

Disability Research and Dissemination Center

2015-2016 Annual Report

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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 fourth year (September 30, 2015 – September 29, 2016) of the Cooperative Agreement #1U01DD001007 continued successful operations and programs initiated in the previous three years of the agreement, in collaboration with the National Center on 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 successfully continued activities initiated within the first three years of the cooperative agreement, achieved several of the designated goals for the fourth year, and developed new goals and targets for the fifth, and final, year of the agreement.

TABLE OF CONTENTS

OVERVIEW	3
ADMINISTRATIVE CORE	3
Summary of Activities	3
Year 5 Activities	3
RESEARCH CORE.....	5
Summary of Activities	5
Major Activities and Outputs.....	7
Key Outcomes or Other Achievements.....	7
Year 5 Activities	13
TRAINING AND EVIDENCE BASED CORE	14
Summary of Activities	14
Major Activities and Outputs.....	17
Key Outcomes or Other Achievements.....	18
Year 5 Activities	18
DISSEMINATION CORE	19
Summary of Activities	19
Major Activities and Outputs.....	21
Year 5 Activities	21
EVALUATION CORE.....	22
Summary of Activities	22
Major Activities and Outputs.....	23
Key Outcomes or Other Achievements.....	23
Year 5 Activities	23
APPENDIX A: RFA EVALUATION RUBRIC	24
APPENDIX B: EVALUATION OF DRDC WEBSITE VISITATION	25
Overall Website Visitation.....	25
Traffic Sources and Dissemination Efforts	25

Overview

Cooperative Agreement #1U01DD001007 was initiated on September 30, 2012, with the University of South Carolina acting as the Administrative home of the Disability Research and Dissemination Center (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 fourth year of the project (September 30, 2015 - September 29, 2016), based upon the logic model shown on the following page. This logic model incorporates aims and activities agreed upon during post-award negotiation with the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD).

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 have been filled, and all contracts have been executed. Processes are in place to efficiently execute grant awards through subcontracts.

Subcontracts were established with the AAHD and SUNY Upstate Medical University (SUNY), which are the other two PI institutions, and also with the following external institutions: Mary Imogene Bassett Hospital, University of South Carolina, University of Texas, University of Colorado – Boulder, University of Wisconsin, Cornell University, University of Missouri, Ohio University, University of Florida, OZ Systems, Inc., Family Health International, and the Research Foundation for Mental Hygiene.

In January 2016, the Dissemination Core director, Roberta Carlin, communicated via email to the External Advisory Committee (EAC) to discuss the details of the DRDC's Year 5 RFAs, to solicit advice and assistance in publicizing them, and to secure commitments from the EAC to help with application reviews, evaluation of the DRDC activities, and formulating future targeted research and dissemination areas.

During the Year 4 period, there was some attrition among EAC member for various reasons. Four EAC members either retired from their positions or began new jobs elsewhere. DRDC administration has since started recruiting new members to participate with the EAC.

Year 5 Activities

- I. Submit a proposal for a new cycle of funding through the CDC's NCBDDD
- II. Invite new members to join the EAC, and restore the committee to its original capacity

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					
Core Component	Activities	Planning Outputs	Program Outcomes	Distal Outcomes	
Administrative Core [Specific Aim 1]	<ul style="list-style-type: none">Manage & coordinate Core activities and programs [Target 1a]Form advisory board (EAC) [Target 1b]Establish partnerships [Target 1c]Establish Center agenda	<ul style="list-style-type: none">Management & administrative structures in placeCenter priorities definedProcedures for internal monitoring establishedContent areas identified	<ul style="list-style-type: none">Filled positionsArranged MOAsEstablished networks and partnerships	<ul style="list-style-type: none">Sound yet flexible multi-disciplinary administrative system established through sustainable and responsible partnerships	
Research Core [Specific Aim 2]	<ul style="list-style-type: none">Conduct internal research [Target 2a]Set research priorities [Target 2b]Solicit and award research projects [Target 2c]Provide research support	<ul style="list-style-type: none">Research priorities definedMechanisms for solicitation and evaluation of research project applications established	<ul style="list-style-type: none">Number of research grants awarded by CenterNumber and type of research projects initiated by CenterNumber of completed studies related to developmental disabilities	<ul style="list-style-type: none">Dissemination of research findings through conferences and scholarly journalsIncreased number of PIs managing independent disability studies	
Training/ Evidence Based Core [Specific Aim 3] [Specific Aim 4]	<ul style="list-style-type: none">Develop evaluation strategy & maintain evidence-based programs [Target 3a]Disseminate promising practices supported by research [Target 3b]Develop research fellowship [Target 4a]Conduct learners’ needs analysis (LNA) [Target 4b]Identify, catalog, maintain collection professionals’ education materials [Target 4c]Develop/promote teaching materials to medical/public health schools [Target 4d]	<ul style="list-style-type: none">Mechanisms for solicitation and evaluation of research fellowship applications establishedTeaching modules and programs developed from LNAWeb-based information system devised and managedResearch uploaded and reviewed	<ul style="list-style-type: none">Awarded research fellowshipsManuscripts published by research fellowsNumber of individuals participating in teaching modules and programsEvaluations of program effectiveness	<ul style="list-style-type: none">Increased dissemination of evidence-based programs and policiesIncreased knowledge of evidence-based programs and policies among health professionals working with people with disabilities	
Dissemination Core [Specific Aim 5]	<ul style="list-style-type: none">Establish and maintain web and social media strategy [Target 5a]Organize stakeholder network & conduct coalition meetings [Target 5b; 5c]Provide technical assistance [Target 5d]Support EB health promotion activities [Target 5e]Distribute policy & legislation [target 5f]	<ul style="list-style-type: none">Dissemination strategies identified and prioritized through dissemination meetingProject website establishedTechnical assistance provided where neededMedia campaigns developed	<ul style="list-style-type: none">Information disseminated through a variety of media approachesLaunched media campaignsContinual evaluation of dissemination strategies and media campaign effectiveness	<ul style="list-style-type: none">Progressive dissemination mechanisms implemented and continually updated to effectively communicate knowledge surrounding evidence-based practice	
Evaluation Core [Specific Aim 6]	<ul style="list-style-type: none">Conduct needs assessment [Target 6a]Organize and implement routine evaluations for all processes, research, training, dissemination strategies, and other activities related to the grant [Target 6b]	<ul style="list-style-type: none">Concept mapping conductedMixed-methods evaluation plans establishedMechanisms to monitor stakeholder engagement established	<ul style="list-style-type: none">Findings from process and effect data collection and analysisTargets for intervention identifiedProgram databaseAnnual report	<ul style="list-style-type: none">Strong program fidelity and continual quality improvement within research and training programs	
Inputs		Immediate Outputs	Proximal and Distal Outcomes		

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 Deborah Salzberg, MS, MAT, the DRDC project manager, as well as email communications with research project principal investigators.

During Year 4, the Research Core successfully continued to work on the four major goals. Eight new external research projects, selected in Year 3 for funding, were initiated in Year 4. In addition, the DRDC continued the management of seven research projects initiated during previous years of the Cooperative Agreement. Detailed information on the current progress of each project can be found in the Key Outcomes section below. Also provided in the Key Outcomes section is a comprehensive list of publications and presentations that have resulted from completed and ongoing projects.

During Year 2, the DRDC contracted with the Greenwood Genetic Center (GGC) to identify a subject matter expert to collaborate with CDC's Division of Birth Defects and Developmental Disabilities (DBDDD), providing clinical genetics expertise, technical assistance, and medical and scientific advice to clinicians and epidemiologists studying birth defects and developmental disorders. The work began in May of 2014, and concluded during the Year 4 period of the Cooperative Agreement. During Years 3 and 4, Dr. Bryan Hall, MD, provided expert assistance to the DBDDD by reviewing and classifying CDC records for dysmorphology in infants with major birth defects. A total of 8,112 records were reviewed from the years 1995-2010, in addition to minimal review of 133 cases from 1994.

Five Requests for Applications (RFAs) were established in Year 4, including two that had limited eligibility. Of the three that had more widely available eligibility, one was originally planned to fund two projects, for a total of four funding opportunities. A total of 16 applications were received, and the research projects funded from these RFAs will begin in Year 5 of the Cooperative Agreement. Unfortunately, due to lack of available funding by NCBDDD, one of the Early Hearing Detection and Intervention (EHDI) funding opportunities was retracted (the Parents Pilot) and the other EHDI RFA only funded one applicant, whereas, two were anticipated. Thus, from the four RFAs, only two new projects were selected for funding that will begin in Year 5.

The RFA application evaluations in Year 4 followed a triage-level peer review process, which was similar to that utilized during the Year 2 and Year 3 application reviews. Within this process, triage panels consisting of members of the DRDC External Advisory Committee (EAC) and other selected experts in the RFA subject areas scored applications using a Likert scale (1-5, whole numbers only: 1=superior, 2=very good, minor issues, 3=adequate, some concerns, 4=major issues, 5=poor) in four categories: (1) Responsiveness to the RFA/Significance/Innovation, (2) Merit of the Methods/Approach, (3) Evaluation Plan, and (4) Principal Investigator & Team's Ability to Carry out the Work. An example of the scoring rubric can be found in Appendix A. All reviewers were instructed to self-identify and recuse themselves from reviewing any applications where they had a conflict of interest. The DRDC triage panelists were also required to sign a Reviewer Confidentiality and

Conflict of Interest statement. The DRDC eliminated low-scoring applications and submitted the top proposals for each RFA for further review and selection by the CDC.

In addition to the three generally open RFAs, the CDC also offered RFAs for two other new projects in Year 4 with specific eligibility requirements. Due to the specific and limited eligibility requirements, the DRDC identified appropriate applicants from whom to solicit proposals, and these were not evaluated through the triage-level peer review system. One of these was for a small-scale grain fortification project in Tanzania; and the other was for the DRDC Research Core to continue a project in which Dr. McDermott had led the work with Medicaid data analysis for a 4-state collaborative, but which had been funded through another mechanism, rather than through the DRDC. Thus, a total of four new awards will be funded in Year 5, and there will also be eleven continuing projects.

Internally, USC has concluded the project on the *Disability and Health: Predictors of Onset of Common Health Conditions and Receipt of Preventive Services Among Adults with Disabilities* project. During Years 1 – 3 of the Cooperative Agreement, the primary investigator, Suzanne McDermott, PhD, conducted analyses using NHIS/MEPS data and Medicare/Medicaid data for South Carolina to describe health services receipt for individuals who are blind, have intellectual disability (ID), or spinal cord injury (SCI) for the period of 2000-2010, including:

1. Women's preventive health services (cervical and breast cancer screening) for women who are blind, those who have ID, or those who have SCI in South Carolina (Medicare/Medicaid data)
2. Colorectal cancer screening services for adults who are blind, have ID, or those who have SCI in South Carolina (Medicare/Medicaid data)
3. Sequella of diabetes for people who have ID or SCI (NHIS/MEPS and Medicare/Medicaid data)

These investigations are now complete, and the four manuscripts have been published in academic journals. One manuscript is In Press and one manuscript is In Review.

During the Year 4 project period, Dr. McDermott completed epidemiologic, economic and statistical data analyses investigating questions regarding differences in health care access, health status, and barriers, based on disability groups. The investigation focused on analyses in the following areas:

- Multivariable analyses predicting the completion of preventive services for breast, cervical and colorectal cancer using a dependent variable of United States Preventive Services Task Force recommending screening intervals.
- Multivariate analyses predicting onset of diabetes, coronary artery disease, congestive heart failure, obesity, depression, several forms of cancer, and stroke in people who are blind/low vision, have ID, or have SCI compared to a comparison group during a 10-year follow-up period. The comparison group was comprised of adults who received a service but did not develop or have any of the case disabilities listed. The groups were strata matched for age (in five-year intervals) and sex.

Results of this work will be published in peer-reviewed journals and disseminated via the AAHD website.

Also, internally, the USC Research Core began work in Year 3 with the NCBDDD on the requested hypertension data analysis following a literature review completed by the DRDC Training and Evidence-Based Cores in Year 3. During Year 4, USC continued conducting analysis of medication adherence for people with intellectual and developmental disabilities that have a diagnosis of hypertension, and expects to complete the analysis and manuscript preparation with carryover funds. Manuscripts are underway for this investigation.

Upon an additional literature review performed in Year 4 regarding the economic impact of physical inactivity in adults with disability (also completed by the DRDC Training and Evidence-Based Cores), the NCBDDD and the USC Research Core began considering models, data sets, and analyses for a research study. After considering potential data sources, the team decided to focus on using data from the National Health Interview Survey (NHIS) and

Medical Expenditures Panel Survey (MEPS). The team has begun the process of reviewing the NHIS/MEPS data files for relevant variables, and will pursue conducting analyses and manuscript development into Year 5.

Major Activities and Outputs

Activity 1 [Target 2a]: Conduct internal research

- I. Internal research studies
 - a. *Disability and Health: Predictors of Onset of Common Health Conditions and Receipt of Preventive Services Among Adults with Disabilities*
 - i. Completed analysis using NHIS/MEPS data on sequella of diabetes for people who have ID or SCI; women's preventive health services for women who are blind, have ID or have SCI; and colorectal cancer screening services for adults who are blind, have ID or have SCI
 - ii. Completed analysis on predicting the completion of preventive services for breast, cervical and colorectal cancer and predicting the onset of chronic diseases in people with various disabilities
 - b. *Association of Physical activity and Health Expenditures for People with Disability compared to People without Disability* – in progress
 - c. *Adherence to hypertension medication for people with IDD*- in progress with NCBDDD scientists.

Activity 2 [Target 2b]: Set research priorities

- I. Research topic areas for solicitation targeted and advertised through DRDC website
 - a. RFA-R16-01: EHDI Parents Pilot (funding for 1 project)
 - b. RFA-R16-02: Using EHDI to Assess Outcomes (funding for 2 projects)
 - c. RFA-R16-03: Improving Identification of Tics and Other Conditions in Children (funding for 1 project)
- II. Research topics for funding opportunities with specific eligibility requirements disseminated
 - a. Small Scale Grain Fortification in Tanzania
 - b. Identifying Opportunities to Improve the Care of People with Intellectual and Developmental Disabilities

Activity 3 [Target 2c]: Solicit and award research projects

- I. Fifteen (15) Year 4 projects were funded (RFAs for these projects were solicited in Years 1 through 3)
- II. Five (5) new RFAs were solicited (see list above, Activity 2)
- III. Implemented the previously developed and vetted triage process to evaluate applications
- IV. Top-scoring RFA applications were sent to CDC for funding consideration

Activity 4: Provide research support

- I. Provided support to funded projects
 - a. Attended meetings (at least quarterly for each project) with CDC and project PIs
 - b. Managed subcontract awards and administered budgets
 - c. Provided other assistance as needed
- II. Clinical genetics consulting provided to the NCBDDD by Greenwood Genetic Center through the DRDC was concluded in Year 4
- III. Ongoing analysis of data on hypertension in people with intellectual and developmental disabilities and manuscript preparation
- IV. Ongoing analysis on the economic impact of physical inactivity in adults with disability and manuscript preparation

Key Outcomes or Other Achievements

Activity 1 [Target 2a]: Conduct internal research

- I. Predictors of Use of Preventive Services by Adults with Disability – University of South Carolina, Suzanne

McDermott, PhD (supplemental year)

- a. Four articles have been published on the results of the following NHIS/MEPS data analyses: women's preventive health services for women who are blind, have ID or have SCI; colorectal cancer screening services for adults who are blind, have ID or have SC; and sequella of diabetes for people who have ID or SCI. These publications are:
 - i. Bennett, K. J., McDermott, S., Mann, J. R., & Hardin, J. (2017). Receipt of recommended services among patients with selected disabling conditions and diabetes. *Disability and Health Journal*, 10(1), 58–64. <http://doi.org/http://dx.doi.org/10.1016/j.dhjo.2016.09.001>
 - ii. Xu, X., Mann, J. R., Hardin, J. W., Gustafson, E., McDermott, S. W., & Deroche, C. B. (2016). Adherence to US Preventive Services Task Force recommendations for breast and cervical cancer screening for women who have a spinal cord injury. *The Journal of Spinal Cord Medicine*, 0. <http://doi.org/10.1080/10790268.2016.1153293>
 - iii. Xu, X., Mann, J. R., McDermott, S. W., Deroche, C. B., Gustafson, E., & Hardin, J. W. (n.d.). Women with Visual Impairment and Insured by Medicaid or Medicare Are Less Likely to Receive Recommended Screening for Breast and Cervical Cancers. *Ophthalmic Epidemiology*, 0(0), 1–6. <http://doi.org/10.1080/09286586.2016.1213302>
 - iv. Bennett, K. J., McDermott, S., Mann, J. R., & Hardin, J. W. (2016). Preventive Service Utilization among People Who Are Blind or Have Low Vision. *Journal of Visual Impairment & Blindness*, 110(2), 89–102.
- b. One manuscript is in press and is expected to be published in May 2017. One manuscript is in review as shown below:

In Press:

 - i. Deroche CB, McDermott S, Mann JR, Hardin JW, (2017) Colorectal Cancer Screening Adherence in Selected Disabilities Over 10 Years. *American Journal of Preventive Medicine*. Estimated publication data: May 2017

In Revision:

 - ii. Xu X, McDermott S, Mann JR, Hardin JW, Deroche CB, Carroll DC, Courtney-Long EA. (2017) Adherence to breast and cervical cancer screening recommendations in women with and without intellectual disability. Under Review: *Preventive Medicine*.

- II. Two additional topical areas were initiated during Year 4 and will be completed during Year 5
 - a. Association of Physical Activity and Health Expenditures for People with Disability Compared to People without Disability; one manuscript is currently in review.

In Review:

 - i. Xu X, Ozturk O, Turk MA, McDermott S. (2017) Costs associated with physical activity and disability. *Archives of Physical Medicine and Rehabilitation*. In Review 2/17.
 - b. Adherence to hypertension medication for people with IDD; one manuscript is being prepared for submission.

In CDC Clearance:

 - i. Stevens AC, Royer J, Carroll DD, Courtney-Long EA, McDermott S, Turk MA. (2017) Anti-hypertensive medication use and factors related to adherence among adults with intellectual disability in South Carolina. *Hypertension*.

Activity 2 [Target 2c]: Solicit and award research projects

- I. Sixteen (16) applications in response to the new RFAs were received for Year 5 funding
- II. Four new projects were selected for funding by the CDC for Year 5:
 - a. Using Early Hearing Detection and Intervention (EHDI) to Assess Outcomes – Cincinnati Children's Hospital Medical Center, Jareen Meinzen-Derr, PhD

- b. Improving Identification of Tics and Other Conditions in Children – University of Rochester, Heather Adams, PhD
- c. Small Scale Grain Fortification in Tanzania – Project Healthy Children/Sanku, Felix Brooks-Church, BA
- d. Identifying Opportunities to Improve the Care of People with Intellectual and Developmental Disabilities – University of South Carolina, Suzanne McDermott, PhD

III. Fifteen research projects either began or continued in Year 4

1. Assessing Impact of EHDI: University of Colorado-Boulder – Christie Yoshinaga-Itano, PhD (Year 1 of 2)
 - a. Specific Aims: a) to demonstrate impact of EHDI by comparing the time of screening/diagnosis to receipt of EI before/after universal newborn hearing screening and detection – IN PROGRESS; b) to assess the impact of EI on the developmental/educational outcomes of deaf and hard of hearing children, controlling for other covariates – IN PROGRESS
2. Assessing Impact of EHDI: University of Wisconsin – Anne Harris, PhD (Year 1 of 2)
 - a. Specific Aims: a) to assess the impact of receiving early intervention services on developmental outcomes as measured in the AEIOu study (expressive and receptive language, functional listening, social-emotional development, reading readiness at school entry) for children who are deaf and hard of hearing, controlling for covariates including race/ethnicity, maternal education, age at identification, degree of hearing loss, birth history, co-occurring conditions, type and intensity of intervention – IN PROGRESS; b) Compare two models for EHDI collaboration with Part C Early Intervention on age of enrollment and developmental outcomes as measured by AEIOu for children who are deaf and hard of hearing in Wisconsin in the years 2015-2017 – IN PROGRESS.
3. EHDI-Quality Measures: OZ Systems – Terese. Finitzo, PhD (Year 1 of 1)
 - a. Specific Aims: a) to determine definitional elements in NQF measures 1354, 1360 and 1361 and to map and transform real world data into rigorous measure definitions – IN PROGRESS.
4. EHDI-Development Outcomes: University of Colorado-Boulder – Christie Yoshinaga-Itano, PhD (Year 4 of 4)
 - a. Specific Aims: a) are there system and/or intervention program characteristics that facilitate or prevent the collection and use of population developmental outcome data? – COMPLETED; b) are there EHDI programs (other than Colorado) that incorporate language and development outcomes into their state database? – IN PROGRESS; c) How do the skills, competencies and knowledge of interventionists differ within and across jurisdictional boundaries? – IN PROGRESS; d) How does parent and consumer systems involvement differ within/across states? – IN PROGRESS; e) How do developmental quotients differ by degree of hearing loss and number of ears affected (i.e., unilateral vs. bilateral)? – COMPLETED; f) Which developmental and demographic variables are significantly related to each other? (e.g., degree of hearing loss, Medicaid status, maternal level of education, hours of use of amplification, cognitive status, presence of additional disabilities, age of the child)? – IN PROGRESS; g) What child/family or interventionist characteristics are predictive of developmental outcomes? – IN PROGRESS.
5. LTSAE Book Testing: FHI 360 – Rebecca Ledsky, MBA (Year 1 of 1)
 - a. Specific Aims: a) to develop instruments to conduct observation and in-depth interview-based testing of Where is Bear? with parents of children ages 19-30 months – COMPLETED; b) to submit to and obtain FHI 360 IRB determination – COMPLETED; c) to recruit early child care and education organizations with which to work (they conduct recruitment of parents and host observations and interviews) with English and Spanish speaking parents – COMPLETED; d) to conduct observation and testing with up to 60 (up to 30 English-speaking and up to 30 Spanish-speaking) parents of children ages 19-30 months and their children – IN PROGRESS; e) to develop and submit report

based on Round 1 observations and interviews – IN PROGRESS; f) to conduct testing of the revised Where is Bear? with up to 20 (up to 10 English-speaking and up to 10-Spanish-speaking) parents of children ages 19-30 months and their children – IN PROGRESS; g) to develop and submit report based on Round 2 testing – IN PROGRESS.

6. LTSAE-WIC: University of Missouri – Janet Farmer, PhD (Year 4 of 4)
 - a. Specific Aims: a) to assess the feasibility and sustainability of the WIC Developmental Milestones Program by expanding it to a four-county region of eastern Missouri that is diverse in its racial/ethnic, cultural and geographic characteristics – IN PROGRESS; b) to review and refine the elements of the project, clarifying those that are minimally required so the project can be scaled for nationwide adoption – IN PROGRESS; c) to evaluate the impact of the project on awareness, knowledge and behaviors related to early childhood developmental monitoring, screening and referral – IN PROGRESS.
7. LTSAE Impact on Parents: Mary Imogene Bassett Hospital – Anne Gadomski, MD, MPH (Year 1 of 2)
 - a. Specific Aims: a) to measure how LTSAE materials affect the within-visit processes of discussion of the child's development, identification of a developmental problem, parent engagement, developing a treatment plan and setting expectations for the next visit. We will analyze recordings of well child visits to describe the exchange between the parent and the doctor – IN PROGRESS; b) to measure the parent's perceptions, motivations, and actions related to developmental monitoring and talking with a doctor about child development – IN PROGRESS
8. LTSAE Monitoring: University of Wisconsin – Gail Chodron, PhD (Year 2 of 2)
 - a. Specific Aims: a) Solicit and describe input from early childhood cross-sector stakeholders to inform design of implementation and evaluation – IN PROGRESS. (b) offer and evaluate LTSAE training through state training infrastructure – IN PROGRESS; (c) implement and evaluate Head Start learning cohort using a train-the-trainer model – IN PROGRESS; (d) implement and evaluate LTSAE integration in 12-15 childcare sties – IN PROGRESS; (e) develop and disseminate a model for implementation of integration of use of Learn the Signs. Act Early. in developmental monitoring in childcare settings – IN PROGRESS.
9. PLAY-Mental Health: Ohio University, Julie Owens, PhD (Year 2 of 2)
 - a. Specific Aims: a) describe the prevalence and co-occurrence of mental health disorders and associated health risk behaviors among youth in grades K-12 – IN PROGRESS; b) describe the rates of current and previous mental health treatment among youth previously diagnosed with a mental health disorder, as well as barriers to accessing treatment – IN PROGRESS; c) explore diversion and misuse of psychoactive medications prescribed to treat a mental health disorder – IN PROGRESS.
10. PLAY-Mental Health: University of Florida, Steven Cuffe, MD (Year 2 of 2)
 - a. Specific Aims: a) to estimate the prevalence of psychiatric disorders (internalizing, externalizing and tic disorders) in a school-based population of children aged 5-17, and estimate the rate of over/under-diagnosis – IN PROGRESS; b) to describe the treatment patterns of this cohort, including over and under-treatment, amount, type, and evidence-base of therapy, medication use and number of refills, type of school interventions – IN PROGRESS; c) to describe the patterns of misuse and diversion of psychoactive medications in this population – IN PROGRESS.
11. Re-PLAY 2nd Round of Testing: University of South Carolina – Kate Flory, PhD (Year 1 of 2)
 - a. Specific Aims: a) to extend PLAY-MH, which aimed to describe the prevalence and co-occurrence of internalizing, externalizing, and tic disorders among children and adolescents within a defined population – IN PROGRESS; b) to continue implementing existing screening and diagnostic strategies a second time within the same population to yield information

- regarding the stability of prevalence estimates and to quantify changes over time – IN PROGRESS; c) to examine mental health treatment in children with previously diagnosed mental disorders and the diversion and misuse of psychiatric medications – IN PROGRESS.
12. Healthy Weight Management: University of Texas – Katherine Froehlich-Grobe, PhD (Year 2 of 3)
 - a. Specific Aims: a) to create an appropriate and usable adaptation of the GLB program for people with mobility impairment –COMPLETED; b) to establish whether the adapted GLB program for people with mobility impairment is a feasible intervention – IN PROGRESS; c) to determine if the GLB intervention adapted for those with mobility impairment is effective as determined by significant improvement in the primary and secondary outcomes in the intervention group compared to the wait-list control group at 3 and 6 months from baseline – IN PROGRESS.
 13. EMR Rare Conditions – Univ of South Carolina, Kevin Bennett, PhD, PI (Year 2 of 3)
 - a. Specific Aims: a) to identify individuals with the three conditions within the available data sets, linking the data, describing the integrity of the linkage and characteristics of the individuals identified, and collaboratively developing research questions with CDC – COMPLETED; b) to begin working on a research study, with specific topic to be determined in collaboration with CDC – IN PROGRESS.
 14. India Biomarker surveillance: Cornell University – Julia Finkelstein, ScD (Year 1 of 1)
 - a. Specific Aims: a) to strengthen laboratory capacity for nutritional biomarker and birth defects surveillance at our field site and establish the folate microbiologic assay in our field site laboratory – IN PROGRESS; b) to conduct a pre-intervention biomarker survey to characterize the background burden of micronutrient deficiencies and birth defects in this population – IN PROGRESS; and c) inform the development of a randomized efficacy trial of quadruple fortified salt for prevention of anemia and birth defects in Southern India – IN PROGRESS.
 15. Development of Epi Tool: Research Foundation for Mental Hygiene – Prudence Fisher, PhD (Year 1 of 1)
 - a. Specific Aims: a) to update a widely used epidemiologic tool, DISC-IV, to assess diagnostic criteria specified in the DSM-5 for the more common diagnoses of youth – IN PROGRESS; b) to include “improvements” to the DISC, based on DISC-IV user feedback, data analyses, and expert opinion – IN PROGRESS.

IV. Publications

- a. Yoshinaga-Itano, C. & Wiggin, M. (2016). A look into the crystal ball for children who are deaf or hard of hearing: Needs, opportunities and challenges, *Seminars in Speech and Language*; 37, 252–258.
- b. Seeliger, E.L., Martin, R.A., Gromoske, A.N., & Harris, A.B. (2016). WIC Participation as a Risk Factor for Loss to Follow-Up in the Wisconsin EHDI System. *Journal of Early Hearing Detection and Intervention*, 1(1), 57-65.
- c. Han, M.K., Storkel, H.L., Hoon-Lee, J., & Yoshinaga-Itano, C. (2015). The influence of word characteristics on the vocabulary of children with cochlear implants. *J. Deaf Stud. Deaf Educ.* (2015) 20 (3): 242-251.
- d. Anthony, T., Wiggin, M., Yoshinaga-Itano, C., (2015). Infants and toddlers with sensory disabilities (pp. 216-254). In S.A. Raver & D.C. Childress, (Eds.) *Family-Centered Early Intervention: Supporting Infants and Toddlers in Natural Environments*. Baltimore: Brookes Publishing Company.
- e. Alford, R.L., Arnos, K.S., Fox, M., Lin, J.W., Palmer, C.G., Pandya, A., Rehm, H.L., Robin, N.H., Scott, D.A., & Yoshinaga-Itano, C. (2014). American College of Medical Genetics and Genomics guideline for the clinical evaluation and etiologic diagnosis of hearing loss. *Genetics in Medicine*, 16, 347-355.
- f. Szarkowski, A., Mood, D., Shield, A., Wiley, S., & Yoshinaga-Itano, C. (2014). A summary of current understanding regarding children with Autism Spectrum Disorder who are deaf or hard of hearing. *Seminars in Speech and Language*, 35, 241-259.

- g. Kellogg, E.C., Thrasher, A., & Yoshinaga-Itano, C. (2014). Early predictors of autism in young children who are deaf or hard of hearing: Three longitudinal case studies. *Seminars in Speech and Language*, 35, 276-287.
- h. Carr, J.C., Xu, Dongxin, Yoshinaga-Itano, C. (2014). Language ENvironment Analysis (LENA) Language and Autism Screen (LLAS) and the Child Development Inventory Social Subscale as a possible autism screen for children who are deaf or hard of hearing. *Seminars in Speech and Language*, 35.
- i. Thompson, N., & Yoshinaga-Itano, C. (2014). Enhancing the development of infants and toddlers with dual diagnosis of autism spectrum disorder and deafness. *Seminars in Speech and Language*, 321-330.
- j. Yoshinaga-Itano, C., & Uhler, K. (2014). Early intervention, education, and therapy for children who are deaf or hard of hearing. In J. Katz (Ed.), *Clinical Handbook of Audiology*, 7th Edition.
- k. Raimondo, B., & Yoshinaga-Itano, C. (2014). Legislation, policies and role of research in shaping early intervention. In M. Sass-Lehrer (Ed.), *Infants, Toddlers and their Families: An Interdisciplinary Perspective*, Oxford Press.

V. Presentations

- a. Reyes, N.M., Hightshoe, K.D., Moody, E.J., Rosenberg, S.A., Davidon, S.L., & Kubicek, L.F. "Performance of the English and Spanish Social Communication Questionnaire in 6 to 18 year olds." Poster presentation at the Annual Meeting of the American Psychological Association, Denver, CO, in August 2016.
- b. Reyes, N., Hightshoe, K., Moody, E., Rosenberg, S., Davidon, S., & Kubicek, L.F. "Performance of the English and Spanish Social Communication Questionnaire in 6 to 18 year olds." Poster presentation at the Annual Meeting of the American Psychological Association, Denver, CO, in August 2016.
- c. Bradley, W.J., Sicheloff, E.R., & Flory, K. "Associations between parent self-efficacy and child internalizing/externalizing symptomatology." Presented at the Annual Meeting of the American Psychological Association, Denver, CO, in August 2016.
- d. Flory, K., Bell, B.A., Burgess, K., Sicheloff, E.R., Cipolli, W., & Bower, R. "Bifactor models of the Strengths and Difficulties Questionnaire in a Large U.S. Community Sample." Presented at the Annual Meeting of the American Psychological Association, Denver, CO, in August 2016.
- e. Barnekow, K., G. Chodron, C. Jones, A. Puk, S. Tierney, and S. Viehweg. "Impact of 'Watch Me!' Training on Head Start, Center-, and Family-Based Early Care and Education Providers' (ECEPs) Knowledge and Perceived Capacity to Engage Families in Developmental Monitoring." Poster presentation at the National Research Conference on Early Childhood in July 2016.
- f. Farmer, JE, Falk, L, Clark, MJ, Mayfield, W, Smith, C, & Green, K. "Learn the Signs. Act Early: Promising findings from Phase II of the WIC Developmental Milestones Program." Poster presentation at the National WIC Association Annual Meeting, Cincinnati, OH, in May 2016.
- g. Kubicek, L.F., Hightshoe, K.D., Moody, E.J., Reyes, N.M., Davidon, S.L., & Rosenberg, S.A. "Prevalence and treatment of mental health disorders and developmental disabilities: A comparison of high and low risk Colorado school-aged youth." Poster presentation at the Colorado Clinical and Translational Science Institute 2016 Annual Spring Pediatric Research Poster Session, Aurora, CO, in May 2016.
- h. Chodron G, Farmer J, Nye-Lengerman K. "Building community capacity for early identification of developmental delay with diverse MCH programs and populations in three states." Panel presentation at American Association of Maternal and Child Health Programs Annual Conference, Washington, DC, in April 2016.
- i. Green, K., Chodron, G, Farmer, JE, & Nye-Lengerman, K. "Building community capacity for early identification of developmental delay with diverse Maternal & Child Health populations in three states." Workshop presentation at the Association of Maternal & Child Health Programs Annual Meeting, Washington, DC, in April 2016.
- j. Bradley, W.J., Flory, K., Sicheloff, E.R., Burgess, K. "Parent self-efficacy and youth symptomatology: Could school-based parent training programs make a difference?" Presented at the South Carolina School Behavioral Health Conference, Myrtle Beach, SC, in April 2016.

- k. Flory, K., Sicheloff, E.R., Bradley, W.J., & Burgess, K. "USC Project to Learn about Youth: Universal behavioral/emotional health screening in a SC school district." Poster presentation at the South Carolina School Behavioral Health Conference, Myrtle Beach, SC, in April 2016.
- l. Schwartz, M. E., Owens, J. S., Evans, S., & Kaizar, E. "Examining discrepancies between teacher and student ratings of ADHD on the Strengths and Difficulties Questionnaire." Poster presentation at the Association for Behavioral and Cognitive Therapies Annual Convention, Chicago, IL, in November 2015.
- m. McMahon, A., Sacchetti, G., Schwartz, M., Evans, S. W., Kaizar, E., & Owens, J. S. "Psychometric properties of two teacher-rated screening tools for identifying ADHD in high school youth." Poster presentation at the Association for Behavioral and Cognitive Therapies Annual Convention, Chicago, IL, in November 2015.
- n. Chodron G, Puk A, Viehweg S. "Childcare driving change: Implementing and evaluating a process for developmental monitoring using *Learn the Signs. Act Early.* with Childcare Professionals." Oral presentation at Association of University Centers on Disability Annual Conference, Washington, DC, in November 2015.
- o. Froehlich-Grobe, K, Driver, S, Lee, J, Kramer, MK, *Betts, A. "Accessible weight loss: Translating the GLB for people with impaired mobility." Presented to the Disability Section at the 143rd Annual meeting of the American Public Health Association, Chicago, IL, in November 2015.
- p. Muñoz, D, and Arriaga, RI. "Low-Income Parents' Values Involving the Use of Technology for Assessing Health Information." Presentation at the International Conference on Human-Computer Interaction (Interact), Los Angeles, CA, in September 2015.
- q. Barnekow K, Chodron G, Rizk S, Mission P, Puk A. "Understanding factors that enable or hinder parent and early childcare provider communication about developmental concerns using the LTSAE materials." Poster presentation at Autism CARES Meeting, Washington, DC, in July 2015.
- r. Farmer, JE, Falk, L, Clark, MJ, Smith, C. & Green, K. "Learn the Signs. Act Early-Phase II: Expanding the WIC Developmental Milestones Project." Poster presentation at the National WIC Association Annual Meeting, Los Angeles, CA, in May 2015.
- s. Hunter, LL, Meinzen-Derr, J., Wiley, S., Wexelblatt, S., Rolfes, L., DiStefano, S. "Collaboration Between WIC and EHDI to Improve Follow-Up from Newborn Screening." Oral presentations at 1) The Early Hearing Detection and Intervention Annual Meeting, Jacksonville, FL, in April 2014; and 2) The Advisory Committee of the Ohio Department of Health, Columbus, OH, in August 2014.

Year 5 Activities

Activity 1 [Target 2a]: Conduct internal research

- I. Complete remaining data analyses and develop manuscripts for projects on the following topics:
 - a. Adherence to prescribed hypertension medications among adults with intellectual and developmental (IDD) disabilities
 - b. Physical inactivity among people with disability

Activity 2 [Target 2b]: Set research priorities

- I. Work with NCBDDD to refine research questions and pose hypotheses that can be tested using administrative data

Activity 3: Provide research support

- I. Provide technical assistance to three state health departments to analyze Medicaid Disability data
 - a. South Carolina Disability Analysis (ACDA) team will provide technical assistance to disability analysts from Massachusetts, New York, and Iowa who have access to Medicaid data through state Departments of Health and Departments of Health and Human Services, as they analyze Medicaid disability data to identify opportunities to improve the health of sub-populations with intellectual and developmental disabilities (IDD)

Training and Evidence Based Core

The activities and responsibilities of the Training and Evidence Based Core fall within Specific Aim 3 and Specific Aim 4 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.

TRAIN HEALTH AND PUBLIC HEALTH PROFESSIONALS.

The major activities outlined under the Training and Evidence Core responsibilities include:

1. Develop a search and evaluation strategy, and catalog evidence-based programs [Target 3a]
2. Develop and/or disseminate promising practices that are supported by research [Target 3b]
3. Develop research fellowship [Target 4a]
4. Conduct Learners' Needs Analysis (LNA)[Target 4b]
5. Identify, catalog, and maintain a collection of professionals' education materials [Target 4c]
6. Develop and/or promote promising teaching materials to medical and public health schools [Target 4d]

In addition to these major activities, the Training and Evidence Based Core is tasked with implementing research and evaluation projects related to the Specific Aims listed above.

Summary of Activities

Data for Training and Evidence Based Core activities were collected based upon open-ended interviews with Training and Evidence Based Core director, Margaret Turk, MD.

Research Fellowship

Learn the Signs. Act Early. Fellowship (2013-2015)

Brian Barger, PhD, completed the LTSAE Fellowship in July 2015 (Year 3). He is currently working as a Research Assistant Professor at the Georgia State University School of Public Health. During both years of the Fellowship, Dr. Barger received excellent reviews and comments from his supervisors at the CDC/NCBDDD, Dr. Catherine Rice and Ms. Becky Wolf.

The following expectations were developed for Dr. Barger after the first six months of the fellowship:

- I. Year 1: June 2013 – May 2014
 - a. 1 abstract developed for and submitted to a national meeting presentation - COMPLETED
 - b. 1 manuscript developed and submitted for CDC clearance (Early Identification Leading to Part C Early Intervention) - COMPLETED
- II. Year 2: June 2014 – July 2015
 - a. 1 abstract developed for and submitted to a public health-related national meeting presentation (with a focus on early identification of children with developmental concerns or delays) – COMPLETED
 - b. 1 manuscript submitted to peer reviewed journal – COMPLETED
 - c. 1 new manuscript developed and submitted for CDC clearance – COMPLETED
 - d. 1 grant preparation/writing for internal submission – COMPLETED

From the 2-year LTSAE Fellowship, Dr. Barger completed the following list of publications and presentations:

- Publications:
 - a. Barger, B. D., Campbell, J., & Simmons, C. (2017). The relationship between regression in autism spectrum disorder, epilepsy, and atypical epileptiform EEGs: A meta-analytic review. *Journal of Intellectual & Developmental Disability*, 42(1), 45-60.
 - b. Barger, B., Rice, C., Simmons, C. & Wolf, R. (2016). A Systematic Review of Part C Early Identification Studies. *Topics on Early Childhood Special Education*, 1-13.
 - c. Raspa, M., Levis, D., Doto, J., Wallace, I., Rice, C., Barger, B., Green, K., & Wolf, R. (2015). Examining parents' experiences and information needs in the early identification of developmental delays: Qualitative research to inform a public health campaign. *Developmental and Behavioral Pediatrics*, 36(8), 575-585.
 - d. Barger, B., Campbell, J., & Simmons, C. (2015). Personality in Autism During Middle Childhood: An analysis using the Inventory of Children's Individual Differences. *Focus on Autism and Other Developmental Disabilities*.
 - e. Barger, B., Campbell, J., & Simmons, C. (2014). Measuring Five Factor Personality Traits in Autism During Early Childhood. *Journal of Developmental and Physical Disabilities*, 26(6), 775-792.
- Posters/Presentations
 - a. Rice, C., Barger, B., Shaw, E., Squires, J., & Kavulic, C. (Panel Presentation at the The Division for Early Childhood of the Council for Exceptional Children 2015 annual meeting, Atlanta, GA.). Use of diagnosed conditions for Part C early Intervention Eligibility.
 - b. Barger, B. (2014). Individuals with Disabilities Education Act (IDEA) Part C Child Find Systems: A Systematic Review and Future Directions. Invited presentation for the Department of Human Development and Family Studies at Michigan State University.
 - c. Greer, M., Noyes, D., Barger, B., & Rice, C. (2014). Early Concern to Early Intervention: State of the Data. Panelist for presentation accepted at the Association for University Centers on Disability 2014 meeting, Washington D.C.
 - d. Barger, B. & Rice (2014). Early Identification of Developmental Delays or Concerns to Receipt of Early Intervention Services among Infants and Toddlers: A Systematic Review. Panelist for presentation accepted at the Association for University Centers on Disability 2014 meeting, Washington D.C.
 - e. Greer, M., Noyes, D., Barger, B., & Rice, C. (2014). Early Concern to Early Intervention: State of the Data. Poster presented at the Division for Early Childhood 2014 meeting, Saint Louis, MO.
 - f. Barger, B. (2014). Using R for Data Analysis of Complex Surveys. Presentation at the Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities, Atlanta, GA.
 - g. Barger, B. (2014). The R 'Survey' Package: A peek into an emerging intermediate user's statistical workbench. Presentation at the Centers for Disease Control, R Users Group Meeting, Atlanta, GA.
 - h. Barger, B. & Rice, C. (2014). Might cultural response style influence the identification of autism spectrum disorder among Hispanic children? Exploring public health data with cultural psychology insights. Poster presented at the 2014 Association for Psychological Science meeting, San Francisco, CA.
 - i. Barger, B. & Rice, C. (2014). Might cultural response style influence the identification of autism spectrum disorder among Black children? Panelist presentation presented at the Atlanta Autism Consortium, Atlanta, GA.
 - j. Barger, B. (2014). Meta-analysis of the autism literature: Lessons learned from studying autistic regression. Presentation for the Atlanta Autism Consortium, Atlanta, GA.
 - k. Barger, B. (2014). Doing meta-analysis with R's metafor package. Presentation for Centers for Disease Control, R Users Group Meeting, Atlanta, GA.

- I. Barger, B. (2013). What We Know about Developmental Screening Systems and Linkage to Part C Early Intervention. Presented at the Centers for Disease Control, National Center on 1. Barger, B. & Rice, C. (2014).

Dr. Barger also participated in the composition and submission of three grant proposals in collaboration with colleagues at Georgia State University. However, all three grant proposals were not selected for funding.

Off-site Fellowship Support

The Training and Evidence Based Core initiated the implementation of off-site fellowship training programs in Year 4. The goal of these training programs is to provide an educational curriculum to health care professionals related to disability and health. The long-term goal is to develop three programs: DRDC Disability and Public Health Fellowship, DRDC Disability and Health Policy Traineeship, and DRDC Disability Epidemiology Traineeship. One of these training programs was initiated during Year 4 of the Cooperative Agreement:

- DRDC Work/Study Training Program for MPH students (SUNY Upstate Medical University): one well-qualified MPH student was selected to receive partial tuition support for the 2015 – 2016 academic year in addition to a stipend (~20 hours/week) for their work in disability and health projects. During this period, the MPH student worked on a systematic search of the economic impact of physical activity/inactivity for adults with disability and the availability of online disability education for clinicians. The MPH student also helped to organize a summer learning opportunity about disability and PM&R for medical students completing their first year. The work/study student was also involved in the development of a CDC-sponsored continuing education webinar in collaboration with the New York State Department of Health's Disability and Health Program and the Independent Living Center of the Hudson Valley. The webinar will be completed in Year 5 of the Cooperative Agreement. The student will continue to be involved in this project during the 2016 – 2017 academic year. Two MPH students have been selected to participate in the DRDC Work/Study Program at SUNY Upstate during the 2016 – 2017 academic year. They both will work on the CDC-sponsored webinar (*Practical Recommendations for Enhancing the Care of Patients with Disability*, consisting of 3 self-paced modules) and will also be involved in a new project with the American Association of Medical Colleges (AAMC) to develop a webinar about integrating education about disability into medical school curricula. Additionally, one student will continue to search and begin to catalogue and review the online educational opportunities about disability for clinicians. The plan is to develop a resource repository and to prepare a manuscript about the wealth of tools and their limitations. A longer-term plan to conduct focus groups among medical students about their interest in working with people with disability will be organized in Year 5. Margaret Turk, MD, and Christopher Morley, PhD, will continue to supervise these trainees.

Research and Evidence-based Projects

Systematic Reviews

The Training and Evidence Based Core completed a systematic review of the current literature regarding the measurement of healthy weight among individuals with disabilities. The manuscript for this systematic review was submitted to the CDC in Year 2, and is currently being revised and updated to focus on BMI and (mis)use in people with disability for determining healthy weight. The manuscript is in final preparation for journal submission, which will be completed in Year 5.

The Training and Evidence Based Core also completed a systematic literature search/review regarding hypertension epidemiology and management for people with disability, which focused on people with intellectual and developmental disabilities (IDD) as part of a Disability Research & Epidemiology (Disability & Health Branch, NCBDDD) proposal for a Year 4 activity entitled "Types, Numbers and Associated Costs of Blood Pressure-Lowering Medication among People with and without Disabilities." Results from this literature search were used to

identify and develop a research project. Ultimately, the team (DRDC and DRE) determined that adherence to hypertension medication would be the focus of the study. The DRDC Research Core analyzed the South Carolina claims data for adults with IDD in Year 4, with a goal of completing a manuscript in Year 5 for CDC clearance. DRE has taken the lead on the manuscript development. A panel presentation about hypertension in adults with IDD was accepted by AAIDD as another venue for data presentation, involving NCBDDD and DRDC professionals.

An additional systematic literature review regarding the economic impact of physical inactivity in adults with disabilities was conducted in Year 4. Results from the literature search were very limited when focused on adults with disabilities. Expanding the search to the general population produced possible analytic models that were not yet applied to those with disabilities. Due to the scarcity of relevant data from Medicaid claims, the DRDC Research Core focused on data from the National Health Interview Survey (NHIS) and Medical Expenditures Panel Survey (MEPS) to conduct analyses for a study of physical inactivity among adults with disability and the healthcare economic impact. This work will continue into Year 5, along with manuscript preparation.

Expert Panels and Working Groups

The Training and Evidence Based Core was heavily involved in the development and implementation of an Expert Panel Meeting for the NCBDDD's Division of Human Development and Disability (DHDD) Disability and Health Branch (DHB) in Year 3 of the Cooperative Agreement. The primary goal of the Expert Panel was to develop specific recommendations to inform an innovative plan for the DHB over the next decade. The original goals of the Expert Panel Meeting were conceptualized by DHB leadership and the DRDC to include, but not limited to:

- Identify future DHB priority areas and actions for research, surveillance, epidemiology and national/state/local programs;
- Identify ways to enhance collaborations between CDC and its partners; and
- Identify future areas for support and technical assistance.

Expert Panel membership included state grantee representatives, advocates, people with disability, scientists, health care providers, and non-federal organization or agency directors; 12 individuals were on the panel. Expert Panel activities were conducted in 3 stages:

- Review of DHB history, priorities, organizational structure, and programs and outputs over the past 10 years (March-April 2015)
- Group concept mapping (April 2015)
- Expert Panel Meeting (April 2015)

A detailed account of the Expert Panel group concept mapping and deliberations can be found in the 2014 – 2015 Annual Evaluation Report. The Expert Panel deliberations resulted in the identification of six priority areas and accompanying recommendations for the DHB. The Training and Evidence Based Core completed a report related to the priority areas identified by the Expert Panel in Year 4, with DHB collaboration. This report was used to refocus RFAs for state health department grantees.

The Learners' Needs Analysis was not initiated in Year 4 due to a lack of prioritization by the CDC. Additionally, activities related to Targets 4c and 4d were not selected by the CDC for implementation in Year 4.

Major Activities and Outputs

Activity 1 [Target 3a]: Develop a search and evaluation strategy, and catalog evidence-based programs

- I. Expert Panel convened and established specific recommendations to inform an innovative plan for the NCBDDD's Division of Human Development and Disability (DHDD) Disability and Health Branch (DHB)

Activity 2 [Target 3b]: Develop and/or disseminate promising practices that are supported by research

- I. Systematic literature searches and reviews completed
 - a. Measurement of healthy weight among individuals with disabilities
 - i. Manuscript under revision, being prepared for journal submission
 - b. Hypertension management in people with developmental disabilities
 - i. Search defined IDD population for secondary data analysis
 - ii. Manuscript in preparation to be submitted for CDC clearance
 - iii. Accepted panel presentation for AAIDD as another venue for data presentation; combination of NCBDDD and DRDC professionals
 - c. The cost of physical inactivity in people with disability
 - i. Search noted dearth of literature about people with disability, identified secondary data analyses completed for the general population
 - ii. Manuscript in preparation with plan for CDC clearance review
- II. Systematic searches of literature on disability education for physicians and medical students (in progress)

Activity 3 [Target 4a]: Develop research fellowship

- I. Conducted regular fellowship evaluations and provided feedback as required
 - a. See narrative description above, regarding Fellow (Brian Barger, PhD)
- II. Disability and Health Fellowship established at SUNY Upstate site
 - a. Collaborating with NYS DOH DHP in webinar about providing care for people with disability development for physicians and other health care professionals, continuing education credit through CDC
 - i. Systematic grey literature search above
 - b. Collaborating with AAMC Diversity and Inclusion Working Group to develop a webinar for medical school deans, educators, faculty about integrating disability education into medical school curricula
 - c. Preliminary work (plan for focus group) with medical students about interest in working with people with disability

Activities 4-6 [Targets 4b, 4c and 4d]: LNA, educational and teaching materials

- I. Not conducted in Year 4

Key Outcomes or Other Achievements

Research and Evaluation Projects

- I. Partnered with Evaluation Core on an evaluation project for the Spina Bifida Association (SBA)

Year 5 Activities

Activity 1[Target 3a]: Develop a search and evaluation strategy, and catalog evidence-based programs

- I. Activities will be initiated if funding is awarded in Year 5
 - a. Expert Panel(s) can be convened to explore subject matter selected by NCBDDD leadership

Activity 2 [Target 3b]: Develop and/or disseminate promising practices that are supported by research

- I. Submit healthy weight systematic review for publication

- II. Complete data analysis and manuscript development (in collaboration with Research Core) for the following projects:
 - a. Hypertension management in people with developmental disabilities
 - b. The cost of physical inactivity in people with disability

Activity 3 [Target 4a]: Develop research fellowship

- I. Trainees will be recruited and selected for the DRDC Work/Study Training Program for MPH students

Activity 4 [Target 4b]: Conduct Learners' Needs Analysis

- a. Activities will be initiated if funding is awarded in Year 5

Activities 5-6 [Targets 4c and 4d]: Educational and teaching materials

- I. Activities will be initiated if funding is awarded in Year 5.
 - a. Development of new educational opportunities with continuing education credits

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]
4. Provide technical assistance [Target 5d]
5. Support implementation of evidence-based health promotion activities [Target 5e]
6. Collect/distribute policy and legislation involving those with/at risk for disabilities [Target 5f]

Summary of Activities

The data for the Dissemination Core were collected via an interview with the Dissemination Core director, Roberta Carlin, JD, as well as through the use of Google Analytics.

Website Visitation

Detailed findings of the website evaluation can be found in Appendix B. Briefly, in the period of September 30, 2015 – September 29, 2016, there were 6,469 visitors to the DRDC website. Of the total 6,469 visitors, 75.1% (4,857) were unique visitors. There were a total of 13,267 page views, with an average of 2.05 pages viewed per visit. The average visit duration was 1 minutes 44 seconds per visitor. The visitor bounce rate was 69.5% (bounce rate refers to the number of visits that go only one page before exiting the site). Approximately 3,872 users (60% of all users) visited the site from locations within the United States; other visitors were primarily from Russia, the United Kingdom, and Brazil. The period of highest website visitation volume occurred between January, 2016 and March, 2016; this period coincides with targeted dissemination efforts related to Year 4 RFAs.

Dissemination of Year 5 RFAs

Before and during the launch of the Year 5 RFAs, the Dissemination Core collaborated with the External Advisory Committee (EAC) and other stakeholders to ensure that research announcements were strategically disseminated. The Dissemination Core staff communicated with EAC and external partners through emails and phone calls to convey clarity of their roles and responsibilities and to ensure that the NCBDDD Research RFAs were disseminated

to constituents. Stakeholders utilized their networks differently to disseminate the RFAs, but most utilized their websites, email listservs, and networks. To supplement the outreach of the EAC and stakeholders, the DRDC Dissemination Core staff distributed announcements to numerous national coalitions, advocacy groups, professional organizations, academics, and other public health and medical organizations. The Dissemination Core also used the DRDC website, AAHD website, newsletters, and social media platforms to disseminate the RFAs.

Three RFAs for Year 5 were posted on the DRDC website in January 2016 and applications were due March 1, 2016. During the research solicitation period, the Q & A component on the DRDC website was updated at least every third day. The website was also updated with frequent announcements during the application period.

In addition to dissemination through the website, RFAs were also distributed through the AAHD's weekly online newsletter *Disability and Health in the News*, which is geared toward a professional audience, directly reaching 9,000 readers each week. Dissemination through social media occurred on the DRDC and AAHD Twitter account, within approximately 50 LinkedIn professional groups, and on Facebook pages of stakeholders and similar organizations. Roberta Carlin used the AAHD LinkedIn account to post information about the RFAs to over 50 relevant professional groups, including the American Association on Intellectual and Developmental Disabilities (3,977 members), American Public Health Association (82,698 members), American Speech Language and Hearing Association (21,478 members), Autism Researchers Link (14,083 members), Disability Advocates (19,773 members), Disability.gov (7,576 members), Health Promotion and Education (19,552 members), National Multiple Sclerosis Society (7,285 members), and others.

While DRDC does not have a Facebook page of its own, partners and similar organizations, such as the AAHD and the American Association on Intellectual and Developmental Disabilities, posted links to the RFAs and fellowship opportunities on their pages.

DRDC established a Twitter handle during Year 2, which was used actively during the 2016 RFA application period and throughout the spring of 2016. A link to the Twitter page is posted on the DRDC website, as well as a feed of recent Tweets. The DRDC currently has over 1,300 Twitter followers.

Stakeholder Network and Coalition Meetings

The Dissemination Core participates in and provides technical assistance for semiannual conference calls and other communication efforts between the DRDC leadership and EAC. In January 2016, the Dissemination Core communicated via email to the EAC to discuss the details of the DRDC's Year 5 RFAs. The Dissemination Core also engages the EAC and other external partners through the weekly distribution of the *Disability and Health in the News* newsletter, which provides updates on current DRDC projects and activities.

During Year 4, the Dissemination Core worked with the Training and Evidence Based Core on the exploration of a Disability Medical Health Home. The Public Policy Director for AAHD, Dr. Clarke Ross, is a member, National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid and NQF population health task force (<http://www.qualityforum.org/>) (July 1, 2012-June 30, 2018) and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (<http://www.c-c-d.org/>). In 2014-2015 and 2015-2016, Clarke served as the NQF duals workgroup liaison to the NQF PAC/LTC (Post-Acute Care/Long Term Care) workgroup. Additionally, Dr. Ross closely monitors the following NQF committees and workgroups: care coordination, disparities, health-and-well-being, person-and-family-centered, home-and-community-based services and supports, MAP (Measure Applications Partnership), Medicaid children, Medicaid adults, and socio-economic status and reports back to NCBDDD, DHDD leadership/staff and DRDC Project Officer on initiatives of importance to NCBDDD. Dr. Ross also provides feedback to NQF committees on NCBDDD and DRDC activities and initiatives. Between October 1, 2015 and September 30, 2016, Dr. Ross produced and distributed 153 memos on NQF work and reports for CDC NCBDDD leadership staff.

The DRDC, NCBDDD, and AAHD worked to maintain a presence at NQF and other national coalition meetings to discuss NCBDDD research and policy priorities.

The Dissemination Core highlighted the DRDC project through AAHD staff involvement in the Friends of NCBDDD, coalition through newsletter updates and webinar presentations.

The Dissemination Core also supported funding for content experts to attend the David Smith Workshop at Greenwood Genetics Center in Columbia, SC.

The Dissemination Core continued to update and maintain the NCBDDD Scientific Knowledge Repository. The knowledge repository has been updated to integrate research conducted by the DRDC and NCBDDD with existing and emerging literature. Disability Health Journal publications from 2008 to 2016 have been updated in the repository, which includes a new database of notable publications from the DHDD over the past six years. The repository is currently housed on the DRDC website.

Major Activities and Outputs

Activity 1 [Target 5a]: Establish and maintain web and social media strategy

- I. Implemented social media campaign using Twitter™, Facebook™ and LinkedIn™
- II. Continuously maintained and updated DRDC website in collaboration with NeuConcept Productions, Inc. and Administrative Core staff

Activity 2 [target 5b]: Organize stakeholder network

- I. Weekly newsletter electronically distributed to roughly 9,000 - 10,000 stakeholders
- II. Engaged stakeholders through letters, emails, and phone calls to encourage dissemination of RFAs

Activity 3 [Target 5c]: Organize and conduct coalition meetings

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

Activity 4 [Target 5d]: Provide technical assistance

- I. Posted notices of RFAs and application instructions to DRDC website
- II. Hosted web pages for panel reviewers

Activity 5 [Target 5e]: Support implementation of evidence-based health promotion activities

- I. Updated knowledge repository on AAHD website and DRDC website to include most recent literature and searchable database of notable scientific publications from DHDD

Activity 6 [Target 5f]: Collect/distribute policy and legislation

- I. Clarke Ross, DPA, membership on NQF workgroups
 - a. Distributed 150 memos on NQF work and reports for CDC NCBDDD staff
 - b. Monitored 12 NQF workgroups
 - c. Attended monthly NQF workgroup meetings

Year 5 Activities

Activity 1 [Target 5a]: Establish and maintain web and social media strategy

- I. Revisions and updates to DRDC website on-going
- II. Establish more regular social media presence outside of research solicitation season
 - a. Stronger tracking of dissemination efforts through the use of HootSuite and Buffer social media platform

Activity 2 [Target 5b]: Organize stakeholder network

- I. Continue and expand newsletter distribution to stakeholder groups
- II. Continue stakeholder engagement to encourage dissemination of NCBDDD research opportunities and findings.

Activity 3 [Target 5c]: Organize and conduct coalition meetings

- I. Continue attendance to coalition and stakeholder meetings

Activity 4 [Target 5d]: Provide technical assistance

- I. Will continue support of other Core groups on targeted projects
- II. Will continue support of website management

Activity 5 [Target 5e]: Support implementation of evidence-based health promotion activities

- I. Continued updates to knowledge repository
 - a. Will investigate methods to showcase and reposition knowledge repository in Year 5

Activity 6 [Target 5f]: Collect/distribute policy and legislation involving those with/at risk for disabilities

- I. Continued presence of Clarke Ross, DPA, within NQF workgroups

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 Evaluation Core responsibilities include:

1. Conduct a needs assessment to set DRDC agenda and formalize the evaluation process [Target 6a]
2. Organize and implement routine evaluations for all processes, research, training, dissemination strategies, and other activities related to the grant [Target 6b]

In addition to these activities, the Evaluation Core frequently partners with the Training and Evidence Based Core on targeted projects.

Summary of Activities

During Year 4, the progress of the DRDC was evaluated under the direction of Dr. Christopher Morley, PhD, of SUNY Upstate Medical University. The performance of the DRDC website was evaluated through the use of Google Analytics (see Dissemination Core section and Appendix B for results). Additionally, each CDC-funded project provided a full progress report, enrollment tables, and IRB approval letters to the Evaluation Core in order to track progress.

The Evaluation Core assisted the Training and Evidence Based Core in securing personnel support for the systematic literature reviews conducted during Year 4, and also partnered in the planning and development of the DRDC Work/Study Training Program for MPH students at SUNY Upstate Medical University.

Spina Bifida Association Project

In Year 2 of the Cooperative Agreement, the Evaluation Core worked with the Spina Bifida Association of America (SBA) to conduct a group concept mapping exercise and limited survey for the Spina Bifida Clinical Care Network. This activity was described in the 2013 – 2014 Annual Evaluation Report.

In Year 3, the Evaluation Core worked with the SBA to begin planning a nationwide survey of adults with Spina Bifida. By the end of Year 3, a survey draft was largely completed, as was a draft protocol for the project. The project received IRB approval during Year 4 of the Cooperative Agreement, with additional funding from the SBA under a separate contract. The survey was initially piloted among ten adult patients with Spina Bifida, revised as needed, and the finalized survey was distributed in June of 2016. The survey was disseminated via the SBA website and email lists. Data collection continued into Year 5 of the Cooperative Agreement. During Year 5, research questions will be explored and data analysis will be conducted. These activities are funded and conducted under a separate agreement with the Spina Bifida Association, but are included here as an outgrowth of Year 2 DRDC activities.

Major Activities and Outputs

Activity 1 [Target 6a]: Conduct needs assessment to set DRDC agenda and formalize the evaluation process

- I. Conducted annual internal evaluation of DRDC performance in target areas

Activity 2 [Target 6b]: Organize and implement routine evaluations

- I. Evaluated DRDC website effectiveness and site user engagement
 - a. Conducted assessment utilizing Google Analytics
- II. Collaborated with Training and Evidence Based Core
 - a. DHB Expert Panel Meeting implementation and evaluation

Key Outcomes or Other Achievements

Activity 2 [Target 6b]: Organize and Implement Routine Evaluations

- I. Website effectiveness evaluation report (see Dissemination Core and Appendix B)
- II. Implemented Adult Spina Bifida survey in collaboration with the Spina Bifida Association of America
 - a. Finalized questionnaire and began collecting responses

Year 5 Activities

Activity 1 [Target 6a]: Conduct needs assessment to set DRDC agenda and formalize the evaluation process

- I. Will develop and conduct survey for EAC and external partners for quality improvement purposes
- II. Will conduct annual internal evaluation of DRDC performance

Activity 2 [Target 6b]: Organize and implement routine evaluations

- I. Continue ongoing support to Research, Training and Evidence Based, and Dissemination Core groups
- II. Continue Adult Spina Bifida survey project
 - a. Conduct data analysis
 - b. Prepare manuscripts for journal submission

Appendix A: RFA Evaluation Rubric

INSTRUCTIONS

- A. TYPE YOUR NAME HERE: _____
- B. Link to the password protected website where you will find the applications (see email for URL and password).
- C. For each application, **ASSIGN SCORES** as shown by the example in the table below.
 SCALE (WHOLE NUMBERS ONLY!)
- 1 = Superior
 - 2 = Very Good, minor issues
 - 3 = Adequate, some concerns
 - 4 = Major issues
 - 5 = Poor
- D. Please add a **BULLETED LIST of STRENGTHS and/or WEAKNESSES**, as appropriate, associated with each score in the space provided.
- E. After you finish scoring all assigned applications and listing all comments, please make this into a PDF document and email to salzberd@mailbox.sc.edu.

Name	Review Category	Score (1-5, whole #s only)	Comments
EXAMPLE	Responsiveness to the RFA / Significance / Innovation	3	(1) Response to RFA requirement #4 was underdeveloped/not enough detail; (2) App developed to aid exercise tracking was innovative
	Merit of the Methods/ Approach	4	(1) Recruitment efforts may not capture a fully representative samples of the target population; (2) Power calculations not included, and sampling pln seems overly optimistic
	Evaluation Plan	3	Application adequately describes evaluation process for using evaluation to inform phase 2 of study to be conducted in year 3
	Principal Investigator & Team's Ability to Carry out the Work	2	(1) PI is experienced, has a solid track record, and has assembled an excellent team. (2) Institution and department have a solid record of community based participatory research like the proposed study.

1 = Superior; 2 = Very Good, minor issues, 3 = Adequate, some concerns, 4 = Major issues, 5 = Poor

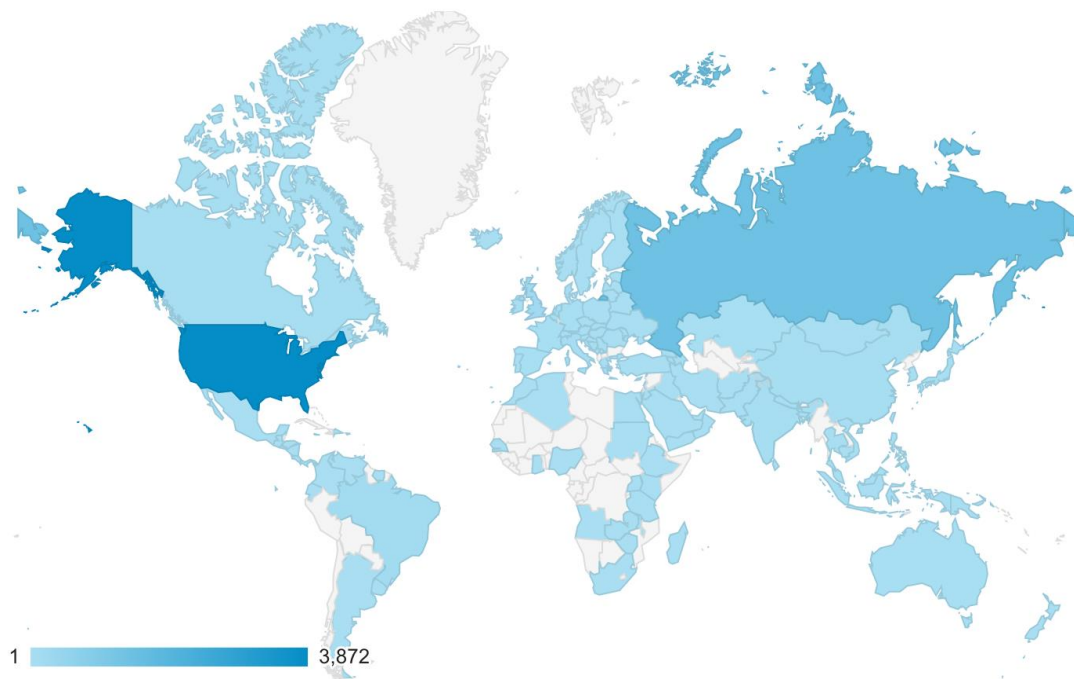
Appendix B: Evaluation of DRDC Website Visitation

Overall Website Visitation

In the period of September 30, 2015 - September 29, 2016, there were 6,469 visits to the DRDC website. Of the total 6,469 visits, 75.1% (4,857) were from unique visitors. There were a total of 13,267 page views, with an average of 2.05 pages viewed per visit. The average visit duration was 1 minute and 44 seconds per visitor. The visitor bounce rate was 69.5% (bounce rate refers to the number of visits that go only one page before exiting the site).

Approximately 3,872 users (60% of all users) visited the site from locations within the United States; other visitors were primarily from Russia, the United Kingdom, and Brazil. Figure 1 displays a map overlay of the geographic locations within which users visited the site between September 30, 2015 and September 29, 2016.

FIGURE 1. MAP OVERLAY WWW.DISABILITYRESEARCHCENTER.ORG VISITATION, SEPTEMBER 30, 2015 - SEPTEMBER 29, 2016



Traffic Sources and Dissemination Efforts

Figure 2 displays the distribution of traffic sources for visitors to the website. The most common traffic source was referral traffic, at 43.19% of all visitors. Referral traffic is the segment of website traffic that arrived at the DRDC website by following links contained within the websites of other organizations. Approximately 3.12% of referral traffic came from social media networks, with Twitter acting as the primary referral site for these visitors. Other social media dissemination efforts were carried out through Facebook, LinkedIn professional groups, and Blogger. Direct traffic was the second-largest traffic source for website visitors, at 29.12%. 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. Another traffic source was organic searching for the website in browser search engines such as Google and Bing (24.04% of visits). Finally, email served as a minor traffic source, and only accounted for 0.53% of visits. In many of the dissemination efforts, viewers were provided a link that led them directly to the research page of the DRDC website, which provided information on the 2016 RFAs.

FIGURE 2. TRAFFIC CHANNELS FOR VISITORS TO WWW.DISABILITYRESEARCHCENTER.ORG, SEPTEMBER 30, 2015 - SEPTEMBER 29, 2016

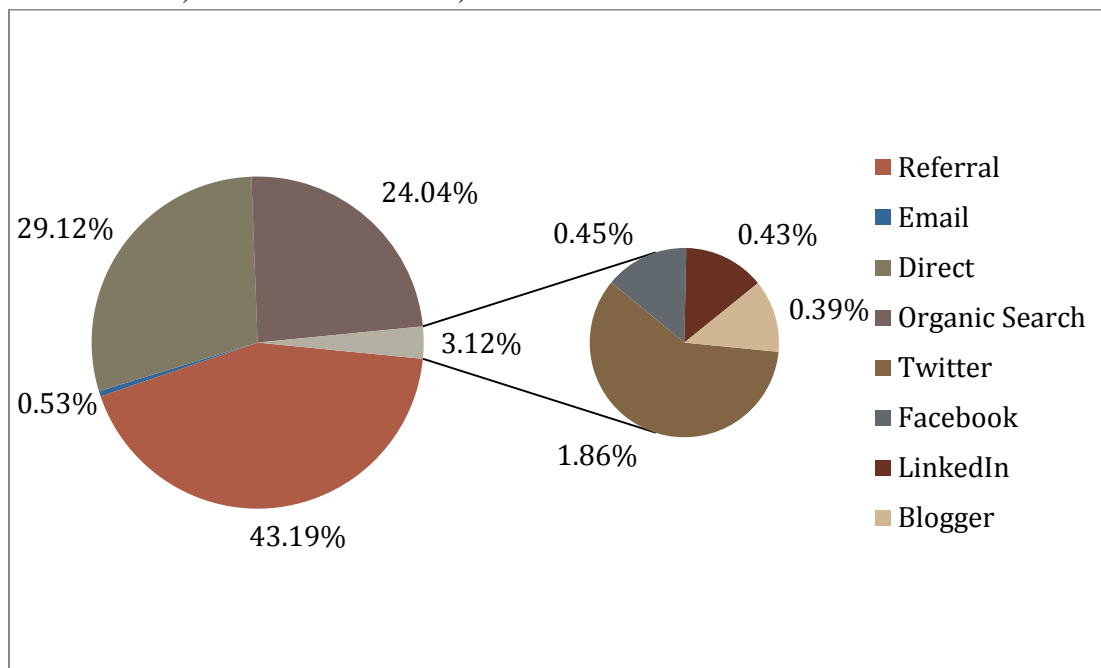
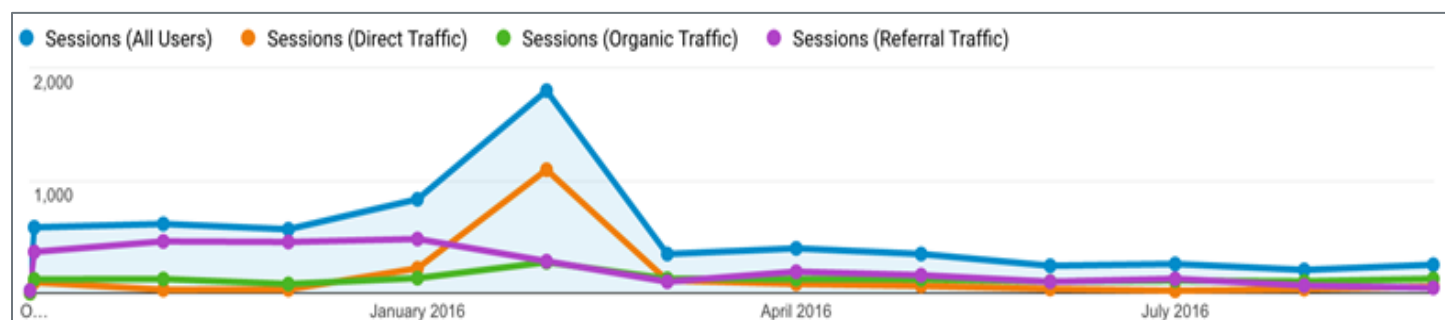


Figure 3 displays a time trend of website visitation during the period of September 30, 2015 - September 29, 2016. The period of highest visitation fell between January and March, 2016, with approximately 1,800 website visits at the highest point in user traffic in February. The lowest period of visitation fell between June and September, 2016, with an average of about 250 website visits per month.

FIGURE 3. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG MONTHLY VISITATION, SEPTEMBER 29, 2015 - SEPTEMBER 29, 2016



Several website dissemination efforts were launched during the period of January to March, 2016, regarding the DRDC Request for Applications (RFAs), including the use of social media and stakeholder networks. This period aligns with the highest website traffic volume observed between September 30, 2015 and September 29, 2016. While Twitter was routinely used throughout the Year 4 period, a larger volume of Tweets were disseminated during February, March, and May of 2016, as can be seen in Figure 4 below. In October of 2015, the DRDC had approximately 60 followers, which grew to about 200 followers by September of 2016. The increasing trend in followers has led to an increase in reach (number of people who have seen posted content). As shown in Figure 5, the average monthly reach of posted content has increased from 0 to about 200 over the course of Year 4. The Dissemination Core sent weekly announcements regarding the RFAs through the *Disability and Health in the News* newsletter produced by the AAHD. LinkedIn professional groups were also targeted for dissemination efforts regarding the RFAs. Specific dates for these communications were not tracked for Year 4; however, the

Dissemination Core and Evaluation Core are developing a standardized tracking method to more accurately document future dissemination efforts through LinkedIn groups.

FIGURE 4. VOLUME OF TWITTER DISSEMINATION EFFORTS, OCTOBER 2015 – SEPTEMBER 2016

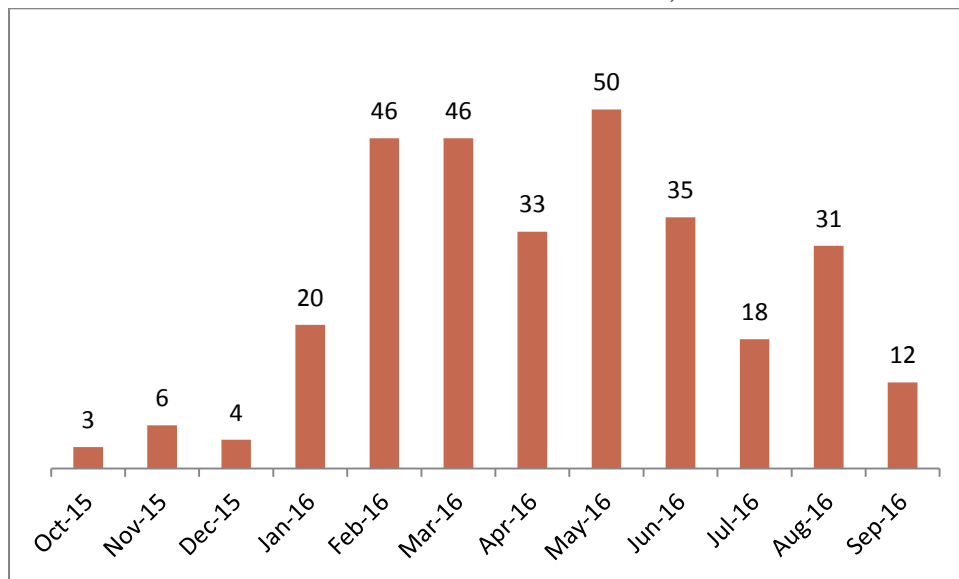


FIGURE 5. AVERAGE REACH OF TWITTER DISSEMINATION EFFORTS, OCTOBER 2015 – SEPTEMBER 2016

