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Impact and Sustainability Evaluation

April 2011

WellFlorida Council

Working Together for Healthy Communities

Florida Office on Disability and Health: Impact and Sustainability

Evaluation report

April 2011

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Executive Summary

Florida Office on Disability and Health (FODH) is one of the 16 state level programs in the country funded by CDC to inform policy and practice at the state level. FODH has established an extensive partnership, organized annual meetings for networking and discussion on strategic planning in disability and health issues and implemented three modules—The Right to Know Campaign-**Module B**; Training Professionals and Paraprofessionals in Disability-**Module E**; and Supplemental Surveillance-**Module F**.

The focus of this evaluation is to gauge the impact of FODH activities and to summarize the sustainability measures undertaken in Year 4 (2010). The evaluation elements included (1) web-based survey of entire FODH partnership to gauge impact of its activities and reach of its partnership (2) phone-based structured interviews of key partners (3) review of FODH activity reports. These data sources were utilized to assess evidence of collaborative work, technical consulting, educational trainings/workshops, materials and data disseminated through FODH; summarize the sustainability measures undertaken by FODH and garner recommendations from the Partnership on potential sustainability measures for FODH.

Each module of FODH has contributed to creation of newer partnerships and enhanced resources for improving the quality of life for persons with disabilities in Florida. The Right to Know Campaign—Module B has been **successfully launched in all the 67 counties of Florida** and has established partnerships with organizations that work in the area of disability, breast health and aging, and health care facilities throughout the state. The **RTK staff has traveled across the state and tabled events at public expos** to increase awareness of people about breast cancer in persons with disabilities. It has **published a Mammography Accessibility Resource Guide** providing information to women about the accessibility of mammography facilities in their area/county in order to help them both select where to make their appointments (if they have a choice), and prepare for their visit based on the accessibility factors. **Analysis is underway using data from the Behavioral Risk Factor Surveillance System (BRFSS) to compile reports on breast cancer screening behavior among Floridian women**. In addition **work is underway to develop** more demographic and health care access **questions** that will enable the RTK staff **to track screening rates and changes in screening behavior**, both statewide and by county, and to elucidate possible outcomes of the Right To Know campaign in counties where dissemination activities have occurred. The RTK campaign is **tracking the dissemination of its materials** as well as **qualitative data on how the materials are being utilized** by partners to find **ways to additionally engage and support partners, describe barriers or facilitators associated** with the dissemination activities, and aid in understanding their reactions and receptivity to the material's content. An **outcome evaluation will be internally conducted by RTK team** to identify and document the extent to which knowledge and awareness of mammography screening has changed among women who received RTK campaign materials, and to describe self-efficacy and health seeking behavior associated with obtaining a mammogram among women who received RTK campaign materials. The RTK campaign has worked on the **establishment of campaign partner organizations that have designated personnel assigned to the campaign** promotion and buy-in due to their missions, which encompass disability support and breast cancer education/screening. The **materials are available digitally and are ready to be reproduced and published beyond the grant period**. To increase the involvement of the partnership, the **campaign team is also exploring additional sustainability strategies such as designating one of the statewide partners as the new campaign liaison for the CDC**. It is expected that year 5 of the Right to Know campaign will be devoted to activities aimed at ensuring its sustainability in Florida beyond Year 5.

Training professionals and paraprofessionals in disability—Module E has **developed a one-hour disability training course for healthcare providers** and **work is underway for a second training** module focused on developmental disabilities to develop a film featuring people with developmental disabilities, family members, and healthcare providers. **An advisory panel** of Florida leaders in disability and health education has been formed **to consult on the continuing education in disability training**. The **training content will be revised at least once a year** to keep it current and to reflect feedback from the advisory panel and training participants. This panel will play a crucial role in dissemination efforts and sustainability planning in years 4 and 5. **Free online CME/CEU courses** for 1 credit hour have been arranged through the **Area Health Education Centers** to offer continuing education credits for physicians, nurses, and mental health providers for this training. Module E is striving to collaborate with the **continuing education office at CDC** to make these online trainings nationally available. Module specific **evaluation** was **conducted** by a team leader **to measure change in medical student's attitude toward people with disabilities, comfort level providing care to patients with disabilities and disability knowledge. Significant gains were found in all three measures.** As part of the curriculum, medical **students conducted home visits with volunteers who have disabilities** and have turned in reflection papers that show that **students are learning very valuable lessons in humility, respect and consideration of the rights of persons with disabilities** to comprehensive quality of care. An **evaluation plan has been designed for the training of the healthcare providers** by the Project Coordinator. **Module specific sustainability plans** are underway and disseminating the training through **the continuing education office at CDC will make the training resources and certification to national** audiences. The **web-based trainings will be hosted on Nisonger center's website** (The principal investigator is affiliated with this center) to enhance nationwide access to training opportunities.

Supplemental surveillance-Module F has **enabled quantification of risks and outcomes of interest** across populations. **During 2008, 13 questions collected information from Florida adults on their experiences with caregiving** and about people they provide care for. **During 2009, 9 questions were added to BRFSS on access to healthcare** for people with disabilities. **During 2010, the focus was to collect disability attitudes/perceptions data** through 8 questions; in 2011 five questions will be added to BRFSS to analyze Visitability. **The partners have commented that the data have assisted them in evidence based program planning, resource allocation, and pursuing newer grant resources where needed**. The surveillance module has made all its reports available on the FODH website as well as disseminated them to the partnership. The **data has been used to inform the annual recommendations and policies of the Governor's Commission on Disabilities**. The FODH also **works with agencies to develop their capacity to analyze BRFSS data** when possible using CDC's new Web-Enabled Analysis Tool (WEAT) for the BRFSS. FODH also is **available to contract with partners for larger data collection projects and provide expert testimony** to the Governor's Commission on Disabilities and the Governor's Commission on Autism. The FODH director served on the Institute of Medicine's committee on The Future of Disability in America. The FODH **has applied for and been awarded a number of related grants and contracts** to extend its work on disability and health issues.

The web-survey of the partnership shows that the **partnership organizations are a diverse mix of organizations from at least 50 of the state's 67 counties** speaking to the evidence of the broad reach of the FODH partnership. **Partner organizations described their association** with FODH as (**30.4%**) *Share information only (**Communication**)*, **14.5%** described their relationship as *Work together as an informal work group to achieve common goals (**Cooperation**)* and an equal number (**13%**) said they *Work together as a formal team to achieve common goals (**Collaboration**)* **or** said they *work together as a formal team across multiple projects to achieve common goals (**Partnership**).* An additional **29%** reported that they did not work together at all (**Unlinked**). At least **70% respondents agreed about the effective functioning of FODH**. At least two-thirds of respondents (60%) agreed that *FODH effectively*

provides technical assistance as needed and a third (30%) were undecided with the statement. It is possible that the respondents choosing "undecided" are unaware of these functions of FODH and therefore unsure about their effectiveness. **Between 38% and 48% respondents were not aware of the specific modules.** At least another third were aware of the modules but had not utilized them. More respondents had shared the module materials or recommended them to others than having utilized it themselves. **Overall, the FODH has had a great impact on enhancing the quality of life for persons with disabilities in the state of Florida within a short span of 4 years. It has developed a rich network of partner organizations, transferred skills, developed newer resources, inspired collaborative work and brought the disability community together to make lasting contributions that have been widely appreciated by the stakeholders.** Each module has specific evaluation plan that adds to the credibility and effectiveness of the Office on Disability and Health. Each of its modules has begun taking steps towards sustainability of the program after the end of initial grant period.

Interviews with key partners compared the nature of resources that existed in the disability arena before the existence of FODH and how having FODH had made any difference to the opportunities, services and resources available in the disability arena. The interviews gauged key partner's perceptions about the impact of collaboration with FODH on the direct working, resources, activities and policies of each organization and solicited their feedback for future improvement in FODH as well as development of a sustainability plan for FODH in near future. **Creation of FODH as a comprehensive statewide disability organization was thought to have enhanced the capacity of disability organizations to see overlapping issues across disabilities and partner with each other for common goals.** As a central independent organization, FODH was said to have helped pool resources and give increased visibility to disability issues in public health arena. **Creation of FODH was perceived as a capacity building measure for the disability community in Florida.** Partner organizations acknowledged that FODH has **created very valuable resources through the three modules** and helped in bringing disability to the forefront. FODH was considered by all its partners as a **credible source of information** on account of the quality data generated and its **ability to balance the role of academicians with that of community based stakeholder-focused work through its modules** for healthcare professional education and Right to Know campaign. While most partners thought that the data generated through FODH can **potentially help channel more funding for their programs**, they commented that it was difficult to keep track of such an increase based on data used to justify need. Partners agreed that their collaboration with FODH had **enhanced their organizational capacity as well as strategies adopted, activities undertaken and services provided**. Partners were aware that FODH is a grant funded project and acknowledged that CDC grant award funds will end at some point and **expressed willingness to take on a few elements of the FODH functions** as their own. It was suggested that partner agencies could **incorporate some aspect of FODH strategic plan element into their organizational plan** to ensure uniform focus and policies across the state. It was observed that **partners could help by collecting and disseminating raw data to other agencies** identified by **FODH**. It was suggested that the **training for providers and law enforcement** as well as the **Right to Know Campaign materials can be housed on partner websites**. Partners expressed **willingness to participate in sustainability initiatives** and suggested that FODH can bring partners together to discuss the same.

Anticipating future needs for sustaining the program is challenging. However, FODH will need to take steps to **anticipate needs for integration of its program elements into the Universities, law enforcement agencies, state departments, community based organizations**, etc. and take steps to facilitate such an integration. A great step has been FODH supporting 50% of a position within the Bureau of Chronic Disease Prevention and Health Promotion to better integrate disability into the state's activities. **Partners have indicated willingness to participate in sustainability planning**. This is an excellent opportunity for FODH as high participant morale is a sign of their commitment to the goals of

the organization beyond its grant period. FODH should include sustainability as a topic in all its partnership calls and conferences. To ensure sustainability of the FODH, staffing structures that can work on **integrating elements of the current program into partner organizations** will be crucial. One step in this direction has been taken by RTK campaign by designating one of the statewide partners as the new campaign liaison for the CDC. The training of healthcare providers may be added to CDC's continuing education courses making it available long after the grant goes away. Something similar could be done for data surveillance module by integrating aspects of it into state health department or another such state entity which can make the data available to partners for analysis. It may be noteworthy that each partner organization has nominated one staff member to the partnership. **Due to staffing limitations, the partner organization may have had limited opportunity for direct interaction** (annual meeting, partnership phone call) with FODH. It might be prudent to **ask the partners to designate an alternate contact whenever possible.** At least 70% respondents agreed (Strongly agree/Agree) about the effective functioning of FODH and nearly a third of Partners rated the effectiveness of some of the FODH functions as "undecided". 47.9% indicated that they were not aware of the surveillance module. From among these, nearly half, 47.6% (n=10) had been a partner for less than a year, 56.5% (n=13) had no contact with FODH in the past year and 81.8% (n=18) had never attended a partnership call. While FODH does update its Partners about its activities through partnership calls and newsletters, it may want to consider showcasing its achievements and partner collaboration results at the annual meeting to address this issue in the future. FODH can also **conduct a periodic survey of partnership members and direct its awareness, dissemination and outreach activities at those members that are new and/or who have not attended any partnership calls or annual conferences**. A periodic survey of partners to ascertain any benefits they may have gained as a result of their collaboration with FODH be helpful in evaluating the impact of a capacity building project such as FODH. This evaluation may include assessing grant awards, recognitions, paper publications, increases in use of disability graphics, etc. as a result of FODH activities such as data reports.

Overall FODH has made a great impact on statewide programs that include health promotion activities and surveillance of health disparities with specific reference to disability. It will be interesting to study and learn from other 15 statewide disability offices about the impact and sustainability measures of CDC grant activities in each state. The strength of FODH and its accomplishments have been amplified through its successful partnerships at local, regional, state and national level.

Introduction

Florida Office on Disability and Health (FODH) is one of the 16 state level programs in the country funded by CDC to inform policy and practice at the state level. The programs include health promotion activities and surveillance of health disparities. While each state program is different, they ensure that individuals with disabilities are included in ongoing state disease prevention, health promotion, and emergency response activities. As such the FODH has established an extensive partnership, organized annual meetings for networking and discussion on strategic planning in disability and health issues and implemented three modules—The Right to Know Campaign-**Module B**; Training Professionals and Paraprofessionals in Disability-**Module E**; and Supplemental Surveillance-**Module F**.

The focus of this evaluation is to gauge the impact of FODH activities and to summarize the sustainability measures undertaken in Year 4 (2010). The evaluation plan consisted of the following activities:

- Web-based survey of entire FODH partnership to gauge impact of its activities and reach of its partnership
- 30 minute phone-based structured interviews of following key partners to assess impact and sustainability of FODH activities:
  i. Governor's Commission on Disabilities
  ii. Agency for Persons with Disabilities
  iii. Bureau of Chronic Disease Prevention and Health Promotion, Florida Department of Health
  iv. Department of Elder Affairs
  v. Florida Center for Inclusive Communities, University of South Florida (USF)
- Document review of FODH activity reports to assess value of FODH, its modules and their activities to statewide partners. Evaluate reports for evidence of collaborative work, technical consulting, educational trainings/workshops, materials and data disseminated through FODH.
- Summarize the sustainability measures undertaken by FODH and garner recommendations from the Partnership on potential sustainability measures for FODH.

Table 1: Evaluation timeline

WHAT?	WHEN?	WHO?
Development of web-based survey	Before September 30, 2010	WellFlorida Council
Data collection: survey	October 1—29, 2010	WellFlorida Council
Development of key-informant interview guide	Before October 18, 2010	WellFlorida Council
Conducting interviews	Before October 29, 2010	WellFlorida Council
Preparation of module reports and other FODH activity reports	Before November 4, 2010	FODH
Data analysis, report writing	Before December 4, 2010	WellFlorida Council
Submission of preliminary draft	December 8, 2010	WellFlorida Council
Initial comment/review period	Until January 31, 2011	FODH and partners
Revised draft of evaluation report for further review	Before February 28, 2011	WellFlorida Council
Final review	Before March 14, 2011	FODH and partners
Final report	April 1, 2011	WellFlorida Council

An overview of tasks accomplished under each module, impact achieved and sustainability measures planned are described below:

THE RIGHT TO KNOW CAMPAIGN- Module B

The goal of this campaign is to raise awareness about the importance of breast cancer screening, and encourage recommended screening among women who are forty years and older, and living with a physical disability in Florida.

In Florida, by the end of 2010 over 14,000 women were predicted to be diagnosed with breast cancer, resulting in roughly 2,650 deaths. Increased and regular use of early detection measures along with enhanced treatment options have been attributed to improved breast cancer survival rates. Still, many women living with physical disabilities are significantly less likely to have been screened with the recommended guidelines, than women without disabilities[1].

This is a significant public health concern in Florida as nearly 1 in 5 women in the state are living with at least one disability. Low or inconsistent screening rates put these women at a risk for late-stage diagnosis and poor health outcomes. To address this issue the CDC created the Right to Know (RTK) campaign (which includes health promotion materials – such as posters, flyers, print ads, tip sheets, and MP3 audio files) designed to increase awareness of breast cancer among women with physical disabilities and encourage regular screening. This new campaign is being implemented in four US states, including Florida from 2007 to 2012. Through the Florida Office of Disability and Health, Allyson Hall, PhD, an Associate Professor in the Department of Health Services, Research, Management and Policy at University of Florida and Eva Egensteiner, MA, CPH, Health Communication Specialist are leading this collaborative effort.

Target Audience

The target audience for this campaign is women forty years of age and older, residing in Florida, who are living with physical disabilities, and are English or Spanish speakers. The campaign has also reached women with other types of disabilities (cognitive, sensory) through the translation of campaign materials and by acquiring additional breast health materials. Some materials have also been translated into Haitian Creole.

Objectives

1. To increase knowledge about breast cancer screening among women living with physical disabilities, health care providers and the larger community;
2. To build capacity among partners to disseminate health information about breast health screening to and for women living with physical disabilities; and
3. To provide accurate information about mammography facility accessibility and other factors that impact accessibility to breast health care.

Strategies

1. Leverage existing partner networks and events to promote the RTK campaign and disseminate campaign materials and messages. Set the stage for buy-in from the partners' affiliate offices throughout the state.

[1] Right to Know campaign module: summary and activity report prepared by Eva Egensteiner, November 4, 2010

2. Use local media outlets (including Television, Radio, Web and local newspapers) to generate interest in the RTK campaign, and bring broad attention to the issue of breast cancer screening for women living with physical disabilities.
3. Augment campaign materials with local information on mammography sites (including location and accessibility), transportation options, and other important breast health information; and
4. Organize and attend breast health and disability events, and hold special dissemination pushes during the month of October (in addition to specific regional launch months) to generate broad attention to the campaign.

Proposed activity timeline

The state of Florida was divided into 4 regions for the purpose of staggering the launch of the campaign throughout the state during the 5-year project.

I. 23 North Florida Counties (Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Hernando, Lafayette, Lake, Levy, Marion, Putnam, Sumter, Suwannee, Union, Baker, Clay, Duval, Flagler, Nassau, St. Johns, Volusia)

II. 18 Florida Panhandle Counties (Bay, Calhoun, Escambia, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Okaloosa, Santa Rosa, Taylor, Wakulla, Washington, Walton)

III. 16 Central Florida Counties (Pasco, Hillsborough, Pinellas, Polk, Orange, Seminole, Osceola, Brevard, Manatee, Sarasota, Hardee, Desoto, Highlands, Okeechobee, Indian River, St. Lucie)

IV. 10 South Florida Counties (Charlotte, Glades, Lee, Hendry, Collier, Monroe, Martin, Palm Beach, Broward, Miami-Dade)

Years 1 and 2

As the CDC-developed health communication materials had not yet been approved and released during the first two years of the campaign, the initial efforts focused on the development of a comprehensive dissemination and implementation plan; forging campaign partnerships (statewide, regional and county level); campaign presentations within Florida to develop partners; meeting with CDC staff and researchers; attending /participating in FODH and CDC meetings and conference calls; research and development of a Florida mammography facility accessibility survey tool with the goal of producing resource guides for women with disabilities; publication of transportation guides for women needing ride services; and the development and acquisition of supplementary breast health materials from other organizations /centers to reach women with other types of disabilities. Work on developing the website for Florida Right to Know began in this period.

Year 3

After the CDC printed campaign materials were delivered in June 2009 (year 3), the RTK campaign was launched in 41 counties in northern Florida (23 North Florida and 18 Panhandle counties).

Year 4

The RTK campaign was launched in 16 counties in Central Florida in April of 2010, and in 10 South Florida counties in October of 2010. At the time of this preliminary evaluation draft, the campaign has been launched in all 67 counties of the state.

Campaign partnerships

The number of partnerships is continuously evolving with 40 primary partner offices and about 20 secondary partner organizations/offices throughout the state of Florida as of November 2010. The campaign focused on partnering with primary statewide partners that have multiple regional affiliate offices that serve 1 or more counties; as well as the secondary partnerships with organizations that work in the area of disability, breast health and aging, and health care facilities throughout the state.

Primary state-level partnerships

16 Florida Centers for Independent Living and 10 satellite branches; 16 Florida Breast and Cervical Cancer early Detection Program offices within county health departments and 6 Susan G. Komen for the Cure affiliate offices constitutes the primary state-level partnership. Each of these partners has offices in North, Central and South Florida regions.

Secondary partnerships

The Brain and Spinal Cord Injury Program (serving entire state); Lighthouse Central Florida (servicing entire state); Florida Breast Cancer Foundation (serving primarily South Florida); Florida Area Agencies on Aging (serving entire state with 11 offices in Florida); Moffitt Cancer Center (serving entire state); MammaCare (international agency, based in Gainesville); Rural Women's Health Project (based in Gainesville, outreach in several counties); and Multiple healthcare/mammography facilities constitute the secondary partnership.

Tasks accomplished

Year 1 and 2

As noted previously, primary focus of Years 1 and 2 was **development of statewide partnerships**. As such the **RTK materials were showcased** and prior **research supporting the campaign's need were presented** at the statewide meeting of Florida Breast and Cervical Cancer Early Detection Program coordinators at the Florida Department of Health in Tallahassee. A co-presentation was made with CDC to over 20 potential regional campaign partners and showcased RTK campaign materials as well as **reviewed public health significance of the campaign**. In January 2009, RTK was presented at the 10th Statewide Audio-conference on Best Practices in Women's Health, organized by the Women's Health Program, Florida Department of Health, which was attended by over 50 participants.

Year 3

During Year 3 the **RTK was launched in 41 counties** in the state. In July 2009, **RTK had a table at the (Americans with Disabilities Act) ADA Celebration**/Expo in Gainesville and distributed materials to people with disabilities and service providers. In August 2009, **the RTK campaign was presented to health educators** from within and outside of the health department as part of a Moffitt Cancer Center organized presentation at the Alachua County Health Department. In October 2009 the **campaign was promoted to 3 state level departments** at the Florida Department of Health, Bureau of Chronic Disease Prevention and Health Promotion, including: Breast and Cervical Cancer Early Detection Program; Comprehensive Cancer Control Program; and Healthy Communities, Health People Community Based Program. The RTK team also participated in the Spirit of the ADA Expo held in Jacksonville. A similar opportunity was made available at the November 2009 Alachua County Health Department CHOICES health fair (CHOICES is a county-funded health services program offered by the Alachua County Board of Commissioners for working uninsured residents in the county). Tabling was also undertaken at the February 2010 National Marathon to Finish Breast Cancer Expo, Jacksonville, and the Dream Society

Expo "On Our Own", in Citrus County. Throughout the year, **roughly 120 mammography facilities received information about the Right to Know campaign** as part of Mammography Accessibility Survey (described below). A **Mammography Technologist Tip Sheet was developed** to provide disability – specific information to mammography facilities. This material has been used widely by the Florida Right To Know team, as well as by the other states. **Transportation guides were developed** for North Florida counties to provide information that can help women get to their breast health exams and other medical visits. These are available on the campaign website (http://www.rtk.phhp.ufl.edu/campaign/).

Year 4

With Year 4, the **campaign was launched in the remaining 26 counties** across the state. The events attended or organized by Florida Right To Know staff included:

- *June 2010 Florida Association of Independent Living Annual **statewide conference**:* Roughly 50-60 people attended, which included the statewide director, and employees from 16 main offices and 10 satellite offices of Centers for Independent Living. Many of the directors and staff members are living with disabilities.
- *July 2010 ADA Celebration/**Expo**, Gainesville:* Roughly 100 people living with disabilities and disability service providers attended this event.
- *July 2010 **ADA Anniversary Celebration** at the Suncoast Center for Independent Living, Sarasota:* Roughly 60 people living with disabilities and disability service providers attended this event.
- *July 2010 **Disability Awareness Day** in Tampa, hosted by the Alliance for Citizens with Disabilities in Hillsborough County:* Roughly 1000 people living with disabilities and disability service providers attended this event.
- *A **RTK staff member was featured in April 2010 Comcast Cable Television series** produced by the Center for Independent Living in Jacksonville, where she discussed the Right To Know as one of 2 guests during a 30 minute program that airs four times in 3-4 counties:* While the RTK staff was unable to determine the number of people that viewed this program, but they estimated estimate that between 1000 – 2000 people viewed this program for the following reasons: 1) it aired 3 times in 4 counties, including the highly populated Duval County; 2) the other guest was a prominent breast cancer surgeon at the regional hospital; and 3) the program was promoted by the Center for Independent Living in Jacksonville on their website and in their newsletters.
- *In June 2010, a RTK **presentation was organized for community members** in Gainesville through the Shands Eastside Community Relations and Education Program:* 15 African American women attended this event from the community. RTK staff could not determine what proportion of these women had any form of disabilities.
- *Similar presentations were organized in September 2010 at the Self-Reliance Center for Independent Living, Tampa:* Roughly 20 women attended this event, including mostly women living with disabilities, but also several breast health educators from Moffitt Cancer Center, and a disability and health researcher from the Florida Center for Inclusive Communities of the University of South Florida.
- *October 2010 at Center for Independent Living of Central Florida, Winter Park/Orlando:* Roughly 15 women attended this event, including mostly women living with disabilities.

The RTK staff was tracking information regarding the events and activities carried out by its campaign partners in Year 4. This data was still in the process of being collected and entered when this evaluation report was being written. Throughout Year 4, **roughly 380 mammography facilities received**

information and materials about the RTK as part of its Mammography Accessibility Survey. Additional **campaign materials** were **developed**, such as an **Accessibility Tip Sheet** to provide additional disability-specific information to medical facilities. The women's tip sheet was also **translated into Haitian Creole**, as well as transcribed and **reformatted for low-vision readers in English, Spanish and Haitian Creole**. **Transportation guides** were being developed **for Central and South Florida counties** and will be made available on the campaign website. **A county-searchable web-based database of breast health programs** (for screening, funding opportunities, etc.) was also under development as this report was being written.

Mammography Accessibility Resource Guides

The Florida Right To Know team recognized the importance of **providing information to women about the accessibility of mammography facilities in their area**/county in order to help them both select where to make their appointments (if they have a choice), and prepare for their visit based on the accessibility factors. **Year 2 focused on the research and development of the survey tool** with input from previous studies that team members participated in, existing literature and *mammography accessibility survey* tools and guides from other states. In **Year 3, the survey was implemented** by telephone with roughly 120 facilities in North Florida. **Information gathered with the survey tool was converted into Mammography Accessibility Resource Guides**. These were **published in both English and Spanish**. Each guide contains an updated list of facilities by county, followed by a one page summary for each facility (that elected to participate) and includes: the facility information; hours of operation; a small map to assist with navigation; and a check list of 10 items that were determined to be most useful. These **guides are available on the campaign website** in downloadable Acrobat format and were distributed to campaign partners and stakeholders besides being handed out at presentations and health/disability events. **In Year 4, the survey was mailed to roughly 180 Central Florida and roughly 200 South Florida facilities** with a nearly 30% response rate. The RTK team plans to contact the non-responding facilities in an effort to increase the response rate. The team is also looking into other dissemination options to make the findings available through additional resource guides in various formats.

BRFSS Reports

The RTK team is **currently working with data from the Behavioral Risk Factor Surveillance System (BRFSS) to compile reports on breast cancer screening behavior** among Floridian women. In addition work is underway to develop additional demographic and health care access questions that **will enable the RTK staff to track screening rates and changes in screening behavior**, both statewide and by county, to elucidate possible outcomes of the RTK campaign in counties where dissemination activities have occurred. More specifically, these reports will be generated from the 2007, 2008 and 2010 data. No breast cancer screening questions were included in the 2009 survey. For both the 2007 and 2010 surveys, county level data were collected, while the 2008 survey collected statewide data only. The **reports from the 2007 and 2008 data have been completed**. The report from the 2010 survey is projected to be completed between August and December of 2011 (pending release of the data).

The relevant BRFSS questions are as follows:

1. A mammogram is an X-ray of each breast to look for breast cancer. Have you ever had a mammogram?
2. How long has it been since you had your last mammogram?
3. A clinical breast exam is when a doctor, nurse or other health professional feels the breast for lumps. Have you ever had a clinical breast exam?

4. How long has it been since your last breast exam?

Module specific evaluation

The RTK program maintains a master list that records the recipients of dissemination kits and bulk printed materials and tracks distribution to campaign partners as well as non-partners (such as healthcare facilities). A CDC-developed tracking form has been modified to record the types and quantities of materials that are distributed as part of RTK as well as track partners' dissemination activities/events. This information is currently being entered into a Microsoft Access database.

Process Evaluation

In-depth telephone interviews with 10 primary North Florida campaign partners representing a range of organization types and 10 mammography facilities were undertaken in year 4 (2010) by the RTK program team. The aim was to supplement the information on the tracking forms and assess the process and effectiveness of the distribution of materials by partners and healthcare offices. The questions gathered specific information on how the materials were being utilized by partners; how the materials were being used in health education activities of the partner organizations; indicate ways to additionally engage and support partners; describe any barriers or facilitators associated with the dissemination activities; understand their reactions and receptivity to the material's content; attempt to trace the path of dissemination to the target audience; and solicit advice to inform subsequent dissemination in remaining areas of the state. All 10 partner organization interviews were successfully completed with only 2 of the mammography facilities participating in the process. A report from this evaluation is forthcoming. The Right To Know team is still planning on interviewing mammography facilities in Central and South Florida and feels fairly confident that they can complete the 10 facility interviews that had been initially planned. The primary barriers to getting only two completed interviews included the inability to directly reach mammography technologists by phone to explain RTK project and scheduling interviews. The goal was to interview mammography technologists (rather than other office staff). These mammography technologists were recruited using one of the two methods—First, RTK staff spoke with office staff and requested a call back from mammography technologists. This resulted in very few returned calls. Secondly, recruitment fliers were mailed to facilities and a free disability training DVD (from BHAWD – Breast Health Access for Women With Disabilities) was offered to the mammography technologists with the hope of meeting their continuing education unit requirements. Very few mammography technologists responded to these mails. To enhance participation in future process evaluation interviews, the RTK staff has now identified several facilities that may be willing to participate in the interviews and the staff is currently in the process of contacting them. The other aspect of the process evaluation, interviews with campaign partners did not face similar barriers. This may be attributed to higher involvement in the campaign activities, familiarity with the RTK project and willingness of the campaign partners to provide feedback.

Outcome Evaluation

As written in the year 5 work plan an outcome evaluation of the Florida Right To Know health campaign will be conducted by its project team with the following objectives: 1) to identify and document the extent to which knowledge and awareness of mammography screening has changed among women who received RTK campaign materials, and 2) to describe self-efficacy and health seeking behavior associated with obtaining a mammogram among women who received RTK campaign materials.

The rationale for this evaluation is that understanding the effectiveness of the campaign and its subsequent impact on women and their providers will inform other health education and dissemination activities aimed at persons living with disabilities. The data collection activities have already begun in the form of feedback forms filled out by participants at two RTK educational presentations in September and October of 2010. The feedback forms included questions regarding information gained from the educational session, self-reported breast cancer screening behavior, and measured intent to change screening behavior/rates as a result of the information among women. A follow up with these women is intended to determine changes in their screening behavior over time. This feedback form will be expanded into a mail survey and sent to the target audience together with campaign materials as part of a collaborative effort with Centers for Independent Living. This will accomplish two important campaign activities: 1) conducting a targeted mail out to reach women with the campaign materials in up to four Centers for Independent Living (CIL) service areas, and 2) directly reaching women with our evaluation survey. The RTK staff believes that women will be more likely to participate in the survey if they have the campaign materials in the same packet of information. The RTK staff will also consider provision of an online survey option for women and include the website and login information in this mail out. The campaign staff acknowledges that this may expand the opportunity of participation in an evaluation survey to women in other CIL regions. Recruitment flyers to conduct more in-depth interviews with women and to collect personal testimonies that describe their knowledge and awareness, self-efficacy, and health care behavior related to mammography screening will also be included with the campaign materials.

Module specific sustainability plan

Components for the sustainability of this campaign were integrated into the strategies described in the Comprehensive Dissemination and Implementation Plan developed in Year 1. This included the establishment of campaign partner organizations that have designated personnel assigned to the campaign promotion and buy-in due to their missions which encompass disability support and breast cancer education/screening. Each partner office has digital files to reproduce and publish all of the campaign materials beyond the grant period. The materials are also available on the CDC website. The campaign team is also exploring additional sustainability strategies such as designating one of the statewide partners as the new campaign liaison for the CDC. Year 5 of the RTK campaign will devote activities aiming at ensuring the sustainability of the RTK campaign in Florida beyond the initial grant period.

TRAINING PROFESSIONALS AND PARAPROFESSIONALS IN DISABILITY- Module E

The overall goal of this project is to increase the disability competence of health professionals and paraprofessionals in Florida to increase the capacity of health care providers to respond to the health care needs of individuals with disabilities. Towards this goal, the module proposes to establish and evaluate a core competence in disability by providing disability training to medical students and continuing education training to medical and allied health professionals. Susan M. Havercamp, PhD, Assistant Professor, Florida Center for Inclusive Communities, Florida Mental Health Institute at University of South Florida (USF) is leading this collaborative effort.

Target Audience

This project works with faculty members in the department of medicine at USF by enhancing their clinical curriculum to provide disability training to 600 students enrolled in the 3rd year of medical school and to measure the growth in knowledge, aptitude, comfort and attitude in providing treatment to individuals with disabilities. In addition, the project proposes to disseminate the field-tested core competence in disability curriculum and implementation guide to other interested programs for integration into their clinical training.

Objectives

Student specific objectives were developed by the module staff as follows:

1. Demonstrate an adequate comfort level when interacting with patients with disabilities in the clinical setting
2. Practice and demonstrate appropriate history and physical exam techniques with standardized patients with disabilities
3. Locate and provide adequate community resources for patients with disabilities
4. Develop an understanding of living with a disability through engagement in service learning activities such as providing health education to people with developmental disabilities and visiting community sites.

   Community partners who provided the service learning activities had an opportunity to give feedback on each student's engagement and professionalism (attitudes and behaviors that serve to maintain patient interest above physician interest). Similarly, students visited the homes of volunteers who have disabilities and the volunteers provided feedback on the student's professional and cultural competence (using Professional and Cultural Competencies rating form).

Two objectives guided activities for year 4.

Objective 1: To evaluate the impact of disability training on 3rd year undergraduate medical students.

Objective 2: To provide 100 health professionals with continuing education training on disabilities by the end of the project year.

Training initiatives exposed students to disability issues and built their core competence in intellectual, sensory, and physical disabilities. The focus of the second objective was to provide continuing education on disability to healthcare professionals. Two continuing education training modules were developed—(i) focused on access to healthcare for people with physical or sensory disabilities and (ii) focused on access to healthcare for people with developmental disabilities.

The Healthy People 2010 (HP2010) goals and objectives addressed by these module activities include: Goal 2: Eliminate Health Disparities (The second goal of Healthy People 2010 is to eliminate health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation); and Goal 6. Disability and Secondary Conditions (promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population) thereby meeting HP2010 Objective 1: Access to Quality Health Services and 1-7: Core competencies in health provider training. Strategies toward these objectives are described below.

Strategies

1. In order to complete the first objective of evaluating the disability module for 3rd year medical students, an assessment protocol and a feedback survey was developed by module staff. Model patients were recruited and a clerkship training opportunity was coordinated with medical students. Evaluation data was collected as per planned timeline and data were periodically analyzed. Findings are summarized in the module specific evaluation section of this report (below).
2. The second objective was to develop continuing education training on disability for healthcare professionals. Two one-hour disability training courses were developed for healthcare providers. The first training, Part 1, was titled "Healthcare Access for Persons with Disabilities: Physical and Sensory Disabilities" and was made available free of charge through the Florida Area Health Education Centers Network (an organization accredited by the Florida Medical Association to provide continuing medical education for physicians) and Gulfcoast South Area Health Education Center (a Florida Board of Nursing approved provider of continuing nursing education). One continuing education credit was made available to Florida physicians, nurses, nursing home administrators, and mental health providers. A second training, Part 2, titled "Healthcare Access for Persons with Developmental Disabilities" was made available at http://nisonger.osu.edu/disabilityconted.htm. Continuing education credits were approved through Centers for Disease Control and Prevention (CDC) for physicians, nurses, and certified health education specialists, and generic CE. An advantage of collaboration with the CDC office was enhanced ability for the module to reach a national audience because the certification was national instead of being limited to Florida providers. The Module staff learned of the CDC Continuing Education office through AUCD technical assistance and is grateful to AUCD for sharing information about such a vital resource.
3. An advisory panel of Florida leaders in disability and health education was formed to consult on the continuing education on disability training. The module staff is striving for continuous improvement to the training content to reflect feedback from advisory panel and training participants.
4. During the final year of this project, the long term sustainability of project activities will be the main focus while continuing evaluation of the undergraduate medical curriculum on disability and providing continuing education on disability to healthcare providers.

Proposed activity timeline

1. Revise and update the Part 1 training on Physical and Sensory Disabilities to reflect current statistics and references. (Date: June 2011)
2. Submit revised Part 1 training to CDC continuing education and complete the required steps and forms for CDC approval. (Date: December 2011)
3. Obtain approval for CME/CEU credit through the continuing education office at CDC to accredit the training for physicians, nurses, and certified health education specialists as well as generic CE for other healthcare providers. (Date: December 2011)
4. Make the Part 1 training available on the http://nisonger.osu.edu/disabilityconted.htm site instead of through the Florida AHEC. (Date: January 2012)
5. Collect and enter evaluation data and feedback from healthcare providers who take the either of the two online disability trainings. (Date: March 2012)

6. Analyze evaluation data provided by the healthcare providers periodically and analyze the comments regularly. (Date: March 2012)

Tasks accomplished

Approximately **120 students participate in the USF Disability Module every year**. However the valuation protocol was established and implemented in 2009 thus evaluation data is available for approximately 250 students. Some data is missing because students either refused to complete the evaluation or were absent when either the pre-test or post-test was administered. The surveys were added to the database at each rotation and the reported analyses and conclusions are based on the total number of students with complete data at that time. At the time of this evaluation report, the analyses are based on approximately 250 students. The **first training** focuses **on access to healthcare for persons with mobility and sensory disabilities** and is maintained on a Florida Area Health Education Centers (AHEC) website **for physicians, nurses, nursing home administrators and mental health providers**. Approximately **49 individuals have completed this** online course. Feedback from these learners has been reported in the FODH continuation draft previously submitted. The **second training addresses access to healthcare for people with developmental disabilities**. It has been maintained on the CDC website since October 1, 2010. So far, **36 individuals have completed this** course.

Both courses are free and qualify for continuing education credit. A notable trend is that, when the course is advertised, there is a surge in participation. Module staff recognizes that many people have not been able to find the training on their own and continue to work on improving this.

An advisory panel of Florida leaders in disability and health education has been formed to consult on the continuing education on disability training. The module staff is striving for continuous improvement to the training content to reflect feedback from advisory panel and training participants. The panel **members are expected to play a key role in developing strategies for dissemination and sustainability** of the module in Years 4 and 5.

The module staff has **successfully demonstrated that providing disability training to medical undergraduate students significantly increases their disability knowledge, improves their attitudes toward people with disabilities, and helps them feel more comfortable caring for patients with disabilities**. Both continuing education activities on disability for healthcare providers are available online for continuing education credit, free of charge and have been well-received.

Module specific evaluation

The project leader conducted a module specific evaluation[2] based on 245 medical students in the third year of their medical school who participated in the Disability Module curriculum as part of their primary care clerkship in the third year of medical school at USF. An evaluation protocol consisting of the Disability Knowledge Scale, the Multidimensional Attitudes Scale Toward Persons with Disabilities (MAS), and the Healthcare Provider Self-Attributions (Comfort) scale, was administered to students immediately before starting the Disability Module curriculum (pre-test) and then again 6 weeks later, upon completion of the Disability Module (post-test). Students were assured that their responses would be used to evaluate and improve the course and the performance scores will neither be shared with their instructors nor affect their grade in the course. A change in medical student's disability knowledge, attitudes toward persons with disabilities, and their comfort in providing care to persons with disabilities was measured.

[2] Disability Training for Medical Students, evaluation report prepared by Susan Havercamp, September 2, 2010.

As seen in Table 1, students fairly represented both genders and were predominately Caucasian, Asian or African-American. Ethnicity was reported by students as 11.3% Hispanic or Latino. Students ranged in age from 22 to 44 years (average= 25.7 years, standard deviation= 3.1 years) and, for the most part, were single (77%) either living alone (31.0%), living with a roommate (31.9%), with a significant other (8.9%), or with family members (5.2%). Fewer students were married (14.9%); two students were divorced and another was widowed. Before the disability module began, students were asked several questions about disability awareness. A little over half (56.9%) of the students reported that they personally knew someone with a disability.

Table 2: Student demographics

Demographic Characteristic	Percentage
GENDER	
Men	48.7%
Women	50.9%
RACE	
Caucasian	64.5%
Asian	23.4%
African American	3.2%
PERSONALLY KNEW SOMEONE WITH A DISABILITY	
Very well	26.6%
Well	10.9%
Somewhat	12.1%
A little bit	4.4%
Not much at all	2.4%

Source: Evaluation of Disability Training for Medical Students, Susan Havercamp, September 2010.

Paired sample t-tests were conducted between pre-test and post-test scores for attitude toward people with disabilities (total score and subscale scores were computed), comfort level providing care to patients with disabilities (total score and scores for each of the three cases were computed), and disability knowledge. All measures were scored so that higher scores indicated more favorable responses (e.g., more positive attitudes, greater comfort, more knowledge).

Table 3: Changes in Disability knowledge, attitudes, and comfort level after training

Measure	Difference (Post-Pre)	SD	t-value (df)	Significance (2-tailed)
Knowledge	2.36	2.40	14.76 (224)	**< .001**
Attitude	4.20	17.27	3.62 (221)	**< .001**
Cognitive	1.66	6.89	3.70 (234)	<.001
Affective	2.71	11.33	3.60 (225)	<.001
Behavioral	.02	6.10	.04 (235)	ns
Comfort	15.00	37.45	5.95 (220)	**<.001**
Case 1	2.58	13.11	2.99 (230)	<.01
Case 2	4.35	13.11	5.01 (227)	<.001
Case 3	8.29	15.60	8.11 (232)	<.001

Source: Evaluation of Disability Training for Medical Students, Susan Havercamp, September 2010.

As shown in Table 2, **significant gains were found in all three measures**. Subscale analyses revealed that attitude **change was most pronounced in the cognitive and affective dimensions**, with the behavioral dimension showing negligible change. The Comfort findings were notable because the greatest gains in comfort were associated with patients presenting with more significant disabilities, indicating that this **curriculum was particularly effective in helping students feel more at ease with patients who have significant disabilities.**

As part of the curriculum, medical students conducted home visits with volunteers who have disabilities. Some of the quotes indicating impact on the students are cited below:

> *This home visit showed me much I could never have learned in a fifteen minute office visit.*
>
> *We don't read about a lot about disabled patients in our text books and this visit enabled us to see what her life is like first hand.*
>
> *I had a wonderful time at my home visit with S.T. and I found it to be enlightening. I have come to realize that as a physician you never know who is going to come walking through your door and it's important to always be willing to step out of your comfort zone and try something new; whether that's a different way to communicate, or simply modifying how a history and physical exam are performed, or just having the humility to appreciate that a patient, or a patient's parents, might have a far greater knowledge about an illness than you do.*
>
> *The most important lesson that I took from my home visit with Scottie is that people with disabilities, no matter how profound, can be members of a family and lead fulfilling lives…my visit with Scottie and his parents reinforced the idea that as a physician, it is important to consider people with disabilities first and foremost as people, and then consider their disability.*
>
> *I got a lot out of this home visit with Ms. C. I realized that it is important to be familiar with and knowledgeable about the disabilities your patients have, as well as the secondary medical conditions, social and psychological issues that may also affect them. Most importantly, I learned the importance of listening, making good eye contact, and treating each patient with respect.*

Training for healthcare providers

An evaluation plan has been designed for the training for the healthcare providers by the Project Coordinator. Feedback forms will be collected from healthcare providers who take the online disability training. The comments received will be analyzed regularly. The training content will be revised at least once a year to keep it current and to reflect feedback from the advisory panel and training participants. This panel has been helpful in offering feedback on training. While the scheduled training has been completed, module staff continues to collect and enter evaluation data at the time of this report. The Part 1 training (sponsored by the Florida AHEC) has had 56 participants. Feedback thus far has been very positive with overall rating of program ranging from excellent (60.4%), very good (37.5%), to good (2.1%). A total of 89.6% of participants reported that the information presented in the training would help them do a better job of treating patients and 58.3% indicated that they would make changes in their practice as a result of information presented during training.

Module specific sustainability plan

The Part 1 training will be revised and module staff with continue to work with CDC continuing education branch to get it approved for CME/CEU credit for physicians, nurses, certified health education specialists, and generic CE. Once the training is approved through CDC, it will be hosted at the Nisonger website. This will have two advantages: 1) continuing education credit will be available to providers nationally instead of restricted to Florida providers and 2) there will be no cost to the project

associated with web hosting or providing continuing education credit. An advisory panel of Florida leaders in disability and health education has been formed to consult on improving the continuing education on disability training. The members are expected to play a key role in implementing sustainability strategies for the module in Years 4 and 5.

SUPPLEMENTAL SURVEILLANCE- Module F[3]

The FODH believes that surveillance is a vital component of public health that enables quantification of risks and outcomes of interest across a population. Surveillance is also an established priority of the Disability and Health Program in Florida in line with Centers for Disease Control and Prevention (CDC) as well as the Healthy People 2010 goals for improved disability surveillance data. As such, the module goal was to collect, analyze, and disseminate disability and health data in Florida. The data historically collected on Florida's Behavioral Risk Factor Surveillance System (BRFSS)— a telephone survey administered by Florida and all states and territories in partnership with the CDC—did not include many issues of interest to the disability stakeholders in Florida. The FODH Supplemental Surveillance module added questions to BRFSS to increase the richness of disability and health data collected and analyzed through the Office on Disability and Health for its Partners. Elena Andresen, PhD, Professor and Chair in the Department of Epidemiology and Biostatistics at University of Florida is the module leader along with Erin DeFries-Bouldin, MPH.

Objectives

During program Year 4, the module objectives were to:

1. Analyze disability and health data from the 2010 Florida BRFSS: During calendar year 2010 (grant Years 3-4), the FODH supported the inclusion of 8 questions about disability perceptions and attitudes on the Florida BRFSS. These data will be available for analysis early in Year 5. During calendar year 2011 (grant Years 4-5), the FODH will support the inclusion of 5 questions about visitability on the Florida BRFSS. Although these data will not be available until the end of Year 5 or after the end of the grant, some pilot data will be available for analysis during Year 5.
2. Analyze data from other relevant disability and health data sources and/or data from previous years' or other states' BRFSS: While BRFSS is the primary data source for FODH reports; the module staff is exploring opportunities to partner with the Florida Center for Medicaid and the Uninsured at the University of Florida to analyze Medicaid claims data during Year 5. The module staff will also work with other CDC state grantees for disability and health, when possible, to create joint reports.
3. Work with Partners to identify and address data needs: FODH regularly seeks Partner input to identify the topics supported by BRFSS questions for analysis, however, there continue to be some topics of which Partners may be unaware. Module staff plans to continue working with Partners and bringing potential data sources to their attention, thereby strengthening their ability to plan impact policy.
4. Disseminate disability and health data throughout the state: Since public health data are not useful unless people are aware of them and can put them to use for planning, policy development, and evaluation; the module staff will work to disseminate its data reports to Partners and stakeholders throughout the state.

[3] Data and Surveillance module: summary and activity report prepared by Erin Bouldin, November 8, 2010

Strategies and timeline

To address the BRFSS 2010 data analysis, module staff will procure 2010 Florida BRFSS dataset from Florida BRFSS Coordinator and pilot visitability dataset from University of Florida Survey Research Center. The module staff will also meet with Medicaid center staff/other state BRFSS staff to discuss requirements for using Medicaid data/other state BRFSS for FODH analyses. The module staff will work with graduate research students in specific analysis projects following the model of previous FODH-BRFSS and FODH pilot data reports (i.e., caregiving and attitudes reports) with the goal of completing first report by FODH Annual meeting around May, 2011. The module PI will also explore the use of these datasets in graduate level Epidemiology Methods II course at University of Florida during summer, 2011. The Medicaid and/or other state BRFSS analyses are expected to be completed in program Year 5.

To increase Partner awareness about existing FODH analyses and potential data sources on disability, the module staff will continue to discuss data needs with Partners on phone meetings and during in-person meetings. Module staff will continue to work with Partners to identify avenues for dissemination of data through the Partner network. The module will also utilize FODH-sponsored newsletter, "Accessibility for All". The staff will identify state agencies and other organizations that may be interested in FODH findings; work with College of Public Health and Health Professions media office to disseminate FODH stories and attend disability-related meetings to share disability data. The module will continue to post data reports on FODH website/submit reports for newsletters and/or public health journals and create "briefs" for use by agencies and policy makers. The module staff will also continue to proactively seek opportunities for active engagement with Florida Transition Task Force (to assess health care access among young adults with disability and to create and pilot questions that assess medical home and other transition topics) and Governor's Commission on Disabilities (to assess emergency preparedness among people with sensory disabilities and to offer suggested data resources and assistance, when possible).

Tasks accomplished

In each grant year, the FODH has **added questions to the Florida Behavioral Risk Factor Surveillance System (BRFSS)** to collect information of interest to our partners. The topics for the supplemental questions were proposed by FODH Partners. During 2008, 13 questions collected information from Florida adults on their *experiences with caregiving* and about people they provide care to. During 2009, 9 questions were added to BRFSS on *access to healthcare for people with disabilities*. During 2010, the focus is to collect *disability attitudes/perceptions* data through 8 questions; in 2011 five questions will be added to BRFSS to analyze *Visitability*.

For each of these topics, the FODH has undertaken several analysis projects. A descriptive report has been completed for each year, along with additional reports on topics of interest to FODH partners. A complete list of reports is available (see Appendix 1).

In 2008, the FODH **generated reports on caregiving in Florida** overall and on caregivers of persons with cognitive impairment. Reports were also generated about caregiving and older adults in Florida that investigated caregiving characteristics by the age of the care recipient. **Analysis of 2009 data is in process** and a draft descriptive report and planned analytic paper using these data is proposed in near future. The 2010 BRFSS is underway and those data will be available in mid-2011. In addition to utilizing FODH-supported questions, the office also has used standard BRFSS questions to generate reports. Examples include reports on the **overall prevalence of disability in Florida and county-level disability prevalence** (2007 BRFSS) and **access to care among young adults with disability** (2007 BRFSS).

The FODH has generated several **web-based surveys** of its own in an effort to reach individuals who would not be sampled by the BRFSS. (Specifically, people with communication disabilities who cannot answer a phone, people living in group homes or other institutional settings, and children under age 18). The FODH **continues to field two surveys modeled on the BRFSS**: one for adults with disability to respond for themselves and one for proxies to respond on behalf of individuals with a disability under age 18. Interim reports have been completed on these two surveys and final reports will be generated when the surveys close at the end of the year. The FODH also **created a web-based survey to assess employment among people with disabilities at the state level in response to interest by the Governor's Commission on Disabilities**. A report is available on this brief survey.

Module specific evaluation

The surveillance module has made all its data analysis reports available on the FODH website and they can be accessed and downloaded freely by anyone. FODH office also disseminates all newly published reports and data/policy updates to its partnership listserv on a regular basis via email. Although it is difficult to evaluate the full extent of use of these data analysis reports, a review of technical assistance and collaboration opportunities documented by the module staff provide evidence of benefits derived from FODH analyses.

- **The Governor's Commission on Disabilities** has used FODH reports to inform its annual recommendations and reports, especially on access to health care. In addition, they are using the results of the state employee survey to plan and move forward on recommendations and activities for employment of people with disabilities.
- **The Health and Transition Services workgroup** requested the regional report on access to health care among young adults with disabilities and has used those data to inform planning and to develop questions they may use on future BRFSS surveys in the state.
- The Florida Department of Elder Affairs was not aware of the BRFSS as a potential resource and the initial report published by FODH on caregiving among older adults has developed their interest leading to subsequent work with Elder Affairs to **create a policy brief on caregiving**.
- The FODH also **works with agencies to develop their capacity to analyze BRFSS data** when possible. Many groups do not have a dedicated statistician or anyone proficient in statistical software and weighted data analysis; in those cases, FODH has conducted a training using CDC's new Web-Enabled Analysis Tool (WEAT) for the BRFSS. FODH has worked with Elder Affairs on a preliminary basis in this capacity as they have statistical support and can benefit from additional training in BRFSS analysis. FODH will be collaborating in the future to provide support as needed and to enable them to conduct their analyses.
- FODH also is available to **contract with partners for larger data collection projects**. For example, the Florida Developmental Disabilities Council (FDDC) awarded a grant to the FODH to survey individuals on the wait-list for services from the Agency for Persons with Disabilities (APD).
- **Expert testimony:** FODH staff has contributed information and data summaries to the Governor's Commission on Disabilities and the Governor's Commission on Autism. The FODH director served on the Institute of Medicine's committee on The Future of Disability in America.

Module specific sustainability plan

The FODH has applied for and been awarded a number of related grants and contracts to extend its surveillance work on disability and health issues. The following list includes all grant opportunities that were applied for and notes those that were awarded.

Awarded

- Florida Developmental Disabilities Council: Web-based proxy survey
- Florida Developmental Disabilities Council: APD wait-list survey - $80,000 total award
- Suwannee River AHEC:
  - Support for graduate intern in Year 2
  - Support for graduate intern in Year 3
- Centers for Disease Control and Prevention: Healthy aging and caregiving - $24,000 total award in 2009, $10,000 total award in 2010
- Alzheimer's Association: Analysis of 2007 and 2009 caregiving data: $14,000 total support

Applied, Not Awarded

- National Institutes of Health: Community-based participatory research (CBPR)breast cancer screening for women with disabilities (R01) – currently in second submission review; proposed $1 million over 5 years
- Centers for Disease Control and Prevention: Prevention Research Center on disability; proposed $2.48 million over 5 years

TRAINING OF LAW ENFORCEMENT ON DISABILITY AWARENESS AND SENSITIVITY[4]

Based on Partner feedback during Year 1 and 2 of the program and the first external evaluation (completed by WellFlorida) FODH partnered with the Florida Center for Inclusive Communities (FCIC) of USF to identify gaps in the training of law enforcement deputies and to develop and pilot a training curriculum that focuses on disability awareness and sensitivity. The curriculum focuses on interacting and communicating with individuals with disabilities as victims, offenders, witnesses, and complainants of crime. The curriculum includes up-to-date content, disability data, video vignettes, and experiential activities.

FODH staff made initial training contacts at local police departments and academies including the Ocala Police Department and the University of Florida Police Department. Both agencies face difficulties in garnering resources to include additional training due to State budgetary cutbacks. However the FODH is hopeful that it can present USF's disability training to these agencies by the end of Year 4.

A success story has been in development of FODH Partnership with the Santa Fe Police Academy. This partnership has resulted in a proposed collaboration to promote the update materials for standard use for all Florida law enforcement training. Banking on the collaboration with FCIC and Santa Fe Academy FODH plans to approach the Florida Department of Law Enforcement (FDLE) with a proposal to use FCIC's current training to revise and update its current basic recruit curricula. If successful, the new material will be taught and learned by all future law enforcement officers statewide. Additionally, FODH plans to add training approved for continuing education credits as an advanced and specialized training online course which would target existing law enforcement personnel seeking re-certification.

Proposed Target Audience

Florida Law Enforcement cadets and existing law enforcement personnel seeking re-certification training

[4] Law enforcement training update report prepared by Claudia Tamayo, January 26, 2011

Objectives

1. To update the following disability topics and get them included in the Florida Basic Recruit Manual.
   a. Person First Language
   b. Developmental Disabilities
   c. Intellectual Disabilities
   d. Mobility Disabilities (including Cerebral Palsy)
   e. Mental Health Condition
   f. Deafness
   g. Blindness
   h. Epilepsy
   i. Autism
   j. Alzheimer's Disease
2. Also to use FCIC's current disability training (which includes above topics) to produce an online course for advanced and specialized training credit.

Proposed strategies and timeline

Updating Basic Recruit Manual

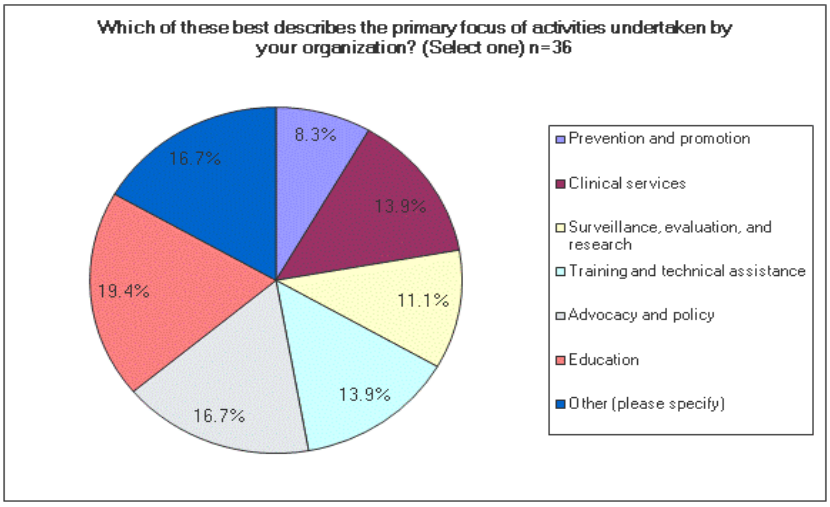
1. Contact the Criminal Justice Standards and Training Division of FDLE and approach them with the idea of updating the curricula (By March 2011.)
2. Using support from the Santa Fe Training Academy and the Hillsborough County Sherriff's Department (who currently use the FCIC developed disability course) to justify the need for updated training (By April 2011).
3. Prepare for the Training Advisory Board Meeting in May and present our case, if successful the basic recruit curricula would be updated in July.

Certification of Online Specialized and Advanced Training Course

In order for the current FCIC training to become an online course endorsed by the FDLE it has to meet the objectives that are currently listed in that section of the training. Subsequently the course will be developed and advertised through 43 training centers in the state. (Timeline for this component has not been determined yet).

Web-Based Survey of FODH Partners

Figure 1 Primary focus of partner organizations



WellFlorida planners met with FODH staff and partners to finalize the survey instrument (See Appendix 2). The survey was hosted on FODH website and an email invitation to participate in the web-based survey was sent to the partnership list (N=147). The survey was fielded between October 1 and December 1, 2010. Partners were sent email reminders at one week intervals for three weeks from the date of launch.

The survey was completed by 74 individuals (response rate of 50%, not taking into account participation via FODH website link). Response to all questions was voluntary. 27.8% respondents (n=15) described themselves as Lay individual/Self-advocate and 72.2% (n=39) described themselves as representative of an organization/agency.

As can be seen from figure 1 (above), 82% (n=36) of the respondents who described themselves as representatives of a partner organization answered the question describing the primary focus of their organization. **Most respondents represented educational institutions (19.4%), Advocacy and policy (16.4%), Clinical services (13.9%), and Training and technical assistance (13.9%); and prevention and promotion (8.3%).** The respondents who chose "other" (n=6) described their organizational focus to be Emergency Management, healthcare coverage and resource coordination, all of the above activities, a nursing model--not social or medical but a blend, Early Intervention, and Home and Community Based Program Funding. Fourteen respondents representing partner organizations (36%) answered the question about what areas they served in the state of Florida. They represented 20 North Florida Counties (Alachua, Bradford, Citrus, Columbia, Dixie, Gilchrist, Hamilton, Hernando, Lafayette, Lake, Levy, Marion, Putnam, Sumter, Suwannee, Union, Baker, Clay, Duval, St. Johns) ; 14 Florida Panhandle Counties (Bay, Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Wakulla, Washington); nine Central Florida Counties (Hillsborough, Pinellas, Orange, Seminole, Osceola, Brevard, Hardee, Highlands, St. Lucie) and seven South Florida Counties (Charlotte, Glades, Lee, Hendry, Collier, Martin, Palm Beach). **Thus, the FODH partnership from at least 50 of the state's 67 counties was reached through this survey speaking to the evidence of its broad reach.**

73% of respondents (n=71) were aware of the mission of FODH. The respondents varied in duration of partnership with FODH (See table 2 below) with **39% of the respondents noting their association with FODH for between one to three years and 32% reporting an association of less than one year** (n=22). 38% respondents (n=27) had not had any direct contact with FODH within the past year, close to 20% (n=14) had monthly contact and a little over a quarter (n=19) reported quarterly direct contact with the FODH (e.g., meetings, phone calls, emails, faxes, or letters). It may be noteworthy that each organization has nominated one staff member to the partnership. Due to staffing limitations, the partner staff may

have had limited opportunity for direct interaction. It might be prudent to ask the partners to designate an alternate contact whenever possible.

Table 4: Duration of partnership with FODH

How long have you/your organization been part of the FODH partnership?		
Answer Options	**Response Percent**	**Response Count**
Less than 6 months	20.6%	14
More than 6 months but less than one year	11.8%	8
One to 2 years	22.1%	15
Two to 3 years	17.6%	12
Three to 4 years	7.4%	5
More than 4 years	20.6%	14
	answered question	**68**
	skipped question	**6**

Source: Web-based survey of FODH partnership, 2010

A nearly equal number (12-14%) of partnership survey respondents (n=9) had attended a partnership call at least once every quarter, at least twice a year or more than three times a year whereas 60% reported not having attended any partnership calls. **Approximately 60% of the respondents (n=44) had attended at least one of the 2008, 2009 or 2010 annual meetings.**

The partnership members were asked to select an answer choice that best describes their/ their organization's relationship with FODH. Of the 69 respondents answering this question, the majority described their association as (30.4%) *Share information only (Communication)*, 14.5% described their relationship as *Work together as an informal work group to achieve common goals (Cooperation)* and an equal number (13%) said they *Work together as a formal team to achieve common goals (Collaboration)* or said they *work together as a formal team across multiple projects to achieve common goals (Partnership).* An additional 29% reported that they did not work together at all (Unlinked). **Thus, nearly 4 in ten of the survey respondents were in some close working relationship with the FODH as cooperators, partners or collaborators and an additional three communicated with FODH regularly. Nearly half of the 70 respondents who answered the question whether FODH offered them/their organization an opportunity to meet new disability related organizations/individuals said *yes* (n=34).** Some of the partners' comments describing these new opportunities are summarized below—

> *FODH personnel are quick to make note of common interests. They make appropriate introductions during joint projects, conference calls, emails and annual meetings. These provide avenues for expert input from other partners and stakeholders. It facilitates networking, communication and linkages.*
>
> *The FODH website also lists contacts and resource organizations. In the past, FODH has sent a number of materials related to open activities given by partners or associate organizations. We met with a partner agency staff at an annual conference and worked with them eventually on another project.*
>
> *In our region our network is just beginning to develop a relationship with the disability community. During partnership conference calls I learn about the work of other organizations with similar missions. We now have contact with other organizations interested in mobilization of community with focus on activities for persons with disability.*

The survey respondents were also asked to rate the effectiveness of FODH functions. 66% of the total respondents answered this question (n=49).

Table 5: Rating of effectiveness of FODH functions by survey respondents (n=49)

Statement	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
FODH encourages diverse partnership representation.	38.78% (n=19)	32.65% (n=16)	24.49% (n=12)	2.04% (n=1)	2.04% (n=1)
FODH offers opportunities for partners to leverage resources.	27.08% (n=13)	37.5% (n=18)	27.08% (n=13)	6.25% (n=3)	2.08% (n=1)
FODH helps to minimize duplication of efforts and services.	15.22% (n=7)	26.09% (n=12)	50% (n=23)	6.52% (n=3)	2.17% (n=1)
FODH promotes public support of programs and issues to sustain its mission.	22.45% (n=11)	57.14% (n=28)	14.29% (n=7)	4.08% (n=2)	2.04% (n=1)
FODH offers opportunities to voice opinions in community/statewide issues or to participate in the strategic planning.	26.53% (n=13)	44.9% (n=22)	24.49% (n=12)	2.04% (n=1)	2.04% (n=1)
FODH helps advocate for policy change efforts by enlisting political/constituent support.	14.58% (n=7)	35.42% (n=17)	41.67% (n=20)	4.17% (n=2)	4.17% (n=2)
FODH helps with changing community values around disability through systems change by promoting community buy-in.	16.67% (n=8)	43.75% (n=21)	31.25% (n=15)	4.17% (n=2)	4.17% (n=2)
FODH publishes disability specific data and resources.	41.67% (n=20)	39.58% (n=19)	16.67% (n=8)	0% (n=0)	2.08% (n=1)
FODH provides technical assistance as needed.	18.75% (n=9)	39.58% (n=19)	31.25% (n=15)	4.17% (n=2)	6.25% (n=3)

Source: Web-based survey of FODH partnership, 2010

As can be seen in Table 5 above, **at least 70% respondents agreed (Strongly agree/Agree) about the effective functioning of FODH** when it came to its function of *encouraging diverse partnership representation* (71.4%); *promoting public support of programs and issues to sustain its mission* (79.5%); *offering opportunities to voice opinions on community/statewide issues or to participate in the strategic planning* (71.4%) and *publishing disability specific data and resources (79.5%)*. Nearly half (46.9%) of the respondents were undecided on the effectiveness of FODH in *helping to minimize duplication of efforts and services.* 40% were undecided whether FODH effectively *helps advocate for policy change efforts by enlisting political/constituent support.* An additional 30% were undecided about the effectiveness of FODH *in helping with changing community values around disability through systems change by promoting community buy-in.* At least two-thirds of respondents (60%) agreed that *FODH effectively provides technical assistance as needed* and a third (30%) were undecided with the statement. **It is possible that the respondents choosing "undecided" are unaware of these functions of FODH and therefore unsure about their effectiveness. However, since "don't know" was not an answer choice, it is difficult to state the reasons for nearly a third of Partners rating the effectiveness of some of the FODH functions as "undecided".** While FODH does update its Partners about its activities through partnership calls and newsletters, it can also showcase its achievements and partner collaboration results at the annual meeting to address this issue in the future.

The respondents were also asked to rate the extent of their/their organization's familiarity with the three FODH module activities by selecting one of the following responses-- *Not aware; Aware but NOT utilized; Utilized; Utilized AND recommended to others; and Shared with others/Recommended to others.*

67% of the respondents (n=50) answered this question (see Table 4 below). If the respondents answered as "Utilized" or "Utilized and recommended to others", they were also asked to describe its usefulness.

Table 6: Respondent rating of familiarity with FODH modules (n=50)

Module	Not aware	Aware but NOT utilized	Utilized	Utilized AND recommended to others	Shared with others/Recommended to others
Module B: Right to know campaign (This campaign promotes breast cancer screening among women living with physical disabilities through the dissemination of print and audio health education materials)	38% (n=19)	30% (n=15)	6% (n=3)	8% (n=4)	18% (n=9)
Module E: Training Professionals and Paraprofessionals in Disability (This project provides disability training to medical students and continuing education training to health professionals across the state)	46% (n=23)	38% (n=19)	0% (n=0)	2% (n=1)	14% (n=7)
Module F: Supplemental Surveillance (This module supports collection of disability specific data through Florida's Behavioral Risk Factor Surveillance System (BRFSS) to increase the richness of disability and health data collected and analyzed through FODH)	47.9% (n=23)	27.1% (n=13)	4.2% (n=2)	6.3% (n=3)	(14.6% (n=7)

Source: Web-based survey of FODH Partnership, 2010

As seen in Table 4 above, between 38% and 48% respondents were not aware of the specific modules. At least another third were aware of the modules but had not utilized them. **More respondents (14-18%) had shared the module materials or recommended them to others compared to having utilized it themselves (0-6%).**

The respondents indicating having used the Right to Know campaign materials commented that it was thought to be useful and was distributed with state health department and state and university aging partners; it was thought to be a great educational resource for women living with and without disabilities, lay individuals and healthcare professionals; it was used to increase awareness within County Health Departments; had helped get the word out concerning "access to care" issue; and had empowered women with disabilities that received information through partner organizations. **Among the 38% indicating that they were not aware of the RTK module, 41% (n=7) had been a partner for less than a year, 63% (n=12) had no contact with FODH in the past year and 66% (n=12) had never attended a partnership call.**

The respondents that had utilized and/or recommended Module E indicated that it was useful because it was shared via listserves and posted fliers; it had elicited positive feedback from Veterans Affairs partners; its training material was very relevant to healthcare providers; and it had helped USF become a pioneer university in offering such a training to medical students. **Among the 46% indicating that they were not aware of the provider education module, 47.6% (n=10) had been a partner for less than a**

year, 52% (n=12) had no contact with FODH in the past year and 72.7% (n=16) had never attended a partnership call.

The respondents who had utilized the Surveillance module commented that it was useful to them as a great resource for additional data; setting organizational goals; revealing statistics of immense public health importance such as number of persons caring for someone with dementia; to supplement advocacy efforts and to verify need when writing grants. **Among the 47.9% indicating that they were not aware of the surveillance module, 47.6% (n=10) had been a partner for less than a year, 56.5% (n=13) had no contact with FODH in the past year and 81.8% (n=18) had never attended a partnership call.**

Interviews with Key Partners

Seven key partner interviews were facilitated by WellFlorida to gauge partner organization's perception of the FODH activities as well as their suggestions on its sustainability (see Appendix 3: Key Partner Interview guide for interview questions). A brief description of individuals interviewed and the professional association between FODH and the partner organization is given below:

Bryan Vaughan, Executive Director, Governor's Commission on Disabilities

FODH and the Governor's Commission on Disabilities were established at nearly the same time and have worked together to advance disability data and policy. The FODH has participated in Commission meetings and has provided data on specific topics like transportation and education. In 2010, FODH worked together to survey state employees on disability (via web survey). Besides being a resource for various data needs, FODH has been included in an advisory function in a grant application submitted by the Governor's commission.

Tom Rice, Ops Review Specialist, Agency for Persons with Disabilities

The Agency for Persons with Disabilities (APD) has helped FODH to identify areas of data needed for individuals with developmental disabilities, particularly children. The APD has been very helpful in assisting FODH in field-testing surveys like the proxy and self-response web surveys hosted on FODH website and as modeled after BRFSS phone-surveys. FODH also conducted a separate survey of APD wait-list individuals and prepared data reports that have helped APD in policy planning.

Annie Todd, Health Educator Consultant, Bureau of Chronic Disease Prevention and Health, Promotion, Arthritis Prevention and Education Program, Florida Department of Health (DOH)

Betsy Wood, Bureau Chief, Bureau of Chronic Disease Prevention and Health Promotion, Florida Department of Health

FODH supported a joint position within the Bureau of Chronic Disease (Ms. Annie Todd, MSW) to work on dissemination, partnership building in Tallahassee and DOH, and to increase disability awareness within DOH. Year 4 (2010) was the official start of this joint position. Though the position was only active for 9 months, FODH created inroads for improving disability and accessibility awareness within DOH through a dual hosted live accessibility training session, by dissemination of the Accessibility for All Bulletins (now in their 4th installment) and by continuing to engage leadership in the Bureau of Chronic Disease. Currently, due to the political transition in the state capitol, FODH will be taking steps to move the position to the University of Florida and support a half time individual whose job will include monthly trips to Tallahassee to continue to engage DOH departments on disability awareness and

accessibility of programs as well as continue the work that Annie Todd began. [5]These activities are facilitated by the more direct involvement of Ms. Betsy Wood, Bureau Director, who now personally responds to our FODH questions and actions by directly assigning tasks to her DOH staff.

Accessibility Training Session

The training session marked the kick off to a push by FODH and DOH to help improve accessibility for individuals with disabilities throughout the state of Florida. The training event titled: "Accessibility and Wellness in Public Health" was advertised extensively and reached a variety of agencies in Florida and locally. The event was approved for 1 hour of free Continuing Education Units (CEUs) and Continuing Medical Education (CME) which will be provided by Suwannee River Area Health Education Centers (Suwannee River AHEC). The presentation informed organizations, wellness program organizers, nurses, and marketers about how to communicate information to people with various disabilities so that they are aware of the program and feel welcome to participate. It also highlighted how to ensure that the services they offer are provided in a physically accessible way. The event culminated with a total of 53 live attendees at 4 sites streaming video feed from the University of Florida. Live viewing sites included Gainesville-UF, Tallahassee- DOH, Okaloosa County Health Department and Levy County Health Department. The session was taped and FODH and DOH are currently in the process of uploading the video on the Suwannee River AHEC website for enduring continuing education credits. FODH expects to have many more viewers to watch this free online training, and plans are underway for using this opportunity to help in building a state-wide network of partners interested in accessibility issues for individuals with disabilities. Due to the overwhelming success of the accessibility training, FODH and DOH have been disseminating short Accessibility Bulletins titled "Accessibility for All" to all those who attended the live accessibility training, and it is expected that once the training is on the web the number of people receiving accessibility information and resources from FODH will increase dramatically. Additionally, this event paved the way for Gainesville's local Meeting Planners Association to host Catherine Graham as a speaker at their monthly meeting "Are Your Meetings Accessible to Everyone?" while she was visiting Gainesville. That meeting reached meeting planners throughout the state and educated them on Meeting Accessibility. Attendees of this meeting enjoyed Ms. Graham's presentation so much they have submitted it for the National Meeting Planners Association Conference next year and Ms. Graham's attention now includes targeting conference planners as a part of her consulting business.

Mindy Sollisch, Bureau Chief, Department of Elder Affairs, Planning and Evaluation and Carol W Waters, Senior Management Analyst, Department of Elder Affairs, Planning and Evaluation

FODH has worked with Elder Affairs to produce reports with Florida BRFSS data that focus on their population of interest-- Floridians age 60 and older. To date, FODH has worked with them on a report about caregiving, which includes specific information about caregivers for individuals age 60 and older and also caregivers who are age 60 and older. Elder Affairs assisted FODH in planning for the second annual meeting that focused on caregiving. FODH plans to continue working with Elder Affairs on data reports and linking their work with the Department of Health and other partners.

***Bobbie Vaughn*, Associate Professor and Training Director, Florida Center for Inclusive Communities, College of Behavioral and Community Sciences, University of South Florida**

FODH has a subcontract with USF to produce an updated law enforcement training video and manual, highlighting different disabilities and teaching law enforcement how to address each. USF has excelled in

[5] Update status report prepared by Claudia Tamayo, January 26, 2011

law enforcement training in Hillsborough County and through the FODH partnership are now branching out to law enforcement around Alachua County. Plans are underway for replicating the curriculum in Hillsborough County for training of the Ocala Police Department, The University of Florida Policy Department and Santa Fe College Law Enforcement Training Program (which will be reaching police officers seeking in-service specialized training within the Alachua County Sheriff's Department, Gainesville Police Department and University Police Department.)

Interview findings

The interviews were planned to address four things: (i) comparison of the nature of resources that existed in the disability arena before the existence of FODH and how having FODH had made any difference to the opportunities, services and resources available in the disability arena; (ii) the impact of collaboration with FODH on the direct working, resources, activities and policies of each organization and (iii) suggestions for future improvement (iv) feedback on how FODH could work towards a sustainability plan.

Comparison of the opportunities and resources available in disability arena before and after FODH

- A common opinion voiced by most interviewees was that FODH has served the role of a "silo-buster". Partners acknowledged that before FODH, the disability arena was a highly segregated where organizations worked on a specific disability or demographic group such as developmental disability, Alzheimer's disease, Autism, etc. **Creation of FODH as a comprehensive statewide disability organization has enhanced the capacity of disability organizations to see overlapping issues across disabilities and partner with each other for common goals.** As a central independent organization, FODH has helped pool resources and has given increased visibility to disability issues in public health arena.

An example cited was that of the medical student disability training being adapted into a curriculum for law-enforcement.

"Most visible work for general public in the disability arena was in Developmental Disability and interventions in early ages. A broader focus on health among all persons with disabilities has helped in increasing awareness about chronic disease and health challenges for persons with disabilities."

"Cognitive ability is a common cause of concern for Alzheimer's disease/dementia in elderly as well as developmentally disabled children. A disability curriculum addressing these issues is beneficial to both the groups when designing a curriculum for doctors and law-enforcement. FODH has helped in unifying the vision for disability."

- Partner organizations commonly felt that the resources such as trainings for health care professionals, disability specific information, etc. had been available through various local, regional and statewide issue-focused organizations long before the existence of FODH. However, since no comprehensive organization existed at state level, creation of FODH was perceived as a capacity building measure for the disability community in Florida.

"FODH is a central warehouse of resources, while each partner is funded from a different pot of money—Department of Education, CDC, Maternal and Child Health bureau, Department of Health, etc.—collaborative work has helped varied organizations to think of common priorities for a concerted effort. When someone needs anything they can ask FODH."

"FODH partnership, communication links and connections created have helped in improving programs. The Alzheimer's association partners, law enforcement partners and USF have together been able to

integrate their expertise into development of the curriculum for law enforcement. The training for one county (Hillsborough) is now being considered in two additional counties (Alachua and Marion)."

- Partner organizations acknowledged that FODH has **created very valuable resources through the three modules** and helped in bringing disability to the forefront.

"The healthcare professional training is also unique since medical school students are trained while in school versus being introduced to disabled individuals when practicing as healthcare professionals. It is different when a established professional takes CMEs as opposed to increased awareness about disability issues in prospective patient among medical students which increases quality of care by sharpening sensitivity skills."

"Data expertise of FODH is irreplaceable. Evidence based program planning and policy development has been facilitated as a direct result of the valuable county level data on disability in the state. Earlier, there were indirect estimates, now there are real numbers that help us to put face to the issues in disability statistics."

- Since FODH is first statewide organization for comprehensive public health focus on disability, partners acknowledged a few stumbling blocks as they are working with FODH. However, they attributed these to the **newness of the organization or internal working hierarchies in place at the partner organizations**.

"FODH staff is wonderful! They are very approachable and are tenacious, persistent and very proactive. They don't wait around for an organization to join but approach all organizations that could possibly benefit from partnering with each other. Sometimes, it takes time on our end to get the ball rolling or we may not be able to fully participate in larger numbers in an annual conference or event due to budget restrictions."

"The new FODH funded position was a long exercise, given the hoops we had to jump through before it became a reality. Both DOH and UF were new to creating such a unique university funded position at DOH so it took a while. However, now that we have created one, it has paved a way for future similar University-Department collaborations."

Impact of collaboration with FODH on the direct working, resources, activities and policies of each organization

- FODH was considered by all its partners as a **credible source of information** on account of the quality data generated and its **ability to balance the role of academicians with that of community based stakeholder-focused work through its modules** for healthcare professional education and Right to Know campaign.

"FODH are magnanimous collaborators. They have extended a helping hand every step of the way. They helped us in analyzing the caregiver data at county level so that we could link our ageing county profiles to BRFSS data reports. Regional agencies in aging have been able to create tailored annual plans based on this data. As a data warehouse, FODH brings tremendous capacity to any project on which it serves as a partner."

"It is a win-win for everyone. As a partner with statewide offices, we have helped them with dissemination of their module materials and they have connected us to resources in the state and brought visibility to our work. When you are working on a grant proposal or a project, ***partnering with a University of Florida based, CDC funded statewide organization is extremely valuable.****"*

- While most partners thought that the data generated through FODH can **potentially help channel more funding for their programs**, they commented that it was difficult to keep track of such an increase based on data used to justify need.

"When we write grants, FODH generated BRFSS data and other reports have tremendously helped in describing rationale behind an evidence based program; resource allocation; needs assessments and policy planning."

"We have seen increased funding for breast and cervical cancer and the caregiver data had led to a request for increased funding. The cancer funding increased and while the caregiver data didn't lead to increased funding, there were no reductions in previous funding levels. Now… we can't really say if it was because of the data or the Right to Know Campaign. But there is a fat chance it influenced it! The data are also very recent and it remains to be seen how far-reaching impact it might have."

- Partners agreed in one voice that their collaboration with FODH had **enhanced their organizational capacity as well as strategies adopted, activities undertaken and services provided**.

"Since two universities are collaborating (UF and USF), we both have our niche areas of expertise and geographic presence. Our collaboration has led to multiplication of resources and helped in taking our disability research to wider state-wide audience and broadened the scope of our work."

"The DOH had always worked in an inclusive manner. However, having partnered with FODH has increased our awareness of disability issues at every level. More staff is attuned to it. Disability images and graphics are becoming standard part of our outreach campaigns. More staff participated in the shadowing event and mentored high school children through the High-school High tech program of Center for Independent Living. Greater involvement with FODH partnership has made us more cognizant of including disability in every message. Suggestions for inclusiveness have started coming from all quarters of the department instead of a select few people."

"FODH brought diverse organizations across disability to one table. It helped us see areas of overlap and increased inter-agency collaboration. We didn't know there were other agencies struggling with same issues, the networking and work-group activities in annual conferences helped to see that. Synergy has helped in improving our approach to issues."

"Our work with FODH taught us the methodology for adding questions to BRFSS and analyzing data. It has increased our capacity to use data to shape decisions and enhanced organizational effectiveness."

Feedback on how FODH could work towards a sustainability plan

- Partners were aware that FODH is a grant funded project and acknowledged that CDC grant award funds will end at some point. However, they thought of FODH as a **capacity building project and expressed willingness to take on a few elements of the FODH functions** as their own.

"Many of FODH partners are state agencies with strategic plans. To ensure that FODH recommendations don't end up in just another 3 ringed-binder, all these agencies can work to incorporate some aspect of FODH strategic plan element into their organizational plan. This will ensure uniform focus and policies across the state. Without policy changes, long term sustainability is simply not possible."

"Data and surveillance are the most crucial outputs of FODH. If they can show some of its partners who have capacity to collect statewide or countywide data; how to start doing some data collection and analysis, we can take up parts of the data collection from FODH. We will need training. But, it will be a shame to see the data being lost if FODH was to go away. That needs to keep happening. Partners may

not have the capacity to analyze data, but they can certainly make efforts to collect and disseminate raw data."

"The training for providers and law enforcement as well as the Right to Know Campaign materials can be housed on partner websites as a regular feature. At least parts of FODH activities can be transitioned over to partners. Partners can't do a state-wide activity, but can commit to different regions and divide the work."

- Partners expressed **willingness to participate in sustainability initiatives** and suggested that FODH can bring partners together to discuss the same.

"FODH should inventory what kind of networks each of its partners has. They should look into the mechanisms of distribution of information for each network. It will help them in figuring out what help can be provided by which organization."

"FODH should organize a special work-group session for this during annual conference. Partners can brainstorm and decide what each of them can do. FODH needs to tell us what they need, how we can integrate some of their elements. It makes it easier to be a part of the solution when you have identified the problem."

Summary of Findings

Each module of FODH has contributed to creation of newer partnerships and enhanced resources for improving the quality of life for persons with disabilities in Florida.

Right to Know Campaign—Module B

The RTK campaign has been **successfully launched in all the 67 counties of Florida** and has established partnerships with organizations that work in the area of disability, breast health and aging, and health care facilities throughout the state. The **RTK staff has traveled across the state and tabled events at public expos** to increase awareness of people about breast cancer in persons with disabilities. It has **published a Mammography Accessibility Resource Guide** providing information to women about the accessibility of mammography facilities in their area/county in order to help them both select where to make their appointments (if they have a choice), and prepare for their visit based on the accessibility factors. **Analysis is underway using data from the Behavioral Risk Factor Surveillance System (BRFSS) to compile reports on breast cancer screening behavior among Floridian women**. In addition **work is underway to develop** more demographic and health care access **questions** that will enable the RTK staff **to track screening rates and changes in screening behavior**, both statewide and by county, and to elucidate possible outcomes of the Right To Know campaign in counties where dissemination activities have occurred.

The RTK campaign is also **tracking the dissemination of kits and bulk printed materials** to campaign partners as well as non-partners (such as healthcare facilities). A CDC-developed tracking form has been modified to record the types and quantities of materials that are distributed as part of RTK as well as **track partners' dissemination activities/events**. This information is currently being entered into a Microsoft Access database. The RTK has also **collected qualitative data on how the materials are being utilized** by partners and how the materials are being used in health education activities of the partner organizations. These data **indicate ways to additionally engage and support partners, describe barriers or facilitators associated** with the dissemination activities, and aid in understanding their reactions and receptivity to the material's content. They also help to trace the path of dissemination to the target audience and inform subsequent dissemination in remaining areas of the state. An **outcome evaluation will be internally conducted by RTK team** to identify and document the extent to which knowledge and

awareness of mammography screening has changed among women who received RTK campaign materials, and to describe self-efficacy and health seeking behavior associated with obtaining a mammogram among women who received RTK campaign materials. A follow up with these women is intended to determine changes in their screening behavior/rates over time.

The RTK campaign has worked on the **establishment of campaign partner organizations that have designated personnel assigned to the campaign** promotion and buy-in due to their missions, which encompass disability support and breast cancer education/screening. The **materials are available digitally and are ready to be reproduced and published beyond the grant period**. To increase the involvement of the partnership, the **campaign team is also exploring additional sustainability strategies such as designating one of the statewide partners as the new campaign liaison for the CDC**. It is expected that year 5 of the Right to Know campaign will be devoted to activities aimed at ensuring its sustainability in Florida beyond Year 5.

Training professionals and paraprofessionals in disability—Module E

Module E has **developed a one-hour disability training course for healthcare providers**. **Work is underway for a second training** module focused on developmental disabilities to develop a film featuring people with developmental disabilities, family members, and healthcare providers. **An advisory panel was also formed** of Florida leaders in disability and health education **to consult on the continuing education in disability training**. This panel will play a crucial role in dissemination efforts and sustainability planning in years 4 and 5. **Free online CME/CEU courses** for 1 credit hour have been arranged through the Area Health Education Centers to offer continuing education credits for physicians, nurses, and mental health providers for this training. Collaborative **work is in process with the continuing education office at CDC** to ensure that the certification will be national instead of being limited to Florida providers.

Data collection is underway with two objectives of gathering and analyzing **evaluation data for the Disability Module** and providing continuing education on disability to healthcare providers. The first training addressed healthcare access for persons with physical and sensory disabilities. Module specific **evaluation** was **conducted** by a team leader **to measure change in medical student's attitude toward people with disabilities, comfort level providing care to patients with disabilities and disability knowledge. Significant gains were found in all three measures.** As part of the curriculum, medical **students conducted home visits with volunteers who have disabilities** and have turned in reflection papers that show that **students are learning very valuable lessons in humility, respect and consideration of the rights of persons with disabilities** to comprehensive quality of care. An **evaluation plan has been designed for the training of the healthcare providers** by the Project Coordinator. Feedback forms will be collected from healthcare providers who take the online disability training. The comments received will be analyzed regularly. The **training content will be revised at least once a year** to keep it current and to reflect feedback from the advisory panel and training participants.

Module specific sustainability plans are underway and **collaborative work is in process with the continuing education office at CDC to ensure that the certification will be national** instead of being limited to Florida providers. The **web-based trainings will be hosted on Nisonger center's website** (The principal investigator is affiliated with this center) to enhance nationwide access to training opportunities.

Supplemental surveillance—Module F

Module F has **enabled quantification of risks and outcomes of interest** across populations. The FODH Supplemental Surveillance module added questions to BRFSS to increase the richness of disability and

health data collected and analyzed through the Office on Disability and Health for its Partners. **During 2008, 13 questions collected information from Florida adults on their experiences with caregiving** and about people they provide care for. **During 2009, 9 questions were added to BRFSS on access to healthcare** for people with disabilities. **During 2010, the focus was to collect disability attitudes/perceptions data** through 8 questions; in 2011 five questions will be added to BRFSS to analyze Visitability. **The partners have commented** in the interviews **that the data** reports on caregiving in Florida, FODH-supported questions and standard BRFSS questions on the county-wide prevalence of disability in Florida, web-surveys modeled on the BRFSS and access to care among young adults with disability **have assisted them in evidence based program planning, resource allocation, and pursuing newer grant resources where needed**. The surveillance module has made all its reports available on the FODH website as well as disseminated them to the partnership. The **data has been used to inform the annual recommendations and policies of the Governor's Commission on Disabilities**.

The FODH also **works with agencies to develop their capacity to analyze BRFSS data** when possible using CDC's new Web-Enabled Analysis Tool (WEAT) for the BRFSS. FODH also is **available to contract with partners for larger data collection projects and provide expert testimony** to the Governor's Commission on Disabilities and the Governor's Commission on Autism. The FODH director served on the Institute of Medicine's committee on The Future of Disability in America. The FODH **has applied for and been awarded a number of related grants and contracts** to extend its work on disability and health issues.

Findings from web-survey of partnership

- The web-survey of the partnership shows that the **partnership organizations are a diverse mix of organizations** representing educational institutions (19.4%), Advocacy and policy (16.4%), Clinical services (13.9%); Training and technical assistance (13.9%); and prevention and promotion (8.3%) **from at least 50 of the state's 67 counties** speaking to the evidence of the broad reach of the FODH partnership.
- **Partner organizations described their association** with FODH as (**30.4%**) *Share information only (**Communication**)*, **14.5%** described their relationship as *Work together as an informal work group to achieve common goals (**Cooperation**)* and an equal number (**13%**) said they *Work together as a formal team to achieve common goals (**Collaboration**)* **or** said they *work together as a formal team across multiple projects to achieve common goals (**Partnership**).* An additional **29%** reported that they did not work together at all (**Unlinked**).
- At least **70% respondents agreed about the effective functioning of FODH** when it came to its function of *encouraging diverse partnership representation* (71.4%); *promoting public support of programs and issues to sustain its mission* (79.5%); *offering opportunities to voice opinions in community/statewide issues or to participate in the strategic planning* (71.4%) and *publishing disability specific data and resources (79.5%)*. At least two-thirds of respondents (60%) agreed that *FODH effectively provides technical assistance as needed* and a third (30%) were undecided with the statement. It is possible that the respondents choosing "undecided" are unaware of these functions of FODH and therefore unsure about their effectiveness.
- The respondents rated the extent of their/their organization's familiarity with the three FODH module activities by selecting one of the following responses-- *Not aware; Aware but NOT utilized; Utilized; Utilized AND recommended to others; and Shared with others/Recommended to others. 67% of the respondents (n=50) answered this question.* **Between 38% and 48% respondents were not aware of the specific modules.** At least another third were aware of the modules but had not

utilized them. More respondents had shared the module materials or recommended them to others than having utilized it themselves.

The above findings show that the FODH has had a great impact on enhancing the quality of life for persons with disabilities in the state of Florida within a short span of 4 years. It has developed a rich network of partner organizations, transferred skills, developed newer resources, inspired collaborative work and brought the disability community together to make lasting contributions that have been widely appreciated by the stakeholders. Each of its modules has begun taking steps towards sustainability of the program after the grant period is exhausted and has its own evaluation plan that adds to the credibility and effectiveness of the Office on Disability and Health.

Interviews with key partners

The interviews compared the nature of resources that existed in the disability arena before the existence of FODH and how having FODH had made any difference to the opportunities, services and resources available in the disability arena. The interviews gauged key partner's perceptions about the impact of collaboration with FODH on the direct working, resources, activities and policies of each organization and solicited their feedback for future improvement in FODH as well as development of a sustainability plan for FODH in near future.

Creation of FODH as a comprehensive statewide disability organization was thought to have enhanced the capacity of disability organizations to see overlapping issues across disabilities and partner with each other for common goals. As a central independent organization, FODH was said to have helped pool resources and give increased visibility to disability issues in public health arena. Partner organizations commonly felt that the resources such as trainings for health care professionals, disability specific information, etc. had been available through various local, regional and statewide issue-focused organizations long before the existence of FODH. However, since no comprehensive organization existed at state level, **creation of FODH was perceived as a capacity building measure for the disability community in Florida.** Partner organizations acknowledged that FODH has **created very valuable resources through the three modules** and helped in bringing disability to the forefront.

FODH was considered by all its partners as a **credible source of information** on account of the quality data generated and its **ability to balance the role of academicians with that of community based stakeholder-focused work through its modules** for healthcare professional education and Right to Know campaign. While most partners thought that the data generated through FODH can **potentially help channel more funding for their programs**, they commented that it was difficult to keep track of such an increase based on data used to justify need. Partners agreed in one voice that their collaboration with FODH had **enhanced their organizational capacity as well as strategies adopted, activities undertaken and services provided**.

Partners were aware that FODH is a grant funded project and acknowledged that CDC grant award funds will end at some point. However, they thought of FODH as a **capacity building project and expressed willingness to take on a few elements of the FODH functions** as their own. It was suggested that partner agencies could **incorporate some aspect of FODH strategic plan element into their organizational plan** to ensure uniform focus and policies across the state. It was observed that partners may not have the capacity to analyze data like FODH, however, **partners could help by collecting and disseminating raw data to other agencies** identified by **FODH**. It was suggested that the **training** for providers **and** law enforcement as well as the Right to Know Campaign **materials can be housed on partner websites** as a regular feature. While partners acknowledged their limitation in carrying out state-wide activity, it was suggested that regional partners can shoulder the responsibility of hosting

these materials or their specific region. Partners expressed **willingness to participate in sustainability initiatives** and suggested that FODH can bring partners together to discuss the same.

Recommendations

1. It may be noteworthy that each organization has nominated one staff member to the partnership. Due to staffing limitations, the partner staff may have had limited opportunity for direct interaction (annual meeting, partnership phone call)with FODH. It might be prudent to **ask the partners to designate an alternate contact whenever possible.**
2. At least 70% respondents agreed (Strongly agree/Agree) about the effective functioning of FODH and nearly a third of Partners rated the effectiveness of some of the FODH functions as "undecided". 47.9% indicated that they were not aware of the surveillance module. From among these, nearly half, 47.6% (n=10) had been a partner for less than a year, 56.5% (n=13) had no contact with FODH in the past year and 81.8% (n=18) had never attended a partnership call. While FODH does update its Partners about its activities through partnership calls and newsletters, it may want to consider showcasing its achievements and partner collaboration results at the annual meeting to address this issue in the future. FODH can also **conduct a periodic survey of partnership members and direct its awareness, dissemination and outreach activities at those members that are new and/or who have not attended any partnership calls or annual conferences**.
3. To ensure sustainability of the FODH, staffing structures that can work on **integrating elements of the current program into partner organizations** will be crucial. One step in this direction has been taken by RTK campaign by designating one of the statewide partners as the new campaign liaison for the CDC. The training of healthcare providers may be added to CDC's continuing education courses making it available long after the grant goes away. Something similar could be done for data surveillance module by integrating aspects of it into state health department or another such state entity which can make the data available to partners for analysis.
4. A periodic survey of partners to ascertain any benefits they may have gained as a result of their collaboration with FODH will need to be documented for evaluating the impact of a capacity building project such as FODH. This may include grant awards, recognitions, paper publications, increases in use of disability graphics, etc. as a result of FODH activities such as data reports.
5. Anticipating future needs for sustaining the program is challenging. However, FODH will need to take steps to anticipate needs for integration of its program elements into the Universities, law enforcement agencies, state departments, community based organizations, etc. and take steps to facilitate such an integration. A great step has been FODH supporting 50% of a position within the Bureau of Chronic Disease Prevention and Health Promotion to better integrate disability into the state's activities.
6. Partners have indicated willingness to participate in sustainability planning. This is an excellent opportunity for FODH as high participant morale is a sign of their commitment to the goals of the organization beyond its grant period. FODH should include sustainability as a topic in all its partnership calls and conferences.

Appendix 1: List of publications and reports by FODH

FODH peer review publications

1. *Cannell MB*, Brumback BA, Bouldin ED, Hess, J, Wood DL, Sloyer PJ, Reiss JG, Andresen EM. Age group differences in health care access for people with disabilities: Are young adults at increased risk? Results from the 2007 Florida Behavioral Risk Factor Surveillance System. (Submitted: *J Adolescent Health*)
2. Hall AG, Bouldin ED, Andresen EM, *Ali AK*. Factors associated with residential stability and caregiver employment among individuals with developmental disabilities living in the community. (Submitted: *J Intellectual Dis Research*)
3. Horner-Johnson W, *Suzuki R*, Krahn G, Andresen EM, Drum C. The structure of health-related quality of life in US populations: people with and without functional limitations. *Qual Life Res:* in press.
4. Brumback BA, Bouldin ED, *Cannell MB*, Andresen EM. Testing and estimating model-adjusted effect-measure modification using marginal structural models and complex survey data. *Am J Epidemiology* 2010; doi: 10.1093/aje/kwq244.
5. Rapalo D*, Davis J*, Burtner AP, Bouldin ED. Cost as a barrier to dental care among people with disabilities: A report from the Florida Behavioral Risk Factor Surveillance System (BRFSS). Special Care in Dentistry 2010;30(4):133-9.
6. McGuire LC, Bouldin EL, Andresen EM, Anderson LA. Examining modifiable health behaviors, body weight, and use of preventive services among caregivers and non-caregivers aged 65 years and older, Hawaii, Kansas, and Washington using BRFSS, 2007. *J Nutr Health Aging* 2010; 14(5): 373-379.
7. DeFries (Bouldin) EL, McGuire LC, Andresen EM, et al. Caregivers of older adults with cognitive impairment. *Prev Chron Dis* 2009; 6(2): http://www.cdc.gov/pcd/issues/2009/apr/08_0088.htm.
8. Horner-Johnson W, Krahn G, Andresen EM, Hall T. Developing summary scores of health-related quality of life for a population-based survey. *Public Health Rep* 2009; 124(1): 103-110.
9. Boslaugh SE, Andresen EM, *Recktenwald A*, Gillespie K. Evidence for a potential bias in the Health and Activity Limitation Index as a health preference measure for persons with disability. *Disability Health J* 2009; 2(1): 20-26.
10. *Winter KH*, Bouldin ED, Andresen EM. Lack of choice in caregiving increases the carer's risk of stress: findings from the North Carolina BRFSS. *Prev Chronic Dis* 2010; 7(2): http://www.cdc.gov/pcd/issues/2010/mar/09_0037.htm.
11. *Neugaard BI*, Andresen EM, McKune SL, *Jamoom EW*. Health-related quality of life in a national sample of caregivers: Findings from the BRFSS. *J Happiness Studies* 2008; 9: 559-575.
12. DeFries EL, Andresen EM, Classen S. The intersection of public health data and rehabilitation practice. *Topics in Geratr Rehabil* 2008: 24(3): 185-191.

Italics indicate student authors

FODH presentations

1. *Cannell MB*, Brumback BA, Bouldin ED, Andresen EM. Age group differences in health care access for people with disabilities: are young adults at increased risk? (poster). Society for Epidemiologic Research, Seattle, June 2010.

2. *Akhtar WZ*, Andresen EM, Bouldin ED. Vision impairment and falls among non-institutionalized adults aged 65 and older (poster). Society for Epidemiologic Research, Seattle, June 2010.
3. *Knox CA, Crawford AJ, Appleton EJ*, DeFries EL, Rimmer J. Disability and physical activity in Florida: the correlates of physical activity among Floridians with disability using the 2007 Behavioral Risk Factor Surveillance American Public Health Association Annual Meeting. San Diego, California, October 2008.
4. *Winter K,* DeFries EL, Andresen EM. Lack of Choice in Caring Increases the Carer's Risk of Stress: Findings From NC (poster). Society for Epidemiologic Research, Chicago, June 2008
5. *Zeinomar N, Caracciolo J*, DeFries EL, Andresen EM, Brumback BA. Natural disasters and disability: Case study of the Florida 2004 hurricane season (poster). 13th Annual Epidemiology Statewide Seminar, Orlando, FL, May 2008.
6. *Zeinomar N, Caracciolo J*, DeFries EL, Andresen EM, Brumback BA. Natural disasters and disability: Case study of the Florida 2004 hurricane season (poster). American College of Epidemiology: Positioning Epidemiology for a Changing Environment – the Next 25 Years, Ft. Lauderdale, FL, September 2007.
7. DeFries EL, Andresen EM. Development of State Capacity to Conduct Caregiver Surveillance, and Development of the BRFSS Caregiver Module. Using BRFSS to Assess How Caregiving Impacts Your State. 24th Annual BRFSS Conference. Decatur, Georgia, March 27, 2007.
8. DeFries EL, Andresen EM. Caregiver Outcomes: The Public Health Perspective. Caregiver Health: Link between Prolonged Stress and Illness at Family Caregiving: State of the Art, Future Trends; Family Caregiver Alliance Preconference Special Program. Chicago, Illinois, March 6, 2007.

Italics indicate student authors

FODH Reports, Articles, and Book Chapters (not peer-reviewed)

1. Andresen EM. Epidemiology and biostatistics. In: Lollar D, Andresen EM (Eds). *Public health perspectives on disability.* New York: Springer (anticipated publication date: winter 2010).
2. Heaphy DG, Mitra M, Bouldin ED. "Disability and Health Inequity" in Lollar D, Andresen EM (Eds), *Public health perspectives on disability*. New York: Springer (anticipated publication date: winter 2010).
3. Andresen EM, *Cannell B, Akhtar W*, Barney KF. Looming disease burden associated with the aging process. In: Barney KF, Perkinson MA (Eds). *Occupational therapy with older/aging adults: enhancing quality of life through collaborative practice.* Maryland Heights, MO: Elsevier (anticipated publication date: winter 2010).
4. Andresen EM, Bouldin ED, Friary J, Moorhouse M. Disability Perceptions and Experiences in the State of Florida. Florida Focus, Volume 6, no.2 (Publication Date October 2010).
5. DeFries (Bouldin) EL, Andresen EM. Caregiver health. In: Cavanaugh JC and Cavanaugh DK, Eds. *Aging in America: Vol 2. Psychological, physical, and social issues.* Westport, CT: Greenwood Publishing Group, 2010: 81-99.
6. *Cannell MB*, Bouldin ED, *Kusano CT*, Tamayo CC, Andresen EM. Caregiving and Older Floridians. *Florida Office on Disability and Health*, August 1, 2010. On line at http://fodh.phhp.ufl.edu/publications/

7. *Kusano CT*, Bouldin ED, Brumback B, Andresen EM. The Impact of Care Recipient Age among Caregivers in Florida, 2008. *Florida Office on Disability and Health.* July 10, 2010. On line at http://fodh.phhp.ufl.edu/publications/
8. Andresen EM, Bouldin ED. Final Report: A Web-based Proxy Survey of the Health of Floridians with Disabilities. *Florida Office on Disability and Health.* June 28, 2010. On line at http://fodh.phhp.ufl.edu/publications/
9. Bouldin ED, Andresen EM, Vaughn B, Meyer J. State of Florida Employment Survey. *Florida Office on Disability and Health*. June 8, 2010. On line at http://fodh.phhp.ufl.edu/publications/
10. Bouldin ED, Cannell MB, Andresen EM. Interim Report: A Web-based Survey of the Health of Floridians with Disabilities. *Florida Office on Disability and Health,* May 28, 2010. On line at http://fodh.phhp.ufl.edu/publications/
11. Andresen EM, Bouldin ED, *Friary J*, Moorhouse M. *Disability perceptions and experiences in the state of Florida. Results of a telephone survey of randomly selected Florida residents*. The Florida Office on Disability and Health and University of Florida Survey Research Center, April 8th, 2010. On line at: http://fodh.phhp.ufl.edu/publications/
12. *Cannell MB*, Nur U, Bouldin ED, Andresen EM. Access to Health Care and Health Behaviors Among Young Adults With and Without Disability in Florida: A Report from the Florida Behavioral Risk Factor Surveillance System 2007. *Florida Office on Disability and Health,* January 4, 2010. On line at http://fodh.phhp.ufl.edu/publications/
13. Bouldin ED*, Akhtar W,* Brumback B, Andresen E. *Characteristics of caregivers and non-caregivers – Florida, 2008.* May 9, 2009. On line at: http://fodh.phhp.ufl.edu/publications/
14. McKune S, *Lee B*, Andresen EM, Bouldin E. *Health and health care access of persons with disability in Florida.* Preliminary report from a web survey: first 8 weeks. April 6th, 2009 On line at: http://fodh.phhp.ufl.edu/publications/
15. Bouldin ED, *Akhtar W*, Brumback B, Andresen E. *Characteristics of caregivers of care recipients with and without memory or thinking problems – Florida, 2008.* April 6th, 2009. On line at: http://fodh.phhp.ufl.edu/publications/
16. *Crawford AJ*, Bouldin ELD, Andresen EM, Brumback BA. *Health behaviors among people with and without disability: 2007 Florida Behavioral Risk Factor Surveillance System*. April 2nd, 2009. On line at: http://fodh.phhp.ufl.edu/publications/
17. Hauptman H, Wynkoop K, Bouldin ED, Andresen E. Population-level caregiving information for Washington. *Senior Digest*: Seattle King County, April 2009. On line at www.seniordigest.org/skc
18. *Crawford A*, DeFries (Bouldin) E, Brumback B, Andresen E. *Characteristics of caregivers and care recipients – Hawaii, 2007.* December 3, 2008. On line at: http://fodh.phhp.ufl.edu/publications/
19. *Crawford A*, DeFries (Bouldin) E, Brumback B, Andresen E. *Characteristics of caregivers and care recipients – Kansas, 2007.* December 3, 2008. On line at: http://fodh.phhp.ufl.edu/publications/
20. *Crawford A*, DeFries (Bouldin) E, Brumback B, Andresen E. *Characteristics of caregivers and -care recipients – Washington, 2007.* October 13th, 2008. On line at: http://fodh.phhp.ufl.edu/publications/
21. *Crawford A*, DeFries (Bouldin) E, Brumback B, Andresen E. *Characteristics of kinship caregivers and -care recipients – Washington, 2007.* October 8th, 2008. On line at: http://fodh.phhp.ufl.edu/publications/

22. Buchanan M, Andresen EM, DeFries E. *Florida disability and health issues survey*. Final Report Florida Office on Disability and Health, Sep 2008. On line at http://fodh.phhp.ufl.edu/publications/

23. Brumback B, Andresen E, DeFries E, Xu X. *Adult disability prevalence: Florida 2007 Behavioral Risk Factor Surveillance System.* Florida Office on Disability and Health, August 2008. On line at http://fodh.phhp.ufl.edu/publications/

24. Andresen E, Hall A, DeFries (Bouldin) E, *Ali A*. *Agency for Persons with Disabilities waiver program wait list survey.* University of Florida Department of Epidemiology and Biostatistics, August 8th, 2008. On line at: http://fodh.phhp.ufl.edu/publications/

25. Andresen EM. Disability epidemiology. In: Boslaugh S (Ed), *Encyclopedia of epidemiology.* Thousand Oaks, CA: Sage Publications, 2007; Vol 1: 272-275

26. *Jackson W*, DeFries E, *Jamoom E*, Andresen E. *The Florida chartbook on disability and health.* Department of Epidemiology and Biostatistics, University of Florida, 2007. On line at http://ebs.ufl.edu/FloridaChartbookDisabilityandHealth.pdf.

Italics indicate student authors

Appendix 2: Web-based FODH Partnership Survey

Dear Partner: Your input in this evaluation process is much appreciated. We are interested in your thoughts and opinions about the Florida Office on Disability and Health (FODH) and would like to ask you to complete this brief 10 minute survey. Thank you very much for your valuable insight and time!

1. Are you aware that the mission of FODH is to maximize health, well-being, participation, and quality of life, throughout the lifespan, of all Floridians and their families living with disability?
    a. Yes
    b. No
2. How long have you/your organization been part of the FODH partnership?
    a. Less than 6 months
    b. More than 6 months but less than one year
    c. One to 2 years
    d. Two to 3 years
    e. Three to 4 years
    f. More than 4 years
3. Within the past year, how often have you had direct contact with FODH (e.g., meetings, phone calls, emails, faxes, or letters) ?
    a. No contact
    b. Daily
    c. Weekly
    d. Monthly
    e. Quarterly
    f. Yearly
4. How often do you attend a partnership call?
    a. Not at all
    b. At least once every quarter
    c. At least twice a year
    d. More than thrice a year
5. Which of the annual meetings organized by FODH have you attended? (Check all that apply)
    a. None
    b. 2008 (major topic: strategic planning)
    c. 2009 (major topic: caregiving)
    d. 2010 (major topic: access to healthcare)
6. Which of the following best describes your/your organization's relationship with FODH?
    a. Do not work together at all
    b. Share information only
    c. Work together as an informal work group to achieve common goals
    d. Work together as a formal team to achieve common goals
    e. Work together as a formal team across multiple projects to achieve common goals
7. Has FODH offered you/your organization an opportunity to meet new disability related organizations/individuals?
    a. No
    b. Yes
    8. If yes, please describe how FODH has offered the opportunity to network with disability related organizations/individuals? _____

9. Please select an answer choice that best describes the effectiveness of following FODH functions:

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
FODH encourages diverse partnership representation.	☐	☐	☐	☐	☐
FODH offers opportunities for partners to leverage resources.	☐	☐	☐	☐	☐
FODH helps to minimize duplication of efforts and services.	☐	☐	☐	☐	☐
FODH promotes public support of programs and issues to sustain its mission.	☐	☐	☐	☐	☐
FODH offers opportunities to voice opinions in community/statewide issues or to participate in the strategic planning.	☐	☐	☐	☐	☐
FODH helps advocate for policy change efforts by enlisting political/constituent support.	☐	☐	☐	☐	☐
FODH helps with changing community values around disability through systems change by promoting community buy-in.	☐	☐	☐	☐	☐
FODH publishes disability specific data and resources.	☐	☐	☐	☐	☐
FODH provides technical assistance as needed.	☐	☐	☐	☐	☐

10. Which statement best describes the extent of your/your organization's familiarity with the following FODH module activities:

	Not aware	Aware but NOT utilized	Utilized	Shared with others
Which statement best describes the extent of your/your organization's familiarity with Module B: Right to know campaign? (This campaign promotes breast cancer screening among women living with physical disabilities through the dissemination of print and audio health education materials)	☐	☐	☐	☐
Which statement best describes the extent of your/your organization's familiarity with Module E: Training Professionals and Paraprofessionals in Disability (This project provides disability training to medical students and continuing education training to health professionals across the state)	☐	☐	☐	☐
Which statement best describes the extent of your/your organization's familiarity with Module F: Supplemental Surveillance (This module supports collection of disability specific data through Florida's Behavioral Risk Factor Surveillance System (BRFSS) to increase the richness of disability and health data collected and analyzed through FODH)	☐	☐	☐	☐

(If answered "utilized" then ask):

11. If your organization/agency utilized or shared the module materials, how were they useful?

_____
_____

12. If your organization/agency utilized or recommended the training, how was it useful?

_____
_____

13. If your organization/agency utilized or shared the surveillance data, how were they useful?

_____
_____

14. If the funding for FODH was to go away, what would you/your organization be willing to do to sustain the momentum gained by this statewide disability partnership?

_____
_____

15. Please provide your suggestions for what other activities FODH should engage in?

_____
_____

16. Which of the following best describes you? (Select one)

    a) Lay individual/Self-advocate
    b) Representative of an organization/agency

17. (If answered 16-a) What county do you live in? _____

(Answer questions 18-20 ONLY If answered 16-b)

18. What is the name of your agency/organization? _____

19. What is your organization's primary focus?
    a) Prevention and promotion
    b) Clinical services
    c) Surveillance, evaluation, and research
    d) Training and technical assistance
    e) Advocacy and policy
    f) Education
    g) Other. Please specify _____

20. Which of the following is the best description of areas served by your agency/organization?

    a) All Counties in Florida (Statewide)
    b) Some counties in Florida

21. (If answered 20-b) Which of the following counties are served by your agency/organization? (Check all that apply)

☐ All Counties in Florida	☐ **Miami**-Dade	☐ Hendry	☐ Liberty	☐ Pinellas	☐ Wakulla
☐ Alachua	☐ Desoto	☐ Hernando	☐ Madison	☐ Polk	☐ Walton
☐ Baker	☐ Dixie	☐ Highlands	☐ Manatee	☐ Putnam	☐ Washington
☐ Bay	☐ Duval	☐ Hillsborough	☐ Marion	☐ Saint Johns	
☐ Bradford	☐ Escambia	☐ Holmes	☐ Martin	☐ Saint Lucie	
☐ Brevard	☐ Flagler	☐ Indian River	☐ Monroe	☐ Santa Rosa	
☐ Broward	☐ Franklin	☐ Jackson	☐ Nassau	☐ Sarasota	
☐ Calhoun	☐ Gadsden	☐ Jefferson	☐ Okaloosa	☐ Seminole	
☐ Charlotte	☐ Gilchrist	☐ Lafayette	☐ Okeechobee	☐ Sumter	
☐ Citrus	☐ Glades	☐ Lake	☐ Orange	☐ Suwannee	
☐ Clay	☐ Gulf	☐ Lee	☐ Osceola	☐ Taylor	
☐ Collier	☐ Hamilton	☐ Leon	☐ Palm Beach	☐ Union	
☐ Columbia	☐ Hardee	☐ Levy	☐ Pasco	☐ Volusia	

Appendix 3: Key Partner Interview guide

The FODH is one of the 16 state level programs in the country funded by CDC to inform policy and practice at the state level. The programs include health promotion activities and surveillance of health disparities. While each state program is different, they ensure that individuals with disabilities are included in ongoing state disease prevention, health promotion, and emergency response activities. As such the FODH has established an extensive partnership, organized annual meetings for networking and discussion on strategic planning in disability and health issues and implemented three modules.

- The Right to Know Campaign: Promoting breast cancer awareness and encouraging recommended screening among women 40 years of age or older who have a disability.
- Training medical students, as well as medical and allied health professionals: for increasing the capacity of health care providers in Florida to provide quality health care to people with disabilities.
- Surveillance: Increasing the quantity and quality of disability- and health-related data in Florida and providing the epidemiologic capacity to analyze these data.

Baseline questions:

1. In your opinion, before the existence of FODH, what was the nature of **Collaboration and partnerships in the disability arena?**
2. In your opinion, before the existence of FODH, what was the nature of funding and **investment patterns in the disability arena?**
3. In your opinion, before the existence of FODH, what was the nature of what were some of the **local/regional challenges in the disability arena?**
4. In your opinion, before the existence of FODH, what was the nature of state level **political support in the disability arena?**
5. In your opinion, before the existence of FODH, what was the nature of state level **availability of resources in the disability arena?** (e.g. education, dissemination, data collection (Web surveys); training in technology for making conferences/ programs accessible

Assessing Impact:

1. Can you describe any benefits of having collaborated with FODH?
    a. Have you seen any increase in monetary and nonmonetary resources, funding sources, in kind contributions, access to technology, due to your collaboration with FODH? If yes, please describe.
    b. Have you seen any enhancement in activities/services/strategies due to collaboration with FODH? If yes what?
2. As a result of partnering with FODH have there been any changes in your organization?

a. Change in written policies?

3. In your opinion what are some of the potential intended and unintended effects on people locally, regionally, nationally, etc.
4. What are some of the barriers/problems you have observed in the work of FODH and its partnership?
5. When planning sustainability for FODH, how do you think it can be maximized? What elements of the existing FODH activities/program would you will be willing to consider supporting, if funding was to go away?