

**Practice
and
Practice Research**

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.

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.

Last Updated: March 23, 2005 1:46 PM

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 sized 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 to 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 Disabilities”

“Rethinking

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?

Gary May & Martha Raske

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>

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.

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).

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/contact.cfm
Web: www.wv.gov/

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://wvachievers.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.

Publication of this document is made possible through a Cooperative Agreement between the Academy for Educational Development and the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

NICHCY
P.O. Box 1492
Washington, DC 20013
(800) 695-0285 · v/tty
(202) 884-8441 · fax
e-mail: nichcy@aed.org
web: www.nichcy.org

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_whatism.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/ty_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.

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. Westport, 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.msys.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.mspcan.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