**ATTACHMENT F:**

**RESEARCH NETWORK QUESTIONNAIRE**

Public Burden Statement:  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.  The OMB control number for this project is 0915-0335. Public reporting burden for this collection of information is estimated to average 3 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10‑29, Rockville, MD, Maryland, 20857

**Combating Autism Act Initiative (CAAI)**

**Autism Intervention Research Networks**

**Data Collection Form**

***AIR-B/AIR\_P: 2-Year Reporting Period: September 1, 2011 – August 31, 2013***

***DBPNet: 3 Year Reporting Period: September 1, 2010 – August 31, 2013***

1. **CONDUCT RESEARCH ON ASD INTERVENTIONS**

In the following table, please document your Network’s progress in completing the originally proposed studies, developing and implementing additional studies, as well as in obtaining leveraged funding during this 2 (or 3 in the case of DBP net) year period.

|  |  |
| --- | --- |
| **Activity** | **Total Number** |
| **Research Proposals Developed** |
| Number of research proposals developed/supported with Network funding |  |
| Number of research proposals developed/supported with leveraged funding |  |
| **Status of Research Protocols supported with CAAI Network funding ONLY (not leveraged funding)** |
| A: Number of studies approved by the Network, but not yet started |  |
| B: Number of studies in progress |  |
| C: Number of studies completed |  |
| **Total number of studies supported with Network funding (A + B + C)** |  |
|  |  |
| **Status of Research Protocols supported with Leveraged funding** |  |
|  A: Number of studies funded, but not yet started |  |
|  B: Number of studies in progress |  |
|  C: Number of studies completed |  |
| **Total leveraged studies funded (A + B + C)** |  |
| **Sustainability of Projects** |
| Number of studies with mix of CAAI funding and funding from another source**\*** |  |
| Dollar amount of outside funding obtained as a consequence of the CAAI funds (e.g., leveraged funding) |  |

*\*Note: This is for informational purposes and is not a program requirement. Please put N/A if not applicable.*

Below, we provide a list of the studies conducted using only CAAI funding and leveraged funding. Please:

1. Review and correct any information listed.
2. Add the number of participants [families or children] recruited or anticipated to be recruited for each study [last column].
3. Add any new studies to the blank rows at the bottom of the table.
4. Include all studies active during or since 2011 (or 2010 for DBPNet).

***Note: Please make sure the studies listed in the table below match the number of studies reported in the table above.***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Study Title**  | **Goal of Study** | **Current Status (e.g. Proposal under development, study start up phase, in recruitment, recruitment ended still collecting data, all data collected/still undergoing analyses )** | **Anticipated Final Products** | **Number of Participants [Families or Children] Recruited\*** |
| 1. |  |  |  |  |  |
| 2. |  |  |  |  |  |
| 3. |  |  |  |  |  |
| 4. |  |  |  |  |  |
| 5. |  |  |  |  |  |
| 6. |  |  |  |  |  |
| 7. |  |  |  |  |  |

*\* Note: If recruitment efforts are not completed, insert PLANNED number, otherwise input ACTUAL number.*

Please review the following information and add/remove appropriate checks to the table. Please add a row for each study not listed.

***Note: Check all that apply. Please make sure the list of studies matches those listed on P.2. Please check only if the study includes more than 30% of enrolled participants in the population group. If the study is not done recruiting, then check if the anticipated number of enrolled participants is over 30%. Consider each population group separately.***

|  | **Study Title**  |  | **UNDERSERVED POPULATION** |
| --- | --- | --- | --- |
| **Hispanic** | **African-American** | **Low-Income** | **Rural** | **Other Underserved Population Group** |
| 1 |  |  |  |  |  |  |  |
| 2 |  |  |  |  |  |  |  |
| 3 |  |  |  |  |  |  |  |
| 4 |  |  |  |   |  |  |  |
| 5 |  |  |  |  |  |  |  |
| 6 |  |  |  |  |  |  |  |

Please detail your efforts to serve minority and underserved populations and to engage with families.

|  |  |
| --- | --- |
| **Reducing Barriers for Families and Underserved Populations** | **Number of Studies** |
| **Minority and Underserved Populations** |
| Number of studies that are responsive to the cultural and linguistic needs of special populations |  |
| Number of studies listed in above table having one or more underserved category as over 30% of study participants.  |  |
| **Engage in Family-Centered Activities** |
| Number of studies where parents have been consulted over the course of the study, such as in the study design, the design of the instruments, or the interpretation of the results |  |
| Number of parents involved in study process |  |

Please review the following information and add/remove appropriate checks to the table. Please add a row for each study not listed.

***Note: Check all that apply.*** ***Please make sure the list of studies matches those listed on P.2***

|  | **Study Title**  |  | **TOPIC OF STUDY** |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **GI Issues** | **Sleep** | **Diet/****Nutrition** | **Social Skills; Engagement/ Communication** | **Anxiety/ Depression** | **Adult Transi-tion** | **Standardizing Care Practices** | **Disparities to access and early intervention**  | **Clinical Practice Variation** | **Other Topic** |
| **HOME or FAMILY BASED** | **SCHOOL or COMMUNITY BASED** |
| 1 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 2 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 3 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 4 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 5 |  |  |  |  |  |  |  |  |  |  |  |  |  |
| 6 |  |  |  |  |  |  |  |  |  |  |  |  |  |

In the following table please document your Network’s progress in developing publications and scientific conference presentations during this 2 year period.

| **Publication Activities** | **Total Number** |
| --- | --- |
| **Publications in Process** |  |
|  A: Number of manuscripts in preparation |  |
|  B:Number of manuscripts submitted |  |
|  C: Number of manuscripts accepted  |  |
|  D. Number of manuscripts published |  |
| **Total publications (A + B + C + D)** |  |
| **Scientific Conference Presentations** |  |
| Number of scientific conference presentations made (Note: include each presentation made, even if it was the same presentation given several times; Exclude grand rounds presentations) |  |

Below, we provide a list of the papers published, in preparation, submitted or accepted. Please update the citations and list any new papers.

***Note: Please make sure this list matches the numbers reported in the above table.***

|  |  |
| --- | --- |
| **Research Network** |  **Manuscripts** |
| ***Published manuscripts:*** | ***1.******2.******3.******4.******5.*** |
| ***Manuscripts Accepted for Publication (But not yet published):*** | ***1.******2.******3.******4.******5.*** |
| ***Manuscripts Submitted:*** | ***1.******2.******3.******4.******5.*** |
| ***Manuscripts in Preparation:*** | ***1.******2.******3.******4.******5.*** |

In the following table, please document the subject of each of the publications listed above.

***Note: Please count each manuscript only once, even if it covers multiple topics.***

|  |  |  |
| --- | --- | --- |
| **Publications** |  | **Subject of Publication**  |
|  | **TOTAL****NUMBER**  | **Intervention Research** | **Improving Care Practices** | **Measures/ Tools** | **Guidelines** | **Other** |
| Number of manuscripts published, prepared, submitted, or accepted  |  |  |  |  |  |  |

1. **DEVELOP AND VALIDATE TOOLS FOR ASD SCREENING/INTERVENTION**

Note: This Section is for AIR-P and AIR-B only.

In the following table, please list the number of tools, and/or any outcome measures used for the tools that were developed or finalized during this 2 year period.

|  | **Total Measures and Tools** |
| --- | --- |
| Total number of measures/tools developed or validated |  |
| Number of measures/tools piloted in care or community settings (if applicable) |  |
| Number of tools finalized (made available to public or published)  |  |
| Number of tools endorsed by other organizations/associations beyond the network (e.g. American Academy of Pediatrics) (if applicable) |  |

Below, please update and provide a list of tools and outcome measures developed, validated, piloted, or released during this 2 year period. Please:

1. Review and correct any information listed.
2. Update the last column on dissemination plans or progress for these tools.
3. Add any new tools to the blank rows at the bottom of the table.
4. Include only those tools for which activity occurred during or since 2011.

***Note: Please make sure this list matches the numbers reported in the above table.***

|  | **Tool Name** | **Description** | **Current Status (e.g. Under development, In Pilot-Testing, Finalized , etc.)** | **Anticipated Final Products (if applicable)** | **Dissemination Plans/ Progress** |
| --- | --- | --- | --- | --- | --- |
| 1 |  |  |  |  |  |
| 2 |  |  |  |  |  |
| 3 |  |  |  |  |  |
| 4 |  |  |  |  |  |
| 5 |  |  |  |  |  |
| 6 |  |  |  |  |  |
| 7 |  |  |  |  |  |
| 8 |  |  |  |  |  |

1. **DEVELOP GUIDELINES FOR ASD INTERVENTIONS**

Note: This Section is for AIR-P and AIR-B only.

In the following table, please list the number of guidelines that were developed or finalized during this 2 year period.

|  | **Total Guidelines** |
| --- | --- |
| Total number of guidelines developed, drafted, or updated  |  |
| Number of guidelines piloted in care or community settings (if applicable) |  |
| Number of guidelines finalized |  |
|  a. Number of guidelines released to providers and the public (for instance, posted on the website) |  |
|  b. Number of guidelines published in journals and peer reviewed publications |  |
|  c. Both |  |
| Number of guidelines adopted/endorsed by other organizations/associations beyond the network (if applicable) |  |

In the table below, we provide a list of the guidelines developed, piloted or released during this 2-year period. Please:

1. Review and correct any information listed.
2. Update the last column on dissemination plans or progress for these tools.
3. Add any new guidelines to the blank rows at the bottom of the table.
4. Include only those guidelines for which activity occurred during or since 2011***.***

***Note: Please make sure this list matches the numbers reported in the above table.***

|  | **Guideline or Algorithm Name** | **Description** | **Current Status (e.g. Under development, In Pilot-Testing, Finalized etc.)** | **Anticipated Final Products (if applicable)** | **Dissemination Plans/ Progress** |
| --- | --- | --- | --- | --- | --- |
| 1 |  |  |  |  |  |
| 2 |  |  |  |  |  |
| 3 |  |  |  |  |  |
| 4 |  |  |  |  |  |
| 5 |  |  |  |  |  |
| 6 |  |  |  |  |  |
| 7 |  |  |  |  |  |
| 8 |  |  |  |  |  |

**Guideline or Algorithm N**

1. **DISSEMINATE INFORMATION**

Please summarize your Network’s activities directed to disseminating information below.

***Note: these activities should be related to the CAAI funding or to the funded research.***

| **Dissemination Activities****During 3 Year Grant Period**  | **Total Number** |
| --- | --- |
| **Materials Developed and Disseminated** |
| Number of print or electronic materials (e.g., briefs, articles, newsletters or informational materials) developed, excluding study publications and conference presentations  |  |
|  Number of “hits” on Network Web sites |  |
| **Health or School Professional Training Sessions (e.g., grand rounds, medical teleconferences and others)**  |
| Number of grand rounds, training sessions and medical teleconferences geared toward health or school professionals  |  |
| Number of health or school professionals reached |  |
| **Parent Training Sessions (e.g., toward parents, parent volunteers and family advocates)** |
| Number of parent training sessions |  |
| Number of parents trained |  |
| **Community Outreach Sessions Conducted (e.g. presentations, lectures or seminars for the public)** |
| Number of community outreach sessions  |  |
| Number of individuals reached through community outreach sessions |  |

Please list all major collaborations with other CAAI grantees in the last 2 years and describe the activity.

|  |  |  |
| --- | --- | --- |
| **Collaboration Project Title**  | **Primary Target Audience** | **Nature of Collaboration** |
|  | 1. Other CAAI grantees2. Health Care Providers3. Schools4. Associations5. Families6. Individuals With Autism |  |
| 1 |  |  |  |
| 2 |  |  |  |
| 3 |  |  |  |
| 4 |  |  |  |
| 5 |  |  |  |
| 6 |  |  |  |
| 7 |  |  |  |
| 8 |  |  |  |

1. **DEVELOP NEW INVESTIGATORS**

In the following table, please document your Network’s progress in developing and mentoring new investigators during this 2 year period.

|  |  |
| --- | --- |
| **Activity** | **Total Number** |
| **Researchers Trained** |
| Number of new investigators mentored or developed in the ASD/DD field (please include efforts to support small research projects from junior investigators, webinars targeting new investigators, new investigators serving as co-authors, and graduate students and/or postdoctoral fellows on projects) |  |

1. **PROMOTE IMPLEMENTATION OF PRACTICES/ IMPROVE CARE**

Please list your efforts to transfer network findings on the following, as applicable to your network: interventions, guidelines, tools and systems management approaches into practice settings and communities to promote implementation of practices.

|  |  |
| --- | --- |
| **Activity** | **Number of Activities** |
| **Activities designed to promote implementation of practices** |
| Number of care plans developed and implemented by providers? [if applicable] |  |
| Number of tools and/or algorithms implemented in specific community settings such as health, schools, etc. [if applicable]  |  |
| Number of locations where successful implementation occurred [if applicable] |  |
| Implementation of validated outcome measure at Network sites |  |