

Meeting of the Interagency Autism Coordinating Committee

April 19, 2016

National Institutes of Health
31 Center Drive
Building 31, C Wing, 6th Floor, Conference Room 10
Bethesda, MD 20892

Conference Call Access:

Phone: (888) 606-5948

Access Code: 5993307

Meeting of the IACC

Morning Agenda

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

Bruce Cuthbert, Ph.D.
Acting Director, NIMH and Chair, IACC

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

Meeting of the IACC

Morning Agenda

9:10 AM Update from HHS Office of the Assistant Secretary for Health

Thomas E. Novotny, M.D., M.P.H.
Deputy Assistant Secretary for Health
(Science and Medicine)
U.S. Department of Health and Human Services

9:40 Update on ABLE Act, Avonte's Law, Federal Employee Health Benefits Program

Stuart Spielman, J.D.
Senior Policy Advisor and Counsel
Autism Speaks



Update on ABLE Act, Avonte's Law, and the Federal Employees Health Benefits Program

Presented by Stuart Spielman,
Senior Policy Advisor and Counsel
April 19, 2016

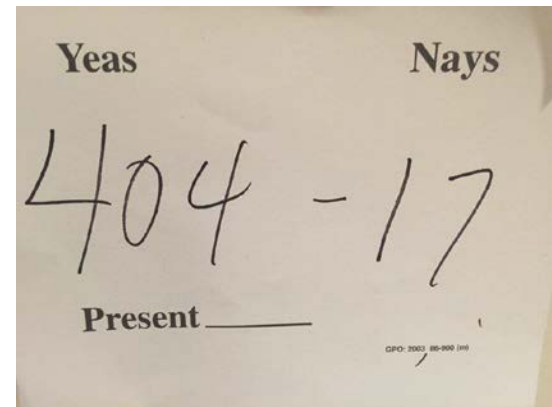
Some Context and Background for ABLE

Many in the autism community have limited assets and difficulty affording health care, housing, and other necessities. People with disabilities earn less and often rely on programs that are means-tested.

- In 2014 for people aged 18 to 64 with a disability, the poverty rate was 28.5 percent. For people aged 18 to 64 without a disability, the poverty rate was 12.3 percent.
- The Supplemental Security Income (SSI) program has a \$2,000 resource limit for individuals. By qualifying for SSI, individuals in most states also qualify for Medicaid. When SSI recipients have income and resources over the limit, their SSI benefits are suspended but they remain eligible for Medicaid.

The ABLE Act

The Stephen Beck, Jr., Achieving a Better Life Experience (ABLE) Act, which became law on December 19, 2014, creates a new option for *some* people with disabilities and their families to save for the future while protecting eligibility for public benefits.

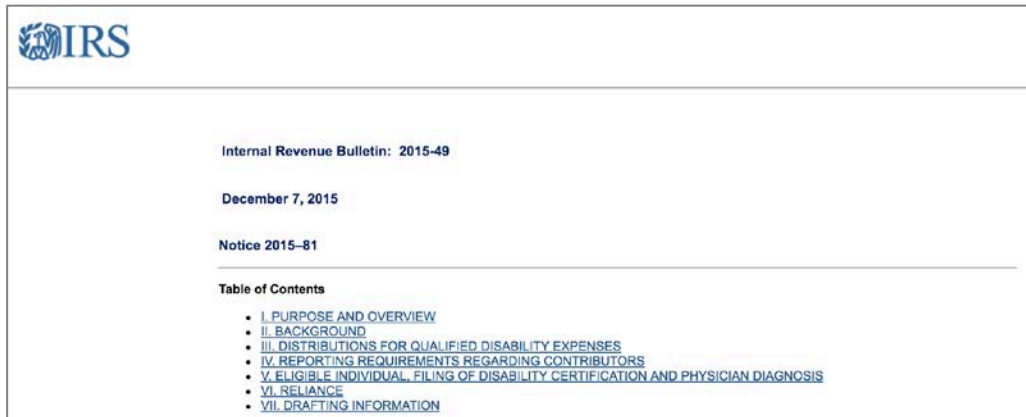


The ABLE Act

The act authorizes states to establish a qualifying program under which an account may be created by or for an individual with autism or another disability.

- Modeled after college savings accounts, ABLE accounts enable people to save for disability-related expenses on a tax-preferred basis.
- Assets in ABLE accounts will generally be disregarded by means-tested federal programs like SSI and Medicaid.

Eligibility



Federal law determines who is eligible for an ABLÉ account. To qualify, an individual must

- 1) be disabled before age 26; and
- 2) be entitled to benefits under title II (SSI) or title XVI (SSDI) of the Social Security Act

OR

file a “disability certification” under guidance provided by the IRS.

Rules, Rules, Rules

ABLE accounts have features both common to and distinct from college savings accounts:

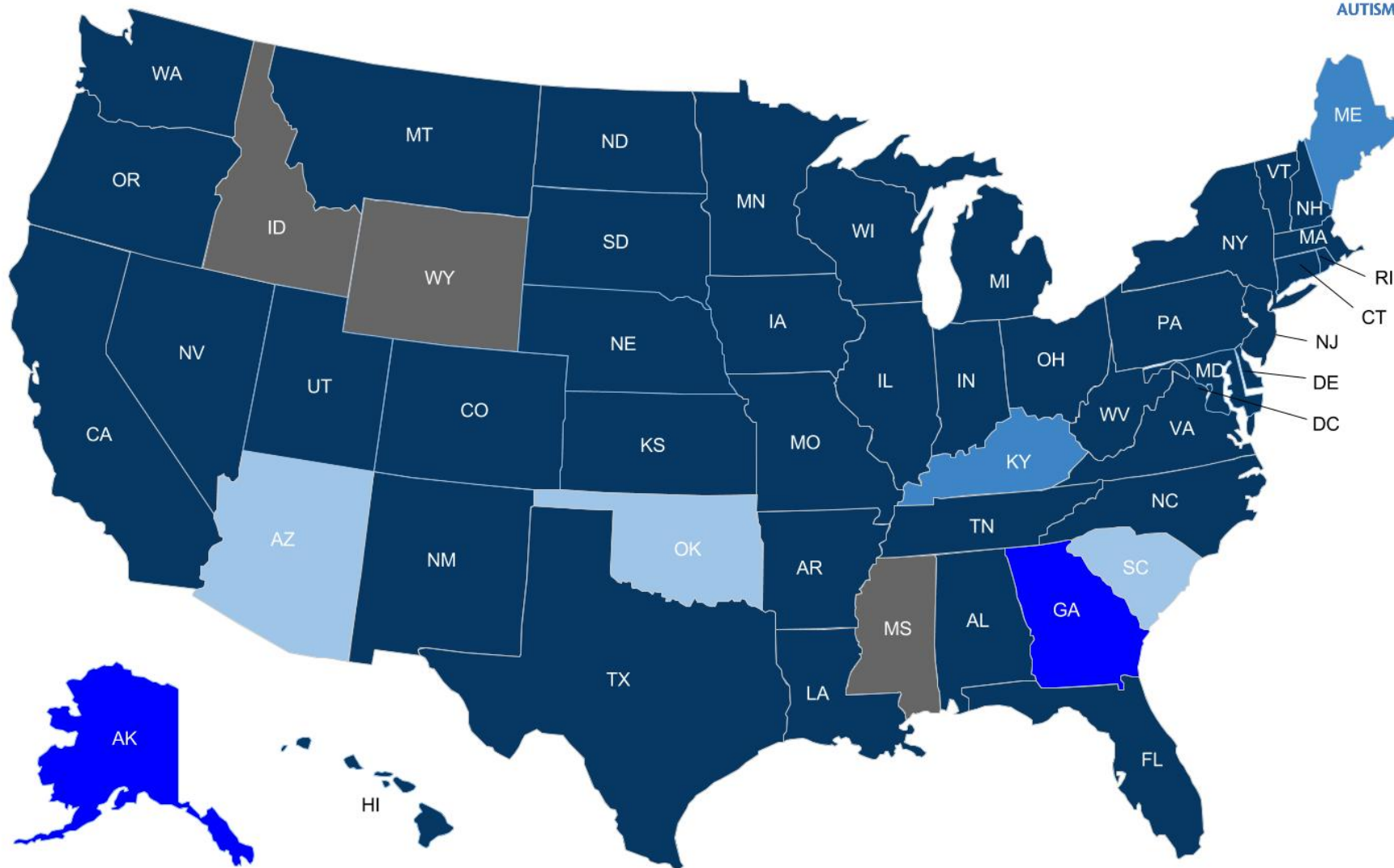
- An eligible individual may have only one ABLE account.
- The beneficiary of an ABLE account owns the account.
- Total annual contributions may not exceed the federal gift tax exclusion, which is currently \$14,000.
- Aggregate contributions may not exceed the state limit for college savings accounts.
- When an ABLE account beneficiary who receives Medicaid benefits dies, amounts remaining in the account may be subject to a claim for medical assistance paid on behalf of the beneficiary.
- A resident of one state can open an ABLE account in the resident's home state or any other state.

How May Funds from an ABLE Account Be Used?

Distributions from an ABLE account may be made for qualified disability expenses related to the individual's disability or blindness and made for his or her benefit, including the following:

- Education
- Housing
- Transportation
- Employment training and support
- Assistive technology and personal support services
- Health, prevention, and wellness
- Financial management and administrative services
- Legal fees
- Expenses for oversight and monitoring
- Funeral and burial expenses
- Any other expenses approved by the Secretary of the Treasury

State ABLE Implementation Map 2016



Signed by Governor

Enacted legislation authorizing
study of ABLE program

Pending Governor's
Signature

Introduced

No bill

ABLE Program Implementation



*Part of a multi-state consortium working to implement accounts

Future Directions

Three new ABLE bills are pending in Congress:

- The ABLE to Work Act (H.R. 4795/S. 2702) would allow individuals and their families to save more money in an ABLE account if the beneficiary works and earns income.
- The ABLE Financial Planning Act (H.R. 4794/S. 2703) would allow amounts in a college savings account to be rolled over into an ABLE account and amounts in an ABLE account to be rolled over into college savings account.
- The ABLE Age Adjustment Act (H.R. 4813/S. 2704) would raise the qualifying age for ABLE accounts from 26 to 46.

Avonte's Law

Following the death of 14-year old Avonte Oquendo in 2014, Senator Chuck Schumer of New York introduced legislation to safeguard children with autism who wander. The legislation did not pass the 113th Congress.

MISSING PERSON

Avonte Oquendo
New York City, NY. (Queens)



Name:	Avonte Oquendo
Date Missing:	October 4 th 2013
Missing From:	New York, NY. (Queens)
DOB:	August 30 th 1999
Age:	14 Years-Old
Hair Color:	Black, (short in a fade)
Height:	5' 3"
Weight:	125 lbs.
Eye Color:	Brown
Sex:	Male
Race:	Black / Hispanic
Complexion:	Light
Police/Sheriff:	New York City Police Dept.
Officer/Deputy Name:	
Officer's Phone #:	(718) 520-7856
Officer's Case #:	1091 112 th Pct. Case # 3767
TES Case #:	13-1399

14 year-old Avonte Oquendo disappeared in Long Island City (Queens) New York, New York on October 4th 2013. Avonte is Autistic, unable to verbally communicate and requires adult supervision, which makes it a critical situation to locate him. Avonte was last seen wearing a white Polo shirt with gray horizontal stripes, dark blue (almost black) pants and solid-black Jordan basketball shoes. It is urgent that Avonte is located immediately. If you have seen Avonte since his disappearance, if you know of his current whereabouts, or if you have any information concerning his disappearance; please contact the New York City Police Department at (718) 520-7856 - or call Texas EquuSearch at (281) 309-9500.



Call Toll Free 877-270-9500

Call Main: 281-309-9500

info@TexasEquuSearch.org



Facebook

Avonte's Law Becomes Kevin and Avonte's Law

- Senator Schumer reintroduced Avonte's Law in the 114th and current Congress.
- The legislation has since changed and been reintroduced by Senators Chuck Grassley, Thom Tillis, and Schumer as Kevin and Avonte's Law of 2016 (S. 2614). Kevin Curtis Wills was a nine-year old boy who jumped into the water near an Iowa park in 2008 and drowned.

Kevin and Avonte's Law Provisions

Reauthorizes the expired Missing Alzheimer's Disease Patient Alert Program (renaming it the Missing Americans Alert Program) and includes new provisions to support people with autism and other developmental disabilities.

- The bill allows Justice Department grants to be used by law enforcement agencies and nonprofits for education and training programs to prevent wandering.
- The grants will facilitate training and emergency protocols for school personnel, supply first responders with additional information and resources, and make local tracking technology programs available for individuals who may wander from a safe environment.
- The bill also includes privacy protections to protect the civil rights of children who use tracking devices.

Status of Kevin and Avonte's Law

On April 14th, the Senate Judiciary Committee reported out Kevin and Avonte's Law by a vote of 15-5. The bill has been placed on the Senate legislative calendar.



Companion Legislation

H.R. 4919, a companion to the Senate bill, was introduced in the House last week by Representative Chris Smith and Representatives Maxine Waters and Mike Doyle.



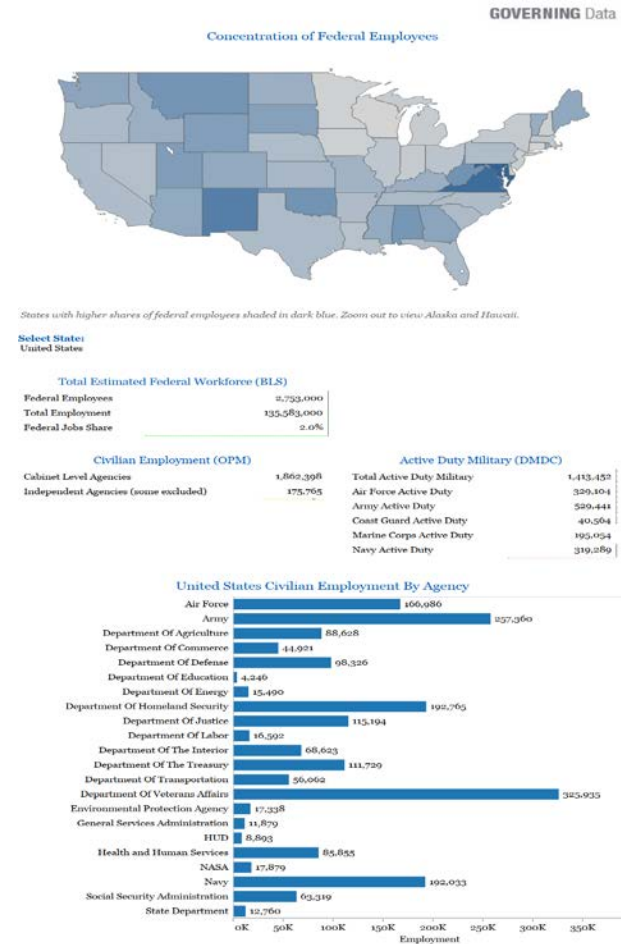
Overview of FEHB



- The Federal Employees Health Benefits Program is the largest employer-sponsored health insurance program in the country, covering about 8.2 million enrollees each year. Employees and retirees make up about half of that figure.
- The program allows competing private insurers to offer coverage within broad federal guidelines. Each carrier offers one or more plans. There are typically more than 250 different health plans to choose from.
- Generally, plans fall into two broad categories: fee-for-service (FFS) plans or health maintenance organizations (HMOs). FFS plans are generally available nationwide, and HMOs tend to be locally available.
- The most popular insurance carrier in FEHB is Blue Cross and Blue Shield (BCBS). It has a 67% market share. The top ten carriers in FEHB cover 94% of the market.

Federal Workforce

The federal jobs share is about 2% of the entire workforce. Federal employees are most concentrated in the District of Columbia (27%) Hawaii (6%), Maryland (6%), and Virginia (5%).

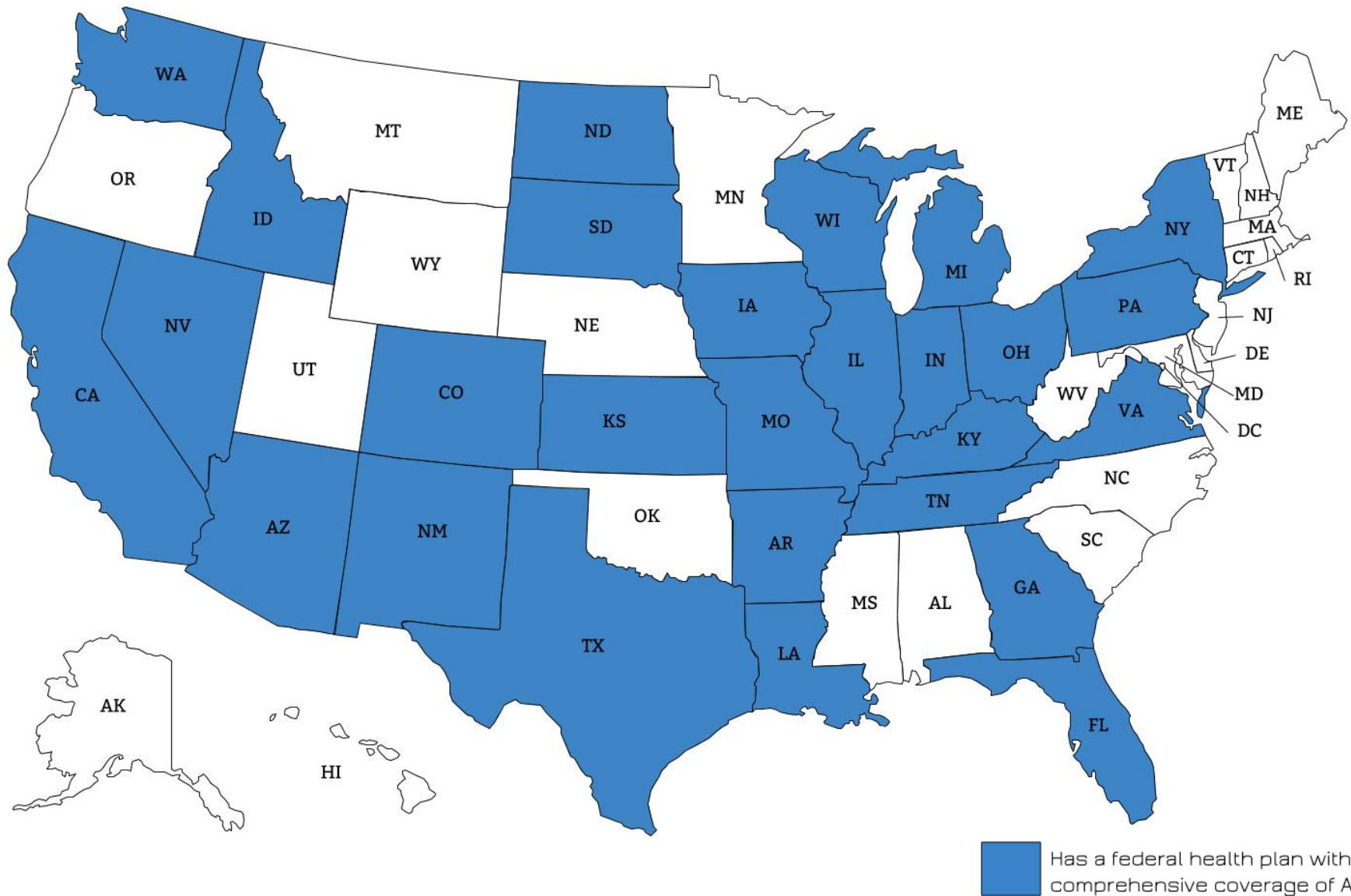


Source: Total federal workforce estimates compiled from BLS Current Employment Statistics for July 2013. Agency totals reported by U.S. Office of Personnel Management, current as of March 2013. Active duty military totals provided by Defense Manpower Data Center on Oct. 2, 2013.

ABA and FEHB

- In 2012 the Office of Personnel Management (OPM), which manages the FEHB program, recategorized applied behavior analysis (ABA) as a medical benefit and allowed plans to propose benefit packages that included ABA for 2013.
- Despite encouragement from OPM, coverage of ABA changed little from 2013 through 2016. The coverage map for 2016 looks as follows:

FEHB ABA Coverage Map 2016



Current FEHB ABA Coverage

The 2016 map shows significant gaps in ABA coverage:

- none of the 15 nationwide health plans cover ABA.
- Although close to 15% of the federal workforce lives around the national capital, only one area health plan offers coverage; no coverage is available for FEHB participants who live and work in the District of Columbia or Maryland.
- Major metropolitan areas such as Boston, Charlotte, and Nashville lack coverage.
- Arizona, Georgia, Idaho, Kentucky, North Dakota, South Dakota, Tennessee, and Washington gained coverage in 2016, but Massachusetts and West Virginia lost coverage from 2015.

Announcement of New Coverage for 2017

FEHB Program Carrier Letter
All FEHB Carriers

U.S. Office of Personnel Management
Healthcare and Insurance

Letter No. 2016-03

Date: February 26, 2016

Fee-for-service [3]

Experience-rated HMO [3]

Community-rated HMO [3]

SUBJECT: Federal Employees Health Benefits Program Call Letter

- In its annual call for rate and benefit proposals from FEHB carriers, OPM announced that carriers may no longer exclude ABA for the treatment of autism. “Appropriate coverage of ABA treatment by all plans/options is necessary.”
- The letter further states that “We expect all carriers to offer clinically appropriate and medically necessary treatment for children diagnosed with ASD. [Carriers] may provide coverage for ABA as a fully case managed benefit, a pre-authorized service, and/or an in-network benefit only.”

Meeting of the IACC

Morning Agenda - continued

**10:10 AM Advisory Committee on Increasing
Competitive Integrated Employment for
Individuals with Disabilities**

Scott Robertson, Ph.D.
Policy Advisor
U.S. Department of Labor
Office of Disability Employment Policy

10:40 Break

Meeting of the IACC

Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities

Meeting of the IACC

Break

Meeting of the IACC

Morning Agenda - continued

10:55 Committee Business

Susan Daniels, Ph.D.

Director

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

IACC Summary of Advances

IACC Strategic Plan Update

IACC Working Groups

12:00 PM Lunch

IACC Committee Business

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

IACC Full Committee Meeting

April 19, 2016

April is National Autism Awareness Month



NIMH Special Lecture for Autism Awareness Month

NIMH Special Lecture for Autism Awareness Month

IN A DIFFERENT KEY:

THE STORY OF AUTISM ***THEN AND TO COME***



JOHN DONVAN
CAREN ZUCKER

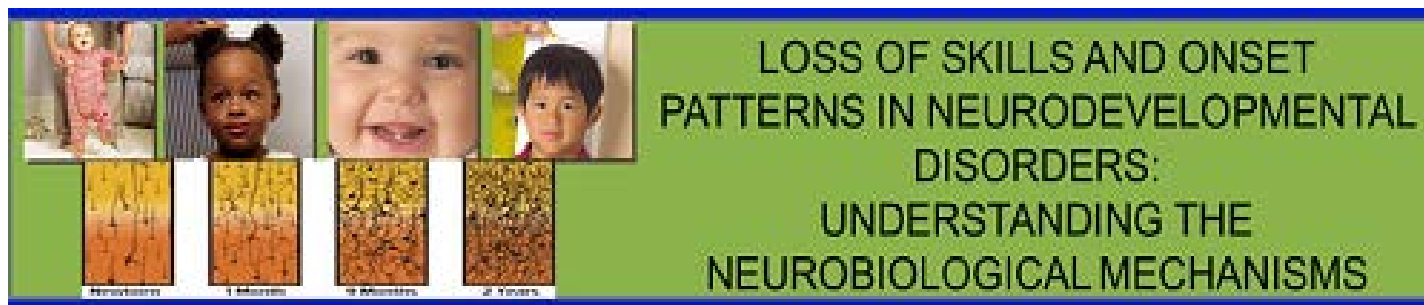
April 11, 2016

Other Recent OARC Sponsored Activities



NIMH Seminar Series: New Discoveries in Mental Health Research - Pathways to New Treatments in Autism Spectrum Disorder

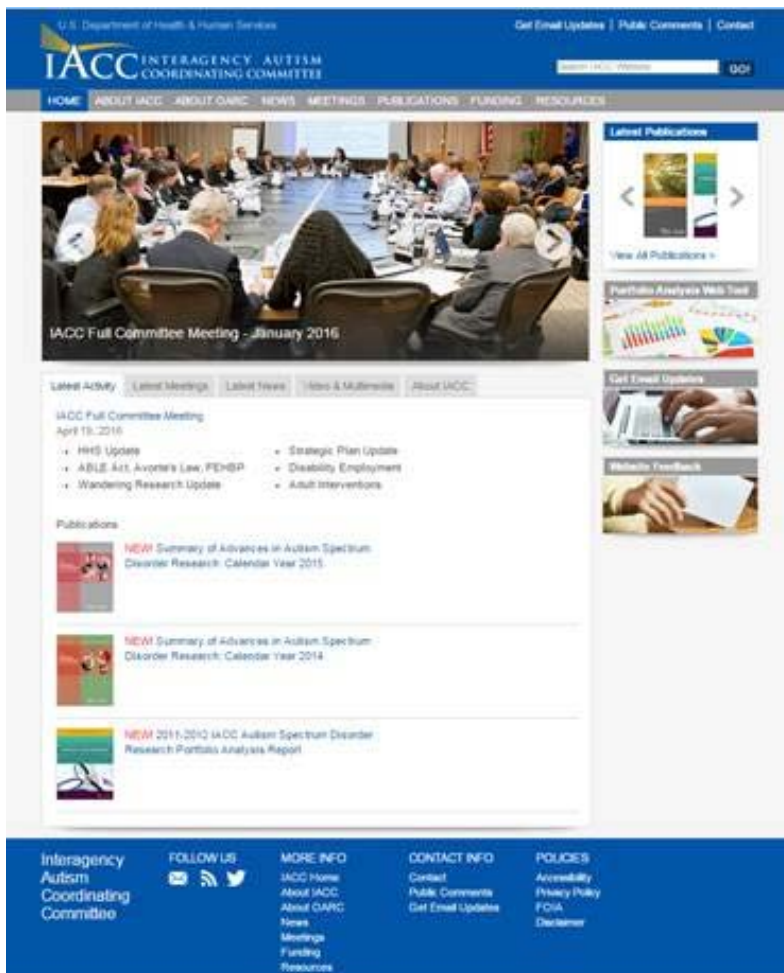
Dr. Jeremy Veenstra VanderWeele – April 13, 2016



NIMH Workshop – February 19, 2016

Agendas and videos available at www.iacc.hhs.gov

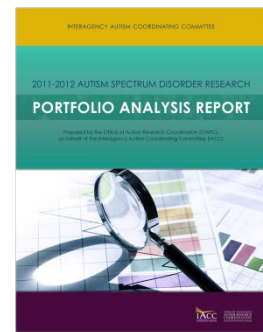
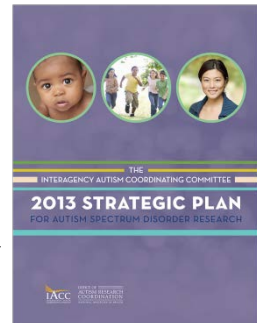
Introducing the IACC's **New Website!**



- Fresh, new look
- Streamlined layout
- Simple navigation
- New features:
 - More autism and disability news & reports
 - Funding opportunities
 - Resources
- Mobile-friendly

IACC Responsibilities

- Develop and annually update a strategic plan for ASD
- Develop and annually update a summary of advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding research or public participation in decisions regarding ASD



2015 IACC Summary of Advances



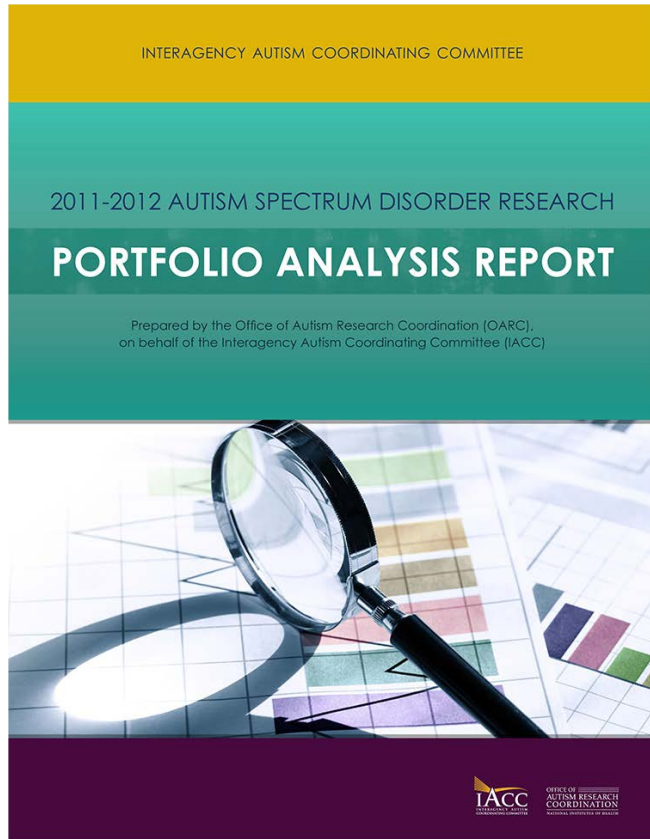
- Annual publication – required by CAA
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
 - Prevalence
 - Diagnosis
 - Biology
 - Risk factors
 - Interventions
 - Lifespan issues

2014 IACC Summary of Advances



- Annual publication – required by CAA
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
 - Prevalence
 - Diagnosis
 - Biology
 - Risk factors
 - Interventions
 - Lifespan issues

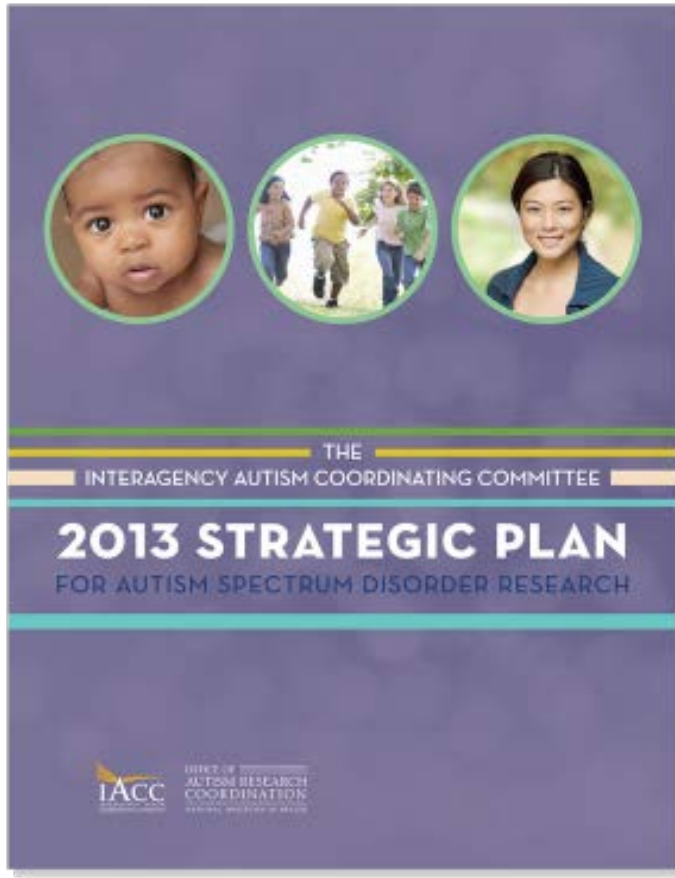
2011-2012 IACC Portfolio Analysis Report



Data sets in PA Web Tool

- Follow-up comprehensive report; overview data published in the 2013 IACC Strategic Plan Update
- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides detailed analysis of the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the funding landscape and current directions in ASD research
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan

IACC Strategic Plan Update



IACC Members volunteered to serve on 7 working groups to cover the 7 Strategic Plan Questions

Members nominated external experts to serve on the working groups

We are in the process of confirming membership of the working groups

Will begin scheduling series of calls To develop updates for each of the 7 Question areas

Structure of IACC Strategic Plan

Framed around 7 consumer-based Questions:

- **Question 1: When Should I Be Concerned?**
- **Question 2: How Can I Understand What Is Happening?**
- **Question 3: What Caused This to Happen and Can It Be Prevented?**
- **Question 4: Which Treatments and Interventions Will Help?**
- **Question 5: Where Can I Turn for Services?**
- **Question 6: What Does the Future Hold, Particularly for Adults?**
- **Question 7: What Other Infrastructure and Surveillance Needs Must Be Met?**

Structure of 2016 Strategic Plan

- **Introduction**
- **Question description and Aspirational Goal**
- **Progress toward the current SP Objectives**
- **Overview of Progress in the field:**
- **Research Update**
 - Science advances
 - Practice to research
 - Gaps, opportunities, needs
- **Services/Policy Update**
 - New programs and policies
 - New research evidence that can inform policy
 - Services needs/gaps, needed policy changes
- **Progress Toward Aspirational Goal**

2016 Strategic Plan Update

- **Recommendations to ensure non-duplication**
- **~3 Broad Objectives per Question (total ~21 for SP) accompanied by examples of responsive research and services projects/programs:**
- **Examples (Q1):**
 - **Increase early detection of ASD.**
 - Develop and improve screening tools.
 - Support awareness campaigns
 - Provide training for providers to enhance workforce
 - **Reduce health disparities in diagnosis.**
 - Increase outreach to special populations
 - Develop culturally adapted screening tools
 - Improve access to screening services in underserved areas
 - **Add budgetary requirements, Repeat x7**
- **Summary/Conclusion**

2016 Strategic Plan Update Resources

- **Data from the 2013 Portfolio Analysis to review research funding – summary data and grant lists**
- **Literature – from IACC Science Updates and Summary of Advances, literature identified by WGs**
- **External experts**
- **RFI? (archive of regular public comments also available)**
- **2012 services and research information from Report to Congress on ASD Activities**
- **Policy information from IACC members and policy experts**

2016 Strategic Plan Next Steps

- **Confirm SP WG membership**
- **Via e-mail – brainstorm some topics to include under the Questions – for public discussion in WGs**
- **Set working group meeting (conference call) schedule – May, June**
- **Review progress at next full committee meeting – July**
- **The update must be completed in this calendar year**

Topical Working Groups

- In January, IACC voted to form a housing working group
 - Will be sending out list of IACC member volunteers and soliciting nominations for external experts
 - Volunteers to date: Alison Singer, Melissa Harris, Jim Ball, Amy Goodman, David Mandell, Brian Parnell, Kevin Pelphrey, Julie Taylor – others welcome
- For discussion:
 - Safety working group?
 - Co-occurring conditions working group?

2015 Summary of Advances Process

The committee used the same process as previous years:

- OARC provided and full committee nominated peer reviewed research publications
- Committee selected up to 20 advances under each of the 7 areas of the Strategic Plan
- OARC provided short, lay-friendly summaries of the selected articles
- The 20 advances from each year were each combined into a booklet format – 2 booklets
- Final documents were completed in April 2016 – a 3 month timeframe

For discussion: Would you like the final product to be different next time; if so, how?

OFFICE OF
**AUTISM RESEARCH
COORDINATION**
.....
NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Director

Amanda Garton, M.S., M.P.P., Presidential Management Fellow

Angelice Mitrakas, B.A., Operations Coordinator

Karen Mowrer, Ph.D., Science Policy Analyst

Miguelina Perez, B.A., Management Analyst

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

Jeff Wiegand, B.S., Web Development Manager

Nam-Andrew Kim, B.S., UI/UX Designer

Meeting of the IACC

Lunch

Meeting of the IACC

Oral Comments Session

Meeting of the IACC

IACC Committee Member Discussion of Public Comments

Meeting of the IACC

Science Update

Bruce Cuthbert, Ph.D.

Acting Director, National Institute of Mental Health and Chair, IACC

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

Q1. When should I be concerned?



January 19, 2016

Parent-Reported and clinician-observed autism spectrum disorder (ASD) symptoms in children with attention deficit/hyperactivity disorder (ADHD): implications for practice under DSM-5.

Grzadzinski R, Dick C, Lord C, Bishop S.



January 2016

Predictors of Age of Diagnosis for Children with Autism Spectrum Disorder: The Role of Consistent Source of Medical Care, Race, and Condition Severity.

Emerson ND, Morrell HE, Neece C



February 2016

Screening for Autism Spectrum Disorder in Young Children: A Systematic Evidence Review for the U.S. Preventive Services Task Force

McPheeters ML, Weitlauf AS, Vehorn A, Taylor C, Sathe NA, Krishnaswami S, Fonnesebeck C, Warren ZE

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

Q1. When should I be concerned?



March 2016

Brief Report: The Feasibility and Effectiveness of an Advocacy Program for Latino Families of Children with Autism Spectrum Disorder

Burke MM, Magaña S, Garcia M, Mello MP

Q2. How can I understand what is happening?



February 20, 2016

Evaluation of Intestinal Function in Children with Autism and Gastrointestinal Symptoms

Kushak RI, Buie TM, Murray KF, Newburg DS, Chen C, Nestoridi E, Winter HS.



January 28 2016

Sleep and Behavioral Problems in Children with Autism Spectrum Disorder

Mazurek MO, Sohl K

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

February 2016

Medical and Behavioral Correlates of Depression History in Children and Adolescents with Autism Spectrum Disorder

Greenlee JL, Mosley AS, Shui AM, Veenstra-VanderWeele J, Gotham KO

Q3. What caused this to happen and can it be prevented?

PEDIATRICS®

February 2016

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

The Association of Maternal Obesity and Diabetes with Autism and Other Developmental Disabilities

Li M, Fallin MD, Riley A, Landa R, Walker SO, Silverstein M, Caruso D, Pearson C, Kiang S, Dahm JL, Hong X, Wang G, Wang MC, Zuckerman B, Wang X.

PEDIATRICS®

May 2016

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Birth Spacing and Risk of Autism and Other Neurodevelopmental Disabilities: A Systematic Review

Conde-Agudelo A, Rosas-Bermudez A, Norton M

Q4. Which treatments and interventions will help?



March 3, 2016

Preschool Deployment of Evidence-Based Social Communication Intervention: JASPER in the Classroom

Chang YC, Shire SY, Shih W, Gelfand C, Kasari C

**Research in
Autism Spectrum
Disorders**

May 2016

A Pilot Study Promoting Participation of Families with Limited Resources in Early Autism Intervention

Carr T, Lord C

Q5. Where can I turn for services?

PEDIATRICS®

February 2016

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Differences in Perceived Need for Medical, Therapeutic, and Family Support Services Among Children with ASD

Benevides TW, Carretta HJ, Mandell DS

PEDIATRICS®

February 2016

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Examination of Parent Insurance Ratings, Child Expenditures, and Financial Burden Among Children With Autism: A Mismatch Suggests New Hypotheses to Test

Thomas KC, Williams CS, deJong N, Morrissey JP

PEDIATRICS®

February 2016

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Improving Access to Care at Autism Treatment Centers: A System Analysis Approach

Austin J, Manning-Courtney P, Johnson ML, Weber R, Johnson H, Murray D, Ratliff-Schaub K, Tadlock AM, Murray M.

Q5. Where can I turn for services?



February 4, 2016

Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States

Kiely B, Migdal TR, Vettam S, Adesman A

Q6. What does the future hold, particularly for adults?

BJPsych
The British Journal of Psychiatry

March 2016

Premature mortality in autism spectrum disorder

Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S

*Journal of Autism
and Developmental Disorders*

April 2016

Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report Versus Maternal Reports

Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JS, Mailick MR

JAMA Pediatrics

Formerly Archives of Pediatrics & Adolescent Medicine

March 2016

Association of Psychiatric and Neurologic Comorbidity With Mortality Among Persons With Autism Spectrum Disorder in a Danish Population

Schendel DE, Overgaard M, Christensen J, Hjort L, Jørgensen M, Vestergaard M, Parner ET

Q6. What does the future hold, particularly for adults?

The International Journal of Research and Practice • Volume 18 Number 1 January 2014

autism

October 15, 2015

The mental health of individuals referred for assessment of autism spectrum disorder in adulthood: A clinic report

Russell AJ, Murphy CM, Wilson E, Gillan N, Brown C, Robertson DM, Craig MC, Deeley Q, Zinkstok J, Johnston K, McAlonan GM, Spain D, Murphy DG

The International Journal of Research and Practice • Volume 18 Number 1 January 2014

autism

October 2015

Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ

Taylor JL, Henninger NA, Mailick MR

Q6. What does the future hold, particularly for adults?

The International Journal of Research and Practice • Volume 18 Number 1 January 2014

autism

October 2015

The health status of adults on the autism spectrum

Croen LA, Zerbo O, Qian Y, Massolo ML, Rich S, Sidney S, Kripke C

The International Journal of Research and Practice • Volume 18 Number 1 January 2014

autism

October 2015

“Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum

Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Dern S, Baggs AE, Kapp SK, Weiner M, Boisclair WC

Q7. What other infrastructure and surveillance needs must be met?



January 2016

Prevalence and Characteristics of Autism Spectrum Disorder Among 4-Year-Old Children in the Autism and Developmental Disabilities Monitoring Network

Christensen DL, Bilder DA, Zahorodny W, Pettygrove S, Durkin MS, Fitzgerald RT, Rice C, Kurzius-Spencer M, Baio J, Yeargin-Allsopp M

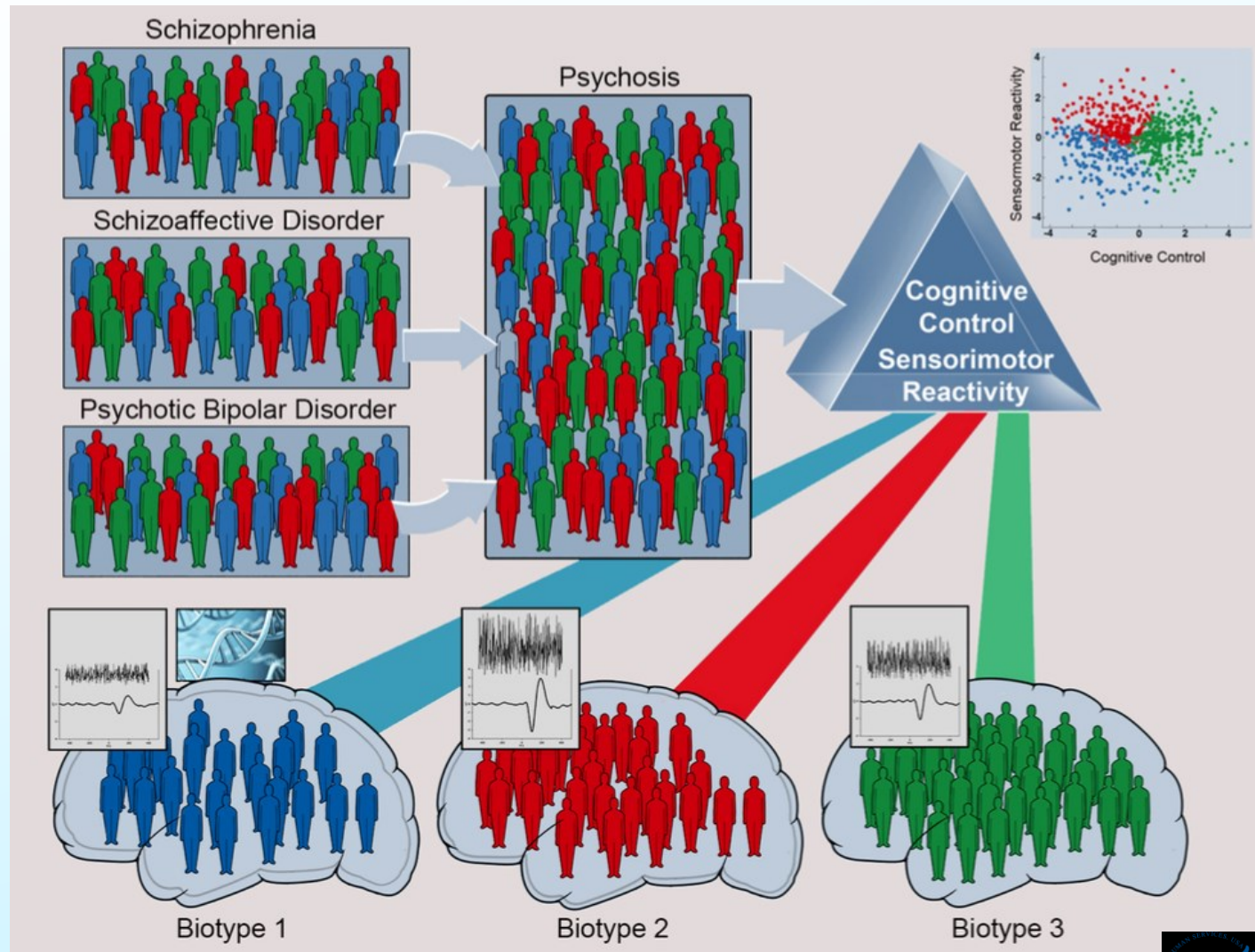
Morbidity and Mortality Weekly Report (MMWR)

April 2016

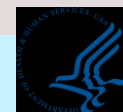
Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012

Christensen DL, Baio J, Braun KV, Bilder D, Charles J, Constantino JN, Daniels J, Durkin MS, Fitzgerald RT, Kurzius-Spencer M, Lee LC, Pettygrove S, Robinson C, Schulz E, Wells C, Wingate MS, Zahorodny W, Yeargin-Allsopp M

BSNIP “Biotypes: (1) Cognitive Control, (2) Sensorimotor Reactivity



Clementz, & Tamminga, *Am J Psychiatry*, in press



Meeting of the IACC

Break

Meeting of the IACC

Wandering Research Update

Meeting of the IACC

Afternoon Agenda

2:30

Wandering Research Update

Wendy Fournier

National Autism Association

Paul Lipkin, M.D.

Interactive Autism Network

Kiely Law, M.D.

Interactive Autism Network



Autism & Wandering: The Road to Prevention

*Interagency Autism Coordinating Committee
NIH | Bethesda, MD | 04.19.16*



Wendy Fournier
President



What We've Learned

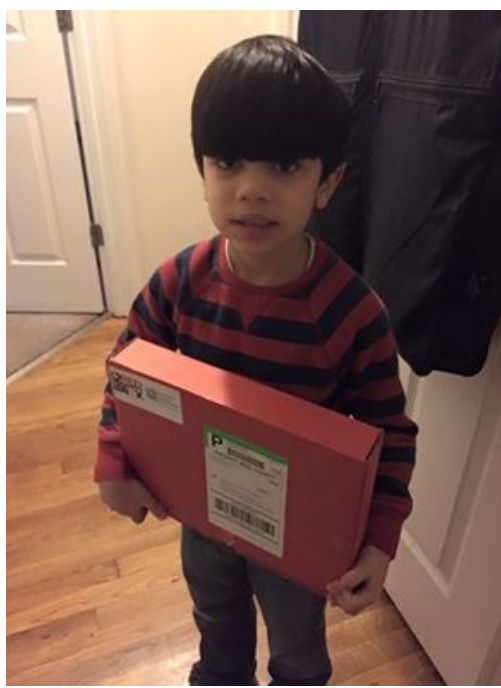
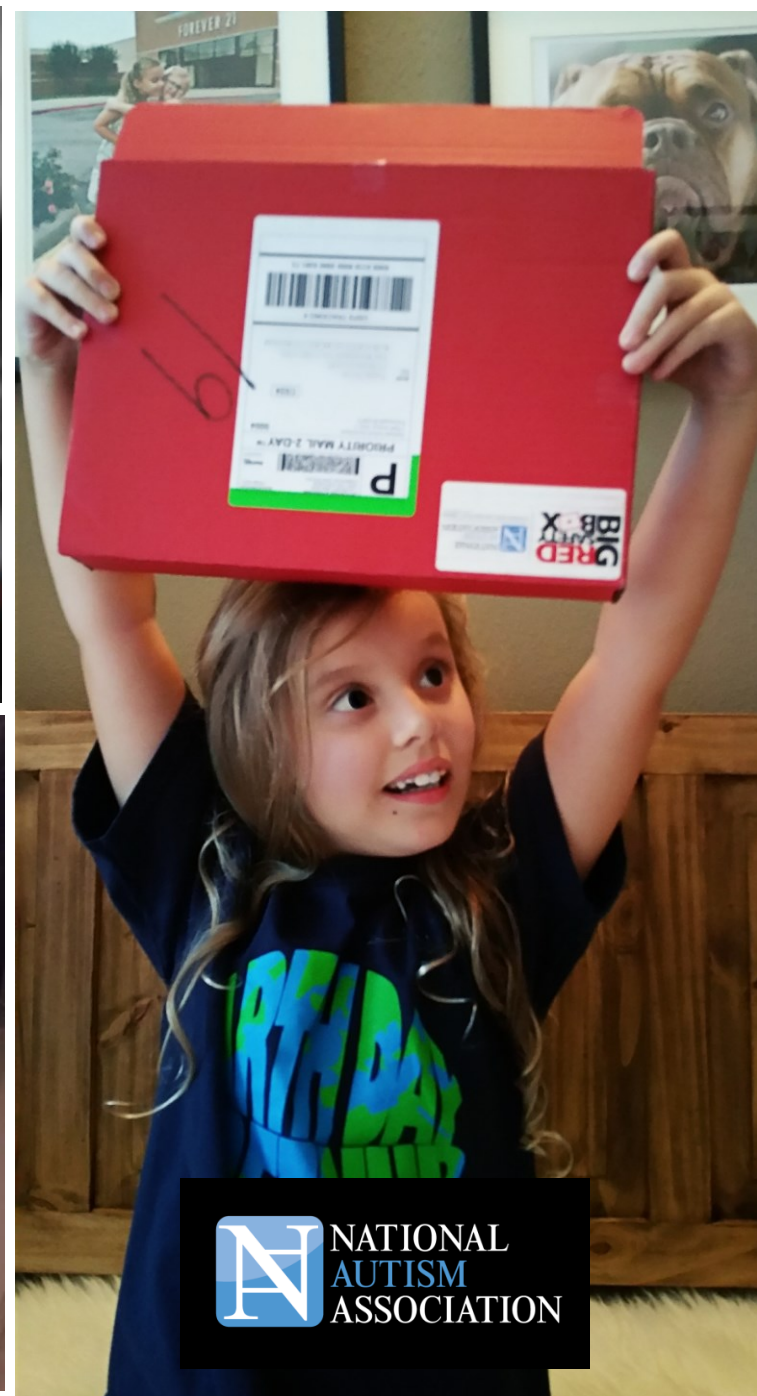
NAA 5-Year Data Collection

Wandering Incidents 2011 – 2015

- Cases involving children age 9 & under ended in death 44% of the time
- Cases involving children age 13 & under ended in death 31% of the time
- 2015 was the deadliest year on record since 2009. Fatal outcomes nearly doubled from the previous year
- Our children die quickly (drowning, hit by vehicles)
- Prevention is key

PREVENTION SAVES LIVES

"I really believe the door chimes in the Big Red Safety Box saved my son's life when he bolted from the house and onto a busy street a few years ago. Because of that door chime I was alerted and able to get to him just in time." -Kelly R.



NAA Big Red Safety Box Program Launched in 2011 23,000 Boxes Shipped to Date



It single handedly put an end to Avery's elopement issues at home. And it kept him safe when he was struggling.
Nicole H.

I got one a couple years ago and we use the alarms and stop signs daily.
Edward L.

Door alarms meant I could finally sleep.
Anne Marie H.

My son's RoadID tag on his shoe from the Big Red Safety Box just brought him home safely after he wandered. I have never been more grateful.

What We've Learned

- Construction headphones can pose secondary safety risks and may impede language development
- We need to develop discrete technology that is customizable to the wearer (See Kickstarter campaign: [HERE Buds](#))
- Must not impair hearing or compromise safety



What We've Learned

- Wandering/Elopement is a non-verbal form of communication: “I want, I need, I don’t want...”
- In many cases, we believe that an Acute Stress Response and loss of control is involved: “I NEED to get out of here RIGHT NOW!”
- Auditory Hypersensitivity is painful and can trigger Fight or Flight/Acute Stress Response

“He understands he is not supposed to wander or run off, but during times of acute stress, he may not understand these rules, his surroundings, or how to stay safe.” - Lori McIlwain, NAA Co-Founder

What We Need

- Development of effective, safe technology in the short-term – Who can help with this?
- Research on the link between seizures and auditory triggers
- Research on Fight or Flight: What's happening on a biological level?
- Let's think out of the box: Sympathetic nervous system, TRPV1 protein affecting Fight or Flight?
- Effective treatment of Acute Stress Response could be the ultimate wandering prevention strategy

Conclusions

- There is compelling evidence between AH and Elopement that should be used to help develop prevention strategies and technology
- 42% of children respond to AH by trying to run, and 33% of elopers overall are trying to escape an anxious situation, indicating an Acute Stress Response
- Acute Stress Response in ASD may go far beyond the elopement issue; contributing to some of the most potentially dangerous symptoms of ASD including Seizures, Emotional Dysregulation, Lack of Impulse Control, Aggression, Self-Injury, Depression and Suicidality
- Acute Stress Response may be one of the most important areas of research to increase safety and improve quality of life for individuals with ASD today



Thank You!

Wendy Fournier
National Autism Association
web: nationalautismassociation.org
e-mail: wendy@nationalautism.org
Phone: 877.622.2884

Auditory Sensitivity and Safety in Children with ASD

Paul H. Lipkin and
J. Kiely Law

Linking the autism community and researchers



share. research. discover.

A PARTNERSHIP OF



SIMONS FOUNDATION

www.ianresearch.org

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ian interactive
autism network
LINKING THE AUTISM COMMUNITY AND RESEARCHERS

PARTICIPATE IN AUTISM
research

Login 

share  research  discover

"Every child is different. And unless we as parents tell the researchers what is specific to our child, how will they know?"
-IAN Participant

Participate in ASD research. Join IAN.

Autism spectrum disorders (ASD) are identified in 1 out of every 68 children in the United States. Other countries observe similar rates with an increasing number of children and adults living with the disorder worldwide.

Families and individuals with ASD play a critical role in helping researchers and clinicians better understand the disorder. IAN Research provides a secure online setting where those affected by autism are active participants in ASD research.

By participating in IAN Research, you can help make new discoveries and empower advocates to improve the lives of children and adults with ASD.

Who can participate in IAN Research?

Individuals with ASD and their family members are eligible to participate. The following ASD diagnoses are included in IAN Research:

- Autism Spectrum Disorder (ASD)
- Autism or Autistic Disorder
- Asperger Syndrome
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder - Not otherwise Specified (PDD-NOS)
- Pervasive Developmental Disorder (PDD)

Participate in the largest online autism research effort.

JOIN NOW

Participants in IAN Research:

- Complete online study questionnaires collecting important information about ASD diagnosis, treatments, services, and other related topics.
- Receive special notices about local, regional and national studies looking for families like theirs.

explore
iancommunity

Families, researchers and anyone impacted by ASDs can take part in the [IAN Community](#), a comprehensive online library and meeting place focused solely on ASD research. Visitors can learn about the latest research, become more informed consumers of research, and join in a worldwide collaboration of people dedicated to finding answers.

©2016 Kennedy Krieger Institute. All rights reserved. [Privacy Policy](#) / [Research Consent](#)
Principal Investigator: Paul H. Lipkin, MD
Contact: ResearchTeam@IANproject.org
JHM IRB #: NA_00002750

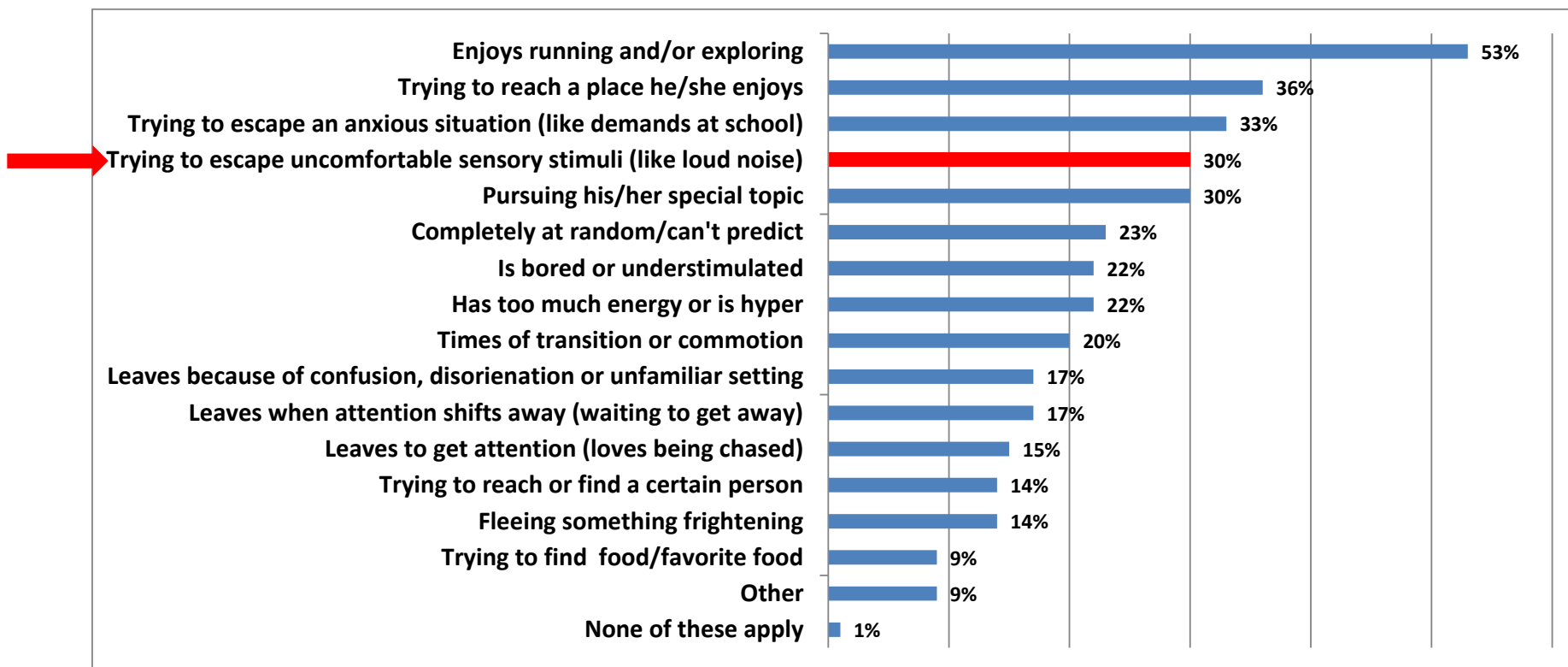
54,000 participants

- 15,000 children with ASD
- 5,000 adults with ASD
- 14,000 siblings
- 20,000 parents/guardians

Background: IAN Elopement Study 2011


- Concern about elopement and child safety
- Possible link between elopement and auditory **hypersensitivity**

Question 10: If you are able, please tell us what you believe causes your child's elopement behavior. *Check all that apply.* (n=725)



Anderson et al, Pediatrics 2012

Auditory Sensitivity

- Abnormal sensory experiences common in ASD (40% - 100%)
 - Auditory **hypersensitivity** affects 30-50% children with ASD
 - Not related to auditory acuity
 - Parent concerns about **hypersensitivity**
 - Child in distress and/or pain
 - Increased unsafe behaviors
 - Difficult to manage
- 
- Safety concerns also related to **hyposensitivity**

Auditory Sensitivity and Child Safety Study

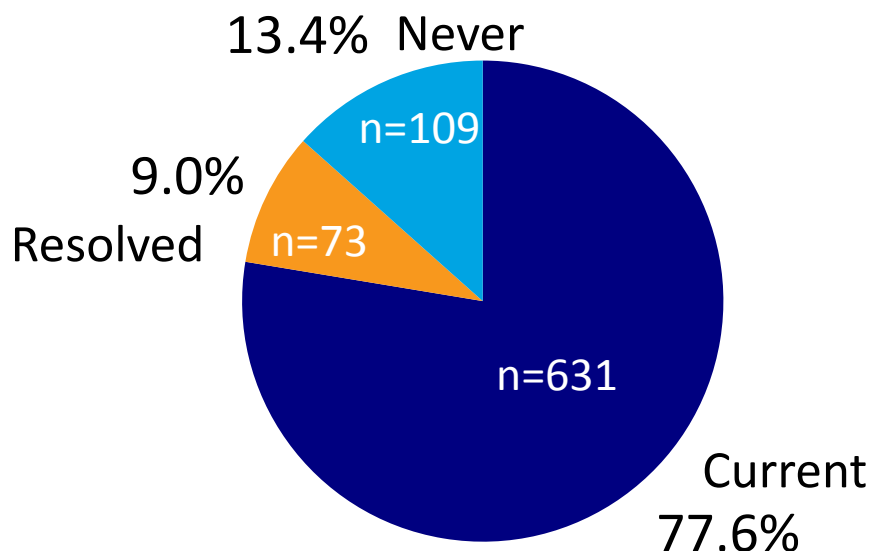
- Funded by National Autism Association
- Team included parents, ASD experts, audiologists, researchers
- Launched Spring 2014
- Aims:
 - Characterize auditory **hyper**- and **hypos**sensitivity in children with ASD
 - Determine relationship between auditory **hypers**sensitivity and potentially unsafe behaviors
 - Assess use and satisfaction of interventions for auditory **hypers**sensitivity

Who participated?

- Survey of parents of children with ASD (n=814)
- Child Characteristics
 - 82.4% male
 - 87.5% non-Hispanic; 84.8% white
 - Median age: 10.3 years
 - ASD Diagnosis
 - ASD 28.1%
 - Autism 34.4%
 - PDD-NOS 21.0%
 - Asperger's Syndrome 13.9%
 - PDD 2.6%

Hypersensitivity: Preliminary Results

- Reported Rates



- Median age

- Onset: 2.0 years
- Resolution: 7.5 years
- Worst symptoms: 4.5 years

- Child's Emotional State

(n=631 responses)

Stressed	77.7%
Irritable	61.3%
Scared	55.2%
Nervous	54.4%
Frustrated	43.9%
Annoyed	40.9%

- Child's Physical Response

(n=631 responses)

Covers ears	85.9%
Yells or screams	52.2%
Tries to run away	42.3%
Cries	36.3%
Tries to stop sound/noise	33.8%
Tries to hide	25.2%

Hypersensitivity: Preliminary Results

- More Severe ASD symptoms
 - SRS raw score
 - 111.6 vs. 99.3 ($p < 0.0004$)
- More likely to have Epilepsy/Seizure Disorders
 - 11.3% vs. 7.3% ($\chi^2 < 0.001$ FET)
- 18/60 (30%) seizure related to auditory triggers

Hypersensitivity: Preliminary Results

- Impact: Always or frequently limits participation
 - 31.1% Family activities
 - 29.8% School activities
 - 38.5% Community activities
- Burden
 - 63.4% episodes weekly (26% daily)
 - 49.5% mod or extreme difficulty managing

Hypersensitivity: Preliminary Results

- Safety Concerns

- 43.2% in an unsafe situation
 - 11.0% very unsafe
 - 10.7% moderately unsafe
 - 21.5% somewhat unsafe
- 18.2% Child physically injured or hurt
- 28.1% Others physically injured or hurt



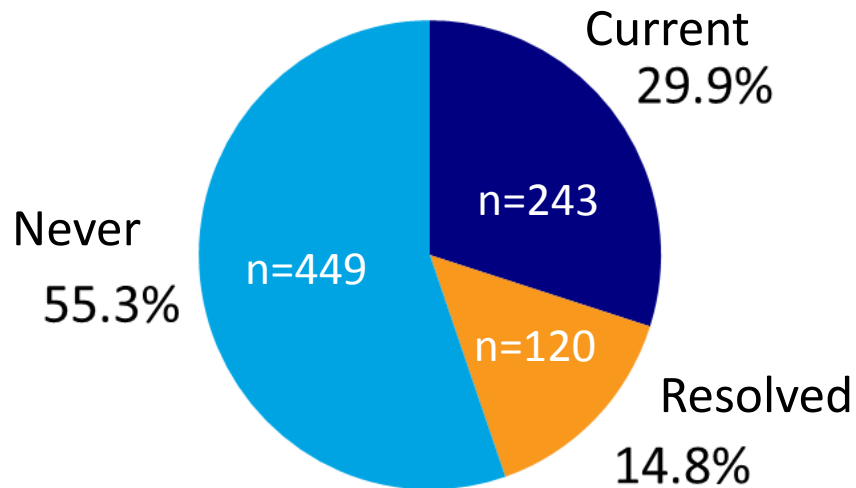
Hypersensitivity: Preliminary Results

- Common Interventions

	USED BY	Very Satisfied	Somewhat Satisfied	Somewhat Unsatisfied	Very Unsatisfied
Warning/preparing child for trigger sounds	90.9%	13.5%	39.5%	9.3%	10.3%
Avoiding trigger sounds	89.8%	23.9%	34.1%	6.4%	4.2%
Taking quiet breaks	85.6%	31.0%	40.4%	4.1%	4.5%
Ear buds/standard headphones with music	57.6%	23.3%	31.1%	11.1%	12.2%
Ear muffs	50.3%	24.0%	27.4%	11.0%	19.2%
Ear plugs	44.8%	7.1%	17.4%	16.7%	45.0%

Hyposensitivity: Preliminary Results

- Reported Rates



- Median age

- Onset: 1.5 years
- Resolution: 4.5 years
- Worst symptoms: 3.0 years

- Safety Concerns

(n=243 responses)

- 52.5% in unsafe situation
 - 16.1% very unsafe
 - 15.7% moderately unsafe
 - 20.7% somewhat unsafe
- 15.6% Child physically injured or hurt
- 10.0% Others physically injured or hurt

Acknowledgements

- **IAN:** Alison Marvin, Jaimie Toroney and Eric Rubenstein (UNC)
- **National Autism Association:** Wendy Fournier and Lori McIlwain
- **Other:** Cathy Rice (CDC/Emory), Joseph Pillion (Audiology/KKI), and Louis Hagopian (Behavior Psychology/KKI)
- **IAN Families**

Other Support

- IAN is a partnership project of the Kennedy Krieger Institute and the Simons Foundation
- IAN is also partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Award for development of the National Patient-Centered Clinical Research Network, known as PCORnet.

Meeting of the IACC

Afternoon Agenda

2:50 **Panel on Adult Therapies for ASD**

2:50 **Shaun M. Eack, Ph.D.**
Associate Professor
University of Pittsburgh

3:20 **John E. Robison**
Self-Advocate and Parent
Neurodiversity Scholar in Residence
College of William and Mary
IACC Member

3:50 **Discussion**

Meeting of the IACC

Panel on Adult Therapies for ASD



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Cognitive Enhancement Therapy for Adults with Autism Spectrum Disorder

Shaun M. Eack, Ph.D.
School of Social Work and
Department of Psychiatry
University of Pittsburgh





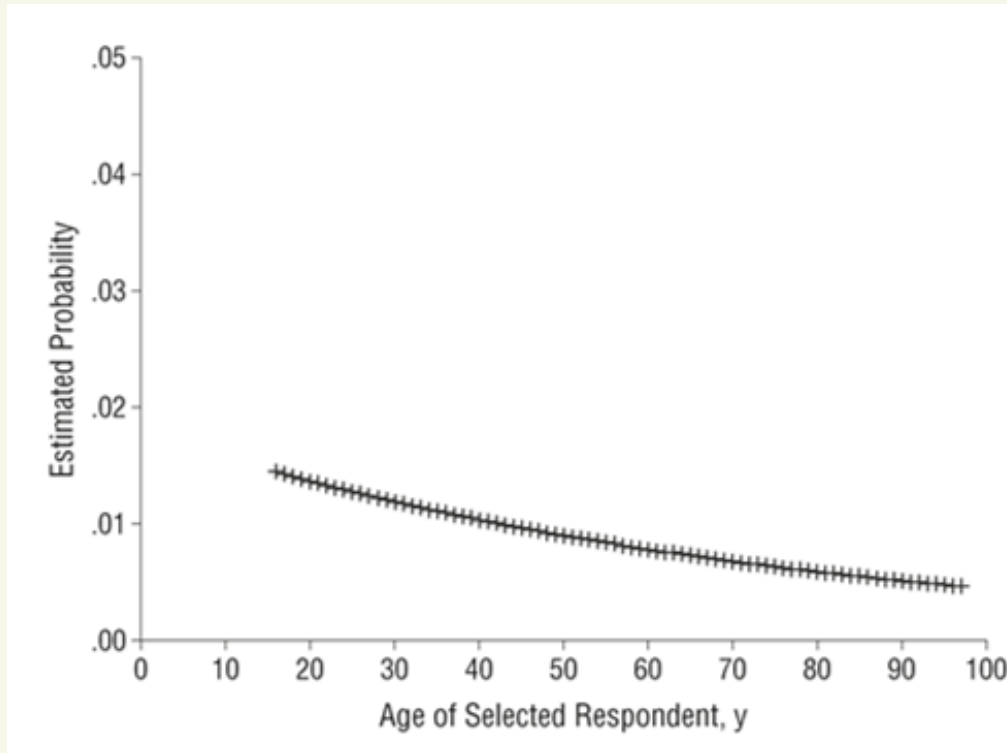
Disclosures

- No financial conflicts
- Grant support from:
 - NIH
 - Department of Defense
 - Autism Speaks
 - Autism Research Institute
 - Commonwealth of Pennsylvania

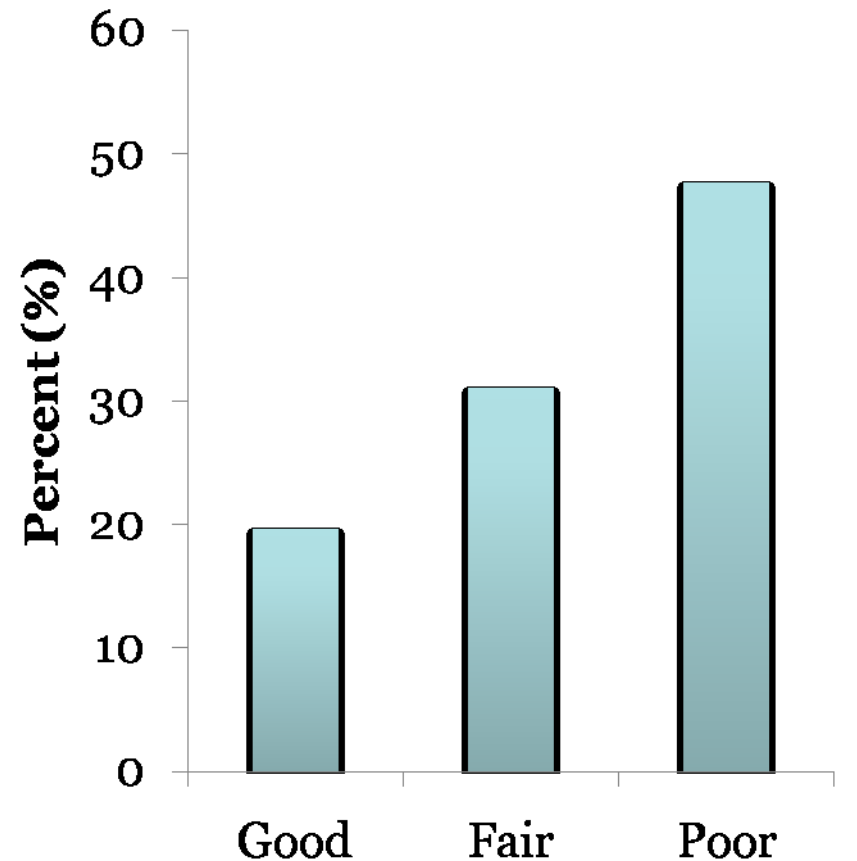


Autism Spectrum Disorder Exists in Adulthood

Prevalence
(*N* = 7403)



Outcome
(*N* = 828)



Brugha et al., 2011. *Arch Gen Psychiatry*. 68:459-465.

Steinhausen et al., in press. *Acta Psychiatr Scand*.



20-Year Outcome in Adult ASD

Rating	Friends/Acquaintances ^a (n = 59 ^b)	n (%)
0	One or more friend of approximately same age	5 (9)
1	One or more friend but restricted range of interests	9 (15)
2	No specific friendships but seeks contact with others in group situations	8 (14)
3	Never any peer relationships involving selectivity/sharing	37 (63)
Close relationships ^a (n = 60)		
0	Close reciprocal relationship(s) (e.g., sexual relationship/marriage) past or present	4 (7)
1	Some reciprocal relationships but short duration and/or reduced sharing of activities	6 (10)
2	Only ever very brief relationships, involving minimal sharing of activities	4 (7)
3	No reciprocal relationships lasting >1 month or never had relationship	46 (77)
Professional or highly skilled	Computer programmer (construction design); engineer (nuclear research)	2 (3)
Nonmanual skilled	Project manager × 2 (civil service; telecom); artist (self-employed); accounts clerk (× 2); town planner; civil servant	7 (12)
Manual skilled	Electronics work	1 (2)
Partly skilled	Postal workers (× 2)	2 (3)
Unskilled and untrained	Postal work (family firm); McDonald's; sales assistant; cleaning/sorting in theatrical costumiers; factory assembly/packing work	5 (8)
Ph.D. student/voluntary lobbying work		1 (2)
Sheltered/voluntary employment	Basic industrial work/cleaning × 2; care-home/charity shop × 4; railway guard; kitchen/ gardening work × 2	9 (15)
Never worked/long-term unemployed		33 (55)



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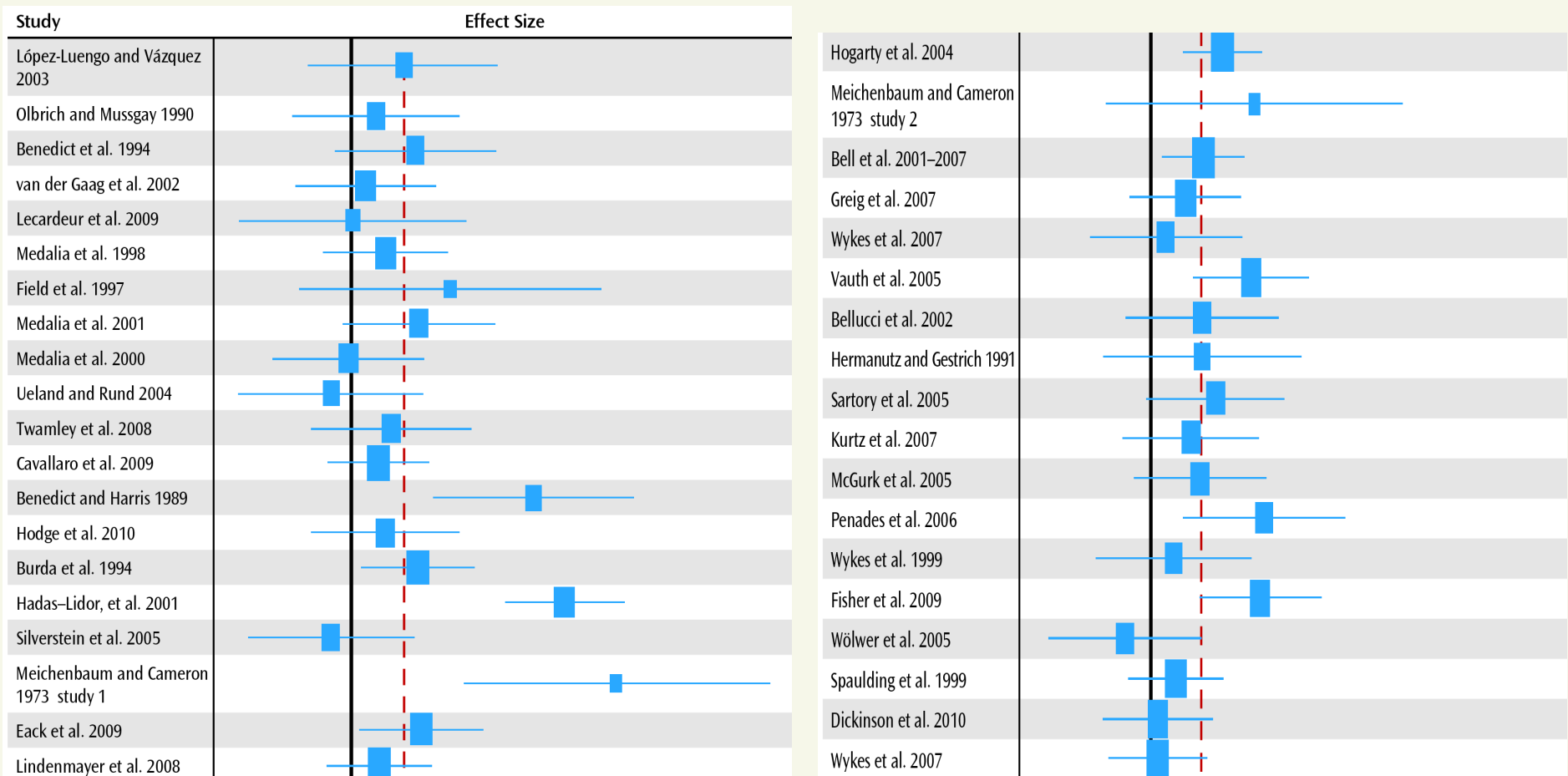
WHAT CAN HELP?



Study	<i>n</i>	Mean age	% male	Mean IQ	Method	Type of intervention	Outcome category	Cohen's <i>d</i>
Baker et al. (2005)	1	–	100	–	Case study	ABA	Repetitive behavior	–
Bölte et al. (2002)	10	27.2	100	104.2 ^a	RCT	Social cognition training	Social cognition	3.59
Faja et al. (2012)	13	22.4	–	116.3 ^a	RCT	Social cognition training	Face and house recognition	0.75
Gantman et al. (2012)	17	20.4	70.6	96.7 ^a	RCT	Social cognition training	Deficits in social interaction	1.209
García-Villamizar and Dattilo (2010)	71	30.81	57.7	–	RCT	Other	Adaptive behavior	0.83
García-Villamizar and Hughes (2007)	44	25.52	72.7	–	Non-randomized controlled	Other	Cognitive functioning	0.45
Golan and Baron-Cohen (2006), Experiment 1	65	28.72	76.73	109.05 ^b	Non-randomized controlled	Social cognition training	Cognitive functioning	0.25
Golan and Baron-Cohen (2006), Experiment 2	39	24.95	84.6	101.1 ^b	Non-randomized controlled	Social cognition training	Social cognition	0.14
McDonald and Hemmes (2003)	1	18	100	–	Case study	ABA	Communication	–
Moore 2009	1	18	100	–	Case study	ABA	Repetitive behavior	–
Rehfeldt and Chambers (2003)	1	23	100	–	Case study	ABA	Repetitive behavior	–
Shabani and Fisher (2006)	1	18	100	–	Case study	ABA	Adaptive behavior	–
Trepagnier et al. (2011)	16	19.77	93.8	109.4 ^a	Non-controlled	Social cognition training	Communication	0.58
Turner-Brown et al. (2008)	11	36.27	90.91	112.07 ^a	Non-randomized controlled	Social cognition training	Deficits of social interaction social cognition	0.27



RCTs of Cognitive Remediation in Schizophrenia ($k = 38$)





State of Treatment for ASD





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WHERE TO START?

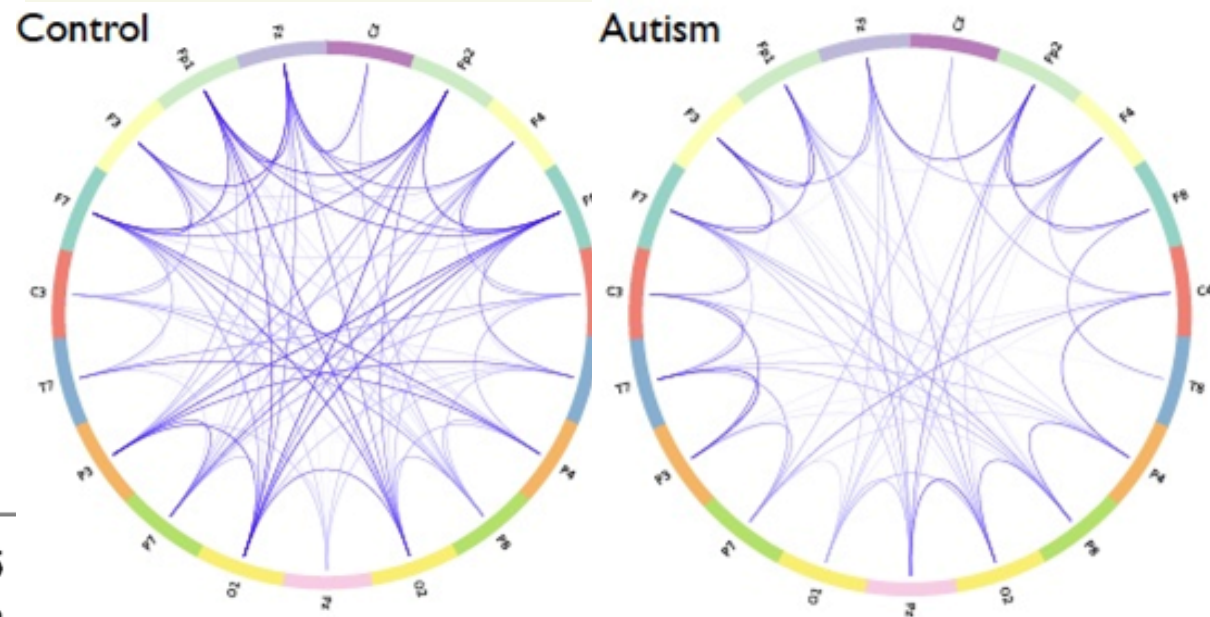
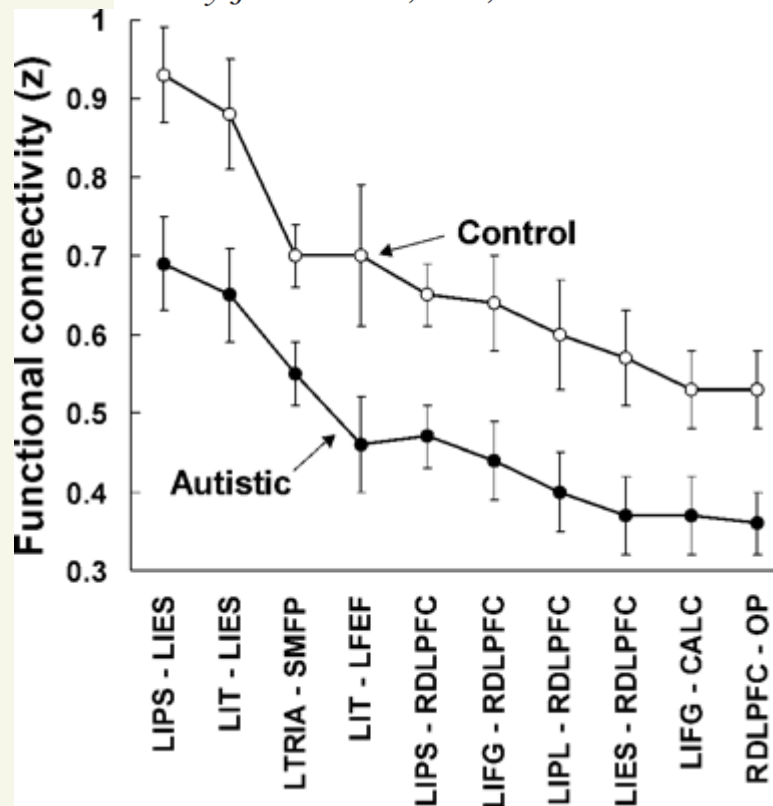


Autism is a Brain Disorder

The New Neurobiology of Autism

Cortex, Connectivity, and Neuronal Organization

Nancy J. Minshew, MD; Diane L. Williams, PhD



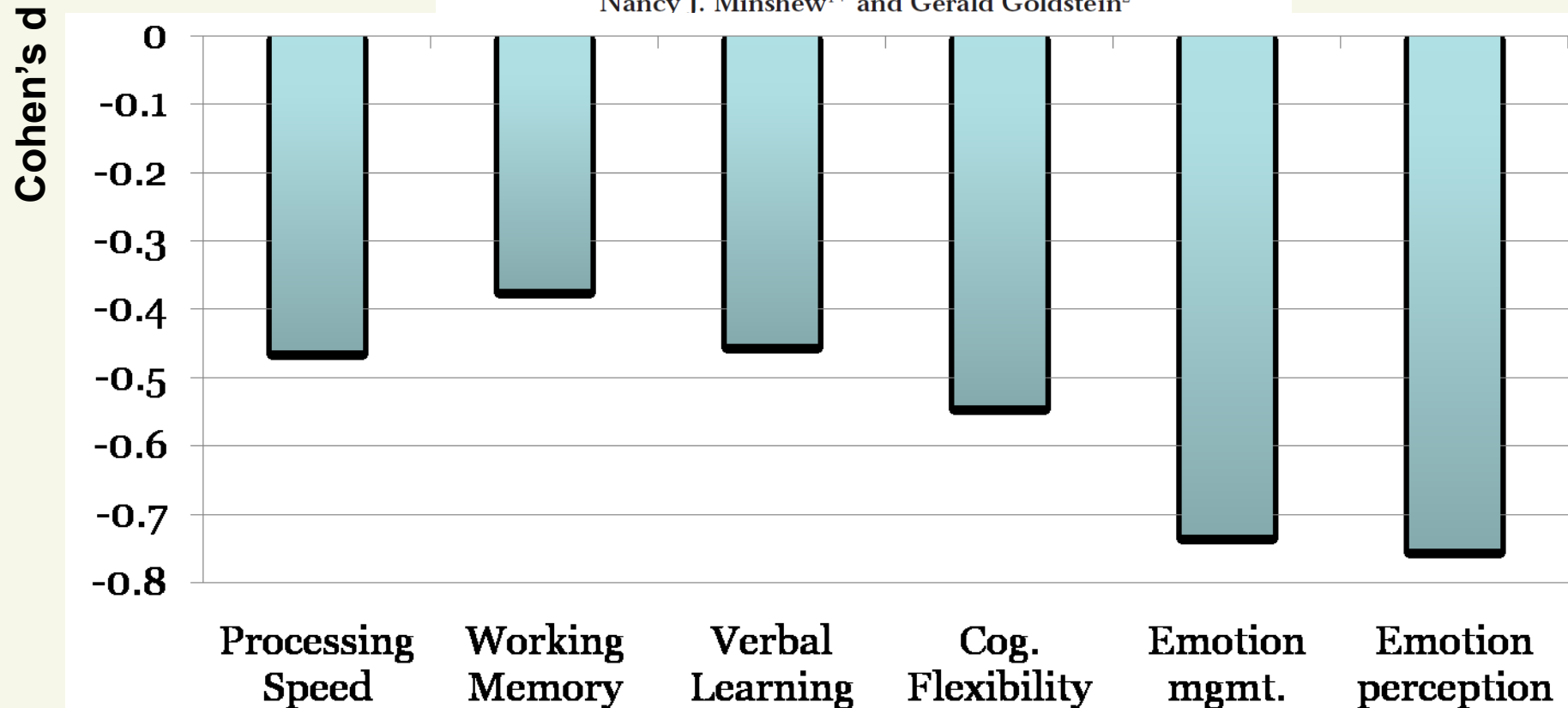
Just et al., 2004. *Brain*. 127:1811-1821; Minshew & Williams, 2007. *Arch Neurol*. 64:945-50; Peters et al., 2013. *BMC Medicine*. 11:54.



Brain-Based Cognitive Impairment in Adult Autism ($N = 40$)

AUTISM AS A DISORDER OF COMPLEX INFORMATION PROCESSING

Nancy I. Minshew^{1*} and Gerald Goldstein²





Promise of Cognitive Remediation

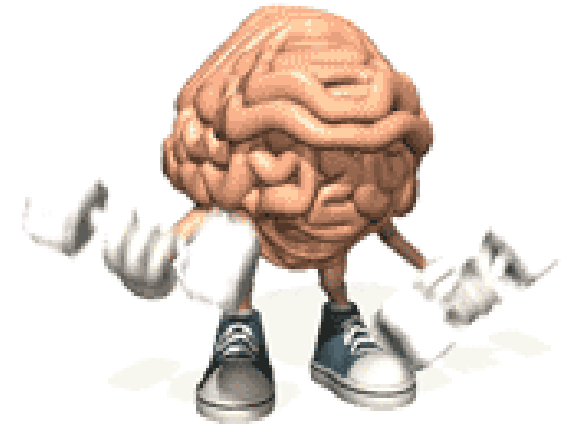
Review Article

Cognitive training in Alzheimer's disease:
a meta-analysis of the literature

Cognitive training in Parkinson disease

A systematic review and meta-analysis

**A Meta-Analysis of Cognitive Remediation
for Schizophrenia: Methodology and Effect Sizes**



Effectiveness of Cognitive Rehabilitation following Acquired Brain Injury:
A Meta-Analytic Re-Examination of Cicerone et al.'s (2000, 2005)
Systematic Reviews

**Computerized Cognitive Training in Cognitively Healthy
Older Adults: A Systematic Review and Meta-Analysis of
Effect Modifiers**

Review

Cognitive intervention for persons with mild cognitive impairment:
A meta-analysis

REVIEW

**Cognitive Remediation in Anorexia Nervosa and Related
Conditions: A Systematic Review**

**Cognitive Training for Attention-Deficit/Hyperactivity
Disorder: Meta-Analysis of Clinical and
Neuropsychological Outcomes From Randomized
Controlled Trials**

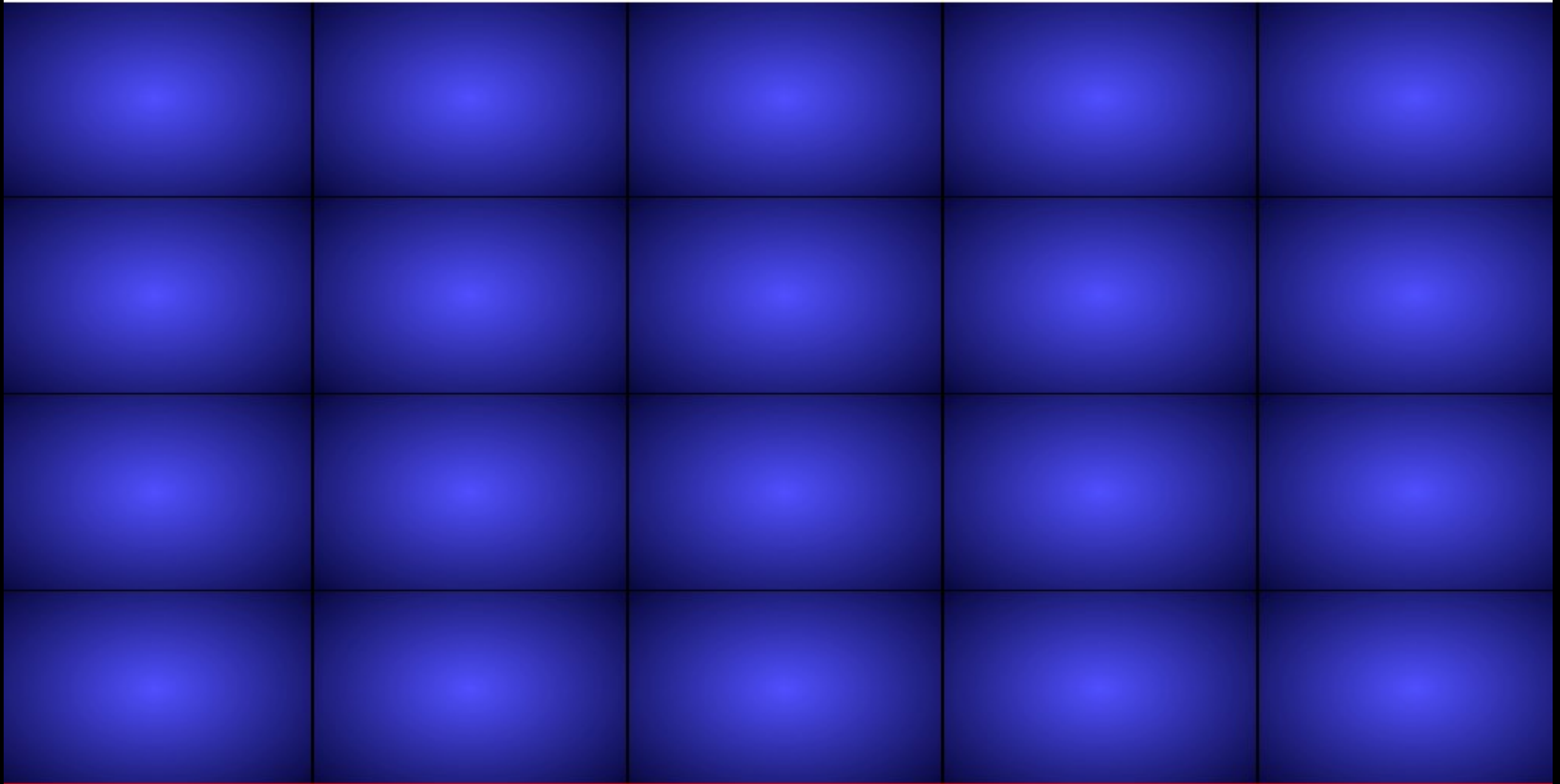


Cognitive Enhancement Therapy

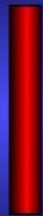
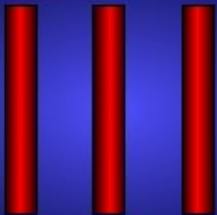
- A recovery-phase intervention for remediating neurocognitive and social-cognitive deficits originally developed by Hogarty and colleagues (2004, 2006) for schizophrenia.
- Neurocognitive Training
 - Computer-based training in attention, memory, and problem-solving.
 - 1 hour/week
 - 60 hours total
- Social-Cognitive Group Therapy
 - Training in perspective-taking, gistfulness, non-verbal communication, emotion perception, and much, much more.
 - 1.5 hours/week
 - 45 sessions
- More information and CET Training Manual (Hogarty & Greenwald, 2006) at
www.CognitiveEnhancementTherapy.com

Please wait while loading images...





Start



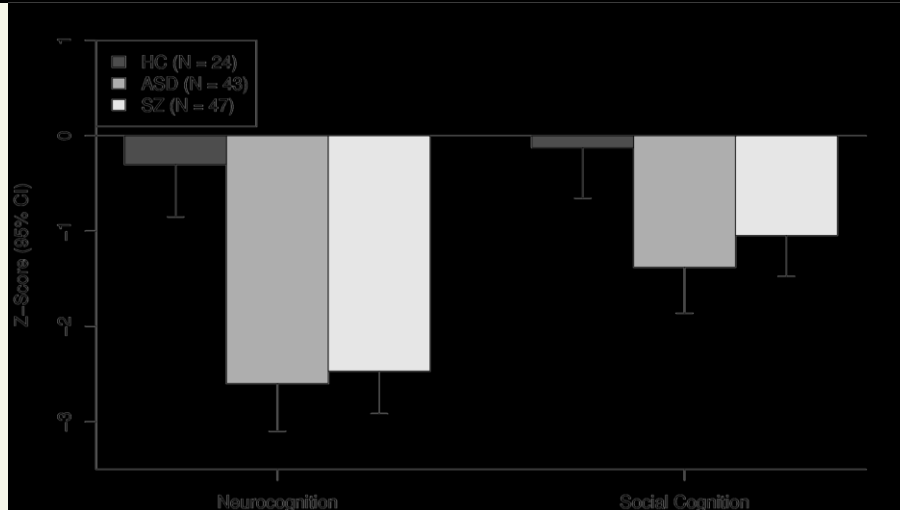
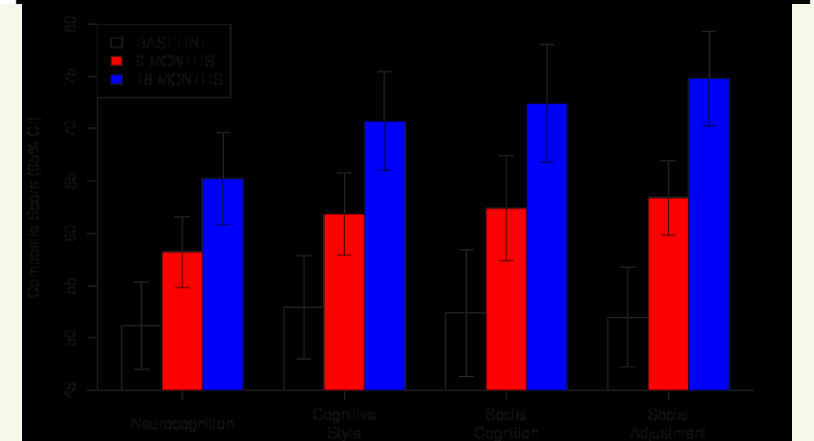
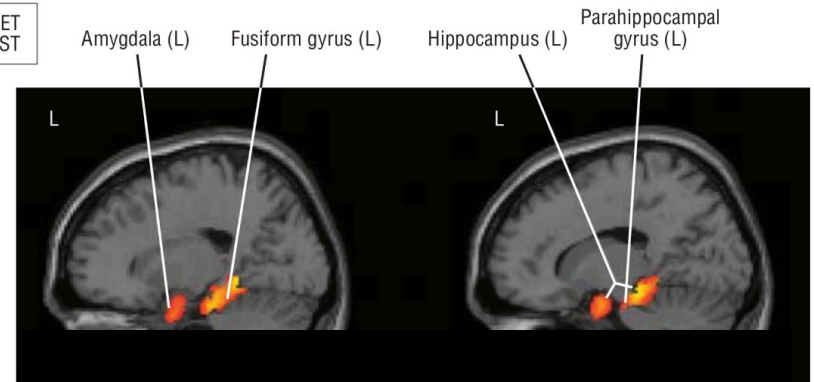
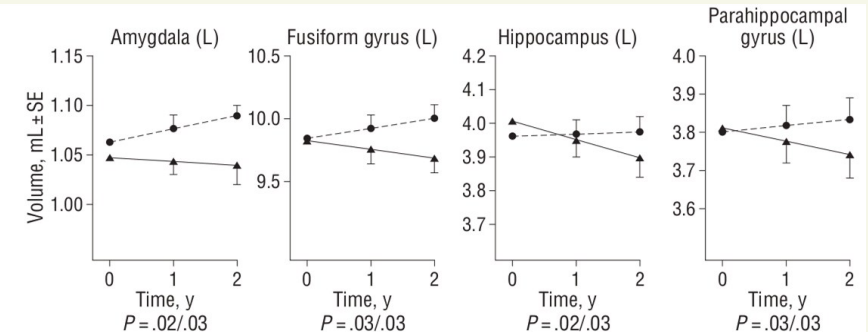
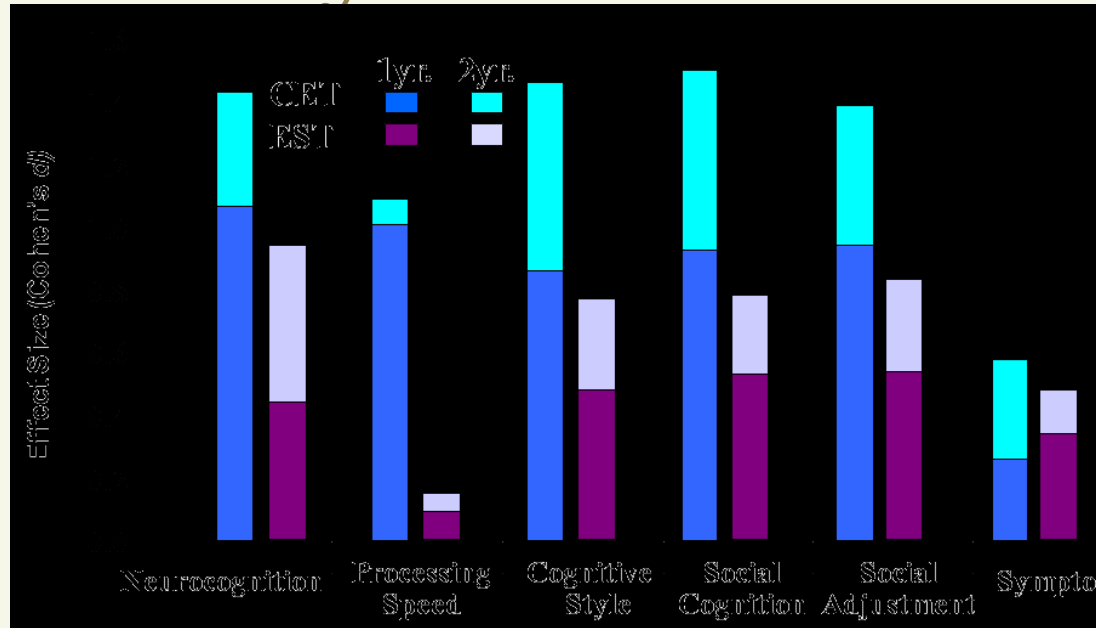


Social-Cognitive Training

- Small group structure (6-8 members)
- Contains coaches rather than therapists
- Structured format
- Example content areas:
 - Understanding ASD
 - Cognitive flexibility
 - Acting wisely in social situations
 - Appraising the social context
 - Taking another person's perspective
 - Reading non-verbal cues



Why CET for Adults with ASD?



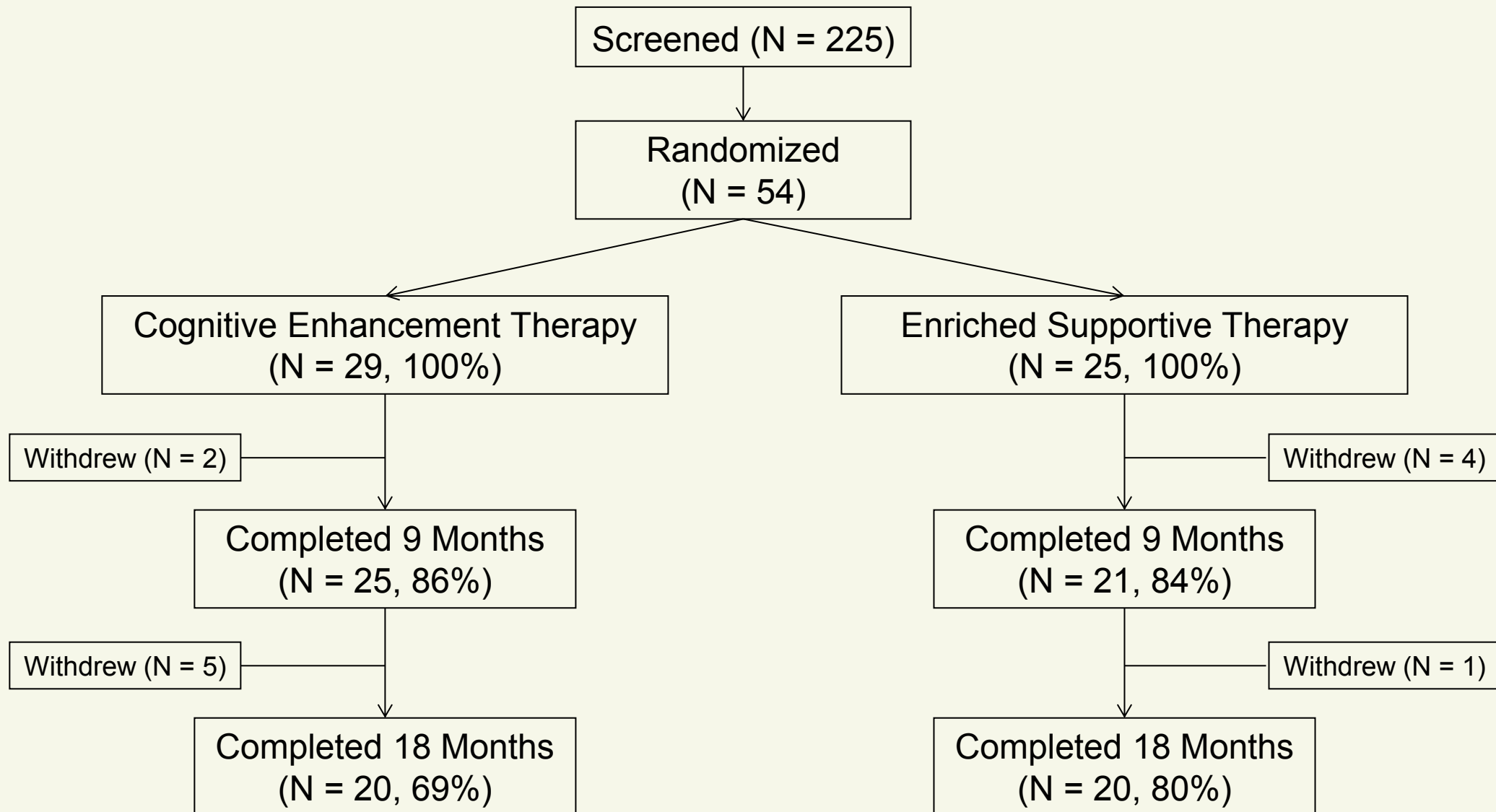


First Trial of CET in Adult ASD

- Thank you NIMH, DoD, Autism Speaks, and ARI!
- Inclusion criteria:
 - Autism or autism spectrum disorder based on the ADOS or ADI-R
 - Age 16-45
 - $IQ \geq 80$
 - Not abusing substance within past 3 months
 - No significant disruptive behavior
 - Significant cognitive and social disability
- Randomized to CET or an active Enriched Supportive Therapy (EST) control and treated for 18 months
- Assessed at baseline, 9, and 18-months



First Trial of CET in Adult ASD



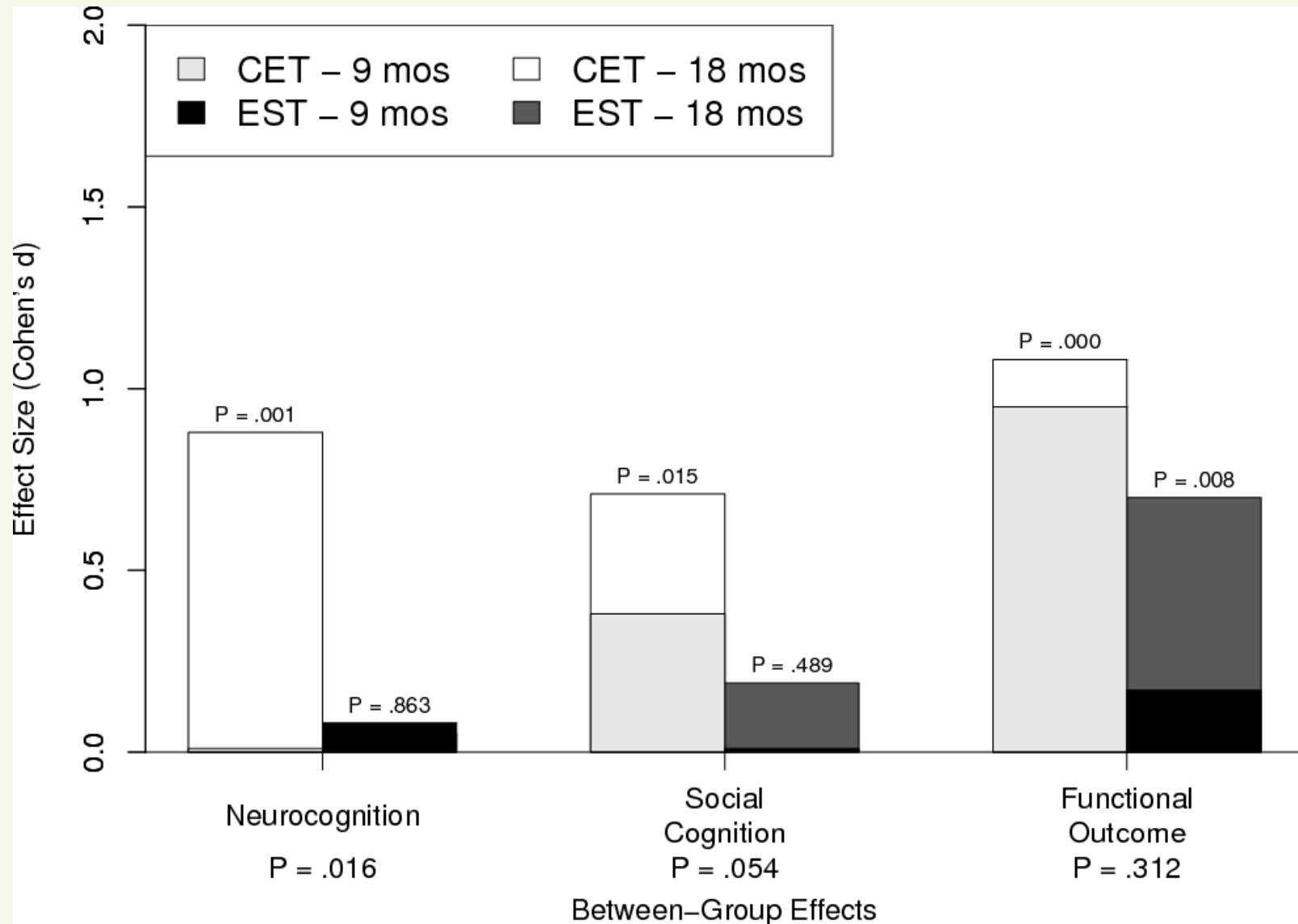


Baseline Characteristics (N = 54)

	CET		EST	
Variable	M / N	SD / %	M / N	SD / %
Age	22.55	6.38	23.52	5.69
% Male	24	83%	23	92%
% College	15	54%	19	79%
% Employed	7	25%	9	38%
% Dependent	24	86%	20	83%
IQ	107.97	14.35	106.24	15.30
% Autism	16	55%	11	44%
MATRICES	26.59	26.23	32.73	30.32

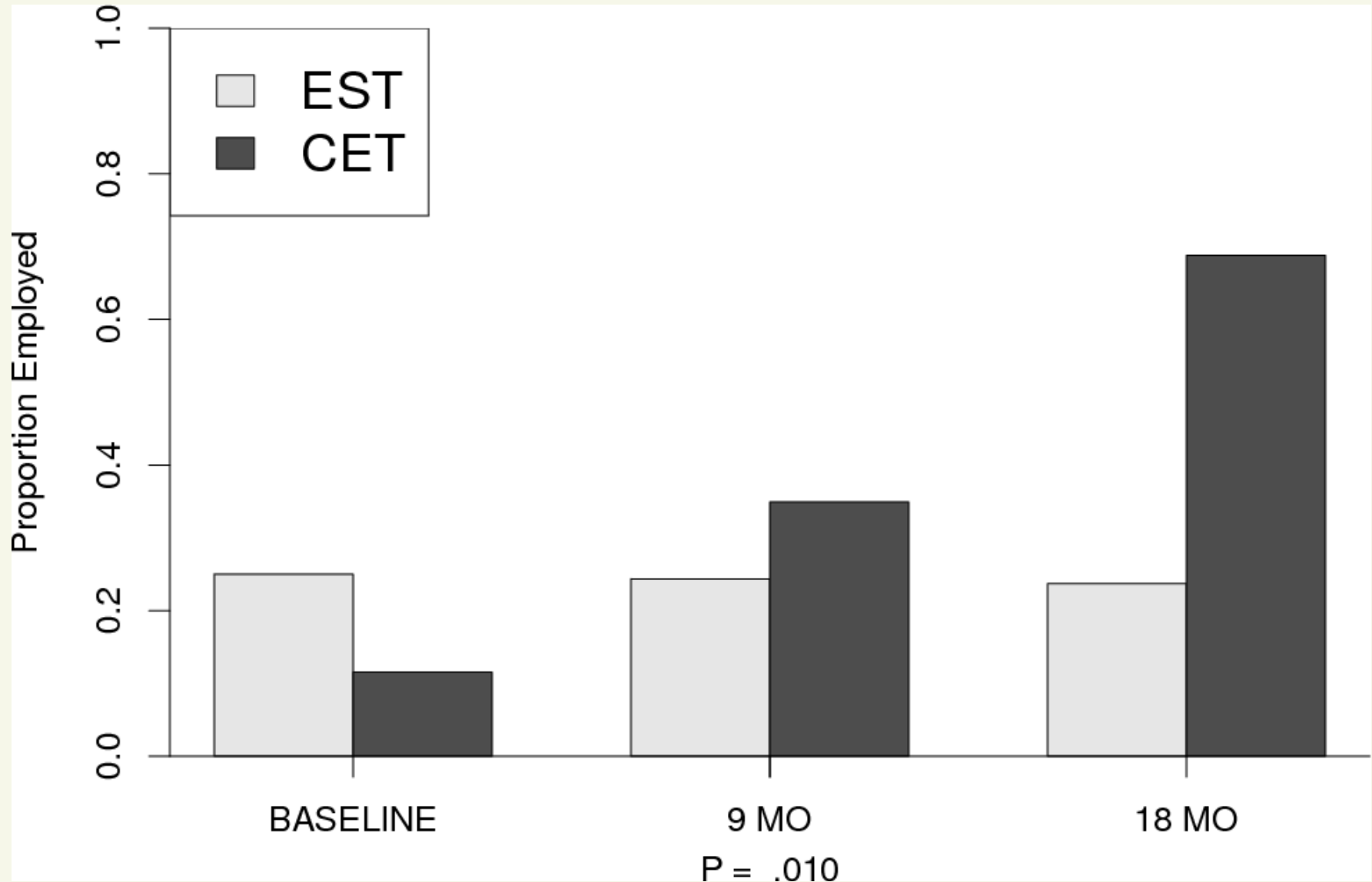


Preliminary Effects on Cognition and Behavior (N = 44)



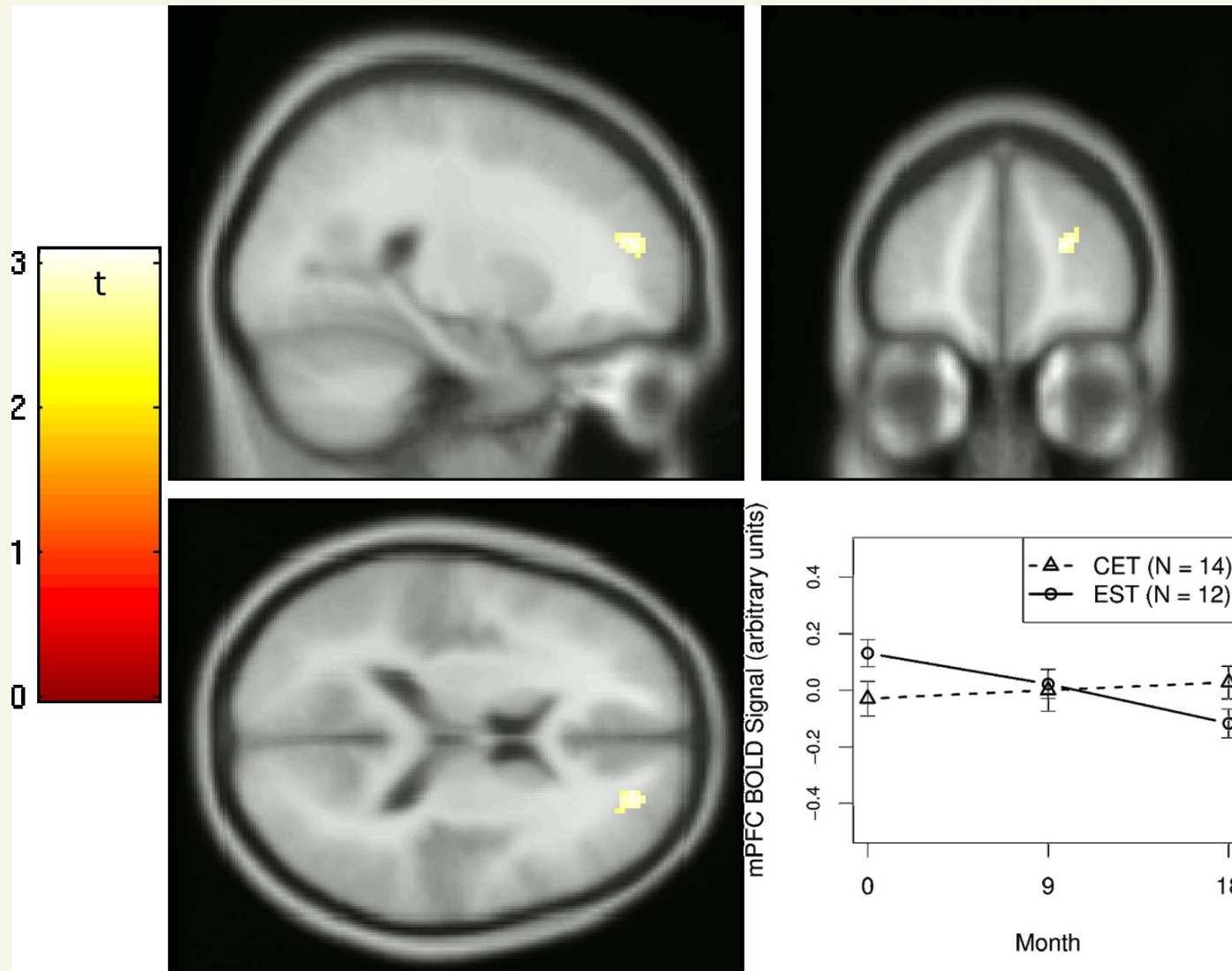


Preliminary Effects on Employment (N = 44)



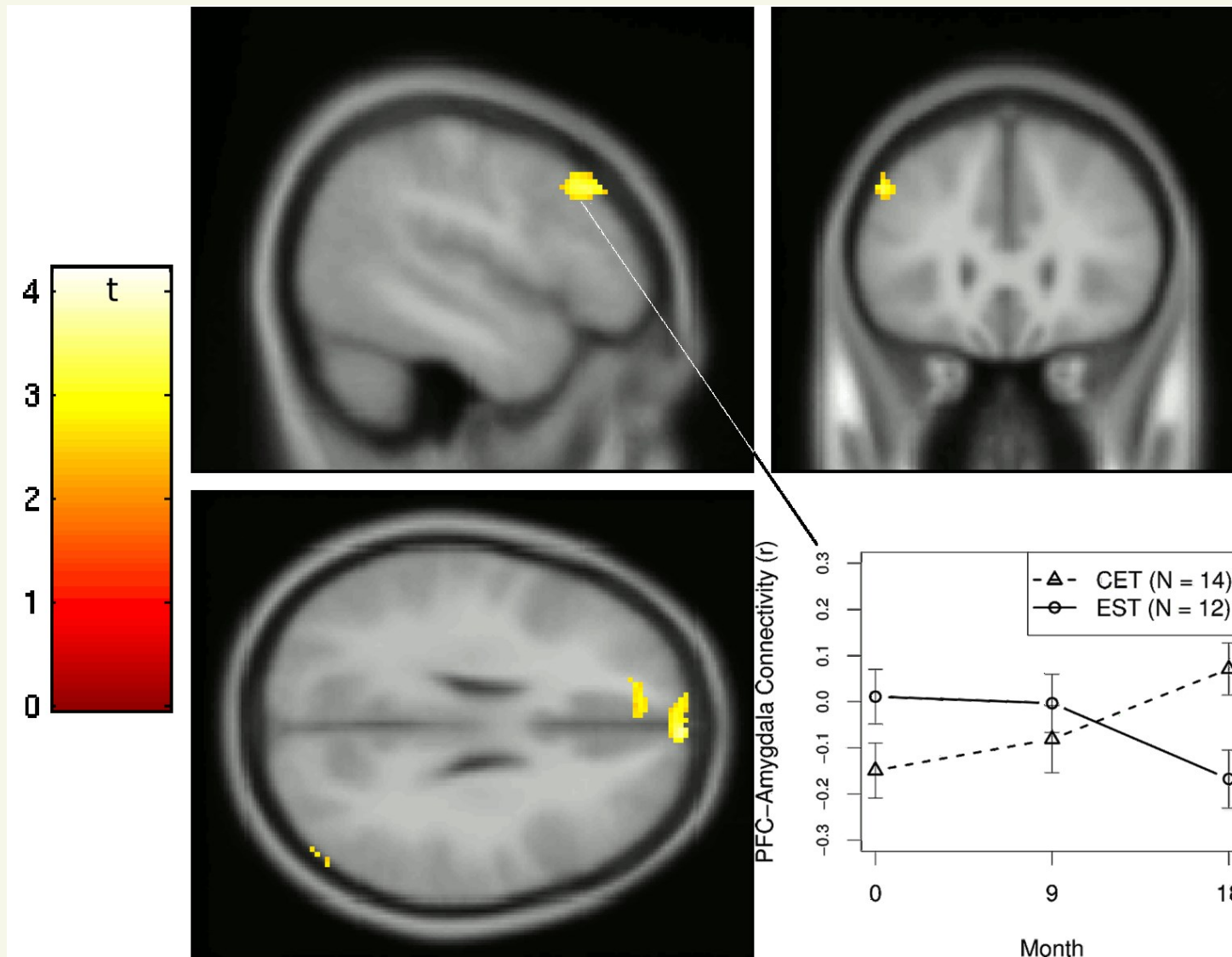


Preliminary Effects on Brain Function (N = 26)





Preliminary Effects on Functional Connectivity (N = 26)





Conclusions

- A crisis exists in treatment development for adults with ASD
- More treatment studies are urgently needed that can be funded and conducted quickly
- Cognitive remediation may help address core deficits in information processing
- Individual support, education, and emotion management may also help
- CET appears to be a promising treatment for adult ASD



Acknowledgments

Key Collaborators

- Nancy J. Minshew, M.D.
- Susan S. Hogarty, M.S.N.
- Deborah P. Greenwald, Ph.D.
- Marcel A. Just, Ph.D.
- Matcheri S. Keshavan, M.D.

Meeting of the IACC

Afternoon Agenda - continued

4:15 Round Robin

4:45 Closing Remarks

5:00 Adjournment

Meeting of the IACC

Round Robin

Prevalence and Characteristics of Autism Spectrum Disorder Among 8-year-old Children

Daisy Christensen, PhD

Centers for Disease Control and Prevention

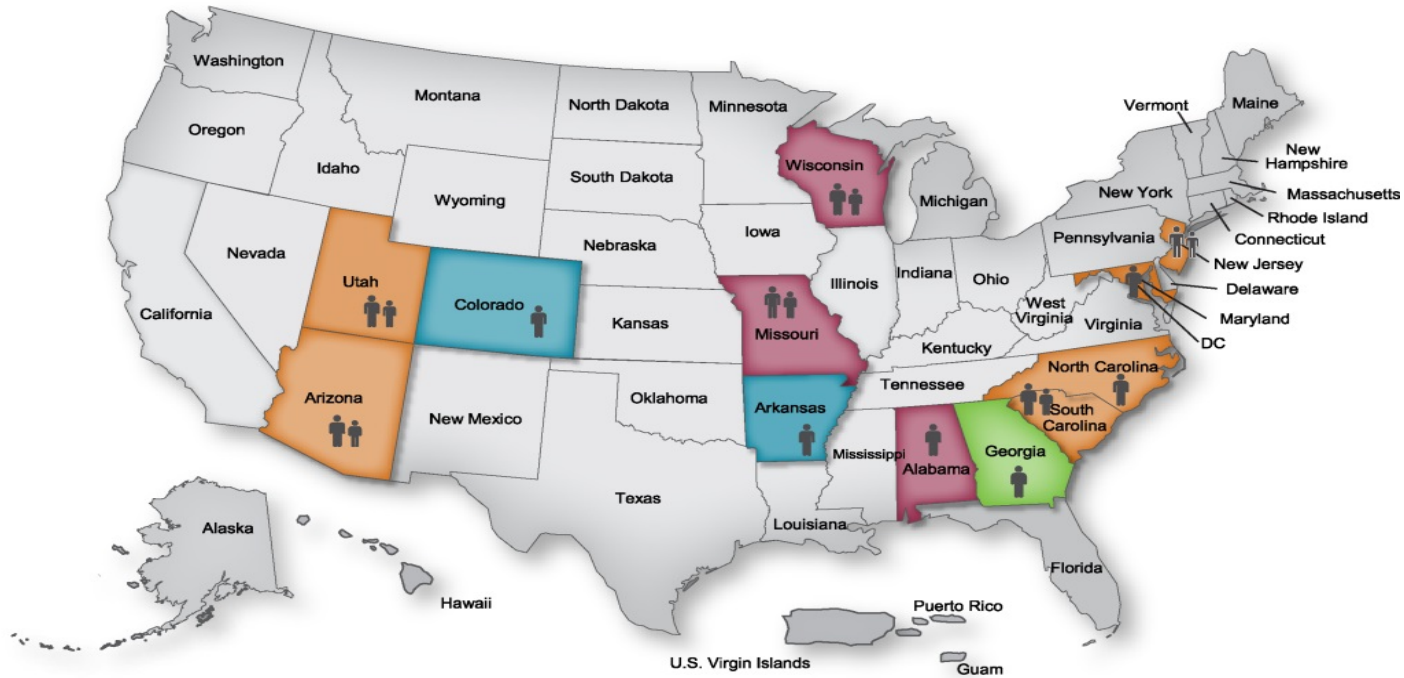
Interagency Autism Coordinating Committee Meeting
Rockville, MD

April 19, 2016

Autism and Developmental Disabilities Monitoring (ADDM) Network

- Active, population-based biannual surveillance of autism spectrum disorder (ASD) since 2000
 - Multiple source record review
 - Health sources
 - Education sources
- Goals:
 - Estimate prevalence and characteristics of ASD
 - Estimate prevalence trends of ASD
 - Understand the impact of ASD in US communities

Current ADDM Network Sites, Surveillance Years 2010 and 2012



CS229603-A

ADDN Network: 2012 ASD Prevalence

	Prevalence (95% CI)
Overall	14.6 (14.2, 15.0)
Education + Health	17.1 (16.5, 17.6)
Health only	10.7 (10.2, 11.3)
Male	23.6 (22.9, 24.3)
Female	5.3 (4.9, 5.6)
Non-Hispanic white	15.5 (14.9, 16.1)
Non-Hispanic black	13.2 (12.4, 14.0)
Hispanic	10.1 (9.4, 10.9)

ADDN Network: 2012 Age at Earliest Evaluation

- 87% had developmental concerns noted in record by age 36 months
- Overall age at earliest known comprehensive evaluation
 - ≤36 months: 43%
 - 37-47 months: 19%
 - ≥48 months: 38%
- Healthy People 2020 goal: 47% will have first evaluation by age 36 months
- Non-Hispanic white children more likely to have earliest evaluation ≤36 months (44%) compared with non-Hispanic black (40%) and Hispanic (39%) children

ADDM Network: 2012 Key Findings

- ASD prevalence in 2012 was similar to 2010 prevalence
 - Too soon to say that prevalence is stabilizing
 - Additional data points needed
 - Variation in prevalence by race/ethnicity and geography
 - Prevalence change at some sites
- Disparities in ASD prevalence by race/ethnicity may indicate that some children are not receiving appropriate services and support
- Progress needed to lower age at first evaluation among all children, particularly non-Hispanic black and Hispanic children

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



Meeting of the IACC

Closing Remarks

Meeting of the IACC

Adjournment