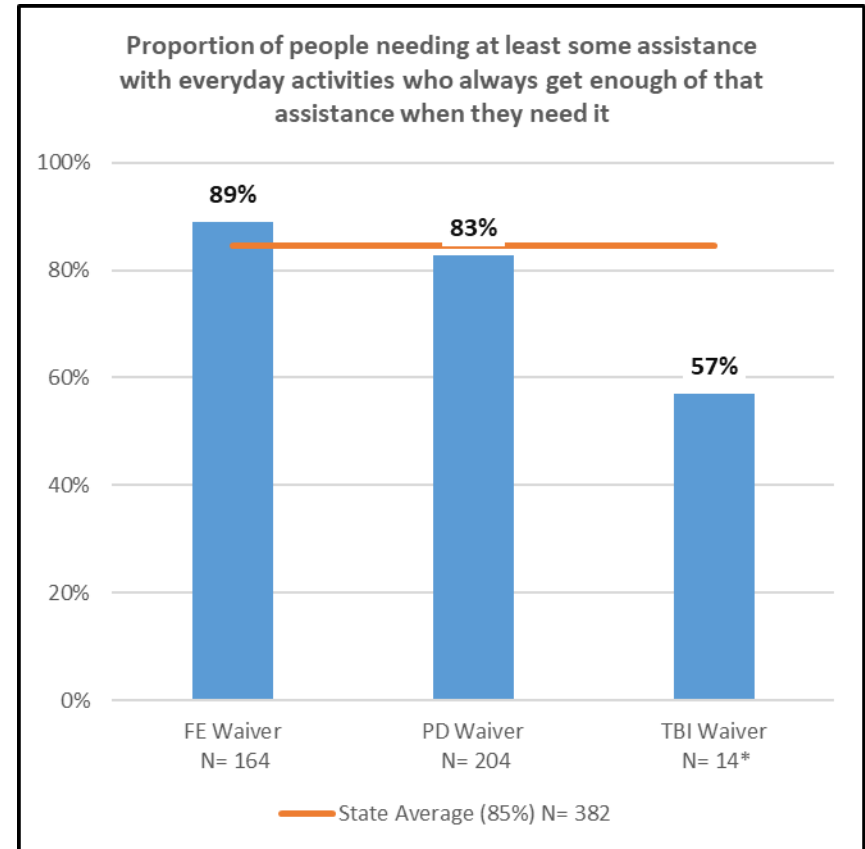
Un-collapsed data are shown in Appendix B.

Graph 101. Proportion of people who generally need at least some assistance with everyday activities (such as preparing meals, housework, shopping or taking their medications)



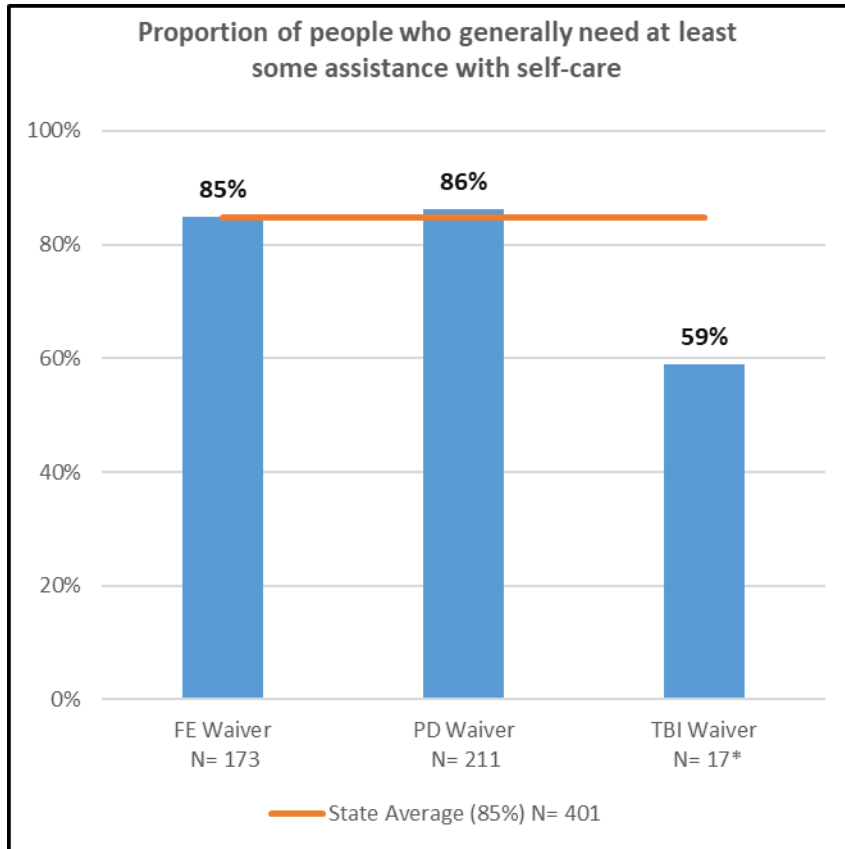
* Very small number of responses

Graph 102. Proportion of people needing at least some assistance with everyday activities who always get enough of that assistance when they need it



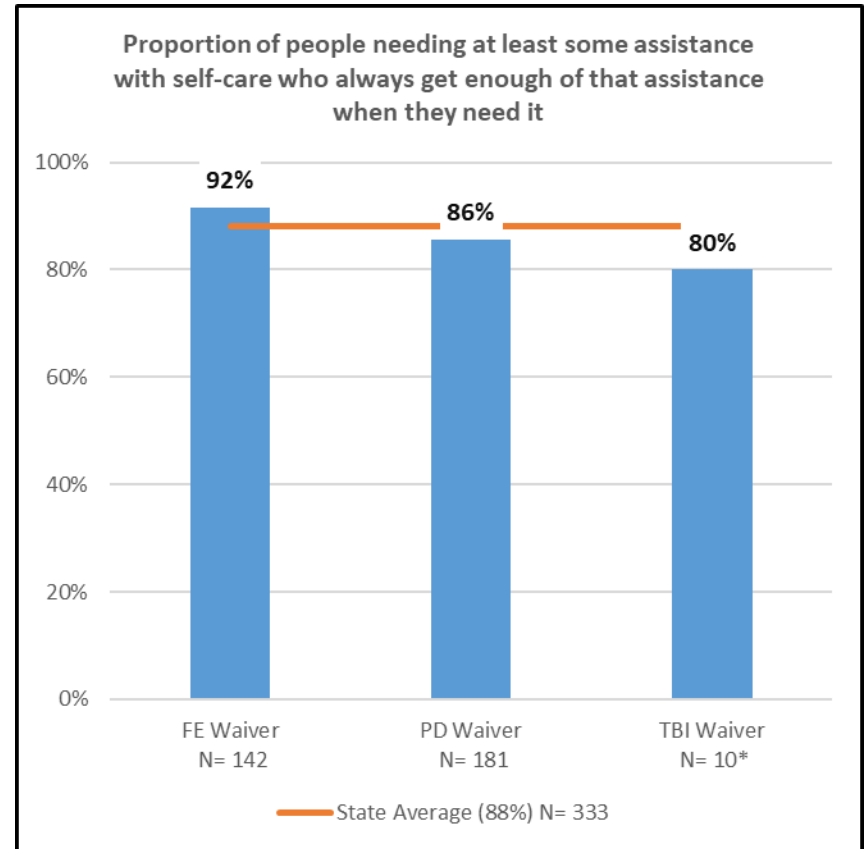
* Very small number of responses

Graph 103. Proportion of people who generally need at least some assistance with self-care (such as bathing, dressing, going to the bathroom, eating, or moving around their home)



* Very small number of responses

Graph 104. Proportion of people needing at least some assistance with self-care who always get enough of that assistance when they need it



* Very small number of responses

Affordability

People have enough available resources.

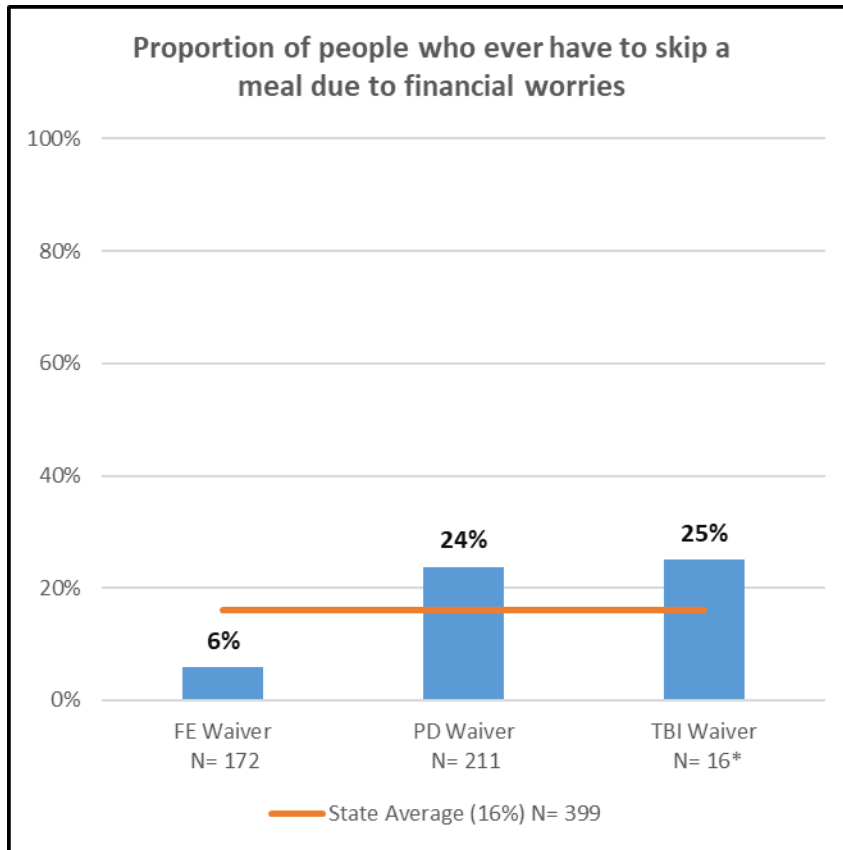
There is one Affordability indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who have to cut back on food because of money.

There is one survey item that corresponds to the Affordability domain.

Un-collapsed data are shown in Appendix B.

Graph 105. Proportion of people who ever have to skip a meal due to financial worries



* Very small number of responses

Control

People feel in control of their lives

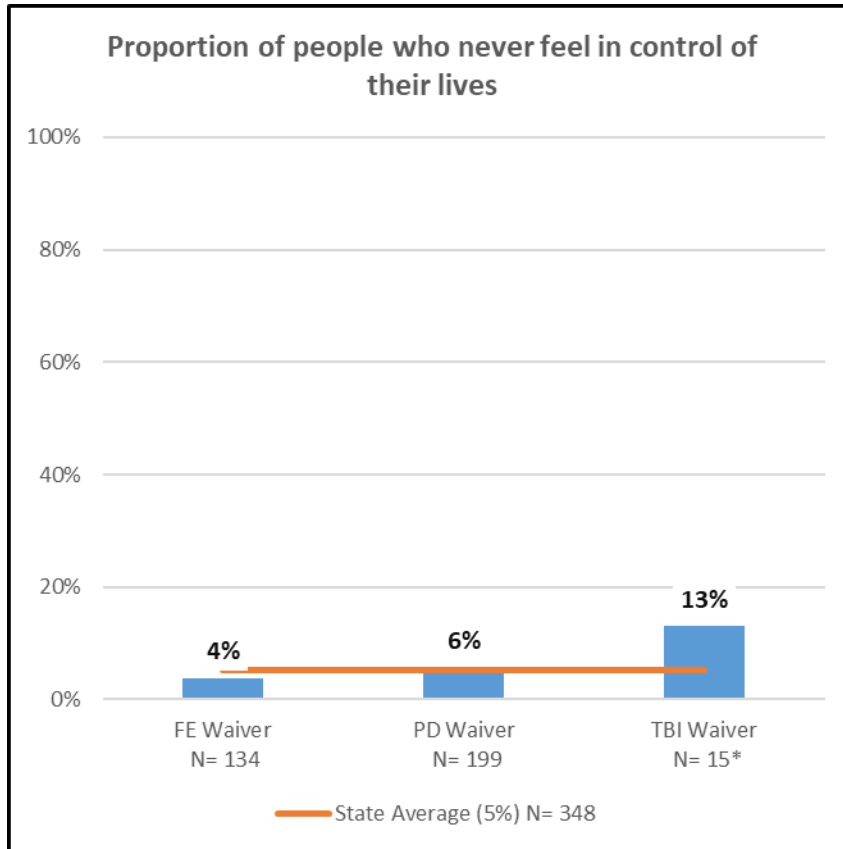
There is one Control indicator measured by the NCI-AD Adult Consumer Survey:

1. Proportion of people who feel in control of their lives.

There is one survey item that corresponds to the Control domain.

Un-collapsed data are shown in Appendix B.

Graph 106. Proportion of people who never feel in control of their lives



* Very small number of responses

Appendix A: Rules for Recoding and Collapsing Responses

Table A1 below details collapsing rules for recoding survey items with three or more response options into binary variables used for analysis. The table also specifies which graphs in this report contain recoded items, as well as their associated NCI-AD domains. Unless otherwise stated, “Don’t Know” and “Unclear/Refused” responses are excluded.

Table A1. Outcome Variables – Collapsing Rules

Domain	Item	Graph #	Collapsing Logic
Community Participation	Proportion of people who are as active in their community as they would like to be	1	Collapse “No” and “Sometimes”
Choice and Decision Making	Proportion of people who get up and go to bed when they want to	4	Collapse “Some days, sometimes” and “No, never”
	Proportion of people who can eat their meals when they want to	5	Collapse “Some days, sometimes” and “No, never”
	Proportion of people who are able to furnish and decorate their room however they want to (if in group setting)	6	Collapse “In all ways” and “In most ways”
Relationships	Proportion of people who are always able to see or talk to friends and family when they want to (if there are friends and family who do not live with person)	7	Collapse “Most of the time, usually, or some family and/or friends” and “No, or rarely”
Satisfaction	Proportion of people who like where they are living	8	Collapse “In-between, most of the time” and “No”
	Proportion of people who would prefer to live somewhere else	9	Collapse “Yes” and “Maybe”
	Proportion of people who like how they spend their time during the day	10	Collapse “Some days, sometimes” and “No, never”
	Proportion of people whose paid support staff change too often	11	Collapse “Yes” and “Some, or sometimes”
	Proportion of people whose paid support staff do things the way they want them done	12	Collapse “Some, or usually” and “No, never or rarely”
Service Coordination	Proportion of people who know whom to contact if they want to make changes to their services	13	Collapse “Not sure, maybe” and “No”
	Proportion of people who know whom to contact if they need help with services or have a complaint	14	Collapse “Not sure, maybe” and “No”
	Proportion of people whose paid support staff show up and leave when they are supposed to	15	Collapse “Some, or usually” and “No, never or rarely”

Domain	Item	Graph #	Collapsing Logic
	Proportion of people whose long-term care services meet all their current needs and goals	18	Collapse “No, not at all” and “Some needs and goals”
	Proportion of people whose family member (paid or unpaid) is the person who helps them most often (if anyone provides support on a regular basis)	20	Collapse “Paid family member or spouse/partner” and “Unpaid family member or spouse/partner”
	Proportion of people who have a family member (paid or unpaid) providing additional assistance (if anyone provides support on a regular basis)	21	Collapse “Paid family member or spouse/partner” and “Unpaid family member or spouse/partner”
	Proportion of people who can reach their case manager/care coordinator when they need to (if know they have case manager/care coordinator)	23	Collapse “Most of the time, usually” and “No, or only sometimes”
	Proportion of people who receive information about their services in the language they prefer (if non-English)	24	Collapse “No” and “Some information”
Care Coordination	Proportion of people who felt comfortable and supported enough to go home (or where they live) after being discharged from a hospital or rehabilitation facility in the past year	26	Collapse “No” and “In-between”
	Proportion of people who know how to manage their chronic condition(s)	28	Collapse “No” and “In-between, or some conditions”
	Proportion of people with concerns about falling or being unstable	29	Collapse “Yes, often” and “Sometimes”
Access to Community	Proportion of people who have transportation when they want to do things outside of their home (non-medical)	31	Collapse “No” and “Sometimes”
	Proportion of people who have transportation to get to medical appointments when they need to	32	Collapse “No” and “Sometimes”
Access to Needed Equipment	Proportion of people who need grab bars in the bathroom or elsewhere in their home but do not have them	33	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have grab bars in the bathroom or elsewhere in their home but need a replacement	34	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need bathroom modifications (other than grab bars) but do not have them	35	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have bathroom modifications (other than grab bars) but need a replacement	36	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”

Domain	Item	Graph #	Collapsing Logic
	Proportion of people who need a specialized bed but do not have it	37	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a specialized bed but need a replacement	38	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a ramp or stair lift in or outside the home but do not have it	39	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a ramp or stair lift in or outside the home but need a replacement	40	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need some other home modification but do not have it	41	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have some other home modification but need a replacement	42	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a walker but do not have it	43	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a walker but need a replacement	44	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a scooter but do not have it	45	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a scooter but need a replacement	46	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a wheelchair but do not have it	47	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a wheelchair but need a replacement	48	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need hearing aids but do not have them	49	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have hearing aids but need a replacement	50	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need glasses but do not have them	51	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”

Domain	Item	Graph #	Collapsing Logic
	Proportion of people who have glasses but need a replacement	52	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a CPAP machine but do not have it	53	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a CPAP machine but need a replacement	54	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need a personal emergency response system but do not have it	55	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have a personal emergency response system but need a replacement	56	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need an oxygen machine but do not have it	57	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have an oxygen machine but need a replacement	58	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who need some other assistive device but do not have it	59	Collapse “Has one, but needs replacement”, “Has one and doesn’t need replacement”, and “Doesn’t need”
	Proportion of people who have some other assistive device but need a replacement	60	Collapse “Needs one”, “Has one and doesn’t need replacement”, and “Doesn’t need”
Health Care	Proportion of people who can get an appointment to see their primary care doctor when they need to	70	Collapse “Usually” and “No, rarely”
Wellness	Proportion of people whose health was described as poor	77	Collapse “Excellent”, “Very good”, “Good” and “Fair”
	Proportion of people whose health was described as having gotten better compared to 12 months ago	78	Collapse “Much better” and “Somewhat better”; Collapse “Much worse”, “Somewhat worse” and “About the same”
	Proportion of people who often feel sad or depressed	81	Collapse “Never, or almost never”, “Not often”, and “Sometimes”
	Proportion of people whose hearing was described as poor (with hearing aids, if wears any)	82	Collapse “Good” and “Fair”
	Proportion of people whose vision was described as poor (with glasses or contacts, if wears any)	83	Collapse “Good” and “Fair”

Domain	Item	Graph #	Collapsing Logic
	Proportion of people who have access to healthy foods if they want them	84	Collapse “No, never” and “Sometimes”
Medications	Proportion of people who understand what they take their prescription medications for	86	Collapse “No” and “In-between, or some medications”
Rights and Respect	Proportion of people whose paid support staff treat them with respect	87	Collapse “No, never or rarely” and “Some, or usually”
	Proportion of people whose permission is asked before others enter their home/room (if in group setting)	88	Collapse “Sometimes, rarely or never” and “Usually, but not always”
	Proportion of people who have enough privacy where they live (if in group setting)	90	Collapse “Sometimes, rarely or never” and “Usually, but not always”
Self-Direction of Care	Proportion of people who can choose or change what kind of services they get	93	Collapse “No” and “Sometimes, or some services”
	Proportion of people who can choose or change when and how often they get their services	94	Collapse “No” and “Sometimes, or some services”
	Proportion of people who can choose or change their paid support staff if they want to	95	Collapse “No” and “Sometimes, or some”
Work	Proportion of people who would like a job (if not currently employed)	97	Collapse “Yes” and “Maybe, not sure”
	Proportion of people who would like to do volunteer work (if not currently volunteering)	100	Collapse “Yes” and “Maybe, not sure”
Everyday Living	Proportion of people who generally need at least some assistance with everyday activities (such as preparing meals, housework, shopping or taking their medications)	101	Collapse “A lot” and “Some”
	Proportion of people who generally need at least some assistance with self-care (such as bathing, dressing, going to the bathroom, eating, or moving around their home)	103	Collapse “A lot” and “Some”
Affordability	Proportion of people who ever have to skip a meal due to financial worries	105	Collapse “Yes, often” and “Sometimes”
Control	Proportion of people who never feel in control of their lives	106	Collapse “Yes, almost always, always” and “In-between, sometimes”

Appendix B: Un-Collapsed and Unweighted Data by Program

Demographic Characteristics

Table 1. Average age (reported for those under 90 years of age)

	Average Age	N
FE Waiver	77	146
PD Waiver	57	213
TBI Waiver	45	17
Sample Average	64	376

Table 2. Age: 90 years and over

	Under 90	90 and Over	Don't Know/Unclear	N
FE Waiver	84%	16%	0%	173
PD Waiver	100%	0%	0%	213
TBI Waiver	100%	0%	0%	17
Sample Average	93%	7%	0%	403

Table 3. Gender

	Male	Female	Other	Don't Know/Unclear	N
FE Waiver	21%	79%	0%	0%	172
PD Waiver	34%	66%	0%	0%	210
TBI Waiver	53%	47%	0%	0%	17
Sample Average	29%	71%	0%	0%	399

Table 4. Race and ethnicity

	American Indian or Alaska Native	Asian	Black or African-American	Pacific Islander	White	Hispanic or Latino	Other	Don't Know/ Unclear	N
FE Waiver	1%	3%	20%	1%	72%	3%	2%	0%	173
PD Waiver	3%	0%	25%	0%	69%	2%	0%	0%	213
TBI Waiver	0%	0%	29%	0%	65%	6%	0%	0%	17
Sample Average	2%	1%	23%	0%	70%	3%	1%	0%	403

Table 5. Marital status

	Single, Never Married	Married or Has Domestic Partner	Separated or Divorced	Widowed	Don't Know/ Unclear	N
FE Waiver	13%	14%	31%	42%	0%	173
PD Waiver	39%	15%	38%	7%	0%	213
TBI Waiver	65%	6%	18%	12%	0%	17
Sample Average	29%	15%	34%	22%	0%	403

Table 6. Primary language

	English	Spanish	Other	Don't Know/ Unclear	N
FE Waiver	89%	1%	10%	0%	173
PD Waiver	100%	0%	0%	0%	213
TBI Waiver	94%	0%	6%	0%	17
Sample Average	95%	0%	5%	0%	403

Table 7. Type of residential area⁶⁵

	Metropolitan	Micropolitan	Rural	Small town	Unknown	N
FE Waiver	64%	14%	8%	13%	2%	173
PD Waiver	54%	23%	7%	15%	0%	213
TBI Waiver	71%	0%	12%	18%	0%	17
Sample Average	59%	18%	7%	14%	1%	403

Table 8. Type of residence

	Own or Family House/Apt	Senior Living Apt/Complex	Group/Adult Family/ Foster/ Host Home	Assisted Living/ Residential Care Facility	Nursing Facility/ Nursing Home	Homeless/ Temporary Shelter	Other	Don't Know/ Unclear	N
FE Waiver	60%	11%	1%	27%	1%	0%	1%	0%	173
PD Waiver	94%	3%	0%	1%	0%	0%	1%	0%	212
TBI Waiver	82%	6%	0%	6%	0%	0%	6%	0%	17
Sample Average	79%	7%	0%	12%	0%	0%	1%	0%	402

Table 9. Who else lives with the person

	No One – Lives Alone	Spouse or Partner	Other Family	Friend(s)	Live-in PCA	Others	Don't Know/ Unclear	N
FE Waiver	57%	12%	18%	0%	2%	12%	0%	173
PD Waiver	61%	15%	25%	2%	0%	1%	0%	210
TBI Waiver	50%	6%	38%	0%	6%	6%	0%	16
Sample Average	59%	14%	22%	1%	2%	6%	0%	399

⁶⁵ Categories created using zip codes and corresponding RUCA codes: Metropolitan - Metropolitan area core, high commuting low commuting; Micropolitan - Micropolitan area core, high commuting, low commuting; Small town - Small town core, high commuting, low commuting; Rural

Table 10. Address changed in the past 6 months

	No	Yes	Don't Know/Unclear	N
FE Waiver	91%	9%	0%	171
PD Waiver	89%	11%	0%	213
TBI Waiver	81%	19%	0%	16
Sample Average	89%	11%	0%	400

Table 11. Where the person moved from (if address changed in the past 6 months)

	Own or Family House/Apt	Senior Living Apt/Complex	Group/Adult Family/ Foster/ Host Home	Assisted Living/ Residential Care Facility	Nursing Facility/ Nursing Home	Homeless/ Temporary Shelter	Other	Don't Know/Unclear	N
FE Waiver	94%	0%	0%	6%	0%	0%	0%	0%	16
PD Waiver	96%	0%	0%	4%	0%	0%	0%	0%	24
TBI Waiver	67%	0%	0%	0%	0%	33%	0%	0%	3
Sample Average	93%	0%	0%	5%	0%	2%	0%	0%	43

Table 12. Formal diagnosis: physical disability

	No	Yes	Don't Know/Unclear	N
FE Waiver	26%	73%	1%	173
PD Waiver	0%	100%	0%	212
TBI Waiver	47%	53%	0%	17
Sample Average	13%	86%	0%	402

Table 13. Formal diagnosis: Alzheimer’s disease or other dementia

	No	Yes	Don’t Know/Unclear	N
FE Waiver	74%	23%	2%	171
PD Waiver	97%	2%	1%	207
TBI Waiver	100%	0%	0%	17
Sample Average	87%	11%	2%	395

Table 14. Formal diagnosis: traumatic or acquired brain injury

	No	Yes	Don’t Know/Unclear	N
FE Waiver	95%	3%	1%	172
PD Waiver	88%	12%	0%	211
TBI Waiver	6%	94%	0%	17
Sample Average	88%	12%	1%	400

Table 15. Formal diagnosis: intellectual or other developmental disability

	No	Yes	Don’t Know/Unclear	N
FE Waiver	95%	3%	2%	172
PD Waiver	95%	5%	0%	210
TBI Waiver	94%	6%	0%	17
Sample Average	95%	4%	1%	399

Table 16. Level of mobility

	Non-ambulatory	Moves Self with Wheelchair	Moves Self with Other Aids	Moves Self Without Aids	Don't know/Unclear	N
FE Waiver	6%	13%	63%	22%	0%	171
PD Waiver	2%	20%	56%	36%	0%	213
TBI Waiver	6%	18%	29%	53%	0%	17
Sample Average	4%	17%	58%	31%	0%	401

Table 17. History of frequent falls (more than two in a six-month period)

	No	Yes	Don't Know/Unclear	N
FE Waiver	72%	27%	1%	172
PD Waiver	66%	34%	0%	212
TBI Waiver	76%	24%	0%	17
Sample Average	69%	31%	0%	401

Table 18. Receives Medicare

	No	Yes	Don't Know/Unclear	N
FE Waiver	4%	96%	0%	170
PD Waiver	32%	68%	0%	208
TBI Waiver	41%	59%	0%	17
Sample Average	21%	79%	0%	395

Table 19. Length of receiving LTSS in current program

	0-5 months	6 months-less than 1 year	1 year-less than 3 years	3 or more years	Don't know	N
FE Waiver	3%	13%	27%	56%	0%	172
PD Waiver	1%	7%	20%	72%	0%	211
TBI Waiver	13%	0%	31%	56%	0%	16
Sample Average	3%	10%	24%	64%	0%	399

Table 20. Has legal guardian

	No	Yes	Don't Know	N
FE Waiver	91%	9%	0%	170
PD Waiver	97%	3%	0%	213
TBI Waiver	82%	18%	0%	17
Sample Average	94%	6%	0%	400

Table 21. Proportion of people participating in a self-directed supports option (as defined and reported by the State – data derived from administrative records)

	No	Yes	Don't Know	N
FE Waiver	48%	52%	0%	172
PD Waiver	20%	80%	0%	212
TBI Waiver	47%	53%	0%	17
Sample Average	33%	67%	0%	401

Community Participation

Table 22. Proportion of people who are as active in their community as they would like to be

	No	Sometimes	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	16%	12%	71%	1%	0%	137
PD Waiver	27%	16%	56%	0%	0%	206
TBI Waiver	27%	27%	47%	0%	0%	15
Sample Average	23%	15%	61%	1%	0%	358

Table 23a. Reasons that people are not as active in the community as they would like to be

	Cost/Money	Transportation	Accessibility/Lack of Equipment	Health Limitations	Not Enough Staffing/Assistance	Feeling Unwelcome in Community	N
FE Waiver	37%	29%	3%	68%	5%	0%	38
PD Waiver	37%	29%	7%	79%	6%	3%	89
TBI Waiver	75%	63%	13%	50%	13%	0%	8
Sample Average	39%	31%	6%	74%	6%	2%	135

Table 23b. Reasons that people are not as active in the community as they would like to be (continued)

	Feels Unsafe	No Activities Outside of Home	Lack of Info/Doesn't Know What's Available	Other	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	5%	3%	5%	0%	0%	38
PD Waiver	4%	2%	0%	4%	0%	0%	89
TBI Waiver	13%	0%	0%	0%	13%	0%	8
Sample Average	4%	3%	1%	4%	1%	0%	135

Table 24. Proportion of people who get to do the things they enjoy outside of their home as much as they want to

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	19%	75%	4%	2%	137
PD Waiver	31%	67%	1%	1%	204
TBI Waiver	27%	73%	0%	0%	15
Sample Average	26%	71%	2%	1%	356

Choice and Decision Making

Table 25. Proportion of people who are able to choose their roommate (if in group setting⁶⁶ and have roommates)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	25%	63%	13%	0%	8
PD Waiver	0%	100%	0%	0%	1
TBI Waiver	n/a	n/a	n/a	n/a	0
Sample Average	22%	67%	11%	0%	9

Table 26. Proportion of people who get up and go to bed when they want to

	No, Never	Some Days, Sometimes	Yes, Always/Almost Always	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	1%	98%	0%	1%	136
PD Waiver	0%	4%	95%	0%	0%	203
TBI Waiver	0%	7%	93%	0%	0%	15
Sample Average	0%	3%	96%	0%	0%	354

Table 27. Proportion of people who can eat their meals when they want to

	No, Never	Some Days, Sometimes	Yes, Always, Or Almost Always	N/A – Unable to Eat Due to Medical Condition	Don't Know	Unclear/Refused/No Response	N
FE Waiver	4%	5%	91%	0%	0%	0%	137
PD Waiver	0%	4%	96%	0%	0%	0%	205
TBI Waiver	0%	0%	100%	0%	0%	0%	14
Sample Average	2%	4%	94%	0%	0%	0%	356

⁶⁶ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Table 28. Proportion of people who are able to furnish and decorate their room however they want to (if in group setting⁶⁷)

	Only in Some Ways, or Not at All	In Most Ways	In All Ways	Don't Know	Unclear/Refused/No Response	N
FE Waiver	3%	8%	86%	0%	3%	36
PD Waiver	0%	0%	100%	0%	0%	4
TBI Waiver	0%	0%	100%	0%	0%	1
Sample Average	2%	7%	88%	0%	2%	41

⁶⁷ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Relationships

Table 29. Proportion of people who are able to see or talk to friends and family when they want to (if have friends and family who don't live with them)

	No, or Rarely	Most of the Time, Usually, or Some Family/Friends	Yes, Always, or Chooses Not to	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	4%	8%	86%	0%	2%	130
PD Waiver	3%	4%	93%	0%	0%	199
TBI Waiver	0%	13%	87%	0%	0%	15
Sample Average	3%	6%	90%	0%	1%	344

Table 30. Reasons people aren't always able to see friends/family

	Availability of Transportation	Accessibility	Staffing/Personal Assistance Unavailable	Health Limitations	Someone Prevents Them or There are Restrictions	Other	Unclear/Refused/ No Response	N
FE Waiver	44%	19%	0%	44%	6%	13%	0%	16
PD Waiver	27%	9%	9%	55%	0%	27%	9%	11
TBI Waiver	0%	50%	0%	0%	0%	0%	50%	2
Sample Average	34%	17%	3%	45%	3%	17%	7%	29

Satisfaction

Table 31. Proportion of people who like where they are living

	No	In-between, Most of the Time	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	7%	10%	82%	0%	1%	137
PD Waiver	14%	7%	79%	0%	0%	205
TBI Waiver	13%	7%	80%	0%	0%	15
Sample Average	11%	8%	80%	0%	0%	357

Table 32a. Reasons for not liking where people are living

	Accessibility	Feels Unsafe in/ Dislikes Neighborhood	Feels Unsafe in Residence	Residence/Building Needs Repairs or Upkeep	Doesn't Feel Like Home	N
FE Waiver	4%	4%	13%	9%	30%	23
PD Waiver	19%	19%	16%	35%	5%	43
TBI Waiver	33%	0%	0%	33%	0%	3
Sample Average	14%	13%	14%	26%	13%	69

Table 32b. Reasons for not liking where people are living (continued)

	Layout/Size of Residence/Building	Problems with Neighbors/Residents/ Housemates/Roommates	Problems with Staff	Insufficient Amount/ Type of Staff	Wants More Independence/ Control	N
FE Waiver	4%	22%	13%	0%	9%	23
PD Waiver	16%	19%	5%	2%	2%	43
TBI Waiver	0%	0%	0%	0%	33%	3
Sample Average	12%	19%	7%	1%	6%	69

Table 32c. Reasons for not liking where people live (continued)

	Wants More Privacy	Wants to Be Closer to Family/Friends	Feels Isolated from Community/Feels Lonely	Other	Don't Know	Unclear/Refused/No Response	N
FE Waiver	17%	4%	4%	17%	9%	4%	23
PD Waiver	5%	2%	2%	16%	0%	0%	43
TBI Waiver	0%	0%	0%	33%	0%	0%	3
Sample Average	9%	3%	3%	17%	3%	1%	69

Table 33. Proportion of people who would prefer to live somewhere else

	No	Maybe	Yes	Unclear/Refused/No Response	N
FE Waiver	75%	6%	18%	1%	135
PD Waiver	67%	9%	24%	0%	205
TBI Waiver	73%	7%	20%	0%	15
Sample Average	70%	8%	21%	1%	355

Table 34a. Where people would prefer to live (if would prefer to live somewhere else)

	Own/Different Own House/Apt	Family Member's House/Apt	Assisted Living/Residential Care Facility	Group Home/Adult Family Home/Shared Living	N
FE Waiver	68%	3%	10%	0%	31
PD Waiver	87%	1%	3%	0%	67
TBI Waiver	75%	0%	0%	0%	4
Sample Average	80%	2%	5%	0%	102

Table 34b. Where people would prefer to live (if would prefer to live somewhere else) (continued)

	Nursing Facility	Other	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	10%	10%	0%	31
PD Waiver	0%	7%	1%	0%	67
TBI Waiver	0%	0%	25%	0%	4
Sample Average	0%	8%	5%	0%	102

Table 35. Proportion of people who like how they spend their time during the day

	No, Never	Some Days, Sometimes	Yes, Always, or Almost Always	Don't Know	Unclear/Refused/No Response	N
FE Waiver	4%	23%	71%	1%	1%	135
PD Waiver	8%	32%	60%	0%	0%	203
TBI Waiver	0%	60%	40%	0%	0%	15
Sample Average	6%	30%	63%	1%	0%	353

Table 36. Proportion of people whose paid support staff change too often

	No	Some or Sometimes	Yes	N/A – Paid Support Staff Is Live-In	Don't Know	Unclear/Refused/No Response	N
FE Waiver	70%	13%	14%	3%	0%	1%	103
PD Waiver	83%	6%	8%	2%	1%	0%	165
TBI Waiver	83%	0%	17%	0%	0%	0%	6
Sample Average	78%	8%	10%	2%	1%	0%	274

Table 37. Proportion of people whose paid support staff do things the way they want them done

	No, Never or Rarely	Some, or Usually	Yes, All Paid Support Staff, Always or Almost Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	3%	10%	86%	0%	1%	103
PD Waiver	0%	7%	93%	0%	0%	164
TBI Waiver	0%	33%	67%	0%	0%	6
Sample Average	1%	8%	90%	0%	0%	273

Service Coordination

Table 38. Proportion of people who know whom to contact if they want to make changes to their services

	No	Maybe, Not Sure	Yes	Unclear/Refused/No Response	N
FE Waiver	2%	11%	86%	1%	133
PD Waiver	1%	12%	86%	1%	197
TBI Waiver	9%	9%	82%	0%	11
Sample Average	1%	12%	86%	1%	341

Table 39. Proportion of people who know whom to contact if they need help with services or have a complaint⁶⁸

	No	Maybe, Not Sure	Yes	Unclear/Refused/No Response	N
FE Waiver	1%	8%	88%	3%	132
PD Waiver	3%	11%	85%	1%	196
TBI Waiver	9%	0%	91%	0%	11
Sample Average	2%	10%	86%	2%	339

Table 40. Proportion of people who reported having a case manager/care coordinator

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	1%	91%	7%	1%	169
PD Waiver	1%	97%	2%	0%	203
TBI Waiver	0%	85%	15%	0%	13
Sample Average	1%	94%	5%	0%	385

⁶⁸ New item added in 2018-2019.

Table 41. Proportion of people who can reach their case manager/care coordinator when they need to (if know they have case manager/care coordinator)

	No, or Only Sometimes	Most of the Time, Usually	Yes, Always	Don't Know	Unclear/Refused/No Response	N
FE Waiver	2%	11%	84%	3%	1%	152
PD Waiver	7%	14%	77%	2%	0%	195
TBI Waiver	0%	27%	73%	0%	0%	11
Sample Average	5%	13%	80%	2%	0%	358

Table 42. Proportion of people who receive information about their services in the language they prefer (if non-English)⁶⁹

	No	Some Information	Yes, All Information	Don't Know	Unclear/Refused/No Response	N
FE Waiver	18%	3%	77%	3%	0%	79
PD Waiver	1%	0%	99%	0%	0%	84
TBI Waiver	0%	0%	100%	0%	0%	3
Sample Average	9%	1%	89%	1%	0%	166

Table 43. Proportion of people whose paid support staff show up and leave when they are supposed to

	No, Never or Rarely	Some or Usually	Yes, All Paid Support Staff, Always or Almost Always	Paid Support Staff Is Live-In	Don't Know	Unclear/Refused/No Response	N
FE Waiver	2%	8%	87%	2%	0%	1%	122
PD Waiver	2%	7%	90%	2%	0%	0%	164
TBI Waiver	0%	33%	67%	0%	0%	0%	6
Sample Average	2%	8%	88%	2%	0%	0%	292

⁶⁹ Item previously reported in the "Access" domain.

Table 44. Proportion of people who have an emergency plan in place

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	5%	95%	0%	0%	170
PD Waiver	7%	90%	1%	1%	206
TBI Waiver	0%	100%	0%	0%	16
Sample Average	6%	93%	1%	1%	392

Table 45. Proportion of people who want help planning for future changes in their needs

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	42%	47%	9%	1%	137
PD Waiver	25%	64%	8%	3%	203
TBI Waiver	27%	67%	7%	0%	15
Sample Average	31%	58%	8%	3%	355

Table 46. Proportion of people whose long-term care services meet their current needs and goals

	No, Not at All, Needs or Goals Are Not Met	Some Needs and Goals	Yes, Completely, All Needs and Goals	Don't Know	Unclear/Refused/No Response	N
FE Waiver	2%	16%	81%	1%	0%	168
PD Waiver	4%	22%	72%	1%	0%	201
TBI Waiver	15%	23%	62%	0%	0%	13
Sample Average	4%	19%	76%	1%	0%	382

Table 47a. Additional services might help meet people’s needs and goals (if have unmet needs and goals)

	Skilled Nursing Facility, Nursing Home Services	Personal Care Assistance, Personal Care Services	Home Maker/Chore Services	Healthcare Home Services, Home Health	Home Delivered Meals	N
FE Waiver	3%	26%	20%	3%	17%	35
PD Waiver	0%	23%	27%	2%	16%	62
TBI Waiver	0%	22%	44%	0%	11%	9
Sample Average	1%	24%	26%	2%	16%	106

Table 47b. Additional services might help meet people’s needs and goals (if have unmet needs and goals) (continued)

	Adult Day Services	Transportation	Respite/Family Caregiver Support	Health Care	Mental Health Care	Dental Care	N
FE Waiver	3%	17%	0%	0%	0%	9%	35
PD Waiver	0%	18%	5%	0%	3%	13%	62
TBI Waiver	0%	22%	11%	0%	0%	0%	9
Sample Average	1%	18%	4%	0%	2%	10%	106

Table 47c. Additional services might help meet people’s needs and goals (if have unmet needs and goals) (continued)

	Housing Assistance	Heating/Cooling Assistance	Hospice	Funeral Planning	Other	Don’t Know	Unclear/Refused/No Response	N
FE Waiver	9%	0%	0%	0%	31%	17%	3%	35
PD Waiver	16%	6%	0%	0%	37%	8%	2%	62
TBI Waiver	22%	11%	0%	0%	33%	22%	11%	9
Sample Average	14%	5%	0%	0%	35%	12%	3%	106

Table 48. Proportion of people whose case manager/care coordinator talked to them about services that might help with their unmet needs and goals (if have unmet needs and goals and know they have case manager/care coordinator)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	28%	62%	10%	0%	29
PD Waiver	25%	69%	4%	2%	51
TBI Waiver	25%	50%	0%	25%	4
Sample Average	26%	65%	6%	2%	84

Table 49a. How people first find out about the services available to them

	Friend	Family	ADRC; AAA; CIL	State/County Agency	Case Manager/ Care Coordinator	Doctor/ Hospital/Clinic	N
FE Waiver	14%	30%	20%	4%	5%	17%	166
PD Waiver	11%	13%	29%	5%	5%	27%	196
TBI Waiver	0%	15%	15%	8%	0%	54%	13
Sample Average	12%	20%	25%	4%	5%	23%	375

Table 49b. How people first find out about the services available to them (continued)

	Other Provider or Provider Agency	Media/Newspaper/ TV/Radio/Ad	Internet/ Website	Other	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	2%	1%	0%	1%	13%	1%	166
PD Waiver	2%	1%	0%	1%	13%	1%	196
TBI Waiver	0%	0%	0%	0%	15%	0%	13
Sample Average	2%	1%	0%	1%	13%	1%	375

Table 50. Proportion of people who have someone that helps them at home or in the community on a regular basis (at least once a week)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	3%	97%	0%	0%	173
PD Waiver	5%	95%	0%	0%	213
TBI Waiver	24%	76%	0%	0%	17
Sample Average	5%	95%	0%	0%	403

Table 51. Who helps people most often (if anybody provides support on a regular basis)

	Paid Support Worker - Not a Friend or Relative	Paid Family Member or Spouse/Partner	Paid Friend	Unpaid Family Member or Spouse/Partner	Unpaid Friend or Volunteer	Other	Don't Know	Unclear/Refused/No Response	N
FE Waiver	57%	30%	2%	10%	1%	0%	0%	0%	168
PD Waiver	39%	31%	14%	13%	2%	1%	0%	0%	202
TBI Waiver	54%	15%	8%	8%	15%	0%	0%	0%	13
Sample Average	47%	30%	9%	11%	2%	1%	0%	0%	383

Table 52. Who else helps (if anybody provides support on a regular basis)

	Paid Support Worker - Not a Friend or Relative	Paid Family Member or Spouse/Partner	Paid Friend	Unpaid Family Member or Spouse/Partner	Unpaid Friend or Volunteer	Other	No One Else Provides Support	Don't Know	Unclear/Refused/No Response	N
FE Waiver	8%	2%	1%	64%	14%	1%	12%	0%	1%	168
PD Waiver	5%	7%	2%	56%	14%	0%	18%	0%	0%	202
TBI Waiver	8%	8%	0%	54%	23%	0%	23%	0%	0%	13
Sample Average	7%	5%	2%	60%	15%	0%	15%	0%	0%	383

Table 53. Proportion of people who have a backup plan if their paid support staff don't show up

	No	Yes	Paid Support Staff Is Live-In	Don't Know	Unclear/Refused/No Response	N
FE Waiver	7%	85%	3%	4%	1%	123
PD Waiver	13%	84%	2%	1%	0%	166
TBI Waiver	17%	83%	0%	0%	0%	6
Sample Average	10%	85%	2%	2%	0%	295

Care Coordination

Table 54. Proportion of people who stayed overnight in a hospital or rehabilitation facility in past year (and were discharged to go home/back where they live)

	Yes	No	Don't Know	Unclear/Refused/No Response	N
FE Waiver	70%	30%	1%	0%	171
PD Waiver	71%	29%	0%	0%	213
TBI Waiver	75%	25%	0%	0%	16
Sample Average	71%	29%	0%	0%	400

Table 55. Proportion of people who felt comfortable and supported enough to go home (or where they live) after being discharged from a hospital or rehabilitation facility in the past year

	No	In-between	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	6%	2%	90%	0%	2%	50
PD Waiver	7%	10%	80%	0%	3%	60
TBI Waiver	0%	50%	50%	0%	0%	4
Sample Average	6%	8%	83%	0%	3%	114

Table 56. Proportion of people who had someone follow up with them after being discharged from a hospital or rehabilitation facility in the past year

	No	Yes	Didn't Need/Want Follow-Up	Don't Know	Unclear/Refused/No Response	N
FE Waiver	8%	88%	0%	0%	4%	49
PD Waiver	28%	64%	2%	2%	5%	61
TBI Waiver	50%	50%	0%	0%	0%	4
Sample Average	20%	74%	1%	1%	4%	114

Table 57. Proportion of people who know how to manage their chronic condition(s)

	No	In-between, Some Conditions	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	7%	12%	79%	2%	0%	163
PD Waiver	2%	13%	83%	0%	1%	201
TBI Waiver	14%	21%	64%	0%	0%	14
Sample Average	5%	13%	80%	1%	1%	378

Table 58. Proportion of people with concerns about falling or being unstable⁷⁰

	No	Sometimes	Yes, Often	Don't Know	Unclear/Refused/No Response	N
FE Waiver	46%	29%	25%	0%	0%	173
PD Waiver	31%	27%	42%	0%	0%	212
TBI Waiver	59%	18%	24%	0%	0%	17
Sample Average	39%	27%	34%	0%	0%	402

Table 59. Proportion of people with concerns about falling or being unstable who had somebody talk to them or work with them to reduce the risk⁷¹

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	12%	84%	3%	1%	93
PD Waiver	14%	84%	1%	1%	141
TBI Waiver	29%	71%	0%	0%	7
Sample Average	14%	84%	2%	1%	241

⁷⁰ Item previously reported in the "Safety" domain.

⁷¹ Item previously reported in the "Safety" domain.

Access to Community⁷²

Table 60. Proportion of people who have transportation when they want to do things outside of their home (non-medical)⁷³

	No	Sometimes	Yes	Doesn't Want to	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	2%	14%	77%	5%	2%	0%	172
PD Waiver	5%	14%	79%	1%	0%	0%	209
TBI Waiver	12%	29%	53%	6%	0%	0%	17
Sample Average	4%	15%	77%	3%	1%	0%	398

Table 61. Proportion of people who have transportation to get to medical appointments when they need to⁷⁴

	No	Sometimes	Yes	Doesn't Go to Medical Appointments	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	1%	2%	94%	3%	0%	0%	173
PD Waiver	1%	5%	94%	0%	0%	0%	210
TBI Waiver	0%	12%	82%	6%	0%	0%	17
Sample Average	1%	4%	94%	2%	0%	0%	400

⁷² New domain in 2018-2019.

⁷³ Item previously reported in the "Access" domain.

⁷⁴ Item previously reported in the "Access" domain.

Access to Needed Equipment⁷⁵

Table 62. Proportion of people who need grab bars in the bathroom or elsewhere in their home⁷⁶

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	9%	78%	3%	9%	0%	0%	172
PD Waiver	16%	62%	3%	18%	0%	0%	212
TBI Waiver	53%	41%	6%	0%	0%	0%	17
Sample Average	15%	68%	3%	14%	0%	0%	401

Table 63. Proportion of people who need bathroom modifications (other than grab bars)⁷⁷

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	32%	57%	3%	6%	1%	1%	172
PD Waiver	48%	39%	1%	10%	1%	0%	212
TBI Waiver	71%	12%	0%	6%	6%	6%	17
Sample Average	42%	45%	2%	8%	1%	1%	401

Table 64. Proportion of people who need a specialized bed⁷⁸

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	76%	20%	1%	4%	0%	0%	172
PD Waiver	75%	17%	3%	5%	0%	0%	211
TBI Waiver	76%	12%	0%	6%	6%	0%	17
Sample Average	75%	18%	2%	5%	0%	0%	400

⁷⁵ New domain in 2018-2019.

⁷⁶ Item previously reported in the "Access" domain.

⁷⁷ Item previously reported in the "Access" domain.

⁷⁸ Item previously reported in the "Access" domain.

Table 65. Proportion of people who need a ramp or stair lift in or outside the home⁷⁹

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	70%	27%	1%	1%	1%	0%	172
PD Waiver	69%	25%	1%	4%	0%	0%	211
TBI Waiver	88%	12%	0%	0%	0%	0%	17
Sample Average	70%	26%	1%	3%	0%	0%	400

Table 66. Proportion of people who need some other home modification(s)⁸⁰

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	83%	4%	1%	1%	8%	3%	159
PD Waiver	86%	3%	0%	1%	9%	1%	209
TBI Waiver	80%	0%	0%	7%	13%	0%	15
Sample Average	85%	3%	0%	1%	9%	2%	383

Table 67. Proportion of people who need a walker⁸¹

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	21%	75%	3%	1%	0%	0%	173
PD Waiver	45%	53%	1%	1%	0%	0%	209
TBI Waiver	76%	24%	0%	0%	0%	0%	17
Sample Average	36%	61%	2%	1%	0%	0%	399

⁷⁹ Item previously reported in the "Access" domain.

⁸⁰ Item previously reported in the "Access" domain.

⁸¹ Item previously reported in the "Access" domain.

Table 68. Proportion of people who need a scooter⁸²

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	90%	5%	2%	2%	0%	1%	170
PD Waiver	86%	5%	2%	5%	2%	0%	212
TBI Waiver	82%	0%	6%	12%	0%	0%	17
Sample Average	88%	5%	2%	4%	1%	1%	399

Table 69. Proportion of people who need a wheelchair⁸³

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	60%	34%	2%	4%	0%	1%	173
PD Waiver	56%	39%	4%	1%	0%	0%	213
TBI Waiver	71%	29%	0%	0%	0%	0%	17
Sample Average	58%	36%	3%	2%	0%	0%	403

Table 70. Proportion of people who need hearing aids⁸⁴

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	74%	20%	1%	5%	0%	1%	172
PD Waiver	87%	7%	1%	5%	0%	0%	212
TBI Waiver	88%	13%	0%	0%	0%	0%	16
Sample Average	81%	13%	1%	5%	0%	0%	400

⁸² Item previously reported in the "Access" domain.

⁸³ Item previously reported in the "Access" domain.

⁸⁴ Item previously reported in the "Access" domain.

Table 71. Proportion of people who need glasses⁸⁵

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	13%	78%	9%	1%	0%	0%	173
PD Waiver	15%	76%	7%	2%	0%	0%	211
TBI Waiver	47%	47%	6%	0%	0%	0%	17
Sample Average	15%	76%	8%	1%	0%	0%	401

Table 72. Proportion of people who need a CPAP machine⁸⁶

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	90%	7%	1%	2%	0%	1%	170
PD Waiver	80%	15%	2%	3%	0%	0%	210
TBI Waiver	100%	0%	0%	0%	0%	0%	17
Sample Average	85%	11%	1%	3%	0%	0%	397

Table 73. Proportion of people who need a personal emergency response system⁸⁷

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	35%	61%	1%	2%	1%	0%	171
PD Waiver	33%	57%	1%	7%	1%	0%	212
TBI Waiver	59%	29%	0%	12%	0%	0%	17
Sample Average	35%	58%	1%	5%	1%	0%	400

⁸⁵ Item previously reported in the "Access" domain.

⁸⁶ Item previously reported in the "Access" domain.

⁸⁷ Item previously reported in the "Access" domain.

Table 74. Proportion of people who need an oxygen machine⁸⁸

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	85%	13%	1%	1%	0%	0%	172
PD Waiver	82%	15%	1%	2%	0%	0%	211
TBI Waiver	100%	0%	0%	0%	0%	0%	17
Sample Average	84%	14%	1%	2%	0%	0%	400

Table 75. Proportion of people who need some other assistive device(s)⁸⁹

	Doesn't Have and Doesn't Need	Has, Doesn't Need a Replacement	Has, But Needs a Replacement	Needs, But Doesn't Have	Don't Know	Unclear/ Refused/ No Response	N
FE Waiver	84%	4%	1%	1%	8%	2%	152
PD Waiver	75%	11%	0%	0%	11%	1%	204
TBI Waiver	87%	0%	0%	0%	7%	7%	15
Sample Average	79%	8%	1%	1%	10%	2%	371

⁸⁸ New item added in 2018-2019.

⁸⁹ Item previously reported in the "Access" domain.

Safety

Table 76. Proportion of people who feel safe at home

	Rarely or Never	Always or Most of the Time	Don't Know	Unclear/Refused/No Response	N
FE Waiver	3%	96%	1%	1%	136
PD Waiver	5%	94%	0%	0%	204
TBI Waiver	13%	87%	0%	0%	15
Sample Average	5%	94%	1%	1%	355

Table 77. Proportion of people who feel safe around their paid support staff

	No, Not All Paid Support Staff or Not Always	Yes, All Paid Support Staff, Always	Don't Know	Unclear/Refused/No Response	N
FE Waiver	1%	99%	0%	0%	103
PD Waiver	0%	100%	0%	0%	165
TBI Waiver	0%	100%	0%	0%	6
Sample Average	0%	100%	0%	0%	274

Table 78. Proportion of people who are ever worried for the security of their personal belongings

	No, Never	Yes, At Least Sometimes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	84%	15%	0%	1%	135
PD Waiver	82%	17%	0%	0%	206
TBI Waiver	87%	13%	0%	0%	15
Sample Average	83%	16%	0%	1%	356

Table 79. Proportion of people whose money was taken or used without their permission in the last 12 months

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	92%	3%	2%	3%	137
PD Waiver	93%	5%	2%	0%	206
TBI Waiver	87%	7%	7%	0%	15
Sample Average	92%	4%	2%	1%	358

Table 80. Proportion of people who are able to get to safety quickly in case of an emergency like a house fire

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	7%	85%	6%	2%	171
PD Waiver	13%	76%	9%	2%	209
TBI Waiver	12%	82%	6%	0%	17
Sample Average	10%	80%	8%	2%	397

Health Care

Table 81. Proportion of people who have gone to the emergency room for any reason in the past year

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	61%	39%	0%	0%	173
PD Waiver	55%	45%	0%	0%	211
TBI Waiver	71%	29%	0%	0%	17
Sample Average	58%	42%	0%	0%	401

Table 82. Proportion of people whose emergency room visit in the past year was due to falling or losing balance

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	60%	40%	0%	0%	67
PD Waiver	68%	32%	0%	0%	96
TBI Waiver	100%	0%	0%	0%	5
Sample Average	65%	35%	0%	0%	168

Table 83. Proportion of people whose emergency room visit in the past year was due to tooth or mouth pain

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	100%	0%	0%	0%	66
PD Waiver	93%	7%	0%	0%	96
TBI Waiver	100%	0%	0%	0%	5
Sample Average	96%	4%	0%	0%	167

Table 84. Proportion of people whose emergency room visit in the past year was due to being unable to see their primary care doctor when they needed to⁹⁰

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	97%	3%	0%	0%	65
PD Waiver	95%	4%	1%	0%	94
TBI Waiver	80%	20%	0%	0%	5
Sample Average	95%	4%	1%	0%	164

Table 85. Proportion of people who can get an appointment to see their primary care doctor when they need to

	No, Rarely	Usually	Yes, Always	Doesn't Have a Primary Care Doctor	Don't Know	Unclear/Refused/No Response	N
FE Waiver	1%	10%	89%	1%	0%	0%	168
PD Waiver	2%	9%	88%	0%	0%	0%	209
TBI Waiver	0%	18%	82%	0%	0%	0%	17
Sample Average	2%	10%	88%	1%	0%	0%	394

Table 86. Proportion of people feeling sad or depressed who have talked to someone about it in the past 12 months

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	29%	69%	2%	0%	49
PD Waiver	23%	75%	0%	2%	114
TBI Waiver	45%	55%	0%	0%	11
Sample Average	26%	72%	1%	1%	174

⁹⁰ New item added in 2018-2019.

Table 87. Proportion of people who have had a physical exam or wellness visit in the past year

	No	Yes	N/A (e.g. Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	14%	84%	1%	1%	0%	171
PD Waiver	16%	83%	0%	1%	0%	213
TBI Waiver	24%	76%	0%	0%	0%	17
Sample Average	15%	83%	0%	1%	0%	401

Table 88. Proportion of people who have had a hearing exam in the past year

	No	Yes	N/A (e.g. Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	80%	18%	0%	2%	0%	173
PD Waiver	80%	19%	0%	0%	0%	213
TBI Waiver	76%	18%	0%	6%	0%	17
Sample Average	80%	19%	0%	1%	0%	403

Table 89. Proportion of people who have had a vision exam in the past year

	No	Yes	N/A (e.g. Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	47%	53%	0%	1%	0%	173
PD Waiver	37%	63%	0%	0%	0%	212
TBI Waiver	53%	41%	0%	6%	0%	17
Sample Average	42%	57%	0%	1%	0%	402

Table 90. Proportion of people who have had a flu shot in the past year

	No	Yes	N/A (e.g. Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	23%	76%	0%	1%	0%	170
PD Waiver	33%	65%	0%	1%	0%	211
TBI Waiver	47%	41%	0%	12%	0%	17
Sample Average	29%	69%	0%	1%	0%	398

Table 91. Proportion of people who have had a dental visit in the past year

	No	Yes	N/A (e.g. Not Recommended)	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	75%	25%	0%	1%	0%	173
PD Waiver	73%	25%	1%	1%	0%	208
TBI Waiver	59%	29%	0%	12%	0%	17
Sample Average	73%	25%	1%	1%	0%	398

Wellness

Table 92. Proportion of people whose health was described as poor, fair, good, very good, and excellent

	Poor	Fair	Good	Very Good	Excellent	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	12%	42%	33%	10%	1%	2%	0%	172
PD Waiver	20%	49%	24%	6%	1%	0%	0%	209
TBI Waiver	6%	41%	41%	6%	6%	0%	0%	17
Sample Average	16%	45%	29%	8%	2%	1%	0%	398

Table 93. Proportion of people whose health was described as having gotten better, staying about the same, or getting worse compared to 12 months ago

	Much Worse	Somewhat Worse	About the Same	Somewhat Better	Much Better	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	8%	23%	55%	11%	3%	0%	0%	173
PD Waiver	5%	37%	39%	14%	5%	0%	0%	210
TBI Waiver	12%	29%	41%	18%	0%	0%	0%	17
Sample Average	7%	31%	46%	13%	4%	0%	0%	400

Table 94. Proportion of people reported to be forgetting things more often than before in the past 12 months

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	47%	48%	4%	1%	172
PD Waiver	57%	40%	3%	0%	210
TBI Waiver	35%	47%	18%	0%	17
Sample Average	52%	44%	4%	0%	399

Table 95. Proportion of people who have discussed their forgetting things with a doctor or a nurse

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	26%	74%	0%	0%	84
PD Waiver	33%	67%	0%	0%	85
TBI Waiver	50%	50%	0%	0%	8
Sample Average	31%	69%	0%	0%	177

Table 96. Proportion of people who feel sad or depressed never or almost never, not often, sometimes, and often

	Never/Almost Never	Not Often	Sometimes	Often	Don't Know	Unclear/Refused/No Response	N
FE Waiver	30%	32%	31%	4%	2%	0%	137
PD Waiver	15%	29%	42%	14%	0%	0%	205
TBI Waiver	13%	13%	47%	27%	0%	0%	15
Sample Average	20%	29%	38%	11%	1%	0%	357

Table 97. Proportion of people whose hearing was described as poor, fair and good (with hearing aids, if wears any)

	Poor	Fair	Good	Don't Know	Unclear/Refused/No Response	N
FE Waiver	17%	33%	49%	1%	0%	172
PD Waiver	9%	24%	67%	0%	0%	210
TBI Waiver	6%	18%	76%	0%	0%	17
Sample Average	13%	28%	60%	0%	0%	399

Table 98. Proportion of people whose vision was described as poor, fair, and good (with glasses or contacts, if wears any)

	Poor	Fair	Good	Don't Know	Unclear/Refused/No Response	N
FE Waiver	11%	35%	54%	1%	0%	170
PD Waiver	15%	30%	56%	0%	0%	206
TBI Waiver	6%	29%	65%	0%	0%	17
Sample Average	12%	32%	55%	0%	0%	393

Table 99. Proportion of people who have access to healthy foods if they want them⁹¹

	No, Never	Sometimes	Yes, Often	N/A – Unable to Eat Due to Medical Condition	Don't Know	Unclear/Refused/No Response	N
FE Waiver	3%	9%	88%	0%	0%	0%	171
PD Waiver	3%	23%	74%	0%	0%	0%	211
TBI Waiver	6%	6%	76%	6%	0%	6%	17
Sample Average	3%	17%	80%	0%	0%	0%	399

⁹¹ Item previously reported in the “Everyday Living” domain.

Medications

Table 100. Proportion of people who take medications that help them feel less sad or depressed

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	73%	24%	3%	0%	169
PD Waiver	52%	46%	1%	0%	211
TBI Waiver	53%	47%	0%	0%	17
Sample Average	61%	37%	2%	0%	397

Table 101. Proportion of people who understand what they take their prescription medications for (if takes prescription medications)

	No	In-between, or Some Medications	Yes	N/A – Doesn't Take Prescription Medications	Don't Know	Unclear/Refused/No Response	N
FE Waiver	4%	11%	79%	4%	1%	0%	136
PD Waiver	0%	11%	84%	4%	0%	0%	206
TBI Waiver	0%	20%	67%	13%	0%	0%	15
Sample Average	2%	11%	82%	4%	0%	0%	357

Rights and Respect

Table 102. Proportion of people whose paid support staff treat them with respect

	No, Never or Rarely	Some, or Usually	Yes, All Paid Support Staff, Always or Almost Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	1%	7%	92%	0%	0%	102
PD Waiver	0%	2%	98%	0%	1%	164
TBI Waiver	0%	17%	83%	0%	0%	6
Sample Average	0%	4%	95%	0%	0%	272

Table 103. Proportion of people whose permission is asked before others enter their home/room (if in group setting⁹²)

	Sometimes/ Rarely, or Never	Usually, But Not Always	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	6%	11%	81%	0%	3%	36
PD Waiver	0%	0%	100%	0%	0%	4
TBI Waiver	0%	0%	100%	0%	0%	1
Sample Average	5%	10%	83%	0%	2%	41

Table 104. Proportion of people who are able to lock the doors to their room if they want to (if in group setting⁹³)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	14%	83%	0%	3%	36
PD Waiver	0%	100%	0%	0%	3
TBI Waiver	0%	100%	0%	0%	1
Sample Average	13%	85%	0%	3%	40

⁹² Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

⁹³ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Table 105. Proportion of people who have enough privacy where they live (if in group setting⁹⁴)

	Sometimes/Rarely, or Never	Usually, But Not Always	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	8%	0%	89%	0%	3%	36
PD Waiver	0%	0%	100%	0%	0%	4
TBI Waiver	0%	0%	100%	0%	0%	1
Sample Average	7%	0%	90%	0%	2%	41

Table 106. Proportion of people whose visitors are able to come at any time (if in group setting⁹⁵)

	No, Visitors Allowed Only Certain Times	Yes, Visitors Can Come Any Time	N/A – No Visitors Who Visit Residence	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	3%	89%	3%	3%	3%	36
PD Waiver	0%	100%	0%	0%	0%	3
TBI Waiver	0%	100%	0%	0%	0%	1
Sample Average	3%	90%	3%	3%	3%	40

Table 107. Proportion of people who have access to food at all times of the day (if in group setting⁹⁶)

	No	Yes	N/A – Unable to Eat Due to Medical Condition	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	6%	92%	0%	0%	3%	36
PD Waiver	0%	100%	0%	0%	0%	4
TBI Waiver	0%	100%	0%	0%	0%	1
Sample Average	5%	93%	0%	0%	2%	41

⁹⁴ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

⁹⁵ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

⁹⁶ Group/adult family/foster/host home, assisted living/residential care facility, nursing facility/nursing home

Self-Direction

Table 108. Proportion of people who can choose or change what kind of services they get

	No	Sometimes, or Some Services	Yes, All Services	Don't Know	Unclear/Refused/No Response	N
FE Waiver	5%	12%	76%	7%	1%	168
PD Waiver	1%	12%	84%	3%	0%	202
TBI Waiver	0%	15%	77%	8%	0%	13
Sample Average	3%	12%	80%	5%	1%	383

Table 109. Proportion of people who can choose or change when and how often they get services

	No	Sometimes, or Some Services	Yes, All Services	Don't Know	Unclear/Refused/No Response	N
FE Waiver	4%	11%	75%	8%	2%	169
PD Waiver	2%	13%	82%	2%	0%	201
TBI Waiver	0%	23%	69%	8%	0%	13
Sample Average	3%	12%	78%	5%	1%	383

Table 110. Proportion of people who can choose or change their paid support staff if they want to

	No	Sometimes, or Some	Yes, All	Don't Know	Unclear/Refused/No Response	N
FE Waiver	10%	5%	81%	2%	2%	124
PD Waiver	1%	2%	95%	0%	1%	161
TBI Waiver	17%	0%	83%	0%	0%	6
Sample Average	5%	3%	89%	1%	2%	291

Work

Table 111. Proportion of people who have a paying job

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	98%	2%	0%	0%	172
PD Waiver	97%	3%	0%	0%	210
TBI Waiver	94%	6%	0%	0%	17
Sample Average	97%	3%	0%	0%	399

Table 112. Proportion of people who would like a job (if not currently employed)

	No	Maybe, Not Sure	Yes	Unclear/Refused/No Response	N
FE Waiver	95%	3%	2%	0%	133
PD Waiver	79%	9%	12%	0%	200
TBI Waiver	43%	7%	50%	0%	14
Sample Average	84%	7%	10%	0%	347

Table 113. Proportion of people wanting a job who had someone talk to them about job options

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	88%	13%	0%	0%	8
PD Waiver	64%	36%	0%	0%	42
TBI Waiver	25%	63%	0%	13%	8
Sample Average	62%	36%	0%	2%	58

Table 114. Proportion of people who do volunteer work

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	94%	6%	0%	1%	172
PD Waiver	91%	9%	0%	0%	211
TBI Waiver	88%	12%	0%	0%	17
Sample Average	92%	8%	0%	0%	400

Table 115. Proportion of people who would like to do volunteer work (if not currently volunteering)

	No	Maybe, Not Sure	Yes	Unclear/Refused/ No Response	N
FE Waiver	94%	6%	0%	0%	126
PD Waiver	85%	7%	8%	1%	182
TBI Waiver	92%	8%	0%	0%	13
Sample Average	88%	7%	5%	0%	321

Everyday Living

Table 116. Proportion of people who generally need none, some, or a lot of assistance with everyday activities (such as preparing meals, housework, shopping or taking their medications)

	None	Some	A Lot	Don't Know	Unclear/Refused/No Response	N
FE Waiver	1%	28%	70%	0%	0%	172
PD Waiver	0%	30%	70%	0%	0%	210
TBI Waiver	18%	18%	65%	0%	0%	17
Sample Average	1%	29%	70%	0%	0%	399

Table 117. Proportion of people needing at least some assistance with everyday activities who always get enough of that assistance when they need it

	No, Not Always	Yes, Always	Don't Know	Unclear/Refused/No Response	N
FE Waiver	11%	86%	1%	2%	169
PD Waiver	17%	82%	0%	1%	207
TBI Waiver	43%	57%	0%	0%	14
Sample Average	15%	83%	0%	2%	390

Table 118. Proportion of people who generally need none, some, or a lot of assistance with self-care (such as bathing, dressing, going to the bathroom, eating, or moving around their home)

	None	Some	A Lot	Don't Know	Unclear/Refused/No Response	N
FE Waiver	15%	44%	41%	0%	0%	173
PD Waiver	14%	46%	40%	0%	0%	211
TBI Waiver	41%	24%	35%	0%	0%	17
Sample Average	15%	44%	40%	0%	0%	401

Table 119. Proportion of people needing at least some assistance with self-care who always get enough of that assistance when they need it

	No, Not Always	Yes, Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	8%	90%	0%	1%	144
PD Waiver	14%	85%	0%	1%	182
TBI Waiver	20%	80%	0%	0%	10
Sample Average	12%	87%	0%	1%	336

Affordability

Table 120. Proportion of people who ever have to skip a meal due to financial worries

	No, Never	Sometimes	Yes, Often	N/A – Unable to Eat Due to a Medical Condition	Don't Know	Unclear/Refused/No Response	N
FE Waiver	94%	4%	2%	0%	0%	0%	172
PD Waiver	76%	16%	8%	0%	0%	0%	212
TBI Waiver	71%	18%	6%	6%	0%	0%	17
Sample Average	84%	11%	5%	0%	0%	0%	401

Control

Table 121. Proportion of people who feel in control of their lives

	No, Rarely or Never	In-between, Sometimes	Yes, Almost Always or Always	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	4%	23%	73%	1%	0%	135
PD Waiver	5%	23%	70%	0%	1%	202
TBI Waiver	13%	47%	40%	0%	0%	15
Sample Average	5%	24%	70%	1%	1%	352

Table 122. Ranking of how important health is to people (out of health, safety, being independent, and being engaged with community and friends)

	1 - Health Most Important	2	3	4 - Health Least Important	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	72%	22%	5%	2%	0%	0%	130
PD Waiver	72%	21%	6%	2%	0%	0%	200
TBI Waiver	54%	38%	8%	0%	0%	0%	13
Sample Average	71%	22%	6%	2%	0%	0%	343

Table 123. Ranking of how important safety is to people (out of health, safety, being independent, and being engaged with community and friends)

	1 - Safety Most Important	2	3	4 - Safety Least Important	N
FE Waiver	11%	46%	32%	12%	130
PD Waiver	9%	49%	31%	12%	200
TBI Waiver	8%	38%	31%	23%	13
Sample Average	9%	47%	31%	12%	343

Table 124. Ranking of how important being independent is to people (out of health, safety, being independent, and being engaged with community and friends)

	1 – Being Independent Most Important	2	3	4 - Being Independent Least Important	N
FE Waiver	14%	26%	49%	11%	130
PD Waiver	14%	26%	54%	7%	200
TBI Waiver	23%	15%	38%	23%	13
Sample Average	14%	25%	51%	9%	343

Table 125. Ranking of how important being engaged with their community and friends is to people (out of health, safety, being independent, and being engaged with community and friends)

	1 – Being Engaged with Community Most Important	2	3	4 – Being Engaged with Community Least Important	N
FE Waiver	4%	6%	15%	75%	130
PD Waiver	6%	6%	10%	79%	200
TBI Waiver	15%	8%	23%	54%	13
Sample Average	6%	6%	12%	77%	343

Appendix C: Kansas' State-Specific Questions

Table 126. Proportion of people who feel they are able to file complaints about their services if they need to (KS-1)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	2%	89%	5%	4%	133
PD Waiver	5%	91%	3%	2%	196
TBI Waiver	0%	91%	9%	0%	11
Sample Average	4%	90%	4%	2%	340

Table 127. Proportion of people who feel they are able to freely voice their opinion about their services to anyone they choose (KS-2)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	2%	91%	4%	4%	133
PD Waiver	3%	94%	2%	2%	196
TBI Waiver	0%	100%	0%	0%	11
Sample Average	2%	93%	2%	2%	340

Table 128. Proportion of people who had an Assessor or an MCO staff review the “Appeal and Grievance” process with them (KS-3)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	7%	76%	16%	2%	167
PD Waiver	10%	75%	13%	2%	202
TBI Waiver	0%	85%	15%	0%	13
Sample Average	8%	76%	14%	2%	382

Table 129. Proportion of people who understand the “Appeal and Grievance” process that was reviewed with them (if had an Assessor or an MCO staff review the process) (KS-4)

	Yes, Sometimes	Yes, Often	Don’t Know	Unclear/Refused/ No Response	N
FE Waiver	0%	99%	0%	1%	97
PD Waiver	0%	99%	1%	0%	147
TBI Waiver	0%	80%	10%	10%	10
Sample Average	0%	98%	1%	1%	254

Table 130. Proportion of people who had an Assessor or an MCO staff review their “Rights and Responsibilities” with them (KS-5)

	No	Yes	Don’t Know	Unclear/Refused/ No Response	N
FE Waiver	4%	80%	15%	2%	169
PD Waiver	7%	82%	9%	2%	203
TBI Waiver	0%	85%	15%	0%	13
Sample Average	5%	81%	12%	2%	385

Table 131. Proportion of people who understand the “Rights and Responsibilities” that were reviewed with them (if had an Assessor or an MCO staff review their “Rights and Responsibilities) (KS-6)

	No	Yes	Don’t Know	Unclear/Refused/ No Response	N
FE Waiver	0%	99%	1%	0%	102
PD Waiver	1%	99%	0%	0%	160
TBI Waiver	0%	90%	10%	0%	10
Sample Average	0%	99%	1%	0%	272

Table 132. Proportion of people who were offered an opportunity to direct their own services (KS-7)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	10%	76%	13%	2%	168
PD Waiver	1%	95%	4%	0%	199
TBI Waiver	8%	75%	17%	0%	12
Sample Average	5%	86%	8%	1%	379

Table 133. Proportion of people who know whom to talk to if they or someone they know are ever mistreated, hurt, disrespected, or neglected by others (KS-8)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	9%	80%	7%	4%	137
PD Waiver	15%	79%	3%	2%	205
TBI Waiver	7%	73%	13%	7%	15
Sample Average	13%	79%	5%	3%	357

Table 134. Proportion of people who feel they have access to affordable housing if they need it (KS-9)

	No	Yes	N/A – Does Not Need Affordable Housing	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	3%	57%	30%	10%	0%	136
PD Waiver	9%	67%	17%	7%	0%	205
TBI Waiver	14%	71%	7%	7%	0%	14
Sample Average	7%	63%	21%	8%	0%	355

Table 135. Proportion of people who feel they receive all the services listed in their service plan (KS-10)

	No	Yes	Don't Know	Unclear/Refused/ No Response	N
FE Waiver	2%	91%	4%	3%	133
PD Waiver	6%	89%	5%	1%	196
TBI Waiver	18%	55%	27%	0%	11
Sample Average	5%	89%	5%	1%	340

Appendix D: Kansas' NCI-AD Person-Centered Planning Module

Table 136. People’s level of involvement in making decisions about their service plan/plan of care and the goals they want for their lives

	Not at All	Very Little	Somewhat	Very/Fully Involved	Don’t Know	Unclear/Refused/No Response	N
FE Waiver	1%	1%	12%	82%	2%	1%	137
PD Waiver	1%	3%	10%	83%	2%	0%	206
TBI Waiver	13%	0%	20%	53%	13%	0%	15
Sample Average	2%	2%	11%	82%	3%	1%	358

Table 137. Proportion of people who remember their most recent service/care planning meeting (if involved in making decisions about their service plan/plan of care)

	No	Yes	Don’t Know	Unclear/Refused/No Response	N
FE Waiver	15%	82%	2%	2%	130
PD Waiver	12%	87%	1%	0%	199
TBI Waiver	0%	100%	0%	0%	11
Sample Average	13%	86%	1%	1%	340

Table 138. Proportion of people whose most recent service/care planning meeting took place at a time convenient to them (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	No	Yes	Don’t Know	Unclear/Refused/No Response	N
FE Waiver	0%	100%	0%	0%	106
PD Waiver	1%	99%	0%	0%	173
TBI Waiver	0%	100%	0%	0%	11
Sample Average	0%	100%	0%	0%	290

Table 139. Proportion of people whose most recent service/care planning meeting took place at a location convenient to them (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	100%	0%	0%	107
PD Waiver	0%	100%	0%	0%	169
TBI Waiver	0%	100%	0%	0%	10
Sample Average	0%	100%	0%	0%	286

Table 140. Proportion of people whose most recent service/care planning meeting included the people they wanted to be there (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	99%	0%	1%	105
PD Waiver	1%	99%	0%	0%	172
TBI Waiver	0%	100%	0%	0%	10
Sample Average	0%	99%	0%	0%	287

Table 141. Proportion of people who felt their preferences and needs were being heard as their service plan/plan of care was discussed during the most recent service/care planning meeting (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	Not at All	Very Little	Somewhat	Mostly	Completely	Don't Know	Unclear/Refused/No Response	N
FE Waiver	0%	0%	3%	13%	84%	0%	0%	107
PD Waiver	1%	1%	3%	14%	80%	0%	0%	173
TBI Waiver	0%	0%	18%	9%	73%	0%	0%	11
Sample Average	0%	1%	4%	14%	81%	0%	0%	291

Table 142. Proportion of people who received a copy of their service plan/plan of care after the most recent service/care planning meeting (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	7%	72%	21%	1%	106
PD Waiver	8%	81%	12%	0%	172
TBI Waiver	0%	73%	18%	9%	11
Sample Average	7%	77%	15%	1%	289

Table 143. Proportion of people whose service plan/plan of care includes what was discussed in their most recent service/care planning meeting (if involved in making decisions about their service plan/plan of care and remember their most recent service/care planning meeting)

	No	Yes, In Part	Yes, Completely	Don't Know	Unclear/Refused/No Response	N
FE Waiver	1%	6%	83%	9%	1%	107
PD Waiver	2%	3%	82%	13%	0%	172
TBI Waiver	9%	18%	55%	9%	9%	11
Sample Average	2%	5%	81%	11%	1%	290

Table 144. Proportion of people whose preferences and choices are reflected in their service plan/plan of care

	No	Yes, Some/In Part	Yes, All/Completely	Don't Know	Unclear/Refused/No Response	N
FE Waiver	3%	18%	65%	10%	3%	136
PD Waiver	5%	18%	60%	16%	1%	204
TBI Waiver	13%	13%	40%	27%	7%	15
Sample Average	5%	18%	61%	14%	2%	355

Table 145. Proportion of people who feel that the care supports and services they receive help them live a better life

	No	Yes	Don't Know	Unclear/Refused/No Response	N
FE Waiver	5%	93%	1%	1%	137
PD Waiver	6%	90%	4%	0%	205
TBI Waiver	7%	60%	20%	13%	15
Sample Average	6%	90%	3%	1%	357