

Alphabet Soup for Community Advisory Councils (CACs)

The disability community is made up of many people. It includes:

- people with disabilities,
- family members,
- Caregivers,
- professionals, and
- Advocates.

The term “disability” is used throughout this document. It is not meant to be a negative word. But it describes a large group of individuals with different needs. These individuals have many different ways of learning, communicating, and understanding.

The disability community tends to have it’s own way of communicating. This is known as “alphabet soup”. This is because the language uses many abbreviations. Abbreviations are short versions of a word or phrase. People who are new to the disability community may find it confusing. People who attend a Community Advisory Council (CAC) meeting for the first time can find it confusing. It can be hard to understand these new acronyms and abbreviations. This guide will help you understand abbreviations that are used in the disability community.



This guide lists abbreviations in alphabetical order. The guide organizes their definitions into ten categories. The last page has a discussion guide for your CAC. The discussion guide can help your CAC to create their own guide for the “alphabet soup”. The ten categories are:

- Federal Agencies
- Federal Laws
- State Developmental Disability (DD) Network
- National Developmental Disability (DD) Network

- Common Terms
- Support Plans
- Education Terms
- Community-Based Supports and Resources
- Professional Supports
- Tools
- Other National Organizations

Acronym	Page Definition Found On
AAIDD - American Association on Intellectual and Developmental Disabilities	20
ABA – Architectural Barriers Act	6
ABA - Applied Behavior Analysis	13
ACLD – Association for Children with Learning Disabilities	20
ADA – Americans with Disabilities Act	6
AIDD – Administration on Intellectual and Developmental Disabilities	5
ADL – Activities of Daily Living	10
AoA – Administration on Aging	5
Arc, or The Arc	20
ASA – Autism Society of America	20
ASD - Autism Spectrum Disorder	10
ASL – American Sign Language	19
AUCD – Association of University Centers on Disabilities	9
BWE - Blind Work Expenses	15
CMS – Centers for Medicare & Medicaid Services	5
COLA - Cost of Living Adjustment	15
COLA – Council on Leadership in Advocacy	9
COTA – Certified Occupational Therapist	17
CP – Cerebral Palsy	10
CPR – Cardio Pulmonary Resuscitation	19
DD – Developmental Delay	10
DD – Developmental Disability	10
DD Act – Developmental Disabilities Assistance and Bill of Rights Act of 2000	6

DD Council – Developmental Disabilities Councils	8
DS – Disability Studies	13
DSP - Direct Support Professional	17
EC – Early Childhood	13
ECSE – Early Childhood Special Education	13
FAPE – Free Appropriate Public Education	13
FC – Facilitated Communication	19
FERPA – Family Educational Rights and Privacy Act	7
FSP – Family Support Plan	12, 13
HH, HOH – Hard of Hearing	11
HI – Hearing Impaired	11
HMO – Health Maintenance Organization	15
IDEA – Individuals with Disabilities Education Act	7
IEP – Individualized Education Plan	12, 14
IFSP – Individualized Family Service Plan	12, 14
ILS – Independent Living Services Program	15
IRWE - Impairment-Related Work Expenses	15
IS - Intervention Specialist	14, 17
ISP – Individualized Service Plan	12
LBPD – Library for the Blind and Physically Disabled	15
LD – Learning Disability or Learning Difference	11
LDA – Learning Disabilities Association	20
LEND - Leadership in Education in Neurodevelopmental and Related Disabilities	9
LRE – Least Restrictive Environment	14
MCHB – Maternal and Child Health Bureau	5
MH – Mental Health	11

MI – Mental Illness	11
NACDD – National Association of Councils on Developmental Disabilities	9
NADS – National Association for Down Syndrome	20
NDRN – National Disabilities Rights Network	9
NDSC – National Down Syndrome Congress	20
NDSS – National Down Syndrome Society	21
NICHCY – National Information Center for Children and Youth with Disabilities	21
NPIN – National Parent Information Network	21
OSEP – Office of Special Education Programs	5
OSERS – Office of Special Education and Rehabilitation Services	5
OT – Occupational Therapy	17
P & A – Protection and Advocacy System	8
PASS – Plans for Achieving Self-Support	12
PCA – Personal Care Attendant	15, 17
SABE – Self Advocates Becoming Empowered	21
Section 503/504 – Sections of the Rehabilitation Act of 1973	7
SE – Signed English	19
SSA – Social Security Administration	5
SSDI – Social Security Disability Insurance	16
SSI – Supplemental Security Income	16
SW – Social Worker	17
TBI – Traumatic Brain Injury	11
TDD – Telecommunication Device for the Deaf	19
UCEDD – University Centers for Excellence in Developmental Disabilities	8
VI – Visual Impairment	11
VR – Vocational Rehabilitation	18

Federal Agencies

University Centers for Excellence in Developmental Disabilities (UCEDDs) work with many federal agencies. These federal agencies are listed below.

AIDD, or the Administration on Intellectual and Developmental Disabilities:

AIDD is a United States (US) Government organization. AIDD is responsible for enacting the Developmental Disabilities (DD) Act. AIDD is part of the Administration for Children and Families, of the US Department of Health and Human Services. Learn more about the AIDD at <https://acl.gov/about-acl/administration-disabilities>.

AoA, or the Administration on Aging:

AoA provides home and community-based services (HCBS) to older people. This is possible because of programs funded by the Older Americans Act. Learn more about the AoA at <https://acl.gov/about-acl/administration-aging>.

CMS, or the Centers for Medicare & Medicaid Services:

The mission of CMS is to ensure health care coverage is up-to-date, effective, and high quality. CMS manages Medicare, Medicaid, and the State Children's Health Insurance Program (CHIP). Learn more about CMS at <https://www.cms.gov/>.

MCHB, or the Maternal and Child Health Bureau:

The MCHB is part of the Health Resources Services Administration. The MCHB manages programs that improve the health of American mothers, infants, children, and teenagers. Learn more about the MCHB at <https://mchb.hrsa.gov/>.

OSEP, or the Office of Special Education Programs:

OSEP supports many programs and projects. These programs and projects are approved by the Individuals with Disabilities Education Act (IDEA). They improve the education and health of infants, toddlers, children, and teenagers with disabilities. OSEP is part of the Office of Special Education and Rehabilitation Services. This office is also part of the US Department of Education. It also includes the National Institute on Disability and Rehabilitation Research. It also includes the Rehabilitation Services Administration. Learn more about OSEP at <https://www2.ed.gov/about/offices/list/osers/osep/programs.html>.

OSERS, or the Office of Special Education and Rehabilitation Services:

OSERS is within the US Department of Education. OSERS:

- supports programs that educate children with disabilities
- provides for rehabilitation, or therapies, for people with disabilities
- supports research to improve the lives of people with disabilities of all ages

Learn more about OSERS at <https://www2.ed.gov/about/offices/list/osers/index.html>.

SSA, or the Social Security Administration:

SSA manages benefits. These include:

- retirement,
- disability, and
- survivors benefits to workers and their families.

SSA also manages the Supplemental Security Income (SSI) program. SSA provides Social Security numbers. Learn more about SSA at <https://www.ssa.gov/>.

Federal Laws

Federal laws that are important to the work of UCEDDs are listed below.

ABA, or the Architectural Barriers Act:

The ABA requires that buildings and facilities be accessible if they were:

- designed, built, or changed using money from the US government, or
- leased by US organizations after August 12, 1968.

Buildings covered by the law must meet accessibility standards. This includes making sure the following are accessible:

- Walkways.
- Ramps.
- Curb ramps.
- Entrances
- Elevators.
- Rest rooms.

The ABA tells us how many of a certain item are required. This includes accessible parking spaces and where they are located, for example. These standards tell us how these things must be built. They also tell us how these things should be installed. This makes sure they can be used by everyone. Learn more about the ABA at <https://www.access-board.gov/law/aba.html>.

ADA, or the Americans with Disabilities Act:

The ADA protects the civil rights of people with disabilities. These laws are similar to laws that protect peoples' race, color, sex, national origin, age, and religion. The ADA promises equal opportunity for people with disabilities in public spaces. This includes having a caregiver come with you to a doctor's appointment, for example. The ADA also promises equal opportunity for communications. This can include having documents in Braille for someone who needs it. The ADA also promises equal opportunity for people with disabilities in:

- Employment
- Transportation
- State and local government services

Learn more about the ADA at <https://www.ada.gov/>.

DD Act, or the Developmental Disabilities Assistance and Bill of Rights Act of 2000:

The DD Act contains four grant programs. These programs are designed to assist people with developmental disabilities. These programs help people with disabilities to:

- increase their independence,
- increase their productivity, and
- increase their inclusion in the community.

These four grant programs give money for:

- Development Disability (DD) Councils.
- Protection and Advocacy Systems (P & As).
- University Centers for Excellence in Developmental Disabilities (UCEDDs).
- Projects of National Significance.

Learn more about the DD Act at

<https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000>.

FERPA, or the Family Educational Rights and Privacy Act:

FERPA is a Federal law that protects the privacy of student education information. FERPA gives parents certain rights with their children's education records. The student gets these rights when they turn 18. They also get these rights if they go to a school after high school. These students are called eligible students.

- Parents or students aged 18 and older have the right to look at the student's education records.
- Parents or students aged 18 and older have the right to ask a school to correct information that might be wrong. If the school decides not to change the record, a formal hearing can be requested.
- Parents or students aged 18 and older can ask for information from a student's education record. Schools must usually have written permission to do this.

Learn more about FERPA at <http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>.

IDEA, or the Individuals with Disabilities Education Act:

IDEA was originally called the EHA in 1975. EHA stood for the Education of Handicapped Children Act. IDEA is the US's special education law. It makes sure that children with disabilities can have free public education in the least restrictive environment. IDEA guides how states and schools provide special education and related services. It affects more than six million children with disabilities.

Learn more about IDEA at <https://sites.ed.gov/idea/about-idea/>.

Section 503/504, or the Sections of the Rehabilitation Act of 1973:

Section 503 is a part of the Rehabilitation Act of 1973. Section 503 applies to anyone getting money from the US Government. It prevents them from discriminating against people with disabilities who

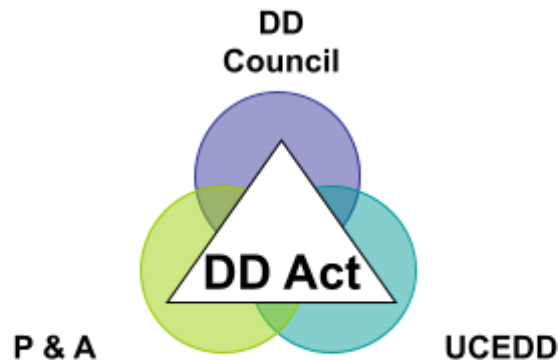
are qualified for certain jobs. Section 503 gives affirmative action for people with disabilities. Section 504 is also a part of the Rehabilitation Act of 1973. Section 504 prevents discrimination of people with disabilities. It does this in programs and activities that receive money from the US government. Learn more about Section 503/504 at

<https://www.dol.gov/general/topic/discrimination/disabilitydisc>.

State Developmental Disability (DD) Network

The Developmental Disabilities (DD) Act states that every US state and territory must have each of the programs described below. The links below can help you find:

- The University Center for Excellence in Developmental Disabilities (UCEDD) in your state or territory.
- The Protection & Advocacy System (P & A) in your state or territory.
- The Developmental Disability (DD) Council in your state or territory.



UCEDD, or University Centers for Excellence in Developmental Disabilities:

Since 1963, UCEDDs have been working to accomplish a shared vision. This vision is one where all Americans participate fully in their communities. This includes Americans with disabilities. Key parts of this shared vision include:

- Independence
- Productivity
- Community inclusion

Today, there are 67 UCEDDs. There is at least one in every US state and territory. They are located in university settings. UCEDDs work with:

- people with disabilities and members of their families,
- state and local government agencies, and
- community providers.

UCEDDs work on projects that offer:

- training,
- technical assistance,
- service,
- Research, and
- Information sharing.

Find UCEDD programs in each state and territory at

<https://www.aucd.org//directory/directory.cfm?program=UCEDD>.

P & A, or Protection and Advocacy Systems:

P & As are located across the US. They are agencies that help to protect the rights of people with disabilities. P & As have the power to legally represent people with disabilities. P & As also provide other advocacy services. Find P & A systems in each state and territory at

<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>.

DD Council, or Developmental Disabilities Council:

DD Councils were formed by the Developmental Disability (DD) Act. DD Councils focus on the most important needs of people with disabilities in their state or territory. They develop new ways to meet these needs. DD Councils also support the rights of people with disabilities. Find DD Councils in each state and territory at <https://www.nacdd.org/councils/>.

National Developmental Disability (DD) Network

The organizations of the UCEDDs, P & As, and DD Councils are listed below.

AUCD, or the Association of University Centers on Disabilities:

AUCD was founded in 1967. AUCD is a non-profit organization that supports all university centers on disabilities. These include:

- UCEDDs,
- Leadership Education in Neurodevelopmental and Related Disabilities (LENDs), and
- Developmental Disability Resource Centers (DDRCs).

The mission of AUCD is to advance policy and practice. AUCD does this for and with people with disabilities, their families, and communities. AUCD supports its members to take part in research, education, and service. These activities support independence, productivity, and good quality of life. Learn more at <https://www.aucd.org/>.

COLA, or the Council on Leadership in Advocacy:

COLA is made up of people with disabilities from each UCEDD across the AUCD network. COLA helps AUCD to advance policy and practice. COLA does this for and with people with disabilities, their families, and communities. Learn more at <https://www.aucd.org/template/page.cfm?id=41>.

LEND, or Leadership in Education in Neurodevelopmental and Related Disabilities:

A LEND is a training program to improve the health of infants, children, and teenagers with disabilities. Participants are usually from different professional backgrounds. Participants can also have lived experience with a disability. Learn more about LEND at <https://www.aucd.org/template/page.cfm?id=473>.

NACDD, or the National Association of Councils on Developmental Disabilities:

NACDD gives support and assistance to state DD Councils. The NACDD guides state DD Councils as they provide services and supports. DD Councils provide services and supports to people with disabilities and their families. Learn more at <https://www.nacdd.org/>.

NDRN, or the National Disabilities Rights Network:

NDRN is a nonprofit organization. P & As and Client Assistant Programs for people with disabilities are a part of the NDRN. The NDRN works to create inclusive communities. This means people with disabilities have equal opportunity to live self-determined lives. The NDRN does this by providing:

- training,
- technical assistance,
- legal support, and
- legislative advocacy.

Learn more at <https://www.ndrn.org/>.

Common Terms

Words that may be commonly used in the work of UCEDDs are listed below..

ADL, or Activities of Daily Living:

ADLs are basic tasks of everyday life. These can include things such as:

- eating,
- bathing,
- dressing, and
- going to the bathroom.

When people are unable to do ADLs, they need help from other people. They may also need helpful equipment to do ADLs. People of all ages may have problems with ADLs. But, people who have physical or psychological needs may need more help. People who are older may also need more help with ADLs. Learn more at

<https://aspe.hhs.gov/reports/measuring-activities-daily-living-comparisons-across-national-surveys-0>.

ASD, or Autism Spectrum Disorder:

ASD is a developmental disability. People with ASD may communicate, learn, and interact with other people differently. Some people with ASD need help with day to day activities but some do not. Learn more at <https://www.cdc.gov/ncbddd/autism/facts.html>.

CP, or Cerebral Palsy:

CP is a disorder that affects a person's ability to move. CP usually appears in the first few years of life. There are many different symptoms of CP. A person with CP may have a hard time with:

- Fine motor skills, like writing or cutting with scissors.
- Balance and walking.

A person with CP may not be able to control movements their body makes. They may not be able to control their hands. Symptoms of CP can be very different for each person. The symptoms of CP can even change during a person's lifetime. Learn more at <https://ucp.org/>.

DD, or Developmental Delay:

A DD happens when a child is delayed in achieving one or more milestones. An example of a milestone is rolling over or walking. DDs may affect a child's speech, communication, and social skills. It can also affect a child's motor skills, like holding a pencil or jumping. DDs should be found as soon as possible by a health professional. Learn more at

<https://www.parentcenterhub.org/dd/>.

DD, or Developmental Disability:

Developmental disabilities, or DDs, are physical or mental impairments that begin before age 22.

A DD can change a person's ability to do at least three of the following:

1. Take care of themselves, like dress, bathe, and eat

2. Speak and be understood clearly
3. Learn
4. Walk and move around
5. Make decisions
6. Live on their own
7. Earn and manage money received from a job

Learn more at <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>.

HH, HOH, or Hard of Hearing:

HH or HOH describe hearing loss. Hearing loss can be mild to severe. Most people who are HOH communicate by using their voice. But, some people learn sign language. People who are HOH can still participate in their community. They usually do this by using a hearing aid, speech reading, and assistive communication devices. Assistive communication devices help people with communicating. Learn more at <https://www.washington.edu/doit/deaf-or-hard-hearing>.

HI, or Hearing Impaired:

HI is when hearing is affected by a disease, disorder, or injury. Hearing impairments can begin when a person is born. They can also begin in childhood or adulthood. There are many causes of hearing impairment. The biggest single cause is age. This is called age-related hearing loss. Learn more at

<https://www.washington.edu/doit/how-are-terms-deaf-deafened-hard-hearing-and-hearing-impaired-typically-used>.

LD, or Learning Disability or Learning Difference:

A child with a LD learns differently than their classmates. They may have a hard time learning compared to children without a LD. Children with a LD may need help with reading, math, writing, or speaking. A child with a LD can feel a disconnect between their ability and achievements without help.

MH, or Mental Health:

Mental health includes our emotional well-being. It also includes our psychological and social well-being. It affects how we think, feel, and act. It also helps determine how we:

- handle stress,
- relate to others, and
- make choices.

Learn more at <https://www.mentalhealth.gov/basics/what-is-mental-health>.

MI, or Mental Illness:

MI is a health condition that involves changes in emotion, thinking, or behavior. MI can also be a combination of these. A person with a MI may feel distressed. They may also have problems getting along in social, work or family activities. Some examples of MIs include:

- Depression
- Bipolar disorder

- Attention-deficit and hyperactivity disorder
- Anxiety disorders
- Eating disorders
- Schizophrenia
- Behavior disorders.

Learn more at <https://www.psychiatry.org/patients-families/what-is-mental-illness>.

TBI, or Traumatic Brain Injury:

TBI is caused when a force damages brain tissue. Some causes of TBI are:

- Car accidents
- Acts of violence
- Falling down
- Sports injuries
- Lightning strikes
- Electric shocks
- Blows to the head
- During birth

TBI can happen without any signs of physical trauma. Memory and personality changes are common among people with a brain injury. Mood swings and fatigue are also common. Learn more at <http://www.headinjury.com/tbitypes.htm#tauamatic>.

VI, or Visual Impairment:

VIs include people:

- who have been blind since birth,
- become blind over time, or
- who can partially see.

VI describes any kind of vision loss. This can include someone who cannot see at all. It can also include someone who has lost part of their vision. It can also include someone who has a reduced field of vision.

Support Plans

Different types of support plans that people with disabilities and their families may use are listed below.

FSP, or Family Support Plan:

The FSP process begins when a child enters an Early Intervention Program. The FSP is a written document. It is based on family concerns and priorities. The FSP also considers evaluations from other professionals. These professionals know and help with the care of the person. The FSP describes what services and supports are needed. The services and supports help the child and family meet the needs of their daily lives.

IEP, or Individualized Education Plan:

An IEP describes the educational goals for a child with a disability. The goals are set for each school year. An IEP is made by the child's parents or caretakers, teachers, and support staff. The goals in an IEP can usually be met in a school environment. Sometimes the goals are met in a special resource room in the school. Learn more at

<https://www2.ed.gov/parents/needs/speced/iepguide/index.html>.

IFSP, or Individualized Family Service Plan:

An IFSP helps guide the early intervention process for children with disabilities and their families. The IFSP has information about the services needed for the child's development. It also describes how the family or caretaker can help. Family members or caretakers and service providers work together during the IFSP process. They do this to plan, implement, and evaluate these services.

Learn more at <https://www.michiganallianceforfamilies.org/ifsp/>.

ISP, or Individualized Service Plan:

The ISP is a written personal plan for a person with a disability who receives services. The ISP lists what type of help the person wants and needs to achieve their life goals.

PASS, or Plans for Achieving Self-Support:

A PASS is a plan for the future. It lets a person with a disability use their own money or other things they own to reach work goals. For example, a person could set aside money to:

- buy a house,
- go to school, or
- get training for a job.

The job that they want should allow them to earn enough money to live. It should be enough to lower the need for Social Security and Supplemental Security Income (SSI) benefits. A PASS helps a person get the items, services, or skills they need to reach their goals. Learn more at:

<https://www.ssa.gov/disabilityresearch/wi/pass.htm>.

Education Terms

Below are some of the terms that are used in schools. Many UCEDDs work with families and schools. They do this to provide the best educational opportunities for children and youth with disabilities.

ABA, or Applied Behavior Analysis:

An ABA is a therapy that helps improve a person's language and communication skills. ABA is adapted for individual needs. ABA teaches skills that are useful in everyday life. Learn more at

<https://www.autismspeaks.org/applied-behavior-analysis>.

DS, or Disability Studies:

DS is a field that includes many experts. It focuses on the contributions, experiences, history, and culture of people with disabilities. DS refers to looking at disability through social, cultural, and political lenses. DS covers the physical, mental, and psychological needs of a person. Disability is a part of the human experience. Learn more by reading about Ohio State University's Disability Studies program: <https://english.osu.edu/disability-studies>.

EC, or Early Childhood:

EC refers to when a child is very young. EC programs are meant to give children the best opportunities to get ready for school and life. EC programs help children learn and relate to other people. Learn more at <http://www.zerotothree.org/>.

ECSE, or Early Childhood Special Education:

ECSE aims to meet the education needs of children with disabilities or developmental delays. ECSE is free through the public school system. It is made available through the Individuals with Disabilities Education Act (IDEA). IDEA is the same law that makes early intervention services accessible. Learn more at (need new link, does not work): <http://www.nichcy.org/index.html>.

FSP, or Family Support Plan:

The Family Support Plan (FSP) is a written document. It is based on family concerns and priorities. The FSP process begins when a child is recommended to the Early Intervention Program. It considers evaluations from other professionals who help care for the person. It also lists the services and supports needed by the child and family. These services help meet the everyday needs of the child and family. Learn more at (need new link, does not work): <http://www.doh.state.fl.us/cms/PPOG/05FSP.pdf#search='family%20support%20plan>.

FAPE, or Free Appropriate Public Education:

FAPE is a right of all children with disabilities in the United States. It is education that is free and appropriate for the child's grade level. FAPE keeps in mind the child's individualized education program or plan. FAPE makes sure a child with disabilities can receive the benefits of education. Learn more at <http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html>.

IEP, or Individualized Education Plan:

An IEP describes the educational goals for a child with a disability. The goals are set for each school year. An IEP is made by the child's parents or caretakers, teachers, and support staff. The goals in an IEP can usually be met in a school environment. Sometimes the goals are met in a special resource room in the school. Learn more at <https://www2.ed.gov/parents/needs/speced/iepguide/index.html>

IFSP, or Individualized Family Service Plan:

An IFSP has information about the services needed to aid a child's development. The IFSP helps guide the early intervention process for children with disabilities and their families. It also describes how the family or caretaker can help. Family members, caretakers, and service providers work together during the IFSP process. They do this to plan, implement, and evaluate services.

LRE, or Least Restrictive Environment:

A LRE is where a child with a disability can receive a Free Appropriate Public Education (FAPE). The FAPE is designed to meet their education needs. A LRE includes receiving education in the same classroom with other students who do not have disabilities. Learning in the LRE helps students with and without disabilities. It promotes inclusion in the learning environment. It allows all students to improve their communication and social skills. Learn more at <https://www.lrecoalition.org/>.

IS, or Intervention Specialist:

An intervention specialist works with children and youth with disabilities. Some intervention specialists teach students life skills and how to read. Most of them work with children who have mild to moderate disabilities. The intervention specialist helps meet the child's education needs. They often use the general education curriculum. They can also use a modified curriculum.

Community-Based Supports and Resources

Below are some of the supports and resources available in the community. People with disabilities might use them to participate in the community.

BWE, or Blind Work Expenses:

BWE are costs that come up for people who are blind. Some examples include:

- Costs of service animals.
- Transportation to get to work.
- Visual aids.
- Braille translations.

Learn more at <https://secure.ssa.gov/poms.nsf/lnx/0500820535>.

COLA, or Cost of Living Adjustment:

A COLA is an increase in the amount of money a person receives. This money comes from Social Security and Supplemental Security Income (SSI). This increase helps when it costs more to live day-to-day. Learn more at <https://www.ssa.gov/oact/cola/colasummary.html>.

HMO, or Health Maintenance Organization:

A HMO provides health care opportunities to people who are enrolled in a healthcare plan. People can usually only see certain health care providers. They see them for medical care stated in their healthcare plan. Learn more at <https://www.healthcare.gov/glossary/health-maintenance-organization-hmo/>.

ILS, or Independent Living Services Programs:

ILS programs support options for community living and independence. ILS programs are for people with disabilities. ILS programs are based on the belief that all people can:

- live with dignity,

- make their own choices, and
- participate fully in society.

These programs provide tools, resources, and supports. These tools help people with disabilities to be fully included in their communities. These tools also help to promote equal opportunities, self-determination, and respect. Learn more at <https://acl.gov/ils-programs>.

IRWE, or Impairment-Related Work Expenses:

An IRWE is a cost for an item or service. A person with a disability may need these items or services for work. Examples of IRWEs include:

- transportation needed to get to work, or
- a service animal.

Learn more at <https://www.ssa.gov/ssi/spotlights/spot-work-expenses.htm>.

LBPDP, or Library for the Blind and Physically Disabled:

The LBPDP provides recorded books and magazines that are free to borrow. The LBPDP also lets you borrow equipment to play recorded materials. You can also borrow large print books and described videos. Learn more about Ohio's Library for the Blind and Physically Disabled at <https://cpl.org/aboutthelibrary/ohio-library-for-the-blind-physically-disabled/>.

PCA, or Personal Care Attendant:

A PCA helps a person with basic daily activities. These activities can include:

- getting in or out of bed,
- bathing,
- dressing,
- driving to do errands like shopping, or
- do cleaning.

PCAs help persons with disabilities to be more independent and active. Having a PCA lets a family member return to work. A PCA can help decide if a person can live independently or not. [Learn more at \(needs link\)](#).

SSDI, or Social Security Disability Insurance:

SSDI is one of the largest Federal programs. SSDI pays benefits to an individual and certain members of their family if they are insured. To be insured, a person must have worked for a certain amount of time. They must have also paid into Social Security taxes. Those who may qualify for benefits include:

- people who have a disability and
- meet certain medical criteria.

SSDI is run by the Social Security Administration. Learn more at <http://www.ssa.gov/disability/>.

SSI, or Supplemental Security Income:

SSI is a Federal program that supplements income. SSI is designed to help aged, blind, and people with disabilities who have little or no income. SSI gives people money to meet basic needs. Some examples include food, clothing, and shelter. Those who may qualify for benefits include:

- people who have a disability and
- meet certain medical criteria.

SSI is run by the Social Security Administration. Learn more at <https://www.ssa.gov/disability/>.

Professional Supports

People with disabilities might use professional supports and resources. These supports help them participate in the community. Examples of these professional resources are listed below.

COTA, or Certified Occupational Therapist:

COTAs have finished their education and taken exams to teach them how to be Occupational Therapists (OT). This means they are certified. A COTA also continues to learn more. They take classes to learn what is new and changing in their field.

Learn more at <https://www.nbcot.org/>.

DSP, or Direct Support Professional:

A DSP is a person who works with a person with an intellectual or developmental disability. DSPs support and empower the person to live the life they choose. A DSP helps the person to do things on their own. DSPs help with things like going grocery shopping or paying the cashier. Learn more at <https://thearc.org/policy-advocacy/direct-support-professionals/>.

IS, or Intervention Specialist:

An intervention specialist works with children and youth with disabilities. Some intervention specialists teach students life skills and how to read. Most of them work with children who have mild to moderate disabilities. The intervention specialist helps meet the child's education needs. They often use the general education curriculum. They can also use a modified curriculum.

OT, or Occupational Therapy:

OT helps people achieve independence in their lives. OT helps people to develop skills needed to live independently. OT services usually include:

- Customized treatment programs to improve a person's ability to perform daily activities
- Home and job site evaluations with recommendations for adaptation
- Performance skills assessments and treatment
- Adaptive equipment recommendations and usage training
- Guidance to family members and caregivers

Learn more at <https://www.aota.org/>.

PCA, or Personal Care Attendant:

A PCA helps a person with basic daily activities. These activities can include:

- getting in or out of bed,
- bathing,
- dressing,
- driving to do errands like shopping, or
- do cleaning.

PCAs help persons with disabilities to be more active and independent. Having a PCA lets a family member return to work. A PCA can help decide if a person can live independently or not. [Learn more at \(needs link\).](#)

SW, or Social Worker:

Social work is a profession for those who want to help people improve their lives. SWs help people to:

- Live well in their environment.
- Deal with their relationships.
- Solve personal and family problems.

SWs often work with people who have a life-threatening disease or a social problem. SWs work with people who may be dealing with:

- A lack of housing.
- Unemployment.
- A serious illness.
- A disability.
- Substance abuse.

SWs also help families that have serious problems at home. These problems sometimes involve the abuse of a child, husband, or wife. Learn more at <https://www.bls.gov/ooh/community-and-social-service/social-workers.htm>.

VR, or Vocational Rehabilitation:

VR agencies help people with disabilities prepare for jobs. They also help assess the type of work that is best for the person. Each state has its own way of accomplishing these tasks. Learn more at <https://www.naric.com/?q=en/FAQ/what-vocational-rehabilitation>.

Tools

Below are tools that may be used by people with and without disabilities. These tools are used to participate in the community.

ASL, or American Sign Language:

ASL is a visual-spatial language. It is used by the Deaf community in the United States and English-speaking parts of Canada. It is the native language of many Deaf people. It is also used by some hearing children born into Deaf families. ASL does not use grammar used by English. ASL is not a broken, mimed, or gestured form of English. Learn more at <https://www.nidcd.nih.gov/health/american-sign-language>.

CPR, or Cardio Pulmonary Resuscitation:

CPR is mouth-to-mouth respiration and chest compression. CPR helps blood that contains oxygen get to organs like the brain and heart. CPR can keep a person alive. It can be used until paramedics are present. Paramedics use more advanced procedures. Examples include an electric shock to the chest (known as defibrillation) to treat the person. Learn more at <https://www.heart.org/>.

FC, or Facilitated Communication:

FC is a way to help people with communication disorders. FC refers to using your hands with a communication device. Communication devices can include:

- Picture boards.
- Speech synthesizers.
- Keyboards.

In FC, a person, or facilitator, offers emotional and physical support. Sometimes the FC will keep the user's hand, wrist, or arm steady. This helps them as they point toward the communication device. Learn more at <https://www.asha.org/policy/ps2018-00352/>.

SE, or Signed English:

Some teachers use Signed English (SE), which uses vocabulary from American Sign Language (ASL). Words that do not carry information, like "to", "the", and "am", are often removed. Word endings, like -ed, -s, and -ment are also removed when using SE. This means that the person can speak more easily while signing. It helps the signer keep pace with spoken English. [Learn more at \(needs link\)](#).

TDD, or Telecommunication Device for the Deaf:

A TDD is a device used by people with hearing and speech impairments. These people cannot use a standard telephone. TDDs are sometimes known as TTY (for Teletypewriter) or TT (for Text Telephone).

Other National Organizations

Below is a list of other national associations. These organizations might be important to the work of UCEDDs.

AAIDD, or American Association on Intellectual and Developmental Disabilities:

AAIDD promotes:

- progressive policies,
- sound research,
- effective practices, and
- human rights for people with disabilities.

Learn more at <http://www.aidd.org/>.

ACLD, or Association for Children with Learning Disabilities:

ACLD is a not-for-profit, private, educational organization. Their mission is to provide opportunities for children and adults with autism and learning and developmental disabilities. The goal of ACLD is for people to pursue enviable lives. ACLD promotes independence. ACLD also helps to build supportive community relationships. Learn more at <http://www.acldonline.org>.

The Arc:

The Arc is the national organization of and for people with disabilities and their families. It is devoted to improving supports and services for people with disabilities and their families. The Arc also advocates for people with disabilities and their families. The Arc advocates for people and families at the Federal level. Learn more at <http://www.thearc.org/>.

ASA, or Autism Society of America:

The ASA was founded in 1965. The ASA increases public awareness about autism. They also help to reduce barriers for people with autism. They also help families and caretakers of people with autism. The ASA works with the professionals who work with people with autism. The ASA provides:

- information and education,
- Support for research, and
- advocates for programs and services for the autism community.

Learn more at <http://www.autism-society.org>.

LDA, or Learning Disabilities Association:

LDA is the largest non-profit volunteer organization in the country. It advocates for people with learning disabilities. Members of the LDA include:

- people with learning disabilities,
- family members,
- professionals, and
- advocates.

Affiliates work with LDA members. Learn more at <https://ldaamerica.org/>.

NADS, or National Association for Down Syndrome:

NADS gives counseling and support. NADS does this for parents of infants who are newly diagnosed with Down syndrome. NADS also advocates for people with Down syndrome. NADS has referral and information services. NADS sponsors conferences and educational programs for parents and professionals. NADS delivers health and psychosocial services and therapeutic programs. They do this for children, teenagers, and adults with Down syndrome. Learn more at <http://www.nads.org/>.

NDSC, or National Down Syndrome Congress:

The NDSC is a national advocacy organization for people with Down syndrome. They offer leadership in all areas related to people with Down syndrome. NDSC is a major source of support and empowerment. They empower people with Down syndrome and their families and caretakers. Learn more at <http://www.ndsccenter.org/>.

NDSS, or National Down Syndrome Society:

The NDSS works with people with Down syndrome. The NDSS helps people with Down syndrome to achieve their fullest potential. The NDSS does this through education, research and advocacy. Learn more at <http://www.ndss.org/>.

NICHCY, or National Information Center for Children and Youth with Disabilities:

NICHCY is a national information and referral center. It gives information on disabilities and disability-related concerns. NICHCY gives information to families, educators, and other professionals. They focus on helping children and youth. They help people from when they are born to age 22. [Learn more at \(needs link\)](#).

NPIN, or National Parent Information Network:

NPIN is also known as the Parent-to-Parent program. It is a program that connects parents and families of children with disabilities within a state. They help by:

- Sharing information.
- Providing resources.
- Giving parents support.

Learn more at <https://www.p2pusa.org/>.

SABE, or Self Advocates Becoming Empowered:

SABE is a national self-advocacy organization. SABE has 9 elected regional representatives. SABE's goals are to:

- Make self-advocacy available at all stages of life.
- Make self-advocacy available in every state.
- Promote self-advocacy in education, the workplace, and living in the community.
- Work, advocate, and speak out on legislation for people with disabilities.
- Close institutions for people with disabilities.
- Build community supports.

Learn more at <http://www.sabeusa.org/>.

Alphabet Soup in My State

The questions below are meant as a guide. They should help guide discussions with your UCEDD Director and staff. They can help you learn the acronyms used in your state.

What acronyms are used at our UCEDD?

What acronyms are used at our state government programs and agencies?

What acronyms are used at our parent advocacy organizations?

What acronyms are used at our self-advocacy organizations?

What acronyms are used at our local chapters of national organizations?