

# Meeting of the Interagency Autism Coordinating Committee

October 11, 2023; 10:00 a.m. - 5:00 p.m. ET



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

Director, Office of National Autism Coordination, NIMH

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

Director, National Institute of Mental Health (NIMH)

And Chair, IACC

# Welcome, Roll Call, and Announcements



**Susan A. Daniels, Ph.D.**  
Executive Secretary, IACC  
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Director, National Institute of Mental Health (NIMH)  
And Chair, IACC

# Housekeeping Notes



- During discussions, please keep your comments brief (~1-2 minutes) to ensure that other members have a turn to speak.
- For Committee members that would like a comment read aloud:
  - Please send the text of your comment via Zoom chat function to the ONAC Staff Member who is using the Zoom screen name “SEND COMMENTS HERE”.
  - When it is your turn to be recognized, Mr. Steven Isaacson from the ONAC staff will read your comment to the group.
- Closed captioning is available in Zoom for Committee members and on Videocast for members of the viewing public.

# Housekeeping Notes



- For in-person participants, please:
  - Turn on your tabletop microphone to speak and turn it off when you are finished.
  - Sign into Zoom but keep your device audio muted.
  - Raise your physical hand or use the “Raise Hand” function in Zoom to be recognized.
- For virtual participants, please:
  - Keep your microphone off unless you are speaking.
  - You may turn your camera on when you are speaking and during committee discussions.
  - Use the “Raise Hand” function in Zoom to be recognized.

# National Disability Employment Awareness Month (NDEAM) Recognition



**Anupa Geevarghese, Esq.**  
Chief of Staff, Office of Disability Employment Policy  
U.S. Department of Labor

# National Autism Coordinator Update

IACC Full Committee Meeting  
October 11, 2023

**Susan A. Daniels, Ph.D.**

HHS National Autism Coordinator

Executive Secretary, IACC

Director, Office of National Autism Coordination



# National Autism Coordinator Appointed

- Susan A. Daniels, Ph.D. has been appointed as the HHS National Autism Coordinator and Director of the Office of National Autism Coordination (ONAC), NIMH/NIH.
- The NAC will play a vital role in ensuring the implementation of national autism research, services, and support activities across federal agencies.
- Dr. Daniels will continue to serve as the Executive Secretary of the [Interagency Autism Coordinating Committee](#) (IACC).
- The new ONAC within NIMH will support both the activities of the NAC and the OARC/IACC.
- Read more in the: [NIMH news announcement](#).



# Overview

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- White House Updates
- Federal Committee Updates
- Federal Department and Agency Updates
- Non-Governmental Activities and Updates

More information about these updates can be found in the meeting materials:

[https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/nac\\_update.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/nac_update.pdf)



## National Autism Coordinator Update

# White House Updates

- President Biden issued several proclamations and statements recently, including:
  - [Proclamation for National Disability Employment Awareness Month \(NDEAM\)](#)
  - [Statement on the 50<sup>th</sup> Anniversary of the Rehabilitation Act](#)
  - [Proclamation on Anniversary of the Americans with Disabilities Act, 2023](#)



## White House Updates

- President Biden announced his intent to nominate cancer researcher and surgical oncologist Dr. Monica Bertagnolli as Director of the National Institutes of Health (NIH). [Read announcement here.](#)



# Overview

- Federal Committee Updates

- Interagency Committee for Disability Research (ICDR)
- RAISE Family Caregiving Advisory Council (FCAC)
- National Council on Disability (NCD)
- Federal Partners in Transition (FPT)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Disability Advisory Committee (DAC)
- President's Committee for People with Intellectual Disabilities (PCPID)
- National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)
- Coordinating Council on Access and Mobility (CCAM)
- Interagency Task Force on Trauma-Informed Care (TIC Task Force)

More information about these updates can be found in the meeting materials:

[https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/nac\\_update.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/nac_update.pdf)

# Interagency Committee on Disability Research ([ICDR](#))

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- Managed by the Administration for Community Living (ACL)
- Scope: Disability, independent living, and rehabilitation research programs
- Recent activities include:
  - Lunch & Learn webinars series:
    - [April 2023](#): Disability Cultural Competence in Healthcare
    - [May 2023](#): How Did the COVID-19 Recession Impact People with Disabilities in Rural America?
    - [June 2023](#): Emergency Preparedness and the Impact of Climate Change on People with Disabilities
    - [July 2023](#): Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility
    - [August 2023](#): Participatory Action Research with People with Disabilities
  - June 2023: [Annual stakeholder meeting](#)
  - Recording and summary available for: February 2023 [State of the Science Conference on Disability Statistics](#)

## RAISE Family Caregiving Advisory Council ([FCAC](#))

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- Managed by the Administration for Community Living (ACL)
- Scope: family caregiving and support for family caregivers
- Recent activities include:
  - July 2023: Joint kick-off meeting for the new RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren
  - September 2023: Joint Councils meeting focused on public comments and implementation of the [2022 National Strategy to Support Family Caregivers](#)
    - [Agenda](#)
    - *Materials and recording not yet posted*

National Autism Coordinator Update  
National Council on Disability ([NCD](#))

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- Independent federal agency
- Scope: disability policies, programs, practices, and procedures
- Upcoming and recent activities include:
  - Upcoming NCD Council meeting on November 16-17, 2023, focused on housing and transportation issues. Additional information, including registration and agenda, is [available here](#).
  - July 2023: Quarterly business meeting. [Agenda](#).
  - July 2023: Americans with Disabilities Act (ADA) anniversary event “On the Threshold of Independence” (Recording available on [Youtube](#))
  - May 2023: Report released on [The Impacts of Extreme Weather Events on People with Disabilities](#)

## National Autism Coordinator Update

# Federal Partners in Transition ([FPT](#))

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- Voluntary, all-federal work group
- Managed by the U.S. Department of Labor
- Scope: transition-related issues for youth with disabilities
  
- Recent activities include:
  - August 2023: Steering Committee Meeting
  - August 2023: General Committee Meeting discussing resources for Native American communities
  - Continuing work on Strategic Plan

National Autism Coordinator Update

# Interdepartmental Serious Mental Illness Coordinating Committee ([ISMICC](#))

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- Managed by the Substance Abuse and Mental Health Services Administration (SAMHSA)
- Scope: issues related to serious mental illness (SMI) and serious emotional disturbance (SED)
- Activities include:
  - Upcoming Meeting on October 18, 2023. For access and additional information, please see the [Federal Register notice](#).



# Disability Advisory Committee ([DAC](#))

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- Managed by the Federal Communications Commission (FCC)
- Scope: communications access, video programming access, and other disability issues
- Recent activities include:
  - September 2023: Committee meeting ([video and agenda](#) are available online)
    - Topics discussed include
      - Disability rights
      - AI accessibility
      - Audio descriptions

# President's Committee for People with Intellectual Disabilities ([PCPID](#))

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- Managed by the Administration for Community Living (ACL)
- Scope: topics that impact people with intellectual disabilities
- Recent activities include:
  - May 2023: Committee Meeting focused on needs associated with various aspects of home- and community-based services (HCBS), including the shortage of direct support professionals and needs for employment and community living services
    - Recording of the meeting is available [here](#)

# National Advisory Committee on Individuals with Disabilities and Disasters ([NACIDD](#))

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- Managed by the HHS Administration for Strategic Preparedness and Response
- Scope: needs of individuals with disabilities before, during, and after disasters and emergencies
- Recent activities include:
  - September 2023: Joint public meeting with the National Advisory Committee on Seniors and Disaster (NACSD) to discuss their respective reports
    - [Recommendations from the NACIDD](#)
    - [Recommendations from the NACSD](#)
    - Additional information is available [here](#)

# Coordinating Council on Access and Mobility ([CCAM](#))

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- Managed by the Federal Transit Administration, U.S Department of Transportation
- Scope: transportation for people with disabilities, older adults, and individuals of low income
- Recent activities include:
  - October 2022: Council approved [2023-2026 CCAM Strategic Plan](#)
  - November 2022: public webinar to discuss the 2023-2026 CCAM Strategic Plan ([presentation](#) and [recording](#) available)

# Interagency Task Force on Trauma-Informed Care (TIC Task Force)

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- Managed by the Substance Abuse and Mental Health Services Administration (SAMHSA)
- Scope: Families impacted by substance use disorders and other forms of trauma
- Recent activities include:
  - November 2021: [National Strategy for Trauma-Informed Care Operating Plan](#) published

# Overview

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- Federal Department and Agency Updates
  - National Institutes of Health (NIH)
  - Administration for Community Living (ACL)
  - Department of Health and Human Services (HHS)
  - Department of Labor (DOL)
  - Centers for Medicare and Medicaid Services (CMS)
  - Department of Justice (DOJ)

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# NIH Designates People with Disabilities as a Population with Health Disparities

- In September 2023, the National Institutes of Health designated people with disabilities as a population with health disparities for research supported by NIH. [Read more here.](#)
- NIH also issued a [notice of funding opportunity](#) calling for research applications focused on the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and health outcomes.



## NIH RFI on Proposed Update to Mission Statement

- NIH has issued a [public RFI](#) (deadline for comments is November 24) regarding proposed changes to its Mission Statement to make it more inclusive.
- The following change is proposed:  
From:  
“To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to **enhance health, lengthen life, and reduce illness and disability.**”  
To:  
“To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to **optimize health and prevent or reduce illness for all people.**”
- The Dr. Larry Tabak, Acting NIH Director has posted a blog discussing the proposed change. [Read more here.](#)





# I/DD Counts National Summit Report Highlights Health Data as Equity Issue

- In November 2022, the Administration for Community Living (ACL) I/DD Counts initiative organized a national summit to discuss progress on its 2030 roadmap for health data equity, remaining gaps, and priorities for the future.
- [This report](#) summarizes the key ideas from the summit and actions recommended by and for the I/DD Counts initiative.

## HHS Issues New Proposed Rule to Strengthen Prohibitions Against Discrimination on the Basis of a Disability in Health Care and Human Services Programs

- The Biden-Harris Administration has taken action to make significant updates to Section 504 of the Rehabilitation Act rule on its 50<sup>th</sup> Anniversary to advance equity and bolster protections for people with disabilities
- On September 7, the HHS Office for Civil Rights announced a proposed rule that prohibits discrimination on the basis of disability in HHS-funded health care and human services programs.
- Read the [press release here](#).
- Public comments on this proposed rule are welcome through November 13, 2023 and can be [submitted here](#).

## DOL Continues Support for Disabled Youth Employment Initiatives

- The U.S. Department of Labor (DOL) announced the award of a \$7.5 million, five-year cooperative agreement to continue support for Center for Advancing Policy on Employment for Youth (CAPE-Youth), a policy center aimed at boosting disabled youth employment.
- The center's development and management will be overseen by the Council of State Governments.
- [Read more here.](#)



# CMS Takes Action to Protect Health Care Coverage for Children and Families

- In August 2023, the Centers for Medicare & Medicaid Services (CMS) [sent a letter](#) to states and territories requiring them to determine whether an eligibility systems issue may have caused eligible individuals to be disenrolled from Medicaid or the Children's Health Insurance Program (CHIP) even if they are still eligible for coverage. [Read more here.](#)
- In September 2023, CMS announced that to-date, nearly 500,000 children and families from 30 states will regain their coverage. Many more are expected to be protected from improper disenrollments going forward. [Read more here.](#)



# Justice Department Advances Proposed Rule to Strengthen Web and Mobile App Access for People with Disabilities

- The U.S. Department of Justice (DOJ) submitted a [FRN](#) on a proposed rule that aims to improve web and mobile applications access for people with disabilities and clarify how public entities can meet their existing Americans With Disabilities Act (ADA) obligations as many of their activities shift online.
- Written comments were requested before October 3, 2023.



## National Autism Coordinator Update

# Overview

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- Non-Governmental Activities and Updates
  - 16th Session Of The Conference Of States Parties To The CRPD
  - International Society for Autism Research (INSAR) Annual Meeting
  - Stanford Neurodiversity Summit 2023
  - OCALICON 2023 autism and disabilities conference
  - National Autism Indicators Report: Health Care Experiences During the COVID-19 Pandemic

More information about these updates can be found in the meeting materials:

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## National Autism Coordinator Update

# Recent Conference: 16th Session Of The Conference Of States Parties To The CRPD

- The 16th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (COSP16) was held at the United Nations Headquarters, New York, from June 13 to 15, 2023.
- On June 15, the Autism Alliance of Canada hosted a side event titled “Challenges, Best-Practices, and a Way Forward: Looking at National Autism Strategies through the lens of the CRPD.”
- Dr. Susan Daniels participated, sharing an overview of the IACC and contributions of its Strategic Plan to US federal autism activities . [Read more here.](#)



## National Autism Coordinator Update

# Recent conference: International Society for Autism Research (INSAR) Annual Meeting

- [Annual meeting](#) featured research presentations on a broad range of topics
- Keynote presentations from the following speakers:
  - Wendy Chung, M.D., Ph.D. (advances in autism genetics research)
  - Gauri Divan, M.B.B.S., M.R.C.P.C.H. (adapting interventions for low-resource settings)
  - Patricia Howlin, Ph.D. (autism in older age)
- Also featured a roundtable discussion about precision health for neurodiverse communities

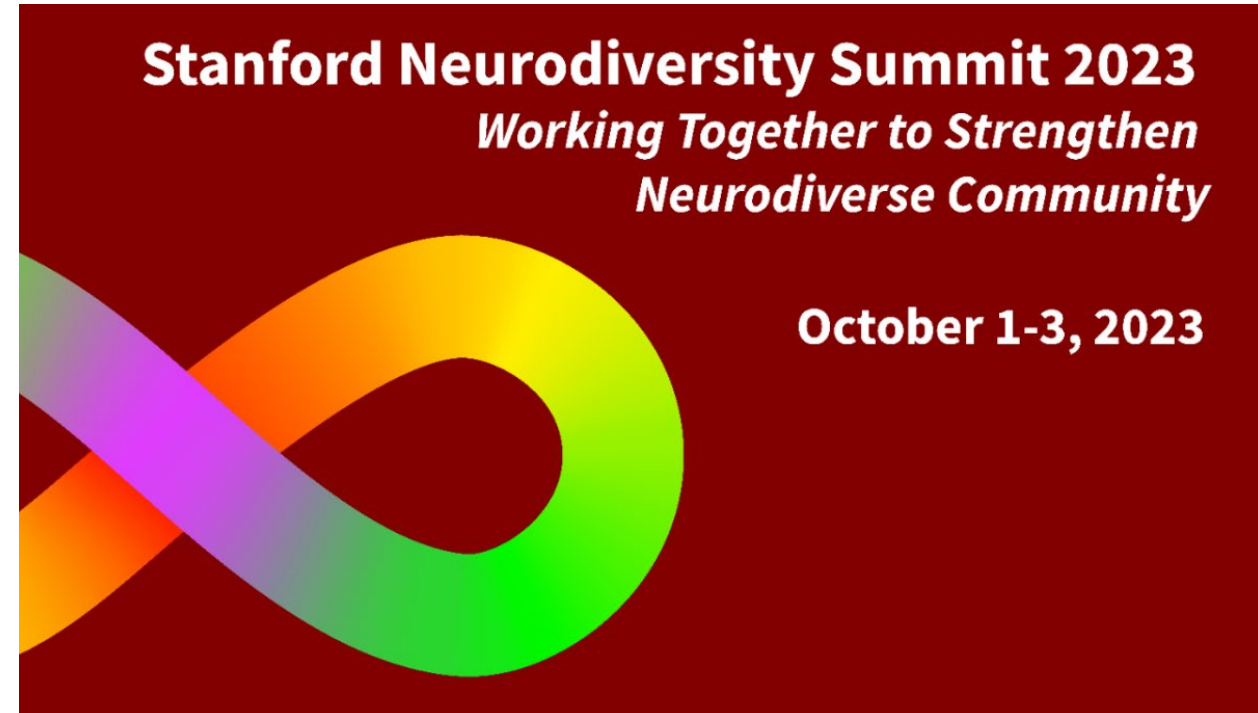




## National Autism Coordinator Update

# Recent conference: Stanford Neurodiversity Summit 2023

- [Annual meeting](#) bringing together neurodiverse/neurodivergent individuals, employers, service agencies, educators and students, parents, and professionals from all areas of the field
- Topics included:
  - Employment
  - Mental Health
  - Higher Education
  - K-12 Education
  - Human Rights



## National Autism Coordinator Update

# Upcoming conference: OCALICONLINE 2023 Autism and Disabilities Conference

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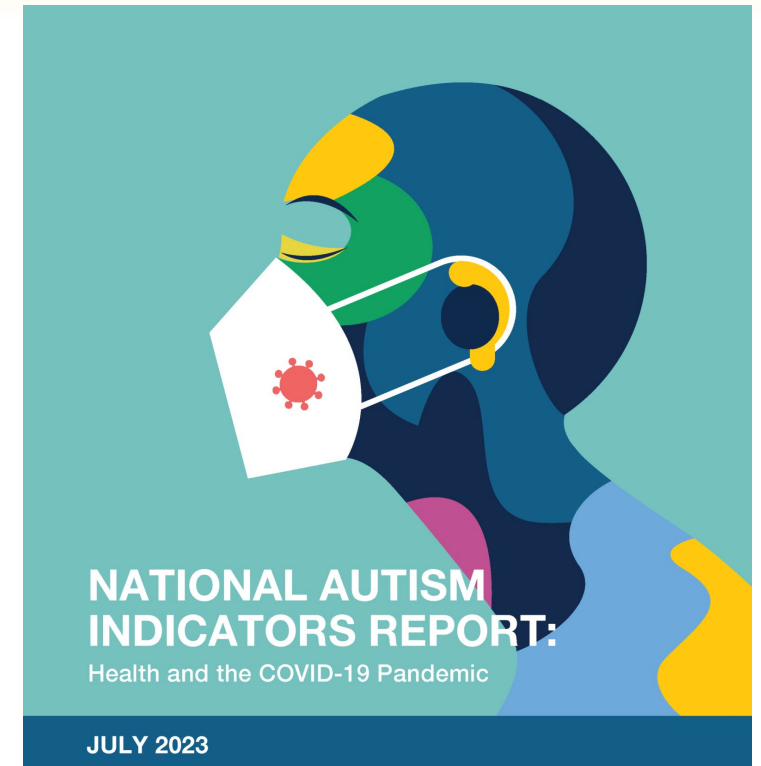
The logo for OCALICONLINE 2023 features the text "OCALICONLINE" in a large, bold, black sans-serif font. The "O" is stylized with a white circle inside. Below "OCALICONLINE" is the year "2023" in a smaller, bold, black sans-serif font. A horizontal bar with a rainbow gradient (green, cyan, blue, purple) is positioned above the text, and another horizontal bar with a red-to-orange gradient is positioned below the text.

# OCALICONLINE 2023

- November 14-17, 2023
- Conference will feature presentations from researchers, practitioners, self-advocates, and other experts
- [More information available here.](#)

# Report: Health Care Experiences During the COVID-19 Pandemic

- According to the National Autism Indicators Report: Health Care Experiences During the COVID-19 Pandemic, the pandemic-related changes in access to health care may have been an extra burden on autistic individual's health and, ultimately, quality of life.
- Researchers at A.J. Drexel Autism Institute's Policy and Analytics Center examined changes in access and disruptions to health care services for autistic children and adults during the beginning of the COVID-19 pandemic.
- These findings will inform better evidence-based practices for future public health emergencies to improve policies and programs for autistic individuals.
- [Read more here.](#)



# Round Robin Updates



**Susan A. Daniels, Ph.D.**  
Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH



# NIMH's Anniversary Celebration



# About the Celebration

- Starting in September 2023, NIMH will celebrate 75 years of transforming the understanding and treatment of mental illnesses.
- To mark this important milestone, we are planning a variety of activities, including **sessions at scientific meetings, lectures, and symposiums.**
- We will also share **stories, discoveries, and inspiration** that span the past, present, and future on our website at [nimh.nih.gov/75years](https://nimh.nih.gov/75years).
- Subscribe to NIMH email updates and follow us on social media to stay up to date about the 75th Anniversary.





Get Excited, Get Involved,  
and Spread the Word!

[nimh.nih.gov/75years](https://nimh.nih.gov/75years)

Follow us on  
social media @NIMHgov



# National Institute on Deafness and Other Communication Disorders (NIDCD) Funding Opportunity



## Promoting Language and Communication in Minimally Verbal/Non-Speaking Individuals with Autism

This NIDCD Notice of Special Interest (NOSI) encourages research applications to promote language and communication in autistic individuals who are minimally verbal/non-speaking.

**Focus:** evaluate and tailor existing interventions, develop novel interventions, develop and apply new research designs and methods to develop interventions, and identify meaningful outcome measures.



<https://grants.nih.gov/grants/guide/notice-files/NOT-DC-23-009.html>



**Break**



# IACC Committee Business

IACC Full Committee Meeting  
October 11, 2023



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

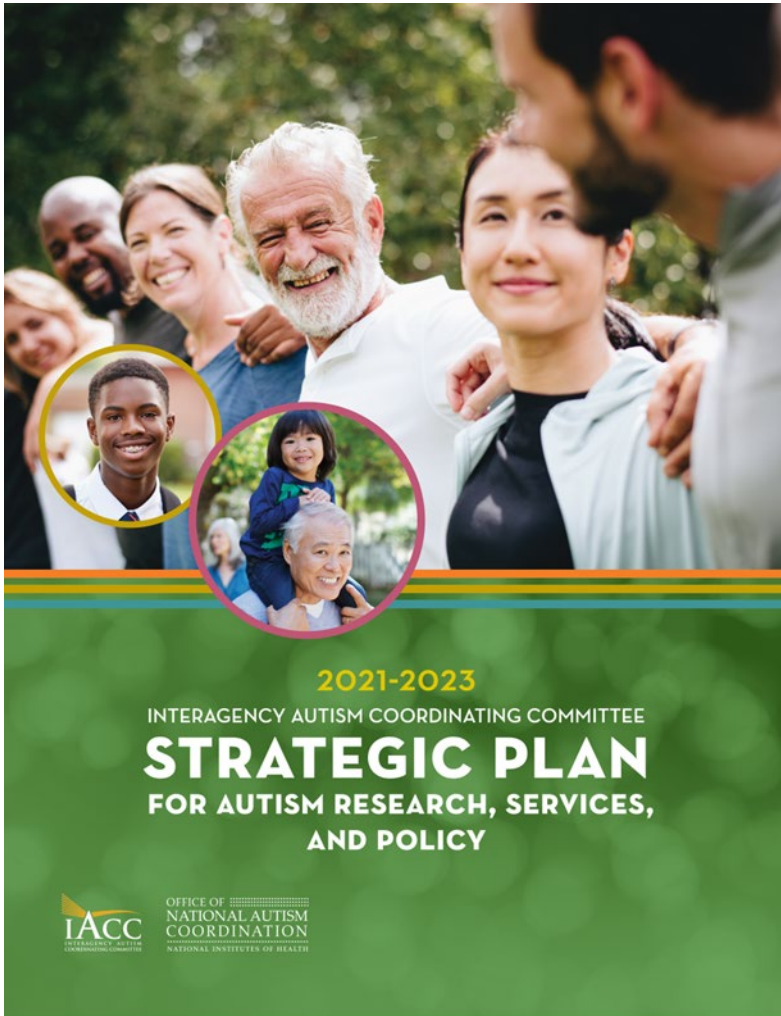
Director, Office of National Autism Coordination, NIMH

# Committee Business Overview



- *2021-2023 IACC Strategic Plan* – Released September 2023
- *2022 IACC Summary of Advances* update
- Planning for the *2024 IACC Strategic Plan Update*
- *2023 IACC Summary of Advances* discussion

# 2021-2023 IACC Strategic Plan: Now Available!

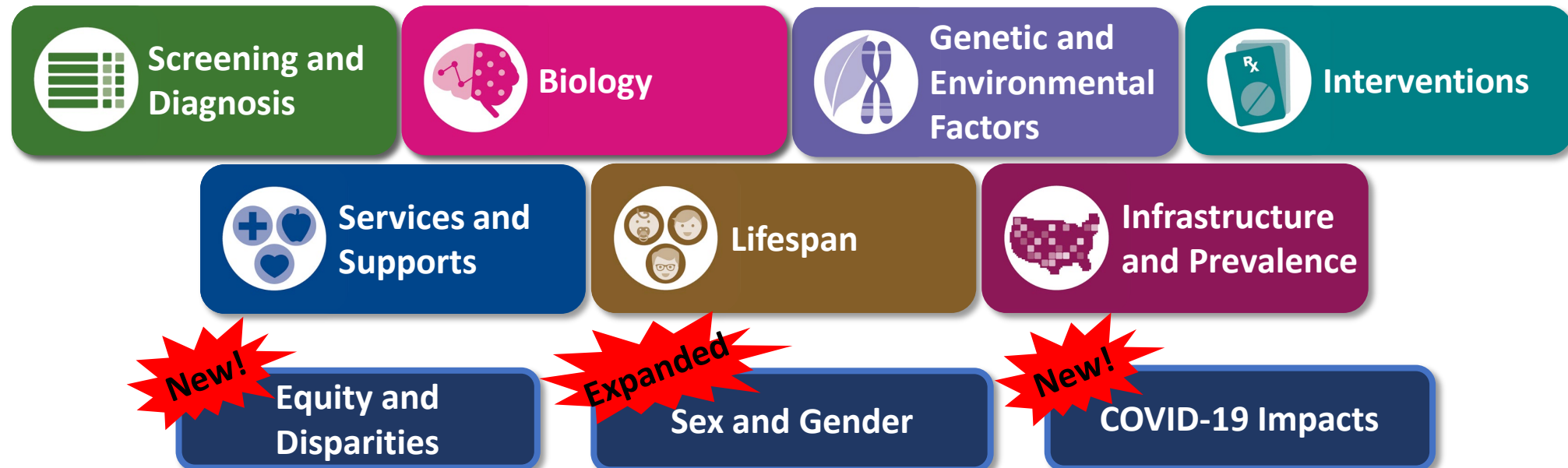


- The IACC voted to approve the *IACC Strategic Plan* at the January 2023 Full Committee Meeting.
- The *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy* and Easy-Read version are now available: <https://iacc.hhs.gov/publications/strategic-plan/2023/>
- The Plan contains 24 recommendations for activities to improve health, well-being, and outcomes for autistic people with diverse needs in all communities.
- The Plan will be submitted to Congress and the President, as required under the Autism CARES Act of 2019
- Thank you to the IACC and members of the public for sharing your input toward successful completion of the *2021-2023 IACC Strategic Plan*!

# 2021-2023 IACC Strategic Plan: Overview



- The Strategic Plan is organized around the **seven community-focused topics** and includes **recommendations** that address **research, services, and policy** activities.
- In addition, the *2021-2023 IACC Strategic Plan* includes **two cross-cutting recommendations** and a section on the **impact of COVID-19** on the autism community.



# 2021-2023 IACC Strategic Plan: Priorities and Overarching Themes



**Greater acceptance and inclusion** of autistic individuals

**Increased accessibility of services and research** for autistic individuals and their families

Solutions for people across the **entire spectrum**, including those with the **highest support needs**

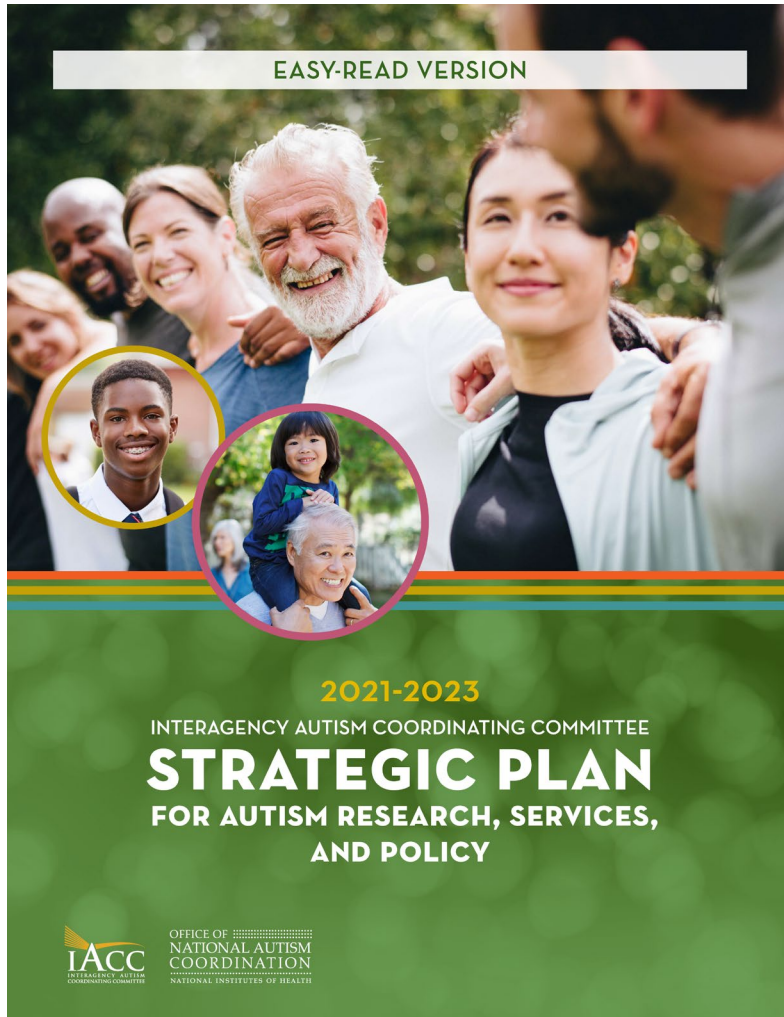
Solutions for people across the **entire lifespan**, including autistic **adults and older adults**

Solutions to improve **physical and mental health** for autistic individuals

Intersection of **social determinants of health** and the services system

**Increase equity and reduce disparities**

# 2021-2023 IACC Strategic Plan: Easy-Read Version



- ONAC has prepared a 16-page easy-read version of the *IACC Strategic Plan* to accompany the full report
- For each section of the full report, the easy-read version contains:
  - An overview of the section
  - A list of the topics covered
  - A list of recommendations
- The easy-read version is available on the IACC website: <https://iacc.hhs.gov/publications/strategic-plan/2023/strategic-plan-2023-easy-read.pdf>

# Status of the **2022** IACC Summary of Advances



- ✓ IACC members nominate articles (October 2022-January 2023)
- ✓ IACC members discuss nominations at committee meeting (January 2023)
- ✓ IACC members vote on top 20 articles (February-March 2023)
- ✓ ONAC prepares article summaries and draft publication (Spring-Fall 2023)
- IACC members preview and comment on draft (Fall 2023)
- ONAC prepares final publication (Fall 2023)



# Final year of the current IACC



The IACC's authorization under the Autism CARES Act of 2019 ends on September 30, 2024 – less than 1 year away!

- Remaining business to complete
  - **2023 IACC Summary of Advances** (compilation of nominations in progress)
  - Begin collecting nominations for the **2024 IACC Summary of Advances**
  - **2024 IACC Strategic Plan Update** (required under the Autism CARES Act)
  - **Report on co-occurring physical and mental health conditions** and their impacts on health outcomes
    - Drafting of report was started by the previous committee
    - In January 2023, the IACC agreed to work toward completion of this report
    - As directed earlier by the IACC, ONAC will work with working group chair, Dr. Julie Taylor, to update the draft to share with IACC for their review

# What are the options for a *2024 IACC Strategic Plan Update*?



- **Option 1:** Focus on summarizing IACC activities relevant to the *2021-2023 IACC Strategic Plan* (similar to the [2018-2019 IACC Strategic Plan Update](#)).
- **Option 2:** Focus on co-occurring conditions, merging content from the existing Co-Occurring Conditions report draft with new updates. The resulting Strategic Plan Update would provide summaries of research and service needs related to these conditions and activities the IACC has conducted relevant to these issues.

# Vote on options for the 2024 Strategic Plan Update



- **Option 1: Strategic Plan Update focused on Committee activities**  
Prepare summaries of IACC activities for the Strategic Plan Update. Prepare a separate report on co-occurring conditions.
- **Option 2: Strategic Plan Update focused on co-occurring conditions**  
Merge the co-occurring conditions report into the Strategic Plan Update.
- **Option 3: Other**
- **Abstain from voting**

A large, stylized red checkmark is positioned in the bottom right corner of the slide. The word "Vote!" is written in a red, cursive script font, overlapping the bottom part of the checkmark.

# Vote on options for completing the Co-Occurring Conditions report



- Would the IACC like to issue a Request for Information (RFI) to receive **public input** on needs related to co-occurring conditions to inform the report?
  - Yes
  - No
  - Abstain
  
- Would IACC members like to receive a survey to share **committee input** on issues related to co-occurring conditions to inform the report?
  - Yes
  - No
  - Abstain

**Vote!**

# Final year of the current IACC: Next Steps



- ONAC staff will continue working to update content on co-occurring conditions for the report
- We will provide an update on the status of the report at the January IACC meeting
- We will work to complete all reports (excluding the 2024 Summary of Advances) by **September 30, 2024**

# 2023 Summary of Advances Nominations



# 2023 IACC Summary of Advances Process



- IACC members nominate articles (January 2023 – January 2024)
- TODAY: IACC members discuss nominations at committee meetings (April 2023 - January 2024)**
- IACC members vote on top 20 articles (January 2024)
- ONAC prepares article summaries and draft publication (Winter-Spring 2024)
- IACC members preview/comment on draft (Spring 2024)
- ONAC prepares final publication (Spring 2024)

**IACC Members - Please continue to submit nominations through the rest of the year!**

# Summary of Advances discussion guidelines



- Goal of today's discussion: review the list of 35 nominated articles
- Selected articles should represent **significant advances or progress** in understanding of autism, across the 7 topic areas of the *IACC Strategic Plan*
- During the discussion:
  - Are there nominated articles you find particularly noteworthy?
  - Are there any articles that should potentially be removed, including any in the following categories?
    - Study too preliminary
    - Small sample size
    - Review article
    - Commentary
    - Workgroup recommendations





# Question 1: Screening and Diagnosis



- James et al. Consistency between parent report and direct assessment of development in toddlers with autism spectrum disorder and other delays: Does sex assigned at birth matter? *Autism Res.*
- Jones et al. Development and Replication of Objective Measurements of Social Visual Engagement to Aid in Early Diagnosis and Assessment of Autism. *JAMA Netw Open.*
- Pham et al. Examination of the impact of the *Get SET Early* program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder. *Autism.*
- Shuster et al. Neurobehavioral and Medical Correlates of Autism Screening: 2-Year Outcomes for Infants Born Very Preterm. *J Pediatr.*

## Question 2: Biology



- Schwartz et al. Auditory evoked potentials in adolescents with autism: An investigation of brain development, intellectual impairment, and neural encoding. *Autism Res.*
- St John et al. Association of Sex With Neurobehavioral Markers of Executive Function in 2-Year-Olds at High and Low Likelihood of Autism. *JAMA Netw Open.*
- Waizbard-Bartov et al. Changes in the severity of autism symptom domains are related to mental health challenges during middle childhood. *Autism.*
- Wright et al. A longitudinal comparison of emotional, behavioral and attention problems in autistic and typically developing children. *Psychol Med.*

# Question 3: Genetic and Environmental Factors



- Carter et al. Maternal exposure to aircraft emitted ultrafine particles during pregnancy and likelihood of ASD in children. *Environ Int.*
- Rahman et al. Prenatal exposure to tailpipe and non-tailpipe tracers of particulate matter pollution and autism spectrum disorders. *Environ Int.*
- Yap et al. Interactions between the lipidome and genetic and environmental factors in autism. *Nat Med.*

# Question 4: Interventions



- Clarke et al. The Relationship Between Augmentative and Alternative Communication Use by Pediatric Psychiatric Inpatients With Autism Spectrum Disorder and Interfering Behaviors. *Am J Speech Lang Pathol*.
- Day et al. A PROMIS<sup>®</sup>ing New Measure for Quantifying Emotion Dysregulation in Toddlers and Preschoolers: Development of the Emotion Dysregulation Inventory-Young Child. *J Autism Dev Disord*.
- Kasari et al. Spoken language outcomes in limited language preschoolers with autism and global developmental delay: RCT of early intervention approaches. *Autism Res*.

# Question 5: Services and Supports



- Adams et al. Associations between social activities and depressive symptoms in adolescents and young adults with autism spectrum disorder: Testing the indirect effects of loneliness. *Autism*.
- Brunt et al. The impact of COVID-19 on receipt of health services among children with and without autism. *Autism*.
- Constantino et al. Prospects for Leveling the Playing Field for Black Children With Autism. *J Am Acad Child Adolesc Psychiatry*.
- Feinberg et al. Effect of Family Navigation on Participation in Part C Early Intervention. *Acad Pediatr*.
- Kenworthy et al. Leveraging technology to make parent training more accessible: Randomized trial of in-person versus online executive function training for parents of autistic children. *Autism*.

# Question 5: Services and Supports



- Koffer Miller et al. Feeling intimidated and uncomfortable: Established and exacerbated educational inequities experienced by black parents of autistic children. *Autism Res.*
- Roux et al. Unrealized Cross-System Opportunities to Improve Employment and Employment-Related Services Among Autistic Individuals. *Milbank Q.*
- Schiltz et al. A Longitudinal Mixed-Methods Characterization of Family Support from Adolescence to Young Adulthood in Autism and Other Developmental Disabilities. *J Autism Dev Disord.*
- Stein Duker et al. Sensory Adaptations to Improve Physiological and Behavioral Distress During Dental Visits in Autistic Children: A Randomized Crossover Trial. *JAMA Netw Open.*

# Question 6: Lifespan



- Chan DV, Doran JD. Mental health counseling is rated as most helpful by autistic adults: Service perspectives in adulthood. *Autism*.
- Hughes et al. Individualized Education Programs and Transition Planning for Adolescents With Autism. *Pediatrics*.
- Lai et al. Self-Harm Events and Suicide Deaths Among Autistic Individuals in Ontario, Canada. *JAMA Netw Open*.
- Liu et al. Age-related physical health of older autistic adults in Sweden: a longitudinal, retrospective, population-based cohort study. *Lancet Healthy Longev*.
- Malow et al. Health conditions in autism: Defining the trajectory from adolescence to early adulthood. *Autism Res*.

## Question 6: Lifespan



- Ratto et al. Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. *Autism Adulthood*.
- Schiltz et al. Anxiety, depression, and well-being in autistic adults and adults with other developmental disabilities: A longitudinal cross-lagged analysis. *Autism Res*.
- Strang et al. The Gender Self-Report: A multidimensional gender characterization tool for gender-diverse and cisgender youth and adults. *Am Psychol*.
- Vincent and Ralston. Uncovering employment outcomes for autistic university graduates in the United Kingdom: An analysis of population data. *Autism*.



# Question 7: Infrastructure and Prevalence



- Hughes et al. The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016. *Public Health Rep.*
- Kahn et al. Co-occurring Autism Spectrum Disorder and Gender Dysphoria in Adolescents. *Pediatrics.*
- Sterrett et al. Predictors of Attrition in a Randomized Trial of a Social Communication Intervention for Infant-Toddlers at Risk for Autism. *J Autism Dev Disord.*

# *2023 IACC Summary of Advances:* Next Steps



- Continue to send article nominations to ONAC
- Final nominations will be discussed at the January 2024 IACC meeting



# Lunch Break



Please scan the lunch option QR code on the printed agenda for additional lunch options

# Public Comment Session



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

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH

# Oral Public Comments



- Nicole Corrado
- Cheryl Chafos

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/october11/public_comments.pdf)

# Summary of Written Public Comments



100 written public comments were submitted on topics below by the following individuals:

## ***Addressing the Needs of Autistic Individuals with High Support Needs – 37 comments***

- Shaji Haq
- Stacy Dallss
- Wilhelmina Murray
- John Saito
- Kimberly Dick
- Robyn Johnson
- Leslie Lussier
- Brandon Becker
- Jill Escher, National Council on Severe Autism
- Deborah Gill
- Jacqueline Ceonzo
- Jamie Cullen
- Gene Bensinger
- Katherine Durden
- Angela Behrend
- Beth Lambert
- Niria Alvarez
- Karen Lepak
- Raymond Lepak
- Melodie L Sharp
- Alexander MacInnis
- Justine Neely
- Heidi Mann
- Rachel Nathan
- Gauri Govil
- Rebecca Persson
- Alessandra Di Credico
- Darlene Borre
- Linda Cox
- Rosamond Delori
- Rick Grossman
- Jennifer Hayward
- Andrea Roell
- Gretchen Mather
- Amy L
- Adrienne Benjamin
- Nancy Maserejian

# Summary of Written Public Comments



100 written public comments were submitted on topics below by the following individuals:

## ***Research and Service Needs, Resources, and Policy Implications – 14 comments***

- Autistic Teenager, 16-Years-Old
- Anné Hill
- Brittany Daniels
- Rachel Kubiak
- Lisa Cooley
- Gwendolyn Harper
- Kathryn Hedges
- Lean Firestone
- Finn Gardiner, Autistic People of Color Fund
- Christina Augliera
- Daniel Koizumi
- Amanda Tipkemper
- Jim Mavity III
- Tracy Moniz

## ***Research, Services, and Supports for Autistic Adults – 8 comments***

- Brittany Daniels
- Josh Irby
- Ruth Horowitz
- Rick Grossman
- Kris Grenier
- Justin Acta
- Sacha Greer
- Rebecca Derr

## ***Inclusion of Autistic Perspectives in Research – 6 comments***

- Lisa Cooley
- Tanya Shields
- Julie Jones
- Sikiti Toga
- Joshua Susser
- Ashia Ray



# Summary of Written Public Comments



100 written public comments were submitted on topics below by the following individuals:

## ***Employment – 3 comments***

- Rick Grossman
- Abe Shapiro
- Kaitlin  
MartinezHall

## ***Mental Health Research, Services, and Treatment – 4 comments***

- Jess Cox
- Jessica Tschida
- Tosha Brothers
- Cheryl Chafos

## ***The Role of the IACC and the Federal Government – 5 comments***

- Lauren Agoratus
- Anna Gray
- Jennifer Tarbutton
- James Perkins M.D., Ph.D.
- Grace Ogden-Parker

## ***Potential Causes of Autism – 4 comments***

- Donald Sutherland
- Albert Enayati
- Fred Brown
- Maurine Meleck

# Summary of Written Public Comments



100 written public comments were submitted on topics below by the following individuals:

***Increase Autism Acceptance and Reduce Stigma – 2 comments***

- Tony Sandy
- Alice Stobart

***Inclusion of Underrepresented Groups – 5 comments***

- Whitney Voltz
- Amina Ahaddad
- Karina Rodriguez
- Sascha Sealie
- Christine Preimesberger

***Educational Needs and Workforce Training – 1 comment***

- Angie Vigliotti

***Communication and AAC – 1 comment***

- AJ Link, Autistic Self Advocacy Network

***Parent/Caregiver Support Needs – 1 comment***

- Fenna Blue

# Summary of Written Public Comments



100 written public comments were submitted on topics below by the following individuals:

***Concerns about Medical Practices – 7 comments***

- B D
- Abi Bartley
- Bianca DiRuocco
- Elissa Hunt
- Sarah Fox
- Kaitlyn Ballenger
- Mary Mulherin

***Language Regarding Autism – 1 comment***

- Lauren Agoratus

***Needs of the Direct Support Professional Workforce – 1 comment***

- Kate Semple

**Break**



# Autism Mental Health Research: Progress and Needs



# Autism Mental Health Research: Progress and Needs



## **Overview**

Carla Mazefsky, Ph.D.

## **Emotion Dysregulation, Behavior, and Mental Health Across the Autism Spectrum**

Carla Mazefsky, Ph.D.

## **Mental Health, Self Injury and Aggression in ASD**

Matthew Siegel, M.D.

## **Supporting Autistic Individuals with Traumatic Stress Across the Lifespan**

Christina McDonnell, Ph.D.

## **Perspectives from Autistic People, Parents, and Clinicians: Mental Health Interventions and Areas of Need**

Kelly Beck, Ph.D., L.P.C., C.R.C.

# Mental Health in Autism: Introductory Opening Remarks

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Interagency Autism Coordinating Committee  
*October 2023*

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Carla A. Mazefsky, PhD  
Nancy J. Minshew Endowed Chair in Autism Research  
Professor, University of Pittsburgh Psychiatry



Website QR Code

[www.reaact.pitt.edu](http://www.reaact.pitt.edu)



# What is “mental health”?

- Psychiatric disorders
- Aspects of emotional and behavioral well-being (whether part of a secondary diagnosis or not)
  - Emotion dysregulation
  - Self-injury
  - Aggression
  - Suicidality
  - Trauma



“Resilience” by Grace



# How common are psychiatric conditions?

- More common than not!
  - Wide ranges
  - Varies by age range and speaking/IQ ability
  - Inconsistent measurement
  - Challenges in differential diagnosis
- General conclusions
  - Especially common disorders: Anxiety, ADHD, Depression, OCD
  - More prevalent than non-autistic population: Psychosis, Bipolar
  - Such little research, it is hard to say: Substance use, eating disorders



**10%** report physical disability

**20%** report other physical health issues



**70%** lack regular interaction with friends

**75%** have never dated



**80%** lack competitive employment



**80%** do not live independently



**37%** experience suicidal thoughts

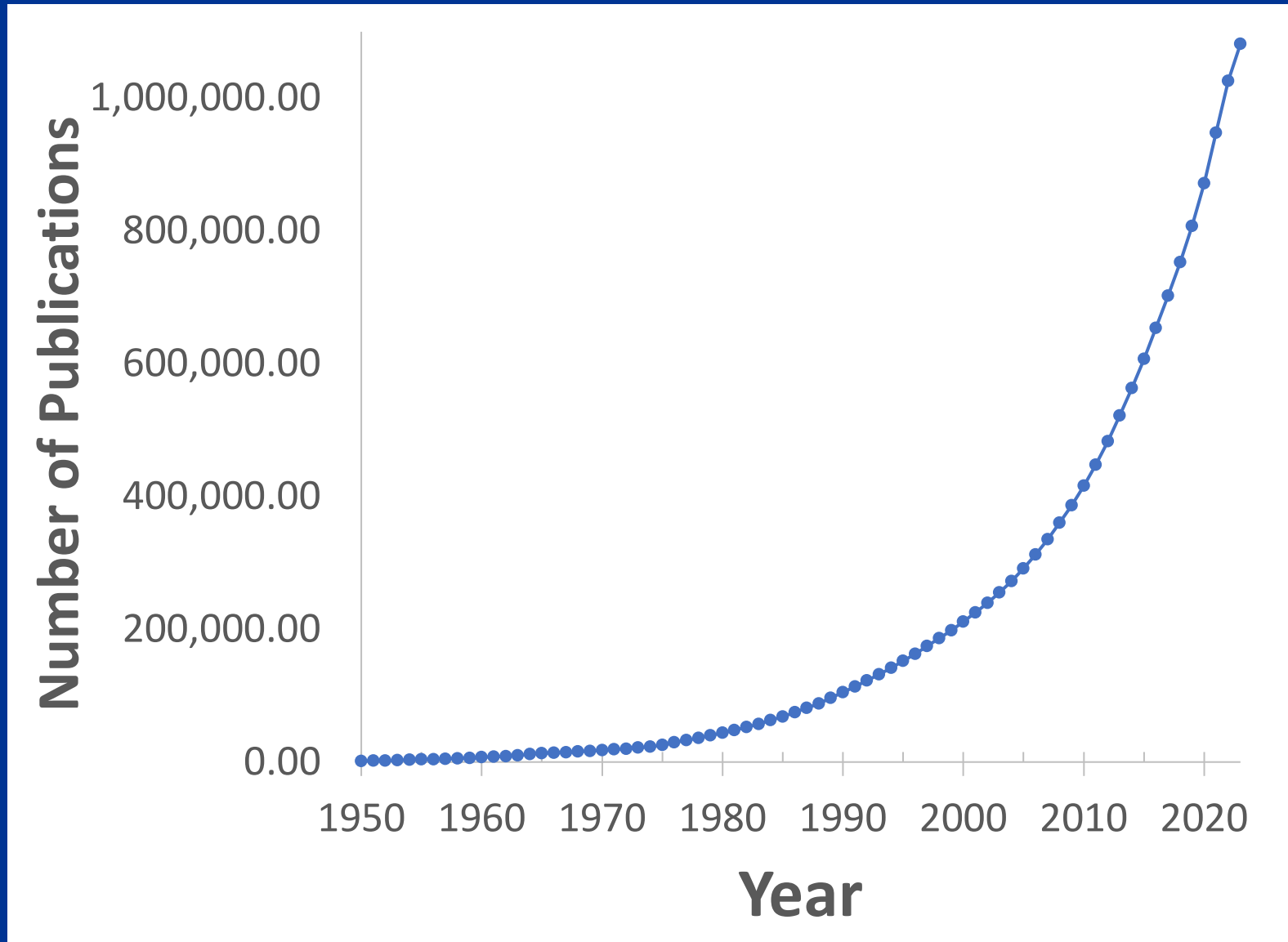


**15%** attempt suicide

Adults on the spectrum have higher physical and mental health problems. There are higher rates of divorce, isolation, homelessness, poverty, police abuse, depression, chronic diseases....  
-IACC Public Comment

**We care about  
mental health  
because it  
impacts every  
aspect of life**

# Progress and momentum!

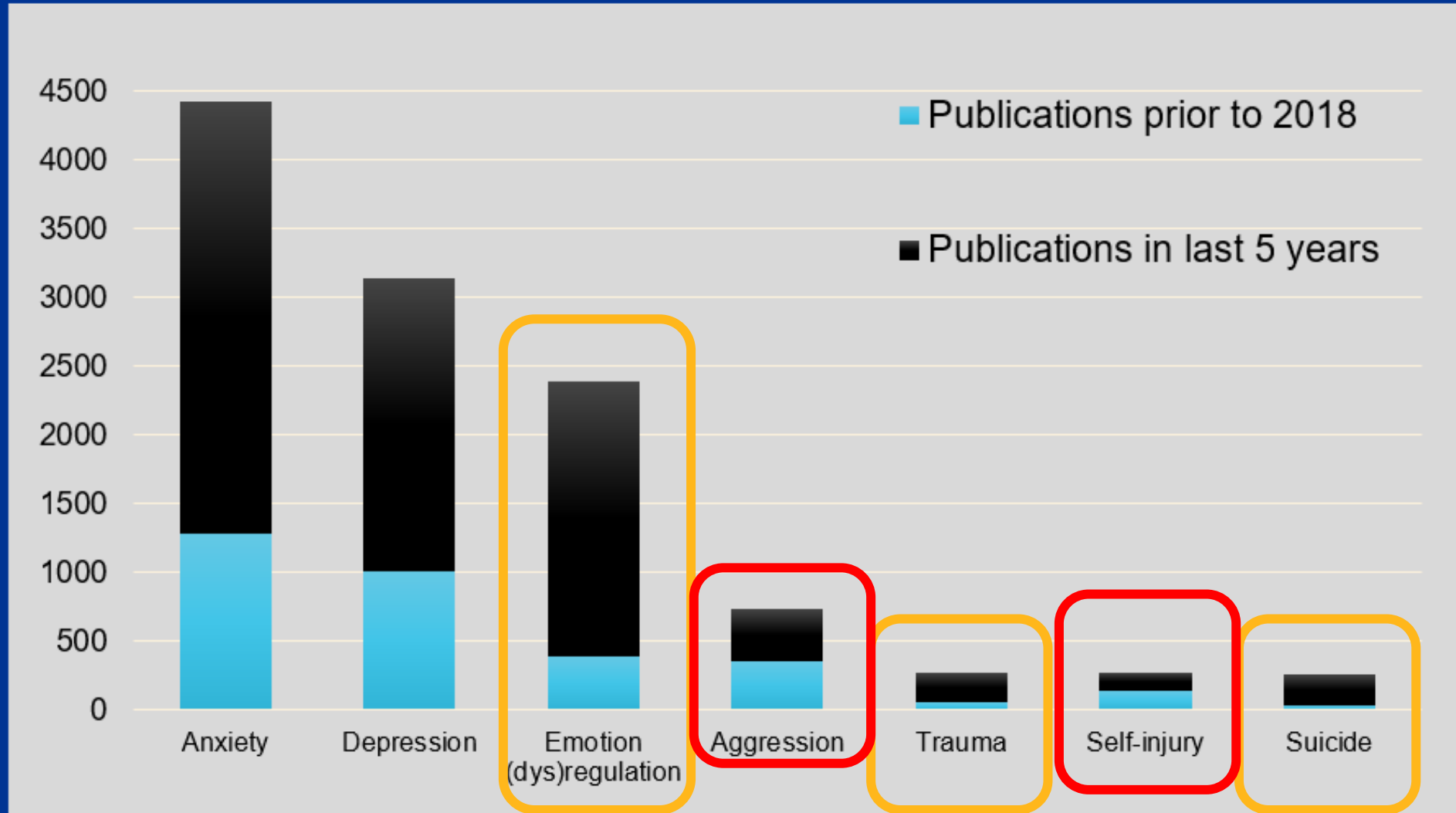


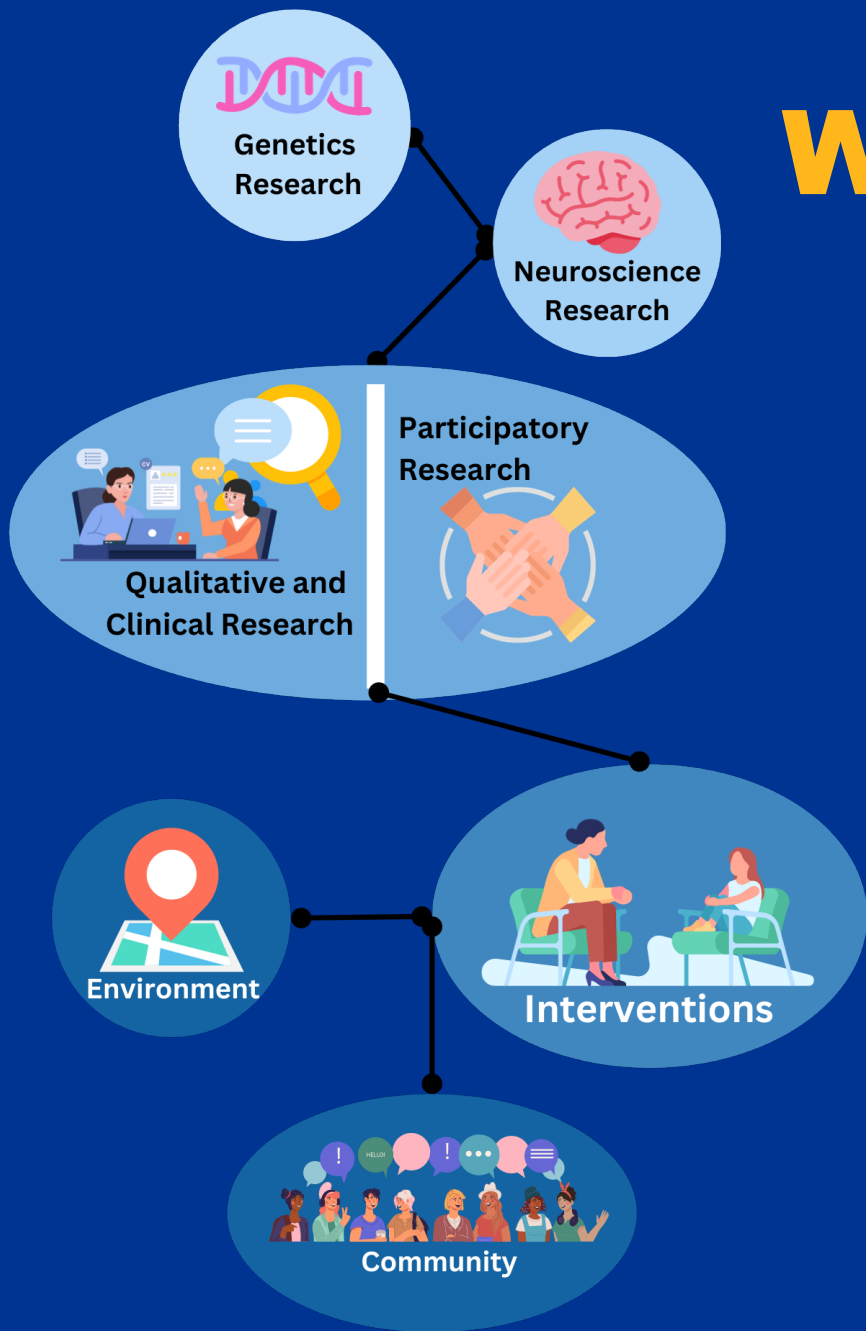
## Search Terms:

Autism +

- mental health
- psychiatric disorder
- anxiety
- depression
- emotion (dys)regulation
- self-injury
- aggression
- trauma
- suicide

# Progress By Topic and Timing





# We are not there yet

- Research needs to be more representative of the diversity in autism
  - All IQ and speaking abilities
  - All racial, ethnic, and gender identities
  - The full lifespan
- Mental health research should incorporate a range of methods and fully consider all perspectives and potential influences



# Urgent need to translate into practice

“My 27-year-old daughter [...] suffers acutely from emotional dysregulation (manifesting through meltdowns, self-injurious behavior and suicidality) that no one [...] seems to know how to treat. My daughter has been hospitalized many times, and medicated heavily, [...]. We have looked extensively, but both the hospital-based and the community-based DBT and CBT programs [...] have uniformly told us either that they don't accept patients with an ASD diagnosis, or that CBT/DBT “cannot be used with autistic patients”.

# Now, onto...

- Research talks on topics that have received relatively limited attention thus far
- Community perspectives
- Then, later, services and programs

It's not always easy, but any mountain can be climbed.

Any mountain can be climbed

Forewell

By an autistic teen after completing our clinical trial



## Regulation of Emotion in Autistic Adults, Children, & Teens

**Mission:** *Conduct research that will improve mental health & well-being for autistic people across the lifespan*

[www.reaact.pitt.edu](http://www.reaact.pitt.edu)

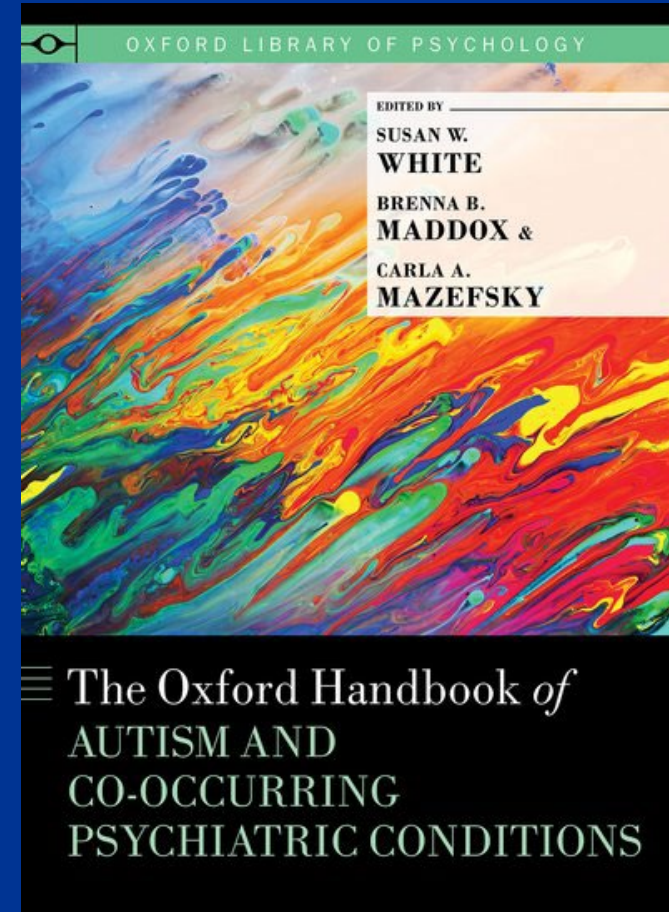




# Disclosures

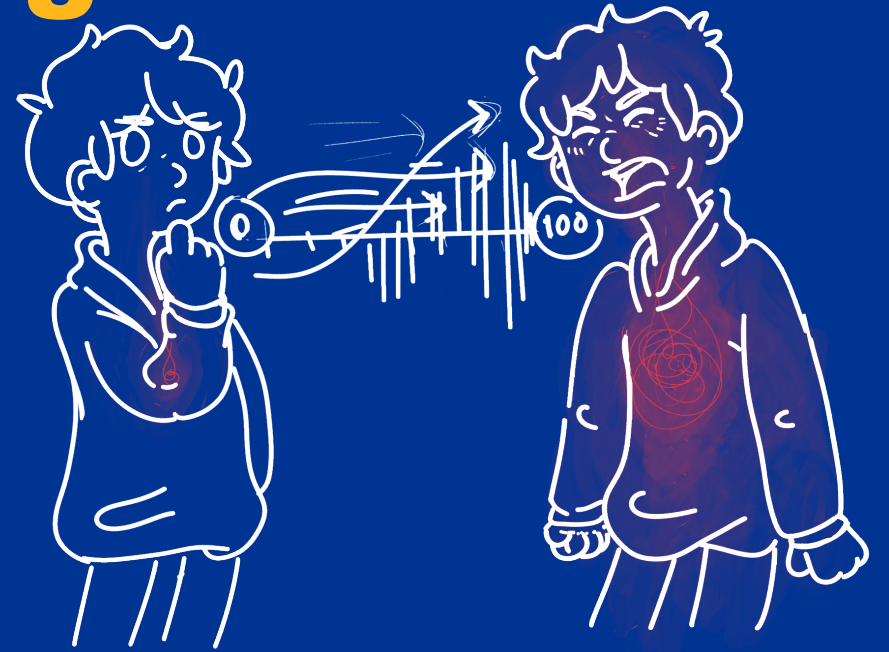
- GRANT FUNDING:

- INSAR Ritvo-Slifka Award for Innovation in Autism Research
- NICHD R01HD079512
- NICHD R01HD100302
- US Department of Defense W81XWH-18-1-0284
- HRSA ATN AIR-P UA3 MC 11054
- Autism Speaks 11923
- The Edith L. Trees Charitable Trust
- PA Department of Health
- NIMH P50 MH130957
- PCORI IDD-2022C1-26418
  
- SFARI 296318 & NLM Family Foundation (PI Siegel)
- National Science Foundation IIS 1844885 (PI Akcakaya)
- NIMH R01MH119172 (PI Foss-Feig)
- KL2 TR001856 (PI Beck)
- K23 MH127420 (PI Northrup)



# What is emotion dysregulation?

- Difficulty changing or controlling strength or length of emotional response
- Interferes with ability to meet goals



“I feel trapped. I have a weird tension in my head or my arms I want to get out. Everything around me suddenly feels extremely real like I’ve just come out of the water, I feel all sorts of emotions all at once and I want to run away from them all. I lose sight of what is socially appropriate and start to say things I either don’t mean or something I’ve wanted to say deep down. Whenever that happens, I end up hurting someone or confusing everyone.”

# We have found that emotion dysregulation is related to:



More depression, anxiety, aggression, and suicidality



Use of more psychiatric medications



Hospitalizations

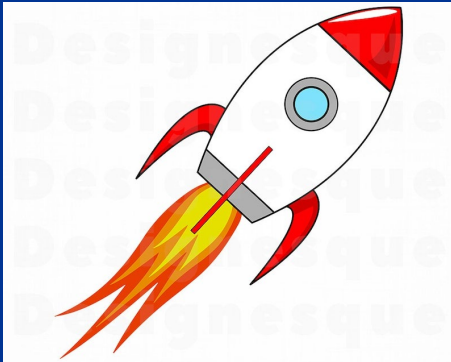


ER visits and police contact



# Emotion Dysregulation Inventory

## Reactivity



**Has explosive outbursts**

**Has extreme or intense emotional reactions**

**Emotions go from 0 to 100 instantly**

**Has trouble calming themselves down**

## Dysphoria



**Does not seem to enjoy anything**

**Not responsive to praise or good things  
happening**

**Seems sad or unhappy**

**Appears uneasy through the day**



**Emotion  
Dysregulation  
Inventory**  
Young Child

Proxy report; Ages 2-5



**EDI**

Proxy report; Ages 6+



**Emotion  
Dysregulation  
Inventory**  
Self-Report

Self-report; Ages 11+

**Validated in autistic  
and non-autistic  
populations**

**Can be used across  
any verbal or  
intellectual ability**

**Sensitive to  
change**

**Has norms and  
clinical cut-offs**

**Brief, efficient, & precise  
- 6 or 7 items!**

**FREE – Request here: [www.reaact.pitt.edu](http://www.reaact.pitt.edu)**

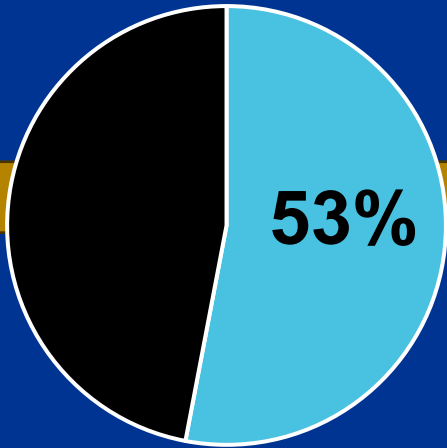
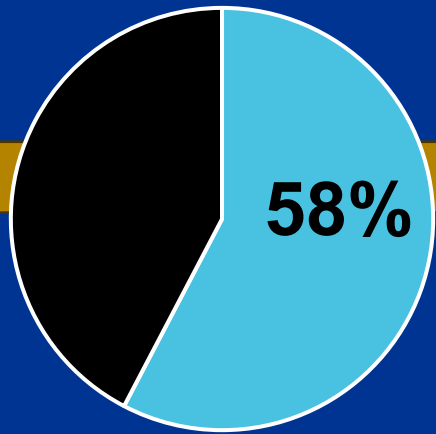


Ages 2-5; N = 853

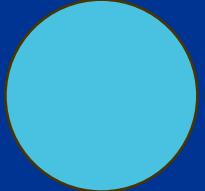


Ages 6-17; N = 1,169

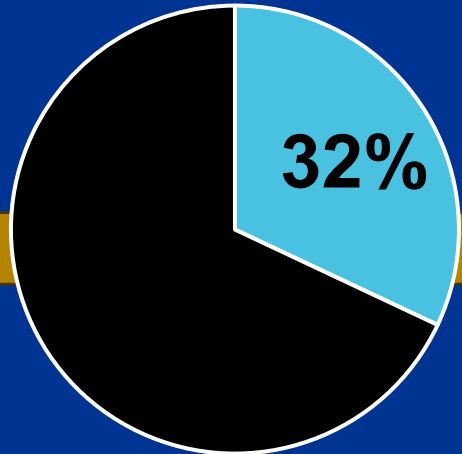
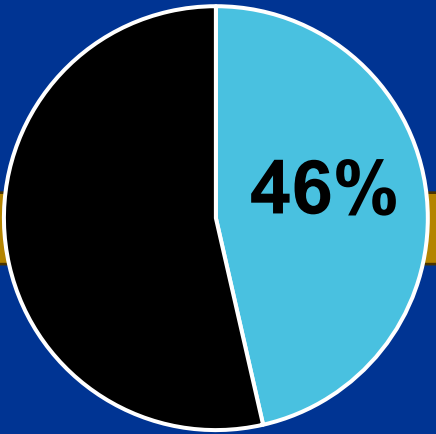
Reactivity



~ 4X more than non-autistic

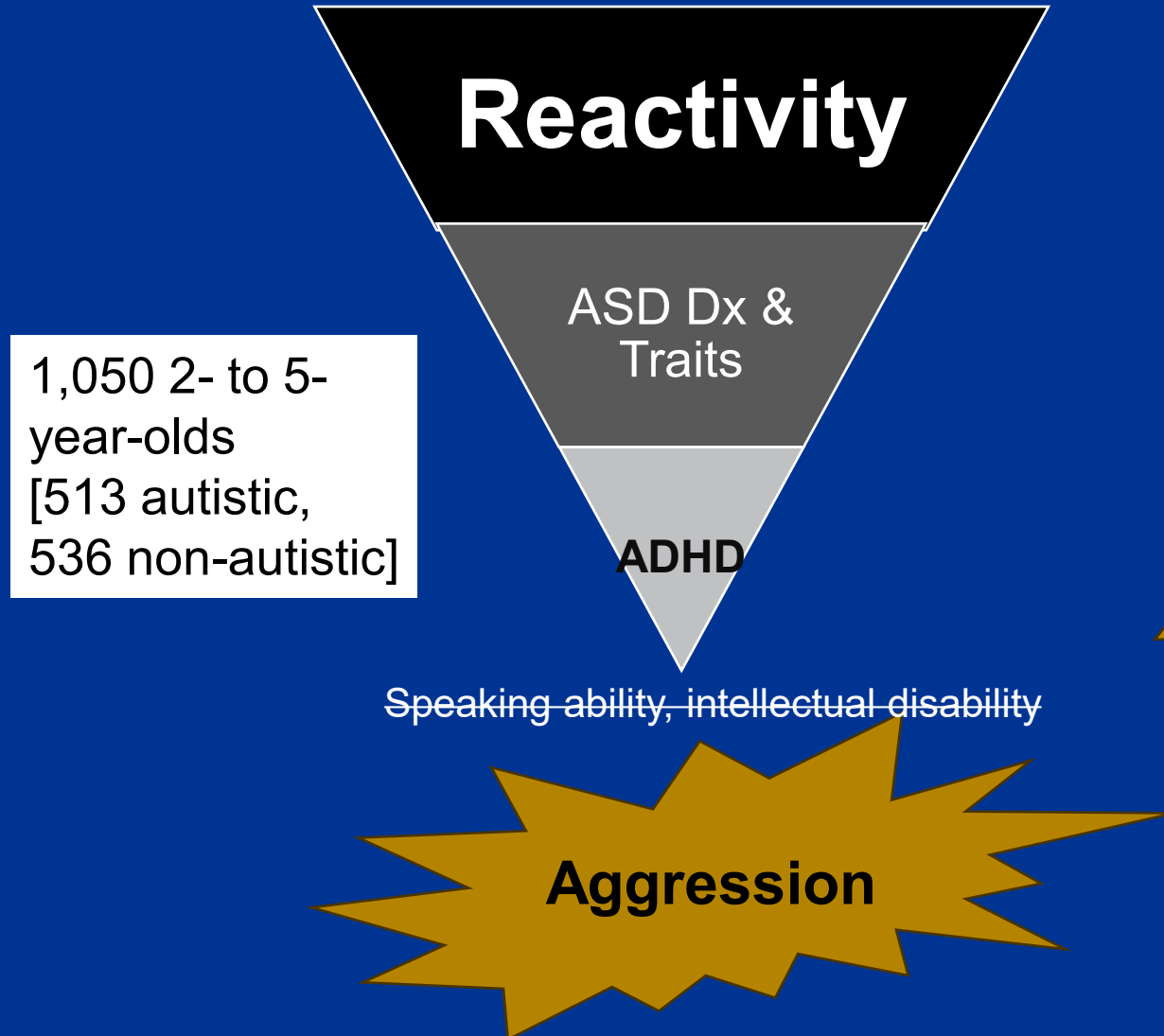
 = Clinically Elevated

Dysphoria

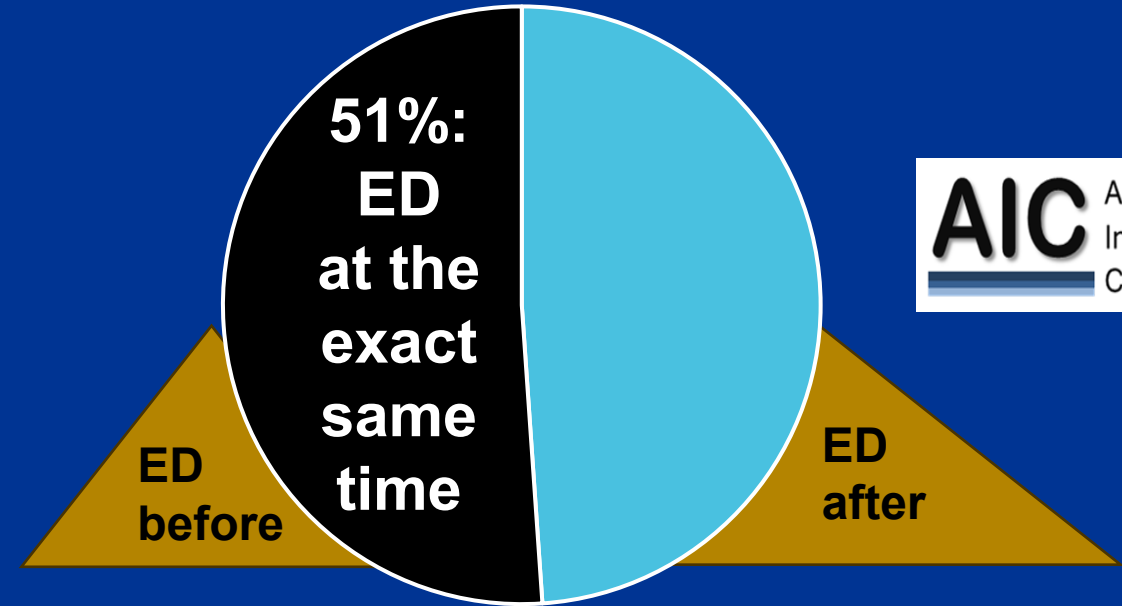


2-3 X more than non-autistic

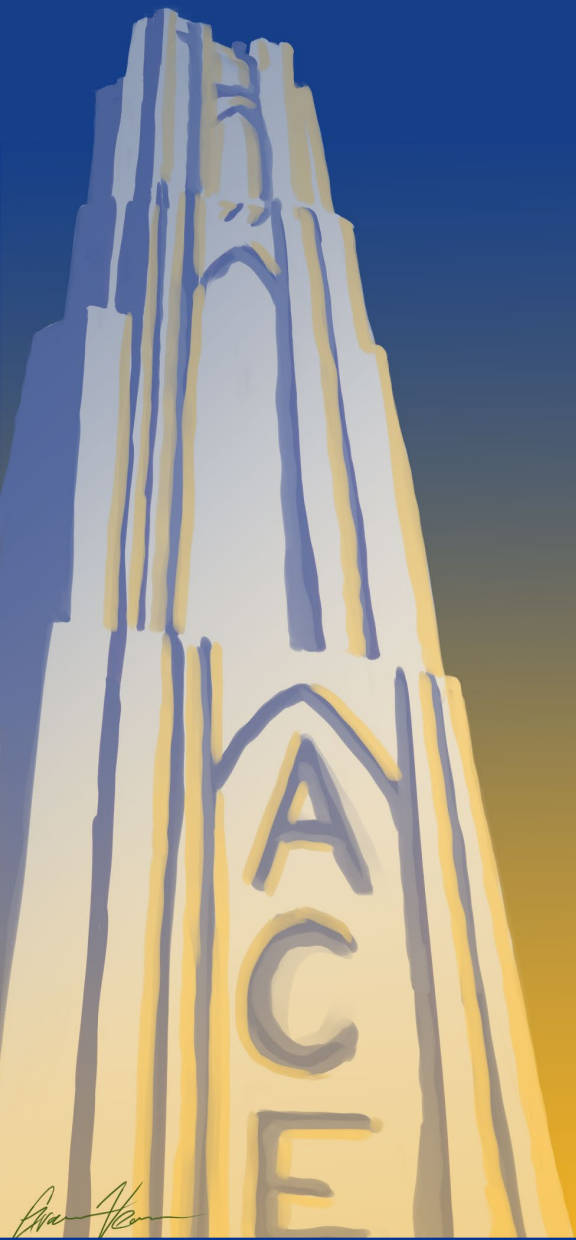
# Strong association with aggression & SIB



## Self-injurious Behavior (SIB)



53 autistic psychiatric inpatients (ages 6-19 years);  
506.55 hours of observation



# Pitt ACE

Autism Center of Excellence

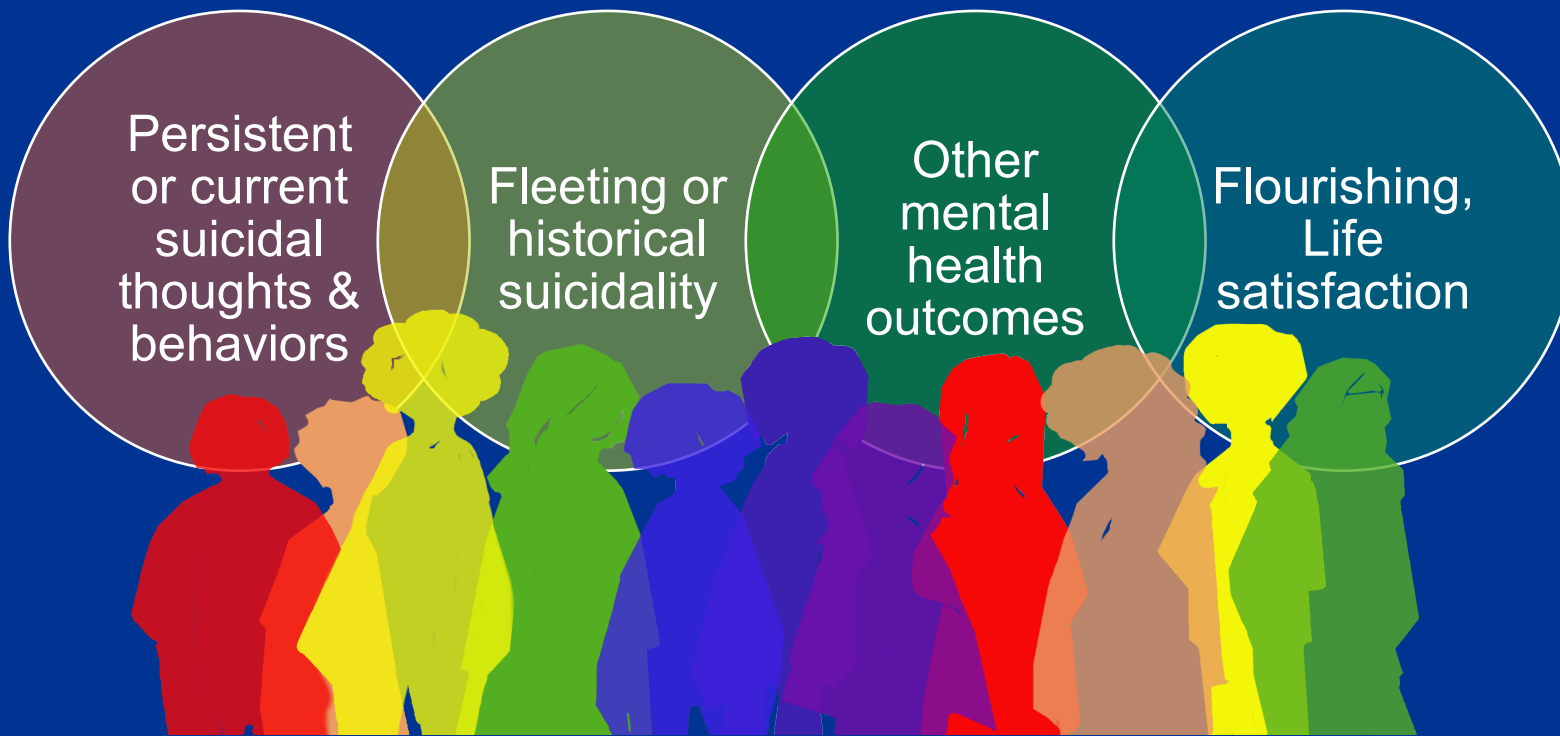
*Advancing research on adult  
mental health & suicide*



# Suicide

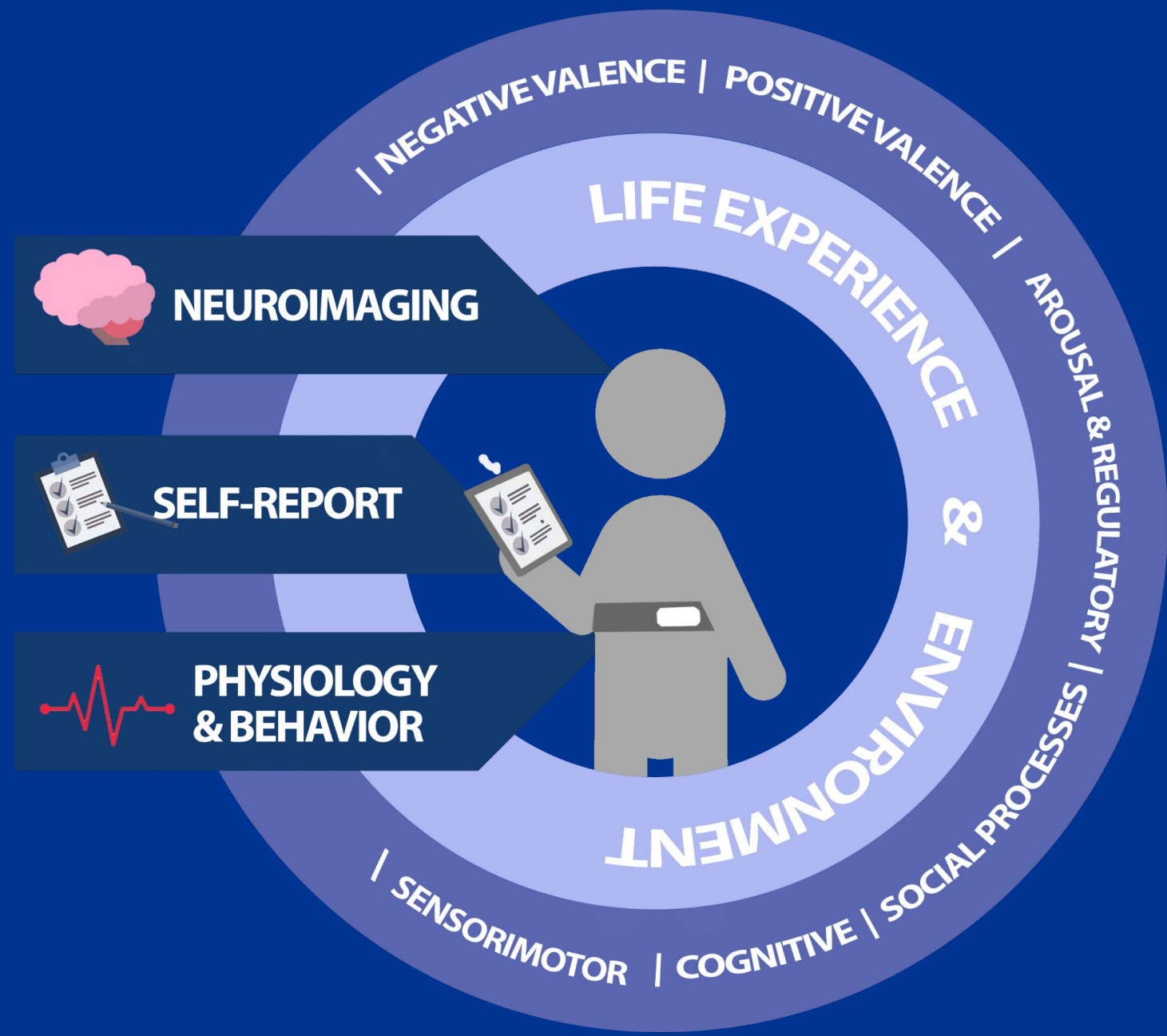
“I hated how everything was so hard for me that was easy for everyone else. And things that were easy for me were not valued. I was miserable and I no longer wanted to be on this earth.”

Focusing on suicide in the context of comprehensive mental health outcomes



# The Pitt ACE is designed to:

Rapidly improve understanding by collecting data **across multiple methods** and many areas of **both individual characteristics and life experiences.**



# Beyond imminent risk

Rate how true the following items are of you on this scale:  
Not at all true, a little bit, somewhat, quite a bit, very much true

The certainty of suicide comforts me

I feel powerless to change or improve my life

I can't think clearly when I am stressed

The option of suicide makes me feel like I have control over my life

When I am overwhelmed, I don't think before acting

I wish more people accepted me for who I am

I am often confused about what emotion I am feeling

I feel like I am screaming inside, and no one knows

I either live in emotional pain or I die; there is no in between for me

I feel like I am pretending to be okay emotionally

I hurt myself to help manage my emotions

Even minor negative emotions make me think about suicide

I make things worse for the people I care about

I work hard to hide how much sensory input bothers me

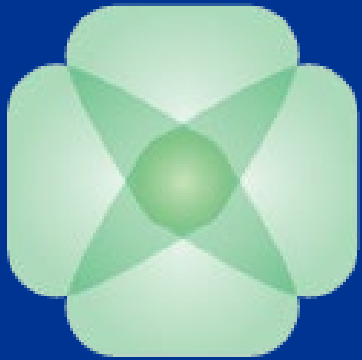
When I am tired, I think about suicide



Team: Autistic adults with and without suicidality, suicide researchers, autism/mental health researchers.

- Examples of items being tested out of 148 possible items.
- Final items will be selected after completion by 1000 autistic adults
- Analyses will identify items that are most tightly linked to suicidality and the least biased.

# Can we improve emotion dysregulation? Yes, we can!



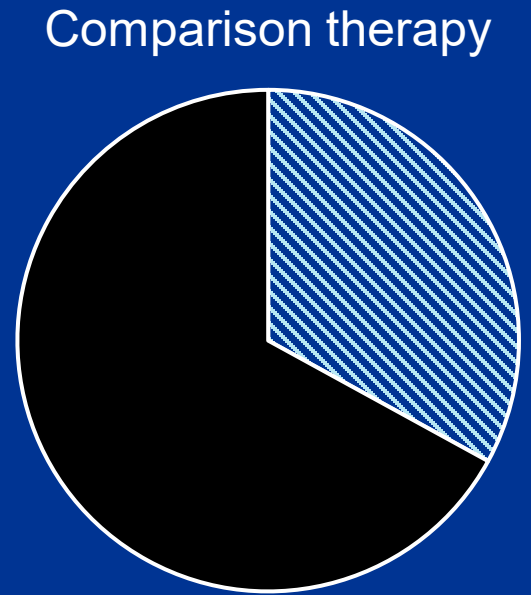
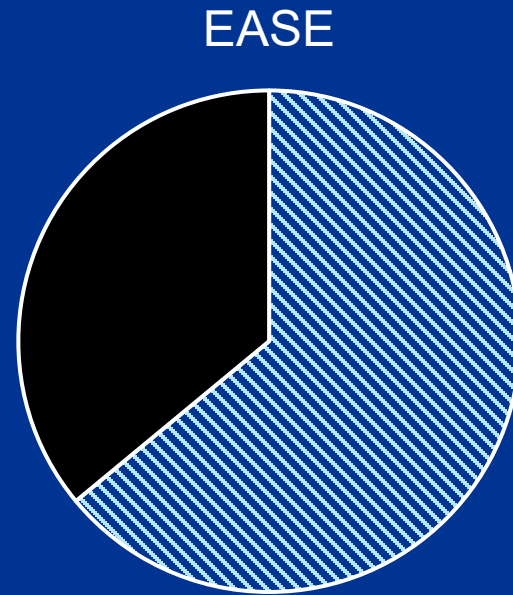
## EASE

The Emotion Awareness and Skills Enhancement Program



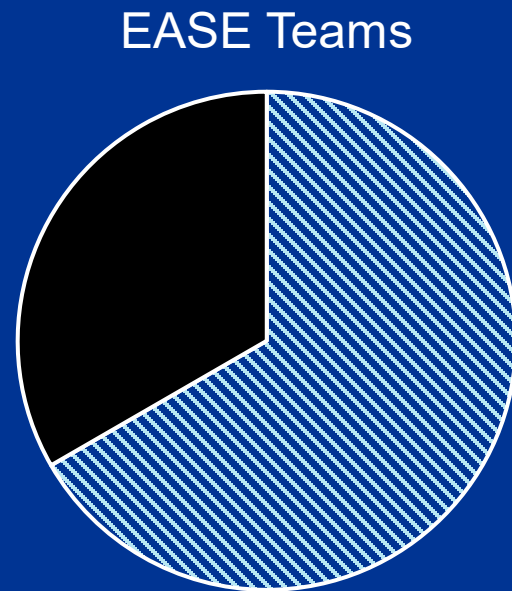
Randomized controlled trial

12-21 years old;  
Verbal IQ > 75



Single arm trial

7-25 years old;  
Non-verbal IQ > 50, speaking not required



# Where we are going



- Early development of emotion regulation
- Test what works in the real world – Combined EASE community effectiveness trial
- ACE – pooling all data to uncover new connections to better understand adult outcomes from suicide to flourishing
- Minority stress in autistic adults
- Interplay between sleep, sensory, & emotion dysregulation
- Self-injury and aggression – narrowing down types
- Identifying markers of distress & developing technology supports

[www.react.pitt.edu](http://www.react.pitt.edu)

## Core REACT Faculty



**Kelly Beck, Ph.D., LPC, CRC »**

Assistant Professor  
beckk12@upmc.edu



**Caitlin Conner, Ph.D. »**

Assistant Professor  
connercm2@upmc.edu



**Carla Mazefsky, Ph.D. »**

REACT Director  
mazefskyca@upmc.edu



**Jessie B. Northrup, Ph.D. »**

Assistant Professor  
northrupjb@upmc.edu



Website QR code

## Early Career Investigators



**Ligia Antezana, Ph.D. »**

T32 Postdoctoral Fellow  
ligiaantezana@pitt.edu



**Safaa Eldeeb, Ph.D. »**

T32 Postdoctoral Fellow  
eldeeb@upmc.edu



**Amy Hartman, Ph.D., OTR/L »**

T32 Postdoctoral Fellow  
agh38@pitt.edu



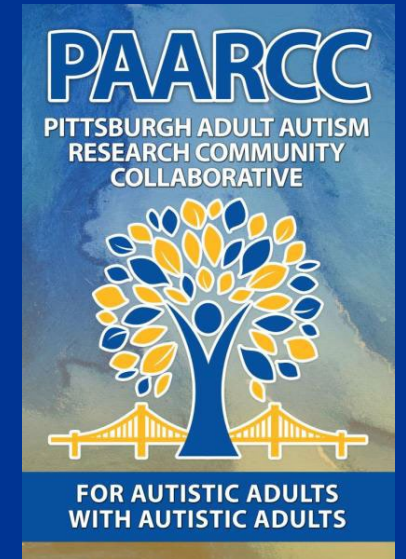
**Kristen MacKenzie, Ph.D., M.S.W. »**

Postdoctoral Associate  
mackenzi@pitt.edu



**Shalini Sivathasan, Ph.D. »**

Postdoctoral Associate  
sivathasans@upmc.edu



# Core REACT Team

[www.react.pitt.edu](http://www.react.pitt.edu)

**Pitt ACE**  
Autism Center of Excellence  
**REACT**

## ACE Leads



**Kelly Beck, Ph.D., LPC, CRC** »  
Assistant Professor  
beckk12@upmc.edu



**Xenia Borue, M.D., Ph.D.** »  
Lead ACE Advisor  
boruex2@upmc.edu



**Lauren M. Bylsma, Ph.D.** »  
Emotions in Daily Life Project Co-Lead  
BylsmaLM@upmc.edu



**Ann D Cohen, Ph.D.** »  
Dissemination & Partnership Core Co-Lead  
cohenad@upmc.edu



**Caitlin Conner, Ph.D.** »  
Assistant Professor  
connercm2@upmc.edu



**Benjamin Handen, Ph.D.** »  
Clinical Core Lead



**Carla Mazefsky, Ph.D.** »  
REACT Director



**Lori N. Scott, Ph.D.** »  
Emotions in Daily Life Project Co-



**Greg Siegle, Ph.D.** »  
Neuroimaging Project Lead

# ACE Lead Investigators & Lead Partners



**Morénike Giwa Onaiwu, Ph.D.**  
»  
ACE Center Advisor  
Staff@AdvocacyWithoutBorders.org



**Camille Proctor** »  
ACE Dissemination and Partnership Core  
camille@thecolorofautism.org



**Luciana M. Randall, M.R.C.** »  
ACE Dissemination and Partnership Core  
lu@autismofpa.org



**Lisa Morgan M.Ed. CAS** »  
Consultant  
lisamorganconsulting@gmail.com



**Jamie Upshaw, MS, MA** »  
ACE Lead Community Engagement Specialist



# Key Collaborators



**Susan W White, PhD, ABPP** »  
EASE Co-Principal Investigator  
swwhite1@ucla.edu



**Matthew Siegel, MD** »  
Autism Inpatient Collection  
Principal Investigator



**Paul A. Pilkonis, Ph.D.** »  
Co-Investigator (ACE, EDI, REALS,  
EXPAND)  
pilkonispa@upmc.edu



**Lan Yu, Ph.D.** »  
Co-Investigator (ACE, EDI, REALS,  
EXPAND)  
lan.yu@pitt.edu



**Helmet T. Karim, Ph.D.** »  
ACE Co-Investigator  
hek26@pitt.edu

Zach Williams, Anne Kirby, Jessica Schwartzman, Christina Nicolaidis, Murat Akcakaya, David Brent, Judy Chang, Valire Copeland, James Kulzer, Oliver Lindhiem

**Staff:** Derica Su, Jacob Semerod, Olivia Boden, Betsy Butler, Mario Crown, Kara Duman, Holly Gastgeb, Laura Greenert, Rachel Harris, Amy Ionadi, Amy Johnston, Annaliese Lausberg, PJ McCarroll, Emily Nettesheim, Autumn Parson, Shelby Parsons, Michelle Perrin, Tyler Sikov, Shannon Sloan, Annabelle Theodat, Katy Zeglen, Kate Breitenfeldt, Jess Vezzoli, Josh Montrenes, Josh Golt, JJ Markiewicz, Trevor Baker, many EASE therapists, and more over time!

**Undergrads:** Elizabeth Rutenburg, Zach Miller, Tanvi Kumar



# Mental Health, Self Injury and Aggression in ASD

**Matthew Siegel, M.D.**

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

**Vice President of Medical Affairs  
Developmental Disorders Service  
Maine Behavioral Healthcare**

# DISCLOSURES PAST 2 YEARS

<b>Research Funding</b>	<b>Consultant</b>
Autism Speaks	U.S. Department of Labor
Maine DHHS	Dayton Children's Hospital
NICHHD	New York State Office of Mental Health
Simons Foundation	Michigan DHHS
Nancy Lurie Marks Family Foundation	
PCORI	

# PREVALENCE OF AGGRESSION AND SELF-INJURY

- **Aggression**

1584 youth  
Autism Treatment Network  
Parent Survey

Is child currently demonstrating  
physical aggression?

53% Yes (Mazurek et al., 2013)

- **Self-Injury**

8065 children  
Autism & Developmental Disabilities  
Monitoring Network (ADDM) (Record review)

27.7% Yes (Soke et al., 2016)

# IMPACT

- Families often report that aggression is **of greater concern and negative impact than the core social and communicative features that define ASD.**
- It increases their stress, isolation, and financial burden, and decreases available support options and access to education, the community, medical and dental treatment and other therapies.

- Hodgetts S, et al. Focus Autism Other Dev Disabl. 2013; 28(3): 166-174  
- Farmer CA, Aman MG. Res Autism Spectr Disord. 2011; 5(1): 317-323.  
- Woodman AC, et al., Dev Psychopathol. 2016; 28(2): 565-581

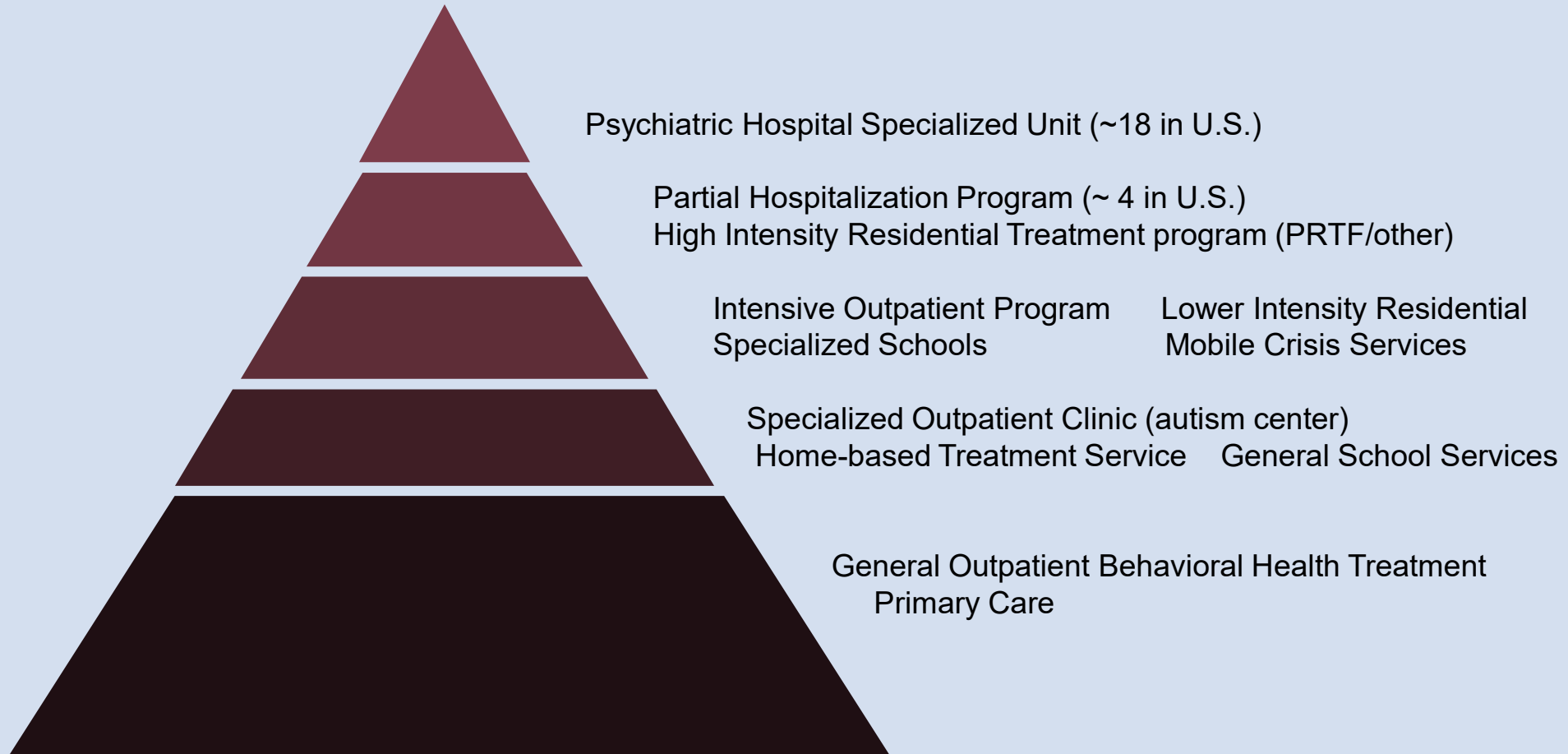
# PARTICULAR CONCERN FOR THE ~30% WITH PROFOUND AUTISM

- **Profound Autism (Lancet Commission, 2021):**
  - Requiring access to an adult 24/7, being unable to be left alone in a residence, and not able to take care of basic daily adaptive needs.
  - Plus/minus:
    - IQ <50, or
    - Minimally verbal (does not have sentences understood by a stranger)
  - 26.7% of those with ASD. Based on IQ and communication. Likely an underestimate as did not measure adaptive functioning.  
(Hughes M, et al., CDC, Public Health Reports, 2023)
- **Aggression more likely** (PR=1.04 95% CI 0.99-1.09)
- **SIB significantly more likely** (PR=1.48; 95% CI 1.41-1.55)

# Aggression/Self-injury Are Final Common Pathway Symptoms



# TREATMENT CONTINUUM IN U.S.

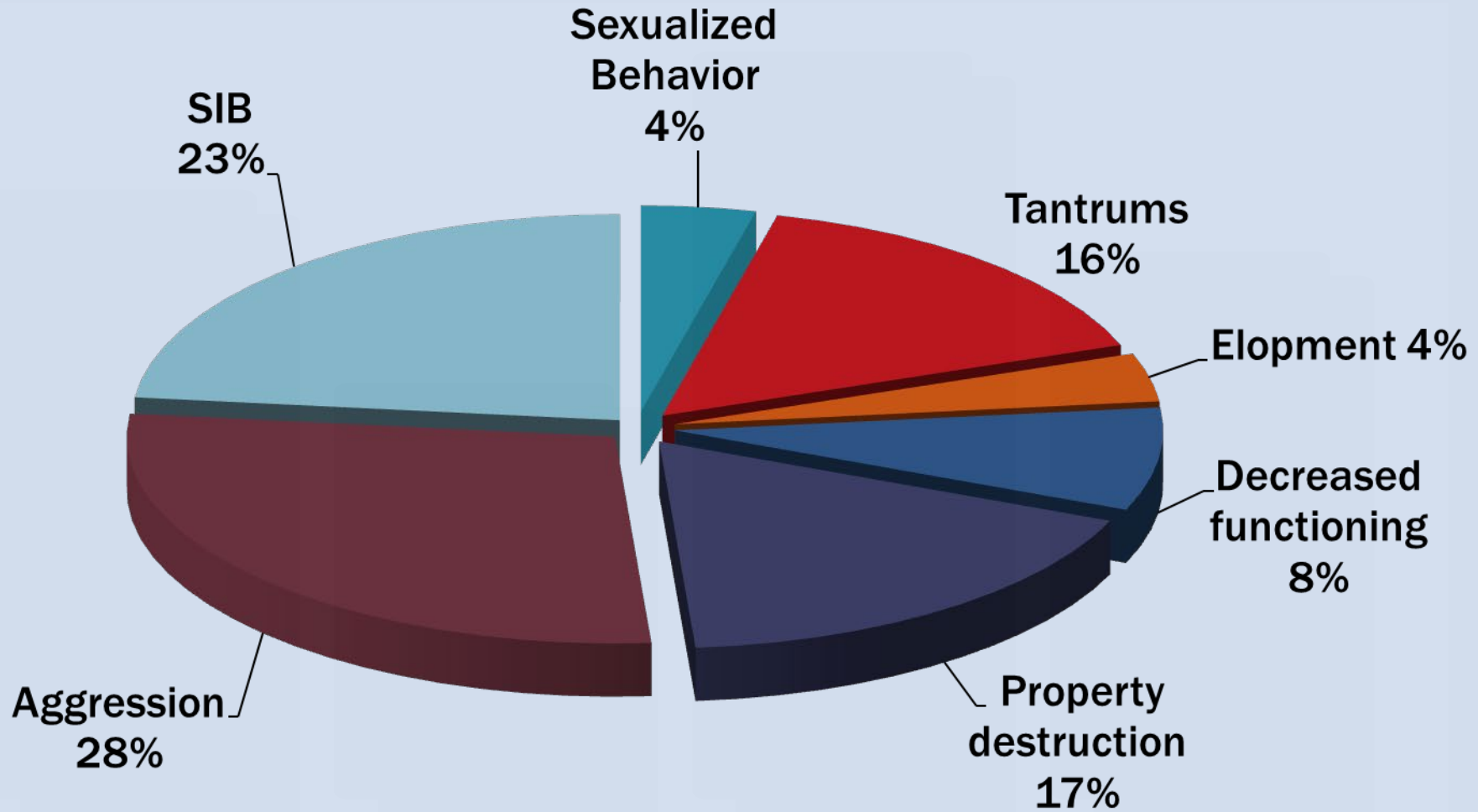


# YOUTH WITH ASD HAVE **VERY** HIGH RATES OF PSYCHIATRIC HOSPITALIZATION

- **11%** have been psychiatrically hospitalized by  
age 21 (Mandell, *Pediatrics*, 2008)
- Study of 33,000 children with ASD. Youth with ASD  
psychiatrically hospitalized at a ratio of **6 : 1** compared to non-  
ASD children.  
(Croen, *Pediatrics*, 2006)



# CHIEF COMPLAINT ON ADMISSION

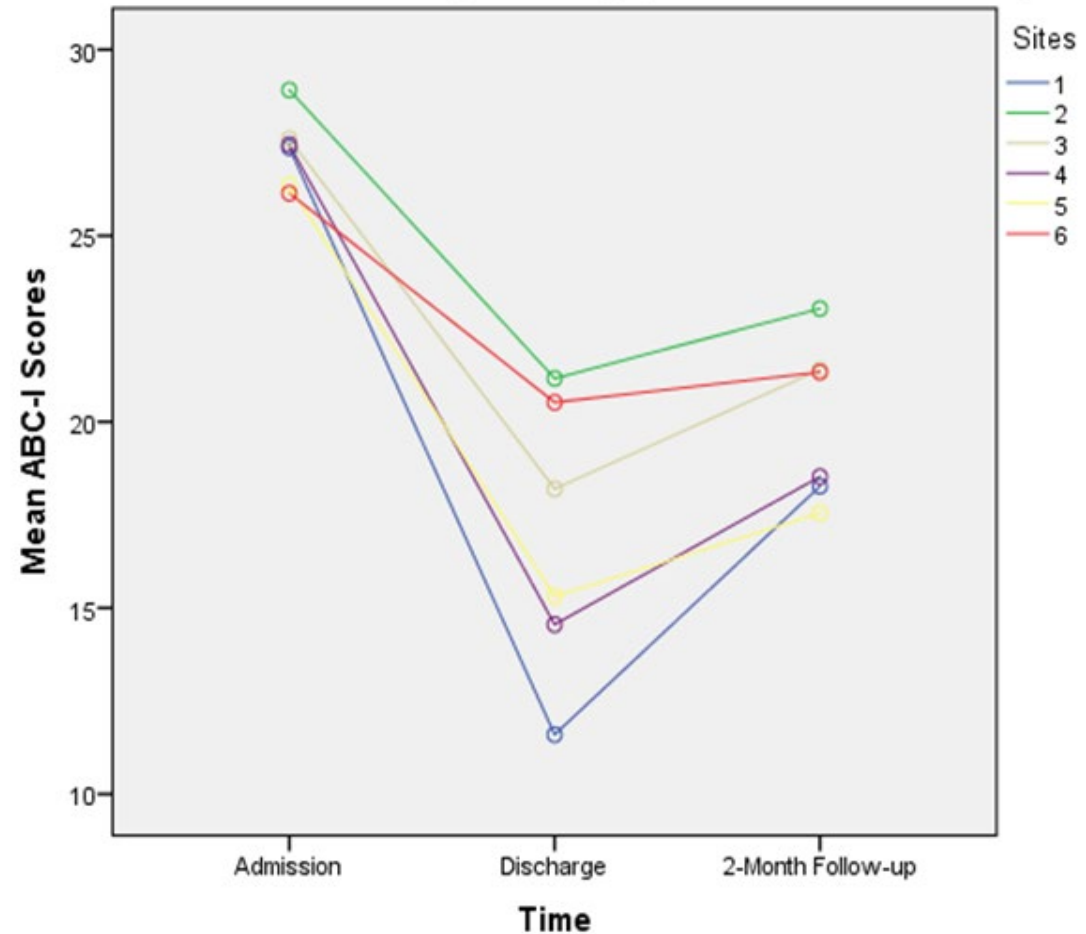


# CHANGE IN AGGRESSION, SELF-INJURY & SEVERE TANTRUMS

## Aberrant Behavior Checklist - Irritability Subscale

n=350 youth  
6 inpatient units

- Admission: 29.7(9.6)
- Discharge: 15.0(10.3)
- 2-Month Follow Up: 19.3(10.3) ( $p \leq 0.05$ )



# SCALABILITY – ASD/ID CARE PATHWAY FOR NON-SPECIALIZED INPATIENT UNITS

## ■ Care Pathway Elements

- Additional Key Information at Admission
- Address basics of toileting, eating, hygiene
- Support predictability with schedules
- Basic positive reinforcement behavior plan
- Offer concrete coping strategies
- Attend to communication

- Average length of hospital stay **decreased 40%**  
(22.4 days to 13.4 days)

- Use of physical holds/restraints **decreased 77%**  
(0.65/day to 0.15/day)

- Kuriakose S, Filton B, Marr M... Siegel M, Horowitz, S, and Havens J, Does an Autism Spectrum Disorder care pathway improve care for children and adolescents with ASD in inpatient psychiatric units? J Autism Dev Disord. 2018 July 3

# COMMON GAPS IN TREATMENT

- Uneven geographic distribution and very limited capacity of specialized services for people with developmental disabilities and aggression/self injury
- Intermediate levels of care rare: partial hospital, intensive outpatient, specialized outpatient clinic
- Most people are seen in primary care or not seen at all.
- Many, many residential treatment centers in the U.S. – very few with significant expertise and there are almost no outcome data.
- Lacking care continuum in most locations

# RESEARCH GAPS FOR AGGRESSION & SELF-INJURY

- Natural History: Vanishingly few longitudinal studies
- Etiology:
  - Early work in novel approaches to aggression and self injury grounded in biological mechanisms and objective measures, such as cardiovascular physiology.
  - Developing validated, clinically practicable diagnostic tools for psychiatric co-occurrence that work across the spectrum.
  - Further parsing functions of behavior – particularly automatically maintained.
  - Relationship of emotion regulation to aggression/self-injury
- Access:
  - Quantifying barriers to access and modifiable factors

# RESEARCH GAPS CONTINUED

## ■ Treatment:

- Controlled group studies of ABA for aggression / self injury
- Controlled group studies of multi-disciplinary treatment packages (e.g.ABA+FCT or ABA+Meds+Parent Training)
- Comparative effectiveness studies of real-world treatment packages (residential treatment)
- Training and implementation of parent training for disruptive behaviors in community, at scale.
- Inclusion of people with profound autism

# DECREASING TREATMENT RESEARCH ATTENTION FOR PROFOUND AUTISM

Journal of Autism and Developmental Disorders  
<https://doi.org/10.1007/s10803-018-3844-y>

ORIGINAL PAPER



## Are Children Severely Affected by Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature

Amy Stedman<sup>1</sup> · Briana Taylor<sup>2</sup> · Michael Erard<sup>2</sup> · Christine Peura<sup>2</sup> · Matthew Siegel<sup>1,2,3,4</sup>

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### Abstract

Despite significant advances in autism research, experts have noted that children severely affected by autism spectrum disorder (ASD) appear to have been understudied. Rigorous analysis of this observation has been limited, and the representation of severity has not been well-described. We assessed three domains of severity (communication ability, cognitive functioning, and adaptive functioning) in 367 treatment studies of children with ASD published 1991–2013. We found that the proportion of studies that included the severely affected population decreased significantly over time, as well as wide variability in measurement and reporting. Inadequate representation of the full autism spectrum in the literature could lead to an unbalanced picture of ASD and leave behind those with arguably the greatest need.

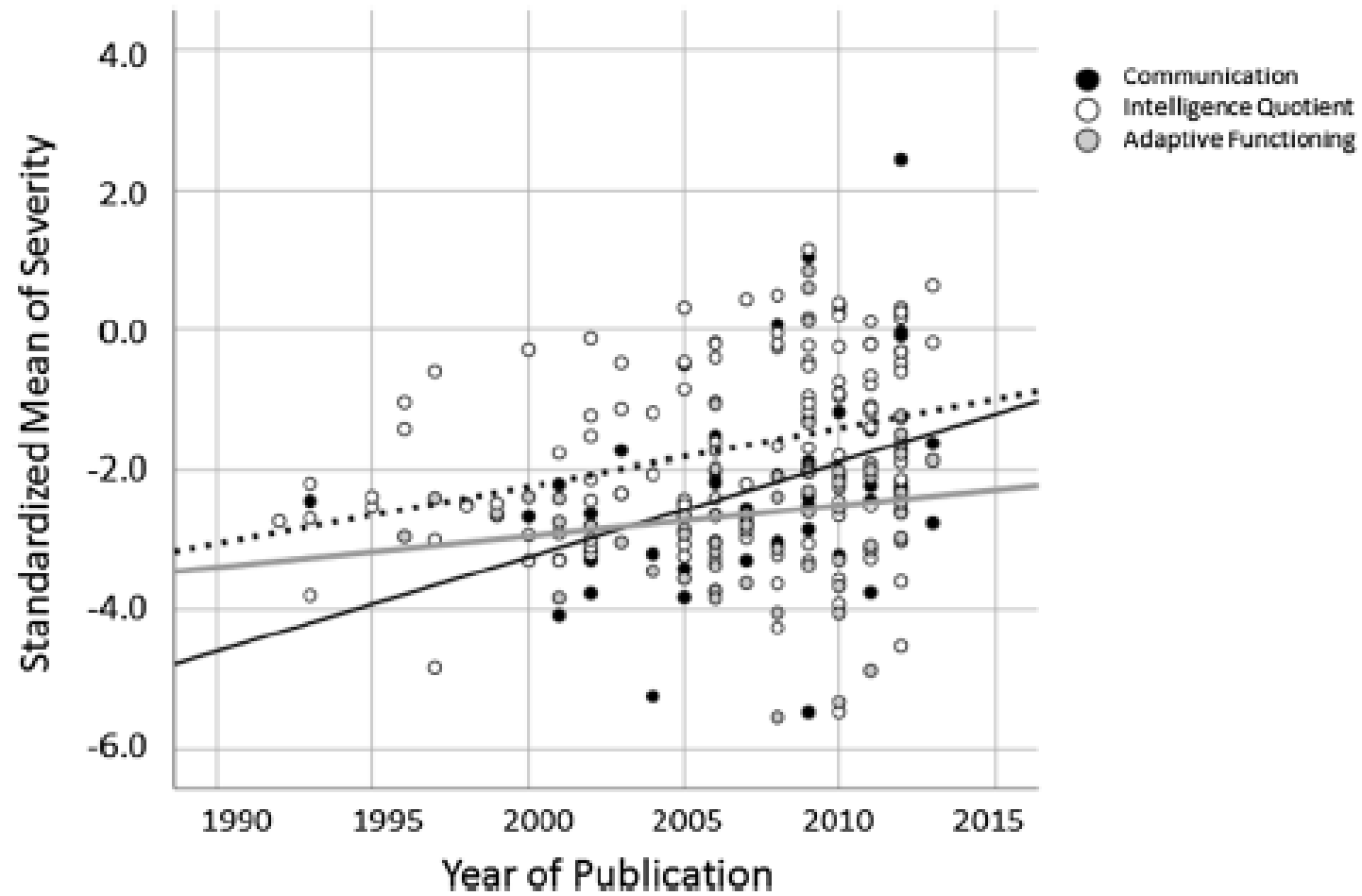
**Keywords** Autism · Severely affected · Communication · Cognitive

### Introduction

There has been an explosion of research in the field of

from the research literature seems to be at risk of bias toward the higher functioning end of a spectrum of impairments.

This important observation—that certain subsets of the





# ACKNOWLEDGEMENTS

## Co-Investigators

- Carla Mazefsky, PhD, University of Pittsburgh
- Robin Gabriels, PsyD., Children's Colorado
- Martine Lamy, MD, PhD, Cincinnati Children's
- Karen Bearrs, PhD, Seattle Children's
- Wayne Fisher, PhD, Rutgers
- Henry Roane, PhD, SUNY Upstate
- Eric Butter, PhD, Nationwide Children's



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- Susan Santangelo, Sc.D., Co-Investigator
- Kahsi A. Pedersen, Ph.D., Methodology/Statistics
- Melanie Houchell, Research Program Director
- Ellyn Touchette, BA, Data Coordinator
- Nicki Goldfeder, BA, Research Coord.
- Talia Greene, BA, Research Coord.



THE NANCY LURIE MARKS FAMILY FOUNDATION

*Fostering Knowledge and Community for Autism and Beyond*

**THANK YOU**



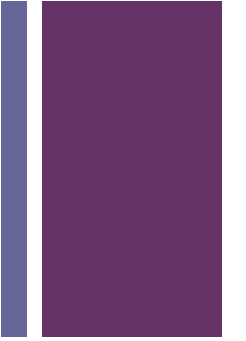
# Supporting Autistic Individuals with Traumatic Stress Across the Lifespan

Christina McDonnell, PhD (she/her)  
Assistant Professor  
[christina.mcdonnell@uwyo.edu](mailto:christina.mcdonnell@uwyo.edu)



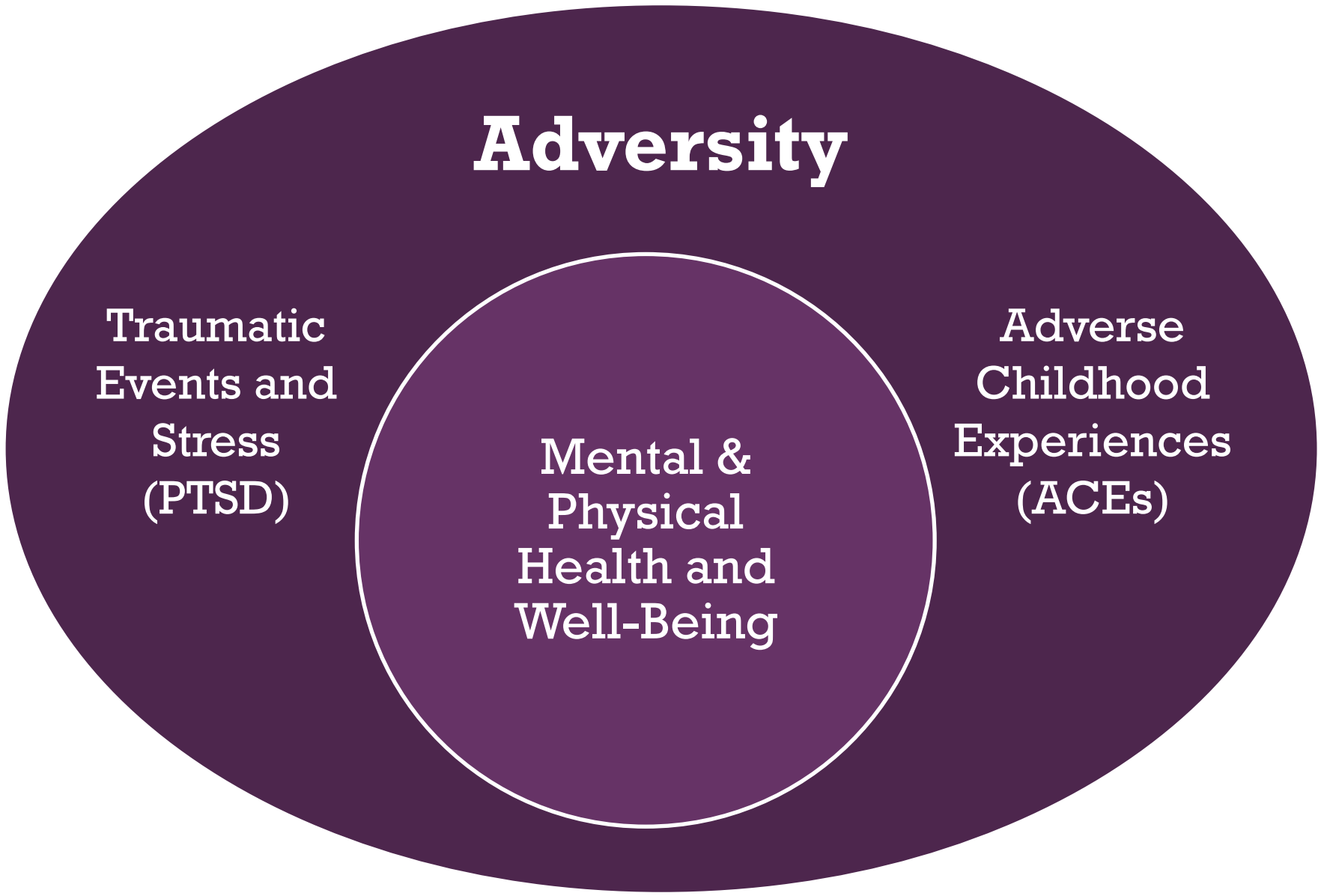
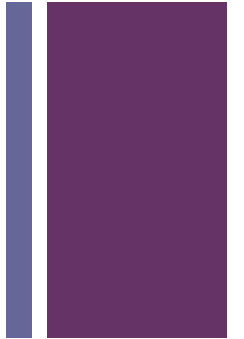
UNIVERSITY  
OF WYOMING

*Note.* We use identity-first (i.e., autistic person) language throughout this presentation (Bottema-Beutel et al., 2021; Kenny et al., 2014), and recognize and affirm language preferences that may differ.

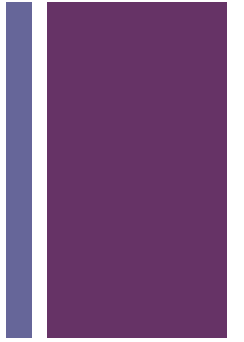


**Adversity**

Mental &  
Physical  
Health and  
Well-Being



# + Today's Outline



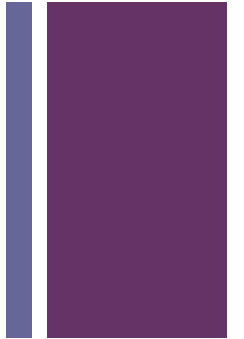
1. Basic research on traumatic experiences among Autistic individuals across the lifespan
2. Program development
  - Trauma-focused cognitive behavioral therapy (TF-CBT) via telehealth for Autistic youth
  - Written Exposure Therapy (WET) via telehealth for Autistic adults
3. Future directions

# + Today's Outline

1. Basic research on traumatic experiences among Autistic individuals across the lifespan
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# Prevalence of Maltreatment in Autism and Intellectual Disability



- 4,988 children identified through South Carolina Autism and Developmental Disabilities Monitoring Network (SC-ADDM), including 607 Autistic youth
- Public maltreatment data linkage with South Carolina Department of Social Services

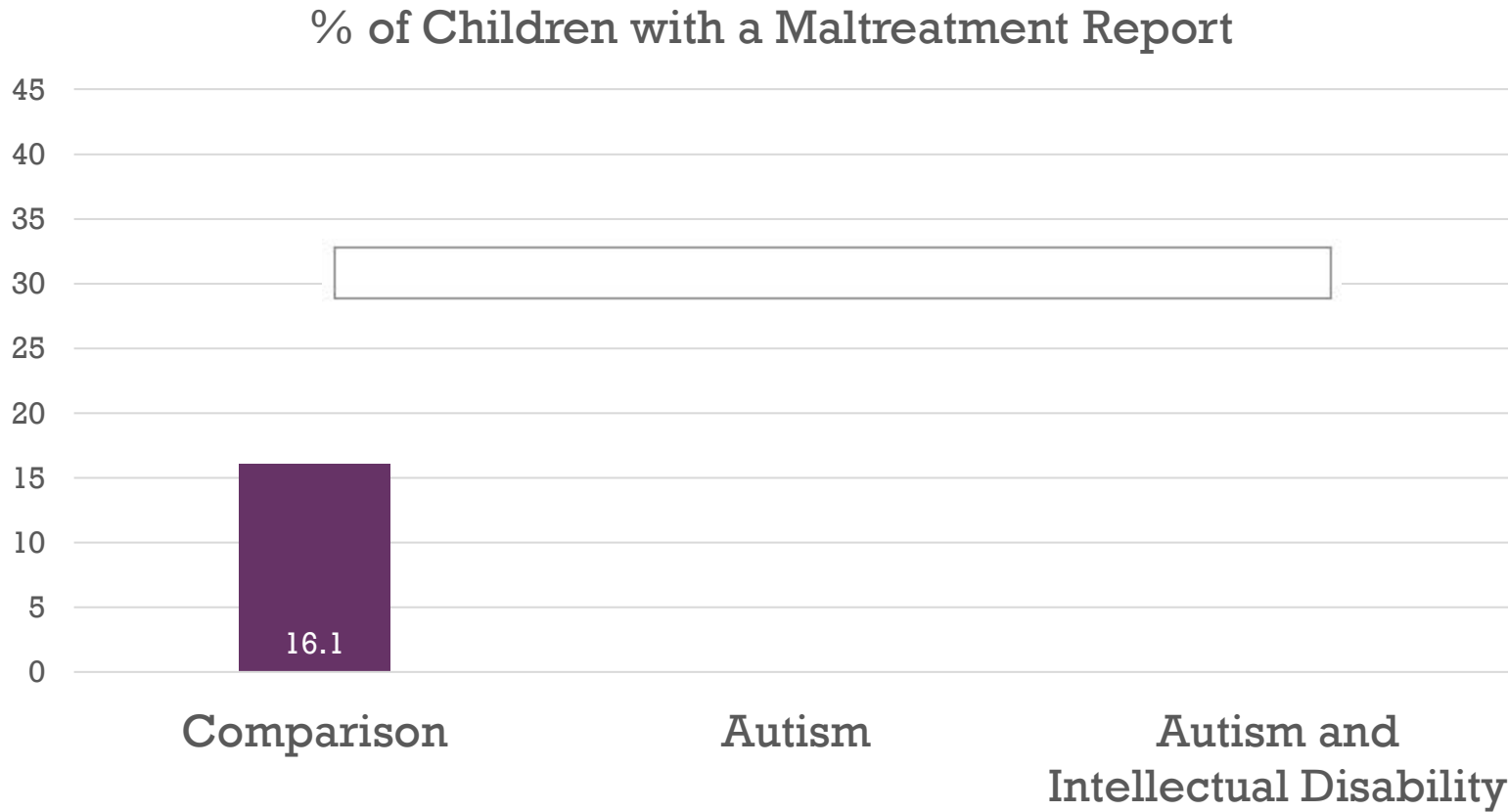
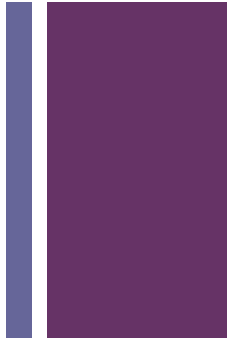


**McDonnell** et al. (2019), *Journal of Child Psychology & Psychiatry*



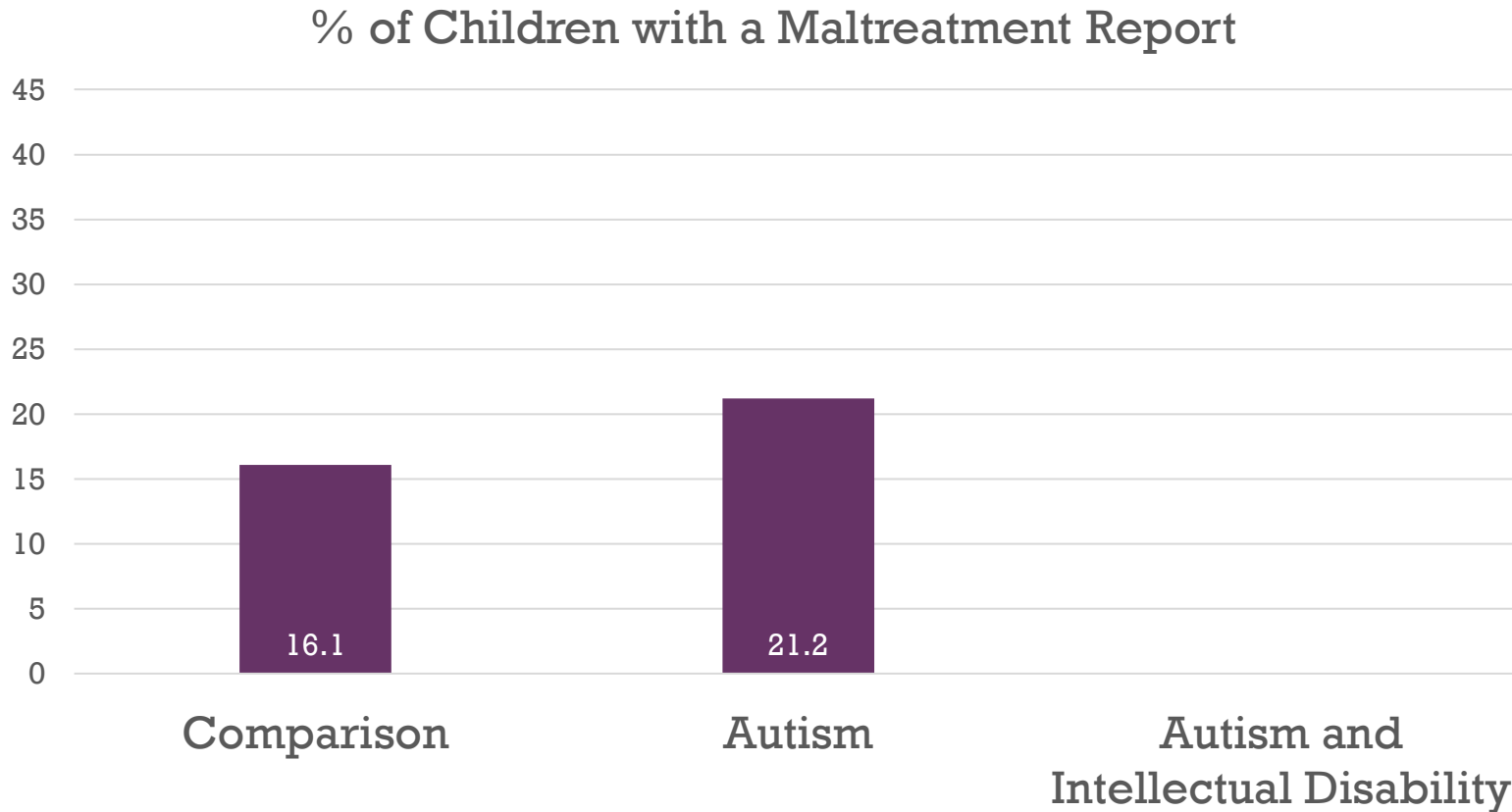
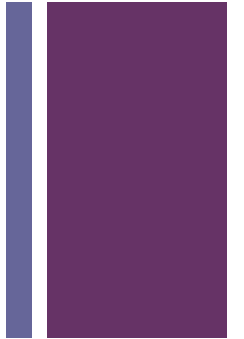


# Elevated Rates of Abuse and Neglect



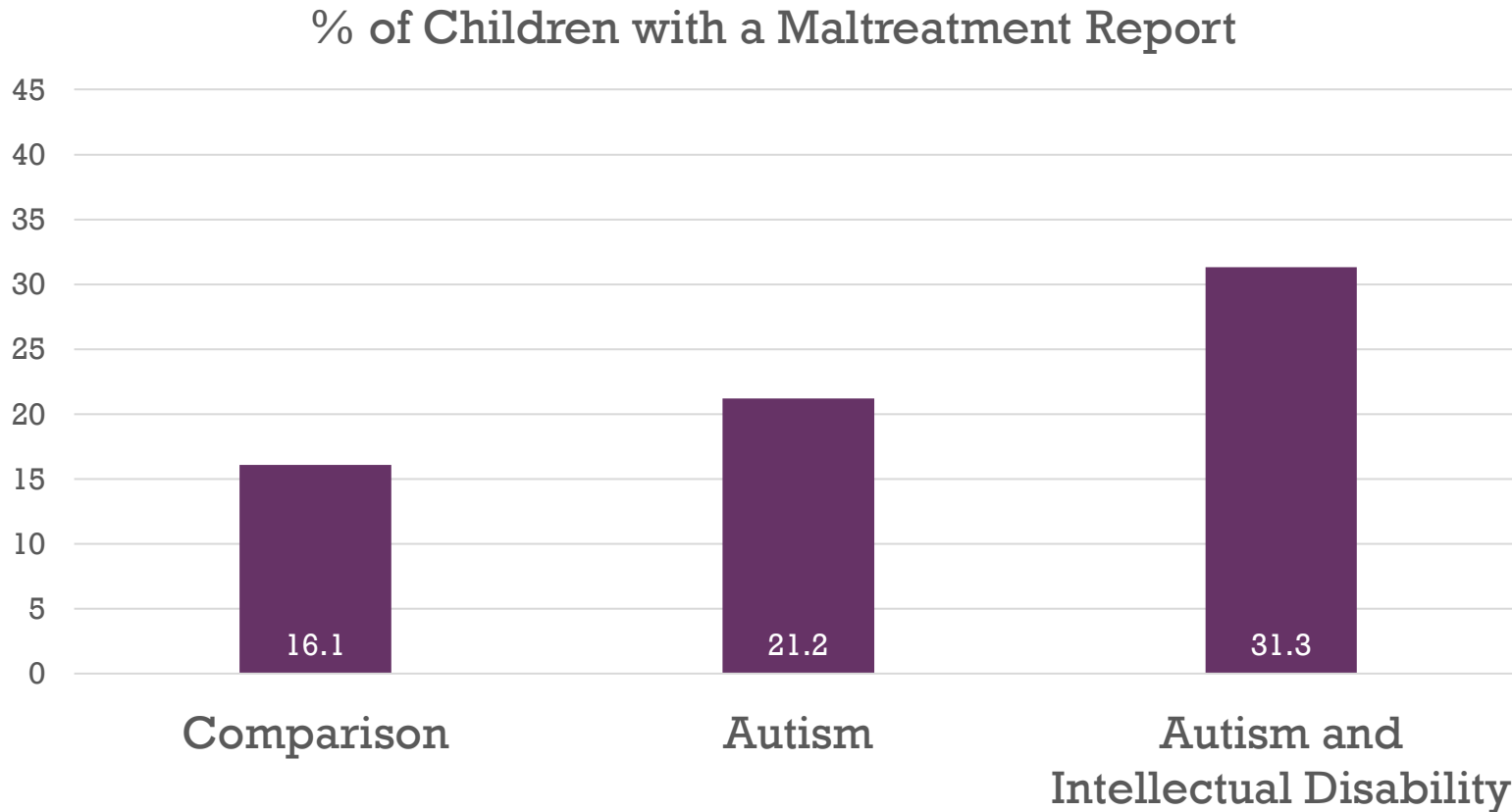
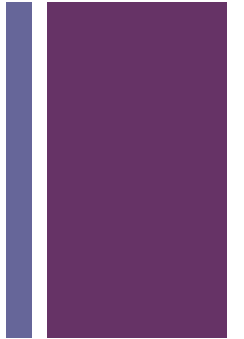


# Elevated Rates of Abuse and Neglect





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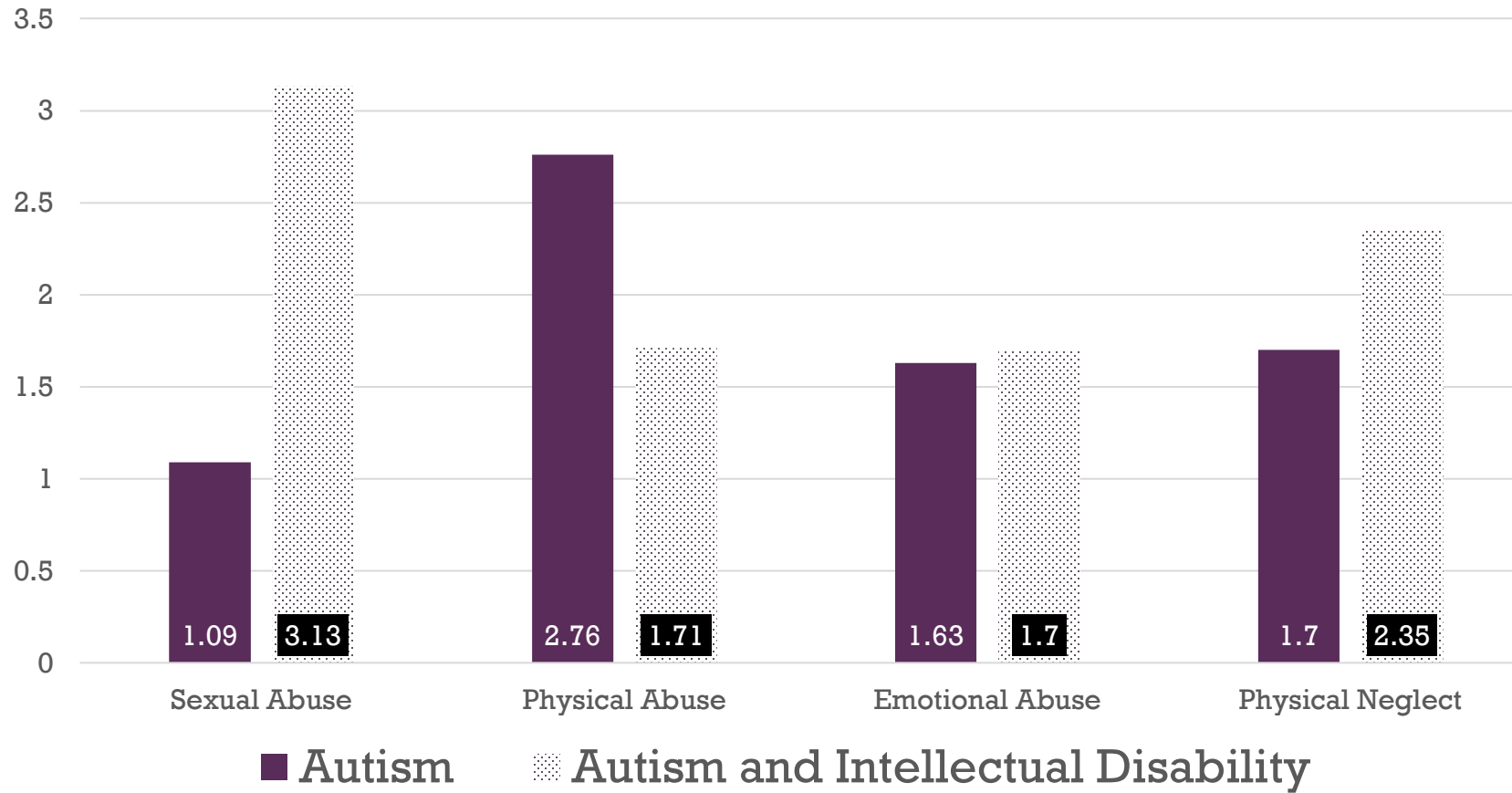


**McDonnell** et al. (2019), *Journal of Child Psychology & Psychiatry*



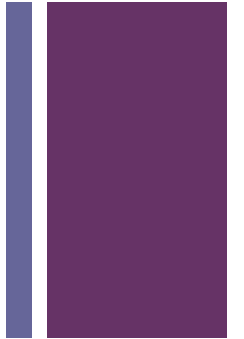
# Elevated Rates of Abuse and Neglect

Odds Ratios Relative to Comparison Group

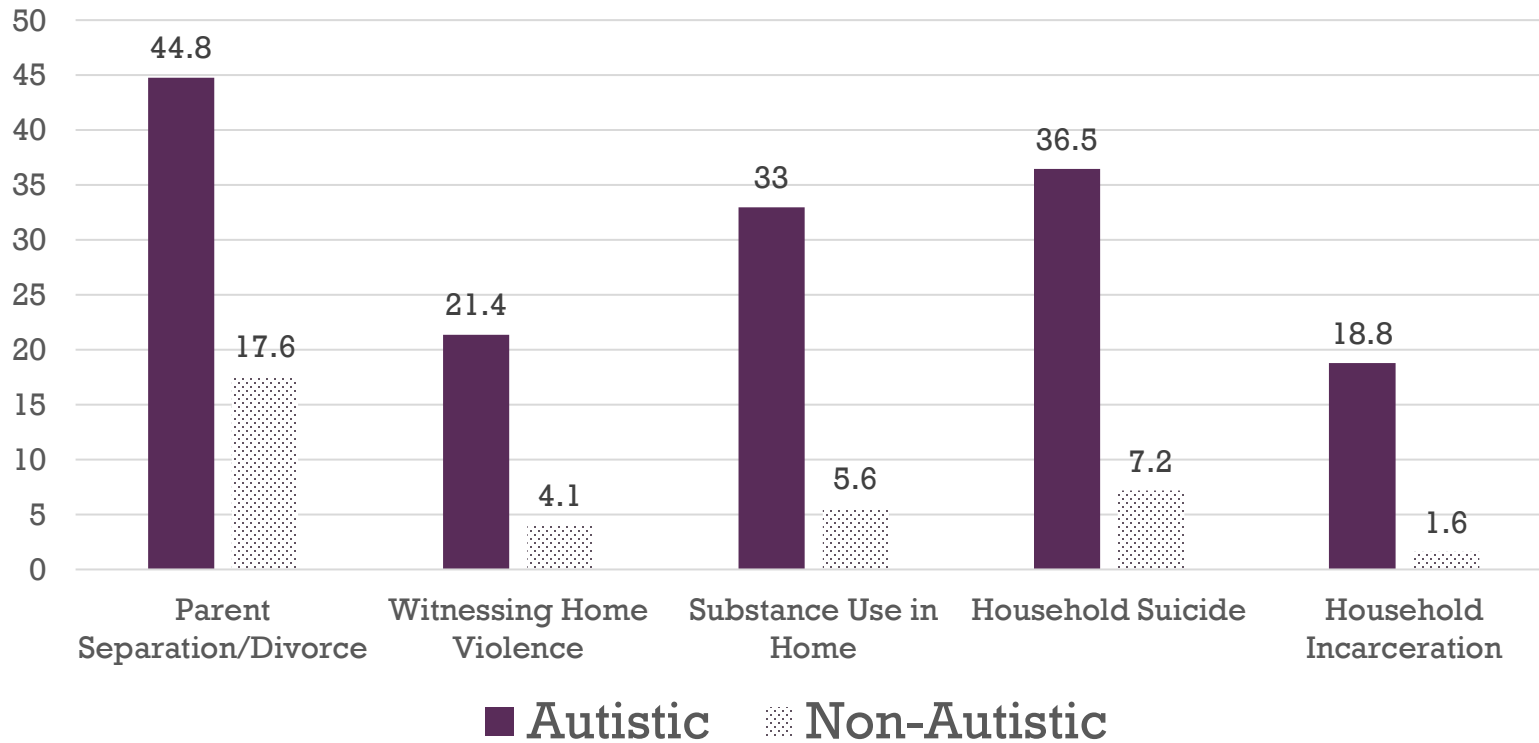




# Significantly Higher Rates of ACEs among Autistic Youth



Prevalence of Household Stress ACEs



Andrzejewski, DeLucia, Semones, Khan, & McDonnell,,  
2023, *Journal of Autism and Developmental Disorders*

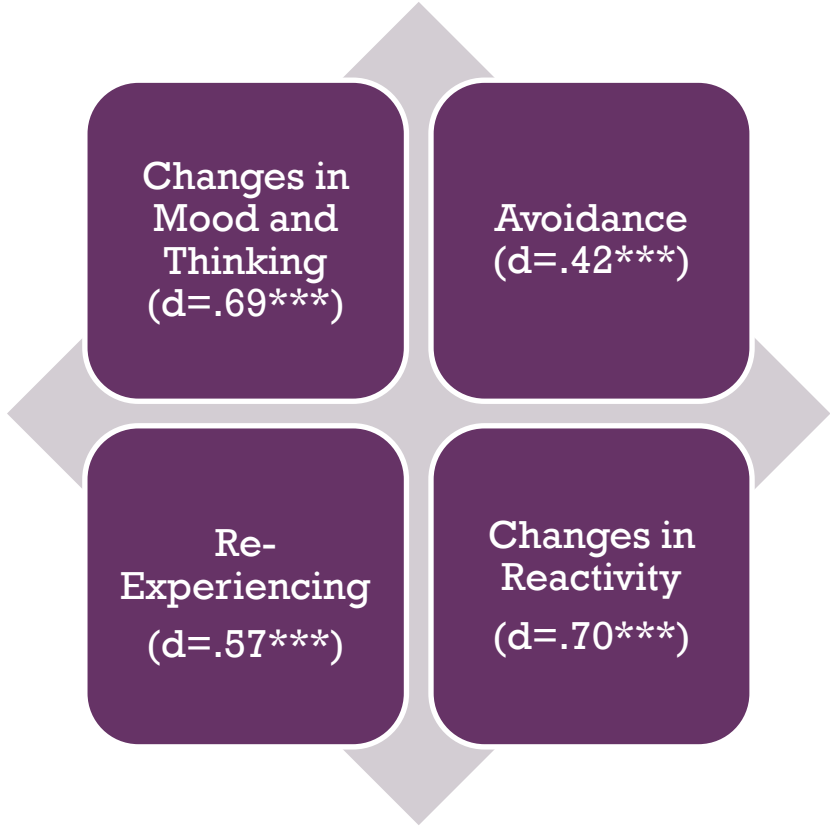
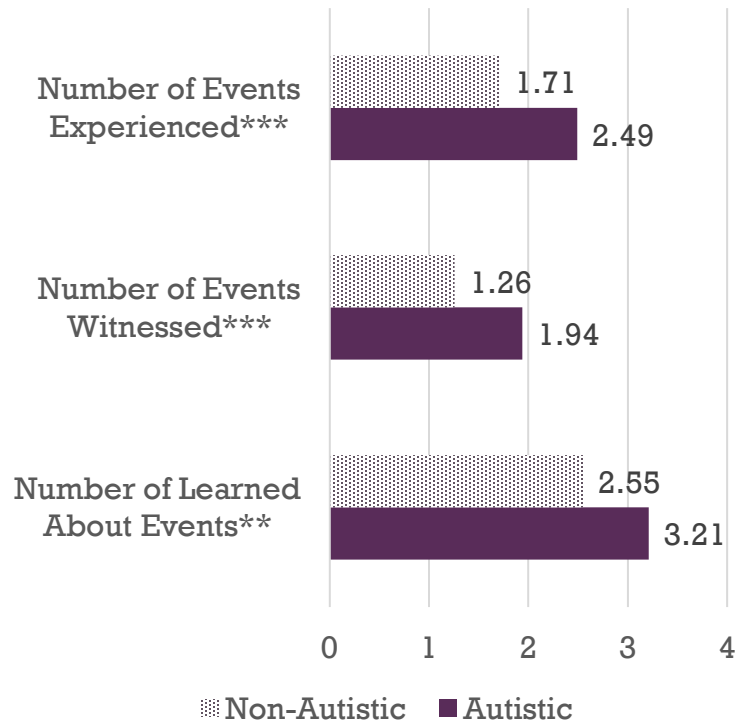
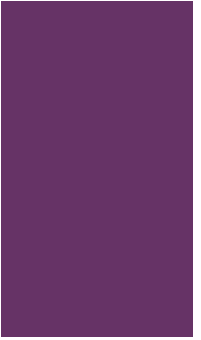


Autistic Adults Report More Traumatic Events

Life Events Checklist for *DSM-5 (LEC-5)*

Autistic Adults Experience Higher PTSD Symptoms

Posttraumatic Symptom Checklist for *DSM-5 (PCL-5)*



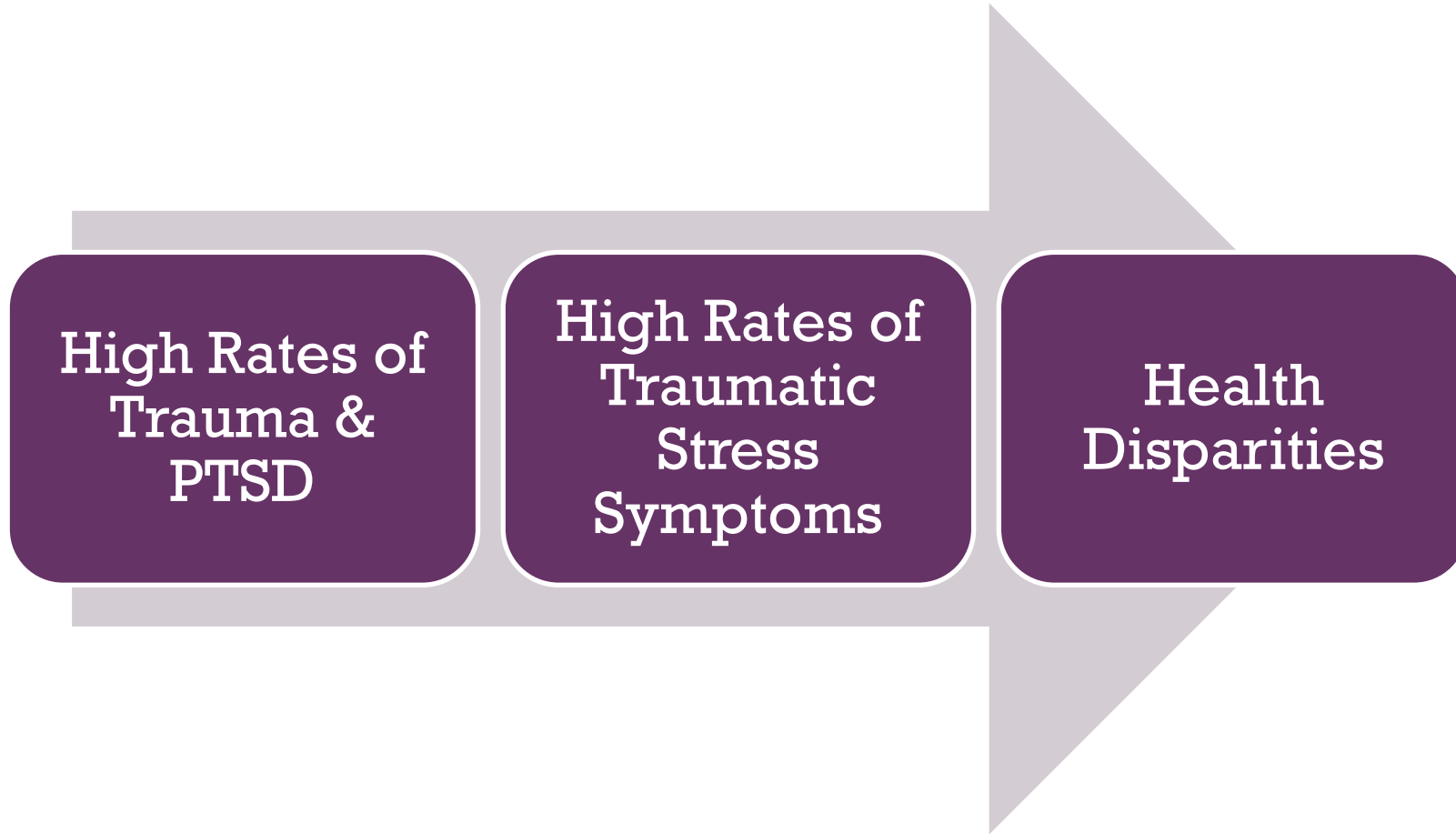
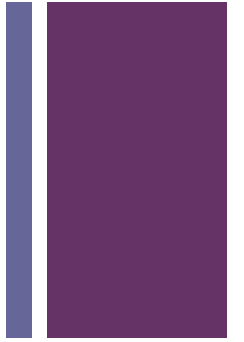
\*\* $p < .01$

\*\*\* $p < .001$

Andrzejewski, Gomez Batista, Abu-Ramadan, Breitenfeldt, Tassone, Winch, Rozek, & McDonnell, C.G., in press, *Autism in Adulthood*



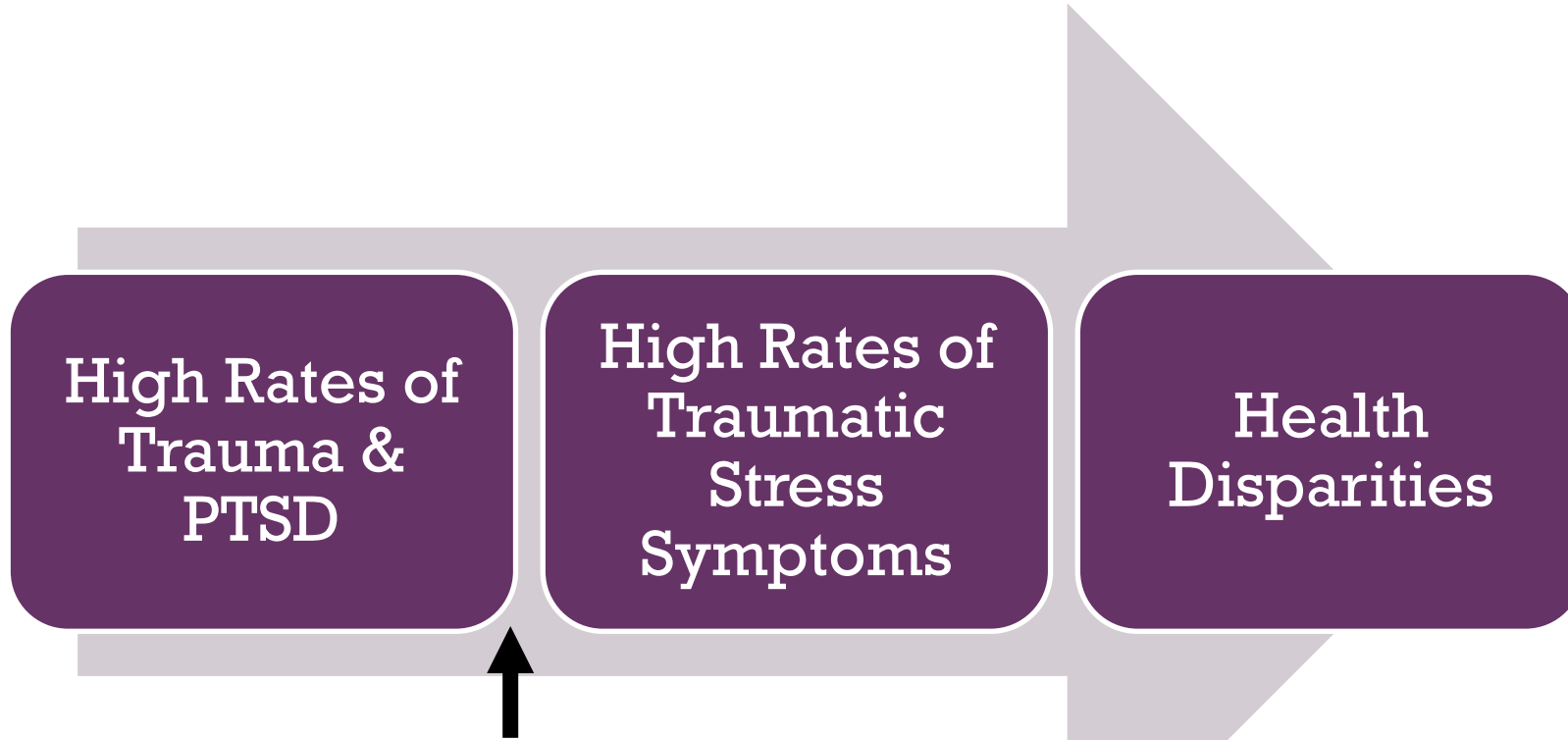
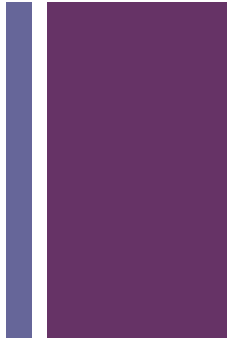
# High Rates of Adversity among Autistic People



Berg et al., 2016, 2018; Ricles et al., 2016; Taylor & Gotham, 2016; Kerns et al., 2015, 2017; Brenner et al., 2018; Fisher et al., 2019; Kerns et al., 2020; Hoover, 2015; Hoover & Kaufman, 2018



# High Rates of Adversity among Autistic People

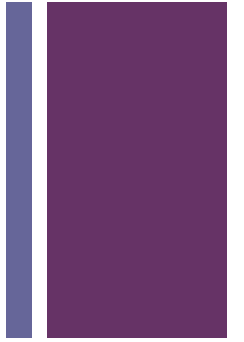


**Evaluating interventions for traumatic stress symptoms a critical priority**

Berg et al., 2016, 2018; Ricles et al., 2016; Taylor & Gotham, 2016; Kerns et al., 2015, 2017; Brenner et al., 2018; Fisher et al., 2019; Kerns et al., 2020; Hoover, 2015; Hoover & Kaufman, 2018



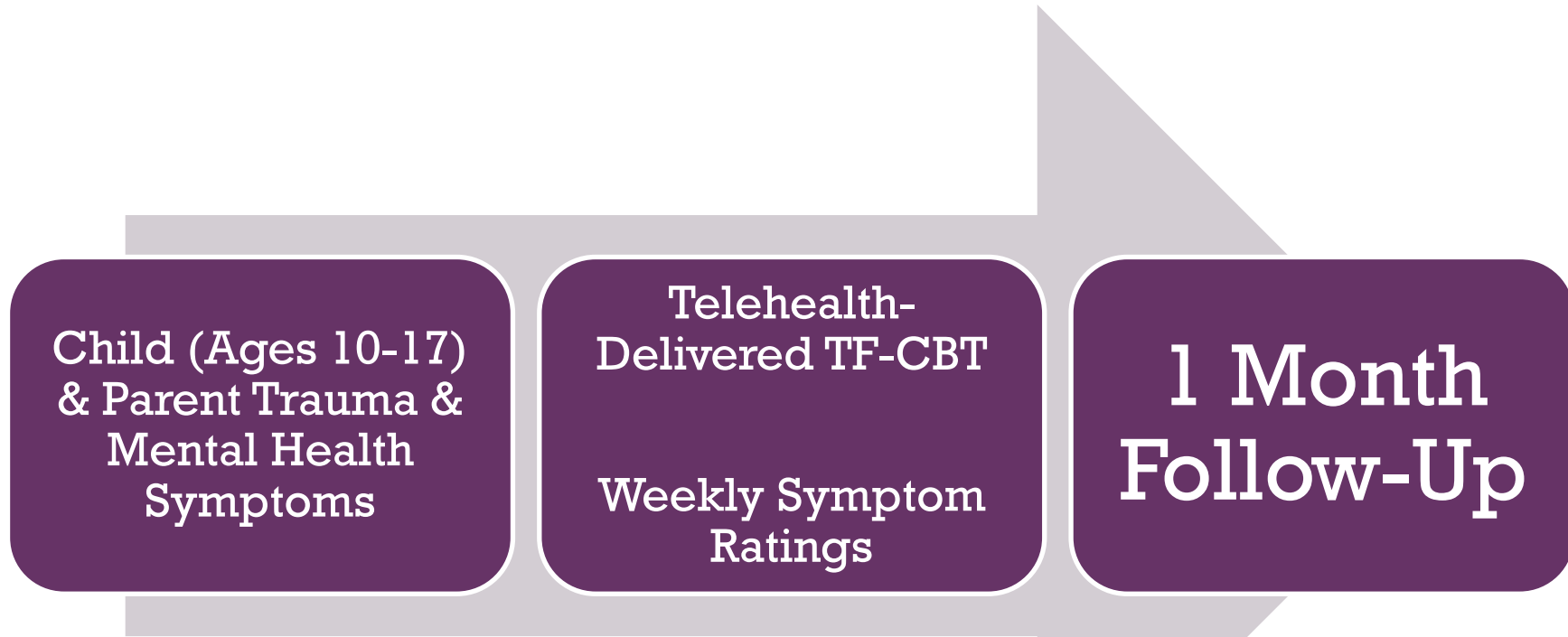
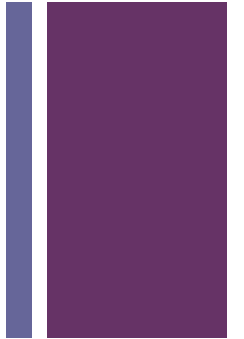
# + Today's Outline



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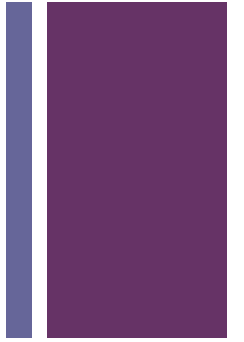


# Pilot Evaluation of Trauma-Focused Cognitive Behavioral Therapy

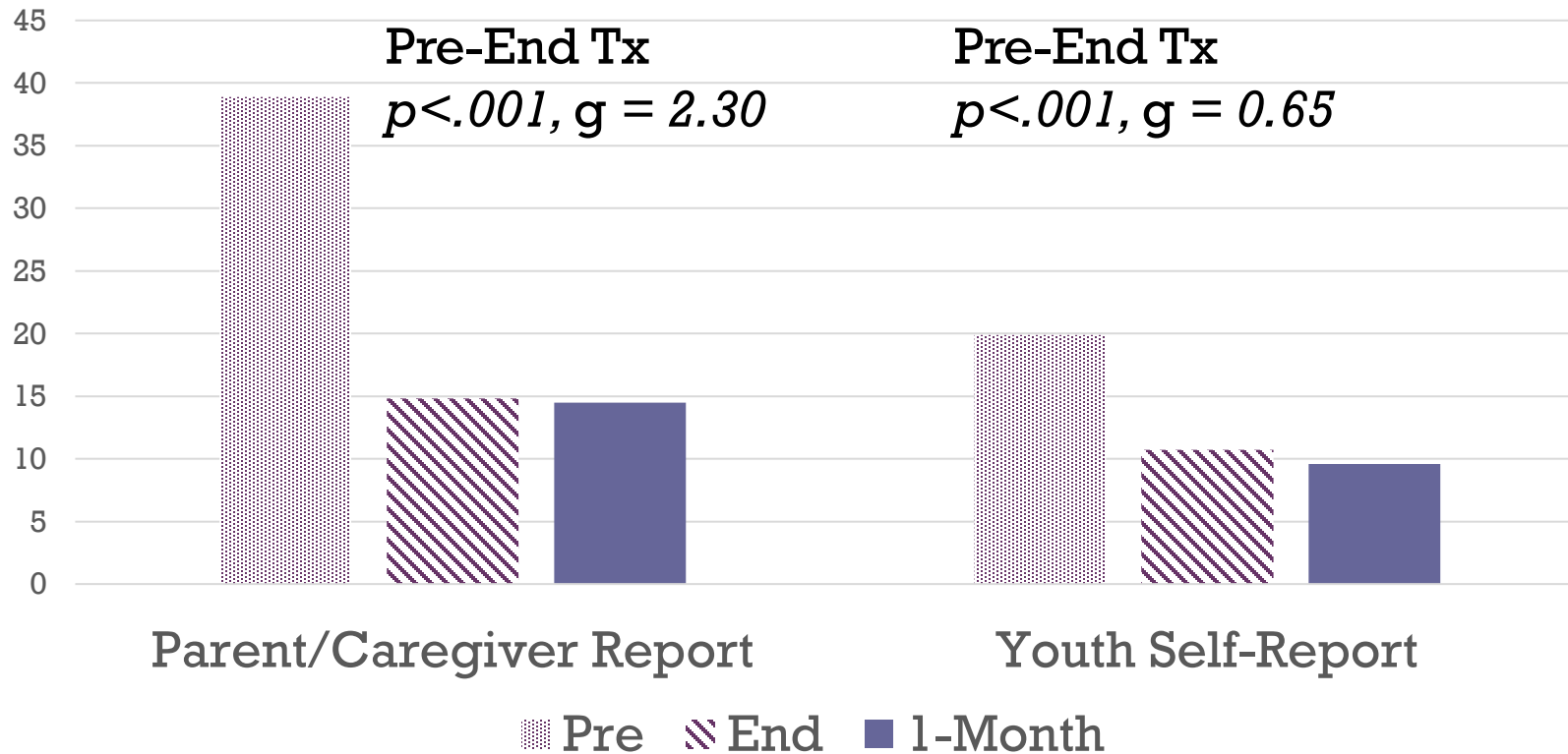




# Improvements in PTSD & Co-Occurring Mental Health (n = 17)

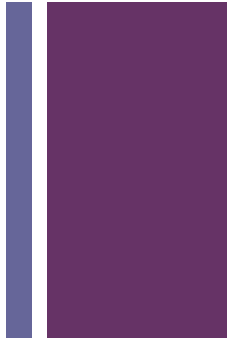


PTSD Symptoms on the Child & Adolescent Trauma Screen (CATS)

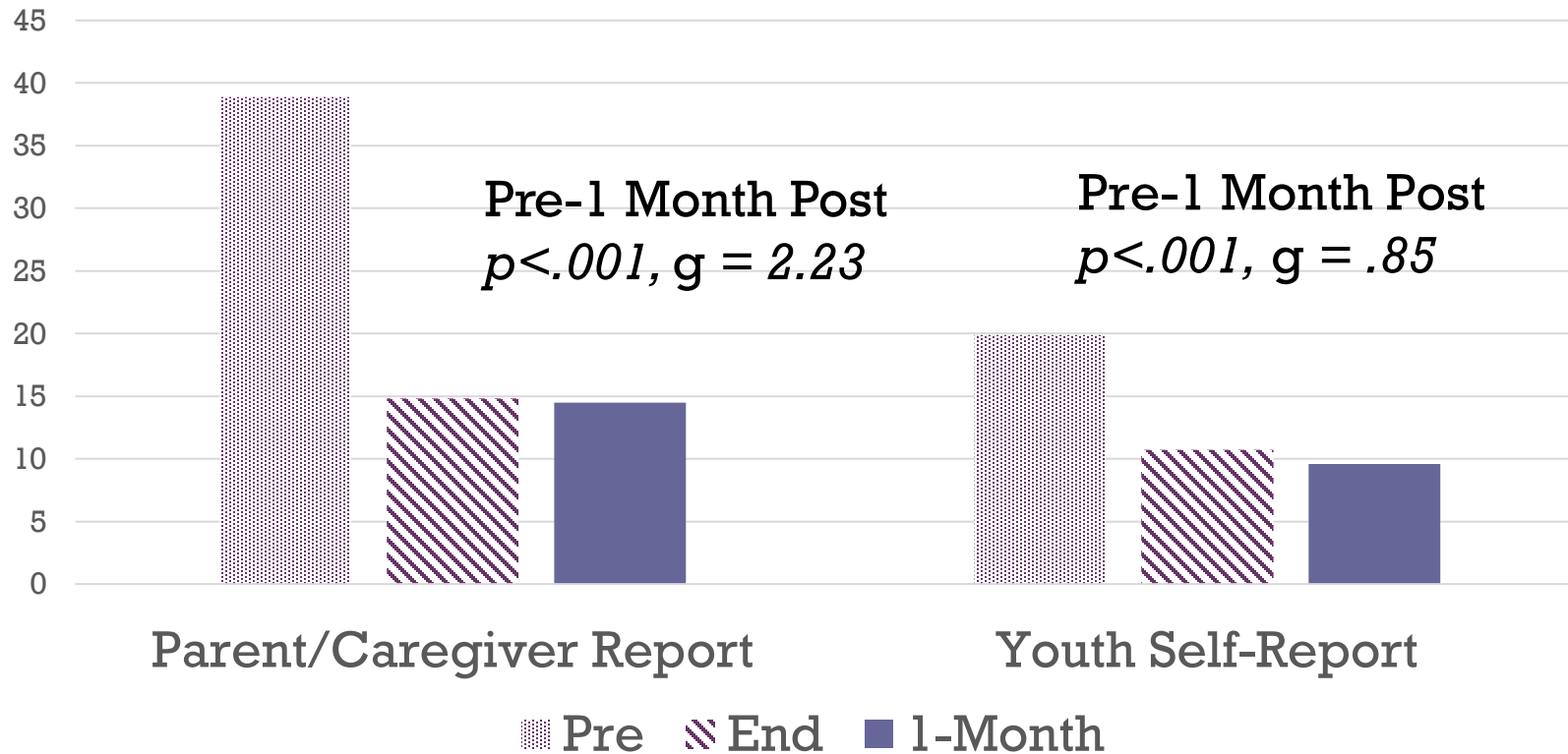


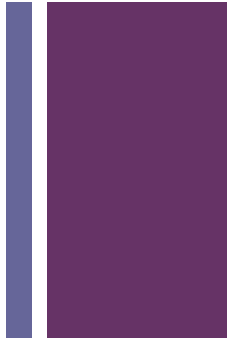


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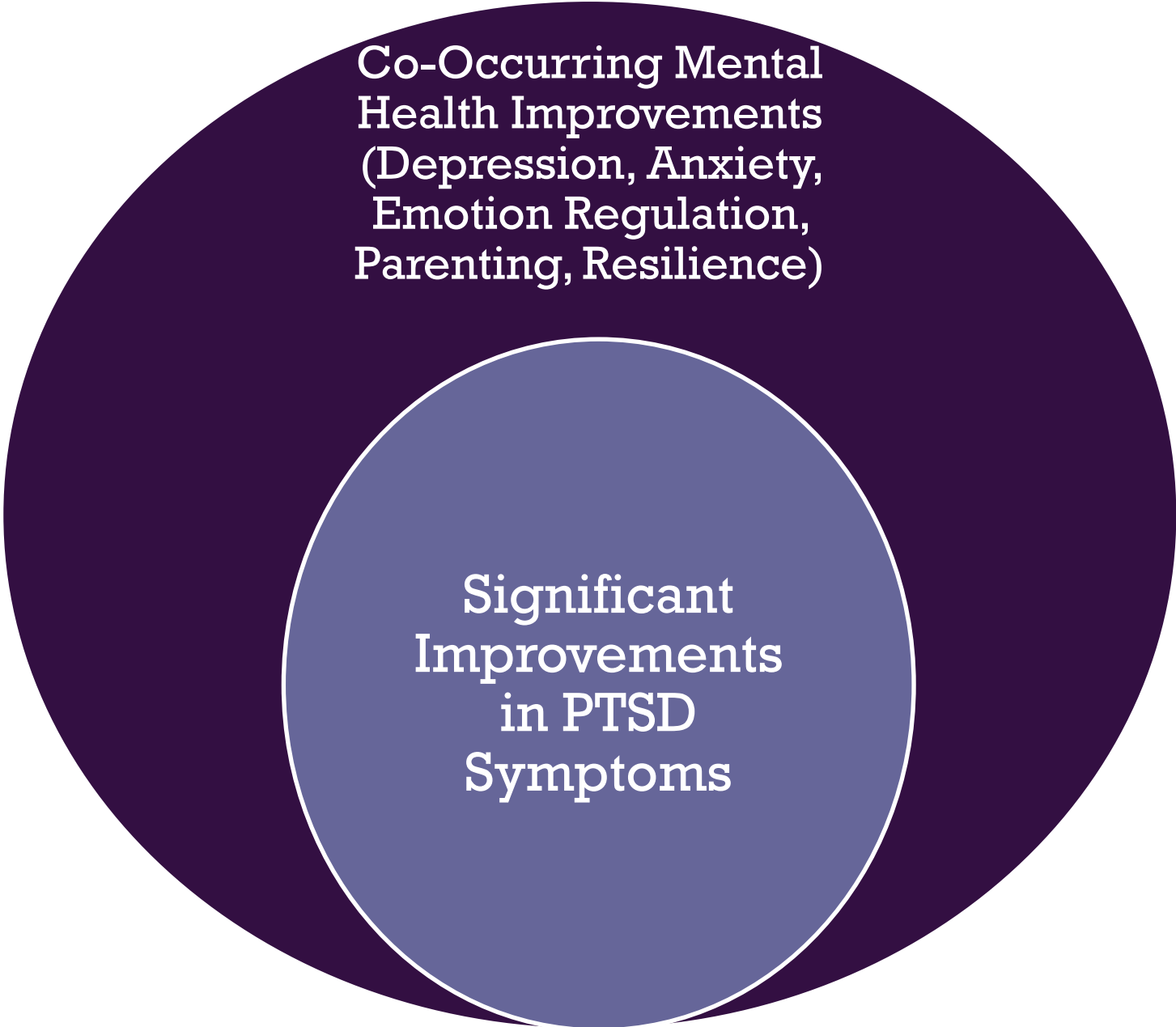
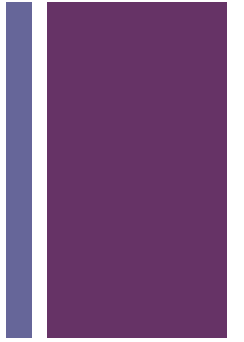


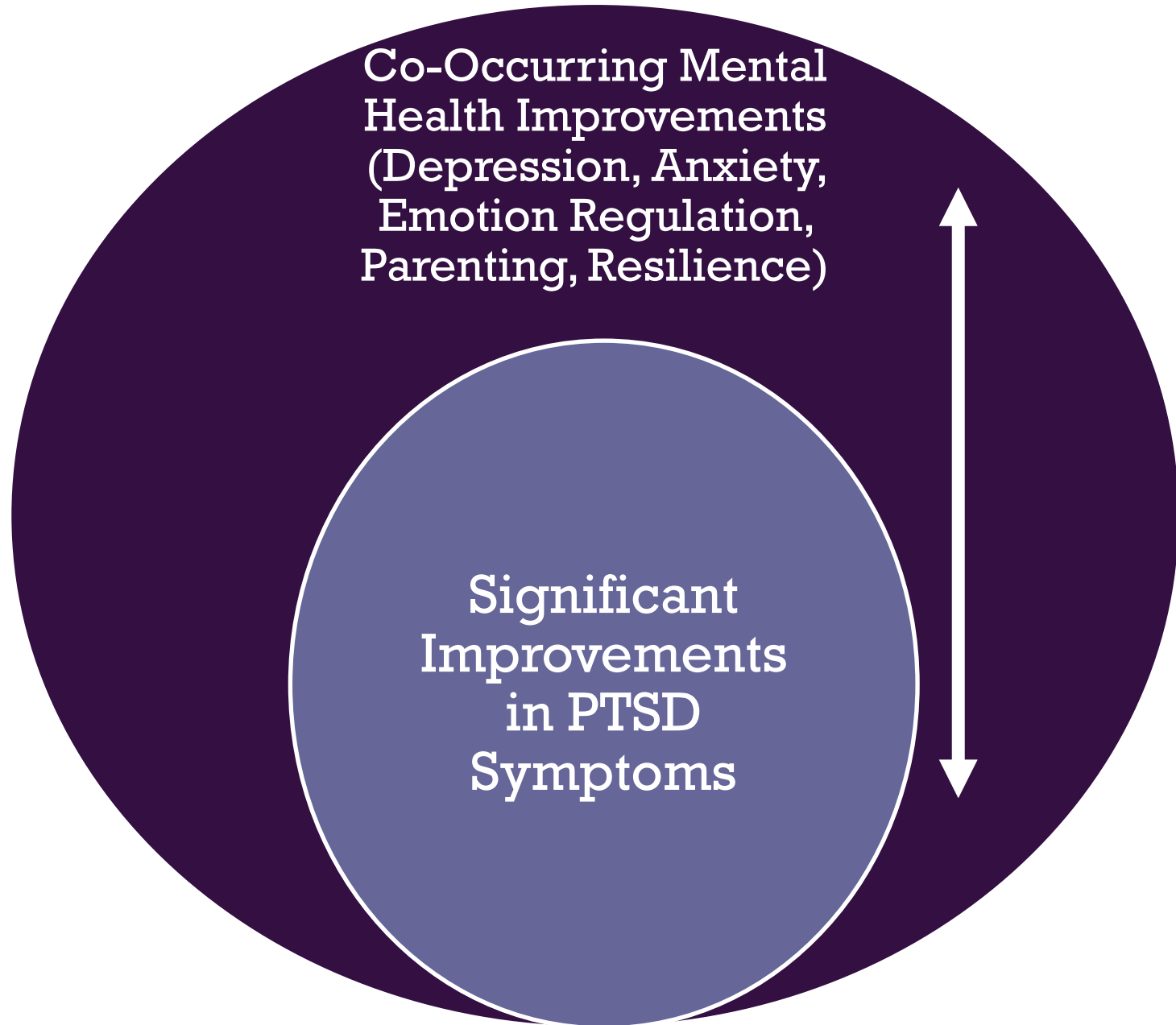
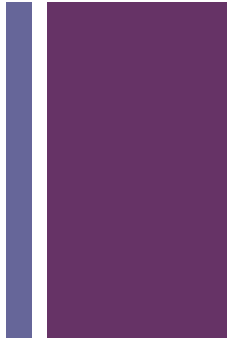
PTSD Symptoms on the Child & Adolescent Trauma Screen (CATS)





Significant  
Improvements  
in PTSD  
Symptoms





# + Treatment Feedback (1-5)

## Parent/Caregiver

- Understand the program?
  - **M = 4.50, Med = 4.5**
- Feel helped by the program?
  - **M = 4.44, Med = 5**
- Recommend the program?
  - **M = 4.50, Med = 5**
- Agree with message?
  - **M = 4.63, Med = 5**

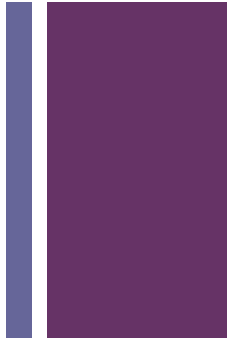
## Youth Self-Report

- Understand the program?
  - **M = 4.35, Med = 5**
- Feel helped by the program?
  - **M = 3.65, Med = 4**
- Recommend the program?
  - **M = 3.82, Med = 4**
- Agree with message?
  - **M = 4.53, Med = 5**





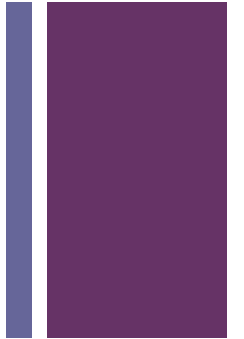
# Pilot Evaluation of Narrative-Based Trauma Program for Autistic Adults



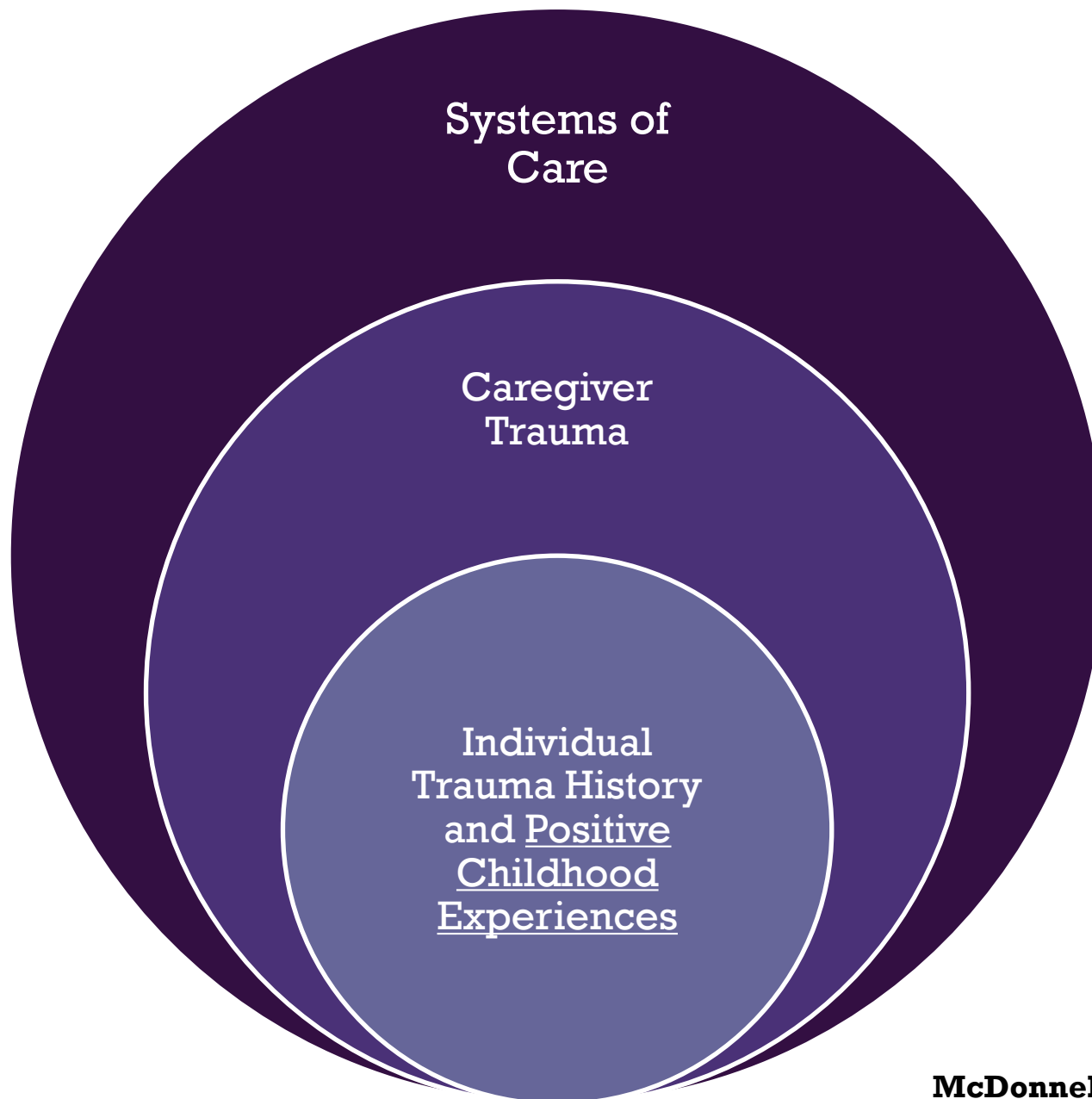
- Consult with advisory board monthly
- Pilot feasibility evaluation of Written Exposure Therapy (Sloan & Marx, 2018)
- 30 Autistic adults via telehealth
- Pre-post changes (up to 6 months post program completion)
- Assessments of mental and physical health outcomes via wearable Fitbit devices



# + Today's Outline



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3. Future directions



**McDonnell** et al., 2022, *Aut Res*  
Andrzejewski, DeLucia, Semones, Khan, & **McDonnell**, 2023, *JADD*

# + Autism Pregnancy Project

Co-Designed Study of Autistic Pregnancy Experiences



AUTISM IN ADULTHOOD  
Volume 00, Number 00, 2021  
© Mary Ann Liebert, Inc.  
DOI: 10.1089/aut.2020.0046

**Pregnancy and Parenthood Among Autistic Adults:  
Implications for Advancing Maternal Health  
and Parental Well-Being**

Christina G. McDonnell, PhD, and Elizabeth A. DeLucia, BA



# Training/Dissemination in Partnership with the Autistic Community





## Future Directions



UNIVERSITY  
OF WYOMING

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College of Arts and Sciences  
Department of  
Psychology



Reach out with  
questions or  
interest



Further Examine  
Effectiveness and  
Individual  
Experiences



Expand and  
Disseminate

# + Questions and Thank You



## Collaborators and Funders

- Organization for Autism Research Applied Research Grant
- National Institutes of General Medical Sciences - Wyoming INBRE Thematic Grant
- Wyoming Institute for Disabilities (WIND) & Wyoming Equality State Research Network (PCORI)
- Kayla Tellier & AIDE Canada
- Medical University of South Carolina, Dr. Laura Carpenter

## Contact Us

- Email
  - **[Christina.mcdonnell@uwyo.edu](mailto:Christina.mcdonnell@uwyo.edu)**
- Community Autism Resilience Emotion and Stress (CARES) Lab at the University of Wyoming
- Graduate Students
  - Theresa Andrzejewski
  - Saily Gomez Batista
  - Kaitlyn Breitenfeldt
  - Alison Tassone
  - Elizabeth DeLucia, Janey Dike
  - Robert Kaya, Natalie Poole

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# Perspectives from Autistic People, Parents, and Clinicians: **Mental Health Interventions and Areas of Need**

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Kelly Beck, PhD, LPC, CRC  
University of Pittsburgh





# Purpose

Understand intervention needs and barriers for autistic people in community mental health care.

- Why are autistic people seeking mental health care?
- What contributes to emotion dysregulation in daily life?
- What mental health interventions are helpful?
- What barriers prevent interventions from being helpful?



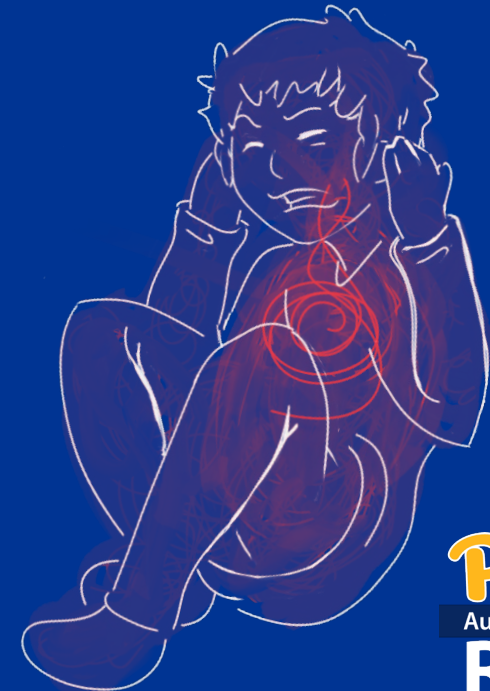
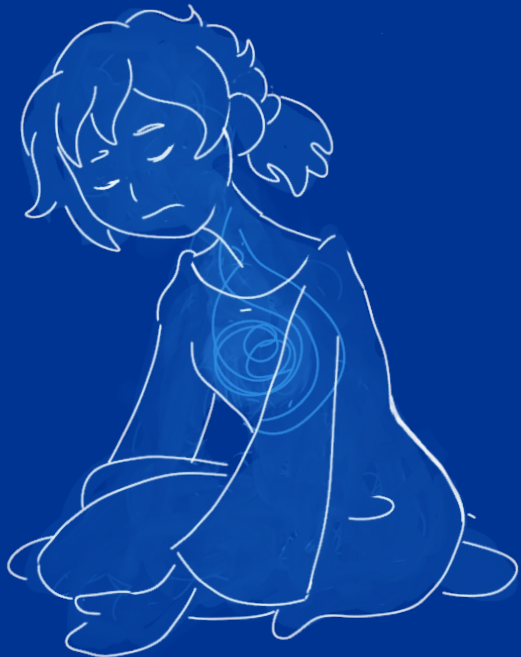
# Who we talked to...

Group	# of people	Key identifying characteristics
Autistic adults	15	Ages 21-68 7 women, 7 men, 1 non-conforming/non-binary 5 non-Hispanic Black, 1 Hispanic White, 9 non-Hispanic White
Autistic teens	8	Ages 14-18 1 woman, 4 men, 3 non-conforming/non-binary, 2 Multiracial, 1 Asian, 5 non-Hispanic White
Caregivers	16	50% have child that is non-speaking or has severe SIB/aggression 11 parents of autistic adults; 5 parent of autistic teenager 1 Multiracial, 2 non-Hispanic Black, 13 non-Hispanic White 2 autistic
Providers	16	6 counselors; 3 social workers; 7 psychologists 15 white; 1 Asian 13 women, 2 men, 1 non-conforming/non-binary 1 autistic
<b>Total</b>	<b>55</b>	

60 minute semi-structured interviews with doctoral-level mental health professional researchers  
 Qualitative analyses using grounded theory analytic approach  
 Autistic adults involved in every stage of project

# Reasons for seeking care

- Emotion dysregulation
- Sensory overload contributing to emotion dysregulation
- Trauma & chronic invalidation



“I want people to know how cripplingly lonely I am. All I have known is gaslighting, lies, hatred, and physical and psychological abuse. So I just, unfortunately, do not have very high self-esteem or really self-care.”

-21-year-old white autistic man



“They're hurt so bad by people. Like, touching the stove a thousand times at some point, you just quit touching the stove. You don't even want a stove because it's dangerous.”

– community mental health therapist

# We asked...

“Can you tell me a story about a recent time you felt out of control of strong emotions?”

- Nearly every autistic adult shared a story of a meltdown that occurred on the way to or in a **healthcare setting**
- Teens most frequently experienced dysregulation in **school**

# Contributors to Emotion Dysregulation

## Contributors

Adults



**Inaccessible  
Environments**



**Discrimination**



**Masking**



**Awareness**



**Social  
Rejection**

# Contributors to Emotion Dysregulation

Teens

## Contributors



Inaccessible  
Environments



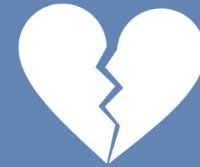
Discrimination



Masking



Awareness



Social  
Rejection

“I am forced to keep it toned down because okay I'm at work can't be seen. Forcing it down actually is worse.”

- 31-year-old Black autistic woman



You're hurt and people don't try to understand things from your perspective. It's like you're expected to understand things from their perspective, but there's no effort on the other person's part.

-45-year-old white autistic female

“There was this bug on the playground that everyone was looking at, and I had no clue what was going on, so I ran over, and I stepped on the bug. So, for the rest of the year, I stayed inside.”

-17-year-old multiracial non-binary teen



# Consequences of Dysregulation

- Frequent unjust responses to emotion dysregulation



Involuntary sedation



Loss of healthcare services, job, friendship



Discipline

- Need safe people or places during dysregulation

**“They’re threatening to suspend me. How are you threatening to suspend me from a mental health treatment program? It makes no sense, because I’m not well enough.”**

**-42-year-old white autistic female**



# Interventions & Barriers

---

# Intervention Approaches

Intervention approaches participating providers reported using:

- Eclectic approaches (75%)
  - Validation, parent-child relations, social skills, mindfulness, sensory
- Behavioral approaches (25%)





# Interventions are a poor fit

- Do they honor lived experiences?
- Do not generalize to real life
- Not designed for the diversity of autism

“And you asked me, What's good? What's positive? What works? Like I said, I can tell you what doesn't. You know, relinquish your child to the county and they'll find them somewhere that's a good program. Are they out there? They tell me they are.

I see them. I see money. I see lots of money. I see money for autism services, autism waiver. I see all these great places having all kinds of fundraisers, and they send me all kinds of emails. Donate now. **But my son has nothing”**

-parent of autistic adult



# Placing Intervention on Individual

“He thinks that he’s seeing providers because something’s **wrong with him**”

-Parent of autistic adolescent

“my feelings are valid and many situations cannot be reduced to faulty thinking patterns [...] if you’re getting discriminated against some emotions arise that are **complicated**”

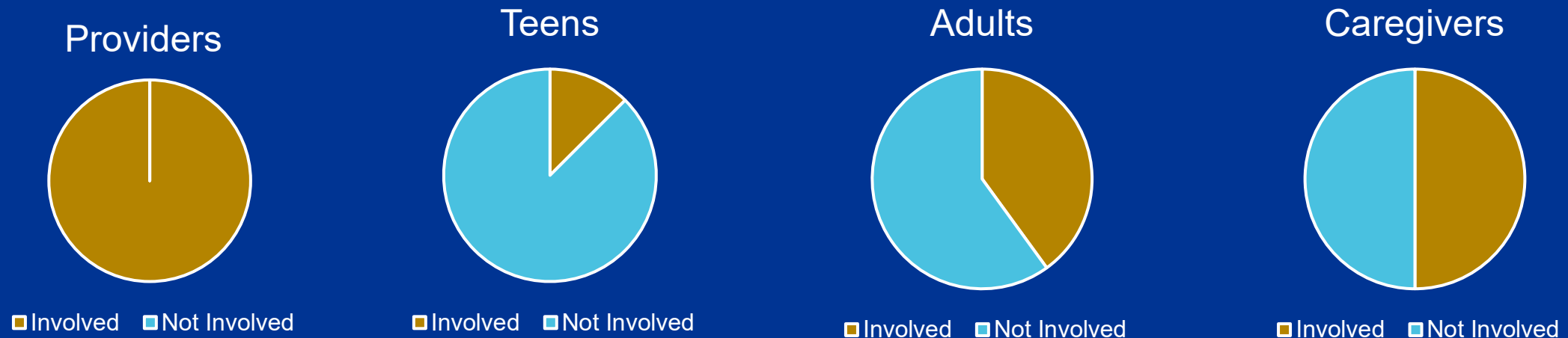
-45-year-old white autistic female

I wish that there were more programs that [...] weren't about, “You can’t regulate, I need to help you regulate”. Or even, “Your social skills aren't good, we need to get you social skills”. I feel like a lot of those things are **deficit based.**”

-community mental health therapist

# Not Translating to Real Life

- Community mental health providers' main tool to support generalization is involving parents or caregivers





# Insufficient service eligibility

- Long term mental health care across lifespan is needed
- Coordinated care with health and mental healthcare team

“You can go to any kind of an exhibit fair, where they have all different kinds of services and they'll say, ‘yes, we welcome people on the spectrum.’ And if you happen to say, ‘even those with behaviors?’ ‘No, no. Sorry, no.’ **So, you don't welcome the spectrum.**

-parent of autistic adult

# Top Overall Themes

- Current mental health system is poor fit for autistic people

## Barriers



**Eligibility**



**Inaccessibility**



**Long  
Waitlist**



**Interventions  
are Poor Fit**



**Provider  
Support**



**No  
Coordinated  
Care**

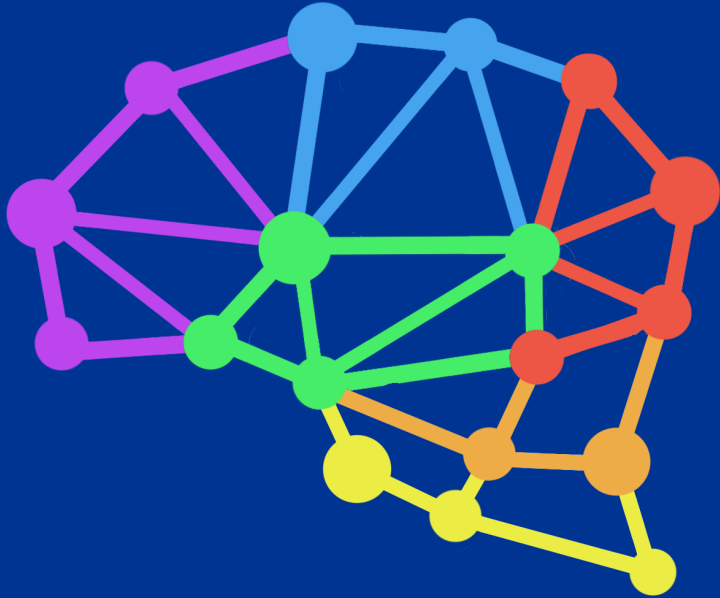


**Doesn't  
Translate to  
Real Life**



# Moving Forward....

- Services eligibility for the diversity of autism
- Mental health Intervention research
  - Honor and address marginalization, invalidation, & trauma
  - Integrate sensory
  - Collaborative & deployment-focused designs for community mental health interventions
  - Flexible to fit diversity of autism
  - New tools for generalization



# Project Co-Investigators & Mentors



**Carla Mazefsky, Ph.D.** »  
REACT Director  
mazefskyca@upmc.edu



**Judy Chang, M.D., M.P.H.** »  
ACE Co-Investigator  
chanjc@upmc.edu



**Caitlin Conner, Ph.D.** »  
Assistant Professor  
connercm2@upmc.edu



**David Mandell, ScD** »



**Kristen MacKenzie, Ph.D.,  
M.S.W.** »  
Postdoctoral Associate  
mackenzi@pitt.edu



**Susan W White, PhD, ABPP** »  
EASE Co-Principal Investigator  
swwhite1@ua.edu



**Staff and Students:** Kate Breitenfeldt, Tanvi Kumar, Elizabeth Rutenberg, Mario Crown, Olivia Boden, Amy Ionadi, Rachel Harris, Michelle Perrin, PJ McCarroll, Shannon Sloan

## **Grant Funding:**

- NCATS 1 KL2 TR001856-05 (PI: Doris Rubio, PhD)
- NIMH 1 P50 MH130957-01
- University of Pittsburgh & Doris Duke Foundation SOS Award
- NICHD Loan Repayment Program
- The Edith L. Trees Charitable Trust
- PA Department of Health



# Committee Discussion



**Break**



# Community Perspectives on Mental Health Needs in Autism



# Community Perspectives on Mental Health Needs in Autism



## Panelists:

- Xenia Borue, M.D., Ph.D.
- Lisa Morgan
- Kayla Rodriguez
- Ian Neumaier
- Angie, mother of a young adult son on the autism spectrum



Angie

Mother of a young adult son on the autism spectrum

# Committee Discussion





**Break**



# Addressing the Mental Health Needs of Autistic People Through the Mental Health Service System





Bridging I/DD and Mental Health Systems

**October 2023**

*A grant funded through the  
Administration of Community Living*

# Key Elements: Supporting Individuals with Co-Occurring I/DD and Mental Health Support needs



## ELEVATING VOICES OF INDIVIDUALS SUPPORTED AND ALLIES

Ensuring that individuals with lived experiences and their families are at the center of all policies, practices and service modalities is key.



## POLICY MODERNIZATION

Many historic federal and state policies, particularly in the Medicaid program, have contributed to the exclusion of individuals with I/DD having equitable access to MH treatment. States making progress in these areas are undertaking policy and practice reviews to identify and eliminate these vestiges.



## COMMUNITY SUPPORTS

Focusing on building a continuum of community supports to foster prevention and post-crisis supports is essential to avoid or minimize institutional utilization and to foster successful transitions back to the community when out-of-home options are needed



## STATE SYSTEM COLLABORATION

State systems supporting individuals with I/DD and those supporting individuals with Mental Health Support needs must collaborate to identify and remove systemic barriers to effective treatment and ongoing supports for individuals with I/DD and MH support needs.



## MULTIFOCAL CAPACITY BUILDING

Ensuring both clinical capacity of treating mental health professionals and capacity to support individuals in their homes and communities is essential for the sustainability of a functioning system that successfully supports individuals with I/DD and MH support needs. Devising scalable and replicable practices are key as is the effective use of technology to stretch available capacity.





# NASDDDS – NASMHPD – NADD

## An Increasingly Necessary Partnership

- While our associations have long recognized the importance of working together on shared issues, our partnership was renewed with vigor on the heels of the 2018 SAMHSA Convening regarding individuals with co-occurring I/DD and MH conditions;
- In 2019, NASDDDS/NASMHPD/NADD convened a roundtable series with a cohort of states to identify promising practices
- We have partnered on several other initiatives like the Dual Diagnosis Capacity Building Institute

## Leading Partners

- NASDDDS
- NADD
- NASMHPD

## Diversity, Equity, Inclusion

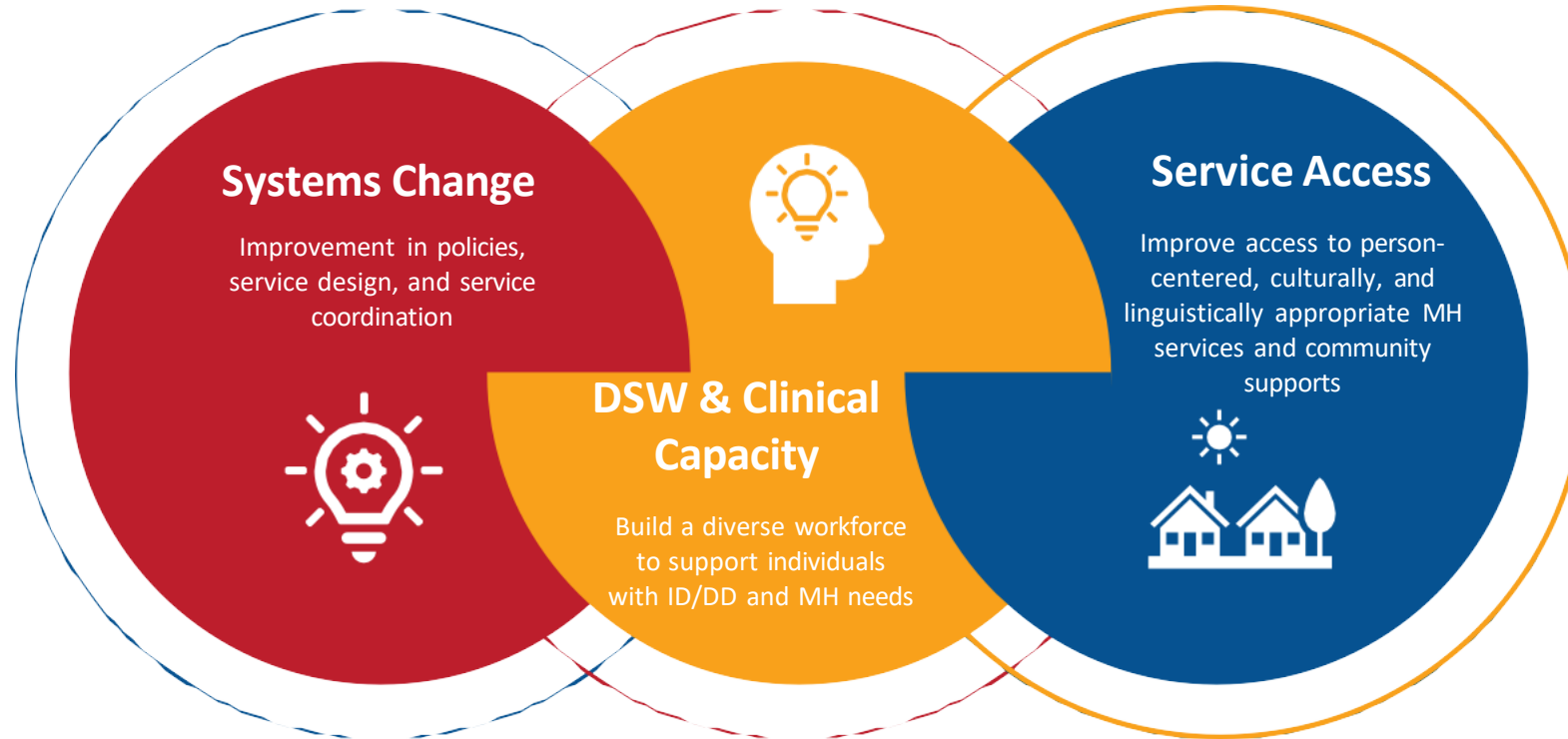
- Green Mountain Self Advocates
- Autistic Self Advocacy Network
- National Association of State Head Injury Administrators
- Communication First

## Continuous Quality

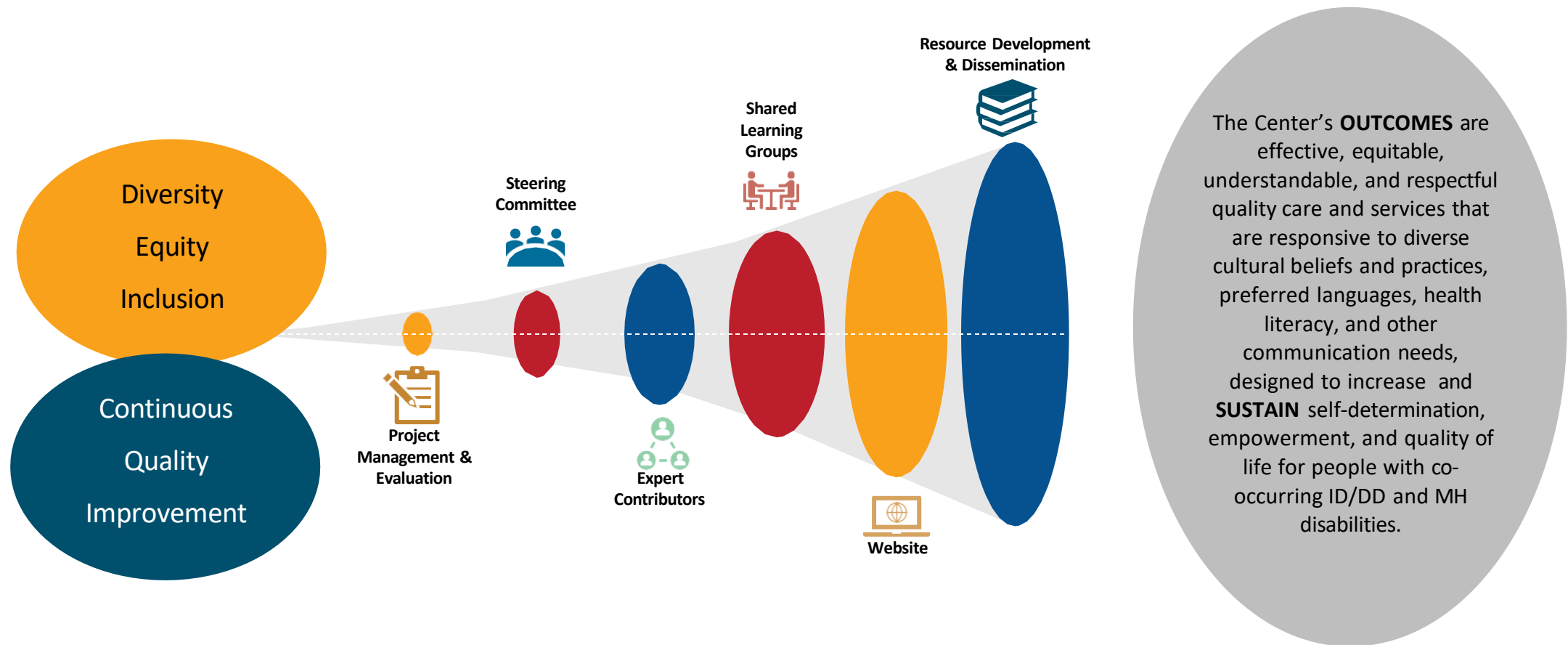
- National Center for START Services
- Sonoran Center
- OSU Nisonger Center



# Key Goals of The Link Center



# The Link Center's Key Activities





An orange starburst graphic with multiple points, containing the text "Website Coming Soon!".

**Website  
Coming Soon!**

**[thelinkcenter@nasddds.org](mailto:thelinkcenter@nasddds.org)**

# Addressing the Mental Health Needs of Autistic People Through the Mental Health Service System



## **The Link Center: Bridging I/DD and Mental Health Systems**

Stacy Nonnemacher, Ph.D.

## **Mental Health Services Presentation**

Debra Pinals, M.D.

## **Partners in Progress: How I/DD and Behavioral Health Face Similar Challenges and Opportunities**

Jonah Cunningham



Bridging I/DD and Mental Health Systems

**October 2023**

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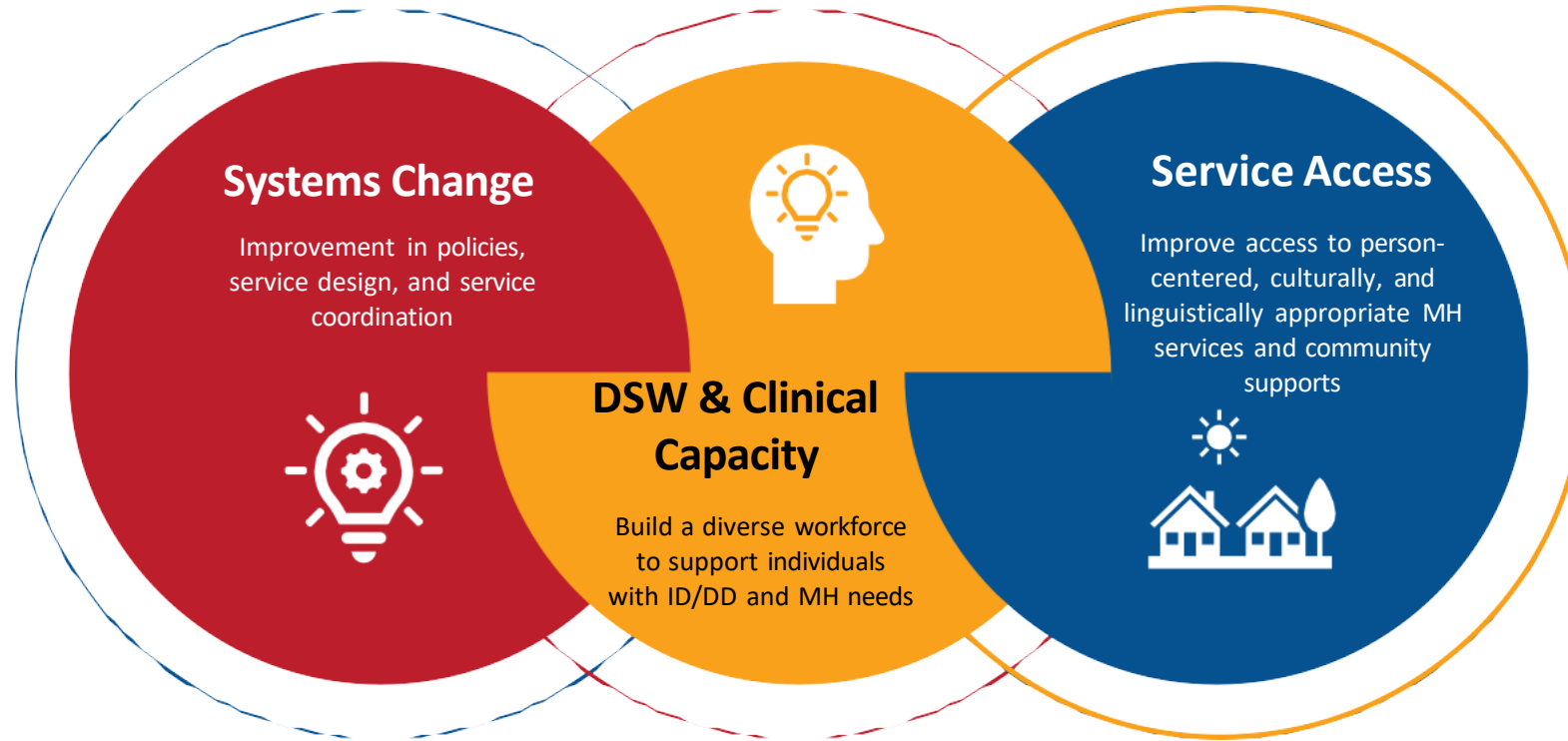
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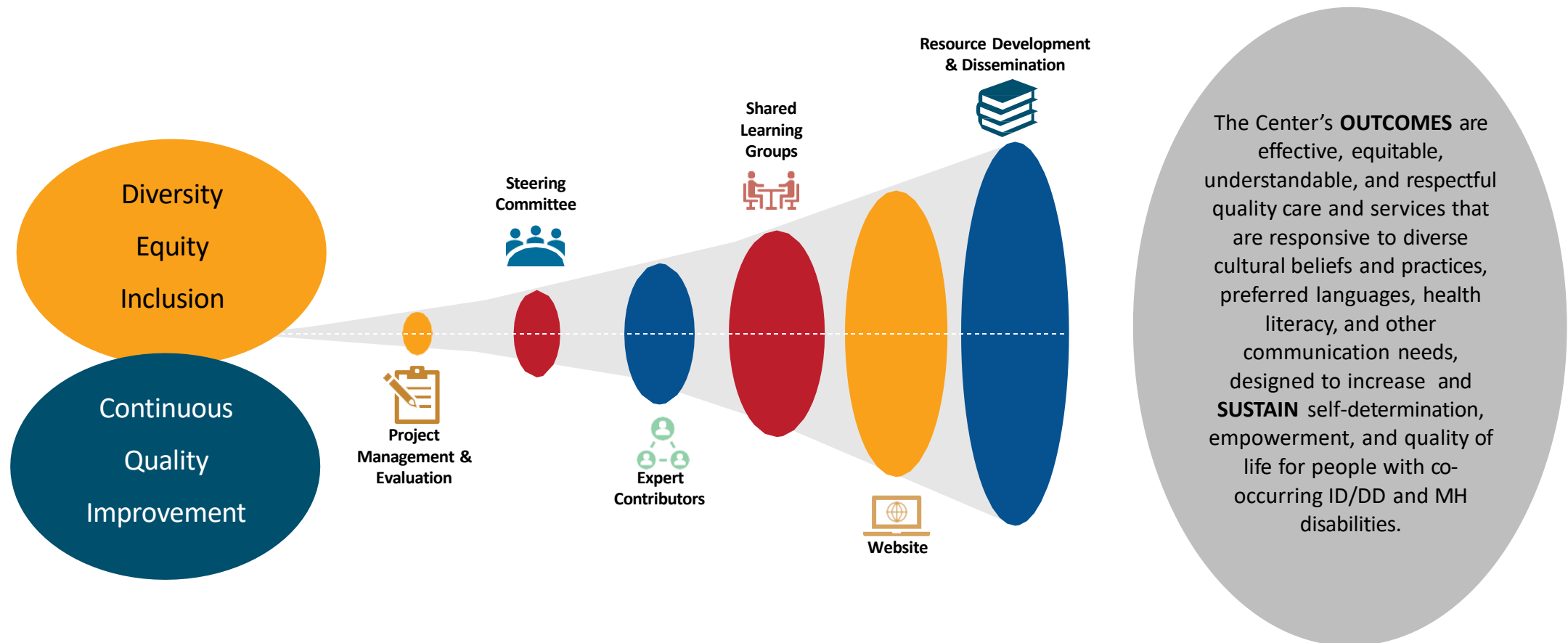
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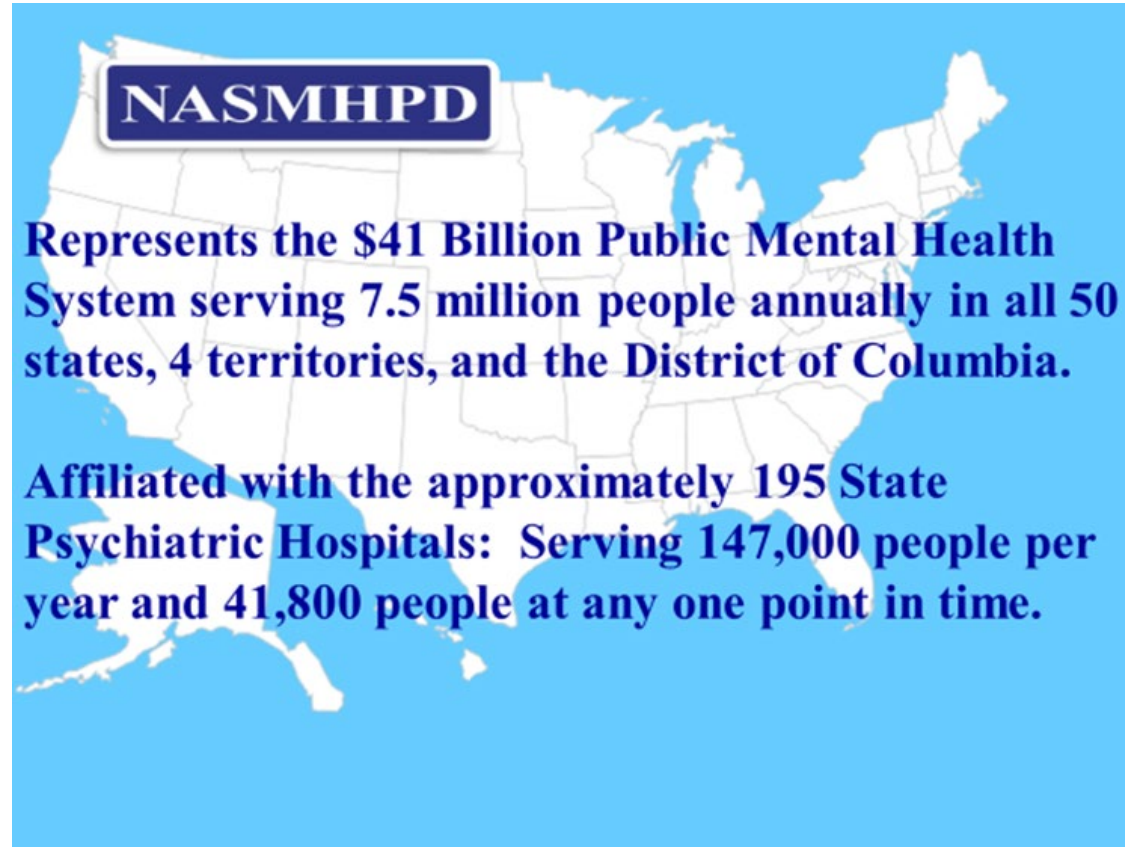
**[thelinkcenter@nasddds.org](mailto:thelinkcenter@nasddds.org)**

# Mental Health Services: Presentation to the Interagency Autism Coordinating Committee

October 11, 2023

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## National Association of State Mental Health Program Directors (NASMHPD)



## People with Autism Spectrum Disorder can often have co-occurring Mental Illness

- ASD study found by age 16 prevalence of comorbidity is 49% (Rosenberg et al 2011)

Behaviors masked as or interpreted as mental illness become treated as mental illness across systems

### Critical importance for:

- Increased understanding of the population and individual needs
- Increased resources to treat individuals across and within systems

---

Historical gap  
between  
Departments of  
Mental Health and  
Departments of  
Developmental  
Disability

-patients with “Dual Diagnosis” are at risk for “falling through the cracks” with each state agency trying to not have responsibility for the person because of the other diagnoses

Systems  
Issues –  
Weaknesses,  
Threats

---

Not enough staff

---

Not enough training and supervision

---

---

Not enough leadership

---

Improper placement - group of individuals

---

Over reliance on medication

---

Opposition to meds

---

Family participation

---

# Why do people with co-occurring BH and IDD conditions struggle to access integrated care to meet their complex needs?

---

## INDIVIDUALS IN NEED

```
graph TD; A[INDIVIDUALS IN NEED] --> B[Departments of Mental/Behavioral Health and Medicaid Managed Care Organizations]; A --> C[Departments of Developmental Disabilities and Global and Targeted Medicaid Waiver Programs];
```

**Departments of  
Mental/Behavioral Health  
and  
Medicaid Managed Care  
Organizations**

**Narrowed eligibility criteria and medical necessity standards limit access to and coverage for behavioral health care.**

**Departments of  
Developmental Disabilities  
and Global and Targeted  
Medicaid Waiver Programs**

**Broader entitlement to developmental services but access is limited to waiver services for special needs subpopulations.**

# Requirements for Training on Intellectual and Developmental Disabilities in General Psychiatry and Many Other Mental Health Specialties

---



## BARRIERS

Siloed policy, regulatory, program and financing structures

Fragmentation of authority, accountability and resources

Exclusionary eligibility and coverage criteria overlooking prevalence of co-occurring conditions

Limited rates, structural integration, review protocols and reimbursement guidance

## OPPORTUNITIES

Migration from targeted populations in limited waivers to Population Health basis for service delivery and payment reforms

ACO, BH and LTSS provider partnerships in emerging service delivery structures

Reexamination of need to regulate markets in specialty care

Pediatric Mental Health Care Access and School-based intervention efforts

Cross system collaboration

# Recommendations

---

# Current Efforts

---

Enhance psychiatric treatment options along a continuum of care

Recognize that conditions can occur at the same time in a person

Develop organizational structures to meet needs

Enhance workforce knowledge and availability

Foster trauma-informed and person-centered care

Consider biology, social circumstances and environmental issues

Develop alternatives to law enforcement, arrest, incarceration whenever feasible and safe

Expand crisis services to address the needs of people with ASD

Promote examples like HRSA Pediatric Mental Health Care Access Programs



Connected and Strong

**Beyond Beds**  
The Vital Role of a Full Continuum of Psychiatric Care

NASMHPD

**BOLDER GOALS  
BETTER RESULTS**  
Seven Breakthrough Strategies to Improve Mental Illness Outcomes

NASMHPD

**BEYOND THE BORDERS:**

Lessons from the International Community to Improve Mental Health Outcomes

NASMHPD

**CRISIS SERVICES**  
Meeting Needs, Saving Lives

SEPTEMBER 2020

Accessible • Interconnected • Effective • Just

**READY TO RESPOND**

MENTAL HEALTH BEYOND CRISIS AND COVID-19

NASMHPD Reimagining a Sustainable and Robust Continuum of Psychiatric Care

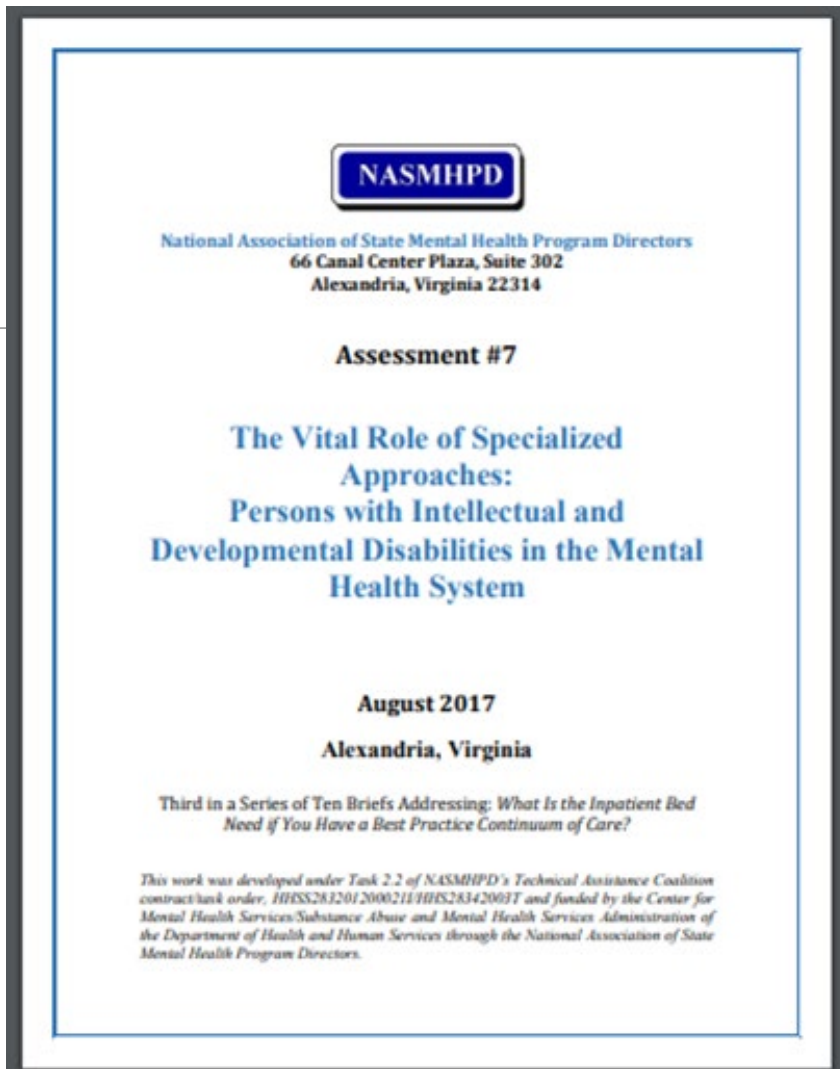
September

**FROM CRISIS TO CARE**  
Building from 988 and Beyond for Better Mental Health Outcomes

NASMHPD  
September 2022

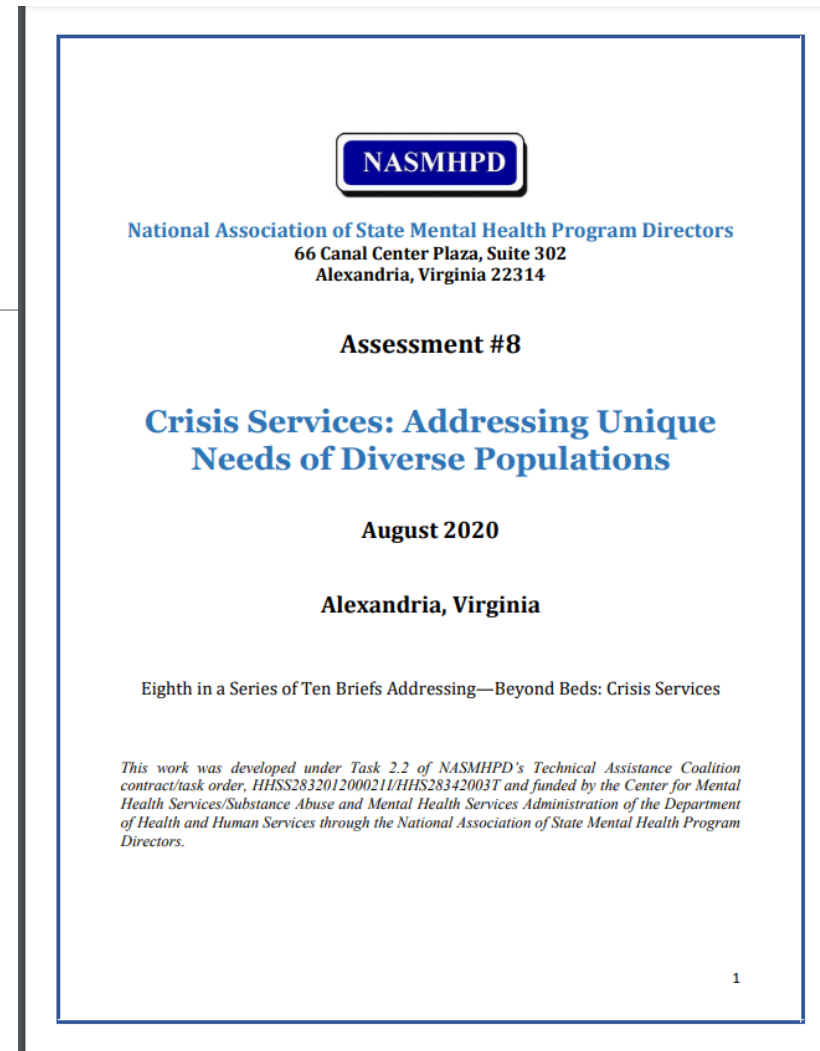
Key elements to help individuals and systems move from crisis to care

Paper No. 1 in the *From Crisis to Care* Series



[https://www.nasmhpd.org/sites/default/files/TAC.Paper\\_7.IDD\\_Final.pdf](https://www.nasmhpd.org/sites/default/files/TAC.Paper_7.IDD_Final.pdf)

GOOGLE: "Vital Role and IDD and State Mental Health"



<https://www.nasmhpd.org/sites/default/files/2020paper8.pdf> GOOGLE:

Crisis Services and Diverse Populations

---

**Workforce development in the community must include attention to personal support, behavioral supports, techniques such as ABA, an understanding of biopsychosocial issues, and the requisite training, as well as salaries that support the challenging work to minimize disruptions in treatment. Encourage advocacy and planning for a workforce that can work by developing training models and early exposure in training and clinical rotations.**

---



Questions?  
Comments?



# Partners in Progress: An Overview of I/DD and Behavioral Health

JONAH C. CUNNINGHAM







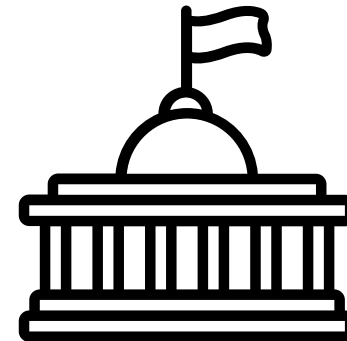
# Goals for Presentation

1. Introduce NACBHDD and NARMH
2. Provide an Overview of Local I/DD and Behavioral Health Systems
3. Highlight Challenges and Opportunities for Collaboration



# About NACBHDD

- Founded in 1989
- Represents local authorities
- Dual focus on I/DD and behavioral health
- Affiliate of NACo





# About NARMH

- Includes Variety of Members
- Improving Access, Availability, and Acceptability
- Affiliate Of NACBHDD



**NARMH**  
National Association for  
Rural Mental Health



# ***Overview of Local Systems***





# Mental Health Systems

- State Comparison Report
- Explain Local Public Systems
- Demonstrate Impact on Communities





# Behavioral Health and I/DD

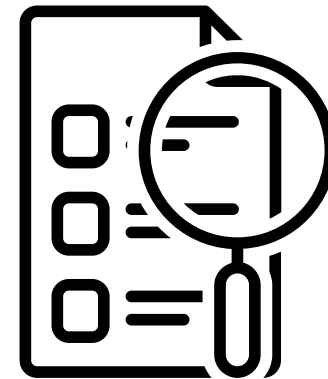
- Populations Can Overlap
- Location of Leadership Matters
- Funding Streams





# A Time of Transformation

- 988
- Mobile Crisis Response
- Certified Community Behavioral Health Clinics (CCBHCs)





# ***Challenges and Opportunities***

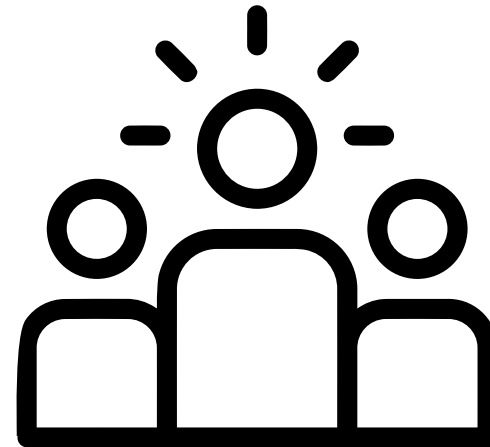






# Challenges

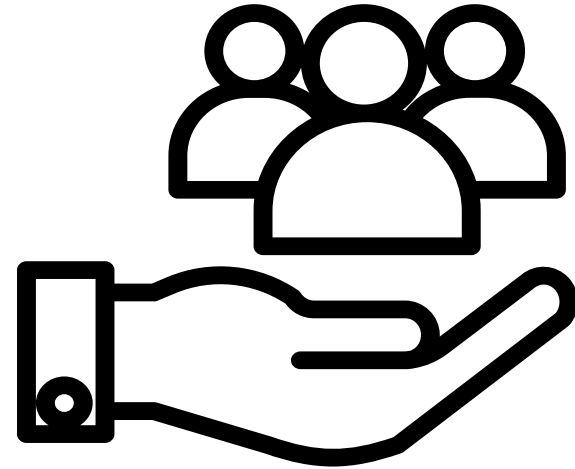
- Workforce
- Funding
- Coverage





# Opportunities

- Collaboration
- New Approaches
- Engagement with Community



# Crisis Funding

- Crisis Continuum Funding Chart
- Designed for Local Leaders
- Includes County Examples



Scan the  
QR code to  
access the  
funding chart



# Crisis Messaging

- Designed for Local Leaders
- Includes County Examples
- Next Report Focused on I/DD Directors





**NACBHDD**

National Association of County  
Behavioral Health & Developmental  
Disability Directors

The voice of local authorities in the nation's capital

# ***THANK YOU***

- [jcunningham@nacbhd.org](mailto:jcunningham@nacbhd.org)
- [NACBHDD.org](http://NACBHDD.org)
- [NARMH.org](http://NARMH.org)



# Committee Discussion



# Closing Remarks and Adjournment



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

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH

# Next IACC Meeting



## **IACC Full Committee Meeting (hybrid)**

January 24, 2024, 10:00 AM – 5:00 PM

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>



# Thank you to the OARC Staff and Meeting Support Team!



**Susan Daniels, Ph.D.**  
Acting National Autism  
Coordinator, HHS  
Director, OARC



**Oni Celestin, Ph.D.**  
Science Policy Analyst



**Katrina Ferrara, Ph.D.**  
Science Policy Analyst



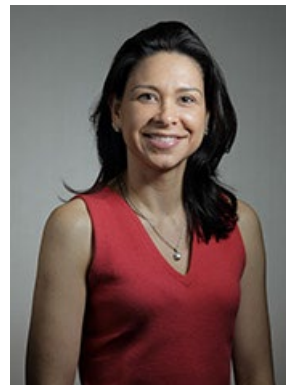
**Steven Isaacson, L.M.S.W.**  
Policy Analyst



**Tianlu Ma, Ph.D.**  
Science Policy Analyst



**Rebecca Martin, M.P.H.**  
Public Health Analyst



**Angelice Mitrakas, B.A.**  
Management Analyst



**Luis Valdez-Lopez, M.P.H.**  
Science Policy Analyst



**Jeffrey Wiegand, B.S.**  
Web Development and  
Digital Outreach Manager

