

Meeting of the Interagency Autism Coordinating Committee

July 10, 2024; 10:00 a.m. - 5:00 p.m. ET



Shelli Avenevoli, Ph.D.

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

Susan A. Daniels, Ph.D.

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

Welcome, Roll Call, and Announcements



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Housekeeping Notes: Committee Discussions



- Members attending **in-person**
 - Raise your hand to be recognized and during votes
 - Turn on your tabletop microphone to speak and turn it off when you are done.
- Members attending **virtually**
 - Use the Raise Hands feature in Zoom to be recognized
 - Use Zoom polls for voting
 - Stay muted and keep your camera off during presentations and breaks.
 - You may turn on your camera during discussions and unmute yourself to speak.
- Members **who wish to comment in writing**
 - Send your comments to SEND COMMENTS HERE (Steven Isaacson) in Zoom.
- Please **keep your comments brief.**

Housekeeping Notes



- **Closed captioning** is available in Zoom for Committee members and on Videocast for members of the viewing public.
- A **sensory room** is available down the hall. Please do not use that room for noisy activities.
- A **“Zoom room”** is available down the hall to take a call or meeting. Please let the registration desk know if you need to use.
- **Restrooms** are located in the main lobby.
- Please **silence your cell phones**.

National Autism Coordinator Update

**IACC Full Committee Meeting
July 10, 2024**

Susan A. Daniels, Ph.D.
HHS National Autism Coordinator
Executive Secretary, IACC
Director, Office of National Autism Coordination



Overview

- White House Updates
- Legislative Updates
- Federal Committee Updates
- Federal Department and Agency Updates
- Additional Updates

More information about these updates can be found in the meeting materials:

<https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#materials>

White House Updates

- In support of President Biden's Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers, HHS selected 20 states to participate in two separate technical assistance programs that together will help participating states better **recruit, train, and retain direct care workers**, who provide home and community-based services (HCBS) for older adults and people with disabilities.
 - [Read detailed press release here.](#)



White House Updates

- The Biden-Harris Administration unveiled a final rule that will protect and improve how millions of eligible people apply for, renew, and maintain health care coverage through **Medicaid, the Children's Health Insurance Program (CHIP), and the Basic Health Program (BHP)**.
 - [Read detailed press release here.](#)



White House Updates

- **WH/OSTP National Science and Technology Council, Disability Data Interagency Working Group**
 - Coordinates activities to strengthen the federal government's use of disability data to advance equity for people with disabilities. Membership crosses multiple departments and agencies.
 - Purpose: To create a **Federal Evidence Agenda on Disability Equity** by Fall 2024
 - Recently held a series of virtual listening sessions with individuals and organizations from the disability community. Individuals representing autism and IDD have been included. Interviews with federal SMEs will also be conducted.
 - The working group has published a **Request for Information (RFI), “Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity”** to collect public input
 - Release Date: May 30, 2024; Closing Date: July 15, 2024
 - [Federal Register Notice](#)

Legislative Updates

- **[H.R. 7213](#), Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024**
 - Key provisions:
 - Reauthorization of the IACC through September 2029
 - Improvements to ensure appropriate channeling of resources towards the most impactful forms of research
 - Additional language to ensure activities include individuals across the full spectrum and the full lifespan
 - Additional language ensuring that all individuals within the autism community have an opportunity to engage in the research process and other activities



Full text of updates can be found in the meeting materials:

<https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#materials>

National Autism Coordinator Update
Legislative Updates

H.R. 7213, Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024

- 2/1/24: Introduced in the House of Representatives (co-sponsored by Reps. Chris Smith and Henry Cuellar)
- 2/14/24: The House Committee on Energy and Commerce, Subcommittee on Health held a [hearing](#) to consider legislative proposals to support patients and caregivers
 - Witnesses included Dr. Andy Shih from Autism Speaks



Full text of updates can be found in the meeting materials:

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National Autism Coordinator Update
Legislative Updates

H.R. 7213, Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024

- 5/16/24: The House Committee on Energy and Commerce, Subcommittee on Health held a [hearing](#) to consider markup of 23 bills, including the Autism CARES Act of 2024
- 6/12/24: The House Committee on Energy and Commerce voted (42-0) to report the bill to the full House



Full text of updates can be found in the meeting materials:

<https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#materials>

Legislative Updates

- **Legislative Hearing on FY25** (June 11, 2024; Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Subcommittee; House Committee on Appropriations). Read the [press release here](#).
 - [Section 722 of the bill](#) includes an amendment that would prevent FDA from banning devices that have been ordered for an individual by a court, which would include electric shock devices.
 - The Appropriations Committee is expected to mark-up and vote on the bill on July 10.



Full text of updates can be found in the meeting materials:

<https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#materials>

Federal Committee Updates

- Interagency Committee for Disability Research (ICDR)
- RAISE Family Caregiving Advisory Council (FCAC)
- National Council on Disability (NCD)
- Disability Advisory Committee (DAC)
- Coordinating Council on Access and Mobility (CCAM)
- Federal Partners in Transition (FPT)
- Children's Interagency Coordinating Council (CICC)
- NSTC Disability Data Interagency Working Group

Updates on these committees can be found in the meeting materials:

<https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#materials>

Federal Committee Updates

- **Interagency Committee on Disability Research (ICDR)**
 - ICDR released an updated [Federal Statutory Definitions of Disability](#) white paper.
 - ICDR released the [Surveying the Landscape of Disability Data and Statistics](#) toolkit.
 - **ICDR's May Lunch & Learn webinar** featured a series of presentations by representatives of federal agencies that provide funding for disability and rehabilitation research.
 - **ICDR's Annual Stakeholder Meeting** took place on June 27. More information available on the [ICDR website](#).
- **RAISE Family Caregiving Advisory Council (FCAC)**
 - Joint Meeting with the **Advisory Council to Support Grandparents Raising Grandchildren** was held June 13. Access meeting information on the [FCAC website](#).

Federal Committee Updates

- **National Council on Disability (NCD)**
 - NCD held its recent council meeting on June 27, 2024. Access meeting information on the [NCD website](#).
- **Disability Advisory Committee (DAC)**
 - The DAC met on May 16 and included a dialogue on **digital accessibility**. Full meeting can be [viewed here](#).
- **Coordinating Council on Access and Mobility (CCAM)**
 - The Federal Transit Administration announced that [17 projects in 15 states](#) will receive funding to improve **public transportation for people with disabilities**, older adults, and individuals with low-incomes.

Federal Committee Updates

- **Federal Partners in Transition (FPT)**

- A Steering Committee Meeting was held on May 16. The Committee is continuing to work on updating the **FPT Strategic Plan**.
- A General Assembly meeting was also held on May 16, featuring a presentation titled “**AI & Disability Employment**.”
- Next Steering Committee and General Assembly meetings are scheduled for September 19, 2024.

- **Children’s Interagency Coordinating Council (CICC)**

- On July 22nd, 2024, the CICC is holding an event to explore issues and opportunities related to **benefit access and utilization** for children and their families experiencing poverty. [Register here](#).

Federal Department and Agency Updates

- **U.S. Department of Health and Human Services (HHS)** marks the one-year anniversary of President Biden's Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers. [Read statements here.](#)
- **Administration on Community Living (ACL)** announces nearly \$2 million to support state implementation of the National Strategy to Support Family Caregivers. [Read more here.](#)

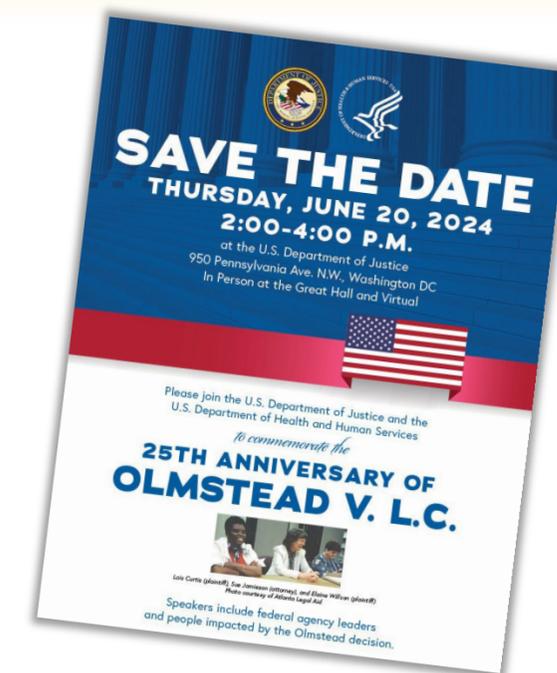


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Federal Department and Agency Updates

- **U.S. Department of Justice’s Civil Rights Division and HHS’s Administration for Community Living and Office for Civil Rights** held an event celebrating the 25th anniversary of *Olmstead v. L.C.* View the [recording here](#). Read ACL’s [blog post](#) here.
- **HHS Office for Civil Rights (OCR)** finalized a rule strengthening protections against disability discrimination under Section 504 of the Rehabilitation Act. [Read press release here](#).



Full text of updates can be found in the meeting materials:

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Federal Department and Agency Updates

■ NIMH Disability, Equity, and Mental Health Research Webinar Series

- The National Institute of Mental Health's (NIMH) Office for Disparities Research and Workforce Diversity is hosting a webinar series exploring the notion of mental health conditions as a disability. Upcoming webinars include:
 - [Nev Jones, Ph.D. - Transforming Mental Health Disability Research Through Lived Experience Leadership and Co-Production](#) (August 8, 2024, 1:00–2:30 p.m. ET)
 - [Register here.](#)
 - [Dielle Lundberg M.P.H. and Jessica Chen, Ph.D. - Framework for Understanding Structural Ableism in Health Care](#) (September 9, 2024, 2:00–3:30 p.m. ET)
 - [Register here.](#)



Non-Governmental Activities and Updates

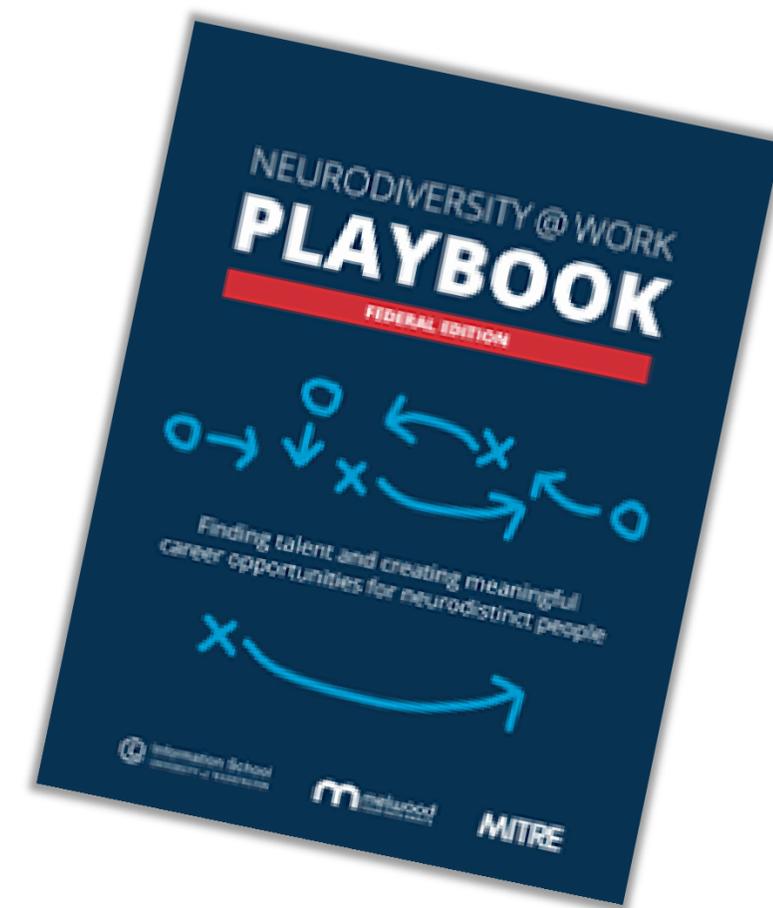
- 17th Session Of The Conference Of States Parties To The UNCRPD (COSP17)

- Held June 11-13, 2024, at the United Nations Headquarters, New York
- The overarching theme focused on **rethinking disability inclusion in preparation for the Summit of the Future**. Additional themes were **disability employment, technology innovations, and persons with disabilities in humanitarian emergencies**.
- IACC Executive Secretary Susan Daniels served on the U.S. Delegation to the conference, along with officials from the U.S. Department of State, USAID, ACL, CDC, and US Access Board, providing support on issues related to autism, neurodiversity, and IDD. IACC member Dena Gassner spoke about employment and family support at a side event sponsored by Malta.
- 3 Side Events focused on autism:
 - Australian event on forthcoming National Strategy
 - South African event on autistic voices in Africa
 - Irish/New Zealand/Hungary/WHO event on supporting autistic people in society



Non-Governmental Activities and Updates

- **Neurodiversity @ Work Playbook: Federal Edition**
 - Developed by the University of Washington, aimed at helping federal agencies establish neurodiversity employment programs and create inclusive workplaces. [Read the report here.](#)



Additional Updates

- The National Autism Coordinator Update Document outlining additional White House activities, Federal committees, news, events, and legislative updates can be accessed in the July 10, 2024 IACC Meeting Materials:
 - [National Autism Coordinator Updates – July 2024](#)

Round Robin Updates



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Federal Interagency Workgroup on Autism (FIWA) Presentations





Health Resources and Services Administration's Autism Program Interagency Autism Coordinating Committee July 10, 2024

Lauren Raskin Ramos
Division of Maternal and Child Health Workforce Development (DMCHWD)
Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People



Health Resources and Services Administration's (HRSA) Autism Programs

HRSA's programs support training, research and state systems grants to:

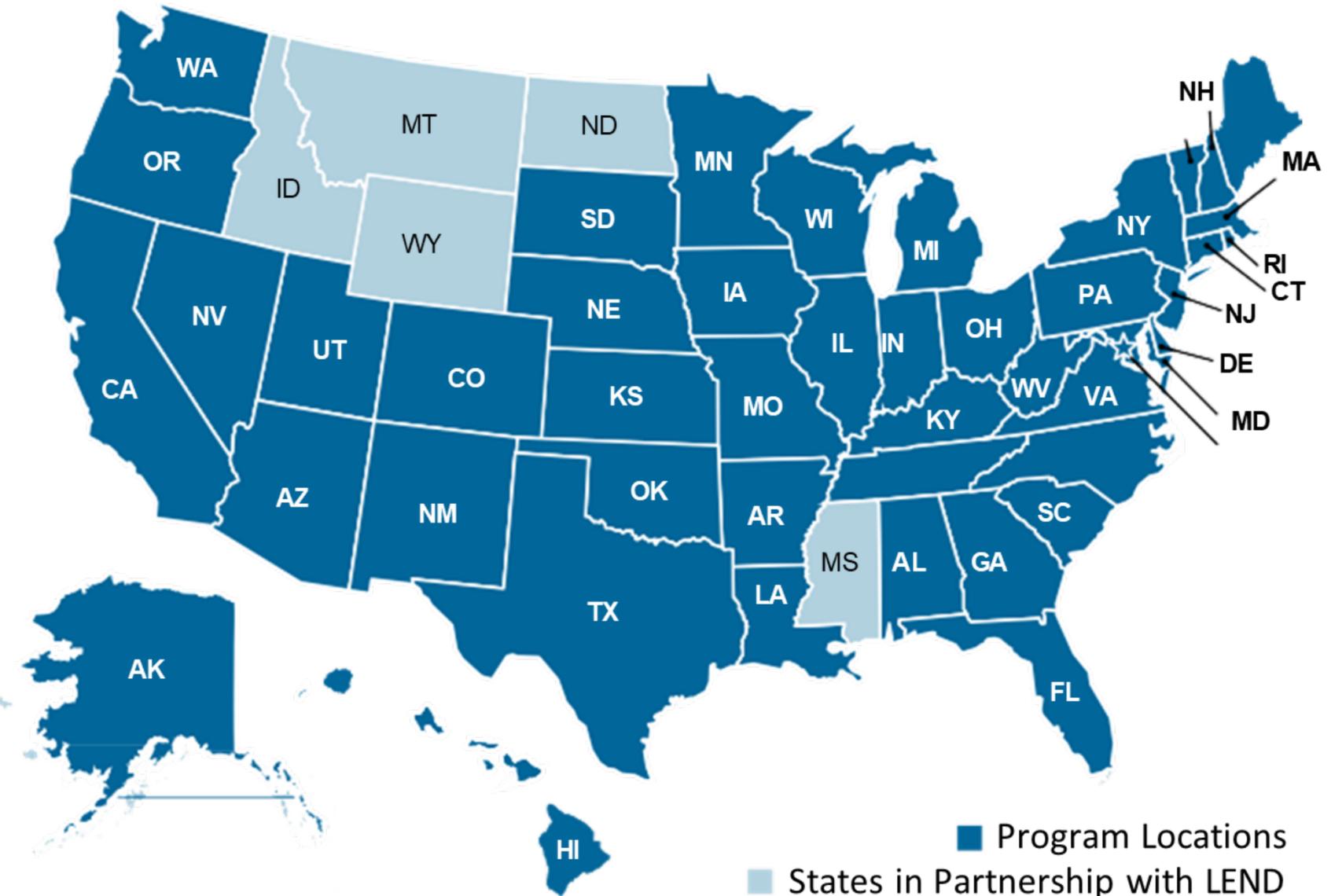
- Train health care and other professionals to **screen, refer and provide services** for children with autism or other developmental disabilities (DD)
- Promote **evidence-based interventions** for individuals with autism or other DD
- Ensure implementation of **best practices** in transition for youth with autism



Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Program

Purpose: Provide interdisciplinary training for health care and other professionals who address the needs of individuals with autism and other DD

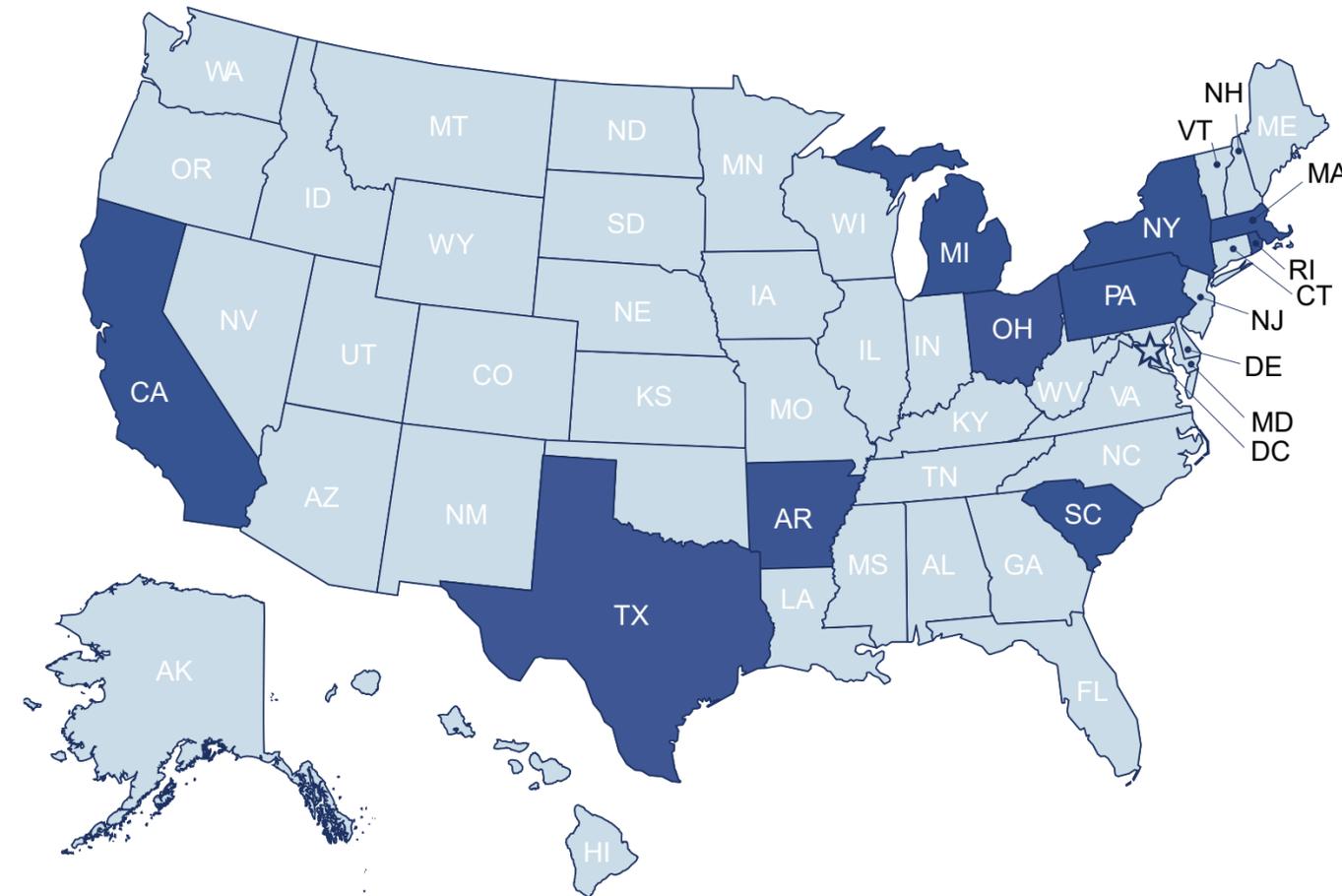
- 60 LEND programs support a national reach
- Provide academic, clinical, leadership and community-oriented training
- Nearly 18,000 trainees in over 25 disciplines reached
- Over 380,000 practicing professionals reached through continuing education



Developmental Behavioral Pediatrics (DBP) Program

Purpose: Increase access to evaluation and services for children with developmental and behavioral concerns

- 13 DBP programs support the 3-year DBP fellowship and provide enhanced clinical, research and teaching experiences
- Provide training and continuing education to pediatric practitioners, residents, and medical students to increase clinical expertise in autism and other DD
- Expanded training to pediatricians through mini-fellowships and intensive training experiences in DBP
- Over 1,900 trainees and over 38,000 practicing professionals reached



Autism Research Investments

Autism Research Networks		Autism Single Investigator Innovation Program (SIIPs)	Investigator Initiated Programs
Autism Intervention Research Network on Physical Health (AIR-P)	Developmental Behavioral Pediatrics Research Network (DBPNet)	Autism Longitudinal Data Project (ALDP)	Autism Field-Initiated Innovative Research Studies (FIRST)
Autism Intervention Research Network on Behavioral Health (AIR-B)	Healthy Weight Research Network for Children with Autism & DD (HWRN)	Autism Transitions Research Project (ATRP)	Autism Secondary Data Analysis Research (SDAR)



Best Practices: Transition for Youth with Autism and/or Epilepsy (YAES)

Purpose

To develop and advance national, state, and community-level **frameworks that support successful transition from child to adult serving systems** for youth with autism and/or epilepsy who have complex health and social needs and require a higher level of family support and coordination (YAES)

Goal

To **improve outcomes, including quality of life and well-being** for YAES and their families/caregivers transitioning from child to adult systems. **These systems include but are not limited to post-secondary education, inclusive post-secondary education, employment, community, independent/daily living, and healthcare.**

Target Population

YAES between the ages of 13 and 26 who have co-occurring conditions, intellectual disabilities, experience challenges in social cognition, communication, interpersonal skills, and or behaviors, and require a higher level of family support and coordination

Supporting Access for Everyone (SAFE) Initiative

- Inter-professional and stakeholder-driven initiative to establish a standard of practice in healthcare for supporting youth with neurodevelopmental disabilities
- 10 consensus statements across 5 domains:
 - Training
 - Communication
 - Access and planning
 - Diversity, equity, inclusion, belonging, and anti-ableism
 - Policy and structural change



Consensus Statement, Executive Summary, and Plain Language Summary at <https://safedbp.org>



Learn more at <https://mchb.hrsa.gov>

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www.HRSA.gov



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Contact Information

Lauren Raskin Ramos

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Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)

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The Congressionally Directed Medical Research Programs

Autism Research Program

Nicole Williams, Ph.D. Program Manager



Transforming Healthcare through Innovative and Impactful Research



CDMRP
DEPARTMENT OF DEFENSE
**CONGRESSIONALLY DIRECTED
MEDICAL RESEARCH PROGRAMS**

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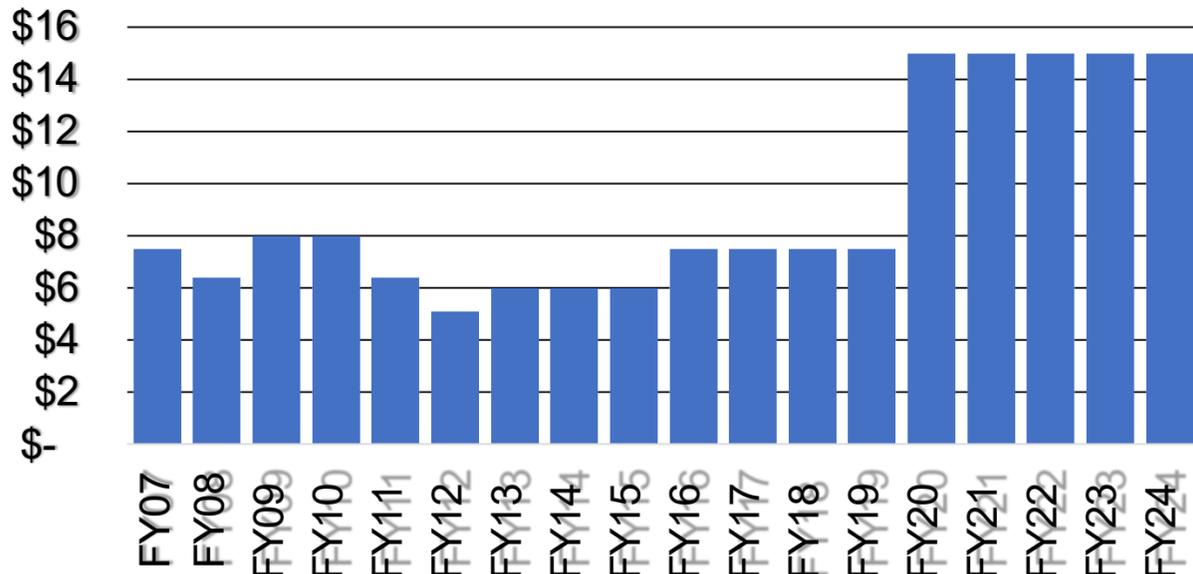
For more information, visit cdmrp.health.mil

Vision: Improve the lives of individuals with autism spectrum disorder now and in their future

Mission: Promote innovative research that advances the understanding of autism spectrum disorder and leads to improved outcomes for Service Members, their Families, and the American public

FY24: \$15.0M
FY07-FY23: \$149.4M
220 Awards

ARP Appropriations



Advance Effective Treatments and Interventions for Autism

- Cultural, socioeconomic, and gender factors in diagnosis, treatment efficacy, delivery, and access to services
- Non-pharmacological and pharmacological therapies for core symptoms/alleviate co-occurring conditions
- Understanding heterogeneity in treatment response

Address Needs of Persons with Autism into Adulthood

- Factors promoting success in key transitions to independence
- Interventions promoting success in key transitions to adulthood
- Understanding physical health and related issues in aging Autistic adults

Improve the lives of individuals with autism spectrum disorder now and in their future

Support Those Caring for the Autism Community

- Healthcare provider-focused training or tools to improve healthcare delivery for individuals with ASD, across the life span and the continuum of care
- Factors impacting quality of life for current and former military families

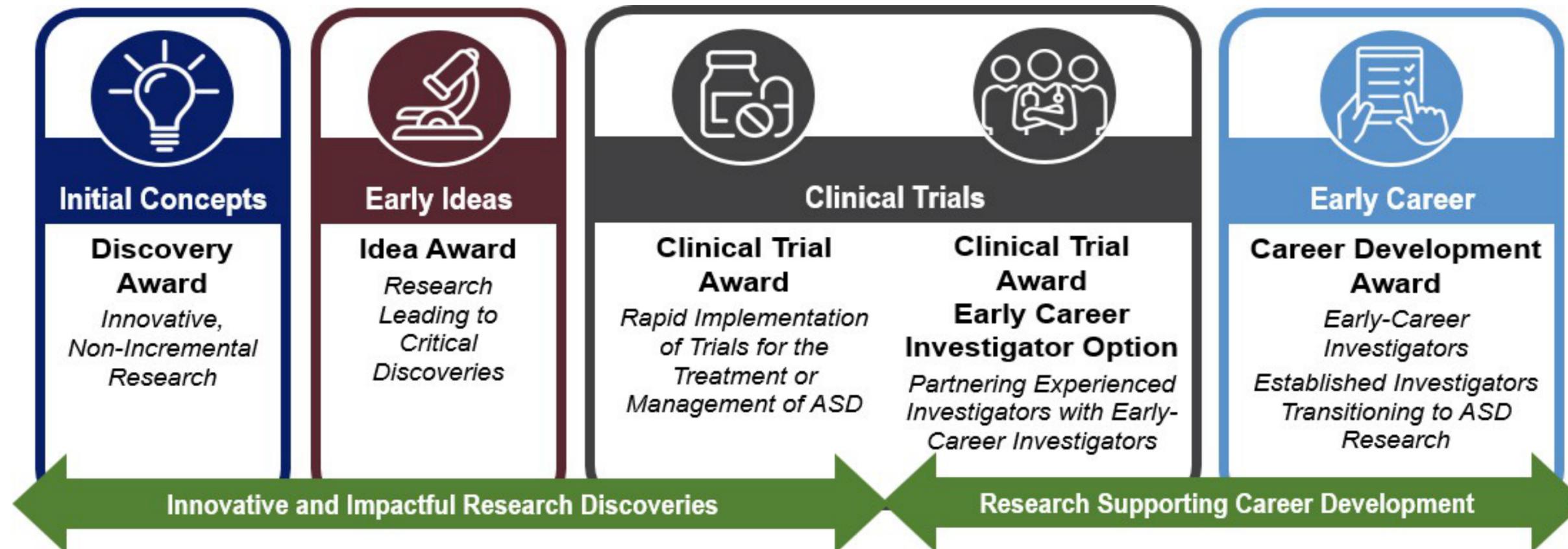
Understand Causes, Mechanisms, and Signs of ASD

- Environmental risk factors for ASD
- Mechanisms underlying conditions co-occurring with ASD
- Improved diagnosis of autism across the life span
- Mechanisms underlying sex differences



<https://cdmrp.health.mil/arp/>

FY24 Funding Opportunities and New Areas of Interest



Discovery Award

- Letter of Intent due: 24 July
- Full Applications due: 15 August

Idea Award, Clinical Trial Award, Career Development Award:

- Pre-proposal deadline has passed
- Invited Full Applications due: 15 August

New Areas of Interest for FY24:

- Community supported and participatory research interventions
- Factors impacting quality of life for current and former military families
- Gender identity and sexual health, including puberty and sexual education for Autistic individuals
- Uncovering new advances using a strength-based model

Across all mechanisms we encourage researchers to involve autistic individuals, family members and/or caregivers in the research project/team

For more information, please visit:



cdmrp.health.mil



CDMRP

DEPARTMENT OF DEFENSE

**CONGRESSIONALLY DIRECTED
MEDICAL RESEARCH PROGRAMS**

Administration for Children & Families

INTERAGENCY AUTISM COORDINATING COMMITTEE

WEDNESDAY, JULY 10, 2024



ADMINISTRATION FOR
CHILDREN & FAMILIES



**Office of
Head Start**

ACF Spotlight: Early Childhood

Early Screening & Assessment

- CDC's Learn the Signs. Act Early; Birth to Five: Watch Me Thrive

Early Childhood Education

- Head Start, Child Care, PreK
- Partnership with IDEA Part B and Part C service providers
- Partnership with ED: Joint Policy Statement on Inclusion





Learn the Signs. Act Early.

Search



Help your child grow and thrive

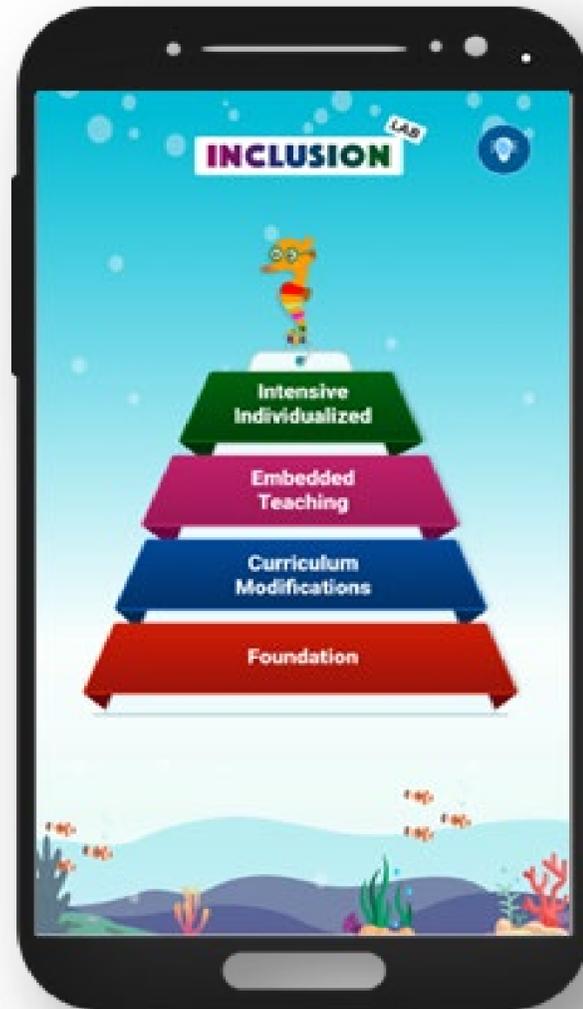


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Download CDC's free **Milestone Tracker** app

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An Educator's Guide to Autism Spectrum Disorder

This guide on autism spectrum disorder is part of a series of briefs that provide basic information about common disabilities, as well as tips for educators as they set out to support children with disabilities.



ADMINISTRATION FOR **CHILDREN & FAMILIES**



Office of Head Start

Early Childhood Behavioral and Mental Health

[Policy and Guidance for State, Territory, and Tribal Leaders | The Administration for Children and Families \(hhs.gov\)](#)





Indian Health Service Autism Services

FACILITATOR: BARBARA ROLAND
MENTAL HEALTH BRANCH CHIEF
DIVISION OF BEHAVIORAL HEALTH
WEDNESDAY, JULY 10, 2024



Indian Health Service (IHS) Provides

- Clinical assessment services & support to American Indian/Alaska Native patients
 - ✓ Services include autism, depression, anxiety, & other mental health issues
- Referrals to outside providers
- Pediatric Neurodevelopmental & Behavioral Health Clinical Consultation



IHS Provides

- IHS partners with the Interagency Autism Coordinating Committee (IACC) to coordinate efforts with the Health and Human Services (HHS) on autism spectrum disorder (ASD)
 - ✓ Mission is to provide advice to HHS
 - ✓ Facilitate the exchange of information & activities
 - ✓ Increase public knowledge & understanding
- Indian Children's Program
 - ✓ Equip healthcare providers with training & education
 - ✓ Tele-behavioral Health Education Webinars & technical support for care through the Telebehavioral Health Center of Excellence (TBHCE)



Tele-Behavioral Health Education Webinars

- IHS provides autism-related webinars through TBHCE
- Current topics include:
 - ✓ Autism Spectrum Disorder & Disruptive Disorders
 - ✓ Autism Spectrum Disorder & Anxiety Disorders
 - ✓ Autism Spectrum Disorder & Attention-Deficit/Hyperactivity Disorder
- Webinar Schedule & archives can be found at:
<https://www.ihs.gov/teleeducation/webinars/>
- Point of Contact: Dr. Chris Fore



Questions?

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ASPR's Advisory Committees on Older Adults and People with Disabilities

IACC Full Committee Meeting

July 10, 2024

Unclassified

ASPR Mission

ASPR leads the nation's medical and public health preparedness for, response to, and recovery from disasters and public health emergencies. ASPR collaborates with hospitals, healthcare coalitions, biotech firms, community members, state, local, tribal, and territorial governments, and other partners across the country to improve readiness and response capabilities.

Agenda

- Legislation and Regulations
- Membership
 - The National Advisory Committee on Seniors and Disasters (NACSD)
 - The National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)
- NACSD and NACIDD Recommendations

Legislation and Regulations

- **Authorities:**

- Pandemic and All-Hazards Preparedness and Advancing Innovation Act (PAHPAIA), 2019
- Federal Advisory Committee Act (FACA)

- **Committee Purpose:**

- NACSD**

- To provide advice and consultation to the HHS Secretary and the ASPR in carrying out medical and public health activities as they pertain to the unique needs of older adults in preparation for, response to, and recovery from all-hazards emergencies and disasters

- NACIDD**

- To provide advice and consultation to the HHS Secretary and the ASPR in carrying out medical and public health activities as they pertain to the unique needs of individuals with disabilities in preparation for, response to, and recovery from all-hazards emergencies and disasters

General Services Administration (GSA) sets additional requirements via the Federal Advisory Committee Act (FACA) Final Rule

NACSD and NACIDD Membership

- **7 Non-Federal Voting Members**
- **NACSD**
 - Disaster-related expertise requirements
 - At least two non-federal health care professionals with expertise in geriatric medical disaster planning, preparedness, response, or recovery; and
 - At least two representatives from State, local, Tribal, or territorial agencies with expertise in geriatric disaster planning, preparedness, response, or recovery.
- **NACIDD**
 - Disaster-related expertise requirements
 - Minimum two health care professionals with expertise in disaster-related disability accessibility and mass care
 - Minimum two State, Local, Tribal, or Territorial representatives
 - Minimum two people with disability and disaster-related expertise.
- **For both NACSD and NACIDD**
 - Nominated for 3-year terms.
 - Special Government Employees (SGEs).
 - Role: Provide recommendations to the Secretary.
- **10 Federal Non-Voting *Ex-officio* Members**
 - Policy experts on disability accessibility and disaster management.
 - Role: Provide agency perspective and expertise, participate in meetings, present on agency activities.

NACSD and NACIDD Recommendations

- The Committees offers **recommendations** to assist the Secretary in best serving older adults and people with disabilities before, during, and after disaster events
- Recommendations focus on **community readiness, infrastructure, and behavioral health**

May 2023 Recommendations

Advance the dissemination of accessible, available, and usable emergency preparedness, response, recovery, and mitigation information and communication support services.

Expand trained community disaster partners.

Establish and sustain Disaster Care Centers of Excellence for older adults as a model of care for regional collaboration, virtual support, and specialized guidance.

Capitalize upon the opportunity to expand the existing Long-Term Care Ombudsman (LTCO) Program with dedicated resources and additional employees to advocate for disaster preparedness, response, and recovery planning across the long-term care continuum.

NACSD September 2023 Recommendations

HHS should seek funding through the Older Americans Act Title VII for an Office of State Long Term Care Ombudsman Program to:

- Develop and provide an emergency preparedness training curriculum targeted for teaching resident and family councils in long-term care facilities (LTCF) about emergency preparedness, response, and recovery.
- Provide and require grant funding through HHS for emergency management and health coalitions to integrate advocates including representatives of the Long-Term Care Ombudsman program, into local coordination for disaster and health emergencies planning.
- Encourage State, Local, Tribal and Territorial emergency responders to include long-term care Ombudsman in their regularly scheduled prep meetings and drills related to issues of long-term care advocacy.

- **HHS should create a Virtual Long Term Care Support & Guidance Center**
- **HHS should create a National Medical Director Registry. All nursing homes should be required to submit specified information on their medical director, including proof of, or progress toward, certification.**
- **HHS should convene a Long-Term Care Leadership and Management Training for Emergency and Disaster Preparedness and Response Commission.**
- **HHS should develop supports and technical guidance for long-term care settings to plan for and implement climate resilience strategies that support patients, staff, and families.**

- **Centers for Medicare and Medicaid Services (CMS) should amend the emergency preparedness rule to require planning for long-term heat and cold emergencies.**
- **HHS should improve equity across the disaster management cycle for older adults.**
- **HHS should develop and provide emergency preparedness training curriculum targeted at healthcare providers in Indian Health Service training programs focused on the health and wellbeing of older adults in relation to preparedness, response, and recovery after emergencies.**

NACIDD September 2023 Recommendations

- **Review and correct HHS's use of blanket waivers under Section 1135 of the Social Security Act to ensure appropriate care and legal protections during PHEs.**
- **Include timely development and distribution of videos, press releases, press conferences, and all other communication in American Sign Language and regional or locally used sign languages appropriate for the populations affected by a PHE.**
- **Develop, require, and frequently update brief just-in-time training for all PHE responders on disaster-related accessibility, equity, inclusion, and health maintenance needs of people with disabilities, and the requirement for compliance with all applicable disability laws.**

Questions



NACSD

- Website
 - [National Advisory Committee on Seniors and Disasters \(NACSD\)](#)
- Resource Mailbox
 - NACSD@hhs.gov

NACIDD

- Website
 - [National Advisory Committee on Individuals with Disabilities and Disasters \(NACIDD\)](#)
- Resource Mailbox
 - NACIDD@hhs.gov

ASPR Mission

**Save Lives
and Protect the
Nation from Health
Security Threats**



Autism Interagency Coordinating Committee Brief: Autism and Emergency Preparedness Overview

Dr. Sherman Gillums Jr.

FEMA Disability Coordinator

Director, Office of Disability Integration and Coordination (ODIC)



FEMA

Guiding Policies & Mission Tenets

Agency Mission Statement: Help people before, during, and after disasters
(FEMA 2022-2026 Strategic Plan)

Disability Coordinator: Account for the needs of people with disabilities, older adults, and those with other access and functional needs
(Post-Katrina Emergency Management Reform Act of 2006)

Office of Disability Integration & Coordination: Shorten the disaster cycle for all survivors, including those who had historically disproportionately suffered the consequences of disasters the longest
(Executive Order 13985, Advancing Racial Equity & Support for Underserved Communities Through the Federal Government)

14 Potential Points of Inequity in the Disaster Cycle



Inclusive planning

Preemptively accounts for the needs of people with disabilities through inclusion



Alerts and warnings

Multiple channels across a range of communication pathways

Information

Clear, complete, consistent, certain, and accurate for broadest audience and accessibility types

Evacuation/transportation

Accessible and accounts for all functional needs

Emergency contact/S&R

Available network and culturally aware search, and rescue

Sheltering

Allows for sustained family and caregiver unification will needs met in an accessible, integrated setting



Communication aids and assistive services

Availability of sign language and certified deaf interpreters, accessibility kits, and 508-compliant web-based content

Recovery/mitigation

Accounts for whole-of-community access and function in rebuild and “pro-build” opportunities

Medical care/health

Access to primary, emergency, and mental health care, and prescription medication point of distribution



Power dependency

Critical life-sustaining medical devices (dialysis, oxygen, feeding tube, mobility device recharge)



Special diets/drinking water

Medically necessary and appropriate dietary options and timely access to potable water

Register for disaster services

Timely access to the full range of FEMA and state support to begin the recovery process

Housing

Allows for time to explore for accessible options, accounts for full range of needs

Pre-disaster home/work/school life

Chance at full community reintegration



Hurricane Ian: The Human Dimensions of Autism in Disasters

Mother of two adult sons with autism sheltered in her car rather than risk stigma and lack of understanding at a nearby emergency shelter

6-year-old boy with autism and his older brother both died by drowning after the little boy wandered off alone

7-year-old boy found a way to cope with noise and darkness by putting on a Bendy & The Ink Machine costume



FEMA

Meeting Autism-related Needs Before, During, and After Times of Crisis

Collaboration between FEMA and Autism Community Together Brings Relief and Support to Parents of Children with Autism

English

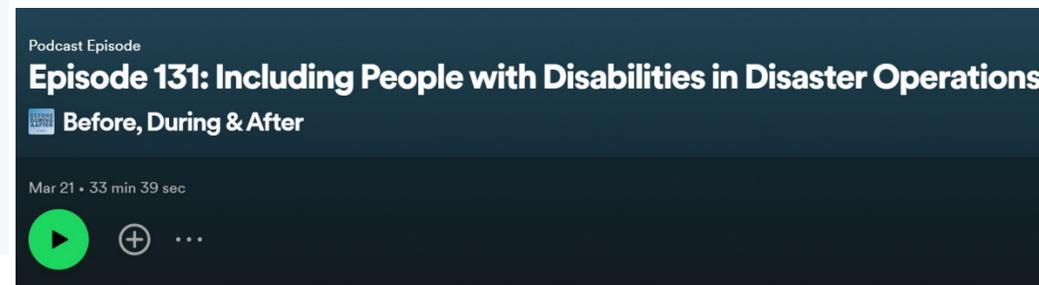


IS-368.A: Including People With Disabilities in Disaster Operations

Format: Independent study

Audience: State, local, tribal, territory, and community partners

Purpose: Increase awareness and enhance coordination in meeting the need for full inclusion of disaster survivors with disabilities and access and functional needs during disaster response.



NACDD 2024 Annual Conference

Dates: July 22 – 26, 2024

Location: Capital Hilton, Washington DC

Break



IACC Committee Business



Shelli Avenevoli, Ph.D.

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

Susan A. Daniels, Ph.D.

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

Committee Business Overview



- IACC Accomplishments
- IACC Closeout planning
 - Completion of pending reports
- *2024 IACC Summary of Advances* discussion

IACC members and alternates, 2021-2024

Thank you all!



IACC Accomplishments



- 11 Full Committee meetings
- 1 Working Group meeting
- Several important autism-relevant topics discussed, including:
 - Housing
 - Communication
 - Mental health
 - Employment
 - Needs across the spectrum
 - Aging
 - Social security
 - Prevalence/epidemiology
 - Racial and ethnic disparities
 - Justice and law enforcement
 - International activities
 - Wandering
 - COVID-19 impacts
 - Supportive services
 - Family caregiving

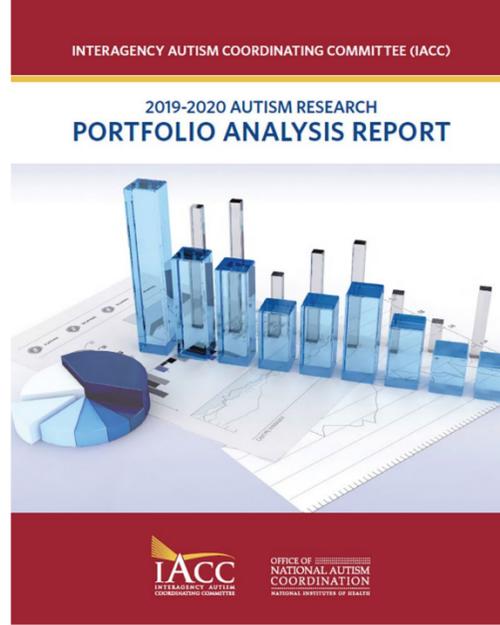
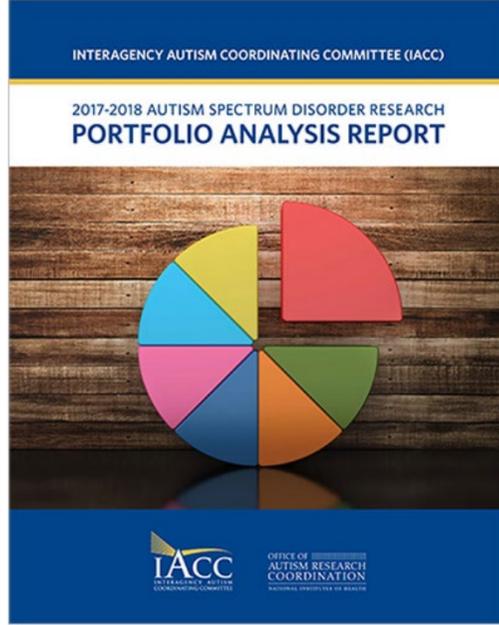
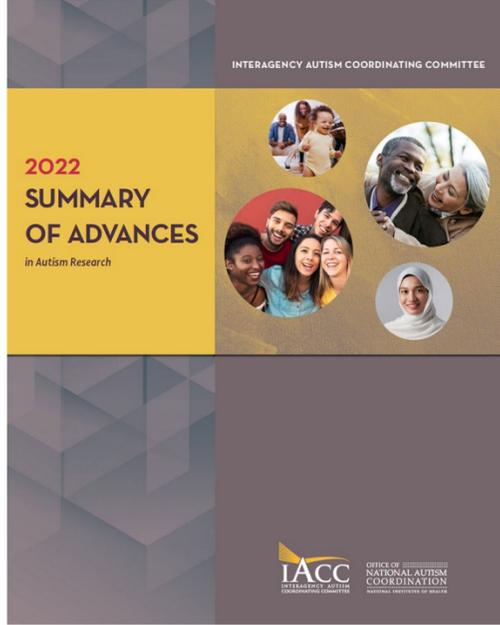
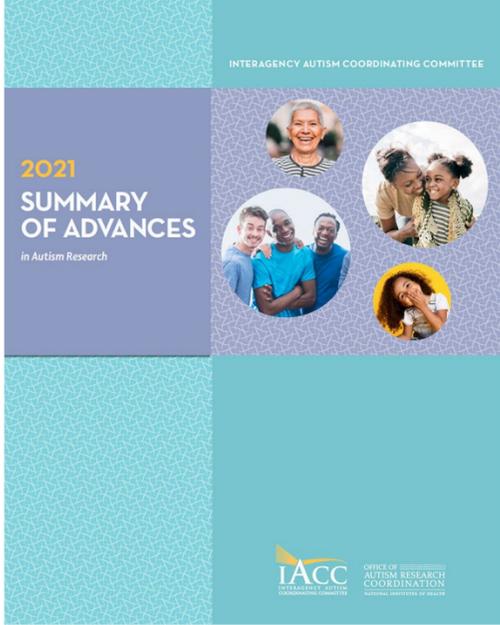
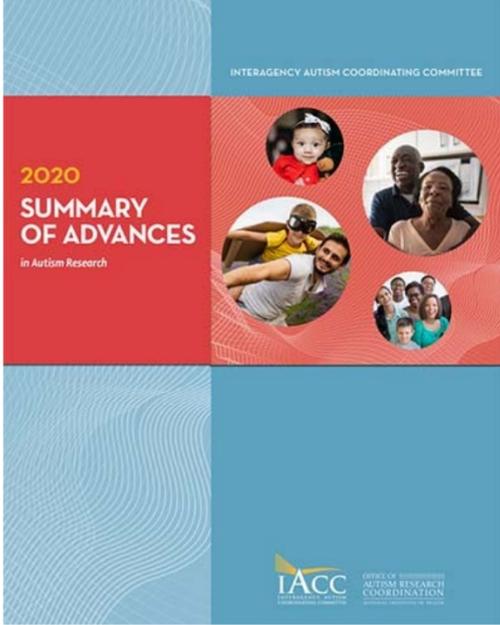
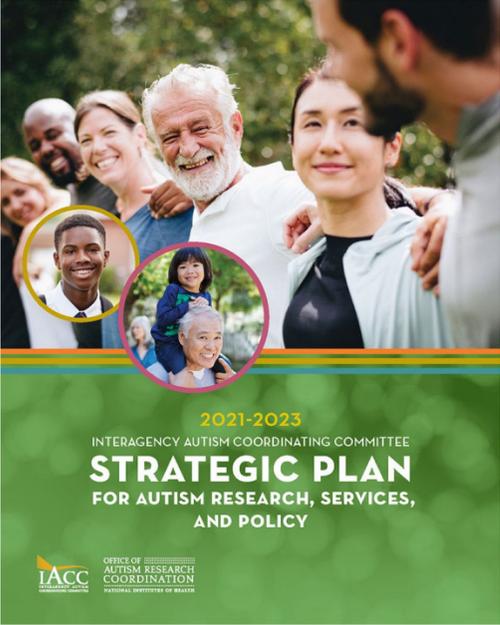


Thank you all for your hard work and dedication over the past 3 years!

IACC Accomplishments



- 6 reports completed
- 3 reports in progress



Thank you all for your hard work and contributions over the past 3 years!

IACC Closeout Planning



- The Autism CARES Act of 2019 sunsets on September 30, 2024. Authorization for the IACC will end at this time.
- Draft legislation to reauthorize the IACC has been introduced in Congress ([H.R. 7213](#)).
- HHS will begin process to solicit nominations of new public members to serve on the IACC once the reauthorizing legislation is enacted.
 - The announcement will appear in the Federal register and will be widely publicized
 - Public members who have only served one term are eligible for renomination.
 - Nominations of new public members are also welcome.

IACC Closeout Planning



- Current IACC member terms will be extended 180 days from September 30 (if reauthorizing legislation has been enacted) to finish projects in progress (through March 2025):
 - *2023 IACC Summary of Advances*
 - *2024 IACC Strategic Plan Update – focused on co-occurring conditions*
 - *2024 IACC Summary of Advances*
- *Post-July 2024 activities will consist of e-mail requests and ~1-3 brief virtual meetings to complete projects.*
- *No new full committee meetings will be held until a new committee is convened*

IACC Closeout Planning:

2023 IACC Summary of Advances



- ONAC has prepared the draft report.
- IACC members will receive draft report for preview/comment soon.
- ONAC will prepare the final report, with anticipated publication in late summer 2024.

IACC Closeout Planning:

2023 IACC Summary of Advances



- One of the articles selected in top 20 was published simultaneously with a companion article.
 - Eye-Tracking-Based Measurement of Social Visual Engagement Compared With Expert Clinical Diagnosis of Autism. *Jones et al. JAMA.* (voted by IACC as a top 20 advance)
 - Development and Replication of Objective Measurements of Social Visual Engagement to Aid in Early Diagnosis and Assessment of Autism. Jones et al. *JAMA Netw Open.*
- One of the articles' authors brought this to our attention and noted that referencing results from both publications is important to describe the scientific advance.

IACC Closeout Planning: *2023 IACC Summary of Advances*



Do you have any concerns about acknowledging both publications in the *2023 IACC Summary of Advances*?

Vote!

- No, I have no concerns. Please acknowledge both publications in the *2023 IACC Summary of Advances*.
- Yes, I have concerns about acknowledging both publications in the *2023 IACC Summary of Advances*.
- Abstain from voting

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



- In October 2023, the IACC voted to focus the *2024 IACC Strategic Plan Update* on **co-occurring physical and mental health conditions** and their impacts on health outcomes.
- ONAC is completing a draft of this report.
- IACC members will receive the draft report by the end of July and have an opportunity to provide written feedback.
- The draft will be posted for public access on the IACC website along with resources related to the topic of co-occurring conditions

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



- ONAC will revise the draft report based on IACC member feedback. A second draft will be distributed to IACC members in fall 2024.
- A brief (1-2 hour) virtual meeting will be scheduled in fall 2024 to discuss the revised draft, with a goal of approving the report.
- ONAC will prepare the final report, with anticipated publication in December 2024.

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



Contents of Draft Report

• Introduction

- Epidemiology of co-occurring conditions
- Health disparities
- Recent IACC Activities and Interest that relate to co-occurring conditions
- Community Perceptions of Research and Services Needs (RFI Summary and analysis)

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



Contents of Draft Report

- Chapter 1: Co-Occurring Physical Health Conditions
 - Epilepsy
 - GI Issues and Disorders
 - Sleep Issues and Disorders
 - Sensory and Motor Challenges
 - Ehlers-Danlos Syndromes and Dysautonomia
 - Health in Older Adulthood and Aging-related Health Conditions

IACC Closeout Planning: 2024 IACC Strategic Plan Update



Contents of Draft Report

• Chapter 2: Co-Occurring Mental Health Conditions

- Anxiety disorders
- Attention-deficit/hyperactivity disorder (ADHD)
- Depression
- Obsessive-compulsive disorder (OCD)
- Self-injurious behavior (SIB), aggression, and emotion dysregulation
- Suicidality
- Additional Mental Health Conditions

- Bipolar disorders
- Feeding and eating disorders
- Gender dysphoria
- Pathological demand avoidance (PDA)

- Schizophrenia
- Substance use disorder (SUD)
- Tourette syndrome (TS) and other tic disorders
- Trauma and adverse childhood experiences (ACEs)

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



Contents of Draft Report

- Chapter 3: Co-Occurring Intellectual, Communication, and Other Developmental Disabilities
 - Intellectual Disability
 - Communication Challenges
 - Related Developmental Disabilities
 - Fragile X Syndrome
 - Rett syndrome
 - Phelan-McDermid syndrome
 - Tuberous Sclerosis Complex
 - Down Syndrome

IACC Closeout Planning: *2024 IACC Strategic Plan Update*



Contents of Draft Report

- Chapter 4: Health Care Service Provision
 - Accessibility
 - Patient-Provider Interactions
 - Considerations for Individuals with High Support Needs
 - Reducing Disparities
 - Impact of COVID-19

Committee members will receive all chapters for review, along with a survey to facilitate collection of committee feedback on the draft.

IACC Closeout Planning:

2024 IACC Summary of Advances



- IACC members will discuss nominations received to date at today's meeting.
- IACC members can continue to nominate articles through the end of 2024 (ONAC will send a bimonthly reminder email).
- IACC members will receive a ballot to vote for the top 20 advances in January 2025.
- Do IACC members wish to have a brief virtual meeting in January 2025 to discuss nominations before voting for top 20 advances?

IACC Closeout Planning:

2024 IACC Summary of Advances



Do IACC members wish to have a brief virtual meeting in January 2025 to discuss nominations before voting for the top 20 advances?

Vote!

- Yes, I would like to have a virtual meeting to discuss nominations for the *2024 IACC Summary of Advances*.
- No, I am comfortable voting (via e-mail) for *2024 IACC Summary of Advances* without a meeting to discuss the nominations.
- Abstain from voting

IACC Closeout Planning:

2024 IACC Summary of Advances



- After the top 20 advances are selected, ONAC will prepare the draft report.
- IACC members will receive draft report for preview/comment in March 2025.
- ONAC will prepare final report, with anticipated publication in late spring 2025.

Lunch Break



Public Comment Session



Shelli Avenevoli, Ph.D.

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

Susan A. Daniels, Ph.D.

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

Oral Public Comments



- Jackie Kancir, National Council on Severe Autism
- Amanda Lopez, Sam's Sibs Stick Together

Full text of public comments available at: <https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#comments>

Summary of Written Public Comments



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

Experiences of Family Caregivers and the Needs of Autistic Individuals with High Support Needs – 47 comments

- Wilhelmina Murray
- Lori Kay
- Allison Leavitt
- Ann Pierce
- Ashley Daly
- Tammy Short
- Nancy Kearney
- Julia Chaney Faughn
- John Saito
- Rose Baumann
- Matthew Murphy
- Marsha Marino
- Rachel Weathers
- Ana Meehan
- Jennifer Bishop
- Colleen Edmondson
- Andrea Taube
- Katherine Troyer
- Mara LaViola
- Allison Frazier
- Rebecca Brimhall
- Sylvia Fogel, M.D.
- Lisa Breunig
- Christina Newendorp
- Lisa Graham-Garza
- Dorothea Iannuzzi
- Mary Christian
- Angela Saturno
- Jamie Cullen
- Dana Hall
- Tanya Statum
- Patricia McCloud
- Adrienne Benjamin
- Nancy Ryan
- Aimee Doyle
- Sharon Beloin Saavedra
- Stephenie Bailey
- Christine Kincaid
- Leigh Powell
- Christine Derr
- Elena Lyons
- Judith Ursitti, Profound Autism Alliance
- Stacy Mayer
- Lynn Cass
- Shannon Rosa, Thinking Person's Guide to Autism
- Shauna Horn, BSA, MPAPA
- John Poulos, Autistic Self Advocacy Network

Full text of public comments available at: <https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#comments>

Summary of Written Public Comments



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

Research and Service Needs, Resources, and Policy Implications – 6 comments

- B.L. Bradley
- Kerry Berger
- Donna Finnie
- Nicole Corrado
- Megan McLaughlin
- Mary Neff

The Role of the IACC and the Federal Government – 2 comments

- Katharine Beals
- Tosha Brothers

Potential Causes of Autism – 2 comments

- Robert C Bransfield, M.D., DLFAPA
- B ker

Inclusion of Autistic Perspectives in Research – 1 comment

- Andrea Strassburg

Full text of public comments available at: <https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/july10/#comments>

Perspectives on Family Caregiving



Advancing Supports for Family Caregivers: The National Strategy as a Catalyst for Change

Jonathan Westin, MPA

Aging Services Program Specialist

Administration on Aging, Administration for Community Living

July 10, 2024



“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

–Carol Zernial, RAISE Council Co-Chair

THE RAISE ACT & THE NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
 - Family Caregiving Advisory Council
 - Initial Report to Congress
 - National Family Caregiving Strategy

Public Engagement at Every Step

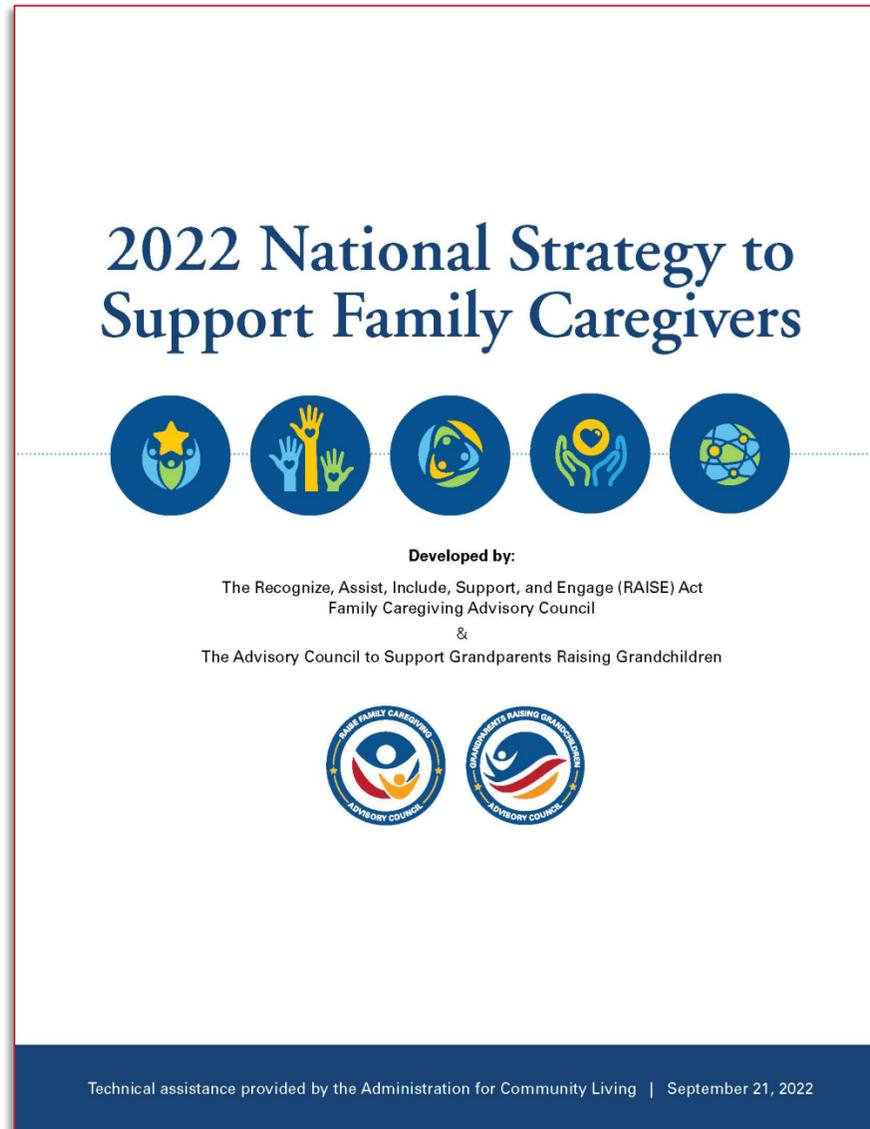
For Starters:

- ACL RFI (2019)
 - 1613 responses
 - 75% from caregivers
- Caregiver Focus Groups
 - 13 sessions/80 individuals
 - All populations, including teens
 - Delved into RFI findings
- Stakeholder Listening Sessions
 - Aging and disability organizations
 - 60 invited/42 participated
 - 6 sessions focused on operationalizing the recommendations
- Public input during council meetings

From 12/2020 - 12/2021:

- Interviews & Listening Sessions
 - 17 key informant interviews
 - 22 listening sessions
 - 145 stakeholder organizations
- Stakeholders included
 - State entities
 - Counties
 - Employers (large and small)
 - LTSS and healthcare providers
 - Respite providers
 - CBOs/faith-based organizations

One Strategy | Four Components



[2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes

[First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) - Describes the four key principles that must be reflected in all efforts to improve support to family caregivers

[Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.

[Actions for States, Communities, and Others](#) - More than 150 actions others can take.

What the Strategy is...and is Not

The Strategy is...

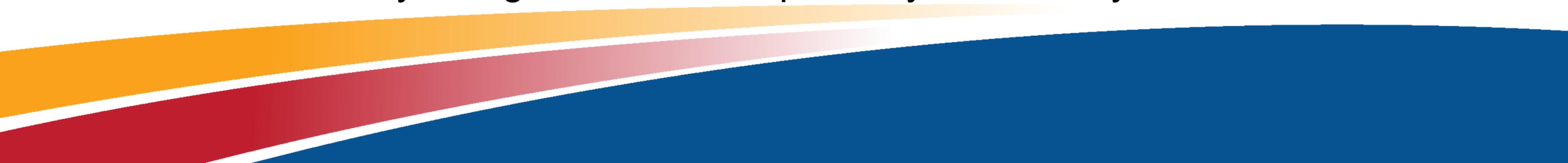
- A vision and roadmap for change
- A baseline for action and progress
- A framework for all caregiving situations and experiences
- Intended for use by many stakeholder groups

The Strategy is not...

- A timeline or how-to document
- A list of requirements or “musts”
- Specific to any particular caregiving situation, topic or condition
- Exhaustive of all the possibilities

Most Importantly...It's the first...Not the last

A “Whole of Society” Approach

- States, tribes, county governments, and communities
 - Community-based providers of long-term services and supports
 - Child welfare agencies
 - Kinship support systems
 - Health care systems
 - Business leaders and employers
 - Communities of faith/faith-based organizations
 - National, state, regional and local philanthropic organizations and funders
 - Academic institutions and researchers
 - Advocates, family caregivers, care recipients, you, me, anyone!
- 

THE NATIONAL STRATEGY AS A DRIVER OF CHANGE FOR STATES, COMMUNITIES & OTHER SECTORS

ACL Initiatives to Support Implementation

- National Caregiver Support Collaborative
 - Five grantees/one goal each
 - TA Coordinating Center
- New Initiatives/Notices of Funding Opportunity (NOFOs)
 - Caregiver navigator demonstration
 - Advancing State Implementation of the Strategy
- The Strategy as Framework for Other NOFOs

The Strategy as Change Agent

- Provide a unifying structure for working together
- Framework for state and community planning efforts
- A rallying point for enhancing collaboration
- Ideas for new service delivery modalities
- Expansion of outreach and awareness campaigns
- Employer engagement
- See state examples here: [NASHP's State Policy Roadmap](#)

Resources for Implementation

Funded by: The John A. Hartford Foundation
National Academy for State Health Policy (NASHP)

- National Alliance for Caregiving
- UMass Boston
- Community Catalyst

[The RAISE Family Caregiver Resource and Dissemination Center](#)

[Support Caregiving.org](http://SupportCaregiving.org)



Looking Ahead

- 2024 Joint RAISE/SGRG Council Update Report to Congress
- Federal agencies will meet regularly to more closely collaborate
- Meeting in subcommittees and working groups to...
 - Gather information and ideas for updating the national strategy
 - Review research and data
 - Begin crafting ideas for non-federal sector updates to the Strategy in 2025

We now have an unprecedented opportunity to achieve – and go far beyond – the goals Congress established in the RAISE Family Caregivers Act

-Alison Barkoff, 2021

Thank you!

Supporting Autistic Adults and their Family Caregivers across the Lifespan



Supporting Autistic Adults and their Family Caregivers across the Lifespan

Christina N. Marsack-Topolewski, Ph.D., LMSW
CNM Services, PLLC – Training & Consulting
Associate Professor of Social Work, Eastern Michigan University
cmarsack@emich.edu

Biographical Information

Christina Marsack-Topolewski, LMSW, PhD is an Associate Professor of Social Work at Eastern Michigan University. She has 20 years of experience working with disabled people and their family caregivers. She has worked as a professor, clinical therapist, special education teacher, consultant, and speaker. She is a licensed clinical social worker, certified special education teacher, and teacher consultant in the state of Michigan. Dr. Marsack-Topolewski has published over 70 research articles in peer-reviewed journal articles and encyclopedia entries predominantly focusing on family caregivers of autistic adults. Specifically, her research has examined family caregiving, caregiver quality of life, social support, future planning, service delivery, and service utilization. Dr. Marsack-Topolewski has served as the lead principal investigator on multiple grant-funded programs tailoring services for family caregivers of disabled people. She is an appointed board member of the U.S. National Task Group (NTG) on Intellectual Disability and Dementia Practices. In 2024, she received the Ronald W. Collins Distinguished Research Award for Research Excellence, as well as the Arc of Oakland County's Advocacy Hall of Fame Award in 2024. Dr. Marsack-Topolewski holds a Ph.D. in Social Work with a dual title in Gerontology from Wayne State University. She is passionate about furthering the development of services, supports, and policies for disabled individuals and their family caregivers as they age across the lifespan.



Contact Information:
cmarsack@emich.edu

Overview

- Continuum or “spectrum” of autism spectrum disorder (ASD)
- Note about person-first (e.g., adult with autism) versus identity-first (e.g., autistic adult) language

Overview

- Personal and professional background
- Context for my work / my “why”

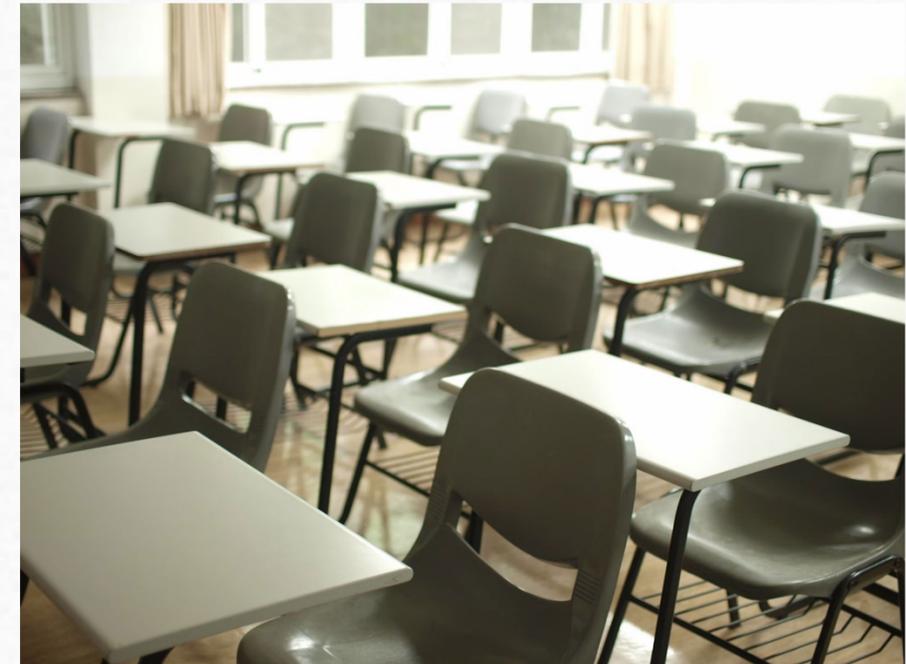


Photo by [MChе Lee](#) on [Unsplash](#)

Research Overview

- National outcomes focus on the experiences of family caregivers of autistic adults
- Three main themes outlined in slides
 - 1. Need for tailored, accessible services
 - 2. Support with service navigation
 - 3. Need to plan for the future

Augmenting Social Support Networks; Think *Quality of Life* and
Family Quality of Life



Theme #1

- Need for tailored, accessible services
 - Autistic adults often reach a “services cliff” (Roux et al., 2017)
 - Avoid a “one-size-fits-all approach” (e.g., often irrelevant, inappropriate groupings of autistic adults / family caregivers with other populations seeking services)
 - Often a mismatch between current needs and what services / support systems provide (Ljungberg, M., & Schön, 2023)
 - Juvenile services are not a solution for providing services in adulthood
 - Need for both tailored health / medical and mental health services for autistic adults
 - Accessing services can be challenging, time consuming, laborious (Anderson & Butt, 2018; Marsack & Graves, 2019; Taylor & Henninger, 2015)
 - Waitlists and geographic reach issues continue to be challenges

Accessibility or 4 As of Services



(Marsack-Topolewski & Weisz, p. 192, 2020 – See Table 1 for more information)

Accessibility or 4 As of Services

- Accommodation
 - “How are the available options organized?”
- Acceptability
 - “What are parents’ attitudes regarding available options?”
- Availability
 - “Do services exist?”
- Affordability
 - “Are the services affordable?”

(Marsack-Topolewski & Weisz, p. 192, 2020 – See Table 1 for more information)

Bidirectional Relationship

- Beneficial services and supports for family caregivers, often benefit autistic adults in some way
- Beneficial services and supports for autistic adults, often benefit family caregivers as well
- Help with balancing the needs



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Theme #2

- Support with service navigation
 - Navigating services can be problematic, time consuming, and challenging
 - Many service networks may be needed (e.g., health / mental health system, disability-specific system, employment services, aging services)
 - “Boutique shopping” often required
 - Few single entry service systems → coordination of services is needed

Theme #2 – Navigation through Peer Support

- Family support navigation (FSN) – family caregiver receives support from a peer to navigation services
 - Peer-mediated program was instrumental in empowering family caregivers
 - Reduced perceived barriers to enable service access, increased use of advocacy and support services (Marsack-Topolewski et al., 2023)
 - Can be helpful to navigating complexity of health, disability, and other service systems (Markoulakis et al., 2019)
- Other cases - support navigation for autistic adults may be of relevance



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Theme #3

- Need to plan for the future
(*Look to the future)
 - 1.) Future planning needs to help family caregivers and support autistic adults
 - 2.) Changing and evolving needs of both family caregiver and autistic adult over time



Photo by [Torsten Dederichs](#) on [Unsplash](#)

Theme #3: Plan for the Future

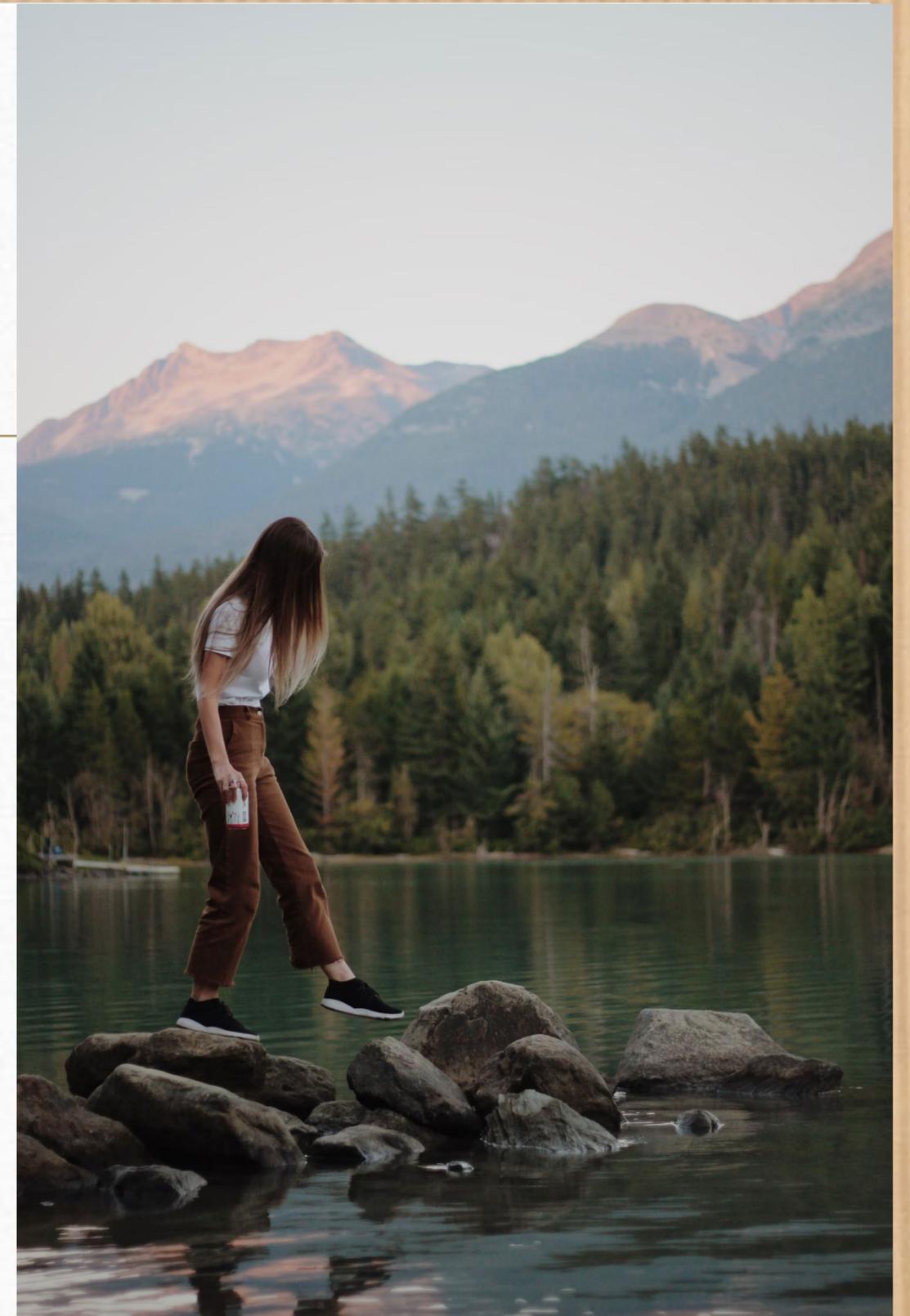
- Need to plan for the future
 - 1.) Support for future planning should help family caregivers and autistic adults
 - Many barriers exist (Marsack-Topolewski & Graves, 2019)
 - Family caregivers of autistic adults reported:
 - “Difficulty identifying caregiving support for the future”
 - “Barriers to making plans and decisions”
 - “Fear of the unknown”
 - “Feeling the need to make plans and decisions now”

Theme #3: Plan for the Future

- Need to plan for the future
 - 2.) Changing and evolving needs of both family caregiver and autistic adult over time
 - Needs change as time goes on
 - Needs change as people age
 - Compound caregiving (e.g., caring for more than one loved one) situations often occur / arise (Marsack-Topolewski, 2020, 2021; Wang et al., 2022)

Professional Implications

- Caregiving can vary in length, duration, and intensity
- Support the practical needs of life
- Recognize the changing and evolving needs
 - Autistic adult
 - Caregiver
- For caregivers - help with the balancing needs of self and loved one
- Offer support networks and resources
- Social support
 - Both formal support networks (e.g., paid supports)
 - & Informal support networks (e.g., unpaid supports)



Key Takeaways

- Programs, services, supports, and policies → should aim to develop systems, structures, pathways to make things more accessible, inclusive, and equitable for both autistic adults and their family caregivers



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Recap & Policy Implications

- 1. Need for tailored, accessible services (coordination of services)
- 2. Support with service navigation
- 3. Need to plan for future

- Funding needs
- Programmatic, structure, and service needs
- Pipeline of providers, training needs

“

Alone, we can do so little;
together we can do so much.

”

~Helen Keller



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Contact Information

Feel free to also reach out to me via email @ cmarsack@emich.edu if I can be of any help!

Google Scholar link:

https://scholar.google.com/citations?hl=en&user=9vlZXEQAAAAJ&view_op=list_works&sortby=pubdate

Bio link: https://www.emich.edu/chhs/social-work/faculty/c_topolewski.php

LinkedIn:

<https://www.linkedin.com/in/christina-marsack-topolewski-19553812/>



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References

- Anderson, C., & Butt, C. (2018). Young adults on the autism spectrum: The struggle for appropriate services. *Journal of Autism and Developmental Disorders*, 48, 3912-3925. <https://doi.org/10.1007/s10803-018-3673-z>
- Ljungberg, M., & Schön, U. K. (2023). Who cares? A scoping review about the experiences of parental caregivers of autistic adults. *Journal of Applied Research in Intellectual Disabilities*, 36(5), 929-939. <https://doi.org/10.1111/jar.13126>
- Markoulakis, R., Chan, S., & Levitt, A. (2019). Identifying the key features and outcomes of family navigation services for mental health and/or addictions concerns: a Delphi study. *BMC Health Services Research*, 19, 1-12. <https://doi.org/10.1186/s12913-019-3968-6>
- Marsack-Topolewski, C. N. (2020). Quality of life among compound caregivers and noncompound caregivers of adults with autism. *Journal of Gerontological Social Work*, 63(5), 379-391. <https://doi.org/10.1080/01634372.2020.1765063>
- Marsack-Topolewski, C. N. (2021). Receipt of social support among compound and noncompound caregivers of adults with autism. *Journal of Gerontological Social Work*, 64(2), 175-189. <https://doi.org/10.1080/01634372.2020.1834045>
- Marsack-Topolewski, C. N., & Graves, J. M. (2019). "I worry about his future!" Challenges to future planning for adult children with ASD. *Journal of Family Social Work*, 23(1), 71-85. <https://doi.org/10.1080/10522158.2019.1578714>

References

- Marsack-Topolewski, C., Milberger, S., Janks, E., Anderson, N., Bray, M., & Samuel, P. S. (2023). Evaluation of peer-mediated systems navigation for ageing families of individuals with developmental disabilities. *Journal of Intellectual Disability Research*, 67(5), 462-474. <https://doi.org/10.1111/jir.13024>
- Marsack-Topolewski, C. N., & Weisz, A. N. (2020). Parents' perceptions of access to services for their adult children diagnosed with autism spectrum disorder. *Families in Society*, 101(2), 190-204. <https://doi.org/10.1177/1044389419881273>
- Roux, A. M., Rast, J. E., Anderson, K. A., & Shattuck, P. T. (2017). *National autism indicators report: Developmental disability services and outcomes in adulthood*. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University. Retrieved from <https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Developmental-Disability-Servicesand-Outcomes-in-Adulthood/>
- Taylor, J. L., & Henninger, N. A. (2015). Frequency and correlates of service access among youth with autism transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 45, 179-191. <https://doi.org/10.1007/s10803-014-2203-x>
- Wang, F., Marsack-Topolewski, C. N., DiZazzo-Miller, R., & Samuel, P. S. (2022). Health of aging families: Comparing compound and noncompound caregivers. *Journal of gerontological social work*, 65(3), 290-304. <https://doi.org/10.1080/01634372.2021.1963024>

Voices of Resilience: Black Families and Autism Advocacy





Voices of Resilience: Black Families and Autism Advocacy

Elizabeth Holliday Morgan, Ph.D.



Positionality Matters



(MORGAN & STAHRMER, 2020)

ASD/ DD in the Black Community



Black children with ASD are diagnosed 1.6-5 years later (Constantino et al., 2020; Mandell et al., 2002; Mandell et al., 2009)

Black children are 3x more likely to be misdiagnosed (Mandell et al., 2007)

Black families have limited access to services after diagnosis. (Longtin & Principe, 2011; Gourdine & Algoood, 2014)



Culturally Relevant Research

Addressing the Intersectionality of Race and Disability to Improve Autism Care

Elizabeth H. Morgan, PhD, EdM,^{1,2} Rylin Rodgers, BA,³ John Tschida, MPP⁴

"We must do the work that justice and equality calls us to do." – John Lewis.

We write this article to (1) summarize intersectionality, (2) consider implications of intersectionality for Black, Indigenous, people of color (BIPOC) autistic communities, and (3) provide a call to action for disability researchers and organizations to foster and maintain an intersectional lens. The authors, who identify as disabled persons and family members of autistic people, seek to show how intersectionality affects the work of researchers and disability organization leaders.

INTERSECTIONALITY OF RACE AND DISABILITY

Intersectionality, coined by Kimberlé Crenshaw, describes the complex and multidimensional social phenomenon

of double oppression that Black women experience in the United States.¹ The term has expanded to include interlocking aspects of identity as it relates to race and disability. To have a Black, Brown, and disabled body in the United States is to be connected to a history saturated in oppressive and discriminatory treatment. The sociohistorical relationship between race and disability perpetuates inequalities that impact Black and Brown disabled people and thus lead to overrepresentation in disability categories associated with more restrictive environments.² Disparities in the diagnosis and treatment of autism in children in the BIPOC communities has resulted in later identification and higher misdiagnosis rates. Black and Brown children are less likely to be

identified for autism spectrum disorder by either a qualified health or educational professional.^{3,4}

In 2021, we see the conversation about race and its intersections with disability as overdue, dynamic, and urgent because of a failure to address systemic barriers to progress. We recognize the Civil Rights movement and the Women's Liberation movement as the inspiration for the Disability Rights movement. These distinct forces served as the foundation for the coalitions that supported the disability community's 1977 San Francisco Federal Building sit-ins, which led to the enactment of Section 504 regulations.⁵ With current movements such as "Black Lives Matter" and "Say Her Name" demanding an end of police violence



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Dr Morgan served as the lead author and drafted and provided critical revisions of the article; Ms Rodgers wrote sections of the article and provided policy content knowledge for the development of the publication; Mr Tschida wrote sections of the article and helped with editing drafts of the document; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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SUPPLEMENT ARTICLE

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Narratives of single, black mothers using cultural capital to access autism interventions in schools

Elizabeth Holliday Morgan & Aubyn C. Stahmer

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(Algood, Harris, & Hong, 2013; Aceves & Black, 2022; Mandell & Salzer, 2007; Clifford & Minnes, 2012; Morgan & Stahmer, 2020, Morgan et al., 2021)

Cultural

Capital

vs

Community

Cultural

Wealth



Theoretical Framing

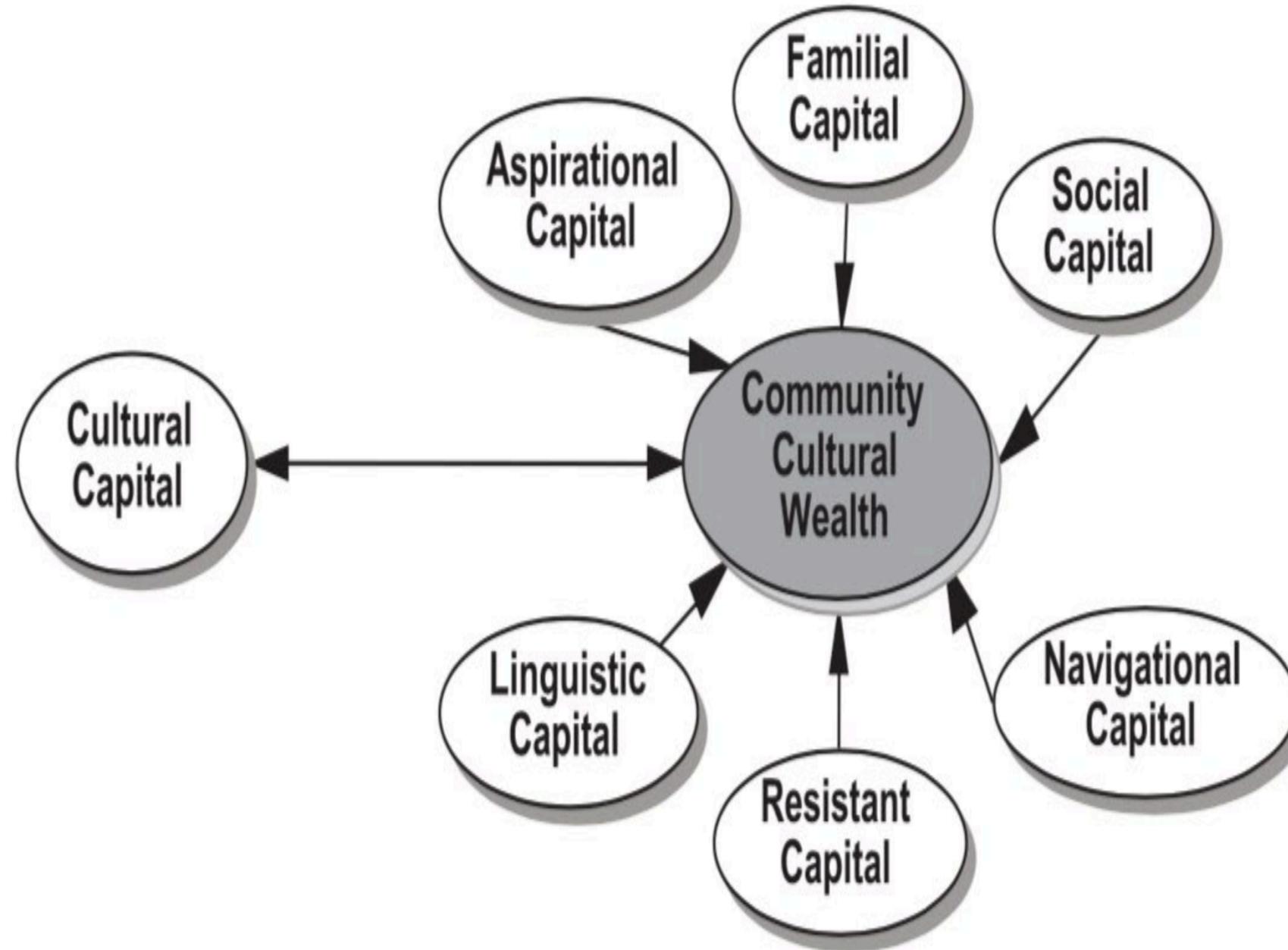


Figure 2. A model of community cultural wealth. Adapted from: Oliver & Shapiro, 1995



Dr. Tara Yosso

Additional Theory

Aspirational Capital

Familial Capital

Linguistic Capital

Social Capital

Resistant Capital

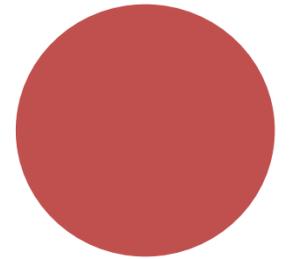
Navigational Capital

Black Cultural Capital (Carter, 2003)

Motherhood Capital (Lo, 2016)



Dr. Prudence Carter



Dr. Ming-Chang Lo

Collaborator Demographics:



Evelyn

- 52 years old
- College Graduate
- IHSS Worker
- Son, 14
- \$40-49K Annual
- Child School Placement: SPED Life Skills Classroom



Mae

- 55 years old
- College Graduate
- Full Time Employment
- Son, 13
- \$80-80K Annual
- Child School Placement: SPED/ GEN Ed Classroom



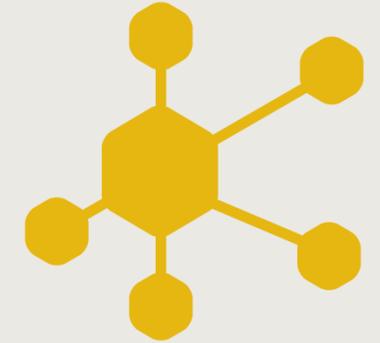
Wilma

- 39 years old
- College Graduate
- IHSS Worker
- Son, 7
- \$30-39K Annual
- Child School Placement: SPED/ ASD Classroom



Josephine

- 42 years old
- Some College
- IHSS Worker
- Daughter, 10
- \$30-39K Annual
- Child School Placement: SPED/ ASD Classroom



Henrietta

- 47 years old
- College Graduate
- Full Time Employment
- Son, 9
- \$60-69K Annual
- Child School Placement: SPED Classroom



Resistance Capital



And I will tell you this. That's what came through the years, standing up to people in a room that don't look like you. It requires you to use the knowledge you have. It requires you to use the understanding you have. It requires you to realize that you got this. You know what's best for your child."

-Evelyn



Navigational Capital

“I think it was harder because I haven’t seen a lot of single Black women out there...It required me to remove myself out of that grief state and realize I have to find out, I have to figure out what it is that's gonna benefit my son.”

--

Josephine



Description of
Sankofa Family
Support Network



sankofa
family
support network

February 2023

Paths to Equity: Parents in partnership with UCEDDs fostering Black family advocacy for children on the autism spectrum

Elizabeth H. Morgan

California State University Sacramento and University of California Davis CEDD at the MIND Institute

Benita D. Shaw

University of California Davis CEDD at the MIND Institute

Ida Winters

University of Wisconsin-Madison Waisman Center

Chiffon King and additional works at: <https://digitalcommons.usu.edu/ddnj>

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See next page for additional authors

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Paths to Equity: Parents in partnership with UCEDDs fostering Black family advocacy for disabled children. *Developmental Disabilities Network Journal* Special Issue on Diversity, Equity, and Inclusion.

<https://digitalcommons.usu.edu/ddnj/vol3/iss1/5>

AIM: The research aim is to address the negative impacts of racism and ableism on Black children and their families in healthcare and education by partnering with UCEDDs and Black parents to support advocacy, peer networking, and qualitative research, to improve the quality of care and challenge biases in the healthcare and education systems.

Sankofa parents said:

“Sankofa is a space for Black families of children with various disabilities to come and meet other families, get mentored, learn skills, and be vulnerable with people they can trust.”

Benita Shaw

“I was fortunate enough to be connected with Sankofa ...I attended one meeting. It changed my life“.

Ida Winters

Goals and Objectives of Sankofa



“My confidence level for creating opportunity for my family is continually increasing. By taking the initiative to access services and supports for positive lifestyle changes, I have become a strong advocate for my children.”

--Valorie Crawford, Sankofa Mother of Twin Boys on the autism spectrum



Video



This video is available in the event recording, located at <https://iaacc.hhs.gov/meetings/iaacc-meetings/2024/full-committee-meeting/july10/#event>





Thank You
For Listening!

REACH OUT FOR ANY QUESTIONS.

<https://www.drehmorgan.com>

Aceves, T., & Black, L. (2022). Leading the fight: An African American mother advocating for her children with disabilities. *International Journal of Inclusive Education*, 1–22.
<https://doi.org/10.1080/13603116.2022.2136771>

Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment*, 23(2), 126–136. <https://doi.org/10.1080/10911359.2012.747408>

Beale, A. K. (2013). Daring to create change agents in Physical Education: The Sankofa philosophy. *Journal of Physical Education, Recreation & Dance*, 84(4), 7–9.
<https://doi.org/10.1080/07303084.2013.773726>

Clifford, T., & Minnes, P. (2012). Who participates in support groups for parents of children with autism spectrum disorders? the role of beliefs and coping style. *Journal of Autism and Developmental Disorders*, 43(1), 179–187. <https://doi.org/10.1007/s10803-012-1561-5>

Lewis, E. M., Dababnah, S., Hollie, K. R., Kim, I., Wang, Y., & Shaia, W. E. (2022). The creator did not give me more than I can handle: Exploring coping in parents of Black Autistic Children. *Autism*, 26(8), 2015–2025. <https://doi.org/10.1177/13623613211070865>

Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism*, 11(2), 111–122. <https://doi.org/10.1177/1362361307077506>

Matemba, Y. (2020). Gazing back and moving forward. *British Journal of Religious Education*, 42(2), 115–119. <https://doi.org/10.1080/01416200.2020.1719464>

Morgan, Elizabeth H.; Shaw, Benita D.; Winters, Ida; King, Chiffon; Burns, Jazmin; Stahmer, Aubyn; and Chodron, Gail (2023) "Paths to Equity: Parents in partnership with UCEDDs fostering Black family advocacy for children on the autism spectrum," *Developmental Disabilities Network Journal: Vol. 3: Iss. 1, Article 5.*

Morgan, E. H., & Stahmer, A. C. (2020). Narratives of single, black mothers using cultural capital to access autism interventions in schools. *British Journal of Sociology of Education*, 42(1), 48–65. <https://doi.org/10.1080/01425692.2020.1861927>

Temple, C. N. (2009). The emergence of Sankofa practice in the United States. *Journal of Black Studies*, 41(1), 127–150. <https://doi.org/10.1177/0021934709332464>

Discussion



Break



Panel Discussion: Family Caregivers



Closing Remarks

Shelli Avenevoli, Ph.D.

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

Susan A. Daniels, Ph.D.

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



Thank you to the ONAC Staff and Meeting Support Team!



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HHS National Autism
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Director, ONAC



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Deputy Director



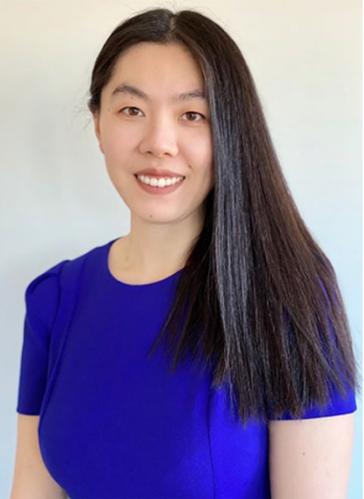
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Keep in touch with the Office of National Autism Coordination



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IACC members and alternates, 2021-2024

Thank you all!

