

FACT SHEET #6

Supporting Collaborations between Navigators, Connectors and Assistors, and Local Disability and Affinity Organizations

This fact sheet is intended to help Navigators, connectors and assistors understand why it is important to identify and build relationships with local disability and affinity organizations

Q1. Some of the people I am assisting are individuals with disabilities. Should I learn more about community resources that might help them?

A. While your primary role is to help consumers obtain health insurance coverage, you might also need to assist some people with disabilities identify additional healthcare programs or services for which they might be eligible. Some local disability and affinity organizations are excellent resources that can assist or advise about programs such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI)¹, Medicare,² the Ryan White HIV/AIDS program,³ pharmaceutical assistance programs,⁴ and Medicaid home and community-based services (HCBS).⁵

These organizations can help you and people with disabilities with whom you are working in other ways, too. For example, local disability and affinity organizations are good locations to spread the word about the Marketplace. Many of these organizations and employees could themselves be Marketplace consumers. They also can help you learn how to arrange and pay for appropriate accommodations that some people might need to understand their health insurance options. For example, people with visual impairments or who are blind might require print materials in accessible formats such as Braille, audio, digital, or large print formats. Or people who are deaf or hard of hearing might require Sign Language interpreters in order to ensure effective communication. It is important to identify and reach out to these groups so you will be able to get assistance when you need it.

¹ Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are income replacement and income support programs administered by the Social Security Administration (SSA). SSDI pays benefits to individuals and certain members of their families if she or he has worked long enough and paid Social Security taxes. SSI pays benefits to consumers with disabilities, based on financial need.

² Medicare provides health coverage for people age 65 and older, as well as younger people with disabilities and those of any age with End-Stage Renal disease.

³ The Ryan White HIV/AIDS Program provides HIV-related services for consumers who do not have sufficient health care coverage or financial resources to manage HIV disease. The program fills gaps in health coverage not met by other health coverage.

⁴ Some pharmaceutical companies offer assistance programs for the drugs they manufacture.

⁵ Medicaid Home and Community Based Services provide opportunities for Medicaid beneficiaries to receive services in their own homes or in the community. See <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html> for more information.

Q2. What types of organizations should I know about?

A. Disability organizations can be local, regional or national in scope and vary in mission and purpose from locale to locale. Here are some examples of: 1) national organizations that have chapters or affiliates in many locations, and 2) local organizations that belong to a national membership group:

- Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. All Centers for Independent Living provide the same core services: peer support, information and referral, and individual and systems advocacy. Centers generally also have expertise in helping people with disabilities apply for federal programs such as SSI and SSDI, and home and community-based services. They also are likely to be aware of additional healthcare and health promotion resources for which people with specific disabilities might be eligible. In addition, they will have ties to other local organizations and therefore are a good starting point because they can help link you to a wide range of community resources. See the NCIL state locator: <http://www.ilru.org/html/publications/directory/index.html>.
- Aging and Disability Resource Centers (ADRC) are another resource for information on Medicaid home and community-based services that some people with disabilities might need to live in their own homes. ADRCs serve as “single points of entry” to these services in many states, offering counseling to consumers and professionals seeking assistance on their behalf. Follow the links to find an ADRC near you. See <http://www.adrc-tae.acl.gov/tiki-index.php?page=HomePage>.

Other organizations focus on issues related to specific disabilities, for example muscular dystrophy, multiple sclerosis, Parkinson’s, spinal cord injury, autism, blindness, deafness, mental health disabilities, and intellectual and developmental disabilities. Examples of such organizations include:

- The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. The Arc has more than 700 state and local chapters, Follow the links to find a chapter near you. See <http://www.thearc.org/find-a-chapter>.
- The National Alliance on Mental Illness (NAMI) is the nation’s largest grassroots mental health organization with 1000 affiliates across the country. Follow the links to find an affiliate near you. See http://www.nami.org/Template.cfm?Section=Your_Local_NAMI&Template=/CustomSource/AffiliateFinder.cfm.
- The National Multiple Sclerosis Society (NMSS) conducts research and advocacy, and operates programs and services for people living with MS. Local and regional chapters operate in many locales. Follow the links to find a chapter

near you. See <http://www.nationalmssociety.org/Chapters>.

- United Spinal Association's works to improve the quality of life of all people living with a spinal cord injury or disease. United Spinal provides active-lifestyle information, peer support and advocacy, which empower individuals to achieve their highest potential in all facets of life. Follow the links to find a chapter or support group near you. See <http://www.spinalcord.org/chapters/directory/> and <http://www.spinalcord.org/nsCIA-support-groups/>.
- The Lighthouse provides resources and information for people with vision loss. Follow the links to find a Lighthouse organization near you. See <http://www.lighthouse.org/resources/help-near-you/>.
- The American Council of the Blind shapes policies that affect people who are blind. Follow the links to find an affiliate near you. See <http://acb.org/node/9>.
- The National Association of the Deaf (NAD) is a leading civil rights organization for people who are deaf and hard of hearing. Follow the links to locate state affiliates. See <http://www.nad.org/community/state-association-affiliates>.

Q3. How do I find out more about the Ryan White HIV/AIDS program in my area?

A. The Ryan White Program, administered by the federal Health Services and Resources Administration (HRSA), is for those who do not have sufficient health care coverage or financial resources to manage HIV disease. Follow the HRSA/Ryan White Program website links to locate service providers, such as Federally Qualified Health Centers, in your locale. (See <http://hab.hrsa.gov/gethelp/index.html>)

Q4. How do I learn more about pharmaceutical assistance programs?

A. Some pharmaceutical companies offer assistance programs for the drugs they manufacture. You can get additional, specific information from the Medicare.gov website at <https://www.medicare.gov/pharmaceutical-assistance-program/index.aspx#>. Local disability groups such as NAMI affiliates, for example, can also provide additional information.

Q5. How do I learn more about home and community-based services?

A. Some people with disabilities might be eligible for home and community-based services under Medicaid, but not be aware that they qualify. These services enable people to live at home or in the community rather than an institution. Such programs serve targeted groups including people with mental health disabilities, intellectual or developmental disabilities, and/or physical disabilities. Because eligibility criteria vary, you should refer people to your state Medicaid agency or the Aging and Disability Resource Center in your locale as a starting point. For more information, go to <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term->

[Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html](#))

Q6. Who can help me if my organization needs to hire a Sign Language interpreter or a transcription service?

A. Many local groups are good resources on specific topics and issues. For example, deaf service organizations, such as associations of the deaf, can help identify qualified Sign Language interpreters for hire and other communications services such as Communications Access Realtime Translation (CART), the instant translation of the spoken word into English text. Often, organizations that work with people with all types of disabilities, such as Centers for Independent Living, can also refer you to other local organizations serving Deaf people. Such disability specific groups can also be found through online directories.

Q7. Who can help me if my organization needs to provide print health insurance information or materials in an accessible format for someone who is blind or has a visual impairment?

A. As with disability specific groups such as those serving Deaf people, there likely will be groups in your community, such as associations for the blind, that provide services to people who are blind or who have visual impairments. You can also follow the links provided above to find local affiliates or chapters of national organizations serving people who are blind. These groups can help you learn how to convert print materials into accessible formats as well as how to make community Marketplace meetings accessible to people with vision impairments. Centers for Independent Living can also be a resource for this information and can refer you to other local organizations. Some of these disability-specific organizations likely can also be found through online directories.

It is best to build relationships with such groups in advance, however. Contact these organizations when you are in the early stages of planning for an outreach event or developing written materials, so when the need arises you will have ready access to referral services. Advance planning also ensures you will be aware of the lead time required to schedule interpreters, convert print materials into accessible formats, or arrange for other accommodations.

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