

RESOURCE FACULTY

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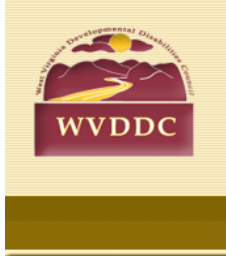
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ABOUT THE COUNCIL



The WV Developmental Disabilities Council is a 32 member organization that was established by an Executive Order of the Governor on March 6, 1972. The Council is authorized and funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). It is administratively supported by the WV Department of Health and Human Resources.

The Council's mission is to assure that West Virginians with developmental disabilities receive the services, supports and opportunities they need to achieve independence, productivity, integration and inclusion into the community of their choice. It does this in four major ways:

- including people with developmental disabilities and their families in the development of policies and programs;
- analyzing needs and proposing changes to the human service system;
- providing training and technical assistance to build competent and inclusive communities; and
- providing grants to community organizations to demonstrate innovative services and practices.

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Introduction

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INTRODUCTION AND OVERVIEW

Does social work practice differ when the client has a developmental disability? No. Social work practice involves starting where the client is and seeing each person as unique; respecting and appreciating diversity. Disability is an element of diversity. Social work practice recognizes and builds on client strengths. Social work practice involves evaluation of the person-in-environment perspective and when appropriate, identifies the environment as the target of change. Social work practice promotes social justice and involves advocacy and elimination of discrimination. Social work practice values self-determination and goals and objectives are developed by the client based on client needs and wants. These social work values apply to all clients.

So why do we need curriculum materials that are specific to developmental disabilities? Because social work students do not always know that people with developmental disabilities are like everybody else – and as diverse as everybody else. There is still a tendency to view a person with a disability as having something “wrong” with that person. A person with a disability simply has something about them that is different, as does everyone. Many people have a sense of pride related to their disability and do not seek to be “cured” or “rehabilitated”. Stereotypes and lack of understanding of disability can inhibit providing appropriate services to clients with developmental disabilities as well as other disabilities. There is a long history of inhumane treatment of people with disabilities. In fact, people with developmental disabilities have historically been treated as nonhuman. Although we have come a long way, there are still remnants of paternalism, judgmental behavior, misunderstanding of disability, and resistance to social acceptance. “Society” including media images, still often portrays people with disabilities in negative, demeaning, and/or “pitiful” ways.

There are a number of paradigms used to understand disabilities in society. While the traditional focus has been the medical model paradigm, models that focus on strengths, not deficits, are more consistent with social work values. Often what is needed, is environmental accommodations and/or change to help an individual achieve their goals or simply have access to all the same activities and opportunities people without disabilities have. All of us, whether or not we have a disability, use accommodations.

This resource manual includes curriculum materials specific to disabilities to help students recognize opportunities and not limitations for people – to help alleviate barriers that prevent people with disabilities from full participation in society. Being familiar with legal mandates, community services, and resources can help students become effective advocates to identify and eliminate discrimination. Dispelling stereotypes and reshaping ways of thinking about disability is the avenue to realization that social work practice with people with disabilities is just good social work practice.

The social work values of strengths perspective, social justice, respect for diversity, and self-determination guide decisions about what to include in course content. It is important for student to understand that as instructors infuse disability into discussions of poverty and unemployment; domestic violence; substance abuse; child abuse; and other social issues, there must be recognition that disability does not cause these problems. It is discrimination against and de-

valuing of individuals with disability that increase vulnerability. The materials in the resource manual emphasize an understanding of the barriers that exist for people with disabilities – including the attitudinal and social barriers. The manual begins with paradigms and definitions of disability and a generalist perspective that highlights some of the content throughout this manual. This is followed by materials organized around CSWE curriculum themes: Values and Ethics; Human Behavior and the Social Environment (HBSE); Policy, Social Justice, and Diversity; Practice and Practice Research. Each of these sections contain student activities, handouts, content information, and/or other resources. The materials included represent a range of resources from academic research, first person accounts, community advocates, government documents, and other websites.

BACKGROUND

A survey determining the saliency of various issues pertaining to developmental disabilities was piloted in 2003. The results of this survey were presented at the Young Adult Institute's (YAI) Annual International Conference on MR/DD and direction was given by those attending as to the next steps. Foremost among these was capturing the capturing the opportunity to assess the level of improvement in the areas of concern as indicated by the survey. Thus, the resultant tool assessed areas of change relative to the first instrument using a six (6) measure Likert scale. The results were shared at the 2004 conference. Again, feedback was sought and plans were made to involve other populations including more advocates, consumers, and providers. Throughout the year, we worked with the Board of the West Virginia Developmental Disabilities Council to develop content areas related to specific disciplines, including social work. We received direction in two areas: to build upon the data gathered relative to the areas of concern and improvement, and to assess the level of selected areas within social work curriculum at the Baccalaureate level. The instrument developed was informed by the previous research and forwarded by the conference. In 2005, the results were once again presented at the conference; input was given and practitioners and educators joined the initiative. The WV Developmental Disability Council extended support for this initiative in order to better understand the issues confronting education targeted at disability and the level at which these issues are addressed in the curriculum.

Faculty members of the West Virginia Social Work Education Consortium felt that their own ability to integrate content into the curriculum related to disability was limited. A survey of social work schools by DePoy & Miller (1996) found that few of those surveyed offered developmental disabilities content in their curricula, and those that did offered it primarily as a field practica experience. In 2005, the West Virginia Developmental Disabilities Council sent a request for proposals to assist in meeting their identified priorities in their state plan. A collaborative of social work faculty from six accredited social work programs in the state submitted a proposal to compile and develop curriculum materials to then distribute to all BSW faculty in WV so that this content could be infused in courses. The combined efforts resulted in this Resource Manual. This is an ongoing project.

Reference

DePoy, E., and Miller, M. (1996). Preparation of social workers for serving individuals with developmental disabilities: A brief report. Mental Retardation, 34 (1),54-57. As cited in: Liese, H., Clevenger, R., and Hanley, B. (1999). Joining University Affiliated Programs and Schools of Social Work: A Collaborative Model for Disabilities Curriculum Development and Training. Journal of Social Work Education, 35 (1) Retrieved from Academic Search Premier Database on 3/7/60 from http://web32.epnet.com/citation.asp?tb=1&_ug=sid=BAA10564%2DDCF7%2D4A.

PROJECT GOALS AND OBJECTIVES

The focus of this project is development of a values based curriculum in developmental disabilities for Baccalaureate Social Work (BSW) students. The overall goal is to develop and compile curriculum materials related to developmental disabilities and to disseminate these materials to BSW faculty across the state to integrate into courses. These materials will also be available to faculty in other disciplines and outside the State as appropriate and within budgetary constraints. A secondary goal is to foster and reinforce a commitment to developmental disabilities within the schools of social work.

The outcome of curriculum infusion will be better preparation of professionals to work with people with developmental disabilities.

Objectives of this project are:

1. Identify and develop curriculum resources related to disability and provide these resources to social work programs.
2. Infuse and/or integrate curriculum materials into BSW courses.
3. Develop and maintain web-based information for social work educators.

Understanding Disability

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DEFINITIONS OF DISABILITY

Following are some selected examples of definitions of disability and developmental disability. Definitions are developed in many ways. For example, some definitions flow from statutory regulations and some definitions arise from advocacy groups. It may be helpful to charge students individually to define disability, and then as a group reach consensus. This activity may impart to students the diverse views we have when defining disability and the resultant difficulty.

General Definitions of Disability

Oregon Office on Disability and Health

(<http://cdrc.ohsu.edu/oodh>)

Disability is a fluid concept that involves the complex interaction between a person's abilities and the physical and social environment. Secondary conditions are defined as aspects of living that negatively impact a person's ability to achieve optimal health and wellness that emerge from underlying impairment or health conditions.

The Center for an Accessible Society

(www.accessiblesociety.org/topics/demographics-identity/nidrr-lrp-defs.htm)

“It is useful to regard an individual with a disability as a person who requires an accommodation or intervention rather than as a person with a condition or impairment. Because accommodations can address person-centered factors as well as socio-environmental factors....a ‘need for accommodation’ is a more adaptable concept.

International Classification of Functioning, Disability and Health (ICF)

(<http://www3.who.int/icf/begines/bg.pdf>)

“Previously, disability began where health ended. Once you were disabled, you were in a separate category. We want to get away from this kind of thinking.” The ICF is moving towards a biopsychosocial model which recognizes “the interaction between health conditions and contextual factors.” Contextual factors include the environment (i.e attitudes, legal structures, etc.) and personal factors (i.e. gender, age, coping mechanisms, education, how one experiences the disability, etc.).

The ICF identifies 3 levels of human functioning: functioning at the level of body or body part; the whole person; and the whole person in a social context.

Disability involves dysfunctioning at one or more of these levels recognizing levels of functioning as impairment, activity limitation, and participation restrictions.

American with Disabilities Act of 1990

(www.usdoj.gov/crt/ada/adahom1.htm)

A physical or mental impairment that substantially limits 1 or more of the major life activities of the individual; a record of such an impairment; or being regarded as having such an impairment. The term “qualified individual with a disability” means an individual with a 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.

Individuals with Disabilities Education Act (IDEA)

(www.ed.gov/offices/OSERS/Policy/IDEA/index.html)

In general, the term “**child with a disability**” means a child:

with mental retardation, hearing impairments, language impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities
AND who, by reason thereof, needs special education and related services.

Rehabilitation Act of 1973

(www.dol.gov/oasam/regs/statutes/sec504.htm)

A physical or mental impairment that constitutes or results in substantial impediment to employment.

Assistive Technology Act of 1998

(www.section508.gov/docs/AT1997.html)

Any individual of any age, race, or ethnicity who has a disability; AND who is or would be enabled by an assistive technology device or assistive technology service to minimize deterioration in functioning, or to achieve a greater level of functioning in any major area of life.

2000 Census

(www.census.gov as reported in **WVDD Council Publication: A Reporter's Guide: Reporting About People with Disabilities** written by Betsy Southall, edited by Steve Wiseman and Jan Lilly-Stewart)

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.

Definitions Specific to Developmental Disability

Developmental Disabilities Assistance and Bill of Rights Act

(www.acf.dhhs.gov/programs/add/DDACT2.htm)

“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.”

“Developmental disability means a severe, chronic disability of an individual 5 years of age or older that (1) is attributable to a mental or physical impairment or combination of mental and physical impairments; (2) is manifested before the individual attains age 22; (3) is likely to continue indefinitely; (4) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (5) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated. (AAUAP, 1996 as cited in Liese, H., Clevenger, R., Hanley, B. (1999). *Joining University affiliated programs and schools of social work: A collaborative model for disabilities curriculum development and training. Journal of Social Work Education, 35 (1)*. Retrieved from Academic Search Premier.

WV Developmental Disabilities Council

(www.wvddc.org)

A developmental disability is 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. A developmental delay is a condition marked by a difference

between a child's actual development and the expected age of reaching developmental milestones.

National Association of Developmental Disabilities Council

(www.naddc.org)

A developmental disability is a severe, chronic disability that begins any time from birth through age 21 and is expected to last for a lifetime. Developmental disabilities may be cognitive, physical, or a combination of both. While not always visible, these disabilities can result in serious limitations in every day activities of life, including self-care, communication, learning, mobility, or being able to work independently. Such disabilities are almost sure to result in a life of dependence on publicly funded services, unless families receive sufficient support, children receive appropriate education and adults receive appropriate services that enable them to live and work in the local communities.

Approximately 4 million Americans have developmental disabilities. Developmental disabilities can occur in any family, no matter what the ethnic, economic, religious or political background.

References

Websites noted above and West Virginia Developmental Disabilities Council publication: [A Reporter's Guide: Reporting About People with Disabilities](#) written by B. Southall, edited by S. Wiseman and J. Lilly-Stewart.

MODELS FOR CONCEPTUALIZING DISABILITY

Moral Model
Medical Model
Social Role Valorization
Social/Minority Model
Disability Discrimination Model
Explanatory Legitimacy Theory

Moral Model

This model views disability as linked to sin and evil. (Mackelprang & Salsgiver, 1999) While this view was popular during through the Middle Ages, there is evidence of its existence today. Some may point to biblical references, believing that disability is a “punishment from God” for one’s immoral acts or acts of one’s parents. This view perpetuates discrimination.

Medical Model

This model views disability as a biological (pathological) condition. The disability is located within the person (not caused by the environment). This view perpetuates the concept of the person with a disability as “sick” and dependent on medical services.

Social Role Valorization

Social Role Valorization (SRV) is described as “a high-level and systematic schema, based on social role theory, for addressing the plight of people who are devalued by others, and especially by major sectors of their society” (Wolfensberger, 2000). The roots of SRV can be found in normalization concepts. Since people with disabilities are included as a population found to be devalued by society, SRV is applied to “upgrade the perceived value of the roles such persons already occupy, and/or to extricate such persons from devalued roles” (Wolfensberger, 2000).

Social Role Valorization holds that certain groups of people experience social discrimination and prejudice which leads to negative life experiences. Groups vulnerable to social discrimination include people with disabilities and/or body characteristics negatively perceived by society, people who exhibit atypical behavior, people who live below the poverty line, and people who do not have skills that are valued by society. Negative life experiences include rejection or ridicule, stigmatization, segregation, limited choices, dehumanization, loss of individual identity, and poverty. These individuals are more likely to be placed in segregated settings engaging in unconstructive activities. Social role valorization seeks to support valued roles for people with disabilities and eliminate stereotypes and other negative life experiences. Examples include assuring that people engage in age-appropriate, constructive activities; moving away from the

view of people with disabilities as medically fragile or sick; treating people with dignity and respect and not as objects, cases, or targets of ridicule; and eliminating the view of people with disabilities as menaces.

Social/Minority Model

This model includes the social constructionist view, discrimination view, and independent living movement. (Mackelprang & Salsgiver, 1999) The view is that disability is created by societal definition rather than by a particular condition. The independent living movement emphasizes competence, self-respect, equality, and self-determination.

The Disability Discrimination Model

by Gary May

The Disability Discrimination Model is designed to give professional social workers a way to conceptualize disability so that their work can play a role in the transformation of how people with disabilities are treated in our society. The guiding principle is that disability-related impairment is a social construction rather than an immutable, objective reality. Impairment operates as a set of beliefs supported by theories and practices within society so that deviations from normative expectations in physical and biological construction are defined as limiting and excluding. The Disability Discrimination Model proposes a theoretical model along with a set of practice principles upon which social workers can restructure their practices.

The Disability Discrimination Model necessitates acceptance of an understanding of disability where “disability” and “impairment” are not inherently linked. This theory asserts that the concepts of disability and impairment are socially constructed, and that the “facts” concerning the consequences of disability are not immutable, objective realities, but merely affirmations of a pejorative and stereotypic perspective.

Pfeiffer (JDPS 2000) has stated that “In a flexible social system which fully accommodates a person with a disability, the disability disappears.” This view precludes the simultaneous existence of a disability, which may be defined as the presence of an appearance or functional characteristic that is a departure from normative expectations, and positive connotations that might be associated with the label “disabled”. By so doing, this perspective implicitly validates the traditional medical model where a disability is a negative aberration that becomes the focus of preventive or remedial intervention.

The Disability Discrimination Model contends that being labeled “disabled” is no different from being labeled “female”, “African American”, “Hispanic”, or any other nominal distinction, but for the consequences of the label. Historically, people with disabilities, unlike these other groups, have not been socialized to experience pride and positive connotation with the label “disabled”. We believe that proud, positive connotations can and do accompany the label “disabled” except under conditions where the consequences of the label are constructed as negative, limiting, and pejorative. Consequently, the fact that I have bilateral above the knee amputations (deviation

from appearance and functional norms) does not mean that I cannot be proud of my total being including that portion of my body and functionality that is appropriately labeled “disabled”.

As Pfeiffer (2000) suggests, a hospitable environment that accommodates my appearance and functional deviations (read disability), is desirable, but the absence of such an accommodating environment does not mean that I move from a non-disabled state to a disabled state. The absence of such necessary and desirable accommodations merely suggests that the socially constructed environment *causes* impairment. I may still proudly maintain the label “disabled” in either instance.

In the previously cited examples of women, African Americans, Hispanics and others, we do not insist that they relinquish identity or proud adherence to the labels that connote their group’s deviation from the ordinary. Nor do we suggest that they no longer occupy a role and status within their labeled group if they experience an accommodating social system. Indeed, great effort is expended to insure that everyone understands the value of diversity (read deviation) in contemporary U.S. culture. Not so when disability is the issue. Here, the focus is on restoring the person labeled disabled so they no longer deviate from normative expectations. There is no systematic effort to identify sources of pride or to instill positive connotations on being “disabled”.

The implications for social workers and other intentional helpers are profound and require a “working with” orientation with the disabled client v. a “working on” orientation. From this working with perspective, the client system is not merely the collection of difficulties or clinical symptomatology, but is one component of an interactive system that may produce impairment. Solutions, then, are not to be found solely in the person with the disability, but in the larger social environment.

Decisions about what needs to be done and who should do it are reached through collaboration and consultation not merely clinical practice or psychotherapy. The Disability Discrimination Model asserts that the “client” system is victimized by poor quality social interaction, not by their personality or behavioral characteristics.

The Disability Discrimination Model makes an essential distinction between disability and impairment and views impairment as a socially constructed phenomenon. From this perspective, disability becomes disabling, or impairment, where an observed or perceived atypical appearance or functional characteristic intersects with a negative, stereotypic, limiting expectation set. Typically, the possessors of the atypical appearance or functional characteristics are labeled “disabled”, and the holders of the negative, stereotypic, limiting expectations are labeled “non-disabled”. Such a depiction allows the person with a disability to continue to “own” and even celebrate the disability, and implicitly, membership in the disability culture, and explains deferential treatment, and limiting elements of the social and physical environment.

Interventions are enacted in a broader field and necessarily include the important human elements of the client’s experience. These other important human elements will need to be educated about the importance that they have in the quality of life of the client. Resistance to this

novel perspective is likely, as the insidious influence of the traditional victim blaming perspective is substantial.

Explanatory Legitimacy Theory

In their book, *Rethinking Disability* (Brooks/Cole, 2004), Depoy and Gilson define disability as a contextually embedded, dynamic grand category of human diversity. Thus, who belongs and what responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse human phenomena. This approach to defining disability differs from previous schemes in which disability was determined by the presence of a medical condition that caused permanent limitations in one's daily function. Explanatory legitimacy theory makes the distinctions among descriptive, explanatory and the axiological or the legitimacy dimensions of the categorization of human diversity and identifies the relationships among these elements. Thus, disability analyzed through the lens of explanatory legitimacy, is comprised of the three interactive elements: description, explanation, and legitimacy.

Description emphasizes the full range of human activity (what people do and do not do and how they do what they do), appearance, and experience and is comprised on two intersecting dimensions (typical/atypical and observable/reportable). Typical involves activity, appearance, and experience as most frequently occurring and expected in a specified context. Atypical refers to activity, appearance, and experience outside of what is considered to be typical.

Observable phenomena are activities and appearance which fall under the rubric of those which can be sensed and agreed upon. Reportable phenomena are experiences which can be known through inference only.

To illustrate the two axes, the use of a wheeled device for mobility would be observable and atypical for young adults, but would be observable and typical for infants. Pain would be reportable since it can not be directly observed and verified.

Explanation is the set of reasons for atypical doing, appearance, and experience. Explanation provides the basis on which one judges eligibility for category membership. For example, "homeless" is a description of one's living situation and may have many explanations. However, if the explanation is drug addiction, the response may be different than if the explanation is the experience of abuse and oppression or even if the explanation is Hurricane Katrina. Relative to disability, Depoy and Gilson look at medical-diagnostic explanations and constructed explanations. Medical explanations view descriptive atypical phenomenon from a pathology perspective. This explanatory model, locating the explanation within an individual, might beget treatment and rehabilitation as a response. Constructed explanations identify the explanation for atypical description as a set of limitations imposed on individuals (with or even without diagnosed medical conditions) from external factors such as social, cultural, economic, political and other environmental influences.

The target for change from this explanatory perspective is the social environment since the disabling factors are not seen as located within individuals. From a constructed perspective, concepts of self-determination, inclusion, power, and justice become important. The authors note that “one may be disabled by a legitimate medical-diagnostic, social barrier, or political powerless explanation”.

Legitimacy is defined as “the set of differential judgments that place explanations for atypicality within or outside of disability status”. “Disability is determined not by the explanation but by the set of beliefs, value judgments, and expectations attributed to the explanation.”

Legitimacy can come from outside the individual in such forms as medical, legal and policy determinations that one is a member of the disability category. This type of legitimate membership in the category of disability may determine one’s eligibility for treatment, medical benefits, protection under nondiscrimination laws or eligibility for various programs and services. Determinations for “eligibility” for the death penalty and rationales for abortion or assisted suicides are effected by value judgments related to disability. Legitimacy can also come from within - how one identifies oneself. Related to this explanation are issues of disability as culture, disability identity, self-determination, and disability studies.

Explanatory Legitimacy Theory can be applied to professional practice, social change, and social justice. The authors emphasize that “the primary purpose of professional activity should be the improvement of experience and social justice within the diversity of people and communities

References

Depoy, E. & Gilson, S. (2004). Rethinking disability. Belmont, CA: Brooks/Cole.

Mackelprang, & Salsgiver, R. (1999). Disability: A diversity model approach in human service practice. Belmont, CA: Brooks/Cole.

May, G. & Raske, M., (2005). Ending disability discrimination. Boston: Pearson.

Wolfensburger, W. (2000). A brief overview of social role valorization. Mental Retardation, (38, 2), 105-123.

**DEVELOPMENTAL
DISABILITY
(POWER POINT SLIDES)**

Values & Ethics

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OVERVIEW: DISABILITY AND SOCIAL WORK VALUES

Self-Determination Social and Economic Justice Non-discrimination Respect and appreciation for diversity

Social Work values provide an ethical framework for social work practice related to disabilities. The most common value statements relevant to disabilities are self-determination, social and economic justice, nondiscrimination, and respect and appreciation for diversity. The Social Work profession generally defines these as:

The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. A historic and defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living. Social workers promote social justice and social change with and on behalf of clients. "Clients" is used inclusively to refer to individuals, families, groups, organizations, and communities. Social workers are sensitive to cultural and ethnic diversity and strive to end discrimination, oppression, poverty, and other forms of social injustice. These activities may be in the form of direct practice, community organizing, supervision, consultation, administration, advocacy, social and political action, policy development and implementation, education, and research and evaluation. Social workers seek to enhance the capacity of people to address their own needs. Social workers also seek to promote the responsiveness of organizations, communities, and other social institutions to individuals' needs and social problems.

The mission of the social work profession is rooted in a set of core values. These core values, embraced by social workers throughout the profession's history, are the foundation of social work's unique purpose and perspective:

- *service*
- *social justice*
- *dignity and worth of the person*
- *importance of human relationships*
- *integrity*
- *competence.*

This constellation of core values reflects what is unique to the social work profession. Core values, and the principles that flow from them, must be balanced within the context and complexity of the human experience. (NASW 1996 as revised 1999).

In this section you will find several activities designed to enliven these values for students as they work with peoples with disabilities. Some are in-class activities and some are web or outside resources. You will also find handouts and activities that have proven to be helpful. Additionally, these activities may be used to inform other content areas such as Human Behavior in the Social Environment, Practice, and Policy.

From a Social Work perspective, disability is a civil rights issue. We cannot simply expect individuals to change to fit society, but society must change to accommodate all people. People with disabilities are entitled to full and equal participation in society. The American with Disabilities Act of 1990 (ADA) was enacted to assure protection of legal rights and prohibit discrimination on the basis of disability in employment, access to public services, public accommodation, commercial facilities, and requires telephone companies to offer telephone relay service for people who use telecommunication services for the deaf (TTY's) or similar devices. But the ADA has not eliminated discrimination or attitudinal barriers for people with disabilities.

The traditional model of providing services to people with disabilities places the control over services with service providers. Disability rights advocates promote a move to greater self-determination for people with disabilities. This is consistent with social work values – even though such self-determination has not and is not always practiced by social service and other programs serving people with disabilities. Self-determination means having the freedom and authority to manage one's own life and make choices. This often means having control over where to live and who to live with, what support staff will be hired and the training of such support staff, choosing community connections and activities, choosing who will help with planning, having authority over resources, and making decisions about employment and education. In other words, having the same rights and opportunities as people without disabilities.

Social workers often serve in role of advocate. Recognizing that people with disabilities can be self-advocates and assisting them in that role, when appropriate, is consistent with empowerment. Social workers must recognize that people with disabilities are capable people who deserve to be treated with respect and held in esteem. Social workers need to identify strengths and abilities and work to remove barriers that prohibit full participation in activities of living. Disability is a complex interaction between person and environment. One may be considered as having a disability because of a physical condition, however, it is barriers in the environment that turn disability into impairment and prevent full participation.

Materials included in this section are as follows:

Student Activity: Manifesto for Persons with Disabilities

This activity may take students some time to complete. It is designed to challenge students to think about macro issues related to disability, disability rights, and appreciation for diversity.

Values Clarification: Self-Assessment

This exercise may be most appropriate for students just beginning their exploration of disability. Educators who have used this survey have found that students show less agreement when responding to 7, 8, 9 and 18 than in other statements. Some educators have found it helpful to challenge students on the more common beliefs that arise in discussion.

Disability Values Questionnaire and Disability Values Clarifications Exercise

This exercise can build upon the previous exercises as it is more complex and best applied after students obtain a beginning level of understanding about disabilities.

Dispelling Myths

There are many readily available handouts that assist when processing values and ethics. For example, the US Department of Labor and the WV Inclusion Campaign both publish and/or web publish handouts aimed at dispelling myths about people with disabilities.

Disability Discussion Activity

It is helpful to use what students see in their everyday lives to understand the genesis and pervasiveness of society's views of disability. This exercise uses TV shows and media images as learning opportunities.

Case Scenarios: Legal and Ethical Issues

The nexus between legal and ethical is more clear when related to a general physical disability. This exercise invokes legal issues as well as ethical issues and the student is challenged to discern between the two.

Developmental Case Study

Discerning the legal and ethical issues related to developmental disabilities may be more challenging to the students. This exercise gives students the opportunity to acquire this ability.

The Moral Imperative of Inclusion (Kathy Snow)

This handout highlights the issue of inclusion as related to social and economic justice.

Abstracts: Ethical Concerns

This provides abstracts of articles related to ethics and disability services.

References/Resources

www.acdl.com/selfguide.html

www.nasw.org, www.sanys.org

www.selfadvocay.com

<http://www.naswdc.org/pubs/code/>

STUDENT ACTIVITY: MANIFESTO FOR PERSONS WITH DISABILITIES

<http://dawn.that.net/manifesto.html>

This activity may take students some time to complete. It is designed to challenge students to think about macro issues related to disability, disability rights, and appreciation for diversity.

Direct students to read the *Manifesto for Persons with Disabilities* by John R. Woodward, MSW, Center for Independent Living of North Fla., Inc - available on-line at <http://dawn.that.net/manifesto.html> . Ask students to respond to one or more of the following discussion questions:

1. Woodward states, “we reject any scheme of labeling or classifying us that encourages people to think of us as having diminished value”. What examples can you think of such labeling or classifying? What evidence, if any, is there that people with disabilities are considered as having “diminished value”?
2. When Woodward refers to institutions “whose purpose it is to punish us for being disabled, or “confine us for the convenience of others”, what is he referring to? Can you give examples?
3. What institutions have been created to “care” for people with disabilities? What do you think of his rejection of such institutions?
4. Who do you think are the “experts from the able-bodied world” that Woodward refers to? In what ways do these “experts” attempt to direct the lives of people with disabilities?
5. What does he mean by “we are not diagnoses in need of a cure”?
6. What are some examples of the “charitable enterprises that exploit our lifestyle to titillate others”? Do you agree that charities and businesses have exploited people with disabilities? Use examples to support your position.
7. Do you agree with the assertion that segregated institutions are not necessary and in fact have been a great source of oppression? Support your position. Can all services needed be provided in the community?
8. What are the implications for social work practice? In what ways might social workers be part of the problem and in what ways can social workers support this Manifesto and eliminate discrimination and devaluation of people with disabilities?

VALUES CLARIFICATION SELF-ASSESSMENT SURVEY

AGREE

4-strongly agree

3-agree

2-disagree

1-disagree strongly

DISAGREE

- ____1. Disability in no way reduces a person's human worth.
- ____2. People with disability have less chance for a fulfilling life.
- ____3. People with cognitive disabilities have the same emotional experience as those with more highly developed intellectual capabilities.
- ____4. People with cognitive disabilities should not be encouraged to have intimate relations.
- ____5. People with a disability should not be sexually active.
- ____6. Parents of children with disabilities have a closer relationship with their children.
- ____7. Parents of children with disability experience more stress than other parents.
- ____8. Children with disabilities should have special schools.
- ____9. It is the responsibility of government to take care of individuals with disabilities.
- ____10. People with disabilities should not be expected to meet the same standards as non-disabled people.
- ____11. People with disabilities are as happy as people without disabilities.
- ____12. It is almost impossible for a person with a disability to lead a normal life.
- ____13. People with disability, regardless of the severity, make responsible choices about their own lives.
- ____14. With adequate support services, people with disability can live as self-sufficiently and actively as people without disability.
- ____15. Effective independent living centers should take funding precedence over state bureaucracies.
- ____16. Independent living centers should be available to all urban and rural people.

- ____17. It is my responsibility to enable families to function as care givers for their child with disability.
- ____18. Parents are experts on their children.
- ____19. The elderly should be sexually active.
- ____20. Most people over the age of 65 are not physically attractive.
- ____21. People should be forced to retire at a certain age.

Developed by: Patricia Chase and Roger Smith

DISABILITY VALUES QUESTIONNAIRE

AGREE

DISAGREE

4-strongly agree

3-agree

2-disagree

1-disagree strongly

- _____1. It is more beneficial to teach a wheelchair user to jump curbs rather than to convince the city to install curb cuts.
- _____2. Walking, if possible, is better than using a wheelchair.
- _____3. People with histories of drug and alcohol abuse should be considered persons with disabilities.
- _____4. A severely physically disabled person in a restaurant makes other diners uncomfortable when the person's eating is sloppy and is perceived as disgusting.
- _____5. Persons with severe disabilities should not be expected to work.
- _____6. Persons with an amputated limb should wear their prosthesis in social situations, including work.
- _____7. The biggest factor in preventing persons with disabilities from accomplishing their goals is the fact that they do not take risks.
- _____8. Few persons with disabilities are ashamed of their disabilities.
- _____9. In spite of all the publicity and activism, persons with severe disabilities can never *really* live on their own.
- _____10. It is a tragedy for parents to have a child with a disability either at birth or in childhood.
- _____11. It is common for persons with disabilities to be angry and resentful toward nondisabled people.
- _____12. People with severe developmental disabilities should be prevented from marrying.
- _____13. Severely developmentally disabled individuals will not benefit from job clubs.
- _____14. Given the choice, nondisabled persons would declare themselves disabled to get out of work and collect the benefits.
- _____15. For a person to acquire a disability from an injury is a tragic event.
- _____16. Persons with disabilities are usually friendly and receptive to being helped.

- _____17. The new “inclusion” movement in primary and secondary education causes more harm than good to both the disabled student and the nondisabled student.
- _____18. Reasonable accommodation under the ADA gives special privileges to workers with disabilities.
- _____19. The biggest factor in preventing persons with disabilities from accomplishing their goals is their lack of hard work.
- _____20. Persons with disabilities cannot produce as much in the work environment as a nondisabled person.
- _____21. Only persons with disabilities should provide human services to other persons with disabilities.
- _____22. Persons with severe developmental disabilities should be prevented from having children.
- _____23. Civil rights laws like the ADA take away rights from productive nondisabled workers.

Permission for printing of this values questionnaire was granted by Romel Mackelprang. The format was revised slightly. The questionnaire can be found in the reference below.

Reference

Mackelprang, R. & Salsgiver, R. (1999). Disability: diversity model approach in human service practice. Belmont, CA: Brooks/Cole – pp.9-10.

DISABILITY: VALUES CLARIFICATION EXERCISE

This is designed to stimulate thinking about disability issues. Answers should reflect your personal views and so there are no right or wrong answers. Circle the number on the scale that most closely fits with the direction you lean. The mid-point on scale is 4, which would indicate no commitment in either direction. For instance, in the first values continuum below, if you strongly believe that disability is a value judgment, you would circle 7, if you lean slightly in that direction you would circle 5, etc.

- | | | |
|---|--|---|
| 1. Disability is based on a medical diagnosis. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | Disability is a value judgment. |
| 2. Disability is a result of a medical condition. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | Disability is a result of environmental barriers. |
| 3. People with disabilities should have special protections under the law. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | Legislation should apply to all people equally. |
| 4. Disability is a tragedy. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | Disability is a natural part of life. |
| 5. Disability means dependency and loss of productivity. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | Disability does not mean dependency and loss of productivity. |
| 6. People with cognitive disabilities should be protected from the death penalty. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | People with cognitive disabilities should not be protected from the death penalty because this legitimizes exclusion from full participation in other aspects of society. |
| 7. Diagnosis of Down syndrome in fetal development is an acceptable rationale for abortion. | <hr style="border: 0; border-top: 1px solid black; margin: 0;"/> 1 2 3 4 5 6 7 | People should not consider abortion based on a diagnosis of Down syndrome. |

8. Society views people with disabilities as asexual.

1 2 3 4 5 6 7

Society views people with disabilities as sexual and sensual.

9. People with disabilities are an oppressed minority.

1 2 3 4 5 6 7

People with disabilities often get special consideration and privileges.

10. Independent living in the community is a civil right of people with disabilities.

1 2 3 4 5 6 7

Society does not have an obligation to ensure independent living for people with disabilities.

References

DePoy, E. & Gison, S.F. (2004). Rethinking disability. Belmont, CA: Brooks/Cole

May, G & Raske (2005). Ending disability discrimination. Allyn & Bacon.

CASE SCENARIOS LEGAL AND ETHICAL ISSUES

The nexus between legal and ethical is clearer when related to a general physical disability. This exercise invokes legal issues as well as ethical issues and the student is challenged to discern between the two.

Mr. Jones has a Medical Power of Attorney which specifies under the “special directives” section, “no tube feeding.” He is hospitalized and is incapacitated. The physician believes that tube feeding would be of benefit and that the patient has a chance of recovery.

What are the legal and ethical issues involved? Should the physician order tube feeding? If the designated medical power of attorney favors tube feeding and believes that this situation was not the patient’s intent when he wrote the directives, should the physician order tube feeding? If there were no special directives written, but the medical power attorney did not want tube feeding ordered, what should the physician do? Would the age of Mr. Jones enter into these decisions?

Mr. Smith is an 85 year-old woman with COPD. She is incapacitated and has not issued a DNR request. The medical power of attorney wants CPR when necessary. Ms. Smith is in the hospital and stops breathing. The physician does not believe she will benefit from CPR.

What are the legal and ethical issues involved? What should the physician do?

Mr. Doe has tuberculosis but refuses to take medication, thus presenting a danger to others in society.

Should Mr. Doe be forced to take medication?

Ms. Doe is 80 years-old and in the hospital. It has been determined that she does not have the capacity to make decisions. She can no longer take care of herself in her own home, but insists on going there. The medical power of attorney decides on nursing home care. When the ambulance arrives, she sits up in bed and says, “I’m not going to a nursing home, don’t touch me. I just want to go home.

What are the legal and ethical issues? Can and should she be taken forcibly? As a social worker, how would you handle this situation?

Mr. Doe was told that he needed to begin dialysis three times per week due to ESRD. Realizing his brother has tuberculosis and his sister lacks capacity, he feels that the pain and expense of dialysis is not worth it. He tells his social worker that he refuses dialysis. The RN and MD caring for Mr. Doe tell the social worker to be a team player and convince Mr. Doe to have dialysis or have him deemed “crazy” as the RN and MD state mental capacity is a medical decision.

The social worker consults with you as to what he should do. What do you tell him?

DEVELOPMENTAL CASE STUDY LEGAL & ETHICAL ISSUES

Discerning the legal and ethical issues related to developmental disabilities may be more challenging to the students. This exercise gives students the opportunity to acquire this ability.

Ms. Brown is a 22 year old woman who is addicted to cocaine. She learns she is 5 months pregnant and wants to terminate the pregnancy as she is afraid the child will be born with disabilities and she will be unable to care for it.

What do you think she should do?

Should the social worker support her decision for termination or try to get her to look at other options?

Should she be reported to the police for substance abuse (whether or not she continues the pregnancy)?

If she continues the pregnancy and continues abusing drugs, should she be charged with a crime?

Should she receive mandatory treatment (whether or not she continues the pregnancy)?

What are the legal and ethical issues?

What assumptions are made about disabilities (i.e. better off not being born)?

Ms. Brown gives birth to a premature baby girl, Emma. Emma is born with FAS and has evidence of cocaine in her system.

Should CPS be contacted?

Should Ms. Brown's rights be terminated?

If Ms. Brown cannot afford medical care for Emma, who should pay?

As Emma develops, many developmental delays are noted in the areas of cognitive functioning, language, and mobility. As she reached school age, ADHD, cognitive disability and behavior problems are diagnosed. The school system believes Emma needs to be in a specialized setting. Ms Brown sees no need for this and wants her in an inclusive classroom.

What are the legal and ethical issues?

At age 16, Emma gets pregnant. The father is unknown. She wants to have the baby. The social worker does not believe she has the capacity to care for a baby or to understand fully what the pregnancy and delivery entail. Ms. Brown wants her to get an abortion.

Who should make the decision regarding the pregnancy?

What are the legal and ethical issues?

At age 25, Emma wants to leave the group home she has been living in. (She had a miscarriage 9 years earlier). She has been taking medication without which she tends to be agitated and prone to violence. She decides she wants to quit taking her medication and move out of the group home to live with a 50 year old man who the social worker fears is exploiting her for her disability check and for sex.

What should the social worker do?

Dispelling Myths About People with Disabilities (www.dol.gov/odep/pubs/fact/dispel.htm)

There are many readily available handouts that assist when processing values and ethics. For example, the U.S. Department of Labor and the West Virginia Inclusion Campaign publish and web publish handouts aimed at the myths about people with disabilities. The following is from the U.S. Department of Labor's Office of Disability Employment Policy (1995):

The major barriers to achievement by people with disabilities in our society continue to be attitudinal barriers, stereotypical thinking, and assumptions about what people can and can't do. The truth is that the range of ability of persons within any disability group is enormous. We need to get rid of our stereotypical images and view each individual as just that: "an individual." Listed below are the kinds of assumptions that can be barriers to employment for persons with disabilities.

Assumption: A person with cognitive disabilities cannot be trained to perform a job as well as an employee without a disability.

Fact: Over two-thirds of the 4,000 participants in Pizza Hut, Inc.'s "Jobs Plus Program" are persons with cognitive disabilities. The current turnover rate among these employees with disabilities is a modest 20% compared to the 150% turnover rate of employees without disabilities. This means a drop in recruitment and training costs.

Assumption: An individual with a psychiatric disability cannot work in a stressful environment where tight timelines have to be met.

Fact: All individuals perceive stress differently and their responses vary. Some individuals with psychiatric disabilities perform effectively in jobs that require specific timelines and structure.

Assumption: There is no way that a wheelchair racer can compete with the world's best marathon runners.

Fact: It takes a good runner over two hours to run a marathon. A competitive wheelchair racer can complete a marathon in less than one and a half hours.

Assumption: A person with a developmental disability and difficulty with fine motor control is unlikely to be able to handle complex operations on the production line of a manufacturing plant.

Fact: A person with this combination of functional limitations was hired for a production line job. The job involved labeling, filling, capping, and packing a liquid product. The only accommodation supplied for the worker was the creation of a plywood jig. The jig enabled the worker to hold the bottle steady for correct labeling.

Assumption: It is unbelievable that a person with a double amputation can compete with the world's fastest 100-meter dash runners.

Fact: The world record is 9.9 seconds. A runner who is a double amputee ran the dash in 11.76 seconds, just 1.8 second off the world mark.

Assumption: A person who is blind and has a missing right hand cannot perform a job as a machinist.

Fact: The applicant lost his vision and right hand in Vietnam. He persuaded a community college to train him as a machinist and was finally given a job on a trial basis. From the very first day, he broke production records and caused others to do the same. His only modification was to move a lever from the right side of the machine to the left.

Assumption: Downhill skiers with one leg cannot really compete against racers with two legs.

Fact: Top racers without disabilities have been clocked at 80-85 miles per hour; downhill skiers with one leg have been clocked at over 74 miles per hour.

Assumption: It is unlikely that a man whose right leg is amputated six inches above the knee can perform the duties of a warehouseman that require loading and unloading trucks, standing, lifting, bending, and delivering supplies to various sections as needed.

Fact: A person with this type of amputation was hired to work in a paper warehouse. He performed the job without any modification. He worked out so well that the company moved him to operating heavy equipment, a log stacker. The company did not have to make any accommodations. He was able to climb ladders and the heavy equipment without any problems.

DISABILITY MYTHS AND REALITIES

(West Virginia Inclusion Campaign)

The following myths and realities are from the West Virginia Inclusion Campaign's *Disability Awareness Guide*.

Myth: People with disabilities are sick or have something wrong with them and they need to be cured.

Reality: Having a disability is not the same as being sick. Disabilities are not contagious, and people with disabilities don't need to be cured.

Myth: People with disabilities have a poor quality of life and deserve sympathy, pity, and charity.

Reality: The quality of a person's life depends on the quality of their living conditions, their access to community activities and social relationships, and their opportunity to contribute to society.

Myth: People with disabilities are inspirational, courageous, and brave for overcoming their disability.

Reality: People with disabilities are simply carrying on normal activities of daily living when they do things such as drive to work, compete in athletic events, or participate in recreational activities. However, they do encounter obstacles in the environment and society that can make life challenging. Access to community services and supports can address many of these barriers.

Myth: People with disabilities need to be protected from failing.

Reality: People with disabilities have the same rights as everybody to participate in the full range of human experiences—including success and failure.

Myth: People with disabilities should live in protective settings, such as group homes or nursing facilities, with other people with disabilities.

Reality: People with disabilities have the right to live as independently as possible in the community setting of their choice.

Myth: People with disabilities always have problems with transportation.

Reality: People with disabilities are capable of arranging their own transportation, although they may have difficulty obtaining affordable, accessible transportation in some areas. People with disabilities drive, ride a bicycle, walk, and use public transportation.

Myth: People with disabilities only want to associate with other people with disabilities.

Reality: People with disabilities want to have friends with and without disabilities.

Myth: *The lives of people with disabilities are totally different from those of most other people.*

Reality: People with disabilities attend school, they work, develop personal relationships, have a family, shop, do chores, pay taxes, vote, and dream like anyone else.

Myth: *Disability is a sign of weakness, character defect, or punishment from God.*

Reality: Disability is a natural part of the human experience. The incidence of disability increases with age.

Myth: *Disability in one area of functioning implies disability in another area.*

Reality: Disability in one area, such as physical disability, does not mean that a person has other disabilities, such as mental impairment.

Myth: *People with disabilities are a drain on society.*

Reality: All people have inherent value. People with disabilities are contributing members of society.

For information visit:

U.S. Department of Labor, Office of Disability Employment Policy www.dol.gov/odep

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, National Mental Health Information Center www.mentalhealth.samhsa.gov

Michigan Community Service Commission www.michigan.gov/mcsc

DISABILITY DISCUSSION ACTIVITY

It is helpful to use what students see in their everyday lives to understand the genesis and pervasiveness of society's views of disability. This exercise uses TV shows and media images as learning opportunities.

Consider the following assumptions people make about disability according to Fine & Asch (2000):

1. Disability is located solely in biology, and thus disability is accepted uncritically as an independent variable.
2. When a person with a disability faces problems, it is assumed that the impairment causes them.
3. The person with a disability is a "victim".
4. Disability is central to the disabled person's self-concept, self-definition, social comparison, and reference groups.
5. Having a disability is synonymous with needing help and social support.

Consider the following alternate assumptions from the disability discrimination model (May & Raske, 2005. Ending Disability Discrimination: Strategies for Social Workers).

1. Disability and impairment are not immutably linked.
2. Disability related impairment is socially constructed.
3. Disability is a nominal state.
4. Disability and pride can coexist.
5. Helpers must assume a "working with" rather than a "working on" orientation.

Student Discussion: Review each of the following examples and identify which of the above assumptions are made. Identify any additional assumptions you believe exist in these examples from the media:

Example 1

Headline: Extreme Makeover: Home Edition has wish list of Maladies
(Huntington Herald Dispatch, March 20, 2006)

Extreme Home Makeover is a "reality" TV series where families are selected to receive a new, custom built home.

A newspaper article reports on a memo sent by the show's casting director to ABC executives. The memo indicates that the producers of the show are looking for families with particular "maladies" or tragic circumstances to be featured on the show which builds houses for people. According to the Associated Press article appearing in the Huntington Herald Dispatch on March 20, 2006, the show's executive producer stated, "at the end of the day you're talking about someone who needs it badly and deserves it badly and building them a home that makes life a little easier for them. It's hard to figure out how that's exploitive."

According to the Smoking Gun (www.smokinggun.com) the following email was sent by the cast department of Home Edition:

As we begin to cast a new season for “Extreme Makeover: Home Edition” we also begin to look for stories of families who are trying to overcome adversity, but just need a little help (especially with their home!).

We are open to any and all story ideas and are especially looking for the following:

- *Extraordinary Mom/Dad recently diagnosed with ALS*
- *Family who has child with PROGERIA (aka “little old man disease”)*
- *Congenital insensitivity to pain with anhidrosis – referred to as CIPA by the few people who know about it. (there are 17 known cases in the US – let me know if one is in your town!) this is where kids cannot feel any physical pain.*
- *Muscular dystrophy child – amazing kid who is changing people’s views about MD*
- *MADD/Drunk Driving – family turns tragedy into triumph after losing a child to drunk driving*
- *Family who has multiple children w/Down Syndrome (either adopted or biological)*
- *Amazing/loved Mom or Dad diagnosed with melanoma/skin cancer*
- *Home invasion – family robbed, house messed up (vandalized)-kids fear safety in their home now*
- *Victims of hate crime in own home – family’s house victim of arson or severely vandalized*

Example 2

(The following is from www.telegraph.co.uk/news)

Autistic boy’s basketball dream becomes a reality

By Nicholas Wapshott in New Yoirk

(Filed 12/02/2005)

It is the stuff of fantasy: an autistic schoolboy is sent onto the basketball court as a last gasp substitute, scores 20 points in four minutes and becomes a national hero.

But that is exactly what has happened to 17-year-old Jason McElwain, from Rochester, New York, who, three weeks on from his triumph, is being courted by Hollywood – and President George W. Bush.

Jason has high-functioning autism – with a reasonable level of capability – but the handicap has not prevented him from becoming “manager” of Greece Athena High School’s basketball team. Apart from a couple minutes in a junior game two years ago, however, Jason’s condition has limited his role to revving up the team before a game.

But on the eve of the annual “senior night” game – held in the students’ final year of high school – the team’s coach handed J-Mac, as he is known, a shirt with 52 sewn on

the back, having told him he would try to get him into the all-important game at some point.

Come the final few minutes, Jason was duly sent onto the court. As his team-mates fed him the ball, Jason calmly took aim and made seven hoops from 13 shots, scoring five points a minute and breaking school records. Athena beat their rivals Spencerport by 79-43. At the final whistle, spectators carried Jason off the court on their shoulders.

His team-mate Rickey Wallace said, "I knew he could shoot, but I didn't know he could score 20 points."

Jason's father, David McElwain, 51, said, "He was really happy on the way home. He didn't sleep a lot that night."

Jason's sporting triumph might have remained a glorious memory had not his performance been captured on videotape. By the evening, a clip of Jason in action was shuttling around the internet, eventually reaching the sports cable network ESPN.

Today he is a national hero. Twenty-five film companies and publishers have bombarded him with offers, starting with the basketball superhero Earvin "Magic" Johnson, who instantly saw Oscar potential in the story of a boy who through courage and determination beats the odds. Johnson is now in a bidding war with, among others, Oprah Winfrey.

President Bush is hoping to stake a claim to Jason's triumph. On Tuesday, when the President makes a rare trip through upstate New York, he will present an award to the teenager.

Mr. Bush hopes that being photographed with Jason will help his sinking approval ratings, now at an all-time low.

What has impressed Jason's friends is how coolly he has taken his overnight success.

Tom Batzold, the sports editor of the Rochester Democrat and Chronicle, said, "Jason didn't ask for the publicity. Through it all he has held up under tremendous scrutiny. He's calm and collected. He's handled this like a champ."

Jason's feet have remained firmly on the ground. His plans "are to graduate, and go to MCC [Monroe Community College] and work at Wegmans [grocery store]".

Rochester, which looks across Lake Ontario to Canada, is speculating who will play Jason on screen.

"We think Tom Hanks should play the coach," said Mr. Batzold. "But for Jason? A few years ago, Leonard DiCaprio would have been perfect. But the actor needs to be much younger, an unknown. Whoever gets the part will be an instant star."

Example 3

A news story features a pre-teen girl who raised money to buy books for libraries destroyed by Hurricane Katrina. The narrator notes: “all this, and she is blind.”

Example 4

Consider the following possible headlines:

_____ Hit by Car

Fill in the above blank with the following descriptors, and consider how it changes your feelings, perceptions, or assumptions:

Child

Grandmother

Heroin Addict

Car Hijacker

Blind Man

Arab

_____ scores 20 points in 4 minutes in basketball game

Boy

Autistic Boy

Grandmother

NBA Hopeful

Mentally Retarded Boy

ABSTRACTS: ETHICAL CONCERNS FOR DISABILITY SERVICES

Overview

The following provides abstracts of articles related to ethics and disability services.

Paterson, B. (2004). Ethical approaches to physical interventions: Responding to challenging behavior in people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 225-228.

This is a literature review of a book devoted to the subject of physical interventions and the ethical issues associated with physical interventions. The research literature on how to address challenging behavior in people with learning disabilities is substantial and growing exponentially. This article addresses the great importance of developing an evidence base in this area of practice that reflects an awareness of the frequency with which challenging behavior takes the form of violence and the regularity with which both unplanned interventions and planned interventions incorporate physical interventions in the form of reactive strategies. According to the reviewer of this article, the book is very timely, useful, and thought provoking on a subject which has been long overdue such treatment.

Beals, K.P. (2003). The ethics of autism: What's wrong with the dominant paradigms and how to fix them. Mental Retardation and Developmental Disabilities Research Reviews, 9, 32-39.

This article addresses the fact that what is most difficult about parenting a person with autism is, presumably, the same as what's most difficult about actually being a person with autism: how the rest of society responds. To fix things, as we urgently need to, we must radically rethink the roles of parents and experts, the conventional models for treating autism, and the ways in which services are recruited and channeled to children with autism and their families. This article discusses a mother's personal experience with raising a child with autism and the challenges, personally and socially, her family faced and continues to face in regards to getting services. The article discusses how society knows little about the problems surrounding children with autism and in its ignorance it tends to make matters worse.

Even what most people do know or imagine about raising children with autism is distorted. The article addresses that people must ask themselves what they are willing to do to help out these families. Will they accept children with autism in practice, as well as in theory, by learning about the outward symptoms so as to recognize these children when they see them, and by

tolerating their public disturbances, welcoming them into their homes, classrooms, day care programs, summer camps, providing medical and dental care to them without insisting that they first be sedated, and helping out their parents?

The article also touches on how many professionals seem to ascribe to nature and nurture and there is an immediate need for these professionals to stop presuming parents are part of the problem. Professionals must also invert certain assumptions about expertise. When the subject is a particular child, as opposed to autism in general, it is not you, but those who spend the most time working directly with the children, who are the experts. It is crucial to notice the good things parents are doing and validate them.

It is crucial to provide programs for these children that not only provide them with the best education and teaching them about life and social skills, but programs and people that also foster their special talents that give them their best chances to become happy and productive members of society.

Feinberg, E., & Vacca, J. (2000). The drama and trauma of creating policies on autism: Critical issues to consider in the new millennium. Focus on Autism and Other Developmental Disabilities, 15(3), 130-137.

There is a need to explore the complex process of creating public policy for autism. The authors offer ideas relating to the four W's. What should be done? Who should do it? Where should it be done? When can results be expected? To accomplish this, the following topics are examined.

- 1.) Reasons why services to children with autism are now a major issue.
- 2.) Current controversies and their public policy implications.
- 3.) Some suggestions for deliberations.

Services to children with autism is now a major issue because there has been an increase in the incidence and prevalence of children with autism, there is no consensus on the disorder's etiology, there is no consensus on the most successful methodology for clinical intervention, the age of diagnosis coincides with the upper limit of IDEA, Part C, there has been a shift to a family-centered paradigm, there has been an increase in due process hearings and litigation, and there are current controversies and public policy issues. The formulation of policy is important as a foundation for service delivery.

Fisher, C.B. (2003). Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. Mental Retardation and Developmental Disabilities Research Review, 9, 27-31.

This article reviews current theory and research on informed consent policies for adults with mental retardation within a relational ethics framework that re-conceptualizes consent

vulnerability in terms of the goodness-of-fit between participant decisional capacities and the specific consent context. All individuals with mental retardation are unique. Some are capable of making decisions for themselves and others may lack the capacity or experience to do so. Impaired decisional capacity is more likely to emerge as a severity of mental retardation and cognitive levels of functioning do not directly predict differences in levels of communicative, interpersonal, or activities of daily living to adaptive functioning. Reframing informed consent as a goodness-of-fit between persons and consent context shifts away from the participant's mental status to examination and enhancement of those aspects of the consent setting that can reduce consent vulnerability.

This article also goes into detail on the MacArthur Scales, communicating a choice, factual understanding, appreciation, rational manipulation, enhancing consent capacity, a goodness-of-fit ethic of informed consent, vulnerability as a relational construct, enhancing informed, rational, and voluntary person-context consent, autonomy as connectedness to others and an informed consent ethic of mutual obligation, respect, and care.

Hutchinson, C. (2005). Addressing issues related to adult patients who lack the capacity to give consent. Nursing Standard, 16(23), 47-53.

This article explores the issues related to adults who are considered to lack the competence to consent to treatment and it aims to provide practical guidance on the assessment of capacity. Consent issues arise in a broad range of circumstances but, in many cases, consent is routine and straightforward. This article considers only those issues relating to adults who lack capacity. If there is a lack of capacity to consent, the healthcare practitioner is required to make and justify a decision on what action would be in the person's best interest. Ethically driven actions need to be taken to ensure that patients understand what consent means and what is going to happen to them and why. It is critical that best interest guidelines are followed to ensure ethical practice. Consent allows patients to exercise their right to autonomy and self-determination and the way they protect their person. The assessment by practitioners requires a flexible and creative approach.

Nachshen, J.S., Woodford, L., & Minnes, P. (2003). The family stress and coping interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment. Journal of Intellectual Disability Research, 47, 285-290.

This article discusses a study that investigated the psychometric properties of the Family Stress and Coping Interview (FSCI), which is a questionnaire designed to quantitatively and qualitatively examine the experiences of parents of children with developmental disabilities. Stress in families of children with developmental disabilities is great and has been the focus of many studies. The FSCI was developed to address parent's experiences related to events in the lives of their child with a developmental disability. The results of the study show that the stress

rating scale on the FSCI is a reliable and valid measure for use with parents of individuals with developmental disabilities. The scale shows to have a high level of internal consistency and a relatively high long-term stability. The results of the study provide preliminary support for the reliability and validity of the stress rating scale portion of the FSCI. The instrument shows promise for use in research and practice.

Paterson, B. (2004). Ethical approaches to physical interventions: Responding to challenging behaviour in people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 225-228.

The purpose of this paper is to outline the development and implementation of social policy for disability services in the 80s and early 90s. That era was driven by a sense of social justice and caring for disadvantaged people in our society, we now appear to be marching to the beat of a different drummer. This article walks the reader through where economically based policies are leading us (Australia), policies and social movements of the 60's and 70's, handicapped programs review, implementation of the disability services act (1986), the emergence of neo-classical economic policies, and then brings us up to date with the commonwealth/state disability agreement and the current scene of social policy. The article discusses that macro and micro economic reforms have resulted in an abrupt move from a sense of social justice to viewing disability programs as something useful and valuable. The article suggests that we need to move from complete government control to a sense of greater sharing of the power between all interested parties. In conclusion, the article states that regardless of disabilities, all people have the right to share equitably in the resources of our community.

Singer, P. (2005). Ethics and disability. Journal of Disability Policy Studies, 16(2), 130-133.

The purpose of this article is a response to someone else's writings on ethics and disabilities. This particular response is in disagreement with Tom Koch's article. Peter Singer (author) believes that many disabilities advocates defend their positions with arguments that are open to rational scrutiny and instead of characterizing views held by bioethicists and disability advocates as ideologies feels it would be more fruitful to examine the arguments that they put forward in defense of their positions. Singer begins his article with examining arguments fairly yet feels that Koch often gives prejudicial misreadings of positions that he and others hold. Singer goes on to give six examples of what Koch stated and then goes into his own detail on how absurd he feels Koch's claims are. For example, Koch states, "I don't hold that anyone with a disability "will be necessarily disadvantaged." Singer fires back at Koch to say that, "I would argue only that, other things being equal, being able to walk, to move one's arms, to hear, to see, to recognize other people and communicate with them, are advantages." Singer goes even further to say that we have to make decisions based on probabilities not on certainties. The article then turns to the topic of the view that all human life is equally to be protected, irrespective of whether it is the life of a capable being able to read or the life of an infant who will never be able

to notice her mother's smile. Singer goes on to explain what difference then does disability make to our life-and-death decision-making for newborn infants in relation to what Koch stated in his article. Singer concludes by stating that his view on the termination of a human fetal or newborn life have no bearing on the right to life of self-aware people with disabilities. He feels that... "they should be given the fullest possible support from the community in integrating into the community, and in living and working as normally as they possibly can. By those standards, most nations, including the United States, still have a long way to go."

Stocker, S. (2001). Disability and identity: Overcoming perfectionism. Frontiers, 22(2), 154-173.

This article discusses how narratives convey the constitutive moves that either enable or disable us being successful in our relationships with others, while ethics are what claim to inform our aspirations with respect to others. In this article, the author draws from her own experience with multiple disabilities while inflecting narratives of relational stories that are told via ethical theories. The article discussed a perfectionistic drivenness which is a distinctly one-sided affair. The author discusses the idea that when we relate to others, we see mirrored back an array of projected ideals which against these ideals we are only too aware of our own flaws. The author also explains her relational stories using Emmanuel Levinas's notion of one-sided obligation of reciprocity and Aristotle's disclosure of genuine mutuality between "noble" friends. After the author describes her relational narrative she leads the reader into Levinas's moral proximity to the other, then the coexistence in a kingdom of ends, a discussion of mutuality and overcoming perfectionism, implications for teaching and then ends with learning mutual solidarity. The author's concluding thoughts are powerful as she recognizes that, "In finding my own actualized agency, I discover that I'm not powerless, but rather powerful, especially when organized and acting in concert with others."

Ware, L.P. (2002). A moral conversation on disability: Risking the personal in educational contexts. Hypatia, 17(3), 143-172.

The purpose of this article is to explore conversations among scholars and philosophers about the attitudes, beliefs, and practices that shape school culture and influence perceptions about disability among school professionals, students, and their families. The article discusses Humanities-Based Disability, with the goal of revisualizing disability by challenging our collective stories through a cultural lens and retracing the institutional and communal histories that inform the construct that we recognize as disability. In a section called "Telling about disability, Telling about me," there were some very profound statements made by individuals who have a disability regarding the purpose of this paper. The article discusses classroom research and follows the teachers and individuals through many sessions, one of the teachers asked the students how best to educate society about disability. One of the students responded with, "You just bring it out in the open. You can't hide from it cause it's there – it's always going to be there – you know, you just can't keep ignoring it. I can't ignore my disability, why would you?" The article goes on to discuss how we as a society need to expand our view of possibilities and our educational systems need to restructure its focus to not one of solutions to

the care and inclusion of the disabled but to that of exploring the opportunities that disabled students bring to the classroom. The article also discusses disability counter narratives, risking the personal, and educating for the common good as well as disability and schools and reviving consciousness.

Human Behavior and the Social Environment

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OVERVIEW: HUMAN BEHAVIOR AND THE SOCIAL ENVIRONMENT

Human Behavior and the Social Environment (HBSE) content views human development and behavior from a person in environment perspective and includes theories and knowledge focusing on the interactions between and among individuals, groups, societies and economic systems. Biological, sociological, cultural, psychological, and spiritual concepts are applied through the life span, and social systems are examined in terms of how they promote or deter people in maintaining or achieving health and well-being. (CSWE, 2003)

Content related to developmental disability is easily integrated into this curriculum area. Definitions of disability can be explored from a person-in-environment/social construct perspective, relying upon strengths and the context of social systems. The definitions of disability and models of disabilities included in the introductory section of this manual can be used as introduction to disability relative to HBSE.

This section provides a values clarification exercise targeted toward HBSE, building upon the general values clarification activities found in the previous section. A sample case study is then provided as a framework that can be used to explain the HBSE paradigm related to disabilities. This is followed by handouts explaining developmental milestones and disability, and in turn, brief descriptions of the most common developmental disabilities seen in practice. This section concludes with interdisciplinary tools and content used by professionals such as the multidisciplinary team approach to abuse and neglect, transition planning, Individual Education Plans, and meeting the needs of mothers with disabilities.

DEVELOPMENT AND DISABILITY

Mackelprang and Salsgiver (1999) review human development within the context of disability. The authors state, “we define disability by the meaning the disability carries for the individual. People with disabilities are people in which a disability is part of their lives – not the definition of their lives. Having a disability means difference, not tragedy.” (63) This is a perspective shared by May and Raske (2005) who state several propositions:

- *disability is not a tragedy*
- *disability does not mean dependency*
- *disability does not mean loss of potential, productivity, social contribution, value, capability, ability, and the like*
- *disability is a natural part of life, everyone’s life*
- *there is as much variation between people with disabilities as between people in general*

With that perspective in mind, Mackelprang and Salsgiver (1999) identify various implications of disability in stages of development:

Birth to 3

From the perspective of trust vs. mistrust, painful interventions or separations from family can complicate development of trust. Gaining autonomy and control over their lives can also be complicated if the atypicality constrains ability to explore and gain competence in managing the environment. It is important to provide supportive and adaptive environments and adaptive devices that allow for maximum control over the environment. Parents should be educated about developmental needs and ways to meet these needs and modify environments and be educated about legal protections and supportive services. Professionals should be alert to any tendency to lower expectations that serve to inhibit maximal development and also should be aware of special vulnerabilities children with disabilities may have related to abuse and maltreatment.

3 to 6 years

Language development may be delayed or acquired differently for children with certain disabilities. Supportive environments, use of sign language, and technological devices should be used as appropriate since communication is a significant factor in gaining a sense of autonomy and empowerment. At this age, interaction with peers is also important as is having role models that include people with disabilities. Children should not be isolated from others.

6 to 12 years

Again, interaction with peers and development of social skills and friendships is important. Role models that include people with disabilities help children develop positive self-images. Integration and inclusion are encouraged. Individualized educational plans may be needed for some children. Mackelprang and Salsgiver also note some difference with children who first

become disabled at this age versus those who have never known anything different. For those whose onset of disability occurs at this point, a change in self-concept may occur and relationships may change. Families may go through a grieving process and need to readjust their concepts related to their child. Financial stress can occur.

12 to 18 years

This is the time of many physical changes brought on by puberty. Exploration of identity, increasing independence, importance of peer relationships, and interest in intimate relationships are tasks of this stage. Discrimination and stereotypes (as well as over-protection) can hinder development of independence, social relationships, and positive self-concept. Good role models; facilitation of independence, autonomy, and control over one's life; education and support in development of sense of sexuality and positive body-image; and maximization of social interactions are important at this age. Professionals should be alert to increased vulnerability to sexual abuse and to effects of discrimination and stereotypes. Adolescents who previously did not have a disability, may have believed some of those stereotypes themselves and may also experience loss of some social relationships and positive self-identity. Supportive, disability-affirming environments are helpful in overcoming potential obstacles to optimum development.

Young Adulthood

Independence, employment, housing, transportation, and intimate relationships become important at this stage. Independent living services and other community support services can help. These may be especially important for those who acquire a disability at this stage. Mackelprang and Salsgiver make the point that “deprofessionalizing services and redirecting resources to the control of individuals allows people who use attendants to hire and direct their personal attendants rather than being dependent on others to control how and from whom they receive care”. (1999, 71) Young adults can also become advocates and role models for others.

Middle Adulthood

Mackelprang and Salsgiver note that “persons with disabilities in their middle years have been instrumental in developing a burgeoning disability culture and in changing the political and legal landscape for those that follow”. (1999, 72). Middle age is also a time when people may first acquire an age-related disability and may need to understand that it is not tragic or inhibiting to living full, satisfying, and meaningful lives.

Older Adulthood

Most older adults will eventually acquire some type of disability. As with adults who acquire a disability in middle age, continuing opportunities to living full, satisfying and meaningful lives are important. Ageism adds to barriers for older adults.

Reference

Mackelprang, R. and Salsgiver, R. (1999). Disability: A diversity model approach in human service practice. Belmont, CA: Brooks/Cole.

ASPERGER'S SYNDROME: A STORY OF CHARLIE EARLY CHILDHOOD

Charlie is an 18-year-old male who has been diagnosed with Asperger's Syndrome. He has three other brothers, two older and one younger. Charlie's birth was normal, but labor was short and severe requiring a few seconds of oxygen to be given to him immediately after birth. As an infant Charlie would scream whenever someone attempted to change a diaper or give him a bath.

Although early development proceeded normally, Charlie started with what was termed by doctors as Passive Aggressive Disorder. At eighteen months of age, Charlie started refusing to eat many foods. He limited his diet to dairy and grains, completely refusing to eat meats, fruits, or vegetables. Even though he started to walk before a year old, he suddenly stopped and decided to crawl until fifteen months of age. He had language ability, but refused to talk until four years old, preferring to grunt and point. He would go without something rather than talk or repeat a phrase he had said. Potty training was an issue due to retained bowel syndrome and refusals.

Charlie preferred to play on his own or to sit quietly against a wall or under a piece of furniture. He could remain so quiet and still for extended periods of time that you could walk right past him and not know that he was there. Charlie was fascinated with anything to do with nature (i.e., animals, plants, etc.). He would only allow you to hold him when he initiated the action, which was always of brief duration. When he was upset, you could not hold or comfort him. If the family went out socially, say to a school function, Charlie would often hide under a table or desk and growl at people who went past. At times this growling would be accompanied by his swatting at people, especially if they attempted to engage him in any way.

Charlie was put in preschool programs starting at age 3-1/2. He would often sit outside of the circle, but listened to everything that was said. In kindergarten his teacher noticed that even though he appeared not to be paying any attention, Charlie knew where she was and everything she said no matter where she was in the room. He continued to be a "loner" not engaging socially with classmates. Charlie had to repeat 1st grade due to his refusal to participate in the class for 3/4 of the year. In fact, Charlie had to be dragged to school kicking, biting, and screaming. Once at school he would behave, but I would get panic calls from the school saying that they could not find him. He would be located in a bathroom stall hiding on the toilet or separating wall, or standing quietly against a hallway wall watching people go past looking for him. Until this point, the school system did not think there was a problem and my concerns had gone unheeded. Now they wanted Charlie to have professional evaluations.

Charlie's first official evaluation was at Newington's Children's Hospital in Connecticut. Both Charlie and his mother were interviewed together and separately along with different tests that were administered to him. The results of all this were that they suspected her of child abuse (something Charlie said while interviewed alone because he didn't understand their question). She was told that Charlie was of low average intelligence*, they diagnosed him with ADHD, and suggested a full psychiatric evaluation/counseling. The mother's opinion was that Charlie was not ADHD. At one point Charlie spent an entire day sitting at the dining room table (except for

bathroom breaks and meals) rather than write three sentences for school. He was not disruptive or restless in any manner; he just refused to write more than three words. She felt this was not ADHD behavior and set up the psychiatric evaluation.

Although the psychiatrist could not diagnose Charlie's disability, he did agree that Charlie did not have ADHD. He stated that Charlie did not have Autism, but it would be helpful to read up on the disorder as Charlie exhibited many of the traits.

These behaviors continued with Charlie receiving occupational and speech therapies, and behavior modification services through the school. When Charlie was eight years old, his father shut down with clinical depression. The family was thrown into a crisis mode. A call from the school alerted his mother to the fact that Charlie might be suffering from depression himself. Charlie began exhibiting suicidal ideations and acting out violently. Although psychiatric counseling and medication management were started immediately, Charlie spent his ninth birthday hospitalized due to a thwarted suicide attempt. This was the start of a year and a half of 911 calls due to violent behavior, emergency room visits, and inpatient and outpatient hospitalizations.

Counseling was problematic as Charlie was not cooperative. He often hid under the table and growled. At one point he locked himself in the men's room, refusing to come out until security finally managed to get the door open. The insurance company finally decided to send a counselor out to the house. On his own turf, Charlie finally started to respond.

The family learned a lot through this process. For one, they learned that Charlie was not necessarily ignoring us when we asked him questions and he talked about something to do with nature. Charlie used analogies with nature in an attempt to communicate with others. The counselor taught Charlie to come to us for comfort and to accept hugs. He was also the first person to mention Asperger's syndrome (then still a new diagnosis) and recommend an evaluation for it. Consequently, Charlie was finally diagnosed with Asperger's at nine years of age.

* Standardized testing has rated Charlie from low average intelligence to gifted depending on the mood he was in and external factors at the time of testing.

DISABILITY DISCRIMINATION: THE INSIDIOUS INSPIRATION QUOTIENT

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Background

Approximately 54 million Americans have a disability according to the U.S. Census Bureau's 1996 data. This represents approximately 20% of the U.S. population. As people age, they face a risk for adventitious disability that is roughly proportional to their ageing. For example, by age 85, 84% of Americans have at least one disability.

In a 1998 survey of U.S. households commissioned by the National Organization on Disability (NOD) conducted by Harris and Associates, the pattern and magnitude of poor quality of life indicators was again substantiated. This survey has been conducted periodically over the past several years. In the 1998 survey, the unemployment rate among persons with disabilities was 6%. Secondary students with disabilities were twice as likely to drop out of high school as students without disabilities. Furthermore, the NOD/Harris survey found that persons with disabilities were 1/3 less likely to socialize with friends, less likely to go to a restaurant at least one time weekly, significantly less likely to be registered to vote when compared persons with no disabilities. Households with a disabled member had a 33% higher exposure to poverty than non-disabled households. One third of respondents said that transportation was a major problem in their lives. Finally, persons with disabilities were significantly less likely to report being satisfied with their lives when compared with their non-disabled peers.

This abysmal state of affairs persists, substantial expenditures of money and effort directed toward "helping" persons with disabilities notwithstanding. When asked, most respondents report a very favorable attitude toward persons with disabilities. Public discourse that seems to reflect this overall favorable attitude seems to betray powerful, insidious limiting and perjorative attitudes toward this population however. There seems to be powerful forces that largely go unchallenged that perpetuate second class citizenship for person with disabilities.

Assumptions that Support the Status Quo

In their 2000 article, "Disability Beyond Stigma: Social Interaction and Activism", Fine and Asch assert that 5 pervasive assumptions conspire to perpetuate ongoing marginalization of people with disabilities. The first of these is the assumption that disability (and disability-related impairment) is located solely in biology, and is therefore immutable. A second assumption is that when a disabled person faces problems, it is the impairment (disability) that causes them. Third, it is assumed that the disabled person is a "victim". Fourth, disability is thought to be central to the disabled person's self-concept, self-definition, social comparison, and

reference groups. Finally, it is assumed that disability is synonymous with needing help and social support.

These assumptions provide a durable framework and suggest a familiar perspective for understanding persons with disabilities—all without the holder of such assumptions having to identify or claim any animus toward persons with disabilities. The assumptions, if unchallenged, help to “explain” and “understand” the experience of disability. In effect, the assumptions provide all the necessary answers. They also direct behavior.

If the assumption that disability and impairment are immutably linked is accepted, then why look any further than individual mitigation to reduce impairment? If all problems are viewed as consequences of disability, why focus interventions beyond the owner of the disability? Because of the rather sympathetic orientation toward victims, and an expectation for their engagement as passive recipients of the helpful beneficence of others, we tend to have low expectations. Furthermore, if a disabled person has the audacity to express dissatisfaction with the well intentioned, but misguided “helpful” assistance of others, they are deemed overly demanding, unappreciative, and the ultimate defense proffered by Samaritans is, “I was only trying to help”. Good intentions are expected to trump ineffectiveness, a conditions I’ve previously referred to as “beneficent incompetence”.

The power and pervasiveness of these assumptions and the predictability of behavior they drive is found broadly in popular culture. Most notably, the assumptions shape and predict the discourse about disability in America.

The Inspiration Quotient

An example from the June 22, 2004 edition of the Evansville Courier and Press serves to illustrate the circular, pejorative, limiting, stereotypic views about persons with disabilities. The article—a full front page story with predictable color photographs—concerned a 22 year old man who uses a wheelchair. The photos and text depicted this young man engaging in activities that most of us would consider being rather routine, and certainly unremarkable. Activities such as greeting worshipers at church, bowling, visiting with benefactors (folks who had “befriend” this young man through their involvement in the community integration program in which he is enrolled), and similar “normal”, “routine” activities were highlighted. The text was replete with references to the young man’s persistence, sense of humor, aspirations, and pleasantness. Again, none of these characteristics would be deemed noteworthy—and certainly not newsworthy—if exhibited by any other person. The editorial bias, to wit; these things are remarkable—and newsworthy—because this man has a disability and uses a wheelchair. The low expectations for persons with disabilities betrayed by the newspapers judgment about the interest and value of this man’s story both reify and nurture the assumptions discussed in the Fine and Asch article. Such stories highlighting “accomplishments” and implicitly unexpected “normal” behaviors are all too commonplace.

Such articles have prompted me to consider how we might understand their appeal. I’m developing the concept of The Inspiration Quotient (In. Q.) The In. Q. can be understood as the relationship between expectations for and achievements of persons with disabilities. Given the

chronic, widespread condition of low expectations, even nominal “achievements”, such as depicted in the Courier and Press article, are “extraordinary”. Their appeal includes an affirmation that people with disabilities—for whom we have no animus—actually can do “normal” things. They are deemed “inspirational”. It makes the non-disabled viewer feel better.

The “average” In. Q. is 100 (a perfect match between expectations and achievement), where the subject does as expected. In. Q.s in excess of 100 occur either because expectations are incredibly low (the usual condition) and achievements are average (such as in the case above), or In. Q. values because achievements exceed the typical low (v. “incredibly low”) expectations. Below average In. Q. values occur when the achievements are substantially lower than expectations. Such condition seems most common in educational settings where expectations have to do with compliant school behavior rather than academic performance.

In the absence of “noteworthy” achievements, effort counts in the In. Q. computation. This is reflected in accounts of the “achievements” of Special Olympics participants, where medals are awarded for skills that are of little or no functional value. (For example, the softball toss is scored on distance rather than accuracy or reciprocity. Most folks who throw a softball throw it to another *person*, not just randomly on the field), and every participant is a “winner” just trying. (Effort counts!) Media accounts of these events are replete with effusive, evocative accounts by the dispensers of copious hugs who attest to the affirming effect of dispensing hugs to such “deserving” recipients. (Beneficence rewarded!) No one questions the paradigm that victimizes Olympians thereby creating opportunities for “normals” to express their generosity and love.

Obviously, the In.Q. is very susceptible to the biases and interpretation of the observer. For some, that we disabled folks are able to get out of bed and go to the supermarket is “inspirational”, warranting a high In. Q. for us—we should feel good, right? Who knows, the newspaper may even want to a story about our shopping, deeming it newsworthy!

Using us and our lives as inspirational icons that reinforce the very limiting judgments and behaviors that serve to perpetuate our marginalization is duplicitous at best, and cruelly exploitive, at worst. This conspiracy of low expectations, ascribing inspirational value and failure to understand the experience of disability as a dynamic, socially constructed phenomenon, where the quality of our lives is predicted more by what happens around us than by what are disabilities are, continues to relegate us to second class citizenship.

Assumptions that Challenge the Status Quo

In our textbook, Ending Disability Discrimination: Strategies for Social Workers, my co-editor Martha Raske, and I argue that disability is only reasonably understood in this dynamic framework where the quality of interaction is a more important predictor of achievement and satisfaction than the disability itself. Disability-related impairment is viewed as a consequence of discrimination, not as a consequence of the disability itself. Our book is based on the assumption that disability and impairment are not immutably linked. As a wheelchair user, I’m not usually impaired, but in an environment that has architectural barriers such as steps, I am impaired even though my disability is exactly the same in both circumstances. So, impairment is not predicted by my disability but by the receptiveness of the environments in which I operate.

A second assumption is that disability-related impairment is socially constructed. It's all about the capacity in communities for all citizens to access opportunities to participate, to achieve, to fail and to be held accountable. This suggests a much broader target system for intervention on behalf of people with disabilities. Continuing to focus interventions on mitigation, restoration, and rehabilitation, while continuing to ignore broader systems, prejudices and marginalizing forces, is short sighted and of very limited positive consequence for people with disabilities.

Raske and I contend that “disability” is a nominal state that is accompanied by limiting assumptions, prejudices, and stereotypes only if it suits the observer. In this sense, disability is a name only. It does not in itself suggest inferiority, superiority or anything else. To the degree that such judgments accompany the conceptualization and discourse about disability, they reflect the biases of the holder of such judgments. Clearly, we have made impressive improvements—even though we have work to do—in understanding race and gender relations. We must work to further this understanding of disability.

Disability and pride can coexist. This assumption casts a different light on the perceptions of and about persons with disabilities than is consistent with rash conclusions about our value as icons of inspiration. Pride is an important confounding variable in the In. Q. calculation. How does one assess the influence of pride as a motivator in our living rich, productive lives—not in spite of or because of our disabilities—but with our disabilities? Most folks think disability is anathema to pride. The concept of “Disability Pride” is an oxymoron to them.

Finally, Raske and I assert that helpers/advocates/activists must assume a “working with” rather than a “working on” orientation when interacting with persons with disabilities. This collaborative, consultative role is contrary to the usual stereotypes and expectations concerning persons with disabilities. The evidence that little is at risk if we change our orientation is abundant. It was again validated in the NOD/Harris survey.

The Americans with Disabilities Act was signed into law on July 26, 1990. The U.S. Supreme Court's Olmstead decision was June 22, 1999. These seminal changes in the glacial movement of legislation and litigation involving people with disabilities have not resulted in radical or even significant granular changes in American culture. People with disabilities may well be the last discovered minority group in the U.S. It's up to all of us who are willing to challenge and question the assumptions that support the status quo to insist that changes be made. We need to challenge In. Q. assumptions. We need to challenge popular portrayals of people with disabilities. We need to challenge low expectations. We need to challenge patronizing treatment of and second class citizenship of persons with disabilities. It's imperative that we each make the changes that we can. The stakes are high. The need is great. LET'S GO DO IT! LET'S END DISABILITY DISCRIMINATION!!!

DEVELOPMENTAL DISABILITIES

The following resource sheets provide brief descriptions of some common developmental disabilities. The attempt is not to compartmentalize these conditions/diagnoses, but rather to give the student some basic information. The instructor should begin by introducing or reviewing the perspective of disability as a social construct (i.e. review the definitions of disability and models of disabilities provided in this resource manual). Viewed in this manner the limitations of the medical model should become salient and the student should be able to recognize the implications of the limitation.

OVERVIEW OF ASPERGER'S SYNDROME

Asperger's Syndrome is a life-long neurobiological disorder. Due to many common characteristics, it is often considered to be an Autism Spectrum disorder although the debate goes on as to whether it should be classified separately. First mentioned by Hans Asperger in 1944, this disorder was not commonly diagnosed until the mid 1990's. Individuals with Asperger's Syndrome are typically on the average to high end of the intellectual scale. According to Dr. R. Kaan Ozbayrak in A Guide for Parents, the prevalence rate for this disorder is 36/10,000, typically affecting males much more frequently than females (4:1). There is current evidence that genetics plays a part in the occurrence of this disorder. Some famous people thought to have Asperger's include Albert Einstein, Thomas Edison, Leonardo da Vinci, and Beethoven.

Individuals with Asperger's vary greatly both in the characteristics of their disorder and in its severity. According to the DSM-IV-TR, criteria for the disorder are qualitative impairments in social interaction and restricted repetitive and stereotyped patterns of behavior, interest, and activities causing significant impairment in social, occupational, or other important areas of functioning with onset occurring before the age of three. It is important to note here that not all individuals consider this to be a disorder. Some refer to those without the disorder as "neuro-typical" individuals and themselves as "Aspies".

Diagnosis is usually made based on a combination of early developmental history, displayed behaviors, and reports from parents, caregivers, and other involved entities. Since diagnosis of this disorder is fairly recent and the first to be diagnosed were children, many adults were either not diagnosed, or misdiagnosed. Criterion for diagnosis in adults is still being developed. It is not uncommon for those with Asperger's to have a dual diagnosis of Depression and/or Anxiety disorders.

Characteristics vary with difficulty with social relationships being a commonality. Children will benefit from Social Skills Training. In addition to problems with social interaction, individuals often have problems reading non-verbal cues, are concrete not abstract thinkers, and are oversensitive to stimuli (i.e.: noise, taste, smell, feel). Stimuli may become overwhelming for the individual resulting in inappropriate behaviors. It is important to have a "safe" spot where the individual may retreat to when they feel overwhelmed. Making eye contact may be difficult especially in the case of children. Their preoccupation with certain interests/activities may lead to them being considered by others as rude, geeks, or bores. It is through these very same limited interests/activities that many attempt to communicate. These interests/activities may therefore be used as an affective means of "connecting" with the client.

Adults have often learned to use their strengths to mask different aspects of their disorder. Adults often run into problems in understanding emotions (theirs and/or others), in work and intimate relationships, social situations, etc. One individual stated that he "learned" how to appropriately respond in social situations, but could not apply that to close relationships where emotions came into play. Adults' limited focus of interests/activities often influences their choice of employment. Inability to remain in this general area becomes more of a crisis for these individuals than the majority of the population. As with children, the effort of attempting to appear "normal" may be emotionally and physically exhaustive.

Since this is a neurobiological disorder with individuals ranging from average to gifted intelligence, their disability is not as apparent to most individuals as a physical disability. It is difficult for parents, teachers, and others to understand how someone who is so intelligent and knowledgeable in certain areas has issues/difficulties with others. For example, there may be strengths in areas of verbal ability with weaknesses in non-verbal areas. The important thing to remember is that everyone is an individual with different strengths and weaknesses. Everyone has their own special gifts. Building on these strengths along with Social Skills training are important aspects of working with individuals with Asperger's.

AUTISM SPECTRUM DISORDERS

Autism is a developmental disability that affects communication, social interaction, and patterns of behavior. Autism is four times more common with males than females. Signs of autism are usually seen by age 3, for some children as early as 18 months. Autism Spectrum disorders (ASD) can range from severe to a milder form (Asperger syndrome). Sometimes the diagnosis of ASD is delayed because teachers or doctors believe the child is just “a little slow” and will catch up.

Children who are diagnosed with ASD demonstrate atypicality in 3 areas: 1) social interaction, 2) verbal and nonverbal communication, 3) repetitive behavior or interests. Each of these atypical behaviors can range from mild to severe. Each child may experience different effects. Children with this disability may follow typical child development patterns for the first year or so and then show less typical patterns. Some children with ASD find it hard to engage in the give and take of everyday social interaction and are not able to play with other children. It can also be hard for some people with ASD to regulate their emotions. Some children do not speak and some become very disturbed if a routine is interrupted in any way. Many children with ASD experience increased sensitivity as the brain seems unable to balance the senses. Facial expression, movements, and gestures may not match verbal communication. Tone of voice is sometimes high-pitched, or flat and robot-like. Tone of voice may not match emotion. Frustration, anxiety and depression may occur as children become more aware of their difficulties in communicating with others.

Generally, diagnostic evaluation is made by a multidisciplinary team including a psychologist, a neurologist, psychiatrist, a speech therapist, a social worker, or other professionals who diagnose children with ASD. Children with ASD are guaranteed special education and services under the Individuals with Disabilities Education Act (IDEA) and public schools must develop an Individualized Education Program (IEP) to meet the child’s needs. Early intervention is important in identifying child and family needs and building on the child’s and family’s strengths. Intervention can help build communication and social interaction skills. In middle and high school years, services can help address work, living, and recreation activities.

Reference

National Institute of Mental Health
[Http://www.nimh.nih.gov/publicat/autism.cfm](http://www.nimh.nih.gov/publicat/autism.cfm)

BRAIN INJURY

Traumatic brain injury (TBI) is an insult to the brain, not of a degenerative or congenital nature, caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning.

Acquired brain injury (ABI) is an injury to the brain which is not hereditary, congenital or degenerative. An acquired brain injury is an injury to the brain that has occurred after birth. Causes of ABI include external forces applied to the head and/or neck (traumatic brain injury), anoxic/hypoxic injury (e.g., cardiopulmonary arrest, carbon monoxide poisoning, airway obstruction, and hemorrhage), intracranial surgery, vascular disruption, infectious diseases, intracranial neoplasms, metabolic disorder, seizure disorders and toxic exposure.

According to the Brain Injury Association of West Virginia, TBI is the number one killer of persons under the age of 44 and a major cause of disability. Motor vehicle accidents cause more than one half of all traumatic brain injuries.

Mild brain injury is also known as a concussion. Moderate brain injury results in loss of consciousness lasting from a few minutes to a few hours. Confusion may last from days to weeks and physical, cognitive and/or behavioral impairments may last for months or be permanent. Severe brain injury almost always results in prolonged unconsciousness or coma. It is also sometimes classified into subgroups (i.e., coma, vegetative state, persistent vegetative state, minimally responsive state, akinetic mutism, and locked-in syndrome). Coma is a state of unconsciousness from which the person cannot be awakened and will not respond to stimuli or initiate voluntary activity.

Reference

Information above taken from the Brain Injury Association of West Virginia website:
<http://www.biausa.org>

CEREBRAL PALSY

Cerebral palsy refers to a group of condition in the motor control centers of the brain which cause problems in movement and motor functioning. These conditions usually are present at birth and may include paralysis, weakness, problems with coordination, or other atypical motor functioning. A child with cerebral palsy generally cannot move his or her muscles in a typical way. There are many possible causes of cerebral palsy including prenatal illness or infection, insufficient oxygen reaching the fetus (i.e. placenta tearing away from the uterus before delivery), prematurity, asphyxia during labor and delivery, blood diseases, server jaundice, other genetic conditions, and post-natal brain injuries (i.e. trauma or brain infection such as meningitis).

Symptoms may range from mild to severe but do not get worse over time. Cerebral palsy is not diagnosed until about age 2 or 3 and generally is based on evaluation of muscle tone and mobility. Another indication may be the presence of reflexes that typically disappear by 6 to 12 months of age. Brain imaging tests may also be used.

The 3 major types of cerebral palsy are:

- spastic – about 70 to 80% of people with cerebral palsy have this type – muscles are stiff and there may be difficulty in walking – arm, mouth, and tongue muscles may also be affected
- athetoid or dyskinetic cerebral palsy – (10%) – this affects the entire body and is characterized by fluctuations in muscle tone (varying from too loose to too tight) and is sometimes associated with uncontrolled movements – also may have difficulty with sucking, swallowing and speech.
- Ataxic cerebral palsy- (5 – 10%) – affects balance and coordination – may have difficulty with writing and may walk at an unsteady gait.

The majority of people with cerebral palsy do not have any cognitive disability. People with cerebral palsy are doctors, lawyers, teachers, social workers, artists, parents, etc..

In many cases, cerebral palsy cannot be prevented. However, some causes can be prevented by pre and post-natal care, vaccinations, nonuse of alcohol and other dangerous or illicit drugs, and prevention of head trauma such as proper use of car seats.

COGNITIVE DISABILITY

The American Association on Mental Retardation defines cognitive disability as a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. It is not a medical disorder, nor a mental disorder. The AAMR further states that "...mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being."

The AAMR advises professionals to:

- evaluate limitations in present functioning within the context of the individual's age peers and culture;
- take into account the individual's cultural and linguistic differences as well as communication, sensory, motor, and behavioral factors;
- recognize that within an individual limitations often coexist with strengths;
- describe limitations so that an individualized plan of needed supports can be developed; and
- provide appropriate personalized supports to improve the functioning of a person with mental retardation.

Intelligent Quotient (IQ) scores are used as a criterion for diagnosis of cognitive disability. Generally, an IQ test score of 70 or below, significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are criteria for determination of cognitive disability.

Reference

Source: http://www.aamr.org/Policies/faq_mental_retardation.shtml

Note: The American Association on Mental Retardation has voted to change their name to American Association on Intellectual and Developmental Disabilities.

DEAFNESS/HARD OF HEARING

Hearing loss can be inherited or caused by illness or injury. Hearing loss involves the decreased ability to hear sounds. Early detection of hearing loss is important in order to assist in language and communication development. Deaf and hard-of-hearing people can communicate as effectively as people without hearing loss.

The Individuals with Disabilities Education Act (IDEA) ensures the right of children between birth and 3 to receive interdisciplinary assessment and early intervention services at little or no cost. After age 3, early intervention and special education programs are provided through the public school system.

The type of sign language preferred by most deaf American adults is the American Sign Language (ASL). Many individuals with hearing loss identify with a deaf culture or deaf community and reject the pathological or medical perspective on deafness. The pathological view focuses on deaf people as different in a negative way and sees deaf people as a group of persons whose hearing loss interferes with the normal reception of speech, who have learning and psychological problems due to hearing loss and perceived communication difficulties, and who are not normal because they cannot hear. The deaf culture perspective defines deaf culture as a group of persons who share a common means of communication (sign language) that provides the basis for group cohesion and identity, who share a common culture, and whose primary means of relating to the world is visual and who share a language that is visually received and gesturally produced.

Deaf culture prefers "deaf people", "deaf" or "hard-of-hearing: rather than "people with deafness."

Reference

Sources; <http://deafness.abobut.com/cs/deafclture/a/deafcuture101.htm>
<http://www.signmedia.com/index.htm>
http://www.marchofdimes.com/pnhec/4439_1232.asp

DOWN SYNDROME

Down Syndrome is a common genetic variation which usually causes delay in physical, intellectual, and language development. It is the leading cause of developmental delay. Down Syndrome includes characteristic facial features, some degree of cognitive disability, and may also include heart conditions, increased risk of infection, vision and hearing disabilities, and other health problems. The effects vary from individual to individual – each person having his/her own unique personality, capabilities, and talents.

Facial characteristics may include eyes that slant upward, small ears that may fold over at the top, small mouth, small nose with flattened nasal bridge. Some babies with Down Syndrome have short necks, small hands, and less muscle tone.

Almost half of babies with Down Syndrome have heart conditions and more than half have some visual or hearing impairment. Most of the visual impairments can be eliminated with glasses, surgery or other treatments. Screening for hearing loss should be done at birth or by 3 months of age. Children with Down Syndrome can benefit from inclusive education, appropriate medical care, early intervention, and positive public attitudes.

In adulthood, many persons with Down Syndrome are employed, live independently, and contribute to and enjoy community activities. About 15 to 20 percent of adults with Down Syndrome develop Alzheimer's disease in middle age.

Reference

Sources: <http://www.ndscenter.org/>
http://www.marchofdimes.com/pnhec/4439_1214.asp

SEIZURE DISORDER/EPILEPSY

People who have been diagnosed with epilepsy have had more than one seizure and possibly more than one type of seizure. A seizure occurs when certain atypical electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness, or behavior. Seizure disorders/epilepsy affect about 2.3 million Americans. People of all ages are affected, but it is more common with the young and old. There is some disagreement about the classification of seizure disorder/epilepsy as a developmental disability.

What causes seizure disorders/epilepsy is not always clear but it can result from another condition such as head injury, brain tumor, brain infection, or stroke. Repeated seizures can happen without warning and for no clear reason. The way a seizure manifests itself may vary from person to person. Some people lose muscle control and the body may twitch or jerk. Some people become “trance-like” or unconscious. Not every one who has a seizure has epilepsy.

There are different types of epileptic seizures including generalized seizures and partial seizures. Generalized seizures begin over the entire surface of the brain and may affect the whole body while partial seizures begin in a specific location in the brain and may cause cognitive impairment on one side of the body or the whole body. A useful test in diagnosing seizure disorder/epilepsy is an electroencephalograph (EEG) or an MRI. Seizure disorder/epilepsy can be treated with medication to control seizures as well as with special diet and, in some cases, surgery.

According to the Center for Disease Control, “people with epilepsy often struggle to overcome low self-esteem and the stigma that is attached to having epilepsy. The stigma is due in part to a lack of understanding by people they see every day – family members, schoolmates, colleagues. Some people mistakenly believe that epilepsy is a form of mental illness or mental retardation, that seizures are something to fear, that drastic first aid measures must be taken to help someone having a seizure, or that people with epilepsy cannot be valuable and productive employees. Public education is needed to eliminate these misconceptions”.

References

National Center for Chronic Disease Prevention and Health Promotion
<http://www.cdc.gov/epilepsy/>

Rowette, L. Dan Yahoo!Health Epilepsy
<http://health.yahoo.com/ency/healthwise/hw108148>

FETAL ALCOHOL SYNDROME

Fetal Alcohol Spectrum Disorders (FASD) result from prenatal exposure to alcohol. Fetal Alcohol Syndrome (FAS) is the most severe and results from alcohol passing from the placenta to the fetus in sufficient amounts to have lifelong effects. FAS is one of the most common known causes of mental retardation and is entirely preventable.

Characteristic physical features of FAS may include small eyes, thin upper lip and smooth skin in place of the usual groove between the nose and upper lip, smaller brain, improperly formed heart, and growth deficiencies. Many children with FAS have some degree of learning or cognitive disability, poor coordination, short attention span, and emotional and behavioral problems. Vision and hearing may also be affected. These characteristics are thought to continue throughout the lifespan.

Fetal alcohol effects (FAE) refer to conditions of babies who are born with lesser degrees alcohol related symptoms.

References

Sources: <http://www.nofas.org/>
<http://cdc.gov/ncbddd/fas/>

FRAGILE X SYNDROME

Fragile X syndrome is the most common inherited form of cognitive disability. It is a genetic condition caused by gene changes in the FMRI gene. Females tend to be affected less often than males and less severely.

Children and adults with Fragile X syndrome have varying degrees of cognitive disability and learning disabilities and behavioral and emotional issues. Young children often have developmental delays and may have more frequent tantrums and attention difficulties. They may appear to be highly anxious, easily overwhelmed by activity around them, have speech problems, and engage in behaviors such as hand flapping or hand biting. Tactile defensive responses (negative response to touch), preservative speech (continued repetition of words or phrases), and poor eye contact may be present. Physical features may include large or prominent ears, large testicles, double jointed, Simean crease (single horizontal crease on the palm instead of the usual 2 creases, or Sydney Line (a horizontal crease that goes from edge to edge across the palm). Fragile X syndrome is the most common known cause of autism or autism associated behaviors.

Most children with Fragile X syndrome do not have serious medical problems although about 20% develop seizures, which are generally controlled by medication.

Fragile X syndrome may be diagnosed by blood test. A blood sample is analyzed to determine if the gene variation is present. Most children with fragile X can benefit from individualized intervention plans that may involve speech therapists, physical and occupational therapists, special educators, psychologists and social workers, and pediatricians.

References

Sources: <http://www.fragilex.org/>
http://www.marchofdimes.com/pnhec/4439_9266.asp

LEARNING DISABILITIES

Learning disability generally refers to a neurobiological condition in which a person's brain is structured or works differently from what is considered typical. Information processing is effected. It may result in differences in listening, thinking, speaking, reading, writing, spelling, or mathematical skills. It is different from a cognitive disability although both are considered developmental disabilities. Usually, there is a discrepancy between a child's expected performance according to IQ test results and actual performance. (Zastrow & Kirst-Ashman, 2004).

Attention Deficit/Hyperactivity Disorder (ADHD) and learning disabilities may coexist, but these are separate and distinct conditions. People with learning disabilities have normal or above normal intelligence. Children with learning disabilities can be successful and experience high achievement with proper instruction, adaptations, and support. Unfortunately, children with learning disabilities sometimes experience feelings of low self-esteem, helplessness and frustration, fear of failure, and withdrawal when appropriate support and assistance is not provided.

The Education for All Handicapped Children Act supports the inclusion concept. Social work roles in working with children with learning disabilities include broker and advocate.

References

Zastrow, C. and Kirst-Ashman, K. (2004). Understanding Human Behavior in the Social Environment. Belmont, CA: Brooks/Cole.

<http://www.coping.org/specialneeds/impac.htm>

SPINA BIFIDA

Spina bifida affects the neural tube that develops into the brain and spinal cord. The neural tube does not close completely. There are 3 forms of spina bifida:

- Occulta – mildest – usually no symptoms. There may be a small gap in one or more of the vertebrae of the spine. Usually no treatment is needed.
- Meningocele – the rarest form. In this form, a cyst or sac pokes through the open part of the spine. The cyst is removed surgically and development generally proceeds typically.
- Myelomeningocele – most severe form. The back may be closed surgically, however some degree of leg paralysis and bladder and bowel control problems occur. The higher the cyst on the back, the more severe the paralysis.

Medical problems associated with myelomeningocele include hydrocephalus; tethered spinal cord resulting in leg weakness, scoliosis, pain in back or legs, and changes in bladder function; urinary tract infections; latex allergy; obesity; and digestive tract disorders. At least 80% of children with myelomeningocele have “normal intelligence” although some have learning problems.

Reference

Source: http://www.marchofdimes.com/pnhec/4439_1224.asp

VISUAL IMPAIRMENT

Visual impairment generally refers to blindness or low vision. The extent of visual impairment can vary greatly from individual to individual and can also vary within an individual based on factors such as lighting, glare, or fatigue. The definition of legally blind is 20/200 vision with best correction.

Possible reading:

Jindal-Snape, D (2005). Self-evaluation and Recruitment of Feedback for Enhanced Social Interaction by a Student with Visual Impairment. Journal of Visual Impairment and Blindness, 99 (8), 486-489.

This article (available on EBSCOhost) describes results of training a student who is visually impaired to evaluate his social behavior and get feedback from peers with sight. The results indicate that the student improved his ability to evaluate social skills requiring visual cues. This is an important skill in developing friendships.

Unger, D. D., Rumrill, P. D., & Hennessey, M.L. (2005). Resolutions of ADA Title I cases involving people who are visually impaired: a comparative analysis. Journal of Visual Impairment & Blindness 99 (8), 453-463. (EBSCOhost)

“Abstract: A comparison of American with Disabilities Act (ADA) Title I case resolutions by the Equal Employment Opportunity Commission (EEOC) involving people who are visually impaired with those involving all other people with disabilities between 1993 and 2002 revealed that people who are visually impaired are more likely than are other complainants to receive settlement benefits from their employers, to withdraw their complaints after they receive benefits without intercession from the EEOC, and to receive administrative closures. In addition, they are less likely than other complainants to have charges resolved by the issuance of a right-to-sue letter from the EEOC and to receive other closures. (ABSTRACT FROM AUTHOR)”

NOTE: This article also provides some examples of approaches to helping workers become self-advocates including increasing their knowledge of the law and role-playing/rehearsing conversations with employers.

Southwell, P. (2005). Vision impaired. Counselling & Psychotherapy Journal, 16(5), 34-37.

“ This article is specifically about work with clients who have acquired sight loss later in life.” Research Findings show higher prevalence of depression. Age-related Macular Degeneration(AMD) was the most common cause of blindness and partial sight in older adults. AMD affects central but not peripheral vision. Central vision effects ability to read, differentiate people’s faces, drive, and watch television. Driving and reading are reported as two of the most difficult losses. Driving means independence and control so it is important to help people regain a sense of control. The article summarizes key tasks of therapy with people with acquired sight loss: “facilitate emotional expression and recognition of what it means to them; help them regain a sense of control of their inner lives and of the possibility of mastering their outer

environment, and to work on the meaning to them of their changed life, and their sense of significance and worth in a changed and often more hostile environment, in which expectations also have to undergo major changes.”

Assisting

Don't assume someone needs help – ask (“May I help you?”)

Allow the person with the visual disability to take your arm rather than grabbing their arm. Let the person control his/her own movements.

When giving directions, be specific (“there are 3 steps” or “go 5 feet and turn left”)

When directing to a seat, place the person's hand on the back or arm of the chair and inform them where the hand is (“your hand is on the left arm of the chair”)

A “clock system” can be used to help locate food on a plate (“potatoes are at two o'clock”).

Ask permission before interacting with a guide dog.

When conversing in a group, say the name of the person to whom you are speaking.

When you move, let the person know where you are.

(From: Video Reference Guide)

Information related to ways to assist/include students with visual impairments in classroom activities can be obtained from the following web-site:

www.as.wvu.edu/~scidis/

GENETIC TESTING: YES OR NO?

Yes

Technology is now available to test or screen for many conditions. Prenatal and newborn screening can inform parents regarding various genetic conditions. Some medical professionals may not advise parents or potential parents about this technology because of expense or personal values including fears that identifying certain genetic conditions could lead to abortion decisions. However, this should be the decision/choice of the patient. Doctors routinely inform pregnant women about tests for Down syndrome and cystic fibrosis, but do not provide information about other available testing including testing for Fragile X, the most common inherited form of cognitive disability. Genetic testing can help parents better prepare for the needs of their child and family and newborn screening can lead to early intervention and appropriate adaptations that can improve quality of life.

No

Genetic testing can be expensive and may not be covered by insurance. The identification of a genetic condition may place pressure on parents to consider abortion. Legitimizing genetic testing in order to inform pregnancy decisions serves to devalue the lives of those who are living with those conditions. There are numerous genetic tests and it would not be feasible to test everyone for everything. Researching a patient's background for which test might be appropriate could be time consuming and many doctors are not trained adequately to make a determination..

Discussion Questions

- Should tests be routinely performed for categories of people who may be at greater risk for certain genetic conditions?
- Should tests be routinely performed for certain conditions?
- Should all possible tests be available upon request?
- Who should pay for any of the above? Should public funding be available? Under what circumstances?
- What are the reasons for genetic testing?
- What are the pros and cons of genetic testing?
- Issues to consider: In what ways (positive and negative) does “knowing” effect outcomes? (Earlier medical intervention, parents more prepared, parents may choose to

terminate pregnancy or not to have children). What values or ethical dilemmas come into play?

- For each of the following, what plans would you make if you knew ahead of time that you or your partner was going to have a baby who:
 - Was deaf?
 - Had Cystic Fibrosis?
 - Had Down's Syndrome?
 - Had Spina Bifida?
 - Was blind?
 - Had Cerebral Palsy?
 - Was a girl?
 - Was a boy?

References

Harmon, A. (2004). As gene test menu grows, who gets to choose? The New York Times. July 21, 2004. In: Themes of the times (2005). Pearson Education, Inc.

See also:

Depoy, E. & Gilson, S. (2004). Rethinking disability. Belmont, CA: Brooks/Cole. (pp. 103, 104)

TRANSITION PLANNING FOR STUDENTS WITH DISABILITIES

Transition services for students with disabilities became codified with passage of the Individuals with Disabilities Education Act (IDEA) of 1990. This legislation was in response to studies that revealed poor postsecondary outcomes for students graduating with Individual Education Programs (IEP's) (Baer, 2005).

Transition planning for students with disabilities, who were 16 years of age, and younger if appropriate, would now be incorporated into their annual IEP's. These IEP's have been a requirement for all children and youth receiving special education services since IDEA, formerly known as the Education of All Handicapped Children Act, was implemented in 1975. The essential components of each student IEP contain the following:

- a. statement of the student's present level of educational performance;
- b. annual goals and short-term objectives for each goal;
- c. specific special education and related services to be provided, and the extent of participation expected in general education;
- d. projected dates for initiation and duration of services; and
- e. criteria and procedures for determining if short term objectives had been met.

(Individuals with Disabilities Act, P.L. 101-476, 34 CFR, Section 30.18)

As a means to address and strengthen the fundamental purpose of secondary education for preparation for adult living, transition services were incorporated into the IEP's in 1990 (Flexer, 2005). Section 300.18 of IDEA (P.L. 101-476) defined these transition services as in four broad ways:

- a. determining student needs, interests, and preferences in transition planning
 - students and their parents must be notified and encouraged to attend the IEP meeting in which transition is discussed;
- b. outcome-oriented planning
 - transition services should be aimed at the "development of employment and other post-school adult living objectives".
 - These activities may include postsecondary education, vocational training, integrated employment (including supported employment, continuing and adult education, adult services, independent living, or community participating).
- c. coordinated set of activities
 - each student's IEP/transition plan (ITP) is to be coordinated by the school's Transition Coordinator and is to include, if appropriate, a statement of any public agency's responsibilities or linkages, or both'
 - formal, written interagency agreements are encouraged between the state Departments of Education and Vocational Rehabilitation (Loyd, Cook, Opperman, & Thurman-Urbanc, 2004).
 - Each students ITP tea should be comprised of the student, parents/guardians, special education teachers, administrators, related service providers such as

speech therapists, guidance counselors as well as community members and service providers who provide health services, employment, leisure/recreational services and residential assistance.

- d. promoting student movement to post-school activities
 - IDEA requires that transition services be designed to successfully move the student towards their identified activities and that they be implemented early enough to ensure success.
 - IDEA of 1997 mandated that a statement of needed *transition services* be incorporated into the students IEP by the age of 16 years, and younger if appropriate.

Relevance to Social Work

The primary purpose of transition services is to prepare students with disabilities for adult life. The coordination of these services is paramount to student success and requires extensive communication among various cooperating agencies. As noted by Brolin & Loyd (2004), this may include:

- a. the Office of Vocational Rehabilitation including its Supported Employment component
- b. the Office of Blindness and Visual Services
- c. State Employment Services
- d. Job Training and Partnership Act (JTPA)
- e. State offices of mental health and mental retardation
- f. Community service organizations such as the Rotary and Lions Clubs
- g. Church organizations
- h. Educational entities such as postsecondary institutions, vocational schools, and trade/proprietary schools

Simmons, Flexer, & Bauder (2005) point out those school personnel need the input and contributions of interagency linkages in order for students to realize their transition goals. Examples of these transition service requirements include:

1. Instruction: tutoring, employability skills training, vocational education, college entrance exam preparation;
2. Community experiences: job shadowing, community work experiences;
3. Development of employment and postschool adult living objectives: career planning, interest inventories, self-determination training
4. Related services: occupational and physical therapy, speech therapy, psychology services
5. Daily living skills training: self-care training, home repair, health training, money management
6. Linkages with adult services: referral to vocational rehabilitation, summer youth employment programs, developmental disability and mental health boards, independent living centers

7. Functional vocational evaluation: situational work assessments, work samples, aptitude tests, job tryouts (pp. 217, 219)

Social workers are often involved in the transition process for clients with disabilities including serving in a case management role. Suggestions on how to assess and appropriately identify which of these agencies may best serve a client includes (Brolin & Loyd, 2004) developing a Community Resource Directory that identifies a whole range of possible client services, determining which needs may best be served by non-school personnel and then providing the appropriate referral for consideration of these services, and establishing personal contact with personnel from these agencies.

References

Baer, R. (2005). Transition planning. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition planning for secondary students with disabilities (pp.305-335). Upper Saddle River, N.J.: Pearson Prentice Hall.

Flexer, R. (2005). History and transition legislation. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition planning for secondary students with disabilities (pp.20-52). Upper Saddle River, N.J.: Pearson Prentice Hall.

Loyd, R.J., Cook, I.P., Opperman, C., & Thurman-Urbanc, M. (2004). Transition planning. In Brolin, D.E. & Loyd, R.J. (Eds.). In Career development and transition services: A functional life skills approach (pp.195-220). Upper Saddle River: Pearson Prentice Hall.

Simmons, T., Flexer, R., & Bauder, D. (2005). Transition services. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition services (pp.211-244). Upper Saddle River: Pearson Prentice Hall.

ABUSE AND NEGLECT

Research has shown that some children are at greater risk for abuse and neglect. Some children can be more demanding and seen as more difficult. There are also situations where a child does not meet a parent's expectations; for example the baby was a girl and the parent was determined that this child would be a boy. This existence of these situations in no way implies that the child deserves punishment. It only implies that some children are at higher risk for child abuse and neglect due to their special circumstances or needs.

Children with disabilities have an increased vulnerability to abuse. Abuse, in turn, causes disabilities. Approximately 18,000 children per year experience a variety of permanent disabilities because of abuse or neglect. Children who have disabilities, due to previous abuse or not, suffer abuse twice as often as children without disabilities.

Many myths create barriers around the issue of child abuse among children with disabilities. These include:

- Belief that children with disabilities are more protected than children without disabilities. This false sense of security can lead to denial that abuse could occur or is occurring.
- Belief that children with disabilities are less important than children without disabilities.
- Belief that children with disabilities are less sensitive to suffering from physical or sexual abuse since they are perceived as infantile or asexual.
- Belief that the victim has provoked the abuse.
- Reluctance to accuse professional caregivers if they are the source of the abuse.
- Belief that children with disabilities are less credible than children without disabilities.

For children with severe disabilities, it might take particularly flagrant signs (death, pregnancy, venereal disease, or a new physical injury) before abuse is noted. This challenge can cause children to be left in danger for many years.

While many of the risk factors for children with and without disabilities are the same, other specific areas of concern that make children with disabilities especially vulnerable include:

- Dependency for care will make a child trusting and unlikely to question.
- Children learn compliance and do not complain.
- Some children with disabilities have a limited social group and fear that if they report the abuse, they will damage or end the relationship with the abuser. They might also fear retribution.
- A child with a disability might never have had the opportunity to learn about personal boundaries and self-protection or have inadequate socialization to understand "right" and "wrong" behavior. They might tolerate, accept, and acquiesce to inappropriate behavior.
- Self-injury will mask the source of abuse.
- Physical disabilities could seriously hamper efforts to flee.
- Communication difficulties prevent children from reporting abuse.

- Communication problems and lower cognitive functioning sometimes make a child appear less credible, and therefore they are not believed.

The consequences of abuse and neglect for children with disabilities are similar to those for children without disabilities. However, due to the nature of certain disabilities and their side effects, these consequences may be more severe. Outcomes can include:

- Mild to severe physical injuries.
- Death.
- Sexually transmitted diseases.
- Pregnancy.
- Emotional distress including anger, anxiety and fearfulness, depression and low self-esteem.
- Social withdrawal.
- Impaired ability to trust.
- Learning difficulties.
- Posttraumatic Stress Disorder.
- Tendency toward re-victimization.

Those who witness or experience abuse may be more likely to abuse others.

Children at increased risk of medical neglect and for who the consequences are serious include children with medically diagnosed diseases or disabilities and children under the care of physician sub-specialists or allied health care specialists, due to a medical diagnosis. Failure to obtain treatment, however, must be considered in light of availability of resources, parents' financial ability to pay for treatment, parents' cultural and religious beliefs, and the spectrum of seriousness as to the consequences of failure to obtain needed medical care. Some children with disabilities, as well as those without disabilities, lack knowledge about sexuality and abuse, thereby not discerning that sexual contact is abusive. Sexual abuse is often facilitated by personal care routines, such as dressing, bathing, and toileting.

Children with disabilities, as well as those without disabilities, are most often maltreated by persons they know and trust including parents, family members, and other caregivers. Since children with disabilities are routinely in contact with and dependent upon service providers, the risk of maltreatment, especially sexual abuse by service providers, is increased. In addition, perpetrators who abuse children with disabilities share the following characteristics:

- predominately male
- in a position of authority and control and perceive their victim as powerless and unable to accuse
- often victims of abuse as children or were exposed to abusive environments
- may claim victim provoked the abuse
- emphasize victim's differences rather than similarities to persons without disabilities, lack empathy, and minimize personal responsibility.

Not all perpetrators have these characteristics and some people who exhibit these characteristics are not perpetrators.

Disability or Abuse?

There are often practical problems in identifying maltreatment of children with disabilities because symptoms of abuse may be masked by the disability or characteristics of the disability can mimic child abuse indicators. For example:

- Some children have rare diseases that mimic the symptoms of abuse. Osteogenesis imperfecta, or brittle bones, is unusual, affecting only one in 25,000 people. (Child abuse is more common). If an undiagnosed child presents at the emergency room and multiple healed fractures show on an X-ray, medical staff should rule out the condition before reporting injuries as suspected child abuse.
- Some children with disabilities may be limited in their ability to communicate information about an abusive incident.
- Some children with behavioral impairments or cognitive disability engage in self-abusive behaviors or are prone to accidental injury.
- Some children with physical disabilities require greater assistance with personal care routines such as dressing, bathing and toileting at a later chronological age than peers who are not disabled. Personal care routines may result in occasional touching of sexual parts of the body with resultant difficulty discerning if the touch was accidental, required or exploitive.

Areas of assessment to help discern whether the presenting situation is characteristic of the disability or indicative of abuse or neglect include:

- Observation of the injury.
- The child's statements.
- Consistency of injury with explanation given.
- Consistency of the injury with the child's developmental and/or physical capacities.
- Witnesses to the incident.
- Medical findings.
- The child's behavior.

The best rule of thumb in discerning maltreatment is to know what is typical for that particular child. When assessing the child's behavior, it is important to:

- Examine the history of the behavior.
- Obtain a behavioral "baseline".
- Determine whether there has been a clear behavior change that has taken place during the time frame in question.

The following behaviors, especially when corroborated with other evidence, may indicate sexual abuse:

- Increased masturbation.
- Touching others.
- New and odd behaviors related to child's own genitals, i.e. pulling, punching, rubbing, inserting objects into orifices.
- Irritability with related behaviors.
- Fears.
- Sexual drawings.

Situations of sexual activity between children are reportable to child protective services when:

- The perpetrator is in a care-taking role.
- There is suspected lack of supervision by the parent or adult caregiver, thereby enabling the activity to take place.

The following variables should also be considered when assessing sexual activity between children:

- Whether the activity is considered to be normal sexual curiosity that is developmentally appropriate.
- The age difference between the victim and perpetrator.
- The use of force or violence.
- The nature and frequency of sexual activity.
- The existence of a power differential, knowledge differential, and gratification differential between perpetrator and victim.

Interdisciplinary Teamwork

Investigation of suspected abuse or neglect of children with disabilities should follow the same thorough investigatory principles as required for children without disabilities. Investigative strategies to help facilitate interdisciplinary teamwork and effective intervention include:

- Specialized knowledge on the part of the law enforcement investigator and child protective services worker about children with disabilities.
- Assistance from a disability specialist either in interviewing or providing advice on how to conduct the interview or interpret the results.
- Interdisciplinary policies and procedures on the management of suspected abuse or neglect of children with disabilities, including identified, trained agency liaisons.

Reference

The preceding information is from *One Child at a Time: A Guide for Professionals in Recognizing and Reporting the Abuse and Neglect of Children with Disabilities* by the TEAM

for West Virginia Children (2002) and is printed with their permission. The entire publication can be downloaded from their website: [www@teamwv.org](http://www.teamwv.org)

**Under the Magnifying Glass:
Meeting the Needs of
Mothers with Physical
Disabilities
(Power Point Slides)**

CHILDCARE EQUIPMENT FOR PARENTS/CARETAKERS WITH DISABILITIES

The following items are examples of some of the equipment available to assist parents and caretakers with disabilities in caring for children.

The First Years Easy Read Medicine Dropper (larger numbers, larger size)

EvenFlo Ellipsa Stroller (baby sits far forward and is more stable and least likely to tip backward; offers one hand steering and one hand recline)

Cosco Beginnings Simple Start High Chair “Mansfield” (open bottom-increased access for wheelchairs)

Bassinettes and Play Pens (a portable play pen and bassinette may be the best option for women with decreased mobility or for those seated in a wheelchair. Because it is meant to break down, one side folds down with the press of a button, creating accessibility to the child.)

Wheel chair accessible crib (a typical crib was raised to allow access by the wheelchair rolling under. Two doors allow the parent to access the child no matter where she or he is.

Nursing Assistant (a piece of gray foam is formed to the shape of the wheel chair with attached canvas straps with a quick-release latch. One end of the latch is on the lap tray; the other end is attached to the armrests.

Toddler Seat (attaches to a wheelchair for a toddler. Seat rotates and has a seatbelt.)

Reference

Sexton, Jennifer in partnership with the West Virginia University Center for Excellence in Disabilities. Under the magnifying glass: meeting the needs of mothers with physical disabilities: a workshop for nursing professionals.

Policy, Social Justice & Diversity

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OVERVIEW: POLICY, SOCIAL JUSTICE, AND DIVERSITY

The previous section, HBSE, illustrated theoretical constructs which often turn on issues of policy, social justice, and diversity. Although viewed separately, these three areas are interrelated and converge to inform practice. In this section it is suggested that students first examine policies as they flow from legislation. To whet students' appetites in this area, a "test your knowledge" activity is presented supplemented with an applied case example ("Alexander"). A summary of relevant legislation is provided and can be used to target learning opportunities revealed from the activities. This section then turns to social policy and diversity as the use of people first language is examined. An exercise designed to reveal student feelings of exclusion (Social Darwinism v. Social Inclusions/Strengths) fits nicely here. The nexus of policy, discrimination, and diversity is then explored through handouts related to social action to end discrimination, diversity and policy abstracts, and selected resources.

AMERICAN WITH DISABILITIES ACT: TEST YOUR KNOWLEDGE

1. The ADA prohibits discrimination on the basis of disability in
(Check all that apply)
 - a. Employment
 - b. Public accommodations
 - c. Commercial facilities
 - d. Transportation
 - e. Telecommunications
 - f. State and Local Government and US Congress

2. A person who does not have a disability may still be protected under the ADA.
 - a. True
 - b. False

3. Which of the following is true:
 - a. The ADA lists specific disabilities that are covered.
 - b. According to the ADA, to be considered an individual with a disability a person must have a physical or mental impairment that substantially limits one or more major life activities.
 - c. A person who has a history of having an impairment or who is perceived by others as having an impairment is protected by the ADA.
 - d. A and b

4. An employer is advised to ask about an applicant's disability before a job offer is made in order to determine whether accommodation will be needed.
 - a. True
 - b. False

5. Employers with 15 or more employees must:
 - a. Make reasonable accommodations to the known physical or mental limitations of otherwise qualified individuals with disabilities regardless of whether it constitutes a hardship or not.
 - b. Make reasonable accommodations as noted above only if it does not result in undue hardship.
 - c. Make reasonable accommodations unless they are a religious entity.

6. Employment (Title 1) complaints:
 - a. Have no time limitations
 - b. Can be filed directly in federal court
 - c. Can be filed with the U.S. Equal Employment Opportunity Commission within time limits.

7. Title II of the ADA refers to State and Local Government Activities. Which of the following is true:
 - a. A local government does not have to provide people with disabilities equal opportunity to benefit from programs and services if it does not receive federal funds.
 - b. Services and opportunities covered include education, employment, transportation, health care, and voting – but does not include social services and recreation.
 - c. State and local governments are required to follow specific architectural standards in new construction or building alterations and provide access to services in inaccessible older buildings and communicate effectively with people who have hearing, vision, or speech disabilities.

8. Public transportation authorities must:
 - a. Comply with accessibility in newly purchased vehicles
 - b. Make good faith efforts to purchase or lease accessible used buses
 - c. Remanufacture buses in an accessible manner
 - d. Provide paratransit where they operate fixed-route bus or rail systems unless it would result in an undue burden
 - e. All of the above
 - f. None of the above

9. The ADA requires telephone companies to establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week.
 - a. True
 - b. False

10. ADA suits are flooding the courts.
 - a. True
 - b. False

11. Restaurants must provide menus in Braille.
 - a. True
 - b. False

12. Which of the following is true:
 - a. The ADA does not protect people who need reasonable accommodation due to obesity.
 - b. The ADA protects people with a history of alcoholism who are judged by/evaluated by their employers based on stereotypes and fears rather than abilities.
 - c. The ADA requires an employer to hire someone who is a sex offender because that is considered a disability.
 - d. All of the above

AMERICAN WITH DISABILITIES ACT QUIZ: ANSWERS

1. All of these are included in the ADA.
2. True. The ADA protects a person with a disability or someone who has a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. An example of someone who has an association with an individual with a disability: A police officer is hesitant to respond to a call to a certain address because there is a resident there who has AIDS – the person in need of law enforcement may be resident who has AIDS or the parent/sibling/roommate, etc – that person is protected by the ADA in this instance as would be the person who has AIDS.
3. C – see above. The ADA does not specifically name all the impairments that are covered.
4. False. The ADA restricts questions that can be asked about an applicant’s disability before a job offer is made.
5. B -The ADA requires that employers make reasonable accommodation unless it results in undue hardship. What constitutes undue hardship may vary from employer to employer depending on circumstances. Religious entities are covered under title I.
6. C – Title I complaints must be filed with the US Equal Employment Opportunity Commission (EEOC) within 180 days of the date of discrimination, or 300 days if the charge is filed with a designated State or local fair employment practice agency. Individual may file a lawsuit in Federal court only after they receive a “right to sue” letter from the EEOC.
7. C – Title II covers all activities of State and local governments regardless of the government entity’s size or receipt of Federal funding. It requires that governments give people with disabilities an equal opportunity to benefit from all their programs, activities, and services (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings). State and local governments are required to follow specific architectural standards in new construction and alteration of their buildings. They also must relocate programs or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being performed. An example of reasonable accommodation/modification in law enforcement would be simplifying the language in the Miranda Warning as needed for someone with a cognitive disability, or handcuffing in front of the body rather than behind to allow someone to sign.
8. All of the Above. Note: paratransit is a service where individuals who are unable to use the regular transit system independently (due to physical or mental impairment) are picked up and dropped off at their destinations.
9. True. TRS enables callers with hearing and speech disabilities who use telecommunications devices for the deaf (TDDs or teletypewriters-TTYs), and callers

who use voice telephones to communicate with each other through a third party communications assistant. Title IV also requires closed captioning of Federally funded public service announcements.

10. False. According to US Dept. of Justice, a surprisingly small number of lawsuits – only about 650 nationwide in 5 years has occurred. -considering the 6 million businesses, 666,000 public and private employers, and 80,000 units of state and local government that must comply.
11. False. Wait staff can read the menu to customers who are blind.
12. B – As far as obesity, just being overweight is not enough – modifications to policies must be made if they are reasonable and do not fundamentally alter the nature of the program or service provided. The Justice Department has received only a handful of complaints about obesity. The ADA does cover people with conditions such as severe depression or history of alcoholism who are treated unfairly based on these conditions rather than ability to perform the job. Sex offending is not considered a disability under the ADA.

STUDENT ACTIVITY: APPLYING POLICY

Alexander is a 22-year-old male who uses a wheelchair to get from place to place. He has just gotten a job with Acme Business Systems. His first day on the job he discovered that there is no stall in the company bathroom wide enough to accommodate his chair. When he asked the Human Resources Department for help in resolving this situation, they told him that was not Acme's problem, since the building was built before the ADA. On the web, find resources that can help support Alexander's contention that Acme has a responsibility to make some changes.

Reference

Shuman, Sherry and Camille Catlett from a presentation handout, "Stump the Experts OR How to Infuse Disability Issues/Adapt Existing Curricula."

RELEVANT LEGISLATION OVERVIEW

DISABILITY RIGHTS

People with disabilities have fundamental civil and human rights guaranteed by the United States Constitution and by various federal and state laws.

The Americans with Disabilities Act

Purpose

The Americans with Disabilities Act (ADA), PL 101-336 is modeled after the Civil Rights Act of 1964 and Title V of the Rehabilitation Act of 1973. The purpose of the ADA is to extend to people with disabilities civil rights similar to those now available on the basis of race, color, national origin, sex and religion through the Civil Rights Act of 1964. It prohibits discrimination on the basis of disability in:

- Employment,
- Services of State and Local Government,
- Public Accommodations,
- Transportation, and
- Telecommunications.

Employment

The ADA prohibits discrimination against a qualified individual with a disability in employment and includes specific features related to reasonable accommodation, qualification standards and other labor-management issues. “No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”

Public Services

The ADA addresses services and activities of State and local governments including public transportation. Transportation provisions of the ADA are intended to improve access in equipment (buses, rail coaches), facilities, and demand response systems. Some of these requirements include: the purchase of new accessible public transportation equipment, special transportation services that are comparable to fixed-route services, modification of key existing facilities to assure access, and inter-city and commuter-rail accessibility improvements.

“No qualified individual with a disability shall, by reason of such disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination by a department, agency, special purpose district, or other instrumentality of a State or a local government.”

Public Accommodations

The ADA addresses public accommodations and businesses and services operated by private entities. Privately owned transportation is also included. Specific features of the Act vary from section to section laying out how equal access is to be achieved by particular entities.

“No individual shall be discriminated against on the basis of disability in the full and quality enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation.”

Telecommunications

The ADA mandates that telecommunications relay services be offered by private companies and includes services operated by States.

“...shall ensure that interstate and intrastate telecommunications relay services are available...to hearing-impaired and speech-impaired individuals in the United States.”

ADA’s Impact on Employment

ADA prohibits discrimination against workers with disabilities. ADA employment provisions apply to private employers, State and local governments, employment agencies, labor organizations, and joint labor-management committees.

ADA requires equal opportunity in selection, testing and hiring of qualified applicants with disabilities. ADA requires equal treatment in promotion and benefits. ADA requires reasonable accommodation for workers with disabilities when such accommodations would not impose an “undue hardship.” Reasonable accommodation is a concept already familiar to and widely used in today’s workplace.

For more information and regulations contact:

ADA Regulations for Title I—Employment contact:
Equal Employment Opportunity Commission
1801 L Street, NW
Washington, DC 20507
800-669-3362- Voice
800-800-3302- TTY
Alternative formats are available.

Information on making job accommodations contact:

JAN (Job Accommodation Network)
800-526-7234—U.S. (Voice/TTY)

Regulations for Transportation contact:

Urban Mass Transportation Administration
400 7th Street, SW

Room 9315
Washington, DC 20590
202-366-4390 or 1656- Voice
202-366-4567-TTY
Alternative formats are available on request.

ADA Regulations for Title III—Public Accommodations contact:

U.S. Department of Justice
PO Box 66738
Washington, DC 20035-6738
202-514-0301- Voice
202-514-0383- TTY
Alternative formats are available.

ADA Accessibility Guidelines for Buildings and Facilities and those for Transportation Vehicles contact:

1331 F Street, NW
Suite 1000
Washington, DC 20004-1111
202-272-5434- Voice
202-272-5449- TTY
800-872-2253- Voice/TTY
Alternative formats are available.

ADA Regulations for Title IV—Telecommunications contact:

Federal Communications Commission
Office of Public Affairs
1919 M Street, NW
Room 254
Washington, DC 20554
202-632-7000- Voice
202-632-6999- TTY

For more information visit:

www.ADABasics.org
www.Adaaction.com
The Job Accommodation Network at West Virginia University
www.jan.wvu.edu

For a challenging game featuring questions on the ADA and real-life applications visit:

www.adagame.org

Reference

Taken from: Disability awareness guide of west virginia inclusion campaign available at:<http://www.wvdhhr.org/wvic>

PROTECTION FROM DISCRIMINATION IN TRANSPORTATION

Title II of the ADA specifically covers publicly funded programs, activities and services on the federal, state and local levels. This includes transportation rights.

The ADA protects the right of people with disabilities to use public transportation, regardless of their disabilities. You do not have to be in a wheelchair, use a scooter or have any visible signs of a disability to be covered under the law. Disability may be physical, psychological or developmental in nature. The ADA defines disability as any “impairment that substantially limits one or more major life activities.” Medical documentation, however, usually is needed.

Public modes of transportation that are covered under the ADA include the following:

- Urban transit
- Paratransit (door-to-door transport service)
- Rail systems and transit facilities (such as Amtrak)
- Buses
- Boats, ships or ferries
- All government-funded transportation

ADA coverage does not extend to air travel because air travel rights already are protected by the Air Carrier Access Act.

The right to transportation also is protected by the ADA if a person uses any privately owned transportation system or service whose “primary business is transporting the general public.” One example is a privately owned bus company. Businesses that offer transportation to the general public also must provide services to all people regardless of disability. Examples include the following:

- Hotels
- Private colleges
- Funeral homes
- Social centers
- Day care centers

Other federal, state and local laws exist to further protect people with disabilities and their right to transportation.

Implementing ADA standards takes time and may sometimes be costly. For example, vehicles covered under the law may need to be structurally altered or new vehicles may need to be purchased or rented. “Reasonable accommodations” such as paratransit services may have to be provided by some transportation services that do not meet ADA standards. However, exceptions exist. For example, while taxis cannot deny service to people with disabilities, they do not have to structurally alter their vehicles to accommodate wheelchairs and scooters.

For more information on the specifics of the ADA, to ask questions or to file a complaint, visit the United States Department of Justice at: www.usdoj.gov/crt/ada/adahom1.htm

You may also contact the U.S. Department of Transportation:
400 7th Street, S.W.
Washington, D.C. 20590
202-366-4000
www.dot.gov

Reference

Taken from: Disability awareness guide of west virginia inclusion campaign available at:<http://www.wvdhhr.org/wvic>

PROTECTION FROM DISCRIMINATION IN PUBLIC ACCOMMODATIONS

Title III of the ADA protects the right of people with disabilities to access the same public accommodations as the general public, regardless of physical or mental disabilities. These include the following:

- Places of lodging (hotels, inns, motels)
- Places of exhibition or entertainment (movies, theaters, concert halls, stadiums)
- Places of public gathering (auditoriums, conventions centers, lecture halls)
- Places of public display or collection (museums, libraries, galleries)
- Places of recreation or entertainment (parks, zoos, amusement parks)
- Places of exercise or recreation (gymnasiums, health spas, bowling alleys, golf courses)
- Places of education (nursery, elementary, secondary, undergraduate or postgraduate schools, including private)
- Establishments serving food or drink (restaurants, cafes, bars)
- Sales or rental establishments (Stores, shopping centers, malls)
- Service establishments (hospitals, health care providers, laundromats, dry cleaners, banks, beauty parlors, barbershops, repair shops, gas stations, funeral parlors, and offices of accountants, lawyers, insurance agents)
- Social service establishments (day care or senior citizen centers, homeless shelters, battered women's shelters, food banks, adoption agencies)
- Stations used for public transportation (terminals, depots)

People with disabilities are also protected from discrimination in public accommodations that are privately owned.

The rights of people with disabilities go beyond access to buildings. People with disabilities have the right to the same services, programs and activities offered to the general public. For example, people with disabilities cannot be held to different standards or requirements nor screened from participating due to disability. They may not be segregated from the general public unless doing so offers equal opportunity access and then only if the disabled person chooses to do so. Safety requirements may be established but only if they indeed offer protection; they cannot be based upon stereotypes or fears of the disabled.

Title III of the ADA establishes the building requirements for all public accommodations. These include making changes to "architectural barriers" when "readily achievable." Examples of this may include modifying or removing curbs or steps; widening doorways, aisles and bathroom stalls; lowering telephones and drinking fountains; adding ramps and grip bars; and when necessary, relocating programs and services.

All new buildings must be accessible to people with disabilities. Elevators, however, usually are not required in buildings "under three stories or with fewer than 3,000 square feet per floor." Exceptions to this would include public transit stations, shopping malls and health care facilities. Structures must pass local building code requirements as well.

Private clubs and religious organizations are exempt from ADA requirements. Private residences (apartments and homes) also are exempt.

However, people with disabilities are protected from discrimination in both renting and selling practices under the Fair Housing Amendments Act of 1988 (FHAA). The Department of Housing and Urban Development, often known as simply “HUD,” administers the FHAA.

For more information on the ADA and protection from discrimination in public accommodations, or to file a complaint, visit the United States Department of Justice at: www.usdoj.gov/crt/ada/adahom1.htm.

Reference

Taken from: [Disability awareness guide of west virginia inclusion campaign](http://www.wvdhhr.org/wvic) available at:<http://www.wvdhhr.org/wvic>

SECTION 504 OF THE REHABILITATION ACT

What is Section 504?

Section 504 of the Rehabilitation Act Amendments of 1973 is a civil rights statute that states in part:

“No otherwise qualified individual with a disability in the United States... shall, solely by reason of her or his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . .” (29 U.S.C. § 794[A])

Who is an “individual with a disability” under Section 504?

An “individual with a disability” is any person who (i) has a physical or mental impairment which substantially limits one or more of such person’s major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such an impairment. (29 U.S.C. § 706[8][B])

What physical or mental impairments qualify as “disabilities”?

Under Section 504, “[p]hysical or mental impairment” means

(A) any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin and endocrine; or (B) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities. (34 C.F.R. 104.3[j][2][i])

What is the relationship between Section 504 eligibility and special education?

Section 504 is a broader category than special education. Every child who is entitled to services under special education is deemed to be an “individual with a disability” under Section 504. But many persons who are “individuals with a disability” under Section 504 are not covered by special education statutes.

What educational rights does an individual with a disability have under Section 504?

Under Section 504 a recipient [of Federal funds] that operates a public elementary or secondary education program shall provide a free appropriate public education [FAPE]to each qualified

handicapped person who is in the recipient's jurisdiction, regardless of the nature or severity of the person's handicap. (34 C.F.R. 104.33[a])

A free appropriate public education (FAPE) under Section 504 entails provision of educational and related services without cost to the handicapped person or to his or her parents or guardian, except for those fees that are imposed on nonhandicapped persons or their parents or guardian. (34 C.F.R. 104.33[c][1])

What procedural rights does a student who may have a § 504 disability have?

Section 504 requires that a person who may have a qualifying disability is entitled to a pre-placement evaluation. That evaluation must be conducted by means of "tests that have been validated for the specific purpose for which they are used and are administered by trained personnel in conformance with the instructions provided by their producer; . . . [that are] tailored to assess specific areas of educational need . . . ; and . . . are selected and administered to a student with impaired sensory, manual, or speaking skills, the test results accurately reflect the student's aptitude or achievement level or whatever other factor the test purports to measure . . ." (34 C.F.R. 104.35[b][1]-[3])

Moreover, Section 504 requires that the placement decision [for a student who may have disability] is made by "a group of persons, including persons knowledgeable about the child, the meaning of the evaluation data, and the placement options . . ." (34 C.F.R. 104.35[c][3])

What if a parent or guardian is dissatisfied with the child's § 504 evaluation and placement?

Section 504 provides that there must be a "system of procedural safeguards that includes notice [to the parent/guardian of the assessment's outcome], an opportunity for the parent or guardian of the person to examine relevant records, an impartial hearing with opportunity for participation by the person's parents or guardian and representation by counsel, and a review procedure." (34 C.F.R. 104.36)

For more information visit:

U.S. Department of Education, Office of Special Education and Rehabilitative Services: www.ed.gov/offices/OSERS

Reference

Taken from: [Disability awareness guide of west virginia inclusion campaign](http://www.wvdhhr.org/wvic) available at:<http://www.wvdhhr.org/wvic>

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

What is the Purpose of IDEA?

The Individuals with Disabilities Education Act (IDEA) is an education act which provides federal financial assistance to State and local education agencies to guarantee special education and related services to eligible children with disabilities.

Who Is Protected?

Children ages 3-21 who are determined by a multidisciplinary team to be eligible within one or more of 13 specific categories of disability and who need special education and related services. Categories include autism, deafness, deafblindness, hearing impairments, mental retardation, multiple disabilities, orthopedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairment.

What is a Free, Appropriate Public Education?

A Free, Appropriate Public Education (FAPE) is defined to mean special education and related services. Special education means “specially designed instruction, at no cost to the parents, to meet the unique needs of the child with a disability....” Related services are provided if students require them in order to benefit from specially designed instruction. States are required to ensure the provision of “full educational opportunity” to all children with disabilities.

IDEA requires the development of an Individualized Education Program (IEP) document with specific content and a required number of specific participants at an IEP meeting.

What are the Procedural Safeguards of IDEA?

IDEA requires written notice to parents regarding identification, evaluation, and/or placement. Further, written notice must be made prior to any change in placement. The Act delineates the required components of the written notices.

What are Evaluation/Placement Procedures?

A comprehensive evaluation is required. A multidisciplinary team evaluates the child, and parental consent is required before an initial evaluation. IDEA requires that reevaluations be conducted at least every three years. A reevaluation is not required before a significant change in placement.

For evaluation and placement decisions, IDEA requires that more than one single procedure or information source be used; that information from all sources be documented and carefully considered; that the eligibility decision be made by a group of persons who know about the

student, the evaluation data, and placement options; and that the placement decision serves the student in the least restrictive environment. An IEP review meeting is required before any change in placement.

What are Due Process Rights under IDEA?

IDEA delineates specific requirements for local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a child.

For more information visit:

U.S. Department of Education, Office of Special Education and Rehabilitative Services: www.ed.gov/offices/OSERS

Reference

Taken from: Disability awareness guide of west virginia inclusion campaign available at:<http://www.wvdhhr.org/wvic>

SEMINAL LEGISLATION

| <u>ACT</u> | <u>YEAR</u> | <u>SUMMARY</u> | <u>FEDERAL ENFORCEMENT AGENCY(IES)</u> |
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| <p>Americans With Disabilities Act (ADA) [42 U.S.C. 12101, et seq.]</p> <p>[28 CFR Part 35] www.access.gpo.gov www.usdoj.gov</p> | 1990 | <p>ADA is a wide-ranging law intended to make American society more accessible to qualified individuals with disabilities. The law consists of five titles covering employment; public services, public accommodations, telecommunications, and anti-retaliation provisions. Title II, Public Services, is the title that is most applicable to public higher education as an instrumentality of State Government. Title II prohibits denying services to people with disabilities or participation in programs or activities which are available to people without disabilities.</p> | <p>Equal Employment Opportunity Commission (EEOC)</p> <p>U.S. Department of Justice</p> |
| <p>The Family and Medical Leave Act (FMLA) [29 U.S.C. 2601, et seq.]</p> <p>[29 CFR Part 825; 41 CFR Part 50, et seq.] www.access.gpo.gov www.dol.gov</p> | 1993 | <p>The FMLA covers employers who employ 50 or more employees for at least 20 workweeks in the current or preceding calendar year and all public agencies, including State, local and Federal employers, and local education agencies. The law makes it unlawful for any employer to interfere with, restrain, or deny the exercise of any right provided by this law which allows for: entitlement of up to 12 workweeks of unpaid leave for maternity or serious personal or family health condition; maintenance of health benefits during leave; job restoration after leave; sets forth notification and certification requirements; protection of employees requesting leave; and certain employer record keeping requirements.</p> | <p>Wage and Hour Division</p> <p>Employment Standards Administration</p> <p>U.S. Department of Labor</p> |
| <p>Occupational Safety and Health Act (OSHA) [29 U.S.C. 651, et seq.]</p> | 1970 | <p>The OSHA Act of 1970 established the Occupational Safety and Health Administration (OSHA) and the National Institute of Occupational Safety and Health (NIOSH) as a supporting body to do research and develop standards. Every employer engaged in commerce who has one or more employees is covered by the act. In order to implement the acts specific standards were established regulating equipment and working environments. Section 5a(1) of the act has come to be</p> | <p>Occupational Safety and Health Administration</p> |

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| <p>[29 CFR Part 1900, et seq.] www.access.gpo.gov www.dol.gov</p> | | <p>known as the "general duty" clause which states that employers have a general duty to provide safe and healthy working conditions for their employees. <i>Note: The definition of "employer" in the act exempts federal, state, and local governments.</i></p> | |
| <p>Fair Labor Standards Act (FLSA) [29 U.S.C. 201, et seq.]</p> <p>www.dol.gov www.opm.gov</p> | <p>1938</p> | <p>The FLSA of 1938 establishes minimum wage, overtime pay, and child labor standards. The Act covers private and public sector employers. With some exceptions, most federal, state, and local government employers are subject to the Act. Military personnel, volunteer workers, and other limited groups are exempted from coverage. The Act requires accurate time records on all employees subject to the Act. Special rules apply to State and local government employment involving fire protection and law enforcement activities, volunteer services, and compensatory time off in lieu of cash overtime pay.</p> | <p>Wage and Hour Division, U.S. Department of Labor, for all private employment, State and local government employment, and Federal employees of the Library of Congress, U.S. Postal Service, Postal Rate Commission, and the Tennessee Valley Authority.</p> <p>Office of Personnel Management, for all other federal employees</p> |
| <p>Drug-Free Workplace Act of 1988 [41 U.S.C. 701 and 702]</p> <p>www.dol.gov www.access.gpo.gov www.law.cornell.edu</p> | <p>1988</p> | <p>The Drug-Free Workplace Act of 1988 requires some Federal contractors and all Federal grantees to agree that they will provide drug-free workplaces as a condition of receiving a contract or grant from a federal agency. Section 701 applies generally to federal contractors, and Section 702 generally applies to federal grantees. Requirements of the Act vary based on whether the contractor or grantee is an individual or an organization. The requirements for organizations are more extensive, because organizations have to take comprehensive, programmatic steps to achieve a workplace free of drugs. Failure to provide a drug-free workplace may be grounds for suspension, termination, or debarment of federal grants.</p> | <p>Enforcement of this Act is delegated to each federal grantor or federal contracting agency.</p> |
| <p>Crime Awareness and Campus Security Act [20 U.S.C. 1092]</p> | <p>1990</p> | <p>The "Campus Security Act" requires all public and private colleges and IHEs receiving federal financial assistance to collect and report information about</p> | <p>U. S. Department of Education</p> |

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| <p>[34 CFR Part 668] www.ed.gov (regulations)</p> | | <p>crime that occurs on their campuses. Each September all eligible post-secondary institutions must publish and distribute comprehensive reports detailing campus security policies, procedures, prevention efforts, and crime statistics detailing murder, sex offenses, robbery, aggravated assault, burglary, vehicle theft, certain hate crimes, and data on arrests where drugs, alcohol, and weapon possessions were involved. Institutions that do not comply with the Campus Security Act may lose federal funding.</p> | |
| <p>The Family Educational Rights and Privacy Act of 1974 (FERPA) a.k.a. "The Buckley Amendment" [20 U.S.C. 1232g]</p> <p>[34 CFR Part 99] www.law.cornell.edu www.ed.gov</p> | <p>1974</p> | <p>The Family Educational Rights and Privacy Act is a federal law designed to protect the privacy of a student's education records. The law applies to all schools that receive federal funds through the U.S. Department of Education. FERPA also gives parents the right to inspect and review all of the student's education records. The law clarifies what information may be disclosed without written consent, who may have access to this information, and in what circumstances this information may be disclosed.</p> | <p>U.S. Department of Education</p> |
| <p>Employee Retirement Income Security Act (ERISA)</p> | <p>1974</p> | <p>ERISA is a comprehensive and reticulated statute that protects an individual debtor's pension benefits from creditors, whether in or out of bankruptcy.</p> | <p>Equal Employment Opportunity Commission (EEOC)</p> |
| <p>Health Insurance Portability and Accountability Act (HIPAA) 1996</p> | | <p>HIPAA was passed requiring the secretary of HHS to publicize standards for the electronic exchange, privacy and security of health information. Due to fear of electronic information theft, the HHS issued what is known as the Privacy Rule to help implement HIPAA. The major goal of the Privacy Rule is to assure that individuals' health information is protected while allowing the flow of health information needed to promote high quality health care. The Privacy Rule requires covered entities (health plans, health care clearinghouses, and any other health care provider who transmits health information electronically) to implement standards to protect and guard against the misuse of individual identifiable health information. With regard to the</p> | <p>Civil Violations - Office of the Inspector General Criminal Violations - FBI</p> |

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| | | mentally disabled, the privacy Rule requires an entity to treat a “personal representative” the same as the individual, with respect to uses and disclosures of the individual’s rights under the rule. A personal representative is defined as a person legally authorized to make health care decisions on an individual’s behalf. Department of Health and Human Services (DHHS) | |
| Social Security Act Amendments Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter’s Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004 | 1965 | Authorized health benefits for eligible elderly individuals or individuals with disabilities. “Part A” reimbursed hospitals or other covered entities. Part “B” provides supplemental medical insurance benefit. 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. | Social Security Administration Department of Health and Human Resources |
| Architectural Barriers Act Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter’s Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004 | 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. | The Access Board (Independent Federal Agency) |
| Developmental Disabilities Assistance and Bill of Rights Act Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter’s Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004 | 1970 | Provided 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 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. | Administration on Developmental Disabilities, Department of Health and Human Services |
| Rehabilitation Act | 1973 | First created to prohibit discrimination on the basis of disability in federal programs or programs receiving federal funding <ul style="list-style-type: none"> • Section 105: Created consumer directed and controlled State Rehabilitation Councils. • Section 501: Requires affirmative action and prohibits discrimination by federal agencies of the executive branch. | U.S. Department of Labor Office of the Assistant Secretary for Administration and Management Section 508 |

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| <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | | <ul style="list-style-type: none"> • Section 504: States that no qualified individual with a disability in the United States shall be excluded from, denied 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. • 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. | |
| <p>Protection and Advocacy for Individuals with Mental Illness Act (PAIMI)</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | <p>1986</p> | <p>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.</p> | <p>United States Department of Health and Human Services / Substance Abuse and Mental Health Services Administration /Center for Mental Health Services.</p> |
| <p>Air Carrier Access Act</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | <p>1986</p> | <p>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.</p> | <p>United States Department of Transportation Office of Aviation Enforcement and Proceedings</p> |
| <p>Fair Housing Act</p> | <p>1988</p> | <p>Prohibits housing discrimination on the</p> | <p>United States</p> |

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| <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | | <p>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.</p> | <p>Department of Housing and Urban Development</p> |
| <p>Mental Health Parity Act</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | <p>1996</p> | <p>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</p> | <p>United States Department of Health and Human Services / Center for Medicare and Medicaid Services</p> |
| <p>Individuals with Disabilities Education Act</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | <p>1997</p> | <p>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 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.</p> | <p>United States Department of Education / Office of Special Education and Rehabilitative Services</p> |
| | <p>2004</p> | <p>Revised by Public Law 108-446 of the No Child Left Behind Act and other legislation.</p> | |
| <p>Olmstead Decision</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004</p> | <p>1999</p> | <p>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.</p> | <p>Stare Decisis</p> |
| <p>Ticket to Work and Work Incentives Improvement Act</p> <p>Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia</p> | <p>1999</p> | <p>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</p> | <p>United States Department of Health and Human Services / Centers for Medicare and Medicaid Services</p> |

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| Developmental Disabilities Council. 2004 | | 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 Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004 | 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 community life. The initiative led to the creation of the New Freedom Commission on Mental Health which is designed to improve America's mental illness and children with serious emotional disturbances | United States Department of Health and Human Services / Centers for Medicare and Medicaid Services |
| Community Based Alternatives for Individuals with Disabilities Executive order 13217 Southall, Betsy. Ed. Steve Wiseman. <u>A Reporter's Guide: Reporting About People With Disabilities.</u> Charleston: West Virginia Developmental Disabilities Council. 2004 | 2001 | Order which called for the Federal government agencies for 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." | United States Department of Health and Human Services / Centers for Medicare and Medicaid Services |
| No Child Left Behind Act (NCLB) H.R. 1 (2001) | 2001 | The purpose of the NCLBA is "to ensure that all children have a fair, equal and significant opportunity to obtain a high-quality education and reach, at a minimum, proficiency on challenging state academic achievement standards and state academic assessments." 20 U.S.C. § 6301. The NCLBA, which is aimed a strengthening elementary and secondary schools, is a comprehensive education reform statute. 20 U.S.C. §§ 6301(1)-(12). The NCLBA's purpose is to be accomplished through a variety of means including, among other things, holding schools, local educational agencies, and States accountable for improving the academic achievement of all students, and identifying and turning around low-performing schools that have failed to provide a high quality education to their students, while providing alternatives to students in | United States Department of Education |

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| | | such schools to *341 enable the students to receive a high-quality education. 20 U.S.C. § 6301(4). | |
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LEGAL PRECEDENTS

| <u>SUBJECT</u> | <u>SOURCE</u> | <u>SUMMARY</u> |
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| Duty to Warn | <i>Tarasoff v. Regents of University of California</i> , 17 Cal.3d 425, 551 P.2d 334 (1976) | The California case in which a therapist was informed by his client that he intended to harm a third party. The case established a legal duty for psychotherapists to warn or otherwise protect an identified person who is threatened with serious danger of violence by a client. Whether one agrees with the decision or not, it is indisputable that <i>Tarasoff</i> established a new standard of care for psychotherapists. The essential elements that support compliance with a court-established standard of care are (a) the legitimacy of the issue to the profession, (b) widespread publicity of the case, making psychotherapists considerably more willing to notify people who might be in danger from clients who threatened harm, and (c) an unacceptable risk to the psychotherapist for noncompliance. It is important to note that this precedent was established in a California State Supreme Court decision and as such is not binding on other states. Many states have accepted this as their controlling precedent; however, other states have declined to follow this case or have modified it. For example, Florida has stated that this duty does not apply to voluntary outpatients <i>Boynton v. Burglass</i> 590 So.2d 446. |
| Confidentiality | <i>MacDonald v. Clinger</i> , 84 A.D.2d 482; 446 N.Y.S. 2d 801 (Sup. Ct. 1982) | A New York case, in which the court recognized a legal compensable injury due to an unauthorized disclosure of information, concluding, "it will be assumed that, for so palpable a wrong, the law provides a remedy." In cases since <i>MacDonald</i> , public policy and privacy arguments have provided the rationale for the decisions against therapists. Regardless of the theory, courts have strongly backed the expectation of confidentiality. |
| Mandated Reporters | State Statutes | Most states have laws in place that require social workers to report incidences of abuse and neglect of children, adults, and the disabled. Also, other groups have received similar status, e.g., victims of rape, domestic violence, and hate crimes. With the exception of child abuse and neglect, states differ significantly in how these are handled. |
| Malpractice | In General | Can be tort or criminal law; usually involves a breach in the standard of care. An action usually includes (1) a duty of care, (2) a breach of that |

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| | | duty, (3) causation, (4) damages. Courts have also included foreseeability in their analysis. |
| Defamation | In General | Defamation is the publishing of a statement about another person that is untrue, misleading, malicious, and damaging to the person being written about. In the content of mental health, the claim of defamation is frequently part of a malpractice or breach of contract claim. Clients and others who file a lawsuit for defamation usually target the unauthorized release of records that publish false statements. |
| Social Worker Privilege | <i>Jaffe v. Redmond</i> , 116 S. Ct. 1923 (1996) | Established a therapeutic relationship between the social worker and the client. The court stated: "Making the promise of confidentiality contingent upon a trial judge's later evaluation of the relative importance of the patient's interest in privacy and the evidentiary need for disclosure would eviscerate the effectiveness of the privilege . . . [P]articipants [in therapy] must be able to predict with some degree of certainty whether particular discussions will be protected. An uncertain privilege, or one which purports to be certain but results in widely varying applications by the courts, is little better than no privilege at all." It is important to note that this decision specified that federal courts recognize this privilege. Therefore, states may decline to recognize this or may assert their own precedent as Georgia has done <i>Price v. State Farm Mut. Auto. Ins. Co.</i> 235 Ga.App. 792, 510 S.E.2d 582. |
| Ending Treatment | Medical Abandonment in General | Claims for abandonment usually fall into three areas: (1) negligent care, (2) terminations by social workers based on self-interest, (3) terminations of clients due to necessity or life events. In all cases, when terminating a client who continued to need treatment, the social worker has an obligation to take reasonable steps to ensure that the client receives the necessary treatment. A simple referral is oftentimes not enough. |
| Record Keeping | In General | Records are to be accurate, adequate, complete, and timely, detailing an account of the therapeutic process, documenting the standard of practice, and appropriate follow-up. Records are usually not the main cause-of-action, but sources of evidence. |
| Health Care Decisions Acts | Various | The purpose is to ensure that a patient's right to self-determination is protected; and sets forth a process that includes the use of advance directives. Each state has laws in place to |

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| | | effectuate the policy of self-determination. |
| Scope of Title II | <i>Olmstead, Commissioner, Georgia Department of Human Resources, et al. v. L.C., by Jonathan Zimring, guardian ad litem and next friend, et al.</i> 527 U.S. 581, 119 S.Ct. 2176 | The court concluded that under Title II of the ADA, states are required to place persons with mental disabilities in community settings rather than in institutions when the state's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. |
| Reasonable Accommodation | <i>U.S. Airways, Inc. v. Barnett</i> , 122 S. Ct. 1516 (2002) | When an employee with a disability seeks reassignment as an accommodation under the ADA, does that employee's right to reasonable accommodation trump another employee's seniority rights when the employer has a seniority system? In the court's view, the seniority system will prevail in the run of cases. As the statutes were interpreted it shows that a requested accommodation conflicts with the rules of a seniority system is ordinarily to show that the accommodation is not "reasonable." Hence such a showing will entitle an employer/defendant to summary judgment on the question-unless there is more. |
| SSDI plus ADA | <i>Cleveland v. Policy Management Systems Corp.</i> , 526 U.S. 795 (1999) | Pursuit, and receipt, of SSDI benefits does not automatically stop a recipient from pursuing and ADA claim or erect a strong presumption against the recipient's ADA success. However, to survive a summary judgment motion, an ADA plaintiff cannot ignore her SSDI contention that she was too disabled to work, but must explain why that contention is consistent with her ADA claim that she can perform the essential functions of her job, at least with reasonable accommodation. However, the court recognized in <i>Roloff v. Commissioner of Dept. of Employment and Economic Development</i> 668 N.W.2d 12 that the <i>Cleveland</i> court "was addressing the interplay between two federal statutes." Based on this reasoning, the <i>Roloff</i> court stated that it did not abrogate a state statute in Minnesota. |
| Disability Defined | ADA and Section 504 | A disability is generally defined as a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment |

DISABILITIES LANGUAGE

Although not all disability rights advocates and disability experts agree on the use of People First Language, proponents believe that such language emphasizes the person rather than the label. A person is much more than just one characteristic, but when a label is placed in front of the person, that label can become the defining characteristic of that individual. Language shapes the way we think, and thus it is important to consider the words that we use. Some language may be preferable than other language when referring to disability – but keep in mind that it is often not necessary to refer to the person’s disability at all. Ask, is it relevant?

As noted above, not all disability rights advocates agree with People First Language. For example, Depoy and Gilson note that People First Language only seems to apply when the descriptor is seen as a negative. Many veterans prefer “disabled veterans” and have a sense of pride related to their disability. “Deaf community” is similarly preferred by some. The WV Developmental Disabilities Council and WV MR/DD Waiver Program (Division of Developmental Disabilities) provide the following guidelines:

Avoid:

Able-bodied/Normal – instead use “person without a disability” or “non-disabled person”.

Autistic, epileptic... instead use person with autism, person with epilepsy....

Birth Defect – instead use “congenital disability” or “person born with a disability”

Confined to a wheelchair/wheelchair bound – instead use “uses a wheelchair”

Cripple or crippled – instead use “person with a physical disability” or “person with a disability”.

The disabled, the blind, the epileptics, the retarded, etc. – instead use descriptive terms as adjectives, not nouns.

Handicapped – instead use “person with a disability”

Handicapped parking/bathroom – replace with “accessible parking or bathrooms

Invalid, mongoloid, defective, special person, afflicted with, deaf and dumb, mute – these terms have negative connotations and devalue the person.

Retarded – “person with cognitive disabilities” is preferred although “persons with mental retardation may be acceptable.

Schizophrenic: instead use “person with schizophrenia” or “person living with a mental illness”

Stricken with or suffers from: assumes the person with the disability has a reduced quality of life compared to a non-disabled person.

Vegetable/vegetative – these terms are offensive and imply that people with disabilities are less than human. “Comatose”, “non-responsive”, or “profound disability” are preferable.

Victim – disabilities are a natural part of the human experience – better to say “person with a disability

STUDENT DISCUSSION ACTIVITY

PEOPLE FIRST LANGUAGE: YES OR NO?

YES

Placing the disability label first leads to defining that person as his/her disability. By placing the person first, recognition is given to the fact that the person is much more than a label. Disability is just one aspect of who a person is – it does not define who that person is. Words are powerful and shape the way we think. Society tends to place stigma and view disability in a negative, problematic way, it is important to use language in a way to create a more positive image.

NO

By promoting people first language, one is accepting that disability is a bad word or a negative characteristic rather than a source of pride. It seems to be promoted only for terms that we would consider problematic or negative. Elizabeth DePoy and others argue that it is euphemistic. “If the modifier is so heinous as to require personhood to be asserted before it, the devaluation of the modifier is pretty obvious.” (DePoy).

What do you think?

**STUDENT ACTIVITY:
SOCIAL DARWINISM V. SOCIAL INCLUSIONS/STRENGTHS**

Imagine a typical day when you were in high school – your friends, the conversations you had, and the clothes you wore. Imagine more deeply – the way you felt, laughed, and the things that made you anxious, nervous, and self-conscious. Now identify:

What made you different from those around you?

Identify what makes you different today?

What makes you the same?

We are all both different and the same: biologically—predisposition, human genome; sociologically—families, diverse, traditions/myths; psychologically—perception in reality, origin/development. Of the differences:

What should the law “class” as exceptional?

What does the law “class” as exceptional?

**Ending Disability
Discrimination: Implications
for Health Clinicians**
Gary May
(Power Point Slides)

SOCIAL POLICY ABSTRACTS

The following materials are organized in two sections; the first drawn from an American perspective and the second providing information with an international viewpoint. The inclusion of the global perspective provides a view of the topic that illustrates both the progressive aspects of the American experience and also areas for further development of the American response to inclusion. It is noted that the diversity of policy analysis research for the topic is relatively limited in scope as evidenced by a literature review for the time period 2000-2006.

From the American Perspective

Overview

These articles provide insight to policy issues in a number of ways. Braddock's work reviews historic influences on present policy and the related public and private trends in the states. The role of activism by persons with disabilities to influence policy and practice changes through participation/advocacy/civil disobedience is highlighted in two articles by Bradley and DePoy. Attention to legitimacy theory (DePoy) and the disability discrimination model (May) highlight the application of theory to policy analysis as an alternative to the traditional paternalistic model. Fox provides an important overview of the implementation of the Olmstead decision in 20 states and the results of the "New Freedom" initiative of 2003. The literature review noted only one article focusing on research application to practice in this topic (LeRoy). Concerns about long-term care are raised by Palley. Parish and Lutwick note an "impending crisis" in long-term care issues for persons with disabilities and while stressing advocacy, the tone is somewhat paternalistic in contrast with the model counseled by May. The story of Jack Eldon Baker offers a unique first person account to help inform our thinking on the topic but unfortunately the NASW policy offering provide no new approaches from the organizations previous (2003) ideas.

Braddock, David. 2002. Disability at the Dawn of the 21st Century and The State of the States. American Association on Mental Retardation. Washington, DC.

This resource provides a comprehensive historical based cross disability perspective overview from ancient times to the present focusing on public support for the disabled at the beginning of the 21st. century. The second section reviews the state of the states in public support for public and private efforts and the trends in public financing of community services. Included is a state by state summary of emerging trends. The final section provides a comparative study of the forces shaping developmental disability services in the states including the methodology utilized and the use of a case study (Michigan) to address the roles of politics, legislative influences, public officials, and the role of advocacy groups in changes to services in this state. Overall, this resource is an excellent summary of the historical and contemporary influences for policy in developmental disabilities.

Bradley, Valerie J. 2000. *Changes in Services and Supports for People with Developmental Disabilities: New Challenges to Established Practice.* *Health & Social Work*, Aug 2000, Vol. 25 Issue 3, p191, 10p.

The article explores the implications of the ideals, the ways in which systems of support for *people with* developmental disabilities are fueling initiatives, the challenges that constrain their full realization, and the steps that must be taken to keep the developmental disabilities system moving in a progressive direction. The notion of inclusion, in one form or another, has been a motivating force for reform in the field of developmental disabilities through the past 25 years. Conceptually, inclusion has evolved from an aspiration linked to "place" to one tied to participation, choice, and relationships. Concepts that stressed integration and "community-based" *services* influenced public policy, which in turn influenced *practice*. As a profession social workers celebrate the emerging models of self-determination and customer choice that are taking root in many parts of the country. However, the gap between our aspirations and practice is still great, and it will take more than additional conversions of the uninitiated to bring current practice into line with these ideals.

DePoy, Elizabeth and Gilson, Stephen F. 2004. *Rethinking Disability: Principles for Professional and Social Change.* Belmont, CA: Thompson/Brooks Cole.

This introductory text on disability provides an overview of legitimacy theory and of interest to those interested in policy, a general overview of the history of disability policy and a section (pp33-40) on social policy development in the 20th century.

Fox-Grage, Wendy, Coleman, Barbara, Folkemer, Donna. 2004 *The States' Response to the Olmstead Decision: A 2003 Update.* Retrieve from: http://www.allhealth.org/recent/audio_06-21-_4/NCSL%20State%20Response%20to%20Olmstead.pdf

This report categorizes current *Olmstead*-related plans, the role of the federal systems change grants, legislative initiatives, structural changes and implementation barriers. The report reflects activity as of December 2003. To obtain accurate and timely information, NCSL relied on telephone interviews with key state contacts; a survey of significant online planning documents, budget analyses and press announcements; and a database review of state legislation that was enacted during the 2003 legislative sessions. State planning efforts and the federal grants to states that have resulted from the President's New Freedom initiative are two of the most significant state and federal activities in direct response to the *Olmstead* Supreme Court decision. Twenty-nine states have issued an *Olmstead*-related plan or report. Of this total, 20 states published their plans between 2000 and 2002. Nine states--Arkansas, California, Delaware, Georgia, Kentucky, Maine, North Carolina, Oklahoma and Virginia--released their plans during 2003. Four states--Alabama, Illinois, Louisiana and West Virginia--were working on their plans during 2003 but did not release them. Several states have task forces that are working on various

Olmstead-like activities but do not intend to write a plan. (See the state profiles section of this document and Table 1 in this report for details on the 29 state plans, many of which can be accessed online.)

LeRoy, Barbara W; Johnson, Donna M; Israel, Nathaniel. 2004. The Perceptions of Welfare Reform by Michigan Families Whose Children Have Disabilities and Welfare Caseworkers. The Social Policy Journal, Vol.3, (1), 23-37.

This article examines family & caseworker perceptions of welfare reform & services as they relate to families who have a child with a disability. Interviews were conducted with 39 families & 77 caseworkers. Family questions addressed their perceptions of the welfare system, factors impacting their self-sufficiency, & their perceptions of needed program changes. Caseworker questions addressed their perceptions of welfare practices & policies & their education needs related to serving families who have children with disabilities. Familial perceptions of the welfare system were validated by caseworker reports. Implications for service improvement are discussed.

Malone, D. Michael; McKinsey, Patrick D.; Thyer, Bruce A.; Straka, Elizabeth. 2000. Social Work Early Intervention for Young Children with Developmental Disabilities. Health & Social Work, Aug., Vol. 25 Issue 3, p169-181.

Social workers' awareness of and formal involvement in family-centered early intervention for infants and toddlers who are at risk of or who have developmental disabilities has increased considerably during the past 15 years. The functional role that social workers can play on early intervention teams and as coordinators of early intervention services is underscored by the formal recognition of the discipline in the Individuals with Disabilities Education Act. Despite the relevance of social work to early intervention, personnel often enter early intervention practice without the benefit of formal preparation related to very young children with developmental disabilities. This article provides an overview of the definition and identification of developmental disabilities, and discusses the role of and challenges to social work in early intervention.

May, Gary E.; Raske, Martha B. (eds). 2005. Ending Disability Discrimination: Strategies for Social Workers. NY, Pearson Education.

Recently published, this compilation provides two chapters relevant to policy. Chapter one, "Academic Debates and Political Advocacy: The US Disability Movement", authored by Harlan Hahn, analyzes the background of the current state of policy based on the concept of a "disabling environment". His orientation is to focus on the role of advocacy and civil disobedience as a catalyst for change and the emergence of activism as a key factor in this social change. In spite of paternalism and "covert resistance from the non-disabled majority", the movement broke through the "legacy of charity" and identification as the "deserving poor" to affect broad scale

changes in social policy. A thorough linkage of the legal process to advance access is provided along with the disappointments associated with this avenue for change.

Chapter 7 (authored by May) addresses policy practice utilizing the disability discrimination model. This model is oriented to viewing disability as "...a social construction rather than an immutable, objective reality". Such an approach argues that "...deviations from normal expectations...are defined as limiting and excluding". Reframing disability away from a medically-oriented perspective, he argues, provides an orientation to policy practice that provides an alternative to previous models of advocacy.

National Association of Social Workers. 2006. People with Disabilities. Social Work Speaks: National Association of Social Workers Policy Statements. NASW, Washington, DC. pp. 284-289.

Providing a brief background and overview of relevant public policy issues related to disabilities, this article focuses on the core policy issues of the movement and recommendations for policy. As a basis of these recommendations is the Code of Ethics and the areas of attention are independent living, housing, and transportation; community accessibility; education; employment; and income and health care. Unfortunately, the new policy statements reflect no change, modification, or revision from the 2003-2006 document on the subject.

Palley, Howard A.; Van Hollen, Valerie. 2000. Long-Term Care for People with Developmental Disabilities: A Critical Analysis. Health & Social Work, Aug., Vol. 25 Issue 3, p181-190.

This article explores how the trends toward long-term community care affecting people with developmental disabilities developed. Appropriateness of care and quality of life issues are discussed. The article also reviews the development of long-term care for frail and disabled elderly people and explores the arguments for a continuum of care that have developed in this area. The authors conclude that future policies with respect to meeting long-term care needs for people with developmental disabilities must be addressed flexibly on an individual basis, related to individual needs, and must provide a continuum of care services.

Parish, Susan L.; Lutwick, Zachary E. 2005. A Critical Analysis of the Emerging Crisis in Long-Term Care for People with Developmental Disabilities. Social Work Volume 50, Number 4, October, pp. 345-354.

These authors argue there is an impending crisis in long-term care for people with developmental disabilities. The demand for care will likely outpace the supply for decades to come. Factors, such as limited existing long-term care resources, increased life expectancy for people with developmental disabilities, changing family demographics, legal actions, and competition for resources with the elderly population are driving the crisis. Virtually every domain of social work practice will face challenges in this area. This article advocates for an immediate response from the social work community in several areas. The profession needs to provide social workers with expanded training in family-centered approaches to working with people with

developmental disabilities, develop new interventions, create new organizational supports, and practice assertive advocacy.

Remembering Community Inclusion: Stories From the Life of Jack Eldon Baker. Rehabilitation Counseling Bulletin 04/01/2005, Vol. 48 (3), p177

This first person account, tells the story of Jack Eldon Baker who was born, lived, and died in Gilbert, Arkansas. The story of his life is retold in excerpts from a memorial publication published by the people of the town. This article also makes the case that his story is an example of community inclusion. Through the voices of those who knew him, we see Jack as a person who gave to the community according to his talents and was supported by the community according to his needs. Although our social services system would have identified him as a person with a significant developmental disability, neither Jack nor his community found such labels meaningful. The importance of Jack's contribution to his town and the implications for the rehabilitation counseling profession are discussed.

From the International Perspective

Overview

The following articles provide insights useful to understanding policies related to the experiences of persons with disabilities from other countries. Bigby's overview of the results in Australia of barriers experienced as a result of life long intellectual disabilities and the resulting gaps in inclusion and services parallels the American experience. In Hong Kong, Chou notes that neither central or local authorities are "seriously involved" in policy modifications to meet needs and that informal care by female family members without policy support is the norm. Similarly, Ngan's research on four dimensions of inclusion of persons in Hong Kong (n = 692) shows patterns similar to the U.S. and a call for empowerment. Doha raises a paradox for a world-wide issue affecting both the aging and disabled individuals: People are living better and longer yet family resources are "ill suited" to assist these persons. The Norwegian experience (Meyer), historically a model for inclusion, notes the shift to "community-invested services" imbedded in the national goal of normalization that emerged in the 1970's has not been without challenges. The devolution of services to the family and community has been difficult for townships and municipalities as competing demands for funds and barriers to social inclusion have emerged. In her cross-Canada analysis of policy, Pedlar sees limited leadership, fewer resources that are "market oriented", and resulting in a "commodification of disability". Her prescription, as noted by several other researchers, is empowerment.

Bigby, Christine. Dec2002. Ageing people with a lifelong disability: challenges for the aged care and disability sectors. Journal of Intellectual & Developmental Disability. Vol. 27 Issue 4, p231-241, 11p.

Australia is experiencing a rapid increase in both the absolute numbers and proportion of people who are ageing with a lifelong disability. Aged care and disability are the two key social policy sectors that impact most directly on formal services available to this group. Potentially they may

be included or excluded from either sector. This paper compares and contrasts Australian policy directions in aged care and disability. Using people with intellectual disability as an exemplar of those who are ageing with a lifelong disability, the paper analyses their location within and the services offered to them by each sector. The paper argues that neither sector adequately addresses the issues raised by the needs of this group and suggests why this is so. Directions for policy and service developments necessary to ensure that the needs of this growing population are met are suggested. These are broadly categorized as; systematically bridging existing gaps with specialist services; supporting inclusion and ensuring older people with lifelong disability are visible within the aged care system; adapting and resourcing the disability sector to facilitate ageing in place; and developing partnerships and joint planning aimed at the removal of cross- and intra-sector obstacles to accessing appropriate services.

Chou, Yueh-Ching; Kroger, Teppo. 2004. Community Care in Taiwan: Mere Talk, No Policy. Social Work in Mental Health. Vol. 2, Number 2-3, 139-156.

This article explores the policy definitions & the funder roles of central & local governments in community care in Taiwan. The notion of community care has been adopted in Taiwan following the model of Hong Kong but the main question of the article is whether this has resulted in actual service provisions at the community level, forming an alternative to institutional care. The data has been collected from several sources: policy documents, official statistics, surveys, general reports, funding provision reports, & empirical studies. The results show that neither central nor local authorities are seriously involved in caring for elderly people or persons with disabilities in Taiwan's communities. In Taiwan, community care for these groups of people still means, in practice, informal care provided by female family members without any support from public policies.

Doka, Kenneth J.; Lavin, Claire. The Paradox of Ageing with Developmental Disabilities: Increasing Needs, Declining Resources; Ageing International, Spring2003, Vol. 28 Issue 2, p135, 20p.

There is a new, still somewhat hidden population - persons ageing with developmental disabilities. This population, though estimates of size vary, has survived to later life due to better health care and deinstitutionalization. Yet as this population of persons with developmental disabilities ages, it will raise new challenges for gerontologists and specialists in the field of developmental disabilities. The situation of persons ageing with developmental disabilities is characterized by a paradox. As persons with developmental disabilities age, they are likely to experience cognitive and physical deficits that increase their need for services and support. Yet their family-based support systems (who are also ageing) may be less available and social services may be ill suited to assist. The growing numbers of persons aging with developmental disabilities may call into question not only the policies and programs designed to serve this emergent population, but also the very ways we educate and train professionals working in the fields of gerontology and developmental disabilities.

Meyer, Jan. 2004. Goals, Outcomes, and Future Challenges for People with Intellectual Disabilities in a Noninstitutional Society: The Norwegian Experience. Journal of Policy and Practice in Intellectual Disabilities, Vol. 1 (2).

The Norwegian Welfare System and how its programs support Norwegians with intellectual and developmental disabilities is described and proffered as a case example of how one nation's public policy shifted to provide community-invested services for people with lifelong disabilities. The foundation of Norway's shift to complete reliance on home and community supports for its citizens with intellectual disabilities lies in the health and welfare system that is in place for all Norwegians. Social change began in the mid-1970s when a governmental commission examined Norwegian social policy for people with developmental disabilities using four factors: (1) the ideological tenets of the principle of normalization, (2) the government's commitment to decentralization of services, (3) the goal of the integration of persons with disabilities, and (4) moving toward a broader definition of developmental disabilities as a target group for services. The commission's recommendations of closure of institutions and the devolution of services led to a reliance on local townships and municipalities. However, this process was not without its problems, such as competing demands for public services and local economies, and dealing with barriers posed by resistance to social integration and inclusion. The author explores the Norwegian experience and the dilemmas faced by local communities in attempting to meet the national goals of a non-institutional society.

Ngan, Raymond. 2004. Community Integration of Older People with Developmental Disabilities in Hong Kong Journal of Social Work in Disability & Rehabilitation, Feb., Vol. 2 (2-3), p101.

To understand the community integration of adults with developmental disabilities in Hong Kong, a comprehensive measure includes four dimensions, pertaining to social activity, social services, interpersonal behavior, and people involved in social interaction. Applying this measure to 692 adults (aged 15-62), the territory-wide study finds that these adults lack company for out-of-home activities and community activities despite their higher knowledge, assertiveness, social interaction, and feeling accepted in the community. With the strengthening of many conditions (including knowledge and community support) for community integration, the adults tend to have greater need for empowerment to enhance their active participation in community activities.

Pedlar, Alison; Hutchison, Peggy. 2000. Restructuring Human Services in Canada: commodification of disability. Disability & Society, June, Vol. 15 Issue 4, p637- 651, 15p.

The human service system in Canada has undergone significant changes as a result of the dismantling of provisions that was once in place to ensure access to services by society's more vulnerable citizens. This paper draws on a cross-Canada examination of services to adults with developmental disabilities to report on the response of service providers in this time of turbulence. Qualitative analysis provides insight into the ways in which services have responded to shrinking budgets. Without leadership and lacking a social policy framework from senior

levels of governments, the changing face of human services has been accompanied by the arrival of a new market-orientated service provider group that has deepened the commodification of disability. The examination concludes with the introduction of an approach to support which resists the trend toward commodification and re-establishes the social good, allowing the individual with a disability the right to participate more fully in community life alongside other members of society.

DIVERSITY ABSTRACTS

Ferrari, M. (2002). Development is also experienced by a personal self who is shaped by culture. Behavioral and Brain Sciences, 25(6), 755.

Abstract:

The author agrees with Thomas & Karmiloff-Smith (T&K-S) in their critique of Residual Normality. However, he insists, first-person data must be integrated into their account of neurobiological development of disabilities. Furthermore, psychological development itself is not only about an individual's brain and how it interacts with the world; rather, development depends crucially on the sociocultural context in which (normal and abnormal children develop.

Tallal, P. (2002). Are developmental disabilities the same in children and adults. Behavioral and Brain Sciences, 25(6), 768.

Abstract:

Thomas & Karmiloff-Smith (T&K-S) raise an issue of considerable theoretical importance: Are developmental disorders like cases of adult brain damage? However, a related question: Are developmental disabilities the same in children and adults? Is rarely addressed. Failure to consider the cumulative and differing effects of aberrant development across the life span confounds the current literature on both developmental dyslexia and Specific Language Impairment.

Nabors, N.A., Pettee, M.F. (2003). Womanist therapy with African American women with disabilities. Women & Therapy, 26(3/4), 331.

Abstract:

African American women are at increased risk for disabilities. There is very little information available, however, regarding psychological interventions with African American women with disabilities. The purpose of this article is to discuss psychological intervention in working with African American women with acquired disabilities from a womanist perspective. Themes and interventions are discussed. Recommendations for working with African American women with disabilities in a therapeutic context are offered.

Parette, H.P., Brotherson, M.J. (2004). Family-centered and culturally responsive assistive technology decision making. *Infants and Young Children, 17(4), 355.*

Abstract:

A family-centered approach is recommended practice for assistive technology (AT) decision making with families who have infants and toddlers with disabilities. Involving families in AT decision making involves careful gathering of information needed to address the family strengths, needs, and priorities, and to match the AT decision-making process with the family's culture. It also involves matching the infant or toddler with a disability to AT and the natural environments and activities where the devices and services will be used. Assistive technology can also enhance opportunities for infants and toddlers to develop early skills of self-determination when this is consistent with a family's cultural values. The article discusses (a) the role of AT in the service planning process; (b) issues related to working with families across cultures; (c) issues related to effective AT decision making when working with culturally and linguistically diverse families who have infants and toddlers with disabilities; and (d) a process of cultural reciprocity for meaningful information gathering during the AT decision-making process. Future issues for family-centered research and personnel preparation training are discussed for infants and toddlers with AT needs and their families.

Rueda, R., Monzo, L., Shapiro, J., Gomes, J., Blacher, J. (2005). *Exceptional Children, 71(4), 401.*

Abstract:

This study used several focus groups to examine culturally based variation in attitudes, beliefs, and meaning of transition. Sixteen Latina mothers of young adults with disabilities participated in the study, recruited from an agency serving low-income, predominantly Spanish-speaking communities. Data analysis identified five primary themes: (a) basic life skills and the social adaptation, (b) the importance of the family and home rather than individualism and independence, (c) the importance of the mother's role and expertise in decision making, (d) access to information and (e) dangers of the outside world. The overarching theme was a view of transition as home-centered, sheltered adaptation as opposed to a model emphasizing independent productivity. The findings and the implications for future research and practice are discussed.

SELECTED INTERNET RESOURCES-POLICY ISSUES

<http://www.kidstogether.org/leg.htm>

An overview of policy resources for development and education, health, income, housing and supports, rights, transportation, and work on the federal, state, and local levels.

<http://www.usdoj.gov/crt/ada/cguide.htm>

A Guide to Disability Rights Laws. September 2005.

Table of Contents: Americans with Disabilities Act, Telecommunications Act, Fair Housing Act, Air Carrier Access Act, Voting Accessibility for the Elderly and Handicapped Act, National Voter Registration Act, Civil Rights of Institutionalized Persons Act, Individuals with Disabilities Education Act, Rehabilitation Act, Architectural Barriers Act, General Sources of Disability Rights Information, Statute Citations.

<http://www.acf.hhs.gov/programs/add/>

US Administration on Developmental Disabilities-an in-depth and detailed overview of policy and services on the Federal level.

http://www.federalgrantswire.com/university_centers_for_excellence_in_developmental_disabilities_education_research_and_service.html

University Centers for Excellence in Developmental Disabilities Education, Research, and Service.

Objectives: To defray the cost of administration and operation of programs that: (1) Provide interdisciplinary training for personnel concerned with developmental disabilities; (2) demonstrate community service activities that include training and technical assistance and may include direct services, e.g., family support, individual support, personal assistance services, educational, vocational, clinical, health and prevention; (3) conduct research (basic and applied), evaluation and analysis of public policy in areas affecting individuals with developmental disabilities; and (4) disseminate information as a national and international resource.

<http://www.dds.ca.gov/general/links.cfm>

From the state of California, Dept. of Developmental Services, this excellent web site provides links to a wide range of web resources for policy issues.

http://www.law.cornell.edu/wex/index.php/Disability_law

This Cornell Law School Legal Information Institute disability law site provides a wide range of information about legal policy issues and a range of relevant links.

http://www.opm.gov/disability/appempl_4-02.asp

The Federal Office of Personnel Management provides information about Federal Employment of People with Disabilities and a wide range of links to programs and services and policies that address the efforts of many government agencies and programs.

http://www.c-c-d.org/legislative_news.htm

The Consortium for Citizens with Disabilities address a broad range of federal legislative and legal issues. Click individual task force names to jump to their page to get detailed information including their mission, how to contact them, and a complete listing of announcements, articles, and reports. Information on policy issues related to housing, employment, fiscal policy, health, etc. are included.

RESOURCES FOR TEACHING DISABILITY

Compiled by
MARISSA JOHNSON

Projects, Curricula, & Lesson Plans

YIELD the Power to the Youth Curriculum

Access Living

Contains several lessons and activities related to disability history and culture.

www.accessliving.org

Access Living of Metropolitan Chicago

614 W. Roosevelt Rd.

Chicago, IL 60607

312-253-7000

Disability Rights History Pilot Project

A project created by the Disability Rights Education Defense Fund (DREDF) to teach 5th and 6th graders about disability history. Includes an activity involving interviewing adults with disabilities in the area.

www.dredf.org

To receive a full report about the project, including a detailed curriculum narrative, project reports, etc., contact Kenneth Stein at DREDF: kstein@dredf.org (510) 644-2555.

Anti-Defamation League Disability Curriculum, lesson 5

The purpose of this lesson is for students to examine how past prejudicial attitudes and social exclusion of people with disabilities led to the rise of a nation wide, grassroots movement for the recognition of equal rights, equal access and equal treatment of people with disabilities.

Students will consider how ableist assumptions are rooted in past stereotypical portrayals of disability, and will be challenged to reflect on their own assumptions and attitudes towards people with disabilities. Students will also learn about current day issues concerning the disability community, and will work in concert with disability advocates to take action in their own community on a disability rights issue.

http://www.adl.org/education/curriculum_connections/fall_2005/fall_lesson_5_2005.asp?cc_section=lesson_5

Teaching History and Disability Studies

This research list is compiled from information provided by Douglas Bayton, Assistant Professor, University of Iowa, with a joint appointment to the Department of History and the American Sign Language Program, University of Iowa, has written extensively on the history of the deaf in the U.S.

<http://www.disabilitystudies.com/history.htm>

Audio & Video

Beyond Affliction: The Disability History Project

Beyond Affliction: The Disability History Project is a four hour documentary radio series about the shared experience of people with disabilities and their families since the beginning of the 19th century. This Web site includes excerpts from the Shows as well as many of the primary source documents - extended interviews, images, and texts- from which the on-air programs were developed.

<http://www.npr.org/programs/disability/>

The Power of 504

A video documenting the 26-day take over of the Federal HEW building in California in 1977 to get the regulations for section 504 of the Rehabilitation Act of 1973 signed.

My Country

Tracing a path from civil rights to disability rights (and the ADA), this awareness training profiles three people faced with vision and developmental disability or war service that resulted in paralysis. They become disability advocates while pursuing their own career paths. Hosted by concert conductor James DePriest, who confronted polio in his 20s, My Country is a Disability SuperFest Best of Festival winner. Now available in DVD!

<http://www.pdassoc.com/disaw.html>

When Billy Broke His Head and Other Tales of Wonder

This breakthrough film blends humor with politics, and individual experience with a chorus of voices, to explore what it is really like to live with a disability in America — where pervasive discrimination and bureaucracy too often keep people with disabilities trapped in a labyrinth of government rules and legislated poverty.

http://www.fanlight.com/catalog/films/136_wbbhh.php

Vital Signs: Crip Culture Talks Back (selections)

This edgy, raw documentary explores the politics of disability through the performances, debates and late-night conversations of activists at a national conference on Disability & the Arts. Including interviews with well known disability rights advocates such as Cheryl Marie Wade, Mary Duffy and Harlan Hahn, Vital Signs conveys the intensity, variety and vitality of disability culture today.

http://www.fanlight.com/catalog/films/230_vs.php

Readings – Print Materials

No Pity by Joseph Shapiro

A chronology of the disability rights movement written for adults.

With 35 million disabled Americans, the American with Disabilities Act and its implications are here to stay. Shapiro, a U.S. News & World Report journalist, explores in depth the thoughts, fears, and facts behind the disability rights movement. The premise throughout this compelling historical account is that there is no pity or tragedy in disability--it is society's myths, fears, and stereotypes that make being disabled difficult. Shapiro's coverage is thorough, ranging from the movement's beginnings in Berkeley in the 1960s to the issues that will emerge in the future. Those interested in gaining a basic understand of the disability rights movement, will find this title is well organized, thoroughly researched, and thought-provoking.

Three Rivers Press, New York (1994). ISBN: 0812924126

<http://www.amazon.com/gp/product/0812924126/102-8005319-8634520?v=glance&n=283155>

The Disability Rights Movement by Deborah Kent

Ages 9-12

Traces the development of the disability-rights movement in fighting discrimination against people with disabilities and in securing civil rights for people with disabilities.

Children's Press (1996). ISBN: 0516066323

http://www.amazon.com/gp/product/0516066323/qid=1149516846/sr=1-2/ref=sr_1_2/102-8005319-8634520?s=books&v=glance&n=283155

A People's History of the Independent Living Movement

Writing by Chava Willig Levy

<http://www.independentliving.org/docs5/ILhistory.html>

The Self-Advocacy Movement

Writing by Bonnie Shoultz, Center on Human Policy

<http://web.syr.edu/~thechp/selfadv.htm>

Deaf President Now Resolution

Resolution by Gallaudet University Faculty supporting the Deaf President Now Protest and Demands <http://pr.gallaudet.edu/dpn/ISSUES/exhibitb.html>

A History Lesson

History from Ragged Edge Online

<http://www.ragged-edge-mag.com/0900/0900editorial.htm>

"Coming Home" to Disabled Country

Writing by Sarah Triano and Laura Obara about their first ADAPT action
<http://www.jfanow.org/cgi/getli.pl?1409>

Web Sites

Disability History Museum

The Disability History Museum's mission is to promote understanding about the historical experience of people with disabilities by recovering, chronicling, and interpreting their stories. Our goal is to help foster a deeper understanding of disability and to dispel lingering myths, assumptions, and stereotypes by examining these cultural legacies.

<http://www.disabilitymuseum.org/>

Disability Social History Project

An opportunity for disabled people to reclaim our history and determine how we want to define ourselves and our struggles.

<http://www.disabilityhistory.org>

Smithsonian Virtual Exhibition: The Disability Rights Movement

This exhibition looks at the efforts - far from over - of people with disabilities, and their families and friends, to secure the civil rights guaranteed to all Americans.

<http://americanhistory.si.edu/disabilityrights/>

Institute on Disability Culture

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.

<http://hometown.aol.com/sbrown8912/index.html>

A Chronology of the Disability Rights Movements

A timeline of events important in disability history.

<http://www.sfsu.edu/~hrdpu/chron.htm>

504 Sit-In 20th Anniversary Site

In 1997, a grand celebration was held commemorating the 20th Anniversary of the 504 Sit-It in S.F. and subsequent signing of the 504 Regulations. Over 600 people attended. We used the opportunity to record video recollections of many of the participants of the sit-in.

<http://www.dredf.org/504/504home.html>

US Holocaust Memorial Museum Pamphlet: “Handicapped”

Describes the Nazi treatment of handicapped people from 1933-1945.

<http://holocaust-trc.org/hndcp.htm>

Image Archive on the American Eugenics Movement

We invite you to experience the unfiltered story of American eugenics – primarily through materials from the Eugenics Record Office at Cold Spring Harbor, which was the center of American eugenics research from 1910-1940.

<http://www.eugenicsarchive.org/eugenics/list3.pl>

Parallels in Time: A History of Developmental Disabilities

Parallels In Time contains over 150 pages of information about the history of society's treatment of persons with developmental disabilities. It also features numerous video and audio clips, and each page is linked to an audio reading of that page.

<http://www.mncdd.org/parallels/menu.html>

Practice and Practice Research

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OVERVIEW: PRACTICE AND PRACTICE RESEARCH

It is important to incorporate the information from the previous sections into an effective practice module. This section begins with applications strategies of selected disability models. Assessment of the students' ability in this arena is effected through the use of detailed case studies. The case studies are based upon a traditional medical model and the student is challenged to identify the model and inherent limitations, suggest applications of other models and then address practical client resource concerns. To support the micro and mezzo knowledge base, student-selected handouts are provided: Developmental Disabilities—Family Centered Concerns; Key Elements of Family Centered Practice; Domestic Violence Issues.

To support the macro knowledge base of the student, two-training modules are provided. This section concludes with selected resources/community services and abstracts of research related to practice. The selected resources may be sources for classroom guest speakers as well as for field placements.

APPLICATION OF MODELS OF CONCEPTUALIZING DISABILITY TO SOCIAL WORK PRACTICE

Medical Model

Intervention based on the medical model would aim to cure, rehabilitate, or change something about the individual as the target of change. The medical model is not strictly “medical”, in that it also refers to other professionals who approach disability from this perspective.

Social Role Valorization

Social Role Valorization (SRV) asserts that people who are devalued by society suffer damage from this devaluation and are more likely than others to be clients of social service agencies. Communities and even some social service agencies perpetuate the harm through rejection, isolation, scapegoating, de-individualization, infliction of loss of autonomy and freedom, and exclusion in full participation in society and control over their own lives. From this perspective, SRV strategies include prevention(not devaluing people), remediation (reducing the harm that has occurred), and compensation (“adding value and competencies to that party”). Strategies would include shaping roles so that they are seen by others as having higher value and enhancing competencies needed to fill valued roles. From a social image standpoint, SRV strategies would serve to enhance social image by “arranging physical and social conditions so as to enhance positive perceptions”, and from a personal competencies perspective, “arranging physical and social conditions so as to enhance competencies. Examples would include promoting valued and age-appropriate activities, providing services in valued locations, enhancing positive personal appearance and body integrity, promoting individuation, and enhancing intellectual skills. SRV also promotes juxtaposing of people in devalued roles with positive images. SRV strategies focus on changing people’s perception of devalued populations. (Wolfensberger, W. Syracuse University Training Institute, Social Role Valorization Workshop, Charleston, WV, 2006).

Wolfensberger is critical of the concepts of “empowerment” and “self-determination”. Empowerment is viewed as coercive and/or reliant on a conflict model, whereas SRV “relies largely on educational and persuasive strategies that change people’s mind content about certain classes of other people by changing their perceptions, expectations, and attitudes”. He argues that people have a better chance of “getting the good things in life” by occupying social roles that are valued by others than by “exercising power, autonomy, and self-determination”. (Wolfensberger, W. 2002).

The Disability Discrimination Model

Social work practice within this model would focus on changing the way people with disabilities are treated in society. Disability related impairment is seen as a social construct rather than an objective reality. This model promotes positive connotations to the label of “disability” rather

than the negative stereotypes and assumptions that exist. People can be proud of their whole being – including “disability”.

Consistent with the strengths perspective, empowerment perspective, and resiliency model, intervention would include focus on the larger environment as the target for change. This does not deny the need for medical services or resources (the medical model), but stresses that those services can exist while social workers also work to transform the environment including intervening to eliminate discrimination, stigma, and oppression. Social work practice in accordance with this model includes: flexibility in worker/client roles, including role-reversal; expanding collaborative partnerships to include advocates and critics beyond client family and friends and organizational staff; setting an intervention triad that includes individual, relationship, and societal targets for all clients in all organizations; and providing cultural and clinical supervision for practitioners, supervisors, and administrators to address issues of oppression and discrimination in addition to clinical services”. (May, 2005). This is consistent with generalist social work practice that addresses all size systems: micro, mezzo, and macro.

May writes “the Disability Discrimination Model makes an essential distinction between the disability and impairment and views impairment as a socially constructed phenomenon. From this perspective, disability becomes disabling, or impairment, where an observed or perceived atypical appearance or functional characteristic intersects with a negative, stereotypic, limiting expectation set. Typically, the possessors of the atypical appearance or functional characteristics are labeled “disabled” and the holders of the negative, stereotypic, limiting expectations are labeled, “non-disabled”. Such a depiction allows the person with a disability to continue to “own” and even celebrate the disability, and implicitly, membership in the disability culture, and explains deferential treatment, and limiting elements of the social and physical environment. Interventions are enacted in a broader field and necessarily include the important human elements of the client’s experience. These other important human elements will need to be educated about the importance that they have in quality of life of the client.” (Gary May, 2006)

Explanatory Legitimacy Theory

DePoy and Gilson’s perspective does not view diversity as group specific and equivalent to oppression and marginalization. Rather, disability is one of many elements of human diversity. Disability is seen as “ a contextually embedded, dynamic grand category of human diversity. Thus, who belongs and what responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse human phenomena.”

Explanatory legitimacy theory distinguishes among descriptive, explanatory, legitimacy aspects of the categorization of human diversity and analyzes the interaction of these factors. Description refers to human activity (what people do or do not do and how they do it), appearance, and experience. It includes the dimension of what may be considered typical or atypical and the dimension of what is observable versus what is known through inference only (reportable). Explanation is the set of reasons for atypical doing, appearance, and experience. Legitimacy is the “set of beliefs, value judgments, and expectations attributed to the explanation”.

DePoy and Gilson describe the use of “human description mapping” to explore multiple explanations and consequences related to problems. Through this process, logical solutions can be implemented to meet the needs of the individual. This process can be applied at many levels of professional practice including social action. The author’s view social change as “a collaborative effort among individuals who are self-determining and who together hold and share a full complement of skills, knowledge, and values that they bring to advance a progressive community legitimacy agenda.” (DePoy & Gilson, 2004)

References

DePoy, E. & Gilson, S. (2004). Rethinking disability. Belmont, CA: Brooks/Cole.

May, G. and Raske, M. (200-5). Ending disability discrimination. Boston: Pearson.

Wolfensberger, W. (2002). Social role valorization and, or versus “empowerment”. Mental Retardation. 40(2).

DEVELOPMENTAL DISABILITY: STUDENT ACTIVITY

Divide students into small groups. Have students state which model(s) were used in the following social histories. Students can then discuss practice limitations relative to that model. Have them apply other models to the facts.

Students can also be challenged to view the written plan from a family-centered perspective noting how “natural networks” and “typical activities” might be incorporated into the plan so that families are not overwhelmed by professional service providers.

Then, students must search out accessible, appropriate, and available resources in the community—they must be actual and not theoretical. (However, theoretical resources may be good ideas that could be implemented and should be noted.) This will give students a good feel for meeting a family’s needs, which may or may not be possible based on the resources that are available at the time.

SOCIAL HISTORY

Participant Name: Suzie

Age: 1 year

I. DEVELOPMENTAL HISTORY:

a) Physical

Suzie is a one year, four month old female who resides with her mother, father, and sister. Suzie has been diagnosed a rare metabolic disorder. Suzie has very little free movement and makes no attempt at communication. She also has a Mickey Button in her abdomen where she receives all of her nutrition via feeding tube and syringe. She currently requires a very structured schedule of feedings, medication administration, diaper and clothing changes, bathing, and positioning changes.

Mom brought Suzie home with Hospice Care because Suzie was not expected to live without the aid of a ventilator. After a short time, Mom decided that Hospice Care was not the right decision for the family. Since that time, Mom has provided nearly all the care and support for Suzie. Mom is unable to sleep more than four hours a night due to the amount of time required to care for Suzie.

Suzie is substantially limited in her functioning in the following areas: self-care, learning, capacity for independent living, receptive and expressive language, self direction, and economic self-sufficiency. Suzie is in need on of ICF/MR level of care.

MEDICATIONS:

Suzie takes ant-seizure medicines and sedatives.

PHYSICIANS RECOMMENDATIONS:

Suzie's physician has recommended that she receive diagnostic services, physical therapy services, occupational therapy services, speech therapy, and an ICF/MR level of care.

b) Social

Suzie has no receptive or expressive language, and she is unable to indicate her wants and desires. She does not demonstrate understanding of words nor does she imitate any sounds or words. Suzie is beginning to demonstrate a weak cry when she is hungry or when she feels pain. Suzie will make some grunting sounds. Reports indicate that Suzie will occasionally turn her eyes and head toward a sound. She is unable to follow directions or commands. Suzie is unable to independently explore her environment and play with toys. Suzie is at high risk of developing respiratory illness. Suzie is substantially limited in her functioning in the following areas: self-care, learning, capacity for independent living, receptive and expressive language, self direction, and economic self-sufficiency. Suzie is in need on of ICF/MR level of care.

c) Emotional

Suzie was reported to have a limited range of affect. Suzie does not appear to respond to the affections of others. Reports indicate that Mom has stated that Suzie has no apparent recognition of the emotions of those around her. Reports indicate that Suzie will

sometimes smile with the presence of a familiar person, and that she will rarely show some facial expressions. Reports also indicate that Suzie rarely attempts to make eye contact. However, Suzie is an integral part of her family and is included in most family activities. Mom reports that each family member spends a great deal of time holding and being affectionate with Suzie. Suzie has a strong support system with her family. Suzie is substantially limited in her functioning in the following areas: self-care, learning, capacity for independent living, receptive and expressive language, self direction, and economic self-sufficiency. Suzie is in need on of ICF/MR level of care.

DIAGNOSIS:

Axis I: Developmental Delay
 313.9 Disorder of Infancy, Childhood, or Adolescence NOS
Axis II: 799.0 Diagnoses Deferred
Axis III: Rare Metabolic Disorder
Axis IV: Global Severe Stressors Due to Medical Diagnoses- Immobile, Delay in
 Motor Development, Communication Delay, Self-Care Delay, Socialization
 Delay
Axis V: Current GAF: 10

PSYCHOLOGIST’S RECOMMENDATIONS:

According to Suzie’s psychologist, “Suzie will require intensive training and supervision for the foreseeable future. She has made progress thus far since birth. It is expected that she will continue to progress in her abilities as long as she receives the intensive assistance through therapy and training in which she requires. Suzie requires a level of services available in an ICF/MR facility. It is recommended that adaptive functioning needs be met in her natural environment through the CDCSP program until the Title XIX MR/DD Waiver Program is available. It is then recommended that adaptive functioning needs be met in her natural environment through the Title XIX Waiver Program to prevent institutionalization.”

II. FAMILY:

Suzie has a very involved and supportive family.

III. EDUCATION/ TRAINING: Describe education and training experiences. Identify schools and programs attended, relationships with peers and teachers, any adjustment problems, levels of accomplishment and any other pertinent information.

Suzie is not of age to attend school. She receives services through WV Birth the Three. She has physical therapy, speech therapy, and developmental therapy services as needed. Suzie also receives service coordination services.

IV. FUNCTIONAL STATUS: Describe levels of functioning relevant to the activities of daily living and self-care skills. Indicate level of care recommendations.

Suzie is not able to take care of any of her basic needs. She is not able to understand simple commands and is unable to communicate her basic wants and needs. Suzie is not able to be employed at a productive wage level without systematic long term supervision and support. Suzie is not able to learn new skills without aggressive and consistent training. Suzie is not able to apply new skills learned in a training situation to other environments or settings without aggressive and consistent training. Suzie is not able to demonstrate behavior appropriate to the time, situation or place without direct supervision. Suzie does not demonstrate severe maladaptive behavior which places the person

or other in jeopardy to health and safety. Suzie is not able to make decisions requiring informed consent without extreme difficulty.

Suzie's current level of functioning and need for intensive care and support places her at risk for institutionalization and in need of the level of care available in an ICF/MR facility. It would optimally benefit Suzie if this level of care could be provided to her in her home environment by providing her family with the appropriate services and supports necessary. Once a child makes it through the infantile stage of Suzie's disorder, which she has, the child may live for years with the appropriate services, supports, and medical care.

V. RECREATION/ LEISURE ACTIVITIES:

Suzie is unable to actively participate in leisure activities nor is she able to initiate participation in activities

VI. HOSPITALIZATIONS: List medical and psychiatric hospital dates and reason for admissions.

Mom reports and records indicate that Suzie has required frequent hospitalizations.

VIII. LEGAL STATUS: (Guardianship, committee, custody)

Mr. and Mom have both physical and legal custody of Suzie. West Virginia Advocates are available as advocates.

IX. OTHER RELEVANT INFORMATION: (Family medical history; religious preference; or significant events of circumstances not covered in other sections.

Mom states that she receives services from Children Specialty Care (they have been helpful in directing her to other resources but have been unable to provide assistance in paying for medical care), WIC (formula is provided to the family at no cost), CARES (a medical home for special needs children provides support and linkage services every 4 months), CHIPs (provides insurance coverage for Suzie's older sister), Home Health Nurse visits twice a month, SSI and Medicaid (these services are inconsistent due to fluctuations in the family income, therefore, some months there is no assistance available), and WV Birth to Three. However, Mom does not have any daily support or relief for caring for Suzie. All services and supports are not regularly provided on a daily basis.

X. RECOMMENDATIONS:

This LSW feels that Suzie would benefit from the following recommendations.

- Intensive adaptive living skills training
- Special precautions to prevent spreading illness to Suzie
- Sensory integration training
- Communication training
- Developmental therapy services
- Speech therapy services
- Physical therapy services
- Linkage to any recommended positioning or adaptive equipment
- Skilled nursing services
- Financial assistance through social programs and grants to help family with medical costs incurred
- Application to the CDCSP program
- Application to the Title XIX MR/DD Waiver Program
- Assistance making the home more wheelchair accessible

- **Transportation assistance and/ or wheelchair accessible transportation**

Due to Suzie's current level of functioning and need for intensive training, constant care, and supervision, this LSW recommends that she receive the level of service and care that would be available in an ICF/MR facility.

SOCIAL HISTORY

Participant Name: Bobby
Age: 2 year

I. DEVELOPMENTAL HISTORY:

d) Physical

Bobby is a two year, three month old male who resides with his parents Bobby has been diagnosed with Developmental Delay in all Areas of Development (Communication, Daily Living, Socialization, Motor), Pervasive Developmental Disorder NOS, Very Little Attempt to Communicate Verbally Nonverbally, Global Moderate to Severe Stressors- Delay in Motor Development, Communication Delay, Self-Care Delay, Socialization Delay, and a current GAF score of 30. Bobby also only eats stage one baby foods and will not tolerate any other foods.

He weighed 5 pounds, 14 ounces and was 19 inches long. Bobby was 3 weeks premature at 36 ½ weeks gestation, but was discharged home after 48 hours. Mom reports a normal pregnancy with no complications during pregnancy or delivery. Mom reports typical development until about one year old. Bobby said “mom”, “up”, “eat” up until one year and then stopped. Bobby currently says “hand” for his hand, but has no other consistent, intelligible words. Mom reports that she believes that Bobby says “hand” because he loves a commercial for Hamburger Helper which features a cartoon talking hand. The family lived near a recent hurricane disaster area until relocated to the local area.

Bobby has a history of chronic illnesses from about 4-6 months through 21 months old. Mom reports that she believes that his sickness was due to mold exposure in their previous home. Mom states that they are relatively sure that the mold was the problem since after they moved, the chronic sickness stopped.

Bobby’s pediatrician states that Bobby needs an evaluation for autism.

Mom reports typical developmental until approximately one year of age. Developmental milestones up to that age include: rolling over at three months, sitting independently at five months, saying about three or four words at ten months, standing independently at eleven months, finger feeding cheerios and Gerber snacks at one year. Bobby demonstrated regression after his first birthday when he stopped talking, finger feeding, and stopped rolling over. Bobby demonstrates a significant fear involving rolling over and continues to refuse to roll over. Bobby slowly weaned himself from eating anything except baby food after his first birthday. He currently only eats baby food. After the hurricane, Bobby stopped eating any foods besides baby foods. Bobby is currently attempting to begin finger feeding but will only eat soft cookies that will melt in his mouth. Bobby will say “eye” but mostly makes sounds in his throat without opening his mouth. Mom reports that Bobby does not appear to want to attempt to communicate or indicate his wants and needs. Bobby is currently working on learning sign language, in which he is inconsistently signing “more” but refuses to learn or demonstrate other signs. Bobby is also attempting to learn to use a picture board for communication. He acknowledges the board, but is not using it for functional communication purposes. Bobby has not experienced regression in his major gross motor development, except for rolling over.

Bobby is substantially limited in his functioning in the following areas: self-care, learning, mobility, capacity for independent living, language, self-direction, and economic self-sufficiency. He is in need of an ICF/MR level of care.

MEDICATIONS:

Bobby is not currently prescribed any medications. Bobby is allergic to penicillin.

PHYSICIANS RECOMMENDATIONS:

Bobby's physician recommends ICF/MR level of care.

e) Social

Bobby does not like strangers and dislikes being around large groups of people. Bobby will initially show some interest in other children, but will quickly move off to play by himself. Mom states that Bobby is not rough or aggressive with the other children, but is not very interested in the other children. He, at times, appears "oblivious" of the other children around him. Bobby enjoys roughhousing with his older brother. He will intermittently interact in activities with his mother, but is frequently distracted and will quickly lose interest. Bobby will participate in back and forth directed activities with his mother. However, it appears that Mom has been very dedicated in routine and repetitive attempts and training him in these activities.

Bobby is substantially limited in his functioning in the following areas: self-care, learning, mobility, capacity for independent living, language, self-direction, and economic self-sufficiency. Bobby is in need of an ICF/MR level of care.

f) Emotional

Bobby is not toilet trained and does not indicate that he is uncomfortable in a soiled or wet diaper. Bobby will wear a soiled diaper until someone else recognizes that his diaper is soiled.

Bobby participates in some self-stimulatory and sensory related behaviors. He will stare at lights, head-bang, spin in circles, line objects up in straight lines throughout the house. Often, Bobby will refuse to respond to his name or appear not to hear his name called and "zone out" while watching television. He often spins objects and exhibits fascination with the parts of objects. He loves to bounce and jump with assistance. Mom describes an extremely high pain tolerance with a history of injuring himself to the point of bruising himself without even crying. He is currently in fear of the smoke detector and the green light on it. He has also demonstrated a fear of running water in the bathtub.

Bobby is substantially limited in his functioning in the following areas: self-care, learning, mobility, capacity for independent living, language, self-direction, and economic self-sufficiency. Bobby is in need of an ICF/MR level of care.

DIAGNOSIS:

- Axis I: Developmental Delay in all Areas of Development
(Communication, Daily Living, Socialization, Motor)
299.80 Pervasive Developmental Disorder NOS
- Axis II: 799.9 Diagnosis Deferred- This diagnosis cannot be determined
At this time due to Bobby's age; however, there are global delays
- Axis III: Very Little Attempt to Communicate Verbally Nonverbally
- Axis IV: Global Moderate to Severe Stressors- Delay in Motor Development,
Communication Delay, Self-Care Delay, Socialization Delay
- Axis V: Current GAF: 30

PSYCHOLOGIST'S RECOMMENDATIONS:

The psychologist's prognosis is that "Bobby will require intensive training and supervision though he has made some progress. It is expected that he will continue to progress with intensive assistance through therapy and training. Placement recommendations include a requirement for a level of service available in an ICF/MR facility. It is recommended that adaptive functioning needs be met in his natural environment through the CDCSP program until for Title XIX Waiver to prevent institutionalization is effected.

II. FAMILY:

Bobby lives with his mother and older brother. Bobby's father's job requires frequent travel out of town. The family has recently experienced several stressful experiences. They have moved twice since Bobby's birth, as well as several moves following severe flooding. Dad is working out of town and is away from the family. Mom is experiencing problems with her current landlord and lease and is worried that she may be forced to move once again.

III. EDUCATION/ TRAINING:

Bobby is currently not of age to attend public school. He is receiving services through the state's early intervention program where he receives occupational therapy, speech therapy, and service coordination services.

IV. FUNCTIONAL STATUS:

Bobby typically wakes between 6:00 and 8:00 am. Bobby will only eat rice cereal for breakfast and requires spoon feeding by his mother. He occasionally attempts to feed self with a spoon, but has extreme difficulty using the spoon with the thin consistency of the cereal and his extreme dislike of having food on his hands. Bobby desires to watch television all day long and will only watch the Disney channel. Mom states that he "hates" to get his diaper changed and that dressing is very challenging. Mom states that Bobby "hates" having clothes on and would rather remain undressed. Bobby will occasionally take his socks off on prompt, but that skill is diminishing. He will step out of his pants after Mom pulls the pants down. He will put his arm out to assist in putting his coat on, but Mom states that is because he knows that he will be going somewhere and he loves to go "bye-bye" in the car. Mom works throughout the day to engage Bobby in developmentally appropriate activities, but is often challenged by Bobby's strong desire to watch television and "zone out." Bobby engages in self-stimulatory behaviors throughout the day, such as spinning in circles, head banging, "zoning out", staring at lights, demonstrating extreme sensitivity to certain loud noises, fear of the sound of water running in the bathtub. Bobby will only eat stage two baby foods and refuses to eat anything with chunks or consistency. Mom reports that she has tried to sneak rice in some of his meals, and Bobby will suck the food off the rice and pack it in his bottom lip until it becomes full and will then spit it out. Bobby will only drink milk. He drinks out of a sippy cup. He can not drink out of an open cup and will choke every time he attempts to drink from an open cup. Bobby will only drink out of certain sippy cups and will refuse all others. Mom is attempting to teach Bobby to drink from a straw, but is very challenged with sucking out of a straw.

Bobby is currently scared of getting in the bathtub while the water is running. Mom states that he is terrified of the water coming out of the spout. Bobby extremely dislikes having his hair washed and will scream and attempt to get out of the bathtub. Mom states that she has reduced his bathing to every other day due to the difficulties while bathing, even though she desires to bath him everyday.

Bobby refuses to color or use finger paint because he dislikes having the paint on his hands. Bobby refuses to hold the crayon and appears to hate the way it feels in his hand. He is just beginning to hold a pencil to scribble but will hold it by the tip so that only his fingertips are touching the pencil.

Bobby requires a certain routine at night for bedtime and will become upset and agitated if the routine is altered in any way. He requires four pacifiers at night. Bobby will not suck on the pacifiers but will place two on each side of our neck.

Bobby is not able to be employed at a productive wage level without systematic long term supervision and support. is not able to learn new skills without aggressive and consistent training. He is not able to apply skills learned in a training situation to other environments or settings without aggressive and consistent training. He is not able to demonstrate behavior appropriate to the time, situation, and place without direct supervision. demonstrates severe maladaptive behavior which places the person or others in jeopardy to health and safety. He is not able to make decisions involving informed consent without extreme difficulty. He is substantially limited in his functioning in the following areas: self-care, learning, mobility, capacity for

independent living, language, self-direction, and economic self-sufficiency. He is in need of an ICF/MR level of care.

V. **RECREATION/ LEISURE ACTIVITIES:**

Bobby does not like strangers or large groups of people. Mom states that she is limited to only going into the community for shopping. Bobby dislikes being approached by strangers and will become extremely upset when approached Bobby used to love to go the beach when they lived near the ocean.

VI. **HOSPITALIZATIONS:**

Mom reports that Bobby has never been hospitalized.

VII. **FAMILY MEDICAL HISTORY:**

| | |
|--------------------------------------|------------------------------|
| _____ MR/DD | <u>Mat. GF</u> Heart Disease |
| _____ Cerebral Palsy | _____ Autism |
| <u>Mat. GF</u> Diabetes | _____ Tuberculosis |
| _____ Hepatitis | _____ Mental Illness |
| _____ Kidney Disease | <u>Mat. GM</u> Cancer |
| <u>Pat. GF</u> Hypertension | _____ Metabolic Disease |
| <u>(client) penicillin</u> Allergies | _____ Thyroid Disease |
| _____ Muscular Dystrophy | _____ Epilepsy |
| _____ Other | _____ Other |

Deceased Siblings, (Cause of Death): _____

VIII. **LEGAL STATUS:** (Guardianship, committee, custody)

Both parents have legal and physical custody of Bobby. Bobby resides with his mother. The state advocacy organization is available to serve as their regional advocates.

IX. **OTHER RELEVANT INFORMATION:** (Family medical history; religious preference; or significant events of circumstances not covered in other sections.

Mom and her family appear to have been under increased amounts of stress in the last year.

X. **RECOMMENDATIONS:**

This LSW feels that Bobby_would benefit from the following recommendations.

- Intensive adaptive living skills training
- Safety skills training
- Photo ID (in case of emergency)
- Use of social stories to teach new skills
- Sensory integration training

- **Respite services**
- **Communication training**
- **Socialization training**
- **Speech therapy services**
- **Physical therapy services**
- **Behavior support plan to address self-stimulatory and maladaptive behaviors**
- **Linkage to any recommended adaptive equipment**
- **Alternate form of communication (e.g. signing, PECS, etc.)**
- **Structured schedule**
- **Nursing services as necessary**
- **Financial assistance through social programs and grants to help family with medical costs incurred**

Due to Bobby 's current level of functioning and need for intensive training and constant supervision, this LSW recommends that he receive an ICF/M

DEVELOPMENTAL DISABILITIES: FAMILY CENTERED CONCERNS

Families Want:

- Sensitivity and respect
- Appreciation for the struggles including the struggle to access services
- Information about services and resources
- Someone to listen who is non-judgmental
- Informed decision making
- Community inclusion – transition services, especially post-high school
- Friendship and social skills help for the child with a disability
- Inclusion in schools
- Presumption of competence; and professionals who will optimize independence
- Acknowledgement that the parents are experts on their children
- Competent, informed professionals – possibly establishing certification programs
- Respectful communication
- Education about legal rights and becoming self-advocates
- Employment: many want to work, can work, and are good employees when give the opportunity and accessible work environments.
- Transportation: both accessible and available. Some may be unable to obtain a license, but still need transportation. Very few programs provide transportation aside from public busses.

Families Are Frustrated By:

- High turnover of professionals make it difficult to establish good working relationships
- Condescending attitudes/approaches

- Lack of respect – being seen as just a number
- Inability to depend on service providers to have a good knowledge of resources
- Systems that do not take the individual and specific needs of clients into consideration when making decisions about their services or supports. Example: a teenager who uses a wheelchair has a growth spurt and no longer fits in her wheelchair, but the service system only allows for a new wheelchair every five years.
- Difficulty navigating service systems to determine eligibility and access needed services.

Impact on Family

- Financial stress (many families make too much money to be eligible for state programs, but are overburdened by the financial strain).
- Inability to plan
- Stress on marriage, other children, family plans, role of siblings (sibling may feel responsible or be considered by parents to be responsible for caring for sibling with a disability).
- Adjustment of goals and dreams.
- Limited in activities that family can participate in due to poor accessibility, lack of understanding of peers concerning special needs.
- Simple tasks can become very challenging.

KEY ELEMENTS OF FAMILY CENTERED PRACTICE

Family centered practice:
when services are delivered in a way that respects the central role of the family as caregiver, advocate, and decision maker for the child.

- The family is the constant –systems and services change
- Families and professionals should work together at all levels of services
- Honor differences among families (ethnic, cultural, and socio-economic)
- Recognize the strengths and individuality of all families
- Share all information with families in a supportive and ongoing manner
- Encourage family to family (and community) support
- Understand and include the developmental needs of families and family members in delivering services
- Develop policies and programs that help meet families' financial and emotional needs
- Design accessible systems that are flexible and responsive to family identified needs

Reference

Edelman, L. (Ed). (1995). Getting on board: training activities to promote the practice of family-centered care (2nd ed). Bethesda, Maryland: Association for the Care of Children's Health.

FACT SHEET: PERSON-CENTERED PLANNING

Q. What is Person-Centered Planning?

This phrase refers to an entire family of approaches to organizing and guiding individual and community change in collaboration with individuals with disabilities, their families, and their friends. PCP requires important investments in order to build both personal and community support.

Q. What Are Some of the Approaches That Use Person-Centered Planning?

- Whole Life Planning;
- Personal Futures Planning;
- Making Action Plans (MAPS);
- Planning Alternative Tomorrows with Hope (PATH); and
- Essential Lifestyles Planning.

Q. What is Family-Centered Planning(FCP)?

This phrase refers to principles which if followed lead to partnership and collaboration between parents and professionals to ensure the best possible supports and services for a child with a disability and for the child's entire family.

Q. What Are The Key Characteristics of Person-Centered Planning?

1. The person who is at the focus of the planning, and those who love the person, are the primary authorities on the person's life direction.
2. The primary purpose of PCP is to learn through shared action (i.e., the process is more than producing paperwork, it is about taking action to reach goals) and reflection/evaluation of that action.
3. PCP aims to change common patterns of community life (e.g., segregation and congregation of people with disabilities, devaluing stereotypes, inappropriately low expectations, denial of opportunity).
4. PCP requires collaborative action and fundamentally challenges practices that separate people and perpetuate controlling relationships.
5. Respect for the dignity and completeness of the focus person.
6. PCP calls for sustained search for the effective ways to deal with difficult barriers and conflicting demands.
7. Promotes and values accurate individual services and supports, and clarifies individual interests and needs.

8. Shaping services to support a person's vision of a valued lifestyle.
9. Facilitates change in services to be more responsive to, the interests of people.
10. Search for capacities.
11. Organize efforts in the community to include person, family, and direct support professionals.
12. Focus on quality of life and emphasize dreams, desired outcomes, and meaningful experiences.

Q. What Are The Key Characteristics of Family-Centered Planning?

1. Incorporate into policy and practice the recognition that the family is the constant in a child's life, while the service system and support persons fluctuate.
2. Strive for family and professional collaboration in all settings (home, community, hospital, school), especially in the areas of care giving, program development, program implementation, program evaluation, program evolution, and policy formulation.
3. Exchange complete and unbiased information between families and professionals in supportive manner at all times.
4. Incorporate into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families: including, ethnic, racial, spiritual, social, economic, educational, and geographic diversity.
5. Recognize and respect different methods of coping.
6. Implement comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports which meet the diverse needs of families.
7. Encourage family-to-family support and networking.
8. Ensure that all service and support systems for children with disabilities and their families are flexible, accessible, and comprehensive in responding to diverse family identified needs.
9. Appreciate families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized services and supports.

Q. What Are the Limitations of Person & Family-Centered Planning?

- Belief that only certain families or individuals can use or will benefit from PCP/FCP,
- Lack of training in understanding and honoring cultural diversity,
- Tendency for professionals to be seen in the role of expert,
- Lack of open and effective communication,
- Traditional model of service delivery is entrenched,
- Moves slowly if the focus person's vision is not clear,
- Requires a lot of learning to develop the supports and create the opportunities the person needs,
- Family members and professionals can define people in clinical terms,
- Often done in isolation from other complementary systems change efforts,
- Requires a large expenditure of time, and
- Not a quick fix or a cure all for people's difficulties.

AAMR's Policy

The AAMR has no official position on person or family centered planning.

References

1. Mount, B. (1992). Person centered planning finding directions for change using personal futures planning. New York, NY: Graphic Futures.
2. Mount, B. (1992). Personal futures planning: promises and precautions. New York, NY: Graphic Futures.
3. Mount, B., Darcharme, G., & Beeman, P. (1991). Person centered development: A journey learning to listen to people with disabilities. New York, NY: Graphic Futures.
4. O'Brien, J., & Lovett, H. (1992). Finding a way toward everyday lives: The contribution of person centered planning. Harrisburg, PA: Pennsylvania Office of Mental Retardation.
5. Shelton, T.L., & Stepanek, J.S. (1994). Family centered care for children needing specialized health and developmental services. Bethesda, MD: Association for the Care of Children's Health.
6. Smull, M. (1991). Supporting people with severe reputations in the community: A handbook for trainers. Baltimore, MD: University of Maryland.

Resources

1. Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, 301 West Franklin Street, #1514, P.O. Box 843020, Richmond, VA, 23284-3020. Point of contact: Anne Malatchi, (804) 828-8593, (804) 828-0042.
2. Inclusion Press, 24 Thome Cresant, Toronto, Ontario, Canada, M6H 2S5, 416-658-5363 (T& F). Points of contact: Jack Pearpoint & Dr. Marsha Forest, creators of PATH and MAPS. Inclusion Press publishes a great deal of material on PATH, MAPS, and Circles of Friends.
3. Dr. Beth Mount, Graphic Futures, Inc., 25 West 81st Street, 16-B, New York, NY 10024, (212) 362-9492.
4. Rehabilitation Research and Training Center on Supported Employment, Virginia Commonwealth University, 1314 West Main Street, Richmond, VA, 23220. (804) 828-1851. Fax: (804) 828-2193.
5. Communitas, Inc., P.O. Box 374, Manchester, CT, 06040. (202) 645-6976.

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DISABILITY AND DOMESTIC VIOLENCE ISSUES

If a Victim has a disability, the batterer may use additional tactics of control, including:

Coercion and Threats: Threatening to withhold basic support and rights; terminate the relationship and leave the person unattended; report noncompliance with the program providing care; institutionalize the person.

Using Intimidation: Mistreating service animals; providing personal care in a way that is frightening.

Emotional/Verbal: Focusing verbal abuse on impairment; denying a person the right to make decisions; refusing to speak or ignoring requests.

Isolation: Limiting employment possibilities due to caregiver schedule; discouraging or preventing contact with case manager or advocate; denying use of assistive equipment or life skills adaptations that facilitate independence.

Minimize, Justify and Blame: Excusing abuse as behavior management or caregiver stress (often accepted by professional helpers); blaming the disability for the abuse.

Using Children: Threatening to take the children and using the disability as evidence of inability to care for children (in custody proceedings and with threats to call child protective services).

Using Caregiver Privilege: Providing care in a way to accentuate the person's dependence and vulnerability; ignoring, discouraging or prohibiting the exercise of full capabilities; dominating treatment decisions by speaking for the person with the disability and intercepting communications from case workers and other potential helpers.

Economic Abuse: Using a person's money or property without their permission using power of attorney and/or payee status as a means to withhold and/or misuse resources.

Physical Abuse: Inappropriate physical handling; over use of bodily restraints; over-medicating; inappropriate behavior modifications; using medication to sedate a person for convenience.

Neglect: Denying food, clothing, shelter; withholding medications, assistive equipment or personal/medical care; withdrawing care or equipment to immobilize the person or leaving the person alone without a way to call for help.

Sexual: Forcing someone to have an abortion or to be sterilized.

Reference

From: WV Coalition Against Domestic Violence (2004) www.wvcadv.org For a safer state of family.

ABUSE AND NEGLECT OF CHILDREN WITH DISABILITIES: INTERVIEWING

Pre-Interview Planning

Effective interviewing of a child with a disability requires that preliminary information be obtained from records or other professionals/persons knowledgeable about the child. Needed preliminary information includes:

- The child's primary disability. Characteristics of a disability are on a continuum, varying in degree from mild to severe with each child being unique in terms of his/her management of the disability.
- The way in which the disability impacts upon the child's current functioning including cognition, language and communication mode, memory, mobility, emotions, behavior, self-care, and relationships. Ask how the disability affects the child's level of independence and need for assistance.
- Any accompanying impairments, e.g., visual, language, cognitive, or mental illness.
- Communication challenges including marked differences in receptive v. expressive communication and use of augmented communication methods.
- Behavior challenges that may affect the interview and require management.
- Distractibility, which may be addressed by control of stimuli in the interview setting.
- Where the child receives treatment or schooling related to the disability. This is a prime source of additional information about the child's need and a resource to the interviewer for management of the interview.
- Special care needed as a result of the disability. This will provide you with information about the challenges for the family as a result of the disability.

It is also important to consider vulnerabilities by asking about:

- Behavioral compliance that has been historically rewarded.
- Training/education in sexuality and/or self-protection.
- Interpersonal dependency.
- Other family stressors unrelated to the child's disability.
- Availability of needed family resources.
- Individual or systemic isolation.

Interview Principles and Use of Language

When interviewing any child about suspected abuse or neglect, including a child with a disability, the interviewer should be:

- Sensitive to the child's developmental level.

- Flexible in following the child’s lead rather than adhering to rigid protocols.
- Objective and nonjudgmental.
- Empathetic.

If the child is deaf or deaf/blind, and his/her primary mode of communication is sign language, a certified interpreter should be present to facilitate communication if the social worker does not use sign language.

General questions, used to develop rapport and check the child’s understanding, might include inquiries about: where the child lives; child’s age or birth date; names and ages of siblings; name of school or teacher; favorite television show; likes and dislikes; and what the child did for fun this week (who, what, when).

The limits on confidentiality should be addressed early in the interview as most children worry about whom you will tell and why.

Interviewing children with language/communication challenges

Some children with disabilities have language or communication difficulties that are challenging during the interview. Understanding the way(s) in which the disability affects the processing of information, so that needed adaptations can be made, is essential to a successful interview. The information-processing model divides communication into three stages:

- Input or the ability to receive information.
- Processing or the ability to make sense of information.
- Output or the ability to communicate information back to the other person.

If a child has a disability, communication can be disrupted at any or all of these points. The effect is often cumulative. For example, problems with processing information will affect output. Input challenges affect the processing and output of information, disrupting all three areas of communication.

Disability types, related communications challenges, and needed interview adaptations are described below:

Input Challenges (visual, auditory, and tactile information)

Disability:

Blind/visual impairment.

Deaf/hard of hearing.

Learning disabilities.

Epilepsy.

Tactile sensory impairment.

Deaf blind or dual sensory impairment.
Cognitive disability
Cerebral palsy.
Spina bifida.
Traumatic brain injury.
Attention deficit hyperactivity disorder (ADHD).

Adaptations:

Sit at same level.
Use normal voice tones.
Speak clearly.
Slower pace and repetition may be needed.
Eye contact is critical.
Written messages and visual aids.
Use of interpreter.
Body language and facial expressions are important.
Quiet setting with limited noise and limited distractions.
Good lighting.
Tactile aids.
Augmentative aids.

Processing challenges (information storage, retrieval, and understanding)

Disability

Emotional disturbance.
Learning disabilities.
Mental retardation.
Autism.
Traumatic brain injury.
Cerebral palsy.
Spina bifida.
Deaf/hearing impaired.
Blind/visually impaired.

Adaptations

Keep interviews short; may need multiple interviews.
Provide structure.
Minimize distractions.
Concrete language.
Developmental age-appropriate language.
Break down known complex ideas.
Focused questions.
Questioning within contexts.
Speak distinctly.

Check for understanding.
Quiet setting with limited noise, limited distractions.
Augmentative devices.

Output Challenges (vocal and motor information)

Disability

Speech and language.
Deaf/hard of hearing.
Learning disability.
Cerebral palsy.
Traumatic brain injury.
Dual sensory impairment or deaf/blind.

Adaptations

Sit at the same level.
Interpreter may be needed.
Listen carefully.
Watch body language.
Drawing boards.
Props may be needed.
Multiple modalities needed.
Quiet setting with limited noise and limited distractions.
Good lighting.

It is important not to confuse communication difficulties with a lack of intelligence. It is also important not to confuse expressive communications ability with receptive communication abilities. Some children can understand more advanced language than they can produce on their own (Crocker, 1994).

Interviewing a child with a disability may require adaptations when there are language/communication challenges. The diversity of disabilities necessitates adaptation of the interview, including the language used by the interviewer, to the age, cognitive functioning, developmental level, and abilities of the child.

Collaboration, including interviewing assistance or advice from a disability professional knowledgeable about the child, will help the investigator to understand the disability, facilitate communication, validate impressions, and determine the need for protective intervention.

Use of Interpreters

In those instances where the child is deaf, hard of hearing, or deaf/blind, a qualified interpreter may be needed to facilitate the investigative interview. Use of a friend with hearing, family

member, or relative of the child with a hearing impairment who knows sign language is not recommended for confidentiality reasons, possible biases, and issues of competency.

The role of the interpreter is to facilitate communication by translating spoken English into Sign language or Cued Speech and vice versa. The interpreter is not part of the conversation. He or she may not advise the interviewer or the child on what to say or how to say it, offer explanations or background information. A summary of what is said or signed is not acceptable. All information discussed in the presence of the interpreter is confidential.

Prior to the interview, the interviewer should:

- Discuss fees for interpreter services.
- Describe the child's limitations, skills, and strengths.
- Clarify roles and expectations with the interpreter.
- Outline the areas to be covered so that the interpreter can be prepared with suitable vocabulary.
- The interviewer and interpreter should also agree on the length and frequency of rest periods. Long sessions of signing can be tiring.

The interpreter should also be allowed time to talk with the child to determine what method of signing is most satisfactory and whether or not his or her interpreting skills are suitable to the child's needs.

In those instances where the child's sign language base is limited (i.e. s/he relies upon gestures or signing that is unique to their home environment), it may be necessary to have a highly experienced interpreter in order to facilitate accurate communication.

Interview Strategies

Begin the interview by developing positive rapport with the child through the use of general questions prior to focusing on the incident in question:

- The interviewer should look at the child, not the interpreter.
- The interviewer should not speak or direct conversation to the interpreter.
- The interviewer should use the words "I" and "you" instead of "tell her" or "does he/she understand."
- Speak clearly and in normal tones. If you tend to talk quickly, slow down.
- Do not interrupt one another. The interpreter can interpret the message of only one person at a time.

Allow time for the child to obtain all the information and to respond. The interpreter will be a few words behind the speaker in transferring information.

Facilitated Communication

Facilitated communication is a process that provides physical assistance, through guidance of the hand or arm of a person with autism, cerebral palsy, or other developmental disability while that person types messages on a computer, typewriter, or other similar device.

Although facilitated communication has been called a form of communication, use of facilitated communication in child abuse and neglect investigative interviews remains controversial due to questions concerning possible influence of the facilitation. For this reason, attempts should be made to corroborate disclosures of abuse or neglect made through facilitated communication with other evidence.

References

This information was taken from One Child at a Time: A guide for professionals in recognizing and reporting the abuse and neglect of children with disabilities by TEAM for West Virginia Children (2002). It is copied with their permission. The entire publication can be downloaded from their website: www@teamwv.org

ELIMINATING BARRIERS TO SERVICES: SUBSTANCE ABUSE

The following information is taken from *Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities*, Treatment Improvement Protocol (TIP) Series #29, reprinted in 2003 by the U.S. Department of Health and Human Services. The publication is available free of charge from the National Clearinghouse for Alcohol and Drug Information (NCADI), (800) 729-6686 or TDD (800) 487-4889.

People with physical and cognitive disabilities are more likely to have a substance use disorder and less likely to get effective treatment than those without such a coexisting disability. (p. xv)

Summary of recommendations are as follows:

Accommodations

- Providers should modify programs as necessary to eliminate four fundamental groups of barriers: attitudinal barriers; discrimination policies, practices and procedures, communications barriers; and architectural barriers.
- Reduce barriers to equal participation in program.
- If barriers cannot be removed, alternative methods should be used to make services available.
- Ongoing and comprehensive staff training should be provided including focus on attitudinal barriers. Program staff should be trained to understand functional limitations, the wide variety of conditions that lead to them, and the barriers that treatment-as-usual may present for persons with specific disabilities. Support staff should be trained to respond knowledgeably and sensitively to people with coexisting disabilities.
- If there is any doubt on the part of the provider regarding the legitimacy of a person's request for accommodation, a disability expert should be consulted to evaluate the request.
- In general, it is beneficial and feasible to integrate people with coexisting disabilities into already existing community-based services used by non-disabled individuals recovering from substance use disorders. However, exceptions may exist based on legitimate, documented reasons. In those cases, specialized services may be needed.
- For clients who are blind or visually impaired, keep pathways clear and raise low-hanging signs or lights. Use large letter signs and add Braille labels to all signs and elevator buttons. Make oral announcements; do not rely on a bulletin board.
- People who are blind or visually impaired will require assistance to orient themselves to a new environment. The treatment provider should give clients who are blind a complete orientation to the facility the first time they visit; the client can be guided by holding her arm just above the elbow and walking with her through the rooms, explaining where the doors, furniture, and other features are.

Screening for Disabilities

- Because many disabilities are not obvious, it is important to screen for them in every person, not just those with obvious functional limitations. Ask all clients entering treatment whether they require any accommodation in order to participate.
- It is the level of abilities and of the functioning for the individual – not the simple determination of whether an impairment exists – that must be assessed if screening is to lead to an effective treatment plan. In situations where a diagnosis of disability is needed (e.g. to qualify for special services) treatment providers should refer the client to a disabilities services professional.
- Although it is a good idea to get background information from as many sources as possible, interview the person alone, if possible. Having others present often distorts the quality of the interview.
- Begin intake interviews with an open and friendly question rather than one focusing on the person's disability.
- An intake interview should address the eye condition and blindness adjustment skills of people who are blind or visually impaired. The counselor should ascertain the pathology of the loss of vision (if it was congenital, adventitious, or traumatic), and precisely how much vision remains.
- People who are blind should have the option of completing forms in the medium of their choice (Braille, large print, audiocassette, or sighted assistance). Individuals who are both deaf and blind will need a tactile interpreter to translate for them during the admissions process and afterward.
- Due to the wide range of reading abilities among people who are deaf, paper and pencil should never be utilized to gather detailed assessment information. Written English forms and questionnaires should be interpreted into sign language for these clients.
- When screening people with cognitive disabilities, be as specific as possible – rather than asking if they “use alcohol”, ask if they like to drink beer, wine, wine coolers, etc.. It may help to use props such as different glass or bottle sizes rather than asking how many ounces were consumed.

Treatment Planning

- All clients must understand the particular strengths that they can bring to the recovery process. A strength based approach is especially important for people with disabilities, who, because they have so frequently been viewed in terms of what they cannot or should not attempt, may have learned to define themselves in terms of their limitations and inabilities.
- It is key to the treatment planning process for the treatment provider to learn where a person with a disability is on the spectrum of understanding and accepting his disability.
- No treatment plan should be static, and treatment providers must continually evaluate and revise the treatment plan with assistance from clients with disabilities. Treatment plans should be flexible enough to take into account changes in a person's condition or new knowledge gained during treatment. Clients with traumatic brain injury, for example, often show a dramatic recovery curve over the year to two years following their accidents.

- An individual with a disability may also need to explore several methods for learning something or fulfilling a goal before an accomplishable approach to the situation can be identified and implemented.
- The treatment plan should document all alterations to the usual treatment procedures that are being made. If an approach does not work, the outcome should still be carefully documented to prevent duplication of effort by other programs in the future. Similarly, details of what is successful for a person should be documented, particularly for persons with cognitive disabilities who may not be able to tell future caregivers which treatments have been effective and why. Documentation of all efforts at accommodations is needed to verify ADA compliance.
- It is helpful to identify early on any needed exceptions to the routines of the treatment program for a person with a disability and to explain to other clients that the accommodations for a person with a disability simply give her the help she needs to meet shared goals. If the client does not object, the exceptions and the rationale for these exceptions should be discussed openly in group meetings.
- Behavioral contracts with people with coexisting disabilities may need to be specifically tailored to what the individual is realistically capable of achieving.
- People who are deaf or hard of hearing (and probably those with other disabilities as well) generally know less about addiction and recovery when they enter treatment than non-deaf (or non-disabled) people, and therefore they will often require lengthier treatment. Treatment providers should be prepared to allow for longer treatment times for clients with disabilities.
- It is essential that all clients participate in planning leisure activities, and programs with rigid approaches that exclude clients from such participation should consider changing their policies.
- If a person with a disability has limited transportation options, conduct individual counseling by telephone, go to the person's house, or meet at a rehabilitation center or other alternative site. It is recommended that providers make home visits if necessary, which may be reimbursable under case management services.
- For people with coexisting disabilities, failure to achieve treatment goals may indicate that the treatment plan lacks the discrete steps necessary to meet these goals. In setting a goal, the client and the counselor must work closely to understand all the physical and cognitive requirements of meeting a goal.
- Early in treatment, a medical professional should conduct an assessment of all the client's medications – both prescribed and over-the-counter, including herbs and vitamins. In addition, it is recommended that a single medical professional try to monitor the client's medication regimen. Under no circumstances, however, should other treatment staff advise clients to take or not to take particular medications, vitamins, or herbs.
- Lack of employment may be a factor in substance abuse; conversely, addressing and overcoming barriers to employment, with the aid of collaborative partners, may greatly enhance the prospect for recovery and should be addressed as a component of treatment planning.

Counseling

- Counseling session times should be flexible, so that sessions can be shortened, lengthened, or more frequent, depending upon the individual treatment plan.
- For people with cognitive impairments, it is important to remember to ask simple questions; to repeat questions; and to ask the client to repeat, in her own words, what has been said. Discussions should be kept concrete. People with mental retardation or traumatic brain injury may not understand abstract concepts; they should be asked to provide specific examples of a general principle.
- The use of verbal and nonverbal cues will help increase participation and learning for people with cognitive disabilities and make the group sessions run more smoothly for all. The counselor and the person with a disability together can design the cues but should keep them simple, such as touching the person's leg and saying a code word (e.g. "interrupting").
- Clients with cognitive disabilities will often benefit from techniques such as expressive therapy or role-playing.
- Assignments that require the use of alternative media in place of writing may work best with clients who have cognitive disabilities as well as those who are deaf. Clients who are blind will need assignments translated into their preferred method of communication (e.g. Braille, audiotape), but no matter what method is used they will need more time to complete reading assignments.
- Regardless of the model of communication used by the person who is deaf or hard of hearing, the visual aspect of communication will be important. Therefore, it is important to look directly at the person when communicating. This will allow him to try to read the lips of the counselor and to see her facial expression.
- Interpreters should usually be provided for people who are deaf or hard of hearing. The interpreter should be a neutral third party hired specifically to interpret for the counselor and the person who is deaf; a family member or friend of the client should not be used as an interpreter. Use only qualified interpreters as determined by either a chapter of the Registry of Interpreters for the Deaf or a State interpreter screening organization.
- If a person who is deaf is using an interpreter, group members will need to take turns during discussions. When addressing a person who is deaf the counselor or group members should speak directly to the person as if the interpreter is not present.
- When working with an individual with a physical disability, make certain that table surfaces are at correct height, and in particular that wheelchairs can fit beneath them. Counselors should try to place themselves so that they are no higher than the client. They should be aware of the pace of the interview, and attempt to gauge when clients are becoming fatigued. Counselors should periodically inquire how the client is doing and offer frequent breaks.
- People who use wheelchairs often come to regard the chair as an extension of themselves, and touching the chair may be offensive to them. Never take control of the wheelchair and push the person without permission.
- For individuals with cognitive disabilities, providers must systematically address what has been learned in the program and how it will be applicable in the next stage of treatment or aftercare. Some people are very context-bound in their learning, and providers cannot assume that the lessons learned in treatment will be applied in aftercare.

- In planning and providing treatment to people with disabilities, the importance of asking questions cannot be overemphasized. Asking before rendering any service is a basic principle.

Linkages

- Coordination with an agency providing case management services for people with disabilities should be a priority if those services are not already being provided by the substance use disorder treatment program. Treatment plans for people with coexisting disabilities should address problems such as unemployment, a lack of recreational options, social isolation, and physical abuse because they are more likely than the general population to experience these situations.
- Service linkages are essential to provide effective substance use disorder treatment for people with coexisting disabilities.
- Treatment providers need to be able to identify what ancillary services are available for their clients, and be able to access those services and funding sources.
- Since a client having a substance use disorder and a disability may also be in a physical rehabilitation or other disability program, treatment professionals should be aware of the various approaches used by these other programs, and know how to collaborate with them. Cross training between vocational rehabilitation or other disability service providers and substance use disorder treatment providers is recommended to help treatment professionals understand the impacts of both disability and substance use disorders.
- In developing partnerships with referring agencies, the treatment program should ensure, through interagency agreements, that mechanisms are in place for exchanging client information.
- It is not unusual for services to be duplicated or ineffective when a case manager is not utilized, and so a substance use disorder treatment provider may need to either case manage these services or find another organization or person to do so. A case manager can be a strong advocate for a person with a disability and help her locate appropriate and accessible services.
- A substance abuse counselor may not have the time or the expertise to work on all the issues that arise because of a client's disability. If that is the case, a referral to a peer counselor at a Center for Independent Living, whose job it is to help disabled individuals come to terms with the limits of their disabilities, may be in order. The two counselors can work together as a team.
- The treatment provider should investigate whether accommodations will be made for a client with a coexisting disability before sending him to an aftercare facility.

Organizational Commitment

- Providers must be prepared to act as advocates for clients when services and supports that are normally readily available and effective prove inaccessible for the client.
- When treatment teams make the effort to accommodate individuals with coexisting disabilities, the quality of care improves for all clients. All clients can get more out of

treatment that is individualized and that takes their specific functional capacities and limitations into account.

- To ensure full organizational support for treating people with coexisting disabilities, it is recommended that a treatment program develop a policy statement that articulates the program's willingness to accommodate an individual with a disability who chooses to attend the program.
- When a program makes a commitment to serving people with coexisting disabilities, board membership of people with disabilities may be implemented immediately or considered as a goal to be reached as the program begins to serve a greater number of people from these groups. A program should try to obtain regular input from the community it seeks to serve; creating a permanent task force or an advisory committee is an idea way to address this need.
- The organization must make a commitment to continually reexamine the program's effectiveness for people with coexisting disabilities. Such inquiry can take place both formally, using quality assurance methods and consumer satisfaction surveys, and informally, through opportunities for individual and group feedback with program staff.
- It is not enough for a program simply to be ready to serve people with coexisting disabilities. Rather, the program should be proactive in making the disability community aware of its services to ensure that disability organizations will support referrals to the program.
- Another sign of organizational commitment is to hire people with disabilities to work in the treatment program. Hiring people with disabilities also benefits other staff members, who can learn from these coworkers.
- An 'open door' policy is recommended - stating that all clients are entitled to an assessment if they are presenting with a chemical dependency problem regardless of whatever other problems they may appear to have. If the proper course of treatment is not available at the facility, it is still possible to perform a substance use disorder assessment and refer the client for treatment elsewhere.

U.S. Department of Labor

Office of Disability Employment Policy

COMMUNICATING WITH AND ABOUT PEOPLE WITH DISABILITIES

The Americans with Disabilities Act, other laws and the efforts of many disability organizations have made strides in improving accessibility in buildings, increasing access to education, opening employment opportunities and developing realistic portrayals of persons with disabilities in television programming and motion pictures. Where progress is still needed is in communication and interaction with people with disabilities. Individuals are sometimes concerned that they will say the wrong thing, so they say nothing at all—thus further segregating people with disabilities. Listed here are some suggestions on how to relate to and communicate with and about people with disabilities.

Words

Positive language empowers. When writing or speaking about people with disabilities, it is important to put the person first. Group designations such as "the blind," "the retarded" or "the disabled" are inappropriate because they do not reflect the individuality, equality or dignity of people with disabilities. Further, words like "normal person" imply that the person with a disability isn't normal, whereas "person without a disability" is descriptive but not negative. The accompanying chart shows examples of positive and negative phrases.

Affirmative Phrases

person with an intellectual, cognitive, developmental disability
person who is blind, person who is visually impaired
person with a disability
person who is deaf
person who is hard of hearing
person who has multiple sclerosis
person with cerebral palsy
person with epilepsy, person with seizure disorder
person who uses a wheelchair
person who has muscular dystrophy
person with a physical disability, physically disabled
unable to speak, uses synthetic speech
person with psychiatric disability
person who is successful, productive

Negative Phrases

retarded; mentally defective
the blind
the disabled; handicapped
the deaf; deaf and dumb
suffers a hearing loss
afflicted by MS
CP victim
epileptic
confined or restricted to a wheelchair
stricken by MD
crippled; lame; deformed
dumb; mute
crazy; nuts
has overcome his/her disability; is courageous (when it implies the person has courage because of having a disability)

Actions

Etiquette considered appropriate when interacting with people with disabilities is based primarily on respect and courtesy. Outlined below are tips to help you in communicating with persons with disabilities.

General Tips for Communicating with People with Disabilities

When introduced to a person with a disability, it is appropriate to offer to shake hands. People with limited hand use or who wear an artificial limb can usually shake hands. (Shaking hands with the left hand is an acceptable greeting.)

If you offer assistance, wait until the offer is accepted. Then listen to or ask for instructions.

Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to all others.

Relax. Don't be embarrassed if you happen to use common expressions such as "See you later," or "Did you hear about that?" that seem to relate to a person's disability.

Don't be afraid to ask questions when you're unsure of what to do.

Tips for Communicating with Individuals Who are Blind or Visually Impaired

Speak to the individual when you approach him or her.

State clearly who you are; speak in a normal tone of voice.

When conversing in a group, remember to identify yourself and the person to whom you are speaking.

Never touch or distract a service dog without first asking the owner.

Tell the individual when you are leaving.

Do not attempt to lead the individual without first asking; allow the person to hold your arm and control her or his own movements.

Be descriptive when giving directions; verbally give the person information that is visually obvious to individuals who can see. For example, if you are approaching steps, mention how many steps.

If you are offering a seat, gently place the individual's hand on the back or arm of the chair so that the person can locate the seat.

Tips for Communicating with Individuals Who are Deaf or Hard of Hearing

- Gain the person's attention before starting a conversation (i.e., tap the person gently on the shoulder or arm).
- Look directly at the individual, face the light, speak clearly, in a normal tone of voice, and keep your hands away from your face. Use short, simple sentences. Avoid smoking or chewing gum.
- If the individual uses a sign language interpreter, speak directly to the person, not the interpreter.
- If you telephone an individual who is hard of hearing, let the phone ring longer than usual. Speak clearly and be prepared to repeat the reason for the call and who you are.
- If you do not have a Text Telephone (TTY), dial 711 to reach the national telecommunications relay service, which facilitates the call between you and an individual who uses a TTY.

Tips for Communicating with Individuals with Mobility Impairments

- If possible, put yourself at the wheelchair user's eye level.
- Do not lean on a wheelchair or any other assistive device.
- Never patronize people who use wheelchairs by patting them on the head or shoulder.
- Do not assume the individual wants to be pushed —ask first.
- Offer assistance if the individual appears to be having difficulty opening a door.
- If you telephone the individual, allow the phone to ring longer than usual to allow extra time for the person to reach the telephone.

Tips for Communicating with Individuals with Speech Impairments

- If you do not understand something the individual says, do not pretend that you do. Ask the individual to repeat what he or she said and then repeat it back.
- Be patient. Take as much time as necessary.
- Try to ask questions which require only short answers or a nod of the head.
- Concentrate on what the individual is saying.
- Do not speak for the individual or attempt to finish her or his sentences.
- If you are having difficulty understanding the individual, consider writing as an alternative means of communicating, but first ask the individual if this is acceptable.

Tips for Communicating with Individuals with Cognitive Disabilities

- If you are in a public area with many distractions, consider moving to a quiet or private location.
- Be prepared to repeat what you say, orally or in writing.
- Offer assistance completing forms or understanding written instructions and provide extra time for decision-making. Wait for the individual to accept the offer of assistance; do not "over-assist" or be patronizing.
- Be patient, flexible and supportive. Take time to understand the individual and make sure the individual understands you.

Remember

Relax.

Treat the individual with dignity, respect and courtesy.

Listen to the individual.

Offer assistance but do not insist or be offended if your offer is not accepted.

Information for this fact sheet came from the Office of Disability Employment Policy; the Media Project, Research and Training Center on Independent Living, University of Kansas, Lawrence, KS; and the National Center for Access Unlimited, Chicago, IL.

October 1995
Updated August 2002

TEACHING MODULE 1

“Rethinking Disabilities”

Overall session theme: The session will introduce a framework to increase awareness of the pervasiveness of discrimination faced by persons with disabilities.

Objectives: After the session, attendees will be able to:

1. Describe the disability discrimination framework; and
2. Give examples of disability discrimination in society and within social service agencies.

Teaching activity

Practice Dilemma:

An experienced, successful clinical social worker with years of experience in mental health settings assumed a supervisory role on a newly created disability services team. The new program was funded by a state grant using Medicaid waiver funds and administered by the state’s vocational rehabilitation agency. The grant proposal enjoyed broad and enthusiastic community support. The introduction to the new role included an open forum with persons with disabilities from the community.

The forum had a great impact on the social worker because most of the disabled attendees were quite angry at the patronizing treatment they had received from local service providers. Many of the complaints had to do with what was perceived as a patronizing, medically-oriented approach by service providers. The social worker learned that most of the attendees at the forum were antagonistic toward the new program.

Questions for discussion and review:

1. How would you feel if you were this social worker?
2. What options does the worker have to reconcile the feeling of surprise at the forum responses?
3. What are the broad cultural characteristics that support the new program?
4. What are the implicit assumptions about people with disabilities that support the new program?
5. Why a “disability services team”?
6. What are the implications of having the new service administered by the state’s vocational rehabilitation agency?
7. What are the implications of using Medicaid waiver funds for this new program?
8. What role should people with disabilities have played in considering this new program?
9. What accounts for the role people with disabilities played in considering this new program?
10. How would you feel if you were a person with a disability targeted by this new program?

TEACHING MODULE 2 “Changing the Future of Disability”

Overall session theme: The session describes strategies for social work practice that can be used in practice to challenge discrimination of persons with disabilities.

Objectives: After the session attendees will be able to:

1. Describe at least two case work strategies to challenge discrimination; and
2. Develop a plan to use a strategy in the work setting.

Teaching Activity:

Give the following instructions to the assembled attendees: Empowerment practice with persons with disabilities means developing ways of working so that clients with disabilities can take charge of defining, organizing, and challenging the terms and conditions of their lives. Today we’re going to look at practice strategies that perpetuate discrimination and strategies that transform and empower. Break up into groups of three and consider this case study. Your client is 55 years old, diagnosed with cerebral palsy and major depression, living in a nursing home for 7 years since the deaths of both parents. The client is a high school graduate with a limited work history, who at one time, with the aid of a wheel chair, was able to meet all self-care needs. At this point the client seldom leaves the room and does not participate in activities. The reason for your visit is the client hates the nursing home and the other residents.

Questions for discussion and review:

1. What would you include in your initial assessment? What do you consider the most challenging aspect of this case? What needs to change?
2. Fill in the following “targets of change”:
 - A. List Client Barriers:
 1. physical
 2. emotional
 3. mental
 4. relational
 - B. List Community Barriers
 1. attitudinal
 2. architectural
 3. sensory
 4. cognitive
 5. economic
3. Write up a “treatment plan” that would remedy client and community barriers.
4. With one of you acting as the client and the other two acting as case workers, conduct a session so that your client feels like a partner in changing all the barriers.

5. Report your successes and failure. Do the assessment strategies you use/know aid in identifying and dealing with community barriers? If not, what would you change to make that happen?

WEST VIRGINIA ADVOCATES

The West Virginia Advocates is part of the West Virginia Protection and Advocacy System and works to protect the rights of persons with disabilities.

Some examples of their activities include:

Intervening on the behalf of a child enrolled in a public school system which consistently refused her right to a free and appropriate education. The result being that the child finally received the special education services to which she was entitled.

General and specific advocacy on behalf of all people with disabilities. An example of such is that the Advocates filed a complaint with the WV Department of Highways which resulted in the installation and maintenance of TDD/TTY assistive technology being installed at interstate rest stops.

Filing of complaints and lawsuits as necessary including one example in which two cases were filed with the WV State Circuit Court on behalf of clients who received MR/DD Medicaid Waivers but live in communities with poor or nonexistent services effectively negating the waiver.

The West Virginia Advocates publish a newsletter quarterly. For more information go to www.wvadvocates.org or call 1-800-950-5250.

A publication of the National Dissemination Center for Children with Disabilities

West Virginia State Resources

Complete update · 3/2006

Partial update · 8/11/2006

The offices listed on this state sheet are primarily state-level offices. Even if an office is not close to your home, they can usually put you in touch with resources in your community, as well as provide you with information and assistance about disability issues in your state. If you find that an address or number has changed or is incorrect, please e-mail us at nichcy@aed.org and let us know.

State Agencies and Organizations

United States Senators

Honorable Robert C. Byrd (D)
311 Hart Senate Office Building
Washington, DC 20510
(202) 224-3954; (202) 224-4849
(TTY)

E-mail:

http://byrd.senate.gov/byrd_email.html

Web: <http://byrd.senate.gov>

Honorable John D. Rockefeller IV
(D)

531 Hart Senate Office Building
Washington, DC 20510
(202) 224-6472; (202) 224-7665 (Fax)

E-mail: senator@rockefeller.senate.gov

Web: <http://rockefeller.senate.gov>

United States Representatives

To find the contact information for your representative in the House of the U.S. Congress, visit the House's Web site at: www.house.gov, or call: (202) 225-3121; (202) 225-1904 (TTY).

Age of Eligibility

Each state sets eligibility ages for services to children and youth with disabilities. For current information concerning this state, please contact the office listed under Department of Education: Special Education.

Governor

Honorable Joe Manchin, III
State Capitol Complex
1900 Kanawha Boulevard
Charleston, WV 25305
(304) 558-2000; (888) 438-2731
E-mail Web Form: www.wv.gov.org/contact.cfm
Web: www.wv.gov.org/

Steve Heasley, Sr. Assistant for Planning and Development
Governor's Cabinet on Children and Families
210 Brooks Street, Lee Building, Suite 300
Charleston, WV 25301
(304) 558-0600
Web: www.wvchildrenandfamilies.org

Official State Web Site

Web: www.wv.gov/

State Department of Education: Special Education

Dr. Lynn Boyer, Executive Director
Office of Special Education
Department of Education
1900 Kanawha Boulevard East
Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-2696; (800) 642-8541
E-mail: lboyer@access.k12.wv.us
Web: <http://wvde.state.wv.us/ose>

State Coordinator for NCLB (No Child Left Behind)

West Virginia Department of Education
1900 Kanawha Boulevard East
Charleston, WV 25305
(304) 558-2699
Web: <http://wvachieves.k12.wv.us/>

Programs for Infants and Toddlers with Disabilities under Part C of IDEA: Ages Birth To 3

Pamela Roush, Director
West Virginia Birth to Three
Office of Maternal, Child and Family Health
Bureau of Public Health
350 Capitol Street, Room 427
Charleston, WV 25301
(304) 558-5388; (800) 642-9704
E-mail: pamroush@wvdhhr.org
Web: www.wvdhhr.org/birth23

Programs for Children with Disabilities: Ages 3 through 5

Ginger Huffman, Coordinator
Office of Special Education
1900 Kanawha Boulevard East
Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-2696
E-mail: vhuffman@access.k12.wv.us
Web: <http://wvde.state.wv.us>

State Vocational Rehabilitation Agency

Deborah Lovely, Acting Director
Division of Rehabilitation Services
State Capitol Complex
P.O. Box 50890
Charleston, WV 25305-0890
(304) 766-4601
E-mail: debbiel@wvdrs.org
Web: www.wvdrs.org

Coordinator for Transition Services

Karen Ruddle, Coordinator
Office of Special Education
West Virginia Department of Education
1900 Kanawha Boulevard East
Building 6, Room 243
Charleston, WV 25305-0330
(304) 558-3075
E-mail: kruddle@access.k12.wv.us
Web: <http://wvde.state.wv.us/ose/>

Office of State Coordinator of Vocational Education for Students with Disabilities

Dr. Stanley Hopkins, Assistant State Superintendent of Schools
Division of Technical and Adult Education Services
West Virginia Department of Education
1900 Kanawha Boulevard East
Building 6, Room B-221
Charleston, WV 25305-0330
(304) 558-2349
E-mail: shopkins@access.k12.wv.us
Web: <http://wvde.state.wv.us>

State Mental Health Agency

John E. Bianconi, Acting Commissioner
Bureau for Behavioral Health and Health Facilities
Department of Health and Human Resources
350 Capitol Street, Room 350
Charleston, WV 25301-3702
(304) 558-0298
E-mail: jbianconi@wvdhhr.org
Web: www.wvdhhr.org/bhhf

State Mental Health Representative for Children and Youth

Sheila E. Kelly, M.A., Assistant Commissioner
Office of Behavioral Health Services
Bureau for Behavioral Health and Health Facilities
Department of Health and Human Resources
350 Capitol Street, Room 350
Charleston, WV 25301-3702
(304) 558-3717
E-mail: sheilakelly@wvdhhr.org
Web: www.wvdhhr.org

State Mental Retardation Program

Frank Kirkland, Director
Division of Developmental Disabilities
Bureau for Behavioral Health and Health Facilities
Department of Health and Human Resources
350 Capitol Street, Room 350
Charleston, WV 25301-3702
(304) 558-0627
E-mail: fkirkland@wvdhhr.org
Web: www.wvdhhr.org

Councils on Developmental Disabilities

Steven A. Wiseman, Executive Director
West Virginia Developmental Disabilities Council
110 Stockton Street
Charleston, WV 25312
(304) 558-0416; (304) 558-2376 (TTY)
E-mail: swiseman@wvdhhr.org
Web: www.wvddc.org

Protection and Advocacy Agency

Clarice Hausch, Director
West Virginia Advocates
1207 Quarrier Street, 4th Floor
Charleston, WV 25301
(304) 346-0847 (V/TTY); (800) 950-5250 (in WV)
E-mail: WVAinfo@wvadvocates.org
Web: **Error! Hyperlink reference not valid.**

Client Assistance Program

Client Assistance Program
West Virginia Advocates
1207 Quarrier Street, 4th Floor
Charleston, WV 25301
(304) 346-0847 (V/TTY); (800) 950-5250 (in WV)
E-mail: WVAinfo@wvadvocates.org
Web: **Error! Hyperlink reference not valid.**

Programs for Children with Special Health Care Needs

Cathy Capps-Amburgey, Director
Children with Special Health Care Needs
Office of Maternal Child and Family Health
Bureau for Public Health
West Virginia Department of Health and Human Resources
350 Capitol Street, Room 427
Charleston, WV 25301-3714
(304) 558-5388
Web: www.wvdhhr.org

State CHIP Program

(health care for low-income uninsured children)
WV CHIP
(877) 982-2447
Web: www.wvchip.org

Programs for Children and Youth who are Deaf or Hard of Hearing or Deaf-Blind

Ruth Ann King, Coordinator
Annette Carey, Coordinator
West Virginia Department of Education
State Capitol Complex
1900 Kanawha Boulevard East
Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-1675; (866) 461-3578
E-mail: acarey@access.k12.wv.us
E-mail: raking@access.k12.wv.us

Telecommunications Relay Services for Individuals who are Deaf, Hard of Hearing, or with Speech Impairments

(800) 982-8772 (V)
(800) 982-8771 (TTY); 711 (TTY)
(800) 229-5746 (Speech to Speech - English)
(866) 260-9470 (Speech to Speech - Spanish)

Programs for Children and Youth who are Blind or Visually Impaired

Annette Carey, Coordinator
Office of Special Education
Department of Education
1900 Kanawha Boulevard East
Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-1675
E-mail: acarey@access.k12.wv.us
Web: <http://wvde.state.wv.us/ose/>

Regional ADA & IT Technical Assistance Center

Marian Vessels, Director
ADA and IT Information Center for the Mid Atlantic Region
451 Hungerford Drive, Suite 607
Rockville, MD 20850
(301) 217-0124 (V/TTY); (800) 949-4232 (V/TTY)
E-mail: adainfo@transcen.org
Web: www.adainfo.org

University Centers for Excellence in Developmental Disabilities

Ashok S. Dey, Director
West Virginia University Center for Excellence in Disabilities
959 Hartman Run Road
Morgantown, WV 26505
(304) 293-4692
E-mail: wwuced@hsc.wvu.edu
Web: www.cedwvu.org/

Technology-Related Assistance

Dale Castilla, Manager
Rehab Technology Department
Division of Rehabilitation Services
P.O. Box 1004
Institute, WV 25112
(304) 766-4600
Web: www.wvdrs.org

State Mediation System

Ghaski Lee Browning, Coordinator
West Virginia Department of Education
Office of Special Education
1900 Kanawha Boulevard East
Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-2696
E-mail: glee@access.k12.wv.us
Web: <http://wvde.state.wv.us/ose/>

Special Format Library

Donna B. Calvert, Librarian
West Virginia Library Commission
Special Libraries-Blind and Physically Handicapped Cultural Center
1900 Kanawha Boulevard East
Charleston, WV 25305-0330
(304) 558-4061; (800) 642-8674
E-mail: calvertd@wvic.lib
Web: <http://librarycommission.lib.wv.us/>

Disability-Specific Organizations

Attention Deficit Disorder

To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/Hyperactivity Disorder
(CHADD)

8181 Professional Place, Suite 150

Landover, MD 20785

(301) 306-7070

(800) 233-4050 (Voice mail to request information packet)

Web: www.chadd.org

Attention Deficit Disorder Association (ADDA)

P.O. Box 543

Pottstown, PA 19464

(484) 945-2101

Web: www.add.org

Autism

Dr. Barbara Becker-Cottrill, Director

West Virginia Autism Training Center

Marshall University

One John Marshall Drive

Huntington, WV 25755-2430

(304) 696-2332; (800) 344-5115 (in WV)

Web: www.marshall.edu/coe/atc

Blind/Visual Impairments

Frances Mary D'Andrea, Director

American Foundation for the Blind-National Literacy Center

100 Peachtree Street, Suite 620

Atlanta, GA 30303

(404) 525-2303

E-mail: literacy@afb.net

Web: www.afb.org

Brain Injury

Peggy Brown, Executive Director

Brain Injury Association of West Virginia, Inc.

P.O. Box 574

Institute, WV 25112

(304) 766-4892; (800) 356-6443 (in WV)

E-mail: BIAWV@aol.com

Web: www.BIAUSA.org/WVVirginia

Learning Disabilities

Jennifer Carriger, President
Learning Disabilities Association of West Virginia
908 Highland Road
Charleston, WV 25302
(866) 985-3211 (in WV)
E-mail: jcarriger@citynet.net
Web: www.wvlda.org

Mental Health

Ellen Ward, Executive Director
Mental Health Association in the Greater Kanawha Valley, Inc.
One United Way Square
Charleston, WV 25301-1098
(304) 340-3512
E-mail: mha@wvinter.net
Web: <http://mha-kanawha.org>

Michael Ross, Executive Director
NAMI WV
P.O. Box 2706
Charleston, WV 25330-2706
(304) 342-0497
E-mail: NAMIWV@aol.com
Web: <http://namiwv.org>

Teri Toothman, Executive Director
Mountain State Parents-CAN
P.O. Box 6658
Wheeling, WV 26003
(304) 233-5399; (800) 244-5385
E-mail: ttoothman@mspan.org
Web: www.mspan.org

Lorie Roberts, Executive Director
West Virginia Health Consumers Association
910 Quarrier Street, Suite 414
Charleston, WV 25301
(304) 345-7312; (800) 598-8847
E-mail: lorieroberts@contac.org
Web: www.wvmhca.org

Tourette Syndrome

Lyn Mox, Executive Director
Tourette Syndrome Association of Greater Washington
33 University Boulevard East
Silver Spring, MD 20901
(301) 681-4133; (877) 295-2148
E-mail: TSAGW@aol.com
Web: www.TSAGW.org

Organizations Especially for Parents**Parent Training and Information Center (PTI)**

Pat Haberbosch, Director
West Virginia Parent Training and Information Project (WVPTI)
1701 Hamill Avenue
Clarksburg, WV 26301
(304) 624-1436 (V/TTY); (800) 281-1436 (In WV)
E-mail: wvpti@aol.com
Web: www.wvpti.org

Parent-To-Parent

Lynn Reichard, Educator
West Virginia Parent-Educator Resource Center (PERC) Project
509 W. Martin Street
Martinsburg, WV 25401
(304) 263-5717
E-mail: bcperc@yahoo.com

Parent Teacher Association (PTA)

Jenny Raber, President
West Virginia Congress of Parents and Teachers
P.O. Box 3557
Parkersburg, WV 26103-3557
(304) 420-9576; (304) 420-9577
E-mail: wv_office@pta.org
Web: www.wvpta.net/

Parent-Educator Resource Center

Betsy Peterson, Parent Coordinator
West Virginia Parent-Educator Resource Center (PERC) Project
West Virginia Department of Education
Office of Special Education
1900 Kanawha Boulevard E, Building 6, Room 304
Charleston, WV 25305-0330
(304) 558-2696

E-mail: bpeterso@access.k12.wv.us

Web: <http://wvde.state.wv.us>

Other Disability Organizations

Lori Untch, President/CEO
Easter Seals West Virginia
1305 National Road
Wheeling, WV 26003-5780
(304) 242-1390 (V/TTY); (800) 677-1390
Web: www.wv.easterseals.com

Recording for the Blind & Dyslexic (RFB&D)
Regional Unit of the Virginias and Carolinas
1021 Millmont Street
Charlottesville, VA 22903
(434) 293-4797; (866) 877-7323
Web: www.rfbd.org

Amy L. Brooks, Founder
SOPHIA'S PLACE
50 Fenwick Drive
Martinsburg, WV 25401
E-mail: wifeof1motherof3@cs.com

West Virginia Family Support Program
350 Capitol Street, Room 350
Charleston, WV 25301-3702
(304) 558-0627
Web: www.wvdhhr.org

Independent Living

***To find out the contact information for the Statewide
Independent Living Council (SILC) in your state, contact:***

Independent Living Research Utilization Project
The Institute for Rehabilitation and Research
2323 South Sheppard, Suite 1000
Houston, TX 77019
(713) 520-0232 (V); (713) 520-5136 (TTY)
E-mail: ilru@ilru.org
Web: www.ilru.org

***To find out the contact information for centers for
independent living (CILs) in your state, contact:***

National Council on Independent Living
1710 Rhode Island Avenue, NW, 5th Floor
Washington, DC 20036
(202) 207-0334 (V); (202) 207-0340 (TTY)
E-mail: ncil@ncil.org
Web: www.ncil.org

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NICHCY State Resources are listings of selected state-wide organizations that can refer people to organizations in their area. We update our state resources continuously; however, the addresses and telephone numbers of these selected groups are constantly changing.

If you find that an address or number has changed or is incorrect, please e-mail us at nichcy@aed.org and let us know.

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[NICHCY](#) > [State Resources](#) : West Virginia

<http://www.nichcy.org/stateshe/wv.htm>

WEB SOURCES

www.trynova.org/victiminfo/ovc-disabilities/myths.html

Myths about the Diversity Community, Carol Guidy Tyislea

www.disabilityisnatural.com/people_firstlanguage.htm

People First Language, Kathie Snow

www.acf.hhs.gov/programs/addl

DHHS: Administration for Children and Families

www.vjoncheray.com/phototheque/en/photos_people/hanidcapped

Photos of Handicapped Persons

www.fvkasa.org/culture_what.is.asp

What is Disability Culture?

www.hometown.aol.com/sbrown8912/page6.html

Disability Culture Beginnings: A Fact Sheet, Steven E. Brown
Institute on Disability Culture

www.disabilitystory.org/people.html

Disability Social History Project

www.apr.org/programs/disability

The Disability History Project (Live Radio)
Corporation for Public Broadcasting

www.wvddc.org

West Virginia Disability Council

www.dds.cahwvnet.gov/tycenter/tv_videos.cfm

Video Resource: Brief Videos on a Variety of Topics at a Cost of \$5.00 each
(This includes shipping and handling.)

www.aucd.org/legislative_affairs/HIGHLIGHTS1.htm

Highlights of Reauthorization of Developmental Disabilities Act of 1999

www.ncd.gov/resources.htm

Legislative Info—Developmental Disabilities—ADA, Rehabilitation Act of 1973, IDEA,
DD Assistance, and Bill of Rights Act and others

www.cec.sped.org/bk/catalog2/autism.html

CEC Catalog 2005: Resources for Educators on Teaching Students with Disabilities and Gifts (low cost videos)

www.independentliving.org/docs3/gill1995.html

A Psychological View of Disability Culture, Carol Gill (1995)

BOOKS

- Depoy, E. & Gilson, S. (2004). Rethinking disability. Belmont, CA: Brooks/Cole. Alex
- Gitterman (Ed)(2001). Handbook of social work practice with vulnerable and resilient populations. New York, NY: Columbia University Press.
Chapter on “people with social disabilities.”
- Harrison, Diane F., Bruce A. Thyer, and John S. Wodarski (Eds.) (1996). Cultural diversity And social work practice. Springfield, ILL: CC Thomas.
Includes a chapter on “persons with developmental disabilities.”
- Henderson, George. (1994). Cultural Diversity in the Workplace: Issues and Strategies.
Wesport, CONN: Quorum Books.
Includes a chapter on “workers with disabilities.”
- Klein, Stanley and John Kemp (2004). Reflections from a Different Journey: What Adults with Disabilities Wish all Parents Knew. New York, NY: McGraw-Hill.
- Mackelprang, & Salsgiver, R. (1999). Disability: A Diversity Model Approach in Human Service Practice. Belmont, CA: Brooks/Cole.
- May, Gary E. and Martha B. Rashe (Eds) (2005). Ending disability discrimination: Strategies for social workers. Boston, MA: Person Allyn and Bacon.
- Reamer, Frederic. (Ed.)(1994). The Foundations of Social Work Knowledge. New York, NY: Columbia University Press.
Includes a chapter on “people with disabilities.”
- Reinders, Hans S. (2000). The Future of the Disabled in Liberal Society: An Ethical Analysis. Notre Dame, IN: University of Notre Dame Press.
Genetics and Human Engineering
- Rose, Mike. (1999). Lives on the Boundary: The Struggles and Achievements of America’s Underprepared. New York, NY: Free Press.
People with social disabilities.
- Rothman, Juliet C. (2003). Social work practice across disability. Boston, MA: Allyn and Bacon.
Disability rights and legislation, stereotypes
- Joseph P. Shapiro (1994). No Pity: People with Disabilities Forging a New Civil Rights Movement. New York, NY: Times Books.
History of Disability Culture

RESOURCES FOR CHILDREN WITH DISABILITIES

Family Support, Education and Advocacy

West Virginia Family Support Program, Bureau for Behavioral Health and Health Facilities- Statewide service to assist families in accessing child care, home modifications, transportation and other needed supports. The Family Support Program provides leadership in family-centered and family-driven service coordination and planning.

Phone: (304) 558-0627

Fax: (304) 558-1008

Website: www.wvdhhr.org/bhhf/mrdd.asp

West Virginia Parent Training and Information, Inc. - Consultation and support for parents of children with disabilities. Education and training services on special education policies, preparing for Individual Education Planning meetings and working collaboratively with school personnel.

Phone: (304) 624-1436 or 1-800- 281-1436

Fax: (304) 624-1438

Website: www.wvpti.org

West Virginia Advocates, Inc. - State designated protection and advocacy program for West Virginians with disabilities. WVA provides consultation and education services on human and legal rights.

Phone: (304) 346-0847 (V/TTY) or 1-800- 950-5250

Website: www.wvadvocates.org

Parent Network Specialists (PNS), WVU Center for Excellence in Disabilities -

Statewide network of parents who serve as advisors to parents of children with disabilities, administered by the University Center for Excellence in Disabilities, funded by the Office of Maternal Child and Family Health/Title V.

Phone/TDD: (304) 293-4692 or 1-800- 841-8436

Fax: (304) 293-7294

Website: www.ced.wvu.edu

Parent Educator Resource Centers (WV Department of Education) - Training and support for parents of students with disabilities. Parents and educators work as a team to provide positive collaborative relationships in school districts statewide. PERCs provide current information and resources on a wide variety of topics including parenting skills, education policies and obligations, problem solving, behavior support and other supports to strengthen the home-school partnership.

Phone: (304) 558-2696 (V/TDD) (800) 642-8541

Fax: (304) 558-3741

Website: <http://wvde.state.wv.us>

Parent Empowerment Network (PEN) - Organization striving to provide individual and systems advocacy and support, education and referral to parents who have disabilities and their families statewide.

Phone: (304) 296-6091

Fax: (304) 292-5217

Governor's Cabinet on Children and Families - Organization that works in partnership with other community programs to support families and children on a wide variety of issues including healthcare, education and social services.

Phone: (304) 558-0600

Website: www.wvchildrenandfamilies.org/

Family Matters - Information and referral hotline with toll-free access to information on programs for children and families throughout West Virginia. Access to financial assistance and support, healthcare, housing, disability services including case management, child care, crisis services, educational programs, emergency services, and entitlement information.

Phone: 1-800-734-2319

Website: www.msyst.net/wvfamily/

Mountain State Parents, Children & Adolescent Network (MSPCAN) - Information and referral, emotional support and advocacy training for parents who have children with emotional, psychiatric and/or behavioral support needs.

Phone: (304) 233-5399

Fax: (304) 233-3847

Website: www.mspscan.org

Early Intervention and Pre-school Services

Office of Maternal, Child and Family Health, WV Birth to Three - Statewide, locally administered program to provide supports and services that assist families in meeting the developmental needs of their infant or toddler with special needs. All children under the age of three who are found eligible by having a developmental delay, medical condition or multiple risk factors are entitled to services needed by them and their family as identified on their Individual Family Service Plan (IFSP). Program provides linkage to specialized therapy services in accordance with Part C of the Individuals with Disabilities Act.

Phone: (304) 558-5388 or 1-800- 642-9704

Website: www.wvdhhr.org/mcfh

WV Department of Education, Office of Instructional Services - Kindergarten, early childhood education and Even Start programs. Programs provide assessment and specialized services for children ages 3 through 5.

Phone: (304) 558-2691 (V/TDD) (800) 642-8541

Website: <http://wvde.state.wv.us>

WV Head Start Association - Lead state agency that oversees 24 Head Start programs in WV. Disability services including individualized programming, inclusive placement, dental, health, nutrition, developmental, family support and social services. Services available to children aged birth to 5 years in low income families.

Phone: (304) 233-4550

Fax: 233-3719

Website: <http://www.wvheadstart.org/>

The National Information Center for Children and Youth with Disabilities (NICHCY) - National information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Focus is on children and youth (birth to age 22).

Phone: 1-800-695-0285

Website: www.nichcy.org

Education (K-12)

West Virginia Department of Education, Office of Special Education - Responsible for ensuring that appropriate instruction and support are provided to students with disabilities. Statewide management, monitoring and technical support for special education programs. Administration of due process and mediation. Find information about Policy 2419 - Regulations for the Education of Exceptional Students and links to state and federal programs and resources on the website listed below.

Phone: (304) 558-2696

Fax: (304) 558-3741

Website: <http://wvde.state.wv.us/ose/>

West Virginia Advisory Council for the Education of Exceptional Children - State advisory council as mandated under the Individuals with Disabilities Education Act (IDEA). The Council evaluates educational services in West Virginia and advises decision makers regarding the unmet needs of students with disabilities. The Council facilitates public meetings, develops reports, informational materials and works cooperatively with the WV Department of Education. The Council is composed of members appointed by the State Superintendent of Schools.

Phone: (304) 746-2076 or 1-800-642-3642 TDD (304) 746-2008

WV Safe Schools HELPLINE - A 24- hour, toll-free number for all of West Virginia for confidentially reporting information that may be harmful to students, staff or school property. Threats of violence, use of weapons, sexual harassment, drug use or other harmful behavior should be reported.

Phone: 1-866-723-3982 (1-866-SAFEWVA)

Medicaid, Social Security and Other Entitlement Programs

WV Bureau for Medical Services - State medical services program as mandated under the West Virginia Code and Social Security Act. Medicaid, behavioral health, home health and Children with Disabilities Services Program (formerly TEFRA).

Phone: (304) 558-1700

Website: www.wvdhhr.org/bms

WV Children's Health Insurance Program (CHIP) - Free or low cost health plan for children from birth to age 19 in low income families. Insurance plan covers preventive care, immunizations, prescriptions, hospital visits, dental, vision and mental health services.

Phone: 1-877-982-2447 (1-877-WV CHIP)

Website: www.wvchip.org

Social Security Administration - Assistance and information about government benefits including Supplemental Security Income (SSI) and Social Security Disability (SSD) programs. Medicaid, CHIP and other health care services and resources.

Website: www.ssa.gov

WV Office of Maternal, Child and Family Health - Early and Periodic Screening Diagnosis and Treatment (EPSDT), care for pregnant women and newborns through the first year of life and children with chronic health conditions through a statewide clinical network. Assistance to families and their children (birth to 21) in accessing benefits and linkage to community services and resources.

Phone: (304) 558-5388 or (800) 624-9704

Fax: (304) 558-2866

Website: www.wvdhhr.org/mcfh

Case Management and Community Services and Supports

Medicaid Title XIX MR/DD Home and Community-Based Waiver Program: Service coordination, respite, qualified professional services, residential habilitation, medical/nursing services and other supports. Program manuals are available by contacting the local behavioral center or the MR/DD Waiver Office.

Phone: (304) 558-3628

Fax: (304) 558-1008

Website: www.wvdhhr.org/bhhf/mrdd.asp

WV Office of Social Services - Support services for children and families. Protective services, early intervention, foster care, specialized family care, child care, adoption, legal assistance and other supports and services.

Fax: (304) 558-4577

Website: www.wvdhhr.org/oss

Bureau for Behavioral Health and Health Facilities (DD Services)- Information and linkage to community case management, crisis services, family support, behavior support, and crisis intervention services. Medicaid Title XIX Home and Community Based Waiver Program.

Phone: (304) 558-0627

Website: www.wvdhhr.org/bhhf/mrdd.asp

Bureau for Behavioral Health and Health Facilities, (Children's Mental Health Services) - Serving children diagnosed as Severely Emotionally Disturbed and their families. Linkage to the statewide service system of mental health programs including referral, assessment, inpatient and outpatient services.

Phone: (304) 558-0627

Website: www.wvdhhr.org/bhhf/mrdd.asp

WV University Center for Excellence in Disabilities - Positive behavior support training, consultation and assistance with public schools. Specialized health care coordination and services.

Phone/TDD: (304) 293-4692 or (800) 841-8436

Website: www.ced.wvu.edu

The WV Autism Training Center, Marshall University - College of Education and Human Services. Training, information and support for West Virginians with autism, their families, educators and others.

Phone: (304) 696-2332 or (800) 344-5115 (WV only)

Website: www.marshall.edu/coe/atc

Brain Injury Association of West Virginia, Inc. - State chartered organization dedicated to providing education, advocacy and support to persons with brain and spinal cord injuries and their families. Toll-free help line to provide information about support groups, case management, crisis services, health care and psychiatric services in West Virginia and nationwide.

Phone: (304) 766-4892 Toll Free in WV - 1-800-356-6443

Website: www.biausa/wvirenia

WV Commission for the Deaf and Hard of Hearing - Programs for children and youth who are deaf or hard of hearing. Information and referral, family support, educational services, interpreter services and telephonic communication device loan program.

Phone: (304) 822-8565 or (877) 461-3578

Website: www.wvdhhr.org/wvcdhh

Assistive Technology

West Virginia Assistive Technology System (WVATS) - Information and referral, toll free hotline, funding, training and education about AT devices and services. Linkage to regional resource centers, lending libraries and tech teams to assist consumers and families. The WVATS is a project funded by the US Department of Education and coordinated by the WVU Center for Excellence in Disabilities.

Phone: Voice and TDD - (304) 293-4692 or (800) 841-8436

Website: www.ced.wvu/Programs/community/WVATS

Partnerships in Assistive Technologies (PATHS) - Coalition of West Virginia agencies and organizations interested in increasing the availability of and access to assistive technology. Technical assistance, training, information and referral and systems change initiatives.

Phone: 1-800-841-8436

WV Office of Special Education - Information and assistance for accessing appropriate AT equipment for school aged children. Technical assistance to school personnel and programs.

Phone: (304) 558-2696

Website: www.wvde.state.wv.us/ose

ABLEDATA - Information, resources, research, support and training about assistive technology. Publications and consumer product reviews. Nationwide database.

Phone: 1-800-227-0216

Website: www.abledata.com

National Institute on Disability and Rehabilitation Research - Information and referral, research projects, public policy advocacy related to assistive technology to increase access to employment, healthcare and independent living.

Phone: Voice: (202) 205-8134 TTY: (202) 205-4475

Website: www.ed.gov/OSERS/NIDRR

Information Technology Technical Assistance and Training Center - Organization that promotes the development of accessible electronic and information technology by providing technical assistance, training and educational services. Informational workshops, conferences and AT related publications.

Phone: Toll Free - 866-9-ITTATC (948-8282) Voice and TTY
Website: www.ittatc.org

National Rehabilitation Information Center - Information and referral service including access to database of more than 70,000 assistive technology products and resources. Education about the Americans with Disabilities Act (ADA), advocacy projects and funding.
Phone: 1-800-346-2742
Website: www.naric.com

Recreation

Adventure Pursuit, Inc.- Parkersburg, WV area program specializing in accessible water sports and recreation. Kayak and canoe trips, rock climbing, rappelling, hiking, camping and bike riding. Clubhouse located on the Kanawha River in Wood County.

Phone: (304) 485-0911
Website: www.adventurepursuit.org

West Virginia Division of Natural Resources - Information and assistance about accessible fishing, hunting and camping areas. Parks and forest information, hunting and fishing licenses for persons with disabilities. Fish stocking schedules, boating and other information.

Phone: (304) 558-2754
Website: www.dnr.state.wv.us

West Virginia Division of Tourism - Lodging, restaurants, attractions and events around the state. Accessibility information for public parks and recreation areas. Information about snow sports, white water rafting, biking and walking trails.

Phone: 1-800-CALL-WVA
Website: www.callwva.com

National Center on Accessibility - Organization committed to the full participation in parks, recreation and tourism by people with disabilities. Education, technical assistance, research and information and referral services. Information on key legislation including the Architectural Barriers Act, Rehabilitation Act, Americans with Disabilities Act (ADA) and the Uniform Federal Accessibility Standards.

Phone: (812) 856-4422 TTY: (812) 856-4421

Website: www.ncaonline.org

The National Park Service - Federal bureau in The Department of the Interior responsible for protection of the national parks, monuments, rivers, reservations and other lands. Accessibility resources and assistance.

Phone: (202) 208-6843

Website: www.nps.gov

US Department of the Interior, Coordinating Committee on Accessibility for People with Disabilities - Current programs and information about legal standards for federal lands regarding accessibility. Information about advocacy initiatives and groups. Accessible federal parks and monument information.

Phone: (202) 208-4727

Website: www.pn.isbr.gov/doiacc