
DRAFT EVALUATION DESIGN PLAN

MCHB Combating Autism Initiative Evaluation

State Implementation Grant Program



And



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I. INTRODUCTION

This report details the proposed plan for the evaluation of the State Implementation Grant program which is part of the *Combating Autism Act Initiative* (CAAI) implemented by the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA). Mathematica Policy Research, a subcontractor to Insight Policy Research, will lead the evaluation of this program.

The evaluation of the State Implementation Grant program will take place over three consecutive project phases including a planning and design phase, a data collection phase, and a data analysis and reporting phase. Each phase is briefly described below.

Phase I Planning and Evaluation Design. This phase began in October 2008 and ended in May 2009. During this phase, our activities included gathering information about the State Implementation Grant program and available data sources; developing and refining a list of research questions and a logic model; developing a draft evaluation design; conferring with grantees at their annual meeting, and afterwards, obtaining their feedback on the initial evaluation design; and finalizing the designs. This report describes the results of our Phase I activities.

Phase II Data Collection. Phase II will begin in June 2009 and end in March 2011. During this time, we will develop data collection protocols and tools, provide specifications for modifying existing tools, collect data from grantees (using both new and existing data sources as required), and deliver periodic presentations to MCHB staff on the preliminary results.

Phase III Data Analysis and Reporting. In Phase III, beginning in April 2011 and ending in September 2011, we will analyze the data and submit a final report on program performance. Additionally, we will write a description of the State Implementation grants and their achievements for the Report to Congress as required by Section 399DD of the authorizing legislation.

A. CHALLENGES TO THIS EVALUATION

Every evaluation has its share of potential challenges. In the case of the State Implementation grants, one challenge involves the relatively short duration of the project, which may prevent measurement of some longer term outcomes (e.g., the states may use the grants to initiate some activities, but the full results of those activities may occur later). This issue is particularly relevant for the three grants awarded in federal fiscal 2009, a full year after the initial six grants were awarded. Accordingly, we have developed an evaluation plan that includes collection of short term/interim data, followed by measures of short term outcomes that can be reasonably obtained within the project timeline. From these data, we will provide the necessary foundation for longer term evaluations in the future.

A second challenge is the September 2011 due date for the final Report to Congress. We will need draft materials for this report by June 2011, to provide adequate time for review by MCHB

and revisions. This timeline means the individual evaluation report for the State Implementation grants must be completed and reviewed by MCHB by May 2011. To make these deadlines and to have sufficient time to analyze the information collected, data collection must end by March 15, 2011. As a result, the evaluation will not be able to obtain a third year of data. For example, Discretionary Grant Information Systems (DGIS) data will not be due until December 31, 2011, and grantees' final reports are not due until November 30, 2011. The only information the evaluation will have for the final year of grant activities will be collected either at the November 2010 grantee conference or through telephone interviews that could be conducted as late as February/March 2011. The last round of data collection will cover no more than the first three months of FY 2011 (the first three months of the third year of funding for the six grantees awarded in 2008 and the first three months of the second year of funding for the three grantees awarded in 2009).

A third challenge for the evaluation of the State Implementation grants is the idiosyncratic nature of the programs the grantees are implementing. Each program is very different from the others, which will make it difficult for the evaluation to draw general conclusions. As a result, much of the evaluation will focus on synthesizing nine case studies (one for each grantee) and describing the programs, their achievements, and lessons learned so that they can serve as models for other states.

B. OVERVIEW OF THE EVALUATION PLAN

The following chapters describe our proposed evaluation plan for the State Implementation grants. Chapter II provides background on the 2006 Combating Autism Act (CAA) and HRSA's CAAI which serves as the foundation for the evaluation. Chapter III presents an overview of the State Implementation grant program, which is one component of the CAAI. Chapter IV provides an overview of our evaluation design. Chapter V outlines our data collection methodology. Chapter VI provides a detailed plan for analysis and Chapter VII discusses a plan for writing the final report, including the chapter for the Report to Congress. The attachments provide supporting materials, including: the logic model for the evaluation (Attachment A); summaries of each grantee, based on the grant applications (Attachment B); a draft interview protocol (Attachment C); a network questionnaire (Attachment D); and network diagrams for each grantee (Attachment E).

II. THE 2006 COMBATING AUTISM ACT AND MCHB'S COMBATING AUTISM ACT INITIATIVE

A. OVERVIEW OF THE CAA LEGISLATION

1. Intent of the Legislation: Goals and Objectives

In response to the growing need for research and resources devoted to Autism Spectrum Disorders (ASD), the U.S. Congress passed the *Combating Autism Act of 2006* (CAA)¹. The goal of the CAA is to enable all children to reach their full potential by developing a system of services that includes: (1) screening children early for possible ASDs, (2) conducting early, interdisciplinary evaluations to confirm or rule out ASDs, and (3) providing evidence-based, early interventions when a diagnosis is confirmed.

2. Funding Levels

In FY 2008, Congress appropriated a total of \$168 million to the following agencies for activities under the CAA:

- **National Institutes of Health (NIH)** received \$114.5 million for research into causes, diagnosis, early detection and treatment through Centers of Excellence
- **Centers for Disease Control and Prevention (CDC)** received \$16.5 million to conduct research and surveillance activities, including collection of state-level epidemiologic data
- **Health Resources and Services Administration (HRSA)** received \$37 million to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions, and train health care professionals (the appropriation of \$37 million included the transfer of approximately \$20 million of Special Projects of Regional and National Significance (SPRANS) funds to the Autism and Other Developmental Disorders program)

In response to the CAA, HRSA implemented the CAAI. The CAAI fits into HRSA's broad range of programs that promote and support the development of family-centered, culturally/linguistically competent, community-based systems of care. These programs are often targeted to meet the needs of specific population groups, such as low-income families, racial and ethnic minority families, families with children with special health care needs (CSHCN), and rural families.

¹ Public Law 109-416§42 U.S.C.§1

B. HRSA's COMBATING AUTISM ACT INITIATIVE

1. Goals and Objectives of the CAAI

The overall goal of HRSA/MCHB's CAAI is to enable all children to reach their full potential (i.e., improving the physical, behavioral, mental, social and/or cognitive health and well-being of children and adolescents with ASD and other DD) by developing a system of services that address the three goals of the CAA:

1. Screening children as early as possible for ASD and other DD
2. Conducting early, interdisciplinary evaluations to confirm or rule out ASD and other DD
3. Providing early, evidence-based interventions if a diagnosis is confirmed

Additionally, in alignment with guidance from the CAA, the CAAI specifies five main objectives:

1. Increase Public/Provider Awareness
2. Reduce Barriers to Screening and Diagnosis
3. Support Research on Evidence-based Interventions
4. Promote the Development of Evidence-based Guidelines and Tested/Validated Intervention Tools.
5. Train Professionals to Diagnose and Provide Evidence-Based Interventions.

2. Activities

To achieve the goals and objectives specified for the CAAI, HRSA/MCHB has provided funding in three areas: (1) training, (2) research, and (3) state implementation grants.

1. Training Programs
 - *Expansion of Leadership Education in Neurodevelopmental Disabilities (LEND) training programs.* A total of 39 LEND grants were funded in FY 2008 (22 grantees) and FY 2009 (17 grantees). In FY 2008, in addition to the base support that was moved from the SPRANS budget to CAAI, 18 LEND grantees were given supplements of \$200,000 per year, for three years, to focus on autism and 4 new LEND programs were funded at a level of \$550,000 each, per year, for three years. In FY 2009, the remaining 16 existing LEND grantees were given \$100,000 supplements per year for two years to focus on autism and 1 new LEND was funded at \$450,000 per year for two years.

- *Expansion of Existing Developmental Behavioral Pediatrics (DBP) training programs.* In addition to the base support that was moved from the SPRANS, 6 grantees received additional funding of approximately \$50,000 each per year, for three years, to focus on autism and one new DBP program was funded.²
- *A National Combating Autism Interdisciplinary Training Resource Center cooperative agreement.* One grantee received \$500,000 in funding.

2. Research Networks Program

- *Two Autism Intervention Research Networks.* These networks focus on intervention research, guideline development and information dissemination. One network is focused on physical/medical health intervention research (AIR-P, with \$4 million) while the other is focused on behavioral, mental, social, and/or cognitive health intervention research (AIR-B, with \$2 million).
- *R40: MCH Autism Intervention Research Program.* (\$2 million annually; beginning in 2009). These include:
 - *Five intervention research grantees.* These grantees are to conduct research leading to improvements in interventions that address the health and well-being of children and adolescents with ASD and other DD. Each grantee is to receive funds of approximately \$400,000 per year for two years. Three R40 grants were funded at \$393,024 each, one R40 grant was funded at \$393,019, and one R40 grant was funded at \$334,359.
 - *Two secondary data analysis grantees.* These grantees are to conduct research leading to improvements in interventions that address the health and well-being of children and adolescents with ASD and other DD, utilizing existing secondary data. Each grantee is to receive funds of approximately \$100,000 for one year. One secondary data analysis grant was funded at \$100,000 and 1 secondary data analysis grant was funded at \$93,533.

3. State Implementation Grants

- *Nine state grantees.* These grantees implement state autism plans and develop models for systems of services for children with ASD and other DD. In 2008, six States received funding of approximately \$300,000 each year, for three years. In 2009, another 3 States received grants of \$300,000 each per year, for two years.

² Another 4 DBP grantees did not receive an expansion over their existing level of approximately \$192,000 per year. Note that all of the DBP grantees were awarded before the CAAI funds were allocated; thus, the DBP grantee guidance did not specifically require autism-specific training.

- *One State Public Health Coordinating Center.* This center will coordinate with the State Implementation grantees to develop and implement a strategy for defining, supporting, and monitoring the role of state public health agencies in assuring that children and youth with ASD and other DD receive early and appropriate identification, diagnosis, and intervention. One grantee received funding of \$250,000 per year.

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III. STATE IMPLEMENTATION GRANTS PROGRAM

HRSA developed the State Implementation grants program to create models of systems that states can adapt and use to improve care for children and youth with ASD and other DD. State grantees are expected to implement an existing state plan designed to increase access to comprehensive, coordinated care for ASD and other DD.

A. GRANT GUIDANCE AND PROGRAM GOALS

In September 2008, HRSA awarded six State Implementation grants to Alaska, Illinois, Missouri, Utah, Washington, and Wisconsin. Then, in April 2009 HRSA awarded three additional grants to New Mexico, New York, and Rhode Island. Grant funds are available through September 2011, which means the first six states will receive three years of funding and the other three will have two years of funding. According to the grant guidance provided to applicants, each grantee needed to have a state plan for improving services for children and youth with ASD and other DD. States were also required to complete a needs assessment describing and documenting their target population, unmet health needs and health disparities, existing strengths and resources of the current state system, system gaps and weaknesses, and relevant barriers to accessing care for children and youth with ASD and other DD. The purpose of the needs assessment is to provide an understanding of the state, communities, and organizations served by the project, and the barriers the project intends to address.

B. GRANTEEES AND GENERAL OVERVIEW OF THEIR PROGRAMS

Each state is implementing a different program. The projects range from the direct provision of services for children and families to diverse methods of infrastructure-building. Two states, Alaska and Missouri, are focused primarily on improving frontline services through the introduction of new services. For instance, Alaska seeks to establish in-home developmental assessments of young children living in rural and remote areas. Specifically, the state intends to establish Rapid Responder teams throughout Alaska to film in-home developmental assessments that will be reviewed by a pediatric autism and neurodevelopmental physician and advanced nurse practitioner at the Providence Neurodevelopmental Center. Similarly, Missouri will expand its Rapid Response Project to additional regions of the state, targeting children 0 through 18. It will also strengthen supportive services for parents and families at three state Autism Centers of Excellence (MO-ACE).

Another three states, Illinois, New York, and Utah, are focused on strengthening the skills of providers and families. Illinois intends to introduce three Regional Health Services Facilitators (HSFs) within the preexisting Autism Program Service Network (TAP). The HSFs will orient 120 practices to medical home principles and facilitate the development of 6 medical homes specific to ASD and other DD. A Family Advisor Training Program will train families to communicate effectively with physicians. New York will implement several new online trainings for providers, including a new training curriculum on applied behavioral analysis (ABA) and a training that promotes universal ASD screening. For families, New York will enhance an existing parent leadership training program to include guidance on how to navigate transitions

between systems of care. Utah will implement an early intervention pilot program to help human service providers and educators recognize the early signs of ASD and make appropriate referrals, expand an online resource and training website for families and health care providers, and train family resource navigators to work with providers and link parents to information and resources. In addition, Utah will train family and pediatric medical homes and dental home practice teams to expand the existing medical home network for children with ASD and other DD, particularly in rural and remote areas.

The programs in New Mexico, Rhode Island, Washington, and Wisconsin will focus on infrastructure building. New Mexico will focus on developing the state's regional infrastructure by establishing five new ASD Regional Resource Centers (ASD-RRCs) that will be staffed by ASD Family Specialists who will build local stakeholder collaboration to build and strengthen regional medical homes for ASD and other DD. The ASD-RRCs will also host telehealth programs. Rhode Island's program is notable for its plans to enhance a statewide registry to include ASD and other DD and to use an existing database to provide data on outcomes to providers and childcare centers and prevalence rates for an annual report to the Governor.

Many of Washington's activities are designed to support and enhance the state's 21 Medical Home Leadership Networks comprised of local primary care providers, school nurses, parents, and public health nurses. A primary focus of this project is statewide provider and parent training. Specifically, Washington will plan and conduct two training summits on screening tools, diagnosis, treatment referrals, and the medical home for frontline providers. In Wisconsin, core teams of developmental specialists, primary care providers, families, and community providers within each of the state's five Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN) will create a statewide network of organizations to improve services for children and youth and will launch a resource mapping initiative to identify current resources, supports, and gaps in services for families and providers at the local, regional, and state level. To develop state-level collaboration, a Community of Practice on ASD (CoP-ASD) will convene to discuss best practices, share existing state and local model practices, and hear from CoP-ASD subcommittee practice groups on areas ranging from medical homes to parent supports.

IV. OVERVIEW OF THE EVALUATION DESIGN

A. PURPOSE

The purpose of the evaluation of the State Implementation grant program is to identify state achievements and the extent to which these achievements address the goals and objectives of the CAAI and are likely to result in increased access to comprehensive, coordinated care for ASD and other DD. To address the requirements for the Report to Congress, the evaluation will focus on short-term indicators related to system improvements specifically with regard to early screening of children for possible ASD and other DD, interdisciplinary evaluations to confirm or rule out ASD and other DD, evidence-based, early interventions when a diagnosis is confirmed, and successful transition to adult services. The evaluation of the State Implementation grant program will rely on qualitative research methods to assess program implementation, systems change, and outcomes.

While this report focuses on the design plan for the evaluation of the State Implementation grant program, Mathematica will also assess the state Public Health Coordinating Center. To do this work, Mathematica will review the Center's progress reports and use information reported by the grantees to document the assistance the grantees receive and its contribution to grantee activities.

1. Evaluation Goals and Objectives

The *overall goals of the evaluation of the State Implementation grant program* are (1) to measure grantee activities and assess whether such activities meet the objectives of the CAAI, and (2) to assess the efforts of the MCHB in addressing the nation's growing need to improve the physical, behavioral, mental, social, and cognitive health and well-being of children and adolescents with ASD and other DD. The evaluation will provide an excellent source of data for HRSA/MCHB to meet their commitment to improving the well-being of our Nation's mothers and children by measuring the short- and intermediate-term impacts of the State Implementation grants program on children and families affected by ASD and other DD. It will also lay the foundation for potential future measurement of the initiative's long-term impact.

The *objectives of the State Implementation grant program evaluation* include the following:

1. Determine whether the States are accomplishing the intended goals and objectives of MCHB's CAAI;
2. Identify problems or barriers that surfaced during implementation and how these problems or barriers were resolved;
3. Identify any existing gaps in the grantees' activities; and
4. Measure the CAAI outputs and outcomes for the Report to Congress.

2. Use of Results

The results of this evaluation will allow MCHB to assess the performance of the State Implementation grants in achieving their short- and intermediate-term outcomes during the three years of the grant period. In addition, the results will provide MCHB with greater insight into how to structure State Implementation grants' funding efforts in the future. To the extent possible, the evaluation will identify successful activities. We expect these grantees will serve as model programs for other states and the evaluation will focus on identifying key ingredients of the models. Additionally, the data will be used in the Report to Congress on the effectiveness of the State Implementation grants in achieving the goals and objectives of the *Combating Autism Act of 2006*.

B. RESEARCH QUESTIONS

In this section we present the major questions that we plan to address in this evaluation, as well as the data we plan to collect in order to answer each question and the proposed data sources.

1. Overall Research Questions

To frame the work, we first linked this grant program to the objectives of HRSA's CAAI. We determined that the State Implementation grants linked to three of the five objectives established for the CAAI (which are numbered below according to the ordering established by HRSA—see Chapter III):

1. How effective are the State Implementation grants in increasing public/provider awareness of ASD and other DD?
2. How effective are the State Implementation grants in reducing barriers to screening, diagnosis, and evidence-based interventions?
3. How effective are State Implementation grants in training professionals to utilize valid screening/diagnostic tools and provide evidence-based interventions?

Because these grants focus on improving systems, we established a fourth objective unique to the state grant program:

What types of contributions did the State Implementation grants make to infrastructure building and systems change?

2. Crosswalk for the Research Questions, Data Elements and Proposed Data Sources

An overview of the evaluation design is presented in Table IV.1 and a logic model for the evaluation is presented in Attachment A. The logic model provides a visual picture of *the short term, intermediate, and long term outcomes* that are critical to assessing the program's success in meeting the CAAI objectives. The information in Table IV.1 is first organized by objective, and the table provides a crosswalk between the research questions and data elements, and also lists

the proposed data source for each indicator. Listed under each objective are a set of research questions. For each question we report the likely data source (or sources) for the information needed to answer the question and the types of analyses to be used to assess the information collected (implementation, network, and outcomes analyses). Where quantitative data may exist (such as measures from the Discretionary Grant Information System [DGIS]), we have included a description of the measures.

The research questions are designed to (1) describe and document the activities of the State Implementation grants and (2) link these activities to short-term and intermediate outcomes when possible.

C. GRANTEE INVOLVEMENT

1. MCHB Autism Grantee Kick-Off Meeting (December, 2008)

During the first Autism Grantee Meeting held December 15-16, 2008, we held a breakout session with the state grantees funded in 2008 to discuss the evaluation plans and activities. In this session, we presented the proposed evaluation design to the grantees and obtained their feedback and suggestions for improving the research questions, logic model, and overall evaluation process in an open discussion forum. Following the meeting, we compiled and submitted individual summaries of each breakout discussion (as well as a list of the proposed/recommended changes). Additionally, the grantees raised some general issues and questions about the evaluation, for which we requested guidance from MCHB. The grantee feedback was then used to revise the logic model and research questions following the meeting. We also incorporated the guidance that we received from MCHB with regard to the list of general issues that were raised during the grantee meeting.

2. Ongoing Communication

At the conclusion of the breakout session at the annual meeting, the state grantees agreed to participate in an on-going process to refine the logic models and research questions. Correspondingly, we sent the revised research questions and logic models to each state grantee and grantees were allowed two weeks to review the document and provide feedback. All states provided written comments to MPR and additional feedback was incorporated into the research questions and logic models.

Grantees were provided the opportunity to indicate the feasibility of reporting quantitative data following the Autism Grantee kick-off meeting in December 2008. For each question grantees were asked their ability to report specific measures. Through this effort, we learned that the reporting capacity of grantees is highly variable and some states will not be able to report many data elements, other than the DGIS measures. The data each can report will be extremely variable and difficult to generalize. Those few grantees who could report data related to screening and diagnosis rates, the information would only be for the children served by the project. As a result, we determined that the quantitative data a state reports will be determined during annual interviews with each state.

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
(Objective #1) How effective are the State Implementation grants in increasing awareness?			
<p>1.1 What did the grantees do to build awareness of ASD and treatment options among general primary care providers? Providers of early childhood services? Educators? Families?</p> <p>a. What types of awareness building campaigns did the grantee implement at the community, provider, and family levels?</p> <p>b. How effective have these campaigns been? How is effectiveness documented and measured?</p> <p>c. Did the program develop its own education/outreach materials or did it use materials developed by others, such as the CDC Learn the Signs, Act Early materials?</p> <p>d. What other organizations were building awareness of ASD during the same period? How did the program coordinate with the organizations conducting these other activities?</p>	<p>-Implementation -Network -Outcomes</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-State-specific outcomes that measure effectiveness of awareness building activities</p> <p>- Number of new materials developed</p>
<p>1.2 How did the awareness building activities address disparity issues and traditionally hard to reach populations or geographic areas?</p>	<p>-Implementation</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Not applicable</p>
<p>1.3 To what extent were families of children with ASD involved in the design and implementation of the awareness building activities?</p> <p>a. How did family input change the design or implementation of these activities?</p>	<p>-Implementation</p>	<p>-Progress reports -Grantee interviews</p>	<p>- Degree of family participation overall</p> <p>- Degree of family participation in planning, implementation, and evaluation (DGIS #7)</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
(Objective #2) How effective are the State Implementation grants in reducing barriers to screening and diagnosis?			
<p>2.1 Which barriers to screening, diagnosis, and treatment have been the focus of the State Implementation grant?</p> <p>a. What progress was made at reducing these barriers?</p> <p>b. What types of efforts has the State Implementation grants engage in to reduce disparities and address barriers faced by traditionally hard to reach populations and geographic areas?</p>	-Implementation	-Grant applications -Progress reports -Grantee interviews	- Assisted state in increasing the percentage of children screened early for special needs, linked to medical homes, followed up, and provided early intervention services (DGIS #23)
<p>2.2 Did the State Implementation grants convene local learning collaboratives?</p> <p>a. Which barriers were the focus of the collaboratives?</p> <p>b. What were the results of the collaboratives?</p> <p>c. What was the role of families in the collaborative?</p> <p>d. What contributions did families make to the results of the collaboratives?</p>	-Implementation	-Grant applications -Progress reports -Grantee interviews	Not applicable
<p>2.3 What strategies did the State Implementation grants use to increase screening rates?</p> <p>a. How effective were these strategies?</p> <p>b. What strategies were implemented to reduce disparities and increase screening rates among traditionally hard to reach populations and geographic areas?</p>	-Implementation -Outcome	-Grant applications -Progress reports -Grantee interviews	-Number of children screened for ASD by the program ^a -Age distribution of the children screened by the program (0-3, 4-5, 6 and older) ^a

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
<p>2.4 What strategies did the State Implementation grants use to decrease the time from screening to diagnosis? Time from diagnosis to treatment?</p> <p>a. How effective were these strategies?</p> <p>b. What has the grantee done to address disparities and decrease the time from screening to diagnosis and diagnosis to treatment within traditionally hard to reach populations and geographic areas?</p>	<p>-Implementation -Outcome</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Of the children screened, number diagnosed with an ASD^a</p> <p>-Average time from screening to diagnosis^a</p> <p>-Of the children diagnosed, number who entered treatment^a</p> <p>-Average time from diagnosis to start of treatment^a</p>
<p>2.5 What steps did the State Implementation grants take to ensure health insurance was not a barrier to screening? Diagnosis? Treatment?</p>	<p>-Implementation -Outcome</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>- Assisted state in increasing the in percentage of CSHCN who have adequate insurance to pay for needed services (DGIS #16)</p> <p>-Number of children grantee helped obtain coverage for ASD services^a</p>
<p>2.6 What strategies did the State Implementation grants use to increase access to medical homes for children with ASD?</p> <p>a. How effective were these strategies?</p> <p>b. What has the grantee done to reduce disparities and address barriers to medical homes within traditionally hard to reach populations and geographic areas?</p>	<p>-Implementation -Outcome</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>- Assisted state in increasing the percentage of CSHCN who have a medical home (DGIS #19)</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
<p>2.7 What strategies did the State Implementation grants use to improve the transition to adulthood for youth with ASD? a. How effective were these strategies?</p>	<p>-Implementation -Outcome</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>- Assisted state in increasing the percentage of YSHCN who received services for the transition to adult health care, work, and independence (DGIS #37) -Number of youth with ASD who received the program’s transition services^a</p>
<p>(Objective #5) How effective are State Implementation grants in training professionals to utilize valid screening tools to diagnose and provide evidence based interventions?</p>			
<p>3.1 What training was developed for providers (health care providers and other types of providers such as early intervention specialists and educators)? a. Did the program develop its own training program(s) (or materials) or did it use a program(s) (materials) developed by others? b. What other organizations offered provider training during the same period? Did the program coordinate with the organizations conducting these activities? c. How was this training linked to the training offered by the state LEND and/or developmental pediatric programs? e. Did the training program(s) (or materials) improve provider knowledge of barriers faced by traditionally underserved or hard to reach populations and geographic areas?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Number of providers by type who participated in the grantee’s training^a -State-specific outcome measures of training program</p>
<p>3.2 What training was developed for families to help them improve their ability to navigate the ASD service system (refers to skill development, not referral resources)? a. Did the grantee collaborate with other local or state initiatives to help families improve their ability to navigate service systems? b. Did the grantee collaborate or coordinate these activities with any Family-to-Family Health Information Center?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Assisted states in increasing the percentage of families of CSHN to partner facilitated families as partners in decision making (DGIS #6)</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
(State Objective) What types of contributions did the State Implementation grants make to infrastructure/system changes?			
<p>4.1 What new services were introduced? What existing services were enhanced/expanded?</p> <p>a. What infrastructure/system/policy/procedural changes were required to implement the new services? To expand or enhance existing services?</p> <p>b. Which partners or other organizations contributed to the introduction or expansion of services?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>Not applicable</p>
<p>4.2 What has the grantee done to expand or enhance services for youth transitioning to adulthood?</p> <p>a. What new services were introduced?</p> <p>b. What existing services were expanded?</p>	<p>-Implementation</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>Not applicable</p>
<p>4.3 What state level partnerships or collaborative efforts did this program pursue?</p> <p>a. Which agencies and organizations did the program seek to develop or enhance as partners or collaborators? Primary care providers? Provider associations? Pediatric specialists? Parent organizations? Local ASD groups? State and community agencies? Public and private insurance providers? Schools?</p> <p>b. What has been the frequency of communication with each partner/collaborator?</p> <p>c. Which partner/collaborator provided the project with the most meaningful support? Which provided the least?</p> <p>d. What was the role of Title V?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Total number of collaborators/partners by type</p> <p>-Frequency of communication by partner</p> <p>- Type of relationship with each partner</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
<p>4.4 What roles have advocates and families of children with ASD played in the state level partnerships or collaborations the State Implementation Grant pursued?</p> <p>a. Have their roles been effective? How did their participation change the program?</p> <p>b. How did they ensure that new policies, guidelines, contracts, and training developed by the partnership/collaborative incorporated cultural competence elements?</p> <p>c. How did they ensure that they are family centered?</p>	<p>-Implementation</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>- Increase in percentage of MCHB supported programs that incorporate cultural competence elements into their policies, guidelines, contracts, and training (DGIS #10)</p>
<p>4.5 To what extent have State Implementation grants implemented their statewide plans for systems of services?</p> <p>a. What were the challenges to implementation?</p> <p>b. What did the program do to overcome these challenges?</p> <p>c. What progress was made?</p>	<p>-Implementation</p>	<p>-Progress reports -Grantee interviews</p>	<p>Not applicable</p>
<p>4.6 During the grant period, was there any state-level policy change that improved access to screening, diagnosis, or the treatment for ASD? If yes, how did the program shape or influence this policy change or its implementation?</p> <p>a. Medicaid policy? Early intervention policy? Education policy? Other?</p> <p>b. Which partners or collaborators helped to achieve the policy change?</p>	<p>-Implementation -Network</p>	<p>-Progress reports -Grantee interviews</p>	<p>Not applicable</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
<p>4.7 What strategies did the State Implementation grants use to improve information sharing among agencies?</p> <p>a. How is information about specific children shared among health care providers, providers of early childhood services (e.g., Head Start, WIC, local child care programs), and educators (including special education)?</p> <p>b. Has interagency/inter-organizational information sharing improved during the grant period so that health care providers, providers of early childhood services, and educators know about ASD diagnoses more quickly?</p> <p>c. What types of referral systems/networks have State Implementation grants established or strengthened?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Degree program organized community based system of services for CSHCN (DGIS #31)</p> <p>-Number of interagency/inter-organizational data sharing arrangements or MOUs established during the grant period^a</p> <p>-Number of separate referral systems/networks used^a</p> <p>-Number of new referral systems/networks established^a</p> <p>-Number of referral systems enhanced or strengthened^a</p> <p>-Number of children/families who received referrals through the systems/networks^a</p>
<p>4.8 Has the state implemented an ASD monitoring or surveillance system, such as the CDC Autism Developmental Disabilities Monitoring (ADDM) Network?</p> <p>a. How does this system operate?</p> <p>b. Is it effective at identifying children newly diagnosed with ASD?</p> <p>c. How did the State Implementation Grant coordinate its activities with this system?</p>	<p>-Implementation -Network</p>	<p>-Grant applications -Progress reports -Grantee interviews</p>	<p>-Data reports from the monitoring or surveillance system^a</p>
<p>4.9 What would have happened if the state had not received the State Implementation grant?</p>	<p>-Implementation</p>	<p>-Progress reports -Grantee interviews</p>	<p>Not applicable</p>

TABLE IV.1

OVERVIEW OF THE EVALUATION DESIGN FOR THE STATE IMPLEMENTATION GRANTS

Research Questions	Type of Analysis	Qualitative Data	Quantitative Data
4.10 What strategies were implemented to sustain the project after the end of the federal grant period? a. Which activities will continue? Which will end? b. For those activities that will continue, what will be the source of funding?	-Implementation -Network	-Progress reports -Grantee interviews	-Sustained in the community after the federal grant period ends (DGIS #5)

^aOnly those states collecting this information will be asked to report this information.

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V. DATA COLLECTION METHODOLOGY

The data collection methods used in the evaluation of the State Implementation grants include three existing data collection tools (the grant application, annual progress reports, and DGIS reporting) and two new data collection tools (grantee interviews and network questionnaires). Each data source is described below.

Because the draft of the Final Report is due by June 2011, the project schedule will not allow us to include complete information for the last program year (federal fiscal year 2011) in our analyses. As described below, the data we obtain will be collected in the fall of 2009 and 2010 shortly after the conclusion of each program year. For the last program year, we will collect information in early 2011 to capture the first three months of the last year. We anticipate the last information we collect will focus on the activities planned for the last year of federal funding and the sustainability of specific activities.

Table V.1 provides a summary of the data collection sources and schedule for the evaluation of state implementation grant program.

TABLE V.1

Data Source	DATA COLLECTION SCHEDULE	
	Data Collection Schedule	
	Cohort One (FY08 grantees)	Cohort Two (FY09 grantees)
Existing Data Collection Tools		
Grant Application Narrative	October 2008	August 2009
Summary Progress Reports	May 2009 May 2010	May 2010
DGIS	January 2009 January 2010 January 2011	January 2010 January 2011
New Data Collection Tools		
Grantee Interviews	December 2009 March 2011	March 2011
Network Questionnaire	December 2008 December 2009 March 2011	December 2009 March 2011

A. EXISTING DATA COLLECTION TOOLS

1. Grant Applications

The grant application provides a baseline description of the program and the activities each grantee intends to pursue. To help inform the evaluation design, MPR read the applications thoroughly and developed short descriptions of each grantee program. The descriptions for the six grantees funded in 2008 were given to the grantees during the December 2008 grantee meeting held in Bethesda, Maryland. Grantees reviewed and commented on their own project descriptions to ensure that the evaluation team understood the purpose and scope of each program. A similar process will be used for the three additional grantees funded in 2009. These

descriptions are located in Attachment B. Each grantee will be asked to review and update the project descriptions in the fall of 2009 and 2010. These updates will help the evaluation track program changes.

2. Annual Continuation Application/ Summary Progress Reports

The evaluation will rely on grantees' annual progress reports to document changes as programs mature, contextual factors facilitating or delaying implementation, and progress. Tracking progress will be particularly important for answering research questions related to systems change and infrastructure building. In addition, progress reports can also help us track changes in activities related to awareness building and training, which will be ongoing activities for most grantees. The evaluation team will work with the MCHB project officer for the State Implementation grants to determine the exact content of the progress reports and what information will be available for the CAAI evaluation. We anticipate updating the content of the 2009 and 2010 program reports in January of each year.

3. Discretionary Grant Information System (DGIS)

Grantees must also track and report their performance on an annual basis. MCHB has developed DGIS, which includes an array of performance measures that capture accomplishments across a variety of maternal and child health areas. The State Implementation grants must report on nine DGIS measures (see Table V.2), and the evaluation team will use these performance measures in its assessment of grantee performance and identify data trends among states.

TABLE V.2

DISCRETIONARY GRANT INFORMATION SYSTEM (DGIS) PERFORMANCE MEASURES FOR THE STATE IMPLEMENTATION GRANTS

DGIS Measure	Description
Performance Measure #5 ^a	The percent of MCHB supported projects that are sustained in the community after the federal grant project period is completed
Performance Measure #6	The degree to which grantees assist families of children with special health needs to partner in decision making and be satisfied with services they receive
Performance Measure #7 ^b	The degree to which MCHB supported programs ensure family participation in program and policy activities
Performance Measure #10 ^b	The degree to which MCHB supported programs have incorporated cultural competence elements into their policies, guidelines, contracts, and training
Performance Measure #16	The degree to which grantees have assisted States in increasing the percent of children with special health care needs, age 0 to 18, whose families have adequate private and/or public insurance to pay for needed services
Performance Measure #19	The degree to which grantees have assisted States in increasing the percent of children and youth with special health care needs ages 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home
Performance Measure #23	The degree to which grantees have assisted States in increasing the percentage of children who are screened early and continuously for special health care needs and linked to medical homes, appropriate follow-up, and early intervention

DGIS Measure	Description
Performance Measure #31	The degree to which grantees have assisted States in organizing community-based service systems so that families of children with special health care needs can use them easily
Performance Measure #37	The degree to which grantees have assisted States in increasing the percentage of youth with special health care needs who have received services necessary to make transitions to adult health care, work, and independence

Source: State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities. HRSA-08-144. Program Guidance, U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Care Bureau.

DGIS = Discretionary Grant Information System; MCHB = Maternal and Child Health Bureau.

^aHRSA reports DGIS measure #5 at the end of the grant period.

^bDGIS measure #7 measures any increase in family or youth participation in MCHB programs and planning activities. For example, family participation includes family or youth involvement on advisory committees or task forces, participation in the planning or evaluation of the program’s activities, the hiring of family members or youths as paid staff or consultants to the program to provide his or her expertise from the family perspective, and the recruitment of family members or youths from racially, ethnically, and linguistically diverse backgrounds as participants or advisors in these activities. DGIS measure #10 measures any increase in the number of MCHB supported programs that have incorporated cultural and linguistic competence into their policies, guidelines, and training. For example, a culturally and linguistically competent program is characterized by elements including (1) the incorporation of culturally competent core functions in an organization such as conducting needs assessments of the culturally diverse groups served by the program, data collection and analysis of populations served according to racial, ethnic, and linguistic groupings, and the development of strategies to address service barriers, (2) the provision of culturally and linguistically competent training and skill building efforts, and (3) collaboration with diverse communities and families with regard to program planning, service delivery, and evaluation or monitoring of services.

Grantees rate their performance on each dimension represented by the DGIS measures. As a result, the DGIS measures represent self-assessments of what grantees accomplished during the year. The evaluation will combine these self-assessments with descriptions of grantees activities and other data they report to develop a picture of the achievements realized by the State Implementation grants.

Grantees will report DGIS measures 120 days after the end of each program year and the evaluation team will access the information as soon as it is available. We anticipate obtaining these data in January 2010 and January 2011. Of the nine grantees, six are state Title V programs and are familiar with DGIS measures and their reporting. However, three grantees are private organizations and new to this type of reporting.

B. NEW DATA COLLECTION TOOLS

Although the application materials, progress reports, and DGIS measures will provide rich information for the evaluation, they are unlikely to provide all the information needed to complete the evaluation. As a result, the evaluation team will augment these data collection tools to include new tools designed specifically for this evaluation. These new tools will include 1) interviews with the grantees and 2) a network questionnaire.

1. Grantee Interviews

While the applications and annual progress reports will be our primary data sources, they will not provide the level of detail necessary for a thorough analysis of the CAAI's State Implementation grants. To obtain detailed information, we will conduct semi-structured interviews at the annual grantee meetings to clarify any outstanding questions and obtain more specific information than is possible from document abstraction. Example questions for these interviews are included in Attachment C. This preliminary material presents expected interview topics and questions organized around the four objectives. Semi-structured interviews provide flexibility to tailor the interview to the respondent and follow unanticipated lines of discussion while covering predetermined topics common across all interviews. If grantees are unable to meet at the December CAAI annual meetings, telephone interviews will be scheduled shortly thereafter. We will also use these interviews to request grantee assistance updating the two-page project description we developed using their grant application materials. This type of exercise will help clarify key changes in their programs. For the last program year, we will conduct abbreviated telephone interviews in February of 2011 to capture information for the first 3 months of that year.

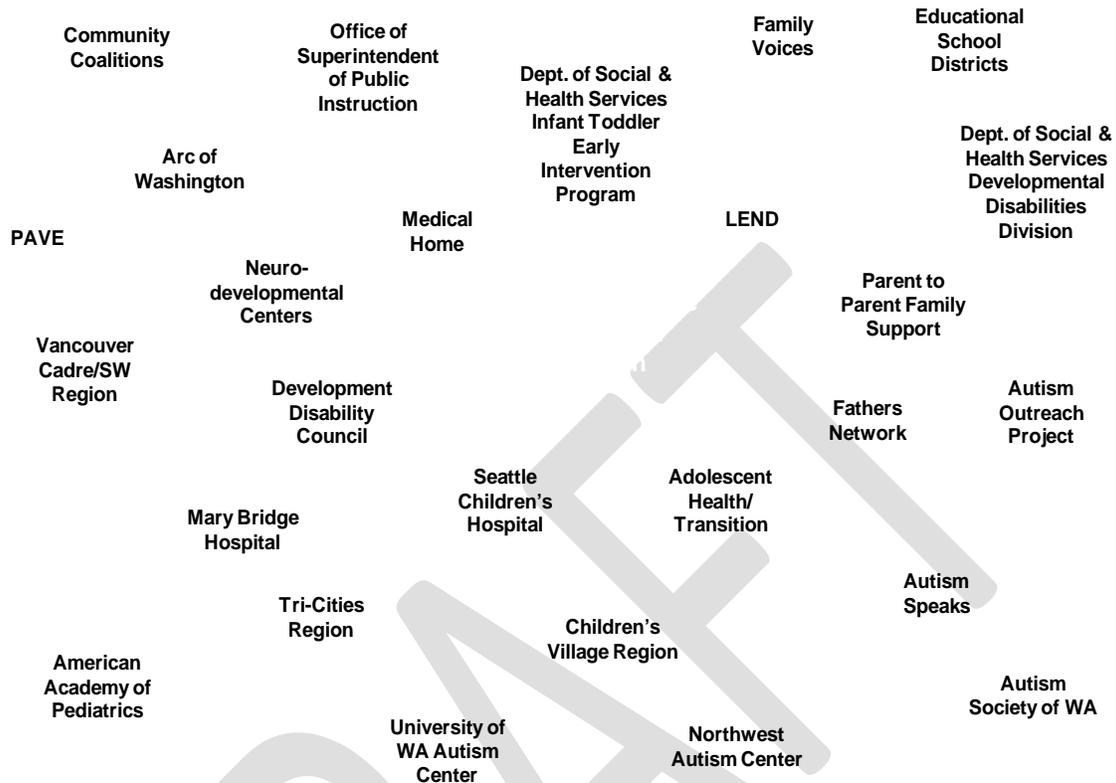
2. Network Questionnaire

In preparation for the December 2008 grantee meeting, we developed a brief questionnaire that asked the six grantees funded in 2008 to diagram their partnerships, report the frequency of partner communication and the nature of their relationship with each partner. This questionnaire, included in Attachment D, was designed to provide baseline information about the network in which each program operates.³ Each year, we will ask grantees to update the information they provided during the first year of grant funding. We anticipate that at least one grantee will have a stable network of partners so that the information we collected at baseline will change very little as the program matures. Other grantees may experience shifts in their partnerships and their networks may become more or less complex over time. Because a changing network of partnerships may be indicative of a changing infrastructure and systems of care, this data collection tool will help the evaluation identify the contributions of the grantees to systems change. In addition, this tool will help us identify the relationships of the grantees to other MCHB programs including LEND grantees and Family-to-Family Health Information Centers.

Figure V.1 provides an illustrative example of Washington's network diagram. Each oval represents a partner and the lines radiating to the grantee represent the level of communication between the grantee and the partner.

³ The network questionnaire uses relationship type definitions developed by Ellen Taylor-Powell, Boyd Rossing, and Jean Geran in "Evaluating Collaboratives" (1998).

FIGURE V.1
 NETWORK OF THE WASHINGTON STATE IMPLEMENTATION GRANT: DECEMBER 2008



Washington’s grantee, the Washington State Department of Health, communicates weekly with three partners, one being the state’s LEND program. The grantee considers the Medical Home Leadership Network to be a collaborator with whom they have developed a shared vision for the system and the relationship is at the stage of sharing resources to build an interdependent system. The grantee coordinates with the LEND and the early intervention program around needs, resources, and activities for more efficient and effective results. Conversely, the Washington grantee only communicates once a year with four partners, including the Autism Society and the state chapter of the American Academy of Pediatrics. The grantee discusses issues and shares information with these partners and their relationship is at the stage of developing a common understanding and exploring common ground. The full set of network diagrams, one for each of the six grantees funded in 2008, is included in Attachment E. Similar network diagrams will be developed the three grantees funded in 2009.

3. Interview with State Public Health Coordinating Center

Mathematica will also assess the state Public Health Coordinating Center. To do this work, Mathematica will review the Center’s progress reports and use information reported by the grantees to document the assistance the grantees receive and its contribution to grantee activities. In addition to providing grantees with technical assistance, AMCHP also ensures coordination of

CAAI projects across grantees. To determine what specific activities AMCHP was able to perform with the CAAI funding, and to capture their contributions to the grantees' performance, we plan to interview AMCHP's CAAI Director at the beginning of the third grant year. The goal of the interview will be to describe AMCHP's support and technical assistance, and the extent to which the states were able to leverage that support to accomplish the objectives of the CAAI. The results of this interview will be included in the final MCHB report.

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VI. DATA ANALYSIS PLANS

The analysis of the State Implementation grants will be designed to assess grantees' achievement of three CAAI objectives and an additional objective related to systems change and infrastructure building (see Overview of the Design in Chapter IV). Below, we describe how we will approach the analysis of each objective to draw conclusions about the influence of the State Implementation grants on general awareness of ASD and other DD and the screening and treatment for these conditions; barriers to services; training of professionals and parents (to navigate the service system); and infrastructure building. The table shells presented below are examples of what we plan to do based on the information available at the time of this report. Our analysis will ensure that we capture grantee's utilization of MCHB's previous expertise in building state capacity to implement and sustain infrastructure change.

All analyses will be descriptive in nature. Whenever possible, quantitative data will be used to describe and document accomplishments.

A. BUILDING PUBLIC AND PROVIDER AWARENESS

MPR will use qualitative research methods to determine the extent to which the State Implementation grants increased awareness of ASD and other DD and the services available for families (achievement of the first objective of the CAAI). An implementation analysis will be used to describe each program's awareness building activities. Several grantees described in their grant applications how they would target different populations for awareness building activities, including families, health care providers, and early intervention programs. Because these activities are likely to vary by targeted population, we anticipate organizing the presentation of the information collected by target group. Table VI.1 provides one example of a strategy that could be used to present basic information about grantee's awareness building activities. The information in the table reflects information abstracted from grantee applications and characterizes what they plan to do. Through annual progress reports and grantee interviews, we will update this information to document what grantees actually do to increase awareness.

TABLE VI.1

AWARENESS BUILDING ACTIVITIES: TOPICS BY TARGET POPULATION AND GRANTEE

Grantee	Targeted Populations			
	Families	Health Care Providers	Early Intervention Programs	Others
Group 1. Frontline Services				
Alaska	-Signs and Symptoms -Screening Tools and Resources	-Signs and Symptoms -Screening Tools and Resources	-Screening Tools and Resources	NA
Missouri	-Signs and Symptoms -Post-Diagnosis Resources	-Signs and Symptoms -Post-Diagnosis Resources	NA	NA
Group 2. Strengthening Skills of Providers and Families				
Illinois	NA	-Screening Tools and Resources -Post-Diagnosis Resources	NA	-Oral Health Providers ^a
New York	-Signs and Symptoms -Screening Tools and Resources	-Signs and Symptoms -Screening Tools and Resources	NA	-County Health Departments ^b
Utah	-Signs and Symptoms -Post-Diagnosis Resources	-Signs and Symptoms -Screening Tools and Resources -Post-Diagnosis Resources	-Signs and Symptoms -Screening Tools and Resources	-Kindergarten Programs ^c
Group 3. Infrastructure Building				
New Mexico	-Post-Diagnosis Resources	NA	NA	-ASD Family Specialists ^d
Rhode Island	-Post-Diagnosis Resources	-Signs and Symptoms	-Signs and Symptoms	-Childcare Providers
Washington	-Signs and Symptoms -Post-Diagnosis Resources	NA	NA	NA
Wisconsin	-Signs and Symptoms -Screening Tools and Resources -Post-Diagnosis Resources	-Signs and Symptoms -Screening Tools and Resources -Post-Diagnosis Resources	NA	-Public Forums ^e

Source: Abstraction of the State Grantee Applications submitted to MCHB.

Note: Topic options include: Signs and Symptoms; Screening Tools and Resources; Diagnostic Tools and Resources; and Evidence-Based Treatment Options. We were unable to identify a grantee that plans to build awareness about Diagnostic Tools and Resources or Evidence-Based Treatment Options.

NA = grantee did not target this group; Signs and Symptoms = CDC’s Learn the Signs/Act Early materials, state-specific public media campaigns; Screening Tools and Resources = American Academy of Pediatrics (AAP) Physician Autism Tool Kit, First Signs Screening Kit, ASD developmental checklists and screening tools; Post-Diagnosis Resources = First

100 Days Kit, adolescent transition resource guides, state-specific autism resource guides, or state education programs developed for caregivers of newly diagnosed children.

^aIllinois is providing dentists with Dental Desensitization Kits to improve treatment for children with ASD/DD.

^bNew York is helping county health departments incorporate ASD developmental information in local child find and public awareness activities.

^cUtah is piloting ASD screening checklists for teachers in select preschool and kindergarten classes.

^dASD Family Specialists will tailor New Mexico's awareness building activities to regional needs.

^eWisconsin is distributing Learn the Signs, Act Early and AAP Physician Autism Tool Kits at health fairs, school transition fairs, conferences, local support groups, and statewide committees and councils.

When describing awareness building activities, the evaluation team will seek to determine the extent to which grantees involve family members in the planning, implementation, and evaluation of these activities. Family involvement is considered critical to the effectiveness of information campaigns and MCHB considers this aspect important enough to require the reporting of a performance measure directly related to family involvement (DGIS measure number 7). Table VI.2 illustrates how the evaluation could combine information about family involvement with a description of the activities grantees pursued when building the awareness of health care providers. Checkmarks would be used to identify the different phases and whether families were involved. The evaluation could use a similar type of table to describe grantee activities to address disparities in awareness where Family Involvement would be replaced with Types of Disparities Addressed to indicate the different disparities grantees sought to address with their awareness building activities (for example, ethnic or geographically isolated groups).

TABLE VI.2

DESCRIPTION OF AWARENESS BUILDING ACTIVITIES TARGETED TO HEALTH CARE PROVIDERS

Grantee	Family Involvement			Description of Activities
	Planning Phase	Implementation Phase	Assessment Phase	
Group 1. Frontline Services				
Alaska				
Missouri				
Group 2. Strengthening Skills of Providers and Families				
Illinois				
New York				
Utah				
Group 3. Infrastructure Building				
New Mexico				
Rhode Island				
Washington				
Wisconsin				

Source: Grantee applications, annual progress reports, and grantee interviews.

A key component of the analysis of awareness building activities will be determining lessons learned and how grantees refined and improved their activities as their programs matured. To conduct this analysis, we will rely on information gathered from annual progress reports and grantee interviews. The DGIS performance measure related to family involvement (DGIS measure number 7), will be incorporated into this analysis to document how performance on this dimension changed during the grant period.

Whenever possible, we will collect and analyze data grantees collect on the effectiveness of their awareness building activities. Several grantees have reported that they will be collecting data on the number of people they reach either through counts of materials distributed or counts of attendees at specific events. At least one grantee reported the program will be collecting data on the knowledge gained by attendees. Because the data we obtain to assess the effectiveness of awareness building activities is likely to vary greatly by grantee, the evaluation will present the information obtained as case studies and illustrations of what grantees learn about their activities and their ability to raise awareness of ASD and other DD and the services that children and families need.

B. REDUCING BARRIERS TO SCREENING AND DIAGNOSIS

The grantees are tackling a range of issues that create barriers to screening and services for ASD and other DD. The evaluation team's assessment of the extent to which grantees reduce barriers to these services will first document and describe the different types of barriers each grantee pursued and then present data on program accomplishments (achievement of the second objective of the CAAI). The documentation of activities will focus on determining what grantees did to

- Reduce barriers to screening, diagnosis, and treatment services
- Increase the number of medical homes knowledgeable about ASD and other DD
- Improve youth transition services.

During the documentation of grantee activities to reduce barriers to care, we will seek information about how the activities addressed disparities in the system and whether the grantee established or participated in any type of learning collaborative related to the service system. The evaluation will also assess lessons learned by grantees to provide information for other states that look to the grantees as model programs. Table VI.3 illustrates one approach to summarizing the activities of each grantee. We include a general service category, *ASD and other DD Services in General*, to capture infrastructure building activities that span the full spectrum of services for children and youth with ASD and other DD.

TABLE VI.3

ACTIVITIES TO REDUCE SERVICE SYSTEM BARRIERS: BY CATEGORY OF SERVICE AND GRANTEE

Grantee	Category of Service					
	Screening	Diagnosis	Treatment	Medical Homes ^a	Youth Transition Services ^b	ASD/DD Services in General
Group 1. Frontline Services						
Alaska	Implemented in-home, filmed assessments					
Missouri						
Group 2. Strengthening Skills of Providers and Families						
Illinois						
New York						
Utah						
Group 3. Infrastructure Building						
New Mexico						
Rhode Island						
Washington						
Wisconsin						

Source: Abstraction of the state grantee applications, annual progress reports, and grantee interviews.

^aMedical homes knowledgeable in ASD and other DD services.

^bServices designed to help youth transition to adult services.

Grantees’ accomplishments in reducing barriers to care will be documented with quantitative data whenever possible. All grantees will report on nine DGIS measures, and we have determined that four of these measures reflect grantees’ assessment of their ability to help the state address overall barriers to care. Table VI.4 illustrates one approach to analyzing the DGIS data for the six states for which we will have two years of information. Because these data will be reported on an annual basis, this table reflects our proposed approach to assessing progress over time. By measuring the year-to-year change in grantee performance along four dimensions, the evaluation will be able to determine the progress grantees made helping the states increase access to (1) care for children with special needs (DGIS measure number 23), (2) insurance coverage for services required by children with special needs (DGIS measure number 16), (3) medical homes (DGIS measure number 19), and (4) youth transition services (DGIS measure number 37). The evaluation will assess the DGIS data by several different program

characteristics to determine whether performance on these measures is associated with types of grantee activities. We will not have access to data that would allow us to determine causation, but identifying the existence of a relationship between activities, such as focused efforts to improve insurance coverage, and performance on specific DGIS measure represents an initial step in determining program effectiveness. When assessing the data grantees report for federal fiscal year 2010, we will include the three states that received funding in 2009.

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TABLE VI.4
ACCOMPLISHMENTS IN REDUCING BARRIERS TO CARE REPORTED BY THE GRANTEES

Year	Assistance Increasing the Percentage Screened, Linked to Medical Homes, Follow up, and Early Intervention DGIS Number 23	Assistance Increasing Percent with Adequate Insurance Coverage to Pay for Needed Services DGIS Number 16	Assistance Increasing Percent of Children Receiving Coordinated, Ongoing, Comprehensive Care within a Medical Home DGIS Number 19	Assistance Increasing Percent of Youth Receiving Services to Help Transitions to Adult Health Care, Work, and Independence DGIS Number 37
Alaska				
2009				
2010				
Percent Change				
Illinois				
2009				
2010				
Percent Change				
Missouri				
2009				
2010				
Percent Change				
Utah				
2009				
2010				
Percent Change				
Washington				
2009				
2010				
Percent Change				
Wisconsin				
2009				
2010				
Percent Change				

Source: DGIS for program years 2009 and 2010.

DGIS = Discretionary Grant Information System.

Note: The three grantees funded in 2009 (New Mexico, New York, and Rhode Island) are not included in a table of this type because the evaluation will have only year of data.

The DGIS measures will provide general information about grantees' performance and their ability to reduce barriers to care. To determine the extent to which the State Implementation grants reduced specific barriers for children and youth with ASD and other DD, we will use data collected directly from the grantees. As mentioned previously, the data reporting of grantees varies greatly. Some, but not all, have indicated an ability to report the number of children they screen, diagnosis, and treat for ASD and other DD. Those grantees capable of reporting such data will be included in a more detailed assessment of grantees' abilities of helping children, youth, and families access services. Table VI.5 illustrates the types of analyses we envision based on our understanding of what states can report. We anticipate that about three grantees will be able to provide data on the number of children screened for ASD and other DD. However, we think that only two states can report a full range of information that will allow us to estimate diagnosis and treatment rates. As a result, the states that can report this information will be illustrative case studies of what states can do.

TABLE VI.5

SCREENING, DIAGNOSIS AND TREATMENT RATES

Measure	State 1	State 2	State 3	State 4
Program's Screening Rate for ASD/DD ^a			NA	
2009				
2010				
Percent change				
Age Distribution of Children Screened ^b (Percent)			NA	
0 through 3				
4 through 5				
6 and older				
Program's Diagnosis Rate for ASD/DD ^c		NA		NA
2009				
2010				
Percent change				
Average Time from Screening to Diagnosis for ASD/DD ^b		NA		NA
ASD/DD Treatment Rate ^d		NA		NA
2009				
2010				
Percent change				
Average Time from Diagnosis to Treatment ^a		NA		NA

Source: Grantee Data Reports and Census data.

Note: If a grantee only serves children in specific areas of the state, the denominators used in the calculation of rates will be adjusted to reflect the total number of children in the targeted regions.

^aCalculated as the number of children screened by the program per 10,000 children ages 0 to 15 in the state or in the region targeted by the grantee.

^bFor the 2010 cohort only.

^cCalculated as the number of children who screened for ASD/DD and were diagnosed for ASD/DD by the program per 10,000 children ages 0 to 15 in the state or in the region targeted by the grantee.

^dCalculated as the number of children who were diagnosed for ASD/DD by the program and entered treatment per 10,000 children ages 0 to 15 in the state or in the region targeted by the grantee.

C. TRAINING PROFESSIONALS AND FAMILIES

All of the state projects intend to introduce or enhance existing training initiatives for health care providers, educators and early intervention providers, and parents. The assessment of grantee training activities will begin with a description of these activities and how they evolve during the grant period. We will then assess the data grantees report on the outcomes of their training activities (achievement of fifth objective of the CAAI). For activities focused on training providers, we anticipate such activities will build knowledge of screening and diagnostic tools and evidence-based interventions. We will document and describe grantee activities, with particular attention given to how the grantees coordinated these activities with other trainings, such as those provided by LEND grantees and developmental pediatric training programs.

A key focus of our evaluation will be to determine what the State Implementation grants added to the array of trainings available to providers and early intervention specialists. We also propose to conduct a case study of Utah's training for early childhood educators. Utah may be an important model for how states may build the knowledge of preschool and kindergarten teachers who are on the frontline working with children who may have signs and symptoms of ASD and other DD. The descriptive assessments of provider trainings will be supplemented with data grantees report about the outcomes of these activities. The six grantees funded in 2008 indicated that they can report on the number of providers trained and several report they will have data on how the trainings affect the knowledge of those who attend. We will use these data to document the size and outcomes of the training programs implemented by the grantees

Other analyses of training programs will assess activities designed to improve the advocacy and navigation skills of families. Several of the grantees are devoting considerable resources to supporting families and helping them become better advocates for their children with ASD and other DD by improving their knowledge of how to navigate the services available. For example, Illinois will implement a Family Advisor Training Program (developed by TAP's two parent liaisons and The Arc of Illinois Family to Family Program), which will train 90 Family Advisors to communicate more effectively with physicians and allied providers. The Utah Chapter of Family Voices (UFV) will train five family resource navigators to work with providers and provide support, link parents to community resources, and assist parents in making informed decisions. The project will additionally train and provide modest stipends to parent advocates in medical home practice teams. An annual conference for families of children and youth with ASD will focus on navigating financing, medical home concepts, adult transition issues, and developing family and professional partnerships. The evaluation will document and describe these activities and will determine how these activities are coordinated with other programs designed to support families, such as MCHB's Family-to-Family Health Information Centers.

Again, the evaluation will seek to determine what the State Implementation grants added to the supports available to families. The data collected to assess the outcomes of activities to help families improve advocacy and navigation skills will be determined by what the grantees can report. We have also linked a DGIS measure to this component of the evaluation and will use these data to track grantee's self-reported performance in assisting families to partner in decision making and be satisfied with services they receive (DGIS measure number 6). Table VI.6

illustrates one possible approach to analyzing the DGIS data for the six grantees funded in 2008 and for which we will have two years of information. We will check off which topics were included in the training each year and report the DGIS data in the last column. As a result, this table links the type of training grantees provide families each year with the DGIS data for the same year. As mentioned previously, the DGIS data represent the grantees' assessment of their performance in each area, which in this case would be their performance helping families become partners in decision making. When assessing the data grantees report for federal fiscal year 2010, we will include the three states that received funding in 2009 and started program operations in federal fiscal year 2010.

TABLE VI.6

FAMILY TRAININGS AND GRANTEE ASSESSMENT OF DEGREE TO WHICH THEY ASSISTED FAMILIES TO PARTNER IN DECISION MAKING AND BE SATISFIED WITH SERVICES THEY RECEIVE

Grantee	Training Contents				Degree to which Grantee Assisted Families to Partner in Decision Making (DGIS Measure Number 6)
	Diagnostic Resources	Evidence-Based Treatment Options	Provider Resources	Family Support Resources	
Alaska 2009 2010 Percent change	NA	NA	NA	NA	
Illinois 2009 2010 Percent change	NA	NA	NA	NA	
Missouri 2009 2010 Percent change	NA	NA	NA	NA	
Utah 2009 2010 Percent change	NA	NA	NA	NA	
Washington 2009 2010 Percent change	NA	NA	NA	NA	
Wisconsin 2009 2010					

Grantee	Training Contents				Degree to which Grantee Assisted Families to Partner in Decision Making (DGIS Measure Number 6)
	Diagnostic Resources	Evidence-Based Treatment Options	Provider Resources	Family Support Resources	
Percent change	NA	NA	NA	NA	

Source: Grantee applications, annual progress reports, grantee interviews, and DGIS.

DGIS = Discretionary Grant Information System

Note: The three grantees funded in 2009 (New Mexico, New York, and Rhode Island) are not included in a table of this type because the evaluation will have only year of data.

D. INFRASTRUCTURE BUILDING AND SYSTEMS CHANGE

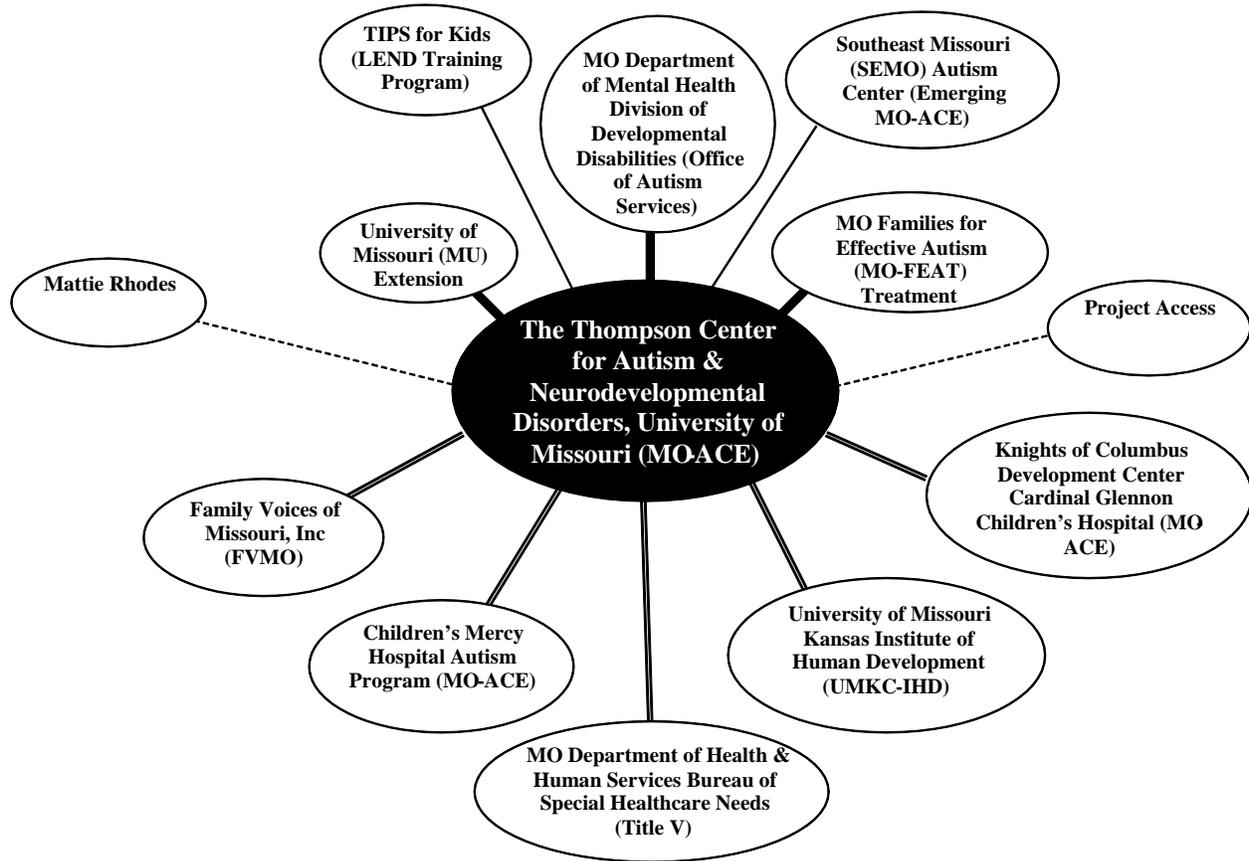
Infrastructure building and systems change will be critical outcomes of the State Implementation grants. Although this aspect of grantee activities does not link directly to any of the CAAI objectives, strengthening the foundation and overall system of ASD and other DD services will be an important determinant of the long-term impact of the State Implementation grants and their ability to improve access to screening, diagnosis, and treatment services. The analyses described below are designed to identify select systemic changes that resulted from grant activities.

Each grantee is pursuing a range of activities that are likely to affect state, regional, or local service systems. To investigate infrastructure building and systems change, we will use a two-stage approach. We will assess each grantee’s network and how it evolved and then link this information with activities and achievements in the areas of awareness building, reducing barriers to care, and training of providers and families.

MPR will use a network analysis to develop an understanding of each grantee’s partners and the nature of their relationships. Using a brief network questionnaire, we will capture information about the size and complexity of each grantee’s network of partners. The questionnaire asks the grantee to identify each partner, report how frequently the grantee communicates with each, and describe the type of relationship the grantee has with each partner. The grantee identifies each partner in a figure, such as Missouri’s network diagram in Figure VI.1 below. This visual depiction of the partnership will illustrate the density of each grantee’s network. The lines between the grantee and partners represent the frequency of communication, where more frequent communication is represented by solid, thicker lines. The lines provide a visual depiction of the partners with whom the grantee most closely works. The questionnaire also collects information about the type of relationship the grantee has with each partner. We will use the relationship types defined by Taylor-Powell, Rossing, and Geran (1998), which are presented in Table VI.7. These types represent a continuum of relationships from simple communication to collaboration based on interdependency and sharing of resources. Using the frequency and type of relationship, we will be able to identify the strongest links in each grantee’s network.

FIGURE VI.1

NETWORK OF THE MISSOURI STATE IMPLEMENTATION GRANT: DECEMBER 2008



In addition to examining changes in each grantee network over time, we may also examine the grantee networks in relation to each other to identify potential gaps in a grantee's network. For example, some grantees may not include a link to early intervention of special education departments – a gap that could serve as a potential area for further outreach and program development. In general, our analyses will define what is potentially absent from each grantee's network, and we will use that information to shape follow-up questions regarding the potential for missed opportunities.

TABLE VI.7

DEFINITIONS OF NETWORK RELATIONSHIPS

Type of Relationship	Description of Relationship Type
Communication	The grantee and partner discuss issues and share information about each other’s activities. The relationship is at the stage of developing a common understanding and exploring common ground.
Contribution	The exchanges between the grantee and partner are about supporting each other’s efforts. The relationship is at the stage of building mutual obligations and trust.
Coordination	The grantee and partner are coordinating needs, resources, and activities. The relationship is at the stage where both parties are adjusting current activities for more efficient and effective results.
Cooperation	The grantee and partner are linking resources to help both organizations achieve joint goals. The relationship is at the stage of building trust by working together.
Collaboration	The grantee and this partner have developed a shared vision for the system. The relationship is at the stage of sharing resources to build an interdependent system.

Source: Taylor-Powell, Rossing, and Geran (1998).

The key to assessing infrastructure building will be administering the network questionnaire each year and tracking the evolution of the grantee’s network of partnerships. The objective will be to identify when a grantee’s network becomes more or less complex (the number of partners increases or decreases), when the frequency of communication increases or decreases, or when relationships with particular partners changes (such as when the relationship with a partner moves from one based on mutual contribution to mutual coordination). Although we will not be able to judge whether a given change in a grantee’s network will result in a positive outcome, such as an increase in access to screening services, each change will be a signal that something has occurred and a line of inquiry should be pursued during our interviews to determine the significance of the change and the likely results. This network analysis will be used to identify changes in the partnership that reflect infrastructure changes. The evaluation will pay particular attention to network changes that indicate relationships between different agencies are being forged or strengthen (for example, Title V and the Department of Education) or between a state agency and key programs (such as Title V and the LEND program or Early Head Start). We anticipate the four grantees with strong infrastructure building components may offer key case studies in state- and regional-level infrastructure building activities.

The information about grantee networks and the changes in these networks will be linked whenever possible to the other information about grantee activities and achievements in the areas of building awareness, reducing barriers to care, and training professionals and families. For example, some grantees are creating systems change by introducing new services or enhancing and expanding existing services. While these activities are likely to improve access to care, to understand the implication of these activities for systems change we need to know what types of

policies and procedures had to be adjusted to accommodate or facilitate these changes in services and which partners and organizations contributed and made the change feasible. Thus, when documenting grantee activities the evaluation will seek to determine the roles of each partner in specific activities and whether the partner had to change policies or procedures to facilitate the implementation of the activities.

When linking the grantee's network of partners and grantee activities we will pay particular attention to identifying the roles of advocates and families. The network analysis will identify whether family advocacy groups are partners, but when key grantee activities are identified, we will follow a line of inquiry to determine the role of advocates and families in the activity and whether they helped to ensure that new policies, guidelines, contracts, and training developed by the grantee were family centered and incorporated cultural competence elements. We will supplement this specific information with the data grantees will report for DGIS measure number 10. This measure captures grantees' assessment of the degree to which they have integrated cultural and linguistic competence into their policies, guidelines, contracts, and training.

Another key analysis of infrastructure building and systems change will focus on the sharing of information at the state, regional, and local levels. The flow of information is critical for an effective system of care, particularly for children and youth who have life-long conditions that require a variety of services and supports from the earliest ages. Currently, the key issue in the care and treatment of ASD and other DD is early and timely screening, diagnosis, and treatment. At the state agency level, we will use grantee interviews to gather information about the types of data sharing arrangements between the grantee and its partners. One key measure will be the presence of Memoranda of Understanding (MOUs) that include data sharing agreements and whether the grantee is able to increase the number of MOUs or enhance existing MOUs to strengthen and improve data sharing arrangements. During the grantee interviews, we will pursue lines of inquiry about the shared data and how it supports the grantee's operation and its overall network of partners. We will be particularly interested in gathering information about any ASD monitoring or surveillance system, such as the CDC Autism Developmental Disabilities Monitoring (ADDM) Network. If one exists, we will determine how the grantee and its partners coordinate with this system and whether and how they use the information produced by it. Rhode Island may offer an important case study on this topic because this program is enhancing an existing statewide registry to include ASD and other DD. They plan to use the registry to provide families with referrals to appropriate programs and resource guides.

The focus of our assessment of information sharing arrangements at the regional and local levels will be the referral systems available to families. During grantee interviews, we will include a line of inquiry about referral systems for families and whether any grant activities have strengthened established referral systems or established new ones. We will supplement this descriptive information with data reported by the grantees. Almost all grantees can report data on the number of individual referral systems available to families they serve, or the number of referral systems grant activities have strengthened or established, or the number of families who received referrals through these systems. We will also have a more general measure from DGIS. Grantees will report data for DGIS measure number 31, which will provide the grantees' assessment of their work to help develop systems of care that are easy to use for families of children and youth with ASD and other DD.

In the final analysis, we will assess the lessons learned and the likely sustainability of grant activities. In our last interview with grantees, scheduled for March of 2011, we will ask them to reflect on the challenges to program implementation and assess the degree to which they were able to implement the initial state plan and why they deviated from the state plan if they did so. We will also discuss facilitating factors that made implementation easier than expected and state-level policy changes that created synergies for their activities. Lastly, we will ask grantees their plans for sustaining program activities and how they may change once the MCHB grant funds end.

VII. FINAL REPORTS

A. REPORT TO MCHB

Following analysis, we will submit a draft report of findings. We envision that the final report will include:

- An executive summary
- Goals and objectives of the state demonstration programs
- Detailed narrative of activities and accomplishments, including supporting tables of results
- Analysis of outputs and outcomes
- Recommendations for future research, implementation, or activities
- Attachments illustrating the evaluation framework.

Following delivery of the evaluation reports, we will meet in person with the MCHB Project Officers to discuss the draft report.

B. DRAFT CHAPTER FOR REPORT TO CONGRESS

Following review of the above report, we will prepare and submit a draft chapter for the MCHB contribution of the HHS Secretary's Report to Congress, as required in Section 399DD of the legislation related to the MCHB CAAI activities. This report will summarize the activities of the State Implementation grants and evaluation results by major objectives:

- Effectiveness in increasing public/provider awareness of ASD and other DD
- Effectiveness in reducing barriers to screening, diagnosis, and evidence-based interventions
- Effectiveness in training professionals to utilize valid screening/diagnostic tools and provide evidence-based interventions
- Effectiveness in infrastructure building and systems change.

B. Requirements of the Legislation for the Report to Congress⁴

The *Combating Autism Act of 2006* requires that the funded agencies provide Congress with a report that, at a minimum, describes the amounts expended on the implementation of the particular provisions of the CAA. In addition, the report is required to provide information on:

- The incidence of ASD and trend data of such incidence since the date of enactment of the *Combating Autism Act of 2006*

⁴ Public Law 109-416§42 U.S.C.§280i-3

- The average age of diagnosis for children with ASD and other developmental disabilities (DD), including how that age may have changed over the 4-year period beginning on the date of enactment of this Act
- The average age of intervention for individuals diagnosed with autism spectrum disorder and other developmental disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of this Act
- The average time between initial screening and diagnosis for ASD and other DD, as well as information on the average time between diagnosis and evidence-based intervention for individuals with ASD and other DD
- The effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including various subtypes, and other developmental disabilities and how the age of the child may affect such effectiveness
- The effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with autism spectrum disorder or other developmental disabilities
- The services and supports provided to individuals with autism spectrum disorder and other developmental disabilities who have reached the age of majority (as defined for purposes of section 615(m) of the *Individuals with Disabilities Education Act* (20 U.S.C. 1415(m)))

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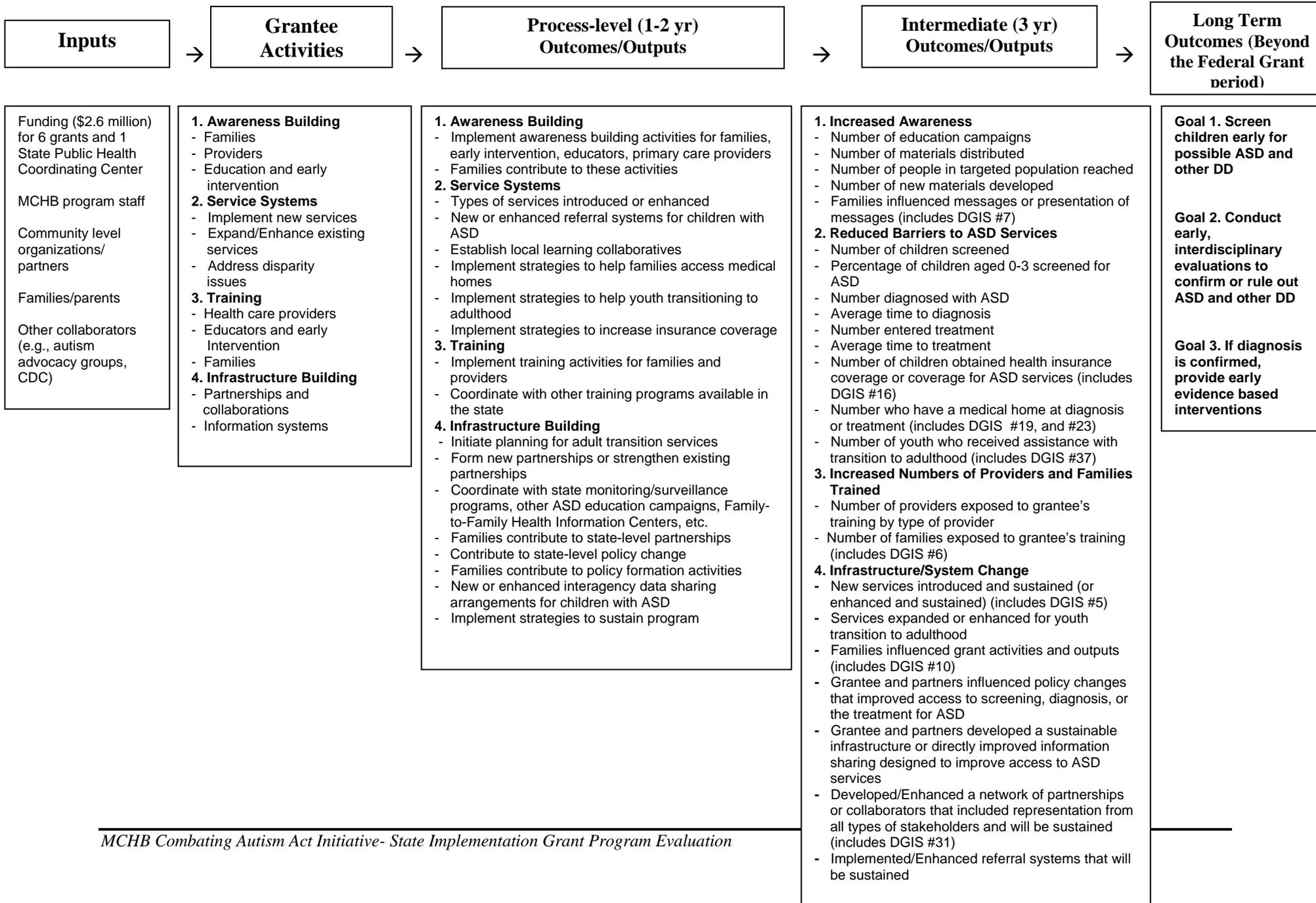
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ATTACHMENT A

LOGIC MODEL FOR STATE IMPLEMENTATION GRANTS

Logic Model for State Implementation Grants



ATTACHMENT B
PROJECT SUMMARIES

The project summaries incorporate comments we received from six of the nine grantees. Alaska, Illinois, Missouri, Utah, Washington, and Wisconsin had the opportunity to review and comment on draft project summaries in late 2008. New Mexico, New York, and Rhode Island have not been given the same opportunity as of the date of this report. All nine programs will have an opportunity to review and provide updates for these summaries during the first quarter of FFY 2010 and FFY 2011.

ALASKA PROJECT SUMMARY

Alaska will improve access to services for children and youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities by expanding services and building awareness. Specifically, the program in Alaska will work on:

1. Establishing in-home assessments of young children living in rural areas
2. Providing statewide multi-disciplinary trainings for a wide variety of paraprofessionals in health care and schools
3. Conducting professional and public outreach campaigns

To achieve these goals, Alaska intends to:

1. Build Awareness

To build general awareness of screening, diagnosis, and treatment for ASD, the project will distribute 250 Autism Tool Kits to primary care providers, parent navigators, early intervention providers, and others throughout the state. This kit was developed by the American Academy of Pediatrics and provides information about the five critical elements in caring for children with ASD. The project will also distribute 7,500 copies of the CDC “Learn the Signs: Act Early” public education materials and 4,500 copies of Alaska specific brochures. These materials will include information on how to access the Rapid Response Team. In addition, the project will present a culturally appropriate public media campaign that is Alaska-focused.

2. Introduce New Services

To improve early identification and diagnosis in rural areas, Alaska will establish Rapid Responder teams through the 17 Infant Learning/Early Intervention regions of the state. These teams will film in-home developmental assessments of children living in rural areas of the state. The filmed assessments will be reviewed by a pediatric autism and neurodevelopmental physician and advanced nurse practitioner at the Children’s Hospital at Providence (TCHAP) in Anchorage, Alaska. Once the film is reviewed, the staff at TCHAP will determine next steps.

3. Expand or Enhance Existing Services

If, based on the filmed assessment, the child and family need services, trained parent navigators located at TCHAP will work with families to provide care coordination services, link families to a medical home, determine financing options, and provide information, referrals, and transportation options.

4. Introduce New or Enhance Existing Provider Training Initiatives

To improve rural services, this project will establish a multidisciplinary training program for a variety of providers in rural Alaska. The project will focus on training providers who conduct well child visits and/or developmental screens on young children ages 0 to 3. They anticipate training 238 individuals during the project period and providing follow-up technical assistance.

To develop and conduct the trainings, the project will collaborate with the University of Alaska Center for Human Development, the Providence Neurodevelopmental Center, the Infant Learning Training Program, the Tribal Health Aide Training program, the Public Health Nursing Training Center, and the Early Comprehensive Care Systems Coordinator. The training program will be developed for on-site rural locations, telehealth and video conferencing systems, and web-based applications.

5. Enhance or Expand State Level Collaborations and Planning Activities

To ensure project activities are aligned with other related state activities, the Governor's Council on Disabilities and Special Education/Ad Hoc Committee on Autism will appoint the project manager as a member to bridge project efforts with other state work groups. In addition, the project director will actively participate as a committee member on the Early Comprehensive Care Systems committee; on the Autism subcommittee of the Department of Health and Human Services Child Health Policy Committee; and on the Interdepartmental Early Childhood Coordinating Council.

ILLINOIS PROJECT SUMMARY

Illinois will augment The Autism Program Service Network (TAP)—a preexisting coalition of 30 partners that links universities and community agencies—by adding supportive services and provider training.⁵ Specifically, the program in Illinois will work on:

1. Developing a constituency of active parents capable of forming working partnerships with their children’s primary care providers
2. Conducting provider training to improve primary care physicians’ screening, referral, and treatment practices for children with ASD and other DD, and to measure the number and quality of medical homes
3. Improving the organization of services through the development of standard referral protocols among statewide disability referral networks and members of the TAP
4. Improving accessibility to ASD and other DD services through improved billing and increased billing opportunities
5. Improving the policy and planning related to transition to adult services and increasing adult resource alternatives

To achieve these goals, Illinois intends to:

1. Build Awareness

To build general awareness among Medicaid providers, Health Services Facilitators (HSF) will distribute four items to 250 primary care providers in Illinois Health Connects, a Medicaid program. They will distribute the AAP Physician Tool Kit, the First Signs Screening Kit, the TAP Family Care Kit, and the TAP Resource Directory. They will also distribute a Dental Desensitization Kit to 250 dentists who provide care to Medicaid children.

2. Introduce New Services

Illinois will introduce three Regional Health Services Facilitators (HSF) and a statewide Financial Specialist (FS). The HSFs will create, implement, and monitor policies, procedures, and supports to ensure that families served through TAP partners have coordinated care consistent with the principles of a medical home. They will work with primary care physicians and coordinate with TAP Centers and develop strategies for improving the system of care for children with ASD. The FS will work on developing a billing rate and sliding fee scale for state autism services and explore public and private funding opportunities for ASD services.

3. Expand or Enhance Existing Services

The program in Illinois will seek to improve current resource and referral systems. The HSFs will work with TAP partners (including the Arc of Illinois Lifespan and the

⁵ TAP is managed by the Hope Institute for Children and Families and includes five training and service centers, seven service centers, and two outreach centers.

Autism Society of Illinois) to establish standardized referral protocols so that resources and referrals are better coordinated across TAP partners.

4. Introduce New or Enhance Existing Provider Training Initiatives

Illinois will implement a Family Advisor Training Program (developed by TAP's two parent liaisons and The Arc of Illinois Family to Family Program). The program will train 90 Family Advisors from TAP's 12 Centers to communicate effectively with physicians and allied providers.

This project will also train the HSFs to orient 120 medical practices to medical home principles and facilitate the development of 6 medical homes specific to ASD/DD. In addition, the HSFs will work with the existing autism service system to provide in-practice training in early continuous screening, diagnosis, and treatment to community providers. These trainings will also be made available in a web-based format. In addition, because cultural differences represent barriers to access across the state, state autism network staff will provide training in culturally competent care to state autism centers.

5. Enhance or Expand State Level Collaborations and Planning Activities

To improve public and private coverage, the state will pursue legislation or policy changes to improve coverage of services for persons with ASD/DD as identified by the FS. To improve the transition to adulthood, the program will organize a multi-state conference on the transition to adult services, create a model Family Resource Room for adults, and host statewide community planning initiatives for adult services.

MISSOURI PROJECT SUMMARY

Missouri will expand the Rapid Response Project—a pilot program launched in 2007 to improve access to timely ASD screening, diagnosis, and intervention—by implementing the project in three additional regions of the state, as well as supporting regional Family Resource Specialists and Parent Mentors, strengthening supportive services at three Autism Centers of Excellence (MO-ACE), and conducting ASD provider training. Specifically, the program in Missouri will work on:

1. Improving access to, and sustainability of, comprehensive and coordinated care through medical homes
2. Developing a constituency of active parents knowledgeable in ASD and capable of forming working partnerships with their child's primary care provider and other community supports
3. Supporting successful adolescent transition to adulthood for youth with ASD

To achieve these goals, Missouri intends to:

1. Build Awareness

The project will develop a system of training to raise awareness and encourage early identification of ASD and other developmental disabilities in communities across the state. The Rapid Response Collaboratives and MU Extension Specialists will support this system of training. To aide this effort, the project will utilize advanced interactive technologies (e.g., MU ITV Network and the Missouri Telehealth Network), which will allow access to the training packages by parents and professionals in rural and underserved communities.

2. Introduce New Services

Missouri will establish three regional Family Resource Specialists and Parent Mentors who will work with families who receive specialized ASD tertiary care services at one of Missouri's three MO-ACEs, (MO-ACEs include The University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders, Knights of Columbus Development Center at Cardinal Glennon Children's Hospital, and Children's Mercy Hospital Autism Program). The Family Resource Specialist will help families navigate the system of care and assist with youth transitioning to adulthood. The Family Resource Specialists at each site will also enhance existing ASD resource guides to help families access community supports across Missouri. Parent mentors will partner with the Family Resource Specialist at each MO-ACE to provide information, resources, and emotional support to other parents. A Parent Advisory Group organized by the project's Parent Consultant will meet regularly with MO-ACE leaders and advise providers on the cultural competency, organization, and delivery of care.

3. Expand or Enhance Existing Services

To improve the coordination and linkage of services at the community level, Missouri will expand its current Rapid Response Project from one to four areas of the state. In Year 1 of the project, Missouri will expand the initiative from a focus on children ages 0

through 5 to a focus on children ages 0 through 18. In Years 2 and 3, the Rapid Response Project will expand to three additional areas of the state, two in urban areas and one in a rural area.

4. Introduce or Enhance Existing Provider Training Initiatives

The Rapid Response Project will develop training packages on best practices in ASD screening and referral for physicians and health care providers across the state, including those in underserved and rural communities. The Rapid Response Project will also contribute to the development of training packages on parent/professional partnerships and youth transition, in collaboration with other state systems improvement grants.

5. Enhance or Expand State Level Collaboration and Planning Activities

To strengthen state systems, the project will partner with state medical associations to improve collaboration around the Medical Home concept; initiate a statewide ASD training network for families and professionals; develop youth transition training materials; provide best practice information to the Missouri Commission on Autism, which is a statewide legislative advisory body for ASD; and partner with advocates to improve financing for ASD services.

NEW MEXICO PROJECT SUMMARY

New Mexico will augment their ASD Family Specialists—a group of parents of children and youth with ASD trained to help families—by expanding their roles to become community liaisons responsible for building local stakeholder collaboration and supporting access to medical homes. Specifically, the program in New Mexico will work on:

1. Developing regional medical homes by supporting local collaborative efforts between primary care pediatric clinics, early intervention and school systems, parent organizations, and other agencies
2. Increasing public and provider awareness of ASD through community outreach activities designed around regional priorities and needs
3. Improving access to information through the establishment of ASD Regional Resource Centers (ASD-RRCs), which will offer telehealth connectivity between the centers and the Center for Development & Disability (CDD), New Mexico's University Center of Excellence in Developmental Disabilities (UCEDD)

To achieve these goals, New Mexico intends to:

1. Build Awareness

The ASD Family Specialists will lead community outreach activities, which will be regional and based on regional priorities and needs. They will receive a Family Navigation Tool that the New Mexico Autism Taskforce (NMAT) will develop.

2. Introduce New Services

The project will establish five ASD-RRCs based in or near existing Department of Health regional offices in Albuquerque, Gallup/Farmington, Taos, Roswell, and Las Cruces. The ASD-RRCs will be staffed by the ASD Family Specialists and support their work and the development of regional medical homes for ASD. They will also host the project's telehealth initiatives.

3. Expand or Enhance Existing Services

New Mexico will expand the role of the ASD Family Specialists, who are currently employed by the CDD Autism Programs. In their expanded role as community liaisons, the ASD Family Specialist will identify local stakeholders such as primary care practices, individuals with ASD and their families, healthcare specialists, educators, and community agencies and bring them together to build and strengthen regional medical homes for ASD and other DD. In years two and three, New Mexico will utilize a "learning collaborative" approach to expand the medical home network and to improve screening, diagnosis, and treatment services.

4. Introduce New or Enhanced Training Initiatives

To prepare for their expanded role as community liaisons, ASD Family Specialists will receive training on establishing the community linkages and relationships that regional medical homes need. In addition, New Mexico will conduct quarterly educational telehealth programs for medical home professionals, primary care physicians and other providers on early and continuous screening, diagnostic criteria, and evidence-based interventions. Program content will be based on assessment of needs that have been developed by the regional stakeholder groups convened by the ASD Family Specialists.

5. Enhance or Expand State Level Collaboration and Planning Activities

The project's advisory board will be the New Mexico Autism Taskforce (NMAT) which is comprised of parents and parent advocates; State Title V program for children with special needs and other state agencies, including the Department of Health; the Special Education Bureau; Medicaid; primary and specialty care providers, including behavioral health providers; and youth leaders. Through the NMAT, the project will collaborate with the Continuum of Care project, which identifies local regional "medical champions" who function as consultants to other local health practitioner, schools, families, community agencies, case managers, and community groups.

At the regional level, the ASD Family Specialists will establish a regional partners/stakeholders group comprised of families, medical homes, providers, and agency and school personnel to provide guidance on local service needs and priorities. Ideally, these groups will include the "medical champion" identified by the Continuum of Care project. In addition, New Mexico will conduct focus groups of families and providers to collect information on: (1) family and provider partnerships, (2) access to culturally competent family-centered medical homes, (3) health insurance coverage, (4) availability of early and continuous screening for ASD and other DD, (5) access to community services, and (6) youth transition to adult health care. Information provided by these groups will be used to determine community awareness and professional training needs.

NEW YORK PROJECT SUMMARY

New York seeks to build upon the state's Autism Platform—a comprehensive interagency plan to improve the state's service system for people with ASD and their families—through provider trainings, disseminating updated guidelines and informational materials, and building knowledge and understanding of family needs for transition services. Specifically, the program in New York will work on:

1. Updating and disseminating information guides to providers and developing online trainings and regional Child Development Teams to affect regional efforts to increase early identification and referral rates
2. Conducting public awareness campaigns that includes expanding online information resources and disseminating informational materials
3. Enhancing transition services by collecting information on the challenges families face when children and youth with ASD transition service providers or levels of care and developing an online resource for families

To achieve these goals, New York intends to:

1. Build Awareness

New York will conduct public awareness campaigns during Autism Awareness Month. In addition to a general multimedia campaign, the state will disseminate an updated version of New York's "Early Help Makes a Difference: ASD Warning Signs" brochure; update the New York State Department of Health (NYSDOH) website to include an ASD page and links to CDC's "Learn the Signs: Act Early" materials and the American Academy of Pediatrics (AAP) autism toolkit; distribute to birthing hospitals or centers information about ASD to include in their parent discharge information kits; and provide pediatric practices with information on ASD early warning signs and referrals. The project will also collaborate with county health departments to incorporate ASD developmental information in local child find and public awareness activities.

2. Introduce New or Enhanced Training Initiatives

New York will implement several new online trainings for providers. Working with the three state chapters of the AAP, the project will develop training materials to promote universal ASD screening and physician involvement in the state's early intervention system. The project will also collaborate with the Institute for Child Development (ICD) at the University at Binghamton and a quality improvement organization (IPRO, Inc.) to develop and assess a new training curriculum on applied behavioral analysis (ABA) that will include a train-the-trainer curriculum.

For families, the project will enhance the Early Intervention Partners Training curriculum to include guidance on how to navigate transitions between systems of care. The end result will be an online parent leadership training program.

3. Enhance or Expand State Level Collaborations and Planning Activities

New York will update the NY Autism Guideline entitled *Clinical Practice Guideline on Assessment and Intervention for Young Children with Autism/Pervasive Developmental Disorders*. A panel of clinical and research experts in ASD and parents of children and youth with ASD will be convened to conduct the revisions. Data collected by the state's early intervention program (as well as any other data available) will be used to evaluate the impact of the revised guideline on professional practices.

To increase adherence to guidelines, the NYSDOH (the lead agency for this project) will convene an autism work group with representatives from local early intervention programs, pediatricians and their clinic administrative staff, and families. The group will focus on developing a plan to increase awareness of recommended guidelines through the use of online technologies. The State will collaborate with the local AAP chapters to conduct a survey of members and develop training materials. The project will establish three regional Child Development Teams that will include representatives from the state LEND programs, the NYS Academy of Family Practice, and parents. These regional teams will identify practice champions who will implement standardized screening tools in their practices. The project will also collaborate with the New York State Interagency Task Force on ASD to convene a work group on transition services.

RHODE ISLAND PROJECT SUMMARY

Rhode Island intends to focus on building infrastructure to support state planning, as well as to support providers. They will collaborate with existing state initiatives-including the Autism Spectrum Disorder Advisory Board and the Pediatric Practice Enhancement Project (PPEP). Specifically, the program in Rhode Island will work on:

1. Implementing a statewide ASD and other DD surveillance system
2. Improving early and continuous screening and treatment by developing and disseminating evidence-based ASD and other DD screening, treatment, and intervention guidelines to physicians, early intervention and childcare providers, and families
3. Improving accessibility to ASD and other DD services through expanded health insurance plan benefits for children and youth with ASD and other DD

To achieve these goals, Rhode Island intends to:

1. Build Awareness

Rhode Island will provide outreach and education to pediatric primary care practices, child care centers, and 10 certified early intervention providers. The project will distribute the CDC's "Learn the Signs: Act Early" materials, research literature on the screening and diagnosis of ASD, the state's EPSDT schedule, and Watch Me Grow materials (a childhood initiative that provides technical assistance and support to providers on developmental screening).

2. Expand or Enhance Existing Services

The project will enhance existing services by continuing to implement the Components of an ASD Diagnosis program. Specifically, Rhode Island will convene a group of clinicians to work on the components of an assessment of function and intervention planning to identify the strengths or weaknesses of children in five domains.

In collaboration with the Autism Project of Rhode Island, a PPEP site that provides ASD information and support services to families and professionals, the project will provide technical assistance to 150 pediatric primary care practices in implementing a screening program within well-baby and well-child visits. To promote continuous quality improvement in screening, the project will also use Rhode Island's KIDSNET database to provide outcome data to participating practices.

3. Introduce New or Enhanced Training Initiatives

For providers, the project will convene ASD clinicians on a quarterly basis for networking and learning. The project will also educate pediatric primary care providers on the developmental screening requirements in the EPSDT schedule.

The project will collaborate with several early childhood initiatives to train child care and early intervention providers on the proper use and scoring of standardized developmental and autism specific screening tools. The training will include approaches to communicating screening results to parents and the medical home.

For families, the project will collaborate with the Autism Project of Rhode Island to provide hands-on training on interventions families can implement. To support this activity, they will provide quarterly workshops and an annual conference on evidence-based interventions, current research, and community resources.

5. Enhance or Expand State Level Collaborations and Planning Activities

Rhode Island will pursue several infrastructure building activities including the development of an ASD and other DD registry. They will enhance a preexisting registry for developmental disorders and traumatic brain injuries. The database will be linked with databases maintained by the state's early intervention and special education programs to verify the completeness of the registry. The registry will be used to provide families with referrals to appropriate service coordination programs and resource guides and to provide prevalence information for reporting to the Governor, state agencies, and local education authorities.

The project in Rhode Island will work with the Office of Special HealthCare Needs to support legislation to mandate that all health plans in Rhode Island adhere to the minimum standards of the EPSDT schedule. This work will include efforts to ensure adequate reimbursement of standardized screening. They will also work on legislation about reporting of children with an ASD, universal standardized screening for ASD and other DD, and qualifications and training for ASD intervention professionals (including educators and clinicians).

UTAH PROJECT SUMMARY

Utah will strengthen the medical home concepts for ASD and DD through training and awareness building. Specifically, Utah will work on:

1. Providing family/pediatric medical homes, dentists, and other providers with useful and up-to-date information and training regarding screening, intervention, and community resources
2. Updating content and improving accessibility of ASD and DD resources for both families and health care providers through www.medicalhomeportal.org
3. Implementing a learning collaborative approach to develop more medical homes and dental practices capable of addressing the needs of children with ASD/DD.
4. Expanding Utah Family Voices' capacity to provide families with support coordination and develop a constituency of active parents capable of forming working partnerships with their children's primary care providers

To achieve these goals, Utah intends to:

1. Build Awareness

Utah will implement an early intervention pilot program (using CDC's Act Early/Know the Signs materials) in three urban and rural counties to help community-based human service providers and educators recognize early signs and refer children to diagnostic and treatment services. In addition, preschool special education teachers will be trained in the Act Early/Know the Signs materials and pilot ASD developmental checklists and screening tools in selected preschool and kindergarten classrooms.

To provide quality information and resources to families and health care providers throughout the state, Utah will expand an online resource website to include modules on screening, diagnosis, treatment, and family partnerships on its Medical Home Portal (www.medicalhomeportal.org) website. The project will also conduct an annual conference for families of children and youth with ASD focusing on financing, the medical home concept, adult transition issues, and family and professional partnerships. An existing ASD training for families will be adapted to reach rural and frontier communities and will be modified for Spanish-speaking families.

2. Introduce New Services

The Utah Chapter of Family Voices (UFV) will train five family resource navigators to work with providers and provide support, link parents to community resources, and assist parents in making informed decisions. The project will additionally train and provide modest stipends to parent advocates in medical home practice teams.

3. Expand or Enhance Existing Services

Utah will expand the existing medical home network that addresses the needs of children with ASD/DD and their families, particularly in remote and rural areas. To improve early screening, diagnosis, and treatment, this project will train 32 new family and

pediatric medical homes and six dental home practice teams. Using a “learning collaborative” approach, each team will include a physician (or dentist), parent advocate, and care coordinator, in addition to peer mentors from previously trained practices.

4. Introduce or Enhance Existing Provider Training Initiatives

The Utah Pediatric Partnership for Improving Health Care Quality (UPIQ) will provide training and support to 12 practice teams. Given the large rural and frontier portions of the state, in Year 2, the curriculum will be adapted for in-office training delivered by project staff and peer mentors at eight sites. To adapt dental care services to accommodate children with ASD/DD, a learning collaborative will be designed for six pediatric dental practice teams. In Year 3, 12 family and pediatric practices will be recruited to participate in a distance-learning approach to coordinate care through medical homes.

5. Enhance or Expand State Level Collaboration and Planning Activities

To improve access and coordination of care, the Utah Bureau of Children with Special Health Care Needs (BCSHCN), the grantee, will work with the Utah State Office of Education to develop and implement the program for preschool special education teachers. The project will also develop the annual conference in partnership with the state offices of education, the Vocational Division of Services for People with Disabilities, the Utah Parent Center, and other organizations.

WASHINGTON PROJECT SUMMARY

Washington will implement the recommendations of the Autism Task Force (ATF)—a preexisting, legislatively mandated panel—by establishing the Combating Autism Advisory Council (CAAC), coordinating provider training, and providing supportive services. Specifically, the program in Washington will work on:

1. Offering training opportunities for providers, parents, interested organizations, and community care coordinators to improve awareness of ASD early screening, diagnosis, and treatment
2. Developing a constituency of active parents knowledgeable in ASD and capable of forming close partnerships with their children’s primary care providers
3. Improving the accessibility to ASD and other DD services through legislative initiatives

To achieve these goals, Washington intends to:

1. Build Awareness

To track autism awareness education opportunities, Washington will contract with an autism support organization to organize and post a statewide calendar of events sponsored by family support organizations, agencies, and non-profits. Project staff will also develop parent curriculum and training sessions. They will use training materials available from local and national sources, including the Autism Speaks “First 100 Day” kits, the *Autism Guidebook*, the CDC’s “Learn the Signs. Act Early” materials, and the Washington State Adolescent Transition Resource Notebook and Checklist. Parents who participate will be asked to become a resource for others by distributing the *Autism Guidebook*. In addition, the CAAC will distribute the *Autism Guidebook*, the Part C Child Find posters and the Parent Information posters that describe how to find resources, and the CDC “Learn the Signs. Act Early” materials.

2. Expand or Enhance Existing Services

The 2005 legislative mandate that created the ATF also mandated the development of a guidebook, which resulted in the development of the *Autism Guidebook for Washington State: A Resource for Individuals, Families, and Professionals*. It is a 200 page resource for professionals, parents, educators, and others. This project will distribute the *Autism Guidebook* through the Council’s community-based activities and people who attend the project’s trainings.

Many of the activities below are designed to support and enhance the state’s 21 Medical Home Leadership Networks. These networks are comprised of local primary care providers, school nurses, parents, and public health nurses.

3. Introduce or Enhance Existing Provider Training Initiatives

A primary focus of this project is statewide provider and parent training. This project will plan two joint training summits, one on each side of the state, for health care and behavioral health care providers, county public health nurse care coordinators, Part C family resource coordinators, Parent-to-Parent coordinators, promotoras, and Medical

Home Leadership Networks. The curriculum will be developed in conjunction with the state's LEND program and Seattle Children's Hospital and will use materials developed by CDC and the American Academy of Pediatrics (AAP). The summits will be designed to educate these frontline providers on screening tools, diagnosis, and referral for treatment. To make the summits as relevant as possible, each will include a youth panel discussion. State chapters of various medical associations will help promote the summits. The project will include training information on the Medical Home. In addition, interested Medical Home Learning Network teams will be recruited to host trainings and events for community members.

The summits will form the basis for the development of a teaching module on autism for primary care providers and specialists. This module will be posted on the Medical Home website, supported by the state's Title V program and available to all providers. They will also investigate adding Autism to Child Health Notes and the annual Dunan Seminar (a one-day update on children with special health care needs for pediatric providers).

4. Enhance or Expand State Level Collaboration and Planning Activities

Washington will establish the CAAC, an oversight body composed of representatives from Medicaid, health plans, physician groups, state agencies, and state ASD and DD organizations. While the Council will continue the work of the ATF, its composition will change slightly and include an adult with ASD and families. The Council will seek to develop partnerships among state agencies and organizations. Using a Community Empowerment Partnership for Autism Awareness process, project staff and council members will develop a toolkit and the staff will conduct 40 to 60 site visits to orient local communities and organizations to project activities and resources, and increase ASD awareness. The Council and project staff will also work on legislative initiatives and issues, and project staff will be trained on the legislative process.

WISCONSIN PROJECT SUMMARY

Wisconsin will implement Connections, the Wisconsin Medical Home Autism Spectrum Disorders (ASD) Initiative. Connections will use the National Medical Home Autism Initiative framework, the national ASD Roadmap, and a Wisconsin-specific ASD plan to create a statewide network of organizations that will work together to improve services for children and youth with ASD. Specifically, Connections will work on:

1. Strengthening statewide infrastructure by connecting ASD-related initiatives under one umbrella, sponsoring a statewide outreach campaign, and assuring access to information for all
2. Establishing Medical Home ASD spread sites to strengthen local and regional partnerships, identify current resources and gaps, provide regional trainings for key partners, and improve connections among services

To achieve these goals, Wisconsin intends to:

1. Build Awareness

In partnership with the five Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN), Connections will build awareness about ASD by using existing educational materials, including the CDC's "Learn the Signs Act Early" materials and the American Academy of Pediatrics' ASD Toolkit. Awareness materials will be distributed at health fairs, school transition fairs, conferences, local support groups, statewide committees and councils. In addition, this project will establish a Wisconsin-specific electronic repository of quality and up-to-date ASD content to provide timely information and resources to families, community-based providers and partners. Development of interactive components to the website will also be explored.

2. Enhance or Expand State Level Collaboration and Planning Activities

To develop state level collaboration, Connections will launch a Community of Practice (CoP) on ASD. The CoP-ASD will convene three times each year to discuss emerging national best practices, share existing state and local model practices, and hear from the Practice Groups, which will be subcommittees of the CoP-ASD. The Practice Groups will focus on professional development, medical homes, parent supports, community systems, school-age issues, youth transition, and policy issues.

3. Expand or Enhance Existing Services

Connections will work with the state's five Regional Centers for CYSHCN to create a Regional Core Team within each region. Implementation sites include the Marathon County Health Department, Wisconsin Children's Hospital, Children's Hospital Fox Valley, Waisman Center at the University of Wisconsin-Madison, and Chippewa County Health Department. These teams will include developmental clinical specialists, primary care providers, parents and youth, ASD-specific organizations, and other community providers including those from early intervention, schools, WIC, oral health, and emergency response. The Regional Core Teams will launch a resource mapping initiative to identify current resources, supports, and gaps in services for families and providers at the local, regional and state level.

4. Introduce or Enhance Existing Provider Training Initiatives

Connections will develop a two-track, sequential training series for primary care providers and community partners. The series will be conducted in the state's five regions to increase the number of providers and parents who understand the importance of early identification and the Medical Home.

The first track will target pediatric and family practice primary care providers. In Year 1, the training will focus on early identification of children with ASD, understanding ASD throughout childhood, and appropriate referrals. In Years 2-3, providers will receive training on care coordination, transition planning, and strengthening family partnerships. The Year 3 training will focus on enhancing Medical Home skills. Trainings will incorporate family issues such as medication management, family stress, sibling issues, understanding alternative or complementary therapy, helping families choose therapies, partnering with mental health, and dental care. Collaboration with Wisconsin's MCH LEND will focus on co-sponsored trainings on identifying children with ASD.

In collaboration with the Department of Family Medicine at the University of Wisconsin School of Medicine and Public Health, a statewide grand rounds video-conference for its family medicine residency programs will be developed. This grand rounds program will present strategies for the use of evidence-based screening tools, care planning, and linkages to community resources.

The second track of training will target community partners and families. Annually, Connections will conduct community training in each region for parents, youth, and community providers. Community trainings will focus on the Medical Home approach to care, general ASD understanding, treatment options, and eligibility issues.

ATTACHMENT C

DRAFT INTERVIEW PROTOCOL

ILLUSTRATION OF THE PROPOSED APPROACH TO THE GRANTEE

INTERVIEWS

SEMI-STRUCTURED INTERVIEW CONVERSATION GUIDE FOR CAAI STATE IMPLEMENTATION GRANTEES

This guide is divided into five domains, one for each CAAI goal associated with the State Implementation grants and a final reflections domain. The questions in each domain provide the general topics to cover and not all are applicable to all grantees. As a result, the following is a guide that will be adapted to the research for a particular grantee. Each discussion will also build on the information that has already been obtained during reviews of program documents.

1. Awareness Building

Based on all the documentation we have received from you, we understand your grant has worked on building awareness of ASD/DD and the services needed by families and children among [list of target populations]. To build this awareness you have [describe our understanding of their awareness building activities]. Is our understanding accurate?

- *Probe for:* Use of CDC Learn the Signs/Act Early materials or materials developed by others
- *Probe:* What have been the key objectives or goals of these activities?

Have you met these objectives or goals?

If yes, how do you know?

If not, why not?

What challenges have you faced implementing these activities?

How have your activities evolved during the last [look back period]?

If the following topics have not been covered during the conversation:

Have any of your awareness building activities focused on reducing disparities?

If yes, please explain.

How have families been involved? What, if anything, did you change as a result of family input?

Have other organizations been involved in building awareness for ASD/DD at the same time? How have you coordinated with them?

- *Probe for:* The nature of the collaboration (discuss and inform one another of activities; plan and coordinate the timing of activities or the populations targeted or the messages provided; or share resources including staff and/or funding)
- *Probe for:* Coordinating with Family-to-Family Health Information Centers

2. Reducing Barriers to Screening and Diagnosis

Our materials also indicate your grant is addressing service barriers and your efforts have focused on [describe our understanding of their efforts]? Is our understanding accurate?

- *Probe for:* Screening, Medical homes, local learning collaboratives, referrals and referral systems, improved insurance billing/increased billing opportunities, transition to adult services
- *Probe:* What have been the key objectives or goals of these efforts to reduce service barriers?

Have you met these objectives or goals?

If yes, how do you know?

If not, why not?

What challenges have you faced in your efforts to reduce service barriers?

If the following topics have not been covered during the conversation:

Have any of your efforts addressed disparities in access to screening and diagnosis?

If yes, please explain.

How have families been involved? What contributions did they make? What, if anything, did you change as a result of family input?

3. Training

We also understand your grant has focused on training initiatives for [list training target, e.g., providers, parents], and this training has [describe our understanding of their training initiatives]. Is our understanding accurate?

- *Probe for:* The grantee's contribution to the array of training already available
- *Probe for:* Use of training programs or materials developed by the grantee or others
- *Probe:* What have been the key objectives or goals of this training?

Has the training met these objectives or goals?

If yes, how do you know?

If not, why not?

What types of challenges have your training initiatives faced?

If the following topics have not been covered during the conversation:

Have any of your training initiatives focused on reducing disparities?

If yes, please explain.

Have other organizations offered [provider or family training] at the same time? How have you coordinated with them?

- *Probe:* [For provider training] Was the training linked to those offered by the state LEND and/or developmental pediatric programs?

- *Probe:* [For family training] Did you collaborate with other local or state initiatives to develop/deliver family trainings? Did you collaborate or coordinate training activities with any Family-to-Family Health Information Center?

4. Infrastructure/Systems Change

We also understand your grant has focused on infrastructure building such as [describe our understanding of their infrastructure changes, e.g., state policy/legislative changes, information sharing, partnerships/collaborative efforts, new or expanded services] to improve the overall system of care for families of children with ASD/DD. Is our understanding accurate?

- *Probe:* What have been the key objectives or goals of this infrastructure building?

Have the infrastructure changes met these objectives or goals?

If yes, how do you know?

If not, why not?

What types of challenges to infrastructure building have you faced during this process?

If the following topics have not been covered during the conversation:

Have other agencies or organizations contributed to infrastructure building efforts? How have you coordinated with them?

- *Probe for:* The partnerships the grantee described in the network analysis.

What roles have families of children with ASD/DD played? How has their participation affected your efforts?

Has your state implemented an ASD monitoring or surveillance system (such as the CDC Autism Development Disabilities Monitoring Network or a registry)? How did you coordinate your activities with this system?

Please describe any special efforts around the sharing of data.

- *Probe for:* Level of data sharing (sharing of aggregate reports; sharing records; linking data systems; electronic medical records; health information technology efforts)
-

5. Overall Reflections

Finally, we would like to discuss your overall assessment of your program.

What has been your greatest achievement so far?

- *Probe:* Why?
- *Probe for:* Other achievements that we think important, but not mentioned.

What types of technical assistance have you received?

What's your overall assessment of the assistance?

What did you change as a result of the technical assistance provided by AMCHP?

- *Probe for:* How AMCHP helped to improve program activities.

What if you had not received the grant from MCHB?

- *Probe for:* Activities/Accomplishes that would not have occurred. Activities/Accomplishes that would have occurred, but on a smaller scale or longer time frame.
- *Probe for:* Activities/Accomplishes in building awareness; new services; enhancements to existing services; training initiatives; and infrastructure building initiatives.

Ask only during the last interview:

What will happen when the grant funding ends?

How will you sustain project activities?

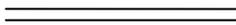
- *Probe for:* Key project activities in building awareness; new services; enhancements to existing services; training initiatives; infrastructure building initiatives.

ATTACHMENT D
NETWORK QUESTIONNAIRE

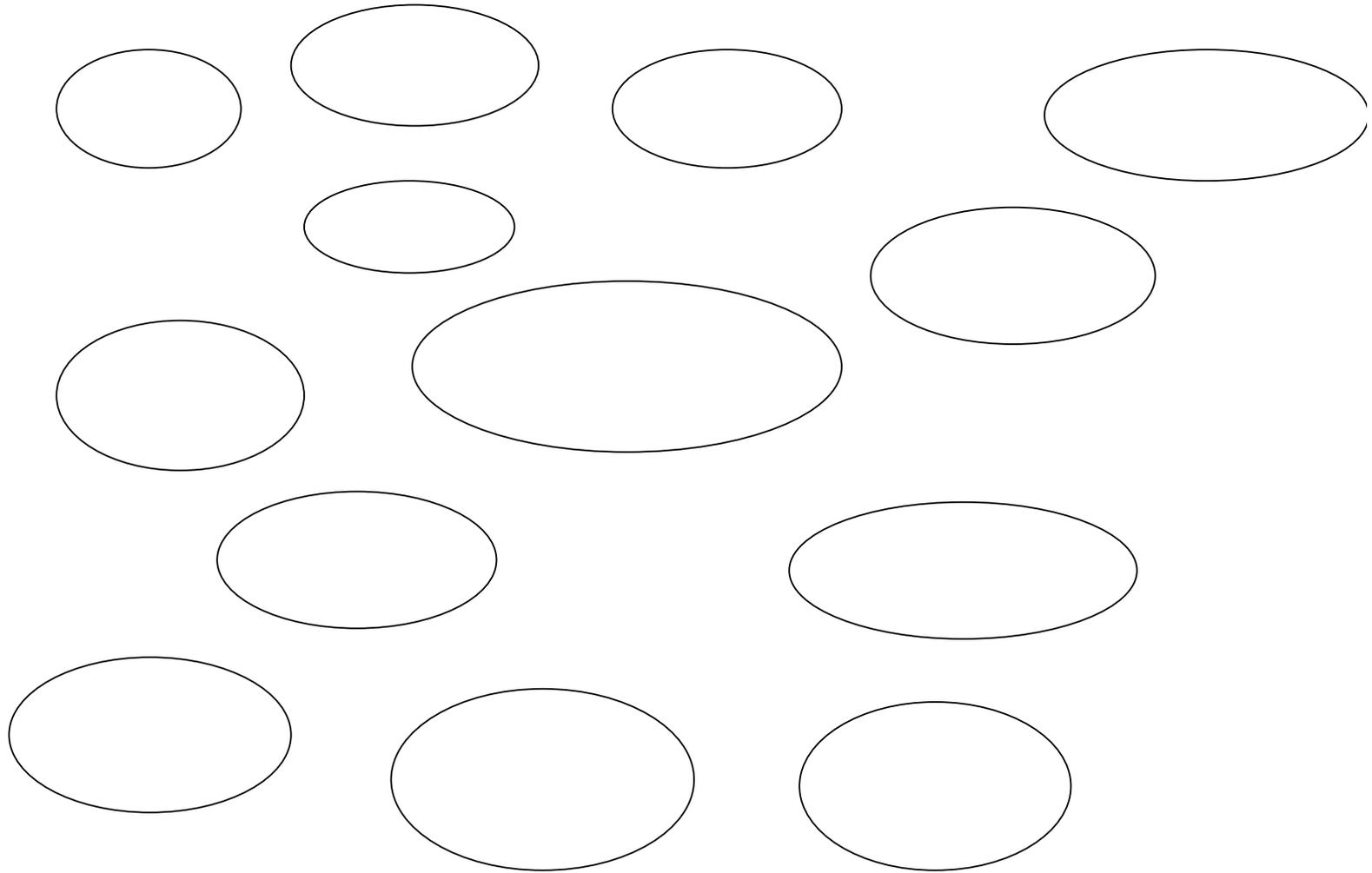
GRANTEE NETWORK: DECEMBER 2008

For a network analysis of your grant program we ask you to complete the Network Diagram on the following page.

1. Enter the names of all organizations you, the grantee, consider to be partners in the implementation of grant activities.
2. Indicate the frequency of communication between the grantee and each partner. Communication can be either by telephone, email, or written reports, but the content of the communication must be regarding grant activities. Use the codes described below.

If communication between the grantee and the partners <u>is at least</u> :	Indicate this level by drawing the following type of line:
Weekly	 (single thick line)
Twice a month	 (double thin lines)
Monthly	 (single thin line)
Quarterly	 (dashed line)
Twice a year	 (dotted line)
Yearly	(no line)

NETWORK OF THE STATE IMPLEMENTATION GRANT: DECEMBER 2008



3. Check the type of relationship the grantee has with each partner regarding grant activities. The definitions for the Relationship Types appear below this table. These definitions are from Taylor-Powell, Ellen, Boyd Rossing, and Jean Geran. "Evaluating Collaboratives." University of Wisconsin-Extension, Madison, Wisconsin. July 1998.

Partner	Type of Relationship				
	Communication	Contribution	Coordination	Cooperation	Collaboration

Communication = The grantee and this partner discuss issues and share information about each other's activities. The relationship is at the stage of developing a common understanding and exploring common ground.

Contribution = The exchanges between the grantee and this partner are about supporting each other's efforts. The relationship is at the stage of building mutual obligations and trust.

Coordination = The grantee and this partner are coordinating needs, resources, and activities. The relationship is at the stage where both parties are adjusting current activities for more efficient and effective results.

Cooperation = The grantee and this partner are linking resources to help both organizations achieve joint goals. The relationship is at the stage of building trust by working together.

Collaboration = The grantee and this partner have developed a shared vision for the *system*. *The relationship is at the stage of sharing resources to build an interdependent system.*

ATTACHMENT E
NETWORK DIAGRAMS

The network questionnaire, from which these diagrams were derived, was administered in December 2008, before the programs in New Mexico, New York, and Rhode Island were funded. These diagrams will be updated and revised in December 2010 and again in December 2011. New Mexico, New York, and Rhode Island will be included in these future data collection efforts.

FIGURE E.1
NETWORK OF THE ALASKA STATE IMPLEMENTATION GRANT: DECEMBER 2008

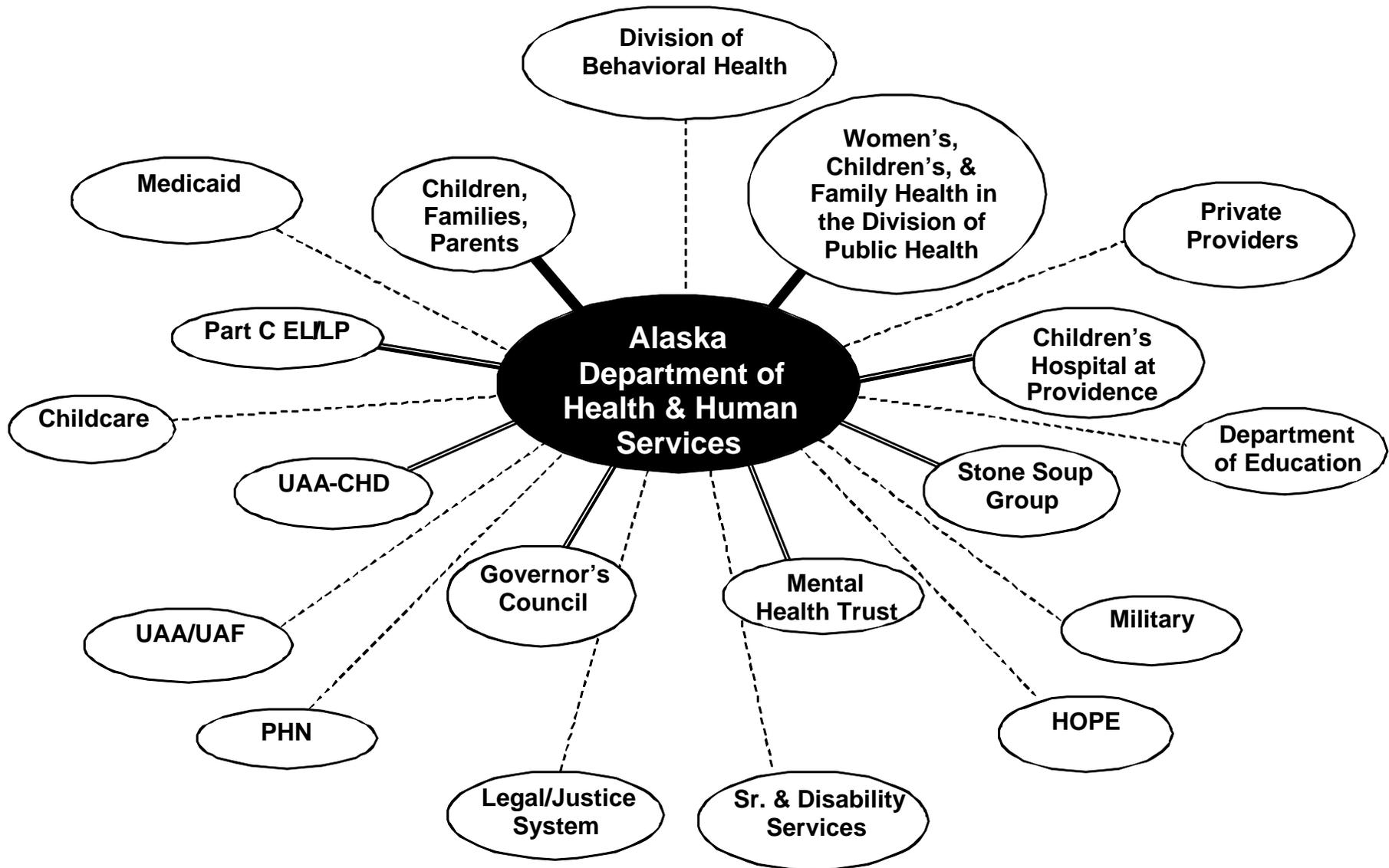


FIGURE E.2
NETWORK OF THE ILLINOIS STATE IMPLEMENTATION GRANT: DECEMBER 2008

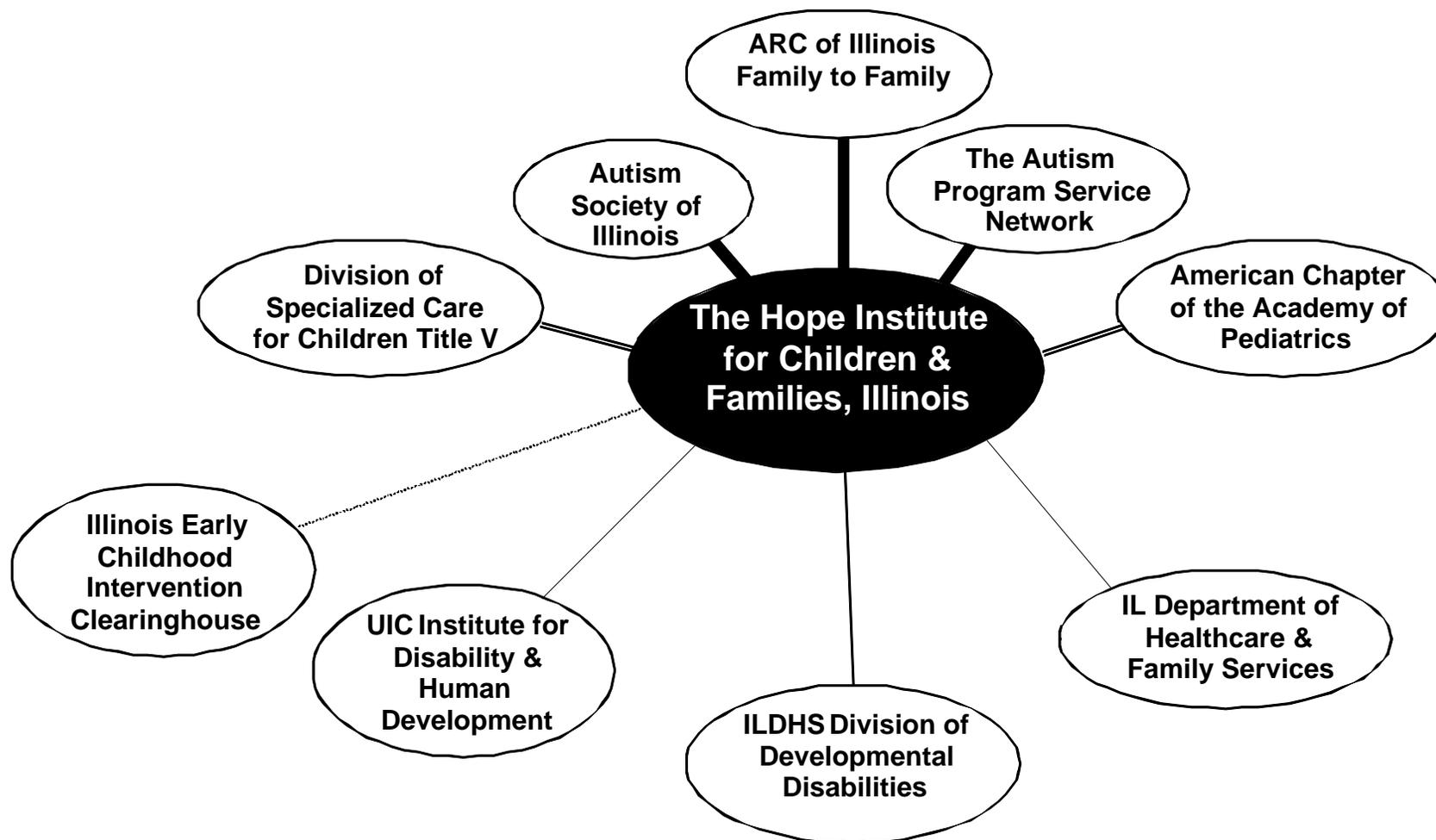


FIGURE E.3
NETWORK OF THE MISSOURI STATE IMPLEMENTATION GRANT: DECEMBER 2008

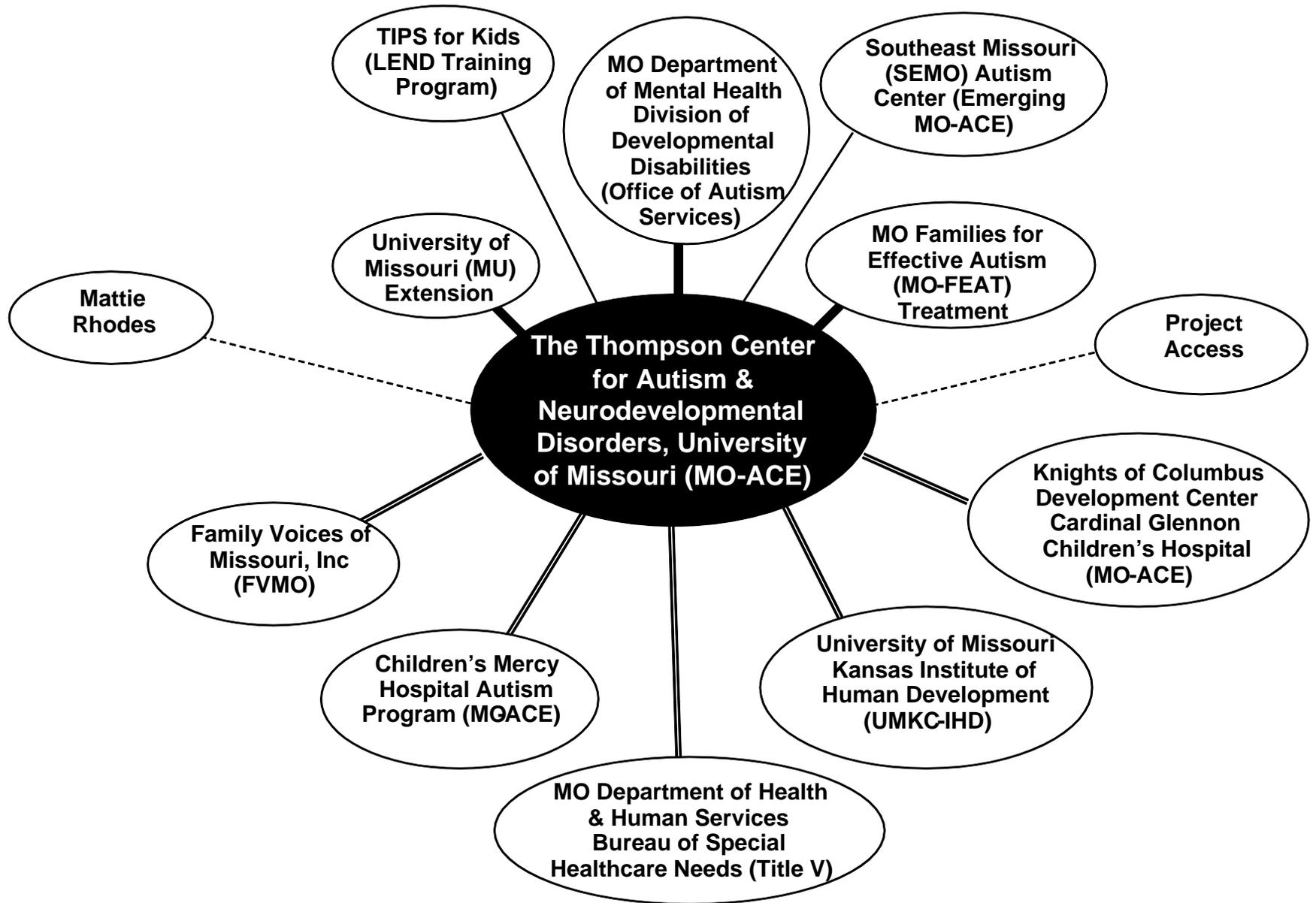


FIGURE E.4
 NETWORK OF THE UTAH STATE IMPLEMENTATION GRANT: DECEMBER 2008

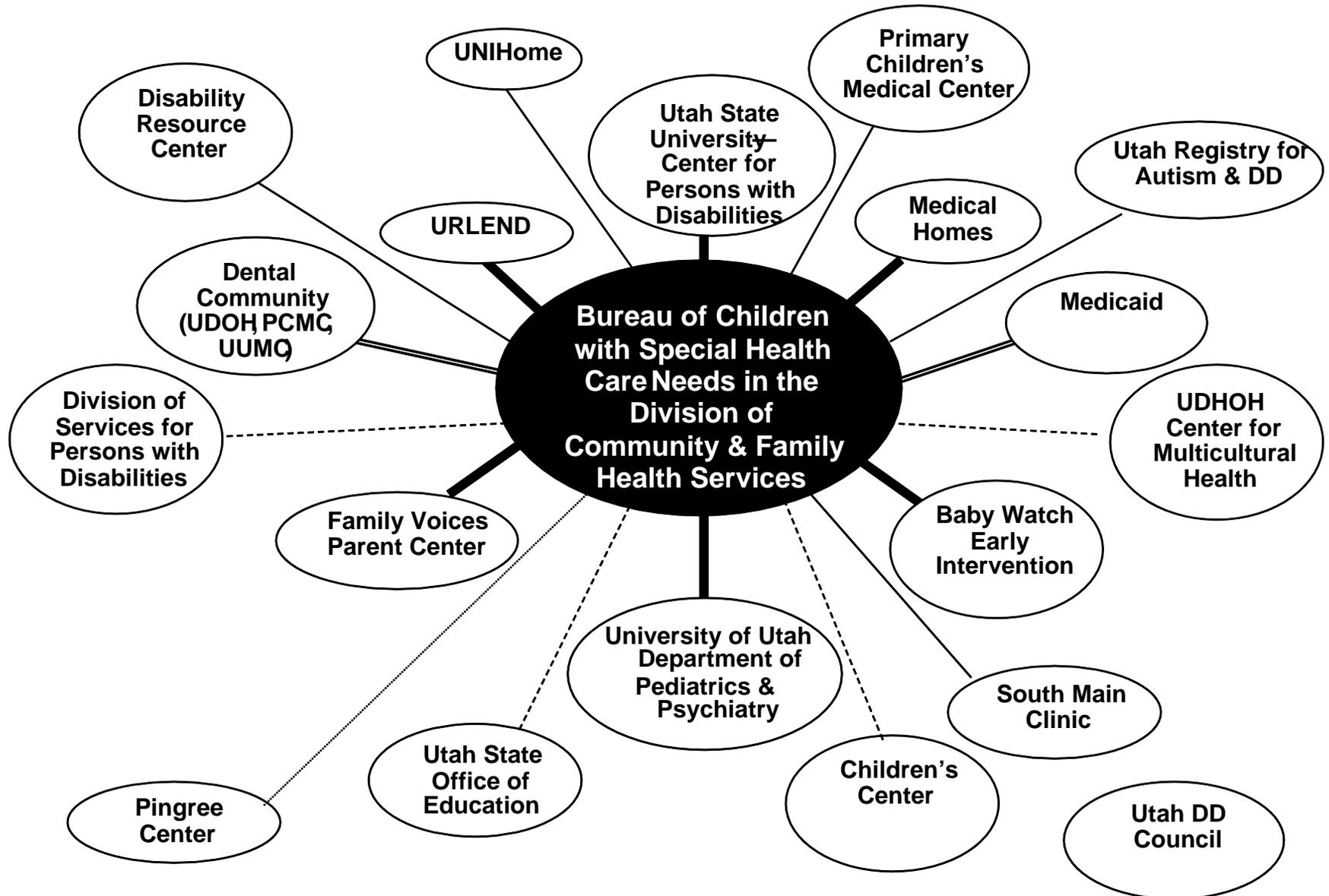


FIGURE E.5
 NETWORK OF THE WASHINGTON STATE IMPLEMENTATION GRANT: DECEMBER 2008

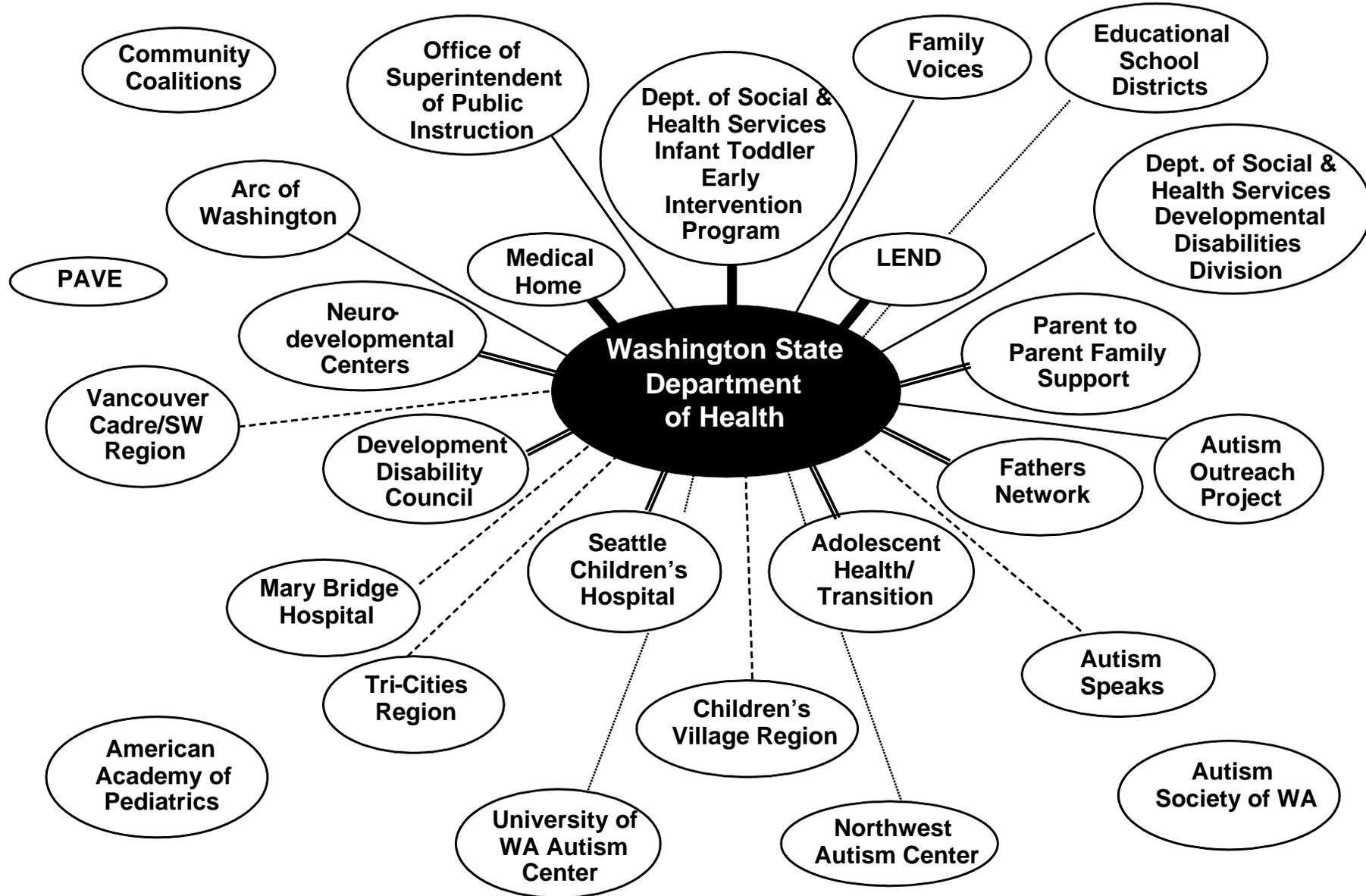


FIGURE E.6
 NETWORK OF THE WISCONSIN STATE IMPLEMENTATION GRANT: DECEMBER 2008

