

Disability for I&R Specialists

OCTOBER 2019

LEARNING OUTCOMES

At the end of this course, participants will be able to:

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

Description

This paper provides an overview of key issues relevant to providing information and referral/assistance (I&R/A) to individuals with disabilities. This course may benefit any I&R specialist who would like to become more proficient at serving people with disabilities.

Content

Section 1: What is a Disability?

Section 2: Disability Awareness

Section 3: Effective Communication

Section 4: Services and Programs

Section 5: Resources

Section 6: Disability Rights and Advocacy

Section 7: Empowerment



Section 1: What is a Disability?

Disabilities are a natural part of living, and disabilities can come at any time during one's life. It is estimated that up to 26 percent of adults in the U.S., or 1 in 4, has a disability that impacts one or more daily life activities. 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.

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. This section reviews various definitions of disability.

Americans with Disabilities Act (ADA), 1990

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.

According to the ADA, a disability is:

- A physical or mental impairment that substantially limits one or more major life activities; or
- A record of such an impairment; or
- Being regarded as having such an impairment.

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 beneficial effects of mitigating measures, such as medication, hearing aids, devices or learned behavioral modifications.

The ADA definition's concept of "being regarded as having such an impairment" 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 ADA Amendments Act of 2008 retained this definition but revised how it should be interpreted, broadening the protections of the ADA.

Social Security Administration

The Social Security Administration defines disability to determine eligibility for benefits. "Disability" under Social Security is 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. Under this definition of disability:



- An individual cannot do work that he or she did before;
- Social Security determines 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.

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.

Developmental Disabilities

Developmental disability (DD) is an umbrella term for hundreds of potential diagnoses, syndromes or conditions. This term is used in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and is defined in the Act to help explain which people may qualify for services outlined in the DD Act itself.

As described in the Act, developmental disability:

- Is a 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: self-care, receptive and expressive language, learning, mobility, self-direction, independent living, and economic selfsufficiency.
- Reflects the individual's need for services, supports, or other forms of assistance.

Having a developmental disability means that a person will need services, supports, or other forms of assistance in their life. These services are of a lifelong or extended duration and are individually planned and coordinated. Recent estimates in the U.S. indicate that about one in six, or about 17%, of children

Types of Disabilities

There are multiple ways to define and classify types of disabilities. For example, types of disabilities can include:

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



ages 3 through 17 years have one or more developmental disabilities, such as: cerebral palsy, learning disability, autism, hearing loss, vision impairments, and attention deficit hyperactivity disorder (ADHD).

Intellectual Disability

Intellectual disability (ID) is a disability that impacts two to three percent of the U.S. population. ID is characterized by significant limitations in both intellectual functioning (i.e. reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience) and adaptive behavior (i.e. meeting developmental and socio-cultural standards for personal independence and social responsibility, communicating, participating socially, and living independently). Intellectual disability originates before the age of 18.

Many people with ID also have a developmental disability. However, this is not always true. There are people who have an ID diagnosis but do not fit into the definition of DD written in the DD Act, and there are people who may fit into the definition of DD in the DD Act but do not have ID. ID used to be referred to as Mental Retardation (MR), which is no longer an acceptable term.ⁱⁱⁱ

Beyond Labels: See the Person

When working with people with disabilities, it is important to see the person, not only a condition, impairment, or label. While an understanding of types of disabilities can be helpful, I&R specialists should provide information, referrals and assistance based on each person's unique circumstances.

- Always respect a person's choices, particularly in reference to services that affect the person's day-to-day life.
- Learn how an individual views their disability and the world around them when providing
 information and referral services. Remember that people may or may not identify as having
 one or multiple types of disability.
- Recognize that the experience of disability may change over time and in different environments. This perspective reflects a social model of disability that focuses attention on the interactions between people living with impairments and their environments.



Section 2: Disability Awareness

Disability awareness and etiquette can help foster rapport and respectful communication when working with people with disabilities. The table below shares ways to practice disability etiquette in I&R and everyday interactions.^{iv}

Disability Etiquette Tips

Listen to the person and avoid making assumptions.

Speak directly to the person with the disability (not their family member, interpreter, attendant, caregiver, guardian, friend, partner).

Ask what the preferred communication style and mode is and follow it whenever possible.

Do not pretend to understand; clarify what is being communicated.

Let the person with the disability set the pace with communication.

Be respectful and non-judgmental.

Be aware of your own biases and work through them.

Treat adults with disabilities as adults and refer to them as you would any other person in a situation.

Avoid touching or leaning on a person's wheelchair, speaking loudly unless asked, grabbing the arm of a person who has a visual disability, and petting a service/support animal.

Watch for architectural barriers and hazards such as inadequate lighting, steep ramps, overhanging branches, slippery walking surfaces, and walking surfaces that are uneven or in disrepair.

Offer assistance by introducing yourself and asking in a matter-of-fact way. If someone asks for assistance, listen to and follow any directions that the person may give.

The Importance of Language

It is important to use appropriate language when speaking to or about individuals with disabilities. Words have power and using inappropriate or offensive language can have an impact on how individuals relate to you. Person-first language and identity-first language are the two main language styles generally used to refer to disability. When speaking with an individual, it is always best to follow their lead. It is important to let the individual decide what language they are most comfortable with. If an I&R specialist is unsure of what language to use, it is generally accepted to start with person-first language. If referring to a broad community, use the language most commonly used by members of that community.

Person-first language (also referred to as people-first language) is based on the idea that disability is only one part of a person. It emphasizes disability as something a person has, rather than something a person is. In other words, disability is seen as one attribute or characteristic of a person. Examples of



person-first language include: people with disabilities, individual with cerebral palsy, or child with diabetes.

Identity-first language is based on the idea that disability is an inseparable part of a person's identity (much like gender identity or race). It emphasizes disability as a fundamental part of who a person is, rather than an attribute separate from or secondary to the person's identity. Examples of identity-first language include: disabled person, blind people, or autistic individuals.

In the table below, the column on the left includes terms that are considered outdated or offensive and should be avoided. The column on the right provides alternative person-first and identity-first language that can be used instead, where appropriate.

Avoid	Preferred Person-First or Identity-First Language
Handicapped	Person with a disability Disabled person
The disabled	People with disabilities Disabled people
Suffers from Afflicted with	Person with X disability (i.e. person who had a stroke)
Deaf and dumb Deaf-mute	Person who is D/deaf or hard of hearing D/deaf or hard of hearing person
Wheelchair-bound Confined to a wheelchair	Person who uses a wheelchair Wheelchair user
Crippled; Incapacitated Invalid; Lame	Person with a physical disability Person with a mobility disability Physically disabled
Slow Retarded (derogatory term)	Person with an intellectual disability
Normal (in reference to someone without a disability)	Non-disabled
Differently abled Handicapable Special needs	Person or people with a disability Disabled person or people



Section 3: Effective Communication

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

- Use active listening skills;
- Paraphrase to help fully understand what the person is saying;
- Clarify to ensure your understanding of the person's situation; and
- Inquire what the best method is for communication if what you are doing is not working (other methods could include written communication, email or text, and in-person rather than a phone call).

More specifically, when working with individuals with speech and language disorders, be patient and respectful as communication may take longer. Do not interrupt or finish the person's sentence. Ask one question at a time, giving the person time to respond before moving on. Communication techniques like repeating, rephrasing, and paraphrasing might help with communication; but if you don't understand after a few tries, do not pretend to understand, ask if there are alternative methods that you can use to communicate.

For individuals with cognitive or intellectual disabilities, avoid complex communication. Use short sentences and complete one topic before moving to the next topic. Additionally, ask the person if there is anything they would like for you to clarify. Providing step-by-step guidance and writing down information can also be helpful.

Additionally, individuals with a cognitive disability related to a traumatic brain injury (TBI) may have deficits related to awareness of their disability; problems with short-term memory, organizing thoughts, impulsive behavior, and fatigue; and other effects of TBI that can impact communication. Individuals with TBI may need short breaks and repetition. I&R specialists can also focus on one topic at a time and reduce background noise and other distractions as much as possible.

The Role of Technology in Communication

When serving diverse I&R inquirers, keep in mind that technology can play an important role in facilitating and enabling effective communication. Technology can also facilitate access to information, including information on programs and services.

The AIRS Standards for Professional I&R emphasize the use of technology to enhance information sharing while accommodating the communication preferences and needs of clients. While technology used for I&R services includes systems like telephone systems, technology can also include communication modes like online chat, text messaging, email, and video conferencing that provide additional options for communicating with inquirers. When evaluating existing and new technology, think about the accessibility of the technology and the communication needs of the people your I&R program serves.



ASSISTIVE TECHNOLOGY

Assistive technology (AT) can help with communication as well. When working with people with disabilities, it is helpful to be familiar with the kinds of assistive technology that support communication. Assistive technology, including augmentative and alternative communication (AAC) devices, can help with different aspects of communication like hearing, speech, and self-expression (such as expressing one's thoughts, feelings, ideas, and needs). AAC includes forms of communication other than oral

speech such as communicating through the use of gestures, body language, sign language, writing, pictures and symbols, communication apps, and speech generating devices.

Communicating with assistive technology can take longer. Be sure to allow extra time and be patient and respectful. Additionally, taking notes might be difficult for someone using assistive technology, and providing written information can help.

Keep in mind that technology changes. AT programs and partners can help I&R professionals stay up to date with developments in AT devices and services, including how universal design features can allow products like smart phones to function as assistive technology.



Section 4: Services and Programs

I&R specialists should understand the types of services and programs commonly accessed by people with disabilities. Additionally, the I&R service should ensure that programs and services for individuals with disabilities are included in its resource database or directory, including information on physical and programmatic accessibility for people with disabilities. I&R specialists should recognize that people with disabilities can benefit from programs that serve a range of individuals, not only disability-specific programs. In providing information and referrals to inquirers with disabilities, consider the person's needs and preferences which may include disability-specific and non-specific services. The following table highlights the types of services that people with disabilities may commonly need.

Types of Services	Examples
Financial assistance	Community aid programs; Social Security disability benefits; Supplemental Security Income; benefits counseling; Supplemental Nutrition Assistance Program (SNAP); county assistance programs
Medical assistance and medical services	Medicaid; Medicare; prescription assistance; low-income health and dental clinics; assistance with accessing options for long-term services and supports (or LTSS)
In-home assistance	Personal care services; chore services; homemaker services
Services and supports for children and families	Early intervention services; disability-specific resources; educational advocacy; family education; respite services; future needs planning
Employment assistance	Vocational rehabilitation; job training and job search assistance; supported and customized employment; assistance with accommodations
Assistive technology	Devices; services; assistance with loans and other financing programs
Case management assistance	Case management; peer support
Legal and advocacy assistance	Long-term care ombudsman program; Protection and Advocacy (P&A) systems; resources related to ADA protections; fair housing resources; resources for self- advocacy
Assistance related to decision-making	Options counseling; person-centered counseling; supported decision making; future needs planning
Housing	Low-income housing programs; supportive housing; utility assistance; home modifications



Crisis assistance	Crisis helplines; behavioral health services
Transportation	Medical and non-medical transportation

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 individuals can apply for Medicaid. It is also important to note that Medicaid programs, eligibility, services, and access to services vary from state to state.

Medicaid is the primary payer of long-term services and supports (LTSS) in the U.S. LTSS includes institutional services and home and community-based services. Medicaid funds home and community-based services (or HCBS) through waivers and state plan services. Depending on the state and waiver, Medicaid covers a 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 and/or developmental disabilities might include, for example, day training and habilitation services, supported employment, assistive technology, case management, and supported living services. As Medicaid home and community-based services are optional services within the Medicaid program, HCBS waiver programs can have wait lists for services. These wait lists can significantly impact participants access to these types of services.

Medicaid programs can also be a source of coverage for mental health services. Additionally, 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.

In more recent years, a growing number of states have transitioned to Medicaid managed care to deliver LTSS to individuals with disabilities. In this model, states typically contract with a Managed Care Organization to provide services to participants instead of working directly with providers.

Disability Benefits: SSI and SSDI

The Supplemental Security Income (or SSI) and Social Security Disability Insurance (or SSDI) programs are important programs for some individuals with disabilities. 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 another source such as a former employer or a Health Insurance Marketplace.

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 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 including benefits counseling and the Work Incentives Planning and Assistance program.

Medicare Low-Income Subsidies

Around 16 percent of people on Medicare are under age 65 with a disability. This population of nonelderly Medicare beneficiaries with disabilities is more likely to have low annual incomes and low levels of savings. That is why it is 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 and the Medicare Part D Low-Income Subsidy. The Medicare Savings Programs, referred to as MSPs, are a set of four programs that are administered by state Medicaid agencies and generally help with, at a minimum, the cost of Medicare Part B premiums. 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.

The MSPs are funded jointly by the federal government and individual states, but the programs are administered by state Medicaid agencies. One eligibility requirement for all four MSPs is that applicants must be enrolled in Medicare Part A.

Medicare Savings Programs

Qualified Disabled Working Individual program or QDWI: is for low-income working beneficiaries with disabilities who have recently lost their Social Security Disability Insurance (SSDI) benefit but would like to continue receiving Medicare benefits and accessing Medicare services.

Qualifying Individual program or QI: covers the cost of the Part B monthly premium for qualified low-income beneficiaries; these beneficiaries cannot be enrolled in Medicaid.

Specified Low-Income Medicare Beneficiary program or SLMB: covers the cost of the Part B monthly premium for qualified low-income beneficiaries who can also be enrolled in Medicaid.

Qualified Medicare Beneficiary program or QMB: is for individuals with very low income and assets; this program covers the Part A and B premiums, deductibles, coinsurances and/or co-pays.

LIS is administered through the Social Security Administration. In order to qualify, applicants must be enrolled in a stand-alone Medicare Part D prescription drug plan or a Medicare Advantage plan that provides prescription drug coverage.



Assistive Technology

Assistive Technology (AT) is any item, device, or piece of equipment used to maintain or improve the functional capabilities of people with disabilities to allow them to be more independent in education, employment, recreation, daily living activities, and community living.

AT includes the services necessary to get and use the devices. AT services can be just as important as 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. vi

There are many types of assistive technology for people with disabilities. AT devices range from "low tech" and everyday devices to "high tech" and specialized devices. Through universal design, AT might also be incorporated into devices used by many people. Mobile applications, or apps, can also serve as AT. Apps can assist individuals with activities like reminders, navigation, and reading.

Examples of Assistive Technology:

Vehicle Modifications

Hand controls

Home Modifications

- Ramps
- Environmental Controls

Hearing Aids

Personal amplification systems

Vision Equipment

Screen Magnification

Daily Living

Weighted utensils

Vocational Rehabilitation

State Vocational Rehabilitation (VR) programs provide vocational and rehabilitative services to individuals with disabilities to help them prepare for, secure, regain 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. States also provide VR services to individuals who are blind or have vision impairments and these programs may be housed in separate agencies or divisions.

VR programs can provide a range of services to individuals from assessment to job placement and postplacement supports; services may include for example information and referral, education and training, assistive technology purchasing, supported employment, job coaching, and orientation and mobility (i.e., travel) skills training.

The Workforce Innovation and Opportunity Act (or WIOA) amended the Rehabilitation Act in important ways. For example, it increased the role of the public VR system in supporting transition for youth with disabilities to adult life including employment and post-secondary education. It also heightened the emphasis on competitive, integrated employment for individuals served by VR and looked to improve how the general workforce development system serves individuals with disabilities.



Trends in Service Delivery

Trends at the federal, state, and local levels are impacting the provision of services to people with disabilities, particularly the provision of long-term services and supports (LTSS). Several of the trends impacting the provision of LTSS are explored below.

No Wrong Door

Many states have developed or are developing systems for consumer access to LTSS and options counseling, such as Aging and Disability Resource Centers (ADRCs) and statewide information resources. The term No Wrong Door may be used to describe state efforts to coordinate such systems. The federal partners in this work – the Administration for Community Living, the Centers for Medicare and Medicaid Services, and the Veterans Health Administration – describe the No Wrong Door model as a system of access to long-term services and supports intended to help people of all ages, disabilities, and income levels to learn about and access LTSS options. NWD systems are also intended to help individuals make informed and person-centered decisions based on their needs, preferences, and goals. It is also intended that NWD systems have linkages with key referral sources in communities including I&R/A programs and 211 systems.

The primary functions of NWD systems as identified by federal partners include the following:

- Public outreach and coordination with key referral sources;
- Person-centered counseling;
- Streamlined eligibility to public LTSS programs; and
- State governance and administration.

PERSON-CENTERED PLANNING

Person-centered approaches are a growing trend in aging and disability services. While there is no universal definition of what it means to be person-centered, person-centered thinking and planning are intended to help individuals direct their own lives. Beyond a functional assessment, person-centered planning reflects an individual's self-identified goals, preferences, strengths, and support needs. Person-centered planning is a process that is directed by the person who receives services and can include supporters chosen by that individual. The practice of person-centered approaches uses a range of skills and competencies, including skills used in I&R like active listening, empathy, individual advocacy, and empowerment.

In 2014, the U.S. Department of Health and Human Services released Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs (under Section 2402(a) of the Affordable Care Act). The guidance includes standards that are to be embedded in all home and community-based services programs, as appropriate, that are funded by the federal Department of Health and Human Services.

Under this guidance, the role of options counselors and other front-line staff in the person-centered planning process is to assist individuals to identify and access a personalized mix of services that can include paid services and informal supports.



MEDICAID-FUNDED HCBS

In 2014, the Centers for Medicare and Medicaid Services (CMS) released a Final Rule that impacts Medicaid Home and Community-Based Services (or HCBS) in several key areas. The rule applies to Medicaid HCBS delivered through 1915(c) waiver programs, 1115 demonstration waivers, and 1915(i) and 1915(k) state plan options. Most notable are requirements for conflict-free assessments and case management services; person-centered planning and service plans; and HCBS settings. With regards to settings, the provisions of the rule are intended to promote full access to the benefits of community living in the most integrated setting appropriate. For example, a setting is integrated in and supports full access of individuals receiving services 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. Importantly, the rule applies to residential and non-residential settings where individuals receive Medicaid-funded HCBS.

Implementing the rule and its provisions is a systems-change process to enhance person-centered approaches, individual choice, and integration into the broader community for individuals who receive Medicaid-funded HCBS.

MEDICAID-MANAGED LTSS

The expansion of Medicaid Managed Long-Term Services and Supports (or MLTSS) within state Medicaid programs is an important delivery system trend. MLTSS is a delivery system that uses managed care plans to deliver long-term services and supports to specified Medicaid beneficiaries. States decide which LTSS services the managed care plans will be responsible for. These can include both institutional services (such as nursing homes) as well as home and community-based services (like personal care, meals, adult day programs, and employment supports). There are a variety of reasons why a state might implement MLTSS within its Medicaid program. Some examples include accountability, quality measurement, and budget predictability.

The implementation of MLTSS can impact traditional service delivery pathways. For I&R specialists, it's important to understand the Medicaid LTSS delivery system operating in your state and plans for expansion or modification of this system. Know the options for people with disabilities who you serve and key referral resources. For example, if your state operates a MLTSS program, know where consumers can receive educational information, choice counseling, and enrollment assistance.

EMPLOYMENT FIRST

In more recent years, the concept of Employment First – the idea that employment in integrated settings within the community should be the priority service option – has gained momentum. 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 people 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 rather seeks to alter expectations and opportunities so that employment in the general workforce is an option.

Employment First is a systems-change process 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 to advance the goal of competitive, integrated employment.



Section 5: Resources

There are a variety of organizations and resources that are helpful for I&R specialists serving people with disabilities to be aware of. Additionally, some of these can also serve as referral resources.

Centers for Independent Living

Centers for Independent Living (CILs) are grassroots, advocacy-driven organizations run by and for people with disabilities. They focus on civil rights, the independent living philosophy, and inclusion. All CILs provide five core services including individual and systems advocacy, information and referral, peer support, independent living skills training, and transition services.

CILs provide I&R 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 own home and community. Individual and Systems Advocacy is carried out in a wide variety of ways, according to the priorities of local communities. Centers can provide, for example, disability awareness training and advocacy for improved accessibility. CIL staff advocate on both an individual and systems-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 institutions and into their own homes and communities. As a core service, this transition support has several components including assistance with transition out of institutions and into community living; diversion for people at risk of institutional placement; and transition for youth with disabilities from school to post-secondary education, employment and/or independent living.

National Council on Independent Living

The National Council on Independent Living (or NCIL) is the longest-running national cross disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of individuals with disabilities, and organizations including Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the human and civil rights of people with disabilities throughout the country. Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs 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. NCIL promotes a national advocacy agenda set by its membership and provides input and testimony on national disability policy. Visit www.ncil.org.

National Directory of CILs and Associations

To find CILs in your state, visit ILRU (Independent Living Research Utilization) which maintains a directory of Centers for Independent Living by state as well as a directory of state associations. Additionally, ILRU provides research, education and consultation in the areas of independent living, home and community-based services, and the Americans with Disabilities Act. Visit www.ilru.org.



I/DD Resources

Each state and community may have a variety of organizations that serve people with intellectual and developmental disabilities (I/DD) and their family members.^{vii}

State developmental disability agencies are responsible for providing services to children and adults with intellectual and developmental disabilities and their families by developing and implementing effective and efficient service delivery systems. For a list of state agencies, visit www.nasddds.org.

There are also 56 Councils on Developmental Disabilities (or DD Councils) across the United States and its territories that are part of the Developmental Disabilities Network. DD Councils receive federal funding to support programs that promote self-determination, integration, and inclusion for all people with developmental disabilities. Visit nacdd.org for more information and contact information for each state DD Council.

There are 67 University Centers for Excellence in Developmental Disabilities (UCEDDs) across the country, authorized under the Developmental Disabilities Assistance and Bill of Rights Act, to serve as resources for individuals with a wide range of disabilities. UCEDDs work with people with disabilities, family members, government agencies, and community providers on projects that provide training, technical assistance, services, research, and information sharing, with a focus on building the capacity of communities. Services include community education and direct services. More information and a directory is available at www.aucd.org.

Organizations that serve parents are an important resource for families with children with disabilities. Each state has at least one Parent Training and Information Center (PTI) that provide families with information on specific disabilities, early intervention, educational and school services, state and national resources, and more. Additionally, many states also have Community Parent Resource Centers that help ensure that underserved parents of children with disabilities, including low-income parents, parents of children who are English learners, and parents with disabilities, have the training and information they need to support their children. To find these Centers, visit www.parentcenterhub.org. There are also Parent to Parent programs that provide emotional and informational support for families of children with disabilities through parent to parent support. Visit www.p2pusa.org for more information. Furthermore, Family Voices is a national family-led organization, with affiliates in many states, that promotes leadership and advocacy to improve health care services and policies for children with disabilities. Visit familyvoices.org for resources.

Self-advocacy organizations work to empower people with disabilities to speak for themselves and to take control of their own lives so that people with disabilities have equal opportunities, choices, rights, and access. There are a variety of self-advocacy organizations in states and communities, including national organizations like Self Advocates Becoming Empowered and the Autistic Self Advocacy Network.

THE ARC

Over the years, The Arc has advocated for the passage of state and federal legislation on behalf of people with disabilities and established a broad network of state and local chapters that range from small voluntary groups to large, professional organizations.



Today, The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families with over 600 state and local chapters that support individuals and families across the country. Chapters provide direct services that can include information and referral as well as individual and systems advocacy. Every chapter determines the types of supports and services they provide in their community.

At the national level, The Arc provides information and resources on a wide range of topics. Visit thearc.org to search for resources. The Arc also supports national initiatives in areas like employment, education, and future planning. The Arc's Center for Future Planning, for example, has tools and resources to help individuals with I/DD and their families to develop a person-centered future plan. Such a plan can support transitions such as when a parent or caregiver is no longer able to provide support.

Mental Health Resources

There are several national resources on mental health that can be helpful to I&R specialists.

<u>MentalHealth.gov</u> provides one-stop access to government mental health information. This site also has educational resources for the public, professionals, and communities.

The Substance Abuse and Mental Health Services Administration (or SAMHSA) is the federal agency that leads public health efforts to advance the behavioral health of the nation and to reduce the impact of substance abuse and mental illness on communities. SAMHSA has a wide range of information and resources for the public and professionals, including the Evidence-Based Practices Resource Center with a searchable website.

The National Council for Behavioral Health represents organizations that deliver mental health and addictions treatment and services. The National Council manages Mental Health First Aid, a skills-based training course that teaches participants how to identify, understand and respond to signs of mental illnesses and substance use disorders. To find a Mental Health First Aid course near you, visit www.mentalhealthfirstaid.org.

NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization. NAMI is an association of more than 500 local affiliates who work in communities to raise awareness and provide support and education. NAMI State Organizations and local Affiliates provide peer-led educational programs to families, individuals and professionals. NAMI support groups are available for individuals, family members, significant others and friends. The NAMI HelpLine is a free, nationwide peer-support service providing information, resource referrals and support to people living with mental health conditions, their family members and caregivers, mental health providers and the public. Visit nami.org for further information.

I&R specialists should also be aware of consumer-led organizations run by and for people with lived experience of mental health issues. One example is the National Empowerment Center (NEC) which offers a variety of programs and services including training, education, and development of self-help resources. Additionally, NEC has a toll-free information and referral line that provides I&R on topics such as self-help groups and advocacy organizations in local communities, self-help techniques, coping with depression, and more. Visit NEC at power2u.org.



Brain Injury Resources

Traumatic Brain Injury (TBI) can effect an individual's cognition, emotions, and behavior as well as cause physical symptoms. There can be, for example, effects on thinking and reasoning, memory, attention, communication, mood, and personality. Individuals can experience physical symptoms such as hearing loss, headaches, seizures, dizziness, blurred vision, and reduced strength and coordination. Individuals with TBI might need short-term services, long-term services and supports, crisis intervention, or intermittent supports and services. Individuals may need services across multiple types of programs. Additionally, states have developed programs specifically designed for people with TBI-related disabilities. States, for example, may offer I&R services; administer service coordination programs; and contract with providers for rehabilitative and community services.

The Brain Injury Association of America has information and resources for individuals, caregivers and professionals. The Association also has a national network of chartered state affiliates that provide direct support and advocacy for individuals living with brain injury, their friends and family, professionals and the general public. A directory of affiliates is available online at <u>biausa.org</u>.

The National Association of State Head Injury Administrators (NASHIA) provides access to information on a range of topics, offers educational webinars, and has a directory of state TBI-related programs to locate programs in your state. Visit nashia.org for more information.

The Centers for Disease Control and Prevention (CDC) has resources on injury prevention and control, including basic information on TBI, data, provider training and tools, and educational resources. Visit the CDC at cdc.gov/injury/.

The Administration for Community Living (ACL) provides funding for the TBI State Partnership Program to support lead state agencies to increase and facilitate access to person-centered services and supports for individuals with TBI and their families and caregivers. Visit tbi.acl.gov for more information.

The Model Systems Knowledge Translation Center works with researchers in the <u>Traumatic Brain Injury Model Systems</u> to develop resources for people living with traumatic brain injuries and their supporters. These evidence-based materials are available in a variety of formats such as printable PDF documents, videos, and slideshows. Individuals and professionals can visit <u>msktc.org/tbi</u> to access resources on living with TBI covering a wide range of topics such as balance problems, changes in memory, driving, returning to school, relationships, vision problems, and more.

Medicare Low-Income Subsidies

In addition to <u>Medicare.gov</u>, which has a range of resources and tools for Medicare beneficiaries, there are several referral resources for Medicare low-income subsidy information and enrollment assistance.

The Medicare Rights Center is a national nonprofit, consumer service organization that helps people with Medicare understand their rights and benefits and navigate the Medicare system. The Medicare Rights Center operates a national helpline to provide information and assistance to people with Medicare, their family members and friends. Additionally, callers are screened for the Medicare Savings Programs and the Low-Income Subsidy/Extra Help. The Medicare Rights Center has also established a free online reference tool known as the Medicare Interactive; this tool provides easy-to-understand Medicare information. Visit medicarerights.org for information.



The Center for Benefits Access, which is administered by the National Council on Aging (NCOA), helps organizations enroll seniors and younger adults with disabilities with limited means into benefits programs including the Medicare Savings Programs and Extra Help. The Center provides tools and resources that help organizations to assist individuals to apply for and enroll in the benefits for which they may be eligible. The Center also establishes and supports Benefits Enrollment Centers across the country that help low-income people with Medicare access benefits programs. Additionally, NCOA assists individuals and professionals through its free online benefits screening tool called BenefitsCheckUp. Visit ncoa.org to access these resources.

An important resource for Medicare-eligible individuals is the SHIP program. The State Health Insurance Assistance Program, or SHIP, offers unbiased, one-on-one Medicare counseling and assistance to people with Medicare and their families. SHIP programs provide free counseling and assistance by telephone, face-to-face sessions, public education programs, and media activities. The national SHIP TA Center has a SHIP Locator to find SHIP programs in each state; visit shiptacenter.org.

ADvancing States has 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 low-income subsidies and referral resources. The tip sheet may be especially helpful for I&R professionals. Visit advancingstates.org/mippa to access these resources.

Assistive Technology Resources

Under the Assistive Technology Act, every state and territory has a state Assistive Technology Act program. State AT Programs serve individuals of any age and with any type of disability or chronic health condition.

State level activities include AT device demonstrations, lending, and reuse, as well as financing activities. AT demonstration activities provide opportunities for people to learn about specific types of AT by comparing and contrasting the functions and features of devices through hands-on experience. Device loan programs allow individuals to borrow devices for a limited time period to use in places such as home, school or work to try out devices in their own environments to determine if a device will meet their needs before a purchase is made. Reuse programs support the reuse of assistive technology that is no longer needed or used by its original owner. Recipients often obtain such devices at significantly lower cost or no cost. Financing activities help individuals to purchase or obtain AT. Financial loan programs provide individuals with affordable, flexible borrowing options. Other programs provide AT directly to consumers at no cost using dollars from non-AT Act sources.

State leadership activities under the AT Act include training, technical assistance, and public awareness. Of note, public awareness includes information and assistance to individuals. I&A services are intended to provide inquirers with accurate and timely responses to their requests for AT-related information.^{ix}

NATIONAL RESOURCES ON ASSISTIVE TECHNOLOGY PROGRAMS AND FINANCING

The National Assistive Technology Act Technical Assistance and Training (or AT3) Center is a resource for information about the Assistive Technology Act, State Assistive Technology Programs, and general assistive technology. The Center offers Explore AT, a clearinghouse for available resources, tips,



financial information, fact sheets, videos, and links to a variety of AT. The Center also has a directory of state AT programs. Visit <u>at3center.net</u> for more information.

The National AT Reuse Center, also known as the Pass It On Center, has information on reuse locations by state that can be searched by type of reuse program, type of equipment, and ages served. Visit pioc.gatech.edu.

AbleData, sponsored by the National Institute on Disability, Independent Living 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 comprehensive database of assistive technology. Visit abledata.acl.gov.

The National Rehabilitation Information Center (NARIC) is the library of the National Institute on Disability, Independent Living, and Rehabilitation Research and links to a variety of resources on AT. For more information visit naric.com.

Americans with Disabilities Act Resources

While the Americans with Disabilities Act (ADA) is comprehensive and far-reaching, there are federally-funded resources that can assist I&R services to access information in this area. The ADA National Network provides information, guidance and training on the ADA to all sectors of society, including those with responsibilities under the ADA such as businesses, employers, state and local governments, disability organizations and individuals with disabilities whose rights are protected under the ADA. The network consists of 10 Regional ADA Centers located throughout the United States. Each regional center focuses on the specific needs of the residents who reside within its service area. ADA specialists in each of the ten centers provide information and guidance to anyone requesting ADA information through 1-800 calls, emails, and in-person consultations. Visit adata.org for information, resources, training opportunities, and to find your regional center.

The Job Accommodation Network (JAN) provides free, confidential technical assistance about job accommodations and the ADA. JAN is supported by the Office of Disability Employment Policy, U.S. Department of Labor. JAN's consultants provide individualized guidance on workplace accommodations, the Americans with Disabilities Act and related legislation, and self-employment and entrepreneurship options for people with disabilities. JAN also provides webcasts and training events. 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. Visit askjan.org for more information.

<u>ADA.gov</u> is a resource of the U.S. Department of Justice, Civil Rights Division. Additionally, the Department of Justice provides information about the Americans with Disabilities Act through a toll-free ADA Information Line: 800-514-0301 (voice) or 800-514-0383 (TTY).

Consumer Access to LTSS Information and Counseling

People with disabilities can have a variety of long-term services and supports (LTSS) needs, yet LTSS programs and systems are often complex and challenging to navigate. When it comes to learning about long-term services and supports, states and communities may have access points where individuals can receive information and counseling on their LTSS options.



Aging and Disability Resource Centers (ADRCs) and No Wrong Door systems are intended to offer information, assistance and counseling to individuals and can serve as entry points to publicly administered LTSS programs. While not all states and communities have such consumer access points, a number do. Your organization may already be part of an ADRC or NWD initiative. If not, it is helpful to know whether such systems operate in your state or where individuals can access LTSS information.

Where they do exist, ADRCs and No Wrong Door initiatives may include a range of partners that serve people with disabilities at the community and state levels. These partners can also be resources where individuals, family members and others can learn about LTSS options and where to access screening, assessment, and eligibility services.

Community Partnerships

Every community has a unique array of services for children, youth and adults with disabilities as well as for families. Organizations that I&R/A agencies should consider building relationships with in order to create inclusive partnerships for serving inquirers include, for example, ADRCs, CILs, I/DD organizations, mental health partners, disability rights groups, Protection & Advocacy (P&A) agencies, LGBTQ+ community advocates, Adult Protective Services, and more.

PARTNERSHIP STRATEGIES

Strategies to build and strengthen I&R partnerships include providing warm transfers, sharing information and resources, cross-training staff, collaborative problem-solving, and co-location.

The best partnerships have used some of the strategies 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

This section on disability rights and advocacy will highlight key legislation that advances the rights of people with disabilities and describe the Protection and Advocacy system.

Key Legislation

Societal attitudes toward disability have changed along with the introduction of legislation that provides protection against discrimination and requirements for public accommodation. 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, as amended, 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 508 of the Act establishes requirements for electronic and information technology developed, maintained, procured, or used by the federal government. Section 508 requires such information technology to be accessible to people with disabilities, including employees and members of the public.

The Americans with Disabilities Act (ADA), signed into law in 1990, is the first comprehensive civil rights legislation for people with disabilities. The Congressional intent of the law is "to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." The ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. ADA complaints alleging disability discrimination under the provisions of the law are filed with the Disability Rights Section of the Office of Civil Rights at the U.S. Department of Justice.

The ADA Amendments Act of 2008 overturned several Supreme Court decisions that Congress believed had interpreted the definition of "disability" too narrowly. In enacting the ADA Amendments Act, Congress made it easier for an individual seeking protection under the ADA to establish that they have a disability within the meaning of the ADA. The Amendments Act emphasizes that the definition of disability should be interpreted in favor of broad coverage of individuals.

Olmstead Decision, 1999

On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* 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 services; and community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. The Supreme Court held that "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."

More Legislation Advancing Rights

Legislation plays an important role in advancing rights, access, and opportunities for people with disabilities. Along with the Rehabilitation Act and the ADA, several other key laws that advance rights include:

- Developmental Disabilities Assistance and Bill of Rights Act, 2000
- Individuals With Disabilities Education Act (IDEA), 1975, as amended
- Fair Housing Act (Title VIII of the Civil Rights Act of 1968)
- Architectural Barriers Act, 1968
- Voter Accessibility for the Elderly and Handicapped, 1984; National Voter Registration Act, 1993;
 Help America Vote Act, 2002
- Civil Rights of Institutionalized Persons Act (CRIPA), 1997
- Telecommunications Act, 1996; 21st Century Communications and Video Accessibility Act (CVAA), 2010

The Architectural Barriers Act, for example, helps to ensure access to the built environment by requiring that buildings and facilities designed, constructed, altered, or leased with certain federal funds must be accessible to people with disabilities. The Fair Housing Act, Title VIII of the Civil Rights Act of 1968, as amended, prohibits discrimination in housing based on characteristics including disability. Additionally, there are several laws that address discrimination and protect the fundamental right to vote for Americans with disabilities. Telecommunications laws seek to ensure access to telecommunications products and services including digital communication technologies.

For I&R specialists serving individuals and families, it may be helpful to be familiar with the DD Act and IDEA. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (also known as the DD Act) funds a range of programs and national initiatives, including family support programs, state councils, and protection and advocacy. The Individuals With Disabilities Education Act (IDEA) governs how states and public agencies provide early intervention, special education and related services to 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 (IEPs) for each eligible child.

Supporting Disability Rights: Protection & Advocacy

The Protection and Advocacy (P&A) System and Client Assistance Program (CAP) comprise the national network of congressionally-mandated, legally-based disability rights agencies. P&As and CAPs work to improve the lives of people with disabilities by guarding against abuse; advocating for basic



rights; and ensuring access and accountability in health care, education, employment, housing, transportation, voting, and within the juvenile and criminal justice systems.

P&As work at the state level to protect the rights of individuals with disabilities by advocating on their behalf. P&A agencies have the authority to provide legal representation and other advocacy services, under federal laws, to people with disabilities. There is a designated P&A agency in each state and territory. While their focus is most often legal, P&As also engage in other efforts to promote the rights of individuals with disabilities such as technical assistance, self-advocacy training, and public awareness activities. There are eight types of P&A programs that 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 (this program provides services to persons with disabilities who are not eligible for services under the three previous P&A programs, enabling P&As to serve people with all types of disabilities); Protection & Advocacy for Assistive Technology; Protection & Advocacy for Beneficiaries of Social Security; Protection & Advocacy for Individuals with Traumatic Brain Injury; and Protection & Advocacy for Voting Accessibility.

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.

Finally, the Client Assistance Program (CAP) provides 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.

Finding Help and Information

Collectively, the P&A and CAP network is the largest provider of legally-based advocacy services to people with disabilities in the U.S. As noted earlier, there is a P&A and CAP agency in every state and U.S. territory. The P&As and CAP program may be in the same agency or may be housed in different agencies. To find the agency or agencies in your state, visit the National Disability Rights Network (NDRN) which provides an online directory of P&A and CAP agencies. Visit NDRN and ACL for more information.



Section 7: Empowerment

This final section will focus on empowerment as expressed through the Independent Living movement, self-advocacy, and the principles of I&R.

Empowerment through Independent Living

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

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 on 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.

The Independent Living Movement continues to be founded in the belief that people with disabilities have a common history and a shared struggle, and are a community and a culture that will advance further when working together for change.^x

INDEPENDENT LIVING PHILOSOPHY

Independent Living philosophy emphasizes consumer control, the idea that people with disabilities are the best experts on their own needs, having crucial and valuable perspective to contribute and deserving of equal opportunity to decide how to live, work, and take part in their communities, particularly in reference to services that powerfully affect their day-to-day lives and access to independence.xi

The Independent Living philosophy supports making decisions that lead to self-determination. This also means having the freedom to fail and to learn from one's failures and experiences just as non-disabled people do.

Empowerment through Self-Advocacy

Like Independent Living, self-advocacy is a movement and a philosophy. The mantra "Nothing About Us Without Us" captures the essence of empowerment through self-advocacy. Self-advocacy empowers people with disabilities to represent themselves, exercise their rights, have a say in decision-making that affects their daily lives and communities, and seek outcomes that they desire.

There are national resources for self-advocacy. Self Advocates Becoming Empowered (SABE) works to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves. The Autistic Self Advocacy Network (ASAN) is run by and for autistic people. ASAN works to empower autistic people to take control of their own lives and the future of their common community. Finally, PeopleFirst.org is a



resource to connect individuals to People First (i.e. self-advocacy) groups across the country and around the world.

Supporting Empowerment through I&R

As empowerment helps people help themselves, it is the essence of I&R. Empowerment helps people understand the steps required to obtain needed services themselves; it also provides the tools to handle similar situations in the future. Empowerment provides respect for people's abilities and builds their personal problem-solving skills. There are various ways that specialists can support empowerment. For example, a specialist can provide individuals with referrals to the programs to contact but also with the details of those services and the questions to ask, as well as the questions that a service might ask of them. Specialists can support individuals to clarify their needs; demonstrate the steps they will need to take in order to obtain services; and can show individuals how to advocate for themselves.

AIRS Ethical Principles for Community Resource Specialists, which serve as a guide to the everyday professional conduct of Specialists in the provision of I&R, reinforce the value of empowerment by including the principle that specialists serve individuals and their community through a person-centered framework that recognizes the right of self-determination.^{xii}

National I&R Support Center

ADvancing States administers the National 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), the National Council on Independent Living (NCIL), and The Arc are 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:

- Support with technical assistance inquiries, including peer-to-peer sharing;
- Online training, AIRS certification training, and training webinars; and
- Workshops and presentations for information and referral professionals at national conferences.

To receive updates and news from the Support Center, subscribe to our distribution list at http://www.advancingstates.org/community-opportunities/stay-informed.

Visit the I&R Support Center at http://www.advancingstates.org/initiatives/national-information-referral-support-center.

ADvancing States thanks the many individuals who contributed to this training course and provided valuable input and review.



END NOTES

ⁱ Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults — United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882–887. DOI: http://dx.doi.org/10.15585/mmwr.mm6732a3

- v Alliance of Information and Referral Systems. AIRS Standards and Quality Indicators for Professional Information and Referral (AIRS, January 2016), https://www.airs.org/i4a/pages/index.cfm?pageid=3371 vi Assistive Technology Act Programs: Improving Access to AT for People of All Ages. ADvancing States webinar presented April 23, 2019, by the AT3 Center, http://www.advancingstates.org/initiatives/national-information-referral-support-center/ira-webinars
- vii Alliance of Information and Referral Systems. 2019 AIRS I&R Training Manual: Training Community Resource Specialists, Section 18: Serving People with Disabilities.
- viii National Association of State Head Injury Administrators. Traumatic Brain Injury (TBI): Overview (August 2015). http://www.nashia.org/pdf/nashia_tbi_fact_sheet.pdf
- ix Assistive Technology Act Programs: Improving Access to AT for People of All Ages. ADvancing States webinar presented April 23, 2019, by the AT3 Center, http://www.advancingstates.org/initiatives/national-information-referral-support-center/ira-webinars
- × National Council on Independent Living. About Independent Living. 4 May 2020: https://ncil.org/about/aboutil/
- xi Ibid.
- xii Alliance of Information and Referral Systems. AIRS Ethical Principles for Community Resource Specialists (AIRS, November 2019),

https://www.airs.org/files/public/AIRS Certification EthicalPrinciples(1).pdf

ⁱⁱ Strengthening Disability and Cultural Competence in Information and Referral/Assistance (I&R/A) Work with People with I/DD and their Families, ADvancing States IQ course developed by The Arc (October 2018)

iii Ibid

^{iv} Alliance of Information and Referral Systems. 2019 AIRS I&R Training Manual: Training Community Resource Specialists, Section 18: Serving People with Disabilities. For additional guidance on disability etiquette, see United Spinal Association, Disability Etiquette: Tips on Interacting with People with Disabilities (2015), https://unitedspinal.org/disability-etiquette/