

## Background

Following a child's diagnosis of autism spectrum disorder (ASD), higher levels of parent satisfaction with the diagnostic experience are associated with:

- 1) Diagnosis at a younger age.<sup>1, 2, 3</sup>
- 2) Receiving more information following diagnosis.<sup>1</sup>
- 3) Parents expressing a positive view of the clinician.<sup>4, 5</sup>
- 4) Parents who received high quality information from the clinician.<sup>4</sup>
- 5) Diagnosis delivery that is unambiguous,<sup>6</sup> gentle, clear, and honest.<sup>1</sup>

Important components of communicating the diagnosis can include:

- 1) General Information about ASD
- 2) Ways ASD presents itself in the specific child
- 3) Community supports for children with ASD
- 4) Information about appropriate services and schools.<sup>1, 5</sup>

With these findings in mind, this project assessed parent perceptions following a child's diagnosis of autism to improve the diagnostic process at a developmental pediatric clinic in South Carolina (SC).

## Aims

- Explore processes at other clinics to improve diagnostic & education experience
- Compile resources and share with clinics statewide
- Determine levels of parent satisfaction among parents whose children received a new autism diagnosis
- Follow-up with past families to provide resources and assistance

## Methods

**Key Informant Interviews:** Five autism professionals were interviewed including 3 psychologists; 1 autism researcher; and 1 eligibility specialist. Their feedback was utilized in constructing the survey.

**Instrument:** The survey included 33 questions related to 1) pre-evaluation experience; 2) provider characteristics; 3) knowledge/information needs; 4) parental self-efficacy; 5) post-evaluation experience; and 6) demographics.

**Procedure:** 42 families of children who received an autism diagnoses between January 2012 and February 2014 were contacted. 18 families were reached. Families were excluded if patients were Spanish-speaking, foster children, diagnosis reconfirmations, or had relocated outside SC.

**Analysis:** The statistical program "R" and Excel were used to analyze quantitative data. Correlations and regression models (multiple and logistic) were run. Qualitative responses were coded in Nvivo 10 software.

## Quantitative Results

Respondent Demographics	% (n)
<b>Gender</b>	
Male	6% (1)
Female	94% (17)
<b>Relationship to Child</b>	
Mother	89% (16)
Father	5.5% (1)
Grandmother	6.5% (1)
<b>Race</b>	
White	44% (8)
Black	39% (7)
Mixed	17% (3)
<b>Education Level</b>	
Less than HS	5% (1)
GED/HS Diploma	39% (7)
College or higher	56% (10)
<b>Child's Insurance Type</b>	
Medicaid	72% (13)
Tri-Care	11% (2)
Multiple	17% (3)
<b>Household Income</b>	
<\$10,000	27.8% (5)
\$10,000 - \$30,000	27.8% (5)
\$30,000 +	27.8% (5)
Prefer not to answer	16.6% (3)

Significant Correlations	Pearson's r	P value
<b>Prior Knowledge*</b>	.4875	.0327
<b>Income</b>		
<b>Prior Knowledge*</b>	.5956	.0046
<b>Change in Knowledge</b>		
<b>Overall Satisfaction*</b>	.4912	.0192
<b>Provider Characteristics</b>		
<b>Self-Efficacy*</b>	.4620	.0325
<b>Provider Characteristics</b>		

- Multiple regression analysis was used to determine the effects of education and race on a prior autism knowledge. **There was a marginal effect of race on prior autism knowledge ( $\beta = -.8545$ ,  $SE = .4122$ ,  $p = .0558$ ).**
- Multiple regression analyses were used to test if education, race, income, prior autism knowledge, or provider characteristics significantly predicted self-efficacy. **Provider characteristics significantly predicted self-efficacy ( $\beta = .6193$ ,  $SE = .2233$ ,  $p = .0216$ ).** The other variables were not significant.

## Qualitative Results

Themes	Quotes
<b>Adequate post-appointment information</b>	<ul style="list-style-type: none"> <li>• "After the evaluation, she made sure we had all the information that we needed to get."</li> <li>• "She did a great job explaining everything and making recommendations for what she thought would benefit him most."</li> </ul>
<b>Resources</b>	<ul style="list-style-type: none"> <li>• "I wish I had known about early diagnosis options and programs. About Babynet [Part C], no one ever told us about that."</li> <li>• "Just resources, helping receive therapy tools and stuff – more information about ABA. Also other organizations that are out there that can help you financially."</li> </ul>
<b>Importance of Prior Knowledge</b>	<ul style="list-style-type: none"> <li>• "One thing that definitely did help us before is having his Early Interventionist. Had we not had her, I think it would be a much different situation."</li> <li>• "I did my own research about autism."</li> </ul>
<b>Wait Time</b>	<ul style="list-style-type: none"> <li>• "The length of time it takes to start services."</li> <li>• "The only thing that I would suggest is maybe get more people who can do the evaluations. More staff. I can't complain because originally his testing was supposed to be done later. But I was persistent and kept calling to see if they had any cancellations to get him in sooner."</li> </ul>
<b>Autism Information Prior to evaluation appointment</b>	<ul style="list-style-type: none"> <li>• "Maybe if I had seen something earlier about the signs of it so I could prepare myself mentally that he might be autistic."</li> <li>• "It's really hard to say because I know you guys don't want to give a whole lot of information before you know for sure if a child is on the autism spectrum or not."</li> </ul>

## Themes for Discussion

- Varying levels of prior knowledge - families come from diverse backgrounds, thus parent education needs will vary.
- Establishing rapport with parents and patients is key.
- Having a positive view of the clinician can influence a parent's receipt of diagnostic information and resources and can affect parental self-efficacy
- Clinicians and clinic staff must strike a balance between preparing families for the appointment and the risk of giving them inappropriate resources for autism before a diagnosis is made.
- Wait times for evaluation appointments and services should guide future workforce development decisions.
- Clinicians have limited time to educate parents about autism after the appointment. If feasible, clinics should provide ongoing resources, referrals, and support to families or refer families to an outside agency who can fulfill that role.

## References

1. Renty, J, Roeyers, H. Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child Care, Health Dev.* 2006; 32(3): 371-385.
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