



IACC Workshop: Addressing Mental Health Needs of People on the Autism Spectrum

Tuesday, May 21, 2019

**Hilton Washington DC/
Rockville Hotel & Executive
Meeting Center**

**1750 Rockville Pike
Rockville, MD, 20892**

Conference Call Access:

**Phone: 800-369-3119
Participant Passcode: 5777378**

Suicide & Mental Health Crisis Resources



- National Suicide Prevention Lifeline:
1-800-273-TALK(8255) www.suicidepreventionlifeline.org
- Veterans Crisis Line: 1-800-273-8255, press 1
- Crisis Text Line: text START to 741-741 (more information:
<https://www.crisistextline.org/textline/>)
- HealthReach (multiple languages)
www.healthreach.nlm.nih.gov/searchindex/Suicide
- Help for Mental Illnesses: NIMH web page
www.nimh.nih.gov/findhelp
- Treatment Referral Routing Service (funded by SAMHSA):
1-800-662-HELP(4357)

Workshop Agenda



Morning Agenda

8:30 AM

Welcome, Introductions, Roll Call, and Approval of Minutes

Shelli Avenevoli, Ph.D.

Deputy Director, NIMH

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

Working Group Co-Chairs

David Amaral, Ph.D.

Distinguished Professor, Department of Psychiatry and Behavioral
Science, University of California, Davis (UC), UC Davis MIND
Institute, Co-Chair, IACC Health Outcomes Working Group

Julie Lounds Taylor, Ph.D.

Associate Professor of Pediatrics
Vanderbilt Kennedy Center Investigator
Vanderbilt University Medical Center,
Co-Chair, IACC Health Outcomes Working Group

Workshop Agenda



Morning Agenda

9:30 **Addressing the Mental Health Needs of People on the Autism Spectrum – An Overview and Path Forward**

Carla Mazefsky, Ph.D.

Associate Professor of Psychiatry and Psychology

University of Pittsburgh

10:00 **Morning Break**

10:15 **Personal Perspectives on Mental Health Issues in ASD**

Lindsey Nebeker

Development Specialist, Autism Society of America, Freelance
Presenter/Speaker

Dennis Mashue

Co-Founder, Tuck's Tooques; LLC

Founder, OuterSelf Initiatives

Workshop Agenda



Morning Agenda

10:35

Alison Morantz, J.D., Ph.D.

James and Nancy Kelso Professor of Law,
Director of the Stanford Intellectual and Developmental
Disabilities Law and Policy Project,
Senior Fellow and Steering Committee Member,
Stanford Institute for Economic Policy Research

11:00

Public Comment

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

Oni Celestin, Ph.D.

Science Policy Analyst
Office of Autism Research Coordination, NIMH

Workshop Agenda



Morning Agenda

11:45 **Anxiety and OCD with ASD**

Co-occurrence of Anxiety Disorders and Obsessive Compulsive Disorder with ASD

Connor Kerns, Ph.D.
Assistant Professor
Department of Psychology
University of British Columbia, Canada

12:00 **Treatment of Anxiety in ASD**

Judy Reaven, Ph.D.
Associate Professor
Departments of Psychiatry and Pediatrics
University of Colorado Anschutz Medical Campus

12:35 PM **Lunch**

Welcome Introductions Roll Call



Shelli Avenevoli, Ph. D.
Susan A. Daniels, Ph.D.
Julie Lounds Taylor, Ph.D.
David Amaral, Ph.D.

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IACC Working Group: Addressing the Mental Health Needs of People on the Autism Spectrum

May 21, 2019



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

The Interagency Autism Coordinating Committee (IACC)



The IACC is a federal advisory committee established by Congress in 2006 and most recently reauthorized by the Autism CARES Act of 2014. IACC is composed of federal and public members.



IACC Federal Member Agencies



- Administration for Children and Families (ACF)
- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Department of Defense (DoD)
- Department of Education (ED)
- Environmental Protection Agency (EPA)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)
- National Institutes of Health (NIH)
- Social Security Administration (SSA)

IACC Public Members



Includes parents and legal guardians; autistic adults; representatives of leading ASD research, services, and advocacy organizations

- David Amaral, Ph.D., University of California Davis MIND Institute (**researcher**)
- James Ball, Ed.D., B.C.B.A.-D., JB Autism Consulting, Autism Society Board Member (**clinician, advocate**)
- Samantha Crane, J.D., Autistic Self Advocacy Network (**self advocate, advocacy organization**)
- Geraldine Dawson, Ph.D., Duke University School of Medicine (**researcher, clinician**)
- David S. Mandell, Sc.D., University of Pennsylvania (**researcher**)
- Kevin Pelphrey, Ph.D., University of Virginia (**parent, researcher**)
- Edlyn Peña, Ph.D., California Lutheran University (**parent, researcher**)
- Louis Reichardt, Ph.D., Simons Foundation Autism Research Initiative (**research organization**)
- Robert H. Ring, Ph.D., Kaerus Bioscience (**industry**)
- John Elder Robison, College of William and Mary (**self advocate, author, lecturer**)
- Alison Tepper Singer, Autism Science Foundation (**parent and sibling, research and advocacy organization**)
- Julie Lounds Taylor, Ph.D., Vanderbilt University (**researcher**)

IACC's Role



- Coordinate federal agencies on issues related to autism; foster collaborative relationships between federal agencies, private organizations, and the autism community.
- Provide advice to the Secretary of Health and Human Services on issues related to autism.
- Provide strategic guidance to the government on priorities for ASD research, services, and policy.
- Serve as a forum for public stakeholders to share their views and concerns on issues related to autism spectrum disorder.
- Share information and updates on federal agency and community activities related to autism, including research, services, policies, programs, and initiatives.
- Issue reports on research and other topics related to autism.

Improving Health Outcomes for Individuals on the Autism Spectrum WG



- The IACC convened a working group on health and wellness issues for individuals with ASD
- The Working Group is exploring ways to:
 - Support research to better understand the health conditions that affect individuals on the autism spectrum
 - Increase community/provider awareness of these conditions and their treatment
 - Foster development of practice guidelines, policies, service approaches and other efforts to improve the health and quality of life of people on the autism spectrum



Working Group Scope



- Health and general wellness for people with ASD
- Co-occurring physical and mental health conditions
- Premature mortality
- Patient-provider interactions (including medical practitioner training)
- Parental/family mental health



Working Group Activities and Products



- **Workshop: Addressing the Mental Health Needs of People on the Autism Spectrum**
 - Co-occurring Mental Health Conditions: anxiety, OCD, self injurious behaviors
 - Depression and Suicide
 - Mental Health Services Issues
- Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 27, 2018)
 - Health epidemiology
 - Patient-provider interactions
 - Co-occurring health conditions
- A written document providing an update on issues
- Continued discussions in Working Group conference calls, Working Group meetings, and/or IACC full committee meetings until September 2019

Working Group Members



Co-Chairs

- David Amaral, Ph.D., University of California, Davis
- Julie Lounds Taylor, Ph.D., Vanderbilt University

IACC and Federal Members

- Patricia Dietz, Dr.P.H., M.P.H., Centers for Disease Control and Prevention
- Jennifer Johnson, Ed.D., Administration for Community Living
- Alice Kau, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Kevin Pelphrey, Ph.D., George Washington University and Children's National Medical Center ●
- Denise Juliano-Bult, M.S.W., National Institute of Mental Health
- Scott Michael Robertson, Ph.D., U.S. Department of Labor ●
- Marcella Ronyak, Ph.D., LCSW, CDP, Indian Health Service ●
- Nina Schor, M.D., Ph.D., National Institute of Neurological Disorders and Stroke
- Alison Tepper Singer, M.B.A., Autism Science Foundation ●

● Self-advocate ● Parent/Family member

Working Group Members



External Members

- Gregory Barnes, M.D., Ph.D., University of Louisville School of Medicine
- Timothy Buie, M.D., Harvard Medical School
- Dan Coury, M.D., The Ohio State University College of Medicine
- Lisa Croen, Ph.D. Kaiser Permanente Northern California
- Orrin Devinsky, M.D., New York University
- Sarah Gardner, MIND Institute, University of California, Davis ●
- Dena Gassner, M.S.W., Adelphi University ● ●
- Antonio Hardan, M.D., Stanford University Medical Center
- Joseph Joyce, M.B.A., Autism Society of America ●
- Connor Kerns, Ph.D., University of British Columbia
- Bryan King, M.D., M.B.A., University of California, San Francisco

Working Group Members



External Members

- Clarissa Kripke, M.D., University of California, San Francisco
- Beth Ann Malow, M.D., M.S., Vanderbilt University Medical Center ●
- Micah Mazurek, Ph.D., University of Virginia
- Donna Murray, Ph.D., University of Cincinnati
- Christina Nicolaidis, M.D., M.P.H., Oregon Health and Science University ●
- Dora Raymaker, Ph.D., Portland State University ●
- Elliott Sherr, M.D., Ph.D., University of California, San Francisco
- Matthew Siegel, M.D., Tufts University
- Sarah Spence, M.D., Ph.D., Harvard Medical School
- Jeremy Veenstra-VanderWeele, M.D., Columbia University

Lancet Commission on Future of Healthcare and Healthcare Research in Autism Spectrum Disorders



- International commission sponsored by Lancet that will be examining mental and physical health and healthcare in ASD and developing reports and recommendations
- Led by Catherine Lord, Ph.D., UCLA and Tony Charman, Ph.D., King's College, London
- Members represent U.S, U.K., Argentina, Canada, Germany, India, South Africa
- Multidisciplinary commission including experts in a wide array of fields including psychology, biology, medicine, education, advocacy, self-advocacy
- Will cover the needs and interests of both high resource countries and low resource countries
- Closed meetings 2019 and 2020; will have an open meeting in the future
- Commission is interested in IACC's work and IACC is interested in commission's work

Suicide & Mental Health Crisis Resources



The next 3 presentations discuss suicide & suicidal behavior
If you are in crisis, call toll-free:

National Suicide Prevention Lifeline
1-800-273-TALK (8255)

The deaf & hard of hearing can call via TTY: 1-800-799-4889
Service is available to anyone 24 hours a day, 7 days a week
All calls are confidential

Text crisis support is available in the US, Canada, UK, Ireland,
& S. Africa: <https://www.crisistextline.org/textline/>

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IACC May 21, 2019

Addressing the Mental Health Needs of People on the Autism Spectrum – **An Overview and Path Forward**

Carla A. Mazefsky, PhD

Associate Professor of Psychiatry, University of Pittsburgh

Director, Regulation of Emotion in ASD Adults, Children, and Teens
(REACT) Program; www.react.pitt.edu



Why we are here today

- Mental health disorders:
 - Are present in 70% or more of youth with ASD
 - Often persist or worsen into adulthood
 - Have a very detrimental effect on quality of life, outcomes, and families

Specific Rates

- Little consensus
 - Changing diagnostic criteria
 - Different methods
 - Sample source
 - Measures
 - Real challenges in assessment

Oxford Handbook of
Autism and Co-Occurring
Psychiatric Conditions

Editors:

Susan White
Brenna Maddox
Carla Mazefsky

In Production
(hopefully out soon!)

Depression 14%-28%	Psychotic spectrum 5-35%	Anxiety Disorders ~40%	Obsessive-Compulsive Disorder 11% - kids ~24% - adults	Post-traumatic Stress Disorder 26-50% - traumatic event 0-17% - PTSD
Oppositional Defiant Disorder 4-37%	ADHD ~30% or more	Substance Use Disorders 16-35%???	Gender Dysphoria 5% or more	Eating Disorders Anorexia – higher in ASD; Bulimia- ??? [70%+ food selectivity]
Sexual Deviance More inappropriate behaviors ??? –problems, offenses	Sleep 45-86% Insomnia	Suicide Ideation 7-72% Attempts ? Death 0.3-12%	Aggression 10-58% >50% (children)	Self-injurious Behavior 30-50%

Rates drawn from Oxford Handbook of Autism and Co-Occurring Psychiatric Conditions

University of Pittsburgh

There IS consensus on the need to focus on mental health in ASD

J Autism Dev Disord (2018) 48:1041–1051
DOI 10.1007/s10803-017-3282-2

S.I. : PARENTING CHILDREN WITH ASD

Parents Suggest Which Indicators of Progress and Outcomes Should be Measured in Young Children with Autism Spectrum Disorder

Helen McConachie¹ · Nuala Livingstone^{2,10} · Christopher Morris³ · Bryony Beresford⁴ · Ann Le Couteur¹ · Paul Gringras⁵ · Deborah Garland⁶ · Glenys Jones⁷ · Geraldine Macdonald^{2,11} · Katrina Williams⁸ · Jeremy R. Parr⁹

Top 10 included:
Happiness, Anxiety,
Distress, Self-esteem,
Aggression, Sleep

Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data

Katherine Gotham¹, Alison R Marvin², Julie Lounds Taylor¹, Zachary Warren¹, Connie M Anderson³, Paul A Law⁴, Jessica K Law^{2,5} and Paul H Lipkin^{2,5}

Autism
2015, Vol. 19(7) 794–804
© The Author(s) 2015
Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361315583818
aut.sagepub.com
SAGE

Both self-reporting adults and legally authorized representatives of adults rated mental health as important

J Autism Dev Disord (2010) 40:1361–1370
DOI 10.1007/s10803-010-0996-9

ORIGINAL PAPER

The Heavy Burden of Psychiatric Comorbidity in Youth with Autism Spectrum Disorders: A Large Comparative Study of a Psychiatrically Referred Population

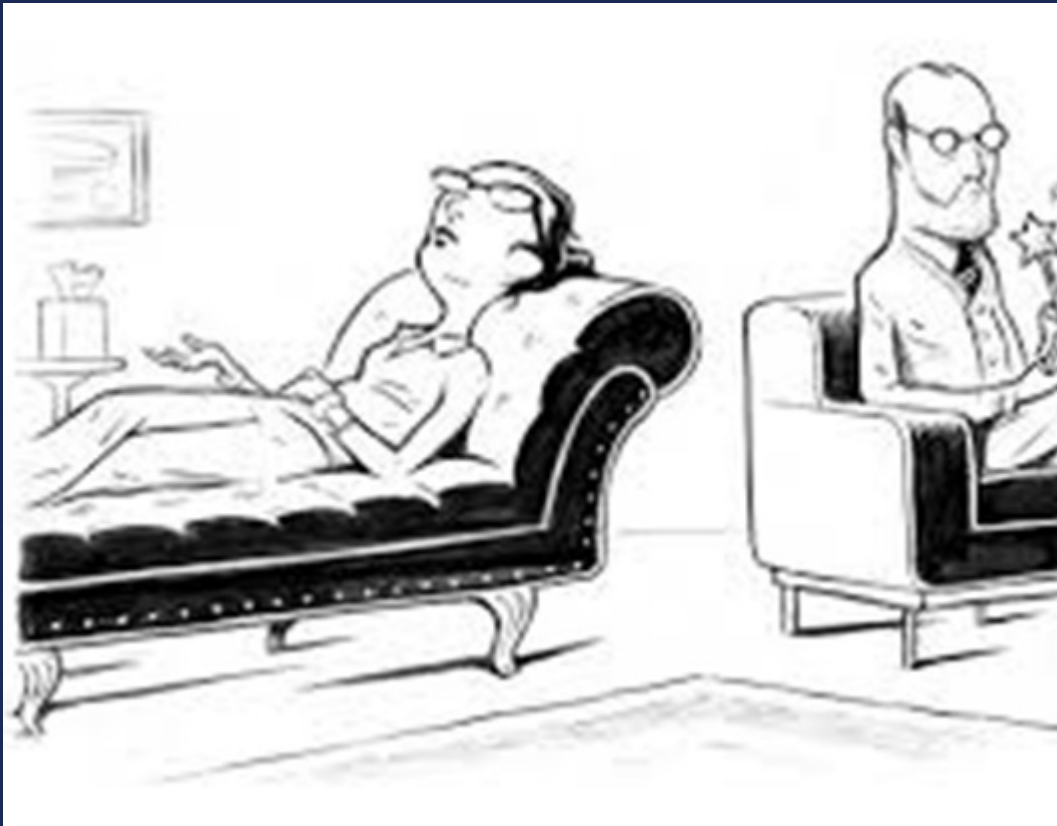
Gagan Joshi · Carter Petty · Janet Wozniak ·
Aude Henin · Ronna Fried · Maribel Galdo ·
Meghan Kotarski · Sarah Walls · Joseph Biederman

- Added impairment, distress, & family stress
- High health care utilization (hospitalization)
- Discontinuation of ASD-related treatments
 - Barrier to school and workplace success
- Disciplinary actions (suspensions, police contact)
- Physical health implications (including injury/death)

Mental Health Problems are Treatable



Therapy Options




Evidence-based—

- Cognitive-behavioral therapy
- Functional behavior assessment (FBA)

Growing interest —

- Mindfulness

Medication Options



Risperidone & Abilify – FDA approved for a cluster of behaviors under the umbrella of irritability

Good evidence for ADHD meds

Increasing interest in drugs that act on glutamatergic and GABAergic systems

These treatment advances
are relatively new and the pace is
increasing.

We should be excited....
but cautious and unsatisfied.



Psychosocial treatment gaps

- Uneven emphasis across disorders
- Very little understanding of what works for whom
- Predominantly for verbal individuals without cognitive disability
- Limited replication, or lower effect sizes
- Long gap from research to practice
- Need for a lifespan approach

DEEP DIVE

Autism's drug problem

BY LAUREN GRAVITZ

19 APRIL 2017

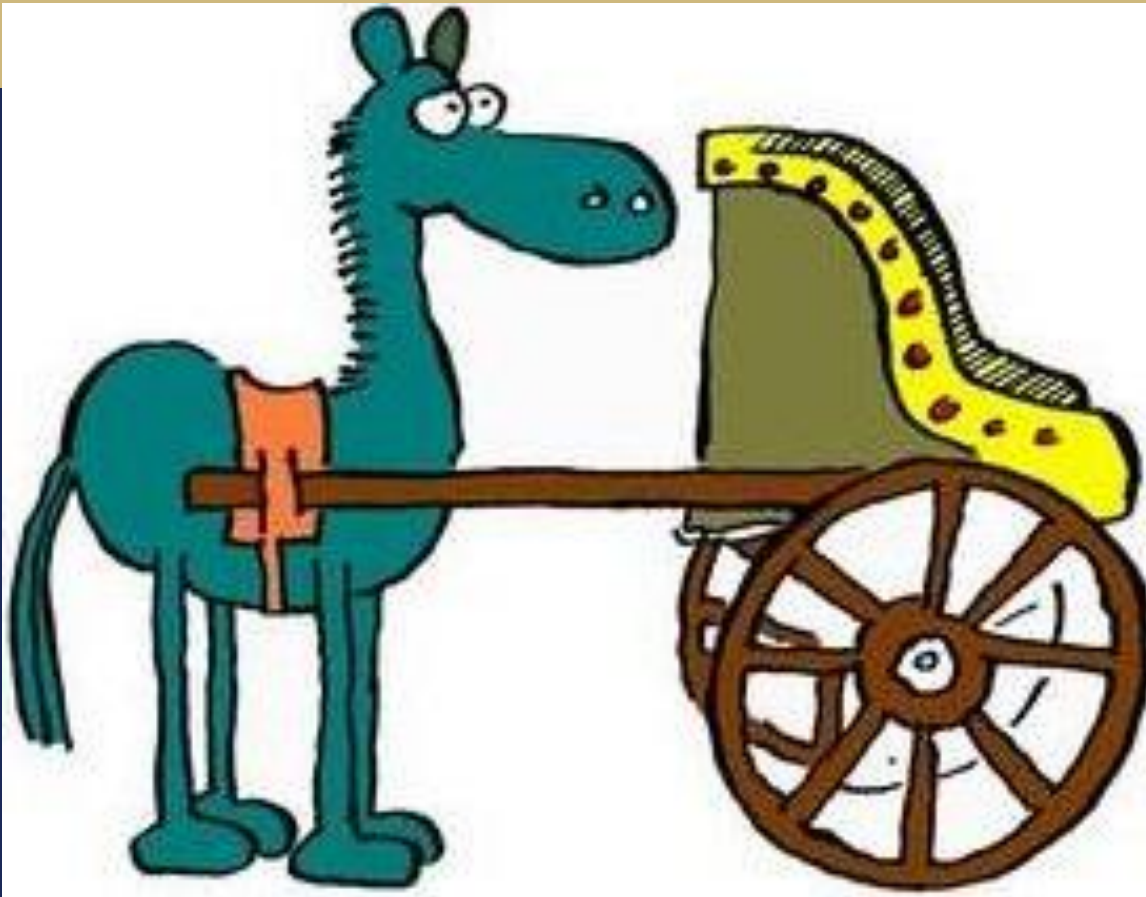
“Psychotropic medications are used pretty extensively in people with autism because there aren’t a lot of treatments available,” says **Lisa Croen**, director of the Autism Research Program at Kaiser Permanente in Oakland, California. “Is heavy drug use bad? That’s the question. We don’t know; it hasn’t been studied.”

- respond less well
- more likely to experience side-effects...

“Overall, the evidence base to inform the practice of psychopharmacology is relatively limited even for situations where an FDA approved indication exists, and considerable work needs to be done to better inform clinical practice.”

Bryan H. King, Agnieszka Rynkiewicz, Małgorzata Janas-Kozik, Marta Tyszkiewicz-Nwafor
Oxford Handbook of Autism and Co-Occurring Psychiatric Conditions

So where should we go from here?



“Don’t put the cart
before the horse”

Measures
matter!

Better diagnostic
measures

Better change-
sensitive
measures



Maybe we need a fresh
perspective.

What is driving the
problem?

Increased prevalence of
risk factors?

Heightened
vulnerability?

Decreased protective
factors?

Core features increasing
risk?

Virginia Carter Leno & Emily Simonoff,
*Oxford Handbook of Autism and Co-
Occurring Psychiatric Conditions*

Can we accomplish more by
targeting shared
processes/mechanisms?



Disorder-specific
approaches are a
challenge

Blurry diagnostic
boundaries

41% have 2+
disorders, and 24%
have 3+ disorders

(Simonoff et al., 2008)

Already a shortage of
providers, trouble with
sufficient training


One example candidate from our work:

Emotion Dysregulation

Development of the Emotion Dysregulation Inventory: A PROMIS[®]ing Method for Creating Sensitive and Unbiased Questionnaires for Autism Spectrum Disorder

Carla A. Mazefsky¹ · Taylor N. Day^{1,4} · Matthew Siegel² · Susan W. White³ · Lan Yu¹ · Paul A. Pilkonis¹ · For The Autism and Developmental Disabilities Inpatient Research Collaborative (ADDIRC)

The Emotion Dysregulation Inventory: Psychometric Properties and Item Response Theory Calibration in an Autism Spectrum Disorder Sample

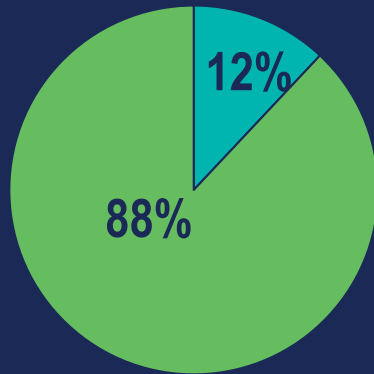
Carla A. Mazefsky , Lan Yu, Susan W. White, Matthew Siegel, and Paul A. Pilkonis

Autism Research 11: 928–941, 2018

INSAR

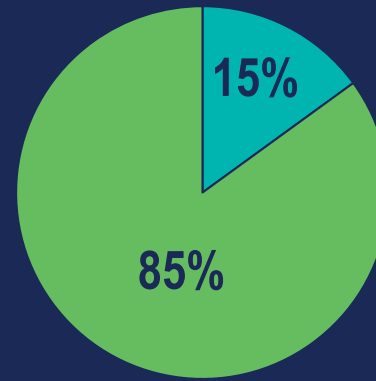
Since published in April 2018, already in use in 11 countries, for 16 treatment studies, 25 other types of studies, and in 15 clinical programs for routine screening and progress monitoring

EDI Reactivity



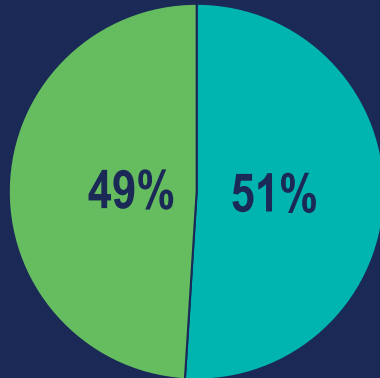
**Representative
US Sample
(n = 1000)**

EDI Dysphoria

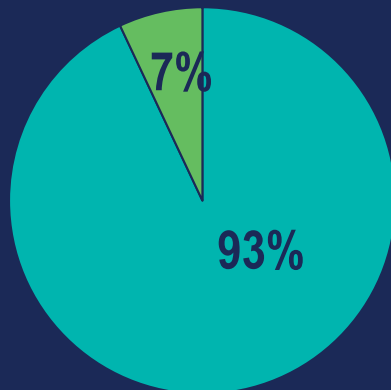
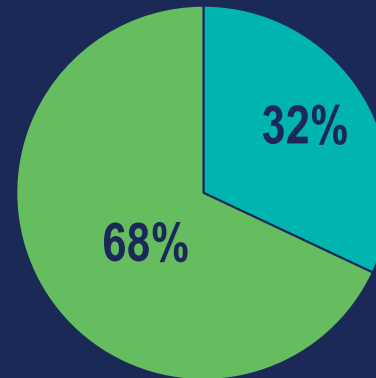


 Below
clinical
cut-off

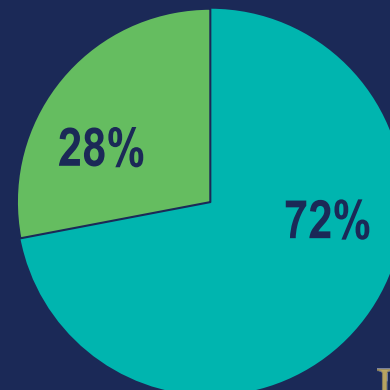
 Above
clinical
cut-off



**Community
Autism
(n = 1169)**



**Inpatient
Autism
(n = 611)**



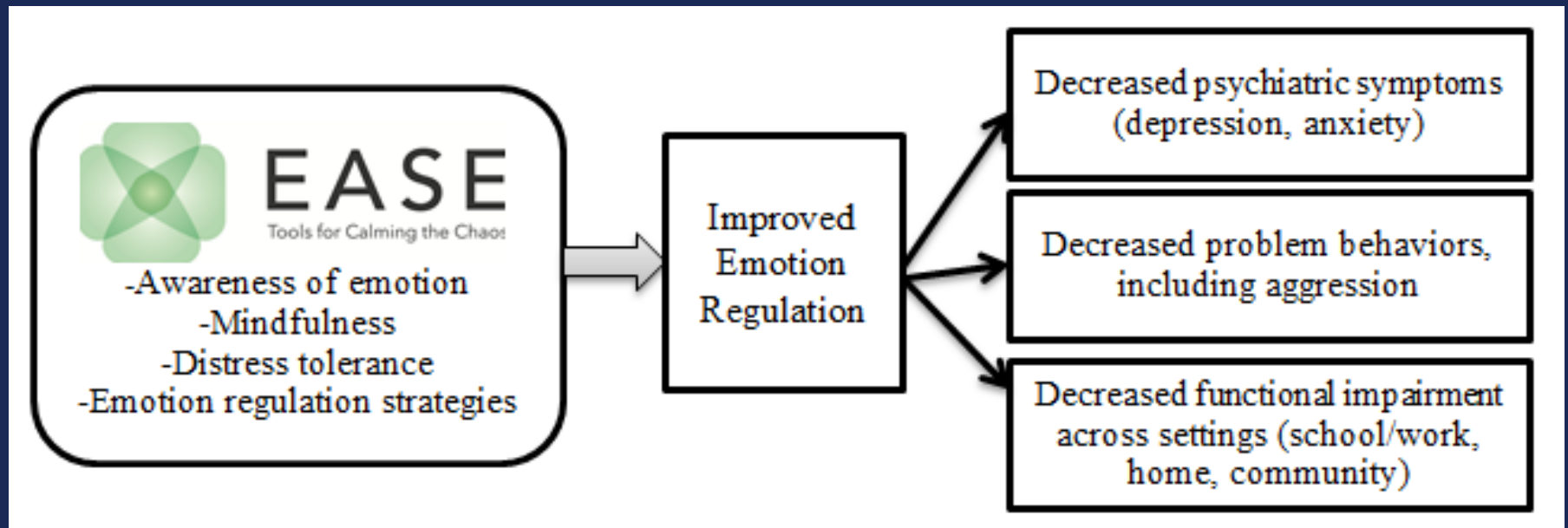
Emotion dysregulation (*but not ASD symptom severity*) increases the odds of:

- Hospitalization
- Police contact
- Suspensions
- In-home crisis evaluations

More emotion dysregulation is associated with:

- More aggression
- More depression
- More suicidal ideation
- More anxiety
- Etc., etc.....

THE EMOTION AWARENESS AND SKILLS ENHANCEMENT (EASE) PROGRAM



EASE is a 16-week individual therapy program for verbal adolescents and adults with ASD

Jointly authored by Carla Mazefsky, PhD, Caitlin Conner, PhD, Kelly Beck, PhD, and Susan White, PhD

University of Pittsburgh

Not sure yet, but hopeful this *could* work

- Completed open trial with 20 adolescents
 - 100% improved emotion regulation, significant improvements in depression, anxiety, and problem behavior (medium to large effects)
- On-going randomized controlled trial (University of Pittsburgh, University of Alabama)
 - Compared to individualized supportive therapy
 - Blind raters, EDI weekly, EEG pre-post, etc!
 - For 12- to 21-year olds with VIQ > 75

Coming soon!

- EASE-ID....
 - Manual development, in partnership with researchers, clinicians, parents of children with ASD, adults with ASD
 - Proof-of-concept, single arm trial
 - 20 12- to 25-year-olds
 - Diagnosis of co-occurring intellectual disability
 - Nonverbal IQ > 50
 - Also explore impact on sleep

Concluding Thought

We are here today, and it is essential that we are.
So, let's get to work!

Feel free to reach out:
Carla Mazefsky
mazefskyca@upmc.edu
www.reaact.pitt.edu

Thank you - Participants, REACT Staff and trainees, NICHD, PA
Dept of Health, Edith L Trees Charitable Trusts, DOD



Discussion



Break

If you are in crisis, call toll-free:

National Suicide Prevention Lifeline

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The deaf & hard of hearing can call via TTY: 1-800-799-4889

Service is available to anyone 24 hours a day, 7 days a week

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Public Comment

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Anxiety and OCD with ASD

Co-occurrence of Anxiety Disorders and Obsessive Compulsive Disorder with ASD

Connor Kerns, Ph.D.

Assistant Professor

Department of Psychology

University of British Columbia, Canada

12:00

Treatment of Anxiety in ASD

Judy Reaven, Ph.D.

Associate Professor

Departments of Psychiatry and Pediatrics

University of Colorado Anschutz Medical Campus

12:35 PM Lunch

Personal Perspective on Mental Health Issues in ASD



Lindsey Nebeker

Development Specialist, Autism Society of America
Freelance Presenter/Speaker



Tucker Mashue

by Dennis Mashue



























Kayaking is very relaxing. I've paddled the Chippewa, Pine, AuSable, Manistee and Platte Rivers in Michigan.



Mountain
biking is one of
my favorite
activities.



**Getting a game ball from Coach Jerry Moore
Appalachian State University, Boone, NC**



Hi, everyone!
I'm Tucker
Mashue!



**I love snow-shoeing
for fun and exercise
during winter.**







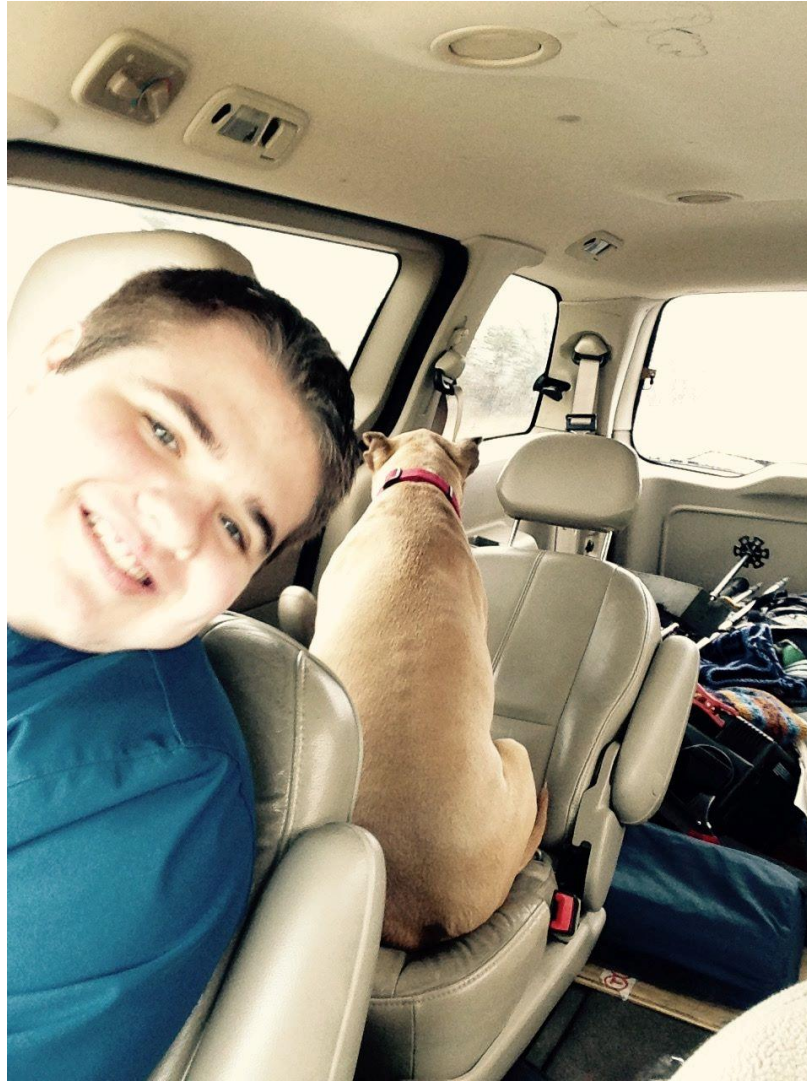
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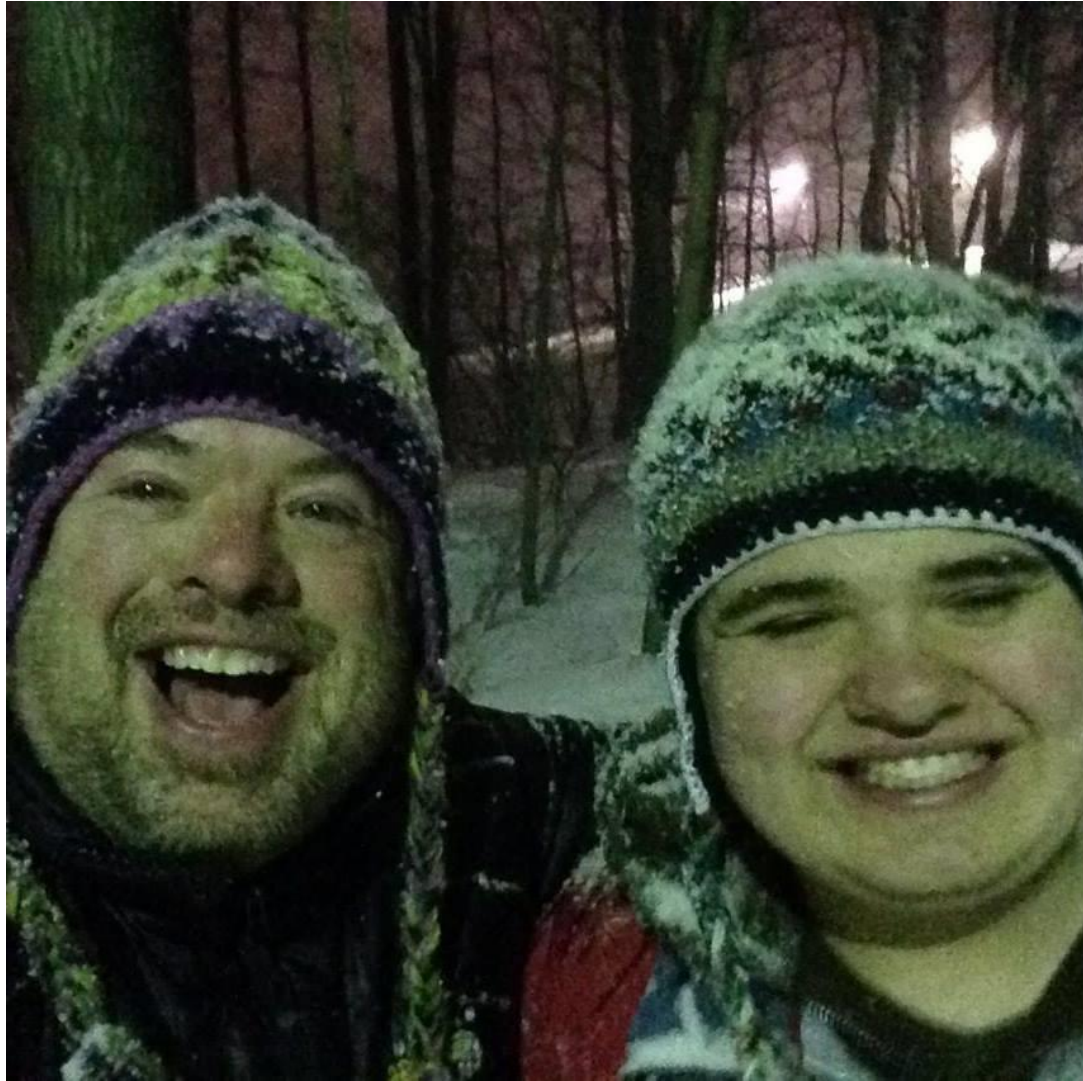


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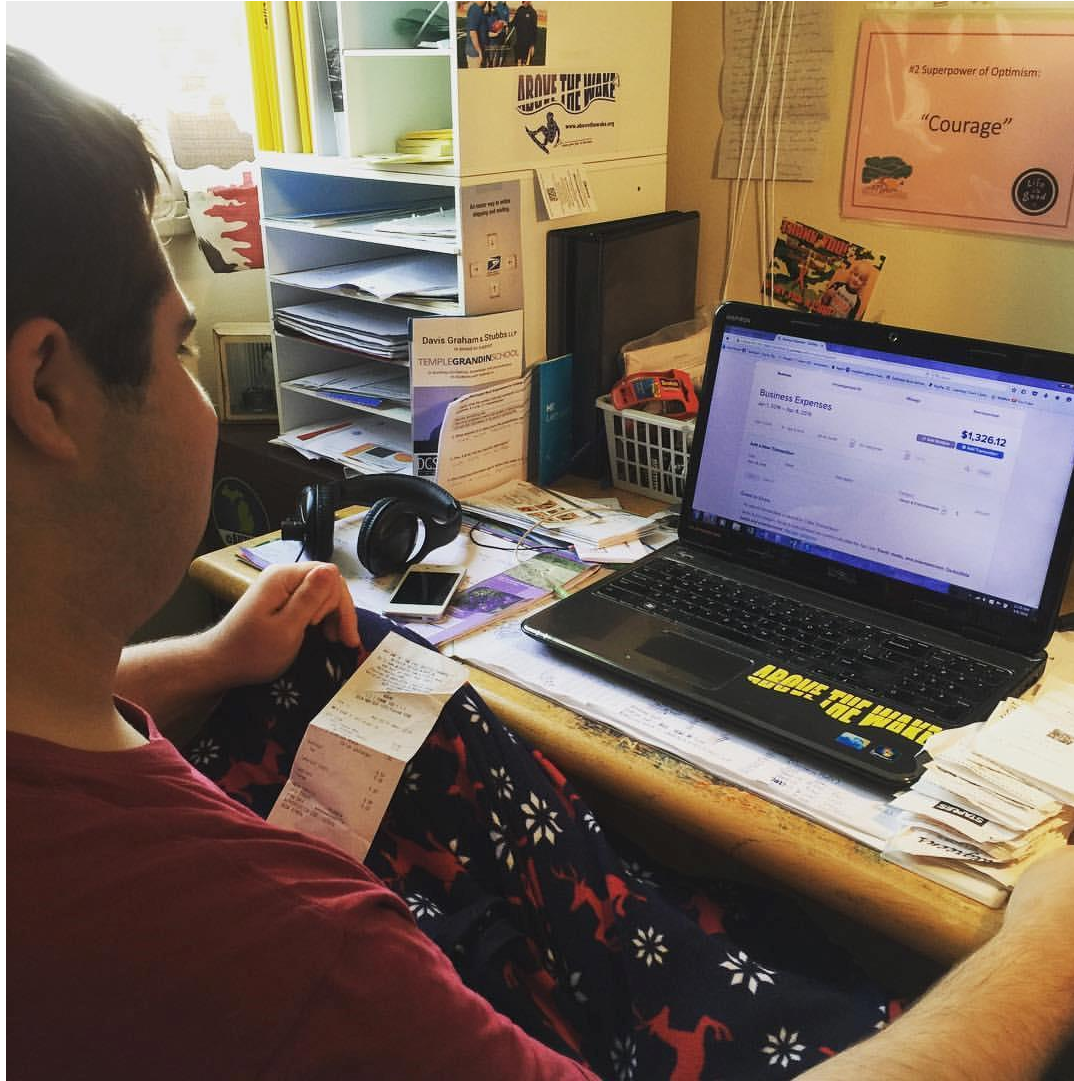














Tuck's Tooques



Hand-crafted in
Nepal
Microfleece Liner
Great Gifts!

Facebook: "Tuck's Tooques"
A Pro-Autism Company

Developing a sustainable young man
and a sustainable business









































Food Storage

Proper food storage will protect bears from becoming accustomed to human food, making food in bear country a hazard to the most effective method of preventing wildlife from taking your food.

High-altitude mountain areas do not have bears, but the mountainous terrain surrounding food from bears. It is recommended that you carry out your food, and in some areas required, that you carry it in a bear canister. Be your part to help maintain a wild bear population in the Sierra Nevada.

Keeping It Wild is EVERYONE's Responsibility

The decisions that you and your party make while visiting the wilderness affect the quality and character of these lands.

Be respectful of other visitors. You are responsible for your actions and those of the people you visit. Respect others' privacy and their interests, and be responsible for your actions.

Plan Ahead and Be Prepared

Learn about your route and destination. Be sure that your group is carrying the correct maps. Make sure that the route and destination meet the needs of your group. Give a head or head count of your group. Give a head or head count of your group.

Know the conditions that may be encountered. Early spring conditions and late season storms may block, or delay, your route and destination. Know the weather forecast and be prepared for changes.

Know the rules and regulations for the area. Know the rules and regulations for the area. Know the rules and regulations for the area.







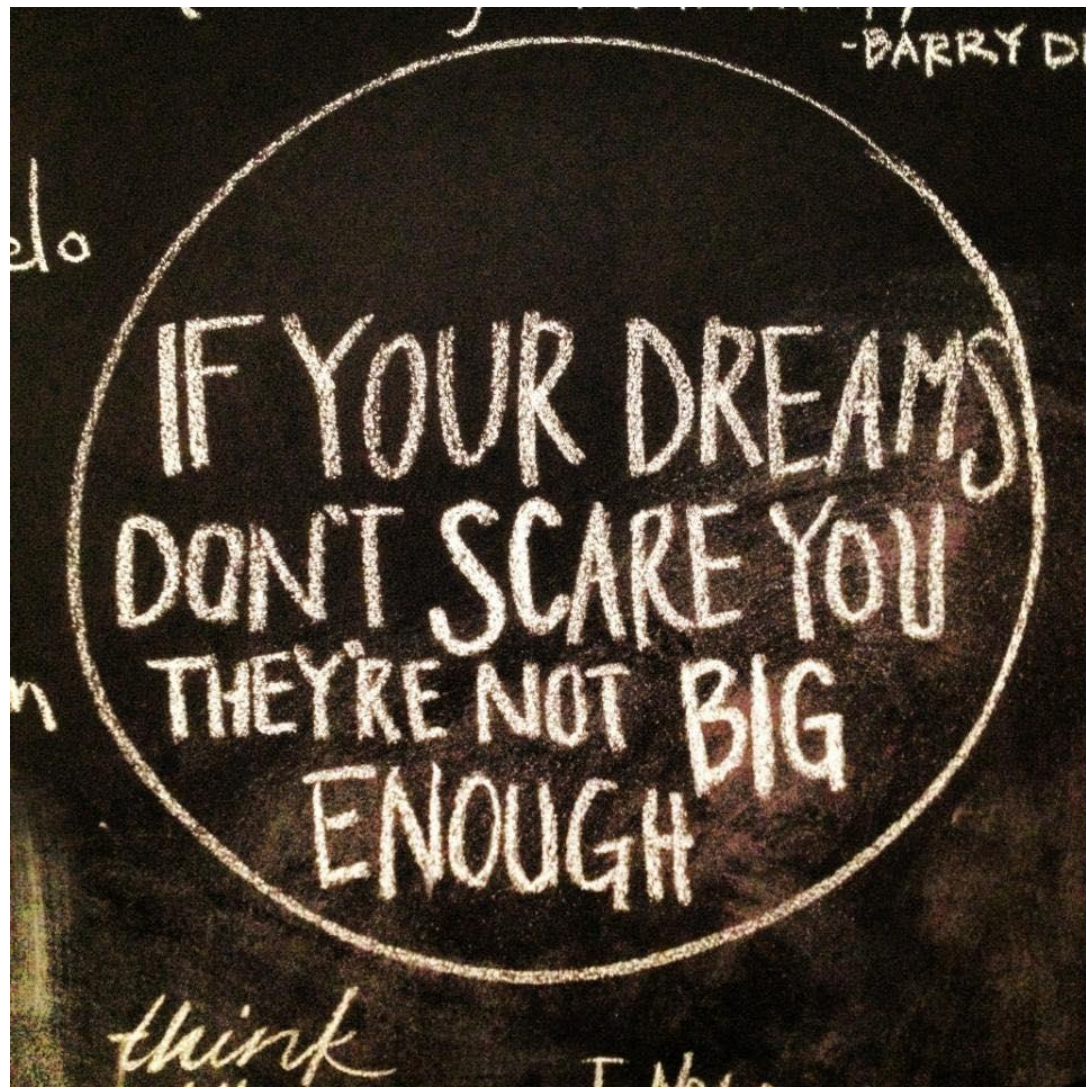










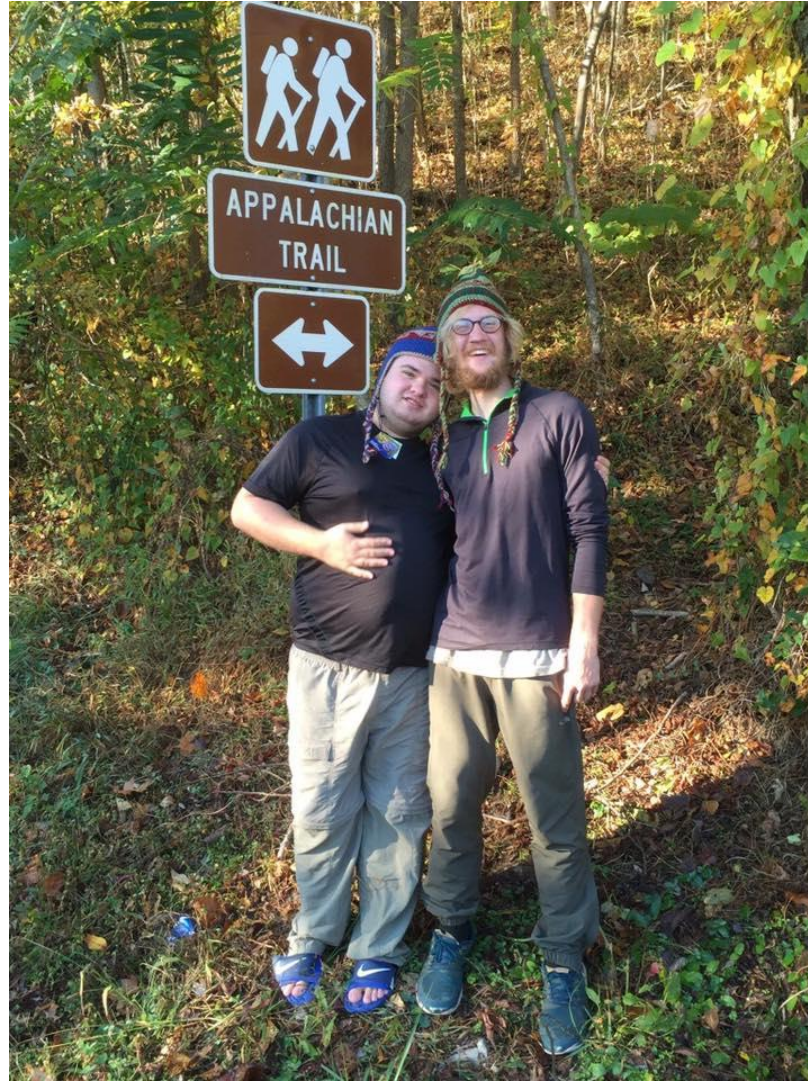








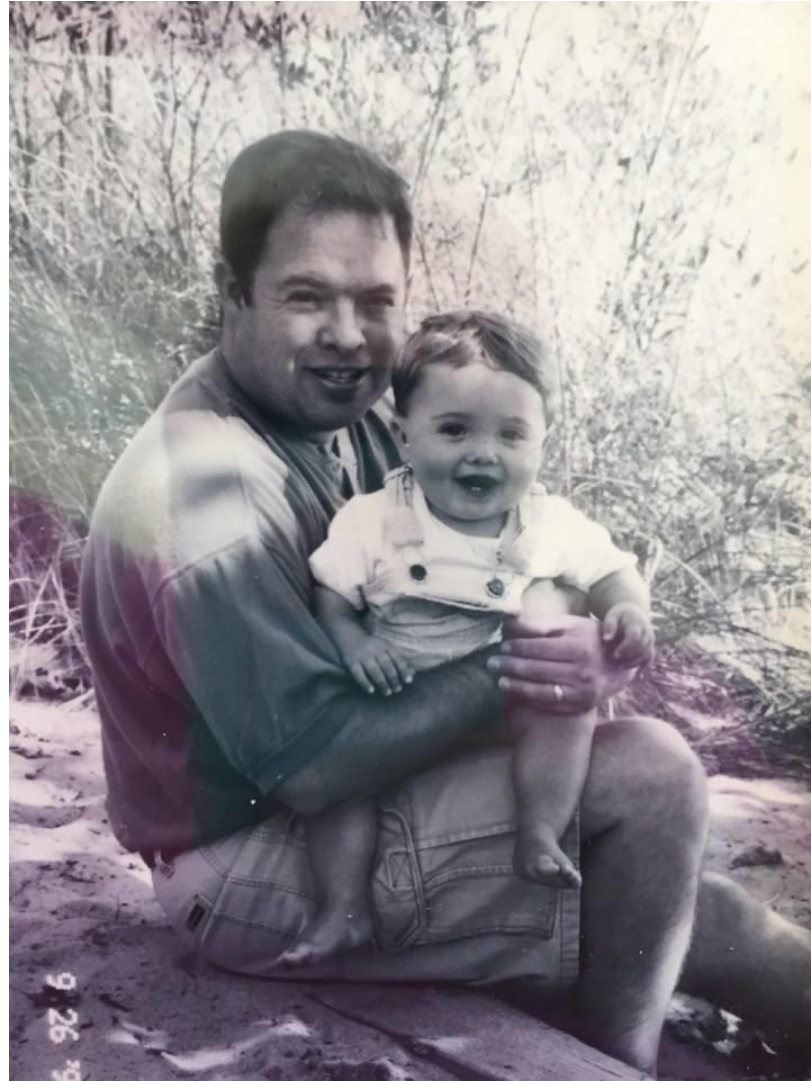


















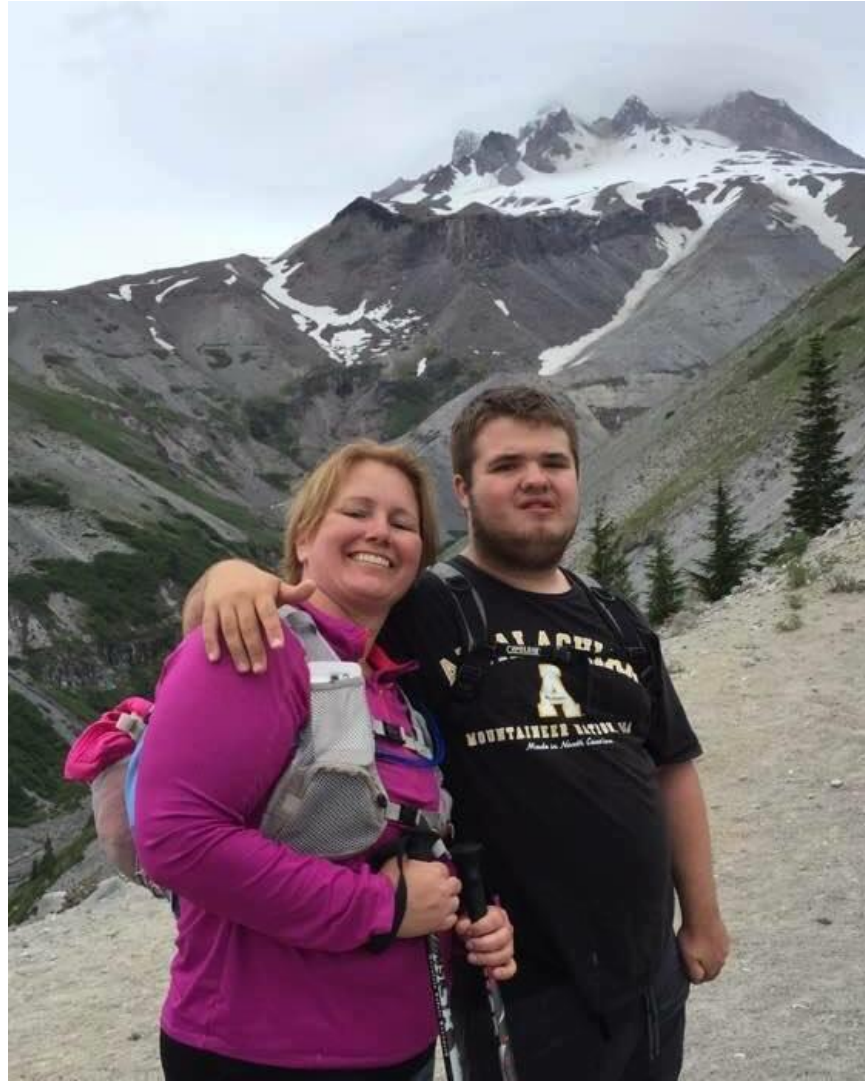












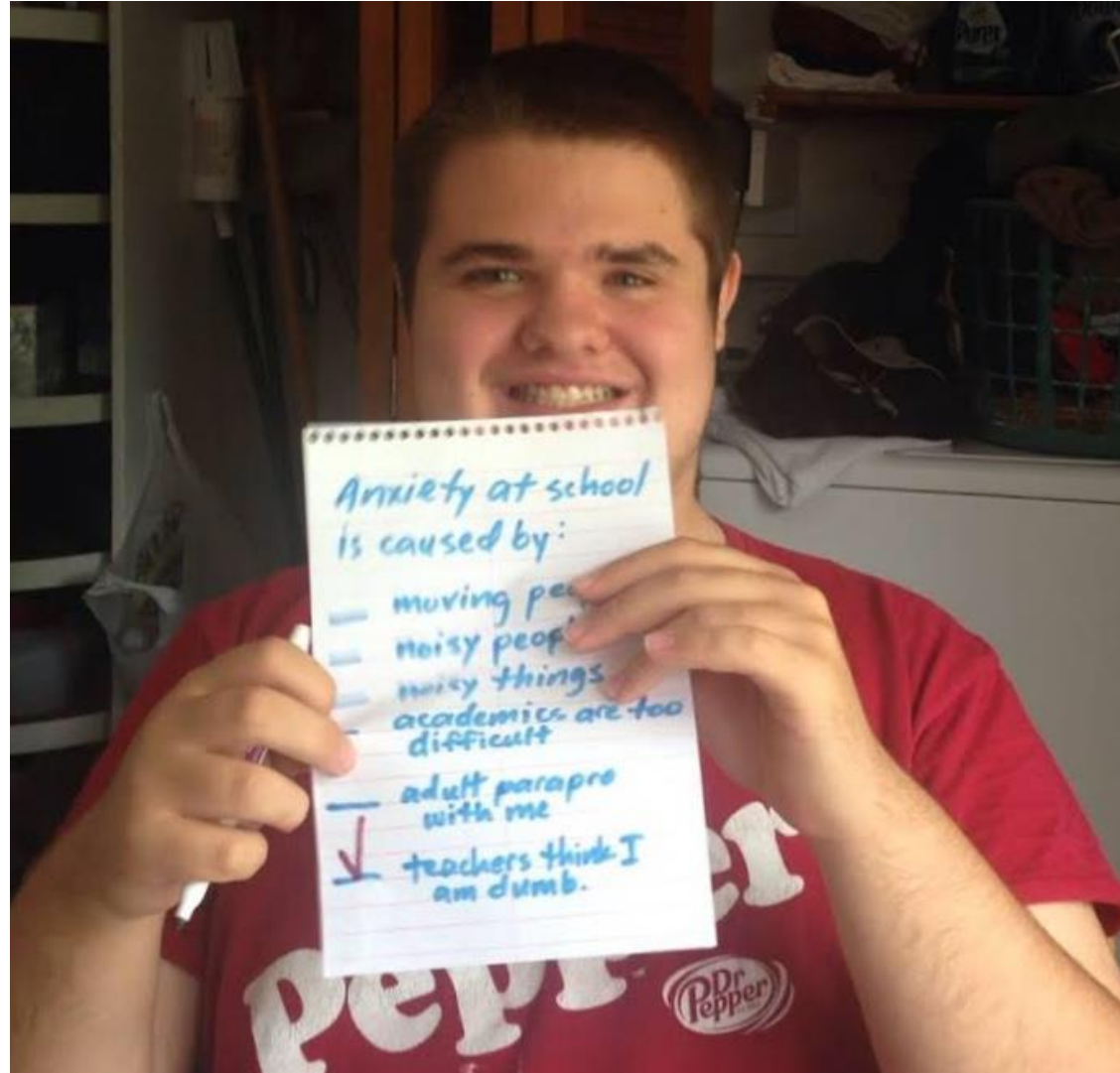












Anxiety at school
is caused by:

- moving people
- noisy people
- noisy things
- academics are too difficult
- adult parapro with me
- ↓ teachers think I am dumb.









an OuterSelf Initiative

tuck's tooques

Himalayan Headwear



TUCKER MASHUE
AUTISTIC ENTREPRENEUR

Hi, I'm Tuck!

I'm 18 and Autistic, but Autism does not define me. I love hiking, paddling, cycling, camping, road-tripping, and rocking out.

My Dad and I launched Tuck's Tooques to help me build an independent, meaningful future!

We're changing lives! In 2016, we logged over 27,000 miles, promoting Neurodiversity, sharing some tooquey goodness, and exploring 39 national parks.

Tuck's Tooques are microfleece-lined Sherpa hats handwoven by Nepali artisans in the shadow of the Himalayan Mountains.

Neurodiversity: It's a thing!

Autism & Childhood-Onset Schizophrenia (COS): One Family's Story & Some Broader Lessons

Alison Morantz, J.D., Ph.D.

**James & Nancy Professor Kelso Professor of Law
Stanford University**

May 21, 2019













Key Takeaway #1: More Treatment Options Are Urgently Needed

- People with autism and disabling mental illness are shunned by many ABA and psychiatric care providers
- Both fields need to develop the capacity to serve people with dual diagnoses
- There is an urgent need for more individualized supports, including wraparound and safety net services, to enable people with dual diagnoses to live safely at home
- There is an equally urgent need for more inpatient treatment and residential living options, so people who cannot live safely at home can do so in their communities or nearby

Key Takeaway #2: NIMH Should Take the Lead on COS Research

NIMH should again play a leading role by:

- Publishing all data from the initial 20-year study; and
- Launching a new intramural research study, with a particular focus on the connection between autism and COS

Key Takeaway #3:

Need for Training, Oversight & Individualized Supports

People with autism and severe comorbid mental illness are especially vulnerable to abuse.

In group settings, protecting their health and safety will require better training and oversight of nurses and other direct-care staff.

To enable more people to live safely at home, we also need to provide more training and support to families and other in-home caregivers.

Key Takeaway #4: Surveillance & Data Collection Must Be Improved

- *We can't build on success without a strong evidence base!*
- Yet data on the quality of services provided to people with autism and co-occurring mental illness is virtually nonexistent.
- To improve safety and long-term outcomes:
 - *In highly restrictive settings:* Reporting requirements for intermediate care facilities (ICF-IIDs) should be upgraded to match the requirements for nursing homes, including the creation of a minimum data set on ICF-IID residents; requirements should be broadened to include *all* highly restrictive settings funded by Medicaid.
 - *In the community:* New surveillance systems should be created to effectively monitor the quality of services delivered in community-based settings (at least those funded through Medicaid waivers).

Final Thought: **Let's Build More Streetlights!**





Discussion

Oral Public Comments



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

Written Public Comments



Oni Celestin, Ph.D.

Science Policy Analyst

Office of Autism Research Coordination, NIMH

Live Feedback Comments



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health



Discussion

The Co-occurrence of Anxiety and Obsessive Compulsive Disorder with Autism Spectrum Disorder

Connor M. Kerns, PhD
Assistant Professor, Department of Psychology
University of British Columbia
Vancouver, BC



Disclosures

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 - Adelphi Center for Health Innovation
 - Hampton Research Fund
 - Kennedy Krieger Institute
- **Royalties & Consulting**
 - Elsevier
 - Connor M Kerns PhD LLC



Defining Anxiety Disorder

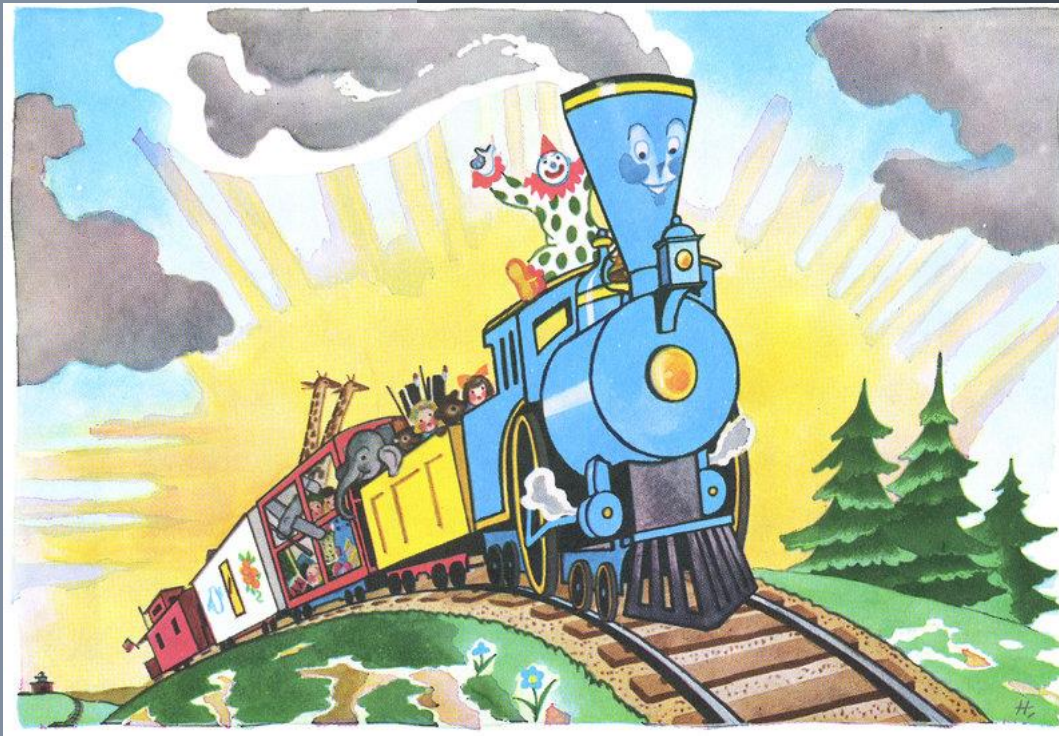
- ***Anxiety** is meant to be adaptive. **Anxiety disorders** occur when this protective mechanism becomes maladaptive and interfering.*



Costs of Anxiety Disorders in ASD

- *Anxiety disorders associated with a specific, more severe clinical profile in ASD*
 - Social initiation, repetitive & restricted behavior
 - Depression and self-injury
 - Sleep problems & gastrointestinal illness
 - Family Stress
 - Quality of life

See Chang et al. (2012), Kerns et al. (2015), Lidstone et al. (2014), Mazurek et al. (2013), Mazurek & Petroski (2015), Sukhodolskey et al. (2008), van Steensel et al. (2012)



From "The Little Engine that Could" by Platt & Munk, Penguin Young Readers Group

Subtler Costs

- Pain v. suffering;
challenge v. distress
- Anxiety limits
resilience and mastery
- May lesson response
to critical treatments
 - Pellechia et al.
(2016)
 - Lecavalier et al.
(2017)



Prevalence of Anxiety Disorders & OCD in ASD

Simonoff et al. (2008): Prevalence anxiety disorders in 112, 10 – 14 year-olds with ASD in UK population-based sample

DSM-IV Disorder	3-mo Prevalence (95% CI)
Any Anxiety Disorder	41.9 (26.8 – 57.0)
Generalized Anxiety Disorder	13.4 (0 – 27.4)
Separation Anxiety Disorder	0.5 (0-1.6)
Panic Disorder	10.1 (0-24.8)
Social Anxiety Disorder	29.2 (13.2-45.1)
Specific Phobia	8.5 (2.8-14.1)
Obsessive Compulsive Disorder	8.2 (3.2-13.1)

Reported range across research studies: 11 – 84 % (Kerns & Kendall, 2012; White et al., 2009; Van Steensel et al. 2011)



Kerns, Rast &
Shattuck
(Unpublished Data)

- **Point prevalence of parent-reported anxiety conditions** in 2016 National Survey of Children's Health, N=43,027 (1,131 ASD) ages 3 – 17 years.
 - **ASD: 39.5%** (95% CI: 33.9, 45.3)
 - **No ASD: 6.3%** (95% CI: 5.8, 6.8)

Children with ASD in 2016 NSCH	%(N)
Age 6 to 11 years	35.1% (177)
Age 12 to 17 years	54.3% (301)

- **Croen et al (2015): 29% adults with ASD**, women > men

* **Mazefsky et al. (2012):** in small sample, only 53% of community anxiety and 0% of OCD diagnoses confirmed by research interview



Challenges to Assessing Anxiety in ASD

- **Overlapping Symptoms**
- **Communication barriers**
- **Distinct presentation of anxiety in ASD**
- **Reliance on measures not designed for this population**

*See Kerns & Kendall (2012); Grondhuis & Aman (2012);
Lecavalier et al. (2014); Wigham & McConachie (2014);
Kerns et al. (2016); Vasa et al (2016)*



Presentation of Anxiety in ASD

Kanner (1943)

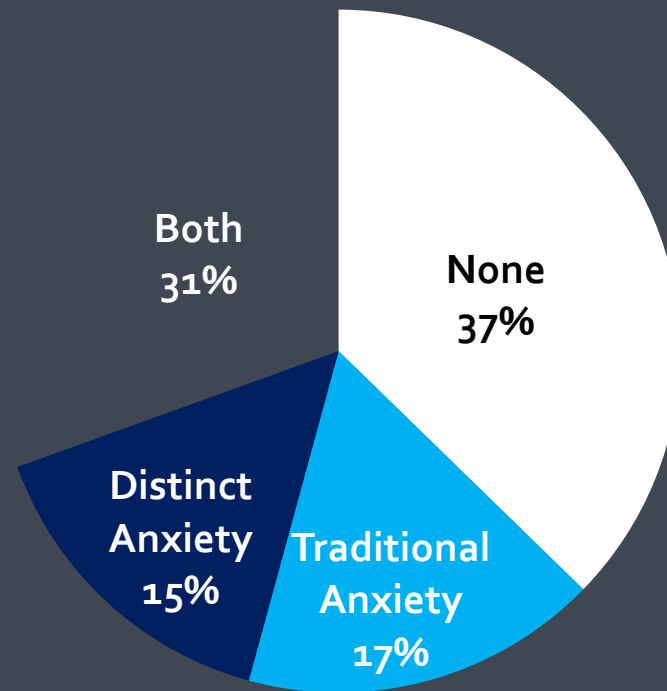
- *Donald: "we brought him to a playground slide...when other children were sliding on it... he would not get on it...he seemed horrorstruck"*
- *Alfred: "...a good deal of 'worrying.' He frets when the bread is put in the oven to be made into toast, and is afraid it will get burned and be hurt...He is upset because the moon does not always appear in the sky at night..."*

Hamlon, Richdale & Urjarevic (2018)

- *Audrey: "I get anxious in social situations as I don't see emotions in people until they get to a 10 ...and then it's an explosion, and I don't know when it's going to happen"*



Kerns et al. (2014),
*Journal of Autism
and Developmental
Disorders*



- *N=59 youth with ASD (age 7 – 18 yrs, IQ 67-158) at CHOP*
- *Verbal ability associated with traditional but not distinct anxiety*
- *Distinct anxiety associated with traditional anxiety and ASD symptoms*



Kerns et al. (2015),
Behavior Therapy

- *The ability of brief parent and self-report measures to detect anxiety disorders in children with ASD may be limited.*
- N=54 children with ASD (IQ 67-158, 7 – 17 yrs), non-treatment seeking.

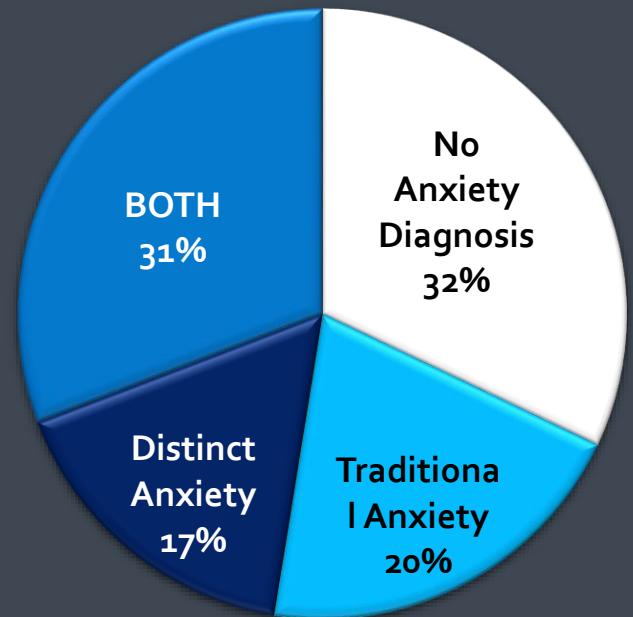
Measure	Sensitivity	Specificity
BASC Anxiety Subscale, Child Report	.06	1.00
BASC Anxiety Subscale, Parent Report	.37	.95
SCARED, Child Report	.46	.65
SCARED, Parent Report	.45	.86

See also Mazefksy et al. (2011) & Zainal et al. (2014),
White et al. (2015), Glod et al (2017), Medeiros et al. (2017)



Kerns et al.
(unpublished data)

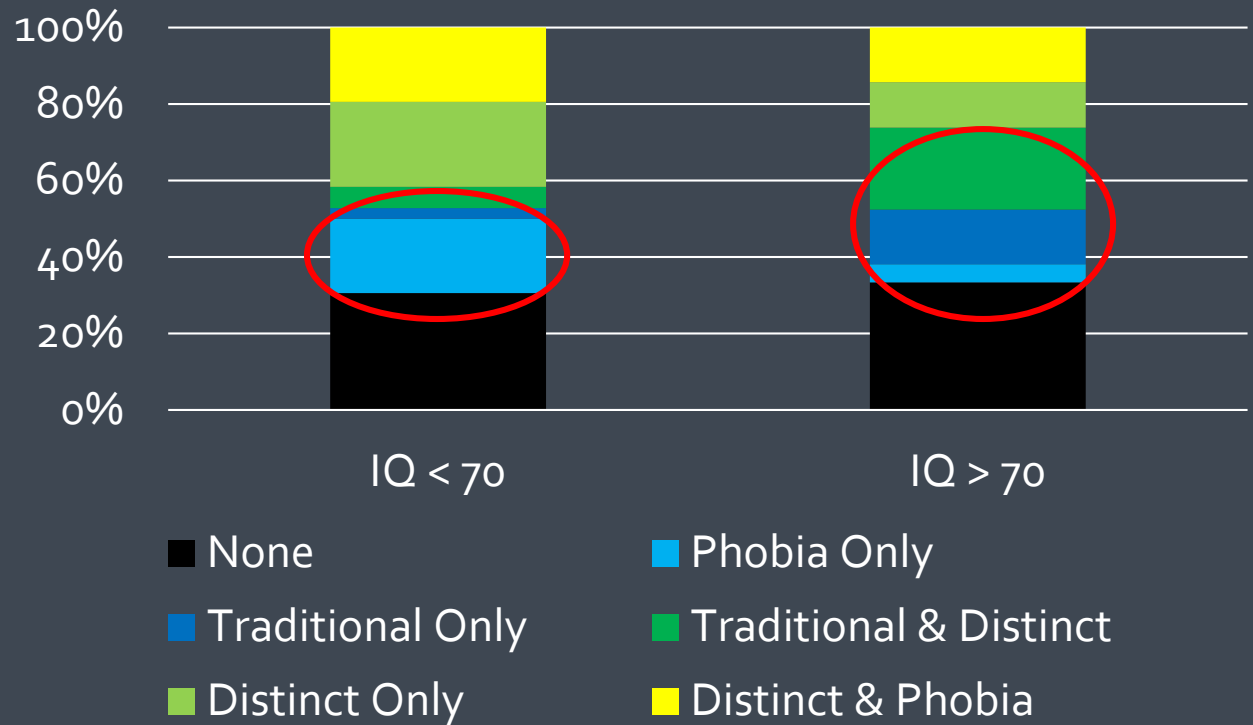
- N= 78 ASD (9-13 yrs) from Autism Phenome Project at UC Davis MIND Institute
- Broader IQ range: <24 to 170
- *Sensitivity brief parent measures (MASC, SCARED, CBCL anxiety) limited:*
 - Total Sample: 0.33 - 0.39
 - IQ < 70 group: 0.04 - 0.13





Kerns et al.
(unpublished data)

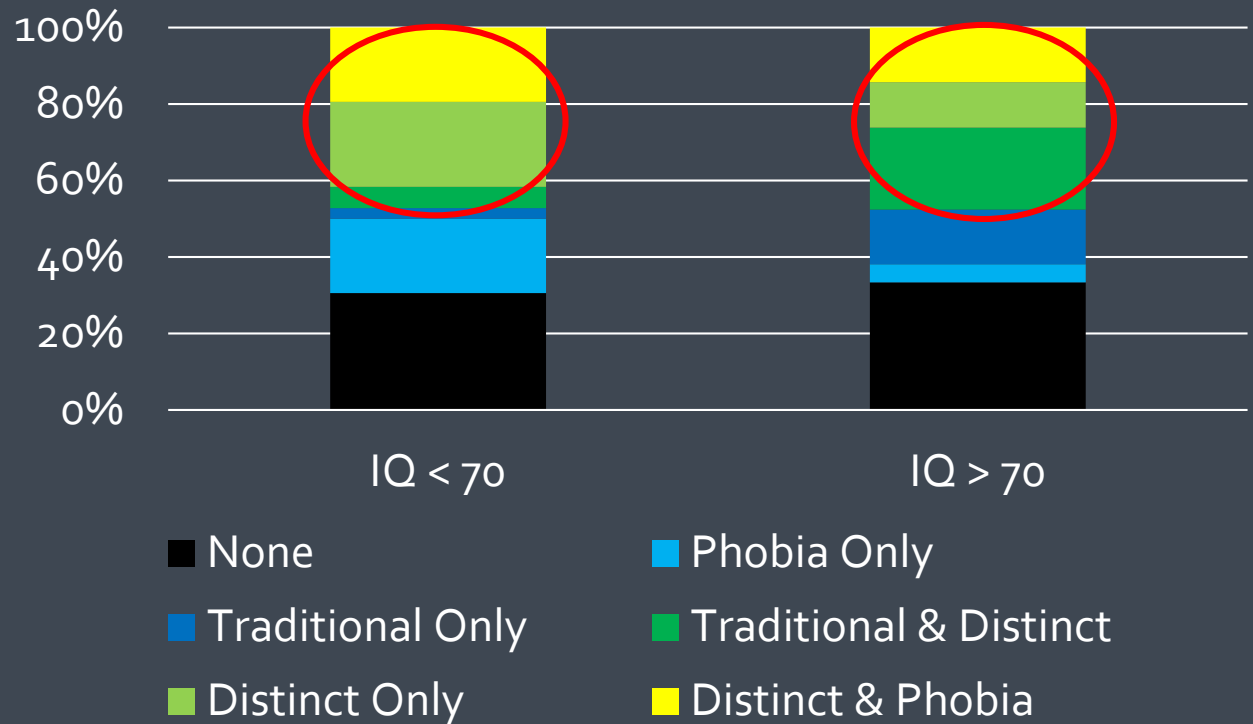
- IQ associated with quality not quantity of anxiety.*





Kerns et al.
(unpublished data)

- IQ associated with quality not quantity of anxiety.*





Summary & Lessons Learned

- Anxiety disorders & OCD are common but not universal amongst those with ASD.
- The study of anxiety in ASD must be rooted in a firm understanding of its phenomenology.
- How we choose to define anxiety disorders in ASD will have substantial ramifications for research and practice.



Future Directions

- **Measurement**
 - New, tailored measures for ASD (Kerns et al., 2017; Rodgers et al., 2016; Scahill et al., 2019)
- Assessing and better understanding the **biological underpinnings** of anxiety
- **Longitudinal and prospective** study designs.
- **Effective and accessible prevention** & early intervention as well as **treatment**.
 - Interdisciplinary cross-talk and training

Acknowledgements

- *Individuals with ASD and their families for their invaluable contributions to research.*
- *All my incredible research collaborators, mentors and support staff.*

Thank you!



Treatment of Anxiety in ASD

IACC Meeting
May 2019

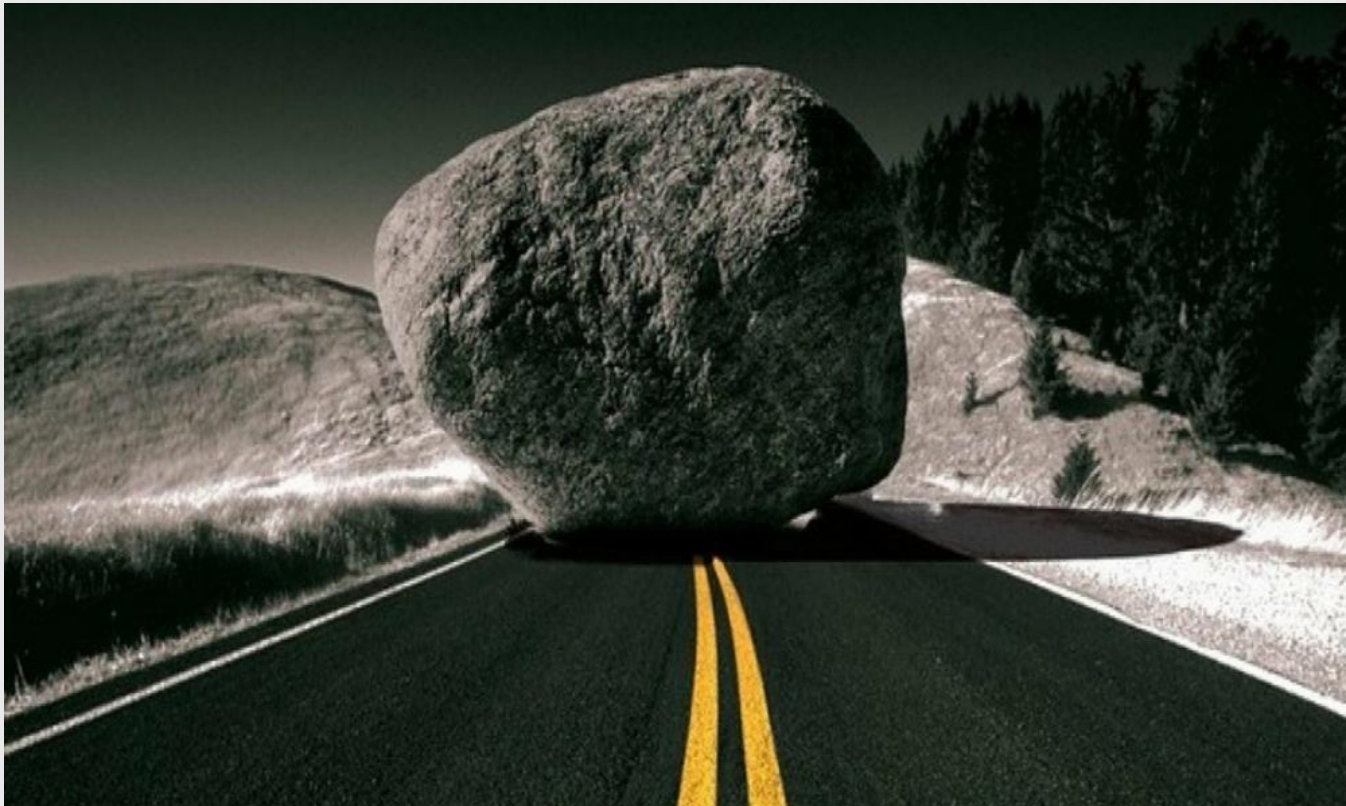
Judy Reaven, Ph.D.
Associate Professor of Psychiatry and Pediatrics
JFK Partners
University of Colorado Anschutz Medical Campus
School of Medicine
Judy.reaven@ucdenver.edu

Real World Impact

- Fear of public bathrooms (e.g., automatic toilets, hand dryers)
- Fear of being late
- Fear of talking to new people/asking for help/ordering in a restaurant
- Fear of separating from parents
- Fear of making mistakes

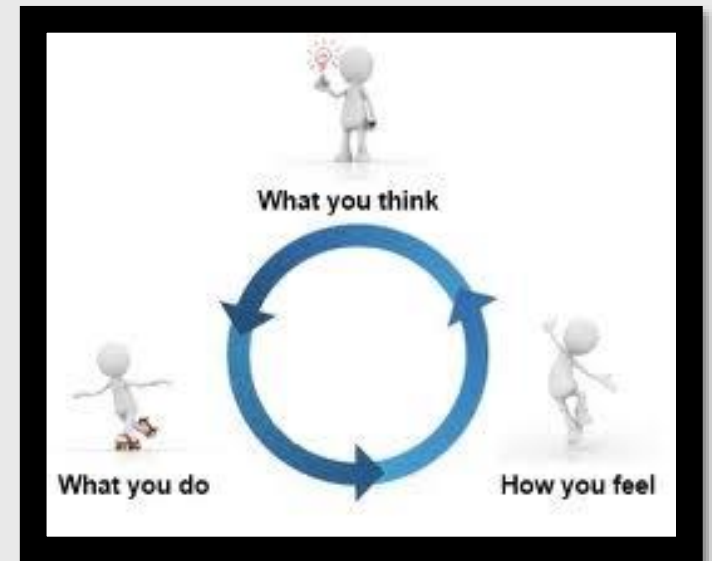
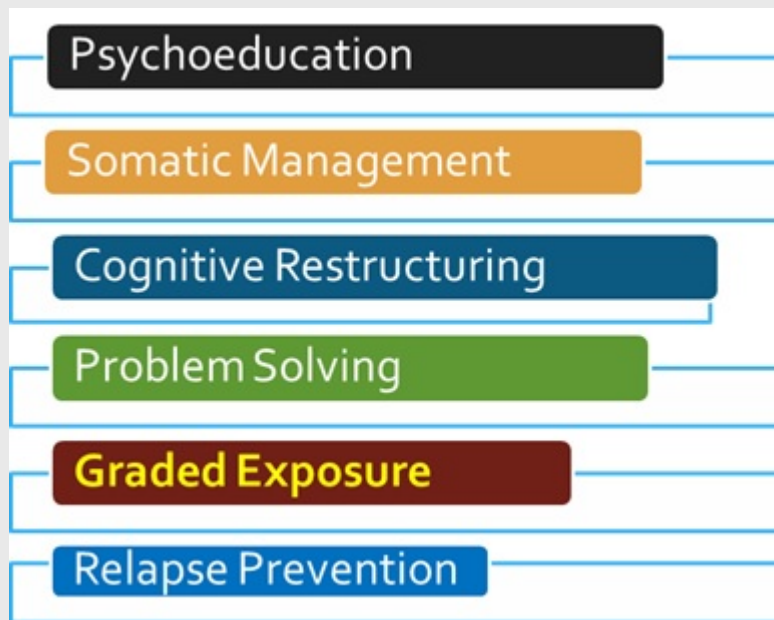


Anxiety as an Obstacle in Our Path



Treatment of Choice

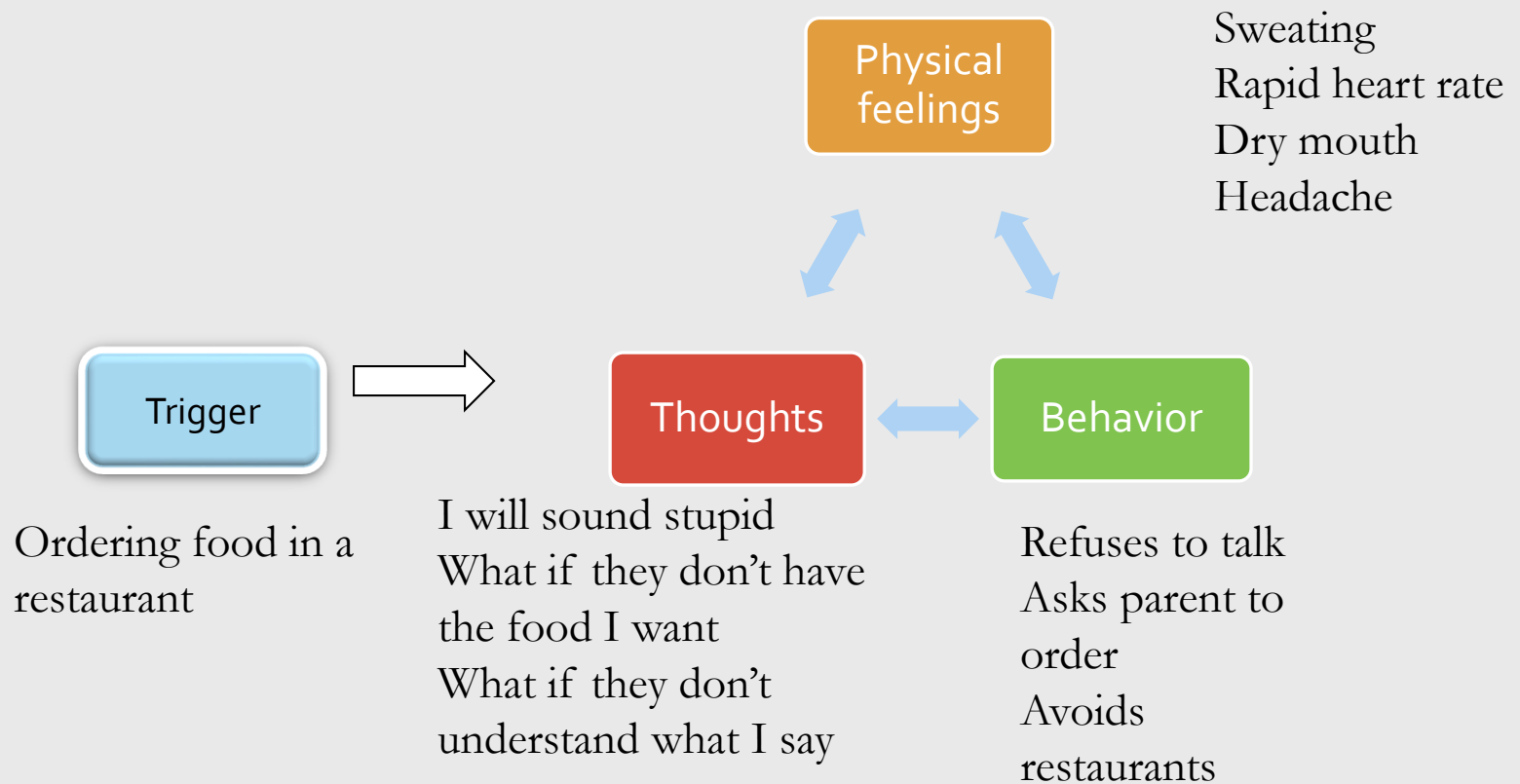
Cognitive-Behavioral Strategies for Anxiety: Core Components



Improvement rates exceed 50% (Olantunji et al. 2010; Walkup et al. 2008).

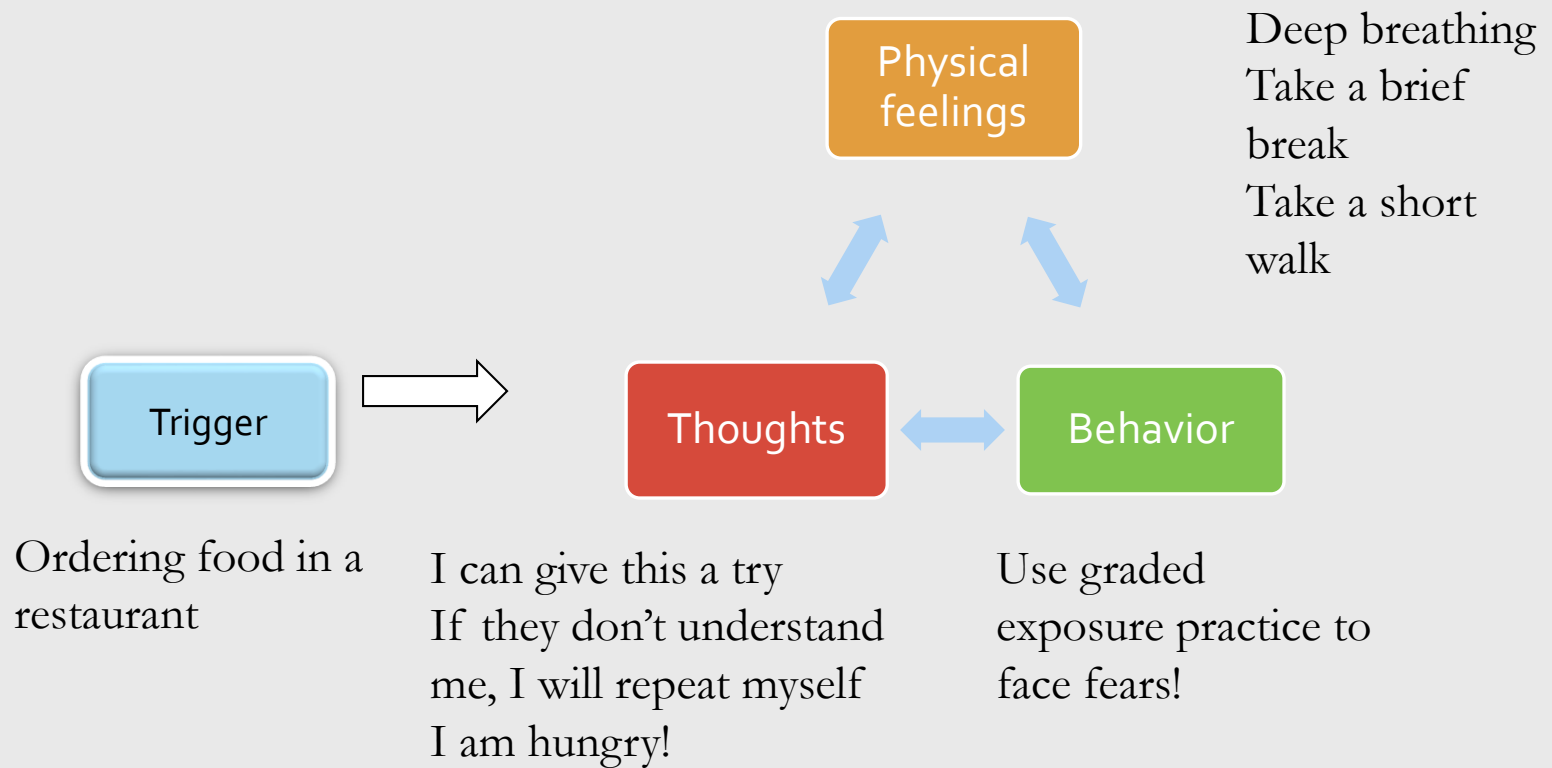
CBT Conceptualization of a Child with Social Anxiety

(adapted by Weissman et al)



CBT Conceptualization of a Child with Social Anxiety

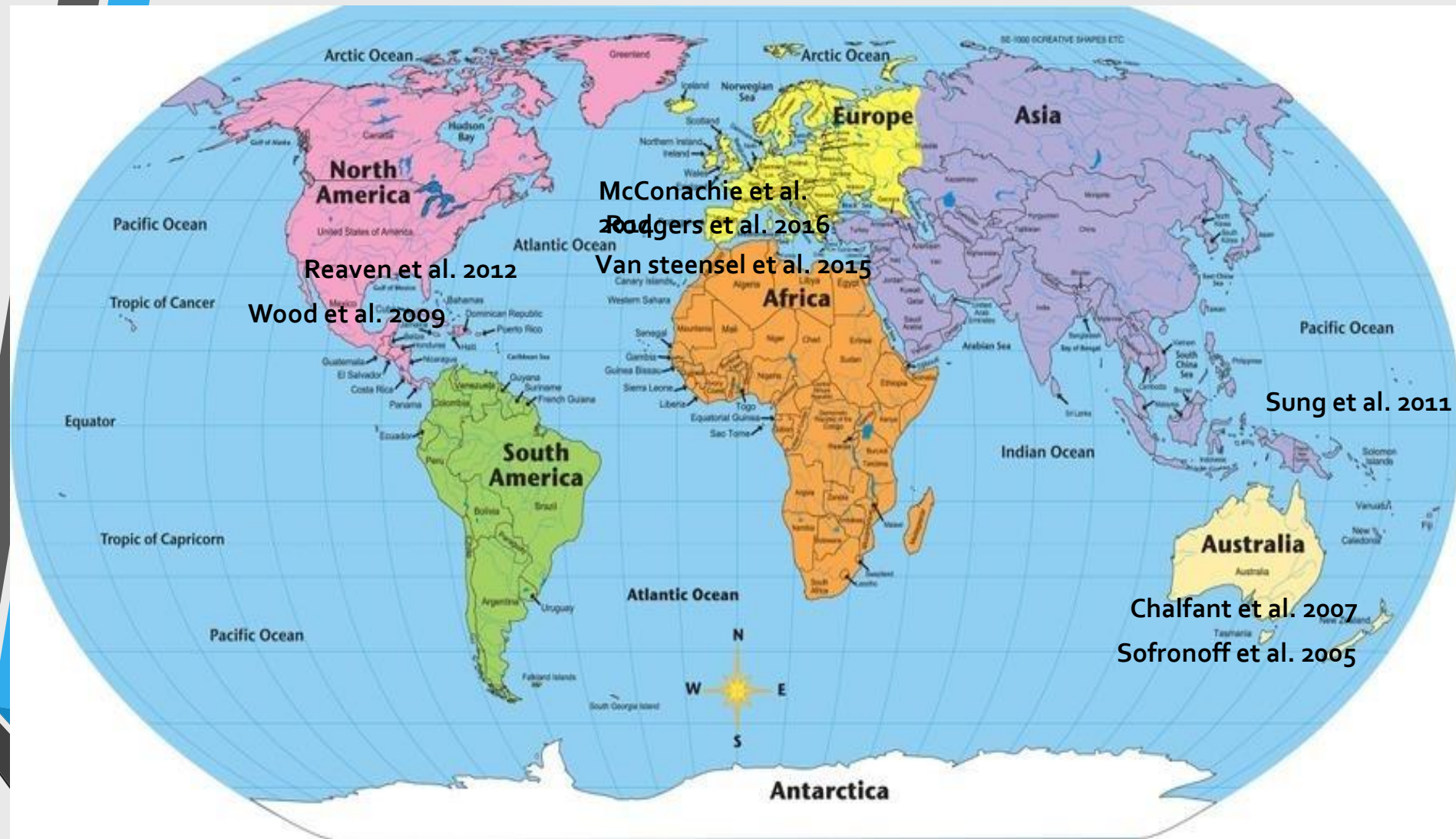
(adapted by Weissman et al)



Graded Exposure: Ordering Food in Restaurant



- 1. telling a parent what food they would like to order
- 2. point to the food on the menu when asked by the waiter
- 3. give a 1-2 word response when asked by the waiter
- 4. responding to a waiter with a full sentence order
- 5. independently ordering food at a counter



CBT for Anxiety in ASD

- Individual treatment (McNally Keehn et al. 2013; Wood et al. 2009; Storch et al. 2013; van Steensel & Bogels, 2015)
- Group Treatment (Chalfant et al. 2007; McConachie et al. 2014; Reaven et al. 2012; Rodgers et al. 2016; Sung et al. 2011)
- Individual plus group treatments (White et al. 2010; 2013)
- Focus on school aged youth; fewer studies with teens; primarily clinic-based



Modifications to CBT for Youth ASD: Road Map for Other Conditions (Moree & Davis, 2010; Reaven et al. 2011)

- Basic CBT content is unchanged
- Modifications based on the cognitive, linguistic and social needs of children with ASD
- Group structure and management
 - Token reinforcement program for in-group behavior
 - Visual structure and predictability of routine
 - Careful pacing of each group session



Modifications (continued)

- Modifications in teaching basic concepts
 - Prerequisite skills (i.e. ,feeling vocabulary)
 - Written worksheets
 - Multiple choice lists
 - Drawing and other creative outlets
 - Repetition and practice
 - Strength based
 - Incorporation of special interest
- **Parent involvement critical**



Parent Involvement

(Barrett et al. 2004; Cobham et al. 1998; Reaven et al. 2011)

Generalize skills across settings by:

- Modeling brave behavior
- Ignoring excessive displays of anxiety
- Identifying “targets” for facing fears
- Helping youth use coping strategies
- Rewarding brave behavior

Treatment for OCD

- Reaven and Hepburn, 2003 (7 year old)
- Lehmkuhl et al. 2008 (12 year old)
- Russell et al. 2013 (n=46; teens/adults) Adaptations to standard treatment for OCD:
 - Understanding/differentiating emotions
 - Connections between thoughts, feelings and behaviors
 - Understanding/rating anxiety – rationale for treatment
 - Visual tools and concrete/special interests to convey analogies
- **Exposure/response prevention**



Example of OCD Treatment

- Contamination fears (from door knobs, bathrooms)
- Strategies
 - CBT as described
 - Exposure/response prevention – initially touch germy objects which triggers anxiety and need to engage in compulsive behaviors
 - Block the ritual (hand washing/hand sanitizer) avoid engaging in compulsive behavior – begin by delaying the compulsive behavior



Third wave...of CBT



- Mindfulness and acceptance-based interventions (Buddhist mindfulness practices)

Breathing meditations, mindfulness, and yoga address stress and negative emotions (teens through young adults)

Mindfulness: “**Awareness that arises through paying attention, on purpose, in the present moment, non-judgmentally**” (Connor et al. 2018; Kabat-Zinn, 2013).

- MBCT modified for adults with ASD (Kiep et al. 2015; Spek et al. 2013)
- Mindfulness Based Stress Reduction (MBSR) – (MyMind; de Bruin et al. 2014)

A Brief Word About Medications: Pharmacological Treatment of Anxiety in ASD

- In general pediatric population, medication (sertraline) + CBT yielded best response (Walkup et al. 2008)
- Very little research investigating the use of medication to treat anxiety (Vasa et al., 2014; Vasa & Mazurek, 2015).
- Recent systematic review found 4 studies, none were randomized, placebo-controlled trials (Vasa et al., 2014).
- All these studies explored the use of SSRI (Selective Serotonin Reuptake Inhibitor) for anxiety in ASD.

Earle, 2016



SSRI treatment of Anxiety



- The US FDA has approved the use of several SSRIs for treating anxiety in adults
- Some data suggest that SSRIs may have utility, especially for youth with comorbid ASD and anxiety/compulsive behaviors.
- Studies with SSRIs are limited despite the prevalent use of these drugs.
- Research suggests contradictory results

More research needed

Nadeau et al. 2011; Howes et al. 2018




Next on the Horizon....





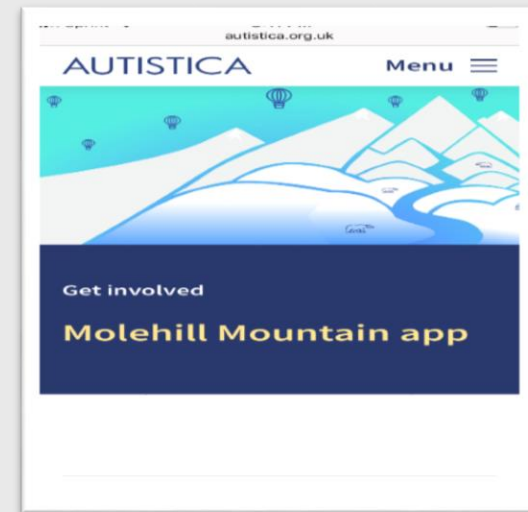
IMPLEMENTATION SCIENCE

Bringing Evidence-Based Practice for Youth with ASD and Anxiety to The “Real World”

-  Specialist Clinic Settings
(Reaven et al. 2014;
Reaven et al. 2018)
-  Schools (Clarke et al.
2017; Drmic et al. 2017;
Luxford et al. 2016)
-  Telehealth to rural
communities (Hepburn et
al. 2016)



Technology



- Adolescents with ASD and anxiety (Reaven et al. 2012)
- <https://www.autistica.org.uk/our-research/research-projects/anxiety-app-for-autistic-young-people>
- Virtual Reality for specific phobias (Maskey et al. 2019 n=32)



Understand **Mechanisms** Contributing to the Development of Anxiety (Maisel et al. 2016)

- **Alexithymia** (identify and understand emotions)
- **Emotional Acceptance** (React aversively to emotional experiences; accept feelings and do not push away negative emotions)
- **Intolerance of Uncertainty** (IU) (Boulter et al. 2014; Rodgers et al. 2016) (negative beliefs about uncertainty and react negatively to uncertainty)
- Develop/implement mindfulness-based interventions targeting **alexithymia, IU**, and increasing **emotional acceptance** recommended

Who has been left out?

- Adolescents/Adults
- Individuals with ASD and Intellectual Disability
- Low income, traditionally underserved racial/ethnic minority communities



Individuals with ASD/Intellectual Disability with Anxiety

- Adolescents with ASD/ID have significant anxiety/behavioral challenges; receive limited mental health (Helveschous & Martinsen 2011)
- Barriers to mental health care for individuals with ASD/ID: reduced service delivery; limited research; and lack of manualized interventions (Whittle et al. 2018)
- Case studies use graded exposure paired with positive reinforcement (Hagopian & Jennett, 2008; Moskowitz et al., 2017)
- Previous research has encouraged cognitive approaches (Vereenough & Langdon, 2013)
- Preliminary work adapting group CBT (Facing Your Fears) for teens with ASD/ID (Blakeley-Smith et al. 2019, INSAR)

Racial Disparities in CBT Research for Anxiety in ASD

(Pickard, Reyes, & Reaven, 2018)

- Reviewed 14 studies, 473 participants with ASD and anxiety in the US
- Compared demographics of the participants with US Census
- Significantly more White participants/significantly fewer Black/Latino youth than what US Census would suggest
- Highly educated sample – most caregivers with college degree or above
- Implications



Real World Success

- ▶ Using public bathrooms at airports, school, etc.
- ▶ Walking into the classroom, even when late.
- ▶ Talking to new people; ordering food in a restaurant
- ▶ Going to another part of the house; outside; left alone
- ▶ Turning in homework, making mistakes on tests



Thank You!!





Discussion



Lunch

If you are in crisis, call toll-free:

National Suicide Prevention Lifeline

1-800-273-TALK (8255)

The deaf & hard of hearing can call via TTY: 1-800-799-4889

Service is available to anyone 24 hours a day, 7 days a week

All calls are confidential

Text crisis support is available in the US, Canada, UK, Ireland, & S. Africa:

<https://www.crisistextline.org/textline/>

Workshop Agenda



Afternoon Agenda

1:35

Depression and Suicide

Depression in ASD

Katherine Gotham, Ph.D.

Assistant Professor Department of Psychiatry and Behavioral
Sciences Vanderbilt University Medical Center

Suicide and Autism, Current Evidence and Research Methods

Anne Kirby, Ph.D., OTR/L

Assistant Professor

Occupational & Recreational Therapies University of Utah

Mechanisms Underlying Suicide Risk in Autism

Darren Hedley, Ph.D.

Olga Tennison Autism Research Centre
School of Psychology and Public Health
La Trobe University, Australia

Workshop Agenda



Afternoon Agenda

2:20

Where do we go from here? Learning how to prevent suicide in partnership with autistic people and their allies

Sarah Cassidy, Ph.D.

Assistant Professor

School of Psychology

University of Nottingham, United Kingdom

2:55

Afternoon Break

3:10

Self Injurious Behaviors (SIB) and Aggression

Matthew Siegel, M.D.

Director, Autism & Developmental Disorders Inpatient Research

Collaborative (ADDIRC)

Maine Medical Research Institute

Vice President Medical Affairs

Developmental Disorders Service

Maine Behavioral Healthcare

Workshop Agenda



Afternoon Agenda

3:25

Craig A. Erickson, M.D.

Director, Fragile X Research and Treatment Center

Medical Director, Psychiatry Neurobehavioral Continuum of Care

Director of Research, The Kelly O'Leary Center for Autism Spectrum Disorders

Cincinnati Children's Hospital Medical Center

University of Cincinnati College of Medicine- Affiliated

4:00

Mental Health Services Issues for People on the Autism Spectrum

Brenna Burns Maddox, Ph.D., LCP

Post-Doctoral Fellow and Licensed Clinical Psychologist

Penn Center for Mental Health

University of Pennsylvania

Workshop Agenda



Afternoon Agenda

4:30

Wrap Up

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

Julie Lounds Taylor, Ph.D.

Associate Professor of Pediatrics
Vanderbilt Kennedy Center Investigator
Vanderbilt University Medical Center,
Co-Chair, IACC Health Outcomes Working Group

David Amaral, Ph.D.

Distinguished Professor, Department of Psychiatry and Behavioral
Science, University of California, Davis (UC), UC Davis MIND
Institute, Co-Chair, IACC Health Outcomes Working Group

5:00

Closing Remarks and Adjournment

Suicide & Mental Health Crisis Resources



The next 4 presentations discuss suicide & suicidal behavior
If you are in crisis, call toll-free:

National Suicide Prevention Lifeline
1-800-273-TALK (8255)

The deaf & hard of hearing can call via TTY: 1-800-799-4889
Service is available to anyone 24 hours a day, 7 days a week
All calls are confidential

Text crisis support is available in the US, Canada, UK, Ireland,
& S. Africa: <https://www.crisistextline.org/textline/>

Depression in Autism Spectrum Disorder

Katherine Gotham, Ph.D.
Department of Psychiatry and Behavioral Sciences
Vanderbilt University Medical Center

National Institute of Health
Interagency Autism Coordinating Committee Workshop:
*Addressing the Mental Health Needs
of People on the Autism Spectrum*

May 21, 2019

Research Program:

Identifying pathways to depressed mood in ASD
to inform precision emotional health treatment
for this population



Overview

Depression in ASD:

- Prevalence
- Impact
- Presentation
- Assessment
- Mechanisms
- Treatment
- Back to Mechanisms...



Depression is common in ASD

- People with ASD are approximately 4 times more likely to experience depression compared to the general population when age ranges are pooled (Hudson et al., 2018)

Per Hudson et al., 2018 meta-analysis, significantly elevated lifetime depression rates in ASD were associated with:

- Increasing age (40.2% adult samples vs 7.7% in < 18 years old)
- Average to above average IQ (52.8% vs 12.2% when mean IQ is below average)
- Structured interviews to assess dep (28.5% vs 6.7% for other assessment methods)
- Self-report (48.6% vs 14.4% via caregiver report)

Developmental course

- Depressive symptoms seem to persist longitudinally in child-to-adult ASD studies
- **Girls:** Marked increase throughout adolescence, on par with TD girls (Gotham, Brunwasser, & Lord, 2015)
- **Boys:** Elevated symptoms in schoolage (compared to TD children and to girls with ASD), which persist into adulthood (Gotham, Brunwasser, & Lord, 2015)
- Depressive symptoms more likely to persist in children who are experiencing bullying or greater social communication difficulties (Rai et al., 2018)

Impact of depression in context of ASD

- Depression causes (greater) impairments in many areas:
 - Social skills and motivated social engagement
 - Adaptive behavior (daily living skills, communication)
 - Quality of Life, independence
 - Challenging behaviors and coping skills
- Depression in ASD also associated with systemic burden and other areas of risk:
 - greater use of service and meds
 - increased burden on caregivers
 - Suicidality
 - Heightened physical (e.g., gastrointestinal problems, seizures), emotional (e.g., anxiety), and behavioral (e.g., aggression, inattention) comorbidities
- Implications for autism interventions

The community is calling for this to be addressed...

- Treatment and/or study of depression in the context of ASD is commonly listed by autistic adult samples among top priorities

(HRSA-funded AASET working group, 2018 conference; Gotham, Marvin, Taylor et al., 2014)



Is there an autism-specific presentation of depression?

- We don't know.
- Depression initially thought to be more “somatic symptoms” in ASD (Stewart et al., 2006; Magnuson & Constantino, 2012)
- We found evidence for high cognitive-attributional symptoms in adults with ASD compared to same-aged TD sample (Gotham, Unruh, & Lord, 2014)
- Recent evidence for insomnia and restlessness marking pre-adolescents with ASD+depression (but “worthlessness” also much higher in ASD than TD depressed comparisons in their sample) (Montazeri, deBildt, Dekker, & Anderson, 2019)

“Traditional” features of depression seem to be common in people with ASD...

- Sadness, crying
- Loss of interest and pleasure in activities
- Social withdrawal and general lack of motivation
- Increased sleeping and eating problems
- Decreased self-care
- Negative cognitions (failure, hopelessness, self-criticism, guilt)
- Thoughts about death

Some depressive symptoms may be more specific to ASD...

- Changes in restricted interests
 - Markedly greater or lesser intensity
 - Change to morbid focus
- Increase in repetitive or ritualistic behaviors
- Irritability
- Increased aggression and/or self-injury
- Regressions or decline in self-care

See Table 1 from Pezzimenti, Han, Vasa, Gotham, 2019, for summary of traditional and atypical symptoms of depression in ASD, with references;

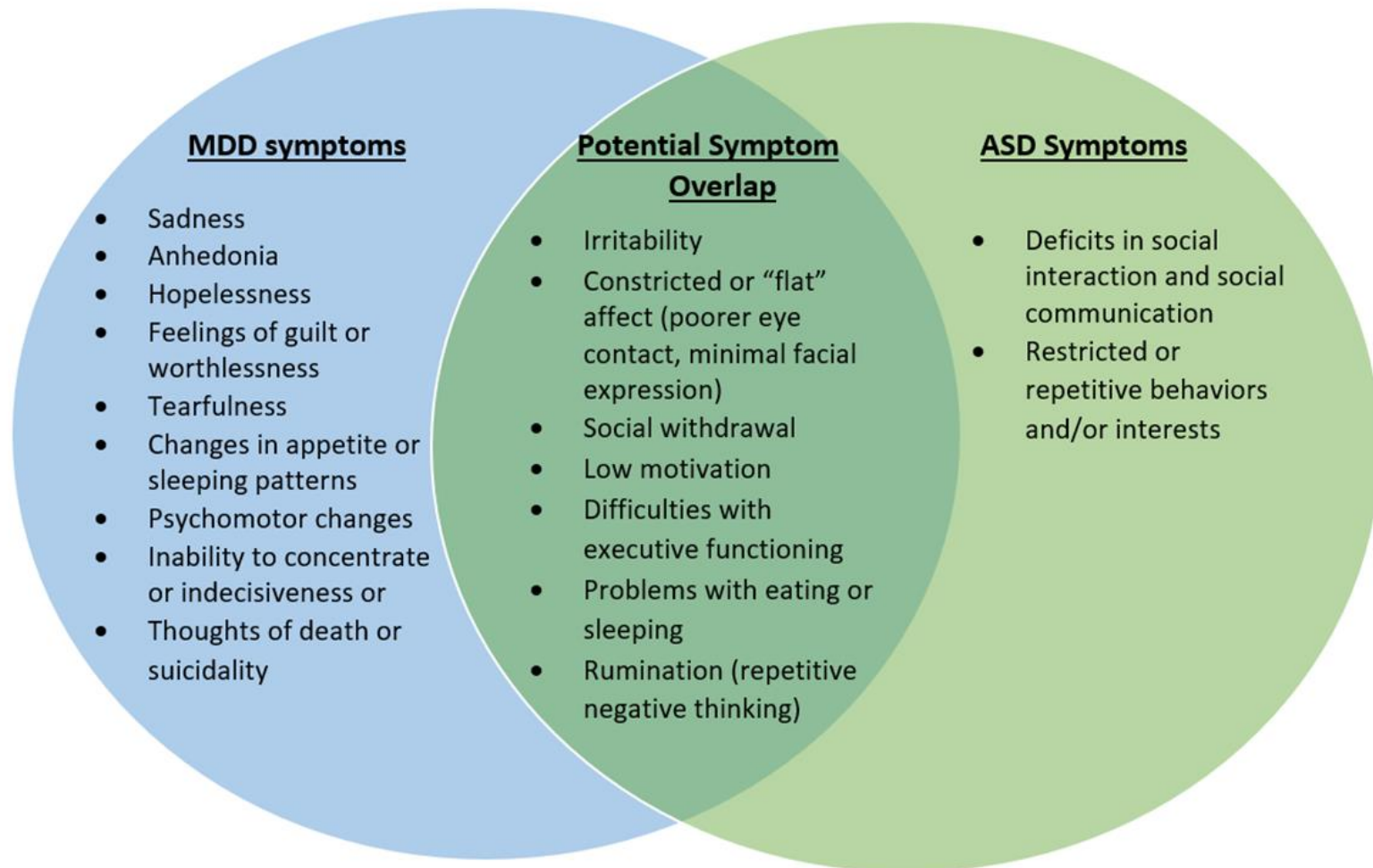
See also Table 1 from Magnuson & Constantino, 2012, for similar but distinct description.

Challenges in assessing depression in ASD

- Core ASD features may “overshadow” depressive symptoms (next slide)
- People with ASD often have difficulty recognizing and/or communicating about depressive symptoms, especially cognitive/emotional symptoms
- We lack understanding of what depression may look like in minimally verbal and/or less cognitively able individuals on the spectrum



Core ASD features may “overshadow” depressive symptoms



Challenges to measurement of depressive symptoms in ASD

- Symptom overlap can obscure assessment in both directions (Hus et al., 2013; Havdahl et al., 2016; Gotham et al., unpublished data)
- Reliability of self-report is unclear (both in general in ASD and then particularly when using instruments not validated in ASD)
- Unclear how to weight/reconcile discrepancies between parent- and self-report ratings
- ...though self-report seems to be associated with more 'true' cases of co-occurring depression and ASD (Gotham, Unruh, & Lord, 2014; Hudson et al., 2018)
- See Cassidy et al., 2018 review of instruments to measure depression in ASD

Predictors or potential risk factors for depression in ASD

- Chronological Age
 - Higher rates in adolescents/adults than children
 - Increasing social challenges and expectations with age
- Cognitive ability and/or autism severity
 - Symptoms of depression have been pos correlated with IQ in research samples
 - Increased insight/self-awareness of deficits
- Individual traits or characteristics associated with proposed pathways
 - e.g., social motivation, rumination
- Environmental context or adverse events
 - e.g., traumatic life events, bullying, lack of independence & vocational/romantic fulfillment
- Genetics
 - Family history of depressive symptoms prior to birth of child with special needs

Note:

**Sex/gender and SES =
contradictory
evidence of
association with
depression in ASD**

Common pathways between Depression and ASD?

Genetic/Biological

- High familial aggregation of Dep in ASD
- EEG resting frontal asymmetry
- Cognitive perseveration
- Decreased amygdala inhibition by PFC
- Anomalous reward circuitry functioning
- Role of serotonin?
- Neural inflammation/microglial dysregulation

Psychological

- Loneliness, social isolation
- Elevated cognitive attributions associated with depression
- High trait anxiety
- Anomalous emotion regulation
- Poor coping skills

Social Context

- Bullying
- Lack of societal understanding
- Poor prospects for independence and goal achievement (vocational, educational, residential, romantic)

Bauminger & Kasari, 2000; Cacioppo et al., 2006; White & Roberson-Nay, 2009

²Gotham, Unruh, & Lord, 2014; Gotham, Bishop, Brunwasser, & Lord, 2014

³Kim et al., 2000

⁴Mazefsky et al., 2013

¹Shtayermman, 2007

²Gotham, Marvin, Taylor, et al., in press

³Henninger & Taylor, 2013

¹ Bolton, Pickles, Murphy, & Rutter, 1998; DeLong, 2004; Mazefsky et al., 2010

² Frick, Williams, & Pittenger, 2013

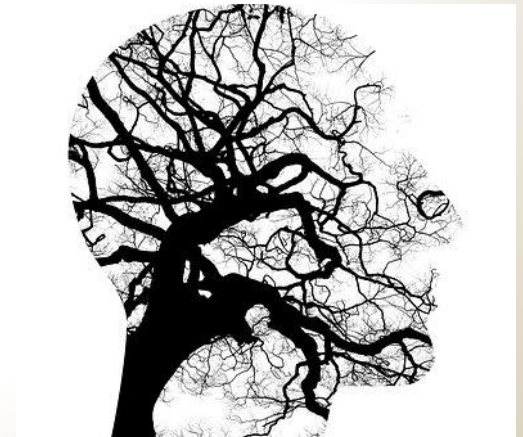
³Burnette et al., 2011

⁴Schipul, Keller, & Just, 2011; Siegle, Steinhauer, Thase, Stenger, & Carter, 2002

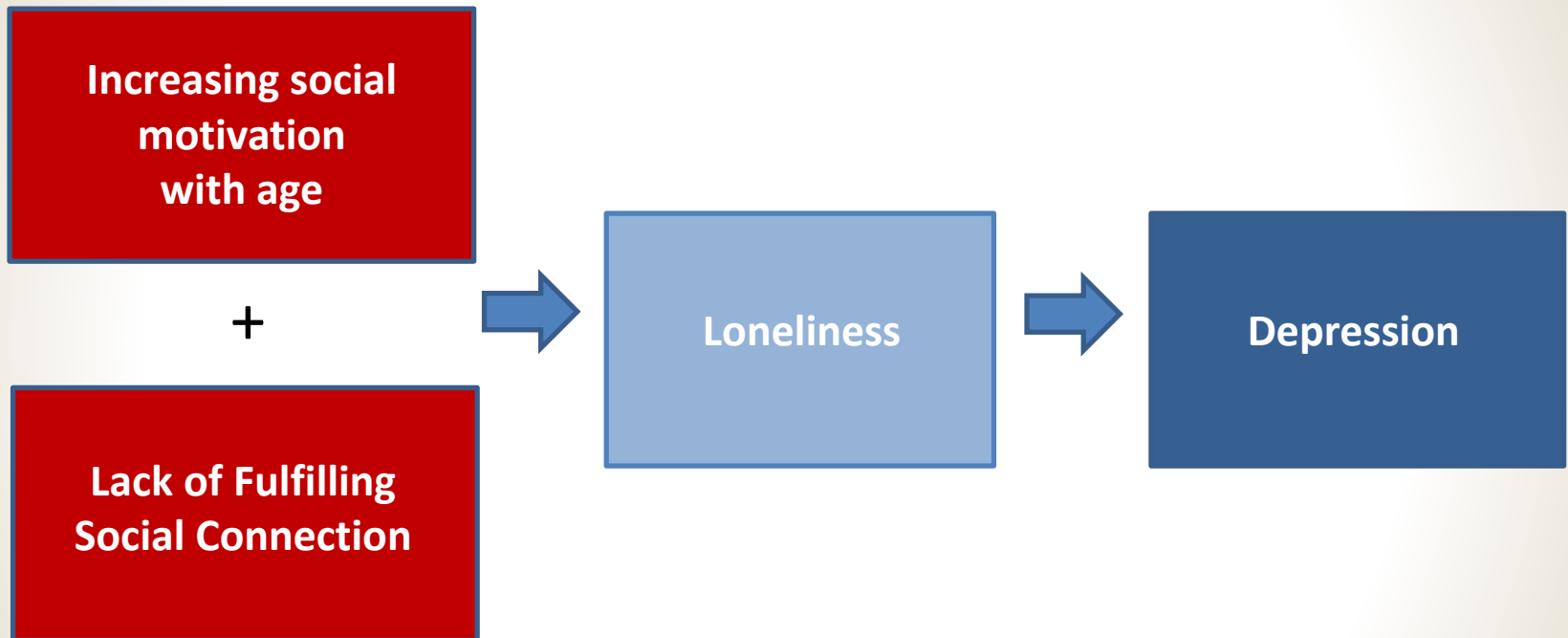
⁵Dichter, Damiano, & Allen, 2012

Singling out two potential pathways to depression in ASD

- Well-studied depression pathways in the general population perhaps particularly applicable to autism
- 1. Social connectedness**
 - 2. Rumination on negative thoughts/events**



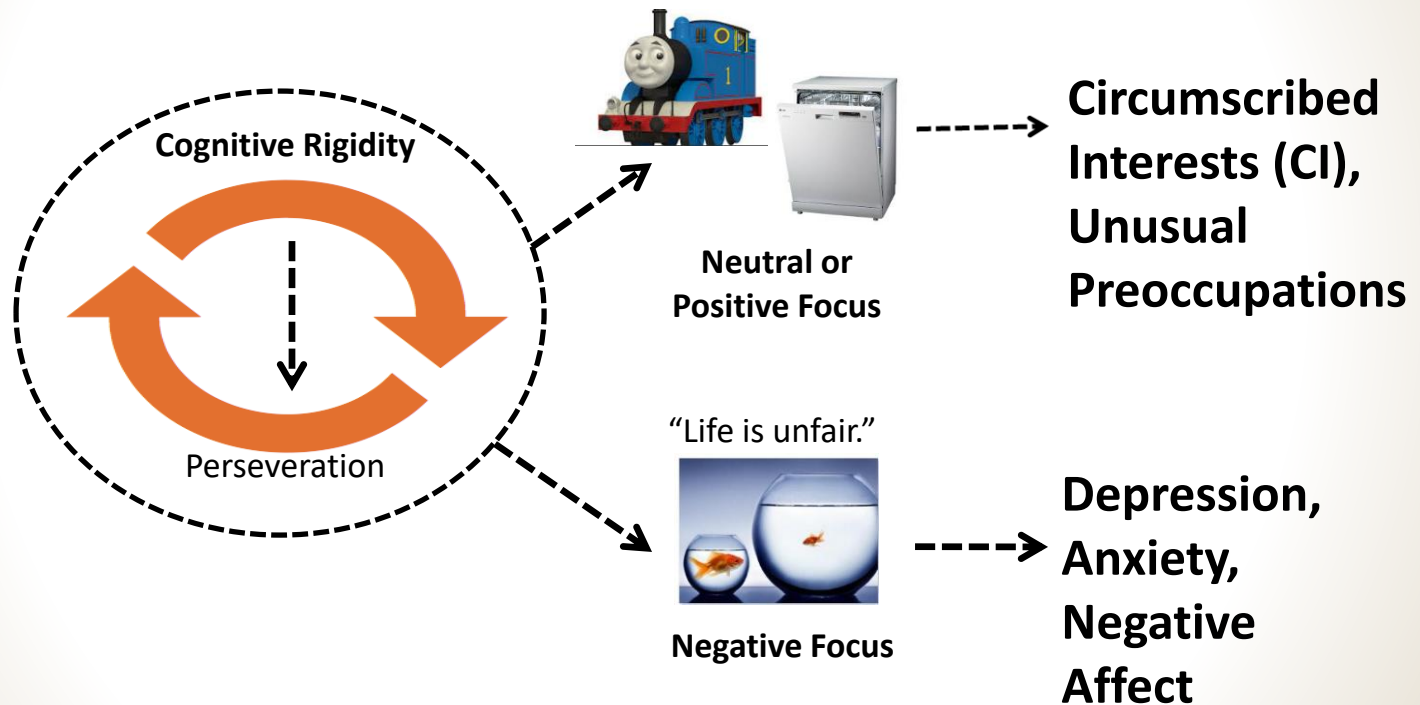
1. Social Connectedness Pathway



Williams & Galliher, 2006; Cacioppo et al., 2006; Hedley et al, 2018; Han, Tomarken, & Gotham, in press; Smith & White, in preparation

- Han, Tomarken, & Gotham, 2019: Adults with intact capacity for social pleasure (i.e., less anhedonia) experienced greater loneliness as a function of increased autism symptoms; loneliness was the strongest predictor of depression.

2. Repetitive Thinking in ASD



(Mazefsky et al., 2012; Gotham et al., 2014; Gotham et al., 2018; Burrows, Timpano, Uddin, 2017; see also Crane et al., 2013; Rieffe et al., 2014; Patel et al., 2016)



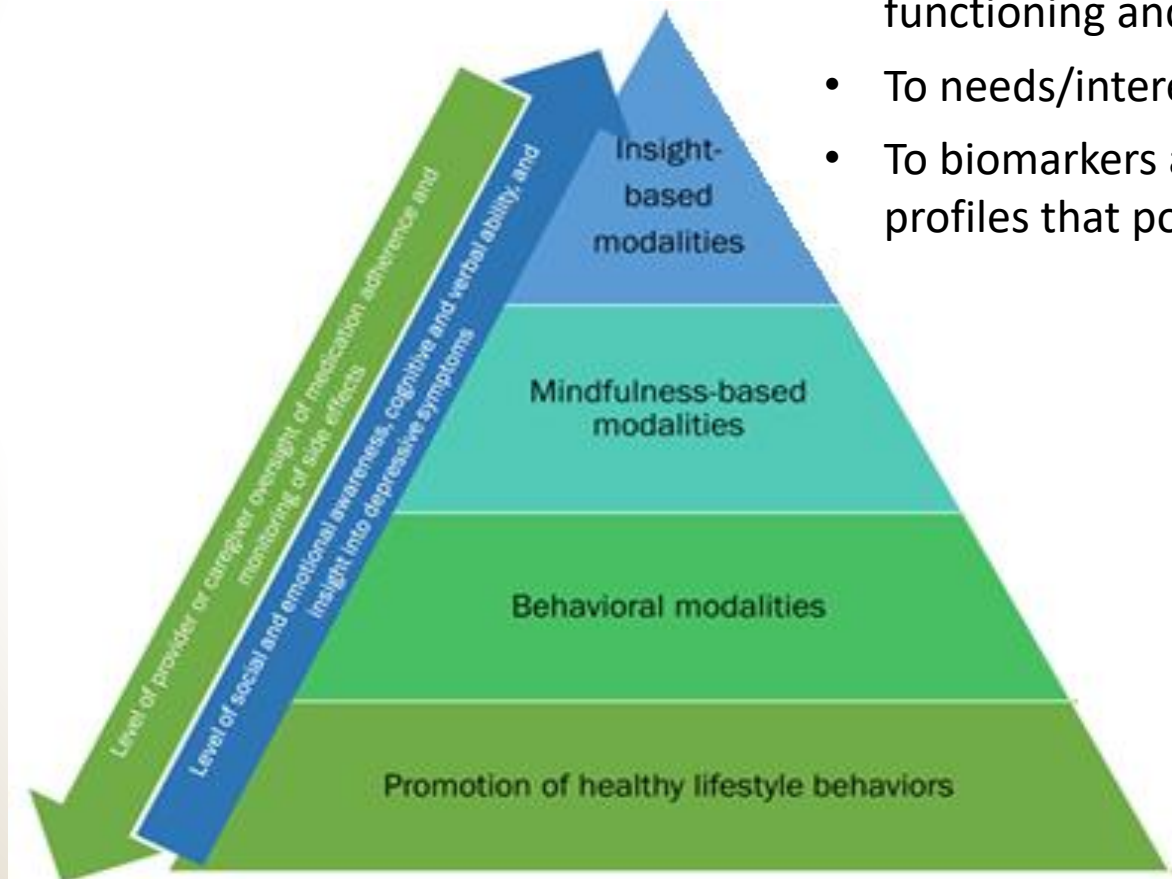
Treatment

Common depression treatments hold promise for adapting to the ASD community

- **Cognitive Behavioral Therapy**
 - Highly effective in general population when delivered well
 - Kerns et al., 2016: Adaptations for using CBT for depression in ASD
 - Challenges in ASD: maintaining/generalizing; not applicable to minimally verbal people
- **Behavioral Activation**
 - Particularly helpful in those with low motivation or social withdrawal, or adults with minimally structured days
- **Mindfulness-Based Therapy**
 - Relies on less insight, more observation/identification; how interacts with RRBs?
- **Pharmacological**
 - Many people with ASD already take anti-depressant medications for depression, anxiety, behavioral management, etc.

We need more data on how to best tailor treatment type

- To individual level of cognitive functioning and insight
- To needs/interests/values
- To biomarkers and individual profiles that point to mechanism

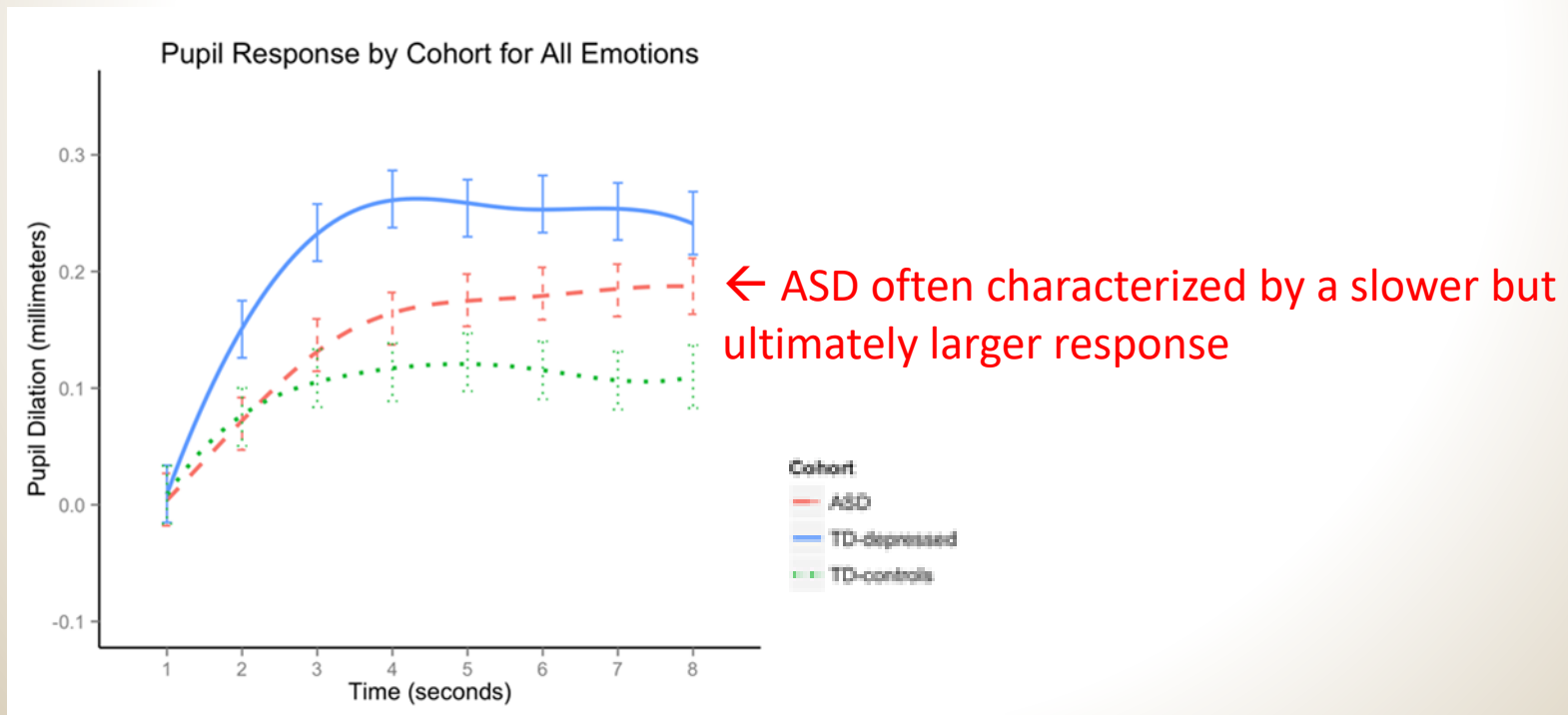


Back to mechanisms...

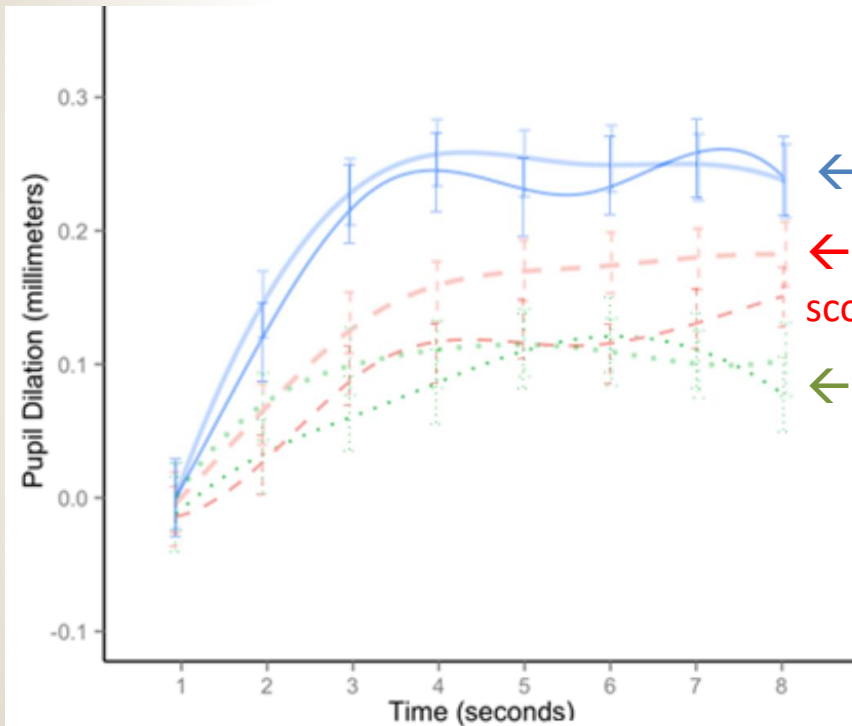
**...and a comment on the broader impact
of depressed mood on autism research**

We observed a common pattern in ASD response to affective material

In previous reviews of social-emotional processing in ASD, participants with ASD tended to show a pattern of social-emotional processing that had a more gradual ramp-up but ultimately increased magnitude compared to controls (Nuske et al., 2013; Lartseva et al., 2015)



... but the response to our task appears to have more to do with mood than with autism.



← High depression symptoms (TD and ASD)

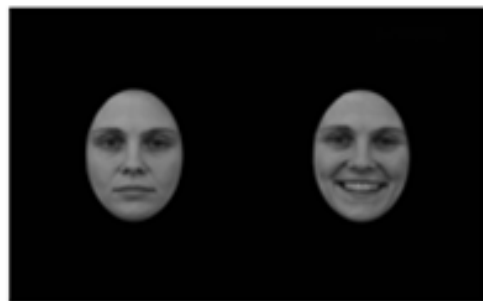
← Aggregate ASD curve – and “medium” depression scores for ASD

← Low depression symptoms (TD and ASD)



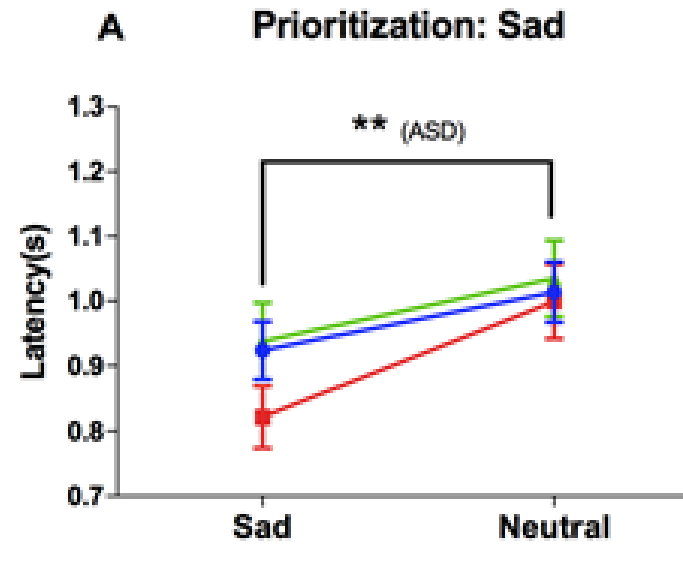
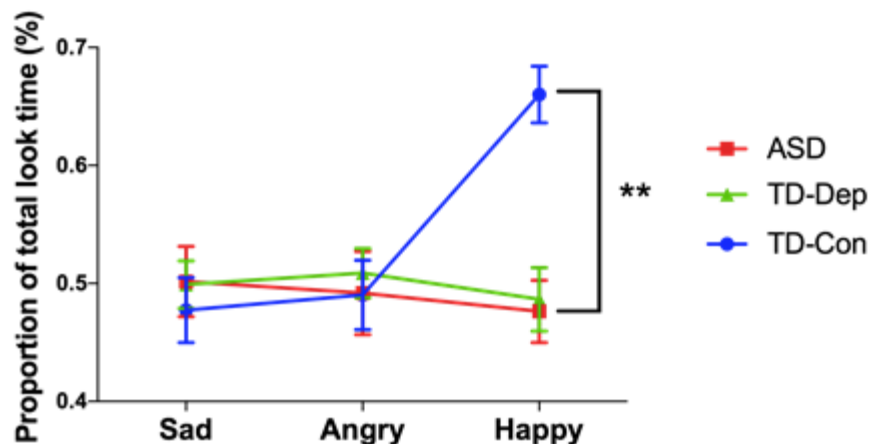
Negative attention bias in ASD

(Unruh, Bodfish, & Gotham, 2018)



5 s

Preference



- ASD was only cohort to orient significantly faster to sad faces when paired with neutral (above).
- But **among participants with ASD, those who had higher depression scores** were signif faster to fixate on angry and sad faces, and spent more overall time on sad than neutral faces.

“Depression-like” phenomena in ASD

- Several parallels in cognitive, attentional, and emotional processing across our ASD and TD-depressed samples in comparison to TD-controls
 - treatment targets?
 - Some “autism-specific” findings in ASD literature actually depression-related?
- Future Directions:
 - Develop precision measurement for various forms of repetitive thinking (by structure, content, valence) and assess neural and behavioral correlates (*currently in Year 2 of this R01 project*)
 - Social reward and emotional health in ASD

Depression in ASD: Summary (1 of 2)

- Depression is common in autism spectrum disorder (ASD), with lifetime rates approx four times greater than the general population when pooled across age ranges (7.7% in child ASD samples; 40.2% in adults with ASD).
- Depression in ASD compromises adaptive functioning and quality of life, and is associated with increased risk of medication and service use, suicidality, other forms of self-injury, and caregiver burden.
- Autism community is calling for study/treatment of depression among their highest priorities.

Depression in ASD: Summary (2 of 2)

- Assessment and diagnosis of depression in people with ASD is challenging due to symptom overlap between the disorders and lack of validated psychometric instruments for assessing depressive symptoms in ASD.
- Evidence for effective treatment of depression in autistic individuals is limited, but adapted psychotherapies show some promise.
- Measuring and analyzing mood, anxiety, and attention may help us to interpret autism research findings more accurately.

In grateful acknowledgement of:

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Collaborators:

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KENNEDY CENTER

for Excellence in Developmental Disabilities

SUICIDE AND AUTISM: CURRENT EVIDENCE & RESEARCH METHODS

Anne V. Kirby, PhD, OTR/L

University of Utah

IACC Workshop: May 21, 2019



No conflicts of interest to disclose.

TERMINOLOGY

- **Suicide (Suicide Death)**

“death caused by self-directed injurious behavior with intent to die as a result of the behavior”

- **Suicide Attempt**

“non-fatal, self-directed, potentially injurious behavior with intent to die as a result of the behavior”

- **Suicidal Ideation**

“thinking about, considering, or planning suicide”

SUICIDE & ATTEMPTS IN THE U.S.

- **Suicide is the #10 cause of mortality**
 - #2 cause in ages 10-34 years
 - 12.93 per 100,000 individuals die by suicide per year
- **Sex differences in suicide and suicide attempts**
 - Males ~3.5x more likely to die from suicide
 - Females ~1.4-2x more likely to attempt suicide
- **Race differences in suicide and suicide attempts**

(CDC, 2018; NIMH, 2016, 2018)

SUICIDE, ATTEMPTS, & IDEATION RATES IN AUTISM

- **Wide ranging rates of attempts & ideation** reported in clinical and convenience samples
 - Suicide attempts: 1-35%; 7-47%
 - Suicidal ideation: 11-66%, up to 72%
 - 66% = over 9x higher than in a U.K. comparison group
- **Little population-based research**
 - Suicide attempts: Taiwan
 - Suicide deaths: Sweden, USA(Utah)

(Cassidy et al., 2014;
Hedley & Uljarević, 2018;
Zahid & Upthegrove, 2017)

EXISTING POPULATION STUDIES

- Taiwan suicide attempts study
 - ASD group 6x more likely than age- and sex-matched controls even after adjusting for demographic factors & co-occurring psychiatric conditions
- Sweden mortality study
 - ASD group almost 8x more likely than age-, gender-, and county-matched controls to die from suicide
 - Over 9x more likely when excluding those w/ ID
 - Those w/ ID were over 2x more likely

(Chen et al., 2017; Hirvikoski et al., 2016)

IDENTIFIED CASES IN UTAH

- **Using administrative data** from the Utah Registry of Autism and Developmental Disabilities, Utah Office of the Medical Examiner, Utah Population Database, and Utah Department of Health, we conducted a 20-year study
- **49 individuals** in Utah who died from suicide between 1998 - 2017 had a documented ASD diagnosis (ASD+suicide cases)
- Compared to **whole population** (not matched controls)
- Ages at death: **14-70 years** (mean = 32.41, median = 27)

(Kirby et al., 2019)

INCIDENCE OF SUICIDE IN UTAH

Years	ASD	Non-ASD	Relative Risk
1998 – 2002	0.04%	0.08%	0.46
2003 – 2007	0.06%	0.09%	0.66
2008 – 2012	0.10%	0.11%	0.95
2013 – 2017	0.17%	0.11%	1.56*
Male	0.16%	0.16%	1.01
Female	0.17%	0.05%	3.42*

- Increases in incidence over time
- Significantly higher in ASD group in 2013-2017 period

(Kirby et al., 2019)

SUICIDE INCIDENCE IN FEMALES

Repeated evidence that females w/ ASD diagnoses are at significantly greater risk than non-ASD females

- Utah: ASD females at 3x greater risk vs. other females
- Sweden: ASD females at 13x greater vs. other females
- No evidence that females > males (females \approx males)
 - Utah: ASD females (0.17%) vs. ASD males (0.16%)
 - Sweden: ASD females (0.32%) vs. ASD males (0.30%)

SUICIDE IN YOUNG PEOPLE

Changes in ASD prevalence over time may affect results due to age group discrepancies

- 2013-2017 relative risk in young people (5-30y in 2013)
 - ASD vs. non-ASD: 2.38 [1.51–3.74][†]
 - Females: 5.07 [1.88–13.64][†]
 - Males: 1.56 [0.94–2.60][†]
- Does not necessarily mean that older adults are not at risk!

[†][95% CI]

(Hirvikoski et al., 2016; Kirby et al., 2019)

SUICIDE DEATH IS STILL RARE

- Despite evidence of greater risk in ASD, it is important to recognize that suicide death is still rare
 - Accounting for time-at-risk for each person, we identified an estimate of **6.4 suicides per 10,000 person-years** during the 2013–2017 period
- Other areas of research & improved practice also needed:
 - Broader mental health and quality of life
 - Other causes of premature mortality

METHODOLOGICAL CHALLENGES

- Changing ASD diagnostic criteria over time
- Missed diagnoses, especially among adults, women, & those without ID
- Suicide (as well as suicide attempt) determinations require clear indication/documentation of intent to die
- Relatively rare occurrence in a subset of the population means small sample sizes with more risk for error
- This challenge is even more profound among ASD subgroups including females and those with ID, as well as racial and ethnic minority groups

POPULATION FINDINGS TO INFORM PREVENTION EFFORTS

- We observed differences in suicide methods between ASD and non-ASD groups (“means restriction” is not enough)
- Employment did not emerge as a prominent protective factor (addressing “protective factors” may not be enough)
- Co-occurring conditions observed in ASD+suicide cases may help inform future screening and prevention efforts
- Conditions of interest from our preliminary work include depression, anxiety, bipolar disorder, psychosis, ADHD, and sleep, personality, & substance use disorders...

PLANNED FUTURE WORK

- Disentangling ASD and co-occurring conditions in risk determinations
- Conducting qualitative and community-engaged (co-produced) research
- Developing tailored strategies to support the autistic community and their loved ones

ACKNOWLEDGEMENTS

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Autistic consultants:

- Sara Luterman, Whitney Geertsens



Mechanisms Underlying Suicide Risk in Autism

Darren Hedley, PhD

Interagency Autism Coordinating Committee(IACC), USA
May 21, 2019

Assumptions

- *Suicide* is a **transdiagnostic phenomena** that cuts across different psychiatric conditions & sub-clinical presentations (Eisner, 2010; Glen et al., 2017)
- *Autism* is an **“umbrella term”** applied to a range of neurodevelopmental conditions (Müller, 2017; Müller & Amaral, 2017)
 - reliable behavioral presentation characterized by challenges w/ **social communication & interaction**, restricted repetitive behavior & interests, and hyper/hyporeactivity to sensory input (APA, 2013)
 - ASD traits extend into typical & other non-ASD clinical populations


Assumptions cont'd

- Both autism & suicide have complex biological, neurobiological, genetic, epigenetic, & environmental origins (Greenspan, 2018; O'Connor & Portzky, 2018)

Research questions

1. Could there be a relationship between ASD traits & suicide risk and behavior (in ASD/non-ASD)? (Pelton & Cassidy, 2017)
2. Could there be common and/or interacting mechanisms underlying suicide risk & ASD? (Cassidy & Rogers, 2017; Hedley & Uljarević, 2018)

Suicidal behavior & autism

-  suicide risk in ASD/ASD-ID* (Hirvikoski et al., 2016; Kirby et al., 2019)
- DX of ASD independently predicts suicide risk (Chen et al., 2017)
 - after controlling for other psychiatric conditions & demographics
- Suggestion that high ASD traits is risk factor for suicide in non-ASD populations (Cassidy et al., 2018; Pelton & Cassidy, 2017)

Risk factors



Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study



Sarah Cassidy, Paul Bradley, Janine Robinson, Carrie Allison, Meghan McHugh, Simon Baron-Cohen


- Depression*
- Age of diagnosis*
 - impact of untreated/recognized ASD; lack of appropriate supports due to no accurate DX
 - Highlights importance of post-diagnostic support in late diagnosed adults
- AQ: +plans/attempts > –plans/attempts

RESEARCH

Open Access

Risk markers for suicidality in autistic adults



Sarah Cassidy^{1,2,3*} , Louise Bradley², Rebecca Shaw^{2,4} and Simon Baron-Cohen^{3,5}

SBQ-R (Suicide Behaviors Questionnaire-Revised)

- Employment, **Satisfaction w/ living arrangements***, ≥ 1 Developmental cond., **Depression***, Anxiety (13-21% SBQ-R variance)
- **Non-suicidal self injury*** (4% SBQ-R variance)
- **Camouflaging*** (3.5% SBQ-R variance)
- **Unmet support needs*** (3.1% SBQ-R variance)
- AQ: ASD ($r = .099$, n.s.); **CON*** (3.2% variance)

- While it is important to identify risk & protective factors, it is equally important to develop and test theories of *why* suicide occurs
- Understanding what factors are involved, and how they interact, is essential for developing effective and targeted interventions
- *Urgent need to identify the underlying processes & mechanisms that underpin suicide behavior (ASD & non-ASD populations)*

Theoretical frameworks

[Front Psychol.](#) 2018; 9: 2139.

PMCID: PMC6277491

Published online 2018 Nov 27. doi: [10.3389/fpsyg.2018.02139](https://doi.org/10.3389/fpsyg.2018.02139)

PMID: [30538647](https://pubmed.ncbi.nlm.nih.gov/30538647/)

Looking to the Future: A Synthesis of New Developments and Challenges in Suicide Research and Prevention

[Rory C. O'Connor](#)^{1,*} and [Gwendolyn Portzky](#)²

Ideation-to-action theoretical framework

- Assumes factors associated with suicidal ideation are distinct from suicide attempt/suicide

Interpersonal-Psychological Theory of Suicide (Joiner, 2005; Van Orden et al., 2010)

Thwarted belongingness + burdensomeness → ideation
 + capability for suicide → behavior

Integrated Motivational-volitional Model (O'Connor & Kirtley, 2018)

Defeat + entrapment → ideation
 + “volitional moderators” (e.g., means) → behavior

3 Step Theory (3ST) (Klonsky & May, 2015)


Psych pain + hopelessness → ideation
 – connectedness + contributors → behavior

- All three theories emphasize **social context**
 - Isolation, disconnection, loneliness, social disadvantage
- *“Suicide is end product of complex interplay of neurobiological, psychological and **social processes**”*
(O'Connor & Portzky, 2018)
- Role for ASD traits in theories concerning suicide risk and behavior?

Mechanisms

RESEARCH ARTICLE |  Open Access |  

Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample

M. K. Pelton, S. A. Cassidy 

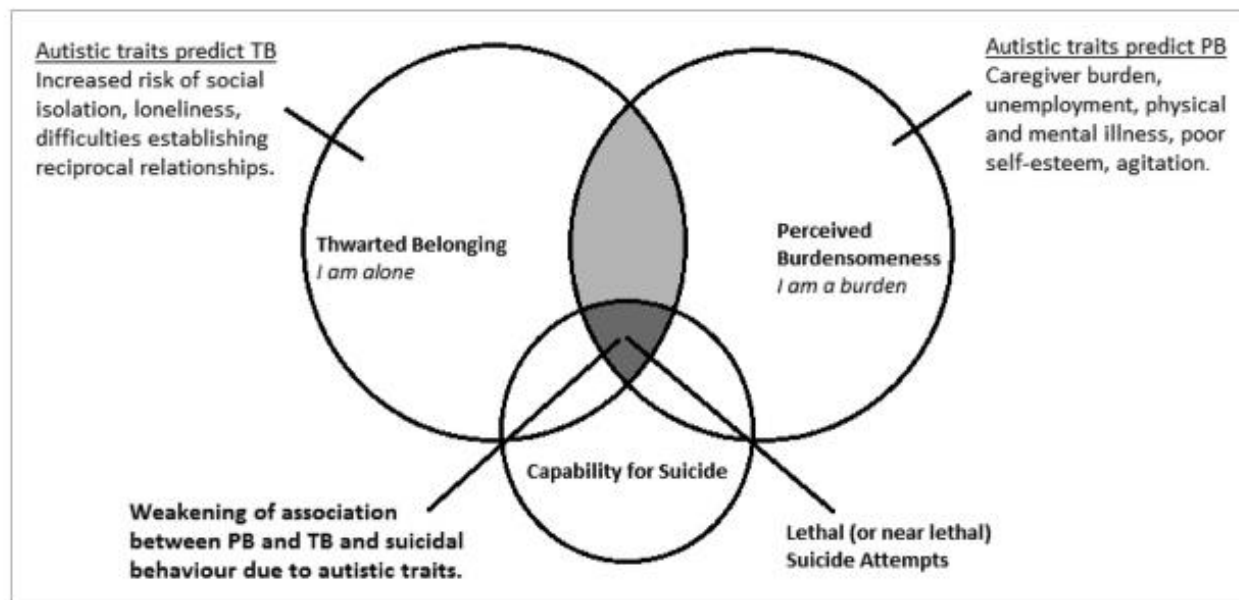
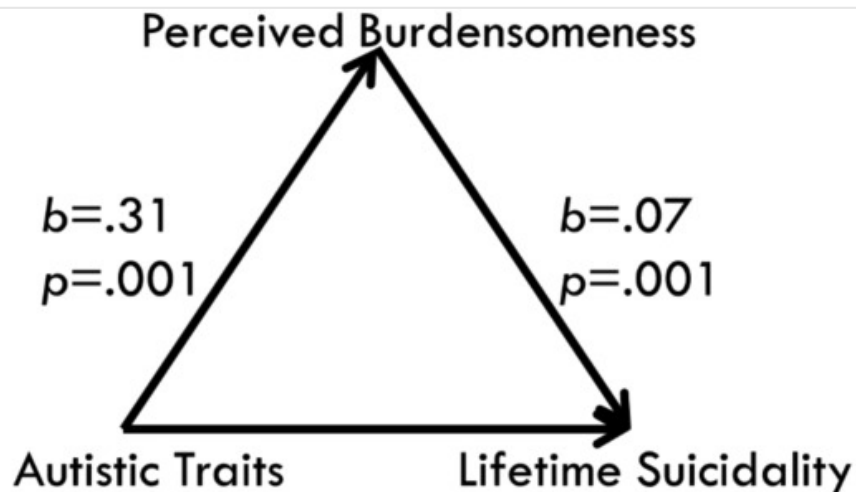


Figure 1

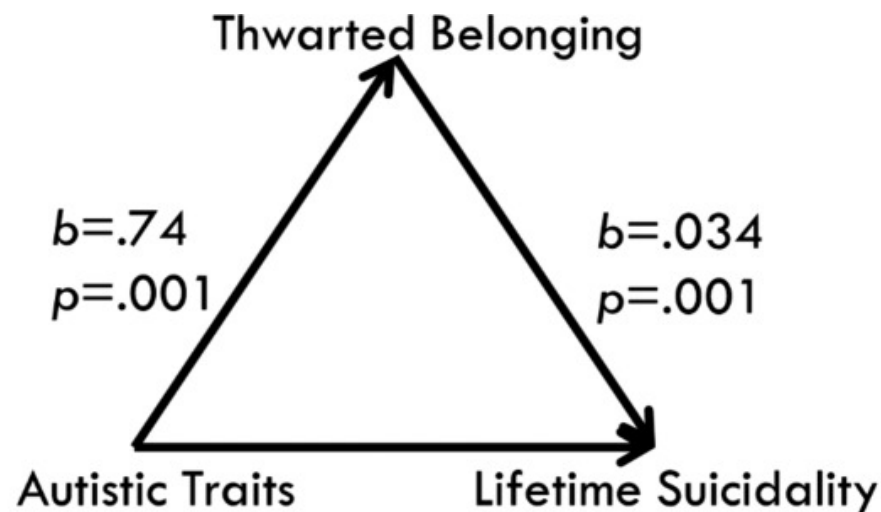
[Open in figure viewer](#) | [PowerPoint](#)

The interpersonal psychological theory of suicide and hypothesized interaction with autistic traits (adapted from Van Orden et al. 2010).



Direct effect, $b = .014$, $p = .08$.

Indirect effect, $b = .021$, 95% CI [.011, .033]




Direct effect, $b = .01$, $p = .32$.

Indirect effect, $b = .025$, 95% CI [.014, .038]

Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder

Authors

Authors and affiliations

Darren Hedley , Mirko Uljarević, Mathilda Wilmot, Amanda Richdale, Cheryl Dissanayake

**AQ n.s.

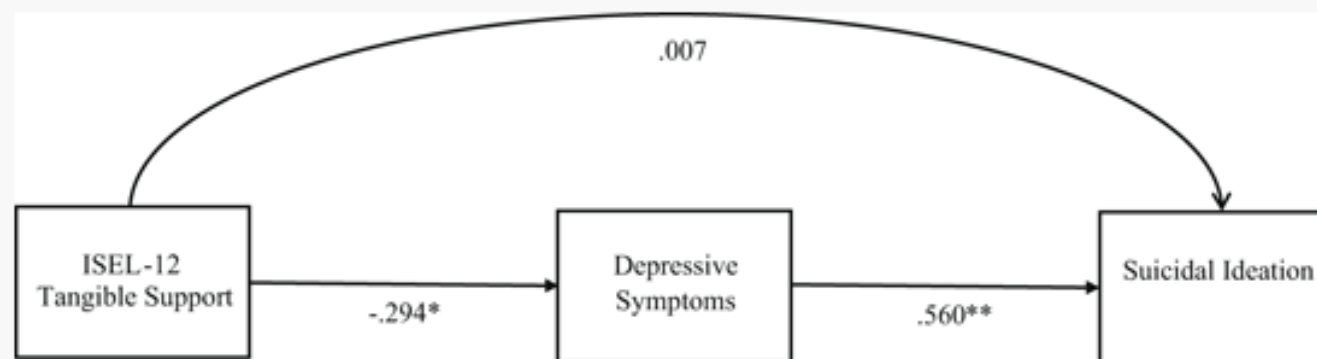


Fig. 1

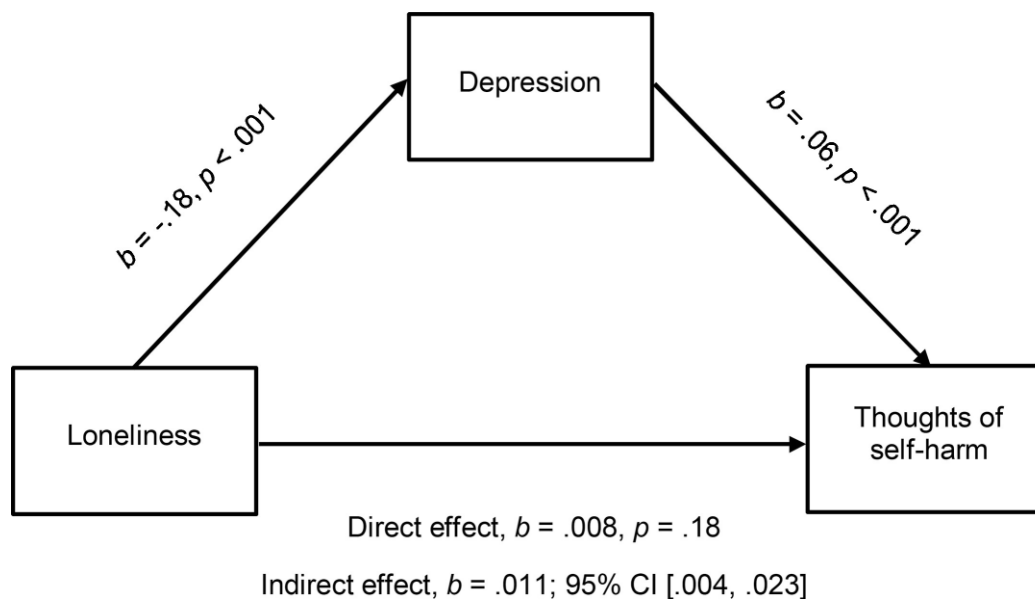
Structural equation modelling analysis of the indirect effect of tangible support on suicidal ideation through depressive symptoms. Values provided are standardized beta coefficients. $*p < .01$, $**p < .001$

Brief Report

Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness


Darren Hedley^a , Mirko Uljarević^{a, b}, Mathilda Wilmot^a, Amanda Richdale^{a, b}, Cheryl Dissanayake^a

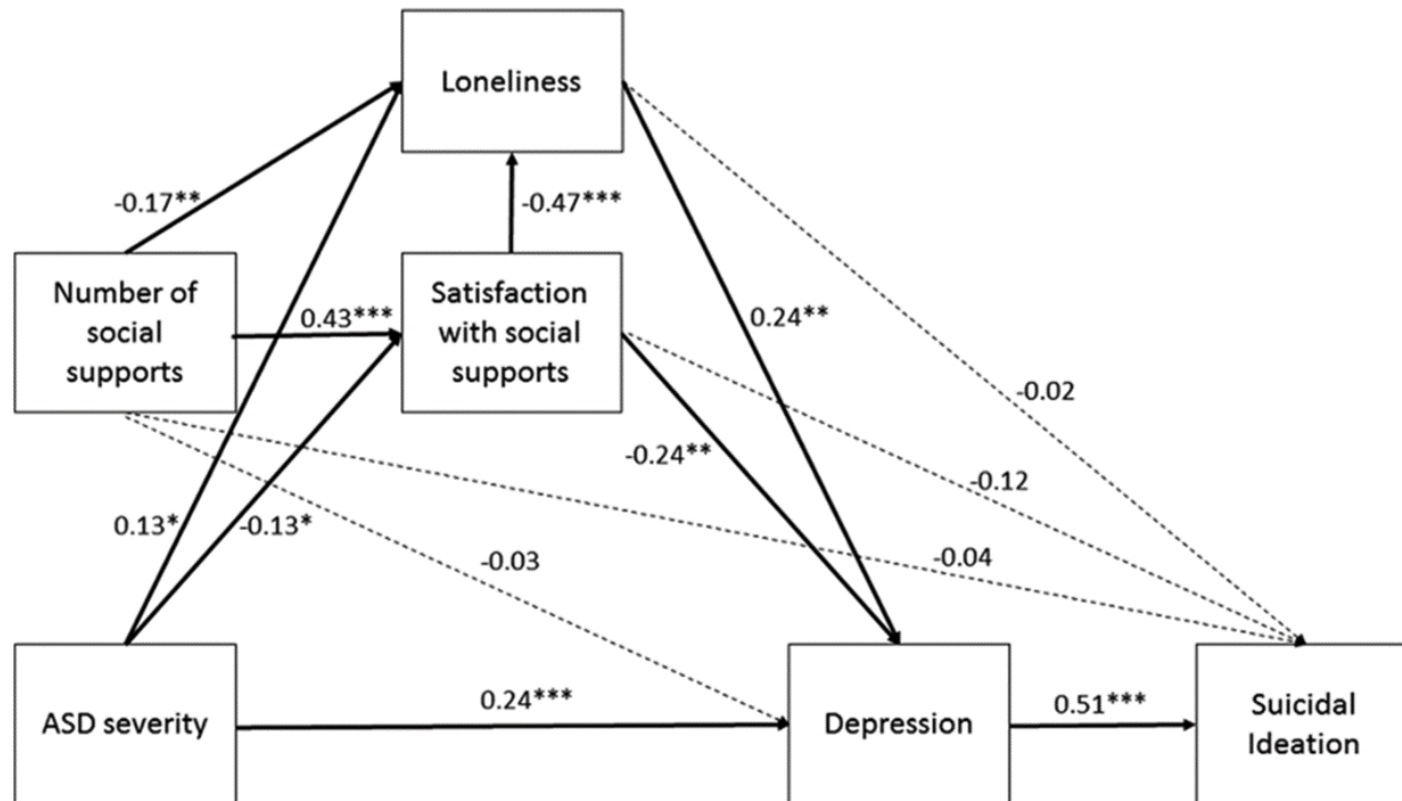
****AQ n.s.**



RESEARCH ARTICLE | [Full Access](#)

Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder

Darren Hedley PhD , Mirko Uljarević PhD, Kitty-Rose Foley PhD, Amanda Richdale PhD, Julian Trollor MD



Summary of main findings

- Social factors are likely to be important in understanding suicide ideation & behavior in ASD
- Specific role of ASD traits in suicide models is unclear
- At least some research findings suggest an interaction between ASD traits & social constructs that feature in contemporary suicide theories

Conclusions

- Prevailing mainstream theories are likely to be useful in understanding suicide risk & behavior in ASD
- Particularly those examining **social factors/constructs**
- Limited evidence of a direct path from ASD traits to suicide ideation/behavior; however,
- Support for indirect paths from AQ to suicidal ideation or behavior in ASD & non-ASD samples

Conclusions cont'd

Understanding the contribution of autistic traits to theories & models concerning suicide risk is likely to have important implications for research in both ASD and non-ASD populations, and therefore to clinical practice more broadly

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Thank you

latrobe.edu.au/otarc



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Nottingham**

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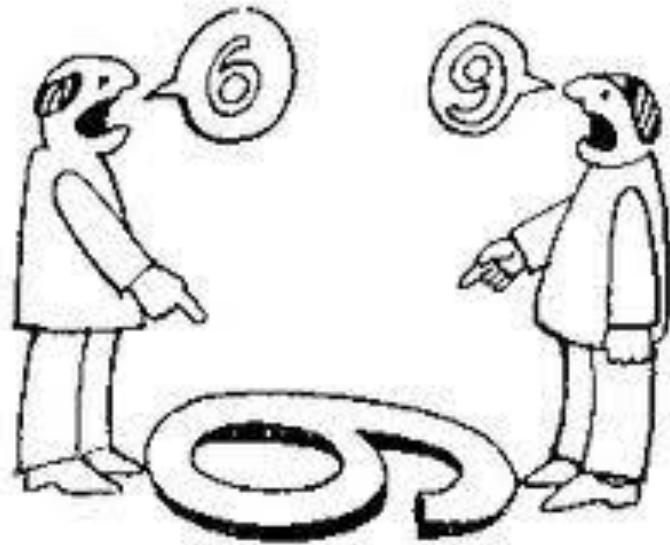
AUTISTICA
Building brighter futures through autism research

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ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

**Where do we go
from here?
Learning how to
prevent suicide in
partnership with
autistic people and
their allies**

**Dr Sarah Cassidy,
Assistant Professor,
University of Nottingham**

Where do we go from here?



Pellicano, Dinsmore and Charman (2013)
Fletcher-Watson et al. (2018)



Identifying shared priorities ...

In association with



James
Lind
Alliance

Priority Setting Partnerships



Collaboration for leadership
in applied health research
and care
East of England

MHAutism



NHS
National Institute for
Health Research



AUTISTICA
Building brighter futures through autism research



2 MHAutism
Workshops
2016-17

3 INSAR
Special Interest
Groups
2016-18

1st
International
SIA Summit
2017

INSAR policy
brief
2019

60 attendees

Generated “buy in”

**Identified broad
topic areas**

Yr 1 40 attendees

Yr 3 100 attendees

Demonstrated
growth

**Informed summit
discussion points**

40 attendees

Identified potential
policy areas

**Identified 48
research
questions**

788 stakeholders
ranked 48 research
questions online

30 stakeholders
ranked top 20

**Top 10 to be
discussed today**



Where do we go from here?



In association with



**James
Lind
Alliance**

Priority Setting Partnerships





Identifying shared priorities

- **1000+ stakeholders worldwide have identified the top 10 priorities - equal representation of autistic people**
- **Systematic review of the available evidence shows no question has been extensively studied**
- **Further community engagement will help develop the final report end of 2019/early 2020 – published on INSAR website**



Priority 10

10. What is the impact of poor sleep on suicide risk in autistic people, and how can this be measured?

“I feel It’s never one thing but accumulative then add lack of sleep to trauma or PTSD and life may become unsustainable”

Prevalent but understudied – what is the impact?

Poor sleep associated with suicidal thoughts and behaviours in the general population ...



9. How well do existing models of understanding suicide apply to autistic people?

What can we learn from the general population regarding suicide in autism, and vice versa?

Emerging evidence that autism and autistic traits increase risk of known risk markers for suicidal thoughts and behaviours

Also evidence for new risk markers (camouflaging) - might apply to the general population?



8. How do autistic people seek help when they are in a crisis?

“There is nothing more disheartening than being told you not trying hard enough to find support”

“I can’t always communicate if I’m in crisis”

Unmet support needs and satisfaction predicts suicidality in autistic people (Hedley et al. 2018; Cassidy et al. 2018)

Support hard to obtain but life-saving – worldwide issue (Camm-Crosbie et al. 2018; Crane et al. 2018; Maddox and Gaus, 2018)



Priority 7

7. What is the experience of suicidality in autistic people? Is this experience different to the general population?

“I felt like I was having a breakdown inside but I didn’t know how to make the inside feelings show to other people”

Are there different pathways to suicide in autistic people which need adapted assessment, treatment and prevention strategies?



6. How should interventions be adapted for autistic people and individual presentations?

“What works not what’s on offer because it’s always ‘done that way’”

Shortage of professionals trained autism and mental health (Raja, 2014), lack of appropriate assessments (Cassidy et al, 2018b, 2018c) and therapies (Ghaziuddin et al, 2002)

Potential of adapting suicide prevention strategies, e.g. suicide safety plans (Cassidy, in press)



5. How can we best identify and assess suicidal thoughts and suicidal behaviours in autistic people, in research and clinical practice?

“it’s a future question ... you don’t really know what’s going to happen to you in the future”

“Whose risk are they for?”

No validated suicidality assessment tool available for autistic people (Cassidy et al. 2018)

Suicide risk assessments do not accurately predict future suicide attempts and are not cost effective (Quinlivan et al. 2016; 2017; 2019) We need something **new** ...



Priority 4

4. How can we further understand suicide where mental health is not a factor across the lifespan?

“It’s more the autistic people without dementia being placed in dementia care due to nowhere else for them to go”

Ageing in autism an understudied area, concerns from the autism community regarding ageing and increased risk of mental health problems and suicidality (Roestorf et al. 2019)



3. To what extent are autistic people not believed about the severity of their distress?

“I just don’t show emotion the way other people do so ... no one believed there was anything wrong with me or that I needed help”

“Who knows me best? Our narrative is often misunderstood dismissed & over written”

Why? Lack of understanding and knowledge - Alexythymia, camouflaging, double empathy problem? (Camm-Crosbie et al. 2018)



2. What are the risk and protective factors for suicide in autism across the lifespan?

Lack of research into ***why*** autistic people are at risk of suicide – necessary for understanding and prevention (Cassidy and Rodgers, 2017)

Some progress being made – much further to go!

Gender Camouflaging Loneliness Sleep
Support Employment Mental Health



Priority 1

1. What barriers do autistic people experience when seeking help which may put them at greater risk of suicide?

“People like me don’t get support” (Camm-Crosbie et al. 2018)

“Attitudes towards me, Attitudes about me, The current system, Being dismissed, No specific autistic pathway”

No funded service delivery research in the UK in 2013-2016, despite being a community priority (Autistica, 2019)



Where should we go from here?

- **Co-production not optional!**
- **Close the gap between community priorities for research and what is actually funded and researched**
 - What will make a positive difference “on the ground”?
- **Learning opportunity between autism and suicidology research – to make things better for everyone!**



Thanks to ...

Mental Health Autism: Dr. Louise Bradley, Dr. Rebecca Shaw, Heather Cogger-Ward.

Newcastle University: Dr. Jacqui Rodgers, Dr. Sarah Wigham, Dr. Magdalena Glod.

ARC and CLASS clinic: Prof. Simon Baron-Cohen, Dr. Carrie Allison, Dr. Gareth Richards, Dr. Rebecca Kenny.

Our autism community partners and all those who participated in our events and research!

Sarah.Cassidy@Nottingham.ac.uk
[@MHAutism](#)

Suicide & Mental Health Crisis Resources



- National Suicide Prevention Lifeline:
1-800-273-TALK(8255) www.suicidepreventionlifeline.org
- Veterans Crisis Line: 1-800-273-8255, press 1
- Crisis Text Line: text START to 741-741 (more information:
<https://www.crisistextline.org/textline/>)
- HealthReach (multiple languages)
www.healthreach.nlm.nih.gov/searchindex/Suicide
- Help for Mental Illnesses: NIMH web page
www.nimh.nih.gov/findhelp
- Treatment Referral Routing Service (funded by SAMHSA):
1-800-662-HELP(4357)



Discussion



Break

If you are in crisis, call toll-free:

National Suicide Prevention Lifeline
1-800-273-TALK (8255)

The deaf & hard of hearing can call via TTY: 1-800-799-4889
Service is available to anyone 24 hours a day, 7 days a week
All calls are confidential

Text crisis support is available in the US, Canada, UK, Ireland, & S. Africa:
<https://www.crisistextline.org/textline/>

Workshop Agenda



Afternoon Agenda

3:10

Self Injurious Behaviors (SIB) and Aggression

Matthew Siegel, M.D.

Director, Autism & Developmental Disorders Inpatient Research
Collaborative (ADDIRC)

Maine Medical Research Institute

Vice President Medical Affairs

Developmental Disorders Service

Maine Behavioral Healthcare

Workshop Agenda



Afternoon Agenda

3:25

Craig A. Erickson, M.D.

Director, Fragile X Research and Treatment Center
Medical Director, Psychiatry Neurobehavioral Continuum of Care
Director of Research, The Kelly O'Leary Center for Autism Spectrum Disorders
Cincinnati Children's Hospital Medical Center
University of Cincinnati College of Medicine- Affiliated

4:00

Mental Health Services Issues for People on the Autism Spectrum

Brenna Burns Maddox, Ph.D., LCP

Post-Doctoral Fellow and Licensed Clinical Psychologist
Penn Center for Mental Health
University of Pennsylvania

Workshop Agenda



Afternoon Agenda

4:30

Wrap Up

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

Julie Lounds Taylor, Ph.D.

Associate Professor of Pediatrics
Vanderbilt Kennedy Center Investigator
Vanderbilt University Medical Center,
Co-Chair, IACC Health Outcomes Working Group

David Amaral, Ph.D.

Distinguished Professor, Department of Psychiatry and Behavioral
Science, University of California, Davis (UC), UC Davis MIND
Institute, Co-Chair, IACC Health Outcomes Working Group

5:00

Closing Remarks and Adjournment

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, Mazur ek 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

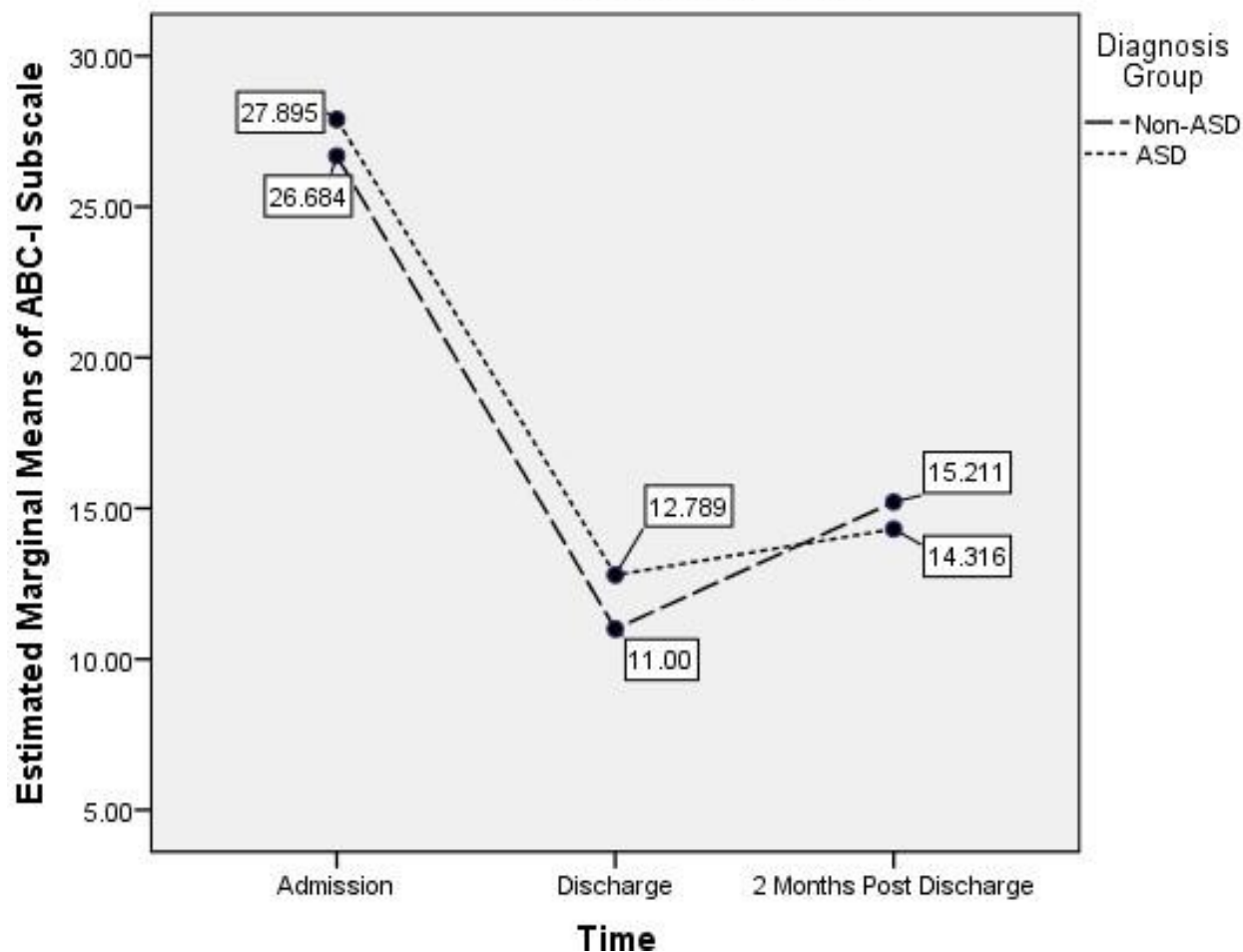
Significant side effects and inconsistent success

- 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



Siegel M, et al.,
JADD, July, 2014



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

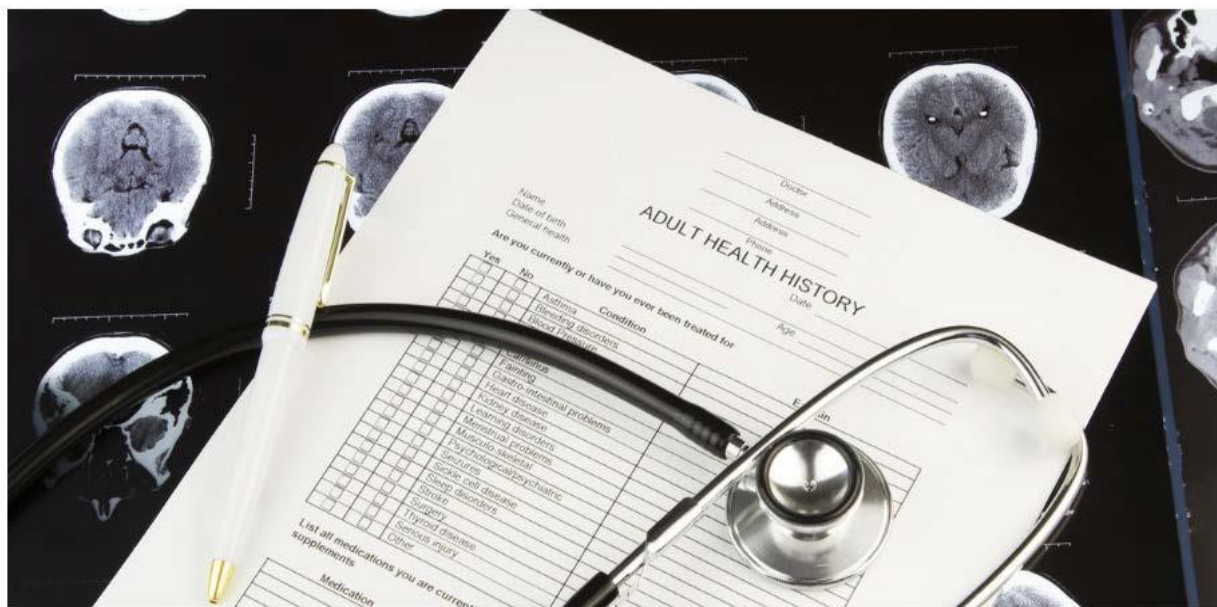


- Goals: Standardized assessment, description of the population, resource for all investigators, research platform for measure development, mechanistic studies and treatment studies.
 - To date, enrolled over 1000 probands and their biological parents
 - Rigorous core assessment battery and ASD diagnostic 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

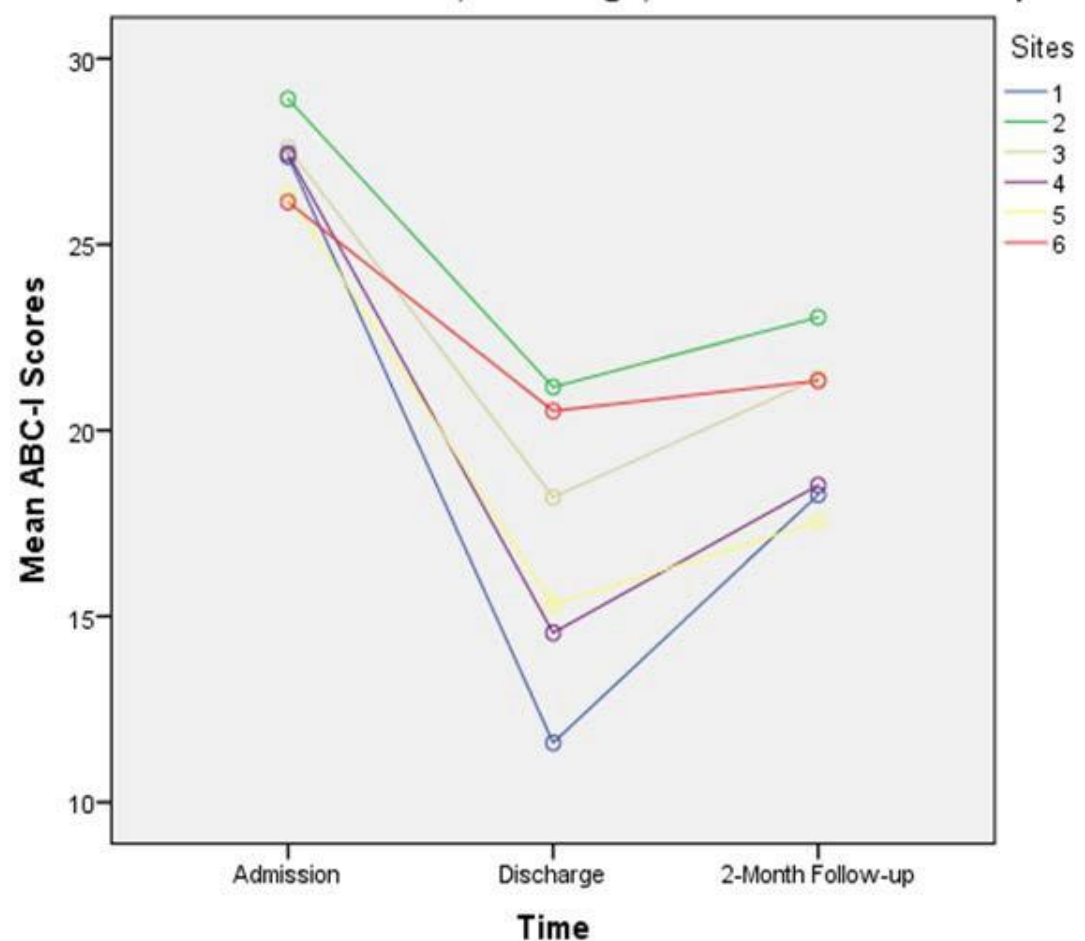
Health
disparities

Parent stress
and problem
behavior

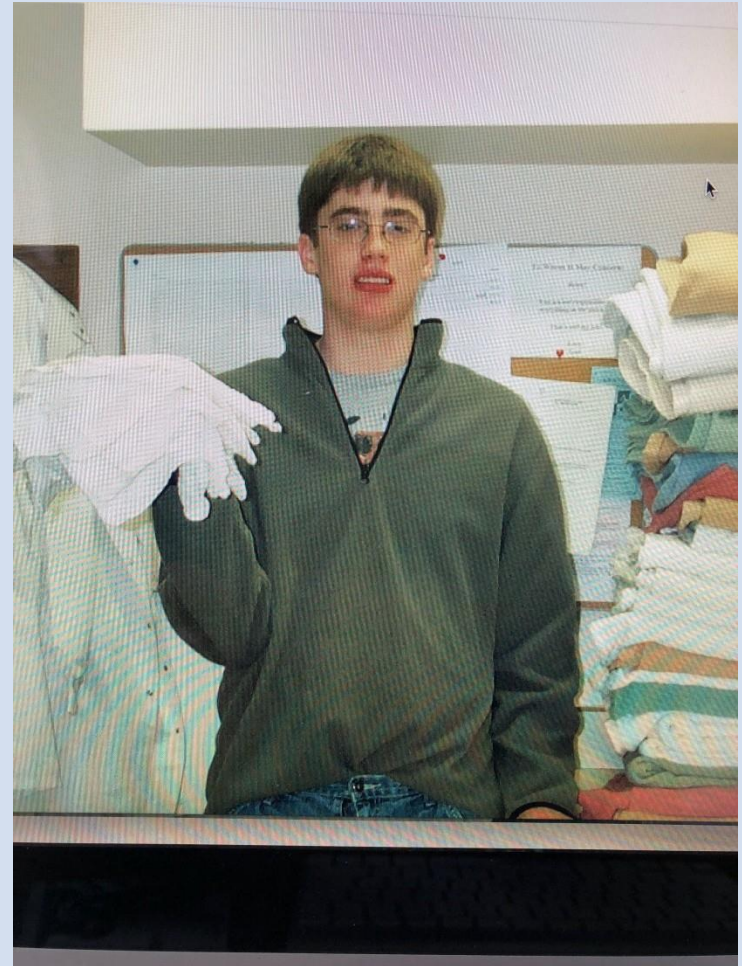
AIC: CHANGE IN PROBLEM BEHAVIORS

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)

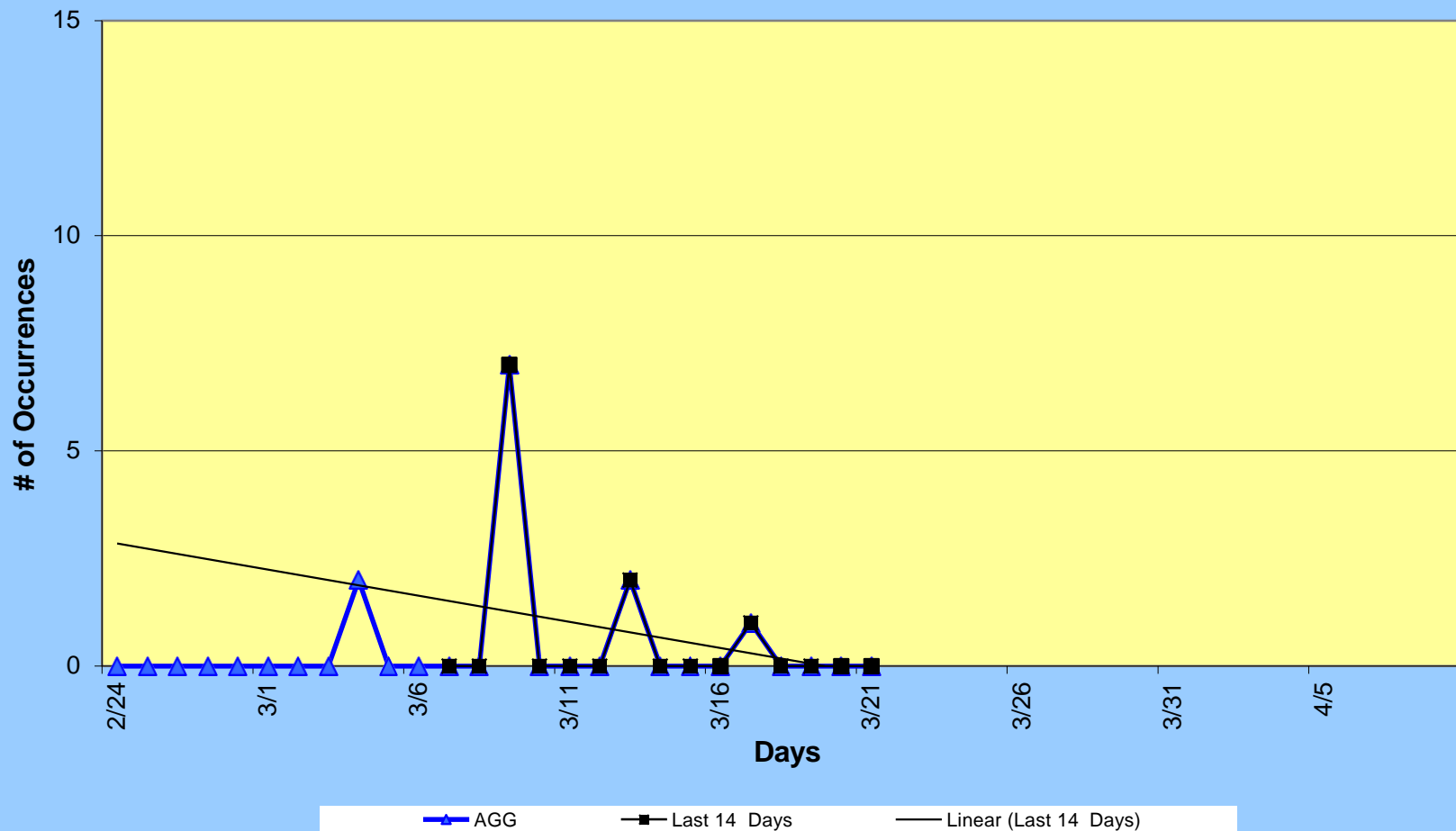


RYAN – THE NEED FOR NOVEL APPROACHES



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 Psychobiology*. 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;
- Greden 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.

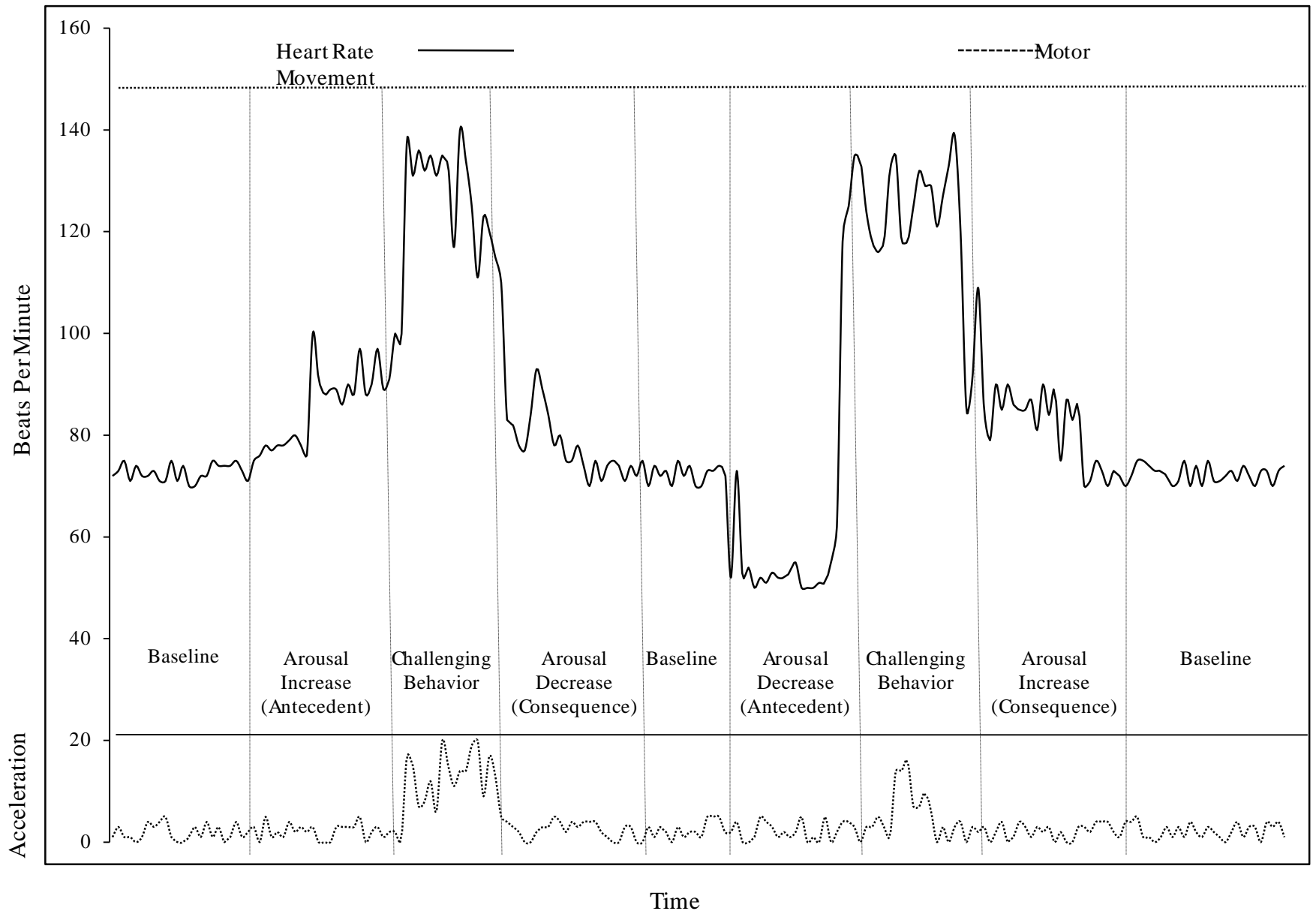
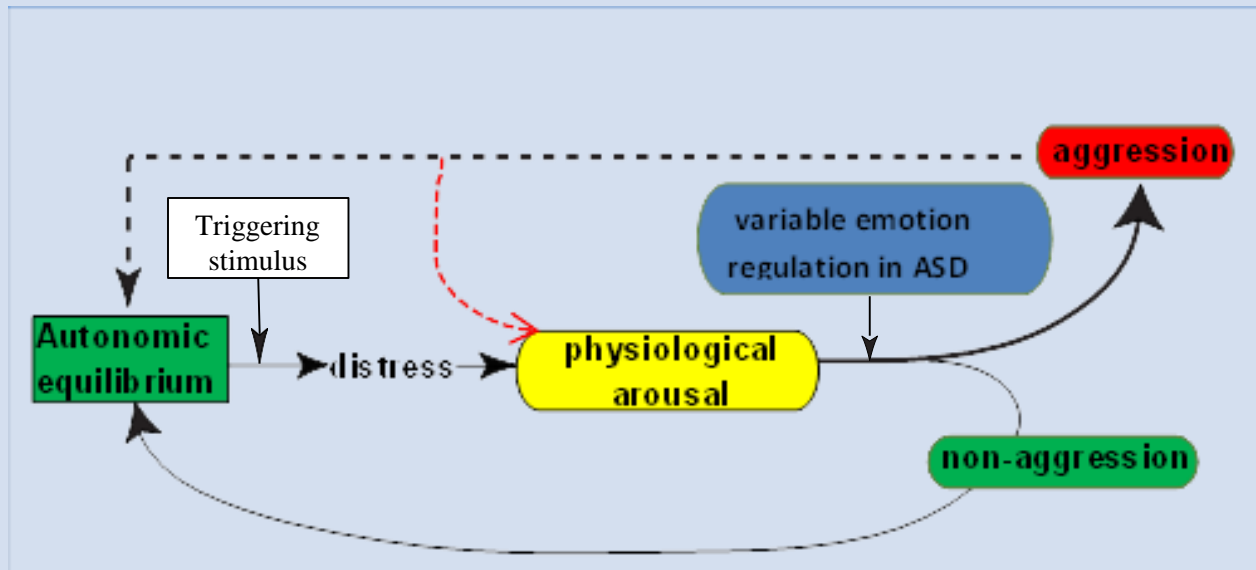
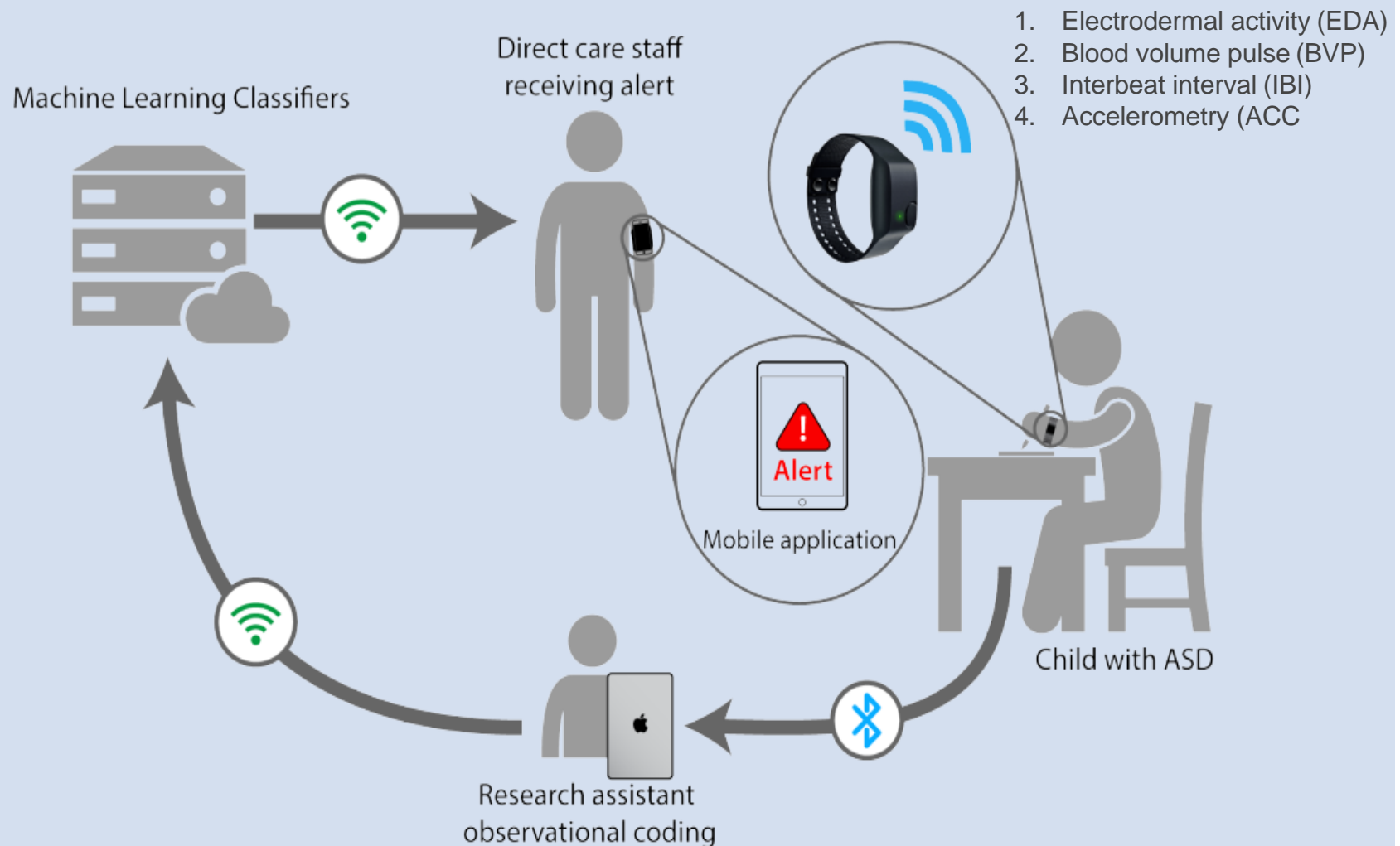


Figure by Matthew Goodwin, PhD

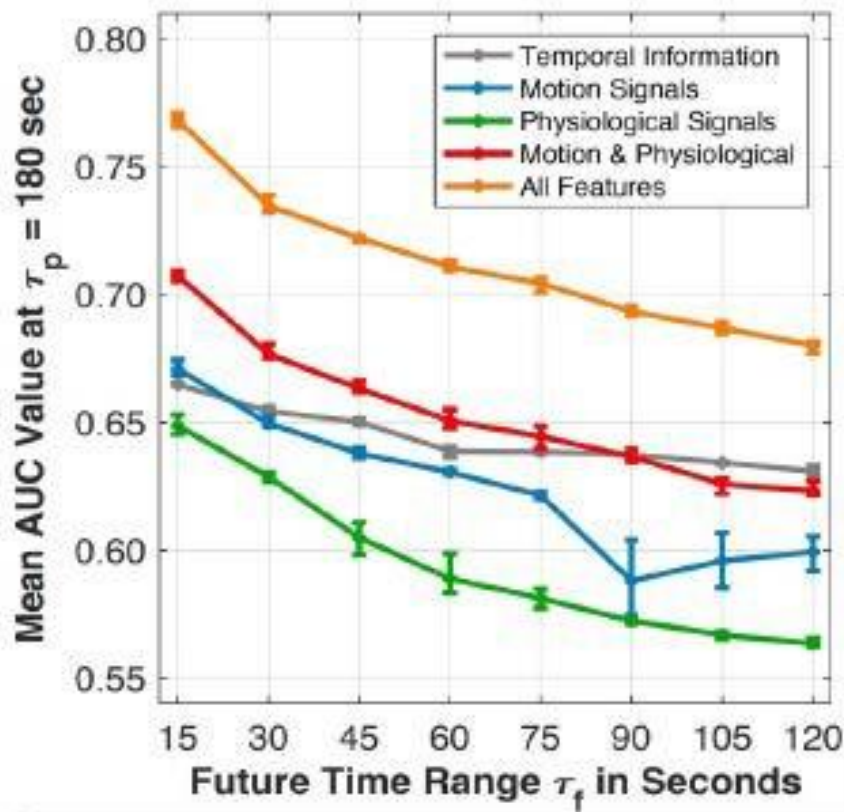
CONCEPTUAL MODEL



TRANSFORMING THE TREATMENT OF CHALLENGING BEHAVIOR – REAL TIME PREDICTION

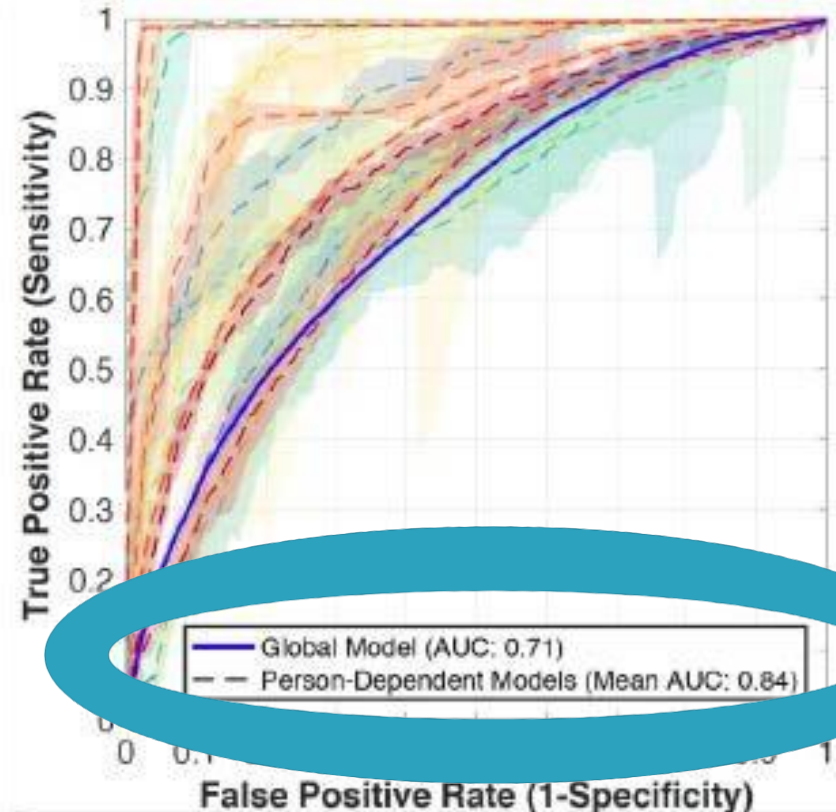


Pilot findings with 20 minimally-verbal inpatients



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

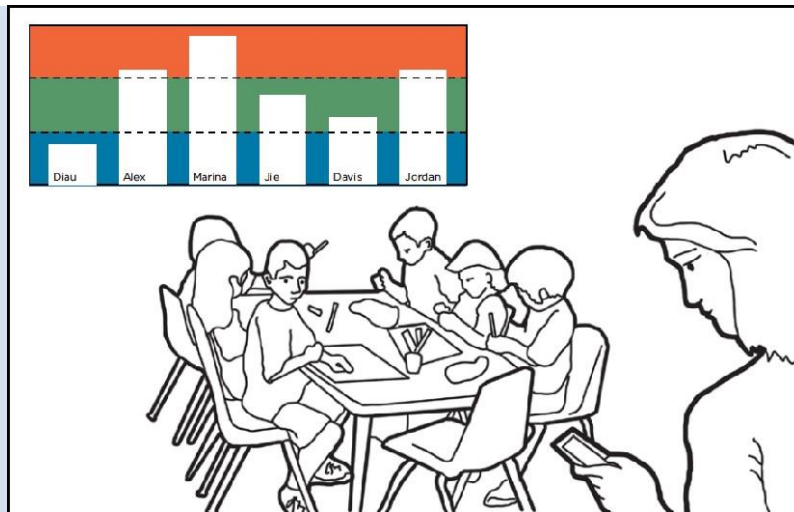


ROC values for global and person-dependent models using all combined features from the past 3 minutes to predict the next 1 minute

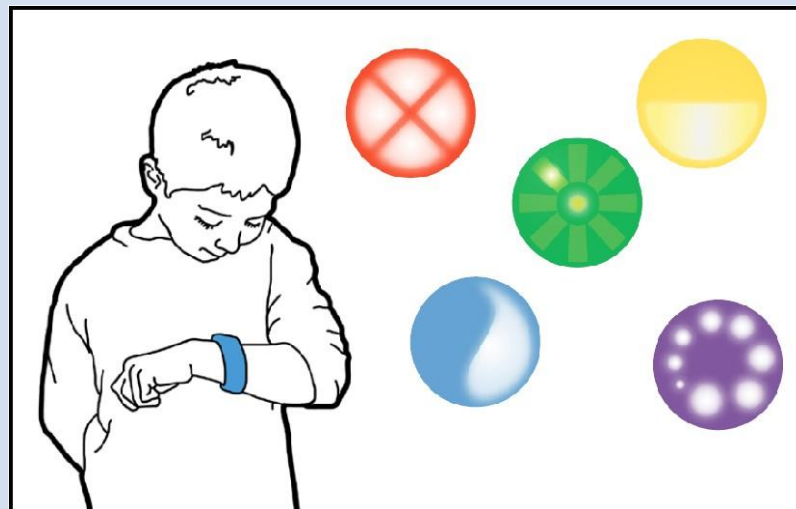
- Goodwin, MS, Ozdenizci, C, ... Mazefsky, C, Siegel, M, ... (in press). Predicting proximal aggression onset in minimally-verbal youth with autism spectrum disorder using preceding physiological signals. *Pervasive Health*.

- 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

- 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.

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Site Co-Investigators

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- Craig Erickson, M. D. & Logan Wink, M. D., Cincinnati Children's



Maine Medical Center Research Institute

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- Deanna Williams, B. A., Data Coordinator
- Christine Peura, B.A., Research Assistant
- Amy Stedman, B.A., Research Assistant
- Briana Taylor, Ph D, Post-doctoral Fellow
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- Diane Williams, Ph. D., Duquesne University

THE NANCY LURIE MARKS FAMILY FOUNDATION

Fostering Knowledge and Community for Autism and Beyond

ADDIRC Scientific Advisory Group

Connie Kasari, PhD, UCLA
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James McCracken, MD, UCLA
Christopher McDougle, MD, Harvard University
Lawrence Scahill, Ph.D, MSN, Emory University
Robert Schultz, Ph.D., University of Penn
Helen Tager-Flusberg, Ph.D., Boston University

Medication Management of Aggression and Self-Injurious Behavior in Persons with Autism

Craig A. Erickson

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Spectrum Disorders

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University of Cincinnati College of Medicine

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Caveat

- Medication management best following evidence-based behavioral interventions
- Best done in combination with behavioral intervention
- Medication utilized to improve safety and enhance ability to participate in educational, therapy, and other daily living opportunities
 - No “magic pill”
 - Best used as part of a interdisciplinary treatment team with patient/family-centered approach

Approved Medication for Irritability in Persons with Autism

- Irritability defined by the US FDA as aggression, self-injurious behavior, and severe tantrums
- Two FDA approved drug treatments of irritability
 - **Risperidone and Aripiprazole**
 - Both atypical or newer generation anti-psychotic drugs
 - Both FDA approved targeting irritability in YOUTH with autism
 - Other indications for these drugs classically recognized as use in schizophrenia and/or bipolar disorder
 - » While not approved for use in adults with autism targeting irritability, each drug used equally in adult persons with autism

Drugs Studied Targeting Irritability with Little Evidence Supporting Use

- Valproic acid
 - Negative placebo-controlled study
- Naltrexone
 - Limited evidence, tolerability concerns
- Lurasidone
 - Negative placebo-controlled study

Other Options

Psychopharmacology (2012) 223:237–245

DOI 10.1007/s00213-012-2711-3

ORIGINAL INVESTIGATION

Paliperidone for irritability in adolescents and young adults with autistic disorder

**Kimberly A. Stigler • Jennifer E. Mullett •
Craig A. Erickson • David J. Posey •
Christopher J. McDougle**

- Active ingredient in risperidone in time-release formulation
 - Not liver metabolized
 - Must be swallowed

FDA Approved Options: Tolerability Concerns

- Risperidone and Aripiprazole
 - Weight gain
 - Extrapyramidal symptoms
 - Abnormal movements
 - Akathisia or constant need to be in motion
- Risperidone
 - Elevated prolactin, risk of gynecomastia
 - Interestingly, can blunt this risk adding low dose aripiprazole to risperidone

Weight Gain on Approved Drugs

JOURNAL OF CHILD AND ADOLESCENT PSYCHOPHARMACOLOGY

Volume 24, Number 2, 2014

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Pp. 78–82

DOI: 10.1089/cap.2013.0099

Body Mass Index Change in Autism Spectrum Disorders: Comparison of Treatment with Risperidone and Aripiprazole

Logan K. Wink, MD,¹ Maureen Early, BS,² Tori Schaefer, PhD,¹ Amy Pottenger, BS,²
Paul Horn, PhD,^{1,3} Christopher J. McDougale, MD,⁴ and Craig A. Erickson, MD¹

- Over long-term treatment, no difference in weight gain associated with risperidone versus aripiprazole use

Weight Gain on Approved Drugs

TABLE 3. TREATMENT RESULTS: GROUP COMPARISONS

	<i>Risperidone</i>	<i>Aripiprazole</i>	<i>Two tailed t test</i>
Treatment duration	2.37 ± 2.55 years	1.47 ± 1.21 years	$p=0.01$
Final dose	2.23 ± 1.30 mg/day	11.85 ± 7.23 mg/day	NA
Final CGI-I ^a	3.2 ± 1.2	2.9 ± 1.2	$p=0.32$
BMI change per year of treatment	2.36 ± 3.80	2.05 ± 5.02	$p=0.68$
BMI Z-score change per year of treatment	0.53 ± 1.21	0.56 ± 2.21	$p=0.91$

^aClinical Global Impressions – Improvement (CGI-I) scale ranges from 1 to 7 with 1 = very much improved and 7 = very much worse.
BMI, body mass index.

Weight Gain Differences Among Atypical Antipsychotics

JOURNAL OF CHILD AND ADOLESCENT PSYCHOPHARMACOLOGY
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Pp. 1–6
DOI: 10.1089/cap.2016.0049

Original Article

Weight Gain Effects of Second-Generation Antipsychotic Treatment in Autism Spectrum Disorder

Yesie Yoon, MD, Logan K. Wink, MD, Ernest V. Pedapati, MD,
Paul S. Horn, PhD, and Craig A. Erickson, MD

Weight Gain Differences Among Atypical Antipsychotics

ANTIPSYCHOTIC-ASSOCIATED WEIGHT GAIN IN ASD

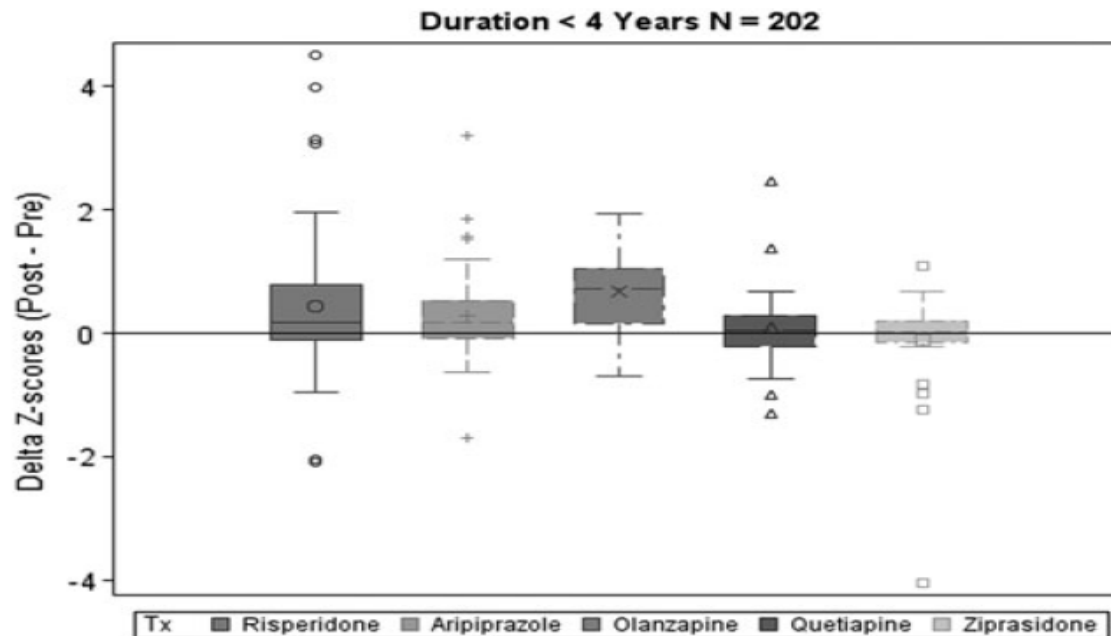


FIG. 1. Change in BMI z-score with second-generation antipsychotic treatment. BMI, body-mass index; *n*, number; Delta z-score, change in BMI z-score; Tx, treatment.



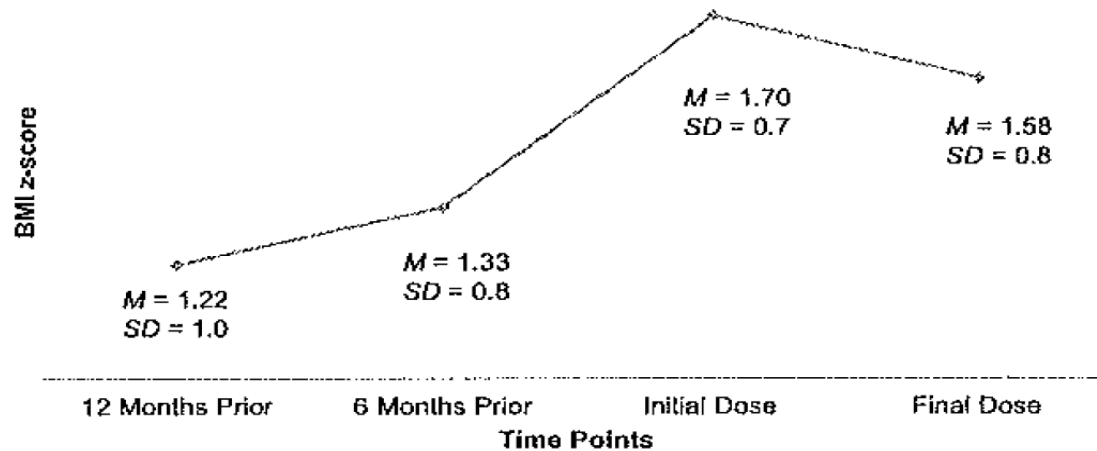
BRIEF REPORT

Brief Report: Metformin for Antipsychotic-Induced Weight Gain in Youth with Autism Spectrum Disorder

Logan K. Wink¹ · Ryan Adams¹ · Ernest V. Pedapati¹ · Kelli C. Dominick¹ · Emma Fox¹ · Catherine Buck¹ · Craig A. Erickson¹

- Metformin use subject of this long-term naturalistic study and of short-term treatment study compared to placebo
 - All reports noting significant weight loss/weight plateau with treatment

Metformin for anti-psychotic associated weight gain



- Metformin blunts weight gain/promotes weight loss overall in those gaining significant weight on antipsychotics

Other Option: Uncontrolled Weight Gain

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Volume 25, Number 5, 2015
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Pp. 397–401
DOI: 10.1089/cap.2014.0111

A Retrospective Naturalistic Study of Ziprasidone for Irritability in Youth with Autism Spectrum Disorder

Kelli Dominick, MD, PhD,¹ Logan K. Wink, MD,¹
Christopher J. McDougle, MD,^{2,3} and Craig A. Erickson, MD¹

- 42 youth, get about a 50% response rate in those not tolerating first line treatments

When First Line Treatment Fails

Drug-refractory aggression, self-injurious behavior, and severe tantrums in autism spectrum disorders: A chart review study

**Benjamin A Adler¹, Logan K Wink², Maureen Early^{3,4},
Rebecca Shaffer^{3,4}, Noha Minshawi^{3,4}, Christopher J McDougle⁵
and Craig A Erickson²**

Autism
2015, Vol. 19(1) 102–106
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361314524641
aut.sagepub.com



- At our tertiary care center, 53 of 135 (39%) referred patients with autism and irritability were drug refractory

Drug Refractory Irritability

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Pp. 1–4
DOI: 10.1089/cap.2015.0123

Brief Report

Multiple Antipsychotic Medication Use in Autism Spectrum Disorder

Logan K. Wink, MD,¹ Ernest V. Pedapati, MD,¹ Paul S. Horn, PhD,¹
Christopher J. McDougle, MD,² and Craig A. Erickson, MD¹

- 6.4% of an 1,100 patient with autism cohort receiving behavioral medication
- Good tolerability noted
 - May be safer than single older generation antipsychotics or other options in a drug refractory population

Drug Refractory Irritability

JOURNAL OF CHILD AND ADOLESCENT PSYCHOPHARMACOLOGY
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Pp. 1–4
DOI: 10.1089/cap.2015.0216

Brief Report

Clozapine for Drug-Refractory Irritability in Individuals with Developmental Disability

Logan K. Wink, MD, Ismail Badran, MD, Ernest V. Pedapati, MD, Rena Sorensen, PhD,
Stacy C. Benton, RN, Mark C. Johnson, MD, Gregory Wissel, BS, and Craig A. Erickson, MD

- Our clozapine cohort is up to 52 persons with autism who have exhausted many other medication options
 - Risks: agranulocytosis, weight gain, sedation, drooling

Drug Refractory Irritability

Curr Opin Psychiatry. 2018 Mar;31(2):116-122. doi: 10.1097/YCO.0000000000000393.

Electroconvulsive therapy for self-injurious behaviour in autism spectrum disorders: recognizing catatonia is key.

Wachtel LE¹, Shorter E², Fink M³.

- When medications fail in the context of intensive behavioral intervention
 - Using more ECT over time
 - Agitated catatonia



Discussion

Barriers to Providing Mental Health Services to Autistic Individuals

Brenna B. Maddox, PhD, LCP
2019 IACC Workshop
May 21, 2019

Background

- High rates of psychiatric conditions
- Mental health concerns often go untreated
- Negative outcomes of untreated psychiatric conditions

Camm-Crosbie et al., 2018; Farley et al., 2009; Leyfer et al., 2006; Maddox et al., 2018; Roux et al., 2015; Shattuck et al., 2011; Sikora et al., 2012; Simonoff et al., 2008; Spain et al., 2018

What are the Barriers to Effective Mental Healthcare for Autistic Individuals?

Many clinicians do not
feel confident about
working with autistic
people.

Brookman-Frazee et al., 2012; Maddox et al., 2019;
Williams & Haranin, 2016

“We’re probably somewhat all **out of scope of practice** when we’re dealing with these kids.”

- Community mental health clinician

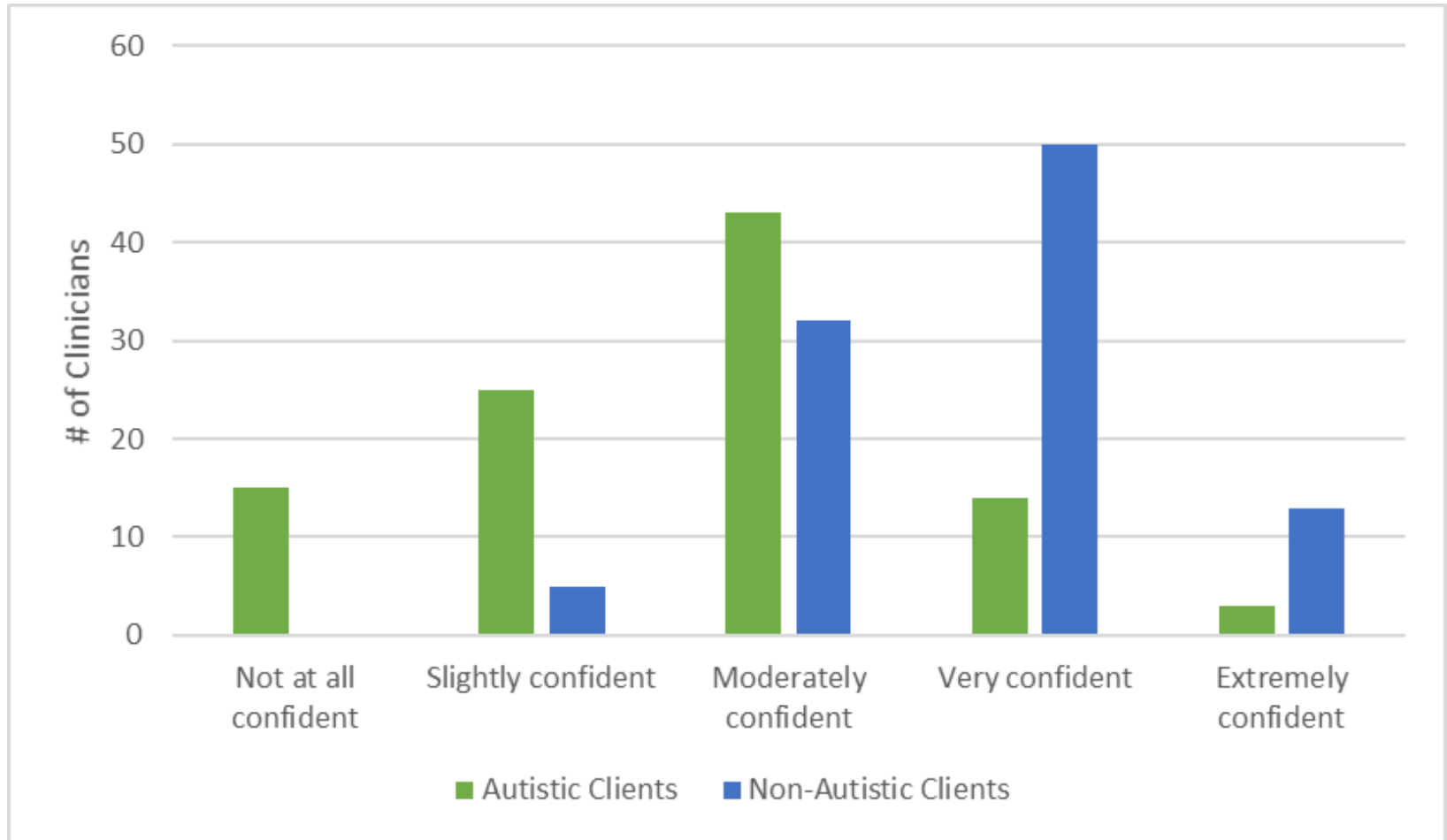
Brookman-Frazee et al., 2012

“I've worked with a lot of diverse populations of all ages, but this is the one area that I would not feel competent to work with.”

- Community mental health clinician

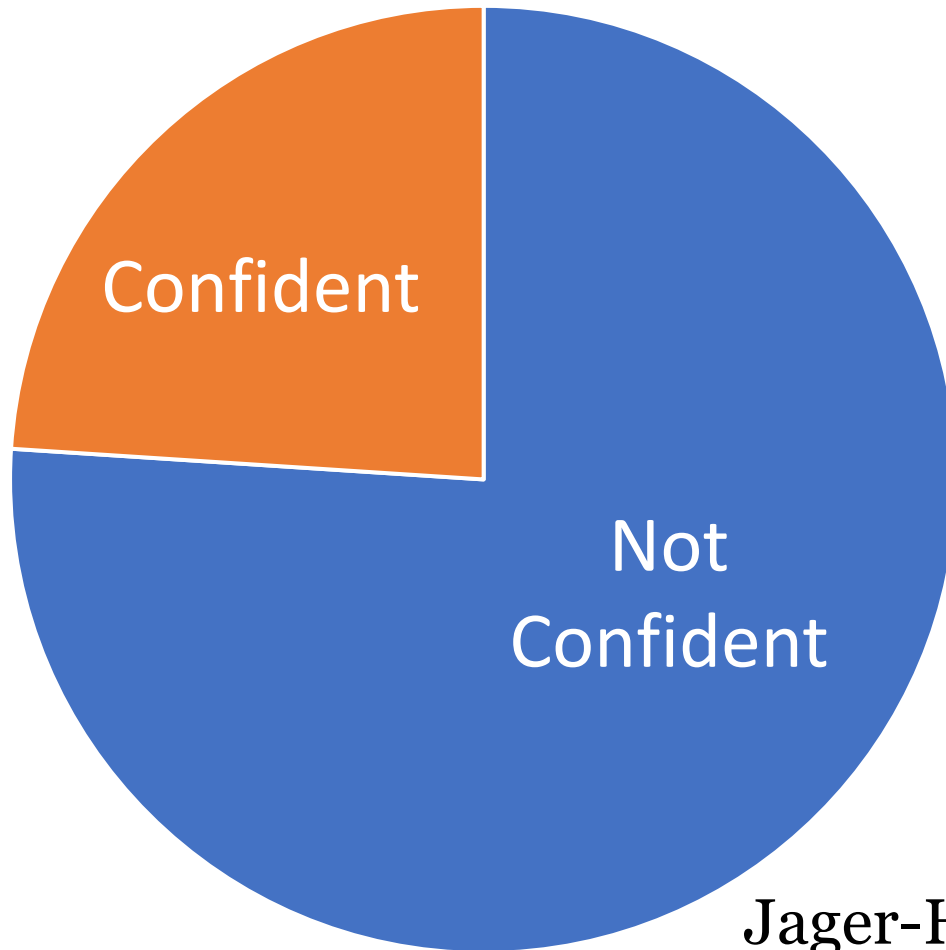
Maddox et al., 2019

Clinicians' Confidence in Treating Anxiety or Depression in Adult Clients



Maddox et al., 2019

Clinicians' Confidence in Intervening with an Autistic Client with Suicidality

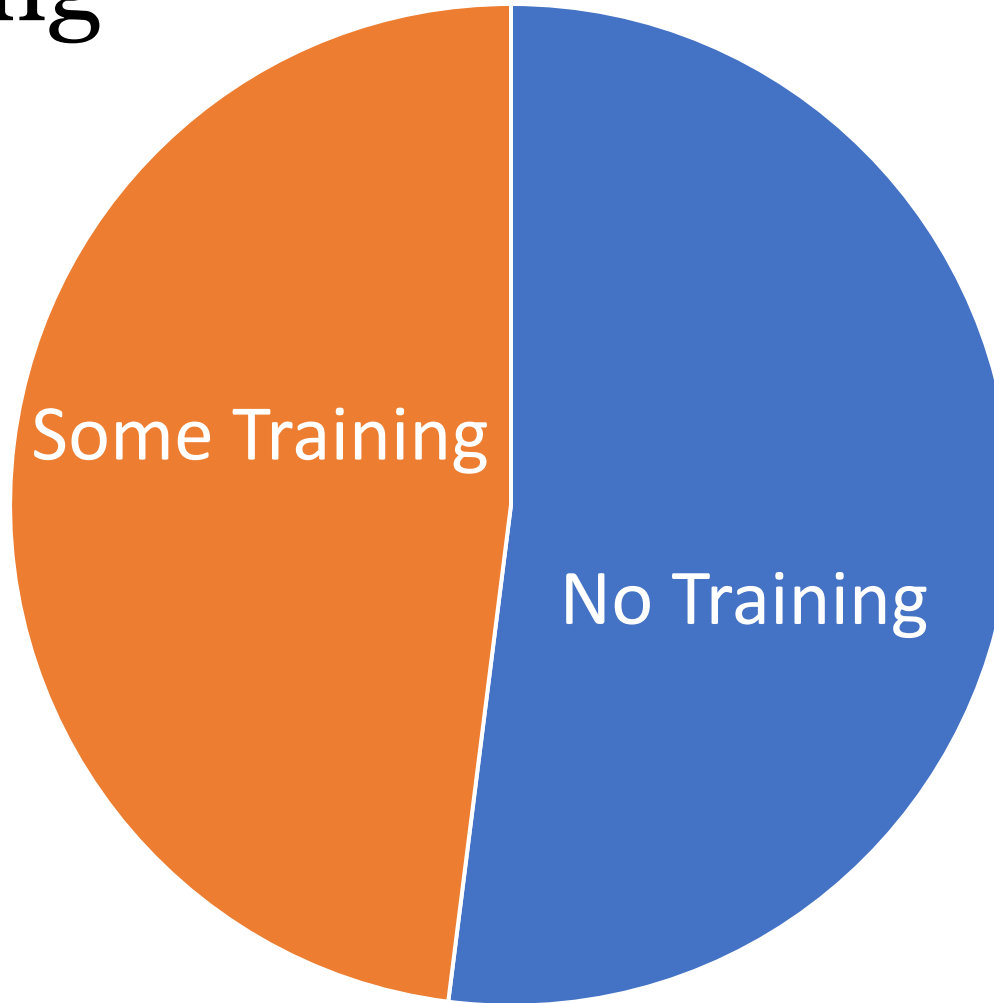


Jager-Hyman et al., 2019

Many clinicians are not
trained to work with
autistic people.

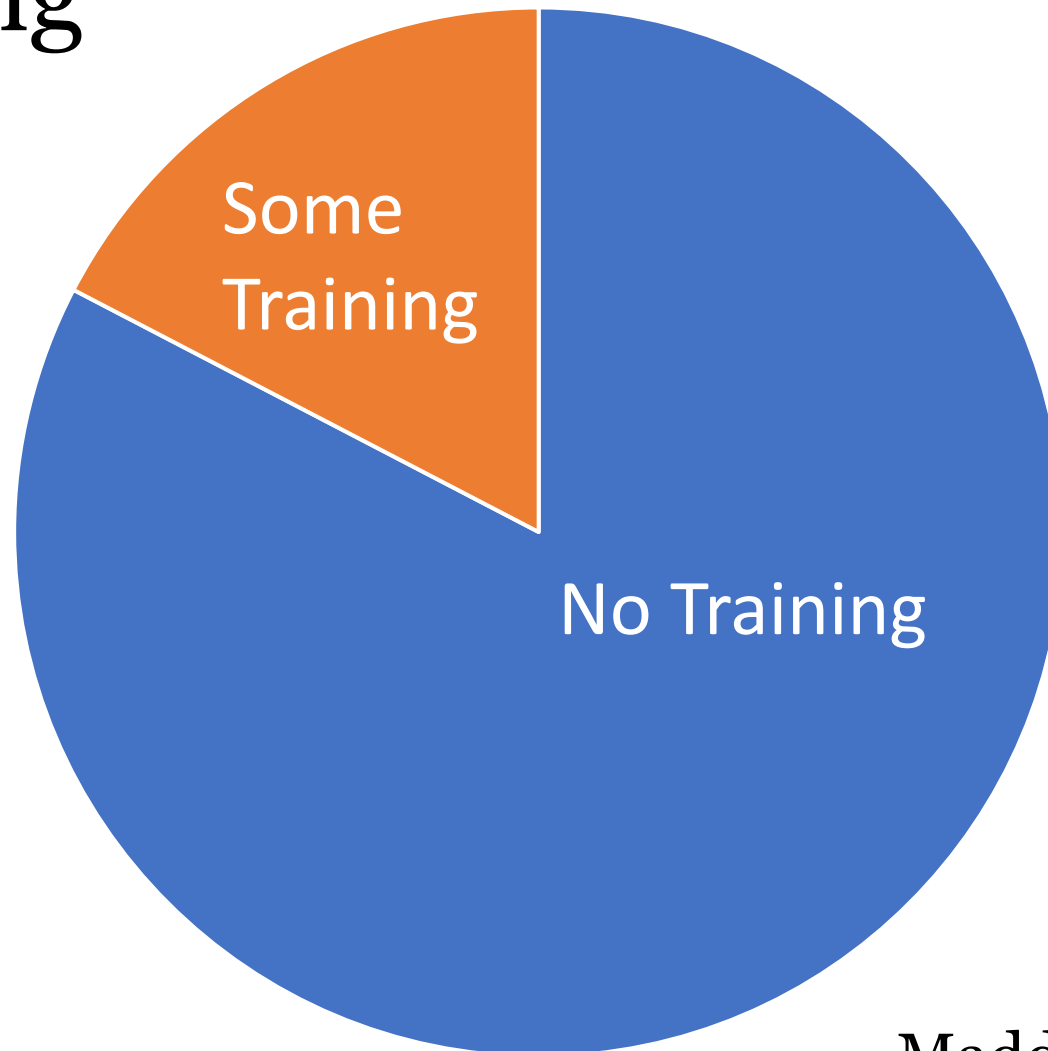
Brookman-Frazee et al., 2012; Camm-Crosbie et al., 2018;
Cooper et al., 2018; Kalb et al., 2017; Lake et al., 2014;
Maddox et al., 2019; Narendorf et al., 2011; Williams &
Haranin, 2016

% of Clinicians with Child Autism Training



Brookman-Frazee et al., 2012

% of Clinicians with Adult Autism Training



Maddox et al., 2019

“I can't even find therapists who know very much about autism spectrum disorders. So I have to continually be trying to tell them that my needs are not the same and it is a real challenge to sometimes work with these folks [therapists].”

– Autistic woman

Maddox et al., 2019

Most evidence-based practices were not designed for autistic people in community mental health settings.

Brookman-Frazee et al., 2012; Wood et al., 2015

The mental health and developmental disabilities systems are disconnected.

Brookman-Frazee et al., 2019; Maddox et al., 2019; Maddox & Gaus, 2019

Autistic adults face
additional challenges
accessing mental
healthcare.

Anderson & Butt, 2018; Camm-Crosbie et al., 2018; Maddox et al., 2019; Shattuck et al., 2011



Possible Solutions

- Clinician training

Drahota et al., 2012; Maddox & Gaus, 2019; Wood et al., 2015

Training Clinicians to Deliver Group CBT to Manage Anxiety in Youth With ASD: Results of a Multisite Trial

Judy Reaven and Eric J. Moody
University of Colorado Anschutz Medical Campus

Laura Grofer Klinger
University of North Carolina–Chapel Hill

Amy Keefer
Johns Hopkins School of Medicine/Kennedy Krieger Institute

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Susan Hepburn
Colorado State University

Audrey Blakeley-Smith
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Possible Solutions

- Clinician training
- Effective implementation strategies

Drahota et al., 2012; Maddox & Gaus, 2019; Wood et al., 2015

STUDY PROTOCOL

Open Access



Effectiveness of a multi-level implementation strategy for ASD interventions: study protocol for two linked cluster randomized trials

Lauren Brookman-Frazee^{1,2*} and Aubyn C. Stahmer^{2,3}

Possible Solutions

- Clinician training
- Effective implementation strategies
- Community-academic partnerships
- Coordination between mental health and developmental disabilities systems

Drahota et al., 2012; Maddox & Gaus, 2019; Wood et al., 2015

Joining Forces to Maximize Impact

- Research-to-practice gap beyond autism



Green, 2008; Morris et al., 2011; Wolitzky-Taylor et al., 2015

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THANK YOU!



**PENN CENTER FOR
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Discussion



Working Group Discussion

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Closing Remarks & Adjournment

Next IACC Meeting



Wednesday, July 24th 2019

Suicide & Mental Health Crisis Resources



- National Suicide Prevention Lifeline:
1-800-273-TALK(8255) www.suicidepreventionlifeline.org
- Veterans Crisis Line: 1-800-273-8255, press 1
- Crisis Text Line: text START to 741-741 (more information:
<https://www.crisistextline.org/textline/>)
- HealthReach (multiple languages)
www.healthreach.nlm.nih.gov/searchindex/Suicide
- Help for Mental Illnesses: NIMH web page
www.nimh.nih.gov/findhelp
- Treatment Referral Routing Service (funded by SAMHSA):
1-800-662-HELP(4357)