



Meeting of the Interagency Autism Coordinating Committee

Wednesday, April 17, 2019

**National Institutes of Health
Neuroscience Center**

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

Conference Call Access:
Phone: 800-369-3337
Participant Passcode: 9975399

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

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.



@MikeLakeMP

“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



@MikeLakeMP



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

Elbert Hubbard



@MikeLakeMP



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

John F. Kennedy



@MikeLakeMP



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

Helen Keller



@MikeLakeMP



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

Mahatma Gandhi



@MikeLakeMP



@MikeLakeMP



Discussion

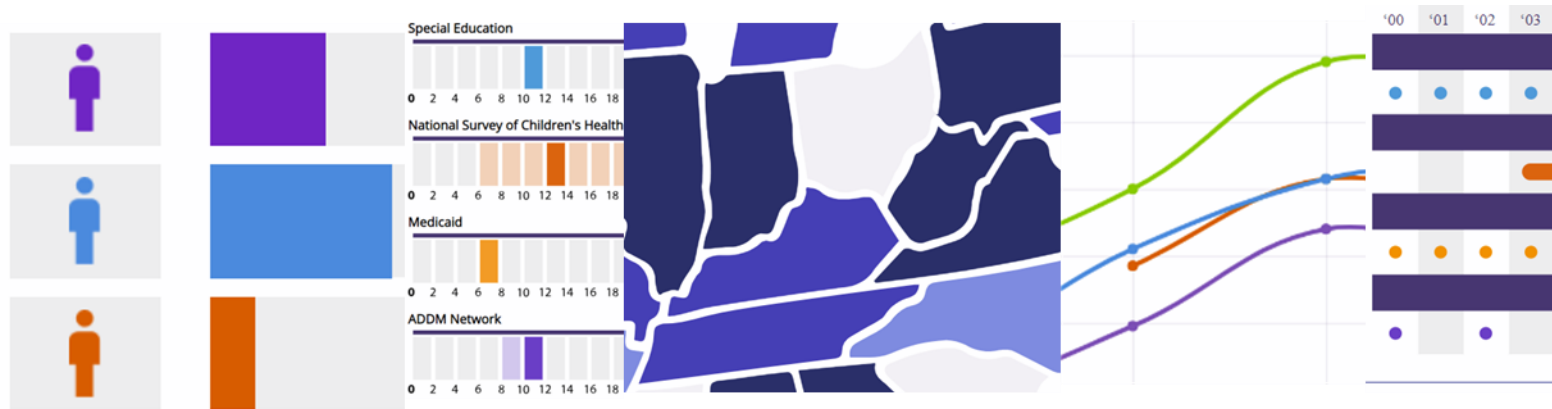
Centers for Disease Control and Prevention Autism Data Visualization Platform



Stuart Shapira, M.D., Ph.D.

Chief Medical Officer, Associate Director for Science (ADS), National Center on Birth Defects and Developmental Disabilities (NCBDDD), 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



Criteria



Sample Size



Method

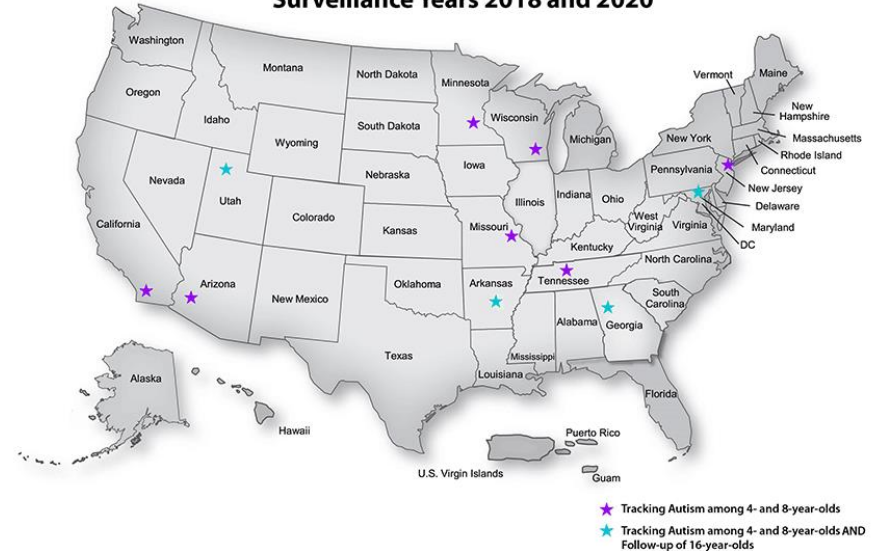
CDC Autism Data Visualization Tool

- 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

Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Years 2018 and 2020



<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*

IDEA Section 618 Data Products: State Level Data Files



*will update soon with new year

<https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html>

<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>

<https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MedicaidDataSourcesGenInfo/MAXGeneralInformation.html>

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
- Years of publicly available data: 2004, 2008, 2012, 2016–17
- 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

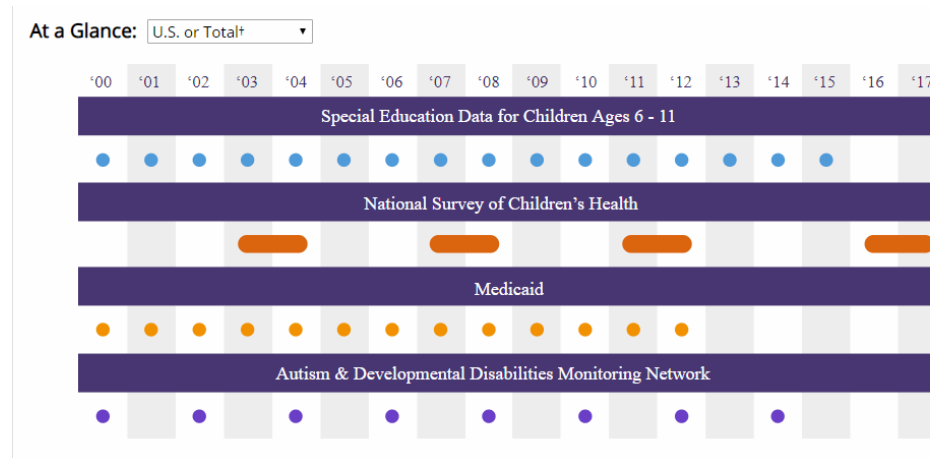


Image from: <https://www.cdc.gov/ncbddd/autism/data/>

Acknowledgments

Daisy Christensen

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Nicole Dowling

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

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

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.

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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

Communications Act, as amended (1996) – Section 255 (47 U.S.C. § 255 (b), (c), codified in Parts 6 and 7 of 47 C.F.R.):

- Telecommunications equipment and services must be accessible and usable
 - “Readily achievable”
 - If not, then “compatible”
 - “Usability” and “functional equivalence”
 - Implications





Background (Cont'd.)

- 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:

- Television and cable boxes
- 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

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



For More Information . . .

Contact Us!

Subscribe to AccessInfo@fcc.gov.

Visit the Commission's Disability Rights Office (DRO) webpage: www.fcc.gov/accessibility, and the DRO's webpage on cognitive disabilities: www.fcc.gov/cognitive-disabilities.

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

IACC Committee Business

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

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

Event page (archived video available): <https://www.ihs.gov/icp/autism/roundtable/>

Assistive Technologies, Active Participation

United Nations

April 2, 2019; New York, NY

Event page: <https://www.un.org/en/events/autismday/>

Archived video available: <http://webtv.un.org/meetings-events/watch/2019-world-autism-awareness-day-observance-theme-assistive-technologies-active-participation/6021777181001>

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

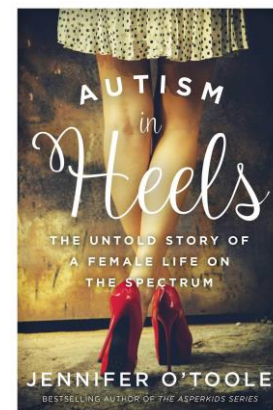
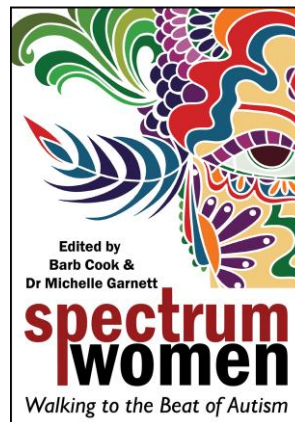


A Woman's Voice: Understanding Autistic Needs

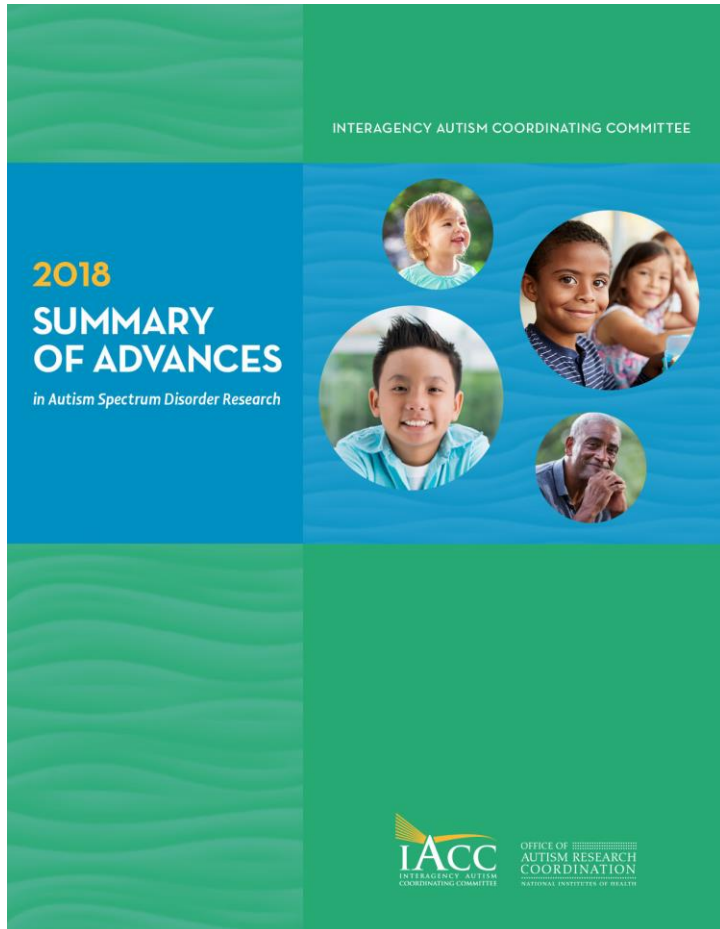
April 23, 2019

2:30 pm – 5:00 pm

- A conversation featuring 4 female authors on the autism spectrum
- Live webcast will be available
- Event information: <https://iacc.hhs.gov/meetings/autism-events/2019/april23/spectrum-women.shtml>
- 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*

<https://iacc.hhs.gov/publications/summary-of-advances/2018/>

Articles selected for the 2018 IACC *Summary of Advances*



QUESTION 1: SCREENING AND DIAGNOSIS

- Bosl WJ, Tager-Flusberg H, Nelson CA. **EEG Analytics for Early Detection of Autism Spectrum Disorder: A data-driven approach.**
- Egger HL, Dawson G, Hashemi J, Carpenter KLH, Espinosa S, Campbell K, Brotkin S, Schaich-Borg J, Qiu Q, Tepper M, Baker JP, Bloomfield RA, and Sapiro G. **Automatic Emotion and Attention Analysis of Young Children at Home: A ResearchKit Autism Feasibility Study.**
- Wolff JJ, Dimian AF, Botteron KN, Dager SR, Elison JT, Estes AM, Hazlett HC, Schultz RT, Zwaigenbaum L, Piven J; IBIS Network. **A longitudinal study of parent-reported sensory responsiveness in toddlers at-risk for autism.**

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.**
- Deneault E, White SH, Rodrigues DC, Ross PJ, Faheem M, Zaslavsky K, Wang Z, Alexandrova R, Pellecchia G, Wei W, Piekna A, Kaur G, Howe JL, Kwan V, Thiruvahindrapuram B, Walker S, Lionel AC, Pasceri P, Merico D, Yuen RKC, Singh KK, Ellis J, Scherer SW. **Complete Disruption of Autism-Susceptibility Genes by Gene Editing Predominantly Reduces Functional Connectivity of Isogenic Human Neurons.**
- Qin L, Ma K, Wang ZJ, Hu Z, Matas E, Wei J, Yan Z. **Social deficits in Shank3-deficient mouse models of autism are rescued by histone deacetylase (HDAC) inhibition.**

Articles selected for the 2018 IACC *Summary of Advances*



QUESTION 3: RISK FACTORS

- The Brainstorm Consortium. **Analysis of shared heritability in common disorders of the brain.**
- Brandler WM, Antaki D, Gujral M, Kleiber ML, Whitney J, Maile MS, Hong O, Chapman TR, Tan S, Tandon P, Pang T, Tang SC, Vaux KK, Yang Y, Harrington E, Juul S, Turner DJ, Thiruvahindrapuram B, Kaur G, Wang Z, Kingsmore SF, Gleeson JG, Bisson D, Kakaradov B, Telenti A, Venter JC, Corominas R, Toma C, Cormand B, Rueda I, Guijarro S, Messer KS, Nievergelt CM, Arranz MJ, Courchesne E, Pierce K, Muotri AR, Iakoucheva LM, Hervas A, Scherer SW, Corsello C, Sebat J. **Paternally inherited cis-regulatory structural variants are associated with autism.**
- Gandal MJ, Haney JR, Parikshak NN, Leppa V, Ramaswami G, Hartl C, Schork AJ, Appadurai V, Buil A, Werge TM, Liu C, White KP; CommonMind Consortium; PsychENCODE Consortium; iPSYCH-BROAD Working Group, Horvath S, Geschwind DH. **Shared molecular neuropathology across major psychiatric disorders parallels polygenic overlap.**
- Gandal MJ, Zhang P, Hadjimichael E, Walker RL, Chen C, Liu S, Won H, van Bakel H, Varghese M, Wang Y, Shieh AW, Haney J, Parhami S, Belmont J, Kim M, Moran Losada P, Khan Z, Mleczko J, Xia Y, Dai R, Wang D, Yang YT, Xu M, Fish K, Hof PR, Warrell J, Fitzgerald D, White K, Jaffe AE; PsychENCODE Consortium, Peters MA, Gerstein M, Liu C, Iakoucheva LM, Pinto D, Geschwind DH. **Transcriptome-wide isoform-level dysregulation in ASD, schizophrenia, and bipolar disorder.**
- 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.**

Articles selected for the 2018 IACC *Summary of Advances*



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.**
- Nevill RE, Lecavalier L, Stratis EA. **Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder.** Stedman A, Taylor B, Erard M, Peura C, Siegel M. **Are Children Severely Affected by Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature.**

QUESTION 5: SERVICES

- Kennedy-Hendricks A, Epstein AJ, Mandell DS, Candon MK, Marcus SC, Xie M, Barry CL. **Effects of State Autism Mandate Age Caps on Health Service Use and Spending Among Adolescents.**
- Zerbo O, Modaressi S, Goddard K, Lewis E, Fireman BH, Daley MF, Irving SA, Jackson LA, Donahue JG, Qian L, Getahun D, DeStefano F, McNeil MM, Klein NP. **Vaccination Patterns in Children After Autism Spectrum Disorder Diagnosis and in Their Younger Siblings.**

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.**
- Dudley KM, Klinger MR, Meyer A, Powell P, Klinger LG. **Understanding Service Usage and Needs for Adults with ASD: The Importance of Living Situation.**

QUESTION 7: INFRASTRUCTURE AND SURVEILLANCE

- Baio J, Wiggins L, Christensen DL, Maenner MJ, Daniels J, Warren Z, Kurzius-Spencer M, Zahorodny W, Robinson Rosenberg C, White T, Durkin MS, Imm P, Nikolaou L, Yeargin-Allsopp M, Lee LC, Harrington R, Lopez M, Fitzgerald RT, Hewitt A, Pettygrove S, Constantino JN, Vehorn A, Shenouda J, Hall-Lande J, Van Naarden Braun K, Dowling NF. **Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014.**

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

<https://iacc.hhs.gov/publications/report-to-congress/2018/>

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)

Autism Cares Act Report to Congress Available Now!



Department/Agency	Research							Services
	Funds research relevant to IACC Strategic Plan for ASD							
	Question 1 (Screening and Diagnosis)	Question 2 (Underlying Biology)	Question 3 (Risk Factors)	Question 4 (Treatments and Interventions)	Questions 5 (Services)	Question 6 (Lifespan Issues)	Question 7 (Infrastructure and Surveillance)	Administers ASD – relevant services and support programs
Administration for Children and Families (ACF)								X
Administration for Community Living (ACL)				X	X	X		X
Agency for Healthcare Research and Quality (AHRQ)	X			X	X		X	
Centers for Disease Control and Prevention (CDC)	X		X		X		X	X
Centers for Medicare & Medicaid Services (CMS)								X
Department of Defense - Air Force (DoD-Air Force)		X						
Department of Defense - Army (DoD-Army)	X	X	X	X	X	X		X

Autism Cares Act Report to Congress Available Now!



Department/Agency	Research							Services
	Funds research relevant to IACC Strategic Plan for ASD							
	Question 1 (Screening and Diagnosis)	Question 2 (Underlying Biology)	Question 3 (Risk Factors)	Question 4 (Treatments and Interventions)	Questions 5 (Services)	Question 6 (Lifespan Issues)	Question 7 (Infrastructure and Surveillance)	Administers ASD – relevant services and support programs
Department of Education (ED)	X			X	X	X	X	X
Department of Housing and Urban Development (HUD)								X
Department of Justice (DO)								X
Department of Labor (DOL)								X
Department of Transportation (DOT)								X
Environmental Protection Agency (EPA)			X					
Food and Drug Administration (FDA)								X

Autism Cares Act Report to Congress Available Now!



Department/Agency	Research							Service s
	Funds research relevant to IACC Strategic Plan for ASD							
	Question 1 (Screening and Diagnosis)	Question 2 (Underlying Biology)	Question 3 (Risk Factors)	Question 4 (Treatments and Interventions)	Questions 5 (Services)	Question 6 (Lifespan Issues)	Question 7 (Infrastructure and Surveillance)	Administers ASD – relevant services and support programs
Health Resources and Services Administration (HRSA)	X	X	X	X	X	X	X	X
Indian Health Service (IHS)								X
National Institutes of Health (NIH)	X	X	X	X	X	X	X	
National Science Foundation (NSF)	X	X	X	X	X	X	X	
Social Security Administration (SSA)								X
Substance Abuse and Mental Health Services Administration (SAMHSA)								X

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



INSAR Autism and Suicide Research Priority Setting Workshop

University of Nottingham, UK, April 4-5, 2019



- 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

INSAR Autism and Suicide Research Priority Setting Workshop

University of Nottingham, UK, April 4-5, 2019



- 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

Update on IACC Health Outcomes Working Group



- 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

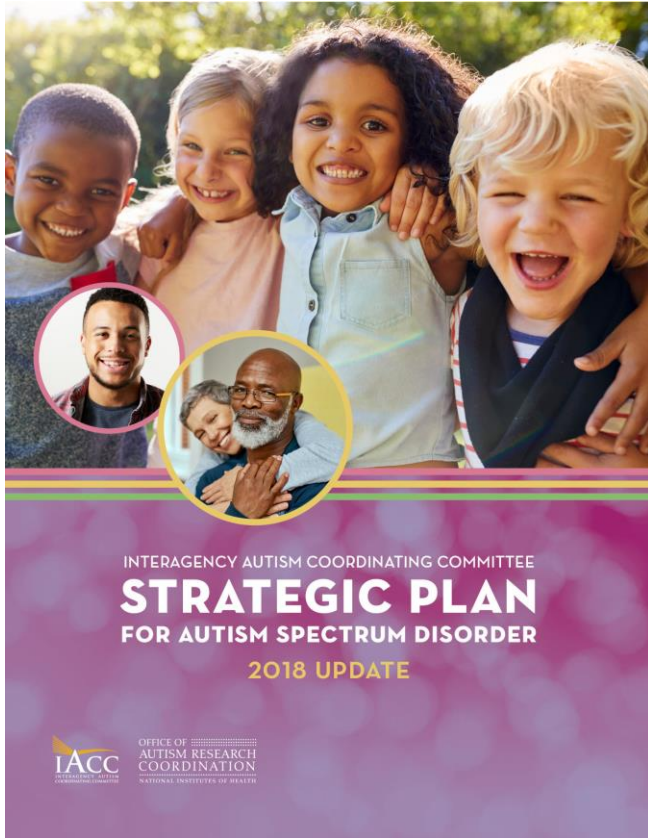


Housing Working Group: Activities



- Activities will include:
 - Working group conference calls
 - Town-hall meeting (target date: June 2019)
- Working group activities will run through September 2019

IACC Strategic Plan 2018-2019 Update



- 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

Meeting of the IACC



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

4:15

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

Written Public Comments



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.



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

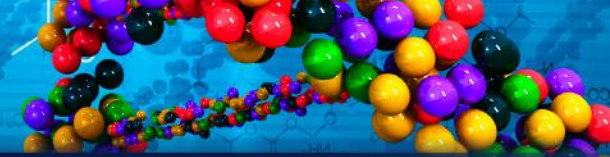


Employment: Current Research and Future Directions

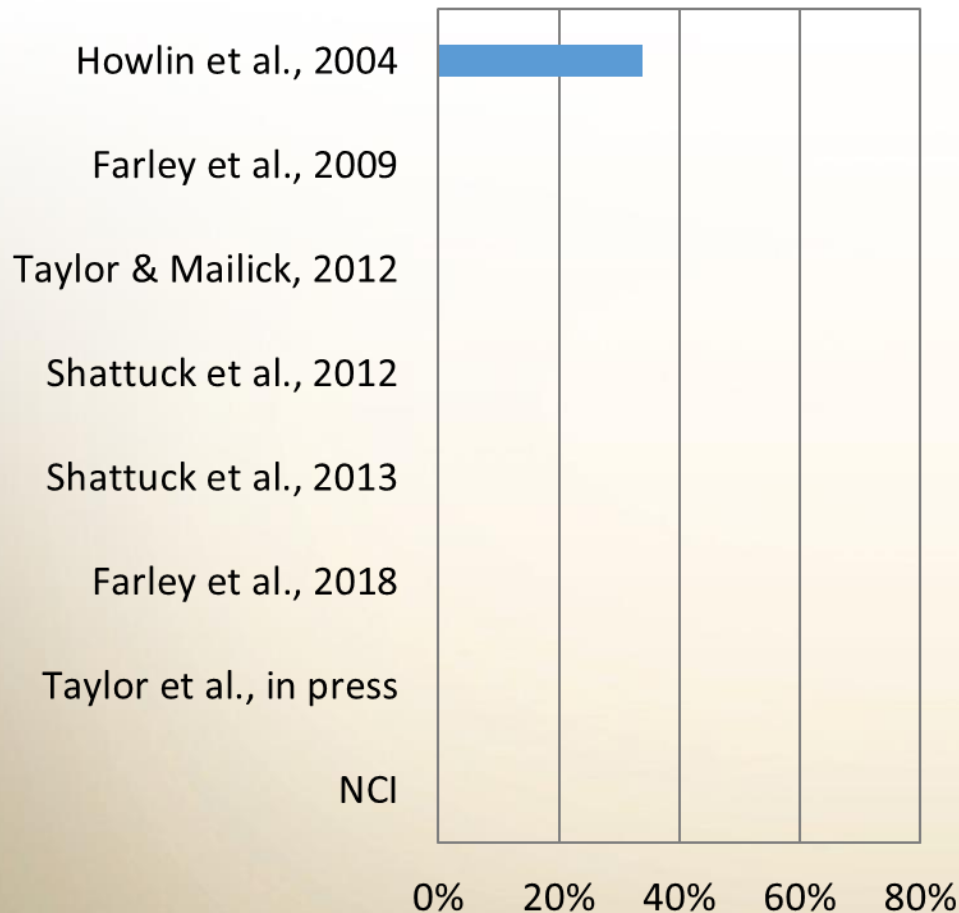
Julie Lounds Taylor, Ph.D.

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

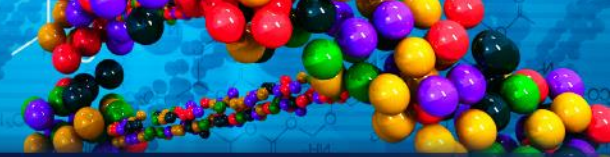
IACC, April 17, 2019



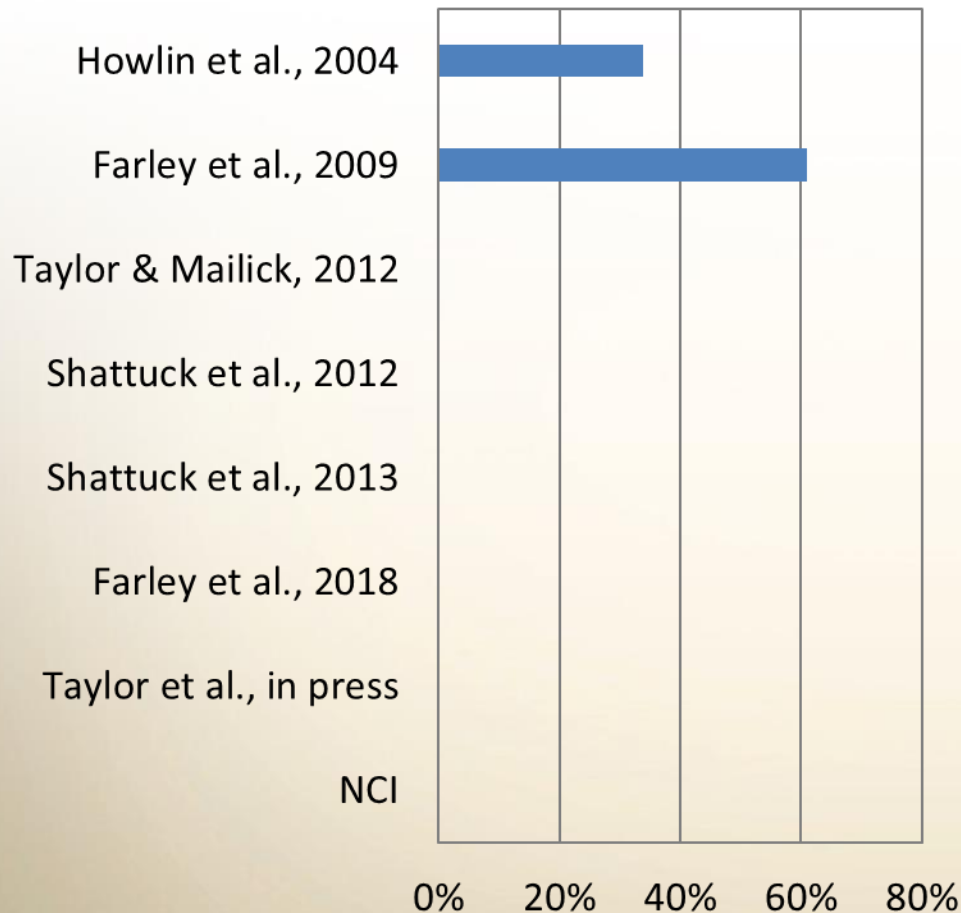
What ARE Employment Rates?



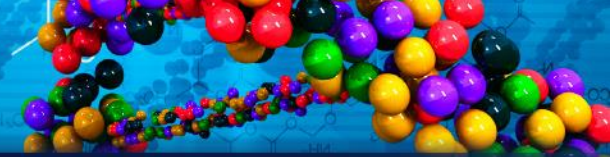
- Howlin (2004) – IQs ≥ 50 , current work



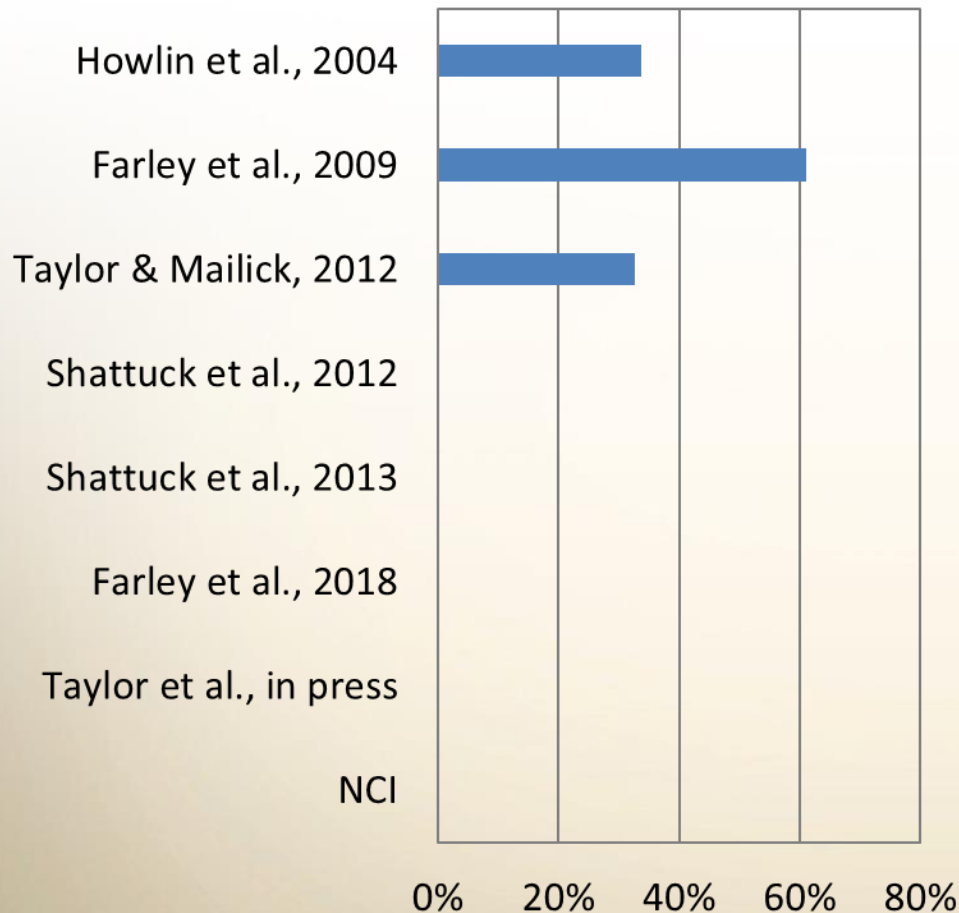
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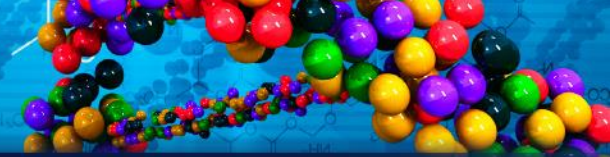
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- Farley (2009) – Average or above IQ, current work



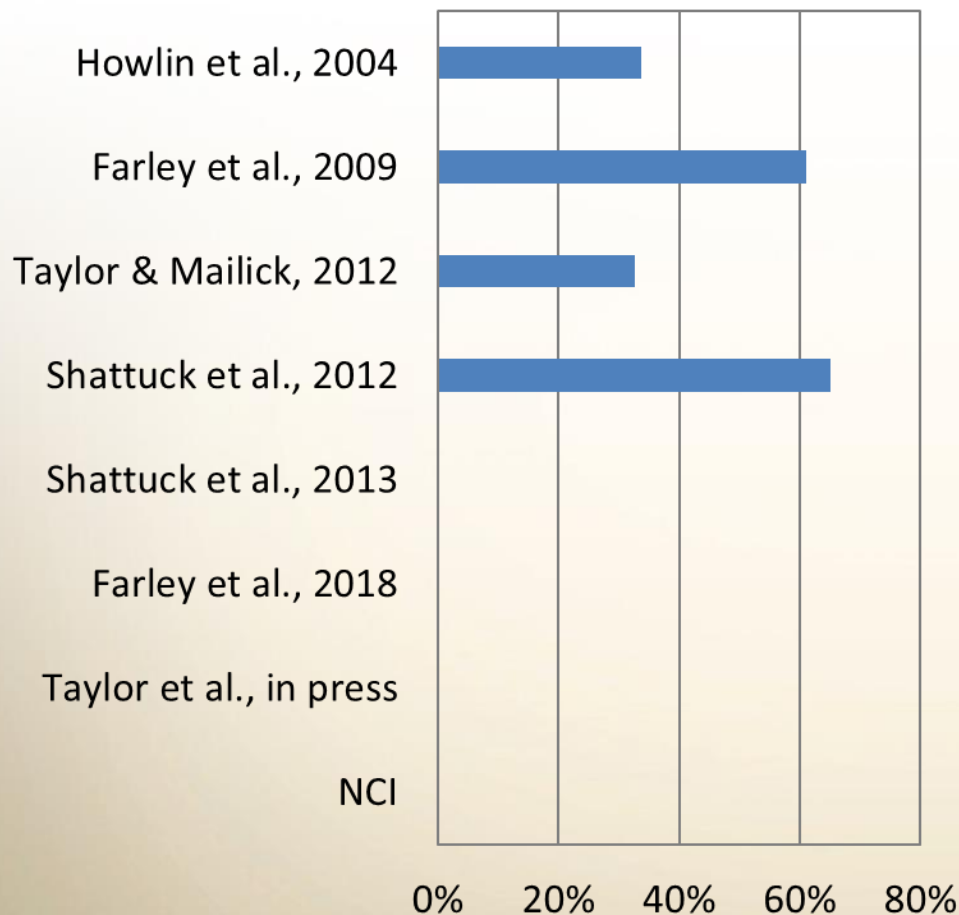
What ARE Employment Rates?



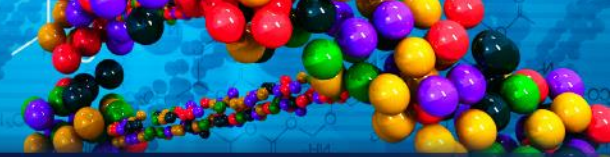
- Howlin (2004) – IQs ≥ 50 , current work
- Farley (2009) – Average or above IQ, current work
- Taylor (2012) – 70% ID, current work or PSE



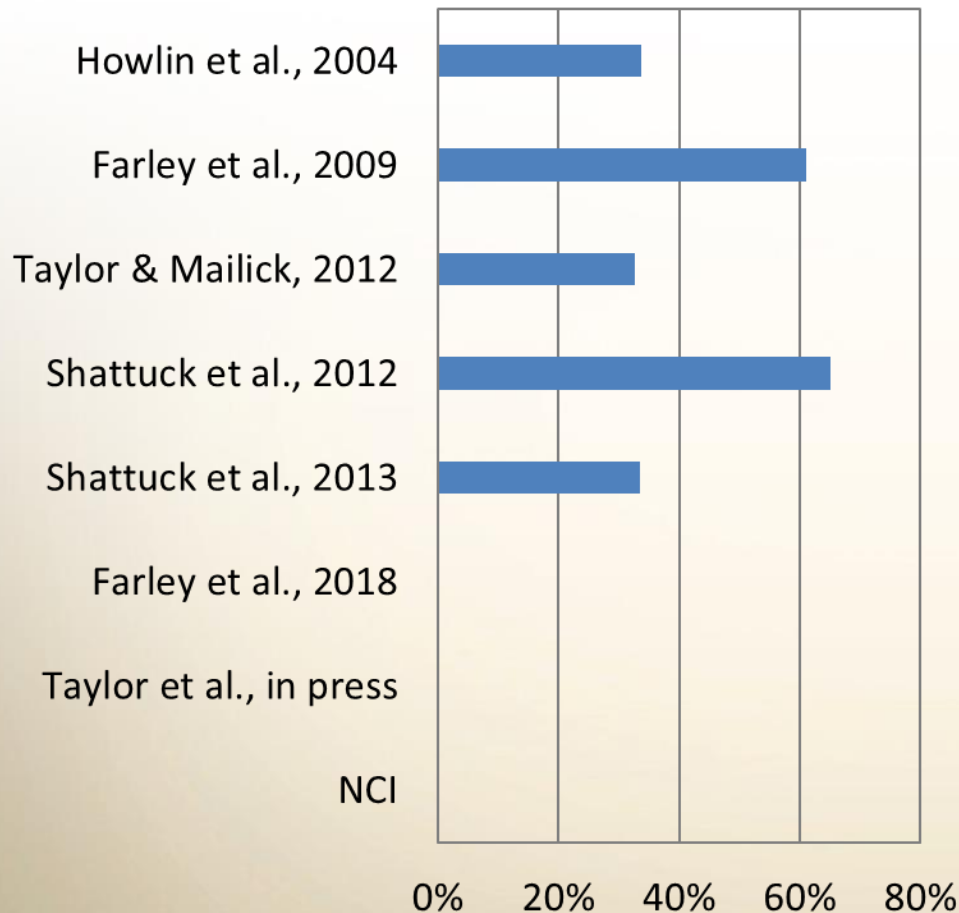
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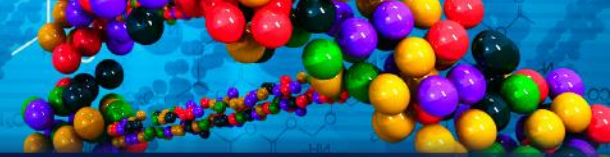
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- Taylor (2012) – 70% ID, current work or PSE
- Shattuck (2012) – ever work or PSE



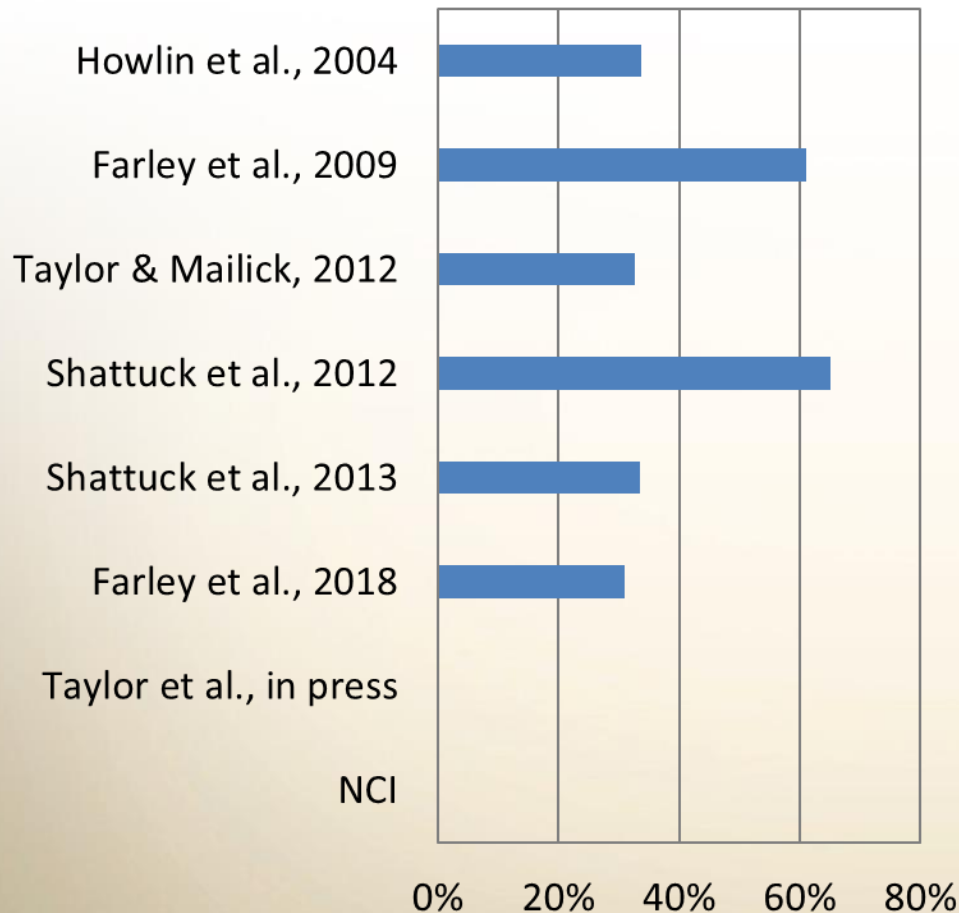
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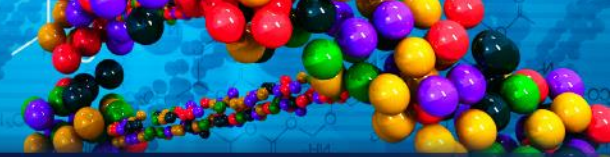
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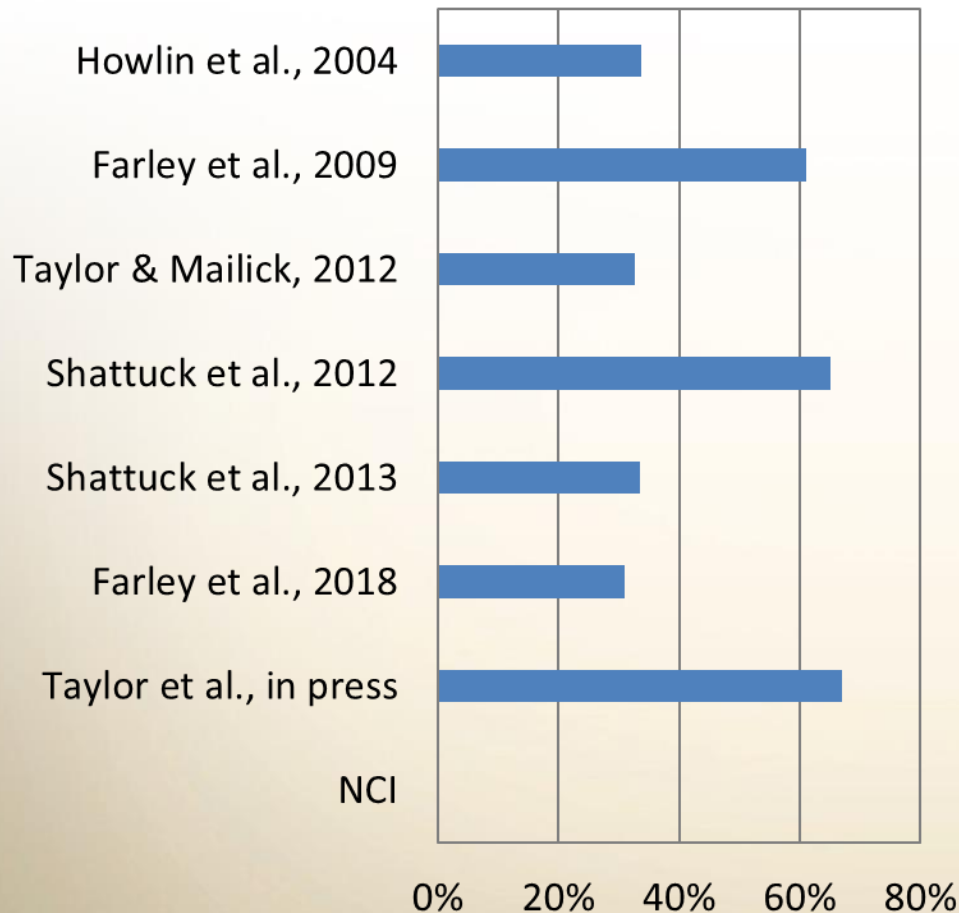
What ARE Employment Rates?



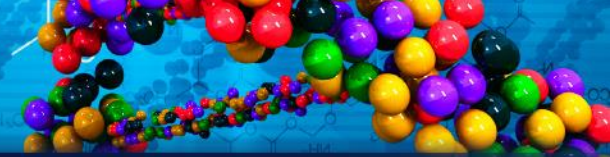
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- Shattuck (2013) – current work (no PSE)
- Farley (2018) mid-life adults, 75% ID, current work



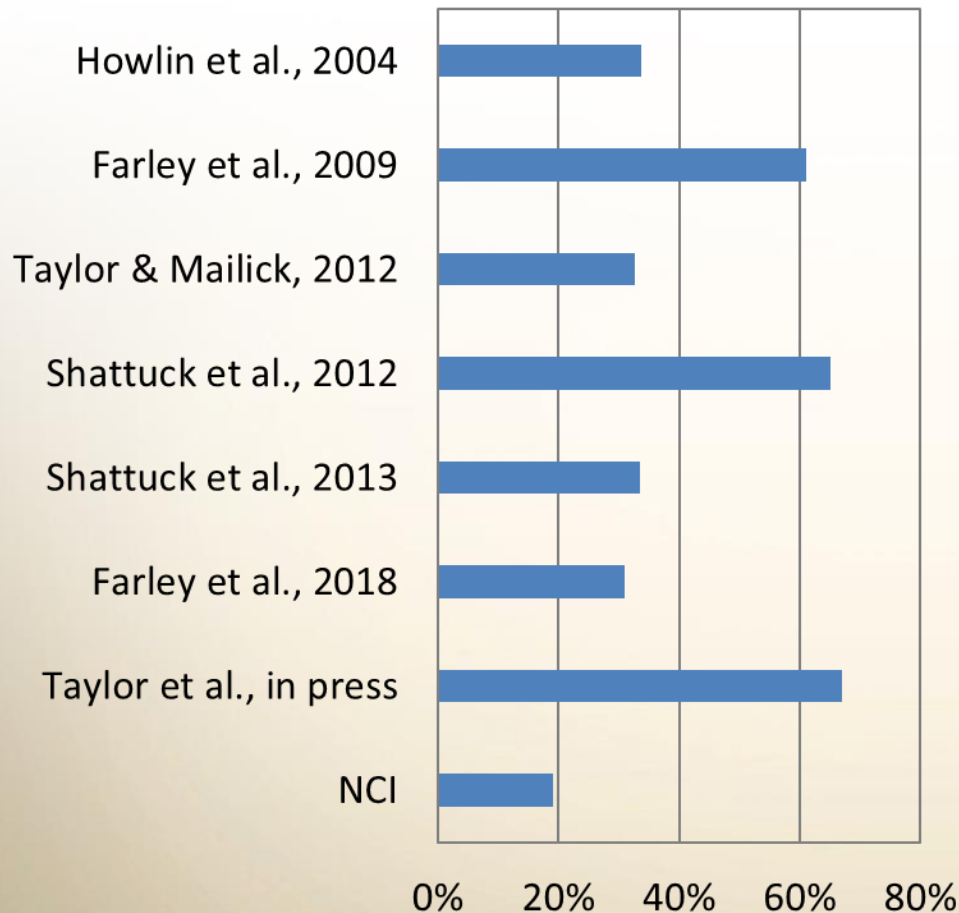
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- Farley (2018) mid-life adults, 75% ID, current work
- Taylor (in press) – self-reporting adults, current work/PSE



What ARE Employment Rates?

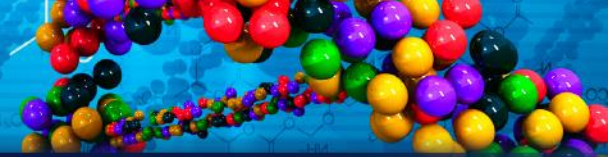


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- Farley (2018) mid-life adults, 75% ID, current work
- Taylor (in press) – self-reporting adults, current work/PSE
- NCI – adults receiving services



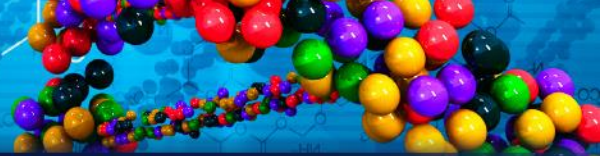
Unemployment is a Concern

- 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

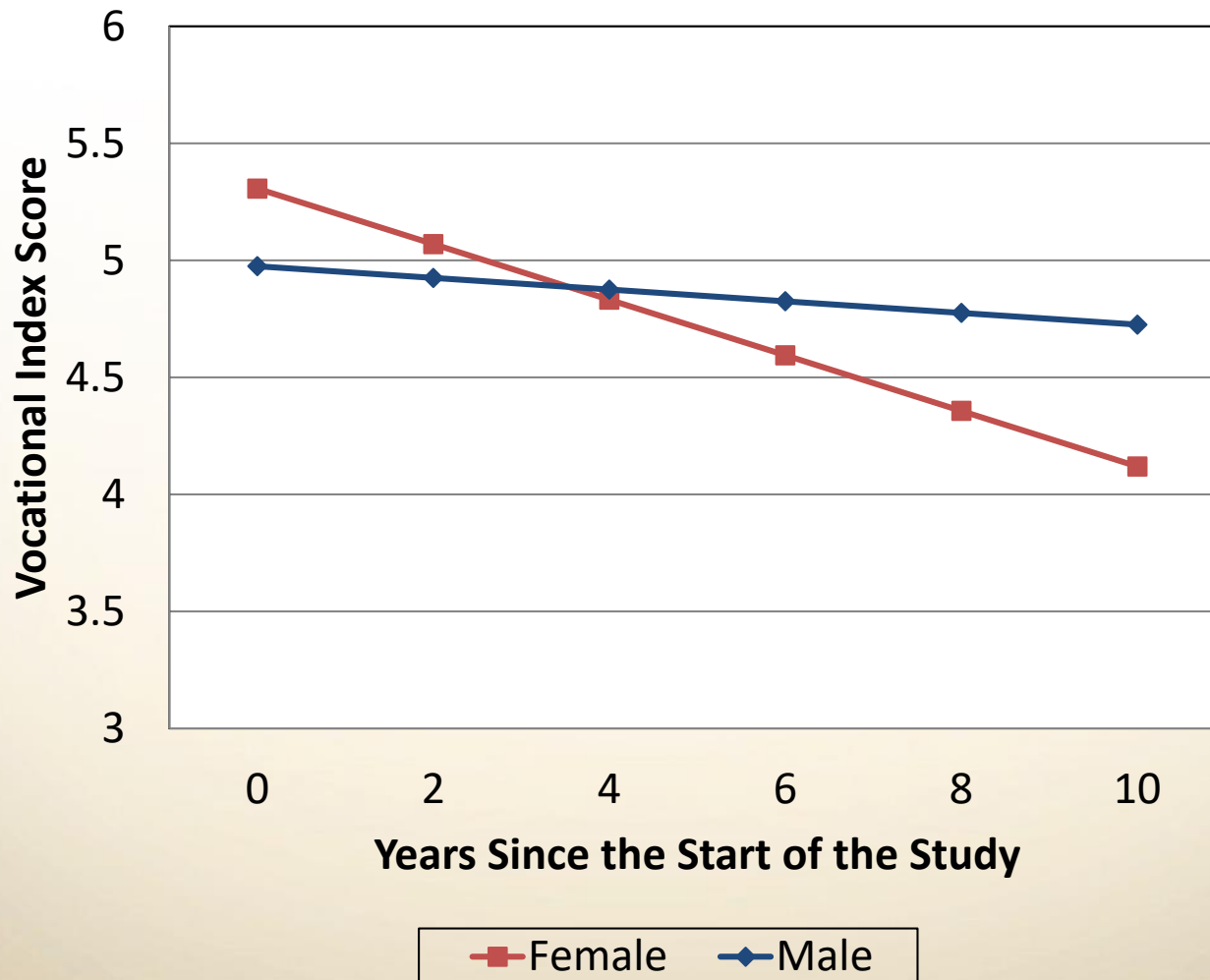


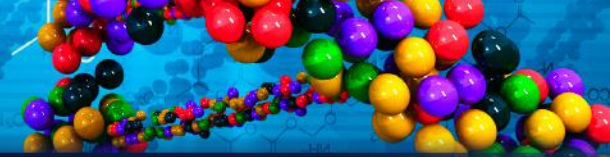
How do Vocational Activities Change over 10 Years?

- 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



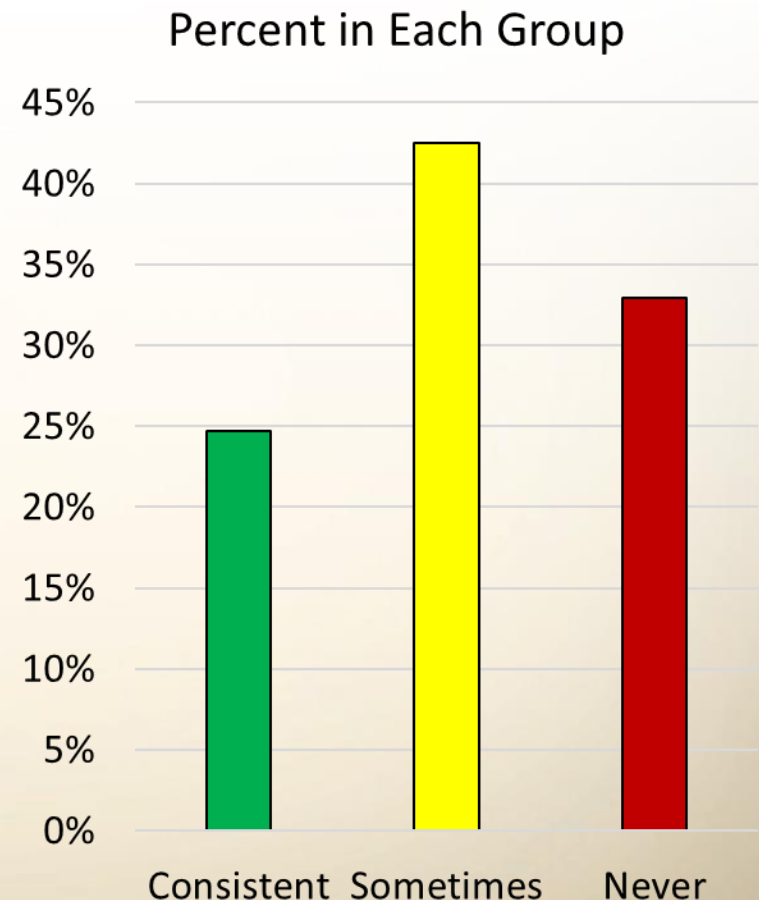
Greater Decline for Females

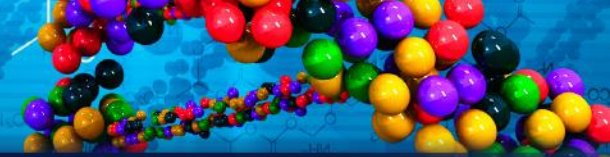




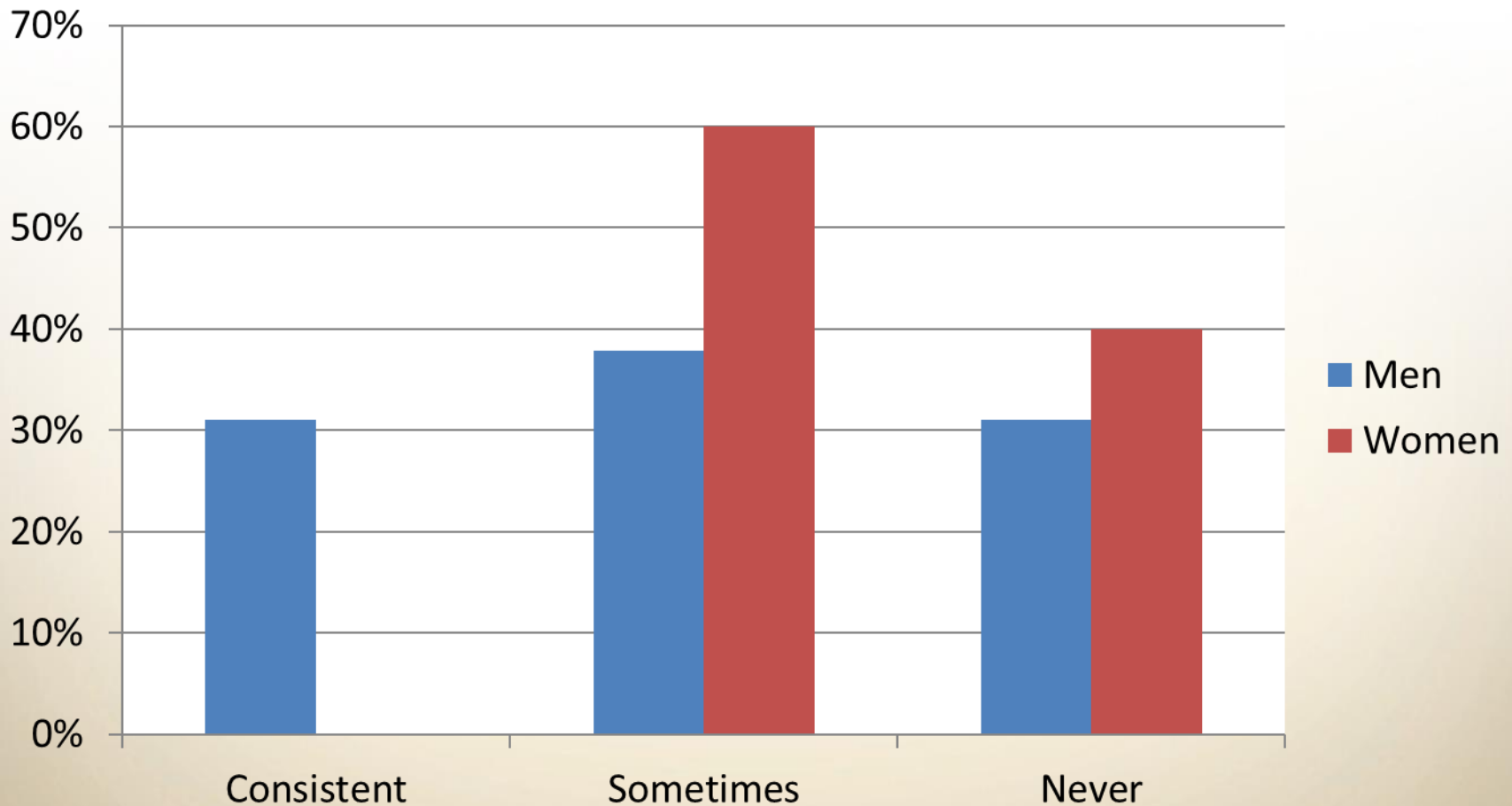
What about Patterns of Employment for Adults Without ID?

- 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





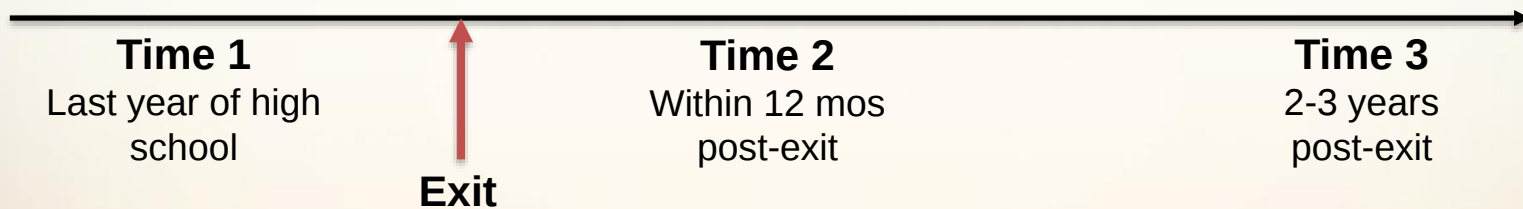
Patterns of Employment/PSE over Time



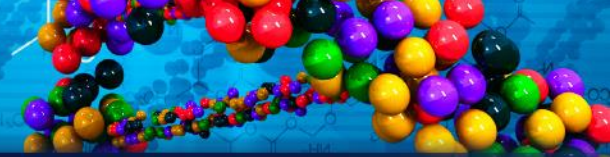


Different predictors for obtaining vs. maintaining activities

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

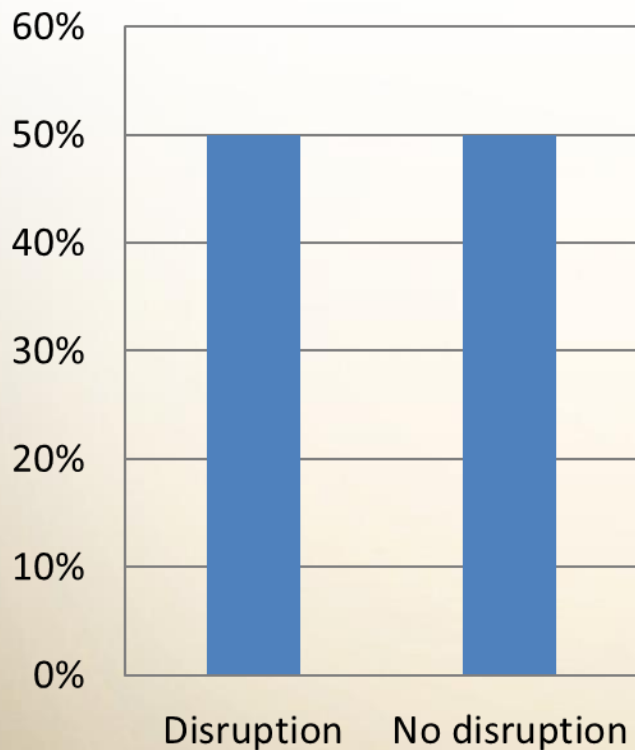


- Coded youth into “disruption” versus “no disruption” groups
 - Not all instability was disruption

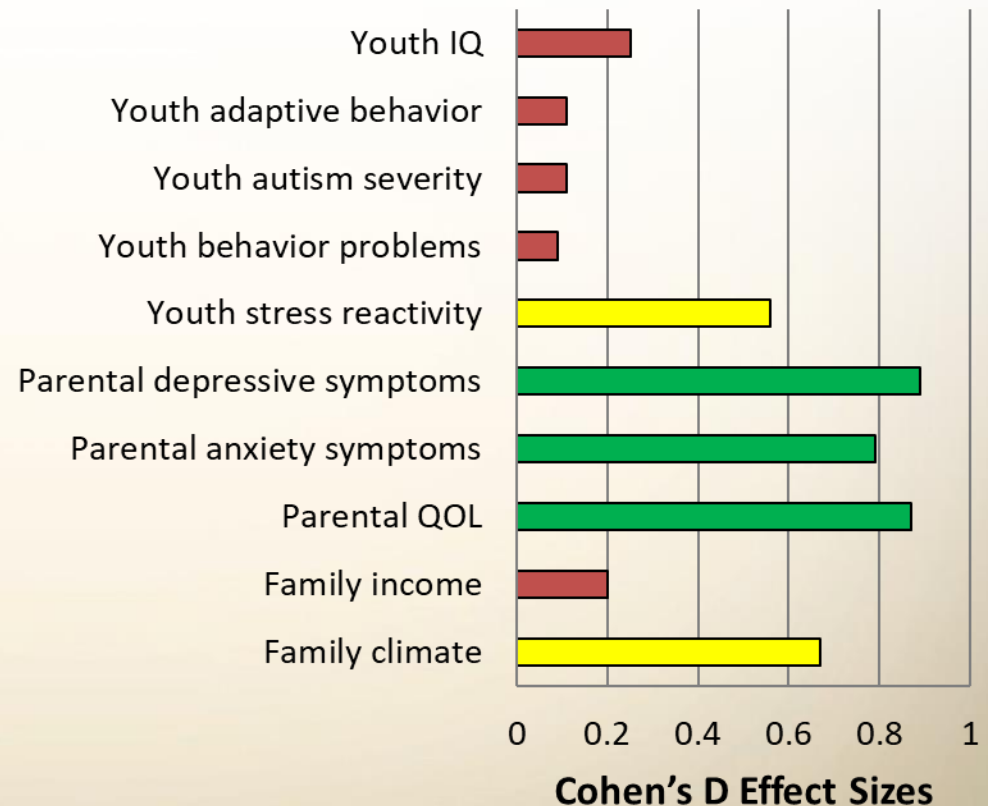


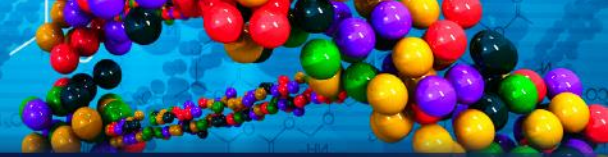
Patterns and Predictors of Disruption

Patterns



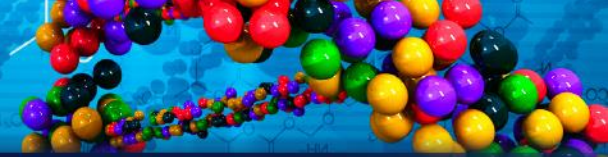
Predictors





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





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



VCU

**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!**



VCU

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!



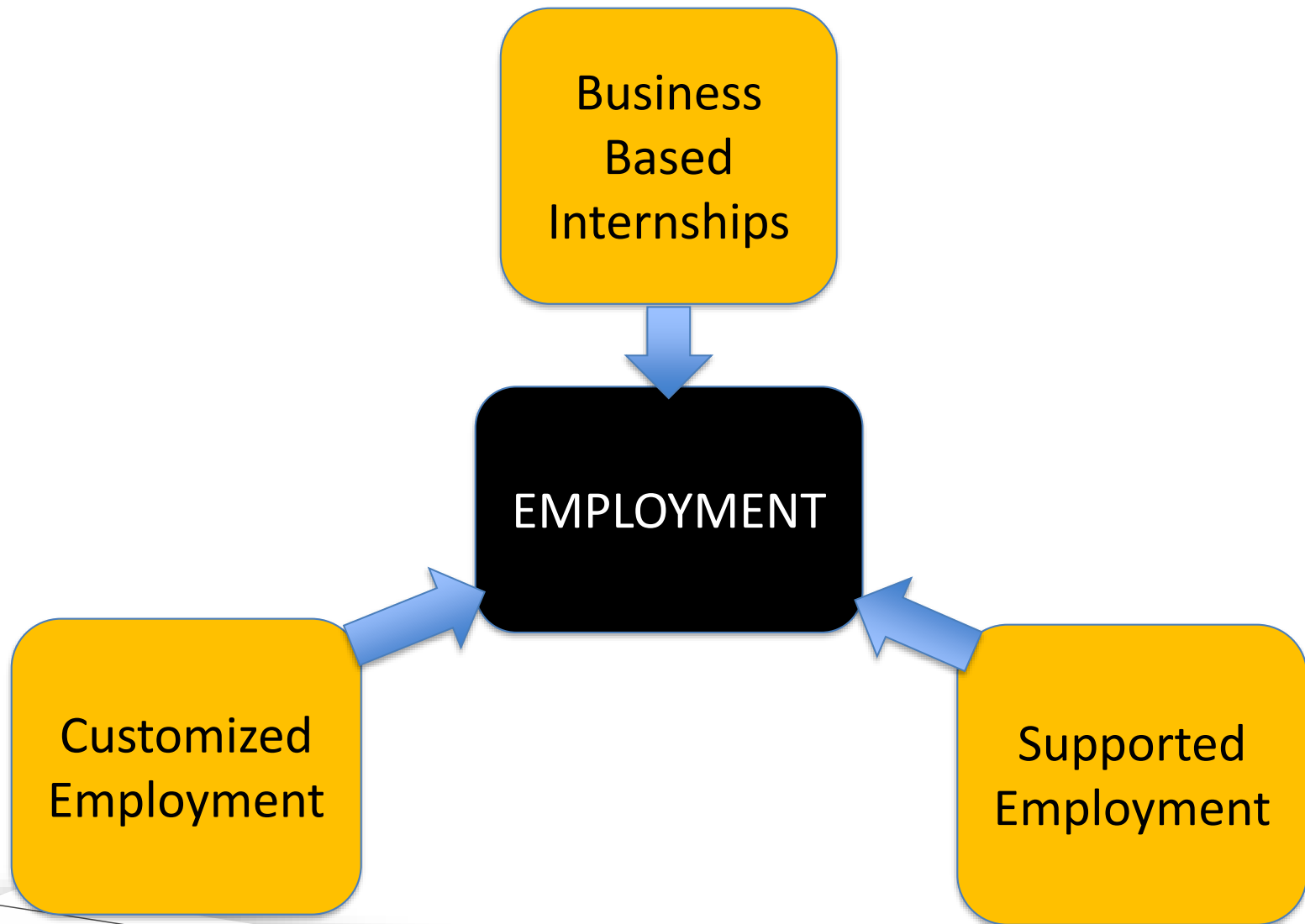
Not Sheltered Workshops or Day Care Centers



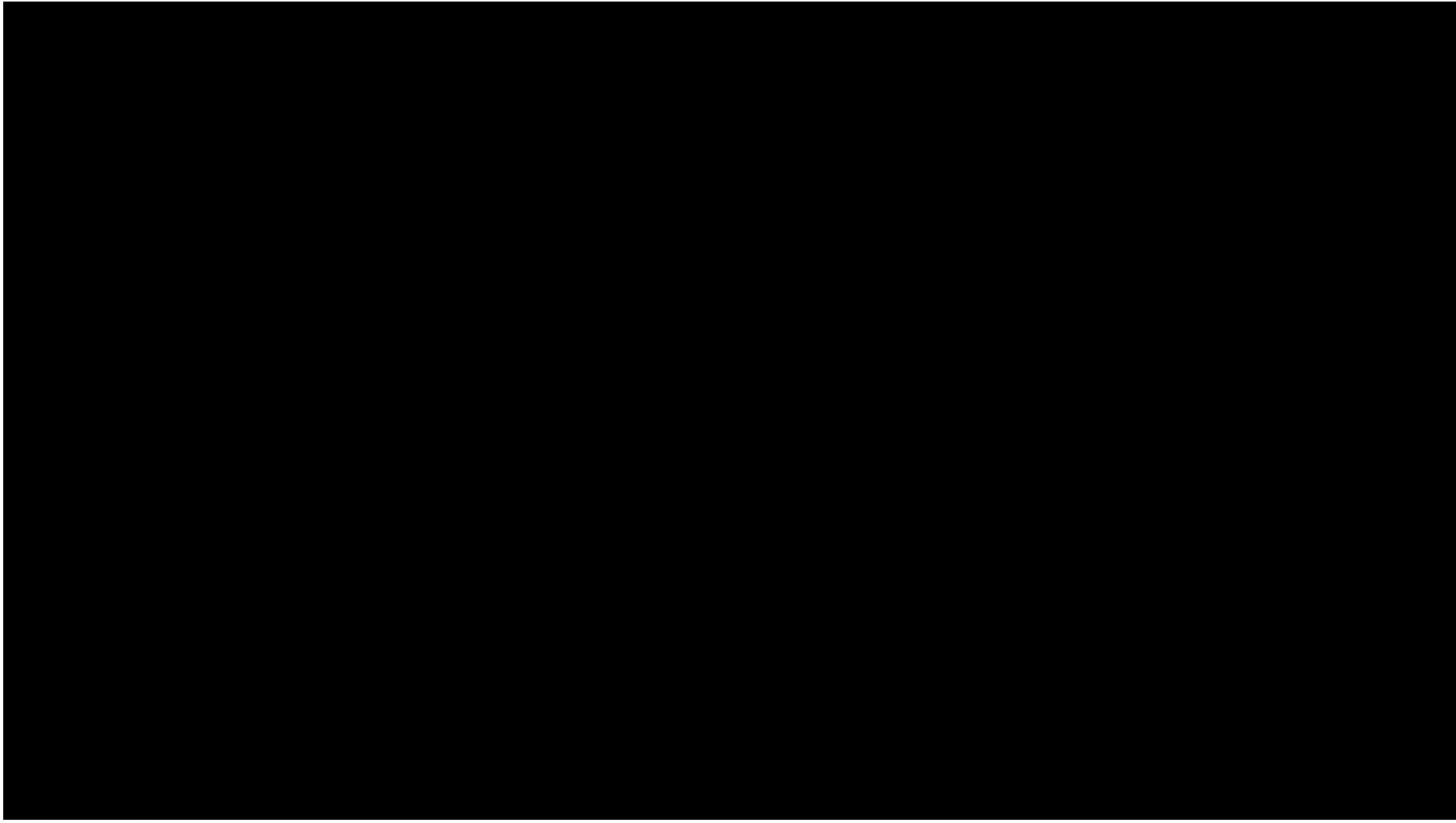
VCU

**So What is One Evidence
Based Pathway to
Competitive Integrated
Employment ?**

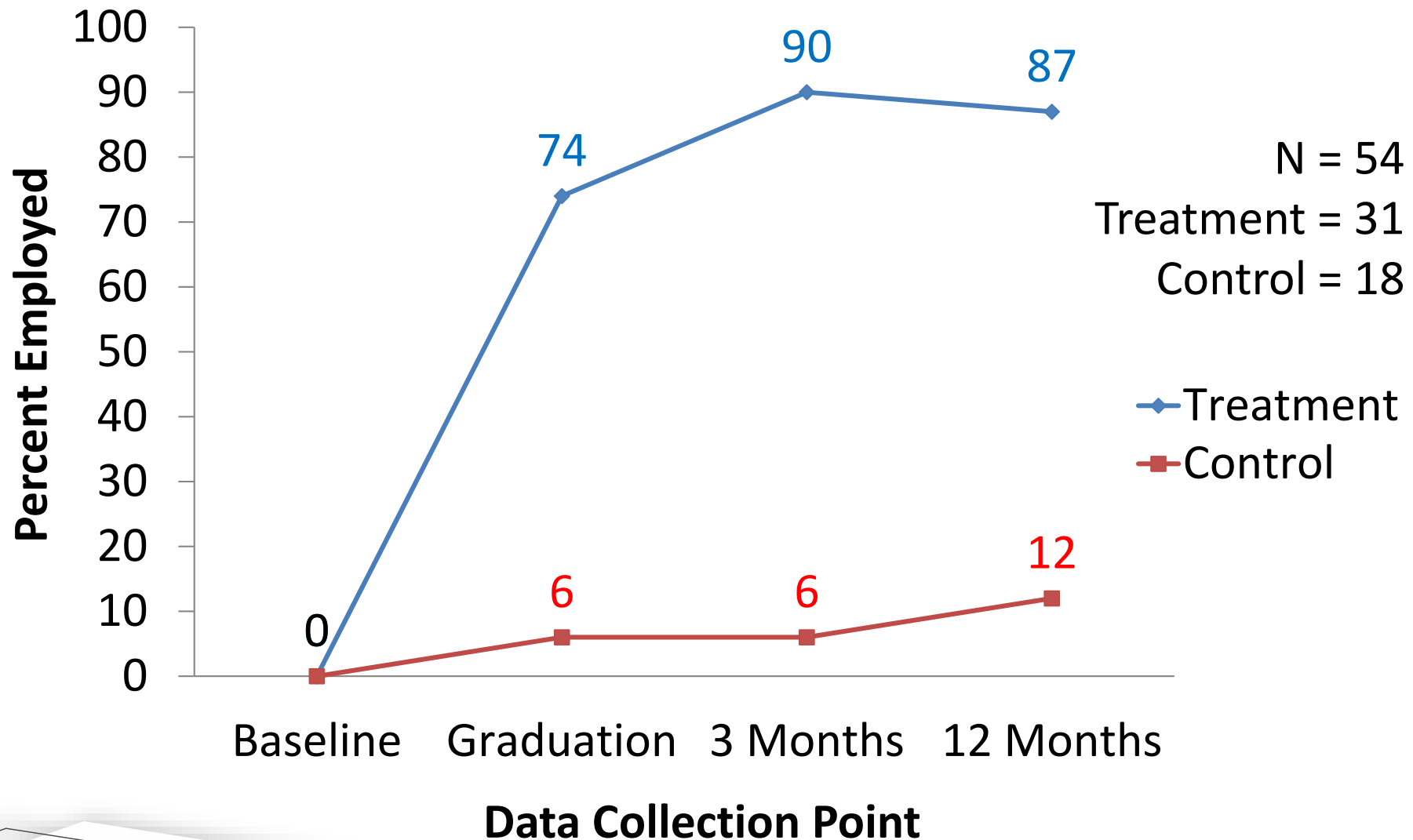
An Internship Based Model



Dillon

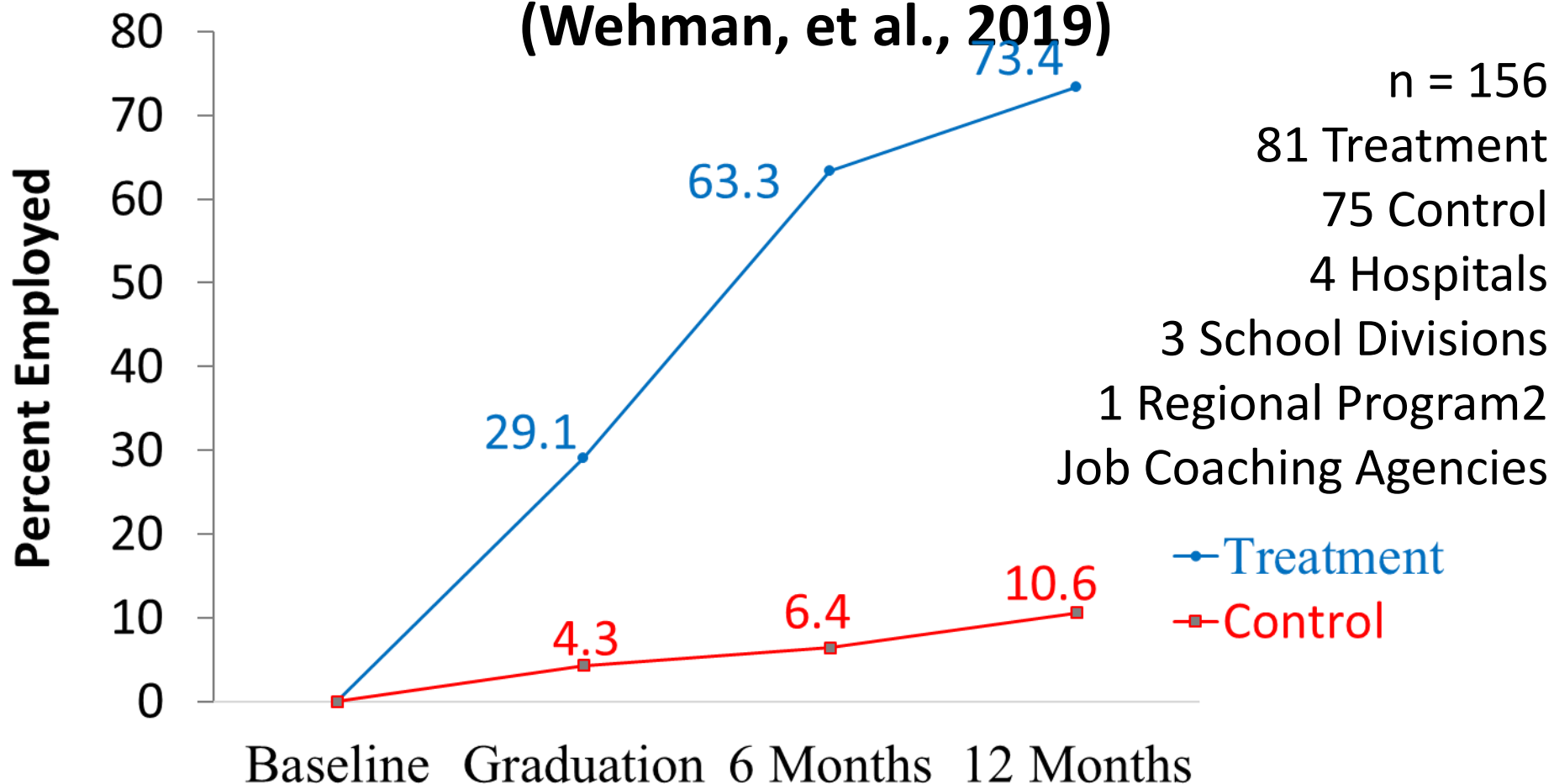


Pilot Randomized Clinical Trial: 2009-2013 Employment Outcomes in Community Based Integrated Employment (Wehman et al., 2017)



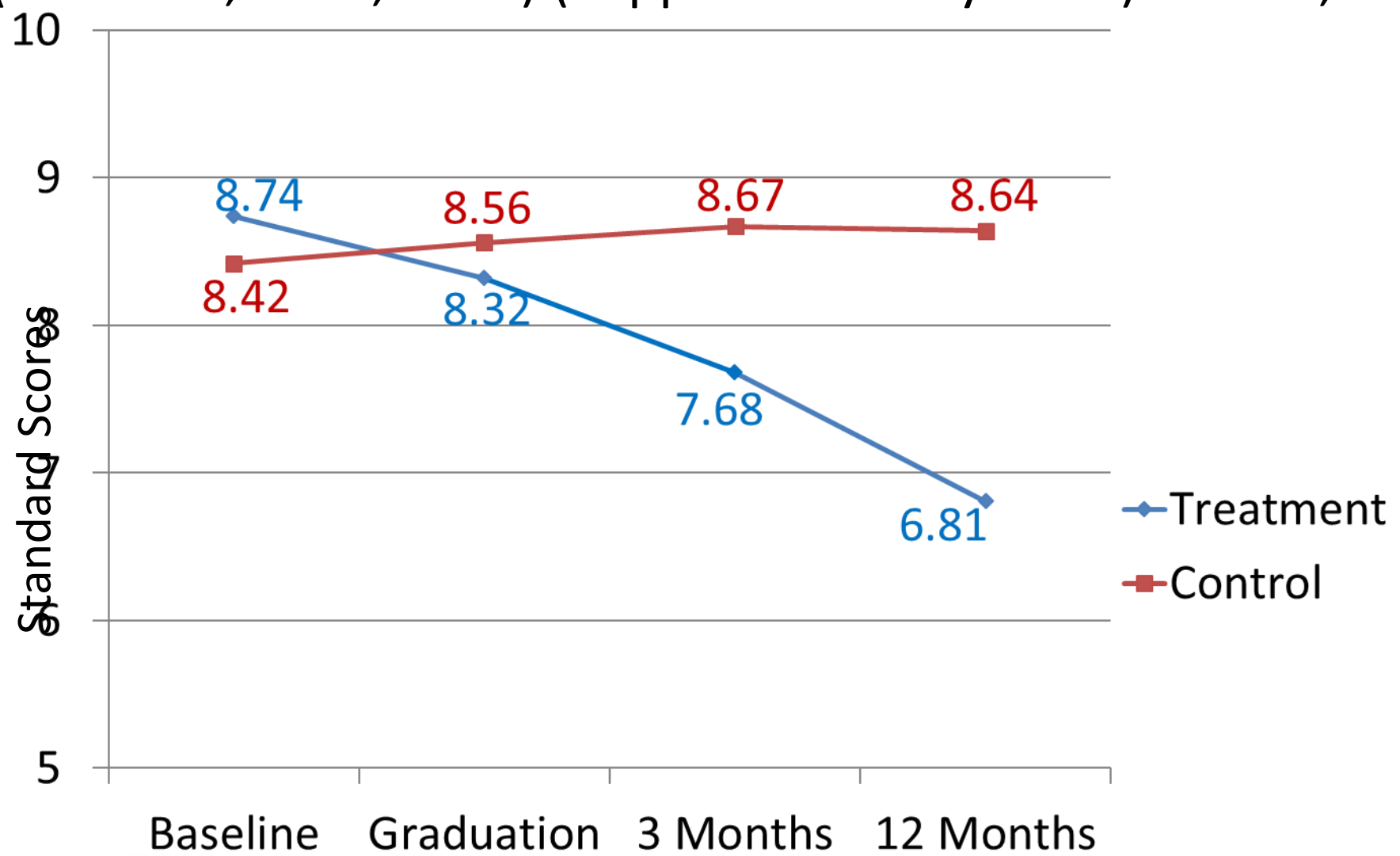
Replication and Expansion Study RCT Across Multiple Hospitals and School Divisions 2013-2018

(Wehman, et al., 2019)



Effect of Employment on Independence Support Intensity

(Wehman, et al., 2017) (Support Intensity Scale) AA IDD,2004



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

Stefanie

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

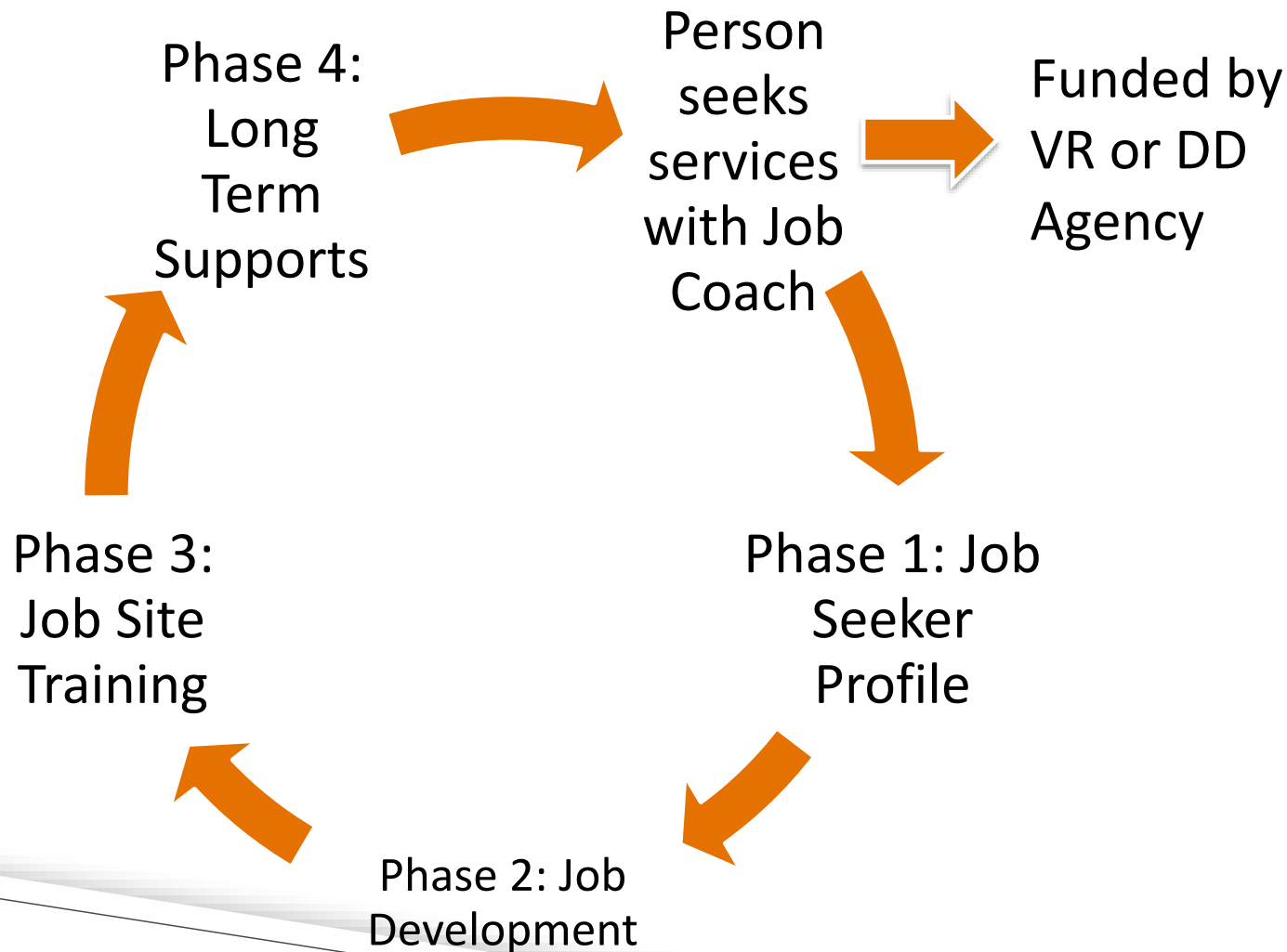
Employment Supports (Schall, et al., 2012)

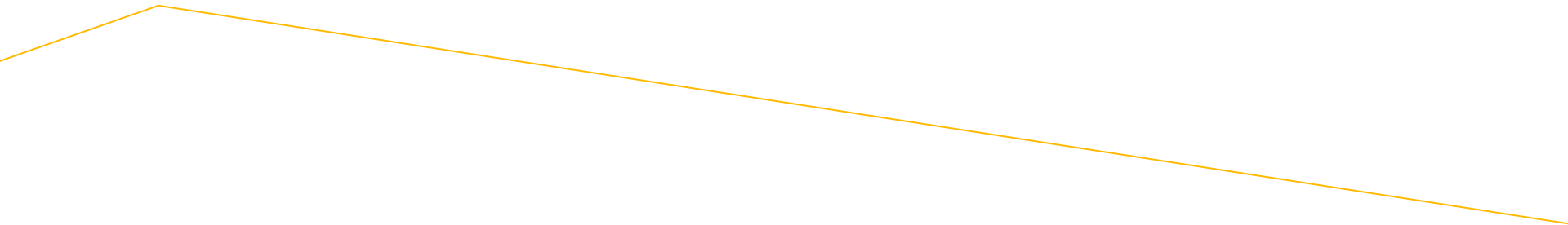
- Behavioral Consultation
- Consistent Structure to Seemingly Unstructured Internships
- Behaviorally Defining Idioms, Social Skills, and Work Expectations
- Visual Supports to Increase Implementation of Strategies
- Self Monitoring Checklists and Reinforcement Programs
- Role-Playing and Practice for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



Supported Employment

(Schall, et al., 2015)



A thin yellow line that starts on the left, rises to a peak, and then slopes downward towards the right.

<https://vcurrtec.org>
<http://vcuautismcenter.org>
<http://centerontransition.org>



VCU

This Presentation is Based Upon the Following Research

- Brooke, V., Brooke, A.M., Schall, C., Wehman, P., McDonough, J., Thompson, K., & Smith, J. (2018). Employees with Autism Spectrum Disorder Achieving Long-Term Employment Success: A Retrospective Review of Employment Retention and Intervention. Research and Practice for Persons with Severe Disabilities. DOI: 10.1177/1540796918783202.
- Ham, W., McDonough, J., Molinelli, A., Schall, C., & Wehman, P. (2014). Employment Supports for Young Adults with ASD: Two Case Studies. *Journal of Vocational Rehabilitation*. DOI: 10.3233/JVR-140677.

- Schall, C. M., Wehman, P., Brooke, V., Graham, C., McDonough, J., Brooke, A., Ham, W., Rounds, R., Lau, S., Allen, J. (2015). Employment interventions for individuals with ASD: The relative efficacy of supported employment with or without prior Project SEARCH training. *Journal of Autism and Developmental Disorders*. 45: 3990-4001. DOI: 10.1007/s10803-015-2426-5.
- Wehman, P., Brooke, V., Brooke, A. M., Ham W., Schall, C., et al. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. *Research in Developmental Disabilities*. DOI: 10.1016/j.ridd.2016.01.015.

- Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G., (2014). Transition from school to adulthood for youth with ASD: What we know and what we need to know. *Journal of Disability Policy Studies*, 25, 30-40; DOI: 10.1177/1044207313518071.
- Wehman, P., Schall, C., McDonough, J., Graham, C., Brooke, V., Riehle, J. E., Brooke, A., Ham, W., Lau, S., Allen, J., & Avellone, L. (2017). Effects of an employer based intervention on employment outcomes for youth with significant support needs due to autism. *Autism:21*: 276-290. DOI: 10.1177/1362361316635826.

- Wehman, P. H., Schall, C. M., McDonough, J., Kregel, J., et al. (2014). Competitive employment for youth with Autism Spectrum Disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders*, 44, 487-500. DOI 10.1007/s10803-013-1892-x.
- Wehman, P., Schall, C., McDonough, J., Molinelli, A., et al. (2014). Project SEARCH for youth with autism spectrum disorders: Increasing competitive employment on transition from high school. *Journal of Positive Behavior Intervention*, 15, 144-155

- Wehman, P., Schall, C., McDonough, J., Sima, A., Brooke, A, Ham, W., Whittenburg, H., Brooke, V., Avellone, L., & Reihle, E. (2019). Competitive employment for transition-aged youth with significant impact from autism: A multi-site randomized clinical trial. *Journal of Autism and Developmental Disorders*. Advance online publication. doi: 10.1007/s10803-019-03940-2



THE TENNESSEE WORK S PARTNERSHIP

.....
Changing the Employment Landscape for Young
People with Disabilities

Erik Carter | Vanderbilt University





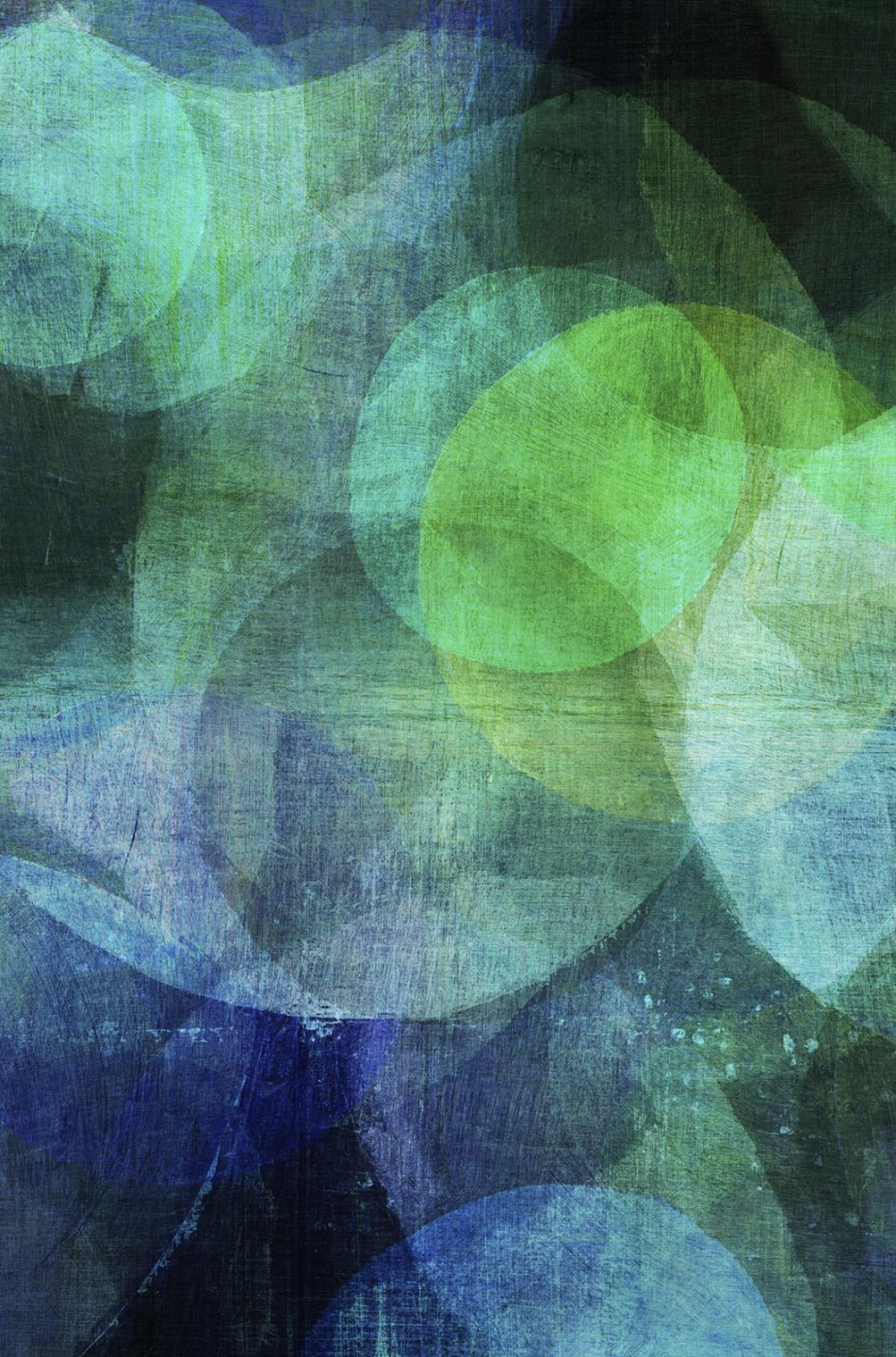
TO EQUIP.....

- ⦿ 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



tennesseeworks





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

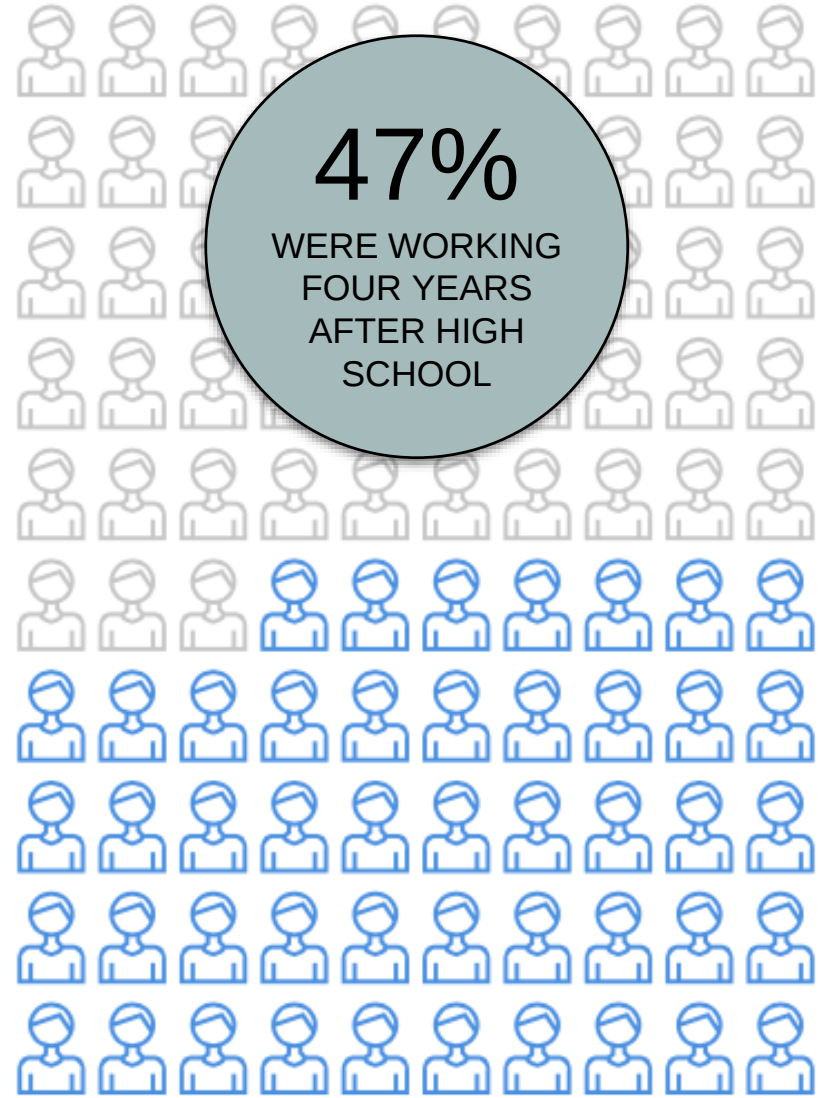


THE ASPIRATIONS OF YOUTH AND YOUNG ADULTS



View at: www.tennesseeworks.org/videos

ASPIRATIONS FOR EMPLOYMENT



ASPIRATIONS

EXPERIENCES

Studies: Lipscomb, Haimson, Liu, Burghardt, Johnson, & Thurlow (2017); Newman et al. (2011)



Youth at ThinkEmployment! Summits



Individuals and Families Workgroup



Advocacy at Disability Day on the Hill

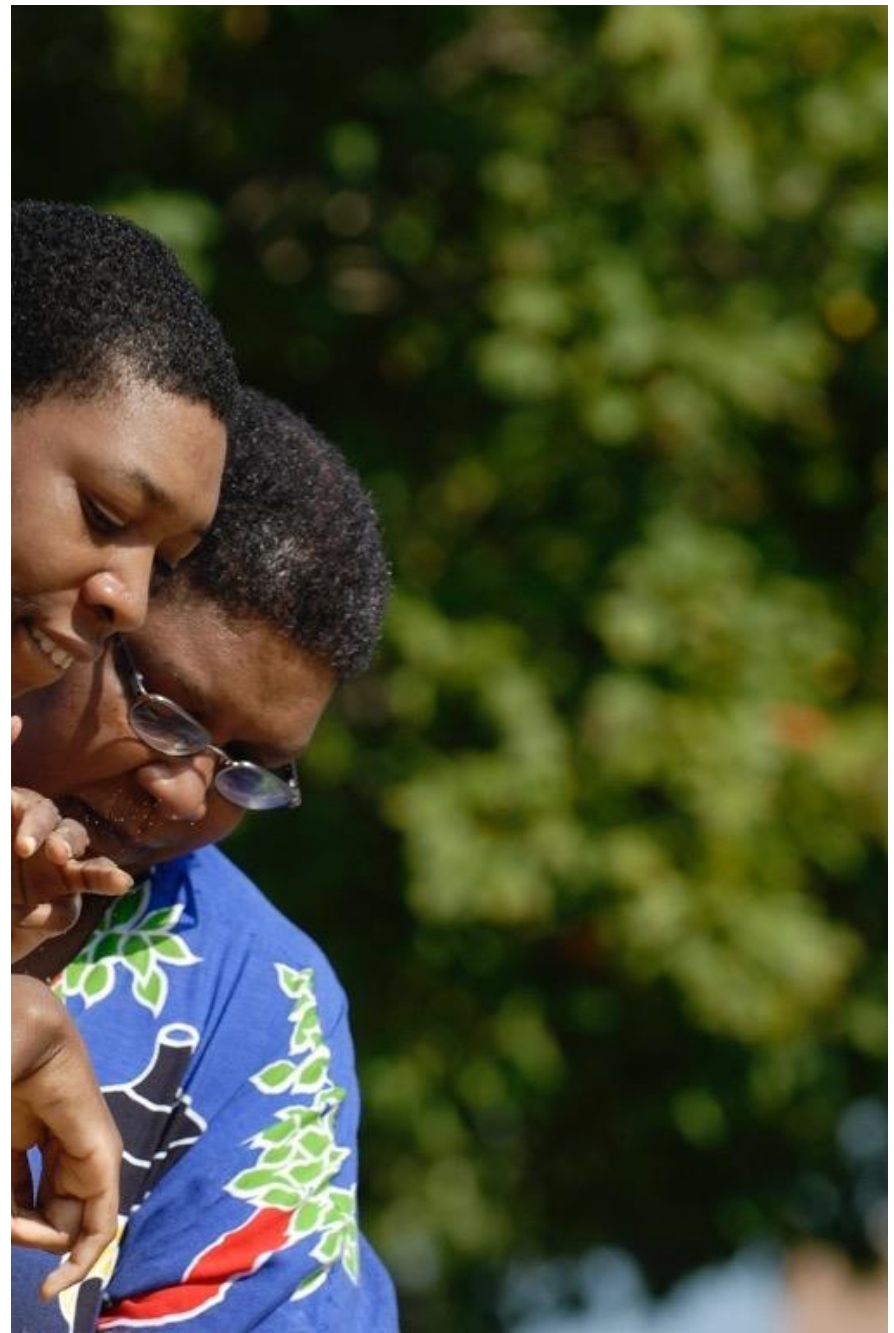
2.

RAISING EXPECTATIONS

.....
Among families,
educators, professionals,
and others

Carter, Austin, & Trainor (2012); Carter et al. (2010)





Blustein et al. (2016); Gilson et al. (2016); Gilson et al. (2017)

Family Expectations



Awsumb et al. (in preparation); Carter et al. (in preparation)

Educator Expectations

3.

CHANGING INTRODUCTIONS

Matching strengths
to community needs



HIRE MY STRENGTHS

OUR PARTNERS TOOLKIT RESOURCES VIDEOS EVENTS



A collage of eight diverse individuals holding signs that celebrate their strengths and abilities. The signs read: 'metology', 'CREATIVE', 'Artist', 'I'm A helper!', 'Fashion Designer', 'ile and a positive', 'leading', and 'RESPECTFUL'.

HIRE MY STRENGTHS

www.hiremystrengths.org

National Disability Employment Awareness Month

www.hiremystrengths.org

4.

ALIGNING POLICIES

.....
With high aspirations
and expectations





<https://www.tn.gov/cdd/projects-and-initiatives/employment-and-transition/employment-first-task-force.html>

5.

EQUIPPING PROFESSIONALS

To implement the best of
what we know works





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

Visit: www.transitiontn.org



Annual Transition Conference

What is the "Business Case?"

The "business case" is an initiative of the **nation's leading companies** to hire applicants with disabilities. Many companies have already established disability recruitment programs to start hiring this **untapped resource of employees**.

Why are applicants with disabilities strong candidates for employment?

- ✓ Employees with disabilities have equal or better **turnover and absentee** rates than employees without disabilities.
- ✓ Employees with disabilities have equal or better **safety records, job performance** ratings, and job assignment **flexibility**.
- ✓ On average, employees with disabilities require an **equal amount of supervision** as employees without disabilities.

How does employing applicants with disabilities affect customers?

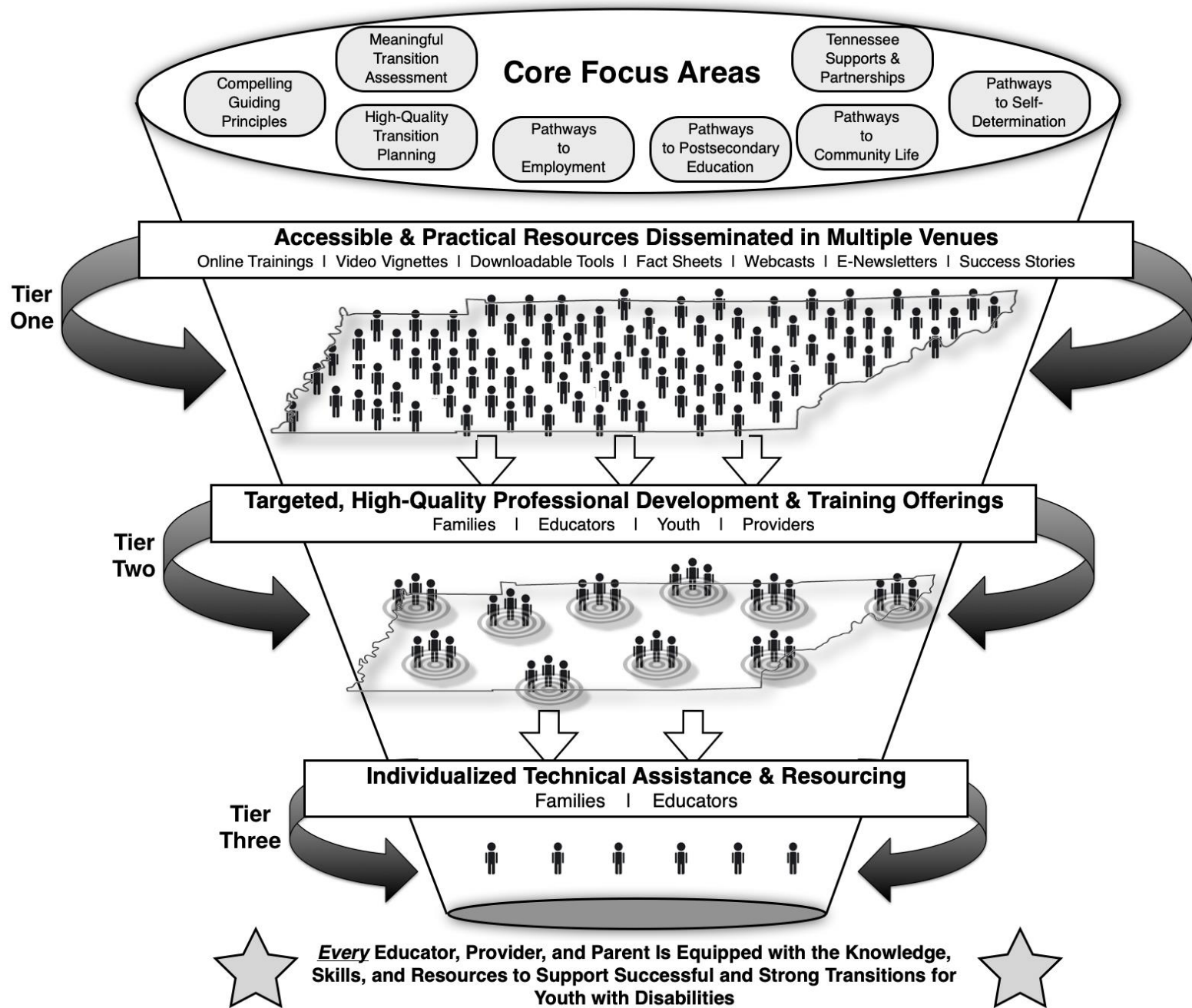
- ✓ **87%** of customers **prefer to do business** with companies that employ people with disabilities.

What are the advantages for employers of hiring applicants with disabilities?

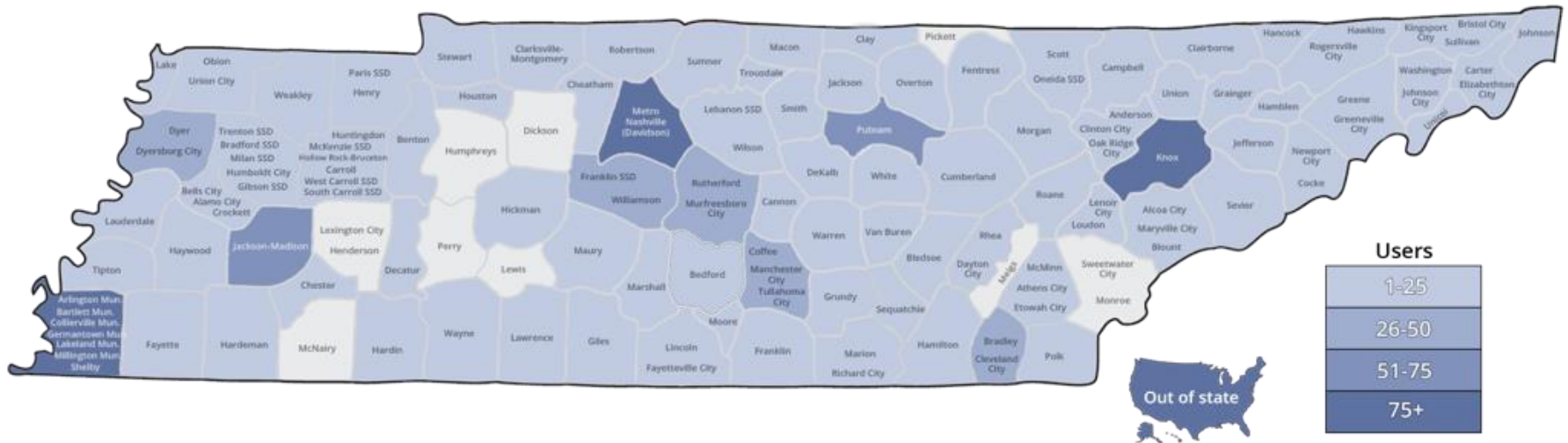
- ✓ Employers find **reduced costs** throughout the workplace turnover and retraining.
- ✓ The company as a whole has **improved morale**.
- ✓ Employees with disabilities **fine-tune** the company to meet the needs of customers with disabilities.
- ✓ Employers find a **return on investment**—each \$1 spent on

1,300 + attendees

Employer Outreach Trainings



TransitionTN Impact



6.

MAKING
INFORMATION
ACCESSIBLE

.....
For everyone at any
time





[AA](#)
[Twitter](#)
[Facebook](#)
[Email](#)

Elevating Employment Outcomes for People with Disabilities

SELF-ADVOCATES & FAMILIES

EMPLOYERS & PROVIDERS

EDUCATORS

POLICYMAKERS

[SUMMIT](#)
[COMMUNITY CONVERSATIONS](#)
[RISE TO WORK BLOG](#)
[HIRE MY STRENGTHS](#)
[ARCHIVED NEWSLETTERS](#)

[ABOUT US](#)
[GETTING TO WORK](#)
[SUCCESS STORIES](#)
[RESOURCES](#)
[BY THE NUMBERS](#)
[EVENTS](#)
[VIDEOS](#)
[CONTACT US](#)
[SUBSCRIBE](#)



Disability Employment Benefits Us All

At ACL's Administration for Disabilities we continue to focus on employment as a key pillar of community living. We know that people who find meaningful work are happier and healthier, and are strong contributors in their communities. While we have participated and led several events to celebrate NDEAM, ACL strives all year round to lead and partner on national programs and initiatives aimed at increasing the number of Americans with disabilities who are working.

Welcome to TennesseeWorks

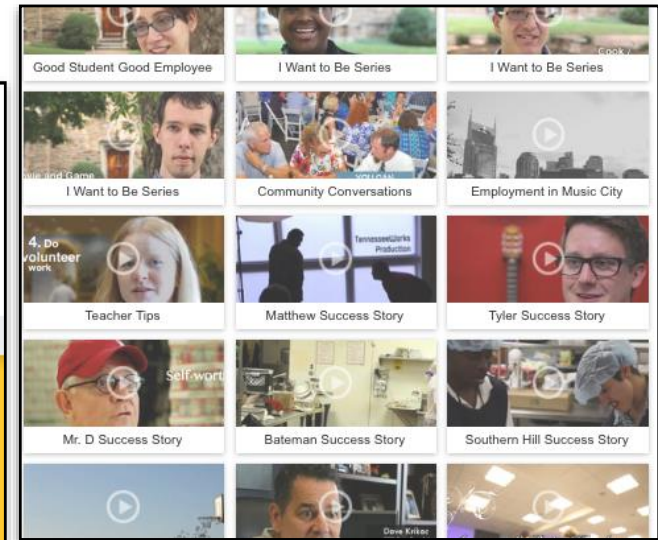
We're transforming the employment landscape for young people with intellectual and developmental disabilities across the state. Meaningful work. Real pay. Opportunities for every Tennessean with a disability.

This new website is an online resource for those in our state committed to these

Subscribe

eNewsletter

Sign Up Today >



Scores of Videos and Success

Expanding Communications

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

Communication

Communication is the conveying information through speech, visuals, signals, exchange of information, communication requires to communicate the



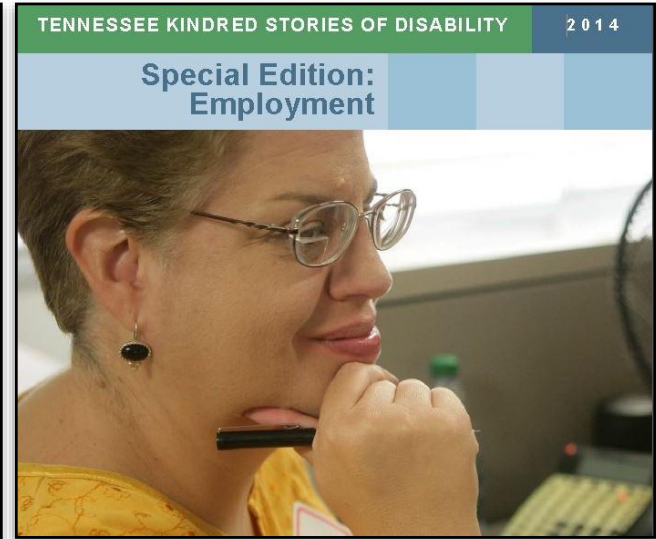
TennesseeWorks Clearinghouse

New Cross-Agency Dissemination

www.tennesseeworks.org



Family Coalitions



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 PIE 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 Vanderbilt

Parent Resources and Blog

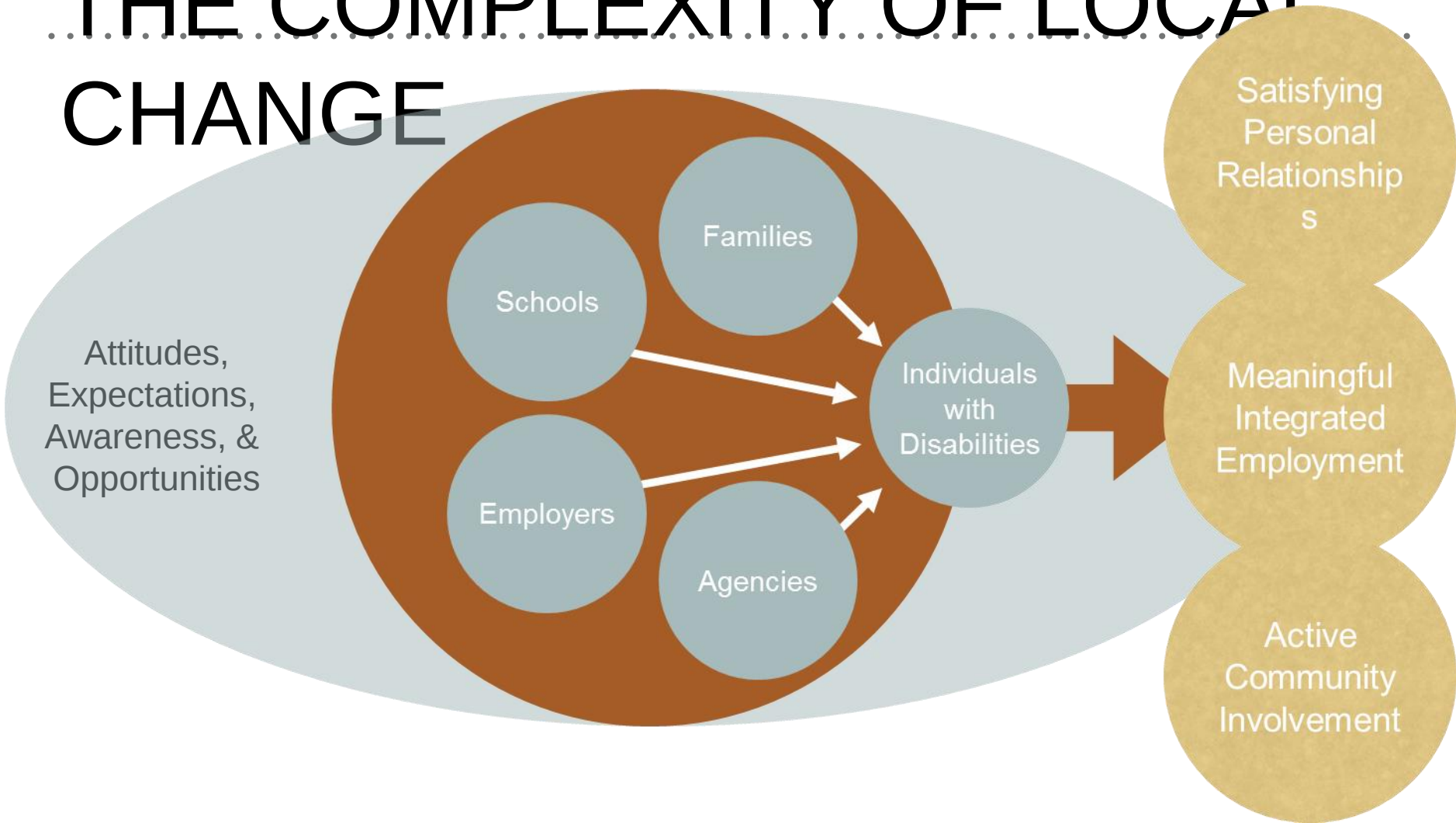
7.

ENGAGING COMMUNITIES

.....
In new and clever
ways



THE COMPLEXITY OF LOCAL CHANGE





Event Topics to Date

- Integrated employment
- Workshop conversions
- Postsecondary education access
- Independent living
- Family engagement
- Community inclusion

Community Conversation Events

Bumble et al. (2017, 2018, 2019, in preparation); Carter et al. (2016, 2017, in preparation)

8.

MEASURING WELL

.....
Data is not a four-letter
word*

Technically, it is.



“

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

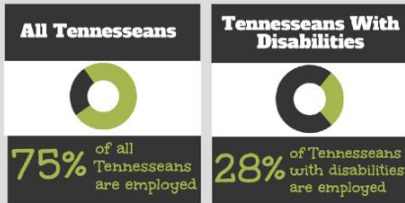
-Yogi Berra

Employment and Disability

By The Numbers



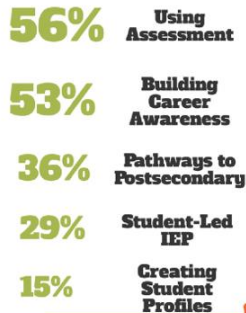
In this section of our website, we present findings from multiple Tennessee projects that each provide important insights into the current employment landscape and suggest possible pathways for making change. We also integrate data from other sources that provide a snapshot of employment outcomes for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



Click here for more data on the current employment landscape for Tennesseans with disabilities

What Do Teachers Need?

Topics Educators Want More Resources On Related to Transition Planning



Click here for more data from our educator survey

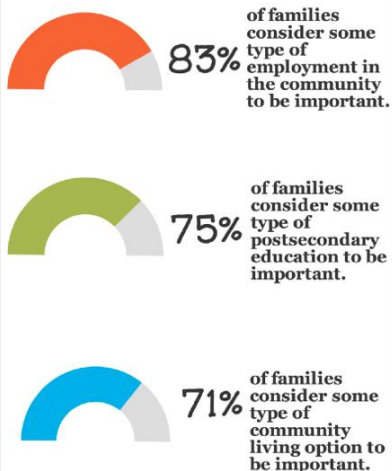
Click here to view tips for transition success from Tennessee educators



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



What Matters Most to Families?



EMPLOYMENT for PEOPLE WITH DISABILITIES

TENNESSEE STATEWIDE EMPLOYMENT GOAL: REDUCE THE EMPLOYMENT GAP

5% BY 2023

EMPLOYMENT FIRST TASK FORCE

Monitors progress towards the strategic plan/goals and delivers the annual Expect Employment Report to the Governor.

CURRENT EMPLOYMENT RATE

According to the U.S. Department of Labor, Bureau of Labor Statistics, 2017 for ages 18-64.



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

TENNESSEEWORKS PARTNERSHIP

Council on Developmental Disabilities
Department of Children's Services
Department of Education
Department of Health
Department of Human Services - Vocational Rehabilitation
Department of Intellectual & Developmental Disabilities
Department of Mental Health & Substance Abuse Services

Division of TennCare
Department of Treasury
Department of Labor & Workforce Development
Department of Economic & Community Development
Vanderbilt Kennedy Center
Disability Rights Tennessee
UT-Boling Center

Self-advocates
Family members

Provider agencies
Employers

The Arc Tennessee

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.*
- **Community conversations on integrated employment: Individualization and impact.** *Journal of Disability Policy Studies.*
- **Parent perspectives on integrated employment for adults with intellectual and developmental disabilities.** *Research and Practice for Persons with Severe Disabilities.*
- **Using community conversations to expand employment opportunities for people with disabilities in rural and urban communities.** *Journal of Vocational Rehabilitation.*
- **The promise and possibilities of community conversations: Expanding employment opportunities for people with disabilities.** *Journal of Disability Policy Studies.*
- **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.*
- **Engaging communities in identifying local strategies for expanding integrated employment during and after high school.** *American Journal on Intellectual and Developmental Disabilities.*
- **School-business partnerships and students with intellectual and developmental**

9.

INVESTING IN RELATIONSHIPS

Across all our partners



A photograph of a man in a pink suit and bow tie, smiling, with two women in the background. The text 'THE TENNESSEWORKS PARTNERSHIP' is overlaid on the image.

THE TENNESSEWORKS 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>

Autism Community Employment Challenge

Only **14%** of
adults with autism
are employed

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

Why focus on employment?

Employment is
core to a
person's
quality of life¹

- 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
experience²

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

Employed
autistic
individuals
experience³

- Financial benefits
- Emotional and health benefits

1 (Hendricks, 2010) – 2 (Eggleton et al., 1999) – 3 (Hurlbutt & Chalmers, 2004; Wei et al., 2015, Guan & Li, 2017)

Interest from Industry

- ✓ Social impact
- ✓ Benefits related to autism

Unique strengths¹

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

Employee characteristics²

- Trustworthiness
- Reliability
- Low absenteeism
- Innovation

1 (Howlin et al., 2004) - 2 (Smith et al., 1986; Austin & Pisano, 2017)

AUTISM @ WORK EMPLOYER ROUNDTABLE

We are a collection of innovative leaders who have been running autism-focused hiring initiatives for at least one year. As a collection of cross industry employers,

SPECIALISTERNE



Passion for details.

JPMORGAN CHASE & CO.



RISING TIDE
CAR WASH



ULTRA
TESTING



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.

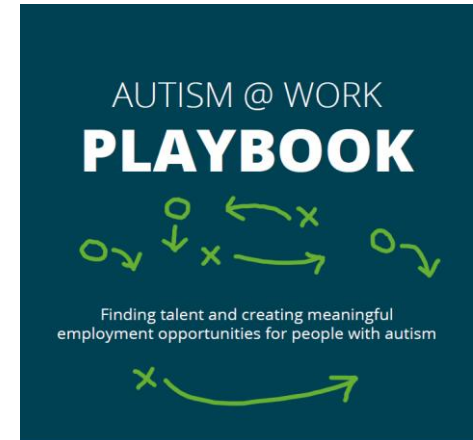
- Exploratory study of emerging autism hiring programs

2.

- Identify key organizational characteristics that enable autism hiring programs

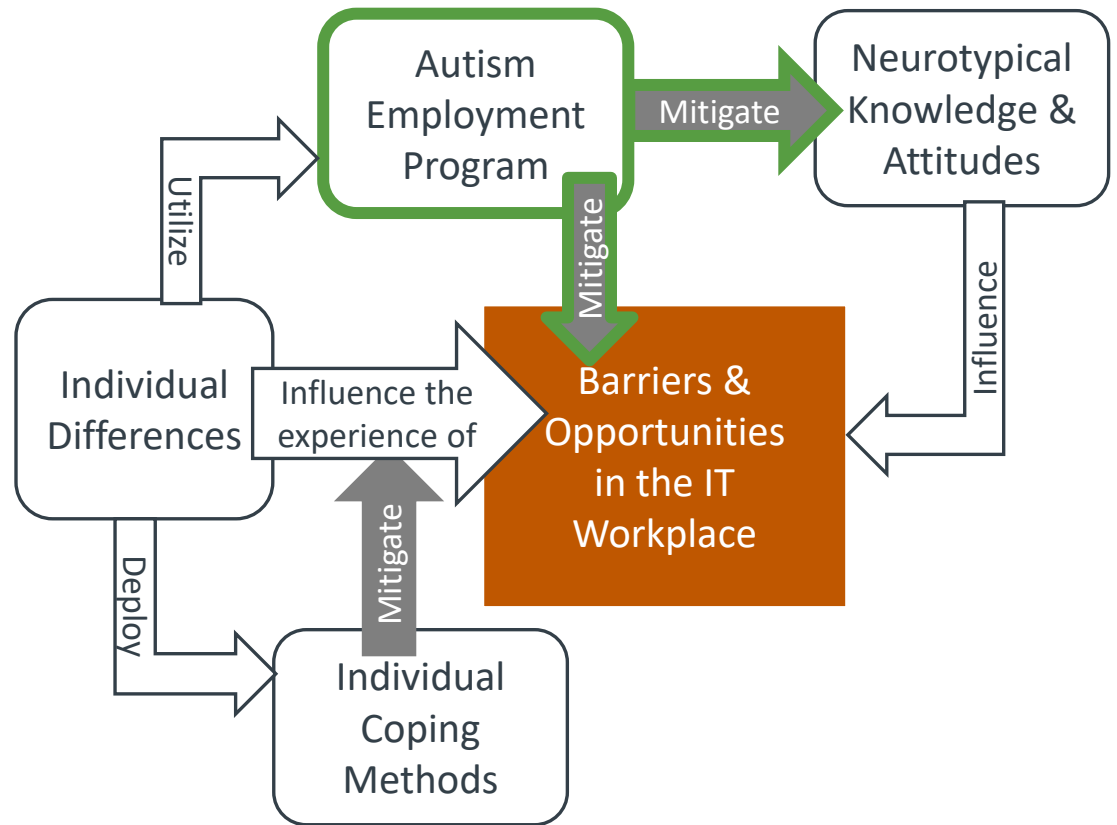
3

- Determine best practices and pathways for more and better employment



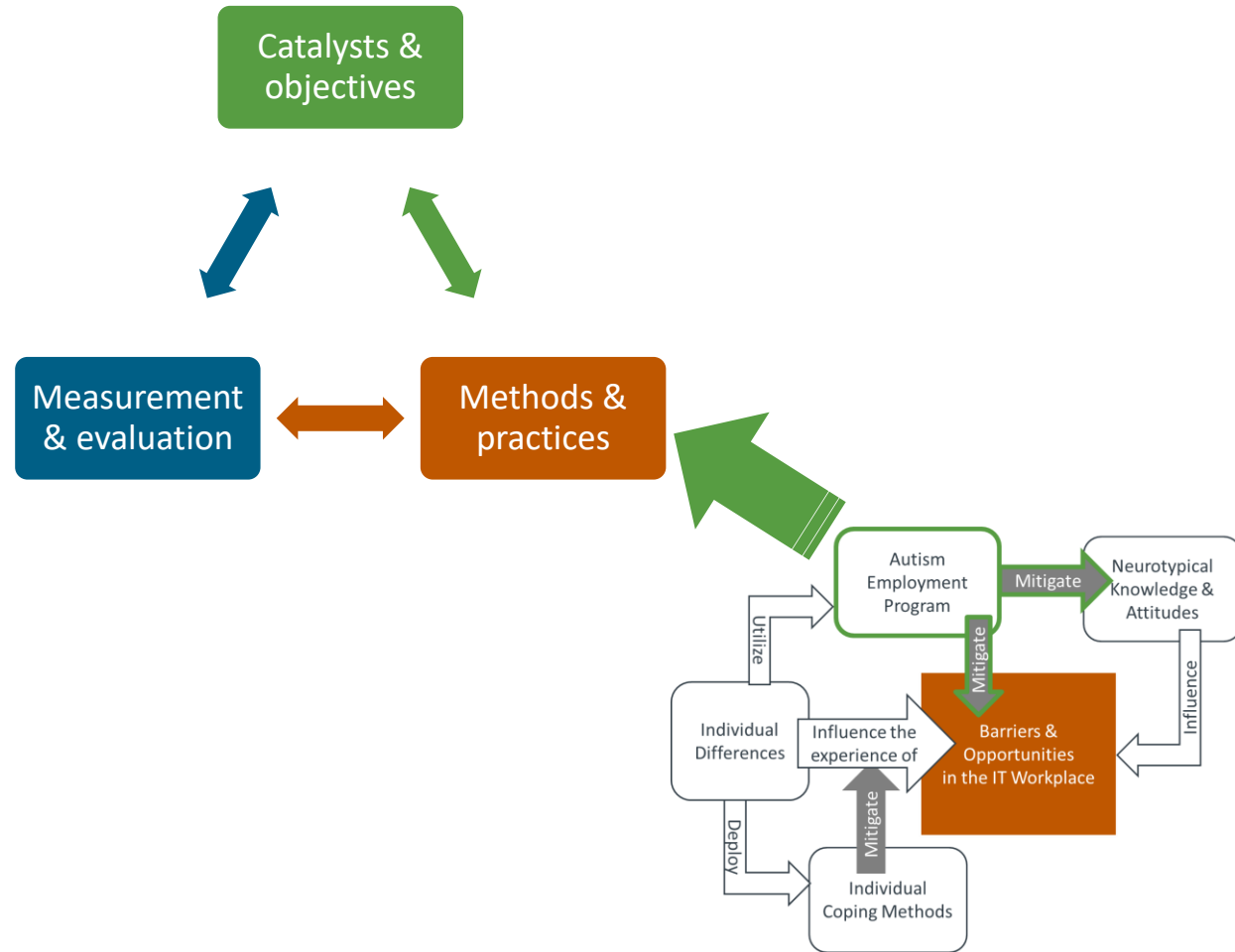
Organizational Interventions Mitigating Individual Barriers Framework

(Annabi & Locke, In Press)



Organizational Interventions Mitigating Individual Barriers Framework

(Annabi & Locke, In Press)



METHOD



Data Sources:

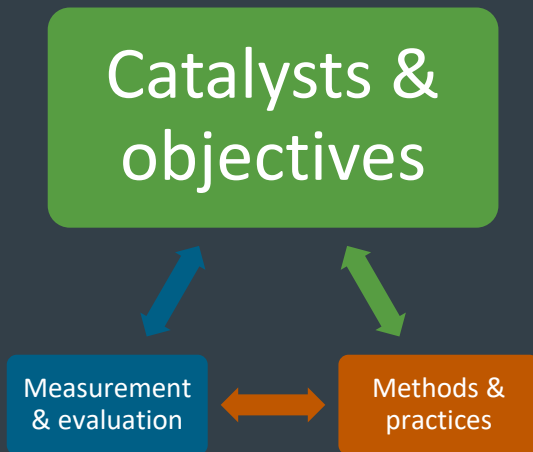


Data Analysis:



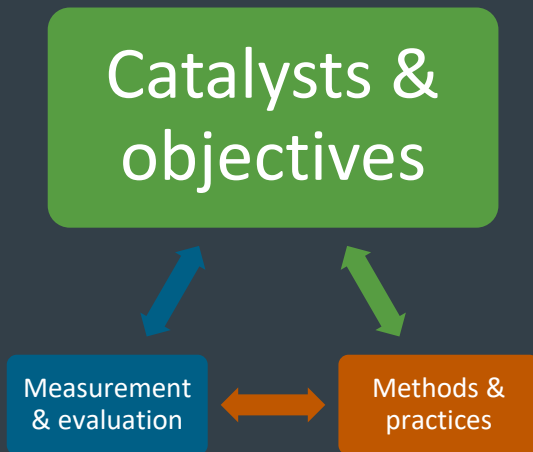
Autism at Work Summit
Research Workshop 2018

Findings



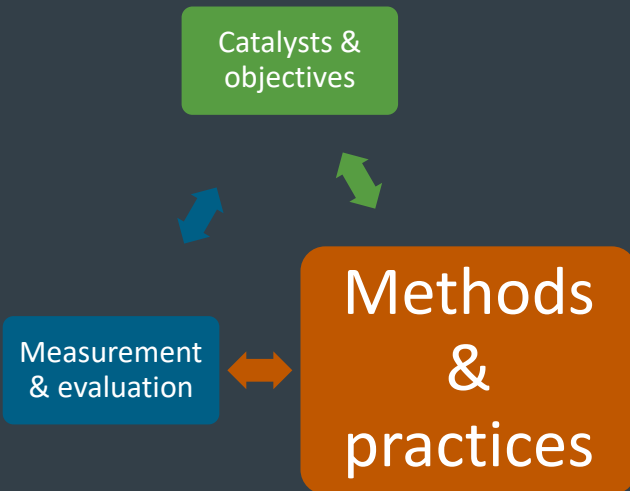
- ✓ Enhance corporate social responsibility
- ✓ Meet rapidly growing demand for tech talent
- ✓ Employee-focused reputation and culture
- ✓ Enhance productivity, efficiency, and innovation
- ✓ Suitability of the local ecosystem

Open Questions



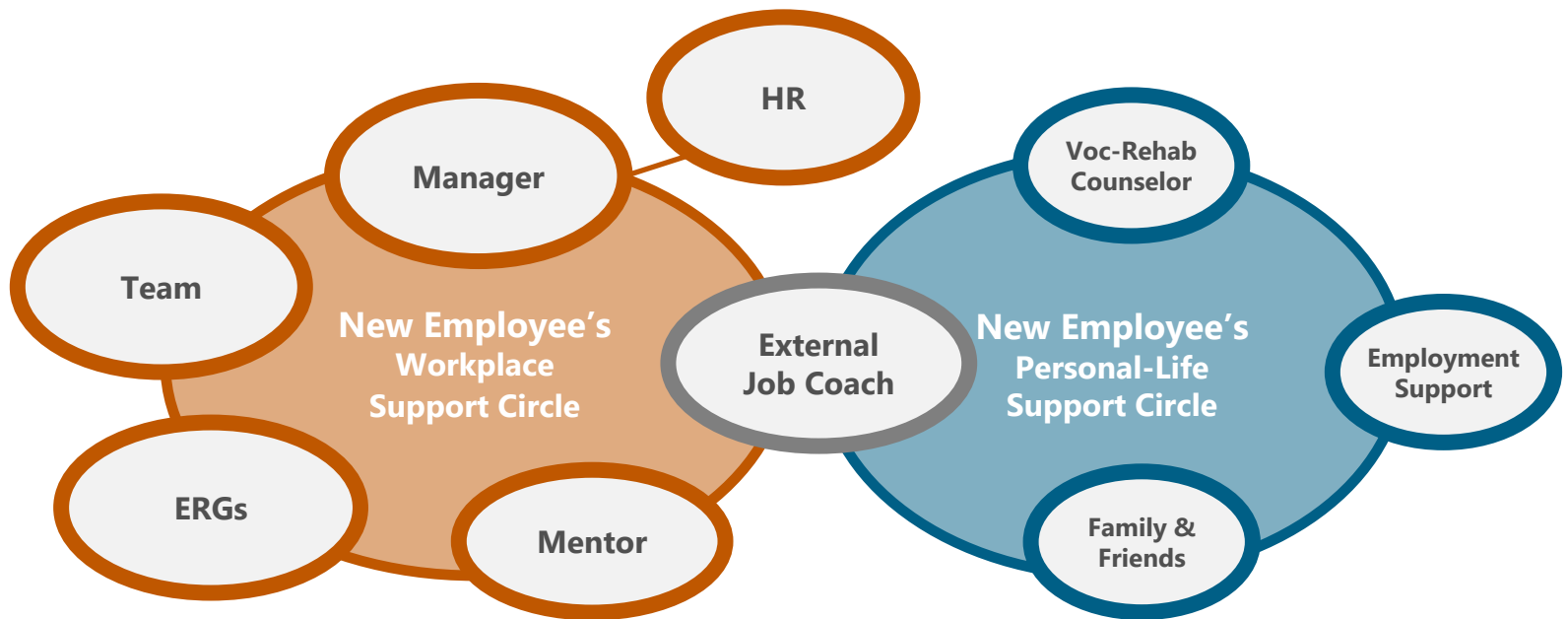
- ✓ How to sustain and scale programs?
- ✓ How to better serve individuals across the spectrum?
- ✓ How to engage a diversity of organizations (e.g., industry sectors, sizes)?
- ✓ How do autism hiring programs fit the broader diversity and inclusion efforts?

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



Findings

Catalysts & objectives

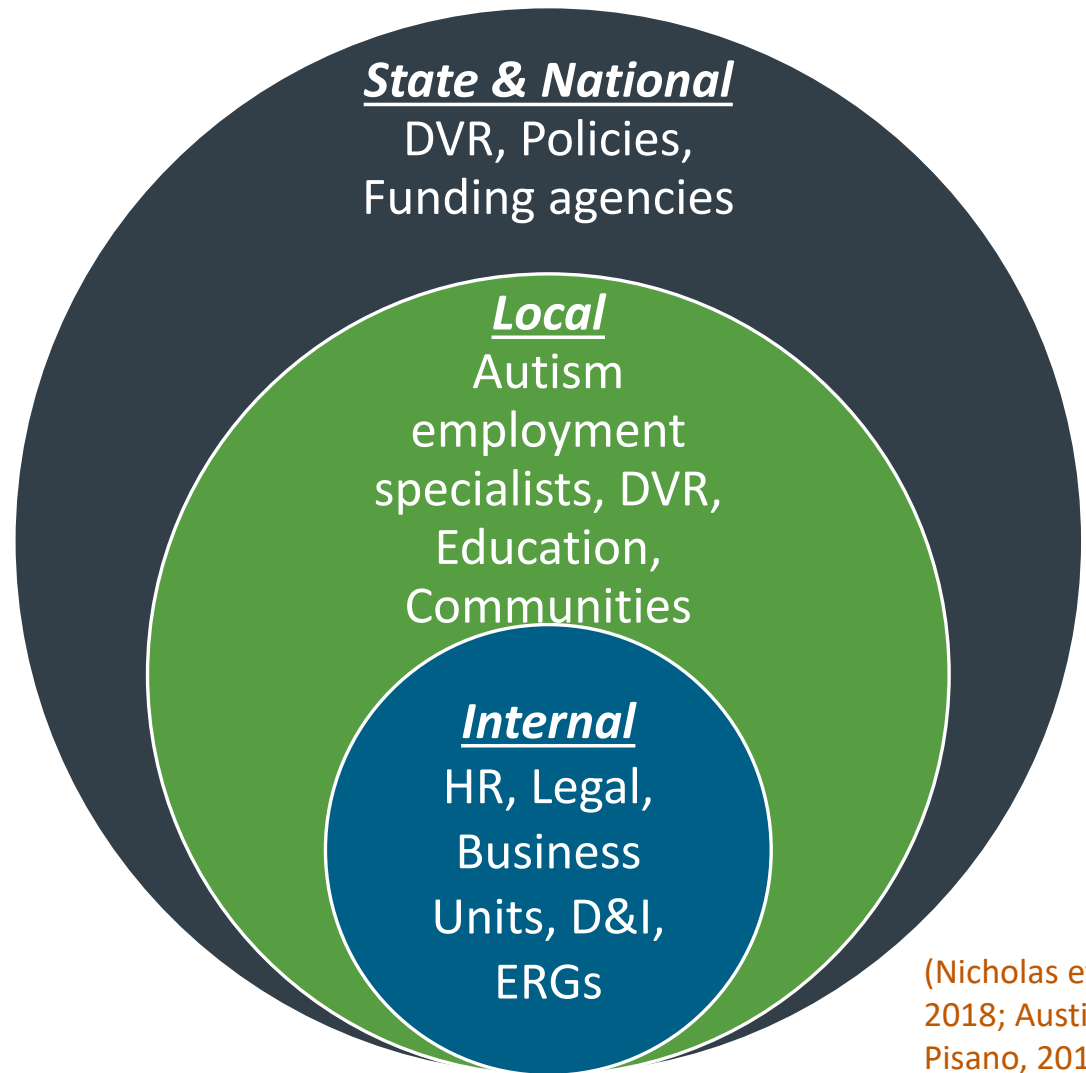


Methods
&
practices

Measurement
& evaluation

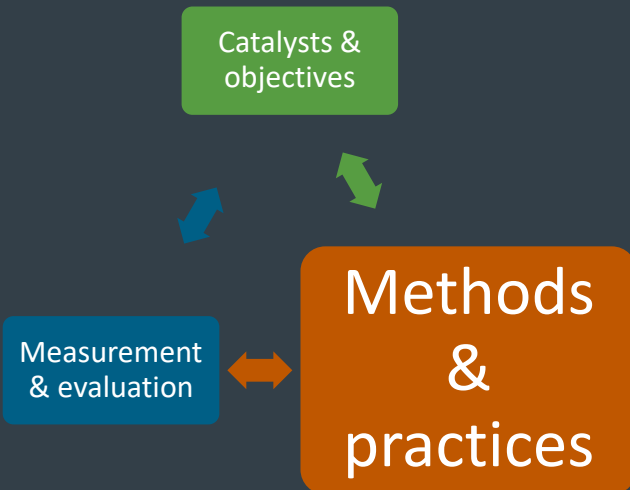


The Significance of the Ecosystem

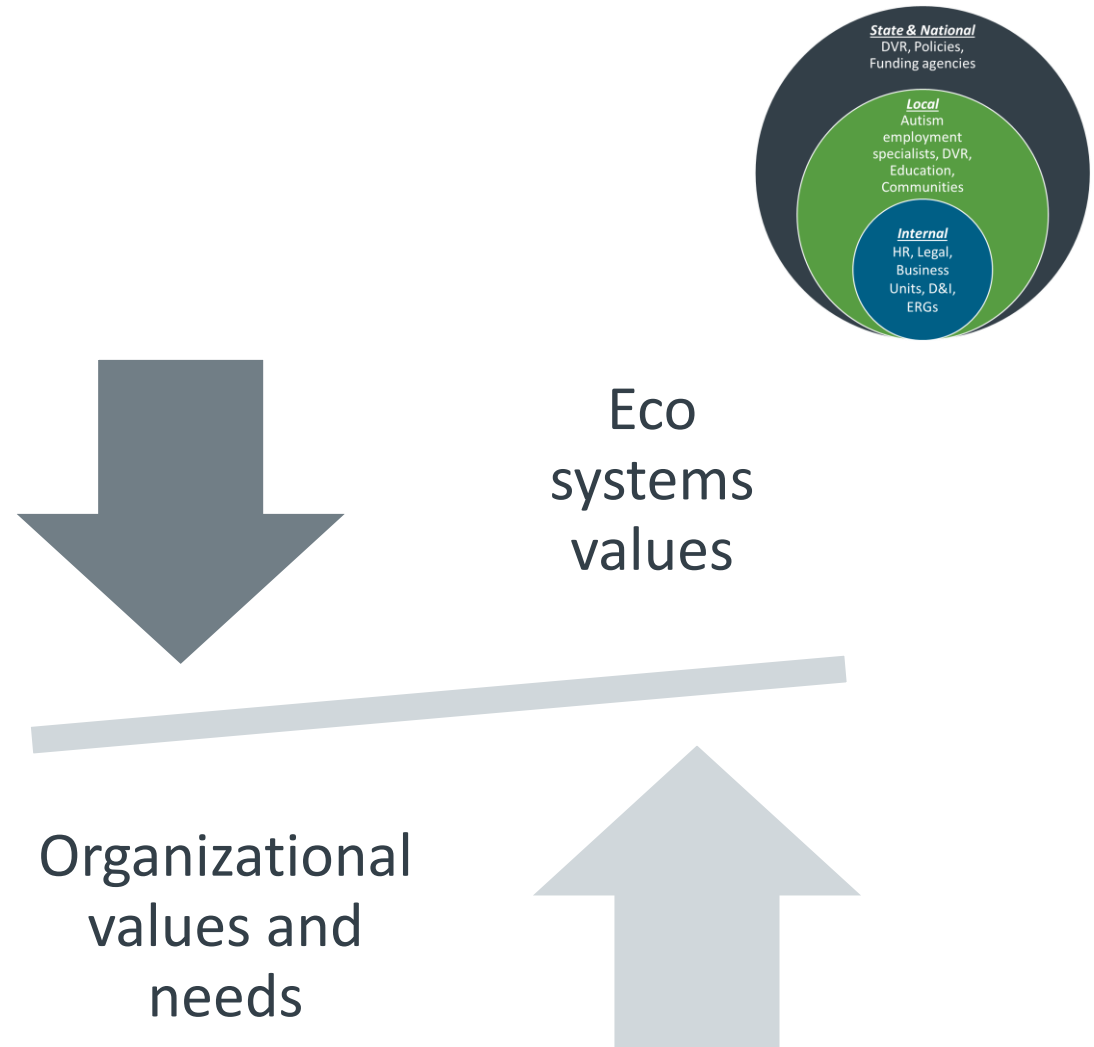


(Nicholas et al.,
2018; Austin &
Pisano, 2017)

Findings



The Significance of the Ecosystem



Open Questions

Catalysts & objectives



Methods
&
practices

Ecosystem

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

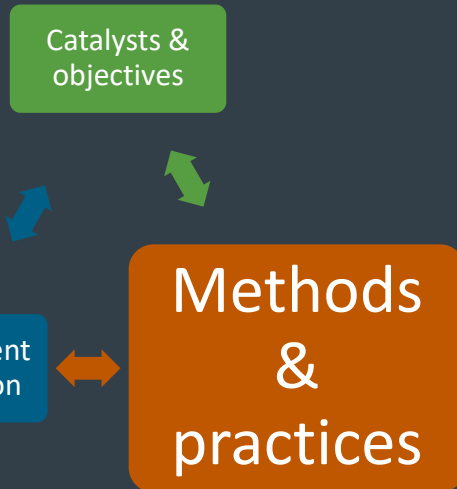
Employee support and advocacy

- ✓ 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?

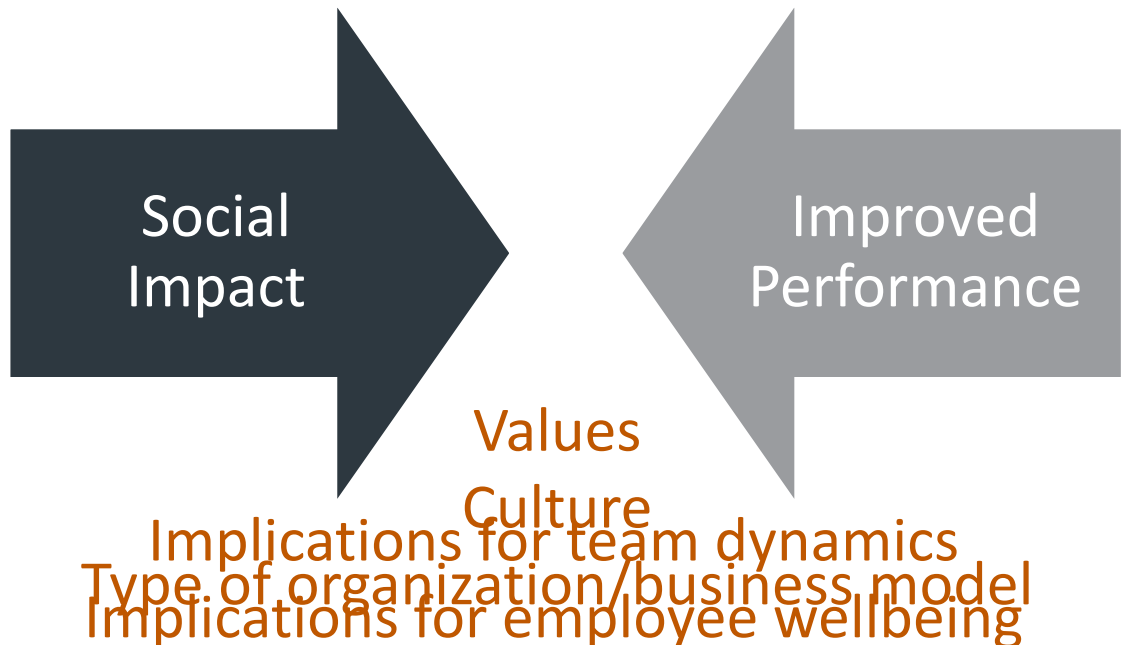
Findings

Catalysts & objectives

Measure
ment &
evaluation

Methods &
practices

- ✓ Established systematic evaluation
- ✓ Use specific metrics to measure impact



Open Questions

Catalysts & objectives



Measure
ment &
evaluation

Methods &
practices

- ✓ 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

4:15

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

- Nicolaidis, C, Raymaker, D et, al. (2013) Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *J Gen Intern Med* 28(6):761–9

- **Nancy Cheak-Zamora, Ph.D.**

Associate Professor, University of Missouri-Columbia

- Cheak-Zamora NC, et al. (2017) Exploration and Comparison of Adolescents With Autism Spectrum Disorder and Their Caregiver's Perspectives on Transitioning to Adult Health Care and Adulthood. *J Pediatr Psychol*, Oct 1;42(9):1028-1039.

- **Gale Whiteneck, Ph.D., F.A.C.R.M.**

Principal Investigator, Craig Hospital Research Department

- Whiteneck G, Dijkers MP. (2009) Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Arch Phys Med Rehabil*, 90(11 Suppl 1):S22-35

- **Mark Salzer, Ph.D.**

Professor of Social and Behavioral Sciences, Temple University

- Thomas, E. C., Snethen, G., & Salzer, M. S. (2017). A developmental study of community participation of individuals with serious mental illnesses: Implications for policy and practice. *American Journal of Orthopsychiatry*, 87(5), 597-605.

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

Question 2: Biology



Apr 2018

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



Feb 2019

Pathological priming causes developmental gene network heterochronicity in autistic subject-derived neurons.

Schafer ST, Paquola ACM, Stern S, Gosselin D, Ku M, Pena M, Kuret TJM, Liyanage M, Mansour AA, Jaeger BN, Marchetto MC, Glass CK, Mertens J, Gage FH

Question 3: Risk Factors



JAMA Psychiatry

Mar 2019

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

Al-Haddad BJS, Jacobsson B, Chabra S, Modzelewska D, Olson EM, Bernier R, Enquobahrie DA, Hagberg H, Östling S, Rajagopal L, Adams Waldorf KM, Sengpiel V

Annals of Internal Medicine

Mar 2019

Measles, Mumps, Rubella Vaccination and Autism: A Nationwide Cohort Study.

Hviid A, Hansen JV, Frisch M, Melbye M

Question 3: Risk Factors



JAMA Psychiatry

Feb 2019

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

European
Child + Adolescent
Psychiatry

Official Journal of the European Society for Child and Adolescent Psychiatry

Feb 2019

Increased risk of ADHD in families with ASD

Septier M, Peyre H, Amsellem F, Beggiato A, Maruani A, Poumeyreau M, Amestoy A, Scheid I, Gaman A, Bolognani F, Honey G, Bouquet C, Ly-Le Moal M, Bouvard M, Leboyer M, Bourgeron T, Delorme R

Question 4: Treatments and Interventions



Journal of the American Academy of
CHILD & ADOLESCENT
PSYCHIATRY

Jan 2019

A Multisite Randomized Controlled Two-Phase Trial of the Early Start Denver Model Compared to Treatment as Usual.

Rogers SJ, Estes A, Lord C, Munson J, Rocha M, Winter J, Greenson J, Colombi C, Dawson G, Vismara LA, Sugar CA, Helleman G, Whelan F, Talbott M

Question 5: Services



AUTISM
RESEARCH January, 2017 | Volume 10 | Number 1

Mar 2019

Treatment patterns in children with autism in the United States.

Monz BU, Houghton R, Law K, Loss G

Question 6: Lifespan Issues



AUTISM
RESEARCH
January, 2017 | Volume 10 | Number 1

Apr 2019

A 20-year study of suicide death in a statewide autism population.

Kirby AV, Bakian AV, Zhang Y, Bilder DA, Keeshin BR, Coon H

*Journal of Autism
and Developmental Disorders*

Mar 2019

Use of Vocational Rehabilitation Supports for Postsecondary Education Among Transition-Age Youth on the Autism Spectrum.

Rast JE, Roux AM, Shattuck PT

Question 6: Lifespan Issues



*Journal of Autism
and Developmental Disorders*

Mar 2019

Competitive Employment for Transition-Aged Youth with Significant Impact from Autism: A Multi-site Randomized Clinical Trial.

Wehman P, Schall C, McDonough J, Sima A, Brooke A, Ham W, Whittenburg H, Brooke V, Avellone L, Riehle E



Round Robin



Adjournment

Next IACC Meeting



Wednesday, July 24th 2019