

Meeting of the Interagency Autism Coordinating Committee

Wednesday, July 26, 2017

National Institutes of Health
31 Center Drive Building
31, C Wing, 6th Floor, Conference Room 6
Bethesda, MD 20892

Conference Call Access:

Phone: 888-323-2720

Access Code: 8420867

Meeting of the IACC

Morning Agenda

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

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive
Secretary, IACC

Meeting of the IACC

Morning Agenda – continued

9:10

**Update from Office of the National
Autism Coordinator**

Thomas Novotny, M.D.

Deputy Assistant Secretary for Health and
National Autism Coordinator
Department of Health and Human
Services

Meeting of the IACC

Morning Agenda – continued

**9:15 Mortality & Risk in ASD Wandering/Elopement:
2011-2016**

National Autism Association

Lori McIlwain

Co-Founder and Board Chair

Meeting of the IACC

Morning Agenda – continued

**9:45 Injury Prevention Strategies for Wandering in
 Families of Children with ASD**

Interactive Autism Network

Paul Lipkin, M.D.
Director

**10:15 Committee Discussion of Wandering
 Presentations**

10:45 Morning Break

Meeting of the IACC

Morning Agenda – continued

11:00 **Committee Business**

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary, IACC

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

Director, NIMH and Chair, IACC

12:00 **Lunch**

Update from Office of the National Autism Coordinator

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Meeting of the IACC

Morning Agenda – continued

**9:15 Mortality & Risk in ASD Wandering/Elopement:
2011-2016**

National Autism Association

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Co-Founder and Board Chair

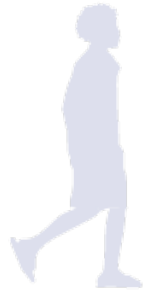
Mortality & Risk in ASD Wandering/Elopement: 2011-2016

National Autism Association
Lori McIlwain
Co-Founder and Board Chair

**Mortality & Risk in
ASD
Wandering/Elopement:
2011-2016**

*Lori McIlwain
National Autism Association*





**From 2011 to 2016, NAA collected
over 800 ASD missing person cases, and
“found missing” cases that occurred within the U.S.**

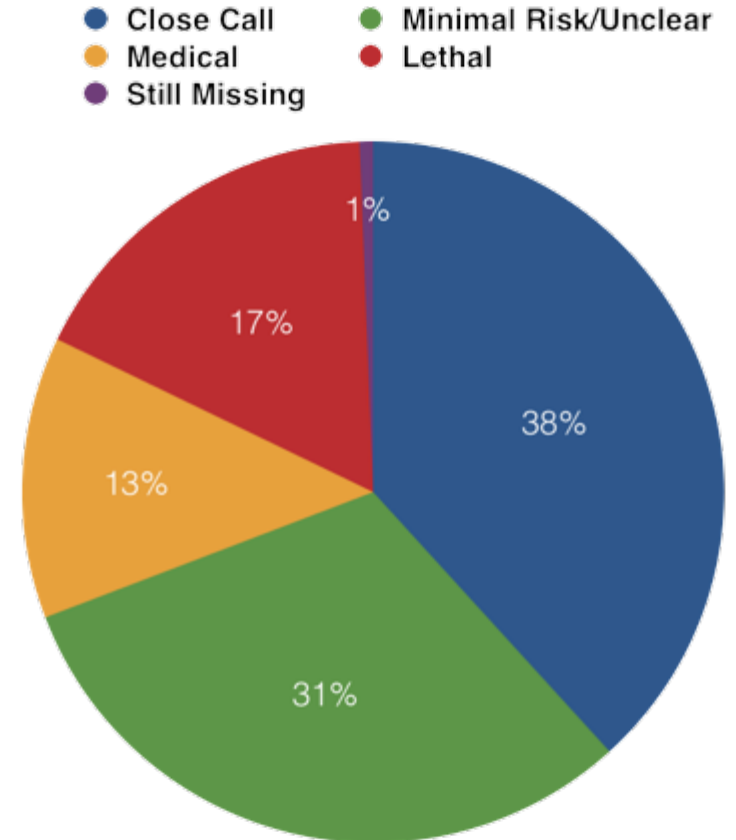
Cases were reviewed to identify:

- Diagnosis
- U.S. location
- Age, gender, race
- Time of year and day
- Search response & interaction
- Outcome



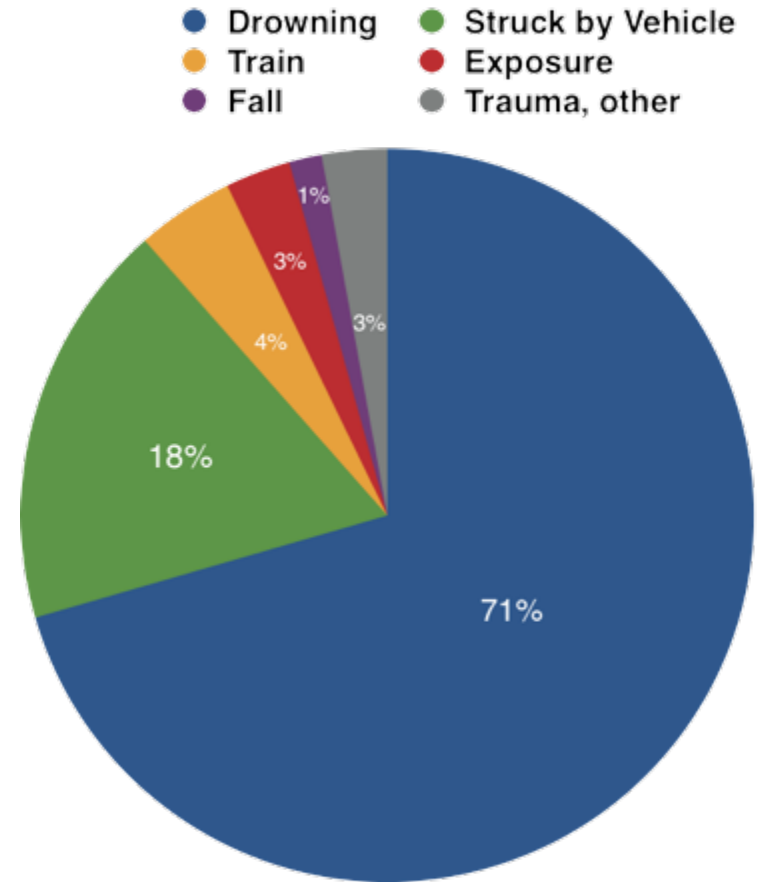
All Outcomes, 2011 to 2016

All Outcomes	808
Lethal	139
Medical Attention	105
Close Call	309
Still Missing	5*
Minimal Risk/Unclear	250



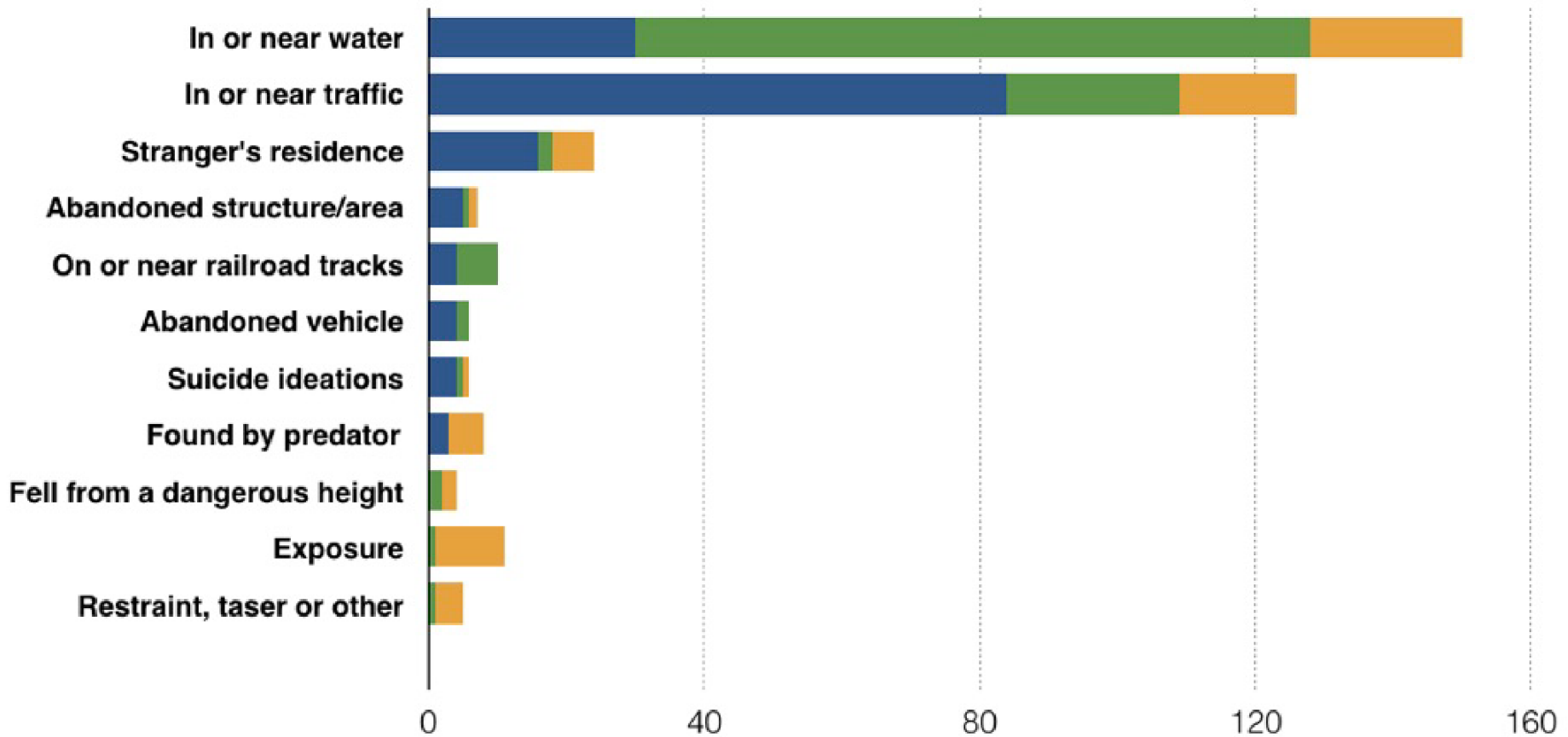
Lethal Outcomes, 2011 to 2016

Lethal Outcomes	139
Drowning	98
Struck by vehicle	25
Struck by train	6
Hyper/Hypothermia	4
Fall	2
Trauma, other	4

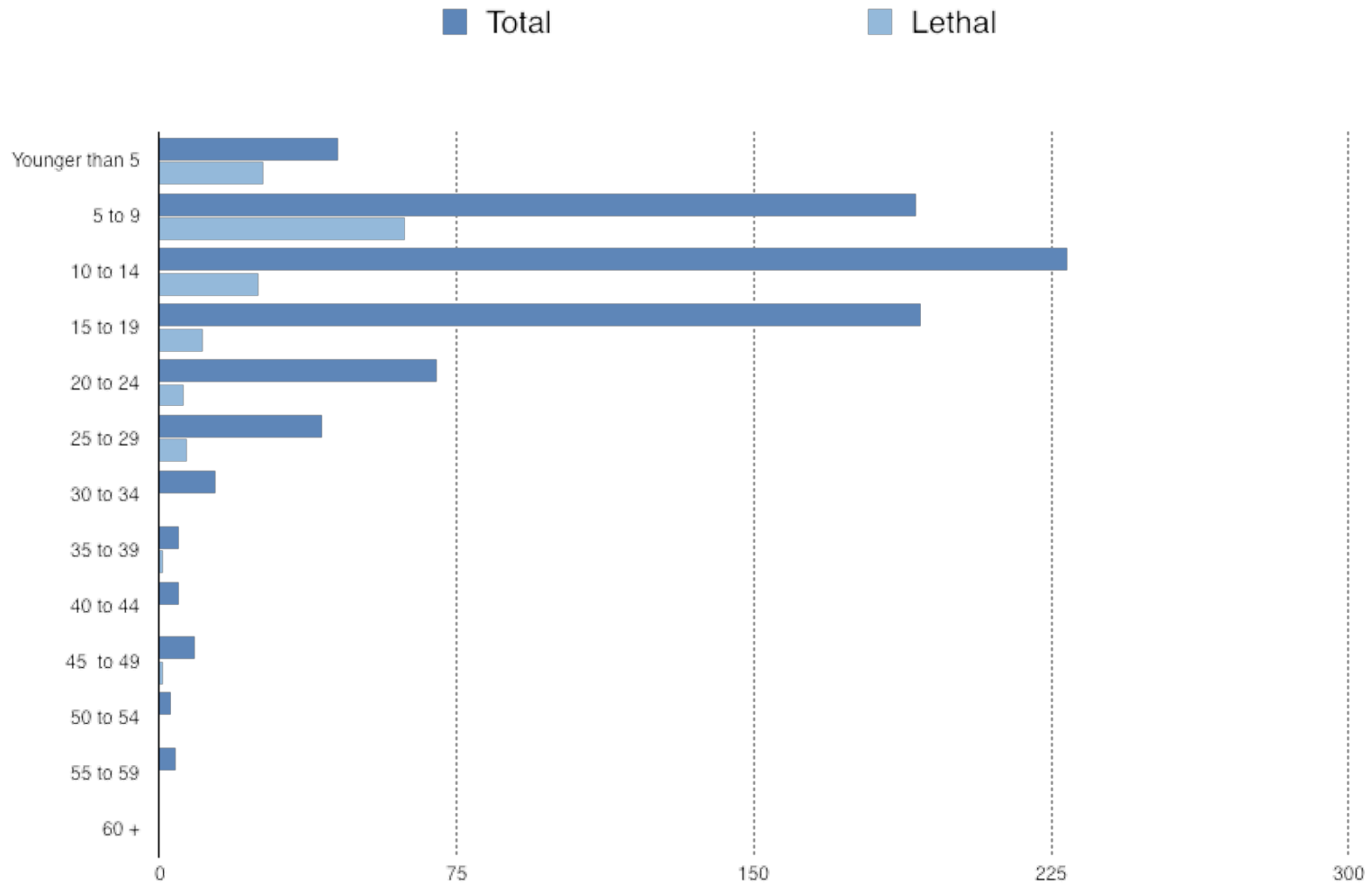


Outcomes by Risk & Injury, 2011 to 2016

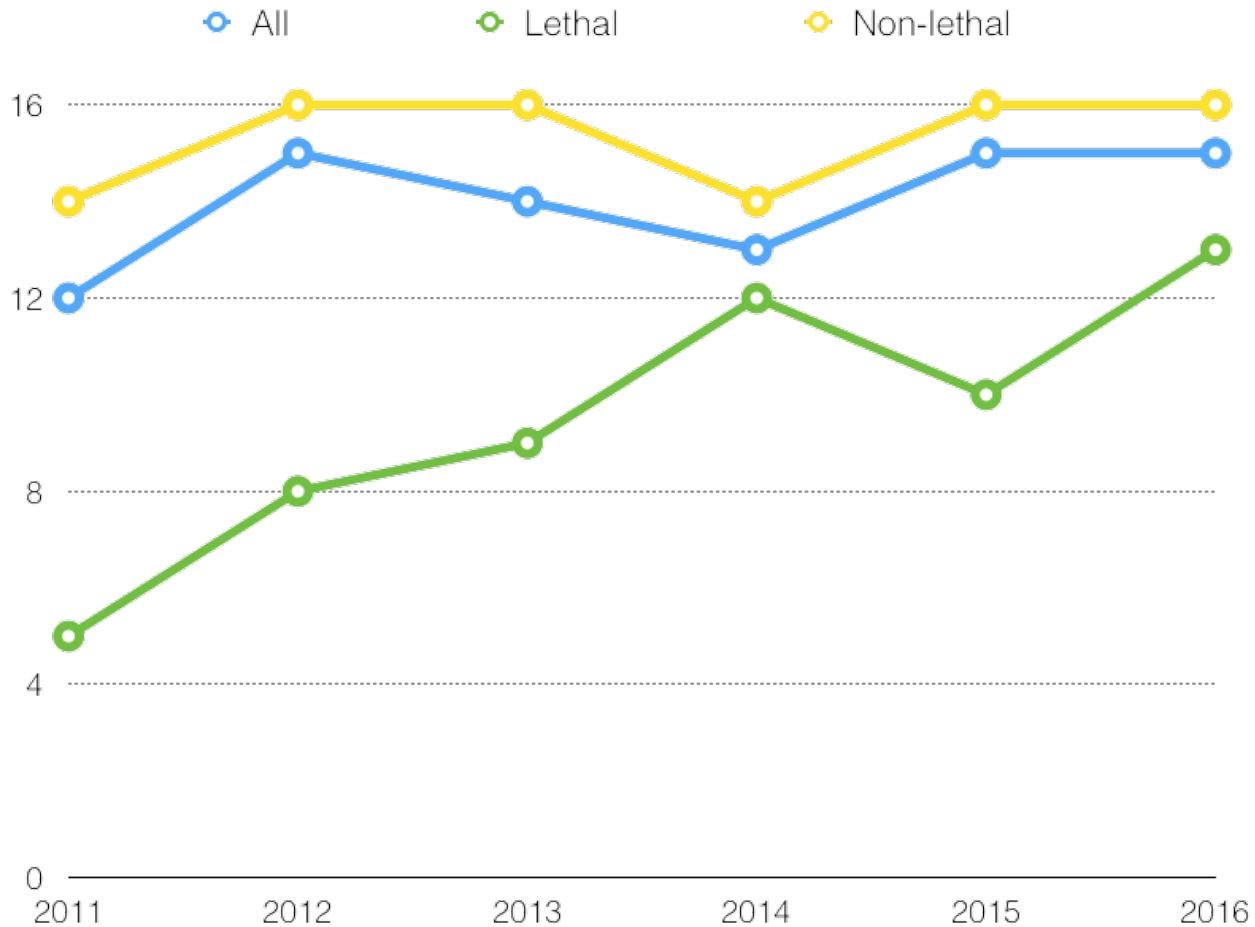
■ Risk ■ Lethal ■ Injury, Trauma or Other



All Outcomes by Age Group, 2011 to 2016



Average Age by Year, 2011 to 2016

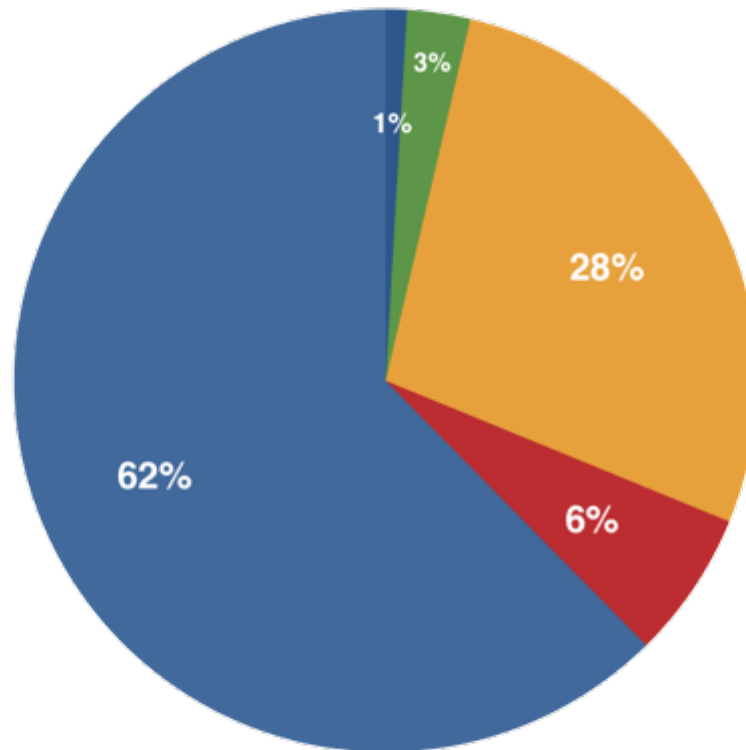


Mean Age, Lethal

Drowning: 9 Struck by Vehicle: 14

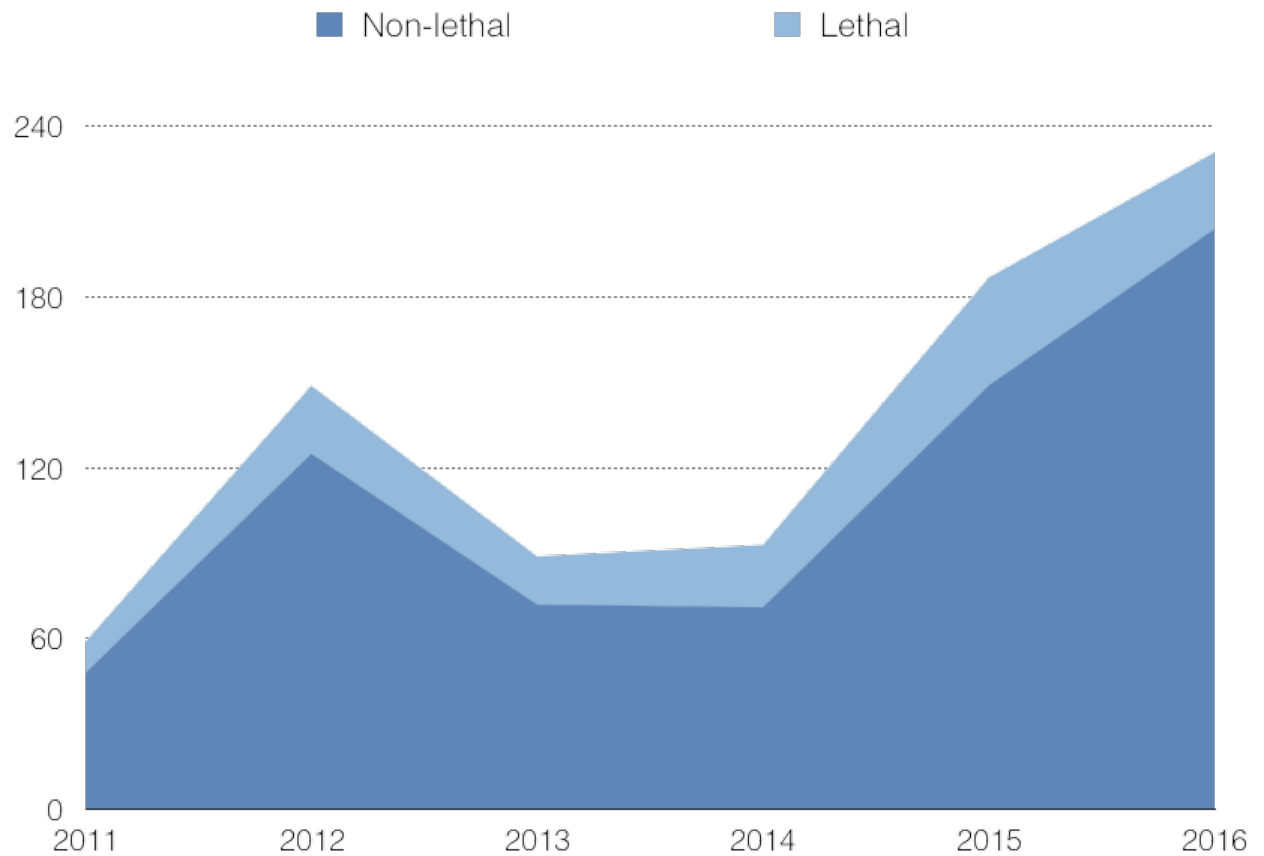
Lethal Outcomes by Ethnicity, 2011 to 2016

- Asian
- Black or African American
- Native American
- White
- Biracial
- Hispanic or Latino
- Pacific Islander

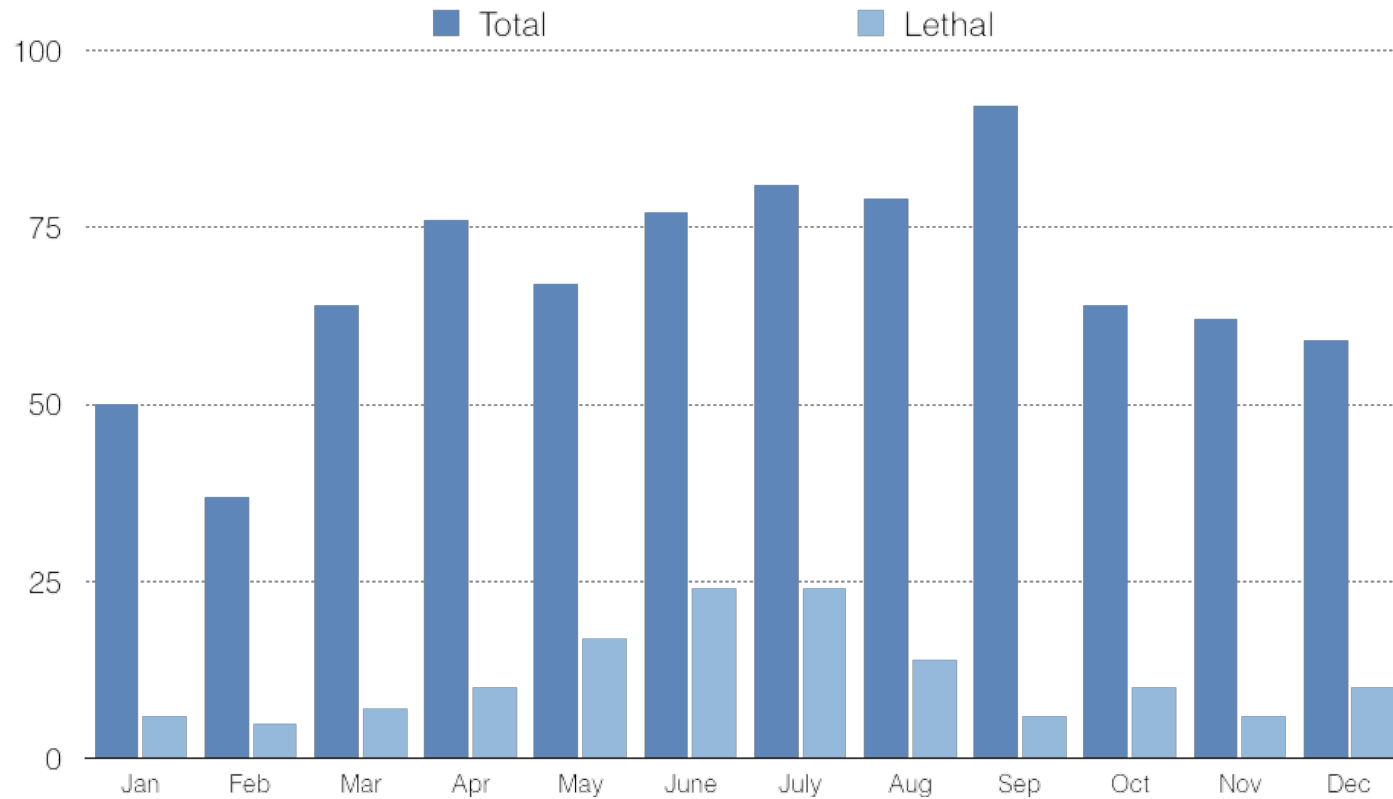


All Outcomes by Year, 2011 to 2016

About half of lethal outcomes happened in the last two years.

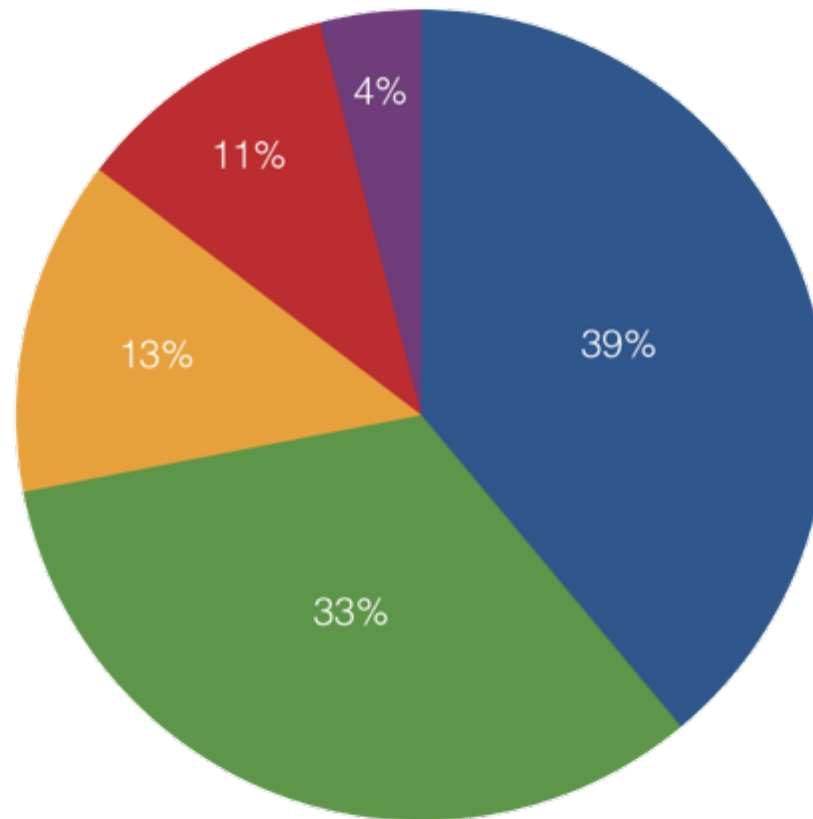


All Outcomes by Month, 2011 to 2016

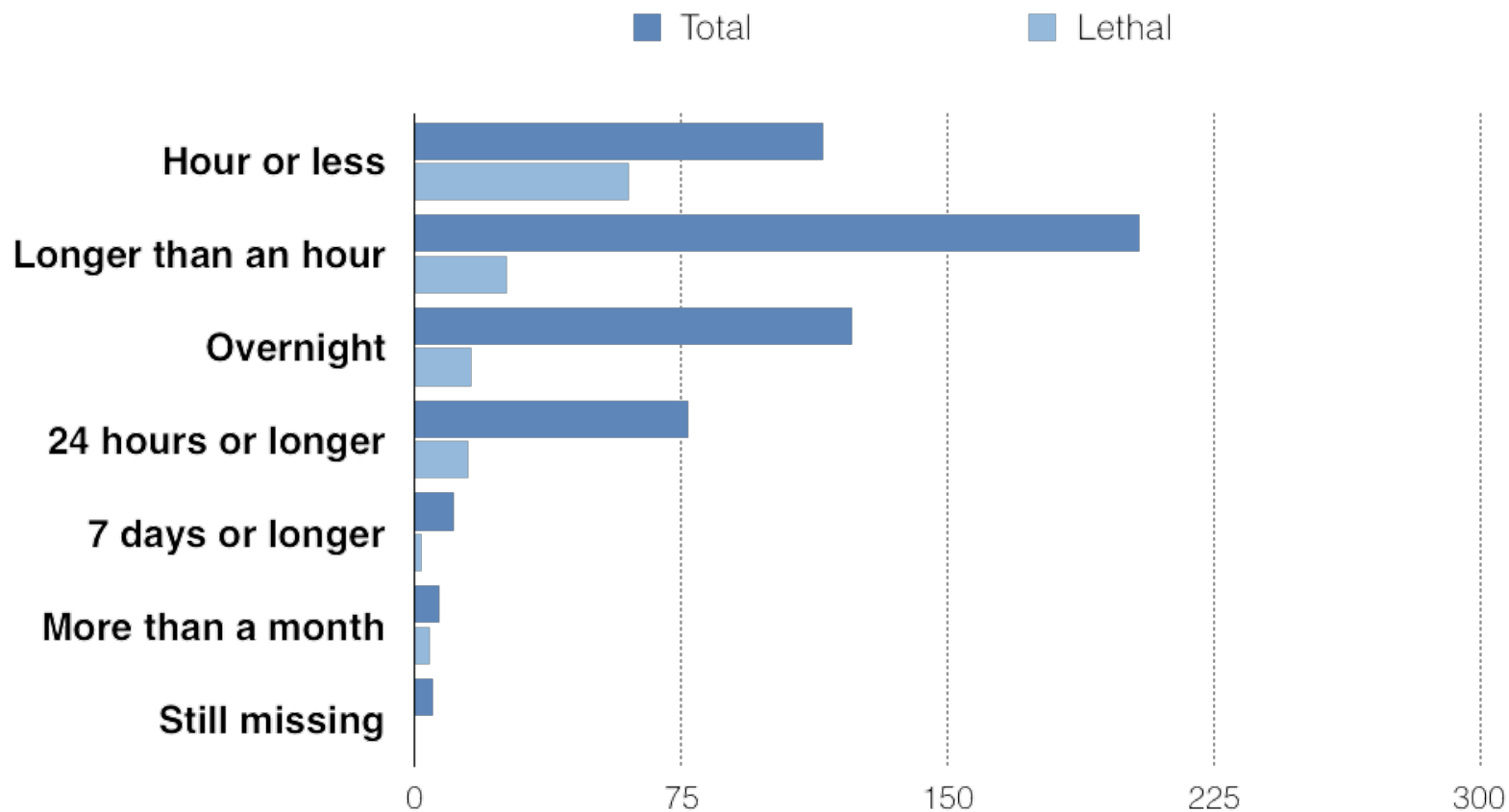


Outcomes by Vulnerable Times/Triggers, 2011 to 2016

- Transition/Commotion/Stress
- Playing Outside
- Family/Social Gathering
- Between 9p-9a
- Unfamiliar Setting



Outcomes by Search Time, 2011 to 2016



*Top Places **Left From***

1. Home
2. School/School Bus
3. Relative's Home *
4. Field Trip/Camp
5. Group Home
6. Store/Restaurant
7. Between Settings
8. Hotel/Vacation Home *
9. Train or Bus Station
10. Church

*Top Places **Found***

1. Water *
2. Streets/Roads
3. Woods or Brush
4. Stranger's Residence
5. Store/Restaurant
6. Train or Bus Station
7. Abandoned vehicle/home
8. Train Tracks *
9. Farm or Field
10. Park

*Highest Lethal Risk

What Increased Lethal/Injury Risk

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



What **Decreased** Lethal/Injury Risk

- Community-based settings, hospitals/schools
- Quicker Response Time
- Response Tools (Alerts, Tracking, Reverse 911)
- Good Samaritans
- Identification
- Police familiar with autism, familiar with individual



Currently...

- About 20 ASD missing person cases per month
- 3 to 4 deaths per month



4-year-old with autism drowns in neighbor's pool

Posted: Jul 03, 2017 7:36 PM EDT
Updated: Jul 05, 2017 1:11 PM EDT

By Devin Turk, Collier County Reporter [CONNECT](#)



*July 3
Naples, FL*

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Police: Autistic RI man was walking in middle of highway in Attleboro when struck by car



By David Linton dlinton@thesunchronicle.com Jul 5, 2017



*July 5
Pawtucket, RI*

Buy Now

MORE INFORMATION



ATTLEBORO — Police say the victim struck by a car late Tuesday night on Route 1A in South Attleboro was an autistic teenager reported missing from his Pawtucket home.



Pedestrian killed on Highway 118 in Simi Valley identified

Christian Martinez , christian.martinez@vcstar.com, 805-437-0245

Published 10:31 a.m. PT July 6, 2017 | Updated 10:31 a.m. PT July 6, 2017



(Photo: CONTRIBUTED PHOTO/CALIFORNIA HIGHWAY PATROL)

577

CONNECT

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EMAIL

MORE

A pedestrian who was killed on Highway 118 in Simi Valley was identified Thursday by a Ventura County Medical Examiner.

Andres Valadez, 19, of Simi Valley, was struck and killed by multiple vehicles Friday on the eastbound 118 just west of Rocky Peak Road, officials said.

The incident occurred sometime after 9:50 p.m. when a California Highway Patrol officer responded to reports of a man walking in the center divider of the westbound 118, officials said.

The officer spotted Valadez along the roadway and pulled up to the area with lights flashing, officials said.

The officer then instructed Valadez to stay in place via loudspeaker, at which time the 19-year-old jumped over the center median onto the eastbound side of the roadway, authorities said.

Valadez did not comply with a second instruction from the officer to stay in place and subsequently began "walking quickly" into eastbound traffic when he was struck by multiple vehicles, officials said.

July 6
Simi Valley, CA

Authorities in Brownsburg searching for missing boy with autism

POSTED 3:27 PM, JULY 7, 2017, BY [CBS4 WEB](#), UPDATED AT 08:54PM, JULY 7, 2017

 FACEBOOK 356

 TWITTER

 REDDIT

 EMAIL

 G+ GOOGLE

 PINTEREST

BROWNSBURG, Ind. – Police in Brownsburg are looking for a missing boy today named Shalom Lawson.

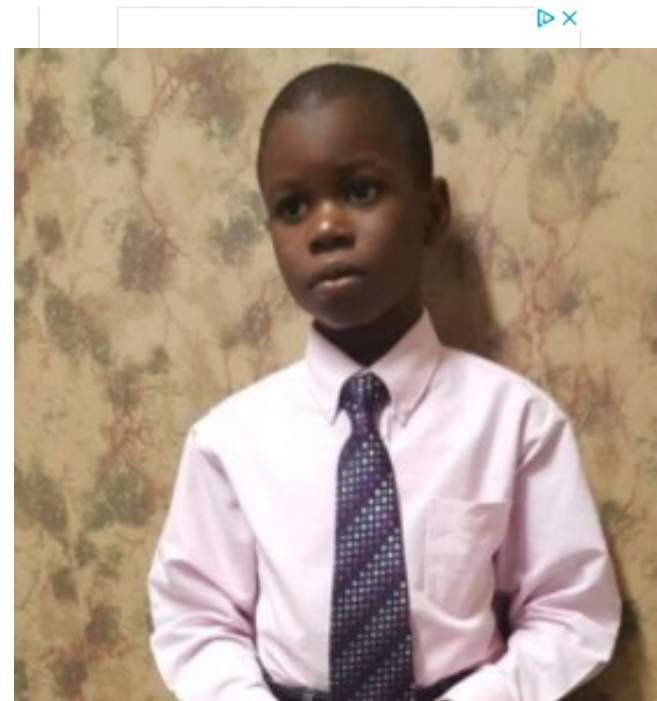
He was last seen at 1:34 p.m. this afternoon on Watercress Way in the area of 900 E and US 136.

Shalom is described as an African-American boy, aged 7-8, with a thin build. He has autism and may not communicate.

The child was last seen wearing a gray t-shirt possibly with some type of robot graphic and gray shorts.

He was not wearing any shoes.

He is 4'7" and weighs approximately 56 lbs.



July 7
Brownsburg, IN

 NATIONAL
AUTISM
ASSOCIATION

Body of 8-year-old Louisville boy found in pond near Indianapolis

Posted: Jul 08, 2017 12:12 PM EDT

Updated: Jul 08, 2017 12:14 PM EDT



*July 8
Brownsburg, IN*

LOUISVILLE, Ky. (WDRB) -- Officials say the body of an 8-year-old Louisville boy was found Saturday morning in a pond near Indianapolis.

Brownsburg Fire Territory Lt. Ryan Miller tells WDRB the boy was 8-year-old Shalom Lawson. The body was found in a nearby retention pond across from a family member's home Saturday just before 10:30 a.m.

Officials say his family is from Louisville and they were visiting relatives in Brownsburg. The area is about 15 miles west of Indianapolis.



**MOST POPULAR
STORIES**

 NATIONAL
AUTISM
ASSOCIATION

7-year-old with autism drowns in Seminole



By WFLA Web Staff

Published: July 9, 2017, 6:07 am



*July 9
Seminole, FL*

SEMINOLE, Fla. (WFLA) — Detectives in Pinellas County say a young boy with autism died Saturday night after being found face down in a pool in Seminole.

Detectives say 7-year-old Artemio Shkulaku was with his mother, father and grandmother when he apparently snuck out of his house through a side door and wandered off. The boy's father was working on the opposite side of the home at the time.



Missing 5-Year-Old With Autism Rescued From River

A missing 5-year-old boy with autism has been rescued from the Blackstone River a few hours after he was reported gone.

July 10, 2017, at 12:54 p.m.

AP

PAWTUCKET, R.I. (AP) — A 5-year-old boy with autism has been rescued from the Blackstone River after he was reported missing and discovered wading by a kayaker.

Police in Pawtucket received a call about the boy being missing around 6:30 a.m. Monday.

A person kayaking on the river then called police to say there was a young boy in the water.

Police say the kayaker stayed with the boy until they arrived, when they found the boy in knee-deep water. They say they tried to help him from the river bank, but he went deeper, so Officer James Doyal went into the river and brought the boy to safety.

Police say the boy was evaluated by Pawtucket Rescue and released to his mother.

*July 10
Pawtucket, RI*



*July 11
Albany, GA*

Command post to be set up as search for autistic Albany boy continues

Police were continuing the search Tuesday night for an 11-year-old Albany boy with autism, Bruce Lemon-Curry, and were asking volunteers to help with the search...

Missing 6-year-old boy struck and killed on I-5 near Albany

56

Posted on July 11, 2017 at 2:44 PM



(The Oregonian/OregonLive)



By **Samantha Matsumoto**, smatsumoto@oregonian.com,
The Oregonian/OregonLive

A 6-year-old boy reported missing from his Albany home was struck and killed on Interstate 5 less than an hour later, Oregon State Police said Tuesday.

The boy was reported missing at about 9:30 p.m. Monday night, state police spokesman Sgt. Jeff Proulx said. Linn County sheriff's deputies and state police officers searched the area.

*July 11
Albany, OR*



Search for missing Albany child ends in tragedy

Jul 12, 2017



Bruce Lemon-Curry (Source: APD)



ALBANY, GA (WALB) - The Albany Police Department sent out a request for the public to be on the lookout for a missing child, Tuesday morning.

Bruce Lemon-Curry, 11, had autism and wandered away from his home at approximately 8:30 a.m. Tuesday.

July 12
Albany, GA

The Good News:

- More awareness, more rescues
- More understanding to search water first



But:

- Increase in cases and deaths in the last two years
- Awareness, training & resources not widespread
- Disproportionate risk among African American individuals with ASD



Missing boy with autism wandered miles before being found

By Mike LaBella mlabella@eagletribune.com Apr 24, 2017



HAVERHILL — The 10-year-old Haverhill boy with autism who was reported missing early Sunday evening and was found several hours later at the edge of a pond in Atkinson had last been seen on the back porch of his home in the upper North Broadway area, according to police.

The boy's parents had called police at about 6:35 p.m. to report they could not find their son.

Police Detective Lt. Robert Pistone said officers searched the boy's home multiple times, because in some cases of missing children, those children are often found hiding their own homes.

“Police Detective Lt. Robert Pistone said officers **searched the boy's home multiple times**, because in some cases of missing children, those children are often found hiding their own homes.”

“The program consists of training videos, direct 8-hour training sessions, two-day train-the-trainer sessions, 15 resources, and a state-by-state guide to state-specific resources.

To date, the direct training has reached over 1,600 participants and the program has disseminated over 50,000 resources to the field.”

ALZHEIMER'S INITIATIVES



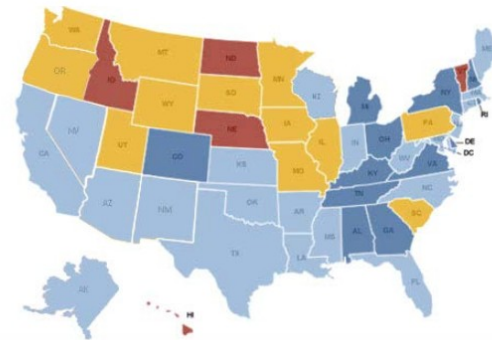
IACP ALZHEIMER'S INITIATIVE

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](#)
- [Evaluate 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](#)
- [Webinars](#)

Award Title: Missing Alzheimer's Disease Patient Initiative

Award Description:

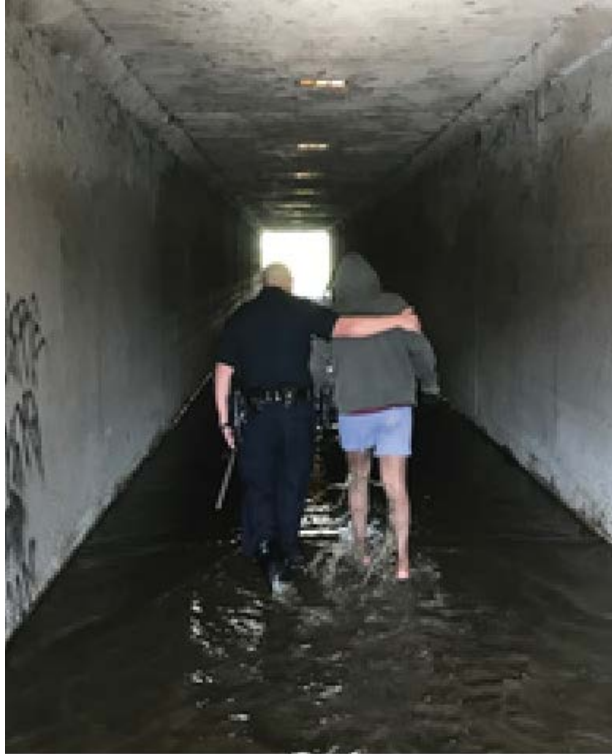
This program is funded under both the Edward Byrne Memorial Competitive Grant Program (Byrne Competitive Program) and the Edward Byrne Memorial Justice Assistance Grant (JAG) Program. Authorized by the Consolidated Appropriations Act, 2009 (Pub. L. 111-8), the Byrne Competitive Program helps local communities improve the capacity of state and local justice systems and provides for national support efforts including training and technical assistance programs strategically targeted to address local needs. The JAG Program (42 U.S.C. 3751(a)) is the primary provider of federal criminal justice funding to state and local jurisdictions, and JAG funds support all components of the criminal justice system. The JAG Program authorization also states that 'the Attorney General may reserve not more than 5 percent, to be granted to 1 or more States or units of local government, for 1 or more of the purposes specified in section 3751 of this title, pursuant to his determination that the same is necessary'(1) to combat, address, or otherwise respond to precipitous or extraordinary increases in crime, or in a type or types of crime' (42 U.S.C. 3756). This program is also funded in part by the Missing Alzheimer's Disease Patient Assistance Program (Consolidated Appropriations Act, 2009 PUB. L. 111-8), which provides funds to defray the cost of planning, designing, establishing, and operating locally based, proactive programs to protect and locate missing patients with Alzheimer's disease and related dementias and other missing elderly individuals. The National Initiatives: Enhancing Law Enforcement Program, administered by the Office of Justice Programs' (OJP) Bureau of Justice Assistance (BJA), helps improve criminal justice systems and provides national programs and national efforts such as training and technical assistance to strategically address the needs of state and local justice systems and communities. The International Association of Chiefs of Police, Inc. (IACP) will develop or enhance a national outreach program to increase awareness among law enforcement agencies and the public in addressing the needs of missing persons with Alzheimer's disease. Law enforcement agencies expend countless hours annually searching for missing persons with Alzheimer's disease, and if not found quickly, they are at high risk of serious injury or even death. In addition, law enforcement officers may not be trained or equipped to handle the special needs of those with Alzheimer's, once they are found. IACP will partner with national level law enforcement and Alzheimer's disease associations to address this issue. They will provide a web site that serves as a national clearinghouse of information and resources for those involved with missing persons. IACP will develop and sustain a national registry for persons living with Alzheimer's disease or other form of dementia, develop and implement a process for aiding in the location of lost persons with Alzheimer's disease, provide training and substantive informational material to law enforcement agencies through a national or regional initiative. They will also support the development of a model policy that can be implemented nationwide by law enforcement agencies.

CA/NCF

Award Title: Project Lifesaver Replication Initiative

Award Description:

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Brandon, age 20 – Found Safe in Water

- January 2017 - Burbank, CA
- Exited his home in the early morning hours
- Was wearing a **Radio Frequency (RF)** tracking unit
- Located by police via tracking unit in the Burbank wash



NNR, age 19 – Found safe in Water

- February 2017 – Santa Maria, California
- Wandered from group home
- Located by police via **Radio Frequency (RF)** tracking unit in reservoir
- Because of tracking unit, Sheriff's volunteer knew the teen and was able to talk him into coming out of the water

114TH CONGRESS
2D SESSION

S. 2614

IN THE HOUSE OF REPRESENTATIVES

JULY 18, 2016

Referred to the Committee on the Judiciary, and in addition to the Committee on Education and the Workforce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

AN ACT

To amend the Violent Crime Control and Law Enforcement Act of 1994, to reauthorize the Missing Alzheimer's Disease Patient Alert Program, and to promote initiatives that will reduce the risk of injury and death relating to the wandering characteristics of some children with autism.

- Would have reauthorized *Missing Alzheimer's Disease Patient Alert Program*
- Passed Senate; revised version passed House
- Revised House version failed to pass in Senate

What Would Help

- Pediatric Community warning caregivers
- Widespread training/federal initiatives, DOJ participation
- Outreach, awareness, resources to ASD African American community
- Exit-seeking, stress response can evolve or crossover into other emerging issues - self-harm, suicidality – study & discussion needed



Missing man with Asperger's last seen in northwest Vegas

Posted: Nov 29, 2016 3:03 PM EST

Updated: Feb 07, 2017 3:50 PM EST

Written by Matt Guillermo

CONNECT

LAS VEGAS (FOX5) - Police said a man with Asperger syndrome went missing and was last seen in the northwest Las Vegas Valley on Monday.

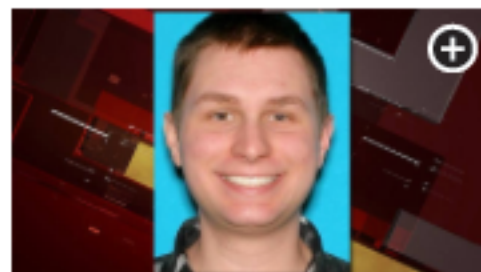
According to Las Vegas Metro police, Christian Harned, 24, was last seen about 2:30 p.m. in an apartment complex near Grand Teton Drive and Hualapai Way.

Harned is described as 5'11" in height and 163 pounds. He has blue eyes, brown hair and a fair complexion, police said.

Harned was also last seen wearing a dark brown jacket, blue jeans, white and black "Jordan" gym shoes, police said. He was last seen carrying a gray backpack.

Police noted Harned may be fearful of police due to his condition.

Police urged anyone with information on Harned's disappearance to contact Metro's Missing Persons Detail at 702-828-3111 or at 702-828-2709.



Christian Harned (Source: LVMPD)

“When you think of Christian you find yourself guilty of being selfish. In our family, Christian was the guy you wanted to have around to help make yourself feel better. He was silly, spontaneous, thoughtful, loving and his smile swept through a room like wildfire. Having been diagnosed in his teen years with early onset schizophrenia and Asperger’s syndrome, those amazing qualities were only visible to those closest to him as Christian struggled connecting with a world that was eager not to take the time to understand him...”

Christian clung to the safety and familiarity of his family but yearned to receive more from this world in which he could never completely find his footing. The difficulties he found in navigating everyday social aspects of human interaction often left him exhausted, frustrated, and on the worst of days, in tears. He sought love and purpose of being; but in the end, this world proved too gruesome to withstand. Christian took his last breath in the coldness of dark and alone, which is perfectly attuned with how he viewed his place in this world.“



LORI McILWAIN
Co-founder & Chair
P: 877.622.2884
lori@na.onalau.sm.org



Mortality & Risk in ASD Wandering/Elopement: 2011-2016

Meeting of the IACC

Morning Agenda – continued

**9:45 Injury Prevention Strategies for Wandering in
 Families of Children with ASD**

Interactive Autism Network

Paul Lipkin, M.D.
Director

**10:15 Committee Discussion of Wandering
 Presentations**

10:45 Morning Break

Injury Prevention Strategies for Wandering in Families of Children with ASD

Interactive Autism Network
Paul Lipkin, M.D.
Director

Injury prevention strategies for wandering in families of children with ASD

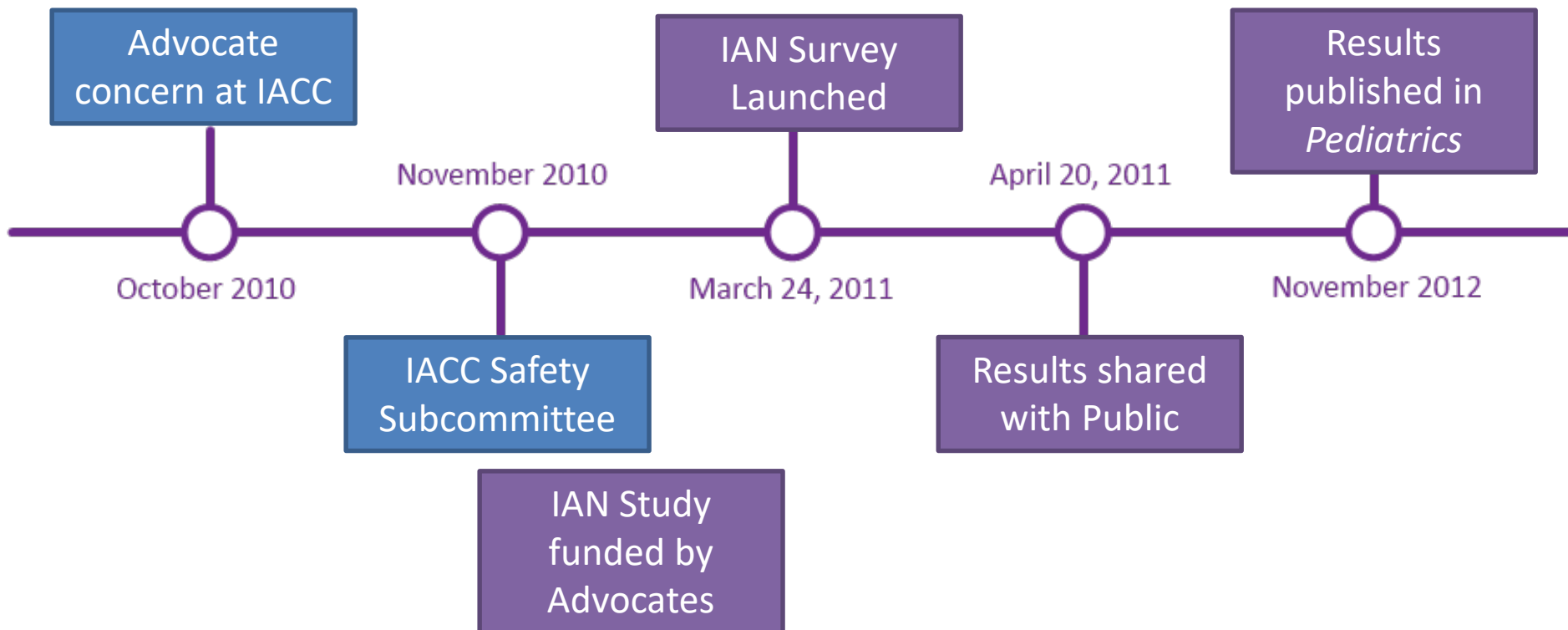
Paul H. Lipkin, M.D.

Director, Interactive Autism Network
Kennedy Krieger Institute

Associate Professor of Pediatrics,
Johns Hopkins Medicine

Wandering and Elopement

A Journey in Online Autism Research



Wandering and Elopement

A Journey in Online Autism Research

- All IAN Research families with a child between 4 and 17.9 years invited
- Online surveys completed by parents of 1218 children with ASD & 1076 siblings
 - All levels of functioning
 - The entire US
 - All ethnic and racial groups
 - Urban and rural

Anderson C, et.al, *Pediatrics*, Nov. 2012



Overall wandering rate: 49%

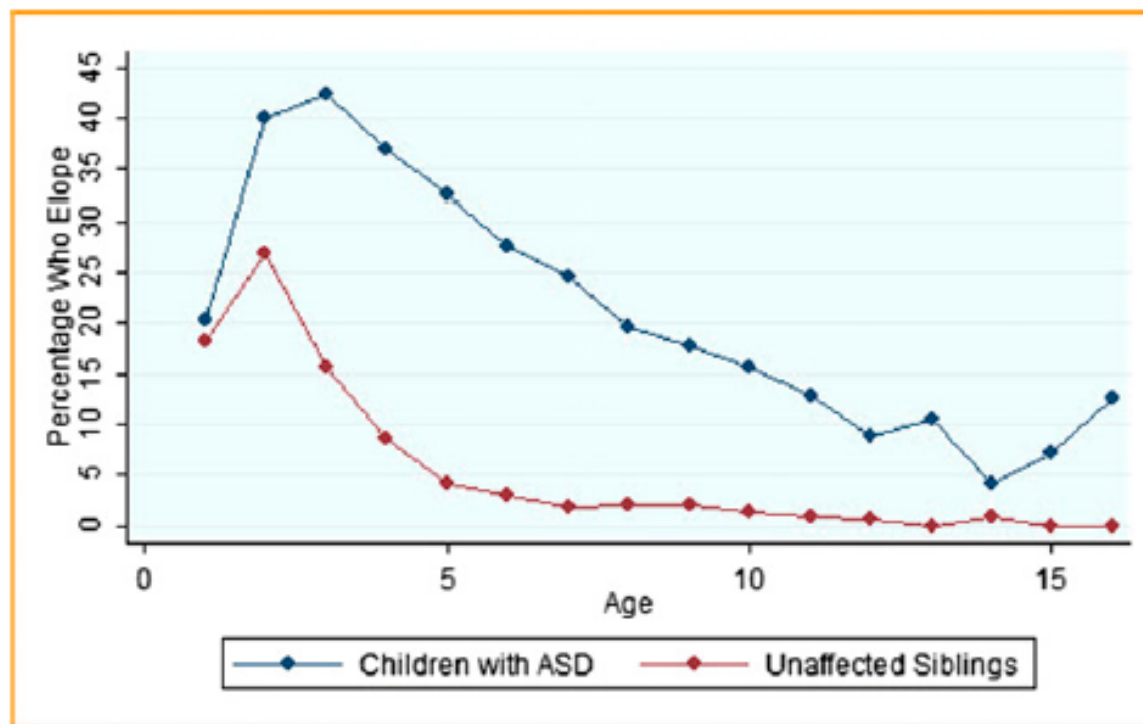


FIGURE 1

Reported rates of elopement at specific ages: a comparison of children with ASD and unaffected siblings. Children with ASD, $n = 901$; unaffected siblings, $n = 1076$.

Image source: Anderson et al. ¹

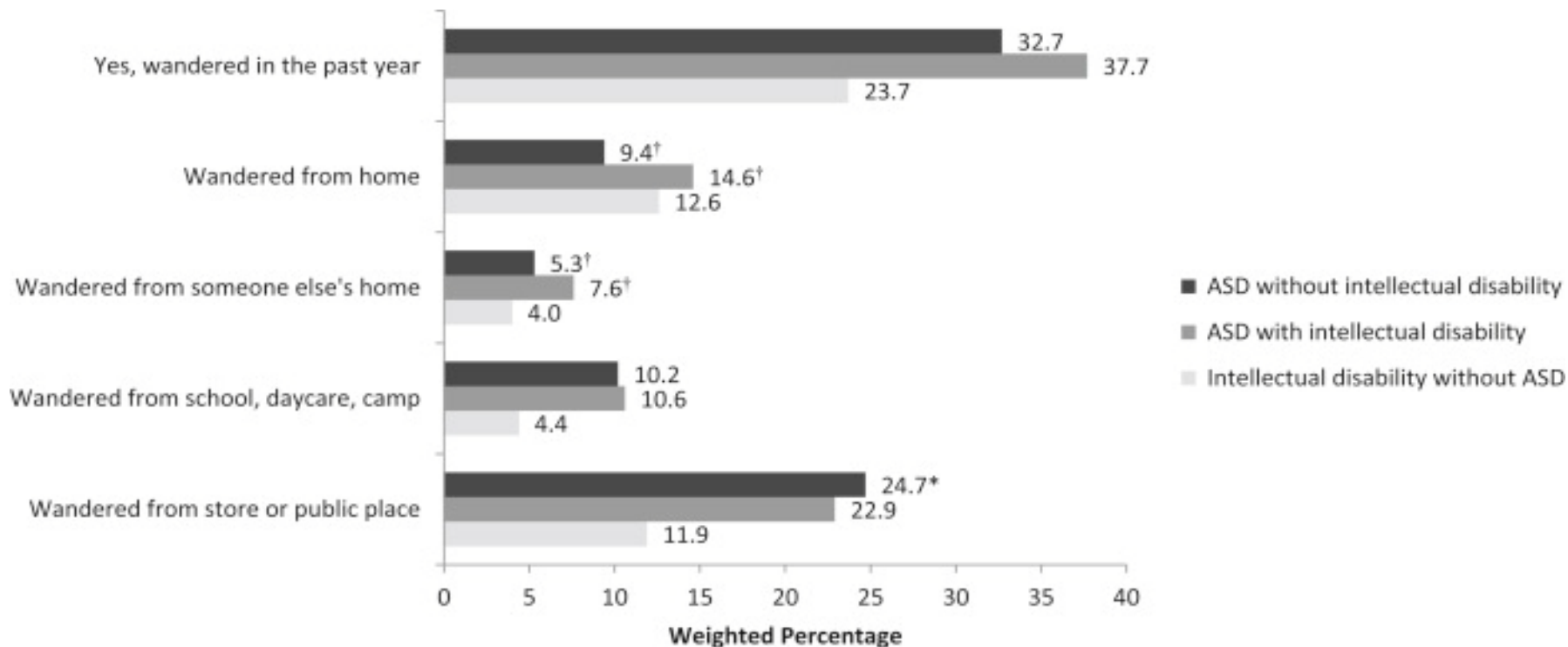
- Of all who attempted, 53% succeeded & missing long enough to cause concern about safety.
- Of those who went missing long enough for concern (26% of total)
 - Police called 31% of the time
 - 65% “close call” with traffic injury
 - 24% “close call” with drowning
- Motivations
 - Parents of children with Asperger’s: need to *escape an anxious situation*
 - Parents of children with autism/PDD-NOS: more likely to simply *run, explore, or head for a favorite place*

Conclusions & Outcomes (2012)

- Wandering common & major concern for families
- Better supports needed
- ICD 9 code for autism wandering achieved
- Research needs:
 - Elucidate whether there are different types of elopement, requiring different prevention strategies.
 - Explore how best to support families
 - Research behavior characterization
 - Developing and refining interventions to address elopement is urgently needed

Reported Wandering Behavior among Children with Autism Spectrum Disorder and/or Intellectual Disability

Rice CE, et. al. J Pediatr. 2016



Reported percent wandering among children with special healthcare needs, by current report of an ASD, with and without intellectual disability and intellectual disability without ASD. *P < .05 for comparison of children with intellectual disability without ASD and children with ASD without intellectual disability. †Estimates have a relative SE 30% or greater and may be unreliable.

Table 7. Preventive Measure Use by Condition Group.

Condition Group	Physical Barriers (% ± SE)	Electronic Measures (% ± SE)	Any Prevention Strategy: Wanderers (% ± SE)	Any Prevention Strategy: Non-Wanderers (% ± SE)	OR (95% CI)
ASD-only	19.4 ± 3.4	2.7 ± 1.3	34.0 ± 7.3	12.8 ± 3.7	3.5 (1.4–8.8)*
ASD + ID/DD	36.9 ± 2.8	3.5 ± 0.8	54.7 ± 5.2	28.5 ± 3.3	3.0 (1.8–5.1)*
ID/DD-only	15.5 ± 2.0	1.5 ± 0.5	45.7 ± 5.9	8.0 ± 1.1	9.6 (5.6–16.6)*

Notes:

*denotes significance. Logistic regression analyses were used to assess the association between elopement history and preventive measure use.

doi:10.1371/journal.pone.0148337.t007

Kiely B, Migdal TR, Vettam S, Adesman A (2016) Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States. PLOS ONE 11(2): e0148337.

<https://doi.org/10.1371/journal.pone.0148337>

<http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0148337>

Elopement Patterns & Caregiver Strategies

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Elopement Prevention Study

- Aim: To report on strategies employed by caregivers of individuals with ASD to prevent elopement behavior, their perceived effectiveness, burden of use, and cost.
- Methods: “Elopement Patterns & Caregiver Strategies Survey”
 - Online survey of parents/caregivers of children with ASD registered in IAN; March - September 2016
 - Inclusion Criteria:
 - Ages 4 to 17+ years
 - Social Communication Quotient score ≥ 12
 - Clinician-confirmed ASD diagnosis
 - Social Responsiveness (SRS) scale completion

Elopement Prevention Study: Definition and Survey Items

- Elopement Behavior (EB): “[Child] tries to leave safe spaces and/or the supervision of caregivers”
 - ASD and other diagnoses
 - Patterns of elopement- past and current
 - Consequences
 - Parental responses
 - Preventive interventions (including medications)
 - Perceived effectiveness
 - Burden of use/side effects
 - Estimated costs

Elopement Prevention Study: Results

- 867 completed; **526** had ongoing preventive interventions and/or elopement behavior
 - Demographics (n = 526)
 - Mean age 10.9 years; Males 83%; White 88%, Non-Hispanic 88%
 - ASD Severity
 - Mean SRS T-score: 90.3
 - Co-occurring diagnoses
 - Intellectual Disability: 16%; Language Disorder: 31%
 - ADHD: 42%; Anxiety Disorder: 38%; Mood Disorder: 10%
 - Clinical Problems
 - Aggression: 20%; Self-Injury: 24%

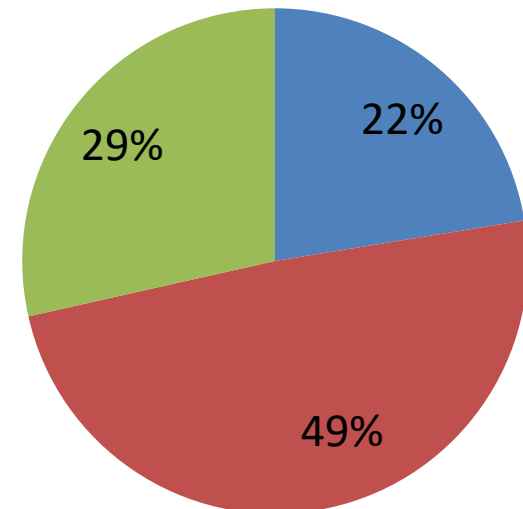
Elopement Prevention Study: Results

Elopement Behavior (EB) Frequency (n = 526)

- No attempts in last 2 years:
118 (22%)
- Low (< 1 attempt/ week):
258 (49%)
- High (≥ 1 attempt/ week):
150 (29%)

Frequency

■ None ■ Low ■ High



Elopement Prevention Study: Patterns

- **Locations:** Home (70%); Stores (47%); Classroom (41%); Transitions (28%)
- **Situations:**
 - **Avoidant/Anxious Situations**
 - Escape anxious situation (43%)
 - Stressful environment (39%)
 - Conflict-laden environment (24%)
 - **Sensory:** Noisy (38%); Uncomfortable sensory experience (34%)
 - **Goal-Directed:** Pursue special interest (27%); Reach play he/she enjoys (18%); Reach favorite food (11%)
 - **Impulsive:** Under-stimulated (27%); “Boring” environment (27%)

Elopement Prevention Study: Environmental Interventions

- 96% use ≥ 1 intervention
 - Environmental (83%)
 - Dead bolts (51%); Latches (49%); Gates (36%)
 - Services/Behavioral (83%)
 - Behavioral psychologist (41%); Social Stories (40%); Aide (39%)
 - Devices:
 - GPS Trackers (19%)
 - Project Lifesaver bracelet (5%)
 - IDs (31%)
 - Bracelet or shoe tag, Medic Alert bracelet

Elopement Prevention Study: Environmental Intervention Effectiveness

Overall effectiveness (“good” or “very good”): 75%

- None: 91%
- Low: 75%
- High: 61%

Mean # interventions tried: 6.1
(± 3.9)

- None: 4.7 (± 3.0)
- Low: 5.9 (± 3.9)
- High: 7.4 (± 4.1)

Two-year Cost (median): <\$1000

- None: <\$500
- Low: <\$1000
- High: \$5000 or more

Burden (“high” or “very high”):
68%

- None: 48%
- Low: 69%
- High: 81%

Elopement Prevention Study: Cost & Burden

- **Good Cost Effectiveness**
 - **Window bars** - 57% effective, 14% burdensome, median cost <\$100
 - **Fencing** - 46% effective, 13% burdensome, median cost <\$500
 - **Project Lifesaver** - 48% effective, 15% burdensome, median cost <\$100
- **Limited Access**
 - **Home Behavioral Specialist** - 35% effective, 15% burdensome, cost \$0 (insurance)
 - **School Aide** - 49% effective, 16% burdensome, cost \$0 (school)
- **Effective But Burdensome/Expensive**
 - **Service Animal** - 53% effective, 33% burdensome, median cost <\$1000
- **Poor Cost Effectiveness**
 - **Security Cameras** - 26% effective, 3% burdensome, median cost <\$500
 - **GPS Trackers** - 15% effective, 29% burdensome, median cost <\$500

Elopement Prevention Study: Medication

- Ever taken psychiatric medication: 48%
- Ever taken any medication for EB: 16%
 - Antipsychotic: 8%
 - ADHD medication: 5%
 - Antidepressant: 4%
 - Benzodiazepine: 2%
 - Mood Stabilizer: 1%
- Most effective (“good” or “very good”) for EB (n ≥10):
 - Lorazepam: 29%
 - Diazepam: 20%
 - Atomoxetine: 19%
 - Melatonin: 18%
 - Lisdexamfetamine: 16%
 - Amphetamine/dextroamphetamine: 16%
 - Escitalopram: 15%

Elopement Prevention Study: Conclusions

- Simple environmental and behavioral interventions are generally rated by caregivers as cost effective and much more effective than medications in reducing elopement.
- Medications are generally perceived as ineffective, with have high rates of side effects

Questions

- For interventions rated as highly effective but less used, what are obstacles to implementation?
 - Cost (e.g. fencing)
 - Availability (e.g. aides, behavioral specialists)
 - Burden/Hassle (e.g. door alarms)
- Do subtypes of elopement require different prevention strategies?

Suicidality in Autism Spectrum Disorders

A National Health Crisis?

Suicidality and ASD Research

- UK: In adults with Asperger's, 66% contemplated suicide (vs. 17% general population; 35% planned or attempted (Cassidy 2014);
 - Greater risk in women, while opposite in general population
- Sweden: Higher mortality rates in ASD vs. general population (1987-2009); suicide leading cause of premature death (Hirvikoski 2016)
- US: “Assessment of Suicide Risk in Children & Adolescents with ASD Presenting to a Pediatric ED” (Vasa IMFAR 2017)
 - **31 of 104** with ASD screened positive suicide risk (ASQ)
 - 65% uniquely identified as experiencing suicidal ideation
 - 12 suicide attempts: stabbing/cutting (5), jumping from a height (2), choking/holding breath/hanging (3), overdose (1), firearms (1)

IAN Mental Health & Suicidal Behaviors Questionnaire

- Aim: To establish a clearer understanding of the prevalence of suicidal behaviors and related factors in children and dependent adults with ASD
- Parent-report for:
 - Children ages 8-17
 - Dependent Adults
- Distributed online through the Interactive Autism Network (IAN)
 - 55,000 participants
 - 14,500 children; 7,500 adults
 - Data collected on this questionnaire can be linked to other IAN data

Mental Health & Suicidal Behaviors Questionnaire Layout

1. Child/Dependent Adult Mental Health History
2. Child/Dependent Adult Life Events
3. Child/Dependent Adult Suicidal Behaviors
4. Sibling Mental Health History
5. Parent Mental Health History
6. Extended Family Mental Health History
7. Demographic Information

Mental Health & Suicidal Behaviors Questionnaire

- Child/Dependent Adult Suicidal Behaviors
 - Verbal ability
 - Ideation
 - “Has |display name| ever expressed any thoughts or feelings about *wanting to die or not wanting to live anymore?*”
 - “Has |display name| ever expressed any thoughts or feelings about *wanting to end his/her life?*”
 - “Has |display name| ever indicated that he/she *had a plan* to end his/her life?”
 - Attempt
 - “Has |display name| ever *tried to end* his/her life?”
 - Follow-up questions:
 - Past 12 months
 - Age
 - Method
 - Treatment-seeking/Hospitalization
 - Satisfaction with treatment
 - Medication use six weeks prior

QUESTIONS?

Linking the autism community and researchers



share. research. discover.

Committee Discussion of Wandering Presentations

Break

Meeting of the IACC

Morning Agenda – continued

11:00 Committee Business

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary, IACC

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

Director, NIMH and Chair, IACC

12:00 Lunch

IACC Committee Business

IACC Full Committee Meeting
July 26, 2017



Susan A. Daniels, Ph.D.

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

Thanks to OARC Staff



- **Susan Daniels, Ph.D.**, Director
 - **Oni Celestin, Ph.D.**, Science Policy Analyst
 - **Jamie Kleiner**, Science Policy Intern
- **Rebecca Martin, M.P.H.**, Public Health Analyst
- **Angelice Mitrakas, B.A.**, Management Analyst
- **Karen Mowrer, Ph.D.**, Science Policy Analyst
- **Julianna Rava, M.P.H.**, Science Policy Analyst
- **Jeff Wiegand, B.S.**, Web Development Manager

New OARC Newsletter



OFFICE OF AUTISM RESEARCH COORDINATION NATIONAL INSTITUTES OF HEALTH

We are pleased to introduce OARC's new quarterly newsletter! This newsletter will share the latest updates on meetings, news, and new publications. We hope you enjoy it and welcome your [feedback](#).

Autism Meetings & Events



IACC Full Committee Meeting

July 26, 2017

The agenda for the upcoming meeting includes presentations on wandering by the National Autism Association and the Interactive Autism Network, an update from Madison House Autism Foundation on their new initiative, Autism After 21 (check out #Imagine21 on social media!), a discussion of the [2016-2017 IACC Strategic Plan](#), and more.

Past Meeting Highlights



IMFAR: OARC and IACC Members in Action

May 10-13, 2017

IMFAR, the annual conference of the International Society for Autism Research (INSAR), took place this year in San Francisco, CA in May. Exciting science advances were shared, and several IACC members and the OARC team participated. Over the summer, INSAR is hosting a [free webinar series](#) to share autism science updates from top researchers.



IACC Full Committee Meeting Highlight

April 26, 2017

Check out the recent IACC Meeting presentation (minute mark 12:50) by Member of Parliament from Canada, Mike Lake, a father of a young adult son on the autism spectrum and dedicated advocate for people with disabilities.



As One Screening

April 25, 2017

In April NIMH and OARC hosted a [screening](#) of the documentary *As One: The Autism Project* for Autism Awareness Month. The film shows the struggles and triumphs of ten children with autism and their families who

- Quarterly, before IACC meeting
- Highlights work of IACC and partners
- Provides latest autism news and publications
- Future editions will include exclusive features, such as videos and interviews

Feedback welcome!

Upcoming Event: Autism in Girls and Women Seminar



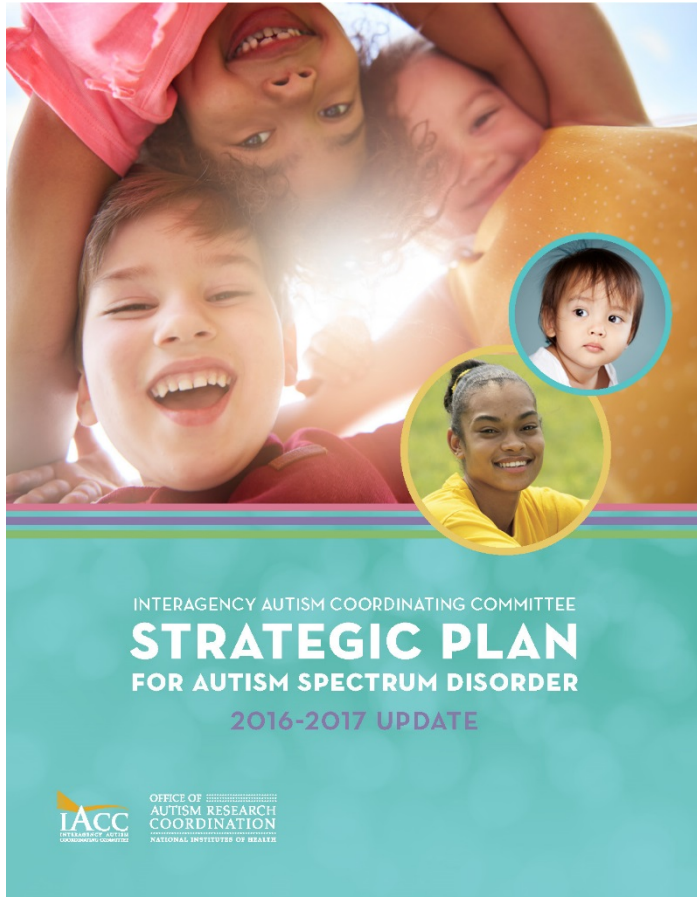
- Joint seminar sponsored by OARC and the NIMH Office for Research on Disparities and Global Mental Health
- Tentative date: September 19, 2017
- Place: NIMH Neuroscience Center, Rockville, MD and webcast
- Panel discussion on issues related to autism in women and girls
 - Underlying biology of ASD in girls – **Dr. Kevin Pelphrey**, George Washington University
 - Clinical phenotype of ASD in girls – **Dr. Pamela Ventola**, Yale Child Study Center
 - Social Context of ASD in girls – **Ms. Zoe Gross**, Autistic Self Advocacy Network
- More information will be posted on the IACC website:
www.iacc.hhs.gov

IACC Portfolio Analysis Update



- Preparation of the 2014-2015 IACC ASD Research Portfolio Analysis Report is underway – expected publication in 2017
- Preparation of the data call for 2016 data set is underway
- **Request:** 3-4 IACC members to serve as volunteer consultants on issues such as addition of new funders

2016-2017 IACC Strategic Plan



- The IACC Strategic Plan (SP) provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.
- The IACC SP is organized around 7 consumer-based questions.
- The first IACC SP was developed in 2009 and focused on research efforts.
- Under the Autism CARES Act, the new IACC Strategic Plan will address both research and services activities.

2016-17 IACC Strategic Plan Status



- ✓ The IACC formed 7 Working Groups to address the 7 chapters of the Strategic Plan.
- ✓ Drafts of the 7 chapters have been completed by the Working Groups and reviewed by the committee
- ✓ OARC staff has edited the 7 chapters and prepared other Strategic Plan sections

Today's goal:

- **IACC will review and approve the 2016-17 Strategic Plan**

2016-17 IACC Strategic Plan Sections



- Introduction
- Vision, Mission, and Core Values Statement
- Overview of ASD Research Funding Progress
- Question 1: Screening and Diagnosis
- Question 2: Underlying Biology of ASD
- Question 3: Risk Factors
- Question 4: Interventions
- Question 5: Services
- Question 6: Lifespan
- Question 7: Infrastructure, Surveillance, Workforce, Outreach
- Duplication of Effort Statement
- Budget Recommendation
- Conclusion



Introduction

Vision, Mission, and Core Values Statement



Vision Statement

The Strategic Plan will accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan. The Plan will provide a blueprint for ASD research and services efforts, engaging the participation and input of government agencies, private organizations, and the broader autism community.

Mission Statement

The purpose of the Strategic Plan is to focus, coordinate, and accelerate innovative research and foster development of high-quality services in partnership with stakeholders to address the urgent questions and needs of people on the autism spectrum and their families.

Vision, Mission, and Core Values Statement



Core Values

- **Sense of Urgency:** We will focus on what steps we can take to respond rapidly and efficiently to the needs and challenges of people and families affected by ASD.
- **Excellence:** We will pursue innovative scientific research of the highest quality and development and dissemination of evidence based services and practices to maximize the quality of life for people on the autism spectrum.
- **Spirit of Collaboration:** We will treat others with respect, listen to diverse views with open minds, thoughtfully consider public input, and foster discussions where participants can comfortably offer opposing opinions.

Vision, Mission, and Core Values Statement



Core Values

- **Consumer Focus:** We will focus on making a difference in the lives of people affected by ASD, including people with ASD, their families, medical practitioners, educators, and scientists. It is important to consider the impact of research on the human rights, dignity, and quality of life of people with ASD, from prenatal development forward.
- **Partnerships in Action:** We will value cross-disciplinary approaches, data sharing, teamwork, and partnerships to advance ASD research and service activities.
- **Equity:** We will prioritize improved access to detection, intervention, and other services and supports for individuals with ASD, and commit to the goal of reducing disparities across the lifespan, spectrum of ability and disability, sex and gender, racial and cultural boundaries, socioeconomic status, and geographic location to improve the health and quality of life of all individuals with ASD.



Overview of ASD Research Funding Progress

Question 1: Screening and Diagnosis



How can I recognize the signs of ASD, and why is early detection so important?

Objective 1: Strengthen the evidence base for the benefits of early detection of ASD.

- Implement innovative designs to evaluate the benefit of universal screening for ASD, including research that addresses the specific research gaps noted by the USPSTF report.
- Ensure that studies take into account differences and needs of special populations such as girls and intellectually delayed individuals

Question 1: Screening and Diagnosis



Objective 2: Reduce disparities in early detection and access to services

- Improve family engagement and help build an awareness of healthy developmental milestones and warning signs of concern.
- Demonstrate the validity of different screening and diagnostic tools for culturally-diverse communities.
- Increase services in high poverty and under-served regions; improve inclusion of these populations in research.
- Address differences in state policy requirements for Medicaid and the requirement of a diagnosis to receive services.
- Develop a culturally competent and more culturally diverse workforce.

Question 1: Screening and Diagnosis



Objective 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.

- Continue research on the potential translation of biomarker findings into feasible and valid screening or diagnostic tools.
- Increase coordination and personalization of screening, diagnosis and early intervention services through use of the medical home model, person centered planning, or other service models.
- Conduct research to better understand and develop strategies to address reasons for lack of compliance with screening recommendations; address barriers to universal screening.
- Analyze the impact of insurance reform and national policy on coverage for screening, diagnosis and intervention for children with ASD and their families.
- Evaluate innovative service delivery methods (e.g., use of technology) to improve detection methods and increase access.

Question 2: Biology



What is the biology underlying ASD?

Objective 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.

- Identify one or more neural circuits that are impaired in significant groups of ASD individuals.
- Understand the role of the immune system and metabolic processes in ASD, including aspects such as the fever effect.
- Identify quantitative and reproducible biomarkers or behavioral monitors for ASD of use for assessing effectiveness of future therapeutic or behavioral intervention trials.

Question 2: Biology



Objective 2: Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.

- Determine the relationship between seizures and ASD.
- Determine the impact of GI dysfunction on ASD related behaviors and cognitive performance.
- Determine the impact of sleep disorders on ASD related behaviors and cognitive performance.
- Determine the relationship of co-occurring psychiatric disorders to ASD and their impact of co- on the health and well-being of people with ASD.

Question 2: Biology



Objective 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.

- Support creation of large cohorts, characterized both phenotypically and genetically with complete health records from early embryogenesis through adulthood.

Question 2: Biology



Proposed 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.

- Conduct research on the underlying biology of ASD in girls/women (differences in brain structure, function, physiology) and how this may create differences in phenotype.
- Identify risk and resilience factors that contribute to sex differences.
- Develop, adapt or validate screening and diagnostic tools to detect ASD in girls.
- Develop strategies to meet the intervention, service and support needs of girls/women with ASD.

Question 3: Risk Factors



What causes ASD, and can disabling aspects of ASD be prevented or preempted?

Objective 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 comorbidities in ASD.

- Understand the contribution of regulatory and other genomic regions to ASD risk. Whole genome sequencing will begin to illuminate the role of non-gene coding regions of the genome.
- Identify additional autism risk genes but also contribute to an understanding of the common variant patterns that enable expression of the mutations.
- Understand the causal relationship between identified ASD risk genes and clinical outcomes so that guidelines for genetic counseling can be illuminated. Understand parental concerns and attitudes when communicating complex genetic information.

Question 3: Risk Factors



Objective 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 comorbidities in ASD.

- Understand the timing of exposures relative to the cascade of events that unfold during brain development to identify and understand the molecular basis of exposure-associated ASD risk.
- Conduct multiple studies in different populations and settings, with high quality measures of exposure and adequate controls, to reconcile disparate findings and establish robust linkages of environmental exposure to ASD risk.
- Refine more targeted, conventional exposure assessment tools to characterize the exposome.

Question 3: Risk Factors



Objective 3: Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.

- Develop low-burden exposure measures that can be incorporated in large-scale genetic studies, perhaps leveraging innovations in exposomics or epigenomics.
- Move beyond identification of genetic and environmental risk factors to reveal functional biological consequences associated with these risk factors.
- Integrate methylation, exposure, and phenotype data in the same population.

Question 4: Treatments and Interventions



Which treatments and interventions will help?

Objective 1: Develop and improve pharmacological and medical interventions to address both core symptoms and comorbidities in ASD.

- Identify biomarkers that can help inform decisions about appropriate interventions and provide objective assessments of treatment response.
- Recruit more individuals for clinical trials testing pharmacological treatments for ASD.

Question 4: Treatments and Interventions



Objective 2: Create and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and comorbidities in ASD.

- Identify “active ingredients” of interventions in order to ensure sustained responses to treatments.
- Adapt interventions so that they can be deployed in a range of community settings.

Question 4: Treatments and Interventions



Objective 3: Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

- Develop tools allowing individuals with ASD to track and direct their own treatment.
- Develop technology-based interventions that help people with ASD improve their social and communication skills, increase their independence, and in many other ways help improve their quality of their lives.
- Increase access to interventions by developing technology-based treatments that can be deployed outside of primary care or clinical settings.

Question 5: Services



What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?

Objective 1: Scale up and implement evidence-based interventions in community settings.

- Identify best practices, including systematic evidence-based collaborative approaches, to scale up existing services and increase access to evidence-based interventions in communities.
- Test and implement cost-effective healthcare services that increase the supply of care
- Develop approaches that scale up the use of evidence-based practices in the educational setting that address the gaps between research and practice
- Funding for provider training is a part of Question 7 Objective 2, but is cross-referenced here because successfully growing the service workforce is necessary to achieve this objective to successfully scale-up and delivery of evidence-based ASD interventions.

Question 5: Services



Objective 2: Reduce disparities in access and outcomes for underserved populations.

- Support research to understand and develop strategies to address health disparities, health inequity, and disparities in services access and utilization for underserved populations. Underserved communities include families with low socio-economic resources, youth and adults with severe intellectual impairment, those who are racial/ethnic minorities, and women.
- Develop culturally competent service provision strategies, improve the quality of care and perception of quality of care to encourage utilization, and increase family centered care as well as other best practices to reduce disparities.

Question 5: Services



Objective 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.

- Develop better metrics and measurement tools for health outcomes for people with ASD across the lifespan should be properly investigated and documented.
- Develop, test, and implement metrics and measurements for ASD services, as well as federal, state and local programs.
- Quantify outcomes in order to inform effective service models.
- Continue research into determinants of service quality, including accessibility, continuity and flexibility of services.

Question 6: Lifespan Issues



How can we meet the needs of people with ASD as they progress into and through adulthood?

Objective 1: Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.

- Use population-level data to understand unmet needs, disparities in access and outcomes, emerging usage trends, cost issues and the effectiveness of services in achieving their desired outcomes.
- Conduct research to determine the prevalence of autism in adults and the scope and distribution of service needs among the population to inform policy and program planning.
- Develop strategies for reducing socio-economic or racial/ethnic disparities in service access and related outcomes for adults with ASD.
- Investigate social capital, the network of supports, and community integration provided by families, service providers, and others to understand the range of formal and informal supports needed to achieve successful adult outcomes.
- Develop additional service coordination across agencies (e.g. educational and vocational rehabilitation; mental health and vocational rehabilitation).

Question 6: Lifespan Issues



Objective 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.

- Conduct large-scale longitudinal studies across adulthood into older age to examine trajectories of physical and mental health conditions, and address the additive and interactive effects of biological, cognitive, behavioral, and environmental factors that lead to co-occurring conditions.
- Conduct studies of approaches to treatments to reduce mental health conditions, including anxiety, depression, and/or suicidality.
- Engage adults on the autism spectrum and their families, through collaborative and participatory research, to be involved in the development of ecologically valid measures of quality of life, which can be used to understand the factors associated with positive quality of life throughout adulthood.
- Create programs to recruit and train more general physical and mental health providers to be knowledgeable about and willing to treat adults with ASD. This applies to primary care providers, community mental health providers as well as specialists.

Question 6: Lifespan Issues



Objective 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.

- Examine factors and support strategies that promote successful participation and retention in post-secondary education, employment, and/or community living activities across the spectrum of ASD and across the adult lifespan.
- Develop reliable outcome measures that take into account the desires of the individual and his/her family, as well as the match of the activity with the interests, skills, and abilities of the adult.
- Conduct long-term follow-up studies examining the effects of interventions and services delivered in childhood on later adult outcomes.
- Conduct large-scale studies of programs to improve the skills that may underlie many aspects of community integration (e.g., adaptive behavior, executive function)
- Better understand the needs of adult service providers, as well as the characteristics of effective providers.
- Encourage more skilled workers to enter and remain in the adult disability service provider field, which is critical to improving self-determination of adults with ASD.

Question 7: Infrastructure



How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the ASD community?

Objective 1: Promote growth, integration, and coordination of biorepository infrastructure.

- Promote biological sample donation to ensure that demand for research studies is met.
- Develop and expand programs and outreach campaigns to encourage families from diverse backgrounds to participate in ASD research, join registries and donate biological samples.
- Create incentives to encourage standardization and sample sharing across data and biorepository banks.

Question 7: Infrastructure



Objective 2: Develop, enhance and link data repositories.

- Adopt a de-identified research participant/subject identifier, such as the GUID, across all research initiatives in order to reduce the likelihood of sample duplication.
- Use common data definitions in order to standardize data collection, and responsibly share all the data supporting any findings when those findings are announced.

Question 7: Infrastructure



Objective 3: Expand and enhance the research and services workforce and accelerate the pipeline from research to practice.

- Expand and enhance programs that provide funds to train current and future researchers on innovative research techniques.
- Provide service providers with training in evidence-based ASD services across multiple settings from clinics to communities.
- Develop programs to translate and disseminate ASD research findings into actionable recommendations and real-world practice.

Question 7: Infrastructure



Objective 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.

- Expand surveillance efforts to include the adult population in order to gain a better understanding of needs and concerns over the lifespan.
- Expand surveillance efforts to collect more descriptive data regarding co-occurring conditions, including cognitive disability, seizure disorders, anxiety and depression to increase understanding of the prevalence of these conditions in the ASD population.



Duplication of Effort Statement



ASD Research Budget Recommendation

Lost Potential Due to Autism



Autism is a lifelong condition:

- **Lifetime cost** for an individual with autism including what was spent and productivity loss across the family was estimated at **\$2.4 million** when involving intellectual disability, and **\$1.4 million** when it does not.
- Another study estimated the additional costs of healthcare, education, therapy, services, and caregiver time associated with caring for a child with ASD aged 3 to 17 years is about **\$17,000 per year**.
- The estimated annual cost of ASD, including combined medical, non-medical, and lost productivity costs, was in the range of **\$162-\$367 billion**, or 0.89-2.0% of the U.S. gross domestic product.
- IACC portfolio data showed total 2015 autism research funding from major government and non-government funders was **\$343 million**: 0.09-0.21% of the estimated total annual cost of autism.

Lost Potential Due to Autism

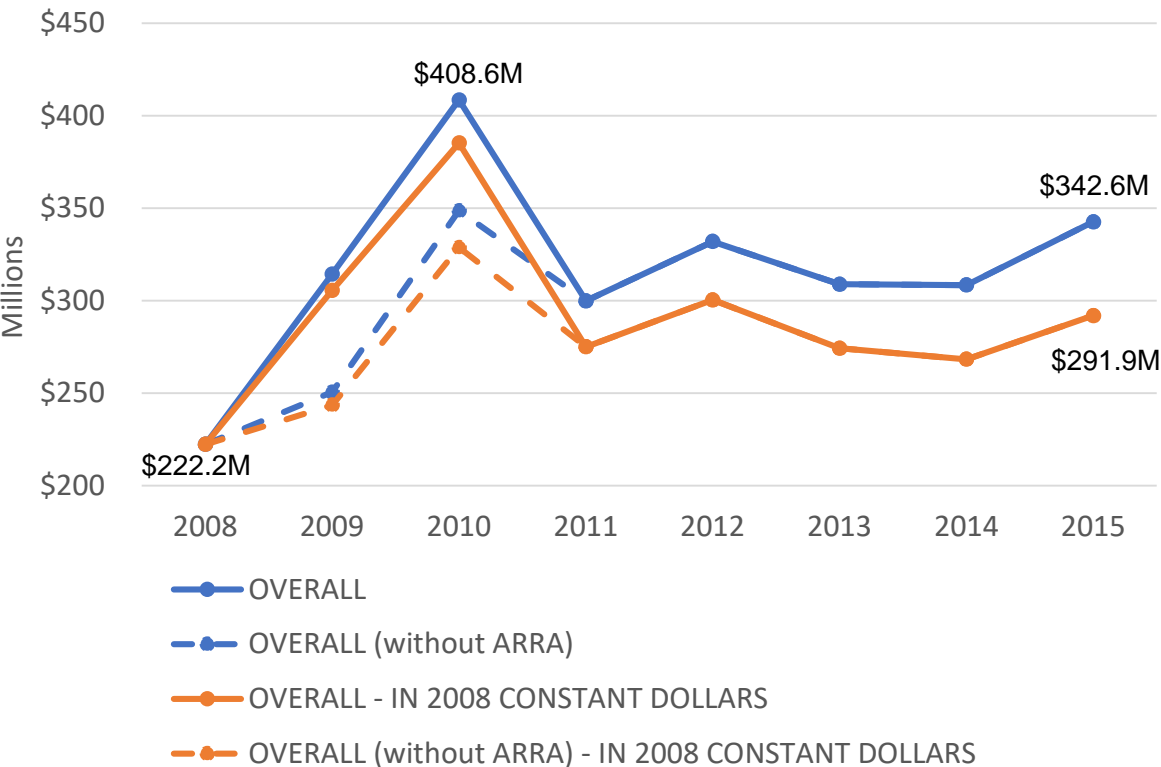


- Four of every ten youth with autism do not transition into a job in the first years after high school and those with jobs tend to work part-time in low-wage jobs.
- Research to better understand the nature of ASD and the needs of children, adolescents and adults on the autism spectrum is important to help build the evidence base for efficacious and cost-effective strategies to address the complex challenges associated with ASD.
- Studies suggest that the costs of research and services that enable delivery of effective early intensive behavioral interventions in childhood can result in cost savings over the lifespan by reducing the need for costly long-term care and support. This suggests that investment in research to improve early detection and intervention could reduce long-term service costs.
- It is likely that more investment in research to improve adolescent and adult services and supports would improve the economic productivity of individuals over their entire lifetime, while also improving their sense of purpose and quality of life.

Autism Research Funding Trends



Overall (Federal + Private) ASD Research Funding Trends
Actual vs. 2008 Constant Dollars



Inflation rate source:

https://officeofbudget.od.nih.gov/pdfs/FY18/BRDPI%20Table%20FY%201950%20to%202022_Jan%202017.pdf

- Combined federal and private autism research funding was 54% higher in 2015 compared to 2008, an annual growth rate of 7.7%.
- When adjusted for inflation by using constant 2008 dollars, the growth in the combined federal and private autism research budget from 2008 to 2015 was 31%, an annual growth rate of 4.5%.
- The highest annual percentage increase was 41% between 2008 and 2009 (including ARRA funding).
- The highest combined budget was \$408.6 million in 2010 (including ARRA funding).

2016-17 IACC Strategic Plan Objectives



Q1: Strengthen the evidence base for benefits of screening; reduce disparities; improve tools, access, and service delivery models

Q2: Advance research on development and neurobiology of autism; understand biology of co-occurring conditions; undertake longitudinal studies that cover the full lifespan

Q3: Continue to identify genetic risk and resilience factors; advance research on environmental risk and resilience factors; understand how genetic and environmental factors interact

Q4: Develop medical and pharmacological interventions; improve psychosocial and naturalistic interventions; advance technological interventions

Q5: Scale up evidence based interventions; reduce disparities in access and outcomes; improve service models

Q6: Develop and coordinate transition services; reduce comorbid conditions and premature mortality; promote acceptance, accommodation, inclusion, independence, and integration

Q7: Encourage tissue donation, data standardization, and data sharing; train researchers and service providers; expand surveillance to cover adults and comorbid conditions

Cross-cutting: Expand research to understand autism in girls to ensure we are meeting the needs of this population.

Potential Rationales for Overall Budget Recommendation



Propose an overall (federal + private) ASD research budget, with a justification, considering historical funding trends.

Option 1: Maintain a Steady Rate of Growth in Research Budget

Extrapolate annual rate of growth to 2020 or another target year in the future

Option 2: Recoup Dollars Lost to Inflation Since 2008

Adjust for the loss of purchasing power due to inflation

Option 3: Return to the Historical High of 2010

Identify a target date/timeframe for returning to the 2010 peak funding level

Option 4: Significantly Grow the Autism Research Budget

Identify a target date/timeframe for doubling the 2015 overall budget level

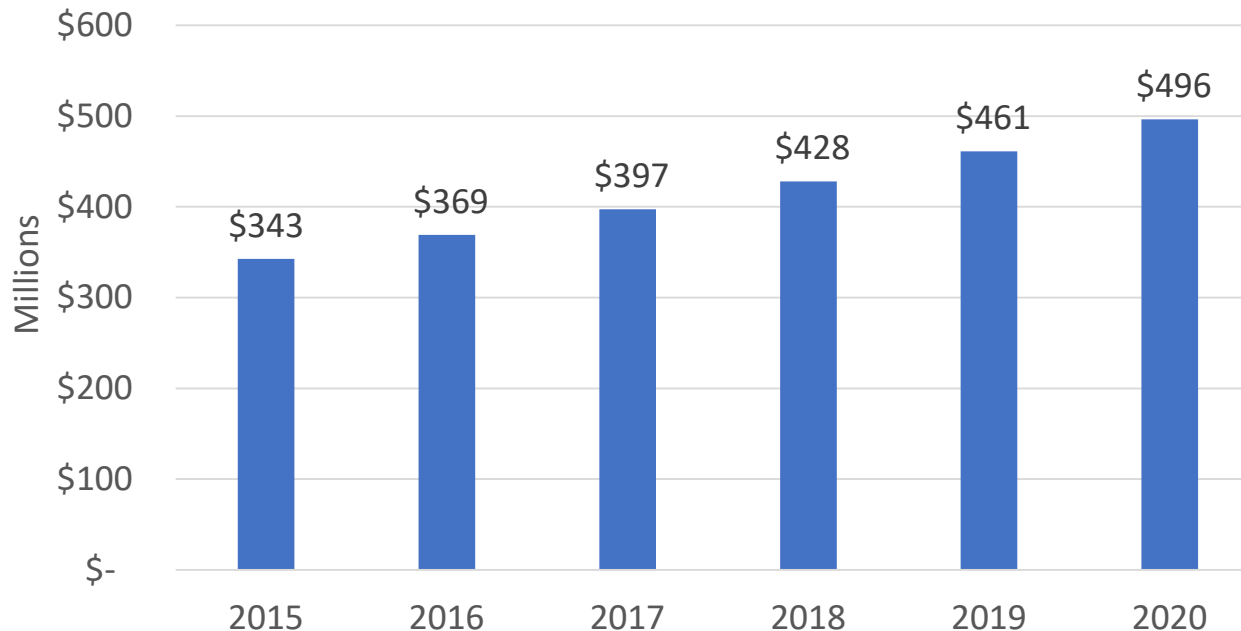
Option 1: Maintain a Steady Rate of Growth in Research Budget



Extrapolate annual rate of growth to 2020 or another target year in the future

Projected Overall (Federal + Private) Autism Research Budget Levels

Based on Continued 7.7% Annual Growth Rate Until 2020



All funding levels are in actual dollars and do not account for future inflation

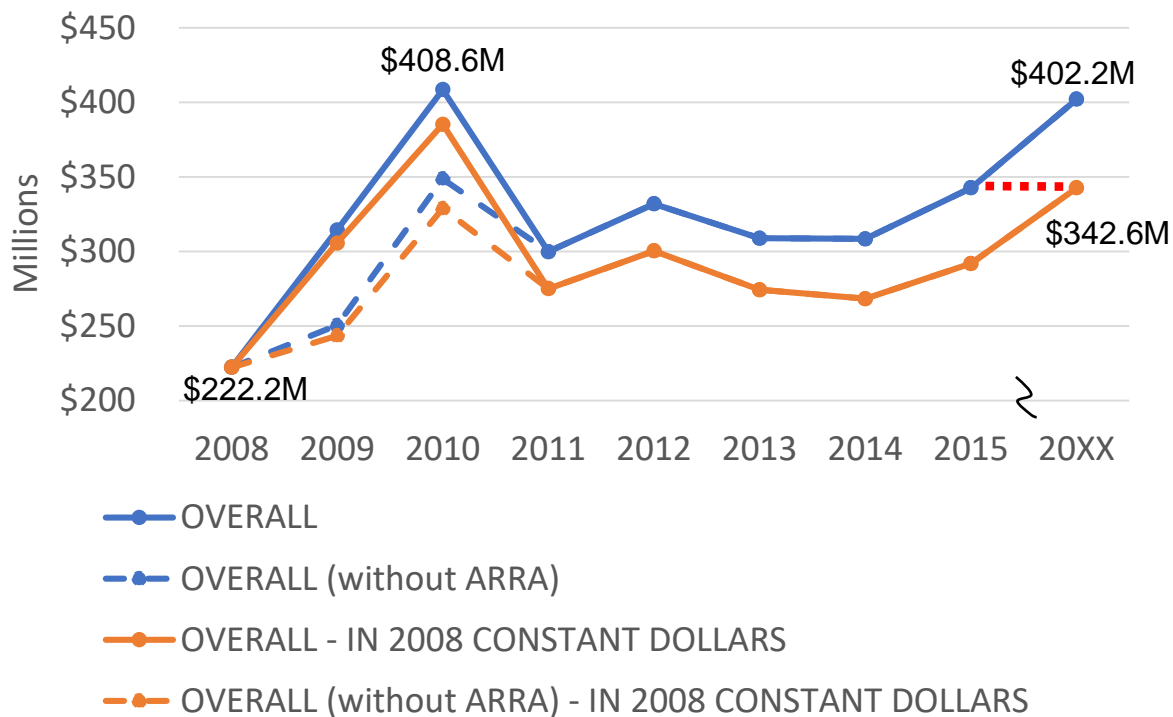
Option 2: Recoup Dollars Lost to Inflation Since 2008



Adjust for the loss of purchasing power due to inflation

Overall (Federal + Private) ASD Research Funding
Trend

Actual vs. 2008 Constant Dollars



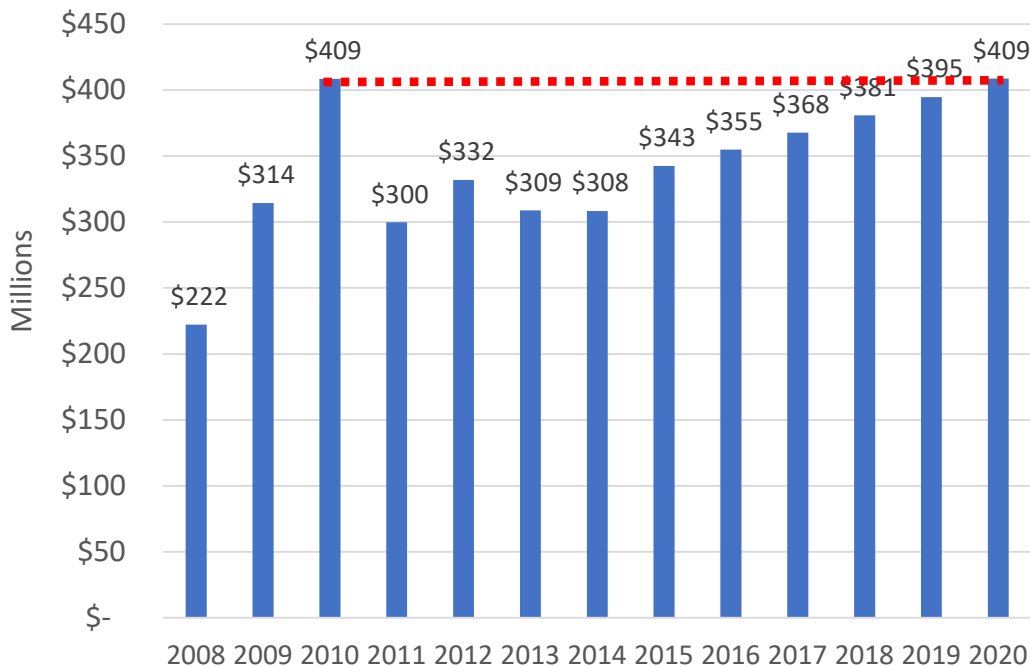
- To negate the loss of purchasing power at the 2015 funding level, a funding level of about \$402 million would be equivalent to \$343 million in 2008 constant dollars.

Option 3: Return to the Historical High of 2010



Identify a target date/timeframe for returning to the 2010 peak funding level

Returning Overall (Federal + Private) Autism Research Budget to 2010 level by 2020
With Increase of 3.6% Per Year Starting in 2016



Examples of Science Advances Enabled by 2009-2010 ARRA Investment

- Brain imaging technology to distinguish between individuals with ASD and those serving as controls.
- An accurate method to assess the risk of ASD in infancy through the analysis of older affected siblings as predictors of ASD recurrence.
- The JobTIPS website to provide young people with ASD and their families with helpful tips and information on developing job skills.

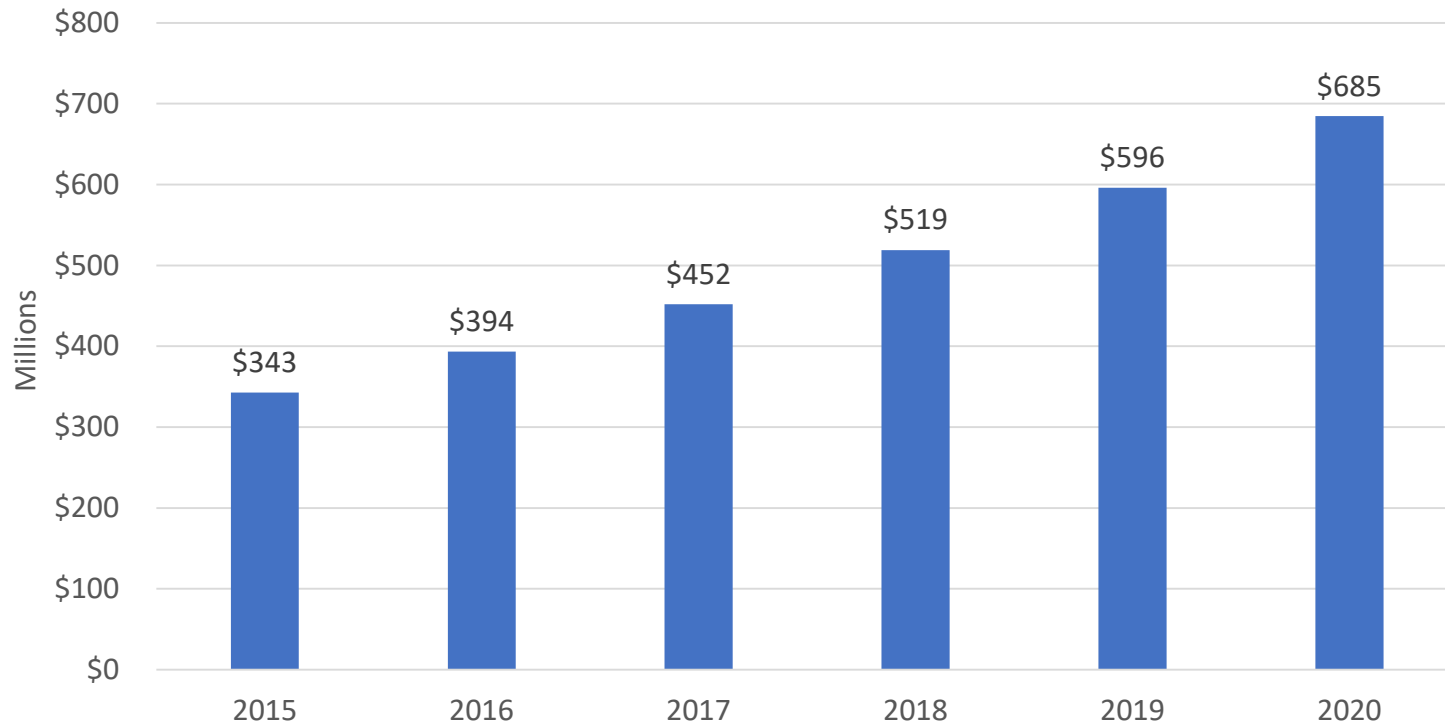
All funding levels are in actual dollars and do not account for future inflation

Option 4: Significantly Grow the Autism Research Budget



Identify a target date/timeframe for doubling the 2015 overall budget level

Doubling of 2015 Overall (Federal + Private) Autism Research Budget by 2020
With Increase of 14.85% Per Year



All funding levels are in actual dollars and do not account for future inflation

Budget Recommendation Discussion



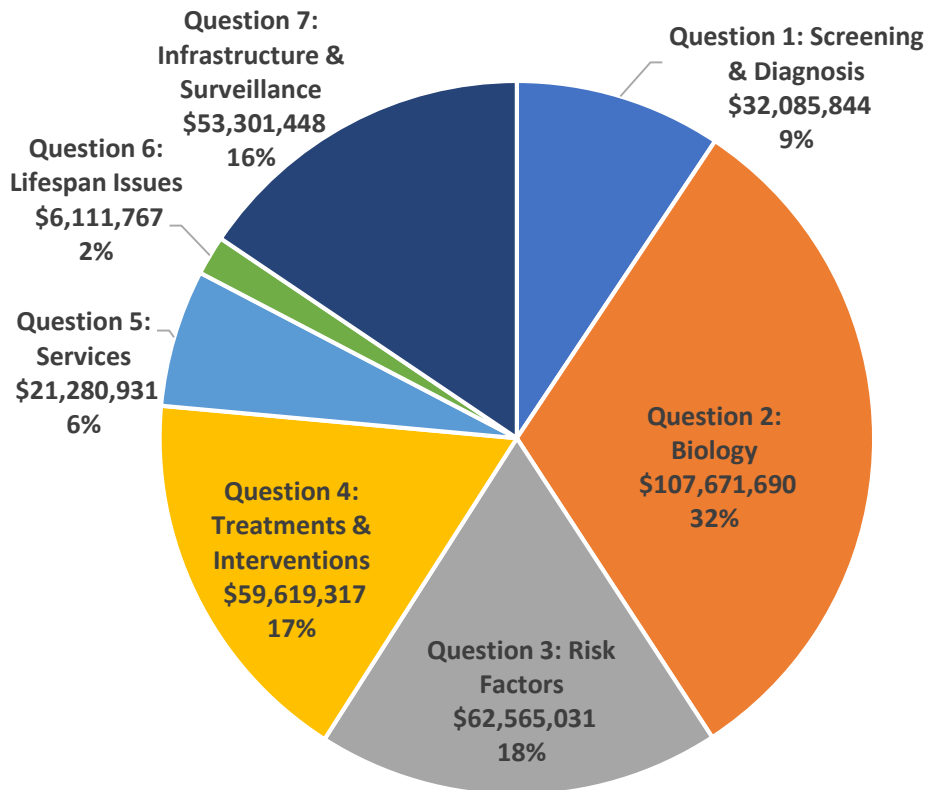
- Which of the options or methods does the IACC want to use to develop the budget recommendation?
- To what target date and/or timeline does the IACC want to apply the budget recommendation?

Considering Portfolio Balance



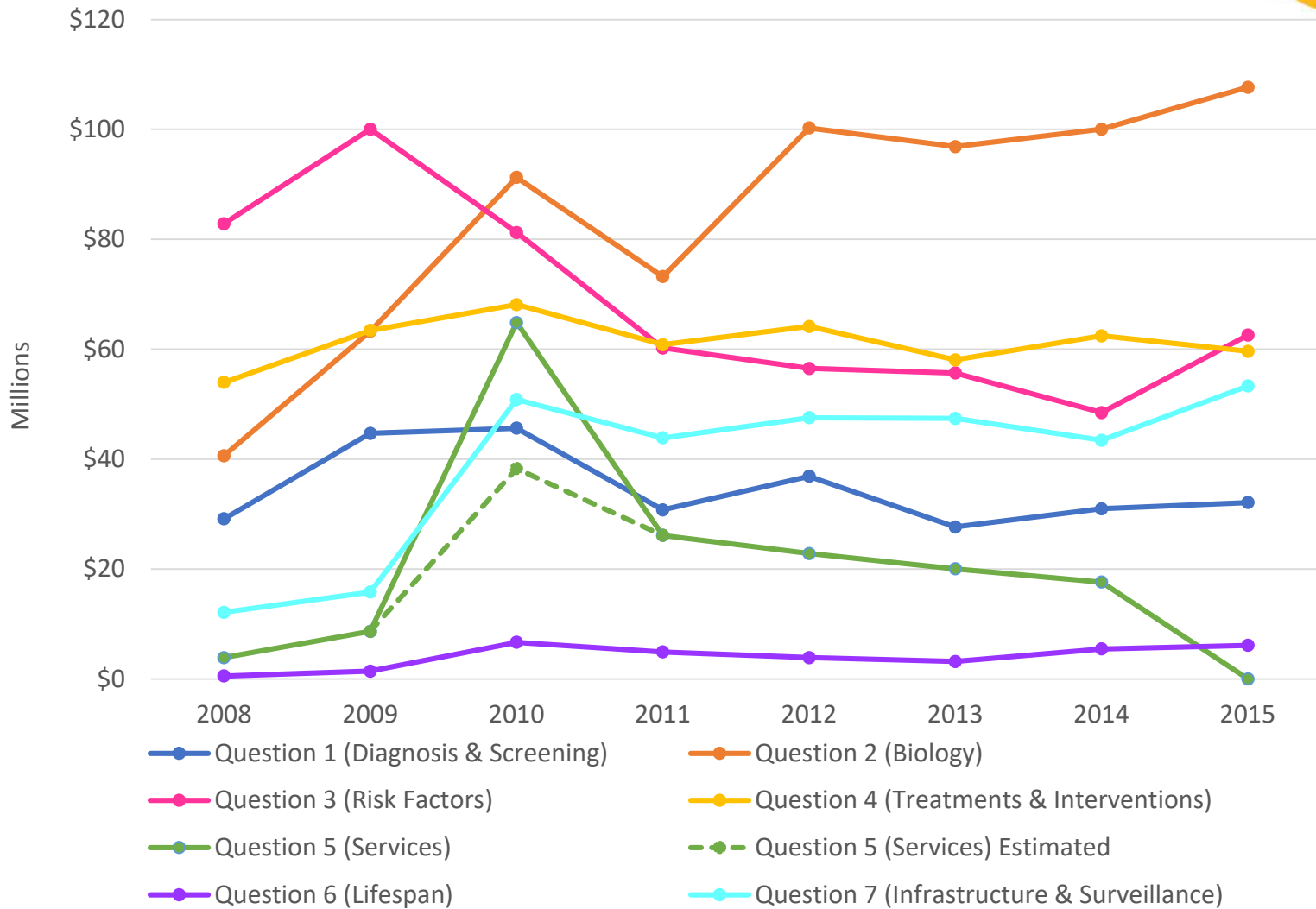
2015 ASD Research Combined Federal and Private Funding by IACC Strategic Plan Question

Total Funding: \$342, 636, 029



- Is this the appropriate balance of funding across SP questions? If not, what should it be?
- Should any additional funds that become available be distributed across the questions with the goal of shifting the balance?
- In 5 years, what should the distribution among Question areas look like?

2008-2015 ASD Research Funding by Strategic Plan Question





Conclusion

2016-17 IACC Strategic Plan



Any other comments?

Written comments due to OARC by
Friday, August 4, 2017

IACC Working Groups



- In 2016, the IACC agreed to form three working groups (WGs) on the following topics:
 - Housing
 - Safety
 - Improving Health Outcomes (including co-occurring conditions/mental health)
- The IACC also agreed to convene these WGs after the completion of the Strategic Plan.
- OARC will be sending a request for WG member nominations and begin arranging WG meetings this fall (some members have already volunteered to participate).

Lunch

Meeting of the IACC

Afternoon Agenda

1:00 **Public Comment Session**

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Karen Mowrer, Ph.D.
Science Policy Analyst, NIMH

Meeting of the IACC

Afternoon Agenda

2:15

Autism After 21

Madison House Autism Foundation

JaLynn Prince

President and Founder

Adrienne McBride

Executive Director

Desiree Kameka

Director of Community Education &
Advocacy

Meeting of the IACC

Afternoon Agenda

2:45 **Committee Discussion**

3:15 **Afternoon Break**

3:30 **Summary of Advances Discussion**

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary,

IACC

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

Director, NIMH and Chair, IACC

Meeting of the IACC

Afternoon Agenda

4:00 Round Robin

5:00 Closing Remarks and Adjournment

Meeting of the IACC

Public Comments Session

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

Autism After 21

Madison House Autism Foundation

JaLynn Prince

President and Founder

Adrienne McBride

Executive Director

Desiree Kameka

Director of Community Education & Advocacy



Autism After 21

Presentation to IACC

July 26, 2017

JaLynn Prince, President/Founder
Adrienne McBride, Executive Director
Desiree Kameka, Housing Director



SCOPE

It is estimated that there are at least 2 million adults in the US who are on the autism spectrum

Over 50,000 individuals with autism become adults each year

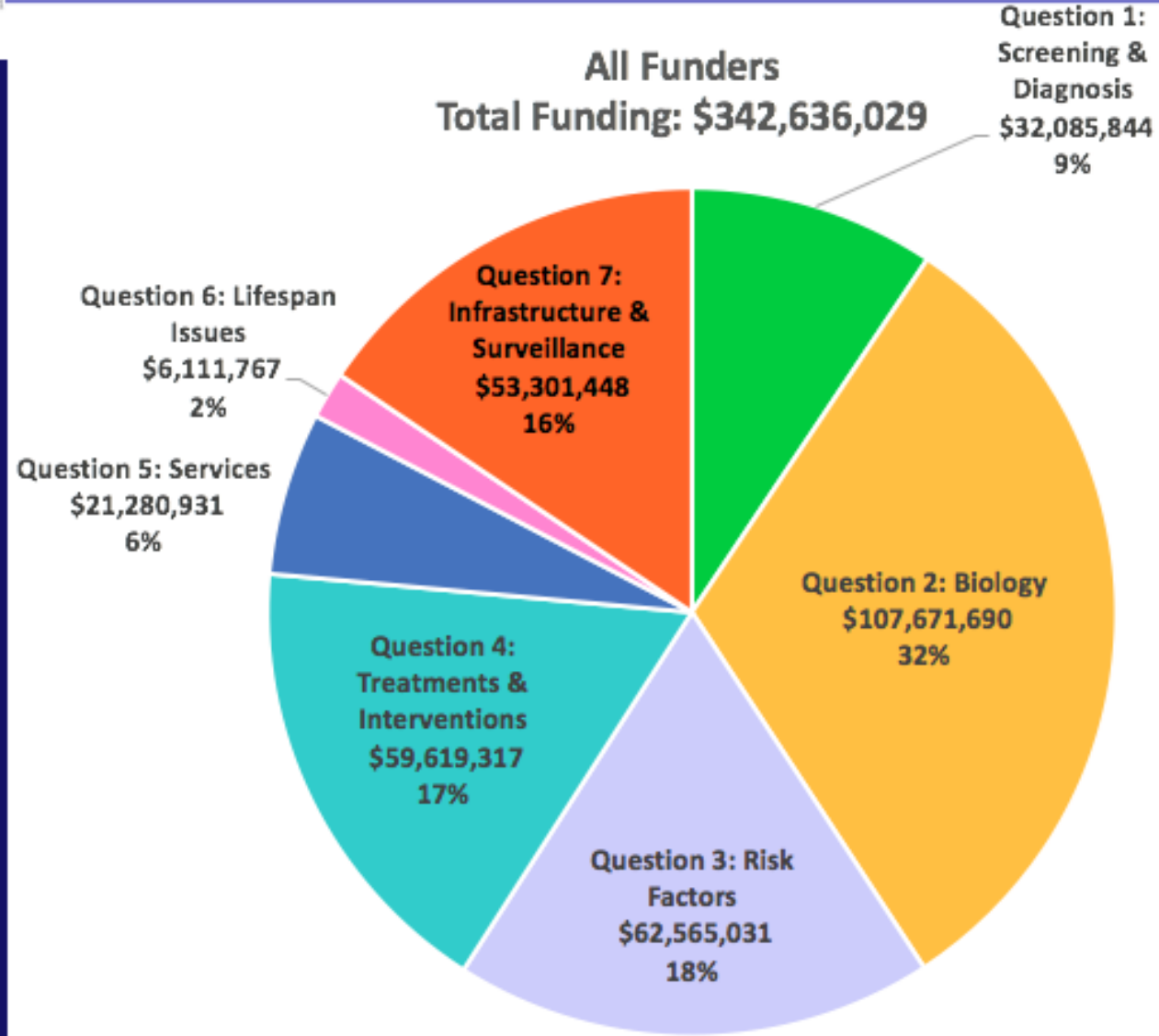
By 2020, more than 500,000 children will age out of the system

Estimated cost (direct services + lost productivity of individuals and parents) is \$300 billion per year

Over 1 million adults with I/DD are living with caregivers over the age of 60

2015 IACC ASD Portfolio Analysis

ASD Research Funding by IACC Strategic Plan Question

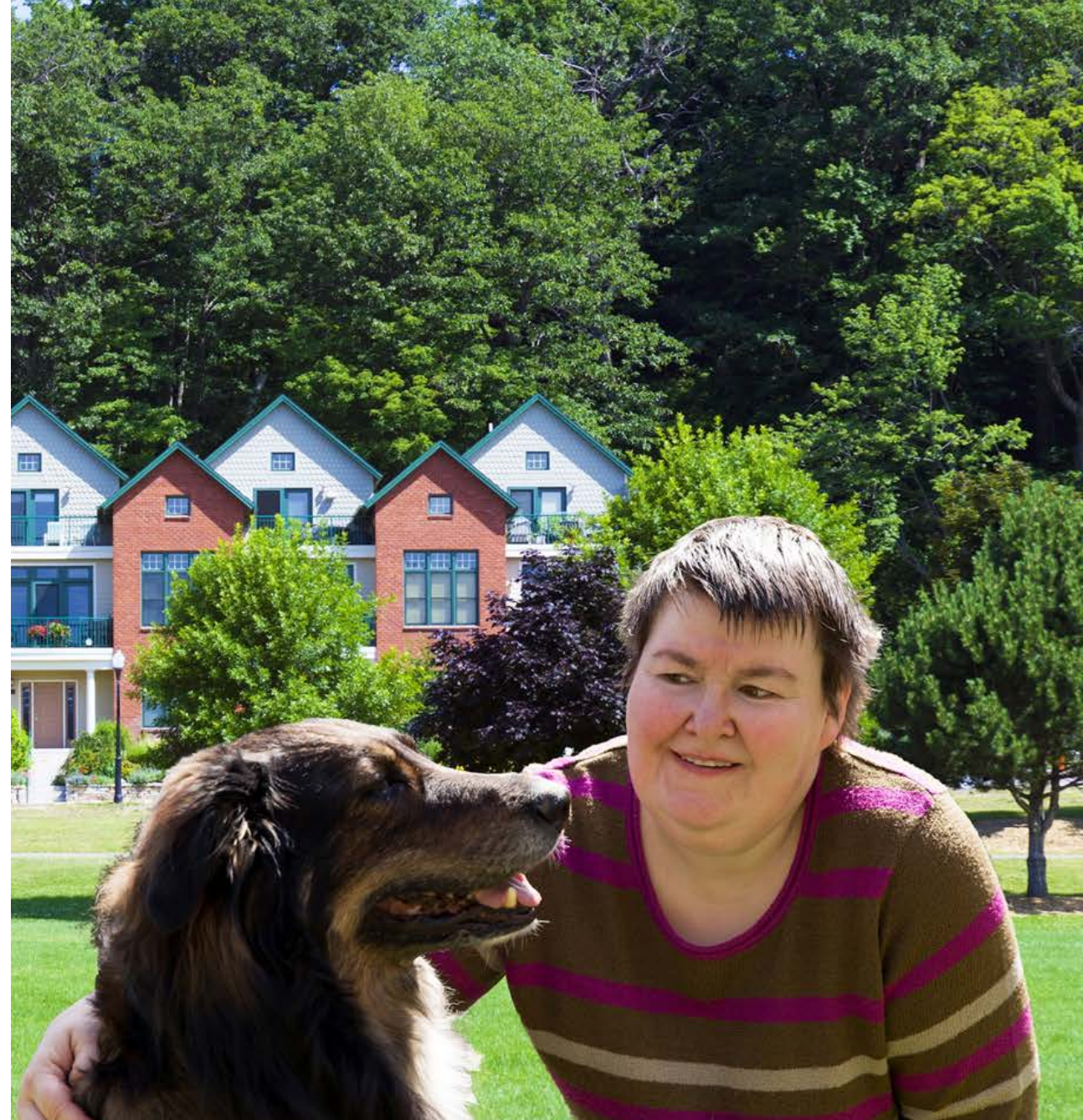


PROGRESS IN NATIONAL TRENDS FOR ADULTS WITH AUTISM & OTHERS

Societal change in expectations

Focus on person-centered planning

Move from institutional models of care toward home
and community-based settings



**Madison House Autism Foundation
has identified the following
lifespan challenges impacting
adults with autism:**

Lack of appropriate and affordable housing

Excessive Unemployment/underemployment

Insufficient post-secondary
education/vocational training

Lack of medical care by informed providers who
understand the unique nature of autism



Our communities need to understand

Autistic children grow up to be autistic adults.

We can't create solutions if we don't know there's a need.

Currently, Madison House Autism Foundation is focusing on three points:

1. Creating a national consciousness about adults on the autism spectrum and their talents, abilities and challenges
2. Addressing housing crisis facing adults with autism and I/DD
3. Working locally to produce prototypes of endeavors to benefit adults on the spectrum at Madison Fields



MADISON HOUSE AUTISM FOUNDATION SALUTES
AUTISM AFTER 21 DAY

An annual observance on April 21
to recognize the abilities of and
issues facing adults with autism

AUTISM AFTER 21 DAY

Success

Montgomery County and the State Maryland proclaimed April 21st as Autism After 21 Day

Shared information, promoted national social media campaign with videos, created blogs posts, and asked groups to commemorate the date

Autism After 21 Day Inaugural Breakfast brought together over 200 community members, elected officials, and business executives to acknowledge that there is a place for autistic adults in the workforce







#IMAGINE21 Mini-documentary Series

The #Imagine21 series is a robust social media campaign that sheds light on the complex issues facing adults with autism, while attempting to break down barriers that prevent the general population from identifying with them.

These extraordinary videos are 10 short shareable films, each introducing an adult on the spectrum and a specific challenge he or she faces.



David's Story

David "The Cartoonist" loves to animate and has a talent for wordsmithing. He recently moved to an intentional community in North Carolina with his family, and while David has made great friends at his new home, he is still struggling to adapt to this major life change.



Adam's Story

AJ's passion for horses developed after he saw the movie "Seabiscuit" in 2004. After pursuing this interest for many years, he became employed at Madison Fields, a project of Madison House Autism Foundation. At Madison Fields, AJ is able to live his dream of working with horses while earning a paycheck.

AUTISM AFTER 21 DAY

With the support of visionary leaders, we can create a powerful social movement

DECLARE: Call on every state and locality to declare April 21st Autism After 21 Day

MEDIA INVOLVEMENT: Follow MHAF on social media, share information, videos, toolkits, and templates

EVENTS: Host a breakfast or other event to provide an opportunity to explain the issues impacting adults with autism; invite elected officials, community leaders, policy makers & stakeholders

EMAIL: info@madisonhouseautism.org for more information

“I want to break the conception that people with autism are unable to do things. They’re just as able to do things in their lives as anybody else.”

-Brian Aubin, 24, NY

HOUSING



AUTISM HOUSING NETWORK

Over the last 10 years,
Madison House Autism Foundation

Created the
Autism Housing Network

Established the
Coalition for Community Choice

Presented and consulted with hundreds of
individuals and groups who want to create
housing opportunities in their communities



NATIONAL EXPERTISE: AUTISM HOUSING NETWORK

Bringing together the best ideas in housing for adults with autism
and other intellectual / developmental disabilities

Culmination of eight years of research & significant financial investment

A direct outgrowth of the Opening Doors Study

The only online platform that connects project starters with other innovators

Provides a growing database of housing options & best practices

Hosts discussion forums to inspire new projects and solutions

Help to launch 200 new projects and expand services to thousands



www.autismhousingnetwork.org




Explore. Learn. Connect. Build. Autism Housing Network

SIGN UP LOGIN


A Project of the Madison House Autism Foundation

There are **5 million** citizens with intellectual / developmental disabilities (I/DD) in the USA.




Only **10%** have access to supports to live outside of their family home.

48% of autistic adults report feeling lonely, **57%** report feeling depressed.



Bringing together the best ideas in housing for adults with autism and other intellectual / developmental disabilities.

[Watch our welcome video to get started.](#)



EDUCATION

Appropriate housing options and funding sources are scarce; however, empowering communities through education is the key to changing this. Let's start learning!

Getting Started on the Autism Housing Network



Advocacy



ONE SIZE DOES NOT FIT ALL

a virtual tour of housing options



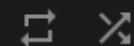
AUTISM HOUSING NETWORK






0:10 / 23:16



One Size Does Not Fit All: A Virtual Tour of Housing Op... +

Madison House Autism Foundation • 1/5 videos



- ▶  **Housing Options for Adults with Autism by Desiree Kameka (1/5)**
Madison House Autism Foundation
- 2  **Housing Options for Adults with Autism by Desiree Kameka (2/5)**
Madison House Autism Foundation
- 3  **Housing Options for Adults with Autism by Desiree Kameka (3/5)**
Madison House Autism Foundation
- 4  **Housing Options for Adults with Autism by Desiree Kameka (4/5)**
Madison House Autism Foundation
- 5  **Housing Options for Adults with Autism by Desiree Kameka (5/5)**
Madison House Autism Foundation

Housing Options for Adults with Autism by Desiree Kameka (1/5)



Madison House Autism Foundation

✓ Subscribed  85

578 views

+ Add to  Share  More

 8  0

Published on Jun 3, 2016

"One Size Does Not Fit All: A Virtual Tour of Housing Options" is a 3-Part, 5-Segment presentation on the various housing options available for adults living with Autism created by Desiree Kameka, the Director of Community Education & Advocacy at Madison House Autism Foundation.



Housing Options for Adults with Autism by Desiree Kameka (2/5)

Madison House Autism Foundation
209 views



Housing Options for Adults with Autism by Desiree Kameka (3/5)

Madison House Autism Foundation
81 views

HOUSING DIRECTORY

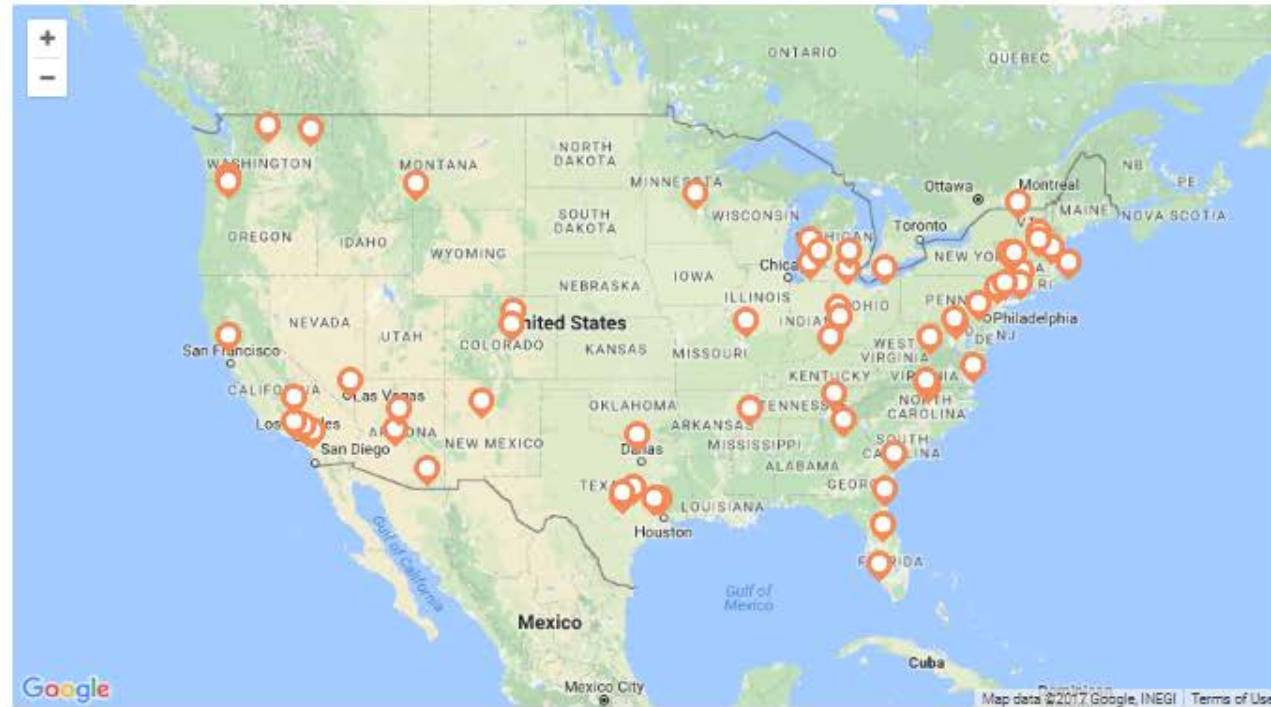


Learn about the array of existing and emerging housing models.

SUBMIT A LISTING

map view

list view



Search...

State(s)

start typing

Property Types

- Apartment
- Cohousing
- Live-Work-Play Community
- Planned Community
- Planned Community with Built-in Support Services
- Single-Family Home
- Townhouse

Support Models

- Adult Foster Care / Family Host Home
- Consumer-Owned / Controlled Setting
- Intentional Community
- Provider-Owned / Controlled Setting
- Shared Living / Roommates

Payment Options

Lifestyles

Support Levels

Primary Residents

LOG IN TO SAVE YOUR FAVORITE LISTINGS

CREATE AN ACCOUNT

LOGIN



SUBMIT A LISTING

Tell us about your favorite residential property!

THE BASICS: part 1 of 2

To submit a housing option, please fill in the fields below as thoroughly as possible. Thank you for helping us build our ever-expanding Housing Directory!

Name of organization / project*

Full name of the organization / project to be displayed on the AHN.

Website URL

If none, leave section blank.

Organization Mission



RESOURCES

Spanning topics from housing design to staff development, use filters to refine your search or submit a resource to help others!

[SUBMIT A RESOURCE](#)

20 of 21 Results Shown



A Sensory Friendly Home

Friendship Circle

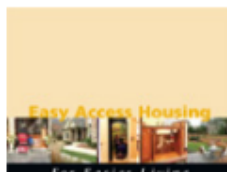
This e-book is full of the ideas that were researched, experimented and dreamed of for a sensory-friendly home – some are small changes and some...



Sensory Preferences: Housing Design for Adults with Autism

RCA Innovation Design Engineering and Textiles, Andrew Brand and Katie Gaudion

This project takes a total design-led approach to sensory needs in order to create better homes for adults with autism. Research Associates: Andrew Brand and...



Accessibility Checklist

Easter Seals

Specific information on making housing more accessible and ADA compliant. Includes helpful checklists.



Objectives



Topics



- Assistance with Living Expenses
- Assistive / Smart Home Technology
- Employment & Entrepreneurship
- Financing Housing Development
- Fundraising & Awareness Raising
- Legal & Financial Planning
- Person-Centered Planning Tools
- Postsecondary Education / Collegiate Life
- Project Formation
- Sensory-Friendly Design & Architecture
- Staff Development
- Surveys & Assessment Tools
- Tiny Homes / Accessory Dwellings
- Tools for Life Skills

Advocacy



Audience-Specific Content



Media Types

[CLEAR FILTER](#)



DISCUSSIONS

Please post questions, concerns, and other ideas as discussion topics in the forum and receive responses by other members on the Autism Housing Network. These forum discussions will become a searchable archive that can be utilized by others who may seek similar information in the future. Have a question? Don't be shy – ask!

[Home](#) » [Forums](#)

Forum	Topics	Posts	Freshness
State Specific Tips Share learning curves, tips, and deadlines for your state here! If you do not see your state listed as a topic, add it!	3	5	1 month, 3 weeks ago Diane A
Exploring Housing Options There is a lot to consider when deciding where to live and how to access supports, and it can feel like navigating a maze! Let's get through it together.	11	21	3 days, 14 hours ago Portfolio
Creating Housing Options There's no need to reinvent the wheel! Whether you are just embarking on the journey to create a housing project in your community or you are well on your way, let's gather here to share helpful tips.	8	15	2 weeks, 2 days ago randyjack
Managing Housing Options	3	4	1 year, 3 months ago

Finding "CommUnity"

Coalition for Community Choice Advocates Unite for Choice in "Finding 'CommUnity'"

Shannon Doty Jun 27, 2017 0 Comments

[READ STORY](#)

Tweets by @AutismHousing

AHN @AutismHousing
 Planned community with built-in supports opens in MN: "The 45-unit Cornerstone Creek complex was designed with a... fb.me/8Z91lbDqt



New Cornerstone Creek apartments may be first of t...
 Independent housing serves adults with developmental disabilities
finance-commerce.com

13 Jul

[Embed](#) [View on Twitter](#)



Out in the World: Promoting Community Involvement for Adults with Autism

Shannon Doty Jun 27, 2017 0 Comments

Going grocery shopping, out for a meal at a restaurant, or to the movie theater can be a minefield for autistic people, presenting many obstacles that neurotypical people do not think twice about. The difficulties that come with the unpredictability...

CATEGORIES

- Advocacy
- AHN Updates
- Best Practices
- Events
- Homes Across the Country
- Housing & Support Tools
- Individual Stories



Schedule a 30-minute Phone Consultation with Desiree



Housing situations can get a little complicated and sometimes require one-on-one support. For these cases, the Autism Housing Network offers 30-minute phone consultations with Desiree Kameka, Director of Community Engagement and Housing Network. She can help with all kinds of issues, including finding housing opportunities and project planning.

We ask for a \$100 donation to Madison House Autism Foundation per 30-minute consultation.

Because of Desiree's busy schedule, we are taking people on a first come, first serve basis. Fill out the form on this page to get started.

<input type="text" value="Full Name"/>	
<input type="text" value="Email Address"/>	
<input type="text" value="Street Address"/>	
<input type="text" value="Address Line 2"/>	
<input type="text" value="City"/>	<input type="text" value="State / Province"/>
<input type="text" value="Zip / Postal Code"/>	<input type="text" value="United States"/>
<input type="text" value="Phone Number"/>	
<input type="text" value="Please provide a brief overview of your situation here."/>	
<input type="text" value="I understand that a \$100 donation is requested for this consultation"/>	
<input type="checkbox"/> I'm not a robot	reCAPTCHA Privacy - Terms

SUBMIT

NATIONAL EXPERTISE: AUTISM HOUSING NETWORK

NEXT STEPS

Research study undertaken by First Place AZ Global Leadership Institute, the Madison House Autism Foundation Autism Housing Network & other collaborators

Define the marketplace of housing and support options for neurodiverse populations to better equip public, private and not-for-profit sectors

Create the foundational nomenclature for housing and service delivery models so the market can begin to respond nationwide with clear examples for replication

Ten (10) strategies for how public, private and not-for-profit interests can build, grow and align communities to serve the vast and diverse needs of people with autism and other neuro divergences



MADISON FIELDS

EMPLOYMENT, HOUSING, WELLNESS



MADISON FIELDS: A PROJECT OF MADISON HOUSE AUTISM FOUNDATION

A partial gift of a 400-acre farm in the Agricultural Reserve in Montgomery County

Launch employment, wellness, and housing programs and prototypes

Partnership collaborations to share the assets and opportunities to a second large and growing vulnerable population: “at-risk” veterans

Inclusive and fully integrated - Three populations served: Autism and I/DD, community-at-large, and veterans

CALL TO ACTION

- ENDORSE OUR MISSION to address issues impacting autistic adults
- HELP INCREASE OUR IMPACT with critical review of our work and identification of funding opportunities
- COLLABORATE WITH US and serve as a catalyst for positive change

QUESTIONS?

Visit www.madisonhouseautism.org or
email us at info@madisonhouseautism.org

“Everyone needs a seat at the table, and how do we do that? We get a bigger table.”

*Isiah "Ike" Leggett
Montgomery County Executive
April 21, 2017*



Thank you to our sponsors.



Meeting of the IACC

Afternoon Agenda

2:45 Committee Discussion

3:15 Afternoon Break

3:30 Summary of Advances Discussion

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary, IACC

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

Director, NIMH and Chair, IACC

Meeting of the IACC

Committee Discussion

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

Break

Meeting of the IACC

Afternoon Agenda

3:30 **Summary of Advances Discussion**

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive
Secretary, IACC

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

Director, NIMH and Chair, IACC

4:00 **Round Robin**

5:00 **Closing Remarks and Adjournment**

2017 Summary of Advances Nominations April – July 2017



Susan A. Daniels, Ph.D.

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

Question 1: Screening and Diagnosis



Science
Translational
Medicine

Jun 2017

Functional neuroimaging of high-risk 6-month-old infants predicts a diagnosis of autism at 24 months of age.

Emerson RW, Adams C, Nishino T, Hazlett HC, Wolff JJ, Zwaigenbaum L, Constantino JN, Shen MD, Swanson MR, Elison JT, Kandala S, Estes AM, Botteron KN, Collins L, Dager SR, Evans AC, Gerig G, Gu H, McKinstry RC, Paterson S, Schultz RT, Styner M; IBIS Network, Schlaggar BL, Pruett JR Jr, Piven J

Question 2: Biology



nature

Jul 2017

Infant viewing of social scenes is under genetic control and is atypical in autism.

Constantino JN, Kennon-McGill S, Weichselbaum C, Marrus N, Haider A, Glowinski AL, Gillespie S, Klaiman C, Klin A, Jones W



Apr 2017

Neurogenetic analysis of childhood disintegrative disorder.

Gupta AR, Westphal A, Yang DYJ, Sullivan CAW, Eilbott J, Zaidi S, Voos A, Vander Wyk BC, Ventola P, Waqar Z, Fernandez TV, Ercan-Sencicek AG, Walker MF, Choi M, Schneider A, Hedderly T, Baird G, Friedman H, Cordeaux C, Ristow A, Shic F, Volkmar FR, Pelphrey KA

Question 2: Biology



***Cerebral* CORTEX**

Mar 2017

Cortical thickness abnormalities in autism spectrum disorders through late childhood, adolescence, and adulthood: a large-scale MRI study.

Khundrakpam BS, Lewis JD, Kostopoulos P, Carbonell F, Evans AC

Question 3: Risk Factors



Jun 2017

Fetal and postnatal metal dysregulation in autism.

Arora M, Reichenberg A, Willfors C, Austin C, Gennings C, Berggren S, Lichtenstein P, Anckarsäter H, Tammimies K, Bölte S



Apr 2017

Grand-maternal smoking in pregnancy and grandchild's autistic traits and diagnosed autism.

Golding J, Ellis G, Gregory S, Birmingham K, Iles-Caven Y, Rai D, Pembrey M

Question 3: Risk Factors



AUTISM RESEARCH
January, 2017 | Volume 10 | Number 1

Apr 2017 [Epub ahead of print]

The joint effect of air pollution exposure and copy number variation on risk for autism.

Kim D, Volk H, Girirajan S, Pendergrass S, Hall MA, Verma SS, Schmidt RJ, Hansen RL, Ghosh D, Ludena-Rodriguez Y, Kim K, Ritchie MD, Hertz-Picciotto I, Selleck SB

nature
neuroscience

Jul 2017

Rates, distribution and implications of postzygotic mosaic mutations in autism spectrum disorder.

Lim ET, Uddin M, De Rubeis S, Chan Y, Kamumbu AS, Zhang X, D'Gama AM, Kim SN, Hill RS, Goldberg AP, Poultney C, Minshew NJ, Kushima I, Aleksic B, Ozaki N, Parellada M, Arango C, Penzol MJ, Carracedo A, Kolevzon A, Hultman CM, Weiss LA, Fromer M, Chiacchetti AG, Freitag CM; Autism Sequencing Consortium, Church GM, Scherer SW, Buxbaum JD, Walsh CA

Question 3: Risk Factors



PSYCHOLOGICAL
MEDICINE

May 2017 [Epub ahead of print]

Autism risk following antidepressant medication during pregnancy.

Viktorin A, Uher R, Reichenberg A, Levine SZ, Sandin S

nature
genetics

May 2017 [Epub ahead of print]

Polygenic transmission disequilibrium confirms that common and rare variation act additively to create risk for autism spectrum disorders.

Weiner DJ, Wigdor EM, Ripke S, Walters RK, Kosmicki JA, Grove J, Samocha KE, Goldstein JL, Okbay A, Bybjerg-Grauholm J, Werge T, Hougaard DM, Taylor J; iPSYCH-Broad Autism Group; Psychiatric Genomics Consortium Autism Group, Skuse D, Devlin B, Anney R, Sanders SJ, Bishop S, Mortensen PB, Børgeglum AD, Smith GD, Daly MJ, Robinson EB

Question 4: Treatments and Interventions



AUTISM RESEARCH
January, 2017 | Volume 10 | Number 1

Jun 2017 [Epub ahead of print]

Cross-site randomized control trial of the Social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder.

Brian JA, Smith IM, Zwaigenbaum L, Bryson SE

BEHAVIORAL DEVELOPMENT BULLETIN
Volume 10 | Number 1 | April 2017

Apr 2017

Measuring developmental outcomes in autism spectrum disorder (ASD).

Commons ML, Adhikari D, Giri S, Weinberg M, Baran JJ, Malik E

Question 4: Treatments and Interventions



The International Journal of Research and Practice ● Volume 21 Number 5 July 2017

autism

Apr 2017

Changes in anxiety following a randomized control trial of a theatre-based intervention for youth with autism spectrum disorder.

Corbett BA, Blain SD, Ioannou S, Balsler M

PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

May 2017

Nutritional and dietary interventions for autism spectrum disorder: a systematic review.

Sathe N, Andrews JC, McPheeters ML, Warren ZE

Question 4: Treatments and Interventions



The Journal of Child
Psychology and Psychiatry

May 2017

Hybrid implementation model of community-partnered early intervention for toddlers with autism: a randomized trial.

Shire SY, Chang YC, Shih W, Bracaglia S, Kodjoe M, Kasari C



Jun 2017

Four-year follow-up of children in the LEAP Randomized Trial: some planned and accidental findings.

Strain PS

Question 4: Treatments and Interventions



PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

May 2017 [Epub ahead of print]

Interventions targeting sensory challenges in autism spectrum disorder: a systematic review.

Weitlauf AS, Sathe N, McPheeters ML, Warren ZE

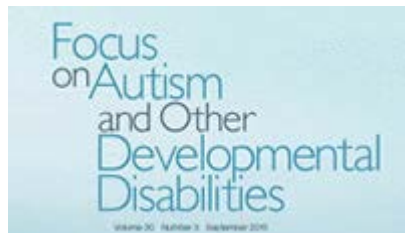
Question 5: Services



Jun 2017

Implementation evaluation of early intensive behavioral intervention programs for children with autism spectrum disorders: A systematic review of studies in the last decade.

Caron V, Bérubé A, Paquet A



Jun 2017

Comparisons of self-determination among students with autism, intellectual disability, and learning disabilities: a multivariate analysis.

Chou Y, Wehmeyer ML, Palmer SB, Lee J

Question 5: Services



PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

May 2017

Disparities in diagnosis and treatment of autism in Latino and non-Latino white families. Zuckerman KE, Lindly OJ, Reyes NM, Chavez AE, Macias K, Smith KN, Reynolds A

Question 6: Lifespan Issues



No articles were nominated in April – July 2017 for Question 6

Question 7: Infrastructure



American Journal of
Epidemiology

May 2017

Geographic patterns of autism spectrum disorder among children of Nurses' Health Study II women.

Hoffman K, Weisskopf MG, Roberts AL, Raz R, Hart JE, Lyall K, Hoffman EM, Laden F, Vieira VM

Journal of the American Academy of
**CHILD & ADOLESCENT
PSYCHIATRY**

Jun 2017

What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis.

Loomes R, Hull L, Mandy WPL

Meeting of the IACC

Round Robin

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



ASD PEDS Network Meeting Convened on June 5-6, 2017

Denise Pintello, Ph.D., M.S.W.

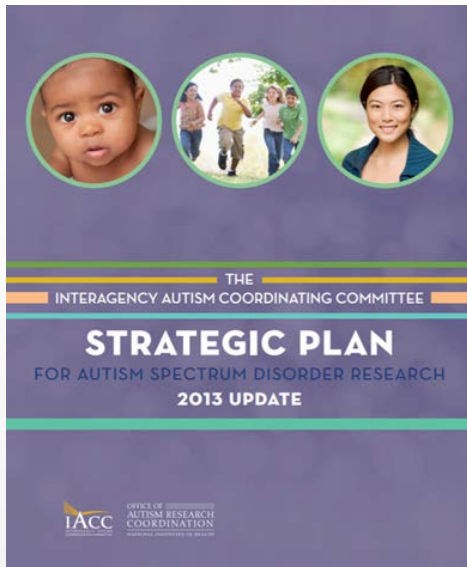
*Division of Services and Intervention Research
Chief, Child & Adolescent Services Research Program*

July 26, 2017



National Institute
of Mental Health

Origin of ASD PEDS Network Research Studies



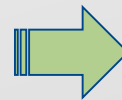
2013 STRATEGIC PLAN for Autism Spectrum Disorder Research



Funding Opportunity Announcement:
Services Research for Autism
Spectrum Disorder across the Lifespan

QUESTION 1

WHEN SHOULD I
BE CONCERNED?



NIMH FOA:

**Research on Early
Identification and Linkage
to Services for ASD (R01)**



Research on Early Identification and Linkage to Services for ASD (R01)

- Test the development of interventions that coordinate ASD screening, evaluation and engagement in treatment and services within the first two years of life
- Emphasize reduction of disparities in outcomes for underserved populations



Research on Early Identification and Linkage to Services for ASD (R01)

Wendy Stone
Univ. of Washington



Alice Carter, Radley Sheldrick
Univ. of Mass.
Boston
Tufts University

Emily Feinberg
Boston University
Yale University
CHOP

Karen Pierce
Univ of California San Diego
Southwest Autism Research
& Resource Center






Amy Wetherby, Ami Klin, Catherine Lord, Craig Newschaffer
Florida State University
Emory University
Drexel University
Weill Cornell Medical College



Research on Early Identification and Linkage to Services for ASD (R01)



FIVE FUNDED RESEARCH STUDIES

	Karen Pierce	Univ. of California San Diego; Southwest Autism Research & Resource Center	Detection of ASD at the 1st birthday as standard of care: The Get SET Early Model
	Wendy Stone	University of Washington	A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention
	Emily Feinberg	Boston University; Yale University; Children's Hospital of Philadelphia	Early Identification & Service Linkage for Urban Children with ASD
	Alice Carter, Radley Sheldrick	University of Massachusetts Boston	Addressing Systemic Health Disparities in Early ASD Identification and Treatment
	Amy Wetherby, Catherine Lord, Ami Klin, Craig Newschaffer	Florida State University; Emory University; Drexel University; Weill Cornell Medical College	Mobilizing Community Systems to Engage Families in Early ASD Detection and Services



Research on Early Identification and Linkage to Services for ASD (R01)

Differences

- Settings
- Screening and Diagnostic Instruments
- Research Designs
- Strategies for Referral to ASD Services and Engagement

	CARTER, ALICE	FEINBERG, EMILY	PIERCE, KAREN	STONE, WENDY	WETHERBY, AMY
Setting	Primary care & EI system	3 urban primary care systems	Primary care & EI system	Primary care & EI system	3 different community svcs systems (including primary care)
Population	Urban, Low SES, Hispanic	Low-income and minority children	Diverse sample (AA, Latino); Phoenix: oldest age (5) of ASD	Underserved population (includes low SES & minority)	Inner city, urban & rural settings; large % ethnic, minority families
Sample Size	Screen 3,886 children Screen +: " 315 ASD Diagnosis: " 236	Screen 19,500 children Screen +: " 951 ASD diagnosis: " 175	Screen: 15,000 (7,500 per city) Screen +: " 820 ASD Diagnosis: " 150-300	Screen 2,660 children Screen +: " 490 ASD Diagnosis: " 90-110	Screen 36,000 children @ 18 mo (+ or - 3 mo) Screen +: " 697 ASD diagnosis: " 411 children
Age Range	14-24 months (up to 33 mo)	pediatrician for 18-24 mo well-child visits	12, 18, 24 and 36 months	16-30 months	18-27 months
Initial Screen Tool(s)	BITSEA; POSI; ACE Family Medical	M-CHAT; ACE Family Medical History	CSBS; ACE Family Medical History	M-CHAT	SMART ESAC (Includes 10 broadband questions & 20 autism-specific questions)
Diagnostic Tools	STAT; MSEL; ADOS-2; VABS-II	M-CHAT-FI; VABS-II; MSEL; ADOS-2	ADOS-2; MSEL; VABS-II; ADI-R	STAT; MSEL; VABS-II; ADOS-2; ACE Family Medical History	ADOS-2; SORF; MSEL; VABS-II; Home Observation; ACE Family Medical History (and other parent questionnaires)

Commonalities

- All studies will be entering study data into NDAR
- All studies are in a position to study health disparities
- Some studies administering same screening and diagnostic instruments

Collectively ...

- Approximately 70,000+ children will be screened
- Anticipate that nearly 1,000 children may be diagnosed with ASD



ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

In 2014

NIMH invited researchers to work together to form the ASD PEDS Network




Four Common Measures are Being Utilized

- Autism Diagnostic Observation Schedule (ADOS-2)
- Mullen Scales of Early Learning (MSEL)
- Vineland Adaptive Behavior Scales (VABS-II)
- Autism Centers of Excellence (ACE) Family Medical History

ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

Since Grants were Awarded in August 2014

- Network researchers developed their own website to share instruments, treatment tracking matrices, publications
- Presentations by researchers at the IACC, IMFAR Conferences
- Conducted cross-trainings for research staff at other Network projects



U.S. Preventive Services
TASK FORCE

Autism Spectrum Disorder in Young Children: Screening
Release Date: February 2016

Recommendation Summary

Population	Recommendation	Grade (What's This?)
Children aged 18 to 30 months	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for autism spectrum disorder (ASD) in young children for whom no concerns of ASD have been raised by their parents or a clinician.	I



JAMA The Journal of the
American Medical Association

Editorial | February 16, 2016

Embrace the Complexity
The US Preventive Services Task Force Recommendation on
Screening for Autism Spectrum Disorder **FREE**

Michael Silverstein, MD, MPH¹; Jenny Radesky, MD²

“NIMH is currently supporting 5 large-scale studies on early identification of ASD ...designed to address overarching questions ... Such initiatives are a promising step in discerning the direct relationship of ASD screening to clinical outcomes.”

ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

Current Status

- Finishing Year 3 of their 5-year projects
- Middle of recruitment and data collection



Convened June 5-6, 2017 ASD PEDS Meeting

Identify potential scientific areas to leverage their data from the ASD PEDS Network to address research gaps

- Impact of parental / provider concern vs. no concern at screening
- Treatment Tracking: Examine pathways from screening to services
- Onset of ASD symptoms at 12, 24 and 36 months
- Implementation Project: Facilitators and barriers



ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

FUTURE DIRECTIONS

- Studies will be completed in Fall 2019
 - Researchers to conduct cross-site analyses
 - Network researchers to co-publish findings
 - Conduct joint presentations
 - Explore future studies that could be conducted via the Network
 - Network could present research findings at the IACC
-



Meeting of the IACC

Closing Remarks

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Meeting of the IACC

Adjournment

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