

# Disability Research and Dissemination Center

## 2016-2017 Annual Report

*Prepared by:*

Jeremy French-Lawyer, MPH, CHES

Telisa Stewart, DrPH

*Department of Public Health and Preventative Medicine*

*SUNY Upstate Medical University*

March 2018

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 fifth year (September 30, 2016 – September 29, 2017) of the Cooperative Agreement #1U01DD001007 continued successful operations and programs initiated in the previous four 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 four years of the cooperative agreement, achieved several of the designated goals for the fifth year, and developed new goals and targets for the no-cost extension year and the next funding cycle.

# 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 fifth year of the project (September 30, 2016 - September 29, 2017), based upon the logic model shown on the following page. This logic model incorporates aims and activities agreed upon during post-award negotiation with the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD).

## Administrative Core

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

*ESTABLISH A NATIONAL DRDC THAT BUILDS ON THE FOUNDATION OF TWO NATIONAL UNIVERSITIES (UNIVERSITY OF SOUTH CAROLINA [USC] AND STATE UNIVERSITY OF NEW YORK UPSTATE MEDICAL UNIVERSITY [SUNY-UPSTATE]) AND A NATIONAL DISSEMINATION AND POLICY ORGANIZATION (AMERICAN ASSOCIATION FOR HEALTH AND DISABILITY [AAHD]).*

The major activities outlined under Administrative Core responsibilities include:

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

## Summary of Activities

Data related to the Administrative Core activities was compiled from the *Annual Progress Report of the Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities (a.k.a. Disability Research and Dissemination Center)*, the *Disability Research and Dissemination Center 2015-2016 Annual Report*, interviews with Deborah Salzberg Clark, MS, MAT, DRDC Project Manager and consultation with Suzanne McDermott, PhD, DRDC Co-PI.

For Year 5, the following subcontracts were in place: SUNY Upstate Medical Center (Co-PI Institution); AAHD (Co-PI Institution); Baylor Research Institute; Cincinnati Children's Hospital Medical Center; Cornell University; Health Research Institute/New York State Department of Health; Mary Imogene Bassett Hospital; Ohio University; Project Healthy Children/Sanku Fortification; Research Foundation for Mental Hygiene/Columbia University; University of Colorado – Denver; University of Colorado – Boulder; University of Florida; University of Iowa; University of Massachusetts Medical School; University of Missouri; University of Rochester; University of South Carolina (sub-accounts for project PIs that were independent from the DRDC Cores); and the University of Wisconsin.

The External Advisory Committee (EAC) was established early in the first year of the DRDC, with 14 nationally acclaimed experts. As the years progressed, contact was made approximately twice per year, with annual teleconferences and separate email updates, in order to solicit advice and commentary on the DRDC activities, and to consult with them on the direction of the future research agenda. Additionally, most of the EAC members served on the DRDC Triage panels, and reviewed grant applications in content areas within their expertise. Over the past five years, there has been some attrition among EAC members for various reasons, such as retirements and job changes that caused a need to step down from service on the EAC. Year 5 was considered a rebuilding year, since

there were not any new RFAs; rather, the Cores prepared for the potential of being refunded. Several new members were recruited. Their service will commence in Year 1 of the competitively renewed cooperative agreement. The EAC now has 20 members, including 8 continuing and 12 new members.

In Year 5 a proposal was completed and submitted for a second cycle of funding through the CDC's NCBDDD. The proposal was submitted in February 2017 for review. Funding was awarded in August of 2017 for a second cycle. A no-cost extension year was added to continue projects from the original DRDC funding cycle into a sixth year.

### No-Cost Extension Year

In the no-cost extension year, the Administrative Core will continue to provide administrative support for the ongoing projects of the DRDC. The contract for all of the sub contracts was extended initially to the end of January 2018, with the option to be extended additionally as needed. A final report will be completed in December 2018 with information from all of the Cores and sub projects for the entire life of the DRDC's first cycle.

Planned activities for Cycle 2 of the DRDC will be discussed in the overall evaluation for years 1 through 5 of the DRDC.

**Logic Model: Cooperative Agreement #DD001—7-02**

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

# 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 related to the Administrative Core activities was compiled from the *Annual Progress Report of the Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities (a.k.a. Disability Research and Dissemination Center)*, the *Disability Research and Dissemination Center 2015-2016 Annual Report*, interviews with Deborah Salzberg Clark, MS, MAT, DRDC Project Manager and consultation with Suzanne McDermott, PhD, DRDC Co-PI.

## Internal Research

The Research Core began new work with the NCBDDD on a requested hypertension data analysis following a literature review completed by the DRDC Training and Evidence-Based Cores in Year 3. During Years 4 and 5, USC completed the analyses of medication adherence during the first year following a hypertension diagnosis for people with intellectual and developmental disabilities. The results were developed in a manuscript, which is under review at the *American Journal of Intellectual and Developmental Disabilities*.

A literature review was performed in Year 4 regarding the economic impact of physical inactivity in adults with disability by the DRDC Training and Evidence-Based Core, which formed the foundation for another joint project between the NCBDDD and the USC Research Core. Data from the National Health Interview Survey (NHIS) and Medical Expenditures Panel Survey (MEPS) was reviewed for relevant variables, and analyses were conducted. A manuscript was produced based on this work in Year 5, which is now accepted for publication by the *Journal of Physical Activity and Health*.

- Xu X, McDermott S, Mann Jr, Turk MA, Ozturk O. Physical Activity and Disability: An analysis on how activity might lower medical expenditures (2018) *Journal of Physical Activity and Health*, in press.

In Year 5, the DRDC picked up the continuation of the “Old States” Medicaid Data Analysis project, entitled, *Identifying Opportunities to Improve the Care of People with Intellectual and Developmental Disabilities*. This project was formerly funded through the Association of University Centers on Disability (AUCD). The participating states that were funded under the DRDC project were South Carolina (SC), New York (NY), Iowa (IA), and Massachusetts (MA). Delaware (DE). A publication from the original collaboration, including DE, was developed and accepted for publication during the DRDC’s Year 5:

- McDermott S, Royer J, Cope T, Lindgren S, Momany E, Lee JC, McDuffie MJ, Lauer E, Kurtz S, Armour B. (2018) *Using Medicaid Data to Characterize Persons with Intellectual and Developmental Disabilities in Five US States*. *American Journal of Intellectual and Developmental Disabilities*. In press.

In addition to the article in press, two other manuscripts are in progress, and will exclude Delaware:

- University of Iowa is leading the preparation of a manuscript on Utilization of Hospital Services by Children with Intellectual and Developmental Disabilities Based on Medicaid Data from Four States.
- University of Mass Medical School is leading the preparation of a manuscript on The Utilization of Hospital Service by Adults with Intellectual and Developmental Disability using Medicaid Data from Four States.

These two manuscripts will be completed and submitted during the 1-year no-cost extension of the DRDC, and first drafts are expected in February of 2018.

Three other states joined the study – Oregon, Arkansas, and New Hampshire. The analysis plan was discussed, and most states want to compare all IDD members with diabetes to non-IDD members with diabetes, but also show the comparison between IDD members and non-IDD SSI members with diabetes. Both comparisons will be continued, and data will continue to be gathered from the newly formed “7 States Project” to be included in a manuscript that is expected in 2018. Funding for the 7 States Project has now been shifted from the DRDC to the State Disability and Health Projects. SC will continue to manage the effort, but funds will come through the SC Disability and Health Grant, rather than the DRDC grant.

## 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
  - b. Association of Physical activity and Health Expenditures for People with Disability compared to People without Disability
  - c. Adherence to hypertension medication for people with IDD
  - d. Identifying Opportunities to Improve the Care of People with Intellectual and Developmental Disabilities

Activity 2 [Target 2b]: Set research priorities

- I. Research topic areas for solicitation targeted and advertised through DRDC website
  - No new RFAs were funded in year 5
  - New research priorities were set in Year 5 as the proposal for Cycle 2 was completed and submitted

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

- I. Three new projects began in Year 5 (RFAs for these projects were solicited in Years 5)
- II. Thirteen (13) projects continued in Year 5 (RFAs for these projects were solicited in Years 1 through 4)

Activity 4: Provide research support

- I. Provided support to funded projects
  - a. Attended meetings (at least quarterly for each project) with CDC and project PIs
  - b. Managed subcontract awards and administered budgets
  - c. Provided other assistance as needed

## Key Outcomes or Other Achievements

Activity 1 [Target 2a]: Conduct internal research

- I. Disability and Health: Predictors of Onset of Common Health Conditions and Receipt of Preventive Services Among Adults with Disabilities
  - a. Two manuscripts were published in Year 5

- i. Deroche CB, McDermott S, Mann JR, Hardin JW. (2017) Colorectal cancer screening adherence in selected disabilities over ten years. *American Journal of Preventive Medicine* Feb 14. pii: S0749-3797(17)30011-9. doi: 10.1016/j.amepre.2017.01.005.
    - ii. Xu X, McDermott S, Mann JR, Hardin JW, Deroche CB, Carroll, DC, Courtney-Long EA (2017) A longitudinal assessment of adherence to breast and cervical cancer screening recommendations among women with and without intellectual disability. *Preventive Medicine*. <https://doi.org/10.1016/j.ympmed.2017.04.034>
- II. Adherence to hypertension medication for people with IDD – Hypertension prevalence, identification, and management in disability in support of analysis of South Carolina administrative data on medication adherence in people with IDD
  - i. Presentation at AAIDD, 6/2017, “Harnessing the Power of Medicaid Data to Identify and Address Health Needs for People with IDD”
  - ii. Manuscript submitted, under review: Stevens AC, Royer J, Carroll DD, Courtney-Long EA, McDermott S, Turk MA. Anti-hypertensive medication use and factors related to adherence among adults with intellectual disability in South Carolina. *Amer J Intellect Dev Disabil*.
- III. Association of Physical Activity and Health Expenditures for People with Disability Compared to People without Disability; one manuscript is currently in review
  - a. One manuscript was published in Year 5
    - i. Economics of physical inactivity for people with disability - Manuscript undergoing re-review of resubmission: Xu X, Ozturk O, Turk MA, McDermott S. Physical activity and disability: an analysis on how activity might lower medical expenditures. *JPhys Act Health* (accepted)
- IV. Identifying Opportunities to Improve the Care of People with Intellectual and Developmental Disabilities
  - a. A publication from the original collaboration, including data from Delaware, was developed and submitted during the DRDC’s Year 5
    - i. McDermott S, Royer J, Cope T, Lindgren S, Momany E, Lee JC, McDuffie MJ, Lauer E, Kurtz S, Armour B. (2018) Using Medicaid Data to Characterize Persons with Intellectual and Developmental Disabilities in Five US States. *American Journal of Intellectual and Developmental Disabilities*. In press.
  - b. Two other manuscripts are being drafted and will be completed in the 1-year no-cost extension of the DRDC, these will exclude data from Delaware:
    - i. University of Iowa is leading the preparation of a manuscript on Utilization of Hospital Services by Children with Intellectual and Developmental Disabilities Based on Medicaid Data from Four States.
    - ii. University of Mass Medical School is leading the preparation of a manuscript on The Utilization of Hospital Service by Adults with Intellectual and Developmental Disability using Medicaid Data from Four States.

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

- I. Work with NCBDDD to refine research questions and pose hypotheses that can be tested using administrative data
- II. Sixteen research projects either began or continued in Year 5  
New Projects

These projects began in Year 5 and were funded through RFAs from Year 4.

- 1. Using Early Hearing Detection and Intervention (EHDI) to Assess Outcomes – Cincinnati Children’s Hospital Medical Center, Jareen Meizen-Derr, PhD
  - a. Specific Aims: 1b) Characterize the health, social development, cognitive, and language status of children who are deaf/hard of hearing (DHH) who have been served by the EHDI system in

- Ohio using the comprehensive linked database - IN PROGRESS 2) Test the relationship between early social-emotional development and language development in children who are DHH served by the Early Hearing Detection and Intervention (EHDI) system - IN PROGRESS 3) Identify factors that are predictive of academic achievement in children who are DHH - IN PROGRESS
- b. Publications
    - i. No publications at this time. Two abstracts have been accepted for presentations and 1 submitted abstract
2. Improving Identification of Tics and Other Conditions in Children – University of Rochester, Heather Adams, PhD
    - a. Specific Aims: The primary objective of the study was to determine sensitivity and specificity for the binary decisions of presence/absence of tics, TD, and ADHD – IN PROGRESS
    - b. Publications
      - i. No publications at this time.
  3. Small Scale Grain Fortification in Tanzania – Project Healthy Children/Sanku, Felix BrooksChurch, BA
    - a. Specific Aims: a. Complete formative research on the acceptability of small-scale maize flour fortification by the community and local millers through an impact evaluation to gauge the success and weaknesses of the advocacy campaign in improving consumer uptake of fortified flour, recognition of the fortification logo, and acceptability of fortification among the population and among millers with co-funding from GIZ - IN PROGRESS b) Raise awareness of the benefits of maize flour fortification among community members and millers through outreach and culturally appropriate education efforts - IN PROGRESS c) Build on the market chain analysis done by HKI in 2014 to identify gaps in the value chain that can be addressed by the program through value add components to improve uptake of fortification among millers - IN PROGRESS d) Evaluate effectiveness of miller value-add components in increasing uptake of fortification technology and production of adequately fortified flour - IN PROGRESS
    - b. Publications
      - i. No publications at this time.

### **Continuing Projects**

1. Assessing Impact of EHDI: University of Colorado-Boulder – Christie Yoshinaga-Itano, PhD (Year 2 of 2)
  - a. Specific Aims: a) Demonstrate the impact of EHDI by comparing the time of screening/diagnosis to receipt of early intervention before and after universal newborn hearing screening and detection – IN PROGRESS b) Assess the impact of early intervention on the developmental/educational outcomes of deaf and hard-of-hearing children, controlling for other covariates – IN PROGRESS c) Determine the impact of early intervention on growth in language/cognitive development – IN PROGRESS d) Examine the impact of early intervention on long-term language and cognitive outcomes – IN PROGRESS
  - b. Publications
    - i. Baca, R., Wiggin, M., Sedey, A., Mason, C., & Yoshinaga-Itano, C. (in process). Successful developmental pathways for children who are deaf or hard of hearing. To be submitted to Pediatrics
    - ii. Wiggin, M., & Yoshinaga-Itano, B. B. (under review). The Value of Educational Programming and Exploring the Impact of Parent Education: Why is continuing summer service vital for children with hearing loss? Manuscript submitted for publication to Volta Review.
    - iii. Wiggin, M., Sedey, A. L., & Yoshinaga-Itano, C. (under review). Describing Phoneme Development in Young Children with Hearing Loss. Manuscript submitted for publication to Journal of Deaf Studies and Deaf Education



- iv. Wiggin, M. Sedey, A. L., Kan, P. F., & Yoshinaga-Itano, C. (2017). Predicting Phoneme Growth in Young Children with Hearing Loss. Manuscript in preparation for Journal of Deaf Studies and Deaf Education.
  - v. Coady, J., Wiggin, M., Sedey, A., Yoshinaga-Itano, C. (in process). The relationship between quantity and quality in child-directed parent talk to children who are deaf or hard of hearing.
  - vi. Coady, J., Wiggin, M., Sedey, A., Yoshinaga-Itano, C. (in process). The relationship between the quality and quality of parent talk on child language outcomes.
2. Assessing Impact of EHDI: University of Wisconsin – Anne Harris, PhD (Year 1 of 2)
- a. Specific Aims: a) to assess the impact of receiving early intervention services on developmental outcomes as measured in the AEIOu study (expressive and receptive language, functional listening, social-emotional development, reading readiness at school entry) for children who are deaf and hard of hearing, controlling for covariates including race/ethnicity, maternal education, age at identification, degree of hearing loss, birth history, co-occurring conditions, type and intensity of intervention. IN PROGRESS b) to compare two models for EHDI collaboration with Part C Early Intervention on age of enrollment and developmental outcomes as measured by AEIOu for children who are deaf and hard of hearing in Wisconsin in the years 2015-2017. IN PROGRESS
  - b. Publications
    - i. No publications at this time. Two abstracts have been accepted and another one has been submitted.
3. EHDI-Development Outcomes: University of Colorado-Boulder – Christie Yoshinaga-Itano, PhD (Year 4 of 4)
- a. Specific Aims: a) are there system and/or intervention program characteristics that facilitate or prevent the collection and use of population developmental outcome data? – COMPLETED; b) are there EHDI programs (other than Colorado) that incorporate language and development outcomes into their state database? – IN PROGRESS; c) How do the skills, competencies and knowledge of interventionists differ within and across jurisdictional boundaries? – IN PROGRESS; d) How does parent and consumer systems involvement differ within/across states? – IN PROGRESS; e) How do developmental quotients differ by degree of hearing loss and number of ears affected (i.e., unilateral vs. bilateral)? – COMPLETED; f) How do developmental quotients differ by the various demographic variables? – COMPLETED g) 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)? – COMPLETED; g) What child/family or interventionist characteristics are predictive of developmental outcomes? – IN PROGRESS.
  - b. Publications
    - i. Yoshinaga-Itano C, Sedey A L, Wiggin M, et al. Early Hearing Detection and Vocabulary of Children With Hearing Loss. *Pediatrics*. 2017;140(2):e20162964
    - ii. Yoshinaga-Itano, C. & Wiggin, M. (2017). A model for the evaluation of family characteristics. In E.A. Rhoades & J.C. Duncan, (Eds.). *Auditory-Verbal Practice: Toward a Family-Centered Approach* (2nd edition), pp. 234-249 Springfield, IL: Charles C Thomas Publisher.
    - iii. Yoshinaga-Itano, C. & Wiggin, M. (2016). A look into the crystal ball for children who are deaf or hard of hearing: Needs, opportunities and challenges, *Seminars in Speech and Language*; 37, 252–258. DOI: <http://dx.doi.org/10.1055/s-0036-1587707>.
4. LTSAE-WIC: University of Missouri – Janet Farmer, PhD (Year 4 of 4)

- a. Specific Aims: a) to develop, implement and evaluate a statewide model for the expansion of the WIC Developmental Milestones Program in Missouri and across the nation. IN PROGRESS
  - b. Publications
    - i. No publications at this time, two abstracts have been accepted.
5. LTSAE Impact on Parents: Mary Imogene Bassett Hospital – Anne Gadowski , MD, MPH (Year 2 of 2)
- a. Specific Aims: a) use visit audiotapes to measure how LTSAE materials affect the within-visit processes of discussion of the child’s development, identification of a developmental problem, parent engagement, developing a treatment plan and setting expectations for the next well visit. IN PROGRESS b) use an exit survey to measure the parent’s perceptions, motivations, and actions related to developmental monitoring and talking with a doctor about child development during a well child visit. IN PROGRESS
  - b. Publications
    - i. No publications at this time.
6. LTSAE Monitoring: University of Wisconsin – Gail Chodron, PhD (Year 2 of 2)
- a. Specific Aims: a) Solicit and describe input from early childhood cross-sector stakeholders to inform design of implementation and evaluation – COMPLETED b) Offer and evaluate online training using Watch Me! module nationally – COMPLETED c) Implement and evaluate Head Start learning cohort using a train-the-trainer model – COMPLETED d) Implement and evaluate LTSAE integration in 12-15 childcare sties – COMPLETED e) Develop and disseminate a model for implementation of integration of use of LTSAE in developmental monitoring in childcare settings – COMPLETED
  - b. Publications
    - i. Chodron, G., J. Ershler, B. Barnekow, S. Viehweg, B. Barger, A. Puk-Ament (2017). Evaluation of Developmental Monitoring Using Learn The Signs. Act Early. in Childcare Settings. Report of study findings provided to the CDC’s Act Early Initiative team.
  - c. Presentations and Posters
    - i. Chodron, G., K. Barnekow, A. Puk, S. Viehweg, and K. Martinson (2017). “Impact of Developmental Monitoring Using Learn the Signs. Act Early. on Provider-Parent Communication, Trust, and Relationships in Childcare Settings.” Poster to be presented at the Association of University Centers on Disability annual conference, Washington, DC: November.
    - ii. Puk, A., G. Chodron, K. Barnekow, S. Tierney (2016). “Impact of Technical Assistance on Implementation and Outcomes of Developmental Monitoring Using Learn the Signs. Act Early. in Childcare Settings.” Poster presented at the Association of University Centers on Disability annual conference, Washington, DC: December
    - iii. Puk, A., G. Chodron, K. Barnekow, S. Tierney (2016). “Key Decisions and Pivot Points: The Path to Successful Developmental Monitoring Using Learn the Signs. Act Early. with Childcare Professionals.” Poster presented at the Association of University Centers on Disability annual conference, Washington, DC: December.
    - iv. Buck, D., G. Chodron, and S. Viehweg (2016). “Promoting Developmental Monitoring and Referral Using the Learn the Signs. Act Early. Campaign.” Poster presented at the Annual International Conference on Young Children with Special Needs and Their Families (DEC Conference): October
    - v. Barnekow, K., G. Chodron, C. Jones, A. Puk, S. Tierney, and S. Viehweg (2016). “Impact of ‘Watch Me!’ Training on Head Start, Center-, and Family-Based Early Care and Education Providers’ (ECEPs) Knowledge and Perceived Capacity to Engage Families in Developmental Monitoring.” Poster presented at the National Research Conference on Early Childhood: July.

- vi. Chodron, G., J. Farmer, and K. Nye-Lengerman. (2016). "Building Community Capacity for Early Identification of Developmental Delay with Diverse MCH Programs and Populations in Three States." Panel presentation presented at the American Association of Maternal and Child Health Programs annual conference, Washington, DC: April.
7. PLAY-Mental Health: Ohio University, Julie Owens, PhD (Year 3 of 3)
- 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.
  - b. Publications
    - i. No publications at this time. One abstract has been accepted.
  - c. Presentations and Posters
    - i. Sacchetti, G., Owens, J. S., Evans, S. W., Coy, M. P., Schwartz, M., Credit, M. E., & Kaizer, E. (2017, June). Emotional/behavioral screening scores predicting academic achievement in K-12th grade students. Poster presented at the biennial meeting of the International Society for Research in Child and Adolescent Psychopathology, Amsterdam, Netherlands.
    - ii. Credit, M., Coy, M. P., Sacchetti, G., Owens, J. S., Evans, S. W., & Kaizar, E. (2017, October). Mental health service utilization patterns, perceived benefits, and barriers for K-12th grade students. Poster presented at the annual conference on Advancing School Mental Health. Washington, D.C.
    - iii. Smith\*, J., Owens, J. S., Evans, S. W., Bitsko, R., & Holbrook, J. (2017, November). Exploring the psychometric properties of a tool to screen for tics in adolescents. Poster presented at the Annual Convention of the Association for Behavioral and Cognitive Therapies (ABCT), San Diego, CA.
8. PLAY-Mental Health: University of Florida, Steven Cuffe, MD (Year 2 of 2)
- a. Specific Aims: a) To estimate the prevalence of psychiatric disorders (internalizing, externalizing and tic disorders) in a school-based population of children aged 5-17, and estimate the rate of over/under-diagnosis – IN PROGRESS b) To describe the treatment patterns of this cohort, including over and undertreatment, 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 d) To conduct gold standard clinical diagnostic interviews on a subsample of children aged 5-17 years who screened positive for symptoms of tic disorders or mania/hypomania or disruptive mood dysregulation disorder during Stage 2 of the PLAY-JAX epidemiological study of school-aged children in Duval County, Florida. – IN PROGRESS e) To generate precise and accurate prevalence estimates of Bipolar Disorders (BPD) in children and adolescents using detailed phenotypic data obtained from clinical diagnostic interviews performed by child and adolescent psychologists and psychiatrists. – IN PROGRESS f) To generate precise and accurate prevalence estimates of Disruptive Mood Dysregulation Disorder (DMDD), differentiated from BPD, in children and adolescents using detailed phenotypic data obtained from clinical diagnostic interviews performed by child and adolescent psychologists and psychiatrists. – IN PROGRESS g) to generate precise and accurate prevalence estimates of tic disorders in children and adolescents using data from clinical diagnostic interviews performed by child and adolescent psychologists and psychiatrists. – IN PROGRESS h) to establish the reliability and validity of a self-report instrument for tic behaviors (the DoTS) compared to gold standard clinical diagnoses. – IN PROGRESS i) To examine psychiatric

treatment patterns in this subset of children and adolescents, including medication use, individual therapy (including cognitive behavioral therapy, interpersonal therapy etc.) and specialized cognitive behavioral therapy for tic disorders. – IN PROGRESS

b. Publications

- i. Leach S, Aldridge P, McKeown RE, Robertson Blackmore E, Cuffe SP. 1.56 The impact of student race and socioeconomic status on teacher ratings of student behavior: An epidemiological study. *J Am Acad Child Adolesc Psychiatry*. 2016;55(10, Supplement): S117-8.
- ii. Phillips NG, Girma MD, Leung K, Aldridge P, Robertson Blackmore E, McKeown RE, & Cuffe SP. 1.50 Effects of teacher gender on child emotional and behavioral ratings: an epidemiological study. *J Am Acad Child Adolesc Psychiatry*. 2016;55(10, Supplement): S115-6.

9. Re-PLAY 2nd Round of Testing: University of South Carolina – Kate Flory, PhD (Year 1 of 2)

- a. Specific Aims: a) to extend PLAY-MH. One of the primary objectives of PLAY-MH was to describe the prevalence and co-occurrence of internalizing, externalizing, and tic disorders among children and adolescents within a defined population. In this continuation, existing screening and diagnostic strategies have been implemented a second time within the same population, thereby yielding important information regarding the stability of prevalence estimates and quantifying changes over time. As with PLAY-MH, we will also examine mental health treatment in children with previously diagnosed mental disorders and the diversion and misuse of psychiatric medications. – IN PROGRESS

b. Publications

- i. Sicheloff, E.R., Bradley, W.J., & Flory, K. (2017). Universal behavioral/emotional health screening in schools: Overview and feasibility. Report on Emotional and Behavioral Disorders in Youth, 17, 32-38.

10. Healthy Weight Management: University of Texas – Katherine Froehlich-Grobe, PhD (Year 3 of 3)

- a. Specific Aims: a) to create an appropriate and usable adaptation of the GLB program for people with mobility impairment - COMPLETE b) to establish whether the adapted GLB program for people with mobility impairment is a feasible intervention. – COMPLETE 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 - COMPLETE

b. Publications

- i. Betts, A.C., Froehlich-Grobe, K., Driver, S., Carlton, D., Kramer, M.K. (2017). Reducing barriers to healthy lifestyle: Planned and responsive adaptations to a lifestyle intervention to serve people with impaired mobility. *Disability and Health Journal* [in press; doi: 10.1016/j.dhjo.2017.10.008. PMID pending].
- ii. Froehlich-Grobe, K., Driver, S., Betts, A.C., Carlton, D., Lopez, A., Lee, J., Kramer, M.K. Six month randomized controlled trial outcomes of the adapted weight loss program, the Group Lifestyle Balance Adapted for individuals with Impaired Mobility (GLB-AIM). *Archives of Physical Medicine & Rehabilitation* (under review).
- iii. Ryan, J., Sandon, L., Carlton, D., Froehlich-Grobe, K. Predictive equations overestimate energy needs in individuals with mobility impairment enrolled in a weight-loss program. *Journal of the Academy of Nutrition and Dietetics* (under review).

11. EMR Rare Conditions – Univ of South Carolina, Kevin Bennett, PhD, PI (Year 3 of 3)

- a. Specific Aims: a) to study MMD patients specifically, in regards to demographics, health care utilization, and health care expenditures - COMPLETE b) To incorporate a matched cohort of patients without the rare conditions (or MMD) as a comparison group – COMPLETE c) to finalize the manuscripts from all years of the project - IN PROGRESS d) Present findings at national meetings – PENDING, COMPLETED
  - b. Publications
    - i. Kevin J. Bennett, Joshua Mann, Lijing Ouyang, Melanie Gwynn. 2017. Utilizing a Combined Claims and Clinical Data Set to Conduct Research on a Vulnerable Population. *International Journal of Healthcare Information Systems and Informatics (In Press)*
12. India Biomarker surveillance: Cornell University – Julia Finkelstein, ScD (Year 1 of 1)
- a. Specific Aims: a) 1. Strengthen laboratory capacity for nutritional biomarker and birth defects surveillance at our field site; and establish the folate microbiological assay in our laboratory at St. John’s Research Institute (SJRI) – IN PROGRESS b) Conduct a pre-intervention biomarker survey to characterize the background burden of micronutrient deficiencies and birth defects in this population – IN PROGRESS c) Inform the development of a randomized efficacy trial of quadruple fortified salt for prevention of anemia and birth defects in Southern India. Status – IN PROGRESS
  - b. Publications
    - i. No publications at this time. One abstract has been accepted.
  - c. Posters and Presentations
    - i. International Congress of Nutrition Presentation: Finkelstein JL, Fothergill A, Bose B, Guetterman H, Johnson C, Bonam W.. Panel: World Health Organization guidelines on optimal blood folate concentrations to prevent neural tube defects in countries with and without folic acid fortification. Buenos Aires, Argentina 15-20 October 2017.
13. Development of Epi Tool: Research Foundation for Mental Hygiene – Prudence Fisher, PhD (Year 1 of 1)
- a. Specific Aims: a) to update a widely used epidemiologic tool, DISC-IV, to assess diagnostic criteria specified in the DSM-5 for the more common diagnoses of youth and to include “improvements” to the DISC, based on DISC-IV user feedback, data analyses, and expert opinion. This includes not only preparing the interview (DISC-5) itself, but also updating the scoring logic and algorithms, scoring manual and interviewer manual. – IN PROGRESS.

## No-Cost Extension Year

In the no-cost extension year, the Research Core will continue to support ongoing projects of the DRDC. The contract for all of the sub contracts was extended initially to the end of January, with the option to be extended additionally as needed.

Planned activities for Cycle 2 of the DRDC will be discussed in the overall evaluation for years 1 through 5 of the DRDC.

# Training and Evidence Based Core

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

*ADVANCE EVIDENCE-BASED PROGRAMS AND PRACTICES THAT PROMOTE THE HEALTH AND WELL-BEING OF PEOPLE WITH DISABILITIES OF ALL AGES AND THEIR FAMILIES.*

*TRAIN HEALTH AND PUBLIC HEALTH PROFESSIONALS.*

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

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

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

## Summary of Activities

Data related to the Administrative Core activities was compiled from the *Annual Progress Report of the Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities (a.k.a. Disability Research and Dissemination Center)*, the *Disability Research and Dissemination Center 2015-2016 Annual Report*, interviews with Margaret Turk, MD, DRDC Co-PI.

### Off-Site Fellowship Support (SUNY Upstate)

The Training and Evidence Based Core initiated the implementation of off-site fellowship training program in Year 4. The goal of the training programs has been to provide an educational curriculum to health care professionals related to disability and health.

During Year 4, the DRDC Work/Study Training Program, a fellowship for MPH students (SUNY Upstate Medical University) was initiated. Through an application and selection process, one well-qualified MPH student was to be selected to receive partial tuition support for the academic year in addition to a stipend (~20 hours/week) for his/her work in disability and health projects. During this period, the MPH student, Michael Ioerger, MS, CSCS, PhD Candidate worked on a systematic search of the economic impact of physical activity/inactivity for adults with disability and began a search to determine information about disability education for professional students and clinicians. Mr. Ioerger also helped to organize a summer learning opportunity about disability for medical students completing their first year through a PM&R summer externship. He initiated and completed a survey of medical students in all 4 years about the "self-other overlap" and its relationship to choice of working with people with disability in medical practice, as a part of a larger project. He was additionally involved in the development of CDC-sponsored continuing education (CE) modules in collaboration with the New York State Department of Health's Disability and Health Program and the Independent Living Center of the Hudson Valley. The CE modules were completed in Year 5 of the Cooperative Agreement. Mr. Ioerger received his MPH in May 2017 and is now employed by the Department of PM&R in the Disability & Health (D&H) Research Office to continue off-shoots of these and other new projects related to education and training about disability and health.

In Year 5, two more MPH students were selected to participate in the DRDC Work/Study Program at SUNY Upstate during the 2016 - 2017 academic year, Katherine Goss, BS (partial tuition plus stipend) and Jeremy French-Lawyer, BS, CAS, CHES (stipend). They both worked on the CDC sponsored webinar, along with Mr. Ioerger (Practical Recommendations for Enhancing the Care of Patients with Disability, consisting of 3 self-paced modules:

<http://www.upstate.edu/pmr/education/disability/index.php> ) and helped to expand the summer externship program for medical students by developing learning activities (e.g., journal article reviews, community-based access workshops) to complement more clinically focused experiences. As a continuation of these activities, they both were involved in a new project with the American Association of Medical Colleges (AAMC) to develop a webinar about integrating education about disability into medical school curricula (Integrating Disability into the Medical School Curriculum: Practical Strategies & Resources: <https://www.aamc.org/members/gdi/pdopportunities/483048/integratingdisabilityintomedicalschoolcurriculumpracticalstrate.html> ).

The AAMC webinar was well-received and Dr. Turk receives email questions related to this topic from medical school faculty nationally. As a part of the AAMC webinar, the successful educational materials developed for the summer program and new materials that have been developed and nationally vetted, are available on line, and are promoted by AAMC. The Association of Academic Physiatrists is now collaborating with the D&H Research Office on development of additional educational products and a national vetting process. Ms. French-Lawyer graduated with an MPH in May 2017 and has continued to work full-time in the Department of PM&R in the D&H Research office.

The MPH students, and full-time employees engaged in systematic searches. There are 2 searches and reviews nearing completion, including manuscript development, and one is in developmental stages. See below for details. A longer-term plan involves focus groups among people with disability to explore their access to or how they receive medical information. Margaret A. Turk, MD provides supervision for the fellowship program at SUNY Upstate.

## Research and Evidence-based Projects

### Systematic Reviews

The Training and Evidence Based Core completed a systematic review of the current literature regarding the measurement of healthy weight among individuals with disabilities. The manuscript for this systematic review was submitted to the CDC in Year 2 and is currently being revised and updated to focus on BMI and misuse in people with disability for determining healthy weight. With changing requirements for systematic review methodology, this topic will need to be revisited with a change to reviewer rigor documentation to be submitted for publication.

The Core also completed a literature search/review regarding hypertension epidemiology and management for people with disability, which focused on people with intellectual and developmental disabilities (IDD) as part of the Research Core activity to study the predictors of adherence to hypertension medicine during the year after a hypertension diagnosis is given to a person with IDD. Ultimately, it was determined (by the DRDC and DRE) that adherence to hypertension medication would be the focus of the study. The DRDC Research Core analyzed the South Carolina claims data for adults with IDD in Year 4. A panel presentation about hypertension in adults with IDD was accepted by American Association on Intellectual and Developmental Disability as another venue for data presentation, involving NCBDDD and DRDC professionals. The joint DRE/DRDC presentation was completed June, 2017. DRE took the lead on manuscript development, and clearance was achieved 7/2017. The manuscript has been submitted for review, and a decision is forthcoming.

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

There are 2 ongoing systematic search and review projects, and one is in development phase. The two that are nearing completion are online resources related to providing health care for people with disability and interventions to increase education about disability for medical students. The third, an assessment of how people with disability access information about health, is in development with an Upstate librarian. Strict methodologies are in place with the first two completing data reconciliation steps, and then manuscript development in December 2017.

## Expert Panels and Working Groups

There were no Expert Panels or Working Groups supported for Year 5. In conjunction with the Evaluation Core, previous activities included support to the development and implementation of the infrastructure for the Spina Bifida Collaborative Care Network (SBCCN), through a strategic planning process. This was completed in Years 2-3. See Evaluation Core for details of ongoing work on this project.

## Major Activities and Outputs

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

- I. As in previous years, only core funding was provided in Year 5

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

- I. Completed manuscripts for systematic search and review
  - a. Healthy weight systematic review for publication was submitted and is being modified based on manuscript reviews
  - b. Hypertension management in people with developmental disabilities manuscript was submitted and is under review
  - c. Economics of physical inactivity in people with disability manuscript was submitted and was accepted for publication in December 2017.
- II. Planned six future research projects
  - a. Online resources related to providing health care for people with disability
  - b. Interventions to increase education about disability for medical students
  - c. Assessment of how people with disability access information about health
  - d. Evaluating the role of self-other overlap in decisions related to working with people with disability
  - e. Exploring the ability of intervention message framing to impact self-other overlap
  - f. Focus groups to explore how people with disability receive health information, how they use online information, the need for modifications to messaging

Activity 3 [Target 4a]: Develop research fellowship

- I. Trainees were recruited and selected for the DRDC Work/Study Training Program for MPH students
  - a. Katherine Goss, BS and Jeremy French-Lawyer selected for program, and Jeremy French-Lawyer continued full time
- II. Mr. Ioerger continued work with the DRDC full-time

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

- a. As in previous years, funding was not awarded in Year 5

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

- I. Developed multiple educational and teaching materials
  - a. Three self-paced continuing education modules for physicians
  - b. Webinar presentation to AAMC faculty/deans
  - c. Online toolkit for medical school curriculum on disability
  - d. Self-other overlap projects
  - e. Teaching modules for SUNY Upstate courses



## Key Outcomes or Other Achievements

### Research and Evaluation Projects

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

### No-Cost Extension Year

In the no-cost extension year, the Training and Evidence Based Core will continue ongoing projects of the DRDC. Planned activities for Cycle 2 of the DRDC will be discussed in the overall evaluation for years 1 through 5 of the DRDC.

# 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

Data related to the Administrative Core activities was compiled from the *Annual Progress Report of the Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities (a.k.a. Disability Research and Dissemination Center)*, the *Disability Research and Dissemination Center 2015-2016 Annual Report*, interviews with Roberta Carlin, MA, MS, JD, DRDC Co-PI.

## Overall Website Visitation

In the period of September 30, 2016 to September 29, 2017 there were 2,388 users of the DRDC website. There were a total of 5,847 page views, with an average of 2.04 pages viewed per session. The average visit duration was 1 minute and 10 seconds per visitor. The visitor bounce rate was 61.78% (bounce rate refers to the number of users that visit only one page before exiting the site). There were 2,863 Sessions and 2,386 Users to the DRDC website. In Year 5, 92.4 % of visitors to the DRDC website were new visitors, while 7.6% were returning visitors (Figure 1).

1,411 users (59.01% of all users) visited the site from locations within the United States; other visitors were primarily from France and the United Kingdom. Figure 2 displays a map overlay of the geographic locations from which users visited the site between September 30, 2016 and September 29, 2017. Table 1 shows the number of users and percent of total users for each of the top twenty countries from which visits originated.

Figure 1 Percentage of New and Returning Visitors to [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org) September 30, 2016 to September 29, 2017

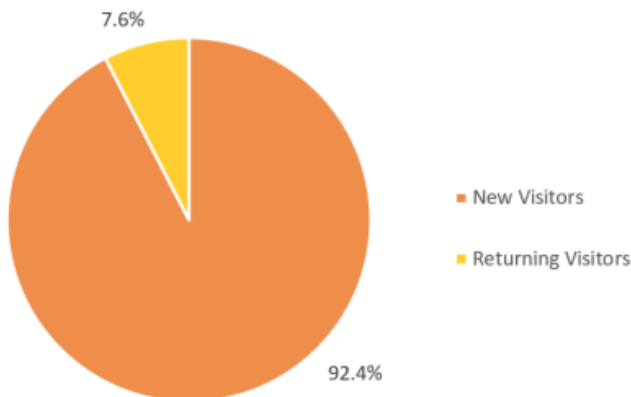


Figure 2. Map Overlay of [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org) Visitation September 30, 2016 to September 29, 2017

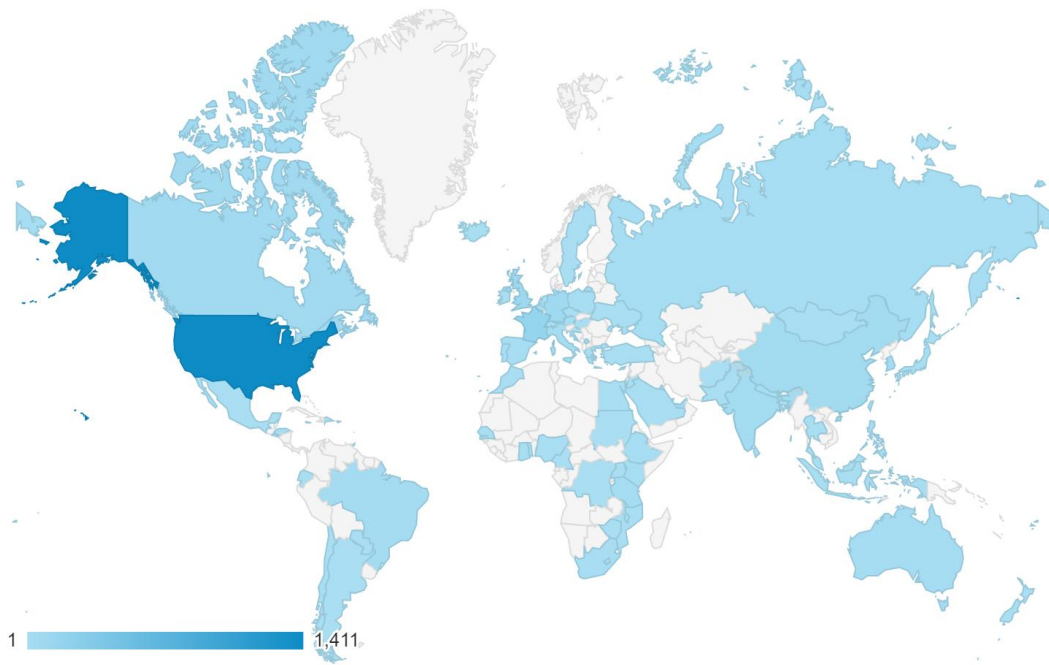


Table 1. Visitation to [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org), by Location September 30, 2016 to September 29, 2017

| Country              | Users | Percent of Total |
|----------------------|-------|------------------|
| United States        | 1,411 | 59.01%           |
| France               | 163   | 6.86%            |
| United Kingdom       | 88    | 3.68%            |
| Germany              | 75    | 3.14%            |
| Canada               | 73    | 3.05%            |
| United Arab Emirates | 64    | 2.68%            |
| China                | 56    | 2.34%            |
| (not set)            | 54    | 2.26%            |
| India                | 40    | 1.67%            |
| Brazil               | 34    | 1.42%            |
| South Korea          | 29    | 1.21%            |
| Italy                | 26    | 1.09%            |
| Austria              | 25    | 1.05%            |
| Tanzania             | 24    | 1.00%            |
| Australia            | 16    | 0.67%            |
| Philippines          | 12    | 0.50%            |
| South Africa         | 11    | 0.46%            |
| Belgium              | 10    | 0.42%            |
| Kenya                | 9     | 0.38%            |
| Russia               | 8     | 0.33%            |
| Total                | 2,388 | 100.00%          |

### Traffic Sources and Dissemination Efforts

Figure 3 shows the distribution of traffic sources for users of the website. The most common traffic source was Organic Searching traffic, at 41.73% of all users. Organic Search captures traffic related to searches for the website in browser search engines such as Google and Bing. Direct traffic was the second-largest traffic source for website users, at 32.68%. 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. Referral traffic, 21.06%, is the segment of website traffic that arrived at the DRDC website by following links contained within the websites of other organizations. Approximately 4.52% of traffic came from social media networks, with Twitter acting as the primary referral site for these users. Other social media referrals were through reddit, LinkedIn, Facebook, and Stacker Exchange.

Figure 3. Traffic Channels for Sessions at [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org), September 30, 2016 to September 29, 2017

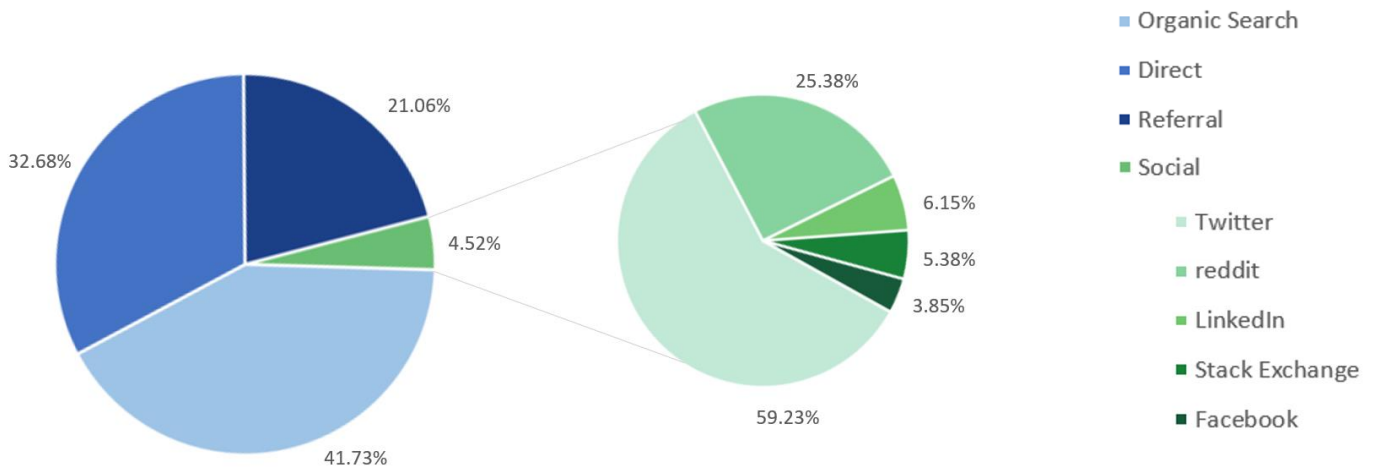
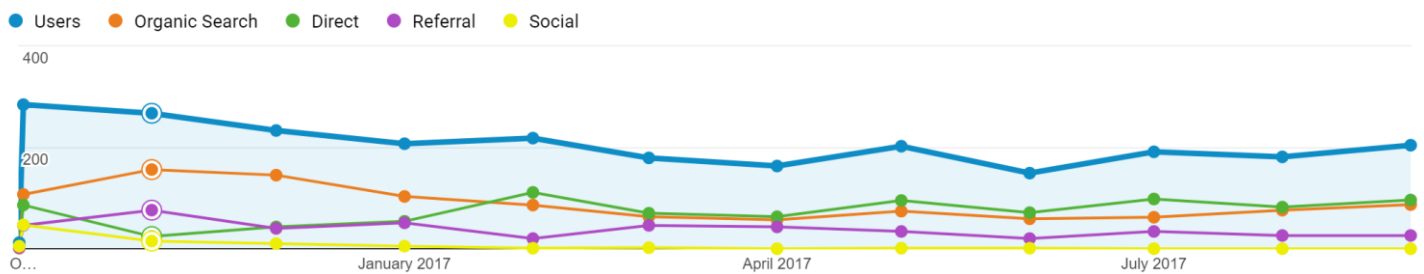


Figure 4 depicts a time trend of website visitation during the period of September 30, 2016 – September 29, 2017. The period of highest visitation fell between October and November, 2016, with approximately 300 website users at the highest point in user traffic in October. The lowest period of visitation was June 2017, with approximately 175 website users in that month.

Figure 4. Time Trend [www.disabilityresearchcenter.org](http://www.disabilityresearchcenter.org) Monthly Visitation by Channel September 30, 2016 to September 29, 2017



While Twitter was routinely used throughout Year 5, the largest volume of Tweets were disseminated during October and December 2016, and January of 2017. In year 5 the DRDC gained 2,503 new followers. Figure 5 shows the number of Tweets in Year 5, while figure 6 shows the number of Twitter Impressions.

Figure 5. Volume of Twitter Dissemination Efforts, October 2016 to September 2017

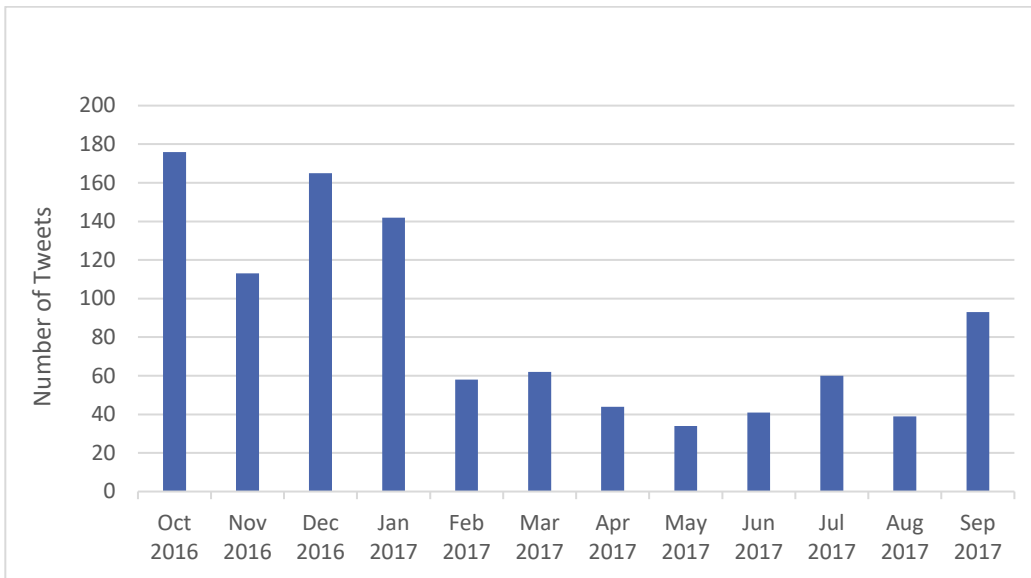
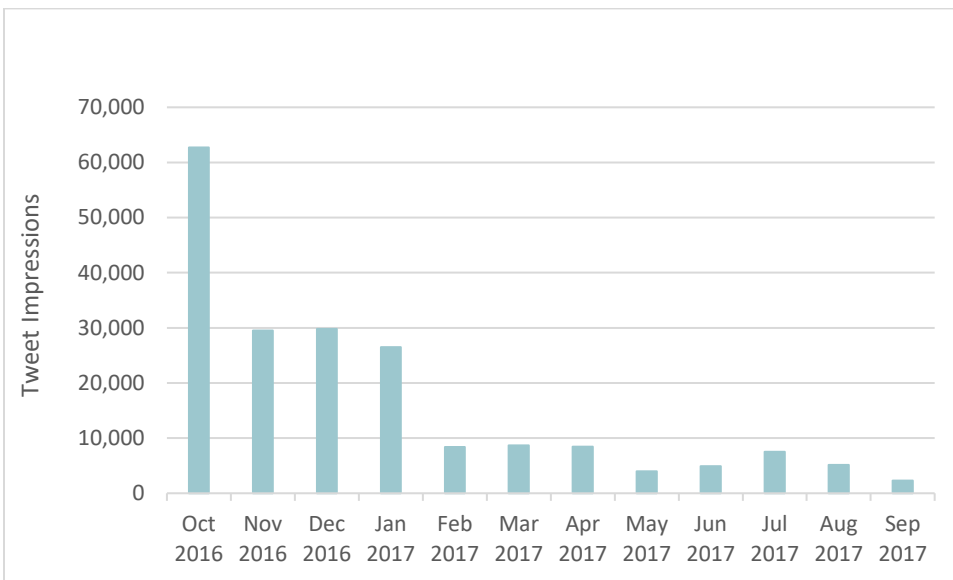


Figure 5. Number of Twitter Impressions, October 2016 to September 2017



### Stakeholder Network and Coalition Meetings

The Dissemination Core participates in and provides technical assistance for semiannual conference calls and other communication efforts between the DRDC leadership and EAC. The Dissemination Core engages the EAC and other external partners through the weekly distribution of the Disability and Health in the News newsletter, which provides updates on current DRDC projects and activities.

During Year 4, the Dissemination Core worked with the Training and Evidence Based Core on the exploration of a Disability Medical Health Home. The Public Policy Director for AAHD, Dr. Clarke Ross, is a member, National Quality Forum (NQF) workgroup on persons dually eligible for Medicare and Medicaid and NQF population health task force (<http://www.qualityforum.org/>) (July 1, 2012-June 30, 2018) and NQF representative of the Consortium for Citizens with Disabilities (CCD) Task Force on Long Term Services and Supports (<http://www.c-c-d.org/>).

In 2014-2015 and 2015-2016, Dr. Ross served as the NQF duals workgroup liaison to the NQF PAC/LTC (PostAcute Care/Long Term Care) workgroup. Additionally, Dr. Ross closely monitors the following NQF committees and workgroups: care coordination, disparities, health-and-well-being, person-and-family-centered, home-and-community-based services and supports, MAP (Measure Applications Partnership), Medicaid children, Medicaid adults, and socio-economic status and reports back to NCBDDD, DHDD leadership/staff and DRDC Project Officer on initiatives of importance to NCBDDD. Dr. Ross also provides feedback to NQF committees on NCBDDD and DRDC activities and initiatives.

The DRDC, NCBDDD, and AAHD has worked to maintain a presence at NQF and other national coalition meetings to discuss NCBDDD research and policy priorities during all five years of the project. The Dissemination Core highlighted the DRDC project through AAHD staff involvement in the Friends of NCBDDD coalition, through newsletter updates, list serve updates and webinar presentations. In Years 4 and 5, the Dissemination Core also supported funding for content experts to attend the David Smith Workshop at Greenwood Genetics Center in Columbia, SC.

The Dissemination Core continued to update and maintain the NCBDDD Scientific Knowledge Repository. The knowledge repository has been updated to integrate research conducted by the DRDC and NCBDDD with existing and emerging literature. Disability Health Journal publications from 2008 to 2017 have been updated in the repository, which includes a database of notable publications from the DHDD over the past six years. The repository is currently housed on the AAHD website and links with the DRDC website.

Data related to the Administrative Core activities was compiled from the *Annual Progress Report of the Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities (a.k.a. Disability Research and Dissemination Center)*, the *Disability Research and Dissemination Center 2015-2016 Annual Report* and interviews with Roberta Carlin, MA, MS, JD, DRDC Co-PI. Other data was collected from Google Analytics.

## Major Activities and Outputs

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

- I. Continued 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
- III. Establish more regular social media presence outside of research solicitation season
  - a. Utilized HootSuite and Buffer platforms to facilitate social media campaign

Activity 2 [Target 5b]: Organize stakeholder network

- I. Continued stakeholder engagement to encourage dissemination of NCBDDD research opportunities and findings
- II. Weekly newsletter electronically distributed to roughly 9,000 - 10,000 stakeholders
- III. Highlighted the DRDC project through AAHD staff involvement in the Friends of NCBDDD coalition and through newsletter and listserv updates and webinar presentations

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

- I. Continued attendance at coalition and stakeholder meetings

Activity 4 [Target 5d]: Provide technical assistance

- I. Continued support of other Core groups on targeted projects
- II. Continued to support website management
- III. Supported funding for content experts to attend the David Smith Workshop at Greenwood Genetics Center in Columbia, SC
- IV. Provided support for semiannual conference calls and other communication efforts between the DRDC leadership and EAC

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

- I. Continued to update and maintain the NCBDDD Scientific Knowledge Repository
  - a. Included a new database of notable publications from the DHDD over the past six years
  - b. The knowledge repository has been updated to include notable publications from Year 5

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

- I. Clarke Ross, DPA, membership on NQF workgroups
  - a. Distributed 153 memos on NQF work and reports for CDC NCBDDD leadership staff
  - b. Monitored 9 NQF workgroups
  - c. Provided feedback to NQF committees on NCBDDD and DRDC activities and initiatives
  - d. Participated in NQF workgroup meetings

## No-Cost Extension Year

In the no-cost extension year, the Dissemination Core will continue to support ongoing projects of the DRDC. The primary focus of the Dissemination Core is the beginning of Cycle 2 activities.

Planned activities for Cycle 2 of the DRDC will be discussed in the overall evaluation for years 1 through 5 of the DRDC.

# 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

### Annual Evaluation

During Year 5, the progress of the DRDC for the previous year was evaluated under the direction of Dr. Telisa Stewart, PhD, of SUNY Upstate Medical University. The performance of the DRDC website was evaluated through the use of Google Analytics (see Dissemination Core section). 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.

### Spina Bifida Association Project

The Evaluation Core (Dr. Chris Morley) and the Evidence Based and Training Core (Dr. Margaret Turk) have continued to work with the Spina Bifida Association of America (SBA) to conduct a pilot survey and begin planning for a nationwide survey of adults with Spina Bifida. This project is an outgrowth of previous work with the SBA, described in the 2013 – 2014 Annual Evaluation Report. Data collection for the SBA survey continued into Year 5 of the Cooperative Agreement. During Year 5, research questions were explored and data analysis was conducted. Very initial information was reported at the Spina Bifida Association Annual Meeting in June 2017. An abstract using a small portion of the data, “Access to Usual Source of Care in US Adults with Spina Bifida,” was accepted by the North American Primary Care Research Group, and presented in November 2017 by Dr. Morley. Manuscripts are in progress, in association with the Spina Bifida Association and select members of the Advisory Board for the National Spina Bifida Patient Registry. As noted, these activities were funded and conducted under a separate agreement with the Spina Bifida Association, but are included here as an outgrowth of Year 2 DRDC activities.

## Major Activities and Outputs

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

- I. Conducted annual internal evaluation of DRDC performance in target areas
- II. Planned survey for EAC and external partners for quality improvement purposes for Cycle 2

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

- I. Continued ongoing support to Research, Training and Evidence Based, and Dissemination Core groups
- II. Continued Adult Spina Bifida survey project
  - a. Data analysis was conducted
  - b. Initial findings presented at the Spina Bifida Association Annual Meeting in June 2017
  - c. Abstract accepted by the North American Primary Care Research Group, and presented in November 2017 by Dr. Morley



- d. Manuscripts in preparation for journal submission

### No-Cost Extension Year

In the no-cost extension year, the Evaluation Core continued the evaluation of the DRDC, and began the evaluation process for the five years overall. Evaluation for Cycle 2 was also planned, and will continue.

Planned activities for Cycle 2 of the DRDC will be discussed in the overall evaluation for years 1 through 5 of the DRDC