Research in Developmental Disabilities & Language Lab (RIDDLL)

Fall 2016 Newsletter

Welcome to the first RIDDLL Newsletter! Our research lab began five years ago when Dr. Audra Sterling was awarded a grant to study grammar in boys with fragile X syndrome and autism. See the article describing our findings later in this newsletter. Early on, we struggled to find the right name to fit the lab. Officially, I think we were called something like ‘Communication in fragile X syndrome and autism.’ However as our research branched out to include other developmental disabilities, the name no longer seemed appropriate, not to mention actually saying ‘Communication in fragile X syndrome and autism’ is quite a mouthful! We searched for a name that accurately represented who we are and also was easy for families to remember. We settled on Research in Developmental Disabilities & Language Lab. One could argue that this is more of a mouthful than our original name, but at least it can be shortened to a nice, memorable acronym, RIDDLL. We use RIDDLL to remind us that we are continually striving to make sense of the riddle that is the communication challenges our participants face.

The RIDDLL lab has grown substantially over the past five years. We started with three members at the beginning and have increased five-fold to 15. Currently, the lab consists of 3 undergraduate students, 7 students enrolled in the Communication Sciences master’s program, 2 students pursuing their PhDs, 1 postdoctoral fellow, 1 lab manager and 1 principle investigator. Does anyone else have The 12 Days of Christmas stuck in their head after reading that? Anyway, look for an article later in this newsletter highlighting where some of our lab members are now.

We give a huge thanks to the over 100 families that have participated in our research studies. We can have the most ambitious ideas and be given all the grant money in the world to make them happen (yeah, right), but really, nothing gets done, no results are produced without our dedicated families. We would be nowhere without your generous donation of time and effort to travel to the Waisman Center. For each and every one of our participants who has said, “sure, I’d be willing to help,” we thank you most sincerely, thank you!
Results from our study on Grammar Development in Boys with Fragile X Syndrome and Autism

In the spring of 2012, we launched a study to examine how boys with fragile X syndrome (FXS) and boys with autism (ASD) use vocabulary and grammar while communicating. Our goal was to understand how the boys were using grammar and vocabulary, as well as the best way to assess their language skills. We want to be able to inform Speech Language Pathologists working with kids with FXS and ASD what the best methods are for assessing language, and what specific areas need to be carefully examined. We had 37 boys with FXS and 26 boys with ASD from all over the country participate! We completed testing using a combination of standardized tests, language samples, and an ASD evaluation. We have two publications from the study so far. We found that although the boys with ASD in our study tended to have higher IQ scores, the boys with ASD and boys with FXS had similar grammar skills. We looked at verbs that we know are very hard for kids with other types of language disorders and found that the kids in our study had some great strengths and also problematic areas. For example, both groups of boys were good at producing the third person singular verb (for example: He walks to the store), but they struggled with past tense verbs (for example: He walked to the store). The boys had a strength in using the verb “BE” (for example: The boy is hungry. The kids are playing), but struggled with the verb “DO” (Does the boy like pizza?). Kids with other language disorders have a hard time with all of these verbs, and so this shows how boys with ASD and FXS have some unique strengths in their grammar, but are still struggling with some aspects as well. We also looked at the vocabulary words kids understand as well as produce. While most of the children in our study understood more words than they said, we did find some of our kids had the opposite pattern. We found that about 25% of the boys with ASD had higher scores on the test for spoken vocabulary compared to the vocabulary they understood. Only 11% of the boys with FXS had this unique profile.

We have a couple of other papers we are working on, including comparing the different ways we assessed language in this study, and how the boys in this study understood grammar compared to how they produced it. We are happy to share the papers with you if you are interested. Thank you for participating in this study!

Where are they now?

Eileen Haebig was one of our primary examiners for nearly four years while she completed her doctoral degree in Communication Sciences & Disorders. She had the pleasure of working directly with our participants. We will greatly miss her skills in the lab. She had a keen awareness of when it was a good idea to take a break or knew exactly what to say to encourage some of our more shy kids to give something new a try.

Now that Eileen has finished her dissertation on word learning in children with Autism, Fragile X Syndrome and Specific Language Impairment, she has moved on to a postdoctoral fellowship at Purdue University. She continues to study children with language impairments, but has added new skills to her repertoire. Her current focus is now on using brain activity to see if the brain responds differently to language according to a child’s language abilities and history of language abilities.

We wish you well at Purdue but we miss you dearly here!
Helpful Resources

The following is a list of resources you may find helpful as your child ages. This list is not exhaustive, but rather a place to start. Many of these websites have age and interest specific information for your child and family. Many of the organizations have chapters based on location, which then have area-specific resources.

Resources for your Family:

**Working Together**
Working Together is a research study that includes an 8-week program including education and support group sessions for young adults with autism spectrum disorder and a separate support group for parents that focuses on supporting their adult child in the community.

For more information, visit [http://www.waisman.wisc.edu/family/study_trans.html](http://www.waisman.wisc.edu/family/study_trans.html)

**Autism Society of Wisconsin**
The Autism Society of Wisconsin is a community in Wisconsin that is dedicated to providing information, advocacy, family support, resources, and more to people with autism spectrum disorders and their families. On the website, you will see a specific link for resources.

For more information, visit [http://www.asw4autism.org/](http://www.asw4autism.org/)

**Gigi’s Playhouse – Madison Location**
Gigi’s Playhouse is opening a location in Madison this spring. These centers support people with Down syndrome as well as their families. They have different programs and services to support families.

For more information, visit [http://gigisplayhouse.org/madison](http://gigisplayhouse.org/madison)

**Down Syndrome Association of Wisconsin**
The Down Syndrome Association of Wisconsin is an organization for individuals with Down syndrome and their families that offers assistance and promotes awareness. This organization has a website containing all types of resources ranging from information on government housing for people with disabilities, the Best Buddies program, sibling networks, and more.

For more information, visit [http://www.dsw.org/resources.aspx#sthash.DrwUtNOK.MwVhC8oq.dpbs](http://www.dsw.org/resources.aspx#sthash.DrwUtNOK.MwVhC8oq.dpbs)

**The National Fragile X Foundation**
The National Fragile X Foundation is an organization for families and people with fragile X. The foundation has a website with information about advocacy, resources, interventions, research, and more.

For more information, visit [https://fragilex.org/](https://fragilex.org/)

**The Arc**
The Arc is an organization with approximately 700 state and local chapters that help families navigate services for their children, both young and grown. This organization has a wealth of information regarding residential, educational, and vocational services and serves people with intellectual or developmental disabilities.

For more information, visit [http://www.thearc.org/what-we-do/programs-and-services](http://www.thearc.org/what-we-do/programs-and-services)

For Parent Support:

**Parent to Parent of Wisconsin**
This is an organization that matches parents of children with special needs with other parents who have had similar experiences.

Call 1.888.266.0028

**For additional resources:**

**Waisman Resource Center**
Call 1.800.532.3321
Research Updates

Gesture use in Fragile X Syndrome and Down Syndrome

Emily Wagner

For her Master’s thesis, Emily investigated how children with Down Syndrome and children with fragile X syndrome (FXS) use nonverbal communication. Specifically, she looked at how these children use gestures during the activities they do while visiting our lab. She was interested in potential differences in gesture use between children who have Down syndrome without an autism spectrum disorder (ASD) and Down syndrome with ASD, as well as differences between children with FXS without ASD and FXS plus ASD. She looked at the type and number of gestures that children in these different groups used and how they related to an ASD co-diagnosis. She found that the children with Down syndrome plus ASD gestured less frequently than the children with Down syndrome without ASD, but both groups used the same types of gestures. In the children with FXS, analyses showed that both groups of children gestured at the same rate, but the children with an ASD co-diagnosis compared to the group without the co-diagnosis used gestures more for regulating the behavior of the conversation partner rather than to interact socially.

Contexts to Study Language of Boys with Fragile X Syndrome

Holly Erbstoesser

Holly Erbstoesser, a second-year graduate student in the lab, did her undergraduate honors thesis on different sampling contexts in which to study language in boys with Fragile X syndrome (FXS). A 10-minute conversation between the child and an examiner has been the traditional, less structured task used to study the language of children with FXS and other language disorders. However, it is important to consider other contexts in which to study the language abilities of these children because communication happens in a variety of contexts. Previous research has suggested that part of the assessment used for diagnosing autism, the ADOS (Autism Diagnostic Observation Schedule), could be used to study the language of this population. The reasoning for this is that many children with FXS have a high level of social anxiety, and the ADOS, being a very structured task with several play-based activities, may create an interaction with less anxiety, and therefore better language. Those opposed to this hypothesis believe that since the ADOS is used to look at autism-like behaviors, it may not be the best context to study language since these behaviors could interfere with language.

Holly’s thesis aimed to examine whether any autism-like behaviors observed in the ADOS interfere with language, or offer a more accurate description of the language profile of boys with FXS. To do this, she analyzed and compared parts of the 45 to 60-minute ADOS with the traditional 10-minute conversations to investigate which context more accurately describes the language abilities of boys with FXS.

Her data showed that even though certain tasks within the ADOS seemed to elicit better language than other tasks within the ADOS, it was during the conversation that boys with FXS produced the greatest amount and most complex language. Holly’s research shows that using the traditional method of a conversation elicits better overall language than what was produced during more structured activities. However, research in the area of language sampling should continue to explore other contexts in order to get the most representative picture of the communication skills in boys with FXS.
For her Master's thesis, Laura examined social deficits in Fragile X syndrome (FXS) and autism spectrum disorder (ASD). These disorders are both associated with social challenges, including eye gaze avoidance and the perseverations, or repetitions, of certain topics or phrases. She coded eye gaze patterns and perseverative language patterns of boys with FXS+ASD and ASD without FXS. These two examples of social deficits were compared between the two groups to determine if there were correlations or patterns. Laura found that children with FXS+ASD and ASD performed similarly on measures of eye gaze and perseverative language, while having significantly different IQ scores. This indicates that ASD features seen in FXS are not due to low IQ alone, but another influence is likely explaining these similarities. Laura's future work will aim to explore this further in order to gain understanding of the social challenges that occur in FXS.

Language of Girls with Fragile X Syndrome
Courtney Ramczyk

For her undergraduate senior honors thesis, Courtney contributed more information to the language profile of females with Fragile X syndrome (FXS). Specifically, she looked at types and amounts of language dysfluencies during conversations. Language dysfluencies are disturbances to the smooth flow of back and forth communication. The dysfluencies Courtney assessed were orphans or abandoned utterances ("We just tried...She is going to the store"), revisions or utterance corrections ("We, she is going to the store"), repetitions of exact words or phrases ("She said, she said, she said, she was going to the store"), and filled pauses or using words or sounds to fill in pauses in an utterance ("She um wants to uh go to the store").

Using recordings obtained from researchers at Stanford University, Courtney performed a language sample analysis on conversation recordings from 22 girls with FXS and 20 of their typically developing (TD) sisters, gathering data to compare the types and amounts of dysfluencies between these two groups. Results showed that girls with FXS seem to produce fewer and less complex sentences (e.g. fewer words, fewer number of different words, etc.) than TD girls. However, there was no significant difference in the amount of dysfluencies between groups. In fact, the typically developing girls had more dysfluencies on average, potentially because they talked more and therefore had more opportunities to be dysfluent.

During these conversation samples, the examiner at first sat very close to the participant (i.e., knees touching) and then after five minutes, moved away to a greater distance (i.e., about 6 feet apart). Examiners alternated these interpersonal distances every five minutes for the duration of the conversation. Since girls with FXS often have social anxiety, Courtney hypothesized that girls with FXS would have more dysfluencies when conversing at a closer distance vs. greater separation. Courtney's hypothesis was rejected as results showed that interpersonal distance during conversation did not seem to affect the type and amount of language dysfluencies in girls with FXS.

Overall, this study showed that more research is needed to further understand the language profile of girls with FXS.