

# National Information and Referral Support Center

# Disability for I&R Specialists

Training for I&R Specialists and for CIRS-A Certificate Holders to Grandfather to CIRS-A/D

#### **Description**

This training module provides participants with an overview of key issues relevant to providing information and referral/assistance (I&R/A) to individuals with disabilities. In partnership with the Alliance of Information and Referral Systems (AIRS), this training module will assist Certified Information & Referral Specialist—Aging (CIRS-A) holders to grandfather to the Certified Information & Referral Specialist—Aging/Disabilities (CIRS-A/D) credential. Additionally, this training module may benefit any I&R specialist who would like to become more proficient at serving people with disabilities.

#### Content

This training module will cover the following topics:

- **Section 1:** What is disability?
- **Section 2:** Disability Awareness
- Section 3: Effective Communication/Technology
- **Section 4:** Services
  - o Trends in Service Delivery
- **Section 5:** Resources
- **Section 6:** Disability Rights and Advocacy
- **Section 7:** Empowerment

#### **Learning Objectives**

This training module is designed to assist participants to:

- Improve the quality of Information & Referral (I&R) service provision for people with disabilities;
- Expand their understanding of disability;
- Increase disability awareness;
- Understand disability resources, services, and support systems; and
- Understand resources and principles of disability rights and advocacy.

#### Section 1

### Disability: A Matter of Perspective

It is estimated that up to 18 percent of the U.S. population has an impairment that is a substantial limitation to one or more daily life activities.

As reported by the U.S. Census Bureau, nearly 1 in 5 people had a disability in the U.S. in 2010, according to a broad definition of disability. The statistics come from the Survey of Income and Program Participation, which contains supplemental questions on difficulty performing a specific set of functional and participatory activities. The Census Bureau also produces annual disability estimates from the American Community Survey (ACS). For data on disability from the Census Bureau, visit <a href="https://www.census.gov/people/disability/">https://www.census.gov/people/disability/</a>.

#### What is a Disability?

Disabilities are a natural part of living, and disabilities can come at any time of one's life. The experience of disability is shaped by a range of factors that include:

- The natural and built environments;
- Services, systems, and policies;
- Culture and attitudes;
- Relationships and support; and
- Technology.

In other words, the context in which people live impacts their functioning.



One framework for understanding disability is the World Health Organization's International Classification of Functioning, Disability, and Health (also known as ICF). ICF provides a biopsychosocial model of disability that synthesizes the medical and social models. In this model, disability is an interaction between the features of the person and the features of the context in which the person lives. To learn more about ICF, visit the World Health Organization at <a href="http://www.who.int/classifications/icf/en/">http://www.who.int/classifications/icf/en/</a>.

#### Americans with Disabilities Act (ADA), 1990

There are many definitions of disability used in federal legislation and federal programs (this contributes to a complex patchwork of programs and eligibility criteria for services). The Americans with Disabilities Act (ADA) definition of disability is far-reaching. This legislation is designed to prevent discrimination on the basis of disability and mandate public accommodation, and is both broad and specific.

According to the ADA, a disability is:

- A physical or mental impairment that substantially limits one or more major life activities (as compared to most people in the general population); or
- A record of such an impairment; or
- Being regarded as having a disability

The ADA Amendments Act of 2008 retains this definition but revised how it should be interpreted, broadening the protections of the ADA.

In this definition, an impairment substantially limits one or more major life activities. An impairment can be episodic or in remission if it would substantially limit a major life activity when active. With one exception ("ordinary eyeglasses or contact lenses"), the determination of whether an impairment substantially limits a major life activity is made without regard to the ameliorative effects of mitigating measures, such as medication, hearing aids, devices or learned behavioral modifications.

The ADA definition's concept of "being regarded as having a disability" has a focus on how a person has been treated because of an actual or perceived physical or mental impairment that is not transitory and minor.

The current text of the Americans with Disabilities Act of 1990 (ADA), including changes made by the ADA Amendments Act of 2008 (P.L. 110-325), which became effective on January 1, 2009, can be found at <a href="http://www.ada.gov/pubs/adastatute08.htm">http://www.ada.gov/pubs/adastatute08.htm</a>.

#### **Major Life Activities**

Under the ADA, major life activities include but are not limited to:

 caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, sitting, reaching, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, interacting with others, and working.

The ADA Amendments Act expanded major life activities to include the operation of major bodily functions. Major bodily functions include functions of the immune system, special sense organs and skin; normal cell growth; and digestive, genitourinary, bowel, bladder, neurological, brain, respiratory, circulatory, cardiovascular, endocrine, hemic, lymphatic, musculoskeletal, and reproductive functions. The operation of a major bodily function includes the operation of an individual organ within a body system.

#### **Social Security Administration**

The Social Security Administration defines disability to determine eligibility for benefits:

- An individual cannot do work that he or she did before;
- Social Security decides that the individual cannot adjust to other work because
  of the individual's medical condition(s); and
- The individual's disability has lasted or is expected to last for at least one year or to result in death.

"Disability" under Social Security is thus based on an inability to work. Social Security pays benefits only for total disability. No benefits are payable for partial disability or for short-term disability. For more information on Social Security's definition of disability, visit <a href="http://www.ssa.gov/dibplan/dqualify4.htm">http://www.ssa.gov/dibplan/dqualify4.htm</a>.

#### **Veterans Affairs**

The Department of Veterans Affairs (VA) defines disability in terms of compensating veterans for their "loss." Disability compensation is a monthly tax-free benefit paid to veterans who are at least 10 percent disabled because of injuries or diseases that were incurred in or aggravated during active duty, active duty for training, or inactive duty training. A disability can apply to physical conditions, such as a chronic knee condition, as well as mental health conditions, such as post-traumatic stress disorder (PTSD).



The benefit amount is graduated according to the degree of the veteran's disability on a scale from 10 percent to 100 percent (in increments of 10 percent). Compensation may also be paid for disabilities that are considered related or secondary to disabilities occurring in service and for disabilities presumed to be related to circumstances of military service, even though they may arise after service. Generally, the degrees of disability specified are also designed to compensate for considerable loss of working time from exacerbations or illnesses. (From the Veterans Affairs website at <a href="http://www.benefits.va.gov/COMPENSATION/types-disability.asp">http://www.benefits.va.gov/COMPENSATION/types-disability.asp</a>)

#### Various Types of Disabilities

There are multiple ways to define and classify types of disabilities. The list below was adapted from the Disability Categories noted on Section 704 of the Annual Performance Report for Centers for Independent Living, Title VII, Chapter 1, Part C of the Rehabilitation Act (U.S. Department of Education, Office of Special Education and Rehabilitation Services, Rehabilitation Services Administration).

#### Types of disabilities:

- Developmental
- Cognitive
- Intellectual
- Physical (mobility)
- Hearing
- Vision
- Mental/Emotional
- Behavioral Health
- Multiple (co-occurring disabilities)

Cognitive disabilities are often defined broadly to address difficulty with various types of cognitive tasks, including tasks related to executive functioning (such as planning, organizing, and working memory). Cognitive disabilities can include traumatic brain injury, dementia, learning disabilities, and attention deficit/hyperactivity disorder. Intellectual disabilities are characterized by significant limitations in intellectual functioning and adaptive behavior, and will be reviewed further in this training.

Mental/emotional disabilities include a wide range of conditions such as anxiety disorder, post-traumatic stress disorder, depression, bipolar disorder, mood disorders, personality disorders, and psychotic disorders such as schizophrenia

(other conditions that may cause psychotic symptoms include alcohol and some drugs, brain tumors, stroke, and bipolar disorder).

Substance abuse and misuse are one set of behavioral health problems. Other behavioral health problems include (but are not limited to) serious psychological distress, suicide, and mental illness. Such problems can be far-reaching and exact a significant toll on individuals, their families and communities, and the broader society.

Next this training will highlight several complex "umbrella" types of disabilities that I&R specialists may encounter in their work, particularly as more individuals with disabilities live and participate in their communities and/or live with their families.

#### **Developmental Disabilities**

Developmental disabilities are described in different ways. According to the Centers for Disease Control and Prevention (CDC), for example, developmental disabilities are a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime (Centers for Disease Control and Prevention, *Developmental Disabilities*, <a href="http://www.cdc.gov/ncbddd/developmentaldisabilities/">http://www.cdc.gov/ncbddd/developmentaldisabilities/</a>).

As described in the Developmental Disabilities Assistance and Bill of Rights Act, developmental disability means:

- A severe, chronic disability that is attributable to a mental or physical impairment, or a combination of both impairments, that appear before age 22, and are likely to be lifelong.
- Results in functional limitations in three or more of the following areas of major life activity: self care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.
- Reflects the individual's need for services, supports, or other forms of assistance.

Developmental disabilities include conditions such as cerebral palsy, epilepsy, fetal alcohol spectrum disorders, or other specific syndromes and neurological conditions that can result in impairment of functioning. Recent estimates in the United States show that about one in six, or around 15 percent, of children aged 3 through 17 years have one or more developmental disabilities or other developmental delays.



Services and supports can vary greatly. Services may include, for example, physical, speech, and occupational therapy; special education classes; psychological counseling; medication; parent training; social skills training; independent living skills; supported or customized employment; and a range of other supports and services.

#### **Intellectual Disability**

Intellectual Disability (ID) is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18. (American Association on Intellectual and Developmental Disabilities, *Frequently Asked Questions on Intellectual Disability*, see <a href="http://aaidd.org/home">http://aaidd.org/home</a>).

Intellectual disability has several characteristics:

- Intelligence quotient (or I.Q.) score of approximately 70 or below (though ID is not determined by an IQ test alone; assessment of ID involves multiple criteria).
- Significant limitations in adaptive behaviors (everyday social and practical skills such as self-care, socializing, and communicating).
- The onset of the disability occurs before age 18.

ID used to be referred to as Mental Retardation, which is no longer an acceptable term. This language has been changed in many laws as well.

#### How Many Individuals Have Intellectual Disabilities?

Estimates on the prevalence of ID vary, though there is some agreement on a small range of percentages of the total general population. Estimates suggest that between one and three percent of the population has an intellectual disability. Prevalence studies may not identify all people with intellectual disabilities. School-age children may receive a diagnosis of learning disability, developmental delay, behavior disorder, or autism instead of intellectual disability (The Arc, Introduction to Intellectual Disabilities, <a href="http://www.thearc.org/page.aspx?pid=2448">http://www.thearc.org/page.aspx?pid=2448</a>).

#### Co-occurrence with Developmental Disabilities

While some people with intellectual disability will also meet the definition of developmental disability, it is estimated that at least half of individuals with intellectual disability will not meet the functional limitation requirement for the developmental disability definition (The Arc, <a href="http://www.thearc.org/page.aspx?pid=2448">http://www.thearc.org/page.aspx?pid=2448</a>). However, since intellectual and other developmental disabilities do co-occur for a number of individuals, disability

professionals often work with people who have both types of disabilities (AAIDD, <a href="http://aaidd.org/home">http://aaidd.org/home</a>).

The impact of having an intellectual disability varies considerably. As adults, some individuals are able to lead independent lives in the community with natural supports rather than paid supports, while others will need significant support throughout their lives. Early intervention, educational supports, and services and supports for adults can all enhance an individual's functioning and opportunities for meaningful community inclusion (The Arc, <a href="http://www.thearc.org/page.aspx?pid=2448">http://www.thearc.org/page.aspx?pid=2448</a>).

#### **Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder (ASD) incorporates a wide range of symptoms and levels of functioning. ASD is characterized by, in varying degrees:

- Persistent deficits in social communication and social interaction across multiple contexts; and
- Restricted, repetitive patterns of behavior, interests, or activities.

Symptoms tend to appear in the early developmental period, though ASD can be complex to diagnose in children and adults. At the same time, an increased prevalence in diagnosis is helping bring greater awareness to ASD.

Autism statistics from the Centers for Disease Control and Prevention (CDC) identify around 1 in 68 American children as on the autism spectrum, a significant increase in prevalence over the past several decades. This increase can be explained in part by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls. (Autism Speaks, *What Is Autism? http://www.autismspeaks.org/what-autism*)

As more families and individuals address ASD in their lives, it may be helpful for I&R specialists to have some familiarity with this spectrum of conditions. Being "on the spectrum" is a unique experience for each individual. Around 40 percent of individuals with ASD have average to above average intellectual abilities. Individuals with autism may have distinctive skills, abilities, and talents. Other individuals with autism have significant disability and are unable to live independently. About 25 percent of individuals with ASD are nonverbal but may learn to communicate using other means. (Autism Speaks, <a href="http://www.autismspeaks.org/what-autism">http://www.autismspeaks.org/what-autism</a>). In working with individuals and families, I&R specialists should also be cognizant that co-occurring conditions such as anxiety disorders, attention-deficit hyperactivity disorder, intellectual disability, sleep



disorders, and other conditions that may co-occur with autism can impact the experiences of individuals and families and needs for services and supports.

There are a range of interventions to improve social and other skills, and reduce symptoms. Applied Behavioral Analysis (ABA) is one treatment that is widely known, but it is important for specialists to recognize that ABA is one of a range of treatments, and each child or individual's unique circumstances should guide thinking on programs and services. The National Institute of Mental Health provides some information on treatments and services at <a href="http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml">http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml</a>.

It may also be helpful for specialists to know that, with the publication of the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), all autism-related disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger syndrome.

#### **Beyond Diagnosis**

While an understanding of types of disabilities is important, I&R specialists seek to provide referrals and assistance based on each person's unique circumstances.

This perspective calls for focusing less on medical diagnosis and more on the abilities, choices, and needs of the person, recognizing that functioning\* can vary widely for any type of disability. It is also important to consider the supports and resources that are available to a person and the individual's own coping strategies.

This perspective also reflects changes in the field to evolve beyond the "medical model" of disability to approaches that emphasize important social and environmental factors and that promote empowerment and consumer control.

\*Functioning can encompass activities of daily living (ADLs) and instrumental ADLs, and much more such as problem-solving, memory, visual comprehension, and verbal comprehension. ADLs are basic self-care tasks including feeding, toileting, grooming, maintaining continence, dressing, bathing, walking, and transferring. IADLs are more complex skills needed to live independently such as managing finances, handling transportation, shopping, preparing meals, using the telephone, housework, and basic home maintenance.

# Section 2 Disability Awareness

#### **Disability Awareness**

As with engagement with any inquirer, in serving individuals with disabilities it is important that the I&R Specialist presumes competence, uses active listening skills to learn from the inquirer, and responds to requests for assistance in a personcentered manner based on the needs and priorities expressed by the inquirer. By presuming competence, an I&R Specialist expects that the inquirer can make their own choices, and is an active participant in addressing their needs.

For more tips on interacting with people with disabilities, see the United Spinal Association's *Disability Etiquette* guide at <a href="http://www.unitedspinal.org/disability-etiquette/">http://www.unitedspinal.org/disability-etiquette/</a>.

Additionally, I&R specialists should avoid touching or leaning on an individual's wheelchair, speaking loudly unless asked, grabbing the arm of a person who has a visual disability, and petting a service or support animal. For persons with speech disabilities, it is important to avoid interrupting or finishing the person's sentences. Disability awareness and disability etiquette can help to foster rapport between inquirers and specialists, an important foundation for assessment and information and referral giving.

#### Disability Etiquette TIPS

- Listen to the person
- Presume competence
- Talk directly to the person (not their family member, interpreter, attendant, caregiver, guardian, friend, or partner)
- Ask what the preferred communication style and mode is, and follow it whenever possible
- Be respectful and non-judgmental
- Be aware of your own biases and work through them
- Ask before offering assistance, and do not touch an assistive device or service animal without permission



#### **Person-First Language**

Always remember to put the person first, not the disability. People with disabilities should not be defined solely by the presence of an impairment or health condition. The chart below provides guidance on preferred person-first language, and language to avoid.

Avoid	Preferred
Handicapped accessible	Accessible parking Accommodations
Handicapped, crippled	Person with a disability Individual with a disability
Quadriplegic, paraplegic, incapacitated	Individual with a spinal cord injury
Wheelchair-bound/ Confined to a wheelchair	Person who uses a wheelchair Wheelchair user
The blind	Individual who is blind or has low vision
The deaf, hearing impaired	Individual who is deaf or hard of hearing
Midget	Individual of short stature Little person
Stroke victim Suffered from a stroke	Person who had a stroke
Slow Retarded	Individual with an intellectual disability
Crazy, mentally ill	Person with a psychiatric disability or with a mental health condition

In addition to the person-first language presented in this chart, I&R specialists should also keep in mind that terms like "special needs" or "challenged" are not the preferred terms to use for people with disabilities.

Section 3
Effective Communication/Technology

#### **Effective Communication**

As with all professional I&R interactions, for effective communication, I&R specialists serving individuals with disabilities should:

- Use active listening skills.
- Ask a person to repeat if you don't understand what is said.
- Paraphrase to help fully understand what the person is saying, and clarify to ensure your understanding of the person's situation.
- Inquire what the best method for communication is if what you are doing isn't working. Alternative methods for communication could include, for example, in-person rather than a phone call, email or text, Skype, and written communication.

#### **AIRS Technology Standard**

Technology can be an important gateway to accessing information and services for persons with disabilities. I&R services and specialists may want to think broadly about how technology can facilitate access to services and think beyond traditional methods of communication like telephone. For example, it is important to be familiar with modes of communication such as diverse relay services for individuals who are deaf, hard of hearing, or have a speech disability. Relay services can include TTY or traditional relay service, video relay service, speech to speech relay service for people with a speech disability, and other services to address diverse communication needs.

The importance of technology to enhance the I&R process is also reflected in the AIRS Standards and Quality Indicators for Professional Information and Referral. A Technology Standard was added to the AIRS Standards in 2013 and requires that "the I&R service uses technology that improves access to information and enhances its ability to serve inquirers efficiently and effectively. The main role of technology is to enhance and strengthen information sharing while accommodating people's communication preferences" (AIRS Standards and Quality Indicators for Professional Information and Referral, Version 7.0, revised March 2013, Alliance of Information and Referral Systems). Under this standard, Technology includes: telephone systems, telecommunications, computer systems and applications, instant messaging (IM), text/SMS messaging, online chat, video relay/chat, social media I&R software platforms, electronic directories and self-service mechanisms such as automated attendants/interactive voice response systems, video relay services, community



kiosks, and searchable I&R databases on the Internet. Quality indicators for this standard include:

- Evaluating new methods of access and technical advances prior to implementation to ensure that access to information and assistance for inquirers is enhanced;
- Reviewing how different populations access information; and
- Creating technology goals that reflect changing inquirer needs.

In evaluating current and new technology, it is important for the I&R service to evaluate and review technology for compatibility with the types of assistive technology used by inquirers and for general accessibility. Technical advances vary in terms of how "friendly" they are to persons who use assistive technology (AT); sometimes AT is not "caught up" to new advances in technology. Other times, new technology incorporates principles of universal design to maximize usability. The United States Access Board can be a resource for accessibility standards and links to other resources on IT accessibility (visit the U.S. Access Board at <a href="http://www.access-board.gov/">http://www.access-board.gov/</a>).

#### **Assistive Technology**

Assistive technology can be essential to effective communication, and can facilitate community living and individual functioning for people with disabilities in many ways. For individuals with disabilities, assistive technology can be vital for independent living. Additionally, assistive technology services may be just as important as AT devices. Services should be paired with devices to help ensure the right fit for the individual and to help introduce the individual to the use of the device.

The Assistive Technology Act defines AT and AT services as follows:

- Assistive technology—"Any item, piece of equipment, product system, whether
  acquired commercially, modified, or customized, that is used to increase,
  maintain, or improve functional capabilities of individuals with disabilities."
- Assistive technology service—"Any service that directly assists an individual
  with a disability in the selection, acquisition, or use of an assistive technology
  device."

#### **Examples of Assistive Technology**

There are many types of assistive technology for children, youth, adults, and seniors with disabilities. AT devices range from "low tech" and everyday devices to "high tech" and specialized devices. Some examples of assistive technology are provided below.

- Vehicle Modifications
- Home Modifications
  - Roll-in showers
  - o Environmental Controls (for lights, shades, etc.)
- Adaptive Software
  - o Screen reader
  - Speech to text
- Apps
  - Social skills apps
  - o Reminder apps
- Mobility Aids
  - o Wheelchairs
  - White cane
- Hearing Aids
- Vision Equipment
  - Screen Magnification
- Communication Devices
  - o Picture board; touch screen with pictures or symbols
- Computer
  - Large print keyboard

It can be helpful for an I&R service to review its products and resources for compatibility with widely-used assistive technology such as screen readers like JAWS (Job Access With Speech), and to make changes or improvements if needed to help ensure accessibility.

Applications, or "apps," are providing opportunities for personalized and portable assistive technology in many domains of life and functioning, such as hearing, communication, memory, health, learning and cognition, navigation, writing, personal care, safety, reading, speech, and vision. Apps may have the benefit of universal design when they are designed to benefit a wide range of users through commonly-used devices such as smart phones and tablets.



Section 4
Services

#### **Services**

- I&R specialists should understand the types of services and resources commonly accessed by people with disabilities.
- The I&R service should be aware of, and verify, the accessibility of facilities and services, and specialists should know who to contact for accommodations.
- The I&R service should ensure that programs and services for people with disabilities in its catchment area are included in the resource database or directory.
- I&R specialists should recognize that people with disabilities can benefit from programs that serve a range of individuals, not only disability-specific programs.
- Many people with disabilities who use I&R services have goals related to increased independence and functioning in a significant life area. These domains could include: community-based living, mobility/transportation, educational and vocational services, information access/technology, relocation from an institution, community/social participation, health care, self-care, financial resources, and self-advocacy/empowerment.

(Drawn from the *ABCs of I&R*, Alliance of Information and Referral Systems, 2014 edition, section 17: "Special Populations—Serving People with Disabilities.")

In providing information and referrals to persons with disabilities, it is important for specialists to consider the person's needs and preferences which may include disability-specific and non-specific services. For example, not all individuals seeking employment services may want to be referred to vocational rehabilitation. Some could prefer to seek services from a universal service provider such as an American Job Center (formerly known as a one-stop career center).

#### Services (examples)

Specific services and resources that people with disabilities commonly access through I&R to meet their goals and needs include those listed below. This list is not exhaustive. Other service needs may include, for example, employment assistance, day programs, and services such as American Sign Language (ASL) interpreter services. (*ABCs of I&R*, Alliance of Information and Referral Systems, 2014 edition, section 17: "Special Populations—Serving People with Disabilities.")

# NASUAD Disability for I&R Specialists

- Financial assistance, including:
  - o Application assistance
  - o Benefits counseling
- In-home assistance
  - Personal care services
  - Chore/homemaker
- Housing, including:
  - Home modifications
  - Utility assistance
- Transportation
- Medical, including:
  - Medical assistance
  - Medical services
  - Long-term supports
- Assistive Technology & IT
- Case management, counseling, peer support
- Crisis assistance
- Legal and advocacy assistance

Financial assistance may include assistance in applying for federal disability benefits (Social Security Disability Insurance or Supplemental Security Income) as well as benefits counseling that helps people with disabilities to understand how disability benefits interact with work and with other benefit programs. Agencies and programs that provide benefits counseling might include vocational rehabilitation, Work Incentive Planning and Assistance programs, and community rehabilitation providers. In providing referrals and assistance for financial needs, I&R specialists should think broadly about the range of programs that improve individuals' and families' economic security, including non-disability specific programs such as the Supplemental Nutrition Assistance Program (SNAP), the Temporary Assistance for Needy Families program (TANF), the Low Income Home Energy Assistance Program (LIHEAP) and county assistance programs. People with disabilities and health conditions can face higher costs of living in many domains, which may contribute to the need for financial assistance.

Medical assistance may include assistance in accessing health coverage (such as Medicaid, Medicare, and coverage/subsidized coverage under the Affordable Care Act); assistance in paying for medications, and assistance with accessing and/or understanding options for long-term services and supports (LTSS).



Assistive technology (AT) and IT might include device purchase, repair, or modification; loan programs; loan or purchase of durable medical equipment; and resources/services for hearing and vision needs.

Legal and advocacy assistance may include a long-term care ombudsmen program, protection and advocacy (P&A) services, resources related to Americans with Disabilities Act (ADA) protections, and fair housing resources.

#### Medicaid—A Critical Program for People with Disabilities

Many key services for people with disabilities are funded through the Medicaid program. While each state Medicaid program is complex, it is important for I&R specialists to have a basic understanding of their state's Medicaid program, including where eligibility is housed. It is also important to note that Medicaid programs, including home and community-based services waiver programs, vary from state to state.

Medicaid is the primary payer of long-term services and supports (LTSS) in the U.S., including institutional services and home and community-based services. Medicaid funds home and community-based services (HCBS) through waivers and state plan services; depending on the state and waiver, Medicaid covers a broad range of services to address functional needs and facilitate participation in community activities, including employment. HCBS waiver services for persons with physical disabilities may include, for example, personal assistance services, homemaker services, case management, medical transportation, and home modifications. HCBS waiver services for people with intellectual/developmental disabilities might include, for example, day training and habilitation services, supported employment, assistive technology, adult day health care, case management, supported living, and respite care.

Medicaid is also an important source of coverage for people with mental health conditions, and the Affordable Care Act includes mental health and substance use disorder services as one of 10 essential health benefits that must be included in some Medicaid coverage options.

Medicaid programs may allow for self-direction. The availability of self-direction varies by state. The option for self-direction enables eligible individuals to hire, train, manage and/or purchase specific HCBS services that they require.

# NASUAD Disability for I&R Specialists

#### Disability Benefits—SSI and SSDI

The Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs are also important programs for some individuals with disabilities, and it is helpful for I&R specialists to have basic knowledge of these federal benefit programs.

SSI is a needs-based program for people with limited income and resources who are disabled, blind, or age 65 or older. Children who are blind or disabled may also receive SSI if eligible. In most states, SSI eligibility automatically qualifies an individual for Medicaid coverage. However, some states use more restrictive eligibility criteria than those used by the SSI program. This means that in those states (commonly referred to as 209(b) states) receipt of SSI does not guarantee eligibility for Medicaid. In a 209(b) state, individuals determined eligible for SSI by the Social Security Administration need to complete a separate Medicaid application. In addition to Medicaid coverage, many states provide a supplement to certain SSI recipients.

SSDI provides benefits to persons who are disabled or blind and who are "insured" by contributions to Social Security based on earnings from employment. SSDI beneficiaries are eligible for Medicare after a 24-month qualifying (i.e. waiting) period. During this qualifying period for Medicare, the beneficiary may be eligible for health insurance through a former employer. Beneficiaries may also be eligible for coverage programs under the Affordable Care Act such as coverage through the Marketplace.

#### SSI and SSDI Quick Facts

- SSI is a needs-based program for individuals with disabilities and older adults.
- In most states, SSI recipients automatically qualify for Medicaid.
- SSDI provides benefits to eligible individuals with disabilities who are insured by contributions based on earnings from employment.
- SSDI beneficiaries are eligible for Medicare after a 24-month qualifying period.
- Both programs have work incentives for beneficiaries with disabilities who want to work.

Both the SSI and SSDI programs have work incentives for individuals who want to return to work or try working. Medicaid also has work incentive programs for SSI recipients who want to work or for SSDI beneficiaries through state Medicaid Buy-In programs. It is important that I&R specialists do not assume that people with disabilities and disability beneficiaries either cannot or do not want to work. Individuals may be interested in work but fear loss of critical benefits. There are resources that can help individuals explore their work options. One national resource is the Ticket to Work website at <a href="http://www.chooseworkttw.net/">http://www.chooseworkttw.net/</a>.



#### **Medicare Low-Income Subsidies**

Medicare is an important source of health coverage not only for older adults. Around 17 percent of people on Medicare are under age 65; primarily individuals with disabilities. Additionally, this population of nonelderly Medicare beneficiaries with disabilities is more likely to live at or below the poverty level. Unlike Medicare beneficiaries who have aged into Medicare, individuals who become eligible for Medicare before turning 65 generally do not enjoy the same streamlined processes to determine and inform them of all the benefits potentially available to low-income Medicare beneficiaries. That is why it is so important when providing outreach to individuals with disabilities to be aware that low-income subsidies exist to help low-income Medicare beneficiaries better afford their Medicare costs.

Medicare Low-Income Subsidies are comprised of the Medicare Savings Programs (MSPs) and the Medicare Part D Low-Income Subsidy. The Medicare Savings Programs, referred to as MSPs, are a set of 4 programs that are administered by state Medicaid agencies and generally help with the cost of Medicare Part B premiums at a minimum. Medicare Part B, also known as the outpatient insurance, covers most medically necessary doctors' services, preventive care, durable medical equipment, hospital outpatient services, laboratory tests, x-rays, mental health care, and some home health and ambulance services.

Medicare Savings Programs (MSPs)		
Administered by State Medicaid agencies	Generally, help pay Medicare Part B premiums	Four different programs:  QDWI: Qualified Disabled Working Individual  QI: Qualifying Individual
		SLMB: Specified Low-Income Medicare Beneficiary  QMB: Qualified Medicare Beneficiary

The Medicare Part D Low-Income Subsidy is a program that helps reduce Medicare Part D prescription drug costs. This program is commonly known as either LIS or Extra Help. Extra Help is administered by the Social Security Administration to assist low-income Medicare beneficiaries afford their Medicare Part D prescription drug costs. Most recipients that qualify for Extra Help will pay: no Medicare Part D

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premiums; no annual deductibles; and no more than \$6.60 (in 2015) for each covered prescription.

In addition to having basic knowledge of the Medicare Low-Income Subsidies and the purpose of the different subsidy programs, it is just as important for I&R specialists to learn where to refer individuals for additional information and enrollment assistance. Information and referral resources will be addressed later in this training.

#### **Vocational Rehabilitation**

State Vocational Rehabilitation (VR) programs provide vocational and rehabilitative services to people with disabilities to help them prepare for, secure, or retain employment. To be eligible for VR services, a person must have a physical or mental impairment that is a substantial impediment to employment; be able to benefit from VR services in terms of employment; and require VR services to prepare for, enter, engage in, or retain employment. Priority is given to those individuals who have the most significant disabilities if a state is unable to serve all eligible individuals. This prioritization process is called an "order of selection," and it can be helpful to know if this process is in effect in your state.

VR programs can provide a range of services from assessment to job placement and post-placement supports; services may include information and referral, education and training, assistive technology purchasing, and related services. Further examples of VR services are provided in the section below. States also provide VR services to individuals who are blind or have vision impairments; these programs may be housed in separate agencies or divisions.

The Workforce Innovation and Opportunity Act of 2014 (WIOA) amends the Rehabilitation Act—including the VR program—in important ways. For example, it increases the role of the public VR system in supporting transition for youth with disabilities to adult life/employment and post-secondary education. It includes efforts to limit the use of subminimum-wage positions (i.e., subminimum-wage sheltered employment) for youth. It defines and emphasizes competitive, integrated employment for individuals served by VR. WIOA also seeks to improve how the general workforce development system serves individuals with disabilities.

#### **Vocational Rehabilitation: Services**

VR programs can provide a range of services to help individuals with all types of disabilities achieve employment outcomes. These include (but are not limited to): assessment (may include vocational, medical, and psychological assessments); vocational counseling, guidance, and information and referral services; physical and mental restoration services; vocational training, including on-the-job training;



transportation to enable an individual to participate in VR services; interpreter services for individuals who are deaf; services to assist students with disabilities to transition from school to work; personal assistance services while an individual is receiving VR services; rehabilitation technology/assistive technology services and devices; supported employment services; and job search, placement, and coaching services. Examples of VR services are listed below.

- Assessment
- Vocational counseling, guidance and referrals
- I&R to other programs/agencies
- Vocational training
- On-the-job training
- Job-site assessment
- Assistance for self-employment
- Youth transition services
- Supported employment
- Job search, placement and coaching
- Rehabilitation/assistive technology
- Transportation
- Orientation and mobility services
- Interpreter and reader services
- Medical services addressing vision such as eye exams and treatment
- Services for individuals who are deaf-blind
- Physical and mental restoration services
- Personal assistance services while an individual is receiving VR services

VR services for individuals who are blind and visually impaired may be housed in separate divisions or agencies. Along with a range of employment services such as those noted above, services for persons who are blind or have visual impairments may include services such as orientation and mobility services to assist persons to gain skills needed for everyday travel tasks; services for individuals who are deaf-blind; reader services; and medical services like eye exams and low-vision evaluations, eye treatment, and assistive technology evaluations.

#### Trends in Service Delivery

There are a number of areas of change and transformation in service delivery to people with disabilities. This report highlights several that may be of interest to I&R specialists, and that will likely impact the landscape of services and programs in your communities. The provision of long-term services and supports (LTSS), in particular, is being transformed by efforts at the federal, state, and community levels. These efforts include the following:

- No Wrong Door access to long-term services and supports;
- Person-centered thinking and planning;
- Regulations addressing the provision of Medicaid-funded home and community-based services; and
- Integrated, competitive employment for persons with disabilities ("Employment First").

#### Trends in Service Delivery: No Wrong Door

In states across the country there are initiatives, including Aging and Disability Resource Centers (ADRCs), to help individuals understand and access LTSS options. A system of access to LTSS might be referred to as a "no wrong door" system, though states and communities may describe their systems in different ways.

At the federal level, *No Wrong Door* (NWD) envisions a statewide system for access to long-term services and supports for all populations and all payers. All populations means all persons regardless of age, income or disability; and all payers means any state administered program that provides access to LTSS. NWD systems are intended to serve as visible and trusted places available in every community where people of all ages, incomes and disabilities go to get information and personcentered counseling on the full range of LTSS options. This effort draws from the lessons and experiences of the ADRC and Balancing Incentive Program initiatives to inform the development and implementation of NWD systems.

It is also intended that NWD systems have formal linkages with key referral sources in communities including local Information, Referral, and Assistance programs and 2-1-1 systems. Key functions of the system as identified by federal partners include:

- Public outreach and coordination with key referral sources (including I&R programs)
- Person-centered counseling
- Streamlined access to LTSS programs
- System governance and administration



Additionally, the NWD system includes Aging and Disability Resource Centers and partnerships between aging and disability organizations.

#### Trends in Service Delivery: Person-centered Planning

- Person-centered thinking and planning help individuals direct their own lives.
- Beyond a functional assessment, person-centered planning (PCP) reflects an individual's self-identified goals, preferences, strengths, and service and support needs.
- Many agencies have implemented different styles of PCP over the years. Federal guidance released in 2014 provides standards on PCP in home and community-based services. The Department of Health and Human Services' *Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs* (Section 2402(a) of the Affordable Care Act) includes standards that are to be embedded in all home and community-based services programs (as appropriate) that are funded by HHS. The guidance also envisions person-centered thinking at all levels. This guidance can be viewed at <a href="http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf">http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf</a>.
- Under this guidance, the role of options counselors and other front-line staff in the PCP process is to assist individuals to identify and access a personalized mix of services (including paid and unpaid services). The PCP process provides a framework for options counseling.

#### Trends in Service Delivery: Medicaid-Funded HCBS

On January 16, 2014, the Centers for Medicare and Medicaid Services (CMS) released a Final Rule (CMS-2249-F/CMS-2296-F) that implements significant changes to Medicaid Home and Community-Based Services. Most notable are new requirements for person-centered planning; conflict free case management; and home and community-based services (HCBS) settings.

The final rule establishes requirements for home and community-based settings in Medicaid HCBS programs operated under sections 1915(c), 1915(i), and 1915(k) of the Social Security Act (these sections provide authority for HCBS waivers, HCBS state plan services, and the Community First Choice option for home and community-based attendant services). The rule seeks to create a more outcomeoriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics, such as the number of beds or residents. The regulatory changes aim to maximize the opportunities for HCBS program participants to have access to the benefits of community living and to receive services in the most integrated setting. The rule intends that Medicaid home and community-based services offer alternatives to services provided in institutions. In other words, CMS does not intend for Medicaid

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HCBS funds to pay for institutional-like living in a home and community-based setting. Importantly, the rule applies to residential and non-residential settings, such as adult day programs, day habilitation programs, and pre-vocational programs.

In the final rule, CMS specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. The rule requires that the person-centered planning process is directed by the individual with long-term support needs, and may include a representative whom the individual has freely chosen and others chosen by the individual to contribute to the process. The rule describes the minimum requirements for person-centered plans developed through this process, including that the process results in a person-centered plan with individually identified goals and preferences. More information on the rule, including fact sheets and a toolkit, is available from CMS at <a href="http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-S

#### Trends in Service Delivery: Medicaid HCBS Settings

This section provides further information on the HCBS setting requirements noted above. Over the past several years, CMS engaged in discussions with stakeholders, states, and federal partners about the qualities of community-based settings that distinguish them from institutional settings. In the final rule, CMS moved away from defining home and community-based settings by "what they are not," or factors such as the number of beds, and toward defining them by the nature and quality of individuals' experiences. This quality of life interpretation considers elements such as relationships, meaningful community participation, employment, daily routines, and areas of life important to the person.

For 1915(c) home and community-based waivers, and for 1915(i) State plan home and community-based services, home and community-based settings must have all of the qualities defined in the regulation, based on the needs of the individual as indicated in their person-centered service plan. Several key qualities are as follows:

 The setting is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.



- Ensures an individual's right to privacy, dignity and respect.
- Optimizes, but does not regiment individual initiative, autonomy, and independence in making life choices.
- Facilitates individual choice regarding services and supports, and who provides them.

This final rule will likely have significant impacts on the nature and mix of residential and non-residential HCBS services available in states and communities. For I&R specialists, options counselors and other front-line staff in aging and disability agencies, these changes may impact the HCBS options available in your communities, and influence how you discuss HCBS with individuals who are or may become Medicaid eligible.

#### Trends in Service Delivery: Employment First

Over the past decade, the concept of "Employment First"—the idea that employment in integrated settings within the community should be the priority service option—has emerged in the disability field. The Employment First concept is also reflected in the HCBS settings rule, which emphasizes employment in competitive, integrated settings for those receiving Medicaid-funded services. Employment First reflects changing expectations and goals for persons with disabilities. Under the Employment First approach, community-based, integrated, competitive employment is the first service option for employment for all youth and adults with disabilities, rather than sheltered employment or non-work day programs being the first option. This does not preclude individuals participating in non-work activities, but seeks to alter expectations and opportunities so that employment in the general workforce is an option.

Employment First is implemented through legislation, regulations, policy directives, changes in financing, training and technical assistance, and other activities at the state level and by agencies and providers. Nearly all states have undertaken some type of Employment First activity. Additionally, systems change at all levels of human services is a critical component of achieving the vision of Employment First so that services and supports, and policy and financing, facilitate employment in the community, including for those needing long-term services and supports.

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### Section 5 Resources

This section will highlight resources for serving inquirers with disabilities, including resources that may be good partners for I&R services and resources that can assist I&R specialists in providing information to individuals. This training will also review Aging and Disability Resource Centers (ADRCs), an important access point in communities for older adults and persons with disabilities.

#### **Centers for Independent Living (CILs)**

Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs) were established as organizations intended to operationalize the principles of the Independent Living movement. Centers for Independent Living are grassroots, advocacy-driven organizations run by and for people with disabilities. They focus on civil rights, the independent living philosophy, and inclusion. CILs provide four core services, and a fifth core service was added by reauthorization legislation:

- Information & Referral
- Independent Living Skills Training
- Peer Support
- Individual and Systems Advocacy
- New fifth core service: Transition

The core services are the hallmark of Centers for Independent Living. All CILs are required to provide these services. CILs provide Information and Referral to ensure people with disabilities have access to information needed to achieve or maintain independence in their community. CILs use peers with disabilities to provide consumers with Independent Living Skills Training to teach some of the specific skills needed to achieve independence in their home and community. The value placed on peer support in the Independent Living Movement is paramount and unique. Individual and Systems Advocacy is carried out in a wide variety of ways, according to the priorities of local communities. Centers can provide disability awareness training and advocate for improved accessibility, for example. Center staff advocate on an individual and system-wide basis to ensure the civil and human rights of people with disabilities.



One of the most common forms of individual advocacy CILs engage in is to help consumers transition out of nursing homes and into their own homes, or back into their homes. In recognition of this function, the Workforce Innovation and Opportunity Act (WIOA, signed into law in 2014 to reauthorize workforce development legislation including the Rehabilitation Act) adds a fifth core service: transition. This includes transition out of institutions; and transition for youth with disabilities from school to post-secondary education, employment and/or independent living.

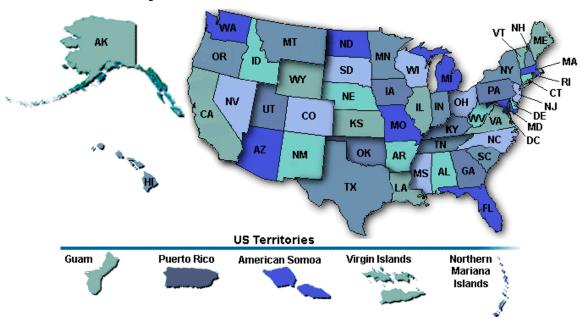
#### **National Council on Independent Living (NCIL)**

The National Council on Independent Living (NCIL) is a national cross-disability, grassroots membership organization run by and for people with disabilities. NCIL:

- Represents individuals with disabilities, CILs, Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the U.S.
- Assists members in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to affect change.

To learn more about NCIL and Independent Living, visit <a href="http://www.ncil.org/">http://www.ncil.org/</a>.

#### **National Directory of SILCs/CILs**



In 2014, there were 365 federally-funded CILS; 715 total CILs including those that are state-funded and satellite offices.

Statewide Independent Living Councils (SILCs) advise Centers for Independent Living on issues, identify the need for expanded independent living services, create a State Plan for Independent Living (SPIL), which sets priorities for Centers statewide, and monitor this state plan. In 2014, there were 56 Statewide Independent Living Councils.

A directory of Centers for Independent Living (CILs) is available from ILRU at <a href="http://www.ilru.org/projects/cil-net/cil-center-and-association-directory">http://www.ilru.org/projects/cil-net/cil-center-and-association-directory</a>.

#### I/DD Resources in Your Area

I/DD (intellectual/developmental disability) support systems are different in each state and community, and may include the types of services and agencies listed below.

Services in your area:

- Community Living
- Consumer-Directed Services
- Options Counseling
- Peer & Family Support
- Supported Employment
- Day Programs
- Supportive In-home Services
- Transition Planning
- Transportation/mobility

Transition planning can include services to assist individuals to transition from institutional to community living, and services to assist youth as they exit secondary education. Youth transition is an important component of transition planning to assist youth with I/DD to transition to their post-secondary lives that may include employment, vocational training, higher education and community or independent living.

Agencies/Organizations in your area:

- University Center for Excellence in Developmental Disabilities
- Center for Independent Living
- The Arc (local chapter)
- State/local Health and Human Services department that provides I/DD services
- Community rehabilitation providers



University Centers for Excellence in Developmental Disabilities were created by federal legislation to serve persons with I/DD. There are sixty-seven (67) Centers across the country, authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to serve as resources for individuals with a wide range of disabilities. Each Center (there is at least one in every state and territory) is affiliated with a major research university and serves as a resource for people of all ages. In addition to professional development, technical assistance, and research, Centers direct clinical or other services to more than 700,000 individuals with developmental disabilities and/or their families annually. More information and a directory of Centers is available from the Association of University Centers on Disabilities, visit <a href="http://www.aucd.org/template/index.cfm.">http://www.aucd.org/template/index.cfm.</a>

Community rehabilitation programs provide a range of vocational services, which may include supported and customized employment, to individuals with disabilities.

#### The Arc

The Arc has national resources and supports, and a network of over 670 state and local chapters, to serve people with intellectual and developmental disabilities of all ages and their families. Resources and supports include:

- Public policy and advocacy
- State and local chapters
- National Programs
  - National Autism Resource Center
  - o National Sibling Council
  - National Council of Self Advocates
- Supports and Services
  - Early intervention
  - Supported Employment
  - Job training
  - Transition planning
  - o Respite care
  - o Supported living
  - Transportation

To access resources, information, and chapters, visit The Arc at <a href="http://www.thearc.org">http://www.thearc.org</a>.

#### **Mental Health Resources**

Several national resources on mental health are highlighted below:

- *Mentalhealth.gov*, a website that provides one-stop access to mental health information from the federal government.
- The Substance Abuse and Mental Health Services Administration (SAMHSA)
  - Visit SAMHSA's National Registry of Evidence Based Programs and Practices at <a href="http://www.nrepp.samhsa.gov/Index.aspx">http://www.nrepp.samhsa.gov/Index.aspx</a>
- The National Council for Behavioral Health, visit <u>http://www.thenationalcouncil.org/</u>
  - o The National Council for Behavioral Health manages Mental Health First Aid, a training course that introduces participants to risk factors and warning signs of mental health concerns, builds understanding of their impact, overviews common treatments, and teaches a 5-step action plan to assess a situation and help. Participants are introduced to local mental health resources, national organizations, support groups, and online tools for mental health and addictions treatment and support. For further information and to find training courses, visit <a href="http://www.mentalhealthfirstaid.org">http://www.mentalhealthfirstaid.org</a>.
- NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization. NAMI advocates for access to services, treatment, supports, and research. NAMI's support and programs include the Information HelpLine; free education and support programs; a Veterans and Military Resource Center; and the NAMI Legal Center that provides lawyer/legal aid referrals as a service to members and the general public. NAMI is the foundation for hundreds of NAMI State Organizations, NAMI Affiliates and volunteer leaders who work in local communities across the country to raise awareness and provide education, advocacy, and support group programs. NAMI has more than 950 affiliates spanning all states that provide local information and referral services, community education, support to individuals, and other services. Visit <a href="http://www.nami.org/">http://www.nami.org/</a>.
  - o The NAMI Information HelpLine is a national information and referral service which offers information to more than 70,000 callers each year. The Information HelpLine is available to individuals by telephone at 1 (800) 950-NAMI (6264), Monday through Friday, 10 a.m.–6 p.m., EST., and at <u>info@nami.org.</u>



#### **Medicare Low-Income Subsidies Resources**

Several key referral resources for Medicare low-income subsidy information and enrollment assistance include the following:

- Medicare Rights Center. The Medicare Rights Center is an independent source of Medicare information and assistance. It is a national nonprofit, consumer service organization that works to help ensure access to affordable health care for older adults and people with disabilities. The Center assists people with Medicare to understand their rights and benefits, and navigate the Medicare system. The Medicare Rights Center has established a free online reference tool known as the Medicare Interactive; this tool provides easy-to-understand answers to Medicare questions.
  - o www.medicarerights.org; (800) 333-4114
  - o www.medicareinteractive.org
- NCOA Center for Benefits Access. The Center for Benefits Access, administered by the National Council on Aging (NCOA), helps organizations enroll seniors and younger adults with disabilities with limited means into benefits programs. The Center provides training and technical assistance on a wide range of benefits access issues through webinars, conferences and individualized support. BenefitsCheckUp is a web-based tool, also administered by NCOA, which is designed to assist Medicare beneficiaries in determining their eligibility for Medicare subsidy benefits; the tool also assists individuals in the enrollment process.
  - o <u>www.centerforbenefits.org</u>; (202) 479-1200
  - o www.benefitscheckup.org
- State Health Insurance Assistance Program. An additional resource is your local SHIP program. SHIP stands for the State Health Insurance Assistance Program, a national program that offers one-on-one counseling and assistance to people with Medicare and their families. State SHIP programs provide free counseling and assistance by telephone, face-to-face sessions, public education programs, and media activities. The National SHIP Resource Center, or SHIPtalk, is a national website where individuals and professionals can locate information about each state's SHIP program, including contact information for the state's local SHIP counselors.
  - o The National SHIP Resource Center: www.shiptalk.org

- MIPPA Outreach Materials from NASUAD. In collaboration with professionals in the aging and disabilities network, NASUAD developed outreach materials to promote Medicare low-income subsidies to beneficiaries with disabilities. These materials include posters to educate Medicare beneficiaries with disabilities about subsidies that may help them save on Medicare costs; and a Tip Sheet for outreach professionals to use as a quick reference tool about Medicare lowincome subsidies and referral resources. The tip sheet may be particularly helpful for I&R specialists. It reviews the four Medicare Savings Programs run by state Medicaid agencies that can help low-income Medicare recipients save on Medicare costs. The programs include the Qualified Disabled and Working Individual (QDWI), Qualifying Individual (QI), Specified Low-Income Medicare Beneficiary (SLMB), and Qualified Medicare Beneficiary (QMB) programs. The tip sheet also reviews the Medicare Part D Low Income Subsidy/Extra Help program (often referred to as either LIS or Extra Help) run by the Social Security Administration that helps low-income Medicare recipients save on Medicare Part D prescription drug costs.
  - <u>http://nasuad.org/initiatives/state-health-insurance-programs/medicare-improvements-patients-and-providers-act</u>
- **Federal Resources.** And finally, some helpful federal resources include Medicare.gov and the Centers for Medicare and Medicaid Services.
  - o Additional Resources: <u>www.medicare.gov</u>; <u>www.cms.gov</u>

#### **Assistive Technology Resources**

Under the Assistive Technology Act, every state and territory has a state Assistive Technology (AT) Act program. Statewide AT programs provide free services that are available to people living with a disability and their families, and each state has its own unique program. State AT programs provide information about Assistive Technology devices, services available, and where to obtain them; device demonstrations and device loans to give individuals an opportunity to try out devices; funding resources for purchasing or acquiring Assistive Technology; and device exchange and recycling programs. Programs also offer training, outreach, and professional development to promote knowledge and understanding of how to apply AT in various sectors of society such as education, work, home, and recreation. In addition to the State AT Act programs, all states and territories have access to a Protection and Advocacy Program for Assistive Technology. These programs offer legal, regulatory, and policy advice and advocate on behalf of AT users. Over half the states and territories offer individuals access to financial loan products to make necessary AT more affordable through Alternative Financing Programs. These programs offer low- or no-interest financing options to obtain assistive devices and services, and many offer additional financial services. Some states also operate Telework projects to facilitate access to AT that enables a person



with a disability to work remotely. (AT Connects, Assistive Technology Act Programs and Projects, <a href="http://www.atconnects.com/at-act-programs">http://www.atconnects.com/at-act-programs</a>; RESNA Catalyst Project: Providing Assistive Technology Support and Technical Assistance, webinar presentation, Nov., 12, 2014, available at <a href="http://www.worksupport.com/documents/j\_wallace2014.pdf">http://www.worksupport.com/documents/j\_wallace2014.pdf</a>)

Resources on AT programs and financing include the organizations and websites described below.

- AT Connects links to state AT Act programs; financing programs;
   Protection and Advocacy (P&A) programs; and Telework programs.
   http://www.atconnects.com/at-act-programs
- The RESNA Catalyst Project is funded to provide assistance to the AT Act Grantees to assist them in increasing awareness, access, acquisition, and advocacy on assistive technology (AT) devices and services for consumers with disabilities of all ages. The project works with the 56 statewide AT programs, the 57 protection and advocacy for AT programs, and the 36 alternative financing programs. It also works with 19 access to telework financial loan programs. The project provides information for individuals on the state programs, alternative financing programs, and protection and advocacy for assistive technology programs at <u>www.findatnow.org</u>.
  - o http://www.resnaprojects.org/index.html; http://www.findatnow.org/
- The National AT Reuse Center has information on reuse locations by state that can be searched by type of reuse program, type of equipment, and ages served.
   http://passitoncenter.org/
- AbleData, sponsored by the National Institute on Disability and Rehabilitation Research, provides information on assistive technology and rehabilitation equipment to consumers, organizations, professionals, and caregivers, serving the disability, rehabilitation, and senior communities. AbleData's most significant resource is the AbleData database of assistive technology, which contains information on almost 40,000 assistive products. Additionally, the AbleData Information Center is open Monday through Friday from 8:30 a.m. to 5:30 p.m. Eastern time to answer questions on assistive technology (phone: 1-800-227-0216).
  - o <a href="http://www.abledata.com">http://www.abledata.com</a>

#### Americans with Disabilities Act (ADA) Resources

ADA implementation is complex, but there are federally-funded resources that can assist I&R services to access information in this area.

- The ADA National Network is comprised of 10 regional centers that provide information, guidance, and training on the Americans with Disabilities Act (ADA), tailored to meet the needs of business, government, and individuals at local, regional and national levels. Each ADA regional center also focuses on the specific needs of the residents who reside within its service area. The regional centers that comprise the ADA National Network staff a toll-free information line (voice or TTY at 1-800-949-4232) and respond to inquiries submitted online via email (<a href="https://adata.org/content/email-us">https://adata.org/content/email-us</a>) or regional center websites.
   <a href="https://adata.org/">https://adata.org/</a>
- The Job Accommodation Network, a service of the Office of Disability
  Employment Policy, U.S. Department of Labor, is a resource on workplace
  accommodations and disability employment issues. JAN's consultants provide
  individualized guidance on workplace accommodations, the Americans with
  Disabilities Act (ADA) and related legislation, and self-employment and
  entrepreneurship options for people with disabilities. Assistance is available over
  the phone and online, and can benefit employers, government agencies, and
  service providers, as well as people with disabilities and their families.
   <a href="http://askjan.org/">http://askjan.org/</a>
- ADA.gov is a resource of the U.S. Department of Justice, Civil Rights Division that provides information and technical assistance on the ADA. Additionally, the Department of Justice provides information about the Americans with Disabilities Act through a toll-free ADA Information Line: 800-514-0301 (voice); 800-514-0383 (TTY).
  - o <a href="http://www.ada.gov/">http://www.ada.gov/</a>
- ADA Anniversary Toolkit, <a href="http://adaanniversary.org/">http://adaanniversary.org/</a>
- ADA Questions and Answers, <a href="http://adata.org/publication/americans-disabilities-act-faq">http://adata.org/publication/americans-disabilities-act-faq</a>

#### **Aging and Disability Resource Centers (ADRCs)**

The Aging and Disability Resource Center (ADRC) initiative is a collaborative effort of the U.S. Administration for Community Living (ACL), the Centers for Medicare and Medicaid Services (CMS), and now the Veterans Health Administration (VHA) to support community and state efforts to streamline consumer access to long term services and supports (LTSS). States and territories have received ADRC grant funding since 2003 to help advance this effort. This initiative is intended to create comprehensive, collaborative "No Wrong Door" systems in every community where people of all ages, incomes, and abilities can access information and counselling on LTSS.



#### What do ADRCs Look Like?

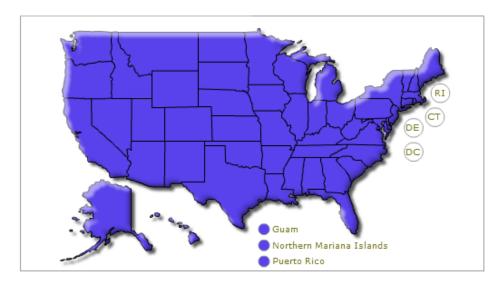
An ADRC is not necessarily a place (such as a physical "center"), but may be a partnership or collaborative of agencies and organizations that provide accessible online and in-person information. Additionally, states are at various points in meeting the goal of having true "No Wrong Door" access to LTSS information.

There are 525 ADRC programs nationally and approximately 77 percent of the U.S. population lives in service areas covered by an ADRC. Around 80 percent of Area Agencies on Aging nationally reported operating or working in close collaboration with an ADRC. (*Aging and Disability I&R/A Networks: Challenges and Opportunities*, NASUAD, May 2013, <a href="http://www.nasuad.org/documentation/I\_R/Aging%20and%20">http://www.nasuad.org/documentation/I\_R/Aging%20and%20</a> Disability%20IRA%20Networks--Challenges%20and%20Opportunities\_

May%202013.pdf; ADRC Quarterly Update, Webinar Series for Part B States, January 2014, available from ADRC Technical Assistance Exchange, see <a href="http://www.adrc-tae.acl.gov/tiki-index.php?page=partb">http://www.adrc-tae.acl.gov/tiki-index.php?page=partb</a>.)

#### **ADRC Locator**

The U.S. Administration for Community Living sponsors the ADRC Technical Assistance Exchange to make information and resources available to states and community organizations. Resources on the Exchange include interactive locator maps, recorded webinars and trainings, and information on several initiatives including ADRCs, Options Counselling, Care Transitions, Alzheimer's Disease Supportive Services Program, Veteran Directed Home and Community-Based Services, and the Community Living Program. The Exchange also provides forums where professionals can connect with each other.



The Exchange's ADRC Locator is available at <a href="http://www.adrc-tae.acl.gov/tiki-index.php?page=ADRCLocator">http://www.adrc-tae.acl.gov/tiki-index.php?page=ADRCLocator</a>.

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#### **Eldercare Locator**

As aging and disability organizations continue to shift towards serving both older adults and people with disabilities, including older individuals with disabilities, the Eldercare Locator is another important resource for I&R specialists to be familiar with. Reflecting this shift, the Eldercare Locator has been serving more individuals with disabilities under age 60 in recent years.

Established in 1991, the Eldercare Locator is a free, public service funded by the Administration for Community Living and administered by n4a to provide a gateway to help older adults, caregivers, and professionals access resources and navigate programs and services. Handling inquiries by phone, web chat or email, the Eldercare Locator's information specialists identify the needs of callers and connect them to their local Area Agencies on Aging, Title VI Native American aging programs, Aging and Disability Resource Centers, or other relevant local, state and national resources. For more complex situations, eldercare counselors provide additional assistance with home and community-based services, long-term care decisions, senior transportation, benefits eligibility, and caregiver issues. The Eldercare Locator can be an especially helpful resource to caregivers who are trying to assist parents or others who live in a different state. Visitors to the Eldercare Locator website may search for local resources and services online, and access a variety of informational materials.

The Eldercare Locator Call Center (toll free 1-800-677-1116) is open five days a week, Monday—Friday, 9:00 a.m. to 8:00 p.m. Eastern Time. Online text chat with an information specialist from the Eldercare Locator is available from 9 a.m. to 8 p.m. Eastern Standard Time, Monday—Friday. The Eldercare Locator can be reached by email at <a href="mailto:eldercarelocator@n4a.org">eldercarelocator@n4a.org</a>. Visit the Eldercare Locator at <a href="http://www.eldercare.gov">http://www.eldercare.gov</a>.



#### **Aging and Disability Partnerships**

Every community has a unique array of services for children, youth, and adults with disabilities. The list below suggests organizations that I&R/A agencies should consider building relationships with in order to create inclusive partnerships for serving inquirers.



- ADRCs
- CILs
- DD/ID Systems
- Mental Health partners
- Vocational Rehabilitation
- Blind and low vision services
- Deaf/hard of hearing resources
- School districts
- Early intervention programs
- Local Veterans Affairs Department
- Adult Protective Services
- Disability Rights Groups
- Protection & Advocacy (P&A)
- Caregiver Advocacy Groups
- Peer and family-to-family programs
- Local Ethnic/Cultural Groups
- LGBT Community Advocates
- Local disability commissions and advocacy boards

#### **Partnerships Tips**

The best partnerships have used some of the strategies listed below to improve their service delivery and provide a more seamless set of services to consumers. Cross-training and co-training among staff teams is often cited as a key to successful partnerships. When a consumer seems to have run out of options, or your organization experiences a lack of resources in a particular area, be willing to collaborate with other organizations, work together on solutions, and include the consumer in the process.



Section 6
Disability Rights and Advocacy

#### **Key Legislation**

Societal attitudes toward disability have changed over the last several decades, along with the introduction of legislation that provides protection against discrimination and requirements for public accommodation. However, monitoring and advocacy are important in order to ensure that legislation is consistently being followed. These changes in attitudes and legislation were brought about by a broad movement in which people with disabilities themselves led the way.

The Rehabilitation Act of 1973, in addition to providing for the establishment of comprehensive programs of vocational rehabilitation and independent living, prohibits discrimination on the basis of disability in programs conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors. It was the first civil rights legislation in the United States designed to protect individuals with disabilities from discrimination based on their disability status. The nondiscrimination requirements of the law apply to employers and organizations that receive federal financial assistance.

Section 504 of the Rehabilitation Act is widely recognized as the first civil rights statute for persons with disabilities, and its implementation paved the way for the Americans with Disabilities Act. Section 504 of the Act prohibits discrimination on the basis of disability in programs, services and activities conducted by any entity that receives federal financial assistance.

Also important is Section 508 of the Act which establishes requirements for electronic and information technology developed, maintained, procured, or used by the federal government. Section 508 requires federal electronic and information technology to be accessible to people with disabilities, including employees and members of the public.

The first comprehensive civil rights legislation for people with disabilities, the ADA prohibits
discrimination on the basis of disability in employment, state and local government, public
accommodations, commercial facilities, transportation, and telecommunications.



The Americans with Disabilities Act (ADA) 1990, as amended, gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. The first comprehensive civil rights legislation for people with disabilities, the ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. The Congressional intent of the law is "to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." Violations of the ADA are enforced by the Office of Civil Rights of the U.S. Department of Justice.

The ADA Amendments Act of 2008 (ADAAA) was enacted on September 25, 2008, and became effective on January 1, 2009. By enacting the ADAAA, Congress overturned several Supreme Court decisions that Congress believed had interpreted the definition of "disability" too narrowly, resulting in a denial of protection for individuals with impairments such as cancer and epilepsy. It also directed the Equal Employment Opportunity Commission (EEOC) to amend its ADA regulations to reflect the changes made by the ADAAA. In enacting the ADAAA, Congress made it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the statute. The ADAAA states that the definition of disability should be interpreted in favor of broad coverage of individuals.

#### Legislation

The list below highlights several other key laws that advance rights for people with disabilities. Please note this list is not exhaustive. More information on legislation advancing rights can be found on the U.S. Department of Justice's ADA website (*Guide to Disability Laws, http://www.ada.gov/cguide.htm*).

Developmental Disabilities Assistance and Bill of Rights Act 2000

The Developmental Disabilities Assistance and Bill of Rights Act (also known as the DD Act) was first passed in 1963 as the Mental Retardation Facilities Construction Act. In its original form, the Act provided federal support for mental retardation research and training centers, and direct service facilities for children and adults. Congress amended this Act in the Developmental Disabilities Services and Facilities Construction Amendments of 1970, which introduced the term "developmental disability" and expanded the population covered. Subsequent amendments continued to define developmental disability, and evolve programs and goals for individuals with developmental disabilities. The DD Act currently funds a range of programs and national initiatives, including family support programs, state councils, and protection and advocacy. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 seeks to assure that individuals with developmental

disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all aspects of community life. (Administration on Community Living, *History of the DD Act*, <a href="http://www.acl.gov/Programs/AIDD/DD\_History/index.aspx#ftn7">http://www.acl.gov/Programs/AIDD/DD\_History/index.aspx#ftn7</a>)

#### Fair Housing Act 1968

Title VIII of the Civil Rights Act of 1968 (the Fair Housing Act), as amended, prohibits discrimination in the sale, rental, and financing of dwellings, and in other housing-related transactions, based on race, color, national origin, religion, sex, familial status and disability. (Department of Housing and Urban Development, Fair Housing—It's Your Right, <a href="http://portal.hud.gov/hudportal/HUD?src=/program\_offices/fair\_housing\_equal\_opp/FHLaws/yourrights">http://portal.hud.gov/hudportal/HUD?src=/program\_offices/fair\_housing\_equal\_opp/FHLaws/yourrights</a>)

#### Architectural Barriers Act 1968

The Architectural Barriers Act requires that buildings and facilities designed, constructed, altered, or leased with certain federal funds after September 1969 must be accessible to and useable by persons with disabilities. (Department of Housing and Urban Development, Fair Housing Laws and Presidential Executive Orders, <a href="http://portal.hud.gov/hudportal/HUD?src=/program\_offices/fair\_housing\_equal\_opp/FHLaws">http://portal.hud.gov/hudportal/HUD?src=/program\_offices/fair\_housing\_equal\_opp/FHLaws</a>)

#### *Individuals with Disabilities Education Act (IDEA)* 1975

IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. The law requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each eligible child. (Department of Education, <a href="https://lidea.ed.gov/">http://lidea.ed.gov/</a>)

#### Voter Accessibility for the Elderly and Handicapped 1984

The Voting Accessibility for the Elderly and Handicapped Act of 1984 generally requires polling places across the United States to be physically accessible to people with disabilities for federal elections. Where no accessible location is available to serve as a polling place, a political subdivision must provide an alternate means of casting a ballot on the day of the election. This law also requires states to make available registration and voting aids for elderly voters and voters with disabilities, including information by TTYs or similar devices. (Department of Justice, *Guide to Disability Laws*, <a href="http://www.ada.gov/cguide.htm">http://www.ada.gov/cguide.htm</a>).



#### National Voter Registration Act 1993

One of the basic purposes of the Act is to increase the low registration rates of minorities and persons with disabilities. The "Motor Voter Act" requires all offices of state-funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate state official. (Department of Justice, *Guide to Disability Laws*, <a href="http://www.ada.gov/cguide.htm">http://www.ada.gov/cguide.htm</a>).

#### Telecommunications Act 1996

Section 255 and Section 251(a)(2) of the Communications Act of 1934, as amended by the Telecommunications Act of 1996, require manufacturers of telecommunications equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by persons with disabilities, if readily achievable. These amendments ensure that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, and operator services that were often inaccessible to many users with disabilities. (Department of Justice, *Guide to Disability Laws*, <a href="http://www.ada.gov/cguide.htm">http://www.ada.gov/cguide.htm</a>).

#### The Civil Rights of Institutionalized Persons Act (CRIPA) 1997

The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U.S. Attorney General to investigate conditions of confinement at state and local government institutions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and institutions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of institutions. The Attorney General does not have authority under CRIPA to investigate isolated incidents or to represent individual institutionalized persons. The Attorney General may initiate civil law suits where there is reasonable cause to believe that conditions are "egregious or flagrant," that they are subjecting residents to "grievous harm," and that they are part of a "pattern or practice" of resistance to residents' full enjoyment of constitutional or federal rights, including title II of the ADA and Section 504 of the Rehabilitation Act. (Department of Justice, *Guide to Disability Laws*, <a href="http://www.ada.gov/cguide.htm">http://www.ada.gov/cguide.htm</a>).

#### 21st Century Communications and Video Accessibility Act (CVAA) 2010

The CVAA updates federal communications law to increase the access of persons with disabilities to modern communications. The law seeks to ensure that accessibility laws enacted in the 1980s and 1990s are brought up to date with 21st century technologies, including new digital, broadband, and mobile innovations. For example, Title I of the law updates the definition of telecommunications relay services (TRS) to include people who are deaf-blind. Title I also authorizes FCC

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action to ensure reliable and interoperable access to next generation 9-1-1 services by people with disabilities. (Federal Communications Commission, 21st Century Communications and Video Accessibility Act, <a href="http://www.fcc.gov/guides/21st-century-communications-and-video-accessibility-act-2010">http://www.fcc.gov/guides/21st-century-communications-and-video-accessibility-act-2010</a>)

#### **Olmstead Decision, 1999**

On June 22, 1999, the United States Supreme Court held in the landmark *Olmstead v. L.C.* decision that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when:

- Such services are appropriate;
- The affected persons do not oppose community-based treatment; and
- Community-based services can be reasonably accommodated.

The Supreme Court explained that its holding "reflects two evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life." Second, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." (Department of Justice, Civil Rights Division, *About Olmstead*, <a href="http://www.ada.gov/olmstead/olmstead\_about.htm">http://www.ada.gov/olmstead/olmstead\_about.htm</a>).

In addition to helping pave the way for persons with disabilities to transition out of institutions and into community living, it is important to recognize that the application of the Olmstead integration mandate goes beyond institutional/residential services to extend to employment and other non-residential long-term supports and services. A recent *Olmstead* settlement agreement, for example, addressed the civil rights of individuals with disabilities who are unnecessarily segregated in sheltered workshops and facility-based day programs to the exclusion of integrated alternatives, such as supported employment and integrated day services. This type of application of *Olmstead*, along with the HCBS settings rule, are continuing to transform the landscape of residential, day, and employment services for people with disabilities.



#### **Disability Rights**

The Protection and Advocacy (P&A) System and the Client Assistance Program (CAP) comprise the nationwide network of Congressionally-mandated, legally-based disability rights agencies.

- P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities.
- CAP agencies provide information and assistance to individuals seeking or receiving vocational rehabilitation services under the Rehabilitation Act, including assistance in pursuing administrative, legal and other appropriate remedies.

P&A agencies maintain a presence in facilities that care for people with disabilities, where they monitor, investigate and attempt to remedy adverse conditions. These agencies also devote resources to ensuring full access to inclusive educational programs, financial entitlements, healthcare, accessible housing, and employment opportunities. There are eight P&A programs, addressing a range of populations and needs. These include Protection and Advocacy for Individuals with Developmental Disabilities; the Client Assistance Program; Protection and Advocacy for Individuals with Mental Illness; Protection and Advocacy for Individual Rights (PAIR programs provide for services to persons with disabilities who are not eligible for services under the three previous P&A programs; with PAIR, the P&As are authorized to serve persons with all types of disabilities); Protection & Advocacy for Assistive Technology; Protection & Advocacy for Beneficiaries of Social Security (this program provides advocacy and other services to assist beneficiaries of Social Security secure or regain gainful employment); Protection & Advocacy for Individuals with Traumatic Brain Injury; and Protection & Advocacy for Voting Accessibility. (National Disability Rights Network, P&A/CAP Network, http://www.ndrn.org/en/about/paacap-network.html).

It is also helpful to know that P&A agencies provide Information & Referral services. In fact, this represents a significant share of the work that they do. P&A agencies may answer dozens of calls a day from individuals. To the extent that they can readily research an answer, identify a resource in the community, or give someone the information they need to self-advocate, they will do that. This I&R assistance is particularly important for those issues that do not the meet the priorities of the agency. Since the funding is limited, P&As are required to develop annual priorities with community input. The priorities guide case acceptance criteria. While P&As do systemic and class action legal work, P&As might also accept individual cases that fit their priorities but may not result in a larger remedy.

Further information on the Protection and Advocacy System is available from National Disability Rights Network (NDRN). NDRN is the nonprofit membership organization of the federally-mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally-based advocacy services to people with disabilities in the United States. Visit <a href="http://www.ndrn.org">http://www.ndrn.org</a>.

#### Finding Help:

- There is a P&A/CAP agency in every state and U.S. territory as well as one serving the Native American population.
- The National Disability Rights Network offers an online directory of P&A/CAP agencies: <a href="http://www.ndrn.org/en/ndrn-member-agencies.html">http://www.ndrn.org/en/ndrn-member-agencies.html</a>

Section 7 Empowerment

#### **Independent Living**

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities, and inclusion.

This training will provide some highlights of the Independent Living movement and philosophy, but for participants who would like more in-depth training on the Independent Living movement, please see our NASUADiQ course on *Introduction to the Independent Living Movement*. That course provides participants with a historical perspective and a deeper understanding of the Independent Living Movement. Participants will learn about the role and services provided by Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs), and gain practical skills that will help them strengthen and promote independence and community living for people with disabilities.

#### **Independent Living Movement**

Inspired by the civil rights and other social movements in the U.S., some disability organizers saw the need to organize across the disability community. These early leaders in the Independent Living and Disability Rights Movements recognized that disability is a natural occurrence and something that many people experience in their lives. They rejected the medical and rehabilitation models that sought to "fix" people with disabilities, and pointed to inaccessible buildings, homes, vehicles, attitudes, and so forth as creating barriers to inclusion for people with disabilities. They also fought against segregated environments, homes, and institutions, demanding equal access to education, employment, housing, and transportation.



In the 1960s early leaders in the Independent Living and Disability Rights Movements advocated for:

- Shifting from a focus on "fixing" the individual, to taking actions to "fix" or modify natural, constructed, cultural, and social environments;
- Rejecting the warehousing of people with disabilities in nursing homes, institutions, sheltered employment, and other segregated environments; and
- Demanding full access and equal opportunity in their communities.

(National Council on Independent Living, About Independent Living, http://www.ncil.org/about/aboutil/).

#### Independent Living Philosophy

Independent Living philosophy is defined in different ways but all approaches emphasize consumer control, equal opportunities, and freedom of choice. These values reflect that:

- People with disabilities are the best experts on their own needs.
- People with disabilities deserve equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that affect their day-to-day lives.
- Independent living has to do with self-determination. It is also the freedom to fail and learn from one's failures just as people without disabilities do.

(National Council on Independent Living, About Independent Living, http://www.ncil.org/about/aboutil/).

> Independent living is participating in day-to-day life, living where you choose and making decisions that lead to self-determination. (Mountain State Centers for Independent Living)

#### **AIRS Bill of Rights**

The AIRS Standards are based on the Basic Principles of I&R, also known as the I&R Bill of Rights. The I&R Bill of Rights reinforces the importance of accessibility, self-determination, and empowerment. Accordingly, an I&R service:

- Maintains accurate, comprehensive, unbiased information about the health and human services available in their community.
- Provides confidential and/or anonymous access to information.
- Provides assessment and assistance based on the inquirer's need(s).
- Provides barrier-free access to information.
- Recognizes the inquirer's right to self-determination.
- Provides an appropriate level of support in obtaining services.
- Ensures that inquirers are empowered to the extent possible.
- Ensures that inquirers have the opportunity to access the most appropriate I&R service available in the system.

(AIRS Standards and Quality Indicators for Professional Information and Referral, Version 7.0, revised March 2013, Alliance of Information and Referral Systems, <a href="http://www.airs.org/files/public/AIRS\_Standards\_7\_Final.pdf">http://www.airs.org/files/public/AIRS\_Standards\_7\_Final.pdf</a>).

I&R specialists can be partners with inquirers in supporting choice and self-determination.

#### **National I&R Support Center**

NASUAD (the National Association of States United for Aging and Disabilities) administers the National Information and Referral (I&R) Support Center. Funding is provided by the Administration for Community Living, U.S. Department of Health and Human Services. The Alliance of Information and Referral Systems (AIRS), the National Association of Area Agencies on Aging (n4a), and the National Council on Independent Living (NCIL) are key partners in the success of the Center.

The I&R Support Center provides training, technical assistance, and information resources to build capacity and promote continuing development of aging and disability information and referral services nationwide. Our services and resources include:

- Technical Assistance webinars
- Online training; AIRS certification training; and a certification train-the-trainer initiative
- Distribution list for sharing information and resources (to sign up, visit <a href="http://www.nasuad.org/community-opportunities/stay-informed">http://www.nasuad.org/community-opportunities/stay-informed</a>)



- Every other year survey of the Aging and Disability I&R/A Networks
- Coordination of the Aging and Disability track of the annual AIRS Conference

Visit the I&R Support Center at <a href="http://www.nasuad.org/initiatives/national-information-referral-support-center">http://www.nasuad.org/initiatives/national-information-referral-support-center</a>.

Contact information for the I&R Support Center director, Nanette Relave, is 202-898-2578, or <a href="mailto:nrelave@nasuad.org">nrelave@nasuad.org</a>.

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