

## 2025 Current Fiscal Year Report: Interagency Autism Coordinating Committee

Report Run Date: 09/12/2025 08:06:47 PM

### 1. Department or Agency

Department of Health and Human Services

### 2. Fiscal Year

2025

### 3. Committee or Subcommittee

Interagency Autism Coordinating Committee

### 3b. GSA Committee No.

31970

### 4. Is this New During Fiscal Year? 5. Current Charter 6. Expected Renewal Date 7. Expected Term Date

No 09/30/2024 09/30/2026

### 8a. Was Terminated During Fiscal Year?

No

### 8b. Specific Termination Authority

42 USC 280i-2

### 8c. Actual Term Date

### 9. Agency Recommendation for Next Fiscal Year

Continue

### 10a. Legislation Req to Terminate?

Not Applicable

### 10b. Legislation Pending?

Not Applicable

### 11. Establishment Authority Statutory (Congress Created)

### 12. Specific Establishment Authority

42 USC 280i-2

### 13. Effective Date

12/19/2006

### 14. Committee Type

Continuing

### 14c. Presidential?

No

### 15. Description of Committee Scientific Technical Program Advisory Board

### 16a. Total Number of Reports

No Reports for this Fiscal Year

### 17a. Open 1 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 1

### Meetings and Dates

#### Purpose

To discuss the committee's nominations of articles for the 2024 IACC Summary of Advances in Autism Research report.

#### Start

01/14/2025 - 01/14/2025

#### End

**Number of Committee Meetings Listed: 1**

	<b>Current Next</b>	
	<b>FY</b>	<b>FY</b>
<b>18a(1). Personnel Pmts to Non-Federal Members</b>	\$0.00	\$0.00
<b>18a(2). Personnel Pmts to Federal Members</b>	\$0.00	\$0.00
<b>18a(3). Personnel Pmts to Federal Staff</b>	\$0.00	\$0.00
<b>18a(4). Personnel Pmts to Non-Member Consultants</b>	\$0.00	\$0.00
<b>18b(1). Travel and Per Diem to Non-Federal Members</b>	\$0.00	\$0.00
<b>18b(2). Travel and Per Diem to Federal Members</b>	\$0.00	\$0.00
<b>18b(3). Travel and Per Diem to Federal Staff</b>	\$0.00	\$0.00
<b>18b(4). Travel and Per Diem to Non-member Consultants</b>	\$0.00	\$0.00
<b>18c. Administrative Costs (FRNs, contractor support, In-person/hybrid/virtual meetings)</b>	\$0.00	\$0.00
<b>18d. Other (all other funds not captured by any other cost category)</b>	\$0.00	\$0.00
<b>18e. Total Costs</b>	\$0.00	\$0.00
<b>19. Federal Staff Support Years (FTE)</b>	0.00	0.00

**20a. How does the Committee accomplish its purpose?**

The Interagency Autism Coordinating Committee (IACC) was established in August 2007 as required by the Combating Autism Act (CAA) of 2006 (P.L. 109-416) to coordinate all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder

(ASD). The Committee was reauthorized by the Combating Autism Reauthorization Act of 2011 (CARA) (P.L. 112-32), enacted on September 30, 2011, and again by the Autism Collaboration Accountability Research Education and Services (CARES) Act, enacted on August 8, 2014. The Autism Collaboration Accountability Research Education and Services (CARES) Act of 2019 was signed by the President on September 30, 2019, reauthorizing the Committee through September 30, 2024. The Continuing Appropriations Act, 2025, reauthorized the committee through December 20, 2024. The IACC's charge (under the Autism CARES Act of 2019) is to: (1) monitor autism spectrum disorder research, and to the extent practicable services and support activities, across all relevant Federal departments and agencies, including coordination of Federal activities with respect to autism spectrum disorder; (2) develop a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, interventions, including school and community-based interventions, and access to services and supports for individuals with autism spectrum disorder across the lifespan of such individuals; (3) make recommendations to the Secretary regarding any appropriate changes to such activities, including with respect to the strategic plan; (4) make recommendations to the Secretary regarding public participation in decisions relating to autism spectrum disorder, and the process by which public feedback can be better integrated into such decisions; (5) develop a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the

families of such individuals, which shall include— (A) proposed budgetary requirements; and (B) recommendations to ensure that autism spectrum disorder research, and 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; (6) submit to the Congress and the President— (A) an annual update on the summary of advances; and (B) an annual update to the strategic plan, including any progress made in achieving the goals outlined in such strategic plan. The IACC Strategic Plan and its subsequent updates have been produced through a collaborative effort between the IACC, self-advocates, family members, members of advocacy and service organizations, researchers, clinicians, federal government employees, and the public to identify needs and opportunities for research, services, and policy to improve the lives of individuals with autism and their families. The Plan cites specific Recommendations for different areas of autism research and services, including Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Infrastructure and Prevalence. The IACC published its first Strategic Plan for ASD Research in January 2009 and has issued updates to the Strategic Plan in subsequent years. Most recently, the Committee completed the 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy, which was published in September 2023. The IACC has also published an annual Summary of Advances in Autism Research in accordance with requirements in the CAA and subsequent legislation. In December 2023, the 2022 IACC Summary of Advances in Autism Research was published, describing the top 20 autism research advances

identified by the Committee from research articles published in calendar year (CY) 2021. The 2023 IACC Summary of Advances is expected to be published in the fall of 2024. When in session, the Committee also monitors federal activities related to autism through presentations at meetings of the full IACC and working groups and provides access to meeting webcasts, minutes, transcripts, and materials on the IACC website. All IACC meetings, including IACC virtual meetings, conference calls, and IACC-sponsored workshops, are open to the public.

**20b. How does the Committee balance its membership?**

Under the Autism CARES Act of 2019, the Interagency Autism Coordinating Committee consists of Federal members and non-Federal public members: Federal Membership (voting Ex Officios): The Committee is composed of the following Federal members or their designees; the Director of the Centers for Disease Control and Prevention; the Director, NIH, and the Directors of such national research institutes of the NIH as the Director, NIMH, by delegation, determines appropriate; the heads of such other agencies of the Department of Health and Human Services as the Director, NIMH, by delegation, determines appropriate, such as the Administration for Community Living, Administration for Children and Families, the Centers for Medicare & Medicaid Services, the Food and Drug Administration, and the Health Resources and Services Administration; and representatives of other Federal Governmental agencies that serve individuals with autism spectrum disorder such as the Department of Education, the Department of Labor, the Department of Justice, the Department of Veterans Affairs, the Department of Housing

and Urban Development, and the Department of Defense. Non-Federal Membership (Public): Not more than one-half, but not fewer than one-third, of the total membership of the committee is composed of non-Federal public members appointed by the Secretary. Public membership is required to include at least three individuals with a diagnosis of Autism Spectrum Disorder (ASD); at least three parents or legal guardians of an individual with ASD; and at least three representatives of leading research, advocacy, and service organizations for individuals with ASD.

**20c. How frequent and relevant are the Committee Meetings?**

Meetings of the full committee are held not less than two times within a fiscal year. The full committee met five times in FY2024 on the following dates 10/11/2023, 1/24/2024, 4/17/2024, 7/10/2024, and 9/23/2024.

**20d. Why can't the advice or information this committee provides be obtained elsewhere?**

This committee is mandated by the Combating Autism Act of 2006 of the Public Health Service Act, as amended, and was reauthorized most recently by the Autism CARES Act of 2019. It coordinates efforts concerning autism spectrum disorder among member federal agencies and private autism research, service, and advocacy organizations. The Committee's primary mission is to provide advice to the Secretary of Health and Human Services on matters concerning autism spectrum disorder and to facilitate the efficient and effective exchange of information on autism activities among the member federal agencies in order to enhance coordination of autism-related programs and activities. The Committee, composed of federal officials and public

stakeholders, assists in increasing public understanding of the member agencies' activities, programs, policies, and research and serves as a public forum for discussions related to autism spectrum disorder. There are U.S. federal advisory committees that are focused on the needs of individuals with disabilities, but there is no other federal advisory committee that is dedicated specifically to the needs of individuals with autism spectrum disorder and that performs functions similar to the IACC.

**20e. Why is it necessary to close and/or partially closed committee meetings?**

All meetings of the IACC are open to the public.

**21. Remarks**

Based on the assignment of duties, Dr. Susan Daniels serves as both the designated federal officer and the committee decision-maker for this committee. Ex Officio Members: Dr. Lawrence Tabak stepped down from the committee on 11/08/2023 and was replaced by Dr. Monica Bertagnolli; Dr. Joshua Gordon (Chair) stepped down from the committee on 06/15/2024; Dr. Shelli Avenevoli was appointed as Chair 06/16/2024 – 09/30/2024; Dr. Walter Koroshetz stepped down in 06/30/2024 and was replaced by Dr. Kristi Hardy. Dr. Brooke Mount stepped down from the committee on 03/30/2024 and was replaced by Ms. Deirdra Assey; Dr. Larry Wexler stepped down from the committee on 12/31/2023 and was replaced by Dr. Christy Kavulic; Dr. Anita Everett stepped down from the committee on 03/31/2024 and was replaced by Dr. Nikhil Patel; Dr. Allyson Dean became a member of the committee on 07/01/2024, replacing Ms. Dayana Garcia who stepped down in 2023; Ms. Barbara Roland stepped down from the committee on

9/30/2024.

### **Designated Federal Officer**

Susan A. Daniels Director, Office of Autism

Research Coordination

Committee Members	Start	End	Occupation	Member Designation
Avenevoli, Shelli	06/16/2024	09/30/2025	Acting Director	Ex Officio Member
Bertagnolli, Monica	11/09/2023	01/20/2025	Director	Ex Officio Member

**Number of Committee Members Listed: 2**

### **Narrative Description**

The Interagency Autism Coordinating Committee (IACC) was established in August 2007 as required by the Combating Autism Act (CAA) of 2006 (P.L. 109-416) to coordinate all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). The Committee was reauthorized by the Combating Autism Reauthorization Act of 2011 (CARA) (P.L. 112-32), enacted on September 30, 2011, and again by the Autism Collaboration Accountability Research Education and Services (CARES) Act, enacted on August 8, 2014. The Autism Collaboration Accountability Research Education and Services (CARES) Act of 2019 was signed by the President on September 30, 2019, reauthorizing the Committee through September 30, 2024. The IACC's charge (under the Autism CARES Act of 2019) is to: (1) monitor autism spectrum disorder research, and to the extent practicable services and support activities, across all relevant Federal departments and agencies, including coordination of Federal activities with respect to autism spectrum disorder; (2) develop a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, interventions, including school and community-based interventions, and access to services and supports for individuals with autism spectrum disorder across the lifespan of such individuals; (3) make recommendations to the Secretary regarding any appropriate changes to such activities, including with respect to the strategic plan; (4) make recommendations to the Secretary regarding public participation in



decisions relating to autism spectrum disorder, and the process by which public feedback can be better integrated into such decisions;

(5) develop a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals, which shall include— (A) proposed budgetary requirements; and (B) recommendations to ensure that autism spectrum disorder research, and 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;

(6) submit to the Congress and the President— (A) an annual update on the summary of advances; and (B) an annual update to the strategic plan, including any progress made in achieving the goals outlined in such strategic plan.

The IACC Strategic Plan and its subsequent updates have been produced through a collaborative effort between the IACC, self-advocates, family members, members of advocacy and service organizations, researchers, clinicians, federal government employees, and the public to identify needs and opportunities for research, services, and policy to improve the lives of individuals with autism and their families. The Plan cites specific Recommendations for different areas of autism research and services, including Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Infrastructure and Prevalence. The IACC published its first Strategic Plan for ASD Research in January 2009 and has issued updates to the Strategic Plan in subsequent years. Most recently, the Committee completed the 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy, which was published in September 2023. The IACC has also published an annual Summary of Advances in Autism Research in accordance with requirements in the CAA and subsequent legislation. In December 2023, the 2022 IACC Summary of Advances in Autism Research was published, describing the top 20 autism research advances identified by the Committee from research articles published in calendar year (CY) 2021. The 2023 IACC Summary of Advances is expected to be published in the fall of 2024. When in session, the Committee also monitors federal activities related to

autism through presentations at meetings of the full IACC and working groups and provides access to meeting webcasts, minutes, transcripts, and materials on the IACC website. All IACC meetings, including IACC virtual meetings, conference calls, and IACC-sponsored workshops, are open to the public.

**What are the most significant program outcomes associated with this committee?**

Checked if  
Applies

Improvements to health or safety	<input checked="" type="checkbox"/>
Trust in government	<input checked="" type="checkbox"/>
Major policy changes	<input type="checkbox"/>
Advance in scientific research	<input checked="" type="checkbox"/>
Effective grant making	<input type="checkbox"/>
Improved service delivery	<input checked="" type="checkbox"/>
Increased customer satisfaction	<input checked="" type="checkbox"/>
Implementation of laws or regulatory requirements	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

**Outcome Comments**

NA

**What are the cost savings associated with this committee?**

Checked if Applies

None	<input type="checkbox"/>
Unable to Determine	<input checked="" type="checkbox"/>
Under \$100,000	<input type="checkbox"/>
\$100,000 - \$500,000	<input type="checkbox"/>
\$500,001 - \$1,000,000	<input type="checkbox"/>
\$1,000,001 - \$5,000,000	<input type="checkbox"/>
\$5,000,001 - \$10,000,000	<input type="checkbox"/>
Over \$10,000,000	<input type="checkbox"/>
Cost Savings Other	<input type="checkbox"/>

**Cost Savings Comments**

The committee's mission is to develop and annually update a strategic plan for autism

spectrum disorder (ASD) research and services.

**What is the approximate Number of recommendations produced by this committee for the life of the committee?**

108

**Number of Recommendations Comments**

These 108 recommendations are the total number of recommendations for FY2008 through FY2024. The committee did not make any new recommendations in FY2024.

**What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?**

43%

**% of Recommendations Fully Implemented Comments**

Of the 108 recommendations (42.59%) have been fully implemented (including 45 Strategic Plan objectives and 1 research recommendation).

**What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?**

55%

**% of Recommendations Partially Implemented Comments**

Of the 108 overall recommendations made by the IACC to date, 55.56% have been partially implemented (including 57 Strategic Plan objectives and 3 letters to the Secretary). Together, 106 of the 108 recommendations (98.15%) have been either partially or fully implemented.

**Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?**

Yes ☒ No ☐ Not Applicable ☐

**Agency Feedback Comments**

The agency provides feedback at the IACC meetings, in reports, in response letters, and on the agency web site. Information is provided to the public at each meeting. The public can view information related to the Committee through the committee's official website.

**What other actions has the agency taken as a result of the committee's advice or recommendation?**

Checked if Applies

Reorganized Priorities	<input checked="" type="checkbox"/>
Reallocated resources	<input checked="" type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

### Action Comments

In response to recommendations, Federal agencies have included consideration of objectives in the IACC Strategic Plan in their programmatic planning effort which has influenced research and policies, though in most cases the Strategic Plan was only one of many factors considered. In some cases, projects such as the funding of specific workshops, were prioritized by agencies largely, but not solely, in response to the IACC Strategic Plan. In addition, in some cases, initiatives were planned in response to IACC recommendations, which has resulted in grants being funded in areas that were not previously covered.

### Is the Committee engaged in the review of applications for grants?

No

### Grant Review Comments

NA

### How is access provided to the information for the Committee's documentation?

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input checked="" type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input checked="" type="checkbox"/>
Other	<input type="checkbox"/>

### Access Comments

NA