2014 FLORIDA DISABILITY AND HEALTH NEEDS ASSESSMENT

UF | Florida Office on Disability and Health
UNIVERSITY *of* FLORIDA

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The mission of the Florida Disability and Health Program (DHP) is to achieve the inclusion of Floridians living with disabilities in local and statewide health promotion, wellness, disease prevention, and disaster preparedness activities.

Introduction

The Florida Disability and Health Program (DHP) is housed at the Florida Department of Health in the Bureau of Chronic Disease Prevention, and is supported by funding from the Centers for Disease Control and Prevention (CDC), National Center for Birth Defects and Developmental Disabilities (CDC/NCBDDD). The DHP works in collaboration with the University of Florida (UF) College of Public Health and Health Professions who were responsible for the Florida Office on Disability and Health under the previous CDC grant period. Currently, University of Florida staff assists the DHP with data collection and analysis necessary to establish baseline targets in Florida.

Methods for Data Surveys

The DHP conducted a needs assessment in the form of an in-depth survey asking key stakeholders, those individuals with a disability or individuals who work with Floridians living with disability, their opinions on local and statewide health promotion, wellness, disease prevention, and disaster preparedness activities. This report is based on Qualtrics survey responses, data from the 2012 Behavioral Risk Factor Surveillance System Survey and the 2012 People with a Disability Survey. This needs assessment is meant to help DHP develop and align goals and objectives to better understand and meet the needs of Floridians living with disabilities.

The 2012 People with a Disability Survey (PWDS) was developed by the University of Florida in partnership with the Florida Department of Health. The survey was administered by the UF Survey Research Center. The PWDS was a one-time random-digit dial telephone survey of non-institutionalized, community-dwelling, civilian adults aged 18 years and older. The sample was based on a sampling frame from completed records for the Florida Consumer Sentiment Index (CSI) Survey. Each month in Florida, a random sample of 500 households in Florida are surveyed. Participants to the CSI were re-contacted in 2012 and asked questions related to socio-demographic characteristics, disability status, access to health care, and emergency preparedness. Respondents (N=1,429) were classified as having a disability if they responded 'yes' to either of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional problems?" or, "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, or a special telephone?" Among respondents, 471 reported having a disability (33%).

We report prevalence estimates for barriers to care, emergency preparedness, and disease management measures for people with and without a disability. We also provide emergency preparedness estimates comparing survey respondents who are and who aren't caregivers of people with a long-term health condition or disability (respondents who respond "yes" to the question, "People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?") Findings are presented as proportions with accompanying 95% confidence intervals. All analyses were conducted using Stata v10.

The Behavioral Risk Factor Surveillance System (BRFSS), coordinated by the Centers for Disease Control and Prevention (CDC) and administered by the UF Survey Research Center, is a random-digit dial telephone survey of non-institutionalized, community-dwelling, civilian adults aged 18 years and older. BRFSS data are weighted to account for the complex sampling design of the survey and to represent the Florida population on the basis of density status, geographic region, number of residential telephone numbers, number of adults, age, gender, and race/ethnicity. The core BRFSS questionnaire includes questions about respondents' disability status, demographics, health behaviors, health outcomes, and health care access. BRFSS respondents (N=7,624) were classified as having a disability if they responded 'yes' to either of two questions: "Are you limited in any way in any activities because of physical, mental, or emotional problems?"(n= 1,997) or, "Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, or a special telephone?" (n=992). Among respondents, 2,229 reported having a disability. We report prevalence estimates for socio-demographic, quality of life, health behavior, healthcare access and utilization, chronic illness, and disease management measures for people with and without a disability. Findings are presented as weighted prevalence estimates with accompanying 95% confidence intervals. All analyses were conducted using Stata v10.

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In order to tailor activities and inform our Disability Community Planning Group (DCPG), one of the primary tasks of the Florida Disability and Health Program (DHP) is to solicit statewide feedback on needs for people with disability in Florida. To accomplish this task and assist DCPG in its mission, a web-based questionnaire was developed and distributed to 123 participants using Qualtrics software. Of 123 participants, 30 responses were received (24.4% response rate) of which 28 were used for analysis.

Survey respondents represented organizations such as Alzheimer's Community Care, the Centers for Independent Living in Florida, the Alliance for Aging, the Florida Disabled Outdoors Association and several county Departments of Health. Respondents' occupations varied and included CEOs, executive directors, nurses, program coordinators, grant writers, fundraisers, and community advocates. These organizations range in their outreach, with some focusing efforts on a few people with disabilities while others serve millions of people across the state.

Greatest Areas of Need

Survey respondents were asked to choose and rank areas of needs for people with disabilities that they felt were of greatest importance. The areas of need of greatest importance identified by our respondents were:

1. **Increasing the skill, knowledge, or awareness of health care professionals to better serve people with disabilities**

2. **Reducing access to health care barriers for people with disabilities**

3. **Increasing the number of people with disabilities receiving preventive and wellness screenings**

4. **Increasing participation and inclusion in health programs (e.g. chronic disease prevention programs such as diabetes prevention, asthma prevention, etc) for people with disabilities**

5. **Educating policymakers about the needs of people with disabilities**

Figure 1: Ranking of areas of need for people with disabilities

The remaining areas of need, as reported by the survey respondents, include:

6. Improving coordination of health care for people with disabilities
7. Improving patient-provider communication for people with disability
8. Educating care providers/caregivers about emergency preparedness
9. Including people with disabilities in inclusive emergency planning exercises.[i]

Please see Table 1 in the Appendix for more information.

Respondents were asked whether there were specific health-related programs that are most needed for the people with disability their organizations serve. Survey respondents overwhelmingly stated that there was a need for specific health-related programs with only one respondent saying there was not. Respondents suggested health promotion programs and disease specific management programs such as diabetes management for the people with disability they serve. Suggestions also included:

- Tobacco cessation programs
- Fall-prevention programs
- Dental care programs
- Wound management programs
- Programs catering to caregivers.[ii]

Respondents were also asked about key barriers faced by people with disabilities when accessing health-related programs. A consistent issue identified by respondents was the lack of proper communication and understanding by providers. Not only were tools needed to accommodate communication, sign language interpreters and video relay machines, but a lack of cultural competency was also evident. One respondent stated that many times a deaf/blind person would be taken by the hand and led around without direction. If an individual did have an interpreter that:

"…that person is talked to and not the Deaf Blind person. The Deaf Blind person is a person that needs to be treat[ed] just like the slighted/hearing [sic] person but at their level."

Other consistent issues included a lack of:

- Transportation to and from the providers offices
- Adequate health insurance to cover costs
- Adequate health care equipment that met people with disabilities' needs
- Follow-up care after discharge from a hospital or rehabilitative care facility.[iii]

Respondents were also asked whether they used or could recommend any strategies to increase participation among people with disability in health-related programs such as primary care, health promotion, and chronic disease management programs. Strategies suggested were both broad and disability specific. For instance, one respondent mentioned using special events and marketing strategies to advocate, educate, motivate, and support active lifestyles and health behaviors in the disability community. Other respondents mentioned providing translation services, cultural competency training for healthcare staff, and even specialized training for first responders and emergency preparedness volunteers. One respondent discussed the work they did targeting young adults aging out of their system or who did not qualify for their services due to reaching the program's age limit. This organization provided them with education and support for increased self-management, knowledge

about health care needs, and working with health care providers. Finally, one respondent reported their organization was helping increase access to primary care by providing a discounted rate/sliding fee scale for payment for patients with limited resources or no health insurance.[iv]

Respondents were then asked to suggest ways in which persons who deliver health programs could optimally reach people with disabilities. Respondents overwhelmingly suggested training programs for health care providers. Various respondents suggested that disability awareness and sensitivity programs be a part of medical school curriculum. Others suggested that the Department of Health should develop a training program that could be adapted to various health care settings to teach providers about cultural, linguistic, and accommodation needs of people with disabilities. One respondent suggested that health care providers use simulated activities during their training to better empathize with the needs of people with disabilities. For instance, this organization used ear plugs and blindfolds to demonstrate the point of view of people with disability.[v]

Ensuring that people with disability have access to health-related programs is critical for providing continuous, high quality health care. This is especially important given that people with disability suffer from a significantly higher proportion of chronic conditions. Data from the 2012 Behavioral Risk Factor Surveillance System Survey indicate that:

- 14.3% of people with disability reported heart attack, compared to 2.9% of people without disabilities
- 14.0% of people with disability reported a heart disease compared to 3.3% of people without disability compared to 3.3%of people without disabilities
- 7.9% of people with disability reported a stroke compared to 1.4% of people without disability
- 14.4% of people with disability reported having any other type of cancer compared to 5.2% of people without a disability.
- 73.1% of people with a disability reported currently having asthma compared to 57.3% of people without a disability.
- 18.7% of people with a disability reported being told by a doctor that they have COPD, emphysema, or chronic bronchitis, compared to 3.6% of people without disabilities.
- 54.5% of people with disabilities report being told by a doctor that they have arthritis, rheumatoid arthritis, gout, or fibromyalgia, compared to 15.4% of people without disabilities.
- 21.2% of people with a disability reported having diabetes compared to 6.3% of people without a disability.
- 9.6% of people with a disability reported having kidney disease compared to 2.2% of people without a disability.

Please see Graph 1 below.

Prevalence of Chronic Diseases in People with Disability, BRFSS 2012
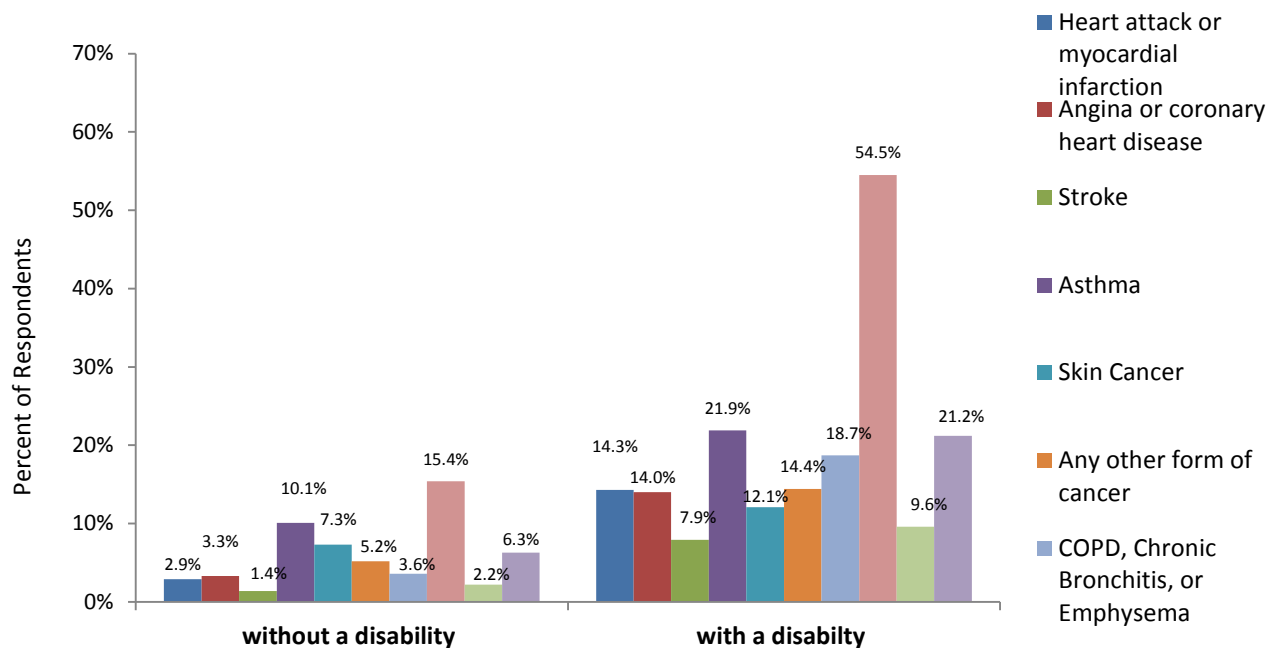
Graph 1: Prevalence of Chronic Diseases in people with disabilities

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Disability Health Program

Respondents were asked how DHP could best work with community health programs to develop protocols and strategies that meet the needs of people with disabilities. Respondents agreed that staff disability awareness training, images of people with disabilities in promotional materials, and accessible locations were all good strategies. Respondents had additional recommendations for DHP, as listed below:

- Assist programs in finding funding to provide services for people with disabilities
- Provide technical assistance and educate community health programs about possible consequences and remedies for violations of the Americans with Disabilities Act relating to access to care
- Raise awareness among community health programs of unmet needs of PWD.[vi]

Respondents were then asked which community programs DHP should prioritize to target their efforts and why those programs should be prioritized. Respondents agreed that rural County Health Departments, Federally Qualified Health Centers (FQHCs), and safety net hospitals should be targeted.

"These providers are in areas of the state [that] do not have the resources that larger metropolitan areas have to address the needs of individuals who are disabled and that might not have the economic resources to receive appropriate medical care."

Respondents also suggested looking into managed care organizations that authorize and approve health services as the state moves to Medicaid Managed Care Programs.[vii]

Emergency Preparedness

Disability affiliated organization representatives were asked how Public Health Emergency Planners can better recruit from the disability community for inclusive emergency planning exercises. Respondents suggested developing and maintaining collaborative working relationships with the following organizations in order to help with recruitment:
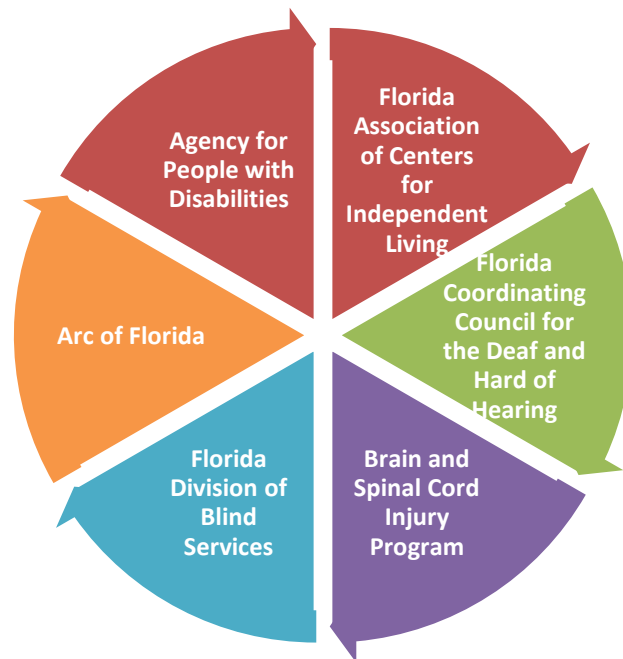

Figure 2: Organizations to Help with Recruiting for Emergency Planning Exercises

Other suggestions included:

- Holding town hall meetings
- Attending special events related to people with disabilities
- Becoming members themselves of disability-related committees and coalitions.

Another respondent suggested recruiting people from the disability community by reaching out to caregivers. One respondent echoed the importance of including people with disabilities in emergency planning exercises and shared an experience with a medical director who stated that it would not be feasible to use people with real disabilities during their exercises. The respondent also mentioned how

these first responders were afraid to deal with people with certain disabilities which, in their opinion, gave a clear indication that they did indeed need advanced training. [viii]

Next, respondents were asked to suggest best strategies for identifying formal and informal care providers for people with disabilities in order to educate them on the importance of planning for emergencies. Respondents suggested using local organizations like community agencies that provide support and services for people with disabilities. Respondents also suggested using the media and spreading the word though neighborhood associations and religious organizations. One respondent suggested that the Governor or the State Surgeon General could send a letter to licensed health care professionals about what actions these providers can take to encourage their patients with disabilities to take appropriate precautions. Another respondent suggested using a marketing professional familiar with healthcare professionals who could suggest strategies for this particular predicament.[ix]

Healthcare Services

Disability affiliated organization representatives were asked to identify and rank the top three healthcare services with the greatest barriers to access, as experienced by the organization's constituents. The healthcare services most often chosen by respondents, in order of most to least often chosen were:

| 1. Training on physical activity and fitness | 2. Annual primary care exams and training on good nutrition (TIED) | 4. Specific disease management training | 5. Preventive cancer screenings |

Figure 3: Healthcare Services with the Greatest Barriers to Access

Of the five healthcare services, annual primary care exams was ranked first most often, training on good nutrition was ranked second, and training on physical activity and fitness was ranked third.[x]

Please see Table 2 in the Appendix for more information.

When asked about the specific barriers faced by people with disabilities when trying to access these healthcare services, respondents mentioned:

- Transportation difficulties
- Unwillingness of providers to serve the disability population
- Lack of access to reasonable accommodations
- Certain programs not having at-home options
- Poor program design making it hard for people with disabilities to participate
- Cost/Service not covered by insurance[xi]

These sentiments are echoed by people with disabilities in the 2012 People with Disability Survey. Medicaid beneficiaries with a disability disproportionately experience barriers to care including issues with physical access and provider communication.

- 86% of Medicaid beneficiaries without a disability reported no barriers to care compared to only 43% of people with disability.
- 6% of people with a disability reported not being able to get into the exam room and 13% reported not being able to get on examination table, compared to 0.2% and 1% respectively for people without a disability.

Please see Graph below for more information.

Barriers to Care by Disability Status in Florida, PWD Survey 2012
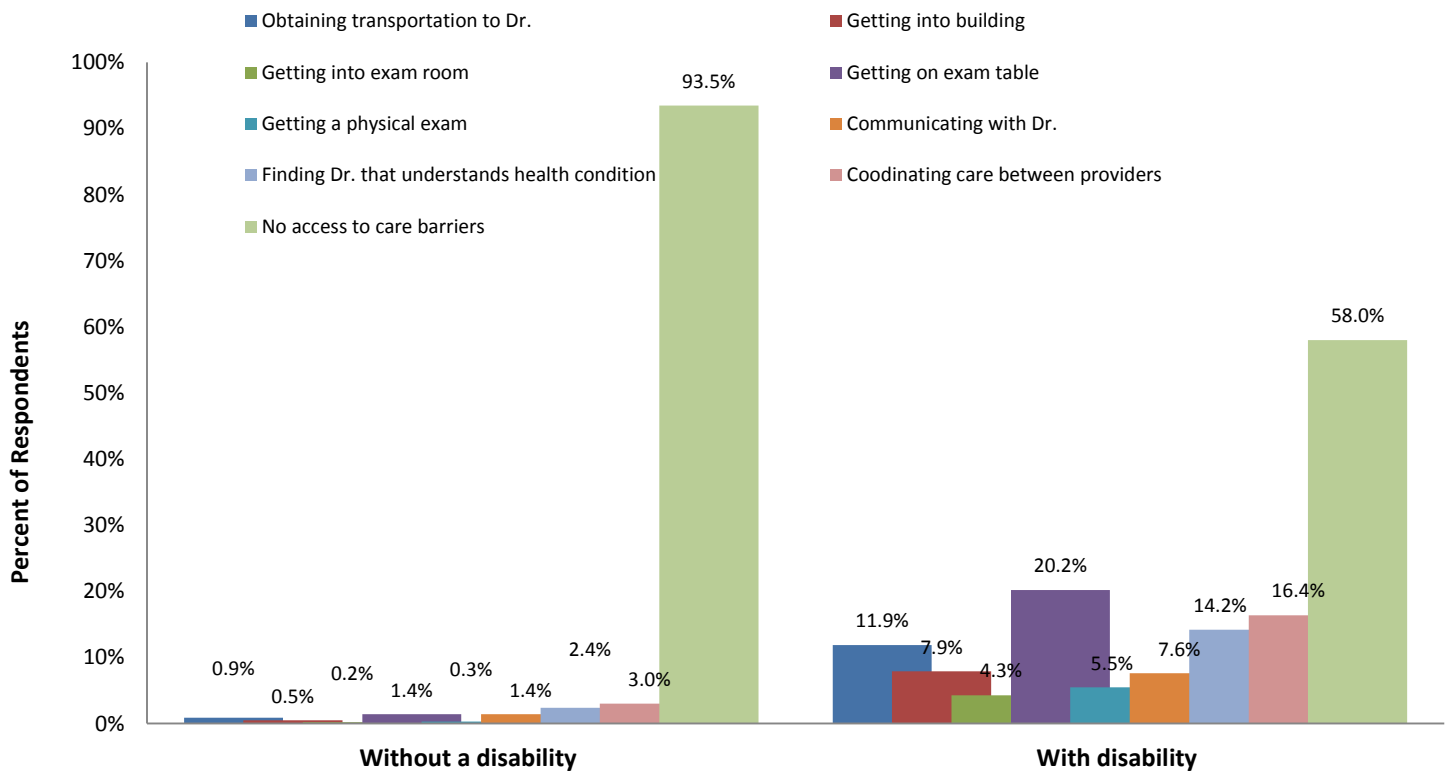
Graph 2: Barriers to Care by Disability Status in Florida, PWD Survey 2012

Respondents were asked to rank the service areas of greatest need among their constituents with disabilities. Of the thirteen options available, the six top choices in order of greatest need were:
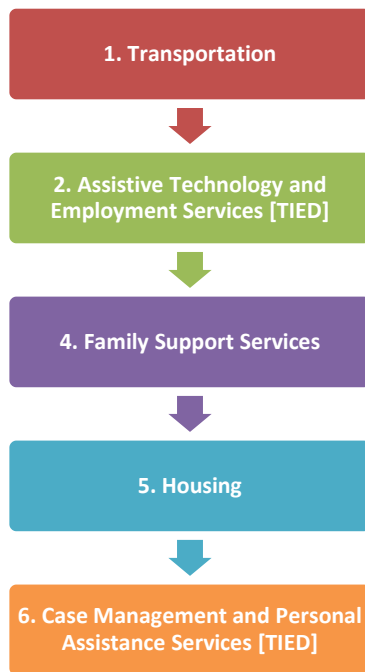

Figure 4: Service Areas of Greatest Need for people with disabilities[xii]

Please see Table 3 in the Appendix for more information.

Respondents were then asked to describe specific barriers related to the service areas listed in the prior question. Many respondents mentioned the lack of accessible and affordable housing. One respondent stated:

"Many advertised accessible housings are actually not accessible."

Other respondents mentioned the lack of reliable transportation and the limited schedules and routes of public and para-transportation. Other specific barriers mentioned included the lack of acceptable day care centers for children with disability and how these centers couldn't afford the staff to provide specialized services. Communication was another major issue mentioned throughout, not only for people who are deaf and hard of hearing but for people with disabilities whose primary language might not be English. Limited resource for caregivers was also mentioned, as there is a lack of support services for family caregivers and money for formal caregivers.[xiii]

Finally, respondents were asked what other health and safety concerns their constituents might have. One respondent identified home modification as one of the top three services requested by people with disabilities in their organization and how they had a waiting list for these services. Another organization representative echoed this need, discussing how people with disabilities sometimes lived in unsafe/unhealthy or risky living conditions:

"[I] have seen people who have been shut in for years due to no ramp for exit. [They] could not escape if a fire occurred."

Another respondent discussed concerns relating to emergency preparedness and response:

"Evacuation alerts, building evacuation, electricity, and transportation assistance to general special needs shelters are issues for these vulnerable populations that should be addressed by local governments, emergency managers, transportation, and housings managers."

Another area of concern mentioned was communication. One respondent discussed how establishing Support Service Providers for the Deaf-Blind would alleviate many barriers. Similarly, another respondent mentioned how many healthcare providers underestimate the importance of developing effective communication with people with disabilities:

"They do not understand their responsibilities under the ADA to provide reasonable accommodations. They don't know how to access the needed accommodations or don't want to for pay for accommodations."

Another concern mentioned repeatedly was support for caregivers. One respondent discussed the difficulties facing family caregivers of those with neurocognitive disabilities:

"The disease process is very aggressive and the financial and emotional toll is overwhelming for families."

If these families had the appropriate educational services and resources, the respondent continued, this would help tremendously in stabilizing the physical, emotional, and financial toll of the disease on these families.

Other specific areas of concern mentioned by respondents included:

- Being unable to afford dental care
- Having no financial support from agencies for physical exercise programs
- Being unable to shop for and afford healthy food choices
- Having a lack of knowledge in terms of resources for their specific disability.[xiv]

In-depth Questionnaire for DCPG Partners

The Florida Disability and Health Program (DHP) established the Disability Community Planning Group (DCPG) in 2012. The DCPG is comprised of community partners including disability agencies and organizations, disability advocates, people with disabilities, and caregivers of people with disabilities. In order to inform future programmatic efforts, the DHP solicited feedback from these partners to gauge partners' opinions of upcoming activities and objectives. A web-based questionnaire was developed and distributed using Qualtrics software. The link to the survey was emailed to 21 key community partners. A total of 17 responses were received, 11 of which were complete and used for analysis.

Ensuring Sustainability

Sustainability is defined as ensuring program activities and/or outcomes are continued over time after the life of the grant. Partners were asked what the DHP can do to ensure sustainability of programmatic activities tailored to people with disabilities. The current DHP activities include health promotion programs for people with disabilities, healthcare provider education to optimize quality care for people with disabilities and emergency planning and preparedness. Partners recommended a variety of solutions to ensure sustainability including:

- Exploring funding opportunities to support ongoing activities, including small grants to support provider education and health promotion programs.
- Communicating and working with local community partners and public health organizations to improve their ability to provide services and materials targeted toward people with disabilities.
- Disseminating DHP educational materials to the community (schools, disability agencies, non-profits).
- Embedding the disability perspective in all programs to help maintain attention to people with disabilities after the grant ends.

Improving Access to Primary Care and Health Promotion Program

Partners were asked what types of health programs people with disabilities would most benefit from (Figure 5).
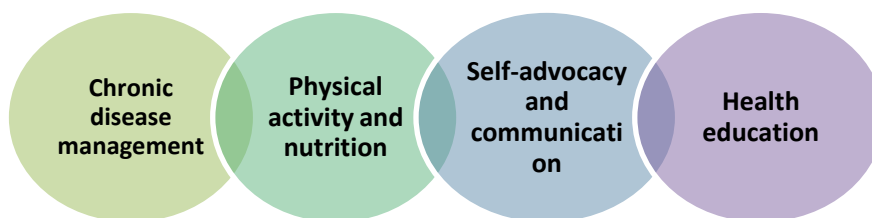

Figure 5: Health programs for people with disabilities

Respondents suggested chronic disease self-management programs such as diabetes self-management education, diabetes prevention lifestyle change and hypertension management would be valuable to

people with disabilities. Programs that focus on physical activity and nutrition were also considered to be important (e.g., programs targeted to help achieve a healthy and an active lifestyle through balanced nutrition choices and exercise).

Respondents also recommended that programs that include self-advocacy and communication components. Examples of communication components include educating people with disabilities on how best to communicate with health care providers, how to ask the right questions to improve understanding and adherence to recommended treatment plans, and how to talk with health care providers about symptoms and concerns. Additional primary care-related health programs that were mentioned by survey respondents included: health education programs (e.g., proper food supplies and nutrition, adequate supply of water and basic sanitation, immunization against major infectious diseases) and appropriate treatment of common diseases using appropriate technology.

Additionally, partners were asked about strategies to increase participation and inclusion in health oriented programs among people with disabilities. Direct communication with evidence-based chronic disease management programs was recommended.

- Organizations in Florida that are licensed to provide the Stanford Chronic Disease Self-Management Program are listed on Stanford's Patient Education Research Center website: http://patienteducation.stanford.edu/organ/cdsiteflorida.html.
- Evidence-based diabetes prevention programs in Florida can be found on CDC's diabetes prevention website: http://www.cdc.gov/diabetes/prevention/recognition/states/Florida.htm?choice=Florida.htm.
- Evidence-based diabetes self-management education programs in Florida can be found on the American Diabetes Association website: http://www.diabeteseducator.org/ProfessionalResources/accred/Programs.html#Florida or http://professional.diabetes.org/ERP_List.aspx.

Communicating and partnering with the following community organizations that promote wellness and direct marketing efforts specifically to people with disabilities was also suggested:

- Local departments of health
- Community health centers (FQHC and community clinics)
- Publix
- YMCA
- Churches that have specific ministries for people with disabilities
- Centers for Independent Living (CIL)
- Fraternal organizations (Lions, Elks, Moose, Kiwanis, etc.) that sponsor certain groups of people with disabilities
- Jewish Community Centers (JCC)

A follow-up question asked partners to recommend approaches to increase the skills and/or knowledge-base of people who deliver health programs to more effectively work with and target programs for

people with disability. There was a consensus among partners that disability sensitivity training is the most effective way to increase professionals' understanding of the needs of Floridians with disabilities. Training should target health program managers, health care providers, and health navigators and should be required for people who deliver health programs at the Department of Health and other state agencies. It could also be offered as a way to fulfill continuing education requirements of workers. It was recommended by respondents that the training be aimed at increasing sensitivity to the challenges of mobility impairments and increase health professionals' awareness of people with disabilities' dependence on transportation and the amount of time and effort it takes to get to appointments. Health professionals should also be informed about how best to modify information and materials based on differing literacy levels and/or other unique needs. For example, providers' knowledge about accessibility could be improved by explaining how to offer reasonable accommodations or assistive technology. The Florida Alliance for Assistive Services and Technology (FAAST) and the Center for Independent Living Options (CILO) were mentioned as resources for developing the training. Partners recommended offering the training through partners such as The Rural South Public Health Training Center and Florida Area Health Education Centers (AHEC).

Partners were asked to rank the types of healthcare services that they thought people with disabilities would most benefit from accessing (Figure 6). The choices were annual primary care exams, preventive cancer screening, training on balanced nutrition, training on physical activity and fitness, specific disease management training, or other.
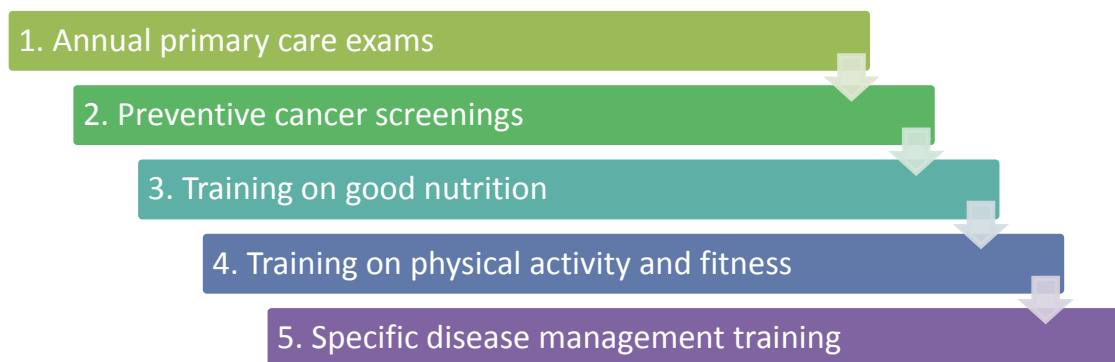
1. Annual primary care exams

2. Preventive cancer screenings

3. Training on good nutrition

4. Training on physical activity and fitness

5. Specific disease management training

Figure 6: Ranking of Healthcare Needs for People with Disabilities

Based on partners' responses, people with disability are most likely to receive healthcare services from primary care providers, local departments of health, FQHCs, and community organizations. Ways to increase the number of people who receive preventive health screenings and wellness screenings included:

- Informing and reminding healthcare providers to offer screenings to people with disability
- Educating people with disabilities about the importance of receiving the screenings
- Promoting screenings in PSAs or local news stories
- Marketing with disability specific literature and health promotion materials

Partners were also asked how the DHP can work with community programs to develop protocols and strategies that meet the needs of the disability community. Rural County Health Departments, FQHCs, safety net hospitals, community clinics, rehabilitation centers, and assisted living facilities are community organizations that should be targeted. Recommendations included helping programs develop protocols and strategies that are focused on meeting the needs of people with disability (e.g., offer staff disability awareness training to increase health care provider's familiarity and comfort with providing care). A global community approach was suggested that focuses not only on the underserved population but also on people with disability who have health insurance and do not receive routine health screenings.

Policy Initiatives

The DHP was interested in knowing whether there were specific local or state standing health committees that could benefit from increased representation of people with disability as members. There was only one response from a partner in Palm Beach County.

- Palm Beach County Medical Society – Project Access
  - Volunteer physician care, diagnostic services, medication for low income uninsured residents of Palm Beach County
- Palm Beach County Health Care District – Dr. Ron Wiewora
  - Coordinated care plan for low income uninsured residents
  - Seven member board appointed by the Governor and County Commissioners
  - Subcommittees that could use representation of people with disabilities
- Palm Beach County United Way – Linda Roman
  - Workgroup looking at needs of children and young adults with disabilities
  - Representation from all the community agencies that serve this population

The DHP is planning on surveying key policy makers and legislative aides to assess knowledge and increase awareness of the needs of people with disability. We asked partners about health and accessibility needs or issues that they think policy makers should be aware of. Identified issues included:

- The need for increased funding for local departments of health to provide educational programs and specific preventive health programs.
- The need to increase awareness of the 22,000 individuals with developmental disabilities on the wait list for services under the Developmental Disabilities Home and Community Based Services Medicaid Waiver.
- The need to address accessibility needs including assistive technology, transportation to appointments, physical accessibility, accessible building layouts, adjustable examination tables, and alternative formats for health information.
- Awareness of health disparities and marginalization of people with disabilities.

Emergency Preparedness

A major goal of the DHP is to improve emergency preparedness for people with disability. This is particularly important in the state of Florida, a state that is in the top five in the U.S. for natural disaster frequency. The DHP wanted to know how Public Health Emergency Planners can best recruit from the disability community to ensure inclusive emergency planning. Partners suggested service providers and local community disability agencies, including: Centers for Independent Living, Agency for Persons with Disabilities, and Family Network on Disabilities. We asked partners for suggestions on how best to identify current informal and formal care providers for people with disability and the optimal environment for educating care providers about emergency preparedness. Suggestions for caregiver communication included social networking sites, Family Care Councils, caregiver support organizations, and community based organizations (e.g., Brain Injury Association of Florida, Florida Spinal Cord Injury Resource Center, Family Network on Disabilities, Florida Developmental Disabilities Council, Epilepsy Foundation). The delivery methods and materials suggested by partners included:

- Online training appears to be effective and user friendly for formal caregivers.
- Younger caregivers would probably prefer online training.
- In-person training could be a more effective forum for middle and older-aged caregivers.

Conclusion

The purpose of this needs assessment was to inform the Health and Disability Program (HDP) about the public health needs of Floridians living with disability. This report utilizes both quantitative and qualitative data using surveys created with Qualtrics software and data from the 2012 Behavioral Risk Factor Surveillance System Survey and the 2012 People with a Disability Survey. Taken together, these sources provide a clear picture of the public health needs of people with disability in Florida.

Common issues that were reiterated throughout included a lack of understanding and communication between providers and patients with disabilities and barriers to care which ranged from transportation to cost. The survey indicated that many respondents feel that providers and staff lack the cultural competency and accommodations to properly care for people with disability. The survey also revealed the need for more people with disability to be included in emergency preparedness drills to ensure that first-responders are able to perform their duties if/when the need arises. Other areas of need identified included increasing participation in chronic disease prevention programs, access to more assistive technology, and increased support for caregivers.

Areas that were highlighted in the in-depth survey portion of the report included ways to sustain DHP initiatives, specifics resources that people with disability could look at to find health-promotion programs and even a recommendation of a health committee that could benefit from increased representation of people with disability as members.

Appendix

Table 1: Areas of Need for People with Disabilities (PWD) Ranked, DHP Needs Assessment Survey 2014

Options	1	2	3	4	5	Total Responses
Increasing the number of PWD receiving preventive and wellness screenings	3	1	3	5	0	12
Increasing PWD participation and inclusion in health programs (e.g. chronic disease prevention programs such as diabetes prevention, asthma prevention etc.)	1	3	3	5	0	12
Increasing the skill/knowledge or awareness of persons who deliver health programs to better serve persons with disabilities (e.g. health care providers)	10	2	3	0	0	15
Including PWD in inclusive emergency planning exercises	1	2	2	1	0	6
Educating care providers/caregivers about emergency preparedness	0	1	1	4	0	6
Educating policymakers about the needs of PWD	4	3	2	1	0	10
Improving patient-provider communication for persons with disability	0	3	3	1	0	7
Improving access to health care barriers for persons with disabilities	1	7	3	3	0	14
Improving coordination of health care for persons with disabilities	3	1	3	2	0	9
Total	**23**	**23**	**23**	**22**	**0**	**-**

Table 2: Healthcare Services with the Greatest Barriers to Access, DHP Needs Assessment Survey 2014

Options	1	2	3	4	5	Total Responses
Annual primary care exams	8	3	2	0	0	13
Preventive cancer screenings	0	5	4	0	0	9
Training on good nutrition	1	7	5	0	0	13
Training on physical activity and fitness	6	3	7	0	0	16
Specific disease management training (e.g. diabetes, arthritis etc.)	6	3	3	0	0	12
Total	**21**	**21**	**21**	**0**	**0**	**-**

Table 3: Service Areas of Greatest Need for People with Disabilities

Options	1	2	3	4	5	6	7	8	9	10	11	12	13	Total Responses
Assistive technology	0	4	2	3	3	2	0	0	0	0	0	0	0	14
Case management	2	1	2	4	2	0	0	0	0	0	0	0	0	11
Counseling	1	0	0	0	0	4	0	0	0	0	0	0	0	5
Education	1	1	0	2	2	1	0	0	0	0	0	0	0	7
Employment services	0	2	3	3	4	2	0	0	0	0	0	0	0	14
Family support services	3	4	2	1	3	0	0	0	0	0	0	0	0	13
Housing	6	1	1	2	1	1	0	0	0	0	0	0	0	12
Medical & Therapeutic Services	2	1	1	0	3	1	0	0	0	0	0	0	0	8
Personal Assistance Services	1	3	2	2	2	1	0	0	0	0	0	0	0	11
Training	0	0	2	1	1	3	0	0	0	0	0	0	0	7
Transportation	6	4	3	3	1	4	0	0	0	0	0	0	0	21
Communication Access	1	2	3	2	0	1	0	0	0	0	0	0	0	9
Emergency Preparedness	0	0	2	0	1	3	0	0	0	0	0	0	0	6
Total	23	23	23	23	23	23	0	0	0	0	0	0	0	-

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[i] This question had 23 respondents.
[ii] This question had 20 respondents.
[iii] This question had 21 respondents.
[iv] This question had 19 respondents.
[v] This question had 21 respondents.

[vii] This question had 19 respondents.
[viii] This question had 18 respondents.
[ix] This question had 18 respondents.
[x] This question had 21 respondents.
[xi] This question had 19 respondents.
[xii] This question had 23 respondents.
[xiii] This question had 21 respondents.
[xiv] This question had 16 respondents.

Thank you for taking the time to assist us today.

One of the necessary components of the Florida Disability and Health Program (DHP) is to solicit statewide feedback on needs for persons with disabilities (PWD) in Florida; in order to tailor activities and inform our Disability Community Planning Group (DCPG). As such, we have put together this survey and would appreciate your feedback based on the knowledge you have about your consumers.

The survey should take no more than 30 min. We would appreciate if you answered as many questions in short answer form to help us produce a list of proposed recommendations to relay back to all who participated.

All responses will be kept confidential. Reported responses will not be linked with your organization. This survey is voluntary and you may end the survey at any time.

Please provide us with a little information about yourself

Your Name:
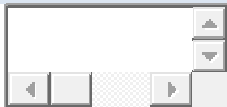
Your Email:

Name of Organization:

Your Role/Title:

Please provide an estimate of the number of persons with disabilities served by your organization.

Which counties in Florida does your organization provide services?

This portion of the survey will assess the need for health-related and planning initiatives in the state of Florida for persons with disabilities.

What do you feel are the top 4 areas of greatest need for the persons with disabilities (PWD) that your organization serves? Please rank the following 1, 2 , 3 or 4 with 1 indicating areas of greatest need for PWD. Please do not rank more than 4 of the following.

- [　　　　] Increasing the number of PWD receiving preventive and wellness screenings
- [　　　　] Increasing PWD participation and inclusion in health programs (e.g. chronic disease prevention programs such as diabetes prevention, asthma prevention etc.)
- [　　　　] Increasing the skill/knowledge or awareness of persons who deliver health programs to better serve persons with disabilities (e.g. health care providers)
- [　　　　] Including PWD in inclusive emergency planning exercises
- [　　　　] Educating care providers/caregivers about emergency preparedness
- [　　　　] Educating policymakers about the needs of PWD
- [　　　　] Improving patient-provider communication for persons with disability
- [　　　　] Improving access to health care barriers for persons with disabilities
- [　　　　] Improving coordination of health care for persons with disabilities

Are there specific health-related programs (e.g. primary care, health promotion, or chronic disease management programs such as diabetes or arthritis prevention programs) that are most needed for persons with disabilities that your organization serves?

[text box]

What are some of they key barriers PWD face when accessing health-related programs (e.g. primary care, health promotion or chronic disease management programs)?

[text box]

Are there strategies that your organization has used or can you provide recommendations for increasing participation of PWD in health-related programs (e.g. primary care, health promotion or chronic disease management programs)?

[text box]

What are ways to increase the skill or knowledge of persons who *deliver* health programs to optimally reach PWD with health-related program services? (e.g., improving health literacy or

examples/opportunities of how/where the Disability and Health Program could train health program managers/health navigators to optimally work with PWD).

How can the Disability and Health Program best work with community health programs to develop protocols and strategies that meet the needs of PWD? (e.g. staff disability awareness training, images of PWD in promotional materials, alternative formats, or accessible locations)?

Which community programs should the Disability and Health Program prioritize for targeted efforts (e.g., rural County Health Departments, Federally Qualified Health Centers, Safety Net Hospitals) and why?

How can Public Health Emergency Planners better recruit from the disability community for inclusive emergency planning exercises?

What would be the best strategies for identifying informal and formal care providers for PWD in order to educate them on the importance of planning for emergencies?

Health and Healthcare-Related Services for Persons with Disabilities

Although the DHP doesn't provide direct health care services for PWD, it is important to understand and assess service needs of PWD to identify key gaps and better inform constituents.

What are the top 3 types of healthcare services that your consumers with disabilities face the greatest barriers trying to access? Please rank the following 1, 2, and 3, with 1 indicating the healthcare service with the greatest barriers. Please do not rank more than 3 of the following.

- [_____] Annual primary care exams
- [_____] Preventive cancer screenings
- [_____] Training on good nutrition
- [_____] Training on physical activity and fitness
- [_____] Specific disease management training (e.g. diabetes, arthritis etc.)

Thinking about the healthcare service you rated as having the greatest barriers for PWD (ranking #1), please describe what specific barriers you are aware of that PWD face when trying to access this healthcare service.

[_____]

What are the top 6 service areas of greatest need among your consumers with disabilities? Please rank the following 1 to 6 with 1 indicating health and service concern areas where there is the greatest need for your consumers with disabilities. Please do not rank more than 6 of the following.

- [_____] Assistive technology
- [_____] Case management
- [_____] Counseling
- [_____] Education
- [_____] Employment services
- [_____] Family support services
- [_____] Housing
- [_____] Medical & Therapeutic Services
- [_____] Personal Assistance Services
- [_____] Training
- [_____] Transportation
- [_____] Communication Access
- [_____] Emergency Preparedness

Thinking about the service area you rated as the greatest need for persons with disabilities (ranking #1), please describe any specific barriers you are aware of that PWD face when trying to access this service.

What other areas of health and safety concerns have you found among your consumers with disabilities?

Thank you for your time. Your feedback is greatly appreciated. A written report of this survey data will be disseminated upon completion.