

2024 Current Fiscal Year Report: Interagency Autism Coordinating Committee

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2024

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 09/30/2022 09/30/2024

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 0 17b. Closed 0 17c. Partially Closed 0 Other Activities 0 17d. Total 0

Meetings and Dates

No Meetings

	Current FY	Next FY
18a(1). Personnel Pmts to Non-Federal Members	\$0.00	\$0.00
18a(2). Personnel Pmts to Federal Members	\$0.00	\$0.00
18a(3). Personnel Pmts to Federal Staff	\$0.00	\$0.00
18a(4). Personnel Pmts to Non-Member Consultants	\$0.00	\$0.00
18b(1). Travel and Per Diem to Non-Federal Members	\$0.00	\$0.00
18b(2). Travel and Per Diem to Federal Members	\$0.00	\$0.00
18b(3). Travel and Per Diem to Federal Staff	\$0.00	\$0.00
18b(4). Travel and Per Diem to Non-member Consultants	\$0.00	\$0.00
18c. Other(rents,user charges, graphics, printing, mail, etc.)	\$0.00	\$0.00
18d. Total	\$0.00	\$0.00
19. Federal Staff Support Years (FTE)	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 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, 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 ASD research and services, including Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Infrastructure and Prevalence. The IACC published their first Strategic Plan for ASD Research in January 2009 and has issued annual updates to the Strategic Plan in subsequent years. The Committee has developed and approved the new 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy, which is expected to be published in the fall of 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 April 2023, the IACC issued its 2021 Summary of Advances in Autism Research, describing the top 20 autism research advances identified by the Committee from research articles published in calendar year (CY) 2021. The 2022 Summary of Advances is expected to be published in the fall of 2023. When in session, the Committee also monitors federal activities related to autism through presentations at meetings of the full IACC and its subcommittees 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 three times in FY2023 on the following dates 10/26/2022, 1/18/2023, and 4/4/2023.

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's title was updated from Performing the Duties of the NIH Director to Acting Director, NIH this fiscal year; Dr. Joshua Gordon was reappointed as Chair 10/01/22-09/30/2024; Ms. Skye Bass stepped down from the committee on 9/8/2023; Ms. Dayana Garcia stepped down from the committee on 3/3/2023; Ms. Georgina Peacock stepped down from the committee on 9/30/2022; Dr. Nina Schor stepped down from the committee on 9/30/2022; Dr. Teresa Souza stepped down from the committee on 12/31/2022; Non-Federal Members: Dr. Joseph Piven stepped down from the committee on 4/4/2023 before his regular term ended; Steven Whitlow stepped down from the committee on 2/26/2023 before his regular term ended;

Designated Federal Officer

Susan A. Daniels Director, Office of Autism Research Coordination

Committee Members	Start	End	Occupation	Member Designation
Avila, Maria	07/18/2021	09/30/2024	Associate Professor, University of Vermont	Special Government Employee (SGE) Member
BIANCHI, DIANA	07/18/2021	09/30/2024	Director, NICHD, NIH	Ex Officio Member

Carter, Alice	01/18/2022	09/30/2024	Professor, University of Massachusetts Boston	Special Government Employee (SGE) Member
Cohen Hubal, Elaine	07/18/2021	09/30/2024	Senior Science Advisor, Office of Research and Development, EPA	Ex Officio Member
Crane, Samantha	07/18/2021	09/30/2024	Legal Director, Quality Trust for Individuals with Disabilities	Special Government Employee (SGE) Member
Dickerson, Aisha	07/18/2021	09/30/2024	Assistant Professor, Johns Hopkins University	Special Government Employee (SGE) Member
Everett, Anita	07/18/2021	09/30/2024	Chief Medical Officer, Substance Abuse and Mental Health Services Administration	Ex Officio Member
Farchione, Tiffany	07/18/2021	09/30/2024	Deputy Director, US Food and Drug Administration	Ex Officio Member
Fryer, Maria	07/18/2021	09/30/2024	Policy Analyst, Bureau of Justice Assistance, DoJ	Ex Officio Member
Gassner, Dena	07/18/2021	09/30/2024	Founder and Director, Center for Understanding	Special Government Employee (SGE) Member
Gordon, Joshua	07/18/2021	09/30/2024	Director, NIMH, NIH	Ex Officio Member
Halladay, Alycia	07/18/2021	09/30/2024	Chief Science Officer, Autism Science Foundation	Special Government Employee (SGE) Member
Johnson, Craig	07/18/2021	09/30/2024	Founder and President, Champions Foundation	Special Government Employee (SGE) Member
Johnson, Jennifer	07/18/2021	09/30/2024	Deputy Director, ACL	Ex Officio Member
Koroshetz, Walter	01/13/2023	09/30/2024	Director, NINDS, NIH	Ex Officio Member
Lozier, Leah	01/13/2023	09/30/2024	Social Science Analyst, Policy Development and Research, HUD	Ex Officio Member

Marvin, Alison	07/18/2021	09/30/2024	Operations Research Analyst, Social Security Administration	Ex Officio Member
Miller, Matthew	07/18/2021	09/30/2024	Director, Office of Mental Health and Suicide Prevention, Veteran Health Administration	Ex Officio Member
Mistry, Kamila	07/18/2021	09/30/2024	Associate Director, Agency for Healthcare Research & Quality	Ex Officio Member
Myrick, Yetta	01/18/2022	09/30/2024	Community Outreach Coordinator, Children's National Health System	Special Government Employee (SGE) Member
Nebeker, Lindsey	07/18/2021	09/30/2024	Development Specialist, Autism Society of America	Special Government Employee (SGE) Member
Onaiwu, Morenike	02/13/2022	09/30/2024	Academic Instructor, Texas State Technical College	Special Government Employee (SGE) Member
Phan, Jenny	07/18/2021	09/30/2024	Post-doctoral Fellow, University of Wisconsin-Madison	Special Government Employee (SGE) Member
Prince, JaLynn	02/13/2022	09/30/2024	Co-Founder and President, Madison House Autism Foundation	Special Government Employee (SGE) Member
Ramos, Lauren	07/18/2021	09/30/2024	Director, Maternal and Child Health Workforce Development, HRSA	Ex Officio Member
Rattay, Karyl	01/13/2023	09/30/2024	Division Director, NCBDDD, CDC	Ex Officio Member
Rivera, Susan	07/18/2021	09/30/2024	Professor and Chair, University of California - Davis	Special Government Employee (SGE) Member
Siegel, Matthew	01/18/2022	09/30/2024	Vice President for Medical Affairs, Maine Behavioral Healthcare	Special Government Employee (SGE) Member

Smith, Laura	04/10/2022	09/30/2024	Self Advocate Faculty, University of Washington	Special Government Employee (SGE) Member
Srinivasan, Hari	02/13/2022	09/30/2024	Self Advocate	Special Government Employee (SGE) Member
Sumeracki, Jodie	07/18/2021	09/30/2024	Senior Policy Advisor, Center for Medicare and Medicaid Services	Ex Officio Member
Tabak, Lawrence	12/20/2021	01/20/2025	Acting Director, NIH	Ex Officio Member
Tager-Flusberg, Helen	07/18/2021	09/30/2024	Director and Professor, Center for Autism Research Excellence	Special Government Employee (SGE) Member
Taylor, Julie	01/18/2022	09/30/2024	Associate Professor, Vanderbilt University Medical Center	Special Government Employee (SGE) Member
Tucci, Debara	07/18/2021	09/30/2024	Director, NIDCD, NIH	Ex Officio Member
Wang, Paul	01/18/2022	09/30/2024	Deputy Director, Simons Foundation	Special Government Employee (SGE) Member
Wexler, Lawrence	07/18/2021	09/30/2024	Director, Office of Special Education Programs, ED Health Science Program Manager,	Ex Officio Member
Williams, Nicole	07/18/2021	09/30/2024	Congressionally Directed medical Research Programs, DoD Managing Director, Poverty to Prosperity Program	Ex Officio Member
Williams, Taryn	04/08/2022	09/30/2024	Center for American Progress, U.S. Department of Labor	Ex Officio Member
Woychik, Richard	07/18/2021	09/30/2024	Acting Director, NIEHS, NIH	Ex Officio Member

Number of Committee Members Listed: 40

Narrative Description

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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, scientists, self-advocates, family members, advocacy organizations, and the public to identify needs and opportunities for research, services, and policy to improve the lives of individuals with autism spectrum disorder and their families. The plan cites specific Recommendations for different areas of ASD research and services, including Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Infrastructure and Prevalence. The IACC published their first Strategic Plan for ASD Research in January 2009 and has issued annual updates to the Strategic Plan in subsequent years. The Committee has developed and approved the new 2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy, which is expected to be published in the fall of 2023. The IACC has also published an annual Summary of Advances in Autism Spectrum Disorder Research in accordance with requirements in the CAA and subsequent legislation. In April 2023, the IACC issued its 2021 Summary of Advances in Autism Research, describing the top 20 autism research advances identified by the Committee from research articles published in calendar year (CY) 2021. The 2022 Summary of Advances is expected to be published in the fall of 2023. When in session, the Committee also monitors federal activities related to autism through presentations at meetings of the full IACC and its subcommittees 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
Trust in government



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 FY2023.

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