

Disability Research and Dissemination Center 2014-2015 Annual Report

Prepared by:

Emily M. Mader, MPH MPP
Christopher P. Morley, PhD MA CAS
*Department of Family Medicine
SUNY Upstate Medical University*

March 2016

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 third year (September 30, 2014 – September 29, 2015) of the Cooperative Agreement #1U01DD001007 continued successful operations and programs initiated in the previous two 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 and second years of the cooperative agreement, achieved several of the designated goals for the third year, and developed new goals and targets for the upcoming years of the agreement.

Contents

| | |
|--|-----------|
| OVERVIEW | 3 |
| ADMINISTRATIVE CORE | 3 |
| Summary of Activities | 3 |
| Future Activities | 3 |
| RESEARCH CORE..... | 5 |
| Summary of Activities | 5 |
| Future Activities | 10 |
| TRAINING AND EVIDENCE BASED CORE | 11 |
| Summary of Activities | 11 |
| Future Activities | 15 |
| DISSEMINATION CORE | 17 |
| Summary of Activities | 17 |
| Future Activities | 20 |
| EVALUATION CORE..... | 21 |
| Summary of Activities | 21 |
| APPENDIX A: RFA EVALUATION RUBRIC | 24 |
| APPENDIX B: EVALUATION OF DRDC WEBSITE VISITATION | 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 third year of the project (September 30, 2014 - September 29, 2015), based upon the logic model shown below. 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 and to hire professionals and trainees who will be working at NCBDDD.

Subcontracts were established with the AAHD, SUNY Upstate Medical University (SUNY), which are the other two PI institutions, and also with the following external institutions: Cincinnati Children's Hospital Medical Center, Greenwood Genetic Center, Johns Hopkins University, Ohio University, Spina Bifida Association, University of Colorado – Boulder, University of Colorado – Denver, University of Florida, University of Missouri, University of Texas, and University of Wisconsin.

An External Advisory Committee (EAC) conference call was held on November 5, 2014, to communicate details of the DRDC's Year 4 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.

Future Activities

- I. The next meeting of the EAC will occur in January 2016 (Year 4).

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 place ▪ Center priorities defined ▪ Procedures for internal monitoring established ▪ Content areas identified | <ul style="list-style-type: none"> ▪ Filled positions ▪ Arranged MOAs ▪ Established 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 defined ▪ Mechanisms for solicitation and evaluation of research project applications established | <ul style="list-style-type: none"> ▪ Number of research grants awarded by Center ▪ Number and type of research projects initiated by Center ▪ Number of completed studies related to developmental disabilities | <ul style="list-style-type: none"> ▪ 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] | <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 established ▪ Teaching modules and programs developed from LNA ▪ Web-based information system devised and managed ▪ Research uploaded and reviewed | <ul style="list-style-type: none"> ▪ Awarded research fellowships ▪ Manuscripts published by research fellows ▪ Number of individuals participating in teaching modules and programs ▪ Evaluations of program effectiveness | <ul style="list-style-type: none"> ▪ 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] | <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 meeting ▪ Project website established ▪ Technical assistance provided where needed ▪ Media campaigns developed | <ul style="list-style-type: none"> ▪ Information disseminated through a variety of media approaches ▪ Launched media campaigns ▪ Continual 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 conducted ▪ Mixed-methods evaluation plans established ▪ Mechanisms to monitor stakeholder engagement established | <ul style="list-style-type: none"> ▪ Findings from process and effect data collection and analysis ▪ Targets for intervention identified ▪ Program database ▪ Annual 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 3, the Research Core successfully continued work on the four major goals. Six external research projects, selected in Year 2 for funding, were initiated within Year 3. In addition, the DRDC continued management for six research projects initiated during Year 2 of the Cooperative Agreement. Thus far, these 12 projects have produced 5 publications/conference presentations. Additional publication and dissemination efforts will be completed following the completion of each research project's implementation. Detailed information on the current progress of each project can be found in the Key Outcomes section below.

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 May, 2014, and continued during the Year 3 period of the Cooperative Agreement. During Year 3, Dr. Bryan Hall, MD, provided expert assistance to the DBDDD by reviewing and classifying CDC records for dysmorphology in infants with major birth defects.

Three Requests for Applications (RFAs) were established in Year 3, and a total of 22 applications were received; the research projects funded from these RFAs will begin in Year 4 of the Cooperative Agreement. The RFA reviews followed a triage-level peer review process similar to that utilized during the Year 2 RFA 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) for 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 recuse themselves from reviewing any applications where the reviewer had a conflict of interest, and 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.

The CDC selected four new projects for Year 4. One project that was competitively selected during the Year 2 (2014) RFA process was not funded in Year 3 (EHDI Quality Measures, Terese Finitzo, PhD); this project is expected to be funded during Year 4. In addition, three other research projects with specific eligibility requirements were also solicited during Year 3 for funding in Year 4. Due to the specific eligibility requirements of these funding opportunities, the applications were not evaluated through the triage-level peer review system. Thus, the total number of awards that will be funded in Year 4 equals eight new projects, and seven continuing projects from Year 3.

Internally, USC is making progress on the *Disability and Health: Predictors of Onset of Common Health Conditions and Receipt of Preventive Services Among Adults with Disabilities* project. During Year 1 and Year 2 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), including:

1. Preventive services for people who are blind/low vision (NHIS/MEPS)
2. Sequella of diabetes for people who have ID or SCI (NHIS/MEPS, Medicare/Medicaid)
3. 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)
4. Colorectal cancer screening services for adults who are blind, have ID, or those who have SCI in South Carolina (Medicare/Medicaid)

Manuscripts are currently being drafted for investigations 1, 3 and 4 listed above.

In the remaining project period, Dr. McDermott plans to conduct epidemiologic, economic and statistical data analyses investigating numerous questions regarding differences in health care access, health status, and barriers, based on disability groups. Specific aims for the remainder of the project include:

- Conduct multivariable analyses to predict 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.
- Conduct multivariate analyses that predict 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 will be comprised of adults who received a service but did not develop or have any of the case disabilities listed. The groups are 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. USC began 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.

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 preventive services for people who are blind/low vision; 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

Activity 2 [Target 2b]: Set research priorities

- I. Research topic areas for solicitation targeted and advertised through DRDC website
 - a. RFA-R15-01: LTSAE Impact on Parents (funding for 1 project)

- b. RFA-R15-02: Assessing Impact of EHDI (funding for 2 projects)
- c. RFA-R15-03: LTSAE Book Testing (funding for 1 project)
- II. Research topics for funding opportunities with specific eligibility requirements disseminated
 - a. Periconceptual Surveillance for Prevention of Anemia and Birth Defects in India
 - b. Developing an Epidemiological Tool Based on DSM-5 Criteria
 - c. Project to Learn About Youth – Mental Health II (Re-PLAY)

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

- I. Twelve (12) Year 3 projects were funded (RFAs for these projects were solicited in Years 1 and 2)
- II. Six (6) new RFAs were solicited (see list above, Activity 2)
- III. Developed and implemented triage process to evaluate applications
- IV. Top-scoring RFA applications sent to CDC for funding consideration

Activity 4: Provide research support

- I. Provided support to funded projects
 - a. Attend quarterly meetings with CDC and project PIs
 - b. Managed subcontract budgets
 - c. Provided other assistance as needed
- II. Clinical genetics consulting being provided to the NCBDDD by Greenwood Genetic Center through the DRDC will continue in Year 4 starting in January 2016
- III. Conduct analysis of data on hypertension in people with intellectual and developmental disabilities

Key Outcomes or Other Achievements

Activity 1 [Target 2a]: Conduct internal research

- I. Predictors of Use of Preventive Services by Adults with ID, SCI and Those Who are Blind – University of South Carolina, Suzanne McDermott, PhD (Year 3 of 3)
 - ii. Currently drafting manuscripts on the results of the following NHIS/MEPS data analyses: preventive services for people who are blind/low vision, 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

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

- I. Twenty-two RFA Applications received for Year 4 funding
- II. Eight new projects selected by the CDC for Year 4:
 - a. Assessing the Impact of Early Hearing Detection and Intervention (EHDI) – University of Colorado-Boulder, Christine Yoshinaga-Itano, PhD
 - b. Assessing the Impact of Early Hearing Detection and Intervention (EHDI) – University of Wisconsin, Anne Harris, PhD
 - c. Development of an Epidemiological Tool for Assessing Mental Disorders in Children Based on DSM-5 Criteria – Research Foundation for Mental Hygiene, Prudence Fisher, PhD
 - d. Early Hearing Detection and Intervention (EHDI) Quality Measures – OZ Systems, Terese Finitzo, PhD
 - e. Learn the Signs. Act Early. (LTSAE) Book Testing – Family Health International, Rebecca Ledsky, MBA
 - f. Learn the Signs. Act Early. (LTSAE) Impact on Parents – Bassett Healthcare Network, Anne Gadomski, MD
 - g. Periconceptual Surveillance for Prevention of Anemia and Birth Defects in India – Cornell University, Julia Finkelstein, ScD

- h. Project to Learn About Youth – Mental Health II (Re-PAY) – University of South Carolina, Kate Flory, PhD
- III. Twelve research projects either begun or continued in Year 3
1. EHDI-Developmental Outcomes: University of Colorado – Boulder, Christie Yoshinaga-Itano, PhD (Year 2 of 3)
 - 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? – IN PROGRESS; (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)? – IN PROGRESS; (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.
 2. EHDI-WIC: Cincinnati Children’s Hospital Medical Center, Lisa Hunter, PhD (Year 2 of 2)
 - a. Specific Aims: (a) to test an intervention designed to increase the rate of follow-through to outcomes of either a passed screening test or completed diagnostic evaluation – IN PROGRESS; (b) to test the impact of rescreening at WIC on the time to follow-up (rescreening or diagnostic evaluation) for infants who refer – IN PROGRESS.
 3. EHDI-WIC: University of Wisconsin, Anne Bradford Harris, PhD (Year 2 of 2)
 - a. Specific Aims: (a) to determine the contribution of WIC involvement in reducing EHDI loss-to-follow-up in Wisconsin – IN PROGRESS; (b) to further evaluate the impact of a variety of WIC involvement strategies in improved follow-up outcomes for families – IN PROGRESS; (c) to disseminate information learned related to successful WIC strategies that contribute to reducing loss-to-follow-up for NHS – IN PROGRESS.
 4. PLAY: Mental Health – University of S. Carolina, Kate Flory, PhD (Year 2 of 2)
 - a. Specific Aims: (a) to describe prevalence and co-occurrence of internalizing, externalizing, and tic disorders among children and adolescents (grades K-12) within a defined population – IN PROGRESS; (b) to describe rates of current and previous mental health treatment among members of the defined population previously diagnosed with a mental disorder – IN PROGRESS; (c) to explore diversion and misuse of psychoactive medications prescribed to treat a mental disorder – IN PROGRESS.
 5. PLAY: Mental Health – University of Colorado–Denver, Lorraine Kubicek, PhD (Year 2 of 2)
 - a. Specific Aims: (a) To adapt and test an existing two-stage methodology to assess the prevalence, treated prevalence, and co-occurrence of internalizing, externalizing, and tic disorders in Colorado school-aged youth. Stage 1 – COMPLETED. Stage 2 – IN PROGRESS.
 6. LTSAE: University of Missouri, Janet Farmer, PhD (Year 2 of 2)
 - 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. PLAY-MH: University of Florida, Steven Cuffe, MD (Year 1 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.

8. PLAY-MH: Ohio University, Julie Owens, PhD (Year 1 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.
9. LTSAE Monitoring: University of Wisconsin, Gail Chodron, PhD, and Joan Ershler, PhD (Year 1 of 2)
 - a. Specific Aims: This project aims to evaluate the acceptability, feasibility, and effectiveness of using Learn the Signs. Act Early. across the levels of statewide professional development and quality rating and improvement systems, multi-site single sector implementation, and site-based implementation. (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.
10. EMR Rare Conditions: University of South Carolina, Kevin Bennett, PhD (Year 1 of 3)
 - a. Specific Aims: (a) Evaluate the effectiveness of linking an EMR data warehouse with state administrative data for people with SB, MD, or FXS – IN PROGRESS; (b) Describe and compare the number and characteristics of individuals identified with each of the conditions by each data source alone and in the combined data set – IN PROGRESS; (c) In collaboration with the CDC, develop a research question and conduct research or conduct public health surveillance with the combined data – IN PROGRESS.
11. Healthy Weight Management: University of Texas, Katherine Froehlich-Grobe, PhD (Year 1 of 3)
 - a. Specific Aims: (a) To create an appropriate and usable adaptation of the GLB program for people with mobility impairment – IN PROGRESS; (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.
12. Genotyping Analysis for SEED Samples: Johns Hopkins University, Daniele Fallin, PhD (Year 1 of 1)
 - a. Specific Aims: (a) Measure genotypes at over 4.5 million loci using the HumanOmni5Exome BeadChip among 376 SEED I children – IN PROGRESS; (b) Apply rigorous genotype data quality control (QC) filters to measured SNPs in these newly generated data and, in addition, perform imputation to obtain high quality genotyping data for ~30 million SNPs in these additional samples – IN PROGRESS; (c) Provide a complete, high quality genotype dataset to allow combination of newly generated data with existing SEED genetic data – IN PROGRESS.

IV. Publications from Year 2 research projects

- a. Uhler, K., Thomson, V., Cyr, N., Gabbard, S.A., Yoshinaga-Itano, C. (2013). State and Territory EHDI Databases: What We Do and Don't Know About the Hearing or Audiological Data From Identified Children. *American Journal of Audiology*. 1-10. DOI: 10.1044/1059-0889(2013/13-0015)
- b. Wiggin, M., Sedey, A.L., Awad, R., Bogle, J.M., Yoshinaga-Itano, C. (2013). Emergence of Consonants in Young Children with Hearing Loss *The Volta Review*, 113(2), 127–148.
- c. Yoshinaga-Itano, C. & Uhler, K. (in press) Early Intervention, Education, and Therapy for Children Who Are Deaf or Hard of Hearing. In Katz, J. *Clinical Handbook of Audiology*, 7th Edition.
- d. Raimondo, B. & Yoshinaga-Itano, C. (in press). Legislation, Policies and Role of Research in Shaping Early Intervention. In Sass-Lehrer, M. (Ed.) *Infants, Toddlers and their Families: An Interdisciplinary Perspective*. Oxford Press.

- e. Muñoz, D. (2014). Developing Technology to Increase Awareness of Developmental Milestones in Low-Income Communities. In Extended Abstracts of ACM Conference on Human Factors in Computing Systems (CHI 2014). Toronto, Canada.
- V. Presentations from Year 2 research projects
- a. Anne Harris, PhD: Poster presentation at National EHDI Conference in April 2014
 - b. Janet Farmer, PhD: Poster presentation at National WIC Association Conference in May 2014
 - c. 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
 - d. 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.
 - e. 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 January 2016.

Future Activities

Activity 1 [Target 2a]: Conduct internal research

- I. Complete manuscripts and remaining data analyses on health care access, health status, and barriers, based on disability groups

Activity 2 [Target 2b]: Set research priorities

- I. Work with NCBDDD on the development of Year 5 RFAs

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

- I. The Year 5 RFAs will be finalized and posted by January 2016 (Year 4)

Activity 4: Provide research support

- I. Provide technical assistance to state health departments to analyze Medicaid Disability data
 - a. South Carolina Disability Analysis (ACDA) team will provide technical assistance to state Departments of Health and Departments of Health and Human Services as they analyze Medicaid disability data to measure baseline characteristics of state programs, identify possible research questions, and evaluate the effectiveness of interventions
- II. Conclude analysis of data on hypertension in people with intellectual and developmental disabilities and prepare manuscript.

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 Research 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 to 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 (after CDC clearance for Year 1)
- c. 1 new manuscript developed and submitted for CDC clearance – COMPLETED
- d. 1 grant preparation/writing for internal submission – COMPLETED

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

- Publications:
 - a. Barger, B., Rice, C., Simmons, C.**, & Wolf, R. A mixed method review of the published literature on Part C monitoring, screening, and Child Find systems. (*currently under review at the Journal of Early Intervention*)
 - b. Raspa, M., Levis, D., Doto, J., Wallace, I., Rice, C., Barger, B., Green, K., & Wolf, R. (in press). 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*.
 - c. Barger, B., Campbell, J., & Simmons, C.** (in press) Autistic regression and epilepsy symptoms: Two meta-analyses. *Journal of Intellectual and Developmental Disability*.
 - 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.
 - f. Barger, B., Rice, C., & Wolf, B. (CDC clearance). Developmental screening and monitoring together best predict Part C Early Intervention receipt.
 - g. Squires, J., Shaw, E., Greer, M., Noyes, D., Wolf, R., & Barger, B. (CDC clearance). Diagnosed Conditions and IDEA Part C Eligibility: Policy Considerations and Future Directions
 - h. Greer, M., Squires, J., Rice, C., Wolf, R., Barger, B., Zubler, J., London, S., & Twombly, E. (CDC clearance). Diagnosed Conditions and IDEA Part C Service Access: State of the States.
 - i. Moody, E., Barger, B., Hepburn, S., & Rosenberg, S. (CDC clearance). Temperament factor structure is not the same in children with autism, children with non-autistic developmental disorders, and typical children: A study using data from the Study to Explore Early Development (SEED).
- Posters/Presentations
 - a. Rice, C., Barger, B., Shaw, E., Squires, J., & Kavulic, C. (Panel Presentation submitted to 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.
- l. 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 planning for off-site fellowship training programs to begin in Year 4 of the Cooperative Agreement. 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 will be implemented during Year 4 of the Cooperative Agreement:

- DRDC Work/Study Training Program for MPH students (SUNY Upstate Medical University): one well-qualified MPH student will be recruited to receive partial tuition support for the 2015-2016 academic year as well as engagement in disability and health projects at a stipend or hourly rate (~20 hours/week). Student activities may include systematic search and reviews related to disability and health, as well as manuscript development; development of an enduring CME activity related to the care of people with disabilities for primary care providers; and collaboration with the New York State Department of Health Disability and Health Programs on the development of Evidence-Based Self-Management Program workshops, mammography toolkits to increase accessibility, and analysis of Medicaid data. Margaret Turk, MD, and Christopher Morley, PhD, will supervise the 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 findings of this systematic review were submitted to the CDC in Year 2, and are currently under CDC clearance review in preparation for journal submission.

The Training and Evidence Based Core also completed a systematic literature search/review regarding hypertension epidemiology for management in people with developmental disabilities 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 limited. The results will be used in Year 4 to guide the development of a research project and secondary data analysis of claims data on the use of blood pressure-lowering medications among adults with intellectual disability and associated outcomes.

An additional systematic literature review regarding the economic impact of physical inactivity in adults with disabilities will also be further discussed and explored in Year 4.

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 Evaluation Core section. The Expert Panel deliberations resulted in the identification of six priority areas and accompanying recommendations for the DHB. The DHB reported that the results of the Expert Panel were to be used to develop Funding Opportunity Announcements for the state health departments and national public health practice centers, as well as the development of other activities and initiatives within the DHB. The Training and Evidence Based Core will continue to work on the composition and publication of a process paper related to the Expert Panel in Year 4, with DHB collaboration.

The Training and Evidence Based Core, in conjunction with the Dissemination Core, explored the development of recognition status for a “Disability Medical (Health) Home” with DHB leadership during Year 3. This working group focused on the development of an integrated health home module to be implemented within existing patient-centered medical homes to aid in the management of the disability population. The Training and Evidence Based Core plans to explore the development of a pilot project in case management for the disability population in Year 4.

The Training and Evidence Based Core is prepared to coordinate with NCBDDD leadership in the development and implementation of up to two additional Expert Panels during Year 4.

As in Year 1 and Year 2, the Learners' Needs Analysis was not initiated in Year 3 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 3; work on these Targets is planned in Year 4, should adequate funding be awarded.

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 reviews completed
 - a. Measurement of healthy weight among individuals with disabilities
 - i. Prepared manuscript to undergo CDC clearance for journal submission
 - b. Hypertension management in people with developmental disabilities
 - i. To be used as background for planned secondary data analysis
- II. Exploration of Disability Medical Health Home with DHB leadership

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).

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

- I. Not conducted in Year 2

Key Outcomes or Other Achievements

Research and Evaluation Projects

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

Future Activities

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

- I. Assist DHB leadership in integrating results of Expert Panel meeting in 2016 RFAs, as requested
 - a. Provide subject and content matter expertise
- II. Activities will be initiated if funding is awarded in Year 4.
 - 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. Healthy weight systematic review manuscript to be submitted for publication in Year 4
- II. Results of hypertension systematic review will guide the development of a research project and secondary data analysis of claims data in Year 4
- III. Systematic review on economic impact of physical inactivity in adults with disability to be explored in Year 4
- IV. Disability Health Home
 - a. Development of integrated health home module
 - b. Possible case management pilot project with DHB leadership

Activity 3 [Target 4a]: Develop research fellowship

- I. Trainees will be recruited and selected for the DRDC Work/Study Training Program for MPH in Year 4

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

- a. Activities will be initiated if funding is awarded in Year 4.

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

- I. Activities will be initiated if funding is awarded in Year 4.
 - 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, 2014 – September 29, 2015, there were 11,010 visitors to the DRDC website; this represents a relative increase in visitation of 22% compared to Year 2. Of the total 11,010 visitors, 82.04% (9,098) were unique visitors. There were a total of 23,141 page views, with an average of 1.72 pages viewed per visit. The average visit duration was 1 minutes 13 seconds per visitor. The visitor bounce rate was 77.61% (bounce rate refers to the number of visits that go only one page before exiting the site). Approximately 6,255 users (57% of all users) visited the site from locations within the United States; other visitors were primarily from Russia, Brazil, Canada, the United Kingdom, and India. The period of highest website visitation volume occurred between February, 2015 and March, 2015; this period coincides with targeted dissemination efforts related to Year 3 RFAs.

DISSEMINATION OF YEAR 3 RFAS

Before and during the launch of the Year 3 RFAs, the Dissemination Core collaborated with the EAC and other stakeholders to ensure that research and fellowship announcements were strategically disseminated. The Dissemination Core staff communicated with EAC and external partners through personal letters, emails, and phone calls on a regular basis to ensure clarity of their roles and responsibilities. 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 coalitions, advocacy groups, 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 3 were posted on the DRDC website in January 2014. Applications were due February 27th, 2015, for these RFAs. 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 (membership 3,200), American Public Health Association (membership 69,384), American Speech Language and Hearing Association (membership 22,949), Autism Researchers Link (membership 12,266), Disability Advocates (membership 16,440), Disability.gov (membership 7,576), Health Promotion and Education (membership 19,957), National Multiple Sclerosis Society (membership 5,504), 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 2015 RFA application period and throughout the spring of 2015. A link to the Twitter page is posted on the DRDC website, as well as a feed of recent Tweets.

STAKEHOLDER NETWORK AND COALITION MEETINGS

The Dissemination Core participates in and provides technical assistance for semiannual conference calls between the DRDC leadership and EAC. One meeting was conducted in November, 2014. 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.

The Dissemination Core provided communication, dissemination and on-site logistic support to the Training and Evidence Based Core in conducting the Expert Panel meeting for the Disability and Health Branch during Year 3. The Dissemination Core also 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 2015-2016 and 2014-2015, Clarke served as the NQF duals workgroup liaison to the NQF PAC/LTC (Post-Acute Care/Long Term Care) workgroup. Additionally, Clarke 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 September 1, 2014-October 31, 2015, Clarke produced and distributed 132 memos on NQF work and reports for CDC NCBDDD staff.

The Dissemination Core and Dr. Ross also worked with targeted state partners and task forces on data collection for the NCBDDD standards for newborn hearing screening and metabolic screening of newborns, and endorsement of these standards by the NQF. Communications on these topics led to the conclusion that existing standards adequately address these screening areas. The DRDC, NCBDDD and AAHD will work to maintain a presence in NQF meetings and discussions regarding newborn screenings.

The Dissemination Core supported the NCBDDD on an Autism Expert Panel meeting in January, 2015. This meeting was held as an invite-only webinar. The Dissemination Core supported funding for content experts to attend the David Smith Workshop at Greenwood Genetics Center in Columbia, SC.

The Dissemination Core communicated with Yochai Eisenberg from University of Illinois at Chicago about Community Health Inclusion Index dissemination in Year 3. The Community Health Inclusion Index was developed by Yochai Eisenberg, MUPP, and will allow disability and health professionals to measure a community's ability to support healthy, active living among individuals with disability. Wider dissemination of the Community Health Inclusion Index will be discussed in Year 4.

The Dissemination Core established a knowledge repository in collaboration with the DHDD and AAHD Health Promotion Resource Center. The knowledge repository has been updated to integrate research conducted by the DRDC and NCBDDD with existing and emerging literature. All Disability Health Journal publications from 2008 to 2015 have been updated in the repository, which includes a new database of notable publications from the DHDD over the past five years. The repository is currently housed on the AAHD website; plans for possible repositioning of the repository began in Year 3 with DHDD staff, and will continue to be explored in Year 4.

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 8,000 - 9,000 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 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
 - a. Attended EAC conference call in November, 2014

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. Provided opportunity for dissemination support to University of Illinois at Chicago for the Community Health Inclusion Index
- II. Updated knowledge repository on AAHD 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 132 memos on NQF work and reports for CDC NCBDDD staff
 - b. Monitored 12 NQF workgroups
 - c. Attended monthly NQF workgroup meetings

Future 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 social media platform

Activity 2 [Target 5b]: Organize stakeholder network

- I. Continue newsletter distribution to stakeholder groups
- II. Continue stakeholder engagement to encourage dissemination of RFAs

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

- I. Provide continued support to Training and Evidence Based Core in work with DHB
- II. 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 RFA dissemination and website management

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

- I. Will provide support and dissemination strategies for Community Health Inclusion Index in Year 4
- II. Continued updated to knowledge repository
 - a. Will investigate methods to showcase and reposition knowledge repository in Year 4

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 3, 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 3, as well as partnered in the planning and development of the DRDC Work/Study Training Program for MPH students at SUNY Upstate Medical University.

EXPERT PANEL

The Evaluation Core partnered with the Training and Evidence Based Core during the group concept mapping portion of the NCBDDD's Division of Human Development and Disability (DHDD) Disability and Health Branch (DHB) Expert Panel, and conducted an evaluation of the deliberation processes conducted throughout all Expert Panel activities.

The DHB Expert Panel participated in Group Concept Mapping (GCM) activities throughout March and April of 2015. GCM is a mixed-method approach that purposefully integrates qualitative individual and group processes using multivariate statistical analyses. These analyses assist a group of individuals to describe ideas on any topic of interest, and represent those ideas visually through a series of two-dimensional maps. The results of GCM were used as a framework for the deliberative Expert Panel Meeting in April 2015. Through the GCM process, 84 individuals submitted 96 items to be included in the framework. Eighteen individuals provided structuring to group these items into six themes:

- I. Surveillance and Research
- II. Infrastructure
- III. Guiding Principles

- IV. Communications
- V. Collaborations
- VI. Programs

The 96 items were also rated on their criticality and feasibility.

Following the close of the Expert Panel Meeting, a set of recommendations was developed by the core project team to summarize the findings of the GCM process into priority statements for these six themes. Additionally, through the deliberations of the large and small working groups, five overarching issues were identified that crossed all themes and were considered instrumental for achieving success with the identified priorities within each theme. These findings were circulated to the Expert Panel via an online survey, asking them to provide clarifying and open-ended commentary as well as provide priority rankings for each recommendation under each theme. Qualitative analysis was conducted on the results of the clarifying commentary, and mean rankings for the priority areas were calculated. The draft final results were circulated to the Expert Panel for final commentary.

At the conclusion of the Expert Panel Meeting, Panel members participated in a post-meeting evaluation survey. This goal of the post-meeting survey was to provide a quality-assurance check to assess whether Expert Panel members were comfortable with the GCM process and meetings.

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 previous year's 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 will receive IRB review and implementation during Year 4 of the Cooperative Agreement, with additional funding from the SBA.

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. Initiated Adult Spina Bifida survey with the Spina Bifida Association of American

- a. Developed draft questionnaire

Future 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. Submit protocol for IRB approval at the SUNY Upstate Medical University Institutional Review Board
 - b. Implement survey and conduct analysis on results

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

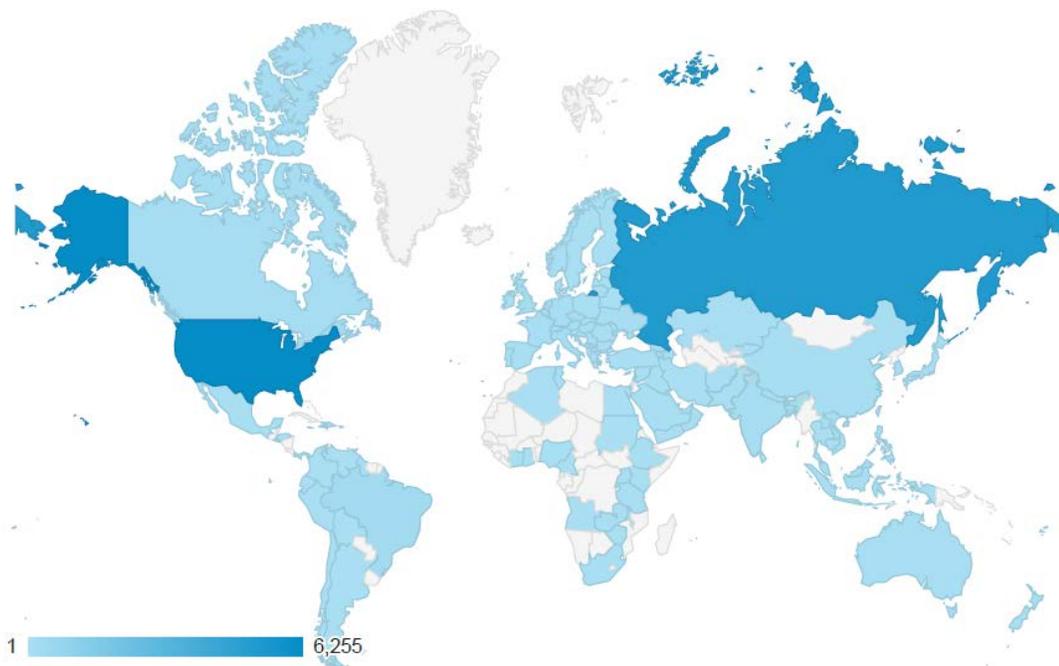
APPENDIX B: EVALUATION OF DRDC WEBSITE VISITATION

Overall Website Visitation

In the period of September 30, 2014 - September 29, 2015, there were 11,010 visitors to the DRDC website, which is a relative increase of roughly 22% from the previous year. Of the total 11,010 visitors, 82.04% (9,098) were unique visitors. There were a total of 23,141 page views, with an average of 1.72 pages viewed per visit. The average visit duration was 1 minutes 13 seconds per visitor. The visitor bounce rate was 77.61% (bounce rate refers to the number of visits that go only one page before exiting the site).

Approximately 6,255 users (57% of all users) visited the site from locations within the United States; other visitors were primarily from Russia, Brazil, Canada, the United Kingdom, and India. Returning visitors spent an average of 2 minutes longer on the site and viewed one additional page per visit compared to new visitors. Figure 1 displays a map overlay of the geographic locations within which users visited the site between September 30, 2014 and September 29, 2015.

FIGURE 1. MAP OVERLAY WWW.DISABILITYRESEARCHCENTER.ORG VISITATION, SEPTEMBER 30, 2014 - SEPTEMBER 29, 2015



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 56.41% 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 3.6% of referral traffic came from social media networks, with LinkedIn acting as the primary referral site for these visitors. Direct traffic was the second-largest traffic source for website visitors, at 29.46%. 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 Bing.

FIGURE 2. TRAFFIC CHANNELS FOR VISITORS TO WWW.DISABILITYRESEARCHCENTER.ORG, SEPTEMBER 30, 2014 - SEPTEMBER 29, 2015

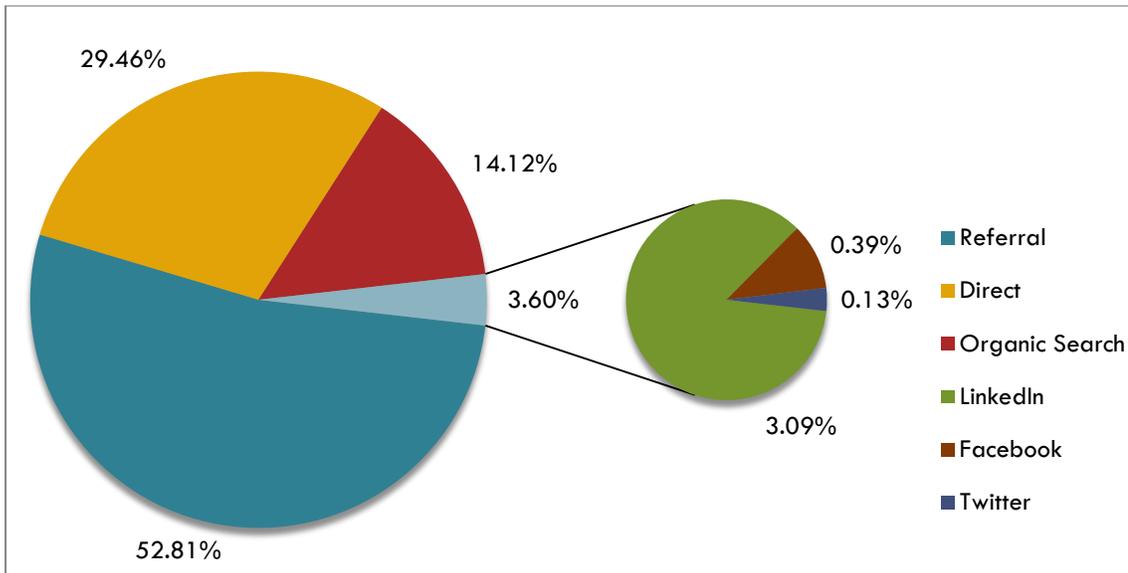
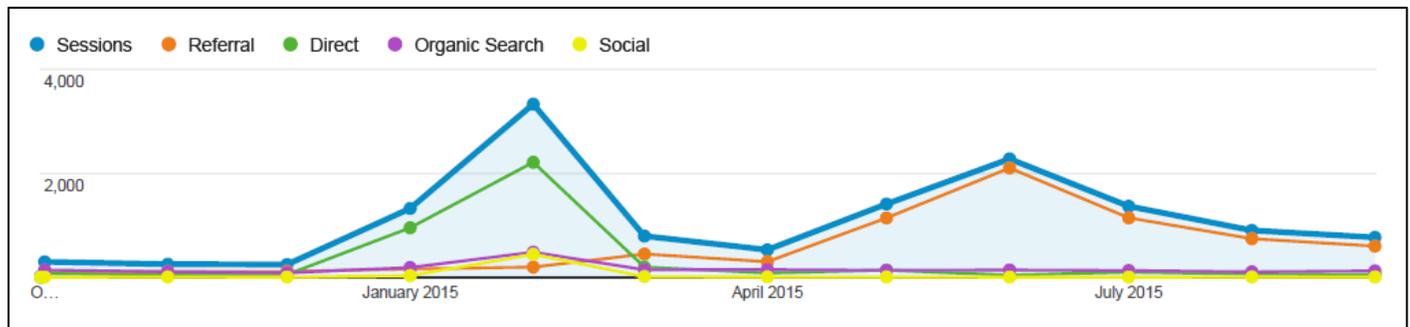


Figure 3 displays a time trend of website visitation during the period of September 30, 2014 - September 29, 2015. The period of highest visitation fell between January and March, 2015, with approximately 3,329 visitors at the highest point in user traffic in February. Another high period of visitation occurred between May and July, 2015, with approximately 2,276 visitors at the highest point in user traffic in June. The weeks with the highest volume of visitors occurred in February and June as well. The lowest period of visitation fell between October and December, 2013, with an average of less than 50 visitors per week.

FIGURE 3. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG MONTHLY VISITATION, SEPTEMBER 29, 2014 –SEPTEMBER 29, 2015



Several website dissemination efforts were launched during the period of January to March, 2014, 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, 2014 and September 29, 2015. While Twitter was routinely used throughout the Year 3 period, a larger volume of Tweets were disseminated during February and March of 2015, as can be seen in Figure 4 below. 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 3; 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 2014 – SEPTEMBER 2015

