

2023 AUCD Autism Acceptance Month Webinar Series

A First Look at the 2023 IACC Strategic Plan

Sponsored by Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities and AUCD's Autism Special Interest Group (SIG)



A project of AUCD to support Autism CARES programs

- Ensure your name is displayed correctly in the participant list. You may also include program name and state and preferred pronouns.
 - Example: Rachel Miller, AUCD, she/her
- Hover over your name in the “Participants” box and select “More” → “Rename”
- Remain muted unless speaking
- State your name prior to speaking
- Captioning is available
- Use chat box to introduce yourself!



A project of AUCD to support Autism CARES programs

Autism SIG Co-Chairs

Anjali Rao, M.D.



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Dr. Susan Daniels

National Autism Coordinator for the U.S. Department of Health and Human Services
Director of the Office of Autism Research Coordination (OARC), NIMH
Executive Secretary of the Interagency Autism Coordinating Committee (IACC)



Updates from the Interagency Autism Coordinating Committee and the National Autism Coordinator: A First Look at the 2021-2023 IACC Strategic Plan

Association of University Centers on Disabilities
April 26, 2023



Susan A. Daniels, Ph.D.
Acting National Autism Coordinator, U.S. Department of Health and Human Services
Executive Secretary, Interagency Autism Coordinating Committee
Director, Office of Autism Research Coordination
National Institute of Mental Health, National Institutes of Health

Updates from the Interagency Autism Coordinating Committee and the National Autism Coordinator



- Overview of **Federal Autism Policy and Coordination**
- **Interagency Autism Coordinating Committee (IACC)**
- A First Look at the ***2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy***
- **National Autism Coordinator (NAC)**





Autism Is a Topic of National Interest

Autism encompasses a wide variety of research, services, and policy issues.

New algorithm detects autism in infants. How might that change care?

 Karen Weintraub
USA TODAY

Published 11:00 a.m. ET Feb. 8, 2023 | Updated 3:36 p.m. ET Feb. 13, 2023

The New York Times

Autism Prevalence Rises Again, Study Finds

The pandemic may have disrupted the detection of autism spectrum disorder in young children, researchers also reported.

U.S. Parents Face Big Disparities in Access to Autism Care Services

By HealthDay | Jan. 30, 2023, at 7:44 a.m.

AUTISM

Why Autistic People Can Struggle in the Workplace

Why masking, fatigue, emotional regulation, and communication can cause issues.

Posted November 18, 2022 | Reviewed by Devon Frye

The Washington Post
Democracy Dies in Darkness

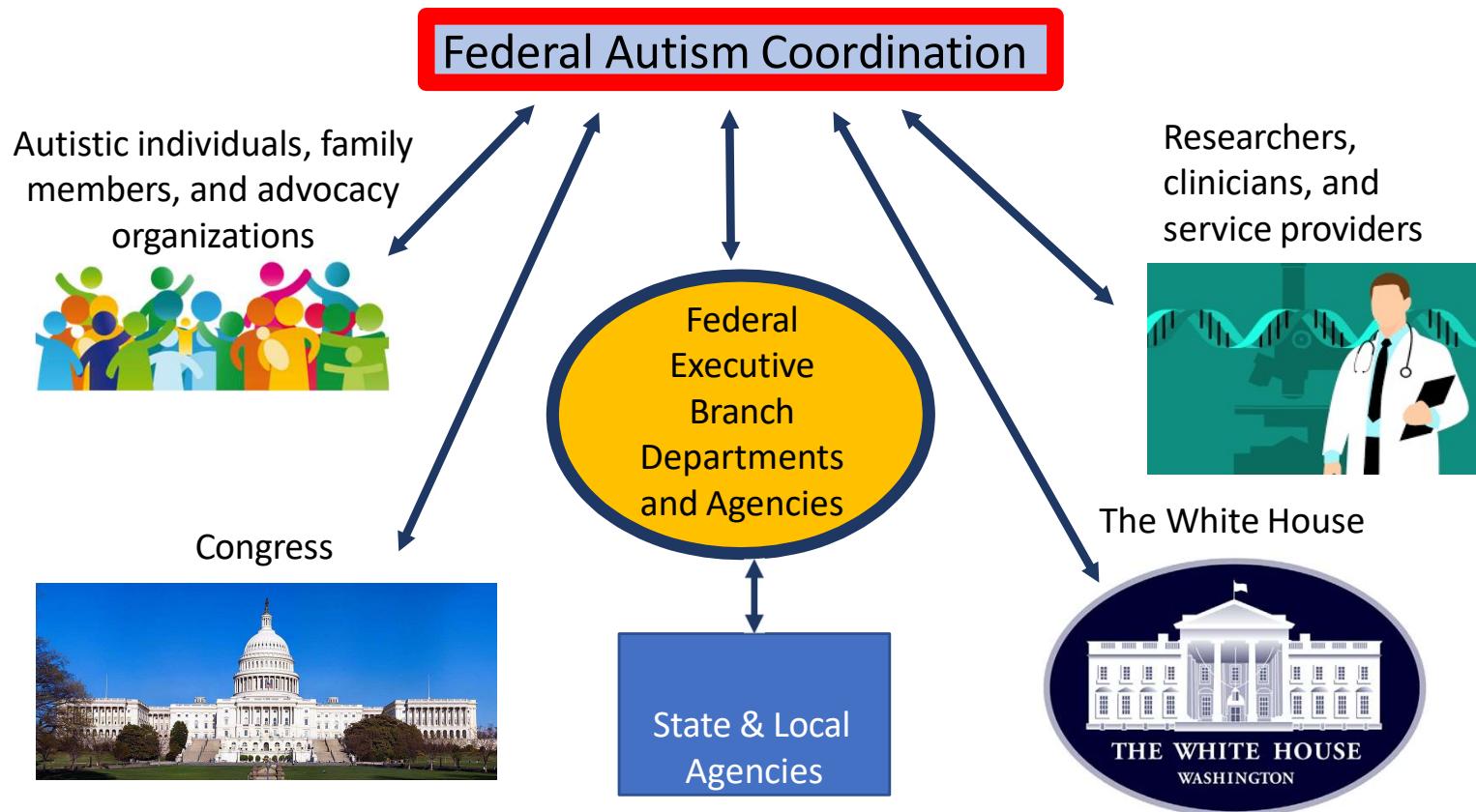
Autism now more common among Black, Hispanic kids in US

By Mike Stobbe | AP
March 23, 2023 at 5:11 p.m. EDT





Many Stakeholders Involved in Federal Autism Coordination





Many Federal Departments/Agencies Are Involved in



National Institutes
of Health



HRSA
Health Resources & Services Administration

**FDA U.S. FOOD & DRUG
ADMINISTRATION**



ADMINISTRATION FOR
CHILDREN & FAMILIES



ACL
Administration for Community Living



SAMHSA
Substance Abuse and Mental Health
Services Administration

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

EPA United States
Environmental Protection
Agency



National
Science
Foundation



Agency for Healthcare
Research and Quality

VA | U.S. Department
of Veterans Affairs



Federal Autism Coordination



- A Congressionally-mandated system of **federal coordination** of autism-related efforts that was established to:
 - Ensure **public input**
 - Foster **communication and collaboration** among federal and non-federal partners
 - Support **autism research, services, and policy** to meet the needs of individuals on the autism spectrum and their families
- There are two key layers of this coordination:
 - **Interagency Autism Coordinating Committee**
 - **National Autism Coordinator**



Federal Autism Legislation



Combating Autism Act of 2006

- Authorized the Interagency Autism Coordinating Committee (IACC)
- Authorized several federal autism research and services-related programs

Combating Autism Reauthorization Act of 2011

- Reauthorized the Combating Autism Act of 2006

Autism Collaboration, Accountability, Research, Education, and Supports (CARES) Act of 2014

- Reauthorized the IACC
- Created a National Autism Coordinator role

Autism CARES Act of 2019

- Added additional federal departments and public members to the IACC



Layers of Federal Autism Coordination

Interagency Autism Coordinating Committee (IACC)

- Federal advisory committee with federal and public members
- Public forum for discussion
- Provides advice and recommendations to the Secretary of Health and Human Services (HHS)

National Autism Coordinator (NAC)

- Federal Interagency Workgroup on Autism (FIWA) (Federal members only)
- Coordination of implementation of IACC recommendations and autism activities across agencies

Office of Autism Research Coordination (OARC)

- Office in National Institute of Mental Health that manages the IACC and staffs the NAC

Disability-Related Federal Advisory Committees

- Address disability issues more broadly

Federal Agencies

- Funders of autism research and services programs that serve autistic individuals

Interagency Autism Coordinating Committee (IACC)



- U.S. federal advisory committee that **coordinates federal efforts and provides advice to the Secretary of Health and Human Services (HHS)** on issues related to autism
- Established under the Combating Autism Act (CAA) of 2006 and currently authorized under the **Autism CARES Act of 2019**
- Membership includes **23 federal agencies and departments and 19-21 public members** representing diverse backgrounds
- Public members include **autistic adults, parents and family members, and leaders of advocacy, research, and services organizations**

IACC Membership



- New IACC Members are nominated and appointed each term:
 - **Federal officials** representing multiple departments and agencies
 - **Autistic adults**
 - **Family members and caregivers** of autistic individuals
 - **Autism researchers**
 - **Clinicians and providers**
 - Representatives of **advocacy and services organizations**
- **Diversity** across geography, gender/gender expression, sexual orientation, race/ethnicity, ability/disability, age, and expertise



2021-2024 IACC Membership: Largest and Most Diverse



Interagency Autism Coordinating Committee (IACC)



Convene

3-4 times annually



Coordinate

federal agency activities related to autism

Gather

public input on issues related to autism



Develop

and annually update a strategic plan for autism

Develop

an annual summary of advances in autism research

Monitor

federal activities related to autism

Advise

and make recommendations to the HHS Secretary





Role of the IACC in Autism Policy

The IACC is **advisory**.

- IACC identifies priorities and makes **recommendations** on autism research, services, and policy.
- **Advice** goes to the HHS Secretary and federal agencies.

The IACC **does not** allocate funding or implement federal programs.

- Federal agencies allocate funding and implement federal programs, **taking into account the recommendations of the IACC Strategic Plan**.



IACC Meetings



A collage of five screenshots from IACC meetings. Top left: "New Data from the Autism and Developmental Disabilities Monitoring (ADDM) Network" featuring Kelly Shaw and Matthew Maenner. Top right: A two-person video call between Kelly Shaw and Matthew Maenner. Middle row: A grid of 12 video feeds from a "Full Committee Meeting" on April 4, 2023, showing various committee members. Bottom left: "National Autism Coordinator Update" for the "IACC Full Committee Meeting April 4, 2023". Bottom right: "Public Comment Session" featuring Susan Daniels and Joshua Gordon.

IACC meetings feature:

- Presentations and panels
 - Including professionals and individuals with lived experience
 - Wide variety of topics of interest to the autism community
 - Examples – aging, communication, housing, employment, services, Kevin & Avonte's Law
- Federal agency updates
- National Autism Coordinator Update
- Committee Business
- Public Comments

The IACC Achieves Its Goals by Fostering:



Collaboration

- Bringing diverse stakeholders to the table
- Creating partnerships among community and federal partners

Cohesion

- Creating a **collective voice** on top priorities
- Covering the full range of needs
- Building consensus

Community

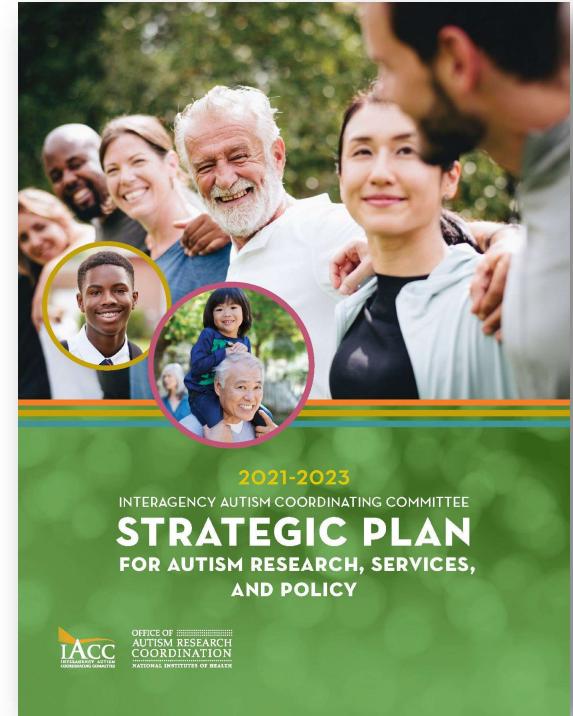
- Valuing people with different experiences
- Committing to meet everyone's needs
- Committing to reducing stigma and discrimination

IACC Strategic Plan



- One of the key statutory responsibilities of the IACC is the development of a strategic plan for **autism research, services, and policy**.
- The plan outlines **priorities and directions for autism-related efforts** across federal agencies and partner private organizations.
- It is one of the main ways the IACC **provides advice and recommendations** to the HHS Secretary and federal agencies on autism activities.
- The **2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy** was approved by the Committee in January 2023 and is expected to be released in Spring 2023.
- This is the **8th edition** of the IACC Strategic Plan.

COMING SOON



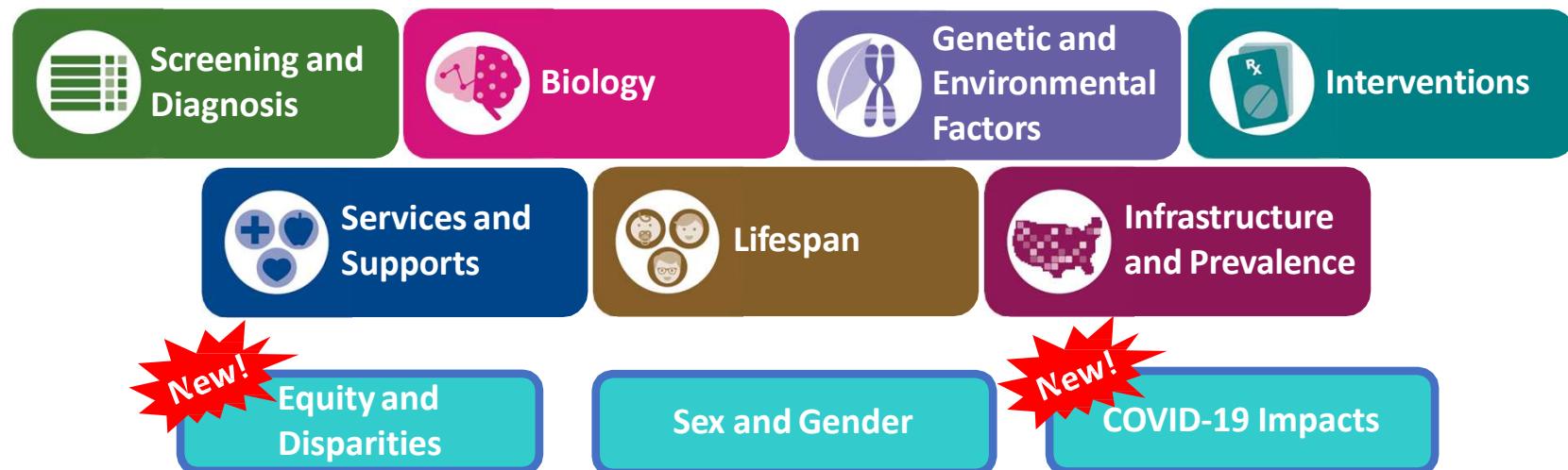
2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy: **A Collective Voice of the IACC**



The Strategic Plan incorporates **extensive input shared by individuals across the autism community and IACC members**, representing a **collective voice** from the IACC to the HHS Secretary on **priorities for autism research, services, and policy**.

IACC Strategic Plan Content

- The Strategic Plan is organized around **seven community-focused topics** and includes **recommendations that address research, services, and policy activities**.
- In addition, the *2021-2023 IACC Strategic Plan* includes **two cross-cutting themes** and a section on the **impact of COVID-19** on the autism community.





Question 1: Screening and Diagnosis



How Can We Improve Identification of Autism?

- Developing new and improved **diagnostic and screening tools**
- Reducing **disparities** in identification of autism

Aspirational Goal

Provide a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes.

IACC Recommendations

1. Support research on how early detection of autism influences outcomes.
2. Reduce disparities in early detection and access to services.
3. Develop and adapt screening and diagnostic tools, including tools that incorporate new technologies to increase efficiency, accuracy, and timeliness of identification.



Question 2: Biology

What Is the Biology Underlying Autism?

- Identifying **differences in brain structure and function**
- Understanding **co-occurring physical and mental health conditions**

Aspirational Goal

Discover the roles of brain development, cognition (thought, emotion, and experiences), and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan.

IACC Recommendations

1. Foster research to better understand the processes of early development, molecular and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of autism.
2. Support research to understand the underlying biology of co-occurring conditions in autism and to understand the relationship of these conditions to autism.
3. Support large-scale longitudinal studies to answer questions about the development and natural history of autism across the lifespan, from pregnancy through childhood, adolescence, adulthood, and older adulthood.



Question 3: Genetic and Environmental Factors



What Are the Genetic and Environmental Factors that Contribute to Autism and its Co-Occurring Conditions?

- Identifying factors that influence **development and trajectory of autism**
- Understanding the **interaction of multiple factors**

Aspirational Goal

Discover and understand genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum.

IACC Recommendations

1. Strengthen understanding of genetic factors that influence autism and its co-occurring conditions across the full diversity of individuals on the autism spectrum.
2. Understand the influence of environmental factors on the development and progression of autism and its co-occurring conditions, enabling the development of strategies to maximize positive outcomes.
3. Expand knowledge about how multiple environmental and genetic factors interact biologically to result in autism phenotypes.



Question 4: Interventions



Which Interventions Will Improve Health and Well-Being?

- Developing new and improved **behavioral and medical interventions**
- Designing **educational approaches and innovative technologies**

Aspirational Goal

Develop a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum.

IACC Recommendations

1. Develop and improve pharmacological and other medical interventions that will maximize positive outcomes for individuals on the autism spectrum.
2. Create and improve a variety of psychosocial, developmental, occupational, and educational interventions that will maximize positive outcomes for individuals on the autism spectrum.
3. Develop and improve technology-based interventions that will maximize positive outcomes for individuals on the autism spectrum.



Question 5: Services and Supports

What Services and Supports Are Needed to Maximize Health and Well-Being?

- Implementing **evidence-based practices in community settings**
- **Reducing disparities** in access to services

Aspirational Goal

Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families.

IACC Recommendations

1. Develop service approaches and scale up and implement evidence-based interventions in community settings.
2. Address disparities in service provision and improve access to services for all, including low resource and underserved communities and individuals and families with high support needs.
3. Improve service delivery to ensure quality and consistency of services across many domains with the goal of maximizing positive outcomes and the value that individuals get from services.



Question 6: Lifespan

How Can We Address the Needs of People on the Autism Spectrum throughout the Lifespan?

- Addressing the **needs of adolescents and adults with autism**, including **employment**, education, life skills, housing, health, etc.

Aspirational Goal

Promote inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships.

IACC Recommendations

1. Support development and coordination of integrated services to help people on the autism spectrum successfully transition to adulthood and progress through the lifespan with appropriate services and supports.
2. Support research and develop and implement approaches to improve physical and mental health outcomes across the lifespan, with the goal of improving safety, reducing premature mortality, and enhancing health and well-being.
3. Support research, services activities, and outreach efforts that facilitate and incorporate accessibility, as well as acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.



Question 7: Infrastructure and Prevalence



How Do We Expand and Enhance Research Infrastructure Systems to Meet the Needs of the Autism Community?

- Developing and coordinating **biobanks, databases**, etc.
- Improving and expanding **prevalence monitoring systems and surveys**

Aspirational Goal

Develop, enhance, and support research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services.

IACC Recommendations

1. Promote growth, linkage, coordination, and security of biorepository and data repository infrastructure systems, equitable access to these systems, and inclusion of diverse samples.
2. Expand and enhance the research workforce, with attention to diversity and inclusion, and accelerate the pipeline from research to practice.
3. Strengthen statistical data gathering systems to advance understanding of the autistic population, while allowing comparisons and linkages across systems as much as possible.



2 Cross-Cutting Topics

Sex and Gender

- Autism characteristics and experiences of **women, girls, and LGBTQIA+ individuals**
- **Better identification/diagnosis and appropriate interventions and services** for these populations

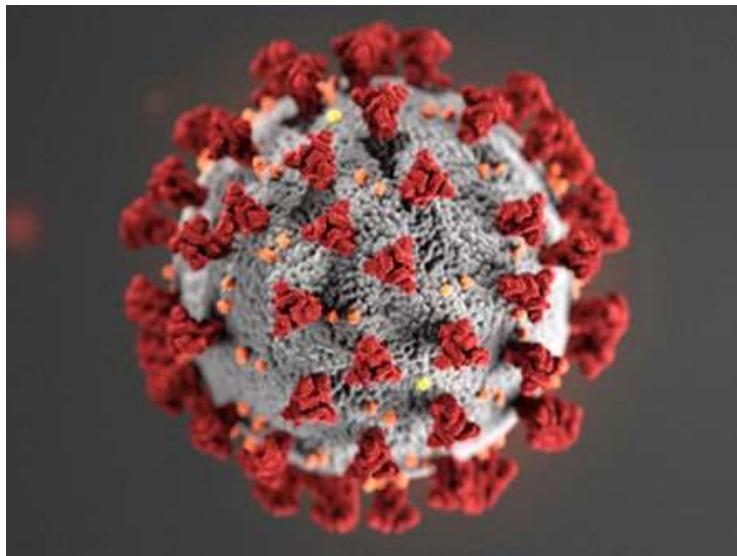
Equity and Disparities

- Impacts of **intersectional identities** on health and well-being
- Development of **culturally competent tools and services**

IACC Recommendations

1. Support research to understand sex and gender differences in autism.
2. Support diversity, equity, inclusion, and accessibility (DEIA) efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people.

Impact of COVID-19 Pandemic



Topics covered in this chapter include:

- Physical and mental health impacts of COVID-19 on people on the autism spectrum
- Impact of COVID-19 mitigation efforts on the autism community, including:
 - Loss of services, social isolation
 - Benefits of new modalities such as telehealth and telework
- Impact the pandemic on autism research

IACC Autism Research Budget Recommendation



The IACC calls for the autism research budget to reach **\$685 million by 2025**.

- **Lifespan issues:** Increased funding is needed for research on issues relevant to autistic adults, such as transition to adulthood, higher education, employment, housing, healthcare, lifelong learning, service, and support opportunities, community integration, and healthy aging.
- **Evidence-based interventions and services:** Increasing the evidence base for new and existing interventions and services will provide additional guidance to autistic individuals and their families as they seek solutions to maximize positive outcomes.
- **Research on disparities and development of culturally competent tools and services:** Continued investment is needed to close the existing gaps in outcome measures due to differences across race/ethnicity/culture, sex/gender, sexual orientation, geographic location, and socioeconomic status.



Priorities of the 2021-2023 IACC Strategic Plan

Greater acceptance and inclusion of individuals on the autism spectrum

Increased accessibility of services and research for autistic individuals and their families

Solutions for people across the **entire spectrum**, including those with the **highest support needs**

Solutions for people across the **entire lifespan**, including autistic **older adults**

Solutions to improve **physical and mental health** for individuals on the autism spectrum

Intersection of **social determinants of health** and the services system

Increase equity and reduce disparities



New or Newly-emphasized Items in the Strategic Plan

- Sensory and motor aspects of autism
- High support needs, e.g. intellectual disability, self-injurious behaviors, lifelong supports
- Communication research and technologies/AAC
- Aging and older adulthood
- Caregiver issues
- Neurodiversity
- Gender identity and expression
- Greater inclusion of autistic people in planning and conduct of research



Next Steps



- The IACC Strategic Plan will be submitted to Congress and the President and disseminated
- IACC Member Agencies and partner private organizations can begin to implement recommendations of the IACC Strategic Plan
- Progress on implementation of Strategic Plan recommendations is monitored and reported
- Reports are used to inform the IACC
- The IACC provides future updates of the Strategic Plan



National Autism Coordinator (NAC)

The Autism CARES Act of 2014/2019 requires that the HHS Secretary designate a **National Autism Coordinator** to:

- **Oversee**, in consultation with the Secretaries of Defense and Education, **national autism research, services, and support activities**.
- **Ensure implementation** of the IACC Strategic Plan.
- **Prevent unnecessary duplication** of effort.





National Autism Coordinator (NAC)

Oversee

national autism research, services, and support activities

Convene

Federal Interagency Workgroup on Autism (FIWA), an all-federal work group

Ensure

implementation of the IACC Strategic Plan

Coordinate

interdepartmental efforts and requests, including reports to Congress

Monitor

other federal advisory committees addressing issues relevant to autism

Facilitate

exchange of information, connections, and collaborations across federal agencies

Prevent

unnecessary duplication of effort



Susan Daniels, Ph.D.
Acting National Autism
Coordinator, HHS

Reports to Congress



- The Autism CARES Act of 2019 requires **two HHS Reports to Congress** – one on federal autism activities and one on the health and well-being of individuals with autism.
- The **NAC coordinates with departments and agencies** across the federal government to produce these reports on behalf of the HHS Secretary.
- **The most recent *2021 Report to Congress on the Health and Well-Being of Individuals with Autism Spectrum Disorder*** includes information on federal activities and recommendations developed by FIWA.
- OARC and the NAC also prepare additional reports to Congress as requested by the HHS Secretary.



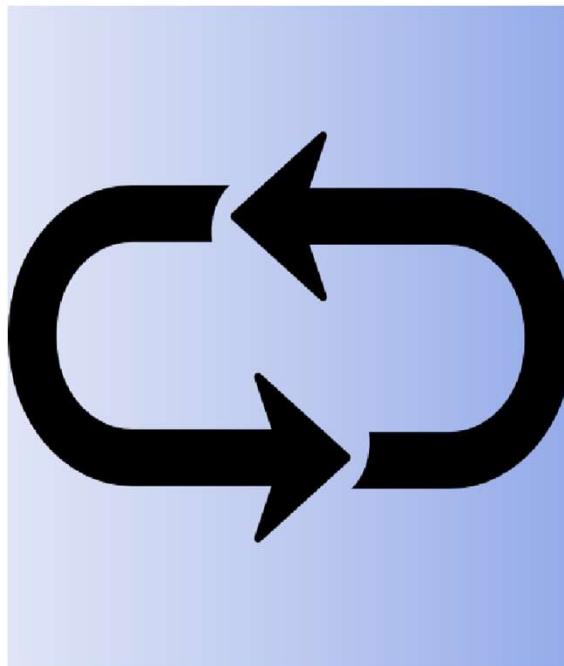
Other Federal Advisory Committees



The NAC monitors the activities of **other federal committees addressing issues relevant to autism**, including:

- [Recognize, Assist, Include, Support, and Engage \(RAISE\) Family Caregiving Advisory Council \(family caregiver issues\)](#)
- [President's Committee for People with Intellectual Disabilities](#)
- [Interagency Committee on Disability Research](#)
- [Federal Partners in Transition \(youth with disabilities\)](#)
- [National Advisory Committee on Individuals with Disabilities and Disasters \(emergency preparedness\)](#)
- [National Council on Disability \(federal agency for disability policy\)](#)

Impact of having a NAC



- More communication and coordination across Federal agencies
- Point of contact for federal autism reporting and cross agency activities
- More sharing of information about the work of other federal advisory bodies
- More sharing of federal agency information with the IACC



Learn more - Connect with us!

A screenshot of the IACC website homepage. The header includes the U.S. Department of Health & Human Services logo, the IACC logo, and links for "Get IACC Updates", "Public Comments", and "Contact". A search bar with "Search IACC Website" and "Search" buttons is also present. The main content area features a banner for "THE 2023 NIMH/OARC AUTISM AWARENESS MONTH SPECIAL EVENT" titled "A Portrait of Autism: ARTISTS & THEIR WORKS", held on Friday, April 14, 2023, from 2:00 PM to 3:30 PM ET. Below the banner are sections for "Latest Activity", "Latest News", "Latest Meetings", and "Latest Publications".

- Visit the **IACC website** at:
<https://iacc.hhs.gov/>
- Join us for the **next IACC meeting** on **October 10-11, 2023**, from 1:00 to 5:00 pm.
 - Public comments are welcome!
- **Email us** at:
iaccpublicinquiries@mail.nih.gov
- Join the **IACC mailing list**:
<https://iacc.hhs.gov/about-iacc/subscribe/>
- Follow us on Twitter (@IACC_Autism)



Thank you to the OARC Team!



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2023 Autism Acceptance Month

- **Autism SIG: Roundtable on Leadership and Mentorship**

May 8, 4:00 PM EST – 5:00 PM EST



A project of AUCD to support Autism CARES programs

Thank You for Joining Us!

The archive of this event will be posted on the AUCD and ITAC websites one week from the event date.

Please provide feedback on this webinar:

<https://www.surveymonkey.com/r/IACCPlan>

Or Scan the QR Code

