

# Parent Education of Stuttering During a Summer Program for Children: Student Perspectives

Craig Coleman, Mary Weidner, Jessica Stevens, Katie Hensel, Jamie Mulraney, & Natalie Saber

Marshall University



## Background

Stuttering U. is a summer program at Marshall University for children who stutter and their families. During the three-day program, children and parents have specific programming designed to improve their knowledge of, and reactions to, stuttering. The camp has operated for 5 summers, drawing campers and parents from West Virginia, Pennsylvania, Kentucky, Ohio, and Maryland. Ongoing research has shown the positive impact of the camp through improved parent and child knowledge and acceptance of stuttering (Weidner, Coleman, & Damron, 2014; Coleman & Weidner, 2014).

In addition to serving the needs of the children and their parents, the camp provides an opportunity for graduate-level students at Marshall University to provide supervised therapy for the children as well as to lead stuttering education seminars for the parents. Two graduate students (under the guidance and supervision of the first and second author) plan and implement the parent programming. There are four parent-only sessions throughout the camp, lasting 60 to 90 min each. Session topics address parental knowledge of stuttering (e.g., causes of stuttering, treatment options for stuttering, etc.), social ramifications of stuttering (e.g., teasing and bullying), and school-based issues (e.g., appropriate goals, IEPs, etc.). In addition, parents complete various surveys, such as the Community Centered Stuttering Assessment-Parent (CCSA-P), to express their perceptions of the impact of stuttering on their children. Their responses on the surveys often lead to pertinent and meaningful discussions about reactions toward their children's stuttering, their fears and anxieties, and comparing perspectives between spouses (see Image 2).

# Purpose

Previous research has examined parent satisfaction and knowledge levels before and after camp, however, no research has been carried out to assess student experiences with the training opportunities that the camp provides. The purpose of this poster presentation is to highlight narratives from the four graduate students who have been involved in running the parent sessions over the past two years.



Image 1. Parents of children who stutter participate in a discussion at Stuttering U. July, 2018

## Student 1 (2017)

By creating presentations and carrying out the parent sessions, 1 learned how to truly take on the counseling aspect of stuttering therapy in real time. The parents 1 worked with were experiencing raw emotion and needed someone to talk to. 1 learned how to balance that analytical side of being a presenter with the sympathetic side of being a listener. Stuttering therapy is such a different type of therapy in the speech world, and 1 believe being a speech-language pathologist who has worked with persons who stutter over the last few years has made me a better clinician, and more importantly, a better person.

#### Student 3 (2018)

Being able to lead the parent sessions this year really helped me identify how programs like Stuttering U. are so important for children who stutter and their families. I learned so much from hearing the parents tell stories about each of their children's journeys, whether it was their first year at Stuttering U. or this was one of many. Each parent shared how their child learned how to advocate for themselves and not feel ashamed of stuttering, which is one of our goals at Stuttering U. I went into this experience thinking I would teach them everything about stuttering, but in turn, they taught me how much our program has helped their children become empowered by their differences.

General Information						General Information						The support of the support	Never	Rarely	Sometimes	Frequently	Alwaye	
Child's name	i.					Child's name	General	mormano			The second second	How often does the child experience					\( \text{\tinx}\text{\ticl{\tint{\texi\text{\tetx}\text{\text{\text{\texi}\text{\text{\texi}}\text{\text{\text{\text{\texi}\text{\texitt{\text{\texi}}\tint{\text{\texitt{\text{\texi}\texitt{\texi}}}\texittt{\text{\texit{\texit{\t	
Today's date	7/606/18					Today's date	€ 7-26-18				teasing or bullying? Describe (i.e., is it related to							
Your name / Relationship to Child	(Mother)					Your name / Relationship to Child	Father				stuttering?): How often can your child speak	Not	40 W/	Knowled	lge			
		~		)		Tour name / Relationship to Child			Lather			freely (stuttering does not stop him/her from communicating) at	0	•	0		0	
Informat	tion about	the child's	stuttering			Informat	tion about	the child's	stuttering	XIII II		home?						
	Never	Rarely	Sometimes	Frequently	Always		Never	Rarely	Sometimes	Frequently	A	Describe:	At hop	re we	always !	try to.		
Overall, how often does your child stutter?	٥	٥	2	٥		Overall, how often does your child stutter?			Sometimes	Prequently	Always	Rate your child's overall confidence level related to speaking?	None	Low	Average	High	Very High	
Describe the severity:	Mild					Describe the severity:	Mills				Describe:  To what extent do you think stuttering will interfere with your	A great deal	A lot	Some	∟hi≲op Little	Not at all		
How often does your child exhibit physical tension (e.g., tense muscles) when s/he stutters?	0	0	0		0	How often does your child exhibit physical tension (e.g., tense muscles) when s/he stutters?	۵	0	₫		0	child's future goals/life overall?  Describe:	Q	ding o	n his d	noiceof	rof <b>e</b> ssi	
Describe:	facial tension					Describe:	Shaking of hands / Leaning Body Back				Is there anything else that would be helpful for use to know about your child's stuttering?		9		,			
How often does your child exhibit secondary behaviors (e.g., hand tapping, head nodding, eye blinking, etc.) when s/he stutters?	٥		1	0	a	How often does your child exhibit secondary behaviors (e.g., hand tapping, head nodding, eye blinking, etc.) when s/he stutters?	0	0	o/		0	cant s stattering:	Never	Rarely				
Describe:	Shahes hands					Describe:	Sane as Albave				How often does the child experience teasing or bullying?		Karely	Sometimes	Frequent	ly Alwa		
	Never	Rarely	Sometimes	Frequently	Always		Never	Rarely	Sometimes	Frequently	Always	Describe (i.e., is it related to stuttering?):	No++	Not that I'm aware of				
How often does stuttering interfere with your child's ability to communicate at home?	٥	4			, a .	How often does stuttering interfere with your child's ability to communicate at home?	0	œ	0	0		How often can your child speak freely (stuttering does not stop him/her from communicating) at home?	0	٥	<b>12</b>	0		
			-	1			-				Describe:	Stuttering comes in waves						
Describe:	Talked over					Describe:	Sonotines opto stipped over in a conversation				Rate your child's overall confidence level related to speaking?			Average	High	Ver Hig		
How often does stuttering interfere with your child's ability to communicate with peers?		9	0		0	How often does stuttering interfere with your child's ability to communicate with peers?	٥	o√			- 0	Describe:  To what extent do you think	Mainh A great		table with	5 peakin		
						conununicate with peers?						stuttering will interfere with your child's future goals/life overall?	deal				Not at	
Describe:	Podeivats					Describe:	Same as Above				Describe:	He is vary confident in his self						
How often does stuttering interfere with your child's academic performance or class participation?	9	0	0	۵	a	How often does stuttering interfere with your child's academic performance or class participation?	۵	ď		o	٥	Is there anything else that would be helpful for use to know about your child's stuttering?	The helpsd	The Stuffering U comps has definely helped make Joel a more confident person				
Describe:	No problems so far						Same as Alone						1 1					

Image 2. CCSA-Parent completed by the mother and father of a 13-year old adolescent

## Discussion

For the four students who participated in planning and running the parent track of the program, these narratives highlight the impact of the experience on their education, not just from a stuttering standpoint, but from a counseling standpoint as well. In addition, the experience helped them to be able to discuss possible negative reactions to stuttering with parents and children.

The Stuttering U. summer program has also resulted in a growing stuttering clinic at the Marshall Speech Language and Hearing Center. This leads to more clinical opportunities for students during the academic year, as well as opportunities for stuttering research.

## Student 2 (2017)

Student Narratives

This experience significantly impacted my clinical, educational, and professional career not only as a student, but as a professional. Being that bridge between what current research/clinical judgement says and the compassion that parents needed during such a trialing time intensified my sense of empathy and understanding that 1 could never gain from a textbook or sitting in lecture.

### Student 4 (2018)

The Stuttering U. parent sessions were both enlightening and inspirational. It shed light on the fact that parents are also students of stuttering, striving to learn as much as they can about the nature of their child's stuttering and how to best support them. Their personal accounts also shed light on the fact that many school personnel still lack sufficient education on stuttering and may foster policies or approaches that are maladaptive for children who stutter. In these cases, it is vital that parents and SLPs act as advocates on behalf of children who stutter to ensure that both the children and their teachers have realistic expectations regarding fluency. Lastly, the parent sessions highlighted a concern for not only how school staff can potentially approach stuttering, but how their children's peers react to stuttering. Many parents discussed that, while their children's fluent peers may not actively mean to be malicious, their limited understanding of stuttering can facilitate some negative attitudes and negative reactions toward stuttering. This further reveals the need for advocates in the stuttering community that can help educate others about stuttering in an effort to normalize it across environments and support positive attitudes about stuttering.



Image 3. Campers and student volunteers at Stuttering U. July, 2018

## References

Coleman, C. & Weidner, M. (November, 2014) Stuttering U.: A summer camp for children who stutter and their families. Presented at the annual convention of the American Speech, Language, and Hearing Association, Orlando, FL.

Weidner, Coleman, & Damron. (October, 2014). Stuttering U: The first annual camp for SLPs, children who stutter, families, and students. Presented at the International Stuttering Awareness Day (ISAD) Annual Online Conference.

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