Alphabet Soup for CACs

People with disabilities, parents, teachers, caregivers and professionals in the disability world have their own language, often referred to as "Alphabet Soup" because it is a mess of acronyms and abbreviations. People new to this world often talk about how confusing it is to come to a CAC meeting for the first time and try to follow along with this new strange language. This is a short guide to commonly used terms in the disability world.



This guide provides an alphabetical list of acronyms and groups their definitions within 10 content areas. The last page of document is a discussion guide for your CAC to put together your own personal glossary for the "Alphabet Soup" in your state or territory. The 10 content areas are:

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Federal Agencies

Following are some of the federal agencies that UCEDDs might interact with.

AIDD – *Administration on Intellectual and Developmental Disabilities*:

AIDD is the US Government organization responsible for implementation of the Developmental Disabilities Act. AIDD, its staff and programs, are part of the Administration for Children and Families, of the U.S. Department of Health and Human Services. www.acf.dhhs.gov/programs/add



AoA – Administration on Aging

AoA has provided home and community-based services to older persons through the programs funded under the Older Americans Act. Its National Family Caregiver Support Program provides a variety of services to help people who are caring for family members who are chronically ill or who have disabilities.



http://www.aoa.gov/

CMS – Centers for Medicare & Medicaid Services

CMS's mission is to ensure effective, up-to-date health care coverage and to promote quality care for beneficiaries. CMS Administers Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP).



http://www.cms.hhs.gov/

MCHB – Maternal and Child Health Bureau

MCHB, within the Health Resources Services Administration, administers programs promote and improve the health of our nation's mothers, infants, children, and adolescents. http://mchb.hrsa.gov/about/default.htm



OSEP – Office of Special Education Programs:

OSEP supports a comprehensive array of programs and projects authorized by IDEA that improve results for infants, toddlers, children and youth with disabilities. OSEP, National Institute on Disability and Rehabilitation Research, and the Rehabilitation Services Administration are components of the US Department of Education's Office of Special Education and Rehabilitation Services.



http://www.ed.gov/about/offices/list/osers/osep/programs.html

OSERS – *Office of Special Education and Rehabilitation Services:*

Within the US Department of Education, OSERS supports programs designed to educate children with special needs; provides for the rehabilitation of youths and adults with disabilities; and supports research to improve the lives of individuals with disabilities, regardless of age.

http://www.ed.gov/about/offices/list/osers/index.html

SSA – Social Security Administration

SSA administers retirement, disability and survivors benefits to workers and their families and the Supplemental Security Income program. SSA also issues Social Security numbers.



http://www.ssa.gov/

Federal Legislation

Following are some of the federal legislative initiatives that are important to the work of UCEDDs.

ABA – Architectural Barriers Act:

The ABA requires that buildings and facilities be accessible if, since 1968, they were:

- designed, built, or altered with certain Federal funds, or
- leased for occupancy by Federal agencies.

Buildings and facilities covered by the law must meet standards for accessibility issued by four Federal agencies. Accessibility standards cover such things as: walks, ramps, curb ramps, entrances, elevators, and rest rooms. They indicate how many of a certain item, such as accessible parking spaces, are required, where they must be located, and how they must be built or installed so they can be used by everyone. http://makoa.org/gov/g15.htm



ADA – Americans with Disabilities Act:

The Americans with Disabilities Act gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications. http://www.usdoi.gov/crt/ada/

DD Act – Developmental Disabilities Assistance and Bill of Rights Act of 2000

The DD Act contains four grant programs designed to assist individuals with developmental disabilities in reaching their maximum potential through increased independence, productivity, inclusion, and community integration. These four grant programs provide funds for: DD Councils, P&As, UCEDDs, and Projects of National Significance.

http://www.acf.hhs.gov/programs/add/ddact/DDACT2.html

FERPA – *Family Educational Rights and Privacy Act:*

FERPA is a Federal law that protects the privacy of student education records. FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Students to whom the rights have transferred are "eligible students."

- Parents or eligible students have the right to inspect and review the student's education records maintained by the school.
- Parents or eligible students have the right to request that a school correct records which they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent or eligible student then has the right to a formal hearing
- Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record.

http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html

IDEA – *Individuals with Disabilities Education Act:*

Originally enacted by Congress in 1975 as the EHA, or the Education of Handicapped Children Act and most recently revised in December 2004, IDEA is the nation's special education law which ensures children with disabilities have the opportunity to receive a free appropriate public education

in the least restrictive environment. IDEA guides how states and school districts provide special education and related services to more than six million eligible children with disabilities. http://asclepius.com/angel/special.html

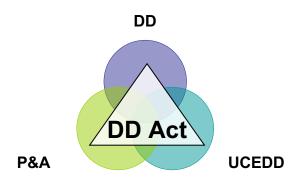
Section 503/504 – *Sections of the Rehabilitation Act of 1973:*

Section 503 of the Rehabilitation Act of 1973 prohibits federal contractors and subcontractors from discriminating against and requires affirmative action for qualified individuals with disabilities in all aspects of employment. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability in programs and activities that receive federal financial assistance and in federally conducted programs.

http://www.dol.gov/dol/topic/discrimination/disabilitydisc.htm

State DD Network

This page provides descriptions of the programs authorized under the DD Act that operate in every US state and territory. The URLs provided link to directories that can be used to find the UCEDDs, P&A, and DD Council in each state and territory.



UCEDD – University Centers for Excellence in Developmental Disabilities Education, Research, and Service:

Since 1963, UCEDDs have been working to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity and community inclusion are key components of this vision. Today, there are 67 grants that establish 68 Centers—at least one in every state and territory that are located in a university setting. Centers facilitate the flow of disability-related information between community and university. Centers work with people with disabilities, members of their families, state and local government agencies and community providers in projects that provide training, technical assistance, service, research and information sharing, with a focus on building the capacity of communities to sustain all their citizens.

http://www.aucd.org/directory/directory.cfm?program=UCEDD

P&A – *Protection and Advocacy:*

A nationwide network of congressionally mandated, legally based disability rights agencies. P&As have the authority to provide legal representation and other advocacy services to all people with disabilities.

http://www.napas.org/aboutus/PA CAP.htm

DD Council – Developmental Disabilities Council:

Established by the Developmental Disability Act, DD Councils identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost-effective ways to meet these needs in a manner that upholds the human and civil value of people with developmental disabilities.

http://www.nacdd.org/images2/pdfs/ExecChair.pdf

National DD Network

Following are the national organizations of the UCEDDs, P&As, and DD Councils.

AUCD – Association of University Centers on Disabilities:

AUCD is a non-profit organization that promotes and supports the national network of university centers on disabilities, which includes UCEDDs, LENDs, and DDRCs. Founded in 1967, the mission of AUCD is to advance policy and practice for and with



people living with developmental and other disabilities, their families, and communities by supporting its members to engage in research, education, and service that support independence productivity, and a satisfying quality of life.

www.aucd.org.

COCA – Council on Community Advocacy:

The Council on Community Advocacy, also known as COCA, is made up of individuals with disabilities and family members from each UCEDD across the AUCD network. COCA assists AUCD to advance policy and practice for and with people with disabilities, their families and communities.

http://www.aucd.org/template/page.cfm?id=41

NACDD – National Association of Councils on Developmental Disabilities:

NACDD's mission is to provide support and assistance to member Councils in order to promote a consumer and family centered system of services and supports for individuals with developmental disabilities.



www.nacdd.org.

NDRN – *National Disabilities Rights Network:*

NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy Systems and Client Assistant Programs for individuals with disabilities. Through training and technical assistance, legal support, and legislative advocacy, the



NDRN works to create a society in which people with disabilities are afforded equality of opportunity and are able to fully participate by exercising choice and self-determination. www.ndrn.org

Common Terms

Following are some of the terms that may be used in the work of UCEDDs.

ADL – *Activities of Daily Living:*

The term ADLs refers to the basic tasks of everyday life, such as eating, bathing, dressing, toileting, and transferring. When people are unable to perform these activities, they need help in order to cope, either from other human beings or mechanical devices or both. Although persons of all ages may have problems performing the ADLs, prevalence rates are much higher for the elderly than for the non-elderly.



http://aspe.hhs.gov/daltcp/reports/meacmpes.htm

CP – *Cerebral Palsy:*

CP is an umbrella-like term used to describe a group of chronic disorders impairing control of movement that appear in the first few years of life and generally do not worsen over time. Symptoms of cerebral palsy lie along a spectrum of varying severity. An individual with cerebral palsy may have difficulty with fine motor tasks, such as writing or cutting with scissors; experience trouble with maintaining balance and walking; or be affected by involuntary movements, such as uncontrollable writhing motion of the hands. The symptoms differ from one person to the next, and may even change over time in the individual. http://www.ucp.org/

DD – *Developmental Delay:*

A "developmental delay" occurs when a child has the delayed achievement of one or more of his/her "milestones." This may affect the child's speech and language, fine and gross motor skills, and/or personal and social skills. Developmental delays, especially if they involve a language delay which may be secondary to a hearing loss, should be identified as early as possible. http://www.keepkidshealthy.com/WELCOME/conditions/developmentaldelays.html

DD – *Developmental Disability*:

Developmental Disabilities are physical or mental impairments that begin before age 22, and alter or substantially inhibit a person's capacity to do at least three of the following:

- 1. Take care of themselves (dress, bathe, eat, and other daily tasks)
- 2. Speak and be understood clearly
- 3. Learn
- 4. Walk/ Move around
- 5. Make decisions
- 6. Live on their own
- 7. Earn and manage an income

http://www.acf.dhhs.gov/programs/add/addabout.html

HH, HOH – *Hard of Hearing:*

The term used to describe a degree of hearing loss ranging from mild to profound for which a person usually receives some benefit from amplification. Most people who are hard of hearing are oralists (communicate by using their voice), although a small number learn sign language. Usually they participate in society by using their residual hearing with hearing aids, speech reading, and assistive devices to facilitate communication.

http://www.cdhh.org/

HI – *Hearing Impaired:*

Hearing impairment is when the hearing is affected by a disease, disorder or injury. Hearing loss can be present at birth (deaf or hard of hearing people) or develop in childhood or adulthood (deafened people). There are a great many causes of deafness and hearing impairment. The biggest single cause is age, called age-related hearing loss.

http://www.nhsdirect.nhs.uk/articles/article.aspx?printPage=1&articleId=518

LD – *Learning Disability or Learning Difference:*

Learning disabilities make it difficult for a child with an average or above average potential to learn in one or more areas (such as reading or math), resulting in a large disconnection between their ability and achievement.

MH - Mental Health

MI – *Mental Illness*:

Mental health is how people look at themselves, their lives, and the other people in their lives; evaluate their challenges and problems; and explore choices. This includes handling stress, relating to other people, and making decisions. Mental illness usually refers to severe mental health problems in adults. These can include depression, bipolar disorder, attention-deficit/ hyperactivity disorder, anxiety disorders, eating disorders, schizophrenia, and conduct disorder. http://www.mentalhealth.samhsa.gov/

TBI – *Traumatic Brain Injury:*

TBI results from damage to brain tissue caused by an external force. Leading causes of TBI are motor vehicle accidents, acts of violence, falls, sports and recreational injuries, lightening strikes, electric shocks, and blows to the head. TBI can occur without any outward physical evidence of injury or trauma. Memory mood and fatigue are common complaints of brain injury patients. Intellectual dullness and mental rigidity are obvious signs of brain injury. Personality changes are common, and rapid mood swings alternate with changes in energy levels. Taken individually, such impairments might not amount to much. However, such impairments usually appear in groups or clusters. In many cases the impairments are widespread and disrupt many brain systems. The overall effect can be profoundly disabling.

http://www.headinjury.com/tbitypes.htm#tauamatic

VI – *Visual Impairment:*

Visual impairments encompass people who have been blind since birth, people who have become blind gradually, and those with selective impairments of parts of the visual field.

Support Plans

Following are some of the types of support plans that individuals with disabilities and their families may use.

FSP – Family Support Plan:

The Family Support Plan process begins upon referral of the child to the Early Intervention Program. It includes a number of activities and culminates in a meeting to develop a written document, the Family Support Plan (FSP). The FSP is based on family concerns and priorities and the multidisciplinary evaluation and assessment results. The FSP documents specific services and



supports that are necessary to help meet the unique needs of the child and family in their everyday routines, activities, and places.

http://www.doh.state.fl.us/cms/PPOG/05FSP.pdf#search='family%20support%20plan

IEP – *Individualized Education Plan*:

An IEP describes the goals set by a team of parents and educators for a child with special needs for the school year, as well as any special supports that are needed to help achieve those goals. In most cases, the services and goals outlined in an IEP can be provided in a standard school environment or in a special resource room in the regular school.

http://www.schwablearning.org/articles.asp?r=73

IFSP – *Individualized Family Service Plan:*

An IFSP documents and guides the early intervention process for children with disabilities and their families. The IFSP is a tool to carry out an effective early intervention process according to Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services tailored to the family's unique concerns, priorities, and resources.

ISP – *Individualized Service Pan*:

The Individualized Service Plan is a written personal plan, or blueprint, for a person with developmental disabilities that summarizes the help he or she wants and needs to achieve his or her own aspirations in life.

PASS – *Plans for Achieving Self-Support:*

A plan for achieving self-support (PASS) is a plan for the future. A plan lets a person with a disability use his/her income or other things he/she own to help him/her reach work goals. For example, he could set aside money to go to school to get specialized training for a job or to start a business. The job that he wants should allow him to earn enough to reduce or eliminate the need for benefits provided under both the Social Security and Supplemental Security Income (SSI) programs. A plan is meant to help get items, services, or skills needed to reach goals. http://www.ssa.gov/pubs/11017.html

Education Terms

Following are some of the terms that are used in school settings.

Many UCEDDs work with families and schools to provide the best educational opportunities for children and youth with disabilities and special needs.

DS – *Disability Studies:*

There are 3 generally agreed upon definitions of Disability Studies:

- 1. Disability Studies is an interdisciplinary field of study, which is focused on the contributions, experiences, history, and culture of people with disabilities. The field of teaching and research in the area of disability studies is growing worldwide.
- 2. Disability Studies refers generally to the examination of disability as a social, cultural, and political phenomenon. In contrast to clinical, medical, or therapeutic perspectives on disability, Disability Studies focuses on how disability is defined and represented in society. It rejects the perception of disability as a functional impairment that limits a person's activities. From this perspective, disability is not a characteristic that exists in the person or a problem of the person that must be "fixed" or "cured." Instead, disability is a construct that finds its meaning within a social and cultural context.
- 3. Disability Studies views disability as a political and cultural identity, not simply as a medical condition. Disability is not solely a set of physical or mental limitations but the product of an interaction between physical and cultural environments shaping the perception and experience of different capacities.

http://disabilities.temple.edu/programs/ds/facultyherald.htm

EC – *Early Childhood:*

Intervening early in the lives of disadvantaged children is assumed to provide the best opportunity to forestall later problems and to ready children for school and life. This assumption is bolstered by evidence that early childhood programs have produced long-term cognitive and social benefits for the children who enrolled in them.

http://www.zerotothree.org/

ECSE – *Early Childhood Special Education:*

Special education is instruction that is specially designed to address the educational and other needs of children with disabilities, or a child experiencing developmental delays. Special education is provided free of charge through the public school system. It is available through the same law that makes early intervention services available—the Individuals with Disabilities Education Act. Special education services are provided free of charge through the public schools. http://www.nichcy.org/index.html

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http://www.doh.state.fl.us/cms/PPOG/05FSP.pdf#search='family%20support%20plan

FAPE – *Free Appropriate Public Education:*

Free Appropriate Public Education is a right of all children with disabilities in the United States. It is defined by Public Law (PL) 94-142, the EHA (now PL 101-476, IDEA) as special educational and related services at public expense (i.e. without charge), meeting the standards of approximate grade levels of the State education agency within the context of an individualized education program written with parental participation; and due process, including access to judicial review to determine that the State has complied with the Act and that the written individualized educational program is "reasonably calculated to enable the child to receive educational benefits," e.g. achieving passing marks and grade advancement. There are also FAPE stipulations in Section 504 of the 1973 Rehabilitation Act as well as in the Americans with Disabilities Act (see ADA). http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

IEP – *Individualized Education Plan:*

An IEP describes the goals set by a team of parents and educators for a child with special needs for the school year, as well as any special supports that are needed to help achieve those goals. In most cases, the services and goals outlined in an IEP can be provided in a standard school environment or in a special resource room in the regular school. http://www.schwablearning.org/articles.asp?r=73

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LRE – *Least Restrictive Environment:*

The educational setting where a child with disabilities can receive a FAPE designed to meet his or her education needs while being educated with peers without disabilities in the regular educational environment to the maximum extent appropriate. Learning in less restrictive environments benefits students with and without disabilities in so much as all children are more likely to improve their academic performance, and increase their communication and socialization skills. http://www.lrecoalition.org/index.htm

SPED Teachers– Special Education Teachers:

Special education teachers work with children and youths who have a variety of disabilities. A small number of special education teachers work with students with mental retardation or autism, primarily teaching them life skills and basic literacy. However, the majority of special education teachers work with children with mild to moderate disabilities, using the general education curriculum, or modifying it, to meet the child's individual needs. Most special education teachers instruct students at the elementary, middle, and secondary school level, although some teachers work with infants and toddlers.

Community-Based Supports and Resources

Following are some of the supports and resources available in the community that people with disabilities might use to help them fully participate in the community.

HMO – *Health Maintenance Organization:*

A Health Maintenance Organization (HMO) is an organization that provides comprehensive health care to voluntarily enrolled individuals and families in a particular geographic area by member physicians with limited referral to outside specialists and that is financed by fixed periodic payments determined in advance.

http://209.161.33.50/dictionary/HMO

ILC – *Independent Living Center:*

At the heart of the independent living philosophy are core values including cross disability, consumer control, self help and peer support, and equal access to society. In the broadest sense the goals of the independent living philosophy are empowerment and self determination for individuals with disabilities, and achieving equal access through barrier removal and Ed Roberts (1939-1995), reduction in the community. The expected outcome is independent living and full community participation for persons with all disabilities. http://www.ilusa.com/links/ilcenters.htm



a leader in the Independent Living movement for people with disabilities.

LBPH – *Library for the Blind and Physically Handicapped:*

The LBPH provides on free loan recorded books and magazines, equipment to play the recordings, large print books, and described videos.

http://www.loc.gov/nls/

PCA – *Personal Care Attendant:*

The PCA helps with many of the basic daily routines such as getting in or out of bed, bathing, dressing, driving, shopping, or cleaning. The work done by the PCA allows an individual with a disability or special health care need to be more independent and live an active, productive life. The use of a PCA may allow for a family member to return to work. It could also be the deciding factor if an individual can live independently or needs to be in an institutional setting such as a nursing home.

http://www.spinalcord.uab.edu/show.asp?durki=22411

SSDI – *Social Security Disability Insurance:*

SSDI is one of the largest of several Federal programs that provides assistance to people with disabilities. SSDI pays benefits to an individual and certain members of his/her family if they are "insured", meaning the individual has worked long enough and paid Social Security taxes. Only individuals who have a disability and meet medical criteria may qualify for benefits. SSDI is administered by the Social Security Administration. http://www.ssa.gov/disability/

SSI – Supplemental Security Income:

SSI is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people, who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter. Only individuals who have a disability and meet SSI is administered by the Social Security medical criteria may qualify for benefits. Administration. http://www.ssa.gov/disability/.

Professional Supports

Following are some of the professional supports and resources that people with disabilities might use to help them fully participate in the community.

COTA – *Certified Occupational Therapist:*

Certification is an important benchmark of quality in occupational therapy. Key stakeholders rely on certified providers for the following reasons:

- Certified occupational therapy professionals must participate in a comprehensive certification renewal process to demonstrate continuing proficiency.
- Certification helps employers identify applicants who are committed to a personal choice of professional development.

http://www.nbcot.org/index.html



OT – Occupational Therapy:

Occupational therapy is skilled treatment that helps individuals achieve independence in all parts of their lives. Occupational therapy assists people in developing the "skills for the job of living" necessary for independent and satisfying lives. Services typically include:

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

http://www.aota.org/index.asp

PCA – *Personal Care Attendant:*

The PCA helps with many of the basic daily routines such as getting in or out of bed, bathing, dressing, driving, shopping, or cleaning. The work done by the PCA allows an individual with a disability or special health care need to be more independent and live an active, productive life. The use of a PCA may allow for a family member to return to work. It could also be the deciding factor if an individual can live independently or needs to be in an institutional setting such as a nursing home.

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SW – Social Worker:

Social work is a profession for those with a strong desire to help improve people's lives. Social workers help people function the best way they can in their environment, deal with their relationships, and solve personal and family problems. Social workers often see clients who face a

life-threatening disease or a social problem, such as inadequate housing, unemployment, a serious illness, a disability, or substance abuse. Social workers also assist families that have serious domestic conflicts, sometimes involving child or spousal abuse. http://www.bls.gov/oco/ocos060.htm

VR – *Vocational Rehabilitation:*

VR agencies have professionals who help people with disabilities prepare for and find work. Each state has devised practices that are useful for their regional industries, geographic profile and demographics.

http://www.jan.wvu.edu/SBSES/VOCREHAB.HTM

http://www.ed.gov/rschstat/research/pubs/vrpractices/featured.html

Tools

Following are some of the tools that may be used by people with (and without) disabilities to fully participate in the community.

ASL – American Sign Language:

ASL is a complex visual-spatial language that is used by the Deaf community in the United States and English-speaking parts of Canada. It is a linguistically complete, natural language. It is the native language of many Deaf men and women, as well as some hearing children born into Deaf families. ASL shares no grammatical similarities to English and should not be considered in any way to be a broken, mimed, or gestured form of English.



http://www.deaflibrary.org/asl.html

CPR – *Cardio Pulmonary Resuscitation:*

CPR consists of mouth-to-mouth respiration and chest compression. CPR allows oxygenated blood to circulate to vital organs such as the brain and heart. CPR can keep a person alive until more advanced procedures (such as defibrillation - an electric shock to the chest) can treat the cardiac arrest. CPR started by a bystander doubles the likelihood of survival for victims of cardiac arrest. http://www.americanheart.org/presenter.jhtml?identifier=3011764

FC – Facilitated Communication:

Facilitated communication is a method intended to help people with communication disorders to use communication aids with their hands. The facilitator offers emotional and physical support, often steadying the user's hand, wrist or arm as the user points toward the communication device (often a picture board, speech synthesizer or keyboard.

http://home.vicnet.net.au/~dealcc/facil.htm

SE – *Signed English:*

Many teachers use PSE (Pidgin Signed English) or Signed English (SE). The vocabulary is drawn from American Sign Language (ASL) but follows English word order. Words that do not carry information (e.g. to, the, am, etc.) are often dropped, as are the word endings of English (e.g. -ed, -s, -ment, etc.). This means that the signer can easily speak while signing, since it is possible to keep pace with spoken English. It is simpler to learn than ASL or SEE (Signing Exact English), since one does not need to include all English endings, nor does one to master the structure or idioms of ASL.

http://www.listen-up.org/sign2.htm

TDD – *Telecommunication Device for the Deaf:*

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

Other National Organizations

Following are some of the other national associations that might be important to the work of UCEDDs.

AAIDD – American Association on Intellectual and Developmental Disabilities

AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.

http://www.aaidd.org/

ACLD – Association for Children with Learning Disabilities:

AC-ACLD/An Association for Children and Adults with Learning Disabilities, Inc. is a not-for profit, private, educational organization. Their mission is to enhance the quality of life of children and adults with Specific Learning Disabilities (SLD) and related neurobiological disorders by facilitating self-sufficiency and financial independence. http://www.acldonline.org

The Arc:

The Arc is the national organization of and for people with mental retardation and related developmental disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families. The association also fosters research and education regarding the prevention of mental retardation in infants and young children.



http://www.thearc.org/

ASA – Autism Society of America:

The ASA was founded in 1965. ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The Society and its chapters share a common mission of providing information



Society and its chapters share a common mission of providing information and education, and supporting research and advocating for programs and services for the autism community. http://www.autism-society.org/site/PageServer?pagename=homepage

LDA – *Learning Disabilities Association:*

LDA is the largest non-profit volunteer organization advocating for individuals with learning disabilities and has over 200 state and local affiliates in 42 states and Puerto Rico. LDA's international membership of over 15,000 includes members from 27 countries around the world. The membership, composed of individuals with learning disabilities, family members and concerned professionals, advocates for the almost three million students of school age with learning disabilities and for adults affected with learning disabilities. The state and local affiliates, through their affiliation with the national LDA, work continuously for individuals with learning disabilities, their parents and the professionals who serve them.

NADS – *National Association for Down Syndrome:*

NADS provides critical counseling and support for parents of newly diagnosed infants with Down syndrome as well as advocacy, referral and information services. In addition, NADS sponsors conferences and educational programs for parents and professionals, and conducts in-services for medical personnel and educators. Through a partnership with the Adult Down Syndrome Center

(which it helped found) NADS delivers health, psychosocial services and therapeutic programs to teens and adults with Down syndrome.

http://www.nads.org/

NDSC – National Down Syndrome Congress:

The National Down Syndrome Congress is a national advocacy organization for people with Down syndrome. They provide leadership in all areas of concern related to persons with Down syndrome. In that capacity, NDSC is a major source of support and empowerment to persons with Down syndrome and their families.

http://www.ndsccenter.org/

NDSS – *National Down Syndrome Society:*

Through education, research and advocacy, the National Down Syndrome Society works to ensure that all people with Down syndrome have the opportunity to achieve their fullest potential. http://www.ndss.org/

NICHCY – National Information Center for Children and Youth with Disabilities:

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Our special focus is children and youth (birth to age 22).

http://www.nichcy.org/

NPIN – *National Parent Information Network:*

NPIN is also known as the Parent to Parent program. It is a program implemented at the state level that connects parents and families of children with disabilities to share information, resources and offer support to each other. http://www.p2pusa.org/state/map_us_gif.htm



SABE – Self Advocates Becoming Empowered

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

 Make self-advocacy available in every state including institutions, high schools, rural areas and people living with families with local support and advisors to help.



- Work with the criminal justice system and people with disabilities about their rights within the criminal justice system.
- Close institutions for people with developmental disabilities labels nationwide, and build community supports.

http://www.sabeusa.org/

Alphabet Soup in my State

Guidance Questions for Discussions with UCEDD staff/Director:
What acronyms are used in our UCEDD?
State government programs and agencies?
Parent Advocacy Organizations?
Self-Advocacy Organizations?
Local chapters of national organizations?
Other: