

A Reporter's Guide:
Reporting About People
with Disabilities

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Written by Betsy Southall
Edited by Steve Wiseman and
Jan Lilly-Stewart

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Preface

This guide was written to be a point of reference for journalists to help them form a basic understanding of disability issues and disability etiquette. It is not meant to be all encompassing. For this reason, we have included a list of some of the important agencies and organizations who have individuals available to discuss disability related issues with the press. Again, this list is meant to be a stepping stone to more comprehensive resources which are widely available throughout the state.

The purpose of this guide is to discuss the language and methods typically used across the nation to portray people with disabilities in the media and help media professionals understand that some of these methods are outdated and lead to inaccuracy in reporting. We would also like journalists to realize the power and responsibility they have in our society. Perhaps now, more than ever before, people accept what they see and hear in the media as the truth. Therefore, it is imperative that media professionals do all that they can to accurately report on people with disabilities, and all individuals in our society who are negatively stereotyped and thus experience social discrimination and prejudice.

Language and disability etiquette are important, but the most important issues in this guide are those which center around changing the methods used to report on disability issues. Obviously, we would like to see more stories which include people with disabilities, but not necessarily the kind traditionally found in the media. We would like editors and journalists to broaden their definition of what makes a good story and understand that stories on disability aren't just in the health arena. They are in every arena and every facet of life.

We aren't asking reporters to go out and cover every story about people with disabilities and the problems they face, although we do not want to diminish the importance of those stories. What we would rather see is the story which recognizes that people with disabilities have a place in society that is equal to that of people without disabilities. When covering a story on housing or employment in WV, include people with disabilities as part of the story, rather than doing a separate story on them.

Media professionals are in a unique position to include people with disabilities in our communities and lessen the social gap that exists between people with and people without disabilities. By remembering to include them in mainstream stories rather than writing separate stories focusing on one individual with a disability, journalists will be able to report more accurately on the lives of people with disabilities and increase the acceptance of people with disabilities as a vital part of the community.

Introduction

As with most social issues, media coverage plays a crucial role in educating the general public about disability issues, and helps them form positive or negative perceptions about people with disabilities. Unfortunately, more often than not, the reporting done on disability issues perpetuates negative stereotypes and fails to tell the story accurately from the perspective of people with disabilities.

Media professionals seem to be stuck, using outdated methods to portray people with disabilities. Perhaps the most common portrayal is an inspirational human interest story in which the person with the disability “overcomes” the “plight” of their condition. Another common portrayal is the person with a disability who demands too much from society in the way of “special” accommodations to access businesses, health care or recreational opportunities in their communities. Finally, the scenario which casts people with disabilities in the role of a social menace is an all too common sight on the front pages of our community newspapers.

The one common thread in all of these popular media portrayals of people with disabilities is that they focus on isolated

stories about individuals, without connecting them to larger social and political issues. Focusing on an individual's adversity rather than political and social issues does not expose the fact that the individual's adversity is largely due to societal attitudes and practices. Since we, as a society, are becoming increasingly reliant on the media to shape our view of reality, we are not able to see that what these individuals face are not isolated cases, but rather a result of social injustice and a violation of the civil rights of a significant portion of our society. Media coverage does little to show how the adversity could be greatly eased by an enlightened society which takes the accessibility needs of all individuals into consideration without considering it "special" treatment, but rather equal opportunity.

Another commonly noted problem in reporting on disability issues is a lack of sources who can speak with an informed and authentic voice of experience. Reporters often talk with service providers or organizations run by people without disabilities, but rarely go to advocacy organizations run by, or in cooperation with Boards comprised of self-advocates and others with disabilities. This furthers the public perception that people with disabilities are like perpetual children who are not able to speak for themselves and advocate for what is best for them and for people with disabilities as a whole.

It is not surprising that media professionals, just like the vast majority of the general public, fall prey to the negative stereotypes about people with disabilities. After all, we are all a product of our society. The reality that media professionals must accept, however, is that they, more so than any individual citizen, are part of a powerful vehicle for social change. They have the power to perpetuate or shatter harmful myths and stereotypes. They must make a conscious decision to use their power to reflect the reality that disability is a natural part of life and it is the barriers erected by society that are the problem, not the people who face them.

Part One

WV Disability Facts and Figures

According to the 2000 Census reports, West Virginia is the 9th smallest state in the United States with an estimated population of 1,810,354. It has the lowest median income (\$31,000) among the states. It ranks 3rd overall in the percentage of the population living below the federal poverty level. It has the 4th highest percentage of people age 65 years and older. It ranks 49th nationally in the percentage of children living in families where no parent has a full time job, and 47th nationally in the percentage of children living in poverty. Approximately 45% of West Virginians are eligible to receive publicly funded health or social services.

WV has one of the highest percentages (23.5%) of citizens with disabilities in the country according to the 2000 Census which defined disability as a long lasting physical, mental or emotional condition that inhibits a person's ability to perform ordinary functions such as walking, bathing, learning, and remembering. That is almost 21 times the number of people it would take to fill the main arena of Madison Square Gardens. It is approximately 8 times the total population of Charleston, WV.

It is estimated that 32,524 of West Virginia's citizens have

developmental disabilities, which is enough people to fill the Joan C. Edwards Stadium at Marshall University to near capacity. WV has one of highest rates (19%) of children enrolled in special education, and at least 18,000 families in WV are caring for a person with a developmental disability in their homes. National incidence figures indicate that at least 25% (4,500) families need on going support and services.

There are several major factors which are thought to contribute to the increased rate of disability in WV. One of the biggest contributing factors is age. Approximately 3 out of 4 people over age 80 have a significant functional limitation. Poverty is another major concern. Studies show a significant increase in the rates of childhood disability attributable to children living in poverty. Finally, the lack of accessibility to quality health care, particularly prenatal health care and nutrition education for expectant mothers, greatly impacts the risk of developmental delays and related conditions.

People living with disabilities in the Mountain State are at a considerable disadvantage compared to their non-disabled peers. Less than 30% of working age individuals with disabilities are employed full time. Three times as many people with disabilities live in poverty compared to people without disabilities. People with disabilities are twice as likely to drop out of school and lack access to reliable transportation. Less than 35% of people with disabilities in WV report feeling satisfied with their quality of life.

National sources for information on disability statistics:

Administration on DD (DD Act) - www.acf.dhhs.gov/programs/add
Center for Mental Health Services (CMHS) - www.mentalhealth.samhsa.gov/cmhs/
Centers for Disease Control/National Center on Birth Defects and
Developmental Disabilities - www.cdc.gov/ncbddd/dd
MR/DD Data Brief/University of Minnesota, The College of Education &
Human Development, Research and Training Center -
<http://rtc.umn.edu/nhis>
National Center on Outcomes Research (NCOR) - www.thecouncil.org
National Organization on Disabilities Statistics - www.nod.org/stats
Substance Abuse and Mental Health Services Administration (SAMHSA) -
www.samhsa.gov/index.aspx
US Census Bureau- www.census.gov

The Basics of Disability Law

In the last four decades, we have seen the creation of groups to study the needs and shortcomings of the social service system. We have seen the enactment of ground breaking legislation at the state and national level to help assure access to equal rights and privileges to people with disabilities. Just having the laws on the books is not enough, however. Self-advocates and disability advocates, as part of the Disability and Independent Living Movements, are now fighting for the full implementation of legislation and court decisions. Until they are fully implemented, people with disabilities will continue to experience social discrimination and prejudice.

National Legislation, Court Decisions, Executive Orders and Initiatives

Social Security Act Amendments (1965) - Authorized health insurance benefits for eligible elderly individuals or eligible individuals with disabilities. “Part A” reimburses hospitals and other covered entities. “Part B” provides supplemental medical insurance benefits. Title XIX authorized grants-in-aid to the states for the establishment of

a medical assistance program to improve the accessibility and quality of medical care for individuals with low income.

Architectural Barriers Act (1968) - Legislation requiring buildings and facilities which are designed, built or leased with the use of federal funds to comply with federal standards for accessibility.

Developmental Disabilities Assistance and Bill of Rights Act (1970 - revised 2000) - Legislation which first came into law in 1970. It provided the first functional definition of developmental disabilities and the funding to support people who want to live in their communities. It describes the right of self-determination and the right to be free from abuse and exploitation. It provides guidelines for federally funded programs to provide high quality supports to people with developmental disabilities and their families.

Rehabilitation Act (1973) - Legislation first created to prohibit discrimination on the basis of disability in federal programs or programs receiving federal funding. The Act has been amended many times since its inception.

Section 105 - Created consumer directed and controlled State Rehabilitation Councils to advise and assist the WV Division of Rehabilitation Services (DRS) in preparing the State Plan for Vocational Services.

Section 501 - Requires affirmative action and prohibits discrimination by federal agencies of the executive branch.

Section 504 - States that no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under any program or activity that receives federal funding.

Section 508 - Requires electronic and information technology created by federal agencies be accessible to people with disabilities.

Section 701 - Promotes a philosophy of independent living, including consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy. It provided states with funding to improve

independent living services, and develop statewide networks of Centers for Independent Living

Section 705 - Created consumer directed and controlled Statewide Independent Living Councils to advocate for, plan and monitor state independent living services.

Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) (1986) - Legislation which expanded the scope of the state Protection and Advocacy agencies to cover mental illnesses. It protects the statutory and constitutional rights of people with serious mental illness who are in a treatment facility and/or residential program. It was expanded in 2000 to include people with significant mental illnesses who live in the community.

Air Carrier Access Act (1986) - Legislation which prohibits discrimination against qualified individuals with disabilities by domestic and foreign airlines. It only applies to airlines that provide regularly scheduled services to the public. It addresses a wide range of issues including boarding assistance and some accessibility features in newly built aircraft and new or remodeled airports.

Fair Housing Act (1988) - Prohibits housing discrimination on the basis of race, color, religion, gender, disability, familial status and national origin. Coverage includes private housing, housing that receives federal funding, and state and local government housing.

Americans With Disabilities Act (ADA) (1990) - Civil rights law that prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, public services, transportation and telecommunications. The ADA mandates that “reasonable accommodations” must be made to assist people with disabilities. Reasonable accommodations may include making buildings and public transportation accessible to people in wheelchairs, providing assistive technology and equipment, and providing modified work schedules if needed.

National Voter Registration Act (1993) - Also known as the “Motor Voter Act.” Legislation which makes it easier for everyone to exercise their right to vote. Created to increase low registration rates of minorities and persons with disabilities as a result of discrimination. Requires all state funded programs providing services to people with disabilities to provide program participants with voter registration forms, assist them in filling them out, and submit the forms to the appropriate State agency.

Mental Health Parity Act (1996) - This legislation attempts to end the long-held practice of providing less insurance coverage for mental illnesses and brain disorders than is provided for equally serious medical conditions. The Act does not require group insurance providers to offer coverage for mental health services.

Individuals with Disabilities Education Act (IDEA) (1997) - This Act requires the public school systems to develop appropriate Individualized Education Programs (IEP’s) for each child. The IEP must include a description of the education and related services needed by the child. It must be developed by a team of knowledgeable individuals, including the child’s parents, and it must be reviewed annually. IDEA is an amendment of PL 94-142 (1975), The Education of All Handicapped Children Act.

Olmstead Decision (1999) - U.S. Supreme Court decision for the civil rights of people who have disabilities and their right to receive community integrated services and supports. State Olmstead plans are created to assist people with disabilities in nursing homes and other facility based, long-term care institutions to understand their right to live in inclusive, community-based settings.

Ticket to Work and Work Incentives Improvement Act (1999) - Created to assure that people with disabilities no longer have to choose between having access to health coverage and working in the competitive job market. It provides employment preparation and placement services to individuals with disabilities to enable them to: reduce their dependence on cash benefit programs; encourage states

to adopt Medicaid Buy-In programs; and establish a return to work ticket program that will allow people with disabilities to obtain the services necessary to retain employment.

New Freedom Initiative (2001) - A comprehensive national plan to help assure that people with disabilities have the opportunity to live and work in their communities, make choices about their daily lives and participate fully in the life of their community. The goals of the Initiative are to: increase access to assistive technology; expand educational opportunities; promote homeownership; integrate people with disabilities into the competitive workforce; expand accessible transportation; and promote full access to community life. The Initiative led to the creation of the New Freedom Commission on Mental Health which is designed to improve America's mental health service delivery system for individuals with mental illness and children with serious emotional disturbances.

Community-Based Alternatives for Individuals with Disabilities Executive Order 13217 (2001) - Order which called for the Federal government agencies to evaluate policies, programs, statutes and regulations to determine necessary revisions to improve availability of community based services for qualified individuals with disabilities. The Order recognized that community based services for individuals "advance the best interests of the United States."

Help America Vote Act (HAVA/2002) - Legislation which requires states to meet new federal accessibility requirements for polling places and voting machines. In order to receive federal funds to improve the administration of elections, each state must design a plan which includes citizen participation to make voting accessible to all citizens.

West Virginia Court Decisions

West Virginia has been moving toward full implementation of community based supports for people with disabilities since the initiation of class action suits beginning in the early 1980's. Two court orders, Hartley and Medley, were the catalysts for much of this progress. These court orders mandated the closure or downsizing of State institutions. They called for the strengthening of the rights and safeguards for people with developmental disabilities, mental illnesses and substance abuse disorders, and expanded community based services and supports.

Hartley, [E.H. v. Matin (1981)]: The suit was filed in the State Supreme Court alleging that WV was violating the rights of patients in psychiatric hospitals. The Court found that patients were not receiving appropriate therapeutic treatment and were living in inhumane conditions. It led to the development of the “*West Virginia Behavioral Health Care Delivery System Plan,*” and provided protections for people with mental illnesses, developmental disabilities and substance abuse disorders. The Order included the creation of “patient rights” policies, grievance procedures, advocacy services, policies related to health and safety, treatment planning, staff responsibilities and training, case management, and safeguards against the development of additional institutional programs.

Medley, [Macel Medley, et al v. Leon Ginsberg, et al (1981)]: Federal suit filed on behalf of WV school aged children with mental retardation who were institutionalized. The Order mandated the development of a plan to de-institutionalize State facilities specific to developmental disabilities. It mandated the development of a statewide plan to develop community based services, including individualized program planning, case management, advocacy services and other protections.

Benjamin H. (1998) - A class action federal lawsuit that requires the WV Department of Health and Human Resources to work to resolve the waiting lists for people with developmental disabilities determined eligible for the Medicaid Home and Community Based MR/DD Waiver program.

What Disability Is...

So, what is a disability? There is no real, universally-accepted definition. Even in federal legislation, the definition differs from Code to Code. This is because the label of “disability” is not one-size-fits-all. In reality, “disability” is a limitation in a person’s ability to perform an activity considered typical for her/his age and general circumstance. Disability labels are social constructs often used to delineate who is eligible for accommodations, services and supports that people need to live and work in the communities of their choice.

The *Developmental Disabilities Assistance and Bill of Rights Act* states that “Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society and experience full integration and inclusion in the economic, political, social, cultural and educational mainstream of American Society.” While this Act is written to encompass only those with a developmental disability, the truthfulness of its statement extends to everyone with a disability.

If we lived in a society which provided the individual accommodations we all need, and was free of barriers, either architectural or social, there would be no need to define anyone as having a disability.

Federal Statutory Definitions of Disability

<p>Developmental Disabilities Assistance and Bill of Rights Act (www.acf.dhhs.gov/programs/add/DDACT2.htm)</p>	<p>A severe, chronic disability of an individual 5 years of age or older that:</p> <ul style="list-style-type: none"> (a) is attributable to a mental or physical impairment or combination of the two; (b) is manifested before age 22; (c) is likely to continue indefinitely; (d) results in substantial limitations in 3 or more major life activities: <ul style="list-style-type: none"> (i) self care; (ii) language; (iii) learning; (iv) mobility; (v) self direction; (vi) independent living (vii) economic self sufficiency (e) reflects the individual’s need for long-term, individualized supports. <p>The term “developmental delay” may also be applied to infants and children through age 5 who experience significant delay or specific condition with a high probability that it will result in a developmental disability if services are not provided.</p>
<p>Americans with Disabilities Act of 1990 (www.usdoj.gov/crt/ada/adahom1.htm)</p>	<ul style="list-style-type: none"> (a) a physical or mental impairment that substantially limits 1 or more of the major life activities of the individual; (b) a record of such an impairment; or (c) being regarded as having such an impairment <p>The term “qualified individual with a disability” means an individual with a</p>

	<p>disability who, with or without reasonable modifications to rules, policies or practices, the removal of architectural, communication or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or participation in programs or activities which are provided by a public entity.</p>
<p>Individuals with Disabilities Education Act (IDEA) www.ed.gov/offices/OSERS/Policy/IDEA/index.html</p>	<p>In general, the term “child with a disability” means a child:</p> <ul style="list-style-type: none"> (i) with mental retardation, hearing impairments, language impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities and (ii) who, by reason thereof, needs special education and related services.
<p>Rehabilitation Act of 1973 www.dol.gov/oasam/regs/statutes/sec504.htm</p>	<p>The term “disability” means a physical or mental impairment that constitutes or results in substantial impediment to employment.</p>
<p>Assistive Technology Act of 1998 www.section508.gov/docs/AT1998.html</p>	<p>The term “individual with a disability” means any individual of any age, race, or ethnicity -</p> <ul style="list-style-type: none"> (i) who has a disability; and (ii) who is or would be enabled by an assistive technology device or assistive technology service to minimize deterioration in functioning, to maintain a level of functioning, or to achieve a greater level of functioning in any major life area.

And Is Not...

Perhaps more important than what disability is, is what it is not. It is important to realize that neither a person's disability nor a label can define a person. A disability simply means that some part of a person's body works differently. It has nothing to do with their hopes, dreams, or values. Those are the qualities that define the person.

Disability is not an abnormality that needs to be medically treated or "fixed" before the person can live a full and productive life. If a person's life seems atypical, it is because they must adapt their life to the services and supports they receive, rather than having the services and supports which would naturally support the life goals and visions of the person. In many cases, people who have disabilities are forced to relinquish their rights of citizenship for the role of "client" so that they can receive the services and supports they need from the educational, health and social service systems.

Frequently, people with disabilities are introduced as if their disability defines who they are, much like a person who uses their occupational title in conjunction with their name. It is not uncommon to hear "This is Joe, he has cerebral palsy," or "This is my daughter, Mary. She has autism." We may see an interview in the newspaper in which a person is defined as "disabled" when their non-disabled peers carry titles like "housewife," "laborer," or "student." In most cases, it is unnecessary to include the disability. It leads the reader to think of the person as having a lower social status.

Finally, living with a disability is not a sentence to a life fraught with misery and pain. Those are ideas which often get projected onto people with disabilities by non-disabled individuals because of misunderstanding or fear. People with disabilities live happy, full and meaningful lives. They do not need pity from anyone, and more importantly, they don't want it. They want to be treated with the same respect, have the same rights, and experience the same challenges that people without disabilities enjoy.

A Brief History of the Disability Rights Movement

The history of the Disability Rights Movement is closely tied to the Civil Rights Movement of the 1960's. The principles for both movements combat the disgraceful treatment of people based on social prejudice and discrimination in housing, education and employment. The movement is based on the philosophy which says that people with disabilities should have the same civil rights and control over their own lives that people without disabilities have.

Renowned journalist, Joseph Shapiro wrote an excellent account of the disability movement entitled *No Pity*. He includes important personalities which helped shape the movement, as well as detailed discussions about the most important social and political issues surrounding the movement.

The first wave of this movement was deinstitutionalization. The objective was to move people from large institutions back to their communities and provide community based services. This movement was led primarily by parents of people with disabilities who were living in the most inhumane conditions of America's institutions. Although the deinstitutionalization process was a slow process across the nation, WV was actually a leader in this movement. WV's deinstitutionalization process closed all State operated facilities for persons with developmental disabilities, and significantly downsized State operated psychiatric facilities. This process began in the early 1980's with the filing of class action litigation on behalf of people with mental illness, and was not completed until 1998 with the closure of the Colin Anderson Center.

In the late 1960's and early 1970's, people with disabilities and parents of children with disabilities began to fight against

exclusion and segregation. Small groups began organizing themselves to advocate for the rights of people with disabilities. They used tactics used by other civil rights activists. They sat in federal buildings across the country, obstructed the movement of inaccessible buses, and marched through the streets of big cities and small towns to protest injustice. They challenged the notion that people with disabilities needed to be institutionalized, and they fought for services for people with disabilities to live in the community.

In 1973, Section 504 of the Rehabilitation Act was passed. It banned discrimination on the basis of disability by entities receiving federal funds. It was modeled after previous laws which banned discrimination on the basis of race, ethnic origin and gender.

In 1975, Public Law 94 142, the Education for All Handicapped Children's Act was passed. It was a landmark special education law that mandated that children with disabilities be provided a "free, appropriate public education in the least restrictive environment." Before its passage, many children with disabilities were served in institutional or other segregated schools, buildings and classes. Many never received education services at all.

In 1978, ADAPT began organizing the disability community as a whole. Using civil disobedience and other non-violent acts of protest modeled after those used by Dr. Martin Luther King, Jr., members of ADAPT marched repeatedly on Washington D.C. and other cities and towns across the U.S. to challenge societal barriers that excluded them from their communities. For the first time in U.S. history, people with disabilities from all across our nation were demanding to be heard.

Due to social activism by people with disabilities and others, the Americans with Disabilities Act was signed into law on July 26, 1990. The law provides comprehensive civil rights protection for people with disabilities.

Disability rights activists across the nation are still fighting for full implementation of the ADA and similar civil rights legislation. The fight is still largely at the grass roots level, in the communities where people with disabilities want to live and work, just like everyone else.

Who Are Society's Vulnerable Populations?

Any group of people which is considered to be significantly different in some way from what society considers to be “normal” is vulnerable to social discrimination and oppression.

When a group becomes vulnerable in society, everything that is communicated about them becomes vitally important. Every aspect of communication, from the way we interact personally with an individual to what is put forth in the media about the group, serves to either improve or decrease public perception of the group as a whole.

In our society, the media plays an important role in creating our perceptions of reality. As a society, we tend to believe what we see on television, read in the newspapers, or hear on the radio. This places a great responsibility on the shoulders of journalists. Because of the hectic schedules and short deadlines faced by journalists, it is often easier to rely on stereotypical portrayals of vulnerable individuals. There is also an established precedent for using these types of portrayals that often goes unchallenged. These depictions provide a set framework, and all the journalist has to do is fill in the blanks. The negative effect of using stereotypes when reporting about people who are vulnerable (including those with disabilities) is that stereotypes misinform the public and inhibit individuals from successfully living and working in their communities.

Groups Which Typically Experience Social Discrimination and Prejudice

1. People who have physical or mental disorders . Historically referred to as “impairments” or “handicaps.”
2. People who have unorthodox behavior or conduct.
 - People who are excessively active, such as someone with attention deficit/hyperactivity disorder.
 - People who are excessively inactive, such as someone who has a severe physical disability or someone with some type of depressive disorder.
 - People who have self-destructive behaviors such as a substance abuse problem.
3. People who have body characteristics which are negatively perceived by society.
 - Someone with physical difference such as an artificial limb or visible disability.
 - Someone considered to be obese.
4. People who live at or below the poverty level.
5. People who have few of the typical valued skills.
 - People who can’t read.
 - People who don’t have the necessary skills to compete in a competitive job market.
6. People who are unassimilated into the culture.
 - People whose race or ethnic affiliation is different from the cultural norm.
 - People who belong to a religious minority.
 - People for whom English is a second language.
 - Illegal immigrants/laborers or immigrants from groups which traditionally experience social discrimination.

Typical Negative Life Experiences of Individuals Who Experience Social Discrimination

- Being rejected or ridiculed by society, family, and community.
- Experiencing more than one socially vulnerable role in society. For example, someone who has a disability may experience additional discrimination because they are poor.
- Experiencing stigmatization because of labels.
- Being subjected to threats and/or vulnerabilities.
- Being segregated from others.
- Having little or no choice over one's life and/or personal freedoms.
- Experiencing separation from one's family, friends, home, community and/or personal possessions.
- Experiencing dehumanization.
- Involuntary poverty or economic exploitation.
- Being defined as a "Client" or a "Consumer."
- Being denied the right to seek employment or participation in social activities within the community.
- Loss of individual history and identity.
- Heightened awareness of being considered a social and family "burden."
- Experience "life wasting" activities in segregated settings.

Part Two

People First Language

There are many social barriers to full community inclusion for people with disabilities. One of the biggest barriers is our language. It is common in our society to either refer to a person with a disability as a “disabled person” or lump them into an all inclusive category called “the disabled.” This robs the person of their individuality and implies that they are the disability rather than what they really are - a person with a disability. They are people first.

People First Language is exactly what the name implies. It is language which places the focus on the person, not the disability. Often times, people mistake it as just being “politically correct,” and dismiss it. People First has nothing to do with political correctness. It is an attitude. It has to do with respect and dignity. It is a language that rejects labeling individuals. It is a language that recognizes that the individual is what is important, not the disability. No one would dare say that someone *is* “cancerous.” To say that would be to say that they are dangerous and deadly. It is an inaccurate term. Instead, we would say that the individual *has* cancer. Saying that someone is “disabled” is just as inaccurate. People with disabilities live full, rich and productive lives.

Acceptable Terms and Terms to Avoid

Avoid	Replace with
<p>Able-bodied - This term implies “us” vs. “them” since it excludes the majority of people with physical disabilities.</p>	<p>Person without a disability or non-disabled person.</p>
<p>Afflicted with - This term assumes that a person is prohibited from enjoying their life because of their disability. It is meant to elicit pity from the reader.</p>	<p>If it is necessary to the story, simply state the nature of the disability. For example, “David has cerebral palsy.”</p>
<p>Birth defect - The word “defect” or “defective” implies that there is something inherently wrong with the individual or they are somehow less than human.</p>	<p>“Congenital disability” is the preferred term. “Person born with a disability” is also acceptable.</p>
<p>Confined to a wheelchair - Wheelchairs give a person the freedom to live active and productive lives. If a person didn’t have a wheelchair, they would be confined.</p>	<p>Say that someone “uses a wheelchair” or is a “wheelchair user.” If the fact that someone uses a wheelchair isn’t directly related to the story content, it shouldn’t be mentioned at all.</p>
<p>Cripple or crippled - These are archaic terms which have</p>	

become derogatory and are frequently shortened to slang terms. They are offensive and should be avoided at all costs.

Deformed - Avoid using this term. It is offensive and implies that the individual is not fully human. Never say things like “She has severe facial deformities.”

Handicapped - This is an archaic term generally reserved for legislation and legal statutes. It should be avoided when writing about people with disabilities.

Invalid - This term should never be used to describe a person with a disability. It implies that the person has no abilities at all and is completely inactive. For the vast majority of people with disabilities, nothing could be further from the truth. Generally, this term is used to elicit pity.

Lunatic, looney/looney bin - These are slang terms and have no place in professional journalism. Sadly, on occasion, they find their way into news stories. They should be avoided at all costs.

Again, using “person with a physical disability” or “person with a disability” is preferred.

Consider if it is truly necessary to the story to mention specifics about someone’s disability. Generally speaking, it probably isn’t. Saying “she has a disability” is probably sufficient.

“Person with a disability” is preferred.

Consider why you would want to use this term. If you are writing an article meant to elicit pity for people with disabilities, consider changing the angle. People with disabilities do not want to be pitied.

Because of their position of influence, professional journalists should model the use of People First Language. Use “person with a mental illness” or “hospital.” If it is necessary to the story, you can use “psychiatric facility.”

Retarded - This is an outdated term and now carries derogatory meanings in our society.

Schizophrenic - Terms such as this focus primarily on the disability, not the person.

Stricken with or suffers from - These are terms which assume that the person with the disability has a reduced quality of life compared to a non-disabled person.

Vegetable/vegetative - Sadly, these terms are still used by media professionals. They are highly offensive and compare human beings to something that is not human. The general public comes to view people with disabilities, particularly those with profound disabilities, as being less than human.

Victim - Never say that a person is a “victim” of his or her disability. Disabilities are a natural part of the human experience and should be reported as such. People with disabilities live full and rich lives. Calling them victims is offensive and inaccurate.

“Person with cognitive disabilities” is the preferred term. “Person with mental retardation” is acceptable, but not preferred.

“Person with schizophrenia” or “person living with a mental illness” is preferred.

Use respectful and neutral terms like “person with a disability.” Never make assumptions about the quality of someone’s life. If it is important to the story, ask the person.

It is preferable to use precise medical terminology such as “comatose” or “non-responsive.” Depending on the situation, it may also be appropriate to say “profound disability.”

Simply say “person with a disability.” Again, do not try to elicit pity. People with disabilities do not want to be pitied.

Creating Positive Images

Because the media has a decisive role in helping people form perceptions about the world around them, it should be no surprise that the images media professionals put before the general public are powerful influential factors. Therefore, it is critical that media professionals recognize their responsibility to portray individuals in a truthful and honest light, free from stereotypes and social bias.

Media professionals, particularly photographers and videographers, need to realize that images always speak louder than words. They need to know the stereotypical representations of people with disabilities which are common in our society, and avoid those stereotypes at all costs (see page 25). They are not accurate representations of the lives of people with disabilities.

Society needs to realize that people with disabilities lead full, rich and meaningful lives in their communities. They are not perpetual children. They have the same interests, likes and dislikes that non-disabled people have. Unfortunately, we will never be able to come to that conclusion unless we are able to see coverage of people with disabilities living in our communities, participating in community events, and learning in community schools. Until we can see them taking part in the life of our community, we will never consider them part of our lives.

Positive Examples



Shows a man doing valued work in his community. Camera angle conveys a sense of equality with the viewer.



Picture with vibrant colors showing woman doing things she enjoys. Independence is focus of picture rather than dependence or disability.

Negative Examples



Portrays a sense of being “off-balance,” blue, isolated, depressed, alone, rejected. Lack of facial detail, gender recognition and silhouette appearance conveys a sense of not being fully human. Camera angle conveys a sense of inferiority to the viewer.



The children’s cake, staff person cutting it, and the non-involvement of individual with a disability in his birthday party reinforces the stereotype that people with disabilities aren’t “capable” of exercising choice or participation in their lives

Image Checklist

- √ Are the images you chose of good quality and in focus?
- √ Are they shot from a traditional and flattering point of view?
- √ Do the images provide a fair, accurate and respectful portrayal of the individual?
- √ Does the image portray the individual as independent?
- √ Is he/she making his/her own choices?
- √ Are the individuals in socially valued roles?
- √ Are they working/living/learning in inclusive environments with their non-disabled peers?
- √ Is he/she making his/her own choices?
- √ Are you sure that the images do not inadvertently support negative stereotypes?
- √ Is the image cropped so that unimportant or potentially negative items are not visible or the center of the photograph?
- √ Have you portrayed this individual in an accurate and respectful manner?
- √ Is the person portrayed in a way that is age and culturally appropriate?
- √ Will the use of the person's image possibly subject them to ridicule or victimization?

Recognizing and Avoiding Common Stereotypes

Stereotypes are standardized, oversimplified conceptions of a specific group of people, places or objects. They function much like cookie cutters in that they apply limited and generalized characteristics to a broad population without regard to individuality.

Stereotyping is a natural function of the human mind. We process information by grouping and classifying it. When stereotypes are used to refer to individuals who comprise society's vulnerable populations however, they can be dangerous, particularly when they are applied to individuals who rely on the social services system for support. There are several common stereotypes about people with disabilities present in our society, and they are not fair or accurate.

Stereotypes pose a unique problem for media professionals. They are so prevalent in our society that we naturally accept them to be true, and contradictory evidence is often dismissed as an exception. We hear stereotypes used by those we consider to be "experts" in the field. We see them in practice by agencies serving people with disabilities. The key to helping combat these erroneous perceptions is to learn to recognize them and then look past them in search of the truth.

The harsh reality is that far too many individuals with disabilities live in poor conditions because of societal practices that demean people, and reporters cannot rewrite people's current reality. They can, however, help to combat stereotypes in a very significant and powerful way by avoiding oversimplified and inaccurate representations, such as saying that someone has the mind of a 5 year old. By rejecting these long-held misconceptions, reporters can help reshape how we, as a society, view people with disabilities.

Recognizing Common Stereotypes About People With Disabilities In Our Society

People with Disabilities as Perpetual Children

- Encouraging age inappropriate interests, hobbies, possessions or dress.
- Locating services for adults next to services for children.
- Encouraging the perception of lowered competence.
- Encouraging the acceptance of childlike roles, means of expression or language.
- Using age inappropriate or degrading forms of personal reference, such as “sweetie” or “baby” or using a patronizing voice when addressing someone.
- Using age inappropriate personal contact such as a pat on the head or other forms of contact generally reserved for children.

People with Disabilities as Sick or Medically Fragile

- Treating non-medical concepts with medical terms: e.g. “bathing therapy.”
- Using hospital schedules, shift changes and having “visiting hours.”
- Using nurses or other medical professionals to administer medicines.
- Interpreting ordinary problems or challenges as attributes of an illness: e.g. a person who has a mental illness is angry about something and the anger is viewed as a manifestation of the mental illness, rather than a genuine human response.
- Facility design, appearance or history is medical in nature.
- Labeling non-medical programs or services with medically charged names: e.g. “mental health clinic” or “nursing home.”

People with Disabilities as an Object

- Facility design or history as a warehouse.

- Language which objectifies individuals such as “cases,” “beds” or “slots.”
- Speaking about someone in their presence as if they were not there.
- Referring to individuals by their disability or mental illness or condition, such as “MRs,” “the poor,” or “bipolars.”
- Reimbursement policies that cast people in consumer roles.

People with Disabilities as an Object of Pity

- Donation plaques on walls, personal belongings, doors.
- Signs, plaques, logos, etc. declaring “service is funded by . . .”
- Images associated with recycled goods.
- Grossly underpaying workers with disabilities or mental illness.
- Agency names which suggest pity or charity.
- Use of “poster children.”
- Referring to people as “victims” of a condition or as “suffering” from a disability.

People with Disabilities as Not Fully Human

- Denial of human dignity, such as no privacy for toileting, mass showers, etc.
- Use of easy to clean or soil proof furniture and bedding, and drains in the floors.
- Lack of support or encouragement of proper grooming, bathing, personal hygiene.
- Bathrooms and other areas for exclusive use by staff.
- External control of lights, temperature, and access.
- Use of animal names for people, conditions or programs.
- Talking about individuals in their presence as if they were not there.

People with Disabilities as an Object of Ridicule

- Clown or circus imagery in or around facility.

- Use of clowns for fundraising or entertainment.
- Displaying people to satisfy curiosity.
- Encouraging or teaching bizarre or inappropriate behaviors for entertainment or ridicule.
- Dressing individuals to look like clowns or hobos.
- Failure to provide support and encouragement to eliminate devalued mannerisms.

People with Disabilities as a Menace

- Use of external control devices. E.g. locks on doors, security monitors, one way mirrors.
- Bars on windows, security stations, seclusion rooms, prison imagery.
- Signs which cause alarm: e.g. “Caution Handicapped,” or “No Firearms.”
- Located adjacent to or in close proximity to a detention center.
- Dressing individuals as prisoners.
- Absence of private space for individuals.



Part Three

Interviewing People with Disabilities

Before the Interview:

When setting up an interview with a person with a disability:

Ask the person if they need specific accommodations:

- a specific location
- parking needs
- a location that is wheelchair accessible
- an interpreter
- assistive technology

Allow extra time for the interview. Some individuals will have needs that require extra time, such as interpreters or communication devices. It may also take some individuals longer to articulate what they want to say.

Make sure that you both have a very clear understanding of where and when you will meet. It may also be helpful if you give the individual clear guidelines about what you want to discuss with them.

Finding an Accessible Location

Things to look for:

Is there ample accessible parking available within easy walking distance from your interview location? Remember, individuals who have ramp equipped vans may require more space on the passenger side or in the rear of the vehicle.

Does the location have curb cuts on the sidewalks, automatic doors and a ramp or lift if the entrance is not step free?

Is there an elevator if the interview is not on the first floor?

Are the rest rooms accessible?

Are the water fountains low enough for wheelchair use or is there other access to water?

Is there a public telephone low enough for wheelchair use or have you made arrangements so that the person can make a phone call if needed?

The Interview: General Etiquette

When interviewing a person with a disability:

Talk directly to the person, not to his or her interpreter or personal assistant. These individuals may assist the person with a disability to communicate, but they will not communicate for them. People with disabilities can and do speak for themselves.

When you meet a person with a disability, it is appropriate to offer to shake hands. Even individuals who appear to have limited use of their arms or have prosthetic devices will generally shake hands.

If you feel that you can assist the person in some way, ask if they would like your help first, and wait for an answer. Don't assume that they want your help with something and understand if they say they would rather do it for themselves.

Be patient, particularly if the person has a speech difficulty. Don't finish their sentences for them or pretend that you understood something that you didn't. People who have difficulty with speech know that it is sometimes hard for people to understand what they are saying. Most are willing to repeat things as many times as necessary.

Relax and be yourself. Don't construct a special repertoire of "politically correct" phrases for the occasion, and don't be embarrassed if you use common expressions such as "let's take a walk" to someone who uses a wheelchair or "see you later" to someone who is blind.

Don't be afraid to ask questions if you are unsure about something. People will appreciate your taking the time to ask a question about what would be best.

The Interview: People with Physical Disabilities

When interviewing someone with a physical disability:

Don't lean on a person's wheelchair. The wheelchair is part of that person's personal space. It would be comparable to leaning on someone's shoulder or standing with your arm around them during an interview. Most people consider it annoying and unprofessional.

Place yourself at the same level as the individual. Standing over the person will communicate a feeling of superiority and it may be physically uncomfortable for both of you.

The Interview: People with Visual and Hearing Disabilities

When interviewing someone with a visual disability:

Always identify yourself and anyone else who is present. Let the person know if you leave the room.

When you first meet, give them a verbal cue that you would like to shake hands by saying “May I shake your hand?”

If a service animal is present, remember that the animal is working. Don’t distract it by petting it or playing with it.

If you need to assist someone in moving from one place to another, ask them how you can best assist them. Generally, they will ask you to stand on their left and they will gently hold on to your right arm just above the elbow. Never grab on to a person.

When offering a person a place to sit, show the person where the back or arm of the chair is.

When interviewing someone with a hearing disability:

Attract the person’s attention by gently tapping their shoulder or waving.

Always face the person, don’t conceal your mouth with anything, and don’t chew gum or smoke during the interview. These things will inhibit the individual’s ability to read lips.

Make sure you are not sitting in front of a window or a light source. Backlighting will make it difficult for the person if they read lips.

If someone tells you they have partial hearing loss, ask them where it would be best for you to sit.

Part Four

Glossary of Terms and Acronyms

A

AAMR - American Association on Mental Retardation. National and international organization that promotes public policy change, research and rights assurances for people with mental retardation and other disabilities.

ABS - Adaptive Behavior Scale. An assessment tool used to identify persons who may need specialized supports for behavior intervention and/or activities of daily living.

ADA - Americans with Disabilities Act. Landmark 1990 civil rights legislation protecting people with disabilities against discrimination in employment, accessing public services, transportation, private business and telecommunications.

ADD - Administration on Developmental Disabilities. Federal agency in Department of Health and Human Services charged to administer the DD Assistance & Bill of Rights Act.

ADHD – Attention Deficit Hyperactivity Disorder – Condition or syndrome expressed by inappropriate inattention and impulsivity and general excessive physical activity. Condition can result in learning disorders.

ADL - Activities of Daily Living. Daily self-care activities including eating, dressing, bathing, and toileting.

A/D Waiver - Aged and Disabled Waiver (Medicaid). Medicaid program that provides in-home health related services for persons over age 18 who are determined eligible for nursing facility care.

APA - American Psychological Association. Scientific and professional organization with the purpose to advance psychology as a profession and means of promoting health and human welfare.

APD - Advanced Psychiatric Directive. Legal document developed in advance of involuntary psychiatric commitment that expresses one's choices about treatment.

APSE - Association for Persons in Supported Employment. National organization with WV Chapter that seeks to improve and expand integrated employment opportunities, services and outcomes for persons with severe disabilities.

ASL - American Sign language. Considered the native language and primary source of communication by many in the deaf community. It is a complex visual-spatial hand gesture language system.

AT - Assistive Technology. An item, piece of equipment, or product system used to increase, maintain or improve the functional capabilities of children or adults with disabilities.

Autism – Developmental disability, found mostly in males, characterized by withdrawal from people, repetitive behaviors, and impaired communication.

B

BIA WV - Brain Injury Association of WV. Non-profit agency dedicated to providing support, advocacy, education and training on behalf of survivors of brain injuries and their families.

BHHF – WV Bureau of Behavioral Health and Health Facilities. State agency within the Department of Health and Human Resources with a mission to provide services to persons with mental illness, chemical dependency, developmental disabilities and those at-risk.

BOSS – WV Bureau of Senior Services. Cabinet-level agency within State government that acts as the lead entity for programs serving older West Virginians.

BMS - Bureau for Medical Services. Fiscal agent for the Federal Centers for Medicare and Medicaid Services located within the WV Department of Health and Human Resources.

BTT – WV Birth to Three. Program within the Office of Maternal, Child and Family Health that provides services and supports to eligible children and their families. The BTT program aims to provide a coordinated system of supports focused on meeting the developmental needs of infants and toddlers with special needs.

C

CAP - Client Assistance Program. Federal designated advocacy program implemented by the Protection and Advocacy programs (WV Advocates) that assists people who encounter problems with services at the Division of Rehabilitation Services.

CCMHA - Comprehensive Children's Mental Health Act.

Legislation requiring the development of a family and child focused children's mental health system of supports.

CC R&R - Child Care Resource and Referral Agency. Administered by the WV Bureau for Children and Families. Network of local non-profit organizations that provide families with information about funding, child care options and other community resources.

Cerebral Palsy - A condition caused by damage to the central nervous system before, during, or within two years of birth. The disorder is non-progressive and results in various types and degrees of muscle weakness, muscle tone imbalance, and decrease in coordination.

Child Advocate - A parent or professional, paid or unpaid, to protect the rights and interests of a child and their family, and ensure access to eligible services is available.

Child Find - A state and local program mandated by the Individuals with Disabilities Act to identify children with or at risk of developmental delay and refer them to appropriate early intervention services.

Children's Speciality Care Service - A federal and state program that provides direct services to income eligible children less than 21 years of age with certain disabilities or chronic health conditions. CSC holds regular clinics at several locations across the state.

Children with Disabilities Community Services Program - A federal and state Medicaid program that allows a medically eligible child with a severe disability to receive a West Virginia medical card when his/her parents income exceed the limits for SSI.

CIL - Center for Independent Living. A national disabilities rights

program mandated by federal legislation which seeks to affect positive systems change on behalf of persons with disabilities. Independent living centers provide information/referral, advocacy, independent living skills training, and peer counseling.

CMS – Centers for Medicare and Medicaid Services (previously HCFA). Federal agency with the U.S. DHHS that administers the following: Medicare, Medicaid, State Children’s Health Insurance Program (SCHIP), HIPAA (Health Insurance Portability and Accountability Act) and CLIA (Clinical Laboratory Improvement Amendments).

Cognitive Disabilities – Disabilities which effect problem solving, learning and use of language.

Communication Board or Device - An augmentative communication device consisting of a board on which letters, objects, and/or actions are represented.

Congenital - Referring to a condition present at birth that may be hereditary, may be the result of a problem during pregnancy, or may occur due to injury to the fetus prior to the time of birth.

CON - Certificate of Need. Managed by the WV Healthcare Authority, CON was established in State code as a means of controlling the expansion of facilities and services to fit the need for such services.

D

Deafness - A partial or complete loss of hearing.

Developmental Delay - A condition marked by a difference between a child’s actual development and the expected age of reaching developmental milestones.

Developmental Disability – A long term physical and/or mental disability that occurs before a person reaches the age of 22 and that results in substantial limitations in at least three of the following areas: self-care, language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

Developmentally Appropriate Practice - An educational program based on age-appropriate, developmental, and individual needs of each child, emphasizing learning as an interactive process.

Developmental Milestones - Skills that are recognized as a measurement of a child’s functioning or development, and that are typically achieved at a certain age.

Disability - A limitation in a person's ability to perform an activity considered typical for her/his age and general circumstance.

Down Syndrome - A chromosomal disorder that results in variable degrees of developmental delay, medical problems, and cognitive disabilities.

DHHS - Department of Health and Human Services (Federal). The U.S. Government's principal agency for protecting the health of its citizens and providing essential social services, especially for those least able to help themselves.

DHHR - Department of Health and Human Resources (WV). State agency charged with administering public health programs and social services.

DOE - Department of Education (WV) – State agency charged with administering and monitoring state and federal education programs and policies.

DRS - Division of Rehabilitation Services (WV). State agency that provides vocational and medical assessment services to people with disabilities and supports them in working and living independently.

E

Early Intervention – Applies to children of school age or younger, who have or are at risk of developing a disability or other special need that may affect their development. Early intervention services in WV are provided by the WV Office of Maternal and Child Health, including the Birth to Three Program.

EBD - Emotional or Behavioral Disorder. Condition characterized by mild to severe disruptive/acting out behaviors that are evident and persistent in different settings and environments.

EMS-TSN - Emergency Medical Services - Technical Support Network (Medley/Hartley Advocacy). WV non-profit corporation that oversees statewide delivery of emergency medical services and administers the Medley/Hartley Advocacy Program under contract with the Office of Behavioral Health Services.

Epilepsy - A condition characterized by recurrent seizures caused by abnormal electric activity in the brain.

F

Family Support Services - A statewide program that provides supports for the family to improve quality of life and care for an individual with a developmental disability in their home.

FAS - Fetal Alcohol Syndrome. A severe and definitive cluster of developmental difficulties arising from fetal exposure to alcohol. Can include delayed developmental milestones, moderate to severe cognitive disabilities, inappropriate social behavior, and behavioral issues.

FERPA - Family Educational Rights and Privacy Act. Entitles the parent to confidentiality of information, the ability to review and request amendments to the child's early intervention record, and the right to manage the release and receipt of information through informed written consent.

FSN - Fair Shake Network. A cross-disability collaborative advocacy program with the purpose of educating policy makers and training persons with disabilities in the critical issues that affect their lives.

H

Head Start/Early Head Start - Federally funded comprehensive child development programs that serve children from birth to age 5. Each program must accommodate 10% of total enrollment of children with disabilities.

Hearing Impaired - Loss of hearing in one or both ears that can be recorded by an audiometric test. Degree of hearing loss is classified as mild, moderate or severe. Moderate to severe hearing loss affects an individual's speech and language abilities.

I

IDEA - Individuals with Disabilities Education Act. The Federal law originally passed by Congress in 1975 as the Education of All Handicapped Children Act, P.L. 94-142. Established the legal right of all children to appropriate public education in the least restrictive environment.

ICF/MR - Intermediate Care Facility/Mental Retardation and related conditions. An optional Medicaid benefit program consisting of care and active services in group facilities with at least 4 beds.

IDT - Interdisciplinary Team. In behavioral health services, a planning team consisting of representatives from medical, behavioral health, advocacy and specialized therapy services who work with the consumer and family to develop an Individual Program Plan.

IEP - Individualized Education Program. This is a contract between the public school and the child with special needs and his/her family. Evaluations are completed prior to the child entering public school.

The IEP states the child's present levels of functioning, the specific services to be provided, long range goals for the child, and specific objectives for the year.

IFSP - Individualized Family Service Plan. A written plan describing the infant's or toddler's current level of development, the family's strengths and needs related to the enhancement of their child's development, goals for the child and the other family members, and criteria, procedures, and timelines used to evaluate progress.

Inclusion - In education, it is the process by which children with disabilities and children without disabilities participate together in all activities. In adult community living, it includes the supports that allow people with disabilities to participate in community life, develop lasting and meaningful relationships, and choose where they live and work.

IPP - Individual Program Plan. Document developed by an IDT that describes the supports needed for an individual in the areas of medical/health, housing, education, employment and other essential services.

L

LAWV - Legal Aid of WV. Statewide program that provides legal advice and personal advocacy services to individuals with disabilities. It is the Hartley advocacy agency for mental health and substance abuse.

Lead Agency - State agency designated by the Governor to administer and implement a statewide, coordinated, multi disciplinary, interagency, service delivery system for individuals with specialized support needs including disabilities.

Low Birth Weight - Infants born weighing less than 2 pounds.

LRE - Least Restrictive Environment. An educational placement that ensures that, to the maximum extent possible, children with special needs are educated with children not in need of special education services.

M

M-WIN - Medicaid Work Incentive Network. In WV, an initiative to enable people with disabilities to work without losing their Medicaid benefits by allowing them to pay a premium based on a sliding scale.

Medicaid – Federally funded health insurance program for low-

income individuals and eligible individuals with disabilities. Medicaid pays for general healthcare costs, social services, habilitative and rehabilitative services and some specialized medical services.

Mental Retardation – Disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills (definition from American Association on Mental Retardation).

MiCASSA - Medicaid Community Attendant Services and Supports Act. National program of community based attendant services and supports for people with disabilities and people otherwise eligible for nursing home or institutional care.

MR/DD - Mental Retardation/Developmental Disability. Refers to diverse group of severe, life long, chronic mental and physical conditions that affect language, learning, mobility and other functions occurring before age 22.

MR/DD Home and Community Based Waiver Program - A federal and state program for individuals with mental retardation and/or developmental disabilities designed to deliver services to individuals in their home and community surroundings as an alternative to receiving services in an Intermediate Care Facility (ICF).

N

NCLB - No Child Left Behind. Sweeping educational legislation (2002) requiring new standards in student testing affecting all grade levels, as well as teacher training. NCLB provides parents with the option of transferring their child out of failing schools.

NICHCY - National Information Center for Children & Youth with Disabilities. Information dissemination resource concerning children with disabilities with focus on education law and rights for children and families. Funded by the federal Office of Special Education.

O

OBHS - Office of Behavioral Health Services. State agency in WV DHHR that administers programs and services to persons with mental illness, developmental disabilities and addictions.

OMCFH - Office of Maternal, Child and Family Health. Administers multiple programs targeted to mothers, families and children including Birth to Three and Adolescent Health, Perinatal and Women's Health and Early Childhood Health Projects.

“One Stop” - This concept came from the Workforce Investment Act. It is an employment service organization that provides a comprehensive range of services and supports to all persons, regardless of disability label. One stops must provide consistent core services (service coordination, entitlement information, etc.) They are affiliated with other related programs and share a network of communication and collaboration.

OSE - Office of Special Education. State education agency responsible for oversight of the State’s special education services for children from age 3 through 21.

OSERS – Office of Special Education and Rehabilitative Services. Agency of the federal Department of Education addressing educational needs of people of all ages. Comprised of the Office of the Secretary, Office of Special Education Programs (OSEP), National Institute on Disability and Rehabilitative Research (NIDRR), and the Rehabilitative Services Administration (RSA).

P

PAS - Personal Assistance Services. Help provided to people with disabilities to assist them in tasks essential for daily living including bathing, dressing, eating and shopping.

PASS - Program Analysis of Service Systems. Intensive training/workshop on the Principle of Normalization that provides learners with guidelines and tools for evaluating human services programs.

PATHS - Partnerships in Assistive Technologies. Multi-agency (WV) project that includes the Office of Special Education, WV Developmental Disabilities Council, University Center for Excellence in Disabilities and the Division of Developmental Disabilities. PATHS activities include an annual conference on assistive technology which targets families and focuses on information and referral materials.

PBS - Positive Behavior Support. Structured, collaborative assessment and behavior analysis process, within the context of person-centered values, to develop supportive interventions for individuals with challenging behavior.

PDD - Pervasive Developmental Disorder. A childhood condition in which there is a delay across all areas of development: speech and language, cognitive, fine and gross motor, social, emotional, and adaptive behaviors.

PERC - Parent Educator Resource Centers. Provided in most WV

counties, the PERCs are a source of information and support for families in the educational system.

PIP - Partners in Policy Making. WV Developmental Disabilities Council sponsored training program for self-advocates and parents. Education and training about disability issues, the legislative process and leadership skills to influence public policies.

PTI - Parent, Training and Information Program. Statewide (WV) cross disability, parent/professional non-profit group funded through a grant from the U.S. Department of Education and Rehabilitation Services. WVPTI provides education, advocacy and support for parents and their children concerning special education rights and policies.

R

RESA - Regional Education Service Agency. In WV, eight agencies coordinate regional planning, coordinate consultants, and serve as liaison among local, regional and state agencies. RESAs provide assessment and other services for students in multi-county areas.

S

SAMHSA - Substance Abuse Mental Health Services Administration (DHHS). Provides funds and assistance to states on a variety of mental health and safety issues, including systems reform, prevention, substance abuse model programs, children and family services, co-occurring disorders, disaster response, homelessness, HIV/AIDS & Hepatitis treatment, older adult services and criminal & juvenile justice.

SCHIP - State Children's Health Insurance Program. A federal and state program which provides free or low cost health plans for children from birth to age 19.

SCI - Spinal Cord Injury.

Service Coordinator - This person's role is to coordinate assessments, IFSP planning, the evaluation and delivery of services listed on the IFSP, transition, advocacy, and help in the completion of necessary forms and paperwork.

SMI - Serious Mental Illness. Refers to a group of biochemical/neurological conditions of the brain resulting in distorted perceptions, delusions, hallucinations, disordered/confused thinking, unstable emotions and behavior.

Social Worker - A specialist who is trained in the evaluation and

treatment of child and family issues arising from family life circumstances.

SILC - Statewide Independent Living Council. Established in WV in 1992, it is a consumer directed and controlled Council which advocates for, plans and monitors state independent living services.

SSA - Social Security Administration.

SSI - Supplemental Security Income. Federal entitlement program based on disability and income. Qualified persons receive monthly SSI payments.

T

TANF - Temporary Assistance for Needy Families. Federal program that replaced the AFDC (Aid to Families with Dependent Children) as part of welfare reform legislation in 1996.

TASH - The Association for Persons with Severe Handicaps.

TBI - Traumatic Brain Injury. Acquired injury to the brain caused primarily by external force (such as motor vehicle accident). A person with a TBI often requires both acute and long term care rehabilitation. TBI that occurs before age 22 may result in a developmental disability.

Transition – Planning and support for persons with disabilities that prepares them for successful integration into school (and pre-school), work and community living environments.

U

UCED - Center for Excellence in Disabilities (at WVU).

Organization in higher education focusing on developmental disabilities and funded by the Administration on Developmental Disabilities. The UCED operates statewide programs that focus on research, training, and direct services for persons with developmental disabilities and their families.

W

WIA - Workforce Investment Act. Federal legislation seeking to simplify and expand access to employment for a wide range of groups through the creation of “One Stop” service programs. Legislation requires coordination of services between federal departments of Labor, Education, Health and Human Services and Housing and Urban Development.

WVA - West Virginia Advocates. Established to provide protection and advocacy services to individuals with developmental disabilities

or mental illness.

WVATS - West Virginia Assistive Technology Systems.

WVCDHH - WV Commission for the Deaf and Hard of Hearing.

WVDDC – West Virginia Developmental Disabilities Council.

Advocacy organization funded by the Federal Administration on Developmental Disabilities. The Council is comprised mostly (60%) of individuals with developmental disabilities and family members. The WVDDC seeks to assure that people with developmental disabilities receive the supports necessary to achieve independence and inclusion into their communities.

WVEIICC - West Virginia Early Intervention Interagency

Coordinating Council. Includes parents, professionals, legislators, advocates and State agency representatives to develop and implement a statewide system of services and supports for young children with special needs and their families.

WVMHCA - WV Mental Health Consumers Association. Nonprofit organization to promote the rights, representation, respect, and responsibility for consumers of mental health services.

WVMHPC - WV Mental Health Planning Council. Federally mandated to assist in the development of state mental health block grant application and make recommendations on block grant funding.

WVSRC - WV State Rehabilitation Council. Consumer directed and controlled Council to advise and assist the WV Division of Rehabilitation Services (DRS) in preparing the State Plan for Vocational Services.



Part
Five

Information Resources

West Virginia Resources

WV DHHR Bureau of Behavioral Health and Health Facilities
Office of Behavioral Health Services
350 Capitol Street
Room 350
Charleston, WV 25301
304-558-0627
www.wvdhhr.org/bhhf/prof.asp

WV DHHR
Office of Maternal Child and Family Health
350 Capitol Street
Charleston, WV 25301
304-558 - 5388
www.wvdhhr.org/mcfh

WV Office of the Ombudsman for Behavioral Health
Olmstead Coordinator
State Capitol Complex
Bld. 6, Room 850
Charleston, WV 25305
304-558-3287
www.wvdhhr.org/bhhf/olmstead/default.htm

WV ADA Coordinator
1900 Kanawha Blvd. East
Charleston, WV 25305
304-558-1783

WV Mental Health Planning Council
350 Capitol St., Room 350
Charleston, WV 25301
304-558-6179

WV Statewide Independent Living Council
PO Box 625
Institute, WV 25112
304-766-4624
1-800-642-8207, ext. 4624
www.wvsilc.org

WV Statewide Rehabilitation Council
P. O. Box 445
Institute, WV 25112-0445
304 - 766-2544
1-800-642-8207 ext. 2544
www.wv-src.org

WV Developmental Disabilities Council
110 Stockton Street
Charleston, WV 25312
304-558-0416 (voice) / 304-558-2376 (TDD)
www.wvddc.org

WVU Center for Excellence in Disabilities
959 Hartman Run Road
Morgantown, WV 26505
304-293-4692
<http://www.cedwvu.org>

WV Advocates
1207 Quarrier Street
Suite 401
Charleston WV 25301
800-950-5250
<http://www.wvadvocates.org>

Legal Aid of West Virginia
922 Quarrier Street - Suite 550
Charleston, WV 25301
(304) 342-6814
1-800-642-8279

WV Mental Health Consumers Association
P.O. Box 11000
Charleston, WV 25339
Phone: 304-345-7312
Toll Free: 1-800-598-8847
<http://www.contac.org/WVMHCA>

Mountain State Parents Can
P.O. Box 6658
Wheeling, WV 26003
(304)233-5399

Fair Shake Network
PO Box 354
Institute, WV 25112
304-766-0061

West Virginia ADA Coalition
601-3 Brockway Ave.
Suite A&B
Morgantown, WV 26501
1-800-946-9471
<http://wvadacoalition.org>

WV ADAPT
505 Timberline Apartments
Apartment # E-5
Morgantown, WV 26505
304-598-0171
1-877-860-1995
www.labs.net/adapt

Brain Injury Association of WV
P.O. Box 574
Institute, WV 25112-0574
304-766-4892
1-800-356- 6443 (in WV only)
www.biausa.org/WVirginia/index.htm

Web Resources

Administration on Developmental Disabilities
www.acf.hhs.gov/programs/add/index.htm

New Freedom Initiative Online Guide for Americans with Disabilities
www.disabilityinfo.gov

ADA Homepage
<http://www.usdoj.gov/crt/ada>

US Office of Special Education and Rehabilitation Services
www.ed.gov/about/offices/list/osers/nidrr/index.html?src=mr

Centers For Medicare and Medicaid Services
www.cms.hhs.gov/default.asp?

Substance Abuse and Mental Health Services Administration
www.samhsa.gov/index.aspx

ADS Center
www.adscenter.org

DRM Guide to Disability Resources on the Internet
www.disabilityresources.org

Part Six

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Charleston, WV 25312
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