

Developing Partnerships with the Disability Community



People with disabilities often experience poorer health than individuals without disabilities. Some of these disparities include higher rates of cardiovascular disease and obesity and they are also less likely to have recommended health screenings to maintain a healthier life.ⁱ Finding people with disabilities for your wellness programs is an important step in reaching those individuals who are underserved and allowing them to improve their health. The purpose of this fact sheet is to provide background on some disability organizations which can be partners in recruiting people with disabilities for your wellness programs. These organizations include state disability and health programs, Centers for Independent Living, the National Disability Navigator Resource Collaborative Community Outreach Collaboratives, the Consortium for Citizens with Disabilities and other entities that can be valuable partners.

State Disability and Health Programs – CDC, National Center on Birth Defects and Developmental Disabilities

The state disability and health programs are funded by the Centers for Disease Control (CDC) through the National Center on Birth Defects and Developmental Disabilities (NCBDDD).ⁱⁱ The goals of the state disability and health programs are as follows:

- Enhance program infrastructure and capacity.
- Improve state level surveillance and monitoring activities.
- Increase awareness of health-related disability policy initiatives.
- Increase health promotion opportunities for people with disabilities.
- Improve access to health care services for people with disabilities.
- Improve emergency preparedness for people with disabilities.
- Effectively monitor and evaluate program activities.

As of September 2020, there are 19 funded state disability and health programs in the following states: Alabama, Arkansas, Florida, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, New Hampshire, New York, Ohio, Oregon, South Carolina, Utah and Vermont. The state disability and health programs are involved in many projects including implementing the Stanford Chronic Disease Self-Management Program, working with Federally Qualified Health Centers to determine barriers for inclusiveness, supporting programs which improve healthcare outcomes for people with disabilities, working on statewide health action plans to include disability, promoting appropriate screening for people with disabilities, conducting health promotion workshops for people with disabilities and training individuals to be self-advocates for their own health care.

All the state disability and health programs can be found at the CDC website here:

<http://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>.

Centers for Independent Living (CILs)

The Centers for Independent Living (CILs) are funded through the Administration for Community Living (ACL).ⁱⁱⁱ The CILs are nonprofits focused on providing independent living services. The CILs are run by people with disabilities for people with disabilities as every CIL is required to have people with disabilities make up at least 51% of their board and staff. Every CIL is required to perform five core functions. They are:

1. Information & Referral
2. Independent Living Skills Training
3. Peer Counseling
4. Individual & Systems Advocacy
5. Services that Facilitate Transitions

CILs are located in every state and territory. A directory of CILs by state/territory is available through the Independent Living Research Utilization (ILRU) here:

<http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>.

State Councils

Each state and territory has a disability network consisting of agencies and councils designed to serve and advocate for people with disabilities. The State Councils on Developmental Disabilities work to address identified needs by conducting advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.^{iv} The contact information for each Council on Developmental Disabilities can be found here: <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>.

Additionally, each state and territory has a mental health planning council. A mental health planning council ensures collaboration among key state agencies and facilitates consumer input into the state's mental health services and activities, and they are comprised of consumer and family members.^v The mental health planning councils are required to include three groups:

- Include representatives from state education, mental health, rehabilitation, criminal justice, housing, and social services agencies.
- Include adult members (consumers) who receive mental health services.
- Include family members of children with emotional disturbances.

The mental health planning councils work with designated state agencies. Information on the various state mental health programs can be found at the website for the National Association of State Mental Health Program Directors (<http://www.nasmhpd.org/commissioners> edit).

Consortium for Citizens with Disabilities (CCD)

Another source of referrals for people with disabilities can come through local or state chapter/affiliates of national disability organizations which serve specific disability populations.

The Consortium of Citizens with Disabilities (CCD) has many member organizations which have local or state chapter/affiliates. CCD is a coalition of national consumer, advocacy, provider and professional organizations which advocates on behalf of people of all ages with physical and mental disabilities and their families.^{vi} The organizations that make up CCD represent a wide variety of disabilities, both physical, intellectual and developmental. These disabilities include people who are blind or have low vision, amputees, autism, brain injury, paralysis, learning disabilities, epilepsy, mental and behavioral health, Down syndrome, multiple sclerosis and cerebral palsy. For a complete list of member organizations for CCD go to the CCD website here: <http://www.c-c-d.org/rubriques.php?rub=organization.php>.

National Center on Health, Physical Activity and Disability (NCHPAD)

The National Center on Health, Physical Activity and Disability (NCHPAD) has many local programs and organizations with which they work. NCHPAD is a public health practice and resource center on health promotion for people with disability, and they seek to help people with disability and other chronic health conditions achieve health benefits through increased participation in all types of physical and social activities.^{vii} NCHPAD has directories of both programs and organizations aimed at helping people with disabilities maintain their health. Both of these directories are searchable by state and cities. These directories can be found here:

- Programs – <http://www.nchpad.org/Directories/Programs>
- Organizations – <http://www.nchpad.org/Directories/Organizations>

American Association on Health and Disability (AAHD)

The American Association on Health and Disability (AAHD) is an organization with the mission to advance health promotion and wellness initiatives for children and adults with disabilities.^{viii} AAHD has information on state health and disability programs as well as both public and private disability resources for most states. In the section on state health and disability programs, you can find information on state programs in to assist individuals with disabilities such as state departments/agencies on independent living, mental health, intellectual and developmental disabilities, substance abuse services and vocational rehabilitation. These resources can be found on the AAHD website here: <http://www.aahd.us/resource-center/state-resources/#health-disability-prog>. The AAHD public and private disability resources include other state agencies that assist people with disabilities and also private organizations which serve people with disabilities. This includes state chapter/affiliates of national disability organizations such as The ARC, the National Multiple Sclerosis Society, the Spina Bifida Association, United Cerebral Palsy and the University Centers of Excellence in Developmental Disabilities (UCEDDs). This information can be found at the AAHD website here: <http://www.aahd.us/resource-center/state-resources/#public-private-dis-res>.

Other Community Organizations

It's important to remember that people with disabilities can be found in many settings as they can be involved in a wide variety of activities within the community. Any efforts to recruit individuals with disabilities should include other community organizations such as the YMCA as

well as faith communities. Finding people where they live, work, play and pray is an effective recruitment effort in general and applies just as equally to people with disabilities.

Retention

Finally, it is important to remember that recruiting people with disabilities for your wellness programs will only be a success if you are able to retain those individuals for the duration of the program. In order to do so, you need to make sure that your program is fully accessible and accepting for people with disabilities. A great recruitment effort can all go for naught if the individuals do not return because the meeting room or materials are not accessible. For a list of resources with tips on disability etiquette, engaging people with disabilities, virtual accessibility and this fact sheet on developing partnerships with the disability community, check out our webpage on disability outreach resources, which can be found here:

<https://aahd.us/dissemination/disability-outreach-resources/>.

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ⁱ To read more about health disparities among the disability population, be sure to read our fact sheet entitled “Engaging People with Disabilities in Evidence-Based Programs.” https://aahd.us/wp-content/uploads/2021/03/Disabilities-Tip-Sheet_Final061915.pdf.pdf.

ⁱⁱ <http://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>

ⁱⁱⁱ <https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

^{iv} <http://www.acl.gov/programs/aidd/index.aspx>

^v <http://www.samhsa.gov/grants/block-grants/mhbg>

^{vi} <http://www.c-c-d.org/>

^{vii} <http://www.nchpad.org/>

^{viii} <http://www.aahd.us/>