

# Meeting of the Interagency Autism Coordinating Committee

## Day 1

October 13, 2021; 1:00 - 5:00 p.m. ET



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

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

**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination,  
NIMH, and Executive Secretary, IACC  
Acting National Autism Coordinator

# Update from U.S. Department of Labor and Celebration of National Disability Employment Awareness Month



**Taryn Williams. M.A.**  
Assistant Secretary  
Office of Disability Employment Policy  
U.S. Department of Labor

# Interagency Autism Coordinating Committee

Taryn M. Williams

Assistant Secretary

Office of Disability Employment Policy

U.S. Department of Labor

October 13, 2021



**OFFICE OF DISABILITY EMPLOYMENT POLICY**  
UNITED STATES DEPARTMENT OF LABOR

# NDEAM Overview

- Held each October
- Honors the contributions of America's workers with disabilities
- Led by ODEP, but includes events and activities nationwide
- Traces back to 1945



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**AMERICA'S RECOVERY  
POWERED BY INCLUSION**  
National Disability Employment Awareness Month

**#NDEAM**  
[dol.gov/odep](http://dol.gov/odep)



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31 Days of NDEAM | U.S. Depart x +

https://www.dol.gov/agencies/odep/initiatives/ndeam/ideas

An official website of the United States government. [Here's how you know](#)

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Office of Disability Employment Policy

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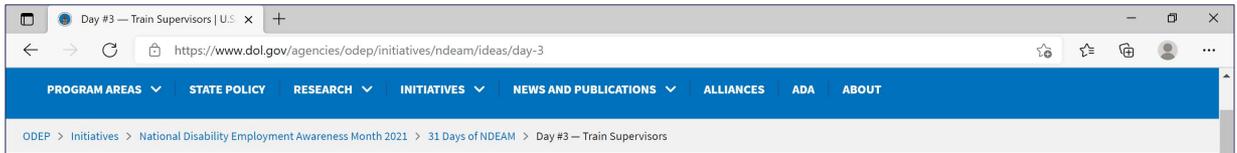
# 31 Days of NDEAM

- Americans with Disabilities Act
- ASPIRE
- Campaign for Disability Employment
- Disability Employment Initiative
- Employment First
- National Disability Employment Awareness Month 2021**
- Resources
- 31 Days of NDEAM**
- Day #1 — Put up an NDEAM

- [Day #1 — Put up an NDEAM poster](#)
- [Day #2 — Review company policies](#)
- [Day #3 — Train supervisors](#)
- [Day #4 — Educate employees](#)
- [Day #5 — Issue an NDEAM press release](#)
- [Day #6 — Participate in Disability Mentoring Day](#)
- [Day #7 — NDEAM provides an interesting hook for social media platforms, including Facebook, LinkedIn, and Twitter.](#)
- [Day #8 — Establish an Employee Resource Group](#)
- [Day #9 — Hold a discussion](#)
- [Day #10 — Organize an assembly](#)
- [Day #11 — Educate about disability history](#)
- [Day #12 — Train front-line staff](#)
- [Day #13 — Engage student leaders](#)

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## Day #3 — Train Supervisors

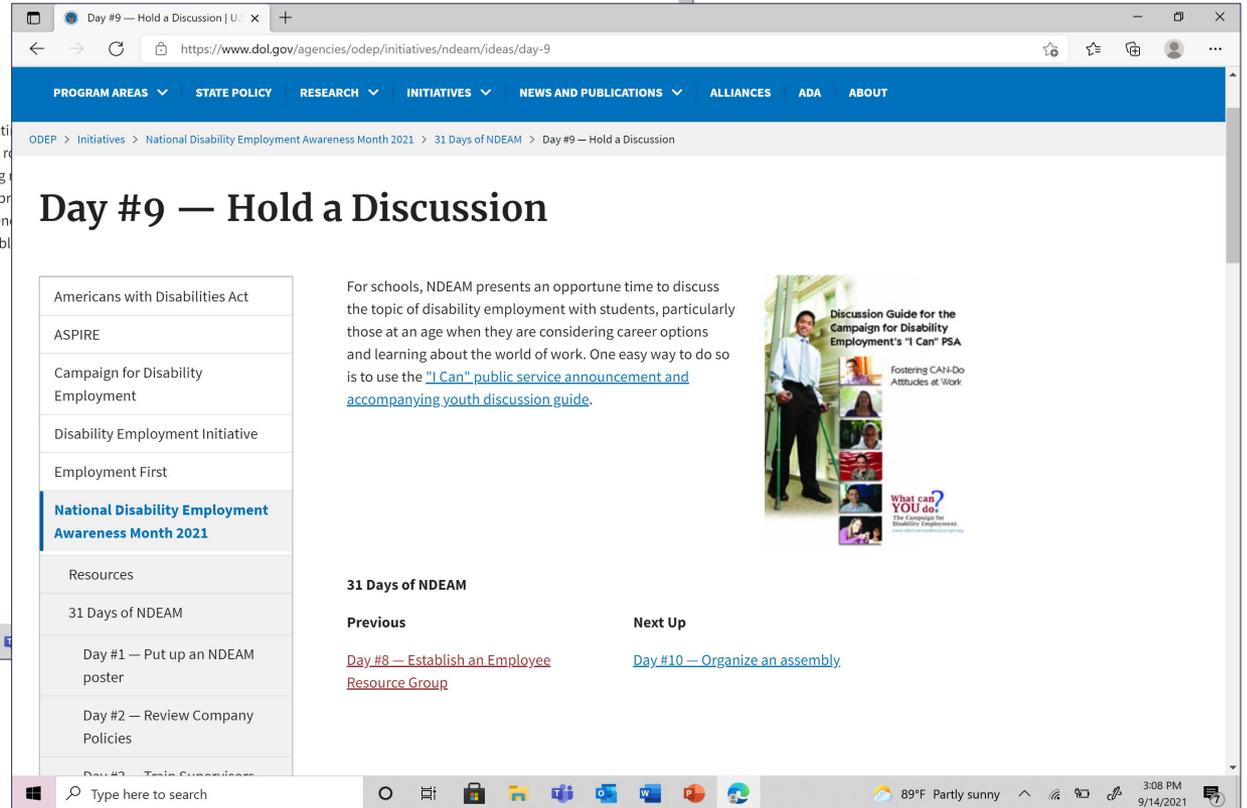
- Americans with Disabilities Act
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- Resources
- 31 Days of NDEAM
- Day #1 — Put up an NDEAM poster
- Day #2 — Review Company Policies
- Day #3 — Train Supervisors**

Employers can consider conducting training to ensure they understand their workplace culture. Such training relevant policies, including the provisions for reasonable accommodations. One type of training is to make use of available [modules](#).

### 31 Days of NDEAM

#### Previous

[Day #2 — Review company policies](#)



## Day #9 — Hold a Discussion

- Americans with Disabilities Act
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- Day #1 — Put up an NDEAM poster
- Day #2 — Review Company Policies
- Day #3 — Train Supervisors
- Day #4 — ...

For schools, NDEAM presents an opportune time to discuss the topic of disability employment with students, particularly those at an age when they are considering career options and learning about the world of work. One easy way to do so is to use the ["I Can" public service announcement and accompanying youth discussion guide](#).



### 31 Days of NDEAM

#### Previous

[Day #8 — Establish an Employee Resource Group](#)

#### Next Up

[Day #10 — Organize an assembly](#)



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Browser: NDEAM Social Media Kit | U.S. D...  
 URL: https://www.dol.gov/agencies/odep/initiatives/ndeam/resources/social-media-kit

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ODEP > Initiatives > National Disability Employment Awareness Month 2021 > Resources > NDEAM Social Media Kit

# NDEAM Social Media Kit

Americans with Disabilities Act  
 ASPIRE  
 Campaign for Disability Employment  
 Disability Employment Initiative  
 Employment First  
**National Disability Employment Awareness Month 2021**  
 NDEAM Social Media Kit  
 Resources  
 31 Days of NDEAM  
 Past Years  
 Stay at Work/Return to Work

We recognize National Disability Employment Awareness Month each October to commemorate the many contributions of people with disabilities to America's workplaces and economy. The theme for NDEAM 2021, "America's Recovery: Powered by Inclusion," reflects the importance of ensuring that people with disabilities have full access to employment and community involvement during the economic recovery from the COVID-19 pandemic.

Help us celebrate NDEAM! Use and share the social media materials in this toolkit to help spread the word online. You can also use the menu at left to find more resources for employers, community organizations, state and local governments, advocacy groups and schools.

## Social Information

Download these transparent .png files to use in your own projects!

- Web: [dol.gov/NDEAM](https://dol.gov/NDEAM)
- Blog: [blog.dol.gov](https://blog.dol.gov)
- Twitter:
  - Department of Labor: [@USDOL](https://twitter.com/USDOL)
  - Secretary of Labor: [@SecMartyWalsh](https://twitter.com/SecMartyWalsh)
  - Spanish: [@DOL\\_esp](https://twitter.com/DOL_esp)
- Facebook:
  - Department of Labor: [DepartmentOfLabor](https://www.facebook.com/DepartmentOfLabor)
  - Secretary of Labor: [SecMartyWalsh](https://www.facebook.com/SecMartyWalsh)
  - Spanish: [USDOLesp](https://www.facebook.com/USDOLesp)

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winning and a

**#NDEAM Spotlight: Andrea LaVant**

[dol.gov/odep](https://dol.gov/odep)

Assistant from f erment

**#NDEAM Spotlight: Kathy Martinez**

[dol.gov/odep](https://dol.gov/odep)

n city and e was

**#NDEAM Spotlight: Haley Moss**

[dol.gov/odep](https://dol.gov/odep)

also the first documented openly autistic attorney to be sworn into the @TheFlaBar. #NDEAM Spotlight

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# Supporting Employment for Young Adults on the Autism Spectrum

- \$2.1 million, 3-year research project launched in August
- Exploring strategies that promote work-based learning, gainful employment and long-term career pathways
- Both qualitative and quantitative components



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# Contact Information

Taryn M. Williams

Assistant Secretary

U.S. Department of Labor

Office of Disability Employment Policy



[ODEP@dol.gov](mailto:ODEP@dol.gov) for questions relating to National Disability  
Employment Awareness Month

[Robertson.Scott.M@dol.gov](mailto:Robertson.Scott.M@dol.gov) for questions relating to Slide 7



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**Break**

# U.K. National Strategy for Autistic Children, Young People and Adults: 2021 to 2026



**James Cusack, Ph.D.**  
Chief Executive  
Autistica

# Autistica's 2030 Plans



Context

**What life is like for autistic people in the UK**

# Autistic people experience significant inequalities in the UK

- Autistic people **continue to die decades before** the rest of the population.
- According to figures from the official for national statistics, autistic people face the **lowest known employment rate** of any disabled group.
- Autistic people **dominate admissions to inpatient mental healthcare.**
- Stories of **neglect and abuse in state-funded care** have become so harrowingly common that scandals hit the headlines on a monthly, sometimes weekly, basis.

# Autistic people have access to very few specialised services or adapted supports

- **Autism diagnostic services** are comparatively well-developed (but overstretched).
- **Post-diagnostic supports** for autistic people are either very limited or non-existent.
- **Healthcare services** are generally not designed for autistic people and few have been effectively adapted.
- **Social care services** for autistic people are usually re-purposes services for people with a learning (intellectual) disability. The evidence base behind their care models and interventions are very poor.
- **Public employment services** are generally limited. Very few adaptations have been made or tested for autistic people. **Specialist education services** do exist but can be difficult for families to access.
- **Data** on autistic people's use-of / outcomes-from public services has been very poor, although is improving.

# There is a big gap in support between receiving a diagnosis and experiencing a crisis



Context

**What UK Public Policy is like towards autism**

# There are various autism policy commitments



HM Government

## National strategy for autistic children, young people and adults: 2021 to 2026 (2021)

- Committed to developing an **Autism Research Action Plan**.
- Made **many commitments** towards improving: autism diagnostic & post-diagnostic pathways, specialist education, employment support, welfare accessibility, public understanding of autism, healthcare accessibility, community care, and support in the criminal justice system.



## The NHS Long Term Plan (2019)

- Made autism an NHS clinical priority for the first time. Leading NHS England to setup their **first Autism Team**.
- Included commitments to reduce premature mortality, improve diagnostic/post-diagnostic pathways, trial health checks for autistic people, introduce reasonable adjustment infrastructure, etc.
- **Seconded Autistica's Heads of Research & Policy** to develop a **Research Strategy** and other workstreams.

# Autism policy initiatives have been superficial

- The two previous Autism Strategies lacked serious investment or implementation planning.
- The new Autism Strategy **only has an implementation plan for it's first year**. Most of projects and funding in the initial implementation plan were pre-existing commitments.
- NHS England's Autism Programme currently **lacks the funding** to deliver the NHS Long Term Plan goals.

## HOWEVER

- The UK Government is currently completing a **Comprehensive Spending Review**, which could enable stronger implementation planning for the Autism Strategy.
- The **NHS Autism Research Strategy** and **UK Government's Autism Research Action Plan** could help start conversations about strategic funding partnerships.

Autistica's Role

**Making breakthroughs**

# Autistica is taking on a new role

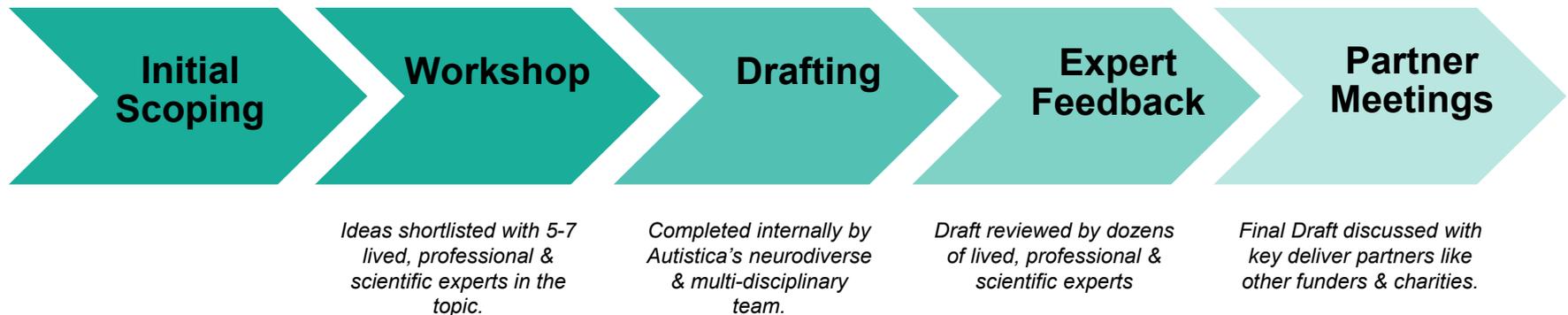
- Autistica has succeeded in influencing autism policy and practice in the UK (making early death a focus, prompted the NHS Autism Programme, partnerships on health checks and mental health research).
- We want to ensure more of our work continues on to improve lives.
- That requires focusing on fewer areas and committing to continue working on them project-after-project.
- We've therefore agreed a maximum of 6 topics on which Autistica's research funding, partnerships and policy development functions will focus for the next 10 years.
- We are developing detailed, long-term plans for each goal, setting out the projects we think are most likely to deliver breakthroughs.

# Autistica's Goals

## **By 2030:**

1. Every autistic person will receive proven support from day one.
2. The employment rate for autistic people will double.
3. Autistic people will have proven treatments for anxiety.
4. Public spaces will be more accessible for neurodivergent people.
5. Every autistic adult will be offered a yearly, tailored health check.
6. Attitudes to autistic people will have changed.

# We're developing detailed Plans for each goal





# Overview of the 2030 Plans

# 1. The Autistica Support Plan

The logo for Autistica, featuring the word "autistica" in a white, lowercase, sans-serif font inside a black semi-circular shape.

**autistica**

**By 2030, all autistic people and families will ...**

## **Support Around Diagnosis**

**...Be empowered to understand their diagnosis and come to terms with being autistic**

## **Support Preparing for the Future**

**...Receive evidenced supports, tailored to their profile of need, that helps them prepare for the future**

## **Lifelong Support**

**...Have lifelong access to supports that help them stay well and specialised support if they need it**

## 2. The Autistica Employment Plan

The logo for Autistica, featuring the word "autistica" in white lowercase letters on a black semi-circular background.

**autistica**

**By 2030, autistic people will...**

### **Becoming Career Ready**

**...Have access to evidenced employment readiness programmes to empower them to compete for the jobs they want.**

### **Finding the Right Job**

**...Find more employers are using recruitment practices that give autistic applicants a fairer chance.**

### **Developing a Career**

**...Have access to an evidence-led library of workplace adjustments and third-party employment support if they need it.**

# 3. The Autistica Anxiety Plan



By 2030, autistic people and families will...

## Supporting Mental Health

...Have access to proven supports to prevent, mitigate and reduce anxiety from early years

## Effective Treatments

...Have access to therapies proven to work to help manage anxiety.

## Preventing crisis

...Be supported by services that know when an autistic person's mental health is at risk and will intervene before it seriously deteriorates.

# 4. The Autistica Spaces Plan

The logo for 'autistica' is a black semi-circle with the word 'autistica' written in white lowercase letters inside it.

**autistica**

**By 2030, neurodivergent people will...**

**Making existing spaces easier to use**

**...have access to up-to-date information on the orientation and sensory environment of any major public spaces they want to use.**

**Designed with autism in mind**

**...have their accessibility needs embedded in UK building guidance, so that more new spaces incorporate design features**

# 5. The Autistica Health Checks Plan



**autistica**

**By 2030, Autistica and the NHS will have...**

**Developing Checks**

**...Co-designed and rigorously tested health checks with autistic people, families and GPs.**

**Implementing Checks**

**...Prepared and resourced GPs to deliver annual health checks to autistic people on the NHS.**

**Accessible appointments**

**...Made it easy for GPs to adjust appointments to suit each autistic person's needs.**

# The Autistica Support Plan in more detail

# 1. The Autistica Support Plan



Projects that could deliver a better system of support



# Personal Support Profiles

**Why is this important?** Support for autistic people should be tailored to their individual needs and goals. In other areas of healthcare, a diagnosis usually tells professional exactly what supports that person should be offered. With autism, the diagnosis only provides part of that information. The support each person needs will vary widely, so few interventions will be universally appropriate for autistic people and families.

**How do we make a breakthrough?** Constructing an accurate, holistic, and consistently formatted profile of a person's support needs would make post-diagnostic support more strategic. It would enable healthcare professionals to offer autistic people the supports (interventions) they are most likely to benefit from, rather than focusing on a generic offering that may be unhelpful.

If profiles have a consistent format, then different services can prepare for using them. Adopting one profile could help break down the siloed bureaucracies that frustrate autistic people, families, and clinicians.

# Personal Support Profiles (*Continued*)

**ICF-Based Assessments** – An international research programme (including studies with autistic adults, parents and clinicians) recently established holistic lists of issues that most often enable or disable autistic people, using the World Health Organisations ICF framework. The scoping review for NHS England recommended adopting the ICF approach and concluded that an operationalised ICF-based tool is likely to be effective and more practical than existing assessment tools. The Karolinska Institutet in Sweden is currently developing an operational assessment tool using the ICF lists. A similar ICF-based tool was recently piloted successfully in Argentina.

## **Autistica will:**

**Fund the adaption and piloting of the ICF Assessment Tool in NHS diagnostic and post-diagnostic services for autistic people.** If the resources are available, it should be possible to develop this tool to help other neurodivergent groups.

# Everyday Tips Network

**Why is this important?** Autistic people and families can face lots of everyday challenges, from finding stim tools to use at work, to figuring out how to help your child try new foods. Rather than systematically collecting and sharing learnings from other autistic people and families, we leave everyone to run the gauntlet of trial and error themselves.

**What is the current situation?** Some practical tips are incorporated in post-diagnostic psychoeducation programmes, but the amount of content they can deliver in these sessions must be carefully managed. Autistic people and families will still be discovering practical difficulties they need ideas for after their time in a post-diagnostic information and empowerment programme has ended.

Many personal experiences and tips are available online from autistic-led, charity-led, or parent-led groups. However, that information is dispersed widely and rarely moderated. This can force newly diagnosed autistic people and parents to hunt for ideas across the web, all while trying to differentiate helpful tips from misleading or harmful information.

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## **Autistica will:**

**Create a citizen science platform (or 'Tip Network') to crowd-source descriptions and practical tips for everyday challenges.** We will then work with autistic people, parents/carers, clinicians, professionals and autism charities to curate those insights into trusted content that can be used across different resources, including the Newly-Diagnosed Companion App.

# Self-Directed Supports Library

**Why is this important?** Autistic people should be empowered to live as independent lives as possible. Realistically, most autistic people will not (and should not) be constantly receiving support from specialist services. Instead, most autistic people and families will need to manage by themselves most of the time. Rather than completely abandoning autistic people and families, we should arm them with well-evidenced supports they can use by themselves (or with a friend/carer) to achieve their goals and lead fulfilling lives.

**What is the current situation?** Currently, most autistic people and families are left to fend for themselves. Many individuals, charities, and local groups have created resources that can be used without direct support from health and care professionals. However, there is no central repository of these supports, and very few are tested to ensure they are acceptable, effective, and safe.

# Self-Directed Supports Library (*Continued*)

## Examples of self-directed supports in development:

- *Self-guided anxiety therapy, Environment navigation platform, Communication aids, Socially prescribed activity programmes, Peer support models.*

## Autistica will:

**Co-produce a list of key support needs that could be effectively met with self-delivered interventions.** The Tips Network and Personal Support Profiles could produce insights on which we would consult autistic people, families, clinicians, and researchers.

**Compile and curate a library of well-evidenced self-directed supports.** Ideally, this support library would later be hosted within the co-owned health record system.



**Break**

# National Autism Coordinator Update

October 13, 2021

**Susan Daniels, Ph.D.**

Acting HHS National Autism Coordinator

Office of the NIMH Director

National Institute of Mental Health



# 2021 HHS Report to Congress



- Required by the Autism CARES Act of 2019
- Focuses on the health and well-being of individuals on the autism spectrum
- Features information from over 20 federal departments, agencies, divisions, and offices
- Includes 23 recommendations for federal agencies to address health and well-being
- The *Report* will be available on the IACC website for public access later this fall

# Federal Partners in Transition (FPT)

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## Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 to facilitate exchange of information between federal agencies on transition-related issues for youth with disabilities.
- Members are now working on developing a new Federal Youth Transition Plan outlining how agencies within the FPT will enhance coordination of activities, goals, and policy priorities to improve outcomes for youth with disabilities.

# Interagency Committee on Disability Research (ICDR)

## Managed by the Administration for Community Living

- All-federal committee established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
  - Publication of [\*Disability and Emergency Preparedness\*](#) and [\*Employment\*](#) toolkits
  - July 2021 Virtual Symposium on [\*Employment for Youth and Young Adults with Disabilities: Translating Evidence Amid the COVID-19 Pandemic\*](#) to examine research, evidence, and strategies for improving education and employment outcomes for youth with disabilities.

# National Council on Disability (NCD)

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- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- NCD held a Council Meeting on October 7, 2021.
- Topics discussed included home and community-based services, health equity, voting rights, and employment.
- The Council's 2021 Progress Report will focus on the impact of COVID-19 on people with disabilities.
- The Council's 2022 Progress Report will focus on environmental injustice and the impact of climate change and extreme weather events on people with disabilities.

# RAISE Family Caregiving Advisory Council (FCAC)

## Managed by the Administration for Community Living

- Federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support to family caregivers.
- Recent activities include:
  - On September 22, 2021, the RAISE Act Family Caregiving Advisory Council delivered its [initial report to Congress](#).
  - The report focuses on infrastructure and systems to appropriately **R**ecognize, **A**ssist, **I**nclude, **S**upport, and **E**ngage family caregivers.
  - The report includes 26 recommendations.
  - The council also created an [inventory](#) of federal programs on caregiving.
  - [Full council](#) meeting held September 2021 included discussion on looking ahead on the development of the National Family Caregiving Strategy, which will serve to guide future efforts.

# Interdepartmental Serious Mental Illness Coordinating Committee ([ISMICC](#))

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## Managed by the Substance Abuse and Mental Health Services Administration

- Federal advisory committee charged with addressing issues related to serious mental illness (SMI) and serious emotional disturbance (SED).
- The [2017 Report to Congress on SMI and SED](#) mentioned autism in the context of co-occurring serious emotional disturbance in children.
- ISMICC met on August 27, 2021, and discussed advances in services for SMI and SED.
- An upcoming virtual meeting is scheduled for [October 27, 2021, from 1:00 – 5:00 pm.](#)

# Disability Advisory Committee (DAC)

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## Managed by the Federal Communications Commission

- Federal advisory committee that provides advice and recommendations to the Federal Communications Commission on a wide array of disability issues, including communications and video programming access.
- The DAC held a meeting on [September 9<sup>th</sup>, 2021](#).
  - White House Office of Public Engagement Associate Director Emily Voorde emphasized that the Biden Administration is committed to partnering to advance the priorities of the disability community.
  - The Committee discussed recommendations to improve communication access for individuals with disabilities.

# The White House

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- The Biden-Harris Administration released a [Fact Sheet](#) in May 2021 to highlight steps taken in the first 100 days of the Administration to support full participation and equality for people with disabilities.
- On July 26, 2021, in celebration of the 31<sup>st</sup> anniversary of the Americans with Disabilities Act (ADA), the Biden-Harris Administration released a [Fact Sheet](#) detailing significant steps undertaken to achieve a more inclusive, accessible, and equitable country for people with disabilities.
- The U.S. AbilityOne Commission administers the [AbilityOne Program](#), one of the largest sources of employment for people who are blind or have significant disabilities. On [August 13, 2021](#), President Biden appointed four disability leaders as Commissioners to lead the AbilityOne Program.
- January 2022 IACC Meeting: tentatively scheduled Kim Knackstedt, Director of Disability Policy for the Domestic Policy Council at The White House

# MITRE Neurodiverse Federal Workforce Initiative

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- MITRE is collaborating with federal, academic, and private industry partners on a [Neurodiverse Federal Workforce Initiative](#) to increase high-tech career opportunities within the federal government for individuals on the autism spectrum. With lessons learned from this pilot project, MITRE and its federal and private partners hope to change the conversation around workers with disabilities and open the door for more neurodiversity inclusion in the federal government.
- MITRE will be holding the [Federal Autism at Work Summit](#) on October 19-20, 2021, to discuss issues related to this effort. Day 1 is open to the public.

# IACC Committee Business

IACC Full Committee Meeting  
October 13-14, 2021



**Susan A. Daniels, Ph.D.**

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health



- 1. OARC Updates**
- 2. Discussion: *IACC Summary of Advances***
- 3. Discussion: *IACC Strategic Plan Update***

# New IACC Website Resources Section



IACC Home > Resources



## Autism Resources

The Office of Autism Research Coordination has compiled a list of resources, from both government and non-government sources, to assist individuals with autism and their families. These resources are provided for informational purposes only. The list is not comprehensive and inclusion of non-government information on this website does not constitute an endorsement by the IACC or HHS.



### About Autism

Learn about facts, signs and symptoms, what to do if you think your child has autism, and resources to help connect you to services.



### Agencies and Organizations

A listing of federal agencies, state councils, private and partner organizations, and federal advisory committees.



### Transition

This section includes information on federal services and support, resources for success in post-secondary education, and more.



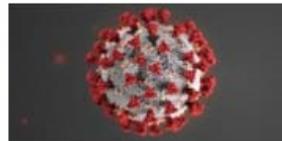
### Employment

Here you will find resources to help you succeed in the workforce. It includes information on federal support, resources for job seekers and employers, and more.



### Housing

Includes information about public funding for housing, home and community-based services, types of housing options, and more.



### Coronavirus

Includes information about the coronavirus, resources for people with autism and other disabilities, and guidance on how to manage anxiety related to COVID-19.

OARC has launched a new Resources Section on the IACC website, covering the following topics:

- About Autism
- Transition
- Housing
- Employment
- Coronavirus
- Agencies and Organizations

The section includes federal and non-federal resources such as websites, toolkits, and videos related to each topic.

More topics will be added in the future.

# Fall 2021 OARC Newsletter



OFFICE OF  
AUTISM RESEARCH  
COORDINATION  
NATIONAL INSTITUTES OF HEALTH

Please enjoy OARC's quarterly newsletter, which includes recent IACC updates, news, events, and publications.

## IACC Updates



### Upcoming IACC Full Committee Meeting

The next IACC Full Committee Meeting will take place on October 13-14, 2021. The Committee will discuss the IACC Strategic Plan, employment, Kevin and Avonte's Law, mental health, and more. The meeting is fully virtual, free, and open to the public on [NIH Videocast](#).



### Launch of New Resources Section

The new resources section of the IACC website includes lists of resources, from both government and non-government sources, to assist people on the autism spectrum and their families. Topics include [About Autism](#), [Transition](#), [Employment](#), and [Housing](#). The [Coronavirus](#) and [Agencies and Organizations](#) pages have also been updated. Keep an eye out for new topics in the future!



### Request for Public Comment: Updating the IACC Strategic Plan for Autism Spectrum Disorder

The IACC is requesting public comments to inform the development of the *2021-2022 IACC Strategic Plan*. The IACC is interested in what the community considers to be the most important issues, needs, and gaps across autism research, services, and policy that could be addressed by federal programs and activities, and/or in partnership with community organizations. The comment period closes on November 30, 2021.



### July 2021 IACC Full Committee Meeting

The first meeting of the new IACC took place on July 21-22, 2021. The Committee discussed business, agency updates, the impact of COVID-19 on the autism community, and racial equity and health disparities in ASD. [Recordings](#) of the meeting are also available.

## Autism Meetings & Events



### AIR-P Research Day at AUCD2021 Conference

The Association of University Centers on Disabilities will host a conference on November 1, 2021. The conference will highlight research supported by the Autism Intervention Research Network on Physical Health (AIR-P) in six nodes: primary care services and quality; community-based lifestyle interventions; gender, sexuality,

# See the OARC Newsletter for the latest updates from the IACC and the autism community.

On the IACC website at:

<https://iacc.hhs.gov/newsletters/2021/october.html>

Subscribe at:

<https://iacc.hhs.gov/about-oarc/contact/>

# 2020 IACC Summary of Advances - Process



- Solicit Nominations from IACC members ✓
- Next step: Refine list of nominations – **TODAY**

## After Meeting:

- OARC creates the ballot and asks IACC members to vote on the articles (via email)
- OARC develops summaries of the top 20 articles selected by the IACC and prepares the report

# IACC Summary of Advances - Criteria



The *IACC Summary of Advances* is a list of research articles representing groundbreaking and significant progress in the field and are selected by the IACC from a larger pool of articles nominated by the members.

Previously, the IACC has excluded articles from nomination lists using the following criteria:

- Editorials & opinion pieces
- Preliminary studies and/or studies of small sample size
- Literature reviews, systematic reviews
- Expert recommendations & reports from panels/taskforces
- Fields related to ASD, but the article is not solely/primarily focused on ASD



**Should the criteria be modified for inclusion of articles into the *Summary of Advances*?**



## **Topics to Discuss:**

1. Request for Public Comments: issued Oct. 1
2. Structure of the *Strategic Plan*
3. Budget Recommendation
4. Statement on Duplication of Effort
5. Language Considerations

\*Note: The Committee will also have an opportunity to submit their feedback and ideas for the *Strategic Plan Update* via written comments.

# IACC Request for Public Comments



- The IACC issued a Request for Public Comments to assist in identifying priorities for the 2021-2022 update of the *IACC Strategic Plan*. Open from **October 1- November 30, 2021**.
- The IACC is requesting public comments on research, services, and policy issues related to the seven topics addressed by the *IACC Strategic Plan*: **Screening and Diagnosis, Biology, Risk Factors, Treatments and Interventions, Services, Lifespan Issues, and Infrastructure and Surveillance**.
- The IACC is also requesting responses to two supplemental questions on 1) the impact of the **COVID-19 pandemic** on the autism community, and 2) the **needs of underserved populations** within the autism community, including racial and ethnic minorities, economically disadvantaged communities, and rural populations.

# IACC Request for Public Comments



- All comments must be submitted electronically via the web-based form at: <https://iacc.hhs.gov/meetings/public-comments/requests-for-information/2021/strategic-plan.shtml>
- Closing date: **November 30, 2021.**
- OARC will compile and organize all comments received and make them available to the Committee for the January full committee meeting.
- The Request for Public Comments is for the public; OARC will send a similar form to the IACC to collect committee members' suggestions for the update of the *Strategic Plan*.

# Structure of the *Strategic Plan*



The *IACC Strategic Plan* chapters are organized around 7 topic areas that are related to community-focused Questions:

- Question 1. How Can I Recognize the Signs of ASD, and Why is Early Detection So Important? (Topic: **Screening and Diagnosis**)
- Question 2. What Is the Biology Underlying ASD? (Topic: **Biology**)
- Question 3. What Causes ASD, and Can Disabling Aspects of ASD be Prevented or Preempted? (Topic: **Risk Factors**)
- Question 4. Which Treatments and Interventions Will Help? (Topic: **Treatments and Interventions**)
- Question 5. What Kinds of Services and Supports Are Needed to Maximize Quality of Life for People on the Autism Spectrum? (Topic: **Services**)
- Question 6. How Can We Meet the Needs of People with ASD as They Progress into and through Adulthood? (Topic: **Lifespan Issues**)
- Question 7. How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community? (Topic: **Infrastructure and Surveillance**)



**Are the Questions still up to date for current needs?**

# Budget Recommendation

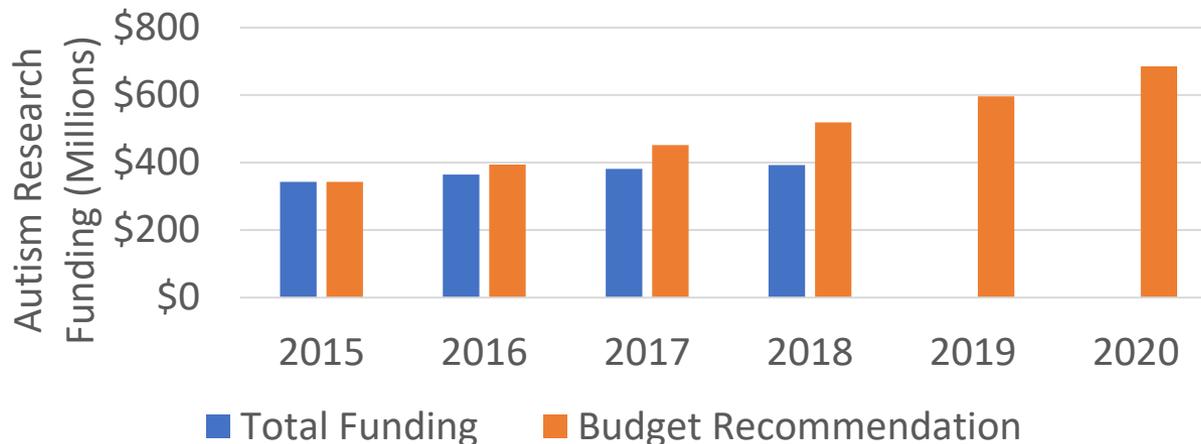


The 2016-2017 IACC Strategic Plan calls for a doubling of the 2015 ASD research budget to \$685 million by 2020. To accomplish this goal, the IACC recommended a nearly 15% annual increase in ASD research funding across combined federal and private funders. The Committee recognized that this was an ambitious goal, but it believed that such an increase could also have a significant impact if achieved.



**Given the funding trend suggesting that the goal has likely not been met, how should the budget recommendation be updated?**

**Total Reported ASD Funding Compared to IACC Budget Recommendation**



\*Note: This graph illustrates funding amounts from the earlier editions of the *IACC ASD Research Portfolio Analysis Report*; 2019 and 2020 funding will be published in the upcoming report.

# Budget Recommendation



Have the key areas that need more focus and attention changed?

Previous statement, *2016-2017 IACC STRATEGIC PLAN FOR AUTISM SPECTRUM DISORDER*, p. 101:

“While all areas of the autism research portfolio require increases in funding, the areas identified by the IACC that are **in particular need of resource growth** include:

1. Research to support development and delivery of new and improved **treatments and interventions**
2. Research to enable development and delivery of **evidence-based services**
3. Research on **lifespan issues**, especially to understand and address the needs of transition-age youth, young adults, and older adults on the autism spectrum.

In addition, the investment of resources targeting these areas would serve not only to incentivize research on these topics, but also to encourage additional well-trained scientists to specialize in these research areas of significant need.”



## Background

The [Autism Collaboration, Accountability, Research, Education and Support \(CARES\) Act of 2019](#) requires the IACC in its *Strategic Plan* to provide:

“Recommendations to ensure that autism spectrum disorder research, services and support activities, to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies, are not unnecessarily duplicative.”

# Statement on Duplication of Effort



To address this in the *2016 Strategic Plan*, the Committee made the following points:

- In scientific research, coordinated efforts by multiple public and private agencies to fund different types of projects within the same Objective represent **cooperation and collaboration**, not duplication.
- The **scientific process** requires that studies be independently **replicated** in order to ensure reproducibility and validate findings.
- The IACC did not find any specific instances of duplication among projects in the portfolio of funded autism research projects, but it noted that there are several instances of the opposite of duplication within the portfolio – **gaps in research** where too few projects are being supported to answer key questions in the field.

# Statement on Duplication of Effort



What else should be included in this section?

## Potential Topics to Include:

- Discussion of any duplication or lack thereof?
- Examples of gaps in current autism research, services, and support activities that are described under the 7 question areas?
- Examples of interagency coordination and public-private partnership efforts (NAC, FIWA, and multiple federal advisory committees) that promote collaboration and synergy and help avoid duplication?



What changes in language are needed to be more sensitive and address different perspectives within the autism community?

## Examples for consideration:

- **The title:** *IACC Strategic Plan for Autism Spectrum Disorder (ASD)*
- **Nomenclature around autism?**
  - Such as: the use of “people with ASD”, “people with autism”, “people on the autism spectrum”, “autism spectrum disorder” (to specify a diagnosis), “autistic individuals”, “autistics”, etc.
  - Disorder, condition vs. disability, developmental disability?
  - Currently, various expressions are used, with ASD being used in the context of discussions of the specific medical diagnosis



What changes in language are needed to be more sensitive and address different perspectives within the autism community?

## Examples for consideration:

- **Moving away from disease prevention and deficit-focused language?**
  - Such as: “strategies for *reducing* disability?”
  - Such as: symptoms, impairments, deficits vs. challenges, problems, difficulties or signs, differences, characteristics, features?
  - Such as: cause, prevention and risk vs. origins, influences, probability
  - Such as: “families *affected* by autism,” etc.
  - Already do not use suffering, burden, illness, disease
- **How to describe the spectrum of differences?**
  - Severe and mild vs. high and low/minimal support needs; profound, with and without ID? Already do not use high and low functioning.

# Adjournment - Day 1



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

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

<https://videocast.nih.gov/watch=42378>

<https://iacc.hhs.gov>

Thank you!