

# Maryland Autism Services Survey

## Summary of Results for Waiver Services

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This project is supported through grant awards from the Maryland State Department of Education (MSDE) Division of Special Education/Early Intervention Services and the Bowen Foundation. We are also extremely grateful to the families who have given so generously of their time to assist us with this project.

Towson University, in collaboration with MSDE, recently completed Phase II of a research study to learn more about the impact of services provided by the Maryland Medicaid Home and Community Based Services (HCBS) Waiver for Children with Autism Spectrum Disorder (Autism Waiver) on several outcomes including: waiver services being utilized, overall family quality of life, progress related to the child's social, academic, independent living skills, behavior and communication as well as family demographics including employment, income, and marital status.

Maryland is one of a number of states utilizing the HCBS Waiver to provide Medicaid home and community services for eligible children with Autism and their families. The Autism Waiver services include: intensive individual support services (IISS), therapeutic integration services, residential habilitation, respite care, environmental accessibility adaptations, adult life planning and family training. Service coordination is also provided to each family. There are 900 Autism Waiver slots which are filled. An Autism Waiver Registry has been created for families who are interested in receiving waiver services when a slot becomes available. In May 2011, MSDE reported that 900 Maryland families were currently receiving Autism Waiver services and 3436 families were listed on the Autism Waiver Registry. These numbers have increased since the last survey was conducted in 2008, which included 800 families receiving Waiver services (it did not include the families that entered the waiver in 2008) and 2649 families on the Registry; the number of families on the registry has increased by 30 percent since 2008.

The Maryland Autism Services Survey (MASS) is a multi-item quantitative questionnaire that includes questions specific to Maryland Autism Waiver Services and a valid and reliable scale to measure family quality of life (FQOL). Family quality of life has been defined as “an interactive process in which individual family member demographics, characteristics, and beliefs interact with family-unit dynamics and characteristics within the context of individual and family level supports, services, and practice” (Zuna, Summers, Turnbull, Xu, & Hu, 2011). The survey tool was developed by Towson University in consultation with the Maryland State Department of Education, which administers the Maryland Autism Waiver, and Dr. Jean Ann Summers, one of the original survey authors at the Beach Center on Disability (Kansas University). Feedback from potential participants was elicited from a focus group session with professionals and parents of children with Autism in 2008. Phase I of the study was completed in 2009, and MSDE contacted the research team in May 2011 to repeat the survey. Respondents could not be identified from the initial study for comparative data thus the current project is identified as a Phase II initiative rather than a direct continuation of Phase I.

#### *Project Goals*

1. Determine the number and percentage of families reporting that the waiver services they receive meet their needs. Specifically determine the percent/number of families who respond positively that services meet their needs based on all families who respond to the question.
2. Gather and analyze data on perceived family quality of life for families with children who have Autism.
3. Determine the relationship between Autism Waiver Services and Family Quality of Life (Working Hypothesis Below)

#### *Working Hypotheses*

- There is a positive correlation between families who receive Autism Waiver services and reported FQOL.
  1. Reported FQOL will increase with the amount and duration of Autism Waiver Services that a family utilizes and participates in (amount and duration to be defined.)
  2. Examine the impact of waiver services predicting FQOL after accounting for the impact of other services and family income.

### *Methods*

To ensure confidentiality, the mailings for the survey were distributed by MSDE to waiver families and a sample of families on the Registry. In total, 2,140 families were sent surveys, including 823 who were on the Waiver, 1289 who were on the Registry and 28 Registry families who would be enrolled in the Autism Waiver as of July 1, 2011. Three separate mailings were made on July 29, August 26, and October 11, 2011. Each subsequent mailing did not include those who had already completed the survey or those whose mail had been returned as undeliverable. The original Plan had been to survey the entire Waiver population (900 families). However, 77 families were not surveyed because they were leaving the Waiver program this year. Of the 823 surveys mailed to families on the Waiver that were mailed, 15 were returned with no forwarding address, 39 had already completed a similar survey earlier in the year, and 34 had more than one child on the Waiver leaving 735 possible participants.

A representative sample of 1520 Registry families was chosen randomly to participate. The sample was used to lower costs and improve efficiency of the sample response rate. Out of the 1520 Registry families, 12 families were not surveyed because their addresses were missing, 184 families were not surveyed because their mail was returned to MSDE with no forwarding address, and 35 families had multiple children on the Registry. The first two survey mailings included a cover letter that directed the respondent to an internet-based survey. The cover letter also included options to respond via paper survey or phone interview. In an effort to increase the number of responses, the third mailing included a revised cover letter, a paper copy of the survey, a postage-paid return envelope addressed to Towson University, and a resource card for families. The cover letter contained background information about the Autism Waiver, a brief description of the survey and survey instructions. Participants were informed that participation was entirely voluntary and their identities would remain anonymous.

## Results

A total of 331 surveys were completed online and 268 were completed via the third paper mailing. Forty-eight surveys that had been completed during a separate project earlier in the year were included in the data analysis, for a total of 647 (31.5%) responses prior to data cleaning and excluding respondents who did not fully answer all questions. Respondents included 292 (39.7%) Waiver recipients and 342 (26.5%) families with children on the Registry. Forty-seven percent of all respondents expressed interest in participating in future, in-depth, interviews and research by providing their contact information in a voluntary section of the survey. A complete description of the survey response rate is presented in Table 1.

**Table 1. Survey response rate**

	<b>Surveys Completed Online</b>	<b>Surveys Completed on Paper</b>	<b>Total Surveys Completed</b>	<b>Response Rate</b>	<b>Survey Respondents Who Provided Contact Information</b>	<b>Total Surveys Included in Analysis</b>
<b>Registry</b>	204 (53.8%)	138	342	26.5%	175	342
<b>Waiver</b>	174 (45.9%)	118	292	37.3%	108	292
<b>Unknown (excluded)</b>	1	12	13	N/A	N/A	0
<b>Total</b>	379	268	647	31.2%	283	634

The majority of survey respondents (> 95%) reported being a parent of the child with autism in their family. The majority of the respondents were female (> 96%). The mean ages of Waiver and Registry respondents are 47.7 and 42.5 respectively. Regarding employment status, 47.7% of Waiver respondents reported being employed full time compared to 44.3% of Registry respondents. In addition, 12.7% of Waiver respondents were employed part time compared to 16.6% of Registry respondents. Income and education level did not differ significantly in the Waiver and Registry groups. Demographic data are presented in Table 2. Education and Income for each group are presented in Figures 1 and 2.

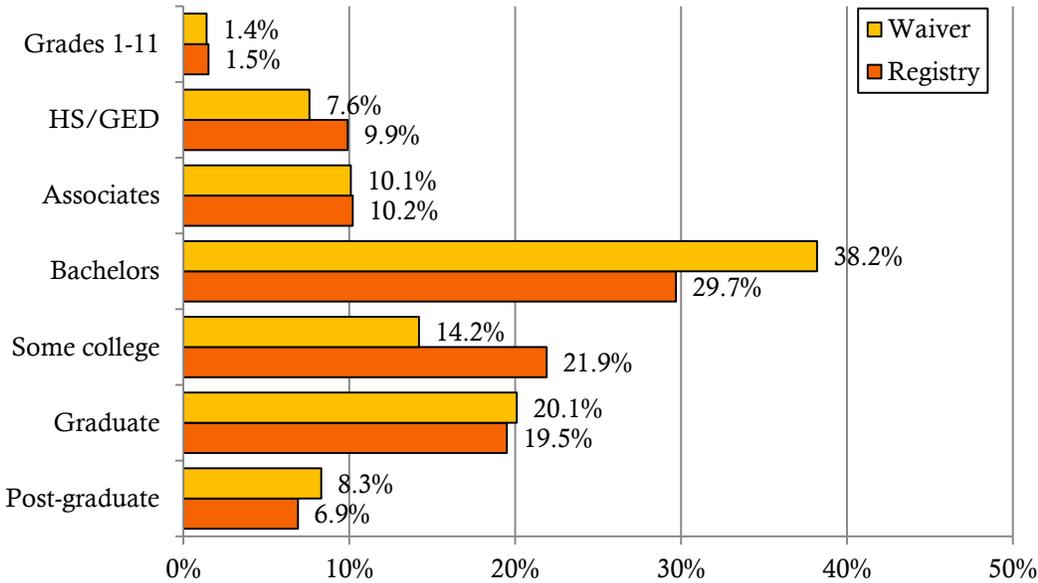
**Table 2. Demographic information about survey respondents**

Survey Question	Response	Waiver	Registry	
<b>What is this person's relationship to you? referred to as your child.</b> <input type="radio"/> <i>Biological/adopted child</i> <input type="radio"/> <i>Grandchild</i> <input type="radio"/> <i>Niece/nephew</i> <input type="radio"/> <i>Sibling</i> <input type="radio"/> <i>Stepdaughter/stepson</i> <input type="radio"/> <i>Foster Child</i> <input type="radio"/> <i>Other (please describe below)</i>	Biological/adopted child	276 (95.5%)	331 (97.1%)	
	Grandchild	6 (2.1%)	6 (1.8%)	
	Niece/nephew	0 (0.0%)	0 (0.0%)	
	Foster child	0 (0.0%)	2 (0.6%)	
	Sibling	1 (0.3%)	1 (0.3%)	
	Step-child	4 (1.4%)	1 (0.3%)	
	Other	2 (0.7%)	0 (0.0%)	
	<b>Gender:</b> <input type="radio"/> <i>Male</i> <input type="radio"/> <i>Female</i>	Female	276 (95.5%)	331 (97.1%)
Male		6 (2.1%)	6 (1.8%)	
<b>Which of the following best describes your current work status?</b> <input type="radio"/> <i>Employee in full-time job (30 hours or more per week)</i> <input type="radio"/> <i>Employee in part-time job (less than 30 hours per week)</i> <input type="radio"/> <i>Self-employed (full- or part-time)</i> <input type="radio"/> <i>Government-supported training</i> <input type="radio"/> <i>Unemployed and available for work</i> <input type="radio"/> <i>Fully retired from work</i> <input type="radio"/> <i>Full-time education at school, college or university</i> <input type="radio"/> <i>Looking after home/family</i> <input type="radio"/> <i>Permanently sick/disabled</i>	Full-time job	135 (47.7%)	144 (44.3%)	
	Part-time job (30 hours or less)	36 (12.7%)	54 (16.6%)	
	Self-employed	50 (17.7%)	55 (16.9%)	
	Government-supported training	3 (1.1%)	2 (0.6%)	
	Unemployed and looking for work	6 (2.1%)	7 (2.2%)	
	Fully retired	10 (3.5%)	13 (4.0%)	
	Full-time education	10 (3.5%)	2 (0.6%)	
	Looking after home/family	33 (11.7%)	41 (12.6%)	
	Permanently sick/disabled	--	7 (2.2%)	
	<b>Date of birth (mm/yyyy):</b>	Mean age of survey respondent (Range 19-74)	47.7	42.5

**Figure 1. Caregiver Level of Education**

What is the highest level of education that you have completed? (please select ONLY one)

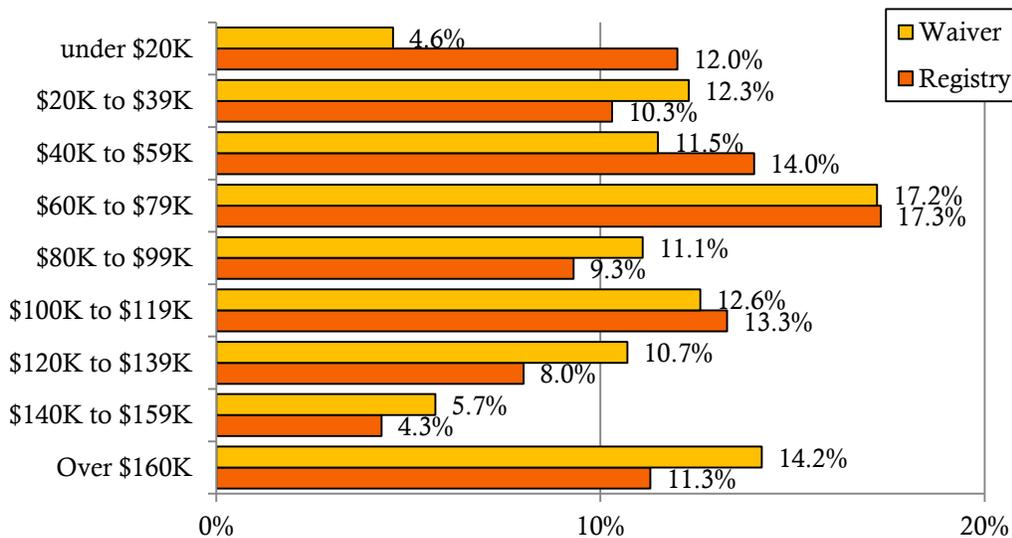
- Grades 1-11
- High school graduate (diploma or GED)
- Some college or post-high school, but no degree
- Associate degree (AA, AS)
- Bachelor's degree (BA, BS)
- Graduate degree
- Post-graduate degree



**Figure 2. Reported Household Income**

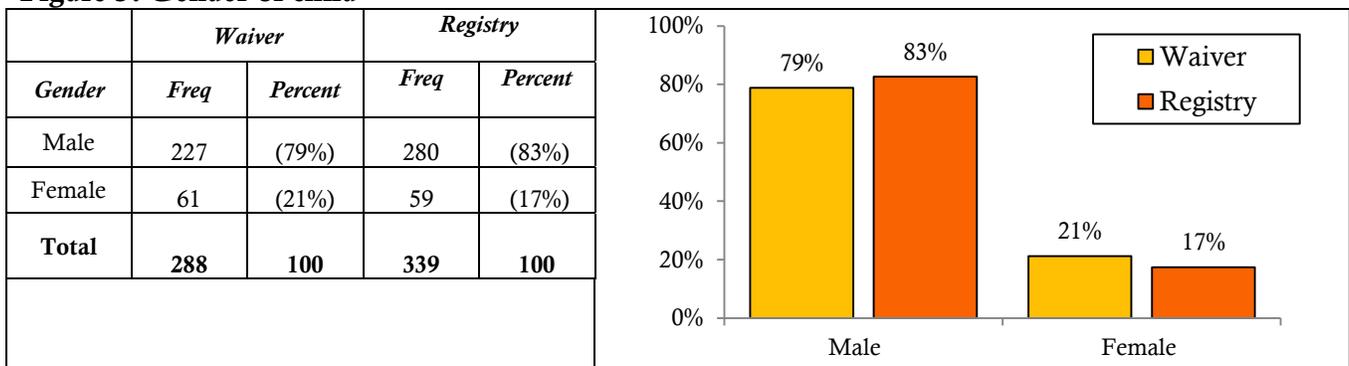
What was your total household income from all sources for the past year? Be sure to include income from all sources (such as family subsidy or child support).

- Less than \$20,000
- \$20,000 to \$39,999
- \$40,000 to \$59,999
- \$60,000 to \$79,999
- \$80,000 to \$99,999
- \$100,000 to \$119,999
- \$120,000 to \$139,999
- \$140,000 to \$159,999
- Over \$160,000

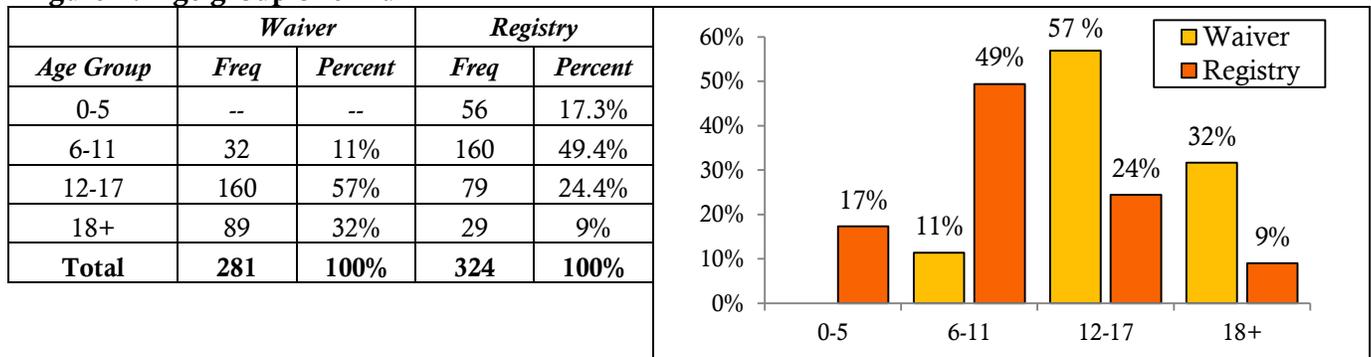


Descriptive data about the children reveal that approximately 80% of the children are male and 20% are female. The gender split does not differ significantly between the Waiver and Registry groups. Child's age does differ between the two groups. Children receiving Waiver services are generally older than those on the Registry. Sixty-six percent of children on the Registry compared with 11.4% of children on the Waiver are under age 12. This may be explained by the fact that many of the children on the Registry are too young to have joined the Waiver when it began in 2001. In addition, the current wait time on the Registry is seven years before having an opportunity to apply to the Waiver for a slot, meaning that most children entering the Waiver are older than the children on the Registry. The majority of the children on the Waiver (65%) have been receiving waiver services for more than five years. These data are presented in Figures 3-5.

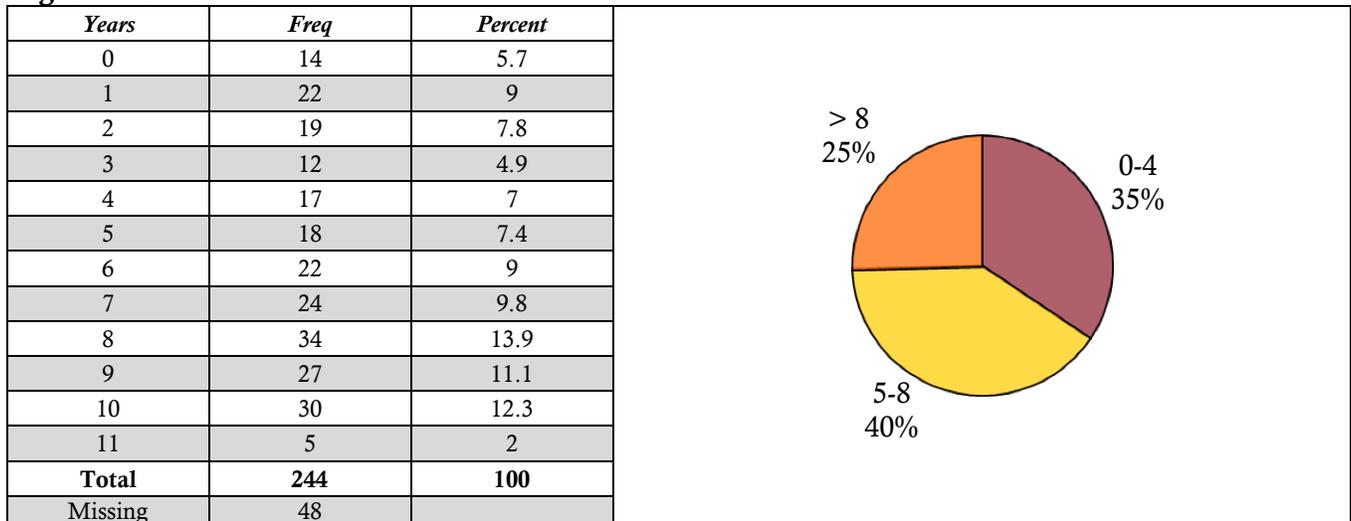
**Figure 3. Gender of child**



**Figure 4. Age group of child**

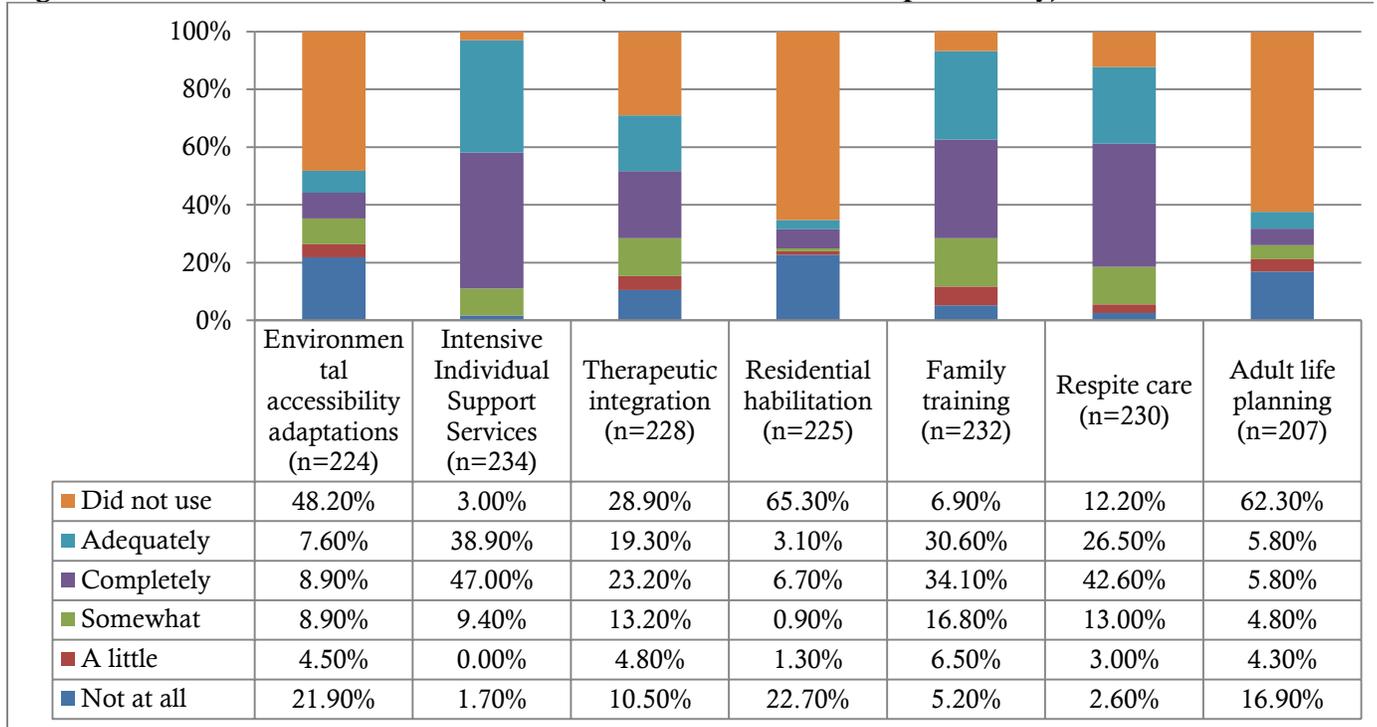


**Figure 5. Years on Waiver**



Waiver recipients reported Intensive Individual Support Services (IISS,) Family Training and Respite as the most frequently used services. Seventy-two percent of those respondents used IISS workers one or more times a week. Family Training services were used by 67% of the respondents one or more times a month. Respite services were used by 88% of the waiver respondents one or more times per year. Lastly, Therapeutic Integration services were used by 57% of the respondents one or more times per month. Over 60% of the respondents reported that they did not use Adult Life Planning, Residential Habilitation, and Environmental Accessibility Adaptations at all. Adult Life Planning is limited to children between the ages of 18 to 21 for a maximum of 45 hours over three years. Residential habilitation is provided under very limited circumstances. Environmental Accessibility Adaptations is limited to \$1,500 over three years when needed for health and safety. The majority of the respondents reported adequate or complete satisfaction with the most frequently used services; IISS, Respite, and Family Training. The highest satisfaction was with IISS workers. Satisfaction with reported services is summarized in Figure 6.

**Figure 6. Satisfaction with Waiver Services (Fall 2011 Waiver Recipients only)**

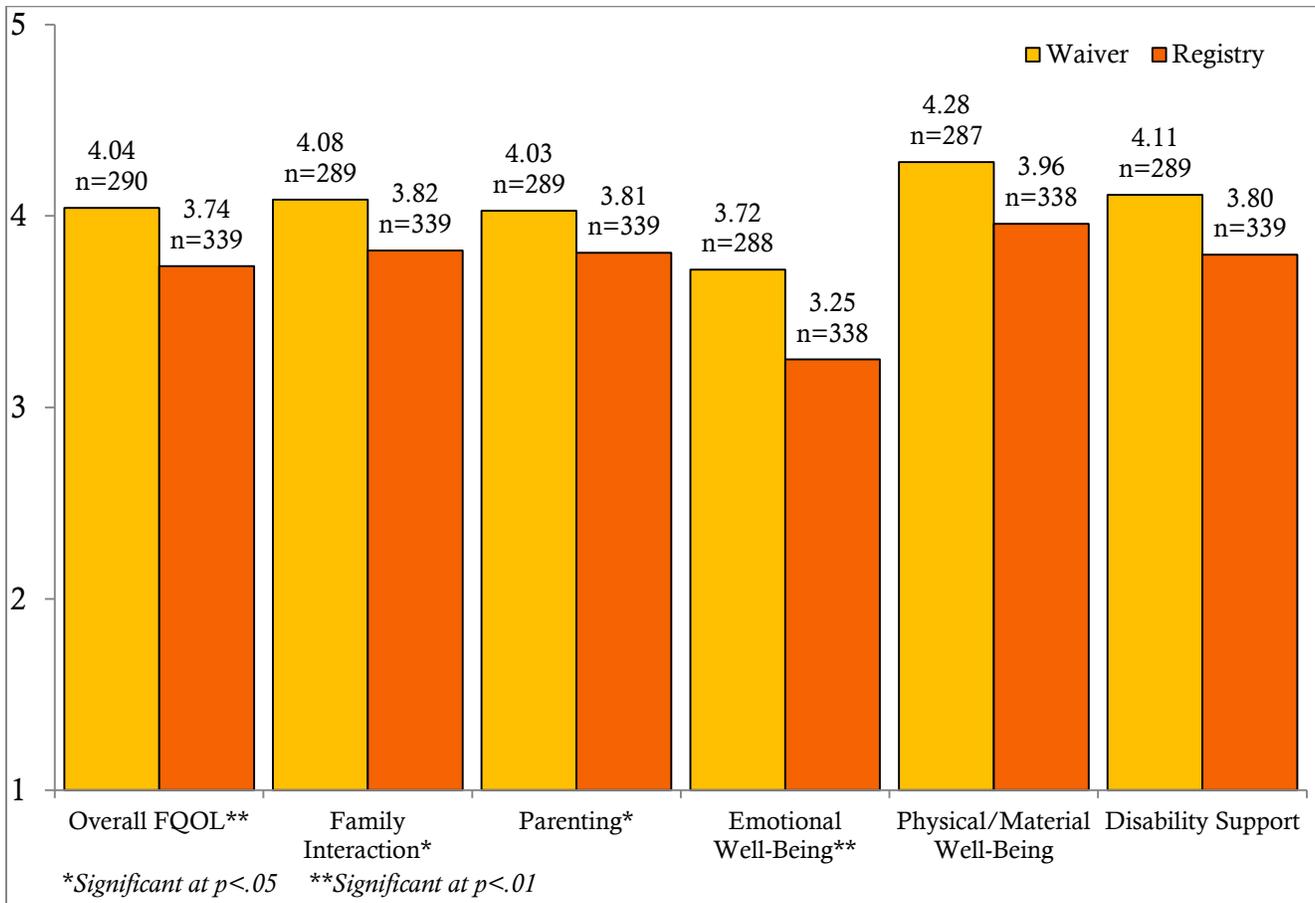


T-tests comparing the Registry and Waiver groups yielded significant differences between the groups in several key areas. Hypothesis 1 was supported; Waiver recipients reported significantly higher satisfaction with their overall family quality of life. In addition to overall FQOL, families on the waiver reported higher satisfaction on three of the five FQOL subscales (Family Interaction, Parenting and Emotional Well-Being). These data are presented in Figure 7. Additionally, a longer time on the Waiver is positively correlated with higher satisfaction with overall Family Quality of Life as well as the Family Interaction, Emotional Well-Being, Physical/Material Well-Being, and Disability Support sub-scales. Supporting Hypothesis 2, waiver recipients reported higher family quality of life after controlling for income.

**Figure 7. Family Quality of Life Overall Mean and Subscales**

The Beach Center Family Quality of Life Scale is a 25-item scale that measures family perceptions of satisfaction within five domains: family interaction, parenting, emotional well-being, physical/material well-being, and disability-related supports. Sample item below and figure follows.

How satisfied are you that...	Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
My family enjoys spending time together.	<input type="radio"/>				
My family members help the children learn to be independent.	<input type="radio"/>				
My family has the support we need to relieve stress.	<input type="radio"/>				

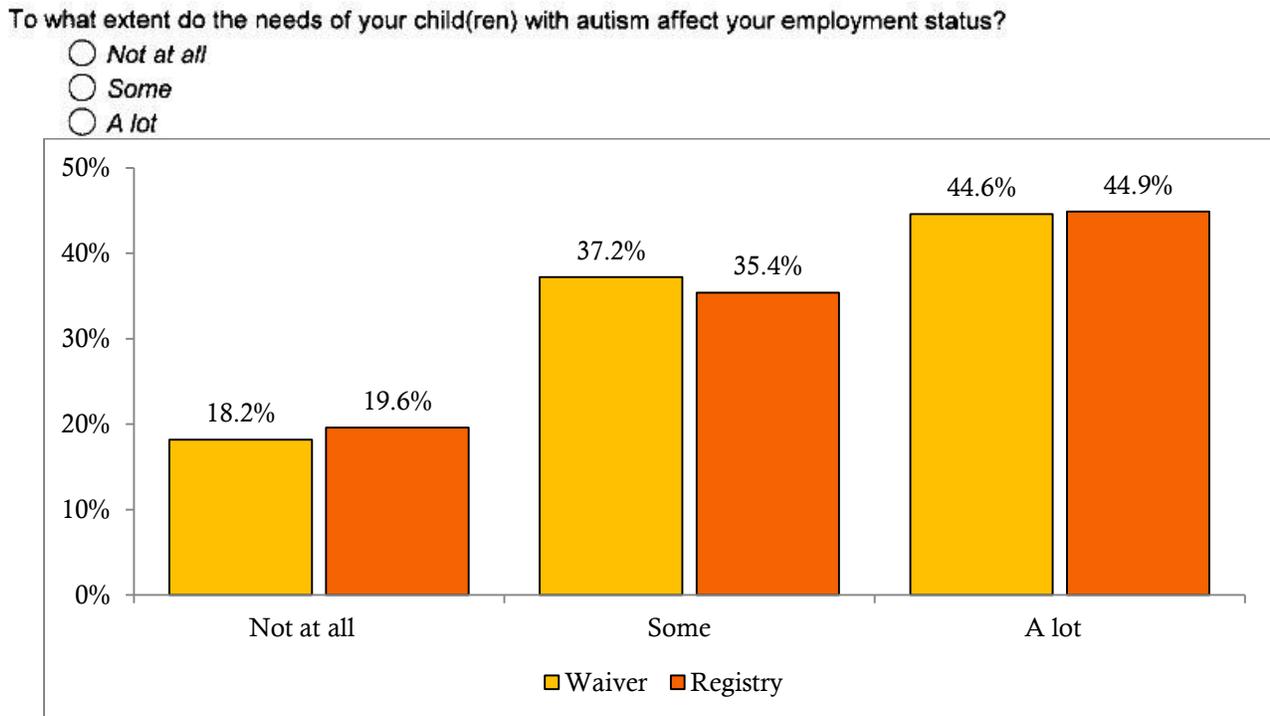


1 = very dissatisfied    2 = dissatisfied    3 = neither    4 = satisfied    5 = very satisfied

A child with Autism impacts parental employment. Eighty-two percent of Waiver respondents and eighty percent of Registry respondents reported that the needs of their child with Autism affected

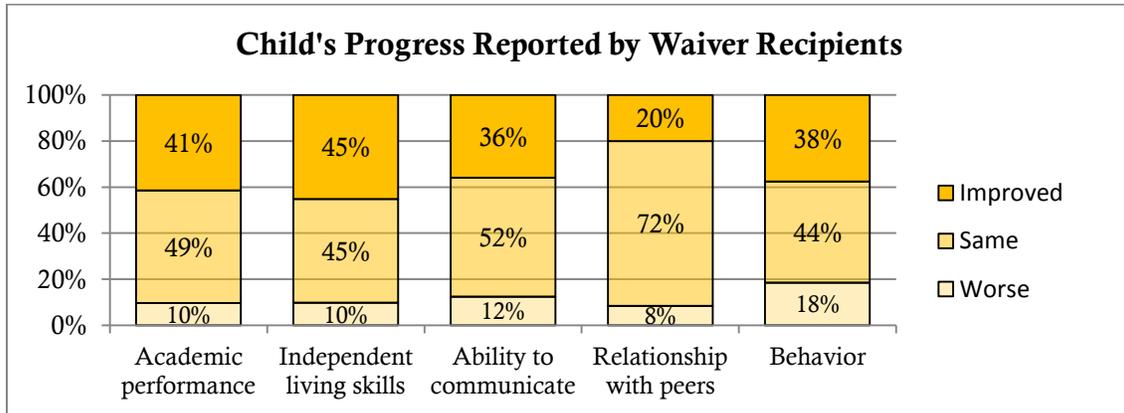
their employment status “some” or “a lot”. Only 19% reported that their employment status was not affected by their child’s needs. These data are presented in Figure 8.

**Figure 8. Effect of child with Autism on caregiver employment**

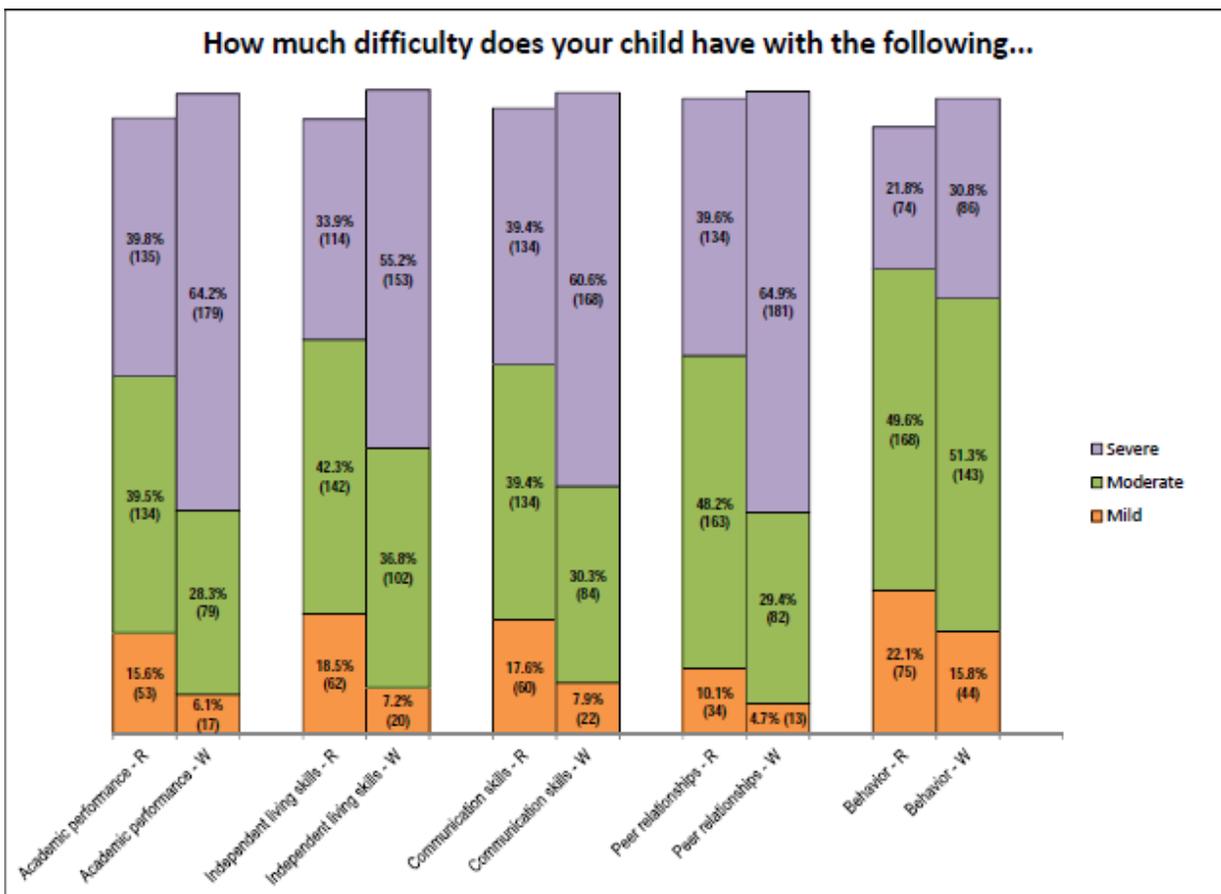


Additional findings reveal that parents’ reported that their children demonstrated improvement in areas of academic performance, independent living skills, ability to communicate, relationships with peers and behavior. The most progress was reported in academic performance and independent living skills figure 9. It is also important to note that over 80% of all respondents indicated that their child either stayed the same or showed improvement in each area. Maintaining function for children with symptoms severe enough for them to be eligible for autism waiver services is important and should be seen as a positive outcome. Figure 10 illustrates reported difficulty of children in specific skill areas for waiver and registry respondents.

**Figure 9. Child Progress Reported by Waiver Recipients**



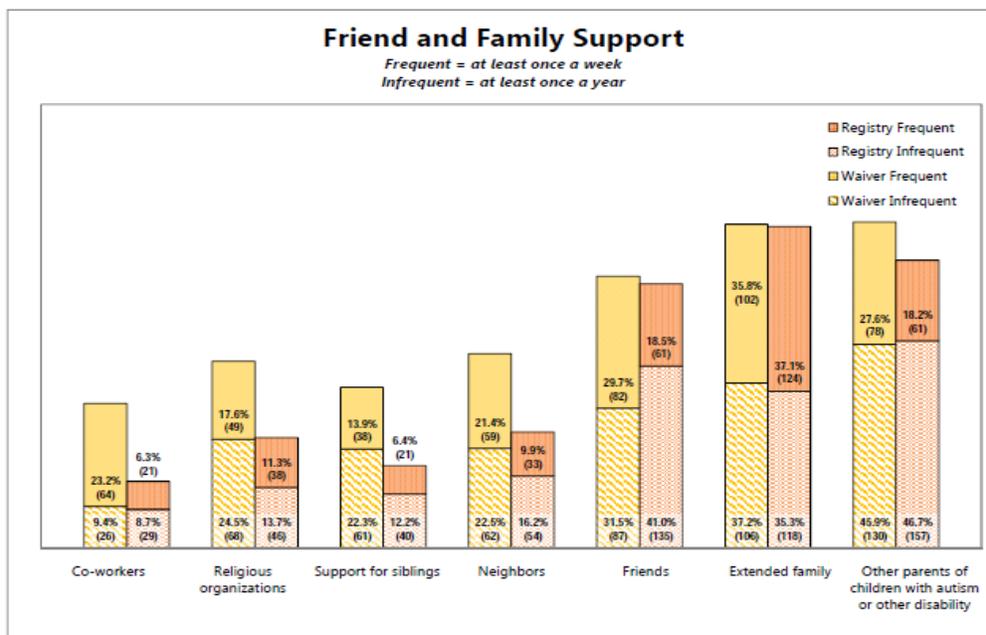
**Figure 10. Perceived Difficulty in Functional Skills**



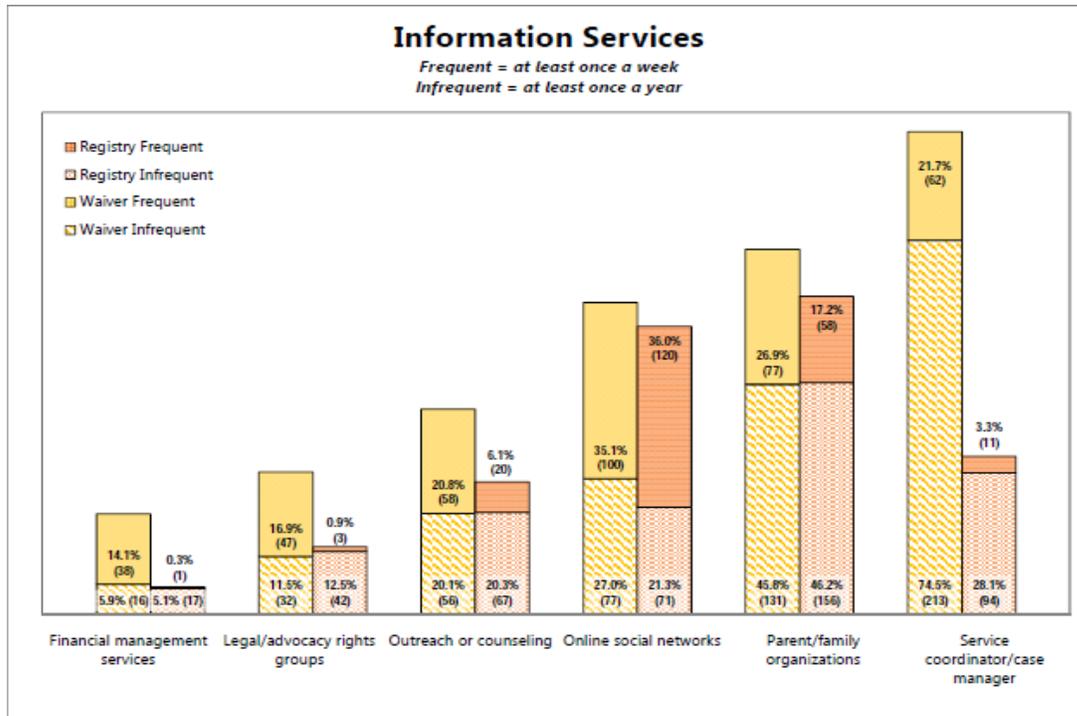
Greater than 50% of all respondents (waiver and registry) reported use of parent/family organizations, online social networks, extended family, friends, other parents of children with autism (or other disability), family care(differentiated from family support), mental health services and healthy

kids check-ups. Of particular interest is the percentage of participants who report use of mental health services. This finding combined with reported low scores on the emotional well-being subscale is worthy of additional consideration. Extended family support (Figure 11) and online social networks (Figure 12) were used by over 35% of waiver and registry families at least once a week. These two informal support service categories were used about the same amount for both groups and were the highest reported usage for both groups. The current data of service use cannot be used for higher level statistical analysis but these descriptive findings may indicate need for future exploration.

**Figure 11. Friend and Family Support**



**Figure 12. Information Services**



Formal and informal service utilization in general was higher for waiver recipients. This information is interesting to note for future investigation. The results could reflect the severity of the child’s symptoms necessitating additional services. A second possibility is that there is an unanticipated boost in parents’ advocacy skills that result in access to and use of other formal and informal services for families. A third consideration is availability of additional Medicaid services. Friend and family supports including extended family, friends and other parents of children with autism or other disability were used by over 25% of waiver families at least once a week. In addition, family care (provision of child care by family member), parent/family organizations and online social networks were used by over 25% of waiver families at least once a week.

## *Discussion*

The MASS project provided an opportunity to gather data from families receiving waiver services and those on the registry. Overall both groups reported a family quality of life that was lower than findings from similar studies (Eskow, Pineles, & Summers, 2011; Summers et al., 2007; Wang et al., 2006). In addition, a significant number of respondents reported that having a child with Autism impacted their employment. Findings support Autism as a complex disorder that impacts the family. Results were both significant and meaningful. The data suggest that Waiver services are effective in promoting overall family quality of life. Waiver services are making a difference in the lives of children with autism and their families. Maryland is one of a small number of states that offer a waiver program specific to individuals with Autism and has the largest enrollment of all such waivers. The Maryland program likely provides the most comprehensive services in the country; however, there are still over 3,400 families on the Registry. The purpose of the Home and Community Based Autism Waiver is to provide services in the home and community for children that met criteria for institutionalization. Those children receive services in the least restrictive environment thus meeting the intended purpose of Home and Community Bases Services Waivers. Current findings indicate a high percentage (67%) of children younger than 12 on the Registry. Early intervention for children with Autism has been found to enhance treatment outcomes (Corsello, 2005; Dunst & Bruder, 2002). Despite Maryland's comprehensive program, more children and families are in need of services.

Additional study is needed to fully understand how waiver programs are enhancing families' quality of life, health and productivity. This research is essential for development and implementation of best practices when treating children with Autism and their families. Perhaps most important is the potential to broadly influence services and policy. Research-based evidence will be used to advocate for expanded provision of services and comprehensive policies. Areas for future consideration include availability of coordinated services, such as those characteristic of the Waiver program, through third party payment as well as additional resources to expand Waiver services to more families in Maryland.

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