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Report to Congressional Requesters

February 2024

AUTISM RESEARCH AND SUPPORT SERVICES

Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened

Accessible Version

GAO-24-106446

GAO Highlights

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Highlights of GAO-24-106446, a report to congressional requesters
February 2024

AUTISM RESEARCH AND SUPPORT SERVICES

Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened

Why GAO Did This Study

The federal government plays an important role supporting research, programs, and other activities to promote the health and well-being of people with autism. Multiple federal agencies are involved in autism activities. To help coordinate and monitor federal autism activities and to ensure activities are not unnecessarily duplicative, Congress directed the Secretary of Health and Human Services to establish the IACC and designate an official to facilitate coordination and implementation of autism activities, known as the National Autism Coordinator.

GAO was asked to examine coordination and monitoring of federal autism activities. This report examines NIH efforts to (1) help coordinate federal autism activities and (2) monitor autism activities to ensure federal autism activities are not unnecessarily duplicative.

GAO reviewed NIH documents and relevant federal laws; assessed NIH's role in supporting coordination of autism activities against key practices that GAO identified in prior work; and gathered information from 19 federal agencies that conduct autism activities.

What GAO Recommends

GAO is making two recommendations: HHS should (1) develop a process to clearly track and report progress toward IACC goals; and (2) ensure that NIH documents the procedures its Office of National Autism Coordination uses to ensure federal autism activities are not unnecessarily duplicative. HHS concurred with the recommendations.

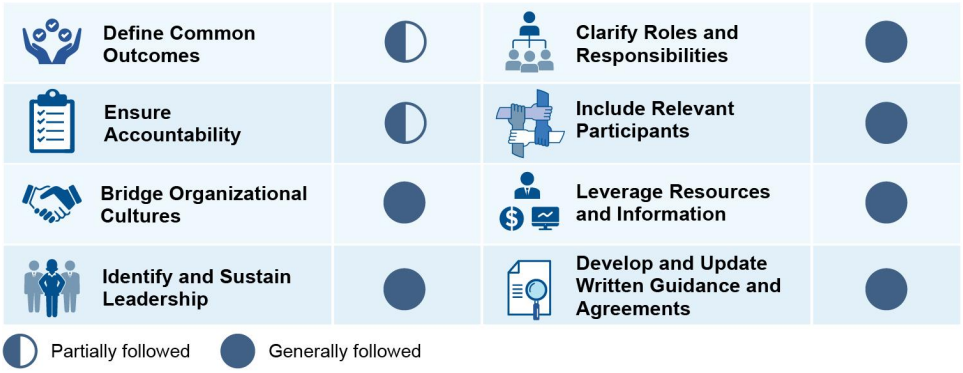
What GAO Found

The National Institutes of Health (NIH), within the Department of Health and Human Services (HHS), plays a key role in supporting the coordination of autism activities across 18 federal agencies, including the Departments of Defense and Education. For example, NIH manages the Interagency Autism Coordination

Committee (IACC), a federal advisory committee composed of federal agencies and public members, through its Office of National Autism Coordination.

GAO found that NIH, in support of the IACC and the National Autism Coordinator, generally followed six of eight key collaboration practices that GAO's prior work has shown can be effective in enhancing and sustaining interagency collaborative efforts among federal entities. For example, NIH has taken steps to bridge organizational cultures by convening meetings of the IACC.

Assessment of the National Institutes of Health's (NIH) Role in Supporting Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Coordination



Source: GAO analysis of information collected from NIH and other federal agencies (data); GAO (icons). | GAO-24-106446

Accessible Text for Assessment of the National Institutes of Health's (NIH) Role in Supporting Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Coordination

Key collaboration practice	Followed assessment
Define common outcomes	Partially followed
Clarify roles and responsibilities	Generally followed
Ensure accountability	Partially followed
Include relevant participants	Generally followed
Bridge organizational cultures	Generally followed
Leverage resources and information	Generally followed
Identify and sustain leadership	Generally followed
Develop and update written guidance and agreements	Generally followed

Source: GAO analysis of information collected from NIH and other federal agencies (data); GAO (icons). I GAO-24-106446

GAO found NIH efforts to support interagency coordination partially followed the remaining two collaboration practices, including ensuring accountability. For example, al!though IACC strategic plans describe high-level progress made toward autism activities, they generally have not described how progress made relates to goals. NIH officials stated their progress tracking approach is driven by

established processes, some of which are required by law. Establishing a clear process for tracking progress would help to determine progress toward IACC's goals and that interagency efforts are effective.

NIH helps ensure federally funded autism activities are not unnecessarily duplicative through various activities, such as holding meetings and through data and information reviews. However, GAO found the processes used by NIH's Office of National Autism Coordination were not documented. For example, NIH does not have written procedures describing the steps these staff should follow when reviewing federal autism research information for potential duplication. Although NIH officials stated that they believe current monitoring processes are sufficient, documenting these procedures will help ensure they are properly designed and executed to provide reasonable assurance that duplication is not occurring.

Contents

GAO Highlights ii

Why GAO Did This Study ii
What GAO Recommends ii
What GAO Found ii

Letter 1

Background 6
NIH Coordination Efforts Include Most, but Not All Leading Interagency Collaboration Practices 12
NIH Takes Some Steps to Help Ensure Federal Autism Activities Are Not Unnecessarily Duplicative, but Does Not Document These Procedures 26
Conclusions 30
Recommendations for Executive Action 31
Agency Comments and Our Evaluation 32

Appendix I: Assessment of the National Institutes of Health's Coordination of Federal Autism Activities 34

Appendix II: Steps Federal Funding Agencies Take to Monitor for Unnecessary Duplication in Federal Autism Activities 38

Appendix III: Comments from the Department of Health & Human Services 40

Accessible Text for Appendix III: Comments from the Department of Health & Human Services 46

Appendix IV: GAO Contact and Staff Acknowledgments 51

GAO Contact: 51
Staff Acknowledgments: 51

Related GAO Products 52

Table

Table 1: Autism-Related Resources Developed by the National Institutes of Health (NIH), Including through the Interagency Autism Coordinating Committee (IACC) 15

Figures

Assessment of the National Institutes of Health's (NIH) Role in Supporting Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Coordination iii

Accessible Text for Assessment of the National Institutes of Health's (NIH) Role in Supporting Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Coordination iii

Figure 1: Examples of Autism Activities Conducted by Federal Agencies 7

Accessible Text for Figure 1: Examples of Autism Activities Conducted by Federal Agencies 8

Figure 2: Interagency Autism Coordinating Committee (IACC) Members, as of December 2023 9

Accessible Text for Figure 2: Interagency Autism Coordinating Committee (IACC) Members, as of December 2023 10

Figure 3: Goals Established in Interagency Autism Coordinating Committee (IACC) Strategic Plan, 2021-2023 21

Accessible Text for Figure 3: Goals Established in Interagency Autism Coordinating Committee (IACC) Strategic Plan, 2021-2023 22

Figure 4: Assessment of the National Institutes of Health's (NIH) Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Collaboration 35

Accessible Text for Figure 4: Assessment of the National Institutes of Health's (NIH) Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Collaboration 36

Abbreviations

CDC	Centers for Disease Control and Prevention
DOD	Department of Defense
Education	Department of Education
HHS	Department of Health and Human Services
FIWA	Federal Interagency Workgroup on Autism
IACC	Interagency Autism Coordinating Committee
NIH	National Institutes of Health
NSF	National Science Foundation
OMB	Office of Management and Budget

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U.S. GOVERNMENT ACCOUNTABILITY OFFICE
441 G St. N.W.
Washington, DC 20548

February 28, 2024

The Honorable Bill Cassidy, M.D.
Ranking Member
Committee on Health, Education, Labor and Pensions
United States Senate
The Honorable Mike Lee
United States Senate
The Honorable Christopher Smith
United States House of Representatives

Autism is a developmental disability that is first observed during early childhood.[1] People with autism may have various characteristics, such as difficulties with social communication, restricted or repetitive behaviors or interests, and different ways of learning, moving, or paying attention. Each individual with autism has a distinct and unique set of strengths and difficulties and may need varying levels of support in different areas. For 2020, the Centers for Disease Control and Prevention (CDC) estimated 1 in 36 8-year old children in the United States were identified with autism.[2] The underlying mechanisms that influence the development and trajectory of autism are not well understood; however, research shows that early diagnosis and intervention can greatly improve outcomes.

The federal government plays an important and growing role in funding research to understand the mechanisms underlying autism, training

[1]What is commonly known as autism is a group of disorders known as autism spectrum disorder. We use the term "autism" to refer to autism spectrum disorder as defined in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, which was effective during the time period covered by our review. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition, Text Revision (Washington D.C.: American Psychiatric Association, 2022).

[2]The CDC regularly collects data on the number and characteristics of 4- and 8-year old children with autism through the Autism and Developmental Disabilities Monitoring Network. Through this network, the number of children with autism is estimated by reviewing development evaluations and records from community medical and educational service providers. This estimate has some limitations, according to the CDC, such as the availability, quality, and completeness of existing information and records to determine autism cases and other indicators. Matthew J. Maenner, Zachary Warren, Ashley Robinson Williams, et al, *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020.* Morbidly and Mortality Weekly Report, vol. 72, no 2 (Atlanta, GA.: Centers for Disease Control and Prevention, March 24, 2023).

health care professionals to diagnose autism, and developing services and supports to promote the health and well-being of people with autism. Because multiple agencies are involved in autism activities, coordination among them is important. To facilitate such coordination and the efficient and effective exchange of such information among federal agencies, organizations, and the public, Congress directed the Secretary of Health and Human Services to establish the Interagency Autism Coordinating Committee (IACC). This committee advises the Secretary on issues related to autism and is required to develop and update a strategic plan for autism.[3]

Congress also directed the Secretary of Health and Human Services to issue progress reports on activities related to autism and to designate an official within the Department of Health and Human Services (HHS) to facilitate coordination and implementation of autism activities across federal agencies—known as the National Autism Coordinator.

The National Institutes of Health (NIH), within HHS, plays a key leadership role in coordinating federal-wide autism activities. Specifically, the Office of National Autism Coordination, within the NIH's National Institute of Mental Health, supports the IACC and National Autism Coordinator in these coordination activities.

In 2013, we reported federal agencies that conducted autism research had limited coordination, and recommended that HHS take specific actions to improve the usefulness of the information it collects on autism activities.[4] We also recommended that HHS and other agencies funding autism research at the time—the Department of Defense (DOD), Department of Education (Education), and the National Science Foundation (NSF)—develop identification and monitoring methods to promote better coordination of autism research. By March 2019, we had closed all of these recommendations as implemented.

You asked us to provide information on the coordination of federal autism activities, including how the IACC coordinates and monitors federally

[3]The IACC was initially established under the Children's Health Act of 2000, and has been reauthorized through the Combating Autism Act of 2006, the Combating Autism Reauthorization Act of 2011, and the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act) of 2014 and 2019. As of the date of this report, the IACC is authorized through September 30, 2024.

[4]GAO, *Federal Autism Activities: Better Data and More Coordination Needed to Help Avoid the Potential for Unnecessary Duplication*, GAO-14-16 (Washington, D.C.: Nov. 20, 2013). For other GAO reports related to federal autism activities, see the Related GAO Products, at the end of this report.

funded autism activities and issues recommendations, as appropriate, to improve them. This report examines:

1. NIH's efforts to help coordinate federal autism activities, including in support of the IACC and the National Autism Coordinator; and
2. how NIH monitors autism activities to ensure they are not unnecessarily duplicative.

For both objectives, we reviewed NIH and IACC documentation, including IACC meeting materials, guidance documents, strategic plans, data reporting, and HHS reports to Congress on federal autism activities.[5] We reviewed laws that authorized autism funding and established federal coordination and responsibilities to ensure autism activities are not unnecessarily duplicative, such as the Autism CARES Act.[6] We interviewed the National Autism Coordinator and other NIH officials regarding NIH's role in supporting coordination and monitoring activities and in ensuring autism activities are not unnecessarily duplicative, including activities of the IACC.[7] We also obtained written responses from

[5]HHS produces reports to Congress, prepared by NIH, on federally funded autism activities that cover 5-year periods. HHS also produces reports to Congress on specific autism topics based on congressional requests. In this report, when we refer to HHS reports to Congress, we are describing the report on federally funded autism activities that cover five-year periods.

[6]We define federal autism activities as any federally funded or operated activity (i.e., program, grant, research, or policy) that specifically targets individuals with autism or when a significant portion of the activity supports individuals with autism.

In some instances, funding similar research on the same topic is appropriate and necessary; for example, for purposes of replicating or corroborating prior research results. We define duplication as when two or more agencies or programs are engaged in the same activities or provide the same services to the same beneficiaries. We consider unnecessary research duplication to mean research that is scientifically unnecessary to replicate or complement prior research results or research conducted or funded that is very similar to other research. This definition is consistent with our prior work which has established standard definitions for fragmentation, overlap, and duplication. Fragmentation refers to those circumstances in which more than one federal agency (or more than one organization within an agency) is involved in the same broad area of national need and opportunities exist to improve service delivery. Overlap occurs when multiple agencies or programs have similar goals, engage in similar activities or strategies to achieve them, or target similar beneficiaries. For the purposes of this report, when we refer to duplication or potential duplication, we include the concept of overlap. See GAO, Fragmentation, Overlap, and Duplication: An Evaluation and Management Guide, GAO-15-49SP (Washington, D.C.: April 2015).

[7]Prior to her appointment to the National Autism Coordinator in May 2023, the coordinator served as the Acting National Autism Coordinator since 2021, as well as the executive secretary for the IACC

NIH on these activities.[8] For the purposes of our report, we refer to methods used to ensure autism activities are not unnecessarily duplicative as monitoring.

We also interviewed or collected information from 18 federal agencies that conduct autism activities, in addition to NIH, on their coordination and monitoring of autism activities, including through the IACC.[9] When characterizing the responses made by these agencies, we use the term "most" when the topic was identified by more than half of the agencies and "some" when it was mentioned by fewer than half of them. Additionally, we interviewed or collected information from six private organizations that conduct autism activities on their perspectives on the IACC, federal coordination of autism activities, and the sufficiency or gaps in autism activities.[10] To help ensure we captured a range of perspectives within the autism community, we selected these organizations to obtain variation in terms of the types of autism activities the organizations conduct (e.g., research or services), and the populations within the autism community that they represent (e.g., age, race and ethnicity, and sex and gender). We also selected some organizations that had a representative appointed to the IACC as a member, and others that had not.

To examine NIH's efforts to help coordinate federal autism activities, including in support of the IACC and the National Autism Coordinator, we assessed NIH and IACC materials and practices against leading practices for interagency collaboration identified in our prior work. In our prior work, we found that many of the meaningful results that the federal government seeks to achieve require the coordinated efforts of more than one federal

[8]For the purpose of our report, we use NIH to refer to the agency's role in supporting the IACC or the National Autism Coordinator through its Office of National Autism Coordination.

[9]The IACC has 18 federal member agencies, as of December 2023, one of which is NIH. We previously reported that NSF conducted autism activities, which is not a member of the IACC. We interviewed or collected information from all federal member agencies of the IACC and NSF. See GAO-14-16.

[10]We interviewed or received information from the Autistic Self Advocacy Network, Autism Speaks, Autistic Women and Nonbinary Network, International Society for Autism Research, Madison House Autism Foundation, and Simons Foundation Autism Research Initiative.

agency.[11] Specifically, we compared documentation—including IACC strategic plans, IACC meeting materials, and HHS reports to Congress—and responses provided by NIH and other federal agencies on coordination and monitoring efforts, mentioned above, to the leading practices.[12] We also assessed the extent to which the NIH's and IACC's efforts for tracking progress followed leading practices for evidence-based policymaking identified in our prior work.[13]

To examine NIH's efforts to ensure federal autism activities are not unnecessarily duplicative, we reviewed documentation of its monitoring activities conducted by the Office of National Autism Coordination—in support of the IACC and National Autism Coordinator—including procedures and policies for collecting and analyzing information on unnecessary duplication in federal autism activities. We compared these monitoring activities with federal standards for internal control, which state agency objectives should be designed to establish an organizational structure, assign responsibility, and delegate authority to achieve the entity's objectives.[14]

We conducted this performance audit from December 2022 to February 2024 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe

[11]GAO, *Government Performance Management: Leading Practices to Enhance Interagency Collaboration and Address Crosscutting Challenges*, GAO-23-105520 (Washington, D.C.: May 24, 2023). Interagency collaboration involves collaboration between two or more federal entities. Collaboration can be broadly defined as any joint activity that is intended to produce more public value than could be produced when the organizations act alone. The term "collaboration" broadly refers to interagency activities that others have defined as "cooperation," "coordination," "integration," or "networking." There are no commonly accepted definitions for these terms. For the purposes of this work, we are not drawing distinctions between them.

[12]Each leading practice has key questions associated with it. For this report, we assessed our evidence against each key question, with some exceptions, as some questions did not apply to the issues of relevance in our report.

[13]GAO, *Evidence-Based Policymaking: Practices to Help Manage and Assess the Results of Federal Efforts*, GAO-23-105460 (Washington, D.C, July 12, 2023).

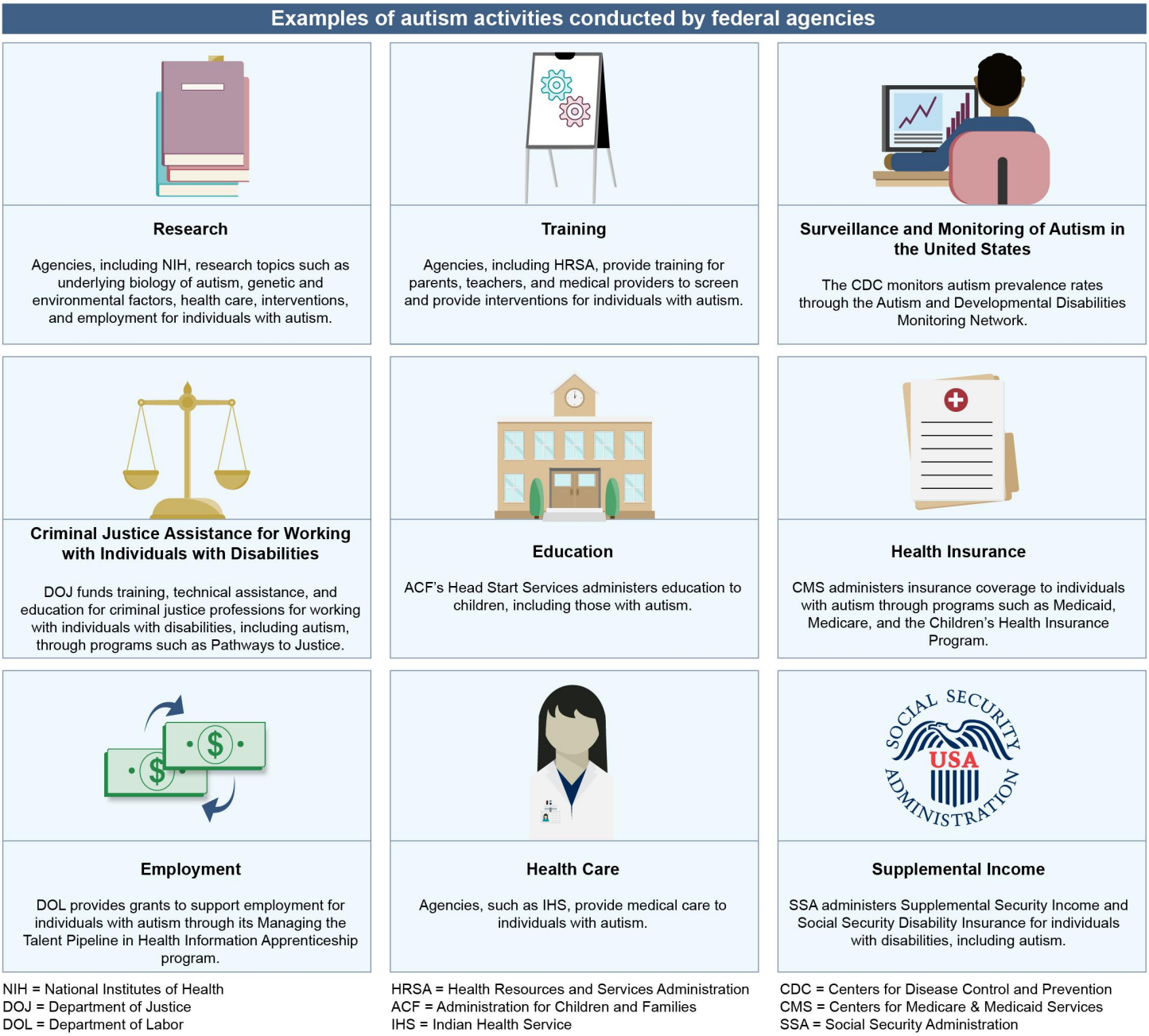
[14]GAO, *Standards for Internal Control in the Federal Government*, GAO-14-704G (Washington, D.C.: Sept. 2014). Specifically, these control standards state that management should assign responsibility and delegate authority to key roles throughout the entity. Management also should develop and maintain documentation of its internal control system. Effective documentation assists in management's design of internal control by establishing and communication the who, what, when, where, and why of internal control execution to personnel.

that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Background

Federal agencies conduct a range of activities directly related to autism or fund programs to support individuals with autism. These activities include, but are not limited to, research, education, training, and the provision of health care services. For a description of some of these activities, see fig 1.

Figure 1: Examples of Autism Activities Conducted by Federal Agencies



Source: GAO analysis of National Institutes of Health information (information); Social Security Administration (seal); GAO (illustrations). | GAO-24-106446

Accessible Text for Figure 1: Examples of Autism Activities Conducted by Federal Agencies

Examples of autism activities conducted by federal agencies

Category	Category description
Research	Agencies, including NIH, research topics such as underlying biology of autism, genetic and environmental factors, health care, interventions, and employment for individuals with autism.
Training	Agencies, including HRSA, provide training for parents, teachers, and medical providers to screen and provide interventions for individuals with autism.
Surveillance and Monitoring of Autism in the United States	The CDC monitors autism prevalence rates through the Autism and Developmental Disabilities Monitoring Network.
Criminal Justice Assistance for Working with Individuals with Disabilities	DOJ funds training, technical assistance, and education for criminal justice professions for working with individuals with disabilities, including autism, through programs such as Pathways to Justice.
Education	ACF's Head Start Services administers education to children, including those with autism.
Health insurance	CMS administers insurance coverage to individuals with autism through programs such as Medicaid, Medicare, and the Children's Health Insurance Program.
Employment	DOL provides grants to support employment for individuals with autism through its Managing the Talent Pipeline in Health Information Apprenticeship program.
Health care	Agencies, such as IHS, provide medical care to individuals with autism.
Supplemental income	SSA administers Supplemental Security Income and Social Security Disability Insurance for individuals with disabilities, including autism.

Source: GAO analysis of National Institutes of Health information (information); Social Security Administration (seal); GAO (illustrations) GAO-24-106446

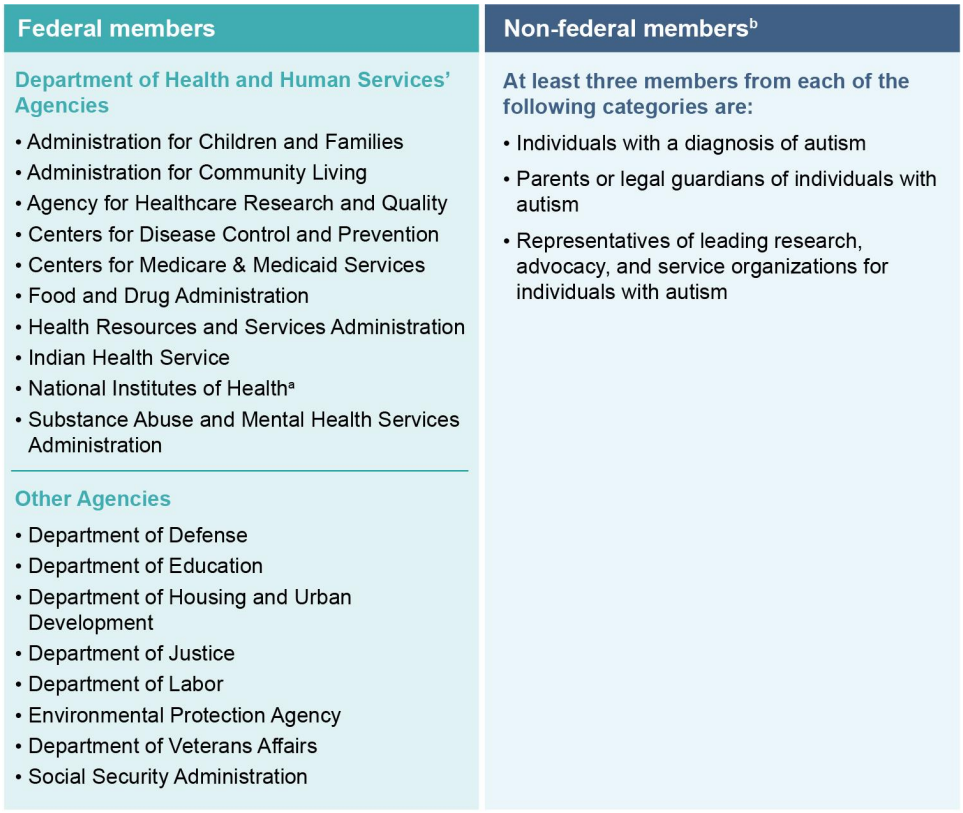
Within HHS, NIH plays a significant role in coordinating federal autism activities. Specifically, the Secretary of Health and Human Services delegated the responsibilities of managing the IACC and appointing of federal members to NIH. NIH is also responsible for recommending a nominee for the position of National Autism Coordinator to the Secretary.[15] Additionally, the Director of NIH's National Institute of Mental Health chairs the IACC.[16]

[15]Under the Autism CARES Act, the Secretary of Health and Human Services appoints the public members of the IACC and the National Autism Coordinator.

[16]The Secretary of Health and Human Services delegated the responsibility to serve as chair of the IACC to the Director of the National Institute of Mental Health.

The IACC is a federal advisory committee comprising representatives from federal departments and agencies that conduct autism activities.[17] It also includes non-federal members who are individuals with autism, family members of individuals with autism, and members of the autism advocacy, research, and service-provider communities.[18] For a list of the federal agencies and types of non-federal members represented on the IACC, see fig. 2.

Figure 2: Interagency Autism Coordinating Committee (IACC) Members, as of December 2023



Source: GAO analysis of National Institutes of Health information. | GAO-24-106446

[17]In this report, we refer to federal departments and federal agencies as federal agencies.

[18]Non-federal members are appointed to a term of 4 years and may be reappointed for one additional 4-year term.

Accessible Text for Figure 2: Interagency Autism Coordinating Committee (IACC) Members, as of December 2023

Category	Category member
Federal members	Department of Health and Human Services' Agencies • Administration for Children and Families • Administration for Community Living • Agency for Healthcare Research and Quality • Centers for Disease Control and Prevention • Centers for Medicare & Medicaid Services • Food and Drug Administration • Health Resources and Services Administration • Indian Health Service • National Institutes of Health[a] • Substance Abuse and Mental Health Services Administration
Federal members	Other Agencies • Department of Defense • Department of Education • Department of Housing and Urban Development • Department of Justice • Department of Labor • Environmental Protection Agency • Department of Veterans Affairs • Social Security Administration
Non-federal members[b]	At least three members from each of the following categories are: • Individuals with a diagnosis of autism • Parents or legal guardians of individuals with autism • Representatives of leading research, advocacy, and service organizations for individuals with autism

Source: GAO analysis of National Institutes of Health information. I GAO-24-106446

Note: The National Science Foundation is not a member of the IACC, but does conduct autism activities and provides information to the IACC.

[a]Five of the National Institutes of Health's 27 institutes and centers and the Office of the NIH Director are separately represented on the IACC.

[b]Non-federal members cannot make up more than one-half or less than one-third of the IACC membership. As of December 2023, the IACC had 21 non-federal members.

As an advisory committee, the IACC does not allocate funds or implement federal programs. However, IACC responsibilities include coordinating and monitoring federal autism activities, making recommendations to ensure these activities are not unnecessarily duplicative, developing a strategic plan for the conduct and support of autism activities, and making recommendations to the Secretary of Health and Human Services

regarding changes to federal autism activities.[19] For example, the IACC's strategic plans can help federal agencies and private organizations plan autism-related research and non-research activities.[20]

NIH also recommends, to the Secretary of Health and Human Services, the appointment of the National Autism Coordinator, who is required by statute to be an HHS employee. The National Autism Coordinator serves as a liaison between HHS, the IACC, and other federal agencies. In addition to overseeing autism activities across federal agencies, the National Autism Coordinator's duties include overseeing the implementation of autism activities, and in so doing considering the IACC strategic plan, and ensuring the autism activities of federal agencies are not unnecessarily duplicative.

On behalf of the IACC and National Autism Coordinator, NIH collects and analyzes autism research funding data and other relevant programmatic data from federal agencies and non-federal entities, and gathers input from agencies and the public to inform the work of the IACC and the National Autism Coordinator.[21] NIH also compiles and disseminates information about the IACC and federal autism activities to the public, Congress, and other government agencies.

[19]The Autism CARES Act of 2014 directed the IACC to monitor autism research—and to the extent practicable, services and support activities—across all relevant federal departments and agencies, including coordination of federal autism activities. The Autism CARES Act also requires the IACC to develop and annually update a strategic plan for autism research, as well as for services and support activities, to the extent practicable, and make recommendations to ensure that federal autism activities are not unnecessarily duplicative.

[20]According to HHS, federal agencies also use other information to help inform their autism activities, such as Congressional requests, research, and meetings with stakeholders.

[21]According to the IACC, federal autism research funding grew from $144 million in 2008 to $327 million in 2018. While NIH collects some information on the non-research activities from federal agencies and non-federal entities, it does not report funding information for non-research activities in a similar way, as it does with research funding data. According to HHS, many agencies do not have autism specific funding information because their programs may broadly serve people with disabilities, including autism.

NIH Coordination Efforts Include Most, but Not All Leading Interagency Collaboration Practices

Coordination Efforts for Federal Autism Activities Are Generally Consistent with Six of Eight Leading Collaboration Practices

Key Considerations for Bridging Organizational Cultures

- Have strategies to build trust among participants been developed?
- Have participating agencies developed ways for operating across agency boundaries?
- Have participating agencies agreed on common terminology and definitions?

Source: GAO. | GAO-24-106446

According to our analysis of documentation and other information we collected from NIH and the other 18 federal agencies that conduct autism activities, we found NIH, in support of the IACC and National Autism Coordinator, has generally followed six of the eight leading practices that can be effective in enhancing and sustaining interagency collaborative efforts. These practices are bridging organizational cultures, including relevant participants, leveraging resources and information, establishing roles and responsibilities, identifying leadership, and developing written guidance and agreements.[22] (See app. I for our assessment of NIH's coordination of federal autism activities compared with each of the eight leading collaboration practices.)

Bridging Organizational Cultures. NIH has implemented practices that our prior work has found to be helpful in overcoming differences in cultures, missions, and perspectives. NIH convenes regular meetings of the IACC—which includes federal and non-federal members—and a separate body comprised only of federal agencies, known as the Federal Interagency Workgroup on Autism (FIWA), which NIH established in 2018. Establishing the FIWA—which is chaired by the National Autism Coordinator—represents a positive step toward bridging organizational cultures since we issued our 2013 report, as it provides another mechanism for federal agencies to coordinate autism activities separate

[22]GAO-23-105520.

from the IACC.[23] According to HHS, the FIWA complements the work of the IACC.

During IACC and FIWA meetings, federal member agencies provide updates on their autism activities, and the National Autism Coordinator provides updates on federal and non-federal activities.[24] NIH officials told us these updates help IACC members stay informed of efforts and events that may be relevant to their work. IACC meetings have included topical presentations on issues such as disparities in the autism community. These presentations are typically given by federal officials, researchers, service providers, or advocates, according to NIH officials. The IACC has also convened working groups on specific topics, such as the IACC Working Group on Housing, which focused on the housing needs of people with autism.

Most IACC member agency officials told us that the IACC and FIWA meetings are important for awareness of autism activities across the federal government, and some officials stated the meetings are important for coordination and have led to discussions and collaboration outside of the IACC. For example, Indian Health Service officials stated they developed training for their health care providers based on information raised during a FIWA meeting and subsequently updated the FIWA on its progress.

Key Considerations for Including Relevant Participants

- Have all relevant participants been included?
- Do the participants have the appropriate knowledge, skills, and abilities to contribute?
- Do the participants represent diverse perspectives and expertise?

Source: GAO. | GAO-24-106446

Including Relevant Participants. NIH has included a diverse group of relevant participants in collaborative efforts, such as the IACC and the FIWA, consistent with leading practices for effective collaboration. Specifically, HHS expanded the IACC's federal and non-federal membership twice, adding six federal members and five non-federal

[23]In that report, we found that members of the IACC provided mixed views on the usefulness of the IACC's efforts to coordinate HHS autism activities. For example, two agencies thought greater information sharing would be helpful, though one noted concerns about the type of information that could be exchanged in a public setting, such as an IACC meeting. See GAO-14-16.

[24]The IACC is statutorily required to hold two full committee meetings a year, and has regularly held three full committee meetings a year. In addition, it also holds working group meetings on topics such as developing the strategic plan and addressing housing and mental health needs for people with autism. These meetings are publicly held.

members since 2014. These expansions in membership changes were in part due to changes to statute. In 2017, we recommended that HHS engage key non-member federal agencies that serve or provide supports to young adults with autism in IACC activities, including by adding them as members, which it did following the enactment of the Autism CARES of 2019.[25]

These expansions increased the representation of federal agencies on the IACC while, according to NIH officials, raising awareness of the types of autism activities those agencies are focused on, such as the housing and employment needs of individuals with autism. Expansions in the number of non-federal members has also increased the types of perspectives from the autism community represented on the committee. For example, the Autism CARES Act of 2019 required the IACC include at least three non-federal members with a diagnosis of autism.[26] According to one individual from a private organization that conducts autism activities, increasing the number of members with a diagnosis of autism on the IACC has been an important step to increase representation, but the organization called for greater representation by members with an autism diagnosis on the committee. Currently, the IACC includes seven non-federal members with a diagnosis of autism.

Key Considerations for Leveraging Resources and Information

- How will the collaboration be resourced through staffing?
- How will the collaboration be resourced through funding? If interagency funding is needed, is it permitted?
- Are methods, tools, or technologies to share relevant data and information being used?

Source: GAO. | GAO-24-106446

Leveraging Resources and Information. NIH has leveraged staff, funds, and information to help coordinate federal autism activities. NIH

[25]GAO, *Youth with Autism: Federal Agencies Should Take Additional Action to Support Transition-Age Youth*, GAO-17-352 (Washington, D.C.: May 2017). The Autism CARES Act of 2019 required the addition of four federal departments—the Department of Housing and Urban Development, the Department of Justice, the Department of Labor, and Department of Veterans Affairs, all of which were added by HHS. Additionally, the Secretary of HHS added the Social Security Administration and Indian Health Service to the IACC, according to NIH officials.

[26]Individuals with an autism diagnosis have been included in the IACC membership since 2007, as required by the Combating Autism Act of 2006 and subsequent reauthorizations. The Autism CARES Act of 2014 expanded the minimum required number of such individuals from 1 to 2, and the Autism CARES Act of 2019 expanded the minimum required number from 2 to 3. According to NIH officials, the IACC membership has typically included more than the required number of autistic individuals.

used funds and staff from its Office of National Autism Coordination to support the IACC, National Autism Coordinator, FIWA, and other autism-related collaborative efforts. NIH developed processes—and continued to refine them since our 2013 report—to collect information from federal agencies and other entities on research and non-research activities. NIH then summarized and disseminated that information so it may be used by others, consistent with leading practices for interagency collaboration. These efforts have resulted in a wide range of resources on autism activities, including the reports to Congress, IACC strategic plans, summary of advances, portfolio analysis reports, and the IACC website. (See table 1.) Officials from one federal agency noted that the IACC website has become a centralized location for resources on autism, which makes it easy for federal agencies to access information.

Table 1: Autism-Related Resources Developed by the National Institutes of Health (NIH), Including through the Interagency Autism Coordinating Committee (IACC)

Product	Statutorily Required	Description
Department of Health and Human Services Report to Congress	Yes	These reports summarize autism-related activities and coordination efforts that span multiple federal agencies and departments. To collect the information necessary to develop the report, NIH sends a detailed questionnaire to federal agencies.
IACC Strategic Plan	Yes	A guide for federal agencies and private organizations in planning autism-related research, services, and support activities. It is organized around seven general topic areas. The IACC develops its strategic plans through working groups, committee meeting discussions, and public feedback.
IACC Summary of Advances	Yes	These publications include plain language summaries of the top autism research studies, as selected by the IACC from a pool of research articles nominated by the IACC members. NIH has developed a process for annually collecting and developing IACC member consensus around noteworthy research studies.
IACC Portfolio Analysis Report	No	An analysis of autism research data that aligns individual research-related projects with topics in the IACC strategic plan. It includes funding data for the projects and highlights trends. To develop the report, NIH collects detailed data from federal agencies and non-federal organizations regarding autism-related research spending. Federal agencies with autism research commit to providing information to NIH and to reviewing their data once summarized by NIH.
IACC Autism Research Database	No	An online database of autism research that aligns with the information captured in the portfolio analysis report. The database is created from information NIH collects from federal agencies and non-federal organizations for the portfolio analysis report.
IACC Website	No	The Department of Health and Human Services maintains IACC's website, which contains committee publications, past meeting information, the Reports to Congress, and non-IACC resources from federal agencies and non-federal organizations, including links to toolkits and guides, reports, and videos. These resources provide information on a range of issues specific to autism, such as services for transitioning into adulthood, employment, and housing.

Source: GAO analysis of NIH information. | GAO-24-106446

NIH has developed several updates to many of these resources over time, sometimes with varying frequency. For example, the 2009 to 2013 IACC strategic plans were published on an annual basis and each plan covered a single year. Since that time, the strategic plans have sometimes covered multiple years. NIH officials told us this variation was primarily due to changes in statute, such as expanding the size and scope of the IACC and the inclusion of autism services and support activities, which resulted in larger plans with additional topics and more detailed descriptions, requiring more time to develop.[27]

Key Considerations for Identifying and Sustaining Leadership:

- Has a lead agency or individual been identified?
- If leadership will be shared between one or more agencies, have roles and responsibilities been clearly identified and agreed upon?
- How will leadership be sustained over the long term?

Source: GAO. | GAO-24-106446

Additionally, NIH generally updated information on research spending (captured by the portfolio analysis reports and in the corresponding autism research database) 2 to 4 years after funding was awarded.[28] For example, NIH published research spending data for fiscal years 2017 and 2018 at the end of 2021.[29] Officials we interviewed from one private organization told us that portfolio analysis reports are essentially out-of-date when published, and, thus, the organization does not use the report, noting their organization would likely use the reports if they were timelier. NIH officials told us the time frames are driven in part by the need to wait for federal agencies and private organizations to close out their data after the end of each fiscal year. In addition, an NIH official noted that as more federal agencies and non-federal organizations are included in the analysis or expand their autism research portfolios, NIH collects more data, which increases the amount of time NIH needs to analyze the data.

Identifying and Sustaining Leadership. NIH plays a significant role in coordinating federal autism activities, by supporting the IACC and the National Autism Coordinator in carrying out their statutory

[27]Additionally, strategic plans do not address 3 years (2014, 2015, and 2020) because of lapses in the IACC's authorization which resulted in the committee not meeting from 2014 to 2015 and in 2020, according to NIH officials.

[28]This is consistent with findings from our 2013 report. See GAO-14-16.

[29]As of February 2024, those were the latest research spending data available on NIH's website. According to HHS, NIH plans to publish research spending data for fiscal years 2019 and 2020 in 2024.

responsibilities.[30] For example, NIH employees serve in key IACC leadership positions and support the operations of the committee.[31] Three individuals have served as National Autism Coordinator since the first was appointed in 2017.[32] Although the position has been unfilled by a permanent coordinator at times, including most recently from June 2021 to May 2023, some federal agencies reported that this did not have an effect on the NIH's coordination activities, as the Acting National Autism Coordinator effectively supported coordination of federal autism activities. Some member agency officials noted the National Autism Coordinator has been helpful in ways, such as leading effective meetings, connecting relevant stakeholder groups to federal staff, and communicating priorities for autism work. One agency noted that the leadership of the National Autism Coordinator has been invaluable to coordinating federal autism activities.

Key Considerations for Clarifying Roles and Responsibilities:

- Have the roles and responsibilities of the participants been clarified?
- Has a process for making decisions been agreed upon?

Source: GAO. | GAO-24-106446

Clarifying Roles and Responsibilities. NIH established roles and responsibilities for IACC and FIWA participants during meetings and in guidance accompanying information collection requests. For example, the IACC provides new federal and non-federal members information about IACC's purpose and responsibilities, member roles and responsibilities, and a description of IACC products. Some IACC and FIWA member agency officials told us NIH clearly communicates roles, responsibilities, and expectations for IACC members. Federal member agency officials told us their roles included participating and providing updates in IACC and FIWA meetings and materials developed to support meetings; attending IACC working group meetings; and contributing to information requests from IACC, such as the HHS reports to Congress, portfolio analysis reports, summary of advances, and strategic plans. While NIH does not have formal guidance outlining member agency roles, we found

[30]Autism CARES Act, Pub. L. No. 113-157, 128 Stat. 1831.

[31]For example, NIH staff serve as the Chair and the Executive Secretary of the IACC.

[32]The current coordinator—an NIH employee—was appointed in May 2023, and served as the Acting National Autism Coordinator from July 2021 to May 2023, as well as from August 2017 to March 2018. According to HHS, the current coordinator also has served as the Executive Secretary of the IACC since 2010.

the committee provides information about agency roles in the IACC's orientation materials.

Key Considerations for Developing and Updating Written Guidance and Agreements:

- If appropriate, have agreements regarding the collaboration been documented? A written document can incorporate agreements reached for any or all of the practices.
- Have ways to continually update or monitor written agreements been developed?

Source: GAO. | GAO-24-106446

Developing and Updating Written Guidance and Agreements. NIH developed a written guidance document to describe the roles and responsibilities of the IACC. As a federal advisory committee, the IACC has a public charter that outlines its authority, objectives, and description of duties.[33] This charter also includes estimated staff and funding resources for the committee, reporting structure, and a general description of leadership. Some IACC member agency officials identified the charter as a document describing the IACC objectives and agency activities.

Coordination Efforts for Federal Autism Activities Do Not Fully Define Common Outcomes or Ensure Accountability

Key Considerations for Defining Common Outcomes:

- Have the crosscutting challenges or opportunities been identified?
- Have the short- and long-term outcomes been clearly defined?
- Have the outcomes been reassessed and updated, as needed?

Key Considerations for Ensuring Accountability:

- What are the ways to monitor, assess, and communicate progress toward the short- and long-term outcomes?
- Have collaboration-related competencies or performance standards been established against which individual performance can be evaluated?
- Have the means to recognize and reward accomplishments related to collaboration been established?

Source: GAO. | GAO-24-106446

While NIH coordination efforts, in support of the IACC and National Autism Coordinator, have generally followed six of the leading practices for interagency collaboration, our examination of IACC strategic plans and related efforts identified limitations in the following two practices: defining common outcomes and ensuring accountability. Specifically, we have

[33]The Federal Advisory Committee Act, as amended, requires federal advisory committees to have a charter. (5 U.S.C. §§ 1001-1014).

reported that collaborative efforts between federal agencies benefit from defining common goals and outcomes through the establishment of both short- and long-term goals. Moreover, leading practices for interagency collaboration outlines several leading practices for ensuring accountability, which include monitoring, assessing progress against defined outcomes, collaborative performance measures, and developing open and transparent methods for communicating progress made on goals. Accountability can help encourage participation, assess progress, and make necessary changes.

Further, according to our work on evidence-based policymaking, to ensure progress can be assessed, outcomes should be broken down into one or more tangible, measurable objectives against which actual achievement is to be compared, which are generally referred to as performance goals. Moreover, our work establishes the importance of clearly communicating progress associated with established goals, as well as where performance is lagging, and why desired results were not achieved.[34] Such actions can help ensure accountability toward achieving established goals.

With respect to the leading practice of defining common outcomes, we found that IACC strategic plans have established goals; however, the IACC does not break down the goals into tangible, measurable objectives, nor does NIH or the National Autism Coordinator. Additionally, NIH coordination efforts also partially followed the leading practice of ensuring accountability because although some NIH and IACC reports describe federal and non-federal autism activities, they do not clearly track or report progress toward goals in a way that ensures accountability.

Define Common Outcomes

Goals. With support from NIH, the IACC establishes goals for autism activities and reassesses them periodically, consistent with leading practices. These goals inform federal agencies and private organizations in planning their autism activities. Strategic plans are organized by seven topics that cover the major needs of the autism community as identified by federal and non-federal members;[35] the topics have generally

[34]GAO-23-105460.

[35]The IACC is required to annually update a strategic plan. 42 U.S.C. § 280i-2(b)(6)(B). NIH officials told us the IACC meets that annual requirement by publishing strategic plans that cover multiple years.

remained consistent since the 2010 Strategic Plan.[36] Each of the seven topic areas in the 2021-2023 Strategic Plan includes an aspirational goal that defines the long-term vision for the respective topic, as well as three recommendations to the Secretary of Health and Human Services for each topic area, which provide examples of activities that could, in part, help to address each aspirational goal.[37] (See fig. 4 for the topics and goals from the 2021-2023 IACC Strategic Plan.)

Collectively, through the aspirational goals and recommendations, IACC has established goals for autism activities, which it reassesses and updates with each new strategic plan.[38] For example, the most recent strategic plan added two new cross-cutting recommendations:

- Support research to understand sex and gender differences in autism.
- Support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people.

[36]The seven topics are as follows: screening and diagnosis, biology, genetic and environmental factors, interventions, services and supports, lifespan issues, and infrastructure and prevalence.

[37]Prior to the 2021-2023 Strategic Plan, recommendations were referred to as objectives.

[38]We refer to strategic plan aspirational goals and recommendations as goals in the remainder of this report. Unlike other IACC strategic plans, the 2018-2019 Strategic Plan is organized by summaries of IACC activities and not by topic areas or aspirational goals.

Figure 3: Goals Established in Interagency Autism Coordinating Committee (IACC) Strategic Plan, 2021-2023

Strategic Plan Topic Areas

Screening and Diagnosis	Biology	Genetic and Environmental Factors	Interventions	Services and Supports	Lifespan	Infrastructure and Prevalence
1. How can we improve identification of autism?	2. What is the biology underlying autism?	3. What are the genetic and environmental factors that contribute to autism and its co-occurring conditions?	4. Which interventions will improve health and well-being?	5. What services and supports are needed to maximize health and well-being?	6. How can we address the needs of people on the autism spectrum throughout the lifespan?	7. How do we expand and enhance research infrastructure systems to meet the needs of the autism community?
Aspirational goal Provide a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes.	**Aspirational goal** Discover the roles of brain development, cognition, and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan.	**Aspirational goal** Discover and understand genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum.	**Aspirational goal** Develop a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum.	**Aspirational goal** Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families.	**Aspirational goal** Promote inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships.	**Aspirational goal** Develop, enhance, and support research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services.

Cross cutting recommendations

- Support research to understand sex and gender differences in autism.
- Support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people.

Source: GAO analysis of National Institutes of Health information (information); iiierlok_xolms/stock.adobe.com (icons). | GAO-24-106446

Accessible Text for Figure 3: Goals Established in Interagency Autism Coordinating Committee (IACC) Strategic Plan, 2021-2023

Strategic Plan Topic Areas

Screening and Diagnosis	Biology	Genetic and Environmental Factors	Interventions	Services and Supports	Lifespan	Infrastructure and Prevalence
1. How can we improve identification of autism?	2. What is the biology underlying autism?	3. What are the genetic and environmental factors that contribute to autism and its co-occurring conditions?	4. Which interventions will improve health and well-being?	5. What services and supports are needed to maximize health and well-being?	6. How can we address the needs of people on the autism spectrum throughout the lifespan?	7. How do we expand and enhance research infrastructure systems to meet the needs of the autism community?
Aspirational goal Provide a timely diagnosis for people on the autism spectrum, so they can be linked to appropriate interventions, services, and supports to maximize positive outcomes.	**Aspirational goal** Discover the roles of brain development, cognition, and physiological function in autism and its co-occurring conditions to enable the development of effective, targeted interventions and societal accommodations that promote positive outcomes across the lifespan.	**Aspirational goal** Discover and understand genetic and environmental factors that influence the development of autism and its co-occurring conditions in order to better inform diagnosis and interventions to improve outcomes for people on the autism spectrum.	**Aspirational goal** Develop a range of interventions that optimize outcomes across the lifespan to maximize the health and well-being of people on the autism spectrum.	**Aspirational goal** Develop and implement high-quality, evidence-based, and widely accessible services and supports that maximize health and well-being across the lifespan for all people on the autism spectrum and their families.	**Aspirational goal** Promote inclusion, support, and acceptance of all people on the autism spectrum so that they can participate in the communities of their choice through school, work, and meaningful relationships.	**Aspirational goal** Develop, enhance, and support research infrastructure and statistical data gathering systems that advance the speed, efficacy, and dissemination of autism research and services.

Cross cutting recommendations

- Support research to understand sex and gender differences in autism.
- Support diversity, equity, inclusion, and accessibility efforts in research, services, and policy that reduce disparities and increase equity for underrepresented, underserved, and intersectional populations within the autism community and enhance opportunities for autistic people.

Source: GAO analysis of National Institutes of Health information (information); iiierlok_xolms/stock.adobe.com (icons). I GAO-24-106446

Notes: In addition to an aspirational goal, the strategic plan includes three recommendations to the Secretary of Health and Human Services for each topic area. For example, the three recommendations in the “Screening and Diagnosis” topic area are: (1) support research on how early detection of autism influences outcomes; (2) reduce disparities in early detection and access to services; and (3) develop and adapt screening and diagnostic tools, including tools that incorporate new technologies to increase efficiency, accuracy, and timeliness of identification.

Tangible, measurable objectives. Neither the IACC, nor NIH and National Autism Coordinator, break down goals into tangible, measurable objectives, against which actual achievement is to be compared.[39] The IACC has identified measurable goals in some of its prior strategic plans.[40] Specifically, the 2009, 2010, and 2011 strategic plans identified short-term goals to be accomplished within 1 to 5 years, long-term goals generally to be accomplished within 2 to 12 years. For example, the 2011 strategic plan identified six short-term and three long-term objectives within the topic area currently referred to as Screening and Diagnosis, and indicated the year in which the objective was added, and if it had been modified. Relatedly, for each of the short-term goals identified in the 2011 strategic plan, the 2013 strategic plan provided information on progress made, as well as remaining gaps, needs, and opportunities.

NIH officials say they no longer use this process because they found that more specific or narrowly defined goals quickly became outdated.[41] For example, NIH officials said two prior strategic plans had a goal of an agency publishing 10 reports that describe successful services and supports being implemented for people with autism. However, the agency that intended to do this work subsequently discontinued the initiative, causing the goal to become outdated, according to NIH officials. NIH officials said the current strategic planning approach—which involves establishing an aspirational goal and three recommendations within each topic area—is intended to be broad to enable a more meaningful approach to progress tracking.

In commenting on a draft of this report, HHS said they consider the recommendations to be actionable. However, the strategic plans do not clearly identify measurable steps that could be taken to implement them.

[39]For instance, the 2021-2023 Strategic Plan also includes examples of activities that could, in part, help to address each goal (referred to as recommendations), but those activities are also broad, do not fully break down the goals, and do not outline specific time frames for their completion. As an example, the goal “support research on how early detection of autism influences outcomes” identifies the following activity, but provides no additional information: “implement innovative designs to evaluate the benefit of universal screening for autism.”

[40]According to our work on evidence-based policymaking, tangible, measurable objectives also help ensure accountability by establishing performance standards which individual performance can be evaluated against.

[41]In commenting on a draft of this report, HHS noted IACC strategic plan goals can be completed in the short- or long-term. However, recent plans do not identify timeframes for their completion.

NIH officials also noted that decisions about the specific steps required to address IACC goals are made by the federal agencies through the activities they implement. An official with one private organization we interviewed told us that the IACC's strategic plan is helpful for Congress and for their autism activities. This individual noted that while the responsibility to commit to action on autism activities ultimately lies with federal agencies, the IACC is not meeting its full potential to encourage and contribute to progress made toward goals by not developing action steps or implementation plans for how federal agencies should use the strategic plan.

Ensuring Accountability

While NIH and IACC produce several reports describing federal and non-federal autism activities, we found that these reports generally do not clearly track progress against goals established through the IACC. Additionally, these reports generally do not identify where performance is lagging, and why desired results were not achieved. In particular:

- *IACC strategic plans.* In general, these plans summarized high-level progress made toward autism research and non-research activities, including within each of the seven topic areas described above.[42] However, strategic plans generally have not described how progress made relates to goals.[43] For example, the 2021-2023 Strategic Plan summarized progress made overall and in each topic area, but does not summarize progress made for each of the established goals. This plan also did not identify where performance is lagging, and why desired results were not achieved.
- *HHS Reports to Congress.* These reports provided detailed summaries of research and non-research activities that, for recent reports, occurred over a 5-year period for each federal agency with autism activities. However, reports are organized by agency and not by the seven topic areas identified in the strategic plans.[44]

[42]In the 2013 Strategic Plan, the IACC included more detailed information assessing progress, such as by tracking research spending to each of the topic areas.

[43]NIH officials stated each new strategic plan supersedes the previous plans and NIH does not continue to track all recommendations from previous plans.

[44]According to HHS, the agency organized the reports according to the authorizing legislation. NIH also notes that since these reports are not IACC products, they are not organized by the strategic plan framework of the IACC.

While some of the agency-specific sections described the relationship between certain agency activities and specific topic areas, the reports generally did not explain how agency activities help to address goals identified in strategic plans.[45] Furthermore, these reports do not identify where performance on goals is lagging, and why desired results were not achieved.

- *Portfolio Analysis Report.* In contrast to the other two reports, the portfolio analysis reports do summarize research funding by recommendation within each of the seven topic areas; however, they do not track non-research activities. Recently, these reports—the last of which was issued in 2021—have generally been issued every 2 years. In addition, in the past, these reports contained more detailed information on progress made and remaining work. Specifically, the 2014-2015 Portfolio Analysis indicated whether previously established recommendations were fully, partially, or not met, as well as an explanation of the rating. Subsequent portfolio analysis reports have not contained this information and focused primarily on descriptions of the amount and trends of projects and funding within each recommendation. NIH officials told us that the upcoming 2019-2020 Portfolio Analysis Report will indicate if research associated with a recommendation is in progress. According to NIH, the upcoming report will show that all recommendations have research that is in progress.

NIH officials said their current approach to progress tracking is driven, in part, by the processes they have established to develop these reports, two of which are required by law.[46] For example, NIH officials said the reports to Congress do not provide information on federal autism activities by goals established by the IACC because those reports are not IACC work products.

Even in the absence of tangible, measurable objectives, which our prior work shows can help progress tracking, establishing a clear process to track progress would help ensure accountability in federal autism

[45]The most recent publicly available 5-year report to Congress, the 2014-2018 Report to Congress, includes some information to help understand how agency activities relate to the seven topic areas. Specifically, it included a section for each agency titled *Interagency Coordination and Implementation of the IACC Strategic Plan*, and a section that included a table that described which agencies conducted activities for each topic area, including non-research activities. However, these sections, for the most part, do not indicate how agencies' activities addressed specific goals.

[46]See 42 U.S.C. § 280i-2(b)(6).

activities. Accountability can help encourage participation, assess progress, and make necessary changes. Clear progress tracking—including by examining how sufficiently goals are being met and whether there are remaining gaps—would allow the Secretary of Health and Human Services, federal agencies, and the public to determine progress toward IACC's goals and provide assurance that interagency efforts are effective. This could also help agencies request or allocate resources for federal autism activities where they are most needed.

NIH Takes Some Steps to Help Ensure Federal Autism Activities Are Not Unnecessarily Duplicative, but Does Not Document These Procedures

Responsibilities of the Interagency Autism Coordinating Committee and National Autism Coordinator

- Interagency Autism Coordinating Committee: Through development of strategic plan, make recommendations to ensure federal autism research activities, and, and to the extent practicable, other federal autism activities, are not unnecessarily duplicative.
- National Autism Coordinator: Ensure that autism activities of the Department of Health and Human Services and of other federal departments and agencies are not unnecessarily duplicative.

Source: See Pub. L. No. 113-157, 128 Stat. 1831 (2014) (codified at 42 U.S.C. § 280i-2) | GAO-24-106446

NIH, in support of the IACC and National Autism Coordinator, takes some steps to reduce the potential for unnecessary duplication in federal autism activities.[47] Both the IACC and National Autism Coordinator have certain responsibilities established in law for ensuring autism activities are not unnecessarily duplicative (see sidebar). NIH officials told us that its Office of National Autism Coordination, which supports the IACC and National Autism Coordinator, is unable to conduct pre-award monitoring for potential duplication in activities funded by federal agencies. This is because that office does not have access to information on projects prior to funding being awarded, according to NIH officials. Monitoring for

[47]In some instances, funding similar research on the same topic is appropriate and necessary; for example, for purposes of replicating or corroborating prior research results. We define duplication as when two or more agencies or programs are engaged in the same activities or provide the same services to the same beneficiaries.

potential duplication before activities are initiated is the responsibility of the funding agency, according to NIH officials.[48]

Questions Directed to Interagency Autism Coordinating Committee (IACC) Members Regarding Duplication

2016-2017 Strategic Plan: National Institutes of Health (NIH) asked working groups established to develop the strategic plan two questions:

- Does the working group observe any areas of this question or specific projects that appear to be duplicative?
- Does the working group have suggestions about how duplication of effort can be avoided in this area?

2021-2023 Strategic Plan: NIH sent a survey to each IACC member, which included the question:

- Are you aware of any duplicative efforts in federal autism research or services programs?

Source: GAO review of HHS documents. | GAO-24-106446

NIH, through the National Autism Coordinator and the Office of National Autism Coordination, takes the following steps, in addition to the monitoring conducted by funding agencies, to help ensure federal autism activities are not unnecessarily duplicative. NIH officials told us that these efforts have not identified any instances of duplicative autism activities.

- *Regular Discussions.* Regular discussions facilitated by NIH that occur through the IACC and FIWA provide opportunities for federal agencies funding autism activities to learn about other autism or autism-related research and non-research activities. According to the National Autism Coordinator and officials from two IACC member agencies, these information sharing opportunities minimize the risk of potential duplication. According to our prior work on managing fragmentation, overlap, and duplication, such coordination can help mitigate duplication.[49]
- *Strategic Plan Development.* In developing two of the last three IACC strategic plans, NIH asked IACC members to consider whether they

[48]For example, the NIH's extramural research program staff oversee NIH grant funding and have their own process for monitoring for potential duplication in the NIH grant portfolio, according to HHS. See app. II for more information on the monitoring efforts of federal agencies that fund autism activities. In commenting on a draft of this report, HHS noted these agency processes are the first step in the prevention of duplication.

[49]GAO-15-49SP.

had observed any potential duplication (see sidebar).[50] Members had varying responses to the questions NIH posed.

For instance, in response to the two questions asked as part of the 2016-2017 Strategic Plan development, some working groups noted that they needed more information to make assessments regarding duplication, which, according to HHS, was provided by NIH staff. Others identified areas that would benefit from enhanced coordination or believed that duplication was not a concern. In responding to the one question asked as part of the 2021-2023 Strategic Plan, multiple members did not answer or indicated that they were not aware of duplicative efforts. Other members thought duplication or replication of autism work was necessary to bolster current scientific findings; and one member did not understand what duplicative efforts meant.

Both member solicitations culminated into a "statement on duplication of effort" included in each strategic plan. The 2016-2017 Strategic Plan stated that the IACC did not find any specific instances of duplication among autism research projects funded in fiscal year 2013. However, that plan did identify a broader issue that could result in some duplication of effort, if not addressed.[51] In contrast, the 2021-2023 Strategic Plan did not include any statements regarding whether duplication was or was not found. Instead, it described the importance of replication in research to ensure reproducibility, validate findings, and build an evidence base, as well as the steps the IACC and National Autism Coordinator take to coordinate autism activities, similar to the 2016-2017 plan.

- *Portfolio Analysis Report Development.* According to NIH officials, in developing the portfolio analysis report—which summarizes information on autism research that has already been funded by federal agencies—NIH staff check if a researcher received awards for

[50]The Autism CARES Act of 2014 added a responsibility for the IACC to, through its strategic plan, make recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of HHS and of other federal departments and agencies are not unnecessarily duplicative. See Pub. L. No. 113-157, 128 Stat. 1831 (codified at 42 U.S.C. § 280i-2(b)(5)(B)).

[51]The IACC identified a need to ensure that research organizations with genetic databases were not sequencing the same individuals. The IACC encouraged organizations to publicly share information on whose DNA is in each database, to use identifiers to help researchers know when they are working with an individual who already has been sequenced, and to share data to the National Database for Autism Research. See Department of Health and Human Services, *2016-2017 Interagency Autism Coordinating Committee Strategic Plan For Autism Spectrum Disorder*. (Washington, D.C.: October 2017).

other research projects that appear to have similar titles and descriptions, which could indicate potential duplication. According to NIH officials, if NIH discovered unnecessary duplication, it would notify the relevant funding agencies. Those funding agencies would then be responsible for making a final determination of whether unnecessary duplication had occurred and what, if any, course of action would be needed.

- *Report to Congress Development.* NIH officials stated they informally monitor non-research activities supported by federal agencies for unnecessary duplication through the development of the HHS report to Congress; those activities are not captured in the portfolio analysis report. Specifically, to develop the report, NIH collects information from agencies approximately every 5 years on federal non-research autism activities. Through this data collection and the report writing process, NIH officials told us they are made better aware of federal non-research autism activities. According to NIH officials, if potential duplication of non-research activities were to be observed while developing the report, they would notify relevant funding agencies for further evaluation and action.

However, we could not corroborate the specific procedures NIH officials told us NIH staff follow in carrying out some of these steps, as NIH did not have documented policies and procedures that outlined roles and responsibilities, time frames, sources of data, and outcomes. For example, with respect to the "statement on duplication of effort" in the IACC strategic plans, NIH officials told us that they provided IACC members documentation to support their determinations, including the IACC strategic plan, the portfolio analysis report, and reports to Congress. However, documentation that NIH provided to us did not outline these procedures, or explain how NIH responded to member input.

Similarly, while NIH officials described steps staff in its Office of National Autism Coordination take to check funded research for potential duplication in response to our questions about its processes, they did not provide documentation outlining which NIH officials were involved in the process; the steps NIH officials took to complete the review, including when steps were taken; the rationale behind assessments of potential duplication; and how outcomes were documented.

Additionally, NIH shared with us varied time frames for when it requested funding information from agencies during development of the portfolio analysis report. Specifically, NIH collected information for fiscal years 2017 and 2018 separately, after each fiscal year ended, whereas the

agency collected fiscal years 2019 and 2020 together, toward the beginning of fiscal year 2022. According to an NIH official, it conducts its review for potential duplication once data are received from all agencies for each portfolio analysis report cycle, which sometimes consist of more than 1 fiscal year. Without documented policies and procedures, it is unclear whether NIH considered the implications of data collection timing on its ability to identify potential duplication as soon as practicable.

This lack of documented policies and procedures is inconsistent with federal internal control standards, which state that agency objectives should establish an organizational structure, assign responsibility, and delegate authority to achieve the entity's objectives. Through this, management should develop and maintain documentation of its internal control system. Effective documentation assists in management's design of internal control by establishing and communicating the who, what, when, where, and why of internal control execution to personnel. According to NIH officials, the agency has not developed written policies and procedures for their examination for potential duplication in federal autism activities, because they believe current monitoring processes are sufficient.

Without documented policies and procedures, we cannot determine if the steps NIH's Office of National Autism Coordination uses to mitigate the risk of unnecessary duplication in federal autism activities are properly designed and executed to provide reasonable assurance that duplication is not occurring. By documenting its procedures, the Secretary of Health and Human Services would have greater assurance that federal funding supporting autism activities was being used in the most efficient manner. Documented procedures should outline the roles and responsibilities of different entities, sources of information used for analyses and the time frames for conducting them, and how the outcomes of the procedures will be reported.

Conclusions

The federal government plays an important and growing role in coordinating and monitoring critical activities to promote the health and well-being of people with autism. These federal efforts support research to identify genetic and environmental factors, training on identification screening, technical assistance to professionals, among other topics. Efficient and effective collaboration across the 18 federal agencies that conduct autism activities is critical to ensure continued progress in addressing the varied needs of the autism community.

NIH—in support of the IACC and the National Autism Coordinator—has developed several practices to coordinate and monitor federal autism activities. However, our review identified additional ways NIH can further enhance these efforts. Clear progress tracking, including by reporting on progress toward goals, can encourage agency participation and help agencies to make necessary changes to achieve progress, such as by requesting or allocating resources for where they are most needed. While IACC's strategic plans have generally established defined goals for federal autism activities, NIH has not clearly tracked or reported progress toward these goals. The IACC no longer includes more detailed, measurable objectives in its strategic plans, which can help track and report progress. Even in the absence of measurable objectives, without clear progress tracking that indicates how goals are achieved while also identifying where performance is lagging, the Secretary of Health and Human Services, federal agencies, and the public will be unable to determine whether progress toward IACC's goals is occurring and that interagency efforts are effective.

Finally, NIH has taken some steps to help ensure federal autism activities are not unnecessarily duplicative. Although NIH officials told us they have not found duplication in federal autism activities, NIH has not documented the procedures used by its Office of National Autism Coordination, and we could not corroborate the specific procedures they follow. Without documented policies and procedures, we cannot determine if the steps NIH uses to mitigate the risk of unnecessary duplication in federal autism activities are properly designed and executed to provide reasonable assurance that unnecessary duplication is not occurring.

Recommendations for Executive Action

We are making the following two recommendations to HHS:

The Secretary of Health and Human Services should establish a process for clearly tracking and reporting progress made toward goals established by the IACC for federal autism activities, coordinating with federal partners as appropriate. Such progress tracking should describe where performance is lagging, and why desired results were not achieved, if any. (Recommendation 1)

The Secretary of Health and Human Services should ensure that NIH documents the procedures the Office of National Autism Coordination uses, in its support of the IACC and the National Autism Coordinator, to help ensure federal autism activities are not unnecessarily duplicative.

Such documentation should describe the roles and responsibilities of different entities, sources of information used, the time frames for conducting analyses, and how outcomes will be reported. (Recommendation 2)

Agency Comments and Our Evaluation

We provided a draft of the report to HHS for review and comment. The department's comments on the report are reprinted in appendix III. In its written comments, HHS concurred with both of our recommendations. In its response, HHS also reiterated the actions NIH, the IACC, the National Autism Coordination, and NIH's Office of National Autism Coordination take related to coordination and reducing the potential for duplication, which we also describe.

In its response to our first recommendation related to progress tracking, HHS noted NIH and the IACC will include new information in the portfolio analysis reports, such as an indication whether research related to the recommendations is "in progress" or "not in progress." Additionally, HHS stated that NIH and its Office of National Autism Coordination will identify other ways to enhance its progress tracking in future reports.

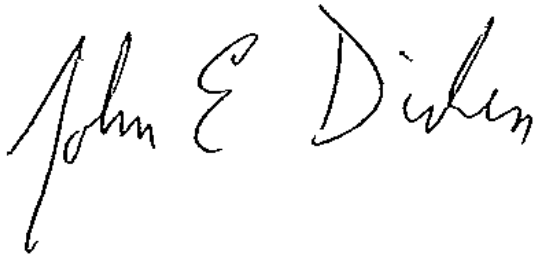
In its response to our second recommendation related to documenting the procedures used help ensure federal autism activities are not unnecessarily duplicative, HHS stated NIH and its Office of National Autism Coordination are in the process of developing such documentation. In commenting on our draft report, HHS noted that the recommendation could be misconstrued to apply to NIH's broader activities as an agency that directly funds autism-related grants and contracts. In response, we revised the wording of our recommendation to clarify that NIH should document the procedures the Office of National Autism Coordination uses to help ensure federal autism activities are not unnecessarily duplicative.

HHS also provided technical comments, which we incorporated as appropriate.

We are sending copies to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report will be available at no charge on the GAO website at https://www.gao.gov.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or DickenJ@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last

page of this report. GAO staff who made key contributions to this report are listed in appendix IV.



John E. Dicken
Director, Health Care

Appendix I: Assessment of the National Institutes of Health's Coordination of Federal Autism Activities

In our prior work, we found that many of the meaningful results that the federal government seeks to achieve require the coordinated efforts of more than one federal agency.[1] Effective interagency collaboration benefits from certain leading practices, such as bridging organizational cultures and defining common outcomes. These practices include key considerations for agency officials when working collaboratively. According to our analysis of documentation and other information we collected from the National Institutes of Health (NIH) and the other 18 federal agencies that conduct autism activities, we found NIH, in support of the Interagency Autism Coordinating Committee and National Autism Coordinator, has generally followed six and partially followed two of these eight leading practices (see fig. 4).

[1]GAO-23-105520.

Figure 4: Assessment of the National Institutes of Health's (NIH) Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Collaboration

Leading Collaboration Practices	Key Considerations	Our assessment of NIH's coordination of federal autism activities compared with leading collaboration practices
Define Common Outcomes	• Have the crosscutting challenges or opportunities been identified? • Have short- and long-term outcomes been clearly defined? • Have the outcomes been reassessed and updated, as needed?	◐
Ensure Accountability	• What are the ways to monitor, assess, and communicate progress toward the short- and long-term outcomes? • Have collaboration-related competencies or performance standards been established against which individual performance can be evaluated? • Have the means to recognize and reward accomplishments related to collaboration been established?	◐
Bridge Organizational Cultures	• Have strategies to build trust among participants been developed? • Have participating agencies established compatible policies, procedures, and other means to operate across agency boundaries? • Have participating agencies agreed on common terminology and definitions?	●
Identify and Sustain Leadership	• Has a lead agency or individual been identified? • If leadership will be shared between one or more agencies, have roles and responsibilities been clearly identified and agreed upon? • How will leadership be sustained over the long term?	●
Clarify Roles and Responsibilities	• Have the roles and responsibilities of the participants been clarified? • Has a process for making decisions been agreed upon?	●
Include Relevant Participants	• Have all relevant participants been included? • Do the participants have the appropriate knowledge, skills, and abilities to contribute? • Do participants represent diverse perspectives and expertise?	●
Leverage Resources and Information	• How will the collaboration be resourced through staffing? • How will the collaboration be resourced through funding? If interagency funding is needed, is it permitted? • Are methods, tools, or technologies to share relevant data and information being used?	●
Develop and Update Written Guidance and Agreements	• If appropriate, have agreements regarding the collaboration been documented? – A written document can incorporate agreements reached for any or all of the practices. • Have ways to continually update or monitor written agreements been developed?	●

◐ Partially followed ● Generally followed

Source: GAO analysis of information collected from NIH and other federal agencies (data); GAO (icons). | GAO-24-106446

Accessible Text for Figure 4: Assessment of the National Institutes of Health's (NIH) Coordination of Federal Autism Activities Compared with Leading Practices for Interagency Collaboration

Leading Collaboration Practices	Key Considerations	Our assessment of NIH's coordination of federal autism activities compared with leading collaboration practices
Define common outcomes	• Have the crosscutting challenges or opportunities been identified? • Have short- and long-term outcomes been clearly defined? • Have the outcomes been reassessed and updated, as needed?	Partially followed
Ensure accountability	• What are the ways to monitor, assess, and communicate progress toward the short- and long-term outcomes? • Have collaboration-related competencies or performance standards been established against which individual performance can be evaluated? • Have the means to recognize and reward accomplishments related to collaboration been established?	Partially followed
Bridge organizational cultures	• Have strategies to build trust among participants been developed? • Have participating agencies established compatible policies, procedures, and other means to operate across agency boundaries? • Have participating agencies agreed on common terminology and definitions?	Generally followed
Identify and sustain leadership	• Has a lead agency or individual been identified? • If leadership will be shared between one or more agencies, have roles and responsibilities been clearly identified and agreed upon? • How will leadership be sustained over the long term?	Generally followed
Clarify roles and responsibilities	• Have the roles and responsibilities of the participants been clarified? • Has a process for making decisions been agreed upon?	Generally followed
Include relevant participants	• Have all relevant participants been included? • Do the participants have the appropriate knowledge, skills, and abilities to contribute? • Do participants represent diverse perspectives and expertise?	Generally followed

Leading Collaboration Practices	Key Considerations	Our assessment of NIH's coordination of federal autism activities compared with leading collaboration practices
Leverage resources and information	• How will the collaboration be resourced through staffing? • How will the collaboration be resourced through funding? If interagency funding is needed, is it permitted? • Are methods, tools, or technologies to share relevant data and information being used?	Generally followed
Develop and update written guidance and agreements	• If appropriate, have agreements regarding the collaboration been documented? (A written document can incorporate agreements reached for any or all of the practices.) • Have ways to continually update or monitor written agreements been developed?	Generally followed

Source: GAO analysis of information collected from NIH and other federal agencies (data); GAO (icons). I GAO-24-106446

Note: We analyzed information from NIH and 18 federal agencies that conduct autism activities.

Appendix II: Steps Federal Funding Agencies Take to Monitor for Unnecessary Duplication in Federal Autism Activities

Federal agencies that fund autism activities described taking various actions to monitor for potential duplication before they award funding.[1] These activities include sharing or reviewing other agencies' project or grant information; communicating on an ad hoc basis with other agencies about awards and their activities; and conducting research to help inform the content and structure of upcoming projects.[2] Specific examples for three federal funding agencies are as follows.

- Department of Labor officials said they conducted literature searches on related autism activities funded by other entities prior to initiating a project focused on the identification of promising practices and policies to support employment of young adults (ages 16 through 28) with autism, known as the Research Support Services for Employment of Young Adults on the Autism Spectrum project.
- Department of Defense (DOD) officials said they search a non-public database containing information about funded and unfunded grant applications from the National Institutes of Health (NIH), the Food and Drug Administration, Centers for Disease Control and Prevention, Substance Abuse and Mental Health Services Administration, Agency for Healthcare Research and Quality, and the Department of Veterans Affairs, which allows them to identify potential overlap in research

[1]We interviewed or collected information from the National Institutes of Health and the 18 other federal agencies that conduct autism activities.

[2]Additionally, we have ongoing work—expected to be issued in early 2024—on practices used by selected HHS agencies that fund biomedical research to identify and avoid unnecessary research duplication, as well as challenges those agencies face in identifying unnecessary research duplication.

projects if not fully disclosed by applicants.[3] DOD officials told us by reviewing data within the non-public database during award negotiations in fiscal year 2021, the DOD's Autism Research Program was able to identify an identical project proposal that had also been submitted to the NIH. During discussions with the applicant, DOD determined that the overlap was too significant to be resolved. Instead, DOD was able to fund three other projects.

- NIH officials told us that their agency uses similar monitoring processes to that of DOD for autism research NIH supports financially.[4] Additionally, NIH's Center for Scientific Review recently developed a tool that could help improve such processes by using artificial intelligence and internal grant information to flag potential duplication, though all final decisions regarding duplication need human review and judgment.[5]

[3]According to DOD documentation, its science officers use DOD and NIH's internal grants management databases and other program-specific sites to investigate potential overlap between projects funded or submitted for funding to DOD as well as other federal or non-federal agencies. See DOD, "Congressionally Directed Medical Research Programs Position on Research Duplication" (Fort Detrick, MD, 2023), accessed May 23, 2023, https://cdmrp.health.mil/funding/researchDup. DOD officials told us they search NIH's Query View Report to identify potential overlap in autism research projects. According to NIH, this system contains information on both funded grants and unfunded grant applications, to include project aims and methodologies, which enables federal grant-processing staff to identify grants that deal with similar areas of science and easily identify researchers and to detect potentially duplicative grants.

In 2022, we reported on DOD's efforts to prevent duplication in research, including in autism research. We found that DOD coordinates with the Department of Veteran Affairs and NIH, and while a few DOD projects were similar in topic and methods to Department of Veteran Affairs and NIH projects, their use of internal grants management databases helped identify and prevent overlap and duplication. See GAO, *Biomedical Research: Observations on DOD's Management of Congressionally Directed Medical Research Programs*, GAO-22-105107 (Washington, D.C.: January 2022).

[4]In commenting on a draft of this report, HHS noted NIH also monitors annual progress reports from grantees for potential duplication or overlap.

[5]According to NIH officials, the Science Similarity Tool leverages artificial intelligence, machine learning, and existing grant information to quickly flag potential duplicate or overlapping applications from the same researcher. However, all final decisions regarding duplication need human review and judgment.

Appendix III: Comments from the Department of Health & Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

February 2, 2024

John E. Dicken
Director, Health Care
U.S. Government Accountability Office
441 G Street NW
Washington, DC 20548

Dear Mr. Dicken:

Attached are comments on the U.S. Government Accountability Office's (GAO) report entitled, **"AUTISM RESEARCH AND SUPPORT SERVICES: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened" (GAO-24-106446).**

The Department appreciates the opportunity to review this report prior to publication.

Sincerely,

Melanie Anne Egorin

Melanie Anne Egorin, PhD
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH & HUMAN SERVICES ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED - AUTISM RESEARCH AND SUPPORT SERVICES: FEDERAL INTERAGENCY COORDINATION AND MONITORING EFFORTS COULD BE FURTHER STRENGTHENED (GAO-24-106446)

The U.S. Department of Health and Human Services (HHS) appreciates the opportunity to review and provide comments on the Government Accountability Office's (GAO) draft report.

GAO Recommendation 1
The Secretary of Health and Human Services should establish a process for clearly tracking and reporting progress made toward goals established by the IACC for federal autism activities, coordinating with federal partners as appropriate. Such tracking should describe where progress is lagging, and why desired results were not achieved, if any.

HHS Response
HHS Concurs with GAO's recommendation regarding opportunities for improvements to the description of tracking and reporting of progress made toward Interagency Autism Coordinating Committee (IACC) goals by components of federal autism coordination, including the NIH Office of National Autism Coordination (ONAC), the National Autism Coordinator, and the IACC.

To clarify, federal advisory committees such as the IACC are advisory in nature. The IACC makes Recommendations (described in GAO Recommendation 1 as "goals") in the IACC Strategic Plan that may be taken into account by federal agencies when implementing activities. Federal agencies also use other information to inform their programmatic planning, such as Congressional requests, findings described in the research literature, and information gathered through meetings and conferences with researchers, service providers, and other relevant groups. IACC Recommendations can also be used by non-federal partner organizations to enhance autism research and services activities. Compared to previous iterations of its Strategic Plans, the IACC developed a broader set of goals, described as Objectives, for its *2016-2017 IACC Strategic Plan*; in the more recent *2021-2023 IACC Strategic Plan*, these goals are now described as Recommendations. Agency and organization activities that align with each of these Objectives/Recommendations can be short-term, long-term, or both. The IACC chose to adopt these more comprehensive goals as the designation of activities as short- or long-term did not add value, as there is not a specific sequence of how the activities should be conducted to ensure progress.

To streamline the process of monitoring these comprehensive Recommendations, the IACC now tracks the progress towards each Recommendation as either "in progress" or "not in progress" (instead of the previous rating system). If an Objective/Recommendation were to be found to be in the status of "Not In Progress", an explanation would be provided for the status, but this has not been the case to date. The total funding and number of projects aligned with each Recommendation are still reported, as was done in the previous rating system. This information is included in the data presented in the IACC Portfolio Analysis Reports, as well as the report narratives. In addition, the accompanying Autism Research Database presents the data in more interactive manner that allows a user to focus on specific Objectives/Recommendations of interest. Research and non-research federal activities that align with the IACC Strategic Plan are also detailed in periodic HHS Reports to Congress

Action Plan: Forthcoming editions of the Portfolio Analysis Report will contain additional details describing progress made toward the Recommendations of the IACC Strategic Plan. This will include a table showing the status of each of the Recommendations, as well as the number of projects and total funding for each Recommendation. All Recommendations are currently In Progress. Information on which federal agencies and non-federal organizations contributed to research funding for each Recommendation will also be included. Similarly, the *2019-2023 HHS Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities* contains a section titled "Implementation of the IACC Strategic Plan." This section provides additional details describing how the research and non-research activities of federal agencies included in the report align with the topic areas and Recommendations of the IACC Strategic Plan.

In future publications, ONAC will continue to identify ways to enhance the analysis and presentation of the detailed data that it is already collecting in order to more clearly describe progress toward IACC Strategic Plan Recommendations.

GAO Recommendation 2
The Secretary of Health and Human Services should ensure that the NIH documents the procedures that the Office of National Autism Coordination uses, in its support of the IACC and the National Autism Coordinator, to help ensure federal autism activities are not unnecessarily duplicative. Such documentation should describe the roles and responsibilities of different entities, sources of information used, the time frames for conducting analyses, and how outcomes will be reported.

HHS Response
HHS concurs with GAO's recommendation.

Federal agencies are each responsible for ensuring that awarded grants and contracts do not have funding overlap with other funders and have internal processes for monitoring for potential duplication in their grant portfolios prior to award and post-award. For example, NIH extramural research program staff oversee grant funding and have a detailed process for monitoring for potential duplication/funding overlap in the NIH grant portfolio prior to award. Annual progress reports from NIH grantees are also monitored for potential duplication/funding overlap. Other examples of agency procedures for monitoring for duplication/funding overlap are provided in Appendix II of this GAO Report. These agency processes are the first step in prevention of duplication. ONAC and the National Autism Coordinator monitor the federal autism research portfolio for duplication, providing a secondary check to further ensure non-duplication of effort.

As stated in the 2021-2023 IACC Strategic Plan, the IACC believes that in the case of scientific research, coordinated efforts by multiple public and private agencies to fund different types of projects within the same topic area represent cooperation and collaboration. Replication contributes to efficiency in research funding by ensuring the creation of a solid base of validated findings that establish the rationale for later-stage, larger, and potentially more costly research efforts. Replication of research is thus valuable and should not be considered duplication of effort. However, as GAO notes, it is also important to provide assurance that federal funding supporting autism activities is being used in the most efficient manner.

The IACC is required under the Autism CARES Act of 2019 to monitor autism research, and to the extent practicable services and support activities, across all relevant federal departments and agencies, including coordination of federal autism activities. Complementarily, the National Autism Coordinator is required to ensure that autism activities of the Department of Health and Human Services and of other federal departments and agencies are not unnecessarily duplicative.

As has been described to GAO during this engagement, there are ONAC procedures in place to monitor autism research activities for unnecessary duplication. During the development of the IACC Portfolio Analysis Report, ONAC staff request research funding data from multiple federal and non-federal funders. The data collected is compiled into a spreadsheet that is then analyzed to identify funding trends. ONAC staff also review the compiled Portfolio Analysis spreadsheet for potential instances of unnecessary duplication, which could include multiple projects awarded to the same investigator or projects with similar titles and/or abstracts.

If potential duplication were to be identified among funded projects collected in the portfolio analysis effort, ONAC would next perform a check to determine whether the projects are co-funds (a single project that are co-funded by 2 or more agencies) or supplements to existing projects. Co-funds and supplements would not be considered unnecessary duplication.

If potential duplication of effort were to be identified, the National Autism Coordinator/ONAC Director would notify the involved funding agency/agencies. The involved agency/agencies would then be responsible for determining if actual duplication had occurred and what course of action is needed/appropriate.

To date, no instances of unnecessary duplication have been identified by ONAC staff. As described in this GAO Report, the National Autism Coordinator also helps ensure non-duplication of effort across federal agencies by convening agencies to meet on a regular basis to discuss their activities and mutual areas of interest, engage in collaborative projects, and share agency updates.

As noted by GAO, collection of research and non-research funding data by ONAC staff for the Portfolio Analysis Reports occurs after awards are made. This is necessary, as neither the IACC, the National Autism Coordinator, nor ONAC staff have access to pre-award information from across the federal government. ONAC staff can only monitor for duplication after awards are made, using publicly available information such as abstracts. As has been previously stated to GAO, determination of grant overlap issues prior to award is within the purview of the federal agencies that issue grants, as only they have the authority and access to the full grant application, including confidential information, to make more detailed determinations prior to award. As described above, ONAC's monitoring for duplication post-award serves as a secondary check of the projects after initial checks are performed by funding agencies as they make awards and check annual progress reports.

The timeframe for collection of funding data by ONAC staff post-award is affected by several factors, including the size of the portfolio and the number of funders involved in the analysis, the amount of time it takes federal agencies and non-federal partner organizations to finalize their

data, and the need for ONAC staff to balance portfolio analysis efforts with other statutory responsibilities assigned to the ONAC for the IACC and National Autism Coordinator, such as development of strategic plans, summaries of research advances, convening of IACC meetings, and reports to Congress.

Action Plan: During this GAO engagement, ONAC staff have provided summaries and documentation describing our procedures to monitor for duplication. ONAC staff are in the process of developing enhanced documentation of these procedures, which will describe the roles and responsibilities of different entities, sources of information used, the time frames for conducting analyses, and how outcomes will be reported.

Accessible Text for Appendix III: Comments from the Department of Health & Human Services

February 2, 2024

John E. Dicken
Director, Health Care
U.S. Government Accountability Office
441 G Street NW
Washington, DC 20548

Dear Mr. Dicken:

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Assistant Secretary for Legislation

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HHS Response
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As stated in the 2021-2023 IACC Strategic Plan, the IACC believes that in the case of scientific research, coordinated efforts by multiple public and private agencies to

fund different types of projects within the same topic area represent cooperation and collaboration. Replication contributes to efficiency in research funding by ensuring the creation of a solid base of validated findings that establish the rationale for later-stage, larger, and potentially more costly research efforts. Replication of research is thus valuable and should not be considered duplication of effort. However, as GAO notes, it is also important to provide assurance that federal funding supporting autism activities is being used in the most efficient manner.

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As has been described to GAO during this engagement, there are ONAC procedures in place to monitor autism research activities for unnecessary duplication. During the development of the IACC Portfolio Analysis Report, ONAC staff request research funding data from multiple federal and non-federal funders. The data collected is compiled into a spreadsheet that is then analyzed to identify funding trends. ONAC staff also review the compiled Portfolio Analysis spreadsheet for potential instances of unnecessary duplication, which could include multiple projects awarded to the same investigator or projects with similar titles and/or abstracts.

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If potential duplication of effort were to be identified, the National Autism Coordinator/ONAC Director would notify the involved funding agency/agencies. The involved agency/agencies would then be responsible for determining if actual duplication had occurred and what course of action is needed/appropriate.

To date, no instances of unnecessary duplication have been identified by ONAC staff. As described in this GAO Report, the National Autism Coordinator also helps ensure non- duplication of effort across federal agencies by convening agencies to meet on a regular basis to discuss their activities and mutual areas of interest, engage in collaborative projects, and share agency updates.

As noted by GAO, collection of research and non-research funding data by ONAC staff for the Portfolio Analysis Reports occurs after awards are made. This is

necessary, as neither the IACC, the National Autism Coordinator, nor ONAC staff have access to pre-award information from across the federal government. ONAC staff can only monitor for duplication after awards are made, using publicly available information such as abstracts. As has been previously stated to GAO, determination of grant overlap issues prior to award is within the purview of the federal agencies that issue grants, as only they have the authority and access to the full grant application, including confidential information, to make more detailed determinations prior to award. As described above, ONAC's monitoring for duplication post-award serves as a secondary check of the projects after initial checks are performed by funding agencies as they make awards and check annual progress reports.

The timeframe for collection of funding data by ONAC staff post-award is affected by several factors, including the size of the portfolio and the number of funders involved in the analysis, the amount of time it takes federal agencies and non-federal partner organizations to finalize their data, and the need for ONAC staff to balance portfolio analysis efforts with other statutory responsibilities assigned to the ONAC for the IACC and National Autism Coordinator, such as development of strategic plans, summaries of research advances, convening of IACC meetings, and reports to Congress.

Action Plan: During this GAO engagement, ONAC staff have provided summaries and documentation describing our procedures to monitor for duplication. ONAC staff are in the process of developing enhanced documentation of these procedures, which will describe the roles and responsibilities of different entities, sources of information used, the time frames for conducting analyses, and how outcomes will be reported.

Appendix IV: GAO Contact and Staff Acknowledgments

GAO Contact:

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Staff Acknowledgments:

In addition to the contact named above, Shannon Legeer, Assistant Director; Colin Ashwood, Analyst-in-Charge; Caylin Rathburn-Smith; and Kirby Callaway made key contributions to this report. Also contributing were Sam Amrhein, Roxanna Sun, Eric Peterson, Diona Martyn, Monica Perez-Nelson, Sarah Veale, Justin Snover, Hayden Huang, Michael Murray, and Scott Spicer.

Related GAO Products

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