

GUIDE TO DISABILITY

for Healthcare Insurance Marketplace Navigators



PRESENTED BY: The American Association on Health and Disability



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Introduction

The Supplemental Guide to Disability for Healthcare Insurance Marketplace Navigators aims to strengthen Navigators' capacity to assist individuals with disabilities to make informed and appropriate healthcare insurance choices. It expands upon the online course for Navigators entitled, "Working with Consumers with Disabilities," developed by the US Department of Health and Human Services (HHS).¹ The Guide is not intended to be a comprehensive stand-alone resource on all of the provisions of the Affordable Care Act. Rather, it should be used together with resources provided by HHS, other federal agencies including the US Department of Justice (DOJ), and other health policy advocates. (See Resources.)

Building on the content of the HHS guide, the Supplemental Disability Guide provides additional information on the relationship between physical, mental, cognitive and intellectual impairments, and related activity limitations that affect the health insurance benefits individuals likely will require, and ultimately their choice of health insurance coverage. It also provides information that is intended to build awareness among Navigators about the need for physical accessibility of locations where consumers seek assistance to determine their eligibility and select healthcare coverage from the Healthcare Insurance Marketplace. The Guide also presents methods Navigators can use to ensure they are communicating effectively with people with disabilities during inperson meetings and by call centers operated by navigator organizations. Effective communication may require accommodations, policy modifications, and auxiliary aids and services such as providing printed materials in alternative, accessible formats including Braille, large print, or digital for people with vision disabilities, Sign Language interpreters and video recordings for people who are deaf or hard of hearing, and additional meeting and discussion time, and possibly simplified language for people with cognitive or intellectual disabilities.

Fact sheets, presented in a question and answer format, supplement the guide and are updated over time with state-by-state experiences. Fact sheet topics will include, for

example, the process for Medicaid eligibility, determination of "medically frail" status for Medicaid, information on rehabilitation, habilitation, devices(e.g. durable medical equipment such as wheelchairs), and pharmacy benefits, mental health and substance abuse parity, comparing health plans' benefits and coverage summaries, and using health plan customer services. Population specific fact sheets also address what a navigator needs to know when assisting a consumer with a specific disability. The populations covered in these fact sheets include, for example, autism spectrum disorder, intellectual disability and multiple sclerosis. (See NDNRC Fact Sheets for a complete list of fact sheet topics.)

What are the purposes of the Supplemental Disability Guide?

- To strengthen disability literacy among Navigators so they can more effectively communicate with and assist people with disabilities to assess their healthcare insurance needs, eligibility, and options
- To help Navigators identify and provide appropriate accommodations and support that people with disabilities might require when they seek information on healthcare insurance options during face-to-face or telephone encounters
- To assist Navigators to correctly identify issues that are central to healthcare insurance eligibility and needs of people with disabilities and to provide accurate and understandable coverage information, options, and additional referrals

Key questions for Navigators

- Who are people with disabilities?
- What problems and barriers have people with disabilities historically encountered obtaining healthcare insurance?
- How do disability rights laws affect the operation of the Marketplace?
- How is disability defined?

- What disability questions appear on the streamlined application for health insurance or Medicaid submitted through the Marketplace?
- Why is understanding disability important?
- What is disability literacy?
- What is disability etiquette?
- What is physical accessibility?
- How can effective communication with people with disabilities be ensured?
- How can Navigators assist people with disabilities evaluate the adequacy of provider networks within specific plans?
- How can Navigators assist people with disabilities evaluate the adequacy of Essential Health Benefits (EHBs)?
- How is Medicaid eligibility being determined for people with disabilities?
- What types of accommodations should Navigators know about?

Who are people with disabilities?

Between 40 and 50 million people in the US report some kind of disability in national health surveys.² About 30 percent of non-institutionalized people living in the United States experienced either some difficulty with basic movement, or cognitive, sensory, or emotional problems. About 14 percent experience complex activity limitations that affect their ability to work, shop, or care for their personal needs. The number of people with disabilities will likely grow even more significantly in the next 30 years as the baby boom generation enters late life, when the risk of disability is the highest.³

People with disabilities are found in every age group, in every community, and in every walk of life. Because disability is not immutable, people can acquire a disability at any point in life. While many people with disabilities experience poverty and employment rates are lower than among people who do not have disabilities, some people with disabilities are employed and self-supporting. Some types of disabilities are visible while others are hidden.⁴ While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, impairment does not occur

uniformly among all racial and ethnic groups. National surveys define and identify disability in different ways, yet they consistently indicate that disability prevalence is highest among African Americans who report disability at 20.5 percent compared to 19.7 percent for whites, 13.1 percent for Hispanics/Latinos, and 12.4 percent for Asian Americans.⁵ Disability prevalence among American Indians and Alaskan Natives is 16.3 percent.⁶

What problems and barriers have people with disabilities historically encountered obtaining healthcare insurance?

People with disabilities historically have experienced difficulty purchasing healthcare insurance in the individual commercial market because some insurers would not provide coverage for people with pre-existing conditions and also because policies could be prohibitively expensive. (An estimated 3.5 million people with disabilities did not have health insurance when the Affordable Care Act was enacted in 2010.⁷) Even when people with disabilities could obtain group healthcare coverage through their employer or they were covered by a family member's policy, the health care benefits they needed might have been limited or not available at all, co-pays also might have been prohibitively expensive, and annual or lifetime benefit limits on certain types of services, care, and equipment could have prevented them from obtaining the care they required. Moreover, most people who become disabled before the age of sixty-five and are eligible for Medicare still face a two-year waiting period for coverage, frequently leaving them with no healthcare insurance at a time when they need it most.⁸

The specific problem of historic discrimination in health insurance coverage for mental illness and substance abuse treatment led to the enactment of the 2008 Mental Health Parity and Addiction Equity Act (MHPAEA), a federal law that required group health plans and group health insurance coverage (both public and private) that offered mental health and substance use disorder treatments to offer coverage that is "generally comparable" to the medical and surgical care offered in the plan. MHPAEA did not *require* plans to offer those treatments in the first place, however, and the act also did

not apply to the small group⁹ or individual insurance market. In 2010 the Affordable Care Act (ACA) extended the reach of the MHPAEA in two critical ways. First, "mental health and substance use disorder services, including behavioral health treatment" is one of the ten categories of Essential Health Benefits (EHB) that must be covered as of January 1, 2014 by non-grandfathered plans¹⁰ in individual and small group markets, both inside and outside of the Marketplace. Second, HHS enacted regulations under the ACA that extend MHPAEA's parity requirements to the EHB mental health and substance use disorder category.¹¹

The Health Insurance Marketplace therefore offers an excellent opportunity for people with all disabilities who either have gone without coverage or have had limited access to needed health care benefits to obtain health insurance in the individual market. It also affords an opportunity for some people who have costly individual coverage to lower the cost of their health insurance and/or obtain adequate coverage for the services, medications, or equipment they require by switching policies. In addition, the Marketplace offers some people with disabilities the opportunity to determine their eligibility for Medicaid under both existing and new expansion rules and for other federal or state health care benefits such as the Children's Health Insurance Program (CHIP).

How do disability rights laws affect the operation of the Marketplace?

The 1990 Americans with Disabilities Act and the 2008 ADA Amendments Act along with Section 504 of the 1973 Rehabilitation Act prohibit discrimination against people with disabilities.¹² These laws apply to the programs delivered through the Marketplace, the federally conducted Marketplace infrastructure, and to the organizations that will assist consumers to learn about their healthcare insurance options. They also apply to the operation of healthcare services and programs. (See "HHS Guide to Working with People with Disabilities" for a detailed explanation of the ADA.) Another federal law, Section 508 of the Rehabilitation Act requires any electronic information technology (EIT) products or services that are "developed, procured, maintained, or used" by the

Federal Government to be accessible to persons with disabilities.¹³ Section 508 applies to the federal Healthcare Insurance Marketplace. In addition, Section 1557 of the Affordable Care Act also prohibits discrimination in programs that are established and funded by the ACA.¹⁴ Taken together, these laws ensure that people with disabilities have an equal opportunity to access and participate effectively in the services provided by the Marketplace. They require that the Marketplace website meet accessibility standards, establish standards for physical accessibility of facilities where people with disabilities will be served or employed, and identify specific types of accommodations they may require to participate effectively in the marketplace.

In addition to federal laws, regulations issued by HHS governing the operation of the Marketplace also recognize that people with disabilities require accessible information technology, facilities, and accommodations in order to participate in and benefit from the information available through the Marketplace. HHS therefore has called for an accessible infrastructure that empowers people with disabilities to obtain the vital information they require to act as informed consumers of health insurance. The regulations require that the Marketplace operated by HHS and non-navigator assistance personnel funded through an Exchange Establishment Grant:

- Ensure that any consumer education materials, websites, or other tools utilized for consumer assistance purposes be accessible to people with disabilities including those with sensory impairments, such as visual or hearing impairments, and those with mental illness, addiction, and physical, intellectual, and developmental disabilities
- Provide auxiliary aids and services for individuals with disabilities, at no cost, when necessary or when requested by the consumer to ensure effective communication
- Provide assistance to consumers in the location and in a manner that is physically and otherwise accessible to individuals with disabilities
- Ensure that authorized representatives are permitted to assist an individual with a disability to make informed decisions

- Acquire sufficient knowledge to refer people with disabilities to local, state, and federal long-term services and supports programs when appropriate
- Be able to work with all individuals regardless of age, disability, or culture, and seek advice and experts when needed.¹⁵

What do Navigators need to know about disability?

How is disability defined?

For purposes of the Marketplace, HHS defines disability as, "A limit in a range of major life activities. This includes activities like seeing, hearing, walking and tasks like thinking and working."¹⁶ HHS also references the definition found in the ADA and its amendments. The ADA definitions explain who the law protects from discrimination and therefore is an important legal guide post for Navigator organizations. (See "HHS Guide to Working with People with Disabilities" for a detailed explanation of the ADA.)

(Note that for purposes of accessibility, accommodation and other disability rights, the definition of "disability" that is used by state Medicaid programs or the Social Security Administration, for example, are not applicable.)

In order to assist Navigators to recognize disability, understand how to accommodate people with disabilities during interactions about Marketplace options, and be aware of the types of services and benefits consumers are likely to require from their health insurance, it is helpful to understand disability from two perspectives:

- The practical experience of disability begins with the presence of one or more physical, mental, cognitive, intellectual or other impairment or condition. Such impairments or conditions may or may not be visible and the person who has the conditions may or may not perceive them or identify them as a disability.
- Specific impairments or conditions might result in one or more functional or activity limitations in domains such as seeing, hearing, thinking, walking, communicating,

remembering, and making decisions, and tasks like working, shopping, self-care, and other activities of daily living. Even though some people may have these functional or activity limitations, they may not see themselves as having a disability. Nevertheless, the presence of the condition and related activity limitations has important implications regarding eligibility for and selection of appropriate insurance coverage. The person might also require specific accommodations in order to access and understand information about possible coverage options.

What disability questions appear on the streamlined application for health insurance or Medicaid submitted through the Marketplace?

The streamlined application for Medicaid and the Marketplaces asks whether the person or any family members have a disability. The question on the form is:

Do you have a physical, mental, or emotional health condition that causes limitations in activities (like bathing, dressing, daily chores, etc.) or live in a medical facility or nursing home?¹⁷

While this question serves as a starting point for identifying people with disabilities, it is broadly drafted and does not help identify the specific impairments or activity limitations that Navigators should be aware of in order to provide comprehensive assistance. Some people with disabilities also might elect not to answer 'yes' to the question because they do not think it applies to them. For example, someone with osteoarthritis who has some difficulty walking may not perceive that problem as a "limitation in activity" and therefore does not identify as a person with a disability. Even if someone elects not to self identify as having a disability, it will be important for Navigators to identify disability by eliciting information from the person about possible needed assistance related to functional impairments so appropriate accommodations can be offered. Navigators also require this information in order to assist individuals to identify appropriate, specific healthcare benefits, services, and equipment they might require from a health plan or product.

Why is understanding disability important?

By recognizing the activity limitations that flow from certain impairments, Navigators will be able to identify some of the types of accommodations people with disabilities require so they can participate in an informed manner in the process of making healthcare insurance selections. Navigators will also be better equipped to help people with disabilities select appropriate insurance coverage that meets their individual requirements.

Here are some examples of activity limitations that might be associated with specific impairments and conditions:

- Someone with a chronic condition such as arthritis may experience activity limitations such as difficulty walking, bending, or lifting. Why is this information important to Navigators?
 - The person may require physical accessibility in order to access the building where the navigator is located
 - The person may be receiving regular physical therapy or visiting a specialty provider such as a rheumatologist. She or he therefore will require insurance coverage that includes either current providers or comparable, equivalent providers within the same specialty, and affordable, ongoing access to physical therapy services
 - The person may require a mobility device such as a walker or wheelchair, so she or he will need access to a durable medical equipment supplier that can provide the appropriate device as well as follow-on services that may be needed to maintain it
- Someone with a chronic condition such as diabetes or multiple sclerosis may have activity limitations related to seeing or mobility. Why is this information important to Navigators?
 - The person may require physical accessibility in order to access the building

where the navigator is located. She or he might also require printed materials in alternative, accessible formats such as digital or large print in order to gain access to and compare summaries of benefits and coverage for various plans and to determine if his or her preferred providers participate in any of the networks being offered.

- Someone with a cognitive impairment or an intellectual disability may experience activity limitations that affect understanding, remembering, and/or communicating. Why is this information important to Navigators?
 - Navigators are required to ensure that information about health insurance options are presented in a manner that the person can understand.
 - Navigators might need to spend additional time with this applicant in order to ensure that communication is clear and that the person has had sufficient time to ask questions or to process the information that has been provided.
 - Navigator should be aware that the information might need to be presented in more than one format to be fully understood.
 - Navigators should consider ways they could help memorialize the conversation for the person's future reference, such as suggesting places where a person could take notes or offering to send an email with major discussion topics after the meeting, but only after having obtained the express consent of the person receiving the communication to use her or his email address,
 - If a consumer with a cognitive impairment or developmental disability is accompanied by an authorized person who is facilitating communication, it might also be appropriate for the Navigator to provide that person with information regarding the major discussion topics, but only if they have obtained express permission to use her or his contact information.
 - People with chronic conditions are likely to require periodic or ongoing treatment by multiple providers as well as care coordination. These providers likely have long-standing familiarity with this individual's specific disability, therefore it will be important to determine if they participate in the networks of

the plans she or he is considering. If this individual is eligible for Medicaid, the Navigator should assist her or him to understand how to evaluate the choices that may be available under the Medicaid program. (See "How is Medicaid eligibility being determined for people with disabilities?")

- Someone with a neuro-degenerative condition such as muscular dystrophy or multiple sclerosis may have activity limitations related to walking, self-care, and/or communication. Why is this information important to Navigators?
 - This person might use a mobility device such as a walker or wheelchair and therefore will require physical accessibility in the location where he or she will be meeting with the Navigator.
 - She or he will likely need to consider insurance options that provide for access to suppliers who specialize in mobility equipment such as motorized wheelchairs, specialists such as neurologists, radiologists, and rehabilitation therapists for physical, occupational, and speech therapy. It will be important therefore to highlight and compare overall costs for the services, equipment, and medications in relation to premiums, co-pays, and deductibles.
 - Some Benchmark plans, which states have chosen to guide the benefits available from insurance plans that are offered through the Marketplace, may not include benefits such as habilitation, even though habilitation is an essential health benefit required by the ACA. They might also include, for example, annual benefit limits on durable medical equipment such as wheelchairs or ventilators even though the ACA bars such lifetime and annual limits. Navigators should be aware that these discrepancies might be replicated in plans available through the Marketplace and be prepared to advise consumers to carefully review and compare the type and scope of benefits being offered by plans they are considering.
 - If this individual lives in a state that is participating in the Medicaid expansion and she or he is eligible for Medicaid, the Navigator should assist her or him to understand how to evaluate the choices that may be available under the Medicaid program. (See "How is Medicaid eligibility being determined for

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people with disabilities?" for a discussion of Medicaid eligibility and options.)

- Someone with a mental health condition or cognitive impairment may have difficulty concentrating or following detailed instructions. Why is this information important to Navigators?
 - It will be important for Navigators to spend the time required to ensure that this individual understands her or his coverage options and is able to make an informed decision.
 - This person either may be taking prescription medications or require such medications at some point in the future. Therefore it will be important that needed medications be included on the formularies of the various plans being considered, and that the person is made aware of the right to request an exemption if a future prescribed medication is not on the formulary.
 - She or he may also require mental health counseling, which plans are required to provide. It may also be important to this person to preserve ongoing relationships with one or more trusted healthcare professionals for both mental and physical health services, so the Navigator should help the consumer understand how to determine if these providers participate in the networks of the plans she or he is considering.
- Someone who is deaf will not be able to understand verbal communications. Why is this information important to Navigators?
 - In order for most people who are deaf to participate meaningfully in face-toface discussions with a Navigator about insurance options available through the Marketplace, a Sign Language Interpreter likely will be required.
 Navigators should arrange for this accommodation when the person requests it for effective communication. This accommodation is especially important because of the complexity of the insurance choices that are available and to ensure that the person who is deaf has meaningful access to the information required in order to make an informed purchase decision. People who are deaf have varying levels of familiarity and proficiency with written English and

other languages. Therefore, Navigators should provide standard written materials, but not assume that the discussion can skip important information that would typically be discussed verbally just because those same topics are covered in the written materials.

- Someone with a substance use disorder may have cognitive or decision-making difficulties. Why is this information important to Navigators?
 - The person may require treatment services, therefore it is important that Navigators assist the person to understand whether or not those services are included in the benefits package that she or he is considering.

What is disability literacy?

Basic disability literacy means that navigator organizations and Navigators themselves are aware of the elements of disability etiquette involving how to refer to and interact with people with disabilities. It also means that Navigators are aware of the need for physical accessibility of the offices where they meet with consumers and methods to ensure that communication with people with disabilities is effective both by telephone and in person. Disability literacy implies that navigator organizations have adequate internal, organizational capacity to provide accommodations when consumers request them or they are needed. In the context of the Marketplace, organizational disability literacy also involves being able to recognize the need for and identify the specific, unique health care services and benefits that people with disabilities may require, and the capacity to help them assess and understand their insurance options.

What is disability etiquette?

Basic disability etiquette involves treating people with disabilities with respect. For example, speak to the person directly, not to the person accompanying them. Do not make assumptions about what they can or cannot do. The impact of a specific impairment can vary widely from person to person, so offer assistance only if it appears to be needed. Acknowledge and respect the individual's ability to make decisions and judgments on their own behalf. Always use "people first" language. For example, use

the term "people with disabilities." Do not use terms such as "the disabled" or "the handicapped." Avoid referring to people by their disability. For example, do not say, "She is an epileptic." Instead, say, "She has epilepsy." Do not say "wheelchair-bound" or "confined to a wheelchair." Most wheelchair users perceive their wheelchair as liberating, not confining. Do say, "She uses a wheelchair." Do not use negative, demeaning, and outdated terms such as "cripple," "deaf and dumb," or "retarded." Be aware that many people with disabilities do not wish to be referred to euphemistically. So, avoid using terms such as "physically challenged," or "differently abled." Also, avoid referring to an individual with a disability as someone who is "suffering from cerebral palsy or Parkinson's."

What is physical accessibility?

Navigator organizations that are conducting outreach to inform members of their communities about the availability of health insurance through the Marketplace are required by federal disability rights laws to ensure that their activities are accessible to people with disabilities. For example, locations where workshops or meetings are held to discuss the Marketplace with the public or constituents should be physically accessible. Similarly, when Navigators counsel individuals face-to-face about their insurance options and assist them to enroll in healthcare coverage through the Marketplace, accessible physical locations where these activities take place are required. Practically speaking, at a minimum this means:

- If parking is provided, wheelchair accessible parking should be available
- A level entrance into the facility
- An accessible path within the facility and to any microphone stands that participants can use to ask questions
- An elevator if meetings are held in rooms above the first floor
- Wheelchair accessible restroom facilities that are close by
- Signage indicating where accessible facilities are located
- Tactile signage such as raised lettering and Braille labels in locations such as elevators, and indicating the location of facilities such as restrooms, meeting rooms,

and other facility functions and services

(See Resources for additional information on accessibility requirements.)

How can Navigators ensure effective communication with people with disabilities?

In order for people with disabilities to participate effectively in the Marketplace, they require meaningful access to information being provided. For example, Navigator organizations that are conducting outreach to inform members of their communities about the availability of health insurance through the Marketplace should indicate on flyers and other print and digital announcements that print materials distributed at such gatherings can be provided in alternative formats such as Braille when people who are blind request them. One way that navigator organizations can build their capacity to produce documents in formats such as Braille is to develop relationships with community groups that can assist them. People with other visual and sensory disabilities may also require alternative formats such as audio, digital, and large print, which navigator organizations can produce in-house relatively easily and inexpensively when they are needed. Similarly, navigator organizations should indicate on print and digital announcements that accommodations such as Sign Language interpreters, assistive listening devices, and Computer Aided Real-Time Transcription (CART) are available when people who are deaf or hard-of-hearing request them so they will be able to understand what is being said.

Similarly, when Navigators counsel individuals face-to-face about their insurance options and assist them to enroll in healthcare coverage through the Marketplace, print materials, such as Qualified Health Plan (QHP) provider directories, should be provided in accessible formats and Sign Language interpreters provided when people who are deaf request them for effective communication. Some people with cognitive, intellectual, or other related disabilities might require additional time and repetition in order to understand the options being presented and have adequate opportunity to ask questions and make decisions. Navigators who provide answers at a literacy level that meets individual needs will help to ensure effective communication.

When people with communication disabilities telephone navigator organizations for assistance, Navigators should be aware of methods of communication these callers might use. For example, people who are deaf or hard of hearing, or who have speech disabilities may use the Telephone Relay Service (TRS), which is a telephone service that allows people with hearing or speech disabilities to place and receive telephone calls. Telecommunications Relay Service is available in all US states and territories for local and long-distance calls at no additional cost to the consumer or the places that they call. (See "What types of accommodations should Navigators know about?" for more information on providing alternative formats, Sign Language interpreters, CART, Telecommunications Relay Service and other methods for ensuring effective communication.)

How can Navigators assist people with disabilities evaluate the adequacy of provider networks within specific plans?

In order to help people with disabilities make informed decisions about their health care insurance, Navigators should understand how to assist consumers examine health plan options to determine if they will provide the required coverage and when consumers may be eligible for marketplace insurance subsidies. Moreover, Navigators should also understand when consumers are potentially eligible for traditional Medicaid, the Medicaid expansion, or other government healthcare coverage programs such as the Children's Health Insurance Program (CHIP), and be able to explain those possibilities to consumers.

This determination is important because people with certain impairments will likely also have very specific healthcare services needs. Meeting these needs will depend upon a number of factors including cost and availability of specific benefits and services. For example, some people depend on a network of specialty providers such as rheumatologists, neurologists, endocrinologists, physiatrists (doctors who specialize in rehabilitative medicine), mental health and substance use providers, physical, occupational, and speech therapists, and equipment suppliers who specialize in mobility devices such as motorized wheelchairs or respiratory equipment such as ventilators.

Because people with disabilities often have long-standing relationships with providers who are familiar with their complex medical needs, it is particularly important that Navigators help consumers determine if these providers participate in the provider networks of any of the health plans that individuals are considering. In other cases, people with disabilities who do not have insurance but hope to obtain coverage through the Marketplace, may also require access to specific specialty providers, therapies, pharmacies, and suppliers. It will be important therefore to determine if such providers are available under the Marketplace plans being considered. Navigators should also urge people with disabilities who are eligible for Medicaid to contact their state Medicaid office to inquire if these providers accept Medicaid or are available through the contracted Medicaid health plans.

How can Navigators assist people with disabilities evaluate the adequacy of Essential Health Benefits (EHBs)?

The Affordable Care Act ensures health plans offered in the individual and small group markets, both inside and outside of the Health Insurance Marketplace, provide a comprehensive package of items and services, known as Essential Health Benefits (EHBs). EHBs must include items and services within at least the following ten categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care.

Insurance policies must cover these benefits in order to be certified and offer products in the Health Insurance Marketplace. States expanding their Medicaid programs must provide these benefits to people newly eligible for Medicaid.

People with disabilities may need access to certain benefits and services that differ

substantially either in amount, scope or duration from those required by members of the general public. For example, some individuals may need rehabilitation and habilitation services including occupational, physical, and/or speech therapy, behavioral health treatment, and devices such as complex wheelchairs. Others may require ongoing mental health treatment and non-generic prescription drugs, or ongoing diagnostic and specialty visits.

The role of Navigators is to provide fair and impartial information about all healthcare insurance options that are available. Within this role, they can help consumers understand how to determine if the scope and amount of essential health benefits are adequate to cover such services. Navigators also can provide information that will help people with disabilities understand how to evaluate and compare the cost of the benefits they require in relation to various insurance premium levels, co-payments, co-insurance, and deductibles. For example, in some cases, a more expensive monthly health insurance premium may reduce overall costs if out-of-pocket expenses for multiple visits, therapies, or for particular medications or types of equipment are lower in the more expensive plan.

How is Medicaid eligibility being determined for people with disabilities?

States with Partnership or Federally Facilitated Marketplaces are coordinating with the Federal Government on Medicaid eligibility and enrollment. Each state Medicaid agency has chosen whether the Marketplace will assess or determine Medicaid eligibility for individuals applying through the Marketplace. When an individual applies for coverage in states that have elected not to establish their own Marketplaces, the federal Marketplaces should always consider the individual's eligibility for Medicaid. If a state has chosen the assessment model, the federal marketplace makes an initial assessment of eligibility for Medicaid, and the state Medicaid agency makes the final Medicaid eligibility determination. In states that have chosen the determination model, the federal Marketplace makes the final Medicaid eligibility determination and transmits this determination to the state Medicaid agency. Regardless of the model the state has

chosen for determining an individual's Medicaid eligibility, the process should be streamlined with minimal burden on the applicant. The state Medicaid agency will continue to have final oversight of the accuracy of all eligibility determinations, including those made by Marketplaces.

States that are participating in the Medicaid expansion program have selected a benchmark plan among several types of health plans. The benchmark plan will be used to establish Alternative Benefit Plan benefits. While states have the flexibility to make the Alternative Benefit Plan the same as the traditional benefits available in Medicaid, they also have the flexibility to offer different benefits, provided the plan covers the ten essential health benefits services categories.

Most people who are eligible for the expansion group will receive Alternative Benefit Plans. However, states also have the flexibility to establish more than one plan and identify specific plans to meet the needs of certain groups including people with certain health conditions. States also have the flexibility to add Home and Community-Based Services (HCBS) to their Alternative Benefit Plan packages. In general, most states appear to be choosing Alternative Benefit Plan packages for the expansion group that are the same as the state's standard Medicaid package. At the same time, at least a few states are seeking permission from the Center for Medicare and Medicaid Services (CMS) to apply conditions that come with traditional Medicaid to the expansion package. So, for example, a state could seek to apply an asset test to individuals in the expansion Medicaid group before they can access Medicaid long-term services and supports (which includes HCBS), even though the expansion group is supposed to qualify for Medicaid on the basis of income alone. Navigators need to be aware of these important nuances and help people with disabilities, who currently or in future may rely on HCBS to remain in their homes and communities, to understand any special conditions in their state.

Some people who are eligible for the newly expanded Medicaid program and who may

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have greater medical needs will not be *required* to enroll in the Alternative Benefit Plan. For example, eligible people who are blind or who have a disability, are eligible for both Medicaid and Medicare, or who are "medically frail" can choose to enroll in traditional Medicaid if the state's Alternative Benefit Plan does not include that state's full slate of Medicaid state plan benefits.¹⁸ Federal regulations issued in July, 2013 give states some freedom to define "medically frail" but establish that, at a minimum, the definition of "medically frail" includes children with serious emotional disturbances, individuals with disabling mental disorders, individuals with serious and complex medical conditions, and individuals with physical and/or mental disabilities that significantly impair their ability to perform one or more activities of daily living.

In states where traditional Medicaid and the Alternative Benefit Plan differ, traditional Medicaid may offer more benefits, services, and prescription drug options than the Medicaid Alternative Benefit Plans. Similarly, physician and provider networks may be larger with more options for specialty care and services such as rehabilitation and habilitation. Therefore, Navigators should help applicants understand if they might meet the newly expanded definition of "medically frail." Navigators also should make sure that individuals understand that it will be important to check the state's definition of "medically frail" to determine if additional eligibility requirements, such as an asset test apply in order to qualify as "medically frail." Ultimately, if a given state's Alternative Benefit Plan offers the *same* benefits as their traditional Medicaid plan, then it is not significant if the individual fits the state's definition of "medically frail" or not. If the Alternative Benefit plan and the traditional Medicaid plan differ, then the individual, with the help of the Navigator, should give very careful consideration to the different Medicaid options available to them.

Scenarios that illustrate the interaction between impairment or condition, activity limitation, and health insurance coverage needs

People with disabilities may experience more than one form of impairment or condition

and thus possibly more than one activity limitation. They may also have specific and sometimes unique healthcare coverage needs that need to be considered when they choose health insurance. The following questions can be used as a guide to aid the consumer to identify their basic insurance needs:

- Do you or members of your family for whom you are purchasing insurance have health issues that require a higher level of health services than people might require who do not have those health issues?
- Which healthcare services that you or your family use currently are the most costly (e.g., prescription drugs, therapies, medical equipment), or are likely to be costly in the future?
- Among the plans you are considering, which one provides the best coverage for those costs, taking into account premiums, deductibles, co-payments and potential subsidies?
- Do you or your family members currently have healthcare providers or suppliers who you want to make sure are a part of your potential coverage network?
- Is it more important to you to limit how much you pay for monthly premiums or to limit how much you pay when you need health care services?

TIPS:

- Not everyone with a disability will automatically be eligible for Medicaid
- Some people with disabilities will wish to purchase healthcare insurance through the Marketplace
- Some people with disabilities may not be aware of government healthcare insurance programs for which they are eligible
- The lowest cost health insurance premium may not automatically be the best fit for everyone with a disability
- Some people with disabilities, such as a dependent adult child, could qualify for more than one kind of insurance, such as Medicaid and a parent's private insurance

The following scenarios illustrate the relationship between impairments or conditions, possible related activity limitations, and healthcare coverage needs.

Scenario One: Marie

Marie, age 29, has cerebral palsy, a developmental disability that affects her ability to walk and to speak clearly. She also has a seizure disorder that requires specific, nongeneric medication and close monitoring by her longtime neurologist. She uses a motorized wheelchair for mobility. Marie requires regular wheelchair maintenance and repair, and customized seating to prevent back pain. She was covered by her partner's healthcare policy until recently. Marie is employed, but her employer does not provide health insurance. Now she has to acquire healthcare insurance on her own.

What are key issues for Marie in selecting healthcare insurance coverage?

• Is Marie eligible for Medicaid?

Possibly. It depends on several key factors. Marie may be eligible for Medicaid depending upon her annual income and whether or not her state is participating in the Medicaid expansion program. If her state is participating in the Medicaid expansion and her income is below about \$15,282 per year, she will be eligible for the Medicaid expansion program and potentially the benefit package available in traditional Medicaid, which may be desirable for her if it is different from the Alternative Benefit Plan and covers more services and benefits that she needs. In order to be eligible for traditional Medicaid.

• Can she continue to see her regular neurologist who is familiar with her primary condition, cerebral palsy, and her physiatrist (a physician who specializes in rehabilitation medicine)?

Possibly. Marie needs help to determine if her preferred providers participate in Medicaid or the physician networks of either Medicaid or private health plans she is considering. The role of Navigators is to advise Marie that one important factor for her to consider when choosing a health plan is whether or not her preferred providers participate and to provide information that will help Marie answer this important question. For example, some of this information might be available on the Marketplace website. The Navigator also could suggest that Marie check directly with her providers or with the plans she is considering. If it is likely that she will be eligible for Medicaid, then Navigators could suggest that she contact her state Medicaid office directly to determine if her providers participate in that state's Medicaid program.

• What should Maria do if her preferred providers do not participate in any of the physician networks of the plans available to her?

Navigators should help Marie determine if the types of specialty care she requires, such as physiatry, are available in any of the networks of providers who participate in the plans she is considering. If it has been determined that she is eligible for the Medicaid Alternative Benefit Plan, and potentially for traditional Medicaid if she meets the definition of "medically frail," then she should determine if these specialists are available through either or both of these Medicaid options by directly contacting either her state Medicaid office or her providers, themselves.

 Is Marie's seizure medication available either through the plans she is considering or Medicaid?

Possibly. Because Marie takes a specific, non-generic drug for her seizure disorder, she requires prescription drug coverage that includes this particular medication in the prescription formulary. She does not have the option of substituting other medications because she has tried them in the past and either they are ineffective or she has had an adverse reaction to them.

Navigators should help Marie understand how to evaluate each of the prescription formularies for the plans she is considering to determine if her preferred medication is included. If this information is not readily available on the Marketplace website, then she should contact the plans she is considering. If some plans cover her required prescription drug while others do not, she may want to consider the plan that does cover the medication, even if it is more costly, because her cumulative annual healthcare costs may be lower after taking the unsubsidized cost of her prescription drug into consideration. Similarly, if she is eligible for Medicaid, she should inquire with her state Medicaid office to determine if the medication is covered and if it is available through both the Medicaid Alternative Benefit Plan and, if applicable, through traditional Medicaid.

 Is Marie's trusted durable medical equipment supplier, who has maintained her motorized wheelchair and provided her specialized seating, in any of the plans she is considering or in Medicaid?

Possibly. Due to the complexity of Marie's disability, she visits an equipment supplier who specializes in providing high mobility and complex rehabilitation equipment (e.g., motorized wheelchairs, customized seating systems, adapted electronic wheelchair controls, etc.). There is only one such supplier in her geographic area. Navigators should help Marie determine if the plans she is considering contracts with the supplier she currently uses to service and maintain her motorized wheelchair and supply her customized seating. If this information is not available for the plans on the Marketplace website, then Maria should check directly with both the equipment supplier and the carrier selling the plans she is considering. If she is likely to be eligible for the Medicaid expansion program, and if applicable, traditional Medicaid due to a "medically frail" status, Navigators should encourage her to contact both the supplier and her state's Medicaid office for this information. If she is eligible for the Medicaid expansion, then she should be encouraged to determine if the supplier is available through either the Alternative Benefit Program or the benefits package for traditional Medicaid, or both.

• Will any of the plans Marie is considering continue to pay for physical therapy on the ongoing, twice-monthly schedule she requires?

Possibly. Navigators should help Marie determine the number of rehabilitative and habilitative services (e.g. therapy visits) that are covered by the plans she is considering, and their various premium, deductible, and out-of-pocket costs. Each plan is required to have a summary of benefits and coverage (SBC) that may provide more detailed and accurate information than is available on the Marketplace website. Therefore, Marie should check for any important differences by contacting the carrier selling the plans she is considering. The Navigator should also assist Marie to evaluate the overall cost of her therapy visits by comparing premiums, deductibles, and therapy co-payments for the various plans she is considering.

• Will Marie be eligible for financial help to pay for her insurance premiums, if she purchases a private insurance plan?

That depends on Marie's income. While Marie is employed, if her income is below about \$45,960 annually, she may qualify for lower costs on health coverage. Navigators should assist Marie to determine her eligibility for subsidies.

Scenario Two: Peter

Peter, age 41, has bipolar disorder, HIV, and a history of substance use disorder. He also has begun to exhibit symptoms of cardiac disease and needs to undergo additional testing for a final diagnosis and potential treatment plan. Peter has information technology and systems software expertise and works periodically as a consultant when he feels able to do so. He has not historically qualified for Medicaid due to his income levels and existing asset. In the past he has paid out-of-pocket for expensive private insurance, but since 2012 he has subscribed to the Pre-Existing Condition Insurance Plan (PCIP). Peter wants to know if he is eligible for subsidies in the Marketplace or under Medicaid expansion. He is especially concerned about difficulties he has experienced getting sufficient mental health coverage through private insurance, keeping his current mental health professionals, maintaining his ongoing treatment regimen for HIV, and having access to cardiac specialists who either have expertise in HIV/AIDS or who are willing and able to work with providers who do have such

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expertise. Peter also wants to know how he could deal with potential "churn" between successive periods of eligibility for public healthcare and private Marketplace health insurance.

What are key issues for Peter in selecting healthcare insurance coverage?

• Is Peter eligible for Medicaid?

Possibly. If Peter's state is participating in the Medicaid expansion and his income is below about \$15,282 per year he will be eligible for the Medicaid Alternative Benefit Plan. Since Peter has complex medical conditions, he should be advised that the federal definition for "medically frail" individuals in the Medicaid expansion population has recently been expanded and includes "individuals with disabling mental disorders" in addition to "individuals with serious and complex medical conditions."¹⁹ This is an important fact for Peter to weigh as "medically frail" individuals will have the option to enroll in standard Medicaid and potentially have access to greater services and supports than those available under the Alternative Benefit Plan benefit package developed by his state. While the Alternative Benefit Plan benefits that are important to Peter could still fall short of the scope, duration and amount of benefits included in the state's standard Medicaid coverage. Navigators should assist Peter to understand and weigh his various Medicaid options, beyond simply whether his income level makes him eligible for enrollment.

• Is Peter eligible for lower costs on private health coverage?

Possibly. If Peter's income is less than about \$45,960 annually, and he is not eligible for Medicaid coverage, he likely will be eligible for lower costs on his health insurance coverage through the Marketplace. The variation in Peter's income, both within a year and over multiple years means that Navigators need to take particular care to inform Peter of both the likely consequences of under- or over-estimating his income for the upcoming year, and the fact that the Federal Government can adjust his premium subsidies over the course of a year if he informs them of how his actual income does or does not meet the forecast that he provided. Since continuity of care in both treatments, prescription drugs, and providers is particularly important to Peter, he has a vested interest in maintaining a stable relationship with his health plan to the maximum extent possible. Furthermore, individuals with chronic conditions almost invariably have numerous out-of-pocket health-related expenses and costs that can arise unexpectedly and monopolize available resources. If Peter attempts to maintain a reasonable liquid "emergency fund," he needs to be advised that when he files his next income tax return, the Federal Government is likely to ask him to refund any excess Marketplace subsidies that have been provided.

• Will Peter be able to get the mental health coverage that he needs through the Marketplace or under the Medicaid expansion?

Probably. Peter is justifiably anxious though, as historically many health plans and insurers offered no or little coverage of mental health services or substance use disorder treatments. However, the 2008 Mental Health Parity and Addiction Equity Act (MHPAEA) required group health plans and group health insurance coverage (both public and private) that offered mental health and substance use disorder treatments to offer coverage that is "generally comparable" to the medical and surgical care offered in the plan. In 2010 the ACA extended the reach of the MHPAEA by including "mental health and substance use disorder services, including behavioral health treatment" as one of the ten categories of Essential Health Benefits (EHB) that must be covered as of January 1, 2014 by non-grandfathered plans²⁰ in individual and small group markets, both inside and outside of the Marketplace. In addition, HHS enacted regulations under the ACA that extend MHPAEA's parity requirements to the EHB mental health and substance use disorder category.

• Could Peter still face any special limitations on his mental health benefits?

Probably not. Since Peter has been most recently enrolled in a PCIP plan, he was not in a "grandfathered" plan. MHPAEA and the EHB requirements of the ACA both apply to any plan that he purchases through the Marketplace, and also to the Alternative Benefit Plans that will be offered to the Medicaid expansion. This means that whether Peter obtains coverage through an individual Marketplace plan or through the Medicaid expansion, he should obtain mental health or substance use disorders service coverage that is no more restrictive than the coverage for medical/surgical conditions. This requirement applies to treatment limitations such as limits on office visits or inpatient days, financial requirements such as copayments, coinsurance, and deductibles, and the use of care management tools such as a plan's policy requiring that lower cost therapies be proven ineffective before higher cost therapies are approved.

However, Peter could still possibly encounter some historical limitations in mental health treatment. This is because the ACA allowed individual states to choose a "benchmark" for Marketplace coverage among existing plans. If the benchmark plan did not cover an EHB category, then the state had to supplement the benchmark and establish standards for the coverage of the missing EHB category. If the chosen benchmark plan contained existing historical limitations on specific categories of coverage, for example an annual monetary cap or limit on office visits that applied to mental health treatments overall or to specific types of treatment, it is unclear whether those restrictions can be "imported" into the standards that all plans in the Marketplace must meet. For this reason, Navigators should assist Peter to check into the specific mental health coverage offered by plans in the Marketplace to choose a product that will come closest to meeting his mental health treatment needs. Navigators should also help Peter to determine the overall cost of his healthcare if he chooses a plan with higher premiums because it offers access to more visits and/or the cost of co-payments for each visit is lower as compared with other plans.

• Will Peter be able to continue seeing his longtime mental health providers, including a psychiatrist and psychologist?

Possibly. Peter needs to ask his providers if they contract with or are in the provider networks of any of the plans that he is considering in the Marketplace. Alternatively, if Peter qualifies for the Medicaid expansion, he should ask his mental health providers if they accept Medicaid. If he is in a state where Medicaid is offered through mandatory managed care, he needs to check if his providers contract with the Medicaid plans that are available to him. Navigators can also help Peter to get information from plans concerning their mental health provider networks, and if he can continue to see his providers as a new plan member. Some providers can be administratively unavailable to new plan members, regardless of the fact that the new member may be an "old" feefor-service patient of that provider.

Since Peter's variable income could place him in a position of being alternately eligible for Medicaid expansion coverage and Marketplace coverage, with or without federal credits, Navigators should assist Peter to look for any plans that may offer a range of products to both Marketplace consumers and Medicaid beneficiaries. Peter's purchase of health coverage through such a plan will not guarantee that he can retain his health care providers since the plan could conceivably choose to make some providers exclusively available through certain products. However, in light of Peter's need to retain certain long-time therapists and a treatment professional who understands the potential interactions among his bipolar medications, HIV treatment regimen, and a potential new chronic cardiac condition, Navigators should take extra steps to provide Peter with as much in-depth information about plans' provider networks as possible. This should include information about an individual plan's continuity of care policies, any relevant continuity of care rights that the state gives Peter, and potential grievance and appeal procedures than can apply to out-of-network continuity of care requests.

Scenario Three: Juan

Juan, age 56, has recently become blind due to his Type I diabetes. He also has long standing depression. He takes medication for depression and also uses an insulin pump to maintain appropriate glucose levels. He is employed part-time, but his employer does not provide health insurance. He relies on County operated mental health clinics for limited mental and behavioral health counseling. He pays out-of-pocket for his prescription drugs. When he became blind, he received some "vision rehabilitation" services from a local nonprofit, but those services have ended even though he would continue to benefit from them.

What are key issues for Juan in selecting healthcare insurance coverage?

• Is Juan eligible for Medicaid?

Possibly. If Juan's state is participating in the Medicaid expansion and his income is below about \$15,282 per year, but too high for traditional Medicaid, he will be eligible for the Medicaid Alternative Benefit Plan. If he is eligible for the Alternative Benefit Plan, he will also have the option to enroll in traditional Medicaid because, as a person who is blind, he is a member of an exempt population with high medical needs. This is an option Juan should consider if traditional Medicaid offers a greater level of benefits he requires than those available through the Alternative Benefit Plan. Navigators should help Juan explore and understand these various options so he can make an informed choice.

• Is Juan eligible for lower costs on private health coverage?

Possibly. If Juan's income is less than about \$45,960 annually, he likely will be eligible for lower costs on his health insurance coverage. Navigators should assist Juan to evaluate his income eligibility for lower costs on private health coverage.

• Will healthcare insurance pay for vision rehabilitation services?

Possibly. The term "vision rehabilitation" includes a wide range of professional services that can restore functioning after vision loss, just as physical therapy restores function after a stroke or other injury. Historically, health insurance plans have not included vision rehabilitation as a covered benefit and for this reason it likely will not be included

in the state's benchmark plan, which guides benefits available through plans offered in the Marketplace. However, the ACA prohibits disability-based discrimination in healthcare coverage, so Juan could try requesting vision rehabilitation services under the Essential Health Benefit category of habilitation, rehabilitation and devices, even if all of the individual services he requires are not explicitly mentioned as a covered benefit by the plans he is considering. Navigators should also suggest that he contact his state's Department of Rehabilitation and other community-based organizations serving people who are blind, which may be able to provide the services. (See Resources.)

• Will mental health services be available to Juan?

Yes. The Affordable Care Act includes mental health services as an Essential Health Benefit category that health plans must offer. These services include behavioral health treatment, such as psychotherapy and counseling. They also include mental health inpatient services and substance use disorder treatment. The specific mental health benefits available to Juan will depend on the state he lives in and the particular health plan he chooses. Navigators should help Juan understand and evaluate the overall cost of his healthcare if he chooses a plan with higher premiums because it offers access to more visits and/or the cost of co-payments for each visit is lower as compared with other plans. (See Scenario Two for more information on mental health coverage.)

Scenario Four: Tyrone

Tyrone, age 62, has rheumatoid arthritis that causes chronic pain and a mobility impairment that prevents him from walking long distances or climbing stairs. He also has a hearing loss that prevents him from understanding ordinary conversation without the assistance of a hearing aid. He is a lawful permanent resident, but not a citizen of the United States.

What are key issues for Tyrone in selecting healthcare insurance coverage?

• Is Tyrone eligible to purchase healthcare insurance through the Marketplace?

Possibly. Lawfully residing immigrants such as permanent residents who are not enrolled in Medicare are free to purchase healthcare coverage through the Marketplace. Tyrone might also be eligible for subsidized health care coverage if he meets the income level and residency requirements.

• Is Tyrone eligible for Medicaid?

Possibly. Naturalized citizens and green card holders who have been in the country for five years or more will qualify for Medicaid if they meet the income eligibility requirements. If Tyrone had refugee status he could qualify for Medicaid without waiting for five years.²¹

• Are hearing aids covered under the plans that are available to Tyrone?

Probably not. It depends on several factors including the state Tyrone lives in. Most states have selected benchmark plans that exclude hearing aids for adults. As of August 2013, only 7 states' benchmark plans provided some level of coverage for hearing aids for adults without age limits.²² The benchmark, selected by each state, guides the benefits and services that plans operating in the Marketplace will make available. However, the ACA prohibits disability-based discrimination in healthcare coverage, so Tyrone could try requesting hearing aids under the Essential Health Benefit category of habilitation, rehabilitation and devices, even if they are not explicitly mentioned as a covered benefit by the plans he is considering. Navigators could refer Tyrone to local advocacy organizations for assistance to pursue this option. (See Resources.)

• Would Medicaid cover hearing aids if Tyrone is eligible for Medicaid?

Possibly. About two thirds of state Medicaid programs cover some or all of the cost of

hearing aids. So Tyrone's access to coverage for some or all of his hearing aid costs depends on his state of residence.

Scenario Five: Alexa

Alexa, age 57, has heart disease, diabetes, obesity, and a limb amputation. She is developing diabetes-related vision problems that are progressing rapidly. She also walks using a below-knee prosthetic limb, which is fitting poorly due to its age. The ill-fitting prosthetic limb is causing her skin to break down where it makes contact with her residual limb. She has an expensive individual health plan, but recently reduced the number of hours she is working and can no longer afford the plan.

What are key issues for Alexa in selecting healthcare insurance coverage?

• Is Alexa eligible for Medicaid?

Possibly. It would depend on her income and whether or not she lives in a state that is participating in the Medicaid expansion program.

 If Alexa meets the eligibility requirements for Medicaid and her state is participating in the Medicaid expansion, would she meet the definition of "medically frail," which would give her the option of selecting traditional Medicaid if it affords better benefits than those provided in the Alternative Benefit Program?

Possibly. HHS has provided guidelines on who will qualify as "medically frail" and therefore will be eligible to select the traditional state Medicaid benefits package. Each state expanding Medicaid will get to establish specific guidance on the issue that may place additional conditions on who can qualify as "medically frail." Moreover, states are required by federal regulation to develop a screening tool or process to identify "medically frail" individuals within the expansion population who should get the option to enroll in traditional Medicaid. Because Alexa has multiple medical conditions including a leg amputation that causes limitations in activities including walking, she might meet the

definition for being "medically frail." Navigators should first assist Alexa in determining if she is eligible for the Medicaid expansion, and if she is, advise her that if she is eligible for traditional Medicaid by virtue of being determined to be "medically frail," the benefits available to her may be different than those available under the Alternative Benefit Program. Navigators should assist Alexa to complete the required paperwork and inform her of the possible options available.

• Is Alexa eligible for subsidized health insurance from the Marketplace?

Probably. If her annual income is less than around \$45,960, she may be eligible for insurance coverage at a lower cost.

• Will Alexa have access to prosthetics suppliers?

Almost certainly, yes. Prosthetic services are available from insurance plans being offered through the Marketplace. Prosthetics are included within the category of habilitative and rehabilitative services and devices, one of the ten Essential Health Benefit categories required by the ACA. However, the number of suppliers providing prosthetics may vary from plan to plan and Alexa's preferred supplier may not be under contract with any of the plans she is considering. Also, almost every state includes coverage of prosthetics in the Medicaid program. Before the ACA was enacted, a number of states had existing laws covering Orthotics and Prosthetics, and in those states the mandate would already most likely already have been included within the plan that the state chose as its Exchange or Alternative Benefit Plan benchmark.

What types of accommodations should Navigators know about?

Methods to communicate effectively

Effective communication means that whatever is written or spoken should be as clear

and understandable to people with disabilities as it is for people who do not have disabilities. This is important because some people have disabilities that affect how they communicate. It is equally important that standard policies and procedures be modified, and reasonable assistance provided, to ensure that people with disabilities can provide information and answer questions as independently and privately as possible. For example, someone with a cognitive or intellectual disability might require more face-to-face meeting time with the navigator in order to fully understand health plan options than is typically scheduled for consumers seeking information about health insurance through the Marketplace.

Auxiliary Aids and Services

Most individuals with disabilities communicate the same way people without disabilities communicate. But people who have disabilities that affect hearing, seeing, speaking, reading, writing, remembering or understanding may use different ways to communicate than people who do not. Affective communication depends upon the complexity of the information being exchanged. There are many ways to provide equal access to communications for people with disabilities. Often referred to as "auxiliary aids and services," these are devices or services that enable effective communication. Generally, the requirement to provide an auxiliary aid or service is triggered when a person requests it, though there may be some circumstances where it would be appropriate to at least proactively notify an individual, for example a person who is blind, that they have a right to request auxiliary aids and services since that individual could not be expected to read of such a right on their own. Different auxiliary aids and services may be required for the same person at different times depending upon the complexity of the communication.

Here are some examples of different auxiliary aids and services that may be used to provide effective communication for people with disabilities. Not all ways work for all people with disabilities or even for people with one type of disability, so consult with the individual to determine what is effective for her or him.

- qualified interpreters
- notetakers
- screen readers
- Computer Aided Real-Time Transcription (CART)
- written materials
- telephone handset amplifiers
- assistive listening devices
- hearing aid compatible telephones
- text telephones

- open or closed captioning
- video interpreting services
- email
- text messaging
- qualified readers
- taped texts
- audio recordings
- Braille materials
- large print materials
- material in electronic formats

Sign Language Interpreters

Most deaf individuals consider the Deaf community a distinct cultural and linguistic group. The syntax and grammar of Sign Language is independent of English or other languages, and those who use it are a distinct linguistic group. People who use Sign Language as their primary language share experiences that parallel those of other cultural and linguistic minority groups. In order for a hearing person, such as a Navigator, to communicate effectively with someone who is deaf and whose primary language is Sign Language, an interpreter will likely be necessary. Sign Language interpreters are highly skilled, certified professionals that facilitate communication between hearing individuals and people who are deaf or hard-of-hearing. Navigator organizations should identify community groups that refer Sign Language interpreters in order to be prepared to accommodate any consumers who request interpreters. (See Resources.)

Computer Aided Real-Time Transcription (CART)

Computer Aided Real-Time Transcription (CART) refers to the instant translation of the spoken word into English text using a stenotype machine, notebook computer and real-time software. The text produced by the CART service can be displayed on an individual's computer monitor, projected onto a screen, combined with a video presentation to appear as captions, or otherwise made available using other transmission and display systems. CART is a method to provide access to spoken communication for people who are deaf, hard of hearing, or who have certain cognitive or learning impairments. Navigator organizations should establish relationships with local community organizations that can refer qualified CART transcriptionists when consumers either request or need them.

Written Communications

Accessing written communications may be difficult for people who are blind or have visual impairments, who have certain cognitive or learning impairments, or who have other related disabilities. Alternative formats such as Braille, large print text, emails, text messages, or other digital formats, or audio recordings are often effective ways of making Marketplace information accessible to these individuals. In instances where information is provided in written form, Navigators should ensure effective communication for people who cannot read the text. Consider the context, the importance of the information, and the length and complexity of the materials. When planning ahead to print and produce documents, it is relatively easy to print or order the materials in alternative formats, such as large print, Braille, audio recordings, and documents stored electronically. It is also easier to produce these alternative formats with accuracy and within a reasonable time if navigator organizations have established relationships with community organizations that produce materials in accessible formats. (See Resources.)

Telecommunications Relay Service

Relay service allow people with communications disabilities, such as those who are deaf, hard of hearing, and who have speech disabilities, to interact with voice telephone users through a keyboard or other input method. People with disabilities may use the relay service to communicate with Marketplace Navigators. Types of relay service include:

• Telecommunications Relay Service (TRS)

Telecommunications Relay Service (TRS) is a telephone service that allows persons with hearing or speech disabilities to place and receive telephone calls. TRS is available in all 50 states, the District of Columbia, Puerto Rico and the U.S. territories for local and/or long distance calls. TRS providers – generally telephone companies – are compensated for the costs of providing TRS from either a state or a federal fund. There is no cost to the TRS user.

• 711 Access to TRS

Anyone can dial 711 to connect to certain forms of TRS anywhere in the United States.²³

How Does TRS Work?

TRS uses operators, called communications assistants (CAs), to facilitate telephone calls between people with hearing and speech disabilities and other individuals. Either a person with a hearing or speech disability, or a person without such a disability may initiate a TRS call. When a person with a hearing or speech disability initiates a TRS call, the person uses a teletypewriter (TTY) or other text input device to call the TRS relay center, and gives a CA the number of the party that he or she wants to call. The CA in turn places an outbound traditional voice call to that person. The CA then serves as a link for the call, relaying the text of the calling party in voice to the called party, and converting to text what the called party voices back to the calling party.

(See Resources for other forms of TRS that are available.)

NDNRC Fact Sheets

Fact sheets, posted on the NDNRC website and updated over time with state-by-state experiences, will expand on the topics presented in the "Supplemental Guide to Disability for Healthcare Insurance Marketplace Navigators." Fact sheet topics include:

- 1. Comparing Health Plans' Benefits and Coverage Summaries
- 2. Getting and Using Health Plan Evidence of Coverage
- 3. Using Health Plan Customer Service
- 4. Rehabilitation and Habilitation Services and Devices
- 5. Prescription Medication Benefits
- Supporting Collaborations between Navigators, Connectors and Assisters and Local Disability and Affinity Organizations
- 7. Mental Health and Substance Abuse Parity
- Medically Frail Status As an Exemption to Receiving Medicaid Alternative Benefit Plan with Essential Health Benefits
- 9. Streamlined Marketplace Application Process
- 10. Medical Supplies Benefits
- 11. Civil Rights of People with Disabilities under the Americans with Disabilities Act and Section 504 and Section 508 of the Rehabilitation Act
- 12. Process for Medicaid Eligibility
- 13. Referral and Resource Lists
- 14. Information for People on Medicaid Home and Community-Based Services Waiver Waiting Lists
- 15. Medicaid Buy-In
- 16. Renewals and Redeterminations
- 17. Moving from Coverage-to-Care for People with Disabilities
- 18. Meeting the Communication Needs of Specific Disability Populations
- 19. Disability Etiquette

Population Specific Fact Sheets

- What to Know When Assisting a Consumer with Autism Spectrum Disorder
- What to Know When Assisting a Consumer with a Child with Special Health Care Needs
- What to Know When Assisting a Consumer with Intellectual Disability
- What to Know When Assisting a Consumer with Mental Illness
- What to Know When Assisting a Consumer with Multiple Sclerosis
- What to Know When Assisting a Consumer with Paralysis
- Information for Veterans Regarding Department of Veterans Affairs Healthcare

Resources

For a thorough list of resources on enrollment issues related to disability specific issues, mental health and behavioral health issues, populations with special health care needs and general resources on the ACA, please visit the NDNRC website at http://www.nationaldisabilitynavigator.org/resources-links/.

Glossary

For a glossary of terms related to the ACA, health insurance, enrollment and coverage, please see the list at <u>https://www.healthcare.gov/glossary/</u>.

Endnotes

¹US Department of Health and Human Services, Centers for Medicare and Medicaid Services, *Working with Consumers with Disabilities*, (Washington DC, August 29, 2013). ²Institute of Medicine, *The Future of Disability in America*, Introduction,

<http://books.nap.edu/openbook.php?record_id=11898&page=16> (accessed December 10, 2013)

³B. Altman and A. Bernstein, *Disability and Health in the United States, 2001–2005*, (Hyattsville, MD: National Center for Health Statistics, 2008).

⁴ U.S. Surgeon General, "The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities,"www.surgeongeneral.gov/library/

disabilities/calltoaction/forward.html(accessed December 10, 2013).

⁵ U.S. Census Bureau, *Americans With Disabilities: 2005*, Current Population Reports, by Matthew Brault, (Washington, DC: U.S. Census Bureau, 2008), 70-117,

<u>http://www.census.gov/prod/2008pubs/p70-117.pdf</u>(accessed December 10, 2013). Many of the differences between the disability rates by race and Hispanic origin can be attributed to differences in the age distributions of their populations. For example, Hispanics are predominantly younger than non-Hispanic whites.

⁶U.S. Census Bureau, *2009 American Community Survey*, S1810. Disability Characteristics 1 year estimates, *available at*

http://factfinder.census.gov/servlet/STTable? bm=y&-

qr_name=ACS_2009_1YR_G00_S1810&-geo_id=01000US&ds_name=ACS_2009_1YR_G00_&lang=en&-format=&-CONTEXT=st.

⁷ Steve Kaye, University of California San Francisco, Center for Personal Assistance Services, San Francisco, California, June 2012, unpublished data.

⁸The National Council on Disability, *The Current State of Health Care for People with Disabilities*, <u>http://www.ncd.gov/publications/2009/Sept302009 (accessed December 10, 2013)</u>

⁹ However, numerous state mental health parity laws applied to small group insurance plans, typically defined as a plan that covers 50 or fewer employees. The ACA amended this definition to 100 or fewer employees, but states can choose to maintain a definition of 50 or fewer until 2016.

¹⁰ "Grandfathered" plans are plans that existed when the Affordable Care Act was enacted (i.e., March 23, 2010) that have not been changed in certain specified ways

¹¹HHS estimates that as a result, approximately 11 million people with current individual market coverage and 24.5 million people with current small group coverage should be able to get access to mental health and substance disorder that is comparable to their general medical and surgical coverage. In additional, an anticipated 27 million currently uninsured individuals will gain access to health coverage through private health insurance, the Marketplaces, and Medicaid that will include mental health and substance use disorder services that must be generally comparable to their medical and surgical plan coverage. ¹²42 U.S.C. §§12101 *et seq.* (1990) and29 U.S.C. § 701 et seq.

¹³29 U.S.C. § 798

¹⁴42 U.S.C. § 1557 et seq. (2010)

¹⁵Patient Protection and Affordable Care Act, 78 Fed. Reg. 42,824, 42,859 (July 17, 2013) (to be codified at 45 C.F.R. pt. 155), http://www.gpo.gov/fdsys/pkg/FR-2013-07-

17/pdf/2013-17125.pdf (accessed December 10, 2013).

¹⁶ HealthCare.gov, https://www.healthcare.gov/glossary/disability/

¹⁷ "Application for Health Coverage & Help Paying Costs (Short Form),"

http://marketplace.cms.gov/getofficialresources/publications-and-articles/individual-short-form.pdf (accessed December 10, 2013).

¹⁸See 42 C.F.R. § 440.315.

¹⁹ 42 C.F.R. 440.315.

²⁰ "Grandfathered" plans are plans that existed when the Affordable Care Act was enacted (i.e., March 23, 2010) that have not been changed in certain specified ways

²¹ Kaiser Health News,

http://www.kaiserhealthnews.org/stories/2012/october/11/health-careimmigrants.aspx (accessed December 10, 2013).

²² Hearing Loss Association of America, <u>http://www.hearingloss.org/content/hearing-aids-and-affordable-care-act</u> (accessed December 10, 2013).Twenty-two states include some

coverage for hearing aids and related services, of which 18 are included as state required benefits. The "benchmark plans" for each state covering hearing aids specify the minimum requirements for the qualified health plans that may be offered on the exchange in that state.

²³For more information regarding 711, visit

http://transition.fcc.gov/cgb/consumerfacts/711.pdf.