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State of Maine

Department of Mental Health & Mental Retardation

BUREAU OF MENTAL RETARDATION

The Report of the Task Force on Sexuality and Sexual Abuse/Assault of People with Mental Retardation

October, 1991

Task Force Report on Sexuality and SexualAbuse/Assault of People with Mental Retardation

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Foreword

The topic of sexuality is one that produces a certain amount of embarrassment and reluctance in all of us. Sexuality as it pertains to people with mental retardation often generates even more discomfort. Sexuality is not a problem to be overcome, it is an aspect of our humanity to be respected and celebrated.

This report is designed to address some of the common myths about sexuality and people who have a label of mental retardation. It also sets forth some recommendations for providing support and education for all of us working with and on behalf of people with mental retardation. Although the report addresses both <u>sexuality</u> and <u>sexual abuse/assault</u>, we emphasize that these two issues are separate from one another. Sexual abuse and assault are crimes of violence, and are not considered to be related in any way to the mutual and respectful expression of human sexuality. In light of the particular vulnerability of the people with whom we work, we strongly advise that all persons involved in administrative service, case management, and direct service provision be alerted to the particular dangers facing people with mental retardation. Clear guidelines need to be established and enforced relative to the fair and just identification, prevention, and response to suspected or alleged sexual abuse. In addition, appropriate information and support about sexuality and good health needs to be provided, so that people can make informed choices in their daily lives.

In the case of many people who have mental retardation, the experience of sexual abuse and assault has been largely ignored by persons in the service delivery system. For those who have experienced powerlessness in the face of aggression, encountering unknowledgeable staff has compounded the problem. People who are acting out their own pain are often subject to behavior plans designed to stop the acting out. Less common is a concomitant response of compassion and support for those who have suffered the pain of abuse. Furthermore, clear and useful information about sexuality is not always made available to persons with mental retardation in Maine, on a consistent and routine basis.

The enclosed report is designed to provide a framework to dispel myths, to present facts, and to make recommendations that will lead to healing and empowerment. In doing so, the members of the Task Force wish to emphasize that we are living in a culture that supports the continuation of abuse on vulnerable people, including women, children, and people with disabilities. It is important to address cultural issues by joining forces with organizations committed to the same goals, each with its own role in creating a healing environment. It is also important to support each individual who has been victimized by using practices which promote healing and empowerment.

Our hope is that the information and recommendations contained within will bring us closer to being part of the healing.

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Special thanks to Carol Ippoliti for producing much of this final report.

*BMR refers to the Bureau of Mental Retardation

PART I SEXUALITY EDUCATION

To date there has been some recognition on the part of service providers and families that people with mental retardation need education and training in order to be more able to be assimilated into the communities in which they live. Emphasis has been on the need for the person with disabilities to change her/his behavior. While this aspect of skill training is important, the Task Force proposes that equal emphasis be placed on the need for the further education and training of community members, service providers, and BMR personnel, in order to dispel the many myths surrounding sexuality and mental retardation, and promote thoughtful and respectful practices as we provide services, advocacy, and assistance to people in the full enjoyment of their civil rights:

Some common misconceptions about the sexuality of people with mental retardation are:

MYTH
People with mental retardation are incapable of forming relationships.

FACT
People with mental retardation, like everyone else, develop sexually and have the right to expression in all aspects of their lives including sexuality. People are capable of love, emotions, and relationships. People need to have privacy and need to be able to express their sexuality in a variety of ways.

It is not easy to teach about abstract concepts such as relationships, but it can and needs to be done through discussion, therapy, modeling, problem-solving, and exposure to social settings, as well as through curricula specifically designed for the purpose.

MYTH
If you talk to people about sex, they'll only want to "do it". Sexuality education increases risks.

FACT
Sexuality education is more than teaching about intercourse. It gives people an understanding of their own bodies, about their relationships with other people, and about the customs that are acceptable in this society. People with mental retardation express individual preferences and interests, and engage in sexual activity, just as any other person. Education can work to decrease vulnerability and empower people to make choices, decisions, and to protect themselves.

Implications and Recommendations

A. People in the community at large need to understand that people with mental retardation are more like them than unlike them, because we are all human with a range of emotion and experiences. The Bureau of Mental Retardation (BMR) needs to pursue a public education effort which would address this need. Components of this program should include the following recommendations:

Each person should be encouraged and supported in her/his efforts to develop friendships in the community.

-We need to give individuals an opportunity to develop friendships with all kinds of people. Getting folks involved in school, church, and community activities; promoting a development of leisure time and recreational interests; and encouraging people to join clubs, groups or volunteer organizations will give them a chance to meet a variety of people who are fun, interesting, and not required to be with them as paid staff.

-In the interest of promoting relationships, Maine should consider developing a citizen advocacy program similar to those operating in Georgia, Vermont, and other states. Successful citizen advocacy programs have been highly localized projects fostering networks of community members who are willing to have meaningful, respectful, ongoing relationships with people who have mental retardation. Successful CA programs are supported by but not part of state government.

B. The Bureau of Mental Retardation needs to pursue a comprehensive education program for its own staff and for service providers, in order to facilitate the safe and gratifying pursuit of personal friendships. Specific recommendations include:

-Each person should be supported in her/his efforts to make friends.

-Each person should be granted the respect due to any human being who has relationships, and experiences normal emotions revolving around these relationships. These include feelings of grief and loss when people move away or relationships break down, and the desire to express affection in ways which adequately reflect the nature of a particular relationship.

-All agencies and providers need to be required to address the needs of people with mental retardation in regards to human sexuality, through thoughtful policy development and implementation, and provision of on-going training for staff.

-Providers, staff, parents, and caseworkers need to be provided with ongoing opportunities for education about sexuality.

-People must be supported in their choice to mutually fulfilling, safe and non-exploitive expression of their sexuality. Health considerations should be clearly presented and reinforced. Providers need good information about issues confronting persons with same-sex orientation.

-People must be given the opportunity to make choices in a context which is reasonable, respectful, and non-exploitive.

-We need to teach about private places and private activities.The CIRCLES curriculum or some modification of it can be used to teach people about the variety of relationships there are and about the types of touch appropriate for different types of relationships.

-The dangers of unprotected sexual activity among people who are woefully underinformed cannot be overemphasized. In addition to the supports BMR has offered service providers to increase knowledge and understanding of AIDS and other sexually transmitted diseases, continued dialogue needs to occur among providers and caseworkers, in order to humanely and respectfully address the issues of education and informed choice-making which confront persons with mental retardation who are sexually active.

C. The Bureau of Mental Retardation needs to pursue a comprehensive program to assist and monitor Bureau personnel and service providers in the modeling and teaching of mutual social and relational behaviors, and in teaching about sexuality. Specific recommendations to service providers should include:

-Staff and consumers must be clearly oriented about expectations regarding personal care and respect for the privacy/modesty of the individual.

-In order to learn to respect privacy, people need to have their own privacy respected. Each person should have a place that is designated their private space. Everyone should knock prior to entering that private space and should not enter until given some kind of a signal that it is ok.

-If a person requires assistance in the area of personal hygiene, only a few people should be designated with that task. The individual should know those people and know what they are supposed to be helping with. Specific protocol need to be designed, taught, implemented, and monitored, to ensure that contact between providers and service recipients is

appropriate, respectful, and safe. Most important, this protocol should include clear, definitive guidelines relative to the kinds of touching which is and is not permissible for providers to engage in. **PERSONAL KINDS OF TOUCHING SHOULD NEVER BE ASSOCIATED WITH PERSONAL CARE TASKS.**

PART II SEXUAL ABUSE

It is difficult to obtain accurate data on the incidence of sexual abuse perpetrated on people with mental retardation. Evidence which has been collected, however, reveals an alarmingly high rate of abuse of this vulnerable population. The Seattle Rape Relief Project of 1979 estimated that between 79% and 99% of people with developmental disabilities are sexually abused at least once by the age of 18 (Hard & Plumb 1987). Drawing on their research, Sobsey & Varnhagen (1988) estimate that the "risk [of being sexually abused] for individuals with disabilities is about one and one-half times that for non disabled individuals of the same sex and age." Their study of 94 cases of sexual abuse revealed that 88% of the offenders were known to the victim. Of these 88 %, 27% were <u>service providers</u>! Of the 94 cases, 74 victims <u>did not bring charges against their assailant</u>. Of the 20 charges brought, only 9 resulted in convictions. (Sobsey & Varnhagen, 1988).

The prevalence of sexual abuse perpetrated against people with disabilities is an outrage which will require the active and immediate attention of all systems concerned with the safety and well-being of people with mental retardation. First and foremost, people working in the field have an obligation to take measures to reduce risks for all persons with mental retardation. Action must be taken on several fronts in order to discourage and prevent further abuse. Sobsey and Varnhagen (1988) recommend that:

- we become better at recognizing the signs of sexual abuse
- we establish "better protocols" for response to suspected abuse
- we embark on an education program which will promote greater public awareness of the problem
- we encourage legal reform in order to provide better protection for people.
- medical services need to be modified to meet the needs of victims of sexual exploitation and abuse.

The high degree of perpetration of sexual crimes on people with mental retardation may be compounded by current judicial rules of evidence, which often have a deleterious impact on the victims' ability to participate in the judicial process. Under current rules of evidence in Maine, a judge may rule inadmissible testimony provided by a witness who lacks "any reasonable ability to perceive the matter or...lacks any reasonable ability to remember the matter." (Amendment to Maine Rules of Evidence 601, 1990). It is possible that, in light of communication and other expressive disabilities, persons with mental retardation who are able to perceive and remember incidents of sexual abuse may be considered by attorneys and judges to be lacking the legal qualifications to witness.

A review of the literature on sexual abuse of people with mental retardation will quickly dispel these commonly held myths:

MYTH
People with mental retardation are less vulnerable to sexual assault because they are unattractive and they live in safe, well supervised and protective settings.

FACT
As the Sobsey and Varnhagen study illustrates, the incidence of sexual abuse victimization among people with developmental disabilities is probably higher than among people who are non-disabled, and a significant proportion of this abuse occurs with someone in a care giving role. People with mental retardation are often taught compliance to those they perceive in roles of power or authority, and this learned compliance tends to increase vulnerability.

MYTH
Sexual assault against people with mental retardation is not a crime. People with mental retardation cannot give reliable testimony. As a group, they don't remember well, get confused, are easily influenced, can't understand, and can't be understood. People with mental retardation are not credible witnesses, and they make up stories about abuse.

FACT
Assault is a crime, whether adjudicated or not, and no matter who has been victimized.

The District Attorney decides whether or not to prosecute before bringing the case to a judge. Most allegations of sexual assault of persons with mental retardation are not prosecuted, in part due to the perceived inability of the victim to be a reliable witness. Many people have the ability to state the facts but struggle with the perception of incompetence held by others.

Many people with mental retardation are "conditioned" to be passive and compliant. Because of this it is possible and likely for a victim to have submitted to assault without a fight, even though s/he did not want to have sexual contact with the perpetrator.

Most people with mental retardation have been sexually exploited or assaulted. (Hard & Plumb, 1987)

MYTH

People with mental retardation who are victims of sexual assault aren't affected the same way as other victims, because they don't have the same capacity for awareness or feelings. They do not benefit from psychosocial therapy.

FACT

People with mental retardation can and do suffer from the long term effects of sexual victimization. There is increasing documentation in the literature relative to the use of individual and group work in an effort to heal emotional wounds and reduce antisocial behaviors associated with having experienced trauma (Lee, 1976, Monfils, 1985). No one forgets a traumatic event.

People may benefit from, in addition to cognitive therapy, the use of alternative therapies, such as art, play, dance, music, etc. (Plan for People, 1988)

Implications and Recommendations

The Bureau of Mental Retardation needs to ensure that people are reasonably protected from sexual exploitation and abuse by alerting caseworkers and service providers to the 'red flags' which may be symptomatic of past or current victimization. Current literature on the sexual abuse of children and of other vulnerable populations can provide a description of symptoms. One excellent reference is the book, Adoption and the Sexually Abused Child (McNamara et.al, 1990). (Other resources are listed in the Bibliography of this report). The Bureau of Mental Retardation needs to establish, promote, and support protocol for caseworkers, direct service providers, supervisory service providers, and administrators to follow when 'red flag' symptoms are present. Further guidelines and support will be needed from BMR in the areas of:

-provision of training

-mandating provider training and monitoring adherence to protocol

-assisting with the development of programs for consumers

-developing guidelines for agencies to use in employee screening designed to reduce the risk of victimization, and adequately orienting and training agency staff.

It is further recommended that:

1.Training be made available to educators, families, medical personnel, attorneys, law enforcement personnel, family planning workers, social workers, and others involved with

people who have mental retardation who have been victimized, in order to increase these people's understanding of the ability of persons with mental retardation to report assault and feel pain.

2. Information needs to be disseminated to funding sources, including those who interpret federal regulations regarding Medicaid reimbursement, relative to the ability of people with mental retardation to benefit from therapies, as well as their special needs regarding repetition and length of therapy commitment. BMR, as the "expert" on this segment of the service delivery system, needs to advocate with funding agencies.

3. BMR needs to pursue publication and dissemination of literature pertaining to the use of therapy with people with mental retardation, to include documentation of benefits as well as a description of methodology which has been useful in the treatment of trauma victims who are developmentally disabled.

4. The public at large needs to be made aware of the tragedy of sexual exploitation and abuse among people with mental retardation. It is recommended that BMR pursue an aggressive public education effort, including dissemination of literature, regional symposia, and documentary films.

5. BMR continue its commitment to holistic programs which address social and emotional aspects of life and most particularly the skill of communication.

6. BMR and other advocates for persons with mental retardation support legislation which would revise the sexual assault statutes in an effort to make the laws more inclusive of situations which affect persons with mental retardation.

7. It is recommended that the Bureau of Mental Retardation actively assert the expertise of professional staff within the agency, to educate and lobby legislators and the Advisory Committee on Rules of Evidence, in order to achieve equity relative to a person's right to testify. It should also be considered that persons with mental retardation be allowed to testify in a setting outside of a courtroom, with interpreters available, and that such testimony be made admissible in court.

PART III SEXUAL OFFENDERS WHO HAVE MENTAL RETARDATION

It has been documented that sexual offenders often have been victims themselves (Groth, 1979). Sexual offense has been described by some as an act of rage and violence, perpetrated to establish power and control over the victim, rather than a sexually motivated crime (Groth, 1979). In light of the vulnerable position of people with mental retardation, it is reasonable to assume, then, that some of these oppressed individuals are in danger of becoming offenders, themselves. Recent news reports assert the problem of identification, adjudication, and treatment of sexual offenders to be an unresolved social issue of crisis proportions. The issue becomes even more complicated when the alleged perpetrator is a person who is has the label of mental retardation.

MYTH
If a person with mental retardation is accused of a sexual offense, he/she should not have to go through the legal system. People with mental retardation who are perpetrators can't be held responsible for their actions, cannot benefit from therapy, are incompetent to stand trial and need to be " put away". We cannot or should not send people with mental retardation to jail.

FACT
People with mental retardation who are accused of a criminal offense are entitled to due process.

Implications and Recommendations

If a person is accused of a sexual offense, he/she should always have the right to go through a process that determines whether the charge is true or false.

People with mental retardation who commit a sex offense may be behaving in ways they learned when they themselves were victimized. In this regard, it will be important for BMR to take the lead in developing treatment programs which respond to the special needs of this particular population.

Specific recommendations include:

1. Treatment programs for sex offenders should be expanded/modified to meet the needs of people with mental retardation.

2. In cases where jail is deemed inappropriate for a person with mental retardation who has been convicted of a sex crime, specific options and procedures should be developed, perhaps along the lines of alternatives that have been developed for youth offenders.

3. Any alternative settings which are expected to provide restriction must have legal authority to do so.

SUMMARY

The Task Force study has revealed substantial need in three major areas. These are:

I. The need to educate persons with mental retardation, caseworkers, residential and other service providers, family and community members, persons who provide social, recreational, religious, educational, and protective services in the community, and all others having interaction with or impact on the lives of people with disabilities, relative to the normalcy ofsexuality, and the necessity to maintain the civil rights and civil protection of all persons. Active attention must be paid to the issues of self esteem and acquisition of social, communication, and problem solving skills, in order for people with mental retardation to fully exercise their right to choose and pursue safe and meaningful relationships.

II. The <u>urgent</u> need to take active measures to reduce the risk of sexual abuse and exploitation perpetrated on persons with mental retardation, through the enforcement of concrete guidelines, protocol, and other educational and supervisory measures.

III. The need to provide equal access to judicial due process for all offenders and victims, including those who have mental retardation. The need to address the antecedents to sexually acting out behaviors, by identifying and reporting warning signs, and by developing the resources necessary to treat sexual offenders who have mental retardation in order to reduce risks to the person and to others.

References

Groth, A.N. (1979). Men Who Rape: Psychology of the Offender.

Groth, A.N. (1982). The incest offender. In S.M. Sgroi (ed.), Handbook of clinical intervention in child sexual abuse. Lexington, MA: Lexington Books.

Hard, S.& Plumb, W. (1987). Sexual abuse of persons with developmental disabilities: A case study.

Lee, D. (1976). Evaluation of a group counseling program designed to enhance social adjustment of mentally retarded adults, pp. 319-323.

Long Range Planning Task Force (1988). Plan for People. Augusta: Maine Bureau of Mental Retardation.

Maine Advisory Committee on Rules of Evidence. 1990. Proposed amendment to MR EV 601.

Monfils, M. (1985). Theme-centered group work with the mentally retarded. Social Casework: The Journal of Contemporary Social Work. March, 1985, pp 179-184.

Sobsey, D. & Varnhagen, C. (1988). Sexual abuse and exploitation of people with disabilities: Toward prevention and treatment. In M.Csapo & L. Gougen (Eds.). Special education across Canada: Challenges for the 90's. Vancouver: The Centre of Human Development and Research.

Resources

For materials on socialization and sexuality, there are books, articles, and tapes which are available through the Pineland Center Library.

For information on AIDS, STD, and other hazards associated with unprotected sexual activity:

Calten, M. (ed.), Surviving and Thriving with AIDS. New York: People with AIDS Coalition.

Griggs, J. (ed.), AIDS: Public Policy Dimensions, (1987). United Hospital Fund.

Kempton, W. Life Horizons, I & II (1988). (slides and training materials). James Stanfield & Co., distributors. Santa Monica, CA.

Young Adult Institute of New York (organization which disseminates materials relating to issues for persons with disabilities)

For information about sexual preference:

Pharr, S. Homophobia: A Weapon of Sexism. Verness, CA: Chardon Press.

Mullencott & Scanzonni. Is the Homosexual My Neighbor?

For information about sexual abuse:

McNamara et.al. (1990). Adoption and the Sexually Abused Child. Greensboro: Family Resources.

Sgroi, S. (1989). Vulnerable populations, Vol.2. Sexual Abuse Treatment for Children, Adult Survivors, Offenders, and Persons with Mental Retardation. Lexington, MA: Lexington Books.

Davis and Bass, The Courage to Heal

Training materials related to sexual abuse:

Circles: Moonstone Group Sex Education Services. RFD 1 Hanover St., Yorktown Heights, New York 10598. Produced and distributed by James Stanfield & Co.

Circles: Stop Abuse (1986). Santa Monica: James Stanfield & Co.

For general information about sexuality:

Kempton, W. Life Horizons (see above)

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