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  Expect More: An Autism Adventure
The Hon. Mike Lake, P.C., M.P.

9:45  CDC Autism Data Visualization Platform
Stuart Shapira, M.D., Ph.D.
Chief Medical Officer
Associate Director for Science (ADS)
National Center on Birth Defects and Developmental Disabilities (NCBDDD)
Centers for Disease Control and Prevention
Meeting of the IACC

Morning Agenda

10:30  Break

10:40  Update from the Federal Communications Commission

Theodore Marcus, J.D.
Deputy Chief, Disability Rights Office, Consumer and Governmental Affairs Bureau, Federal Communications Commission
### Meeting of the IACC

**Morning Agenda**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker(s)</th>
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</table>
| 11:25  | Committee Business     | Susan Daniels, Ph.D.  
Director, Office of Autism Research Coordination, National Institute of Mental Health, and Executive Secretary, IACC  
Joshua Gordon, M.D., Ph.D.  
Director, National Institute of mental Health and Chair, IACC |
| 12:00 PM | Lunch                  |                                                                            |
Welcome
Introductions
Roll Call
Approval of Minutes

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

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

The Hon. Mike Lake, P.C., M.P.
“I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”

Maya Angelou
“He who does not understand your silence will probably not understand your words.”

Elbert Hubbard
“Things do not happen. Things are made to happen.”

John F. Kennedy
“Life is a succession of lessons which must be lived to be understood.”

Helen Keller
“A small body of determined spirits fired by an unquenchable faith in their mission can alter the course of history.”

Mahatma Gandhi
Discussion
Centers for Disease Control and Prevention
Autism Data Visualization Platform

Stuart Shapira, M.D., Ph.D.
Chief Medical Officer, Associate Director for Science (ADS), National Center on Birth Defects and Developmental Disabilities (NCBDDDD), Centers for Disease Control and Prevention
CDC Autism Data Visualization Tool
CDC Autism Data Visualization Tool

- Interactive website provides up-to-date autism spectrum disorder (ASD) prevalence data among children in the United States
  - Four different data sources by year and state (when available)
    - Autism and Developmental Disabilities Monitoring Network
    - Special Education
    - Medicaid
    - National Survey of Children’s Health
  - Description of how different data sources are used to estimate the ASD prevalence
CDC Autism Data Visualization Tool

- Makes it easy to find available ASD prevalence data in each state
  - Highlights changes over time for specific states or communities
  - Improves access to data for public health researchers, state health officials, and the public
  - Improves understanding of ASD and its impact across communities in the United States
  - Can be used to plan for services, guide research, and inform policies to help children with ASD
Data Source 1: Autism and Developmental Disabilities Monitoring (ADDM) Network

- Features published ADDM prevalence estimates 2000–2014 in participating communities
- ADDM Data: Uses record review of 8-year-old children and combines information across communities
- **Numerator**: children meeting ADDM ASD case definition
- **Denominator**: National Center for Health Statistics bridged population estimates
- Sample sizes allow for more detailed data at state/community level

https://www.cdc.gov/ncbddd/autism/addm.html
Data Source 2: Special Education

- Special education primary exceptionality classification of autism
- **Numerator**: Individuals with Disabilities Education Act (IDEA) state child count data of autism classification for 6–17-year-olds
- **Denominator**: National Center for Education Statistics school enrollment counts for grades 1–12
- Publicly available data from almost all states in each year
- Currently available through 2015*

*will update soon with new year

https://nces.ed.gov/
Data Source 3: Medicaid (MAX)

- Medicaid Analytic eXtract (MAX)
- **Numerator:** Children with ASD ICD (medical billing) code for ≥1 inpatient or ≥2 outpatient claims in a given year
  - Same as CMS-endorsed autism algorithm
- **Denominator:** Children enrolled in Medicaid during each year
- Available 2000–2012 for most states

https://www.ccwdata.org/web/guest/condition-categories
Data Source 4: National Survey of Children's Health (NSCH)

- Estimates match published NSCH data (www.childhealthdata.org)
  - Use complex survey design and weights
- **Numerator:** Children with ASD or "current ASD" (in more recent years)
  - Survey questions on ASD have changed over time
- **Denominator:** Children participating in NSCH each year, nationally representative complex survey sample
- Re-designed annual survey began in 2016

https://www.census.gov/programs-surveys/nsch/data.html
https://www.childhealthdata.org/
Data Visualization Tool Features

- Data are downloadable in spreadsheets for custom analyses
- Contains links to primary sources of data, deeper technical notes, and other information for each data source
- Updates as new data are available

Image from: https://www.cdc.gov/ncbddd/autism/data/
Acknowledgments
Daisy Christensen
Melissa Danielson
Patty Dietz
Nicole Dowling
Bruce Heath
Chrissy Hillard
Matthew Maenner
Sarabeth Mathis
Sue Williams

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

www.cdc.gov/ncbddd/autism/data/

The findings and conclusions in this presentation have not been formally disseminated by the Centers for Disease Control and Prevention and should not be construed to represent any agency determination or policy.
Discussion
Break
Meeting of the IACC

Morning Agenda

10:40  Update from the Federal Communications Commission

Theodore Marcus, J.D.
Deputy Chief, Disability Rights Office, Consumer and Governmental Affairs Bureau, Federal Communications Commission

11:25  Committee Business

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

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

12:00 PM  Lunch
THE FEDERAL COMMUNICATIONS COMMISSION (FCC)

Agency Activity Concerning Rights of People with Cognitive Disabilities

Presentation by Theodore Marcus, Deputy Chief
FCC Disability Rights Office
Background

Communications Services, Products and Equipment

- Telecommunications


- Telecommunications equipment and services must be accessible and usable
  - “Readily achievable”
    - If not, then “compatible”
  - “Usability” and “functional equivalence”
  - Implications
• **Advanced Communication Services and Equipment (ACS)**

*Twenty-First Century Communications and Video Accessibility Act of 2010* – amended the Communications Act to update accessibility requirements for persons with disabilities consistent with advances in the communications marketplace:

- ACS (includes **text messaging**, **instant messaging**, **interoperable video conferencing**, [newer] **VoIP services**, and **e-mail**)
  - ACS and ACS equipment must be accessible, unless not “achievable”
  - May be accessible through an accessibility solution available at nominal cost

- **Implications**
  - **Computers, tablets, smart phones, and software used for ACS**
  - **must be “operable with limited cognitive skills”**
Relay Services

- For people who are deaf, hard of hearing, deaf-blind, or who have a speech disability
- Implications
  - Relay for people with auditory or speech processing disabilities:
    - Speech-to-Speech Relay Service
    - Captioned Telephone Service
Closed Captioning Requirements

Closed captioning required:
  • on TV and
  • for most TV programs later shown on the Internet

Captions must be available on most devices:
  o Television and cable boxes
  o Devices used to play TV programs, like tablets, cell phones, laptops

Remote controls must have a caption button or an easy way to access captions

- Implications
  • Helps those with auditory processing disabilities
  • Helps reading skills for those with learning disabilities
Audio Description Requirements

- Audio description is audio-narrated descriptions of a television program's key visual elements. These descriptions are inserted into natural pauses in the program's dialogue.

- Audio description is required for some television programs

- Implications
  - Assists those with visual processing disabilities
Emergency Information on Television

- MUST BE VISUAL
  - Emergency audio information must also be provided in closed captioning or visually.
  - Emergency scrolls and closed captioning cannot block each other.

- MUST BE AUDIBLE
  - Emergency text crawls must be made audible on the secondary audio stream
  - Audible tone must accompany emergency scrolls

- Implications
  - Access to emergency information on TV for individuals who
    - cannot read emergency text crawls or
    - have auditory processing disabilities
Relevant Activities – Post-2010

• FCC’s 2015 Summit on the Telecommunication Needs of People with Cognitive Disabilities (Held October 28, 2015)
• FCC’s Disability Advisory Committee’s Cognitive Disabilities Working Group best practices recommendations, 2016
• FCC’s “White Paper” on Individuals with Cognitive Disabilities: Barriers to and Solutions for Accessible Information and Communication Technologies (“ICT”), October 6, 2016
• Dispute Assistance, Consumer Complaints, and Outreach Efforts
Contact Us!

Subscribe to AccessInfo@fcc.gov.
Contact FCC DRO at:

DRO@fcc.gov (e-mail)
844-432-2275 (videophone)
202-418-2517 (voice)
888-835-5322 (TTY)

Online Complaint Form: www.fcc.gov/complaints.

Presentation by Theodore C. Marcus, Deputy Chief, DRO
Theodore.Marcus@fcc.gov
Discussion
Thank you to OARC Staff

Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

Rebecca Martin, M.P.H
Public Health Analyst

Angelice Mitrakas, B.A.
Management Analyst

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

Matthew Vilnit, M.B.A.
Operations Coordinator

Jeff Wiegand, B.S.
Web Development Manager
April is National Autism Awareness Month
Autism Awareness Month News

• 2019 Presidential Proclamation: [President Donald J. Trump Proclaims April 2, 2019, World Autism Awareness Day](#)

• 2019 UN Secretary-General Message: [António Guterres' Message on World Autism Awareness Day](#)
Autism Awareness Month Events

Autism Awareness Interagency Roundtable
Indian Health Service
April 2, 2019; Rockville, MD

Assistive Technologies, Active Participation
United Nations
April 2, 2019; New York, NY

Reddit Ask Me Anything: The Role of Environmental Risk Factors in ASD
National Institute of Environmental Health Sciences
April 2, 2019
Transcript:
https://www.reddit.com/r/askscience/comments/b8hqa7/askscience_ama_series_hi_were_drs_rebecca_schmidt/
NIMH Special Event for Autism Awareness Month

A Woman’s Voice: Understanding Autistic Needs
April 23, 2019
2:30 pm – 5:00 pm

• A conversation featuring 4 female authors on the autism spectrum
• Live webcast will be available

• Featuring:
  • Barb Cook
  • Liane Holliday-Willey
  • Jennifer Cook O’Toole
  • Dena Gassner
2018 IACC Summary of Advances Available Now!

• Annual report required by the Autism CARES Act

• Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC

• Includes articles addressing all 7 topic areas of the IACC Strategic Plan

Articles selected for the 2018 IACC Summary of Advances

QUESTION 1: SCREENING AND DIAGNOSIS

QUESTION 2: BIOLOGY
- Avino TA, Barger N, Vargas MV, Carlson EL, Amaral DG, Bauman MD, Schumann CM. Neuron numbers increase in the human amygdala from birth to adulthood, but not in autism.
**QUESTION 3: RISK FACTORS**

- The Brainstorm Consortium. *Analysis of shared heritability in common disorders of the brain.*
- Short PJ, McRae JF, Gallone G, Sifrim A, Won H, Geschwind DH, Wright CF, Firth HV, FitzPatrick DR, Barrett JC, Hurles ME. *De novo mutations in regulatory elements in neurodevelopmental disorders.*
QUESTION 4: TREATMENTS AND INTERVENTIONS

• Morgan L, Hooker JL, Sparapani N, Reinhardt VP, Schatschneider C, Wetherby AM. Cluster randomized trial of the classroom SCERTS intervention for elementary students with autism spectrum disorder.


QUESTION 5: SERVICES


Articles selected for the 2018 IACC Summary of Advances

QUESTION 6: LIFESPAN ISSUES
- Bal VH, Kim SH, Fok M, Lord C. Autism spectrum disorder symptoms from ages 2 to 19 years: Implications for diagnosing adolescents and young adults.
- Davignon MN, Qian Y, Massolo M, Croen LA. Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD.

QUESTION 7: INFRASTRUCTURE AND SURVEILLANCE
Autism CARES Act Report to Congress
Available Now!

- Required by the Autism CARES Act of 2014
- Prepared by OARC on behalf of HHS, including information from 21 federal Departments/agencies
- Report details progress on activities related to ASD and other developmental disorders across the federal government

Autism CARES Act Report to Congress: Departments and Agencies Included

- 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)
  - Centers for Disease Control and Prevention (CDC)
  - Centers for Medicare & Medicaid Services (CMS)
  - Food and Drug Administration (FDA)
  - Health Resources and Services Administration (HRSA)
  - Indian Health Service (IHS)
  - National Institutes of Health (NIH)
  - Substance Abuse and Mental Health Services Administration (SAMHSA)
Autism CARES Act Report to Congress: Departments and Agencies Included

- Department of Education (ED)
- Department of Defense (DoD)
  - Army
  - Air Force
  - Military Health System (MHS)/TRICARE
- Environmental Protection Agency (EPA)
- Department of Housing and Urban Development (HUD)
- Department of Justice (DOJ)
- Department of Labor (DOL)
- National Science Foundation (NSF)
- Social Security Administration (SSA)
- Department of Transportation (DOT)
## Federal Involvement in the Implementation of the IACC Strategic Plan, By Agency

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<th>Research Fund</th>
<th>Service Services</th>
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## Autism Cares Act Report to Congress

**Available Now!**

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Coming soon! IACC International ASD Research Portfolio Analysis Report

• OARC is leading a collaborative effort to produce the first International ASD Research Portfolio Analysis Report
• Based on 2016 research funding portfolio
• Describes and compares trends in ASD research funding
• Contributors
  • United States - OARC
  • United Kingdom - Autistica
  • Canada - Canadian Institutes of Health Research
  • NEW – Australia - Macquarie University
• Final publication expected summer 2019
• Data will be added to the IACC/OARC Autism Research Database
Following a multi-tiered series of meeting and requests for public input conducted by Autistica and other partners in the UK, a list of 48 priority areas for research on ASD and suicide were identified.

The goal of the April 4-5 meeting was to further narrow down the list to 10 research priorities.

Participants included self-advocates, family members, researchers, and other community members.

Meeting sponsors included the University of Nottingham, Newcastle University, Coventry University, Autistica, INSAR, and the James Lind Alliance.
• The 10 research priorities will be presented at the upcoming INSAR annual meeting, May 1-4, 2019.

• Dr. Sarah Cassidy, co-organizer of this workshop, will be a speaker at the upcoming IACC Workshop: Addressing the Mental Health Needs of People on the Autism Spectrum
The IACC convened a working group on health and wellness issues for individuals with ASD

Co-chairs: Dr. David Amaral and Dr. Julie Taylor

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

- Working Group conference call (September 5, 2018)

- Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 27, 2018)
  - Health Epidemiology
  - Three co-occurring conditions: epilepsy, gastrointestinal disorders, and sleep disturbances
  - Improving patient-provider interactions

- Working Group conference call (December 17, 2018)
Health Outcomes Working Group: Upcoming Workshop

Addressing the Mental Health Needs of People on the Autism Spectrum

May 21, 2019, 9:00am – 5:00pm
Neuroscience Center, Rockville, MD

- Workshop will focus on mental health-related topics, including:
  - Anxiety
  - Depression
  - Suicide
  - Self-injurious behaviors and aggression
  - Mental health services
Health Outcomes Working Group: Next steps

- Continued discussions in Working Group conference calls
- A written document providing an update on issues
- Working Group activities will conclude in September 2019
Update on IACC Housing Working Group

• The IACC voted to convene a working group on housing issues for individuals with ASD.

• Scope
  • Research and best practices on housing
  • Implementation of current federal regulations
  • Housing issues faced by autistic individuals with more severe disabilities

• Chair: Alison Singer
• Working group is being convened
Housing Working Group: Activities

• Activities will include:
  • Working group conference calls
  • Town-hall meeting (target date: June 2019)

• Working group activities will run through September 2019
The 2018-2019 IACC Strategic Plan Update will provide a summary of the IACC’s recent activities and progress related to the Strategic Plan, including:

- Summary of Health Outcomes working group and 2018 workshop
- Summary of 2016 IACC Portfolio Analysis Report
- Summary of Autism CARES Act Report to Congress

- Committee members have received a draft for review and comments
- Additional 2019 activities to be added
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 Presentation: Disability Employment

Introduction - Julie Taylor

2:05  Employment: Current Research and Future Directions

Julie Taylor, Ph.D.
Associate Professor of Pediatrics
Vanderbilt Kennedy Center Investigator
Vanderbilt University Medical Center
Afternoon Agenda

2:25 Competitive Employment for Youth with Significant Autism: A Multi-Site, Randomized Clinical Trial

Paul Wehman, Ph.D.
Professor of Physical Medicine and Rehabilitation
Chairman Division of Rehabilitation Research
Director of VCU-RRTC
Medical College of Virginia
Virginia Commonwealth University

2:45 The TennesseeWorks Collaborative: Lessons Learned on Elevating Employment Outcomes for Young People with Disabilities

Erik Carter, Ph.D.
Cornelius Vanderbilt Professor of Special Education
Vanderbilt University
Meeting of the IACC

Afternoon Agenda

3:05  Autism-Ready Workplace: Creating and Scaling Autism Hiring Initiatives

Hala Annabi, Ph. D.
Associate Professor, Information School
University of Washington

3:55  Afternoon Break

4:10  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 Translational Research National Institute of Mental Health
Meeting of the IACC

Afternoon Agenda

4:15  Summary of Advances Discussion

Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

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

4:50  Round Robin

5:00  Closing Remarks and Adjournment
Oral Public Comments

IACC Full Committee Meeting
April 17, 2019

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

Joshua A. Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC
Oni Celestin, Ph.D.
Science Policy Analyst
Office of Autism Research Coordination, NIMH
Panel Presentation: Disability Employment

Julie Taylor, Ph.D.
Paul Wehman, Ph. D.
Erik Carter, Ph. D.
Hala Annabi, Ph.D.
Employment: Current Research and Future Directions

Julie Lounds Taylor, Ph.D.
Department of Pediatrics, Division of General Pediatrics
Vanderbilt Kennedy Center
Vanderbilt University Medical Center

IACC, April 17, 2019
What ARE Employment Rates?

- Howlin (2004) – IQs ≥ 50, current work
What ARE Employment Rates?

- Howlin (2004) – IQs $\geq 50$, current work
- Farley (2009) – Average or above IQ, current work

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What ARE Employment Rates?

- Howlin (2004) – IQs ≥ 50, current work
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- Taylor (2012) – 70% ID, current work or PSE

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- Farley (2009) – Average or above IQ, current work
- Taylor (2012) – 70% ID, current work or PSE
- Shattuck (2012) – ever work or PSE
What ARE Employment Rates?

- Howlin (2004) – IQs $\geq$ 50, current work
- Farley (2009) – Average or above IQ, current work
- Taylor (2012) – 70% ID, current work or PSE
- Shattuck (2012) – ever work or PSE
- Shattuck (2013) – current work (no PSE)
What ARE Employment Rates?

- Howlin (2004) – IQs ≥ 50, current work
- Farley (2009) – Average or above IQ, current work
- Taylor (2012) – 70% ID, current work or PSE
- Shattuck (2012) – ever work or PSE
- Shattuck (2013) – current work (no PSE)
- Farley (2018) mid-life adults, 75% ID, current work
- Taylor et al., in press
- NCI
What ARE Employment Rates?

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- Shattuck (2013) – current work (no PSE)
- Farley (2018) mid-life adults, 75% ID, current work
- Taylor (in press) – self-reporting adults, current work/PSE
What ARE Employment Rates?

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- **Taylor (2012)** – 70% ID, current work or PSE
- **Shattuck (2012)** – ever work or PSE
- **Shattuck (2013)** – current work (no PSE)
- **Farley (2018) mid-life adults**, 75% ID, current work
- **Taylor (in press)** – self-reporting adults, current work/PSE
- **NCI** – adults receiving services
Unemployment is a Concern

• Underemployment also a problem

• Programs have been developed to improve employment
  – Research has lagged behind

• Important directions for future research
  – Promoting stability
  – Focusing on needs of subgroups
How do Vocational Activities Change over 10 Years?

• Longitudinal study of 400 families of adolescents and adults with ASD (PI: Mailick; R01 AG08768 and Autism Speaks)

• 161 adults out of high school at T1 (80% had ID)

• On average, vocational activities becoming less independent

• Predictors of initial scores
  – Intellectual disability
  – Behavioral variables

Taylor & Mailick Dev Psychol, 2014
Greater Decline for Females

Vocational Index Score vs. Years Since the Start of the Study

Taylor & Mailick, *Dev Psychol*, 2014
What about Patterns of Employment for Adults Without ID?

- 73 adults with ASD without ID
- Data on Employment/PSE at up to 7 time points over 12 years
- Grouped into 3 categories
  - Consistently employed/in PSE
  - Sometimes employed/in PSE
  - Never employed/in PSE

Patterns of Employment/PSE over Time

Different predictors for obtaining vs. maintaining activities

- 36 families of youth with ASD who had data collected at 3 time points (funded by NIMH K01 MH092598)

- Coded youth into “disruption” versus “no disruption” groups
  - Not all instability was disruption

Taylor & DaWalt, 2017, *JADD*
Patterns and Predictors of Disruption

Patterns

<table>
<thead>
<tr>
<th></th>
<th>Disruption</th>
<th>No disruption</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>60%</td>
<td>50%</td>
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<td>10%</td>
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</tr>
</tbody>
</table>

Predictors

- Youth IQ
- Youth adaptive behavior
- Youth autism severity
- Youth behavior problems
- Youth stress reactivity
- Parental depressive symptoms
- Parental anxiety symptoms
- Parental QOL
- Family income
- Family climate

Cohen’s D Effect Sizes

Taylor & DaWalt, 2017, *JADD*
Understanding Needs and Supports for Subgroups

- Extreme heterogeneity that must be taken into account

- Cognitive functioning
  - How do needs/outcomes differ? How are they the same?

- Sex/Gender
  - Women obtain positions at same rate, greater difficulty maintaining

- Other behavioral variations
  - Adaptive behavior, social motivation, co-occurring conditions
Supporting Employment is Multi-faceted

- Individuals
- Families
- Employers/Work places
- Services/Systems

Successful Employment
Panel Presentations

Competitive employment for youth with significant autism: A multi-site randomized clinical trial
Paul Wehman, PhD
Virginia Commonwealth University

The TennesseeWorks Collaborative: Lessons learned on elevating employment outcomes for young people with disabilities
Erik Carter, PhD
Vanderbilt University

Autism-ready workplace: Creating and scaling autism hiring initiatives
Hala Annabi, PhD
University of Washington
Competitive Employment for Youth with Significant Autism: A Multi Site, Randomized Clinical Trial

April 17, 2019
Interagency Autism Coordinating Committee Meeting

Paul Wehman, Ph.D.
Virginia Commonwealth University
Rehabilitation Research and Training Center
What are the current employment outcomes for young adults with ASD? (Wehman et al., 2014)

• Unemployed and underemployed at higher levels than others with disabilities (e.g., Shattuck et al.)
• Low rates of independent living -- Most individuals with ASD continue to live at home with their parents
• Low incidence of friendships and relationships
Key to Changing This...

Refocus on Strengths, Interests, and Preferences!
The Goal of Education is to have a life where you have:

- A place to call home
- Places to go
- People to see
- Important tasks to do that you like!
How do you get that life?

A REAL JOB!
What kind of job?
Real Work for Real Pay!
Not Sheltered Workshops or Day Care Centers
So What is One Evidence Based Pathway to Competitive Integrated Employment?
An Internship Based Model

Business Based Internships

Customized Employment

Supported Employment

EMPLOYMENT
Pilot Randomized Clinical Trial: 2009-2013 Employment Outcomes in Community Based Integrated Employment (Wehman et al., 2017)

- N = 54
- Treatment = 31
- Control = 18

Data Collection Point:
- Baseline: 0%
- Graduation: 6%
- 3 Months: 6%
- 12 Months: 12%

Funded by NIDILRR

- n = 156
- 81 Treatment
- 75 Control
- 4 Hospitals
- 3 School Divisions
- 1 Regional Program
- 2 Job Coaching Agencies

Funded by NIDILRR
Effect of Employment on Independence Support Intensity (Wehman, et al., 2017) (Support Intensity Scale) AA IDD, 2004

Low Scores = More Independence
What is the impact of work on individuals with ASD?

- Statistically Significant Improvement in All Domains on the Support Intensity Scale (including:
  - Employment Activities
  - Community Living Activities
  - Home Living Activities
  - Health and Safety Activities
  - Lifelong Learning Activities
  - Social Activities
What Types of Jobs Did Students Acquire?

- Health Care
- Foodservice
- Retail
- Hospitality
- Distributor
- Manufacturer
- Entertainment
- Sports/Recreation
- Education
- Transportation
- Facilities management
How Long Did It Take For Students To Become Employed After 900 Hours Of The Internship

Average 3-6 Months
Impact of Persons with ASD on Employers and Co-Workers

• Increased morale among co-workers

• Increased sense of mission among staff

• Increased productivity in unit

• Managers learn management skills that help them with all staff
Employment Supports (Schall, et al., 2012)

- Behavioral Consultation
- Consistent Structure to Seemingly Unstructured Internships
- Behaviorally Defining Idioms, Social Skills, and Work Expectations
- Visual Supports to Increase Implementation of Strategies
- Self Monitoring Checklists and Reinforcement Programs
- Role-Playing and Practice for Required Social Skills
- Ongoing Intensive Instruction and Monitoring of Student Success
Supported Employment
(Schall, et al., 2015)

Phase 4: Long Term Supports

Phase 3: Job Site Training

Phase 2: Job Development

Phase 1: Job Seeker Profile

Person seeks services with Job Coach

Funded by VR or DD Agency
https://vcurrtc.org
http://vcuautismcenter.org
http://centerontransition.org
This Presentation is Based Upon the Following Research


THE TENNESSEE WORKS PARTNERSHIP

Changing the Employment Landscape for Young People with Disabilities

Erik Carter | Vanderbilt University
TO EQUIP

- Young people with disabilities to aspire toward competitive work from an early age
- Families to pursue competitive work for their members with disabilities
- Educators across school levels to prepare their students for future careers
- State systems to support competitive work in every corner of the state
- Communities to receive the gifts and contributions of young people with disabilities
SOME KEY THEMES

1. Chasing aspirations
2. Elevating expectations
3. Changing introductions
4. Aligning policies
5. Equipping professionals
6. Making information accessible
7. Engaging communities
8. Measuring well
9. Investing in relationships
10. Coming soon…
1. LED BY ASPIRATIONS
At the forefront of everything
THE ASPIRATIONS OF YOUTH AND YOUNG ADULTS

View at: www.tennesseewerks.org/videos
95% of youth with autism expect to have had a job

47% were working four years after high school

Studies: Lipscomb, Haimson, Liu, Burghardt, Johnson, & Thurlow (2017); Newman et al. (2011)
Advocacy at Disability Day on the Hill

Individuals and Families Workgroup

Youth at ThinkEmployment! Summits

Advocacy at Disability Day on the Hill
RAISING EXPECTATIONS
Among families, educators, professionals, and others

Carter, Austin, & Trainor (2012); Carter et al. (2010)
Family Expectations
Awsumb et al. (in preparation); Carter et al. (in preparation)
3. CHANGING INTRODUCTIONS
Matching strengths to community needs
www.hiremystrengths.org

Carter, Boehm, Biggs, et al. (2015); Carter, Carlton, & Travers (submitted)
4. ALIGNING POLICIES With high aspirations and expectations
5. EQUIPPING PROFESSIONALS
To implement the best of what we know works
Employer Outreach Trainings

Annual Transition Conference

1,800+
teachers

1,300+
attendees

Free, Online Professional Development Portal (with Pre-ETS coming)

Visit: www.transitiontn.org
MAKING INFORMATION ACCESSIBLE
For everyone at any time
Scores of Videos and Success Stories

Expanding Communications
Matthew Parriott, Department of Intellectual and Developmental Disabilities
Emma Houshe, Council on Developmental Disabilities
Courtney Taylor, Vanderbilt Kennedy Center
Kyle Jonas, TennesseeWorks
Rachael Jenkins, TennesseeWorks

Communication is the exchange of information through speaking, reading, writing, listening, and 4hearing. Examples of communication are listening, speaking, reading, writing, and texting.

www.tennesseeworks.org
Employment Success Stories

Rise to Work: An Insider’s Look at Disabilities and Employment

Each week, we will bring you interesting and important information on employment-related topics for family members of individuals with disabilities. Want our weekly blogs delivered straight to your inbox? Click here to subscribe.

March 15th: How Employment Can Change the Life of Someone with a Disability (and Everyone Involved)
March 8th: What is “Supported Employment”?
March 1st: How Does This “Work Stuff” Work?
February 23rd: What are the Top Predictors of Employment for Young People with Disabilities?
February 16th: You Expect Him to Do What?
February 9th: Young Advocate Finds Disability Day on the Hill “Very Exciting”
February 2nd: Disability Day on the Hill: Confessions of a First-Timer
January 26th: What is the RIE Conference?

About the Author

Janet Shouse is a parent of a young adult with autism, and she is passionate about inclusion, employment of people with disabilities, medical issues related to developmental disabilities, supports and services, public policy, legislative initiatives, advocacy, and the intersection of faith and disability. She wears many hats at the Leadership Alliance.

Parent Resources and Blog

Family Coalitions
7. ENGAGING COMMUNITIES
In new and clever ways
THE COMPLEXITY OF LOCAL CHANGE

Attitudes, Expectations, Awareness, & Opportunities

Schools

Families

Employers

Agencies

Individuals with Disabilities

Satisfying Personal Relationships

Meaningful Integrated Employment

Active Community Involvement
Community Conversation Events


Event Topics to Date

➤ Integrated employment
➤ Workshop conversions
➤ Postsecondary education access
➤ Independent living
➤ Family engagement
➤ Community inclusion
Data is not a four-letter word*

Technically, it is.
If you don't know where you're going, you might not get there.

-Yogi Berra
Employment and Disability
By The Numbers

In this section of our website, we present findings from multiple Tennessee projects that each provide important insights into the current employment landscape and suggest possible pathways for making change. We also integrate data from other sources that provide a snapshot of employment outcomes for Tennesseans with disabilities.

What Do Teachers Need?

Topics Educators Want
More Resources On
Related to Transition Planning

56% Using Assessment
53% Building Career Awareness
36% Pathways to Postsecondary
29% Student-Led IEP
15% Creating Student Profiles

What Matters Most to Families?

Click below to watch a Tennessee family discuss why employment is important for their family member.

83% of families consider some type of employment in the community to be important.
75% of families consider some type of postsecondary education to be important.
71% of families consider some type of community living option to be important.

EMPLOYMENT for PEOPLE WITH DISABILITIES

TENNESSEE STATEWIDE EMPLOYMENT GOAL: REDUCE THE EMPLOYMENT GAP 5% BY 2023

CURRENT EMPLOYMENT RATE


PERSONS WITH ANY DISABILITY 33.3% GAP OF 44.2% 77.5% PERSONS WITH NO DISABILITY

GOALS

1. ALIGN SERVICE DELIVERY SYSTEMS AND STRENGTHEN COORDINATION TO INCREASE EMPLOYMENT OPPORTUNITIES FOR TENNESSEANS WITH DISABILITIES
2. BUILD SHARED COMMUNITY COMMITMENT TO EMPLOYMENT FIRST
3. INCREASE THE NUMBER OF EMPLOYERS THAT HIRE PEOPLE WITH DISABILITIES
4. MAKE TENNESSEE STATE GOVERNMENT A MODEL EMPLOYER OF PEOPLE WITH DISABILITIES
5. PREPARE STUDENTS FOR EMPLOYMENT AND POST-SECONDARY SUCCESS

TENNESSEEWORX PARTNERSHIP

Want to learn more about our efforts? Visit www.tennesseeworks.org

www.tennesseeworks.org/data-dashboard
SOME EXAMPLE STUDIES

➤ Family perspectives on the appeals of and alternatives to sheltered employment for individuals with severe disabilities. *Research and Practice for Persons with Severe Disabilities*

➤ Community conversations on inclusive higher education for students with intellectual disability. *Career Development and Transition for Exceptional Individuals.*


➤ Using community conversations to expand employment opportunities for people with disabilities in rural and urban communities. *Journal of Vocational Rehabilitation.*


➤ Informing and equipping parents of individuals with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities.*

➤ The voices of parents: Post–high school expectations, priorities, and concerns for children with developmental disabilities. *The Journal of Special Education.*


➤ School-business partnerships and students with intellectual and developmental
9. INVESTING IN RELATIONSHIPS
Across all our partners
THE TENNESSEEWORKS PARTNERSHIP
Changing the Employment Landscape for Young People with Disabilities
Erik Carter | Vanderbilt University
Autism-Ready Workplace
Creating and Scaling Autism Hiring Initiatives

Hala Annabi
Associate Professor
hpannabi@uw.edu
http://access-it.ischool.uw.edu/Wordpress

©Annabi
Over the next decade 500,000 children on the spectrum will enter adulthood.

Adults with autism face many more barriers in securing and sustaining employment compared to all other groups of adults with disabilities.

Only 14% of adults with autism are employed.
Why focus on employment?

Employment is core to a person’s quality of life

- Means for independent living
- Pursue interests & improve cognitive performance
- Key to an individual’s ability to contribute to society
- Meet their need for inclusion & belonging

Employed disabled individuals experience

- Higher quality of life
- Especially when it is paid integrated employment

Employed autistic individuals experience

- Financial benefits
- Emotional and health benefits

---

Interest from Industry

✓ Social impact
✓ Benefits related to autism

Unique strengths
- Attention to detail
- Focus on work and results (productivity)
- Accept repetitive tasks
- Analytical thinking
- Visualization
- Systemizing

Employee characteristics
- Trustworthiness
- Reliability
- Low absenteeism
- Innovation

1 (Howlin et al., 2004) - 2 (Smith et al., 1986; Austin & Pisano, 2017)
The Rise of Autism Hiring Initiatives
Autism Hiring Initiatives

- Great potential
- Challenges persist
- Unanswered questions

What *organizational* and *intervention* characteristics maximize opportunities for inclusion of and reduce challenges for employees on the autism spectrum?

(Austin and Pisano, 2017; Morris et al., 2015, Annabi et al., 2017, Hedley et al., 2018)
STUDY OBJECTIVES

1. • Exploratory study of emerging autism hiring programs

2. • Identify key organizational characteristics that enable autism hiring programs

3. • Determine best practices and pathways for more and better employment
Organizational Interventions Mitigating Individual Barriers Framework
(Annabi & Locke, In Press)
Organizational Interventions Mitigating Individual Barriers Framework
(Annabi & Locke, In Press)
METHOD

Data Sources:
- Autism at Work Summit
- Research Workshop 2018

Data Analysis:
Findings

- Enhance corporate social responsibility
- Meet rapidly growing demand for tech talent
- Employee-focused reputation and culture
- Enhance productivity, efficiency, and innovation
- Suitability of the local ecosystem
Open Questions

- How to sustain and scale programs?
- How to better serve individuals across the spectrum?
- How to engage a diversity of organizations (e.g., industry sectors, sizes)?
- How do autism hiring programs fit the broader diversity and inclusion efforts?
Findings

- Secure leadership support
- Design employment model aligned with organization values and business model
- Build a culture of diversity
- Educate employees
- Improve supervisor relationship
- Provide accommodations
- Provide suitable recruitment & onboarding processes
Support throughout the employee lifecycle

New Employee’s Workplace Support Circle
- Manager
- Team
- ERGs
- Mentor

New Employee’s Personal-Life Support Circle
- External Job Coach
- Voc-Rehab Counselor
- Employment Support
- Family & Friends

Prepare → Recruit → Onboard → Retain → Advance

ACCESS-IT
The Significance of the Ecosystem

State & National
DVR, Policies, Funding agencies

Local
Autism employment specialists, DVR, Education, Communities

Internal
HR, Legal, Business Units, D&I, ERGs

©ANNABI

Findings

Catalysts & objectives

Methods & practices

Measurement & evaluation

(Nicholas et al., 2018; Austin & Pisano, 2017)
The Significance of the Ecosystem

Findings

Catalysts & objectives

Methods & practices

Measurement & evaluation

Eco systems values

Organizational values and needs

©ANNABI
Open Questions

Ecosystem
✓ How to create a strong and well-aligned ecosystem?

Employee support and advocacy
✓ How to best include the voice of self-advocates in program design and execution?
✓ How do you best respect and protect the privacy of employees?
✓ How do we address mental health issues in the workplace?

Prepare the workplace
✓ How to prepare supervisors to better include autistic employees into the team?
✓ What are effective interventions to improve the knowledge, attitudes, and know how of coworkers and managers?
Open Questions

Preparation
✓ How to prepare autistic individuals for the workplace?
✓ How to prepare autistic individuals with life skills?
✓ How to improve individuals’ positive self image?

Recruitment
✓ How do we scale recruitment in numbers and type of jobs?
✓ How do we identify and use alternative mediums (e.g., social media, networks) to increase diversity (e.g., ethnicity, gender, socio-economic status)?
✓ How do you increase the participation of managers in autism hiring programs?
Findings

- Established systematic evaluation
- Use specific metrics to measure impact

Catalysts & objectives

Methods & practices

Measure & evaluation

Social Impact

Improved Performance

Values

Culture

Type of organization/business model

Implications for team dynamics

Implications for employee wellbeing

©ANNABI
Open Questions

- How do autistic people measure and talk about their own success?
- How to measure the organizational impact (KPI)?
- How to create evaluation systems aligned with organizational values and culture, and equitable to autistic employees?
Challenges for Researchers

Autism at Work Research Workshop 2018

How to developing partnerships between researchers and companies and create a win-win?

- The legal liability that the company holds
- The risk of confidentiality
- Practical implication for industry partners

How do you get schools to start preparation earlier to prepare students for the workplace?

How to best include the voice of self-advocates in research?

Challenges associated with regulatory environments/ legal environment/lobbying
Questions
Break
Meeting of the IACC

Afternoon Agenda

3:55  
Afternoon Break

4:10  
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 Translational Research
National Institute of Mental Health
Meeting of the IACC

Afternoon Agenda

4:15  Summary of Advances Discussion

Susan Daniels, Ph.D.
Director, Office of Autism Research Coordination, NIMH
and Executive Secretary, IACC

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

4:50  Round Robin

5:00  Closing Remarks and Adjournment
National Autism Coordinator Update

Ann Wagner, Ph.D.

Interagency Autism Coordinating Committee Meeting
April 17, 2019
Federal Interagency Workgroup on ASD (FIWA)

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

- Department of Education (ED)
- Department of Defense (DoD)
- Department of Justice (DOJ)
- Department of Labor (DOL)
- Department of Transportation (DOT)
- Social Security Administration (SSA)
Focus on Outcome Measures for Transitioning Youth and Adults with ASD

- The 2017 Report to Congress, Young Adults and Transitioning Youth with Autism Spectrum Disorders identified gap
  - Outcome measures needed to evaluate supports and services
  - Broadly addressing “quality of life”
- FIWA identified researchers working in this area
  - Research supported by grants from DoD, ACL, and NIH
- On March 19, 2019, FIWA held a special meeting to hear about these efforts
- Next steps
  - Work with presenters to disseminate their ideas
  - Work within federal programs to facilitate work in this area
Focus on Outcome Measures; Presenters and Selected References

- **Christina Nicolaidis, M.D., M.P.H.**
  Professor, Portland State University & Oregon Health and Science University

- **Nancy Cheak-Zamora, Ph.D.**
  Associate Professor, University of Missouri-Columbia

- **Gale Whiteneck, Ph.D., F.A.C.R.M.**
  Principal Investigator, Craig Hospital Research Department

- **Mark Salzer, Ph.D.**
  Professor of Social and Behavioral Sciences, Temple University
Opportunities for Coordination with Broader Effort on Adolescents Transitioning to Adulthood

- Federal Partners in Transition
  - Since 2005; led by DOL, SSA, and DOE
  - Guided by *2020 Federal Youth Transition Plan: A Federal Interagency Strategy*
  - Goal: To improve transition outcomes for youth with disabilities

- Trans-NIH Pediatric Research Consortium (N-PeRC)
  - Since 2018; led by the *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)*
  - Subgroup focusing on adolescent transition to adulthood

- HHS Coordination of Efforts on Youth in Transition
  - ACL initiated meeting to coordinate cross-HHS activities
  - Health care transition for youth, particularly those with disabilities and special health care needs
2019 Summary of Advances Nominations
January – April 2019

Joshua A. Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC
Shank3 Modulates Sleep and Expression of Circadian Transcription Factors.
Ingiosi A, Schoch H, Wintler TP, Singletary KG, Righelli D, Roser L, Medina E, Risso D, Frank MG, Peixoto L

Pathological priming causes developmental gene network heterochronicity in autistic subject-derived neurons.
Question 3: Risk Factors

JAMA Psychiatry
Long-term Risk of Neuropsychiatric Disease After Exposure to Infection In Utero.

Annals of Internal Medicine
Measles, Mumps, Rubella Vaccination and Autism: A Nationwide Cohort Study.
Hviid A, Hansen JV, Frisch M, Melbye M
Question 3: Risk Factors

Association of Maternal Prenatal Vitamin Use With Risk for Autism Spectrum Disorder Recurrence in Young Siblings
Schmidt RJ, Iosif AM, Guerrero Angel E, Ozonoff S

Increased risk of ADHD in families with ASD
A Multisite Randomized Controlled Two-Phase Trial of the Early Start Denver Model Compared to Treatment as Usual.
Question 5: Services

Treatment patterns in children with autism in the United States.
Monz BU, Houghton R, Law K, Loss G
A 20-year study of suicide death in a statewide autism population.
Kirby AV, Bakian AV, Zhang Y, Bilder DA, Keeshin BR, Coon H

Use of Vocational Rehabilitation Supports for Postsecondary Education Among Transition-Age Youth on the Autism Spectrum.
Rast JE, Roux AM, Shattuck PT
Competitive Employment for Transition-Aged Youth with Significant Impact from Autism: A Multi-site Randomized Clinical Trial.
Round Robin
Adjournment
Next IACC Meeting

Wednesday, July 24th 2019