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 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
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life and control personal resources
- 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
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.
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
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

Home & Community Based Services Training Series
https://www.medicaid.gov/medicaid/hcbs/training/index.html

Statewide Transition Plans
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

“Medically Ready Force...Ready Medical Force”
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 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 (ADFM))
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.
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.
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.

“Medically Ready Force...Ready Medical Force”
ABA services 1st provided by DoD under the Program for Persons with Disabilities

ABA services provided under ECHO Enhanced Access to Autism Services Demonstration (ADFM diagnosed with ASD). Added tiered model services

ABA services provided under the ECHO for ADFMs diagnosed with ASD & by only certified providers with a bachelor’s degree or above

One year ABA Pilot for non ADFM beneficiaries diagnosed with ASD was implemented

CPT Code change/benefit overhaul

ACD began

ABA services under TRICARE Basic available for all beneficiaries diagnosed with ASD to include retiree family members (non ADFMs)

“Medically Ready Force...Ready Medical Force”
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)

“Medically Ready Force...Ready Medical Force”
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

“Medically Ready Force...Ready Medical Force”
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
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](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](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
Title: *Comparative Effectiveness of EIBI and Adaptive ABA for Children with Autism*


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?
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.
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

“Medically Ready Force…Ready Medical Force”
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

Rebecca Martin, M.P.H
Public Health Analyst

Juliana Rava, M.P.H.
Science Policy 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
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/
The analysis includes data from 18 federal agencies and private organizations.

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<thead>
<tr>
<th>FEDERAL AGENCIES</th>
<th>PRIVATE ORGANIZATIONS</th>
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<tbody>
<tr>
<td>Administration for Community Living (ACL)</td>
<td>Autism Research Institute (ARI)</td>
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<tr>
<td>Agency for Healthcare Research and Quality (AHRQ)</td>
<td>Autism Science Foundation (ASF)</td>
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<td>Centers for Disease Control and Prevention (CDC)</td>
<td>Autism Speaks (AS)</td>
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<td>Department of Defense – Army (DoD – Army)</td>
<td>Brain &amp; Behavior Research Foundation (BBRF)</td>
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<td>Department of Education (ED)</td>
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<td>Environmental Protection Agency (EPA)</td>
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<td>Organization for Autism Research (OAR)</td>
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<td>National Institutes of Health (NIH)</td>
<td>Patient-Centered Outcomes Research Institute (PCORI)</td>
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<tr>
<td>National Science Foundation (NSF)</td>
<td>Simons Foundation (SF)</td>
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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.
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.
## IACC 2016-2017 Strategic Plan Objectives

<table>
<thead>
<tr>
<th>Question 1 - Screening and Diagnosis</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Strengthen the evidence base for the benefits of early detection of ASD.</td>
<td>$27,968,124</td>
<td>107</td>
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<tr>
<td>1. Reduce disparities in early detection and access to services.</td>
<td>$1,105,355</td>
<td>5</td>
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<td>1. 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.</td>
<td>$6,728,655</td>
<td>16</td>
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<tr>
<td>1. Not specific to Question 1 objectives</td>
<td>$19,941,251</td>
<td>82</td>
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<tr>
<td>1.0. Not specific to Question 1 objectives</td>
<td>$192,864</td>
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<table>
<thead>
<tr>
<th>Question 2 - Biology</th>
<th>2016 Funding</th>
<th>Project Count</th>
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<tbody>
<tr>
<td>2. 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.</td>
<td>$127,393,937</td>
<td>491</td>
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<tr>
<td>2. Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.</td>
<td>$96,027,190</td>
<td>402</td>
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<td>2. 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.</td>
<td>$8,449,763</td>
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<td>2.0 Not specific to Question 2 objectives</td>
<td>$12,885,786</td>
<td>17</td>
</tr>
<tr>
<td>2.1. Not specific to Question 2 objectives</td>
<td>$5,101,895</td>
<td>20</td>
</tr>
</tbody>
</table>
## IACC 2016-2017 Strategic Plan Objectives

<table>
<thead>
<tr>
<th>Question 3 - Risk Factors</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>$86,521,542</td>
<td>240</td>
</tr>
<tr>
<td>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.</td>
<td>$52,584,621</td>
<td>143</td>
</tr>
<tr>
<td>3.3. Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.</td>
<td>$14,434,906</td>
<td>46</td>
</tr>
<tr>
<td>3.O. Not specific to Question 3 objectives</td>
<td>$18,728,984</td>
<td>46</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 4 - Treatments and Interventions</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1. Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.</td>
<td>$23,567,797</td>
<td>70</td>
</tr>
<tr>
<td>4.2. Create and improve psychosocial, development, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD.</td>
<td>$24,175,752</td>
<td>118</td>
</tr>
<tr>
<td>4.3. Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.</td>
<td>$7,861,639</td>
<td>54</td>
</tr>
<tr>
<td>4.O. Not specific to Question 4 objectives</td>
<td>$2,144,880</td>
<td>11</td>
</tr>
</tbody>
</table>
### IACC 2016-2017 Strategic Plan Objectives

<table>
<thead>
<tr>
<th>Question 5 – Services</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1. Scale up and implement evidence-based interventions in community settings.</td>
<td>$7,791,530</td>
<td>19</td>
</tr>
<tr>
<td>5.2. Reduce disparities in access and in outcomes for underserved populations.</td>
<td>$209,020</td>
<td>3</td>
</tr>
<tr>
<td>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.</td>
<td>$7,500,189</td>
<td>39</td>
</tr>
<tr>
<td>5.O. Not specific to Question 5 objectives</td>
<td>$4,080,747</td>
<td>23</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question 6 - Lifespan Issues</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.</td>
<td>$6,733,188</td>
<td>24</td>
</tr>
<tr>
<td>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.</td>
<td>$574,730</td>
<td>3</td>
</tr>
<tr>
<td>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.</td>
<td>$1,234,501</td>
<td>16</td>
</tr>
<tr>
<td>6.O. Not specific to Question 6 objectives</td>
<td>$573,696</td>
<td>5</td>
</tr>
</tbody>
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## IACC 2016-2017 Strategic Plan Objectives

<table>
<thead>
<tr>
<th>Objective</th>
<th>2016 Funding</th>
<th>Project Count</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Question 7 - Infrastructure and Surveillance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.1. Promote growth, integration, and coordination of the biorepository infrastructure.</td>
<td>$36,068,982</td>
<td>136</td>
</tr>
<tr>
<td>7.2. Develop, enhance, and link the data repositories.</td>
<td>$4,202,497</td>
<td>17</td>
</tr>
<tr>
<td>7.3. Expand and enhance the research and services workforce and accelerate the pipeline from research to practice.</td>
<td>$11,553,624</td>
<td>25</td>
</tr>
<tr>
<td>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.</td>
<td>$9,891,875</td>
<td>58</td>
</tr>
<tr>
<td>7.0. Not specific to Question 7 objectives</td>
<td>$7,422,083</td>
<td>18</td>
</tr>
<tr>
<td><strong>Cross-Cutting Objective</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td>$5,189,546</td>
<td>20</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>$364,435,254</strong></td>
<td><strong>1360</strong></td>
</tr>
</tbody>
</table>
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/
• 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
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
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
Timeline

- **October 2010:**
  - Wandering issue presented at IACC during public comments by President of the National Autism Association
  - 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)
Timeline

- **February 2011:**
  - Letter sent to Secretary Sebelius

- **March 2011:**
  - Response received

---

**February 9, 2011**

The Honorable Kathleen Sebelius
Secretary, U.S. Dept. of Health and Human Services
Robert M. Humphrey Building
200 Independence Ave SW
Washington, DC 20201

Dear Ms. Sebelius,

The Interagency Autism Coordinating Committee (IACC) would like to bring to your attention the issue of wandering/flight risk related to ASD, a serious matter that was discussed in detail by members of the public at the IACC meeting that took place on October 22, 2010. This issue is of great importance to children and adults with ASD who are at risk for wandering behavior, as they may be unable to escape an unsafe situation or may not be aware of the danger.

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

For example, Mason, a nonverbal 5-year-old boy with autism and no functional language skills, has a history of wandering. In one instance, his mother noticed that he was missing and began searching for him. She finally found him, but he had wandered into the street and was nearly struck by a car.

I am writing to extend my sincere appreciation to you and the Interagency Autism Coordinating Committee for your work related to autism spectrum disorder (ASD) and your recommendations for changes in federal agencies, the Department of Health and Human Services (HHS) as you may consider in accordance with the Combating Autism Act of 2009.

I also wish to thank you for providing background information on how the issue of autism-related wandering/flight risk is affecting the autism community and how your recommendations are helpful. I understand that the Committee has already taken action to encourage research on wandering behavior and working on this issue in the research objectives of the 2011 IACC Strategic Plan for Autism Spectrum Disorder Research, and has also undertaken the issue of medical coding for autism-related wandering in connection with consideration by the International Classification of Diseases Coordination and Maintenance Committee, with a focus on care and services provided to individuals with autism spectrum disorder.

Please keep the IACC apprised of the effort put forth by this Committee and how the recommendations continue to be communicated in this Committee’s advisory reports. On behalf of the Department, I thank you and the Committee for your dedication and commitment to enhancing and supporting federal and community efforts to improve the health and well-being of people with autism spectrum disorder.

Sincerely,

[Signature]

Kathleen Sebelius
Initial Data Presented April, 2011

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

Percentage Who Elope

Age

Children with ASD
Unaffected Siblings

Anderson, Law, et al (KKI/IAN)
Classification of Diseases, Functioning, and Disability

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:
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, c, d Catherine Rice, PhD, e David S. Mandell, ScD, e Louis Hagopian, PhD, c, d and Paul A. Law, MD, MPH c, d

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
Nearly half of children with autism wander from safety

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 "elooped" 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 all or after age 4, developmentally the age when such behavior becomes less common," finds the study.

---

Nearly Half of Children With Autism Wander From Safety: Survey

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

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.

A behavior that has led to numerous accidental deaths.
Wandering More Common in Autistic Children Than Once Thought

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

By LARA SALAH (@BostonLara)
October 5, 2012

Lori McIwain, 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 McIwain. "You're always on high alert."

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

![Image of a bar chart showing the percentage of respondents who received advice or guidance from various professionals about how to prevent elopement.]

- Pediatrician or other physician: 14%
- Psychologist or other mental health professional: 18%
- Local health or disabilities agency: 8%
- Law enforcement agency: 8%
- Autism advocacy organization: 17%
- Vendor of safety devices, trackers, GPS, etc.: 10%
- School or day program personnel: 20%
- Other - please specify: 8%
- No - I have not received advice or guidance about this from professionals: 51%
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 or unfamiliar situations
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
March, 2018: Kevin and Avonte’s Law

- Still no Appropriation for Kevin and Avonte’s Law
  - Autism “alert”
  - GPS tracking devices
  - First Responder training
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.
On average: 20 cases, 2 to 3 deaths per month. Drowning remains leading cause of death.
Average Age by Year, 2011 to 2016

*Current average age for lethality, 15*
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
Autistic woman, reported missing, dies after being found in creek

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


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

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

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

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.
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 1.6 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
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.*

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 somewhere 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.thiACP.org/alzheimers.

* Estimates courtesy of the Alzheimer Association. 2010 Facts & Figures Report. The Alzheimer’s Association is the nation’s leading organization fighting Alzheimer’s, and its mission is to eliminate Alzheimer’s through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of Alzheimer’s through the promotion of brain health.

This project was supported by Grant No. 2010-MU-BX-0035 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 policy of the United States Department of Justice.
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
Wandering/Elopement in ASD: 2019 Update
The Justice and Mental Health Portfolio

Maria Fryer
Policy Analyst for Mental Health and Substance Addiction

Programs, Policy Initiatives and Improved Responses
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’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

*Achieve with us.*
Disability Response Teams

*Multidisciplinary Teams of Community Stakeholders*
## 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 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.
• 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.
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
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
• 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

Core Metrics
1. Increased connections to resources
2. Fewer arrests
3. Reduced repeat encounters
4. Reduced use of force
The Stepping Up Initiative

Launched in May 2015

Vision:
There will be fewer people with mental illnesses in jails than there are today.
Almost 461 counties across 43 states have committed to reduce the number of people with mental illnesses in jails.
The Six Questions Guide

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

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

Determine who will serve as the project coordinator in the first step of the planning process. A general planning committee can be formed at this stage, including representatives of the communities affected by the issue. The project coordinator should develop the necessary skills and knowledge to effectively carry out the planning process and ensure a successful implementation.

The Role of the Project Coordinator

Your role in the project coordinator is critical to the success of your county’s Stepping Up Initiative. It is the project coordinator’s responsibility to coordinate and manage the planning process, providing guidance and support to the planning team. The Stepping Up Initiative is designed to assist counties in developing a comprehensive plan for reducing the number of people with mental illnesses in jail.

Online County Self-Assessment

Welcome

Welcome to the Stepping Up County Self-Assessment. This assessment is designed to help you identify and address challenges in your county’s planning process. It is an online tool that provides guidance and support to help you implement the Six Questions.

Sign In

Create Your Account

Password

Log In

Series of Briefs

In Focus: Implementing Mental Health Screening and Assessment

This brief focuses on implementing mental health screening and assessment programs. Specifically, it highlights the benefits of implementing a comprehensive mental health assessment program in your county. The brief is designed to provide guidance and support to help you implement the Six Questions.

Why It’s Important

To reduce the number of people with mental illnesses in jail, counties need to have a clear and accurate understanding of the prevalence of mental illness in their communities. Implementing a comprehensive screening and assessment program can help identify individuals who may be at risk of mental illness and provide early intervention and support.

Why It’s Challenging

Implementing a comprehensive screening and assessment program can be challenging, especially for counties with limited resources. However, with the right support and guidance, counties can successfully implement the Six Questions and reduce the number of people with mental illnesses in jail.
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?
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:

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Thank you!
NCMEC’s Response to Children Missing with Autism

IACC Meeting 2019
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
Notifications

NCMEC Call Center

NAA

NIXLE

NEXT DOOR
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

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 stopped 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 reuniting a missing child with autism presents unique and difficult challenges for families, law enforcement, first responders and search trains. This running away or wandering behavior puts these children at risk of accidental drowning, traffic injury and other dangers. As police and EMT 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 EMT 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 have in response to these emergency 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 agency 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 representatives if they want children and teens, or if they wish to keep it more low key for the kids. Arrange to have Child EIs provided that include maps of existing hazards, including water. Distribute EMC Autism Roadmap for participating families and students.

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 student parents or guardians before posting any photographs or videos of student.

5. **Mobile 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. Always use a autism-friendly microphone or speaker, but also use them to record children at another event. Children with autism activity may all the time under stimulus, it’s not too hot, loud, or too. If they hear the other, they may not be aware.

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 behavior 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 even bigger success

9. **Be ready for different responses from the kids:** Having enough support from teachers and kids 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.
OTHER RISKS
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?

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

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.
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
• 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
Question 1: Screening and Diagnosis

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.

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

Fragile X mental retardation 1 gene enhances the translation of large autism-related proteins. Greenblatt EJ, Spradling AC.
Question 3: Risk Factors

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

Transcriptome-wide isoform-level dysregulation in ASD, schizophrenia, and bipolar disorder.
**Question 3: Risk Factors**

**JAMA Psychiatry**


**AUTISM RESEARCH**

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

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.

Schendel DE, Thorsteinsson E.
Round Robin
Adjournment
Next IACC Meeting

Wednesday, April 17th 2019