

# Meeting of the Interagency Autism Coordinating Committee

January 18, 2023; 10:00 a.m. - 5:00 p.m. ET



**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination,  
NIMH, and Executive Secretary, IACC  
Acting National Autism Coordinator

# Welcome and Announcements



**Joshua Gordon, M.D., Ph.D.**

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# Virtual Meeting Etiquette



- Please keep microphones off unless you are speaking
- You are welcome to turn your cameras on when you are, speaking but may leave them off if you prefer.
- During discussion, please keep your comments brief (~1-2 minutes) to enable other members to have a turn speaking
- For Committee members that would like a comment read aloud:
  - Please send the text of your comment via Zoom chat function to the OARC Staff Member who is using the Zoom screen name "SEND COMMENTS HERE"
  - When it is your turn to be recognized, the OARC staff member will read your comment to the group.
  - Mr. Steven Isaacson from the OARC team will be reading member comments sent through the Zoom chat.
- Closed captioning is available in Zoom for Committee members and on Videocast for members of the viewing public.

# National Autism Coordinator Update

IACC Full Committee Meeting  
January 18, 2023

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**Susan Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Office of the NIMH Director  
National Institute of Mental Health



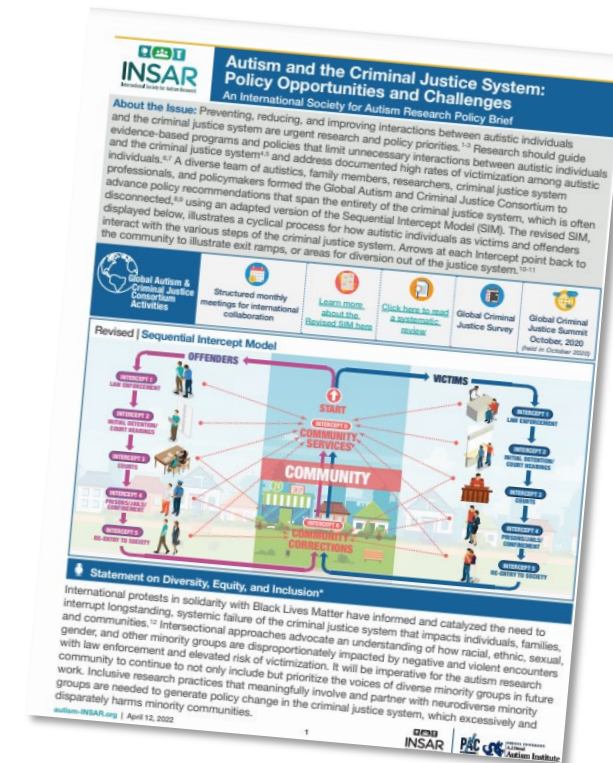
# Non-Governmental Updates

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- INSAR: Autism and the Criminal Justice System: Policy Opportunities and Challenges
- PCORI Awards UNC Researchers \$4 million to Evaluate Mental Health Interventions for Autistic Adults
- U.N. Secretary-General Statement for International Day of Persons with Disabilities
- Launch of the WHO Global Report on Health Equity for Persons with Disabilities

# INSAR: Autism and the Criminal Justice System: Policy Opportunities and Challenges

- With a grant from the International Society for Autism Research (INSAR), Drexel University's A.J. Drexel Autism Institute convened a consortium of international experts to explore ways to improve interactions between autistic individuals and the justice system.
- Recommendations of the consortium to improve the justice system were recently published in the INSAR policy brief, ***Autism and the Criminal Justice System: Policy Opportunities and Challenges***.
- The brief includes recommendations that are specific to different aspects of the justice system – community services, law enforcement, confinement and re-entry.
- [Document can be accessed here.](#)



# PCORI Awards UNC Researchers \$4 million to Evaluate Mental Health Interventions for Autistic Adults

- The **Patient-Centered Outcomes Research Institute** (PCORI) announced the approval of funding totaling \$96 million for 18 new research studies, including \$4 million for a study to assess which mental health intervention, either cognitive behavioral therapy (CBT) or mindfulness-based therapy, is the best fit for autistic adults.
- Dr. Brenna Maddox and Dr. Micah Mazurek will co-lead the study
- The researchers partnered with **Autistic Adults and other Stakeholders Engage Together** (AASET) to develop this proposal.
- This collaborative study aims to provide knowledge to help patients and clinicians select the most effective mental health intervention for autistic adults with depression and anxiety.
- [Press release can be found here.](#)



# U.N. Secretary-General Statement for International Day of Persons with Disabilities



**United  
Nations**

**International Day of Persons with  
Disabilities, 3 December**

- In his December 2022 message, UN Secretary-General António Guterres discussed the role of innovation and technology in achieving an accessible and equitable world. He also stated that the cornerstone of public-private cooperation toward this is the active participation of persons with disabilities in their full diversity, and their full inclusion in all decision-making processes.
- The [United Nations Disability Inclusion Strategy](#) presents a roadmap for advancing disability inclusion and accessibility globally.



# Launch of the WHO Global Report on Health Equity for Persons with Disabilities

- At the 74th World Health Assembly in May 2021, Member States adopted resolution WHA74.8 on [The highest attainable standard of health for persons with disabilities](#). The WHO Director General, was asked to develop a Global Report on the highest attainable standard of health for persons with disabilities by the end of 2022.
- In response, the **WHO Global Report on Health Equity for Persons with Disabilities** was developed in consultation with Member States and disability and health sector stakeholders.
- Report can be accessed [here](#).



# Federal Updates

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- White House
- Legislative Updates
- Interagency Committee for Disability Research (ICDR)
- RAISE Family Caregiving Advisory Council (FCAC)
- National Council on Disability (NCD)
- Federal Partners in Transition (FPT)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Federal Communication Commission Disability Advisory Committee (DAC)
- President's Committee for People with Intellectual Disabilities (PCPID)
- National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

# Federal Updates, continued

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- DOL Blog: COVID-19 and Employment Trends for People with Disabilities
- NIH Request for Information (RFI): Innovative approaches to prevent mental health problems and promote mental wellness in populations that experience health disparities

# White House

- President Joseph R. Biden issued a [Presidential Proclamation](#) to recognize the International Day of Persons With Disabilities on December 2, 2022.
- In his proclamation, he reaffirmed his administration's commitment to ensuring that people with disabilities are afforded opportunities, independence, and respect. He emphasized his Administration's support for equity in healthcare and employment, as well as disability rights and disability pride.



# Legislative Updates

- The newly approved [Consolidated Appropriations Act of 2023](#), includes funding towards autism and disability-related programs, such as the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, ED's IDEA grants for special education, DoD's Autism Research Program, grants under Kevin and Avonte's Law, and Medicaid's Money Follows the Person program that helps people move from institutions to community-based settings.
- Kevin and Avonte's Law was reauthorized with the passage of the [National Defense Reauthorization Act](#) on December 23, 2022. The program supports grants to protect children with autism and DD who wander.
- News articles: [Disability Scoop](#), [Autism Speaks](#), [Autism Society](#)



# Interagency Committee on Disability Research ([ICDR](#))

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## Managed by the Administration for Community Living

- All-federal committee established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
  - On [December 7, 2022](#), ICDR held an Executive Committee Meeting. The Committee heard updates from the GWI Work Group and the Disability Data & Statistics Work Group, which subsequently held its first meeting on December 12, 2022.
  - Following publication of ICDR's white paper on the [Impact of COVID-19 on Disability Research](#), the Committee published an [updated paper](#) in December 2022 that presents recent information on how the field of disability research has changed and adapted throughout the pandemic, highlighting important areas of new research and how the shift to virtual research methods has modified the research landscape.

# RAISE Family Caregiving Advisory Council ([FCAC](#))

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## Managed by the Administration for Community Living

- Federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support for family caregivers.
- Recent activities include:
  - ACL recently made their [2022 National Strategy to Support Family Caregivers](#) (the Strategy) available for public comment through November 2022. Details on a 2023 meeting are forthcoming.

# National Council on Disability ([NCD](#))

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- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- Recent activities include:
  - NCD released a report which examines weaknesses in the HCBS ecosystem, entitled [Strengthening the HCBS Ecosystem – Responding to Dangers of Congregate Settings During COVID-19](#). NCD found that about 14 million Americans of all ages need HCBS, with 40% being adults under 65 years old, and people younger than 30 years old making up the fastest growing nursing home population. Chairman Andres Gallegos says that severe worker shortages are compounding the large demand for services.



# Federal Partners in Transition ([FPT](#))

## Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 to facilitate exchange of information between federal agencies on transition-related issues for youth with disabilities.
- Recent activities include:
  - Members are continuing to work on developing a new Strategic Plan for transition age youth with disabilities.
  - The FPT Steering Committee met on December 15th, 2022.

# Interdepartmental Serious Mental Illness Coordinating Committee ([ISMICC](#))

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## **Managed by the Substance Abuse and Mental Health Services Administration**

- Federal advisory committee charged with addressing issues related to serious mental illness (SMI) and serious emotional disturbance (SED).
- Recent activities include:
  - The ISMICC met on October 28th at 10:00 a.m. ET. The full agenda is [here](#).

# Disability Advisory Committee ([DAC](#))

## Managed by the Federal Communications Commission

- Federal advisory committee that provides advice and recommendations to the Federal Communications Commission on a wide array of disability issues, including communications and video programming access.
- Recent activities include:
  - The previous iteration of the DAC held its [last meeting](#) on November 1<sup>st</sup>. The archived meeting is available online through [FCC Webcast](#).
  - The DAC will meet again this year in 2023 with new membership. This iteration will last until 2024.

# President's Committee for People with Intellectual Disabilities ([PCPID](#))

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## Managed by the Administration for Community Living

- An advisory committee that aims to provide advice and assistance to the President and the HHS Secretary on a broad range of topics that impact people with intellectual disabilities with the goal of improving the quality of life experienced by people with intellectual disabilities by upholding their full citizenship rights, independence, self-determination, and lifelong participation in their communities.
- No new updates since the July 28, 2022 meeting.

# National Advisory Committee on Individuals with Disabilities and Disasters ([NACIDD](#))

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## **Managed by the Administration for Strategic Preparedness and Response**

- The NACIDD advises the Secretary of Health and Human Services (HHS) on actions HHS can take before, during, and after disasters and emergencies to meet the unique needs of individuals with disabilities.
- No new updates since the August 4, 2022 meeting.

# COVID-19 and Employment Trends for People with Disabilities

## Blog Posting by the U.S. Department of Labor (DOL)

- As the economy continues to recover from setbacks related to the COVID-19 pandemic, people with disabilities have re-entered the labor force in greater numbers and have even surpassed the pre-pandemic level. This encouraging trend improves the historically persistent, substantial gaps between workers with and without disabilities. Structural changes in business practices prompted by the pandemic, such as greater flexibilities in work schedules and more opportunities to telework, may have opened additional opportunities for workers with disabilities who had fewer such opportunities in the past.
- [Read more here.](#)



# Innovative approaches to prevent mental health problems and promote mental wellness in populations that experience health disparities

- The National Institutes of Health (NIH) Advancing Prevention Research for Health Equity (ADVANCE) initiative is seeking public comment from community-based health and service providers and organizations on interventions or programs that prevent mental health problems or promote mental health wellness in populations that experience health disparities.
- Comments related to individuals with disabilities as a group that experiences health disparities are welcome, though not listed specifically in the announcement.
- Comments are due by **March 1, 2023** and [can be submitted here](#).



# IACC Committee Business

IACC Full Committee Meeting  
January 18, 2023



**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC



# Committee Business Overview



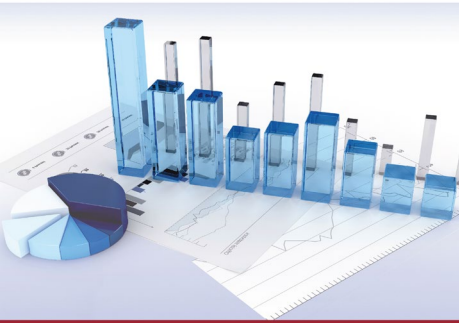
- IACC/OARC Portfolio Analysis Report
- *2021-2023 IACC Strategic Plan* Discussion
- *2022 IACC Summary of Advances* Discussion

# Update on the IACC Portfolio Analysis Report



INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

2019-2020 AUTISM RESEARCH  
PORTFOLIO ANALYSIS REPORT



OFFICE OF  
AUTISM RESEARCH  
COORDINATION  
NATIONAL INSTITUTE OF HEALTH

- The **IACC Portfolio Analysis Report**
  - Provides comprehensive information about autism research funding across federal agencies and private research organizations in the U.S.
  - Tracks progress towards *Strategic Plan* Objectives
  - Provides analysis of funding trends over time
  - Tracks progress towards the *IACC Strategic Plan* Budget Recommendation
  - Tracks funding towards special topics of interest, including research on autism in girls and women and research on racial/ethnic disparities.
- OARC is in the final stages of preparing the **2019-2020 IACC Portfolio Analysis Report**, planned to release in Spring 2023.
- OARC is also currently preparing the **2021 IACC Portfolio Analysis Report** for publication in late 2023/early 2024.

# ***2021-2023 IACC Strategic Plan Discussion***



**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

# The IACC Strategic Plan Charge



The **Autism CARES Act of 2019** requires the IACC to develop a **Strategic Plan** “for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals”

# Recap of the 2021-2023 IACC Strategic Plan Process



- ✓ October-November 2021: On behalf of the IACC, OARC collected input on the *Strategic Plan* from the general public in a Request for Information (RFI). Results of the RFI were presented at the January 2022 IACC Meeting.
- ✓ November 2021-March 2022: OARC collected survey input toward initial development of the *Strategic Plan* from IACC members. Survey results were presented/discussed at the April 2022 IACC Meeting.
- ✓ April-June 2022: OARC prepared the first draft of the *Strategic Plan* on behalf of the committee.
- ✓ July 2022: Strategic Plan Working Group Meeting was held. The first draft of the *Plan* was discussed and input collected by OARC.
- ✓ July 2022-September 2022 IACC members responded to a second survey to collect further input on the first draft of the *Plan*. Results were posted ahead of the October 2022 IACC meeting.

# 2021-2023 IACC Strategic Plan Process



- ✓ July-October 2022: OARC prepared a second draft of the *Strategic Plan*.
- ✓ October IACC Full Committee Meeting: IACC members discussed the second draft of the *Plan*.
- ✓ November-December 2022: IACC members submitted feedback on the second draft. Results were posted ahead of the January 2023 IACC meeting.
- ✓ January 2023: OARC sent a third draft to IACC members for review and some additional comments were incorporated.
- ✓ The draft plan will be discussed at the January 2023 meeting of the IACC.
- ❑ **January 2023 IACC Full Committee Meeting (TODAY): IACC members will have the opportunity to vote to approve the new *Strategic Plan*.**

# 2021-2023 IACC Strategic Plan: Opportunities for Input and Feedback



## In Summary:

Throughout the development of the Strategic Plan, IACC members and members of the general public have had multiple opportunities to provide input and feedback on the Plan:

- Request for Information (RFI) issued to the general public in October 2021
  - IACC members surveys issued in November 2021, July 2022, and November 2022
  - Public comments submitted October 2021 – December 2022
  - Discussions at the January 2022, April 2022, and October 2022 full committee meetings
  - Strategic Plan Working Group meeting in July 2022
- 
- All comments submitted by IACC members and the general public were carefully considered, and the draft Plan was developed with the goal of building a consensus document that addresses the needs of individuals **across the whole spectrum, across the whole lifespan, and from diverse communities.**
  - **Thank you to the Committee and the community for sharing your feedback toward the development of the 2021-2023 IACC Strategic Plan!**

# 2021-2023 IACC Strategic Plan: Major Topics and Themes



Major topics and themes covered in the Plan:

- Major research, services, and policy issues
- Major federal activities and initiatives, interagency coordination
- Commitment to developing solutions to the challenges faced by individuals and their families in health needs, services access, opportunities, and community inclusion
- Addressing the whole spectrum and the whole lifespan including those with high support needs
- Addressing the needs of those from diverse communities
- Commitment to inclusion, acceptance, and equity and reducing stigma, disparities, and discrimination
- Need for greater inclusion in research, including community-based participatory research
- Update on research portfolio and budget recommendation



# 2021-2023 IACC Strategic Plan: Revisions in the third draft



- All sections of the Plan have been updated, incorporating feedback from the Committee, including the Introduction, Conclusion, and core chapters:
  - Chapter 1: Screening and Diagnosis
  - Chapter 2: Biology
  - Chapter 3: Genetic and Environmental Factors
  - Chapter 4: Interventions
  - Chapter 5: Services and Supports
  - Chapter 6: Lifespan
  - Chapter 7: Infrastructure and Surveillance
  - Cross-Cutting Topic 1: Sex and Gender
  - Cross Cutting Topic 2: Promoting Equity and Reducing Disparities
  - Impact of the COVID-19 Pandemic

# ***2021-2023 IACC Strategic Plan:*** **Revisions in the third draft**



- Content on the following topics has been added or emphasized in the current draft:
  - Individuals with intellectual disability
  - Individuals with high support needs
  - Self-injurious, aggressive, and other challenging behaviors
  - Minimally-speaking individuals and communication supports
  - Mental health services and supports
  - Co-occurring conditions
  - Autism in older adulthood
  - Sex and gender issues
  - Equity and racial/ethnic and other disparities
  - Financial need and financial planning

# Committee Discussion



- We welcome comments/discussion from the committee about the draft
- Today the committee will have an opportunity to vote to approve the new IACC Strategic Plan
- The committee may vote to approve with agreed upon changes if needed

# Committee Discussion of the IACC Strategic Plan Draft



# Vote to approve the *2021-2023 IACC Strategic Plan*



A large, vibrant red checkmark is positioned on the left side of the slide. Overlaid on the lower part of the checkmark is the word "Vote!" written in a bold, red, cursive script font.

Vote ONLY if you are:

- ☐ A public member of the IACC;
- ☐ A federal member of the IACC; or
- ☐ An IACC alternate representing a federal member who is not participating in the vote

Votes may not be anonymous\*

# Vote to approve the *2021-2023 IACC Strategic Plan*



**Vote!**

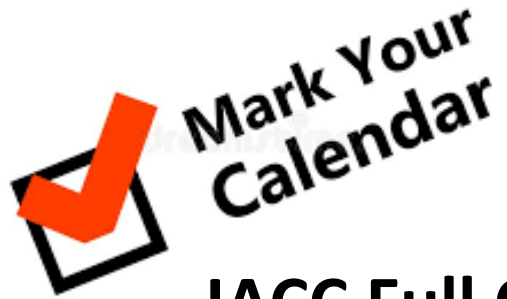
- ☐ In favor of accepting the new 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy (with any changes agreed upon at the IACC meeting on 1/18/23)
- ☐ Against accepting the new 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy on 1/18/23
- ☐ Abstaining from voting on the 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy on 1/18/23

# 2021-2023 IACC Strategic Plan: Final Steps



- Following approval of the *IACC Strategic Plan*, OARC will finalize the plan and prepare it for publication by Spring 2023
- The *Strategic Plan* will be published on the IACC website, distributed via the IACC mailing list, and transmitted to Congress and the President (as required by the Autism CARES Act of 2019)
- An easy-read version will be prepared for accessibility

# Next IACC Meeting



## **IACC Full Committee Meeting (virtual or hybrid)**

April 4, 2023

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>



# IACC Summary of Advances Update



**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

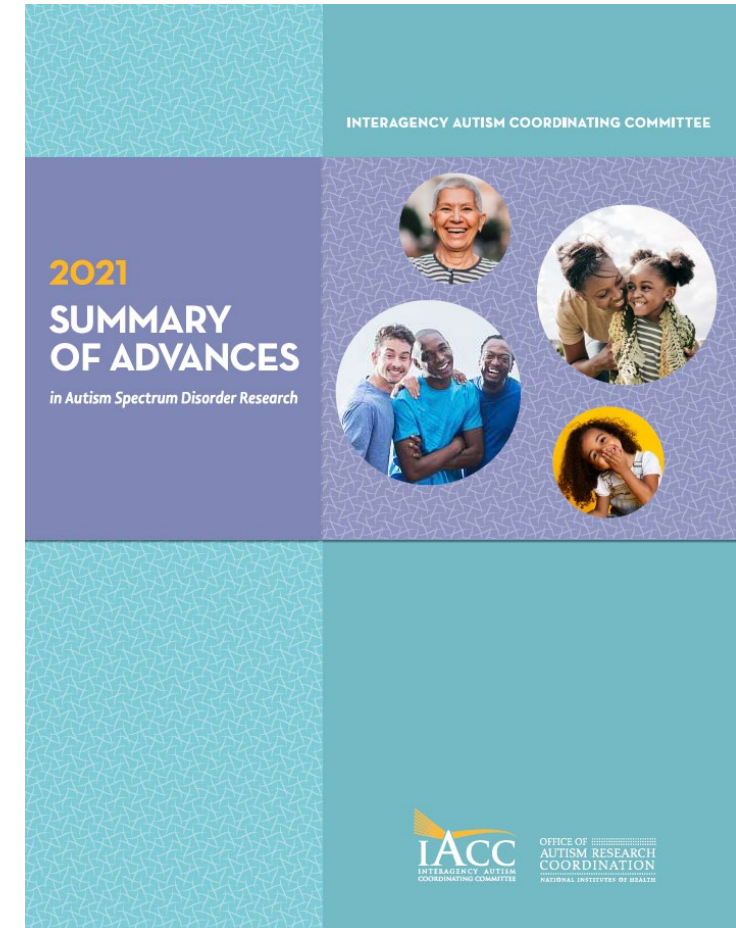
**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

# IACC Summary of Advances: Overview



- The IACC develops an annual *Summary of Advances* report, highlighting the top 20 advances in autism research, as required by the Autism CARES Act of 2019.
- Preparation of the **2021** and **2022** reports is in progress, and we will soon begin work on the **2023** report.



# Status of the **2021** IACC *Summary of Advances*



- ✓ IACC members nominated articles (July-December 2021)
- ✓ IACC members discussed nominations at committee meeting (April 2022)
- ✓ IACC members voted on top 20 articles (Summer 2022)
- ✓ OARC prepared article summaries and draft publication (Fall 2022)
- ☐ IACC members preview draft (Early 2023)**
- ☐ OARC prepares final publication (Spring 2023)

# Status of the **2022** IACC Summary of Advances



✓ IACC members nominate articles (October 2022-January 2023)

**☐ IACC members discuss nominations at committee meeting (TODAY)**

☐ IACC members vote on top 20 articles (January 2023)

☐ OARC prepares article summaries and draft publication (February-April 2023)

☐ IACC members preview and comment on draft (Spring 2023)

☐ OARC prepares final publication (Summer 2023)

# **2023** *IACC Summary of Advances* Process



- ☐ IACC members nominate articles (January 2023 – January 2024)
- ☐ IACC members discuss nominations at committee meetings (April 2023 - January 2024)
- ☐ IACC members vote on top 20 articles (January 2024)
- ☐ OARC prepares article summaries and draft publication (Winter-Spring 2024)
- ☐ IACC members preview/comment on draft (Spring 2024)
- ☐ OARC prepares final publication (Spring 2024)

# Summary of Advances discussion guidelines



- Goal of today's discussion: finalize the list of nominated articles to appear on the ballot
- Selected articles should represent **significant advances or progress** in understanding of autism, across the 7 topic areas of the *IACC Strategic Plan*
- During the discussion:
  - Are there nominated articles you find particularly noteworthy?
  - Do you agree with removing nominated articles that have been flagged by OARC staff for one of the following reasons?
    - Study too preliminary
    - Small sample size
    - Review article
    - Commentary
    - Workgroup recommendations



# 2022 IACC Summary of Advances Nominations Statistics



- A total of 85 nominations were received:
  - Question 1 (Screening and Diagnosis): 6
  - Question 2 (Biology): 20
  - Question 3 (Genetic and Environmental Factors): 13
  - Question 4 (Interventions): 8
  - Question 5 (Services and Support): 7
  - Question 6 (Lifespan): 22
  - Question 7 (Infrastructure and Prevalence): 9
- 3 items flagged as potentially not fitting within guidelines for significant original research findings – Talbott et al. (Q4), Kuo et al. (Q7), and Singer et al. (Q7)

# 2022 Summary of Advances Nominations





# Question 1: Screening and Diagnosis



- Barbaresi et al. **Clinician Diagnostic Certainty and the Role of the Autism Diagnostic Observation Schedule in Autism Spectrum Disorder Diagnosis in Young Children.** *JAMA Pediatrics.*
- Bodfish et al. **Measuring the Functional Impact of Behavioral Inflexibility in Children with Autism Using the Behavioral Inflexibility Scale: Clinical Interview (BIS-CI).** *Journal of Autism and Developmental Disorders.*
- Dursun et al. **A new model for recognition, referral, and follow-up of autism spectrum disorder: A nationwide program.** *Autism Research.*
- Rooney et al. **Screening for Autism in 2-Year-Old Children: The Application of the Systematic Observation of Red Flags to the Screening Tool for Autism in Toddlers and Young Children.** *American Journal of Speech-Language Pathology.*
- Schaaf et al. **Sensory Phenotypes in Autism: Making a Case for the Inclusion of Sensory Integration Functions.** *Journal of Autism and Developmental Disorders.*
- Wiggins et al. **Features that best define the heterogeneity and homogeneity of autism in preschool-age children: A multisite case-control analysis replicated across two independent samples.** *Autism Research.*

## Question 2: Biology



- Ahmed et al. **Screening of gastrointestinal symptoms and celiac disease in children with autism spectrum disorder.** *Egyptian Journal of Otolaryngology.*
- Baribeau et al. **Developmental cascades between insistence on sameness behaviour and anxiety symptoms in autism spectrum disorder.** *European Child & Adolescent Psychiatry.*
- Bradshaw et al. **Capturing the complexity of autism: Applying a developmental cascades framework.** *Child Development Perspectives.*
- Burrows et al. **A Data-Driven Approach in an Unbiased Sample Reveals Equivalent Sex Ratio of Autism Spectrum Disorder-Associated Impairment in Early Childhood.** *Biological Psychiatry.*
- Che et al. **Maternal mid-gestational and child cord blood immune signatures are strongly associated with offspring risk of ASD.** *Molecular Psychiatry.*
- Gandal et al. **Broad transcriptomic dysregulation occurs across the cerebral cortex in ASD.** *Nature.*

## Question 2: Biology



- Girault et al. **Infant Visual Brain Development and Inherited Genetic Liability in Autism.** *The American Journal of Psychiatry.*
- Hirsch et al. **Neural correlates of eye contact and social function in autism spectrum disorder.** *PLoS One.*
- Lee et al. **Altered Development of Amygdala-Connected Brain Regions in Males and Females with Autism.** *Journal of Neuroscience.*
- Lyons-Warren et al. **Cluster Analysis of Short Sensory Profile Data Reveals Sensory-Based Subgroups in Autism Spectrum Disorder.** *International Journal of Molecular Sciences.*
- Niarchou et al. **Investigating the genetic pathways of insomnia in Autism Spectrum Disorder.** *Research In Developmental Disabilities.*
- Northrup et al. **Mapping the time course of overt emotion dysregulation, self-injurious behavior, and aggression in psychiatrically hospitalized autistic youth: A naturalistic study.** *Autism Research.*

## Question 2: Biology



- Pecukonis et al. **Early predictors of language skills at 3 years of age vary based on diagnostic outcome: A baby siblings research consortium study.** *Autism Research.*
- Pickles et al. **Predictors of language regression and its association with subsequent communication development in children with autism.** *Journal of Child Psychology and Psychiatry.*
- Safar et al. **Shared and Distinct Patterns of Functional Connectivity to Emotional Faces in Autism Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder Children.** *Frontiers in Psychology.*
- Shen et al. **Subcortical Brain Development in Autism and Fragile X Syndrome: Evidence for Dynamic, Age- and Disorder-Specific Trajectories in Infancy.** *The American Journal of Psychiatry.*
- Supekar et al. **Deep learning identifies robust gender differences in functional brain organization and their dissociable links to clinical symptoms in autism.** *British Journal of Psychiatry.*
- Supekar et al. **Robust, Generalizable, and Interpretable Artificial Intelligence-Derived Brain Fingerprints of Autism and Social Communication Symptom Severity.** *Biological Psychiatry.*

## Question 2: Biology



- Xiao et al. **Neural responses to affective speech, including motherese, map onto clinical and social eye tracking profiles in toddlers with ASD.** *Nature Human Behaviour.*
- Wiggins et al. **Toileting Resistance Among Preschool-Age Children with and Without Autism Spectrum Disorder.** *Journal of Developmental and Behavioral Pediatrics.*

# Question 3: Genetic and Environmental Factors



- Antaki et al. **A phenotypic spectrum of autism is attributable to the combined effects of rare variants, polygenic risk and sex.** *Nature Genetics*.
- Havdahl et al. **Associations Between Pregnancy-Related Predisposing Factors for Offspring Neurodevelopmental Conditions and Parental Genetic Liability to Attention-Deficit/Hyperactivity Disorder, Autism, and Schizophrenia: The Norwegian Mother, Father and Child Cohort Study (MoBa).** *JAMA Psychiatry*.
- Hertz-Picciotto et al. **Maternal tobacco smoking and offspring autism spectrum disorder or traits in ECHO cohorts.** *Autism Research*.
- Hessami et al. **COVID-19 Pandemic and Infant Neurodevelopmental Impairment: A Systematic Review and Meta-analysis.** *JAMA Network Open*.
- Lyall et. **Cardiometabolic Pregnancy Complications in Association With Autism-Related Traits as Measured by the Social Responsiveness Scale in ECHO.** *American Journal of Epidemiology*.

# Question 3: Genetic and Environmental Factors



- Mattheisen et al. **Identification of shared and differentiating genetic architecture for autism spectrum disorder, attention-deficit hyperactivity disorder and case subgroups.** *Nature Genetics*.
- Suarez et al. **Association of Antidepressant Use During Pregnancy With Risk of Neurodevelopmental Disorders in Children.** *JAMA Internal Medicine*.
- Schendel et al. **Evaluating the interrelations between the autism polygenic score and psychiatric family history in risk for autism.** *Autism Research*.
- Trost et al. **Genomic architecture of autism from comprehensive whole-genome sequence annotation.** *Cell*.
- Wang et al. **Association of mitochondrial DNA content, heteroplasmies and inter-generational transmission with autism.** *Nature Communications*.
- Warrier et al. **Genetic correlates of phenotypic heterogeneity in autism.** *Nature Genetics*.

# Question 3: Genetic and Environmental Factors



- Wigdor et al. **The female protective effect against autism spectrum disorder.** *Cell Genomics*.
- Zhou et al. **Integrating de novo and inherited variants in 42,607 autism cases identifies mutations in new moderate-risk genes.** *Nature Genetics*.



# Question 4: Interventions



- Benevides et al. **Occupational Therapy Service Delivery Among Medicaid-Enrolled Children and Adults on the Autism Spectrum and With Other Intellectual Disabilities.** *American Journal of Occupational Therapy.*
- Hume et al. **Efficacy of a School-Based Comprehensive Intervention Program for Adolescents With Autism.** *Exceptional Children.*
- Li et al. **Meeting the 24-h movement guidelines and health-related outcomes among youth with autism spectrum disorder: a seven-country observational study.** *Child and Adolescent Psychiatry and Mental Health.*
- Panganiban and Kasari. **Super responders: Predicting language gains from JASPER among limited language children with autism spectrum disorder.** *Autism Research.*
- Shenouda et al. **Disparities in Early Intervention Program Participation by Children With Autism Spectrum Disorder in a US Metropolitan Area, 2006 to 2016.** *JAMA Pediatrics.*
- Shurtz et al. **Concomitant medication use in children with autism spectrum disorder: Data from the Autism Biomarkers Consortium for Clinical Trials.** *Autism.*

# Question 4: Interventions



- Steinbrenner et al. **Patterns in reporting and participant inclusion related to race and ethnicity in autism intervention literature: Data from a large-scale systematic review of evidence-based practices.** *Autism*.
- Talbott et al. **Short report: Experiences of Caregivers Participating in a Telehealth Evaluation of Development for Infants (TEDI).** *Journal of Autism and Developmental Disorders*.
  - Note from OARC: Article describes a feasibility study with a sample size of 32.

# Question 5: Services and Supports



- Davies et al. **Autistic adults' views and experiences of requesting and receiving workplace adjustments in the UK.** *PLoS One*.
- Eapen et al. **Factors Impacting Parental Quality of Life in Preschool Children on the Autism Spectrum.** *Journal of Autism and Developmental Disorders*.
- Kaiser et al. **A culturally grounded autism parent training program with Black parents.** *Autism*.
- Sridhar et al. **Patterns of Intervention Utilization Among School-Aged Children with Autism Spectrum Disorder: Findings from a Multi-Site Research Consortium.** *Research in Autism Spectrum Disorders*.
- Stadnick et al. **Mental health screening in pediatric primary care for children with autism.** *Autism*.
- Stockham et al. **An Informatics Analysis to Identify Sex Disparities and Healthcare Needs for Autism across the United States.** *American Medical Informatics Association Annual Symposium Proceedings*.

# Question 5: Services and Supports



- Yousefvand et al. **Broader Autism Phenotype and Communication Skills in Parents of Children with Autism.** *Journal of Modern Rehabilitation.*

# Question 6: Lifespan



- Al-Beltagi et al. **Effects of COVID-19 on children with autism.** *World Journal of Virology.*
- Bury et al. **Understanding language preference: Autism knowledge, experience of stigma and autism identity.** *Autism.*
- Cope and Remington. **The Strengths and Abilities of Autistic People in the Workplace.** *Autism in Adulthood.*
- Doherty et al. **Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study.** *BMJ Open.*
- Forbes et al. **How do autistic people fare in adult life and can we predict it from childhood?** *Autism Research.*
- Goldfarb et al. **Implications of Employment Changes Caused by COVID-19 on Mental Health and Work-Related Psychological Need Satisfaction of Autistic Employees: A Mixed-Methods Longitudinal Study.** *Journal of Autism and Developmental Disorders.*

# Question 6: Lifespan



- Groenman et al. **Menstruation and menopause in autistic adults: Periods of importance?** *Autism*.
- Harmens et al. **Autistic women's diagnostic experiences: Interactions with identity and impacts on well-being.** *Womens Health (London)*.
- Hendriks et al. **Autistic Traits, Empathizing-Systemizing, and Gender Diversity.** *Archives of Sexual Behavior*.
- Huang et al. **Autistic Adults' Experiences of Diagnosis Disclosure.** *Journal of Autism and Developmental Disorders*.
- Jadav and Bal. **Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research.** *Autism Research*.
- Kim et al. **Discrimination and Harassment Experiences of Autistic College Students and Their Neurotypical Peers: Risk and Protective Factors.** *Journal of Autism and Developmental Disorders*.

# Question 6: Lifespan



- Lee et al. **Vocational Outcomes in ASD: An Examination of Work Readiness Skills as well as Barriers and Facilitators to Employment Identified by Autistic Adults.** *Journal of Autism and Developmental Disorders.*
- Martin et al. **Sustainable employment depends on quality relationships between supervisors and their employees on the autism spectrum.** *Disability and Rehabilitation.*
- Martini et al. **Sex Differences in Mental Health Problems and Psychiatric Hospitalization in Autistic Young Adults.** *JAMA Psychiatry.*
- Must et al. **Relationship between Childhood Obesity and Autism Spectrum Disorder Varies by Child's Age and Parents' Weight Status in a Sample of Sibling Dyads.** *Childhood Obesity.*
- Petty et al. **Workplace Adjustments for Autistic Employees: What is 'Reasonable'?** *Journal of Autism and Developmental Disorders.*
- Shea et al. **Medicaid Disruption Among Transition-Age Youth on the Autism Spectrum.** *Medical Care Research and Review.*

# Question 6: Lifespan



- Schott et al. **Co-occurring conditions and racial-ethnic disparities: Medicaid enrolled adults on the autism spectrum.** *Autism Research.*
- Stratton et al. **Understanding the vocational functioning of autistic employees: the role of disability and mental health.** *Disability and Rehabilitation.*
- Taylor et al. **Contrasting Views of Autism Spectrum Traits in Adults, Especially in Self-Reports vs. Informant-Reports for Women High in Autism Spectrum Traits.** *Journal of Autism and Developmental Disorders.*
- Whelpley and May. **Seeing is Disliking: Evidence of Bias Against Individuals with Autism Spectrum Disorder in Traditional Job Interviews.** *Journal of Autism and Developmental Disorders.*



# Question 7: Infrastructure and Prevalence



- Catalá-López et al. **Mortality in Persons With Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder: A Systematic Review and Meta-analysis.** *JAMA Pediatrics*.
- D'Mello et al. **Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline.** *Autism Research*.
- Etyemez et al. **The role of intellectual disability with autism spectrum disorder and the documented cooccurring conditions: A population-based study.** *Autism Research*.
- Heyl et al. **Data quality and autism: Issues and potential impacts.** *International Journal of Medical Informatics*.
- Kuo et al. **The Autism Intervention Research Network on Physical Health (AIR-P) Research Agenda.** *Pediatrics*.
  - Note from OARC: Research agenda with recommendations - does not present original research.
- Shaw et al. **Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016.** *Journal of the American Academy of Child and Adolescent Psychiatry*.

# Question 7: Infrastructure and Prevalence



- Singer et al. **A full semantic toolbox is essential for autism research and practice to thrive.** *Autism Research*.
  - Note from OARC: Commentary - does not present original research.
- Varcin et al. **Occurrence of psychosis and bipolar disorder in adults with autism: A systematic review and meta-analysis.** *Neuroscience & Biobehavioral Reviews*.
- Zubler et al. **Evidence-Informed Milestones for Developmental Surveillance Tools.** *Pediatrics*.

# *IACC Summary of Advances:*

## Next steps



- OARC will finalize the 2022 ballot based on today's discussion

### Upcoming Action Items

- January 2023: Use emailed ballot to vote for the top 20 articles from the list of nominations
- January 2023 – January 2024: Submit nominations for the *2023 IACC Summary of Advances*

# Lunch Break



# Public Comment Session



**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC



- **Finn Gardiner, M.P.P.**, Autistic People of Color Fund
- **Stacey Blecher**
- **Areva Martin, Esq.**, Special Need Network of Los Angeles
- **Joseph P. Joyce, M.B.A.**, Autism Society
- **Thomas W. Frazier, Ph.D.**, Autism Speaks

Full text of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)

# Summary of Written Public Comments



118 written public comments were submitted on topics below by the following individuals:

## ***Research and Service Needs, Resources, and Policy Implications - 47 comments***

- Trixie Morales-Miller
- Andrea Davis, Ph.D.
- Joshua Feder
- Diane Cullinane
- Kaitlyn Ballenger
- Lisa Wanionek
- Marrok Sedgwick
- Tifiny Spiva
- Melissa Woronoff
- Natalie Dowd
- JL Angell
- Jasmine Etienne
- Lisa Graf
- Paola Simi
- Eliza May
- Tosha Brothers
- Cindy Rieck
- Star Ford
- Elizabeth Ashby
- Julia Heslin
- Alison Greathouse
- Miyako Jones
- Dora Csurgai
- Alivia Strong
- Brady McBride
- Naomi Bishop
- Isaac Frandsen
- Maria Ciano
- Freya Harris
- Chris Leah
- Meg Hartley
- Ariella Lilien
- Marja Erwin
- Karen McWay
- Alexandra Maher
- Meg Perine
- Alison Stanton
- Shelley Hendrix McLaughlin
- Jessy Rice
- Anna Gray
- Wensheng Li, Ph.D.
- Katherine Marchant
- Lisa Sosnowski
- Desiree Enos
- Fred Madrid
- Nicole Corrado
- Daniel Bevagna

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Research, Services, and Supports for Adults with Autism - 14 comments***

- Eileen Nicole Simon, R.N., Ph.D.
- Benjamin Moore, B.S.W., CFRS, CRS, CPS
- Alexandra Gass
- Ian Muse
- Alicia Arellanes
- Philip Harlow
- Emma Sloan
- Daniele Colozzi
- Julia Clausen
- Jason Brown
- Rachel Braun
- Brittany Daniels
- Susan Robins
- Lauren Janas

## ***Inclusion of Autistic Perspectives in Research - 12 comments***

- Brandon Germer
- Jennifer Natalya Fink
- Kathleen Brennan
- Frederick Grossman
- Nicholas Greaves
- Paityn Bowen
- Ani Moller
- Elliott Walker
- Amy Hitchcock
- Alex Sprague
- Keira Crone
- Rachel Hedin

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)



# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Educational Needs and Teacher Workforce Training - 8 comments***

- Shawn Belt
- Sarah Carmany
- Cody Fletcher
- Ebru Eser
- Tracey Stanislawski
- Jennifer Brooks
- Robin Bellinger
- Mairead Keogan

## ***Addressing the Needs of Autistic Individuals with High Support Needs - 4 comments***

- Sharon Castellanos
- Emilie "Jenn" Brown
- Brandon Becker
- Eileen Nicole Simon, R.N., Ph.D.

## ***Mental Health Research, Services, and Treatment - 4 comments***

- Elizabeth Bonnell
- Chelsea Sarring
- Daniel Hardy
- Laura Contreras

## ***Employment - 5 comments***

- Lauren Agoratus
- Steve Condrey
- Josh Huffman
- Steven Clark
- John Comegys

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***The Role of the IACC and the Federal Government - 5 comments***

- Theodore Szpakowski
- Anthony Goleman
- Alex Candeloro
- Daron Williams
- Eileen Nicole Simon, R.N., Ph.D.

## ***Potential Causes of Autism - 2 comments***

- Eileen Nicole Simon, R.N., Ph.D.
- Parrish Hirasaki

## ***Increase Autism Acceptance and Reduce Stigma - 4 comments***

- Tracey Stanislawski
- Chris Cottrell
- Emma Peacock
- Deanna Durben

## ***Inclusion of Underrepresented Groups - 5 comments***

- Beth Carey
- Merideth Hartsell-Cooper
- River Bradley
- Sara Ackermann
- Nicole Lewis

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Communication and AAC - 2 comments***

- Eileen Nicole Simon, R.N., Ph.D.
- Tony Sandy

## ***Language Regarding Autism - 4 comments***

- Joseph, Joe, and Michele Atkinson
- Michael Baron
- Justin Acta
- Jillian Rhoades

## ***Parent/Caregiver Support Needs - 2 comments***

- Steph Herold
- Erin Garcia

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public\\_comments.pdf](https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/public_comments.pdf)

# BREAK



# Supportive Services Discussion



**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC

# Supportive Services Discussion: Goals



- We would like IACC members to share their lived experience, expertise, and research knowledge on the current landscape of supportive services for autistic people, including:
  - What evidence-based services are most beneficial to improved outcomes?
  - How easily these services can be accessed?
  - What types of coverage or access are available, and what barriers have been experienced in trying to obtain services?
- We also are interested in learning whether there are areas in which there are service needs that are not addressed by existing services.

# Supportive Services Discussion: Structure



- We will have about 25 minutes to discuss each question.
- For each question, we will begin by requesting responses from 3 IACC members in the following categories:
  - Autistic individuals
  - Family members
  - Researchers/clinicians/providers
- We recognize that many of our members fit more than one category.
- After the first 3 members have spoken, all other IACC members are welcome to provide input.
- Effort will be made to hear comments from as many different members of the committee as possible.
- As a reminder, we are asking members to share their lived experience and/or expertise. Please be **mindful and respectful** of those whose perspectives may differ from your own.

# Supportive Services Discussion: Question 1



What evidence-based services are most beneficial for children and adults with autism?



# Supportive Services Discussion:

## Question 2



- Which services are widely accessible (i.e., widely available, covered by health insurance, or available at little or no cost)?
- For those that are not, what are the barriers that need to be addressed to make these services more widely available and accessible?

# Supportive Services Discussion:

## Question 3



What are some unmet needs for which services do not currently exist (or exist at scale)?

# BREAK



# Advancing Engaged Research: Highlights Related to Intellectual and Developmental Disabilities

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Nakela L. Cook, MD, MPH  
Meghan Warren, PT, MPH, PhD

Interagency Coordinating Committee Meeting  
January 18, 2023

# Our Discussion Today

- **About PCORI**
- **Engaged Research**
- **Strategic Plan**
- **PCORI's IDD Portfolio**
  - **Study Highlights**
- **Discussion**



# PCORI's Mission

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from ***research guided by patients, caregivers, and the broader healthcare community.***





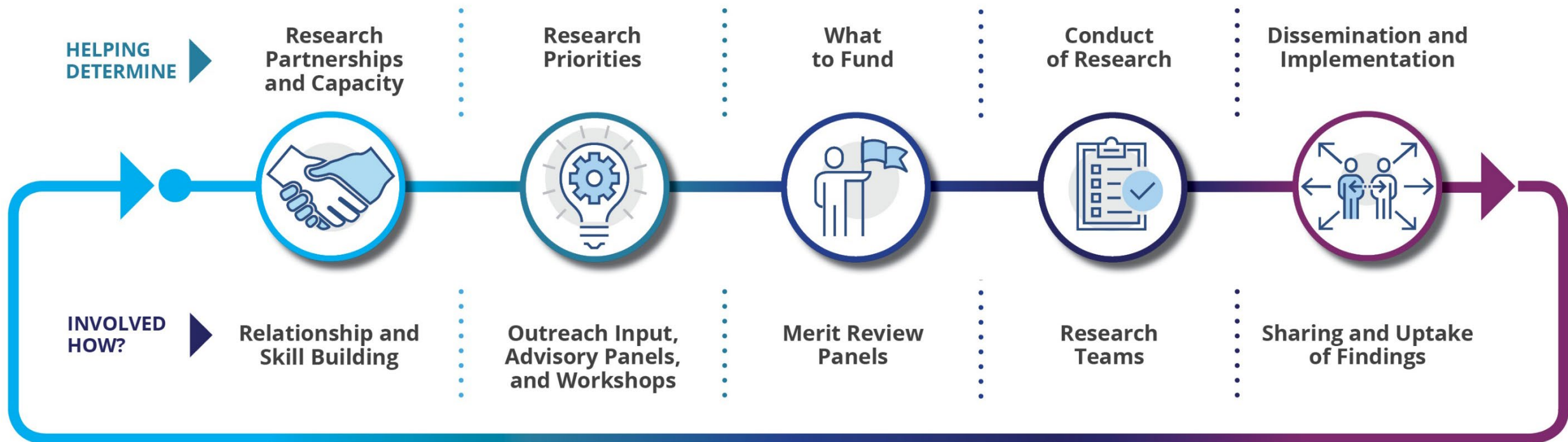
# How Is PCORI Research Different?

- We aim to produce evidence that can be easily **applied in real-world settings**
- We focus on **answering questions most important to patients** and those who care for them
- We **engage** patients, caregivers, clinicians, payers, employers, and other stakeholders throughout the research process
- We work to ensure the **dissemination and implementation** of study results



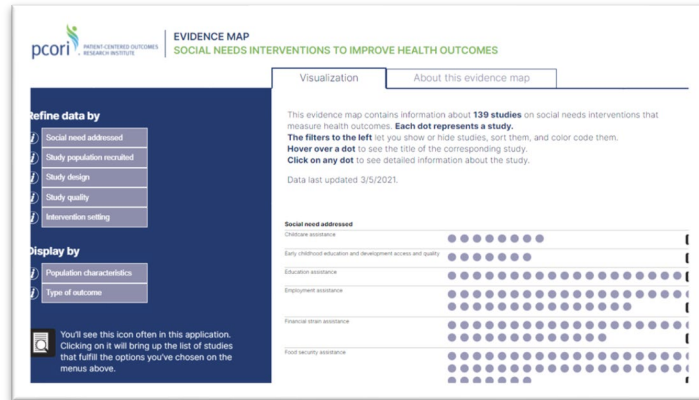
# Research Done Differently: Engagement in Research

## PATIENTS AND OTHER STAKEHOLDERS ARE INVOLVED IN...





# Balancing Long- and Short-term Activities



- Horizon scanning reports
- Emerging technology reports
- Evidence maps



- Systematic reviews and evidence products
- Focused observational research



- Phased trials (up to \$22M)
- Broad pragmatic studies (up to \$10M)

Time to Complete

Up to 1 year

1-2 years

3-7 years

*D&I activities occur throughout timeline*

*Stakeholders provide input for report and research topics*

# PCORI Funding Opportunities



## Research

### Focused Research Opportunities:

*Stakeholder-Driven Topics*

### Broad Pragmatic Studies:

*Topics aligned to National Priorities  
Proposals up to \$5M;  
Proposals up to \$10M*

### Phased Clinical Trials:

*Large-scale, high-impact CER trials  
Proposals up to \$22M*

## Research-Related

### Research Infrastructure:

*PCORnet,  
Learning Health Systems*

### Engagement Projects:

*Capacity Building,  
Dissemination,  
Stakeholder Convening*

### D&I Projects:

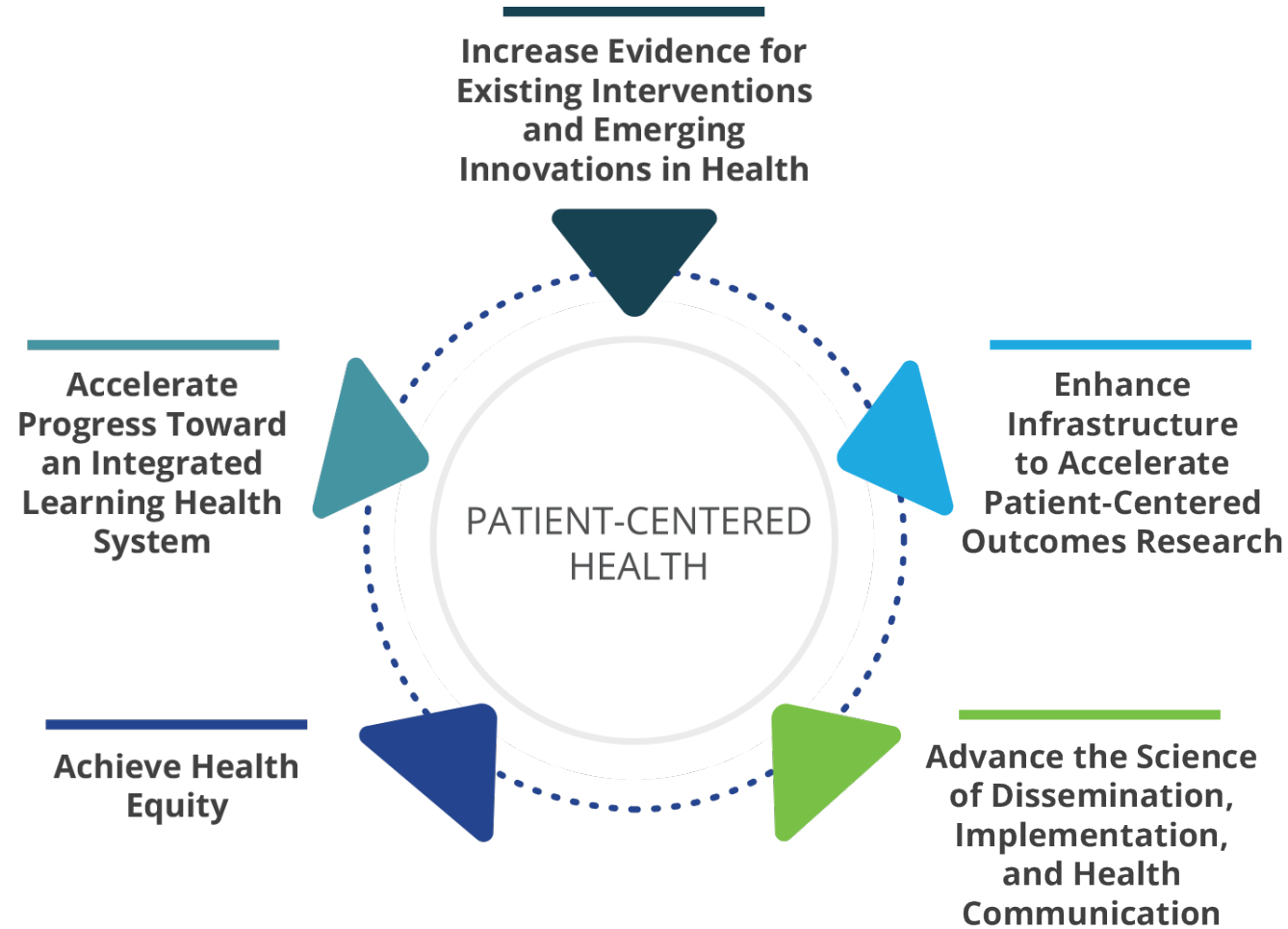
*Limited Competition,  
Shared Decision Making*

## Holistic Approach

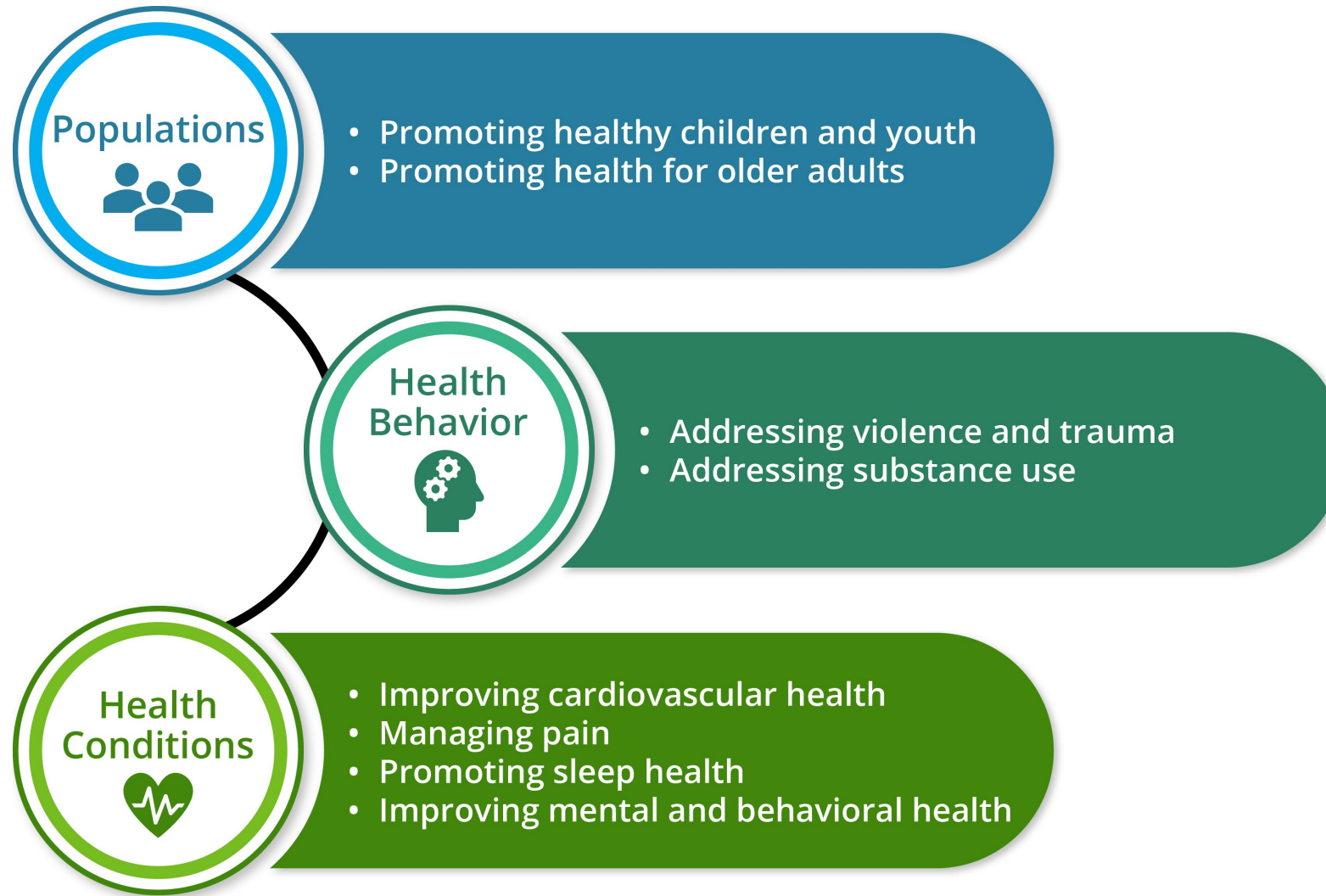
- Reflects a holistic approach to generating and promoting the use of evidence designed to enable a more patient-centered system of health
  - CER Funding
  - Engagement
  - Dissemination & Implementation
  - Infrastructure
- Working in concert with one another, these components drive and facilitate our mission and enable us to be responsive



# National Priorities for Health



# PCORI Topic Themes for Focused Funding



Work also continues in open/broad funding topics, intellectual and developmental disabilities, maternal morbidity and mortality, rare diseases, and COVID-19

# Reauthorization Priorities

## Priority Research Areas

- Intellectual and developmental disabilities
- Maternal morbidity and mortality

## Provision on Cost/Economic Data

- Expanding PCORI's role in collecting and generating relevant evidence

**Engagement Awards**  
**Evidence Products**  
**Funding Opportunities**

### **Full Range of Outcomes Data**

"Research shall be designed, as appropriate, to take into account and capture the full range of clinical and patient-centered outcomes ... In addition to the relative health outcomes and clinical effectiveness, clinical and patient-centered outcomes shall include the potential burdens and economic impacts of the utilization of medical treatments, items, and services on different stakeholders and decision-makers."

— From PCORI's 2019 reauthorizing legislation

# Intellectual and Developmental Disabilities Focus

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A long-term commitment of  
approach and work to date

Meghan Warren, PT, MPH, PhD





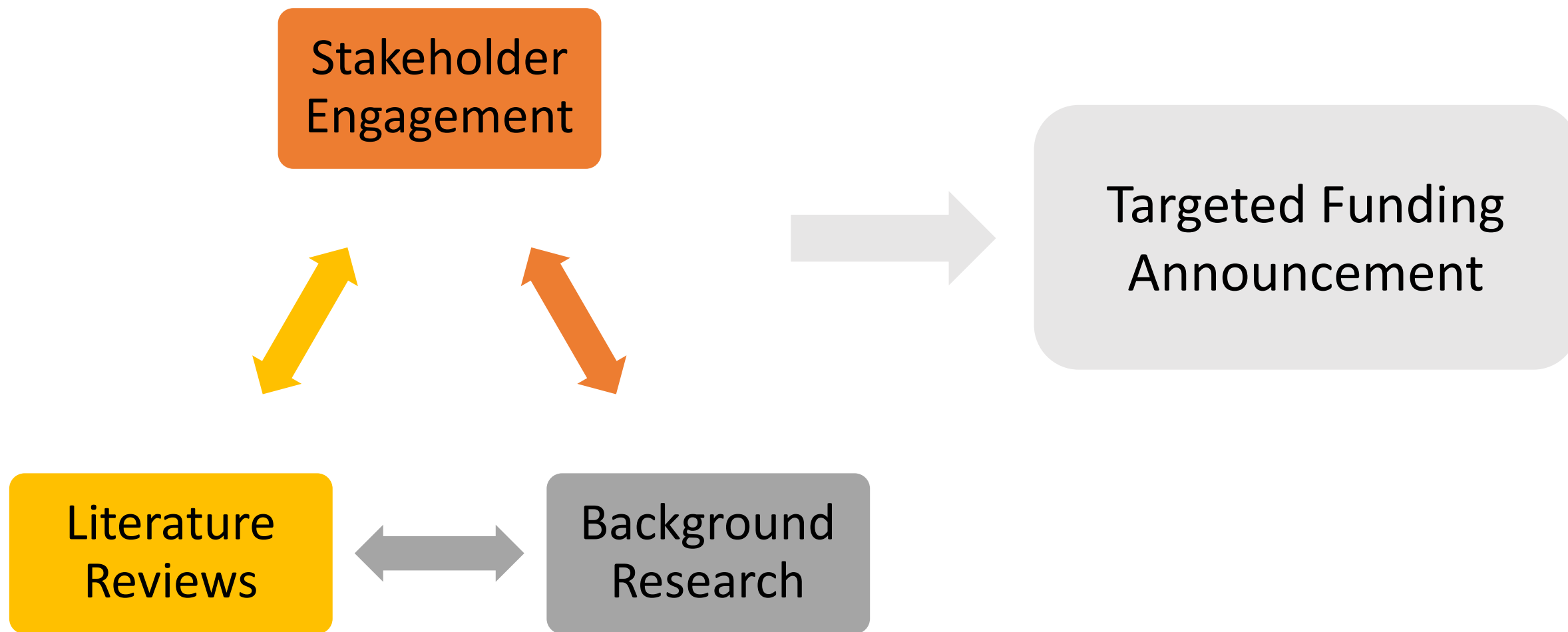
# PCORI's Working Definition for IDD



Developmental disabilities are chronic disabilities that originate at birth or in the developmental period and cause impairment in physical, learning, language, and/or behavioral areas. Intellectual disabilities, which fall under the umbrella term of developmental disabilities, involve limitations to cognitive function (reasoning, learning, problem solving) and adaptive behavior.



# PCORI's Stakeholder-Guided Process for CER Topics



# Multipronged Approach to Improving Health for Individuals with IDD



**Funding high-priority  
research**

Building capacity  
for PCOR

**Dissemination and  
implementation  
activities**

**Enhancing efficiency and  
research design**

# Funding High Priority Research:

## Building capacity for PCOR/CER in IDD



### Special Cycle Funding Announcement – 2021

- Support projects that enable organizations and communities to build capacity for stakeholder engagement with PCOR/CER in IDD
  - Addressing health equity and advancing IDD health outcomes for underserved populations
  - Leveraging community-based and patient-centered models of care delivery
  - Challenges related to clinical care delivery and access
  - Telehealth solutions
  - Transition to adulthood
  - Caregiver needs and access to wraparound support
  - Patient needs and preferences

# Funding High Priority Research:

Focused funding to address the needs of individuals with IDD



- **Caregiver Delivered Interventions – 2022**

- **Question of interest:** What is the comparative effectiveness of evidence-based and/or commonly used caregiver-delivered/led interventions for persons with IDD? Outcomes of interest should focus on the person with IDD or the person with IDD and the caregiver delivering the intervention.
- **\$20M committed, applications under review**

- **Improving Care Transitions for Individuals with IDD – 2020 & 2021**

- **Question of interest:** What is the comparative effectiveness of models of care, or of components of such models, to support the healthcare transition from childhood to adulthood and the continuation of patient-centered primary and specialty healthcare for individuals with IDD?
- **\$12M committed, 3 studies funded**

# Funding High Priority Research:

Focused funding to address the needs of individuals with IDD



- **Funding Announcement: Comparative Effectiveness of Interventions Targeting Mental Health in Individuals with IDD – 2021 & 2022**
  - **Question of interest:** What is the comparative effectiveness of evidence-based approaches (e.g., specific pharmacologic and behavioral interventions) that address mental health conditions in individuals with IDD?
  - **\$40M committed, 2 studies funded**

# Intellectual and Developmental Disabilities Portfolio Spotlight



**SINCE 2012, PCORI HAS AWARDED**  
**\$112** **MILLION** **87**  
**TO FUND**

comparative clinical effectiveness research  
studies and research support projects with a  
focus on **intellectual and developmental  
disabilities**

AS OF November 2022

\*PCORI has also funded three Methods and Infrastructure awards related to IDD

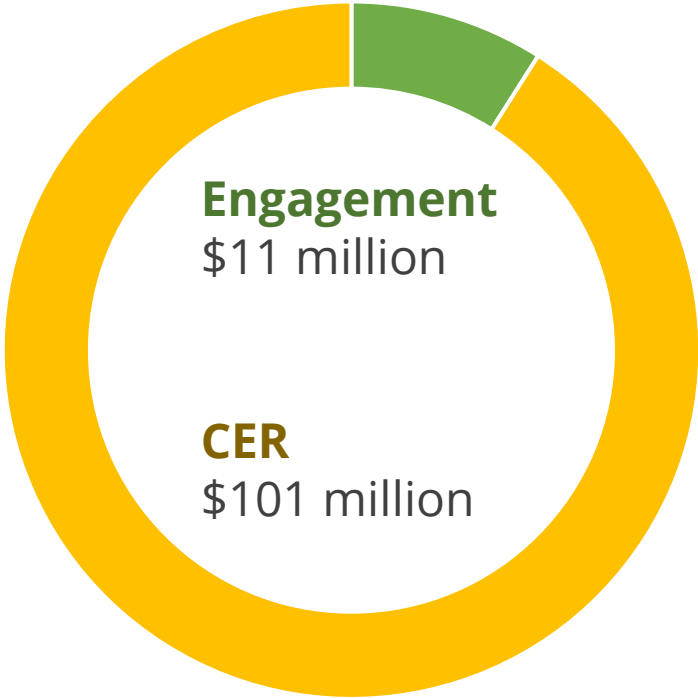
# Intellectual and Developmental Disabilities Portfolio Spotlight



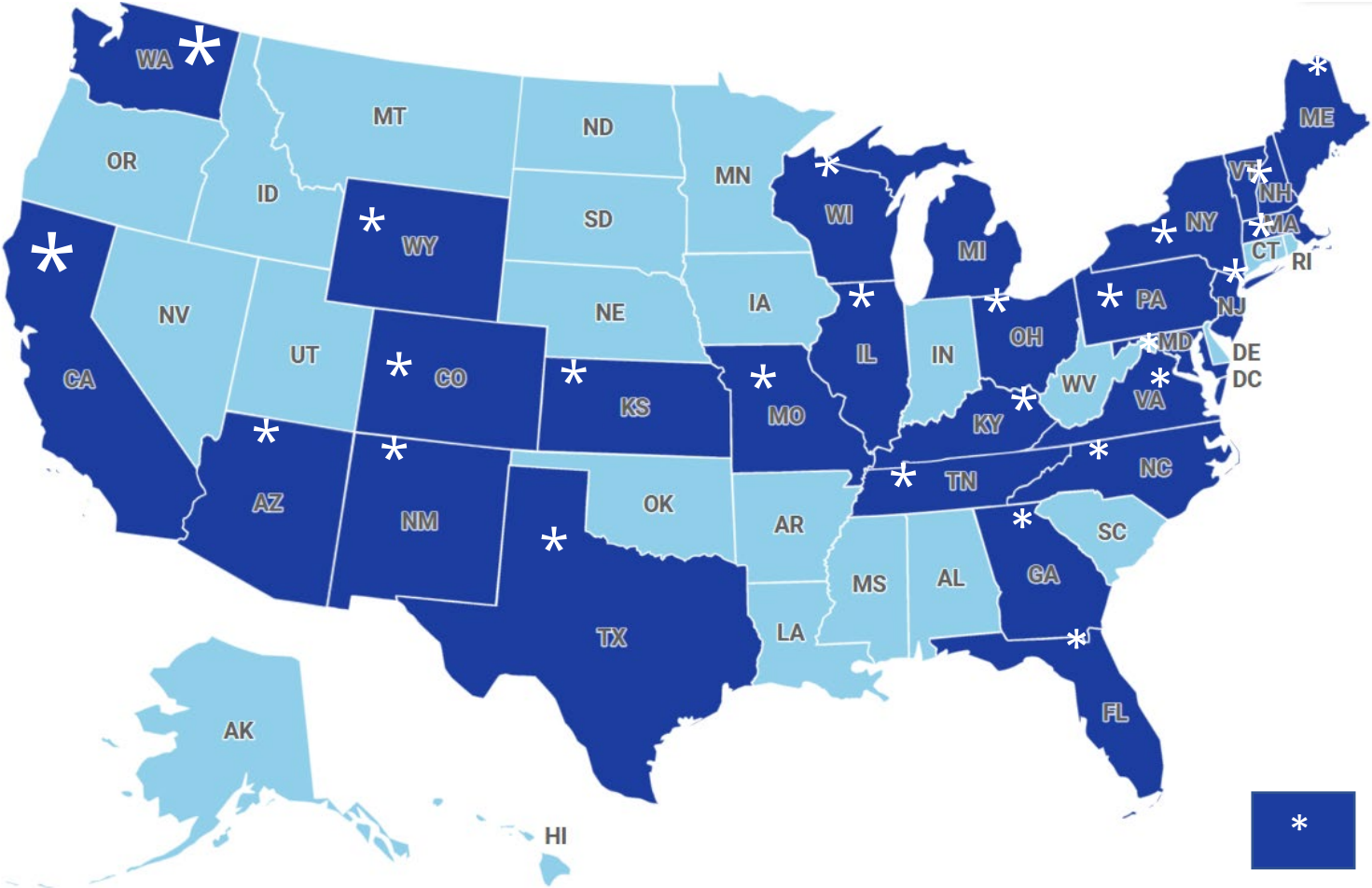
Number of projects



Funding amounts



# Intellectual and Developmental Disabilities Portfolio Spotlight



27 states + D.C.

\* = project funded



# PCORI Awards Related to Autism



Type of Award	Engagement	Research	Other funding	All Autism funding
Number of Projects	14	5	2	20
Investment	\$3,207,877	\$27,537,690	\$1,360,862	\$32,106,429
Sample size	n/a	Median: 300 Range: 148 – 1,500	Range: 63 – 219	Median: 219 Range: 63 – 1,500

# Autism Study Examples

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- Building Capacity for CER/PCOR Participation among Black, Indigenous, and other People of Color (BIPOC) Adults on the Autism Spectrum†

- **Problem**


- Perspective of autistic BIPOC adults is essential for comparative effectiveness (CER) and patient-centered outcomes research (PCOR), but rarely included as expert advisors

- **Proposed Solution**

- Increase the capacity of 10 BIPOC autistic adults in MA and TX as advisors on future CER/PCOR, and autism researchers to include BIPOC autistic adults as advisors

- **Outputs**

- Toolkit for BIPOC autistic adults interested in partnering with researchers as expert advisors
- Toolkit for researchers to engage BIPOC autistic adults



•Project includes 12 virtual meetings to educate members about CER/PCOR using existing PCORI toolkit and identify outcomes that matter to BIPOC autistic individuals. The goal is to establish a collaborative of BIPOC autistic stakeholders with expertise needed for CER/PCOR.



•Megan Bair-Merritt, MD, MSCE  
•Boston Medical Center Corporation

•Awarded 2021

† = Awarded; In progress

# Improving Classroom Behaviors among Students with Symptoms of Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder

- **Potential Impact**


- Compare usual classroom support with a new program to help students learn better

- **Methods**

- Randomized controlled trial in 24 schools with 148 3<sup>rd</sup>-5<sup>th</sup> graders in D.C.

- **Engagement**

- Parents and parents of children with ASD and/or ADHD, school staff, psychologists, and physicians provided input on the proposed study measures and protocol, especially adaptations for low-income populations and Spanish-speaking families; retention ideas; training; interpretation of results



•Project compared the support in 148 students with ADHD or ASD in a new program called Unstuck and On Target (UOT) to what is usually done. In UOT, school staff actively teach students how to plan, set goals, and be flexible for 21 sessions over 6 months. Outcomes were measured at baseline and 10 months and included classroom-observed behaviors and problem-solving skills, and parent reports about their behavior.



•Lauren Kenworthy, PhD/Laura Anthony, PhD  
•Children's Research Institute

•Awarded September 2013

# Improving Classroom Behaviors among Students with Symptoms of Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder



## •Results

- Executive functioning behaviors for all students did not differ between programs
- Among students with ASD, the UOT program improved classroom-observed executive functioning behaviors
- Parent-reported executive functioning outcomes or students' problem solving

## •How can people use the results?

- Schools can use results when considering ways to support students with ADHD or ASD

•Project compared the support in 148 students with ADHD or ASD in a new program called Unstuck and On Target (UOT) to what is usually done. In UOT, school staff actively teach students how to plan, set goals, and be flexible for 21 sessions over 6 months. Outcomes were measured at baseline and 10 months and included classroom-observed behaviors and problem-solving skills, and parent reports about their behavior.

•Lauren Kenworthy, PhD/Laura Anthony, PhD  
•Children's Research Institute

•Awarded September 2013

# Comparing Cognitive-Behavioral Therapy versus Mindfulness-Based Therapy for Autistic Adults§

## •Potential Impact


- Determine which interventions are most helpful for autistic adults with mental health problems

## •Methods

- Randomized controlled trial of 300 autistic adults in NC and VA

## •Engagement

- Partnered with PCORI-funded stakeholder engagement group
- Autistic individuals, family members, and clinicians will help participate with shared leadership and decision-making



•Project will compare cognitive-behavioral to mindfulness-based therapy in 300 people with autistic adults (age 18 or older) with co-occurring anxiety and/or depression. Outcomes are planned at baseline, post-intervention, and 6 months and will include anxiety and depression symptoms, overall clinical severity, quality of life, well-being, functional impairment, use of emergency services, and acceptability and feasibility of the treatment.

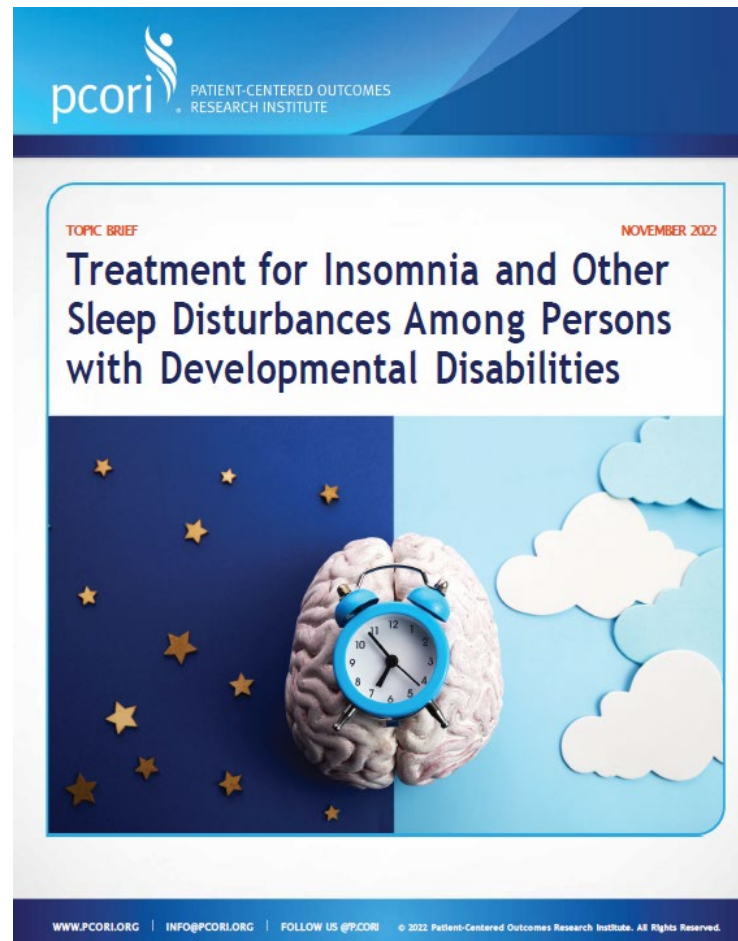


•Brenna Maddox, PhD  
•The University of North Carolina at Chapel Hill

•Awarded November 2022

§ = Awarded; Contract pending

# Short-term Evidence Products



<https://www.pcori.org/research-results/2022/topic-brief-treatment-insomnia-and-other-sleep-disturbances-among-persons-developmental-disabilities>



MEETING SUMMARY

## Methodologic Challenges in Intellectual and Developmental Disabilities Research Meeting Summary

March 15, 2021

[Meeting Details and Materials](#)

### Overview

On March 15, 2021, PCORI's Methodology Committee held a public workshop to discuss methodologic issues encountered in research evaluating the effects of interventions for children and adults with intellectual and developmental disabilities (IDD). IDD is a new research priority for PCORI, which is responding to a congressional mandate in the legislation that reauthorized PCORI in 2019 for another 10 years. The purpose of this workshop was to offer an overview of IDD methodology issues.

The first session of the workshop addressed a broad range of measurement issues. Maureen Durkin, PhD, DrPH, University of Wisconsin, called for the use of social contract theory, which aims for the greatest benefit for the least advantaged members of a society, to study IDD. Dr. Durkin also described IDD definitions, types of outcomes (beyond biomedical ones) that IDD studies should measure, and categorization schemes for interventions. Tracy M. King, MD, MPH, of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), commented that more work is needed to identify which outcomes are most meaningful to persons with IDD and how best to measure these meaningful outcomes. She also discussed that IDD studies need to measure the many levels of individual exposures, interpersonal factors, and societal influences that affect outcomes in people with IDD, and emphasized the need to measure both positive and negative outcomes.

The second session focused on observational and interventional study designs. David Mandell, ScD, University of Pennsylvania, called for merging public and private healthcare claims data with special education data from the Department of Education. Combining these data and linking them to registry data could help answer important questions about children with IDD. Luther Kalb, PhD, MHS, Kennedy Krieger Institute (KKI), described the learning health system (LHS) model and its use to analyze the data collected during the delivery of services to children with IDD. Such a system can track changes over time, collect information from several informants, and facilitate recruitment for traditional efficacy studies.

The topic of the third session was heterogeneity. Sarabeth Broder-Fingert, MD, MPH, Boston University and Boston Medical Center, described the many differences among people with autism spectrum disorder (ASD) and their families. The experiences and characteristics of families that deliver interventions to children with IDD can affect how they implement these interventions and thus the outcomes in their children. Tawara Goode, MA, Georgetown University, called for greater recognition of the diversity of people with IDD in research by, for example, not treating all persons with IDD as a homogeneous group and using approaches that produce nuanced portraits of these individuals.

<https://www.pcori.org/events/2021/pcori-workshop-methodologic-challenges-intellectual-and-developmental-disabilities-research>



# Questions and Discussion

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<https://www.pcori.org/collection/intellectual-andor-developmental-disabilities>

**iddpcori@pcori.org**





# Round Robin Updates



**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination,  
NIMH, and Executive Secretary, IACC  
Acting National Autism Coordinator

# Closing Remarks

**Joshua Gordon, M.D., Ph.D.**

Director, National Institute of Mental Health  
(NIMH) and Chair, IACC

**Susan A. Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Director, Office of Autism Research Coordination, NIMH  
and Executive Secretary, IACC





## Upcoming Action Items

- January 2023: Vote on the top 2020 nominated articles for the *2022 IACC Summary of Advances* via e-mail ballot
- January 2023 – January 2024: Submit nominations for the *2023 IACC Summary of Advances*
- Next IACC Full Committee Meeting: April 4, 2023 (virtual or hybrid TBA)

# Thank you to the OARC Staff!



**Susan Daniels, Ph.D.**  
Acting National Autism  
Coordinator, HHS  
Director, OARC



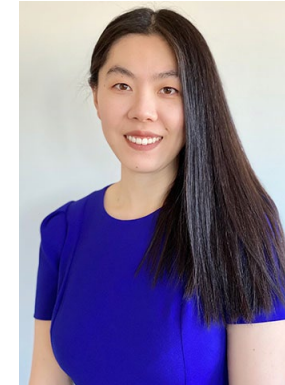
**Oni Celestin, Ph.D.**  
Science Policy Analyst



**Katrina Ferrara, Ph.D.**  
Science Policy Analyst



**Steven Isaacson, B.A.**  
Policy Analyst



**Tianlu Ma, Ph.D.**  
Science Policy Analyst



**Rebecca Martin, M.P.H.**  
Public Health Analyst



**Angelice Mitrakas, B.A.**  
Management Analyst



**Luis Valdez-Lopez, M.P.H.**  
Science Policy Analyst



**Jeffrey Wiegand, B.S.**  
Web Development and  
Digital Outreach Manager

# Adjournment



Thank you for joining us for today's IACC meeting.

<https://iacc.hhs.gov>