ADVOCACY: AN ESSENTIAL SKILL FOR FAMILIES OF CHILDREN WITH ASD

Due to a unique set of needs, families and children with ASD use more services compared to families of children with other special healthcare needs. While insurance reforms have expanded coverage for autism-related services, parents of children with ASD still have trouble accessing much needed services and are often less satisfied with the services they do receive. It is clear that the service needs of families and children with ASD are not being met, leaving parents with the burden to advocate for additional or more appropriate services.

Parental advocacy involves acting on behalf of one’s child to resolve issues, obtain services, or promote change. Advocacy can take many forms and changes with the needs of the family. For some families, advocacy involves:

1) attending workshops to learn about their child’s special needs,
2) reading about special education rights,
3) learning effective communication strategies,
4) building relationships with their child’s service providers,
5) asking questions about the services their child receives, or
6) engaging in procedural safeguards when their child’s needs are not being met at school.

Advocacy also includes actions parents take to make changes in their communities. “Beyond IEPs: Eight Ways Parents Can Help Advocate for Children with Autism” shows other ways to advocate for your child and your community:

https://www.autismspeaks.org/docs/family_services_docs/BeyondIEP_spdf

To speak to a parent mentor or access free online trainings about advocacy and other skills, visit the Michigan Alliance for Families website:

http://www.michiganallianceforfamilies.org/webinar/
RESEARCH HIGHLIGHTS

ADAPTING PROJECT IMPACT FOR MEDICAID SYSTEMS

Within the autism field, it has been noted that Medicaid eligible families may have a more difficult time accessing services for their child with autism. This same research has also shown that these families are at a greater risk of dropping out of autism services once they do begin. All of this suggests that high-quality autism interventions that have been designed in research settings may not be the best fit when they are used in underserved, community-based settings. Currently, we are running a project in which we have formed community partnerships with a number of Medicaid service agencies in Michigan. As part of these partnerships, we have been meeting with parents and providers who work and receive autism services through the Medicaid system in order to get their advice on how to make Project ImPACT a better service for Medicaid eligible families in Michigan. If you have questions about this study or would like to know how you could get involved, feel free to contact Katherine Pickard at pickar11@msu.edu.

SERVICE USE AMONG FAMILIES AND CHILDREN WITH ASD

Families of children with ASD use many different services to address a complex set of needs and concerns. While recent insurance reforms have helped to increase access to some ASD-specific services, there are still gaps in service access for these and other much needed services.

In order to better understand these gaps in service access, parents were asked to complete a survey about their services as part of a larger project on parental advocacy.

Responses from 239 families across the United States indicate that they receive an average of 7.5 different types of services, but need over double that amount as seen in the following chart.

<table>
<thead>
<tr>
<th>Services</th>
<th>Family-Received</th>
<th>Family-Needed</th>
<th>Child-Received</th>
<th>Child-Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7.3</td>
<td>2.2</td>
<td>4.4</td>
<td>5.3</td>
</tr>
</tbody>
</table>

These services were obtained through a mix of private insurance (60%) and public assistance (35%); however, 40% of the families participating said that they still paid out of pocket for services.

Based on the large number of unmet services needs and the substantial proportion of parents paying out of pocket, it is clear that many families and children with ASD are having difficulty accessing services for their child.

One possible way that families can increase the number of services that they receive is to engage in advocacy. However, advocacy is a time consuming and potentially stressful activity.

This project aims to better understand what strategies and supports make advocacy more successful in order to give parents appropriate levels of support in finding services that match their needs.

If you are interested in participating in this ongoing project, please contact Karis Casagrande at 517-432-8031 or casagra3@msu.edu. You can also see “Current Projects” on the next page for more information.
CURRENT PROJECTS

PARENT INVOLVEMENT PROJECT

Parent involvement in intervention is key to improving outcomes for children with ASD. This project, funded by the US Health Resources and Services Administration’s Maternal and Child Health Bureau, is designed to measure the effectiveness of different components of an internet-based program designed to improve parent involvement in intervention for families of young children with ASD. Since the program will be administered remotely, families do not need to live near the research site.

Participating families will be administered a variety of standardized, observational, and parent report assessments at intake, after approximately 4 months, and at a 3 month follow-up to determine gains in skills over time. Families will be provided with an assessment report of the child’s developmental skills and will be compensated $25 for each assessment period ($75 total). Participation will take approximately nine months.

Families will be randomly assigned to a self-directed training group, a therapist-assisted training group, or a web-based information and support group. Participation is free and all required software and hardware will be provided at no cost.

To participate, your child must:
- Have a diagnosis of an autism spectrum disorder
- Be between the ages of 18 and 72 months at intake
- Meet other inclusion criteria

If you have questions about participation, please contact Nikki Bonter at bonterni@msu.edu or 517-432-8031.

UNDERSTANDING HEALTHCARE DISPARITIES IN ASD

Children with ASD require more services than other children due to a complex set of needs that affect both the child and the family. However, these services can be hard to access and children with ASD remain at high risk for unmet service needs. This study focuses on understanding more about how caregivers of children with ASD access services for their family. To thank you for helping us better understand you and your family, you will be entered for a chance to win one of three $50 Amazon gift cards.

To participate, your child must:
- Have a diagnosis of an autism spectrum disorder (ASD)
- Be between 3 and 22 years

What you will do:
- Complete an anonymous 30 minute survey.
- Tell us about your family, your child, and the services you receive

To access the online survey, go to:
http://bit.do/MSU-Autism-Study

If you have questions or would like a paper copy of the survey, please contact Karis Casagrande: casagra3@msu.edu; 517-432-8031.
AUTISM AND SOCIAL COGNITION RESEARCH PROJECT

The Autism Research Laboratory is working with the Health Behaviors and Cognition Lab at Michigan State University to recruit children with high-functioning autism aged 7-11 who are interested in helping us study the link between autism and the processing of social information.

Where does this study take place?
Participation takes place at Michigan State University, with easily accessible parking.

What will my child be asked to do?
Children who participate will be asked to go through a screening session on the first day. Those who qualify will be asked to participate in one additional session where we will ask your child to play some brief computerized games while wearing an EEG cap. Each session lasts ~ 90 minutes and can be done whenever works best for your schedule (after school, evenings, weekends, early-out school days, we will make it work!).

How will my child be compensated?
Children who complete both days of testing will be paid $35.

How can we get involved?
If you are interested in participating or have any questions please contact us: (517) 432-8031 or bergema@msu.edu.

FAMILY TIDBITS

Jacob, 10y
SO proud of Jacob!!! We had his conferences this week and he has grown so much socially AND academically since last year! :-). It's so exciting to hear about him raising his hand to answer questions and playing with the fifth grade boys out on the playground! We are so blessed to have such amazing teachers for Jacob. Thank you Mrs. Dama and Ms. Raymer!!!
Awesome Job Jacob!!!

Aidan, 10 years
Aidan was diagnosed with classic autism shortly before his 3rd birthday. He was classified as 'severe', had no language, empathy or eye contact until well after his 7th year. Aidan is now 10 years old and has been mainstreamed in public school since kindergarten. He is in grade 5, academically on track and for the first time he has been extremely interested in joining other children in extra activities. He decided he wanted to run for student council for the first time, made his speech/essay and won the election! His platform is 'Kids who are different can make a difference too'. I'm not sure I have ever seen him so proud of himself, and my heart is so full of pride that I may burst.
Our hearts may burst too! So proud of you Aidan!!!

CJ, 3 years
CJ had a team at the Walk Now for Autism Speaks event Sunday 10/4 at Ford Field. Our group picture doesn't include everyone who participated but Team Super CJ had over 35 people walking which included his 91 year old great grandfather and 87 year old great grandmother. CJ even got to see Katherine from the MSU Autism Lab. It was a great day raising autism awareness!

What a team of family supporters for CJ! Awesome!
Richie, 1 year 8 months
Richie is finally started to mimic! Clapping his hands or stomping feet when he is asked. I'm super excited to say that we've discovered that when he's going through a tantrum, that being outside is the key to helping calm him. (That's super big!!) We've started ABA classes last week and already showing some progress! I'm excited to start the Online [Parent Project] and start learning and understanding more about Autism and how it affects my son.

Emerson, 4.5 years
Attached are a series of selfies that Emerson took.

Emerson will begin a general education preschool in a few weeks due to the all the progress he has made in the recent months. We have seen tremendous growth in Emerson's play skills and in his social interaction.

We were at McDonalds Play Land, and Emerson was able to answer questions from a play partner! Months ago, he would've thrown himself on the ground and quoted Charlie Brown.

Great Job Richie!!!

Emerson will begin a general education preschool in a few weeks due to the all the progress he has made in the recent months. We have seen tremendous growth in Emerson's play skills and in his social interaction.

Way to go Emerson!!!

Dominic, 11 years
For close to nine years, Mom has had to cut Dominic’s hair at home. Back in August, Dominic "asked" to go to the barbershop for the very first time!! Mom and Dominic went to the Okemos Barber Shop where we had "Vince," the owner cut his hair! Vince made it such a pleasant experience that Dominic asked to get his hair cut as soon as he got home! Mom had to gently explain to Dominic that he had to wait at least a few weeks!

Way to go Dominic! We love your new haircut!

Thank you to all of the families who contributed stories for the Newsletter.

We love reading them!
UPCOMING EVENTS

DECEMBER 2 (Wednesday), 2015, 5:30-7:00PM:
Family Gathering at Jumpin’ Jax Bounce Arena!

Bring a dish to share if you choose. We will provide pizza and drinks. Look for an e-mail with more details soon!

MAY 2015:
Project ImPACT Introductory Workshop will be scheduled in May, 2015.

For professionals interested in learning the intervention and providing parent training. Please stay tuned for more details regarding dates/times.