FACT SHEET #6 - Summary

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

This fact sheet is intended to help Navigators, connectors and assisters 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), Medicare, the Ryan White HIV/AIDS program, pharmaceutical assistance programs, and Medicaid home and community-based services (HCBS).

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:

- <u>Centers for Independent Living</u> 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.
- <u>Aging and Disability Resource Centers (ADRC)</u> 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.

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:

- <u>The Arc</u> is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.
- <u>The National Alliance on Mental Illness (NAMI)</u> is the nation's largest grassroots mental health organization.
- <u>The National Multiple Sclerosis Society (NMSS)</u> conducts research and advocacy, and operates programs and services for people living with MS.
- <u>United Spinal Association's</u> works to improve the quality of life of all people living



with a spinal cord injury or disease.

- <u>The Lighthouse</u> provides resources and information for people with vision loss.
- The American Council of the Blind shapes policies that affect people who are blind.
- <u>The National Association of the Deaf (NAD)</u> is a leading civil rights organization for people who are deaf and hard of hearing.

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

A. The Ryan White Program is for those who do not have sufficient health care coverage or financial resources to manage HIV disease. More information can be found on the website for the Health Services and Resources Administration (HRSA), the federal agency that administers the program.

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 Medicare.gov.

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. 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.

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.

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. 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.

www.nationaldisabilitynavigator.org