Meeting of the Interagency Autism Coordinating Committee

Day 2
October 14, 2021; 1:00 - 5:00 p.m. ET

Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health (NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

Update on Kevin and Avonte's Law

Kristie Brackens, M.S., M.P.A.
Senior Policy Advisor
Bureau of Justice Assistance
Office of Justice Programs
U.S. Department of Justice

Joy Paluska
Program Manager
Missing Children Division
National Center for Missing & Exploited Children (NCMEC)
NCMEC Data, Resources, & Outreach Related to Children on the
Autism Spectrum

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

BUREAU OF JUSTICE ASSISTANCE

KEVIN AND AVONTE UPDATE

Program History

- Kevin and Avonte's Law enacted in 2018

- Kevin and Avonte's Law is **named in honor of two boys with autism** who perished after wandering

- Nine-year-old Kevin Curtis Wills wandered from home, slipped into Iowa's Raccoon River and drowned in 2008

- Fourteen-year-old Avonte Oquendo wandered away from his school and drowned in New York City's East River in 2014.

MISSING
Avonte Oquendo

Avonte Oquendo (14 yrs.) was last seen at his Long Island City, Queens, NY school at 12:38 p.m. on Friday (10/4/2013). Avonte is autistic and is not able to communicate verbally. He was caught on surveillance video running out of the school located on 51st Avenue. Avonte Oquendo is described as a Black male, 5'3" tall, and weighs 120 lbs. He was last seen wearing a gray striped shirt, black jeans, and black sneakers. Avonte Oquendo has no history of running away. If you have seen Avonte Oquendo, know of his whereabouts, or have information on this case, you are asked to contact the NYPD Crime Stoppers at (800) 577-TIPS, log onto the Crime Stoppers website http://crimestoppers.nyc.gov, or text tips to 274637 (CRIMES) and enter TIP577.

(800) 577-TIPS

share this flier

Program Goal and Objectives

Program Goal: Reduce and prevent injuries and deaths of missing individuals with forms of dementia, such as Alzheimer's Disease, or developmental disabilities, such as autism, who due to their condition wander from safe environments.

- It provides funding to law enforcement and public safety agencies to implement locative technologies to track missing individuals; and to such agencies and partnering nonprofit organizations to develop or operate programs to prevent wandering, increase individuals' safety, and facilitate rescues.

BJA Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities Program

Minot State University

Lowell
Boston
The Autism Project
National Autism Association
East Orange
Allegheny County
Pathfinders for Autism
Ascendigo Autism Services
Cincinnati
Spotsylvania County
Chesterfield County
Alzheimer's Los Angeles
Los Angeles County WDACS
Mental Health America - TN
Get Safe Personal Safety
Madison County
Franklin County
Montgomery County
Blessed Be Hope for Three, Inc.
Sumter County
Harris County
Osceola County
United Way of Lee,
Hendry, Glades and
Okeechobee
Alzheimer's Community Care
Broward County

Legend

Most Recent Funding Year

★ FY19
★ FY20

6

Site Highlights

- Alzheimer's Community Care
- ReUnite Program
- Mental Health America of the Midsouth
- Boston Police Department
- Osceola County Sheriff's Office
- Sumter County Sheriff's Office

Alzheimer's Community Care
ID Locator Service

Is a comprehensive Dementia Specific Provider

- − With 7 Core Services for Patients and Caregivers

They provide an ID Locator Service − Which served over 500 patients this past year

- − There are 207 active RF Patients and 126 active ID Bracelet Patients
- − 100% Elopement Recovery Success Rate

The program goals are:

- 👥 Expansion, Education, Awareness,
- 👥 Strengthen Partnerships, Silver Alert/Lost On Foot

Accomplishments include:

- 👥 Advisory Committees with Law Enforcement
- 👥 Representation, Established Technology Platform
- Service Video (2:32): https://youtu.be/MdASWxh1XrY

The ReUnite Program is a community-based collaborative program between United Way and the Lee, Hendry and Glades County Florida Sheriff's Offices, a non-profit organization that is dedicated to improving the quality of life in the community

- The United Way's ReUnite Program aims to assist in the safety and security of those in the community who are at high risk to wander

- ReUnite is inclusive of Scent Evidence K9 kits, bloodhounds and technology

The Goals:

- Enroll 300 participants into ReUnite program for three-year grant period, currently have 228 participants enrolled in the 10-month period.
  - Between January and April, 218 people were reported missing to the Lee County Sheriff's Office, 47 were ReUnite members and all were found.

- Work closely with local law enforcement partners and partner agencies to educate the five-county area by collaborating in ways that benefit the prevention and awareness of wanderers

Mental Health America of the Midsouth

The Work:

➢ Provides education, information, and resources for those struggling with mental health issues including Alzheimer's and dementia.

The Goal:

➢ Provide and place information in the hands of those who are care for those living with Alzheimer's and dementia.

The Accomplishments:

➢ Have conducted 15 trainings (389 First Responders) in Alzheimer's and dementia with a focus on wandering behavior.

➢ Provided File of Life cards to over 5,000 Tennessee residents.

➢ Have distributed over 7,000 individual pieces of information to the older adult population in 13 counties.

Boston Police Department

- Aims to provide lifetime SafetyNet service (Radio Frequency tracking) and/or ID bracelets to 225 families of individuals who have a tendency to wander due to dementia or developmental disabilities

The goals:

- Goal 1: Reduce injury and death of individuals who have a tendency to wander due to dementia or developmental disabilities by locating them as quickly as possible utilizing SafetyNet tracking
- Goal 2: Increase knowledge and skills related to dementia and developmental disabilities among the members of the BPD's Street Outreach Unit

Accomplishments:

- 26 new clients enrolled in SafetyNet Radio Frequency tracking as of 6/30/2021 utilizing current grant funds
- 65 clients enrolled in Radio Frequency tracking since inception of BPD-SafetyNet partnership in 2012

Osceola County Sheriff's Office
Project Lifesaver

The Work:

❖ Offers a Project Lifesaver band to Osceola county residents with cognitive disorders that may lead to elopement.

    ❖ Available at no cost to any potential clients.

    ❖ The Sheriff's Office will also change out batteries and check on the client every 60 days.

The Goals:

❖ 100 clients banded.

❖ Training all Patrol Sergeants on how to track missing clients and outfitting them with receivers.

The Accomplishments:

❖ First client was banded in April 2021.

❖ Currently we have 30 clients in the Project Lifesaver Program.

❖ Two successful finds.

Sumter County Sheriff's Office

Provides professional law enforcement services through well-trained staff, technology, crime prevention, and a results-oriented, proactive approach to public safety in Sumter County, Florida

Program Goals:
- Provide families with GPS enabled devices to give caregivers peace of mind and empower them to locate their loved one in case of a wandering event
- Ensure any missing person in the community is quickly and safety reunited with their families through the use of GPS enabled devices and assistance of law enforcement

Accomplishments:
- 59 devices distributed
  - December 2020 to April 2021 = 32
  - May 2021-June 2021 = 27
- 9 participants have been located and brought home safely by family
- 4 caregivers reported getting safe zone alerts which allowed them to avoid wandering incident
- January to June 2021 – 8 CFS for Missing Person/Alzheimer's (not participants in program)

Locative Technology Roundtable

Recommendations for how existing suitable HHS standards and best practices could be adopted relating to the use of tracking technology.

Recommendations for modifying suitable HHS standards and best practices relating to the use of locative technology.

Recommendations concerning the needs and requirements that new standards and best practices must address relating to the use of locative technology

Locative Technology Roundtable Key Take-Aways

Creation of federal and national standards for the use of tracking technology to locate missing individuals who have wandered due to their conditions should include perspectives of everyone affected by the standards, including families, law enforcement, special education teachers, experts, manufacturers, and people with lived experience.

Any standards created for the use of tracking technology to locate missing individuals who have wandered due to their condition need to be flexible and adaptable to different departments and jurisdictions.

Locative tracking technology should be used as a last resort. All other prevention methods should be utilized first.

Every vulnerable individual has their own pattern of behavior, and it can be difficult to generalize and define a single cause for wandering across a large population with various personalities and disabilities.

Training for officers, first responders, and 9-1-1 dispatchers, focused on identifying key characteristics and behaviors associated with intellectual and or developmental disabilities and dementia, is essential to direct clients to the appropriate services they require.

Training and Technical Assistance Providers

- International Association of Chief of Police
- The National Center for Missing and Exploited Children
- The Arc of the United States

Home Safe

https://www.theiacp.org/projects/home-safe

FY21 and Beyond

- Plan to make 17 new awards totaling $2.3 million.
- Stakeholder Workshop Spring 2022
- FY 22 Planned Program enhancements:
  - Development of Prevention toolkit
  - Increase focus on public education/awareness
  - Expand focus to include resources specific to exploitation of children who wander online

Contact Information

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Sr. Policy Advisor

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National Center for Missing & Exploited Children

Data, Resources, & Outreach Related to

Children on the Autism Spectrum

October 2021

Agenda Topics

- Mission & History

- Missing Child Data & Resources

- Reducing Child Sexual Exploitation

- Preventing Future Victimization

- Questions

OUR MISSION

Find Missing Children

Reduce Child Sexual Exploitation

Prevent Future Victimization

Hope is why we're here.

Finding Missing Children

NCMEC Data (2011-2020)

Causes of Accidental Deaths

- Vehicular 4%
- Undisclosed/Undetermined 2%
- Asphyxiation/Suffocation 2%
- Exposure/Weather 7%
- Drowning 84%
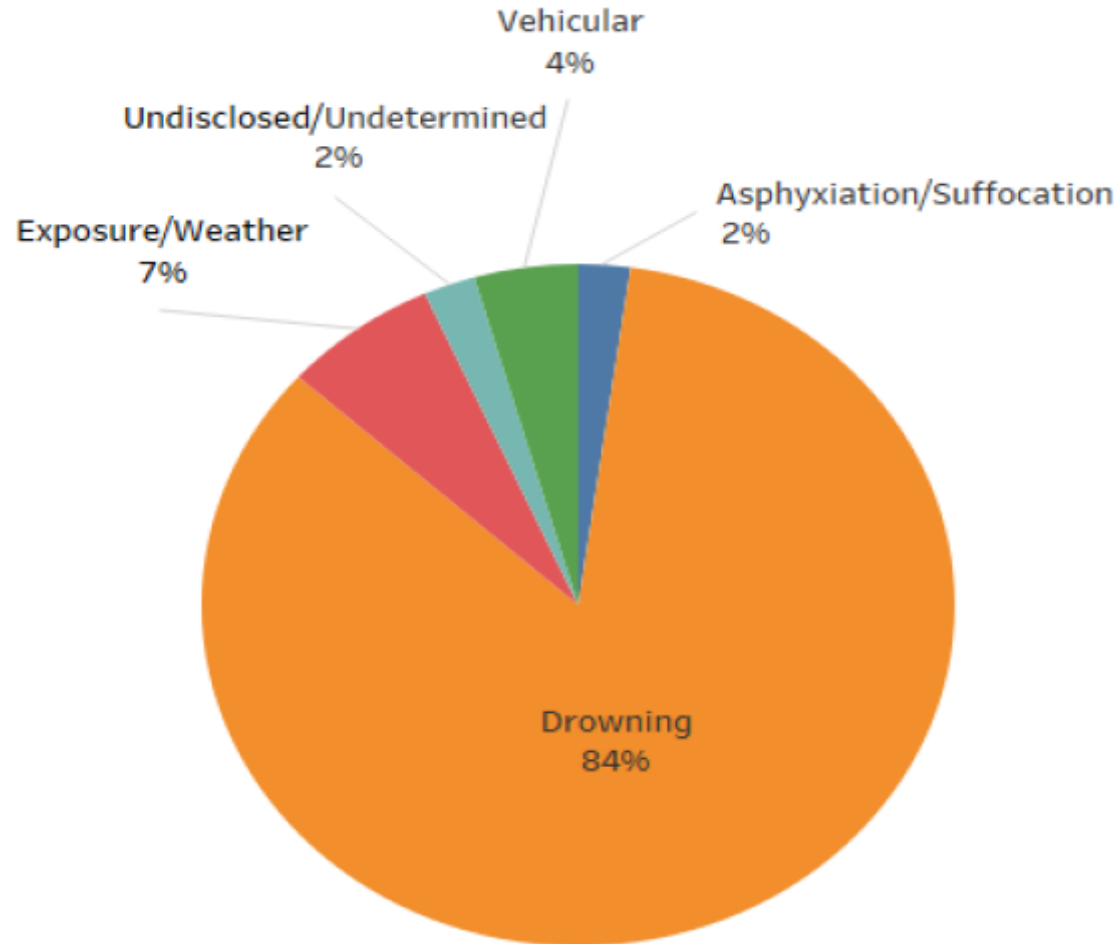
Most Common Recovery Methods

Police Investigation: **46%**

Child Returned Home on Own: **17%**

Family/Friend Turned Child in: **14%**

- 1,516 children on the autism spectrum were reported missing to NCMEC
- These children were involved in 1,986 missing incidents
- 64 (4%) children recovered deceased

NCMEC Data (2011-2020)

Missing Month Across All Years
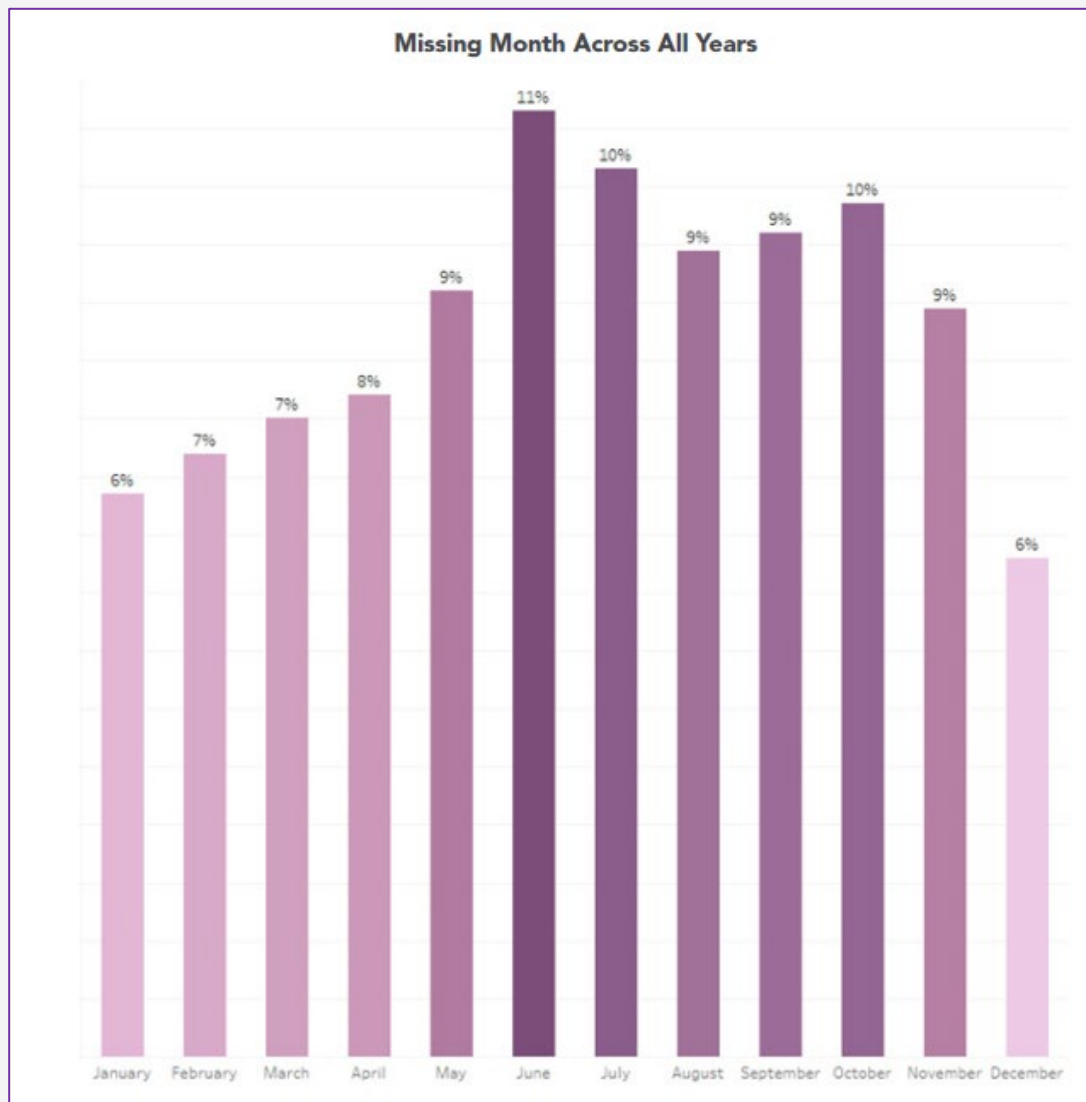
Highest reported missing incidents are during the summer

98% recovery rate for cases reported to NCMEC

How Does NCMEC Help?

Case Management

- On call 24/7
- Provide support to parents/guardians & LE
- Create & disseminate posters to generate leads
- Review & share all leads/ new information with LE
- Gather information & coordinate analytical support
- Referrals to family advocacy services
- Coordinate with specialized LE resources [Team Adam, federal liaisons]
- Long-term missing cases [age progressions, forensics, case review]

Team Adam Consultants

- **Deploy and provide on-site assistance**

- **Critical Case Assistance**
  - Rapid deployment
  - On-site assistance
  - Search assessment/management
- **Long Term Case Assistance**
  - Organization & analysis
  - Investigative strategies
  - Lead development

Analytical Support

Corporate data partners, data resource management, & public record accounts

Leading data analytics & public records database organizations in the U.S.

Social media & open-source searches

NCIC / NLETS searches
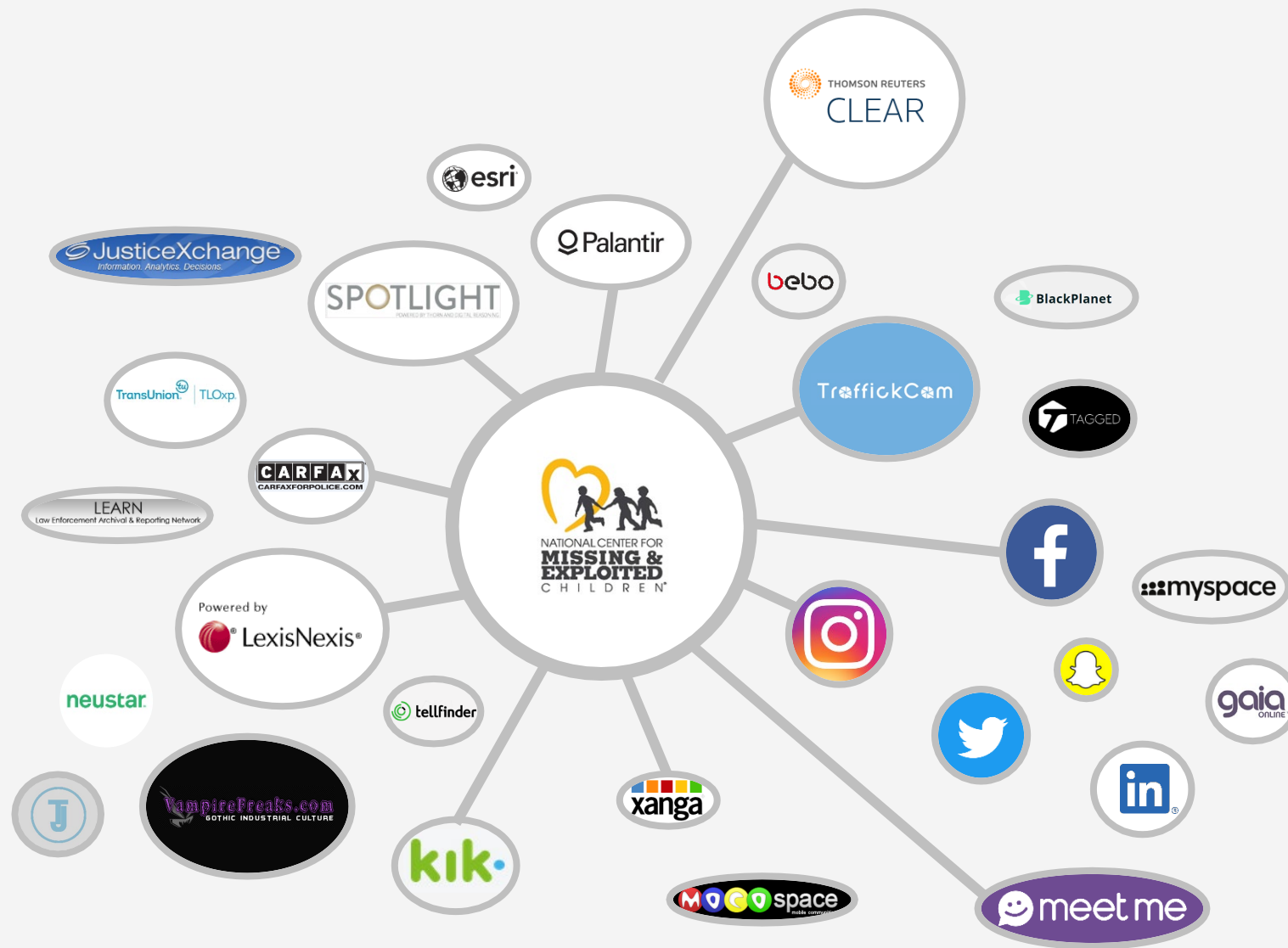
Family Services

Family Advocacy Division

- Specialized support to family members

- Crisis intervention support

- Reunification assistance

Team HOPE

- Peer support for families with missing or sexually exploited children

- Families are matched with experienced and trained volunteers who have experienced a missing or sexually exploited child in their own family

Federal Partners

Core Components of Law Enforcement Outreach & Awareness

- Officer Training

- Community Education & Outreach

- Community Partnerships & Events

- Communication

NCMEC's Outreach & Awareness

- Model Programs & Resources for LE & Families: https://www.missingkids.org/theissues/autism

- 2011-2020 Report on Missing Children on the Autism Spectrum

- NCMEC CONNECT:

  https://connect.missingkids.org/

- Blogs on Swimming Safety & Searching Water

- Partnership with National Autism Association

- Grant & Webinar with The International Association of Chiefs of Police/Bureau of Justice Assistance
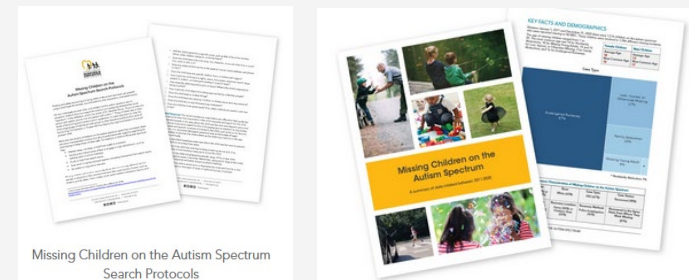
Reducing Child Sexual Exploitation

What is Child Sexual Exploitation?

CyberTipline.org

- Child Sexual Abuse Materials (CSAM)
- Online enticement of children for sexual acts
- Child sex trafficking
- Child sex tourism
- Child sexual molestation
- Unsolicited obscene materials sent to children
- Misleading domain names
- Misleading words or digital images on the internet
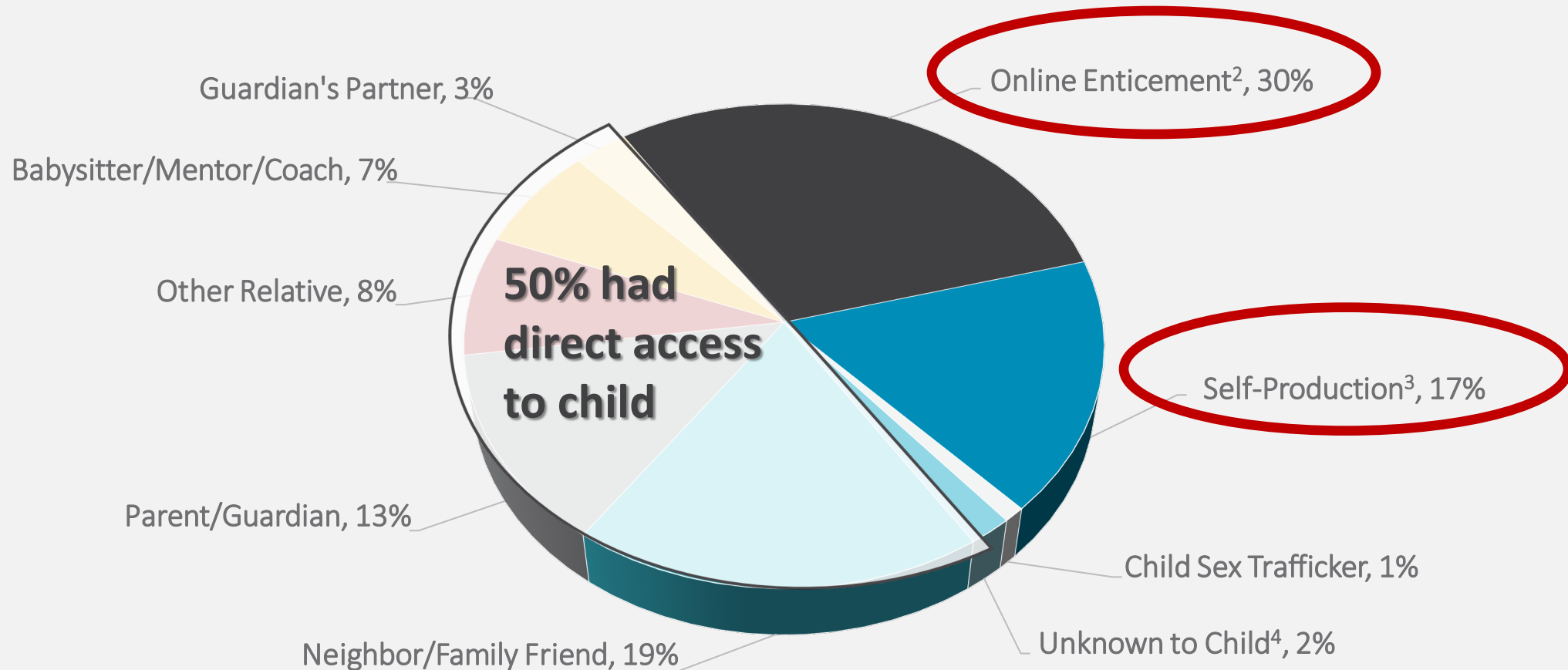
Online Enticement

• Involves an individual communicating with someone believed to be a child via the internet with the intent to commit a sexual offense or abduction.

• This is a broad category of online exploitation and includes sextortion, in which a child is being groomed to take sexually explicit images and/or ultimately meet face-to-face with someone for sexual purposes, or to engage in a sexual conversation online or, in some instances, to sell/trade the child's sexual images.

CYBERTIPLINE WORKFLOW
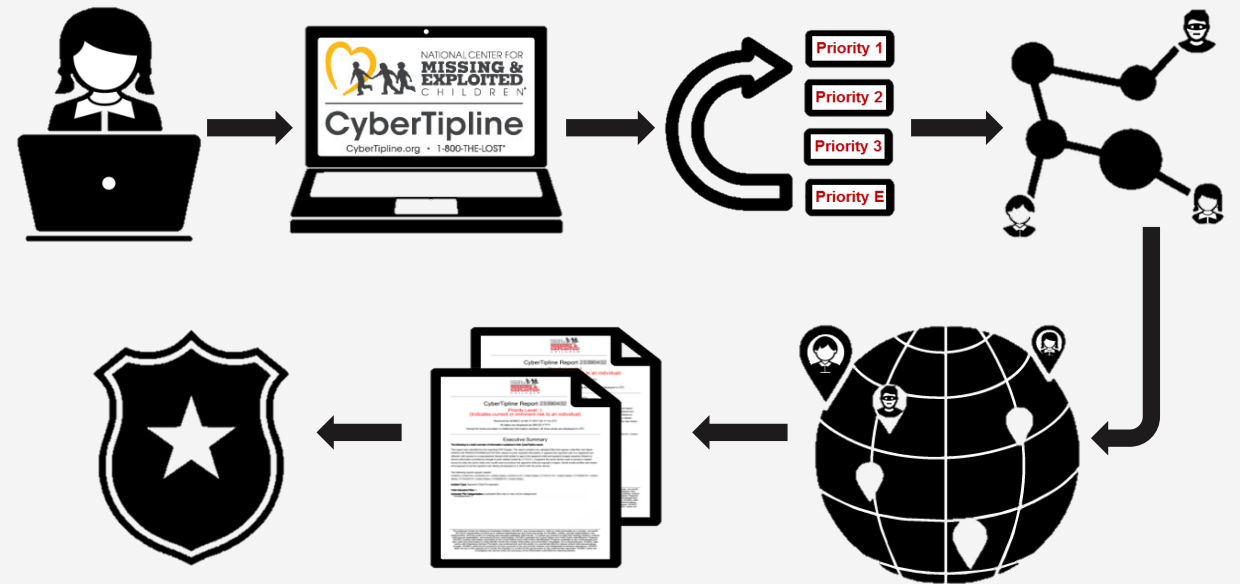
All Identified Children: Relationship of Exploiter to Child[1]

Pie chart segments:
- Online Enticement[2], 30%
- Self-Production[3], 17%
- Child Sex Trafficker, 1%
- Unknown to Child[4], 2%
- Neighbor/Family Friend, 19%
- Parent/Guardian, 13%
- Other Relative, 8%
- Babysitter/Mentor/Coach, 7%
- Guardian's Partner, 3%

50% had direct access to child

1. Abuser data based upon victim information submitted to NCMEC by law enforcement, as of December 31, 2020. The data represent the known relationships from 14,407 series (19,208 children).
2. *"Online Enticement"* includes either (1) victims who met a perpetrator online and transmitted self-produced images or (2) victims and offenders who met online and then met offline, producing images.
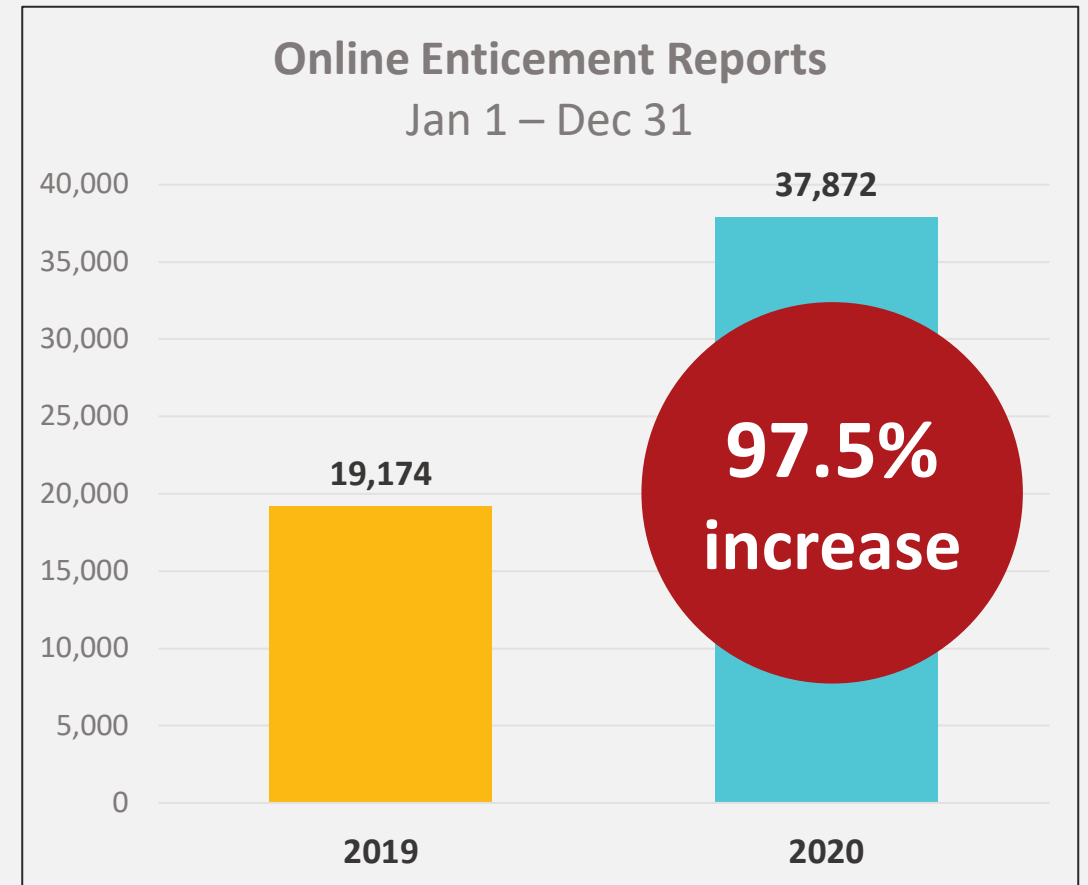3. *"Self-produced"* includes those victims who have produced and distributed images of themselves.
4. *"Unknown to Child"* includes un-established relationships, i.e. photographers, runaways, etc.
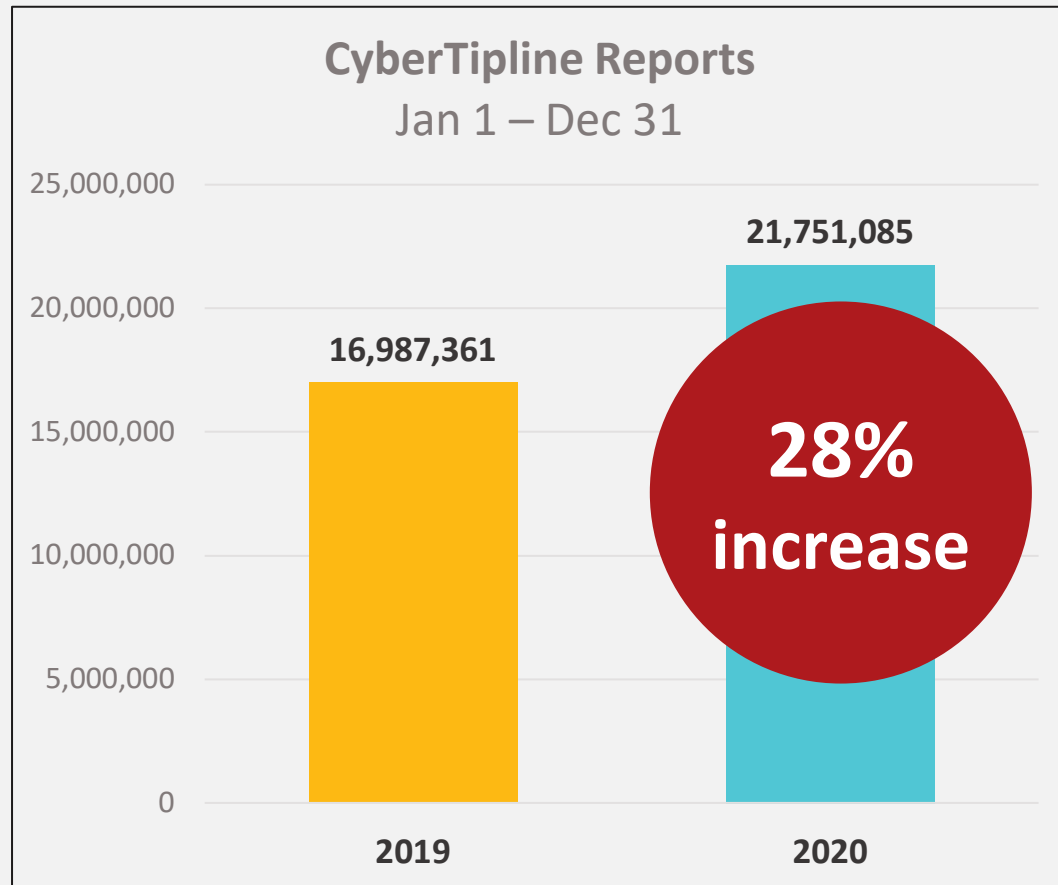
Online Enticement

- Perpetrators look for easy targets
- Many children can fall victim to manipulation
- Children can have trouble discerning bad behavior or danger which increases their risk
- Children who feel excluded or are seeking a connection are at risk
- Children with intellectual and developmental disabilities are at risk

Preventing Future Victimization

NetSmartz®

Online safety program for children and families in grades K-12.

Empower children to take an active role in solving problems safely

Engage children and adults in two-way conversations about safety and risky behaviors

Encourage children to report unsafe behaviors or victimization

Internet Safety
Parents • Guardians • Communities
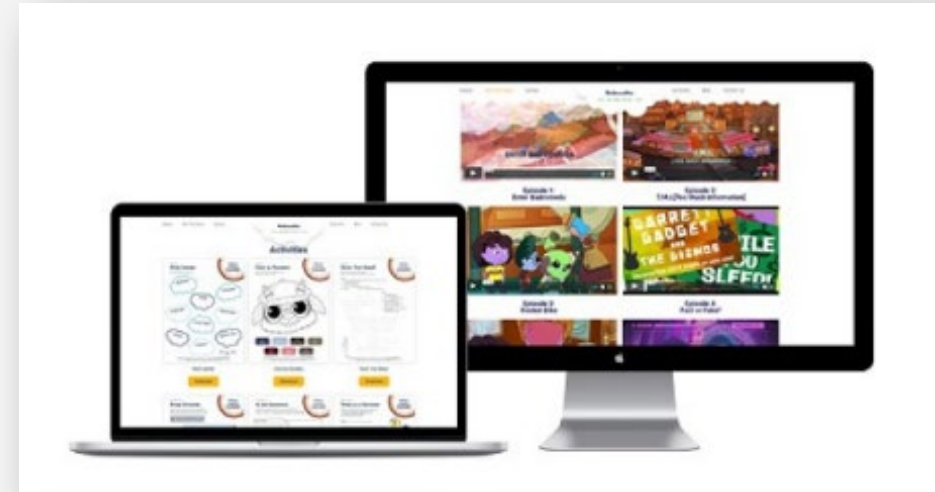
Internet Safety at Home

As adults and children alike have turned to digital tools for school, work, and socialization, online safety matters now more than ever.

Here are **five tips** for keeping kids safer online, adapted to fit the current "safer at home" environment.

Tip 1: Keep the Ground Rules

Even if our online habits have changed significantly, you can still set boundaries that work for your family and schedule. Involving children in setting these rules may help them stick to the guidelines.

Consider:
• Distance learning tasks **before** social media or gaming
• **No devices** during meals
• At least ____ **minutes** of non-electronic activities per day
• "**Digital curfew**": no devices after a certain hour

Tip 2: Modify How You Monitor

Even the strictest monitoring programs and content blockers can't ensure that children are totally protected online. The best tools for keeping kids safe are time, attention and active conversation about digital behaviors.

Consider: Setting up **workstations** for children and teens that provide **quick visual access** to the screens for **easy check-ins** from parents/caretakers as they telework or complete household tasks.

More Resources from NetSmartz®

Activity Guides
From discussion tools to classroom lessons, these resources supplement NetSmartz video content and let students practice safety skills.

Online Games
Interactive games that help children review online safety issues in fun and unique ways.

Peer Education & Leadership Kits
Project-based learning opportunities for older students to teach younger students about digital citizenship and safety.

NetSmartzKids.org
A safe site for kids! Watch "Into the Cloud" and classic NetSmartz videos, play games, read e-books and more, in a child-safe environment.

Presentations
Scripted PowerPoint® presentations describing the main online safety issues and how to address them.

Tip Sheets
Reference guides to remind parents and children about ways they can stay safer online.

Videos
Animated and live-action videos, including the new web series "Into the Cloud", that show students how to apply important safety skills to on- and offline life.

MissingKids.org/NetSmartz
Adults can learn more about the issues facing children online and accesss tools to help keep kids safer at MissingKids.org.

Asking for Help
Resource

So, You Need Some Help…

NetSmartz®

Maybe you made a mistake. Maybe you need some advice about something uncomfortable. It's not always easy to approach an adult in these situations. This guide has tips for talking to a trusted adult and how to navigate their responses.

Tip #1

Practice

Practice what you want to say *to start the conversation* as well as the *main points* you want to be sure to include. It's easy to leave out important details when you're nervous or if a conversation gets heated. Say the words out loud. Try practicing in front of a mirror.

Tip #2

Be Clear About What You Want

What do you want your trusted adult to do? Give advice? Help make a report? Just listen? Whatever it is, be clear about how they can help you.

Tip #3

Be Honest, Even If It's Hard

You might feel embarrassed or ashamed of a mistake, or worried that if you tell the whole truth, adults will get mad or people will get in trouble, but honesty really is the best policy. Laying it all out there may even mean the problem gets solved faster because everyone has all the facts.

Tip #4

Focus on Forward

Answer any questions your trusted adult has about what happened, but try to keep the conversation moving and focused on what actions you and your trusted adult will take next to resolve the situation.

Tip #5

Keep Calm

Try to keep calm throughout the conversation. You may feel nervous at the beginning, someone may get angry in the middle – that's normal. If things become too tense to move on, it's OK to take a break and come back to the conversation. Practicing what you want to say (tip 1) will also help you stay calm during this discussion.

Most importantly **know that it's always OK to ask for help.** It may not be easy, but it will be worth it.

- If the first trusted adult you go to can't or won't help, **KEEP TRYING.**
- No matter what you're dealing with, there is someone who can help. You're not alone.
- You can report sexual abuse or online sexual exploitation to **CyberTipline.org.**
- You can find more resources at the **National Child Traumatic Stress Network.**

A program of the
NATIONAL CENTER FOR
MISSING & EXPLOITED CHILDREN

NCMEC'S CSAM SURVIVOR SERVICES

TECHNICAL

Removing images, videos and comments online

Hash Sharing of "Worst-"of" and "Exploitative"

Flagging images, videos, comments that could impact survivors

EMOTIONAL

Provide immediate, crisis intervention for victims and their families

NCMEC's Family Advocacy Outreach Network helps survivors and families find long-term counseling services

LEGAL

Assistance in locating an attorney to guide survivors through restitution and victim rights' options

INFORMATIONAL

Working with the survivor advocates, NCMEC educates victim-serving professionals to improve the response, processes and resources for survivors

Includes Law Enforcement, Mental Health, Private Attorneys, Medical, Education, Caregivers, CPS, Prosecutors, Tech and more

Welcome to NCMEC CONNECT

Your virtual gateway to trainings, resources and best practices related to missing and exploited children. Build your knowledge set around these issues to better protect children in your community

connect.missingkids.org

FREE on-demand trainings, resources and best practices related to missing and exploited children.

New Courses:

- Understanding CSAM and Its Impacts
- Introduction to Child Sex Trafficking
- Child Safety Resources

CONTACT INFORMATION:

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Program Manager

Special Projects

jepaluska@ncmec.org

1-800-THE-LOST

For more resources please visit MissingKids.org

@MissingKids

Break

Public Comment Session

Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

Summary of Written Public Comments

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

- ***Programs, Supports, and Housing Options for Autistic Individuals with High Support Needs***
  - Julie Fackrell
  - Patricia Athitakis
  - Alice Taylor
  - Mel Persion
  - Sara Polito
  - Vance Goforth
  - Christine Miles Kincaid
  - Martha Gabler

- ***Concern about Medical Practices and Potential Causes of Autism***
  - Eileen Nicole Simon
  - David M. DeMarini
  - Carole Yauk
  - Robert Castleberry
  - Joe Rashid

- ***The Role of the IACC and the Federal Government***
  - Gene Bensinger
  - Chris Colter
  - Hoangmai Pham

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2021/full-committee-meeting/october13-14/public_comments.pdf?ver=4

Summary of Written Public Comments (cont.)

- ***Service Needs, Resources, and Policy Implications***
  - Melvin Rodgers
  - Peggy Kilty

- ***Needs of the Direct Support Professional Workforce***
  - Kathryn Ashley

- ***Treatment of Autistic Individuals in Medical Settings***
  - Brian Gene Evans

- ***Services and Supports for Adults with Autism***
  - Ilene Lainer
  - Kastur Halai

- ***Comments for the IACC Strategic Plan update***
  - Douglas Bass
  - Martha Gabler

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2021/full-committee-meeting/october13-14/public_comments.pdf?ver=4

Summary of Written Public Comments (cont.)

- **_Concern about the Use of Graduated Electronic Decelerators (GEDs)_**

Sasha P.	Sophie Hughes	Aminata Camara	Ella Ward
Kerry Recht	Emily Chicklis	Frank Corso IV	Ivy Schmid
Ariana Uriati	Anish Krishna	Samantha Ayala	William Spangler
Holly Manning	Cypher Chu	Sathya Siddapureddy	Anne Sydor
Quin Potter	Beatrice Augustine	Carolina Semedo	Megan Denardo
Veronica Poquette	Liz Franzone	Lydia Jung	Grecia Negra
Caden McIsaac	Mark Blokpoel, Ph.D.	Gareth Jones	Brianna Mau
Magdalene Ho	Rebecca Margolick	Shoshana Levy	Sarah Showich
Athithya Aravinthan	Dan Schwartz	Mia Van	Bashirat Oladele
Ivan Corn	Emily Sandford	Sarah Maue	Belle
Vanessa Matelski	K.E. Eckerman	Ariana Martinez	Lydia Jung
Nicole Dannen	Sandy Avrutin	Pheobe Timms	Katie Krasinski
Baker Kipping	Kate Murphy	Ashley Hazim	Sprite Minton
Ulysse Bartolomey	E. Gill	Hannah Judson	Miranda Jackel
Kristy Dodds	Alexandra Bance	Kelly Stanton	Tristen Koffink
Mirphy Harrison	A. Héraud	Janine Briones	Emma Fixmer
Sara Rocha	Sherry Midi	Kristin M. Paschall	Karli Hayden
Ira Kraemer	A C	Nicholas Smith	Shannon Cardinal
Ryan Robinson	Meghan Kelly	Hayden Day	Stephannie Bethel

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2021/full-committee-meeting/october13-14/ged_public_comments.pdf

Break

Priorities and Potential for Autism and Mental Health Research

Presented to the NIMH/OARC Interagency Autism Coordinating Full Committee (IACC)

Teal Benevides, PhD, Jessica Rast, MPH,
Lindsay Shea, DrPH, MS, Stephen Shore, EdD

AASET

Life Course Outcomes
Research Program

PAC
POLICY & ANALYTICS
CENTER

October 14, 2021

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

Life Course
Outcomes Program

PAC
POLICY & ANALYTICS
CENTER

A quick introduction: Jessica Rast

- Mental health
  - is a vital component of health
- Mental health care
  - is an integral part of health care

A quick introduction: Lindsay Shea

Health care system factors:
How services are accessed and provided

AUTISTIC INDIVIDUALS
- Beliefs/preferences
- Race/ethnicity
- Culture
- Family context

USE SERVICES
- Types of mental health services available
- Assessments for mental health service need

PROVIDED BY CLINICIANS
- Knowledge and attitudes
- Bias

Adapted from: Kilbourne AM, et al. Advancing health disparities research within the health care system: a conceptual framework. Am J Public Health. 2006;96(12):2113-21

Strengthen Public Health Impact

DREXEL UNIVERSITY
A.J Drexel
Autism Institute

Life Course Outcomes Program

PAC
POLICY & ANALYTICS CENTER

Autism Transitions Research Project

Our goal: Identify factors associated with healthy life outcomes and access to needed services.

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Autism Institute

Life Course
Outcomes Program

PAC
POLICY & ANALYTICS
CENTER

Mental Health Matters

- In transitions
- In systems
- In families
- Because mental health diagnoses are common
- Because care is complex

NATIONAL AUTISM INDICATORS REPORT:
Mental Health

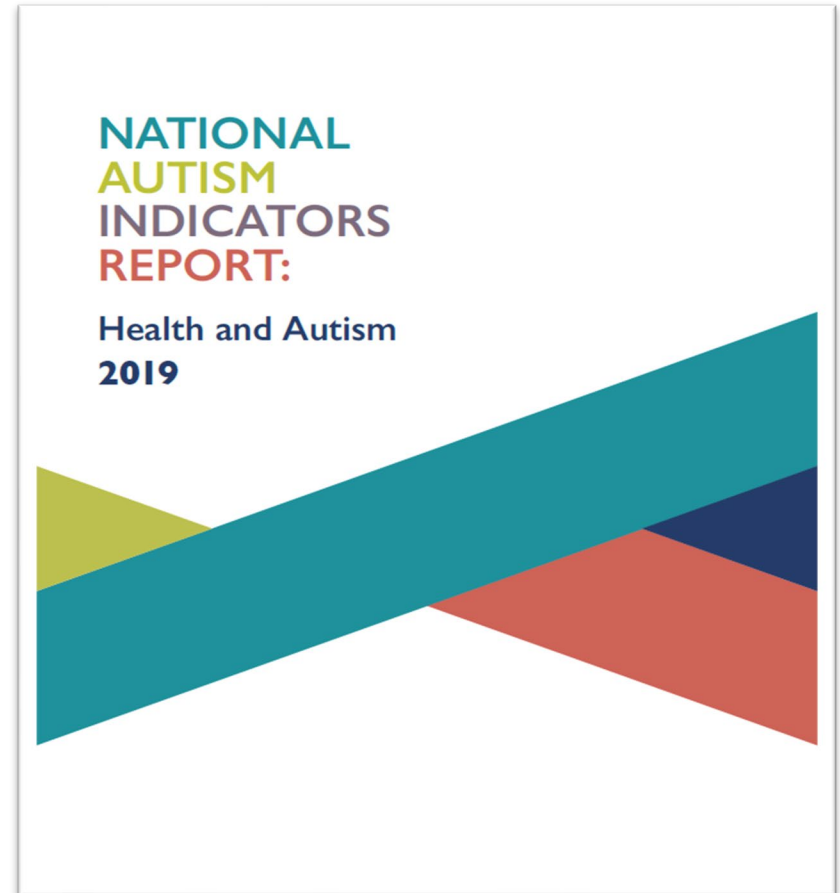drexel.edu/AutismOutcomes/MentalHealth

Life Course
Outcomes Program

PAC
POLICY & ANALYTICS

DREXEL UNIVERSITY
A.J. Drexel
Autism Institute

DREXEL UNIVERSITY
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Autism Institute

Life Course
Outcomes Program

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CENTER

Why mental health

- Follow-up to previous report

NATIONAL AUTISM INDICATORS REPORT:
Health and Autism
2019

Why mental health in autism

- Autism ≠ mental health
- Autism = family history, ACEs, discrimination, isolation, uncertainty

Mental health services

- Supporting mental health requires accessible and appropriate mental health care

Data used

child

- National Survey of Children's Health 2016-2019

- Medical Expenditure Panel Survey 2013-2017

- National Inpatient Sample 2017

- Centers for Medicare & Medicaid Services (CMS) Medicaid Analytic eXtract (MAX) files 2008-2012

adult

- National Inpatient Sample 2017

- CMS MAX files 2008-2012

- Kaiser Permanente Northern California previously published research
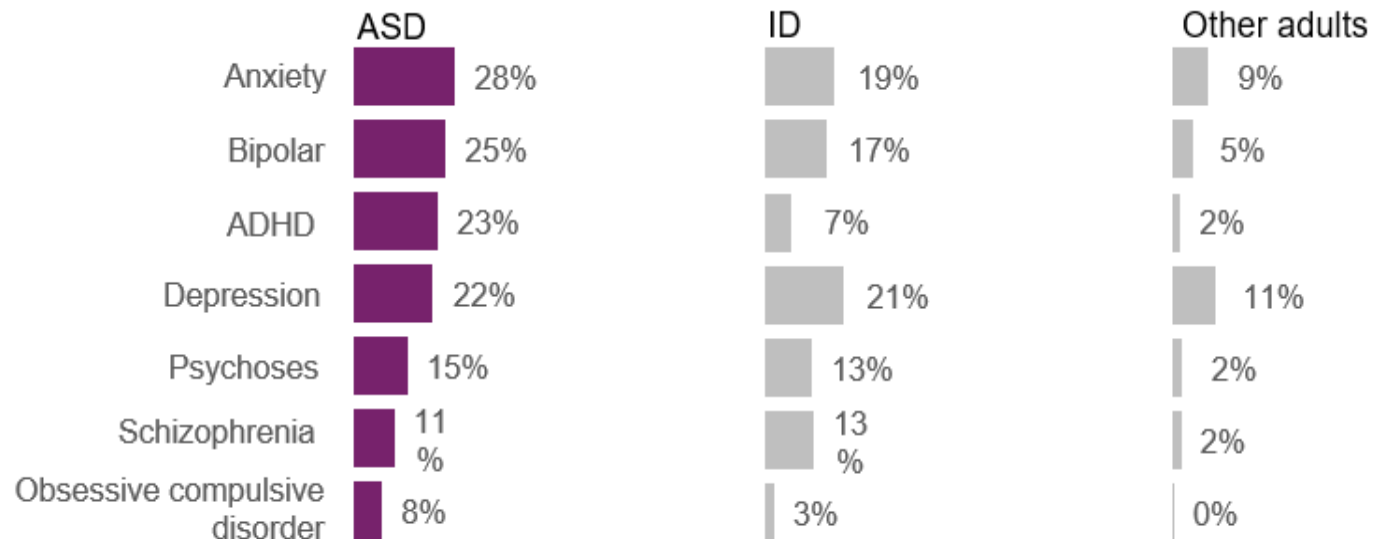 - Findings from NAIR: Health

results

MENTAL HEALTH CONDITIONS

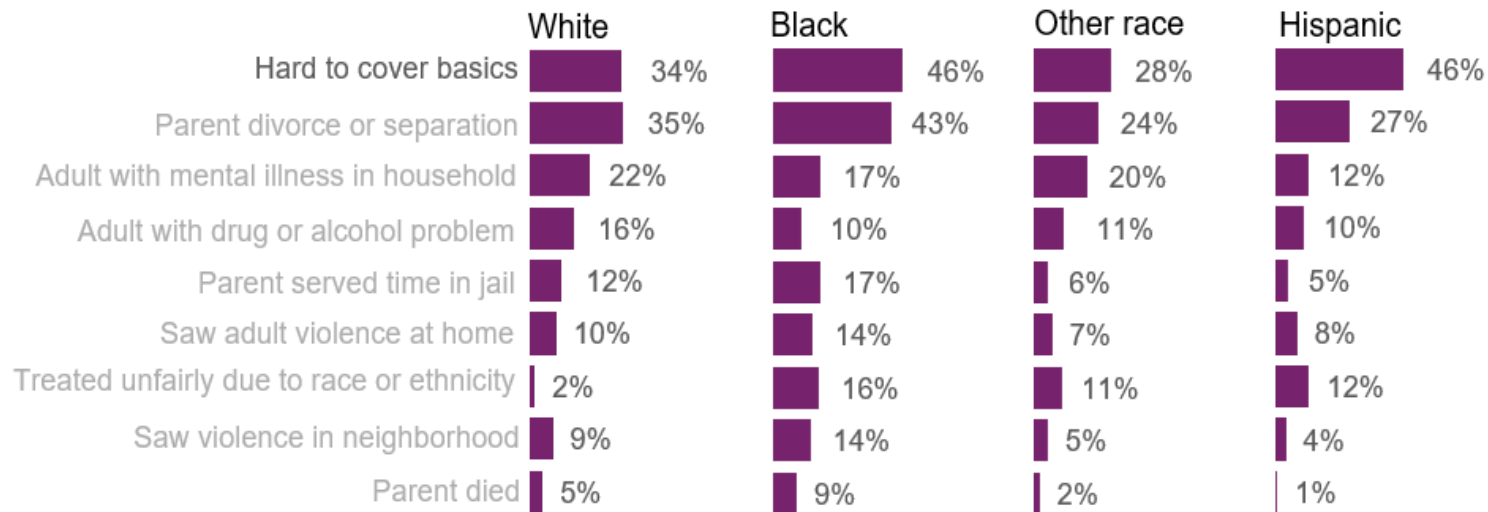# Prevalence of mental health conditions varied by race and ethnicity in autistic children
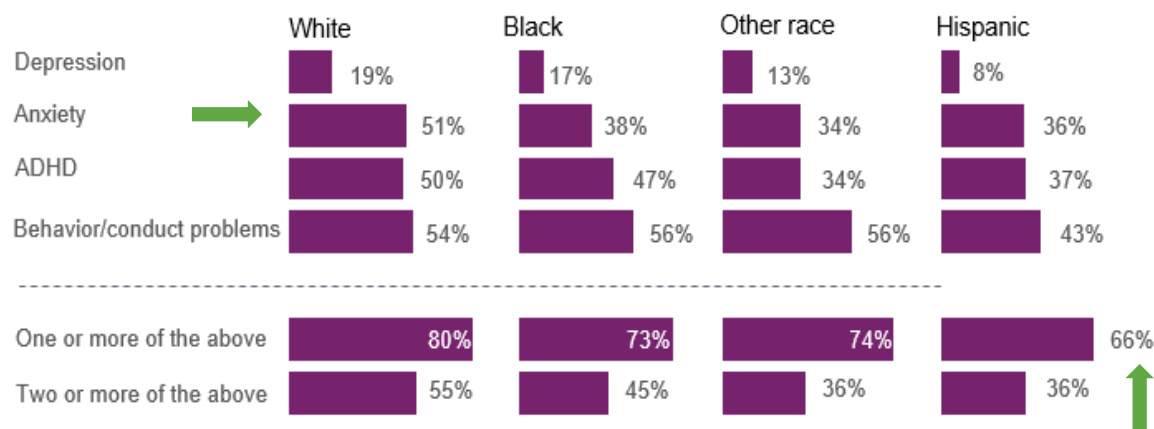
Source: National Survey of Children's Health 2016-19

Medicaid: Anxiety and depression were the most common mental health conditions in the health records of autistic adults

	ASD	ID	Other adults
Anxiety	28%	19%	9%
Bipolar	25%	17%	5%
ADHD	23%	7%	2%
Depression	22%	21%	11%
Psychoses	15%	13%	2%
Schizophrenia	11%	13%	2%
Obsessive compulsive disorder	8%	3%	0%

Source: Medicaid MAX 2008-2012

The most common adverse childhood experience experienced by autistic children was difficulty covering the basics like food and housing on the household income.


	White	Black	Other race	Hispanic
Hard to cover basics	34%	46%	28%	46%
Parent divorce or separation	35%	43%	24%	27%
Adult with mental illness in household	22%	17%	20%	12%
Adult with drug or alcohol problem	16%	10%	11%	10%
Parent served time in jail	12%	17%	6%	5%
Saw adult violence at home	10%	14%	7%	8%
Treated unfairly due to race or ethnicity	2%	16%	11%	12%
Saw violence in neighborhood	9%	14%	5%	4%
Parent died	5%	9%	2%	1%

Source: National Survey of Children's Health 2016-19
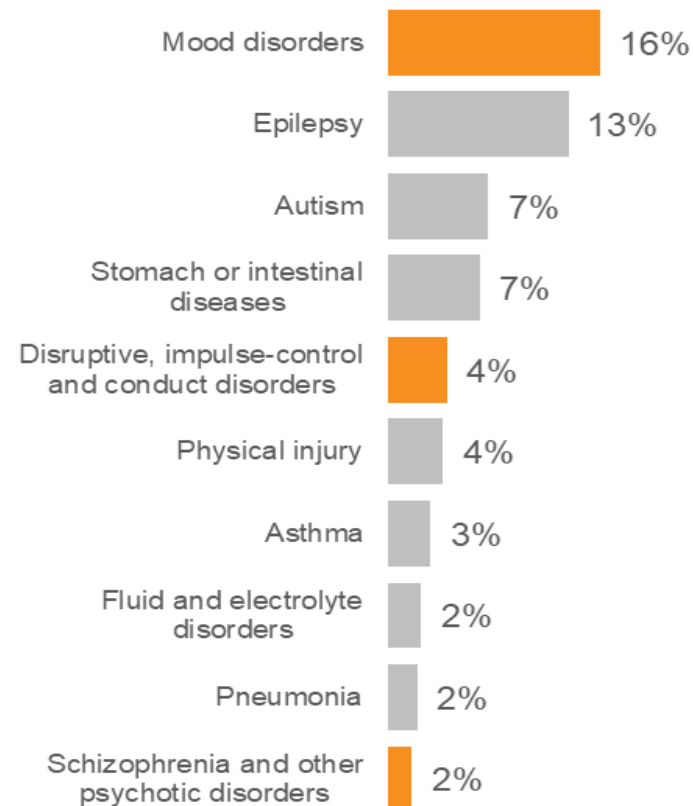
results

MENTAL HEALTH SERVICES

More than half of parents of autistic children reported difficulty getting mental health care
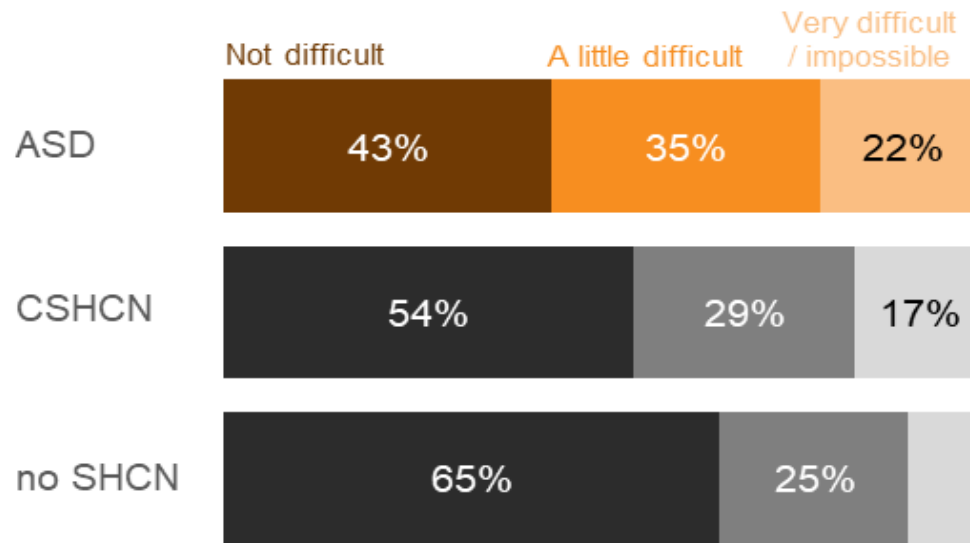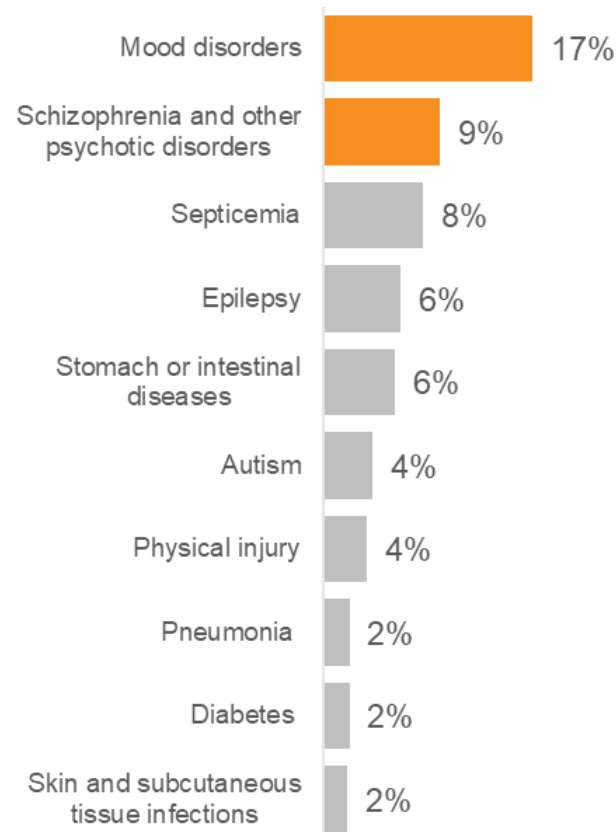

Source: National Survey of Children's Health 2016-19

The most common reasons for hospitalization in autistic children and adults included mental health conditions
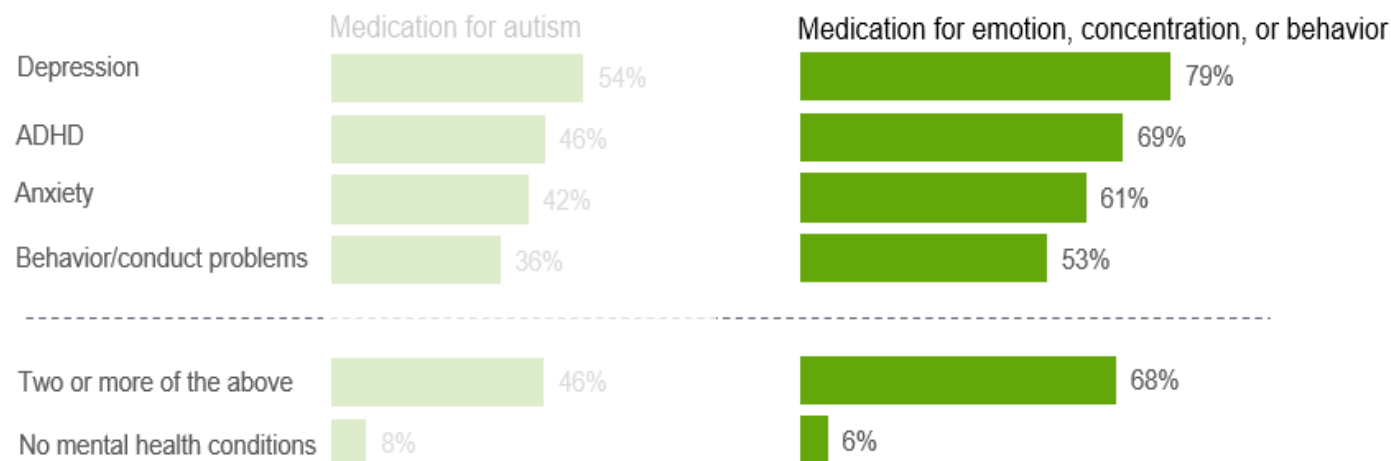
Children (left chart)

Condition	Percentage
Mood disorders	16%
Epilepsy	13%
Autism	7%
Stomach or intestinal diseases	7%
Disruptive, impulse-control and conduct disorders	4%
Physical injury	4%
Asthma	3%
Fluid and electrolyte disorders	2%
Pneumonia	2%
Schizophrenia and other psychotic disorders	2%

Source: National Inpatient Sample 2017

Adults (right chart)

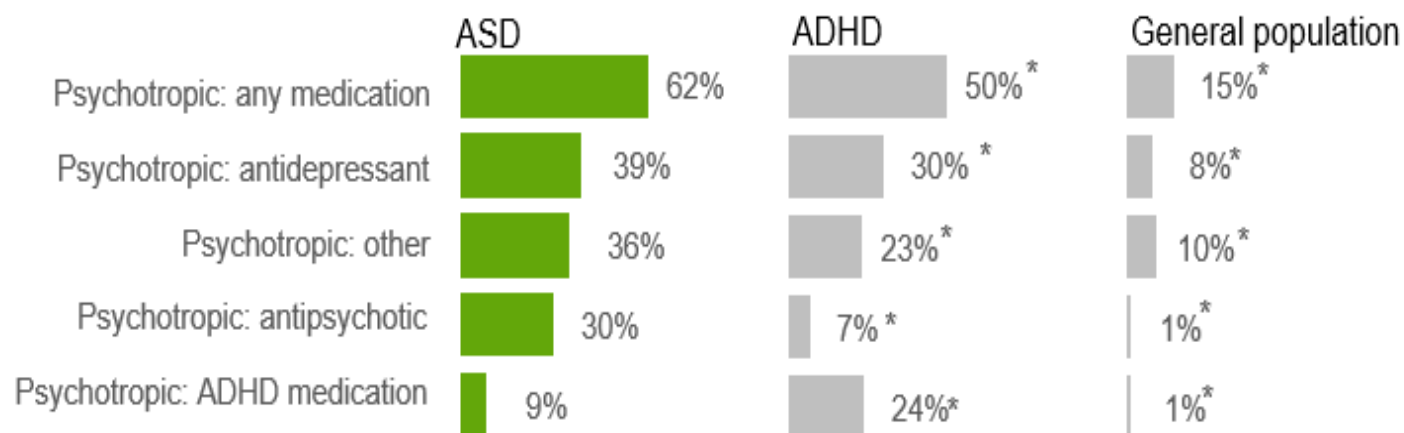| Condition	Percentage
Mood disorders	17%
Schizophrenia and other psychotic disorders	9%
Septicemia	8%
Epilepsy	6%
Stomach or intestinal diseases	6%
Autism	4%
Physical injury	4%
Pneumonia	2%
Diabetes	2%
Skin and subcutaneous tissue infections	2%

Source: National Inpatient Sample 2017

results

MENTAL HEALTH AND MEDICATION

Medication use was more common in autistic children with co-occurring conditions

Medication for autism

Condition	
Depression	54%
ADHD	46%
Anxiety	42%
Behavior/conduct problems	36%
Two or more of the above	46%
No mental health conditions	8%

Medication for emotion, concentration, or behavior

Condition	
Depression	79%
ADHD	69%
Anxiety	61%
Behavior/conduct problems	53%
Two or more of the above	68%
No mental health conditions	6%

Source: National Survey of Children's Health 2016-19

Kaiser: psychotropic medications were more common in autistic adults than in other adults

	ASD	ADHD	General population
Psychotropic: any medication	62%	50%*	15%*
Psychotropic: antidepressant	39%	30%*	8%*
Psychotropic: other	36%	23%*	10%*
Psychotropic: antipsychotic	30%	7%*	1%*
Psychotropic: ADHD medication	9%	24%*	1%*

*Significantly different from the ASD group as tested using logistic regression controlling for age, race/ethnicity, gender, length of KPNC membership, and certain mental and physical co-occurring conditions
Source: Zerbo et al., 2019

results

MENTAL HEALTH AND COMMUNITY PARTICIPATION IN AUTISTIC YOUTH

Autistic youth with unmet need for mental health care were the least likely to participate in community activities.

	Community service or volunteer	Sports teams or lessons	Paid work
Received mental health services, no unmet need	42%	26%	21%
No services and no unmet need	35%	26%	13%
Unmet need for mental health care	25%	12%	13%
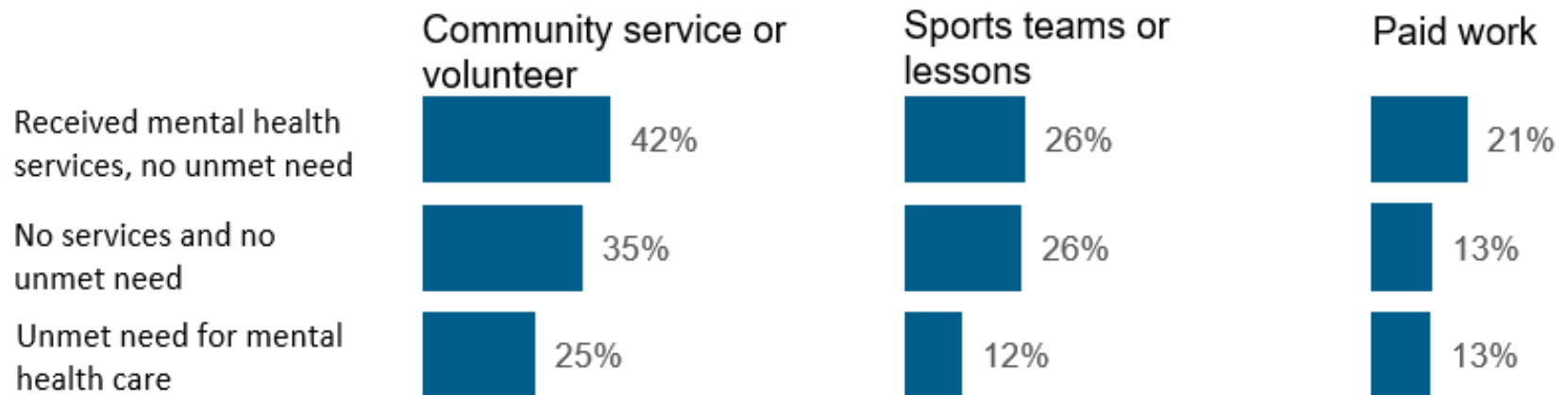
Source: National Survey of Children's Health 2016-19

CONCLUSIONS

Recommendations

- Make access more equitable
  - Racialized communities
  - Evidence-based practices

Recommendations

- Make access more equitable
- Address location problems

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Autism Institute

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Recommendations

- Make access more equitable
- Address location problems
- Improve systems of care

Recommendations

- Make access more equitable
- Address location problems
- Improve systems of care
- Train providers

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Where research and advocacy meet

SYNERGY AND DISCONNECTION ACROSS RESEARCH AND AUTISTIC PRIORITIES

NATIONAL AUTISM INDICATORS REPORT:
Mental Health

AUGUST 2021

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Mental Health Across the Lifespan

autism

Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

Teal W Benevides[1], Stephen M Shore[2], Kate Palmer[3], Patricia Duncan[3], Alex Plank[3], May-Lynn Andresen[4], Reid Caplan[3], Barb Cook[5], Dena Gassner[2], Becca Lory Hector[3], Lisa Morgan[3], Lindsey Nebeker[3], Yenn Purkis[3], Brigid Rankowski[4], Karl Wittig[3] and Steven S Coughlin[1]

Abstract
Autistic adults are significantly more likely to experience co-occurring mental health conditions such as depression and anxiety. Although intervention studies are beginning to be implemented with autistic adults to address mental health outcomes, little is known about what research autistic adults feel is needed, or what mental health outcomes are of value to them. The purpose of this article is to describe a project that involved more than 350 autistic adults and other stakeholders as coproducers of research priorities on mental health. Through a variety of methods including a large online survey, two large stakeholder meetings, and three face-to-face focus groups, the project team identified five top priorities for mental health research which should be incorporated by researchers and practitioners in their work with autistic adults. These included research to inform trauma-informed care approaches; societal approaches for inclusion and acceptance of autistic individuals; community-available approaches for self-management of mental health; evaluation of adverse mental health outcomes of existing interventions; and improvements in measurement of quality of life, social well-being, and other preferred outcomes in autistic adults.

Lay Abstract
Autistic adults commonly experience mental health conditions. However, research rarely involves autistic adults in deciding priorities for research on mental healthcare approaches that might work for them. The purpose of this article is to describe a stakeholder-driven project that involved autistic adults in co-leading and designing research about priorities to address mental health needs. Through a large online survey, two large meetings, and three face-to-face focus group discussions involving over 350 stakeholders, we identified five priorities for mental health research desired by autistic adults. These priorities and preferred outcomes should be used to guide research and practice for autistic adults.

Keywords
autistic, mental health, mental health outcomes, participatory action research, priorities, stakeholder, autism

Introduction

Research suggests that autistic individuals[1] experience greater rates of anxiety than same-aged peers without autism (e.g. Croen et al., 2015; Joshi et al., 2013; Roux et al., 2017; Russell et al., 2016). In addition, autistic individuals experience high rates of depression and other co-occurring mental health conditions (e.g. Hollocks et al., 2019). These and other risk factors may also contribute to greater risk for suicidality (e.g. Cassidy et al., 2018); yet access to mental healthcare and appropriate supports are

[1] Augusta University, USA
[2] Adelphi University, USA
[3] Unaffiliated Author
[4] Quality in Health Care Advisory Group, USA
[5] University of Wollongong, Australia
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DETECTING

- Define health disparities
- Define vulnerable populations
- Measure disparities in vulnerable populations
- Consider selection effects and confounding factors

UNDERSTANDING

Identifying determinants of health disparities at the following levels:

- Patient/individual
- Provider
- Clinical encounter
- Health care system

REDUCING

- Intervene
- Evaluate
- Translate and disseminate
- Change policy

Adapted from: Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M. J. (2006). Advancing health disparities research within the health care system: a conceptual framework. *American Journal of Public Health*, *96*(12), 2113-2121.

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Most autism research about mental health is here

DETECT → **UNDERSTAND** → **REDUCE**
(improve mental health)

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Many priority differences: autistic adults are forging ahead and identifying more complex priorities

- Developing tools to measure mental health in alignment with autistic preferences and care priorities

- Impact of currently recommended therapies and interventions

- Understanding context of mental health needs (lack of accessible services, discrimination, trauma)

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How can we move toward understanding and improving? Catching up to autistic priorities

- Mental health is an integral component of health
  - This needs to be embraced to move forward
- Bolstering autistic involvement in research
  - As researchers
  - As research partners

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Actionable gaps in data to address autistic priorities

- Limited national data from autistic adults
  - Diverse groups
  - Longitudinal
- Surveys and administrative/claims data need to be supplemented with measures of preferences and context
  - Innovative linkages of data requires funding agency, data source, and researcher collaboration and resources

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Matching investment to priorities

- Mental health should be a flagship issue
- Continuous engagement of diverse autistic voices and support for autistic leadership is required
- Investment *in mental health* research **and** the service delivery system is necessary for detecting, understanding, and improving mental health

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Mental Health Priorities to Guide Research in Autism:

Autistic Adults and Other Stakeholders Engage Together

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Associate Professor
Department of Occupational Therapy
Augusta University

Stephen Shore, EdD
Assistant Clinical Professor
Department of Special Education
Adelphi University

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Funding and Disclosure

Our team was funded by a Patient-Centered Outcomes Research Institute (PCORI), Eugene Washington Engagement Award to accomplish the project goal…

… to meaningfully include and engage autistic stakeholders in identifying priorities and methods to support patient-centered outcomes research in collaboration with autistic people.

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Fundamental Need to Ensure Autistic^ Involvement in Research

- Approximately 3% of U.S. research funding in autism is spent in addressing "Lifespan Issues".[1]

- As increased funding is allocated to addressing adult and other lifespan topics, we need to ensure autistic people are driving the process.

- Little research authentically involves autistic people in setting priorities for research and practice. [2-4]

^We purposefully use identity-first language, as opposed to person-first language, in congruence with preferences expressed by adults.

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AASET Project Team and Community Council

Project Team: Teal Benevides, Stephen Shore (Co-Leads)

Alex Plank (Social Media Coordinator), Patty Duncan (Conference Planner)

- May-Lynn Andresen
- Reid Caplan
- Barb Cook
- Dena Gassner
- Amy Gravino
- Becca Lory
- Jamie Marshall
- Lisa Morgan

- Lindsey Nebeker
- Kate Palmer
- Bill Peters
- Yenn Purkis
- Brigid Rankowski
- Liane Holliday Willey
- Karl Wittig
- Cyndi Taylor
- Daria Tyrina

Enhancing Engagement of Autistic Partners

- **Provided materials in advance** to research partners to enhance processing

- **Presented materials in multiple accessible formats**
  - Email (used an email template to facilitate action)
  - Video
  - Live Zoom meetings

- Encouraged interaction in **various modalities**
  - Opportunity to use different interaction modality depending on need and context
  - Text-based options
  - Support for users of augmentative and alternative (AAC) devices
  - Spoken and non-spoken activities for priority-setting

Enhancing Engagement of Autistic Partners

- **Adapted the environment** for in-person meetings

- **Considered other barriers**
  - Transportation
  - Finances
  - Child care responsibilities

- **Provided compensation** appropriate to role and expertise

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Enhancing Engagement of Autistic Partners

Avoid tokenism through building:

- **Trust**
  - Able to bring up differing ideas and concerns
  - Concerns are raised and meaningfully heard and addressed

- **Respect**
  - Contributions are valued
  - Equality of voices in meetings and decision points
  - Contributions are included and recognized in process and products

- **Support**
  - Multiple options for remaining engaged make it easier to participate

Priority-Setting for Health Research

Priority-Setting Methods

- Year 1 Large group stakeholder meeting
  - July 2017 (*n*=51)

- Online survey of autistic adults
  - Aug 2018 (*n*=236)

- Face-to-face focus groups of autistic adults
  - Aug-Nov 2018 (*n*=26)

- Year 2 Large group stakeholder meeting
  - November 2018 (*n*=64)
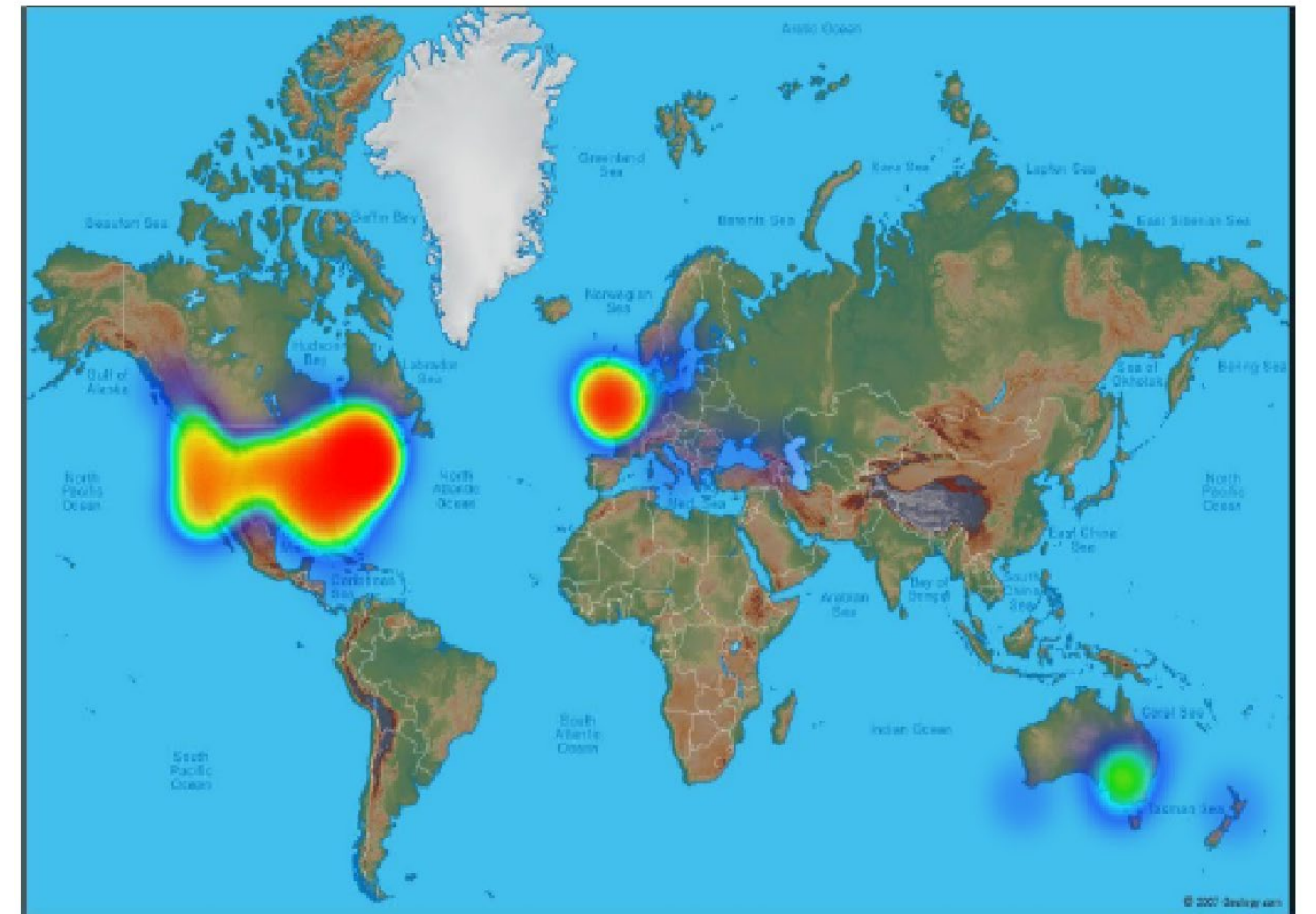
Methods to Enhance Participation in Survey and Focus Groups
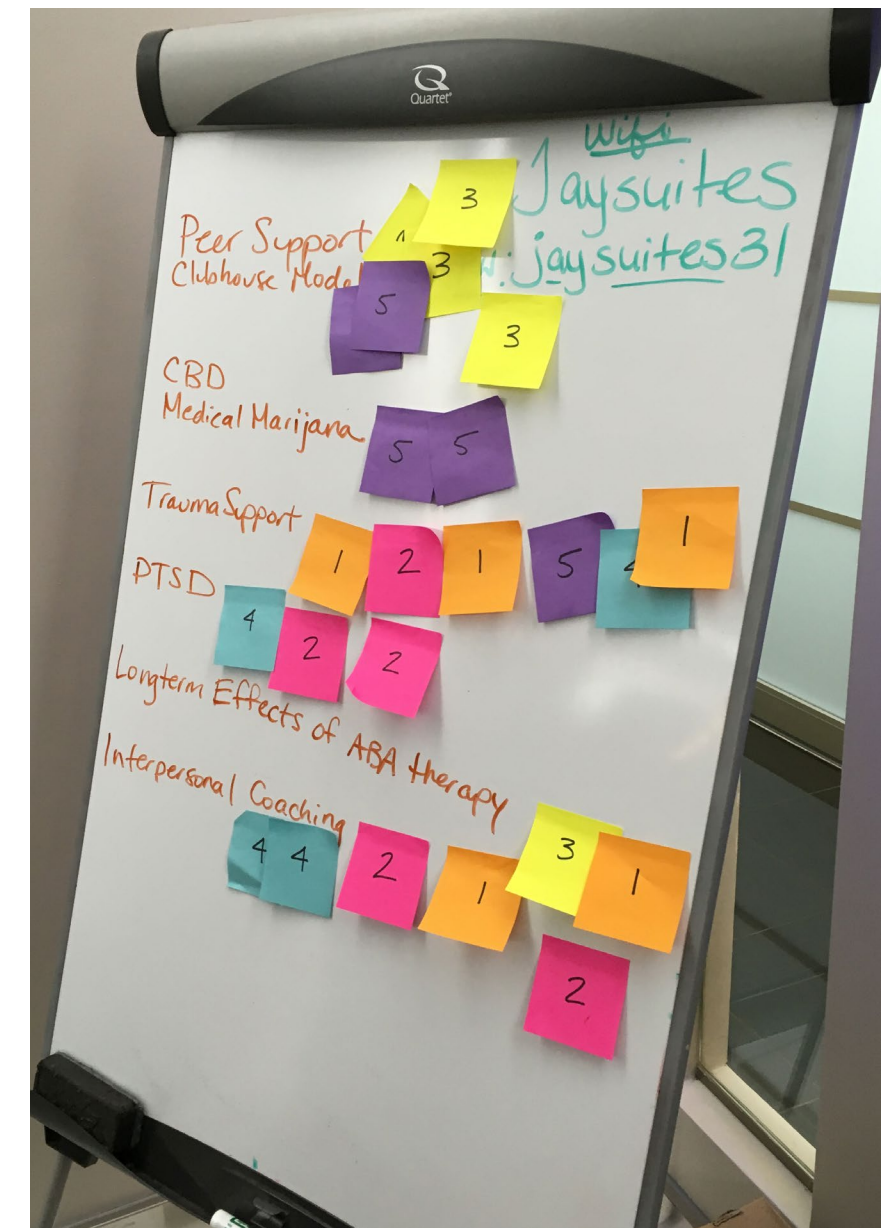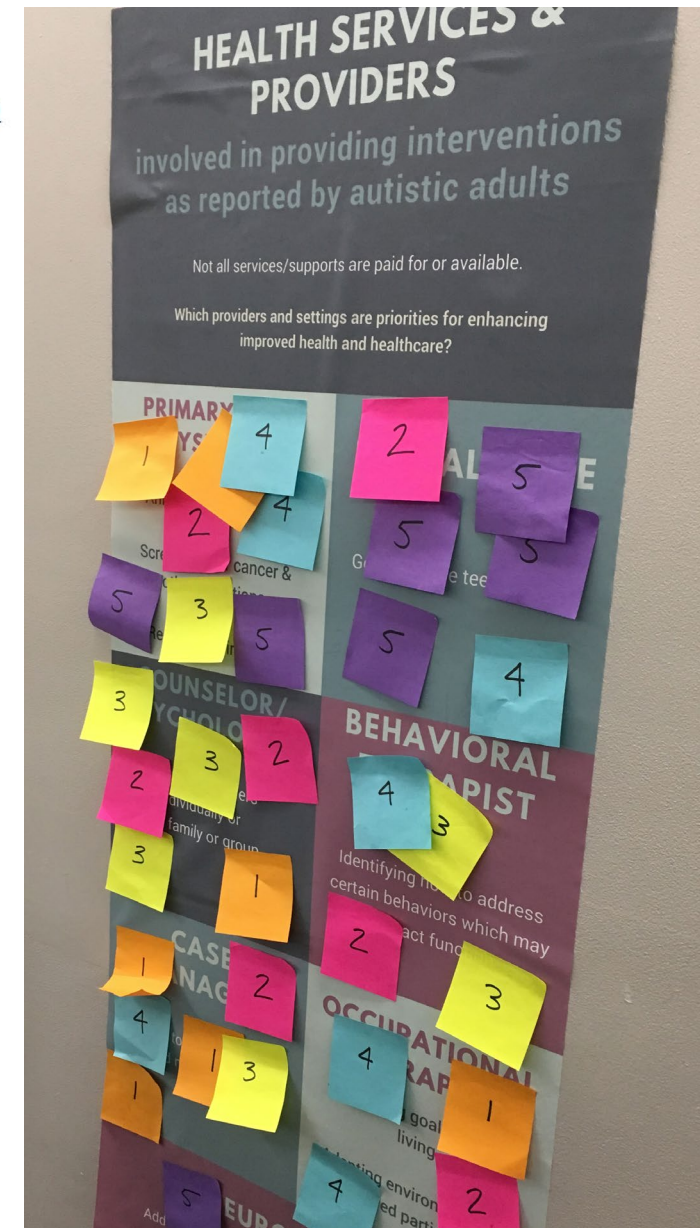
Results of priority-setting revolved around

1. **Mental health interventions and outcomes**

2. Access to healthcare and needed accommodations to get care

3. Gender inequalities in diagnosis, treatment, and sexual health

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	Survey		Focus Group
	Formal diagnosis (n=182)	Self-diagnosed (n=54)	n=26
Mean Age in Years (SD)	38.70 (11.14)	41.26 (14.78)	38.60 (13.8)
Gender, *f* **(% of avail respondents)**			
Male	20 (18.5%)	4 (17.4%)	12 (46.0%)
Female	65 (60.2%)	13 (56.5%)	14 (54.0%)
Non-binary	23 (21.3%)	6 (26.1%)	0
Missing	74	31	0
Hispanic status, *f* **(% of avail respondents)**			
Hispanic	4 (4.0%)	2 (8.7%)	0 (0.0%)
Non-Hispanic	95 (96.0%)	21 (91.3%)	26 (100%)
Missing	83	31	0
Race, *f* **(% of avail respondents)**			
White	89 (82.4%)	20 (90.9%)	22 (85.0%)
Non-white	14 (13.6%)	2 (9.1%)	4 (15.0%)
Missing	79	32	0

Mental Health Priority #1

- What is the **impact of trauma on mental health outcomes** in autistic individuals?
  - o What are the best indicators or measures of PTSD, trauma, and adverse childhood experiences in autistic individuals?

  - o What approaches can be used to effectively address trauma among autistic adults (e.g. trauma-informed care)?

  - ▪ Example from respondent: "I want you to write 'sexual assault.' [on the white board]. Straight up. Let's just be real"

  - ▪ Example from respondent: "I have also been diagnosed with PTSD, where actually I think the symptoms are due to persistent bullying while I was growing up…."

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Mental Health Priority #2

- What is the **impact of social isolation, stigma, discrimination and other forms of marginalization** on mental health and well-being in autistic individuals?
    - Conversely, what is the impact of radical inclusion, such as being part of a social movement, on mental health and well-being?

    - Example from respondent: "…part of the issue was stigma ….we don't have positive representation of people who have been successful with autism and we need to tell those stories and see that as part of the wellness…"
    - Example from respondent: "…[I want to see research on how] society are [is] trained to include, accept, accommodate, and value our neurodiversity…"
    - Example from respondent: "…trying to be normal was a futile waste of time ... so what does that do to a person's mental health?"

"Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project" (2020).
Autism. Open access: https://journals.sagepub.com/doi/full/10.1177/1362361320908410

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Mental Health Priority #3

- When, for whom, and under what conditions do **self-managed interventions** and preferred activities result in improved quality of life and reduced mental health symptoms?

  - What is the effect of employing community-available approaches such as peer-led approaches, exercise/physical activity, yoga, mindfulness and meditation, tai-chi, animal-assisted therapy, art and music-based approaches to well-being?

    - Example from respondent: "If interventions are to be employed, they must ALWAYS be self-motivated. Otherwise, they might as well be someone else's goals or desires."

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Mental Health Priority #4

- What are the **long- and short-term negative side effects or adverse outcomes** of currently recommended therapies and interventions (including behavioral and pharmacological), as measured in autistic individuals across the lifespan?

  - Example from respondent: "…does negative self image occur due to current childhood therapies ?…"

  - Example from respondent: "…does long term use of depression drugs increase risk of fractures [in autistic people]?..."

"Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project" (2020). *Autism*. Open access: https://journals.sagepub.com/doi/full/10.1177/1362361320908410

Mental Health Priority #5

- How can we develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep as experienced by autistic adults?

  - Example respondent: "[We need to measure]….the interests and priorities of autistic people … [these interests should be] respected and considered valid, even if it doesn't line up with what "normal" society considers most important."

  - Example respondent : "I would like research into what creates a successful outcome - what creates a fulfilled, successful life for an autistic person - as defined by them."

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Preferred Mental Health Outcomes for Research and Practice

Priority Outcome	"This Matters to Me"
1. Quality of life	95.6%
2. Anxiety	89.7%
3. Depression	81.6%
4. Social well-being	78.7%
5. Sleep	78.7%
6. Interpersonal relationships	75.7%
7. Suicidal ideation	67.6%
8. Level of participation in activities of daily living	69.1%
9. Level of participation in work	67.6%
10. Suicide attempts	64.0%

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Summary

- Mental health is seen as an essential component for overall well-being and quality of life among autistic adults.

- We need evidence-based practices to equip people with skills to live a fulfilling life, and the information to help them self-manage mental health needs.

- We need a paradigm shift in society to create spaces and places where autistic people have a sense of belonging and are supported to pursue their interests and goals.

DETECTING

- Define health disparities
- Define vulnerable populations
- Measure disparities in vulnerable populations
- Consider selection effects and confounding factors

UNDERSTANDING

Identifying determinants of health disparities at the following levels:

- Patient/individual
- Provider
- Clinical encounter
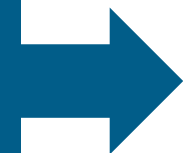- Health care system

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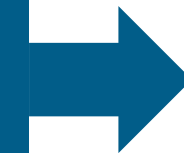
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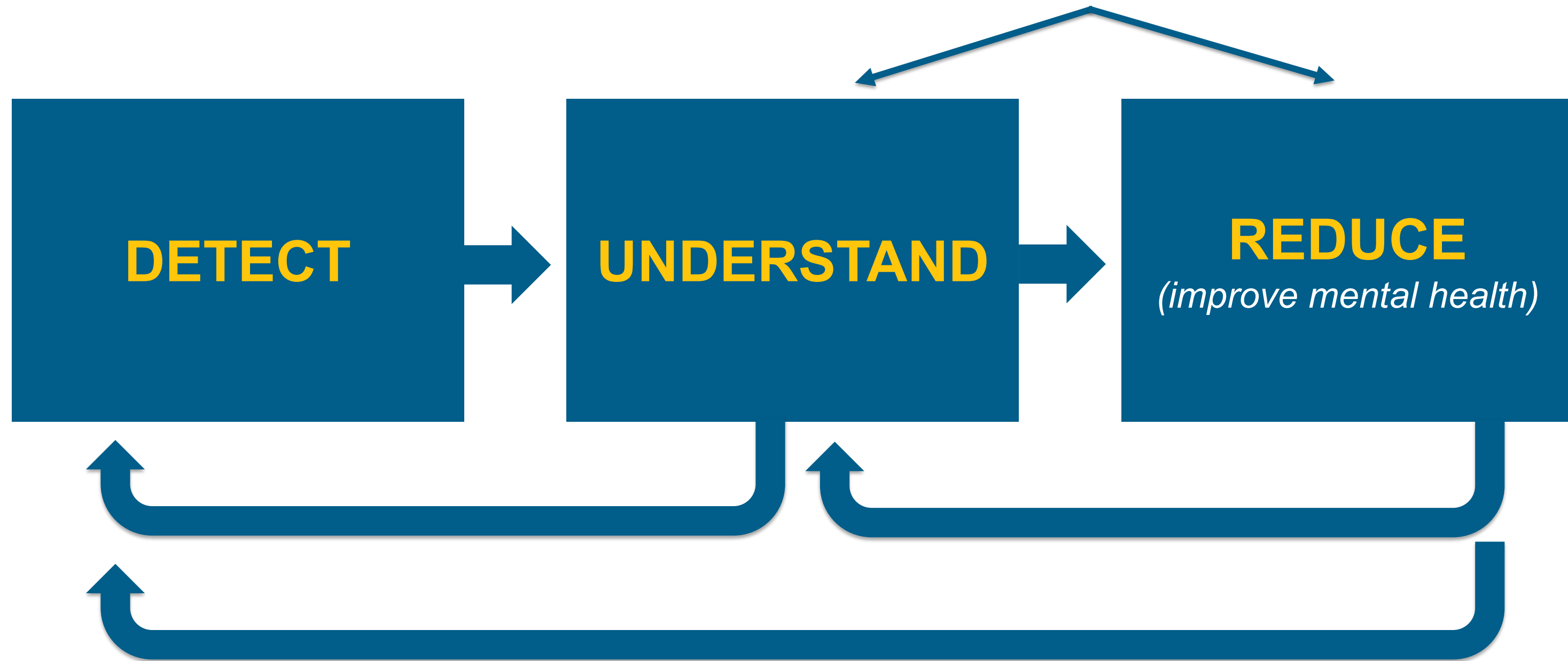
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  - This needs to be embraced to move forward

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  - As researchers
  - As research partners

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Actionable gaps in data to address autistic priorities

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  - Diverse groups
  - Longitudinal
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Resources and Information:
Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822–833. https://doi.org/10.1177/1362361320908410.

Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism*, 24(6), 1345–1359. https://doi.org/10.1177/1362361320913664

Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lory, B., Morgan, L., Palmer, K., Purkis, J & Wittig, K. (2018). *Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide*. https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf

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Break

Round Robin Updates

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination,
NIMH, and Executive Secretary, IACC
Acting National Autism Coordinator

Thank you to the OARC Staff!

Susan Daniels, Ph.D.
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Science Policy Analyst

Katrina Ferrara, Ph.D.
Science Policy Analyst

Steven Isaacson, B.A.
Policy Analyst

Tianlu Ma, Ph.D.
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Management Analyst

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

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

Next IACC Meeting

Mark Your Calendar

January 19, 2022
10:00 am – 5:00 pm ET

This meeting will be completely virtual. Check the IACC Website for meeting information and updates.

https://iacc.hhs.gov