Meeting of the Interagency Autism Coordinating Committee

Thursday, April 19, 2018

Bethesda Marriot Hotel
5151 Pooks Hill Road
Congressional Room
Bethesda, MD 20814

Conference Call Access:
Phone: 800-857-9791
Access Code: 8959122
Meeting of the IACC

Morning Agenda

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

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

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

9:10  Report from the HHS National Coordinator

Ann Wagner, Ph.D.
HHS National Autism Coordinator and Chief, Biomarker and Intervention Development for Childhood-Onset Mental Disorder Branch Division of Translational Research National Institute of Mental Health
Meeting of the IACC

Morning Agenda - continued

9:15    Panel on Employment for People on the Autism Spectrum

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

Jose Velasco, M.S.
Vice-President of Operations and Strategy Global Co-Lead, Autism at Work SAP

Marjorie Madfis, M.B.A.
Yes She Can, Inc.
Meeting of the IACC

Morning Agenda - continued

Panel on Employment for People on the Autism Spectrum

Lori Ireland, M.B.A.
Co-Founder and Board Member
Extraordinary Ventures

Paige Morrow
Managing Director
Extraordinary Ventures

11:00 Morning Break
Meeting of the IACC

Morning Agenda - continued

11:15 Committee Business

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

Joshua Gordon, M.D., Ph.D.
Director, NIMH 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
Report from the HHS National Autism Coordinator

Ann Wagener, Ph.D.
HHS National Autism Coordinator and Chief, Biomarker and Intervention Development for Childhood-Onset Mental Disorder Branch
Division of Translational Research
National Institute of Mental Health
Interagency Autism Coordinating Committee
April 2018 Public Meeting

Increasing Employment Access for Youth and Adults on the Autism Spectrum

Office of Disability Employment Policy
U.S. Department of Labor

Scott Michael Robertson, PhD
Policy Advisor

April 19, 2018
ODEP Seeks to Increase Employment Access for Americans with Disabilities

Only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities

- **Mission**: Develop and influence policies that increase the number and quality of employment opportunities for people with disabilities
- **Vision**: A world in which people with disabilities have unlimited employment opportunities
ODEP’s Current Priorities Include...

- Implementation of the Workforce Innovation and Opportunity Act of 2014 (WIOA)
- Employer Engagement
- Inclusive Apprenticeship and Work-Based Learning
- Career Pathways for Youth and Adults
- Employment First
- Return to Work/Stay at Work
- TA to States on Employment Policy and Practices
- Accessible Workplace Technology and Transportation to Work, including Transportation Technology Innovation
Hiring People with Disabilities Bolsters Large, Medium, and Small Businesses

• 2018 systematic review (20 years of research)¹:
  – Improvements in profitability (profits, retention rate, reliability, company image, etc.)
  – Enhancements to competitive advantage (innovation, work ethnic, productivity, customer loyalty, etc.)
  – Inclusive work cultures and awareness of diverse abilities to enhance workplaces

• Benefits of workplace accommodations to employers far outweigh the relatively low cost²
Neurodiversity Benefits Employers

2017 Australian study\(^3\) (survey) of 59 employers regarding their employees on the autism spectrum:

- Above average performance: attention to detail, work quality, and work ethic
- 56\% of employers report positive adaptations in workplace culture
- 32\% of employers report new creative and different skills brought to the workplace
- 24\% report improvements in workplace morale
- No significant additional costs to employers
Job Seekers on the Autism Spectrum Have Untapped Skills and Talents

• Diverse focused interests foster specialized talents supporting employment opportunities

• Strengths, skills, and talents enhance employers’ performance, missions, and bottom lines

• Supports can help tap skills and talents
Key Facilitators Bolster Employment for People on the Autism Spectrum

• Disability trainings for staff, including focuses on autism
• Trained coaches, mentors, team buddies, etc.
• Enhanced hiring and onboarding processes
• Technological aids
• Individualized workplace trainings in multiple areas
• Customized long-term supports for sensory/motor, social, communication, and executive functioning challenges
• Workplace supports, including for transit to work and executive functioning for tasks to secure accommodations
ODEP Provides Resources on Autism

• ODEP’s webpage on autism (for employers, service providers, policymakers, individuals, and youth: https://www.dol.gov/odep/topics/Autism.htm

• Job Accommodation Network (JAN):
  – http://askjan.org | 800-526-7234
  – assistance for employers, employees, job seekers, etc.
  – JAN’s webpage on autism (accommodations, interviewing tips): https://askjan.org/media/autism.htm
DOL Supports Autism-Related Initiatives

• ODEP’s Pathways to Careers Demonstration Grants
  – Universal Pathways to Employment (UPEP) project at Pellissippi Community College (Knoxville, TN)
  – Onondaga Pathways to Careers (OPC) project at Onondaga Community College (Syracuse, NY)

• Employment and Training Administration (ETA) grants for job development and training
ODEP’s Pathways to Careers Grants Include Students on the Autism Spectrum

• Prioritize work-based learning, accommodation access, and persistence to degree completion
• Integrate Universal Design for Learning
• Support youth and young adults with disabilities who are aged up to 24
• Include a high % of students on the autism spectrum:
  – UPEP: 35% of participants identify on the autism spectrum
  – OPC: 19% of participants identify on the autism spectrum
ETA’s Grants for Job Development Support Autism-Related Initiatives

- **Tech Hire grant to Exceptional Family Center (5 yrs.)**
  - Supports Next Step Job Training and Employment Partnership in 3 California counties
  - Plans to foster job development and training for an anticipated 450 people on the autism spectrum in healthcare, IT fields

- **American Apprenticeship grant to AHIMA Foundation (5 yrs.)**
  - Supports Managing the Talent Pipeline in Health Information Apprenticeship program
  - Incorporates a medical coding apprenticeship for people on the autism spectrum
References


References (Cont.)


About Autism

Autism Spectrum Disorder (ASD) is a developmental disorder that impairs the ability to communicate and interact.

**Impact**

1/42 Boys and 1/189 Girls according to CDC

**Unemployment**

85% of people diagnosed with autism spectrum disorders are unemployed even though 60% have average to above average cognitive abilities. Many people who are employed are under-employed or partially employed.

**Opportunity**

50,000 Unfulfilled STEM jobs in the Bay Area alone
Is Bias Getting in the Way?

Failure to make eye contact can alienate hiring managers.

Establishing eye contact builds essential rapport. But eye contact isn’t the only must-have attribute.

Other interview killers are the failure to smile, bad posture, inappropriate clothing, too much fidgeting, a weak handshake, playing with hair or face, or arms crossed over the chest.
Why do we Hire People with Autism?

- Attract the Best Talent in Our Industry
- Bring a Different Perspective to Our Creative Process
- Tap into Underutilized Source of Talent
- Capture Special Skills of People with ASD
- Retention
- Because we CAN
10 Countries
Argentina, Australia, Brazil, Canada, China, Czech Republic, India, Ireland, Germany, U.S.

Currently, 132 Employed
Full and Part Time Jobs, Internships, Contractors, Vocational School (in Some Countries)

A Total of 300 Opportunities
Present and Past Paid Opportunities + HS/College Training Opportunities
21 Roles

- Software Developer
- Information Developer/KM
- Software Tester
- Business Analyst
- IT Technical Support
- System Administrator
- Marketing Operations Associate
- Networking Specialist
- Procure-to-Pay Service Associate
- Development Associate Consultant
- HR Service Associate
- IT Project Management
- Customer Support Associate
- Graphic Designer
- Multimedia Specialist
- Employee Communications
- Data Analyst
- Associate Consultant
- Product Manager
- Finance Operations Associate
- Channel Sales Development
Roadmap

2013     2015     2016     2017     2019     2020     ...

LEARN VIA PILOTS AT LOCATIONS WORLDWIDE

PROCESS MAINSTREAMING & SUSTAINABILITY

PROCESS MATURITY ONBOARDING EQUIVALENCY

Change Management

Mainstreaming Best Practices
Implementation
Our Partners

GLOBAL

Argentina
Brazil
Czech Republic
Germany
India
U.S.
High Level Process

1. Position Search
   - Requisitions
     - Developers
     - Software Testers
     - ...
   - Candidate Search via
     - Partners
     - SAP
     - Universities, Colleges
   - Pre-Screening
     - Phone Interviews
     - References
   - 4+ weeks

2. Candidate Search & Pre-Screening
   - Candidate Search via
     - Partners
     - SAP
     - Universities, Colleges
   - Pre-Screening
     - Phone Interviews
     - References
   - 4+ weeks

3. Soft Skills Training
   - 1-Week Soft Skills
     - Social
     - Communications
     - Interviewing
     - Disclosure
     - ...
   - 2 weeks

4. Pre-Emp. Training
   - For Candidates
     - 5 Weeks Training
     - Awareness Training (extended)
     - Autism Awareness (Brief)
   - For Host Teams
     - Awareness Training (extended)
   - For Other Employees
     - Autism Awareness (Brief)
   - 5 weeks

5. Onboarding
   - Admin
     - Forms / Paperwork
     - Facilities / IT
     - Managers / Job Coach Comm. Plan
     - Support Circle Prep
   - 3+ weeks
Impact on Talent

Patrick  Janis  Mark
Thank you
Yes She Can
DEVELOPING JOB SKILLS FOR YOUNG WOMEN WITH AUTISM.

NIH Interagency Autism Coordinating Committee

MARJORIE MADFIS, PRESIDENT
APRIL 19, 2018
Introduction

- Marjorie Madfis
- Parent of 22 year-old daughter with ASD
  - diagnosed at age 2.6
  - advocate for inclusion
- Professional background
  - Economic Development, public sector
  - MBA
  - 30 year career in corporate marketing
  - Founded Yes She Can nonprofit in November 2013
Characteristics of Successful Employees

- Motivated and ability to persevere
- Good social communication skills
- Problem solving skills
- Cognitive and emotional adaptability
- Flexibility
- Good emotional regulation

All these characteristics are core challenges for people with ASD
Are transitioning adults prepared?

<table>
<thead>
<tr>
<th></th>
<th>Special Ed.</th>
<th>Workplace</th>
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<tbody>
<tr>
<td><strong>Support</strong></td>
<td>Teacher and TA</td>
<td>Peers</td>
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<tr>
<td><strong>Goal</strong></td>
<td>Right answer</td>
<td>Solutions to problems</td>
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<tr>
<td></td>
<td>No melt down</td>
<td></td>
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<tr>
<td><strong>Organization</strong></td>
<td>Structured, Predictable</td>
<td>Flexible, Fluid, Hidden</td>
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<td>rules</td>
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<td><strong>Approach</strong></td>
<td>Independent</td>
<td>Collaboration, Discretion</td>
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<tr>
<td><strong>Communication</strong></td>
<td>Selective, Dependent</td>
<td>Necessary, Initiate</td>
</tr>
<tr>
<td><strong>Intensity</strong></td>
<td>50-minute class, breaks</td>
<td>until it is done</td>
</tr>
</tbody>
</table>

© 2017 Yes She Can Inc.
Change the model: Teach from a business perspective

- Tasks with a reason - why
- Process – how to get things done
- Problem-solving – no clear rule
- Dealing with uncertainty
- Collaborative decision-making
- Understanding shifting priorities
- Responsibility and commitment
- It’s not about you- it’s about the customer or the manager
Program & Curriculum
Skilled staff
Operating business

Product supply:
Donated American Girl dolls and accessories

Market demand:
Customers for dolls at lower prices; collectors

Employment
Independence
Advocacy
Program target participants

- Women with ASD and related social, language and learning disabilities
  - ultimate goal of employment
    - supportive, independent, part-time or full-time
- High school
  - Last year
- High School grads
  - Not engaged
- College students
  - No work experience
Key Differentiators

- Immersive learning design, with professional staff
- Social workers, psychologists, business executives
- Communication skills practiced in safe, integrated setting
- “The Hidden Curriculum” directly taught
- Self-Advocacy
- Direction and feedback from manager
- Individualized goals
- Assessment process
What we are teaching: business

Merchandising
- Assess, research, price, inventory

Sales
- Communicate, selling, transactions

Marketing
- Customer database
- Social media, web e-commerce

Administration
- Quick Books
- Store maintenance
What we are teaching: how to work

- Information-gathering
- Recommendations with rationale
- Negotiating
- Decision-making
- Collaborating with peers
- Answering to management
- Problem-solving for business needs
What we are teaching: how to interact

- Perspective-taking
  - business objectives
  - manager expectations
- Interacting with customers
- Sensitivity to others
- Appropriate conversation
- Collaborating with co-worker
- Participation in team meetings
What we are teaching: emotional regulation

- Accountable for own actions
- Cooperative and courteous
- Motivation
- Execute “non-preferred” tasks
- Sustain attention and pace
- Accept critical feedback
- Strategies to deal with frustration
Team meeting
Case study: Maki

- Graduated 4-year college 2015; with support
- Lives at home, Independent travel, bi-lingual
- VR: 1 year to find job; placed in job at job developer’s agency
- Working now 15 hours per week, paid by VR

After enrolled in program for 18 months, 6 hr/week

Change over last 4 months

<table>
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<tr>
<th>Skill Category</th>
<th>Base Score</th>
<th>Post Score</th>
<th>Pre Score</th>
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<tr>
<td>Self-Advocacy Skills</td>
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<tr>
<td>Technical Skills</td>
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<tr>
<td>Social Emotional Skills</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>General work skills</td>
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</tbody>
</table>
Case study: Isabelle

- Completed high school, no diploma; work experience program
- Lives at home, para-transit
- Attends college / transition program 20 hr/week with mentors

Coaching 2 hr/week; involved from beginning

Change over last 4 months:
Assessment outcomes

- At work: all had improvements in
  - Flexibility
  - Stamina
  - Appropriate social engagement
  - Ability to accept critical feedback

- At home: parents observed
  - Increased independence
  - Engaged in decision-making, offering suggestions
  - Taking more responsibility
  - Greater self-confidence
Findings

- Intellect or academic attainment does not predict success
- Learn tasks quickly, particularly computer and digital
- Limiting factor: Lack of perspective
  - Leads to inflexible
  - Leads to anxiety
- No one likes being autistic
  - “Why was I cursed with autism”
- Isolated, no other options
  - Girl AGain is the highlight of their week
  - Depression

Izzie, go help the customer

Not now. I’m busy.
Observations

- VR provider agencies don’t “get” autism
- OPWDD – rejects 80% for “employment training program”
  - Cake needs to be baked before going into the oven
- Job developers should work with smaller businesses
  - Flexibility: No HR or legal department
  - Identify opportunities to help company be more efficient
- Businesses need training
  - Afraid of behaviors, burdens
- Technology to support more independence at work
  - Develop solutions
  - Business buy-in and use
Video

https://www.youtube.com/watch?v=10EM6g8C7Oc
Thank you

Women with autism. We work. With you.

© 2017 Yes She Can Inc.
Organization

Incorporated in New York, November, 2013

IRS tax exempt designation  501c3    EIN 46-4224215

Executive Director:  Marjorie Madfis, MBA

Yes She Can Inc. office
35 Hubbard Drive
White Plains, NY 10605
◦ 914-428-1258
◦ YesSheCanInc.org
◦ info@YesSheCanInc.org

Girl AGain boutique
4 Martine Avenue
White Plains, NY 10606
◦ 914-358-1460
◦ GirlAGain.com

Donate
donate dolls
Back up
As a result of specific challenges for individuals with ASD, employment outcomes are poor.

Full-Time Employment (21-25 Year Olds)

(NLTS2 Study; Roux et al., 2013)
Who is focused on employment?
Autism Employment Models

- **Agency managed**
  - Employment
  - SAARC: Beneficial Beans
  - Ability Beyond: Roses for Autism

- **Family created**
  - For profit or non-profit
  - Goal: Long-term employment
  - Extraordinary Ventures (NP)
  - Rising Tide Car Wash (P)
  - Spectrum Designs (NP)
  - Autonomy Works (B corp.)

- **Training for competitive placement**
  - Yes She Can Inc. (Girl Again)

- **Competitive differentiation**
  - Ultra Testing
  - SAP

- **Supported employment at conventional business sites**
  - VR agency placements
  - DD agency placements

- **Business with design to employ people with DD**
  - Walgreens
Yes She Can Impact

Vision of need

Program creation and test (Girl AGain Hartsdale)

Program expansion (Girl AGain White Plains)
  • Training
  • Social
  • Placement

Yes She Can program implementation in multiple locations, businesses; placement

Meaningful Employment for Adults with Developmental Disabilities

Lori Ireland, M.B.A.
Co-Founder and Board Member
Extraordinary Ventures

Paige Morrow
Managing Director
Extraordinary Ventures
Morning Break
Thanks 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

Karen Mowrer, Ph.D.
Science Policy Analyst

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

Matthew Vilnit, B.S.
Operations Coordinator

Jeff Wiegand, B.S.
Web Development Manager
April is National Autism Awareness Month
NIMH Special Event for Autism Awareness Month

The Story Behind Julia, Sesame Street’s Muppet with Autism
April 9, 2018

- Panel presentation featuring speakers from Sesame Workshop, the nonprofit educational organization behind Sesame Street
- Meet-and-greet with a costumed Julia character


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Autism Awareness Month News

• 2018 Presidential Proclamation: [President Donald J. Trump Proclaims April 2, 2018, World Autism Awareness Day](#)

• 2018 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, 2018; Bethesda, MD

• Empowering Women and Girls with Autism
  *United Nations*
  April 5, 2018; New York, NY
  Archived video available: [https://www.youtube.com/watch?v=Tyhm7p8Gr2A](https://www.youtube.com/watch?v=Tyhm7p8Gr2A)

• Developing Individuals Who Have Different Kinds of Minds,
  featuring Temple Grandin, Ph.D.
  *National Institute of Environmental Health Sciences*
  April 12, 2018; Research Triangle Park, NC
  Archived video will be available: [https://videocast.nih.gov](https://videocast.nih.gov)
2017 Summary of Advances

- Annual publication – 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
- Covers articles aligning with all seven Strategic Plan Question areas

https://iacc.hhs.gov/publications/summary-of-advances/2017
2016 ASD Research Portfolio Analysis

- OARC is currently analyzing data for the 2016 IACC ASD Research Portfolio Analysis Report
- Using 2016 data, OARC/NIMH/NIH, Autistica (UK), and the Canadian government are planning to collaborate to produce the first International Autism Research Portfolio Analysis Report
  - Preliminary results of this analysis will be presented at the INSAR Annual Meeting, May 2018
  - Hope to stimulate broader international participation in future years
Autism CARES Act Report to Congress

• Report details progress on activities related to ASD and other developmental disorders across the federal government (required by the Autism CARES Act)

• OARC is coordinating preparation of the Report

• Requests for data have been received from relevant federal agencies

• Report expected in Fall 2018
Improving Health Outcomes for Individuals on the Autism Spectrum WG

- The IACC is in the process of convening a working group on health and wellness issues
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor
- Scope
  - General health and wellness for individuals with ASD
  - Co-occurring conditions and preventative approaches to address them, e.g. obesity
  - Co-occurring mental health conditions
  - Long-term medication use
  - Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
  - Patient-provider interactions
  - Medical practitioner training
  - Parental/family mental health
  - Reproductive/maternal health care

These slides do not reflect decisions of the IACC and are for discussion purposes only.
Improving Health Outcomes for Individuals on the Autism Spectrum WG

Next steps

• Working Group workshop in Summer 2018
  • Select 1-2 topics from:
    • General health and wellness for individuals with ASD
    • Co-occurring conditions and preventative approaches to address them, e.g. obesity
    • Co-occurring mental health conditions
    • Long-term medication use
    • Premature mortality (e.g. epilepsy, suicide, chronic health conditions)
    • Patient-provider interactions
    • Medical practitioner training
    • Parental/family mental health
    • Reproductive/maternal health care

These slides do not reflect decisions of the IACC and are for discussion purposes only.
2018 Summary of Advances Discussion

IACC Full Committee Meeting
April 19, 2018

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

Joshua A. Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC
Parent and clinician agreement regarding early behavioral signs in 12- and 18-month-old infants at-risk of autism spectrum disorder.
Neuron numbers increase in the human amygdala from birth to adulthood, but not in autism.
Avino TA, Barger N, Vargas MV, Carlson EL, Amaral DG, Bauman MD, Schumann CM

Overlapping and Distinct Cognitive Impairments in Attention-Deficit/Hyperactivity and Autism Spectrum Disorder without Intellectual Disability.
Karalunas SL, Hawkey E, Gustafsson H, Miller M, Langhorst M, Cordova M, Fair D, Nigg JT
Question 3: Risk Factors

**Shared molecular neuropathology across major psychiatric disorders parallels polygenic overlap.**

**Air Toxics in Relation to Autism Diagnosis, Phenotype, and Severity in a U.S. Family-Based Study.**
Nevill RE, Lecavalier L, Stratis EA
Question 5: Services

Effects of State Autism Mandate Age Caps on Health Service Use and Spending Among Adolescents.

Rubenstein E, Daniels J, Schieve LA, Christensen DL, Van Naarden Braun K, Rice CE, Bakian AV, Durkin MS, Rosenberg SA, Kirby RS, Lee LC
Vaccination Patterns in Children After Autism Spectrum Disorder Diagnosis and in Their Younger Siblings.
Question 6: Lifespan Issues

(There were no nominations covering Question 6 topics from January – April 2018)
Question 7: Infrastructure and Surveillance

(There were no nominations covering Question 6 topics from January – April 2018)
Lunch
Meeting of the IACC

Afternoon Agenda
1:00 Public Comment Session

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

Oni Celestin, Ph.D.
Science Policy Analyst, Office of Autism Research Coordination, NIMH
2:45 Aggression and Self-Injury: Research Needs for the Severely Affected End of the Spectrum

Matthew Siegel, M.D.
Director, Autism & Development Disorders Inpatient Research Collaborative (ADDIRC)
Maine Medical Research Institute
Vice President Medical Affairs
Developmental Disorders Service
Maine Behavioral Healthcare
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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<tr>
<td>3:15</td>
<td>Committee Discussion</td>
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<tr>
<td>4:00</td>
<td>Afternoon Break</td>
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<tr>
<td>4:15</td>
<td>Round Robin</td>
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<tr>
<td>5:00</td>
<td>Closing Remarks and Adjournment</td>
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</table>
Oral Public Comment Session

Joshua 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
National Institute of Mental Health
Background

- Accept vs. Afraid
- Limitations
  - Policy
  - Funding
  - Access
- Where do aggressions come from?
Carson

- Big guy - The Mancub
- 95% teddy bear - 5% tiger
- No easy fix
  - Medication
  - Behavioral interventions
Self-injury
Biting
Biting
Pinching
Destruction of property
What is the answer?
Let’s do this thing!

- Quality life skills day program - Pingree Autism Center
  - Academics
  - Library
  - Culinary
  - Agriculture
  - Arts & Crafts
  - Fitness Education
  - Home Living
  - Vocational Training
  - Social & Leisure Skills
Road Blocks...

Medicaid Settings Rule

[Image: Cartoon of a person facing a maze with a sign that says "AUTISM INTERVENTIONS THIS WAY"]
Autism never sleeps, it doesn’t go on vacation, it’s there on Sunday’s and holidays, it never takes a day off.

Autism never takes a break
Therefore...neither can we!

Thank you

Cheryl and Carson
Oral Public Comment Session

Joshua 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
National Institute of Mental Health
Written Public Comment Session

Joshua 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
National Institute of Mental Health
AGGRESSION AND SELF-INJURY: RESEARCH NEEDS FOR THE SEVERELY AFFECTED END OF THE SPECTRUM

Matthew Siegel, M.D.
Associate Professor of Psychiatry & Pediatrics
Tufts University School of Medicine
VPMA, Developmental Disorders Service
Maine Behavioral Healthcare
Faculty Scientist II
Maine Medical Center Research Institute
## DISCLOSURES

<table>
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<th>Source</th>
<th>Clinical Advisor</th>
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<tr>
<td>NIMH, Simons Foundation, NLM Family Foundation</td>
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<tr>
<td>Camp Alsing</td>
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</table>
Aggression and self injury – prevalence and impacts
Multi-disciplinary approaches to serious challenging behaviors
Studying the severely affected: The Autism Inpatient Collection (AIC)
Novel approach to challenging behaviors
Critical areas for further research
“My son is 19. Severely autistic. Can’t speak. Getting more and more aggressive !!! Not only bites his wrist, he bangs walls and breaks things, and then comes after us. I can’t keep locking myself in a room because he will bang the door down... No doctor in our area knows anything of what to do...Please, please I’m reaching out. There must be something for him...not fair for me and most certainly not fair to him! Cry for help!”
Aggression Prevalence & Impacts

- Up to 2/3 of youth with ASD develop aggression
  - Kanne SM, Mazurek MO. J Autism Dev Disord. 2011

- Aggression is one of the primary reasons youth with ASD use behavioral healthcare services

- Families report that aggression is often of greater concern and negative impact than the core social and communicative deficits that define ASD
  - Farmer CA, Aman MG. Res Autism Spectr Disord. 2011

- Studies in ASD suggest that broadly-defined problem behaviors are heightened in ASD compared to typically developing (TD) and intellectually disabled (ID) samples; further, some ASD subgroups engage in persistent or increasing problem behaviors into adulthood.
Particularly for the minimally verbal

Inability to efficiently report distress makes aggression seem to occur “out of the blue.”

- Results in:
  - Caregivers unable to anticipate an aggressive outburst
  - Increasingly restrictive educational settings or exclusion
  - Inability to access community
  - High utilization of psychotropics, hospitalizations, out of home placements
  - Limits opportunities for real-time prevention (calming strategies, de-escalation techniques, functional communication)

The unmeasured effect of serious problem behaviors is a bending of the developmental trajectory downward
Developmental Disorders Service
Maine Behavioral Healthcare

Spring Harbor Hospital DD Unit,
Spring Harbor Academy, Day Treatment,
Outpatient Clinic, Autism Research Team
Aggression is a final common pathway symptom.
FOUNDATION OF TREATMENT

- Highly individualized behavioral plan with embedded communication and occupational therapy supports
- Targeted psychopharmacology
- Transfer of management skills to parents, local school, in-home staff
MULTI-DISCIPLINARY TREATMENT TEAM

- Child Psychiatry and Pediatrics
- Behavioral Psychologist
- Behavioral Coordinator (BCBA)
- Special Education
- Speech Pathologist
- Occupational Therapist
- Nursing
- Social Work
- Milieu Coordinator (OT)
THERAPEUTIC APPROACHES FOR CHALLENGING BEHAVIORS

- Applied Behavioral Analysis
- Psychotropic Medication
- Communication strategies (AAC/Functional Communication)
- Treat Medical Problems
- Family treatment
- Parent Management Training (RUBI)
- Sensory regulation strategies
- Social skills / social cognitive strategies
- Psychotherapy approaches – CBT / Emotion regulation

30% of functional behavioral assessment studies are inconclusive about behavioral function

Significant side effects and inconsistent success
- Siegel M & Bealieu, A, JADD, 2011
Figure 1. Estimated Marginal Means of Abberant Behavior Checklist Irritability (ABC-I) Subscale Between Children with and without Autism Spectrum Disorder (ASD) Over Time
Knowledge & treatment options continue to lag for those with autism who are non-verbal, have an intellectual disability and/or display challenging behaviors; under-represented in current, large data collections

- Communication: 30-50% do not develop functional verbal communication.
- Cognitive: 20-40% of individuals with Intellectual Disability (FSIQ<70)
- Behavioral: 20-30% with lifetime incidence of serious challenging behaviors

High volume of individuals - in a unique position to efficiently collect large amounts of data and improve understanding of this understudied portion of the ASD population

Inpatient setting an ideal platform to identify mechanisms underlying emotional and behavioral symptoms to inform treatment. Unique ability to study challenging behaviors in situ due to safety of inpatient environment and control over environmental factors
Autism Inpatient Collection

- Goals: Standardized assessment, description of the population, resource for all investigators, research platform for measure development, mechanistic studies and treatment studies.

- To date, enrolled over 1000 probands and their biological parents

- Rigorous core assessment battery and ASD diagnostic reliability

- 48% minimally verbal, 42% Intellectual Disability (NVIQ <70; Molc Aut, 2015)

- Whole exome sequencing to be performed 2018-19

- Data available to approved investigators through SFARIbase

- On-line community to facilitate recontacting through
SFARI Base is a central database of phenotypic and genetic information about families affected by autism and other neurodevelopmental disorders, provided as part of the Simons Foundation Autism Research Initiative (SFARI). It contains data from the following cohorts:

- Simons Simplex Collection (SSC)
- Simons Variation in Individuals Project (Simons VIP)
- Simons Foundation Powering Autism Research for Knowledge (SPARK)
- Autism Inpatient Collection (AIC)
Predictors of Psychiatric Hospitalization

Psychotropic Medication Use

AIC Methods

Problem behaviors and verbal ability

Talking about death or suicide

Expression of Trauma

Verbal ability and psychiatric symptoms

Development of the EDI

Sleep and caregiver stress

Best practices for inpatient treatment

Risk factors for Self-injurious behavior

Sleep and problem behavior

Anxiety

Parent stress and problem behavior

Health disparities
AIC: Change in Problem Behaviors

ABC-I Scores, n=350

- Significant reduction in problem behavior scores from admission to discharge, and 2-month follow-up (p≤0.05)
- Admission: 29.7(9.6)
- Discharge: 15.0(10.3)
- 2-Month Follow Up: 19.3(10.3)

- Pedersen K, et al., JADD, 2017
RYAN – THE NEED FOR NOVEL APPROACHES
IN HOSPITAL

Ryan O's Aggression Over Stay 2011

# of Occurrences

Days


AGG  Last 14  Days  Linear (Last 14  Days)
Due to his inability to manage his emotions and communicate, he attacks us when he becomes agitated or stressed. This behavior is very unpredictable and often occurs with little to no warning signs. It has happened in our home, his school, in the community and sometimes while driving a car. It is so bad that we can no longer safely live in our home with Ryan.”

-Wendi
In typically developing youth, greater ability to modulate physiological arousal is associated with fewer behavior problems. - Calkins SD. Dev Psychobilly. 1997; Porges, S.W. Dev Psyche; 1996

Association between physiological arousal and problem behavior in ASD


Hypothesis: Individual with ASD engages in a problem behavior as an attempt to alleviate distress and reestablish physiological homeostasis.
Heart Rate Movement

Baseline Arousal Increase (Antecedent)

Challenging Behavior Arousal Decrease (Consequence)

Baseline Arousal Decrease (Antecedent)

Challenging Behavior Arousal Increase (Consequence)

Figure by Matthew Goodwin, PhD
CONCEPTUAL MODEL

- Triggering stimulus
- Autonomic equilibrium
- Distress
- Physiological arousal
- Variable emotion regulation in ASD
- Aggression
- Non-aggression
TRANSFORMING THE TREATMENT OF CHALLENGING BEHAVIOR – REAL TIME PREDICTION

1. Electrodermal activity (EDA)
2. Blood volume pulse (BVP)
3. Interbeat interval (IBI)
4. Accelerometry (ACC)
Pilot findings with 20 minimally-verbal inpatients

AUC values as a function of time to aggression, and signals used from past 3 minutes of data

- ~80 hrs of collection over ~70 naturalistic observation sessions
- Increasing accuracy as you increase # of signal streams utilized

ROC values for global and person-dependent models using all combined features from the past 3 minutes to predict the next 1 minute


CRITICAL UNMET RESEARCH NEEDS FOR THE SEVERELY AFFECTED

- Novel approaches to aggression and self injury that utilize objective, mechanistically-informed data
- Natural history of aggression and self-injury across the lifespan in ASD
- Validated, clinically practicable diagnostic tools for psychiatric co-morbidity
- Emotion regulation measurement and treatment
- Sleep biology and relationship to challenging behaviors
- Study of complex, real-world treatment packages (comparative effectiveness studies)
- Study of residential treatment and in-home behavioral services.
**Summary**

- Individuals with ASD can develop serious behavioral challenges, which can become more impairing than the ASD itself.

- Parents report it is the unpredictability and lack of warning that causes the greatest impairment.

- Aggression and self injury are under-researched, and their underlying biology not well understood, particularly in those who are minimally verbal or have intellectual disability.

- Pilot data from the AIC suggests that measurement of physiological arousal, combined with other data streams, can be used to predict the proximal onset of aggression.

- Critical need for novel research approaches to the assessment and treatment of aggression, self-injury and other problem behaviors, focusing on objective, biological mechanisms and measures.
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THANK YOU & DISCUSSION

SIEGEM@MAINEBEHAVIORALHEALTHCARE.ORG
Afternoon Break
Round Robin
Closing Remarks
Adjournment
Next IACC Full Committee Meeting

October 17, 2018
Location - TBD