

**Attachment B.**  
**Grantee Survey**

## Grantee Survey

On behalf of the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), 2M Research is conducting this web survey as part of an evaluation of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act. Your program, **[PROGRAM NAME]**, is one of the many grantees that will participate in the evaluation.

The purpose of this web survey is to gather more information on how your program may have (1) raised awareness of autism spectrum disorder (ASD)/other developmental disabilities (DD); (2) reduced barriers to ASD/DD care; (3) contributed to research to advance evidence-based screening, evaluation, and intervention for ASD/DD; (4) promoted health equity for children and youth with ASD/DD; and (5) improved the quality of care for individuals with ASD/DD.

Please answer as openly and honestly as possible, as your feedback will help HRSA better understand the contributions of the Autism CARES program. We encourage you to work with other staff if you do not have the answers to some of the questions. For example, it may be helpful to consult someone from your data and/or evaluation team while completing this survey. For each question, please report on activities or outcomes that have occurred **in the past year**. When thinking about your responses, please include all activities or outcomes that are funded by the HRSA Autism CARES funding your program is receiving (e.g., if your program provides HRSA Autism CARES funding to subcontractors and/or partners, please also include activities or outcomes related to these). In addition, if you are involved in another HRSA Autism CARES grant, please answer the questions on this web survey considering only **[PROGRAM NAME]**. The other HRSA Autism CARES grantees will also be receiving a survey, from which we will receive information about those specific programs.

This web survey is designed to be completed within 30 minutes. We encourage you to complete the web survey as soon as possible. As you answer the survey questions, please note the following:

- **Do not use your browser's "Back" button during the survey.** Instead, use the "Back" button at the bottom of each screen.
- Hovering your cursor over highlighted text will show more information about the term.
- Please answer all questions thoroughly and to the best of your ability.
- Please select only one answer for each question, unless the instructions indicate otherwise. For example, some questions ask you to "select all that apply."
- You may complete parts of the survey and save it by clicking "Save & Continue" at the end of each page.
- After saving, you can exit by closing the browser.
- You can log in to continue the survey later by using the same link.

If you have any questions about the survey or the overall evaluation, please email [AutismCARESevaluation@2mresearch.com](mailto:AutismCARESevaluation@2mresearch.com) or call toll-free at **1-844-XXX-XXXX**. Thank you for your participation in this important study.

According to the Paperwork Reduction Act of 1995, an agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0915-0335. The time required to complete this information collection is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.

## Introductory Questions

First, we would like to capture some basic background information and details about your program.

1. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Which of the following are your program's primary focus area(s)? (Select all that apply)
  - Screening and diagnosis of children ( $\leq 18$  years old)
  - Screening and diagnosis of adults
  - Interventions
  - Transition issues (i.e., issues with transitioning from adolescence to adulthood)
  - Treatment of ASD/DD across the lifespan
  - Primary care
  - Preventive care
  - Systems of care**
  - Care coordination
  - Behavioral health
  - Physical health
  - Self-advocacy
  - Outreach
  - Research
  - Guidance and tool development
  - Diversity/cultural awareness
  - Premature mortality
  - Caregiver mental health
  - Other (please specify): \_\_\_\_\_

## Increasing Awareness

The next questions ask about your program's primary audiences for your efforts to increase awareness of ASD/DD among providers, professionals, researchers, and the public. Please consider only the activities or interactions during the past year when answering the questions.

2. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** In the past year, who were the primary groups of individuals that your program targeted to raise awareness of ASD/DD? (Select all that apply)
  - Pediatricians
  - Other primary care providers
  - Health care providers who serve **geographically isolated, economically vulnerable, or medically vulnerable populations**
  - Behavioral health care providers (e.g., therapist, psychologist)
  - Researchers
  - Social workers
  - Care coordinators
  - Educators
  - The public
  - Families
  - Policymakers
  - State agencies or leaders
  - Other (please specify): \_\_\_\_\_

3. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** In the past year, what types of dissemination activities did your program implement? (Select all that apply)
- Developed and disseminated print or electronic materials (e.g., briefs, articles, newsletters, or informational materials)
  - Conducted health or school professional training sessions (e.g., grand rounds, medical teleconferences, or webinars)
  - Conducted parent training sessions (e.g., webinars or in-person forums directed toward parents, parent volunteers, and family advocates)
  - Convened meetings of experts
  - Presented at academic conferences
  - Showcased information on website(s)
  - Conducted community outreach sessions (e.g., presentations, lectures, or seminars for the public)
  - Engaged in press communications (e.g., TV/radio/newspaper interviews, public service announcements, or editorial articles)
  - Leveraged social networking/media (e.g., blogs, podcasts, wikis, RSS feeds, social networking sites, Twitter, or phone alerts)
  - Other (please specify): \_\_\_\_\_
  - Our program is currently in the planning stage of implementing dissemination activities.
  - Our program has not implemented any dissemination activities. **[SKIP QUESTION 4]**
4. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the target audiences for your program's dissemination activities in the past year. (Select all that apply)
- Families
  - Teachers
  - The public
  - Research/scientific community
  - Policymakers
  - Health care providers
  - Advocacy groups
  - The media

## Reducing Barriers

The next questions ask about barriers to ASD/DD care and how your program addressed them in the past year. Please consider only the past year when answering the questions.

5. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please indicate how often each of the following issues was a barrier to ASD/DD care in your community/state in the past year.

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Very Often (5)
Shortage of ASD/DD providers					
Long wait times for ASD/DD health care services					
Poor coordination of ASD/DD services across agencies and systems of care					
Families/caregivers not considered by providers to be equal partners in the ASD/DD care team					
Lack of professional education and/or training about ASD/DD					
Lack of parental/guardian education about ASD/DD					
Parental/guardian fear/stigma of ASD/DD diagnosis					
Parental/guardian desire for ASD/DD diagnosis to be able to access services					
Families/caregivers have difficulty paying for care					
Providers are not adequately reimbursed					
Lack of culturally and linguistically appropriate ASD/DD services					
Mismatch in eligibility and diagnostic criteria for ASD/DD					
Other (please specify):					

6. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the strategies your program implemented to address barriers to ASD/DD care in your community/state in the past year. (Select all that apply)
- Targeted outreach efforts to priority populations
  - Improved care coordination across agencies and systems
  - Engaged community stakeholders
  - Provided workforce development activities
  - Provided continuing education activities
  - Used family navigation
  - Taught self-advocacy skills
  - Used telehealth
  - Used tele-education or e-learning
  - Documented the existence or nature of barriers
  - Other (please specify): \_\_\_\_\_
  - Our program is currently in the planning stage of implementing strategies to address barriers to ASD/DD care.
7. **[LEND, DBP, STATE SYSTEMS]** Please select the strategies your program used to improve the systems of care for children and youth with ASD/DD in the past year. (Select all that apply)
- Provided technical assistance to other organizations (e.g., medical practices)
  - Collaborated with other organizations, such as state agencies, schools, family groups, Title V agencies, self-advocacy groups/networks, and/or community-based organizations to improve care integration at a system level
  - Established different entry points to service
  - Engaged state officials to improve systems of care
  - Worked with medical providers to improve the services they offer to children and youth with ASD/DD and their families/caregivers
  - Developed resources to assist children and youth with ASD/DD and their families through the transition to adulthood
  - Other (please specify): \_\_\_\_\_
  - Our program is currently in the planning stage of implementing strategies to improve systems of care for children and youth with ASD/DD.
8. **[LEND, DBP, STATE SYSTEMS]:** Did your program develop specific plans to reduce barriers to care among underserved children and youth with ASD/DD in the past year?
- Yes
  - No
  - Our program is currently developing plans to reduce barriers to care among underserved children and youth with ASD/DD.
  - Unsure (please explain): \_\_\_\_\_
9. **[RESEARCH GRANTS, RESEARCH NETWORKS]** Did your program conduct research on approaches to reduce barriers to care among underserved children and youth with ASD/DD in the past year?
- Yes
  - No
  - Unsure (please explain): \_\_\_\_\_

10. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the strategies your program undertook to improve access to care in your community/state for children and youth with ASD/DD in the past year. (Select all that apply)

- Expanded local capacity of health care providers to treat more patients
- Provided evidence-based guidelines
- Identified and shared promising practices
- Established partnerships
- Educated policymakers on ASD/DD issues
- Provided telehealth
- Provided tele-education or e-learning
- Provided family navigation services
- Facilitated enabling services (e.g., transportation, childcare, culturally competent information)
- Other (please specify): \_\_\_\_\_
- Our program is currently in the planning stage of implementing strategies to improved access to care in our community/state for children and youth with ASD/DD.
- Did not use strategies to improve access to care in the community/state

11. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS] [IF "USED TELEHEALTH" IN Q6 OR "PROVIDED TELEHEALTH" IN Q10 WAS SELECTED]** Please select the ways your program used telehealth in the past year. (Select all that apply)

- Provided access to specialists to aid in ASD/DD diagnosis
- Facilitated ASD/DD interventions through virtual behavioral health therapy sessions
- Provided access to medical and non-medical ASD/DD providers in medically underserved communities
- Other (please specify): \_\_\_\_\_

12. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS] [IF "USED TELE-EDUCATION OR E-LEARNING" IN Q6 OR "PROVIDED TELE-EDUCATION OR E-LEARNING" IN Q10 WAS SELECTED]** Please select the ways your program used tele-education or e-learning in the past year. (Select all that apply)

- Trained interdisciplinary providers, professionals, and/or researchers
- Expanded cross-system coordination, integration, and/or data sharing between and among providers and/or families
- Provided education on ASD/DD to families
- Other (please specify): \_\_\_\_\_

13. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the ways your program used family navigators to improve health outcomes for children and youth with ASD/DD in the past year. (Select all that apply)
- Reduced delays in accessing the continuum of care services (i.e., closing the referral loop)
  - Understood and/or used private or public health insurance (e.g., Medicare, Medicaid, Children's Health Insurance Plan [CHIP])
  - Coordinated enabling services (e.g., transportation or translation)
  - Provided care management by and through multiple providers
  - Facilitated access to culturally and linguistically competent care
  - Delivered time-limited case management
  - Coordinated services and appointments
  - Facilitated communication among families and providers
  - Encouraged children, youth, and families to play an active role in their care decisions
  - Conducted intervention studies that incorporated family navigators
  - Other (please specify): \_\_\_\_\_
  - Our program is currently in the planning stage of implementing family navigators to improve health outcomes for children and youth with ASD/DD.
  - We did not use family navigators

## Supporting Research to Advance Evidence-Based Interventions for ASD/DD

Next, we ask you about your program's efforts related to research to advance evidence-based interventions for ASD/DD. Please consider only the activities or interactions during the past year when answering the questions.

14. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Did your program work to translate research into practice to support adoption of evidence-based practice in the past year? Translating research into practice could include utilizing research (either conducted by individuals affiliated with your program or with the broader field) to inform evidence-based practice.
- Yes
  - No
  - Unsure (please explain): \_\_\_\_\_
  - Our program is currently working on translating research into practice to support adoption of evidence-based practices.

## Mentoring and Training Professionals

Next, we ask you about your program's mentoring and training efforts. Please consider only the activities your program has engaged in during the past year.

15. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS]** Please select the approach(es) your program used to mentor and/or support investigators in the field of ASD/DD in the past year. (Select all that apply)
- Engaged new investigators on research projects
  - Invited new investigators to be co-authors on manuscripts and/or presentations
  - Provided informal training on research methods in practice
  - Facilitated peer-to-peer mentoring
  - Other (please specify): \_\_\_\_\_
  - We did not mentor and/or support investigators in the field of ASD/DD
16. **[STATE SYSTEMS]** Please select the topics that were covered in the resources your program shared with providers in the past year. (Select all that apply)
- Innovative strategies to improve developmental screening and surveillance
  - Referral and follow-up practices for children and youth with or at risk for ASD/DD
  - Ongoing care for children and youth with or at risk for ASD/DD who are in a medical home
  - Family navigator roles
  - Care coordination for children and youth with or at risk for ASD/DD
  - Availability of community and social support for children and youth with ASD/DD and their families
  - Other (please specify): \_\_\_\_\_
  - We did not share any resources with providers

## Engaging National Resource Centers

The next questions ask about your engagement with the **Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities (ITAC)** operated by the **Association of University Centers on Disabilities (AUCD)** and/or the **State Public Health Autism Resource Center (SPHARC)** operated by the **Association of Maternal and Child Health Programs (AMCHP)**. Please consider only the activities or interactions during the past year when answering the questions.

17. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please indicate how often your program engaged with **ITAC (AUCD)** and/or used its materials as a resource in the past year.
- Never **[SKIP QUESTIONS 18 AND 19]**
  - Rarely (once last year)
  - Sometimes (2-3 times last year)
  - Often (4-5 times last year)
  - Very often (more than 6 times last year)

18. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the ways your program interacted with **ITAC (AUCD)** during the past year. (Select all that apply)
- Attended a conference hosted by ITAC (AUCD) (e.g., AUCD's annual meeting, directors' meetings, or Autism CARES grantee meeting)
  - Participated in an ITAC (AUCD)-sponsored webinar
  - Participated in other meetings with ITAC (AUCD) staff. Please describe: \_\_\_\_\_
  - Received technical assistance or other support from ITAC (AUCD)
  - Other (please specify): \_\_\_\_\_
  - My program did not interact with ITAC (AUCD) in the past year **[SKIP QUESTION 19]**
19. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the type(s) of technical assistance or support your program received from **ITAC (AUCD)** in the past year. (Select all that apply)
- Facilitated collaborations with other Autism CARES grantees
  - Facilitated collaborations with organizations that are not Autism CARES grantees
  - Participated in ITAC (AUCD) webinars or viewed archived webinars for technical assistance purposes
  - Used the ITAC (AUCD) training toolbox
  - Received newsletters from ITAC (AUCD)
  - Received **individualized technical assistance**
  - Facilitated **peer technical assistance**
  - Received site visit support from ITAC (AUCD) (onsite assistance)
  - Attended continuing education courses
  - Attended workshops
  - Attended distance learning classes
  - Received one-on-one remote consultation
  - Other (please specify): \_\_\_\_\_
  - My program did not receive any technical assistance from ITAC (AUCD) in the past year
20. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please indicate how often your program used **SPHARC (AMCHP)** as a resource in the past year.
- Never **[SKIP QUESTIONS 21 AND 22]**
  - Rarely (once last year)
  - Sometimes (2-3 times last year)
  - Often (4-5 times last year)
  - Very often (more than 6 times last year)

21. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the ways your program utilized **SPHARC (AMCHP)** resources in the past year. (Select all that apply)
- Used the listserv to communicate with other HRSA Autism CARES grantees
  - Received technical assistance from SPHARC (AMCHP)
  - Visited the SPHARC (AMCHP) website
  - Downloaded materials through the SPHARC (AMCHP) learning modules available on the SPHARC (AMCHP) website
  - Participated in at least one webinar hosted by SPHARC (AMCHP)
  - Utilized the peer-to-peer exchange program hosted by SPHARC (AMCHP)
  - Other (please specify): \_\_\_\_\_
  - My program did not utilize SPHARC (AMCHP) resources in the past year **[SKIP QUESTION 22]**
22. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the type of technical assistance or support your program received from **SPHARC (AMCHP)** in the past year. (Select all that apply)
- Facilitated collaborations with other Autism CARES grantees
  - Facilitated collaborations with organizations that are not Autism CARES grantees
  - Participated in SPHARC (AMCHP) webinars or viewed archived webinars for technical assistance purposes
  - Received newsletters from SPHARC (AMCHP)
  - Received individualized technical assistance
  - Facilitated peer technical assistance
  - Received site visit support from SPHARC (AMCHP) (on-site assistance)
  - Attended continuing education courses
  - Attended workshops
  - Attended distance learning classes
  - Received one-on-one remote consultation
  - Other (please specify): \_\_\_\_\_
  - My program did not receive any technical assistance from SPHARC (AMCHP) in the past year

## Partnerships, Collaborations, and Sustainability

The next questions ask about the partnerships and collaborations your program has established. Please consider only the activities or interactions that occurred during the past year.

23. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select all the stakeholders with which you collaborated in the past year. (Select all that apply)

- Universities
- State agencies
- Community-based organizations
- State Title V programs
- Policymakers
- Family to Family Health Information Center (F2F HIC)
- Social service agencies
- Local hospitals
- Schools
- Self-advocate organizations
- Family organizations
- Other Autism CARES grantees
- Other (please specify): \_\_\_\_\_
- We did not collaborate with any stakeholders in the past year

24. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please select the activities your program implemented, through collaboration with a partner (either other Autism CARES grantees or other stakeholders) to improve systems of care in the past year. (Select all that apply)

- Conducted research
- Provided training
- Offered technical assistance
- Developed evidence-based tools
- Shared information to raise awareness
- Utilized telehealth to improve clinical practice
- Other (please specify): \_\_\_\_\_

25. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Which of these strategies did your program implement in the past year to ensure sustainability? (Select all that apply)

- Created partnerships with other organizations
- Identified/obtained additional, diverse funding sources
- Developed a long-term plan to ensure viability
- Involved community and local professionals in interventions
- Obtained buy-in and support from key decision makers and/or community stakeholders
- Utilized quality improvement procedures to monitor results
- Launched marketing strategies to increase the program's visibility and utility
- Other (please specify): \_\_\_\_\_
- No sustainability strategies have been implemented

## Perceived Impact of Programs

Next, we would like to understand how your HRSA Autism CARES efforts have made an impact in the past year. The next questions ask you to rate how you believe your program has affected change in the past year as a result of the HRSA Autism CARES funding.

26. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please rate the degree to which you believe HRSA Autism CARES efforts have, in the past year, increased awareness of ASD/DD among maternal and child health professionals, providers, and/or researchers in your program.

<b>No change</b>	<b>Increased slightly</b>	<b>Increased a lot</b>
1	2	3

27. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please rate the degree to which you believe HRSA Autism CARES efforts have increased public awareness of ASD/DD as a result of your program in the past year.

<b>No change</b>	<b>Increased slightly</b>	<b>Increased a lot</b>
1	2	3

28. **[LEND, DBP]** Please rate the degree to which you believe that access to health care for children and youth with ASD/DD improved as a result of your program during the past year.

<b>No change</b>	<b>Improved slightly</b>	<b>Improved a lot</b>
1	2	3

29. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please rate the degree to which you believe that your program's efforts to build partnerships impacted the support for children and youth with ASD/DD and their families in the past year.

<b>No change</b>	<b>Impacted slightly</b>	<b>Impacted a lot</b>
1	2	3

30. **[LEND, DBP]** In the past year, what ways has HRSA Autism CARES funding influenced your training program? (Select all that apply)

- Increased training capacity (i.e., enabling you to support a larger number of trainees)
- Increased clinical opportunities for trainees
- Increased training opportunities in community settings
- Adjusted or expanded training curriculum
- Expanded interdisciplinary workforce available to address ASD/DD
- Allowed for faculty and trainee time to conduct research on ASD/DD
- Supported dedicated time for faculty to teach and/or mentor trainees
- Encouraged information dissemination and knowledge translation

Other (please specify): \_\_\_\_\_

31. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please describe in two or three sentences how you believe your program within HRSA Autism CARES has made an impact on the lives of children, youth, and families affected by ASD/DD in the past year.

32. **[LEND, DBP, RESEARCH GRANTS, RESEARCH NETWORKS, STATE SYSTEMS]** Please describe in two to three sentences the most serious barriers your program has faced in providing care to children and youth with ASD/DD in the past year.

## Closeout

Thank you so much for completing the web survey. We truly appreciate the time and effort you invested. If you have any questions, please feel free to email [AutismCARESevaluation@2mresearch.com](mailto:AutismCARESevaluation@2mresearch.com).

