

Disability Research and Dissemination Center 2013-2014 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 second year (September 30, 2013 – September 29, 2014) of the Cooperative Agreement #1U01DD001007 continued successful operations and programs initiated in the previous year, 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 year of the cooperative agreement, achieved several of the designated goals for the second year, and identified areas for targeted improvement for future years of project implementation. Future plans to meet unmet goals and activities are outlined within the following report.

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OVERVIEW

Cooperative Agreement #1U01DD001007 was initiated on September 30, 2012, with the University of South Carolina acting as the Administrative home of the DRDC. Subcontracts were established at the American Association on Health and Disability (AAHD) and SUNY Upstate Medical University. This annual report presents results of the second year of the project (September 30, 2013 -September 29, 2014), based upon the logic model shown below, which 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: Spina Bifida Association, Greenwood Genetic Center, University of Missouri, Georgia Institute of Technology, University of Colorado – Denver, University of Colorado – Boulder, University of Wisconsin, and Cincinnati Children's Hospital Medical Center.

An External Advisory Committee (EAC) conference call was held on January 27, 2014, to communicate details of the DRDC's Year 3 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 November, 2014 (Year 3).

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 Suzanne McDermott, PhD, the Research Core director and overall project principal investigator (PI), and Deborah Salzberg, MS, MAT, the DRDC project manager.

During Year 2, the Research Core successfully continued work on the four major goals. Seven research projects, selected in Year 1 for funding, were initiated within Year 2; additionally, one contract for technical assistance was established with the Greenwood Genetic Center. Thus far, these seven projects have produced 5 publications and 2 presentations at national conferences; additional publications are in progress. The DRDC worked 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 included the following activities: 1) providing technical assistance to better understand genetic and environmental risk factors for birth defects, with opportunities for collaboration on population-based research on modifiable risk factors for birth defects and trends in health outcomes among infants and young children with birth defects; 2) providing technical expertise and algorithms for dysmorphology classification in children; 3) education and/or training presentations on genetic counseling, neurodevelopmental and related disabilities as needed; and 4) serving as clinical experts with scientific leaders and principle investigators for case reviews, birth defects classifications with other scientists.

Seven Requests for Applications (RFAs) were established in Year 2, and a total of 47 applications were received; the research projects funded from these RFAs will begin in Year 3 of the Cooperative Agreement. While a full review process was used to evaluate applications in Year 1, a triage process was developed and used during Year 2. This process proved to be less time consuming and more efficient than the full review. Triage panels consisting of members of the DRDC External Advisory Committee (EAC) scored applications using a Likert scale (1-3, whole numbers only: 1=poor, 2=adequate, 3=promising) for three categories: (1) Responsiveness to the RFA, (2) Merit of the Methods, and (3) Investigator and Institutional ability to carry out the work. All reviewers were instructed to recuse themselves from reviewing any applications where the reviewer had a conflict of interest. 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 six new projects for Year 3. Thus, the total number of awards that will be funded in Year 3 equals six new projects, and five continuing projects from Year 2. One project housed at the University of Missouri will also continue into Year 3 via carryover of funds.

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. The primary investigator, Suzanne McDermott, PhD, has acquired the data for both the national and South Carolina portions of the study. The analysis for preventive services using NHIS/MEPS data is complete for the national portion of the study, and a manuscript is being drafted related to the experience of individuals who are blind. For the South Carolina portion of the study, data from Medicare and Medicaid have been merged with administrative data to produce one large dataset.

Additionally, age- and sex-matched groups of individuals with and without disabilities have been created. Manuscripts are currently being drafted for the national study and for the South Carolina study.

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. Analysis
 1. Complete for national data
 2. In progress for South Carolina data
 - ii. Drafting of manuscripts
 1. In progress for national data
 2. In progress for South Carolina data

Activity 2 [Target 2b]: Set research priorities

- I. Research topic areas for solicitation targeted and advertised through DRDC website
 - a. RFA-NR14-01 EHDI Quality Measures
 - b. RFA-NR14-02 LTSAE Monitoring
 - c. RFA-R14-001 EHDI – C-Section
 - d. RFA-R14-002 EMR Rare Conditions
 - e. RFA-R14-003 Healthy Weight
 - f. RFA-R14-004 Project to Learn About Youth
 - g. RFA-NR14-SPECIAL Genotyping Analysis

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

- I. Seven Year 2 projects were funded (RFAs for these projects were solicited in Year 1)
- II. Seven 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

Key Outcomes or Other Achievements

Activity 1 [Target 2a]: Conduct internal research

- I. No publications at this time

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

- I. Forty-seven RFA Applications Received
 - a. RFA-NR14-01 EHDI Quality Measures—2 applications
 - b. RFA-NR14-02 LTSAE Monitoring —16 applications
 - c. RFA-R14-001 EHDI - C-Section—4 applications
 - d. RFA-R14-002 EMR Rare Conditions—4 applications
 - e. RFA-R14-003 Healthy Weight— 11 applications
 - f. RFA-R14-004 Project to Learn About Youth—3 applications
 - g. RFA-NR14-SPECIAL Genotyping Analysis—7 applications
- II. Eight new projects selected by the CDC for Year 3, six of which were funded:
 - a. PLAY-MH: University of Florida, Steven Cuffe, PI, 2 year project
 - b. PLAY-MH: Ohio University, Julie Owens, PI, 2 year project
 - c. GENOTYPING ANALYSIS: Johns Hopkins University, M. Daniele Fallin, PI, 1 year project
 - d. LTSAE MONITORING : University of Wisconsin, Gail Chodron, PI, 2 year project
 - e. EMR-RARE CONDITIONS: University of S Carolina, Kevin Bennett, PI, 3 year project
 - f. HEALTHY WEIGHT: University of Texas, Katherine Froehlich-Grobe, PI, 3 year project
- III. Seven research projects either begun or continued in Year 2
 - a. Predictors of Use of Preventive Services by Adults with ID, SCI and Those Who are Blind – University of South Carolina, Suzanne McDermott, PI, Year 2 of 3
 - b. EHDI-Developmental Outcomes: University of Colorado – Boulder, Christie Yoshinaga-Itano, PI, Year 1 of 3
 - c. EHDI-WIC: Cincinnati Children’s Hospital Medical Center, Lisa Hunter, PI, Year 1 of 2
 - d. EHDI-WIC: University of Wisconsin, Anne Harris, PI, Year 1 of 2
 - e. PLAY: Mental Health – University of S. Carolina, Kate Flory, PI, Year 1 of 2
 - f. PLAY: Mental Health – University of Colorado–Denver, Lorraine Kubicek, PI, Year 1 of 2
 - g. LTSAE: University of Missouri, Janet Farmer, PI, Year 1 of 2
 - h. LTSAE: Georgia Institute of Technology, Rosa Arriaga, PI, Year 1 of 1
- 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

Future Activities

Activity 1 [Target 2a]: Conduct internal research

- I. Complete analysis for South Carolina data
- II. Complete three manuscripts for South Carolina data on the following topics
 - a. Disparities in Preventive Services
 - b. Comorbid Conditions Comparison
 - c. Value Added by Medicaid Data
- III. Complete manuscript including both national and South Carolina data

Activity 2 [Target 2b]: Set research priorities

- I. Work with NCBDDD on the development of Year 3 RFAs

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

- I. Broaden RFAs to increase applicant pool and encourage investigator-initiated research
 - a. The RFAs will be finalized and posted by January 2015 (Year 3)
- II. The RFA evaluation triage rubric was revised to expand scoring options to a 5-unit scale and will be implemented during the Year 3 RFA evaluations

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 catalogue 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, Brian Barger, PhD, LSAE Fellow, and Catherine Rice, PhD, of the NCBDDD.

RESEARCH FELLOWSHIP

The Training and Evidence Based Core oversaw the recruitment and selection of an NCBDDD "Learn the Signs. Act Early." Fellow during Year 1 of the Cooperative Agreement. Brian Barger, PhD, was successfully hired in June 2013, and continued working toward targeted goals during Year 2. Dr. Barger receives guidance and oversight primarily from Catherine Rice, PhD, and Rebecca Wolf, MA, of the CDC/NCBDDD. Margaret Turk, MD, also provides periodic evaluation of fellowship progress through semi-annual evaluations.

At the initiation of the fellowship, Dr. Barger expressed goals of increased professional networking, gaining experience using national data sets and conducting systematic reviews, developing project leadership skills, and having two publications in print or in press by the end of the fellowship. The evaluation for Dr. Barger's first year in the fellowship was conducted in May, 2014, using an established Evaluation Form. 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 (accomplished)
 - b. 1 manuscript developed and submitted for CDC clearance (Early Identification Leading to Part C Early Intervention)
- II. Year 2 – June 2014 to May 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)
 - b. 1 manuscript submitted to peer reviewed journal (after CDC clearance for Year 1)
 - c. 1 new manuscript developed and submitted for CDC clearance
 - d. 1 grant preparation/writing for internal submission

At the time interviews were conducted, Dr. Barger reported that he has started analysis using data from a variety of publicly accessible data sets, and plans to generate manuscripts for publication from these analyses. Due to

constraints within the NCBDDD in the use of statistical software packages, Dr. Barger initiated self-directed learning and use of R, which is open access statistical software program; as part of this process, Dr. Barger started a CDC-wide R interest group.

Dr. Barger also reported that three manuscripts are currently staged at either pre-review or under-review by the CDC and DRDC, including one systematic review; two of these manuscripts are estimated to reach clearance by January, 2015. In addition to these manuscripts, Dr. Barger participated in the composition of two grant projects in collaboration with colleagues at Georgia State University; one grant has been submitted for review, and the second will be submitted by December, 2014. In addition to his work with the NCBDDD, Dr. Barger has developed two articles from his dissertation research that have been submitted to peer-reviewed journals for publication.

No major barriers for the fellowship were identified in Year 2. Dr. Barger expressed strong satisfaction in the fellowship, stating that the supportive environment with responsive feedback from his immediate supervisors at NCBDDD, as well as the directors of the Research Core and Training and Evidence Based Core of the DRDC, has been valuable to his training and professional development. Additionally, Dr. Rice provided positive feedback regarding the performance of Dr. Barger in the fellowship. Dr. Rice remarked that Dr. Barger has been a positive asset to NCBDDD. Dr. Barger will complete the fellowship in May 2015. The Training and Evidence Based Core will initiate planning for a second fellowship to begin in Year 4 of the Cooperative Agreement in the fall of 2015.

Both Dr. Turk and Dr. Rice provided feedback on communication between the DRDC and NCBDDD regarding the fellowship. One area for potential improvement mentioned in their feedback is in communication regarding evaluation time lines and deliverables; both parties recognize the need to communicate on and adhere to established time lines and deliverables for fellowship evaluations.

RESEARCH AND EVIDENCE-BASED PROJECTS

During Year 2 of the Cooperative Agreement, the Training and Evidence Based Core, in conjunction with the Evaluation Core and NCBDDD, partnered with the Spina Bifida Association (SBA) to gather stakeholder feedback on the development of a Spina Bifida Collaborative Care Network (SBCCN), the goal of which is to monitor, track and evaluate patterns of care provided in Spina Bifida clinics, with the aim of improving and standardizing care through evidence-based effectiveness analysis and quality improvement. The SBCCN project aimed to develop a strategic plan for the development and implementation of the infrastructure for a SBCCN. The charge was to develop the building blocks to define good care for children and adults; identify key concepts, processes, and capabilities needed by clinic sites to participate in the SBCCN; define benefits to clinics; and plan for consumer participation in the SBCCN, specifically through affiliate and corporate SBA Chapters and Hispanic outreach. Two groups that represented the stakeholders of the Spina Bifida community were established: Leadership and Overall Planning. Through a series of meetings and a vetting process involving consumers and providers, a Strategic Plan was developed. The Strategic Plan has five overarching goals:

- Improve communication among all stakeholders in the care and lives of people with Spina Bifida
- Develop Spina Bifida clinic site performance expectations for quality improvement programs
- Improve the care of adults with Spina Bifida
- Develop best practices for clinic programs for health outcomes improvement
- Sustain the capacity of the SBCCN

The Leadership Group will be meeting one final time in January 2015, by phone, to debrief about the process and move the SBCCN planning into the implementation stages. Details regarding the specific work of the Evaluation Core can be found in the Evaluation Core section, beginning page 16. The Training and Evidence Based Core and Evaluation Core, with the involvement of NCBDDD, intend to develop a descriptive article detailing the process of

engaging stakeholders in the development of the SBCCN to submit for publication in Year 3 of the Cooperative Agreement.

The Training and Evidence Based Core also 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. Future developments from this systematic review include one manuscript for publication that will summarize the overall findings of the review, as well as up to two additional manuscripts detailing the measurement of healthy weight for specific disabilities or age groups. The Training and Evidence Based Core is planning to initiate an additional two systematic reviews in Year 3 of the Cooperative Agreement, subjects to be determined.

The Training and Evidence Based Core will be heavily involved in the development and implementation of an expert panel for the NCBDDD's Division of Human Development and Disability (DHDD) in Year 3 of the Cooperative Agreement. The DRDC is working with DHDD to better identify the goals of an expert panel and to identify possible experts working in relevant fields and to guide the CDC in the establishment of an updated agenda for the DHDD. Additionally, the expert panel will provide feedback on future directions for State Disability and Health programs to ensure they are responsive to the needs of the communities they serve. Initial steps to be undertaken in Year 3 include group concept mapping and strategic planning exercises.

Furthermore, the Training and Evidence Based Core will convene a working group to explore the development of recognition status for a "Disability Medical (Health) Home." The Training and Evidence Based Core, Dissemination Core, and working group will collaborate with an organization that bestows the recognition of "Medical (Health) Home", such as the National Committee for Quality Assurance, Joint Commission, or Accreditation Association for Ambulatory Healthcare.

The Dissemination Core will provide the venue planning, travel, and coordination for the DHDD expert panel as well as the Disability Medical Home exploration project.

As in Year 1, the Learners' Need Analysis was not initiated in Year 2 due to a lack of prioritization by the CDC. Furthermore, activities related to Targets 3a, 4c and 4d were not selected by the CDC for implementation in Years 1 or 2; work on these Targets is planned in Year 3 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. Not conducted in Year 2.

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

- I. Systematic literature review completed
 - a. Measurement of health weight among individuals with disabilities
 - b. Findings submitted to CDC

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

- II. Partnered with Evaluation Core on the Spina Bifida Collaborative Care Network (SBCCN) stakeholder feedback evaluation project for the Spina Bifida Association (SBA)
 - a. Evaluation Core facilitated group concept mapping with SBCCN Leadership Group in January, 2014
 - b. Evaluation Core collaborated with SBA on development of online surveys to distribute to stakeholders

Future Activities

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

- I. Expert panel will be convened to explore development of a standard for recognition of a Disability Medical Home

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

- I. Three manuscripts will be developed from healthy weight systematic review and submitted for publication in Year 3
 - a. Overall summary of findings
 - b. Two targeted summaries based on specific disabilities or age groups
- II. Two additional systematic literature reviews will be conducted in Year 3
 - a. Subjects to be determined
 - b. Plan to initiate reviews in Fall 2014

Activity 3 [Target 4a]: Develop research fellowship

- I. Dr. Barger will complete the current fellowship in May 2015 (Year 3)
- II. Preparation for the recruitment and selection of a second Fellow will begin in Year 3, with the fellowship beginning in Year 4 of the Cooperative Agreement

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

- I. Will develop and institute a blue ribbon panel for the NCBDDD's Division of Human Development and Disability
 - a. Initial steps include group concept mapping and strategic planning exercises
 - i. Provide the CDC with feedback from experts working in relevant fields to inform future agendas for the Division
 - ii. Provide feedback on future directions for state disability and health programs

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

- I. Activities will be initiated if funding is awarded in Year 3.
 - a. Development of expert panels and/or new educational opportunities with continuing education credits

Research and Evaluation Projects

- I. Evaluation Core submitted report to SBA evaluating the alignment of the SBCCN Strategic Plan with stakeholder feedback in November 2014 (Year 3)
 - a. Plan to develop descriptive manuscript on process of stakeholder engagement for publication in Year 3

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 A. Briefly, in the period of September 30, 2013 – September 29, 2014, there were 9,010 visitors to the DRDC website; this represents a relative increase in visitation of 56% compared to Year 1 (note: website was launched January 17, 2013, resulting in shorter evaluation period for previous year). Of the total 9,010 visitors, 61.21% (5,515) were unique visitors. There were a total of 24,512 page views, with an average of 2.72 pages viewed per visit. The average visit duration was 3 minutes 10 seconds per visitor. The visitor bounce rate was 52.71% (bounce rate refers to the number of visits that go only one page before exiting the site). The large majority of website visitors (90%) visited the site from locations within the United States. The period of highest website visitation volume occurred between January, 2014 and March, 2014; this period coincides with targeted dissemination efforts related to Year 2 RFAs.

DISSEMINATION OF YEAR 2 RFAS

Before and during the launch of the Year 2 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 weekly 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, newsletters, and social media to disseminate the RFAs.

Six RFAs for Year 2 were posted on the DRDC website in January 2014, and an additional RFA was posted in February. Applications were due March 7th, 2014, for the original RFAs and March 31st, 2014, for the additional RFA. 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 Public Health in the Media*, which is geared toward a professional audience. Dissemination through social media occurred on the DRDC's Twitter account, within 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 College of Mental

Health Administrators, Disability and Public Health, American Association on Intellectual and Developmental Disabilities, American Public Health Association, , Autism Society of America, Council for Disability Awareness, Disability Policy Consortium, 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 RFA application period from January-early March, 2014. However, since then, it has been largely inactive, with only 4 new tweets since April 2014, and only 23 followers. It is questionable whether the Twitter account can effectively reach stakeholders if it is only active a few months out of the year. 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 January, 2014; however, the second conference call meeting was postponed until November 2014 (Year 3) due to scheduling conflicts. The Dissemination Core also engages the EAC and other external partners through the weekly distribution of the *Disability and Public Health in the Media* newsletter, which provides updates on current DRDC projects and activities.

The Dissemination Core will provide support to the Training and Evidence Based Core on its work with the DHDD and State Disability and Health programs, as well as support an expert panel to inform the development of a standard for the recognition of “Disability Medical Home.” Additionally, the Dissemination Core will work 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 National Quality Forum. Preliminary discussions on topics and locations for the expert panel meetings were discussed on the March, 2014, DRDC call with Rick Roman, NCBDDD Deputy Director. However, meetings did not occur during Year 2 due to staffing changes within the NCBDDD.

The Dissemination Core will also be involved in the rollout of the DHDD Community Health Inclusion Index in Year 3, and will establish a knowledge repository in collaboration with the DHDD and AAHD Health Promotion Resource Center. This knowledge repository will integrate research conducted by the DRDC and NCBDDD with existing and emerging literature. As noted above, the Dissemination Core will organize the meeting venue, travel, and coordination for the DHDD expert panel and exploration of a Disability Medical Home project.

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. Newsletter electronically distributed to roughly 7,000—8,000 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 semiannual conference call in January, 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

Activities 5 and 6 [Targets 5e and 5f]

- I. Not conducted in Year 2

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. Higher utilization of Twitter handle
 - b. 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. Support Training and Evidence Based Core in work with DHDD and State Disability and Health programs
 - a. Develop targeted educational activities to promote DHDD's research, surveillance and programs
- II. Support development of expert panel to explore standard of recognition for Disability Medical Home
- III. Support NCBDDD's work with National Quality Forum on endorsement of newborn hearing screening and metabolic screening of newborns standards

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 rollout of Community Health Inclusion Index

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

- I. Collaboration with DHDD and AAHD Health Promotion Resource Center to develop knowledge repository

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 2, 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 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. So far, five publications and two conference presentations have been produced from the Year 2 projects, and additional publications are underway.

The Evaluation Core assisted the Training and Evidence Based Core in securing personnel support for the systematic literature reviews conducted during Year 2, and provided feedback to the Research Core on the RFA evaluation rubric.

SPINA BIFIDA CLINICAL CARE NETWORK PROJECT

See details of the entire project under the Training and Evidence Based Core on page 10. The Evaluation Core led members of the SBCCN Leadership Group in a concept mapping exercise in January, 2014. Group concept mapping is a process through which a group can organize and visually capture its ideas on a certain topic of interest. The primary topic of interest for the SBCCN Leadership Group concept mapping exercise was to gain a better understanding of the future directions and areas of influence on which the SBCCN leadership and stakeholders should focus in the development of the SBCCN Strategic Plan.

Feedback for the Draft 5-point Strategic Plan was gathered through conference-based focus groups at the 2014 National Spina Bifida Association Conference and through online surveys. The Evaluation Core assisted the SBA with the development and analysis of the online surveys, which were targeted toward health care professionals and adults and families living with Spina Bifida. Data collection was completed by the end of July 2014.

The Evaluation Core submitted a report to the SBA evaluating the alignment of the SBCCN Draft 5-point Strategic Plan with stakeholder feedback gathered from the group concept mapping, online surveys and conference focus groups in November 2014 (Year 3 of the Cooperative Agreement).

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 Research Core
 - a. Collaborated on improvements to evaluation tool for fellowship applicants
- III. Collaborated with Training and Evidence Based Core
 - a. Spina Bifida Association national strategic plan for a Spina Bifida Clinical Care Network stakeholder feedback assessment

Key Outcomes or Other Achievements

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

- I. Website effectiveness evaluation report (see Dissemination Core)
- II. Spina Bifida Clinical Care Network stakeholder feedback analysis report
- III. 9-criteria scoring rubric for fellowship applicant evaluation

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

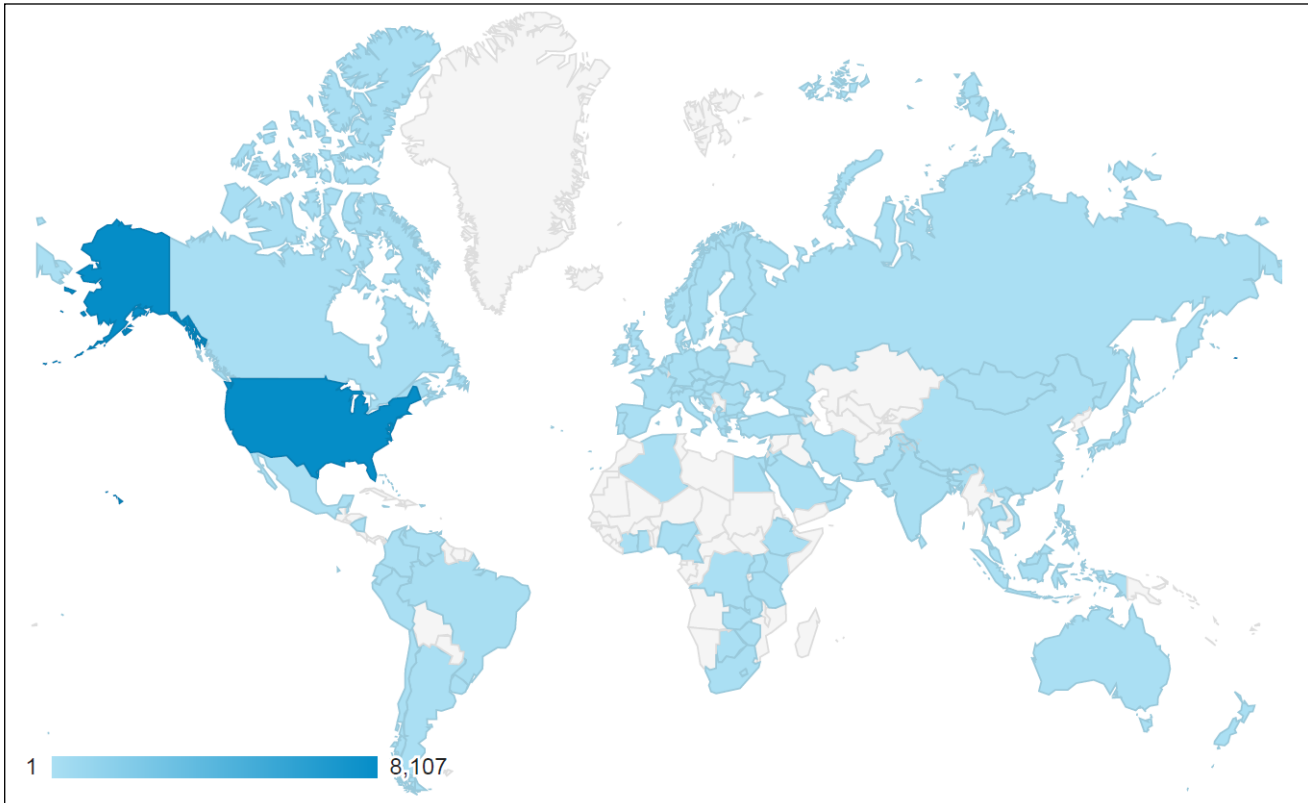
APPENDIX A: EVALUATION OF DRDC WEBSITE VISITATION

Overall Website Visitation

In the period of September 30, 2013 - September 29, 2014, there were 9,010 visitors to the DRDC website, which is a relative increase of roughly 56% from the previous year (note: website was launched January 17, 2013, resulting in shorter evaluation period for previous year). Of the total 9,010 visitors, 61.21% (5,515) were unique visitors. There were a total of 24,512 page views, with an average of 2.72 pages viewed per visit. The average visit duration was 3 minutes 10 seconds per visitor. The visitor bounce rate was 52.71% (bounce rate refers to the number of visits that go only one page before exiting the site).

Approximately 8,107 users (90% of all users) visited the site from locations within the United States; other visitors were primarily from India, Brazil and Canada. 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, 2013 and September 29, 2014.

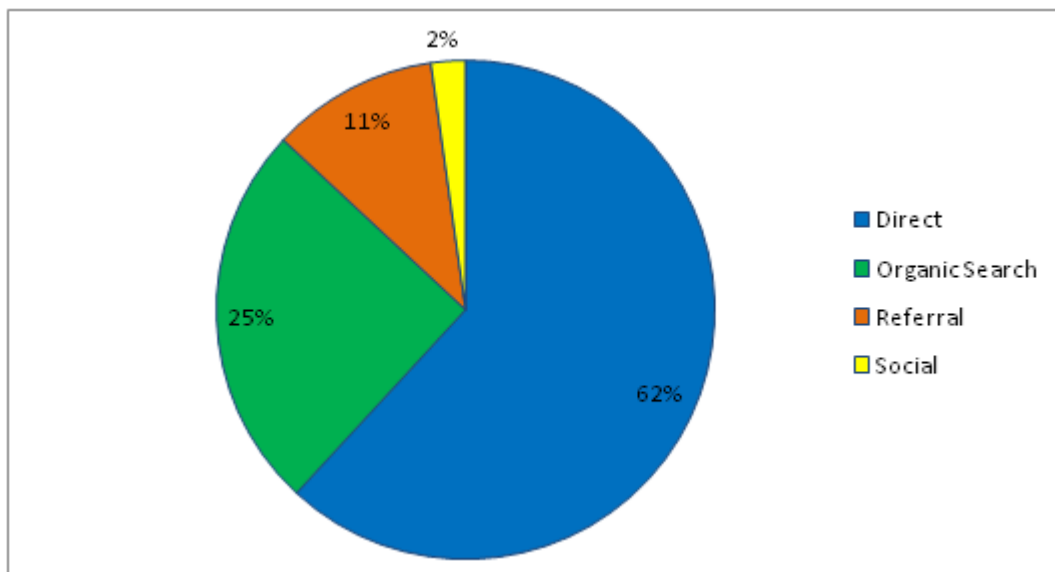
FIGURE 1. MAP OVERLAY WWW.DISABILITYRESEARCHCENTER.ORG VISITATION, SEPTEMBER 30, 2013 - SEPTEMBER 29, 2014



Traffic Sources and Dissemination Efforts

Figure 2 displays the distribution of traffic sources for visitors to the website. The most common traffic source was direct traffic, at 61.9% of all visitors. Direct traffic refers to any scenario in which an individual clicked a link leading directly to the DRDC website (e.g. links contained in PDF documents or emails) or typed the website address directly into the browser. Other traffic sources included searching for the website in browser search engines, including Google and Bing, and following links to the DRDC website contained within the websites of other organizations, also known as referral sites. Approximately 10.8% of all visitors to the DRDC website fell into the category of referral traffic; the American Association on Health and Disability website (www.aahd.us) and LinkedIn (www.linkedin.com) were the leading referral sites during this time period.

FIGURE 2. TRAFFIC CHANNELS FOR VISITORS TO WWW.DISABILITYRESEARCHCENTER.ORG, SEPTEMBER 30, 2013 - SEPTEMBER 29, 2014



Figures 3 through 6 display time trends of website visitation during the period of September 30, 2013 - September 29, 2014; the time trend is displayed across four quarters. The period of highest visitation fell between January and March, 2014, with approximately 1,200 visitors per week at the highest point in user traffic. The lowest period of visitation fell between October and December, 2013, with an average of less than 50 visitors per week. The top two avenues of user visitation were direct traffic and organic search traffic; it is important to note that during the period of highest visitation, most users (72%) arrived at the DRDC website via direct traffic. Social media was the least represented form of visitor traffic to the DRDC website between September 30, 2013 and September 29, 2014.

FIGURE 3. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG WEEKLY VISITATION, OCTOBER 1, 2013 - DECEMBER 31, 2013

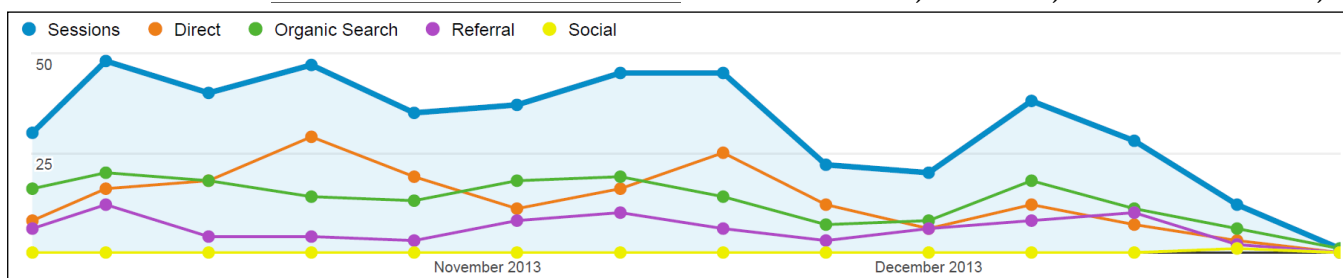


FIGURE 4. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG WEEKLY VISITATION, JANUARY 1, 2014 - MARCH 31, 2014

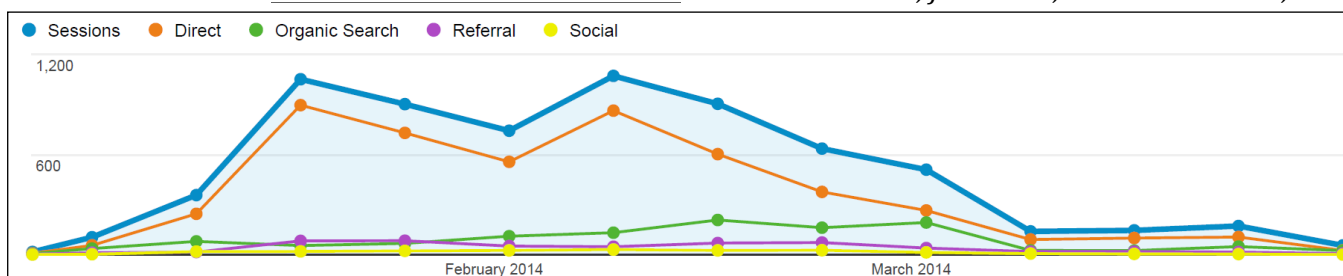


FIGURE 5. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG WEEKLY VISITATION, APRIL 1, 2014 - JUNE 30, 2014

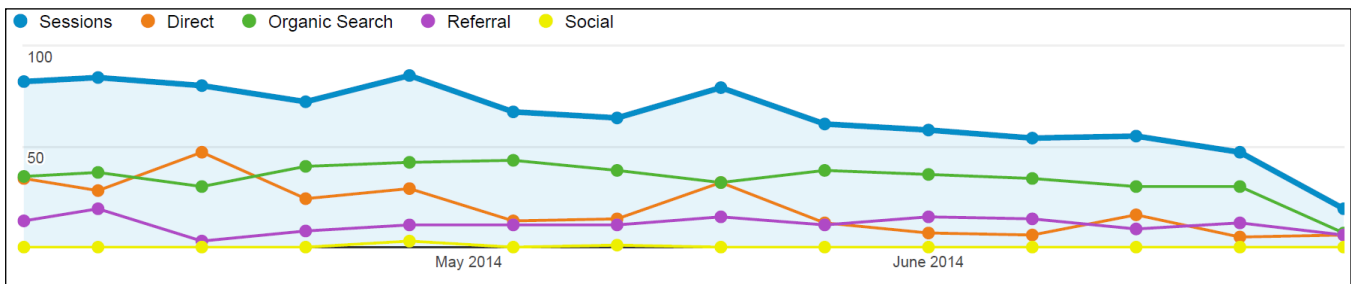
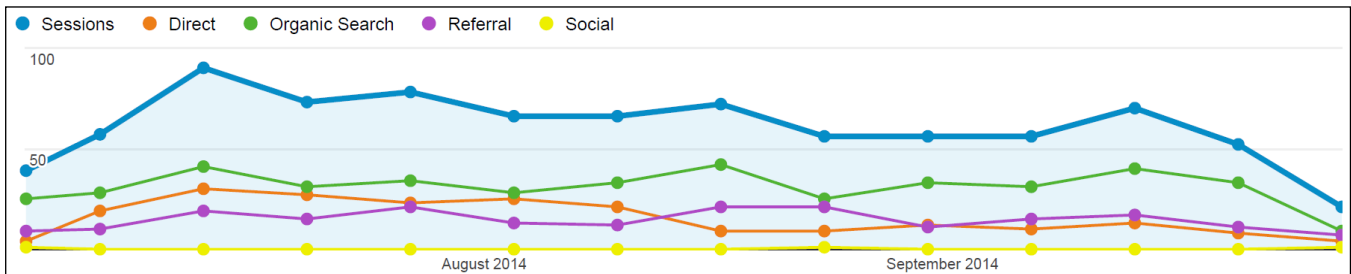
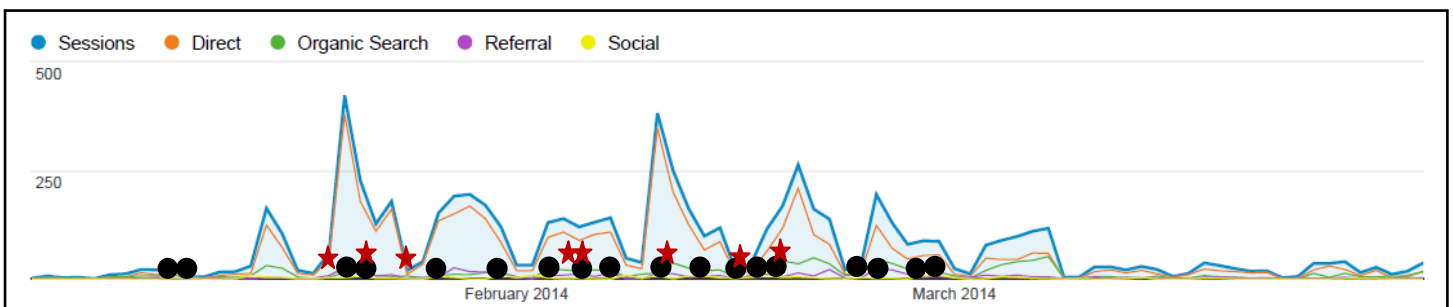


FIGURE 6. TIME TREND WWW.DISABILITYRESEARCHCENTER.ORG WEEKLY VISITATION, JULY 1, 2014 – SEPTEMBER 29, 2014



Several website dissemination efforts were launched during the period of January to March, 2014, regarding the DRDC Request for Applications (RFAs). This period aligns with the highest website traffic volume observed between September 30, 2013 and September 29, 2014. Figure 7 displays a time trend of website visitation between January and March 2014, with the dates of DRDC dissemination efforts noted. The dates of Twitter dissemination efforts are marked with black dots. Red stars mark the dates of email communications delivered to EAC and other external partners. Many of these partners distributed the information from these emails through their respective listservs.

FIGURE 7. TIME TREND OF DRDC WWW.DISABILITYRESEARCHCENTER.ORG DAILY VISITATION, JANUARY 1, 2014 – MARCH 31, 2014



Multiple Tweets were sent out on several of the dates marked in the figure above; for example, on January 10, 2015, a total of 12 Tweets were issued regarding the RFAs. The Dissemination Core also sent weekly announcements regarding the RFAs through the *Disability and Public Health in the Media* 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 2; however, the Dissemination Core and Evaluation Core are

developing a standardized tracking method to more accurately document future dissemination efforts for Year 3 of the Cooperative Agreement.

No major dissemination efforts were conducted in March 2014, using the Twitter account or LinkedIn groups. Personal email communication advertising the RFA for Genotyping Analysis for SEED Samples was used to contact targeted universities and laboratories; this approach was chosen due to the specialized nature of the RFA, which required strategic outreach. Seven applications for this RFA were received in a short time period, which highlights the efficacy of this approach.