

SEXUALITY AND PEOPLE WITH MENTAL DISABILITIES – THE ISSUES, THE LAW, AND THE GUARDIAN

Course Level: Intermediate

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Course Objectives:

- The guardian will be able to recognize that people with disabilities are loving, sexual individuals who need, and have a right to enjoy human relationships.
- The guardian will acquire knowledge about the issues relating to sexual matters and the role of the guardian in the decision making process for the individual.
- The guardian will understand how their own attitudes toward sexuality may influence their professional decisions.
- The guardian will examine the legal system as it applies to sexual activity and understand its applications.
- The guardian will examine the fundamental rights and responsibilities which apply to people with disabilities and the people who provide them with support.
- The guardian will be introduced to real-life situations dealing with sexuality and people with disabilities and will develop strategies for the education and protection of the wards they serve as guardian.

Learning Modules:

Sexual Rights Of Persons With Disabilities Sexual Activity And The Law Of Consent
Constitutional, Criminal And Civil Law
Evaluation Of Competence In Making Choices And Decisions About Sexual Behavior
Clinical Determination Of Competency
Judicial Determination Of Competency
Surrogate Decision Making Vs. Voluntary Participation
Probate Court Decisions
Related Healthcare Issues
Policy For Professional Guardians
Sex Education And Guardianship Program Policy
Conclusion

INTRODUCTION

The subject of sex and sexuality is confusing for most of us. We do not have uniform ideas about what sex is and we do not have consistent beliefs and attitudes about it. "For many people, sex is like pornography, they can't define it, but know it when they see it."¹ Sexuality is an important part of the total life experience of all human beings. Human sexuality refers to a broad spectrum of experiences and issues including self-concept, dress, body language, social interactions with the same or opposite sex, dating, marriage, and the physical aspects of sex, including intercourse.² The topic of sexuality and people with mental disabilities raises a number of complex legal, social, ethical, religious, health care, and political questions. People with mental disabilities are entitled to certain fundamental constitutionally protected rights, including the right to personal privacy in sexually related matters, if the person has the capacity to exercise them.³

Central issues relating to balancing rights and protections are: informed consent, evaluation of competency in making choices and decisions about sexual behavior, and the provision of education and policy guidance to individuals with disabilities, their families/guardians, and the persons who serve them.⁴ Institutional policies about sexuality for those who are disabled and the people who care for them are the best way to state philosophy, establish sexual rights and responsibilities, and influence programming needs.⁵

¹Patricia Miles Patterson, "Doubly Silenced: Sexuality, Sexual Abuse and People with Developmental Disabilities," 33, Wisconsin Council on Developmental Disabilities (1991).

²Susan Heighway, Marsha Shaw and Susan Kidd Webster, STARS--Skills Training for Assertiveness, Relationship- Building and Sexual Awareness, 33, A Waisman Center Program Promoting Positive Sexuality and Preventing Sexual Abuse for People with Developmental Disabilities, Wisconsin Council on Developmental Disabilities.

³ Paul Stavis and Louise Tarantino, "Sexual Activity in the Mentally Disabled Population: Some Standards of the Criminal and Civil Law," *Counsel's Corner*, 28 Quality of Care, Issue 28 (Oct.-Nov. 1986).

⁴ "Sexuality and People with Developmental Disabilities," New York State Commission on Quality of Care,

⁵Patterson, ""Doubly Silenced," 49.

Guardians and advocates, clinicians, providers of services, and family members face dilemmas as they try to honor the values for personal choice, self-determination, and independence for persons with mental disabilities. At the same time, they face the responsibilities to protect vulnerable persons with disabilities from sexual abuse, exploitation, and other related harms.⁶

SEXUAL RIGHTS OF PERSONS WITH DISABILITIES

As with every other segment of the American population, mentally disabled individuals are entitled to certain fundamental, constitutionally protected rights. Among those is the right to personal privacy in sexual matters. The right to personal privacy has been recognized to include: access to and use of contraceptives for all persons, married or single; a fundamental right to procreate; and the right to control one's body.⁷ Rights and responsibilities which apply to people with disabilities and the people who provide them with support include:

- < The right to maintain privacy concerning sexual thoughts, feelings and behaviors.
- < The right to be protected from exploitation and assault.
- < The right to express sexual feelings appropriately without fear of punishment.
- < The right to receive sex education regardless of age, gender or mental capacity.
- < The right to have friendships and the right to have love relationships.
- < The right to enjoy sexuality, not suffer from it.
- < The right to express affection with others.
- < The right to have body space respected.
- < The right to determine individual sexual values.
- < The right to be free of sexist or stereotypical labeling.

⁶"Choice and Responsibility: Legal and Ethical Dilemmas in Services for Persons With Mental Disabilities," New York State Commission on Quality of Care, Symposium Monograph, Albany New York, (June 21-22, 1994).

⁷Stavis and Tarantino, "Sexual Activity in the Mentally Disabled Population," Op Cit, 6.

< The right to make mistakes and to receive help and correction.

Corresponding sexual responsibilities are:

< The responsibility to respect individual and others' values.

< The responsibility to respect individual and others' bodies. Bodies are private property and should be treated as such.

< The responsibility to inform others of a sexually transmitted disease.

< The responsibility to refrain from imposing sexual preference(s) on another.

< The responsibility to prevent pregnancy unless it is desired.⁸

EXERCISE: Review rights, and corresponding responsibilities, related to privacy and sexuality.

SEXUAL ACTIVITY AND THE LAW OF CONSENT

- **CONSTITUTIONAL, CRIMINAL AND CIVIL LAW**

There are three bodies of law which potentially apply to sexual activity--the U.S. and state Constitutions, criminal law, and civil law. These bodies of law which potentially apply to sexual activity create a triangular framework which surrounds the sexual rights of persons with mental disabilities. In each body of law, the concept of consent is the hinge upon which to determine whether or not that law applies.⁹ These elements are:

1. *Knowledge* by the person of the nature of the activity and its consequences including physical, moral, ethical, psychological, and emotional consequences;

⁸Patterson, "Doubly Silenced," Op Cit, 50-51.

⁹ Paul F. Stavis, Counsel to the Commission, "Sexual Activity and the Law of Consent," New York State Commission on Quality of Care, 1- 2.

2. *Intelligence* of the person in realizing the benefits and risks of the activity, and a demonstrated ability to rationally process the knowledge or information by applying to personal standards of living; and

3. *Voluntariness* in that the decision is free of any unreasonable coercion to choose to engage in, or refrain from, sexual activity.¹⁰

The personal right of consent is synonymous with the concepts of personal autonomy, free will, choice, and individual freedom. It defines the right of adulthood and full citizenship in our democracy. The issue of competency, consent and sexual rights has been debated for over thirty years. The United States Supreme Court declared in 1965 that the constitutional right to privacy, established in the Bill of Rights, extended to sexual relations. However, they qualified this right by saying a person must be able to give consent. Furthermore, an adult with a mental disability must be capable of giving a knowledgeable, well thought-out, and voluntary consent.¹¹

The Court also declared that persons unable to protect themselves are the states' responsibility. The state must, therefore, not only protect from harm, but also maintain the person at the highest level of functioning while protecting all their rights. This responsibility is known as *parens patriae* derived from Roman law. The first obligation of this parental power is to protect from harm so that nurturing or care and treatment can take place. The government also protects from harm by prosecuting persons who violate the criminal law by engaging in sexual activities with those who cannot consent to such activity.¹²

¹⁰Stavis, "Sexual Activity and the Law of Consent," *Ibid.*, 3.

¹¹*Ibid.*, 6. *Griswald v. Connecticut*, 381 U.S. 479 (1965)

¹²Paul F. Stavis, Counsel to the Commission, "Recent Developments in Law and Recent Data on Sexual Incidents, Policy Considerations for Providers," 2, New York State Commission on Quality of Care.

The legal definition of competency to consent to sexual activity depends on state law and varies greatly among states. For example, New York State has the narrowest definition of competency to consent, while its neighbor, New Jersey, has the broadest definition.¹³

Although some may think that it is paradoxical to believe that a mentally incompetent person could have the capacity to make a reasoned and informed decision on sexual issues, the New York Court of Appeals pointed out in *Rivers v. Katz*, 67 N.Y. 2d 485 (Ct. App., 1986), that a finding of mental incompetence does not necessarily apply to every aspect of a person's life. Under some state laws, individuals may be found incapacitated in some areas but still retain the capacity to make decisions concerning their own bodies.¹⁴

When a mentally disabled person is subjected to abusive or coercive sexual activity, or where there is no capacity to consent, a crime has been committed and the abuser can be prosecuted. Pursuant to state laws, an element of every sex offense is that the sexual act was committed without consent of the victim. In order to judge whether or not a criminal act occurred, an assessment must be made whether or not the alleged victim consented to such an act.¹⁵ One of the difficulties in prosecuting these types of cases, however, is whether the quality of the alleged victim's testimony might also be affected by the mental disability. The victim will have to provide as many specifics as possible about an alleged criminal incident for there to be a successful prosecution. It is not necessary for the victim to remember the exact date and time, however, as long as he/she can designate a time period in which the criminal activity took place.¹⁶

¹³Stavis, "Sexual Activity and the Law of Consent," Loc Cit.

¹⁴Stavis, "Sexual Activity in the Mentally Disabled Population," Op Cit, 1.

¹⁵Ibid, 2.

¹⁶Stavis, "Sexual Activity in the Mentally Disabled Population," Ibid., 2 - 3.

There is also some difficulty prosecuting cases when corroboration is required, as in non forcible sexual offense cases when the incapacity to consent is because of the victim's mental disability. Evidence in addition to the victim's testimony may come from other witnesses, physical evidence that the defendant was involved, or medical evidence. A person with a mentally disability can give testimony if he or she understands the nature of the oath and possesses sufficient intelligence and capacity to testify.¹⁷

In addition to criminal prosecutions, civil law remedies may also be available if a person with a mental disability is sexually assaulted or abused. The civil law requires professionals or caregivers to protect persons in their charges from harm. This means that the professional guardian or caregiver should be careful to make a correct decision on a ward's or client's ability to consent to, and safely engage in, sexual conduct consistent with the law of jurisdiction and state regulatory or professional standards. Failure to do so may result in legal liability for allowing injury to the ward, or professional malpractice.

Exercise: Review relevant legislation in your state that defines "competency" in matters relating to consenting to sexual activity.

EVALUATION OF COMPETENCE IN MAKING CHOICES AND DECISIONS ABOUT SEXUAL BEHAVIOR

- **CLINICAL DETERMINATION OF COMPETENCY**

Clinical determination of competency means that the determination is made by a clinical professional with the appropriate ability to make it. This could be a psychiatrist or psychologist or other professionals who are legally or ethically required to do so. They may determine whether their patient or client is competent to make a decision about sexual activity.¹⁸

¹⁷Ibid., 3.

¹⁸Stavis, "Sexual Activity and the Law of Consent," Op Cit, 3.

Clinical determinations must be made consistent with law, regulations, or the applicable standards of the respective profession. Clinical determinations are most often used in cases of emergency, or when someone is being admitted to a hospital or psychiatric facility. These individuals are generally viewed as in "immediate danger to self or others."¹⁹

The decision of competency is not an exact science. Many variables must be taken into account including not only the differences among the persons with disabilities and among the professionals, but the differences in each situation. Higher functioning individuals may have difficulty with decisions such as sexual activity, contraception, personal relationships and/or personal welfare decisions, and their competency is often brought into question. Deciding their competency, or lack thereof, is seen in some instances as a way of protecting the individual. Other decisions concerning simple activities require less knowledge or understanding, and competency may not be an issue.

Whether an individual is competent to give consent is harder to establish when the handicap is severe. When it cannot be established that the individual knows what is going on, had the option to stop the activity, or lacks the ability to communicate agreement, providers may assume lack of consent. The Skills Training for Assertiveness, Relationship-Building and Sexual Awareness (STARS) Program, A Waisman Center Program published by the Wisconsin Council on Developmental Disabilities, contains a "Sexual Attitudes and Knowledge Assessment" which can be helpful in assessing the ability of severely mentally disabled persons to consent to sexual activity (Resource List).

- **JUDICIAL DETERMINATION OF COMPETENCY**

Judicial determination of competency means it has been formally made by a court of law. Judicial determinations are required in some states, or are used to settle disputes when

¹⁹405 ILCS § 5/1-119

serious questions are raised about the person's competency, or the clinical evaluation itself. Even in the event of litigation, a court of law will listen to, and heavily rely upon, the professional expert's testimony.²⁰ In the State of Illinois, competency is always judicially determined and the person is represented in the proceedings by a Guardian ad Litem.

SURROGATE DECISION MAKING VS. VOLUNTARY PARTICIPATION

What is the proper role and legal authority of a legal guardian in decisions on sexual activity for persons with mental disabilities? Guardians should apply the professional judgment of qualified clinicians in developing individualized plans. These plans for services and supports should address competencies which the ward possesses, areas where education and training are required, and current incompetencies which may implicate a duty to protect the individual.²¹ What this means in practical terms for professional guardians can be stated in four simple principles:

1. Know the law and regulations in the jurisdictions of your practice.
2. Know the bounds of your decision-making authority within your professional standards and ethics.
3. Know the extent and/or limitations of your decision-making authority imposed by the court.
4. Utilize treatment teams and ethics committees whenever possible.

Professional guardians would be well advised to know the wards for whom they are undertaking responsibility. A way for guardians to evaluate consent on the part of a ward is to ask questions. Ask the ward directly if they want to be sexual, if they like their partner, and

²⁰Stavis,"Sexual Activity and the Law of Consent," Op Cit, 3.

²¹Sundram and Stavis,"Sexual Behavior and Mental Retardation." Op Cit, 455.

what they do together. Look for affection and caring between partners.²² Ensure that thorough and comprehensive assessments of the ward's strengths and needs are made by qualified professionals. These assessments include all relevant aspects of functioning, and assessing competence to make voluntary decisions regarding sexual conduct.²³

When a person has been determined to be incapacitated, all too often it is standard practice to believe that they cannot engage in, or be engaged by another individual, in a sexual activity. It is important to understand that a surrogate decision maker, who has been appointed to represent the incompetent person, cannot consent to the sexual activity. Fact: there is no such thing as surrogate consent for sexual activity; to the contrary, it is a crime.²⁴

In the case of a higher functioning individual who has been declared incapacitated but who is able to determine their own sexual feelings or need for a relationship, the role of the surrogate decision maker may be primarily to protect the person's right to privacy.

Exercise: Review the NGA Standards of Practice, "NGA Standard 10, The Guardian's Duties Regarding Diversity and Personal Preference of the Ward." www.guardianship.org.

PROBATE COURT DECISIONS

Sterilization and abortion are two major sexually related decisions that are reserved by state law to the discretion of the Probate Court. Decisions concerning individual use of contraceptives, marriage and procreation are usually not a matter for court decision. Persons with mental disabilities may marry if they have sufficient mental capacity to consent to marriage. However, state law may allow for voiding of the marriage due to mental disability. For example, Illinois law allows for a Declaration of Invalidity if a party lacked capacity to consent to the marriage at the time the marriage was solemnized, either because of mental

²²Patricia Patterson, "Doubly Silenced," Op Cit, 106.

²³Sundram and Stavis, "Sexual Behavior and Mental Retardation," Op Cit, 454.

²⁴Stavis, "Sexual Activity and the Law of Consent," Op Cit, 3.

incapacity or infirmity or because of the influence of alcohol, drugs or other incapacitating substances, or if a party was induced to enter into a marriage by force or duress or by fraud involving the essentials of marriage.²⁵

Exercise: Review your state Probate laws to determine when judicial decision making is required in sexually related matters, such as abortion, sterilization, marriage, or contraception.

PERSONAL AND PROFESSIONAL VALUES IN DECISION MAKING

Human sexuality encompasses the sexual knowledge, beliefs, attitudes, values, and behaviors of individuals. It deals with anatomy, physiology, and biochemistry of the sexual response system. It involves roles, identity, and personality; with individual thoughts, feelings, behaviors, and relationships.²⁶

Many people who choose careers in social service fields have very caring personalities. At times they let personal concern override professional judgment. It is difficult, and yet very important, to separate personal feelings from professional duties when making decisions for wards. Quite often conflicting values come into play when dealing with issues such as contraception, abortion, marriage, parenthood, and homosexuality.

Views about sexual conduct are shaped by differing spiritual and religious beliefs, as well as moral, ethical, and cultural values. Strong opinions of agency staff and direct care givers, as well as those of the guardian, often make these types of decisions more difficult. Guardians not only have to deal with protecting their wards' rights to privacy and sexual relationships, with which they may personally disagree, but also with the complications that may arise.

²⁵750 ILCS § 5/301.

²⁶“Sexuality Education for Children and Youth With Disabilities,” 1, No. 3 News Digest 2, National Information Center for Children and Youth with Disabilities, Washington, D.C. (1992).

Psycho-social development plays a large part in certain types of sexual activity such as masturbation or homosexuality. It is very important for the guardian and the provider to understand the principles of psycho-social development and apply them when making decisions or preparing programs.

There are two types of decision making methods:

1. Substituted judgment – the representative makes the decision as the ward would when the ward's wishes are known or can be established by interviewing the ward, their friends and family, or through a preference stating document such as a living will.
2. Best interest - the representatives use their values and beliefs to make the decision they feel would best serve the ward.

Remember, the surrogate decision maker cannot give consent for sexual activities, but must protect the rights to privacy for their wards when dealing with issues such as contraception or marriage, if the situation is appropriate.

What we learned as a child, and the new things we learn everyday, make us stronger and wiser. We can take our knowledge and help others lead a more "normal," fulfilling life if we can focus on the individual and not society as a whole. As surrogate decision makers, we must always try to understand that which may not be understandable, and allow for the differences in people.

Exercise: Review the NGA Model Code of Ethics, "Rule 1, Decision-Making, General Principles." <http://www.guardianship.org> .

RELATED HEALTH CARE ISSUES

In many cases, it is not the ward's rights or sexual orientation, but the ward's safety that represents the key issue. Quite often, guardians, parents and care givers need to become more informed themselves concerning the health risks of certain types of sexual activity before they can address these issues with their wards, family members or clients. Information must be tailored to the level of disability of the targeted population. People with severe or profound

levels of retardation will have difficulty understanding sexual health. And often, no matter what the level of functioning, information has to be re-taught and re-emphasized.

People with a disability are not immune to the diseases other individuals contract. Sexually Transmitted Diseases (STDs), such as gonorrhea, syphilis, chlamydia, genital herpes and warts, and HIV infection (which in advanced stages leads to AIDS), are known and transmitted among the normal population. Hepatitis is also transmitted through the exchange of infected blood, like the HIV infection, and can, depending on the circumstances, be considered a STD.²⁷

In some cases, due to mental retardation and cognitive limitations, persons with disabilities are more at risk of being harmed by sexual activity. It is often difficult for a disabled person to determine if a situation is safe. Lack of social skills and good judgment, impulsivity, limited social opportunities, and limited information are additional factors which have to be recognized.²⁸

In 1972, it was argued that "it is unrealistic for normal society to demand responsible sexual behavior from people who have never been taught what constitutes responsibility and irresponsibility in sexuality."²⁹ The lack of understanding of the responsibility which one must accept when entering into a relationship may be one of the largest problems which adds to the transmission of STDs between partners within the disabled community.

PROVISION OF POLICY GUIDANCE AND EDUCATION

- **POLICY FOR PROFESSIONAL GUARDIANS**

Organizational and/or agency policies about sexuality are the best way to state philosophy,

²⁷"Sexuality Education for Children and Youths," Ibid., 21-22.

²⁸Loc Cit.

²⁹James W. Chapman and Amanda S. Pitceathly, "Sexuality and Mentally Handicapped People: Issues of Sex Education, Marriage, Parenthood, and Care Staff Attitudes," 10, No. 4 Australia and New Zealand Journal of Developmental Disabilities 1 (1985).

establish sexual rights and responsibilities, and influence educational needs. Good policies should be formal, positive and proactive.

They should:

- < encourage sexual development,
- < encourage positive expression of sexual feelings,
- < encourage relationships,
- < encourage freedom from sexual harassment.³⁰

SEX EDUCATION AND GUARDIANSHIP PROGRAM POLICY

Programming and educational guidelines are derived directly from policy statements. Programming guidelines for support providers should specify training and education to be provided, and criteria for program and procedural development. Support providers need to be trained in the same social and sexuality concepts as people with disabilities. The support person's awareness of personal attitudes and beliefs about sexuality, and sexual expression of people who are disabled, profoundly influences how that person provides education and support to wards or clients.³¹

Sex education subject areas should include:

- < Sexual awareness including self image, body parts
- < Human growth and development
- < Social norms and values about sexuality and touching
- < Sexual hygiene and teaching about sexually transmitted diseases, including AIDS
- < Understanding and establishing relationships with themselves and others
- < Identifying behavior appropriate to an individual, their role and the environment

³⁰Patterson, "Doubly Silenced," 49-52.

³¹Ibid., 56 - 57.

- < Development of personal power
- < Recognition of potentially unsafe environments or situations
- < Assertiveness skills, like saying "no"
- < Basic self protection skills
- < How and where to get help for sexual problems and reporting abuse.³²

The Sex Education and Information Council of the United States provide an annotated listing of currently available sex education programs. Professional guardians can assist providers of services to wards by becoming knowledgeable about the sex education programs available, and their content (Reference List). Two widely known programs are the Circles program, and the Stars program (Reference List). When faced with sexuality issues regarding wards, guardians should consult with professionals trained in sexuality issues. The three categories of professionals who are specifically trained in sexuality are sex educators, sex counselors, and sex therapists. Sex educators teach others about sexuality, while sex counselors and sex therapists help those who have problems in the area of sexuality. The American Association of Sex Educators, Counselors and Therapists certifies these three groups of people and can provide names of local professionals who meet the requirements for certification (Reference List).³³

CONCLUSION

People with mental disabilities are entitled under the Bill of Rights to personal privacy in sexually related matters. Sexual activity and consent are covered, not only by constitutional law, but also by civil and criminal legal systems.

There are two forms of competency evaluation, clinical and judicial. The manner in which, and reasons why, guardians are appointed varies from state to state. The need for a

³²Patterson, "Doubly Silenced," Loc Cit.

³³Patterson, "Doubly Silenced," Op Cit, 65.

guardian also varies with each person and their situation. Being a guardian is not an easy task; separating personal and professional feelings and attitudes is often very difficult. Most of our ideas and opinions are formed by years of believing in the same values and morals. It is hard to realize that those same values may not be shared by the people we were appointed to represent.

It is difficult to protect our wards from harm and assure they are receiving the necessary sex education. Guardians should be aware of, and work for, policies and programs which are beneficial for the community of persons with disabilities and society as a whole. To assist guardians in assessing their decision making abilities in the area of sexuality, three vignettes are included in the test at the end of this paper. These vignettes are based on real-life situations and the sexuality issues they represent. Working through these vignettes will help guardians in meeting their mandate to provide surrogate decision-making on behalf of wards, to protect them from possible harm, and to allow them to exercise their sexual freedom.

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REFERENCE LIST

Sex Education and Information Council of the United States (SEICUS), 80 Fifth Ave., New York, NY 10011. SEICUS maintains a library service and a newsletter which regularly reviews new books, curricula, and audiovisual materials on all aspects of sexuality. http://www.seicus.org/school/sex_ed/sex_ed0000.html

American Association of Sex Educators, Counselors, and Therapists (AASECT), Suite 1717, 435 N. Michigan Avenue, Chicago, Illinois 60611, (312) 664-0828. This organization maintains a listing of certified sex educators, counselors and therapists. <http://www.aasect.org>

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