THE IMPORTANCE OF ENGAGEMENT VERSUS OUTREACH IN ASD RESEARCH

The MSU Autism Research Lab strives to form active and collaborative partnerships with parents and providers in the community. The goal of these partnerships is to involve community members in the research process. However, many parents and individuals with ASD feel disconnected from research in general. This may be due in part to how communities are typically involved in research.

Communities are most frequently involved during recruitment and delivery of findings, which can be described as outreach. In contrast, community-engaged research allows us to learn from the expertise of community members by jointly developing research goals that will make a meaningful difference. In fact, partnering with communities this way leads to the development of interventions that make a broader public health impact than those that are developed without input or collaboration from communities. More importantly, engaging parents and providers in the development of our research projects helps to empower parents and give communities a stronger voice in ASD research.

We have several research projects that have been created with community input or have goals of engaging and supporting the ASD community. While we still have room to grow, our sincere hope is to develop meaningful and collaborative relationships where communities have a voice and a place in the process of ASD research.

MSU AUTISM RESEARCH LAB IN THE NEWS

Our research team has been in the news since our last newsletter. Feel free to check out the following articles:

- https://www.sciencedaily.com/releases/2016/05/160524121554.htm
WHAT ABOUT INTERVENTIONS FOR PARENTS?

Families of children with ASD will find a large number of interventions directed at improving their child’s skills, but little to address well-being at the family level. However, we know that families of children with ASD experience increased rates of parental stress and depression, and research shows that parent mental health is a significant factor in child outcomes.

Although a handful of researchers have suggested that parent-focused interventions may improve family functioning, these parent-focused interventions have not been incorporated into best practice guidelines for the treatment of ASD.

As part of our work with the MSU Psychological Clinic, we are currently working on a research-based intervention to support parents of children with ASD.

This intervention is based on the idea that the most pronounced gains will be made when the family as a unit receives targeted intervention. The parent group will focus on topics such as: how to manage stress through emotion-based and problem-focused coping skills, advocacy and communication skills, identifying and utilizing formal and informal supports, optimism training, and planning for the future.

This parent well-being group will be run alongside a social skills group for children with ASD aged 8 to 12 years.

For more information, please contact the MSU Psychological clinic at (517)355-9564.

A MOVE TO TELEHEALTH: PROJECT IMPACT ONLINE OPEN TRIAL STUDY

Through our Open Trial (OT) Study, families outside of Michigan have access to Project ImPACT as a self-directed, online tutorial. Families were referred to the program through a provider. To better understand open access, we compared these families to those participating in lab-based (LB) versions of Project ImPACT Online. Families who enrolled in the OT study were similar to families who enrolled in our LB studies. However, families in the LB studies were more engaged in the program than were families in the OT study. This is evidenced by the LB participants having a higher percentage of completion of program components, increased number of hours of the website, and more logins.

Perhaps better methods for engaging families outside of lab-based settings should be employed; only 1/5th of those referred to the OT study actually accessed the website. For families who accessed the website, only parent outcome expectations, knowledge quiz scores, and communication skills of the child scores improved. Since there was such a high percentage of families that did not access the program, determining better strategies to increase the reach of the program will be important.
CURRENT PROJECTS

PARENT INVOLVEMENT PROJECT

WHAT IS IT?
Parent involvement in intervention is key to improving outcomes for children with ASD. This project, funded by the US Health Resources and Service Administration 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.

WHAT WILL YOU DO?
Families will complete the following over a 9 month period:
- An initial intake assessment
- Participation in one of three groups over 4 to 6 months: a web-based information and support group, a self-directed training group, or a therapist-assisted training group
- 3 month follow-up assessment

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

FAMILIES WILL:
- Receive $25 during each assessment period ($75 total)
- Receive an initial and follow-up assessment report
- Be provided all technology if needed at no cost

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

ADAPTING PROJECT IMPACT FOR MEDICAID SYSTEMS

Over the past year, we have been making some updates to the Project ImPACT program in partnership with local parents and providers. The goal of our partnership has been to use the advice of local parents and providers in the Medicaid system to make Project ImPACT more accessible to families of all backgrounds. We are running a research study that asks parents and providers to watch a video and rate either the updated or original Project ImPACT program.

If this is of interest to you or families you work with, please see more information below, or feel free to contact Katherine Pickard at pickar11@msu.edu.

TO PARTICIPATE IN THIS STUDY:
You are a provider who works with children with autism with Medicaid insurance OR you are a parent of a child with autism with Medicaid insurance.

WHAT YOU WILL DO:
You will watch a 13-minute video of a parent-training intervention. You will complete a questionnaire that asks you about your background, your opinion of Project ImPACT, and whether you would want to use the program. You will be compensated a $15 Amazon.com gift card. Your participation will take about 30-40 minutes.

If you are interested in this study, please copy and paste this into your browser:
http://bit.do/impact_study
FAMILY TIDBITS

**Olivia (Liv), 7 years**
This year, Liv successfully made her first international trip to Spain over the winter break to visit her grandparents in-person. Despite traveling over 24 hours (by plane and train) each way and experiencing the extremely different Spanish holiday traditions, Liv adjusted with the poise of a seasoned frequent flyer. For 3 weeks, she braved a foreign language, unknown cities, unfamiliar foods, strange bathrooms and miles (and miles) of daily walking. By the time we left, she’d even started speaking Spanish. She enjoyed being spoiled by her abuelos so much that she can’t wait to return next year.

![Liv on the second leg of our flight from Paris to Madrid, Spain.](image)

Liv with her abuelos in Gijón, Spain (next to the Cantabrian Sea) on Christmas Eve.

**Jacob, 11 years**
We are so proud of our son, Jacob! He participated in the Summer Special Olympics last month at Central Michigan University. He did a fabulous job being away from home and won a Gold Medal in Bocce Ball!

![Jacob with his Gold Medal](image)

**Noah, 9 years**
Two weeks ago, Noah learned how to ride a bike with NO TRAINING WHEELS! He also has learned how to swim recently.

**Jack, 9 years**
Jack is getting ready to start 4th grade and doing well in math and still loves anything science related. He still is working hard on reading. He has also been trying new fruits and vegetables! In the last few months he has started eating pineapple, peppers (green, red and orange) but NOT YELLOW and potatoes and even tried ice cream for the first time!

**Dominic, 12 years**
Dominic was not feeling well a few months back and had to stay home from school for part of the week. In the past, we have had to rely on how he is acting, he won’t say things like, “my tummy hurts,” or “my throat hurts.” We knew he was feeling better when he told mommy, “it’s good to be back to normal!”

**Henry, 3.5 years**
Over the last 6 weeks, we have seen a huge improvement in Henry! He is less sluggish, his eye contact has increased dramatically, and his language skills have more than doubled! This is a miracle and we are so happy!