

## In-depth Questionnaire for DCPG Partners

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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, persons with disabilities, and caregivers of persons 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 sustained over time after the life of the grant. Partners were asked what the DHP can do to ensure sustainability of programmatic activities tailored to persons with disabilities (PWD) after the grant period ends. The current DHP activities include health promotion programs for PWD, healthcare provider education to optimize quality care for PWD and emergency planning and preparedness for PWD. 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 PWD.
- Disseminating DHP educational materials to the community (schools, disability agencies, non-profits).
- Embedding the disability perspective in all programs to help maintain attention to PWD after the grant ends.

### Improving Access to Primary Care and Health Promotion Program

Partners were asked what types of primary care health programs PWD would most benefit from (Figure 1).

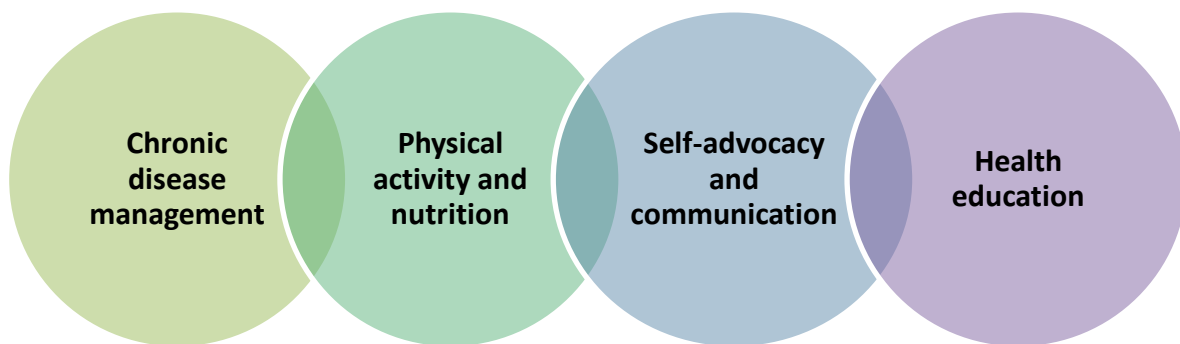


Figure 1: Primary care health programs for PWD

Responses suggested chronic disease self-management programs such as diabetes self-management education, diabetes prevention lifestyle change and hypertension management would be valuable to PWD. Programs that focus on physical activity and nutrition were also considered to be important to PWD (e.g., programs targeted to help PWD achieve a healthy and an active lifestyle through balanced nutrition choices and exercise). Respondents also suggested that programs that include self-advocacy and communication components would also be helpful for PWD. Examples of communication components include educating PWD on how best to communicate with health care practitioners, ask the right questions to improve understanding and adherence to recommended treatment plans, and 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.

Partners were additionally asked about strategies to increase PWD participation and inclusion in health oriented programs. 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](http://professional.diabetes.org/ERP_List.aspx).

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

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

A follow-up question asked partners to recommend approaches to increase the skills and/or knowledge-base of persons who deliver health programs to more effectively work with and target programs for PWD. There was a consensus among partners that disability sensitivity training is the most effective way to increase professionals' understanding of the needs of PWD. Training should target health program managers, health care providers, and health navigators who work with PWD. The training could 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 professional awareness of PWDs' 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 of PWD. For example, providers' knowledge about accessibility could be improved by explaining how to offer reasonable accommodations or assistive technology to PWD. 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 PWD would most benefit from accessing (Figure 2). 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.

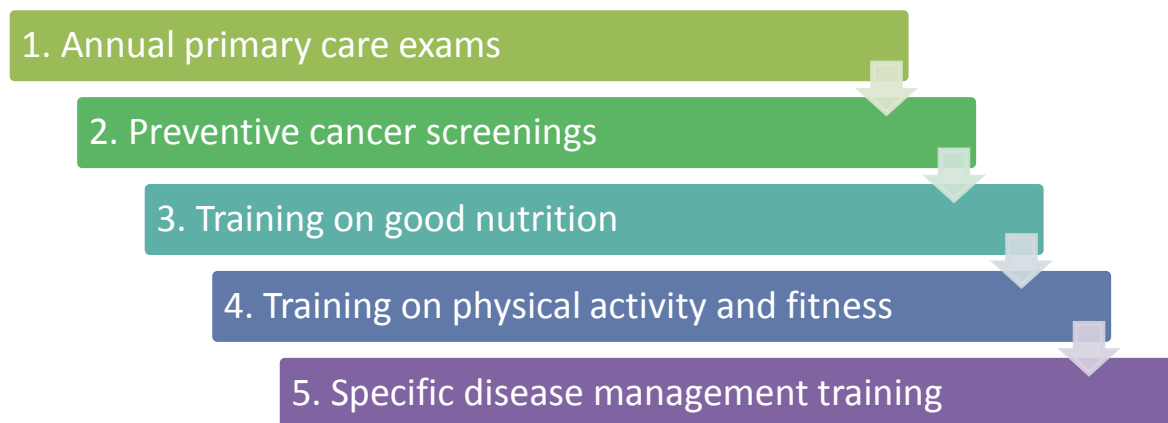


Figure 2. Ranking of healthcare needs for PWD

Based on partners' responses, PWD are most likely to receive healthcare services from primary care providers, local health departments, federally qualified health centers, and community organizations. Ideas to increase the number of PWD who receive preventive health screenings and wellness screenings included:

- Informing and reminding healthcare providers to offer screenings to PWD

- Educating PWD about the importance of receiving the screenings
- Promoting screenings for PWD in PSAs or local news stories
- Marketing to PWD 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 PWD. Rural county health departments, Federally Qualified Health Centers (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 PWD (e.g., offer staff disability awareness training to increase health care provider's familiarity and comfort with providing care to PWD). A global community approach was suggested that focuses not only on the underserved population but also PWD 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 PWD as members. There was only one response from a partner in Palm Beach County.

- Palm Beach County Medical Society – Project Access – Tenna Wiles, 561-433-3940
  - Volunteer physician care, diagnostic services, medication for low income uninsured residents of Palm Beach County
- Palm Beach County Health Care District – Dr. Ron Wiewora, 561-659-1270
  - Coordinated care plan for low income uninsured residents
  - 7 member board appointed by the Governor and County Commissioners
  - Subcommittees that could use representation of PWD
- Palm Beach County United Way – Linda Roman, 561-375-6600
  - 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 PWD. We asked partners about health and accessibility needs or issues that they think policy makers should be aware of. The issues included:

- The need for increased funding for local health departments to provide educational programs and specific preventive health programs for PWD.
- The need to increase awareness of the 22,000 individuals with developmental disabilities on the wait list for services under the DD HCBS Medicaid waiver.
- The need to address accessibility needs of PWD 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 PWD.

## **Emergency Preparedness**

A significant goal of the DHP is to improve emergency preparedness for PWD. This is particularly important in the state of Florida, a state that is in the top 5 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 of PWD 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 PWD 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., BIAF, SCIRC, FND, FDDC, 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.