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If you would like to learn more about our research, please visit our website: www.towson.edu/fmst/autismresearch

If you have survey content-related questions, please contact either Beth Merryman, Ph.D. at bmerryman@towson.edu or Nancy Miller, Ph.D. at nanmille@umbc.edu.

If you would like to receive a copy of our findings, please check the box below.

Instructions

All of the information you provide in this survey is confidential. Your name will not be attached to any of the information. Please answer as many questions as possible but feel free to skip questions you are unable to answer. It will take you approximately 20 minutes to complete this survey.

Answering Questions

- You may use a pencil or pen to fill in your answers.
- For open-ended answers, please write as legibly as possible and stay within the boundaries of the answer box.
- For multiple choice or grid questions, please place a check in the appropriate box to indicate your response.



• If you change any answers, please erase or cross out any previous answers.

<u>Before proceeding</u>, please indicate that you agree to participate in this survey by checking the box below.

I agree to participate in this survey.

Section 1: General Information

In this brief section, we ask some basic questions about you. Your responses will be confidential but this information will enable us to contact you if we have any questions.

1.	l itle:			
	Mr.	Mrs.	Ms.	🗌 Dr.
2.	Last Name:			
3.	First Name:			
4.	Position:			
5.	Email Address:			
6.	State:			

Section 2: Facilitators and Issues

In this section, we ask questions related to the status of 1915(c) waivers for children and youth with autism in your state. Depending on how you answer Question 1 below, you will be directed to a series of applicable questions in either Section 2A, 2B, 2C or 2D.

1. Does your state currently have a 1915(c) waiver for children and youth with autism? (Please choose one response.)

Yes, we have a 1915(c) waiver for children and youth with autism. (If you check this box, <u>please go to</u> <u>Section 2A beginning on page 5</u>.)

No, we used to have a 1915(c) waiver for children and youth with autism. **(If you check this box, <u>please</u>** skip to Section 2B beginning on page 10.)

No, we would like to have a 1915(c) waiver for children and youth with autism. (If you check this box, please skip to Section 2C beginning on page 12.)

No, we don't feel we need a 1915(c) waiver for children and youth with autism at this time. (If you check this box, please skip to Section 2D beginning on page 15.)

Section 2A

Please complete Section 2A <u>only</u> if you checked "Yes, we have a 1915(c) waiver for children and youth with autism" in response to Section 2, Question 1.

1. Please indicate how influential the following factors were in your state's adoption of a 1915(c) waiver for children and youth with autism. (Please choose one response for each factor.)

	Extremely	Very	Somewhat	Slightly	Not at all
Governor					
State legislators					
Researchers					
State agencies					
Autism Speaks					
Other advocacy group(s)					
Parents or family members					
Increased prevalence of autism					
Research/community expertise ent	ity				
Task force or blue ribbon panel					
Prior experience with 1915(c) waive	ers				
Availability of an evidence-base for autism specific waivers					
Insurance mandate proposal					
Other					

Please identify and describe the "Other" influential factor(s), if checked above.

2. Of all the factors which were influential in your state, please identify and rank the top two entities or factors that helped your state the most in adopting a 1915(c) waiver for children and youth with autism.

<u>Section</u>	on 2A continued				
3.	Please indicate the pri amount of waiver serv autism. (Please choos	ices included i	in your state's 1915		
	Essential) High priority	Medium priority	Low priority	□ Not a priority
4.	What ages does your	state serve in i	ts 1915(c) waiver fo	or children and youth	with autism?
5.	Why did your state ele youth with autism?	ect to focus on	this age group in it	s 1915(c) waiver for o	children and
6.	How many children do	bes your state's	s 1915(c) autism wa	iver serve?	
7.	Is your state consider waiver for children an			dren with autism serv	ved by its 1915(c)
	Yes)	
8.	Does your state's 191 cap?	5(c) waiver for	children and youth	with autism have a s	ervice dollar
	Yes)	
	If yes, what is the doll	ar cap?			
9.	Does your state's 1915 limit?	5(c) waiver for	children and youth	with autism have a t	ime-in-waiver
	Yes)	
	If yes, what is the limit	1?			

Section 2A continued

- 10. What eligibility criteria with regard to diagnosis and/or functional limitation does your state use for its 1915(c) waiver for children and youth with autism?
- 11. How did your state decide which services to offer through the 1915(c) autism waiver for children and youth?
- 12. In designing your waiver, please indicate how much your state struggled with the following issues related to its 1915(c) waiver for children and youth autism. (Please choose one response for each issue.)

	Very difficult	Difficult	Neutral	Easy	Very easy
Determining which children and families would be eligible (e.g., ages and diagnoses)					
Children aging-off the waiver shortly after receiving a waiver slot					
Establishing a time-in-waiver limit					
Establishing the number of children to be served					
Determining waiver services					
Establishing service authorization needs					
Determining service reimbursement rates					
Determining whether to deem or disregard parental income to determine eligibility	e 🗌				

If your state did deem, how much?

Section 2A continued

13. Please indicate how much difficulty your state experiences with the following implementation and maintenance aspects of its 1915(c) waiver for children and youth with autism. (Please choose one response for each aspect.)

	Very difficult	Difficult	Neutral	Easy	Very easy
Number of trained/certified providers					
Geographic location or distribution of trained/certified providers					
Inability to maintain full-time employment for trained providers					
Identifying and contracting with service providers					
Medicaid provider enrollment requirements					
Parental hesitancy (e.g., giving up state funded services)					
Limited time to create waiver service structure					
Issues with policy and development of procedures and training of staff					
Limited funding availability					
Bureaucratic restrictions regarding waiver authorization (e.g., number of target groups permitted)					
Tension between departments/units or within legislature					
Other issues					

Please identify and describe the "Other issues," if checked above.

14. Of the implementation and maintenance issues, please identify and rank the top two your state encounters with its 1915(c) waiver for children with autism.

Section 2A continued

- 15. What are the strengths and weaknesses of providing services to children and youth with autism through an autism specific 1915(c) waiver compared to a different 1915(c) waiver (e.g., general intellectual and developmental disabilities waiver, children's waiver) and relative to the optional rehabilitation benefit?
- 16. In addition to your 1915(c) waiver for children and youth with autism, is your state thinking about offering the new Health Home State Plan Amendment for children and youth with autism?

] Yes

\square	No

No

17. In addition to your 1915(c) waiver for children and youth with autism, is your state thinking of offering a 1915(j) waiver for children and youth with autism?

	Yes
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Section 2B

Please complete Section 2B <u>only</u> if you checked "No, we used to have a 1915(c) waiver for children and youth with autism" in response to Section 2, Question 1.

1. Please indicate how influential the following factors were in your state's adoption of a 1915(c) waiver for children and youth with autism. (Please choose one response for each factor.)

	Extremely	Very	Somewhat	Slightly	Not at all
Governor					
State legislators					
Researchers					
State agencies					
Autism Speaks					
Other advocacy group(s)					
Parents or family members					
Increased prevalence of autisi	m 🗌				
Research/community expertis	e entity				
Task force or blue ribbon pane	el 🗌				
Prior experience with 1915(c)	waivers				
Availability of an evidence-bas autism specific waivers	se for				
Insurance mandate proposal					
Other					

Please identify and describe the "Other" influential factor(s), if checked above.

2. Of all the factors which were influential in your state, please identify and rank the top two entities or factors that helped your state the most in adopting a 1915(c) waiver for children and youth with autism.

Section 2B continued

3. Please indicate the priority level given to research evidence when finalizing the type and amount of waiver services included in your state's 1915(c) waiver for children and youth with autism. (Please choose one response.)

|--|

High priority

) Medium priority

Low priority

Not a priority

- 4. How did your state decide which services to offer through the 1915(c) waiver for children and youth?
- 5. Why did your state elect to no longer serve children and youth with autism through a 1915(c) children and youth autism waiver?
- 6. What are the strengths and weaknesses of providing services to children and youth with autism through an autism specific 1915(c) waiver compared to a different 1915(c) waiver (e.g., general intellectual and developmental disabilities waiver, children's waiver) and relative to the optional rehabilitation benefit?

Section 2C

Please complete Section 2C <u>only</u> if you checked "No, we would like to have a 1915(c) waiver for children and youth with autism" in response to Section 2, Question 1.

1. Please indicate how much the following factors explain why your state has not adopted a 1915(c) waiver for children and youth with autism. (Please choose one response for each factor.)

	Completely	Mostly	Somewhat	Not at all	
Children and youth with autism are served well enough under other waivers					
Insufficient funding availability					
Lack of legislative support					
Lack of trained/certified providers					
Provider resistance					
Insufficient evidence base for autism specific services					
Lack of advocacy support					
Other					

Please identify and describe the "Other" factor(s), if checked above.

2. Of the factors mentioned in the above grid, please identify and rank the top two challenges in your state's pursuit of adoption of a 1915(c) waiver for children and youth with autism.

Section 2C continued

3. Please indicate how influential the following factors would be in your state's pursuit of adoption of a 1915(c) waiver for children and youth with autism. (Please choose one response for each factor.)

	Extremely	Very	Somewhat	Slightly	Not at all
Support from the governor					
Support from state legislators					
Support from state agencies					
Support from Autism Speaks					
Support from other advocacy group(s)					
Support from parents or family members					
Increased prevalence of autism					
Support from research/community expertise entities					
Support from task forces or blue ribbor panel					
Prior experience with 1915(c) waivers					
Availability of an evidence base for autism specific services					
Private insurance mandate proposal or law					
Other					

Please identify and describe the "Other" factor(s), if checked above.

4. Of the factors mentioned in the above grid, please identify and rank the top two factors that would help your state adopt a 1915(c) waiver for children and youth with autism.

Section 2C continued

5. What are the strengths and weaknesses of providing services to children and youth with autism through an autism specific 1915(c) waiver compared to a different 1915(c) waiver (e.g., general intellectual and developmental disabilities waiver, children's waiver) and relative to the optional rehabilitation benefit?

Section 2D

Please complete Section 2D <u>only</u> if you checked "No, we don't feel we need a 1915(c) waiver for children and youth with autism at this time" in response to Section 2, Question 1.

1. Please indicate how much the following factors explain why your state has not adopted a 1915(c) waiver for children and youth with autism. (Please choose one response for each factor.)

	Completely	Mostly	Somewhat	Not at all	
Children and youth with autism are served well enough under other waivers					
Insufficient funding availability					
Lack of legislative support					
Lack of trained/certified providers					
Provider resistance					
Insufficient evidence base of autism specific services					
Lack of advocacy support					
Other					

Please identify and describe the "Other" factor(s), if checked above.

2. Of the factors mentioned in the above grid, please identify and rank the top two challenges in your state's pursuit of adoption of a 1915(c) waiver for children and youth with autism.

Section 2D continued

3. What are the strengths and weaknesses of providing services to children and youth with autism through an autism specific 1915(c) waiver compared to a different 1915(c) waiver (e.g., general intellectual and developmental disabilities waiver, children's waiver) and relative to the optional rehabilitation benefit?

Section 3: Provision of Services

This is the final section of the survey. Please respond to the questions regardless of whether or not your state has adopted a 1915(c) waiver for children and youth with autism.

1. Please select which services your state provides to children (birth to age 13) with autism through the different options listed below:

	Autism 1915(c)	Rehab Benefit	ID/DD 1915(c)	Childrens 1915(c)	Other 1915(c)	1115	1915(j) SPA	Other
Screening assessment								
Functional assessment								
Clinical assessment								
Intervention and treatment								
Behavioral support analysis (ABA)- based treatment								
Mental health services								
Personal assistance services								
Independent living skills acquisition								
Financial management services								
Habilitation, community integration								
Speech therapy								
Occupational therapy								
Physical therapy								
Parent support and training								
Respite								
Transportation								
Environmental accessibility adaptations/ vehicle modifications								
Assistive technology services								
Self-directed service delivery models								
Care/Service coordination								
Case management								
Other services								

Section 3 continued

Please identify and describe the "Other services" your state provides.

Please describe the "Other" options your state uses for providing services.

Section 3 continued

2. Please select which services your state provides to transition age youth (ages 14-21) with autism through the different options listed below:

	Autism 1915(c)	Rehab Benefit	ID/DD 1915(c)	Childrens 1915(c)	Other 1915(c)	1115	1915(j) SPA	1915(a)	Other
Screening assessment	\Box	\Box	\Box	\Box	\Box	\Box	\Box	\Box	\square
Functional assessment									
Clinical assessment						\Box			
Intervention and treatment									
Behavioral support analysis (ABA)- based treatment			\Box			\Box			
Supported housing									
Supported employment									
Mental health services									
Personal assistance services						\Box			
Independent living skills acquisition									
Financial management services									
Habilitation, community integration									
Speech therapy									
Occupational therapy									
Physical therapy									
Parent support and training									
Respite									
Transportation									
Environmental accessibility adaptations/ vehicle modifications									
Assistive technology services									
Self-directed service delivery models									
Care/Service coordination									
Case management									
Other services									

Section 3 continued

Please identify and describe the "Other services" your state provides.

Please describe the "Other" options your state uses for providing services.

3. We are preparing a survey which will be administered to families in Maryland who have children or youth with an autism spectrum disorder. We hope to gain a better understanding of service utilization and family quality of life. Would you be willing to review and/or pilot this survey in your state?

] Yes

] No

Thank You for completing our survey.