RI-CART
RHODE ISLAND CONSORTIUM FOR AUTISM RESEARCH AND TREATMENT

RI-CART SPOTLIGHT
Alyssa Hillary is an Autistic PhD student in the Interdisciplinary Neuroscience Program at the University of Rhode Island

ASK A DOCTOR
What is the process of Autism diagnosis?

FEATURED STUDY
New RI-CART Survey about perceptions about genetic testing. Watch your email for a personal invitation.

RI-CART SPEAKER SERIES
Save the Date for Marsha Mailick, PHD
“Aging and Autism: Findings from a Longitudinal Family Study”

Art Created by Bradley Hospital CADD Patients
WELCOME FALL

The fresh air of fall approaches the beaches of Rhode Island and little by little we say goodbye to the warm weather that accompanied us during these past months.

We had a season filled with outdoor events! We enjoyed the heat and had fun with many local organizations that helped the ASD community have an incredible summer full of new experiences, fun, and connections with other people, families, and resources. One of them was Camp WANNAGOAGAIN! organized by The Autism Project. Our team participated as support for the children and families, and at the same time, we learned a little more about them. Thanks to The Autism Project for letting us participate, and thanks also to the Surfers Healing organization for inviting us be a part of their great event in September.

We also had several new referrals to our study, and these families and individuals are now part of this community that continues to grow. Thank you for listening and giving us the opportunity to create a unique connection that will help advance research and understanding of autism.
WHAT WE’VE BEEN UP TO

Are you planning an event and would you like RI-CART to participate? Please send an email to us at RICART@LIFESPAN.ORG.

Camp WANNAGOAGAIN!

Our research assistants Kayla and Becca, and our outreach coordinator Lauren, enjoyed the many activities organized by The Autism Project at Camp WANNAGOAGAIN this year. To see more photos, visit their Facebook page @theautismproject.

Surfers Healing

Becca and Silvana had a fun and sunny day at Narragansett Town Beach with Surfers Healing, the original surf camp for children with autism. For more information about them visit www.surfershealing.org.

Laura Lewis, PhD visits RI-CART

The most recent RI-CART Speaker Series featured Dr. Laura Lewis, autism researcher and Assistant Professor of Nursing at the University of Vermont. Read one of Dr. Lewis’s recent articles titled “A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults” HERE.

Julia of ‘Sesame Street’ visits Museum of Work and Culture

It was a fun day with Julia!! Carrie, our Project Coordinator, and Kayla, one of our research assistants, had the chance to meet Sesame’s Street’s Walkaround Julia! Julia made her debut on Sesame Street in 2017 as the sweet and curious four-year-old-girl with autism. Thanks to the Museum of Work and Culture Preservation Foundation for organizing this kind of event for our community.

Ri-CART Quarterly Meeting

We had our Ri-CART Quarterly meeting a few weeks ago. This community meeting is where doctors, researchers, teachers and organizations come together to talk about activities, questions, and research projects important to the ASD community. In this meeting, we had the pleasure to hear from Maria Cotto, a Bilingual Children’s Librarian at the Pawtucket Public Library. She received the 2018 Outstanding Librarian of the Year from the Rhode Island Library Association (RILA). In her presentation, she talked about the sensory-friendly activities that libraries around RI are offering, and the importance of these activities for the ASD community. If you are interested in learning more about this topic, send an email to risensorystorytimema@gmail.com. Our next meeting will be in December; if you want to participate, send us an email at ricart@lifespan.org.
THANKS TO ALL THE PEOPLE WHO VISITED OUR TABLES AND RECEIVED OUR BOOKMARK. IF YOU DIDN’T GET ONE, YOU CAN DOWNLOAD HERE.
ASK A DOCTOR

• WHAT IS THE PROCESS OF AUTISM DIAGNOSIS?
A diagnostic assessment typically includes several visits that involve interviews with parents about developmental history, standardized tests to assess a child’s strengths and needs, and observations of play and social interactions to assess for the presence or absence of ASD symptoms. These assessments can include IQ and language ability tests and assessments of everyday life skills. For some individuals, the diagnosis can be made with a high degree of confidence after 2 to 3 visits. However, for others there may be the need for observations over time. For example, very young children may benefit from multiple visits in order to ensure that the assessments are accurate.

• HOW MANY SESSIONS OR TESTS SHE WOULD BE GOING THROUGH?
That depends on the situation, but a common scenario is an initial interview and observation, a follow up visit for more structured observations and assessments, and then a follow up visit to discuss results and recommendations.

• WHO CAN MAKE A DIAGNOSIS?
The kinds of professional that typically make autism diagnosis are clinical psychologists, psychiatrists, developmental pediatricians or neurologists. All of these kinds of doctors have training and experience in what is called “differential diagnosis.” This means that these doctors have training in helping to decide whether the signs and symptoms present for a child are caused by ASD or instead being caused by some other condition.

• IS THERE ANY PHYSICAL TEST EG. BLOOD TEST?
There is no physical test (such as a blood test) for autism. However, it is the standard of care to offer genetic testing if an individual receives a diagnosis of autism. Genetic testing can identify a genetic cause for autism in up to 30% of people.

• HOW MUCH WE WILL BE CHARGED FOR THIS DIAGNOSIS PROCESS? IS IT INCLUDED UNDER INSURANCE?
This evaluations should be covered by insurance, as long as the provider is part of the plan’s network. Costs would include standard co-payments and in some cases deductibles (if that is part of your plan). Costs could be higher if you choose a provider who is out of network, but that depends on your plan. Depending on your insurance plan and depending on what kind of doctor is doing the assessment, you may need to get a referral from your primary care doctor. The RI-CART resource guide (www.autismri.org/resources) lists a number of options of clinics that can conduct autism evaluations.
What were challenges and supports in your elementary/middle high school?
I didn’t really have any formal supports until university thanks to late diagnosis, but informally I had some help with organization. It was always a sort of weird situation where my teachers knew something was up, but I didn’t have paperwork. Some of my teachers tried to help; others just got out of the way while I did things I needed to do. I’d have two pairs of pliers in my hands, making chain mail in class, raising my hand with pliers still in my hands. Letting me do what I needed to do was one of the best supports I got in school, ever – including university. Just understanding that I won’t look normal. I can be quietly fidgety but I am not going to sit still and take notes and look straight at you. That’s not happening.

Any advice for individuals or families who may pursue a higher level of education?
1. Disclosure is complicated.
2. Be thoughtful about who you tell and how. You can go through disability services, and professors aren’t entitled to anything more than what your accommodations are. They’re not entitled to your diagnosis, though sometimes it’s useful to tell anyway. If you’re going to negotiate anything informally, you’re probably going to need to tell them.

3. Go ahead and ask for the “weird” accommodations that will help you. When I say weird or unique, I am the first student at URI to have text to speech for class participation. The template accommodations aren’t necessarily what we actually need.
4. Build informal supports as well as the disability services stuff. Informally, I’ve used handwriting options instead of text to speech, I’ve used claiming the seat next to the white board and bringing a marker to class, I’ve used FlipWriter. Of all the classes where I needed AAC, and that’s a lot of them, I’ve only used speech generation in one of them. Everything else is sort of an informal support; it’s not actually what my paperwork says I get.

What are some of the difficulties you’ve encountered that you felt were specific to being an autistic graduate student, and any advice for others whom might encounter similar situations?
I don’t think anything is 100% autism specific, but some things are much more common. Sensory Issues. The building where my lab is, at Schneider Electric, there’s some industrial floor stuff going on there. I work from home as much as I can. Overload, I do my best to avoid having overload wipe me out for a shift but it happens. When you’re planning on doing any given project, plan that you’re going to lose a certain percentage of your work time. I have a meal plan. That’s super important, because when I get overloaded, feeding myself is one of the first skills I lose. Mathematics, reading, writing, all work longer.

What do you feel your strengths as an autistic graduate student are?
The first thing: there’s a lot of writing involved in grad school. I’m already extremely accustomed to writing or typing my ideas out rather than saying them orally, because that’s what my main AAC option is. And then because I’ve had quite a few different interests, I have a very eclectic background. Reading an unusual combination of things makes it much easier to come up with new ideas.

Can you talk about your research areas and interests?
There’s a bunch! Formally, I work in AAC, with two main areas of focus. Because it’s personally important to me, I look at AAC for autistic adults. And then my dissertation work is on brain computer interfaces for people with ALS. Informally, I’ve done work related to autism and neurodiversity. Autism and queerness, neurodiversity in young adult fantasy or sometimes dystopia. I have one piece about neurodiversity in Tamora Pierce’s work, I reviewed Diane Duane’s Young Wizards series, and then I’ve done stuff about teachers with disabilities, specifically teachers that use AAC. I’ve got work in Criptiques, and in several Autonomus Press anthologies.
FEATURED STUDY
CURRENTLY ENROLLING

We invite you, as members of the RI-CART community, to complete a short survey that will help us understand the barriers, challenges, and opportunities of clinical genetic testing for ASD. We would like to get the widest perspective possible and would appreciate hearing from people who are in favor or against genetic testing for ASD, from people who have been tested and those who haven’t, and from people familiar with genetics concepts and those for whom all of this is new information. In appreciation of your prompt participation in this survey we will provide you with a $20 or $10 gift card. Thank you for your partnership in helping the ASD community! If you have any questions about our study or want to learn more about any of the areas included here, please don’t hesitate to contact Dr. Daniel Moreno De Luca at (401) 432-1200 or ricartlifespan.org.

Take a holistic approach to child development with the SmartPlayroom The Developmental Cognitive Neuroscience Lab is looking for children of all ages to participate in a fun and interactive Brown University research study in our lab and in our SmartPlayroom. We are especially interested in working with children with an ASD diagnosis. The SmartPlayroom room looks like any playroom in a home or school but is designed to naturalistically collect data in real time and simultaneously on all aspects of children’s behavior. These behaviors include movement, language, eye movements, and social interaction while a child performs naturalistic tasks, plays and explores without instruction, walks or crawls, and interacts with a caregiver. Contact Diego Placido at (401) 863-7668 or DCNL@brown.edu

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UPCOMING EVENTS

Are you planning an event or you know of event that other families can enjoy? Send us an email and we’ll put it in our events update!

SATURDAY, OCTOBER 6 🎥
SMALLFOOT AT SHOWCASE CINEMA
Tickets will be available at the box offices. More information visit www.showcasecinemas.com/sensorysensitive
Location: Showcase Cinema Warwick and Blackstone Valley
Time: 10:00 AM

MONDAY, OCTOBER 8 🧑‍👩‍👧‍👦
SOCIAL GROUP FOR ADULTS WITH ASPERGERS
This support group is facilitated by Arthur Mercurio of the Center for Autism and Developmental Disabilities at Bradley Hospital. It is free and meets the second Monday of each month. The group may cancel on holidays or in bad weather. Please call for more information and to verify the meeting date and time. For more information please contact Arthur Mercurio at 401-452-1189.
Location: 1011 Veterans Memorial Parkway East Providence, RI
Time: 6:30 - 8:00 P.M

MONDAY, OCTOBER 8 🧑‍👩‍👧‍👦
SUPPORT GROUP FOR PARENTS OF ADULTS WITH ASPERGERS
This support group is for parent of adults or older children with Asperger’s Syndrome. It is free and meets the second Monday of each month during the school year. The group may cancel on holidays or in bad weather. Please call for more information and to verify the meeting date and time. Pre-registration required. For more information visit www.aane.org.
Location: Bradley Hospital Staff Dining Room
Time: 6:30 - 8:00 P.M.

SATURDAY, OCTOBER 13
SENSORY FRIENDLY STORYTIME
AT THE EXETER PUBLIC LIBRARY
An interactive storytime that can be enjoyed by children of all ages, abilities and sensibilities and their favorite adult. No registration is required - just come! And please share this information with family and friends! If you have questions or if your child would benefit from a social story before the program, we’ll have some at the desk or you can email Miss Aimee at childrensexeterpubliclibrary.org
Location: 773 Ten Rod Road (RT 102) Exeter, RI 02822
Time: 1:00 PM-2:00 PM

SATURDAY, OCTOBER 20 🍼
BOWLING TIME FOR INDIVIDUALS WITH ASD 17+
AT TOWN HALL LANES
Registration is required. Contact Alicia at 401-785-2666 Ext.4 - or by email-AEADALIFESPAN.ORG
Location: 1463 Atwood Avenue Johnston RI
Time: 2:00 PM-4:00 PM

THURSDAY, OCTOBER 25 🍹
AN EVENING WITH TEMPLE GRANDIN: “CALLING ALL MINDS”
Come spend an evening with Dr. Temple Grandin, professor of animal science at Colorado State University, consultant to the livestock industry on animal behavior, and autism spokesperson. More information click here
Location: RI Convention Center Exhibit Hall A, 3rd Floor
Time: 5:30 PM

THURSDAY, OCTOBER 30 🎭
PRIDE AND PREJUDICE SENSORY-FRIENDLY PERFORMANCES
AT TRINITY REP
Trinity rep offers a series of moderately-adjusted performances of every show to meet the needs of audience members with autism, PTSD, and/or sensitivities to light and sound. Patrons should note that Sensory-Friendly performances are more appropriate for an audience of teenagers and adults. More information click here.
Location: 201 Washington Street Providence, RI 02903
Time: 7:30 PM

SATURDAY, NOVEMBER 10
SENSORY STORY TIME CLASS
AT PAWTUCKET LIBRARY
This is a monthly program for children who are on the autism spectrum or have other development delays. Program will include: picture schedule, songs/rhymes, movement, fun stories sensory activities! Great for families looking for a small group. Best for children ages 3 to 8 year olds, but any child is welcome. No registration required. For a social story, please email www.pawtucketlibrary.org/contactus.htm
Location: 13 Summer Street Pawtucket, RI 02860
Time: 2:30 PM-3:30 PM
EVERY MONTH

SENSORY SENSITIVE EVENTS

Low Light  Low Sound  Fewer Crowds

Sensory Sensitive Sundays

Chuck E. Cheese’s
Low Light  Low Sound  Fewer Crowds

Sky Zone Trampoline Park

Cinemaworld Lincoln

Showcase Cinemas

Launch Trampoline Park

• Chuck E. Cheese’s
  First Sunday Every Month at 9-11 AM

• SkyZone Providence
  Second Sunday Every Month at 8-10 AM

• Launch Warwick
  First Tuesday Every Month at 6-8PM

• Cinemaworld Lincoln
  First Saturday Every Month at 10 AM

• Showcase Cinemas
  First Saturday Every Month at 10 AM

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RI-CART
RHODE ISLAND CONSORTIUM FOR AUTISM RESEARCH & TREATMENT
SAVE THE DATE
RI-CART SPEAKER SERIES
MARSHA MAILICK, PHD

Dr. Mailick is Emeritus Vice Chancellor for Research and Graduate Education at the University of Wisconsin-Madison. She received her PhD in social policy from Brandeis University and became an associate professor at Boston University before joining UW-Madison. The focus of Dr. Mailick’s research is on the life course trajectory of developmental disabilities. She is interested in how the behavioral phenotype of specific developmental disabilities, including autism, fragile X syndrome, and Down syndrome changes during adolescence, adulthood, and old age. In addition, she studies how the family environment affects the development of individuals with disabilities during these stages of life, and reciprocally how parents and siblings of individuals with disabilities are affected. Her current research includes three projects: a 14-year longitudinal study of autism during adolescence and adult-hood, research on a demographically-representative sample of parents of individuals with developmental disabilities, and a study of family adaptation to fragile X syndrome (FXS).

RI-CART Community talk
Aging and Autism: Findings from a Longitudinal Family Study
Day: Monday, November 5th
Time: 5:30 - 7pm
Where: Shriners Imperial Room. 1 Rhodes Pl, Cranston, RI 02905

RI-CART Science talk:
From Fragile X Syndrome to fMRI Gene Variation: How Neurodevelopmental Disorders Can Inform Population Health
Day: Tuesday, November 6th
Time 4:00-5:00pm
Where: Brown University -Room (TBA)
Providence, RI
Halloween

SOCIAL STORY

On October 31
I will wear my costume
I will get my Treat Bag

I will go outside to trick-or-treat
I will walk to a house
I will knock on the Door

TRICK OR TREAT
I will say "Trick or Treat"
I will get Candy or small toys
I will say thank you

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Access the Resource Guide online at www.AutismRl.org/resources, or by opening the camera on your phone, and scanning this QR code:

If you would like a printed copy, please let a research assistant know during your visit or call us at 401-432-1200, and we’ll get one to you!