

Burden Statement

Public reporting burden for this collection of information is estimated to average 15 minutes per response¹, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0682*). Do not return the completed form to this address.

Guidance for Submitting and Coding 20XX Autism Research Funding Data

The Interagency Autism Coordinating Committee (IACC), in order to perform the monitoring of autism spectrum disorder (ASD) activities mandated by the Combating Autism Act and to inform the next annual update of the Strategic Plan for ASD research, is asking agencies and organizations that make significant contributions to ASD research to report how their 20XX investments in ASD research correspond to the questions and research objectives of the [2011 IACC Strategic Plan](#)². This will greatly help the IACC to understand the current funding landscape and identify areas of progress, opportunity and need. To view the analysis that was conducted using the 2010 ASD research project data collected last year, please see the [2010 Autism Spectrum Disorder Research Portfolio Analysis Report](#).

Overview:

The [2011 IACC Strategic Plan](#) is organized around seven critical questions faced by people and families living with ASD:

- Question 1 (Diagnosis) – When should I be concerned?
- Question 2 (Biology) – How can I understand what is happening?
- Question 3 (Risk Factors) – What caused this to happen and can it be prevented?
- Question 4 (Treatments and Interventions) – Which treatments and interventions will help?
- Question 5 (Services) – Where can I turn for services?
- Question 6 (Lifespan Issues) – What does the future hold, particularly for adults?
- Question 7 (Infrastructure and Surveillance) – What other infrastructure and surveillance needs must be met?

The “20XX ASD Research Spreadsheet” accompanying this guidance contains a listing of projects provided by your organization to the IACC for the previous fiscal year, as well as space for you to include projects that were newly funded in 20XX. On behalf of the IACC, the Office of Autism Research Coordination (OARC) is requesting

¹ Please note that the use of the word 'response' in the Burden Statement refers to each individual project that is reported, and not the data call in its entirety

² The *IACC Strategic Plan* research objectives were last modified in the *2011 IACC Strategic Plan*. Since then, the IACC has issued *Strategic Plan Updates for 2012 and 2013*, but without changes to the objectives. Thus, the objectives listed in the *2011 Strategic Plan* are currently used for project coding and analysis activities.

information on your organization's 20XX projects. This would include all ongoing and newly funded projects from 20XX (either fiscal year 20XX or calendar year 20XX, whichever measure is used by your organization). Please refer to the instructions below to fill out the 20XX ASD Research spreadsheet. In deciding which projects to include in the spreadsheet, please list all projects that are responsive to objectives in the [2011 IACC Strategic Plan](#). In cases where potentially relevant projects that were new in 20XX could be identified through websites or online databases, OARC pre-populated the spreadsheet with these projects and provided draft coding for agency review. Projects may be added or deleted, and revised coding may be suggested as needed.

In the past, some funders had questions regarding projects that pertain to Objectives 5LC and 5LE, which involve practitioner training. In response to these questions, we have the following additional guidance: For these objectives, please include projects that are related to evaluating pre-service or in-service training for service providers. This may include projects that are launching, piloting or testing new or innovative services practitioner training approaches in community based settings, evaluating the effectiveness of these programs in order to improve service practitioner training efforts, and/or contributing to the evidence base supporting various practitioner training methods. This may also include efforts to test new or innovative services approaches in various settings, make improvements in services methodologies, test effectiveness, develop best practices and improve targeting and dissemination of services. Many of these projects may be focused on practical, field-based and community-based approaches used by services agencies and organizations in their efforts to improve services. When including these projects, please be sure to note the evaluative component in the project description to ensure that the projects that are included are designed to test and improve programs rather than simply to administer them (service provision). If you have any questions about whether a particular project should be included, please feel free to contact OARC for assistance.

Instructions:

1) Verify information for ongoing projects

All of the information for autism research projects that was provided by your organization for the previous year is already in the spreadsheet in the second tab labeled "20XX ASD Projects." Please review this information for accuracy and fill in additional information where required in the following columns:

- **Project Status in 20XX:** If a project had any funding or any project activity at any time in 20XX, then please use the drop-down box to list the project as "Ongoing." If there was no funding or project activity in 20XX, then please use the drop-down box to list the project as "Terminated."
- **Award Period:** Please verify the year or years that funding will be awarded for this project. For example, if a grant was awarded in 2008 and is set to continue through 2013, then the "Award Period" would be 2008-2013.
- **New or Revised Weblink/New or revised Project description:** Please fill out only if any information has changed from 2012.
- **20XX Funding:** Please fill in the 20XX funding amount (if applicable).
- **20XX PA Question/20XX PA Objective:** Please also verify the coding of each project according to the *2011 IACC Strategic Plan*. The coding from the previous year is listed (in the "Previous SP Question Code" and "Previous SP Objective Code" columns) and has been carried over into the columns for the 20XX Portfolio Analysis. If you feel that the coding should be the same, then no action is required on your part. If you would like to change the code for a project, please use the drop down boxes in the Alternate SP Question and Objective Code columns to select first the Question and then the Objective that you think best describes the project according to the *IACC Strategic Plan*. Please include a note in

the “Comments” column to explain the reason(s) for the change in coding. For your convenience, a Coding Reference Sheet is in the first tab of the spreadsheet and lists all of the Strategic Plan objectives.

Please Note: If other aspects of a project have changed since 20XX (e.g., PI, Project Title, Institution), please do not alter the information in these cells; instead, provide revised data in the “Comments” column in the spreadsheet. Please ignore any cells that are blacked out; you do not need to put any information in that column.

2) Provide information on projects that are new in 20XX

Also in the second tab, labeled “20XX ASD Projects,” is space to list all the **new** projects funded by your organization in 20XX. This new project data should be entered in rows below the ongoing project data. The beginning of this section for data entry can be found by looking for rows that have a **yellow highlighted cell** on the far left. These cells indicate that all new project information should be entered into the adjacent cells to the right. Please fill in the missing information in the green cells for each project. The **Project Status in 20XX** (“New”) has been filled in for you in **Column C**. If you know of any projects that are ongoing that were inadvertently left out of the 20XX Data Call, please provide them in these rows as well, and choose “Ongoing” from the drop-down options for Project Status. ****Note that for projects new in 20XX that could be identified online, OARC has pre-populated the spreadsheet with these projects. Please fill in all of the required columns to the best of your ability according to the instructions above, including:**

- **Project Status in 20XX:** This has been auto-populated to “New”.
- **Award Period:** Please fill in the column for start date and the column for end date. If available, use specific dates and not just the year.
- **20XX Funding:** Please fill in the 20XX funding amount, if the project was active but did not receive funding fill in \$0.
- **Project Description and Weblink:** A short, accurate project description (a few sentences is enough) or a weblink to a site where a project description can be found is very useful for verifying coding of the projects, as well as helping readers understand the activities included in the projects. If no project description or weblink is available, please type “Project description/weblink unavailable.”

Columns where previous information does not exist for new projects, such as 20XX funding, previous project descriptions or last year’s codes, have been blacked out. You need not put any information into these cells for the new projects.

For some organizations with publicly available databases, OARC has pre-populated the spreadsheet with new projects that began in 20XX that were identified from the database as potentially being related to ASD research. We have made every attempt to include as much available data as possible as well as provide suggested objective and question coding. Please review these projects and revise the list as needed, supplementing any missing and/or incorrect data as well as adding additional projects if necessary.

Coding

In previous years, OARC has requested that funders code each project according to the objectives in the IACC Strategic Plan. **To reduce the burden on agencies and organizations participating in the IACC portfolio analysis data collection , the Office of Autism Research Coordination (OARC) is offering the option to have organizations send their new project listings to OARC to assign preliminary codes, and then for OARC to return the coding to the organization for verification. Hopefully this second option may reduce the effort required of**

organizations to determine which code best fits each project. If you would like to take advantage of this opportunity, please follow the procedure below:

Instructions for obtaining pre-coding of new projects from OARC:

If you would like OARC to assign preliminary codes for new 20XX projects, then simply leave the 20XX Suggested and Alternate Strategic Plan (SP) Question and Objective Code columns blank and return the spreadsheet with a note stating that you would like the office to assign codes. Once OARC has assigned preliminary codes to the Suggested SP Question and Objective Code columns, the office will return the spreadsheet to you for coding verification. Once you receive the list of projects with preliminary coding added, you may review the coding and determine whether you would like to keep the preliminary codes or suggest alternate codes in the Alternate SP Question and Objective coding columns.

Instructions for organizations that wish to do the preliminary coding of their own projects:

If, instead, your organization would prefer to assign the codes, then you may use the drop-down boxes in the 20XX SP Question and Objective Code columns to assign first the Question and then the Objective that best describes each project according to the Strategic Plan (the assignments must be made in that order). If a project is not specific to Plan objectives, then you may select that option from the drop-down menu. A project may also fit within a question but not a specific objective, in which case you can select the appropriate Question followed by "Not specific to Question X objectives" in the Objective column.

3) Provide information regarding other projects if applicable

If you are aware of additional projects funded by your organization that may address a broader scientific scope (e.g., that may include autism but are not limited to autism, such as projects pertaining to multiple disabilities or disorders) but still have relevance to autism or the IACC Strategic Plan for Autism Disorder Research, please provide the project information in the "other project" tab. These projects will not be included in the autism research projects listing for your agency or organization and their funding will not be included in your agency's or organization's total for autism spending, but summary information about these projects may be made available to the IACC for their information and to the public via the IACC Portfolio Analysis Report, with the goal of informing the community of additional projects that may have relevance to autism research.

4) Please submit completed ASD Research Spreadsheet by xxxx.

Send your completed ASD Research Spreadsheet to Dr. Susan Daniels, Director, Office of Autism Research Coordination, National Institute of Mental Health by email at sdaniels@mail.nih.gov .

Please direct questions about this request to:

Dr. Susan Daniels

Director

Office of Autism Research Coordination (OARC)

National Institute of Mental Health

sdaniels@mail.nih.gov

Phone: 301-443-2756