

Maryland Autism Services Survey

Summary of Results

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Towson University recently completed Phase I 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 (ASD; Maryland Autism Waiver) on several outcomes including: overall family quality of life, child's social and academic progress and parent employment status.

Maryland is one of few states utilizing the HCBS Waiver to provide specific home and community services for eligible children with ASDs and their families. The Autism Waiver services include intensive individual support services (IISS), therapeutic integration services, residential habilitation, respite care, accessibility adaptations including physical adaptations to the home, family training and service coordination. Although the 900 Autism Waiver slots are filled to capacity, an Autism Waiver Registry has been created for families who are interested in receiving services. In January 2009, the Maryland State Department of Education (MSDE) reported that 890 Maryland families were currently receiving Autism Waiver services and 2649 families were listed on the Autism Waiver Registry to receive services.

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, and Turnbull, 2009). The survey tool was developed by Towson University in consultation with the Maryland State Department of Education (MSDE), 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 parents of children with Autism. Separate versions of the survey were developed for families on the Registry and the Waiver. The Waiver survey included an extra section rating the family’s Waiver service coordinator and a question regarding the effect of Waiver services on caregiver employment.

Hypotheses

1. There is a positive correlation between families who receive Autism Waiver services and reported FQOL.
2. Reported FQOL will increase with the amount and duration of Autism Waiver Service that a family utilizes and participates in.
3. Waiver services will affect FQOL after accounting for the impact of other services and family income.

Methods

Using lists provided by MSDE, 723 Waiver surveys and 2298 Registry surveys were mailed with a 2-week deadline. The survey mailing included a cover letter, the survey packet and a postage-paid return envelope addressed to Towson University. 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.

On September 13, reminder postcards were sent to all Registry and Waiver families using mailing labels provided by MSDE. The postcards informed the families that the deadline had been

extended by one month. We also gave them the option of contacting Towson University to participate by phone or online.

Results

A total of 869 surveys were returned, yielding a response rate of 28.77%. Of the Waiver surveys, 229 responses (31.67%) were returned. A total of 632 (27.5%) Registry surveys were returned. Fifty-six percent of all respondents expressed interest in participating in future in-depth interviews 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.

The majority of survey respondents (> 95%) reported that they were a parent of the child with autism in their family. The respondents were mostly female (> 87%). The mean ages of Waiver and Registry respondents are 46 and 42.6 respectively. Regarding employment status, 45.6% of Waiver respondents reported being employed full time compared to 44.5% of Registry respondents. In addition, more Waiver respondents were employed part time (27%) compared to 17.9% of Registry respondents. Registry respondents were almost twice as likely to be “unemployed but looking”. Demographic data are presented in Table 2.

Descriptive data about the children reveal that approximately 80% of the children described are male and 20% 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. 70% of children on the Registry are *under* age 12 while 85% of children on the Waiver are *over* 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 majority of the children on the Waiver (75%) have been receiving services for at least four years. These data are presented in Figures 1-3.

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, this difference was found in each of the five FQOL subscales. FQOL was not correlated with the number of years on the waiver (Hypothesis 2); however, the majority of the children on the Waiver have been receiving services for several years. These data are presented in Figure 4. Regarding reported child's progress, Waiver recipients reported significantly greater social and independent living skills progress; reported academic progress did not differ between the two groups. These data are presented in Figures 5, 5a and 6.

In addition to the predicted findings, significant differences were found in service adequacy ratings for non-waiver services. Of the services respondents expressed they needed, the Waiver group reported significantly higher service adequacy ratings. These data are presented in Tables 3 and 4 and Figure 7.

Income and education level were different in the Waiver and Registry groups. Waiver recipients reported significantly higher overall income and education levels; however, the differences in family quality of life and progress remained significant even after controlling for these variables. These results support Hypothesis 3. Income and education for each group are presented in Figures 8 and 9.

A child with Autism impacts parental employment. Eighty-six percent of both Waiver and Registry respondents reported that the needs of their child with Autism affected their employment status "some" or "a lot". Only 14% reported that their employment status was not affected by their child's needs. These data are presented in Figure 10. In addition, there was a significant positive correlation between the number of years on the Waiver and employment status; that is, employment status increased with number of years on the Waiver. Thirty-eight percent of Waiver recipients reported that their employment status was "better" after receiving Waiver services. These data are presented in Figure 11.

Service coordinators were rated using 10 items from the Beach Center Family-Professional Partnership Scale, which assesses perceived satisfaction of family-professional partnerships. Service coordinator ratings and county distribution are presented in Figures 12 and 13. Overall, Waiver recipients reported satisfaction with their service coordinator (mean = 4.25 out of 5).

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 (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 as well as progress in children's social and independent living skills. Findings also indicated improved employment status for families enrolled in the waiver program. Non-waiver services such as special education, mobility services, assistance/training with self-care skills/activities of daily living and transition services were also reported as significantly more adequate for waiver recipients as for those families on the registry.

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 2500 families on the registry. Current findings indicate a high percentage (70%) of children younger than 12 on the Registry. Early intervention for children with Autism has been found to enhance treatment outcomes (Corsello, 2005; Dunst and 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 nationwide.

Table 1. Survey response rate

	Total Received	Excluded ¹	Total Sent	Response Rate	Provided follow-up info	Final included in analysis
Registry	632	5	2298	27.50%	377 (59.65%)	627
Waiver	229	1	723	31.67%	113 (49.34%)	228
Disenrolled ²	8	8	50	16.00%	5 (62.50%)	0
Total	869	14	3021	28.77%	490 (56.39%)	855

Table 2. Demographic information about survey respondents

Survey Question		Waiver	Registry	
Please tell us your relationship to the child with autism in your family. <input type="radio"/> Parent (biological, step, foster, or adoptive) <input type="radio"/> Sibling (brother or sister) <input type="radio"/> Grandparent <input type="radio"/> Foster parent <input type="radio"/> Aunt or uncle <input type="radio"/> Other non-relative (please specify below)	Relationship of survey respondent to child	Parent	95.6%	96.1%
		Grandparent	2.6%	2.3%
		Other relative	0.4%	0.9%
		Foster parent	1.3%	0.6%
What is your gender? <input type="radio"/> Male <input type="radio"/> Female	Gender of survey respondent	Male	12.3%	2.4%
		Female	87.7%	87.6%
What is your employment status? <input type="radio"/> Working <u>full-time</u> <input type="radio"/> Working <u>part-time</u> <input type="radio"/> Unemployed but looking <input type="radio"/> Not employed (e.g. stay-at-home parent)	Employment	Full Time	45.6%	44.5%
		Part Time	27.0%	17.9%
		Unemployed but looking	3.1%	6.0%
		Not employed	24.3%	31.7%
What year were you born? □ □ □ □	Age of survey respondent (mean, range = 21-77)	46	42.6	

¹ Reasons for elimination include: duplicates surveys based on matching participant contact information (3), child's age reported to be 35 (1), no useable data (2).

² Disenrolled participants will be analyzed separately.

<p>Children on the WAIVER</p> <p>For each child ages 1-21 in your household <u>currently receiving services provided by the Maryland Autism Waiver</u>, please provide the following information:</p> <p>3. Gender: <input type="radio"/> Male <input type="radio"/> Female</p> <p>Year of birth: <input style="width: 80px;" type="text"/></p> <p>Year this child began receiving Waiver services: <input style="width: 80px;" type="text"/></p>	<p>Children on the REGISTRY</p> <p>For each child in your household ages 1-21 <u>currently on the Maryland Autism Waiver Registry (waiting list)</u>, please provide the following information:</p> <p>6. Gender: <input type="radio"/> Male <input type="radio"/> Female</p> <p>Year of birth: <input style="width: 80px;" type="text"/></p> <p>Year this child joined the Registry: <input style="width: 80px;" type="text"/></p>
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Figure 1. Gender of child

	Waiver		Registry	
	<i>Freq</i>	<i>Percent</i>	<i>Freq</i>	<i>Percent</i>
Male	185	81.5%	454	81.1
Female	42	18.1%	106	18.9%
Total	227	100%	560	100%

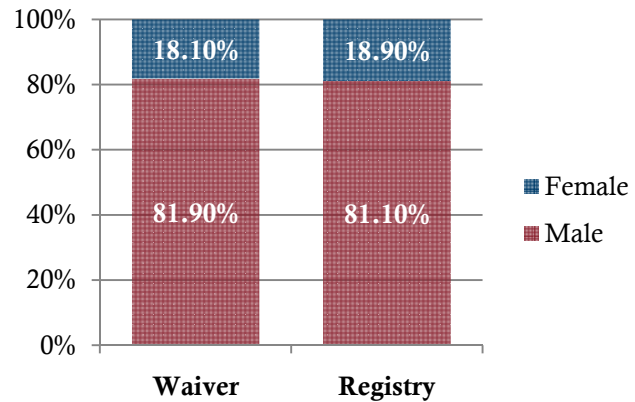


Figure 2. Age group of child

<i>Age Group</i>	Waiver		Registry	
	<i>Freq</i>	<i>Percent</i>	<i>Freq</i>	<i>Percent</i>
3-5	1	0.5%	132	23.7%
6-11	69	31.8%	264	47.4%
12-17	116	53.5%	128	23.0%
18-24	31	14.3%	33	5.9%
Total	213	100%	557	100%

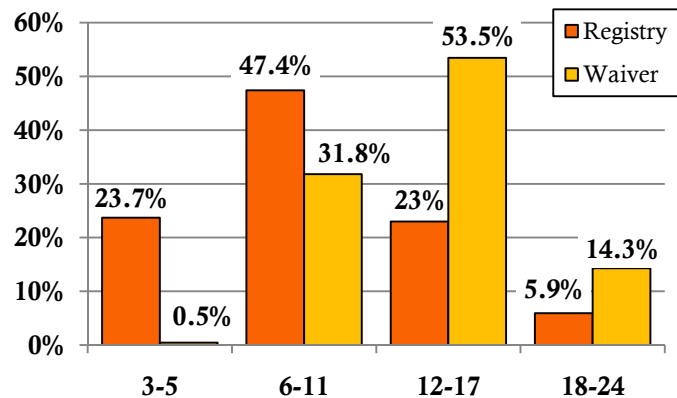
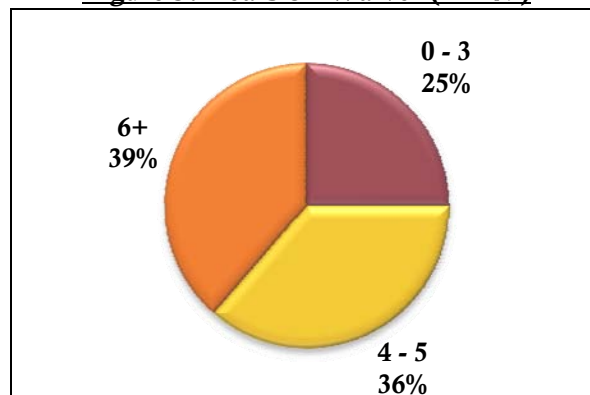


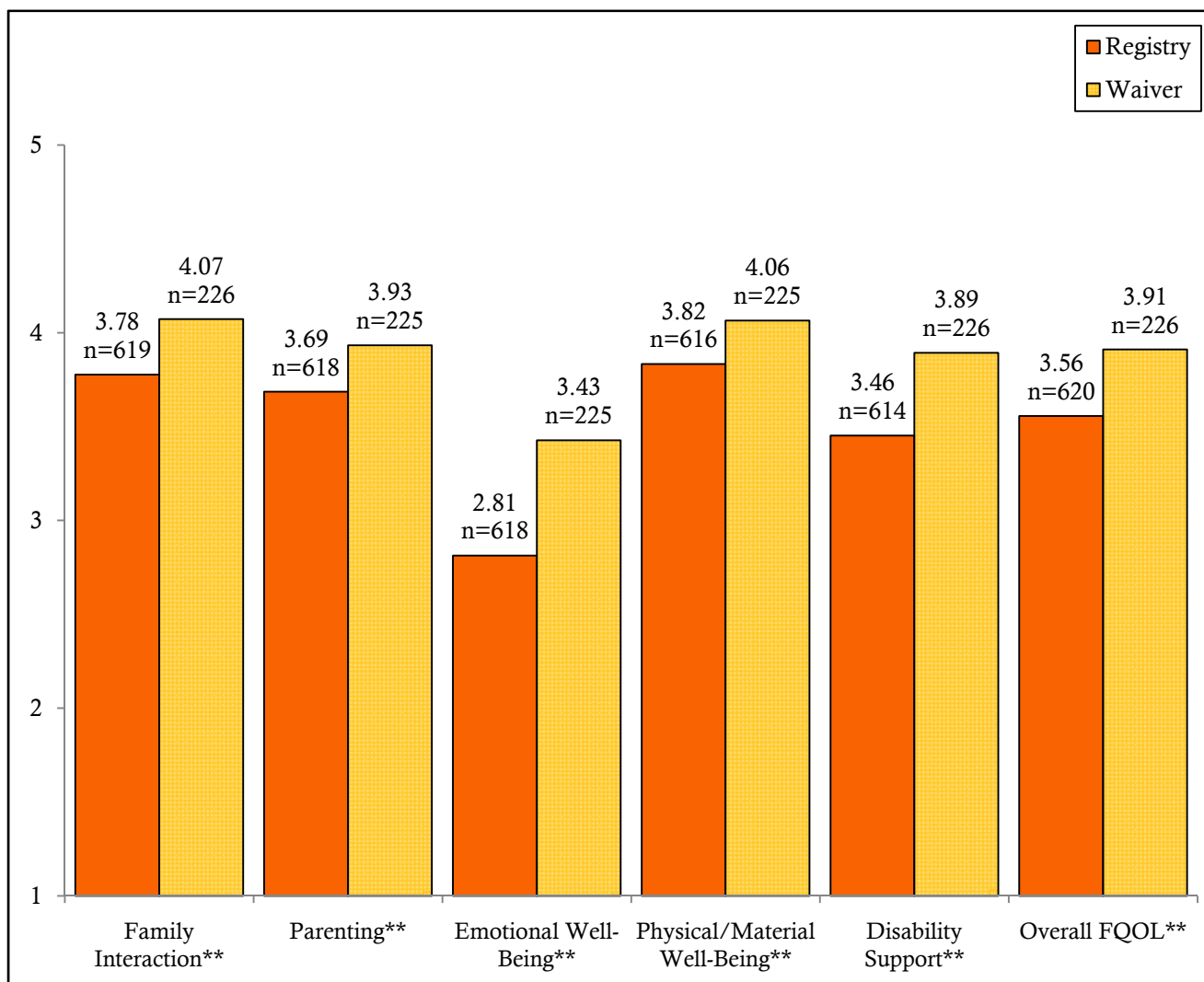
Figure 3. Years on Waiver (n=179)



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.

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

Figure 4. Family Quality of Life Overall Mean and Subscales



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

** Significant at $p < .001$

	<i>Improved</i>	<i>Stayed the same</i>	<i>Gotten worse</i>
1. In the past 12 months, has your child's academic report...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. In the past 12 months, has your child's social performance...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. In the past 12 months, have your child's independent living skills...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Registry				Waiver			
	<i>Gotten worse</i>	<i>Stayed the same</i>	<i>Improved</i>	<i>Total n</i>	<i>Gotten worse</i>	<i>Stayed the same</i>	<i>Improved</i>	<i>Total n</i>
Academic progress	9.9%	38.5%	51.6%	616	7.0%	42.7%	50.2%	227
Social progress	14.6%	40.0%	45.3%	622	8.8%	39.6%	51.5%	227
Independent living	6.6%	46.2%	47.2%	617	4.8%	41.9%	53.3%	227

Figure 5. Reported Progress (Registry)

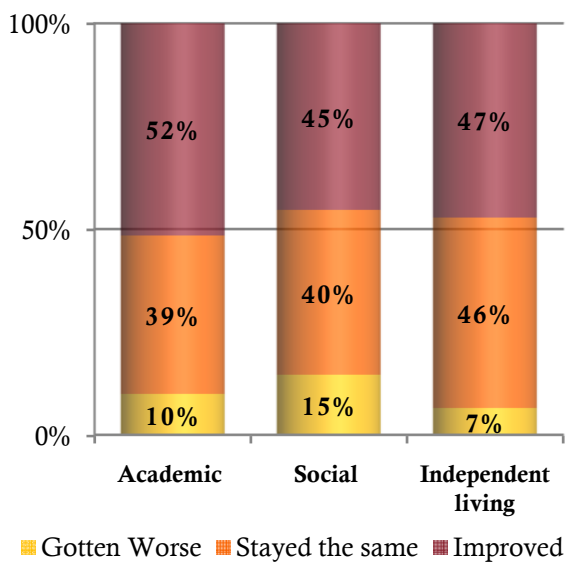


Figure 5a. Reported Progress (Waiver)

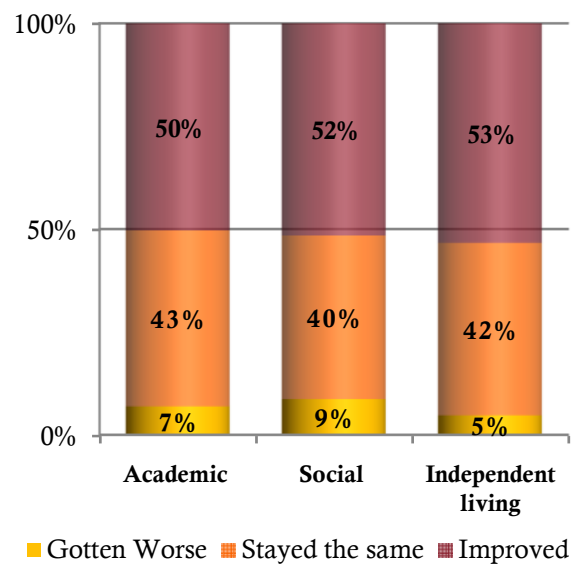
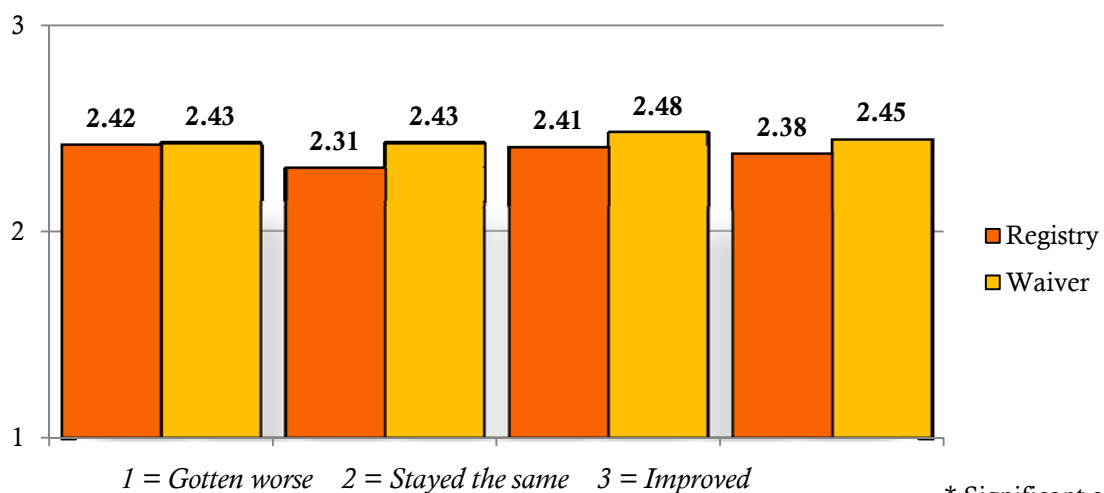


Figure 6. Mean Progress Ratings



* Significant at $p < .05$

Section 1B: Other <i>(services you may need or receive from other sources e.g. Medicaid, school, private insurance)</i>					
Please tell us about the types of other services you think your child with autism and your family need.			If yes, how much service do you receive?		
	Yes	No	None	Some, but not enough	Enough
1. Advocacy services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Health services (medical evaluations, nutrition, nursing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Table 3. Reported Need for Other Services

	Registry				Waiver			
	No		Yes		No		Yes	
	Freq	Percent	Freq	Percent	Freq	Percent	Freq	Percent
1. Advocacy	104	18.6%	456	81.4%	59	27.7%	154	72.3%
2. Health services	123	21.1%	461	78.9%	52	24.9%	157	75.1%
3. Child care	176	30.0%	411	70.0%	86	41.3%	122	58.7%
4. Hearing services	443	81.9%	98	18.1%	153	75.7%	49	24.3%
5. Vision services	380	69.0%	171	31.0%	129	63.9%	73	36.1%
6. Occupational therapy	87	14.8%	501	85.2%	42	19.8%	170	80.2%
7. Physical therapy	289	52.3%	264	47.7%	109	53.7%	94	46.3%
8. Speech and/or language	36	6.0%	568	94.0%	16	7.2%	206	92.8%
9. Psychological services	143	25.1%	426	74.9%	63	30.3%	145	69.7%
10. Assistance/training w/self-care skills/ADLs	149	25.5%	435	74.5%	21	9.9%	192	90.1%
11. Special education	32	5.3%	568	94.7%	8	3.7%	211	96.3%
12. Info about child's disability	189	33.0%	384	67.0%	80	37.7%	132	62.3%
13. Info about where to get services	69	11.5%	530	88.3%	45	21.1%	168	78.9%
14. Info about legal rights	96	16.4%	490	83.6%	38	17.8%	175	82.2%
15. Parent support groups	112	19.0%	479	81.0%	54	25.8%	155	74.2%
16. Sibling support groups	222	39.1%	346	60.9%	93	45.1%	113	54.9%
17. Transportation	283	49.2%	292	50.8%	87	41.8%	121	58.2%
18. Mobility services	427	79.1%	113	20.9%	166	84.3%	31	15.7%
19. Transition services	208	37.3%	350	62.7%	72	35.0%	134	65.0%
20. Counseling services	175	30.5%	399	69.5%	96	47.1%	108	52.9%

Section 1B: Other
(services you may need or receive from other sources e.g. Medicaid, school, private insurance)

Please tell us about the types of other services you think your child with autism and your family need.

If yes, how much service do you receive?

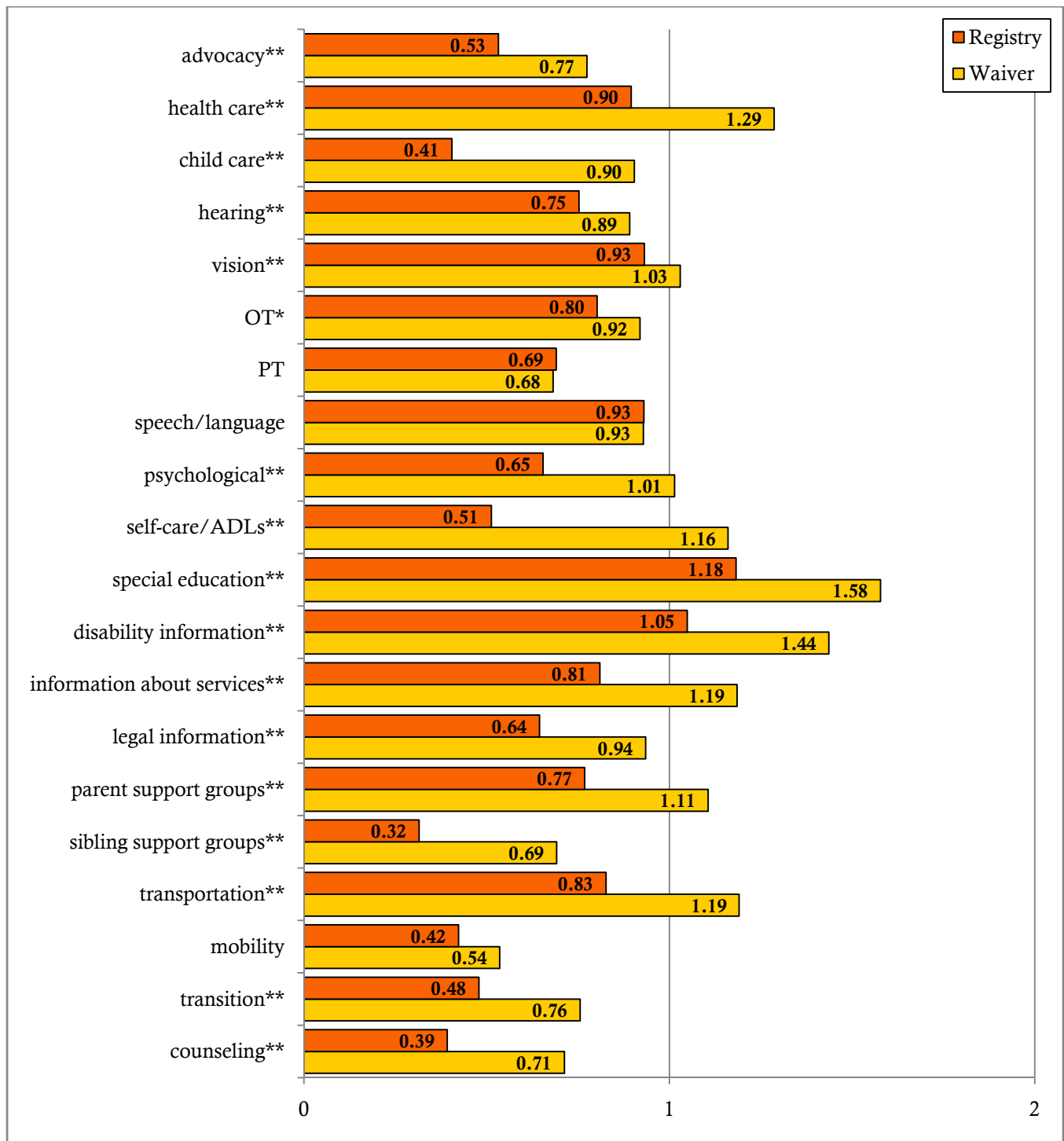
	Yes	No	If yes, how much service do you receive?		
			None	Some, but not enough	Enough
1. Advocacy services	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
2. Health services (medical evaluations, nutrition, nursing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Table 4. Reported Adequacy of Other Services

Service Adequacy reported by participants who answered “yes” to Part 1

	Registry				Waiver			
	None	Some but not enough	Enough	Total n	None	Some but not enough	Enough	Total n
1. Advocacy	56.2%	34.6%	9.4%	434	43.0%	36.6%	20.4%	154
2. Health services	30.9%	48.6%	20.5%	440	16.7%	38.0%	45.3%	150
3. Child care	65.8%	27.8%	6.3%	395	33.0%	43.5%	23.5%	115
4. Hearing services	46.2%	32.3%	21.5%	93	45.7%	19.6%	34.8%	46
5. Vision services	41.0%	24.8%	34.2%	161	37.3%	22.4%	40.3%	67
6. Occupational therapy	29.0%	61.8%	9.2%	476	25.3%	57.4%	17.3%	162
7. Physical therapy	41.7%	47.6%	10.7%	252	44.3%	43.2%	12.5%	88
8. Speech and/or language	16.5%	74.0%	9.5%	546	22.8%	61.4%	15.7%	197
9. Psychological services	45.7%	43.1%	11.2%	411	32.1%	34.3%	33.6%	140
10. Assistance/training w/self-care skills/ADLs	54.9%	39.0%	6.2%	421	15.5%	52.9%	31.6%	187
11. Special education	9.7%	62.4%	27.9%	537	2.9%	36.4%	60.7%	206
12. Info about child’s disability	18.0%	59.1%	22.9%	367	10.3%	35.7%	54.0%	126
13. Info about where to get services	27.3%	64.5%	8.2%	510	11.7%	58.0%	30.2%	162
14. Info about legal rights	44.0%	47.6%	8.5%	473	33.5%	39.4%	27.1%	170
15. Parent support groups	41.8%	39.6%	18.6%	462	23.2%	43.0%	33.8%	151
16. Sibling support groups	74.2%	20.0%	5.8%	330	48.6%	33.6%	17.8%	107
17. Transportation	41.2%	35.0%	23.8%	277	25.5%	30.0%	44.5%	110
18. Mobility services	65.4%	26.9%	7.7%	104	53.6%	39.3%	7.1%	28
19. Transition services	59.9%	32.3%	7.8%	334	37.8%	48.8%	13.4%	127
20. Counseling services	68.2%	24.5%	7.4%	380	46.5%	35.6%	17.8%	101

Figure 7. Mean Service Adequacy Ratings

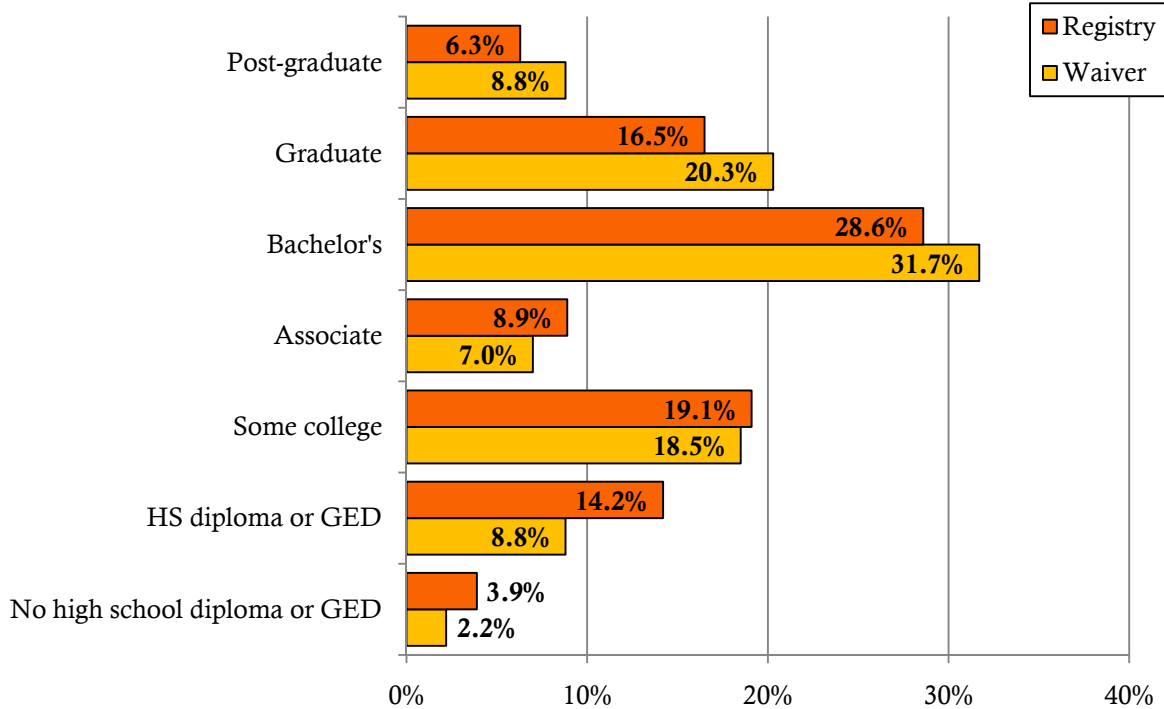


0 = None 1 = Some but not enough 2 = Enough

* Significant at $p < .05$
 ** Significant at $p < .01$

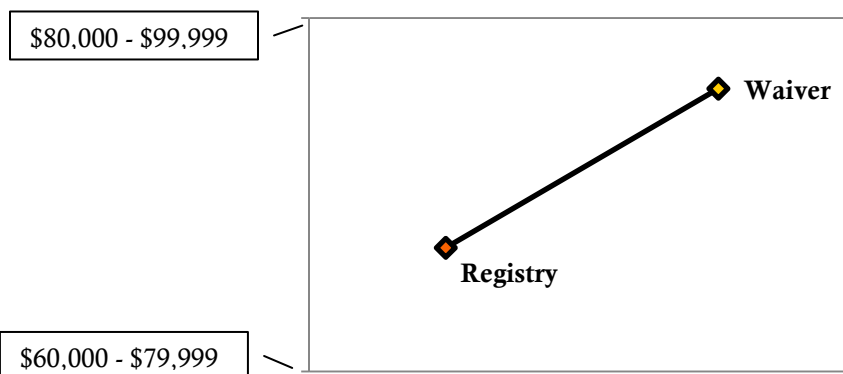
5. What is the highest level of education that you have completed? (please select ONLY one)
- No high school diploma or GED
 - High school graduate (diploma or GED)
 - Some college or post-high school, but no degree
 - Associate degree (AA, AS, etc.)
 - Bachelor's degree (BA, BS, etc.)
 - Graduate degree
 - Post-graduate degree
 - Other (please specify below)

Figure 8. Level of Education



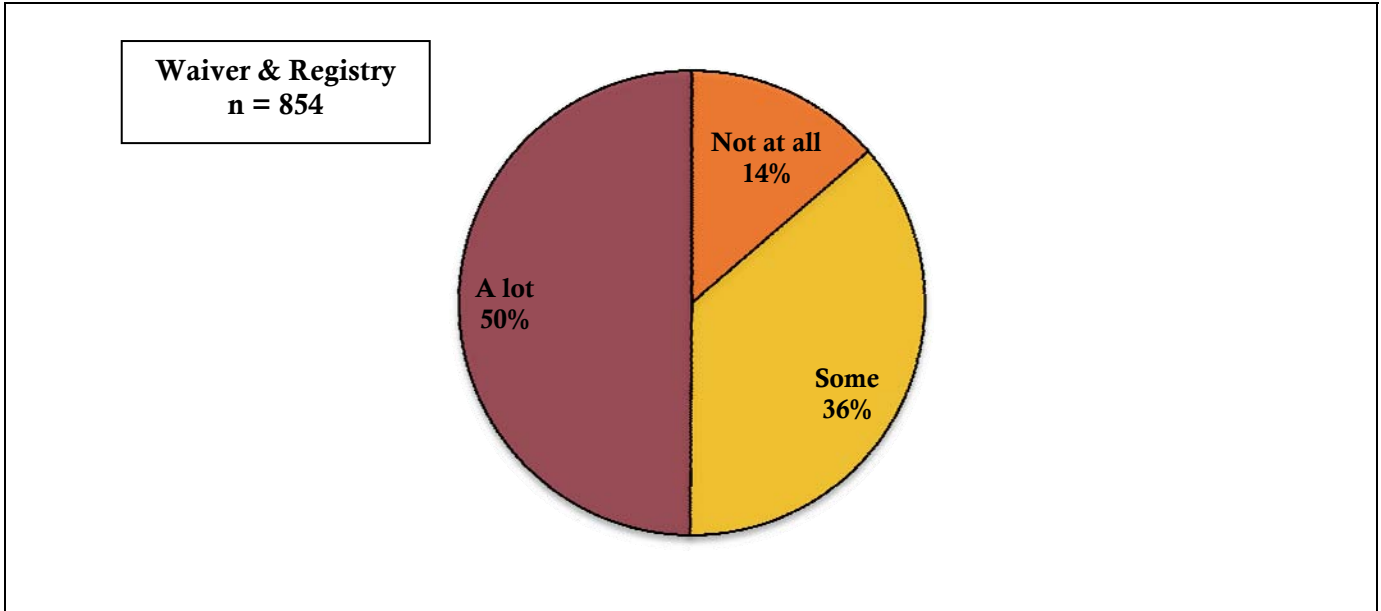
13. What was your total household income from all sources for the past year? Be sure to include income from all sources (such as family subsidy or child support).
- Less than \$20,000
 - \$20,000 to \$39,999
 - \$40,000 to \$59,999
 - \$60,000 to \$79,999
 - \$80,000 to \$99,999
 - \$100,000 to \$119,999
 - \$120,000 to \$139,000
 - \$140,000 to \$159,999
 - Over \$160,000

Figure 9. Reported Household Income (Mean)



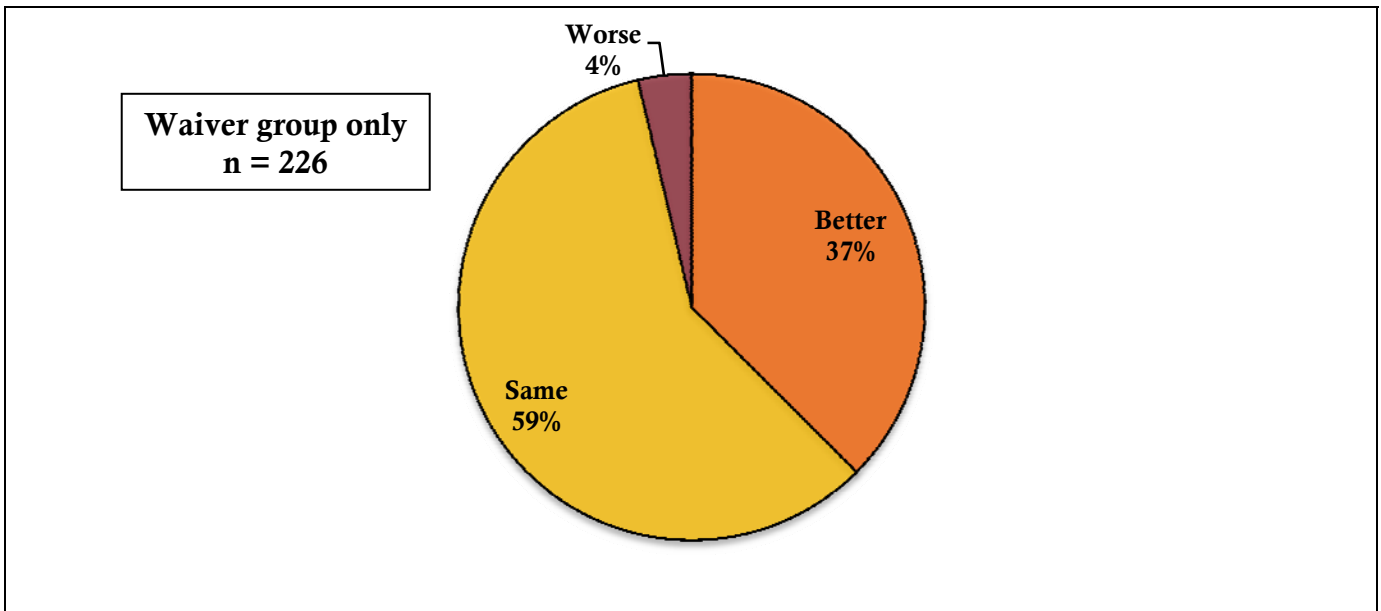
7. To what extent do the needs of your child(ren) with autism affect your employment status?
- Not at all*
 - Some*
 - A lot*

Figure 10. Effect of child with Autism on caregiver employment



8. Since you began receiving waiver services, is your employment status...
- Better*
 - The same*
 - Worse*

Figure 11. Employment since receiving Waiver services



Next, please answer the following questions about the service coordinator who works with your family.

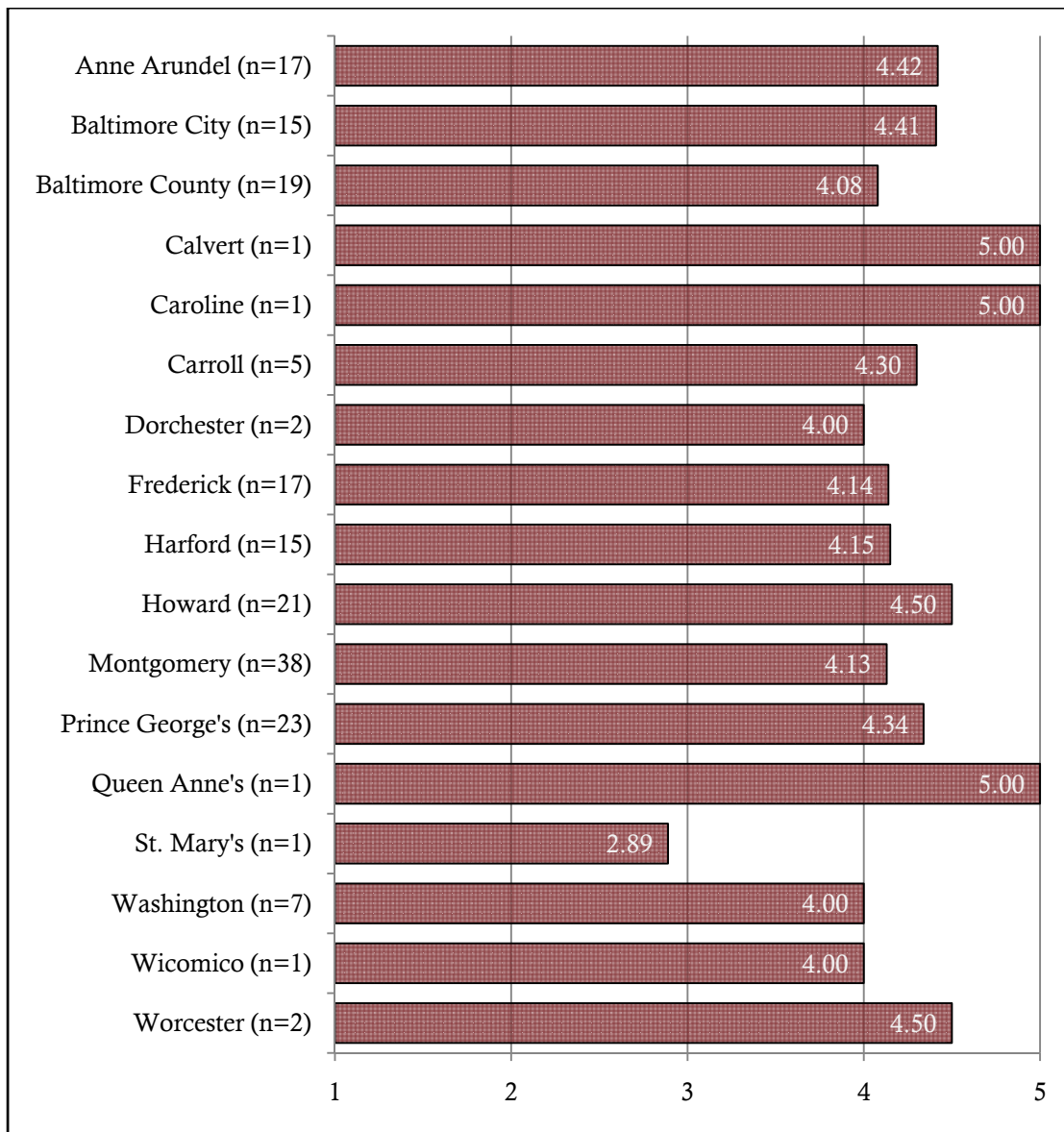
Please specify the county where you live: _____

How satisfied are you that your service coordinator...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
1. Values your opinion about your child's needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Is honest, even when there is bad news to give.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Is available when you need them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall mean for service coordinator: **4.26** (n = 192)

Figure 12. Mean Service Coordinator Ratings by County (n=186)*

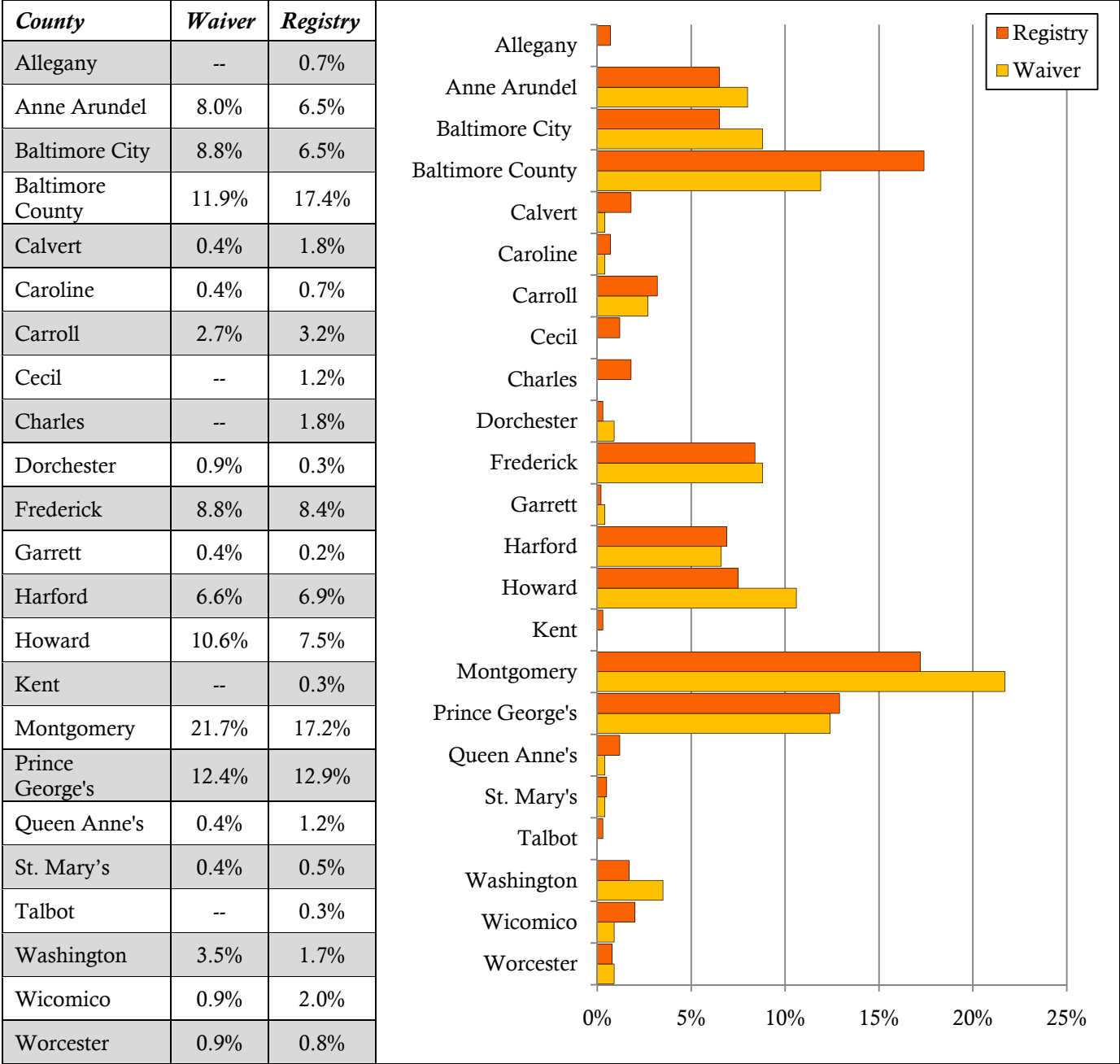
**Not all participants reported county for service coordinator*



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

11. County where your child receives services:
- Allegany County
 - Anne Arundel County
 - Baltimore City
 - Baltimore County
 - Calvert County
 - Caroline County
 - Carroll County
 - Cecil County
 - Charles County
 - Dorchester County
 - Frederick County
 - Garrett County
 - Harford County
 - Howard County
 - Kent County
 - Montgomery County
 - Prince George's County
 - Queen Anne's County
 - St. Mary's County
 - Somerset County
 - Talbot County
 - Washington County
 - Wicomico County
 - Worcester County

Figure 13. County where child receives services



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