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# DRAFT EVALUATION DESIGN PLAN

## *MCHB Combating Autism Act Initiative*

### *LEND Training Programs*



**Author:**

*Claire Wilson*

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Submitted to:

LT Deidre Washington  
U.S. Public Health Service  
Maternal and Child Health Bureau  
5600 Fishers Lane  
Rockville, MD 20857

Submitted by:

Insight Policy Research, Inc.  
1901 N. Moore Street, Suite 601  
Arlington, VA 22209  
(703) 373-6645

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## I. INTRODUCTION

Under the authority of the Combating Autism Act of 2006 (CAA), the Maternal and Child Health Bureau (MCHB) established the Combating Autism Act Initiative (CAAI), which provides funding for training, research, education and the development of systems of services relating to autism spectrum disorders (ASD) and other developmental disorders (DD). To assess the effectiveness of MCHB's activities in meeting the legislative goals of the Combating Autism Act, Insight Policy Research has designed a detailed evaluation plan for each program funded under the CAAI. This document presents Insight's evaluation design plan for the Leadership Education in Neurodevelopmental Disabilities (LEND) Interdisciplinary Training Programs that received CAAI supplemental/expansion grants in Fiscal Year (FY) 2008 and FY 2009. The evaluation of these LEND programs will take place over three consecutive project phases, including a base year and two option years. Each phase is briefly described below.

***Phase I. Planning and Evaluation Design.*** Phase I took place over the first eight months of the contract, beginning in October 2008 and ending in May 2009. During this phase, our activities included: gathering information on the LEND program activities; reviewing grant applications; identifying available data sources; developing and refining evaluation questions and a logic model to guide the program evaluation; formulating a draft evaluation design; conferring with grantees to obtain their feedback on the evaluation design; and finalizing the design. To ensure timely collection of quantitative data for the first grant year, we also developed new data elements and detailed specifications for incorporating those elements into the National Information and Reporting System (NIRS) database. These data elements were reviewed by LEND Directors and MCHB in April 2009 and subsequently submitted to the Association of University Centers on Disabilities (AUCD) for inclusion in the current version of NIRS.

***Phase II. Data Collection.*** Phase II will begin in June 2009 and end in March 2011. During this period, we will obtain grantees' summary progress reports from MCHB, collect quantitative information through DGIS and NIRS, develop qualitative data collection protocols, conduct in-depth interviews with LEND directors, and deliver periodic presentations to MCHB staff on the preliminary results. We will also prepare presentations for the annual grantee meetings to be held in November 2009 and November 2010.

***Phase III. Data Analysis and Reporting.*** In Phase III, beginning in April 2011 and ending in September 2011, we will analyze the data collected and draft and submit our final evaluation report. Additionally, we will write the MCHB contribution to the Report to Congress as required by Section 399DD of the Combating Autism Act of 2006. This report will summarize the activities and outcomes for the LEND programs and will report on national measures, as required.

## **A. CHALLENGES TO THIS EVALUATION**

Every evaluation has its share of potential challenges. In the case of the LEND interdisciplinary training programs, one potential challenge that we have anticipated involves the relatively short duration of the project, which may result in relatively small changes in long term outcomes, such as time between screening and diagnostic assessment, or average age of first intervention for ASD/DD. Accordingly, we have developed an evaluation plan that includes collection of interim data and measures of short term outcomes that can feasibly be obtained within the project timeline. The measured outcomes will indicate what the LEND programs have been able to accomplish with the supplemental CAAI funding. Additionally, the data collected can provide a foundation for assessing longer term outcomes in future years.

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 LEND grants must be completed and reviewed by MCHB by May 2011. To make these deadlines and to have sufficient time to analyze the data, 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 October 2011, and grantees' final summary reports are not due until April 2011. The only information the evaluation will have for 2011 will be the data collected as late as March 2011, through NIRS.

## **B. OVERVIEW OF THE EVALUATION PLAN**

The following chapters describe our proposed plan for evaluating the LEND grantees' performance in meeting the goals of the CAAI. Chapter II describes the goals and objectives of the Combating Autism Act of 2006, and reviews MCHB's Combating Autism Act Initiative. Chapter III provides an overview of the goals, objectives and activities of the LEND interdisciplinary training programs that have received supplemental/expansion grants under the CAAI. Chapter IV describes the evaluation design plan for the LEND interdisciplinary training programs. Chapter V outlines the proposed data collection methodology. Chapters VI and VII provide plans for data analysis and writing the final reports, respectively. Attachment A provides a list of the 22 LEND programs that were awarded expansion/supplemental CAAI grants in FY 2008 (cohort one) and the 17 LEND programs that were awarded CAAI funding in FY 2009 (cohort two). Of the FY 2008 grantees, 18 were existing LEND programs that received supplemental grants and four were newly established. Of the FY 2009 awardees, 16 were existing LEND programs that received supplemental grants and one new program was established.

Attachment B presents the detailed logic model developed for the LEND evaluation. Attachment C includes the in-depth, semi-structured interview guide for collecting qualitative data from the LEND grantees. Attachment D presents the data elements that were developed to collect quantitative data from the LEND grantees through the new NIRS module.

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

### **A. OVERVIEW OF CAA LEGISLATION**

#### **1. Intent of Legislation: Goals and Objectives**

In response to the growing need for research and resources devoted to autism spectrum disorders, the U.S. Congress passed the Combating Autism Act of 2006.<sup>1</sup> The goal of the CAA is to enable all children to reach their full potential by developing a system of services that includes:

- Screening children early for ASD and DDs;
- Conducting early, interdisciplinary evaluations to confirm or rule out ASDs and other DDs; and
- 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)**, which received \$114.5 million for research into causes, diagnosis, early detection and treatment through the Centers of Excellence;
- **Centers for Disease Control and Prevention (CDC)**, which received \$16.5 million to conduct research and surveillance activities, including collection of state-level epidemiologic data; and
- **Health Resources and Services Administration (HRSA)**, which received \$37 million to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions, and train health care professionals (note: the appropriation of \$37 million included a transfer of approximately \$20 million of Special Projects of Regional and National Significance (SPRANS) funds to the Autism and Other Developmental Disorders Program).

### **B. HRSA's COMBATING AUTISM ACT INITIATIVE**

#### **1. Goals and Objectives**

In response to the Combating Autism Act, HRSA implemented the Combating Autism Act Initiative through MCHB. MCHB administers a broad range of programs that promote and

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<sup>1</sup> Public Law 109-416§42 U.S.C.§1

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, children with special health care needs, and rural families. MCHB also builds maternal and child health services capacity by training health professionals, developing standards of care, and increasing assessment, planning and quality assurance capabilities of state and local government maternal and child health programs.

The overall goal of HRSA/MCHB's Combating Autism Act Initiative is to enable all children to reach their full potential 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. If a diagnosis is confirmed, providing early, evidence-based interventions.

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

1. Increase public/provider awareness of ASDs and other DD.
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 use valid and reliable screening tools, to confirm or rule out a diagnosis of ASD/DD and to provide evidence-based interventions.

## **2. Activities**

To achieve the aforementioned goals and objectives, HRSA/MCHB has provided support to three different programs that focus on training, research and implementation, respectively. Each program is briefly described below.

### **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.<sup>2</sup>
- *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.
  - *Five intervention research grantees.* These grantees 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 was awarded 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 conduct research that addresses the health and well-being of children and adolescents with ASD and other DD, utilizing existing secondary data. 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.
- *One State Public Health Coordinating Center.* This center will coordinate with the State Implementation grantees to develop and implement a strategy for defining,

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<sup>2</sup> 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.

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. LEND INTERDISCIPLINARY TRAINING PROGRAMS**

The LEND programs aim to improve the health of infants, children, and adolescents with developmental disabilities by: 1) providing high quality interdisciplinary training to child health professionals from diverse disciplines; 2) preparing those professionals to assume leadership roles in their respective disciplines; and 3) providing interdisciplinary services and care to children with special health care needs and their families. Under the CAAI, eighteen existing LEND programs were awarded supplemental funding and four new programs were established in FY 2008 to support the training of individuals who will be able to provide screening, evaluation, and evidence-based interventions for ASD and other DD. Additionally, sixteen LENDs that did not receive supplemental grants in 2008 were awarded supplements in FY 2009, and a new LEND was also established, for a total of 39 LEND grantees supported by CAAI funding.

#### **A. GRANT GUIDANCE AND PROGRAM GOALS**

The long term goal of the LEND expansion grants, as set forth under the CAAI, is to increase early screening and diagnostic evaluation for ASD and other DD, and to provide early, evidence-based intervention for children with a confirmed ASD or other DD. More generally, the LEND programs strive to improve systems of care for children and the families of children with ASD and other DD. LEND grantees work towards achieving these improvements by building partnerships with state Title V agencies and other maternal and child health (MCH) programs, and by providing exemplary didactic, clinical, and community-based training that is interdisciplinary, family-centered, and culturally competent.

MCHB released the CAAI expansion/supplemental funding announcement in May, 2008, with an application deadline of July 1, 2008. A new competitive announcement was also released in May 2008 with an application due date of June 30, 2008. A list of the LEND programs awarded new or expansion/ supplemental grants in FY 2008 and FY 2009 is presented in Attachment A.

Grant funds are available through September, 2011.

#### **B. OVERVIEW OF LEND ACTIVITIES AND CAAI OBJECTIVES**

Funding for the LEND expansion was designed, primarily, to support the training of medium and long-term trainees who can accurately confirm or rule out a diagnosis of ASD or other developmental disabilities and provide evidence based interventions to individuals with a confirmed ASD, and to support continuing education opportunities in the area of ASD for practicing professionals. Grantees were asked to propose plans related to the following key areas: 1) recruiting/selecting long term trainees, 2) curriculum,<sup>3</sup> 3) training content, 4) clinical

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<sup>3</sup> The training program design, competencies, and curriculum must prepare interdisciplinary health professionals for the full range of childhood neurodevelopmental disabilities, with special focus on ASD, and new leadership roles they will play in the emerging health care system for children with special health care needs and their families. The role of genetics and environmental influences are emphasized in the curriculum. Interdisciplinary approaches to care, training, and research are also emphasized.

preparation,<sup>4</sup> and 5) settings. Grantees were encouraged to coordinate clinical training opportunities with centers in the Autism Treatment Network (ATN)<sup>5</sup>, if they were located in their areas.

There are five main LEND objectives which support the accomplishment of MCHB's long term goals. These objectives include:

- 1) Training professionals to effectively utilize valid and reliable tools for screening and diagnosis of ASD and other DD, and to provide evidence-based interventions.
- 2) Reducing barriers to screening and diagnosis.
- 3) Increasing provider and trainee awareness of ASD/DD.
- 4) Contributing to research on evidence-based practices.
- 5) Expanding leadership in the MCH field and contributing to improved systems of care for children with ASD and other DD and their families.

To accomplish the five aforementioned objectives, each LEND grantee has proposed specific activities to be carried out throughout the three year grant period. An overview of the activities related to each objective is presented below.

**Objective 1: Train professionals to effectively utilize valid and reliable tools for screening and diagnosis of ASD and other DD, and to provide evidence-based interventions.**

LEND grantees are using the CAAI funding to both increase the number of trainees supported by the program and to intensify the training experience, through enhanced program activities. Specific activities include: recruiting and training more long and medium term health and human service professionals from various disciplines; providing didactic, clinical and community-based training with content in ASD screening, diagnosis and intervention; developing and implementing coursework that includes information on evidence-based screening, assessment, and treatment of ASD; providing supervised clinical training opportunities to trainees that include administering valid and reliable diagnostic tests for ASD and participating in the development and implementation of an evidence-based treatment plan; and delivering continuing education events that address screening, diagnosis and/or evidence-based interventions for ASD and other DD.

**Objective 2: Reduce barriers**

LEND training programs are seeking to reduce barriers to screening and diagnosis primarily by preparing more professionals to accurately screen for and diagnose/rule out ASD and other DD. Specific activities include expanding recruitment efforts, increasing the number of medium and long-term trainees in disciplines that perform screening and diagnosis, and expanding clinical training opportunities for trainees. LEND programs are also seeking to reduce barriers by

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<sup>4</sup> Training is based on a comprehensive, exemplary, interdisciplinary clinical services model which is family-centered, and culturally and linguistically appropriate.

<sup>5</sup> The ATN, funded by the advocacy organization Autism Speaks, is a network of treatment and research centers dedicated to improving medical care for children and adolescents with autism.

recruiting trainees from ethnic/racial minority groups, by providing direct clinical services, including clinics in underserved areas, and by incorporating curriculum on cultural and linguistic competency into coursework.

#### Objective 3: Increase awareness

To increase awareness of autism spectrum disorders, LEND training programs are disseminating current, evidence-based information on screening, diagnosis and intervention through workshops, seminars, and continuing education events. Their dissemination efforts target various audiences, including practicing professionals, families, and MCHB's national networks. To expand their reach and ensure wide dissemination of information about ASD and other DD, LEND grantees are also partnering with state Title V and community based organizations to widely disseminate information about ASD and other DD.

#### Objective 4: Contribute to research

Although the LEND grantees differ in terms of their level of involvement in ASD-related research, many LENDs are incorporating specific research activities into their program plans. Activities include faculty-sponsored studies of screening tools and procedures and trainee participation in ongoing research projects on evidence-based practices.

#### Objective 5: Expand leadership and contribute to improved systems of care

An overarching goal of the LEND programs is to expand leadership in the field of maternal and child health and to improve systems of health care delivery for children and the families of children with special health care needs. Their activities include providing technical assistance and consultation to state Title V agencies, family advocacy groups, community-based organizations, and other key stakeholders. The technical assistance focuses on the delivery of evidence-based services for children with ASD and other DD, recruiting and integrating family faculty for teaching and consultation, and addressing health service delivery issues relating to ASD and other DD in collaboration with local, regional, and national groups.

## IV. OVERVIEW OF THE EVALUATION DESIGN

### A. PURPOSE

The evaluation design presented here was developed to measure the LEND grantees' performance in meeting the goals of the CAAI, as well as their progress towards fulfilling MCHB's broader objective of improving the well being of the maternal and child health population through health systems change. The evaluation of this grant program will rely on both qualitative and quantitative research methods to assess program implementation, systems change, and outcomes.

#### 1. Evaluation Goals and Objectives

The *overall goals of the LEND Evaluation* are 1) to measure CAAI activities and assess whether these activities meet the objectives of the legislation that mandated them, and 2) to assess the efforts of the MCHB in addressing the nation's 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 also lay the foundation for future measurement of the initiative's long-term impact.

The *objectives of the LEND Evaluation* include the following:

1. Determine whether the LEND programs are accomplishing the intended goals and objectives of MCHB's CAAI;
2. Identify barriers encountered during implementation and how these barriers were addressed or resolved;
3. Identify remaining gaps between intermediate outcomes and longer term goals (i.e., what remains to be accomplished); and
4. Measure the CAAI outputs and outcomes for the Report to Congress.

#### 2. Use of Results

The results of this evaluation will be used to inform two reports: one for MCHB and one for Congress. The first report will inform MCHB about the LEND grantees' performance, particularly with respect to their short- and intermediate-term objectives under the CAAI. The results of this report can also help future grantees build on the successes of those grantees already funded. The Report to Congress will describe the measurable impacts of federal investments on LEND training programs, and the LEND grantees' contributions toward meeting the goals and objectives of the Combating Autism Act of 2006. Finally, the results will provide grantees with an external assessment of their effectiveness in increasing the number of professionals trained, increasing awareness of ASD and other DD, reducing barriers to screening

and diagnosis, contributing to research on evidence based practices, and building leadership in the MCH field.

## **B. EVALUATION QUESTIONS**

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

### **1. Development of the Evaluation Questions**

As a starting point for developing the evaluation questions, we reviewed each of the LEND grant applications and developed a short summary of each grantee's project goals, objectives, activities, and key outcomes. We also considered how their activities aligned with the five major goals of the CAAI. We determined that the LEND grantees are primarily dedicated to training professionals, but in doing that, they are also reducing barriers, increasing awareness and, in some cases, contributing to research on evidence-based practices. Also, all LEND programs are fundamentally committed to the broader goal of expanding leadership in the MCH field and improving systems of care for children and families of children with ASD and other DD. Based on these determinations, we formulated the following major evaluation questions:

1. How have the LEND programs impacted the supply and training of professionals who can effectively:
  - (a) use valid, reliable tools to screen for ASD and other DD;
  - b) confirm or rule out a diagnosis of ASD and other DD using valid and reliable diagnostic tools; and
  - (c) provide evidence-based interventions to individuals with ASD and other DD?
2. To what extent have the LEND programs reduced barriers to screening and diagnosis?
3. To what extent have the LEND programs increased provider and trainee awareness about ASD/DD screening, early assessment, and treatment?
4. To what extent have the LEND training programs contributed to research on evidence-based practices for children and adolescents with ASD/DD?
5. To what extent have the LEND training programs expanded leadership in the MCH field and contributed to improved systems of care for children with ASD/DD and their families?

### **2. Crosswalk for the Evaluation Questions, Data Elements and Proposed Data Sources**

In Table IV.1 below, we provide an overview of the evaluation design, organized by objective. Listed under each objective are the five major evaluation questions identified above, along with more specific secondary questions. These questions are designed to 1) qualitatively describe and document how the grantees use federal funds to achieve their program objectives, and 2) quantitatively measure the short term and intermediate outcomes of their federally funded

activities and 3) set the foundation for measuring the grantees' long-term impact on individuals with ASD and other DD.

For each research question, we report the data source (or sources) we plan to use to answer the question, and some specific data elements we plan to collect. Specifically, column 1 provides the research question (grouped by the overall CAAI objective). Column 2 provides the key data source (or sources). Last, column 3 lists the detailed data elements. These will be reported in MCHB's 2011 Report to Congress on the outcomes of the CAAI.

To frame the evaluation design, we also developed an overall logic model that links the LEND activities to the desired short, intermediate, and long-term outcomes which are critical to assessing the program's success in meeting the CAAI objectives. This logic model is shown in attachment B. Note that the intermediate objectives are grouped by the MCHB CAAI objectives and the long term outcomes are grouped by the three goals of the CAA (identified in Chapter II above).

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TABLE IV.1

EVALUATION DESIGN MATRIX

Evaluation Questions	Key Data Sources	Data Elements
<p><b>LEND Objective I: Training professionals to effectively utilize valid and reliable tools for screening and diagnosis of ASD and other DD, and to provide evidence-based interventions.</b></p>		
<p>How have the LEND programs impacted the supply and training of professionals who have the capacity to:</p> <p>(a) use valid, reliable tools to screen for ASD/DD;</p> <p>(b) confirm or rule out a diagnosis of ASD/DD;</p> <p>(c) provide evidence-based interventions to individuals with ASD/DD.</p> <p>Secondary questions:</p> <p>What groups of professionals are being trained to screen, evaluate and provide evidence-based interventions?</p> <p>How effective are these training efforts in increasing the number of professionals who can skillfully (a) use valid screening tools (b) use valid diagnostic tools (c) provide evidence-based interventions?</p> <p>What have the LEND programs done to ensure that the coursework, practica, and continuing education (CE ) activities include adequate training in the use of the most current valid diagnostic tools? In the delivery of evidence-based interventions?</p>	<p>NIRS</p> <p>Grantee summary progress reports</p> <p>In-depth interviews</p>	<p><b>Quantitative:</b></p> <p>Number of LEND medium/long term (M/LT) trainees who completed coursework in one or more of the following: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.</p> <p>Number of LEND M/LT trainees who receive clinical experience/mentoring that included:</p> <ul style="list-style-type: none"> <li>• Screening for ASD/DD</li> <li>• Performing diagnostic evaluations for ASD/DD</li> <li>• Providing evidence-based interventions for ASD/DD</li> </ul> <p>Number of LEND M/LT trainees participating in fieldwork that included:</p> <ul style="list-style-type: none"> <li>• Screening for ASD/DD</li> <li>• Performing diagnostic evaluations for ASD/DD</li> <li>• Providing evidence-based interventions for ASD/DD</li> </ul> <p>Number of courses developed, modified and/or taught by LEND faculty and/or trainees that included information on one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.</p> <p>Total number of students/professionals trained through courses.</p> <p>Number of CE events that addressed one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD . .</p> <p>Total number of professionals trained through CE events.</p> <p>Number of training events (other than CE) offered by LEND faculty relating to one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.</p> <p>Total number of professionals trained through training events</p> <p><b>Qualitative:</b></p> <p>Narrative description of training activities and outcomes including disciplines of trainees, specific diagnostic tests covered and clinical training opportunities.</p>

TABLE IV.1

EVALUATION DESIGN MATRIX

Evaluation Questions	Key Data Sources	Data Elements

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TABLE IV.1

EVALUATION DESIGN MATRIX

Evaluation Questions	Key Data Sources	Data Elements
<b>LEND Objective II: Reducing barriers to screening and diagnosis.</b>		
<p>To what extent have the LEND programs reduced barriers to screening and diagnosis?</p> <p>Secondary questions:            What are some of the barriers to screening and diagnosis and have they been reduced under the CAAI?</p> <ol style="list-style-type: none"> <li>How has the LEND program contributed to the knowledge base regarding screening for and diagnosing ASD/DD in young children?</li> <li>What have the LEND programs been doing to expand access to timely and accurate screening and evaluation services for young children?</li> <li>Which efforts have been most successful and why?</li> </ol> <p>How have the LEND grantees reduced barriers to screening and diagnosis among underserved populations?</p> <ol style="list-style-type: none"> <li>How has the LEND program expanded the supply of health care professionals from underserved populations?</li> <li>To what extent does the training curriculum include cultural competency elements?</li> <li>How is the LEND program working to expand access to screening and diagnostic services in underserved populations?</li> </ol>	<p>NIRS</p> <p>Grantee summary progress reports</p> <p>In-depth interviews</p>	<p><b>Quantitative:</b></p> <p>Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid screening tools for ASD/DD.</p> <p>Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid diagnostic tools for ASD/DD</p> <p>Number of LEND medium/long term trainees who are skilled in providing evidence-based interventions for ASD/DD</p> <p>Number of infants/children screened for ASD/DD.</p> <p>Number of infants/children who received interdisciplinary diagnostic services to confirm or rule out ASD/DD.</p> <p>Number of LEND faculty and/or trainees who worked in clinical settings located in an underserved area or who are working with underserved populations.</p> <p>The percent of participants in MCHB long-term training programs who are from underrepresented groups</p> <p>Collaboration with State Title V Agencies</p> <p><b>Qualitative data</b></p> <p>Identification of barriers</p> <p>Description of planned and implemented efforts to expand services</p> <p>Description of efforts to extend training to professionals working with underserved populations</p> <p>Description of outreach and recruitment activities conducted or planned to assure diversity among faculty and trainees</p> <p>Description of how cultural and linguistic competencies are incorporated into training</p>

TABLE IV.1

EVALUATION DESIGN MATRIX

Evaluation Questions	Key Data Sources	Data Elements
<b>LEND Objective III: Increasing provider and trainee awareness of ASD/DD</b>		
<p>To what extent have the LEND programs increased provider and trainee awareness about ASD/DD screening, early assessment and/or treatment?</p> <p>Secondary questions:            What are the LEND grantees doing to increase awareness among MCH professionals (e.g., health care and allied health professionals, psychologists and social workers, educators, community service providers)?</p> <ol style="list-style-type: none"> <li>In what specific areas of focus are the LEND grantees increasing the awareness of MCH professionals (e.g., early signs and symptoms, valid screening tools, assessment, etc)?</li> <li>What specific activities are the LEND grantees performing to increase awareness?</li> <li>Which awareness building efforts have been most successful and why? Explain how this success was defined, measured, and documented.</li> </ol>	<p>NIRS</p> <p>Grantee summary progress reports</p> <p>In-depth interviews</p>	<p><b>Quantitative</b>            Number of TA/consultations/collaboration activities provided to state or local health agencies, education or social service agencies, community based organizations or other entities.</p> <p><b>Qualitative</b>            Identification of specific areas of focus (e.g., screening, assessment) for increasing awareness, by professional discipline            Description of planned and implemented efforts to increase awareness in those areas, and their effectiveness            Description of educational products and opportunities developed            Description of strategies and activities used to disseminate educational products and publications</p>
<b>LEND Objective IV: Contributing to research on evidence-based practices</b>		
<p>To what extent have the LEND training programs contributed to research on evidence-based practices for children and adolescents with ASD and other DD?</p> <p>Secondary questions:            To what extent have LEND faculty or trainees participated in ongoing research studies investigating evidence based interventions?</p> <p>Are there other ways in which LEND programs have contributed to the knowledge base on evidence-based practices (including screening, diagnosis, and intervention)?</p>	<p>Grantee summary progress reports</p> <p>In-depth interviews</p>	<p><b>Quantitative</b>            Number of ASD/DD related articles published in peer-reviewed journals.            Number of ASD/DD related educational products developed or disseminated (other than peer reviewed).            Number of ASD/DD related presentations delivered at conferences by LEND faculty and/or trainees.</p> <p><b>Qualitative</b>            Description of LEND faculty and trainee involvement in ASD-related research projects, Interim milestones reached on long term research projects, and discussion of any outcomes (e.g., presentations, papers, preliminary findings )</p>
<b>LEND Objective V: Expanding leadership in the MCH field and contribute to improved systems of care for children with ASD and other DD and their families</b>		
<p>To what extent have the LEND training programs expanded leadership in the MCH field and contributed to improved systems of care for children with ASD/DD and their families?</p>	<p>NIRS</p> <p>DGIS</p>	<p><b>Quantitative</b>            Total number of LEND medium and long term trainees this year.            Degree to which MCHB-supported programs ensure family participation in</p>

TABLE IV.1

EVALUATION DESIGN MATRIX

Evaluation Questions	Key Data Sources	Data Elements
<p>Secondary questions:            What activities are the LENDs performing to increase MCH leadership?            What have the LEND grantees been doing to engage families in program and policy activities?            What have the LEND grantees been doing to promote comprehensive, coordinated, culturally competent and interdisciplinary care for children with ASD?            Have the grantees promoted collaborative partnerships with State Title V agencies/other MCH programs/entities on issues pertaining to ASD?</p>	<p>Grantee Summary progress reports</p> <p>In-depth interviews</p>	<p>program and policy activities</p> <p>Narrative description of activities aimed at obtaining family participation</p> <p>Degree to which MCHB long-term training programs grantees include cultural competency in their curricula</p> <p>Description of how cultural and linguistic competencies are incorporated into training</p> <p>Degree to which Long-term trainees are working in an interdisciplinary manner</p> <p>Degree to which LEND programs incorporate medical home concepts</p> <p><b>Qualitative</b></p> <p>Description of ways in which the program promotes MCH leadership competencies.</p> <p>Narrative description of activities in which trainees and faculty are engaged to promote leadership development</p> <p>Description of leadership activities of faculty and trainees</p> <p>Description of collaboration and coordination activities with agencies/organizations that strengthen MCH training.</p> <p>Description of how the program activities promote an interdisciplinary approach to MCH program development and implementation.</p>

## **C. GRANTEE INVOLVEMENT**

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

During the first Autism Grantee Meeting held on December 15-16<sup>th</sup>, Insight facilitated a breakout session with the LEND grantees to discuss the evaluation plans and activities, and to obtain their feedback. A discussion guide was developed in advance of the session to ensure that the facilitator was able to gather all the information needed to refine the evaluation questions. At the start of the session, we presented the logic model, and asked grantees to comment on our understanding of their primary activities, and the link between those activities and their measurable outputs and outcomes. We also discussed, in detail, the evaluation questions, their associated data elements and the proposed data sources to assess: (1) whether we should revise any of the questions, (2) which data elements would provide the most appropriate measure of their performance, and (3) which elements could feasibly be collected within the data collection timeline.

Throughout the session, we took notes and recorded the grantees' suggestions for improving the evaluation questions and the overall evaluation process. Following the meeting, we summarized the discussion and developed a list of the grantees' recommendations. Based on these recommendations and our review of the discussion, we revised some of the evaluation questions and our proposed list of data elements. No changes were needed for the logic model.

### **2. Ongoing Communication**

Following the annual meeting, Insight collaborated with AUCD in organizing a small work group of LEND grantees to discuss specific aspects of the evaluation design. Participating LEND Directors met with Insight's evaluation team via teleconference to review revised versions of the evaluation questions and to provide feedback on our proposed data collection plan. Two teleconferences were conducted. During the first teleconference, we discussed our efforts to address, in our evaluation plan, the questions and issues that the grantees had raised during the Annual meeting. We also requested their feedback on the revised evaluation questions. During the second teleconference, we reviewed subsequent changes to the evaluation design with the intent of finalizing the evaluation questions and data elements.

In April 2009, Insight delivered a presentation at the Annual LEND Directors meeting. The purpose of this presentation was to inform current and future grantees about the evaluation plan and the proposed data collection schedule.<sup>6</sup> The LEND Directors also had an opportunity to review the evaluation questions and corresponding data elements, so that they would know what kind of data they would be asked to report either in 2009 (for those grantees who received CAAI funding in 2008) or 2010. Following the presentation, the LEND Directors had an opportunity to ask questions and provide comments. They offered specific feedback on the wording and clarity of the questions, the feasibility of reporting certain types of data, and the alignment between the proposed data elements and their program goals and objectives. This feedback helped to inform the current draft evaluation plan.

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<sup>6</sup> By "future grantees" we are referring to those LENDS that were not awarded supplemental CAAI grants in 2008, but were awarded a supplemental/expansion grant in 2009.

## V. DATA COLLECTION METHODOLOGY

Data collection for the LEND evaluation will begin in July, 2009 and end in March, 2011. To meet the requirements of the Report to Congress, the evaluation will measure the results of the grantees' activities in clear, quantifiable terms. Quantitative measures alone, however, may not adequately capture the full spectrum of achievements that these programs may realize under the CAAI expansion. For example, an increase in the number of trainees that each LEND program can support is an important quantifiable outcome of the supplemental funding, but an equally important outcome might be an expanded trainee skill set, including the ability to accurately confirm or rule out an ASD diagnosis, resulting from changes in the depth and intensity of training that future providers are receiving through LEND. These and other important outcomes, such as changes in access to and quality of clinical services, call for a combination of qualitative and quantitative data to provide a more comprehensive picture of the LEND grantees' performance. Accordingly, the evaluation will use a mixed-method data collection approach that includes quantitative measures of the grantees' outputs and outcomes, and qualitative accounts of their activities directed towards accomplishment of programs goals and objectives.

Quantitative data for this evaluation will be collected through two sources: NIRS and DGIS. Qualitative data will be collected through grantee summary progress reports and in-depth, semi-structured interviews. In the sections that follow, we describe our specific plans with respect to the data elements and the schedule for collecting them from each source.

Table V.1 provides a summary of the data collection sources and schedule for the evaluation of LEND grantees.

TABLE V.1

LEND DATA COLLECTION SCHEDULE

Data Source	Data Collection Schedule	
	Cohort One (FY08 grantees)	Cohort Two (FY09 grantees)
<i>Quantitative Data</i>		
NIRS	July 2009 July 2010 January 2011	July 2010 January 2011
DGIS	October 2009 October 2010	November 2009 (baseline) November 2010
<i>Qualitative Data</i>		
Grant Application Narrative	October 2008	August 2009
Summary Progress Reports	May 2009 May 2010	May 2010
Informal interviews	November/December 2009	
In-Depth Interviews	December 2010	December 2010

**A. QUANTITATIVE DATA**

**1. National Information Reporting System (NIRS)**

All LEND grantees will be asked to track and report through NIRS the degree to which their programs address several outcome measures that reflect the goals and priorities of the MCHB. The data collection instrument is shown in Attachment D.

*a. Data Elements*

To assess the LEND grantees’ progress toward meeting the objectives of the Combating Autism Act Initiative, Insight developed a set of new data elements to be collected through NIRS. These data elements are based on our understanding of the grantees’ goals, objectives, activities, and the intended outputs/outcomes of those activities. The list of these data elements is shown in Table V.2 below, organized by objective.

TABLE V.2

NEW NIRS DATA ELEMENTS

Objective I: Training professionals to effectively utilize valid and reliable tools for screening and diagnosis of ASD and other DD, and to provide evidence-based interventions.	
Number	Data Element
I.1	Number of LEND medium/long term trainees who completed coursework in one or more of the following: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.
I.2	Number of medium/long term trainees who receive clinical experience/mentoring that included: <ul style="list-style-type: none"> <li>• Screening for ASD/DD</li> <li>• Performing diagnostic evaluations for ASD/DD</li> <li>• Providing evidence-based interventions for ASD/DD</li> </ul>
I.3	Number of medium/long term trainees participating in fieldwork that included: <ul style="list-style-type: none"> <li>• Screening for ASD/DD</li> <li>• Performing diagnostic evaluations for ASD/DD</li> <li>• Providing evidence-based interventions for ASD/DD</li> </ul>
I.4	Number of courses developed, modified and/or taught by LEND faculty and/or trainees that included information on one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.  Total number of students/professionals trained through these courses.
I.5	Number of CE events that addressed one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.  Total number of professionals trained through these CE events.
I.6	Number of training events (other than CE) offered by LEND faculty and/or trainees relating to one or more of the following topics: valid reliable screening tools; valid reliable diagnostic tools; evidence based interventions for ASD/DD.  Total number of professionals trained through these events

<b>Objective II: Reducing barriers to screening, diagnosis, and treatment</b>	
II.1	Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid screening tools for ASD/DD.
II.2	Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid diagnostic tools for ASD/DD
II.3	Number of LEND medium/long term trainees who are skilled in providing evidence-based interventions for ASD/DD
II.4	Number of infants/children screened for ASD/DD.
	Number of infants/children who received interdisciplinary diagnostic services to confirm or rule out a diagnosis of ASD/DD.
II.5	Number of LEND faculty and/or trainees who worked in clinical settings located in an underserved area or who are working with underserved populations.
<b>Objective III: Increasing provider and trainee awareness of ASD/DD</b>	
III.1	Number of TA/consultations/collaboration activities provided to state or local health agencies, education or social service agencies, community based organizations or other entities
<b>Objective IV: Contributing to research on evidence-based practices</b>	
IV.1	Number of ASD/DD related articles published in peer-reviewed journals.
IV.2	Number of ASD/DD related educational products developed or disseminated (other than peer reviewed).
IV.3	Number of ASD/DD related presentations delivered at conferences by LEND faculty and/or trainees.
<b>Objective V: Expanding leadership in the MCH field and contribute to improved systems of care for children with ASD and other DD and their families</b>	
V.1	Total number of LEND medium/long term trainees this year

***b. Data Acquisition Plan and Schedule***

The twenty-two LEND grantees that were awarded supplemental funds under the CAAI in FY08 (henceforth referred to as “cohort one”), will be asked to provide their responses to the quantitative data elements shown in Table V.1 beginning July 1, 2009. These grantees will have until July 31, 2009 to report this data in the new NIRS module. At the end of the reporting period, Insight will obtain a raw data file from AUCD for analysis. We expect this data will be available mid-September 2009.

Prior to the release of this module, Insight will develop a detailed data dictionary that grantees can access through NIRS, to assist them in responding. The data dictionary will explain the general intent of each question, provide specific meanings for certain terms, and include details on how to answer each question, as needed. Insight will also conduct a webinar when the new module is released. The purpose of the webinar will be to review the data elements and to clarify any questions or concerns grantees may have about particular items or how to report their data. All twenty-two cohort 1 grantees will be invited to participate. The webinar will also be archived so grantees can reference it at any time during the data collection period.

The data collected through the new NIRS module in July 2009 will be considered pilot data, in part because the questions were developed post-award, so grantees did not know, at the time of their award, what data they would be asked to report. Treating this data collection effort as a pilot will provide an opportunity to assess what information the grantees are able to report with confidence, what information is not available at this point but could be reported in the future

(e.g., if grantees are asked to start tracking it), and what information might not be feasible to collect. Conducting this pilot will also provide an opportunity to refine the questions to ensure that they provide good quality data.

Based on what we learn from the pilot, we will revise the NIRS module as needed for the 2010 reporting period. Both the cohort one and cohort two grantees (i.e., those awarded supplements in FY09) will be asked to report their data in the supplemental NIRS module in 2010. Because the grantees are accustomed to entering their data in NIRS by July 31, they will be asked to report in the new module at the same time. In addition, to ensure that we collect the most recent possible data for the final Report to Congress, we will also ask grantees to enter provisional data for FY 2010 in January 2011. This plan will provide us with first year data from every grantee, second year data from the FY 2008 grantees, in addition to provisional data from each program's final grant year.

## 2. Discretionary Grant Information System (DGIS)

All LEND grantees track and report the degree to which their programs address several performance measures that reflect the goals and priorities of the MCHB. These data are collected through DGIS on an annual basis. Insight reviewed these performance measures to identify those that met two criteria: (1) they were relevant to the LEND grantees' goals under the CAAI, and (2) they could contribute to the evaluation information that was not being collected through another source.

### a. Data Elements

Six out of eight performance measures were selected for use in the evaluation.<sup>7</sup> They are shown in Table V.3 below.

TABLE V.3

DATA ELEMENTS FROM DISCRETIONARY GRANT INFORMATION SYSTEM (DGIS)

DGIS Measure	Description	Associated Objective
PM #7	The degree to which MCHB-supported programs ensure family participation in program and policy activities	V: Contributing to improved systems of care
PM #9	The percent of participants in MCHB long-term training programs who are from underrepresented groups	II: Reducing barriers to screening and diagnosis
PM #11	The degree to which MCHB long-term training programs grantees include cultural competency in their curricula	V: Contributing to improved systems of care
PM #59	Degree of collaboration with State Title V Agencies	III. Increasing awareness

<sup>7</sup> PM 08 and PM 62 were the two performance measures that were not included in our plan. PM 08 is the percent of graduates of MCHB long-term training programs that demonstrate field leadership after graduation. This PM is not relevant for the evaluation since the data pertains to former trainees who are 5 years post graduation and therefore, did not receive training under the CAAI grant. PM 62 is the number of products and publications that were produced by a training program's faculty and trainees each year. This PM is not needed because we will be collecting data on the number of autism-specific products and publications through NIRS.

		V. Contributing to improved systems of care
PM #60	The degree to which long-term trainees are working in an interdisciplinary manner	V. Contributing to improved systems of care
PM #63	The degree to which LEND programs incorporate medical home concepts	V. Contributing to improved systems of care

One caveat in using the performance measures reported in DGIS is that the questions are not specific to Autism Spectrum Disorders. It is clear, however, from both the language of the legislation and our discussions with MCHB that the intent of the legislation is to achieve improved outcomes for all children with neurodevelopmental disabilities through changes in training, health care delivery systems, and infrastructure. Additionally, it can be argued that it is impractical to try to parse out the impact of the grant funding on a single segment of the population that the LEND programs serve, because advances specific to autism are likely to impact the identification and treatment of other disabilities and vice-versa. We anticipate that the data obtained from these performance measures will be useful in assessing movement towards these broad goals.

***b. Data Acquisition Plan and Schedule***

Grantees report on DGIS measures 120 days after the end of each grant year. The LEND grant cycle runs from July 1- June 30<sup>th</sup>. Based on this cycle, they report DGIS data towards the end of September.

In October 2009, we will obtain DGIS data from the cohort one grantees. In October 2010, we will collect DGIS data from cohort one and cohort two grantees.

**B. QUALITATIVE DATA**

**1. Grant Applications**

The grant applications provide a baseline description of the activities each grantee intends to pursue. To help inform the evaluation design, Insight’s evaluation team read the applications thoroughly and developed short lists of the planned activities for each grantee. Insight will also obtain updates on the grantees’ activities each grant year by conferring with them at the annual grantee meetings in the fall of 2009 and 2010, and by reviewing their annual continuation applications/summary progress reports. These updates will help the evaluation team track changes between the proposed and actual activities.

**2. Annual Continuation Application/Summary Progress Reports**

A non-competing continuation application is required for continuation of grant funding for a subsequent budget period. The continuation application, also referred to as a summary progress report, submits the budget request for the next year of funding and serves as the primary source of information regarding activities, accomplishments, outcomes, and obstacles related to achieving project outcomes during the current budget period. It also provides documentation necessary to justify continuation of the project, including plans for upcoming project periods.

In order to reduce respondent burden and maximize efficiency, Insight plans to use the LEND grantees' continuation applications/summary progress reports as a key source of qualitative data for this evaluation.

**a. Data elements**

To determine the extent to which grantee summary progress reports might fulfill our qualitative data needs, Insight reviewed the continuation grant guidance along with several summary progress reports provided to us by MCHB. We considered the information in these reports alongside our evaluation questions and identified several sections of the report that we plan to draw from for this evaluation. These sections are listed in Table V.4 by their associated CAAI objective.

TABLE V.4

DATA ELEMENTS FROM GRANTEE PROGRESS REPORTS, BY OBJECTIVE

Objective	Progress Report Section or Form	Description of data to be extracted
I. Training	Section C: Training	Training activities and outcomes
	Section G: New Knowledge	Description of activities that promote the transfer and application of new knowledge (e.g., applying classroom knowledge to MCH program settings).
	Form 5: Number of Individuals served by type of individual	
III. Increasing Awareness	Form 9: Didactic	Description of educational products and opportunities developed
	Form 9: PM 62 <sup>8</sup>	Description of strategies and activities used to disseminate educational products and publications
IV. Research	Form 7: Discretionary Grant Project Summary Data	
V. Expanding MCH leadership and contributing to improved systems of care	Section D: Collaboration/Coordination in Support of MCH Training	Description of collaboration and coordination activities with agencies/organizations that strengthen MCH training.
	Form 9: PM 08 Field leadership of faculty and trainees	Narrative description of activities in which trainees and faculty are engaged to promote leadership development
	Form 9: PM 07 Family participation in policy and program activities	Narrative description of activities aimed at obtaining family participation
	Form 9: Applied	Description of leadership activities of faculty and trainees
	Form 9: PM 11 Cultural competency	Description of how cultural and linguistic competencies are incorporated into training.
Section G: MCH Competencies	Description of ways in which the program promotes MCH leadership competencies.	
Section G: Interdisciplinary practice	Description of how the program activities promote an interdisciplinary approach to MCH program	

<sup>8</sup> Although we do not plan to use the numeric self-report ratings for PM 62, we will review the grantees' narratives for this PM to identify their dissemination plans and outcomes with respect to educational products.

Objective	Progress Report Section or Form	Description of data to be extracted
		development and implementation.

**b. Data Acquisition Plan and Schedule**

FY 09 summary progress reports were due on April 2, 2009 for cohort one grantees. Insight will obtain copies of these progress reports in May 2009 and extract the data that are relevant to this evaluation.

We expect the FY10 reports will be available in May 2010. At this time, we will request the year two summary progress reports for the cohort one grantees and the year one summary progress reports for the cohort two grantees. Note that we do not anticipate being able to use the final summary progress reports as they will be delivered to MCHB too late to include the information in the final Report to Congress.

**3. Semi-Structured, In-Depth Interviews**

To supplement the qualitative data that grantees submit in their summary progress reports, Insight plans to interview LEND project directors in 2009 and 2010. In fall/winter 2009, we plan to talk with each LEND Director from cohort one to discuss any new developments that have occurred in their program since the FY 09 summary progress report was submitted. This discussion will fill any remaining information gaps regarding the grantees’ accomplishments and challenges during the first CAAI grant year. In 2010, we will conduct formal in-depth interviews with all cohort one and cohort two LEND Directors. The purpose of these interviews will be to (1) gather additional information about program level activities and accomplishments related to specific CAAI objectives; (2) identify barriers encountered in implementing proposed activities and achieving interim goals; and (3) identify gaps between current outcomes and long term goals, and what is needed to ensure continued progress towards those long term goals.

For the formal, in-depth interviews, Insight developed a detailed, standardized interview guide and supporting statement for requesting OMB clearance. We sent these materials to MCHB in August 2009, for review. Following MCHB’s review, Insight will revise the guide and provide a final version to MCHB for submission to OMB.

The interview guide will gather qualitative data not available through other sources, focusing primarily on the five major objectives and research questions outlined in Chapter III. Additionally, this guide will include questions that explore synergistic partnerships between the LEND and DBP training programs and the other CAAI grantees, to help inform the overall CAAI evaluation.

**a. Data Elements**

Table V.5 below provides examples of some of the qualitative data we plan to collect through the in-depth interviews. For the complete interview guide, see Attachment C.

TABLE V.5

TARGETED IN-DEPTH INTERVIEW DATA

LEND OBJECTIVE	QUALITATIVE DATA ELEMENTS
Training	<p>In what ways has your LEND training program changed or expanded since receiving the CAAI supplemental grant?</p> <p>In what ways has your LEND program helped to increase the number of professionals who are skilled in administering valid screening tools and diagnostic assessments for ASD? What disciplines or groups of professionals have been trained in the use of valid and reliable screening and diagnostic tools through LEND?</p> <p>Has this program taken any measures to evaluate, upon completion of training, trainees’:</p> <ul style="list-style-type: none"> <li>• <i>ability to use appropriate screening methods</i> to identify children suspected of having an ASD, and, when indicated, refer children for a full evaluation?</li> <li>• <i>ability to perform diagnostic evaluations</i> to confirm or rule out ASD and other DD?</li> <li>• <i>ability to effectively implement evidence based interventions</i> with children who have an ASD?</li> </ul>
Reducing Barriers	<p>What are the major barriers to screening and diagnosis both across the nation and in your area?</p> <p>Which of these barriers, if any, has your LEND program been working to address since receiving the supplemental grant?</p> <p>What specific activities has your LEND program undertaken to expand children’s access to timely and accurate screening and diagnostic services for ASD and other developmental disabilities since receiving the supplemental grant?</p> <p>Have you developed or carried out any specific plans to reduce barriers to screening and diagnosis among underserved children?</p> <p>Does the clinical training include working with children and families from underserved populations? Are those children getting screened and evaluated for ASD by LEND faculty and/or trainees?</p> <p>What current activities do you think are making the most important contribution towards realizing this goal?</p>
Increasing Awareness	<p>What, if any, activities has your LEND program performed to increase awareness about ASD and other developmental disabilities among MCH professionals?</p> <p>Has your LEND program aimed to increase ASD awareness among other groups, such as families or the general public?</p> <p>To what extent has your LEND program engaged family members in activities related to screening, evaluation and intervention for ASD and other DD?</p> <p>Has your LEND program formed any partnerships or collaborations with State Title V or other agencies to provide ASD-related technical assistance or training?</p> <p>In general, where do you think your awareness building efforts have had the most impact, and what more remains to be done in order to promote more widespread understanding of ASD and the importance of early detection, evaluation and intervention?</p>
Contributing to research	<p>Are any of your LEND faculty members or trainees currently involved in planning or conducting any research studies relating to ASD and related developmental disabilities, particularly with respect to evidence-based screening, diagnosis and treatment? Please describe the study or studies.</p>
Expanding MCH leadership and contributing to improved systems of care	<p>How is your LEND program preparing its trainees to become future leaders – for example, what activities are specifically designed to provide them with the skills and knowledge they need to assume a leadership role in the field of maternal and child health?</p> <p>Are any of these activities specifically geared towards promoting leaders in autism-related work, such as research, clinical practice or program administration?</p> <p>What are some ways that trainees come to demonstrate leadership?</p> <p>Are there ways that your LEND program has extended its impact beyond its short, medium and long term trainees? Please explain.</p>

***b. Data Acquisition Plan and Schedule***

In November and December 2009, Insight will contact the LEND Directors from cohort one to discuss the program's accomplishments and any challenges encountered since April, when the summary progress reports were submitted.

Insight also prepared a supporting statement requesting OMB clearance to conduct the formal in-depth interviews with all LEND Directors in 2010. The Supporting Statement was sent to MCHB in August 2009, for submission to OMB.

Pending OMB Approval, Insight will contact each LEND Director in November 2010 to schedule the in-depth telephone interview. At this time, we will briefly describe what topics we plan to cover during the interview, and provide the Director with an opportunity to suggest additional program staff we should interview, if some of the questions would best be answered by another program representative. All interviews will be completed no later than January 2011.

**4. Interview with AUCD**

In addition to awarding supplemental grants to existing LEND programs and funding five new ones, MCHB also funded a National Interdisciplinary Training Resource Center (NTRC) to provide technical assistance to the LEND and other interdisciplinary training programs. The Association for University Centers on Disabilities (AUCD) is the designated NTRC. AUCD ensures coordination of CAAI projects across grantees in addition to providing technical assistance. To determine what specific activities AUCD was able to perform with the CAAI funding, and to capture their contributions to the grantees' performance, we plan to interview AUCD's Director at the beginning of the third grant year. One goal of the interview will be to describe AUCD's support and technical assistance, and the extent to which the LENDS 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.

## **VI. DATA ANALYSIS PLAN**

The data analysis plan for the LEND evaluation will be designed to assess grantees' achievement of four CAAI objectives and an additional objective related to expanding MCH leadership and contributing to improved systems of care for children and the families of children with ASD and other DD. Below, we describe how we will approach the analysis of each objective to draw conclusions about the influence of the LEND grantees on: the supply and skills of professionals trained to screen for, diagnose and provide evidence based intervention for ASD/DD; barriers to screening and diagnosis; awareness of ASD and other DD; and research on evidence based practices. Additionally, we will assess the LEND grantees' contributions to building leadership and improving health service delivery for the MCH population. The tables in the following sections provide a preview of how we plan to organize and report the findings.

### **A. TRAIN PROFESSIONALS TO USE VALID AND RELIABLE SCREENING TOOLS, TO CONFIRM OR RULE OUT A DIAGNOSIS OF ASD/DD AND TO PROVIDE EVIDENCE-BASED INTERVENTIONS**

Insight will use both quantitative and qualitative research methods to assess the impact of the LEND grants on the training of professionals, particularly with respect to using valid and reliable screening and diagnostic tools, and providing evidence-based intervention for children with ASD and other DD. The quantitative analyses will include: the number of didactic training events and courses offered that cover valid screening tools, valid diagnostic instruments and evidence based interventions; participation of short, medium and long term trainees in such training; number of medium and long term trainees who have gained clinical experience and participated in fieldwork involving screening, diagnosis and intervention for ASD and other DD; and the number of medium and long term trainees who, through their LEND training, have gained the requisite skills in diagnostic assessment and have developed or implemented evidence-based treatment plans. All quantitative data for the 38 grantees will be reported in aggregate. Tables VI.1, VI.2 and VI.3 below show how these data will be presented.

In addition to providing a descriptive profile of the grantees' training activities, these analyses will provide a measure of how many trainees and currently practicing professionals are benefitting from the LEND grants and how many are gaining the knowledge and skills needed to accurately screen for and confirm or rule out a diagnosis of ASD.

To supplement the quantitative results, we will also analyze qualitative data collected through summary progress reports and in-depth interviews. Using the qualitative data from Section C of the progress report, we will conduct an implementation analysis to describe the different ways in which the LEND grantees have expanded training opportunities for child health care professionals and more specifically, what activities they have carried out to increase the number of professionals who can accurately screen for and diagnose or rule out ASD using evidence-based tools. Additionally, we will draw upon data collected from the in-depth interviews with selected grantees to assess how the CAAI grant has influenced the depth and breadth of training

offered through LEND. Analysis of the in-depth interview data will describe how the LEND training has been enhanced under the CAAI expansion grant. These analyses will also identify which training activities were most effective in ensuring the competency of professionals in using valid and reliable screening tools, in administering diagnostic instruments and in providing evidence-based intervention for ASD and other DD.

TABLE VI.1

TRAINING ACTIVITIES FOR MEDIUM AND LONG TERM TRAINEES		
APPLIED TRAINING ACTIVITY	TOTAL NUMBER	
<b>Total Trainees</b>		
Medium term:		
Long term:		
<b>Didactic training</b>	<b>2009</b>	<b>2010</b>
Trainees who completed coursework covering one or more of the following: valid, reliable screening tools for ASD/DD, valid, reliable diagnostic tools for ASD/DD and/or evidence based interventions for ASD/DD		
Medium term:		
Long term:		
<b>Clinical experience/mentoring</b>	<b>2009</b>	<b>2010</b>
Trainees who received clinical experience/mentoring that included <i>screening for ASD and other DD</i>		
Medium term:		
Long term:		
Trainees who received clinical experience/mentoring that included performing diagnostic evaluations to <i>confirm or rule out a diagnosis of ASD or other DD</i>		
Medium term:		
Long term:		
Trainees received clinical experience/mentoring that included <i>providing evidence-based interventions for ASD and other DD</i>		
Medium term:		
Long term:		
<b>Practica/Fieldwork</b>	<b>2009</b>	<b>2010</b>
Trainees who participated in practica/fieldwork that included <i>screening for ASD and other DD</i>		
Medium term:		
Long term:		
Trainees who participated in practica/fieldwork that included performing diagnostic evaluations to <i>confirm or rule out a diagnosis of ASD or other DD</i>		
Medium term:		
Long term:		
M/L term trainees who participated in practica/fieldwork that included <i>providing an evidence-based intervention for ASD and other DD</i>		
Medium term:		
Long term:		

TABLE VI.2

## TRAINING ACTIVITIES BY TYPE OF ACTIVITY

TRAINING ACTIVITY	TOTAL NUMBER	
	2009	2010
<b>University Courses</b>		
University courses developed, modified or taught by LEND faculty/trainees that included information on valid screening tools, valid diagnostic tools and/or evidence based interventions for ASD/DD		
Professionals trained through those courses		
<b>Continuing Education (CE) events</b>	<b>2009</b>	<b>2010</b>
CE events that addressed valid, reliable <i>screening tools</i> , valid, reliable <i>diagnostic tools, and/or evidence-based interventions</i> for ASD/DD		
Professionals trained through those CE events		
<b>Other training events</b>	<b>2009</b>	<b>2010</b>
Training events (other than CE) offered by LEND faculty/trainees relating to: valid, reliable <i>screening tools</i> , valid, reliable <i>diagnostic tools, and/or evidence-based interventions</i> for ASD/DD		
Professionals trained through those training events		

**B. REDUCING BARRIERS TO SCREENING AND DIAGNOSIS**

Ensuring that young children receive appropriate screening and, when indicated, appropriate diagnostic evaluation for ASD and other DD requires an adequate number of child health care professionals who are trained and available to provide these services. As the prevalence of ASD has risen, however, the demand for screening and diagnostic services has exceeded the availability of such qualified professionals. The LEND expansion grants aim to reduce this barrier by increasing the number of professionals who are trained to screen for and perform diagnostic evaluations for ASD and other DD, with the long term goal of increasing early screening rates and, for children who screen positive for ASD, reducing the time between screening and diagnostic evaluation.

To assess the extent to which the LEND grants have impacted access to appropriate screening and diagnostic services, we will examine how many trainees were prepared to perform these services during each year of the grant. Additionally, though it may be too early to see impacts in the area of health service delivery, we will also report how many infants and children received diagnostic evaluation for ASD or other DD through LEND during the first two years of the grant. Should this evaluation serve as the foundation for assessing long term impacts in the future, these data will provide an opportunity to measure changes over time in the number of children who are receiving appropriate diagnostic services.

In accordance with HRSA's focus on underserved and special needs populations, the evaluation will also examine the extent to which the LEND grants reduced barriers to screening and diagnosis among underserved children. To the extent that the LEND programs increase the number of faculty and trainees who are working in underserved settings, they promise to improve access to qualified health care professionals. Additionally, increasing the number of trainees from underrepresented groups may improve retention rates in underserved settings.

Quantitative data on these three factors will be reported for 2009 and 2010, as shown in Table VI.4.

TABLE VI.3

TRAINING OUTCOMES: ENHANCED PROFESSIONAL SKILLS AND COMPETENCIES		
TRAINING OUTCOME	TOTAL NUMBER	
	2009	2010
<b>Screening</b>		
M/L term trainees who are skilled in the administration of reliable, valid screening tools for ASD and other DD		
<b>Diagnosis</b>		
M/L term trainees who are skilled in the administration of reliable, valid diagnostic tools for ASD and other DD		
<b>Interventions</b>		
M/L term trainees who are skilled in evidence-based interventions for ASD and other DD		

TABLE VI.4

REDUCING BARRIERS TO SCREENING AND DIAGNOSIS		
ACTIVITY OR OUTCOME	TOTAL NUMBER	
	2009	2010
<b>Service delivery</b>		
Infants/children screened for ASD/DD		
Infants/children who received interdisciplinary diagnostic services to confirm or rule out ASD and other DD through a LEND program.		
<b>Improving access among underserved populations</b>		
LEND faculty who worked in clinical settings located in an underserved area or working with underserved populations		
The percent of participants in MCHB long-term training programs who are from underrepresented groups (DGIS #09)		

Whereas quantitative data analysis will be used to assess the impact of the LEND grants on some known barriers to screening and diagnosis, qualitative data analysis will be used to identify additional barriers that the LEND grantees are working to address. For each barrier, we will report the LENDs' plans for addressing the barrier and, in 2010, the progress they have made toward implementing those plans. We note that some grantees have already set specific goals with respect to increasing capacity for screening and diagnosis. If these grantees report specific outcomes on screening and diagnostic assessment rates, we will incorporate that information into our descriptive analysis.

### C. INCREASING AWARENESS

The Insight team will use both qualitative and quantitative research methods to determine the extent to which the LEND grantees increased awareness of ASD and other DD. Practicing professionals are an important target group for awareness building efforts because they are the providers who may have the most opportunity to see early signs of an ASD or other DD yet, at

the same time, may not have the most current information on what to look for, how to screen for it, and what the proper response is when an ASD is suspected. The evaluation will assess the LEND grantees' efforts to reach these professionals by analyzing the number of trainings offered through LEND and the participation rates in continuing education events each year. We will also report the number of educational products disseminated each year, as another indicator of how the LENDs are building awareness among professionals. Table VI.5 below shows how these data will be presented.

To supplement the quantitative results, which focus primarily in awareness building efforts for health care professionals, we will describe the broader scope and impact of the grantees' awareness building efforts using qualitative data obtained through in-depth interviews. We expect to describe the particular target groups reached (e.g., parents, rural health providers, early childhood educators, community service workers, etc.), particular ASD topics that were covered (e.g., early signs and symptoms, importance of early identification, navigating the referral process, etc), and the communication mediums used. Additionally, if grantees can provide specific examples of how their awareness building activities impacted a particular target group, we will incorporate such examples into our analysis. This analysis will also likely describe technical assistance that the LEND grantees provided to partnering agencies and organizations.

TABLE VI.5

INCREASING AWARENESS

ACTIVITY OR OUTCOME	TOTAL NUMBER	
	2009	2010
<b>Educational products developed and disseminated</b>		
ASD/DD-related articles published in peer-reviewed journals		
ASD/DD-related educational products (other than peer-reviewed) developed or disseminated		
ASD/DD-related presentations delivered at conferences by LEND faculty/trainees		
<b>Technical Assistance (TA)</b>	<b>2009</b>	<b>2010</b>
TA/consultation/collaboration activities provided to state or local health agencies, education or social service agencies, community based organizations or other entities.		

**D. CONTRIBUTIONS TO RESEARCH ON EVIDENCE-BASED PRACTICES**

For this objective, the evaluation team plans to provide case studies of selected LEND programs that are involved in innovative research on ASD and evidence-based practices. The case studies will describe the purpose of the research study, its relevance to the goals of the CAAI, and any interim outcomes (e.g., presentations on preliminary findings) achieved during the first two years of the grant. We believe this format will provide the best method of charting the LEND programs' contributions to research, since it will provide rich detail about the kinds of scientific advances that LEND faculty are making in the field of ASD.

**E. EXPANDING MCH LEADERSHIP AND CONTRIBUTING TO IMPROVED SYSTEMS OF CARE**

Expanding MCH leadership and contributing to improved systems of care for children and the families of children with ASD/DD will be critical outcomes of the LEND programs. Although this aspect of grantee activities does not link directly to any of the CAAI objectives, building leadership and strengthening the overall system of services will be an important determinant of the long-term impact of the LEND grants and their ability to improve access to screening, diagnosis, and treatment services. We will assess accomplishment of these outcomes using data obtained from grantees through NIRS, DGIS, summary progress reports and the in-depth interviews.

To assess the extent to which the LEND programs are expanding leadership in the field, we will examine how many medium and long term trainees are enrolled each year, since leadership training is an essential component of the program. We will also analyze interview data regarding the programs’ leadership training activities and outcomes.

To assess the LEND programs’ contributions to improving systems of care, we will analyze data relating to the formation of partnerships, the provision of technical assistance, and efforts to engage families in program and planning activities. Additionally, we will analyze grantees’ self-reported assessments on the degree to which their programs incorporate medical home concepts. Table VI.6 shows how the quantitative data will be reported.

TABLE VI.6

EXPANDING LEADERSHIP AND CONTRIBUTING TO IMPROVED SYSTEMS OF CARE		
ACTIVITY OR OUTCOME	TOTAL NUMBER	
<b>Building Leadership</b>	<b>2009</b>	<b>2010</b>
Medium term trainees		
Long term trainees		
<b>Partnerships and Technical Assistance</b>		
Degree of collaboration with State Title V Agencies (DGIS # 59)		
<b>Family involvement</b>		
Degree to which MCHB-supported programs ensure family participation in program and policy activities (DGIS #07)		
<b>Promotion of culturally competent, interdisciplinary care</b>		
Degree to which MCHB long-term training programs grantees include cultural competency in their curricula (DGIS #11)		
Degree to which LEND programs incorporate medical home concepts (DGIS #63)		
Degree to which Long-term trainees are working in an interdisciplinary manner (DGIS #60)		

Our analysis will also aim to the extent to which the LEND grantees have collaborated with other entities to leverage their resources and expand the impact of their activities. One way to measure this outcome will be to qualitatively analyze the scope and depth of the LEND programs’ collaborations with other agencies serving similar populations. We will specifically

examine the extent to which the LEND programs have collaborated with other grantees to benefit from and build on each other's work. For example, we know that in Washington State, the LEND program works closely with the State Implementation grantee. We will analyze these partnerships with an eye towards documenting ways in which the LEND programs are contributing to systems-level improvements in health care for children and the families of children with ASD and DD.

## **VII. FINAL REPORTS**

### **A. REPORT TO MCHB**

The final report will be designed for MCHB's Division of Research, Training and Education (DRTE) through the Maternal and Child Health Research Program to determine the success of the LEND training programs in meeting the overall CAAI goals and objectives, as well as their own goals and objectives. We envision that the final report will include the following chapters:

#### Executive Summary

- I. Introduction
- II. The 2006 Combating Autism Act
- III. Description of the LEND programs
  - A. Goals and objectives of the LEND training programs
  - B. Activities and accomplishments
  - C. Challenges to implementation
- IV. Evaluation Design
- V. Effectiveness of LENDs
  - A. Training professionals to screen for and diagnose/rule out ASD and other DD.
  - B. Removing barriers to screening and diagnosis
  - C. Increasing provider awareness of ASD and other DD
  - D. Contributing to research on evidence-based interventions
  - E. Expanding MCH leadership and contributing to improved systems of care for children with ASD and other DD.
- VI. Conclusions

We will also include attachments illustrating the logic models and evaluation questions and questionnaires.

## **B. DRAFT CHAPTER FOR REPORT TO CONGRESS**

Insight will also prepare and submit a draft chapter for the MCHB contribution to the HHS Secretary's Report to Congress, as required in Section 399DD of the legislation. This chapter will summarize the activities and outcomes of the LEND and other CAAI grantees, and report evaluation results by major objectives. In addition, the HHS Secretary's Report to Congress will address several key outcomes, as described below.

The Combating Autism Act of 2006 requires that the DHHS provide, at a minimum, the following core elements in the report to Congress:

- Description of the amounts expended on the implementation of the particular provisions of the Combating Autism Act of 2006;
- Information on the incidence of autism spectrum disorders and trend data of such incidence since the date of enactment of the Combating Autism Act of 2006;
- Information on the average age of diagnosis for children with autism spectrum disorders 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;
- Information on the average age of intervention for individuals diagnosed with an 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;
- Information on the average time between initial screening and confirmation/ruling out a diagnosis of ASD or other developmental disability, as well as information on the average time between diagnosis and evidence-based intervention for individuals with an autism spectrum disorder or other developmental disabilities;
- Information on the effectiveness and outcomes of interventions for individuals diagnosed with an autism spectrum disorder, including various subtypes, and other developmental disabilities and how the age of the child may affect such effectiveness;
- Information on the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with an autism spectrum disorder or other developmental disabilities; and
- Information on services and supports provided to individuals with an 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)).

## REFERENCES

Combating Autism Act of 2006. Public Law. No. 109-416, § SEC. 399BB, 120 Stat 2821, 2823-2827 (2006).

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Care Bureau (2008). Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Expansion (Supplemental Funding) Announcement, Program Guidance. Announcement Number: HRSA 08-149.

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Care Bureau (2008). Maternal and Child Health Long-Term Training Programs. Announcement Type: Non-Competing Continuation. Announcement Number HRSA 5-T73-09-001.

**Attachment A: LEND Grantees**

**ATTACHMENT A: LEND CAAI GRANTEES**

	<b>Funding Announcement Number</b>	<b>Grantee</b>	<b>Grant Cycle</b>	<b>Continuation Announcement Number</b>	<b>Summary progress reports due</b>	<b>Funding Amount</b>
EXISTING LENDS THAT RECEIVED CAA SUPPLEMENTS IN FY08						
1	08-149	University of Alabama at Birmingham	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
2	08-149	Children’s Hospital of Los Angeles – School of Physical Therapy	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
3	08-149	Children’s Research Institute (Washington DC)	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
4	08-149	Indiana University School of Medicine	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
5	08-149	University of Kansas Medical Center Research Institute (Kansas City)	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
6	08-149	Children’s Hospital (Boston, MA)	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
7	08-149	University of Nebraska	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
8	08-149	Dartmouth Medical School/ Department of Pediatrics	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
9	08-149	Albert Einstein College of Medicine (Bronx, NY)	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
10	08-149	University of Rochester	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
11	08-149	University of North Carolina at Chapel Hill	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
12	08-149	The Children’s Hospital of Philadelphia	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
13	08-149	University of Tennessee Boiling Center for DD	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
14	08-149	Vanderbilt University	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
15	08-149	University of Utah	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
16	08-149	University of Vermont	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years

17	08-149	University of Washington	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years
18	08-149	West Virginia University	July 1-June 30	5-T73-09-001	April 2, 2009	\$200,000 per year for 3 years

NEW LENDS ESTABLISHED IN FY08 WITH CAA FUNDING

1	08-148	University of Arkansas for Medical Sciences	September 1-August 31	5-T73-09-001	April 2, 2009	\$550,000 per year for 3 years
2	08-148	University of Colorado Denver	September 1-August 31	5-T73-09-001	April 2, 2009	\$550,000 per year for 3 years
3	08-148	University of Connecticut Health Center	September 1-August 31	5-T73-09-001	April 2, 2009	\$550,000 per year for 3 years
4	08-148	University of Illinois at Chicago	September 1-August 31	5-T73-09-001	April 2, 2009	\$550,000 per year for 3 years

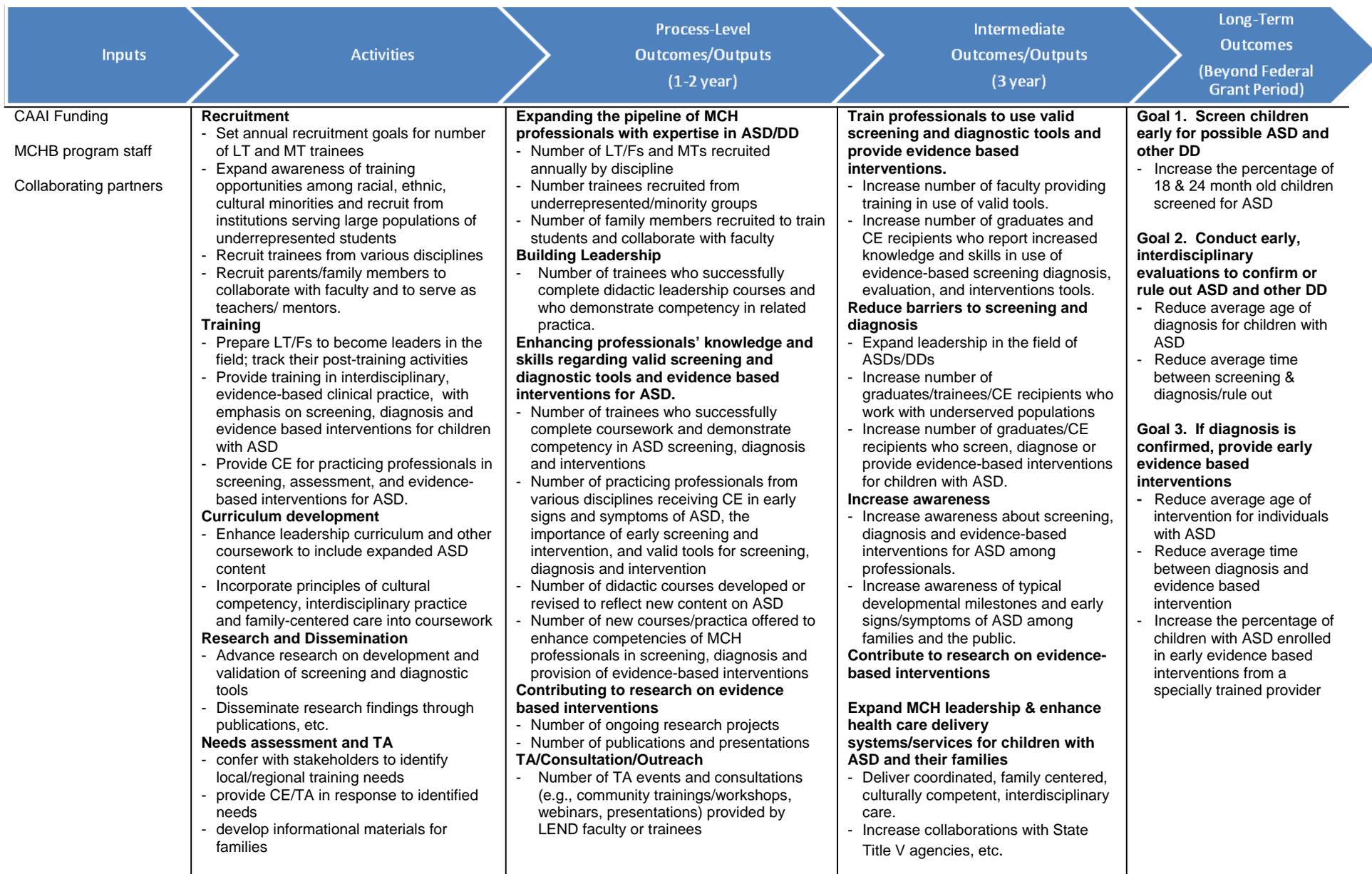
EXISTING LENDS THAT RECEIVED CAA SUPPLEMENTS IN FY09

1	08-149 (and revised scope of work request)	University of Iowa	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
2	08-149 (and revised scope of work request)	University of Hawaii at Manoa	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
3	08-149 (and revised scope of work request)	University of Cincinnati	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
4	08-149 (and revised scope of work request)	Johns Hopkins University	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
5	08-149 (and revised scope of work request)	New York Medical College	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
6	08-149 (and revised scope of work request)	Virginia Commonwealth University	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
7	08-149 (and revised scope of work request)	Ohio State University	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
8	08-149 (and revised scope of work request)	Curators of University of Missouri - Columbia	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
9	08-149 (and revised scope of work request)	University of South Dakota	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
10	08-149 (and revised scope of work request)	University of Wisconsin Madison	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
11	08-149 (and revised scope of work request)	Oregon Health & Science University	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
12	08-149 (and revised scope of work request)	University of Miami	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
13	08-149 (and revised scope of work request)	University of New Mexico Health Sciences Center	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
14	08-149 (and revised scope of work request)	University of Oklahoma HSC	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year

	of work request)					for 2 years
15	08-149 (and revised scope of work request)	University of Pittsburgh	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
16	08-149 (and revised scope of work request)	University of Massachusetts Medical School	July 1- June 30	5-T73-09-001	April 2, 2009	\$100,000 per year for 2 years
NEW LEND ESTABLISHED IN FY09 WITH CAA FUNDING						
1	08-148	Regents of the University of Minnesota	July 1- June 30			\$450,000 per year for 2 years

**Attachment B: Logic model**

## ATTACHMENT B: LOGIC MODEL FOR LEND TRAINING PROGRAMS



**Attachment C: LEND Interview Guide**



CAAI Evaluation  
Semi-Structured Interview Guide for LEND grantees

The purpose of this interview is to obtain some descriptive data about your program's activities and outcomes for the evaluation of MCHB's Combating Autism Act Initiative. Towards that end, we will be asking you questions on five main topic areas which relate to the goals and objectives of the Combating Autism Act Initiative. We have already collected some quantitative and qualitative data on your program from other sources, such as the electronic handbook and your summary progress reports. The information we collect today is intended to supplement the data we have already collected.

For each set of questions, we'd like you to report on activities or outcomes that have occurred since receipt of the Combating Autism Act Supplemental funds. Also, unless otherwise indicated, please report on activities pertaining to both ASD and other DD.

Objective I: Train professionals

One of the primary goals of the Combating Autism Act Initiative is to train professionals to use valid and reliable screening tools, to confirm or rule out a diagnosis of ASD/DD and to provide evidence-based interventions for children with a confirmed diagnosis.

We understand that this goal is also an essential part of the LEND training programs. We have already gathered information about the numbers of students and professionals that are being trained through LEND since the CAAI supplemental grants were awarded. Now we'd like you to tell us about some other ways that the supplemental grants have impacted the training that your program provides, particularly with respect to screening and diagnosis of ASD.

First, we'd like to discuss any ways in which your program's LEND training has changed or expanded since receiving the CAAI supplemental grant.

Has the content of the long and medium term trainees' curriculum been modified since receipt of the supplemental grant? For example, have you incorporated any new training in the use of specific screening tools (e.g., MCHAT) or diagnostic assessments (e.g., ADOS)?

Are there any other ways in which training opportunities have changed or expanded since receiving the supplemental grant? If so, please provide one or more examples, describing the content of any new training opportunities, specific instruments covered if any, the medium for delivery and the audience reached.

What disciplines or groups of professionals have been trained in the use of valid and reliable screening and diagnostic tools through LEND? Have you seen any changes in the range of disciplines that have received such training since the supplemental grant was awarded? (Probe: if more disciplines have been targeted, how did the program begin reaching these additional disciplines?)

The next questions ask about the trainee competencies in screening and diagnosis of ASD. For these questions, we'd like you to consider only those trainees who received training in these areas.

We've discussed some ways that your program has been training students and professionals to accurately screen and evaluate individuals for ASD and other developmental disabilities, with the support of the supplemental grant. Are there any other ways that your LEND program has helped to increase the number of professionals who are skilled in administering valid screening tools and diagnostic assessments for

ASD? (If not adequately covered yet: What specific training activities enable trainees to become proficient in screening and diagnosis?)

Has this LEND program taken any measures to evaluate, upon completion of training, the ability of trainees to use appropriate screening methods to identify children suspected of having an ASD, and, when indicated, refer children for a full evaluation? If yes, please describe.

Has the program taken any measures to evaluate, upon completion of training, the ability of trainees to perform diagnostic evaluations to confirm or rule out ASD and other developmental disabilities? If yes, please describe.

Has the program taken any measures to evaluate the competency of trainees who, upon completion of their training, can effectively implement evidence based interventions with children who have an ASD? If yes, please describe.

Objective II: Reduce barriers to screening and diagnosis.

Another objective of the Combating Autism Act is to reduce barriers to screening and diagnosis.

What are the major barriers to screening and diagnosis both across the nation and in your region?

Which of these barriers, if any, has your LEND program been working to address since receiving the supplemental grant?

Please describe any specific activities that your LEND program has undertaken to expand children's access to timely and accurate screening and diagnostic services for ASD and other developmental disabilities since receiving the supplemental grant.

Probes: Has the program provided any outreach trainings aimed at improving access to early screening and diagnosis?

Have this LEND program partnered with any other agencies or groups to help promote the goal of early screening and diagnosis?

Have you been able to observe any results of those activities yet?

If not already covered:

To what extent is this LEND program reaching children from underserved populations?

Have you developed or carried out any specific plans to reduce barriers to screening and diagnosis among underserved children? If so, please describe those activities and any preliminary results you may have observed.

Does the clinical training include working with children and families from underserved populations? Are those children getting screened and evaluated for ASD by LEND faculty and/or trainees?

To what extent does your program work to recruit trainees from cultural and ethnic minority groups? Can you describe any specific efforts to ensure the diversity of your trainees?

The Combating Autism Act legislation specifies a long term goal of screening children as early as possible and conducting early, interdisciplinary evaluations to confirm or rule out ASD and other developmental disabilities in children.

What part do you think the LEND programs can play, both now and in the future, to achieve this goal of early screening and evaluation?

What current activities do you think are making the most important contribution towards realizing this goal?

Objective III: Increasing provider and trainee awareness of ASD and other developmental disabilities.

We've already discussed how your LEND program is training professionals to provide skilled screening and assessment for ASD and other developmental disabilities. In addition to this training, we understand that the LEND programs are committed to promoting awareness of ASD and other developmental disabilities among MCH professionals and others.

What, if any, activities has your LEND program performed to increase awareness about ASD and other developmental disabilities among MCH professionals?

Probes: What disciplines have been targeted in these awareness building efforts (e.g., practicing pediatricians aiming to get the latest evidence based information on screening, rural health care providers, social workers, educators)?

What topics/content areas did these efforts focus on (e.g., early signs and symptoms, evidence based screening tools, referral procedures)?

Has your LEND program aimed to increase ASD awareness among other groups, such as families or the general public? Please describe any particular plans or activities, and comment on any outcomes of implemented awareness building efforts.

Has your LEND program formed any partnerships or collaborations with State Title V or other agencies to provide ASD-related technical assistance or training? Please describe any outcomes of these partnerships or collaborations, in terms how they may have contributed to the goal of increasing awareness of ASD and other developmental disabilities among various interest groups (e.g., health professionals, paraprofessionals, family members, advocates, etc).

In general, where do you think your awareness building efforts have had the most impact, and what more remains to be done in order to promote more widespread understanding of ASD and the importance of early detection, evaluation and intervention?

Objective IV: Contributing to research on evidence-based practices

Are any of your LEND faculty members or trainees currently involved in planning or conducting any research studies relating to ASD and related developmental disabilities, particularly with respect to evidence-based screening, diagnosis and treatment?

If yes, please describe the study or studies.

Probes: What topic or area is being investigated?  
Who is doing the research?  
What is the anticipated impact of the results/how might they be used (e.g., will they provide evidence about an intervention's effectiveness? Might they contribute to evidence-based practice guidelines?)  
How is the research being funded?

Objective V: Expanding leadership in the MCH field and contributing to improved systems of care for children with ASD and other DD and their families

One of the primary objectives of the LEND grants is to and leadership in the MCH field by preparing trainees to assume leadership roles.

How is your LEND program preparing its trainees to become future leaders – for example, what activities are specifically designed to provide them with the skills and knowledge they may need to assume a leadership role in the field of maternal and child health?

Are any of these activities specifically geared towards promoting leaders in autism-related work, such as research, clinical practice or program administration?

What are some ways that trainees come to demonstrate leadership?

Are there ways that your LEND program has extended its impact beyond its short, medium and long term trainees? Please explain.

Probes: If there have been collaborations between LEND and other agencies, please describe those collaborations, their intent, and any outcomes.

In what ways, if any, has your LEND program coordinated with other grantees, including State Implementation grantees, to achieve either specific goals or overall improvements in the system of care available to children with ASD/DD and their families?

Can you provide any examples of collaboration or coordination that enabled you to effectively leverage resources and achieve greater impacts than might have been possible if your program worked in isolation?

Attachment D: NIRS Pilot Instrument for LEND

## 2009 Pilot NIRS Data Elements

### Topic Area I:

How have the LEND programs impacted the supply and training of professionals who can effectively: (a) use valid, reliable tools to screen for ASD and other DD; (b) confirm or rule out a diagnosis of ASD and other DD using valid and reliable diagnostic tools; (c) provide evidence-based interventions to individuals with ASD and other DD.

1. Total number of LEND trainees this year:  
Medium term:  
Long term:
2. Number of LEND trainees who completed coursework covering one or more of the following topics: valid, reliable screening tools; valid, reliable diagnostic tools; evidenced-based interventions for ASD/DD:  
Medium term:  
Long term:
3. Number of LEND trainees who received clinical experience/mentoring that included *screening* for ASD/DD:  
Medium term:  
Long term:
4. Number of LEND trainees who received clinical experience/mentoring that included *performing diagnostic evaluations* to confirm or rule out a diagnosis of ASD/DD:  
Medium term:  
Long term:
5. Number of LEND medium/long term trainees who received clinical experience/mentoring that included *providing evidence-based intervention* for ASD/DD:  
Medium term:  
Long term:
6. Number of LEND trainees who participated in practica/field work that included *screening* for ASD/DD:  
Medium term:  
Long term:
7. Number of LEND trainees who participated in practica/field work that included *performing diagnostic evaluations* to confirm or rule out a diagnosis of ASD/DD:  
Medium term:  
Long term:
8. Number of LEND trainees who participated in practica/field work that included *providing evidence-based intervention* for ASD/DD:  
Medium term:  
Long term:

### Topic Area II: Training Activities

9. Total number of LEND CE events that addressed one or more the following topics: valid, reliable screening tools; valid diagnostic tools, and/or evidence-based interventions for ASD/DD:
10. Total number of professionals trained through CE events in #9 above:

11. Number of training events (excluding CE) offered by LEND faculty relating to one or more the following topics: valid, reliable screening tools; valid diagnostic tools, and/or evidence-based interventions for ASD/DD:
12. Total number of professionals trained through training events in #11 above:
13. Number of university courses developed, modified and/or taught by LEND faculty and/or trainees that included information on one or more the following topics: valid, reliable screening tools; valid diagnostic tools, and/or evidence-based interventions for ASD/DD:
14. Total number of professionals trained through courses in #13 above
15. Number of TA/consultation/collaboration activities provided to state or local health agencies, education or social service agencies, community based organizations, or other entities:

### **Topic Area III: Training Outcomes**

16. Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid screening tools for ASD/DD:
17. Number of LEND medium/long term trainees who are skilled in the administration of reliable, valid diagnostic tools for ASD/DD:
18. Number of LEND medium/long term trainees who are skilled in providing evidence-based interventions for ASD/DD:

### **Topic Area IV: Service Delivery**

19. Number of infants/children screened for ASD/DD:
20. Number of infants/children who received interdisciplinary diagnostic services to confirm or rule out ASD/DD:
21. Number of LEND faculty who worked in clinical settings located in an underserved area or who are working with underserved populations:

### **Topic Area V: Educational Products**

22. Number of ASD/DD-related:

Articles published in peer reviewed journals:

Educational products developed or disseminated (other than peer reviewed):

Presentations delivered at conferences by LEND faculty and/or trainees: