This annual report presents a summary of the results of work conducted by the Disability Research and Dissemination Center (DRDC). The DRDC is composed of professionals from the University of South Carolina, American Association on Health and Disability, and SUNY Upstate Medical University. The first year (September 30, 2012 – September 29, 2013) of the Cooperative Agreement #1U01DD001007-01 established operations and programs in collaboration with the National Center for Birth Defects and Developmental Disabilities (NCBDDD), which is part of the Centers for Disease Control and Prevention (CDC). The project team members worked with NCBDDD to target major goals and activities to be completed during this period in each of the five project cores (administrative, research, training & evidence, dissemination, and evaluation). The DRDC achieved several of the designated goals, and identified areas for targeted improvement for future years of project implementation. Future plans to meet unmet goals and activities are outlined within the following report.
OVERVIEW

Cooperative Agreement #1U01DD001007-01 was initiated on September 30, 2012, with the University of South Carolina acting as the Administrative home of the DRDC. Subcontracts were established at the American Association on Health and Disability (AAHD) and SUNY Upstate Medical University.

This annual report presents results of the first year of the project (September 30, 2012-September 29th, 2013), based upon the modified logic model shown on page 2, which incorporates aims and activities as agreed through post-award negotiation with the CDC’s National Center for Birth Defects and Developmental Disabilities (NCBDDD).
# LOGIC MODEL: COOPERATIVE AGREEMENT #DD001—7-02

**Mission:** Establish a Disability Research and Dissemination Center (DRD) that will expand NCBDDD’s capacity to conduct research and training, and to disseminate evidence-based practice related to birth defects and developmental and other disabilities.

<table>
<thead>
<tr>
<th>Core Component</th>
<th>Activities</th>
<th>Planning Outputs</th>
<th>Program Outcomes</th>
<th>Distal Outcomes</th>
</tr>
</thead>
</table>
| **Administrative Core** [Specific Aim 1] | • Manage & coordinate Core activities and programs [Target 1a]  
• Form advisory board (EAC) [Target 1b]  
• Establish partnerships [Target 1c]  
• Establish Center agenda | • Management & administrative structures in place  
• Center priorities defined  
• Procedures for internal monitoring established  
• Content areas identified | • Filled positions  
• Arranged MOAs  
• Established networks and partnerships | • Sound yet flexible multi-disciplinary administrative system established through sustainable and responsible partnerships |
| **Research Core** [Specific Aim 2] | • Conduct internal research [Target 2a]  
• Set research priorities [Target 2b]  
• Solicit and award research projects [Target 2c]  
• Provide research support | • Research priorities defined  
• Mechanisms for solicitation and evaluation of research project applications established | • Number of research grants awarded by Center  
• Number and type of research projects initiated by Center  
• Number of completed studies related to developmental disabilities | • Dissemination of research findings through conferences and scholarly journals  
• Increased number of PIs managing independent disability studies |
| **Training/Evidence Based Core** [Specific Aim 3] [Specific Aim 4] | • Develop research fellowship [Target 4a]  
• Conduct learners’ needs analysis (LNA) [Target 4b] | • Mechanisms for solicitation and evaluation of research fellowship applications established  
• Teaching modules and programs developed from LNA  
• Web-based information system devised and managed  
• Research uploaded and reviewed | • Awarded research fellowships  
• Manuscripts published by research fellows  
• Number of individuals participating in teaching modules and programs  
• Evaluations of program effectiveness | • Increased dissemination of evidence-based programs and policies  
• Increased knowledge of evidence-based programs and policies among health professionals working with people with disabilities |
| **Dissemination Core** [Specific Aim 5] | • Establish and maintain web and social media strategy [Target 5a] | • Dissemination strategies identified and prioritized through dissemination meeting  
• Project website established  
• Technical assistance provided where needed  
• Media campaigns developed | • Information disseminated through a variety of media approaches  
• Launched media campaigns  
• Continual evaluation of dissemination strategies and media campaign effectiveness | • Progressive dissemination mechanisms implemented and continually updated to effectively communicate knowledge surrounding evidence-based practice |
| **Evaluation Core** [Specific Aim 6] | • Organize and implement routine evaluations for all processes, research, training, dissemination strategies, and other activities related to the grant [Target 6b] | • Concept mapping conducted  
• Mixed-methods evaluation plans established  
• Mechanisms to monitor stakeholder engagement established | • Findings from process and effect data collection and analysis  
• Targets for intervention identified  
• Program database  
• Annual report | • Strong program fidelity and continual quality improvement within research and training programs |

**Inputs**

**Immediate Outputs**

**Proximal and Distal Outcomes**
ADMINISTRATIVE CORE

The activities and responsibilities of the Administrative Core fall within Specific Aim 1 of the Cooperative Agreement:

Establish a national DRDC that builds on the foundation of two national universities (University of South Carolina [USC] and State University of New York Upstate Medical University [SUNY-Upstate]) and a national dissemination and policy organization (American Association for Health and Disability [AAHD]).

The major activities outlined under Administrative Core responsibilities include:

1. Manage and coordinate Core activities and programs [Target 1a]
2. Form an advisory board: External Advisory Committee (EAC) [Target 1b]
3. Establish partnerships for solicitation and dissemination [Target 1c]
4. Establish a Center agenda

Summary of Activities

All open positions are filled, and all contracts are executed. Processes are in place to efficiently execute grant awards through subcontracts and to hire professionals and trainees who will be working at NCBDDD.

RESEARCH CORE

The activities and responsibilities of the Research Core fall within Specific Aim 2 of the Cooperative Agreement:

Conduct research related to NCBDDD priorities using a network of University partners that includes medical, social and basic science, and public health approaches.

The major activities outlined under Research Core responsibilities include:

1. Conduct internal research [Target 2a]
2. Set research priorities [Target 2b]
3. Solicit and award research projects [Target 2c]
4. Provide research support

Summary of Activities

Data for Research Core activities were collected based upon open-ended interviews with Suzanne McDermott, PhD, the Research Core director and overall project principal investigator (PI), and Deborah Salzberg, MS, MAT, the DRDC project manager; as well as from the annual progress report submitted to the CDC/NCBDDD.

The major goals of the Research Core were met. Four Requests for Applications (RFAs) were established in year 1, with a total of 13 applications. DRDC review panels were formed using outside
experts, and through a formal review process; the panels passed 9 of these applications on to the CDC for additional review and funding determination. The DRDC’s EAC was established early in year 1; its members were invited to serve as DRDC reviewers and to refer other qualified individuals to serve. Several of them were utilized in conducting the application reviews.

In addition, the research project that was funded at USC, with Suzanne McDermott, PhD as PI, is underway and is meeting expectations for thorough data analyses. Technical monitoring is provided by the assigned NCBDDD Project Officer. Research output for both the Research Core and for grantees is not yet measurable, which is as expected in the first year of funding.

One area appears in need of further development. The Review Process for the RFA’s was overly intensive on the DRDC side, as a duplicative intensive review was conducted by the CDC after applications were referred to them. This has already been addressed in Year 2.

Major Activities and Outputs

ACTIVITY 1 [TARGET 2A]: CONDUCT INTERNAL RESEARCH

I. Initiation of internal research studies
   a. Disability and Health: Predictors of Onset of Common Health Conditions and Receipt of Preventive Services Among Adults with Disabilities
      i. PI – Suzanne McDermott, PhD, USC School of Medicine, Columbia, SC
      ii. Analysis of national data from National Health Interview Survey (NHIS) and Medical Expenditure Panel Survey (MEPS)
          1. All of the NHIS data were analyzed.
          2. Identified areas of insufficient MEPS data for full analysis and developed plan to modify approach
      iii. Analysis of state data from South Carolina Medicaid, Medicare and administrative data
          1. Data requests completed for Medicare
          2. Full Medicaid and administrative data obtained
          3. Merging and cleaning data

ACTIVITY 2 [TARGET 2B]: SET RESEARCH PRIORITIES

I. Research topic areas for solicitation targeted and advertised through DRDC website
   a. RFA #1 – Project to Learn About Youth – Mental Health (up to 2 projects funded)
   b. RFA #2 – Early Hearing Detection and Intervention – Developmental Outcomes (up to 1 project funded)
   c. RFA #3 – Early Hearing Detection and Intervention – WIC (up to 2 projects funded)
   d. RFA #4 – Learn the Signs Act Early (up to 1 project funded)
ACTIVITY 3 [TARGET 2C]: SOLICIT AND AWARD RESEARCH PROJECTS
I. In partnership with the Administrative Core, application and evaluation procedures were developed
II. Management of the review process:
   a. Formed 3 review panels
      i. Panelists emailed applications and review documents
      ii. Password-protected review panel web pages established to share review documents
      iii. Panel reviews April 2-4, 2013, via 2-hour conference calls and web assisted discussions
   b. DRDC compiled top 2-3 proposals for each RFA to be submitted to CDC for funding consideration

ACTIVITY 4: PROVIDE RESEARCH SUPPORT
I. To begin in Year 2, with new grantees.

Key Outcomes or Other Achievements

ACTIVITY 1 [TARGET 2A]: CONDUCT INTERNAL RESEARCH
I. One internal research project initiated
   a. Analysis of national data completed
   b. Data collection initiated for South Carolina analyses
II. No publications at this time

ACTIVITY 3 [TARGET 2C]: SOLICIT AND AWARD RESEARCH PROJECTS
I. RFA Applications Received
   a. RFA #1 – 2 applications received
   b. RFA #2 – 5 applications received
   c. RFA #3 – 3 applications received
   d. RFA #4 – 3 applications received
II. RFA Applications sent to CDC for funding consideration
   a. 9 submitted

Future Activities

ACTIVITY 1 [TARGET 2A]: CONDUCT INTERNAL RESEARCH
I. Commentary to be submitted to Disability and Health journal on limitations of national data to assess impairment specific disabilities
II. Once full data set is merged and cleaned, analysis will begin for South Carolina data

ACTIVITY 3 [TARGET 2C]: SOLICIT AND AWARD RESEARCH PROJECTS
I. Once approved by CDC, subcontracts for projects funded from the 4 RFAs were to be established at the beginning of year 2.
TRAINING AND EVIDENCE BASED CORE

The activities and responsibilities of the Training and Evidence Based Core fall within Specific Aim 3 of the Cooperative Agreement:

Advance evidence-based programs and practices that promote the health and well-being of people with disabilities of all ages and their families; and Specific Aim 4: Train health and public health professionals.

The major activities outlined under Research Core responsibilities include:

1. Develop research fellowship [Target 4a]
2. Conduct Learners’ Needs Analysis (LNA)[Target 4b]

Summary of Activities

The Training and Evidence Based Core oversaw the recruitment of an NCBDDD “Learn the Signs. Act Early.” fellow, including the development of a selection rubric and screening process (Appendix A). The Evaluation Core is administratively housed within the Training and Evidence Based Core, and the Training and Evidence Based Core Director, Margaret Turk, MD, the Evaluation Director, Christopher P. Morley, PhD, and support staff were engaged in this activity.

The selection process ultimately yielded 14 applicants; the top four were forwarded to CDC, and the top candidate was successfully hired (Brian Barger, PhD).

Interviews were held with Dr. Barger and with Catherine Rice, PhD, and Rebecca Wolf, MA, of the CDC/NCBDDD. Dr. Barger reports tangible goals to publish and present his work, with a goal of 2 publications in print or in press by the end of the fellowship, a journal submission schedule of one manuscript every 5-6 months, and a working draft of a manuscript, for review by CDC and DRDC supervisors, every quarter. These may be over-optimistic goals, although submission of any manuscripts for review will ultimately be determined based upon the results generated by Dr. Barger’s analyses. Dr. Barger also expressed goals of increased professional networking, gaining experience in using national data sets and conducting systematic reviews, and developing project leadership skills. An additional future goal was stated as employment in an academic institution. Dr. Rice and Ms. Wolf expressed concordance with these overall goals, and confidence in both the candidate selection and in the likelihood of achieving stated goals. At the time interviews were conducted, one systematic review was nearing completion, and another analysis and manuscript were in the planning stages. A major barrier existed in Year 1 due to the shutdown of the federal government.

Dr. Rice and Ms. Wolf further expressed satisfaction with the overall pool of candidates. One area for improvement was noted in the overall level of communication and feedback among Dr. Barger, his immediate supervisors at CDC, and the Training and Evidence Based Core director. This was noted during the government shutdown, when there was no precedent for supervision of a fellow during that event. There has been improvement in communication between the CDC supervisors and the Core director, with a planned joint annual fellowship review in May 2014.

The Training and Evidence Based Core initiated planning activities for a Year 2 activity, the Spina Bifida Collaborative Care Network (SBCCN) development project. A single meeting was held September 2013 in Washington DC with representation from the Spina Bifida Association, CDC, and DRDC. The plan established at that time has provided the base of all Year 2 activities for the SBCCN.
Major Activities and Outputs

ACTIVITY 1 [TARGET 4A]: DEVELOP RESEARCH FELLOWSHIP
I. Wrote fellowship core processes, including material for website, material for partners to distribute to potential applicants, and material for fellowship reviewers
II. See narrative description above, regarding Fellow (Brian Barger, PhD).
III. Management of the review process:
   a. Committee of 3 faculty at SUNY Upstate conducted initial review of applications
      i. Applications and SUNY Upstate committee findings sent to NCBDDD March 21, 2013
   b. Conference call between NCBDDD and DRDC March 22, 2013
      i. Three candidates selected for phone interviews
      ii. Phone interview questions developed
   c. Phone interviews conducted March 29, 2013
   d. Offer to final applicant issued April 12, 2013

ACTIVITY 2 [TARGET 4B]: CONDUCT LEARNERS’ NEEDS ANALYSIS
I. Not conducted in year 1.

Key Outcomes or Other Achievements

ACTIVITY 1 [TARGET 4A]: DEVELOP RESEARCH FELLOWSHIP
I. Fellowship applications received: 14
II. Fellowship recipient: Brian Berger, PhD
   a. Began working at NCBDDD June 2013

Future Activities

ACTIVITY 1 [TARGET 4A]: DEVELOP RESEARCH FELLOWSHIP
I. Dr. Turk will conduct fellowship evaluation every 6 months

ACTIVITY 2 [TARGET 4B]: CONDUCT LEARNERS’ NEEDS ANALYSIS
I. Will be conducted based upon future funding levels.

DISSEMINATION CORE
The activities and responsibilities of the Dissemination Core fall within Specific Aim 5 of the Cooperative Agreement:

   Communicate and disseminate intervention and other information with and for stakeholders and other audiences.

The major activities outlined under Dissemination Core responsibilities include:

1. Establish and maintain web and social media strategy [Target 5a]
2. Organize stakeholder network [Target 5b]
3. Organize and conduct coalition meetings [Target 5c]²
4. Provide technical assistance [Target 5d]²
Summary of Activities

The data for the Dissemination Core was collected via an interview with the Dissemination Core director, Roberta Carlin, JD, as well as through the use of Google Analytics. The main outputs are listed after the outline below; the primary focus of this narrative is our analysis of data from Google Analytics.

Overall Website Visitation
In the period of January 7 to March 8, 2013, there were 3,986 visitors to the DRDC website. Of these, 67.8% (2,704) were new, unique visitors. There were a total of 14,329 page views, with an average of 3.59 pages viewed per visit. The average visit duration was 3 minutes 42 seconds per visitor. The visitor bounce rate was 39.16% (bounce rate refers to the number of visits that go only one page before exiting the site).

When looking exclusively at the 2,704 new, unique visitors to the DRDC website during the period of January 7 to March 8, the majority (96%) were visiting the site from locations within the United States; other visitors were primarily from Canada and India. The new, unique visitors accounted for 69.7% (9,986) of the page views on the website. New users visited 3.69 pages per visit, and spent 3 minutes, 22 seconds on the website, on average.

Traffic Sources and Dissemination Efforts
The most common traffic source for new visitors was direct traffic, at 82.8% of new visitors. Direct traffic refers to any scenario in which an individual clicked a link leading directly to the DRDC website (e.g. links contained in PDF documents or emails) or typed the website address directly into the browser. Other traffic sources included searching for the website in browser search engines, including Google and Yahoo, and following links to the DRDC website contained within the websites of other organizations, also known as referral sites. Approximately 15% of new visitors to the DRDC website fell into the category of referral traffic.

Several website dissemination efforts were launched during the period of mid-January to late February, 2013. During this same period, notable fluctuations of new-user traffic occurred on the DRDC website. Figure 1 displays a time trend graph of this time period, beginning January 7 and ending March 8.

Figure 1. Time Trend of DRDC website Visitation, by User Type, Jan 7 – Mar 8, 2013
The dates of dissemination efforts are marked with black dots; dates with multiple, co-occurring dissemination efforts are marked with red stars. Despite the lack of activity in early January, it appears that there is a relationship between dissemination efforts and new user website activity. The activities associated with the highest peaks in new user activity appear to be those occurring on January 29 and January 31, 2013. Dissemination efforts at these two times included alerts sent via email blasts, printing alerts in organizational newsletters, and posting alerts in group user sites, such as LinkedIn.

The period following March 8, 2013, is marked by a drastic decline in all user activity on the DRDC website, as displayed in Figure 2. There were no concentrated dissemination efforts during this period.

*Figure 2. Time Trend of DRDC website Visitation, by User Type, Jan 7 – Oct 31, 2013*

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**Major Activities and Outputs**

**ACTIVITY 1 [TARGET 5A]: ESTABLISH AND MAINTAIN WEB AND SOCIAL MEDIA STRATEGY**

I. Established contract with NeuConcept Productions, Inc., to design DRDC website

II. Developed communication strategy for DRDC external partners, EAC, stakeholders and community to disseminate information on DRDC mission, research and fellowships

III. Implemented social media campaign with utilization of Twitter™, Facebook™ and LinkedIn™

**ACTIVITY 2 [TARGET 5B]: ORGANIZE STAKEHOLDER NETWORK**

I. Stakeholder list established

II. Newsletter electronically distributed to roughly 7,000—8,000 stakeholders

**ACTIVITY 3 [TARGET 5C]: ORGANIZE AND CONDUCT COALITION MEETINGS**

I. Announcements for RFAs and fellowship distributed to coalitions, advocacy groups, and public health/medical organizations

II. Attendance at coalition and stakeholder meetings to disseminate information about mission of DRDC and funding opportunities

**ACTIVITY 4 [TARGET 5D]: PROVIDE TECHNICAL ASSISTANCE**

I. Work with Research Core
   a. Posted notices of RFAs and application instructions to DRDC website
   b. Hosted web pages for panel reviewers

II. Work with Training and Evidence Base Core
   a. Posted notice of fellowship opportunity to DRDC website
Key Outcomes or Other Achievements

ACTIVITY 1 [TARGET 5A]: ESTABLISH AND MAINTAIN WEB AND SOCIAL MEDIA STRATEGY
I. Conceptualized, designed, developed and implemented DRDC website
II. Assessment of dissemination activities and website visitation available in Appendix A
III. Established listserv for EAC and external partners

Future Activities

ACTIVITY 1 [TARGET 5A]: ESTABLISH AND MAINTAIN WEB AND SOCIAL MEDIA STRATEGY
I. Revisions and updates to DRDC website on-going

ACTIVITY 3 [TARGET 5C]: ORGANIZE AND CONDUCT COALITION MEETINGS
I. Participation in coalition and stakeholder meetings specific to DRDC current and future initiatives is on-going.

EVALUATION CORE

The activities and responsibilities of the Evaluation Core fall within Specific Aim 6 of the Cooperative Agreement:

*Evaluate and report on processes of the DRDC and assure research and product integrity.*

The major activities outlined under Research Core responsibilities include:

1. Organize and implement routine evaluations for all processes, research, training, dissemination strategies, and other activities related to the grant [Target 6b]

The primary activities of the evaluation core are conducted within the Training and Evidence Based Core infrastructure, and further detail is available in the Training and Evidence Based Core section beginning on page 6-7.

Major Activities and Outputs

ACTIVITY 1 [TARGET 6B]: ORGANIZE AND IMPLEMENT ROUTINE EVALUATIONS
I. Developed DRDC website effectiveness evaluation and site user engagement
   a. Conducted assessment utilizing Google Analytics
II. Collaborated with Training and Evidence Based Core
   a. Developed evaluation tool for fellowship applicants
   b. Fellowship evaluation mechanisms established
III. Established mixed-method evaluation plans
Key Outcomes or Other Achievements

ACTIVITY 1 [TARGET 6B]: ORGANIZE AND IMPLEMENT ROUTINE EVALUATIONS
I. Website effectiveness evaluation report (see Dissemination Core; Early version delivered to DRDC management team in February 2014)
II. Concept mapping report and presentation (Not selected for implementation by CDC)
III. 9-criteria scoring rubric for fellowship applicant evaluation (see following page).

Future Activities

ACTIVITY 1 [TARGET 6B]: ORGANIZE AND IMPLEMENT ROUTINE EVALUATIONS
I. Conducted concept mapping exercise for Spina Bifida Association stakeholders
II. Develop surveys as needed.
# APPENDIX A: EVALUATION RUBRIC – DRDC NCBDDD FELLOWSHIP APPLICANTS

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Comprehensively Fulfills Criteria</th>
<th>Generally Fulfills Criteria</th>
<th>Minimally Fulfills Criteria</th>
<th>Does not Fulfill Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Experience with early childhood developmental screenings &amp; early identification data systems</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>2. Experience in early intervention (Part C and Section 619 of special education programs)</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>3. Experience using data to support program monitoring and development</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>4. Recommendation of present faculty or supervisor</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
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<tr>
<td>5. Meets the priorities established by the NCBDDD</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>6. Implies a systems approach to address the needs of children with ASD or related developmental disabilities</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
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<tr>
<td>7. Focuses on conducting public health and disability through program development</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>8. Allows for the use of new approaches to public health programming or innovative methodologies to research</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
</tr>
<tr>
<td>9. Has a publication record</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
<td>0 points</td>
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</tbody>
</table>