

Meeting of the Interagency Autism Coordinating Committee

November 17, 2015

Fishers Lane Conference Center
Terrace Level
5635 Fisher Lane, Room 508/509/510
Rockville, MD 20852

Conference Call Access:

Phone: (888) 946-7302 Access

Code: 1453351



Morning Agenda

9:30 AM Call to Order

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive Secretary, IACC

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9:35 Welcome and Opening Remarks

Bruce Cuthbert, Ph.D.

Acting Director, NIMH and Chair, IACC



Morning Agenda

9:45 AM Francis Collins, M.D., Ph.D.

Director, National Institutes of Health

10:00 Introduction of New and Returning

IACC Members

11:00 Break

11:15 Committee Business

Susan Daniels, Ph.D.

Director, OARC, NIMH and Executive

Secretary, IACC



Break



Committee Business



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 November 17, 2015

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



The Interagency Autism Coordinating Committee

- A federal advisory committee
- Established under the Children's Health Act (CHA) of 2000
- Reauthorized by:
 - Combating Autism Act (CAA) of 2006
 - Combating Autism Reauthorization Act (CARA) of 2011
 - Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2014



IACC Charter

The Committee's role is to:

 Coordinate efforts within DHHS and among member federal agencies, as well as member organizations concerning autism spectrum disorder.

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- Provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder.
- Facilitate exchange of information on autism activities among the member agencies in order to enhance coordination
- Increase public understanding of the member agencies' activities, programs, policies and research.
- Serve as a public forum for discussion of issues related to autism spectrum disorder.



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









Autism CARES Act

The Autism Collaboration, Accountability, Research, Education and Support Act of 2014 (P.L. 113-157):

- Reauthorized the IACC to continue through September 30, 2019
- Increased membership requirements for certain categories of members; each category increased from 1 member required to 2 members required:
 - Individuals on the autism spectrum
 - Parents/legal guardians of individuals on the spectrum
 - Representatives of leading research, advocacy, and service organizations for individuals on the autism spectrum
- Incorporated a greater emphasis on services and supports into various activities of the IACC (e.g., strategic planning, monitoring of federal activities)



Autism CARES Act (cont'd)

The Autism Collaboration, Accountability, Research, Education and Support Act (P.L. 113-157):

- Continues to require the IACC to prepare an annual update of the IACC Strategic Plan and a new edition of the IACC Summary of advances
- Requires that the IACC Strategic Plan continue to address research, but also include as practicable, services and supports for individuals with ASD and their families as well as recommendations to ensure that federal ASD research and services activities are not unnecessarily duplicative
- Requires that the IACC Strategic Plan and Summary of Advances be submitted to Congress and the President



What the IACC does NOT do:

The IACC is an <u>advisory</u> body; therefore it <u>does not</u>:

- Fund research (it has no research budget) or allocate research dollars
- Control funding of federal programs
- Set policy



What the IACC Does:

- Provides advice to the HHS Secretary
 - Strategic Plan, letters, statements
- Provides coordination for federal and member organization activities
 - Strategic Plan, monitoring activities, fostering collaborations
- Identifies priorities to focus and accelerate progress
 - Strategic Plan, workshops
- Serves as a forum for public input



IACC Coordination and Monitoring

- Sharing information about agency and organization activities at meetings including:
 - New and ongoing programs, initiatives, reports
- Information about the activities of other related federal advisory committees such as:
- Interagency Committee on Disability Research (ICDR)
- National Council on Disability
- President's Committee for People with Intellectual Disabilities
- Gathering and sharing data from federal agencies and private organizations



What Can Members Do?

- Plan to share important updates and reports from your agency/organization at each meeting or request time on the agenda for longer presentations
- Suggest issues and speakers for future meetings
- Identify opportunities for coordination and collaboration
- Actively contribute input to committee discussions
- Volunteer to participate in and/or lead planning group activities



IACC Core Values

- Sense of urgency
- Scientific excellence
- Spirit of cooperation
- Consumer focus
- Partnerships in action
- Accountability (SMART objectives specific, measurable, achievable, realistic, time-bound)

"Finding common ground"



IACC Traditions

- Public comments (written and oral)
- Research and policy updates
- Committee member updates (round robin)
- Committee business (Fulfilling responsibilities required in the Autism CARES Act)



Welcome

Vision Statement

The Strategic Plan will accelerate and inspire research [and services efforts] that will profoundly improve the health and well-being of every person on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement.

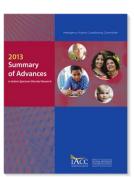
IACC Strategic Plan Introduction 2011



IACC Responsibilities

- Develop an annual update of the IACC Strategic Plan for ASD
- Develop an annual Summary of Advances in ASD Research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding federal activities or public participation in decisions regarding ASD



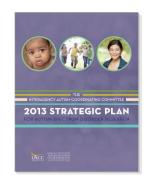






Immediate To-Do List

- Develop an update of the IACC Strategic Plan that will cover 2014 and 2015
 - Is it time to do a significant revision?
 - The new plan is required to include guidance on priorities for services and supports activities.
- Develop two volumes of the IACC Summary of Advances in ASD Research (2014 and 2015)







IACC Subcommittees and Planning Groups

Subcommittees of the Previous IACC:

- Basic and Translational Research
 Addressed biomedical research issues
- Services Research and Policy
 Addressed services research and services policy issues
 - Subcommittees must be smaller in size than a quorum of the committee
 - Subcommittees may form several different planning groups to focus on different tasks and activities



Subcommittee Process:

- Chair or Co-chairs
- Members limited to IACC members
- All meetings public
- Reports/recommendations/actions subject to full IACC approval



Decisions for Today

How does the committee want to divide the subcommittees?

After the meeting:

- Which subcommittee will you serve on?
- Who will volunteer to be considered to chair subcommittees? (Later will discuss chairs for each planning group.)



Decisions for Today Part 2

Does the committee want to use the same process as previous years to develop the Summary of Advances?

- OARC provides and committee nominates peer reviewed research publications
- Up to 20 advances under each of the 7 areas of the Strategic Plan are selected by committee vote
- OARC writes short, lay-friendly summaries of the selected articles
- The 20 advances are combined into a booklet format
- If few changes, we can start this project in January



For Discussion at Next Meeting

What aspects of the Strategic Plan do we want to update?

Update objectives as well as text?

In what format do we want to incorporate services activities?

What process do we want to use?

- Planning groups with external expert consultation?
- Other process?



Introducing OARC

- The Office of Autism Research Coordination (OARC) coordinates and manages the Interagency Autism Coordinating Committee (IACC) and related crossagency autism spectrum disorder (ASD) activities, programs, and policies.
- OARC provides assistance to the IACC by:
 - Communicating information about the IACC and federal ASD research activities to Congress, other government agencies, and the public
 - Coordinating cross agency efforts



OARC - Continued

OARC assists the IACC by:

- Communicating information about the IACC and federal ASD research activities to Congress, other government agencies, and the public
- Coordinating cross agency efforts
- Planning meetings, conferences, and other IACC activities
- Facilitating the IACC strategic planning process and monitoring of ASD-related activities
- Conducting analyses and preparing reports for the IACC, Congress and others
- Gathering public input on issues related to ASD to inform the committee's work
- Developing and disseminating information about ASD to the public

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Coming Soon: New IACC Website





New IACC Website Features

- Layout Redesign
- Tablet and mobile friendly
- New Content

www.iacc.hhs.gov





Susan Daniels, Ph.D., Director
Chumba Kitur, B.A., Operations Coordinator
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



Morning Agenda

12:00	PM	Lunch
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1:00 Or	al Public	Comments	Session
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1:45	IACC Committee Member Discussion of
	Public Comments

2:15 Break

2:25 Committee Member Updates

4:45 Closing Comments

5:00 Adjournment

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Oral Comments Session



Break



Committee Member Updates



NIMH Update

November 17, 2015

Bruce Cuthbert, Ph.D.

Acting Director, National Institute of Mental Health Chair, Interagency Autism Coordinating Committee

IACC Full Committee Meeting – November 17, 2015

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National Institute of Mental Health

- One of the 27 institutes and centers at NIH
- Supports research on mental health, including basic and clinical research, and incorporating the evolving science of brain, behavior, and experience.
- NIMH Budget ~\$1.4B
- Has largest portfolio of autism research at NIH
- Portfolio includes basic, translational, clinical, and services research



NIMH ASD Services Research Initiative September 2014

 NIMH awarded 12 new grants (\$15M) to support research to develop effective, real-world-ready approaches to providing early diagnosis, treatment, and supportive services for children, transition-age youth, and adults with autism spectrum disorder (ASD)

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- Birth to 2 years 5 projects to test strategies for coupling children who test positive in universal screens with referral to and engagement in services.
- Transition-age youth and families 4 projects to develop strategies for school-based service coordination of transition planning in order to reduce or eliminate disconnection from needed supports, services, or age-relevant activities.
- Adults 3 projects to develop and test strategies to maintain engagement in community support, vocational and employment programs, and other services aimed at supporting independent living.



NIMH ASD Services Research Initiative II

Issued October 28, 2015 Applications Due February 3, 2016

Services Research for Autism Spectrum Disorder across the Lifespan II (ServASD II): Pilot Research on Services for Transition-Age Youth - RFA-MH-17-200 (R34)

Pilot Research on Services Strategies for Adults with ASD - RFA-MH-17-200 (R34)

https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-17-200.html



NIH Neurobiobank Update

 The NIH Neurobiobank and the privately-funded Autism BrainNet are collaborating to form a joint biobanking effort which will result in a national networked resource for tissue specimens that can be used for ASD research.

Partners include:

- Three NIH institutes: NIMH, NINDS, and NICHD, Autism Science Foundation, Autism Speaks, and Simons Foundation
- This networked resource fulfills a priority identified in the IACC Strategic Plan for ASD Research.



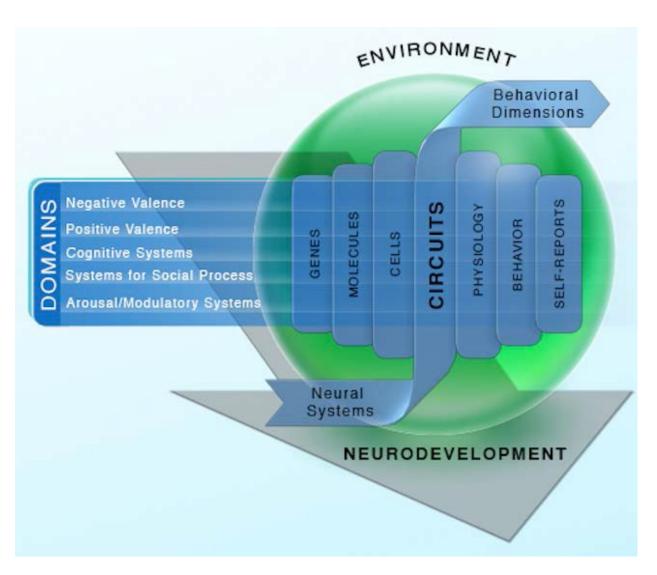
Autism Biomarkers Consortium (ABC) Project

July 2015

- NIH (NIMH, NICHD and NINDS), Foundation for the NIH (FNIH), Simons Foundation, and other partners have invested \$28M in a multi-year project to evaluate EEG and eye-tracking as potential biomarkers to:
 - Help define ASD subtypes that share a common biological phenotype
 - Be used as markers of response in clinical trials focusing on social and cognitive aspects of ASD



Research Domain Criteria (RDoC): Unpacking Diagnostic Categories





Research Domain Criteria (RDoC): Unpacking Diagnostic Categories

	T Act Project Year Sub#	Project Title	Contact PI/ Project Leader	Organization	0	5 R01 MH104648 02	CONTROL AND REWARD CIRCUITS AS TARGETS FOR REPETITIVE THOUGHTS AND BEHAVIORS	MARSH, RACHEL et al.	NEW YORK STATE PSYCHIATRIC INSTITUTE
0	2 R01 MH085300 06A1	3/3 BRAIN FUNCTION AND GENETICS IN PEDIATRIC OBSESSIVE- COMPULSIVE BEHAVIORS	ARNOLD, PAUL DANIEL et al.	HOSPITAL FOR SICK CHLDRN (TORONTO)		1 R01 MH107431 01	DIMENSIONAL ANALYSIS OF DEVELOPMENTAL BRAIN DISORDERS USING AN ONLINE, GENOME-FIRST APPROACH	MARTIN, CHRISTA LESE	GEISINGER CLINIC
	5 U01 MH101723 03	3/5 INTERNATIONAL CONSORTIUM ON BRAIN AND BEHAVIOR IN 22Q11.2 DELETION SYNDROME	BASSETT, ANNE S. et al.	CENTRE FOR ADDICTION AND MENTAL HEALTH		1 R01 MH107426 01	MULTIMODEL ASSESSMENT OF SOCIAL PROCESS SYSTEMS ACROSS NEURODEVELOPMENTAL	MCPARTLAND, JAMES CHARLES et al.	YALE UNIVERSITY
	5 R01 MH105094 02	KNOCK-IN MOUSE MODEL OF DOPAMINE DYSFUNCTION UNDERLYING TRAITS OF ADHD	BLAKELY, RANDY D.	VANDERBILT UNIVERSITY		1 K99 MH106642 01A1	DISORDERS SHARED AND DISTINCT DEVELOPMENTAL PATHWAYS TO	MILLER, MEGHAN	UNIVERSITY OF
0	1 K01 MH105625 01A1	DYNAMIC BRAIN MECHANISMS OF PROACTIVE AND REACTIVE CONTROL IN CHILDHOOD ADHD	CAI, WEIDONG	STANFORD UNIVERSITY			ADHD AND AUTISM SPECTRUM DISORDER 1/3 BRAIN FUNCTION AND GENETICS	RHYS	CALIFORNIA AT DAVIS
0	5 R01 MH104324 02	INFANT BRAIN AND BEHAVIORAL	ELISON, JED THOMAS	UNIVERSITY OF MINNESOTA		2 R01 MH059299 15A1	IN PEDIATRIC OBSESSIVE- COMPULSIVE BEHAVIORS	ROSENBERG, DAVID R	WAYNE STATE UNIVERSITY
		RISK FOR PSYCHOPATHOLOGY CHARACTERIZING MECHANISTIC		OREGON HEALTH &		5 R01 MH103284 02	PREDICTORS OF COGNITIVE DEVELOPMENT IN AUTISM SPECTRUM DISORDER	SOLOMON, MARJORIE	UNIVERSITY OF CALIFORNIA AT DAVIS
	5 R01 MH096773 04	HETEROGENEITY ACROSS ADHD AND AUTISM	FAIR, DAMIEN A	SCIENCE UNIVERSITY	0	1 R01 MH107508 01	DEVELOPMENTAL EXPOSURE TO MATERNAL OBESITY-INDUCED INFLAMMATION IMPACTS OFFSPRING BRAIN AND NEGATIVE VALENCE BEHAVIORS	SULLIVAN, ELINOR L.	OREGON HEALTH & SCIENCE UNIVERSITY
	2 U01 MH070890 11A1	EARLY BRAIN DEVELOPMENT IN TWINS	GILMORE, JOHN H	UNIV OF NORTH CAROLINA CHAPEL HILL					
0	5 U01 MH101719 03	1/5 INTERNATIONAL CONSORTIUM ON BRAIN AND BEHAVIOR IN 22Q11.2 DELETION SYNDROME	GUR, RAQUEL E	UNIVERSITY OF PENNSYLVANIA		5 <u>U01</u> <u>MH101722</u> 03	"4/5 INTERNATIONAL CONSORTIUM ON BRAIN AND BEHAVIOR IN 22Q11.2 DELETION SYNDROME"	SWILLEN, ANN	KATHOLIEKE UNIVERSITEIT LEUVEN
0	2 R01 MH085321 06A1	2/3 BRAIN FUNCTION AND GENETICS IN PEDIATRIC OBSESSIVE-	HANNA, GREGORY L.	UNIVERSITY OF MICHIGAN	0	5 U01 MH101724 03	5/5 INTERNATIONAL CONSORTIUM ON BRAIN AND BEHAVIOR IN 22Q11.2 DELETION SYNDROME	VAN DEN BREE, MARIANNE et al.	CARDIFF UNIVERSITY
0	5 R01 MH101493 03	COMPULSIVE BEHAVIORS ACTION MONITORING AND GENOMIC VARIANTS IN PEDIATRIC OBSESSIVE-COMPULSIVE BEHAVIOR	HANNA, GREGORY L. et al.	UNIVERSITY OF MICHIGAN		5 <u>U01</u> <u>MH101720</u> <u>03</u>	2/5 INTERNATIONAL CONSORTIUM ON BRAIN AND BEHAVIOR IN 22Q11.2 DELETION SYNDROME	WARREN, STEPHEN T.	EMORY UNIVERSITY

IACC Meeting Round Robin 11/17/15

Shannon M. Haworth, MA

Public Health Program Manager
Association of University Centers on
Disabilities (AUCD)

Personal Connection to Autism

- * Parent of a child with Autism
- * Spouse is on the spectrum
- * Experienced the frustration of getting a diagnosis for my child and appropriate services and school support
- * Advocacy



Organizational Activities

- * Accomplishments of LEND/DBP programs under the CARES legislation
 - * 2,663 LEND & DBP trainees completed coursework early signs of ASD/DD; screening; diagnosis; and/or evidenced-based interventions for ASD/DD
 - 1,283 LEND & DBP trainees completed coursework covering early signs of ASD/DD; screening; diagnosis; and/or evidenced-based interventions for ASD/DD
 - * 89,872 infants/children who received interdisciplinary diagnostic services to confirm or rule out ASD/DD
 - 1,942 LEND/DBP faculty and/or fellows worked in clinical settings located in an underserved area or work with underserved populations

- * 2015 CARES Grantee Meeting
 http://www.aucd.org/docs/Ben/CARES2015
 AutismIdentificationResources.pdf
- * ASD Special Interest Group
- * <u>Including People with Disabilities Public</u> <u>Health Workforce Competencies</u>
- * **Pediatrics commentary "**System wide Solutions to Improve Early Intervention for Developmental–Behavioral Concerns" bit.ly/1L6EwVP



What the IACC Can Address

- * The need to increase the number of LEND programs as originally intended under the Autism Cares Act to target the lack of trained professionals to diagnose/rule out, and provide evidence-based interventions
- School to Prison pipeline for minority children with ASD
- * ASD and Mental Health
- * "I would like an effort to allocate a higher percentage of research for and about autistic adults, with a focus to be on services and improvement of quality of life/independence... more community-based, participatory research that partners with autistic adults would be wonderful." Sara Luterman, Autism Self Advocate

HRSA Autism Investments November 17, 2015

Laura Kavanagh, MPP
Deputy Associate Administrator
Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA)





Autism CARES Act Supports:

- CDC: surveillance and public awareness efforts
- HRSA: health professions training, autism intervention research and state implementation grants and
- NIH: Interagency Autism Coordinating Committee





HRSA Roles:

- increase public awareness;
- promote research into the development and validation of reliable screening tools and interventions
- promote early screening
- increase number able to confirm or rule out a diagnosis of ASD
- increase the number able to provide evidence-based interventions





Collaboration with CDC

- Learn the Signs Act Early
- Act Early Ambassadors
- Natl Survey of Children's Health
- Autism Case Training







Three Program Areas

Autism Intervention Research **Training**

- DBP
- LEND

State Implementation





Autism Intervention Research

- Supports research networks and autism intervention research projects
- Research on behavioral and physical health through support of 2 research networks, AIR-B and AIR-P
- Multi-site research on innovative treatment models targeting underserved minority and rural populations, including use of telehealth
- Health Care Transitions Research Network (HCT-RN), first collaborative research network to address the health, family, and social needs of adolescents and young adults on the autism spectrum.



Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

- 43 interdisciplinary, graduate level training programs in 39 states
- Train wonderful clinicians, and also emphasize an interdisciplinary approach, family-centered care, cultural competency, and policy skills
- Dedicated to caring for children with neurodevelopmental disabilities, including autism







How Does LEND Fit within Larger Autism Efforts?

- Increases the number of professionals in the pipeline of prepared, knowledgeable providers
- Train an average of 1,300 long-term trainees, 3,200 medium-term trainees, and 11,000 short-term trainees each year
- Influence curricula nation-wide pertaining to ASD
- Gives students more ASD field and clinical experience
- LEND graduates become leaders in the fields of MCH and developmental disabilities



Families Are Involved in LEND Programs

- All LEND programs required to have Family Faculty on staff to train and mentor the students
- Family Faculty members are parents, siblings, related to a person with a disability, or they may have ASD or other DD themselves
- They are a critical component of the program, sharing their expertise in living in a family with disabilities, and bringing resources to the trainees as part of their formal curriculum





Developmental Behavioral Pediatrics (DBP)

- 10 MCHB-funded DBP programs around the country that focus on autism and related disabilities
- Nation-wide shortage of DBP-trained physicians
- Train nearly 50 long-term trainees each year and at least
 350 medium-term trainees each year





State Programs

- Currently fund 13 State Grants (4 planning in NH, AR, TX, MA and 9 implementation in AR, MI, MN, GA, OR, MD, IA, NC, VA)
- Grantees work to improve state systems of services such as:
 - improving early screening, including the training of professionals on validated screening tools;
 - family engagement;
 - coordination of family-centered services through a medical home,
 - preparing youth and families for transition to adult systems of services; and
 - Increasing awareness.





Contact Information

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Facebook: facebook.com/





Research Update

Julie Lounds Taylor, Ph.D.

Department of Pediatrics, Division of General Pediatrics Vanderbilt
Kennedy Center
Vanderbilt University

IACC Meeting November 17, 2015

1. Adolescents and Adults with Autism Study (PI: Mailick)

- 406 families of adolescents and adults with ASD
 - Funded by NIA (R01 AG08768, PI: Mailick) and Autism Speaks
 (PI: Taylor, PI: Mailick)
- Data collected 7 times over 12 years (mostly from mothers)
- Wide age range -- 10 to 52 years of age at Time 1
 - 62% adolescents age 10-21
 - 38% adults age 22-52

Key Findings

- Leaving high school disrupts behavioral and relationship improvements for youth with ASD
- Obtaining a vocational or PSE position is difficult.
 Maintaining it is an even greater challenge
- Certain subgroups of individuals with ASD are at increased risk
 - Those without an intellectual disability
 - Women
- Vocation/PSE may serve as a catalyst for behavioral improvement

2. Transitioning to Adulthood with Autism Study

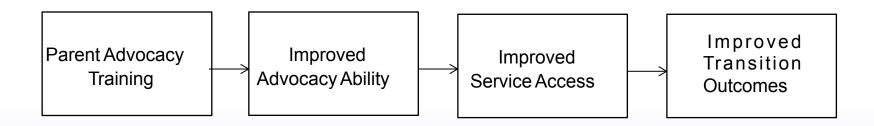
- 40 youth with ASD (and their families) who were exiting high school in the next 12 months
 - Funded by NIMH (K01 MH 92598, PI: Taylor)
- 2 data collection points
 - Time 1: last year of high school
 - Time 2: within 12 months after high school exit
- How do stress response profiles, behavioral profiles, and environmental resources change as youth transition out of high school?
 - How do these factors influence post-transition outcomes?

Key Findings (to date)

- Existing publications have focused on the first wave of data
 - Examined service receipt and unmet service needs
 - Described the bullying experiences and post-school expectations of these youth
- Current analyses are examining changes in social participation, behaviors, and service profiles after exit. We are also looking at the factors that predict disengagement from vocation/PSE
- Families at Wave 1 had little to no information about what services/supports might be available after high school exit

3. Parent Advocacy Training

- We are developing and testing a parent advocacy training to promote transition outcomes for youth with ASD
 - 12-week program teaching parents about the services and support available to their family after high school, and the most effective ways to access them.
- Funded by NIMH (R34 MH104428, PI: Taylor)



Study Design

Phase 1

- Adapt existing curriculum
- Pre-pilot the program with families of youth who recently left high school
- Families reported increased knowledge, advocacy skills, and connectedness

Phase 2

- Randomly assigned 45 participants to treatment (Fall 2015) or wait-list control (Spring 2017) groups
- Does participating in the program lead to differences in services and community integration 6-months and 12-months post-program?



Autism Science Foundation

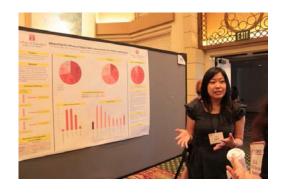
IACC Meeting November 17, 2015

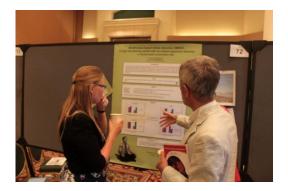


Our Programs

Early Career Support for Autism Scientists:

- Undergraduate Summer Research Grants
- Predoctoral Fellowships
- Postdoctoral Fellowships
- Medical School Gap Year Research Fellowships
- 3-year Early Career Award
- Treatment Grants









Our Programs

Research Acceleration:

- Research Accelerator Grants
- Autism BrainNet (Collect brain tissue)
- Autism Sisters Project (Collect DNA)







Our Programs

Stakeholder Education:

- Annual Autism TED talks (April 14, 2016)
- IMFAR Stakeholder Travel Awards
- Weekly PodCast









Meeting of the IACC

Closing Comments