

Easy Read

# Strengthening Coordination and Monitoring of Autism Activities in the Federal Government

March 2024 | GAO-24-107314

Accessible Version



U.S. GOVERNMENT ACCOUNTABILITY OFFICE

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This is an **Easy Read** version of a report we wrote. **Easy Read** is a way that some groups have made their written information easier to understand. This can include shorter sentences or simpler language.



In this document, certain words are in **bold**. We explain what these words mean in the sentence after they have been used.



Some words are [blue and underlined](#). These are links that will go to GAO reports, which have more information.



### Why is GAO creating this document?

We wrote a report related to **autism**. **Autism** is a developmental disability that can affect how some people interact with and experience their environment.

We created this Easy Read version to make our work more accessible to certain people with autism and intellectual and developmental disabilities. This document is one way we are working for full inclusion of people with disabilities.



You can see the full report on our website, at: [\*Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened.\*](#)

To prepare the full report, we read through information from the National Institutes of Health and talked to people who work there about how they complete their work. We also collected information from the other **agencies** that work on autism activities. **Agencies** are government offices. For more information on our approach, see the full [report.](#)

# GAO and Congress



### What is GAO?

The Government Accountability Office, or GAO, is part of the legislative branch of the United States government. We are an independent agency that works for Congress. We help keep Congress informed about how agencies are working. If we find ways agencies can work better, we can make **recommendations**.

**Recommendations** are ideas of changes agencies should make to their activities.

### What was GAO asked by Congress to do?

Congress asked us to look at how the agencies that study autism or that provide support to people with autism work together.



# The Federal Government's Role



### What do federal agencies do to help individuals with autism?

Many agencies work on activities to help people with autism. These activities can include a lot of things. We do not list them all here. A few examples include looking into what causes autism, teaching people about autism, and caring for people with autism.

You can read about some ways agencies help people with autism in Figure 1 of our full report [here](#).

# The Federal Government's Role



### **What is the National Institutes of Health (NIH)?**

The National Institutes of Health (NIH) is a U.S. agency that studies human health. It also gives researchers money to study medical topics like autism. NIH is part of a bigger government agency called the Department of Health and Human Services (HHS).



# The Federal Government's Role



### **What is the Interagency Autism Coordinating Committee?**

The Committee is a group of people from many agencies who work on autism activities. The Committee also includes people who are not part of the U.S. government. For example, people with autism and their family members are on the Committee. Other examples of people on the Committee are people outside the government who study autism, such as doctors or scientists.

## The Federal Government's Role

**The Committee is made up of people from:**

### Agencies

#### Department of Health and Human Services

- Administration for Children and Families
- Administration for Community Living
- Agency for Healthcare Research and Quality
- Centers for Disease Control and Prevention
- Food and Drug Administration
- Health Resources and Services Administration
- Indian Health Service
- National Institutes of Health
- Substance Abuse and Mental Health Services Administration

#### 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

### Outside the government

Individuals with autism

Parents or legal guardians of individuals with autism

Representatives of leading research, advocacy, and service organization for individuals with autism

Source: GAO analysis of National Institutes of Health information. | GAO-24-107314

# The Federal Government's Role



### Who is the National Autism Coordinator?

The Autism Coordinator is a person who helps make sure agencies with autism activities know what each agency is doing. Another job of the Autism Coordinator is to help make sure agencies are not doing the same autism activities without a good reason. Sometimes it is OK for agencies to do the same activities. Other times it is not OK because it could be a waste of government resources.

### What role does NIH have with autism activities?

NIH manages the Committee. The Autism Coordinator also works for NIH.

### What is in this report?



#### **This report looks at 2 things:**

1. How NIH helps the Committee and Autism Coordinator make sure all agencies know about all of the autism activities being worked on.
2. How NIH checks that agencies do not work on the same autism activity without a good reason.

## Leading Interagency Collaboration Practices



### What are the Leading Interagency Collaboration Practices?

GAO has come up with some actions that agencies should take to make sure they are working well together. These actions are called **Leading Interagency Collaboration Practices**. Interagency collaboration means getting different agencies to work together and share information with each other. Sometimes, it is better for agencies to work with each other instead of trying to do some activities alone.



There are 8 practices. They are connected, support each other, and do not occur in a specific order. In this Easy Read version, we describe the practices in the same order as our [report](#).

## Leading Interagency Collaboration Practices

What are the 8 Leading Interagency Collaboration Practices?



**Bridging Organizational Cultures**



**Including Relevant Participants**



**Leveraging Resources and Information**



**Identifying and Sustaining Leadership**



**Clarifying Roles and Responsibilities**



**Developing and Updating Written Guidance and Agreements**



**Defining Common Outcomes**



**Ensuring Accountability**

## Leading Interagency Collaboration Practices



The following sections describe each Leading Interagency Collaboration Practice. They also show some of the related questions agencies or others should ask. The sections also include examples from our full Autism [report](#) on what we found.

In this Easy Read version, we have rewritten the questions. That means some of the details about how to use these practices have been omitted or simplified.

For a complete description of the practices and how they can be applied, you can see the original report on these practices on our website, at: [Government Performance Management: Leading Practices to Enhance Interagency Collaboration and Address Crosscutting Challenges](#).

### Bridging Organizational Cultures



#### What did we ask?

Have agencies come up with ways that help them work together?



#### What did we find?

NIH takes action to help agencies work together. This includes holding meetings with both agencies and other organizations that are not part of the U.S. government. During meetings, agencies tell others about their autism activities. The Coordinator can also use the meetings to update agencies and others about federal and non-federal autism activities.



### Including Relevant Participants



#### What did we ask?

Do participants come from different points of view and have the right skills?



#### What did we find?

NIH has made sure the people involved in the Committee come from different backgrounds. Since 2014, the Committee has added 6 agencies and 5 people that do not work for the federal government. This has increased what the Committee knows about the types of activities agencies are working on, and what people with autism need.

### Leveraging Resources and Information



#### What did we ask?

Are ways for sharing data and information being used?



#### What did we find?

NIH created ways to share information from agencies and others working on autism activities. NIH has continued to update how it does this. These actions have resulted in many resources on autism activities. These resources include reports to Congress and a Committee website.

You can read about autism-related resources developed by NIH in Table 1 of our full report [here](#).

## Identifying and Sustaining Leadership



### What did we ask?

Who is in charge?



### What did we find?

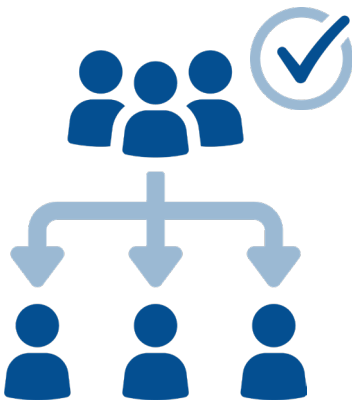
NIH staff lead and support the Committee and the Autism Coordinator. Some agencies said the Autism Coordinator leads meetings that are helpful to everyone involved.

## Clarifying Roles and Responsibilities



### What did we ask?

Have all roles and duties been made clear to everyone involved?



### What did we find?

NIH provides information to new Committee members so they understand their roles and duties. NIH also created guidance for agencies to explain the information NIH collects from them.

## Developing and Updating Written Guidance and Agreements



### What did we ask?

Have ways for working together been written down?



### What did we find?

NIH created a document that lays out the roles and duties of the Committee. The document also explains the Committee's goals and its activities.

### Defining Common Outcomes



#### What did we ask?

Have short- and long-term goals been clearly defined?

Have goals been examined and changed, as needed?

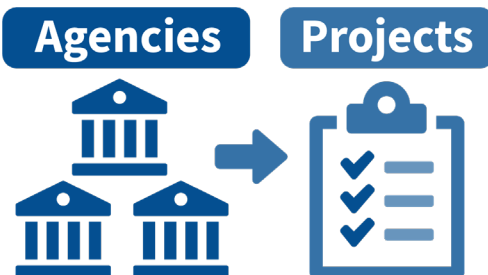
In addition, we have other past work that says agencies should break down goals into specific tasks that can be tracked and measured.



#### What did we find?

The Committee has created goals for autism activities. These goals can help agencies and organizations that are not part of the U.S. government plan their autism activities. From time to time, the Committee takes a look at the goals and decides if they need to be updated.

### Defining Common Outcomes



However, the Committee and NIH do not break down the goals into specific tasks that can be tracked and measured. Having these types of targets would help determine if agencies are making progress on the goals.

In the past, the Committee set short-term and long-term goals that could be used to measure progress. But NIH officials say they no longer do so because they found that the goals quickly became outdated.

NIH officials also said each agency—not the Committee—decides what specific autism activities should begin.

### Ensuring Accountability



#### What did we ask?

How do agencies track and tell others about progress on their short- and long-term goals?

In addition, we have other past work that says agencies should clearly tell others how they are doing on their goals and why.

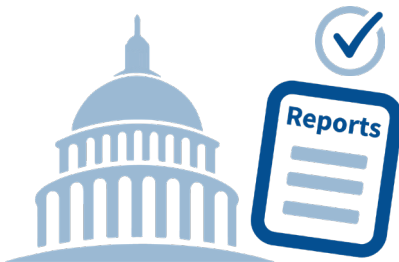


#### What did we find?

NIH and the Committee put together three reports on autism activities taking place both in the government and outside of the government. These reports provide some updates on activities that relate to the Committee's autism goals.



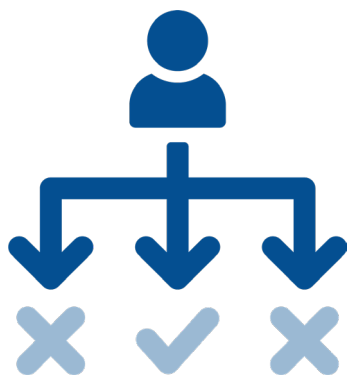
### Ensuring Accountability



The three reports are:

- **Committee strategic plans.** The plans talk about progress made in research studies and other autism activities.
- **Reports to Congress.** These reports come out every 5 years and tell Congress what autism activities have taken place.
- **Portfolio Analysis Reports.** These reports only talk about research studies about autism.

### Ensuring Accountability



#### What else is needed?

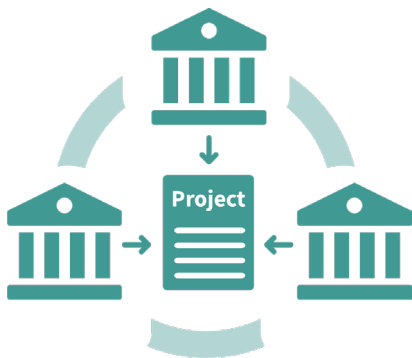
NIH could find other ways to track progress on the Committee's autism goals and to identify any problems reaching goals. This would help make sure agencies and others with autism activities understand the types of steps being taken on Committee goals. This would also help show where there may be gaps.

#### What did GAO recommend?

We recommended that HHS report progress made on autism activities and compare them to the goals that were set by the Committee. If goals are not being met, these reports should say so and explain why. (Recommendation 1)

HHS agreed with this idea.

## Addressing Unnecessary Duplication in Federal Autism Activities



### Duplication



### Unnecessary Duplication



### What is unnecessary duplication?

**Duplication** can mean doing the same thing that someone else has already done or is doing right now. For example, two agencies might be studying the same thing about autism.

Sometimes it is OK if agencies are studying the same thing. Doing the same thing on purpose to make sure you get the same results is OK.

But sometimes, it is not OK because it is **unnecessary duplication**. **Unnecessary duplication** is when two groups study the same thing without a good reason. That could be a waste of government resources.

## Addressing Unnecessary Duplication in Federal Autism Activities



**What are the ways the NIH, the Committee, and the Autism Coordinator check to make sure there is not unnecessary duplication in federal autism activities?**

The Committee and the Autism Coordinator are both responsible for making sure agencies are not working on the same autism activities without a good reason. NIH's Office of National Autism Coordination helps them with this responsibility.

Also, NIH officials said that checking for potential duplication before autism activities begin is the responsibility of the agencies that fund those activities.

# Addressing Unnecessary Duplication in Federal Autism Activities



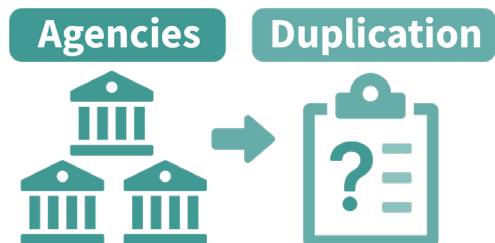
There are a couple ways NIH helps check for potential duplication after autism activities begin.

**Regular Discussions:** The Committee meets on a regular basis. This gives agencies a chance to learn about what activities other agencies are working on.

**Reports:** NIH officials create reports that describe what autism activities are being funded by agencies. NIH can use these reports to see if autism activities seem similar.

NIH officials said they have not found any duplication in autism activities. If they had, they would have contacted the agencies that funded the activities. Then, those agencies would have to decide how, or if, those activities should continue.

# Addressing Unnecessary Duplication in Federal Autism Activities



But we were not able to determine the exact ways the NIH’s Office of National Autism Coordination helps check for duplication.

That is because NIH does not write down the steps it takes.

For example, NIH did not give GAO any written guidance that showed:

- Who checked to make sure agencies were not working on the same activities.
- The reasoning that went into deciding if activities were the same.
- How the results of these checks would be written down.

## Addressing Unnecessary Duplication in Federal Autism Activities



### What else is needed?

Without written guidance, GAO could not tell if the steps NIH follows are good enough to reduce the risk that agencies are working on the same activities without a good reason.

By writing these steps down, HHS would have a better idea that resources used on autism activities are being used wisely.

### What did GAO recommend?

We recommended that NIH write down the steps its staff in the Office of National Autism Coordination use to check for possible duplication. This should include what information sources are used to check for duplication, when the checks are done, and what was found. (Recommendation 2.)

HHS agreed with this idea.

## GAO's Commitment to People with Disabilities

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In line with GAO's core values, we work for full inclusion of people with disabilities. We show our commitment to the disability community through accessibility efforts for our employees and the public who read our reports.

Additionally, GAO has provided Congress with analysis of accessibility and disability issues in several areas, including veterans with disabilities, health care access, voting, disability benefits, equal employment opportunity, and more.



## GAO Contact and Staff Acknowledgments



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### Staff Acknowledgments

In addition to the contact named above, Shannon Legeer, Assistant Director; Colin Ashwood, Analyst-in-Charge; Sam Amrhein; Maria McMullen; Michael Murray; and Caylin Rathburn-Smith made key contributions to this report. Also contributing were Hayden Huang, Susan Murphy, Monica Perez-Nelson, and Sarah Veale.

## Appendix

### Additional Sources for Images

This appendix contains source information for images in this product when such information was not listed adjacent to the image.

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