



Meeting of the Interagency Autism Coordinating Committee

Wednesday, October 17, 2018

**National Institutes of Health
Neuroscience Center**

Rooms C and D
6001 Executive Blvd
Rockville, MD, 20892

Conference Call Access:

Phone: 800-369-3190
Participant Passcode: 1724926

Meeting of the IACC



Morning Agenda

9:00 AM

Welcome, Introductions, Roll Call, and Approval of Minutes

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

Director, National Institute of mental Health and Chair, IACC

Susan Daniels, Ph.D.

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

Meeting of the IACC



Morning Agenda

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

Ann Wagner, Ph.D.

HHS National Autism Coordinator and Chief, Biomarker and Intervention Development for Childhood-Onset Mental Disorders Branch

Division of Translation Research
National Institute of Mental Health

9:15 **Autism Society Presentation: Unintentional Injury in Children and Youth with ASD**

Jack Scott, Ph.D., B.C.B.A.-D.

Member, Autism Society Panel of Professional Advisors
Executive Director, Florida Atlantic University Center for Autism and Related Disabilities

Meeting of the IACC



Morning Agenda

10:30

Break

10:45

Committee Business

Susan Daniels, Ph.D.

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

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

Director, National Institute of mental Health and Chair, IACC

Meeting of the IACC



Morning Agenda

11:00

Discussion of IACC Workshop: Addressing the Health Needs of People on the Autism Spectrum

Davis Amaral, Ph.D.

Distinguished Professor, Department of Psychiatry and Behavioral Science, University of California, Davis (UC), UC Davis MIND Institute Co-Chair, IACC Health Outcomes Working Group

12:00 PM

Lunch

Welcome

Introductions

Roll Call

Approval of Minutes



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

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



National Autism Coordinator Update

Ann Wagner, Ph.D.

Interagency Autism Coordinating Committee Meeting
October 17, 2018

National Autism Coordinator Role

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

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

Federal Interagency Workgroup on ASD (FIWA)

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



Federal Interagency Workgroup on ASD (FIWA)

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



Federal Interagency Workgroup on ASD (FIWA)

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



2017 Report to Congress on Transition Age Youth (TAY) and Adults with ASD

Epidemiological Data Collection and Monitoring

New activities:

- CDC piloting the teen Study to Explore Early Development (SEED) Survey (14-15 years old)
- CDC posted funding announcement for Autism and Developmental Disabilities Monitoring (ADDM) sites including an option to conduct follow-up at age 16

Next steps:

- Analyzing existing surveys to identify gaps



2017 Report to Congress on TAY and Adults with ASD

Research

Newly funded research projects evaluating programs for TAY and adults

- Achieving competitive employment
 - Employment-related social skills training; vocational soft skills
 - Addition of ASD support to Project SEARCH internship program
 - Tools to improve primary care for autistic adults
 - Healthcare transition planning and health-related independence
 - Daily living skills training for adolescents and TAY
 - Engaging siblings in family future planning
-
- Next steps: identify and share outcome measures under development



- Continue individual/small group meetings with members of the Federal Interagency Workgroup on ASD
- Focus on Supports & Services recommendations from the 2017 Report to Congress on Transition-Age Youth and Adults with ASD
- Consider approaches used by Federal programs to influence State and local policy and programs



Safety Issues and Individuals with Autism Spectrum Disorder

Submitted by the Autism Society of America to the
Interagency Autism Coordinating Committee

October 17, 2018



Autism Society

Founded in 1965 the Autism Society of America has been improving the lives of all affected by autism for over 50 years and envisions a world where individuals and families living with autism are able to maximize their quality of life, are treated with the highest level of dignity, and live in a society in which their talents and skills are appreciated and valued. The Autism Society of America provides advocacy, education, information and referral, support, and community-based services at national, state and local levels through our strong nationwide network of Affiliates.

The Autism Society and Safety for Persons with ASD

The ASA has developed and implemented safety programs that have been delivered in over half of the United States and trained over 20,000 police, firefighters, and first responders collectively.

The ASA is aware of the magnitude of issues surrounding ASD and Safety, yet we do not see a national agenda to appropriately document the problem and deliver consistent training for families, individuals with ASD, educators and all first responders.

Characteristics of ASD and Risk

Are children with an Autism Spectrum Disorder at Higher Risk for Unintentional Injury, Wandering and Even Death?

Is the risk higher due to some of the characteristics of autism?

Sadly, the answer is

Yes!

ASD Mortality is High

Svend E. Mouridsen (2013) Mortality and Factors Associated with Death in Autism Spectrum Disorders - a Review. *American Journal of Autism*, 1, 17-25.

A review of the published systematic mortality studies suggest that the observed number of deaths is **nearly three times higher** in populations with ASD than in the general population.

Key risk factors cited:

1. Moderate to profound intellectual disability
2. Epilepsy
3. Female gender

ASD Mortality Studies

- Gillberg, C., Billstedt, E., Sundh, V., & Gillberg, I. C. (2010). Mortality in autism: a prospective longitudinal community-based study. *Journal of Autism and Developmental Disorders, 40*, 352-357.
- Mouridsen, S. E. (2013). Mortality and factors associated with death in autism spectrum disorders - a Review. *American Journal of Autism, 1*, 17-25.
- Mouridsen, S. E., Brønnum-Hansen, H., Rich, B., & Isager, T. (2008). Mortality and causes of death in autism spectrum disorders: an update. *SAGE Publications and The National Autistic Society, 12*(4), 403-414.
- Shavelle, R. M., Strauss, D. J., & Pickett, J. (2001). Causes of death in autism. *Journal of Autism and Developmental Disorders, 31*(6), 569-576.

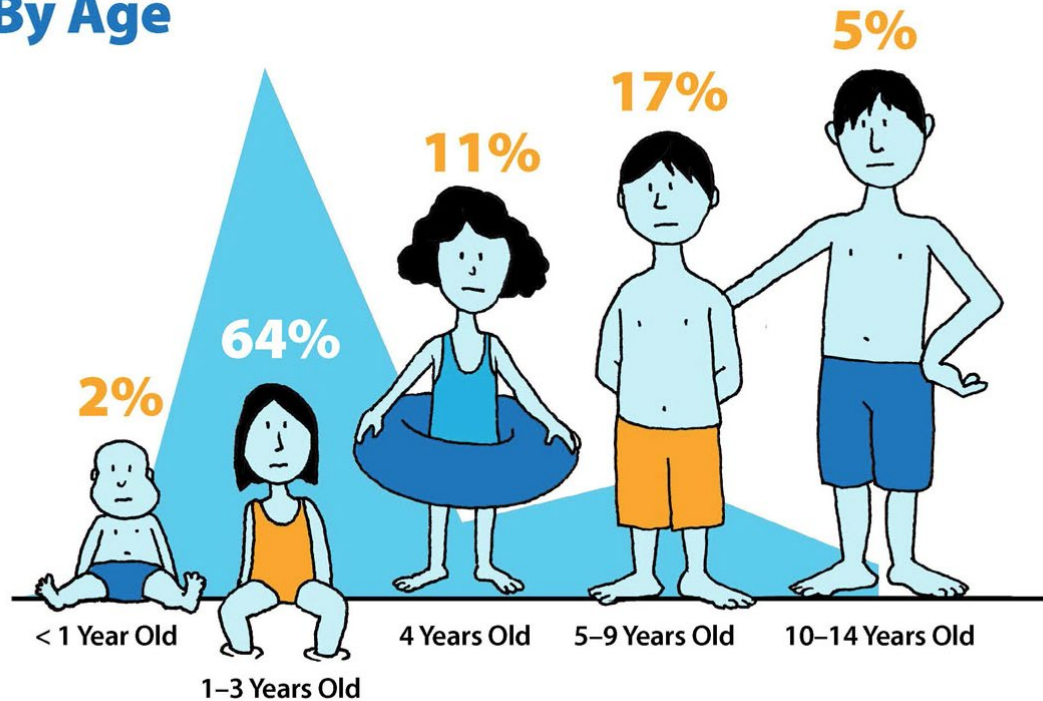
All report excessive mortality for persons with ASD



Drowning is Likely the #1 Cause of Unintentional Death for Children with ASD

Drowning is the # 1 Cause of unintentional death for children ages 1-4, and the probably the largest cause of unintentional death for children with ASD ages 1-10 years of age.

By Age



[a 1% percent loss due to rounding]

Our Problem: So many of our children stay in the younger age levels developmentally with higher risk status

Wandering or Elopement: A Huge Problem

Rice, C. E., Zablotsky, B., Rosa, A. M., Colpe, L. J., Schieve, L. A., Pringle, B., & Blumberg, S. J. (2016). Reported wandering behavior among children with autism spectrum disorder and/or intellectual disability. *The Journal of Pediatrics*, 174, 232-239.

37.7% of children with ASD and intellectual disability
wandered in the previous year.



Jared J. McGuire



Feb 23, 2006;
Greenacres, FL,
Jared McGuire,
missing since
Thursday afternoon.
Eloped from his home.
Later found dead due
to drowning.

Feb 24, 2006; Greenacres, FL, USA; Palm Beach County Sheriff Deputy Ray Griffith stands near the body of Jared J. McGuire, missing since Thursday afternoon. Griffith found the body in the pond about 100 yards from the family's front door Friday morning as officers were preparing to search the ponds in The Pines community. Mandatory Credit: Photo by Lannis Waters/Palm Beach Post/ZUM. Used with permission.



The dangers of wandering

At Tremendous Risk! Has severe autism! Frantic Search!



\$70,000.00 USD Reward

#findAvonte - Avonte Oquendo (14 yrs.) is at great risk and he is missing! He is Autistic and has vanished from his Long Island City, Queens, NY school at 12:38 p.m. on Friday (10/4/2013). Avonte is not able to communicate verbally. He could be anywhere by now! Avonte Oquendo is described as a Black male, 5'3" tall, and weighs 120 lbs. He was last seen wearing a gray striped shirt, black jeans, and black sneakers. Volunteers are desperately needed to help search for him and distribute his flier, everywhere. The search is frantic. If you have seen Avonte Oquendo, know of his

Electronic Tracking- the Technology is Available

Project Lifesaver International offers Radio-Frequency tracking devices. These are used as a system with local law enforcement



Recent Elopement Missions for Project Lifesaver International

Number Assigned	Date of Mission	City/County/Province State/Country	Diagnosed with	Search Time	Agency Conducting Search
3477	09/26/18	Vincennes, IN	Autism	16 min.	Vincennes Fire Department
3476	09/23/18	Savannah, GA	Autism	38 min.	Chatham County Sheriff's Office
3474	09/16/18	Phoenix, NY	Autism	17 min.	Oswego County Sheriff's Dept.
3467	08/17/18	Cheyenne, WY	Severe ADHD	58 min.	Laramie County Sheriff's Department
3466	08/14/18	Lynchburg, VA	Autism	6 min.	Lynchburg Sheriff's Office
3465	08/12/18	Norfolk, VA	Autism	26 min.	Norfolk Sheriff's Office
3462	08/06/18	Charlotte, NC	Autism	28 min.	Charlotte-Mecklenburg Police Department
3459	07/25/18	Lynchburg, VA	Autism	15 min.	Lynchburg Sheriff's Office
3458	07/29/18	Shreve, OH	Autism	38 min.	Holmes County Sheriff's Office
3456	07/25/18	Denver, NC	Autism	13 min.	Lincoln County Sheriff's Office
3455	07/22/18	Lynchburg, VA	Autism	11 min.	Lynchburg Sheriff's Office
3454	07/19/18	Port Washington, WI	Autism	5 min.	Ozaukee County Sheriff's Office
3453	07/21/18	Heath, OH	Autism	9 min.	Licking County Sheriff's Office
3451	07/20/18	Norfolk, VA	Autism, AD/HD	25 min.	Norfolk Sheriff's Office
3449	07/16/18	Phoenix, NY	Autism, Taurette's Syndrome	58 min.	Oswego County Sheriff's Dept.
3448	07/15/18	Phoenix, NY	Autism, Taurette's Syndrome	54 min.	Oswego County Sheriff's Dept.
3446	07/17/18	Baraboo, WI	Prader-Willi Syndrome	15 min.	Sauk County Sheriff's Office
3445	07/12/18	Vincennes, IN	Autism	10 min.	Vincennes Fire Department
3444	07/11/18	Willingboro, NJ	ADHD, OCD, PDPNOC	16 min.	Burlington County Sheriff's Dept. Task Force
3440	07/03/18	Norfolk, VA	Autism	19 min.	Norfolk Sheriff's Office
3431	06/17/18	Vincennes, IN	Autism	15 min.	Vincennes Fire Department
3430	06/13/18	Burlington, NJ	Developmental Delay	11 min.	Burlington County Sheriff's Dept. Task Force
3429	06/11/18	Pensacola, FL	Autism	14 min.	Escambia Search and Rescue
3428	06/07/18	Oswego, NY	Autism	9 min.	Oswego County Sheriff's Dept.



PROJECT LIFESAVER®
 Bringing Loved Ones Home
The Original 501(c)(3) Non-Profit Organization



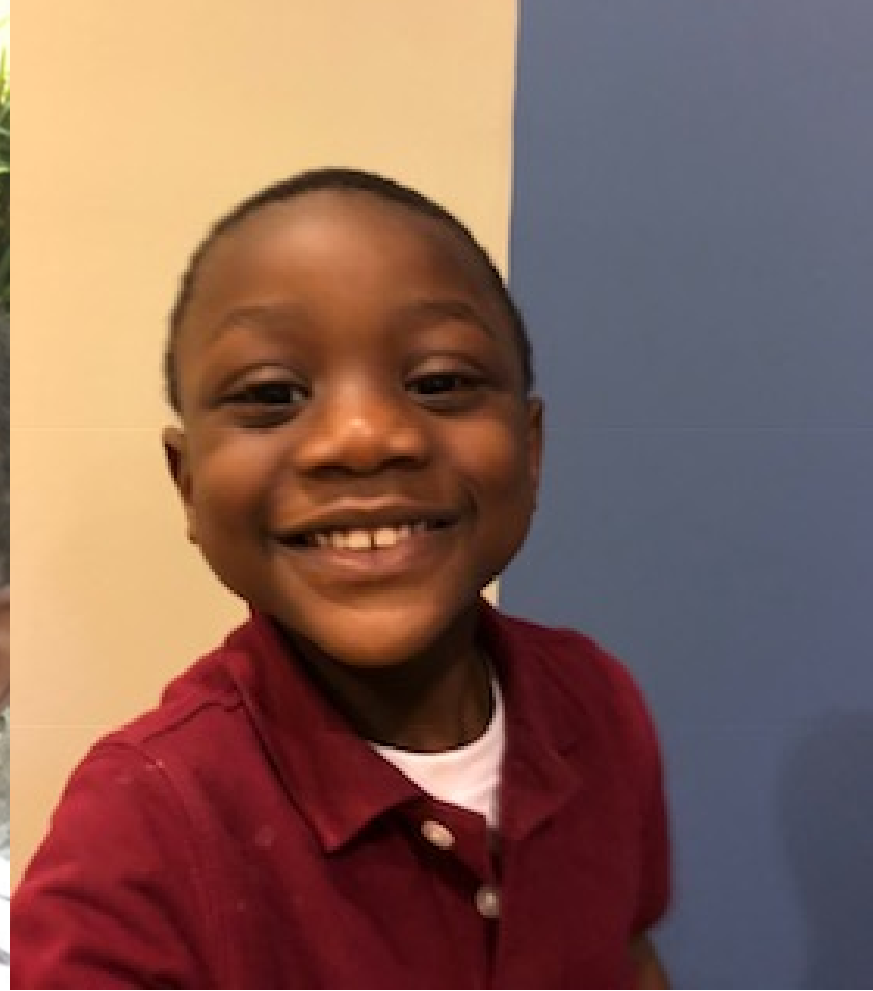
The father of a 6-year-old autistic boy found dead after a 5-day search speaks out: 'Today I found out I'm not a dad anymore'



Date of Death: September 27th, 2018.

(WCNC) He had a contagious smile and he was a happy child. Everything you hear about Maddox is true, every bit of it.

(CNN) The six-day search for Maddox Ritch, the 6-year-old boy with autism who went missing at a North Carolina park, ended Thursday afternoon with the discovery of a body in a creek,



Ezekiel Matthew Surratt,
age 4 years



Ezekiel Matthew Surratt (4yrs old) passed away from elopement and eventual drowning on August 25th, 2018. We are residents of Tobaccoville, NC but he passed away in my mothers pond in King, NC.



Ezekiel (Zeke)
Matthew Surratt,
age 4 years

Law Enforcement Training is Available



A program of the Autism Society of America providing training for over 20,000 law enforcement officers



A program of the Autism Society of America and the Pensacola, Florida Police Department as an adjunct to 911 to speed ASD search efforts.



Law Enforcement Training is Available

Other examples of training curriculum include The Organization for Autism Research- *Think Safety*, National Autism Association- *Autism Safety Initiative*, Autism Speaks, *Autism Safety Project*- Emily Iland- *Be Safe* and *Experience Autism*.
As well as qualified consultants such as Dennis Debbaudt and others

Autism Autism Emergency
Risk & Safety
Management Contact Form

Place
Photo
Here

Name of Child/Adult with Autism

Nickname (if any)

Date of Birth

Height

Weight

Eye Color

Hair Color

Medical Conditions

Scars or Identifying Marks

Address

City, State, Zip

Home Phone

Other Phone

Method of Communication, if non-verbal: sign language, picture boards, written word, etc.

Identification Worn: (ex. Jewelry/Medic Alert®, clothing tags, ID card, tracking monitor, etc.)

Current Prescriptions (include dosage):

Sensory/Medical/Dietary issues and requirements, if any:

Inclination for wandering behaviors or characteristics that may attract attention:

Favorite attractions or locations where person may be found, if missing:

Likes/Dislikes (Include approach and de-escalation techniques):

Please attach any additional information.
Use extra paper if necessary.

For additional information & tips, please go to
www.AutismRiskManagement.com

Medical Care Providers

Name/Phone: _____

Name/Phone: _____

Name/Phone: _____

Parent/Caregiver Info

Name: _____

Address: _____

Home/Other Phone: _____

Other Contact Info: _____

Emergency Contact Info

Name: _____

Address: _____

Home/Other Phone: _____

For a comprehensive search for a missing child we must rely on local law enforcement professionals.



CEO/Founder, Gene Saunders of Project Lifesaver International, a non-profit agency.

A system used in conjunction with local law enforcement agencies



Research: The Need for Data

Data-

Address the weakness in current death records-
failure to ascertain ASD unintentional injury
deaths

Research: The Need for Data

STANDARDIZED REPORTING SYSTEMS

must be put into place across the nation.

In most states, calls (EMS, police, fire department) are not tracked. Outcomes are not tracked. Data are coming from narratives in police reports and through news media.



Research

Support and lend coordination to tracking/searching of persons with ASD. This of electronic and other methods.

Lack of funding for such efforts now



Research: ASD and Water Safety

Fund research on the impact of early swim instruction on ASD drowning deaths

Very little is known of the potential benefits of such training

Swim Central Broward County, Florida

**A collaboration between the Broward County School District,
Broward County Commission and Children's Services Council
Broward.**

- **Over 450,000 trained with no drowning of a trained child**

Today, there are more than 130 elementary schools that participate in **SWIM Central** educational programming and transporting students to neighborhood pools for in-pool water safety instruction.

SWIM Central provides ten 30-minute classes over a two-week period for Broward County School Board elementary school children to learn basic and valuable water safety and swimming skills -- at no cost to the parent.

The curriculum-based program is taught by certified water safety instructors that have been selected and carefully trained through **SWIM Central**.

The success of **SWIM Central** has gained attention nationwide. It is the only program of its type in the country, which has heightened parent and community awareness and acted as a conduit of water safety programs -- benefiting many thousands of children, protecting our County's most precious commodity and our future.

- **Source: <http://www.broward.org/parks/swimcentral.htm>**



Research on Elopement

Funding for elopement research.

Descriptive research and interventions to treat children who elope

Intervention for Wandering and Elopement

Behavioral assessment using functional assessment procedures

. . . . are the most effective strategies for elopement at this time.

See: Piazza et al (2011) or Tarbox et al, (2003), and specifically for school settings:

Lang, R. et al., (2010). Functional analysis and treatment of elopement across two school settings. *Journal of Applied Behavior Analysis, 43*, 113-118.

Research and Research Sharing

Sponsor a nationwide conference on unintentional injury and ASD, with a focus on the high-risk areas (elopement, drowning, poisoning)



Awareness Research

Inform the public and ASD community of the
7.6 times greater risk for poisoning for
children with ASD

Source: McDermott, S., Zhou, L., & Mann J. (2008). Injury treatment among children with autism or pervasive developmental disorder. *Journal of Autism and Developmental Disorders*, 38(4), 626-633.

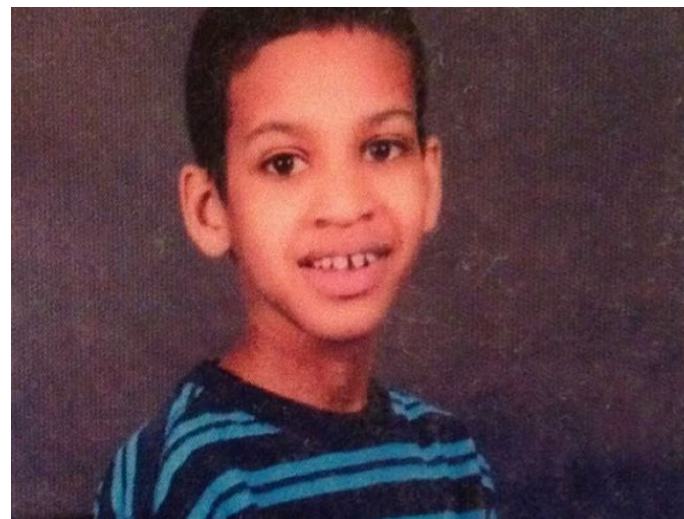
Kevin and Avonte's Law March 23, 2018

9 year old Kevin Curtis Wills

14 year old Avonte Oquendo

Both wandered and drown

Imperative that this law be sufficiently funded to meet the challenges





First Responder Training

First responder training has increased in many states over the years but is not a national effort.

Every state should have mandatory autism training.



Tracking Devices

Tracking devices should be funded for all who have the need for one.

Expand availability of Project Lifesaver and investigate the utility of other emerging technologies for tracking vulnerable persons with ASD who are missing.



Enhance 911 System

911 systems nationwide should be expected to allow parents to register a child with ASD or other vulnerabilities to the 911 database.

Take Me Home, a free ASD registration program for law enforcement agencies to use with parents on a voluntary basis demonstrates the value of such an approach.

Families Need More Information on Safety and ASD

Families must be educated about wandering prevention strategies, prevention of poisoning strategies and availability of safety devices.

Information must be developed and disseminated



Awareness

Foster efforts to have a lack of **self-preservation skills** included among the characteristics of ASD



Awareness of the Risks

Promote an awareness that persons with ASD are at a x3 risk for death. Children at even greater risk.

There is some hesitation on the part of many professionals to share this information

Federal Programs: Service

Encourage the Centers for Disease Control and Prevention to develop increased cooperation between developmental disabilities and child injury

Federal Issues: Policy

CDC could develop a new and expanded agenda that targets *ASD and* safety. This would, we suggest, bring together the researchers from the CDC National Center of Birth Defects and Developmental Disabilities with those from the National Center for Injury Prevention and Control in a new ASD focused safety initiative.

The Seven CDC Risk Areas Plus the Big ASD Issue

1. Motor vehicle-related
2. Suffocation
- 3. Drowning**
4. Poisoning
5. Fires/Burns
6. Falls
7. Sports and recreation

Potential #8. Wandering and Elopement for ASD and other children with special need (Scott addition for discussion)



Federal Issue: Policy

Consider a reallocation of federal resources from ASD surveillance and ASD vaccines to unintentional injury and ASD



Federal Issues: Service

The National Institutes of Health could take a leadership role in recognizing ASD safety as a critical health issue with both internal investigations of the nature of these risks and by awarding grants to examine the extent of ASD risk and effective prevention and treatment strategies.



Federal Policy

The National Institutes of Health could authorize funding for investigations of the effectiveness of electronic tracking technologies and how they can be best used in urban, suburban and especially rural settings.



Federal Issues

ASD Training curriculum for rangers and officers with the National Parks, National Wildlife System and all federal officers serving in any geographic area in which the elopement of a person with ASD could pose substantial risk.



Education Policy

Expect that all state education agencies have policies and procedures addressing elopement of ASD and other vulnerable students.

Education Policy

All schools should be mandated to have elopement policies and plans, most schools do not have such policies.





Education Policy

Clarify that school IEPs contain safety provisions and accommodations for children with ASD in emergency and crisis drills and crisis events.

Education Policy and the IEP

Every child with ASD who has safety issues should have a safety plan attached to the IEP and fire drill and active shooter protocols must be individualized for each child with ASD/ID and added to the child's safety plan and noted in the IEP.

Education Policy: Safety Skills on the IEP

Agran, M. &
Krupp, M.
(2010)

A preliminary investigation of parents' opinions about safety skills instruction: An apparent discrepancy between importance and expectation.

Education and Training in Autism and Developmental Disabilities, 2010 45,

Survey of parents

Has there ever been a safety skill listed as an instructional goal on your child's IEP?

NO = 81%

Parents who considered safety skills to be a very important part of their children's educational experience.

Yes = 93 %

Safety Skills on the IEP

Teach Functional Skills

Answering questions

“what is your name?”

“what did you eat?”

“what happened?”

Responding to receptive directions

“Stop”

“Come here”

“Put that down”



Jonny Smith

141 Parsons Creek Dr.
West Palm Beach, FL
33407

Ph.# 561-672-2500

DOB: 02/29/1999

7th grade: Jupiter Middle School

Education Policy and IDEA

Reference to elopement or other safety issues should be included in the next reauthorization of the Individuals with Disabilities Education Act IDEA along with language that makes it clear that school-based prevention and behavioral treatment for elopement are potentially suitable goals for the IEP. Schools must educate families that they can ask for safety goals to be included in a personal safety plan in their IEP.



Education Policy

Schools are currently required to conduct a Functional Behavioral Assessment (FBA) *for some students with challenging behaviors*. For children who elope, this plan should include understanding and preventing possible triggers or antecedents for wandering. Students with ASD who do wander from school should, additionally, have an FBA that examines the likely behavioral functions of their elopements, informing prevention and treatment.

Autism Society “Asks”

Data- a nationwide tracking system. Sound public policy is based on accurate data.

Strategies- sufficiently fund Kevin and Avonte’s Law. Mandatory training on ASD for all first responders nationwide.

Education- enhance IDEA to include ASD safety issues- elopement and other safety issues

CDC- funded to target safety and ASD issues with greater collaboration between injury prevention and developmental disability.

NIH- formulate plans to address ASD safety as a national health issue. Increase internal efforts and increase external grant funding

Initial Expected Outcomes

A unified National tracking system will show the true scope of the crisis and then provide impetus for a national agenda to address the high risk to these children and adults.

- a. Incidents of elopement/wander and death will decrease
- b. Incidents of unintentional injury (accidents) will decrease
- c. Families will be more informed on ASD child safety with a reduction of stress on the family.
- d. Persons with ASD will be safer in home and community settings



In Closing

It is the hope of the Autism Society of America, on behalf of the many families and individuals with ASD across the country, that safety outcomes will improve for children and adults with ASD and that fewer will be injured and die.



In Closing

We further hope that with continued efforts by the Autism Society and other autism organizations, parents, professionals and advocates and the federal government with the facilitation of this Committee, that greater safety awareness will be achieved and that safety for all persons with ASD becomes a

shared value

for all members of the autism community.

Thank You

Presented by Jack Scott, PhD, BCBA-D

Member, Autism Society Panel of Professional Advisors

Florida Atlantic University

jscott@fau.edu

561-251-4104

Members of the White Paper on ASD Safety Committee

Barbara Becker-Cottrill, Ed. D, BCBA, Chair Autism Society of America (ASA) Panel of Professional Advisors

James Ball, Ed.D., BCBA-D, JB Consulting, ASA Past Chair, Member of ASA Panel of Professional Advisors

Jack Scott, Ph. D., BCBA-D, Executive Director Florida Atlantic University Center for Autism and Related Disabilities (CARD),
Member of ASA Panel of Professional Advisors

Marc Ellison, Ed.D., LPC, Executive Director The West Virginia Autism Training Center at Marshall University, Member of the
ASA Panel of Professional Advisors

Kate Palmer, MA, CCP, CAS, Chair Panel of People on the Spectrum of Autism, President/CEO of Global and Regional
Asperger Syndrome Partnership (GRASP)

Kim Musheno, BA, Vice President of Public Policy for the Autism Society of America

Captain Bill Cannata, Program Director for the Autism and Law Enforcement Education Coalition, Massachusetts

LT. Jimmy Donahoe, Pensacola Florida Police Department & ASA Safe and Sound Task Force



Discussion



Break

Meeting of the IACC



Morning Agenda

10:45

Committee Business

Susan Daniels, Ph.D.

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

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

Director, National Institute of mental Health and Chair, IACC

Meeting of the IACC



Morning Agenda

- 11:00** **Discussion of IACC Workshop: Addressing the Health Needs of People on the Autism Spectrum**
- Davis Amaral, Ph.D.**
Distinguished Professor, Department of Psychiatry and Behavioral Science, University of California, Davis (UC), UC Davis MIND Institute Co-Chair, IACC Health Outcomes Working Group
- 12:00 PM** **Lunch**

IACC Committee Business

IACC Full Committee Meeting
October 17, 2018



Susan A. Daniels, Ph.D.

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

Thank you to OARC Staff



Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

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

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

Matthew Vilnit, M.B.A.
Operations Coordinator

Angelice Mitrakas, B.A.
Management Analyst

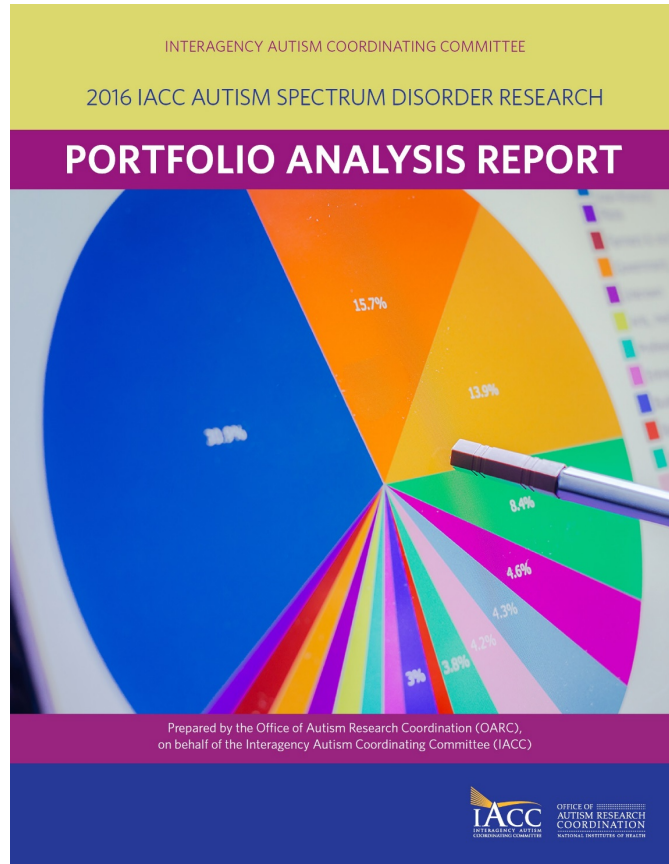
Jeff Wiegand, B.S.
Web Development Manager

Autism CARES Act Report to Congress – in progress



- Report details progress on activities related to ASD and other developmental disorders across the federal government (required by the Autism CARES Act)
- OARC coordinated responses from Departments/agencies and prepared the report
- Final report expected in Fall 2018

IACC Portfolio Analysis



- *2016 IACC Portfolio Analysis Report*
 - Final report expected by the end of 2018
 - This is the first *Portfolio Analysis Report* that codes projects to the new objectives of the *2016-2017 IACC Strategic Plan*
- *2017 IACC Portfolio Analysis*
 - OARC is in the process of collecting 2017 data from funders
 - Final report expected in 2019

2018 IACC Strategic Plan update



- Proposed plan for 2018 update: A summary of the IACC's activities and progress to date related to the *Strategic Plan*, to include:
 - Summary of Health Outcomes working group and workshop
 - Summary of *2016 IACC Portfolio Analysis Report*
 - Summary of Autism CARES Act *Report to Congress*
- Will be prepared by OARC staff and reviewed/approved by the IACC
- Proposed update would be completed by the end of 2018

Improving Health Outcomes for Individuals on the Autism Spectrum WG



- The IACC voted to convene a working group on health and wellness issues for individuals with ASD
- The Working Group will explore ways to:
 - Support research to better understand the health conditions that affect individuals on the autism spectrum
 - Increase community/provider awareness of these conditions and their treatment
 - Foster development of practice guidelines, policies, service approaches and other efforts to improve the health and quality of life of people on the autism spectrum



Working Group Scope



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





Working Group Members

Co-Chairs

- David Amaral, Ph.D., University of California, Davis

IACC and Federal Members

- Patricia Dietz, Dr.P.H., M.P.H., Centers for Disease Control and Prevention
- Jennifer Johnson, Ed.D., Administration for Community Living
- Alice Kau, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Kevin Pelphrey, Ph.D., George Washington University and Children's National Medical Center ●

- Julie Lounds Taylor, Ph.D., Vanderbilt University

- Denise Juliano-Bult, M.S.W., National Institute of Mental Health
- Scott Michael Robertson, Ph.D., U.S. Department of Labor ●
- Marcella Ronyak, Ph.D., LCSW, CDP, Indian Health Service ●
- Nina Schor, M.D., Ph.D., National Institute of Neurological Disorders and Stroke
- Alison Tepper Singer, M.B.A., Autism Science Foundation ●

● Self-advocate ● Parent/Family member

Working Group Members



External Members

- Gregory Barnes, M.D., Ph.D., University of Louisville School of Medicine
- Timothy Buie, M.D., Harvard Medical School
- Dan Coury, M.D., The Ohio State University College of Medicine
- Lisa Croen, Ph.D. Kaiser Permanente Northern California
- Orrin Devinsky, M.D., New York University
- Sarah Gardner, MIND Institute, University of California, Davis ●
- Dena Gassner, M.S.W., Adelphi University ● ●
- Antonio Hardan, M.D., Stanford University Medical Center
- Joseph Joyce, M.B.A., Autism Society of America ●
- Connor Kerns, Ph.D., University of British Columbia
- Bryan King, M.D., M.B.A., University of California, San Francisco

● Self-advocate ● Parent/Family member

Working Group Members



External Members

- Clarissa Kripke, M.D., University of California, San Francisco
- Beth Ann Malow, M.D., M.S., Vanderbilt University Medical Center ●
- Micah Mazurek, Ph.D., University of Virginia
- Donna Murray, Ph.D., University of Cincinnati
- Christina Nicolaidis, M.D., M.P.H., Oregon Health and Science University ●
- Dora Raymaker, Ph.D., Portland State University ●
- Elliott Sherr, M.D., Ph.D., University of California, San Francisco
- Matthew Siegel, M.D., Tufts University
- Sarah Spence, M.D., Ph.D., Harvard Medical School
- Jeremy Veenstra-VanderWeele, M.D., Columbia University

● Self-advocate ● Parent/Family member

Expected Working Group Activities and Products



- Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 27, 2018)
- A written document providing an update on issues
- Continued discussions in Working Group conference calls, Working Group meetings, and/or IACC full committee meetings
- Working Group activities will run from September 2018 – September 2019

Workshop Summary

Addressing the Health Needs of People on the Autism Spectrum



- An overview of health conditions that affect people with ASD across the lifespan was presented
- Three co-occurring conditions were discussed:
 - Epilepsy
 - Gastrointestinal Disorders
 - Sleep Disturbances
- The working group also discussed approaches to improve patient-provider interactions

Workshop Summary

Addressing the Health Needs of People on the Autism Spectrum



- A number of policy issues were raised during the workshop:
 - Development of better tools and guidelines for primary care physicians to survey for medical conditions
 - The need for adult physicians to receive training in how to work with patients with disabilities such as ASD
 - The need for guidelines on how to address common health conditions in people with ASD
 - Developing a team approach for providers, patients, and caregivers, including consultation of specialists during primary care visits
 - Allowing for longer appointments or other accommodations for individuals with disabilities (would need support from insurance companies)

Workshop Summary

Addressing the Health Needs of People on the Autism Spectrum



Key takeaway

Families, clinicians and researchers are all on the same page concerning the importance of treating co-occurring health conditions to improve the quality of life for autistic individuals.





Working Group Next Steps

- There are other co-occurring health conditions that need to be addressed, particularly co-occurring mental health conditions:
 - Anxiety
 - Suicide
 - ADHD
 - Self-injurious behavior
- Unanswered questions to consider:
 - Does the underlying biology that causes autism also cause the co-occurring health conditions?
 - To what extent will reduction of co-occurring conditions help to ameliorate the core features of autism? e.g. If sleep was better regulated, would the symptoms of social impairment be reduced?

2018 Summary of Advances Discussion

IACC Full Committee Meeting
October 17, 2018



Susan A. Daniels, Ph.D.

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

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

Director, National Institute of Mental Health
Chair, IACC

Question 1: Screening and Diagnosis



SCIENTIFIC
REPORTS



May 2018

EEG Analytics for Early Detection of Autism Spectrum Disorder: A data-driven approach.

Bosl WJ, Tager-Flusberg H, Nelson CA.

npj | Digital Medicine

Jun 2018

Automatic Emotion and Attention Analysis of Young Children at Home: A ResearchKit Autism Feasibility Study.

Egger HL, Dawson G, Hashemi J, Carpenter KLH, Espinosa S, Campbell K, Brotkin S, Schaich-Borg J, Qiu Q, Tepper M, Baker JP, Bloomfield RA, and Sapiro G.

Question 1: Screening and Diagnosis



JAMA Pediatrics

Jul 2018

Prevalence and Variation of Developmental Screening and Surveillance in Early Childhood.

Hirai AH, Kogan MD, Kandasamy V, Reuland C, Bethell C.

Question 2: Underlying Biology



*Journal of Autism
and Developmental Disorders*

Jan 2018

Risk Factors for Self-injurious Behavior in an Inpatient Psychiatric Sample of Children with Autism Spectrum Disorder: A Naturalistic Observation Study.

Handen BL, Mazefsky CA, Gabriels RL, Pedersen KA, Wallace M, Siegel M; Autism and Developmental Disorders Inpatient Research Collaborative (ADDIRC).

**Molecular
Psychiatry**

Jun 2018

Autism-specific maternal autoantibodies produce behavioral abnormalities in an endogenous antigen-driven mouse model of autism.

Jones KL, Pride MC, Edmiston E, Yang M, Silverman JL, Crawley JN, Van de Water J.

Question 2: Underlying Biology



nature
neuroscience

Sept 2018

Sexually dimorphic behavior, neuronal activity, and gene expression in Chd8-mutant mice.

Jung H, Park H, Choi Y, Kang H, Lee E, Kweon H, Roh JD, Ellegood J, Choi W, Kang J, Rhim I, Choi SY, Bae M, Kim SG, Lee J, Chung C, Yoo T, Park H, Kim Y, Ha S, Um SM, Mo S, Kwon Y, Mah W, Bae YC, Kim H, Lerch JP, Paik SB, Kim E.

nature
neuroscience

Apr 2018

Social deficits in Shank3-deficient mouse models of autism are rescued by histone deacetylase (HDAC) inhibition.

Qin L, Ma K, Wang ZJ, Hu Z, Matas E, Wei J, Yan Z.

Question 3: Risk Factors



Jun 2018

Analysis of shared heritability in common disorders of the brain.
The Brainstorm Consortium



Paternally inherited cis-regulatory structural variants are associated with autism.

Brandler WM, Antaki D, Gujral M, Kleiber ML, Whitney J, Maile MS, Hong O, Chapman TR, Tan S, Tandon P, Pang T, Tang SC, Vaux KK, Yang Y, Harrington E, Juul S, Turner DJ, Thiruvahindrapuram B, Kaur G, Wang Z, Kingsmore SF, Gleeson JG, Bisson D, Kakaradov B, Telenti A, Venter JC, Corominas R, Toma C, Cormand B, Rueda I, Guijarro S, Messer KS, Nievergelt CM, Arranz MJ, Courchesne E, Pierce K, Muotri AR, Iakoucheva LM, Hervas A, Scherer SW, Corsello C, Sebat J.

Question 3: Risk Factors



The American Journal of
Psychiatry

Aug 2018

Association of Maternal Insecticide Levels With Autism in Offspring From a National Birth Cohort.

Brown AS, Cheslack-Postava K, Rantakokko P, Kiviranta H, Hinkka-Yli-Salomäki S, McKeague IW, Surcel HM, Sourander A.

nature
genetics

Jul 2018

An interactome perturbation framework prioritizes damaging missense mutations for developmental disorders.

Chen S, Fragoza R, Klei L, Liu Y, Wang J, Roeder K, Devlin B, Yu H.

Question 3: Risk Factors



Science Advances | AAAS
SIGNIFICANT RESEARCH. GLOBAL IMPACT

May 2018

Dynamical features in fetal and postnatal zinc-copper metabolic cycles predict the emergence of autism spectrum disorder.

Curtin P, Austin C, Curtin A, Gennings C, Arora M; (for the Emergent Dynamical Systems Group), Tammimies K, Willfors C, Berggren S, Siper P, Rai D, Meyering K, Kolevzon A, Mollon J, David AS, Lewis G, Zammit S, Heilbrun L, Palmer RF, Wright RO, Bölte S, Reichenberg A.

nature

Mar 2018

De novo mutations in regulatory elements in neurodevelopmental disorders.

Short PJ, McRae JF, Gallone G, Sifrim A, Won H, Geschwind DH, Wright CF, Firth HV, FitzPatrick DR, Barrett JC, Hurles ME.

Question 3: Risk Factors



May 2018

Dysbiosis of microbiome and probiotic treatment in a genetic model of autism spectrum disorders.

Tabouy L, Getselter D, Ziv O, Karpuj M, Tabouy T, Lukic I, Maayouf R, Werbner N, Ben-Amram H, Nuriel-Ohayon M, Koren O, Elliott E.



May 2018

An analytical framework for whole-genome sequence association studies and its implications for autism spectrum disorder.

Werling DM, Brand H, An JY, Stone MR, Zhu L, Glessner JT, Collins RL, Dong S, Layer RM, Markenscoff-Papadimitriou E, Farrell A, Schwartz GB, Wang HZ, Currall BB, Zhao X, Dea J, Duhn C, Erdman CA, Gilson MC, Yadav R, Handsaker RE, Kashin S, Klei L, Mandell JD, Nowakowski TJ, Liu Y, Pochareddy S, Smith L, Walker MF, Waterman MJ, He X, Kriegstein AR, Rubenstein JL, Sestan N, McCarroll SA, Neale BM, Coon H, Willsey AJ, Buxbaum JD, Daly MJ, State MW, Quinlan AR, Marth GT, Roeder K, Devlin B, Talkowski ME, Sanders SJ.

Question 4: Treatments and Interventions



Journal of
Consulting and
Clinical
Psychology

Jul 2018

Cluster randomized trial of the classroom SCERTS intervention for elementary students with autism spectrum disorder.

Morgan L, Hooker JL, Sparapani N, Reinhardt VP, Schatschneider C, Wetherby AM.

Question 5: Services



Jul 2018

Sustainability of Early Intensive Behavioral Intervention for Children With Autism Spectrum Disorder in a Community Setting.

Waters CF, Amerine Dickens M, Thurston SW, Lu X, Smith T.

Question 6: Lifespan Issues



**AUTISM
RESEARCH**
January, 2017 | Volume 10 | Number 1

Aug 2018

Autism spectrum disorder symptoms from ages 2 to 19 years: Implications for diagnosing adolescents and young adults.

Bal VH, Kim SH, Fok M, Lord C.

PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Apr 2018

Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD.

Davignon MN, Qian Y, Massolo M, Croen LA.

Question 6: Lifespan Issues



*Journal of Autism
and Developmental Disorders*

Aug 2018

Understanding Service Usage and Needs for Adults with ASD: The Importance of Living Situation.

Dudley KM, Klinger MR, Meyer A, Powell P, Klinger LG.



Discussion



Lunch

Meeting of the IACC



Afternoon Agenda

1:00 PM **Public Comment Session**

Joshua Gordon

Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH and
Executive Secretary, IACC

Oni Celestin, Ph.D.

Science Policy Analyst

Office of Autism Research Coordination, NIMH

Meeting of the IACC



Afternoon Agenda

2:00

Panel: The ABLE Act and Financial Planning for People with Disabilities

Stuart Spielman, Esq.

Senior Vice President, Advocacy, Autism Speaks

Bette Ann Mobley

Director, Maryland ABLE

Colin Meeks, C.F.P., Ch.F.C., C.L.U.

Certified Financial Planner, Maryland Financial Advocates;
Host, Special Needs Connection Podcast

Phoebe Ball, Esq.

Legislative Affairs Specialist, National Council on Disability

Meeting of the IACC



Afternoon Agenda

3:45

Break

4:00

Round Robin

5:00

Closing Remarks and Adjournment

Oral Public Comments

IACC Full Committee Meeting
October 17, 2018



Susan A. Daniels, Ph.D.

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

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

Director, National Institute of Mental Health
Chair, IACC

Written Public Comments

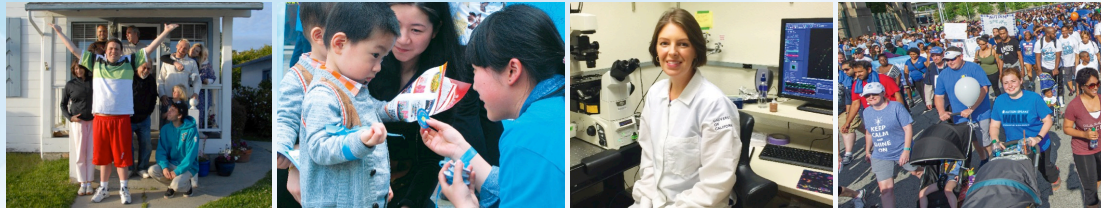


Oni Celestin, Ph.D.
Science Policy Analyst
Office of Autism Research Coordination, NIMH

Panel: The ABLE Act and Financial Planning for People with Disabilities



Stuart Spielman, Esq.
Bette Ann Mobley
Colin Meeks, C.F.P., Ch.F.C., C.L.U.
Phoebe Ball, Esq.



AUTISM SPEAKS®

ABLE: A New Way to Save

Presented by Stuart Spielman, Senior Vice President, Advocacy

October 17, 2018



529 Plans

- To understand ABLE plans, it's worthwhile to trace the history of their statutory relative, education savings plans, which are commonly known as 529 plans (after the section in the Internal Revenue Code where these plans can be found).
- Today's 529 plans originated out of an effort by the state of Michigan in the mid-1980's to make college more affordable. That effort ultimately culminated in the passage of federal legislation in 1996, establishing section 529 of the Code. Subsequent federal legislation shaped the benefits available under current law.



Financial Challenges of Disability

- 529 plans have provided a convenient and popular means of savings for education expenses. Of course, not every child, disabled or not, goes on to college. Moreover, many children and adults with disabilities have significant current or anticipated expenses. Planning for those expenses has often proven difficult.
- Compounding the usual difficulties of saving is the reliance of many people with disabilities on programs like Medicaid and Supplemental Security Income (SSI). These programs are means tested, meaning that even a small amount of savings can make an individual ineligible for benefit programs. Rather than risk jeopardizing eligibility for these programs, people with disabilities have often foregone saving.

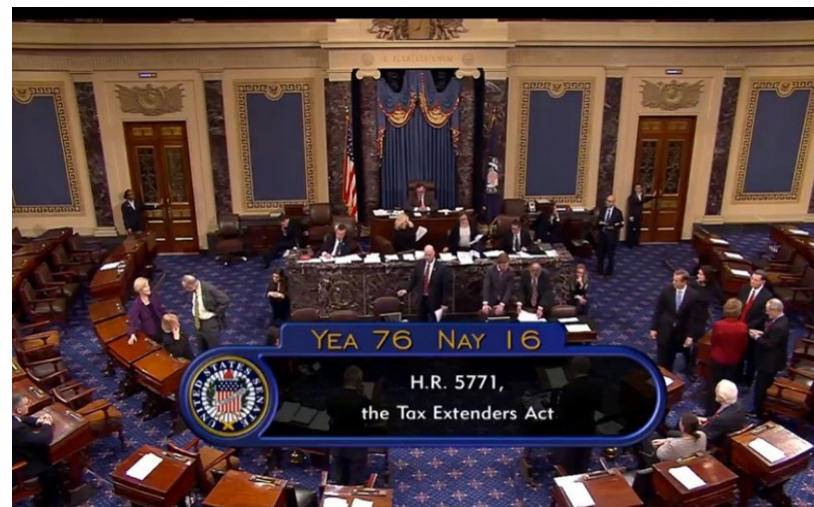
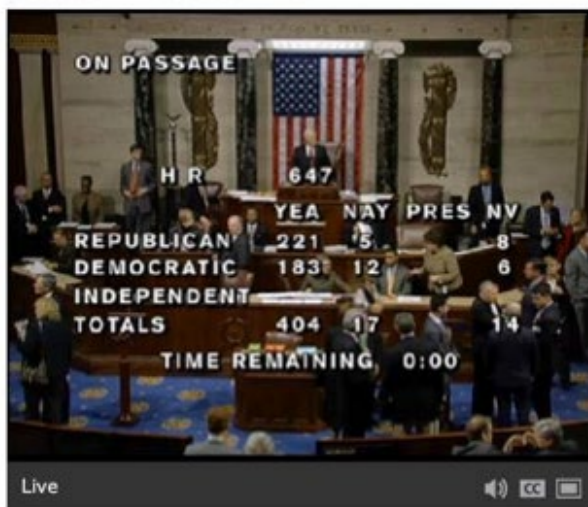


Economic Impact of Autism

- Children with autism are
 - 1.5 times more likely to belong to low-income families.
 - 3 times more likely to belong to families who experience difficulty in paying for food and housing, compared to children without disabilities.
- Parents of children with ASD are about 15 times more likely to have stopped working or reduce work hours compared to children without disabilities.
- The lifetime cost of supporting one person with autism can range from \$1.4-\$2.4 million.

ABLE Becomes Law

- Beginning around the mid-2000's, advocates from the disability community coalesced around an effort to create an analog to the 529 plans.
- After about a decade of effort, Congress passed and the president signed into law the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014 as part of the Tax Increase Prevention Act of 2014. The margins of passage of the legislation were extraordinary.



Steve Beck

I would be remiss if I did not mention the namesake of the Act, Steve Beck. Steve passed away after the House acted but before the bill came up in the Senate. Steve was committed to ensuring that both of his daughters lived the fullest life possible.





ABLE Continues To Enjoy Strong Congressional Support

The FY '19 Labor, Health and Human Services, Education, and Related Agencies Conference Report (H.R. 6157) encourages the Administration on Community Living, the National Council on Disability, and other federal agencies to raise awareness on the eligibility and benefits of ABLE accounts. The National Council on Disability serves as an interagency coordinator to ensure consistency across federal agencies and programs.



Steve's Legacy – A Viable and Growing Financial Product

Historical ABLA Assets and Number of Accounts, 2Q 2016-2Q 2018			
	AUM	Accounts	Average Account Size
2Q 2018	119,985,967	25,171	4,767
1Q 2018	98,595,352	20,653	4,774
4Q 2017	71,978,679	17,314	4,157
3Q 2017	48,520,170	13,190	3,679
2Q 2017	35,580,625	10,114	3,518
1Q 2017	24,652,538	7,019	3,512
4Q 2016	13,910,026	4,064	3,423
3Q 2016	4,133,146	1,934	2,137
2Q 2016	820,000	820	1,000

Source: Strategic Insight



ABLE Basics: How it Works

Wednesday, October 10, 2018, 1:00 p.m. - 2:00 p.m. ET

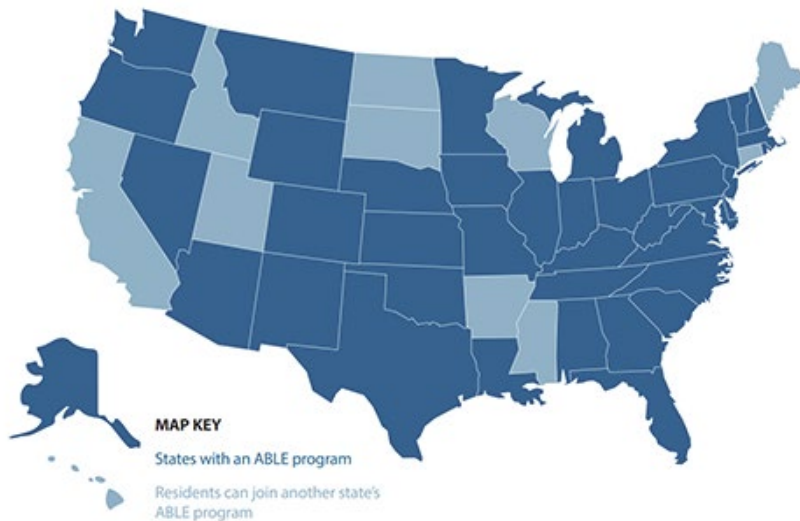
ABLE Act



Achieving a Better Life Experience Act of 2014 created savings and investment accounts for individuals with disabilities

Individuals with disabilities and families came together to pass this law to ensure individuals with disabilities did not remain poor.

ABLE in Your State



39 states and DC have launched ABL programs

AND federal law allows U.S. citizens to open accounts in any state, not just their home states.

ABLE Growth



25,619

total ABLE accounts
opened nationwide

**\$120
million**

invested in ABLE accounts nationally

*as of 6/30/18

The Purpose of ABLE



ABLE Accounts do not affect eligibility for benefits programs

SSI

Medicaid

ABLE = ASSET SHIELD



1

ABLE Accounts are asset shields, not income shields. Beneficiary's own wages still count as income even if contributed to an ABLE Account

2

SSI Consideration: Balances over \$100,000 count as a resource – but SSI merely suspended, not terminated. Medicaid benefits maintained regardless of account balance.

BENEFITS OF ABLE ACCOUNTS



Dramatically increases ability to save:

BEFORE ABLE

- ✗ Could not save over \$2,000 if on SSI
- ✗ Risk losing health care & other benefits

NOW WITH ABLE

- ✓ Can save well over \$2,000!
- ✓ Keep all your benefits!

BENEFITS OF ABLE ACCOUNTS



OWNERSHIP

Account is owned by the individual with the disability



FINANCIAL INDEPENDENCE

New Investment Opportunities



TAX BENEFITS

Earnings are tax-free on the state and federal level

ELIGIBILITY



Individuals with disabilities that occurred prior to age 26

PLUS ONE OF THE FOLLOWING:

- Eligible to receive SSI or SSDI due to disability; or
- Condition listed on SSA's "*List of Compassionate Allowances Conditions*"; or
- Self-certification

How to Enroll: Find a Plan at www.nast.org/able



Free online enrollment



Quick & easy – approx. 20 minutes



\$25-\$50 minimum opening deposit

Can be done by either:

Individual with disability
(Beneficiary)

or

Authorized Legal Representative
(parent, guardian, power of attorney)



Important Contribution Limits



LIFETIME LIMIT

Most states have a lifetime limit (i.e. how much can be in an account) that range from \$300,000 to \$500,000 balance limit



IF NOT EMPLOYED

\$15,000 per year from all sources



IF EMPLOYED

Up to \$27,060 per year

\$15,000 + wages up to an additional \$12,060

***HI and AK have different poverty levels*

ABLE Financial Planning Act



- Congress passed legislation in late 2017 to empower families who opened 529 accounts
- ABLE account owners can now rollover funds from a 529 account to an ABLE account

FUNDING YOUR ACCOUNT



EFT
ELECTRONIC FUNDS
TRANSFER

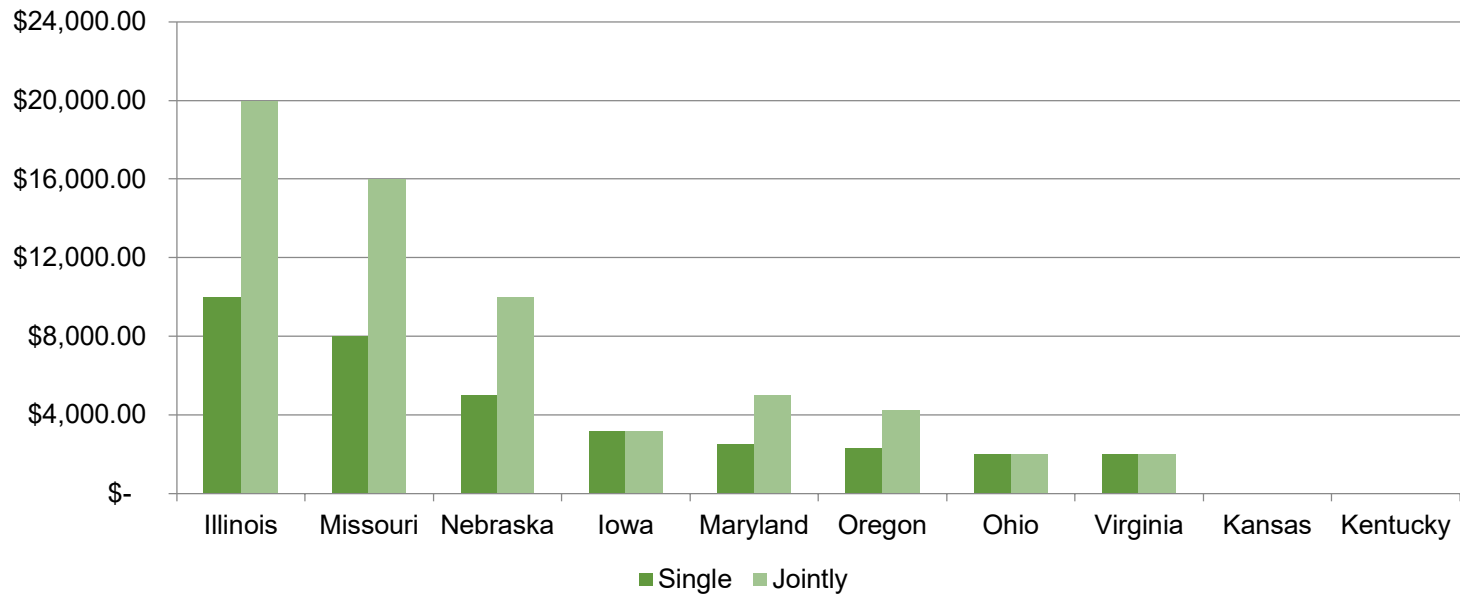


CHECK



State Income Tax Deduction

Some states offer a state income tax deduction on contributions made to the account.





SPENDING YOUR FUNDS

Withdrawals must be used on **“Qualified Disability Expenses”**



Housing & Rent



Basic Living Expenses



Transportation



Education



Assistive Technology



Financial Management



Health & Wellness



Legal Fees

And many more..

NON-QUALIFIED EXPENDITURES



If you spend on non-qualified expenditures, this could...



Affect Benefits

The amount of the expenditure may be considered a countable resource



Incur Penalties

Pay taxes plus 10% penalty on the earnings portion of the withdrawal

SPENDING FROM YOUR ACCOUNT



Free Withdrawals + No Limits



CHECKING & SAVINGS

Transfer to personal checking or savings



THIRD-PARTY

Pay with a Third-Party Check



PRE-PAID DEBIT CARD

Transfer onto Card

ABLE will not ask what you spend on, but benefits agencies and IRS can

ABLE ACCOUNT & SPECIAL NEEDS TRUSTS



Complementary tools that can be used together

- ✓ Trusts can be written or amended for distributions to an ABLE Account
- ✓ Trusts can accept unlimited cash and non-cash assets

Unique ABLE Account benefits

- ✓ Broader spending power (i.e. housing and food)
- ✓ No federal or state income tax on earnings
- ✓ Can be established, administered and owned by an individual with a disability

IF ACCOUNT HOLDER PASSES AWAY



Account will pass to the account holder's estate



The estate administrator notifies ABLE and can take over account access



No designated transfer upon death



If the beneficiary does not have a will then account will go through normal probate process

MEDICAID SERVICES



Medicaid can ask for payback in some cases, but there are protections:

Limitations
Medicaid Payback is only from date the account was opened



Deductions
Deduct Medicaid Buy-In premiums you paid

Outstanding Bills
Pay any outstanding bills for QDEs



Funeral Expenses
Pay for funeral and burial expenses

WE'RE HERE TO HELP!



chris@statetreasurers.org



www.nast.org/able

The 3 Things Your Special Needs Financial Plan MUST Have

Presented by:
Colin Meeks, CFP®

Disclosures

- **Colin Meeks is affiliated with LPL Financial**
- **Securities and Advisory services offered through LPL Financial, a registered investment advisor. Member FINRA/SIPC.**

THE 3 MUST Haves.....

- Updated Legal Documents
- Protection and Liquidity Plan
- A Planning Strategy That Mirrors Your Family's Goals and Priorities (updated annually like a tax return)

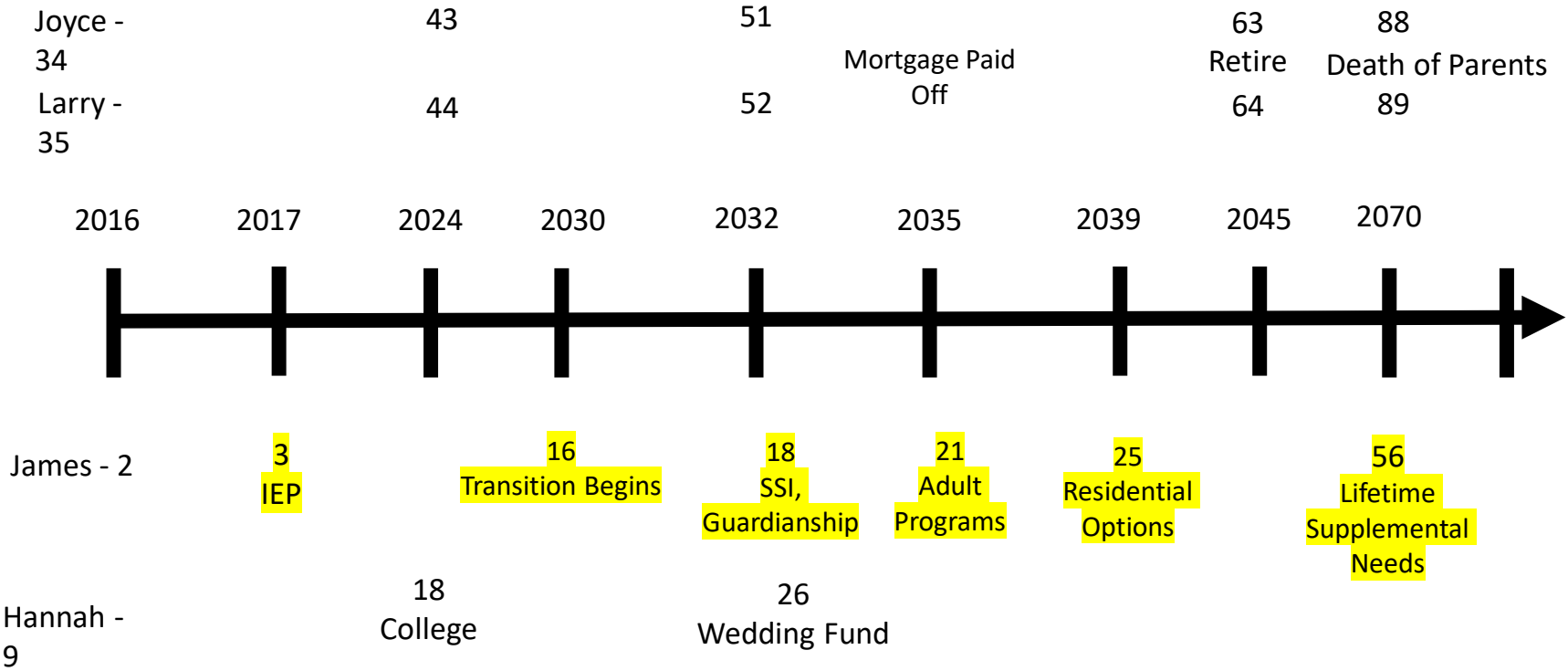
Special Needs Planning Is The Same, But Different

- You still must consider traditional financial planning techniques
- But you must add to that the fact that you are planning for 2 lifetimes – yours and your child with special needs.
- Special Needs planning adds an entirely new perspective
- What happens when I'm gone?
- We parents want our kids to thrive, not just survive.
- Lifetime Care versus Quality of Life
- Creating a Special Needs Planning Timeline is a the first step in creating a plan for your family

Benefits of Planning – Special Needs Focus

1. Provide Financial Security
2. Leverage Means Tested Public Benefits and any other government benefits
3. Select Proper Team to Provide Lifetime Management
4. Plan for Appropriate Housing
5. Utilize State Disability Systems for supports
6. Provide Ongoing System for Advocacy
7. Plan for Caregiving Needs
8. Coordinate Entire Extended Family's Planning
9. Protect Beneficiary from Predators
10. Preserve Assets for other Heirs

A Sample Planning Timeline



Common Misconceptions

- Planning is expensive (financial planners, attorneys, advocates, etc. – not planning is way more expensive)
- Someone will be there to help – both financially and with the processes and benefits (do you really want “free” help?)
- Planning is only for the wealthy
- Siblings will be there to step in
- I have life insurance and a will, that should do it.

Thank you

Colin Meeks

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Panel: The ABLE Act and Financial Planning for People with Disabilities



Phoebe Ball, Esq.
Legislative Affairs Specialist,
National Council on Disability



Discussion



Break



Round Robin



Adjournment

Next IACC Meeting



Wednesday, January 16th 2019