

Meeting of the Interagency Autism Coordinating Committee

Day 1

April 13, 2022; 1:00 - 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

Autism Awareness Month Greeting from the National Institutes of Health (NIH)



Tara Schwetz, Ph.D.
Acting Principal Deputy Director
National Institutes of Health

Updates on Disability Housing Programs



Teresa Souza, Ph.D.

Social Science Analyst
Office of Policy Development and Research
U.S. Department of Housing and Urban
Development

Lori Gerhard

Director
Office of Interagency Innovation
Administration for Community Living

Julia Orlando

(Presented by Susan Daniels, Ph.D.)

Director
Bergen County (NJ) Housing, Health and
Human Services Center

Interagency Autism Coordinating Committee

HUD Supportive Housing Programs & Research

Teresa Souza, Ph.D.

April 13, 2022

Office of Policy Development & Research (PD&R)

U.S. Department of Housing & Urban Development (HUD)



Topics

- ★ HUD Assistance
- ★ Section 811 Supportive Housing for People with Disabilities
- ★ Mainstream Voucher Program
- ★ Emergency Housing Voucher
- ★ Housing Discrimination Research
- ★ Health-Housing Linked Data

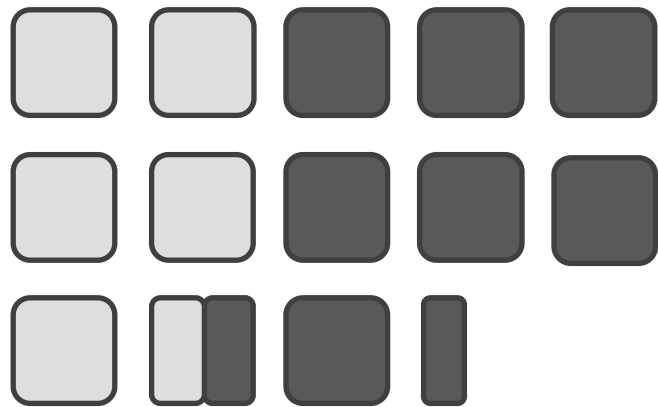


HUD Assistance

“HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all.”



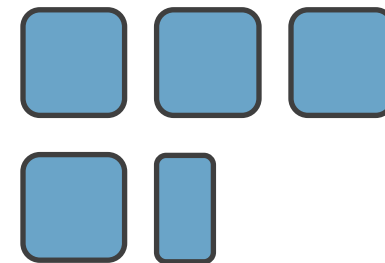
Housing Need vs. HUD Assistance



13.3 Million
Unassisted
Very-Low
Income Renter
Households in
2019

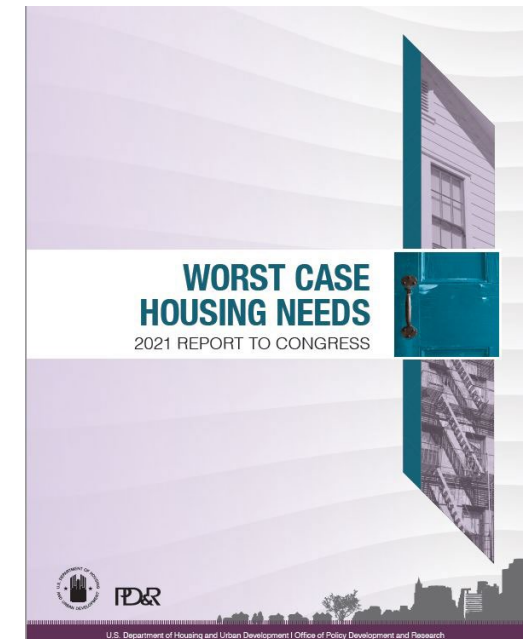


7.8 Million
with “Worst
Case Housing
Needs”



4.6 Million
HUD-Assisted
Households in
2019

**Only 26% of the
housing need is
assisted!**



Major HUD Programs

HUD Programs	Number of Assisted Households 2021	Percent Older Adults 62+	Percent Non-Elderly w/ Disabilities
ALL PROGRAMS	4,565,867	39	35
Housing Choice Vouchers	2,327,707	30	36
Project-Based Rental Assistance	1,217,108	51	32
Public Housing	843,749	35	31
Supportive Housing for Older Adults (S.202)	121,562	100	61
Supportive Housing for Non-Elderly People with Disabilities (S.811)	31,325	27	99
Other Assistance Programs	24,416	35	40

Source: Picture of Subsidized Households, 2021: <https://www.huduser.gov/portal/datasets/assthsg.html>

Household Types

Trend in the proportion of household types in HUD programs: 2012-2021



Source: Picture of Subsidized Households: <https://www.huduser.gov/portal/datasets/assthsg.html>



Section 811 Supportive Housing for People with Disabilities

“The biggest difference between me living here and somewhere else like a nursing home, living center, rehab, is that my children are with me.”

- Tanesha, 811 PRA Resident



Section 811 – Project Rental Assistance (PRA)

- **HUD grants to state housing agencies to subsidize rent for people with disabilities in affordable housing developments – 2012-present**
 - Integrated units: affordable properties where less than 25% of units are set aside for people with disabilities
 - Participants must be extremely low-income
 - 18 to 61 years old at time of admission
 - Eligible for Medicaid or other health and human services
- **State housing agencies administer funds and partner with health agencies to connect to home and community-based services**
 - PRA awards in 2012, 2013, and 2019 → \$342M total
 - Over 3,000 households assisted from 2015 to 2020
 - 46% homeless/at risk; 43% institutionalized/at risk; 11% other
- **More information:** <https://www.hudexchange.info/programs/811-pra/>

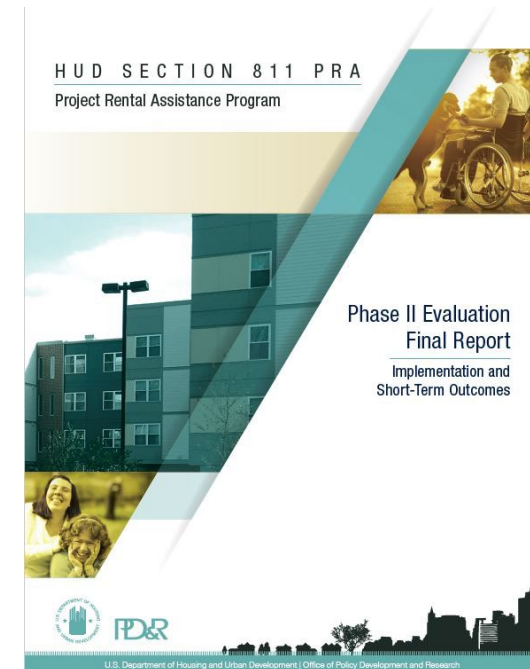


Section 811 PRA Evaluation

- Effectiveness of 811 PRA compared to similar households in other HUD programs and without HUD assistance
- Mixed methods
- Focused on six states → California, Delaware, Louisiana, Maryland, Minnesota, and Washington

Key Findings:

- 811 PRA residents have lower incomes and more healthcare needs than residents in other HUD programs
- Residents report high levels of autonomy and independence
- Neighborhood and housing quality indicators are mixed
- Exit rates high in the first 3 years after move-in



Section 811 PRA Evaluation: Resident Survey

- In-person survey: 75-items - 25-45 min → Oct 2017 - May 2018
- 194 completed surveys with PRA residents in the six study states

Key findings → tenancy support

- 77% of PRA residents received help on rental application
- 70% received help setting up apartment
- 50% receive ongoing help paying bills, resolving disputes

Key findings → community-based services

- A small percentage of PRA residents report going without the help they need with bathing, meals, and medication.

More information: <https://www.huduser.gov/portal/sites/default/files/pdf/Section-811-Phase-II.pdf>



Mainstream Voucher Program



Mainstream Voucher Program

- **Program provides rental assistance to people with disabilities with the same policies as the Housing Voucher Program**
 - Target population: transitioning out or at risk of institutional care; homeless, previously homeless, or at risk of homelessness
- **Public Housing Agencies (PHAs) administer funds, but are encouraged to partner with homeless assistance and health and human services agencies**
 - About 67,000 vouchers awarded to PHAs
 - About 45,000 households assisted and 20,000 vouchers available to new households
- **More information:** <https://www.hudexchange.info/programs/public-housing/mainstream-vouchers/>



Emergency Housing Voucher



Emergency Housing Voucher (EHV)

- **Under the American Rescue Plan, HUD awarded about 70,000 EHVs to subsidize the rent of individuals and families facing housing instability**
 - Target population: homeless, at-risk of homelessness, fleeing/attempting to flee domestic violence, dating violence, sexual assault, stalking, or human trafficking, recently homeless
 - New feature: Includes funds for housing search assistance
 - Limited life: no re-issuances by Sep 2023; funds obligated by Sep 2030; funds expire by Sep 2035
- **Public Housing Agencies (PHAs) administer funds, but must get participant referrals from homeless assistance agencies**
 - 16,343 households assisted
 - 27,518 households with a voucher looking for a rental unit
- **More information:** <https://www.hud.gov/ehv>



Housing Discrimination Research

“Disability discrimination is prohibited by the Fair Housing Act, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act, and other federal, state, and local laws.”

- HUD’s Office of Fair Housing and Equal Opportunity



Housing Discrimination Research

PD&R has been studying the presence and extent of housing discrimination in the rental market for over 40 years. Here are some examples:

- **People who are deaf or hard of hearing:** systematic evidence of unfavorable treatment during housing searches with telecommunication relay services
- **People who use wheelchairs:** systematic evidence of unfavorable treatment during housing searches for accessible buildings and units
- **People with mental illness and intellectual or developmental disabilities:** pilot testing found significant levels of unfavorable treatment during housing search and when requesting a reasonable accommodation
- **More information:** <https://www.huduser.gov/portal/publications/housingdiscriminationreports.html>



Health-Housing Linked Data

“Without data, you’re just another person with an opinion.”

- Edwards Deming, Statistician

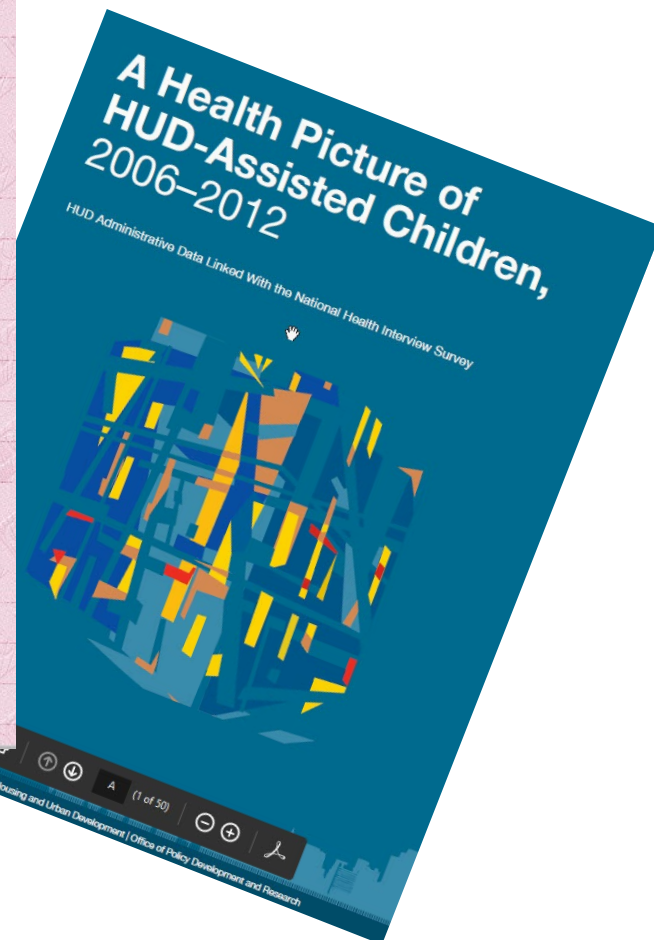
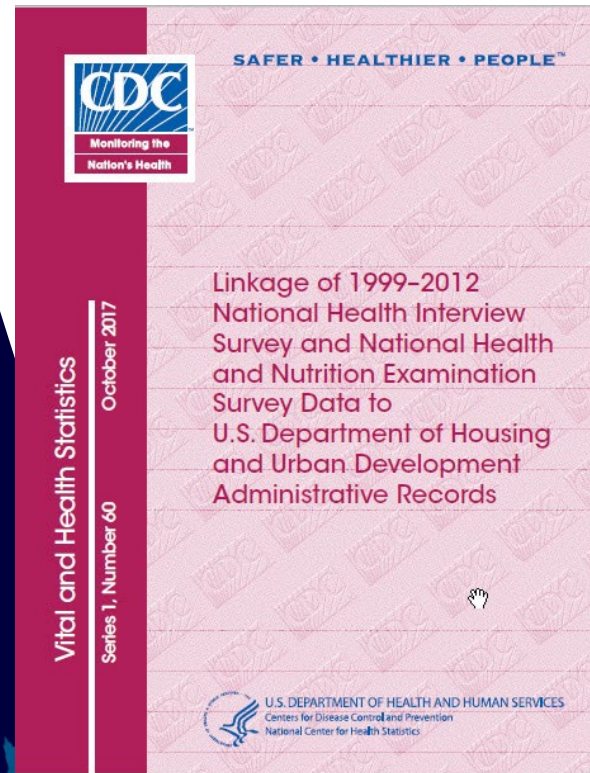
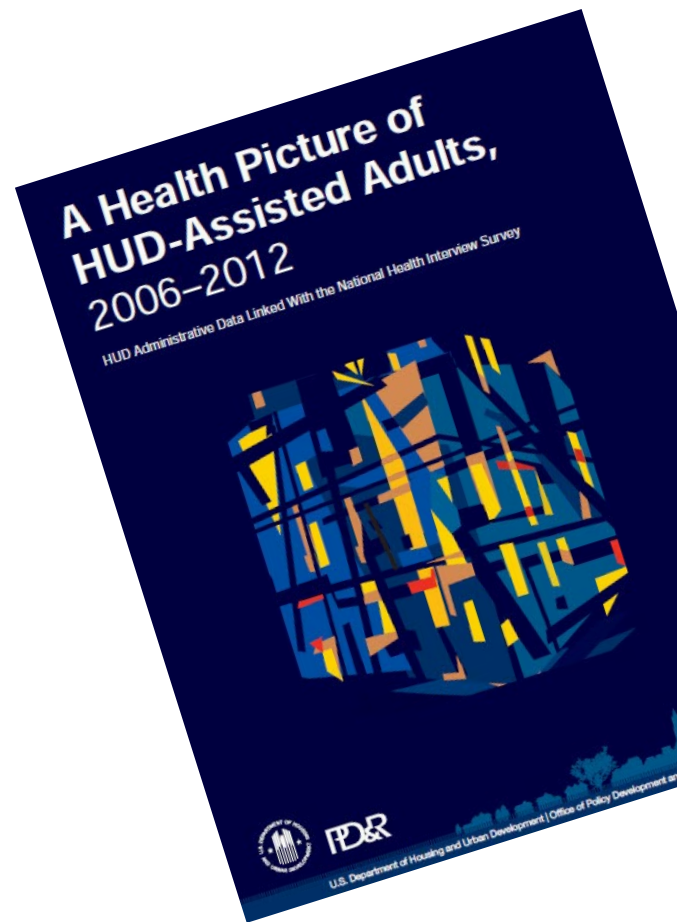


HUD-NCHS Data Linkage

- Ongoing National Center for Health Statistics (NCHS)-HUD Collaboration
- HUD geocodes NCHS data; NCHS performs the linkage
- Two national health interviews linked with HUD data
 - National Health Interview Survey
 - National Health and Nutrition Examination Survey (NHANES)
- New → National Hospital Care Survey (NHCS; Released August 2021)
- Continuously updated → Last update released February 2022
- **More Information:** [NCHS Data Linkage - HUD Administrative Data](#)



Technical Reports



Studies Using the Linked NCHS-HUD Data

- Brucker DL, Garrison VH. [Health disparities among Social Security Disability Insurance and Supplemental Security Income beneficiaries who participate in federal rental housing assistance programs.](#)
- Brucker DL, Helms VE. [Health, Health Behaviors, and Health Care Utilization Among Adults with Serious Psychological Distress Who Receive Federal Housing Assistance.](#)
- Brucker DL, Helms VE. [Measuring disability.](#)
- Brucker DL, Helms VE, Souza T. [Health and Health Services Access Among Adults with Disabilities Who Receive Federal Housing Assistance.](#)



Select Findings from one NCHS-HUD Study

Brucker DL, Helms VE, Souza T. [Health and Health Services Access Among Adults with Disabilities Who Receive Federal Housing Assistance.](#)

Findings:

44% of HUD-assisted adults have disabilities; higher than 30% based on HUD data

Prevalence of disabilities is similar across HUD major programs

HUD-assisted adults with disabilities are significantly more likely to experience poor health than those without disabilities

HUD-assisted adults with disabilities are significantly more likely to be connected to the health care system than those without disabilities, but have higher odds of reporting unmet care and 2+ ER visits



Thank You! Questions?

Teresa Souza

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Interagency Autism Coordinating Committee (IACC)

Overview of the Housing and Service Resource Center

An HHS/HUD Partnership



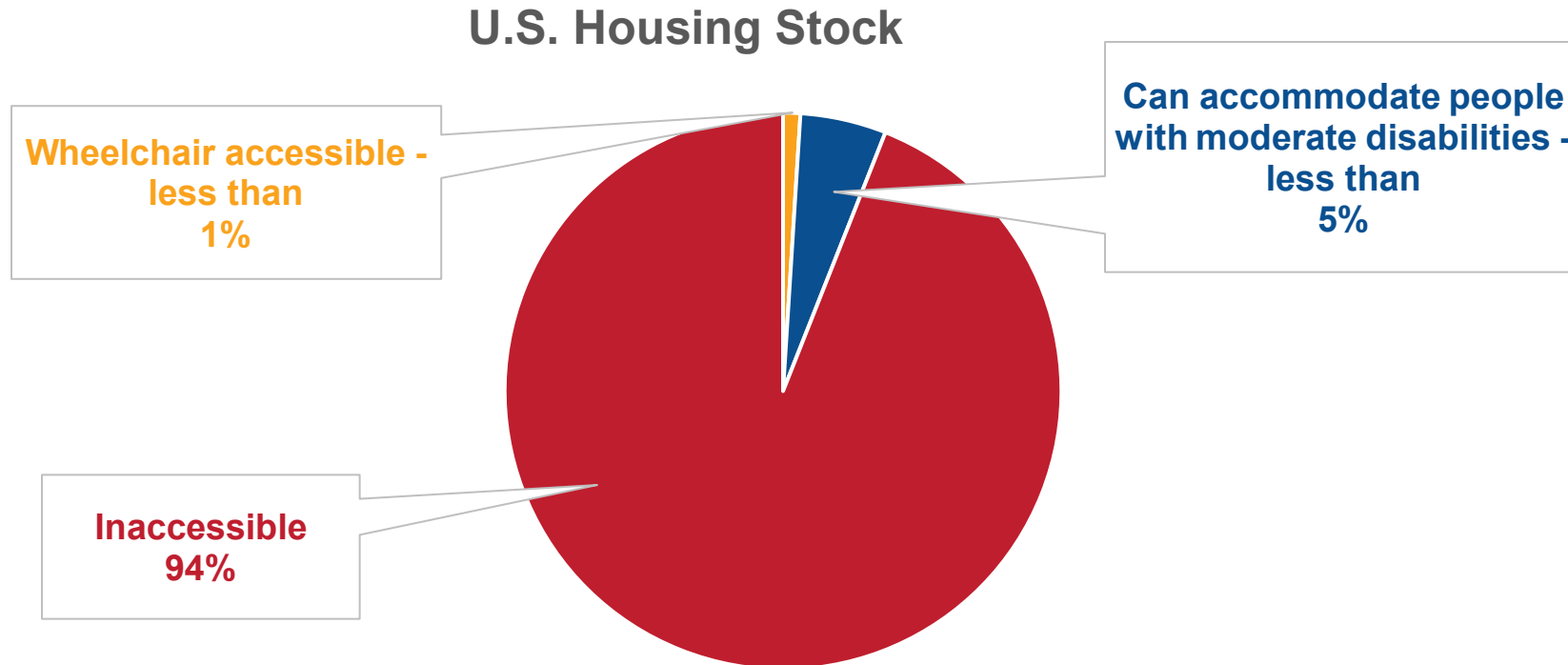
**Housing and Services
Resource Center**

April 13, 2022

Today's Agenda

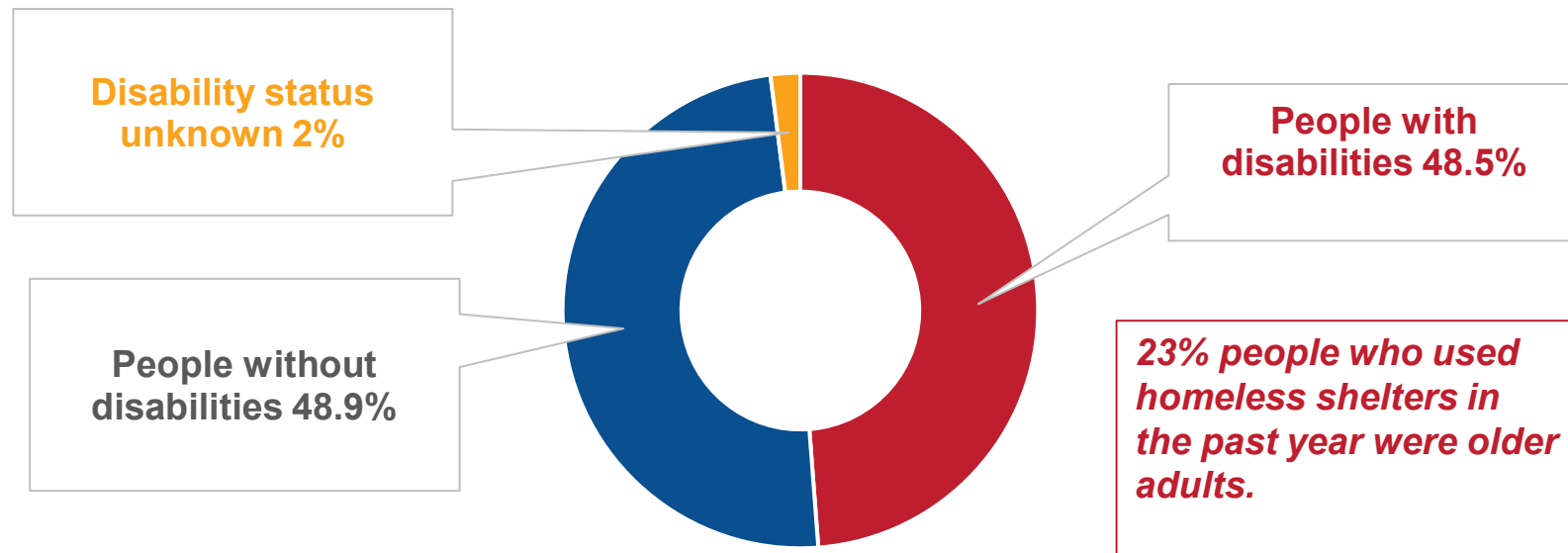
- Housing and Services Challenges
- Solutions and Opportunities
- The New Housing and Services Resource Center and HHS/HUD Partnership
- Questions and Discussion

It's Difficult to Find Accessible and Affordable Housing



People with Disabilities and Older Adults Experience Homelessness

Heads of Households and Adults Experiencing Sheltered Homelessness



Finding, Navigating and Obtaining Services is Challenging

- People aren't aware of the services and programs that can help them.
- The array of programs and funding streams that provide services are complex and difficult to navigate.
- Workforce shortages impact service availability.
- Program innovation and disability, aging, health and housing sector success strategies occur and may be solutions for additional states and communities.

Solutions

- American Rescue Plan Investment
 - Housing Vouchers
 - Money Follows the Person
 - Older Americans Act funds for Services and Assistive Technology
- HHS/HUD Partnership
- Housing and Services Resource Center
- Strengthen and Increase Partnerships across the disability, aging, health and housing sectors at all levels.



Housing and Services Resource Center

**JUST
LAUNCHED!**

acl.gov/HousingAndServices [#HousingResources](https://twitter.com/HousingResources)



Connecting

the housing sector and the
community living networks



- 1. Coordinate Technical Assistance**
- 2. Facilitate Partnerships**
- 3. Recognize and Share Innovations**
- 4. Leverage and Align Resources**

Learn more at: acl.gov/HousingAndServices

Closing

- Thank you for your research and the work you do each day to serve people with disabilities, their families, older adults, and caregivers.
- Visit the [HSRC What's New page](#) to learn about upcoming webinars and or review recorded webinars
- Please email us at hsrc@acl.hhs.gov to
 - Tell us about your partnerships with the disability, aging, health and housing sector and how you're helping people stay stably housed, transition out of institutions, and/or obtain, maintain accessible, affordable housing and services.
 - Ask a question, or
 - To be added to the HSRC list serve



Housing and Services
Resource Center

Questions & Discussion

Contact Information



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Autism and Homelessness: Experiences from the Bergen County, New Jersey Housing, Health & Human Services Center

IACC Full Committee Meeting
April 13, 2022



Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

Julia Orlando, Bergen County Housing, Health & Human Services Center



- Julia Orlando is the Director of the Bergen County Housing, Health & Human Services Center in Hackensack, NJ.
- The mission of this nationally recognized and award-winning Center is to end homelessness in Bergen County.
- In 2016, Ms. Orlando provided leadership for the successful community-wide effort to end veteran homelessness in Bergen County.
- Ms. Orlando also provided leadership that led to Bergen County becoming the first in the nation in 2017 to successfully reach functional zero for chronic homelessness in Bergen County and the only community to date to sustain zero for more than one year.



Julia Orlando on Autism and Homelessness at the Housing, Health & Human Services Center of Bergen County, NJ





Challenges serving autistic individuals and those with IDD who are experiencing homelessness

- Two primary groups:
 - Youth and young adults with autism/IDD whose families are unable to care for them (in some cases, the parents are in economic hardship, also have autism/IDD, mental illness, substance abuse disorders, health issues, or other complex needs)
 - Middle aged to older adults with autism/IDD whose parents have passed away and did not have care plans in place for them



Challenges serving autistic individuals and those with IDD who are experiencing homelessness

- Both groups not connected to DD services
- There are major barriers in connecting individuals to DD services if they had not previously been connected prior to adulthood
- Major challenges for managing in the shelter environment: social/emotional skills, communication challenges, lack of self-care or independence skills, high levels of anxiety, co-occurring conditions, and vulnerability to unsafe situations with others in the shelter population
- Homeless shelter staff need more guidance, training, and/or a toolkit or roadmap to recognize/identify individuals with autism/IDD, understand how to address their needs, and connect them to social services and supports that could make them successful in assisted housing



Break

Discussion of the IACC Charge



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

National Autism Coordinator Update

IACC Full Committee Meeting
April 13-14, 2022

Susan Daniels, Ph.D.

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



National Autism Coordinator Update

- White House and Global Policy Updates
- U.S. Federal Advisory Committee Updates

White House and Global Policy Updates

- White House
- United Nations World Autism Awareness Day Observance
- World Health Organization (WHO) Online Caregiver Skills Training
- Canadian Autism Spectrum Disorder Alliance (CASDA)

White House

- In March 2022, [President Biden appointed 21 new citizen members to the President's Committee for People with Intellectual Disabilities \(PCPID\)](#). The Committee, managed by Administration for Community Living (ACL), advises the President and the Secretary of the U.S. Department of Health and Human Services on issues related to people with intellectual disabilities.
- On March 15, 2022, President Biden signed into law the [\\$1.5 trillion Consolidated Appropriations Act of 2022](#) that sends federal agencies \$14.5 billion for special education and \$6 million for home and community-based services (HCBS). This was the first federal appropriations bill to be approved since President Biden took office and funds the government through September 2022.
- On April 2, 2022, President Biden issued his [2022 Presidential Proclamation for World Autism Awareness Day](#), reaffirming his Administration's commitment to support and opportunities for people on the autism spectrum and their families.

United Nations World Autism Awareness Day Observance

- On April 2, World Autism Awareness Day, in his [statement](#), United Nations (UN) Secretary-General António Guterres affirmed the UN's support of the rights of people on the autism spectrum to fully participate in society in accordance with the UN Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development. The Secretary-General acknowledged that the COVID-19 pandemic has exacerbated many inequalities and highlighted the critical importance of community-based support systems, such as systems for inclusive education.
- This year's [UN special event](#) took place April 8, 2022 and the theme was "Inclusive Quality Education for All." It organized by the UN with the support of civil society partners including the Autistic Self Advocacy Network, the Global Autism Project, and the Specialisterne Foundation.

World Health Organization (WHO) Online Caregiver Skills Training

- In advance of World Autism Awareness Day, the World Health Organization launched an [online version of its training program for caregivers of children with developmental delays or disabilities \(DD\)](#). This program has been piloted in more than 30 countries and teaches skills that can be used to promote the well-being and development of children. The online training includes recorded information sessions on a variety of topics. Sessions also help caregivers improve their own well-being.
- In April, WHO will launch companion manuals for facilitators of in-person trainings. The program was developed in collaboration with Autism Speaks.

Canadian Autism Spectrum Disorder Alliance ([CASDA](#))

- CASDA is an alliance formed in 2007 focused on addressing complex issues that Autistic Canadians and their families face across their lifespan and has been at the forefront of calling for the creation of a comprehensive national autism strategy addressing funding and policies for the autism community in Canada.
- Over the years, CASDA has done several consultations with stakeholders to collect data and issued [Blueprint for a National ASD Strategy](#) (2019 – focused on community needs) and a [Roadmap for a National Autism Strategy](#) (2020 – focused on process and timeline). Future step – form an advisory committee with broad representation.
- CASDA also oversees the national [Ready, Willing & Able](#) inclusive employment program with Inclusion Canada.
- CASDA recently held their 8th annual [Canadian Autism Leadership Summit](#) on April 4-5, 2022, focused on themes such as: equity, diversity, and inclusion in policy development, including indigenous and other underrepresented populations; employment, housing, non-speaking autism, and the experience of adults diagnosed later in life.
- The meeting featured a panel discussion of autism strategic plans from around the world, including perspectives, and lessons. Countries and organizations included the U.S., U.K., Malta, Autism Europe, and the Public Health Agency of Canada. The IACC and the role of the IACC Strategic Plan in shaping federal autism policy in the U.S. was shared.

U.S. Federal Advisory Committee Updates

- Federal Partners in Transition (FPT)
- Interagency Committee for Disability Research (ICDR)
- National Council on Disability (NCD)
- RAISE Family Caregiving Advisory Council (FCAC)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Federal Communication Commission Disability Advisory Committee (DAC)

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.
- Members are continuing to work on developing a new Strategic Plan and updating the mission/vision statement for FPT.
- Recent activities include:
 - Held a meeting on March 17, 2022. The meeting featured presentations from the DOL's Office of Disability Employment Policy (ODEP) and representatives of the [Center for Advancing Policy on Employment for Youth \(CAPE-Youth\)](#), a collaboration between ODEP, The Council of State Governments, and the Yang-Tan Institute on Employment and Disability at Cornell University.

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

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:
 - Publication of [FY 2021 ICDR Accomplishments Report](#). Details of specific ICDR accomplishments and research highlights throughout FY 2021 are included in the report.
 - The ICDR Executive Committee held a meeting on February 24, 2022. The Executive Committee provided feedback on and brainstormed ideas on the new ICDR focus areas of Equity, Disability Data and Statistics, and COVID-19 and Disability Rehabilitation Research.

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

- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- In February 2022, NCD published their [Health Equity Framework for People with Disabilities](#) and held a virtual meeting to share the details of the Framework with the community.
 - The Framework is a blueprint to help policy makers to address disparities and inequities within disability and included input from national disability advocacy organizations.
 - The Framework includes four core goals :
 - Designating people with disabilities as a Special Medically Underserved Population (SMUP)
 - Standardizing and implementing Comprehensive Disability Clinical-Care Curricula to train providers on all disabilities across the lifespan
 - Requiring Accessibility of Medical Diagnostic Equipment
 - Improving Data Capture by including indicators of disability status in all public health surveillance systems and capturing data across the lifespan.

National Council on Disability (NCD), cont.

- In March 2022, NCD published a report on [*Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis*](#). The report examined how state Medicaid dental benefits and state waiver programs impacted the receipt of dental care among adults with intellectual and developmental disabilities (I/DD) and strategies for expanding dental care for adults with I/DD.

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

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 held an open call for nominations for this council](#) through the deadline of April 11, 2022. Up to 15 non-federal voting members from the following groups will be appointed for three-year terms: family caregivers; older adults who need long-term services and supports; individuals with disabilities; health care and social service providers; providers of long-term services and supports; employers; paraprofessional workers; state and local officials; accreditation bodies; veterans; and as appropriate, other experts and advocates engaged in family caregiving.

Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)

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).
- The ISMICC will meet on April 13, 2022. The full agenda for the meeting, along with meeting minutes and other materials, is available [at this link](#).
- The agenda includes a presentation on how state courts address mental illness and several working group reports.

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 DAC is currently [seeking public feedback](#) on the implementation of the Twenty-First Century Communications and Video Accessibility Act. The biennial report is due in October 2022.
 - Areas for comment include compliance with mandates for telecommunications and advanced communications services (ACS), equipment used with these services, and Internet browsers built into mobile phones, to be accessible to and usable by people with disabilities.
 - Also seeking comments on barriers to access to new communications technologies for people with disabilities.

IACC Committee Business

IACC Full Committee Meeting
April 13-14, 2022



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Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

Committee Business Overview



- Autism Awareness Month
- Upcoming Meetings
- IACC Strategic Plan Discussion
- IACC Summary of Advances Discussion

April is Autism Awareness Month



NIMH Special Event for Autism Awareness Month



NIMH/OARC SPECIAL EVENT FOR AUTISM AWARENESS MONTH:

Animating the Future for Exceptional Minds



WEDNESDAY, APRIL 27, 2022 • 1:00 PM TO 2:30 PM
VIRTUAL EVENT • [HTTPS://IACC.HHS.GOV](https://iacc.hhs.gov)



National Institute
of Mental Health

OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

EXCEPTIONAL MINDS

Check out the April 2022 edition of the OARC Newsletter



Please enjoy OARC's quarterly newsletter, which includes Autism Awareness Month activities, recent events, news, and publications.

Autism Awareness Month



A Proclamation on World Autism Awareness Day

In his 2022 Presidential Proclamation for World Autism Awareness Day, President Joseph R. Biden reaffirms his Administration's commitment to equity for people on the autism spectrum across all races, ethnicities, genders, cultures, and geography in access to services, inclusion of people with lived experience in research, opportunities for competitive integrated employment, and the ability to pursue their life interests free of discrimination.



U.N. Secretary-General Statement for World Autism Awareness Day

For World Autism Awareness Day, United Nations (UN) Secretary-General António Guterres affirmed the UN's support of the rights of people on the autism spectrum to fully participate in society. The rights of people with disabilities are supported in the UN's Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development. Secretary Guterres recognizes that the COVID-19 pandemic has exacerbated many inequalities as well as the need for community-based support systems, such as systems for inclusive education, which is the topic of this year's [UN World Autism Awareness Day Special Event](#) on April 8, 2022.

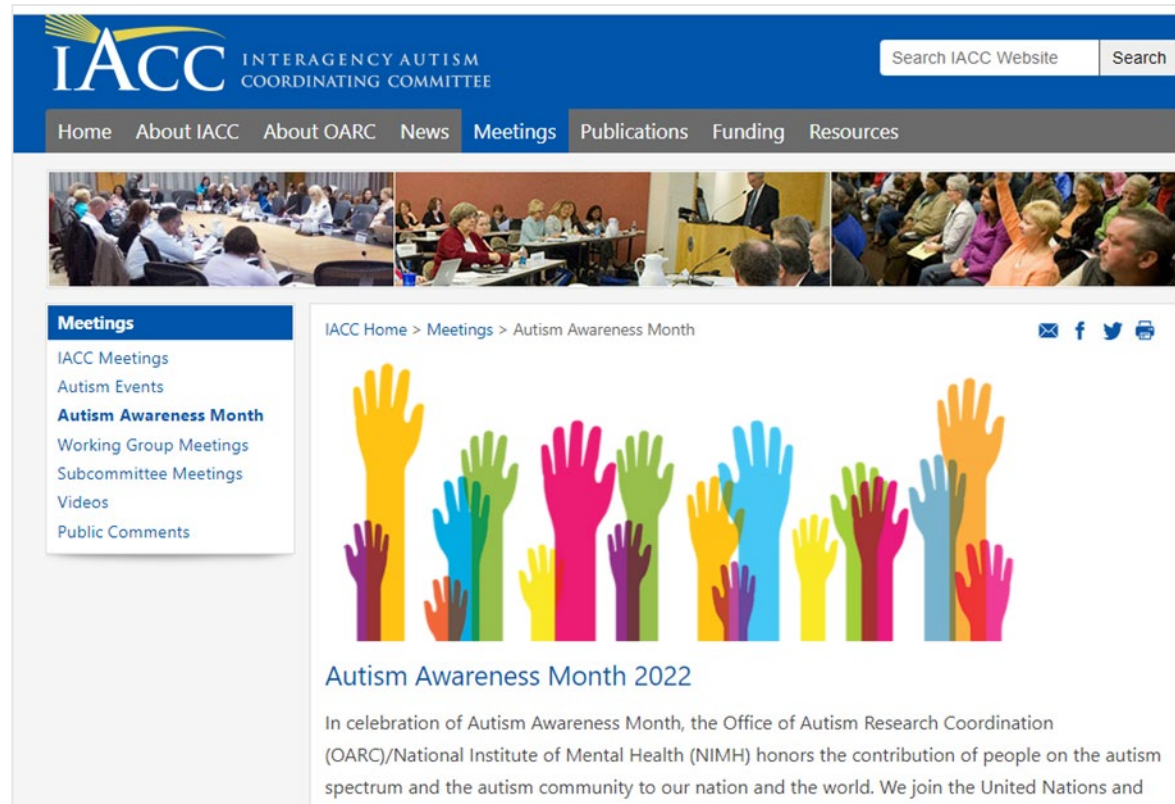


NIMH/OARC Special Event for Autism Awareness Month: Animating the Future for Exceptional Minds

The National Institute of Mental Health (NIMH) and the Office of Autism Research Coordination (OARC) are hosting their 9th Annual Autism Awareness Month Special Event, *Animating the Future for Exceptional Minds*. The event will feature Exceptional Minds, a non-profit organization in Los Angeles, California, that prepares young adults on the autism spectrum for careers in the digital arts and entertainment industry.

- The OARC Newsletter provides updates on autism news from around the community.
- The April 2022 newsletter highlights Autism Awareness Month activities, federal agency updates, and more.

Visit Our Autism Awareness Month Page!



Check the IACC website for more information and a list of events

<https://iacc.hhs.gov/meetings/autism-awareness-month/2022/>

Upcoming IACC Meetings



Strategic Plan Workgroup Meeting (virtual)

July 13-14, 2022

IACC Full Committee Meeting (virtual or hybrid)

October 26, 2022

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>

2021-2022 IACC Strategic Plan Discussion



Susan A. Daniels, Ph.D.

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

2021-2022 IACC Strategic Plan Process



- ✓ October-November 2021: OARC collected feedback on the Strategic Plan from the general public in a Request for Information (RFI). Results of the RFI were presented at the January IACC Meeting.
- ✓ January 2022: IACC members discussed aspects of the Strategic Plan at the Full Committee Meeting. Members voted to:
 - Add a section to the upcoming Plan addressing the impact of the COVID-19 pandemic.
 - Add a cross-cutting objective to address disparities.
 - Extend the timeline on the current budget recommendation by 5 years.
- ✓ November 2021-March 2022: OARC collected feedback on the Strategic Plan from IACC members in a survey. Results will be presented today.

2021-2022 IACC Strategic Plan Process



- ☐ TODAY: Discuss IACC member feedback on the Strategic Plan
- ☐ April-June 2022: OARC staff will prepare a draft of the updated Strategic Plan, incorporating feedback received from IACC members and the public
- ☐ May 2022: OARC will send another survey to IACC members in requesting feedback on the Mission and Values Statements
- ☐ July 2022: OARC will send first draft of the Strategic Plan to IACC members
- ☐ July 13-14, 2022: Strategic Planning Workgroup Meeting (virtual)
 - ☐ Open to all IACC members
 - ☐ Members will review first draft of the Strategic Plan and provide global comments

2021-2022 IACC Strategic Plan Process



- ☐ July-September 2022: OARC will prepare a revised draft of the Strategic Plan
- ☐ Early October 2022: OARC will send a revised draft of the Strategic Plan to IACC members for review
- ☐ October 26, 2022: IACC Full Committee Meeting
 - ☐ Members will review the revised draft, **with a goal of approving the Strategic Plan**
- ☐ November-December 2022: OARC will prepare the approved draft for publication

2021-2022 IACC Strategic Plan Discussion

IACC Member Feedback Survey Results



Susan A. Daniels, Ph.D.

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Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

What should be the title of the 2021-2022 Strategic Plan?



Proposed Title	Number of Votes
IACC Strategic Plan for Autism Research, Services, and Policy	28
IACC Strategic Plan for Autism Spectrum Disorder	6
Other	3

Note: Since the enactment of the Autism CARES Act of 2014, the IACC Strategic Plan has been required to address issues related to services and supports, as well as research.

Updating the IACC Strategic Plan: General Comments



- Increased need for inclusion in research, including community-based participatory research
- Addressing disparities
- Address the whole spectrum and the whole lifespan
- Emphasize actions and solutions where possible
- Emphasize commitment to equity and elimination of stigma and discrimination
- Language considerations
 - Move away from deficits-based language and toward more neutral, strengths-based, or inclusive language
 - Maintain accuracy when referring to issues that may be scientific, medical, or clinical in nature

Q1: Screening and Diagnosis Important Topics to Address



- Biomarkers
- Universal screening
- Availability of and access to services
- Disparities
- Detection and intervention/support before behavioral differences are apparent
- Telehealth approaches
- Tools (e.g. milestone tracking)
- Translating research findings into practice
- Medical practitioner training
- Caregiver engagement
- Systems navigation

Q2: Biology

Important Topics to Address



- Biology across the lifespan
- Co-occurring physical and mental health conditions
- Sensory and motor differences
- Cognition and behavior
- Brain function and connectivity
- Sex differences; female protective effect
- Human neuroimaging studies
- Longitudinal studies
- Translational studies
- Microbiome
- Ethics of human studies

Q3: Genetic and Environmental Factors Important Topics to Address



- Interactions among multiple genetic, epigenetic, and/or environmental factors
- Large genetic and epigenetic studies
- Inclusion of diverse populations in genetic studies
- Deeper understanding of genetic variants
- Common factors that impact both autism and co-occurring conditions
- Modifiable environmental factors (e.g. maternal diet)
- Influence of genetic factors on response to medications and interventions

Q4: Interventions

Important Topics to Address



- Medical, behavioral, educational, and complementary approaches
- Interventions that improve quality of life
- Personalized, culturally-competent interventions
- Naturalistic Developmental Behavioral Interventions (NDBIs)
- Pre-emptive intervention for challenging behaviors
- Parent/caregiver-mediated interventions
- Communication tools, alternative and augmentative communication (AAC)
- Outcome measures and biomarkers
- Community access to information about safety and efficacy
- Telehealth approaches
- Technology-based interventions

Q5: Services and Supports Important Topics to Address



- Scaling and implementing interventions
- Health system integration
- Community-based service delivery
- Identifying and reducing disparities
- Family dynamics, support, and engagement; parent and sibling perspectives
- Services workforce training and development
- Person-centered services
- Systems navigation
- Medicaid, Medicare, and Social Security policies

Q6: Lifespan Important Topics to Address



- Adult diagnosis
- Transition age youth and young adult outcomes
- Employment
- Housing
- Safety
- Family dynamics and trauma
- Community inclusion
- Aging autistic adults
- How issues such as those listed above act as social determinants of health

Q7: Infrastructure and Surveillance Important Topics to Address



- Improvement and expansion of systems that track autism prevalence
- Public-private partnerships
- Data banks and biobanks
- Privacy guidelines
- Adult prevalence studies
- Community outreach/dissemination of information
- Research and clinical workforce development
- Support for early career researchers

COVID-19 Pandemic Important Topics to Discuss



- Mitigating increased risk of COVID-19 in autistic individuals
- Effect of disruptions in school, access to intervention/services
- Mental health supports
- Impact of switch to remote school, work, healthcare, and services
- Impact of the pandemic on autism research community

Disparities

Important Topics to Discuss



- Reduce disparities in diagnosis, access to services and supports
 - Race/ethnicity
 - Gender
 - Sexual orientation/gender identity
 - Disability status
 - Socioeconomic status
 - Geographical location
- Increase inclusion and engagement with underserved communities
- Increase diversity in research and clinical workforce
- Increase cultural competency of educators, medical practitioners, and other service providers

2021-2022 IACC Strategic Plan

Next Steps



Upcoming Action Items

- May 2022: Members to respond to survey requesting feedback on the Mission and Values Statements
- July 2022: Review first draft of the Strategic Plan
 - Two options to provide feedback:
 - Attend Strategic Plan Workgroup Meeting, July 13-14
 - Send written feedback via survey
 - In both cases, feedback will be in the form of global comments

IACC Summary of Advances Discussion



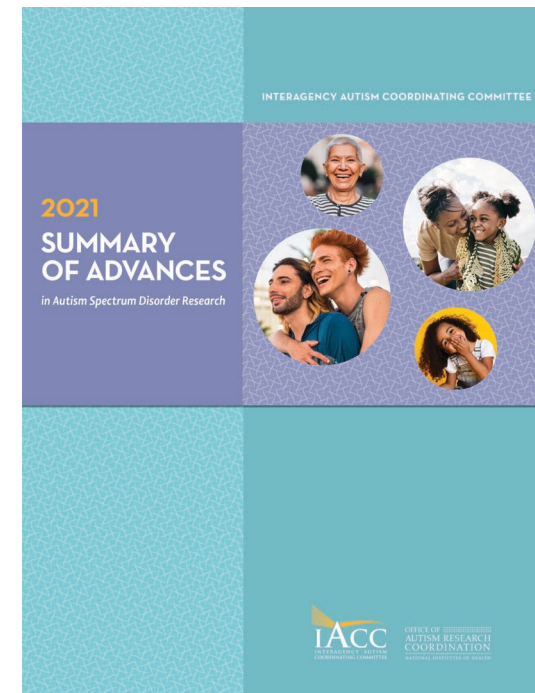
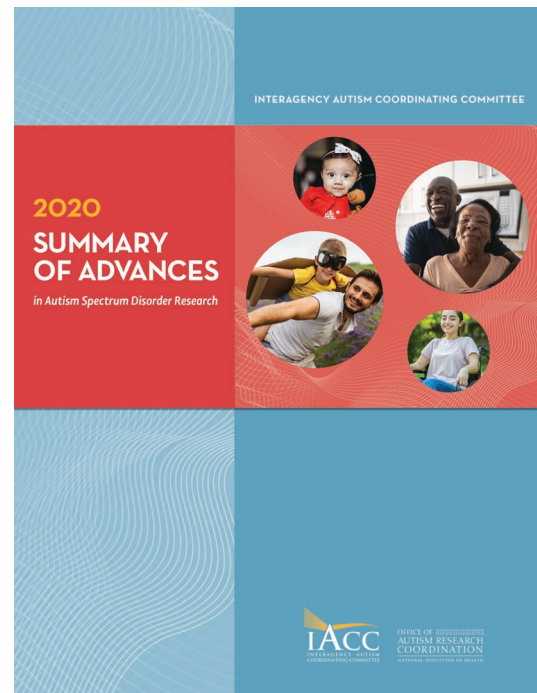
Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
(NIMH) and Chair, IACC

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

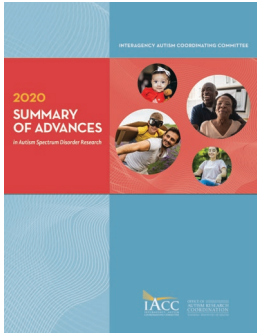
IACC Summary of Advances



- Annual report required by the Autism CARES Act of 2019
- Provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- IACC members have been working to complete **2020** and **2021** editions of the publication

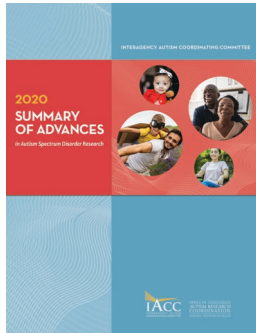


2020 IACC Summary of Advances Process



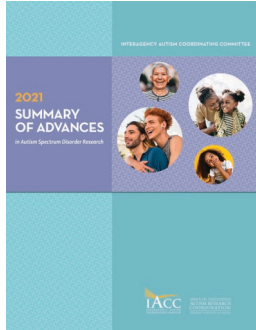
- ✓ IACC members nominate articles (July-October 2021)
- ✓ IACC members discuss nominations at committee meeting (January 2022)
- ✓ IACC members vote on top 20 articles (February 2022)
- ✓ OARC prepares article summaries and draft publication (February-March 2022)
- ✓ IACC members review draft and provide feedback (March 2022)
- ❑ OARC prepares final publication (April-May 2022)

2020 IACC Summary of Advances Available soon!



- Anticipated publication: May 2022
- Includes articles addressing all 7 topic areas of the *IACC Strategic Plan*
- **NEW THIS YEAR:** Easy-read version containing 1-sentence summaries of the top 20 advances

2021 Summary of Advances Process



- ✓ IACC members nominate articles (July-December 2021)
- ☐ IACC members discuss nominations at committee meeting **(TODAY)**
- ☐ IACC members vote on top 20 articles (May 2022)
- ☐ OARC prepares article summaries and draft publication (Summer 2022)
- ☐ IACC members review draft and provide feedback (Summer 2022)
- ☐ OARC prepares final publication (Fall 2022)

2021 Summary of Advances Nominations



During the following slides:

- Are there articles you find particularly noteworthy?
- Are there articles you would like to flag for potential removal from the list?



2021 Summary of Advances Nominations



Question 1: Screening and Diagnosis

- **Race/ethnic inequities in conjoint monitoring and screening for U.S. children 3 and under: Disparities in Monitoring and Screening.**

Barger B, Benevides T, Ritzk S, Rice C, et al.

- **Computational Methods to Measure Patterns of Gaze in Toddlers With Autism Spectrum Disorder.**

Chang Z, Di Martino JM, Aiello R, Baker J, et al.

- **Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet.**

Feinberg E, Augustyn M, Broder-Fingert S, Bennett A, et al.

- **Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis.**

Kaat AJ, Shui AM, Ghods SS, Farmer CA, et al.

2021 Summary of Advances Nominations



Question 1: Screening and Diagnosis, cont.

- **Information Avoidance and Information Seeking Among Parents of Children With ASD.**

Sicherman N, Law K, Lipkin PH, Loewenstein G, et al.

- **The Early Screening for Autism and Communication Disorders: Field-testing an autism-specific screening tool for children 12 to 36 months of age.**

Wetherby AM, Guthrie W, Hooker JL, Delehanty A, et al.

- **Rethinking autism spectrum disorder assessment for children during COVID-19 and beyond.**

Zwaigenbaum L, Bishop S, Stone WL, Ibanez L, et al.



Question 2: Biology

- **Early social communication development in infants with autism spectrum disorder.**

Bradshaw J, McCracken C, Pileggi M, Brane N, et al.

- **A voxel-wise assessment of growth differences in infants developing autism spectrum disorder.**

Cárdenas-de-la-Parra A, Lewis JD, Fonov VS, Botteron KN, et al.

- **A Longitudinal Study of Parent Gestures, Infant Responsiveness, and Vocabulary Development in Infants at Risk for Autism Spectrum Disorder.**

Choi B, Shah P, Rowe ML, Nelson CA, Tager-Flusberg H.

- **Long-term maturation of human cortical organoids matches key early postnatal transitions.**

Gordon A, Yoon SJ, Tran SS, Makinson CD, et al.

- **Quantitative and Qualitative Sex Modulations in the Brain Anatomy of Autism.**

Hammill C, Lerch JP, Taylor MJ, Ameis SH, et al.

2021 Summary of Advances Nominations



Question 2: Biology, cont.

- **Age of walking and intellectual ability in autism spectrum disorder and other neurodevelopmental disorders: a population-based study.**

Havdahl A, Farmer C, Schjølberg S, Øyen AS, et al.

- **Controlling litter effects to enhance rigor and reproducibility with rodent models of neurodevelopmental disorders.**

Jiménez JA, Zylka MJ.

- **Infant vocalizing and phenotypic outcomes in autism: Evidence from the first 2 years.**

Plate S, Yankowitz L, Resorla L, Swanson MR, et al.

- **Children with ASD and Communication Regression: Examining Pre-Loss Skills and Later Language Outcomes Through the Preschool Years.**

Prescott KE, Ellis Weismer S.

2021 Summary of Advances Nominations



Question 2: Biology, cont.

- **Parental Language Input Predicts Neurooscillatory Patterns Associated with Language Development in Toddlers at Risk of Autism.**
Romeo RR, Choi B, Gabard-Durnam LJ, Wilkinson CL, et al.
- **Influence of siblings on adaptive behavior trajectories in autism spectrum disorder.**
Rosen NE, McCauley JB, Lord C.
- **Functional connectivity during language processing in 3-month-old infants at familial risk for autism spectrum disorder.**
Tran XA, McDonald N, Dickinson A, Scheffler A, et al.
- **Patterns of delay in early gross motor and expressive language milestone attainment in probands with genetic conditions versus idiopathic ASD from SFARI registries.**
Wickstrom J, Farmer C, Green Snyder L, Mitz AR, et al.
- **Parallel in vivo analysis of large-effect autism genes implicates cortical neurogenesis and estrogen in risk and resilience.**
Willsey HR, Exner CRT, Xu Y, Everitt A, et al.

2021 Summary of Advances Nominations



Question 3: Risk Factors

- **How rare and common risk variation jointly affect liability for autism spectrum disorder.**

Klei L, McClain LL, Mahjani B, Panayidou K, et al.

- **Impact of autism genetic risk on brain connectivity: a mechanism for the female protective effect.**

Lawrence KE, Hernandez LM, Fuster E, Padgaonkar NT, et al.

- **Maternal prenatal selenium levels and child risk of neurodevelopmental disorders: A prospective birth cohort study.**

Lee ASE, Ji Y, Raghavan R, Wang G, et al.

- **Developmental vitamin D and autism spectrum disorders: findings from the Stockholm Youth Cohort.**

Lee BK, Eyles DW, Magnusson C, Newschaffer CJ, et al.

- **Patterns of de novo tandem repeat mutations and their role in autism.**

Mitra I, Huang B, Mousavi N, Ma N, et al.

2021 Summary of Advances Nominations



Question 3: Risk Factors, cont.

- **Gene-Environment Interactions in Developmental Neurotoxicity: a Case Study of Synergy between Chlorpyrifos and CHD8 Knockout in Human BrainSpheres.**

Modafferi S, Zhong X, Kleensang A, Murata Y, et al.

- **Prenatal exposure to per- and polyfluoroalkyl substances in association with autism spectrum disorder in the MARBLES study.**

Oh J, Bennett DH, Calafat AM, Tancredi D, et al.

- **Association between self-reported caffeine intake during pregnancy and social responsiveness scores in childhood: The EARLI and HOME studies.**

Patti MA, Li N, Eliot M, Newschaffer C, et al.

- **Gestational Exposure to Phthalates and Social Responsiveness Scores in Children Using Quantile Regression: The EARLI and HOME Studies.**

Patti MA, Newschaffer C, Eliot M, Hamra GB, et al.

- **Rates of contributory de novo mutation in high and low-risk autism families.**

Yoon S, Munoz A, Yamrom B, Lee YH, et al.

2021 Summary of Advances Nominations



Question 4: Treatments and Interventions

- **Research Review: Conflicts of Interest (COIs) in autism early intervention research - a meta-analysis of COI influences on intervention effects.**

Bottema-Beutel K, Crowley S, Sandbank M, Woynaroski TG.

- **Predicting progress in word learning for children with autism and minimal verbal skills.**

Brady NC, Kosiog C, Fleming K, Williams L.

- **Chapter Eight - Lifestyle intervention adaptations to promote healthy eating and physical activity of youth with intellectual and developmental disabilities.**

Curtin C, Bowling AB, Boutelle KN, Broder-Fingert S, et al.

- **Medication Use in Youth With Autism and Attention-Deficit/Hyperactivity Disorder.**

Rast JE, Anderson KA, Roux AM, Shattuck PT.

2021 Summary of Advances Nominations



Question 4: Treatments and Interventions, cont.

- **Intranasal Oxytocin in Children and Adolescents with Autism Spectrum Disorder.**

Sikich L, Kolevzon A, King BH, McDougle CJ, et al.

- **Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis.**

Whitehouse AJO, Varcin KJ, Pillar S, Billingham W, et al.

2021 Summary of Advances Nominations



Question 5: Services

- **Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services.**

Bhat A.

- **Correlates of oral health fatalism in caregivers of children with autism spectrum disorder.**

Hammersmith KJ, Harlan TA, Fenning RM, Chan J, et al.

- **The Lancet Commission on the future of care and clinical research in autism.**

Lord C, Charman T, Havdahl A, Carbone P, et al.

- **Who gains and who loses? Sociodemographic disparities in access to special education services among autistic students**

Sturm A, Williams J, Kasari C.

2021 Summary of Advances Nominations



Question 5: Services, cont.

- **Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort.**
White LC, Law JK, Daniels AM, Toroney J, et al.
- **Healthcare Costs of Pediatric Autism Spectrum Disorder in the United States, 2003-2015.**
Zuvekas SH, Grosse SD, Lavelle TA, Maenner MJ, Dietz P, Ji X.

2021 Summary of Advances Nominations



Question 6: Lifespan Issues

- **"Best Things": Parents Describe Their Children with Autism Spectrum Disorder Over Time.**
Cost KT, Zaidman-Zait A, Mirenda P, Duku E, et al.
- **Comparison of Motor Vehicle Crashes, Traffic Violations, and License Suspensions Between Autistic and Non-Autistic Adolescent and Young Adult Drivers.**
Curry AE, Metzger KB, Carey ME, Sartin EB, et al.
- **Self-reported parkinsonism features in older autistic adults: A descriptive study.**
Geurts HM, McQuaid GA, Begeer S, Wallace GL.
- **Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services.**
Schott W, Nonnemacher S, Shea L.

2021 Summary of Advances Nominations



Question 6: Lifespan Issues, cont.

- **The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder.**

Vivanti G, Tao S, Lyall K, Robins DL, Shea LL.

- **Identifying School-Based Factors that Predict Employment Outcomes for Transition-Age Youth with Autism Spectrum Disorder.**

Wong J, Coster WJ, Cohn ES, Orsmond GI.



Question 7: Infrastructure and Surveillance

- **A lost generation? The impact of the COVID-19 pandemic on early career ASD researchers.**

Harrop C, Bal V, Carpenter K, Halladay A.

- **Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018.**

Maenner MJ, Shaw KA, Bakian AV, Bilder DA, et al.

- **Biases, Barriers, and Possible Solutions: Steps Towards Addressing Autism Researchers Under-Engagement with Racially, Ethnically, and Socioeconomically Diverse Communities.**

Maye M, Boyd BA, Martínez-Pedraza F, Halladay A, et al.

2021 Summary of Advances Nominations



Question 7: Infrastructure and Surveillance, cont.

- **Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018.**

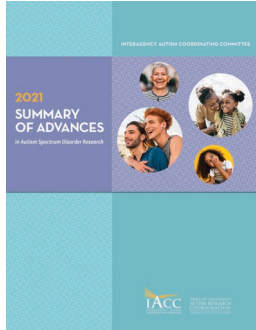
Shaw KA, Maenner MJ, Bakian AV, Bilder DA, et al.

- **Making Research Possible: Barriers and Solutions For Those With ASD and ID.**

Thurm A, Halladay A, Mandell D, Maye M, et al.

2021 IACC Summary of Advances

Next steps



Upcoming Action Items

- May 2022: Use emailed ballot to vote for top 20 advances
- Summer 2022: Provide feedback on draft publication

Adjournment - Day 1



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

Please join us for the continuation of this meeting tomorrow from 1:00-5:00 p.m. ET.

<https://videocast.nih.gov/watch=44690>

<https://iacc.hhs.gov>

Thank you!