Meeting of the Interagency Autism Coordinating Committee

January 24, 2024; 10:00 a.m. - 5:00 p.m. ET



Susan A. Daniels, Ph.D.

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

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

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

Welcome, Roll Call, and Announcements



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Housekeeping Notes



- During discussions, please keep your comments brief (~1-2 minutes) to ensure that other members have a turn to speak.
- For Committee members that would like a comment read aloud:
 - Please send the text of your comment via Zoom chat function to the ONAC Staff Member who is using the Zoom screen name "SEND COMMENTS HERE".
 - When it is your turn to be recognized, Mr. Steven Isaacson from the ONAC staff will read your comment to the group.
- Closed captioning is available in Zoom for Committee members and on Videocast for members of the viewing public.

Housekeeping Notes



- For in-person participants, please:
 - Turn on your tabletop microphone to speak and turn it off when you are finished.
 - Sign into Zoom but keep your device audio muted.
 - Raise your physical hand or use the "Raise Hand" function in Zoom to be recognized.
- For virtual participants, please:
 - Keep your microphone off unless you are speaking.
 - You may turn your camera on when you are speaking and during committee discussions.
 - Use the "Raise Hand" function in Zoom to be recognized.

Update from the National Institutes of Health



Monica Bertagnolli, M.D.

Director
National Institutes of Health (NIH)

IACC Full Committee Meeting January 24, 2024

Susan A. Daniels, Ph.D.

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



2022 Report to Congress on Supportive Services for Individuals with Autism NOW AVAILABLE!

- This Report to Congress was requested in the U.S. House of Representatives Committee on Appropriations Report on the FY22 Consolidated Appropriations Act (H. Rept. 117-96).
- The report:
 - Describes supportive services that, in addition to healthcare, may be beneficial for improving outcomes for autistic individuals and their families
 - Reviews existing coverage policies under federal programs
 - Highlights needs and opportunities for strengthening supportive services for individuals on the autism spectrum
- NAC/ONAC coordinated the development of this report on behalf of the HHS Secretary in collaboration with 18 federal departments, agencies, and offices.
- The report is available on the IACC website: http://iacc.hhs.gov/publications/report-to-congress/2022/



2022 Report to Congress on Supportive Services for Individuals with Autism Types of Services Discussed in the Report

- Diagnostic services
- Applied behavior analysis (ABA) and other behavioral interventions
- Speech/language therapy and augmentative and alternative communication (AAC) supports
- Assistive technology, specialized medical equipment, and associated services and training
- Technology-based, robot-assisted, and artificial intelligence interventions
- Physical therapy
- Occupational therapy and sensory integration therapy
- Academic services and supports
- Mental and behavioral health services and supports
- Self- and family-directed services and supports
- Family/systems navigation
- Caregiver-, family-, and peer-mediated interventions
- Family and caregiver supports

- Support, social, and community groups
- Peer-to-peer mentoring and autistic-led support groups
- Caregiver supports and respite care
- In-home caregivers, aides, and nursing care
- Dietary and nutritional support
- Therapies for sleep disorders
- Environmental assessment and modifications
- Transportation vehicle modifications
- Empowerment, education, and advocacy training and services
- Healthcare transition (HCT) services
- Employment services, vocational rehabilitation services, job coaching
- Housing support services
- Remote services
- Recreational therapies
- Complementary and alternative interventions (e.g., music, animal-assisted, emotion regulation, and mindfulness therapies)

2022 Report to Congress on Supportive Services for Individuals with AutismHighlighted Needs and Opportunities to Strengthen Autism Services

Family Navigation

 Services are often fragmented among many different providers and in some cases, families may not be aware of the types of supports that are available. Navigation services can help address this issue.

Consistency of Coverage

 The type of healthcare coverage (e.g., private, HCBS waiver) can impact the services that an individual receives

Workforce Shortages

 Autistic individuals and their families face difficulties in accessing direct service professionals with sufficient training and experience in autism and related areas of expertise

Diagnostic Services

Long gap between referral and diagnostic assessment (for both children and adults)

Waitlists for Services

 People often face barriers to accessing services, such as long waitlists for Medicaid HCBS waiver slots

Telehealth

 New technologies in telemedicine can be leveraged to increase access to services, decrease diagnosis waiting times, and aid in neurodevelopmental disability monitoring



Additional Updates

- A National Autism Coordinator Updates Document outlining recent White House activities, Federal committees, news, and events can be accessed in the meeting January 24, 2024 IACC Meeting Materials:
 - National Autism Coordinator Updates January 2024

Federal Interagency Workgroup on Autism (FIWA) Presentation on Agency Initiatives

Susan A. Daniels, Ph.D.

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



About the Federal Interagency Workgroup on Autism (FIWA)

- An all-federal working group was first convened to address requirements of the Autism CARES Act of 2014; the group was re-named the FIWA in 2018.
- FIWA is composed of representatives of 20 federal departments and agencies with programs related to autism and disabilities and is convened and chaired by the National Autism Coordinator (NAC).
- The FIWA meets 3 times per year for regular meetings and convenes additional meetings as needed.
- The NAC works through the FIWA to coordinate of research, services, and support activities related to autism, taking into account the IACC Strategic Plan.
- Information exchanged in FIWA meetings and through other activities of the FIWA also facilitate prevention of duplication of effort across federal agencies.
- Meetings are not open to the public; non-public information such as plans for future initiatives or reports under development are shared in meetings to facilitate federal coordination.
- Information generated by the FIWA that needs to be shared publicly is disseminated by the NAC/FIWA in reports, public documents, or in the NAC update at IACC meetings.



FIWA Membership

- Administration for Children and Families (ACF)
- Administration for Community Living (ACL)
- Agency for Healthcare Research and Quality (AHRQ)
- Assistant Secretary for Planning and Evaluation (ASPE)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Food and Drug Administration (FDA)
- Health Resources and Services Administration (HRSA)
- Indian Health Service (IHS)

- National Institutes of Health (NIH)
- Substance Abuse and Mental Health Services Administration (SAMHSA)
- U.S. Department of Education (ED)
- Environmental Protection Agency (EPA)
- U.S. Department of Defense (DoD)
- U.S. Department of Justice (DOJ)
- U.S. Department of Labor (DOL)
- U.S. Department of Transportation (DOT)
- Social Security Administration (SSA)
- U.S. Department of Housing and Urban Development (HUD)
- U.S. Department of Veterans Affairs (VA)

Membership is voluntary and open to any Federal agency engaged in autism-related work.

Agency Activities: Today's Featured Speakers

- Christy Kavulic, Ed.D. (U.S. Department of Education), FIWA Member
- Matthew Maenner, Ph.D. (Centers for Disease Control and Prevention), FIWA Member
- Lisa Gilotty, Ph.D. (National Institute of Mental Health), FIWA Member
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Department of Education

- Mission: ED's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.
- Relationship to Autism/Disability: ED administers the Individuals with Disabilities Education Act (IDEA). IDEA serves about 900,000 school-age children with autism in addition to infants, toddlers, and preschool children with autism and their families.
- Topics of Portfolio Focus: Through IDEA national activities, ED funds research, personnel preparation, educational technology and media, and technical assistance that focuses on autism

Department of Education Grants

- Personnel Preparation: In FY24, the Office of Special Education Programs intends to run competitions for:
 - 325B: Center to support minority serving intuitions
 - 325H: Doctoral training consortia
 - 325M: Minority serving institutions: Preparation of special education, early intervention, and related services
 - 325R: Preparation of related services providers
 - 325S: Enhancing related services programs
 - 325X: Expanding preparation programs in minority serving institutions
- Educational Technology: In FY24, the Office of Special Education Programs intends to run for:
 - 327S: Stepping Up Technology Implementation
 - 327Z: National Center on Digital Access in Education

Department of Education Grants

- Research: In FY24, the National Center for Special Education Research intends to run competitions for:
 - 324A: Special Education Research Grants: This program supports research conducted over a maximum of five years, in four project types: Exploration; Development and Innovation; Impact; and Measurement
 - 324B: Research Training Programs in Special Education: Grants to prepare individuals to conduct rigorous and relevant special education and early intervention research that advances knowledge within the field
 - 324C: Research and Development Center on the K-12 Special Education Workforce: Grants to fund a Research and Development Center to conduct a focused program of research on the special education teacher workforce.

Department of Education Guidance

- Policy Statement on the Inclusion of Children with Disabilities in Early Childhood Programs
- Released jointly by the Departments of Education and Health and Human Services
- Sets the expectation that all young children with disabilities should have access to highquality inclusive early childhood programs that provide individualized and appropriate support so they can fully participate alongside their peers without disabilities, meet high expectations, and achieve their full potential.

<u>https://sites.ed.gov/idea/idea-files/policy-statement-inclusion-of-children-with-disabilities-in-early-childhood-programs/</u>

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Overview of CDC's Autism Programs

Matthew Maenner, PhD
Chief, Child Development and Disability Branch
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention

Mission: "CDC works 24/7 to protect America from health, safety and security threats, both foreign and in the U.S. ... To accomplish our mission, CDC conducts critical science and provides health information that protects our nation against expensive and dangerous health threats, and responds when these arise."

Source: Mission, Role and Pledge | About | CDC

CDC's Autism Programs

Surveillance and research activities first authorized by the Children's Health Act of 2000







Program
Learn the
Signs. Act Early

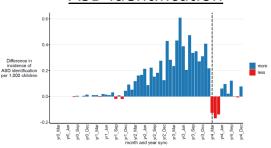
Current Focus:

Early detection and intervention Access to services Needs for support across the lifespan

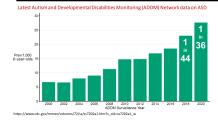
Autism and Developmental Disabilities Monitoring (ADDM) Network 2023

2023 Data Release

COVID Disrupted Early ASD Identification



Latest ASD Prevalence Data

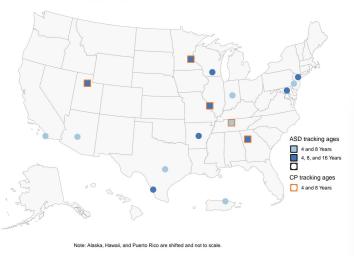


Community Report



Expansion and cerebral palsy tracking in 2023





- 5 new ADDM sites (16 total)
- 4 more sites tracking 16year-olds (9 total)
- 5 sites tracking CP

Data on needs of adolescents with ASD

disabilityscoop The Premier Source for Developmental Disability News

In First, CDC Issues Data On Teens With Autism

by Michelle Diament | April 13, 2023



"Learn the Signs. Act Early."

Milestones and Materials



CDC, AAP update developmental milestones for surveillance program



SE Early Development is a Journey

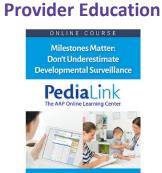


>1.9M App Downloads

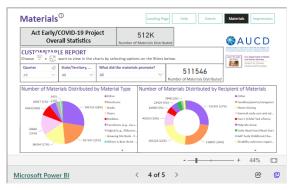
60 Act Early Ambassadors in 49 States, Washington DC, 4 territories, and 3 tribal communities







Act Early Response to COVID-19 Project Data Dashboard



Act Early COVID Projects

For more information, contact CDC 1-800-CDC-INFO (232-4636) TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



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NIH Autism Research Initiatives

Lisa Gilotty, PhD

Program Chief, Research Program in Autism Spectrum Disorders Division of Translational Research, NIMH

January 24, 2024



NIH Autism Centers of Excellence (ACE)

- **Description:** The ACE program supports research on autism throughout the lifespan, including innovative and cost-effective services and interventions. The awards support research at individual centers, which feature collaboration between a team of experts, and at research networks, which involve multiple institutions. Each ACE has adopted a specific Plan for Enhancing Diverse Perspectives (PEDP) that outlines strategies to increase the number of individuals from traditionally underrepresented backgrounds in the autism biomedical, behavioral, and clinical workforce, and to increase the participation of underrepresented populations in autism research.
- **Partners/Collaborators:** Multiple institutes including NICHD, NIDCD, NIEHS, NIMH, and NINDS
- Funding/Scope: \$100M for 10 awards (5 Centers and 5 Networks) from 2022-2027
- Additional information: https://www.nimh.nih.gov/news/science-news/2022/nih-awards-100-million-for-autism-centers-of-excellence-program

Intellectual and Developmental Disabilities Research Centers Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD)

- Description: Established in 1963, the NICHD-supported IDDRCs are located at 15 universities and children's hospitals across the U.S. to provide support for state-of-the-art research in intellectual or developmental disabilities (IDDs) including autism, using multidisciplinary, collaborative, and integrated approaches, to advance the development of services and interventions for IDDs. Research projects include approaches to increase understanding of risk and resilience, use of novel technologies to improve assessment and treatment, and development of interventions for management of co-occurring mental health conditions.
- Funding/Scope: \$11.7M for 9 awards from 2020-2025.
- Additional information: https://grants.nih.gov/grants/guide/rfa-files/RFA-HD-20-016.html

Rare Disease Clinical Research Network National Center for Advancing Translational Sciences (NCATS)

- **Description:** The Rare Diseases Clinical Research Network (RDCRN) program is designed to advance medical research on rare diseases by providing support for clinical studies and facilitating collaboration, study enrollment and data sharing. Through a network of consortia, scientists from multiple disciplines at hundreds of sites around the world work in partnership with patients and patient advocacy groups to study more than 280 rare diseases.
- **Goal:** The current RDCRNs include 20 active consortia working on multisite longitudinal studies, as well as pilot and feasibility projects, to advance treatment for rare diseases, including Phelan-McDermid Syndrome which is associated with autism.
- Funding Mechanism: Cooperative Agreements
- Partners/Collaborators: Multiple institutes including NCATS, NICHD, NIMH and NINDS.
- Additional information: https://www.rarediseasesnetwork.org/



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U.S. Department of Labor Office of Disability Employment Policy

- Mission: Develop and influence policies and practices that increase the number and quality of employment opportunities for people with disabilities (diverse backgrounds and disability experiences)
- Relationship to Autism/Disability: Cross-disability emphasis, plus focus on neurodiversity at work and priorities under the Autism CARES Act
- Topics of Portfolio Focus: employment and careers
 - Competitive integrated employment access
 - Career pathways and Good Jobs initiative
 - Diversity, Equity, Inclusion, and Accessibility (DEIA) priorities





Research Support Services for Employment of Young Adults on the Autism Spectrum DOL/DEP

- **Description:** Research project investigating barriers, promising practices, and strategies and approaches for employment success
- Goal: Expanded access to inclusive employment and career paths
- Funding Mechanism: Contract with Mathematica (partnership)
- **Funding/Scope:** \$2.9 million, FY2021-present | data analysis, listening sessions, literature reviews, etc.
- **Key Resources Released**: <u>Programs, Models, and Strategies</u>; <u>Evidence on the Effectiveness of Programs, Models, and Strategies</u>; <u>Barriers and Facilitators to Employment and Careers</u>; <u>Vocational Rehabilitation Characteristics, Service Use, and Outcomes</u>
- Future Activities: Survey of autistic young adults (planning phase)
- **Point of Contact:** David Rosenblum (federal project manager), Scott Robertson (subject matter expert on neurodiversity at work)

Other Neurodiversity-Focused Activities DOL/DEP

- Employer Assistance and Resource Network on Disability Inclusion (EARN)
 - Neurodiversity in the Workplace Guide
 - Workplace Mental Health Toolkit
 - Webinar (archived) on <u>Hiring and Supporting Neurodivergent Workers: Strategies for Success</u>
- Job Accommodation Network (JAN)
 - <u>Neurodiversity</u> webpage and webinar (archived) on <u>Accommodation Solutions for Neurodivergent</u> Workers
 - Webpages on <u>Autism</u>, <u>Mental Health Conditions</u>, and <u>Other Disabilities</u> in the A to Z <u>Library</u> for work accommodations
 - Assistance and brainstorming on work accommodations and supports from the Cognitive and Neurological Team (free, expert, and confidential)

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Administration for Community Living

Disability Initiatives and Priorities

Advancing independence, integration, and inclusion throughout life

ACL: Advancing Administration Priorities

- Expanding HCBS & Addressing the Institutional Bias
 - Supporting people to age in place
 - Delay/prevent nursing home entry
 - Breaking the pipeline of hospital to nursing home
 - Transition people from facilities to the community
- Supporting Caregivers and Building the Caregiving Economy
 - Projects to stabilize the direct care workforce: https://acl.gov/DCWcenter
 - National Family Caregiver Support Program
 - Lifespan Respite Program
 - RAISE Family Caregiver Act, Supporting Grandparents Raising Grandchildren Act
- Advancing Equity: Programs prioritize marginalized populations
 - People with disabilities and older adults
 - Lower income, racial and ethnic minorities, rural populations
 - Low English-language proficiency

Creating Change, Improving Lives

Promoting Health Equity

- I/DD Counts: https://acl.gov/iddcounts
- Partnering with Persons with I/DD to Improve Health Care Outcomes: https://iddhealthequity.org/
- Center for Transition to Adult Health Care for Youth with Disabilities: https://movingtoadulthealthcare.org/
- The Link Center: Bridging I/DD and Mental Health Systems website launching soon
- National Center for Disability, Equity, and Intersectionality: https://thinkequitable.com/
- Peer Supports for Augmentative Alternative Communication (AAC) Devices
- National Training Initiative to Support People with I/DD with Co-Occurring Mental or Behavioral Health Disabilities

Creating Change, Improving Lives

Achieving Economic Security and Mobility

- <u>Disability Employment Technical Assistance Center</u> a cross-program, evidence-based training and technical assistance center to support AoD grantees further expand their knowledge, skills, and partnerships to improve alignment around increasing competitive integrated employment and economic self-sufficiency for people with disabilities. https://aoddisabilityemploymenttacenter.com/
- Community Collaborations for Employment (7) five-year grants supporting local level collaborations to increase
 community capacity to better facilitate transition of youth with IDD and optimize opportunities for competitive
 integrated employment.
- <u>Access to Integrated Employment</u> an employment longitudinal data study analyzing trends in employment. https://www.thinkwork.org/aie

Creating Change, Improving Lives

Protecting Rights and Preventing Abuse

- <u>Center for Youth Voice Youth Choice</u> aimed at diverting high school students with I/DD from guardianship to supported decision making (SDM): https://youth-voice.org/
- <u>Living Well in the Community</u> developing and testing model approaches for enhancing health and safety in HCBS: https://acl.gov/news-and-events/announcements/living-well-grants-evaluation-update

Creating Change, Improving Lives

Empowering Individuals, Families, and Communities

- National Limb Loss Resource Center: https://www.amputee-coalition.org/
- National Paralysis Resource Center: https://www.christopherreeve.org/todays-care/living-with-paralysis/
- <u>Self-advocacy Resource and Technical Assistance Center</u>: <u>https://selfadvocacyinfo.org/</u>
- National Aging and Disability Transportation Center: https://www.nadtc.org/
- Bridging Aging and Disability: https://nacdd.org/bridging-aging-and-disability/
- State of the States in Intellectual and Developmental Disabilities: https://stateofthestates.ku.edu/
- National Residential Information Systems Project (RISP): https://risp.umn.edu/
- Housing and Services Resource Center: https://acl.gov/HousingAndServices

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Interagency Autism Coordinating Committee

U.S. Department of Housing and Urban Development (HUD) Programs for Persons With Disabilities

Leah Lozier, Ph.D.

January 24, 2024
Office of Policy Development & Research
U.S. Department of Housing & Urban Development



HUD's Mission

- HUD's mission is to create strong, sustainable, inclusive communities and quality affordable homes for all. HUD is working to strengthen the housing market to bolster the economy and protect consumers; meet the need for quality affordable rental homes; utilize housing as a platform for improving quality of life; build inclusive and sustainable communities free from discrimination, and transform the way HUD does business.
- HUD does not have autism-specific programs but serves
 persons with disabilities through all of its housing programs,
 including programs specifically for those with disabilities



Housing Programs for Persons with Disabilities-1

- Section 811 Supportive Housing Program (Traditional)
 - Interest-free capital advances and operating subsidies to develop housing for people with disabilities
 - Households must be very low-income (50% AMI)
 - At least one adult member with a disability
 - https://www.hudexchange.info/programs/section-811/
- Section 811 Project Rental Assistance (PRA) Program
 - Integrated units: affordable properties where fewer than 25% of units are set aside for people with disabilities
 - Participants must be extremely low-income (30% AMI)
 - At least one adult member with a disability
 - https://www.hudexchange.info/programs/811-pra/



Housing Programs for Persons with Disabilities-2

Mainstream Vouchers

- Rental assistance for non-elderly people with disabilities
- Follows policies of regular Housing Choice Voucher program
 - At least one adult member with a disability
- https://www.hudexchange.info/programs/public-housing/mainstream-vouchers/

Non-Elderly Disabled (NED) Vouchers

- Rental assistance for non-elderly people with disabilities
- Category 1: enable non-elderly people with disabilities to access affordable housing on the private market
- Category 2: enable non-elderly people with disabilities to transition from nursing homes and other healthcare institutions into the community
- https://www.hud.gov/program offices/public indian housing/programs/hcv/ned



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Social Security Administration (SSA)

The mission of the Social Security Administration (SSA) is to ensure equity and accessibility in delivering Social Security services by improving the customer experience and addressing systemic barriers to participation in our programs.

Disability Programs

SSA manages two disability programs: the *Social Security Disability Insurance (SSDI) program* (pays benefits to "insured" disabled individuals and certain family members) and the *Supplemental Security Income (SSI) program* (for those with limited income and resources; funded by general tax revenues).

Employment Support

Work Incentive Policies & Resources: Policies to help beneficiaries work by protecting cash and medical benefits.

<u>Employment Services</u>: Programs and services to help beneficiaries return to work and succeed in the labor force.

• <u>Ticket to Work Program</u>: A free and voluntary program that connects eligible individuals with free employment services; available to those ages 18-64 who receive SSDI and/or SSI benefits because of the individual's disability. Offers beneficiaries with disabilities expanded choices when seeking service and supports to enter, re-enter and/or maintain employment in order to increase the financial independence and self-sufficiency of beneficiaries.

Social Security Administration (SSA)

(Continued)

Research & Demonstrations

<u>Demonstrations</u>: Temporary initiatives to identify services, supports, and policies to support people with disabilities.

- <u>Lessons Learned from Past Demonstrations State of the Science Meeting</u> (June 2021; Virtual)
- SSA concluded its multi-year <u>Supported Employment Demonstration (SED)</u> and <u>Promoting Readiness of Minors in SSI</u> (PROMISE) evaluation in 2023

Other Research & Analysis: Articles, reports, evaluations, briefing papers, and other studies related to disability, work, and related topics. SSA also has its own quarterly journal—the <u>Social Security Bulletin</u>.

<u>Data & Surveys</u>: SSA releases <u>Public Use Files</u> for the public to use in statistical analyses.

<u>Statistics</u>: SSA releases program statistics on an annual basis, often broken down by primary diagnosis (including ASD).

Social Security Administration (SSA)

(Continued)

Research Funding Opportunities

<u>Interventional Cooperative Agreement Program (ICAP)</u>: Annual award allows SSA to partner with non-federal groups and organizations on interventional research related to SSA programs. Up to three projects with an award of up to \$3 million each.

<u>Retirement and Disability Research Consortium (RDRC)</u>: An interdisciplinary extramural research program funded by SSA through 5-year cooperative agreements.

Analyzing Relationships between Disability, Rehabilitation and Work (ARDRAW): An annual stipend program awarded to graduate-level students. In the process of creating new award, with new partner and stipend levels; same goals.

Agency Activities: Today's Featured Speakers

- Christy Kavulic, Ed.D. (U.S. Department of Education), FIWA Member
- Matthew Maenner, Ph.D. (Centers for Disease Control and Prevention), FIWA Member
- Lisa Gilotty, Ph.D. (National Institute of Mental Health), FIWA Member
- Scott Michael Robertson, Ph.D. (U.S. Department of Labor), FIWA Member
- Jennifer Johnson, Ed.D. (Administration for Community Living), FIWA Member
- Leah Lozier, Ph.D. (U.S. Department of Housing and Urban Development), FIWA Member
- Alison R. Marvin, Ph.D. (Social Security Administration), FIWA Member
- Robert Ochsendorf, Ph.D. (National Science Foundation), not a member of FIWA, but collaborates with FIWA



Overview of Research at NSF

IACC Meeting – January 2024

ROB OCHSENDORF
PROGRAM DIRECTOR



Preparing a diverse STEM workforce and a well-informed citizenry



NSF Mission



"to promote the progress of science; to advance the national health, prosperity, and welfare; [and] to secure the national defense"



Examples of Notable NSF Investments



3-D PRINTING BREAKTHROUGH



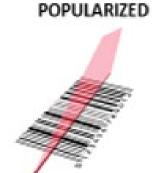
AUTONOMOUS CAR SOFTWARE



HL TAU DISCOVERY







BARCODES



EARLY WEB BROWSER

NSF investments related to ASD tend to focus on:

- a) K-12 STEM Education
- b) undergraduate STEM education
- c) informal STEM education
- d) accessibility and accommodations
- e) technology and small business innovation
- f) STEM workforce development
- g) cognitive and behavioral research
- h) convenings and workshops



Thank you!

Rob Ochsendorf

rochsend@nsf.gov



Agency Activities: Today's Featured Speakers

- Christy Kavulic, Ed.D. (U.S. Department of Education), FIWA Member
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- Leah Lozier, Ph.D. (U.S. Department of Housing and Urban Development), FIWA Member
- Alison R. Marvin, Ph.D. (Social Security Administration), FIWA Member
- Robert Ochsendorf, Ph.D. (National Science Foundation), not a member of FIWA, but collaborates with FIWA

Questions?

Project: <u>SBIR Phase I: Prototyping a Wearable Device that Continuously Monitors</u> <u>Biometrics using Machine Learning to Predict Meltdowns in Children with Autism</u>

This project seeks to develop a wearable device that detects, predicts, and helps prevent meltdowns in children with autism. Wearable devices that measure physiological parameters are available in the market, but none of them are specific to autism, and none of them proactively predict behavior episodes. A unique feature of this wearable device is that it will use machine learning to predict meltdowns.

PI: Brent Chase, Products for Any Lifestyle, Inc.



Project: Multimodal Algorithms for Motor Imitation Assessment in Children with Autism

The goal of this project is to design, develop and test an objective, reproducible and highly-scalable multimodal system to observe children performing a brief videogame-like motor imitation task, quantitatively assess their motor imitation performance, and investigate its validity as a phenotypic biomarker for autism.

PI: Stewart Mostofsky, Hugo W. Moser Research Institute at Kennedy Krieger, Inc.



Project: <u>CAREER: Learning Visual Representations of Motor Function in Infants as Prodromal Signs for Autism</u>

The goal of this project is to establish a computer vision-based, artificial intelligence-guided infant motor function monitoring and assessment system to enable unobtrusive tracking of measures of motor impairment while the infant is in their natural environment. The research could aid in early identification of motor deficits in infants, thereby enabling early treatment resulting in better quality of life.

PI: Sarah Ostadabbas, Northeastern University



Project: <u>A Gamified Mobile System for Real-Time Mental Health Data Modeling and Personalized Autism Care Across Sociocultural Settings</u>

Working with families and their affected children ages 2-8, the team will establish a gaming system for mobile devices. This system will use augmented reality and AI to adapt to the child's needs and foster a social exchange between the primary caregiver and the child. This mobile solution will connect families to care, fostering the development of a community of stakeholders, together with AI models capable of personalizing care and tracking progress.

PI: Dennis Wall, Stanford University



Project: Modeling Zoos and Aquariums as Inclusive Communities of Science: Developing a framework of inclusive practices for broadening the participation of autistic individuals

The project intends to develop a research-informed framework and associated tools (i.e. case studies, discussion guides, self-guided audits, etc.) and strategies to support science learning for autistic individuals. The project will also help practitioners expand access and inclusion of autistic audiences by applying inclusive practices for programs, exhibit development, internships, volunteer opportunities, and employment.

PI: Kelly Riedinger, Oregon State University



Project: <u>Connecting Students with Autism to Geographic Information Science & Technology</u> <u>Careers</u>

The project's goal is to develop an innovative, research-based workforce development model that increases student self-regulation, interest, and motivation and expands students' understanding of Geographic Information Science and workforce development Technology (GIST). The project will motivate and prepare high school students with ASD to enter postsecondary educational training programs and careers in geospatial and data science sectors.

PI: Jason Painter, North Carolina State University



Project: <u>Enhancing Employment for Neurodiverse Individuals through Next-Generation, Al-Enabled Assessments of Visuospatial Cognition</u>

This research investigates new tools and methods for matching individual job-seekers on the autism spectrum to employment opportunities that leverage their unique cognitive skills, with a focus on visuospatial cognitive skills.

PI: Maithilee Kunda, Vanderbilt University



60 MINUTES - NEWSMAKERS >

Recruiting for talent on the autism spectrum



BY ANDERSON COOPER

OCTOBER 4, 2020 / 7:42 PM EDT / CBS NEWS







Break



IACC Committee Business

January 24, 2024



Susan A. Daniels, Ph.D.

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

Committee Business Overview



- ONAC Staff Updates
- 2022 IACC Summary of Advances
- Co-Occurring Conditions Request for Public Comments and report
- 2023 IACC Summary of Advances discussion

ONAC Staff Updates



 Ana Cappuccio, LL.B. has joined ONAC as the new Operations Coordinator and will be assisting with administrative issues, along with Angelice Mitrakas, ONAC's Management Analyst.



• Steven Isaacson, L.M.S.W. recently completed his Master's degree in clinical social work and has taken on a new role as ONAC's Neurodiversity Liaison. He will be assisting ONAC with community outreach and projects related to issues such as neurodiversity at work.



2022 IACC Summary of Advances: Available Now!





- Required by the Autism CARES Act of 2019
- Provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Includes articles addressing all 7 topic areas of the IACC Strategic Plan
- The full Report can be found here: https://iacc.hhs.gov/publications/summary-of-advances/2022/
- An easy-read version of the Report can be found here:
 https://iacc.hhs.gov/publications/summary-of-advances/2022/summary of advances/2022 easy read.pdf?ver=3

2024 IACC Strategic Plan Update: Co-Occurring Conditions



- In October 2023, the IACC voted to focus on **co-occurring physical and mental health conditions** and their impacts on health outcomes for the *2024 IACC Strategic Plan Update*.
- A draft report on co-occurring conditions was initiated by the previous committee and will be used as the foundation for this report.
- As decided in 2023 by the current IACC, ONAC will work with working group chair, Dr. Julie Taylor, to update the draft.
- ONAC has published a formal Request for Public Comments on co-occurring conditions on behalf of the IACC; the results will be shared with the IACC at the next IACC meeting.
- The IACC will have an opportunity to review the draft and provide suggestions.
- The Report is anticipated to be finalized in 2024.

Co-Occurring Conditions Request for Public Comments

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

- On behalf of the IACC, ONAC recently released a Request for Public Comments to assist the IACC in identifying priorities related to physical and mental health conditions, and other related conditions that commonly cooccur with autism
- Comment period is open from January 3 February 14, 2024
- As of January 22, ONAC has received 678 completed submissions
- We have also received 247 incomplete submissions
 - Only completed submissions will be provided to the IACC
- To respond to the Request for Public Comments, go to: https://iacc.hhs.gov/meetings/public-comments/requests-for-information/2023/co-occurring-conditions.shtml
- Please share this Request for Public Comments with your networks. If you need publicity materials, send an e-mail to
 <u>IACCPublicInquiries@mail.nih.gov</u>



2024 IACC Strategic Plan Update: Next Steps



- ONAC will categorize feedback provided from the Request for Public Comments and provide it to the IACC at the April 17, 2024 IACC Meeting.
- ONAC will continue updating the draft report, incorporating feedback from the Request for Public Comments.
- IACC members will have an opportunity to review the draft and provide feedback.
- ONAC will incorporate feedback and finalize the report for publication.

2023 Summary of Advances Nominations



2023 *IACC Summary of Advances* Process



- □IACC members nominate articles (January 2023 January 2024)
- □<u>TODAY:</u> IACC members discuss nominations at committee meetings (April 2023 January 2024)
- □IACC members vote on top 20 articles (January-February 2024)
- □ONAC prepares article summaries and draft publication (Winter-Spring 2024)
- □IACC members preview/comment on draft (Spring 2024)
- □ONAC prepares final publication (Spring-Summer 2024)

Summary of Advances discussion guidelines



- Goal of today's discussion: review the list of 76 nominated articles
- Selected articles should represent **significant advances or progress** in understanding of autism, across the 7 topic areas of the *IACC Strategic Plan*
- During the discussion:
 - Are there nominated articles you find particularly noteworthy?
 - Are there any articles that should potentially be removed, including any in the following categories?
 - Study too preliminary
 - Small sample size
 - Review article
 - Commentary
 - Workgroup recommendations



Question 1: Screening and Diagnosis



- 1. Herkert et al. Prevalence and nature of prior developmental and medical concerns in toddlers who screen positive for autism in primary care. Autism.
- 2. James et al. Consistency between parent report and direct assessment of development in toddlers with autism spectrum disorder and other delays: Does sex assigned at birth matter? Autism Res.
- 3. Jones et al. Eye-Tracking-Based Measurement of Social Visual Engagement Compared With Expert Clinical Diagnosis of Autism. *JAMA*.
- 4. Jones et al. Development and Replication of Objective Measurements of Social Visual Engagement to Aid in Early Diagnosis and Assessment of Autism. JAMA Netw Open.

Question 1: Screening and Diagnosis



- 5. MacKenzie et al. Obtaining a First Diagnosis of Autism Spectrum Disorder: Descriptions of the Diagnostic Process and Correlates of Parent Satisfaction from a National Sample. J Autism Dev Disord.
- 6. Perochon et al. Early detection of autism using digital behavioral phenotyping. Nat Med.
- 7. Pham et al. Examination of the impact of the Get SET Early program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder. Autism.
- 8. Shuster et al. Neurobehavioral and Medical Correlates of Autism Screening: 2-Year Outcomes for Infants Born Very Preterm. *J Pediatr*.

Question 2: Biology



- 9. Buch et al. Molecular and network-level mechanisms explaining individual differences in autism spectrum disorder. Nat Neurosci.
- 10. Chari et al. A Novel Head-Fixed Assay for Social Touch in Mice Uncovers Aversive Responses in Two Autism Models. J Neurosci.
- 11. Faerman et al. Language Abilities are Associated with Both Verbal and Nonverbal Intelligence in Children on the Autism Spectrum. Dev Neuropsychol.
- 12. Fountain et al. **Developmental Trajectories of Autism.** *Pediatrics*.

Question 2: Biology



- 13. Garic et al. Enlarged Perivascular Spaces in Infancy and Autism Diagnosis, Cerebrospinal Fluid Volume, and Later Sleep Problems. JAMA Netw Open.
- 14. Jourdon et al. Modeling idiopathic autism in forebrain organoids reveals an imbalance of excitatory cortical neuron subtypes during early neurogenesis. Nat Neurosci.
- 15. Mohamed and Klann. Autism- and epilepsy-associated EEF1A2 mutations lead to translational dysfunction and altered actin bundling. *Proc Natl Acad Sci*.
- 16. Morton et al. Multi-level analysis of the gut-brain axis shows autism spectrum disorder-associated molecular and microbial profiles. Nat Neurosci.

Question 2: Biology



- 17. Neuhaus et al. Frontal EEG alpha asymmetry in youth with autism: Sex differences and social-emotional correlates. Autism Res.
- 18. Schwartz et al. Auditory evoked potentials in adolescents with autism: An investigation of brain development, intellectual impairment, and neural encoding. Autism Res.
- 19. St John et al. Association of Sex With Neurobehavioral Markers of Executive Function in 2-Year-Olds at High and Low Likelihood of Autism. JAMA Netw Open.
- 20. Waizbard-Bartov et al. Changes in the severity of autism symptom domains are related to mental health challenges during middle childhood. Autism.
- 21. Wright et al. A longitudinal comparison of emotional, behavioral and attention problems in autistic and typically developing children. *Psychol Med*.

Question 3: Genetic and Environmental Factors



- 22. Ames et al. Prenatal Exposure to Per- and Polyfluoroalkyl Substances and Childhood Autism-related Outcomes. *Epidemiology*.
- 23. Carter et al. Maternal exposure to aircraft emitted ultrafine particles during pregnancy and likelihood of ASD in children. *Environ Int*.
- 24. Feinberg et al. Epigenetic changes in sperm are associated with paternal and child quantitative autistic traits in an autism-enriched cohort. Mol Psychiatry.
- 25. Rahman et al. Prenatal exposure to tailpipe and non-tailpipe tracers of particulate matter pollution and autism spectrum disorders. Environ Int.

Question 3: Genetic and Environmental Factors



- 26. Song et al. Associations of prenatal exposure to a mixture of persistent organic pollutants with social traits and cognitive and adaptive function in early childhood: Findings from the EARLI study. Environ Res.
- 27. van Jaarsveld et al. **Delineation of a KDM2B-related neurodevelopmental disorder and its associated DNA methylation signature.** *Genet Med*.
- 28. Yap et al. Interactions between the lipidome and genetic and environmental factors in autism. Nat Med.

Question 4: Interventions



- 29. Chang et al. **Developmental Play Skills as Outcomes of Early Intervention.** *J Autism Dev Disord*.
- 30. Che et al. Impact of consuming a Mediterranean-style diet during pregnancy on neurodevelopmental disabilities in offspring: results from the Boston Birth Cohort. Precis Nutr.
- 31. Clarke et al. The Relationship Between Augmentative and Alternative Communication Use by Pediatric Psychiatric Inpatients With Autism Spectrum Disorder and Interfering Behaviors. Am J Speech Lang Pathol.
- 32. Day et al. A PROMIS[®]ing New Measure for Quantifying Emotion Dysregulation in Toddlers and Preschoolers: Development of the Emotion Dysregulation Inventory-Young Child. J Autism Dev Disord.

Question 4: Interventions



- 33. Hatfield et al. **GamerFit-ASD beta test: adapting an evidence-based exergaming and telehealth coaching intervention for autistic youth.** *Front Pediatr*.
- 34. Imbiriba et al. Wearable Biosensing to Predict Imminent Aggressive Behavior in Psychiatric Inpatient Youths With Autism. JAMA Netw Open.
- 35. Kasari et al. Spoken language outcomes in limited language preschoolers with autism and global developmental delay: RCT of early intervention approaches. Autism Res.
- 36. Mittal et al. Receipt of Behavioral Therapy in Preschool-Age Children with ADHD and Coexisting Conditions: A DBPNet Study. J Dev Behav Pediatr.

Question 5: Services and Supports



- 37. Adams et al. Associations between social activities and depressive symptoms in adolescents and young adults with autism spectrum disorder: Testing the indirect effects of loneliness. Autism.
- 38. Brunt et al. The impact of COVID-19 on receipt of health services among children with and without autism. Autism.
- 39. Constantino et al. **Prospects for Leveling the Playing Field for Black Children With Autism**. J Am Acad Child Adolesc Psychiatry.
- 40. Feinberg et al. Effect of Family Navigation on Participation in Part C Early Intervention.

 Acad Pediatr.

Question 5: Services and Supports



- 41. Kenworthy et al. Leveraging technology to make parent training more accessible: Randomized trial of in-person versus online executive function training for parents of autistic children. Autism.
- 42. Koffer Miller et al. Feeling intimidated and uncomfortable: Established and exacerbated educational inequities experienced by black parents of autistic children. Autism Res.
- 43. Rast et al. Disparities by Race and Ethnicity in Inpatient Hospitalizations Among Autistic Adults. J Autism Dev Disord.
- 44. Roux et al. Unrealized Cross-System Opportunities to Improve Employment and Employment-Related Services Among Autistic Individuals. *Milbank Q*.

Question 5: Services and Supports



- 45. Schiltz et al. A Longitudinal Mixed-Methods Characterization of Family Support from Adolescence to Young Adulthood in Autism and Other Developmental Disabilities. J Autism Dev Disord.
- 46. Stein Duker et al. Sensory Adaptations to Improve Physiological and Behavioral Distress During Dental Visits in Autistic Children: A Randomized Crossover Trial. JAMA Netw Open.
- 47. Taylor et al. Improving parents' ability to advocate for services for youth with autism: A randomized clinical trial. Autism Res.



- 48. Chan and Doran. Mental health counseling is rated as most helpful by autistic adults: Service perspectives in adulthood. Autism.
- 49. Davies et al. Access to employment: A comparison of autistic, neurodivergent and neurotypical adults' experiences of hiring processes in the United Kingdom. Autism.
- 50. Gibbs and Pellicano. 'Maybe we just seem like easy targets': A qualitative analysis of autistic adults' experiences of interpersonal violence. Autism.
- 51. Hedley et al. Cost-benefit analysis of a non-government organization and Australian government collaborative supported employment program for autistic people. Autism.



- 52. Hong et al. Autism through midlife: trajectories of symptoms, behavioral functioning, and health. J Neurodev Disord.
- 53. Hughes et al. Individualized Education Programs and Transition Planning for Adolescents With Autism. *Pediatrics*.
- 54. Kahn et al. Mental Health of Youth With Autism Spectrum Disorder and Gender Dysphoria. Pediatrics.
- 55. Kim et al. Discrimination and Harassment Experiences of Autistic College Students and Their Neurotypical Peers: Risk and Protective Factors. J Autism Dev Disord.



- 56. Lai et al. Self-Harm Events and Suicide Deaths Among Autistic Individuals in Ontario, Canada. JAMA Netw Open.
- 57. Liu et al. Age-related physical health of older autistic adults in Sweden: a longitudinal, retrospective, population-based cohort study. Lancet Healthy Longev.
- 58. Malow et al. Health conditions in autism: Defining the trajectory from adolescence to early adulthood. Autism Res.
- 59. McNair et al. Seeking contexts that promote neurodiverse social success: Patterns of behavior during minimally-structured interaction settings in autistic and non-autistic youth. Dev Psychopathol.



- 60. Penton et al. Attitudes to Interpersonal Touch in the Workplace in Autistic and non-Autistic Groups. J Autism Dev Disord.
- 61. Pryke-Hobbes et al. The workplace masking experiences of autistic, non-autistic neurodivergent and neurotypical adults in the UK. PLoS One.
- 62. Ratto et al. Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. Autism Adulthood.
- 63. Schiltz et al. Anxiety, depression, and well-being in autistic adults and adults with other developmental disabilities: A longitudinal cross-lagged analysis. Autism Res.



- 64. Steinberg et al. Same Transition, Different Perspectives: Comparing Dyadic Interviews with Autistic Young Adults and Parents. Autism in Adulthood.
- 65. Strang et al. The Gender Self-Report: A multidimensional gender characterization tool for gender-diverse and cisgender youth and adults. Am Psychol.
- 66. Szechy et al. Autism and employment challenges: The double empathy problem and perceptions of an autistic employee in the workplace. Autism in Adulthood.
- 67. Togher and Jay. Disclosing an autism diagnosis: A social identity approach. Autism Res.



- 68. Vincent and Ralston. Uncovering employment outcomes for autistic university graduates in the United Kingdom: An analysis of population data. Autism.
- 69. Wilson et al. Caregiver perceptions and experiences surrounding employment of their adult-aged children on the autism spectrum. Family Relations.

Question 7: Infrastructure and Prevalence



- 70. Hughes et al. The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016. Public Health Rep.
- 71. Kahn et al. Co-occurring Autism Spectrum Disorder and Gender Dysphoria in Adolescents. *Pediatrics*.
- 72. Rubenstein et al. **Prevalence of Autism Among Medicaid-Enrolled Adults.** *JAMA Psychiatry*.
- 73. Schott et al. Prevalence of high-risk conditions for severe COVID-19 among Medicaid-enrolled children with autism and mental health diagnoses in the United States. Autism.

Question 7: Infrastructure and Prevalence



- 74. Sterrett et al. Predictors of Attrition in a Randomized Trial of a Social Communication Intervention for Infant-Toddlers at Risk for Autism. J Autism Dev Disord.
- 75. Yu et al. Neighborhood Disadvantage and Autism Spectrum Disorder in a Population With Health Insurance. JAMA Psychiatry.
- 76. Zahorodny et al. Prevalence and Characteristics of Adolescents with Autism Spectrum Disorder in the New York-New Jersey Metropolitan Area. J Autism Dev Disord.

2023 IACC Summary of Advances: Next Steps



- IACC members will soon receive a ballot to vote for the top 20 articles
- ONAC staff will prepare summaries of the top 20 articles for the report
- IACC members will have a chance to preview the draft report

Lunch Break



Please scan the lunch option QR code on the printed agenda for additional lunch options

Public Comment Session



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

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



- Nicole Corrado
- Anthony Tucci
- Jordyn Jensen

Summary of Written Public Comments



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

Justice and Law Enforcement – 3 comments

- Rose Baumann
- Gene Bensinger
- Bjørn Ivesdal

Research and Service Needs, Resources, and Policy Implications – 2 comments

- Dr. Sharief Taraman
- AJ Link, Autistic Self Advocacy Network

Research, Services, and Supports for Adults with Autism – 2 comments

- Scott Patterson
- Nicole LeBlanc

Addressing the Needs of Autistic Individuals with High Support Needs – 2 comments

- Dawn Dougherty
- Jill Escher, National Council on Severe Autism

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/january24/public comments.pdf

Summary of Written Public Comments



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

Mental Health Research, Services, and Treatment – 1 comment

Nicole LeBlanc

Increase Autism Acceptance and Reduce Stigma – 1 comment

- Dr. Sharief Taraman
- AJ Link, Autistic Self Advocacy Network

Concerns About Medical Practices – 1 comment

Jennine Donahue

Needs of the Direct Support Professional
Workforce – 1 comment

Nicole Corrado

Full text of public comments available at: https://iacc.hhs.gov/meetings/iacc-meetings/2024/full-committee-meeting/january24/public comments.pdf

Justice and Law Enforcement Presentations and Panel



Community Perspectives on Mental Health Needs in Autism



Panelists:

- Steven Gordon, Esq.
- Carlean Ponder, Esq.
- Leigh Anne McKingsley, M.S.S.W., M.P.A.
- Brooke Mount, PhD.
- Kelly Burke, MPH
- Officer Laurie Reyes

Community Perspectives on Mental Health Needs in Autism



Panelists:

- Steven Gordon, Esq.
- Carlean Ponder, Esq.
- Leigh Anne McKingsley, M.S.S.W., M.P.A.
- Brooke Mount, PhD.
- Kelly Burke, MPH
- Officer Laurie Reyes

Interagency Autism Coordinating Committee



Assistant United States Attorney Civil Rights Enforcement Coordinator USAO Eastern District of Virginia

Introduction to Panel

Individuals with autism, like any other person, are likely to encounter law enforcement officers at some point. It can be as a crime victim, a criminal suspect or a witness. Unfortunately, because of the lack of understanding of autism in the law enforcement community, sometimes these interactions end badly.

Introduction to Panel

Without proper training, criminal justice personnel may misinterpret the conduct of individuals with autism as intentional disrespect or disobedience, which may escalate encounters and lead to unnecessary criminal justice involvement.

Introduction to Panel

An important tool for addressing lack of knowledge is providing law enforcement with training to increase cultural competency and cultural humility for people with autism.

This afternoon, you will hear from people who have worked with law enforcement agencies to increase cultural competency and cultural humility for people with intellectual and developmental disabilities, including autism.

This Is An Appetizer Presentation: A Presentation That Covers All of the Americans with Disabilities Act Issues In Law Enforcement Settings Would Take At Least A Full Day



Americans with Disabilities Act

The Americans with Disabilities Act is a civil rights law that prohibits discrimination based on disability. It affords similar protections against discrimination to people with disabilities as the Civil Rights Act of 1964, which prohibits discrimination based on race, color, religion, sex and national origin.

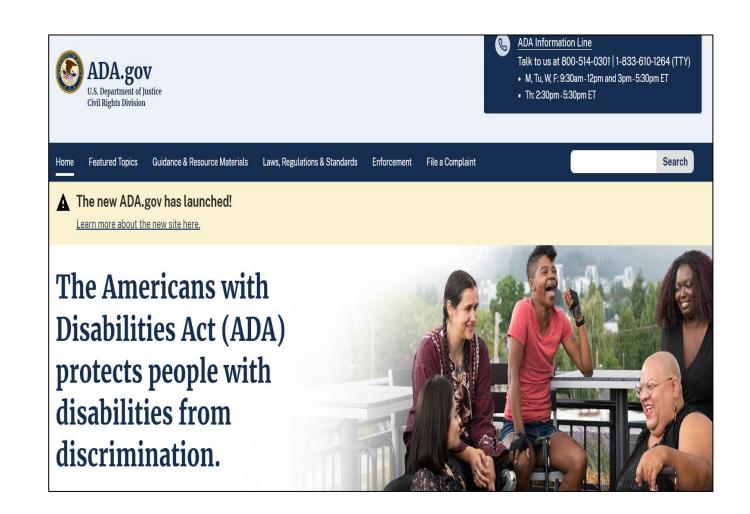
Important Government ADA Resource: ADA.gov

Statutory Language

Regulations

Technical Assistance

Settlement Agreements



Archive.ADA.gov



United States Department of Justice

archive ADA gov Information and Technical Assistance on the Americans with Disabilities Act

Search archive.ADA.gov

go

Law / Regulations

Civil Rights Division

Design Standards

Technical Assistance Materials

Enforcement

New on ADA.gov

U.S. v. the Massachusetts Parole Board

Settlement Agreement (posted 11/17/22)

NYC Transit Authority Access-A-Ride Program

Findings Letter (posted 11/17/22)

Fayette County Detention Center

Settlement Agreement (posted 11/17/22)

Contra Costa County Kids at Work

Settlement Agreement (posted 11/17/22)

U.S. v. LA Nail Spa

Settlement Agreement (posted 11/17/22)

Town of Limerick, Maine

Settlement Agreement (posted 11/17/22)

City of Hudson, New York

Settlement Agreement (posted 11/17/22)

ADA Information Line

The U.S. Department of Justice provides information about the ADA through a toll-free ADA Information Line. 800-514-0301 (voice) 833-610-1264 (TTY)

Introduction to the ADA

File an ADA Complaint on www.ada.gov

Featured Topic: Guidance on Nondiscrimination in Telehealth





DOJ Technical Assistance Publications Related to the ADA and Law Enforcement Commonly Asked Questions About the ADA and Law Enforcement

Examples and Resources to Support
Criminal Justice Entities in Compliance
with Title II of the Americans with
Disabilities Act

The ADA Covers All State & Local Entities In The Criminal Justice System

- Law enforcement agencies
- Courts
- Jails, prisons, and correctional facilities
- Community corrections, including probation, work release, and pre-trial services
- Public defender services
- Prosecutors
- State and local social service agencies, including the Community Service Board

Title II of the Americans with Disabilities Act Covers All Activities of Criminal Justice Entities. A Few Examples:

- Operating telephone (911) and (988) emergency centers
- Law enforcement on the street interactions, including taking and responding to complaints
- Interviewing and questioning witnesses, victims, or suspects
- Assessing individuals for diversion programs
- Arresting, booking, holding suspects, and setting conditions for probation or parole
- Providing emergency medical services
- Enforcing laws

Examples of Discrimination Under the ADA

- Failing to make reasonable modifications in policies, practices, or procedures when necessary to avoid disability discrimination in all interactions with people with disabilities unless the modifications would fundamentally alter the nature of the service, program, or activity.
- Failing to conduct individualized assessments to determine how to ensure equal access.
- Failing to communicate in a way that an individual with a disability can understand.
- Screening out people with disabilities from programs.

Individualized Assessment Is Key Because One Size Solutions Do Not Fit All



Equity-Based Verses Equality Based Solutions

EQUALITY:

Everyone gets the same – regardless if it's needed or right for them.



EQUITY:

Everyone gets what they need – understanding the barriers, circumstances, and conditions.



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Discrimination Under the ADA Not Limited To Affirmative Animus

"The ADA . . . Specifically prohibits discrimination against [individuals with disabilities], not just based on invidious 'affirmative animus,' but also based on thoughtlessness, apathy, and stereotypes about disabled persons."

Title II Discrimination: Criminal Justice

- Examples of Failures to modify policies, practices or procedures
 - Failing to deploy alternate responses for behavioral health calls and failing to coordinate with community mental health agency. See DOJ's <u>LOF</u> in Investigation of Louisville Metro Police Department and Metro Government.
 - Denying a request for a support person to assist an individual with I/DD during an interrogation.
 - Prison GED program fails to modify curriculum for person with intellectual disability.

Modification of Policies, Practices or Procedures

"Louisville Metro could modify MetroSafe's policies, procedures, and training program and deploy community-based, provider-operated mobile crisis teams to behavioral health calls—both initial calls for service and encounters when an officer determines that a police response is not necessary."

DOJ Has Similar <u>Letter of Finding</u> in Minneapolis

DOJ Report on Louisville Metro PD

"A behavioral health-focused response should be available to people experiencing behavioral health issues instead of a traditional law enforcement response, when appropriate."

Systemic Considerations

It is important that criminal justice entities anticipate and prepare for the disability-related needs of people with autism. Three ways to prepare:

- Training criminal justice personnel.
- · Conducting reviews of policies and procedures.
- Collaborating with mental health and disability services providers.

Examples of How To Ensure Accessibility

- Train law enforcement officers that, when responding to a person in mental health crisis who does not pose a significant safety threat, they should consider providing time and space to calm the situation.
- Require court staff to explore reasonable modifications to allow qualified individuals with autism to participate in diversion and probation programs and specialty courts.

Examples of How To Ensure Accessibility

- Implement policies that encourage corrections staff to seek assistance from crisis intervention teams and mental health professionals when interacting with inmates that exhibit negative or disruptive behavior.
- Train corrections staff in the use of de-escalation techniques and to forego discipline and provide treatment where it is apparent that a prisoner's behavior was related to a disability.

Collaboration

Increased collaboration and improved resource allocation between criminal justice agencies and disability service systems can also help reduce the disparities people with disabilities experience.

Actions required by the ADA are not special privileges, but instead measures that ensure accessibility.

Bureau of Justice Statistics

From 2011-2015:

The rate of serious violent crime (rape or sexual assault, robbery, and aggravated assault) against persons with disabilities was three times the rate for persons without disabilities.

Bureau of Justice Statistics National Crime Victimization Survey

Those with **cognitive disabilities** had the **highest rate** of total violent victimization among disability types measured.

Source: https://bjs.ojp.gov/content/pub/pdf/capd0919st.pdf

Bureau of Justice Statistics National Crime Victimization Survey

Twenty-one percent of unreported violence against persons with disabilities was not reported because the victim did not think the police would help

Community Engagement is an important component of the USAO for EDVA's Civil Rights Enforcement Practice Loudoun County Disability & Justice Coalition Hosted by The Arc of Loudoun



The Arc of Loudoun: https://www.thearcofloudoun.org/

Loudoun County Disability & Justice Coalition Training



Virginia Department Of Corrections Training



Virginia Public Defenders' Annual Training



International Association of Chiefs of Police's Annual Conference



Virginia Sheriffs' Association



The Arc of Northern Virginia/Arlington County Police Program



The Arc of Northern Virginia is partnering again with the Arlington County Police to offer a great opportunity for people with disabilities and their loved ones to practice emergency situations.

Saturday, March 26, 2022

11:00 a.m. to 1:00 p.m.





My Contact Information

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Civil Rights Enforcement Coordinator
Assistant United States Attorney
Eastern District of Virginia
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(703) 299-3817

Community Perspectives on Mental Health Needs in Autism



Panelists:

- Steven Gordon, Esq.
- Carlean Ponder, Esq.
- Leigh Anne McKingsley, M.S.S.W., M.P.A.
- Brooke Mount, PhD.
- Kelly Burke, MPH
- Officer Laurie Reyes

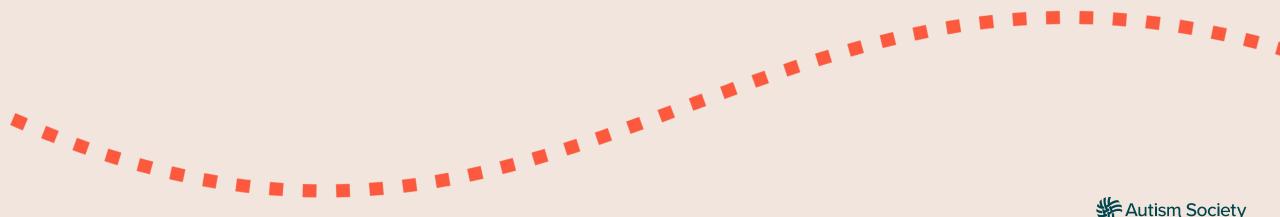


The Autism Justice Center

January 2024

The Autism Justice Center

The Autism Justice Center serves as a **resource** for Autistic people, family members, and advocates impacted by societal bias, neglect, and discrimination in the critical areas of housing, healthcare, employment, education, and the criminal legal system.





Who We Are

- Includes individuals with Autism,
 researchers, lawyers, and professional
 advocates
- Advise on developing priority issues, share resources, and serve as expert advisors
- Partnerships



Agenda

- Autism and Justice System
- Race and Autism
- Issues
- Recommendations





Autism & Justice System



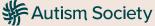
- 7X more likely to interact with criminal system
- Mental health co-morbidities/behavioral health contribute to increased interactions
- Autistic children experience disproportionate levels of school discipline



Race & Autism

- Fewer Black and Latino children are diagnosed as Autistic
- Asian children have the highest diagnosis rate
- Black Autistic <u>individuals</u> are more likely to be hurt or killed during police encounters
- Black Autistic individuals are disproportionately held in jails and sentenced to long prison terms







Issues

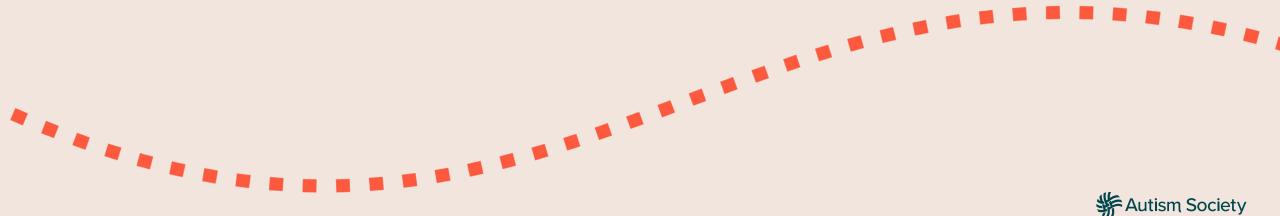
- Autism in the judicial system
 - Distinguishing mental illness; Competency
- Intellectual versus social limitations
 - > Bias
- Strict liability laws
 - ➤ A legal conundrum for the developmentally disabled



Autism in the Courts

Distinguishing Mental Illness

Scientifically, Autism is a neurologically based developmental disability that May SIGNIFICANTLY impair social learning, and the ability to to interact in a socially appropriate manner.



Autism in the Courts

> Intellectual v. Social Limitations

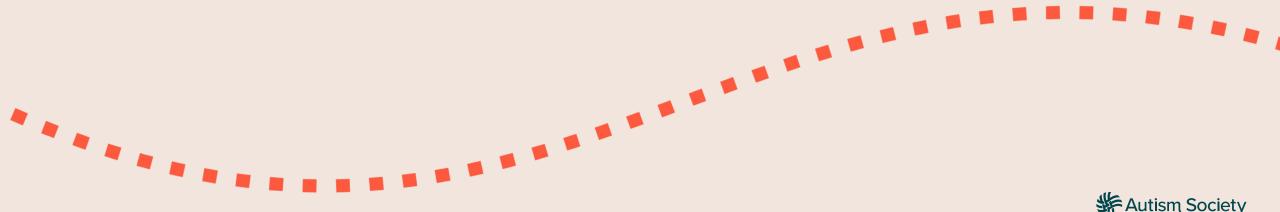
- Bias
- Presenting Without Disability
- Conveying Compromised Adaptive Functioning



Autism in the Courts

> Strict Liability Laws

The prosecution doesn't need to prove that a defendant intended to do something that's illegal; nor, that the defendant was reckless or negligent. It's enough for a conviction to prove that the act was committed and the defendant committed it.



Strict Liability Commonly Applies in Cases Involving Sexual Interactions Either Online or In Person

Case Example:

An Autistic Idaho teen was jailed for sexual contact with underage girls. State charges include life in prison as a possible penalty.



Questions for Consideration

- What does this mean for ADA rights?
- 14th amendment—equal protection?
- Would mandating consideration of disability help?



Recommendations

•••••

Diversion

The Autism Justice Center supports early and maximum diversion efforts as an alternative to incarcerating Autistic people in jails and prisons.

Judicial system training on Autism

Recognizing and understanding symptoms of Autism; this allows for appropriate accommodations throughout the legal process; and better sentencing outcomes.



Questions?





Thank you.

Carlean Ponder

Director, Autism Justice Center



Community Perspectives on Mental Health Needs in Autism



Panelists:

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- Carlean Ponder, Esq.
- Leigh Anne McKingsley, M.S.S.W., M.P.A.
- Brooke Mount, PhD.
- Kelly Burke, MPH
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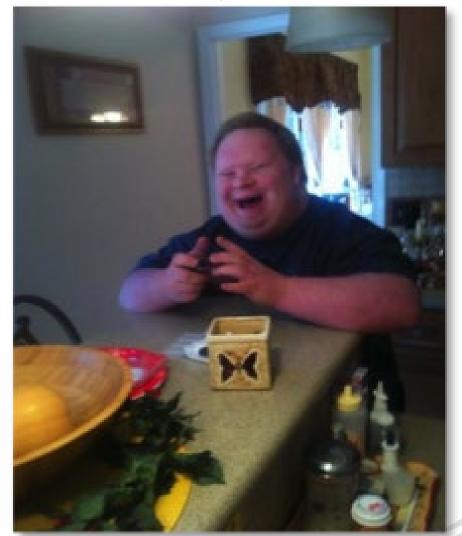
Advocating at the Intersection of Disability Rights and Criminal Justice Reform

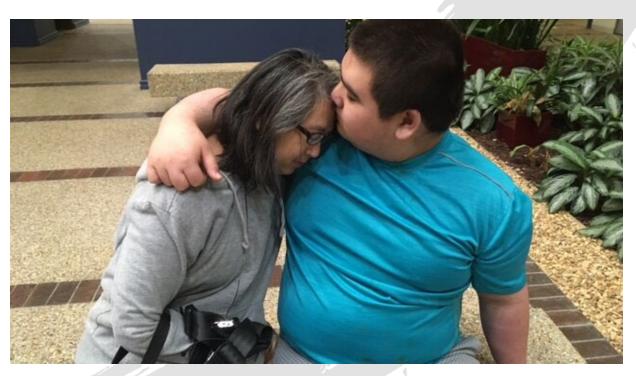


National Center on Criminal Justice & Disability

WHY WE CAN'T STOP ADVOCATING

Ethan Saylor (2013)





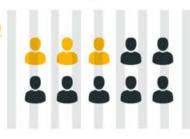
Eric Parsa (2020)

Achieve with us.





2 in 10 prisoners and 3 in 10 jail inmates reported having a cognitive disability*, the most commonly reported type of disability.



*Cognitive disabilities include Down syndrome, autism, dementia, learning disabilities, intellectual disability, and traumatic brain injury.

Source: Bureau of Justice Statistics



of those later exonerated after giving a false confession to police had characteristics of intellectual disability.

Source: National Registry of Exonerations





to Justice

- Disability goes unrecognized or is dismissed as irrelevant
- Face higher rates of arrest, conviction, and longer sentences
 - Inaccessible diversion and rehabilitation programs



Race & Disability

- American Journal of Public Health article (McCauley, 2017)
 found that young people with disabilities are 13% more likely
 to be arrested than their peers without disability
 - That figure jumps to 17% for Black youth with disabilities
- People with disabilities have an overall 43% chance of arrest, with a disproportionate risk falling on young Black men



WHY WE CAN'T STOP ADVOCATING

At least 1 in 6 men have been sexually assaulted

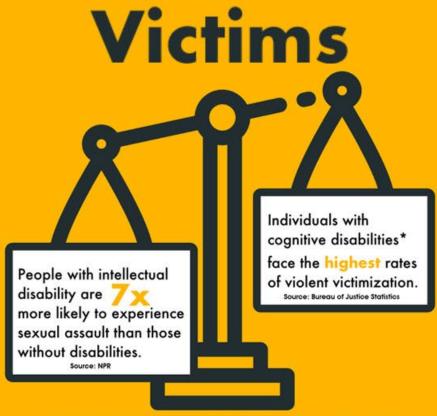
1in6 PSA - first time to include male with

disabilities

Image: Picture of man (James Meadours) shaking hands with woman who just read his story about surviving sexual assault for the first time. Both are sitting on stools and smiling.







*Cognitive disabilities include Down syndrome, autism, dementia, learning disabilities, intellectual disability, and traumatic brain injury.



- Reports of victimization are not believed
- Cases may go unprosecuted, especially if there are communication challenges
 - Inaccessible services and supports

NCCJD: A Decade of Advocacy





Training and technical assistance

- Pathways to Justice® www.nccjdpathwaystojustice.org
- Community-based program that creates Disability Response Teams (or DRTs)



Information and referral

- For people with disabilities and their families as well as criminal justice and allied professionals
- https://thearc.org/our-initiatives/criminal-justice/



Resource collection and creation

Policy briefs, fact sheets, other publications



Education

National media outlets, social media, webinars and national/international conferences and outreach

NCCJD Projects & Initiatives

- *Just Policing In-Person and Online Training on IDD –* COPS Office
- Language Access Barriers to Justice Among Victims with IDD
- Crisis Response Intervention Training: Academic Training Project
- Home Safe: People with autism/IDD and wandering
- Talk About Sexual Violence: Educating health care professionals
- Improving healthcare transition for justice involved youth with IDD
- Access to Justice international knowledge hub
- Council of State Government Justice Center contracts/publications
- NCCJD's Community of Practice for The Arc's chapter network



Pathways to Justice®

STEP 1:
Disability
Response
Team (DRT)

STEP 2:
Training
for Justice
Professionals

STEP 3:
Ongoing
Technical
Assistance





Pathways Principles:

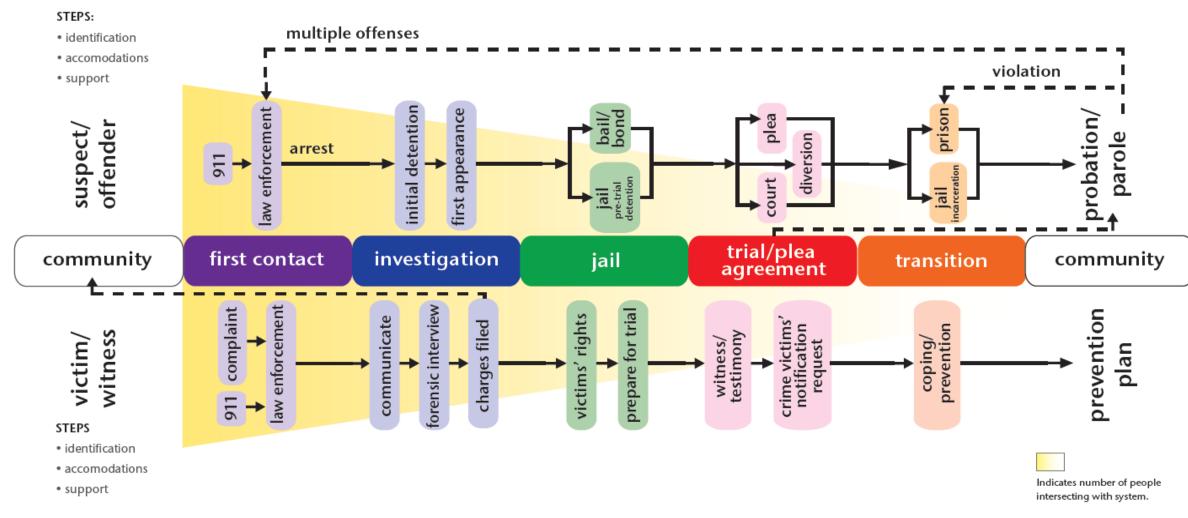
- Nothing about us, without us
- Community-based
- Multidisciplinary
- Relationship-oriented

Achieve with us.



Pathways to Justice™ Model

National Center on Criminal Justice & Disability



This model is based on The Sequential Interceptor Model. SAMHSA's GAINS Center for Behavioral Health and Justice Transformation. (2013). Developing a comprehensive plan for behavioral health and criminal justice collaboration: The Sequential Intercept Model. Delmar. NY: Author.

The Impact of Pathways to Justice

- 15 Disability
 Response Teams
 in 12 different states
- Over 1,700 justice professionals trained since 2015







NCCJD Resources

- NCCJD Resources: https://thearc.org/find-resources/
- Blog NCCJD Celebrates 10 Years of Disability & Criminal Justice Advocacy
- Academic Training Project Crisis Response Intervention Training
- Talkboutsexualviolence.org
- NCCJD/Council of State Government publications & webinars
- RAND reports: Agenda for Future Research
- NBC News How the Mental Health Crisis Impacts Americans with Disabilities @ The Arc YouTube
- Comcast Newsmakers Disability Rights and the Criminal Justice System















Disability Rights and the Criminal Justice System with Leigh Anne McKingsley of The Arc

Related Segments



Contact Information

- NCCJD Staff
 - Leigh Anne McKingsley, Senior Director Mckingsley@thearc.org
 - Josh Branch
 <u>Branch@thearc.org</u>
 - Jessica Oppenheim
 Oppenheim@thearc.org
- Visit NCCJD® online www.thearc.org/NCCJD
- Pathways to Justice®

https://thearc.org/our-initiatives/criminaljustice/pathway-justice/



National Center on Criminal Justice & Disability

Community Perspectives on Mental Health Needs in Autism



Panelists:

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ENHANCING LAW ENFORCEMENT RESPONSE TO INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

JANUARY 24, 2023









Presenters

- Brooke Mount, Ph.D. Senior Policy Advisor, Justice and Behavioral Health, BJA
- Kelly Burke, MPH Senior Program Manager, International Association of Chiefs of Police



What is the Office of Justice Programs?

- The Office of Justice
 Programs (OJP) provides
 grant funding, training,
 research, and statistics to the
 criminal justice community.
- OJP is one of three grantmaking components of the Department of Justice along with the Office on Violence Against Women (OVW) and the Office of Community Oriented Policing Services (COPS).

BJA – Bureau of Justice Assistance



BJS – Bureau of Justice Statistics



NIJ - National Institute of Justice



OVC – Office for Victims of Crime



OJJDP – Office of Juvenile Justice and Delinquency Prevention



SMART – Office of Sex Offender Sentencing, Monitoring, Apprehending, Registering, and Tracking





U.S. Department of Justice Bureau of Justice Assistance

Mission: BJA's mission is to provide leadership and services in grant administration and criminal justice policy development to support state, local, and tribal justice strategies to achieve safer communities. BJA works with communities, governments, and nonprofit organizations to reduce crime, recidivism, and unnecessary confinement, and promote a safe and fair criminal justice system.

Karhlton F. Moore, BJA Director



https://bja.ojp.gov/





How BJA Supports the Field





Provide diverse funding to accomplish goals.



Sharing Knowledge

Research, develop, and deliver what works to build capacity and improve outcomes.



Engagement

Consult, connect, and convene.





Academic Training to Inform Police Responses Initiative

- Support police in responding to people with behavioral health conditions and intellectual and developmental disabilities (IDDs).
- Facilitate collaboration between police, behavioral health, and disability stakeholders.
- Share information on evidenceinformed and best practices in crisis response.

















Crisis Response and Intervention Training (CRIT) Curriculum Goals



Expand knowledge of mental health conditions, substance use disorders, and IDD



Create connections with people with lived experience



Enhance awareness of community services



Emphasize the de-escalation of crisis situations



Support officer safety and wellness





Integrating IDD into CRIT

- Exploring perceptions and attitudes on disabilities and disability culture and community.
- Identifying characteristics of IDD, identification tips, and strategies for responding more effectively as an officer.
- Encouraging the inclusion of people with IDD in the Family and Peer Perspectives Panel.







Integrating IDD into CRIT

Recommends site visits to locations that deliver IDD services to provide opportunities for participants to interact with people with IDD.

Includes content on laws and policies specific to disability rights.

Encourages inclusion of representatives from IDD service system to describe IDD services.

Provides participants with specific skills and scenarios for responding to people with IDD.





Resources for Law Enforcement

Mental Health Conditions & Developmental Disabilities: Why Know the Difference

Describes mental health conditions and developmental disabilities, common behaviors and characteristics, and the differences between mental health conditions and developmental disabilities.

<u>Developmental Disabilities: What Law</u> <u>Enforcement Officers Need to Know</u>

Provides examples of law enforcement encounters with people with IDD, discusses how understanding more about IDD leads to safe and effective interactions, and provides examples of possible behaviors of people with IDD and recommended responses.





Resources for Law Enforcement

<u>Law Enforcement Response to People with Developmental Disabilities: Steps for Deflection or Pre-Arrest Diversion</u>

- Provides insights into the developmental disability community.
- Offers suggestions for successful interactions with people with developmental disabilities.
- Outlines options for safe and effective deflection and pre-arrest diversion when people with developmental disabilities encounter law enforcement.





The Kevin and Avonte Program: Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities



- Supporting local communities to reduce the number of deaths and injuries
 of individuals with dementia or developmental disabilities, such as autism,
 who due to their condition wander from safe environments.
- Providing training and technical assistance to BJA grantees in communities around the country.













Wandering Resources for Law Enforcement

- Understanding Children on the Autism Spectrum: A Guide for First Responders
- Children on the Autism Spectrum: Search Protocols &
- Questionnaire for First Responders
- <u>Tips for Caregivers Supporting Children on the Autism Spectrum</u>
- Children on the Autism Spectrum: 911 Telecommunicator & Dispatcher
 Checklist
- Considering Locative Technology in the Disability Community:
 Balancing Autonomy and Safety





Contact Information

Scan the QR code to access the resources and projects discussed in this presentation.



CRIT@theiacp.org



This project is supported by Grant No. 15PBJA-22-GK-03562-NTCP awarded by the Bureau of Justice Assistance (BJA). BJA is a component of the Department of Justice's Office of Justice Programs, which also includes the Bureau of Justice Statistics, the National Institute of Justice, the Office of Juvenile Justice and Delinquency Prevention, the Office for Victims of Crime, and the SMART Office. Points of view or opinions in this document are those of the author and do not necessarily represent the official position or policies of the U.S. Department of Justice

Community Perspectives on Mental Health Needs in Autism



Panelists:

- Steven Gordon, Esq.
- Carlean Ponder, Esq.
- Leigh Anne McKingsley, M.S.S.W., M.P.A.
- Brooke Mount, PhD.
- Kelly Burke, MPH
- Officer Laurie Reyes

Montgomery County Police Autism/IDD Unit

Training/Education
Outreach
Empowerment
Follow up
Response

Providing a layered approach since 2004.

Officer Laurie Reyes

Laurie.Reyes@montgomerycountymd.gov



Autism/IDD and Law Enforcement We ALL need to ensure POSITIVE, EFFECTIVE AND SAFE interactions.

Montgomery County Police average 30-40 calls monthly

The Montgomery County Autism/IDD Unit began in 2004

We ALL need to work together...Awareness to ACTION



AUTISM STATISTICS

2022 1 in 44

2018 - 1 in 59 births

2015 - 1 in 68 births

2009 – 1 in 91 births

2005 – 1 in 166 births

2000 – 1 in 500 births



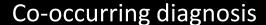






MCPD Autism/IDD Unit Addressing Officer Concerns/Challenges

Those diagnosed with autism is increasing in AGE and PREVALANCE. With this, we have seen an increase in calls of a more serious, more complicated nature, which can significantly increase the need for additional resources. (2004-2024)



MCPD is averaging 3-8 missing found or missing searching for cases weekly, The unit began in response to wandering and elopement but in the last fifteen years has seen a shift in our officers handling serious calls for those who have Autism.





The MCPD Autism/IDD Unit, in response to wandering/general calls provides resources for concerns raging from the mundane to the very serious in both proactive and reactive outreach.



In 2023 the MCPD unit provided over 600 follow ups to caregivers and families.

- Immediate Follow Ups (wandering and general to serious calls)
- Respond when possible
- Proactive Outreach
- "ON CALL" for on scene questions from officers
- Resource partnering with other resource agencies/organizations

Officer Laurie Reyes cell (240) 855-1605 Officer Amy Stoughton cell (240)907-9869

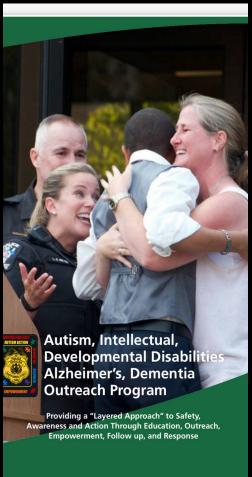
MCPD Autism/IDD Unit

Updated Brochure

New Version Available 2/2024

Online/Hard Copy
Tons of Resources!!

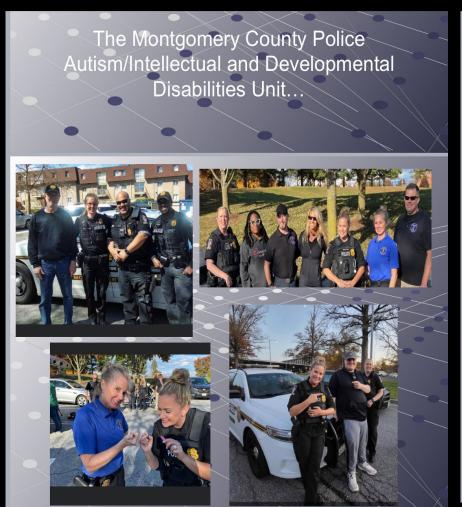


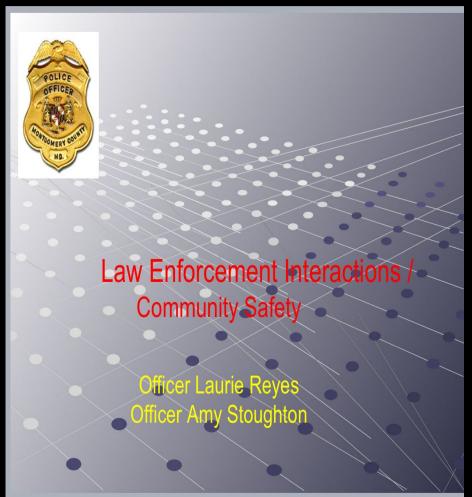




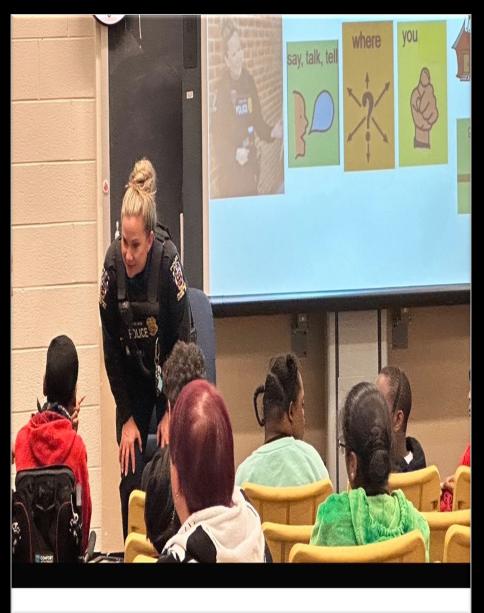
Autism/IDD Community Safety and Law Enforcement Interactions

School and community presentations for individuals on the Autism Spectrum.

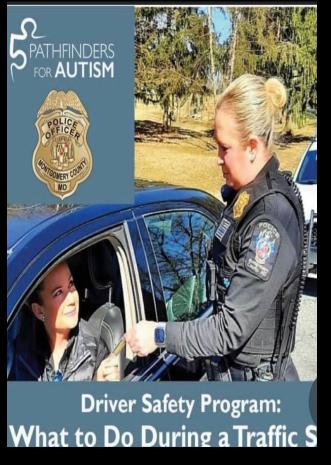




School Presentations











Partnering with Pathfinders for Autism for our MCPD Autism/IDD Unit Mock Traffic Stop webinar and in person mock traffic stops

Self Disclosure to First Responders

It is a personal decision to self disclose but we try to explain how it can assist in an interaction with law enforcement.



Education of those who have Autism/IDD on how they can

stay safe in the community

"Officer can I show you my ID Bracelet?"
"Can I tell you a little about me?"

ID BRACELET or other ID SAFETY VS INDEPDENCE

Why an ID bracelet?



We understand that not everyone shares the same journey

Officer Laurie Reyes
Montgomery County Police Autism/IDD Unit
© 240-855-1605
Laurie.Reyes@montgomerycountymd.gov

Committee Discussion



Break



Community Perspectives on Justice and Law Enforcement in the Autism Community



Community Perspectives on Mental Health Needs in Autism



Panelists:

- Maria Mercedes Avila, Ph.D., M.S.W., M.Ed.
- Lindsay Naeder, M.S.W.
- Camille Proctor
- Amanda Wroten
- Greg Robinson, M.P.H.

Committee Discussion



Round Robin Updates



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

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

Susan A. Daniels, Ph.D.

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

Closing Remarks



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

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

Next IACC Meeting





IACC Full Committee Meeting (hybrid)

April 17, 2024

Check the IACC website for meeting information and updates.

https://iacc.hhs.gov

Thank you to the ONAC Staff and Meeting Support Team!





Susan Daniels, Ph.D.
HHS National Autism
Coordinator and
Director, ONAC



Ana Cappuccio, LL.B.
Operations Coordinator



Oni Celestin, Ph.D.
Science Policy Analyst



Katrina Ferrara, Ph.D. Science Policy Analyst



Steven Isaacson, L.M.S.W.Neurodiversity Liaison





Tianlu Ma, Ph.D.Science Policy Analyst



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



Angelice Mitrakas, B.A. Management Analyst



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



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



