

What Are We Waiting For? Waiver Supported Services Needed by Individuals and their Caregivers

**A Report Prepared by the Ohio Colleges of Medicine Government
Resource Center for the Ohio Developmental Disabilities Council**

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The results contained in this report and the statements and opinions expressed are those of the GRC only and are not to be attributable to ODDC or DODD. This report is located on the GRC website at <http://grc.osu.edu> and on the ODDC website at www.ddc.ohio.gov.

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Executive Summary

Across the nation, the demand for Home and Community-Based Services for individuals with developmental disabilities has exceeded the ability of states to satisfy the need for these services. The demand for Home and Community-Based Services has grown in part due to the increased lifespan of individuals with developmental disabilities and the general aging trends of the population. In response to the high demand for services, some states have created service waiting lists. Unfortunately, the time many individuals must stay on waiting lists before they are able to access Home and Community-Based Services has increased over time. In order to address the amount of time spent on waiting lists, many states have undertaken initiatives to either reduce or eliminate them.

In Ohio, each County Board of Developmental Disabilities manages waiting lists for services as required by Ohio Revised Code 5126.042. This includes waiting lists for the Individual Options, Level 1, and Self-Empowered Life Funding waivers. As of June 2013, there were 41,260 unduplicated people who were actively on a waiting list in Ohio. Analysis of current waiting list data has shown that time on the waiting list varies by residential setting, age of respondent, and the type of waiver desired. The median waiting list time is more than nine years for the Individual Options waiver and five years for the Level 1 waiver.

Although the current waiting list data captures the specific waiver individuals are seeking and the initial waiting list registration date, the information has limited usefulness from a policy planning perspective because it does not indicate what the specific unmet service needs of the individual are. In order to provide more clarity about the specific needs of individuals on the waiting list, the Ohio Developmental Disabilities Council enlisted the Ohio Colleges of Medicine Government Resource Center to undertake a study to “demystify” the waiting lists by illuminating the characteristics of those who are currently on the waiting lists and the specific needs of these individuals.

Specifically, a telephone survey of a representative sample of 1,131 individuals on the waiting list was conducted to determine their current and future needs. Key results of the waiting list survey include:

- Forty-six percent (46%) of all respondents reported no current unmet needs, and 15% did not anticipate having future unmet needs;
- Seventy-nine percent (79%) of respondents reported one or no current unmet need – in comparison, 30% of respondents said they anticipated one or no unmet need in the future;
- The greatest category of unmet future need reported by individuals and families was “Something to do during the day” with twenty-one percent (21%) selecting this category as a primary unmet future need;
- Many unmet needs may be addressed through the Level 1 waiver; Based upon inferences made from the survey, approximately twenty-one percent(21%) of current unmet needs can be addressed with the Level 1 waiver.

Given the disability levels of the population, the increasing age of caregivers, and the demand for services, it is likely that waiver support service needs will continue to grow (Braddock et al., 2013; Mehdizadeh, 2008). Accordingly, the Ohio Waiting List Study is an essential first step to discovering how to reduce waiting lists and to better meet the current and future needs of Ohioans with developmental disabilities.

Introduction

Each County Board of Developmental Disabilities (CBDD) manages a waiting list for Home and Community-Based Services (HCBS) waivers for individuals with developmental disabilities (DD) in accordance with the Ohio Revised Code (ORC) 5126.042. The ORC requires a CBDD to establish a waiting list if “available resources are not sufficient to meet the needs of all individuals who request HCBS.” This includes the Level 1, Individual Options (I/O), and Self-Empowered Life Funding (SELF) waivers. The Level 1 waiver was created to allow individuals with DD to live in their homes and obtain services at home or in the community, rather than in an Intermediate Care Facility. The Level 1 waiver, which has a spending limit of \$5,000, pays for seven different services, including respite, transportation, emergency assistance, environmental adaptations, day habilitation, supported employment, and homemaker/personal care services (Ohio Department of Developmental Disabilities (DODD), 2011). The I/O waiver is similar to the Level 1 waiver but has considerably higher spending limits ranging from \$5,001 to more than \$150,000 depending on the acuity level of the individual. In addition, the I/O waiver pays for additional services like remote monitoring and home delivered meals (DODD, 2011). The SELF waiver pays for services similar to the other two waivers, but is unique because the service user and his or her family make decisions about their waiver-funded services (DODD, 2012). The SELF waiver provides up to \$25,000 of funding for children, and \$40,000 for adults. All three waivers are Medicaid funded.

Individuals on the waiting list include persons receiving no services and who are waiting to receive waiver services as well as individuals receiving some services but who are waiting for funding to become available for additional services. Each CBDD submits waiting list data to the Ohio Department of Developmental Disabilities (DODD). However, neither CBDD waiting lists nor the data collected by DODD reveal the specific needs of persons on the waiting lists. For that reason, the Ohio Developmental Disabilities Council (ODDC) enlisted the Ohio Colleges of Medicine Government Resource Center (GRC) to undertake a study that would “demystify” the waiting lists by illuminating the characteristics of those who are currently on the waiting lists and the specific needs of these individuals.

Background

National Perspective

Waiting lists for services for individuals with DD have existed for more than 35 years. In 1974, there were approximately 200,000 individuals receiving services within state institutions (Sells, West, & Reichert, 1974). At that time, there were already several thousand individuals on waiting lists for admission to state institutions. Beginning in the early 80’s, deinstitutionalization helped move individuals from institutional settings to living in the community. As a complement to life in community settings, waiver services became available in 1981 and provided a wider range of services for individuals with DD. Waivers have become an important part of the service support network for individuals with DD and their families (Kitchener, Ng, Miller, & Harrington, 2005). There has been an increase in the need for waiver services and an increase in the length of time spent on waiting lists (Lakin, 1998; Parish & Lutwick, 2005; Smith, Agosta & Fortune, 2007; Schwalb, 2010). In response, several federal lawsuits have addressed the length of waiting lists and the length of time spent on waiting lists and at least 39 states have mounted initiatives to reduce or eliminate waiting lists (Agranoff, 2013).

In 2009, 35 states reported 99,870 persons with intellectual and developmental disabilities (I/DD) on waiting lists for residential services. From this number, Lakin et al. (2010) estimated 122,870 persons were on waiting lists nationally for

all services. The estimated number of individuals on waiting lists tripled over two years. In 2011, there were 393,096 individuals with I/DD on waiting lists in 2011 across the country (Kaiser Commission on Medicaid and the Uninsured, 2012). The Kaiser Commission (2012) also estimated that individuals spent an average of 40 months waiting for waivers.

Braddock et al., (2013) suggests the primary causes for the growing size of waiting lists are the increased lifespan of individuals with DD, aging of caregivers for individuals with DD, the closing or downsizing of public institutions, and litigation designed to increase access to services. The result is an increased need for waivers, which often go beyond the capacity of the resources available to most states (Research and Training Center on Community Living, 2000).

In 1998, researchers from the University of Minnesota gathered data on the use of waiting lists across the nation. They looked at the type and content of waiting lists, state laws regarding waiting lists, the policies and initiatives within each state designed to reduce or eliminate waiting lists, and the types of services provided in the interim to those enrolled on waiting lists. They discovered that states' and the District of Columbia's activities related to waiting lists varied. For instance, 42 states and the District of Columbia maintained waiting lists for people with DD. Approximately half of the 42 states maintained a single comprehensive waiting list, while the remainder maintained multiple waiting lists categorized by service or another indicator (see Table 1). Later on in 2008, a Kaiser Commission study found that for developmental disability services, 28 states and the District of Columbia reported having waiting lists, 17 reported not having waiting lists, and information was not available for six states. In 1998, 84% of states maintained waiting lists for services. By 2008, the percentage dropped to 55%.

Table 1: State Agency Lists of Persons with Developmental Disabilities Waiting for Services (Summary)

Type of List	Number	Specific States
A single inclusive list	21	AK, AZ, CO, GA, KS, LA, MD, MI, MT, NE, NH, NM, NC, OK, PA, TN, UT, VT, WA, WV, WY
More than one list, by service	21	AL, AR, CO, CT, DC, FL, HI, ID, ME, MN, MS, NV, NJ, NY, OR, SC, SD, TX, UT, WA, WI
More than one list by other categories	6	DE, IN, KY, MA, MO, NJ, UT
No statewide list	6	IL, IA, OH*, PA, UT, VA
No list	3	CA, ND, RI

Note: Several states (CO, NJ, PA, UT, WA) fall into multiple categories.

Source Research and Training Center on Community Living Report (2000).

* In Ohio, waiting lists are kept at the county level and then submitted to the state.

In the past, waiting lists have been kept to address the following service needs for individuals with DD (Research and Training Center on Community Living Report, 2000):

- Support services in family homes
- Residential services not in family homes
- Vocational and other day training
- Respite
- Case management
- Homemaker or personal care assistant or attendant care
- Therapies or clinic services
- Modification to home, vehicle, or other adaptive device
- Transportation
- Other (Includes: sexual offender treatment, early intervention, community supports, and day supports)

Each state was also asked to report priority areas for waiting list members. The priority categories included (no order intended) (Research and Training Center on Community Living Report, 2000):

- Severity of the disability
- Length of time waiting on the list
- Crisis or emergency in the family
- Costs of needed services
- Age of the individual needing services
- Strength of advocacy or family influence
- Potential benefits of services
- Other (Includes: age of caregiver, county discretion, prevention of abuse/neglect, prevention of homelessness, response to death or loss of caregiver, prevention or end of institutionalization, health and safety, and support for young adults)

For several reasons, some states, including Ohio, do not maintain a statewide wait list. For instance, in some states there is a mandate to provide services to all who need them. In other states, services are provided on a “first come” basis (Research and Training Center on Community Living Report, 2000). In another group of states, services are allocated and data is gathered at a local level. In Ohio, the state gathers waiting list information from CBDDs, but these lists are initiated and managed at the county level.

The challenges of managing waiting lists are multidimensional and are affected by the availability of resources as well as the growth in service need. The literature indicates there is concern about waiting lists across the country and that many states have taken steps to manage or reduce waiting lists to better address service needs. The Research and Training Center on Community Living (2000) investigated the efforts of states around reducing or eliminating their waiting lists. The report found that states had various rules about how to manage individuals who were on an existing waiting list. In addition to priority categories, many states required regular reporting on waiting lists and provided other services to individuals while they waited (see Table 2). Initiatives to reduce or eliminate (e.g., DC, DE, HI, MA, NE, NH, NJ, and NY) waiting lists have been undertaken with several jurisdictions between 2000 and 2011 (Research and Training Report, 2000; Kaiser Report, 2012).

Table 2: State Laws/Policies Regarding Waiting Lists (Summary)

State Rules	Yes	No	In progress	N/A
Periodic reporting of number on waiting list.	24*	23	3	1
Limit the time individuals are required to wait.	3	47*	0	1
Required to provide services to individuals while they wait.	13	36*	1	1
Provided assistance to individuals waiting	39*	3	0	5

*Includes Ohio

Data Source: Research and Training Center on Community Living Report (2000).

Waiting Lists in Ohio

The Ohio Department of Developmental Disabilities' waiting list rule (OAC 5123:2-1-08) requires CBDDs to establish waiting lists when individuals request either HCBS or non-Medicaid programs or services and available resources are not sufficient to meet the needs of all individuals making requests. In Ohio, each CBDD maintains a waiting list for the I/O waiver, Level 1 waiver, and SELF waiver (DODD, 2012). Services available for funding under the waivers may include respite, transportation, supported employment, day habilitation, homemaker/personal care services, home delivered meals, and adaptive/assistive equipment (DODD, 2011). An individual may register for services in multiple counties and so be added to the waiting list in multiple counties. Moreover, an individual has a single statewide waiting list date that establishes his or her place on the waiting list; when an individual establishes their initial waiting list date in one county, the individual establishes his or her waiting list date for all other counties.

Individuals on waiting lists who qualify for emergency status or have other priority status receive waivers first. An emergency is defined as an instance where an individual is, "facing a situation that creates for the individual a risk of substantial self-harm or substantial harm to others if action is not taken within thirty days" (OAC 5123:2-1-08(B)(5)). Examples of circumstances that may result in an emergency include loss of residence, loss of caregiver, and abuse, neglect, or exploitation of an individual. Priority categories include individuals with aging caregivers or intensive needs (OAC 5123:2-1-08(F)).

The waiting list rule (OAC 5123:2-1-08) contains various other requirements designed to achieve fair and consistent administration of the waiting list. For example, when an individual requests HCBS for which there is a waiting list, a CBDD is required to identify the individual's immediate needs and assist the individual in identifying and obtaining alternative services that are available to meet those needs. On an annual basis, a CBDD must review the individual's current status, reassess the service needs of individuals on the waiting list, and inform individuals of their position on the list. Individuals also have due process rights if they feel aggrieved by the way in which a county board is managing the waiting list.

Objectives of the Waiting List Study

In order to better understand the nature of the waiting list in Ohio, the ODDC developed two key research objectives: 1) provide general demographics for the waiting list population by analyzing the available data on individuals currently on the waiting list, and 2) understand the specific needs of individuals on the waiting list.

In order to accomplish the objectives of the study, the project relied upon two data sources: 1) current DODD statewide waiting list data gathered from the 88 counties, and 2) a telephone survey of individuals on the waiting list.

Waiting list information obtained from DODD included the following: the individual's date of birth, gender, race and ethnicity, initial county board enrollment date, resident county, and the type of waiver being sought.

Key Findings of DODD Waiting List Information

As of June 2013, there were 41,260 people who were waiting for at least one of the three HCBS waivers included in this study. Appendix A shows the median waiting list time for these individuals is 6.4 years. The appendix also shows the median, 25th, and 75th percentile waiting list times by age, living arrangement, gender, race, and ethnicity. For example, for individuals living in institutions the median wait time is 13.7 years while the 25th and 75th percentile is 8.6 and 18.4 years respectively.

Figure 1: Median Waiting List Times by Age Category

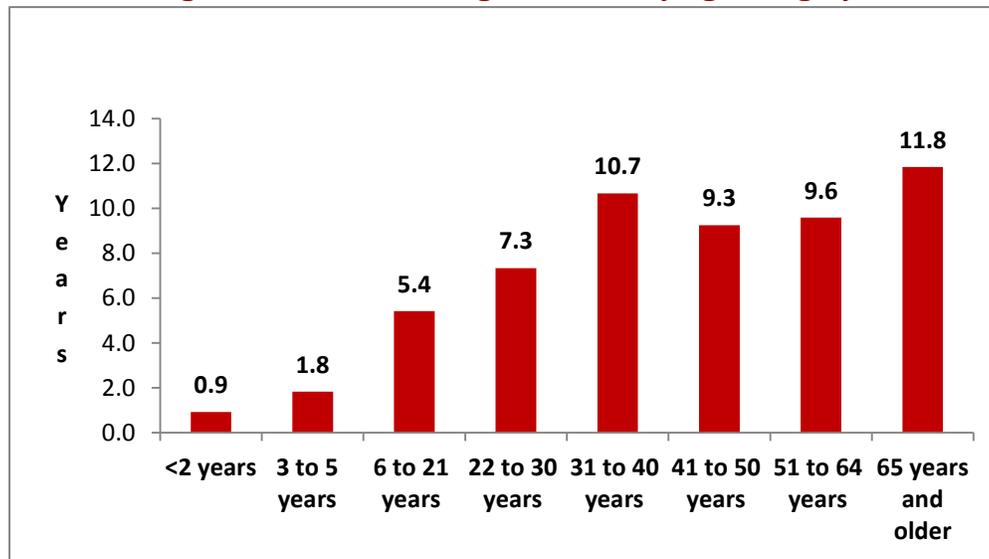


Figure 1 shows the median waiting list times of individuals of different age groups. The length of time on the waiting list grows with age until about 40-years, where it levels off or declines slightly until age 65. After age 65, the median waiting list time increases to 11.8 years. It is important to consider the age of the caregiver as well as the age of the individual with DD when examining waiting list times. Based on the average age of mothers at first childbirth, individuals who are 65 and older, for example, will often have caregivers who are 88 years and older (Martinez, Daniels, & Chandra, 2012). Despite the potential for increased limitations of the caregiver as the individual ages, Figure 1 shows that waiting list times are positively associated with age. The relationship between age and longer waiting list times may reflect the ability of caregivers, in part, to better adapt to the needs of individuals over time (Heller, Caldwell, & Factor, 2007).

Figure 2: Median Waiting List Times by Type of Waiver

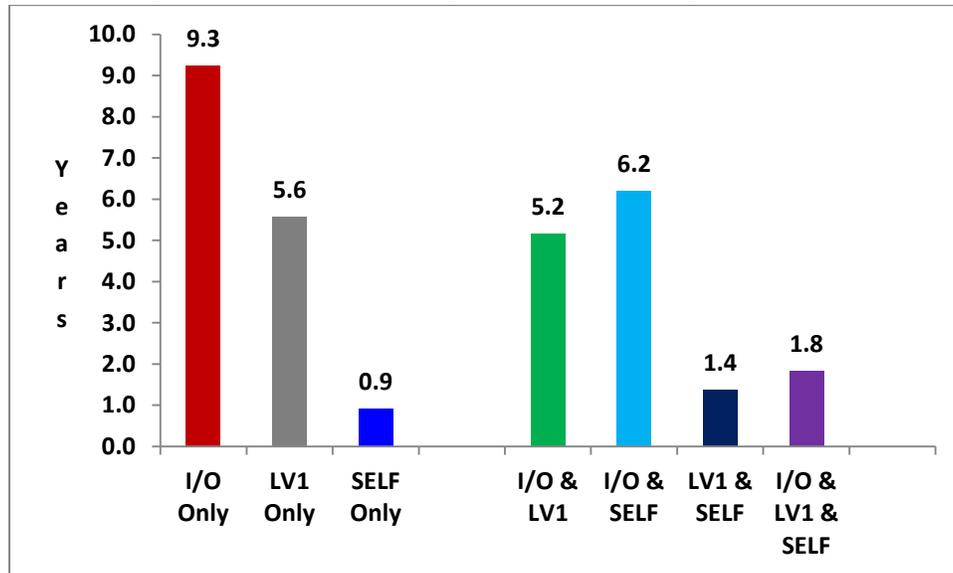
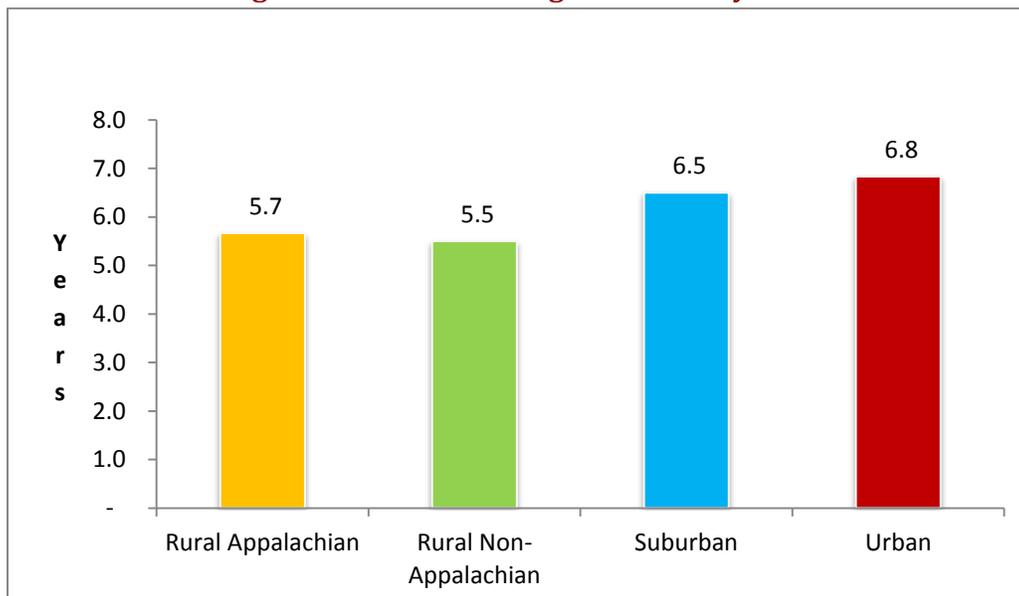


Figure 2 shows the median length of time that individuals have been waiting for various waivers. Individuals can register to wait for one or multiple waivers at the same time. The vast majority of individuals, 18,649, are registered for both the I/O and Level 1 waivers, or the I/O waiver alone, 17,645 (a complete table of the number of individuals on the waiting list by the type of waiver and their waiting times is provided in Appendix B). In general, the waiting list times are higher for those who are waiting for one waiver compared to multiple waivers. Individuals registered for more than one waiver have a better chance of obtaining a waiver compared to someone registered for a single waiver. Figure 2 also shows that the wait time for the Level 1 only waiver (median = 5.6 years) is much less than for the I/O only waiver (median = 9.3 years), reflecting the relative ease of obtaining this lower cost waiver. Since the SELF waiver has only been in existence since July 2012, the waiting list time for this waiver reflects its brief time offered as a service.

Figure 3: Median Waiting List Times by Area



Health care services are often more widely available in urban areas as compared to rural areas (Arcury et al., 2005). Although it is unclear whether service availability for DD services is distributed like health care services, the waiting list rule allows individuals to register for services in more than one county. Figure 3 shows that waiting list times are actually greater in urban and suburban areas as compared to rural areas, indicating at least by this measure that waivers are more difficult to obtain in urban areas (a complete table of the number of individuals on the waiting list by county/area and their waiting times is provided in Appendix C).

Limitations of Waiting List Information

Available waiting list data merits caution for use in service planning. A first caution is that waiting list data show that individuals often wait for many years before obtaining a waiver. This results in data that may be limited in describing the current needs of some individuals with DD, since it is hard for individuals and parents to know precisely what their future needs will be years in advance at their initial application. The individual's service needs may change between the time they sign up for a waiver and the years spent on the waiting list. A second caution is that these data lack service specificity – these data are limited in ability to inform policy makers of what specific needs the individual has. Signing up for a waiver, each of which pays for a different collection of services, does not in itself inform policy makers of true individual need. For instance, an individual could require medical services only, which could be met through a Medicaid card, but be signed up for medical and non-medical services through a Level 1 waiver. In other words, being placed on a waiting list for a waiver does not in itself indicate the precise service needs of an individual.

Survey Methodology

A survey was developed to determine the primary current and future needs of individuals on the waiting list. To achieve this goal, a telephone-based survey was administered to a randomly selected sample of 1,131 individuals who were currently on the HCBS waiver waiting list.

The DODD provided a random sample of 14,978 out of a possible 41,260 persons currently on the waiting list for an HCBS waiver. This list was sent to the Kent State University Survey Research Lab (SRL) as the primary call center for the project. The HCBS waiver list included names, addresses, and some phone numbers drawn from Medicaid records. The addresses contained in the HCBS list were sent to Survey Sampling International, Inc. (SSI), where addresses were used to find associated telephone numbers. This process resulted in 4,959 phone numbers (33.1% of the sample), which were folded into the sample file along with phone numbers taken from Medicaid enrollment files. The result was that telephone numbers were available for 11,025 respondent records (73.6% of the original sample received from DODD). The list of telephone numbers consisted of: (1) address-matched-only phone numbers, (2) Medicaid-list-only phone numbers, and (3) address-matched and Medicaid-list verified phone numbers.

A survey was designed by the GRC in conjunction with the Waiting List Panel (see Acknowledgements) to obtain information about individual's current and future needs, caregiver characteristics, and perceptions about the waiting list. The survey consisted of 21 questions with Likert-based multiple-choice answers (see Appendix D). The survey instrument underwent multiple revisions based on stakeholder review and input. The survey also benefitted from SRL and stakeholder-conducted cognitive testing to help ensure understandability for persons taking the survey. The survey

instrument was cognitively tested by survey methodologists at OSU. The mean time for completion was approximately 13 minutes.

After initial survey development was completed, the survey was rigorously tested by the SRL project team. Testing included:

- Developing scenarios to test all possible paths through the questionnaire;
- Checking frequencies of randomly generated data;
- Verifying frequencies of the data after the first day of interviewing; and
- Conducting a pretest to identify and fix potential issues in the collection of live data.

Experienced, supervised personnel conducted the Waitlist Survey interviews using the WinCati version 4.2 Supervisor and Interviewer CATI package. Interviewers underwent extensive study-specific training prior to data collection. To maximize response rates, calls were concentrated in the afternoons and evenings during the weekday and on the weekends.

Survey interviews were conducted between September 5, 2013, and September 27, 2013. The survey was conducted with the individual or a family member/guardian who was able to speak on behalf of the individual with DD. All respondents were required to be 18-years old or older. Of the completed surveys, 134 (13%) were completed by individuals with DD and 997 (87%) were completed by another adult, primarily the parent or guardian.

During the data cleaning process, in preparation for analysis, approximately 50 data records were corrected in cases where there were inconsistencies in the data.¹ An additional five surveys were removed due to incomplete data. The final dataset was reduced to 1,131 after data cleaning. The response rate was 51.8%.² For the key questions of the survey (questions where everyone was asked), the 95% confidence interval spanned less than +/- 3% of the estimated percentage. The survey methodology report can be found in Appendix H.

¹ Individual cases where there was no primary unmet need selected and no other areas of unmet need selected were recoded to show that the individual had no primary unmet need. Similarly, cases where the individual had a record showing a primary unmet need yet there was also a selection of another category of unmet need were recoded to show that the individual had a primary unmet need.

² This response rate was calculated using the American Association for Public Opinion Research's (AAPOR) Response Rate 3 (RR3) method, which rates the completion of successful surveys against survey eligibles and survey disposition (For a full discussion of response rates see [AAPOR's Standard Definitions](#)).

Survey Instrument

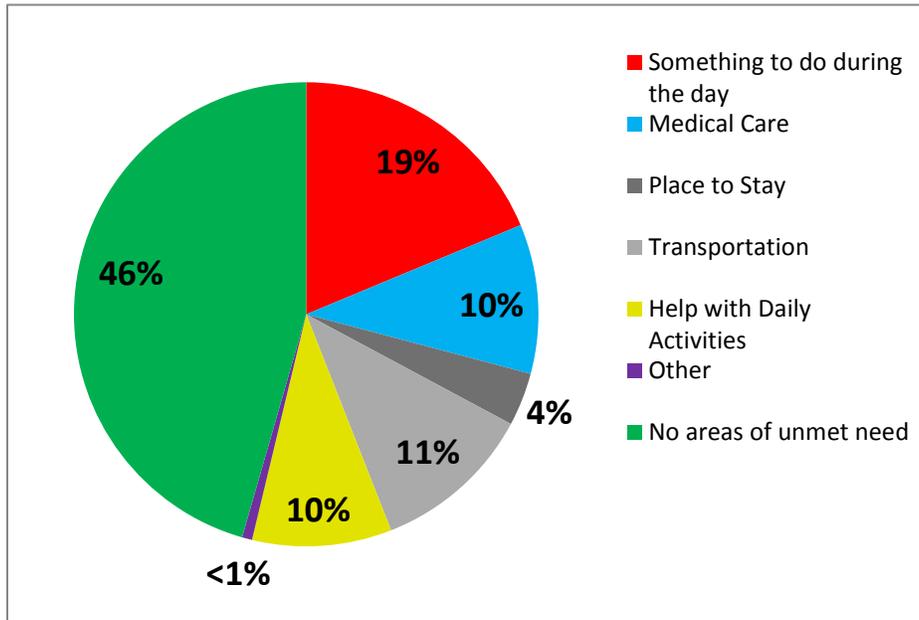
Table 3: Questions Addressed in the Ohio Waiting List Survey

CURRENT NEEDS	FUTURE NEEDS
<u>In which of the following areas do you have an unmet need? In which of the following areas will you need help in the future?</u>	
(1) Something to do during the day	(1) Something to do during the day
(2) Medical Care	(2) Medical Care
(3) Place to Stay	(3) Place to Stay
(4) Transportation	(4) Transportation
(5) Help with Daily Activities	(5) Help with Daily Activities
(6) Other	(6) Other
(7) No areas of unmet need	(7) No areas of unmet need
	-When in the future - 0 to 1 year?
	- When in the future - 1 to 5 years
	-When in the future - 5 or more years?
<u>Of the areas you picked which one is the most important ?</u>	
Demographic \ Perception Questions	
Do you have a primary caregiver?	
How is your primary caregiver related to you?	
How old is your primary caregiver?	
Does your primary caregiver live with you?	
Which of the following reasons is your primary caregiver not able to continue caring for you?	
How did you or your caregiver find out about waiver services?	
What services do you plan to use your waiver for?	
How long did you think it would take to get your waiver?	
Health Insurance of Individual	

Table 3 details the questions of the survey. Major components of the survey included items on current and future unmet needs, demographic information, and waiting list perceptions. For the current and future unmet need questions, respondents were given categories to choose from, including: (1) Something to do during the day; (2) medical care; (3) place to stay; (4) transportation; (5) help with daily activities; (6) other needs, and (7) no areas of unmet need. For each current and future unmet need, the respondent was asked a follow up question addressing that specific need. For example, if the individual indicated that his or her primary unmet need was for transportation services, then the respondent would further be asked if he or she had unmet needs in the area of learning to access transportation, needing someone to take him or her places, or equipping his or her van for wheel chair accessibility. For questions about future unmet needs, respondents were also asked to anticipate when they would need the service (i.e., 0-1, 1-5 or 5 or more years from the time of the survey). The complete questionnaire is provided in Appendix D.

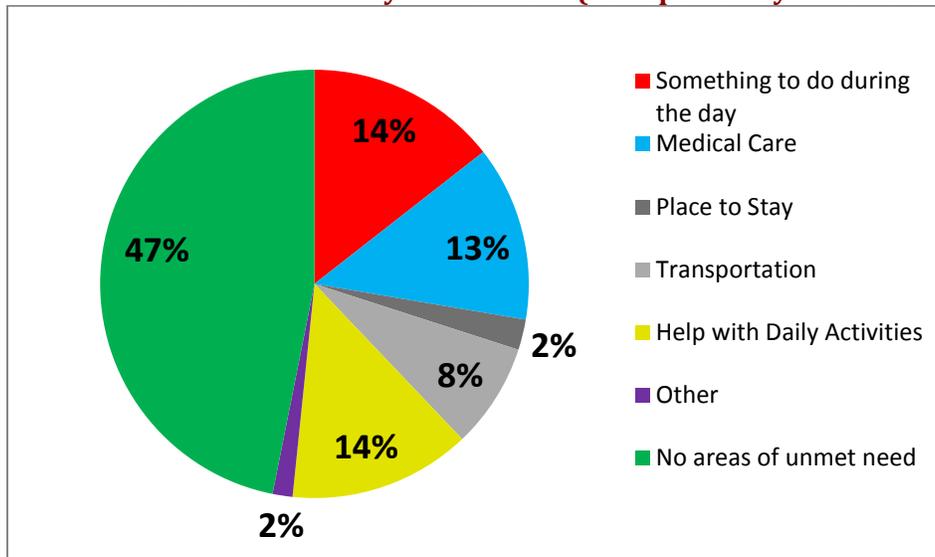
Survey Results

Figure 4a: Individual's Current Primary Unmet Need (as Reported by Individuals)



Percentages may not add to 100% due to rounding.

Figure 4b: Individual's Current Primary Unmet Need (as Reported by Parents or Guardians)

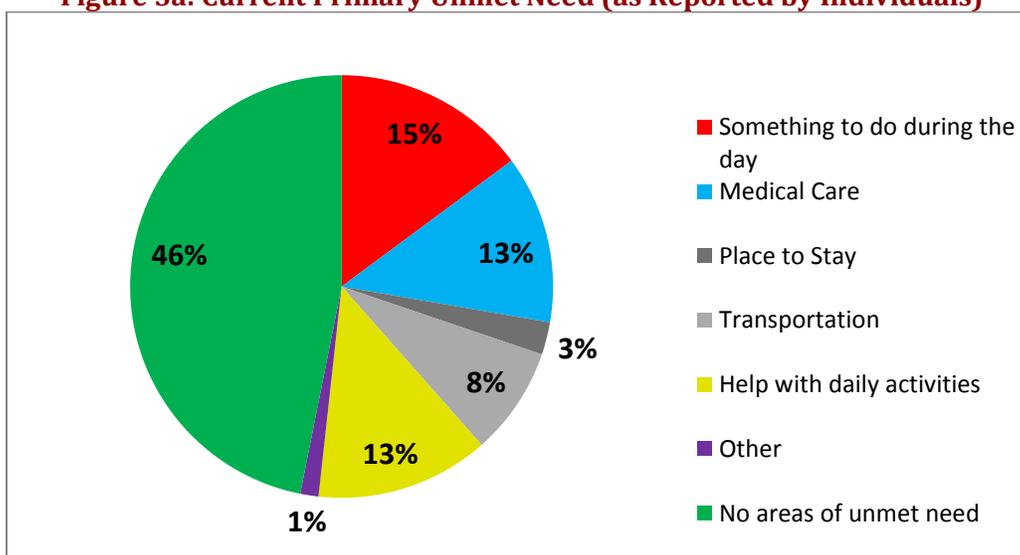


Percentages may not add to 100% due to rounding.

Figures 4a and 4b show the percentage of total responses for current primary unmet needs. Figure 4a tallies the responses obtained from individuals on the waiting list. Figure 4b shows the responses of persons answering the survey questions on behalf of individuals, primarily parents or guardians. For both groups of respondents the most prevalent response was "No areas of unmet need." Forty-six percent (46%) of individuals reported "No areas of unmet need" while 47% of parents/guardians reported "No areas of unmet need." This result supports the idea that many families sign up

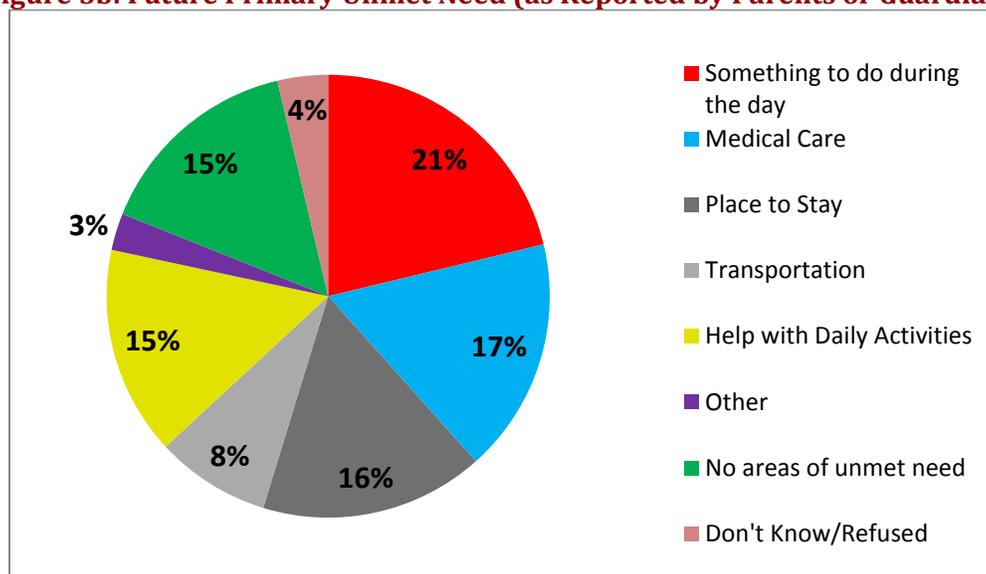
for services well in advance of service need – indicated by waiting list duration. In other words, need may be minimum at the period of waiting list initiation and anticipated as higher into the future. The highest prevalent need category both for individuals and for parents/guardians is “Something to do during the day” (19% and 14%, respectively), followed by “Help with Daily Activities” (14% and 10%, respectively). Concerning the need for transportation, 11% of individuals indicated this need compared to 8% of parents/guardians. Slight variations in these findings may indicate variation in perceptions about service needs between individuals with DD and parents/guardians. A complete question breakdown of survey results by individuals, parents/guardians, and combined totals are provided in Appendix E of the report. For each question, the percentage of affirmative responses, the 95% confidence level, and the total possible number of responses are listed. Note that for many questions, more than one response was possible so that the percentages do not always add to 100%.

Figure 5a: Current Primary Unmet Need (as Reported by Individuals)



Percentages may not add to 100% due to rounding.

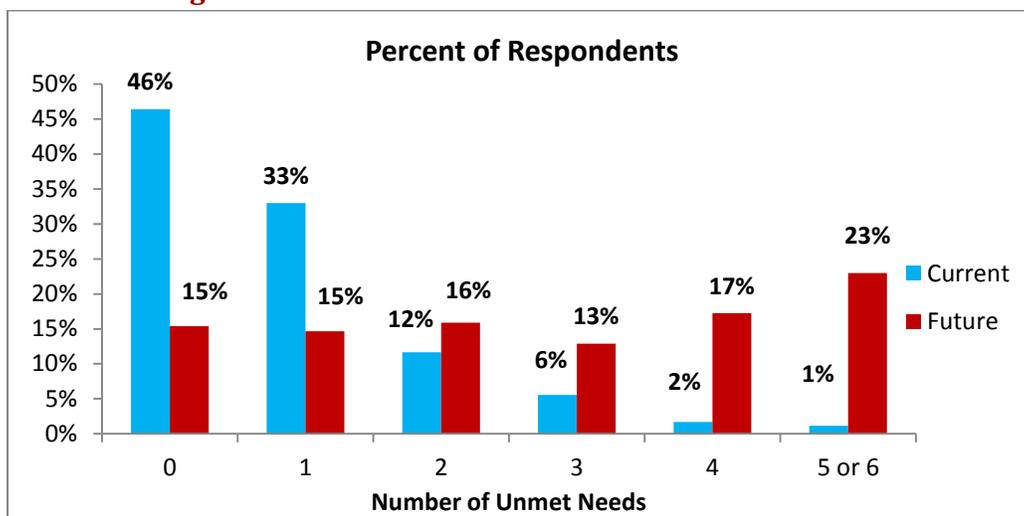
Figure 5b: Future Primary Unmet Need (as Reported by Parents or Guardians)



Percentages may not add to 100% due to rounding.

The remainder of the tables and figures presented in the report are for the total responses of both individuals and parents/guardians. Figures 5a and 5b compare the prevalence of current versus future primary unmet need. Note that the category “No areas of unmet need” decreases considerably when looking at current versus future unmet need. However, this begs the question of why 15% of those on the waiting list indicated they have no future unmet need continue to be on the waiting list. Further research is needed to understand why this is the case. “Something to do during the day” is the most prioritized category for unmet needs in either the present or future (15% versus 21%, respectively). The category that shifts the most in terms of prevalence between current to future unmet needs is “Place to Stay” (3% compared to 16%, respectively). This shift suggests that parents/guardians and individuals may be concerned about who will take care of the individual in the future after the decease of the caregiver (Hayes, et al., 2012; Heller & Caldwell, 2006; Heller, Caldwell, & Factor, 2007)

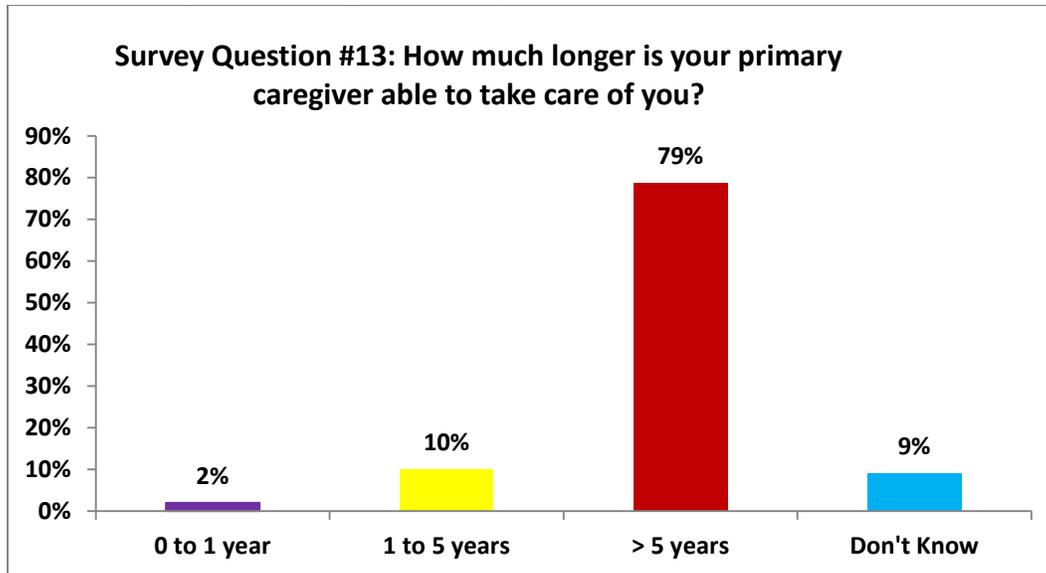
Figure 6: Number of Current and Future Unmet Needs



Percentages may not add to 100% due to rounding.

Another way to compare current and future unmet needs is by contrasting the number of unmet needs respondents reported in each of these periods. Seventy-nine percent (79%) of respondents stated one or no unmet need in the present. Comparatively, 30% of respondents had one or no unmet need in the future. Forty percent (40%) of respondents had four or more unmet needs in the future and 23% of these respondents indicated they had five or six unmet needs. Appendix E also details when respondents believed they would need services in the future, by 0 to 1 year, 1 to 5 years, and 5 or more years. For example, 58% of respondents chose “Something to do during the day” as a future unmet need. Of this percentage, 29% of respondents indicated they would have this need within one year, 31% between 1 to 5 years, and 41% in 5 or more years.

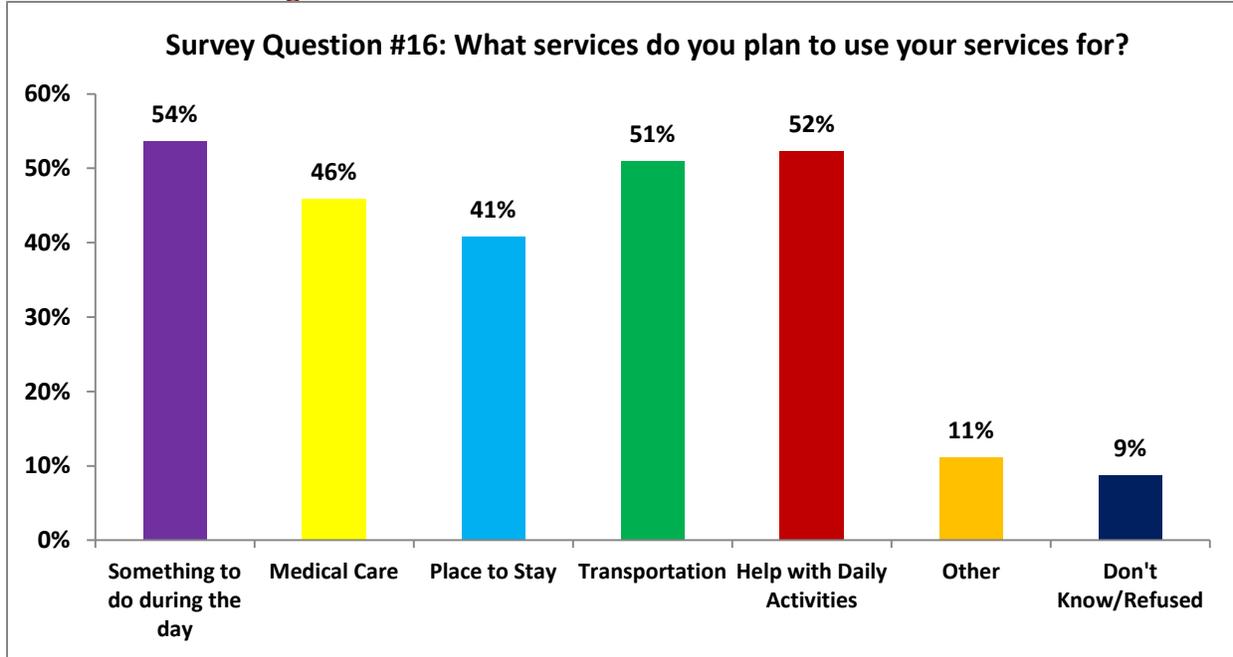
Figure 7: Caregiver Ability to Take Care of the Individual



Percentages may not add to 100% due to rounding.

Question 13 of the survey asked respondents how much longer their caregivers would be able to care for them. Figure 7 shows that a majority, 79%, believed they would be able to provide care for the individual for an additional 5 or more years from the date of the survey. The question, however, does not indicate if the primary caregiver may need at least some help in the future in order to continue to take care of their individual with DD. One can use the detail provided in Appendix E to address this question. Specifically, Appendix E shows what percent of individuals indicated needing “Help with Daily Activities” in the future and when that care is needed. To the extent caregivers are providing this help, the Appendix E responses offers insights as to who needs at least some support and when this support is needed. Fifty-seven percent (53%) of individuals indicated needing some “Help with Daily Activities” in the future. Of those who indicated needing help, 36% need help within a year, 28% between 1 and 5 years, and 37% in more than 5 years.

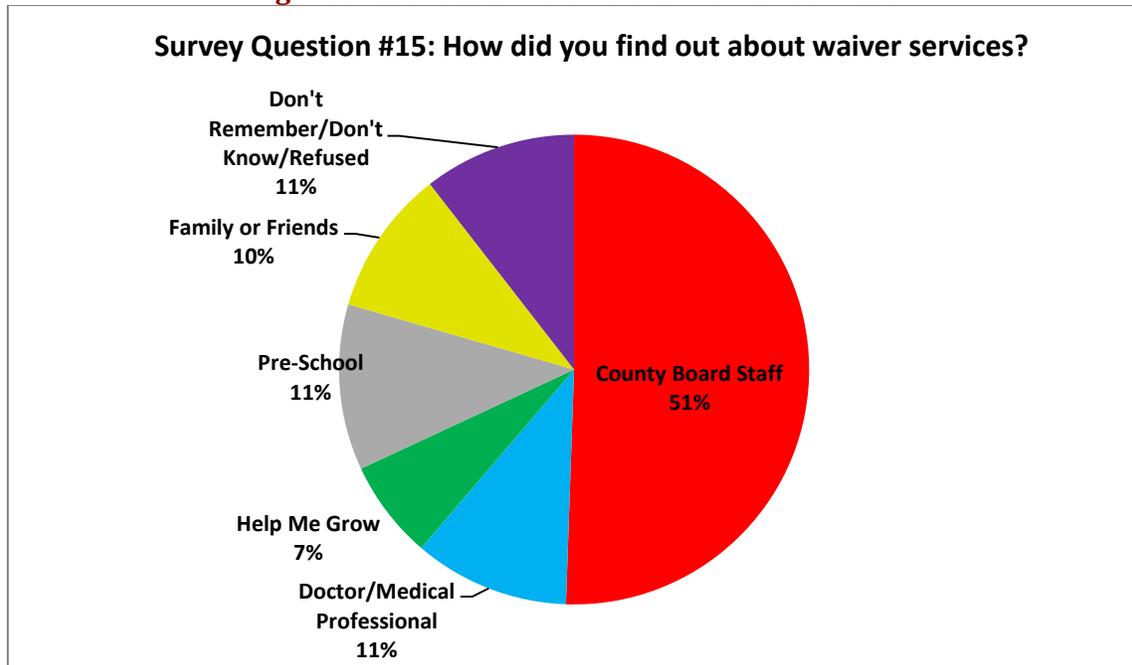
Figure 8: How Individuals Intend to Use Their Services



Multiple options allowed. Percentages do not add to 100%

Question 16 asked respondents specifically what services they intended to use the waiver for, once obtained. Figure 8 shows the range of responses. There was no dominant response among the service choices: individual and families intend to use the waiver for a variety of purposes. Fifty-four percent (54%) of respondents chose “Something to Do During the Day” and 46% chose “Medical Care.” These services are not directly provided by the DODD waivers (Individuals, however, who obtain a waiver also become eligible for these services).

Figure 9: Sources of Referrals to Waiver Services

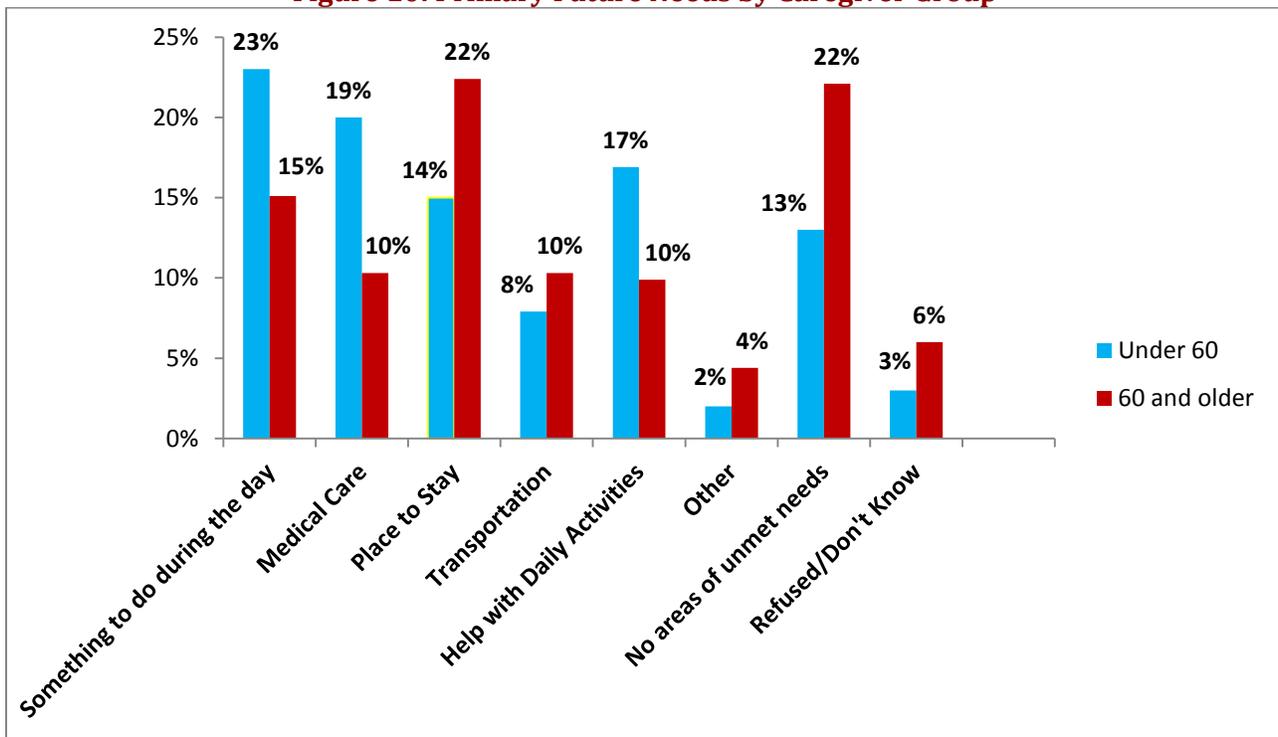


Percentages may not add to 100% due to rounding.

Figure 9 shows how important CBDDs are in helping individuals connect to services. Approximately half (51%) of the respondents indicated they found out about waiver services through their county board. Other referral sources are preschool (11%), Help Me Grow or Early Intervention (7%), medical professionals (10%), and family or friends (10%). A complete question breakdown of survey results by individuals and parents/guardians is provided in Appendix E of the report.

Many survey questions allowed respondents to provide comments. Appendix G provides a complete listing of comments from respondents who chose to comment for any given question. The GRC research team in conjunction with representatives from DODD recoded comments that clearly belonged in one of the question categories (e.g. “therapy” = Medical Care). Although most of the comments were easily assigned to existing categories, there were some comments that were left in the “Other” category. Appendix D shows that 2.7% of responses to “Future Unmet Need” were classified as “Other” even after recoding the comments into appropriate categories. Common themes behind these comments included home modifications, financial management, and tutoring. These areas of unmet need were not specifically addressed in this survey.

Figure 10: Primary Future Needs by Caregiver Group



Percentages may not add to 100% due to rounding.

Comparing survey responses of groups of respondents of interest can provide meaningful insights as to what unmet needs various cross sections of respondents have. Figure 10, for example, compares the responses of respondents with caregivers under the age of 60 and age 60 and older for the question, “What is your primary unmet need in the future?” Studies show that as caregiver age increases, they must address their own increasing needs in addition to those of the individual with DD (Lakin, 1998). Given the increased needs of caregivers themselves as they age, one could reason that the primary future unmet needs of individuals with older caregivers would be higher compared to those with younger

caregivers. Figure 10 shows, however, that this is not the case. Twenty-two percent (22%) of respondents with caregivers over the age of 60 indicated they did not anticipate any area of unmet need in the future compared to 13% of respondents with caregivers under the age of 60. Given this finding, it is important to restate that caregivers are the overwhelming majority of respondents (88%).

Heller et al., (1997) notes that greater support from an adult child to a caregiver reduces caregiver burden. Others have documented that adult children provide considerable support and assistance to their aging relatives (Rossi & Rossi, 1990). The survey data also supports the conclusions from these studies. Proportionally, more respondents with caregivers under the age of 60 reported having a primary unmet need in the category of “Help with Daily Activities” than those over the age of 60 (17% vs 10% -see figure 10). Individuals who responded on the survey and who had older caregivers had different perspectives of what their needs are and what is most important compared to respondents with younger caregivers. Respondents with younger caregivers selected “Something to do during the day” as the highest primary unmet need compared to respondents with older caregiver who selected “Transportation” as the highest primary unmet need (Appendix F details all survey responses by caregiver under and over age 60).

Inferences from Survey

Table 4: Inferred Waivers Needed from Waiting List Survey

	% From Survey	Total Possible From Survey	Inferred Waivers Needed	Non Federal Cost
Current				
Level One	21%	1,131	8,764	\$ 38,889,160
I/O Waiver	26%	1,131	10,609	\$ 243,227,817
				\$ 282,116,978
Future				
Level One	13%	1,131	5,367	\$ 23,817,285
I/O Waiver	67%	1,131	27,632	\$ 633,545,975

* Non-federal cost is calculated using a federal medical assistance percentage of 63.02%. Total waiver cost averages used are: Level 1 \$12K and I/O waiver cost of \$62K (Source: DODD)

Finally, one can use the survey results to infer how many additional waivers are needed in the present and the future by mapping the various unmet need categories to a Level 1 or I/O waiver (e.g. transportation = Level 1) (Rizzolo et al., 2013) Using the assumptions described in the footnote³, 21% of individuals on average have current needs that could be met with a Level 1 waiver. This translates to 8,764 individuals based upon a statewide waiting list figure of 41,260. Using average waiver cost data of \$12K (combined total costs including Medicaid card costs) for Level 1 and \$62K for the I/O waiver, the total non-federal costs of filling these waivers are roughly \$282 million dollars annually. The non-federal costs of filling the Level 1 waiver for current needs alone are approximately \$39 million dollars annually. The table also shows that for individuals on the waiting lists, the unmet needs relating to I/O waiver services is anticipated to increase

³ The inferred waiver calculations were made using the following selection criteria: selections made for “Something to do during the day”, “Medical Care”, “Transportation”, or any combination of these categories were assigned to the Level 1 waiver. Any combination of the “Place to Stay” and “Help with Daily Activities” category along with the other unmet categories were assigned to the I/O waiver. Selections for the “Other” category were split equally between the Level 1 and I/O waiver.

substantially in the future. Unmet needs that could be met with an I/O waiver would rise from approximately \$243 million currently to approximately \$634 million in non-federal funds in the future.

Waiting List Survey Data Limitations

Although the waiting list survey provides useful information about individual and family needs, there are limits as to how the data can be used to make inferences about the DD population. The sample of 1,131 is relatively small for making inferences about the unmet needs for various population subgroups (e.g., small geographies such as counties, or age groupings). Another limitation of the survey data lies with the composition of survey respondents; the vast majority of these data come from a parent or guardian as opposed to an individual with DD. Although the parental/guardian perceptions of current unmet needs for individuals with DD are roughly in line with responses from individuals with DD, they diverge considerably when examining future unmet needs. Further study needs to examine why variation occurs and to what extent this variation indicates true difference in the description of need. Subsequent surveys should consider devoting more resources for obtaining higher response from individuals with DD. Finally, refinements to the survey questionnaire should emphasize more comprehensive categories of need from individuals with DD and parents/guardians, allowing for greater survey specificity. For example, respite care is a need that is often expressed by families in the survey. Yet, the survey only addresses this need as a subcategory of “Help with Daily Activities.” Since respite was only addressed at the subcategory level, it is possible that respite care is under represented as an unmet need. To address these issues, future surveys should make respite services a separate category of questioning.

Discussion

The waiting list survey data illuminates the needs of individuals with DD in the present and into the future. It was noted that a large percentage of individuals with DD and their parents/guardians expressed having no current unmet need. The study shows that individuals with DD are, on average, on a waiting list several years. Anticipating these long waiting list times, some individuals register well in advance of their need for a waiver. The potential time-gap between registration and reception of waiver services may indicate why 46.4% of individuals with DD reported no current unmet need during the study. However, the data shows unmet needs do change over time. For example, those who indicated needing a place to stay shifts dramatically from 5.4% currently to 45% in the future – the survey shows specific breakouts of anticipation in the future (< 1 year, 1 to 5 and > 5 years). Continuing with the example of unmet needs in the “Place to Stay” category, almost 2/3 of respondents indicated this need would occur in 5 or more years. This information may be useful to policy makers who are considering future needs and budgets.

Future studies need to focus on waiting list survey results that appears counter intuitive in order to better understand the needs of individuals. For example, the survey data reveals that nearly all individuals have medical insurance; however, 17% of respondents indicate that their primary future need is for medical care. Although studies do show that individuals with disabilities have problems accessing psychiatric and dental care (Hayes et al., 2012), respondents may also have trouble accessing medical services generally or in the case of those with private insurance, have difficulty paying for high out of pocket medical costs. Parents or guardians may not also be fully aware of what medical coverage is available for the individual. Further qualitative research could help policy makers better understand the needs of individuals who have unmet medical needs.

In order to measure progress in meeting the needs of individuals with DD, the waiting list survey could be regularly administered. Benchmarks can be established for the percentage of individuals on the waiting list. The inferred number of waivers needed over time to address unmet needs may be another useful measure of progress. Finally, since the waiting list and service delivery is arranged at the county level, future surveys could be administered by individual counties as well as the state level. Information obtained at the county level would be useful for county planners to determine the needs of individuals with DD in their service area and to assist in planning for those needs in the future.

Conclusion

The Ohio Waiting List Survey offers valuable information about specific needs individuals with DD currently have and will have in the future. This study achieved its objective to “demystify” the waiting list. Given the likely growth in the waiting lists and the demand for services, it is an essential first step to discovering how to reduce waiting lists and to better address the current and future needs of Ohioans with DD. It is our hope that policy makers and DD stakeholders will continue to use the survey results as information concerning the nature of Ohio’s waiting lists in order to better meet the current and future needs of Ohioans with DD.

References

- Agranoff, R. (2013). The transformation of public section intellectual/developmental disabilities programming. *Public Administration Review*, 73(s1), s127-s138.
- Arcury TA, Preisser JS, Gesler WM, [Sherman J.](#), [Spencer J.](#), and [Perin J.](#) (2005). "The Effects of Geography and Spatial Behavior on Health Care Utilization among the Residents of a Rural Region. *Health Services Research* 40(1): 135–156.
- Braddock, D., Hemp, R., Rizzolo, M., Tanis, E., Haffer, L., Lulinski, A. & Wu, J. (2013). *The State of the States in Developmental Disabilities* (9th ed.). Boulder: Department of Psychiatry and Coleman Institute, University of Colorado and Department of Disability and Human Development, University of Illinois at Chicago.
- Braddock, D. (1999). Aging and developmental disabilities: demographic and policy issues affecting American Families. *Mental Retardation*, 155-161.
- Hayes, W., Jamieson, B., Sahr, T., Yao, X., (2012). Evaluating Services that Support Families with Children with Disabilities. Unpublished report for the Ohio Developmental Disabilities Council. https://hsldigital.osu.edu/sitetool/sites/grc2public/documents/Research_Report_Final.pdf.
- Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: Policies and practices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 136-142.
- Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with developmental disabilities in future planning. *Mental Retardation*, 44(3), 189-202.
- Heller, T., Miller, A. and Factor A. (1997) Adults with Mental Retardation as Supports to Their Parents: Effects on Parental Caregiving Appraisal. *Mental Retardation*, 35(5), 238-346.
- Kaiser Commission on Medicaid and the Uninsured, The. (December, 2012). *Medicaid Home and Community-Based Service Programs: Data Update. Executive Summary*. Retrieved from <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7720-06.pdf>.
- Kim H., Chang M., Rose K. & Kim S. (2012) Predictor of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing* 68(4), 846-855.
- Kitchener, M., Ng, T., Miller, N., & Harrington, C. (2005). Medicaid home and community-based services: national program trends. *Health Affairs*, 24(1), 206-212.
- Lakin, K. (1998). On the outside looking in: attending to waiting lists in systems of services for people with developmental disabilities. *Mental Retardation*, 157-162.
- Lakin, K. C, Larson, S., Salmi, P., & Webster A. (2010). Residential services for persons with developmental disabilities: Status and trends through 2009. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Martinez, G., Daniels, K., ^ Chandra, A. (2012). Fertility of men and women aged 15-44 years in the United States: National survey of family growth, 2006-2010. *National Health Statistics Reports*. Division of Vital Statistics, U.S. Department of Health and Human Services, Centers for Diseases Control and Prevention, National Center for Health Statistics, Hyattsville, MD.
- Mehdizadeh, S. (2008). *Disability in Ohio: Current and Future Demand for Devices*. [Report] Department of Sociology, Miami University.

- Miller, A., Armstrong, R., Masse, L., Klasssen, A., Shen, J., & O'Donnell, M. (2008). Waiting for child developmental and rehabilitation services: an overview of issues and needs. *Developmental Medicine and Child Neurology*, 50, 815-821.
- Ohio Department of Developmental Disabilities, The. (2011). *The Level 1 Waiver Handbook: A Guide to What Services are Covered? For How Much? And Who is Eligible?* Retrieved on February 3, 2014 from <https://doddportal.dodd.ohio.gov/Documents/handbook-level1waiver.pdf>.
- Ohio Department of Developmental Disabilities, The. (2011). *The Individual Options Waiver Handbook: A Guide to Services and Eligibility*. Retrieved on February 3, 2014 from <https://doddportal.dodd.ohio.gov/INF/finditfast/publications/Documents/IO%20Waiver%20Handbook,%20New%20Rev.%2007-15-11.pdf>.
- Ohio Department of Developmental Disabilities, The. (2012). *The Self Empowered Life Funding (SELF) Waiver: A handbook about the newest waiver administered by the Ohio Department of Developmental Disabilities (DODD)*. Retrieved on February 3, 2014 from <http://dodd.ohio.gov/medicaid/Documents/SELF%20Handbook.pdf>.
- Ohio Disability Rights Law and Policy Center, Inc., The. (2012). <http://www.disabilityrightsohio.org/frequently-asked-questions-about-medicaid-waiting-lists-priority-status-and-emergency-status>.
- Parish, S. & Lutwick, Z. (2005). A critical analysis of the emerging crisis in long-term care for people with developmental disabilities. *Social Work*, 50(4), 345-354.
- Parish, S., Pomeranz-Essley, A. & Braddock, D. (2003). Family support in the United States: Financing trends and emerging initiatives. *Mental Retardation*, 41(3),174-187.
- Perkins, J. & Boyle, R. (2001). *Addressing Long Wait Lists for Home and Community-Based Care Through Medicaid and the ADA*. [Report] National Health Law Program.
- Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota. (2000). *Policies and Resources Related to Waiting Lists of Persons with Mental Retardation and Related Developmental Disabilities*. [Report]. Retrieved on December 2, 2012 from <http://rtc.umn.edu/docs/waitlist2000.pdf>.
- Rizzolo, M., Friedman, C., Lulinski-Norris, A. & Braddock, D. (2013) Home and community based services (HCBS) waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1),1-21.
- Rossi, A. S., & Rossi, P.H. (1990). *Of human bonding: Parent-child relations across the life course*. New York: Aldine de Gruyter.
- Schwalb, E. (2010). Reconsidering *Makin v. Hawaii*: the right of Medicaid beneficiaries to home-based services as an alternative to institutionalization. *Georgia State University Law Review*, 26 (3), 803-852.
- Smith, G, Agosta, J., & Fortune, J. (2007). *Gauging the Use of Support Waivers for People with Intellectual and Developmental Disabilities*. [Report] Research Triangle Institute. Prepared for the Office of Disability, Aging, and Long-Term Care Policy. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.

Appendix A: Median Waiting List Times (in years) by Category

Median Waiting List Times (in years) By Category

Category	Number	Median	25th	75th
ALL	41,260	6.4	3.4	10.6
Age				
Under 2 years of age	391	0.9	0.5	1.6
3 to 5 years of age	1,922	1.8	0.9	2.8
6 to 21 years of age	18,383	5.4	3.0	8.5
22 to 30 years of age	8,364	7.3	4.7	10.8
31 to 40 years of age	4,441	10.7	6.0	14.9
41 to 50 years of age	3,130	9.3	4.9	15.3
51 to 64 years of age	3,578	9.6	5.2	16.1
65 years and older	1,051	11.8	6.8	18.1
Living Arrangement				
Home	32,197	6.0	3.2	9.6
Institution	3,020	13.7	8.6	18.4
Other	1,419	6.5	2.6	13.5
Other Non-Licensed Facility	4,624	7.3	4.1	11.8
Gender				
Female	15,263	6.7	3.6	10.8
Male	25,855	6.3	3.3	10.4
Unknown	142	3.5	1.6	7.4
Race				
American Indian or Alaskan Native	338	4.8	2.8	7.9
Asian	354	5.8	3.0	9.4
Black or African American	5,659	6.9	4.2	11.3
Native Hawaiian and Other Pacific Islander	6	3.0	1.2	5.2
Some Other Race	1,683	4.6	2.2	7.5
Two or More Races	468	4.8	2.1	8.3
Unknown	3,368	3.6	1.5	7.8
White/Caucasian	29,384	6.8	3.8	10.8
Ethnicity				
Hispanic or Latino	697	5.2	2.7	9.0
Non-Hispanic or Latino	40,537	6.5	3.4	10.6
Unknown	26	3.4	1.8	4.7

Appendix B: Median Waiting List Times (in years) by Type of DODD Waiver

Median Waiting List Times (in years) by Type of DODD Waiver

Waiver Type	Number	Median	25th	75th
I/O & LV1	18,649	5.2	2.8	8.2
I/O & LV1 & SELF	2,254	1.8	0.6	4.3
I/O & SELF	740	6.2	3.6	9.8
I/O Only	17,645	9.3	5.7	13.3
LV1 & SELF	22	1.4	0.5	4.1
LV1 Only	1,854	5.6	2.0	8.3
SELF Only	96	0.9	0.7	0.9

Appendix C: Median Waiting List Time (in years) by County

Median Waiting List Time by County				
County	Number	Median (years)	25 th (years)	75 th (years)
Adams	52	4.5	2.2	6.8
Allen	429	4.8	2.2	10.5
Ashland	109	5.3	3.0	10.7
Ashtabula	209	5.1	2.2	13.5
Athens	300	4.5	2.1	7.3
Auglaize	151	4.8	2.6	11.3
Belmont	247	8.9	5.0	12.8
Brown	147	3.3	1.6	6.0
Butler	1,213	5.5	2.5	9.3
Carroll	26	6.0	4.1	12.0
Champaign	198	4.6	2.8	7.6
Clark	1,195	6.6	3.7	9.8
Clermont	722	4.2	2.2	7.3
Clinton	110	5.8	2.8	8.1
Columbiana	224	5.8	3.0	10.1
Coshocton	103	3.7	1.8	7.5
Crawford	137	5.8	2.8	8.6
Cuyahoga	2,144	8.3	3.5	16.5
Darke	296	6.9	3.3	9.7
Defiance	38	2.8	1.7	6.6
Delaware	882	6.3	4.3	10.0
Erie	330	5.2	3.5	11.2
Fairfield	537	8.5	4.3	11.1
Fayette	72	4.9	2.1	9.2
Franklin	7,995	7.0	3.6	10.9
Fulton	103	5.5	2.8	7.3
Gallia	96	13.5	7.8	18.2
Geauga	309	5.3	2.8	9.2
Greene	245	6.7	2.3	14.0
Guernsey	133	4.8	3.1	10.7
Hamilton	2,031	8.8	6.3	13.9
Hancock	362	6.0	2.4	9.2
Hardin	20	5.2	1.5	10.6
Harrison	33	8.8	6.6	14.8
Henry	110	3.0	1.1	8.6
Highland	97	5.6	1.8	8.1

Waiver Supported Services Needed by Individuals and their Caregivers

Hocking	194	5.1	2.6	9.8
Holmes	52	2.5	1.4	4.0
Huron	221	4.4	2.2	7.1
Jackson	76	2.6	1.7	7.6
Jefferson	106	5.2	2.5	7.1
Knox	274	6.3	4.1	9.8
Lake	1,139	7.0	3.3	11.9
Lawrence	193	5.6	2.2	9.1
Licking	940	5.3	2.8	8.9
Logan	87	8.1	4.8	10.9
Lorain	643	7.7	4.3	14.9
Lucas	2,379	7.4	4.0	11.4
Madison	133	4.3	1.8	7.2
Mahoning	781	8.5	4.6	11.2
Marion	59	7.5	6.3	10.4
Medina	486	6.8	3.1	11.6
Meigs	34	6.3	4.8	11.4
Mercer	162	5.6	2.7	8.0
Miami	520	7.5	4.2	10.7
Monroe	23	5.2	0.8	8.4
Montgomery	1,160	4.3	2.4	8.1
Morgan	53	5.2	2.1	17.0
Morrow	125	7.0	3.4	10.3
Muskingum	130	5.9	2.9	9.9
Noble	31	4.3	1.8	10.3
Ottawa	176	8.3	3.9	11.5
Paulding	51	5.1	3.1	9.3
Perry	244	5.5	3.3	10.1
Pickaway	136	10.0	5.1	17.5
Pike	176	5.5	2.9	7.6
Portage	408	5.3	3.0	9.6
Preble	194	5.8	2.1	9.8
Putnam	110	10.0	4.8	14.7
Richland	469	7.8	4.4	12.2
Ross	200	4.3	1.8	7.9
Sandusky	318	4.8	2.1	8.0
Scioto	215	10.3	8.3	11.9
Seneca	242	12.3	5.0	15.8
Shelby	127	5.6	2.5	9.0

Waiver Supported Services Needed by Individuals and their Caregivers

Stark	1,315	6.3	3.8	8.7
Summit	1,772	5.8	4.3	7.6
Trumbull	764	7.3	3.6	10.4
Tuscarawas	186	5.0	3.3	7.3
Union	151	6.8	5.4	9.7
Unknown	308	8.8	5.0	12.3
Van Wert	118	7.1	3.2	11.0
Vinton	77	4.8	2.5	8.0
Warren	702	3.6	1.8	9.3
Washington	348	6.7	3.6	9.0
Wayne	275	3.2	1.7	5.9
Williams	153	4.8	2.8	10.1
Wood	551	6.9	2.9	12.0
Wyandot	68	9.1	5.7	10.3

Median Waiting List Time by Geographic Area				
Regions*	Number	Median (years)	25th (years)	75th (years)
Rural Appalachia	5,491	5.7	2.8	9.6
Rural Non-Appalachia	5,244	5.5	2.7	9.8
Suburban	7,886	6.5	3.3	10.6
Urban	22,331	6.8	3.9	10.9

Waiver Supported Services Needed by Individuals and their Caregivers

*Regions were defined as follows:

Rural Appalachian		Urban		Rural Non Appalachian		Suburban
Adams		Allen		Ashland		Auglaize
Ashtabula		Butler		Champaign		Clark
Athens		Cuyahoga		Clinton		Delaware
Belmont		Franklin		Crawford		Fairfield
Brown		Hamilton		Darke		Fulton
Carroll		Lorain		Defiance		Geauga
Clermont		Lucas		Erie		Greene
Columbiana		Mahoning		Fayette		Lake
Coshocton		Montgomery		Hancock		Licking
Gallia		Richland		Hardin		Madison
Guernsey		Stark		Henry		Medina
Harrison		Summit		Huron		Miami
Highland				Knox		Pickaway
Hocking				Logan		Portage
Holmes				Marion		Union
Jackson				Mercer		Wood
Jefferson				Morrow		
Lawrence				Ottawa		
Meigs				Paulding		
Monroe				Preble		
Morgan				Putnam		
Muskingum				Sandusky		
Noble				Seneca		
Perry				Shelby		
Pike				Van Wert		
Ross				Warren		
Scioto				Wayne		
Trumbull				Williams		
Tuscarawas				Wyandot		
Vinton						
Washington						

Appendix D: Waiting List Survey Final Questions

9/12/13

Unmet Needs - Current

1. These next few questions are about your current unmet needs. By unmet need, I mean an area requiring paid or unpaid help that you are not currently receiving or you are not receiving enough of. In which of the following areas do you currently have an unmet need?
 - Something to do during the dayⁱ
 - Medical Careⁱⁱ
 - Place to Stayⁱⁱⁱ
 - Transportation^{iv}
 - Help with Daily Activities^v
 - No areas of unmet need
 - Other^{vi}: (please describe)
2. Of the areas you picked in question one, which one is the most important to you?
3. You indicated that your most important current unmet need is (*refer to question 2 response*) Do you have an unmet need in any of the following?
 - a. Something to do during the day
 - School (By "school" I mean special education services or support in elementary or high school)
 - A job^{vii}
 - Job training^{viii}
 - Activities to do
 - Volunteer Work
 - College
 - b. Place to Stay
 - Finding an apartment, or other home of your own^{ix}
 - Getting into a group home^x
 - c. Transportation
 - Learning to access transportation (for example, cab, bus) independently
 - Someone to take you places
 - Equipping your van for wheel chair accessibility
 - d. Medical Care
 - Finding a therapist^{xi} (such as physical, occupational or speech therapist)
 - Finding a medical care provider
 - Finding a mental health provider
 - Help filling prescriptions, paying for or taking medications
 - Obtaining Medicaid or private insurance
 - e. Help with Daily Activities

3 e - i: You indicated that your most important current unmet need is for "help with daily activities." In a typical week, how many days do you not get enough help with your daily activities?

- Five or more days
- Fewer than five days

3 e - ii: On a typical day, how many hours do you not get enough help with your daily activities?

- 8 or more hours
- Fewer than 8 hours

3 e iii. Respite services are services that allow your caregiver to take a short period of time off from taking care of you. Do you or the person who regularly takes care of currently have an unmet need for respite services?

- Yes
- No

Unmet Needs - Future

4. You have told me about your current needs, next I will ask you about your future needs. In which of the following areas will you need help in the future?

- Something to do during the day
- Medical Care
- Place to Stay
- Transportation
- Help with Daily Activities
- No areas of future need
- Other: (please describe)

5. When in the future will you need help with (*each identified future need from question 4*)?

- 0 to 1 year from now
- 1 to 5 years from now
- More than 5 years from now

6. Of the area(s) you picked in the previous question, which one will be most important to you in the future?

- Something to do during the day
- Medical Care
- Place to Stay
- Transportation
- Help with Daily Activities
- No areas of future need
- Other: (please describe)

7. You indicated that your most important future need is (*refer to question 6 responses*). Will you need help in the future with any of the following?

a. Something to do during the day

- School (By "school" I mean special education services or support in elementary or high school)
- A job^{xii}
- Job training^{xiii}
- Activities to do
- Volunteer Work
- College

b. Place to Stay^{xiv}

- Finding an apartment, or other home of your own^{xv}
- Getting into a group home

c. Transportation

- Learning to access transportation (for example, cab, bus) independently
- Someone to take you places

- Equipping your van for wheel chair accessibility

d. Medical Care

- Finding a therapist^{xvi} (such as physical, occupation or speech therapist)
- Finding a medical care provider
- Finding a mental health provider
- Help filling prescriptions, paying for or taking medications
- Obtaining Medicaid or private insurance

e. Help with Daily Activities

8e – i: You indicated that your most important future need is for “help with daily activities.” In a typical week, how many will you need help with your daily activities in the future?

- Five or more days
- Fewer than five days

8e – ii: On a typical day, how many hours will you need help with your daily activities in the future?

- 8 or more hours
- Fewer than 8 hours

8e –iii. Respite services are services that allow your caregiver to take a short period of time off from taking care of you. Will you or the person who regularly takes care of you need respite services in the future? Will you or the person who regularly takes care of you need respite services in the future?

- Yes
- No

Primary Caregiver Information

9. A primary caregiver means the individual who regularly takes care of you and accepts formal responsibility for addressing your daily needs. A primary caregiver may be paid staff, or an unpaid friend or relative. Do you have a primary caregiver?

- Yes *If yes, proceed to question 10.*
- No *If no, proceed to question 15.*

10. How is your primary caregiver related to you? (Check one.)

- Parent
- Grandparent
- Sibling
- Other family member
- Friend
- Paid Staff *(If paid staff^{xvii} selected, skip to question 15)*

11. How old is your primary caregiver?

12. Does your primary caregiver live with you?

- Yes
- No

13. How much longer is your primary caregiver able to take care of you?

- 0 to 1 year *(go to question 14)*
- 1 to 5 years *(go to question 15)*
- More than 5 years *(go to question 15)*

14. Which of the following reasons is your primary caregiver not able to continue caring for you?

- Age of caregiver

- Medical Issues^{xviii} of caregiver
- Safety issues^{xix} related to taking care of you
- Other

General Questions about the Waiting List

15. A waiver means a package of support services that allows for the individual to stay in a community setting. How did you find out about waiver services^{xx}? *(Choose one)*
- County board staff
 - Doctor or other medical professional
 - Help Me Grow or Early Intervention
 - Pre-school or school
 - Family or friends
 - I don't remember
16. What services do you plan to use your waiver for? *(You can select as many as you like)*
- Something to do during the day
 - Medical care
 - A place to Stay
 - Transportation
 - Help with Daily Activities
 - Other _____
17. Have you been on the waiting list longer than you expected?
- Yes
 - No
18. How long did you think it would take to get your waiver?

Consumer Demographics

19. Now we would like to check our records. Are you *(verify only from list provided by DODD)*
- Male
 - Female
20. We have you listed as age (xxx), is that correct? *(verify only from list provided by DODD)*
- Yes
 - No
21. What health insurance do you currently have? *(check all that apply)*
- None
 - Private Health Care Insurance Plan
 - Medicaid^{xxi}
 - Medicare^{xxii}
 - Other

EXPLANATION FOR SURVEY TERMS

Note: Explanations for the terms may be read to the respondent he or she is unclear or requests more information.

ⁱ **Something to do during the day** – means developmental, recreational or other activities which are offered outside the home.

ⁱⁱ **Medical Care** – means primary care, specialty care, mental health care, dental, vision, reproductive and sexual health care, therapy and prescriptions.

ⁱⁱⁱ **Place to Stay** – means a safe and permanent place to live which meets all of your housing needs.

^{iv} **Transportation** – means reliable and flexible travel arrangements which are adapted to your needs and provide rides to and from important activities such as employment or school, medical appointments, and community activities.

^v **Daily activities** – means those small but essential tasks which are a part of the routine of daily life such as dressing, bathing, eating, and toileting.

^{vi} **Other** – means something else

^{vii} **Job** – means paid competitive or supported employment.

^{viii} **Job training** – means education, training, coaching, skill reinforcement, vocational assessment, job development and placement, worksite accessibility, ongoing job support and other services needed to prepare people with disabilities for work, define a suitable employment goal and become employed.

^{ix} **Apartment or other home of your own** – means a dwelling for independent living which may be occupied by you alone or with a limited number of other individuals.

^x **Group home** – means a home where a small number of people with similar needs live together, and where an appropriate level of care, support and supervision is provided by paid staff.

^{xi} **Therapist** – means a licensed professional whose practice includes services to individuals with disabilities. This includes individuals who provide speech, physical, or occupational therapy.

^{xii} **Job** – means paid competitive or supported employment.

^{xiii} **Job training** – means education, training, coaching, skill reinforcement, vocational assessment, job development and placement, worksite accessibility, ongoing job support and other services needed to prepare people with disabilities for work, define a suitable employment goal and become employed.

^{xiv} **Place to Stay** – means a safe and permanent place to live which meets all of your housing needs.

^{xv} **Apartment or other home of your own** – means a dwelling for independent living, which may be occupied by you alone or with a limited number of other individuals.

^{xvi} **Therapist** – means a licensed professional whose practice includes services to individuals with disabilities. This includes individuals who provide speech, physical, or occupational therapy.

^{xvii} **Paid staff** – means someone who receives a salary or hourly wage as compensation for providing services in the primary residence.

^{xviii} **Medical issues** - means illnesses or conditions which affect the physical body or mental health and which impact the individual's ability to function adequately as a caregiver.

^{xix} **Safety Issues** - means conditions or behavior that might cause danger, risk, or injury.

^{xx} **Waiver** –For this survey we are interested in the four waivers supported by the Ohio Department of Developmental Disabilities: I/O, Level 1, SELF, and Transitions waivers.

^{xxi} **Medicaid** – means the State of Ohio government health care assistance program.

^{xxii} **Medicare** – means the federal health insurance for people 65 years or older and people with disabilities run by the Social Security Administration.

Appendix E: Summary Frequencies by Respondent Group

Unmet Need – Current (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	29.1%	21.3%	36.9%	134	21.7%	19.1%	24.2%	997	22.5%	20.1%	25.0%	1131
Medical Care	15.7%	9.4%	21.9%	134	17.5%	15.1%	19.8%	997	17.2%	15.0%	19.4%	1131
Place to Stay	10.4%	5.2%	15.7%	134	4.7%	3.4%	6.0%	997	5.4%	4.1%	6.7%	1131
Transportation	22.4%	15.2%	29.5%	134	16.6%	14.3%	19.0%	997	17.3%	15.1%	19.5%	1131
Help with Daily Activities	16.4%	10.1%	22.8%	134	22.8%	20.2%	25.4%	997	22.0%	19.6%	24.4%	1131
Other Need	0.7%	-0.7%	2.2%	134	2.0%	1.1%	2.9%	997	1.9%	1.1%	2.6%	1131
No areas of unmet need	45.5%	37.0%	54.1%	134	46.5%	43.4%	49.6%	997	46.4%	43.5%	49.3%	1131
Don't Know	0.0%	.	.	134	0.0%	.	.	997	0.0%	.	.	1131
Refused	0.0%	.	.	134	0.0%	.	.	997	0.0%	.	.	1131

Unmet Need – Primary (Only one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	18.7%	12.0%	25.3%	134	14.4%	12.3%	16.6%	997	14.9%	12.9%	17.0%	1131
Medical Care	10.4%	5.2%	15.7%	134	13.2%	11.1%	15.3%	997	12.9%	11.0%	14.9%	1131
Place to Stay	3.7%	0.5%	7.0%	134	2.3%	1.4%	3.2%	997	2.5%	1.6%	3.4%	1131
Transportation	11.2%	5.8%	16.6%	134	7.9%	6.2%	9.6%	997	8.3%	6.7%	9.9%	1131
Help with Daily Activities	9.7%	4.6%	14.8%	134	13.7%	11.6%	15.9%	997	13.3%	11.3%	15.2%	1131
Other	0.7%	-0.7%	2.2%	134	1.5%	0.7%	2.3%	997	1.4%	0.7%	2.1%	1131
No areas of unmet need	45.5%	37.0%	54.1%	134	46.5%	43.4%	49.6%	997	46.4%	43.5%	49.3%	1131
No areas selected	0.0%	.	.	134	0.3%	0.0%	0.6%	997	0.3%	0.0%	0.6%	1131

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need: Something to do during the day (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
School	0.0%	.	.	23	16.1%	9.4%	22.8%	118	13.5%	7.8%	19.2%	141
Job	26.1%	6.7%	45.5%	23	31.4%	22.9%	39.9%	118	30.5%	22.8%	38.2%	141
Job training	21.7%	3.5%	40.0%	23	33.1%	24.4%	41.7%	118	31.2%	23.5%	38.9%	141
Activities to do	43.5%	21.6%	65.4%	23	63.6%	54.7%	72.4%	118	60.3%	52.1%	68.5%	141
Volunteer work	17.4%	0.6%	34.2%	23	26.3%	18.2%	34.3%	118	24.8%	17.6%	32.0%	141
College	26.1%	6.7%	45.5%	23	11.0%	5.3%	16.7%	118	13.5%	7.8%	19.2%	141
None selected	26.1%	6.7%	45.5%	23	11.0%	5.3%	16.7%	118	13.5%	7.8%	19.2%	141

Unmet Need: Medical Care (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding a therapist	7.7%	-9.1%	24.5%	13	42.6%	32.4%	52.7%	94	38.3%	29.0%	47.7%	107
Finding a medical care provider	15.4%	-7.3%	38.1%	13	19.1%	11.0%	27.3%	94	18.7%	11.2%	26.2%	107
Finding a mental health provider	15.4%	-7.3%	38.1%	13	21.3%	12.8%	29.7%	94	20.6%	12.8%	28.3%	107
Help filling prescriptions, paying for or taking medications	23.1%	-3.4%	49.6%	13	21.3%	12.8%	29.7%	94	21.5%	13.6%	29.4%	107
Obtaining Medicaid or private insurance	30.8%	1.7%	59.8%	13	24.5%	15.6%	33.3%	94	25.2%	16.9%	33.6%	107
None selected	38.5%	7.9%	69.1%	13	24.5%	15.6%	33.3%	94	26.2%	17.7%	34.6%	107

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need-Place to Stay (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding an apartment, or other home of your own	100.0%	.	.	5	45.0%	21.1%	68.9%	20	56.0%	35.1%	76.9%	25
Getting into a group home	20.0%	-35.5%	75.5%	5	40.0%	16.5%	63.5%	20	36.0%	15.8%	56.2%	25
None selected	0.0%	.	.	5	20.0%	0.8%	39.2%	20	16.0%	0.6%	31.4%	25

Unmet Need-Transportation (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Learning to access transportation (for example, cab, bus) independently	21.4%	-3.2%	46.0%	14	24.1%	14.4%	33.7%	79	23.7%	14.9%	32.5%	93
Someone to take you places	57.1%	27.5%	86.8%	14	75.9%	66.3%	85.6%	79	73.1%	63.9%	82.3%	93
Equipping your van for wheel chair accessibility	14.3%	-6.7%	35.3%	14	15.2%	7.1%	23.3%	79	15.1%	7.6%	22.5%	93
None selected	28.6%	1.5%	55.6%	14	11.4%	4.2%	18.6%	79	14.0%	6.8%	21.2%	93

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need-Daily Activities (Only one response allowed)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
How many days do you not get enough help with your daily activities?: 5 or more days	45.5%	10.4%	80.5%	11	38.9%	29.5%	48.2%	108	39.5%	30.6%	48.4%	119
How many days do you not get enough help with your daily activities?: Less than 5 days	36.4%	2.5%	70.3%	11	57.4%	47.9%	66.9%	108	55.5%	46.4%	64.5%	119
Don't Know/Refused	9.1%	-11.2%	29.3%	11	3.7%	0.1%	7.3%	108	4.2%	0.5%	7.9%	119
How many hours do you not get enough help with your daily activities?: 8 or more hours	27.3%	-4.1%	58.7%	11	15.7%	8.8%	22.7%	108	16.8%	10.0%	23.6%	119
How many hours do you not get enough help with your daily activities?: Less than 8 hours	63.6%	29.7%	97.5%	11	77.8%	69.8%	85.7%	108	76.5%	68.7%	84.2%	119
Don't Know/Refused	9.1%	-11.2%	29.3%	11	6.5%	1.8%	11.2%	108	6.7%	2.2%	11.3%	119
Respite -Yes	36.4%	2.5%	70.3%	11	66.7%	57.6%	75.7%	108	63.9%	55.1%	72.6%	119
Respite - No	54.5%	19.5%	89.6%	11	32.4%	23.4%	41.4%	108	34.5%	25.8%	43.1%	119
Respite – Don't Know/Refused	9.1%	-11.2%	29.3%	11	0.9%	-0.9%	2.8%	108	1.7%	-0.7%	4.0%	119

Waiver Supported Services Needed by Individuals and their Caregivers

Future Unmet Need (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	38.8%	30.4%	47.2%	134	60.7%	57.6%	63.7%	997	58.1%	55.2%	61.0%	1131
When in the future - 0 to 1 year?	42.3%	28.4%	56.2%	52	27.3%	23.7%	30.9%	594	28.5%	25.0%	32.0%	646
When in the future - 1 to 5 years	21.2%	9.7%	32.6%	52	31.6%	27.9%	35.4%	594	30.8%	27.2%	34.4%	646
When in the future - 5 or more years?	36.5%	23.0%	50.1%	52	41.1%	37.1%	45.0%	594	40.7%	36.9%	44.5%	646
Medical Care	31.3%	23.4%	39.3%	134	52.3%	49.2%	55.4%	997	49.8%	46.9%	52.7%	1131
When in the future - 0 to 1 year?	26.2%	12.3%	40.1%	42	31.6%	27.5%	35.6%	507	31.1%	27.3%	35.0%	549
When in the future - 1 to 5 years	28.6%	14.3%	42.8%	42	23.7%	20.0%	27.4%	507	24.0%	20.5%	27.6%	549
When in the future - 5 or more years?	45.2%	29.5%	60.9%	42	44.8%	40.4%	49.1%	507	44.8%	40.6%	49.0%	549
Place to stay	26.9%	19.3%	34.5%	134	47.4%	44.3%	50.5%	997	45.0%	42.1%	47.9%	1131
When in the future - 0 to 1 year?	27.8%	12.4%	43.1%	36	11.1%	8.3%	14.0%	468	12.3%	9.4%	15.2%	504
When in the future - 1 to 5 years	30.6%	14.7%	46.4%	36	23.1%	19.2%	26.9%	468	23.6%	19.9%	27.3%	504
When in the future - 5 or more years?	41.7%	24.7%	58.6%	36	65.8%	61.5%	70.1%	468	64.1%	59.9%	68.3%	504
Transportation	45.5%	37.0%	54.1%	134	61.5%	58.5%	64.5%	997	59.6%	56.7%	62.5%	1131
When in the future - 0 to 1 year?	41.0%	28.3%	53.7%	61	29.9%	26.3%	33.5%	612	30.9%	27.4%	34.4%	673
When in the future - 1 to 5 years	18.0%	8.1%	28.0%	61	27.5%	23.9%	31.0%	612	26.6%	23.3%	29.9%	673
When in the future - 5 or more years?	41.0%	28.3%	53.7%	61	42.6%	38.7%	46.6%	612	42.5%	38.8%	46.2%	673

Waiver Supported Services Needed by Individuals and their Caregivers

Help with Daily Activities	31.3%	23.4%	39.3%	134	60.0%	56.9%	63.0%	997	56.6%	53.7%	59.5%	1131
When in the future - 0 to 1 year?	55.0%	38.9%	71.1%	40	34.1%	30.3%	38.0%	583	35.5%	31.7%	39.2%	623
When in the future - 1 to 5 years	15.0%	3.4%	26.6%	40	28.5%	24.8%	32.1%	583	27.6%	24.1%	31.1%	623
When in the future - 5 or more years?	30.0%	15.2%	44.8%	40	37.4%	33.5%	41.3%	583	36.9%	33.1%	40.7%	623
Other	9.0%	4.1%	13.9%	134	3.4%	2.3%	4.5%	997	4.1%	2.9%	5.2%	1131
When in the future - 0 to 1 year?	58.3%	25.6%	91.1%	12	50.9%	43.4%	58.3%	175	51.3%	44.1%	58.6%	187
When in the future - 1 to 5 years	8.3%	-10.0%	26.7%	12	22.3%	16.1%	28.5%	175	21.4%	15.5%	27.3%	187
When in the future - 5 or more years?	33.3%	2.0%	64.6%	12	26.9%	20.2%	33.5%	175	27.3%	20.8%	33.7%	187
No areas of future need	32.8%	24.8%	40.9%	134	12.9%	10.9%	15.0%	997	15.3%	13.2%	17.4%	1131

Primary Future Unmet Need												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	11.2%	5.8%	16.6%	134	22.7%	20.1%	25.3%	997	21.3%	18.9%	23.7%	1131
Medical Care	13.4%	7.6%	19.3%	134	17.7%	15.3%	20.0%	997	17.2%	15.0%	19.4%	1131
Place to Stay	14.9%	8.8%	21.0%	134	16.5%	14.2%	18.9%	997	16.4%	14.2%	18.5%	1131
Transportation	14.2%	8.2%	20.2%	134	7.6%	6.0%	9.3%	997	8.4%	6.8%	10.0%	1131
Help with Daily Activities	7.5%	3.0%	12.0%	134	16.2%	14.0%	18.5%	997	15.2%	13.1%	17.3%	1131
Other	0.7%	-0.7%	2.2%	134	2.9%	1.9%	4.0%	997	2.7%	1.7%	3.6%	1131
No areas of unmet needs	32.8%	24.8%	40.9%	134	12.9%	10.9%	15.0%	997	15.3%	13.2%	17.4%	1131
Refused	0.0%	.	.	134	1.2%	0.5%	1.9%	997	1.1%	0.5%	1.7%	1131
Don't Know	5.2%	1.4%	9.0%	134	2.2%	1.3%	3.1%	997	2.6%	1.6%	3.5%	1131

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Future Need –Something to do during the day (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
School	6.7%	-7.6%	21.0%	15	4.2%	1.5%	6.9%	215	4.3%	1.7%	7.0%	230
Job	40.0%	11.9%	68.1%	15	11.6%	7.3%	15.9%	215	13.5%	9.0%	17.9%	230
Job training	13.3%	-6.2%	32.8%	15	12.1%	7.7%	16.5%	215	12.2%	7.9%	16.4%	230
Activities to do	26.7%	1.3%	52.0%	15	16.3%	11.3%	21.3%	215	17.0%	12.1%	21.8%	230
Volunteer work	13.3%	-6.2%	32.8%	15	7.0%	3.5%	10.4%	215	7.4%	4.0%	10.8%	230
College	13.3%	-6.2%	32.8%	15	2.3%	0.3%	4.4%	215	3.0%	0.8%	5.3%	230
None selected	33.3%	6.3%	60.4%	15	1.4%	-0.2%	3.0%	215	3.5%	1.1%	5.9%	230

Unmet Future Need –Medical Care (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding a therapist	37.5%	10.9%	64.1%	16	51.8%	44.1%	59.6%	164	50.6%	43.2%	57.9%	180
Finding a medical care provider	31.3%	5.7%	56.8%	16	50.0%	42.3%	57.7%	164	48.3%	41.0%	55.7%	180
Finding a mental health provider	31.3%	5.7%	56.8%	16	30.5%	23.4%	37.6%	164	30.6%	23.8%	37.3%	180
Help filling prescriptions, paying for or taking medications	50.0%	22.5%	77.5%	16	61.0%	53.4%	68.5%	164	60.0%	52.8%	67.2%	180
Obtaining Medicaid or private insurance	25.0%	1.2%	48.8%	16	59.1%	51.5%	66.7%	164	56.1%	48.8%	63.4%	180
None selected	25.0%	1.2%	48.8%	16	7.9%	3.7%	12.1%	164	9.4%	5.1%	13.8%	180

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Future Need -Finding a Place to Stay (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding an apartment, or other home of your own	70.0%	48.0%	92.0%	20	4.3%	1.2%	7.5%	161	11.6%	6.9%	16.3%	181
Getting into a group home	5.0%	-5.5%	15.5%	20	5.0%	1.6%	8.4%	161	5.0%	1.8%	8.2%	181
None selected	5.0%	-5.5%	15.5%	20	1.2%	-0.5%	3.0%	161	1.7%	-0.2%	3.5%	181

Unmet Future Need --Transportation (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Learning to access transportation (for example, cab, bus) independently	21.1%	0.9%	41.2%	19	35.5%	24.5%	46.5%	76	32.6%	23.0%	42.2%	95
Someone to take you places	78.9%	58.8%	99.1%	19	81.6%	72.7%	90.5%	76	81.1%	73.0%	89.1%	95
Equipping your van for wheel chair accessibility	10.5%	-4.7%	25.7%	19	22.4%	12.8%	32.0%	76	20.0%	11.8%	28.2%	95
None selected	10.5%	-4.7%	25.7%	19	2.6%	-1.1%	6.3%	76	4.2%	0.1%	8.3%	95

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Future Need -Daily Activities												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
How many days do you not get enough help with your daily activities: 5 or more days	44.4%	3.9%	85.0%	9	53.8%	45.6%	62.1%	143	53.3%	45.3%	61.3%	152
How many days do you not get enough help with your daily activities: Less than 5 days	22.2%	-11.7%	56.1%	9	30.8%	23.1%	38.4%	143	30.3%	22.9%	37.6%	152
Don't Know /Refused	33.3%	-5.1%	71.8%	9	15.4%	9.4%	21.4%	143	16.4%	10.5%	22.4%	152
How many hours do you not get enough help with your daily activities? 8 or more	44.4%	3.9%	85.0%	9	34.3%	26.4%	42.1%	143	34.9%	27.2%	42.5%	152
How many hours do you not get enough help with your daily activities? < 8 hours	44.4%	3.9%	85.0%	9	49.7%	41.4%	57.9%	143	49.3%	41.3%	57.4%	152
Don't Know /Refused	11.1%	-14.5%	36.7%	9	16.1%	10.0%	22.2%	143	15.8%	9.9%	21.7%	152
Respite-Yes	55.6%	15.0%	96.1%	9	83.9%	77.8%	90.0%	143	82.2%	76.1%	88.4%	152

Waiver Supported Services Needed by Individuals and their Caregivers

Caregiver												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Do you have a primary caregiver? - Yes	73.1%	65.5%	80.7%	134	96.9%	95.8%	98.0%	997	94.1%	92.7%	95.5%	1131
How is your primary caregiver related to you?												
Parent	57.1%	47.2%	67.1%	98	89.3%	87.4%	91.3%	966	86.4%	84.3%	88.4%	1064
Grandparent	2.0%	-0.8%	4.9%	98	3.5%	2.4%	4.7%	966	3.4%	2.3%	4.5%	1064
Sibling	6.1%	1.3%	11.0%	98	2.1%	1.2%	3.0%	966	2.4%	1.5%	3.4%	1064
Other Family	6.1%	1.3%	11.0%	98	2.6%	1.6%	3.6%	966	2.9%	1.9%	3.9%	1064
Friend	4.1%	0.1%	8.1%	98	0.3%	0.0%	0.7%	966	0.7%	0.2%	1.1%	1064
Paid Staff	22.4%	14.0%	30.9%	98	2.2%	1.3%	3.1%	966	4.0%	2.9%	5.2%	1064
Don't Know/Refused	2.0%	-0.8%	4.9%	98	0.0%	.	.	966	0.2%	-0.1%	0.4%	1064
How old is your caregiver?												
Age under 45	14.9%	6.6%	23.2%	74	29.0%	26.1%	31.9%	945	28.0%	25.2%	30.7%	1019
Age 45 to 54	31.1%	20.3%	41.9%	74	29.2%	26.3%	32.1%	945	29.3%	26.5%	32.1%	1019
Age 55 to 64	24.3%	14.3%	34.3%	74	23.2%	20.5%	25.9%	945	23.3%	20.7%	25.9%	1019
Age 65 +	16.2%	7.6%	24.8%	74	17.4%	14.9%	19.8%	945	17.3%	14.9%	19.6%	1019
Don't Know/Refused	13.5%	5.5%	21.5%	74	1.3%	0.6%	2.0%	945	2.2%	1.3%	3.1%	1019
Does your primary caregiver live with you? Yes	77.0%	67.2%	86.8%	74	97.6%	96.6%	98.6%	945	96.1%	94.9%	97.3%	1019

Waiver Supported Services Needed by Individuals and their Caregivers

	Individual				Parent/Guardian				Total			
How much longer is caregiver able to take care of you?												
Label	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
0 to 1 year	4.1%	-0.5%	8.7%	74	1.8%	0.9%	2.6%	945	2.0%	1.1%	2.8%	1019
1 to 5 years	14.9%	6.6%	23.2%	74	9.7%	7.8%	11.6%	945	10.1%	8.3%	12.0%	1019
5 or more years	56.8%	45.2%	68.3%	74	80.3%	77.8%	82.9%	945	78.6%	76.1%	81.1%	1019
Don't Know	24.3%	14.3%	34.3%	74	7.7%	6.0%	9.4%	945	8.9%	7.2%	10.7%	1019
Refused	0.0%	.	.	74	0.4%	0.0%	0.8%	945	0.4%	0.0%	0.8%	1019
Reasons unable to be caregiver (More than one response possible)												
Age of caregiver	33.3%	-110.1%	176.8%	3	17.6%	-2.6%	37.9%	17	20.0%	0.8%	39.2%	20
Medical issues of the caregiver	66.7%	-76.8%	210.1%	3	58.8%	32.7%	84.9%	17	60.0%	36.5%	83.5%	20
Safety issues related to taking care of you	33.3%	-110.1%	176.8%	3	23.5%	1.0%	46.0%	17	25.0%	4.2%	45.8%	20
Other	33.3%	-110.1%	176.8%	3	35.3%	10.0%	60.6%	17	35.0%	12.1%	57.9%	20
Don't Know/Refused	0.0%	.	.	3	0.0%	.	.	17	0.0%	.	.	20

Waiver Supported Services Needed by Individuals and their Caregivers

Waiting List Referral (Only one response allowed)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
County Board Staff	41.0%	32.6%	49.5%	134	51.8%	48.7%	55.0%	976	50.5%	47.6%	53.5%	1110
Doctor or other medical professional	13.4%	7.6%	19.3%	134	10.3%	8.4%	12.3%	976	10.7%	8.9%	12.5%	1110
Help me Me Grow or early Early Intervention	0.0%	.	.	134	7.8%	6.1%	9.5%	976	6.8%	5.4%	8.3%	1110
Pre-school	6.7%	2.4%	11.0%	134	12.1%	10.0%	14.1%	976	11.4%	9.6%	13.3%	1110
Family or friends	12.7%	7.0%	18.4%	134	9.6%	7.8%	11.5%	976	10.0%	8.2%	11.8%	1110
I don't remember	11.2%	5.8%	16.6%	134	4.6%	3.3%	5.9%	976	5.4%	4.1%	6.7%	1110
Don't Know	14.2%	8.2%	20.2%	134	3.7%	2.5%	4.9%	976	5.0%	3.7%	6.2%	1110
Refused	0.7%	-0.7%	2.2%	134	0.0%	.	.	976	0.1%	-0.1%	0.3%	1110

Services to Use Waiver For (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	47.0%	38.5%	55.6%	134	54.6%	51.5%	57.7%	997	53.7%	50.8%	56.6%	1131
Medical Care	38.1%	29.7%	46.4%	134	46.9%	43.8%	50.0%	997	45.9%	43.0%	48.8%	1131
Place to Stay	31.3%	23.4%	39.3%	134	42.0%	39.0%	45.1%	997	40.8%	37.9%	43.6%	1131
Transportation	46.3%	37.7%	54.8%	134	51.7%	48.5%	54.8%	997	51.0%	48.1%	53.9%	1131
Help with Daily Activities	34.3%	26.2%	42.5%	134	54.8%	51.7%	57.9%	997	52.3%	49.4%	55.3%	1131
Other	3.7%	0.5%	7.0%	134	12.2%	10.2%	14.3%	997	11.2%	9.4%	13.1%	1131
Don't Know	14.9%	8.8%	21.0%	134	7.2%	5.6%	8.8%	997	8.1%	6.5%	9.7%	1131
Refused	1.5%	-0.6%	3.6%	134	0.5%	0.1%	0.9%	997	0.6%	0.2%	1.1%	1131

Waiver Supported Services Needed by Individuals and their Caregivers

Waiting List Longer than Expected?												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Yes	48.5%	39.9%	57.1%	134	44.3%	41.1%	47.4%	976	44.8%	41.8%	47.7%	1110
No	30.6%	22.7%	38.5%	134	43.5%	40.4%	46.7%	976	42.0%	39.1%	44.9%	1110
Don't Know	20.1%	13.3%	27.0%	134	12.1%	10.0%	14.1%	976	13.1%	11.1%	15.0%	1110
Refused	0.7%	-0.7%	2.2%	134	0.1%	-0.1%	0.3%	976	0.2%	-0.1%	0.4%	1110

How long did you think it would take to get your waiver?												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
0 to 1 year	18.7%	12.0%	25.3%	134	18.8%	16.3%	21.2%	976	18.7%	16.4%	21.0%	1110
2 to 4 years	11.2%	5.8%	16.6%	134	16.9%	14.6%	19.3%	976	16.2%	14.0%	18.4%	1110
5 to 10 years	9.7%	4.6%	14.8%	134	17.7%	15.3%	20.1%	976	16.8%	14.6%	19.0%	1110
11 or more years	2.2%	-0.3%	4.8%	134	4.8%	3.5%	6.2%	976	4.5%	3.3%	5.7%	1110
Don't Know/Refused	58.2%	49.7%	66.7%	134	41.8%	38.7%	44.9%	976	43.8%	40.9%	46.7%	1110

Waiver Supported Services Needed by Individuals and their Caregivers

What Insurance do you currently have? (More than one response possible)												
Label	Individual				Parent/Guardian				Total			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
None	2.2%	-0.3%	4.8%	134	0.6%	0.1%	1.1%	997	0.8%	0.3%	1.3%	1131
Private Health Insurance Plans	26.1%	18.6%	33.7%	134	48.4%	45.3%	51.6%	997	45.8%	42.9%	48.7%	1131
Medicaid	66.4%	58.3%	74.5%	134	59.3%	56.2%	62.3%	997	60.1%	57.3%	63.0%	1131
Medicare	39.6%	31.2%	47.9%	134	21.9%	19.3%	24.4%	997	24.0%	21.5%	26.5%	1131
Other (Please specify):	2.2%	-0.3%	4.8%	134	2.8%	1.8%	3.8%	997	2.7%	1.8%	3.7%	1131
Don't Know	6.7%	2.4%	11.0%	134	1.1%	0.5%	1.8%	997	1.8%	1.0%	2.5%	1131
Refused	0.7%	-0.7%	2.2%	134	0.6%	0.1%	1.1%	997	0.6%	0.2%	1.1%	1131

Appendix F: Frequencies by Caregiver Age Group

Unmet Need — Current (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	24.6%	21.7%	27.4%	859	16.2%	11.8%	20.6%	272
Medical Care	19.4%	16.8%	22.1%	859	10.3%	6.7%	13.9%	272
Place to Stay	5.4%	3.8%	6.9%	859	5.5%	2.8%	8.2%	272
Transportation	16.6%	14.2%	19.1%	859	19.5%	14.7%	24.2%	272
Help with Daily Activities	23.3%	20.5%	26.1%	859	18.0%	13.4%	22.6%	272
Other Need	1.9%	1.0%	2.8%	859	1.8%	0.2%	3.4%	272
No areas of unmet needs	43.0%	39.6%	46.3%	859	57.4%	51.4%	63.3%	272
Don't Know	0.0%	.	.	859	0.0%	.	.	272
Refused	0.0%	.	.	859	0.0%	.	.	272

Unmet Need — Primary (Only one response allowed)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	16.3%	13.8%	18.8%	859	10.7%	7.0%	14.4%	272
Medical Care	14.9%	12.5%	17.3%	859	6.6%	3.6%	9.6%	272
Place to Stay	2.4%	1.4%	3.5%	859	2.6%	0.7%	4.5%	272
Transportation	7.3%	5.6%	9.1%	859	11.4%	7.6%	15.2%	272
Help with Daily Activities	14.4%	12.1%	16.8%	859	9.6%	6.0%	13.1%	272
Other	1.3%	0.5%	2.0%	859	1.8%	0.2%	3.4%	272
No areas of unmet needs	43.0%	39.6%	46.3%	859	57.4%	51.4%	63.3%	272
Don't Know	0.3%	0.0%	0.7%	859	0.0%	.	.	272

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need: Something to do during the day (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
School	15.7%	8.9%	22.4%	115	3.8%	-4.1%	11.8%	26
Job	32.2%	23.5%	40.8%	115	23.1%	5.7%	40.4%	26
Job training	33.0%	24.3%	41.8%	115	23.1%	5.7%	40.4%	26
Activities to do	58.3%	49.1%	67.4%	115	69.2%	50.2%	88.2%	26
Volunteer work	24.3%	16.4%	32.3%	115	26.9%	8.7%	45.2%	26
College	15.7%	8.9%	22.4%	115	3.8%	-4.1%	11.8%	26
None selected	13.9%	7.5%	20.3%	115	11.5%	-1.6%	24.7%	26

Unmet Need-Medical Care (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding a therapist	41.9%	31.7%	52.2%	93	14.3%	-6.7%	35.3%	14
Finding a medical care provider	15.1%	7.6%	22.5%	93	42.9%	13.2%	72.5%	14
Finding a mental health provider	20.4%	12.1%	28.8%	93	21.4%	-3.2%	46.0%	14
Help filling prescriptions, paying for or taking medications	21.5%	13.0%	30.0%	93	21.4%	-3.2%	46.0%	14
Obtaining Medicaid or private insurance	25.8%	16.7%	34.9%	93	21.4%	-3.2%	46.0%	14
None selected	26.9%	17.7%	36.1%	93	21.4%	-3.2%	46.0%	14

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need-Place to Stay (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding an apartment, or other home of your own	55.6%	30.1%	81.0%	18	57.1%	7.7%	106.6%	7
Getting into a group home	27.8%	4.9%	50.7%	18	57.1%	7.7%	106.6%	7
None selected	22.2%	0.9%	43.5%	18	0.0%	.	.	7

Unmet Need-Transportation (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Learning to access transportation (for example, cab, bus) independently	25.8%	14.6%	37.0%	62	19.4%	4.6%	34.1%	31
Someone to take you places	72.6%	61.2%	84.0%	62	74.2%	57.9%	90.5%	31
Equipping your van for wheel chair accessibility	17.7%	8.0%	27.5%	62	9.7%	-1.3%	20.7%	31
None selected	16.1%	6.7%	25.5%	62	9.7%	-1.3%	20.7%	31

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Need- Help with Daily Activities (Only one response allowed)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
How many days do you not get enough help with your daily activities?: 5 or more days	38.2%	28.6%	47.8%	102	47.1%	20.6%	73.5%	17
How many days do you not get enough help with your daily activities?: Less than 5 days	55.9%	46.1%	65.7%	102	52.9%	26.5%	79.4%	17
Don't Know/Refused	4.9%	0.6%	9.2%	102	0.0%	.	.	17
How many hours do you not get enough help with your daily activities?: 8 or more hours	16.7%	9.3%	24.0%	102	17.6%	-2.6%	37.9%	17
How many hours do you not get enough help with your daily activities?: Less than 8 hours	76.5%	68.1%	84.8%	102	76.5%	54.0%	99.0%	17
Don't Know/Refused	6.9%	1.9%	11.9%	102	5.9%	-6.6%	18.4%	17
Respite -Yes	65.7%	56.3%	75.1%	102	52.9%	26.5%	79.4%	17
Respite - No	32.4%	23.1%	41.6%	102	47.1%	20.6%	73.5%	17
Respite – Don't Know/Refused	2.0%	-0.8%	4.7%	102	0.0%	.	.	17

Waiver Supported Services Needed by Individuals and their Caregivers

Future Unmet Need- When in the future?								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	62.3%	59.0%	65.5%	859	44.9%	38.9%	50.8%	272
When in the future - 0 to 1 year?	28.3%	24.5%	32.2%	526	29.2%	20.9%	37.4%	120
When in the future - 1 to 5 years	30.4%	26.5%	34.4%	526	32.5%	24.0%	41.0%	120
When in the future - 5 or more years?	41.3%	37.0%	45.5%	526	38.3%	29.5%	47.2%	120
Medical Care	54.4%	51.0%	57.7%	859	35.3%	29.6%	41.0%	272
When in the future - 0 to 1 year?	29.9%	25.7%	34.1%	455	37.2%	27.3%	47.2%	94
When in the future - 1 to 5 years	23.7%	19.8%	27.7%	455	25.5%	16.6%	34.5%	94
When in the future - 5 or more years?	46.4%	41.8%	51.0%	455	37.2%	27.3%	47.2%	94
Place to Stay	45.5%	42.2%	48.9%	859	43.4%	37.5%	49.3%	272
When in the future - 0 to 1 year?	12.7%	9.4%	16.0%	386	11.0%	5.3%	16.7%	118
When in the future - 1 to 5 years	20.5%	16.4%	24.5%	386	33.9%	25.2%	42.6%	118
When in the future - 5 or more years?	66.8%	62.1%	71.6%	386	55.1%	46.0%	64.2%	118
Transportation	62.0%	58.8%	65.3%	859	51.8%	45.9%	57.8%	272
When in the future - 0 to 1 year?	30.8%	26.8%	34.7%	533	31.4%	23.6%	39.2%	140
When in the future - 1 to 5 years	25.7%	22.0%	29.4%	533	30.0%	22.3%	37.7%	140
When in the future - 5 or more years?	43.5%	39.3%	47.7%	533	38.6%	30.4%	46.7%	140
Help with Daily Activities	60.2%	56.9%	63.5%	859	45.2%	39.3%	51.2%	272
When in the future - 0 to 1 year?	34.8%	30.6%	39.0%	503	38.3%	29.5%	47.2%	120
When in the future - 1 to 5 years	27.4%	23.5%	31.3%	503	28.3%	20.2%	36.5%	120
When in the future - 5 or more years?	37.8%	33.5%	42.0%	503	33.3%	24.8%	41.9%	120
Other	4.2%	2.8%	5.5%	859	3.7%	1.4%	5.9%	272
When in the future - 0 to 1 year?	52.6%	44.6%	60.5%	156	45.2%	26.6%	63.7%	31
When in the future - 1 to 5 years	21.8%	15.2%	28.3%	156	19.4%	4.6%	34.1%	31
When in the future - 5 or more years?	25.6%	18.7%	32.6%	156	35.5%	17.6%	53.3%	31
No areas of future need	13.0%	10.8%	15.3%	859	22.4%	17.4%	27.4%	272

Waiver Supported Services Needed by Individuals and their Caregivers

Primary Future Unmet Need								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	23.3%	20.5%	26.1%	859	15.1%	10.8%	19.4%	272
Medical Care	19.3%	16.7%	22.0%	859	10.3%	6.7%	13.9%	272
Place to Stay	14.4%	12.1%	16.8%	859	22.4%	17.4%	27.4%	272
Transportation	7.9%	6.1%	9.7%	859	9.9%	6.4%	13.5%	272
Help with Daily Activities	16.9%	14.4%	19.4%	859	9.9%	6.4%	13.5%	272
Other	2.1%	1.1%	3.1%	859	4.4%	2.0%	6.9%	272
No areas of unmet need	13.0%	10.8%	15.3%	859	22.4%	17.4%	27.4%	272
Refused	0.9%	0.3%	1.6%	859	1.5%	0.0%	2.9%	272
Don't Know	2.1%	1.1%	3.1%	859	4.0%	1.7%	6.4%	272

Unmet Future Need –Something to do during the day (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
School	4.7%	1.7%	7.7%	191	2.6%	-2.6%	7.8%	39
Job	14.7%	9.6%	19.7%	191	7.7%	-1.1%	16.4%	39
Job training	13.1%	8.3%	17.9%	191	7.7%	-1.1%	16.4%	39
Activities to do	16.2%	11.0%	21.5%	191	20.5%	7.3%	33.8%	39
Volunteer work	7.9%	4.0%	11.7%	191	5.1%	-2.1%	12.4%	39
College	3.7%	1.0%	6.4%	191	0.0%	.	.	39
None selected	2.6%	0.3%	4.9%	191	7.7%	-1.1%	16.4%	39

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Future Need --Medical Care (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Finding a therapist	52.3%	44.3%	60.3%	153	40.7%	20.9%	60.5%	27
Finding a medical care provider	47.7%	39.7%	55.7%	153	51.9%	31.7%	72.0%	27
Finding a mental health provider	32.0%	24.5%	39.5%	153	22.2%	5.5%	39.0%	27
Help filling prescriptions, paying for or taking medications	60.8%	53.0%	68.6%	153	55.6%	35.5%	75.6%	27
Obtaining Medicaid or private insurance	58.8%	50.9%	66.7%	153	40.7%	20.9%	60.5%	27
None selected	7.8%	3.5%	12.2%	153	18.5%	2.9%	34.2%	27

Unmet Future Need --Transportation (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Learning to access transportation (for example, cab, bus) independently	35.3%	23.6%	46.9%	68	25.9%	8.3%	43.6%	27
Someone to take you places	80.9%	71.3%	90.5%	68	81.5%	65.8%	97.1%	27
Equipping your van for wheel chair accessibility	23.5%	13.2%	33.9%	68	11.1%	-1.6%	23.8%	27
None selected	5.9%	0.1%	11.6%	68	0.0%	.	.	27

Waiver Supported Services Needed by Individuals and their Caregivers

Unmet Future Need -Daily Activities								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
How many days do you not get enough help with your daily activities: 5 or more days?	55.1%	46.3%	63.9%	127	44.0%	23.1%	64.9%	25
How many days do you not get enough help with your daily activities: Less than 5 days?	28.3%	20.4%	36.3%	127	40.0%	19.4%	60.6%	25
Don't Know /Refused	16.5%	10.0%	23.1%	127	16.0%	0.6%	31.4%	25
How many hours do you not get enough help with your daily activities? 8 or more hours	37.0%	28.5%	45.5%	127	24.0%	6.0%	42.0%	25
How many hours do you not get enough help with your daily activities? Less than 8 hours	48.8%	40.0%	57.6%	127	52.0%	31.0%	73.0%	25
Don't Know /Refused	14.2%	8.0%	20.3%	127	24.0%	6.0%	42.0%	25
Respite-Yes	82.7%	76.0%	89.3%	127	80.0%	63.1%	96.9%	25
Caregiver								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Do you have a primary caregiver? - Yes	92.2%	90.4%	94.0%	859	100.0%	.	.	272
Parent	87.5%	85.2%	89.8%	792	83.1%	78.6%	87.6%	272
Grandparent	1.1%	0.4%	1.9%	792	9.9%	6.4%	13.5%	272
Sibling	2.4%	1.3%	3.5%	792	2.6%	0.7%	4.5%	272
Other Family	2.9%	1.7%	4.1%	792	2.9%	0.9%	5.0%	272
Friend	0.4%	0.0%	0.8%	792	1.5%	0.0%	2.9%	272
Paid Staff	5.4%	3.8%	7.0%	792	0.0%	.	.	272
Don't Know/Refused	0.3%	-0.1%	0.6%	792	0.0%	.	.	272
What is the age of your caregiver?								
Age under 45	38.2%	34.7%	41.6%	747	0.0%	.	.	272
Age 45 to 54	40.0%	36.5%	43.5%	747	0.0%	.	.	272
Age 55 to 64	21.8%	18.9%	24.8%	747	27.2%	21.9%	32.5%	272
Age 65 +	0.0%	.	.	747	64.7%	59.0%	70.4%	272

Waiver Supported Services Needed by Individuals and their Caregivers

Don't Know/Refused	0.0%	.	.	747	8.1%	4.8%	11.3%	272
Does your primary caregiver live with you? Yes	97.3%	96.2%	98.5%	747	92.6%	89.5%	95.8%	272
How much longer is your primary caregiver able to take care of you?								
0 to 1 year	1.7%	0.8%	2.7%	747	2.6%	0.7%	4.5%	272
1 to 5 years	7.0%	5.1%	8.8%	747	18.8%	14.1%	23.4%	272
> 5 years	85.5%	83.0%	88.1%	747	59.6%	53.7%	65.4%	272
Don't Know	5.4%	3.7%	7.0%	747	18.8%	14.1%	23.4%	272
Refused	0.4%	-0.1%	0.9%	747	0.4%	-0.4%	1.1%	272
Reasons unable to be a caregiver (More than one response possible)								
Age of Caregiver	7.7%	-9.1%	24.5%	13	42.9%	-6.6%	92.3%	7
Medical issues of the caregiver	61.5%	30.9%	92.1%	13	57.1%	7.7%	106.6%	7
Safety issues related to taking care of you	30.8%	1.7%	59.8%	13	14.3%	-20.7%	49.2%	7
Other	30.8%	1.7%	59.8%	13	42.9%	-6.6%	92.3%	7
Don't Know/Refused	0.0%	.	.	13	0.0%	.	.	7

Waiting List Referral (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
County Board Staff	49.9%	46.5%	53.3%	838	52.6%	46.6%	58.5%	272
Doctor or other medical professional	11.0%	8.9%	13.1%	838	9.9%	6.4%	13.5%	272
Help me grow or early intervention	8.4%	6.5%	10.2%	838	2.2%	0.4%	4.0%	272
Pre-school	10.9%	8.7%	13.0%	838	13.2%	9.2%	17.3%	272
Family or friends	10.9%	8.7%	13.0%	838	7.4%	4.2%	10.5%	272
I don't remember	4.5%	3.1%	5.9%	838	8.1%	4.8%	11.3%	272
Don't Know	4.4%	3.0%	5.8%	838	6.6%	3.6%	9.6%	272
Refused	0.1%	-0.1%	0.4%	838	0.0%	.	.	272

Waiver Supported Services Needed by Individuals and their Caregivers

Services to Use Waiver For (More than one response possible)								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Something to do during the day	56.9%	53.6%	60.2%	859	43.4%	37.5%	49.3%	272
Medical Care	49.0%	45.7%	52.4%	859	36.0%	30.3%	41.8%	272
A Place to Stay	41.4%	38.1%	44.7%	859	38.6%	32.8%	44.4%	272
Transportation	52.4%	49.0%	55.7%	859	46.7%	40.7%	52.7%	272
Help with Daily Activities	54.9%	51.6%	58.3%	859	44.1%	38.2%	50.1%	272
Other	12.1%	9.9%	14.3%	859	8.5%	5.1%	11.8%	272
Don't Know	6.8%	5.1%	8.4%	859	12.5%	8.5%	16.5%	272
Refused	0.5%	0.0%	0.9%	859	1.1%	-0.1%	2.4%	272

Waiting List Longer than Expected								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
Yes	47.3%	43.9%	50.6%	838	37.1%	31.4%	42.9%	272
No	40.9%	37.6%	44.3%	838	45.2%	39.3%	51.2%	272
Don't Know	11.7%	9.5%	13.9%	838	17.3%	12.8%	21.8%	272
Refused	0.1%	-0.1%	0.4%	838	0.4%	-0.4%	1.1%	272

How long did you think you would be on a waiting list?								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
0 to 1 year	19.6%	16.9%	22.3%	838	16.2%	11.8%	20.6%	272
2 to 4 years	17.7%	15.1%	20.2%	838	11.8%	7.9%	15.6%	272
5 to 10 years	17.8%	15.2%	20.4%	838	13.6%	9.5%	17.7%	272
Don't Know	5.0%	3.5%	6.5%	838	2.9%	0.9%	5.0%	272
Refused	40.0%	36.7%	43.3%	838	55.5%	49.6%	61.5%	272

Waiver Supported Services Needed by Individuals and their Caregivers

Insurance								
Label	Caregiver younger than 60				Caregiver 60 and older			
	%	95% CL L	95% CL U	Total Possible	%	95% CL L	95% CL U	Total Possible
None	0.7%	0.1%	1.3%	859	1.1%	-0.1%	2.4%	272
Private Health Insurance Plans	49.7%	46.4%	53.1%	859	33.5%	27.8%	39.1%	272
Medicaid	58.1%	54.8%	61.4%	859	66.5%	60.9%	72.2%	272
Medicare	16.4%	13.9%	18.9%	859	47.8%	41.8%	53.8%	272
Other (Please specify):	3.4%	2.2%	4.6%	859	0.7%	-0.3%	1.8%	272
Don't Know	1.2%	0.4%	1.9%	859	3.7%	1.4%	5.9%	272
Refused	0.5%	0.0%	0.9%	859	1.1%	-0.1%	2.4%	272

Appendix G: Full Listing of Comments for the 'Other' Response Category

Question 1: In which of the following areas do you currently have an unmet need?

Question 1: Comments from Individuals
Employment
Medical Supplies
Nothing to do after workshop
Financial
More in-home help for personal care
Services for behavior management
Social activities
Someone to teach to drive
Supervision

Question 1: Comments from Parents/ Guardians on behalf of Individuals	
Another Care taker to provide friendship as well	Independent skills (2)
Babysitter/Child care	Nutrition (3)
Being involved with different programs for autism	Outreach programs for children her age
Bridges program	Participating in the community
Child Care in order to work	Personal needs
Child raising	Resources
Day care	Respite care (18)
Day programs unaccepting of TDD waiver	Social activities at varied times (7\)
Vision	Someone to look after him or be with him.
Everyday living responsibilities	Someone to take care of her at certain times
Finding someone to watch him so he's never alone	Sports activities outside of school
General financial (2)	SSA billing
Help with paperwork regarding to child services	Supervision (2)
Home care (7)	Supplemental programs that would benefit her
Home modifications (7)	Therapy, Behavioral (2)
Housing (3)	Therapy, Massage (1)
Information about available programs for disabled	Therapy, Physical (3)
Knee surgery	Therapy, Occupational (6)
Learning to handle an emergency	Therapy, Speech (14)
Medication and/or Medical supplies (6)	Therapy, Unspecified (10)
Mobility specialist/ services for blind	Summer activities
Need assistance when school not in session	Time with Provider
Needs a Eceive card	Weekend activities

Job/Vocation (6)

Weekend help

Question 4: In which of the following areas will you need help in the future?

Question 4: Comments from Individuals

Financial (3)

Home and personal care (2)

Homework needs

Job placement (3)

Medical supplies

Meds/prescription

Nighttime health care

Physical/aquatic therapy

Recreation, vacation

Question 4: Comments from Parents/ Guardians on behalf of Individuals

Everyday activities (3)

Independent living skills (3)

24 hour care

Job placement/training (9)

All of them are equally important (3)

Medical bills

Caregiver (2)

Mobility

Communication needs

No current unmet need (5)

Counseling (4)

Own apartment

Dental care

Resources

Does not want to change living situation

Respite (2)

Eating

Safety skills

Embracing his culture

Self -care (2)

Equipment (3)

Smaller living environment

Feeling important in the community

Social interaction (4)

Finances (3)

Something to do in the evening

Hearing aids

Speech therapy (4)

Home care (5)

Staying with grandparents

Home modifications (7)

Supervision (3)

In case of emergency (2)

Therapy, Unspecified (4)

Tutoring after school

Question 14: Which of the following reasons is your primary caregiver not able to continue caring for you?

Question 14: Comments from Individuals

- Parents want to move, the individual does not want to move.

Question 14: Comments from Parents/ Guardians on behalf of Individuals

Moving into group home

Has aggressive issues with other family members

Placement

She is too heavy, it is a two person lift

Living conditions

Retired from job

Question 16: What services do you plan to use your waiver for?

Question 16: Comments from Individuals

Anything

Behavior management

Clothes, essentials, anything that needs fixed in home

Driving

Get a provider

Job Placement (4)

More in home help with personal care

Most needs are met at this facility

Participating in the community

Physical therapy

Places to go, help with financial things such as budgeting

Smaller living environment (2)

Supervision, someone to take care of her, safety

Wheel chair, respite, shower

Question 16: Comments from Parents/ Guardians on behalf of Individuals

Activities (4)

Organizational skills (2)

Any services that would be available

Orthodontics

Assistance in the home (2)

Provider

Childcare/babysitter

Recreational activities (2)

Community support

Resources

Dental care (2)

Respite (17)

Does not need anything right now

Sheltered workshop

Waiver Supported Services Needed by Individuals and their Caregivers

Don't know	Socialization (7)
Education / Academics (10)	Some extra help. Extra care givers (3)
Financial (6)	Something to do in the evening
Hearing aids	Swimming (2)
Help with everything	Therapy, Behavioral (3)
Help with provider	Therapy, Occupational
Home healthcare (7)	Therapy, Physical (2)
Home modification (18)	Therapy, Speech (7)
Housing (5)	Therapy, unspecified (4)
In case of emergency	Training
Independent living skills (3)	Vacationing
Job Placement (15)	Vision (2)
Learning to get healthy	Visual learning activities
Medical expenses (3)	Volunteer work
Mobility (2)	Wheel chair lift
Not able to receive because he makes too much money	Wherever its needed
NOT Planning on Waiver	Workshop
Nutrition (5)	

Question 21: What health insurance do you currently have?

Question 21: Comments from Individuals

AARP
BCMh
Buckeye
CareSource (2)
ETNA
Medicare
Mom's employer
Social Security
United health care
VA
Welfare (2)

Question 21: Comments from Parents/ Guardians on behalf of Individuals

Waiver Supported Services Needed by Individuals and their Caregivers

Anthem BlueCross, BlueShield (18)	Mail handlers
Bureau for children with medical handicaps BCMH (16)	Medical card (2)
Buckeye (4)	Medical mutual of Ohio (9)
CareSource (9)	March of dimes
Caremark	Medigold
Cigna	Molina (5)
Cigna health care	Military services insurance
Cleveland clinic health plan	Military Tricare (3)
ETNA (3)	OSU medical care
Express	OSU prime
Extra help not sure if insurance, name unknown	Paramount advantage
Fathers retirement	Parent/caregiver employer health plan (5)
Franklin county funded (2)	Prescription plan
Handicap disabilities	Social Security
Healthy start healthy families	Summa care
Humana	Tricare
Ibew	United health care (3)
Life insurance	

Appendix H: Survey Methodology

DODD 2013 METHODOLOGY REPORT

Prepared by the Survey Research Lab

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INTRODUCTION

In January 2013, the Ohio State University Research Foundation contracted with the Survey Research Lab (SRL) at Kent State University to conduct a telephone survey assessing the experiences, current needs, and potential future needs of persons on the DODD waitlist for services. Recognizing that persons on the waitlist may not be physically able to speak to their own present and anticipated future needs, the data collection instrument was designed to capture information collected from the adult “most knowledgeable” as to the person’s needs for these situations. The project required 1,000 completed surveys. Surveys were conducted with the actual person on the waitlist, if they were able to speak to the telephone interviewer about his/her needs, or with the most knowledgeable adult when the person on the waitlist was unable to speak about his/her needs.

In this report, we describe the survey implementation for the 2013 DODD Waitlist Survey. This survey obtained data from persons on the waitlist or an adult most knowledgeable about the person (often a caregiver) regarding: (1) current unmet needs (2) future unmet needs (3) caregiver issues (the presence of the caregiver, the caregiver’s relationship to person on waitlist, age of caregiver, living arrangement for caregiver, and the durability of caregiver arrangement) (4) planned use for the waitlist service(s) when received (5) waitlist time expectations (6) confirmation of gender and age of person on waitlist, and (7) current insurance coverage for person on waitlist.

SAMPLE DESIGN

A random sample of 14,978 persons currently on the DODD waitlist was generated by DODD and sent via secure email transmission to the SRL. This list included names, addresses, and some phone numbers drawn from Medicaid records. There were 9,082 Medicaid list phone numbers (60.64% of the sample) in the sample received from DODD. The Medicaid telephone numbers were initially stripped away from the file, which was then sent to Survey Sampling International, INC., for an address-match telephone number identification process. This process resulted in 4,959 phone numbers (33.11% of the sample), which were folded into the sample file with Medicaid phone numbers. The end result was 11,025 respondent records with a phone number for contact (73.61% of the original sample received from DODD) consisting of: (1) address-matched only phone numbers (2) Medicaid list only phone numbers or (3) address-matched and Medicaid list phone number.

Records with just address-matched telephone numbers were assigned a telephone source code of “1,” respondent records with just a Medicaid list telephone number were assigned a phone source code of “2,” and records with both telephone number sources were assigned a phone source code of “3,” with addressed-matched telephone numbers to be called first. Although it did not prove necessary, if needed, Medicaid telephone numbers paired with an address-matched telephone number were assigned a telephone source code of “4” and would have been called last to acquire the required number of completed surveys.

SURVEY DESIGN

The survey instrument underwent 13 revisions benefitting greatly from continuous stakeholder review and input. The survey also benefitted from SRL and stakeholder conducted cognitive testing to help ensure understandability for persons taking the survey. Three meetings were attended by SRL personnel, including an initial meeting in February, a stakeholder meeting at the state building on July 17, 2013, and preliminary findings meeting on November 20, 2013. Although initially contracted for just a five minute survey, the contract was later expanded to seven minutes.

The Survey Research Lab (SRL) programmed the questionnaire using Sensus 4.2 survey authoring software, and WinCati version 4.2 Supervisor and Interviewer software package, which is designed specifically for managing CATI studies.

WinCati software, used by the SRL to program all of its CATI surveys, is a powerful questionnaire programming language that provides:

- Call management;
- Quota controls;
- Multilingual interviewing capabilities;
- Data back-up; and
- Active monitoring

Final approval from Barry Jamieson, Senior Project Manager, Ohio Colleges of Medicine Government Resource Center was received on September 5, 2013.

After initial programming was finished, the survey was rigorously tested by SRL project team. Testing included:

- Developing scenarios to test all possible paths through the questionnaire;
- Checking frequencies of randomly generated data;
- Verifying frequencies of the data after the first day of interviewing; and
- Conducting a pretest to identify and fix potential issues in the collection of live data.

To track quality control indicators, the SRL manager and staff generated reports that read the survey data file, including interviewer efficiencies (completes per hour, both on an individual and project level) and a review of all call dispositions. Interviewer “tags” (the requiring of interviewers to provide their names to continue with the survey) enabled the project management team to detect and immediately correct telephone interviewer coding issues. These checks were generally performed daily but at intervals no longer than every 48 hours.

Inconsistencies or problems were documented in internal progress reports. One issue was discovered during pretesting with Spanish speaking respondents that centered on U.S. citizenship status. However, the issue was addressed prior to full fielding. Once full fielding began, there were no issues related to quality assurance for the 2013 DODD waitlist survey.

The survey was completed on September 27, 2013. The data collection effort resulted in 1,136 completed surveys, which was reduced to 1,131 after data cleaning efforts. Of the completed surveys, 135 were completed by persons and 996 were completed by the most knowledgeable adult. The data collection also produced 5 partially completed surveys.

INTERVIEWING PROTOCOL

The landline telephone survey followed a 15-attempt protocol. A final disposition was attained when:

- The respondent completed the interview;
- The telephone number was found to be invalid;
- The record reached 15 attempts (landline) or 6 attempts (cell) distributed among three different day times;
or
- The respondent gave a final refusal.

Experienced, supervised personnel conducted the DODD Waitlist Survey interviews using WinCati version 4.2 Supervisor and Interviewer CATI package. To maximize response rates, calls were concentrated between 1 p.m. and 9 p.m. E.S.T. Monday through Friday, and between 10 a.m. and 5 p.m. E.S.T. on Saturday, and between 1 p.m. and 9 p.m. on Sunday except on holidays. A portion of calls was conducted between 9 a.m. and 5 p.m. E.S.T., Monday through Friday, in order to complete interviews in an effort to reach respondents who were only at home during the day.

Contacting Respondents

The following protocols were followed when contacting households and potential respondents:

- **Treatment of No Answers.** If a call to a sampled telephone number was not answered, the number was repeatedly called at different times, during the daytime and evening hours (9 a.m. to 9 p.m. E.S.T., Monday through Friday; 10 a.m. to 5 p.m. E.S.T. on Saturdays and 1 p.m. to 9 p.m. on Sundays), on different days of the week—in a pattern designed to maximize the likelihood of contact with a minimum number of calls. At least 15 contact attempts, (landline) and 6 attempts (cell) were made to reach a sampled number. Once any contact was made at a residence, as many calls as necessary were made to reach the selected person or most knowledgeable adult if the person was physically unable to address questions as to his/her current and future unmet needs (within the permitted time schedule).
- **Rings per Attempt.** The telephone rang a minimum of seven times for each attempt made on a record.
- **Busy Lines.** Busy lines were called back at least twice at 10-minute intervals. If the line was still busy after the third attempt, the number was assigned a “busy” disposition and called during the next shift.
- **Respondent Selection.** Several important checks were performed to ensure data were collected from the proper respondent. First, the interviewer checked to make sure they were calling the residence of the respondent appearing on the interviewing calling record (“Is this the residence of //READ NAME FROM CALLING RECORD//?”). Next, the person answering the phone was asked about the respondent’s ability to speak with the interviewer about his/her needs (“Is //READ NAME FROM CALLING RECORD// able to speak with me about HIS/HER needs?”). If the respondent was physically able, they were then asked if they were an adult (“Are you 18 years of age or older?”). If yes, they continued with the survey. If the person answering the phone indicated that the respondent was unable to speak about his/her needs, or if the respondent was not an adult, the survey was routed to the person most knowledgeable about the respondent’s care (“Then can I speak with the person most knowledgeable about //READ NAME FROM CALLING RECORD//’s care?”). If the person most knowledgeable about the respondent’s care was able to take the survey, they were routed to reading of a consent script specially written for the person most knowledgeable about the respondent’s care. If they were unable to complete the survey at this time, a callback was scheduled.

No interview was conducted if the selected respondent, or the adult most knowledgeable about the respondent’s care was:

- Unavailable during the survey period;
- Unable or unwilling to participate;
- Did not speak English or Spanish well enough to be interviewed; or

- Was not qualified to take the survey, was not the respondent of record, or the person who acknowledged be the most knowledgeable about the respondent's care.
- **Language of Interviewing.** Interviewing for the DODD Waitlist survey was conducted in both English and Spanish. The actual number of interviews conducted in Spanish was small and not captured by the approved survey.

INTERVIEWER TRAINING

Interviewers underwent extensive study-specific training prior to data collection. The training assured consistent, high quality interviewing throughout data collection.

The quality of data collection depends largely on the performance of the interviewing staff. Some of interviewers on this study were recruited from health care research, e.g., The College of Public Health.

The SRL's training sessions for the DODD Waitlist Survey focused on these important aspects of the survey research process and included Barry Jamieson from the Ohio Colleges of Medicine Government Resource Center and Hope McGonigle, Medicaid Administrator:

- **Introduction to the Survey:** background about DODD; the survey's purpose and scope; the importance of conducting high quality interviews and how the data will be used.
- **Introduction to Sampling:** type of sampling being used; the interview targets; the importance of making multiple attempts and obtaining a high response rate.
- **The Role of the SRL Director:** explanation of the role of each member of the SRL staff (such as the SRL manager, the Senior SRL Supervisor, Shift Supervisors, Survey Team Leaders, and Interviewers).
- **Overview of the Questionnaire:** overview of the questionnaire by respondent type and instrument; brief review of the most important aspects related to administering the survey (such as survey length, verification of telephone numbers, protocol, and question type overviews).
- **Approaches to Interviewing:** moving respondents through the survey and asking the questions appropriately; keeping question non-response to a minimum; avoiding respondent refusals; and probing techniques (such as clarification of respondent responses, open-end verification, and re-reading of response categories).
- **DODD Waitlist Survey Protocols:** reading verbatim; particular respondent selection procedures; probing and clarifying; dealing with refusals; and assuring respondent confidentiality.
- **Knowing the Questionnaire:** being prepared with survey material to answer respondent questions; paying close attention to the interviewer notes provided in the script; understanding what each question is asking; being comfortable with suspending and resuming interviews; and a thorough review in using the WinCati Interviewer program, including a review of disposition codes.

INTERVIEWER MONITORING

Throughout data collection, interviewer performance was monitored by the lead supervisor, shift supervisors, and team leaders, and assessed through formal and informal performance evaluations.

Supervisors and team leaders monitored at least 10 percent of live interviews by unobtrusively tapping into the interviewers' telephone line (using the WinCati system's monitoring capability) to carefully follow the course of the interview on a computer screen. Interviewers were scored using several evaluation measures assessing interview performance. These formal evaluation measures were designed and implemented by the SRL to help ensure proper interviewer protocol:

- Verbatim response entry;
- Disposition calls and scheduling callbacks;
- Reading scales properly;
- Knowing the mechanics of the DODD Waitlist Survey;
- Reading and probing on open-ended questions;
- Reading multiple response lists;
- Reading the introduction and persuading respondents to complete interviews;
- Pace of reading the survey;
- Clarity and/or clarifying responses that are not clear;
- Keeping control of the interview;
- Converting refusals on specific questions;
- Overall professionalism;
- Being neutral while interviewing, not leading the respondent; and
- Overall dialing habits.

If monitoring revealed any defects in the interviewing process, Shift Supervisors conducted corrective measure meetings with the individual interviewer. Supervisors also assured that interviewers:

- Coded incomplete interviews properly;
- Left useful messages for the next interviewer; and
- Made every attempt to complete an interview on every contact.

DATA COLLECTION QUALITY CONTROL

The Survey Research Lab (SRL) programmed the English and Spanish questionnaires using WinCati version 4.2 Supervisor and Interviewer software package, which is designed specifically for programming and managing CATI studies. WinCati software, used by the SRL to program all of its CATI surveys, is a powerful questionnaire programming language that provides:

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To track quality control indicators, the SRL manager and staff generated reports that read the survey data file, including interviewer efficiencies (completes per hour, both on an individual and project level) and a review of all call dispositions.

These reports were distributed to the SRL management team for daily review. This enabled the management team to quickly detect and resolve any problems. Inconsistencies or problems were documented in internal progress reports. Once full fielding began, there were no issues related to quality assurance for the 2013 DODD Waitlist Survey.

RESPONSE RATE

A total of 5,764 respondent records were used during the September fielding of the DODD Waitlist Survey. Utilizing the American Association of Public Opinion Research's Response Rate Calculator, the SRL's DODD Waitlist Survey data collection effort produced these response rates:

- RR1: 46.5%
- RR2: 46.7%
- RR3: 51.8%
- RR4: 52.1%

DATA FILE

Data were collected and placed in an SPSS file. All labels in the data set consisted of the actual items asked in the survey. Values were added for each variable as well. The final data file contained a total of 249 variables. A fully annotated data file and code book containing variables, survey items, and response options were sent to the Senior Project Manager.