



Meeting of the Interagency Autism Coordinating Committee

Thursday, April 19, 2018

Bethesda Marriot Hotel

5151 Pooks Hill Road
Congressional Room
Bethesda, MD 20814

Conference Call Access:

Phone: 800-857-9791
Access Code: 8959122

Meeting of the IACC



Morning Agenda

9:00 AM **Welcome, Introductions, Roll Call, and
Approval of Minutes**

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive
Secretary, IACC

9:10 **Report from the HHS National Coordinator**

Ann Wagner, Ph.D.
HHS National Autism Coordinator and Chief,
Biomarker and Intervention Development for
Childhood-Onset Mental Disorder Branch
Division of Translational Research
National Institute of Mental Health

Meeting of the IACC



Morning Agenda - continued

9:15

Panel on Employment for People on the Autism Spectrum

Scott Michael Robertson, Ph.D.

Policy Advisor, Youth Policy Team, Office of Disability Employment Policy,
U.S. Department of Labor

Jose Velasco, M.S.

Vice-President of Operations and Strategy
Global Co-Lead, Autism at Work
SAP

Marjorie Madfis, M.B.A.

Yes She Can, Inc.

Meeting of the IACC



Morning Agenda - continued

Panel on Employment for People on the Autism Spectrum

Lori Ireland, M.B.A.

Co-Founder and Board Member
Extraordinary Ventures

Paige Morrow

Managing Director
Extraordinary Ventures

11:00

Morning Break

Meeting of the IACC



Morning Agenda - continued

11:15 **Committee Business**

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive Secretary,
IACC

Joshua Gordon, M.D., Ph.D.

Director, NIMH and Chair, IACC

12:00 PM **Lunch**

Welcome

Introductions

Roll Call

Approval of Minutes



Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC

Susan A. Daniels, Ph.D.
Director, Office of Autism Research
Coordination
Executive Secretary, IACC
National Institute of Mental Health

Report from the HHS National Autism Coordinator



Ann Wagener, Ph.D.

HHS National Autism Coordinator and Chief, Biomarker and Intervention
Development for Childhood-Onset
Mental Disorder Branch
Division of Translational Research
National Institute of Mental Health

**Interagency Autism Coordinating Committee
April 2018 Public Meeting**

Increasing Employment Access for Youth and Adults on the Autism Spectrum

Office of Disability Employment Policy
U.S. Department of Labor

Scott Michael Robertson, PhD
Policy Advisor

April 19, 2018



ODEP Seeks to Increase Employment Access for Americans with Disabilities

Only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities

- **Mission:** Develop and influence policies that increase the number and quality of employment opportunities for people with disabilities
- **Vision:** A world in which people with disabilities have unlimited employment opportunities



ODEP's Current Priorities Include...

- Implementation of the Workforce Innovation and Opportunity Act of 2014 (WIOA)
- Employer Engagement
- Inclusive Apprenticeship and Work-Based Learning
- Career Pathways for Youth and Adults
- Employment First
- Return to Work/Stay at Work
- TA to States on Employment Policy and Practices
- Accessible Workplace Technology and Transportation to Work, including Transportation Technology Innovation



Hiring People with Disabilities Bolsters Large, Medium, and Small Businesses

- 2018 systematic review (20 years of research)¹:
 - Improvements in profitability (profits, retention rate, reliability, company image, etc.)
 - Enhancements to competitive advantage (innovation, work ethic, productivity, customer loyalty, etc.)
 - Inclusive work cultures and awareness of diverse abilities to enhance workplaces
- Benefits of workplace accommodations to employers far outweigh the relatively low cost²



Neurodiversity Benefits Employers

2017 Australian study³ (survey) of 59 employers regarding their employees on the autism spectrum:

- Above average performance: attention to detail, work quality, and work ethic
- 56% of employers report positive adaptations in workplace culture
- 32% of employers report new creative and different skills brought to the workplace
- 24% report improvements in workplace morale
- No significant additional costs to employers



Job Seekers on the Autism Spectrum Have Untapped Skills and Talents

- Diverse focused interests foster specialized talents supporting employment opportunities⁴
- Strengths, skills, and talents enhance employers' performance, missions, and bottom lines^{3, 5-6}
- Supports can help tap skills and talents⁷⁻⁹



Key Facilitators Bolster Employment for People on the Autism Spectrum

- Disability trainings for staff, including focuses on autism⁷
- Trained coaches, mentors, team buddies, etc.⁸
- Enhanced hiring and onboarding processes⁹
- Technological aids⁸
- Individualized workplace trainings in multiple areas⁸
- Customized long-term supports for sensory/motor, social, communication, and executive functioning challenges⁸
- Workplace supports, including for transit to work and executive functioning for tasks to secure accommodations⁸



ODEP Provides Resources on Autism

- ODEP's webpage on autism (for employers, service providers, policymakers, individuals, and youth):
<https://www.dol.gov/odep/topics/Autism.htm>
- Job Accommodation Network (JAN):
 - <http://askjan.org> | 800-526-7234
 - assistance for employers, employees, job seekers, etc.
 - JAN's webpage on autism (accommodations, interviewing tips): <https://askjan.org/media/autism.htm>



DOL Supports Autism-Related Initiatives

- ODEP's Pathways to Careers Demonstration Grants
 - [Universal Pathways to Employment](#) (UPEP) project at Pellissippi Community College (Knoxville, TN)
 - [Onondaga Pathways to Careers](#) (OPC) project at Onondaga Community College (Syracuse, NY)
- Employment and Training Administration (ETA) grants for job development and training



ODEP's Pathways to Careers Grants Include Students on the Autism Spectrum

- Prioritize work-based learning, accommodation access, and persistence to degree completion
- Integrate Universal Design for Learning
- Support youth and young adults with disabilities who are aged up to 24
- Include a high % of students on the autism spectrum:
 - UPEP: 35% of participants identify on the autism spectrum
 - OPC: 19% of participants identify on the autism spectrum

ETA's Grants for Job Development Support Autism-Related Initiatives

- Tech Hire grant to Exceptional Family Center (5 yrs.)
 - Supports Next Step Job Training and Employment Partnership in 3 California counties
 - Plans to foster job development and training for an anticipated 450 people on the autism spectrum in healthcare, IT fields
- American Apprenticeship grant to AHIMA Foundation (5 yrs.)
 - Supports Managing the Talent Pipeline in Health Information Apprenticeship program
 - Incorporates a medical coding apprenticeship for people on the autism spectrum



References

1. Lindsay, S., Cagliostro, E., Albarico, M., Mortaji, N., & Karon, L. (2018). A systematic review of the benefits of hiring people with disabilities. *Journal of occupational rehabilitation*, 1-22.
2. Job Accommodation Network (JAN). (2017). *Workplace Accommodations: Low Cost, High Impact*. Retrieved March 28, 2018 from <https://askjan.org/media/downloads/LowCostHighImpact.pdf>
3. Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PloS one*, 12(5), e0177607.



References (Cont.)

4. Koenig, K. P., & Williams, L. H. (2017). Characterization and utilization of preferred interests: a survey of adults on the autism Spectrum. *Occupational Therapy in Mental Health, 33*(2), 129-140.

5. Annabi, H., Sundaresan, K., & Zolyomi, A. (2017, January). It's Not Just About Attention to Details: Redefining the Talents Autistic Software Developers Bring to Software Development. In *Proceedings of the 50th Hawaii International Conference on System Sciences*.

6. Pfeiffer, B., Braun, K., Kinnealey, M., Derstine Matczak, M., & Polatajko, H. (2017). Environmental factors impacting work satisfaction and performance for adults with autism spectrum disorders. *Journal of Vocational Rehabilitation, 47*(1), 1-12.



References (Cont.)

7. Hensel, W. F. (2017). People with Autism Spectrum Disorder in the Workplace: An Expanding Legal Frontier. *Harvard Civil Rights-Civil Liberties Review*, 52.

8. Harmuth, Silletta, Adams, Beck, & Barbic (2018). Barriers and Facilitators to Employment for Adults with Autism: A Scoping Review. *Annals of International Occupational Therapy*, 1, 31-40

9. Markel, K. & Elia, B. (2016). How Human Resource Management Can Best Support Employees with Autism: Future Directions for Research and Practice. *Journal of Business and Management*, 22, 71-85.



AUTISM AT WORK



Jose H. Velasco, VP Products and Innovation

Diversity  Inclusion

About Autism

Autism Spectrum Disorder (ASD) is a developmental disorder that impairs the ability to communicate and interact.

Impact

1/42 Boys and 1/189 Girls according to CDC

Unemployment

85% of people diagnosed with autism spectrum disorders are unemployed even though 60% have average to above average cognitive abilities. Many people who are employed are under-employed or partially employed.

Opportunity

50,000 Unfulfilled STEM jobs in the Bay Area alone

Is Bias Getting in the Way ?

ADVICE

Failure to make eye contact can alienate hiring managers

Establishing eye contact builds essential rapport. But eye contact isn't the only must-have attribute.

Other interview killers are the failure to smile, bad posture, inappropriate clothing, too much fidgeting, a weak handshake, playing with hair or face, or arms crossed over the chest.

Why do we Hire People with Autism ?

Attract the Best Talent in Our Industry

Bring a Different Perspective to Our Creative Process

Tap into Underutilized Source of Talent

Capture Special Skills of People with ASD

Retention

Because we CAN

10 Countries

Argentina, Australia, Brazil, Canada, China, Czech Republic, India, Ireland, Germany, U.S.

Currently, 132 Employed

Full and Part Time Jobs, Internships, Contractors, Vocational School (in Some Countries)

A Total of 300 Opportunities

Present and Past Paid Opportunities + HS/College Training Opportunities

21 Roles

- Software Developer
- Information Developer/KM
- Software Tester
- Business Analyst
- IT Technical Support
- System Administrator
- Marketing Operations Associate
- Networking Specialist
- Procure-to-Pay Service Associate
- Development Associate Consultant
- HR Service Associate
- IT Project Management
- Customer Support Associate
- Graphic Designer
- Multimedia Specialist
- Employee Communications
- Data Analyst
- Associate Consultant
- Product Manager
- Finance Operations Associate
- Channel Sales Development

Roadmap

2013

2015

2016

2017

2019

2020

...

**LEARN VIA
PILOTS AT
LOCATIONS
WORLDWIDE**

**PROCESS
MAINSTREAMING
& SUSTAINABILITY**

**PROCESS
MATURITY
ONBOARDING
EQUIVALENCY**

Change Management

Mainstreaming Best Practices



Implementation

Our Partners

GLOBAL



Brazil

Germany

U.S.



Argentina

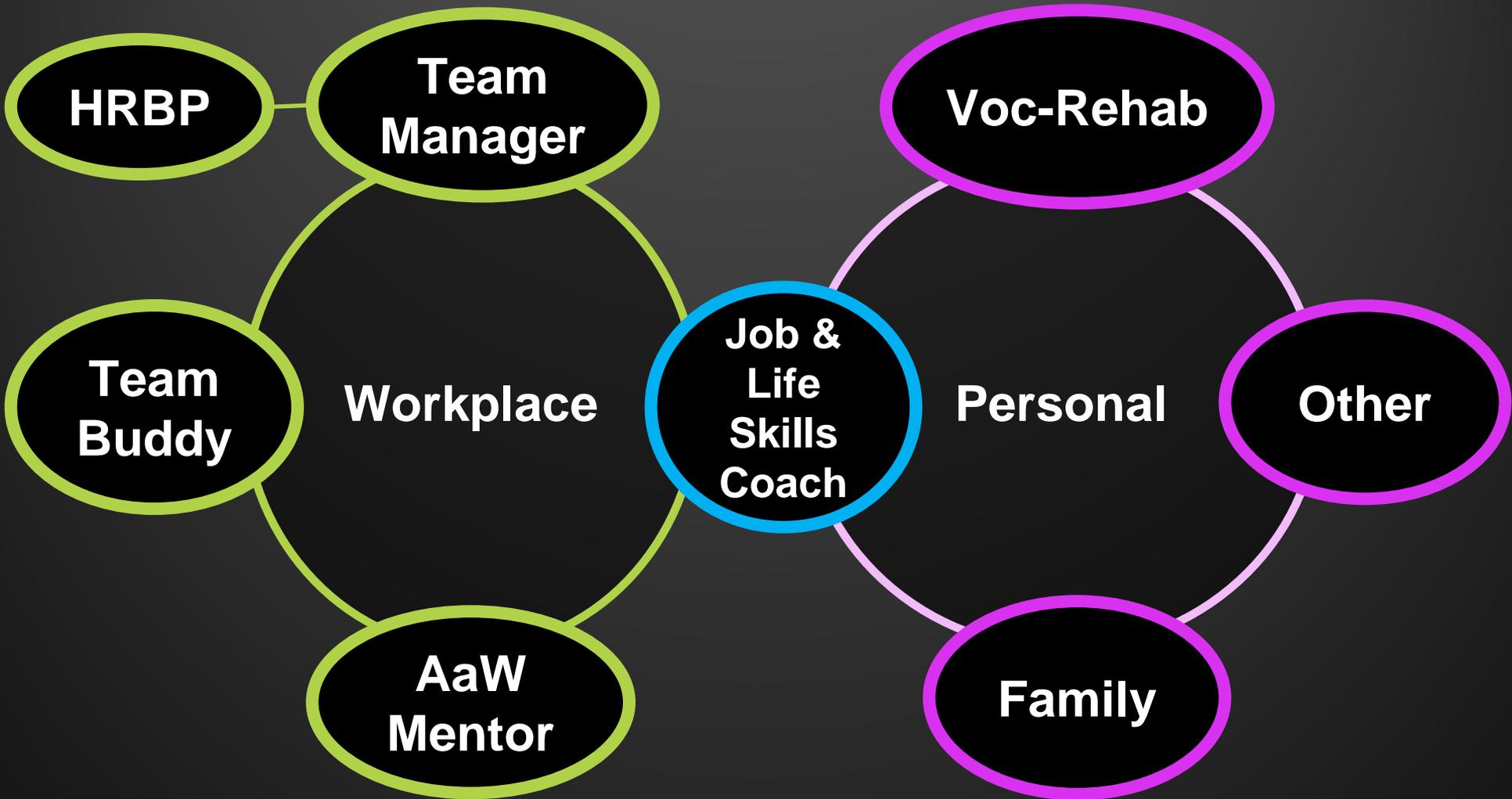
Czech Republic

India

High Level Process



Support Circles



Impact on Talent



Patrick



Janis



Mark



Thank you

Diversity+Inclusion

Yes She Can^{INC.}TM

DEVELOPING JOB SKILLS FOR YOUNG WOMEN WITH AUTISM.

NIH Interagency Autism Coordinating Committee

MARJORIE MADFIS, PRESIDENT

APRIL 19, 2018

Introduction

- Marjorie Madfis
- Parent of 22 year-old daughter with ASD
 - diagnosed at age 2.6
 - advocate for inclusion
- Professional background
 - Economic Development, public sector
 - MBA
 - 30 year career in corporate marketing
 - Founded Yes She Can nonprofit in November 2013

Characteristics of Successful Employees

- ✓ Motivated and ability to persevere
- ✓ Good social communication skills
- ✓ Problem solving skills
- ✓ Cognitive and emotional adaptability
- ✓ Flexibility
- ✓ Good emotional regulation

All these characteristics are core challenges for people with ASD

Are transitioning adults prepared?

	Special Ed.	Workplace
Support	Teacher and TA	Peers
Goal	Right answer No melt down	Solutions to problems
Organization	Structured, Predictable	Flexible, Fluid, Hidden rules
Approach	Independent	Collaboration, Discretion
Communication	Selective, Dependent	Necessary, Initiate
Intensity	50-minute class, breaks	until it is done

Change the model: Teach from a business perspective

- Tasks with a reason - why
- Process – how to get things done
- Problem-solving – no clear rule
- Dealing with uncertainty
- Collaborative decision-making
- Understanding shifting priorities
- Responsibility and commitment
- It's not about you- it's about the customer or the manager





Program & Curriculum
Skilled staff
Operating business



Product supply:
Donated
American Girl dolls
and accessories



Employment
Independence
Advocacy



Market demand:
Customers for
dolls at lower
prices; collectors

Program target participants

- Women with ASD and related social, language and learning disabilities
 - ultimate goal of employment
 - supportive, independent, part-time or full-time
- High school
 - Last year
- High School grads
 - Not engaged
- College students
 - No work experience



Key Differentiators

- Immersive learning design, with professional staff
 - Social workers, psychologists, business executives
- Communication skills practiced in safe, integrated setting
 - “The Hidden Curriculum” directly taught
 - Self- Advocacy
- Direction and feedback from manager
- Individualized goals
- Assessment process



What we are teaching: business

Merchandising

- Assess, research, price, inventory

Sales

- Communicate, selling, transactions

Marketing

- Customer database
- Social media, web e-commerce

Administration

- Quick Books
- Store maintenance



What we are teaching: how to work



- Information-gathering
- Recommendations with rationale
- Negotiating
- Decision-making
- Collaborating with peers
- Answering to management
- Problem-solving for business needs

What we are teaching: how to interact

- Perspective-taking
 - business objectives
 - manager expectations
- Interacting with customers
- Sensitivity to others
- Appropriate conversation
- Collaborating with co-worker
- Participation in team meetings



What we are teaching: emotional regulation



- Accountable for own actions
- Cooperative and courteous
- Motivation
- Execute “non-preferred” tasks
- Sustain attention and pace
- Accept critical feedback
- Strategies to deal with frustration

Team meeting

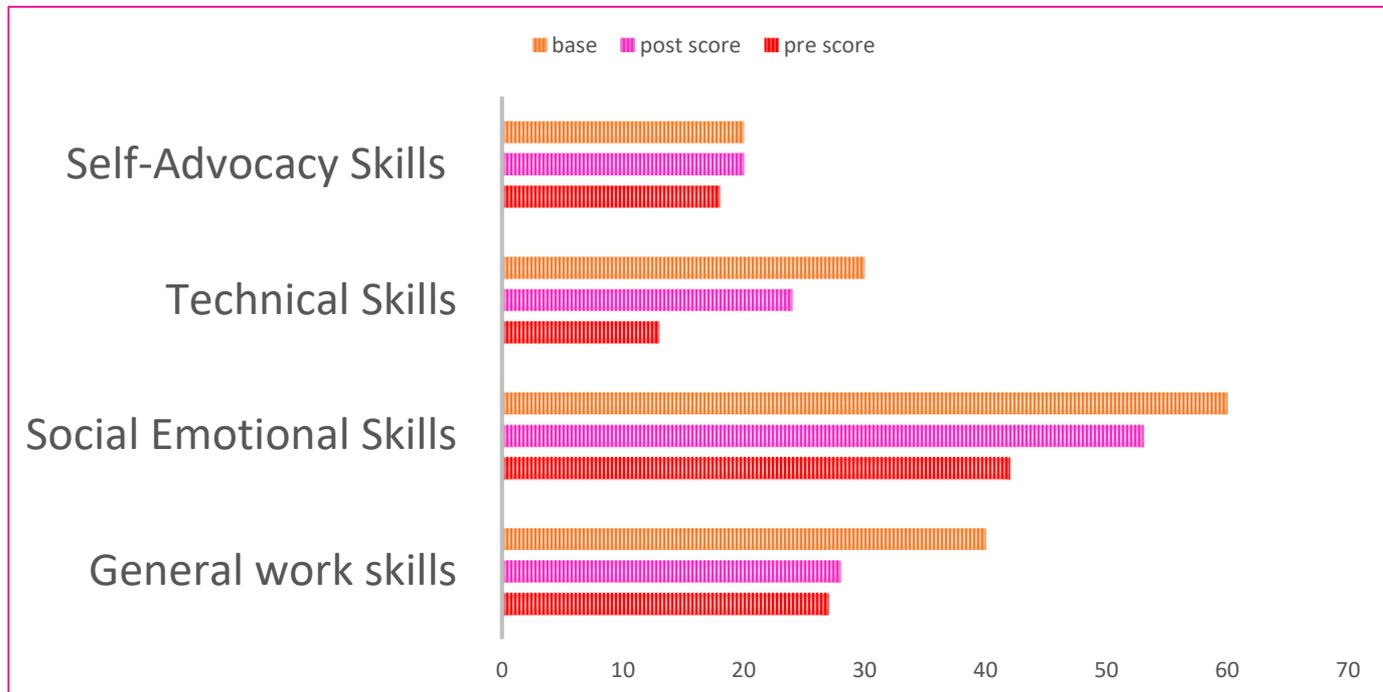


Case study: Maki

- Graduated 4-year college 2015; with support
- Lives at home, Independent travel, bi-lingual
- VR: 1 year to find job; placed in job at job developer's agency
- Working now 15 hours per week, paid by VR

After enrolled in
program for 18
months,
6 hr/week

Change over last
4 months

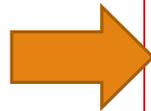


Case study: Isabelle

- Completed high school, no diploma; work experience program
- Lives at home, para-transit
- Attends college / transition program 20 hr/week with mentors

Coaching 2
hr/week; involved
from beginning

Change over last
4 months:



Assessment outcomes

- At work: all had improvements in
 - Flexibility
 - Stamina
 - Appropriate social engagement
 - Ability to accept critical feedback
- At home: parents observed
 - Increased independence
 - Engaged in decision-making, offering suggestions
 - Taking more responsibility
 - Greater self-confidence



Findings

- Intellect or academic attainment does not predict success
- Learn tasks quickly, particularly computer and digital
- Limiting factor: Lack of perspective
 - Leads to inflexible
 - Leads to anxiety
- No one likes being autistic
 - “*Why was I cursed with autism*”
- Isolated, no other options
 - Girl AGain is the highlight of their week
 - Depression



*Izzie, go
help the
customer*



*Not now.
I'm busy.*

Observations

- VR provider agencies don't "get" autism
- OPWDD – rejects 80% for “employment training program”
 - Cake needs to be baked before going into the oven
- Job developers should work with smaller businesses
 - Flexibility: No HR or legal department
 - Identify opportunities to help company be more efficient
- Businesses need training
 - Afraid of behaviors, burdens
- Technology to support more independence at work
 - Develop solutions
 - Business buy-in and use

Video

<https://www.youtube.com/watch?v=10EM6g8C7Oc>

Thank you



**Women with autism.
We work. With you.**

Organization

Incorporated in New York, November, 2013

IRS tax exempt designation 501c3 EIN 46-4224215

Executive Director: Marjorie Madfis, MBA

Yes She Can Inc. office

35 Hubbard Drive

White Plains, NY 10605

- 914-428-1258
- YesSheCanInc.org
- info@YesSheCanInc.org

[Donate](#)

Girl AGain boutique

4 Martine Avenue

White Plains, NY 10606

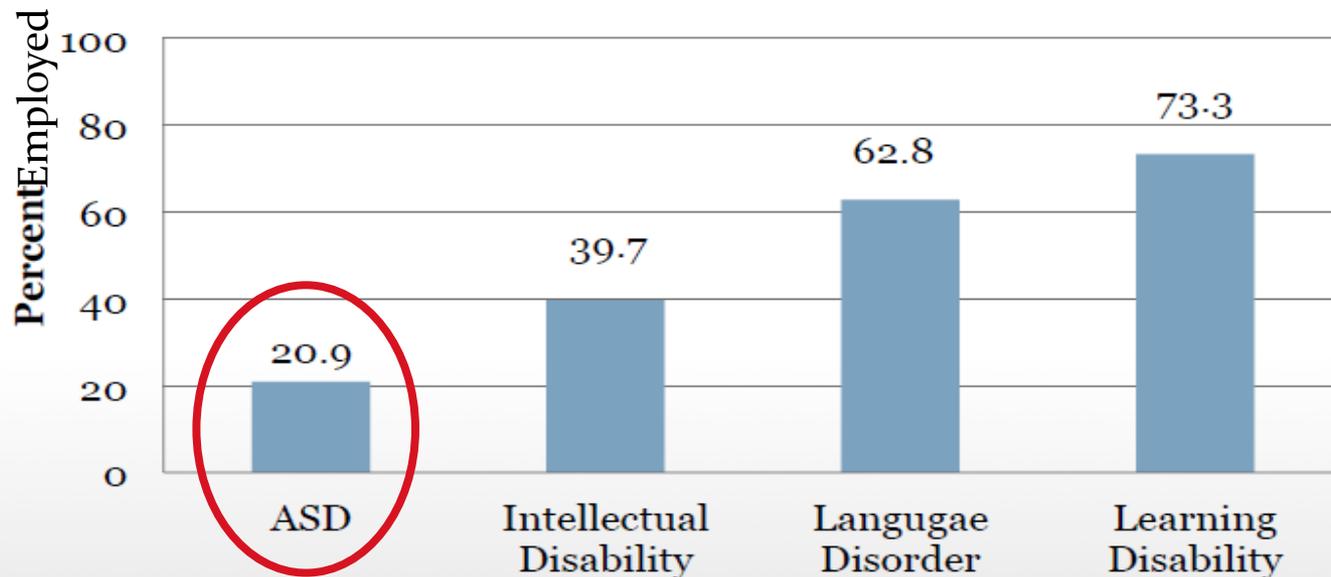
- 914-358-1460
- GirlAGain.com

[Donate dolls](#)

Back up

As a result of specific challenges for individuals with ASD, employment outcomes are poor

Full-Time Employment (21-25 Year Olds)



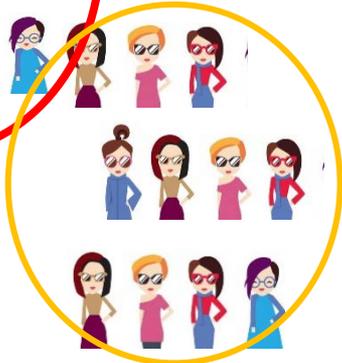
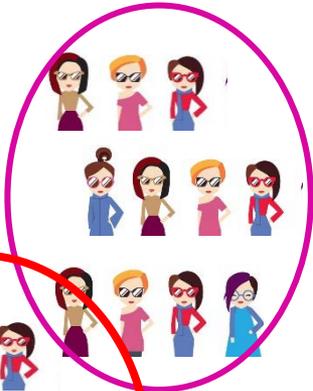
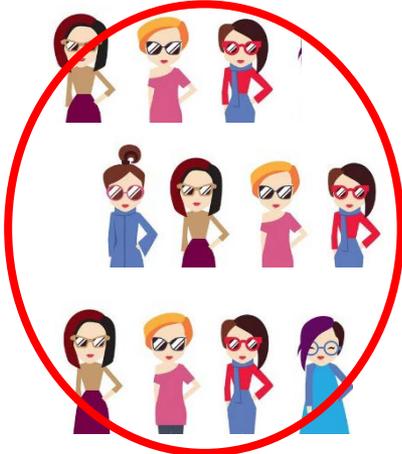
(NLTS2 Study; Roux et al., 2013)

Who is focused on employment?

Autism Employment Models

- **Agency managed**
 - Employment
 - SAARC: Beneficial Beans
 - Ability Beyond: Roses for Autism
- **Family created**
 - For profit or non-profit
 - Goal: Long-term employment
 - Extraordinary Ventures (NP)
 - Rising Tide Car Wash (P)
 - Spectrum Designs (NP)
 - Autonomy Works (B corp.)
- **Training for competitive placement**
 - Yes She Can Inc. (Girl AGain)
- **Competitive differentiation**
 - Ultra Testing
 - SAP
- **Supported employment at conventional business sites**
 - VR agency placements
 - DD agency placements
- **Business with design to employ people with DD**
 - Walgreens

Yes She Can Impact



Vision
of
need



Program
creation
and test
(Girl AGain
Hartsdale)



Program
expansion
(Girl AGain
White Plains)
• Training
• Social
• Placement



Yes She Can program
implementation in
multiple locations,
businesses; placement

2013 ->

2014 ->

2015 - 2019 ->

2020

Meaningful Employment for Adults with Developmental Disabilities



Lori Ireland, M.B.A.

Co-Founder and Board Member
Extraordinary Ventures

Paige Morrow

Managing Director
Extraordinary Ventures



Morning Break

IACC Committee Business

IACC Full Committee Meeting
April 19, 2018



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

Thanks to OARC Staff



Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

Rebecca Martin, M.P.H
Public Health Analyst

Angelice Mitrakas, B.A.
Management Analyst

Karen Mowrer, Ph.D.
Science Policy Analyst

Julianna Rava, M.P.H.
Science Policy Analyst

Matthew Vilnit, B.S.
Operations Coordinator

Jeff Wiegand, B.S.
Web Development Manager



April is National Autism Awareness Month



NIMH Special Event for Autism Awareness Month



The Story Behind Julia, Sesame Street's Muppet with Autism April 9, 2018



- Panel presentation featuring speakers from [Sesame Workshop](#), the nonprofit educational organization behind *Sesame Street*
- Meet-and-greet with a costumed Julia character

Archived video available:
<https://iacc.hhs.gov/meetings/autism-events/2018/april9/sesame-street.shtml#video>

Autism Awareness Month News



- 2018 Presidential Proclamation:
[President Donald J. Trump Proclaims April 2, 2018, World Autism Awareness Day](#)
- 2018 UN Secretary-General Message:
[António Guterres' Message on World Autism Awareness Day](#)

Autism Awareness Month Events



- **Autism Awareness Interagency Roundtable**

Indian Health Service

April 2, 2018; Bethesda, MD

- **Empowering Women and Girls with Autism**

United Nations

April 5, 2018; New York, NY

Event page: <https://www.un.org/en/events/autismday/>

Archived video available: <https://www.youtube.com/watch?v=Tyhm7p8Gr2A>

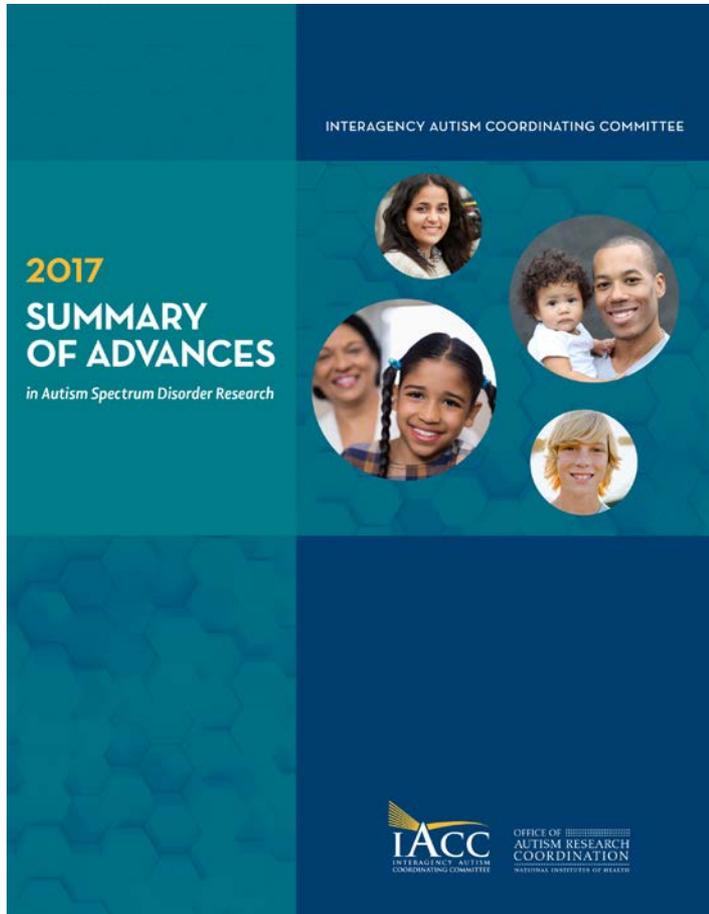
- **Developing Individuals Who Have Different Kinds of Minds,
featuring Temple Grandin, Ph.D.**

National Institute of Environmental Health Sciences

April 12, 2018; Research Triangle Park, NC

Archived video will be available: <https://videocast.nih.gov>

2017 Summary of Advances



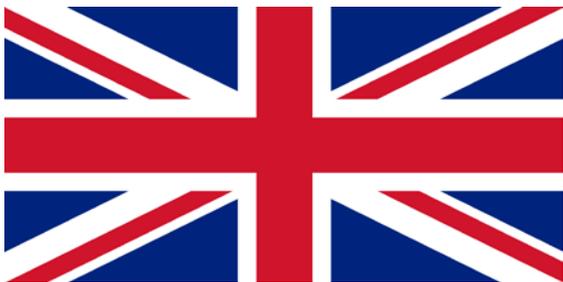
- Annual publication – required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Covers articles aligning with all seven Strategic Plan Question areas

<https://iacc.hhs.gov/publications/summary-of-advances/2017>

2016 ASD Research Portfolio Analysis



- OARC is currently analyzing data for the 2016 *IACC ASD Research Portfolio Analysis Report*
- Using 2016 data, OARC/NIMH/NIH, Autistica (UK), and the Canadian government are planning to collaborate to produce the first International Autism Research Portfolio Analysis Report
 - Preliminary results of this analysis will be presented at the INSAR Annual Meeting, May 2018
 - Hope to stimulate broader international participation in future years



Autism CARES Act Report to Congress



- Report details progress on activities related to ASD and other developmental disorders across the federal government (required by the Autism CARES Act)
- OARC is coordinating preparation of the Report
- Requests for data have been received from relevant federal agencies
- Report expected in Fall 2018



Improving Health Outcomes for Individuals on the Autism Spectrum WG



- The IACC is in the process of convening a working group on health and wellness issues
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor
- Scope
 - General health and wellness for individuals with ASD
 - Co-occurring conditions and preventative approaches to address them, e.g. obesity
 - Co-occurring mental health conditions
 - Long-term medication use
 - Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
 - Patient-provider interactions
 - Medical practitioner training
 - Parental/family mental health
 - Reproductive/maternal health care

Improving Health Outcomes for Individuals on the Autism Spectrum WG



- Next steps
 - Working Group workshop in Summer 2018
 - Select 1-2 topics from:
 - General health and wellness for individuals with ASD
 - Co-occurring conditions and preventative approaches to address them, e.g. obesity
 - Co-occurring mental health conditions
 - Long-term medication use
 - Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
 - Patient-provider interactions
 - Medical practitioner training
 - Parental/family mental health
 - Reproductive/maternal health care

2018 Summary of Advances Discussion

IACC Full Committee Meeting
April 19, 2018



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Joshua A. Gordon, M.D., Ph.D.

Director, National Institute of Mental Health
Chair, IACC

Question 1: Screening and Diagnosis



AUTISM
RESEARCH
January, 2017 | Volume 10 | Number 1

Mar 2018

Parent and clinician agreement regarding early behavioral signs in 12- and 18-month-old infants at-risk of autism spectrum disorder.

Sacrey LR, Zwaigenbaum L, Bryson S, Brian J, Smith IM, Roberts W, Szatmari P, Vaillancourt T, Roncadin C, Garon N

Question 2: Underlying Biology

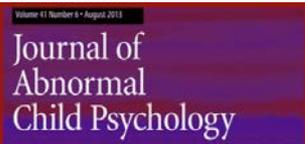


The logo for the Proceedings of the National Academy of Sciences (PNAS) is located on the left side. It features the letters 'PNAS' in a large, blue, serif font. Below the letters, the text 'Proceedings of the National Academy of Sciences of the United States of America' and the website 'www.pnas.org' are written in a smaller, blue font.

Apr 2018

Neuron numbers increase in the human amygdala from birth to adulthood, but not in autism.

Avino TA, Barger N, Vargas MV, Carlson EL, Amaral DG, Bauman MD, Schumann CM



Feb 2018

Overlapping and Distinct Cognitive Impairments in Attention-Deficit/Hyperactivity and Autism Spectrum Disorder without Intellectual Disability.

Karalunas SL, Hawkey E, Gustafsson H, Miller M, Langhorst M, Cordova M, Fair D, Nigg JT

Question 3: Risk Factors



Feb 2018

Shared molecular neuropathology across major psychiatric disorders parallels polygenic overlap.

Gandal MJ, Haney JR, Parikshak NN, Leppa V, Ramaswami G, Hartl C, Schork AJ, Appadurai V, Buil A, Werge TM, Liu C, White KP; CommonMind Consortium; PsychENCODE Consortium; iPSYCH-BROAD Working Group, Horvath S, Geschwind DH



Mar 2018

Air Toxics in Relation to Autism Diagnosis, Phenotype, and Severity in a U.S. Family-Based Study.

Kalkbrenner AE, Windham GC, Zheng C, McConnell R, Lee NL, Schauer JJ, Thayer B, Pandey J, Volk HE

Question 4: Treatments and Interventions



The International Journal of Research and Practice ● Volume 21 Number 5 July 2017

autism

Feb 2018

Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder.

Nevill RE, Lecavalier L, Stratis EA

Question 5: Services



Journal of the American Academy of
**CHILD & ADOLESCENT
PSYCHIATRY**

Feb 2018

Effects of State Autism Mandate Age Caps on Health Service Use and Spending Among Adolescents.

Kennedy-Hendricks A, Epstein AJ, Mandell DS, Candon MK, Marcus SC, Xie M, Barry CL

**PUBLIC
HEALTH**
Reports

Jan/Feb 2018

Trends in Special Education Eligibility Among Children With Autism Spectrum Disorder, 2002-2010.

Rubenstein E, Daniels J, Schieve LA, Christensen DL, Van Naarden Braun K, Rice CE, Bakian AV, Durkin MS, Rosenberg SA, Kirby RS, Lee LC

Question 5: Services



Mar 2018

JAMA Pediatrics

Vaccination Patterns in Children After Autism Spectrum Disorder Diagnosis and in Their Younger Siblings.

Zerbo O, Modaresi S, Goddard K, Lewis E, Fireman BH, Daley MF, Irving SA, Jackson LA, Donahue JG, Qian L, Getahun D, DeStefano F, McNeil MM, Klein NP

Question 6: Lifespan Issues



(There were no nominations covering Question 6 topics from January – April 2018)

Question 7: Infrastructure and Surveillance



(There were no nominations covering Question 6 topics from January – April 2018)



Lunch

Meeting of the IACC



Afternoon Agenda

1:00

Public Comment Session

Joshua Gordon, M.D., Ph.D.

Director, NIMH and Chair, IACC

Oni Celestin, Ph.D.

Science Policy Analyst, Office of Autism Research
Coordination, NIMH

Meeting of the IACC



Afternoon Agenda (continued)

2:45

**Aggression and Self-Injury:
Research Needs for the Severely Affected End of
the Spectrum**

Matthew Siegel, M.D.

Director, Autism & Development Disorders Inpatient
Research Collaborative (ADDIRC)
Maine Medical Research Institute
Vice President Medical Affairs
Developmental Disorders Service
Maine Behavioral Healthcare

Meeting of the IACC



Afternoon Agenda (continued)

- | | |
|-------------|--|
| 3:15 | Committee Discussion |
| 4:00 | Afternoon Break |
| 4:15 | Round Robin |
| 5:00 | Closing Remarks and Adjournment |

Oral Public Comment Session



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health
Chair, IACC

Oni Celestin, Ph.D.

Science Policy Analyst, Office of Autism
Research Coordination
National Institute of Mental Health

Autism and Aggressions

Cheryl C. Smith

Background



- Accept vs. Afraid
- Limitations
 - Policy
 - Funding
 - Access
- Where do aggressions come from?

Carson

- Big guy - The Mancub
- 95% teddy bear - 5% tiger
- No easy fix
 - Medication
 - Behavioral interventions



Self-injury



Biting



Biting

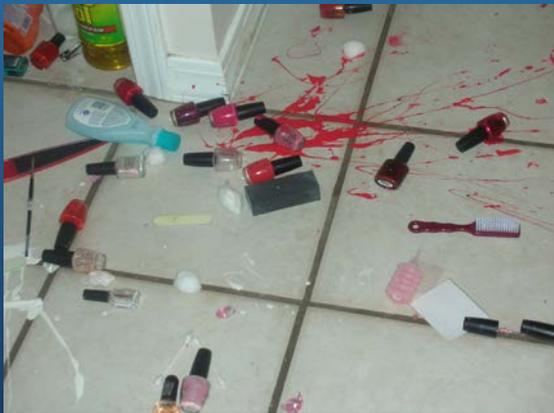
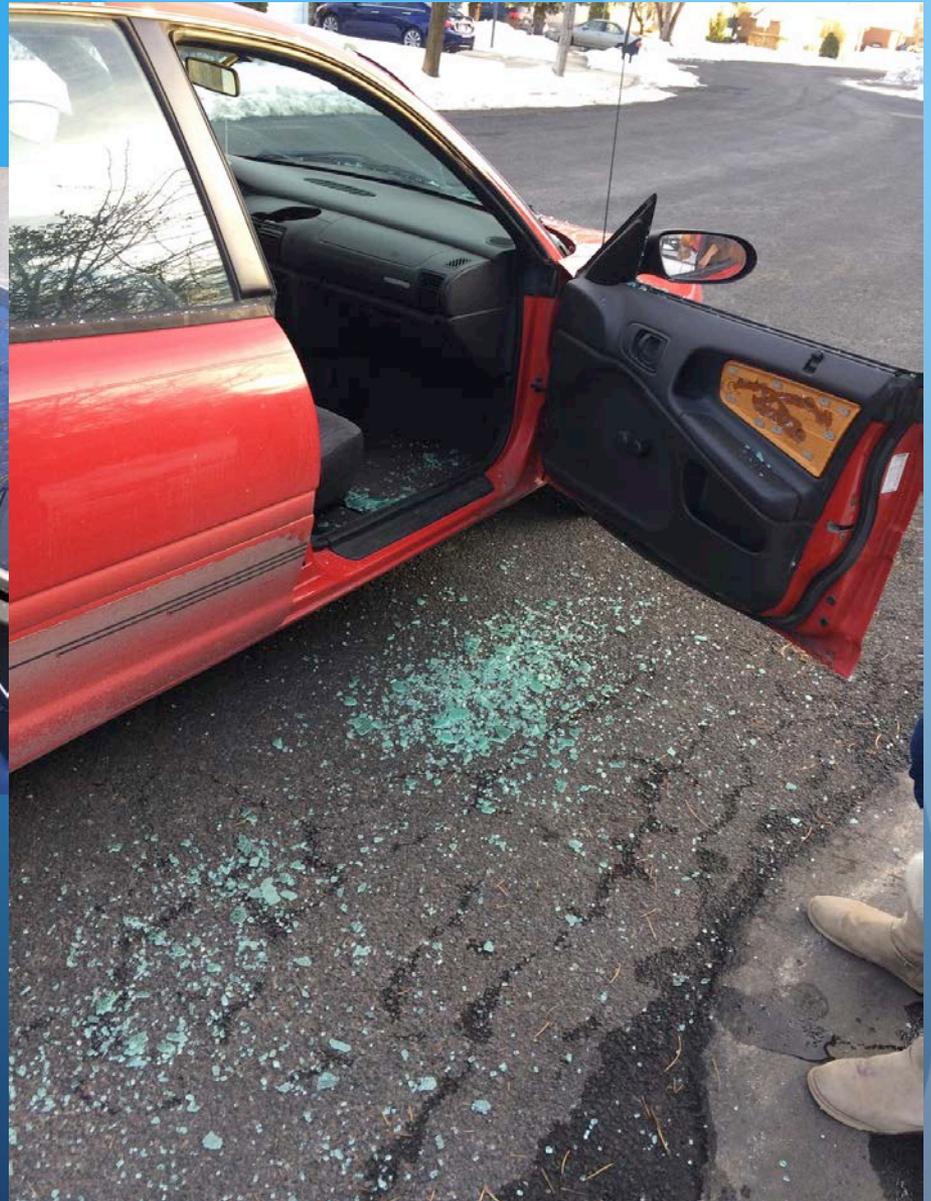


Pinching





Destruction of property



What is the answer?



Let's do this thing!

- Quality life skills day program - Pingree Autism Center
 - Academics
 - Library
 - Culinary
 - Agriculture
 - Arts & Crafts
 - Fitness Education
 - Home Living
 - Vocational Training
 - Social & Leisure Skills



Road Blocks...

Medicaid Settings Rule



Autism never sleeps, it doesn't go on vacation, it's there on Sunday's and holidays, it never takes a day off.

Autism never takes a break
Therefore...neither can we!

Thank you

Cheryl and Carson



Oral Public Comment Session



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Written Public Comment Session



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Science Policy Analyst, Office of Autism
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National Institute of Mental Health

AGGRESSION AND SELF-INJURY: RESEARCH NEEDS FOR THE SEVERELY AFFECTED END OF THE SPECTRUM

Matthew Siegel, M.D.

**Associate Professor of Psychiatry & Pediatrics
Tufts University School of Medicine**

**VPMA, Developmental Disorders Service
Maine Behavioral Healthcare**

**Faculty Scientist II
Maine Medical Center Research Institute**

DISCLOSURES

Source	Clinical Advisor	Employee	Research Funding
Maine Behavioral Healthcare		X	
NIMH, Simons Foundation, NLM Family Foundation			X
Camp Alsing	X		

AGENDA

- Aggression and self injury – prevalence and impacts
- Multi-disciplinary approaches to serious challenging behaviors
- Studying the severely affected: The Autism Inpatient Collection (AIC)
- Novel approach to challenging behaviors
- Critical areas for further research

AGGRESSION AND SELF INJURY: A BIG PROBLEM

“My son is 19. Severely autistic. Can’t speak. Getting more and more aggressive !!! Not only bites his wrist, he bangs walls and breaks things, and then comes after us. I can’t keep locking myself in a room because he will bang the door down... No doctor in our area knows anything of what to do...Please, please I’m reaching out. There must be something for him...not fair for me and most certainly not fair to him! Cry for help!”

AGGRESSION PREVALENCE & IMPACTS

- Up to 2/3 of youth with ASD develop aggression

- Kanne SM, Mazurek MO. *J Autism Dev Disord.* 2011

- Aggression is one of the primary reasons youth with ASD use behavioral healthcare services

- Arnold LE, Vitiello B, McDougle C, et al. *J Am Acad Child Adolesc Psychiatry.* 2003

- Families report that aggression is **often of greater concern and negative impact than the core social and communicative deficits that define ASD**

- Hodgetts S, et al. *Focus Autism Other Dev Disabl.* 2013

- Farmer CA, Aman MG. *Res Autism Spectr Disord.* 2011

- Studies in ASD suggest that broadly-defined problem behaviors are heightened in ASD compared to typically developing (TD) and intellectually disabled (ID) samples; further, some ASD subgroups engage in persistent or increasing problem behaviors into adulthood.

- Gray K, et al. *Am J Intellect Dev Disabil.* 2012

- Woodman AC, et al., *Dev Psychopathol.* 2016

PARTICULARLY FOR THE MINIMALLY VERBAL

- Inability to efficiently report distress makes aggression seem to occur “out of the blue.”
 - Results in:
 - Caregivers unable to anticipate an aggressive outburst
 - Increasingly restrictive educational settings or exclusion
 - Inability to access community
 - High utilization of psychotropics, hospitalizations, out of home placements
 - Limits opportunities for real-time prevention (calming strategies, de-escalation techniques, functional communication)
- The unmeasured effect of serious problem behaviors is a bending of the developmental trajectory downward

DEVELOPMENTAL DISORDERS SERVICE MAINE BEHAVIORAL HEALTHCARE

Spring Harbor Hospital DD Unit,
Spring Harbor Academy, Day Treatment,
Outpatient Clinic, Autism Research Team



Aggression is A Final Common Pathway Symptom

Aggression

Psychiatric Co-Morbidity

Behavioral Function & Reinforcement

Functional Communication Deficits

Side Effects

Dysregulated Sensory System

Demands : abilities mismatch

Family Changes

Medical Illness/Pain

Genetically Linked

Emotion Regulation

FOUNDATION OF TREATMENT

- **Highly individualized behavioral plan with embedded communication and occupational therapy supports**
- **Targeted psychopharmacology**
- **Transfer of management skills to parents, local school, in-home staff**

MULTI-DISCIPLINARY TREATMENT TEAM

- Child Psychiatry and Pediatrics
- Behavioral Psychologist
- Behavioral Coordinator (BCBA)
- Special Education
- Speech Pathologist
- Occupational Therapist
- Nursing
- Social Work
- Milieu Coordinator (OT)



THERAPEUTIC APPROACHES FOR CHALLENGING BEHAVIORS

- Applied Behavioral Analysis
- Psychotropic Medication

30% of functional behavioral assessment studies are inconclusive about behavioral function

- Derby KM, et al, 1992, *J Appl Behav A*; Iwata BA, et al., *J Appl Behav Anal.* 1994; Vollmer TR, et al., *J Appl Behav Anal.* 1994

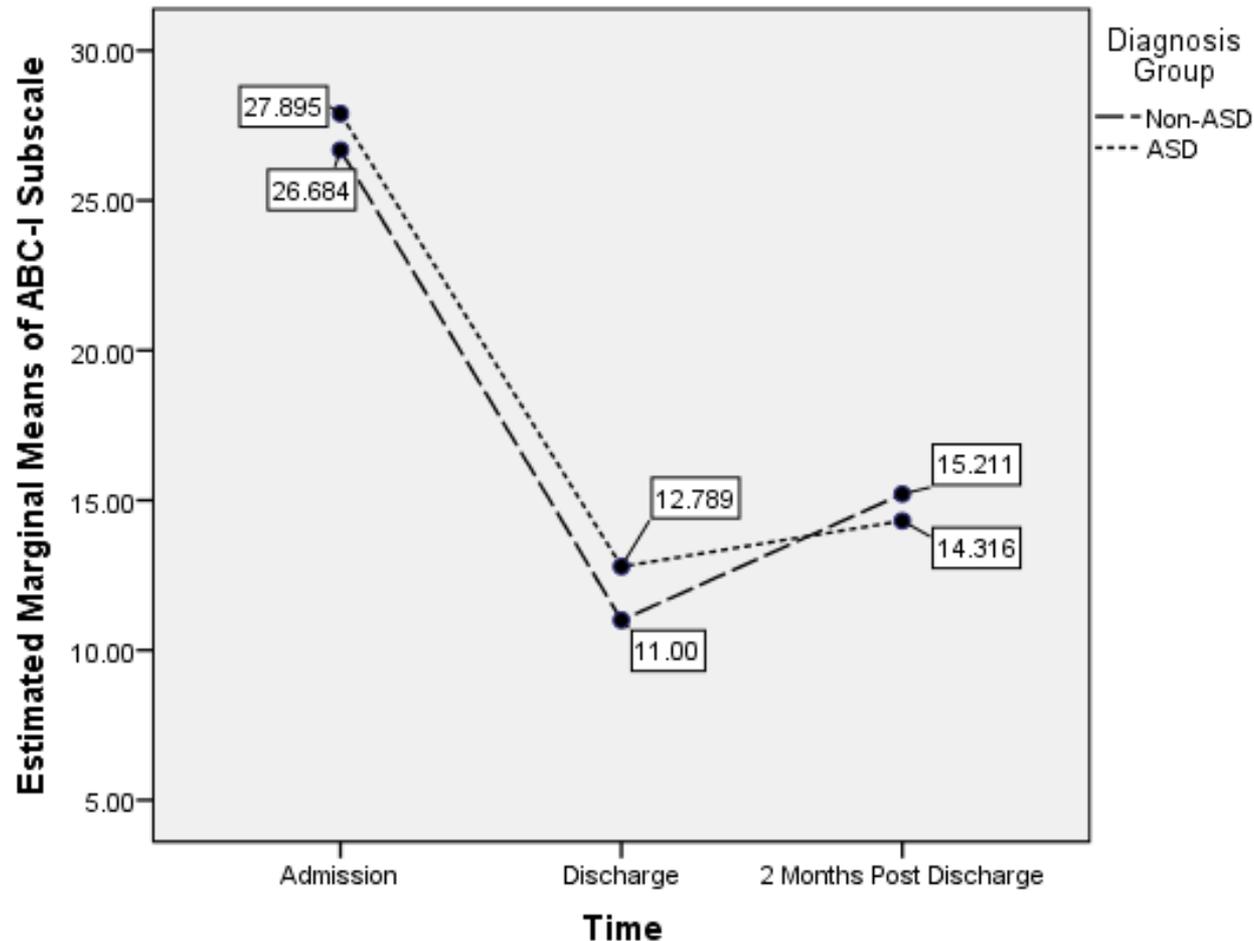
Significant side effects and inconsistent success

- Siegel M & Bealieu, A, *JADD*, 2011

- Communication strategies
(AAC/Functional Communication)
- Treat Medical Problems
- Family treatment
- Parent Management Training (RUBI)
- Sensory regulation strategies
- Social skills / social cognitive strategies
- Psychotherapy approaches – CBT / Emotion regulation

CHANGE IN BEHAVIORAL FUNCTIONING

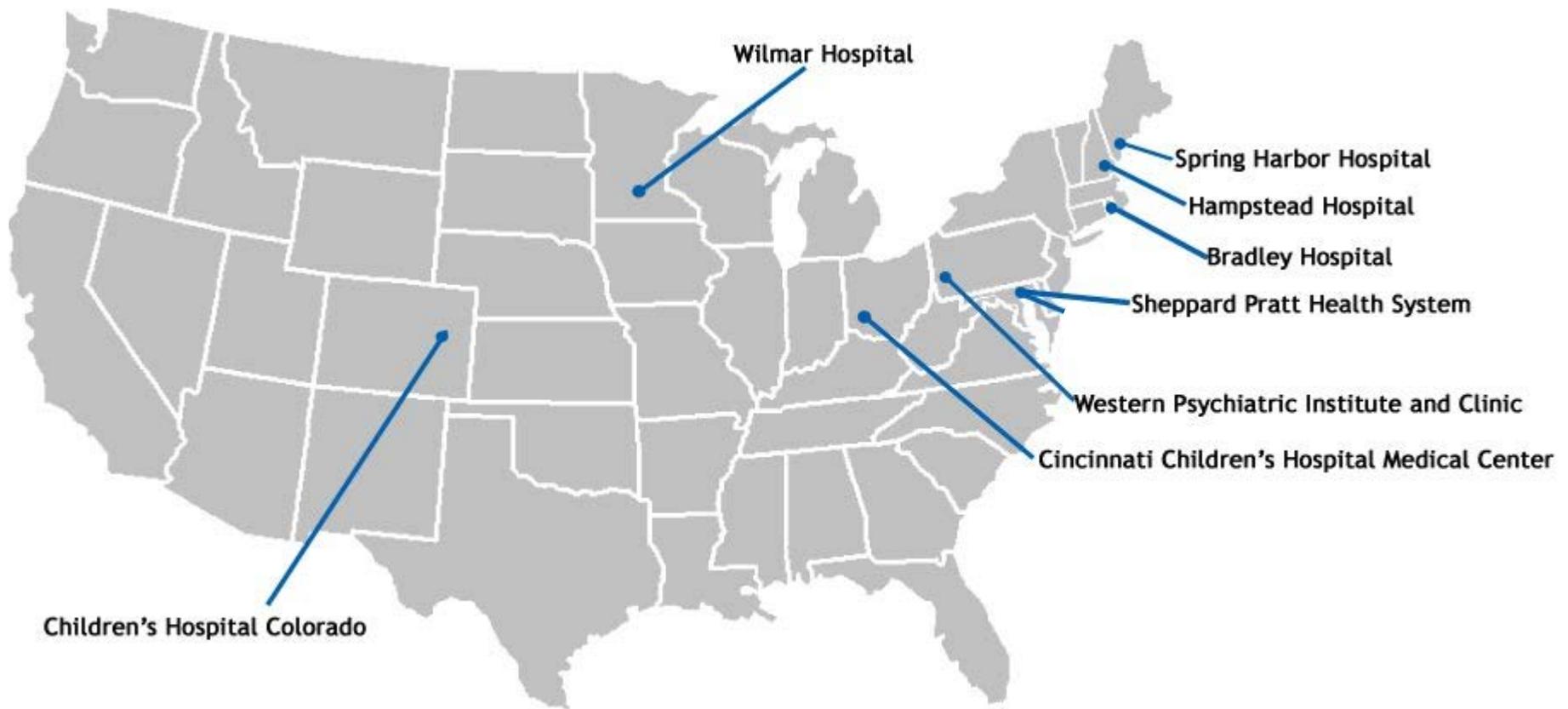
Figure 1. Estimated Marginal Means of Abberant Behavior Checklist Irritability (ABC-I) Subscale Between Children with and without Autism Spectrum Disorder (ASD) Over Time





ADDIRC Autism & Development Disorders
Inpatient Research Collaborative

AIC Autism
Inpatient
Collection



AIC RATIONALE



Knowledge & treatment options continue to lag for those with autism who are non-verbal, have an intellectual disability and/or display challenging behaviors; under-represented in current, large data collections

- Communication: 30-50% do not develop functional verbal communication.
- Cognitive: 20-40% of individuals with Intellectual Disability (FSIQ<70)
- Behavioral: 20-30% with lifetime incidence of serious challenging behaviors

High volume of individuals - in a unique position to efficiently collect large amounts of data and improve understanding of this understudied portion of the ASD population

Inpatient setting an ideal platform to identify mechanisms underlying emotional and behavioral symptoms to inform treatment. Unique ability to study challenging behaviors *in situ* due to safety of inpatient environment and control over environmental factors

AUTISM INPATIENT COLLECTION

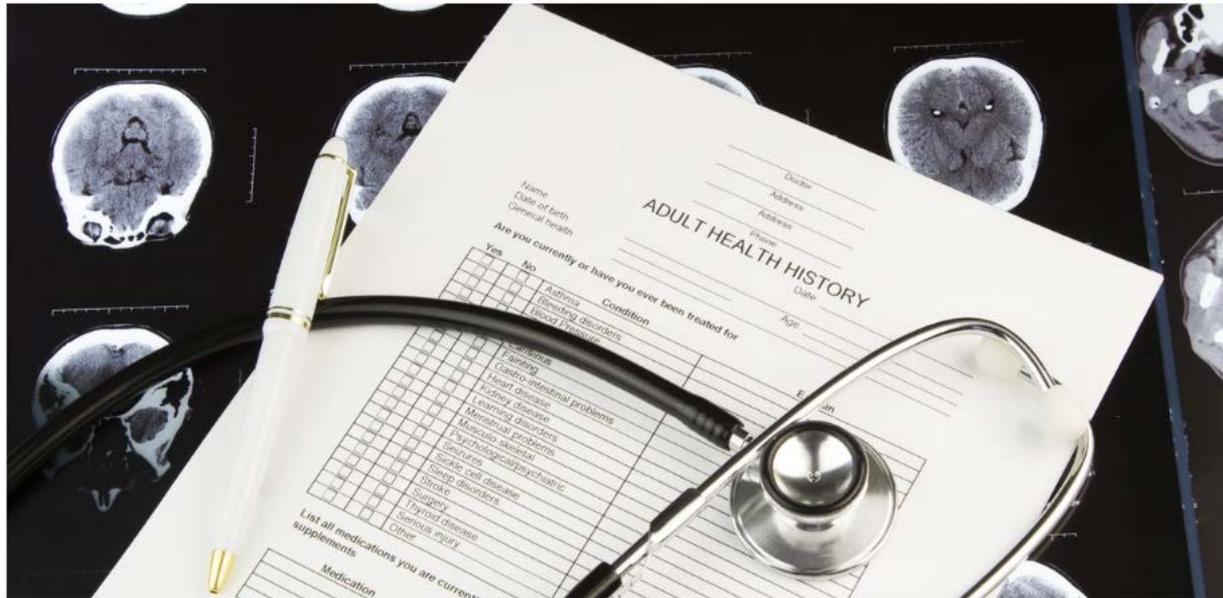


- **Goals:** Standardized assessment, description of the population, resource for all investigators, research platform for measure development, mechanistic studies and treatment studies.
 - To date, enrolled over 1000 probands and their biological parents
 - Rigorous core assessment battery and ASD diagnostic reliability
 - 48% minimally verbal, 42% Intellectual Disability (NVIQ <70; Molec Aut, 2015)
 - Whole exome sequencing to be performed 2018-19
 - Data available to approved investigators through SFARIBase
 - On-line community to facilitate recontacting through

**AUTISM INPATIENT
COMMUNITY**
@interactive autism network

AIC ON SFARI BASE

SFARI Base



How to access SFARI Base and request SFARI resources:

SFARI Base is a central database of phenotypic and genetic information about families affected by autism and other neurodevelopmental disorders, provided as part of the Simons Foundation Autism Research Initiative (SFARI). It contains data from the following cohorts:

- [Simons Simplex Collection \(SSC\)](#)
- [Simons Variation in Individuals Project \(Simons VIP\)](#)
- [Simons Foundation Powering Autism Research for Knowledge \(SPARK\)](#)
- [Autism Inpatient Collection \(AIC\)](#)



Predictors of
Psychiatric
Hospitalization

Inpatient
Outcomes

Best practices for
inpatient treatment

Psychotropic
Medication
Use

AIC
Methods

Problem
behaviors and
verbal ability

Risk factors for
Self-injurious
behavior

Talking
about death
or suicide

Expression of
Trauma

Sleep and
problem
behavior

Verbal ability and
psychiatric
symptoms

Development of
the EDI

Anxiety

Sleep and caregiver
stress

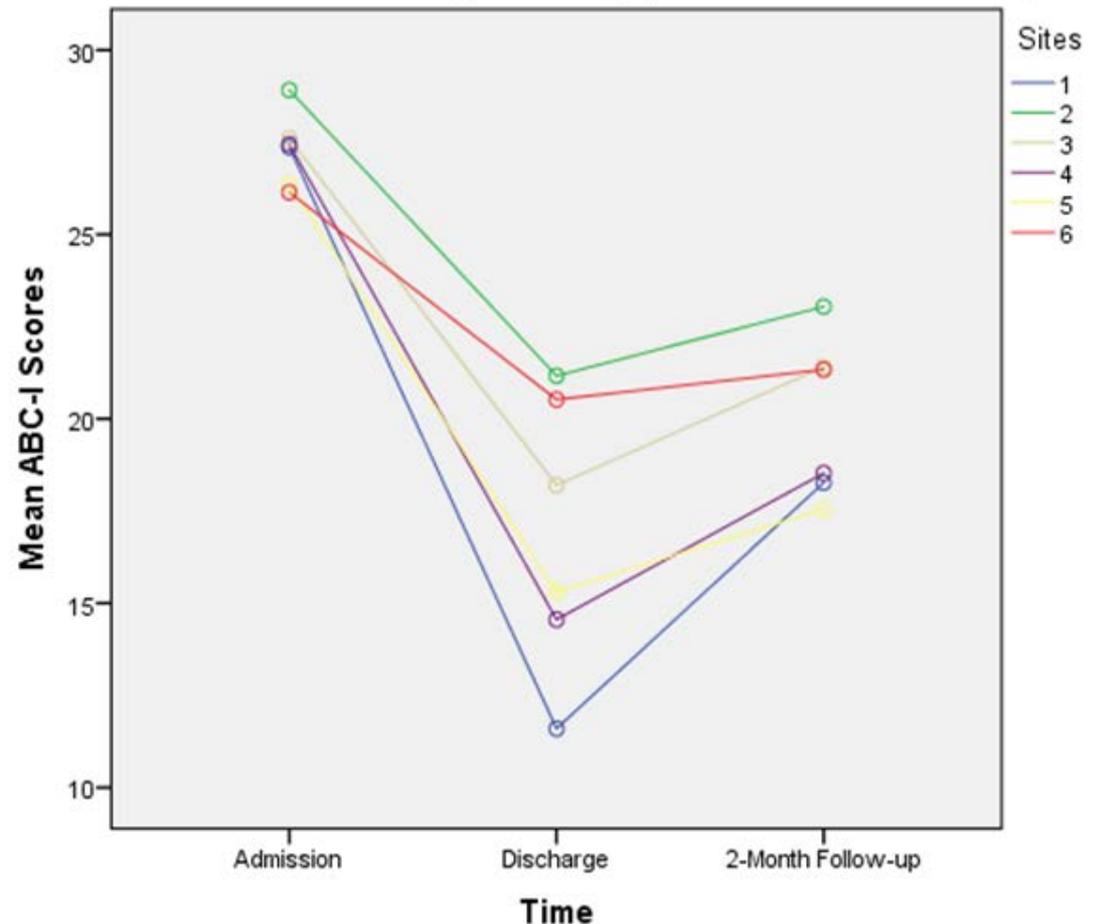
Health
disparities

Parent stress
and problem
behavior

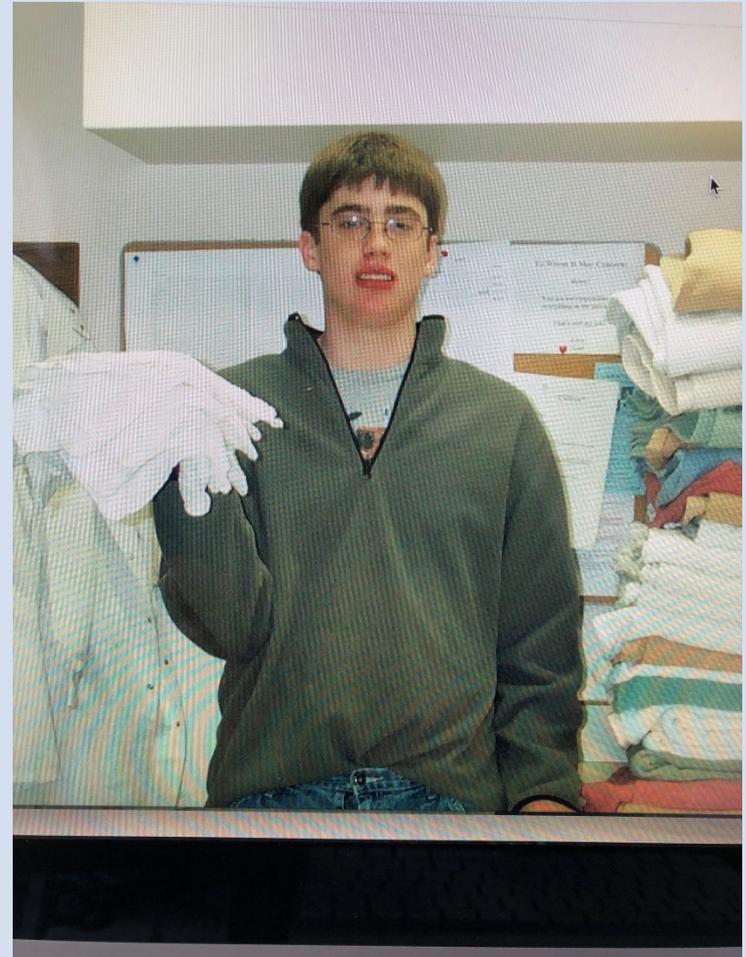
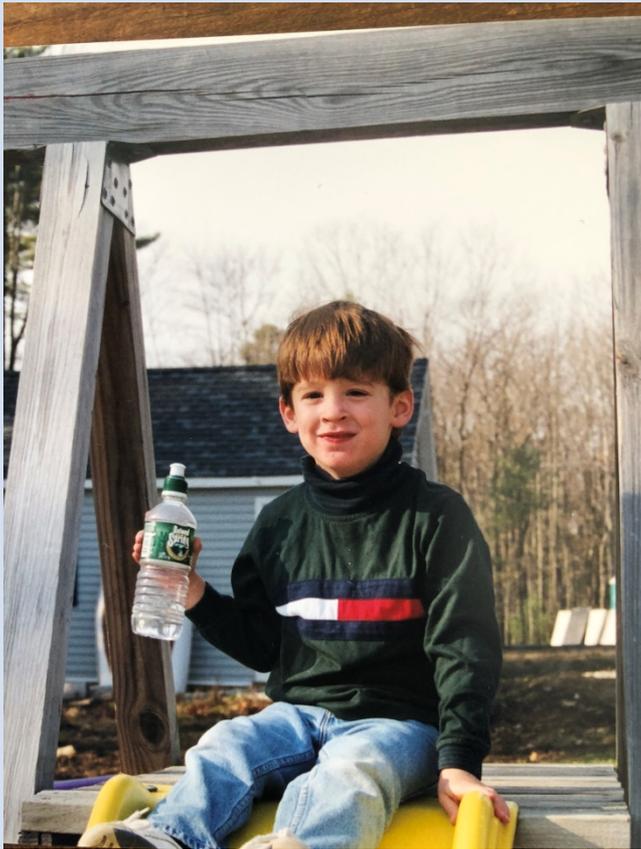
AIC: CHANGE IN PROBLEM BEHAVIORS

ABC-I Scores, n=350

- Significant reduction in problem behavior scores from admission to discharge, and 2-month follow-up ($p \leq 0.05$)
- Admission: 29.7(9.6)
- Discharge: 15.0(10.3)
- 2-Month Follow Up: 19.3(10.3)

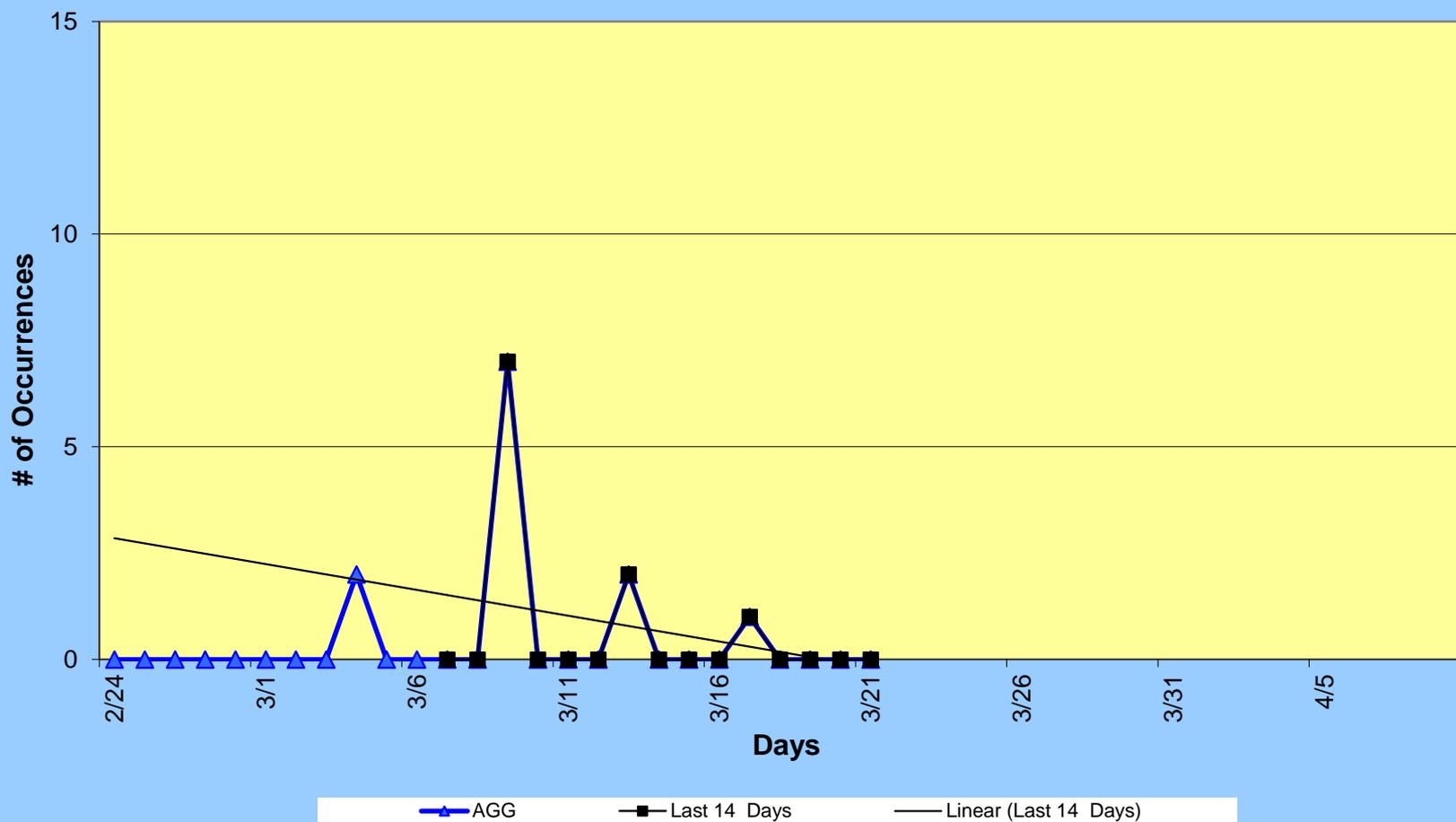


RYAN – THE NEED FOR NOVEL APPROACHES



IN HOSPITAL

Ryan O's Aggression Over Stay 2011



RYAN - 23 YEAR OLD MAN



“Due to his inability to manage his emotions and communicate, he attacks us when he becomes agitated or stressed. This behavior is very unpredictable and often occurs with little to no warning signs. It has happened in our home, his school, in the community and sometimes while driving a car. It is so bad that we can no longer safely live in our home with Ryan.”

-Wendi

PHYSIOLOGICAL AROUSAL AND CHALLENGING BEHAVIOR

In typically developing youth, greater ability to modulate physiological arousal is associated with fewer behavior problems.

-Calkins SD. *Dev Psychobilly*. 1997;
Porges, S.W. *Dev Psyche*; 1996

Association between physiological arousal and problem behavior in ASD

- Cohen IL, et al., Assessing challenging behaviors in Autism Spectrum Disorders: Prevalence, rating scales, and autonomic indicators. In: *International handbook of autism and pervasive developmental disorders*. New York, NY: Springer; 2011;
- Groden J, et al, The impact of stress and anxiety on individuals with autism and developmental disabilities. In: *Behavioral Issues in Autism*. New York, NY: Springer; 1994;
- Romanczyk RG. Self-injurious behavior: Conceptualization, assessment, and treatment. In: *Advances in Learning & Behavioral Disabilities*. UK: Emerald Insight; 1986;
- Romanczyk RG, Lockshin S, O'Connor J. Psychophysiology and issues of anxiety and arousal. In: *Self-injurious Behavior*. New York, NY: Springer-Verlag; 1992

Hypothesis: Individual with ASD engages in a problem behavior as an attempt to alleviate distress and reestablish physiological homeostasis.

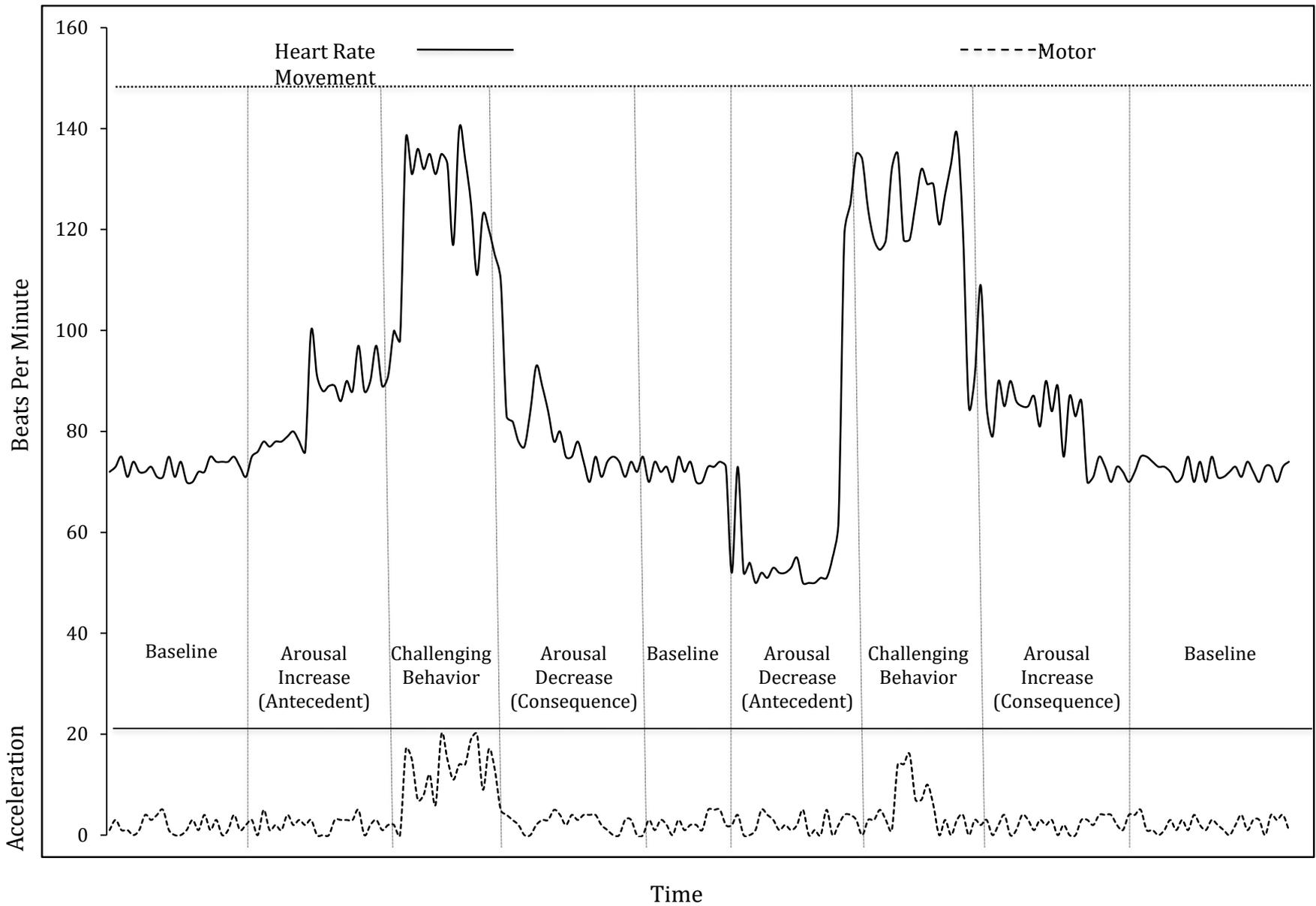
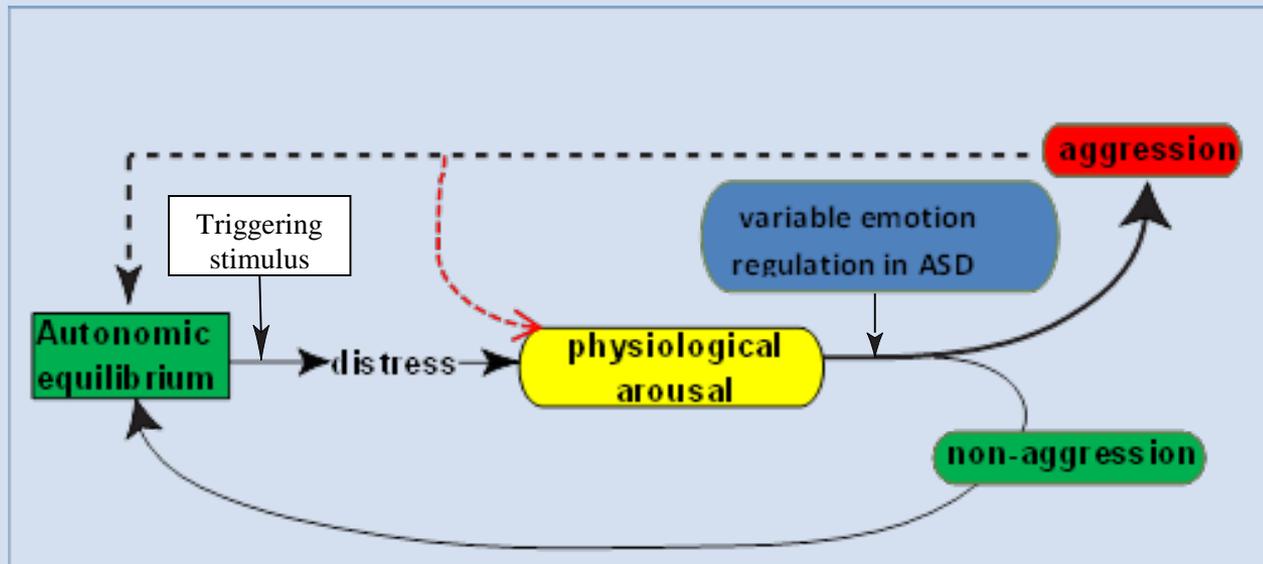
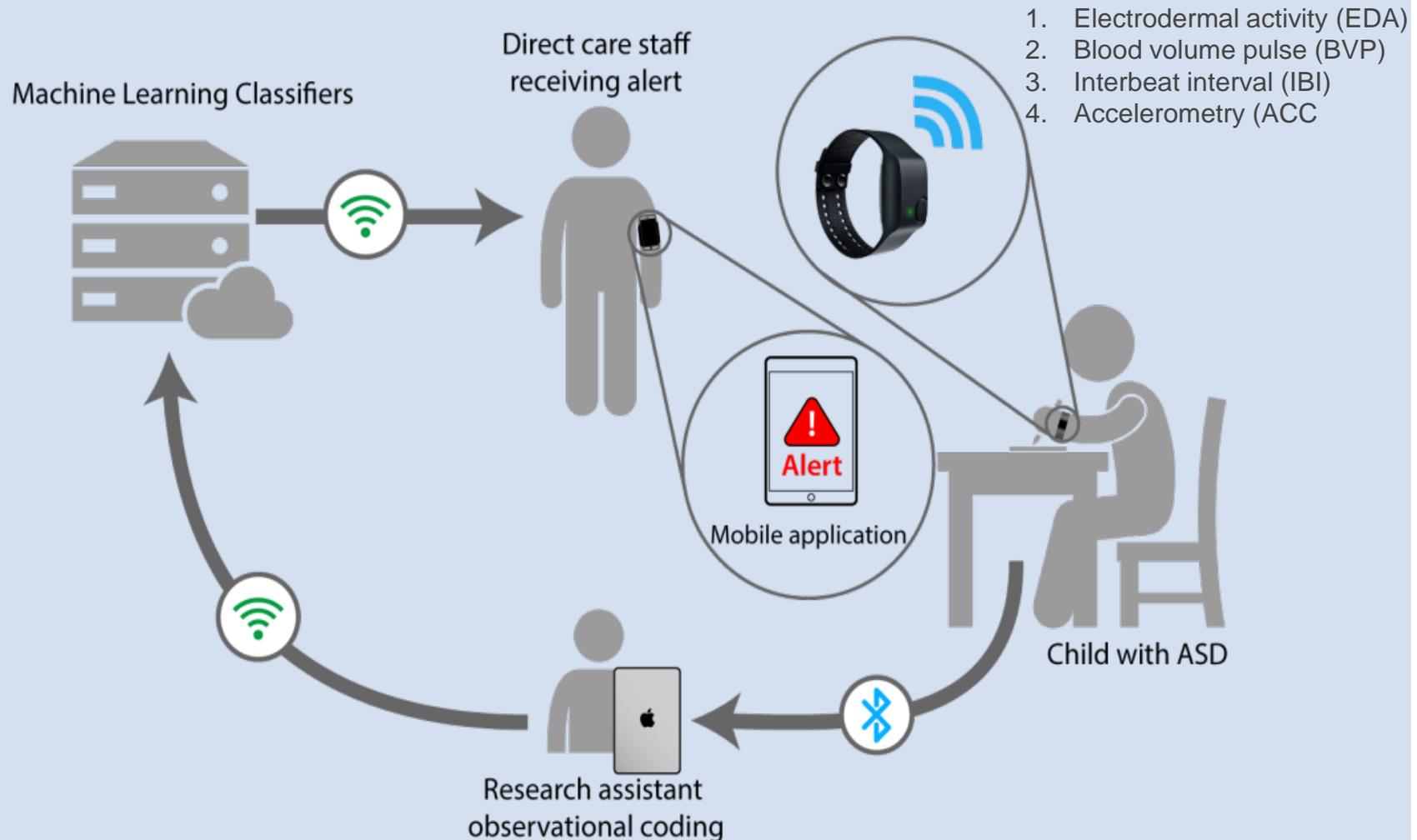


Figure by Matthew Goodwin, PhD

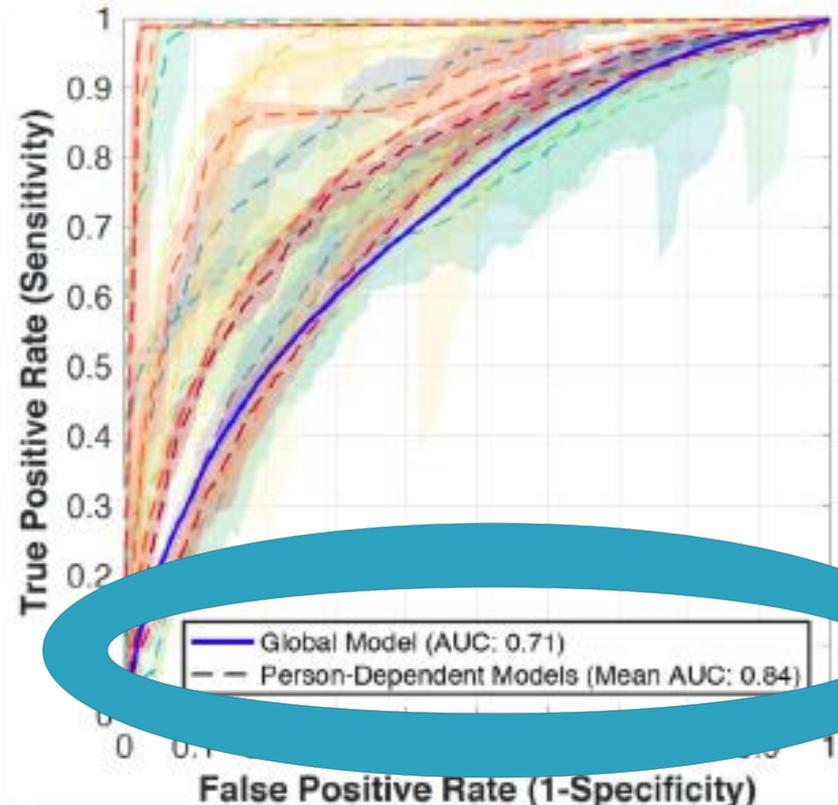
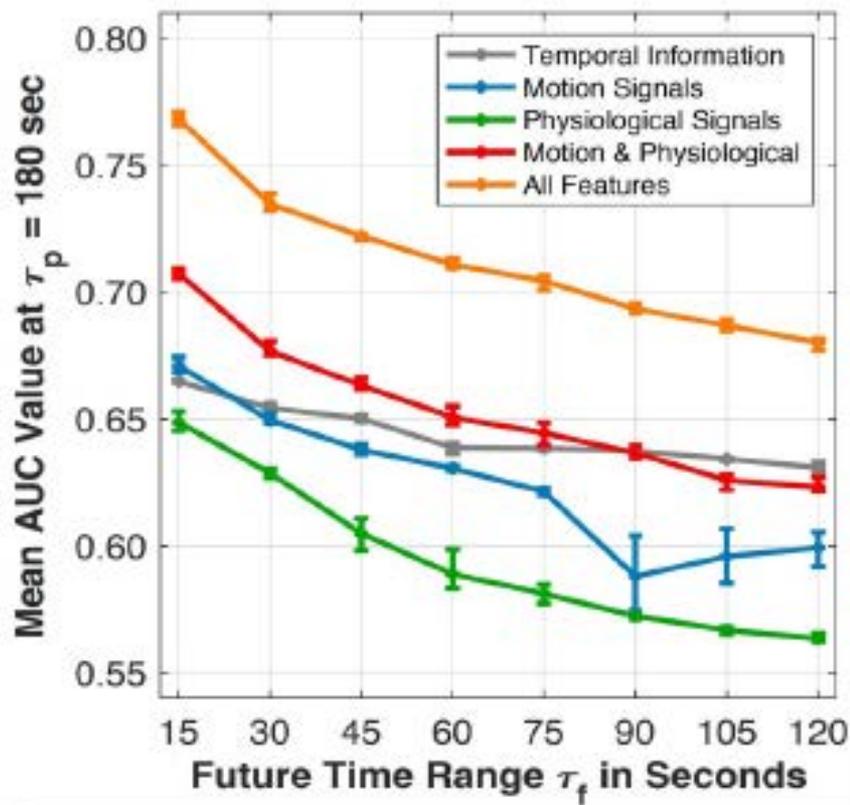
CONCEPTUAL MODEL



TRANSFORMING THE TREATMENT OF CHALLENGING BEHAVIOR – REAL TIME PREDICTION



Pilot findings with 20 minimally-verbal inpatients



AUC values as a function of time to aggression, and signals used from past 3 minutes of data

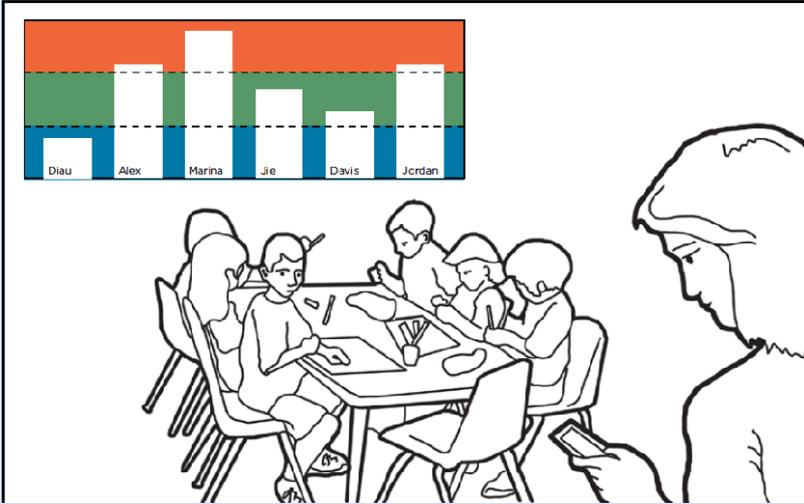
- ~80 hrs of collection over ~70 naturalistic observation sessions
- Increasing accuracy as you increase # of signal streams utilized

ROC values for global and person-dependent models using all combined features from the past 3 minutes to predict the next 1 minute

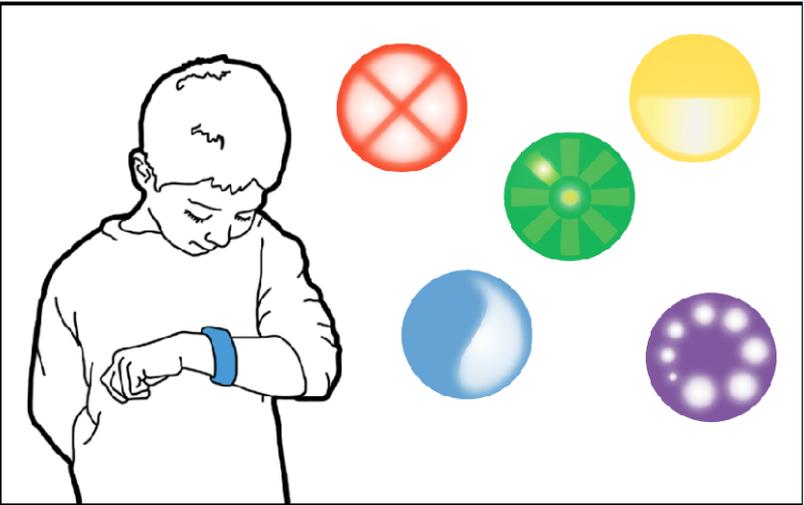
- Goodwin, MS, Ozdenizci, C, ... Mazefsky, C, Siegel, M, ... (in press). Predicting proximal aggression onset in minimally-verbal youth with autism spectrum disorder using preceding physiological signals. *Pervasive Health*.

- Ozdenizci, C, ... Mazefsky, C, Siegel, M, ... & Goodwin, MS (in press). Time-series prediction of proximal aggression onset in minimally-verbal youth with autism spectrum disorder using physiological biosignals. Accepted to 40th International Conference of the IEEE Engineering in Medicine and Biology Society.

Staff Monitoring



Self Monitoring



CRITICAL UNMET RESEARCH NEEDS FOR THE SEVERELY AFFECTED

- Novel approaches to aggression and self injury that utilize objective, mechanistically-informed data
- Natural history of aggression and self-injury across the lifespan in ASD
- Validated, clinically practicable diagnostic tools for psychiatric co-morbidity
- Emotion regulation measurement and treatment
- Sleep biology and relationship to challenging behaviors
- Study of complex, real-world treatment packages (comparative effectiveness studies)
- Study of residential treatment and in-home behavioral services.

SUMMARY

- Individuals with ASD can develop serious behavioral challenges, which can become more impairing than the ASD itself.
- Parents report it is the unpredictability and lack of warning that causes the greatest impairment.
- Aggression and self injury are under-researched, and their underlying biology not well understood, particularly in those who are minimally verbal or have intellectual disability
- Pilot data from the AIC suggests that measurement of physiological arousal, combined with other data streams, can be used to predict the proximal onset of aggression.
- Critical need for novel research approaches to the assessment and treatment of aggression, self-injury and other problem behaviors, focusing on objective, biological mechanisms and measures.

ACKNOWLEDGEMENTS

Site Co-Investigators

- **Carla Mazefsky, Ph.D, University of Pittsburgh**
- **Robin Gabriels, PsyD., Children's Colorado**
- **Giulia Righi, Ph.D. and Eric Morrow, MD, PhD, Brown University**
- **Craig Erickson, M.D. & Logan Wink, M.D., Cincinnati Children's**



Maine Medical Center Research Institute

- **Susan Santangelo, Sc.D., Co-Investigator**
- **Kahsi A. Smith, Ph.D., Methodology/Statistics**
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- **Donald St. Germain, M.D., Institute Director**

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- **Matthew Goodwin, Ph.D., Northeastern University**
- **Matthew Lerner, Ph.D. & Kenneth Gadow, Ph.D & SUNY Stonybrook**
- **Louis Haggopian, Ph.D., Kennedy Krieger Institute**
- **Diane Williams, Ph.D., Duquesne University**

THE NANCY LURIE MARKS FAMILY FOUNDATION

Fostering Knowledge and Community for Autism and Beyond

ADDIRC Scientific Advisory Group

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Helen Tager-Flusberg, Ph.D., Boston University

**THANK YOU
&
DISCUSSION**

SIEGEM@MAINEBEHAVIORALHEALTHCARE.ORG

Committee Discussion





Afternoon Break

Round Robin



Closing Remarks Adjournment





Next IACC Full Committee Meeting

October 17, 2018

Location - TBD