Meeting of the Interagency Autism Coordinating Committee

Wednesday, January 16, 2019

National Institutes of Health Neuroscience Center

Hilton Washington / Rockville Hotel &
Executive Meeting Center

1750 Rockville Pike

Rockville, MD 20852

Conference Call Access:
Phone: 888-829-8668
Participant Passcode: 1308901

These slides do not reflect decisions of the IACC and are for discussion purposes only.

Meeting of the IACC

Morning Agenda

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

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

Director, National Institute of mental Health and Chair, IACC

Susan Daniels, Ph.D.

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

Meeting of the IACC

Morning Agenda

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

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

9:15 **HCBS Final Rule: Current Issues and Future Directions**

Melissa Harris
Acting Deputy Director, Disabled and Elderly Health Programs Group, Center Medicare and CHIP Services
Centers for Medicare and Medicaid Services (CMS)

Meeting of the IACC

Morning Agenda

10:00	**TRICARE Autism Care Demonstration**
	Capt. Edward Simmer, M.D. Chief Clinical Officer, TRICARE Health Plan Defense Health Agency Department of Defense
10:45	**Break**

Meeting of the IACC

Morning Agenda

11:00	**Committee Business**
	Susan Daniels, Ph.D. Director, Office of Autism Research Coordination, National Institute of Mental Health, and Executive Secretary, IACC
	Joshua Gordon, M.D., Ph.D. Director, National Institute of mental Health and Chair, IACC
12:00 PM	**Lunch**

Welcome
Introductions
Roll Call
Approval of Minutes

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

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

National Autism Coordinator Update

Ann Wagner, Ph.D.

Interagency Autism Coordinating Committee Meeting

January 16, 2019

National Autism Coordinator Role

HHS employee authorized by Autism CARES Act of 2014 to oversee Federal ASD activities and prevent unnecessary duplication

- 2017 Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder (Dr. Thomas Novotny)

Federal Interagency Workgroup on ASD (FIWA)

- Internal working group of reps from across governmental Departments and Agencies
- Coordinating the implementation of activities in response to recommendations from IACC, reports to Congress and other advisory committees

Federal Interagency Workgroup on ASD (FIWA)

- **Department of Health and Human Services (HHS)**
  - Administration for Children and Families (ACF)*
  - Administration for Community Living (ACL)*
  - Agency for Healthcare Research and Quality (AHRQ)*
  - Assistant Secretary for Planning and Evaluation (ASPE)*
  - Center for Disease Control and Prevention (CDC)*
  - Centers for Medicare and Medicaid Services (CMS)*
  - Health Resources and Services Administration (HRSA)*
  - Indian Health Services (IHS)*
  - National Institutes of Health (NIH)*
  - Substance Abuse and Mental Health Administration (SAMHSA)*

Federal Interagency Workgroup on ASD (FIWA)

- Department of Education (ED)*
- Department of Defense (DOD)*
- Department of Justice (DOJ)*
- Department of Labor (DOL)*
- Department of Transportation (DOT)
- Social Security Administration (SSA)*

Approaches used by Federal programs to influence State and local policy and programs (10/29/18 FIWA)

Engagement with State and local entities

- DoL: described work with State and local associations and councils (e.g., National Governors Assoc., National Conference of State Legislators) on disability employment initiatives, policy, and legislature.
- IHS: described the National HOPE Committee (opioid crisis) as an example of bringing together local providers, community leaders and Federal partners on critical health-related topics

Approaches used by Federal programs to influence State and local policy and programs (10/29/18 FIWA)

Targeted grants programs

- ACL: System Change Grants that support efforts to make positive changes in social systems and service delivery programs.
  - State councils on developmental disabilities
  - State protections and advocacy systems
  - University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)
  - Projects of National Significance

Approaches used by Federal programs to influence State and local policy and programs (10/29/18 FIWA)

Education and Professional Development

- ED: professional development grants support 8,000 masters and doctoral-level scholars.
- ED: IRIS Centers create free, online learning modules to teachers
- ED: Autism-Focused Intervention Resources and Modules (AFIRM).
- HRSA: Leadership Education in Neurodevelopment and other Related Disabilities (LEND) and Developmental-Behavioral Pediatrics (DBP) programs provide continuing education, training and technical assistance to Title V and other MCH professionals, and partner with state and local MCH programs to provide training opportunities.

Ongoing FIWA activities

- Focus on Supports & Services recommendations from the 2017 Report to Congress on Transition-Age Youth and Adults with ASD
- Continue to evaluate government-sponsored survey data sets on TAY and adults with ASD
  - Identify gaps
- Gathering information on outcome measures in development for TAY and adults with ASD
  - DoD, ACL, NIH planning committee for special FIWA meeting

Discussion

HCBS Final Rule: Current Issues and Future Directions

Melissa Harris

January 2019

2014 HCBS Final Rule

- Published January 2014 – Effective March 17, 2014
- Addressed CMS Requirements across HCBS provided through:
  - 1915(c) waivers, 1915(i) state plan, 1915(k) Community First Choice, and 1115 Demonstration Waivers
- Some requirements were effective immediately, others were given a transition period in order to allow states sufficient time to come into compliance.
- Guidance issued in May 2017 extended the transition period for settings in existence as of the effective date of the final regulation from March 2019 to March 17, 2022. Extension of the transition period recognized the significant reform efforts underway and is intended to help states ensure compliance activities are collaborative, transparent and timely.
- This session does not cover all aspects of the Final Rule; in today's presentation we will focus specifically on the regulation's impact on home and community-based settings.

Home and Community-Based Setting Criteria

- As the percentage of LTSS funding attributable to HCBS continues to rise, the settings criteria are an important tool for states' continuous quality improvement efforts
  - The home and community-based setting requirements establish an outcome oriented definition that focuses on the nature and quality of individuals' experiences
  - The requirements maximize opportunities for individuals to have access to the benefits of community living and the opportunity to receive services in the most integrated setting

Home and Community-Based Settings Criteria

Is integrated in and supports access to the greater community

Provides opportunities to seek employment and work in competitive integrated settings, engage in community life and control personal resources

Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS

Is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

Home and Community-Based Settings Criteria (cont.)

The setting options are identified and documented in the person-centered service plan

The setting options are based on the individual's needs, preferences, and, for residential settings, resources available for room and board

Ensures an individual's rights of privacy, dignity, respect and freedom from coercion and restraint

Optimizes individual initiative, autonomy, and independence in making life choices

Facilitates individual choice regarding services and supports and who provides them

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

Provider-Owned or Controlled Settings: Additional Criteria (1 of 4)

- Unit/dwelling is a specific physical space owned, rented, or occupied under legally enforceable agreement
- Same responsibilities/protections from eviction as all tenants under landlord tenant law of state, county, city or other designated entity
- If tenant laws do not apply, state ensures lease, residency agreement or other written agreement is in place, providing protections to address eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law

Provider-Owned or Controlled Settings: Additional Criteria (2 of 4)

- Each individual has privacy in their sleeping or living unit
- Units have entrance doors lockable by the individual, with only appropriate staff having keys to doors as needed
- Individuals sharing units have a choice of roommates
- Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement
- Individuals have freedom and support to control their schedules and activities and have access to food any time
- Individuals may have visitors of their choosing at any time
- Setting is physically accessible to the individual

Provider-Owned or Controlled Settings: Additional Criteria (3 of 4)

Modifications of the additional criteria must be:

- Supported by specific assessed need
- Justified in the person-centered service plan
- Documented in the person-centered service plan

Provider-Owned or Controlled Settings: Additional Criteria (4 of 4)

Documentation in the person-centered service plan of modifications of the additional criteria includes:

- Specific individualized assessed need
- Prior positive interventions and supports including less intrusive methods
- Description of condition proportionate to assessed need
- Ongoing data measuring effectiveness of modification
- Established time limits for periodic review of modifications
- Individual's informed consent
- Assurance that interventions/supports will not cause harm

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

Statewide Transition Plans: Status of Review and Implementation Activities

As of January 1, 2019:

- 10 States have final approval: AK, AR, DC, DE, KY, ID, OK, TN, WA, WY
- 43 States have initial approval: AL, AK, AR, AZ, CA, CO, CT, DC, DE, GA, HI, ID, IN, IA, KY, LA, MD, MI, MN, MS, MO, MT, NE, NH, NM, NY, NC, ND, OH, OK, OR, PA, RI, SC, SD, TN, UT, VT, VA, WA, WV, WI, WY

Timelines for Approvals

- States should continue progress in assessing existing operations and identifying milestones for compliance that result in final Statewide Transition Plan approval by March 17, 2019.
- The transition period for states to demonstrate compliance with the home and community based settings criteria has been extended until March 17, 2022 for settings in which a transition period applies.

Review of the Criteria for Initial Approval

- Identification of all settings subject to the rule in the Statewide Transition Plan (STP);
- Systemic assessment completed, including outcomes;
- Remediation strategies outlined, with timelines, and actively worked on;
- Draft STP widely disseminated for 30-day public comment period; comments responded to, summarized and submitted to CMS.

Key Elements in the Process for Final Approval

- Summary of completed and validated site-specific assessments, including aggregated outcomes completed;
- Draft remediation strategies with timelines for resolution by the end of the transition period (March 17, 2022);
- Detailed plan for identifying and evaluating those settings presumed to have institutional characteristics;

Key Elements in the Process for Final Approval, cont.

- Process for communicating with beneficiaries who are currently in settings that cannot or will not come into compliance by March 17, 2022;

- Description of ongoing monitoring and quality assurance to ensure all settings remain in full compliance with the settings criteria;

- Updated version of the STP is posted for minimum 30-day public comment period.

Settings that are not Home and Community-Based

Settings that are not home and community-based include:

- A Nursing Facility;
- An Institution for Mental Diseases;
- An Intermediate Care Facility for Individuals with Intellectual Disabilities;
- A Hospital; or
- Any other locations that have qualities of an institutional setting, as determined by the Secretary.

Presumptively Institutional Settings

- In response to stakeholder comments/concerns about types of settings that may be presumed to have institutional characteristics and do not meet the threshold for Medicaid HCBS, regulatory language was included identifying these categories of settings and allowing states to present evidence that a particular setting is home and community-based.
  - Settings on the grounds of/adjacent to a public institution
  - Settings in the same building as a public or private institution
  - Settings that isolate HCBS beneficiaries from the larger community
- States can choose to include such settings in their HCBS programs by submitting information to CMS, through the heightened scrutiny process, demonstrating that the settings do have the qualities of home and community-based settings.

Key Themes

- The regulation is intended to serve as a catalyst for widespread stakeholder engagement on ways to improve how individuals experience daily life.
- The rule is not intended to target particular industries or provider types
- Federal financial participation (FFP) is available for the duration of the transition period
- The rule provides support for states and stakeholders making transitions to more inclusive operations
- The rule is designed to enhance choice

Resources

HCBS Training and Resources on Medicaid.gov:

Home & Community Based Settings Requirements Compliance Toolkit

https://www.medicaid.gov/medicaid/hcbs/guidance/settings/index.html

Home & Community Based Services Training Series

https://www.medicaid.gov/medicaid/hcbs/training/index.html

Statewide Transition Plans

https://www.medicaid.gov/medicaid/hcbs/transition-plan/index.html

Discussion

Interagency Autism Coordinating Committee

TRICARE Autism Care Demonstration

January 16, 2019

Presented by:
Krystyna Bienia, Psy.D., Clinical Lead/ACD, Medical Affairs, DHA
CAPT Edward Simmer, MC, USN, Chief Clinical Officer, TRICARE Health Plan, DHA

Overview

- Military Health System (MHS) Introduction
- TRICARE Benefit
- Hierarchy of Reliable Evidence
- History of Applied Behavior Analysis (ABA) services under TRICARE
- Autism Care Demonstration (ACD) – Information
- Outcome Measures
- ACD initiatives
- Future of the ACD
- Questions

The Military Health System (MHS)

The MHS is an integrated, world-wide system of care that ensures the *health and readiness* of America's service members to go anywhere, at anytime.

It delivers and coordinates care for 9.4 million Americans – which include service member families, as well as military retirees and their families, by operating 55 hospitals and 373 clinics and managing a global health benefit through the *TRICARE program*.

The Defense Health Agency

Priorities & Goals

Combat Support Agency: enables the Army, Navy, and Air Force medical services to provide a *medically ready force* and *ready medical force* to Combatant Commands in both peacetime and wartime.

Enterprise Approach: drives greater integration of clinical and business processes across the Military Health System, to include managing the *TRICARE program*.

Priorities and Goals:

- Optimize operations across the MHS
- Co-create optimal outcomes for health, well-being, and readiness
- Deliver solutions to Combatant Commands

TRICARE

Fulfilling the promise

TRICARE remains one of the most comprehensive health benefits available in this country at exceptionally low costs – a benefit that is commensurate with the sacrifice of those who it serves.

The TRICARE Benefit

- The TRICARE Program supports the physical and mental health of 9.4 million beneficiaries worldwide.
- TRICARE is not health insurance, but rather a health benefit entitlement program governed by statute under Title 10, Armed Forces, Subtitle A General Military Law, Part II, Personnel, Chapter 55, Medical and Dental Care
  - § 1076 and § 1079 - govern dependent beneficiary care
  - § 1074 and § 1086 - govern benefits for certain members and former members of the Armed Forces
- Of the approximately 9.4 million beneficiaries covered, approximately one-fifth of beneficiaries are children (ages newborn to age 21).

TRICARE Basic Program

- The TRICARE Basic Program is the medical (healthcare) benefit.
- "Medically or psychologically necessary" treatments are covered under the Basic Program.
- Medically or psychologically necessary treatments defined as:

"The frequency, extent, and types of medical services or supplies which represent appropriate medical care and that are generally accepted by qualified professionals to be reasonable and adequate for the diagnosis and treatment of illness, injury, pregnancy, and mental disorders or that are reasonable and adequate for well-baby care."

- (32 Code of Federal Regulations (CFR), Definitions)

Covered Services for Autism Spectrum Disorder (ASD)

- TRICARE Basic Benefit covers medically necessary services:
  - Occupational therapy
  - Physical therapy
  - Speech and language therapy
  - Primary Care Services
  - Psychological services and testing
  - Prescription drugs
  - Respite Care (under Extended Care Health Option (ECHO) for Active Duty Family members (ADFMs))

Hierarchy of Reliable Evidence

- In order to be considered a medically or psychologically necessary treatment under the TRICARE Basic Program, a treatment or procedure must be determined to meet the reliable evidence standard for coverage.
- As used in CFR 199.4(g)(15), the term reliable evidence means only:
  - Well controlled studies of clinically meaningful endpoints, published in refereed medical literature.
  - Published formal technology assessments.
  - The published reports of national professional medical associations.
  - Published national medical policy organization positions; and
  - The published reports of national expert opinion organizations.
- Meeting this standard means that a given treatment is deemed safe and effective, proven medical care.

DoD Medical Benefit Determination June 28, 2013

Dr. Jonathan Woodson, Assistant Secretary of Defense for Health Affairs, signed an interim medical benefit determination regarding ABA treatment of ASD:

- ABA as delivered by ABA practitioners does not meet the TRICARE definition of "medical" as defined in 32 CFR §199.2;
- ABA has not been shown by reliable evidence to meet the requirements of 32 C.F.R. §199.4(g)(15) to be proven as medically or psychologically necessary or as appropriate medical care for ASD;
- The reliable evidence standard for cost-sharing required by 32 § C.F.R. 199.4(g)(15) has not been met;
- Final decision pending reassessment based on experience providing ABA under the Department's Demonstration authority.

DoD Medical Benefit Determination
June 28, 2013

The findings of the studies reviewed:

a) do not consistently present or characterize the ABA interventions provided, which vary widely in terms of provider, setting, and targeted age range of the recipient;

b) are generally not well-controlled, with comparatively few randomized clinical trials;

c) generally study very small sample sizes which limits generalization of findings to the clinical population of interest; and,

d) present conflicting findings across studies or fail to demonstrate clinically meaningful outcomes.

The evidence overall is not reliable, and there have been no comparative effectiveness studies of ABA to TRICARE cost-shared treatments such as speech and language pathology or occupational therapy.

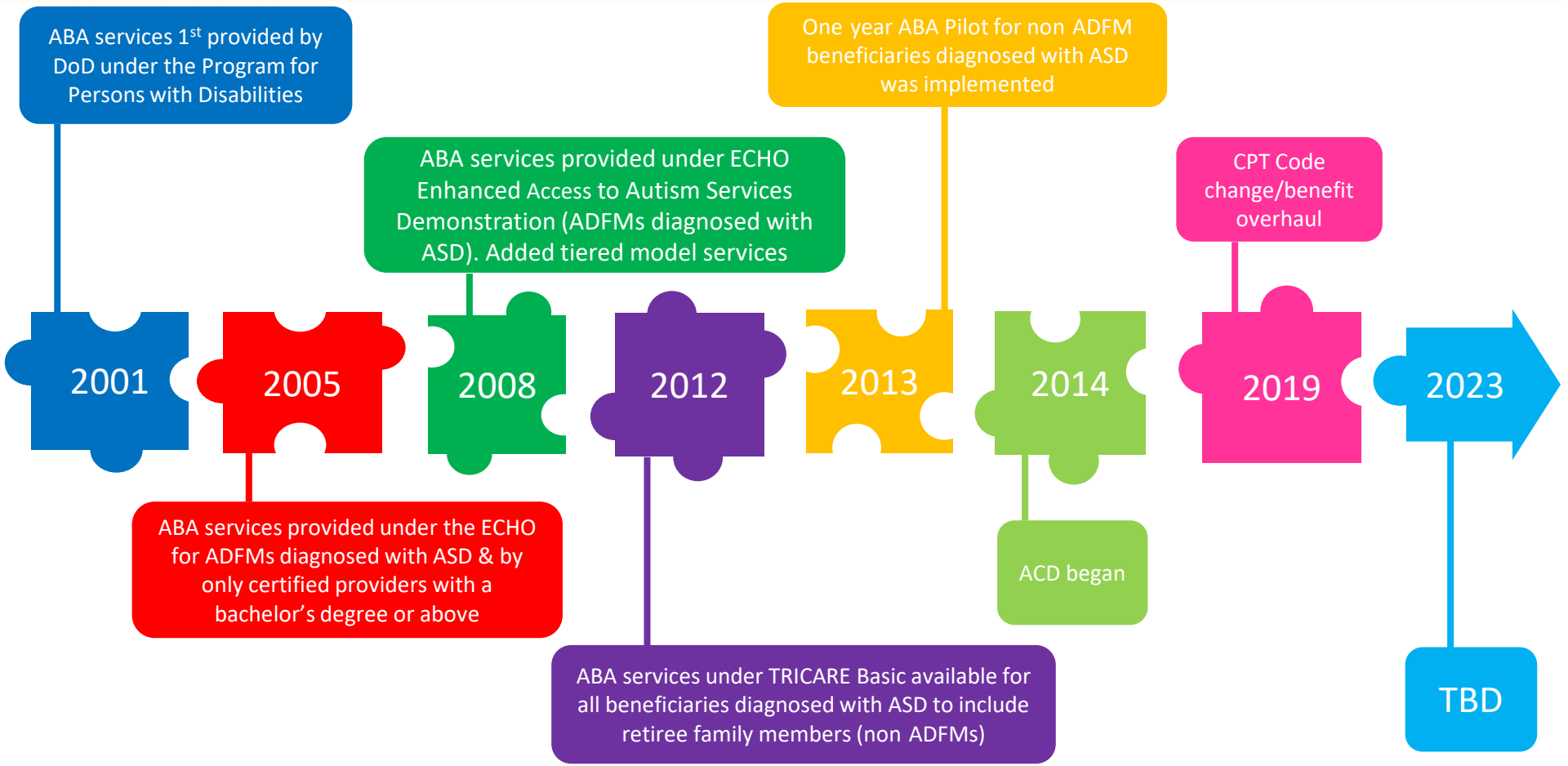
Gaps in Research

- Multiple reviews and meta-analyses have noted persistent gaps in ABA research, such as:
  - knowledge regarding specific ABA interventions; lack of comparative effectiveness studies
  - intensity, duration, level of treatment fidelity
  - therapist experience and/or training necessary to achieve optimal outcomes
  - patient-specific predictors of outcome
  - small sample sizes; lack of participant matching
  - heterogeneity in outcome measures used and interventions applied

What is the ACD?

- The Autism Care Demonstration (ACD) is:
  - A demonstration benefit that provides ABA services to TRICARE eligible beneficiaries diagnosed with ASD
  - Purchased care benefit administered by the regional Managed Care Support Contractors (MCSC) (Health Net Federal Services and Humana Government Business) and U.S. Family Health Plan contractors
  - One component of a comprehensive ASD care plan
  - Goals of the ACD is to determine how to best provide services to beneficiaries diagnosed with ASD

History of ABA Services under TRICARE



ACD – Information

- Update of ACD statistics (for Fiscal Year 2017):
  - ACD participants: 15,454
  - ABA providers: Almost 25,000
  - Cost: $268M/year (estimated to increase to over $400 M/year by 2023)

Covered ABA Services

- The following ABA services are covered under the ACD:
  - ABA assessment
  - Treatment plan development
  - 1:1 ABA services
  - Guidance for parents, and other caregivers
- The ACD has no treatment limits:
  - No minimum/maximum age limits
  - No caps on numbers of hours per week
  - No caps on duration of ABA services
  - No caps on reimbursement.
- Medically necessary services

Outcome Measures

- Currently, the ACD implements the following measures:
  - ❑ At baseline and every 2 years of services
    - Vineland Adaptive Behavior Scales, Third Edition
    - Social Responsiveness Scale, Second Edition
  - ❑ At baseline and every 6 months of services
    - Pervasive Developmental Disabilities Behavior Inventory
- Diagnostic measures are inconsistently used and often not reported to DHA
- Are there other measures we could/should use?

ACD Initiatives

- 16 Provider Information Meetings/Stakeholder Round Tables since 2014
- Presentations at ABA conferences
- ACD email-box
- GovDelivery – proactive messaging platform
- Parent/Caregiver surveys
- TRICARE Quality Management audits
- Industry Day regarding best practices for ABA services

ACD Initiatives cont.

- Military Treatment Facility Initiatives:
  - FBCH and WRNMMC, Autism Resource Center (ARC) program
  - JBLM Center for Autism Resources, Education and Services (CARES), Madigan Army Medical Center
  - WPAFB P.L.A.Y. Project
- DoD Office of the Inspector General (OIG) North and South Audit reports published
- Congressionally Directed Medical Research Program (CDMRP) – study awarded Sept 2018

DoD OIG ABA Audits

- South Audit: *The Defense Health Agency Improperly Paid for Autism-Related Services to Selected Companies in the TRICARE South Region*
  - Published: 10 MAR 2017 https://media.defense.gov/2017/Dec/19/2001858335/-1/-1/1/DODIG-2017-064.PDF
  - Determined that many payments were improper
- North Audit: *TRICARE North Region Payments for Applied Behavior Analysis Services for the Treatment of Autism Spectrum Disorder*
  - Published: 16 MAR 2018 https://media.defense.gov/2018/Mar/22/2001893494/-1/-1/1/DODIG-2018-084.PDF
  - Determined that 2/3 ($80M of $120M) of payments for ABA services were improper, mostly due to missing or inadequate documentation

CDMRP Study

- Title: *Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism*
- Public abstract available at: https://cdmrp.army.mil/search.aspx (Proposal Number: PT170183)
- Early intensive behavioral intervention (EIBI), (20+ hours/week) vs "Adaptive" ABA (< 20 hours/week)
- Study to address 4 key questions:

1) Do children improve more in an EIBI or in an adaptive ABA intervention on core features of ASD?
2) What is the impact of EIBI and adaptive ABA on families?
3) What factors predict whether children and families will benefit more from EIBI or from adaptive ABA?
4) What factors would help or hinder agencies from continuing to implement EIBI or adaptive ABA in the future?

CDMRP Study cont.

- Findings could benefit the larger community

1) Knowing how EIBI compares to adaptive ABA gives families a basis for choosing an intervention approach with confidence.
2) Knowing that ABA interventions work well in children who are covered by TRICARE justifies insurance funding for these interventions.
3) If we could know in advance whether EIBI or adaptive ABA is likely to be more effective, families could more easily select an ABA intervention for their child.
4) If the adaptive intervention is found to be as effective as EIBI for many children with ASD, it may be possible to lower costs and increase access to effective services.
5) Knowing what helps or hinders agencies from implementing EIBI and adaptive ABA could guide future efforts to make these interventions more available to children with ASD and their families.

Future of the ACD

- To truly to a comprehensive benefit, the ACD will include:
- Larger parental/family component
- More holistic, beneficiary-centered approach
- Respite care
- Case management/Care coordination
- Case consultation
- Utilization management
- Quality oversight
- Value-based care

Questions DHA is Attempting to Find

- Is there any research underway addressing “dose response”?
- Are there other outcome measures we could/should use?
- Are medical necessity criteria developed? If so, what might those be?

Questions

Break

Meeting of the IACC

Morning Agenda

11:00	**Committee Business**
	Susan Daniels, Ph.D. Director, Office of Autism Research Coordination, National Institute of Mental Health, and Executive Secretary, IACC
	Joshua Gordon, M.D., Ph.D. Director, National Institute of mental Health and Chair, IACC
12:00 PM	**Lunch**

IACC Committee Business

IACC Full Committee Meeting
January 16, 2019

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

Thank you to OARC Staff

Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

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

Rebecca Martin, M.P.H
Public Health Analyst

Matthew Vilnit, M.B.A.
Operations Coordinator

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

Jeff Wiegand, **B.S.**
Web Development Manager

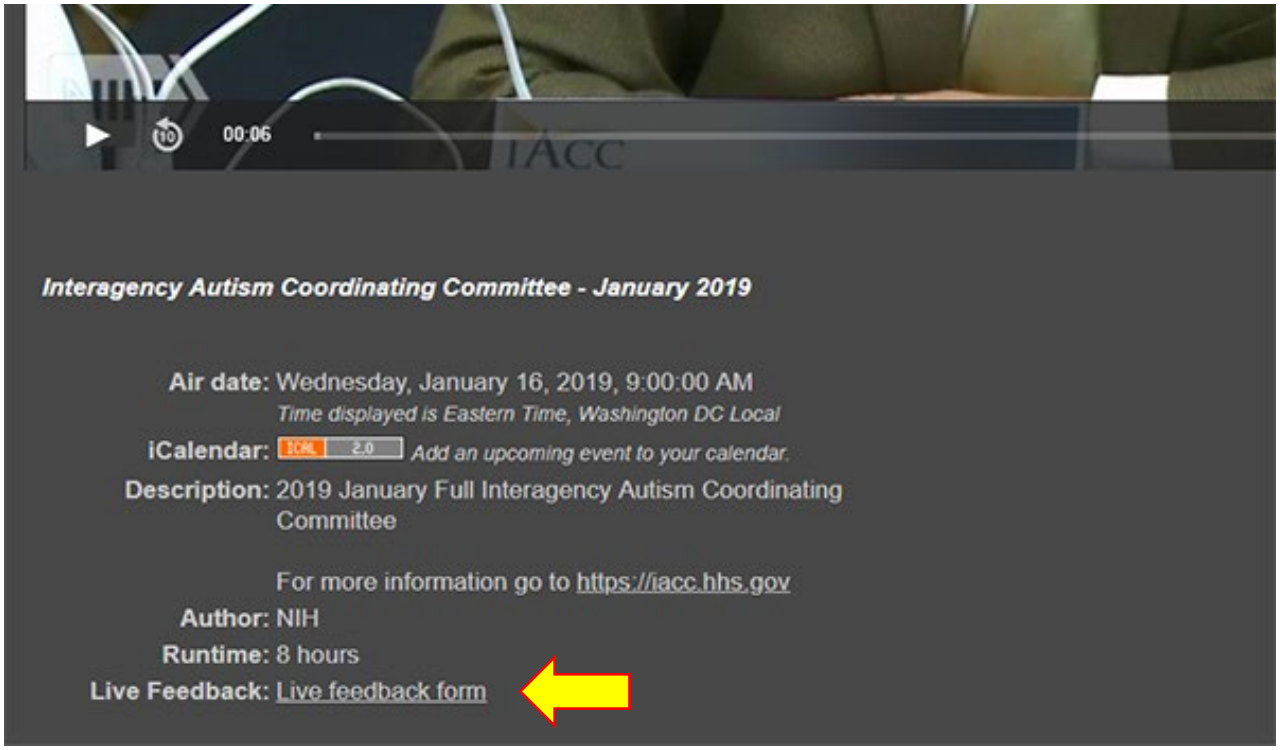
New option for submitting public comments

- Since 2008, the IACC has had two methods for public comment:
  - Written comments (submitted in advance)
  - Oral comments (presented in person)
- These are the methods used by the vast majority of federal advisory committees across the government

New option for submitting public comments

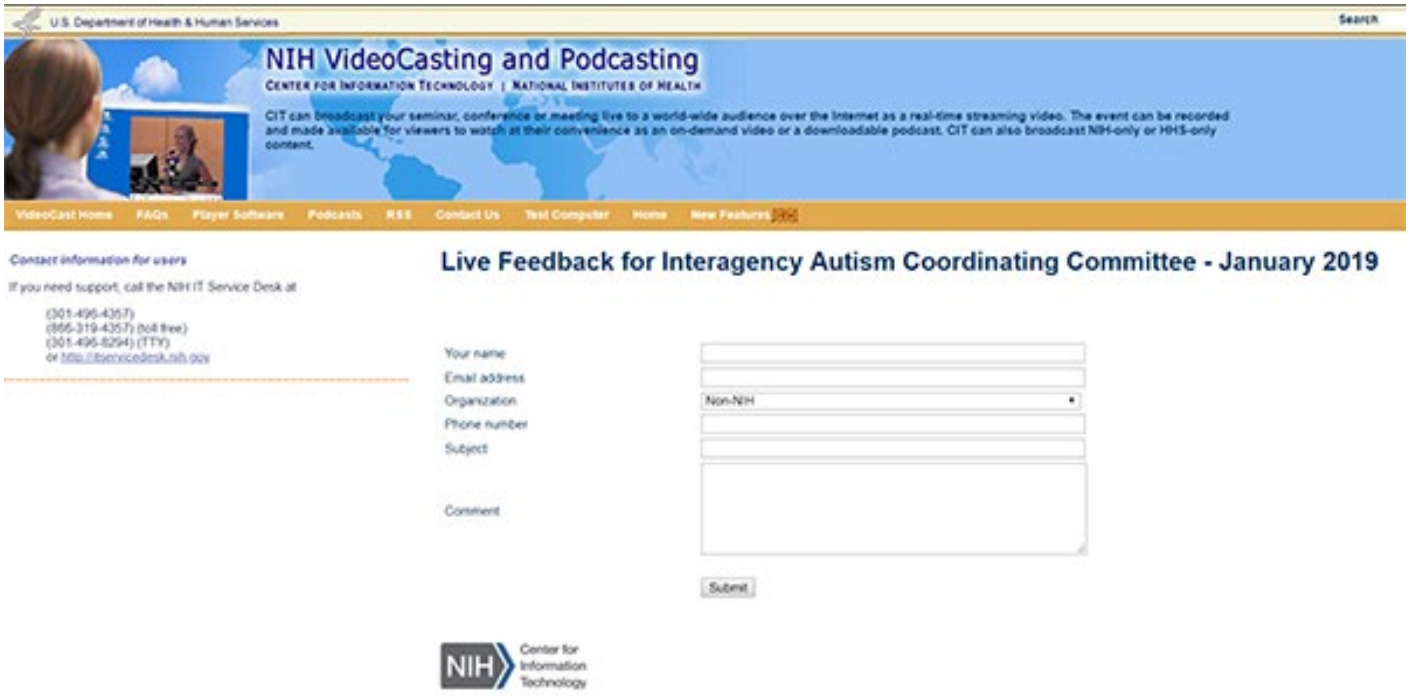
- The IACC is now offering a third option for public comments: **Live Feedback**
  - This option will provide additional flexibility to those who are not able to attend the meetings in person or submit a written comment in advance
  - Comments can be submitted online from **9:00am – 11:00am** on the day of the meeting
  - Comments that adhere to the guidelines will be collected and presented to the IACC before the public comment session in the afternoon

Live feedback instructions



- Live feedback form is accessible from the IACC meeting videocast page: https://videocast.nih.gov/summary.asp?live=29099&bhcp=1
- For commenting guidelines, visit: https://iacc.hhs.gov/meetings/iacc-meetings/2019/full-committee-meeting/january16/live-feedback.shtml

Live feedback instructions

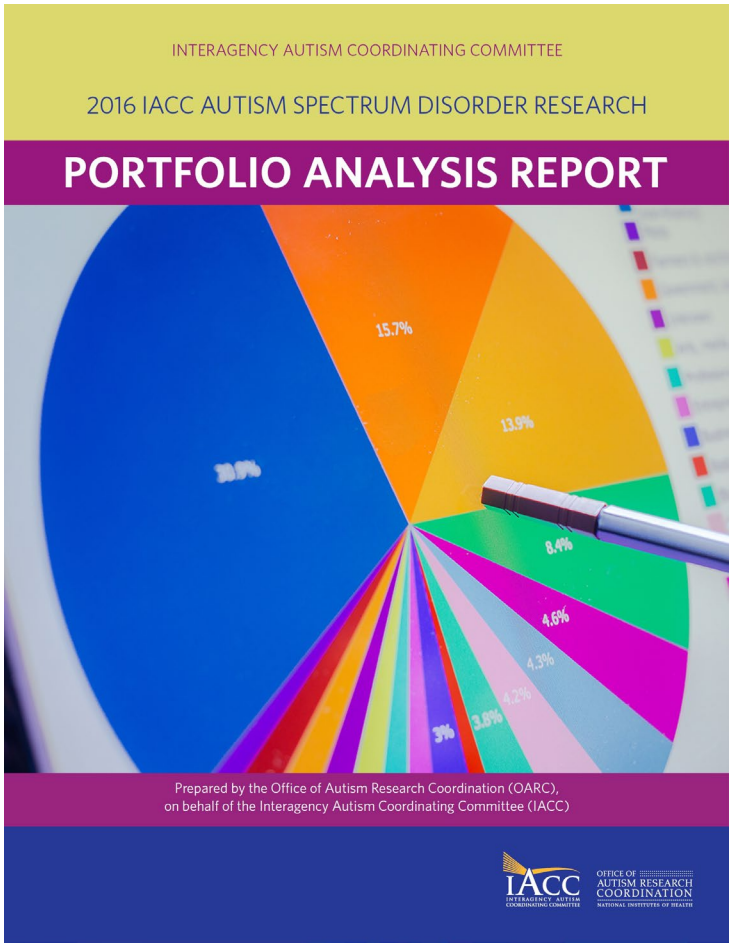


- Live feedback form is accessible from the IACC meeting videocast page: https://videocast.nih.gov/summary.asp?live=29099&bhcp=1
- For commenting guidelines, visit: https://iacc.hhs.gov/meetings/iacc-meetings/2019/full-committee-meeting/january16/live-feedback.shtml

Disability Accommodations

- Closed Captioning – available through the NIH VideoCast
- Quiet Room – started in April 2018
- CART Services – started in October 2018
- Other disability accommodations may be made available upon request

2016 IACC ASD Portfolio Analysis Report – Available now!



- This is the first *Portfolio Analysis Report* coding projects to the 23 new objectives of the *2016-2017 IACC Strategic Plan.*

- To accompany the Report, detailed 2016 project data are now available in the Autism Research Database (ARD), accessible via the IACC website.

https://iacc.hhs.gov/publications/portfolio-analysis/2016/

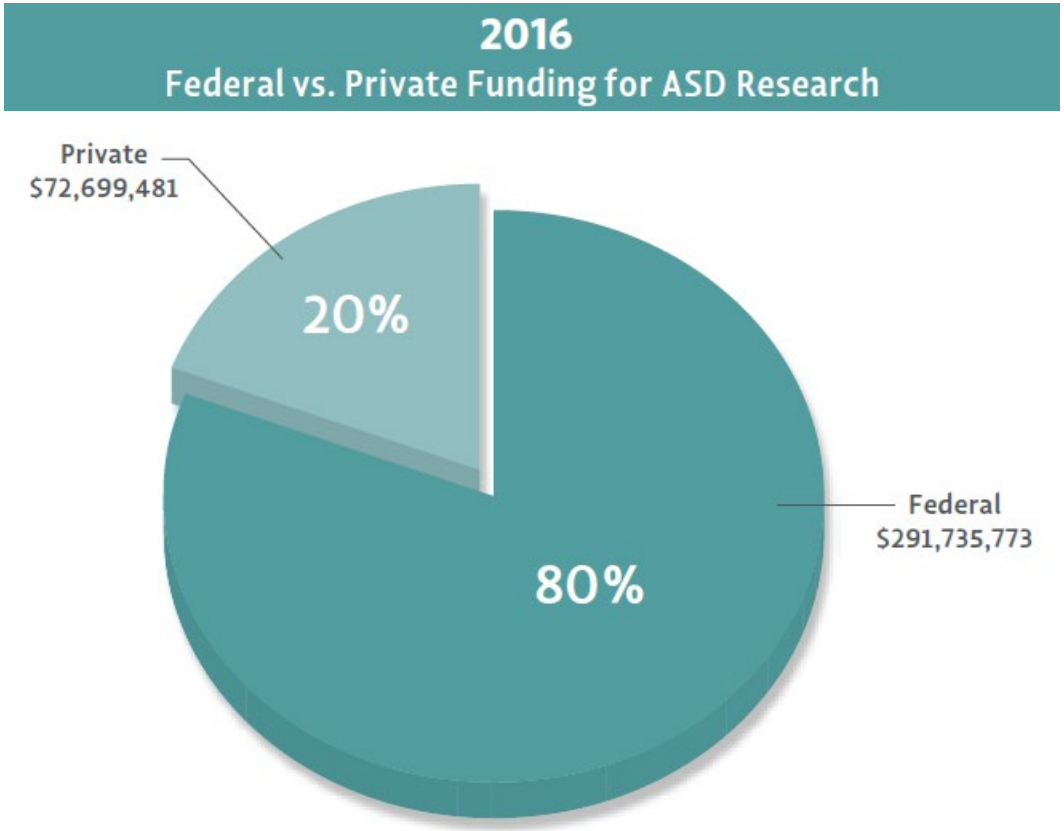
2016 IACC ASD Portfolio Analysis Report: Highlights

The analysis includes data from 18 federal agencies and private organizations.

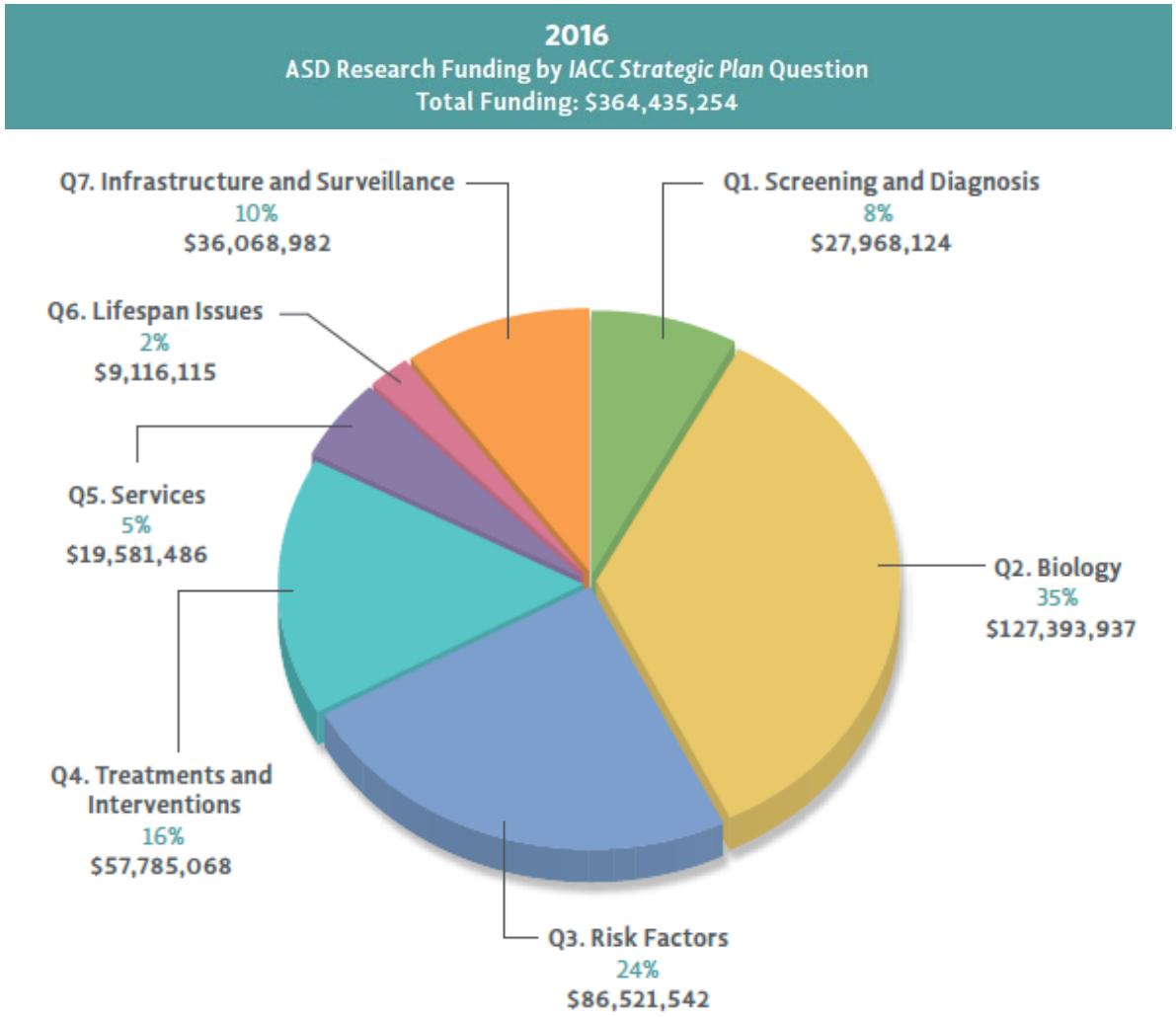
FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
• Administration for Community Living (ACL) • Agency for Healthcare Research and Quality (AHRQ) • Centers for Disease Control and Prevention (CDC) • Department of Defense – Army (DoD – Army) • Department of Education (ED) • Environmental Protection Agency (EPA) • Health Resources and Services Administration (HRSA) • National Institutes of Health (NIH) • National Science Foundation (NSF)	• Autism Research Institute (ARI) • Autism Science Foundation (ASF) • Autism Speaks (AS) • Brain & Behavior Research Foundation (BBRF) • Center for Autism and Related Disorders (CARD) • New England Center for Children (NECC) • Organization for Autism Research (OAR) • Patient-Centered Outcomes Research Institute (PCORI) • Simons Foundation (SF)

2016 IACC ASD Portfolio Analysis Report: Highlights

- ASD research funding totaled $364,435,254 and included 1,360 projects.
- Federal agencies supported 80% of overall funding.

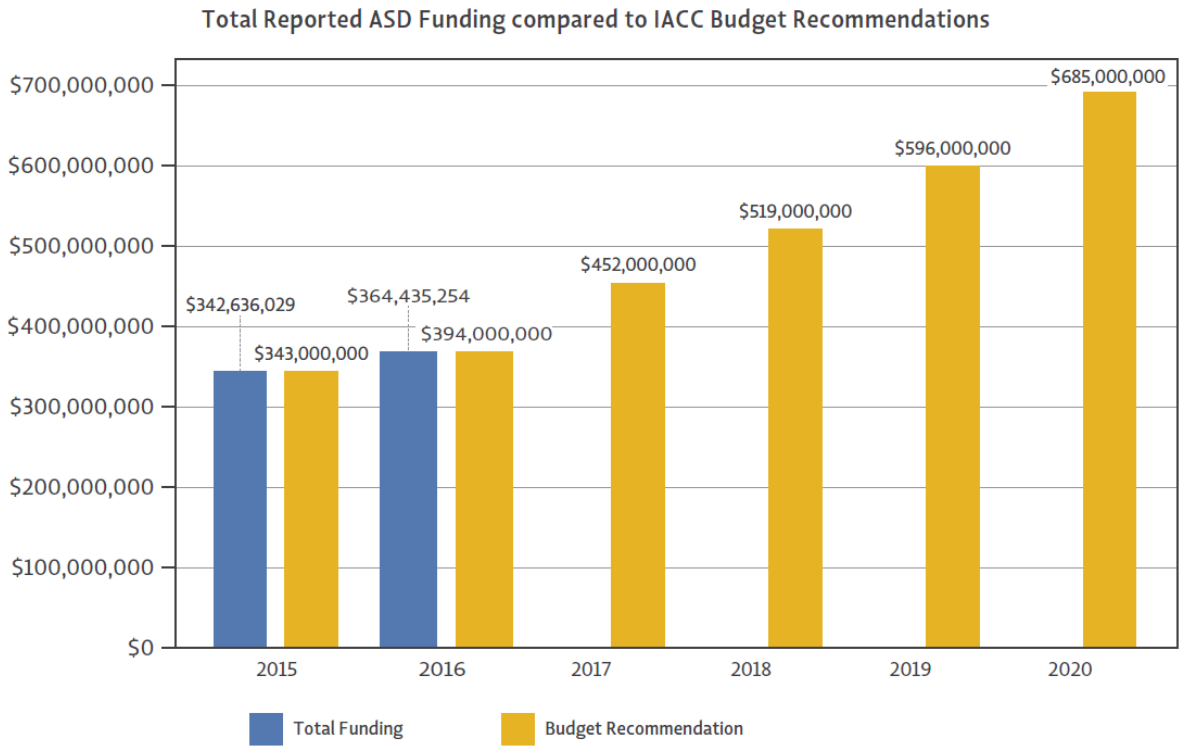


2016 IACC ASD Portfolio Analysis Report: Highlights



- Federal agencies and private organizations supported research in all seven of the *IACC Strategic Plan* questions.
- In 2016, Question 2 (Biology) continued to be the most highly-funded research area.

2016 IACC ASD Portfolio Analysis Report: Highlights



- The *2016-2017 IACC Strategic Plan* calls for a doubling of the 2015 ASD research budget to $685 million by 2020. To accomplish this goal, the Committee recommended a nearly 15% annual increase in ASD research funding.

- Since 2015, funding for autism research increased 6.3% in funding.

2016 IACC ASD Portfolio Analysis Report: Highlights

IACC 2016-2017 Strategic Plan Objectives	2016 Funding	Project Count
Question 1 - Screening and Diagnosis	**$27,968,124**	**107**
1.1. Strengthen the evidence base for the benefits of early detection of ASD.	$1,105,355	5
1.2. Reduce disparities in early detection and access to services.	$6,728,655	16
1.3. Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.	$19,941,251	82
1.O. Not specific to Question 1 objectives	$192,864	4
Question 2 - Biology	**$127,393,937**	**491**
2.1. Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of ASD.	$ 96,027,190	402
2.2. Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.	$8,449,763	37
2.3. Support large scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.	$12,885,786	17
2.O Not specific to Question 2 objectives	$5,101,895	20

2016 IACC ASD Portfolio Analysis Report: Highlights

IACC 2016-2017 Strategic Plan Objectives	2016 Funding	Project Count
Question 3 - Risk Factors	**$86,521,542**	**240**
3.1. Strengthen understanding of genetic risk and resilience factors for ASD across the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and co-occurring conditions in ASD.	$52,584,621	143
3.2. Understand the effects on ASD risk and resilience of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in ASD.	$14,434,906	46
3.3. Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.	$18,728,984	46
3.O. Not specific to Question 3 objectives	$547,789	1
Question 4 - Treatments and Interventions	**$57,785,068**	**254**
4.1. Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.	$23,567,797	70
4.2. Create and improve psychosocial, development, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD.	$24,175,752	118
4.3. Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.	$7,861,639	54
4.O. Not specific to Question 4 objectives	$2,144,880	11

2016 IACC ASD Portfolio Analysis Report: Highlights

IACC 2016-2017 Strategic Plan Objectives	2016 Funding	Project Count
Question 5 – Services	**$19,581,486**	**84**
5.1. Scale up and implement evidence-based interventions in community settings.	$7,791,530	19
5.2. Reduce disparities in access and in outcomes for underserved populations.	$209,020	3
5.3. Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.	$7,500,189	39
5.O. Not specific to Question 5 objectives	$4,080,747	23
Question 6 - Lifespan Issues	**$9,116,115**	**48**
6.1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.	$6,733,188	24
6.2. Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.	$574,730	3
6.3. Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.	$1,234,501	16
6.O. Not specific to Question 6 objectives	$573,696	5

2016 IACC ASD Portfolio Analysis Report: Highlights

IACC 2016-2017 Strategic Plan Objectives	2016 Funding	Project Count
Question 7 - Infrastructure and Surveillance	**$36,068,982**	**136**
7.1. Promote growth, integration, and coordination of the biorepository infrastructure.	$4,202,497	17
7.2. Develop, enhance, and link the data repositories.	$11,553,624	25
7.3. Expand and enhance the research and services workforce and accelerate the pipeline from research to practice.	$9,891,875	58
7.4. Strengthen ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible.	$7,422,083	18
7.O. Not specific to Question 7 objectives	$2,998,903	18
Cross-Cutting Objective		
CC1. Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.	$5,189,546	20
Grand Total	**$364,435,254**	**1360**

2016 IACC ASD Portfolio Analysis Report: Highlights

In addition, the *2016 IACC ASD Research Portfolio Analysis Report* includes:

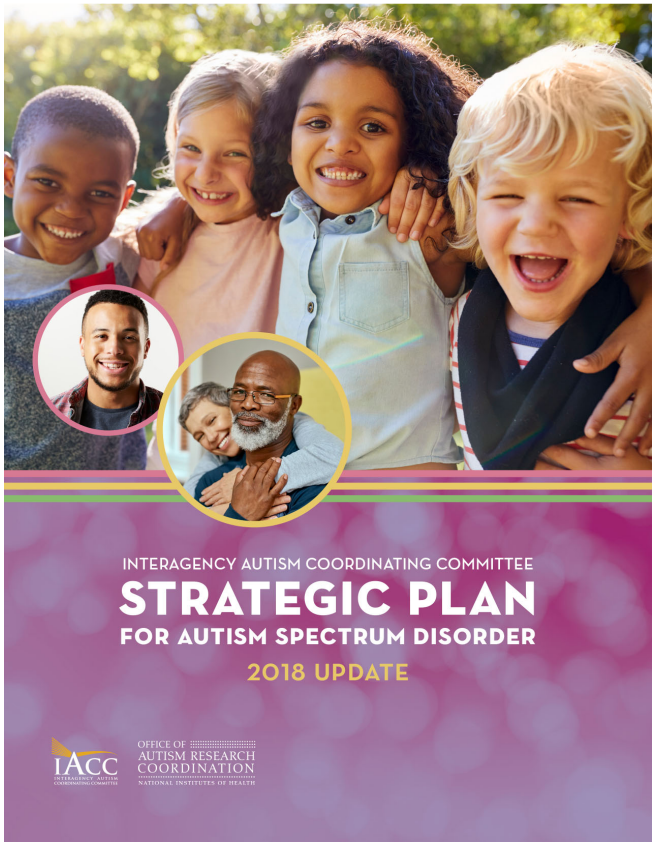
- A map displaying institutions involved in ASD research across the U.S.
- A list of countries receiving ASD research funding from U.S. funders
- Funder contributions aligned with the seven *Strategic Plan* questions
- Subcategory analyses for each *Strategic Plan* question
- ASD research funding trends from 2008-2016 by *Strategic Plan* question

The full report is available at
https://iacc.hhs.gov/publications/portfolio-analysis/2016/

Autism CARES Act Report to Congress

- Report required by the Autism CARES Act
- Report details progress on activities related to ASD and other developmental disorders across the federal government
- On behalf of HHS, OARC coordinated responses from federal Departments/agencies and prepared the report
- Report expected in 2019

2018 IACC Strategic Plan Update



- The *2018 IACC Strategic Plan Update* will provide a summary of the IACC's 2018 activities and progress related to the *Strategic Plan*, including:
  - Summary of Health Outcomes working group and workshop
  - Summary of *2016 IACC Portfolio Analysis Report*
  - Summary of Autism CARES Act *Report to Congress*
- Committee members will receive a draft for review and comments
- Final publication expected in Spring 2019

Other reports in preparation

- *2017 IACC Portfolio Analysis Report*
  - OARC has collected 2017 data from funders, is in the process of performing analysis
  - Final report expected in 2019

- *2016 International Portfolio Analysis Report*
  - Canada, the United Kingdom, and the United States have contributed data for this report
  - Final report expected in Spring 2019

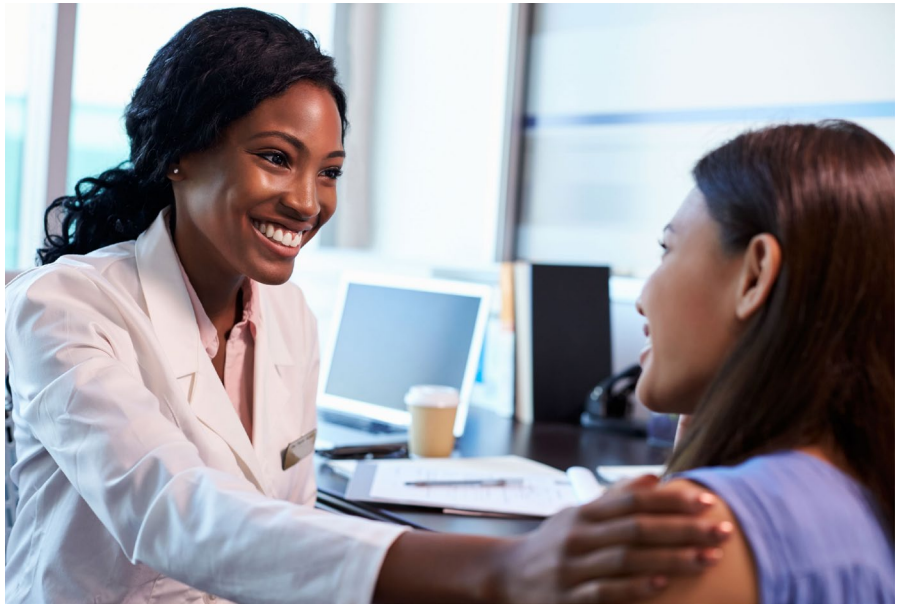
Improving Health Outcomes for Individuals on the Autism Spectrum WG

- The IACC voted to convene a working group on health and wellness issues for individuals with ASD
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor

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

Health Outcomes Working Group: Scope

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



Health Outcomes Working Group: Previous Activities

- Working Group conference call (September 5, 2018)

- Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 27, 2018)
  - Health Epidemiology
  - Three co-occurring conditions: epilepsy, gastrointestinal disorders, and sleep disturbances
  - Improving patient-provider interactions

- Working Group conference call (December 17, 2018)
  - Discussion of plans for written product
  - Discussion of plans for a workshop on mental health issues in ASD

Health Outcomes Working Group: Expected Activities and Products

- A written document providing an update on issues
- A workshop addressing mental health conditions and ASD – in 2019
- Continued discussions in Working Group conference calls and/or IACC full committee meetings
- Working Group activities will run from September 2018 – September 2019

Housing Working Group

- The IACC voted to convene a working group on housing issues for individuals with ASD.
- Scope
  - Research and best practices on housing
  - Implementation of current federal regulations
  - Housing issues faced by autistic individuals with more severe disabilities
- Alison Singer has volunteered to serve as chair of this working group

Housing Working Group

Draft mission statement

In the autism community we face a mounting housing crisis, with a growing population of autistic adults with diverse needs lacking appropriate living situations. The goal of this subcommittee is to examine a wide variety of housing options and service models for people with autism, and to develop strategies to achieve a broad array of supported housing options throughout all of our communities that enable autistic individuals to achieve person-centered outcomes.

Housing Working Group: Expected Activities and Products

- Activities will include:
  - Working group phone calls
  - Possible in-person meeting or workshop

- Working group activities will run through September 2019

Discussion

Lunch

Meeting of the IACC

Afternoon Agenda

1:00 PM **Public Comment Session**

Joshua Gordon
Director, NIMH and Chair, IACC

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

Oni Celestin, Ph.D.
Science Policy Analyst
Office of Autism Research Coordination, NIMH

Meeting of the IACC

Afternoon Agenda

2:15 **DOJ Presentation: Kevin and Avonte's Law, and Disability Programs**

Introduction
Alison Singer, M.B.A.
IACC Member
President, Autism Science Foundation

2:00 **Lori McIlwain**
Co-Founder, Board Member, National Autism Association

2:40 **Maria Fryer**
Policy Advisor for Substance Abuse and Mental Health
Bureau of Justice Assistance
Office of Justice Programs
Department of Justice

Meeting of the IACC

Afternoon Agenda

DOJ Presentation: Kevin and Avonte's Law, and Disability Programs (Con't)

3:00 **Leemie Kahng-Sofer**
Program Manager
Missing Children Division
National Center for Missing and Exploited Children

3:45 **Afternoon Break**

Oral Public Comments

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

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

Written Public Comments

Oni Celestin, Ph.D.
Science Policy Analyst
Office of Autism Research Coordination, NIMH

Discussion

Department of Justice Presentation: Kevin and Avonte's Law, and Disability Programs

Alison Singer, M.B.A.
Lori McIlwain
Maria Fryer
Leemie Kahng-Sofer

AUTISM SCIENCE FOUNDATION

SEARCHING
SHARING
SOLVING

Autism & Wandering

Alison Singer
President
Autism Science Foundation

IACC
January 16, 2019


BANNED
AUTISM SCIENCE FOUNDATION

Timeline

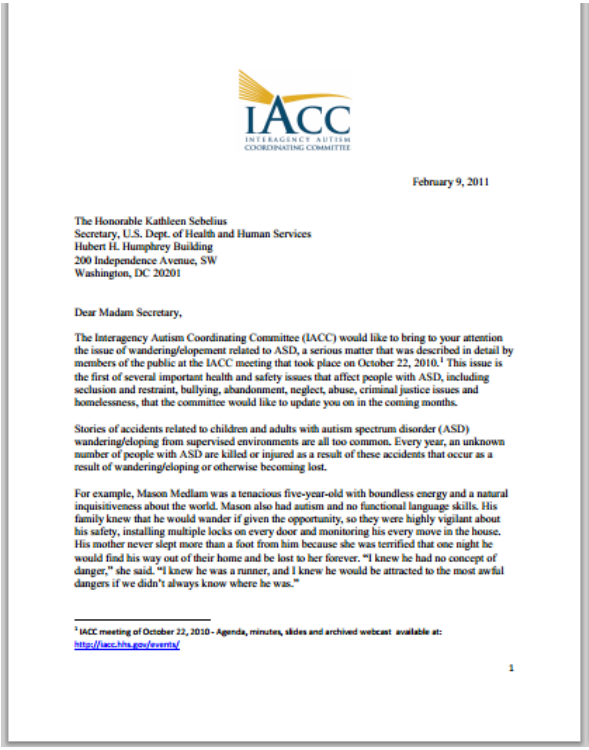
- October 2010:
  - Wandering issue presented at IACC during public comments by President of the National Autism Assocaition
  - Safety committee formed to investigate wandering

- November 2010:
  - Consortium Formed to Study Wandering
    - Jan-Feb 2011: Survey designed
    - March 2011: Survey released to community
      - (Parents of 1218 kids with ASD, 1076 sibs)

AUTISM SCIENCE FOUNDATION

Timeline

- February 2011:
  - Letter sent to Secretary Sebelius
- March 2011:
  - Response received



IACC
INTERAGENCY AUTISM COORDINATING COMMITTEE

February 9, 2011

The Honorable Kathleen Sebelius
Secretary, U.S. Dept. of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Madam Secretary,

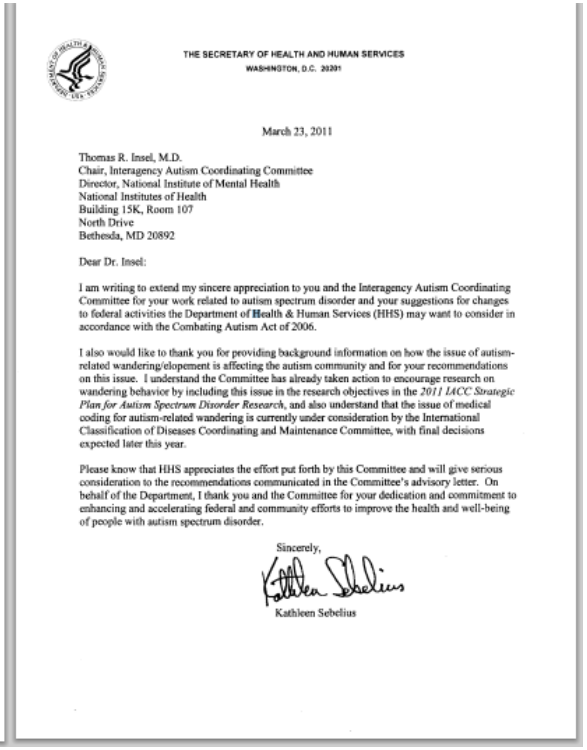
The Interagency Autism Coordinating Committee (IACC) would like to bring to your attention the issue of wandering/elopement related to ASD, a serious matter that was described in detail by members of the public at the IACC meeting that took place on October 22, 2010.[1] This issue is the first of several important health and safety issues that affect people with ASD, including seclusion and restraint, bullying, abandonment, neglect, abuse, criminal justice issues and homelessness, that the committee would like to update you on in the coming months.

Stories of accidents related to children and adults with autism spectrum disorder (ASD) wandering/eloping from supervised environments are all too common. Every year, an unknown number of people with ASD are killed or injured as a result of these accidents that occur as a result of wandering/eloping or otherwise becoming lost.

For example, Mason Medlam was a tenacious five-year-old with boundless energy and a natural inquisitiveness about the world. Mason also had autism and no functional language skills. His family knew that he would wander if given the opportunity, so they were highly vigilant about his safety, installing multiple locks on every door and monitoring his every move in the house. His mother never slept more than a foot from him because she was terrified that one night he would find his way out of their home and be lost to her forever. "I knew he had no concept of danger," she said. "I knew he was a runner, and I knew he would be attracted to the most awful dangers if we didn't always know where he was."

[1] IACC meeting of October 22, 2010 - Agenda, minutes, slides and archived webcast available at: http://iacc.hhs.gov/events/

1



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

March 23, 2011

Thomas R. Insel, M.D.
Chair, Interagency Autism Coordinating Committee
Director, National Institute of Mental Health
National Institutes of Health
Building 15K, Room 107
North Drive
Bethesda, MD 20892

Dear Dr. Insel:

I am writing to extend my sincere appreciation to you and the Interagency Autism Coordinating Committee for your work related to autism spectrum disorder and your suggestions for changes to federal activities the Department of Health & Human Services (HHS) may want to consider in accordance with the Combating Autism Act of 2006.

I also would like to thank you for providing background information on how the issue of autism-related wandering/elopement is affecting the autism community and for your recommendations on this issue. I understand the Committee has already taken action to encourage research on wandering behavior by including this issue in the research objectives in the *2011 IACC Strategic Plan for Autism Spectrum Disorder Research*, and also understand that the issue of medical coding for autism-related wandering is currently under consideration by the International Classification of Diseases Coordinating and Maintenance Committee, with final decisions expected later this year.

Please know that HHS appreciates the effort put forth by this Committee and will give serious consideration to the recommendations communicated in the Committee's advisory letter. On behalf of the Department, I thank you and the Committee for your dedication and commitment to enhancing and accelerating federal and community efforts to improve the health and well-being of people with autism spectrum disorder.

Sincerely,

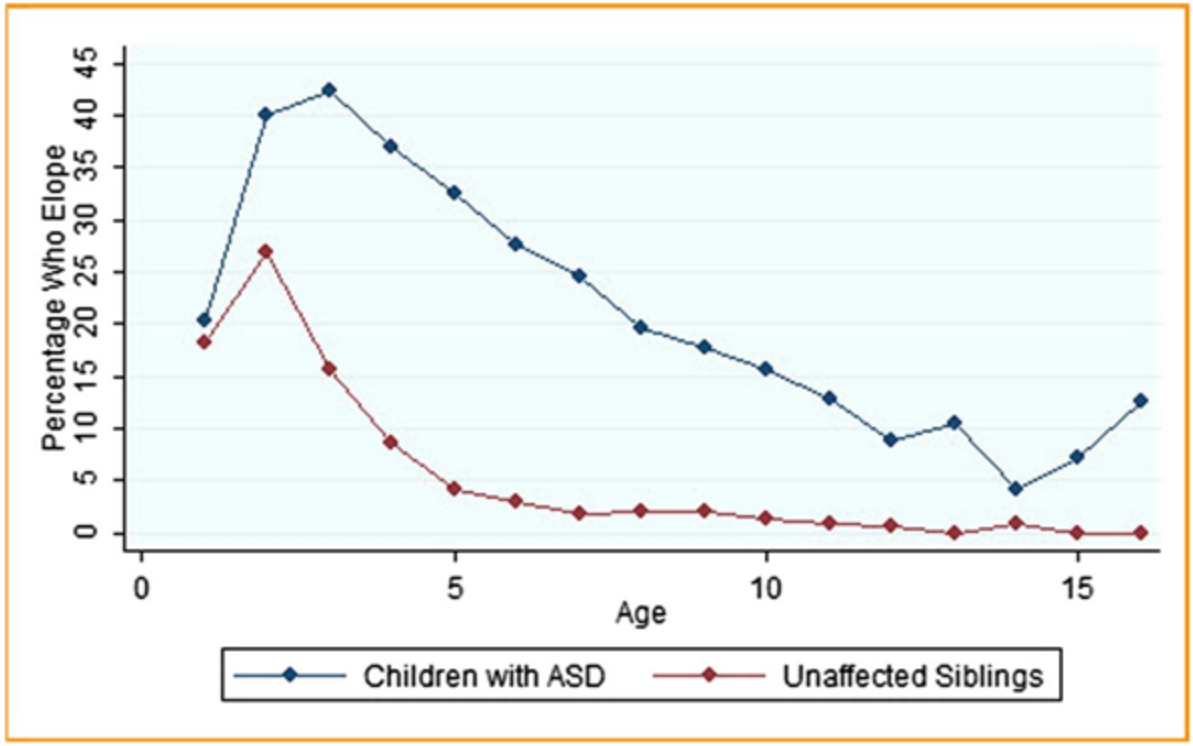
Kathleen Sebelius

Kathleen Sebelius

AUTISM SCIENCE FOUNDATION

Initial Data Presented April, 2011

Reported rates of elopement at specific ages: a comparison of children with ASD and unaffected siblings.



AUTISM SCIENCE FOUNDATION

Anderson, Law, et al (KKI/IAN)

October, 2011

CDC Home

Centers for Disease Control and Prevention

CDC 24/7: Saving Lives. Protecting People.™

A-Z Index A B C D E F G H I J K L M N O P Q R S T U V W X Y Z #

Classification of Diseases, Functioning, and Disability

ICD and ICF Home
▶ICD-9
ICD-10
ICD-9-CM
ICD-10-CM
ICF
Classification of Death and Injury Resulting from Terrorism
North American Collaborating Center

Related Sites
Centers for Medicare and Medicaid Services
World Health Organization

NCHS Home > ICD and ICF Home

Recommend 15 Tweet Share

International Classification of Diseases, Ninth Revision (ICD-9)

The International Classification of Diseases (ICD) is designed to promote international comparability in the collection, processing, classification, and presentation of mortality statistics.

This includes providing a format for reporting causes of death on the death certificate. The reported conditions are then translated into medical codes through use of the classification structure and the selection and modification rules contained in the applicable revision of the ICD, published by the World Health Organization. These coding rules improve the usefulness of mortality statistics by giving preference to certain categories, by consolidating conditions, and by systematically selecting a single cause of death from a reported sequence of conditions. The single selected cause for tabulation is called the underlying cause of death, and the other reported causes are the nonunderlying causes of death. The combination of underlying and nonunderlying causes is the multiple causes of death.

The ICD has been revised periodically to incorporate changes in the medical field. To date, there have been 10 revisions of the ICD. The years for which causes of death in the United States have been classified by each revision are as follows:

AUTISM SCIENCE FOUNDATION

May, 2012

AUTISM SCIENCE FOUNDATION

October, 2012

PEDIATRICS®

CELEBRATING 65 YEARS 1948 2013

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders

AUTHORS: Connie Anderson, PhD,[a] J. Kiely Law, MD,[a,b] Amy Daniels, PhD,[a,c] Catherine Rice, PhD,[d] David S. Mandell, ScD,[e] Louis Hagopian, PhD,[a,b] and Paul A. Law, MD, MPH[a,b]

[a]Kennedy Krieger Institute, Baltimore, Maryland; [b]Johns Hopkins University School of Medicine, Baltimore, Maryland; [c]Autism Speaks, New York, New York; [d]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia; and [e]University of Pennsylvania Perelman School of Medicine, Center for Mental Health Policy and Services Research, Philadelphia, Pennsylvania.

KEY WORDS
autism spectrum disorders, elopement, wandering

WHAT'S KNOWN ON THIS SUBJECT: Anecdotal accounts suggest elopement behavior occurs in children with autism spectrum disorders (ASDs), that injuries and fatalities can result, and that associated family burden and stress are substantial. However, there has been little research characterizing the phenomenon or its frequency.

WHAT THIS STUDY ADDS: Nearly half of children with an ASD elope, and more than half of these "go missing." Elopement is associated with autism severity, and is often goal-directed. Addressing elopement behavior is an important aspect of

AUTISM SCIENCE FOUNDATION

USA TODAY

SPORTS | LIFE | MONEY | TECH | TRAVEL | OPINION | 77°

This story is part of HEALTH AND WELLNESS

Vision-related diseases are a hefty financial burden

Doctors more concerned about kids' repeat concussions

Vitamin D levels in USA peak in August, study finds

Nearly half of children with autism wander from safety

12:12 a.m. EDT October 8, 2012

(Photo: Ron Chapple, jupiterimages)

STORY HIGHLIGHTS

The fear that overtakes a parent when a child wanders away from home or other safe place is easily compounded when that child has an autism-spectrum disorder. A new study shows that such behavior occurs more often than in other kids, and that the hazards can be significant.

In a sample of 1,200 children with autism, 49% had wandered, bolted or "eloped" at least once after age 4; 26% went missing long enough to cause their family concern. By comparison, only 13% of 1,076 siblings without autism had ever wandered off at or after age 4, developmentally the age when such behavior becomes less common, finds the study

Study Shows Children With Autism Tend to Stray

By RONI CARYN RABIN

When Patrick Murphy was 6, he became obsessed with vacuum cleaners. The boy, who has autism, used to slip out of his house near Buffalo without telling his parents, running to a nearby appliance store or into strangers' homes to marvel at vacuum cleaners.

Patrick is now 14, and his parents have double bolts on the doors in their home and brackets on their windows. Still, Patrick — who is now focused on dogs — manages to sneak out. Two weeks ago, he crept from the house after his mother went to bed. When his father came home, he alerted the police. They found Patrick running barefoot in his pajamas at 2 a.m., three miles from his home.

"That was very scary," said Patrick's father, Brian Murphy, who has now added an alarm system to the house to keep his son safe. "He has broken through brackets, windows, picked locks, you name it. It's absolutely the most stressful part of parenting a child with autism."

The behavior, called wandering or elopement, has led to numerous deaths in autistic children by drowning and in traffic accidents. Now a new study of more than 1,200 families with autistic children suggests wandering is alarmingly common. Nearly half of parents with an autistic child age 4 or older said their children had tried to leave a safe place at least once, the study reported. One in four said their children had disappeared long enough to cause concern. Many parents said their wandering children had narrowly escaped traffic accidents or had been in danger of drowning.

Those at greatest risk of wandering off were autistic children with severe intellectual deficits and those who do not respond to their names. The research was published on Monday in the journal Pediatrics.

"I knew this was a problem, but I didn't know just how significant a problem it was until I really began to look into it," said Dr. Paul A. Law, senior author of the study and director of the Interactive Autism Network, a registry that is a project of the Kennedy Krieger Institute in Baltimore. "This is probably one of the leading causes of death and morbidity for kids with autism."

A behavior that has led to numerous accidental deaths.

Advocates for families affected by autism say the findings underscore the need to raise public awareness and alter policy. While Amber alerts are used to mobilize the public when a child is believed to have been abducted, for instance, generally they are not used when a disabled child goes missing, said Alison Singer, president and a founder of the Autism Science Foundation, one of the organizations that supported the study.

Emergency responders should receive special training on how to search for autistic children who are nonverbal and often scared by lights and sirens, she said. Emergency personnel also need to know to check streams or ponds, since many children with autism are drawn to bodies of water, as well as highways.

One in 88 children in the United States received a diagnosis of autism, Asperger syndrome or a related disorder in 2008, according to the Centers for Disease Control and Prevention. While some of these children are socially awkward but high functioning, others have limited intellectual and cognitive abilities.

"For children who are prone to wander, this is a pervasive problem that affects all aspects of families' lives," Dr. Law said. "Many parents just don't go out in public with their child because they don't feel safe with them, or they don't get any sleep at night because the child once escaped through the upstairs window."

The idea for the new study came from a family coping with autism, and it was financed by several advocacy organizations. Researchers surveyed families who had a child with autism or a related disorder between the ages of 4 and 17.

Most of the respondents came from 1,098 of Interactive Autism Network's most active participants, 60 percent of whom completed the survey. Families who chose to participate knew the survey was about wandering, and those coping with wandering children may have been more likely to respond, skewing the results, Dr. Law acknowledged.

Over all, 49 percent of families who participated said a child with autism had tried to wander from home, school or another safe place at least once after age 4; the peak age for wandering was 5. Some parents said their child wandered off several times a week or even several times a day.

"This is the first study to quantify the scope of the problem, and it was much larger than we thought," Ms. Singer said.

Patrick Murphy, 14, will sometimes sneak out of the house to pursue his latest interest.

BRENDAN BANNON FOR THE NEW YORK TIMES

U.S. News & WORLD REPORT

Nearly Half of Children With Autism Wander From Safety: Survey

Advocates say a system such as Amber Alerts is needed for these kids

October 8, 2012 | RSS Feed | Print

HealthDay

By Maureen Salamon
HealthDay Reporter

MONDAY, Oct. 8 (HealthDay News) -- Nearly half of children with autism wander or "elope" from safety -- often to pursue a special interest or goal -- with more than half of those kids disappearing long enough to cause great concern about their well-being, new research suggests.

Researchers from the Interactive Autism Network, a project of the Kennedy Krieger Institute in Baltimore, found that close calls with traffic injuries were reported for 65 percent of the missing children and near-misses with drowning were reported in nearly a quarter of all cases.

Wandering More Common in Autistic Children Than Once Thought

Twelve-year-old Connor McIlwain is one of many children with autism who have repeatedly wandered away from home. (Courtesy Lori McIlwain)

ABC GOOD MORNING AMERICA

By LARA SALAHI (@BostonLara)
October 5, 2012

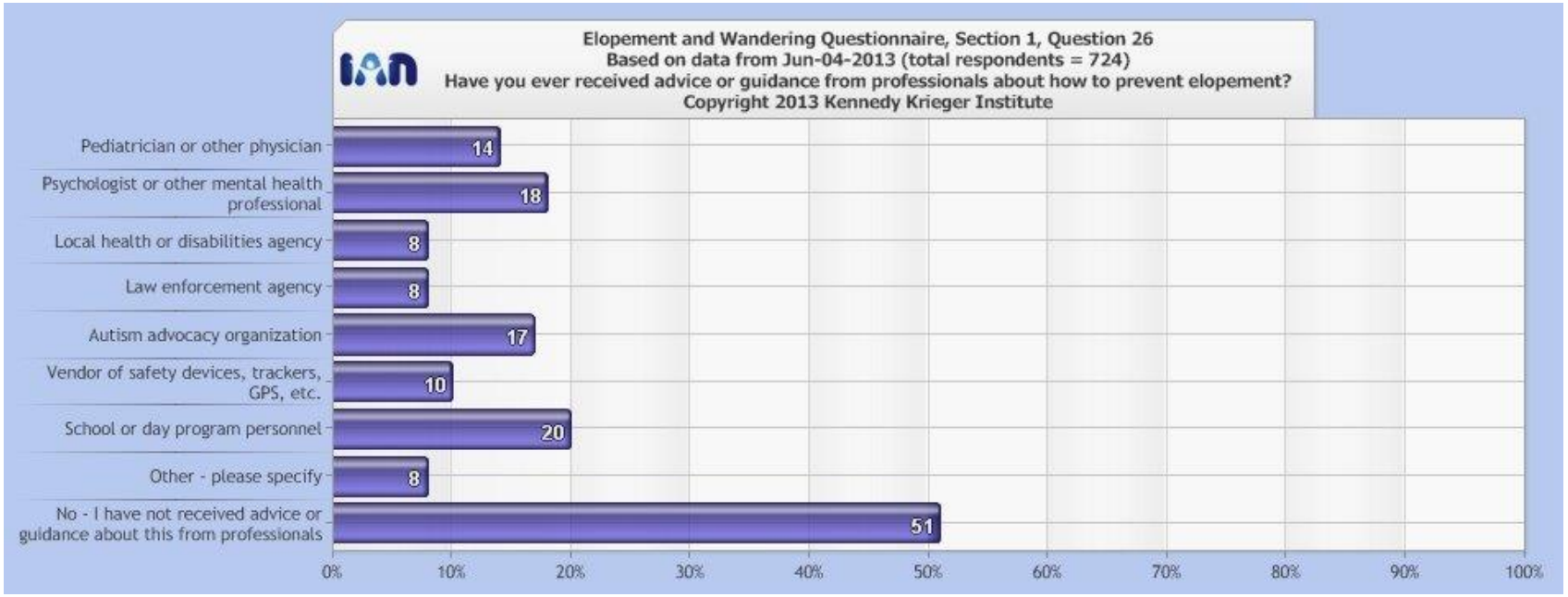
Lori McIlwain, 39 of Cary, N.C., lives in constant fear that her 12-year-old son, Connor, who is autistic, will bolt from home or school if he is ever left unsupervised.

"You live in constant prevention mode," said McIlwain. "You're always on high alert."

Four years ago, Connor wandered away from a school playground and headed right toward a busy highway.

AUTISM SCIENCE FOUNDATION

Anticipatory Guidance Lacking



AUTISM SCIENCE FOUNDATION

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

AUTISM SCIENCE FOUNDATION

2013

Autism

CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS: A RESOURCE TOOLKIT FOR CLINICIANS, 2ND EDITION FAMILY HANDOUTS

Wandering Off (Elopement)

What is wandering off *(elopement)*?

This is the tendency for an individual to try to leave the safety of a responsible person's care or a safe area, which can result in potential harm or injury. This might include running off from adults at school or in the community, leaving the classroom without permission, or leaving the house when the family is not looking. This behavior is considered common and short-lived in toddlers, but it may persist in children and adults with autism spectrum disorders (ASDs). Children with ASDs have challenges with social and communication skills and safety awareness. This makes wandering a potentially dangerous behavior.

Why do children with ASDs wander off?

Parents of children with ASDs report the following top 5 reasons for wandering:

- Simple enjoyment of running or exploring
- Desire to reach a place he enjoys (such as the park)
- Trying to escape an anxious situation (like demands at school)
- Pursuit of a special interest (as when a child fascinated by trains heads for train tracks)
- Trying to escape uncomfortable sensory stimuli (like loud

t http://awaare.org/docs/wanderingbrochure.pdf, and IAN Research Report: Elopement and
· Institute, Baltimore, Maryland. This information appeared originally at: www.iancommunity.org/cs/

AUTISM SCIENCE FOUNDATION

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

Other AAP initiatives

- Presentation by Dr. Susan Hyman and Dr. Susan Levy at 2017 AAP meeting.
- Article in AAP magazine in 2017; another one planned in 2019

AUTISM SCIENCE FOUNDATION

March, 2018: Kevin and Avonte's Law

- Still no Appropriation for Kevin and Avonte's Law
  - Autism "alert"
  - GPS tracking devices
  - First Responder training

AUTISM SCIENCE FOUNDATION

NATIONAL AUTISM ASSOCIATION

Wandering/Elopement in ASD
2019 Update

Lori McIlwain
National Autism Association

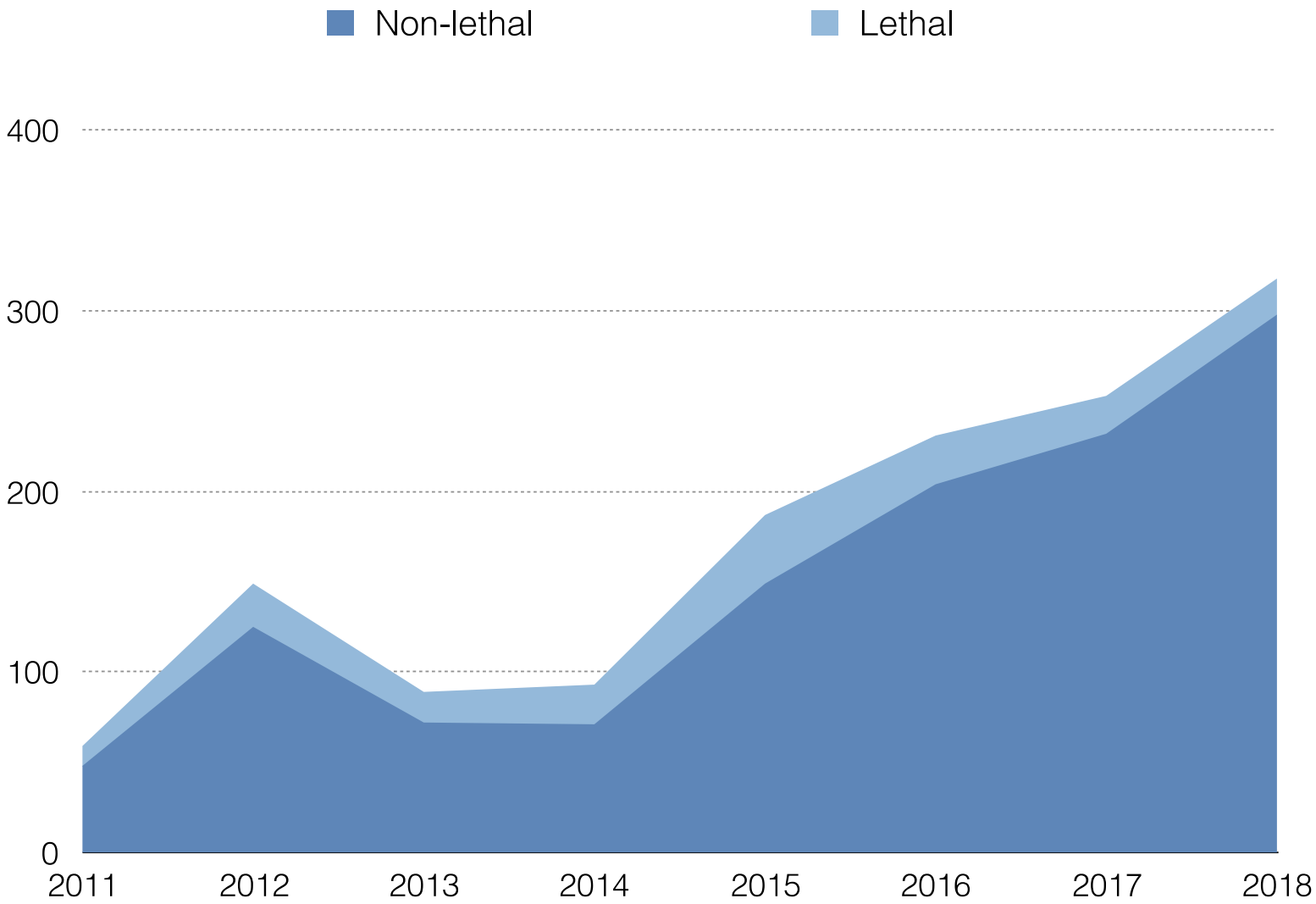
IACC
January 2019

1338 ASD missing and
“found missing” person cases in
the U.S. since 2011,
180 reported fatalities.

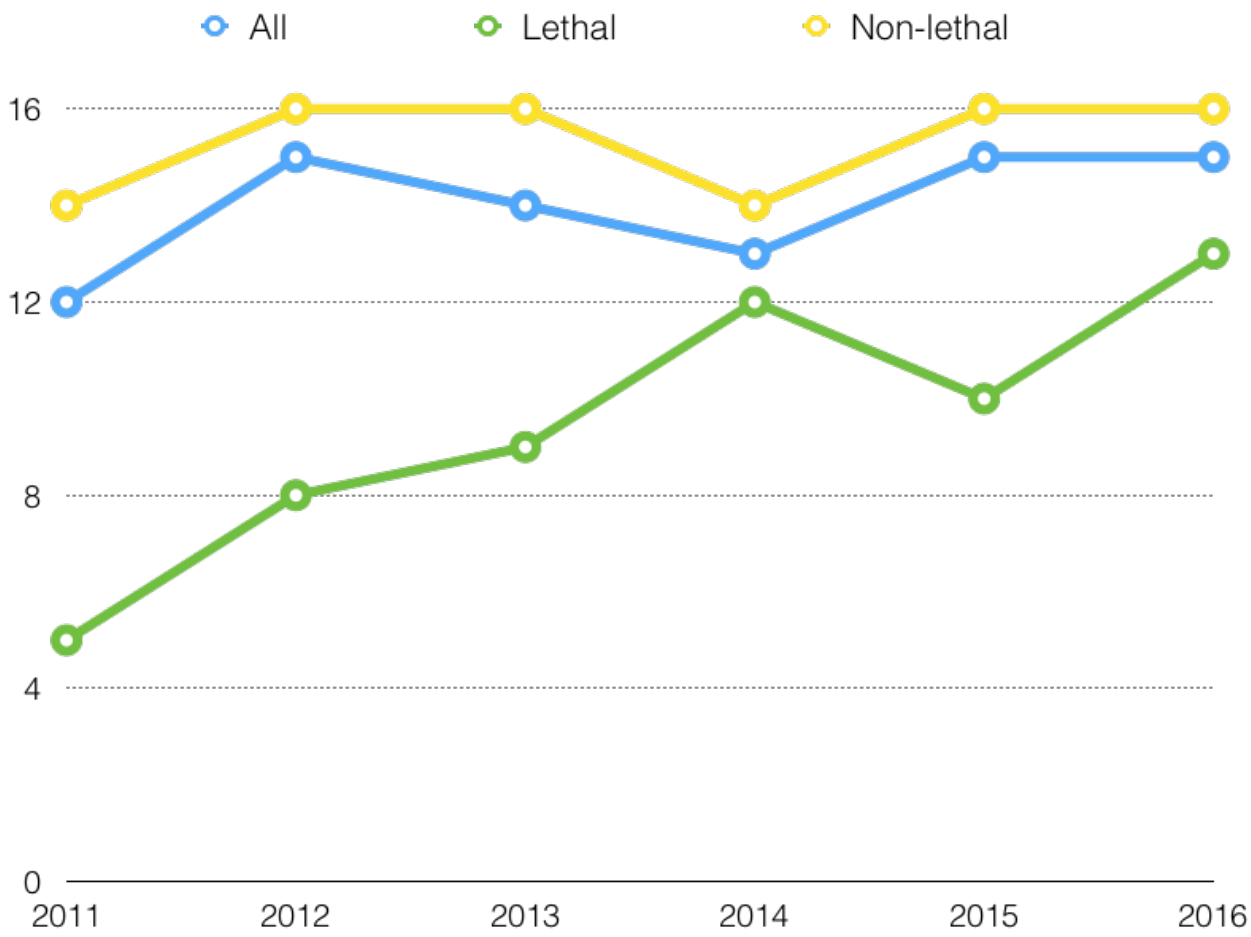
NATIONAL AUTISM ASSOCIATION

On average: 20 cases,
2 to 3 deaths per month. Drowning remains leading cause of death.

NATIONAL AUTISM ASSOCIATION


Non-lethal
Lethal
400
300
200
100
0
2011
2012
2013
2014
2015
2016
2017
2018

Average Age by Year, 2011 to 2016



***Current average age for lethality, 15**

NATIONAL AUTISM ASSOCIATION

*What **Increased** Lethal/Injury Risk*

- Residential settings, esp. those unfamiliar, near water
- Times of transition, disruption
- Heightened response to stress
- Caregiver/staff distracted
- Commotion, esp. during holidays/family gatherings
- Longer Search Time
- Police unaware, unprepared

NATIONAL AUTISM ASSOCIATION

01/12/2019, 04:14am

Autistic woman, reported missing, dies after being found in creek

Wendy M. Lippard | Kendall County sheriff's office

By Sun-Times Wire email

A woman with autism died Thursday following a five-hour police search that led to her rescue from a creek in west suburban Bristol.

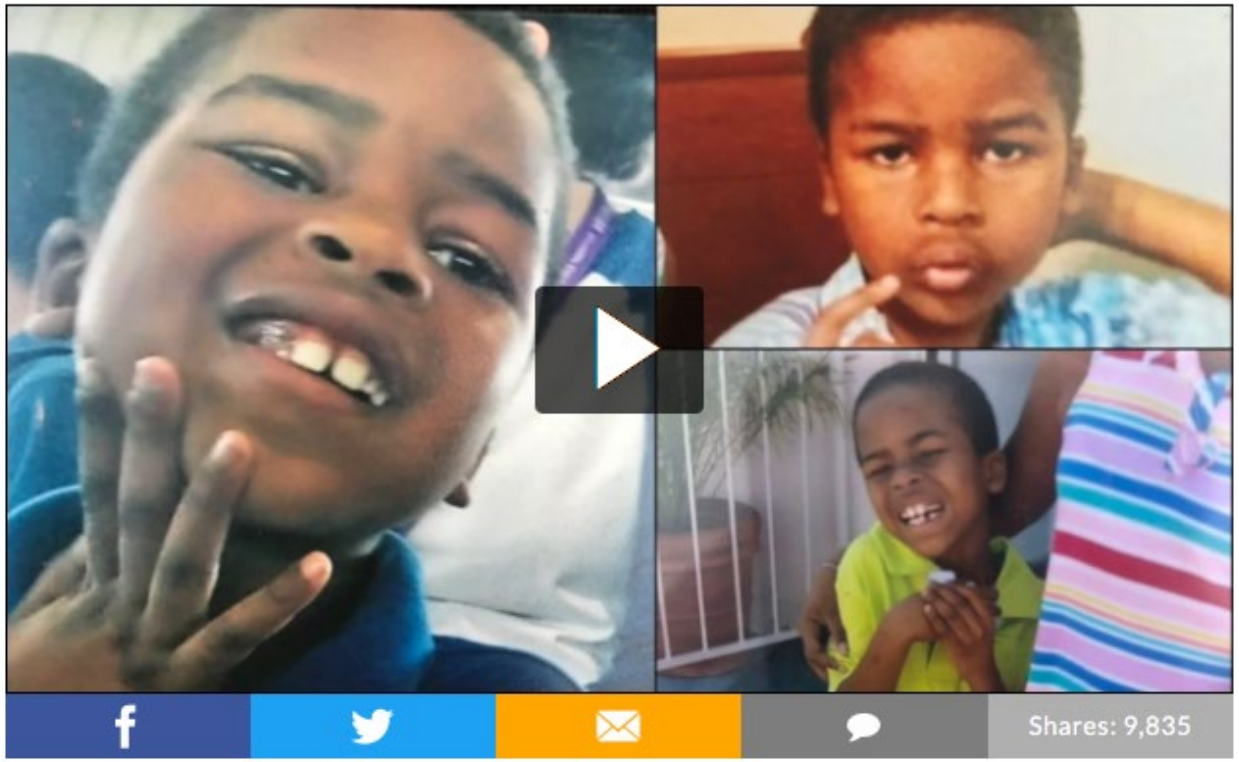
Last Week

NATIONAL AUTISM ASSOCIATION

Body found in pond confirmed as missing Texas City child with autism, officials say

By Andy Cerota - Anchor/Reporter, Jacob Rascon - Anchor-Reporter, Brittany Taylor - Digital News Editor, Daniela Sternitzky-Di Napoli - Digital News Producer, Sofia Ojeda - Anchor/Reporter

Posted: 4:53 PM, January 06, 2019
Updated: 11:34 AM, January 09, 2019



TEXAS CITY, Texas - A body found in a pond has been identified as a boy with autism who recently went missing in Texas City, officials said Tuesday.

Two weeks ago

NATIONAL AUTISM ASSOCIATION

Maddox Ritch, who disappeared from park, died from accidental drowning

The Gastonia Police Department in North Carolina said no criminal charges will be filed.

The FBI has joined in on the search for 6 year old Maddox Ritch. Gastonia Police Dept.

Notable Recent Cases

Missing 9-year-old safe with parents on the way to hospital; asked for pizza

by Taylor Johnson | Wednesday, November 7th 2018

UPDATE: 12:40 p.m.

The Pittsylvania County Sheriff's Office said Andrew Yarboro was located Wednesday morning in the 6000 block of Strawberry Road in Chatham, about 1.4 miles away from his home.

They said he had scratches on his back and was very tired, but appeared to be okay.

He was being treated by EMS, helping with the search, when searchers and the boy's father said he got away from them again.

Body pulled from Genesee River identified as Trevyan Rowe

By Spectrum News Staff | Rochester
PUBLISHED March 12, 2018 @4:16 PM

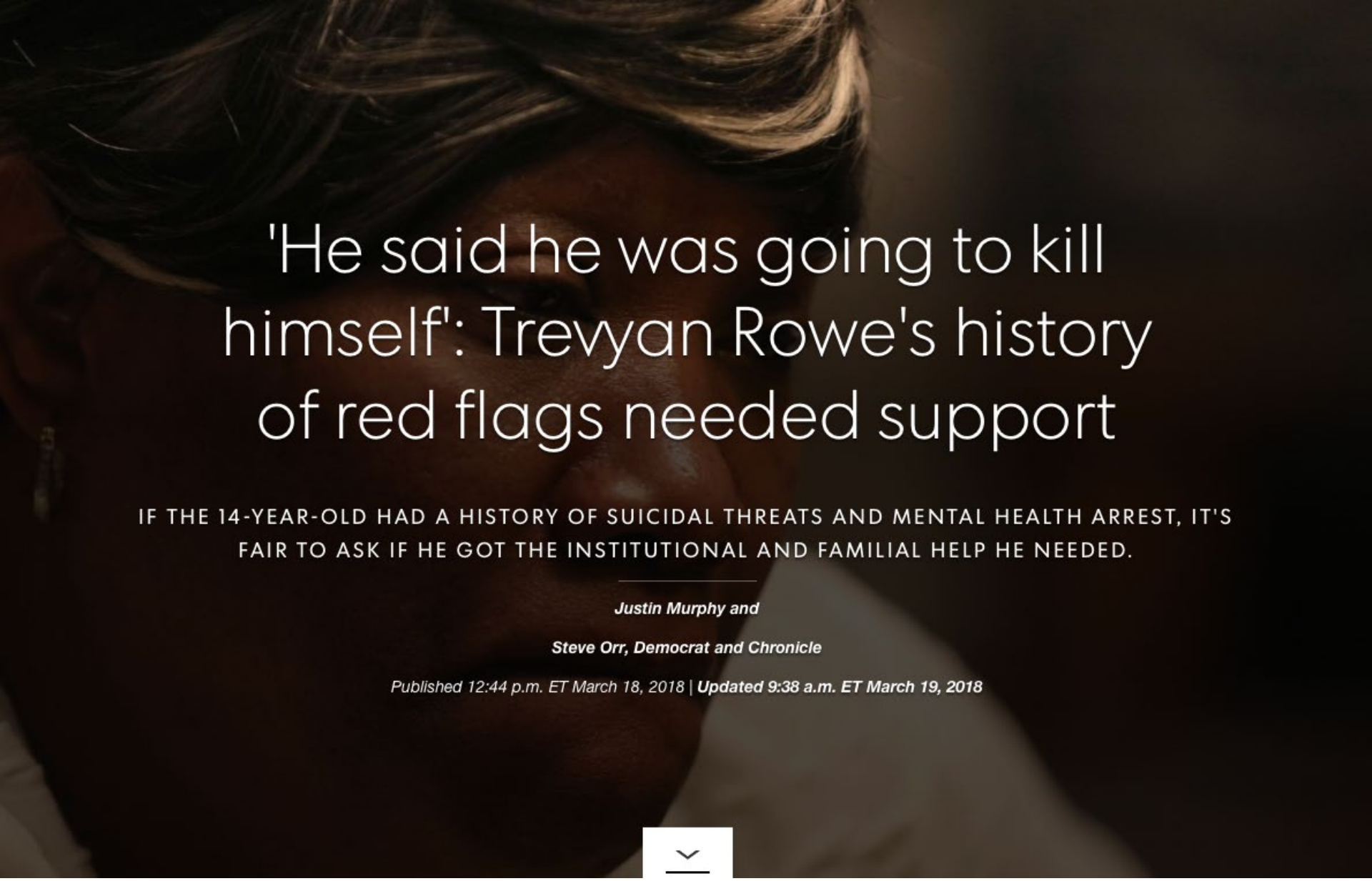
SHARE

ROCHESTER N.Y. — Rochester Police say the body recovered from the Genesee River Sunday has been identified as 14-year-old Trevyan Rowe.

Police say they found the body near the Frederick Douglass-Susan B. Anthony Memorial Bridge. They say tips made to the department focused their search efforts along the river in that section.

"State police responded because they have a responsibility for the express way, were unable to find anything," Ciminelli said. "In tracking this back, our investigators located one of the individuals who called and they pointed out the location where they had seen the person standing and in fact I think this individual met with our scuba squad to try to pinpoint the location."

Rowe was last seen leaving School No. 12 Thursday morning. His family says they did not know he was missing until he did not get off the bus with his sister later that afternoon. They say Rowe is autistic and may have been upset when he walked away after getting off the bus Thursday morning.



'He said he was going to kill himself': Trevyan Rowe's history of red flags needed support

IF THE 14-YEAR-OLD HAD A HISTORY OF SUICIDAL THREATS AND MENTAL HEALTH ARREST, IT'S FAIR TO ASK IF HE GOT THE INSTITUTIONAL AND FAMILIAL HELP HE NEEDED.

Justin Murphy and

Steve Orr, Democrat and Chronicle

Published 12:44 p.m. ET March 18, 2018 | ***Updated 9:38 a.m. ET March 19, 2018***

IACC Impact:

- April 2010: NAA statement on wandering
- October 2010: NAA IACC presentation on wandering
- April 2011: IAN data

Data created incredible amount of awareness, opened door for resources.

NATIONAL AUTISM ASSOCIATION

NAA Program Impact:

- Nearly 50,000 NAA Big Red Safety Boxes shipped across the U.S.
- Over $100,000 provided to agencies for tracking technology by NAA
- Ongoing training for agencies, families and service professionals
- No current funding for agency resources, tracking and training

NATIONAL AUTISM ASSOCIATION

Prevention is Essential.

	Not Helpful	Helpful	Very Helpful
Door/Window Alarms	2%	19%	78%
Adhesive Stop Signs	12%	38%	50%
Safety Alert Wristband	15%	36%	49%
Safety Alert Window Clings	6%	33%	61%
Personalized ID Tags	8%	28%	64%
BeREDy Booklet	2%	35%	62%
Child ID Kit from the National Center for Missing & Exploited Children	3%	35%	63%

NATIONAL AUTISM ASSOCIATION

Missing Saratoga boy located with Project Lifesaver

9-year-old with autism was wearing bracelet transmitter

By Rachel Silberstein Updated 6:00 pm EDT, Saturday, September 29, 2018

Gaston County Sheriff's Office sees spike in Project Lifesaver requests after search for Maddox Ritch

Device capable of tracking missing people

By Alex Giles | October 1, 2018 at 8:28 PM EST - Updated October 1 at 10:56 PM

GASTONIA, NC (WBTV) - In the wake of a community-wide tragedy, more and more people are requesting to be a part of a potentially life-saving program used to find missing persons.

Too many counties still carry age exclusions.
Funding for autism and other disabilities needed.

How to obtain a Bracelet:
Eligibility Age 60 or older Saginaw County resident Suffering from a dementia related illness
Contact Saginaw County Commission on Aging at (989) 797-6880 or 1-866-763-6336
Process Initial Assessment from a Commission on Aging caseworker to determine eligibility. Once approved, client will be set up with the Lifesaver Bracelet. Staff will make monthly in-home visits to ensure equipment is working properly.

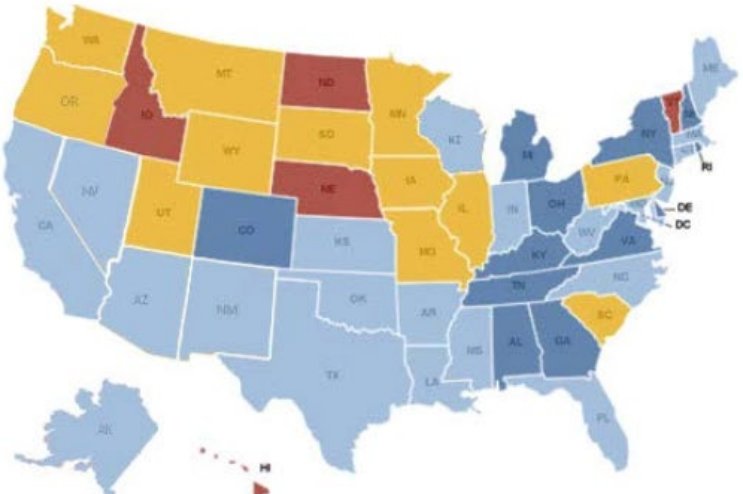
NATIONAL AUTISM ASSOCIATION

With more than 5 million Americans currently living with Alzheimer's disease and approximately 500,000 new cases of this disease emerging each year, projections pronounce that there could be as many as 16 million Americans that will have Alzheimer's by 2050. To help law enforcement protect this special population, IACP's Alzheimer's Initiatives program is committed to helping first responders improve their knowledge and skills to safeguard this special population.

A STATE-BY-STATE GUIDE TO:

Missing Senior/Adult Public Alert Systems

choose a state



DOWNLOADS **HELPFUL LINKS**

- Pocket Card: 10 Signs & Steps
- Guide to Voluntary Registry Systems
- Identifying and Helping Drivers
- MedicAlert Access
- Program Overview Brochure
- ID & Evaluate the At-Risk Older Adult
- Evaluative Questions to Ask Caregivers
- IACP Model Policy
- Concepts and Issues Paper
- Training Key
- Locative Technologies 101
- Podcast: Alzheimer's Initiatives
- Post Card: Alzheimer's - Do's and Don'ts
- Post Card: Alzheimer's - Senior Drivers

DID YOU KNOW?

5.4 million Americans of all ages currently have Alzheimer's disease. That could be as many as 16 million by 2050.*

IACP's Alzheimer's INITIATIVES

Safeguarding the Maturing Population

It's not a question of *if* law enforcement will be dealing with persons with Alzheimer's disease, but rather *when* and how we'll respond.

First responders need to become skilled at effective interactions with people with Alzheimer's disease:

"Do's"

- Introduce yourself and explain you are there to help
- Remain calm, smile, and use a friendly voice
- Speak slowly and ask simple questions
- Check for a tracking device or MedicAlert ID
- Change the topic to something pleasant if the person becomes agitated
- Provide security and comfort (i.e. blanket, water, or someplace to sit)

"Don'ts"

- Don't take comments personally
- Don't correct the person
- Don't approach from behind without warning
- Don't argue
- Don't touch without asking/explaining
- Don't repeat a question too many times as it may provoke agitation

To help law enforcement protect this special population, IACP's Alzheimer's Initiatives program is committed to helping first responders improve their knowledge and skills, and interact appropriately with persons with Alzheimer's disease and their families and caregivers.

For more information, please visit: www.theiacp.org/alzheimers.

To request additional postcards for your department, please email alzheimers@theiacp.org.

* Statistics courtesy of the Alzheimer's Association's 2012 Facts & Figures report. For more information, please visit www.alz.org.
This project was supported by Grant No. 2010-SJ-BX-K001 awarded by the Bureau of Justice Assistance. The Bureau of Justice Assistance is a component of the Office of Justice Programs, which also includes the Bureau of Justice Statistics, the National Institute of Justice, the Office of Juvenile Justice and Delinquency Prevention, the SMART Office, and the Office for Victims of Crime. Points of view or opinions in this document are those of the author and do not represent the official position or policies of the United State Department of Justice.

alzheimer's association

BJA Bureau of Justice Assistance U.S. Department of Justice

INTERNATIONAL ASSOCIATION
OF CHIEFS OF POLICE
515 North Washington Street
Alexandria, VA 22314

Summary

- Wandering/elopement is still an urgent issue in need of federal support
- Less notifications to NCMEC due to age, but more cases overall
- Major differences in Alzheimer's versus autism, but similar resources needed
- Increase in average age of lethal cases
- More agencies requesting training, especially centered on interaction
- Mental health and other conditions adding complexity to the issue, more discussion needed

NATIONAL AUTISM ASSOCIATION

NATIONAL AUTISM ASSOCIATION

LORI McILWAIN
National Autism Association
P: 877.622.2884
lori@nationalautism.org

Wandering/Elopement in ASD: *2019 Update*

BUREAU OF JUSTICE ASSISTANCE

The Justice and Mental Health Portfolio

Maria Fryer
Policy Analyst for Mental Health and Substance Addiction

Programs, Policy Initiatives and Improved Responses

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Today's Discussion:

IMPROVING RESPONSES TO PEOPLE WITH AUTISM/IDD AND ALZHEIMER'S DISEASE

THE JUSTICE AND MENTAL HEALTH COLLABORATION PROGRAM

OTHER LAW ENFORCEMENT INITIATIVES THAT BUILD COLLABORATION AND IMPROVE RESPONSE

BJA
Bureau of Justice Assistance
U.S. Department of Justice

BJA
Bureau of Justice Assistance
U.S. Department of Justice

BJA's role is to assist law enforcement at the state, tribal and local levels: Programs and Initiatives that provide the foundation to operationalize Kevin and Avonte's Law. What have we learned? And, How can we build this together?

National Center on Criminal Justice & Disability (NCCJD) and Serving Safely

- NCCJD: In 2013, BJA recognized the need to take a closer look at the prevalence of people with IDD in the Justice System and through the National Arc, the Pathways to Justice Program was established.
- Serving Safely: In 2017, BJA recognized the need to increase products and services to support law enforcement in their response to people with MHD and IDD and the first National Center, focusing on the delivery of expert TTA in both areas, was established.

National Center on Criminal Justice & Disability (NCCJD)

- Created in 2013 with funding from Bureau of Justice Assistance
- Advocates at the intersection of criminal justice reform and the advancement of disability rights
  - Serve as a bridge connecting the criminal justice and disability worlds
  - Build capacity to respond to gaps in existing services

Why Pathways to Justice?

Victims/Witnesses

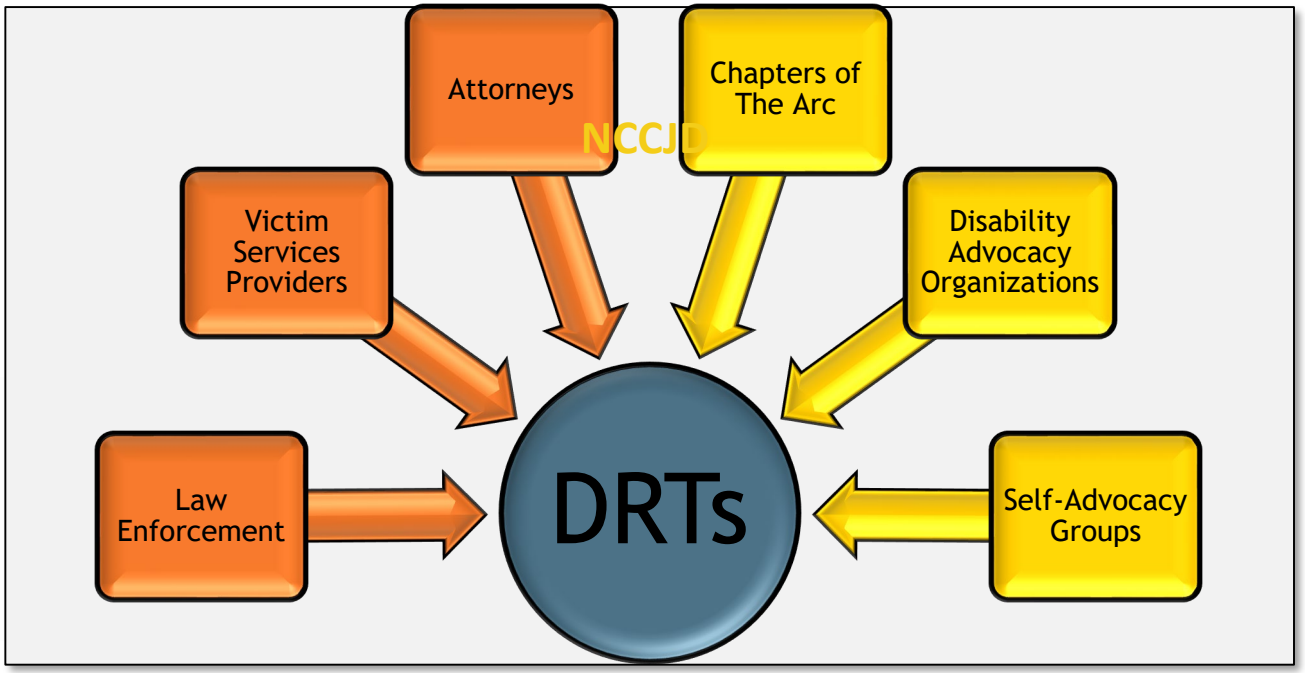
- ✓ Not considered credible witnesses
- ✓ Targeted for victimization
- ✓ Difficulties reporting
- ✓ Confuse actions for friendship
- ✓ Lack of inclusive services

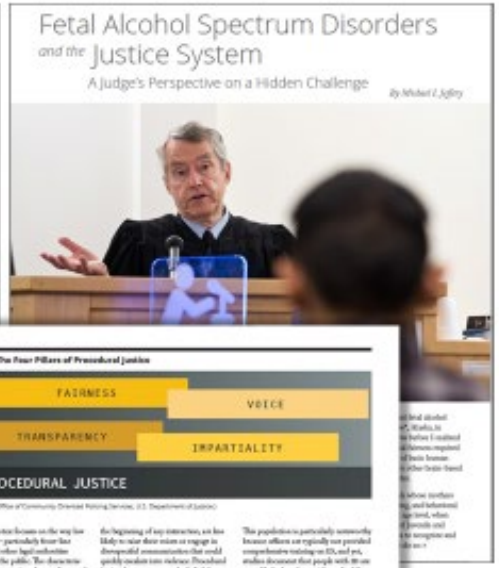
Suspects/Defendants

- ✓ Account for mental state (competency)
- ✓ "Cloak of competence"
- ✓ Eager to please
- ✓ High risk for false confessions
- ✓ Confused about who is responsible

Disability Response Teams

Multidisciplinary Teams of Community Stakeholders





ici.umn.edu/products/impact301

Serving Safely: The National Initiative to Enhance Policing for Persons with Mental Illness and IDD

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Objectives
Facilitate greater access to mental illnesses (MI) and intellectual developmental disabilities (IDD) training, technical assistance, resources, research, and subject-matter experts to enhance practice
Equip police and their service partners with tangible tools and knowledge to safely respond to and resolve incidents involving persons with MI/IDD
Build and support a national community of practice
Promote a no-wrong-door approach to MI/IDD training and technical assistance

Contributions to the Field
Expose police agencies to a wide range of response models
Streamline access to other BJA- and federally-funded MI/IDD training and resources
Identify gaps and recommend an agenda to inform future police-oriented MI/IDD research

Practical Benefits to Your Agency
Ensure safe interactions with persons with MI/IDD
Facilitate clear and effective communication between your agency, MI/IDD service providers, and community stakeholders
Identify partnership strategies and models to refer MI/IDD cases to professionals and community supports rather than jail, when appropriate
Promote the destigmatization of MI/IDD across your agency and in community
Support planning, deployment, tactics training, and other operational priorities through the use of data and technology

Serving Safely

"Local law enforcement is most effective when it has the necessary guidance and tools to ensure the safety of all residents, particularly those who come into contact with the system at higher rates," said Ron Serpas, Retired Police Chief and Professor of Practice at Loyola University, New Orleans.

"Smart initiatives like Serving Safely will be an invaluable source to any department committing to building and maintaining trust between law enforcement and the communities they serve."

To Request Technical Assistance:

www.vera.org/projects/serving-safely/training-and-technical-assistance

The JMHCP Program

The Justice and Mental Health Collaboration Program (JMHCP) supports innovative cross-system collaboration to improve responses and outcomes for individuals with mental illnesses or co-occurring mental health and substance abuse who come into contact with the justice system.

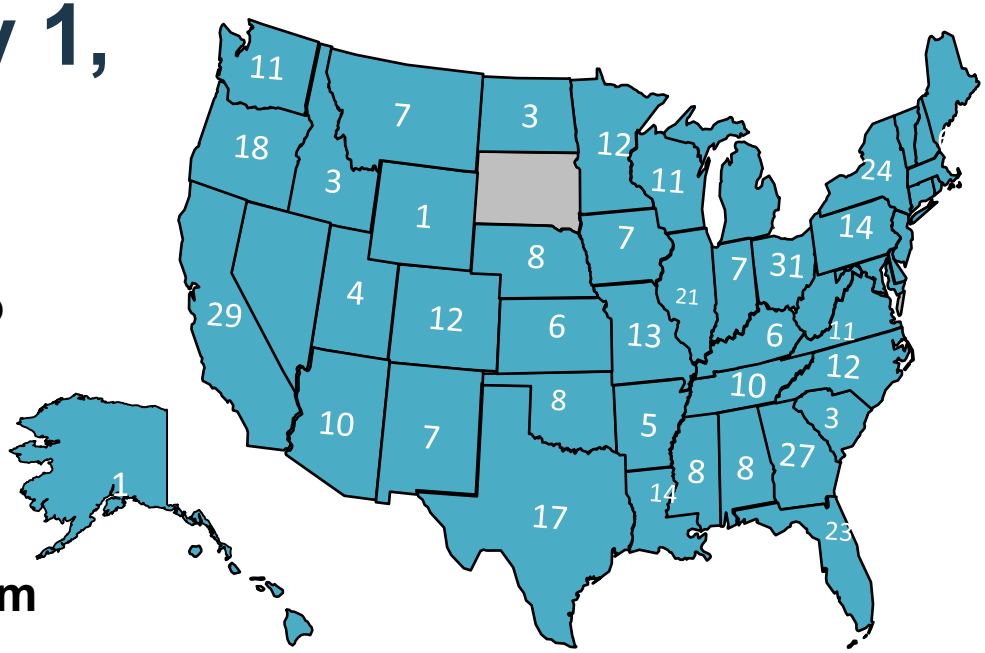
The JMHCP Program

Grantees in Category 1, 2 and 3

Nearly 122 million dollars in grants to

482 Awardees from across the nation

Representing 49 states and two U.S. territories, American Samoa and Guam



JMHCP also provides resources for unfunded communities with Training and Technical Assistance.

The JMHCP Program

- Category 1: Collaborative County Approaches
  - ID and train stakeholders, SIM mapping, service gap analysis, data collection, process evaluation, validated screening and assessment, connections to treatment.
- Category 2: Law Enforcement Strategies
  - Law enforcement response model, review of policies and procedures, MOUs with behavioral health, baseline data, peer to peer learning.
- Category 3: Implementation and Expansion
  - Enhancing Law Enforcement, Courts, Pretrial, Corrections, direct services, wrap around services.

BJA
Bureau of Justice Assistance
U.S. Department of Justice

The Law Enforcement-Mental Health Learning Sites

The sites serve as national learning sites to expand knowledge, by providing peer-to-peer learning for law enforcement agencies; and respond to technical assistance requests from the field.

1. **Arlington (MA) Police Department***
2. Houston (TX) Police Department
3. **Jackson County (OH) Sheriff's Office***
4. Los Angeles (CA) Police Department
5. Madison (WI) Police Department
6. **Madison County (TN) Sheriff's Office***
7. Portland (ME) Police Department
8. Salt Lake City (UT) Police Department
9. **Tucson (AZ) Police Department***
10. University of Florida Police Department

Online and Mobile Resources for Law Enforcement

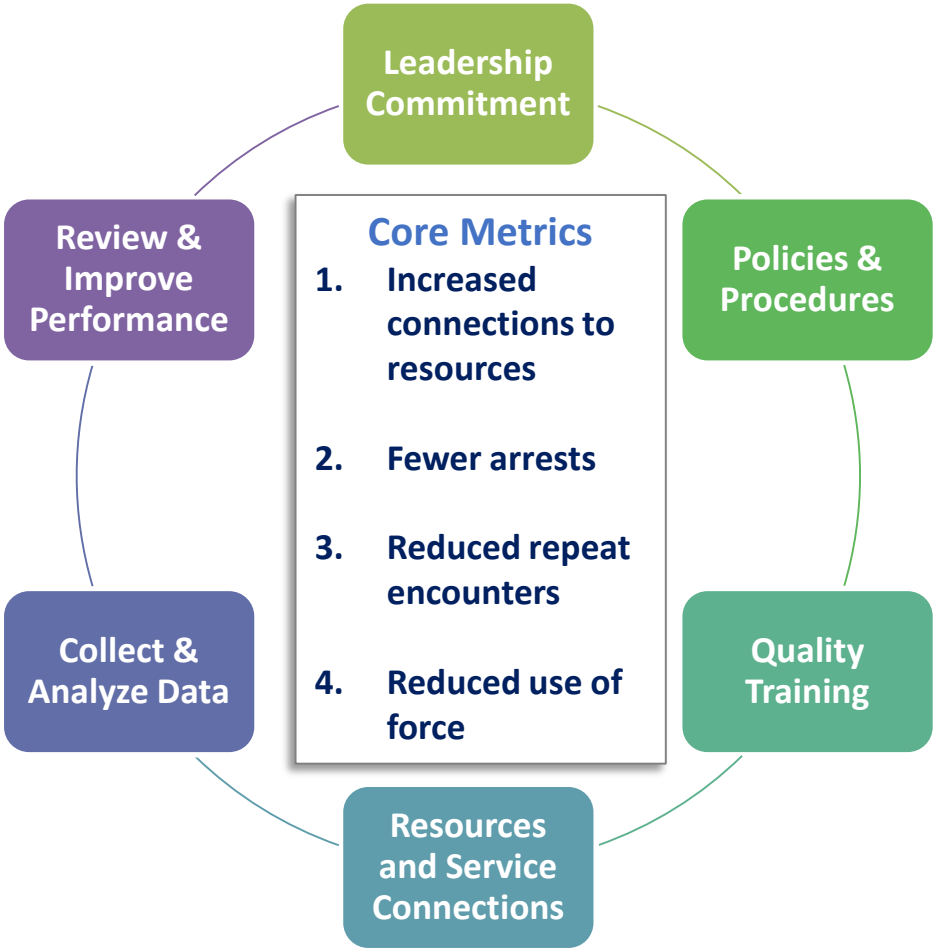
A comprehensive online reference that provides resources for law enforcement agencies to partner with mental health providers to effectively respond to calls for service, improve outcomes for people with mental illnesses, and advance the safety of all.

www.bja.gov/pmhc

Police-Mental Health Collaboration Framework

BJA
Bureau of Justice Assistance
U.S. Department of Justice

- Draws upon the experience of most advanced PMHCs in the nation
- Articulates the core components of a comprehensive and robust PMHC that can produce improvements in communitywide outcomes
- Shifts the focus away from stand-alone training or small-scale programs/teams toward agencywide collaborative responses and metrics-driven performance management



The Stepping Up Initiative

BJA
Bureau of Justice Assistance
U.S. Department of Justice

THE STEPPING UP INITIATIVE

Launched in May 2015

Vision:

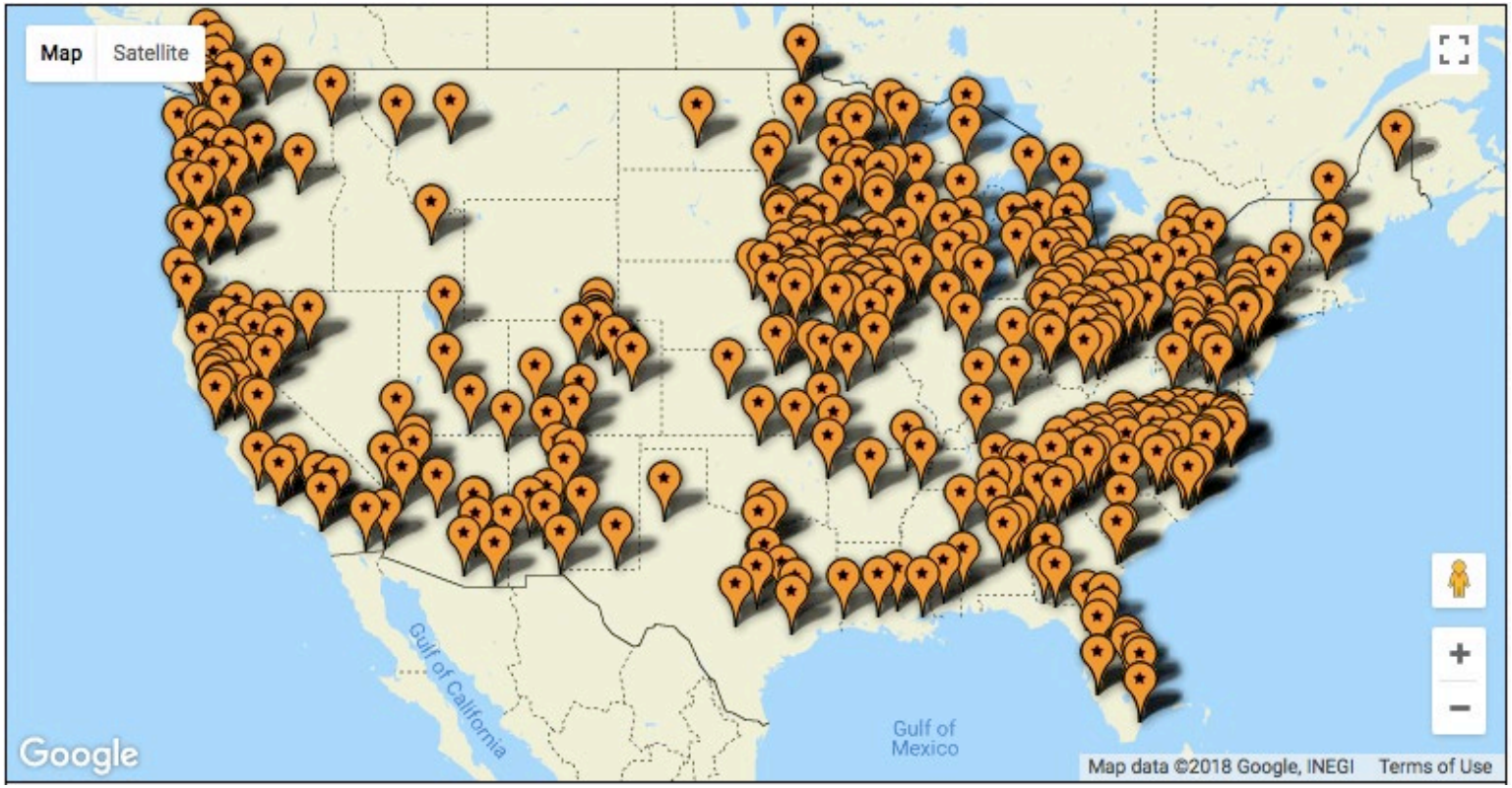
There will be fewer people with mental illnesses in jails than there are today

The Stepping Up Initiative

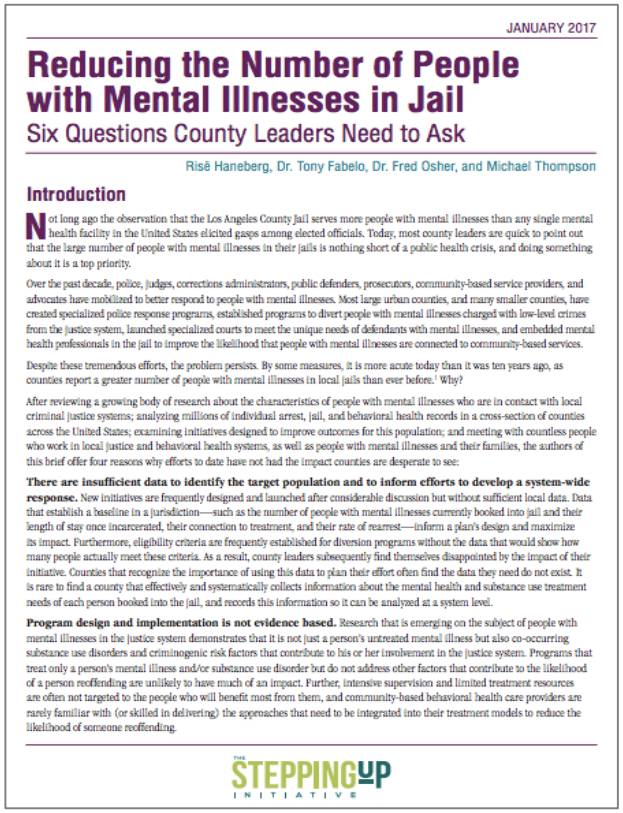
BJA
Bureau of Justice Assistance
U.S. Department of Justice

THE STEPPING UP INITIATIVE

Almost 461 counties across **43 states** have committed to **reduce the number of people with mental illnesses in jails.**



The Six Questions Guide



JANUARY 2017

Reducing the Number of People with Mental Illnesses in Jail

Six Questions County Leaders Need to Ask

Risë Haneberg, Dr. Tony Fabelo, Dr. Fred Osher, and Michael Thompson

Introduction

Not long ago the observation that the Los Angeles County Jail serves more people with mental illnesses than any single mental health facility in the United States elicited gasps among elected officials. Today, most county leaders are quick to point out that the large number of people with mental illnesses in their jails is nothing short of a public health crisis, and doing something about it is a top priority.

Over the past decade, police, judges, corrections administrators, public defenders, prosecutors, community-based service providers, and advocates have mobilized to better respond to people with mental illnesses. Most large urban counties, and many smaller counties, have created specialized police response programs, established programs to divert people with mental illnesses charged with low-level crimes from the justice system, launched specialized courts to meet the unique needs of defendants with mental illnesses, and embedded mental health professionals in the jail to improve the likelihood that people with mental illnesses are connected to community-based services.

Despite these tremendous efforts, the problem persists. By some measures, it is more acute today than it was ten years ago, as counties report a greater number of people with mental illnesses in local jails than ever before.[1] Why?

After reviewing a growing body of research about the characteristics of people with mental illnesses who are in contact with local criminal justice systems; analyzing millions of individual arrest, jail, and behavioral health records in a cross-section of counties across the United States; examining initiatives designed to improve outcomes for this population; and meeting with countless people who work in local justice and behavioral health systems, as well as people with mental illnesses and their families, the authors of this brief offer four reasons why efforts to date have not had the impact counties are desperate to see:

There are insufficient data to identify the target population and to inform efforts to develop a system-wide response. New initiatives are frequently designed and launched after considerable discussion but without sufficient local data. Data that establish a baseline in a jurisdiction—such as the number of people with mental illnesses currently booked into jail and their length of stay once incarcerated, their connection to treatment, and their rate of rearrest—inform a plan's design and maximize its impact. Furthermore, eligibility criteria are frequently established for diversion programs without the data that would show how many people actually meet these criteria. As a result, county leaders subsequently find themselves disappointed by the impact of their initiative. Counties that recognize the importance of using this data to plan their effort often find the data they need do not exist. It is rare to find a county that effectively and systematically collects information about the mental health and substance use treatment needs of each person booked into the jail, and records this information so it can be analyzed at a system level.

Program design and implementation is not evidence based. Research that is emerging on the subject of people with mental illnesses in the justice system demonstrates that it is not just a person's untreated mental illness but also co-occurring substance use disorders and criminogenic risk factors that contribute to his or her involvement in the justice system. Programs that treat only a person's mental illness and/or substance use disorder but do not address other factors that contribute to the likelihood of a person reoffending are unlikely to have much of an impact. Further, intensive supervision and limited treatment resources are often not targeted to the people who will benefit most from them, and community-based behavioral health care providers are rarely familiar with (or skilled in delivering) the approaches that need to be integrated into their treatment models to reduce the likelihood of someone reoffending.

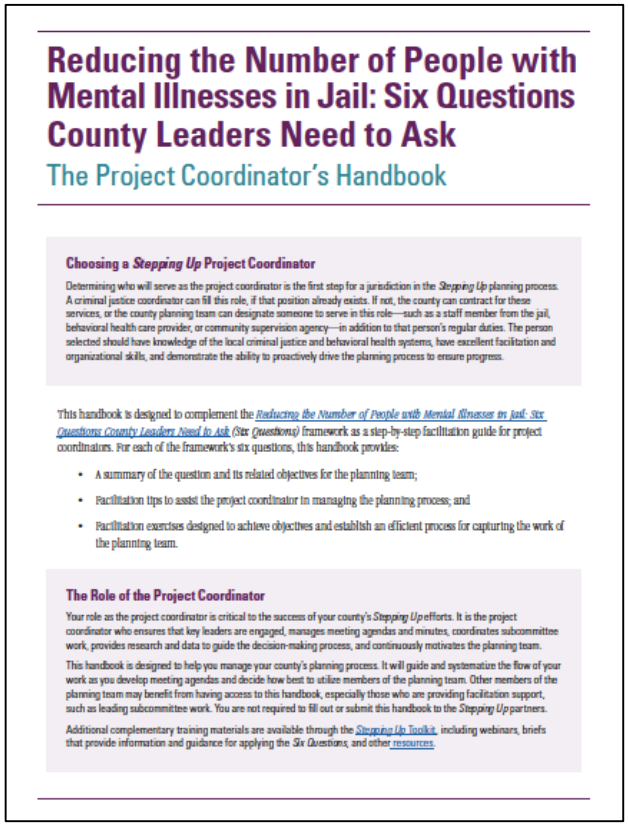
THE STEPPING UP INITIATIVE

1	Is our leadership committed?
2	Do we conduct timely screening and assessments?
3	Do we have baseline data?
4	Have we conducted a comprehensive process analysis & inventory of services?
5	Have we prioritized policy, practice, and funding improvements?
6	Do we track progress?

Implementing the Six Questions and Getting Guidance

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Project Coordinator's Handbook



Reducing the Number of People with Mental Illnesses in Jail: Six Questions County Leaders Need to Ask

The Project Coordinator's Handbook

Choosing a *Stepping Up* Project Coordinator

Determining who will serve as the project coordinator is the first step for a jurisdiction in the *Stepping Up* planning process. A criminal justice coordinator can fill this role, if that position already exists. If not, the county can contract for these services, or the county planning team can designate someone to serve in this role—such as a staff member from the jail, behavioral health care provider, or community supervision agency—in addition to that person's regular duties. The person selected should have knowledge of the local criminal justice and behavioral health systems, have excellent facilitation and organizational skills, and demonstrate the ability to proactively drive the planning process to ensure progress.

This handbook is designed to complement the *Reducing the Number of People with Mental Illnesses in Jail: Six Questions County Leaders Need to Ask* (*Six Questions*) framework as a step-by-step facilitation guide for project coordinators. For each of the framework's six questions, this handbook provides:

- A summary of the question and its related objectives for the planning team;
- Facilitation tips to assist the project coordinator in managing the planning process; and
- Facilitation exercises designed to achieve objectives and establish an efficient process for capturing the work of the planning team.

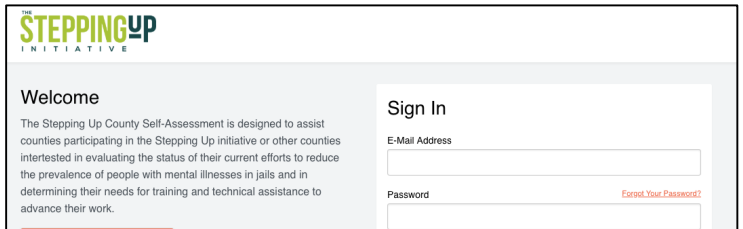
The Role of the Project Coordinator

Your role as the project coordinator is critical to the success of your county's *Stepping Up* efforts. It is the project coordinator who ensures that key leaders are engaged, manages meeting agendas and minutes, coordinates subcommittee work, provides research and data to guide the decision-making process, and continuously motivates the planning team.

This handbook is designed to help you manage your county's planning process. It will guide and systematize the flow of your work as you develop meeting agendas and decide how best to utilize members of the planning team. Other members of the planning team may benefit from having access to this handbook, especially those who are providing facilitation support, such as leading subcommittee work. You are not required to fill out or submit this handbook to the *Stepping Up* partners.

Additional complementary training materials are available through the Stepping Up Toolkit, including webinars, briefs that provide information and guidance for applying the *Six Questions*, and other resources.

Online County Self-Assessment



THE STEPPING UP INITIATIVE

Welcome

The Stepping Up County Self-Assessment is designed to assist counties participating in the Stepping Up initiative or other counties intertested in evaluating the status of their current efforts to reduce the prevalence of people with mental illnesses in jails and in determining their needs for training and technical assistance to advance their work.

Create Your Account

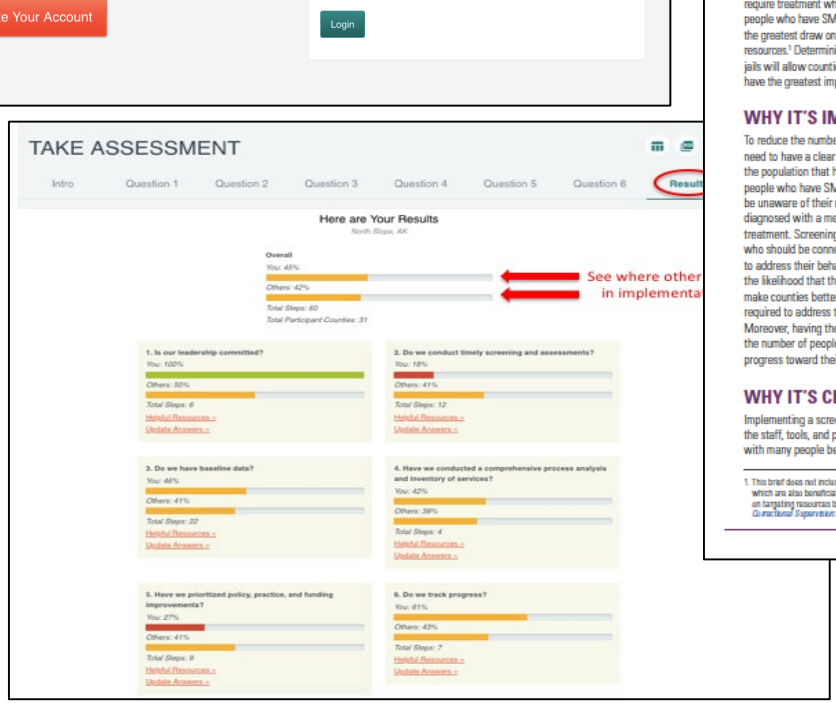
Sign In

E-Mail Address

Password

Forgot Your Password?

Login



TAKE ASSESSMENT

Intro | Question 1 | Question 2 | Question 3 | Question 4 | Question 5 | Question 6 | Results

Here are Your Results

North Slope, AK

Overall

You: 45%

Others: 42%

Total Steps: 60

Total Participant Counties: 31

See where other
in implementa

1. Is our leadership committed?
You: 100%
Others: 50%
Total Steps: 6
Helpful Resources »
Update Answers »

2. Do we conduct timely screening and assessments?
You: 18%
Others: 41%
Total Steps: 12
Helpful Resources »
Update Answers »

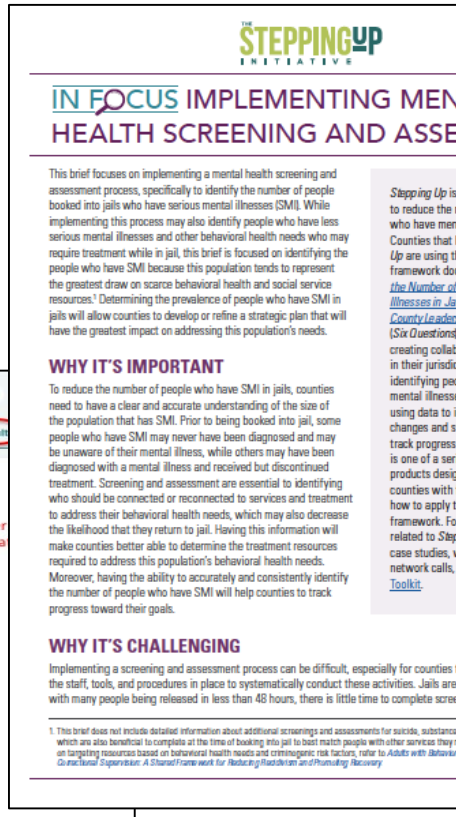
3. Do we have baseline data?
You: 46%
Others: 41%
Total Steps: 22
Helpful Resources »
Update Answers »

4. Have we conducted a comprehensive process analysis and inventory of services?
You: 42%
Others: 38%
Total Steps: 4
Helpful Resources »
Update Answers »

5. Have we prioritized policy, practice, and funding improvements?
You: 27%
Others: 41%
Total Steps: 9
Helpful Resources »
Update Answers »

6. Do we track progress?
You: 61%
Others: 43%
Total Steps: 7
Helpful Resources »
Update Answers »

Series of Briefs



THE STEPPING UP INITIATIVE

IN FOCUS IMPLEMENTING MEN
HEALTH SCREENING AND ASSE

This brief focuses on implementing a mental health screening and assessment process, specifically to identify the number of people booked into jails who have serious mental illnesses (SMI). While implementing this process may also identify people who have less serious mental illnesses and other behavioral health needs who may require treatment while in jail, this brief is focused on identifying the people who have SMI because this population tends to represent the greatest draw on scarce behavioral health and social service resources.[1] Determining the prevalence of people who have SMI in jails will allow counties to develop or refine a strategic plan that will have the greatest impact on addressing this population's needs.

Stepping Up is
to reduce the
who have men
Counties that
Up are using t
framework do
the Number of
Illnesses in Ja
County Leader
(*Six Questions*)
creating collab
in their jurisdic
identifying pe
mental illness
using data to i
changes and s
track progress
is one of a ser
products desig
counties with
how to apply t
framework. Fo
related to *Step*
case studies, v
network calls,
Toolkit.

WHY IT'S IMPORTANT

To reduce the number of people who have SMI in jails, counties need to have a clear and accurate understanding of the size of the population that has SMI. Prior to being booked into jail, some people who have SMI may never have been diagnosed and may be unaware of their mental illness, while others may have been diagnosed with a mental illness and received but discontinued treatment. Screening and assessment are essential to identifying who should be connected or reconnected to services and treatment to address their behavioral health needs, which may also decrease the likelihood that they return to jail. Having this information will make counties better able to determine the treatment resources required to address this population's behavioral health needs. Moreover, having the ability to accurately and consistently identify the number of people who have SMI will help counties to track progress toward their goals.

WHY IT'S CHALLENGING

Implementing a screening and assessment process can be difficult, especially for counties
the staff, tools, and procedures in place to systematically conduct these activities. Jails are
with many people being released in less than 48 hours, there is little time to complete scre

1. This brief does not include detailed information about additional screenings and assessments for suicide, substance
which are also beneficial to complete at the time of booking into jail to best match people with other services they
on targeting resources based on behavioral health needs and criminogenic risk factors, refer to *Adults with Behavior*
Correctional Supervision: A Shared Framework for Reducing Recidivism and Promoting Recovery.

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Going Forward:

- Exploring what has been done: what works, what doesn't work
- What do we know/ don't know?
- Gaps in knowledge
- Gaps in service
- How can we leverage what we have and help each other?

BJA
Bureau of Justice Assistance
U.S. Department of Justice

Additional Resources:

- Justice and Mental Health Resources list
- Law Enforcement-Mental Health Resources
- Justice and Mental Health Program Brief
- Serving Safely one-pager
- PMHC/Effective Community Responses P-C
- Pathways to Justice Handout and Information

Contact Information:

Maria C. Fryer.....Maria.Fryer@usdoj.gov

Thank you!

NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN

NCMEC's Response to Children Missing with Autism

IACC Meeting 2019

NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN®

National Center for Missing & Exploited Children

- Founded in 1984
- Nonprofit, non-governmental organization
- National resource center for families, law enforcement and other professionals
- Assistance to more than 18,000 law enforcement agencies
- Headquartered in Virginia, with regional offices in California, Florida, New York and Texas

Learn more at missingkids.org

NCMEC Data & Autism: What Have We Learned?

Data reported to NCMEC: January 1, 2007 and December 31, 2016

- 952 children with autism reported missing to NCMEC
- A majority of missing children with autism were male (74%)
- Endangered Runaways made up 61% of intaked cases of children with autism
- The second most common case type was the Lost, Injured or Otherwise Missing (20%).

Additional NCMEC Data

Recovery time:

- 48% of children with autism reported missing to NCMEC were recovered within one day of going missing
- 74% were recovered within one week

Deceased children:

- 43 missing children with autism were recovered deceased (4% of the total 952).
- 72% of the time, manner of death was described as accidental
- For 65% of deceased missing children with autism, drowning was listed as the official cause of death.

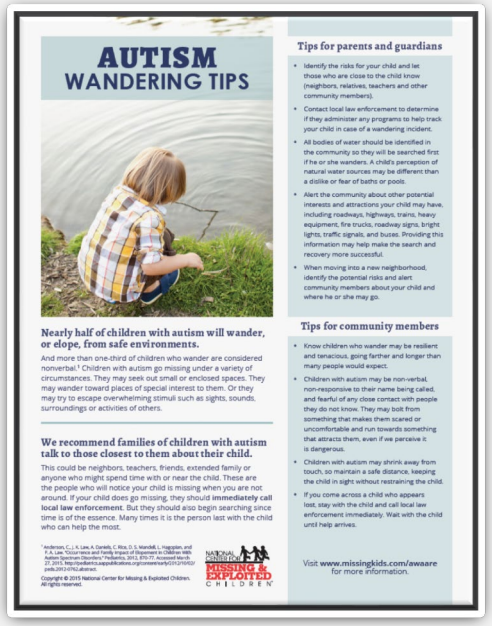
Data reported to NCMEC: January 1, 2007 and December 31, 2016

Texas City, TX - 2019

NCMEC's Response

Building Awareness

- Law Enforcement Checklist, Questionnaire, Search Considerations
- Call Center Protocol
- “Train the Trainer”
- Awareness materials and publications
- Focus Group
- Sensory Friendly First Responder Event
- Partnerships and Trainings



AUTISM
WANDERING TIPS

Nearly half of children with autism will wander, or elope, from safe environments.

And more than one-third of children who wander are considered nonverbal.[1] Children with autism go missing under a variety of circumstances. They may seek out small or enclosed spaces. They may wander toward places of special interest to them. Or they may try to escape overwhelming stimuli such as sights, sounds, surroundings or activities of others.

We recommend families of children with autism talk to those closest to them about their child.

This could be neighbors, teachers, friends, extended family or anyone who might spend time with or near the child. These are the people who will notice your child is missing when you are not around. If your child does go missing, they should **immediately call local law enforcement**. But they should also begin searching since time is of the essence. Many times it is the person last with the child who can help the most.

[1] Anderson, C., J. K. Law, A. Daniels, C. Rice, D. S. Mandell, L. Hagopian, and P. A. Law. "Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders." Pediatrics, 2012, 870-77. Accessed March 27, 2015. http://pediatrics.aappublications.org/content/early/2012/10/03/peds.2012-0742.abstract.

NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN

Tips for parents and guardians

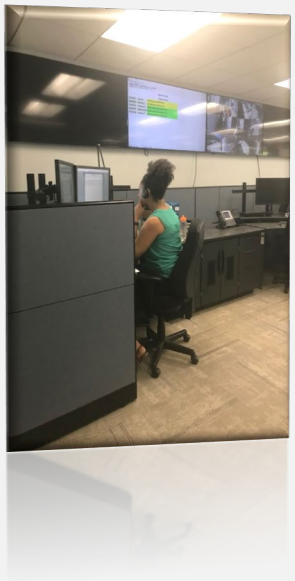
- Identify the risks for your child and let those who are close to the child know (neighbors, relatives, teachers and other community members).
- Contact local law enforcement to determine if they administer any programs to help track your child in case of a wandering incident.
- All bodies of water should be identified in the community so they will be searched first if he or she wanders. A child's perception of natural water sources may be different than a dislike or fear of baths or pools.
- Alert the community about other potential interests and attractions your child may have, including roadways, highways, trains, heavy equipment, fire trucks, roadway signs, bright lights, traffic signals, and buses. Providing this information may help make the search and recovery more successful.
- When moving into a new neighborhood, identify the potential risks and alert community members about your child and where he or she may go.

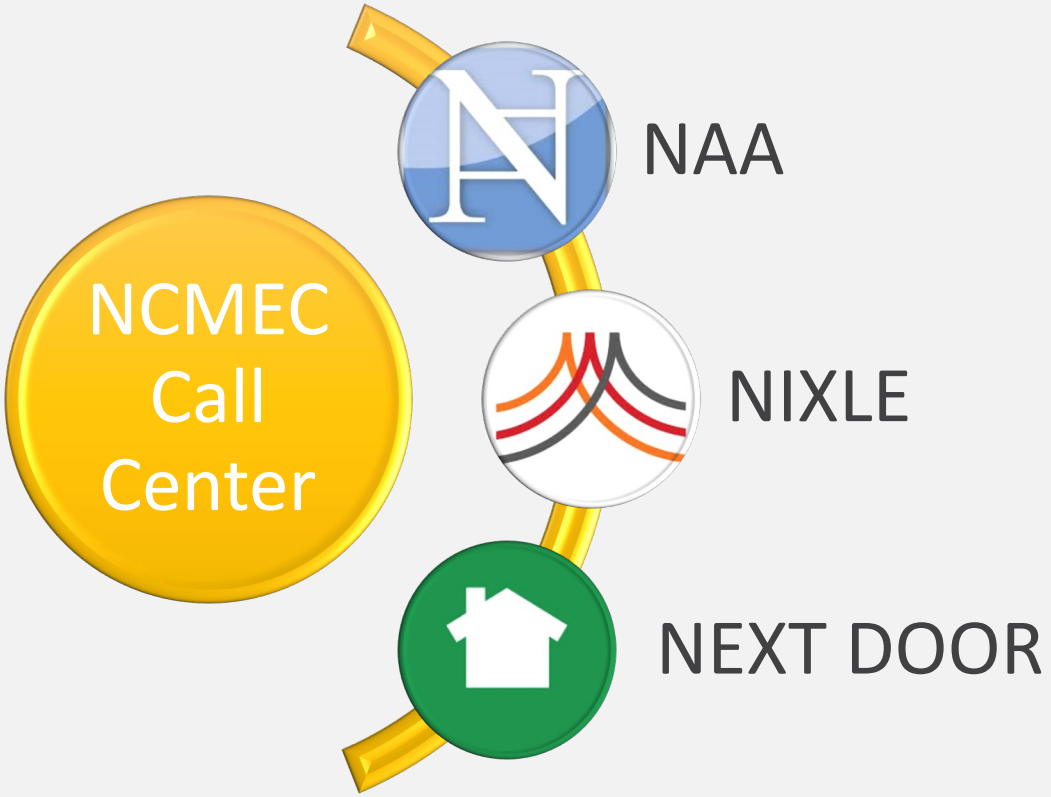
Tips for community members

- Know children who wander may be resilient and tenacious, going farther and longer than many people would expect.
- Children with autism may be non-verbal, non-responsive to their name being called, and fearful of any close contact with people they do not know. They may bolt from something that makes them scared or uncomfortable and run towards something that attracts them, even if we perceive it is dangerous.
- Children with autism may shrink away from touch, so maintain a safe distance, keeping the child in sight without restraining the child.
- If you come across a child who appears lost, stay with the child and call local law enforcement immediately. Wait with the child until help arrives.

Visit **www.missingkids.com/awaare** for more information.

Notifications





Lafayette, LA - 2018

Team Adam Consultants

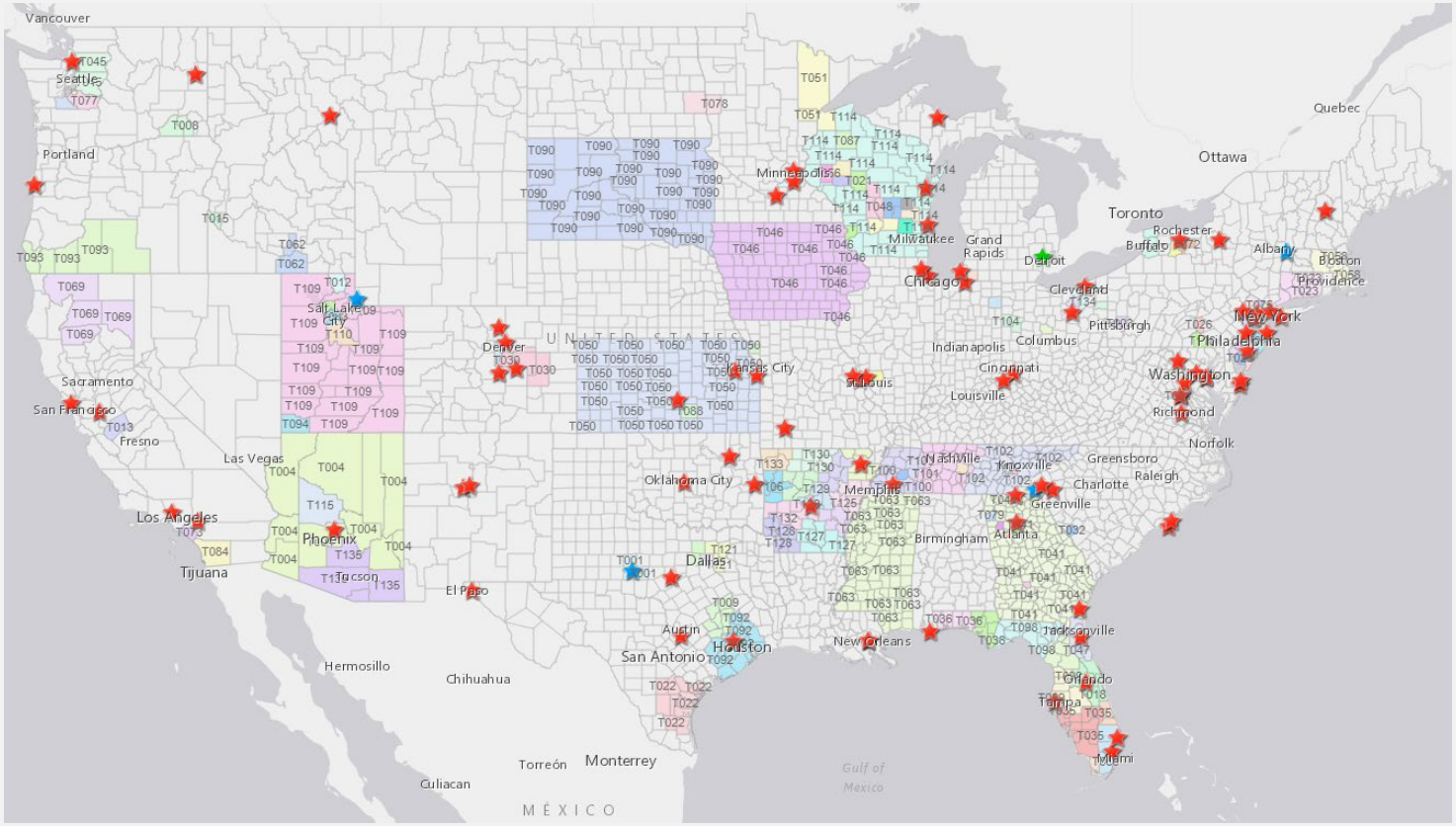
Team Adam will deploy on cases of missing children with special needs

- Specialized Team Adam search personnel may also deploy

Quickly provide law enforcement with the following recommendations:

- Investigative measures
  - Sex Offenders/Attempted Abductions
- Search and rescue measures
- Recovery and reunification measures
- Other supporting resources
  - Families: Victim Services Support referrals

Team Adam & CART Initiative



Sensory Friendly First Responder Events

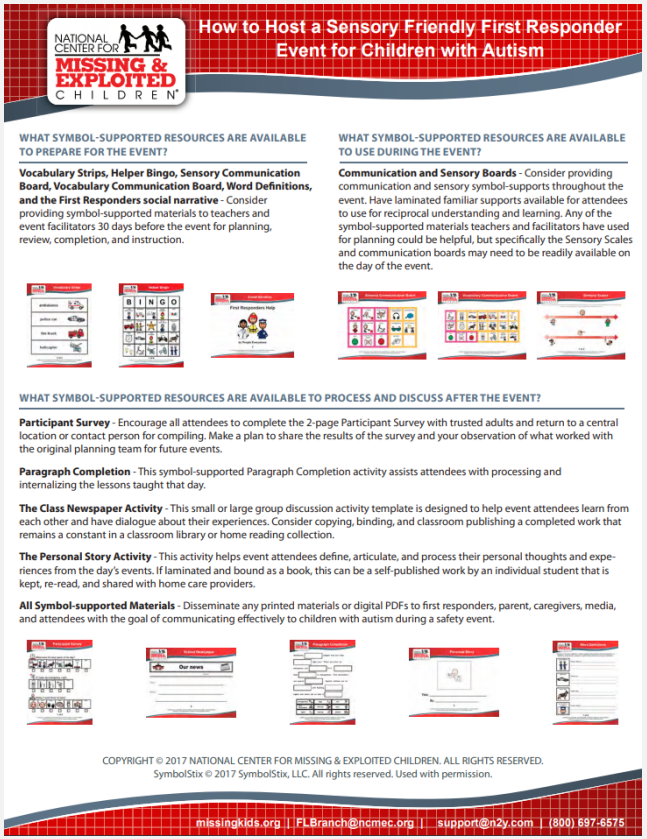
NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN®

How to Host a Sensory Friendly First Responder Event for Children with Autism

According to survey data published in the journal Pediatrics, nearly half of families reported their children with autism wandered or eloped from safe environments. And more than a third of the children who wandered were unable to communicate their name and/or address. Finding and safely recovering a missing child with autism presents unique and difficult challenges for families, law enforcement, first responders and search teams. This running away or wandering behavior puts these children at risk of accidental drowning, traffic injury and other dangers. As police, fire and EMS personnel are often the first to respond in these situations, it is important that autistic children are comfortable with the various types of first responders, and not fearful or overwhelmed by their presence.

The goal of hosting a sensory friendly event is to familiarize children with autism to the sights and sounds associated with different types of law enforcement, fire and rescue units. This includes introducing them to police officers, firefighters and EMS personnel, demonstrating how different equipment looks, functions and sounds, and other things they may see in the case of a wandering incident, like special K-9 teams. Making these resources more familiar may help alleviate some of the fears children may associate with rescuers and rescue situations.

1. **Find the right partners-** If you have a school for children with autism in your community, approach them to see if they'd like to participate. Check with public schools and other community groups to find programs for children with autism. Approach local law enforcement/fire rescue through crime prevention or community policing units to see if they'd like to be part of the event.
2. **Assemble a planning committee-** Determine a date, time and agenda for the event. Find out from the school/community group personnel if they want lights and sirens, or if they wish to keep it more low key for the kids. Arrange to have Child IDs provided that include maps of existing hazards, including water. Distribute NCMEC *Autism Wandering Tips* to participating students and families.
3. **Keep it simple-** Sometimes less is more, especially with a population that can be overwhelmed with too much stimulation. Make sure the assets are positioned in a way it's easy for kids to access and not too much for the experience.
4. **Publicize the event-** Let local media know, and follow-up, so the event gets good coverage. Make sure the host school/community group has obtained signed permission slips from students' parents or guardians before posting any photographs or videos of students.
5. **Mobilize social media-** Letting your followers know what's happening is a great way to spread the word. And remember, a picture is worth a thousand words.
6. **Observe what works-** The kids will let you know their favorite parts. At one event, a custom police microphone might be a big hit, but could over stimulate children at another event. Children with autism actively engage all five of their senses in order to process the scene. Ensure that if they reach out to touch something, it's not too hot, sharp, or toxic if they then taste it.
7. **Make the event a learning experience for first responders-** Remember, they may not have a lot of experience dealing with children with special needs, so it may be new to many of them. Gather the first responders on the day of the event and ask an administrator from the school/community group to share some of the coping behaviors that may be observed while interacting with the kids.
8. **Get feedback-** Once the event is over, talk to parents and teachers to find out how the kids reacted. You'll want to gather as much feedback as possible to make the next event an even bigger success!
9. **Be ready for different responses from the kids-** Having adequate support from teachers and aides help manage the kids and keep the event on track.
10. **Thank everyone who participated-** It takes cooperation and commitment to pull off an event like this. With the right partners, you can have a great and memorable event for the kids.



NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN®

How to Host a Sensory Friendly First Responder Event for Children with Autism

WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO PREPARE FOR THE EVENT?

Vocabulary Strips, Helper Bingo, Sensory Communication Board, Vocabulary Communication Board, Word Definitions, and the First Responders social narrative - Consider providing symbol-supported materials to teachers and event facilitators 30 days before the event for planning, review, completion, and instruction.

WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO USE DURING THE EVENT?

Communication and Sensory Boards - Consider providing communication and sensory symbol-supports throughout the event. Have laminated familiar supports available for attendees to use for reciprocal understanding and learning. Any of the symbol-supported materials teachers and facilitators have used for planning could be helpful, but specifically the Sensory Scales and communication boards may need to be readily available on the day of the event.

WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO PROCESS AND DISCUSS AFTER THE EVENT?

Participant Survey - Encourage all attendees to complete the 2-page Participant Survey with trusted adults and return to a central location or contact person for compiling. Make a plan to share the results of the survey and your observation of what worked with the original planning team for future events.

Paragraph Completion - This symbol-supported Paragraph Completion activity assists attendees with processing and internalizing the lessons taught that day.

The Class Newspaper Activity - This small or large group discussion activity template is designed to help event attendees learn from each other and have dialogue about their experiences. Consider copying, binding, and classroom publishing a completed work that remains a constant in a classroom library or home reading collection.

The Personal Story Activity - This activity helps event attendees define, articulate, and process their personal thoughts and experiences from the day's events. If laminated and bound as a book, this can be a self-published work by an individual student that is kept, re-read, and shared with home care providers.

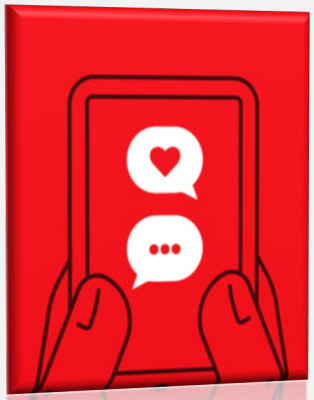
All Symbol-supported Materials - Disseminate any printed materials or digital PDFs to first responders, parent, caregivers, media, and attendees with the goal of communicating effectively to children with autism during a safety event.

COPYRIGHT © 2017 NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN. ALL RIGHTS RESERVED.
SymbolStix © 2017 SymbolStix, LLC. All rights reserved. Used with permission.

missingkids.org | FLBranch@ncmec.org | support@n2y.com | (800) 697-6575

OTHER RISKS

Case Illustrations



Children with Autism in Foster Care

- Fifteen percent of reported children with autism were missing from foster care. They were more likely to be Endangered Runaways (79%) and older teens (a mean age of 15)

- A little over half (54%) of children with autism who were missing from group or foster care were recovered within a week after they went missing.

Data reported to NCMEC: January 1, 2007 and December 31, 2016

Results: “Train the Trainer” State Trooper Participant

Thank you! Questions?

Leemie Kahng-Sofer
Missing Children Division
1-877-446-2632 ext. 2161
Lkahng-sofer@ncmec.org

@MissingKids

cmfc.missingkids.org

Missing Kids

www.missingkids.org

1-800-THE-LOST®

Points of view or opinions expressed in this webinar are those of the presenter(s) and do not necessarily represent the official position or policies of OJJDP or the U.S. Department of Justice.

NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN®

For more resources please visit
MissingKids.org

#MissingKids

Discussion

Break

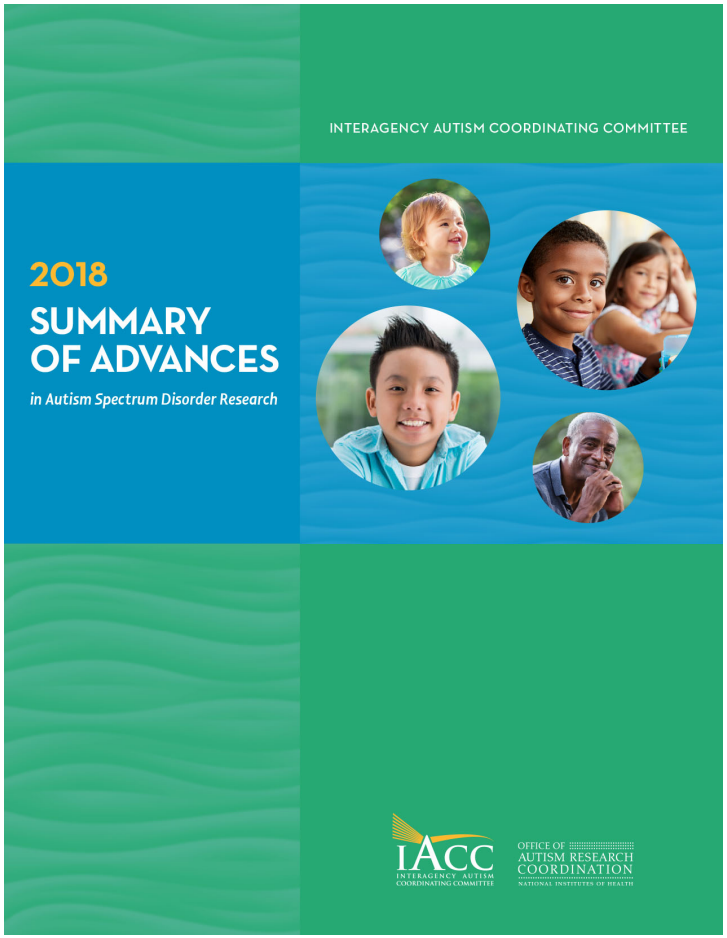
2018 Summary of Advances Discussion

IACC Full Committee Meeting
January 16, 2019

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

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

Summary of Advances



- Annual report required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Typically includes articles addressing all 7 topic areas of the IACC Strategic Plan

Summary of Advances Process

- ✓Monthly emails to solicit article nominations from IACC members
- ✓Advances compiled quarterly and discussed at IACC meetings
- ❑**At January IACC meeting, discussion of top articles among those nominated**
- ❑IACC members vote on top 20 articles to be included in 2018 Summary of Advances – **ballots due February 1, 2019**
- ❑Tie-breaker vote (if necessary)

Summary of Advances Process

- Selected articles are summarized
- Nominated articles not selected are listed in the appendix
- Draft publication is prepared and sent out to committee for very brief review
- Final publication is prepared for release
- Target for release – April 2019 IACC meeting

2018 IACC Summary of Advances Nominations Statistics

- 10 IACC members submitted a total of 43 nominations:
  - Question 1 (Diagnosis & Screening): 6
  - Question 2 (Biology): 8
  - Question 3 (Risk Factors): 14
  - Question 4 (Treatments & Interventions): 3
  - Question 5 (Services): 5
  - Question 6 (Lifespan Issues): 3
  - Question 7 (Infrastructure & Surveillance): 4

2018 Summary of Advances Nominations October – December 2018

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

Question 1: Screening and Diagnosis

Journal of the American Academy of Child & Adolescent Psychiatry

Nov 2018

Diagnosis of Autism Spectrum Disorder After Age 5 in Children Evaluated Longitudinally Since Infancy

Ozonoff S, Young GS, Brian J, Charman T, Shephard E, Solish A, Zwaigenbaum L.

The Journal of Child Psychology and Psychiatry

Oct 2018

A longitudinal study of parent-reported sensory responsiveness in toddlers at-risk for autism.

Wolff JJ, Dimian AF, Botteron KN, Dager SR, Elison JT, Estes AM, Hazlett HC, Schultz RT, Zwaigenbaum L, Piven J; IBIS Network.

Question 2: Underlying Biology

STEM CELL REPORTS

Nov 2018

Complete Disruption of Autism-Susceptibility Genes by Gene Editing Predominantly Reduces Functional Connectivity of Isogenic Human Neurons.
Deneault E, White SH, Rodrigues DC, Ross PJ, Faheem M, Zaslavsky K, Wang Z, Alexandrova R, Pellecchia G, Wei W, Piekna A, Kaur G, Howe JL, Kwan V, Thiruvahindrapuram B, Walker S, Lionel AC, Pasceri P, Merico D, Yuen RKC, Singh KK, Ellis J, Scherer SW**.**

Science AAAS

Aug 2018

Fragile X mental retardation 1 gene enhances the translation of large autism-related proteins.
Greenblatt EJ, Spradling AC.

Question 3: Risk Factors

Molecular Autism

Jun 2018

Case-control meta-analysis of blood DNA methylation and autism spectrum disorder.

Andrews SV, Sheppard B, Windham GC, Schieve LA, Schendel DE, Croen LA, Chopra P, Alisch RS, Newschaffer CJ, Warren ST, Feinberg AP, Fallin MD, Ladd-Acosta C.

Science AAAS

Dec 2018

Transcriptome-wide isoform-level dysregulation in ASD, schizophrenia, and bipolar disorder.

Gandal MJ, Zhang P, Hadjimichael E, Walker RL, Chen C, Liu S, Won H, van Bakel H, Varghese M, Wang Y, Shieh AW, Haney J, Parhami S, Belmont J, Kim M, Moran Losada P, Khan Z, Mleczko J, Xia Y, Dai R, Wang D, Yang YT, Xu M, Fish K, Hof PR, Warrell J, Fitzgerald D, White K, Jaffe AE; PsychENCODE Consortium, Peters MA, Gerstein M, Liu C, Iakoucheva LM, Pinto D, Geschwind DH.

Question 3: Risk Factors

JAMA Psychiatry

Dec 2018

Association of Autism Spectrum Disorder With Prenatal Exposure to Medication Affecting Neurotransmitter Systems.
Janecka M, Kodesh A, Levine SZ, Lusskin SI, Viktorin A, Rahman R, Buxbaum JD, Schlessinger A, Sandin S, Reichenberg A.

AUTISM RESEARCH

Jan 2018

Autism spectrum disorder and birth spacing: Findings from the study to explore early development (SEED).
Schieve LA, Tian LH, Drews-Botsch C, Windham GC, Newschaffer C, Daniels JL, Lee LC, Croen LA, Fallin MD.

Question 4: Treatments and Interventions

Journal of Autism and Developmental Disorders

Dec 2018

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

Stedman A, Taylor B, Erard M, Peura C, Siegel M.

Question 5: Services

Autism in Adulthood

Apr 2018

Healthcare Service Utilization and Cost Among Adults with Autism Spectrum Disorders in a U.S. Integrated Healthcare System.

Zerbo O, Qian Y, Ray T, Sidney S, Rich S, Massolo M, Croen LA.

Question 6: Lifespan Issues

(There were no nominations covering Question 6 topics from October – December 2018)

Question 7: Infrastructure and Surveillance

MMWR Surveillance Summaries

Apr 2018

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014.

Baio J, Wiggins L, Christensen DL, Maenner MJ, Daniels J, Warren Z, Kurzius-Spencer M, Zahorodny W, Robinson Rosenberg C, White T, Durkin MS, Imm P, Nikolaou L, Yeargin-Allsopp M, Lee LC, Harrington R, Lopez M, Fitzgerald RT, Hewitt A, Pettygrove S, Constantino JN, Vehorn A, Shenouda J, Hall-Lande J, Van Naarden Braun K, Dowling NF.

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Dec 2018

The Prevalence of Parent-Reported Autism Spectrum Disorder Among US Children.

Kogan MD, Vladutiu CJ, Schieve LA, Ghandour RM, Blumberg SJ, Zablotsky B, Perrin JM, Shattuck P, Kuhlthau KA, Harwood RL, Lu MC.

Question 7: Infrastructure and Surveillance

The Journal of Child Psychology and Psychiatry

Oct 2018

Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample.
McDonnell CG, Boan AD, Bradley CC, Seay KD, Charles JM, Carpenter LA.

JAMA The Journal of the American Medical Association

Nov 2018

Cumulative Incidence of Autism Into Adulthood for Birth Cohorts in Denmark, 1980-2012.
Schendel DE, Thorsteinsson E.

Round Robin

Adjournment

Next IACC Meeting

Wednesday, April17th 2019