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
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

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

Source: Picture of Subsidized Households, 2021: [https://www.huduser.gov/portal/ datasets/assthsg.html](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/assthsq.html
“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

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 helped 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/](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 EHV s 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](https://www.hud.gov/ehv)
“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](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

A Health Picture of HUD-Assisted Adults, 2006–2012


Studies Using the Linked NCHS-HUD Data


● Brucker DL, Helms VE. *Health, Health Behaviors, and Health Care Utilization Among Adults with Serious Psychological Distress Who Receive Federal Housing Assistance.*


Select Findings from one NCHS-HUD Study


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

Email: Teresa.Souza@hud.gov

Phone: 202-402-5540
Interagency Autism Coordinating Committee (IACC)

Overview of the Housing and Service Resource Center

An HHS/HUD Partnership

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

U.S. Housing Stock

- Wheelchair accessible - less than 1%
- Can accommodate people with moderate disabilities - less than 5%
- Inaccessible 94%
People with Disabilities and Older Adults Experience Homelessness

Heads of Households and Adults Experiencing Sheltered Homelessness

- People with disabilities: 48.5%
- People without disabilities: 48.9%
- Disability status unknown: 2%

23% people who used homeless shelters in the past year were older adults.
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.
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
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 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)
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.
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.
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:
  o 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.
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.
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.
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

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
Committee Business Overview

- Autism Awareness Month
- Upcoming Meetings
- IACC Strategic Plan Discussion
- IACC Summary of Advances Discussion
April is Autism Awareness Month
Check out the April 2022 edition of the OARC Newsletter

- 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
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
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.
Acting National Autism Coordinator
Director, Office of Autism Research Coordination
Executive Secretary, Interagency Autism Coordinating Committee
National Institute of Mental Health
What should be the title of the 2021-2022 Strategic Plan?

<table>
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<th>Proposed Title</th>
<th>Number of Votes</th>
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<tr>
<td>IACC Strategic Plan for Autism Spectrum Disorder</td>
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<td>Other</td>
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**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
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
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
• 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)
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.

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

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

• Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis.
Question 1: Screening and Diagnosis, cont.

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

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

Question 2: Biology

- Early social communication development in infants with autism spectrum disorder.
  Bradshaw J, McCracken C, Pileggi M, Brane N, et al.

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

  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.
Question 2: Biology, cont.

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

• 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.
Question 2: Biology, cont.

- Parental Language Input Predicts Neurooscillatory Patterns Associated with Language Development in Toddlers at Risk of Autism.
- 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.
- Parallel in vivo analysis of large-effect autism genes implicates cortical neurogenesis and estrogen in risk and resilience.
Question 3: Risk Factors

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

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

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

• 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.
Question 3: Risk Factors, cont.

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

• 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.

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

• Rates of contributory de novo mutation in high and low-risk autism families.
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, Kosirog 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.
Question 4: Treatments and Interventions, cont.

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

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


- Who gains and who loses? Sociodemographic disparities in access to special education services among autistic students
  Sturm A, Williams J, Kasari C.
• Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort.
  Zuvekas SH, Grosse SD, Lavelle TA, Maenner MJ, Dietz P, Ji X.
Question 6: Lifespan Issues

• "Best Things": Parents Describe Their Children with Autism Spectrum Disorder Over Time.

• 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.
Question 6: Lifespan Issues, cont.

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

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

  Wong J, Coster WJ, Cohn ES, Ormond 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.

  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.
Question 7: Infrastructure and Surveillance, cont.

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

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

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
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!