

**ADDRESS CORRECTION
TO
MR BULLETIN 00-96-23**

MR Bulletin 00-96-23, Guidelines Concerning Sexuality, contained a Membership Listing for the Sexuality Subcommittee. The address for Linda Ross was listed incorrectly and should be corrected as follows:

**United Way of Wyoming Valley
9 East Market Street
Wilkes-Barre, PA 18711**



MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA • DEPARTMENT OF PUBLIC WELFARE

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NUMBER

00-96-23

SUBJECT

**Guidelines Concerning
Sexuality**

BY

A handwritten signature in cursive script, appearing to read "Nancy R. Thaler", is written over the "BY" label.

**Nancy R. Thaler
Deputy Secretary for Mental Retardation**

SCOPE:

County Mental Health/Mental Retardation Administrators
Community Home Directors
Family Living Home Directors
Adult Training Facility Directors
Vocational Facility Directors
Early Intervention Program Directors
Non-State Operated Intermediate Care Facilities
for the Mentally Retarded (ICF/MR) Directors
State Operated Intermediate Care Facilities
for the Mentally Retarded (ICF/MR) Directors

PURPOSE:

The purpose of this Bulletin is to distribute the "Guidelines Concerning Sexuality".

BACKGROUND:

In 1993, the Office of Mental Retardation established a subcommittee to study and provide advice on education, training and policy development on human sexuality and people with mental retardation. The subcommittee is composed of people with disabilities, parents, professionals, educators, therapists and advocates. The subcommittee has developed "Guidelines Concerning Sexuality" as a first step toward helping men, women, and children and those who support them address this important aspect of life.

REFER COMMENTS AND QUESTIONS TO:

Any Member of the Sexuality Subcommittee of the OMR Planning Advisory Committee

The Guidelines must be enhanced by education and support at the local level. The subcommittee members have organized regional committees. They continue to plan statewide training events, and they will make themselves available to assist people in understanding the guidelines. A list of subcommittee members is attached.

Sexuality is an important aspect of personal health, safety and expression. These guidelines provide a framework to help agencies develop policies that support the rights of people with disabilities; to assist self-advocates in obtaining information and education and considering personal responsibility, as well as serving as a reference for families on rights and protections.

Attachments

GUIDELINES CONCERNING SEXUALITY

Prepared by:
Sexuality Subcommittee
of the
Office of Mental Retardation
Planning Advisory Committee

PURPOSE

The purpose of these guidelines is two-fold:

- (1) to ensure that the sexual rights and basic human needs of persons with mental retardation are affirmed, defended and respected; and,
- (2) to protect men, women and children with mental retardation from harm (for example, mental and physical).

This statement may serve as a guide to men, women and children with mental retardation, family members, friends, advocates, and professionals on matters related to sexual rights and responsibilities.

PRINCIPLES

All men, women and children are sexual beings growing up with individually and socially determined values.

All men, women and children have the right to love and be loved.

All men, women and children have the right to associate with other people of both sexes, with or without disabilities and to have opportunities to develop independent, interpersonal relationships of mutual trust.

All men, women and children have the right to develop self-identity, self-esteem, self-respect, and their sexual identity.

All men, women and children have the right and should have the opportunity to receive individualized education which is appropriate to their level of maturity, and to receive support regarding sexuality throughout life.

All men, women and children have the right and should have the opportunity for choice regarding sexual expression and emotional relationships. Support should be offered to persons with mental retardation to enable them to make decisions regarding the expression of their sexuality.

All men, women and children have basic rights including privacy, confidentiality, right to informed risk and freedom of association. These rights must be fostered, protected and defended.

All men, women and children with mental retardation are entitled to protection from abuse, exploitation, unwanted pregnancy, and sexually transmitted diseases in a context which safeguards their dignity and maintains their rights.

These guidelines have been developed to ensure that human sexuality issues are addressed in a progressive, sensitive, and individualized manner.

PRIVACY

Men, women and children with mental retardation have the need and the right as individuals to communicate and discuss or refrain from communicating and discussing personal sexual issues on a formal, informal, and private level with persons of their choice.

Personal or intimate sexual issues are not to be communicated and discussed in group settings, except at the discretion of the people involved. Discussion of sexual issues should conform to accepted standards of confidentiality.

All men, women and children have the right to privacy in order to have the opportunity for sexual expression.

All men, women and children have the right to privacy in daily living such as dressing, showering, etc.

Men, women and children should be afforded the opportunity to choose and develop friendships and emotional relationships.

Men, women and children should have the right to experience variations in sexual orientation and sexual expression.

Men and women have the right to choose with supports if needed, a lifestyle which may include living alone or with others, co-habitation, marriage, and having or not having children.

EDUCATION, INFORMATION & SUPPORTS

Education relative to sexuality should include issues of interpersonal responsibilities, respect and mutual understanding, social skills and relationship building, verbal and non-verbal communication, including dating protocol, levels of intimacy and affection, and behaviors appropriate to each.

Education should include understanding of laws governing sexual conduct, the contractual nature of marriage, the responsibilities of maternity and paternity, the nature of pregnancy, the options available for avoiding it as well as the importance of prenatal and infant care if it occurs. An educational program must also include useful information of the risks of sexually transmitted diseases, their detection and means of avoidance, with special attention to AIDS. (AIDS education should also cover risks from other causes.)

Training in self-protection and how to avoid being exploited should be available to persons with mental retardation. This should include assertiveness training, understanding that abstinence is an option, learning to say "no" to unwelcome advances, learning to recognize that "no" means "no", reporting incidents of abuse and exploitation. It may also include self-defense training.

Men, women and children with mental retardation should have access to assistance and/or adaptive devices for purposes of sexual expression and activity.

Education should be provided to persons with mental retardation interested in marriage, parenting, other lifestyles; on-going support and assistance should be offered to individuals in these areas.

Men, women and children with mental retardation who have maladaptive sexual behavior, sexual disorders, or sexual dysfunction should have access to appropriate treatment.

Each community should develop a resource guide of available services in human sexuality and training.

FAMILY RESPONSIBILITIES

In order to ensure that individuals with mental retardation are afforded the sexual rights that are guaranteed to them and are also protected from harm, it should be each family's responsibility to:

- * Be supportive and open regarding sexuality issues and provide access to sex education, counseling, social opportunities, or sexual activities, as needed.
- * Give consistent messages to all siblings in the household, providing the same opportunities for developing one's own sexuality among all children, with disabilities and without.
- * Participate in your daughter/son's individualized planning process, if invited, recognizing his/her right to sexual expression and education.

- * Access the information available to families on how to adapt responses to sexual questions and issues to the level of functioning and the age of the individual involved, working in concert with your son/daughter, a sexuality counselor, physician, and appropriate staff to ensure the most supportive, least restrictive, environment for sexual development and expression.
- * Review the current sexuality policy of your son/daughter's residential placement, day program, or other programs.
- * Understand that sterilization without permission of the individual or the court, is not a viable alternative to sound birth control practices.
- * Review the current information available regarding sexually transmitted diseases, including information regarding AIDS.
- * Following transition to adulthood, families/advocates should respect that the sexual rights and basic human needs of men and women with mental retardation are affirmed and defended.

PERSONAL RESPONSIBILITIES

Men, women and children should learn about sexuality and how it relates to ethics and to physical and emotional health through participating in a comprehensive human sexuality program (education, counselling, information, and supports) including the following examples:

- * Share any sexuality issues with a trusted person. Ask questions honestly, in an appropriate place and time.
- * Learn about positive forms of communication and assertiveness.
- * Learn the difference between public, semi-private, and private places from a trusted person.
- * Ask questions and convey concerns regarding sexual expression and orientation from a trusted person.
- * Respect other people's rights.
- * Be aware of the sexuality policies of where you work and where you live.
- * Learn the consequences of responsible and irresponsible behavior.

- * Learn about community resources regarding sexuality. If there are no people you feel you can trust, contact your local advocacy agencies.
- * Celebrate the relationships in your life. Trust yourself and your judgements.

AGENCY RESPONSIBILITIES

Agencies that deliver direct services to men, women and children with mental retardation, including residential, vocational, educational and other day services, have a responsibility, to promote healthy sexual development, self-understanding, and a capacity for making personal choices. Agencies have the responsibility to facilitate the understanding of the personal, social, legal, health, and safety implications of various forms of sexual activity.

Service agencies also have a responsibility to protect individuals from approaches by others that may be unwanted or misunderstood. The leadership of such organizations share a responsibility to mitigate the risk of sexual harassment and sexual abuse in the organizational context.

It is recommended that each agency:

- * Develop a sexuality policy, using this document as a guide.
- * Assure the participation of men, women and children with mental retardation in the development of policies and practices which promote privacy and recognize the right to opportunities for appropriate sexual expression.
- * Make available to men, women and children with mental retardation ongoing education, counseling, and support in human sexuality, including but not limited to social skills training, anatomy, physiology, hygiene, sexually transmitted disease, and AIDS education; birth control, verbal and non-verbal communication, and ethics.
- * Identify and use community resources regarding human sexuality; i.e., support groups, family planning services, therapist, physicians.
- * Assist and support men, women and children with mental retardation in addressing sexual issues with parents, family members, and other providers. This support may include obtaining an advocate.
- * Establish procedures to investigate allegations of sexual abuse. Any suspected illegal activity should be reported immediately to the appropriate agency; i.e., law enforcement and/or social service agency.

- * Intervene in an appropriate manner when sexual behavior is considered to be socially inappropriate, while preserving the dignity of the individuals involved.
- * Intervene in sexual activities of men and women with mental retardation only when necessary to reduce risks associated with sexual practices, exploitation, and/or rape.
- * Consult concerned staff and friends, in cases where a man or woman's ability to give consent to sexual activity is in question.
- * Prohibit sexual abuse (including sexual harassment) by staff and volunteers.
- * Ensure that staff give consistent messages about sexuality issues.
- * With respect to individual privacy and choice, ensure that sexual issues and concerns are sensitively included and addressed in any individualized planning process. The plan should maximize independence and autonomy in decision making in those aspects of life, to the extent that the person is capable. It should identify areas where the person needs to be protected from harm or exploitation. The plan should also identify qualified staff or referral sources who can provide sexuality education, training, and/or counseling.
- * Designate a coordinator to be responsible for providing continuing and comprehensive staff training in human sexuality and in the rights of individuals with mental retardation to sexual expression, including their right to remain inactive.
- * Provide all staff with an orientation to these guidelines. Issues shall include the development and support of positive attitudes, and respect for the dignity, privacy, personal rights and religious values of the individual.

GLOSSARY

Children - For the purposes of this document, children refers to people under the chronological age of 18.

Confidentiality - Confidentiality is the guarantee that information about a person is made available to others only with the knowledge and consent of the individual or his/her guardian. Dissemination of such information involves only as much information as others need to know in order to serve and benefit the individual in a sensitive manner.

Consent - Consent can apply to a number of decisions, including the decision to engage in sexual behavior. Consent generally has three basic elements: capacity, information, and voluntariness. If any one of those three elements is missing, we can say that consent, or the ability to give consent, is not present. Capacity is the ability to comprehend the act and its consequences, and is a measure of both intellectual ability and maturity. Information about the decision must be given in a way in which the decision-maker can understand his or her decision and its consequences. And, the decision must be voluntary, meaning that it cannot be forced or coerced. Voluntariness also means that the decision-maker must not feel that he or she would be punished or harmed by making a decision, such as when confronted by an authority figure.

Exploitation - Sexual contact that takes advantage of the difference in the status of the parties and their authority relationship.

Human Sexuality Education - This is a process that starts at birth. It includes self-awareness, issues of interpersonal responsibility, respect and mutual understanding, social skills and relationship building, verbal and non-verbal communication, intimacy and affection, and appropriate social behavior.

Inappropriate Sexual Behavior - Any behavior with sexual overtones in which one party infringes on the personal rights of another, is unlawful, or is injurious to one's self or others.

Privacy - The right to engage in activities with the minimum amount of intrusion that is reasonably possible; the right to have information concerning one's self held confidentially.

Protection from Abuse - The right to be protected from sexual harassment, sexual abuse, or sexual exploitation by strangers or known individuals. Generally, this applies to all people with mental retardation whether or not they have the capacity to understand short-range or long range significance of their actions. Specifically, it puts the responsibility on family, guardian, and/or direct care staff to protect those people incapable of comprehending the meaning of sexual activity on any level.

Sexual Abuse - Any sexual activity which occurs as a result of coercion, physical force, or taking advantage of a person.

Sexual Harassment - Unwelcome verbal or physical conduct of a sexual nature.

Sexuality - The aspect of a human being that encompasses his or her sexual identity, knowledge, beliefs, emotions, attitudes, values, behaviors, roles and relationships, as well as the anatomy, physiology, and biochemistry of a man, woman or child's sexual response system. An individual's sexuality is influenced by his or her ethical, spiritual, and moral concerns and by group or cultural identifications.

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