

Legal Issues and Developmental Disabilities

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THE NORTH DAKOTA STATEWIDE
DEVELOPMENTAL DISABILITIES
STAFF TRAINING PROGRAM

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Introduction

Historically, individuals with developmental disabilities have been separated from the main stream of community life. Many times they were restricted in their personal freedoms and segregated in institutions without adequate treatment, education, habilitation, or medical care. In many cases, their basic human needs were not met, and their rights as citizens of the United States were ignored.

In the state of North Dakota, at the turn of the century, the majority of individuals with mental retardation (cognitive disabilities) lived with their families. Few services, where available, were tailored to the needs of individuals with cognitive disabilities and their families.

In 1904, North Dakota's constitution was amended to establish an institution at Grafton (as of July 1, 1989, the name Grafton State School was changed to North Dakota Developmental Center). This "institution for the feebleminded" was necessary in the legislature's view as such persons, unprotected and unprepared, found life in the community difficult, particularly since families raising such children at home could draw upon few resources to assist their effort. The institution offered protection and furnished the most decent alternative to home care given the knowledge and technology available at that time.

Unfortunately, the institution at Grafton came to be regarded as the principle treatment facility for individuals with cognitive disabilities in the state. Even though the legislature established a Division of Mental Health and Mental Retardation in 1961, the development of community services lagged far behind due to inadequate funding. By 1966, the population at Grafton State School and its San Haven subdivision had reached an all time high of approximately 1400 residents. By the late '70s, North Dakota had institutionalized more persons per capita and spent less on institutional services than any other state in the nation.

During the last three decades, a great deal of legislation and litigation has occurred in the field of developmental disabilities. The result of this has been an affirmation of the basic human and legal rights of individuals with developmental disabilities. The focus today is on a positive approach to habilitation. The philosophical bases which underlie today's attitudes, the developmental assumption and the normalization principle open up a whole world for individuals with disabilities. These ideas have led to deinstitutionalization, participation in public education, and freedom to exercise one's constitutional rights. Public attitude has shifted dramatically, which has resulted in many more people with disabilities experiencing opportunities never previously offered or allowed. Throughout the 70s and 80s, community programs emerged in almost every state of the union. Habilitative technology assisted individuals with developmental disabilities to acquire new skills. Advances in behavioral technology and adaptive equipment, coupled with increased community awareness of the capabilities of individuals with developmental disabilities, have resulted in more and more services for people with severe and profound disabilities. Let us continue to move to a time when all citizens with developmental disabilities will receive the support and services they need to live, work, and play in the community they choose.

UNIT I - Normalization and Social Role Valorization

Objectives

After completing this unit direct support and other professionals will be able to:

- Describe the major components of the Normalization Principle and provide examples of its implementation.
- Define the concept of the social role valorization.
- Explain how social role valorization can prevent maltreatment and devaluation

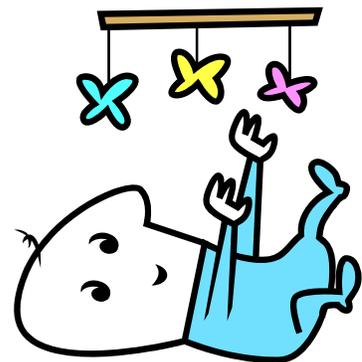
The normalization concept first gained notice in Scandinavia in the late 1950s and early 1960s. According to Wolfensberger (1972), the principle was first delineated by Bank-Mikkelsen, head of the Danish Mental Retardation Service, who phrased it as "letting the mentally retarded obtain an existence as close to normal as possible." It was written into the 1959 Danish law governing services for individuals with cognitive disabilities.

In 1969, Bengt Nirje elaborated on the normalization principle. In a chapter of *Changing Patterns in Residential Services for the Mentally Retarded*, he stated:

The normalization principle means making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.

Normalization means sharing a normal rhythm of the day, with privacy, activities, and mutual responsibilities; a normal rhythm of the week, with a home to live in, a school or work to go to, and leisure time with a modicum (small amount) of social interaction; a normal rhythm of the year, with the changing modes and ways of life and family and community customs as experienced in the different seasons of the year.

Normalization also means opportunity to undergo the normal developmental experiences of the life cycle: infancy, with security and the respective steps of early childhood development, school age, with exploration and the increase of skills and experience, adolescence, with development towards adult life and options. As it is normal for a child to live at home, it is normal for adults to move away from home and establish independence and new relationships. Like everybody else, retarded people should experience the coming of adulthood and maturity through marked changes in the settings and circumstances of their lives. Normalization also means that understanding and respect should be given to the silent wishes or expressed self-determination of retarded persons; that relationships between sexes should follow the regular patterns and variations of society; that the same basic economic patterns of life followed by others should apply also to retarded persons.





Finally, normalization also means that if a person with a cognitive disability cannot or should not any longer live in their family or own home, the homes provided should be of normal size and situated in normal residential areas, being neither isolated nor larger than is consistent with regular mutually respectful or disinterested social interaction and integration. (Nirje, 1976, pp. 231-232).

Nirje pointed out that the normalization principle depends on an understanding of how the normal rhythms, sequences, and patterns of life in any cultural environment relate to the development, maturity, and life of individuals with cognitive disabilities. It is important to use these patterns as criteria for the development of services for people with developmental disabilities.

He stated that the principle applies to all persons, whatever the degree of disability and wherever they live. It is useful in every society for all age groups and can be adapted to social changes and individual developments. As such, it can serve as a guide for direct support and other professionals in human services. Decisions and actions based on the principle of normalization are almost always correct ones.

Nirje (1976), emphasized that application of the normalization principle will not make individuals with cognitive disabilities "normal", however,

. . . it will make their life conditions as normal as possible, respecting the degrees and complications of the handicap, the training received and needed, and the social competence and maturity acquired and attainable. So, the aims of care and services and the goals of training, in striving to develop a better adjustment to society, are also part of normalization. (p. 232)

A Reformulation

In 1972, Wolf Wolfensberger published what has become a classic reference book for human service professionals--*The Principle of Normalization in Human Services*. In it he proposed a reformulation of the normalization principle. He wrote:

For purposes of a North American audience, and for broadest adaptability to human management in general, I propose that the definition of the normalization principle can be further refined as follows: "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" [emphasis added]. (p. 28)

He suggested that the application of the normalization principle is culture specific. This means that the kind of human services models which are established should be typical of the culture in which they are placed. The goal of services for people with cognitive disabilities should be to elicit and maintain appearance and behavior that is as close as possible to the appearance and behavior of other people in the same society.

Social Role Valorization

Wolf Wolfensberger (1983), after much debate in the literature regarding the meaning of normalization and what constitutes "normal", proposed a new term for the principle of normalization: social role valorization. "Social role valorization has as its primary goal the establishment and protection of positively valued social roles for people who are devalued by society or at risk of devaluation." (Wolfensberger, 1995). Thus, the ultimate goal of human services under this philosophy is social role enhancement for persons served.

People with developmental disabilities, and particularly those with cognitive disabilities, have been stigmatized and are not fully accepted in our society. If the role definition imposed on a person is a negative one, that person has been devalued. People may be devalued because of the way they look, how they behave, or because of race, color, or creed. This devalued status, according to Wolfensberger, is not something which exists within the individual but something imposed by society.

Example: Behavior from a socially valued person that would be tolerated, such as talking too loudly in a restaurant, is less likely to be tolerated from a person with a cognitive disability. That person must act in a more conservative manner in order to attain societal acceptance.



Both the normalization principle and the concept of social role valorization suggest that employees of agencies serving individuals with developmental disabilities should minimize the perceived differences of people with developmental disabilities. Service providers should seek to reduce the stigma and deviancy associated with developmental disabilities.

Social role valorization, according to Wolfensberger (1985), may prevent devaluation and maltreatment by:

- Reducing or preventing the differentness that may cause a person to become devalued in the eyes of observers; and/or
- Changing other people's perceptions and values in regard to a particular characteristic or condition, so that special or different people are no longer seen as devalued (Wolfensberger, 1985).

These two goals can be achieved through enhancement of the social image and competencies of the person or group by using culturally valued means.

The patterns of life for individuals with disabilities should be like those of other people of the same age and culture. The majority of adults in our culture work a five-day week schedule and spend two days of the week in home activities, recreation, and religious observance. When

community agency employees develop opportunities for individuals with developmental disabilities, they must pay attention to the activities already available in the community.



According to the principle of normalization, there are two kinds of integration: physical and social. In order for a program to be physically integrated, it must be located in the same place as other facilities of the same kind used by the rest of the population. Social integration takes place when there are opportunities for interaction with different kinds of people, such as church, shopping, recreation, and work environments that are generic and available to all. The numbers of individuals with disabilities in these environments should remain small.

In our society, some expectations and life benefits occur because an individual has reached a certain chronological age. When designing and implementing programs for individuals with developmental disabilities, it is very important for direct support professionals to consider the chronological age of the individual and to create an age-appropriate environment. Possessions and clothing, forms of address, schedules of work, and teaching strategies should be chronologically age-appropriate.

In summary, the principles of normalization and social role valorization are exciting concepts with many components that should be a part of the day-to-day environments and activities of community based programs. Their acceptance by human service professionals and the general public has greatly enhanced the quality and availability of programs to individuals with developmental disabilities.

Feedback Exercise I

1. List two ways social valorization may prevent devaluation of people with disabilities.
 - (a) _____
 - (b) _____

2. What is wrong in the following scenario? (List at least 5 items). Jane is 22 years old. She is on her way to the day program on a Monday morning. She is wearing a red sweatshirt and sweat pants which are size XL (Jane is a size medium). She is wearing black crew socks and white sandals. It is raining outside, but Jane carries no umbrella or rain coat. Jane has a curly perm similar to what older ladies prefer. The barrettes in her hair have kittens on them because Jane loves cats and would really like to have one but the group home rules prohibit pets. Jane is trying to learn to use makeup and enjoys nail polish. It's been about a week since she put on the bright pink shade that she likes the most. The polish is pretty chipped, but June, the direct support professional who is the primary staff for Jane, doesn't work until the weekend. Jane has enjoyed her breakfast, her mouth is encircled by a milk ring, and bits of toast are between her two front teeth.
 - (a) _____
 - (b) _____
 - (c) _____
 - (d) _____
 - (e) _____

3. State what is appropriate in the following scene: Mary and Susan are involved in a wide variety of activities which are different every weekend. They offer suggestions to direct support professionals and help plan the activities. Sometimes they go to the swimming pool at the "Y" in the evening. They sometimes invite friends to the house for popcorn and movies. Other activities have included attending a concert at the State fair, eating Saturday night dinner out at a steak house, volunteering at the local food pantry, and swinging in the porch swing in the backyard. Mary enjoys needlework and often chooses to sit out when others are playing games, in order to work on her latch hook rug. In the summer they invite the neighbors over for a backyard barbecue. Susan is very active in her church and participates as a greeter on the first Sunday of every month.
 - (a) _____
 - (b) _____
 - (c) _____
 - (d) _____
 - (e) _____

4. One of the founders of the normalization theory, Bengt Nirje, pointed out that "normalization also means an opportunity to undergo the normal developmental experiences of the life cycle." For example, a normal life cycle experience of a school-age child is to go to school (rather than to be left at home). A normal life cycle experience of adolescence is to become concerned with peer group interests, such as popular music or fashions. A normal life cycle experience of adulthood is involvement in the world of work. A life cycle experience of old age is retirement. People with developmental disabilities should also experience these stages.

Name a normal and appropriate activity for the age given:

- (a) 2 years of age _____ (d) 24 years of age _____
(b) 12 years of age _____ (e) 68 years of age _____
(c) 17 years of age _____
5. According to the principle of normalization, there are two kinds of integration. They are _____ and _____.
6. Give two examples of social integration:
- (a) _____
(b) _____
7. Give two examples of physical integration:
- (a) _____
(b) _____

NOTE: A substantial portion of this Unit was drawn from:

- (a) Legal and Ethical Considerations for Persons with Disabilities of the M.C.R.I. Kellogg Curriculum
(b) New York State Office of Mental Retardation and Developmental Disabilities Training Curriculum
(c) Aging and Developmental Disabilities - A Training Inservice Package of Indiana University, Institute for the Study of Developmental Disabilities

UNIT II - Human and Legal Rights

Objectives

After completing this unit, direct support and other professionals will be able to:

- Explain the difference between constitutional and statutory rights.
- Provide a brief history of treatment of individuals with developmental disabilities.
- Describe the three basic principles underlying the United States Constitution.
- Describe the North Dakota lawsuit and its ramifications.
- Give examples of rules the agency and staff must follow in order to be in compliance with HIPAA

HUMAN RIGHTS

In 1948, the United Nations adopted a "Universal Declaration of Human Rights." One of the major goals of the United Nations is to see these human rights established for all persons in every country. Although it lacks authority, this universal declaration provides a model and a moral framework for the rights of all people.

Some principles underlying the Protection of Human Rights according to Wolfensberger (1978) is the presumption that all persons have full and equal rights; rights may only be restricted through law; laws may not discriminate except for legally relevant reasons; procedures for restricting rights must observe minimal fairness requirements; and laws, practices, and means should be available to promote the exercise of rights. In the United States, these principles are reflected in the Constitution.

LEGAL RIGHTS



Legal rights are rights which are established and enforced as law and they continue to evolve. Changes occur to expand rights to more and more people. Examples of these are the constitutional amendments which expanded the right to vote to African-Americans, women, etc. Amendments to the constitution also correct injustices as when the 13th Amendment abolished slavery. Laws also expand rights to correct injustices.

Types of Legal Rights

Legal rights are either *constitutional* or *statutory*. Constitutional rights are established through the Constitution of the United States and through the constitutions of the various states. Statutory rights are established legislatively, that is, state and federal branches of government pass laws and establish codes and administrative rules. Rights are delineated judicially through lawsuits filed by citizens or classes of citizens which are then "litigated" or resolved through the court system.

Even when rights are established and made into law, their effectiveness to remedy an injustice depends on enabling legislation, the development of administrative policies and procedures, the establishment of enforcement and implementation agencies, fiscal resources available, and the ability of people to assert themselves.

APPLICATION OF LEGAL RIGHTS

Historically individuals with developmental disabilities have been treated inhumanely. During the 1950s and through the 1960s conditions for individuals with disabilities were deplorable. Most persons who had physical or mental disabilities were institutionalized, generally without due process and often against their will. Many institutions were located in remote areas which led to physical and social segregation. Most institutions were overcrowded and understaffed. Only custodial care was provided. In many cases, individuals with disabilities experienced inhumane and abusive treatment.

Due to these inhumane conditions, as well as a lack of alternatives to institutional care, parents united to lead the formation of advocacy organizations (e.g. Association for Retarded Citizens) to promote change. One of the major goals of these advocacy organizations was to establish both human and legal rights for individuals with disabilities. Although the movement gained much momentum in the 1960s, it was not until the 1970s that most of the actual gains were made in the establishment of rights and in the development of alternatives to custodial care. Individuals with disabilities have the same human and legal rights as every other citizen. This seemingly self evident statement needs to be emphasized because of the long history of denial of rights to citizens with disabilities. These rights are based on three basic principles of the United States Constitution:

- a. Equal Protection
- b. Due Process
- c. Least Restrictive Alternative

Equal Protection

The 14th Amendment of the United States Constitution has been interpreted to mean that all citizens should be treated justly, fairly, and equally under the law. One cannot be excluded from legal justice, public services, or facilities because of race, religion, sex, national origin, age, or disability.



The concept of "equal protection" has been the basis for much of the civil rights, legislation, recent court decisions, and legislative actions concerning individuals with disabilities. This concept is independently protected by North Dakota state constitution (Sections 1, 21, and 22 of article I).

Due Process

The guarantee of the due process of law is a fundamental principle that is protected by the Bill of Rights and the 14th Amendment of the United States Constitution and by North Dakota State Constitution (sections 9 and 12 of article I).



Due process indicates that none of our rights may be withheld without proof that such action is necessary. Due process prevents anyone (agency or governmental body included) from arbitrarily infringing on individual rights. Due process means the following:

- Law is administered the same for all people,
- People must have the opportunity for a fair hearing before an impartial decision maker,
- The burden of proof is upon those who wish to limit another's rights as opposed to individuals already granted these rights by law,
- The law must be clear if it is being used to deprive someone of rights.

The right to due process is mandated in federal laws such as Public Law 94-142, and is included in many regulations governing programs for individuals with disabilities. If an individual's rights are restricted in any way, there must be due process which allows the person and a representative (parents, advocate, or others) to attend and take part. In community programs, this process begins at the team meetings. There must also be an appeal process if the person disagrees with the decision.

Individuals with disabilities have the same rights as any other citizen. These rights cannot be denied, restricted, or limited in any way without due process. Rights may be restricted if it is determined that without restriction, harm can be done to the person or to others. They can also be taken away because of criminal action, but they can never be restricted or denied without due process.

Least Restrictive Alternative

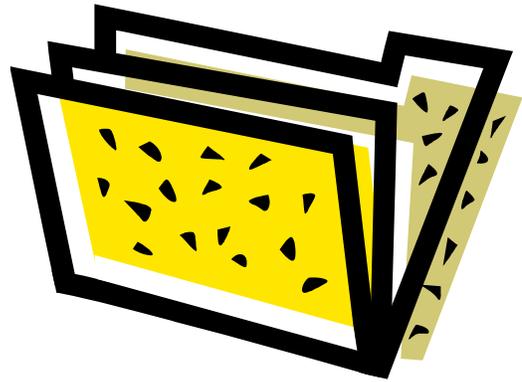
The least restrictive alternative principle guarantees that when rights are restricted, they will be restricted in the least intrusive manner possible. In addition, any restriction of an individual's rights is reviewed and approved through the IPP/IHP process, which includes consent of the individual or legally designated substitute.

It is the responsibility of state and local governments to guarantee constitutional protections and safeguard these rights through the development and implementation of policies and procedures. It is the responsibility of service provider agencies to provide for due process.

It is important to note that since the early 1970s, the concepts of due process, equal protection and least restrictive alternative, have provided the basis for arguments by advocates for more humane treatment and have been relied upon by the courts and the legislative bodies in making their decisions.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA)

Regulations issued under the HIPAA (1996) federal legislation protect the privacy of medical records and other personal health information for all Americans. The law enables people to find out how their personal information may be used, and about certain disclosures of their information that have been made. It generally limits release of information to the minimum necessary. It gives people the right to examine and obtain a copy of their own health records and request corrections. It empowers people to control certain uses and disclosures of their health. Sensitive information (i.e. HIV/AIDS information, and mental health records) may have additional regulations depending on the state.



Direct support and other professionals are legally responsible to protect health information of individuals with disabilities receiving supports. There are special rules for the ways in which the agency stores and shares this information. Each agency has a Privacy Officer to study regulations, guide the agency, and assess agency practices for protecting health information, both hard copies and information stored on computers or electronic files. Agencies were required to adopt HIPAA policies and procedures, train staff, and implement the procedures by April of 2003.

Compliance with HIPAA includes the following practices:

- Do not reveal any information to people outside of the agency. You may tell people that you work with people with disabilities, but don't talk about individuals even if you don't use their name.
- Know which records are appropriate for you to access.
- Do not talk within the agency to co-workers or any other employee about a person beyond what is needed to carry out job functions. Do not talk about people receiving services when everyone there does not need to know the information.
- Safeguard records. Do not use them where others can read them. When not in use, store them in the designated secure area.
- Never share your computer password with anyone. Close all applications that access private health information when stepping away from the computer.
- When sending a fax with private health information, make sure the person receiving it is at the other end to receive it.
- Follow agency policies and procedures for how to disclose personal health information.
- Follow your agency policies for reporting violations of the privacy rights of a person receiving services.
- If unsure whether or not information should be given out, speak to the agency's designated privacy officer.

AMERICANS WITH DISABILITIES ACT OF 1990s (ADA)

The Americans with Disabilities Act (ADA), was approved by the Congress after long and thorough deliberation and was signed by the President on July 26, 1990s. George Bush, upon the signing of the Americans with Disabilities Act, said: "Today, America welcomes into the main stream of life all people with disabilities. Let the shameful wall of exclusion finally come tumbling down." The ADA (P.L. 101-336) gives civil rights protection to individuals with disabilities in private sector employment, all public services, public accommodations, transportation, and telecommunications.

Since developmental disabilities service providers work with individuals who seek employment and independent life styles, it is important that service providers be able to apprise individuals with disabilities of their rights and protection under the ADA.

The ADA is patterned after Section 504 of the Rehabilitation Act of 1973. Under the ADA definition, a person with a disability is defined as: (1) a person with a physical or mental impairment that substantially limits that person in some major life activity (such as walking, talking, breathing, or working), (2) a person with a record of such a physical or mental impairment (such as a person with a history of mental illness or heart disease who no longer has the disease, but who is discriminated against because of their record of an impairment), or (3) a person who is regarded as having such an impairment (such as a person who has a significant burn on his/her face which does not limit him/her in any major life activity but who is discriminated against).



Employers with 15 or more employees may not refuse to hire or promote a person with a disability because of the person's disability when that person is qualified to perform the job. In addition, an employer must make reasonable accommodations for a person with a disability if that accommodation will allow the person to perform the essential functions of the job. Reasonable accommodation means that if there is some modification in a job's requirements or structure that an employer can do which will allow the employee with the disability to do the job, that modification must be made, provided that it would not impose an undue hardship on the employer.

The employment provisions of the ADA went into effect for employers with 25 or more employees on July 26, 1992. For employers with 15-24 employees, the effective date was July 26, 1994. Under the North Dakota Human Rights Act (N.D.C.C. ch. 14-02.4), first passed in 1983 and later amended, employment discrimination is prohibited by all North Dakota employers who have at least one employee for more than one quarter of the year. This North Dakota law also applies to all employment related activities that take place in North Dakota, by an out-of-state employer who has a least one employee whose services are to be performed at least partially in North Dakota.

ADA requires that new vehicles bought by public transit authorities be accessible to people with disabilities. No retrofit to current vehicles is required. Paratransit service for people with disabilities who cannot use the mainline system is required unless providing such service would

result in an undue financial burden. The ADA requires new buses ordered by private transit providers (such as Greyhound) after August 26, 1990 to be accessible. In regard to rail systems, ADA requires that one car per train in existing rail systems must be accessible. New rail stations must be made accessible.



Under ADA, it is illegal for public accommodations to exclude or refuse persons with disabilities. Public accommodations are the businesses and services that are used every day by all people such as hotels, restaurants, dry cleaners, grocery stores, schools, and parks. New buildings must be accessible to people with disabilities and existing facilities must remove barriers if the removal is "readily achievable" (i.e., easily accomplished without much difficulty or expense).

Public accommodations are required to provide auxiliary aids and services to enable a person with a disability to use and enjoy the goods and services available at a facility unless doing so would be too burdensome or disruptive to the business. Auxiliary aids and services refer to such things as large print materials, tape recordings, and captioning. Practicality and effectiveness can be considered in choosing among alternative aids. For example, a restaurant would not be required to provide menus in Braille if the waiters read the menu to a person who is visually impaired. Entities such as hotels that offer transportation generally must provide equivalent transportation service to individuals with disabilities. Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices 24 hours a day, 7 days a week, at regular rates.

State or local governments may not discriminate against qualified individuals with disabilities. Since this includes public schools, public school personnel with disabilities have protection against discrimination. ADA further states that all government facilities, services, and communications must be accessible consistent with the requirements of Section 504 of the Rehabilitation Act.

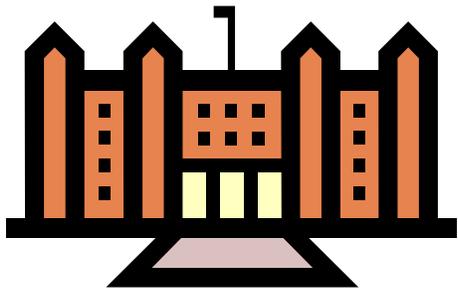
ADA assigns responsibility for regulation writing and other implementing activities to selected federal agencies. These include: (1) the Equal Employment Opportunity Commission for employment; (2) Department of Justice for state and local government operations and public accommodations; (3) Department of Transportation for transportation; (4) Architectural and Transportation Barriers Compliance Board for public accommodations and new vehicle standards; and (5) Federal Communications Commission (FCC) for telecommunication systems.

Other areas covered by the ADA include remedies (which actions are available if an entity fails to meet the requirements), coverage of people with AIDS, and coverage of drug and alcohol users (people who are current users of illegal drugs will not be considered disabled under ADA).



The North Dakota Lawsuit: ARC/ND v. Governor of N.D. et al. (Civil No. A1-80s-141). Based on the above rights, particularly the Fourteenth Amendment dealing with equal protection, two significant events took place in North Dakota beginning in the decade of the 80s which provided the impetus for the development of services as they exist today. In 1980, a lawsuit was filed in the U.S. Federal District Court enumerating inadequacies in services to the state's citizens institutionalized at the Grafton State School and San Haven Subdivision. In 1981, the 47th legislative assembly passed a comprehensive program setting a mission of deinstitutionalization and the corresponding development of community services.

This lawsuit was filed by the Association for Retarded Citizens of North Dakota and the parents of six Grafton/San Haven residents alleging that the constitutionally protected rights of persons residing at Grafton State School and its San Haven subdivision had been violated. The trial on this case did not take place until 1982 and the results were appealed by the defendants (State of ND). The United States Court of Appeals for the Eighth Circuit upheld the District Court. In March 1984, the United States District Court issued permanent injunction against the defendants, their successors, officers, agents, servants, employees, and all persons in active consort with



them, from failing to fully implement and dispatch each of the requirements ordered. The order reaffirmed the definition of the "members of the plaintiff's class" as persons who, as of September 26, 1980, and at any time subsequent, have been or may become residents of Grafton State School located near Grafton, North Dakota, and San Haven, located near Dunseith, North Dakota.

Subsequent to the March 7, 1984, the order of July 11, 1984 affirmed the responsibilities and operation of the Protection and Advocacy Project. Another order to note is the September 19, 1985 order of the Court which among other things **mandated certain staff competencies, staff training, staff recruitment, psychological/psychiatric services**, availability of supported living arrangements, availability of respite care, and availability of placements into long term care facilities. The Court issued an additional order on April 7, 1986 further delineating **requirements for staff training, and internal case management**. On February 6, 1987, the Court issued an order limiting the inclusion of mentally ill individuals into the plaintiff class. Later orders addressed the issues of class member residency and long term care facilities and subsequent responsibilities of the defendants to those class members.

The implication and impacts of the ARC lawsuit on the lives of individuals with developmental disabilities in the State of North Dakota has to this time been tremendous; a **wide scope of the client and resident rights were assured** to class members by the orders, primary of which is the right to treatment and habilitation as contained in paragraph 45 of the March 7, 1984 order. The orders included such wide-ranging issues as rights, the **least restrictive alternative**, normalization, **individualized planning, the team process for plan development, prohibition of abuse**, freedom from harm, seclusion, physical restraints, medication, right to education, right to programming, and medical/therapeutic



services. Also, the reaffirmation of rights contained in state law of religious worship, mail, telephone, and visitation rights, clothing, personal property, right to vote, and confidentiality of personal records were contained under the order.

The results of this lawsuit have had a **profound impact on the availability of services to individuals with developmental disabilities across the state of North Dakota**. The requirements contained in the orders of the Federal District Court towards the reduction in population of the Grafton State School and San Haven Subdivision required that **community services across the State of North Dakota be developed to not only house those individuals who had been or were residents of the Grafton State School but also make available those residential and day service programs in the community for individuals living in their own homes or with relatives**. The defendants responded through the initiation of contracts with local private nonprofit corporations to commence operation of residential facilities and day service facilities to serve members of their community and those that would be returning from the institution. The state developed a methodology for financing construction of these facilities at a very accelerated rate. The Bank of North Dakota was used as an administrative management entity to assist in this development. Construction of these facilities commenced in earnest in 1983 and was generally completed by 1987.

The necessary fiscal resources have increased by biennial levels in the early 1980s of only a few million dollars to current levels of available spending reaching into the realm of approximately \$122.8 million (July, 1997). The Grafton State School/San Haven complex at the beginning of the suit contained a population of residents of approximately 1,050. **By March of 1997, the population at the State Developmental Center had dropped to only 150 residents.**

The March 7, 1984 Implementation Order placed a permanent injunction against the defendants which required them to maintain an improved level of services to class members. This permanent injunction was to ensure that services available to individuals with mental retardation/developmental disabilities within the State of North Dakota would be forever improved and maintained as those capabilities were developed. Individuals working within the service delivery systems for individuals with developmental disabilities would be required to maintain high levels of awareness of and respect for the rights of the individuals they were to serve. They were required to consistently honor and protect those rights forever.

On January 11, 1995, the United States District Court, District of North Dakota, Southwestern Division by order signed by the Honorable Bruce M. Van Sickle, Judge terminated and dismissed the permanent injunction in this case, its purpose having been realized. The lifting of this injunction followed a review by a panel of masters appointed by the court to hear the evidence and make recommendations to the court. The panel of masters heard testimony from forty-four witnesses and reviewed exhibits presented by the plaintiffs and defendants over a twenty-nine trial day period. This process concluded in December 1993. The masters presented their report on November 14, 1994 to the District Court which culminated in the Judge's order of January 11, 1995.



The lifting of the permanent injunction recognized the systemic changes the State had made in the services design, implementation, funding, and delivery on an individualized need basis to individuals of the plaintiff class. Further, the court recognized that rights and the process assuring those rights were contained within State law and implementing regulations. Also, the Court recognized that "The evidence received by the masters vividly demonstrated the introduction of new and developing concepts in this area of social concern and service."

The implications of the lifting of the permanent injunction in Civil No. A1-080-141 are yet to be realized in their entirety by the citizens of North Dakota. The permanent injunction was prescriptive in its requirements on the State in order to insure protection as well as the development of rights and programs to benefit those members of the plaintiff class. By lifting the permanent injunction the court recognized that the laws of North Dakota, along with policies and procedures of the system offered protection of rights and methods for their enforcement to former members of the plaintiff class.

Major Implications of the North Dakota Lawsuit

A wide range of rights and services were assured:

- The right to treatment and habilitation in the least restrictive most normalized environment
- Individualized team planning
- Prohibition of abuse, neglect and exploitation
- Right to education and medical therapeutic services
- Training of direct support and other professionals
- Case management.
- Development of community services across North Dakota
- The population at the State Developmental Center dropped to only 150 residents by 1997

Feedback Exercise II

1. Legal rights are either _____ or _____.
2. Constitutional rights are established by the _____.
3. Statutory rights are established by _____.
4. What was the major goal of the Association for Retarded Citizens when it was formed?
5. List and define three of the basic principles of the United States Constitution which relate to rights of citizens with disabilities.
 - (a)
 - (b)
 - (c)
6. What were the implications and impacts of the ARC lawsuit on the lives of individuals with developmental disabilities in the state of North Dakota?
7. What is the Americans with Disabilities Act?
8. What are the employment provisions under ADA?
9. What does ADA require concerning public accommodations?
10. What are the provisions of ADA regarding telecommunications?
11. What does ADA require concerning state and local government operations?
12. HIPAA covers medical records:
 - a. stored on computers
 - b. stored in file cabinets
 - c. included in program books
 - d. all of the above
13. Compliance with HIPAA requires that direct support and other professionals:
 - a. Do not reveal any information to people outside of the agency.
 - b. Know which records are appropriate for them to access.
 - c. Do not talk within the agency to co-workers or any other employee about a person beyond what is needed to carry out job functions.
 - d. Make sure the person receiving a fax with private health information is at the other end to receive it.
 - e. Follow agency policies and procedures for how to disclose personal health information.
 - f. All of the above.

UNIT III - Rights of Individuals with Disabilities

Objectives

After completing this unit, direct support and other professionals will be able to:

- Define habilitation treatment in the least restrictive environment.
- Describe and provide examples of the right to be treated with dignity and respect.
- Explain and provide examples of the right to make informed choices and to control person and property.
- Define and provide examples of the right to due process.
- List and explain rights mandated by Title XIX and The Council on Quality and Leadership in Supports for People with Disabilities and their implications on services for people with developmental disabilities.
- Identify situations where rights of individuals have been violated and examples of how staff could support

INTRODUCTION

There are numerous declarations of rights - The Council on Quality and Leadership in Supports for People with Disabilities (The Council), Title XIX, the North Dakota Bill of Rights, the United Nations Bill of Rights for the Disabled, and agency policies and procedure manuals. These numerous rights can be divided into four categories:

- A. The right to appropriate habilitative and other services provided in the least restrictive, most integrative environment.
- B. The right to be treated with dignity and respect under all circumstances.
- C. The right to make informed choices and to control person and property.
- D. The right to due process, including the protection of all human rights.



A. The Right to Appropriate Habilitative Treatment in the Least Restrictive Environment

The right to habilitation in least restrictive environment includes, but is not limited to:

- Receiving active treatment (habilitation),
- Freedom from cruel or unusual punishment,
- Freedom from servitude, and
- Right to generic services.

Habilitation is defined as the procedures and interventions designed to help an individual with developmental disabilities achieve greater mental, physical, and social development. The habilitation process enhances the well-being of the individual, teaches skills, and increases the possibility that they will make progressively independent and responsible decisions about social behavior, quality of life, job satisfaction, and personal relationships.

For most individuals with developmental disabilities, the habilitation process will address education, training, employment, physical development and health, mental health, counseling and guidance, and family support. The training is intended to help individuals acquire, improve, or generalize a particular skill. To be most effective, all components of the habilitation process must be consistently applied in all settings in which the individual spends time (transdisciplinary approach).



Habilitation has been defined by the courts as a process by which the direct support and other professionals assist individuals in acquiring and maintaining those life skills that enable them to cope more effectively with the demands of their own person and environment and to raise the level of their physical, mental, and social efficiency. This includes, but is not limited to, formal education and training. Active treatment is a crucial component of the habilitation process. Habilitation is an active treatment.

The right to treatment means that people with developmental disabilities have the right to receive all services (medical, physical, dental, occupational therapy, physical therapy, speech and language, psychological, and nutritional) that the individual program team identifies as needed to help them reach their fullest potential.

Not only do they have the right to those services, but they have the right to those services in the *least restrictive, most integrative* manner possible. This means that, as much as possible, they will use generic (community) services, i.e., they will go to doctors, dentists, etc., in the mainstream of the community.



Least restrictive alternative for treatment includes the right to be free of corporal punishment or unusual punishment and cruel treatment. This concept applies not only to the use of behavior management techniques, but to the use of medication designed to control behavior. Proactive means must be used to reduce inappropriate behavior and to teach appropriate behaviors.

Any treatment restricting their freedoms must be carefully reviewed and must be seen as the only viable option to deal with the situation. The benefits of any proposed rights restriction must clearly outweigh the costs of free choice. For example, we do not put people in a nursing home environment if their medical needs can be met in their own apartment or in a group home.

B. The Right To Be Treated With Dignity and Respect

The right to be treated with dignity and respect includes, but is not limited to:

- Confidentiality of information,
- Respect for privacy,
- Freedom from cruel and unusual punishment, and
- Protection of basic human dignity.



Policy and procedures regarding confidentiality are based on legal requirements and "need to know." One must exercise care over how and when information is shared, i.e., care must be taken that information is not overheard by someone not authorized to have that information. In addition, information should always be shared in a professional manner.

Remember that even when the individual's name is not used, other people may identify the person being discussed. The rule of thumb is to simply not talk about events that happen within the agency, outside of the agency, or with other employees who do not have a need to know. This protects not only the individual but also the facility from liability for acting without prior consent.

To share information outside the agency, it is necessary to obtain a signed release of information. If you have doubts about information being shared outside the agency, contact your supervisor/QMRP. Even what appears to be an innocent, mundane question by someone could be a breach of confidentiality. Answering a question such as "Did so-and-so attend the day program today?" can be a violation of the person's confidentiality when that information is shared with someone outside the agency or even within the agency if they do not have a need to know that information.

Remember never:

- Provide information concerning an individual program to anyone outside the agency without the individual or the guardian consenting.
- Discuss an individual in a public place.
- Discuss individuals with other direct support professionals inside the agency unless the information exchange is part of their "professional role and duties."

All individuals have the right to be treated with dignity and respect and not to be put down by our words or actions. While we would not intentionally do this, it may happen when we attempt to assist individuals or when we become frustrated.



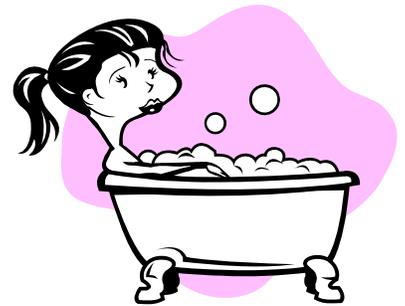
DO

Speak in even tones
Use positive terms
Discuss personal issues in private
Treat with respect
Make eye contact
Call by given name
Be caring

DON'T

Speak in loud, harsh tones
Use negative terms
Use threats/coercion
Avoid eye contact
Be impersonal

Respect for privacy is an important part of the right to be treated with dignity and respect. It includes respecting the privacy of an individual's personal space; that is, not entering a person's room without permission (or due cause). It also includes respect for their body and personal privacy when helping them with self-care skills; that is, be sure that other people are not present when the person is engaged in an activity requiring disrobing or partially disrobing. Do not require them to disrobe any more than necessary when carrying out an activity. Overall, help individuals meet personal needs in the most dignified way possible. The best way to sum up this right is to remember the Golden Rule: "Do unto others as you would have them do unto you."



C. The Right To Make Informed Choices and Control Person and Property

The right to make informed choices and control person and property includes:

- Informed consent
- Manage money/property
- Freedom of religion
- Freedom of free association

The issue of informed choices makes this right less straightforward than the two discussed earlier. *Consent* implies three elements:

- a. Capacity - the ability to express one's choices. This may be affected by the individual's age, situation, or general level of competence. However, an individual is not assumed to lack capacity simply because he/she has a cognitive disability or developmental disabilities. The judgment about ability is based on the individual's previous behavior and the current situation at hand.
- b. Information - The individual must have adequate information about the proposed choices. This includes, but is not limited to, descriptions of the choice, alternatives, risk of the choice, and benefits of the choice.
- c. Voluntariness - The individual is able to act in the absence of overbearingness, coercion, duress, threats, inducements, or undue influence by others.

Informed consent is needed for:

- Participation in any services.
- Use of medication.
- Use of behavior modification procedures.
- Use of medical treatment procedures.
- Participation in experimentation or research.
- Admission to a hospital/treatment center.
- Participation in any activity posing unusual risk.
- Release of information.
- Contracts.



The ability to give consent or the need for informed consent may need to be more closely scrutinized as any of the three following dimensions of a situation change:

- Risks - How dangerous is the situation or procedure?
- Irreversibility - Can the impact of the choice be reversed?
- Intrusiveness - To what degree does the procedure invade the physical, mental, or social integrity of the individual?

It is usually assumed that a person is competent to provide consent unless it has been established by a court of law that he/she is incompetent. Some questions to help the court determine an individual's ability to give consent are:

- Has the individual made a wide variety of choices in the past?
- Does the individual make rational decisions?
- Can the individual describe in his/her own way the choices?
- Is there anyone who stands to benefit from the individual's choice?

The courts have decided that some individuals with developmental disabilities are unable to make informed decisions and, hence, guardians have been appointed. In these cases, guardians have the legal authority to make certain decisions on behalf of their wards. However, state law mandates that wards be included in decisions affecting them as much as possible. There are many day-to-day decisions that can be made by individuals with severe disabilities. These choices can include, which clothes to wear, where to sit, what activities to participate in, etc. People with disabilities have the right to own and use personal property. This includes not only clothing, but other items purchased with personal funds, such as toiletries, magazines, furniture, television, radios, etc.



Individuals have the right to manage personal funds unless this has been contradicted by the IPP/IHP team, which includes the individual. An individual should retain as much control over expendable income (the money remaining once expenses such as room and board have been met)

as possible. Individuals do not need to prove their ability to manage money. Instead there must be evidence they are not able to manage money.

People have the right to freedom of religion. This means not only the right to attend the church of their choice, but the right to not attend any church or religious activities.

Individuals have the right to free association with people of their choice. This includes members of the opposite sex. The right to associate with other people includes the right to receive and send mail unopened, the right to use the phone in private, the right to have guests, and the right to participate or not participate in social, religious, and community activities.



We must strive to maintain a careful balance between not violating individuals' rights and assessing their abilities to make informed choices. The person-centered planning team is a mechanism by which these decisions are made.

D. The Right to Due Process

Due process is one way to protect the individual's rights. Due process means the guaranteed opportunity to protest, to be heard, to be informed, to give consent, to have a determination made by an impartial party. Due process may include the individual's program plans, behavior management committees, human rights committees, and, when required, the court system.

The individual and the parent/guardian advocate, as appropriate, are part of the IPP/IHP team who decide the individual's ability to exercise his/her rights and the restrictions that must be placed on the individual's rights. In addition, an individual or parent/guardian who disagrees with any team decision has the right to file an appeal.

TITLE XIX, THE COUNCIL, AND INDIVIDUAL RIGHTS

Although the specific rights mandated by Title XIX and The Council on Quality and Leadership (CQL) are discussed under the broader rights in the previous section, it is important to review them one-by-one to be sure that we understand them and their full implications.

Title XIX

Title XIX asserts that the facility "must ensure the rights of all clients." Therefore, the facility must:

- a. Inform each person receiving services, parent (if the person is a minor), or legal guardian of the individual's rights and the rules of the facility.
- b. Inform each person receiving services, parent (if the person is a minor), or legal guardian of

the individual's medical condition, developmental and behavioral status, attendant risks of treatment, and the right to refuse treatment. "Ensure" means that the facility actively asserts individual's rights and does not wait for individuals to claim a right. In addition, the informing must be done in a manner that is understandable to the individual and/or guardian; and, if an individual initially refuses or later withdraws consent to treatment, alternatives must be offered and the consequence of the refusal or withdrawal must be explained.

- c. The agency must allow and encourage individuals to exercise their rights as clients of the facility and as citizens of the United States, including the right to file complaints and the right to due process. This means that an individual must be protected from reprisal or intimidation if they file a complaint. In order to exercise this right, Title XIX indicates that advocates must be available, and advocates must have access to needed records.

Each person must participate in the development of his/her program to the fullest extent possible, and mechanisms (self, guardian, advocate, direct support professionals, DD Case Manager, training program, etc.) must be in place to see that no rights are abridged and the individual exercises as many of his/her basic rights as possible.

- d. Allow individuals to manage their financial affairs and teach them to do so to the extent of their capabilities.

Individuals should be involved in the decision of what to buy with their money. They must be taught to handle "pocket" money.

- e. Ensure that people with disabilities are not subjected to physical, verbal, sexual, or psychological abuse or punishment (including threats and abuse).

"Threat" implies anything which might result in mental or physical harm to the individual. "Abuse" is the ill treatment of a person, violation of their rights or exploitation. Abuse is not necessarily purposeful. It can be due to carelessness, inattentiveness, or omission of the perpetrator. Failure to carry out program plans or active treatment may be considered abuse and neglect. (See section on abuse/neglect).



- f. Ensure that individuals receiving services are free of unnecessary drugs and physical restraints and are provided active treatment to reduce dependency on drugs and physical restraints.

This relates to the right of least restrictive treatment; that we are not to use unnecessary, undue, aversive means to control a person's behavior.

- g. Provide each person with the opportunity for personal privacy and ensure privacy during treatment and care of personal needs.

This relates to the issue of treating people with disabilities with dignity and respect.

- h. Ensure that individuals receiving services are not compelled to perform services for the facility and ensure that individuals who do work for the facility are compensated for their effort at prevailing wages and commensurate with their abilities.



- i. Ensure that individuals receiving services have the opportunity to communicate, associate, and meet privately with individuals of their choice and to send and receive unopened mail.
- j. Ensure that individuals have access to telephones with privacy for incoming and outgoing local and long distance calls, except as contraindicated by factors identified within their individual program plans.
- k. Ensure people with disabilities the opportunity to participate in social, religious, and other group activities.
- l. Ensure that individuals receiving services have the right to retain and use appropriate personal possessions and clothing.
- m. Permit husband and wife, who both reside in the facility, to share a room.

The rights listed above deal with the issues of freedom and choice, dignity and respect, as indicated in the four basic rights discussed earlier in this section.

Council on Quality and Leadership

Quality Measures 2005 by the Council on Quality and Leadership (CQL) stress both the rights and responsibilities that apply to all citizens. Provider organizations have a responsibility to assist people to both exercise their own rights and be responsible for the outcome of their actions on others. The following is a partial list of the CQL “Factors” (main topic areas) that relate to basic constitutional rights, federal and state statutes, and court decisions which protect all people.

In CQL’s *Shared Values Around People* section, factors related to rights include:

Dignity and Worth: All people deserve dignity and respect. No person is treated with any less dignity and respect because of a difference in social or economic status, physical or mental capability, race, ethnicity, religious belief, or sexual orientation

Legal and Human Rights: Legal and human rights may not be limited without the due process of law. These rights apply to all people regardless of economic, social or civic status within organizations or communities.

Self-Determination and Choice: People exercise self-determination and choice. People have the autonomy to make decisions that affect their own life situations and those of other people important to them in the community. Communities provide people with the legal, economic, and social resources to develop self-determination skills.

In the *Basic Assurances* section, factors related to rights include:

Rights Protection and Promotion: People exercise their human and civil rights. They retain these human and civil rights despite the presence of intellectual disability or mental illness. Parents, families, service providers, and state or federal governments cannot limit these rights without engaging in legal, due process proceedings. In addition, individual rights are not limited or curtailed to promote outcomes for a larger number of people.

Dignity and Respect: Supports are provided that increase dignity and respect, meaningfully compensate employment, individualized leisure and social opportunities, access to social networks, and educational opportunities that lead to growth and development.

Protection from Abuse, Neglect, Mistreatment, and Exploitation: People are not subjected to abuse, neglect, mistreatment, and/or exploitation of any kind.

Best Possible Health: People are supported to meet their health care needs and have timely access to qualified health care providers.

Safe Environments: The organization and physical environment promote health, safety and independence.

Positive Services and Supports: People are free from unnecessary, intrusive interventions.



In the *Personal Outcome Measures* section, factors related to rights include:

My Self: Safety, health, freedom from abuse and neglect, and legal rights and fairness are foundation outcomes that allow for future development.

My World: People choose where and with whom they live and where they work. They choose where and with whom they spend time. They have access to all that the community has to offer.

HOW TO EXERCISE THESE RIGHTS

Knowing about rights is of no value unless we take active measures to protect the rights and to help individuals exercise those rights. To that end, a few of the rights discussed in this section will be reviewed and suggestions will be offered on how direct support professionals can help people exercise these rights.



The Right To Own Property

Guarantee

1. Do people know they have money to spend?
2. Do they have access to stores and the means to buy things?
3. Are they provided a safe place for storage of their personal property?
4. Are items clearly maintained as an individual's personal property, not communal property?
5. Are they allowed to spend based on their desired budget and needs?

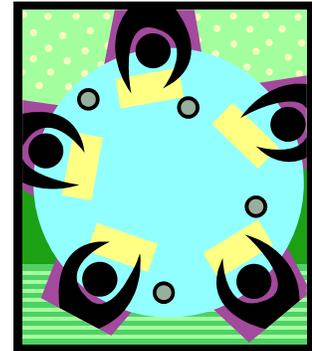
Exercise

1. Are individuals taught to care for personal items?
2. Are they taught budgeting and money management skills?
3. Are they taught about ownership?
4. Are they taught the skills needed to make purchases of items on their own?
5. Are they taught the value of things to protect them from exploitation?

The Right To Be Free From Cruel and Unusual Punishment

Guarantee

1. Does the agency have a human rights & behavior intervention committee?
2. Are all behavior intervention plans the least intrusive? Do they maintain respect for the dignity of the individual?
3. Is there a grievance procedure?
4. Is the emphasis on positive behavior supports?
5. Is respect and kindness modeled by direct support professionals in every interaction with others?
6. Are programs developed by the team and reviewed through proper channels?
7. Does the agency have a clear policy that corporal punishment is not allowed?
8. Do the behavior support plans align with the function of the challenging behavior?



Exercise

1. There is a proactive attempt to teach and reinforce alternative skills.
2. There is a proactive attempt to teach coping skills.
3. Individuals are taught their rights.

The Right of Freedom of Religion

Guarantee



1. People are supported to participate in religious organizations of their choice.
2. All direct support professionals are provided with knowledge of the religious preferences of each resident.
3. An environment that respects religious preferences of each person, to include atheism or being without religion, is provided.

Exercise

1. People are taught the social skills needed to attend church, interact with people at church and Bible class, et cetera.
2. People are helped to obtain the desired religious training.
3. Provide active support for participation and nonparticipation in religious activity.

Right To Privacy and Treatment With Respect

Guarantee

1. Doors are closed for personal care.
2. Records are kept in safe, confidential files.
3. Contact with others is private.
4. Confidentiality is respected at all times.
5. People are treated with dignity and respect at all times.
6. People are allowed time alone.
7. Locks, curtains, and doors are provided at all times to protect a person's privacy.

Exercise

1. Teach person assertiveness when privacy is wanted both from direct support professionals and from others.
2. Teach persons to respect the privacy of others.
3. Teach the person private vs. public behavior.

Feedback Exercise III

PART A:

1. List and describe the three elements of informed consent:
 - a.
 - b.
 - c.

2. List three instances that would require informed consent:
 - a.
 - b.
 - c.

PART B: Please read each of the following statements and identify the legal principle(s) involved in each situation.

- Place a number "1" on the line if you think the principle represented is "due process."
- Place a number "2" on the line if you think the principle involved is "least restrictive alternative."
- Place a "3" on the line if you think the principle of "equal protection," is represented.

- ___ 1. A state passes a law which provides free food to poor people. People with disabilities are excluded from receiving the free food.

- ___ 2. Mr. Shelton receives a ticket for not coming to a complete stop at a stop sign. He decides to go to court instead of paying the \$25 fine through the mail. The judge sends him to the state prison for two years.

- ___ 3. Ms. Jones, who attended special education courses during high school, is arrested for loitering. Based on reports from her former school, the judge finds her incompetent to stand trial and sends her to the state institution "until such time as she is competent."

- ___ 4. A county holds five public hearings before finalizing a new tax rate.

- ___ 5. A city passes an ordinance that says people with developmental disabilities should not use the public transportation system during peak (or "rush hour") periods, as it will cause unreasonable delays for other people using the system.

- ___ 6. The school board passes a policy that all students with mental retardation will participate in special education classes in the resource room.

PART C: In the following exercise, check whether you think a right has been violated or not violated in each situation. In each case, the individual is a person with developmental disabilities over the age of 18.

YES NO

- ___ ___ 1. Miguel joined a Sunday afternoon film club which is two blocks from where he lives. His staff refuses to allow Miguel to attend the film club because it is Miguel's day to do laundry .
- ___ ___ 2. Mel practices his drums late at night. Next door, Jake can't sleep. Mel is asked play drums before 10 pm.
- ___ ___ 3. Harry receives sixty dollars to spend each month. Because his behavior has been less than positive, staff said that he can't spend any money on video games this month. When his behavior improves, he will be able to rent or buy a new game.
- ___ ___ 4. Sally and Teresa, a direct support professional, are having a picnic in the park. One of Teresa's neighbors in her apartment building stops to visit and asks Teresa questions about Sally's family. The direct support professional politely tells her neighbor that she cannot share personal information.
- ___ ___ 5. A direct support professional answers the phone. The caller identifies himself as a caseworker with the County and asks for financial information on Tom. The direct support professional answers all of the questions he is asked.
- ___ ___ 6. Joe wants to masturbate. The direct support professional asks him to go to his room where it is private.
- ___ ___ 7. After dating for a number of years, Lisa and Jerry have decided to apply for a marriage license. They present the appropriate documents at the town clerk's office. They are denied the license because Jerry has Downs Syndrome.
- ___ ___ 8. Millie asks for birth control. She is assisted to visit her doctor and ask for contraceptives.
- ___ ___ 9. While Sue is helping June take a bath, Joe, another staff person, comes in and asks Sue to explain the new medications for another individual. As they talk, June starts grumbling, but Sue and Joe ignore her. Sue helps June out of the tub and assists her to get dressed.
- ___ ___ 10. It was a hectic evening. Sue experienced a seizure, Joe burnt his toast and set off the smoke alarm, and Sally called in sick. Later, the direct support professional decided not to do June's scheduled physical therapy exercises because there had been enough confusion for one night and staff were worn out. Instead she put in a DVD and everyone relaxed in the living room for the rest of the evening.

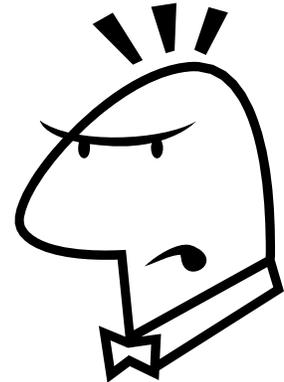
UNIT IV - Individual Justice Planning

Objectives

After completing this unit direct support and other professionals will be able to:

- **Identify what an Individualized Justice Plan (IJP) is and who the IJP is intended to help.**
- **List two purposes of an IJP.**
- **Describe the composition of the IJP team.**
- **Describe the assessment process conducted prior to developing an IJP.**
- **List and explain how recommendations could be made as part of an IJP and how this could be used with the service delivery system.**
- **Describe the procedural steps to be followed when an individual with developmental disabilities is being questioned by police for an alleged offense.**

Individuals with significant mental/cognitive disabilities have skill deficits, often in social, communication, and adaptive behavior. Because of these skill deficits, the person may behave in ways that are considered maladaptive or unacceptable by the rest of the community. An individual may steal from others, may be physically aggressive towards others, or may be destructive to property. These types of behaviors may be tolerated in service settings while the team develops and implements a positive behavior support plan. Getting hit or having a chair damaged in service settings is not generally considered legal or criminal issue, but rather a support issue.



As individuals move into community settings, or from group homes into apartments, the boundaries become less clear. For example, an individual stealing from a neighbor in his/her apartment building will probably be less tolerated than that individual stealing from staff or a roommate. So, the same maladaptive behavior may emerge as a legal/criminal issue.

Background

Previously in North Dakota, offenders with developmental disabilities were committed to the State Developmental Center in Grafton or the State Hospital in Jamestown, generally for an indefinite period of time. Unlike the individual sentenced to a prison who would serve a defined period of time, the offender with developmental disabilities usually served a longer sentence.

In other states, many such individuals have been treated unfairly in the criminal justice system. Major inequities include:

- receiving longer sentences,
- being more vulnerable and at more risk for victimization,

- receiving less habilitation,
- receiving fewer probation determinations, and
- having longer periods of incarceration.

They tend to be subject to abuse and are taken advantage of sexually and financially by other inmates. Not only are they scapegoats and subject to ridicule, they also learn criminal behavior.

Who is the IJP process intended to help?

The IJP process is intended to help people whose disability interferes with the full expression of their rights by the consideration of alternatives not offered through routine legal processes. In this manner, the Criminal Justice System (CJS) will be aided in its due process duties for the individual and in protecting the public.

A person's disability may or may not impair that person's ability to interact with the CJS. The IJP process is designed to assist people for whom the disability limits their ability to adequately interact with the CJS. An IJP is not appropriate for all individuals or situations and may not be agreed upon by all parties in the CJS process.

Purpose:

The purpose of the IJP process is two-fold.

- It presents alternatives for the CJS to consider, as well as the resources, contacts, and tools needed to follow through with the process.
- It provides a framework for education of and cooperation between private/public human service agencies and the various facets of the CJS. It is through this framework the two systems can provide the most appropriate services for people with disabilities with the best outcomes for everyone.



Scope of the IJP process:

This IJP process and materials are an attempt to integrate issues from both human services and the CJS and is designed to be a tool that can be used by people involved in these systems. This process is not intended as a safe-harbor from all consequences or as a shortcut to negate civil rights. Not everyone with a disability who encounters the CJS needs support beyond that of their attorney and other natural networks (family, friends, etc.). Therefore, an Individualized Justice Plan (IJP) is only effective when a concerned, caring, and respectful exchange of information results in the mutual advantage of both society and the individual. The safety of the public is a priority in development of IJP services.

In order for this process to be effective, all people involved must share a common understanding and philosophy of how the process can be used and what can be accomplished with the use of an IJP. The IJP process is voluntary, provides a framework for services, and does not carry any legal authority to mandate or require services. For more information on person-centered planning

processes, see the *Team Planning* training module in the North Dakota Community Staff Training Program curriculum.

Eligibility for an IJP

Eligibility for an IJP is based on significant mental/cognitive impairment. This determination must be made by a qualified mental health professional¹/human service professional and/or may also include a service delivery or treatment team. This impairment can be: (1) a developmental disability; (2) an identified brain injury that has resulted in severe cognitive impairment; (3) major mental illness and significant impairment². Eligibility for IJP should not be construed as excluding individuals with disabilities for assistance from the various identified community services.

Many people with disabilities do not view themselves as incapable, different, or “limited” which can result in the disability going unnoticed. Most people with disabilities assume themselves to be capable and have developed many coping skills to “mask” any limitations, hiding their challenges from those around them. Police officers, attorneys, judges, and correctional staff may have difficulty recognizing subtle disabilities given the number of people they encounter in the system. This may be compounded by co-occurring disabilities such as drug and alcohol abuse or dual diagnoses (developmental disability and coexisting mental health issues).

The individual may not view the process as beneficial or worthwhile, and may be reluctant to participate. This needs to include discussion with the individual about consent for the development and use of an IJP. Therefore, it may require someone within the individual’s support network (e.g., team, physician, provider, advocate, family, defense attorney) to initiate, develop, and/or implement the IJP. These same people may be those that comprise the IJP team.

The following are case examples of individuals with a disability who have become involved with the CJS. Example IJPs for these cases are included in Appendix 5 of the IJP Manual.

Case example 1:

Joe is an 18 year old male with a diagnosis of mild mental retardation and depression. He recently graduated from high school with a modified diploma and is trying to find a job. He lives by himself in an apartment in the community. Joe began dating and is very happy because this is his first girlfriend. They decide that they are going to have an intimate (sexual) relationship. Late in the summer, police arrive on Joe’s doorstep and take him to the police station for questioning. Joe tells the police officer that he has been dating this girl for the summer and that they had intimate relations. As a result, Joe is now being charged with committing a sexual offense because of the girl’s age. Joe has no idea what he did wrong; he does not understand that this was a criminal



¹ Source: NDCC Chapter 25-03.1-02,10a-f

² Any Axis I diagnosis with severe function limitation to include at least two major life areas: self-care, financial, social, occupational, mental/cognitive and legal-at least one of which requires cognitive/mental impairment.

act. Joe's IJP identifies increased compliance with the need for supervision in the community, and treatment and counseling recommendations to assist Joe to prevent further offending behaviors.

Case example 2:

Jim is a 38 year old male who has moderate mental retardation and a diagnosed impulse control disorder. He has struggled with community placements for many years because of physical aggression related to his diagnosis of impulse control disorder. When in community placements, he has had behavioral programming that has focused on maintaining an environment where he maintains control. This has at times been paired with medications to assist with his anxiety and impulse difficulties, however, he has experienced side effects from medications and changes in medications have taken place. During these periods of instability, he has "struck" the direct support professionals members whom work with him, typically when they have made requests of him that he perceives as frustrating. Jim's IJP identifies strategies and options for the provider to implement in an effort to prevent the behaviors from occurring.

How an IJP can be used within the CJS

A system's response to identify and advocate for an individual eligible for an IJP should be at the earliest point of contact by any agency working with the individual. This would require a clear understanding that the individual's disability, as defined in Chapter 2 of the IJP manual, is related to their potential involvement with the CJS.



If an individual with a disability is at risk of becoming involved in the CJS, their support network should be encouraged to consider the development of an IJP to outline responses to prevent involvement in the CJS. An IJP may also provide recommendations for a treatment plan when there is further involvement in the CJS.

The intent of an IJP is to identify the training, services, and support necessary to prevent criminal behavior from re-occurring. The IJP will reference other treatment or service plans that provide detailed information to effectively provide care. Examples of these plans can include: individual treatment plan, crisis plan, behavior support plan, medication management plan, aftercare plan and similar service delivery documents.

Writing the IJP

Prior to developing an IJP there is a period of assessment that is needed in order to understand what behaviors are currently taking place within the persons life and why they are occurring. The social implications of the behavior should also be assessed in terms of the impact on the individual, other people, society and property. The potential impact on the individual may include loss of housing/housing assistance, other entitlement programs, services, prison, jail, parole/probation, fines, hospitalization/treatment, or other residential programs.

The motivation or cause for the presenting problem needs to be thoroughly evaluated. The assessment phase outlines domains that should be considered. Within each domain, some questions to consider are:

- whether the domain is contributing to the presenting problem (e.g., skill deficit, environmental structure, medical problem);
- whether changes in a domain may lessen or eliminate the problem; and
- whether the domain constitutes an area of strength for the individual which may be built upon to assist in eliminating the problem.

The following domains of the individual's life should be examined to determine how they contribute to the problem or potential solutions:

A. Residential

- Does the current residential environment have an impact on the behavior?
- Does the current setting meet the individual's needs in terms of the presenting behavior?
- Would a change in living environment be appropriate/recommended?

B. Vocational

- Does the individual's current job situation contribute to the behavior?
- Does it provide a source of stability and structure for the individual?
- Can the behavior be controlled in this setting?

C. Education/Training

- Does this individual have skill deficits (e.g., social skills, learning deficits, communication) that contribute to the presenting behavior?
- What, if any, further education/training might eliminate the behavior?



D. Medical

- Do medical needs or physical disabilities contribute to the behavior?
- Are there needs in this area that are unmet and may contribute to the behavior?
- Are medications taken and at proper dosage?

E. Mental/Behavioral Health

- Does the individual have a mental illness that contributes to the behavior?
- Does the individual have coping deficits that impact the behavior?
- Are services needed/appropriate to assist the individual?
- Are psychotropic medications taken and at proper dosage?

F. Financial

- Does the individual manage his/her own money?
- Is the behavior related to lack of funds or to mismanagement of money?
- Are services needed/appropriate to assist the individual?



G. Social/Recreation

- Does the individual have excessive free time and/or lack of ability to organize free time that contributes to the behavior?
- Does the individual have friends who may encourage the behavior?
- What services may assist the individual in positive development of skills in this domain?

H. Family

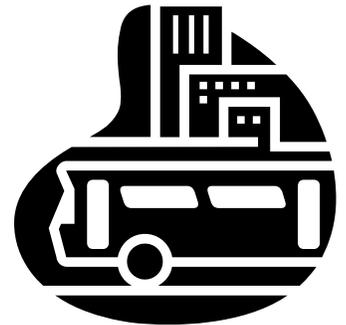
- Does the individual have an active and supportive family?
- Do family influences contribute to the behavior?
- Can family assist in appropriate behavior development?

I. Cultural Background

- Are there cultural factors that should be included in the assessment process?
- Does culture have an impact on the behavior?
- Are services needed/appropriate to assist the individual?

J. Transportation

- How mobile is the individual?
- Do transportation factors contribute to the behavior?
- Is there accessible transportation available in the community?
- Are services needed/appropriate to assist the individual?



K. Advocacy

- Is the individual his/her own legal decision maker?
- Is the individual able to ensure his/her rights are upheld?
- Is an outside advocate needed/desired?
- Is a guardian needed?
- If a guardian has been appointed, is the guardian able to ensure his/her ward's rights are upheld?

L. Further Assessment

- Is there further assessment or other relevant information that would assist in identifying or addressing the behavior?

Recommendations

Once the assessment has been completed, the team makes recommendations. The recommendations regarding resources available should be identified, clearly organized and an integration of the CJS and community-based services. The least-restrictive, most effective services should be recommended for implementation. Specific service providers/responsible parties should be identified for each recommendation.

The following support options should be considered:

- A. Positive Behavior Supports:** Systematic use of reinforcements to strengthen appropriate alternative behavior and consequences to help suppress the illegal behavior.
- B. Counseling:** The individual may benefit from a therapeutic effort such as one to one counseling or group therapy.
- C. Supervision and/or case management:** Increased supervision or case management services may be necessary to support an individual within the community.
- D. Community Service:** Engaging in a relatively less desirable activity may serve to suppress the problem behavior. This is usually a prearranged placement by the court. (Example: helping clean up a local park).
- E. Hospitalization:** Inpatient psychiatric services may be necessary for the individual at this time.
- F. Agency Transfer:** Another facility may be better equipped or provide more specialized treatment to address the behavior.
- G. Other treatment/training:** Further treatment or training may need to be considered.
- H. Psychotropic medication management:** Medication management issues may need to be addressed to ensure compliance, appropriateness of medications, and ongoing review by a physician.
- I. Restitution:** If the individual is found guilty of a charge which involves damage to property or some other type of monetary loss to the victim, it may be appropriate for the individual to make some type of restitution to the victim or do some type of service for the victim.



- J. Fine:** A monetary fine may have the desired impact on the individual and result in suppression of the problem.
- K. Probation:** A probationary period may be indicated. A recommendation regarding level of supervision may be appropriate.
- L. Incarceration:** A sentence of incarceration may be indicated. This may include serving the customary sentence or a shorter but immediate jail sentence.

Based upon the outcomes, an IJP should be shared with entities that are involved. Throughout this process, there may be a need for continued involvement by the service system or case management.

Anticipated Outcome

The plan should specify in descriptive terms what the outcome(s) of the current situation should be. This may be evident by a treatment or service plan or identified services. Additionally, the plan should take into account the possible reoccurrence of the target behaviors and should include a written description of what will take place should the behaviors occur again.

For example: If the person has a developmental disability and one could expect that it would be life-long, an anticipated outcome may be that behavioral supports are developed and that with ongoing training, the individual can learn appropriate behavior which would then eliminate the behavior that places them at risk of involvement in the criminal justice system.

Integration

An IJP should be integrated within the individual's existing service plan.

Review of the IJP

A review process and responsible reviewer should be clearly outlined for each IJP (e.g., monthly, annually, or as needed).

Consent

An individual and their legal decision maker should be involved throughout the process of IJP development. Once the IJP is developed, the individual and/or legal decision-maker (guardian or custodian) must be fully informed of all components of the IJP. Written confirmation of this process and their consent must be documented on the IJP document. See Appendix 6 for informed consent form.



Confidentiality

An individual's records are considered confidential information and should not be disclosed without proper authorization as indicated earlier in this module. The same application of confidentiality practices applies to the IJP document.

Rights of the Individual with Developmental Disabilities

An individual with developmental disabilities has all the rights of any citizen. At the time of the arrest, the individual should be apprised of his/her rights, if that individual is being questioned by police officers. Collectively, these rights are referred to as the Miranda Rights.



Research has shown that at least a 7th grade reading comprehension is required to understand the Miranda Rights. It is recommended that if police suspect the alleged perpetrator is an individual with developmental disabilities, the individual's case worker, QMRP, or advocate be present during questioning if an attorney is not, to ensure that the individual understands his/her rights, and the consequences of waiving those rights. If there is any doubt, the professional should encourage the individual to ask for an attorney, rather than attempt to interpret the rights. It must be emphasized that the

role of the professional is to simply assess the individual's comprehension of these issues. Should an accused individual be under guardianship, the presence of the guardian may be required depending on the nature and extent of the guardianship.

If the police are notified that an individual has violated a law, the police will contact and request the individual to come into the police station for questioning. The individual, of course, has the right to have an attorney present during this time. If the individual expresses the desire for an attorney, questioning should not begin or should stop at this point. After police investigation and questioning of the individual the city or state's attorney will review the report and decide whether or not the person will be prosecuted. If the individual will be prosecuted, a warrant will be issued, and the suspect may be picked up by the sheriff or police. The legal process then begins.

Feedback Exercise IV

- 1.** What is an Individualized Justice Plan (IJP)?
- 2.** Who the IJP is intended to help?
- 3.** List two purposes of an IJP.
- 4.** Describe the composition of the IJP team.
- 5.** Describe the assessment process conducted prior to developing an IJP.
- 6.** Describe the procedural steps to be followed when an individual with developmental disabilities is being questioned by police for an alleged offense.
- 7.** Define the following support options:
 - a.** Positive Behavior Supports
 - b.** Counseling
 - c.** Supervision or Case Management
 - d.** Community Service
 - e.** Hospitalization
 - f.** Agency Transfer
 - g.** Incarceration
 - h.** Psychotropic medication management
 - i.** Restitution
 - j.** Fine
 - k.** Probation

UNIT V - Advocacy

Objectives

After completing this unit, direct support and other professionals will be able to:

- **Define self, personal, citizen, and systems advocacy.**
- **Explain the need for advocacy in all services for individuals with disabilities.**
- **List the steps and describe how to write an advocacy plan.**

Advocacy is a word which is used often, but connotes different meanings for different people. Each individual's interpretation of what advocacy is affects how he/she plays the advocacy role. For some people, advocacy means promoting, supporting, speaking, and even fighting for what that person believes will be best for the individual.

Many people have experienced being both the beneficiary or recipient of another's advocacy, and advocating for someone else. Advocacy is a natural part of human relationships. Parents advocate for their children; friends provide guidance and assistance to each other; relatives are there to help in times of need. On a more formal level, unions advocate for the interests of their members, while Congress advocates for the interests of the people of our country. Advocacy is defined as an act or process of representing a person or group of persons in order to:

- Secure human and legal rights,
- Obtain needed services to which one is entitled, and/or
- Remove barriers toward meeting identified needs

In this module, it has already been emphasized that all citizens of the United States have the same human and legal rights, regardless of sex, race, or religious conviction. Although constitutional rights are guaranteed for all on paper, in practice the legal and judicial systems are not without fault. Minority groups, and more specifically, those who have developmental disabilities, may be at greater risk of having their rights denied or violated for two reasons:



- **Societal attitude.** Frequently, people who have developmental disabilities are not considered valued and contributing members of our society. A lack of knowledge regarding conditions which constitute developmental disabilities may be one factor. The issue can be further complicated by society placing great value on competence, status, and money.
- **The nature of disabling conditions.** Due to the nature of some forms of developmental disabilities, assistance and special services may be needed to help an individual function as independently as possible. This can be looked upon by others to mean that an

individual with developmental disabilities is incompetent and totally dependent on others to meet his/her needs.

Therefore, an assumption can be made that those most in need of advocacy services are:

- Individuals with more severe forms of developmental disabilities which limit the ability to effectively communicate or advocate on one's own behalf;
- Individuals who have developmental disabilities and are without natural supports such as families and friends. (Example: those who are elderly and have developmental disabilities).

TYPES OF ADVOCACY

Self Advocacy

Self advocacy is the act or process of representing one's own rights and interests. The rationale behind the self advocacy movement is clear: individuals who are empowered to speak on their own behalf have ultimate control over their lives and thus, any services they receive.

Since the mission of the developmental disability service delivery system is to promote one's independence and autonomy, there is a distinct correlation between the mission of self advocacy and that of the developmental disabilities service provider. Service providers can play a role in assisting their clientele to advocate on their own behalf by implementing the following models:

Passive

- train direct support professionals about the rights of people who have developmental disabilities
- make individuals who have developmental disabilities aware of their rights
- affirm and protect the rights of their clientele who have developmental disabilities

Active

- teach clientele about legal rights and the responsibilities that accompany them
- teach clientele about choices available, as well as how to go about making responsible decisions
- assist independent self advocacy groups in fulfilling their mission

Personal Advocacy

Personal advocacy is the act or process of assisting or representing an individual in securing rights to which he/she is entitled. Anyone can personally advocate for another individual, however, the recipient of this type of advocacy must consent to these services in advance.



In addition to personal advocacy services provided within a developmental disability facility, this type of advocacy is also available through agencies outside of or independent from the developmental disability service delivery system. The independence of outside agencies is needed to ensure that conflicts of interest are avoided with respect to other services provided to the individual.

The services of independent agencies are most commonly utilized in situations whereby a specific, potential rights violation has been identified. Thus, advocacy services are often discontinued once a remedy has been identified and corrective actions have been implemented and monitored.

Features of Personal Advocacy

Because "advocacy" is such a popular concept, it is possible to encounter situations labeled as "advocacy" which in fact may not be. Personal advocacy has all or most of the following features:

- Advocates perceive the needs and interests of the beneficiary separately from their own needs and interests, as well as those of the third parties;
- Beneficiaries have a voluntary relationship with the advocate. The beneficiary must consent to receiving advocacy services;
- Advocates are independent of the developmental disabilities service delivery system and are free to focus on the needs and wishes of beneficiaries; and/or
- As with developmental disability services, information about the beneficiary is confidential.



Citizen Advocacy

Many people who have developmental disabilities do not have the opportunity to actively participate in their local communities. For many individuals, contact with others is limited to staff who are paid to be a part of their lives or others who also have developmental disabilities and are receiving similar services. Citizen advocacy attempts to meet the needs of such people who are at risk of social isolation. Citizen advocacy can best be described as a one to one match between a mature, competent community volunteer and an individual with a developmental disability in order to advance the interests of the individual with the disability (protégé) as if they were the advocate's own.

Although citizen advocacy relationships are individualized to meet the needs of both the advocate and protégé, the overall function of each relationship remains the same:

- to provide companionship,

- to provide exposure to and involvement in normalizing experiences,
- to assist in solving problems of daily living and/or
- to assist in accessing the local community.

Some citizen advocates choose to expand their relationship with their protégé beyond the more traditional role of companionship to providing assistance and support in their protégée's receipt of developmental disability services. Advocates can assist their protégées in identifying appropriate services, planning for services, and monitoring the outcomes.

Regardless of the level of involvement, the outcome of the citizen advocacy relationships relates to a decreased stigma of people who have developmental disabilities and a portrayal of such people as being valued members of society.

Systems Advocacy

Systems advocacy is defined as the process of influencing social and political systems in order to bring about changes in perceived problems affecting a class or group of people who have developmental disabilities.

The most common methods used to influence social and political systems are:

- Legislation (law)
- Litigation (court action)
- Education and training



It is important to note that major changes in systems often occur as a result of individual effort (personal advocacy) based on a specific incident or situation. Through formal and informal networks, information is shared and gathered in order to determine if the perceived problem identified is widespread or effects large numbers of people in similar situations.

Developing an Advocacy Plan

Whether or not individuals are employed specifically in an "advocacy" position, they may encounter problem situations for which advocacy services may be needed. A written advocacy plan can assist an advocate and the person with a disability in analyzing problem situations as well as developing a course of action. It also provides a means of monitoring the effectiveness of specific strategies during and after implementation of the plan. In this section, direct support professionals will learn the steps to developing an advocacy plan to guide their efforts.

Preliminary Fact Finding An advocate's initial responsibility is to gather as much information about the perceived problem as possible. This may require an advocate to make several contacts with individuals who are or should be familiar with the perceived problem. Answers may need to be found for questions such as: What is the problem or concern? When did this problem occur and is it continuing to occur? Who has been involved in the

problematic situation? Are any other people aware of this problem? Has anyone attempted to remedy the situation and what was the result? What would you consider to be an acceptable remedy or solution to this problem?

It is not uncommon for situations to become problematic due to miscommunication or a lack of knowledge regarding particular areas of concern. Therefore, an advocate's role may become one of facilitating and encouraging constructive communication between disagreeing parties or educating parties involved about topics and issues pertaining to the problem at hand. In addition, providing education and information often enables individuals and/or their parents/guardians to resolve problems independently and without intrusion of a third party.

Developing a Plan Once information has been gathered and it is determined that advocacy assistance is needed beyond the provision of education and information, an advocate may need to research existing laws, regulations, and standards which support the cause. An advocate should consider city, state, and federal law; licensing certification and accreditation standards; and agency policies and procedures.



Strategy Developing a strategy or course of action is often the largest and most difficult part of developing an advocacy plan. Strategy can be thought of as building a bridge from the current situation to what the individual considers an acceptable outcome or resolution. At this stage, it is important for an advocate to remember the importance of working for and enabling the individual to achieve his/her own desired outcome - even though the advocate may not personally agree with what the individual wants.

Principles that guide the developmental disabilities system such as normalization and individualization will also assist an advocate and the person with a disability in developing a strategy. Issues to consider are: Where must changes occur? Who is responsible to make changes? What services are available or unavailable? The unavailability of certain services may not necessarily limit the course of action of an advocate and the person with a disability. New and innovative services are often created as a result of needs and wishes identified by individuals and/or their representatives.

Implementation and Monitoring Once a course of action has been developed, an advocate and the person are ready to implement their advocacy plan. The implementation of a plan may be a long and time consuming process. Therefore, an advocate may monitor each stage of the plan rather than waiting to monitor only the end result. Monitoring each stage of the advocacy plan will also enable an advocate to more readily determine where the plan has failed which may be needed toward revising strategies in the future.

Grievance and Appeals Procedures Most agencies and organizations have grievance or appeals policies and procedures. The purpose of appeals procedures is to provide an avenue for individuals to voice dissatisfaction with services currently being provided and/or the absence of particular services they feel should be available to meet their needs.

Appeals procedures may be used when previous strategies as, written in the advocacy plan, have not materialized or the individual is otherwise dissatisfied with the outcome. Since many organizations have very specific guidelines which must be followed in using an appeal mechanism, an advocate may need to assist the person with the disability in adding additional strategies to the advocacy plan which entail the steps to proceeding with an appeal. Having exhausted local and/or state agency appeals procedures, an individual may have the option of proceeding through the court system.

Feedback Exercise V

1. What is advocacy?
2. Why may individuals with developmental disabilities be at a greater risk of having their rights denied or violated? List at least two reasons.
 - (a)
 - (b)
3. Define self-advocacy:
4. List at least three active ways service providers can use to assist individuals to advocate on their own behalf.
 - (a)
 - (b)
 - (c)
5. Define personal advocacy:
6. Why is advocacy independent from the developmental disability service system necessary?
7. List at least three features of personal advocacy:
 - (a)
 - (b)
 - (c)
8. What is citizen advocacy? Describe it.
9. What are the main functions of the citizen advocacy. Provide at least three.
 - (a)
 - (b)
 - (c)
10. Define systems advocacy:

11. What methods are used by the system advocacy to influence social and political systems?
List three:
 - (a)
 - (b)
 - (c)
12. Why is a written advocacy plan needed in problematic situations?
13. What is the main role of an advocate?
14. What is the purpose of appeals procedures?

UNIT VI - Abuse, Neglect, and Exploitation

Objectives

After completing this unit, direct support and other professionals will be able to:

- **Define and provide examples of abuse, neglect and exploitation.**
- **List and explain three major variables which increase the likelihood of mistreatment of people with disabilities.**
- **Identify causes of abuse, neglect, and exploitation and provide ways of prevention.**
- **Explain who should and where to report alleged abuse, neglect, and exploitation.**

The terms abuse, neglect, and exploitation are freely used by society. Most people, when asked, can define or provide examples of what they believe constitutes abuse, neglect, or exploitation. Unfortunately, in the past, various sources of authority each defined these terms differently, which caused confusion especially among those working in the field of developmental



disabilities. Through efforts of the North Dakota legislature, the State of North Dakota now has state statutes which specifically address definitions of abuse, neglect, and exploitation as they relate to people who have developmental disabilities, as well as how to report these alleged violations. The purpose of this law is clear: to provide a uniform set of rules which can be consistently implemented by all involved in the lives of people who have developmental disabilities.

Definitions

Within the statutory definitions of abuse, neglect, and exploitation, the term "caretaker" is frequently used. A "caretaker", as defined by law, means "a person, organization, association or facility who has assumed legal responsibility or a contractual obligation for the care of a person with developmental disabilities or mental illness, or a parent, spouse, sibling, other relative, or person who has voluntarily assumed responsibility for the person's care." For purposes of this section, direct support professionals employed by developmental disability facilities are to be considered caretakers.

Below you will find the definitions of abuse, neglect, and exploitation as they appear in the North Dakota Century Code, 25-01.3-01.

"Abuse" means:

- a. Willful use of offensive, abusive, or demeaning language by a caretaker that causes mental anguish of any person with developmental disabilities;
- b. Knowing, reckless, or intentional acts or failures to act which cause injury or death to a developmentally disabled or mentally ill person or which placed that person at risk of injury or death;

- c. Rape or sexual assault of a developmentally disabled or mentally ill person;
- d. Corporal punishment or striking of a developmentally disabled or mentally ill person;
- e. Unauthorized use or the use of excessive force in the placement of bodily restraints on a developmentally disabled or mentally ill person; and
- f. Use of bodily or chemical restraints on a developmentally disabled or mentally ill person which is not in compliance with federal or state laws and administrative regulations.

"Neglect" means:

- a. Inability of a person with developmental disabilities or mental illness to provide food, shelter, clothing, health care, or services necessary to maintain the mental and physical health of that person;
- b. Failure by any caretaker of a person with DD or mental illness to meet, either by commission or omission, any statutory obligation, court order, administrative rule or regulation, policy, procedure, or minimally accepted standard for care of persons with developmental disabilities or mental illnesses;
- c. Negligent act or omission by any caretaker which causes injury or death to a person with developmental disabilities or mental illness or which places that person at risk of injury or death;
- d. Failure by any caretaker, who is required by law or administrative rule, to establish or carry out an appropriate individual program or treatment plan for a person with developmental disabilities or mental illness;
- e. Failure by any caretaker to provide adequate nutrition, clothing, or health care to a person with developmental disabilities or mental illness;
- f. Failure by any caretaker to provide a safe environment for a person with developmental disabilities or mental illness; and
- g. Failure by any caretaker to maintain adequate numbers of appropriately trained staff at a facility providing care and services for persons with developmental disabilities or mental illness.



Exploitation, when committed by a caretaker or relative of, or any person in a fiduciary relationship with a person with developmental disabilities or mental illness, means:



- a. The taking or misuse of property or resources of a person with developmental disabilities or mental illness by means of undue influence, breach of fiduciary relationship, deception, harassment, criminal coercion, theft, or other unlawful or improper means;

- b. The use of the services of a person with developmental disabilities or mental illness without just compensation; or
- c. The use of a person with developmental disabilities or mental illness for the entertainment or sexual gratification of others under circumstances that cause degradation, humiliation, or mental anguish to the person with developmental disabilities or mental illness.

State law provides specific definitions of abuse, neglect, and exploitation, yet does not provide for specific examples or situations which constitute such violations. Although developmental disability direct support professionals may appreciate receiving additional information with respect to examples of behaviors which constitute violations, it is difficult to do so for the following reasons:

- No one is able to determine and list every situation or behavior which constitutes a violation; and
- What may constitute abuse, neglect, or exploitation against one person may not necessarily be true for another.

As stated earlier, many people are able to list examples of behaviors which constitute "abuse", such as slapping, pulling hair, or swearing. However, other behaviors, often referred to as "gray areas", are more difficult to define. It is only through in-depth fact finding or investigation procedures that a determination of abuse, neglect, or exploitation can be made.

Causes

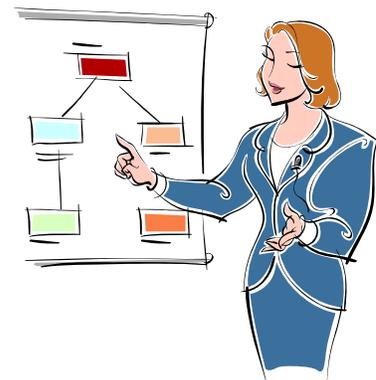
Research into the causes of mistreatment is limited. However, information is available which suggests that the many variables which increase the likelihood of mistreatment of people with developmental disabilities can be divided into three categories (Furey, 1989);

- organizational variables
- staff characteristics
- individual characteristics

Organizational Variables

Zuckerman, Nuehring, and Abrams (1986) surveyed the directors of protection and advocacy agencies in all 50 states. Of the 43 directors who responded to the survey, *staff training* was considered the most important and essential step in preventing abuse and neglect in residential facilities. Unfortunately, even some of the best staff training programs lack components toward addressing the needs of new and existing direct support professionals.

- Many excellent training programs are subverted because they fail to take into consideration the "rules of the



program where the new employee is placed" (Landsmann-Dwyer & Knowles, 1987). According to new employees, they are frequently greeted with "forget what you learned in training, this is how we do things here". Often these "rules" violate the basic human rights of the residents (Furey, 1989).

- A lack of or inadequate training can result in direct support professionals falling back on past practices familiar to them prior to beginning employment. Parenting techniques such as discipline, domination, and punishment can inappropriately be carried over to habilitative settings.

Supervision is another major organizational variable which has received too little attention. Supervisors who may have learned the "old" (custodial or control) way of providing services are expected to teach the "new" (habilitative) way while processing an inordinate amount of paperwork (Furey, 1989). Role modeling is an important part of any training program for supervisors or direct support professionals. Supervisors, because of familiarity with individual programs and direct support professionals are in the best position to role model appropriate programming. Yet, an inadequate amount of time is left to accomplish these duties. Furey (1989) goes on to state, "a common lament of supervisors is the lack of opportunity to get away from their desks and model appropriate teaching techniques or social interactions for direct care staff."



High turnover rates are not uncommon in facilities serving individuals with developmental disabilities. In situations where employees provide little notice prior to termination, facilities may find themselves relying on existing direct support professionals to fill the gap until new employees are hired. The stress of extra shifts, lack of sleep, and responsibility for the care of persons with severe to profound disabilities can precipitate abuse (Furey, 1989). State law also states that failure by a caretaker to maintain adequate numbers of appropriately trained direct support professionals is a form of neglect.

Staff Characteristics

Various crisis intervention courses available to direct support professionals throughout the state emphasize the importance of being in touch with and acknowledging one's own attitudes and feelings. Not only is *poor attitude* contagious to other direct support professionals, but it could also lend itself to non-therapeutic approaches. In such situations, direct support professionals may find themselves *emotionally exhausted* to the point of missing the communicative intent behind an individual's actions or taking such actions personally. The end result may be direct support professionals left frustrated and feeling that their work is not valuable. This, in and of itself, can contribute to incidents of mistreatment.

Another attitude which may affect direct support professionals is one in which direct support professionals *feel they have "control" over the individuals they serve*. Shevin (1984) states, "a dependency on others for making simple daily decisions can be highly stigmatizing and can promote society's perception of an individual as a total incompetent." For those direct support

professionals who are frequently called upon to assist individuals in meeting basic needs, it is easy to fall into the trap of thinking "control" exists. Thus, it becomes somewhat of a power struggle should an individual choose not to conform to what is typically expected of most other individuals. This attitude or mindset of control can be frustrating to direct support professionals and may lead to abusive situations.

Finally, Taylor (1987) suggests that direct support professionals have specific definitions of individuals with whom they work. For example, nicknames may take the form of descriptions of people such as "The Screamer." Furey (1989) concludes that when direct support professionals view individuals as objects, that is, they *do not recognize the residents as human individuals*, an excuse for abuse may be present.

Individual Characteristics

Rood (1993) stated that vulnerability to abuse is enhanced when the person is "unable to physically leave the environment or situation; unable to change the environment or situation; unable to speak or be heard and take action alone; and/or socially or psychologically isolated without other alternatives." Rusch, Hall, & Griffin (1986) studied 160 residents of an institution for individuals with cognitive disabilities, 80 of who experienced physical abuse. The authors compared the 80 abused Individuals with 80 non-abused individuals on nine factors. The six factors found to significantly discriminate between the two groups were that the abused person was:

- profound, social impairment
- age 0 - 20
- aggressive
- self-injurious
- non-verbal
- ambulatory



Individuals possessing one or more of the above characteristics may potentially be candidates for abuse. The authors also report that aggression was the most significant variable distinguishing the two groups. In some situations, people with developmental disabilities may not know of appropriate ways to express feelings of anger, frustration, or boredom. Therefore, their actions may appear aggressive or inappropriate to others. In similar situations, individuals may understand appropriate ways of expressing feelings, but find that they can gain more immediate attention of direct support professionals by expressing their feelings in ways typically considered inappropriate. Other individuals, as well as direct support professionals, can be the target of such "inappropriate" behavior. Both types of situations can lead to abusive or neglectful acts.

Prevention

As an agency wide effort, information regarding abuse, neglect, and exploitation must be consistently provided to and practiced by direct support and other professionals at all levels of the organization. Inconsistencies in the delivery of services can occur if veteran direct support

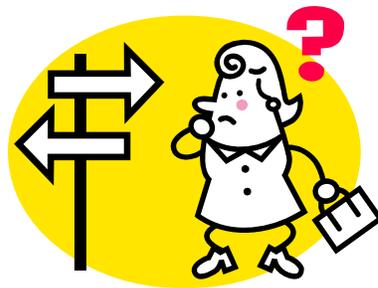
professionals do not receive or practice that which is provided to new direct support professionals. As a result, new direct support professionals may model the inappropriate actions of their peers or not feel comfortable in questioning the behavior of other direct support professionals, even if it appears inappropriate to them personally. Consistency also allows for better follow up by direct support professionals other than staff trainers, such as administrators, immediate supervisors, and direct support professionals. Follow up from all levels of staff provides the agency with an informal quality assurance mechanism and direct support professionals with immediate feedback.



As discussed earlier, a lack of training can result in direct support professionals falling back on past practices which may be inappropriate in habilitative settings. Past practices, as well as current attitudes, can have an obvious effect on services provided to people with developmental disabilities. In a non-judgmental manner, direct support professionals need to be confronted about their attitudes toward people with cognitive disabilities (Furey, 1989). Within staff training programs, emphasis needs to be placed on the importance and value of personal experiences and attitudes, yet attempt to modify those experiences and attitudes which conflict with philosophies that govern the developmental disabilities system such as normalization, dignity, and respect.

Many organizations across the country are recognizing the need for employee assistance programs. Various life stressors, whether they occur at home or work, can greatly affect an employee's work performance. Employee assistance programs allow employees access to counseling and guidance needed to deal effectively with stress. The value of employee assistance programs is not only in that they can provide confidential assistance, but also indicates the organization's concern for the overall well being of its employees.

The findings of several studies in recent years regarding stress indicates that the less control one has over his/her life, the higher and more intense the stress felt by the individual. Lack of control can be directly related to this inability or lack of opportunity to make decisions or choices. Typically, most people are allowed to make decisions and later change their minds without great admonishment. In addition, most people do not like having someone else telling them what to do. Yet, people with developmental disabilities are often denied opportunities to make choices or change their minds - areas we would typically consider normal and necessary toward promoting independence. Zeph (1985) emphasized the need for all, no matter how cognitively and/or physically limited, to have some control over their worlds. Shevin (1984) stated that in addition to the obvious benefits, choice making skills also contribute to progress as a means of decreasing deviance. Programs which integrate the concept of choice making can serve several purposes toward preventing abusive, neglectful, or exploitative situations.



- Allowing people with developmental disabilities the opportunity to make choices may lower stress levels, which in turn may decrease the frequency of behaviors considered by direct support professionals to be aggressive or otherwise inappropriate.

- Allowing direct support professionals the opportunity to make choices promotes flexibility in schedules and routines, which in turn may allow direct support professionals to respond more spontaneously to individual needs and desires.
- The ability to make choices is consistent with philosophies of normalization.

Reporting Abuse, Neglect, and Exploitation

Prior to July, 1989, requirements for the reporting of abuse, neglect, and exploitation of adults with developmental disabilities by those working in developmental disability facilities was limited to state administrative policy. There were no reporting requirements for others who may have had contact with people with developmental disabilities, such as medical, mental health, and educational professionals.



State law enacted by the 1989 legislature now specifies who must report (mandatory), as well as who may report (voluntary) alleged violations. Every medical, mental health, developmental disabilities or educational professional, law enforcement officer, or caretaker must report any alleged abuse, neglect, or exploitation they may suspect. In addition, all licensed North Dakota DD providers are required to implement DDD-PI-006, which is the policy and procedure for responding to reports of alleged incidents of abuse, neglect, and exploitation. This policy clearly outlines the risk management process and includes guidelines for delineating those incidents that need to be reported. State law also emphasizes that those who willfully fail to report abuse, neglect, or exploitation (if mandated by law to do so) are guilty of an infraction.

State law has also recognized the need to have safeguards established for those who fear reprisal or retaliation as a result of making a report. Therefore, individuals who make reports in good faith are immune from civil or criminal liability. In addition, any employer who imposes any form of discipline or retaliation against an employee due to the reporting of alleged abuse, neglect, or exploitation is guilty of a class B misdemeanor.

Investigations

Once a report of alleged abuse, neglect, or exploitation has been made within a developmental disability facility, the facility is required to investigate the allegation/situation. The purpose of an investigation is threefold:

- To gather information in order to describe and explain an incident or event
- To determine strategies that will decrease the potential of future recurrence of the mistreatment, and
- To lay groundwork for further legal action, if pursued by the victim or legally authorized substitute.

In accordance with state law, independent agencies outside of a developmental disability facility

such as advocacy agencies, social service agencies, or law enforcement, may also conduct investigations.

In order to appropriately conduct investigations, independent agencies must also have access to individuals receiving services, direct support professionals, records, or other information considered relevant to an investigation.

Feedback Exercise VI

1. List at least four components of the definition of Abuse as they appear in the North Dakota Century Code.

(a)

(b)

(c)

(d)

2. List at least four components of the definition of Neglect as they appear in the North Dakota Century Code.

(a)

(b)

(c)

(d)

3. List at least two components of the definition of Exploitation as they appear in the North Dakota Century Code.

(a)

(b)

4. List at least three categories of variables which increase the likelihood of mistreatment of people with disabilities.

(a)

(b)

(c)

5. What is the most important step in preventing abuse in residential facilities according to studies?

6. List at least three staff characteristics which may contribute to abuse, neglect, and exploitation.
 - (a)
 - (b)
 - (c)

7. List at least four characteristics of individuals with developmental disabilities which may make them potential candidates for abuse.
 - (a)
 - (b)
 - (c)
 - (d)

8. List at least three ways through which abuse, neglect, and exploitation could be prevented.
 - (a)
 - (b)
 - (c)

9. Who should report abuse, neglect, and exploitation according to the new state law enacted by the 1989 legislature?

10. What is the purpose of investigation once a report of alleged abuse, neglect, or exploitation has been made within a developmental disability facility? List three reasons.
 - (a)
 - (b)
 - (c)

UNIT VII - Guardianship

Objectives

After completing this unit, direct support and other professionals will be able to:

- **Define guardianship.**
- **Describe the process of appointing guardians.**
- **Explain when and what kind of guardianship is needed.**

Guardians, who can be appointed by the courts to protect the interests of people (wards) unable to represent their own interests, are a type of advocate. Very young people, people with impaired mental capacities, or seriously ill people may require guardians. Because guardians assume the exercise of some legal rights and make some decisions for their wards, it is a drastic measure and should only be used when the person (ward) might be seriously harmed or exploited because they are unable to protect or care for themselves and their own best interests.

North Dakota Law

North Dakota's laws regarding guardianship:

- ensure legal due process of proposed wards,
- clarify the guardianship process,
- clarify the responsibilities of the guardian,
- allow for use of limited guardianships based on the specific needs of the proposed ward,
- generally disqualifies the superintendent of the State Developmental Center (Grafton) from being guardian for individuals residing there, and
- identifies the roles and responsibilities of persons appointed by the court in the guardianship process.

How Guardians Are Appointed - Due Process

The process to appoint a guardian is quite complex in order to ensure due process and to protect the rights of the proposed ward. This process is the same regardless of the proposed ward's disabling condition or diagnosis. It is as follows:

1. The interested party files petition to establish guardianship of the alleged incapacitated individual.
2. The court notifies the proposed ward of the petition.
3. An alternative resource plan is developed and presented to Court, outlining alternatives considered or/and attempted prior to determining need for guardianship.
4. The court appoints:



- Physician/clinical psychologist to examine the proposed ward and to submit written reports to the court regarding the current conditions and level of functioning/needs.
 - Visitor who will interview the proposed ward, review the alternative resource plan and submit a written report to the court regarding current conditions and level of functioning/needs.
 - Attorney to: serve as "guardian ad litem"; interview proposed ward; and to explain situation, process, consequences, and alternatives relative to guardianship to the proposed ward.
5. Court sets/has a hearing. The proposed ward is present unless good reason is shown for absence. Proceedings must be accessible/understandable to impaired individual. Proceeding must be held at location best for proposed ward. The proposed ward's attorney presents evidence and cross examines witnesses. Proceeding is closed at proposed ward's request.

Considerations to Determine Need

The court must determine if the proposed ward is incapacitated. Based on North Dakota Century Code (30.1-26-01) "incapacitated person" means any adult person who is impaired by reason of mental illness, mental deficiency; physical illness or disability, or chemical dependency to the extent that the person lacks capacity to make or communicate responsible decisions concerning that person's matters of residence, education, medical treatment, legal affairs, vocation, finance, or other matters, or which incapacity endangers the person's health or safety.

Findings cannot be based on age, eccentricity, poverty, or medical diagnosis alone. The findings must be made based on clear and convincing evidence that:

- proposed ward is an "incapacitated person"
- no available alternative resource plan is suitable to safeguard the proposed ward's health, safety or/and habilitation
- guardianship is necessary as best means of providing care, supervision, and/or habilitation to the ward
- powers and duties conferred upon the guardian are appropriate as the least restrictive form of intervention

Limitations of Guardianship and Duties of Guardians

Except upon specific findings of the court, no ward may be deprived of the right to:

- Vote,
- Seek change in marital status,
- Obtain driver's license, or
- Testify in any judicial or administrative proceedings.



Without court consent a guardian cannot provide consent for:

- psychosurgery,
- abortion,
- sterilization, or
- experimental treatment.

A guardianship order is specific and the guardian has only those powers identified in the order. The court's order will reveal that the guardian has been given "no authority," "limited authority," or "general authority" in each of these areas:

- Residential - place of residence, living arrangements, comfort/care
- Educational - choice of educational/training programs and services
- Medical - treatment decisions based on informed consent
- Legal - exercise and protection of legal rights
- Vocational - choice of employment opportunities and services
- Financial - protection and use of property and money

Whenever the court gives "limited authority" to a guardian in any of these areas, the court will specify the limits of the guardian's authority in that area. The ward retains authority that has not been given to the guardian.

An example in the financial area: while the guardian may be responsible for the overall finances of the ward, the ward might be entrusted to handle modest sums of money with increasing responsibilities as the ward demonstrates an increasing ability to deal with such funds.

An example in the medical area: the ward may have the right and authority to grant consent or withhold consent to medical treatment which involves a low degree of seriousness in terms of risk, intrusiveness, or irreversibility. Such treatment might include health maintenance matters and dental services of a general routine nature, as well as physical examinations and routine evaluations. Such treatment could also include nonprescription "over the counter" medication and the provision of simple First Aid, such as treatment of a minor cut. With respect to treatment involving a higher degree of seriousness, the guardian might be given full decision-making authority.



The guardian is to ensure that the ward has the best quality of life, the greatest opportunity for personal growth, and the maximum amount of independence possible considering the limits/abilities of the ward. Guardians may be requested to provide regular reports to the court on the condition of ward, the living and training situation of ward, or efforts on behalf of ward.

A court ordinarily oversees a guardian's work by reviewing the guardian's written reports. The ward also receives a copy of the guardian's written reports, along with a notice of the ward's right to ask the court to alter, limit, or terminate the guardianship at any time.

The ward or any person interested in the ward's welfare may present a formal petition to the court to remove the guardian and to appoint a successor guardian. The ward or a person interested in the ward's welfare, can send an informal letter to the court to ask for an order that the ward is no longer incapacitated and for removal of the guardian. On the other hand, a guardian can resign only by filing a formal petition seeking court approval.

Before removing a guardian, accepting a guardian's resignation, or terminating a guardianship because the ward has been found to be no longer incapacitated, the court may appoint a visitor to submit a written report on conditions at the guardian's residence and at the ward's residence. If the ward no longer lives in the same county as the court that established the guardianship, later hearings and proceedings may be moved to the county of the ward's new residence.

In summary, the guardian's responsibilities/duties are to:

- Protect the ward,
- Encourage the overall personal development of the ward,
- Exercise power and authority in best interests of the individual, in such a way as to encourage the individual to become capable of caring for self and making reasonable judgements, and in the least restrictive and normalized setting.

Who May Be a Guardian

Anyone may serve as a guardian if they are found to be fit and proper, and there is no conflict of interest. The North Dakota Century Code (Section 30.1-28-11) identifies the priority for appointment as guardian.

Temporary Guardianship

When an individual is in immediate danger or a decision regarding medical care must be made, the court can waive the procedures described earlier and can appoint a temporary/emergency guardian. The length of time for a temporary guardian must be specific and may not exceed 90 days. A temporary guardian doesn't establish incapacity.



On the other hand, it may not be necessary to involve a court in order to obtain health care decisions. If an individual is so impaired by mental illness, mental deficiency, physical illness, physical disability, or chemical dependency that the individual cannot make OR communicate responsible decisions about health care, a physician can decide on the spot that the individual is unable to give informed consent about health care. In this narrow instance, North Dakota law identifies and prioritizes categories of individuals who are authorized to provide informed consent to health care on behalf of the patient.

When any person provides informed consent under this arrangement, the person must first have determined in good faith that the patient, if not incapacitated, would have consented to the

proposed health care. If a determination cannot be made about what the patient would have decided if competent, informed consent can be given only if the authorized person believes the proposed health care would be in the patient's best interests.

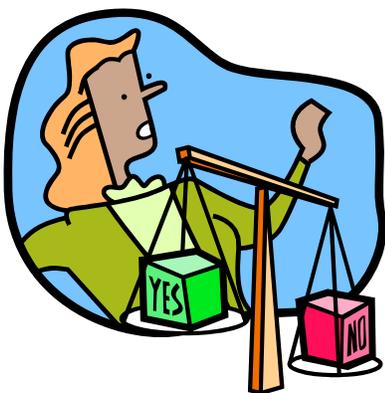
No one can provide informed consent for another adult for sterilization, abortion, psychosurgery, or admission to a state mental health facility for more than forty-five days. Any of these procedures may be taken only by a court acting in a mental health proceeding or otherwise.

If the patient or a person interested in the patient's welfare, objects to a physician's decision that the patient cannot make or communicate responsible decisions about health care, a court hearing must be held to decide the issue.

Guardianship and Individual Rights

Each right or authority granted to a guardian has been taken away from the ward. Guardianship is a serious and invasive process that has far reaching ramifications on the civil and human rights of the proposed ward. Guardianship should not be pursued unless *all alternatives* have failed or have been proven unacceptable.

Guardianship for individuals with developmental disabilities should only be ordered to the extent necessitated by the *person's actual mental and adaptive limitations*.



The level of guardianship should be reviewed carefully so that the least amount of control/authority is taken from the ward and given to the guardian. If too much authority is given to the guardian, the ward may develop a sense of powerlessness and diminished self worth. The decision making ability of the individual should be the primary factor when determining the level of guardianship. The individual should maintain the right to make as many decisions as possible. A question to pose is "Could this individual exercise his/her rights in these situations without guardianship, if support services such as advocacy or professional guidance are provided."

Although guardianship is a beneficial legal way to protect incapacitated individuals, it is not a panacea and cannot replace caring, competent professional and direct contact staff using well thought out comprehensive treatment plans.

Cost of Guardianship

The cost of guardianship proceedings will be billed to the proposed ward based on the "ability to pay." Family members may also participate in the cost if they desire. The individual's IPP/IJP/IP team and/or DD Case Management should contact public and private agencies such as Legal Assistance of North Dakota, local Public Administrators or Partners, Inc. to gather information on the most affordable means to acquiring guardianship. If corporate guardianship is being considered for an individual, Catholic Charities North Dakota can, in some cases, cover some or

all of the cost of the guardianship proceedings. In addition, Protection and Advocacy may be able to assist in emergency situations.

Guardianship and the IPP/IJP/IHP Team

The team has two related functions regarding guardianship. First, they make recommendations about the type (areas) of guardianship that is most appropriate for the individual. Then they review the guardianship annually to ensure that it continues to meet the individual need; protects but does not deprive of any rights the person is able to exercise.

Least Restrictive Alternatives

If there is concern about the individual's ability to make decisions and care for him/herself, the following less restrictive alternatives should be explored prior to considering guardianship:

- **ADVISING:** The individual can be provided advice regarding the risks, advantages and consequences of proposed actions/procedures. The individual can then make their own decision based on the advice. Some issues to consider regarding this option are: will the individual heed the advice that is given? Will the advice be sound?
- **TEACHING:** In areas such as money management and independent living, the individual can be taught the skills needed to make decisions and manage independently.
- **ADVOCATING:** Advocates can serve as guides and advisors.
- **PROVIDING SUPPORT SERVICES:** Direct support and other professionals can provide individualized training and assistance.
- **TEMPORARY GUARDIANSHIP:** Temporary guardianships may provide the solutions to specific short term concerns and "what if's."

Where the concern for an individual is a financial concern regarding the ability to manage income or financial resources, the following less restrictive alternatives should be investigated prior to a recommendation of guardianship or conservatorship.

- **ADVICE:** Can the person manage finances with advice/support from family/friends?
- **TEACHING:** Can the person be taught the skills needed to manage their own affairs?
- **SPECIAL BANK ACCOUNTS:**
 - *Cosigners:* Two persons must sign to authorize withdrawals. Neither person can withdraw without the knowledge/consent of the other.
 - *Ceiling limit accounts:* These accounts allow the



withdrawal of only a limited amount of funds in a given time period, or a limited amount of funds per transaction. Withdrawal orders written over the specified amount would not be valid.

- *Direct deposit of benefit checks*: Checks can be sent from the issuing agency (social security, etc.) to the bank for deposit.
 - *Permanent withdrawal order*: Establishes a specific amount of money that will be sent by the bank to a specified party (e.g. landlord each month).
- **INSURER OR GUARANTOR**: For making purchases an insurer or guarantor might be an alternative. An insurer or guarantor would co-sign a contract or purchase agreement with the individual. The insurer or guarantor is responsible for meeting the terms of the contract if the persons with developmental disabilities cannot fulfill the contract.
 - **TRUST**: When the person with disabilities has a substantial amount of money or/and property, a trust can be established. A trust is a plan for placing the control of a certain amount of funds in the hands of a trustee, who manages the funds for the benefit of the named individual.
 - **REPRESENTATIVE PAYEE**: A representative payee can be used for the individual receiving benefits from Social Security, SSI, or the Veterans Administration. If the person entitled to these funds is not able to manage the income, the office issuing the checks can appoint a representative payee who signs them and uses the money for the benefit of the person with disabilities.

Conservatorship or Limited Conservatorship

Conservatorship or Limited Conservatorship may be an option when a person has property which will be wasted or dissipated unless property management is provided, or when funds are needed for the support, care, and welfare of a person and that protection is necessary or desirable to obtain or provide funds. However, this type of arrangement may provide a conservator indirect

power or control over other aspects of the protected person's life in addition to financial resources. While not expressly authorized by the court, a conservator may have control over other issues in a protected person's life which effect financial resources such as determining place of residence. Therefore, this alternative should be carefully considered because of the impact on other areas of the person's life.



Power of Attorney

A *traditional power of attorney* is a written document which gives one person (the agent) the authority to act on behalf of another (the principal). The power of attorney may be general, in which case the agent can act in all respects for the principal, or special, in which case the agent can only act in limited circumstances for the principal. The principal must be legally competent when the power of attorney is made and remain competent for it to be valid.

A durable power of attorney generally remains valid if the principal becomes incompetent. This distinction is very important because it means that by using a durable power of attorney a principal can designate an agent to make decisions and act for the principal if s/he becomes incapacitated at some later date. Due to this advance planning, it may never become necessary to have a court appoint a legal guardian to make decisions and act for the person who made the durable power of attorney. A durable power of attorney must be made while the principal is legally competent to execute a document. The applicable legal standard is that the person making a durable power must have the requisite capacity to understand the nature and significance of his or her act at the time the document is signed. Thus a person suffering from a disease or disability (e.g., Alzheimer's, Down's Syndrome, or a brain injury) may be legally capable of executing a durable power of attorney if he or she understands the purpose of the document at the time of execution.

The right to delegate decision-making authority is very personal and cannot be made by another person. If decisions must be made for a person who has not named an agent and who no longer has the capacity to make or communicate such decisions, there may be no alternative but to ask a court to appoint a guardian to act for that person (Stiegel, L. A. 1992). There are many advantages and disadvantages to using power of attorney, which should be explored prior to considering this alternative.

Limited Guardianship

With the creation of a limited guardianship, the ward is not presumed to be incompetent, and retains all legal and civil rights except those which have been expressly limited by court order, or those that have been specifically granted by court order to the guardian.

Possible Areas for Limited Guardianship

Legal

- To release others from liability for use of pictures or participation in special activities,
- To secure identification cards, social security cards, or other types of required identification or documents,
- To obtain state or governmental licenses,
- To make applications for services such as counseling and social services,
- To give permission and sign releases for the inspection and dissemination of confidential information and records to third parties,
- To enter into contracts, or
- To sue and be sued.

Residential

- To apply for residential services from public and private agencies,
- To choose his/her own living arrangement, or
- To enter into any agreement for the lease or purchase of residential accommodations.

Educational

- To apply for educational services from public or private agencies or organizations, or
- To plan his/her own educational program.

Medical

- To give consent for general medical and dental services or examinations,
- To administer own medications as prescribed by the physician,
- To consent to treatment for mental illness, or
- To consent to surgery.

Vocational

- To apply for vocational services and training,
- To obtain employment of own choosing, or
- To plan own vocational development program.

Financial

- To manage specific limited amounts of money,
- To receive and manage income from wages,
- To receive and manage income from governmental sources,
- To sign tax returns,
- To secure insurance,
- To hold and convey personal property,
- To make investments, or
- To hold and convey real property.

Summary

Although guardianship may be a necessary appropriate protection for some individuals, it also infringes on their rights. Hence, options should be carefully considered before full guardianship is recommended or granted.

Feedback Exercise VII

1. What is the definition of an "incapacitated person" according to North Dakota Century Code?
2. What are four considerations for determining the need for guardianship?
 - (a)
 - (b)
 - (c)
 - (d)
3. Who may serve as guardian?
4. When is temporary guardianship granted and for how long?
5. What question should be asked before deciding on guardianship?
6. What are the two responsibilities of the IPP/IHP team regarding guardianship?
 - (a)
 - (b)
7. List five less restrictive alternatives to be explored before considering guardianship.
 - (a)
 - (b)
 - (c)
 - (d)
 - (e)

Feedback Answers

Unit 1

1. a. Reducing or preventing the differentness that may cause a person to become devalued in the eyes of observers
- b. Changing other people's perceptions and values in regard to a particular characteristic or condition so that different people are no longer seen as devalued.
2. The following answers, as well as others you may have identified, are correct:
 - a. Clothing too large.
 - b. Sweatpants aren't normally worn to most workplaces
 - c. No umbrella or rain coat
 - d. Hair style is out of date for a young woman
 - e. Kitten barrettes are not appropriate for a 22 year old
 - f. Chipped nail polish
 - g. Milk ring on mouth and food between teeth
3. The following answers, as well as others you may have identified, are correct:
 - a. A variety of activities takes place.
 - b. The schedule of activities is not rigid.
 - c. Individuals are involved in choosing and planning activities.
 - d. Activities are those which many young adults might like.
 - e. Individuals preferences and interests are taken into account.
4. Many answers could be appropriate. Discuss with your trainer. Remember that individuals with developmental disabilities are entitled to the same life cycle experiences as other people.
5. social; physical
6. Many answers are correct. Discuss with your trainer
7. Many answers are correct. Discuss with your trainer

Unit II

1. a. constitutional
- b. statutory
2. constitution
3. legislation
4. The major goal of the Association for Retarded Citizens was to establish both human and legal rights for individuals with developmental disabilities.
5.
 - o Equal protection - All citizens should be treated justly, fairly, and equally under the law.

- Due process - Guarantees that rights cannot be denied, restricted, or limited in any way without proof that such action is necessary.
 - Least restrictive alternative - When rights are restricted, they will be restricted in the least intrusive manner possible.
6. A wide range of rights and services were assured. The right to treatment and habilitation in the least restrictive, most normalized environment, individualized team planning, prohibition of abuse, neglect and exploitation, right to education and medical therapeutic services are a few among the many other rights contained in the court order.
 7. The Americans with Disabilities Act (P.L. 101-336) gives civil rights protection to individuals with disabilities in private sector employment, all public services, public accommodations, transportation, and telecommunications.
 8. Employers with 15 or more employees may not refuse to hire or promote a person with a disability when that person is qualified to perform the job.
 9. Under ADA, it is illegal for public accommodations to exclude or refuse persons with disabilities. New buildings must be accessible.
 10. Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunication devices for the deaf.
 11. State or local governments may not discriminate against qualified individuals with disabilities. All government facilities, services, and communications must be accessible.
 12. d. all of the above
 13. f. all of the above

Unit III

PART A

1.
 - a. Capacity – ability to express ones choices
 - b. Information – description of choices, alternatives, risks and benefits
 - c. Voluntariness – acting in the absence of coercion, duress, threats, inducements, or under the influence of others.
2.
 - a. participation in any service
 - b. use of medication
 - c. use of behavior intervention procedures
 - d. participation in experimentation or research
 - e. admission to a hospital/treatment center
 - f. participation in any activity posing unusual risk
 - g. release of information
 - h. contracts

PART B

1. equal protection
2. least restrictive alternative
3. due process
4. due process

5. equal protection
6. least restrictive alternative

PART C

- | | | |
|-----|-----|------------------------------|
| 1. | Yes | Right has been violated. |
| 2. | No | Right has not been violated. |
| 3. | Yes | Right has been violated. |
| 4. | No | Right has not been violated. |
| 5. | Yes | Right has been violated. |
| 6. | No | Right has not been violated. |
| 7. | Yes | Right has been violated. |
| 8. | No | Right has not been violated. |
| 9. | Yes | Right has been violated |
| 10. | Yes | Right has been violated |

Unit IV

1. If an individual with a disability is at risk of becoming involved in the CJS, their support network should be encouraged to consider the development of an IJP to outline responses to prevent involvement in the CJS. An IJP may also provide recommendations for a treatment plan when there is further involvement in the CJS. The intent of an IJP is to identify the training, services, and support necessary to prevent criminal behavior from re-occurring.
2. The IJP process is designed to assist people for whom the disability limits their ability to adequately interact with the CJS.
3.
 - a. It presents alternatives for the CJS to consider, as well as the resources, contacts, and tools needed to follow through with the process.
 - b. It provides a framework for education of and cooperation between private/public human service agencies and the various facets of the CJS. It is through this framework the two systems can provide the most appropriate services for people with disabilities with the best outcomes for everyone.
4. The individual's support network (e.g., team, physician, provider, advocate, family, defense attorney) and initiate, develop, and/or implement the IJP. Members of the CJS may be involved at various points in the process.
5. The social implications of the behavior should also be assessed in terms of the impact on the individual, other people, society and property. The motivation or cause for the presenting problem needs to be thoroughly evaluated. The assessment phase outlines domains that should be considered. Within each domain, some questions to consider are:
 - whether the domain is contributing to the presenting problem (e.g., skill deficit, environmental structure, medical problem);
 - whether changes in a domain may lessen or eliminate the problem; and
 - whether the domain constitutes an area of strength for the individual which may be built upon to assist in eliminating the problem.

6. It is recommended that if police suspect the alleged perpetrator is an individual with developmental disabilities, the individual's case worker, QMRP, or advocate be present during questioning if an attorney is not, to ensure that the individual understands his/her rights, and the consequences of waiving those rights. If there is any doubt, the professional should encourage the individual to ask for an attorney, rather than attempt to interpret the rights. It must be emphasized that the role of the professional is to simply assess the individual's comprehension of these issues. Should an accused individual be under guardianship, the presence of the guardian may be required depending on the nature and extent of the guardianship.
7.
 - a. **Positive Behavior Supports:** Systematic use of reinforcements to strengthen appropriate alternative behavior and consequences to help suppress the illegal behavior.
 - b. **Counseling:** The individual may benefit from a therapeutic effort such as one to one counseling or group therapy.
 - c. **Supervision and/or case management:** Increased supervision or case management services may be necessary to support an individual within the community.
 - d. **Community Service:** Engaging in a relatively less desirable activity may serve to suppress the problem behavior. This is usually a prearranged placement by the court. (Example: helping clean up a local park).
 - e. **Hospitalization:** Inpatient psychiatric services may be necessary for the individual at this time.
 - f. **Agency Transfer:** Another facility may be better equipped or provide more specialized treatment to address the behavior.
 - g. **Incarceration:** A sentence of incarceration may be indicated. This may include serving the customary sentence or a shorter but immediate jail sentence
 - h. **Psychotropic medication management:** Medication management issues may need to be addressed to ensure compliance, appropriateness of medications, and ongoing review by a physician.
 - i. **Restitution:** If the individual is found guilty of a charge which involves damage to property or some other type of monetary loss to the victim, it may be appropriate for the individual to make some type of restitution to the victim or do some type of service for the victim.
 - j. **Fine:** A monetary fine may have the desired impact on the individual and result in suppression of the problem.
 - k. **Probation:** A probationary period may be indicated. A recommendation regarding level of supervision may be appropriate.

Unit V

1. Advocacy is defined as an act or process of representing a person or group of persons in order to:
 - a. Secure human and legal rights,
 - b. Obtain needed services to which one is entitled, and/or
 - c. Remove barriers toward meeting identified needs.
2.
 - a. Societal attitudes
 - b. The nature of disabling conditions
3. Self advocacy is an act or process of representing one's own rights and interests.

4.
 - a. Teach individuals about legal rights and the responsibilities that accompany them
 - b. Teach individuals about choices available as well as how to go about making responsible decisions
 - c. Assist independent self advocacy groups in fulfilling their mission
5. Personal advocacy is an act or process of assisting or representing an individual in securing rights to which he/she is entitled.
6. The independence of outside agencies is needed to insure that conflicts of interest are avoided with respect to other services provided to the individual.
7.
 - a. Advocates perceive the needs and interests of the beneficiary separately from their own needs and interests, as well as those of the third parties;
 - b. Beneficiaries have a voluntary relationship with the advocate. The beneficiary must consent to receiving advocacy services;
 - c. Advocates are independent of the developmental disabilities service delivery system and are free to focus on the needs on the needs and wishes of beneficiaries; and/or
 - d. As the developmental disability services, information about the beneficiary is confidential.
8. Citizen advocacy can be described as a one to one match between a mature, competent community volunteer and an individual with a developmental disability in order to advance the interests of the individual.
9.
 - a. To provide companionship
 - b. To provide exposure to and involvement in normalizing experiences
 - c. To assist in solving problems of daily living
 - d. To assist in accessing the local community
10. System advocacy is the process of influencing social and political systems in order to bring about changes in perceived problems effecting a class or group of people who have developmental disabilities.
11.
 - a. Legislation
 - b. Litigation
 - c. Education and training
12. A written advocacy plan can assist an advocate and his or her client in analyzing problem situations as well as developing a course of action. It also provides a means of monitoring the effectiveness of specific strategies during and after implementation of the plan.
13. An advocate's role may become one of facilitating and encouraging constructive communication between disagreeing parties involved.
14. Appeals procedures may be used in situations whereby previous strategies have not materialized or the individual is dissatisfied with the outcome.

Unit VI

1.
 - a. Willful use of offensive, abusive, or demeaning language by a caretaker that causes mental anguish of any person with developmental disabilities;
 - b. Knowing, reckless, or intentional acts or failures to act which cause injury or death to a developmentally disabled or mentally ill person or which placed that person at risk of injury or death;
 - c. Rape or sexual assault of a developmentally disabled or mentally ill person;
 - d. Corporal punishment or striking of a developmentally disabled or mentally ill person;

- e. Unauthorized use or the use of excessive force in the placement of bodily restraints on a developmentally disabled or mentally ill person; and
 - f. Use of bodily or chemical restraints on a developmentally disabled or mentally ill person which is not in compliance with federal or state laws and administrative regulations.
2.
 - a. Inability of a person with developmental disabilities or mental illness to provide food, shelter, clothing, health care, or services necessary to maintain the mental and physical health of that person;
 - b. Failure by any caretaker of a person with developmental disabilities or mental illness to meet, either by commission or omission, any statutory obligation, court order, administrative rule or regulation, policy, procedure, or minimally accepted standard for care of persons with developmental disabilities or mental illness;
 - c. Negligent act or omission by any caretaker which causes injury or death to a person with developmental disabilities or mental illness or which places that person at risk of injury or death;
 - d. Failure by any caretaker, who is required by law or administrative rule, to establish or carry out an appropriate individual program or treatment plan for a person with developmental disabilities or mental illness;
 - e. Failure by any caretaker to provide adequate nutrition, clothing, or health care to a person with developmental disabilities or mental illness;
 - f. Failure by any caretaker to provide a safe environment for a person with developmental disabilities or mental illness; and
 - g. Failure by any caretaker to maintain adequate numbers of appropriately trained staff at a facility providing care and services for persons with developmental disabilities or mental illness.
 3.
 - a. The taking or misuse of property or resources of a person with developmental disabilities or mental illness by means of undue influence, breach of fiduciary relationship, deception, harassment, criminal coercion, theft, or other unlawful or improper means;
 - b. The use of the services of a person with developmental disabilities or mental illness without just compensation; or
 - c. The use of a person with developmental disabilities or mental illness for the entertainment or sexual gratification of others under circumstances that cause degradation, humiliation, or mental anguish to the person with development disabilities or mental illness.
 4.
 - a. Organizational variables
 - b. Staff characteristics
 - c. Individual characteristics
 5. Staff training
 6.
 - a. Poor attitude
 - b. Feeling of control over the individual they serve
 - c. Using nicknames which may take the form of descriptions of individuals
 7.
 - a. Profoundly socially retarded
 - b. Age 0-20
 - c. Aggressive
 - d. Self injurious

- e. nonverbal
- f. ambulatory
- 8. a. Consistency in the delivery of services
- b. Staff training
- c. Employee assistance programs
- d. Choice making opportunities both for individuals and direct support professionals
- 9. Every medical, mental health, developmental disabilities or educational professional, law enforcement officer or care taker.
- 10. a. To gather information in order to describe and explain an incident or event
- b. To determine strategies that will decrease the potential of future reoccurrence of the mistreatment
- c. To lay groundwork for further legal action, if pursued by the victim or legally authorized substitute

Unit VII

1. "Incapacitated person" according to the North Dakota Century Code means any adult person who is impaired by reason of mental illness, mental deficiency; physical illness or disability, or chemical dependency to the extent that the person lacks capacity to make or communicate responsible decisions concerning that person's matter of residence, education, medical treatment, legal affairs, vacation, finance, or other matters, or which incapacity endangers the person's health or safety.
2. a. Proposed ward is an "incapacitated person."
- b. No available resource plan is suitable to safeguard the proposed ward's health, safety, and/or habilitation.
- c. Guardianship is necessary and is the best means of providing care, supervision and/or habilitation to the ward.
- d. Powers and duties conferred upon the guardian are appropriate as the least restrictive form of intervention.
3. Anyone may serve as a guardian if he/she is found to be fit and proper, and there is not conflict of interest.
4. When an individual is in immediate danger or a decision regarding medical care must be made, the temporary guardianship must be specific and may not exceed 90 days.
5. "Could this individual exercise his/her rights in these situations without guardianship, if support services such as advocacy or professional guidance are provided?"
6. a. They make recommendations about the type (areas) of guardianship that is most appropriated for the individual.
- b. They review the guardianship annually to ensure that it continues to meet the individual need.
7. a. Advising (risks, consequences, etc.)
- b. Teaching (money management, etc.)
- c. Advocating
- d. Providing support services
- e. Getting temporary guardianship